

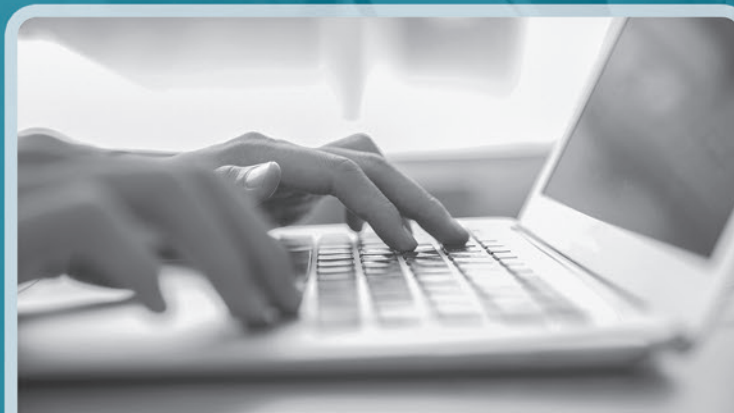


# SHARED DECISION MAKING

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DESIGNING FOR CANCER CARE

SIEMON VAN OPSTAL  
MASTER THESIS





# Shared Decision Making

## Designing for Cancer Care

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Master Thesis

MSc. Integrated Product Design | Medisign

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# ACKNOWLEDGEMENTS

This master thesis presents my final project, by which I conclude the master Integrated Product Design of the Industrial Design Engineering faculty at the Delft University of Technology.

Over the past months, I have worked on a web application that supports shared decision making in consultations for people with colon cancer concerning adjuvant chemotherapy. Different people have contributed and supported me in different ways, to a successful completion of this project.

First, I would like to thank my supervisory team for mentoring and guiding me along this process. I struggled to get a grip on this project in the beginning, but they keep asking me the right questions during the multiple meetings to guide me in the right direction. Marijke, Huib, Olga and Gijs, it was a pleasure to be working with you for the final phase of my TU Delft student career.

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Finally, a big thanks to all the people and patients, that were willing to work with me and talk about this terrible disease. Especially, the informal caregivers. Thank you for talking about your experiences, I could not imagine what they have went through by losing the person they love to the effects of colon cancer. Your insights did not just help me, but made me even more motivated to successfully finish my master thesis.

Siemon van Opstal

*Breda, September 2018*

# EXECUTIVE SUMMARY

What role patients should assume in medical decision making is an issue that has stimulated much debate. A wide variety of opinions exist, ranging from the view that patients should assume at least some responsibility for their own treatment, to the position that it is unwise to encourage such participation because patients do not have the specialised knowledge required to make treatment decisions (Degner, Sloan, 1992). The difficult process of shared decision making (SDM), is a process in which the physician shares with the patient all relevant risk and benefit information on all treatment alternatives and the patient shares with the physician all relevant personal information that might make one treatment or side effect more or less tolerable than others (King, Eckman, & Moulton, 2011). SDM is currently being advocated by both healthcare professionals and patients as the ideal for decision making (Stiggelbout, Pieterse, & De Haes, 2015). The process of SDM is difficult to implement, for example because it has proven difficult to create access to balanced and easy to understand information for patients.

The difficulty of implementing SDM also applies to adjuvant chemotherapy treatment decisions regarding patients with colon cancer. This decision-making moment occurs after surgery when the pTNM-classification (UICC, 2010) shows a certain value which suggests if adjuvant chemotherapy is applicable. During the multidisciplinary consultation (IKNL, n.d.) the best treatment option is discussed in the eyes of the physicians. This is then shared with the patient during the consultation with the oncological surgeon. During the next consultation with the oncologist, it is expected of the patient to make a final treatment decision.

Different research methodologies like literature research, semi-structured interviews and observations were performed to obtain the understanding of the current decision-making procedure concerning adjuvant chemotherapy for colon cancer patients. The insights obtained from the observations and semi-structured interviews, were used to create the patient physician experience journey. Combining this with the theoretical framework, the design goal for this project emerged.

