FACE IT;

a visual fore-glimpse in AR for facial skin cancer patients' surgery?

Master Thesis Final Report

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Preface.

What I think and thank at the end of this journey

It is done! After this journey of a project I can say that it has shown other parts of myself. Along the way I found out that studying is learning a particular way of thinking. I hope that you, the reader of my thesis, will take something along from my graduating journey encompassed in this thesis.

Since the beginning of my studies I have been intrigued by design for empowerment of groups of people that really could be impacted in their lives by design. Ranging from sports to vitality to wellbeing. Often the topics are involving interesting vulnerable groups are labeled as ‘difficult to design for’, however from a design perspective you could also see it as challenging and intriguing to find out what they really experience and want.

When I came to Delft for my masters I wanted to dive in diverse projects. I was hoping to get answers along the way on questions like: What kind of designer do I want to become? What kind of work would I love to do in the future? I ended up not knowing an exact answer to these questions and maybe even more questions arose along the way, however I did learn more about myself, especially in this project.

At the time that I write this I am insouciant; free from concern and worry -that postit has been on my monitor for 2 months now-. If there is something that I have taken along is that at some points in the process there was this pressure that I laid upon myself that made the playing field more into a tension field.

Luckily I had very helpful and thoughtful mentors in this project. Along the whole project it felt like ‘we’ made this project possible. It never felt as supervisory meetings for me, they always felt like a team meeting. This lengthy project could not have been possible without their help, or at least would have been really different.

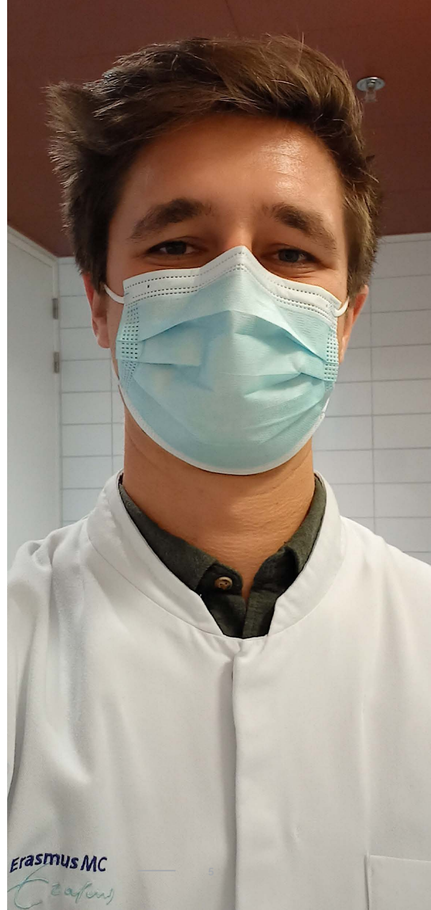
So I want to take this moment to thank everyone that was of support for me in this projects’ journey:

A big thank you to Armagan, Valentijn and Eveline! I want to thank you for the weekly meetings. Your personal openness has done wonders at times, giving me the encouragements and coaching to make this project into a succes.

To all the patients that were open to talk about their personal experiences, thanks for your inspirational stories. They gave me the drive since I knew where I was doing it for and that what I was doing was actually helpful.

To the healthcare professionals that I got to interview, a big thanks for offering me an insight in your work and sharing your ideas.

And lastly and most of all I want to thank my housemates, dear friends, Tunya, Rob, Doreen and especially Olga for supporting me during the hard times and fun times. Also thanks for, at some points, distracting me in a good way. You helped me keeping my sanity to question throughout this project, but most of all lend a listening ear when needed.



Executive Summary.

A glimpse into the future; exploring the promise of immersive technology within facial skin cancer care.

Skin cancer is the most common form of cancer in the Netherlands, often caused by having too much exposure to UV radiation from the sun. An effect of this is that the part of the body that is exposed the most to the sun is also the body part where skin cancer is seen more often; the head. When the skin cancer gets removed surgically, the defect is sometimes so big that a reconstructive surgery has to take place. This treatment is impactful for patients, since their face can abruptly change, impacting their social interactions.

This project explores the patient experience that facial skin cancer patients have throughout their treatment and how augmented reality (AR) could contribute in this treatment, to ultimately bring about a better quality of life (QoL).

In the first phase of this project qualitative research was conducted. Interviews with healthcare professionals (HCPs) and observations in the hospital helped to understand the context for patients. Contextmapping interviews with patients gave insights on the patient journey they went through. It was found that this journey can best be explained as an emotional roller coaster with a long recovery phase.

In the second phase of this project the final concept “Face it” came about through experimentation with AR software and co-creation with HCPs using the patient journey as a basis. A final interactive mock-up was created and tested with ex patients to evaluate the concept as whole.

The final concept Face it is a tool that helps patients to look at themselves in three different ways during the recovery phase of their treatment; the current selves, back in the past and the future selves. This is done by taking photos, keeping track with photos and looking to the future phases of the recovery in AR. The final concept was evaluated as a good example of digitalization to evoke patient engagement in their own care and with that patient empowerment.

This design research showed that there is a need and opportunity for more digitalization in healthcare. Furthermore, the project has shown that solutions in healthcare can benefit from taking a more holistic approach to a problem. Taking this a different perspective offers interesting opportunities for future projects on AR in healthcare, as does this project, offering a glimpse into the future.

Reading Guide.

Guide for reading this thesis

This report is built up from separate sections, since there are different parts to this project. Hopefully that makes it easier for you as the reader to read, for instance if you want to focus on a certain topic or want to quickly scan through the section.

In every section there can be multiple chapters, since some chapters fit together, yet their content differs. Every chapter has the same buildup; a small introduction, explaining the used methods and tools in detail, results of these methods and a short concluding summary are given. The main takeaways of the chapter are given at the very end of each chapter in an orange frame like below.

All the important insights are highlighted in the text.

> *“All the quotes from actors along the project are given in this way.”*

Abbreviations

QoL	**Quality of Life**
NMSC	**Non Melanoma Skin Cancer**
FSK	**Facial Skin Cancer**
SDM	**Shared Decision Making**
PJM	**Patient Journey Mapping**
HCP’s	**Healthcare Professionals**
AR	**Augmented Reality**
PRO’s	**Patient Reported Outcomes**
PE	**Patient Experience**
EM	**Expectation Management**
CCS	**Co-creation Session**
PSS	**Product Service System**

Figure 1. Example of a takeaway box, listing takeaways of a chapter.

Takeaways of this chapter

- In every chapter there are also some takeaways to summarize the chapter.
- Takeaway 2
- Takeaway 3
- Takeaway ...

Table of Contents.

“The best part of beauty is that which no picture can express.”
- Francis Bacon

Introduction.

Innovation for healthcare is a gratifying challenge

If you think of design for healthcare, your mind can go in the direction of physical solutions within the hospital. That is not that strange to do, since design is generally associated with products and therefore product design.

If you ask people what they think of when you talk about innovation, answers are also given regarding products, to be more precise; high tech appliances and state of the art technology. Also mentioned a lot is the fast pace of change that has to happen within the domain to count it as innovation. Whereas innovation can better be seen as the application of novel ideas in novel areas.

If you combine these two notions into the topic of innovation for healthcare, not many people have a well-formed idea what that is. This can be because it doesn’t fit the idea of innovation in the sense of high tech, computerized or mechanized. For our idea the hospital is something that is to be seen as human oriented. Rightfully so, since the most vulnerable groups can end up in the hospital.

On the other hand it can be seen that there is a tendency to make healthcare as efficient as possible to make sure costs are minimized. In a chaotic ever-changing atmosphere of a hospital, care is mainly performed manually, and not digitally. Since this everyday work can be made more efficient, there is still a lot to gain by looking at digital solutions.

Spiraling costs in healthcare and time efficiency should be taken into account, since hospitals are often seen as companies, however that should not go at expense of the human-oriented approach that can be obtained for innovation in healthcare.

Expectation management and shared decision making are seen as potential ways to make healthcare more patient centered and therefore are relevant proposals for skin cancer care at the Erasmus Medical Centre. The need for a humanlike approach through new technologies makes this project want to explore these two ways through the use of Augmented Reality. The state of the art tool through which a visual fore-glimpse can be given to patients.

Section I: This Project.

Chapter 1 Project Background

Chapter 2 Project Approach

This section introduces the topic, scope, and design approach that lay the foundation of this project. Through an introductory literature review on the status of skin cancer care and promising developments in healthcare, the scope of this project is presented in Chapter 1. This offers the initial focus and objective for this project.

In Chapter 2 a description is given on the assignment and the followed approach for this graduation project is explained in depth.

01 Project Background.

Every day when one looks in the mirror they see themselves in a certain way. What defines the person in the mirror is a big part of the identity of that person, the face. It has such a great social function, that one of the first things babies recognize is the human face. Changes in the face, due to muscles and skin moving, are seen as emotions and ways of communication. It is learning these subtle differences in facial features that not only help use identify people, but also identify how people feel from a young age (Samuels et al., 2013).

As discussed by McLean et al. (2015), if body features that have a social function change abruptly, this can have a big impact on a person and their personality. For instance if facial characteristics change due to facial burns, this can have a big impact, both mentally and physically. Especially when this is unexpected and unwanted these changes can cause the person to become very emotional, which can also reflect on their direct environment.

The same goes for skin cancer in the face, which can cause the person to undergo a whole process of change. It starts as a small wound or deformity, however, under the skin it can be that the cancer cells have been spreading widely. So widely that resecting the tumor causes such a big defect that it has to be reconstructed by a plastic surgeon. This shows the importance of early diagnosis of facial skin cancer (Bolouri, 2017).

01.1 Facial Skin Cancer Care

Skin cancer is the most common form of cancer in the Netherlands, with 52% (Schreuder et al., 2019). About 1 out of 5 people in the Netherlands will get a form of skin cancer (Kanker.nl, 2021). Of all these incidences, the head is the most common place for skin cancer, since it is the most exposed to sunlight.

At the department of Plastic and Reconstructive Surgery in the Erasmus Medical Centre, around 100 to 200 facial reconstructions are performed annually. These procedures are required for patients that have facial defects after being treated for - mainly non-melanoma - skin cancer (NMSC).

Although patients are advised to have the tumor resected to prevent further local growth, NMSC is rarely life-threatening. In the Netherlands only 4.6 out of 100.000 people die from NMSC (Schreuder et al., 2019). This outcome is due to a considerably low risk that cancer will spread to other parts of the body, however, it can grow in size which can have complications when not acted upon (NHS, 2020). For example not daring to go outside or having not being able to talk.

Therefore, the primary goal of these reconstructions is to maintain quality of life (QoL). This means that the goal of the surgery is to minimize the nuisance patients experience in their daily social interactions due to the visible effects of skin cancer treatment. As stated the face is an important part of the body and often plays a key role in the first way of interacting with another human. This emphasizes the need to restore both function (e.g. talking, smiling, eating) and appearance, supporting (mental-) health and ultimately well-being.

01.1.1 Patient Experience; definition briefly explained

In recent years, there has been an increase in the interest in the term patient experience (PE). A global shift is seen in the use of PE in both public policy and patient engagement in their healthcare (Baker, 2001; World Health Organization, 2016). Some healthcare leaders are even giving it the top priority for the future of healthcare (Wolf et al., 2014). Although the intention is there and the term is widely spread, how PE is (mis)used in practice can vary a lot. A reason for this can be that the term has different definitions that are being used.

Looking at definitions that are widely used, the Beryl Institute defines the PE as:

> *"the sum of all interactions shaped by an organization's culture that influence patient perceptions across the continuum of care."*

This is a definition that describes, in an objective form, what PE is. What misses in this notion is what the patient experiences. The good part of this definition is that the 'continuum of care' is specified. Taking into account time over the whole treatment shows that care is not a moment, but a process. Seeing a process makes sure that moments that are outside the scope of the treatment can be also taken into perspective.

The Free Dictionary provides a simplistic and subjective definition of the PE (Farlex, 2011). In short, PE is described as:

> *"How the patient feels/felt, i.e., good or bad, as/after he or she undergoes/- went through an episode of care.*

This definition captures the perspective of patients better by describing emotions. Yet, it gives these emotions a moment in time, which is done more often in research; before or after the care is experienced. (See Chapter 1.1.2).

PE is something that changes over time. If you take QoL as an indicator of how patients feel, you can see this change. Irrespective of the outcome of the treatment, the QoL of patients changes throughout the process, it is a dynamic process. Patients go through different emotions and with facial skin cancer (FSC) patients even have a visual change to their face over time.

For this project it is important to state a definition that fits the project scope. The combined definition that will be used for PE in this report will therefore be:

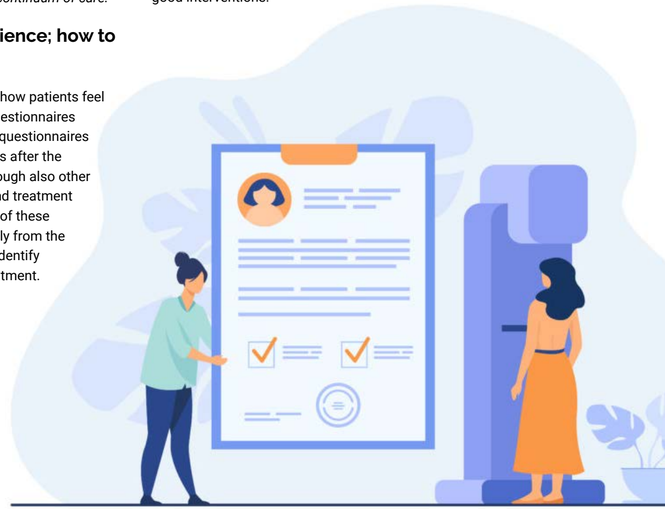
> *"How the patient feels throughout the sum of all interactions that influence patient perceptions across the continuum of care."*

01.1.2 Patient Experience; how to measure?

A common way to measure how patients feel is by use of standardized questionnaires (Snyder et al., 2019). These questionnaires typically are given to patients after the surgery and include QoL, though also other topics such as well-being and treatment satisfaction. The outcomes of these measures are coming directly from the patient and can be used to identify possible changes in the treatment.

Patient-reported outcomes (PROs) are already being mapped in an ongoing prospective study at the Erasmus MC. By using the current study as a control group, the outcomes of this design project could potentially be tested over a longer period. A designed intervention could be given preoperative, such that the effect can be seen as a positive effect in the QoL after surgery.

The current research of the Erasmus MC is more focused on the preoperative part of the treatment because not much is known about it. A next step and research potential is in this preoperative part and that is where this design project could investigate what could be good interventions. A next step and research potential is in this preoperative part and that is where this design project could investigate what could be good interventions.



01.1.3 Patient Experience; facial skin cancer briefly described

To understand the treatment of patients, a basic knowledge of the illness and accompanying PE are important to introduce.

As said before, the face has functionalities that are taken for granted by most of us (Bull & Rumsey, 2012). From a patient perspective, the importance of the face can become apparent from one moment, for instance, when one hears the diagnosis of skin cancer or that the tumor should be resected and the face needs to be reconstructed by the plastic surgeon. This can have a big impact on the patient, but cannot be seen as the sole moment that makes up the patient' experience.

The experience starts way earlier, for instance before the diagnosis. Often it starts when the patient, or close ones, notice the first symptoms. Skin cancer is caused most of the time by excessive sun exposure and therefore is likely to appear in areas that are exposed often, such as the face (Armstrong & Kricker, 2001).

Image 1. Skin cancer lesion on the face, from skincancer.org

skin; an irregularity in the growth of skin cells. Initially, skin cancer appears as a nodule, rash, or irregular patch on the surface of the skin. This form often turns into a spot that bleeds easily or stays a small wound. In some cases, a lesion or spot develops to grow. Occasionally patients take years before acting upon the first symptoms, causing them to potentially have lived with the distress a long while.

If the symptoms are acted upon, by going to a General Practitioner (GP), the GP can do part of the diagnosis and treatment themselves. Often they observe, do a biopsy (a tissue sample), or even excision (removal of tissue). If it seems likely to be a more complex case of cancer they refer the patient to a specialist; a dermatologist (Baaten et al., 2019).

The first diagnosis is often the start of the treatment process. It is a moment where for patients the situation becomes 'real' and is the start of a roller coaster of emotions. Until the surgery, there are often multiple hospital visits within a short period of time.

Hansen et al., (2012) explains that what makes this period even more apprehensive is the uncertainty of the size of the lesion. Like 'an iceberg', the tip of a tumor can come to the surface, though having roots spread more under the skin surface (NHS, 2020).

Also, the amount of surgeries differs per patient. In most cases, the cancer is removed by surgery, for instance with the Mohs surgery technique (Skin Cancer Foundation, 2021). During Mohs, thin layers of cancer-containing skin are progressively removed and examined until only

Image 2. Skin defect after Mohs

cancer-free tissue remains (See Image 2) This often takes a day in the hospital, with local anesthesia, so patients can go home after.

After the resection of the tumor, sometimes the hole has become too big to heal from itself. In these cases, reconstructive surgery can take place to have better results (See Figure 3). In most cases this surgery is under anesthesia. Often these treatments take multiple surgeries to come to the best results (Selber, 2019).

What follows is a long period of recovery and

Figure 2. Sometimes the defect is too big and reconstruction is necessary

healing of the wounds. This takes up to three months. In most cases, however, the patient has to undergo multiple reconstructive surgeries,

each with their own recovery phase.

The surgeries leave their physical scars. Normally it takes up to two years for scars to be fully healed. In this time frame, the physical appearance of the patient is altered, causing additional distress.

01.2 Shared Decision Making and Expectation Management

In healthcare, there is an increased attention for patient-centered care (Fix et al., 2018; Schuster et al., 2001). Within this the patient and its needs are central, but therefore also requires the patient to be actively involved.

In this project, the preoperative phase in the outpatient clinic was taken as an initial focus. Before the surgery, shared-decision making (SDM) and expectation management (EM) are central to achieve a patient-oriented treatment (Rigby, 2015; R. D. Vromans et al., 2020). The communication and giving of information has to be bilateral. Meaning both sides are in it, a third side is the context that the decision is made in. Sharing goes from patient to doctor and vice versa. To have SDM in cancer care requires the patient and doctor to both be well-informed about the clinical case and personal situation at hand (See Figure 3) (R. Vromans et al., 2019).

The benefit of this is that more informed personal decisions can be made before surgery, by offering a glimpse into the future. The particular importance of SDM and EM in this project is that they can offer a way to empower and inform patients and strive to

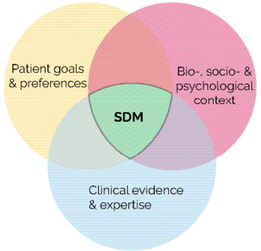


Figure 3. Shared Decision Making Model, Elwyn et al., 2012

optimize their needs in the most supportive environment possible. Ultimately this leads to better healthcare, because SDM leads to value-based-care. The patients gets the treatment that brings the most value to them. When better personal decision is made, the better the patient experience, improving the healthcare outcomes, since the costs per QoL are improved.

01.3 VR/AR in Healthcare

A recent example of innovation in healthcare is the application of new technologies such as virtual reality (VR) and augmented reality (AR) (Lee et al., 2021; Sutherland et al., 2019).

With the help of these immersive technologies patients can be aided in forming a more realistic perception of their treatment. The ability to merge reality with simulation is something that can spark interest and comprehension of what is to come. This results in patients being better informed, for instance, informing a lively example of what to expect.

The visual component of these technologies is especially valuable for skin cancer patients that undergo reconstructive surgery. Visuals and 3D Models can facilitate the comprehension of complex 3-dimensional concepts. An added value of a different way of information is that you could be tackling literacy problems too (Love et al., 2016; Wake et al., 2019).

There are good examples that these technologies are increasingly adopted in the medical field. VR and AR applications in the medical field can be classified on a spectrum of patient involvement (See Figure 4). First, on the clinician-as-user side, applications focus

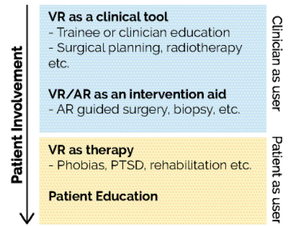


Figure 4. Delineation of VR/AR by amount of patient involvement Sutherland et al., 2019

more on being a clinical tool or an aid in surgery. On the patient-as-user side, applications of the technologies can be found as aids in therapy or patient education.