The aim of the design process was to;

*"Create a User Interface for a web application that ensures that both patient and physician are aware of the different possible treatment options, understand what these treatment options involve concerning risks, treatment options and possible outcome, according to the principles of risk communication, and that interaction can take place, so that the preferences and values of both patient and physician can be shared, to support the process of SDM concerning adjuvant chemotherapy for colon cancer patients."*

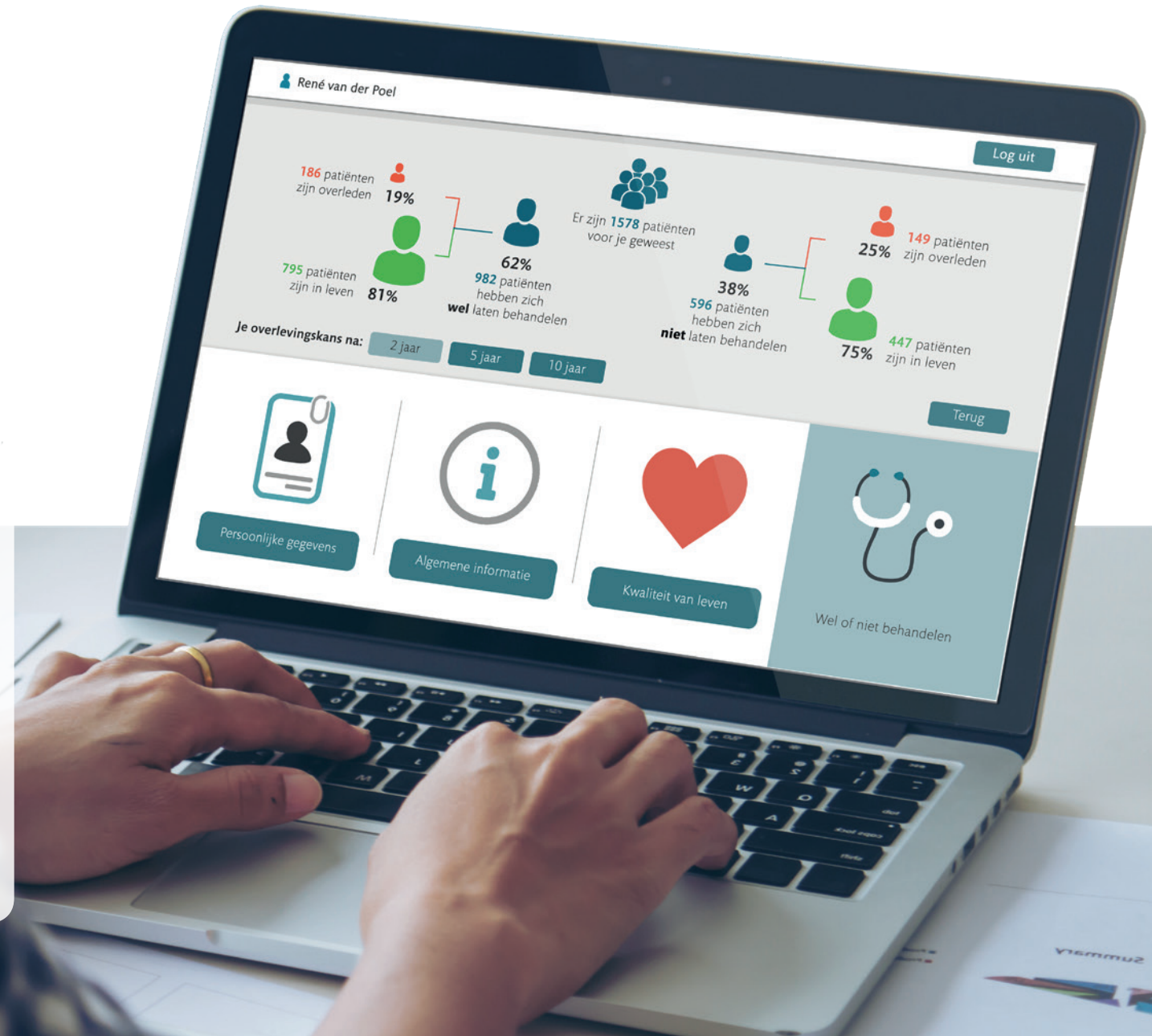
From the patient physician experience journey, combined with the theoretical framework, the IPD was created through multiple iteration steps, involving physicians, patients, and potential patients. The IPD allows the patient to find general information about adjuvant chemotherapy, and triggers the patient to think about their preferences and values concerning quality of life, which can be scored and communicated with the treating physicians. Added to that, the patient and

physician are both enabled to gain insights from prediction information about life expectancy.

The IPD allows both patient and physician to be aware of the same amount of information and to understand what this information entails, which, according to the literature, is the condition to be able to implement the SDM process properly.

Because this project was carried out in the name of IKNL, the IPD was created for a small fraction of the numerical information database they possess, with the purpose to be able to project the principle of the IPD on their entire database to help as many cancer patients as possible with their valuable information.

When patients are more involved in making treatment decisions based on the process of SDM, it may have influenced the patient experience in a positive way, leading to a better quality of life of the patient. When the quality of life of the patient is improved due to the provided care, it can be said that the quality of care has also improved.



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# GLOSSARY & ABBRIVIATIONS

## Glossary

**Patient** - When patient is mentioned, then a colon cancer patient is meant who is confronted with the decision about adjuvant chemotherapy.

**pTNM / cTNM** - TNM is the classification model which is used to determine the tumour and the state of the tumour. The difference between the 'p' and 'c' is pathological and clinical.

**IPD** - The IPD is the name of the created web application. IPD stands for; inform, prepare and decide.

## Abbreviations

**SDM** Shared Decision Making

**IKNL** Netherlands Comprehensive Cancer Organization

**PPEJ** Patient Physician Experience Journey

**MDC** Multidisciplinary Consult

# INTRODUCTION

This graduation project aims to provide insight in the process of Shared Decision Making (SDM) for patients with colon cancer during the consultation with the oncologist at the hospital when a decision needs to be taken considering adjuvant chemotherapy. It also suggests a design solution based on the numerical information from the Netherlands Comprehensive Cancer Organisation (IKNL) to improve the process of SDM among colon cancer patient and physician. The project was carried out for IKNL.



The VUmc wants to make a substantial contribution to the quality of health care and thus to the welfare of people. As a university medical centre, VUmc focuses on a leading position in education and training, scientific research and patient care. VUmc is there for patients, loved ones, referrers, students, train professionals and clients of research (VUmc, n.d.). Information and insights were gathered in collaboration with a specialist of the VUmc in the field of SDM and risk communication.

IKNL, is the quality institute for oncological and palliative research and practice. IKNL collaborates with hospitals, healthcare professionals and managers and patients on the continuous improvement of oncological and palliative care (IKNL, n.d.). IKNL gathers the information of numerous patient cases by means of IKNL staff members whom are working at the oncology department of different hospitals in the Netherlands. Manually, they go through every case. The information gathered is put in the Netherlands Cancer Registry (NCR).

Currently, the objective of IKNL is to serve the public interest by promoting the fight against cancer, particularly by helping those suffering from cancer and by promoting palliative care (IKNL, n.d.). IKNL aims to disseminate a variety of information on

colon cancer and its treatment for patients and medical professionals to contribute to the process of SDM and creating more transparency in the world of health care:

- The clinical guidelines are presented in a computer- and human interpretable format via Oncoguide.nl for medical professionals.
- The Netherlands Cancer Registry is a rich data source on virtually all colon cancer patients in the Netherlands. It provides detailed information on diagnosis, primary treatments and survival. The NCR is the foundation of many scientific publications. It is publicly available, but not for a wide audience.
- In collaboration with Tilburg University, the Profiles studies gather information about quality of life for patients with colon cancer.

## DECISION MAKING IN HEALTHCARE

What role patients should assume in medical decision making is an issue that has stimulated much debate. A wide variety of opinions exist, ranging from the view that patients should assume at least some responsibility for their own treatment, to the position that it is unwise to encourage such participation because patients do not have the specialised knowledge required to make treatment decisions (Degner, Sloan, 1992). The difficult process of SDM, is a process in which the physician shares with the patient all relevant risk and benefit information on all treatment alternatives and the patient shares with the physician all relevant personal information that might make one treatment or side effect more or less tolerable than others (King, Eckman, & Moulton, 2011). SDM is currently being advocated by both healthcare professionals and patients as the ideal for decision making (Stiggelbout, Pieterse, & De Haes, 2015). The process of SDM is difficult to implement, for example because it has proven difficult to create access to balanced and easy to understand information for patients.