01.4 Project Scope: Focus and Objective

The main focus of this project is to obtain an in-depth understanding of the whole Patient Journey that FSC patients go through and the preoperative phase in particular. Essentially, because the choices that are made in this period and the actions are done. To put it in other words:

> *"From the moment of surgery, once the scalpel incises the face, there is no way back, it's irreversible."*

The way patients experience the preoperative process can impact how patients value their QoL postoperatively.

The goal of facial reconstructive surgery is to optimize the QoL. This means it is not a matter of life or death, which makes motivating patients to act immediately sometimes difficult. Not acting upon symptoms becomes problematic when their cancer grows to proportions that do affect their QoL. e.g. when their daily life gets hindered when a wound wont stop bleeding or when people do not dare to go outside anymore without hiding a tumor.

This shows that in this project also motivation and therefore behavior change is touched upon, which makes this project more complex. There is a level of convincingness needed in the information that is shared, though that level is different for each person. Some people want to know everything, where others are fine with doctors making choices. Providing a personalized way of care is therefore necessary, since every person is different. SDM and EM are central to achieve a patient-centered treatment.

It is assumed that time, investment and (visual-) expectation are important design elements that can be used. Patients may change their attitude over time, since sentiments and expectations change over time, as well as visual appearance.

Currently, modern 3D technologies such as VR and AR have several potential applications in healthcare. They have a great link to this project because they allow patients to take in information and content visually in an immersive environment. Since facial reconstructions can bring about visual aesthetic changes, VR and AR could be used to show the expected outcome and promote EM and SDM. The main driver is that perspectives of patients and professionals will be getting closer together and promote not only better patient education, but also a personalized treatment for each patient.

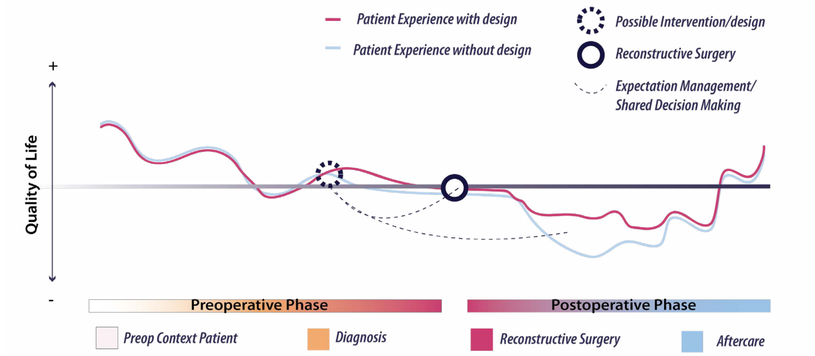


Figure 5. Project Scope, Interventions that take place in the Preoperative phase, that bring about a better QoL after surgery

01.5 Project Aim

The current chapter introduced the context of FSC in which the scope is formed for this project. A few aspects are explained and introduced to form the focus and aim of this project;

> *To bring about positive PE in FSC care, this study aims to implement shared decision making and expectation management, through immersive technologies.*

The next chapter will describe in detail what the chosen assignment is and what the taken Project Approach is for this project.

Takeaways of this chapter

- Reconstructive surgery for FSC influences the life of patients a lot because of the visual change in appearance. The social functions of the face appearance are sometimes overlooked.
- Patient experience is explained as to how a patient feels throughout the sum of all interactions that influence the patient's perception across the continuum of care.
- Shared decision-making and expectation management are means to bring about a more patient-centered treatment.
- Novel 3D immersive technologies are potential solutions to empower patients, especially due to their visual components. With reconstructive surgery this has an explicit means, since it has to do a lot with aesthetics and appearance.

| Photo by Danis Khleber

02 Project Approach.

02.1 Assignment and Approach

Following from chapter 1.4 the assignment for this project could be stated as;

> *"Designing a concept that helps to empower skin cancer patients before having facial reconstruction surgery. This by conducting **in-depth qualitative research** on the **Patient Journey** as a whole. The goal is to improve postoperative patient experience in a personalized way, by focusing on **patient-oriented care** with an emphasis on shared decision-making and expectation management. The aim is to **explore the promising use of 3D technologies** in the preoperative phase."*

This assignment has two sides, a human and a technology side, that require a different approach to tackle. The assignment is two-fold, which can be seen as two phases in the project;

1. Gaining insight into relevant aspects of the Patient Experience (PE) in the patient journey of facial reconstruction for cancer patients.
2. Exploring VR/AR as possible solutions to optimize the patient experience and thereby the QoL postoperatively.

Following the double diamond design approach by the Design Council (2019) could be a way to describe this design process. The first phase being the first diamond in which there is chosen to discover and define. The second phase is more explained as where one chooses to develop and deliver.

The first phase focuses on acquiring knowledge and taking a 'zoomed-out perspective' to see the patient in a journey from a holistic perspective. The PE in this is key and could even be the ultimate aim, showing what and how emotions and motivations play a role for the patient. The goal is to take the patient's perspective and represent this convincingly elaborated through the use of Patient Journey(s).

For this reason, it is also important to gather ideas from the actors within this healthcare context. Through co-creating ideas can be formed together, while getting professional feedback throughout the process of ideation.

Within the second phase, the focus lays upon the experimentation of potential concepts and evaluating their impact. A fitting framework to evaluate and test with is the previously made Patient Journey(s). This can be used as a base to identify and ideate potential applications of new 3D technologies in the process of facial reconstructive surgery.

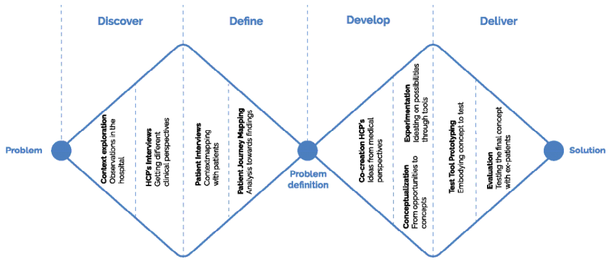


Figure 6. Project Approach as Double Diamond model, from Design Council, 2019.

My interpretation of a design approach.

In this project these diamonds are present, however I like to explain the approach differently, it can be seen as follows;

The canvas on which there was to be designed was made through Patient Journey Mapping.

To do this mapping but also getting to define the project the mindset of Design Thinking was used. Taking Co-creation as the approach to find suitable opportunities and ideas together with the stakeholders. At last, the tool to make these ideas into concepts was chosen to be the exploration of AR.

In this chapter, a more detailed explanation will be given on the elements of this approach.

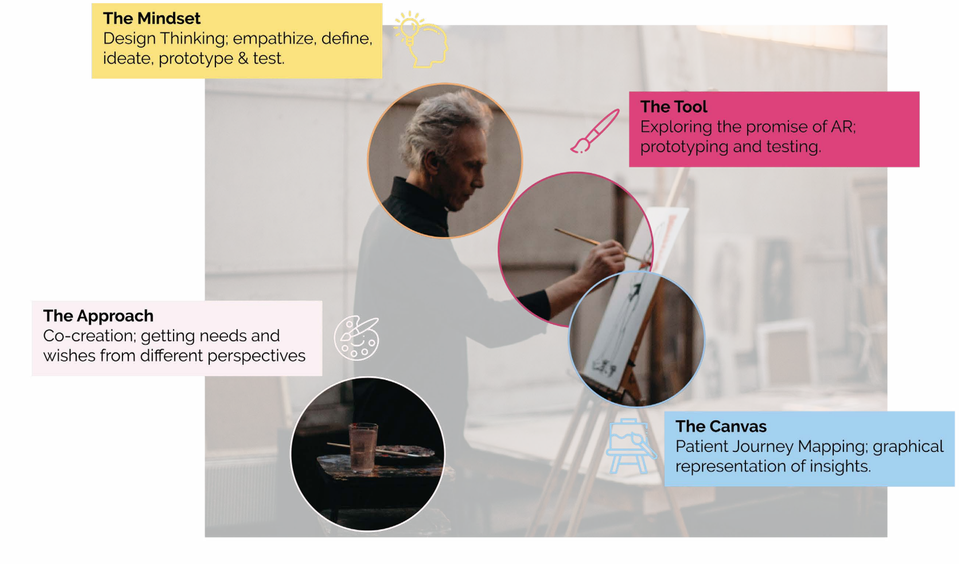


Figure 7. Project Approach, visualized through the four elements of this project.

02.2 Patient Journey Mapping; the canvas

An established methodology to map how patients experience their treatment is Patient Journey Mapping (PJM).

> *"A patient journey is defined as a comprehensible representation of the health service and its procedures, including relationships and feelings from a patient perspective." (Simonse et al., 2019)*

The patient journey method is derived from the customer journey map technique. It is a graphic representation of all the stages a customer goes through when using a service or product (van Boeijen et al., 2013). Instead of looking at a moment in time when interactions take place -also called a touchpoint- it is better to take a zoomed-out perspective to understand the experience a patient goes through, as a whole. This is an advantage of journeys (Rawson et al., 2013).

In this project, a patient journey could function as a canvas to design on. Taking the insights in, through an interpretable graphical form. Designing a solution is made easier in this way because of the interdependencies that become visible. The resulting solution can add value in a wider perspective, for the patient and the Erasmus MC.

02.3 Design Thinking; the mindset

When one wants to design a solution, it can happen that the problem, that is to be tackled, is ill-defined or unknown, also known as a wicked problem (Interaction Design Foundation, n.d.).

Design thinking (DT) is a method that can help to define these wicked problems. DT is a non-linear, iterative process that is applied to understand users, challenge assumptions, redefine problems and create innovative solutions to prototype and test. It involves five phases—Empathize, Define, Ideate, Prototype, and Test. Important to note is that these phases do not have to go in order. The mindset to switch between phases is the most important thing to use.

In this project, the design thinking mindset is used to go through only one cycle with prototyping and testing, though multiple cycles can be seen if a Patient Journey is seen as an iteration.

A key part of DT is the empathize phase, in which the human side of the problem is taken into consideration. A way to highlight this human side is to involve the actual users, so-called Co-creation which is explained in the next paragraph.

02.4 Co-creation; the approach

In healthcare innovation and change is a mix of new technologies combined with a human side of healthcare. In this project, this human side is of such importance that the approach is chosen to involve the actual users, in this case, patients and healthcare professionals. Their needs and wishes are something that can be explored using a co-creation approach (E. Sanders & Stappers, 2008).

The idea of co-creation thrives on the conception that everyone is creative. People have experiences of their own which makes them experts of their own experiences. All these experiences bring along ideas, the ideas are within everyone.

Involving people in the process gives multiple insights into experiences and therefore different perspectives. That makes sure it has a level of abstraction. Obtaining these perspectives makes sure that a project is not fixated on assumptions.

By involving actual people one makes sure that there is a process with intrinsic motivation. Often resulting in supported solutions that are taken up to change.

There is a difference in what kind of information is obtained in a co-creation process.

Sanders & Stappers (2008) explain levels of knowledge; explicit, observative, tacit and latent knowledge. These levels require different methods to unravel the knowledge and can be divided into three categories; say, do and make.

The role of a designer is to help people unravel these ideas by facilitating creativity. By the means of generative tools and methods, the knowledge can be created. As a translator, the designer is also in charge to find patterns and use these as inspiration for new designs.

02.5 Exploring the Promise of AR; the tool

As explained in chapter 1.3 VR and AR are increasingly seen more often in the healthcare domain. Different ways of applying the new technology are tried. It can give a whole new dimension to providing information on treatments for patients.

In this project, AR is chosen as a technology to become familiar with in a playful way. As a technology push, the intention is to find out where it can assist patients, thus seeing the potential along the Patient Journey. You could say that AR is the tool with which knowledge gained in the co-creation process is put on the canvas (Patient Journey). The needs and wishes of the patient are embodied in a digital tool.

02.6 Design Approach Summary

The design approach for this project involves four layers. A canvas, a mindset, an approach and a tool. Combined a design approach is chosen, which takes into account a human and a technology side.

Takeaways of this chapter

- Creating a holistic overview and visual representation of how a patient experiences a health service, can help identify problems, and opportunities along the Patient Journey.
- Design Thinking is a way to define wicked problems in 5 phases; empathize, define, ideate, prototype, and test.
- To help people voice their creativity and unravel their needs and wishes, creative generative tools and methods can be used. Together the act of involving people in the creative processes is called co-creation.
- AR is a promising technology that can work as a tool to embody the needs and wishes of patients.

| Photo by Denis Khleber

Section II: Context Exploration.

Chapter 3 Care at the Erasmus Medical Centre

This section describes the context in which the scope and problem of this project are in; Skin Cancer Care at the Erasmus Medical Centre. Although the patient is the main actor in this project, the context surrounding the patient, mainly the hospital and the actors are taken into account. Chapter 3 has the purpose of showing how this context is explored, by means of analyzing the care path, observing different stages in that path and by having interviews with the main medical actors in that context.

03 Care at Erasmus MC.

The purpose of this chapter is to describe the context of Skin Cancer Care in the hospital itself. To do so, the actors that are involved and the care path are taken into account. From this, a few potential interesting moments are highlighted. These moments were also attended to do observations at the hospital. Additional interviews with the key actors - that are involved the most in the treatment- give a deeper insight into their role is in the treatment and the steps that are taken in the care path. To conclude, a few interesting takeaways are highlighted at the end of this chapter.

03.1 Actors involved

Actors are seen as all that can actively contribute to the healing process of a patient. This is considered both human and non-human, so it is everyone and everything that contributes to the patients' healing. In Figure 8 an Actor Map is shown. The map shows all the main actors that are related to skin cancer patients. The concentric circles indicate the involvement of the actors. Closer to the middle means more involved, making a distinction between; informed, involved, and core.

In addition, there is a grouping of actors regarding the phase/context that they are important in. The different phases are; Preoperative Context Patient, Diagnosis, Reconstructive Surgery, and Aftercare/ Postoperative.

03.2 Care Path

Before a patient undergoes reconstructive surgery a lot of steps are experienced. Especially with the complex cases that come to the Erasmus MC, this path of care is not only complex, but can also differ.

A good example of the care path was provided at the beginning of the project. This showed the time and steps involved, which helped to determine which actors should be taken into account. In Figure 9 you see the given care path. Good to mention is that this explicitly is not called a patient journey, because it resembles a more abstract path, whereas patient journeys highlight the individuality of patients, showing the story and emotions.

From the care path a few moments were found to be interesting to experience and observe in real life, in order to get more feeling for the moments itself and who is involved in what way;

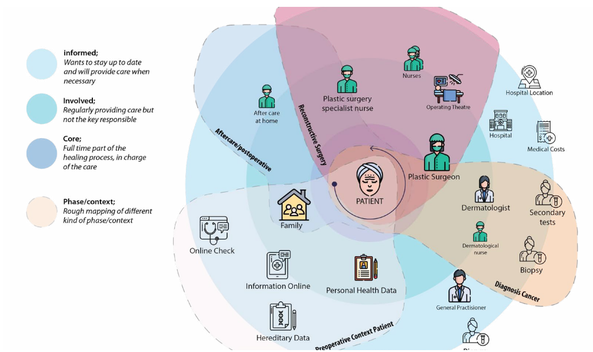
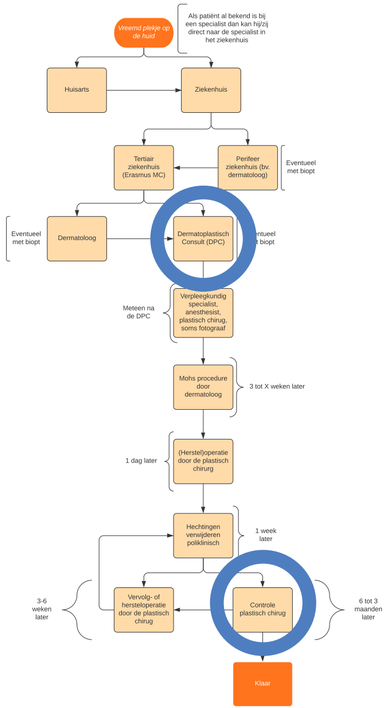


Figure 8 Actor Map; actors involved in skin cancer care.



1. The follow-up appointment, which takes place as a check, but also when a patient experiences complications with the wounds.
2. The dermatoplastic consultation (DPC) , in which the patient gets to speak to the dermatologist and plastic surgeon about the diagnosis and the plastic surgery that will be performed.

03.3 Observations in Context

In order to indulge more into the medical context, various observations were done at the Erasmus MC at the department of Plastic Surgery. This type of fieldwork gives a better understanding of the different roles and moments in the care path.

As mentioned above there were two interesting moments in the care path. For both of the moments the 'participant' type of observation was done. Meaning that the team of doctors and nurses knew that I was observing, however the patients would not know up front that I was a non-medical student. This meant wearing a white doctor's coat, making sure that I would blend in. For the consultations with the specialist nurse, I did get to ask questions during the observations as clarification. For the DPC I had more the role of natural observer, since I didn't get to interact with the patients.

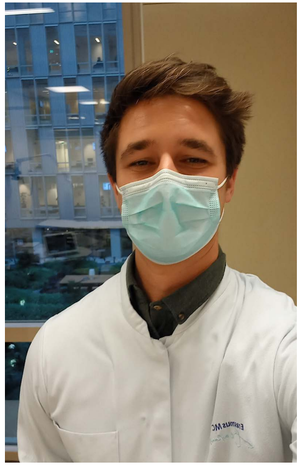


Image 3 Participant Observer, a day in the life of a doctor

Before the observations a few relevant research questions were stated as aim to be answered;

- How do patients get their information and at what points in their care path?
- What kind of information do patients get?
- How does the interaction go between the patient and the HCP's?
- What can be said about the influence of the way of working on patients at the EMC?

03.3.1 Results Observations

Next to making the context to design for more real -as a designer with no background in the field of the hospital- being at the clinic gave also insights into what working in a hospital is like.

Within this observation it was good to always keep in mind who is to be designed for; the user. Taking this perspective, gave a few insights in the matter;

- Time Efficiency
  Time is relatively short at the hospital. This means not so much time to explain a lot. Also reading into someone's history files goes quick and smooth, which is impressive because doctors switch between patients easily.

- Use of Imagery
  To explain to the patient what will happen, sometimes drawing is used, but moreover google images and a small database to show examples during the consultation. Other forms of information are given by digital and printed information documents.

- Empathy in Conversation
  Not much time to make a conversation too broad (e.g. asking how patients feel). This to come to the point. A role division is seen here; the specialist has the technical explanation, the specialist nurse is more in charge of the whole story and therefore the empathy in calming down patients.

- Willingness to Share Visual Information
  Generally patients were very willing to share visual information. This is something that they do from themselves, nobody asks them to share or take photos of their healing.

- Memory is lacking
  The memory of patients of how 'big' their treatment is compared to the results is sometimes lacking. Example: Patient thought the hole in his head was approximately 7 cm, where it was more like 17 cm. Patient immediately wanted to take a photo of the screen.

- Outcome (Dis-)Satisfaction
  Some patients can be dissatisfied with the results and look for it to be caused by the treatment, so outside themselves. Expectancy-Disconfirmation Paradigm; what is negative or positive can't be easily changed.

- Seeing a Team
  Along with the observations, it became clear that there are pro's and con's to seeing a team of doctors. What is positive is that everyone is seen together at once. There are less unclarities due to having to talk later and there is a logical division in the room (Dermatologist gets rid cancer, the Plastic Surgeon 'closes' the wound). On the contrary, patients could have a different team operating them. Also patients get a lot of information in a short time, which can be overwhelming after the DPC.

Image 4 Patient folders, given at/after the DPC.

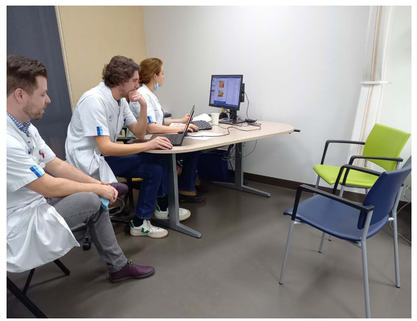


Image 5 DPC Consultation Room.

03.4 Interviews Core Actors

Next to observations, another step was done; open interviews with the involved other medical actors. For the sake of getting a representable look into different perspectives throughout the healing process, different actors along the care path were chosen, making sure to see care as an holistic process.

The benefit of this is that pain points -also called specific problems- during the process can be related to each other, or other events overarching the process.