## SCOPE OF THE PROJECT

The scope of this graduation assignment is on adjuvant chemotherapy treatment decisions regarding patients with colon cancer. This decision-making moment occurs after surgery when the pTNM-classification ( appendix 1) (UICC, 2010) shows a certain value which suggests if adjuvant chemotherapy is applicable. During the multidisciplinary consultation (IKNL, n.d.) the best treatment option is discussed in the eyes of the physicians. This is then shared with the patient during the consultation with the oncological surgeon. During the next consultation with the oncologist, it is expected of the patient to make a final treatment decision.

## PROBLEM DEFINITION

Making decisions about treatments options for patients is still very difficult because of a lack of knowledge about their disease and the possible consequences and side effects each treatment may have. Besides the factual knowledge which is necessary to make the right decision, the preferred decision-making role of the patient is

also affecting the amount of information is desired by the patient (Stiggelbout, Kiebert, 1997).

The physician is expected to come up with a treatment option that they think is suitable for the patient. Currently, the suggested treatment option is based on the clinical information, which is obtained by the examined tissue by the pathologist. An attempt is made to consider the preferences of the patient, but in reality, due to time constraint, this is almost impossible.

To deal with this lack of knowledge, patients tend to search for answers, for example, about the nature of the disease, survival opportunities, quality of life, side effects and treatment options. Sources like the internet, books, flyers, applications, etc. are used to find information. Unfortunately, not every piece of information is trustworthy or applicable for everybody, especially when searching the internet. In addition, misjudging of the information may lead to unrealistic hope or even more uncertainty and fear for the patient (Srini Pillay, 2010).

To find solutions for these phenomena, the following research question and sub-questions were defined;

- How to equip patients and physicians to make an informed shared decision?
  - What information is needed to make an informed decision?
  - How can the information be made understandable for the patients and physicians?
  - How can the information be transferred in a user-friendly way?

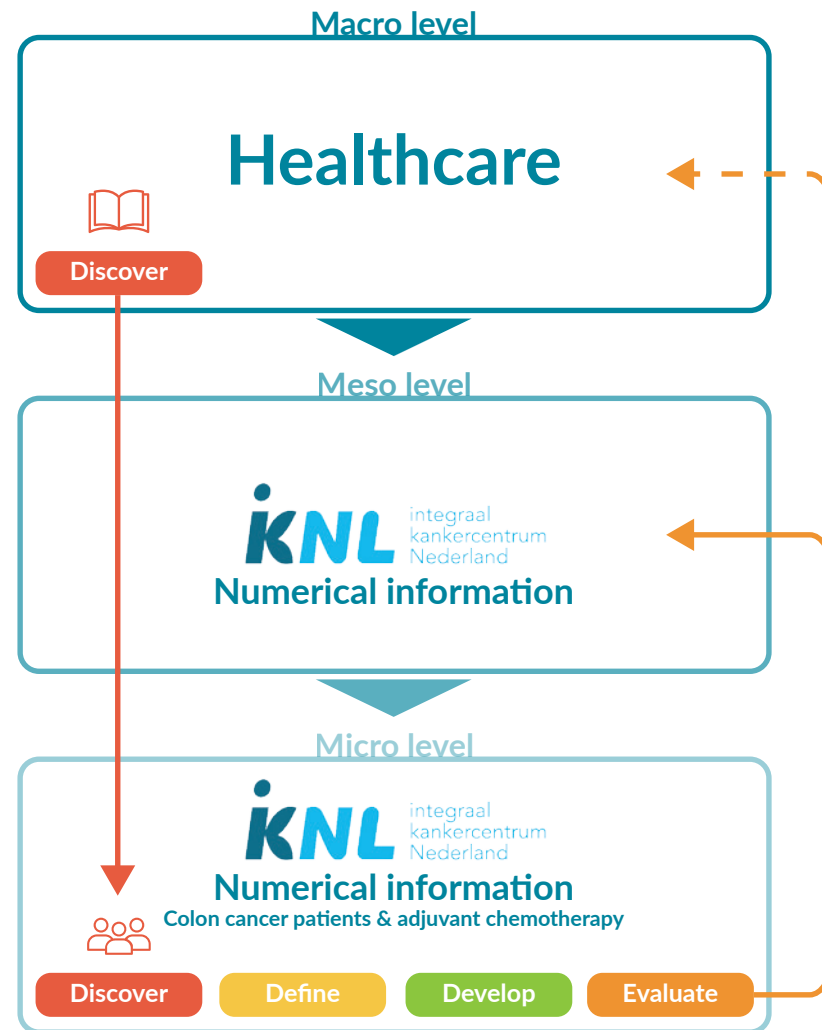


Figure 0.1. Combination of Macro-Meso-Micro approach and the traditional industrial design method

## METHODOLOGY

The methods that are used to answer the research questions can be divided into two parts. These separate parts are connected to each other as shown in figure 0.1. The first part is the overall macro-meso-micro approach (Sanderson et al, 2012). By using this approach, a theoretical framework is created at a macro level, and validated on a micro level. By doing so, if positive results are achieved, the concept can be applied on the numerical information of other types of cancer of IKNL, and even on other numerical databases of other diseases. the distribution within this thesis will be as follows;

- The 'macro level'
  - Literature research and a theoretical framework
- The 'meso level'
  - The client IKNL: Numerical information about cancer patients
- The 'micro level'
  - The validation of the concept with numerical information about colorectal cancer patients and the possible treatment options concerning adjuvant chemotherapy

The second part is based on the traditional industrial design method described by the 'Delft Design Guide' (Van Boeijen, Daalhuizen, Zijlstra, & Van der Schoor, 2013). The book describes different phases in which a design process can be divided; Discover, Define, Develop and Evaluate. This division was used as a template for this thesis. The methods that were used are;

- A desktop literature research (Macro)
- Observations at the hospital cancer consultations (Mirco)
- Interviews with patients and physicians at different moments within the design process (Micro)
- User tests (Mirco)



### Why colon cancer patients & adjuvant chemotherapy? (appendix 2)

Numerous people are confronted with cancer every day. Over 100.000 patients were diagnosed in the year 2016 in the Netherlands (IKNL, 2017), making it still one of the most common causes of death in the Netherlands (CBS, 2017). According to the dataset from IKNL, after the gender related breast and prostate cancer, colon cancer is the most common form. Within the care path of colon cancer patients, whether or not to apply adjuvant chemotherapy, is recognized as a clear decision moment in which both patient and physician are involved (interviews). That is why this case is suitable for creating and validating a design on a 'micro level' in order to contribute to improving the complex process of SDM.

## STRUCTURE OF THE PROJECT

As explained before, the division of; Discover, Define, Develop and Evaluate is used as a template for this thesis. Figure 0.2 is a graphical representation of the structure of the project.

### *Discover*

The project started with the Discover phase. First, literature research (Chapter 1.1) was conducted with emphasis on SDM in healthcare, increasing information provision and changing relation between physician and patient. by connecting these factors to each other, the theoretical framework was created on a 'macro level'. To be able to use the theoretical framework on a 'micro level', user research (Chapter 1.2) was conducted to gain understanding about the patient and physicians' experience through observations of consultations and interviews with physicians and patients. The insights of the user research were used to create the Patient Physician Experience Journey (PPEJ).

### *Define*

In the synthesis (Chapter 2.1), the theoretical framework was projected on the PPEJ. This resulted in identifying bottlenecks within the PPEJ. These bottlenecks were distinguished as design opportunities. This led to the design exploration (Chapter 2.2) for creating a design. The design direction indicated a user interface. To learn from existing UI's in healthcare, a 'competitor analysis' was conducted. Finally, all the information was obtained to formulate an accurate design goal (Chapter 2.3). The interaction vision was stated along with the list of requirements and wishes.

### *Develop*

With the list of requirements and wishes as a starting point, the develop phase started. Because of the demands from the different stakeholders, strict design boundaries emerged. Therefore, the choice was made to use a linear design method instead of the 'multiple concepts' method. The new design was going to be a web application. A concept emerged that was elaborated in the conceptualisation (Chapter 3.1).

Points of attention were; Appearance, usability and risk communication. To be able to actually test the design, a prototype (Chapter 3.2) was created. Using Adobe XD Design, a working prototype was created to test the points of attention with actual users. Through several user test optimizations (Chapter 3.3) the design was optimized to be as user friendly, appealing and understandable as possible.

### *Evaluate*

During the final phase of the project the design was evaluated. First the final design (Chapter 4.1) and its working principles were explained. Through the implementation (Chapter 4.2), various subjects were cited to ensure the achievement of the design in the future. Finally, the conclusions (Chapter 4.3) and recommendations (Chapter 4.4) were made.