The main aim of the interviews was to get an insight in the role of the actor and their perspective on pain points of the patient. The main research questions therefore were;

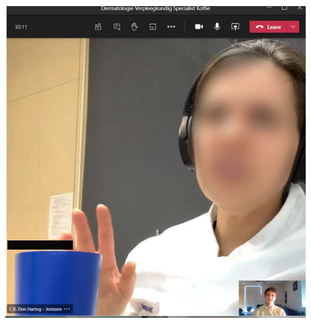


Image 6 Digital interviews with medical actors

- What does that care path entail from their perspective?
- How is information exchanged between actors along the care path?

Along with these questions a few role specific questions were asked. The results of these questions can be found back in the pain points of the patient journey, as well as the different actor descriptions in *chapter 03.6 Main Medical Actors.*

03.5 Skin Cancer Care at Erasmus MC

Thanks to the observations and interviews the care pathway could be made more detailed due to the fact that different steps were highlighted from a medical perspective. In Figure 10 the process steps to get to a more detailed care path are shown, because multiple iterations were made, the eventual detailed care path can be found in *chapter 03.7 Detailed Care Path or in Appendix 3.*

The perception of the skin cancer care as a whole got formed to a long process, with a combination of different expertises. Along the way there were good insights in the form of; basic understanding what the skin cancer care entailed, what information patients get throughout their process and what the different roles of actors are. This all together gives a basis of information to start Contextmapping with the main actor ; the patient, which will be explained in the next *section III Patient Perspective.*

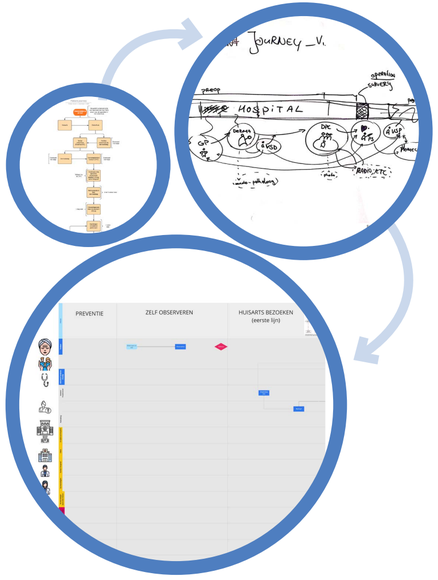


Figure 10 Going from a care path, through interviews, to a detailed care path.

Takeaways of this chapter

- A perception of skin cancer care from a clinical perspective was formed in terms of roles and tasks.
- Information most often gets shared in a verbal way assisted with some patient folders, which can sometimes overload patients.
- There is a willingness to share visual information.

03.6 Main Medical Actors

- General Practitioner
- Dermatologist
- Specialist Nurse Dermatology
- Plastic Reconstructive Surgeon
- Specialist Nurse Plastic Surgery

General Practitioner

Normally the general practitioner (GP) is the first healthcare professional that is contacted in the case of a patient having symptoms. The first diagnostics are done by the GP itself, it really is the researching phase; determining whether there is a case of skin cancer or not.

Tasks:

- Taking a biopsy when the observation can not determine whether it is cancer or not.
- Explaining the disease in a clear, understandable way
- Referring to a specialist in a way that is suitable for the patient (e.g. in paper for elderly)
- Supporting role in the aftercare, not actively involved. Patients are seen, though more as checkups.

Sharing information:
Basic knowledge can be shared on skin cancer, however that is not a task for the GP. The GP is more focused on the diagnosis rather than giving information

Dermatologist

Dermatologists are specialist physicians who diagnose, investigate, treat and manage skin diseases. The difference with the GP is that the patient is already diagnosed with cancer and referred by a GP or a other specialist. The Dermatologists' role is to make the right diagnosis and choose the right treatment. Next to further diagnosis dermatologists are responsible for treatment of cancer. Excision is most common in these cases.

Tasks:

- Performing diagnostic biopsies.
- Excision of cutaneous skin cancers.
- Advanced skin surgery and Mohs' micrographic surgery.

Sharing information:
Within the Erasmus hospital there are special multidisciplinary teams, consisting of e.g. dermatologists and plastic surgeons, who share information amongst each other. The physician is most of the time the one doing the technical medical explanation to the patients. The specialistic nurses normally do the further explanation and provide all the other information.

Specialist Nurse Dermatology

The Specialist nurses at dermatology are specialized in the treatment and care of a variety of skin disease patients. They on the one hand educate patients and on the other hand help in the treatment. All the information patients get from the dermatologists in the short consults can be overwhelming. Therefore the specialistic nurses are there to further explain, as well as presenting the whole story. This entails most of the time additional diagnostics. For an example, verifying if the patient knows what the treatment will be and explaining if this is not clear.

Tasks:

- Making sure the patient knows what is going to happen, explaining unclarities.
- Additional diagnostics that are important to know before surgery.
- Answering questions and asking questions regarding the home situations or someone's memory to prevent delirium.
- Handing over information in the form of folders.

Sharing information:
As the specialistic nurse also shares information with other specialists, for instance to arrange additional imagery, information should be given adequately. Patients are informed verbally, as well as with printed and digital folders.

Plastic Reconstructive Surgeon

After the excision of the cancer by the dermatologist, the wound is in some cases so complex that it should be reconstructed by a plastic surgeon. Plastic surgeons focus on closing the wound, while restoring the proper function and appearance of the patient.

Tasks:

- Explaining the treatment that is envisioned, as well as making sure the patient has the right prior knowledge about the possible outcome.
- Reconstruction of the basic functionalities of the patient's body.
- Closing the wound of the patient
- Creating a more normal appearance to improve self-esteem

Sharing information:
Within hospitals the plastic surgeon is involved in thinking along what the possibilities are for closing the wound. The plastic surgeon is mostly involved in explaining the technicalities of the reconstructive surgery to the patient.

Specialist Nurse Plastic Surgery

Whereas the dermatologists are there to explain the disease, the specialist nurse of plastic surgery is focused on the follow-up and aftercare. The patient care they provide takes place throughout the patient experience with the plastic surgery process. The focus here is on getting the patient ready to go home. This entails demonstration care of wounds and bandage, as well as daily living tips. During checkups after surgery, the specialist nurse is also seen as the 'case manager', since they are the contact person in case of complications. Often they take care of the wounds.

Tasks:

- Giving information on wound care and the healing process.
- Contact person in case of complications as well as information.
- Organizing care for the healing process, such as bandages and homecare.

Sharing information:
Within the care at the Erasmus MC, the contact between plastic surgeon and specialist nurse is direct. The same goes for specialist nurses and the patient.

03.7 Detailed Care Path

Preop Context | Diagnosis | Reconstructive Surgery | Aftercare

Preoperative Phase

SUB-PHASE	DESCRIPTION	INVOLVED
Prevention and prior knowledge	Having awareness from prior skin cancer, hereditary cancer or knowledge in another way.	
Self Observation	First signs of irregularity, observing something on the own face.	
Going to a GP (1st line)	Going to a General Practisioner with the first symptoms. Sometimes the GP can treat	
Refer to a doctor	The referal from a GP to a specialist of a hospital.	
Other Hospital (Peripheral)	Specialist healthcare is considered 2nd line. Complex cases get refered to the 'super specialists' of Erasmus MC (academic).	
Making a Diagnosis	A diagnosis is made by biopsy, and sometimes additional diagnostics. Often patients get to know the results of having cancer.	
Awaiting diagnosis surgery at home	The period between the diagnosis and the plan for surgery.	
Dermatoplastic Consult (DPC)	Consult at the Erasmus MC in which the dermatologist and plastic surgeon both share the options for surgery	
Additional Diagnostics	To have more complete diagnosis, sometimes the patient has to undergo additional diagnostics, such as radiology.	
Awaiting surgery at home	Period between the plan for surgery (often DPC) and the surgery itself.	
Preparing for Surgery	Preparing for the surgery, such as the anesthesist and the life after the surgeries with the specialistic nurses.	

Postoperative Phase

Mohs/Breuninger Surgery	Surgery that is done to resect the tumor. Mohs often happens on one day in rounds, Breuninger is spread over multiple days. Surgery is done by a dermatologist.
Awaiting Reconstructive Surgery	Between the Mohs and Reconstructive Surgery there is a day of waiting time. Sometimes patients can wait at home.
Consultation Defect/ Intake for nursing	After the Mohs or Breuninger the defect gets assesed on what the reconstructive surgery technique will (probably) be.
Reconstructive Surgery	To close the defect surgery the reconstructive surgery takes place by a plastic surgeon. Sometimes takes place multiple times.
Recovering from Reconstructive Surgery	After the reconstructive surgery there is a time of recovering from the surgery in the hospital and then at home with homecare.
Checking wound	After a week the wounds are checked on any complications, healing of the wounds and stiches removed.
Aftercare/wound healing	The aftercare takes place at home, this process takes longer, often 3 months.
Visiting Hospital for complications	If there are any complications, the hospital is visited again, this time only the specialistic nurse is there.
Aftercare/wound healing	The aftercare takes place at home, this process takes longer, often 3 months.
Last checkup plastic surgeon	As a last checkup for the result of the reconstruction 3 months after the surgery there is a checkup with the plastic surgeon.
Scar healingP	The healing of the scars is a timely process that happens over a year.
reventive Checkups	Since a patient has had skin cancer, preventive checkups are there to make sure the cancer cells don't come back

Section III: Taking the Patient Perspective.

Chapter 4 Patient Perspective

Chapter 5 Co-creating with Healthcare Professionals

In the previous section, the context of Skin Cancer Care was explored. Through observations and interviews a better understanding was formed from a clinical perspective.

The purpose of this section is to show the missing perspective and thus context of the patient.

It dives into how patients have experienced the journey themselves by doing a context mapping study described in Chapter 4.

In chapter 5 the patient study is taken as a basis to develop the insights gained into actual ideas, through the use of co-creation sessions with involved healthcare professionals.

04 Patient Perspective.

04.1 Background

Based on the perspectives of the HCPs, a complete overview of the care path for FSC patients could be made. However, understanding what a patient goes through from a clinical perspective does not suffice in gaining an understanding of the needs, concerns and wishes of FSC patients.

As stated in chapter 2 the PE is explained as:

> *"How the patient feels throughout the sum of all interactions that influence patient perceptions across the continuum of care."*

The patient perspective should be taken into account, both preoperatively and postoperatively, outside the scope of the hospital. A more in-depth understanding of how patients perceive and experience their treatment as a whole was necessary. This makes it possible to understand the interrelated problems along the patient journey. To define the user study the focus was laid upon shared decision making between the patient and HCP and expectation management.

The three main research questions for the patient study were the following:

1. *How did the patients experience their treatment process as a whole?*
2. *Which aspects of shared decision making were present through the treatment process and in what form?*
3. *Which aspects of expectation management were helpful, or could have been helpful?*

04.2 Research Method; Context Mapping

To unravel the PE it is important to 'tap' into the deeper levels of knowledge. Not only what people say and think, but also what they know and feel and sometimes even dream about.

A qualitative research method for this is Contextmapping (CM). Visser et al., (2005), propose the procedure of CM as; preparing, sensitizing, making and discussing in a generative session. For this project the generative session was replaced with a semi-structured interview with the sensitized patients, because of the pandemic. Within this session explorative techniques are used to learn about needs, wishes, motivations and experiences. Afterwards the collected data is analyzed, captured and can be used as a basis to design with.

Sensitizing the patients
To sensitize means 'to make sensitive for'. This is an important part of CM, since people are not always remembering experiences or are not aware anymore of what was important for them.

Therefore, patients were sent a sensitizing booklet by post. This booklet is a cultural probe with exercises that make people aware of their own life. In this way they could prepare for the interview by recalling experiences from the past and with that as a basis be able to think about what matters in the future. This follows the 'Path of Expression' as explained by Sanders & Stappers (2012), See Figure 11. Often people

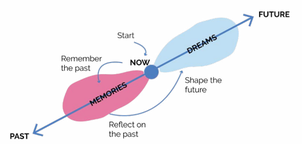


Figure 11 Path of Expression by Sanders & Stappers (2012)

find it difficult to think about the future. That is why it is important to get a idea of the 'Now'. Thereafter you can remember the past, reflect on it and find out how you could shape the future. Taking these thinking steps will making future thinking more easy.

In Appendix 2 the booklet can be found. It consists of six small exercises that had to be done consecutively. Topics of the booklet were chosen deliberately to have more focus on the shared decision making, managing of expectations and the feelings along the treatment process.

Image 7 Sensitizing Material, booklets including stickers

Filling out the booklet and sending it back to the interviewee were not mandatory, though could help to ask more personalized questions. Even if the patient decided not to fill in the booklet, they would have gone through it and thought of the exercises that were in there.

Interview at a distance
As an alternative to the generative session, semi structured interviews were conducted. The semi-structured interviews took place fully digitally. During the interview the booklet that the patient sends back or a digital one were used to work with during the interview.

04.3 Procedure; from interview to data

All the preparation started by sending the sensitizing material to patients to their homes. Some of them wanted the booklet digitally, since that seemed more convenient for them, however, they were sent a physical one too.

All interviews took place all digitally, through Zoom, which was due to corona restrictions. The duration of the interview was a minimal of one hour, however if the patients wanted to take more time this was of course possible.

Ethical considerations
For this project the ethical considerations were taken into account by having the Medical Ethics Committy approval (METC) of an ongoing research at the Erasmus MC.

However, this project had a slightly different approach of working, since it involved sensitizing material, which in some cases can be sensitive material. Therefore a second consent form was used digitally.

Selecting and recruiting participants
For the recruitment process the Electronic Patient Database of the Erasmus MC was used.. FSC patients that had facial reconstructive surgery before were contacted if they would want to cooperate with the research. In total 5 patients were recruited in this way.

To get a wider perspective, personal contacts were recruited as well. They were not part of the group of patients, but had similar surgeries. This group consisted of a cosmetic nose surgery patient, a patient with a smaller excisions of cancer without the need of reconstructive surgery and a patient who had Mohs surgery.

		Description	Time (since surgery)	m/v	Age	Occupation
Contextmapping Interview		Nasal reconstruction, forehead flap	one year	m	55+	Working
		Nose amputation	two years	v	70+	Retired
		Nasal reconstruction, local flap	one year	m	25+	Working
		Nasal reconstruction, local flap	two years	v	45+	Working
		Lip reconstruction, free flap	two years	m	60+	Working
Open Interview		Forehead excision	-2 weeks	m	55+	Working
		Lip reconstruction, local flap	one year	v	50+	Working
		Cosmetic Rhinoplasty	5 weeks	v	25+	Student

Figure 12 Democraphics Patients Interviews

Semi-structured interview
Since these interviews are about the patient, their lives and their experiences, these experiences can strongly vary per individual. To ensure that the topics would not differ too much between patients, it was made sure that the interview was semi-structured (Patton, 2002). This gives freedom to have a flowing conversation exploring unforeseen interesting topics, while still focussing on certain research questions.

To make it easier for the participants, the sensitizing booklet followed a logical order of topics. One can use the booklet, and especially the personal information of the patient, as a guide to talk about. Each interview consisted of:

1. *A brief introduction about the study followed by introductory questions.*
2. *Going through the booklet and asking questions upon these exercises followed by questions on the topic.*
3. *Open ended conversation about the outcomes of the project*
4. *Wrapping up the interview*

Data analysis
Before the interview the patients were asked to send photos of the sensitizing booklet. Unfortunately not all of the patients did this.

During the interview digital booklets were also used digitally together if the patient did not fill in the booklet. In this way the data acquired from the patients would be on the same level.

All the interviews were transcribed after the interviews were recorded. Initial interesting parts of the interview were highlighted.

A day after transcribing, the transcripts were printed and read through a second time to make sure to highlight interesting parts (See image 8).

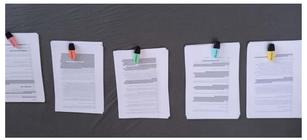


Image 8 Transcripts ready to be scanned.

Thematic analysis
Thematic analysis is a method for identifying, analyzing and reporting patterns (themes) within data. It minimally organizes and describes the data set in (rich) detail. (Braun & Clarke, 2006)

A thematic analysis is a widely-used qualitative analytic method, though there are no concise guidelines around thematic analysis. This is also the advantage, through its theoretical freedom

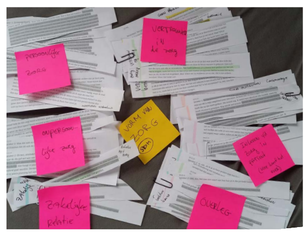


Image 9 Example of a Theme, made up of multiple codes

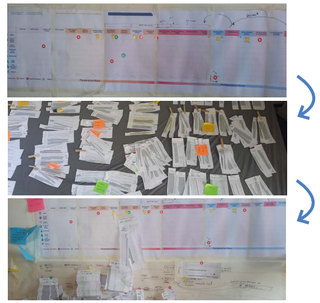


Image 10 a. Clustered themes; b. Empty patient journey; c. Themes on the journey

this potentially provide a rich and detailed, yet complex account of insights.

In this project, the thematic analysis was done physically. This visual way supports an iterative process, being able to move highlights of text around.

The process was as following:

1. Giving color codes to know of which interview the highlight came.
2. Giving codes to highlights, to paraphrase the data, giving an interpretation.
3. Cluster the codes, such that they form encapsulated themes and all the data gets brought together.
4. Taking a day away from the data before evaluating the themes.

The themes were evaluated, by interpreting them, which can be read in Chapter 4.4.

04.4 Interpreting Data; findings

As time consuming as the first part of the thematic analysis is, the data that comes out of it can be very rich. Meaning it conveys a good resemblance of the data acquired.

To interpret the thematic analysis into findings, it was chosen to integrate some of the themes into a Patient Journey (See Figure 14, p. 36-37 or Appendix 3). Some quotes were used to give the patient perspective of the phases in the journey. This journey can be seen as the canvas on which, or with which, you can design.

The other important themes were used to make a theme matrix (See Figure 13 or Appendix 4). In this matrix the sub-themes are organised on their positive or negative effect on the patient during the treatment process.

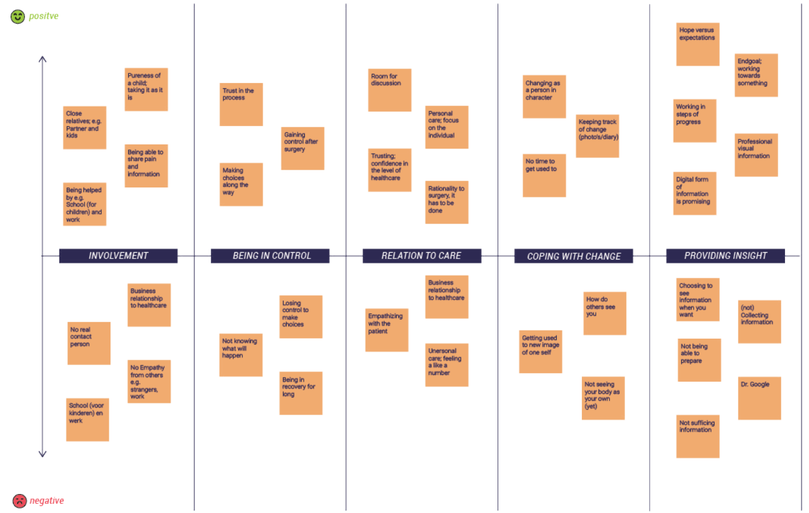


Figure 13 Theme Matrix Patient Study, clustered subthemes

PATIENT JOURNEY; Reconstructive surgery of skin cancer patients.

Pre- and post-operative patient experience of skin cancer patients; journey from prevention to aftercare.

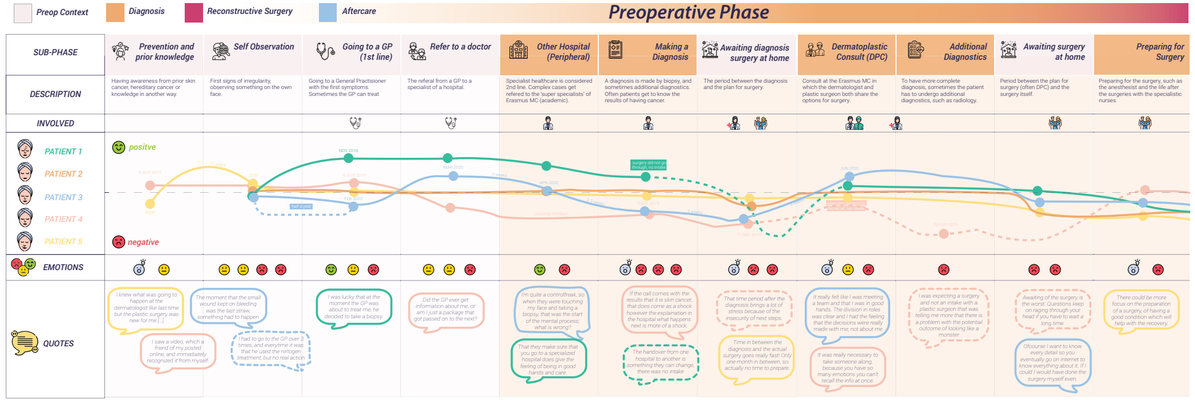
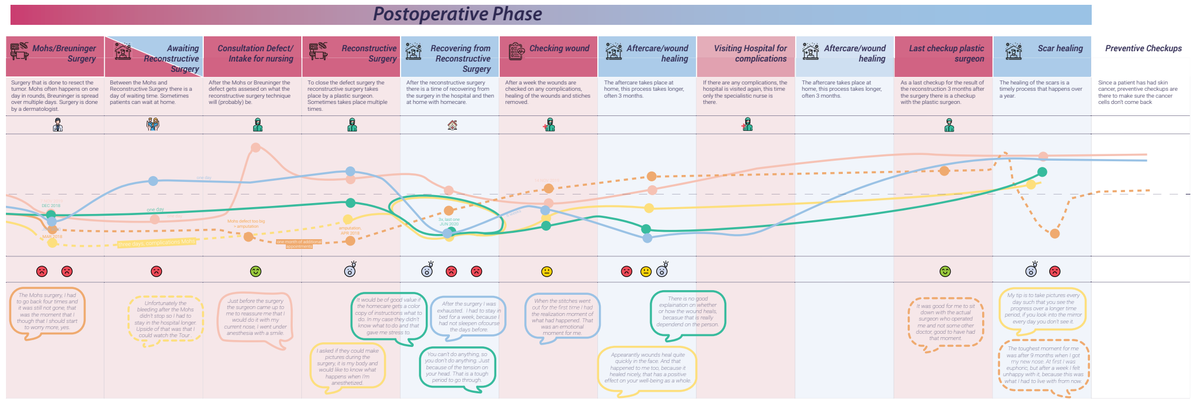


Figure 14 Patient Journey Map: Reconstructive surgery of skin cancer patients



Looking at the results in the form of the patient journey and the theme matrix, a few findings can be described:

1. **Every case is different, so is every treatment process.**

As a result of talking to a variety of patients, there were evidently different cases and treatment processes. This is seen in the patient journey. However, the user group is not the only reason that every treatment proces is different. Since the Erasmus MC is an academic hospital a lot of the complex cases that require reconstruction are treated here.

For these complex cases, patients often come from another hospital. This extra transfer moment can cause problems in the handling of an intake, which influences the patient experience in a negative way. The main tendency is; the more complex or individual the case, the more imperfections in the process become visible. Such as intakes or handing over to home care.

> *"The handover from one hospital to another is something they can change, there was no intake."*

2. **Uncertainty and time; a roller coaster ride.**

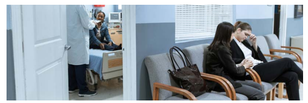
If a closer look is taken at the patient journey, it is seen that it differs per patient how long the preoperative phase is and how this is perceived. The overall explanation of patients is that the preoperative phase is a phase that is full of uncertainty.

This uncertainty is mainly because of the fact that there are indications of the size of the tumor, but it can never be said for sure. Especially in the cases where there is a chance of having to do a nasal reconstructive surgery with a Forehead flap (voorhoofdslap), uncertainty is experienced more.

> *"I was expecting a surgery and not an intake with a plastic surgeon that was telling me more that there is a problem with the potential outcome of looking like a monster."*

Time is also important in the treatment process. The healing process is most of the time experienced as long and without help. For some the time between diagnosis and surgery is a blessing for others the opposite, explaining it as stressful.

> *"Time in between the diagnosis and the actual surgery goes really fast! Only one month in between, so actually no time to prepare."*



3. **Involvement with caring social context.**

Who is involved outside of the hospital is also of great influence on patients. Often partners, family and close friends are of great help. They are often persons to share the pain with, which is positive. The involvement or empathy is not always felt from strangers or people at work.

What was mentioned as particularly important was to take someone along to the appointments at the hospital. Consultations with doctors are moments in which there is a high density of information and also emotions of sometimes unexpected news. Sometimes patients are too overwhelmed and cannot recall information in a good manner.

> *"I was expecting a surgery and not an intake with a plastic surgeon that was telling me more that there is a problem with the potential outcome of looking like a monster."*

4. *Being in control or losing control*

One theme was also very person dependent; the sense of being in control. All of the patients had trust in the knowledge and competence of the healthcare professionals. Some patients were fully trusting the decisions that were made, also because sometimes they did not know they had a choice.

Others were really bad at losing the control over their own choices and would like to be involved in all the choices they could make and wanted to be actively informed.

These patients often found their control back after the surgery by actively working on their recovery.

> *"I'm quite a control freak, so when they were touching my face and taking a biopsy, that was the start of the mental process; what is wrong?"*

5. **Relation to care**

How the actual care is experienced is something that is part of the relation to care. Patients indicated that a personal way of care is preferred, with a focus on the individual. The personal needs and wishes are best met if there is room for discussion and the feeling of being heard. Preferably with the same doctor that they have seen earlier or who is going to do the surgery.

> *"Just before the surgery the surgeon came up to me to reassure me that I would do it with my current nose, I went under anesthesia with a smile."*

Within the Erasmus MC they work with teams, so the surgeons that are seen before surgery are not always the one performing the surgery. Resulting in having impersonal care, having the feeling of a business relationship to care.

> *"It was good for me to sit down with the actual surgeon who operated on me and not some other doctor, good to have had that moment."*

.Patients explain that the change they physically and mentally go through is something to get used to. This can be hard sometimes, having the idea that some parts of your body do not feel like your own. What was also mentioned was having fear of looking at oneself in the mirror or thinking about how others see them.

Patients also mentioned to have changed in character. What helped this was keeping track of their appearance and working towards a goal.

> *"My tip is to take pictures every day such that you see the progress over a longer time period, if you look into the mirror every day you don't see it. "*

6. *Providing insight*

One theme included what information was given now and how patients would like to see information from the hospital in the future.

What was considered negative was the information up front. The timing and the amount of information are important. Having to google information them self can result in the Dr. Google phenomenon; finding the wrong information and even being scared.

What was considered good information was the information that is given by the hospital, but in a different form. This being digital or with the use of professional visuals.

Overall it is important to give insight in the treatment, by going for hope instead of expectations. Working towards an end goal can give this hope. Important is that this is done in steps of progress, though with disclaimers that every person is different.

> *"There is no good explanation on whether or how the wound heals, because that is really dependent on the person."*

04.5 Conclusion and Discussion

The patient interviews showed how different the patients can experience the treatment process. When looking from their perspective they prefer care that is personal and giving insight in the future, to expect what is to come. Although the future outcome is uncertain, and the patients know that the healing process takes time, it is experienced as tougher than expected. An expectation is always different from what it turns out to be.

At the same time patients have trust in the teams and specialists they encountered in the Erasmus MC. The consultations, however, can be very overwhelming due to the overload of information and the sensitive topics which can be a shock to patients. Still, all the personal care they receive and room for thinking along is found pleasant.

On the other hand, there is this sense of control that is lost before and during surgery, which some patients can deal with in a better way than others. This sense of control is also regained after the surgery by taking care of oneself more and seeing progress.

Answering Research Questions

1. *How did the patients experience their treatment process as a whole?*

The patient experience as a whole is best explained as a roller coaster. This is mainly due to the uncertainty and for some due to the hectic months before the surgery. A ride that is without control and without real decision making. The last part of a roller coaster is always slow riding back to the end/beginning, so is the treatment process. This healing process takes a long time, which is mostly done by oneself and not with help of the hospital.

2. *Which aspects of shared decision making were present through the treatment process and in what form?*

Two different aspects of shared decision making are present; informing and coming to a shared understanding. However, there are not many decisions patients can maken, only the moment to do a surgery can be a choice.

In order to make decisions together, patients need to get informed to a certain level. This is also dependent on the patients themselves. If they are eager to know, the questions are welcome and answered. For others it might feel that the information that is given could have been given in more detail or in another, more digital or visual form.

3. *Which aspects of expectation management were helpful, or could have been helpful?*

Expectations are present, when HCPs are explaining to the patient what is ahead. This is easier said than done because there is the difficulty with the uncertainty how big the tumor can be and the way you convey how a patient will feel along the whole process. What makes it harder to explain is that it is not the patient's reality yet.

However, you can only explain what to expect to a certain level. Patients have said that there are things that could be explained differently, such as the preparation for the surgery or staying in good shape. At the end it is not only expectation management on how something will be, the road to the result is more important.

04.6 Summary Patient Study

Once you look at the broader perspective of a patient journey from the treatment as a whole process, overarching themes become visible. With the help of this patient study the patients perspective was mapped more vividly, as well as how patients would like to see the care to be changed in the future.

In the next *chapter 5 Co-Creating with Healthcare Professionals*, the findings of this study will be used; finding ideas for the future, inspired by the information gathered from the patients.

Overall, the Erasmus MC has a positive image if you hear the positive stories of patients. Patients value the professionalism, knowledge and expertise at the Erasmus MC.

There are also some things that can be improved. Referrals are moments that are of importance, since communication errors can occur at these times. Giving information on the whole treatment process is something that can be done in a unique way. Patients suggest that this could be digitalized for instance. This can be at the consults, were it not for the fact that patients are eager for information at a time that is more suitable for them. The consultations themselves are considered to be overwhelming in information and emotion.

Takeaways of this chapter

- Every patient is different, so is every treatment and the way that the patient reacts.
- All patients experience uncertainty due to the nature of the disease.
- For some the time towards a surgery can be experienced as pleasently quick for some more stressful. Time is experienced more as a long process in the months after surgery.
- Consultations are often a density of information and emotions. Patients would like information after the consultations, in their own time.
- The sense of control is lost during the surgery, though in most cases regained after surgery.
- Patients that are coping with change can benefit of keeping track of the improvement.
- When looking at the future it might be better to talk about hope instead of expectation.

| Sculpture Duna by Jaume Plensa

05 Co-creating with HCP's.

05.1 Background

In the previous chapters the perspectives of patients were investigated, resulting in a better understanding of their experiences in the form of a Patient Journey and a themes matrix.

Along this journey healthcare professionals (HCPs) are of great importance in the treatment. They support and inform the patients. Since HCPs see more patients, they have relevant knowledge in regards to needs, wishes and concerns of patients.

As described in chapter 2.4 Co-creation, and by Sanders & Stappers (2008) the approach that was chosen for this project is co-creation. Involving different perspectives helps to prevent being focused on assumptions from one perspective only. Therefore, a series of co-creation sessions was conducted with HCPs, on the basis of the patient perspective.

The goal of the co-creation sessions was to identify, collect and test potential ideas;

- Identifying the moments in the patient journey in which to intervene.
- Collecting assumptions on the critical points during the patient journey.
- Testing, by proposing ideas, getting feedback on them and elaborating on the ideas.

To limit the broadness of the session, one theme was chosen to explore: Dealing with Change. This was chosen to make sure that the HCPs could focus on their perspective.

05.2 Research Method; Co-creating

As described this session's objective was to inspire participants with the data and insights collected in the previous chapter. During this session the perspectives of varied specialists were to be merged into an exploration of different perspectives.

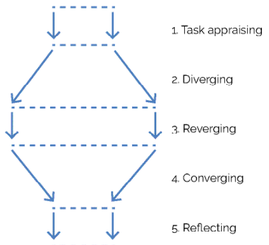


Figure 16 iCPS Module by Heijne & van der Meer (2019)

05.2.1 Creativity process

Creativity is not something that emerges out of nothing, it can be facilitated. Often ideation is seen as the generation of options. This generally comes in three waves, as shown in Figure 15. A first wave with everyday, common and expected ideas. The second wave brings silly and idiotic ideas without any attention given to the usefulness. After this a third wave with useful, combined with novel ideas come up. This is often referred to as 'from silly to good' (Heijne & Meer, 2019).

A common, well-known way to describe the process of creativity is the 'creative diamond', sequencing diverging and converging thinking. The iCPS Basic Module of Figure 16 is an expanded creative diamond with five sub-steps. Here Task appraising, Reverging and Reflecting are added. This formed the basis of the creative session outline.

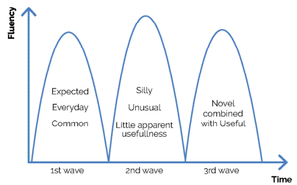


Figure 15 Three Waves of Ideation by Parnes

05.2.2 Small Digital Sessions

Unfortunately, the corona restrictions made it hard to get all the HCPs together at once. We therefore opted for small one-on-one digital sessions instead. A limitation of this is that participants could not react or elaborate on each other's ideas. The benefit, however, was to get more in depth feedback on their personal workflow and ideas from their own perspective.

5.2.3 Participants

The participants were contacted through the Erasmus MC, and were from different specialties along the patient journey;

Department	Role
Dermatology	*Specialist Nurse*
Plastic Surgery	*Specialist Nurse*
Plastic Surgery	*Surgeon*

05.3 Co-creation Sessions

The short co-creation sessions were held on online collaborative platform Miro in combination with a Teams meeting. This was done one-on-one, thus one facilitator and a participant.

1. **Welcome and introduction**
Giving some updates on the project and introducing the Problem as Given (PaG), which was stated as:

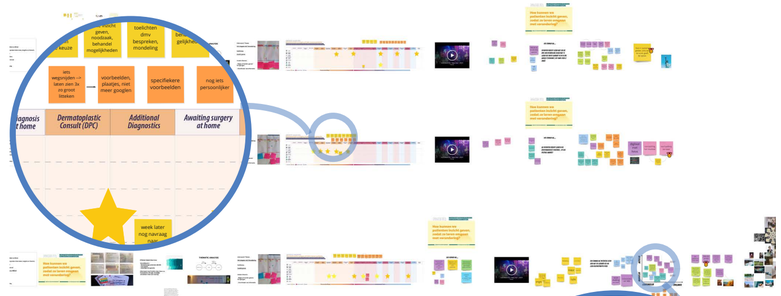


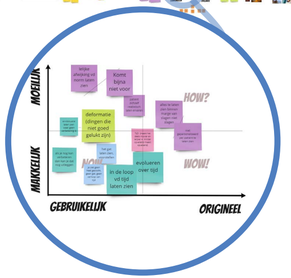
Figure 17 Co-creation, Creative Session in Miro with HCPs

"How can we give patients insight, such that they learn how to cope with change?"

2. **Getting inspired**
Going through the process of the patient study, with examples of the sensitzing booklets of chapter 04.2 and explaining how the process developed to the insights and themes from the patient study. Highlighting the interesting themes for this session; dealing with change and the sub theme giving insight.

3. **Patient Journey and the workflow**
For the session the Patient Journey left blank, with only the phases shown. This was done to focus on the workflow of the specific participant. There were moments highlighted with a star in the workflow on moments where potential ideas would be fruitful, moments of interaction.

Participants were asked in what form they give patients insights at these moments. This was asked see if this information was correct as well as checking the status quo. All of this information got written on the yellow post its in Figure 17 .



4. **Changes in Workflow (wave one)**
Participants were asked what they would change in their current workflow to give more insight to future patients. These ideas are the ideas of the first wave (see Figure 15). These ideas or improvements are shown on the orange postits in Figure 17.

5. **Visual Stimulation (wave two)**
In this break there a sci-fi short movie was shown, with colorful animations. Before the

movie was shown, participants were asked to remember what they found attractive. During the video, the facilitator had time to filter some of the ideas. Afterwards they were asked what they found beautiful, which was written down as inspiration used in the next part.

6. **Problem as Perceived**
As a problem statement should be clear and understandable for the participants, they were asked to rephrase the problem statement in their own words. To make this a little more interesting and specific, a few words from the Visual Stimulation had to be integrated.

7. **Brainwriting ideas (wave three)**
To stimulate a wide variety of ideas, the Brainwriting-on-post it technique was used. This was combining the ideas/changes they mentioned earlier. In this way more developed ideas were the outcome.

8. **C-Box (only once)**
With only one participant was there enough time to use the C-box technique. This technique helps to elaborate the ideas more and at the same time converges ideas since you select them for a specific reason. The already existing ideas are plotted along two axes: originality and feasability, resulting in the interesting quadrants; NOW, WOW! and HOW? (See Figure 17)

9. **Choosing a winner concept**
All participants were asked to select a winner among the ideas that they came up with and why this was the winner. Thisensures reflection upon the ideas and makes explicit why it is a good idea. Participants were also asked to choose a picture they thought resembled their idea.

05.4 Interpreting ideas; Findings

As findings of the co-creation there were two kinds of results; winning ideas and potentiallly critical moments. Both will be described below.

05.4.1 Winning Ideas

The end result of the sessions were winner ideas of the HCPs. All the ideas were interesting, but were not chosen for a reason. For good measure, all the ideas were collected to go through them at a later stage. The final concepts could be explained in more detail:

Concept 1: Automated options

Description
This concept consists of a system, in which a photo is placed. The doctor is able to give the options of surgery up front. It is important to note is that it is completely automated. The doctor does not have to go through the explanation in words, though can show the different outcomes visually.

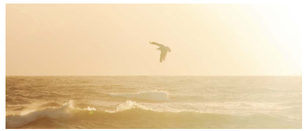
Problem tackled
For doctors it can be difficult to explain verbally beforehand what the potential outcomes will be in the future. Also, the outcomes can be so diverse that it is difficult to show the differences.

Concept 2: Custom Predictions

Description
This concept is all about the predictions of the result after the whole treatment.It may be reassuring and stimulating to grow towards photos of the future situation. What is important to note with this is that the patient can see the pictures as the actual result, and might compare it to the current situation.

Problem tackled
It is difficult to explain or show patients how something will be in the future, something they can not grasp easily. It is not yet their reality.

Concept 3: What if you do nothing?



Description
It would be interesting if you could show per individual patient what happens if they do not take action, within the margins of failure and success. This could help them to accept the surgery. It would give them perspective and relief.

Problem tackled
This has to do with remembering pleasent memories better, the recall bias. People tend to forget what they have won and remember more easily what they have lost.

05.4.2 Potential Critical Moments

As a result of the session, a few critical moments on the Patient Journey could be taken into account to work with. These are moments that otherwise would have been overlooked.

- *Pre-operatively there are things that can be explained better by giving more visual examples, however these* examples should fit the patient well such that a good example can be given and the patient can visualize the final outcome.
- Patients forget *how big the defect was before the reconstructive surgery.* People forget what they have won instead of lost*. Patients do not look back in a way that focuses on the surgery. They also don't think about how it would look if nothing had been done.*

05.5 Conclusions and Discussion

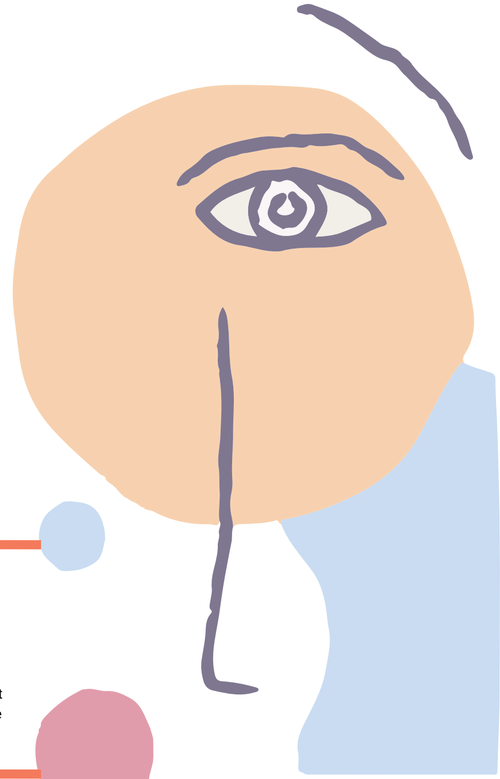
What was interesting to see was that the patient perspective was not prominently present in this co-creation. It was merged with the workflow of the HCP's that participated. This merging of perspectives was of course a goal for the creative co-creation session, but it was not anticipated that it would work.