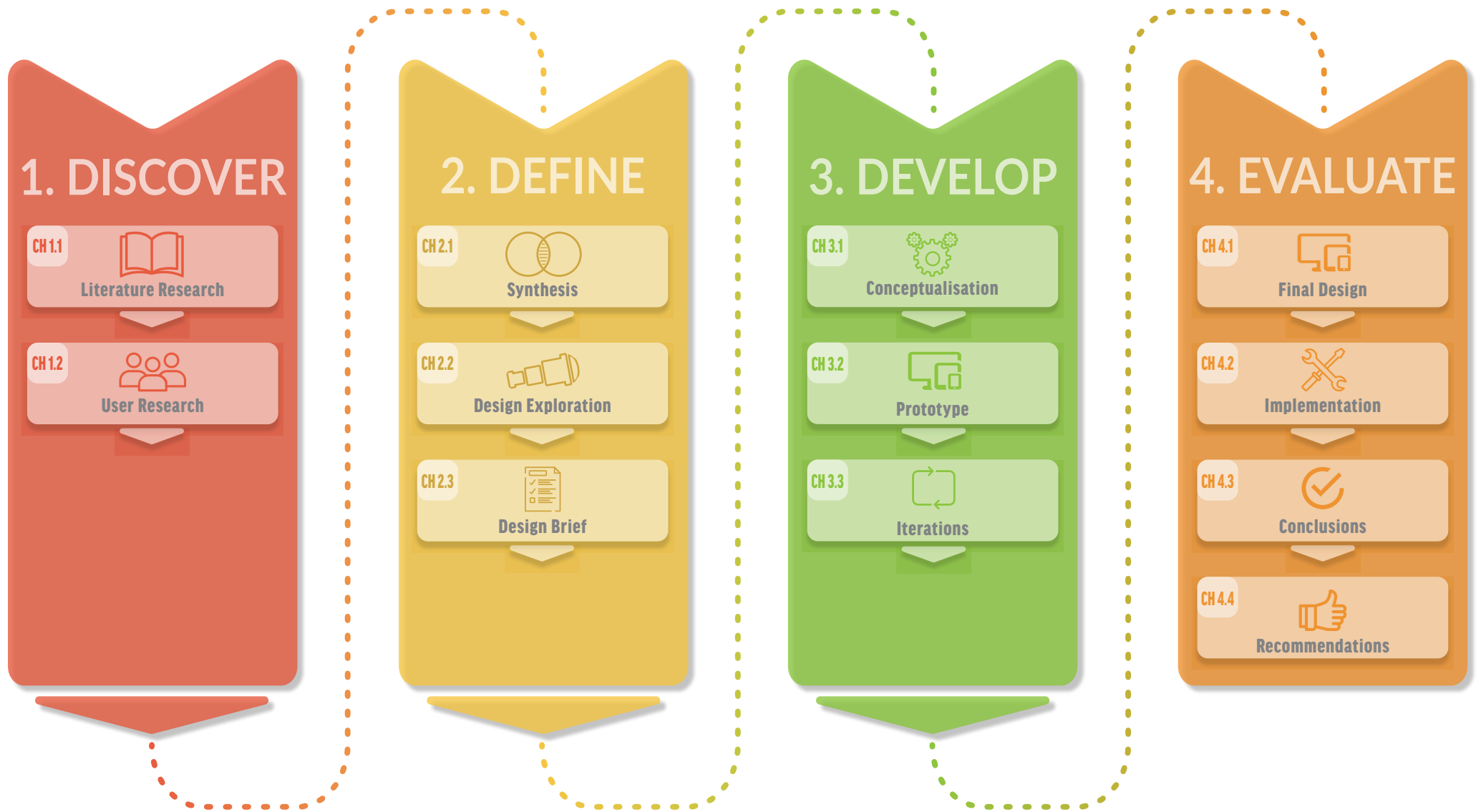


Figure 0.2. Graphical representation of the structure of the project



# ANALOGY

Decision making is an everyday routine for every human being. The extent of the choice that is made differs a lot. From deciding what to wear that day to finally making the decision to buy that specific house you always wanted. Every decision we make is influenced by many facets. If you have to choose your clothing, facets like; branding, price, the weather, and many more influences this decision. But when we finally make the decision to buy some specific jeans, it is based on well thought-through considerations. In other words, it is obvious to us why we have chosen that specific jeans.