Also the limitation of time and the fact that the session was one-on-one, was anticipated to affect the results of it. Still there were a lot of new ideas formed.

What especially became more prominent was that every idea had to do with a timeline. No ideas were for one particular instant moment. All the ideas could be applicable for a longer period in the treatment process. This can be seen as a turning point in wanting to design for longer lasting care.

All together the ideas gathered in the co-creation session gave an impression on how the HCPs see the theme of 'Giving insight to patients' and with that know how to cope with change.

Finally, all the perspectives were brought together, providing a good basis for the next step; defining what should be designed. The following *Chapter 6* will focus on the synthesis towards one design goal. This is done by combining the information in a workable design goal and a design vision on how to tackle this. The chapter debates the objective and the future vision.



Takeaways of this chapter

- People tend to forget what they have won instead of focusing on what is lost.
- Examples that are given, to show the expectations should fit the patient.
- Ideas that are not solely for one moment are interesting, interesting when they are applicable for a longer period of time.

Section IV: Synthesis.

Chapter 6 From findings to design.

This section is about the synthesis of all the information that was gathered in the previous section and chapters. Synthesis literally means to bring together, making one and form. This project understands synthesis as finding out what the key findings are of each chapter. In this sense the key findings of each chapter are consolidated into a desgin foal and design vision. As a consequence, some edsign limitations were defined.

06 From findings to design.

The previous chapters showed that there were a lot of insights and possible critical points to intervene. The co-creation with HCPs helped narrowing down the useful information by combining the patient and the clinical perspective in the form of feedback and small ideation.

In this chapter, the information will be synthesized towards a design goal, a design vision and design considerations.

05.6 Combining studies; Patient Journey Collage

All the information became a little overwhelming. To get into a design mindset, it was chosen to make a collage. A collage is a visual representation of, for instance, a context, user group or product category (Bruens, G. , 2007). It helps to get you into the right visual mood and for this project it helped to convey the treatment process of patients.

A common explanation of patients for the treatment process was that it felt like a roller coaster ride. A ride where there is no time for reflection and you cannot disembark, nor steer.

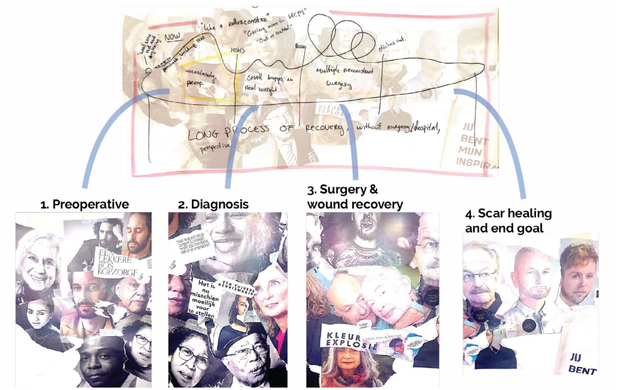


Figure 16 Collage of Faces, resembling the treatment process, with four parts.

In Figure 16 you can see the collage with an overlayed sketch, which resembles the treatment process as a metaphor of a roller coaster, split up in four parts.

Four parts can be distinguished in the collage; Preoperative, Diagnosis, Surgery & wound recovery and, lastly Scar healing.

1. **Preoperative**
   A lot of different people deal with the situation they find themselves in, in a different way. However, everyone has initial concerns.

2. **Diagnosis**
   It is difficult to imagine what the treatment process will be like. People cannot make a good, lively impression of it. In this part, it is of great importance that there is a good intake, e.g. when coming from a different hospital.

3. **Surgery and wound recovery**
   There is a thin line between frightening the patient and depicting reality. This is difficult for the patient itself, as well as the partners. They should be taken into account as well.

4. **Scar healing and end goal**
   Patients want to know what they can expect and what they are doing it for. Facilitating how patients look back on the period of recovery and emphasizing the progress they made.

06.1 Design Goal

In previous *Chapter 02.1*, an inital design goal was stated. During the context and patient study it became clear that the treatment process should be seen in a holistic way. Only focusing on one certain moment would not lead to a solution, since there are more factors in a patient's process. Therefore, the new design goal was defined as above.

*"My design goal is to **empower** facial skin cancer patients to have **a healthy look into the future,** while making sure to **leave the right memories behind.**"*

Empowering, in this context, means to give power to the patients to do something themselves. This can be in a lot of different forms; for instance, being able to inform themselves or keep track of their own treatment.

Healthy look into the future, refers to making sure patients are aware of what is ahead of them with the right information. This will hopefully ensure that they will be better prepared for what is to come, instead of being frightened by incorrect information they found on the internet. what makes this difficult, is that patients should know that everyone is different. So is the future. That uncertainty may be difficult.

By ***leaving the right memories behind*** patients are assisted with looking back to where they came from. The importance of this is to show that there are things won instead of lost in their situation. What makes this a difficult part is that people recall negative moments better than positive moments.

06.2 Design Vision

Metaphors are a way to inspire. For instance, inspiration for new solutions can be derived from the process of mapping between inspirational resources and the problem to be solved. Metaphors are a way to emphasize what qualities a new design should or could have (Casakin, 2007).

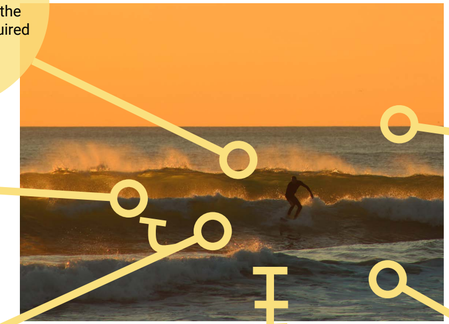
In Chapter 6.1 a metaphor is used to describe the current experience patients have with the treatment process. You can also make use of a metaphor for a future vision on a design and its qualities. Comparing a known situation that is not related to the topic helps to understand what you want to design.

"I want my design to feel like choosing the right wave when surfing on rough sea"

A few qualities that can be deducted from this metaphor can be seen in Figure 17 on the next page.

Design Vision:

"I want my design to feel like choosing the right wave when surfing on rough sea"



See the wave ahead;
Have an idea what will come. The surgery, the impact, what is required as preparation.

Chose the right wave at the right time;
Not having to choose to have surgery immediately.

The sea is in control, with possible waves smashing back;
Have an 'at ease' feeling of the whole process, giving away control to the HCPs, but also to the uncertainty and possible complications.

Decide your own direction;
See what happens if you chose not to take the wave or take it differently.

See the steps ahead to get to the end goal;
Know what you are doing it for and creating perspective.

Enjoy the ride as it is;
Have an 'at ease' feeling of the whole process, at parts of the journey that are out of your control.

Figure 17 Design Vision with some qualities highlighted.

06.3 Design Considerations

To materialize the design vision, some design considerations were stated before the design process.

- There should be decisions made to go in one direction. During the patient study a few stories formed a feeling of who there is to be designed for. Due to the fact all the stories showed a variety of people, not all patient problems can be tackled at once.
- Personalization is something that was mentioned by patients, becasue otherwise information is not perceived as fitting. In order to make sure that this personalization is experienced by the patients, the content of the design should be tailored to them specifically.
- Naturally the design is something that should be aesthetically pleasing. However, it should be taken into account that the target group is of older age. This brings about some usability issues, such as limitations in the user interface.

06.4 Project Aim

The end result of this project aims to be a good combination of feasibility, desirability and viability.

As this project has more characteristics of a research, the feasibility (can it be done?), and desirability (does it fit the users wishes?) are something that would be the core aim. Of course viability (will it last?) is of importance in this project, but will follow the other two.

The aim for this project can be restated as:

> *"This study aims to bring about a positive patient experience along the treatment process, through experimenting with immersive technologies."*

In the next Section V Conceptualization, the ideation of this project will be described that will bring this aim to life.

Section V: Conceptualization.

Chapter 07 From Opportunities to Concepts

Chapter 08 Experimentation

This section is all about going from the information gathered in the previous sections towards actual ideas and concepts. With the final concept evaluation in mind this section also shows how the final concept is prototyped through experimentation with Augmented Reality.

In the previous Section IV Synthesis, the information was brought together to form a design goal, design vision and an aim for the project.

In chapter 07 Conceptualization, the focus is laid upon ideas. By showing the ideation that took place during the observations, interviews, patient studies and co-creation session, this chapter highlights what is valuable ideation given the newly stated design vision and project aim. A hindsight in making sure to show the path of ideas. From opportunities to developed concepts. At last this chapter shows the final concept: Face it.

In chapter 08 the experimentation that was done with AR and the prototyping of functionalities of the final concept Face it are described. All leading to a test tool with which the evaluation tests could be done.

07 From Opportunities to Concepts.

When the actual designing comes into a project there is always a basis of small ideas already there. All the information, actors that were talked to and the context that were explored already have shown promising ideas. In chapter 07.1 a step back is taken to highlight some ideation that was done and showing the process of going towards conceptualization.

The following chapter 07.2 Conceptualization shows how ideas together with the gathered information form three different concept directions.

In chapter 07.3 even more converging takes places by forming one specific concept, which will be summarized in the final concept Face It in chapter 07.4

07.1 Ideation

07.1.1 Ideation Observations and HCP interviews

Experiencing the context by doing observations

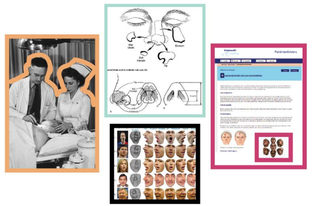


Figure 18 Early Bird Ideas

in person obviously sparked the ideation. In this beginning phase of the project a lot of new experiences show new things. Regarding ideas however this was mainly focused on 'low hanging fruit'. What is meant by this: ideas that are obvious ones, though still interesting ideas, as possibilities to improve. These ideas were also referred to as the 'Early Bird' ideas, based on observations and the interviews. For instance, in Figure 18:

- The observation that there was still no 3D image or side view in the patient information folder could easily be tackled by giving photos of all dimensions.
- A template for sketching the envisioned surgery, instead of non-informative drawings.
- Automation of finding an example that had more resemblance with the patient instead of googling for a good example during the consultation.

Other topics that had interest were the sharing of information and solutions for team dynamics and the duration of consultations. Overall the observations and interviews gave more insights on the, context, the Care Path and the moments to interact with patients.

07.1.2 Ideas from Patient Study

During the patient study stories, experiences and ideas on what could be improved were shared by patients.

The ideas that came forth were more developed than the ones of the observations and HCPs interviews. Ideas involved showing steps in the treatment process, as well as showing the whole treatment digitally. Interesting was that there was a need for a goal to work towards.

To be more precise, a personalized way of information was needed. When an example case is shown of an older man with a mustache, this does not give much insight to a middle aged woman, because she would not feel related and therefor does not identify with that expectation.

Information is also to be given in a more in depth manner, for instance to work as a reference for after care. Especially with complex reconstructions, information needs to be more specific. A black and white information folder doesn't suffice then.

07.1.3 Ideas from HCP sessions

Another switch in idea's could be seen with the creative sessions with the HCPs. In this session there was built on what existed already, overseeing the personal preferences of patients. Focusing on a whole patient journey resulted in ideas that were more holistic. Although the initial focus was solely on the theme Providing Insight, the ideas were formed around automation of treatment outcome, fitting examples for patients and having peace with what is to come. An interesting idea to work with was the fact that people forget what they have won.

07.2 Conceptualization

As strategy to make more elaborated concepts that embodied different parts of the previous obtained knowledge it was chosen to work out three concept directions. Using the Patient Journey as a canvas to design with/on.

Concept 1: Of (in)Estimable Value

What?
Giving the patient an extra lively estimation of how big the defect will be after resection. The different sizes of the defect are shown, after which a technique is proposed to close the wound. This is all shown on the own face of the patient.

When?
At the GP or the take in, to prepare for surgery.

Why?

- Informed (decisions) options, by letting patients be better informed.
- Realistic visual explanations, making it more shocking, seeing the importance.
- Simulating the resection, such that patients become aware of the size of the tumor.

How?
Giving an estimation up front as a support of the verbal words of a doctor. This visual support to the verbal words can change the expectations and perception of how big something will be.

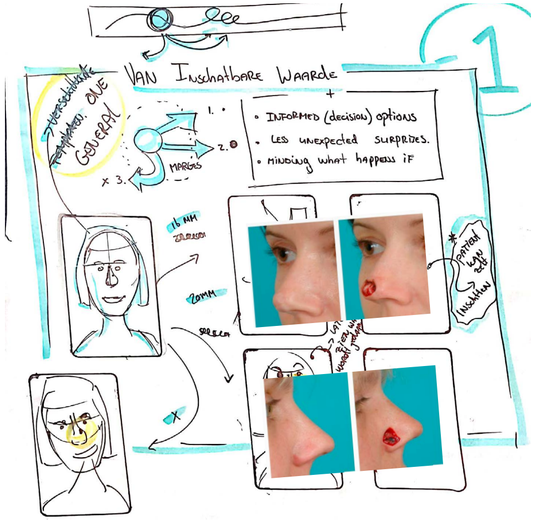


Figure 19 Concept 1 Of (in)Eestimable Value

Concept 2: Tailored Results

What?
Giving more tailored examples to the person, choosing from a wider range of examples. Not seeing them on themselves, but in a realistic form.

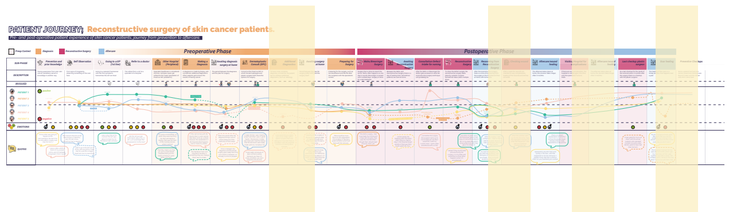
When?
The example is offered at the DPC (Dermoplastic consultation) and is given as something to take home.

Why?

- Tailored information, from examples that fit their situation.
- Insight, in the form of perspective in steps.
- Keeping it from personalization, to keep sure that there is not given an unrealistic perspective.

How?
Patients are offered to see examples that are more tailored to their situation. This will help patients to have the end goal more in mind, as a dot on the horizon, and see what the possibilities are.

Figure 20 Concept 2 Tailored Results



Concept 3: A healthy look back and forth

What?
With personal pictures, working towards the future, making the self-image change in steps.

When?
Given after the reconstructive surgery towards the checkups.

Why?

- Personal, making it that patients are relating to it.
- Coping with change, having a new way to see change.
- Possibility to better aftercare, giving examples how it was, how it should be cleaned, and what to expect from the healing wounds.

How?
The making of photo's is offered by the hospital, making sure that the correct photos are taken. Selfies for instance can have a different angle. Seeing the change over time can help patients to put their change in self-image in perspective.

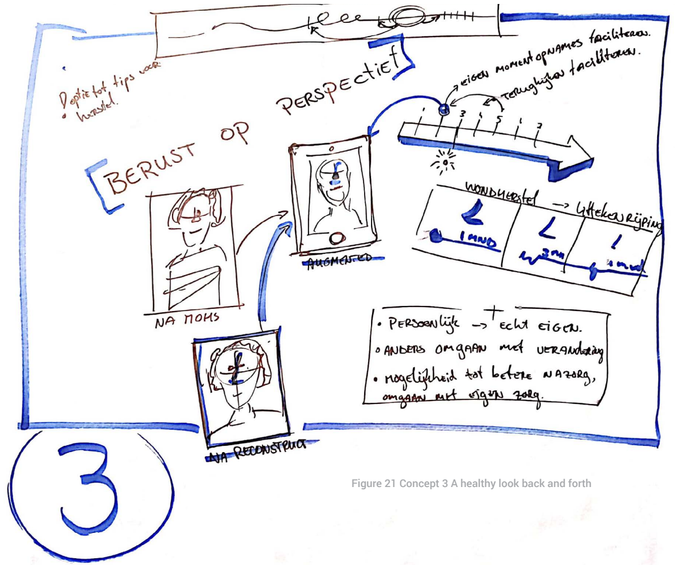
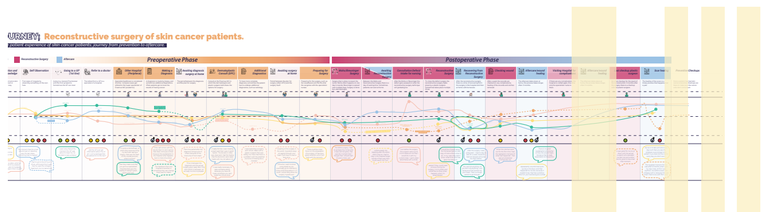


Figure 21 Concept 3 A healthy look back and forth



07.3 Forming one concept

All three directions of chapter 07.2 were promising, however one had to be chosen. Actually already a few design choices had been made earlier on. From the Patient Study onwards the focus was not on the preoperative phase of the treatment. A more perioperative view was obtained.

The Patient Study showed that the treatment is experienced as a roller coaster. The recovery phase, however, was experienced as long, emotional and without real support since patients do not have to go to the hospital in that period. As explained by one of the patients:

> *"When the stitches went out for the first time I had the realization moment of what had happened. That was an emotional moment for me."*

That is why a concept was formed that can be empowering and encouraging patients in their own treatment and recovery. Ultimately patients will be more informed and involved in their own recovery, taking back control on their own health. That is what recovery is: going from patient towards becoming oneself again, going from patient towards an individual.

This is a continuation of concept 3 with the addition of giving example steps of recovery as goal to work towards, of concept 2. What is important to put emphasis on is the patient engagement of the patient.

07.3.1 Reasoning of design choice

Patients can be informed preoperative, before the surgery, though because of the hectic period not all information is taken up. It is good to give patients something they can take a look at later such that they do not have to recall what they have heard.

What was explained by the HCPs is that most patients chose to do the surgery, no one decides not to do surgery. What is wanted is a way to inform them in a realistic way, such that they feel better about the results: creating better expectation on the recovery and the end goal they work to

Observations and co-creation with the HCPs indicated that patients are not remembering what they have won after surgery, instead the focus is sometimes on what is lost.

Also to some extend the insights of the patient study were taken into consideration in the final concept Face it, which can be seen in the next chapter 07.4 Summary Conceptualization. Though to restate the insights:

1. *every patient differs*
2. *uncertainty & time play a big role*
3. *consultations have a high density of information and emotions*
4. *patients react differently to being in control*
5. *a personal relation to care is prefered*
6. *patients can be coping with change*
7. *it is better to focus on hope instead of expectations.*

07.4 Summary Conceptualization

Final Concept: Face it

The design goal stated three things; empowering, giving a healthy look into the future and leaving the right memories behind.

With the concept Face it, patients are better equipped to face the long recovery, going from patient to individual. Face it consists of a an app that helps with four main functionalities:

1. ***A way to learn how to look at oneself.***
   (insights 1, 4, 6)
   From some stories of ex-patients it became clear that it is not easy to look at yourself after surgery. For some people this can really become a burden in their social life. To help these people look at themselves, there is a feature to look at oneself gradually. This can help to start looking at oneself in more detail over time. Everybody knows how confronting it can be to accidentally open a camera app and see yourself up close, so this is really something that has to be avoided. The personal preferences can be made different later on.
2. ***Glimpse into the future in steps, through AR***
   (insights 2, 3, 4, 5, 7)
   For some it is good to know what is to be expected, for others it helps to have an end goal in mind. Even better is a way to look forward in steps. If you give information on the recovery phase in one chunk it can be overwhelming and too much. If you make different phases within the recovery phase it makes the information graspable. Also patients can be more at ease if the information that they read is reflecting the phase that they are in. In this way patients can have the right information at the right time. To make this information more lively, AR is chosen to show how their wound will be healing in the next phases. The form however is something that will be explored in the next chapters.
3. ***Learning to look back.***
   (insights 1, 2, 5, 6)
   Looking back at a treatment can be difficult or confronting. For some it can scare and for some it can put things in perspective. The problem is that some people focus more on what they have lost instead of what they have won. What can be a cause of this is that patients normally do not see the defect after the Mohs surgery, because a bandage goes over it and the next day they have the reconstructive surgery. In this way they compare their face after the surgeries with their face before the surgeries, so focusing on what they have lost. What could cause patients to focus more on what they have won is by giving the option to look at the picture after the Mohs surgery, seeing the defect that was reconstructed.
4. ***Keeping track***
   (insights 1, 2, 4, 5, 6)
   Something that patients are recommended to do is to take pictures during the recovery process. Keeping track and comparing can help to see the improvement one is making in the recovery. Keeping track can also offer as a way to have a journaling the impactful period and reflect on it in that way.

Figure 22 Path to Concept Face it

07.4.1 Conceptualization Sum-up

Chapter 7 described the process of going from obtained information to the final concept Face it. However to test this concept a step had to be made to get a better understanding of future challenges of development. Therefor a testing tool prototype was designed to evaluate the concept. Chapter 8 presents the experimental prototyping process of embodying the Face it concept.

Takeaways of this chapter

- Face it, is a concept application, working as an additional help to get through a recovery phase of a treatment.
- The final concept consists of four main functionalities; learning to look at oneself, having a glympse into the future through AR, learning to look back and keeping track of ones own health.

| Artwork by Sam Spratt

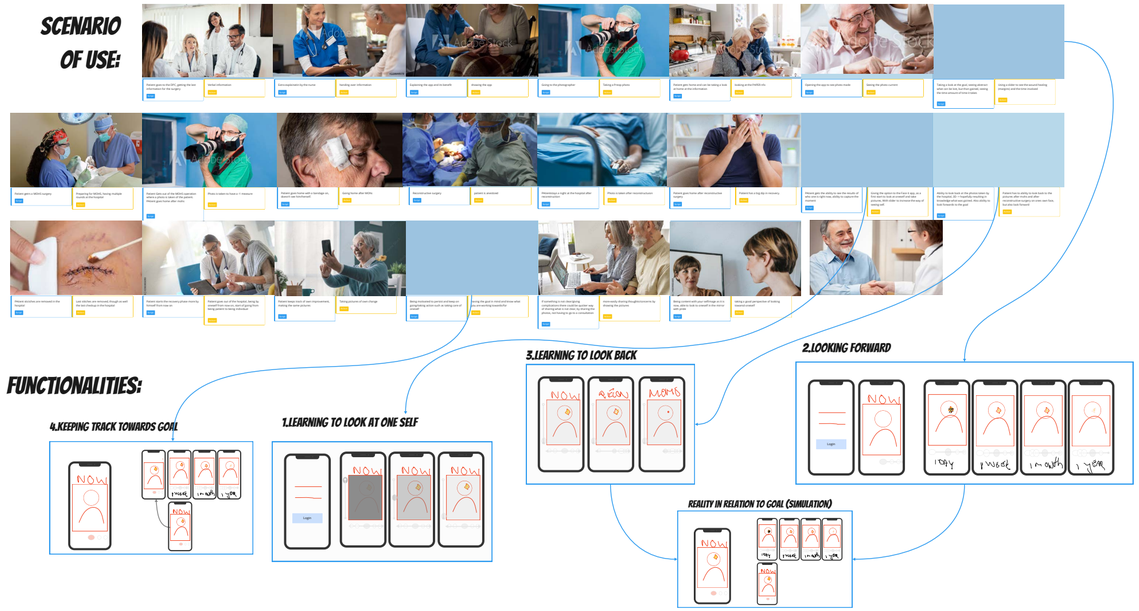


Figure 23 Concept Face it. Scenario and Functionalities

08 Experimentation.

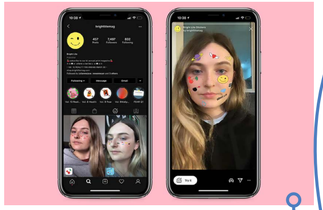
08.1 Background; AR/VR prototyping

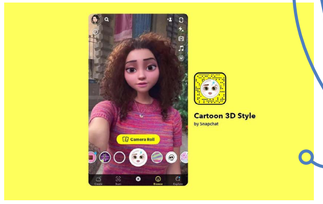
Recently Facebook changed its name to Meta, referring to the 'metaverse' they want to bring to life, of which a first version was launched on December 10th 2021 (Facebook, 2021). This metaverse is a term that refers to a convergence of physical, augmented and virtual reality in a shared online space. The Metaverse is not a new notion though. Neil Stephenson's described it in science fiction novel Snow Crash. (Stephenson, 1992) Augmented Reality (AR) and Virtual Reality (VR) have been buzzwords for years, though we might have to get used to immersive technologies becoming more applied in the world.

The same goes for healthcare, VR and AR are already being applied for years. Already in 2002 Hsieh et al., (2002) made a virtual reality simulator that could be used for preoperative planning of reconstructive surgery. More recently VR has other uses such as pain distraction (Ali et al., 2021).

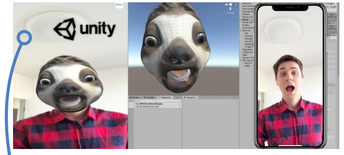
This shows that AR and VR are promising, also in healthcare, but how do you make things with it, how do you prototype with them? This chapter is about experimenting with the technology and how this lead to the final test tool prototype.

At the beginning of this project I also did not have a lot experience with AR or VR. Wore a VR headset or tried Pokémon Go once, though never prototyped with these technology. The VR Zone of the TU Delft was contacted to spar on what software to use. Basically there were four software that were promising; Unreal, Unity, SparkAR and Lens Studio.





Eventually Lensstudio was chosen to be ideating, experimenting and prototyping with first, after which Unity or Unreal would be used to make an downloadable app. Unfortunately this was not possible in the timespan of this project.



Software	Benefit	Best Use
Unity	Standalone app	Game Development
Unreal Engine	VR Zone use	Game Development
SparkAR (Facebook)	Design Tools	AR, Face Filters
Lensstudio (Snapchat)	Easy to learn	AR, Face Filters

Figure 24 AR/VR Development Software Overview

08.2 Lens Studio Experimentation

Within the development software of Snapchat there are a lot of things that can be done, though where to start? Of all the functional features that were present there were three promising elements to dive into for this projects topic; faces.

Snapchat is known for the AR filters that can be used, also known as Lenses. These Lenses make use of the phones camera function an augment a digital layer on top.

Lens Studio is particularly good at using Face Filters, because the platform uses landmarks on the face seen in Figure 25. The software helps to recognize these landmarks and with that enables for instance even face modifications.

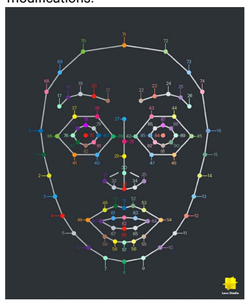


Figure 25 Face Landmarks

Of all the effects possible, three were found promising start points;

- Morphing the phase, which could be used to reshape parts of the face.
- 3D objects, to show for instance the fore head flap drain.
- Animations, the process of healing.

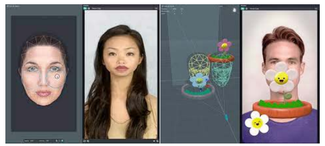


Figure 26 Face morph and 3D objects effect

Mapping on face.
At first trying out what was possible did not have a real function or goal yet. This to also to make sure to not be fixated on a solution already. This trying out worked as an inspiration too, seeing what is possible to make.

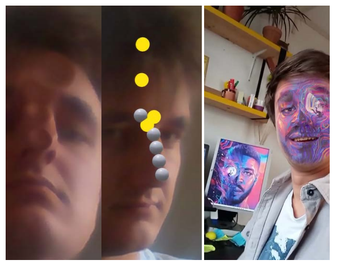


Figure 27 Trying out; Face morph, 3D objects and Mapping photos

Showing time and steps.
During the patient study it become apparent that a concept that involved showing steps or time was probably the direction to design in. A direction that was explored was the steps of a treatment, focusing on the different surgical steps that were part of the Forehead Flap technique. This makes use of a drain and involves multiple surgeries.

It was chosen to take a medical drawing as example of the steps. The steps would be animated after each other on top of the users face. In this way people would experience a visual explanation what surgery steps would be done, on themselves.

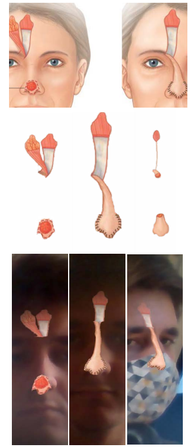


Figure 28 Surgical Steps, from medical image to filter

UI functionalities
Only having an animation playing on the head did not feel engaging enough to let people have a feeling of being empowered. Within Lens Studio there are also user interface (UI) elements that can be used to make the filters configurable. This interactive customization helps to make the filters engaging, and can help the user to have more success in understanding or learning (Zinnen & Godehardt, 2018).

It was chosen to try out how to change the level of realism at which a patient sees oneself when using the app. From the patient study it

became apparent that patients find it difficult to look at oneself. To use an app that involves looking at oneself the ability to gradually increase the level of realism should be taken into account.

A slider is a UI control element that uses a knob moved horizontally or vertically to control a variable, such as volume or brightness on a screen, though in this case the level of realism. It was chosen to test out different ways to bring change the level of realism; color, something blocking the wounds, face blur, and lowering the clarity of the whole screen. These ways were made into three sliders, and can be tried out through Snapchat by scanning the QR code in Figure 30 (requires the Snapchat app). This was tested with other people though Snapchat, where people were asked to control the sliders and afterwards were asked clarifying questions.

Results
The tests showed that:

- Sliders are a good way to indicate a value that does not have to be accurate.
- A slider that is placed horizontally could be indicating time, since it could resemble a timeline.
- Regarding the level of reality: the blurring of the whole face or blocking the sight on the wound, had the opposite effect; it highlighted the deformity more.
- The clarity of the whole screen was considered the best to gradually show the face better, followed by color.
- Small tests through Snapchat are useful, however since nothing is recorded, participants should store themselves.

Figure 29 Three Sliders for face blur, color, screen clarity.

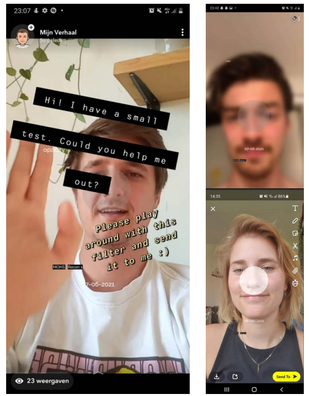


Figure 31 Small Snapchat Tests on level of realism.

Figure 30 Snapchat QR code

UI functionalities
At first there was the idea to show a process of the surgery itself. Eventually as described in Chapter 07 Conceptualization it was chosen to show the process of healing and recovery in AR.

The focus in plastic surgery is often on the outcome and not on the process with the steps in between. There are some examples of wounds healing, however they differ (See Figure 32).

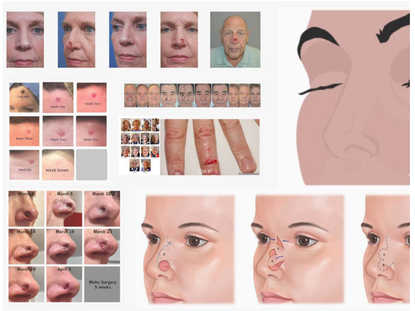


Figure 32 Steps of showing recovery proces in steps.

It was chosen to go for one of the most common cases of skin cancer and its recovery process; reconstruction after Mohs on the nose. Often the whole tip of the nose is removed and reconstructed, with surrounding, local skin flap. The wound often heals neatly and forms a small amount of scar tissue, which is minimally visible after two years. This process is also called scar maturation.

Previous studies (Steenbergen, 2020) have shown that patients have different preferences regarding seeing information more realistic, medical or cartoonist. A way to distinguish between this is by working with patient profiles, however for this project it was chosen to work out one form of information.

Different forms of showing the wound were worked out; having also the nose/surroundings of the wound, accentuating just the wound and an cartoon visualization (See Figure 33). Eventually the option with surroundings of the wound was chosen. This was considered the most realistic and not offsetting, while the others might not relate to the patient. Something that can be backed up by the Uncanny Valley, the relation between human-like appearance and more unnatural, which can lead people feel not at ease (Mathur et al., 2020).

08.3 Wireframing Face it

All the experimentation with AR and Lensstudio gave some basis to know what is possible and how to prototype that. Nevertheless the Concept proposed in chapter 7 was more than just a filter in Snapchat. Since this project is not only about the AR, it was chosen to focus on developing and evaluating a concept as a whole, instead of solely focusing on the AR experience.

A first iteration were some sketches and a scenario, the second iteration needed more details to work towards. The first step; a wireframe. This is a representation of an apps' structure. A wireframe is needed to know what should be made in an app mock-up, which is a mid-fidelity display of a design. In this project this meant a clickable prototype involving interactions, which will be described in chapter 8.4.

The process of getting to a wireframe was also done by switching programs with which the mock-up app was made. A wireframe was first made by sketching, followed by making a quick version of wanted screens and elements in Miro. A third iteration was made in AdobeXD, before making the final one for Protopie.

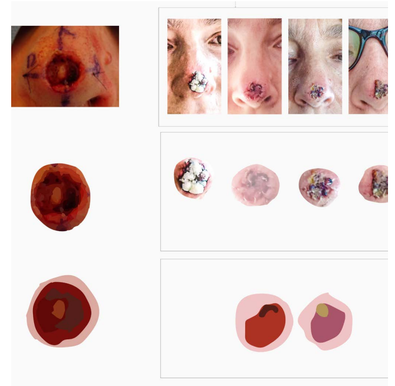


Figure 33 Steps of healing wound to scar maturation, 3 styles.

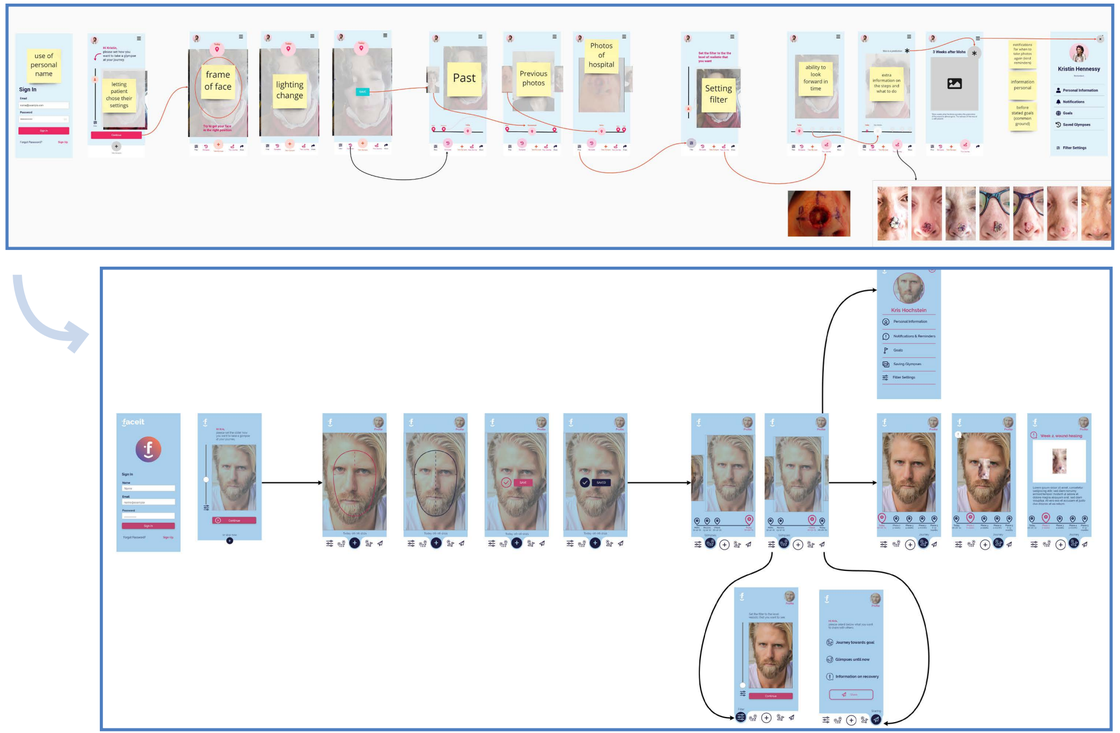


Figure 35 Second (Miro) and fourth (Protopei) Wireframe iteration

08.4 Design Style

In order to go from a wire frame to a mid-fidelity mock-up app, it is useful to have one coherent style. For the concept it was important to have a user interface that takes into account the main user group; older adults. To create a good accessibility for them a few style standards were used.

- A font-size of at least 14 points, because a smaller font size is more difficult to read (sorry to everyone reading this on a screen), especially for users with limited literacy skills (Health Literacy Online, 2016).
- Making sure that there is a right amount of contrast between text and background, this was checked with a contrast checker (WebAIM, 2021).

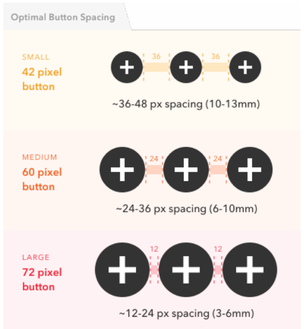


Figure 34 Optimal button sizes & spacing by UXmovement.

- Proposed standards for buttons. Keeping to these button size standards, makes sure they are easily tapped. Creating hierarchy in button sizes is also important. The standards can be found in Figure 34.
- At first the language of the app was slightly more informal, though since it is a medical app the choice was made to make it more formal. Also since the patients with which the test would be conducted were from the Netherlands, the text was translated into Dutch.
- Aesthetically there were some elements designed to guide the eye better, such as the menu bar, highlighting menu buttons better. (See Figure 35)

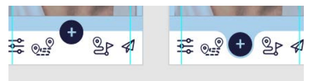


Figure 35 Menu bar elements.

- The chosen colors came from two artworks, which were an inspiration throughout the project.

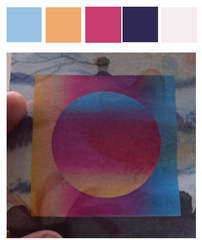


Figure 36 Color Palette.

Figure 37 Forehead flap reconstruction.

Face it logo

The actual logo of the Face it concept also had some thinking behind it. The name tries to resemble how it is hoped patients go into their treatment process. Fully empowered, ready to bring everything they got and go for the treatment, having peace with it. Of course it is also a reference to the facial skin cancer in combination with the IT (technology) being the AR application. In the logo the f is also forming a smiley, though it the upper part of the f is also resembling the foreheads flap reconstruction

Figure 38 Face it logo.

08.5 Face it; Test tool Mock-up

In order to evaluate the concept as a whole it was chosen to make a mid-fidelity mock-up app. This meant that it is a clickable version of the envisioned app, however does not actually work as intended. The intention of the concept for instance was to store photos and have AR elements in it, hence the mid-fidelity.

To make the mock-up the program Protopie was used. This because of the ability to make use of interactions such as a slider, storing values such as input text or slider values and having the ability to access the native camera. In this subchapter all the different functionalities are explained, per page.

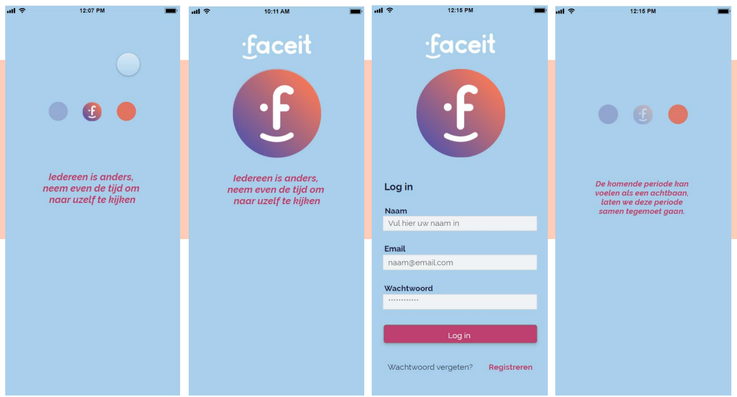
Logging in.

Once the user starts up the Face it app, a loading screen shows. A small text is shown, to get people to get people in the mindset for a moment of ease. “Everyone is different, take a moment to look at yourself.”

After loading, the user is asked to log in with their name, email and password. This functions as a textbox of which the name will be used in the rest of the app to create a more personal feel.

Next another quote is given; “The upcoming period can feel like a roller coaster, let’s face this period together.” With this text the patient might be downhearted because of the comparison with the roller coaster, which is however the truth. That is why Face it can help in this period.