When we are not so sure about what to choose, we tend to search for information to be able to make these well thought-through considerations. Discussing with a friend, looking on internet for information, asking a specialist in the shop, are different ways to obtain the information necessary to make your final decision.

You won't accept it, when you enter a store to buy a television and the seller just gives you one and sends you home. You want to know why you

should take that specific television and not an alternative, which are obviously present.

Unfortunately, this scenario, in a similar way, exists in health care. Although this entire decision process is a lot more complicated and intense for the person who has to make the final decision, still patients tend to leave the final decision up to the physician. The problem that underlies this phenomenon, is the accessibility of the current information provision. Where we now have the ability to fully investigate the purchase of a simple phone cover, we have to pass on the decisions about our own body to someone else. That is

because it requires too much knowledge that is not available in an understanding way for the patient.

For me as a designer and a thinking man, this is strange. With this argumentative analogy I want to trigger the reader to experience the same motivation I had with this project. I want to provide the information needed, and stimulate the process of SDM, to enable the patient to have a well thought-through consideration about the different treatment options for their own body.



Figure 0.3. Visualisation of Analogy

This chapter gives an overview of the gathered information which is obtained during the first phase of the graduation project. First a literature research was conducted to create a theoretical frame work on a 'macro level'. The process of decision making concerning adjuvant chemotherapy for colorectal cancer patients needs to be investigated by performing user research, to fully understand the current situation on a 'micro level'. Various methods have been used for the user research. The conclusions of the Discover phase were the starting point for the Define phase.

## 1.1 Literature Research

## 1.2 User Research



# 1.0



# DISCOVER



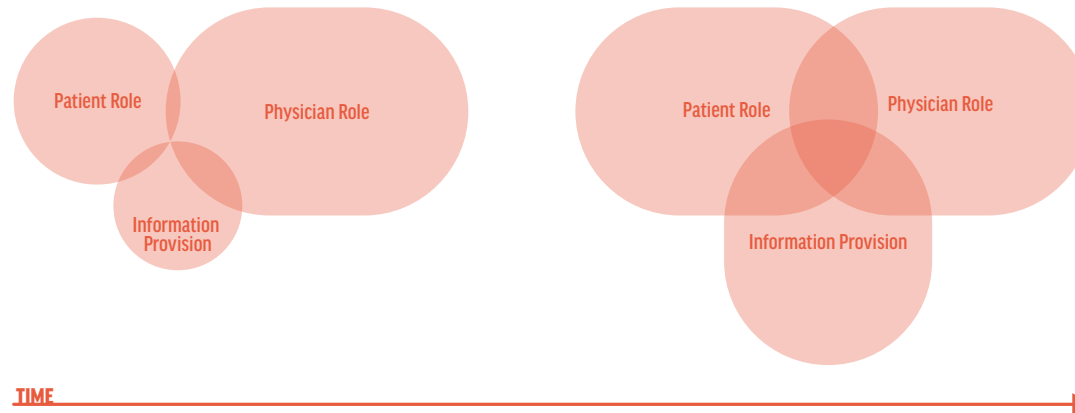
# 1.1 LITERATURE RESEARCH

*Investigating literature to create a theoretical framework on a macro level*

Needless to say, making appropriate **treatment decisions** is very important in the field of health care, because those decisions can be life-determining and directly of impact on the quality of life of the patient and the quality of care (Say, Thomson, 2003). According to Kaba and Sooraikumar (2007), the decision model in which physicians feel comfortable in making decisions on behalf of their patients, shifts to a new alliance between physician and patient (figure 1.1), based on co-operation rather than confrontation, in which the physician must

“understand the patient as a unique human being”. This also implies that the process of decision making becomes more complicated (World Health Organization, 2017). **The changing relationship between physician and patients** (Truog, 2012), is being influenced by the **increasing information provision** (Car et al, 2008). An example of this is the provision of the digital Electronic Health Record for patients (Smulders & Metselaar, 2017). This radical **transparency** by means of information provision, has its benefits when it comes to patient participation

and the process of decision making (Kaba, Sooriakumaran, 2007). However, misjudging of the information may lead to unrealistic hope or even more uncertainty and fear by patients (Srin Pillay, 2010). By better informed and empowered patients, specialized physicians and a growing world of information (figure 1.2), the healthcare system is looking for the best way to cope with this change. This indicates an opportunity to implement **the process of SDM**. In this chapter, these developments are further explained.