Scan the QR code for the Face it mock-up app



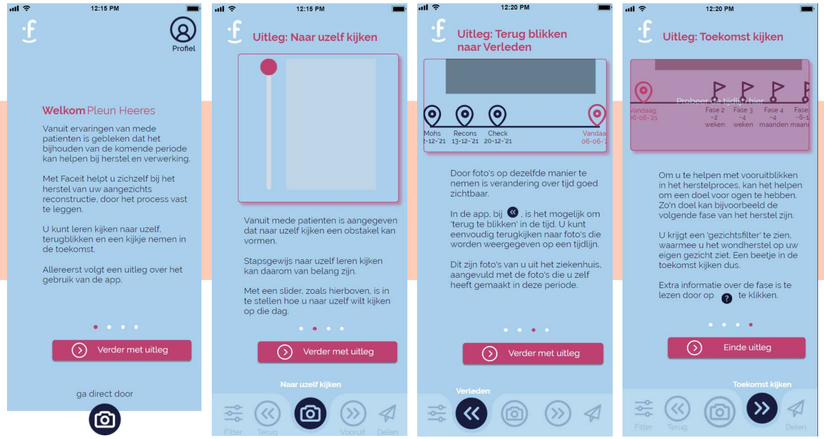
Onboarding.

For the sake of getting familiar with an app, onboarding is necessary. Onboarding is the process of getting users familiar with the new app or interface. It can involve components such as feature promotion, customization and instructions. In this app it was chosen to give more instructions on the features and workflow in the app. Apps should be understandable right away, however in this case some explanation is wanted, since some features might be novel for the users. Also the users should know why some features are there.

To make the onboarding not to daunting, it was chosen to do an interactive walkthrough, which means that users get to interact with elements of the app already when it is explained, causing the user to understand more easily.

There are five tips for onboarding:

1. Show onboarding to 1st time users.
2. Do not use too many screens, around 3-4 screens, giving an insight how the app works.
3. Be aware of the flow, take into account what comes before and after the onboarding.
4. Show how many screens are still coming with progress indicators.
5. Make skipping possible.



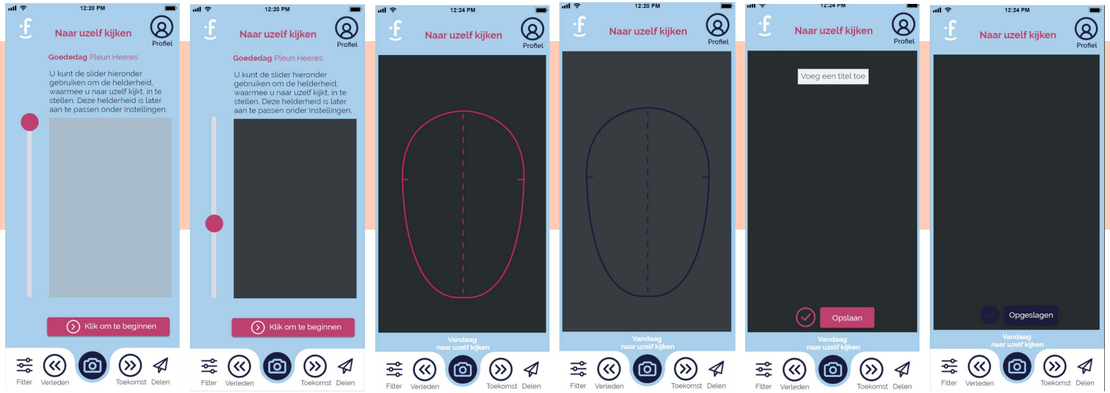
Looking at oneself.

After the walkthrough tutorial where everything is explained, the first concept functionality is offered; the first way of looking at oneself, looking at the current self.

In this functionality, users can set the clarity at which they want to look at oneself, making use of a slider. This works also as a tool to let people who do not want to look at themselves gradually see themselves.

What follows is an camera function in which the face has to be positioned in a frame correctly in order to be able to take a photo. In this way photos are taken in a similar manner, such that they are easily comparable and that the improvement of wounds is seen.

After taking a photo, the photo can be given a description and saved. After saving the user is automatically redirected to the looking back function, as a sort of nudging.

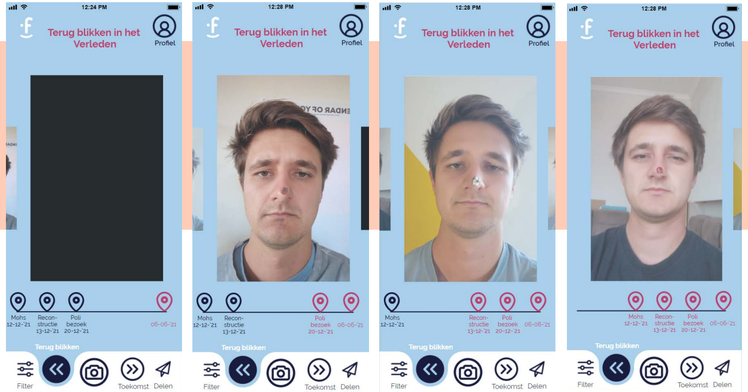


Looking back.

When coming to the looking back function, the first photo that is shown is the last taken picture. A timeline is shown with all the previous photos, which works as a slider, though because there are deliberate moments there is also the possibility to click on the buttons.

At the other moments in time there is shown previous taken photos in combination with pictures that were taken in the hospital. The patient therefore is offered the opportunity to see pictures that would not be accessible without the app.

Looking back hopefully puts in perspective where the patient is now in the healing process, and puts emphasis on what is won instead of that is lost.



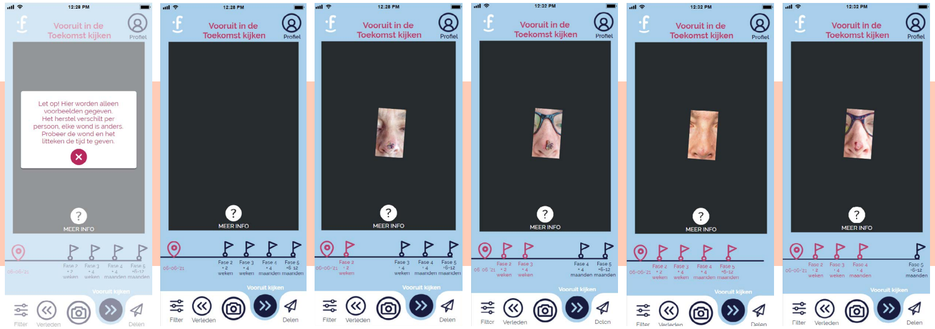
Looking back.

A glympse in the future can be taken through the functionality of looking forward into the future.

This functionality starts with a disclaimer that every person is different and therefore the healing process is also different. All the information in the app is given as an indication.

On the timeline of the forward looking are shown phases. Clicking on them makes slide in a picture that is laid over the camera element. This should recreate the feeling of an AR filter, which is the actual concept.

When the user wants more information on the phase, the More Info button should be pressed. A popup screen with more information is shown. This is just textual in this mock-up and scrollable.



What information is shown?

Within the information there is made use of the actual information folders of the Erasmus MC which are given to patients already. There is however made an addition by splitting up in phases of recovery and giving information on that specific phase.

Basic information is given on:

- What patients can feel.
- What patients can see.
- What causes the body to react.

Other information is given on:

- Living rules
- Wound care
- When to contact and the contact details of hospital.

Other Screens

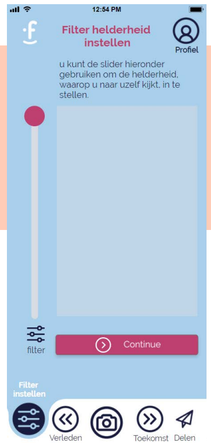
There are three other screens that are secondary uses.

The first being the clarity settings. When a user wants to see their own pictures clearer or the opposite, the settings for this can be reset by accessing the settings tab. This sets the clarity for all the photos, so also the ones that were already taken and for the future filters.

Another tab is Sharing. This is a tab that will be used to ask questions on with whom patients are willing to share their photos or information on their recovery.

The personal profile is accessed through the Profile button in the top right corner.

This takes the user to the personal profile. Also this o works as a trigger for the interview with patients on the topic. In which personal information can be put. Reminders can be set to make sure users are reminded to take another picture after a week or two. Also there are reminders that another phase will take place.



Takeaways of this chapter

- Prototyping with AR and VR has become fairly easy with a number of software to prototype with, of which Lensstudio is a great example.
- Playing around with technology can spark ideation and creativity, it does not always have to come after the creative process.
- The level of realism is something that can be altered through AR or filters.
- With a series of photos the recovery process can be visualized if they are put into a sequence.
- Patients are different in their preferences for a certain way of visualizing, ranging from realistic to cartoonist.
- Wireframing helps to lay out what kind of features are wanted and in what kind of structure something has to be made.
- There are quite some standards to make an app have a better accessibility for everyone, regarding font, button sizes and coloring contrast for instance.
- The Face it app is a clickable mock-up app, made with Protopie, which also is able to show the camera and have values stored across screens.

Section VI: Evaluation.

Chapter 09 Face it Evaluation

In the previous section the experimentation towards a test tool of the Face it concept.

This section, which consists of chapter 9, focuses on finding out what (ex)patients think about final concept Face it as a whole and gathering feedback on the test tool.

First, the goal of the Evaluation in the form of research questions is explained. Secondly, the chosen method of interviewing is explained to get answers on these questions. As third, the results in the form of feedback, impressions and experiences are described. As a followup on these results the recommendations and improvements on the concept are given. The evaluation is concluded with describing the overall project limitations.

09 Face it Evaluation.

09.1 Background

For the previous sections patients and healthcare professionals were interviewed about the general experience they had while experiencing the care as it is right now. These experiences formed the basis on which was to be designed with, which resulted in small iterations of mock-ups that embodied the final concept. After small usability tests, the feedback was used to improve the mock-up Face it app.

However, an evaluation of the overall concept was needed to understand the patient experience and value of the final concept. More specifically the desirability and relevance of seeing oneself in different ways at different moments in the recovery process, were topics that needed evaluation.

Therefore, (ex-)patients were invited for a concept scenario evaluation in which they could share their experiences and thoughts. The aim of the study was to collect experiences of (ex-)patients on the three ways of looking at oneself ('learning to look at oneself', 'looking in the past', 'looking in the future') at different moments in the healing process.

Research Question

What do (ex-)patients find desirable in the proposed Face it concept, for different scenarios in the healing process?

Sub-research questions:

1. *What is the relevance of the mock-up app elements (e.g. camera slider)? (SRQ1)*
2. *Which perspectives will help in the patient experience, and when in the process? (SRQ2)*
3. *Regarding looking at oneself in the future, is it desirable to see phases of healing on oneself, by means of a filter? (SRQ3)*
4. *Regarding looking at current self, how does Face it change the way one looks at oneself? (SRQ4)*
5. *Regarding looking back, does looking back change the one looks at oneself? (SRQ5)*

		Description	Time (since surgery)	m/v	Age	Occupation
Digital		Scalp Removal, other skin cancers	two years	m	65+	Retired
In person		Lip reconstruction, local flap	one year	v	55+	Working
		Nasal reconstruction, local flap	6 weeks	v	70+	Retired
		Cosmetic Rhinoplasty	5 weeks	v	20+	Student

Figure 39 Participants Evaluation Study

09.2 Method

A combination of techniques was used to evaluate the concept. A combination of a scenario-based mockup test and a semi-structured interview. (Patton, 2002) What is important to note is that the experiences of the participants are scenario-based and therefor based on their past experiences they had as a patient. This is close to resembling the patient experience of patients in the moment itself.

A physical interview sheet was used, functioning physical way to show interview results, shared among participant and interviewer. On the sheet existed of a timeline to map out the treatment process and small, physical mirrors representing the perspectives of looking at one self.

During each evaluation, first the final concept and scenario of Face it were explained, after which the participants were shown a walkthrough video of the app as familiarization and instruction.

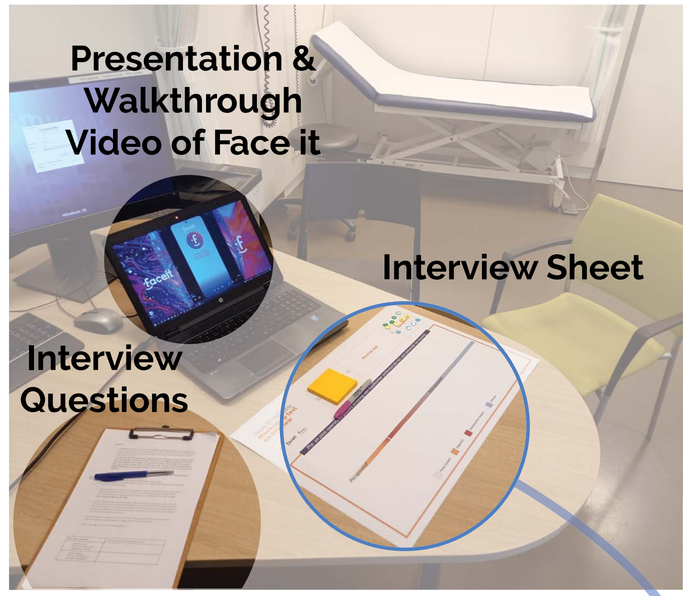
Secondly, a semi-structured interview was conducted. The questions were focused on the relevance of certain aspects (e.g. slider), the different perspectives of looking at oneself and when these perspectives are important.

09.3 Test Procedure

The interviews took place in person at participants their home, at the Erasmus MC right after the follow-up appointment and one took place digitally through Teams and with the use of Miro.

In Figure 40 you can see the test setup with which the following procedure was done:

1. Small introduction of the project and the reason to get together; from patient experiences a mock-up app was designed. However, it is not yet a real app and has to be tested with experts; the patients themselves.
2. As this was a scenario based test with ex patients it was really important to introduce the scenario as lively as possible. An introduction was done by explaining for whom it is and when it will be used, but not diving into the mock-up app immediately.
3. What was important was to get a feeling for the participants' story first. That is why the first exercise was to focus on the recovery process that participants went through themselves. This was done by mapping the events or moments in time (data points) on the interview sheet and asking questions to get a feel for the case of the participant.
4. Now that the background was explained by the participant, they already revisited the moments in their own recovery, making it easier to talk about the experience they would have had. Basically participants were asked to feel how they felt at a moment in time: the moment they are excused out of the hospital after the last checkup in which the stitches are removed. Which is the first moment they get to use the Face it app.
5. The use of the mock-up app was explained, through a walk-through video, explaining that they were going to use it on the phone later. And give a reminder that they should try to get into what they would have been feeling at that time, so in the past.
6. Participants were asked to go through the whole app, performing the steps they found interesting. Important was to talk out loud during, such that the interviewer would know what they were thinking.
7. Interview with for the research sub questions 3, 4 and 5 with the interview sheet and small mirrors.



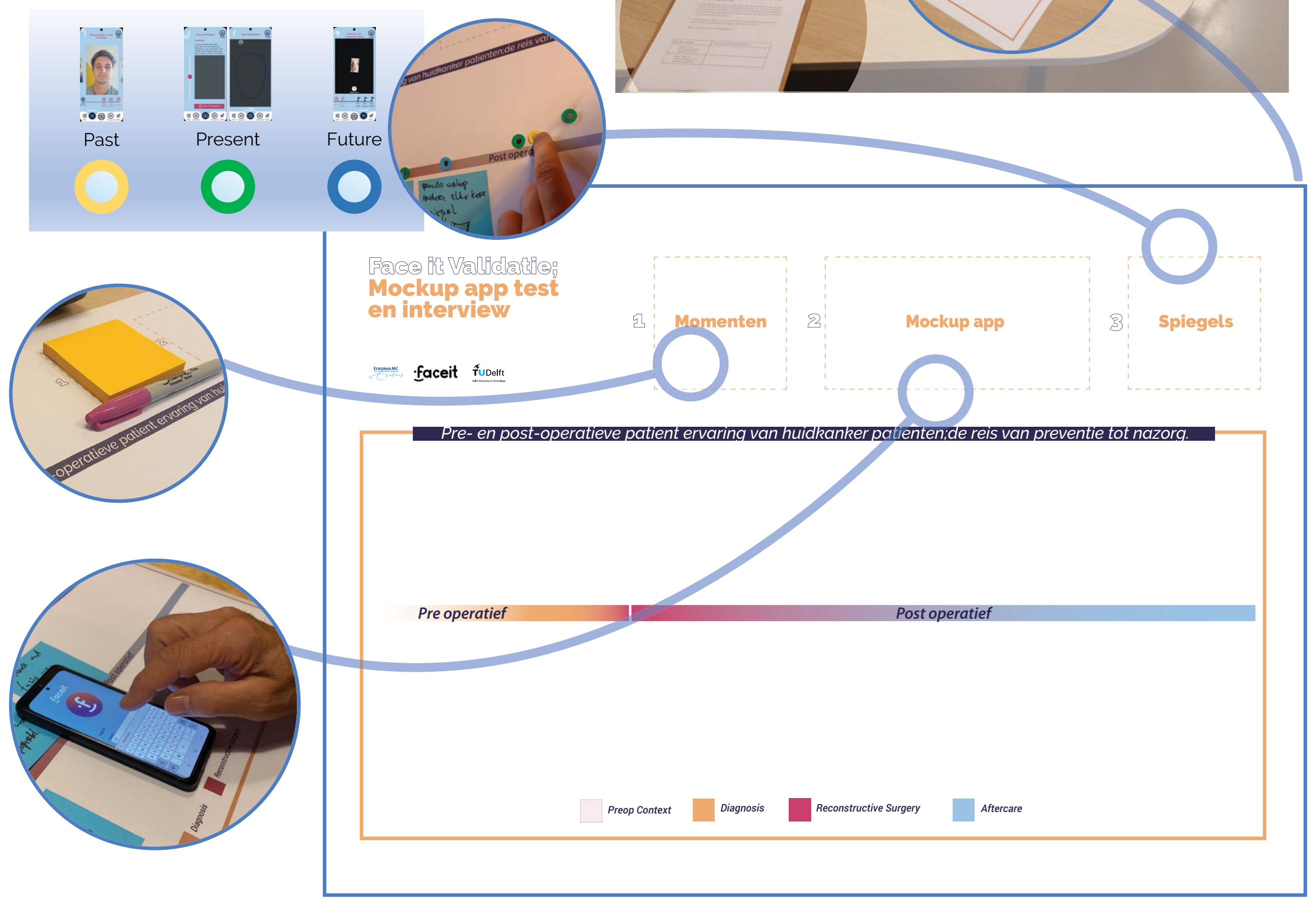


Figure 40 Eveluation Test Setup

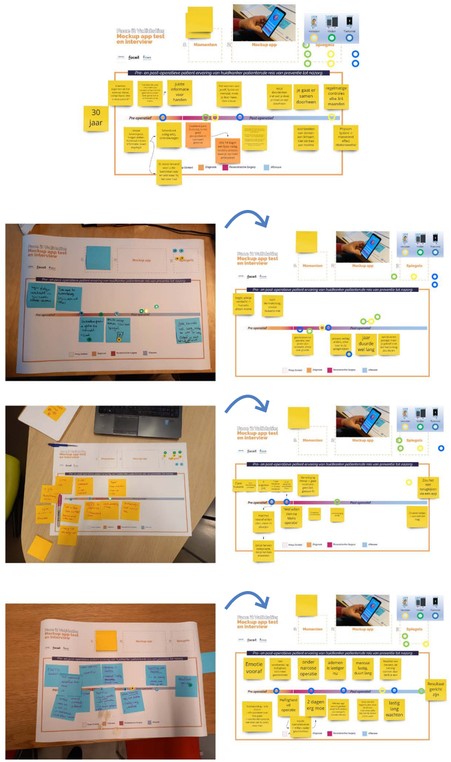


Figure 41 Digitalized Interview Sheets

Data Analysis
For the data analysis, the interview sheets, observations and interview notes functioned as the used data. First all the sheets were digitalized in Miro after which a small thematic analysis was done on overarching themes, recommendations and other insights. (Braun & Clarke, 2006)

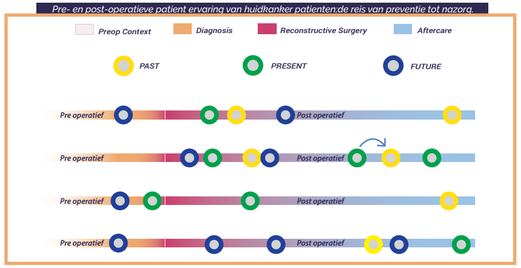


Figure 42 Timelines with Perspective Mirrors

09.4 Insights from patient perspective

1. **Patients needs for perspective differ.**
What became apparent from comparing the timelines was that patients have different needs for perspective and especially the timing of it.

> *"Looking back at the past after my recovery, not during, I am quite result oriented." -P4*

Also patients wanted to look at the recovering phases, and therefore the future, before the surgeries.

> *"It would be great to look forward already in the beginning, such that you know what is coming." -P1*

The use of some perspectives were not applicable for some of the patients in the form of an app.

> *"Looking back is not something, back through an app, maybe in printed form of photo's, I might be to old-fashioned to do so." -P3*

Using the app, to look at a certain perspective can trigger exploration of the others.

> *"If I would take a photo, it makes sense to look back at pictures right after to see how I am doing or how the wound heals." -P2*

2. **Everything in one place.**
Patients found it helpful to have all the information in one place. Having information on recovery in the same app as their own medical records and the contact details seems to be desirable since it is convenient.

> *"When having a talk with someone or with for instance the homecare, I could show them easily how I should take care of the wound or how it should be cleaned." -P1*

3. **Keeping track made easy.**
An added value was that keeping track of oneself was made easier to do. Some patients already made photos or kept a diary, which was expected to be made easier with Face it.

> *"I had the question if I wanted to share my pictures of the hospital, such that a photo collage could be made. Not knowing that there would be coming an app for that. I have the photos stored on my own computer and phone, so I was already doing that. " -P1*

Reminders would be good motivation to use the app, not considering them to be of annoyance if there was one every week.

> *"Sometimes you need to have an trigger, the reminder would work, though then it should be just one photo a day." -P2*

4. **A help when needed.**
It was mentioned that the information they got on recovery was sometimes not detailed enough, causing insecurity. Getting information in phases would help in getting small confirmation about things, where before they would stress about.

> *"If I could have known what was getting to next by use of an app that would be great! I would use it, sure." -P2*

5. **Taking into account the use and user.**
At some points it was interesting to see that patients were happy to see things they would not have thought about, but were pleasantly surprising.

> *"That you open the app and do not see yourself immediately is something I would not have thought about, but that does help."-P4*

09.5 Recommendations of patients

1. **Information could be reconsidered.**
Information given in the app about the phases, should be less textual. Also the onboarding is too much reading.

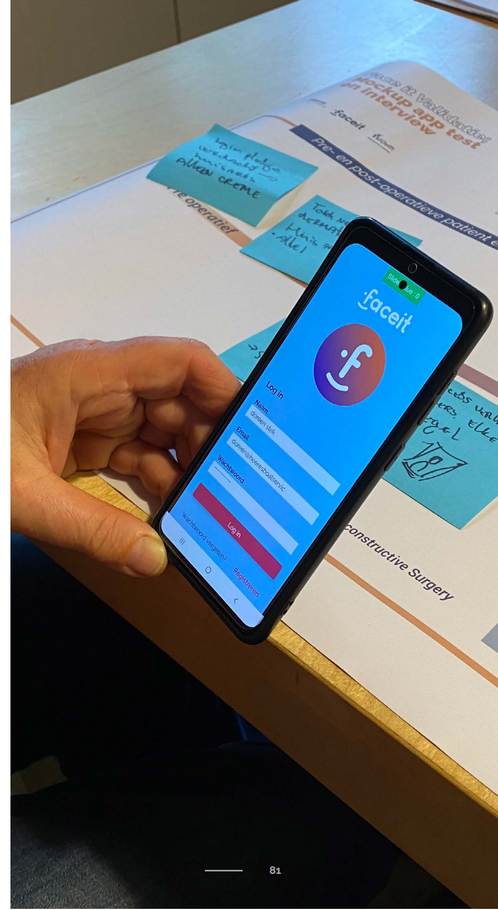
> *"The introduction text when opening the app is too cheesy, it could be a little more formal funny, though still good that you try to get people in the mood for themselves." -P4*

Suggestions were to animate or show videos.

> *"There is too much text, I would like to see a video or an animation. I have to do a lot myself on the phone, I think that is not yet for my age group." -P3*

2. **Caring in sharing.**
When talking about sharing there were raised some concerns about privacy. The tendency was that sharing with peers and with the hospital would be done easily. Only real close friends or family were considered of interest to share information with, if they would ask for it.

> *"I would only share photos and such with real close friends and family. I also did that already when they asked for it. You are on thin ice if you start sharing medical photos.*



If I take a photo, I have the photo and I can share it with whom I want to. This is something to really think about." -P1

"Privacy becomes an issue if sharing is like posting on a forum. I would like to see and read experiences of others before and after surgery and would be willing to share my own stories with others that go through this themselves." -P4

3. **What and how to live.**
It is not so interesting to learn what is happening in the body, but the living rules are important. The day to day things. Also taking care of your wounds and body could be highlighted more. What to do when something is wrong and following actionable steps.

"Of course, information is good right now, but for instance it doesn't say what factor sunscreen I need or such." -P3

"I would be helped if there were more experiences about complaints or small things, such as not being able to breath properly. What to do when having problem with it." -P4

4. **Refreshing insight in care.**
Face it could be a way to see what is next, appointment wise, but also refreshing the mind and memories on what happened.

"As it is now, this app helps to keep track of my physical appearance and nothing more. It would be great to see for instance instead of the phases of what is ahead, also the next appointments for instance." -P2

Also there could be a win-win for both sides. The hospital gets more pictures and an insight on how someone is doing, which can lead to less hospital visits.

"Anyway, you could get a win out of this. Just talked about the basal cell carcinoma. People who have a one-time surgery have to come every 3 months for a check. You could have less costs if you could do these checks with an app."

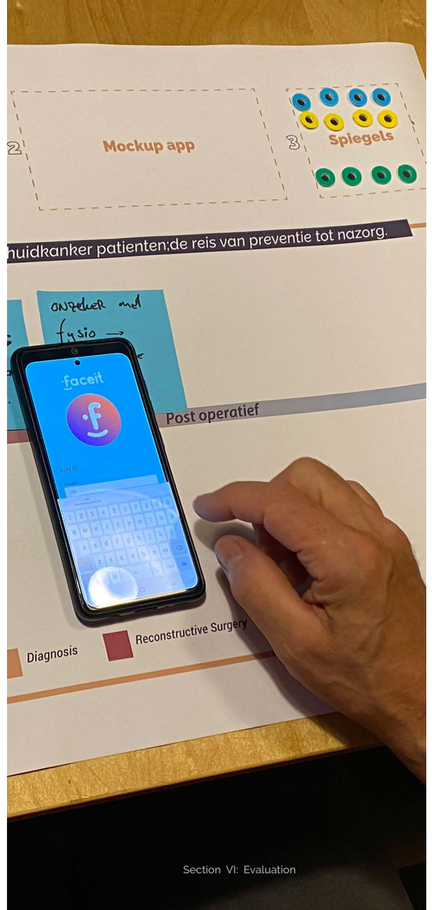
5. **Interaction elements redesign.**
Of course there were some usability issues that got some feedback and recommendations. Especially the slider timelines were not easily understood, they could be made more simple.

"I do not exactly know how to use this. The explanation was not good enough." -P3

"But I don't know if everyone knows what a slider is. It seems clear to you, but maybe change it to scrollbar (schuifbalk)." -P1

The adjustment slider of the clarity was also hard to find or use.

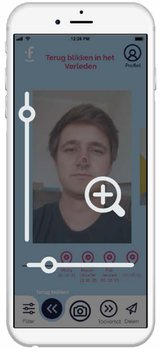
"Putting the slider for the clarity in every screen would be way more convenient. Also this clarity is not for me, it would be better to blur or black and white, but that is personal" -P2



09.6 Proposed Design Changes

The evaluation with the ex-patients showed that there is of course a lot to be improved about the mock-up and the concept itself. The recommendations should be considered since the patients are the experts on their experience and the ones that will be using the eventual app. It is best to adjust to their needs and wishes, to get them to use it.

The recommendations however, should not be translated directly into ideas and changes, a whole design project could be spend on working in an iterative process which design thinking brings about. What can be done is proposing initial ideas to give a direction to change the design.

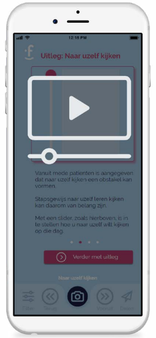


Adjusting sliders, camera and photos.

What was seen during the evaluation test that patients had difficulties with the usability of User Interface elements, such as the sliders.

Also there was the need to add or adjust elements. For instance zooming in on previous photos, or taking a close up photo. It was chosen for this project to take photos and make them easier comparable, however the option to go into details of a picture should be integrated.

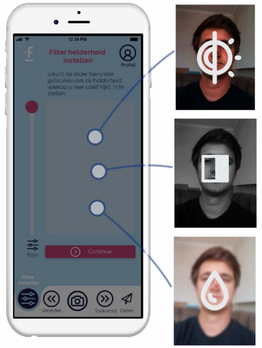
- Zooming in on photos, detailed camera option
- More simple timeline sliders
- Clarity adjusting slider should be easily accessible, not tucked away under settings, for instance on every screen.



Engaging in information.

What was mentioned was the style of language. Some participants found the information up front too textual, and some found the text of the on-boarding too 'cheesy'. In line with this, the examples of functionalities within the app, were not used since they did not catch the attention to try them.

- More visual, explanatory video or animation. Research shows video improves patient education. (Love et al., 2016)
- Moving examples of functionalities, such as sliders, that show in an animation what the use is.



More personalization.

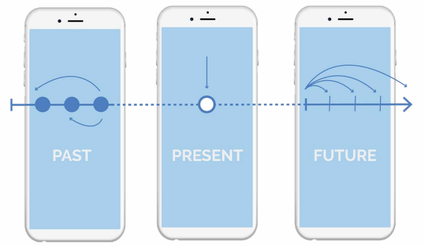
In the current mock-up the personalization is reached a little by having a personal welcome using the name of the patient. However next to this there could be made use of the preferences. For instance showing the medical records of the patient as well as offering a different way to filter the camera.

- Different kinds of filters, such as black/white, contrast or blur, offering the choice to the patient
- Integration of more medical records or appointments, for instance of the Erasmus MC patient portal.

Two sides winning.

A suggestion was made to make the photos also accessible for the hospital. This to have the ability to check patients at a distance. This helps the patient to feel looked after and helped in the long process of recovery, without having to go to the hospital. On the other hand the hospital can be more efficient in seeing more patients and relying on photos to determine who is an more urgent patient.

» Design of a hospital/clinical side of the app as an service



Choosing the perspective to look.

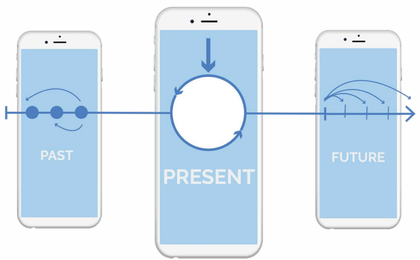
What came apparent in the interviews is that patients differ in when to look at oneself. The perspectives of looking back, to the future and at the present could be more separated. Now there was just one flow of use, but it could be more convenient to separate the ways of looking at oneself more deliberately. In this way patients are offered more freedom to chose the perspective they want.

» Different modules or even apps for the different ways of looking at oneself.

More here and now.

An interesting overall idea was formed when talking about the functionality to learn to look at oneself. In this concept this had a small function of setting a slider to the preferred clarity, however this could be made into a more in-depth reflection. The mental part as well as the functioning of the body were not done justice in this concept.

» More reflection on how one is doing, less focus on the appearance, more on the functioning of the face.



09.7 Project Limitations

All in all, the final design has been evaluated with (ex)patients. This design was the outcome of a project and encompassed information obtained from literature, observations, interviews and user studies. All together offers understanding how AR could be applied for reconstructive surgery in skin cancer care. However, there are some limitations to this project that should be mentioned:

» **Almost real circumstances.**
Some parts of this project have not been as 'real' as hoped for. This is of course a vague notion, though captures a few things in one. Considering the circumstances, the ability to visit the hospital a few times and have some of the evaluations in person did not take away the fact that some elements would have benefitted of more in person moment. Interviews get another layer and especially the ideation would have benefitted of a more offline process.

» **AR evaluation**
'Real' also stands for the fact that AR is not actually used in the form as was hoped for. This could have influenced the way participants thought about having a filter on their own face. In this form it was just a picture in front of their face, so not the real experience of AR. Also, good to mention is that other forms of AR and VR were not explored in more detail. Face it is an experimentation and embodiment of a possible solution involving AR.

» **Evaluation completeness**
The group of participants was quite diverse and a small number of participants. This might not be the most representable user group considering age for instance.

Also the evaluation was short term. It was evaluated through an scenario based mock-up app test in combination with an interview. Uncovering the impact and the desired effects on QoL can only be done on the longer term.

Also the concept was only evaluated with the user, in this case the patient, however evaluating the clinical side of the concept would be giving a more complete evaluation.

» **Subjective yet qualitative.**
Throughout the process only qualitative methods were used. The outcomes are subjective and therefore interpreted differently. Yet, because they are rich in data they could be more insightful, or at least in a different way, than quantitative data would. It would be of great added value if the concept would be evaluated over a longer time period in combination with a before and after study regarding patient reported outcomes studies mentioned in Chapter 1.1.2.

Evaluation Sum-up

Chapter 9 described the evaluation of Face it with ex-patients. It represented the method of testing, using a mock-up app in combination with a semi-structured interview. The final concept Face it was considered a wanted help in the recovery. However, the evaluation also gave valuable insights and recommendations for the future.

Next to the evaluation of the concept, also the project was evaluated as a whole by describing the limitations of the project.

In the next section VII Closure, the project as a whole will be discussed, concluded and reflected. This by revisiting the design goal in comparison to the project results and an personal reflection.

Takeaways of this chapter

» Patients have different needs for perspectives to look at oneself, especially after surgery.
» Having all information on a treatment in one place is appreciated.
» Patients indicated that there is a need for video and animation in explaining information to keep them engaged
» There is a need for hands-on information, in the sense of having applicable actionable information such as knowing which sunscreen to use or how to clean wounds.
» A recommendation is to include more medical data to see for instance when next appointments are or being able to prepare for an appointment.
» Expanding the use of Face it to the hospital could have a win-win for both the hospital and the patient, since there will be more insight into patients and the opportunity to get extra care.
» Patients mentioned that there are some concerns with privacy when sharing information.
» Sharing information or reading of peers is something that could be implemented more. Now only real close friends and family could be seen as allowed to be shared with.

Section VII: Project Closure.

Chapter 10 General Discussion and Conclusion

Chapter 11 Personal Reflection

While the previous chapter 9 concluded with design recommendations and the overall project limitations of the Face it project, this section will summarize, discuss and conclude the overall project outcomes.

In chapter 10 the outcomes are summarized and compared with the design goal. The knowledge contribution towards the field of AR and healthcare will be given, as well as opportunities for future related work.

The last chapter 11 will consist of a personal reflection on what has been learned on a personal level.

10 General Discussion and Conclusion.

10.1 Project Summary and outcomes

This project explored the patient experience that facial skin cancer patients have throughout their treatment and how augmented reality (AR) could contribute in this treatment, to ultimately bring about a better quality of life (QoL).

Conducted interviews with healthcare professionals (HCPs) and observations in the hospital helped to understand the context for patients. Contextmapping interviews with patients showed the patient journey they go through. It was found that this journey can best be explained as an emotional roller coaster with a long recovery phase. The final concept Face it came about through experimentation with AR software and co-creation with HCPs using the patient journey as a basis. A final interactive mock-up was created and tested with ex patients to evaluate the concept as whole.

The final concept Face it is a tool that helps patients to look at themselves in three different ways in the recovery phase of their treatment; the current selves, back in the past and the future selves. This is done by taking photos, keeping track with photos and looking to the future steps with AR.

This design research showed that there is a need and opportunity for more digitalization in healthcare. Furthermore, the project has shown that solutions in healthcare can benefit of taking a more holistic approach to a problem. Taking a different perspective offers interesting opportunities for future work.

10.2 Answering the Design Goal

The Face it concept was the outcome of the design project, in which the design goal was stated as:

> *"to empower facial skin cancer patients to have a healthy look into the future, while making sure to leave the right memories behind."*

The final design still builds on this goal, by looking forwards and backwards. Forwards through AR, informing patients about the recovery phases, providing collected information in an engaging way. Looking backwards is done by keeping track through the act of taking photos and giving the possibility to show what they have won instead of lost.

Evaluating the design showed that a digital extension of care is desirable and that both patients and hospitals could benefit of keeping track of the recovery process. Getting patients interested, informed and engaged in their own health can therefore be seen as empowering them to improve their own health.

10.3 Knowledge Contribution

This project offered a human perspective to facial skin cancer care, the patient perspective, while exploring the use of novel technologies and using AR as a tool in the design process. The subjective quality of the research was translated in an outcome that shows a potential way to use AR in skin cancer care.

What can be learned from this project is that there is a need for not only explaining and educating patients on their surgery, though also thinking outside the box, in this case outside of the care in the hospital.

When taking a holistic approach to see care as a process, different moments in time can be taken into account and inter-dependencies can be mapped

Although the average patients are older, there is a generation becoming older now that grew up with phones and especially with digital photos. There is no escaping the fact that more has to be shown digitally.

Therefore this project could be functioning as an example what this digitalization would look like. The knowledge gained and patient centered approach taken in this project could be used to build upon and learned from by other designers or researchers.

10.4 Future Work

At the start of this project there were ambitious plans to make working AR designs that could be tested over a longer time period to see if the quality of life of patients improved, when using the interventions. The eventual concept mock-up app was a result of the technical limitations, showing only the overarching elements of the concept as a whole, with limited working AR elements.

Throughout the project also the Covid-19 pandemic hindered the actual prototyping and testing with patients in person, which might have caused the end result to not fit the ambitions. Yet, the project showed the possible potentials.

Preoperative Phase.
Regarding educating patients on their care, the preoperative phase has potential for interesting ideas using AR, though was not favorable in this project.

Downloadable app for long term testing.
The potential to use the current design for an app that can be distributed or downloaded to work as an native app is something to be explored. This potential is something to reconsider to test the long term effects of a concept.

More elaborate reflection patients.
The focus within this projects outcome was more on looking back and forth, by focusing on the aesthetics, instead of the functioning of the body. There is an opportunity to focus more on the here and now, letting patients reflect more on how they are feeling in the moment now and how this

| Photo by Sharon Mccutcheon

11 Personal Reflection.

In the initial project brief of this project I stated my aim for the project as: “As this is my final and therefore last moment to show what I am capable of in a personal project, I want to put the highlights of my capabilities in this project.”

At the time I write this I am insouciant; free from concern and worry. However, at some points in the process there was this pressure that I laid upon myself that made the playing field more into a tension field. If there is something that I have taken along is that playing and learning go hand in hand.

When playing around you find out things along the way, when you actively search for something, that becomes harder. The same goes with this project. I believe that informality and chaos breeds creativity. The informal coffee break talk, the creative session with post-its, the informal context around a serious interview in person. Of course the pandemic did not create the best circumstances.

In this project there were some moments of inspiration for me. I had the privilege to attend a few days at the hospital, I even got to see the surgical rooms! This is a once in a lifetime opportunity for a designer maybe, though it has opened my eyes what I want to do further.

Looking at the result of the project, I have come to realize that it is not the impact you should strive for, but what you get out of it personally. In hindsight I see that this is only a small spark of creativity in comparison what is needed to truly explore a topic.

This project showed me that the role of a designer can be to get different perspectives, diving into a topic as a mediator between them and showcase the insights through design, which I hope to also have gotten across to others. Although I can lose myself in diving to deep in a topic, I have found out that letting or getting other people to talk gives me inspiration and motivation.

My desire to do this graduation project came forth out of my interest in design for healthcare and empowerment, the opportunity to work on a topic that was specific yet open for a personal approach, and an underexplored context of AR in clinical health/hospitals.

At the end I am really grateful to have explored these unknown topics, to see what my added value is and how design can play a role in this context. It has shown me that I just have to ask and make insightful what I have been thinking in a visual form. A last underestimated insight was to keep track of things by writing them down, continuously like a diary and celebrate every step of the journey.

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