*Figure 1.1. The changing relationship between physician and patients by the increasing information provision*

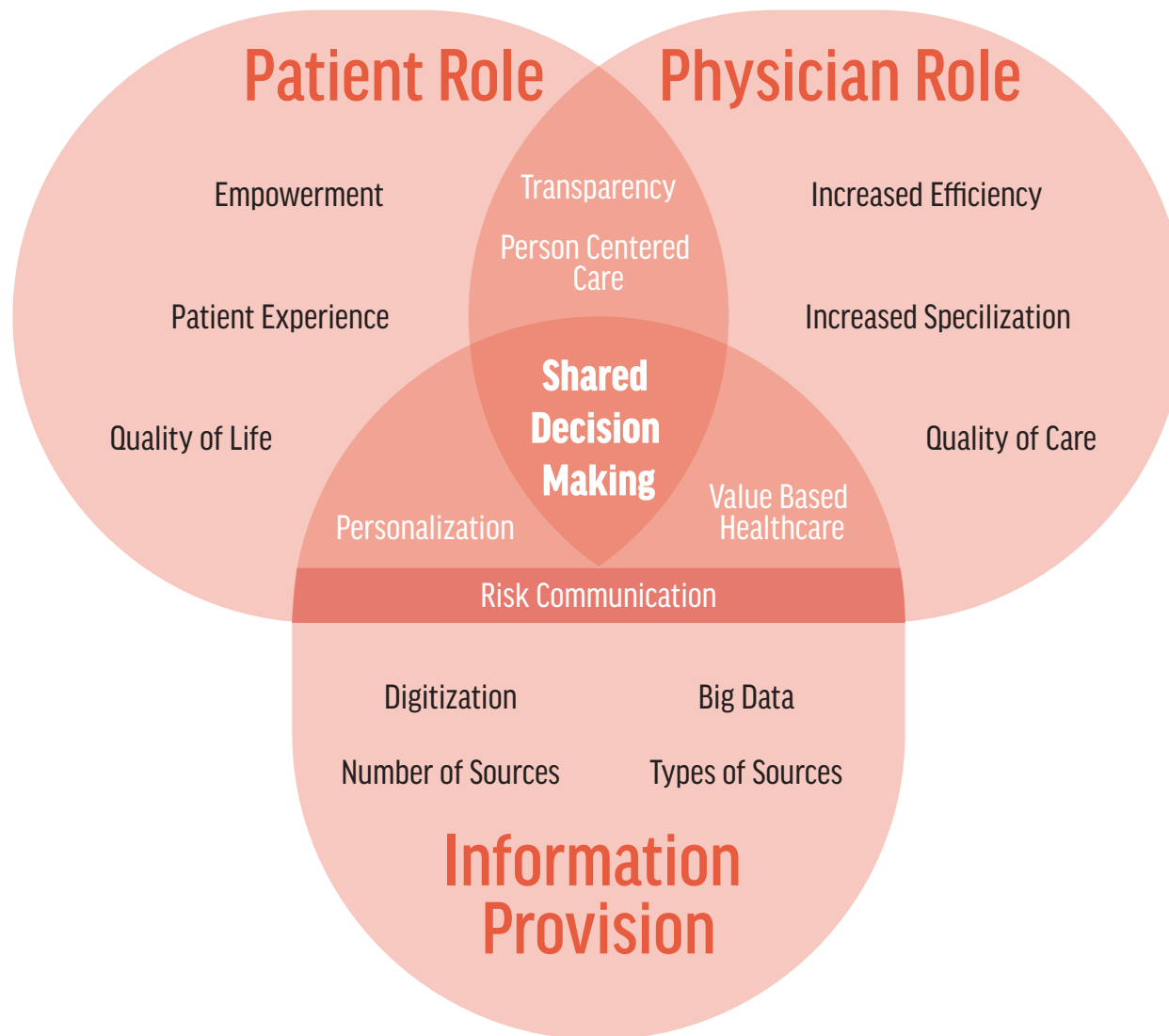


Figure 1.2. Graphical representation of the relations between; patient, physician and information provision

## INCREASING INFORMATION PROVISION

Information provision to both patients and physicians plays an important role in healthcare decision-making, which was already described by Ortiz and Clancy (2003). First, the decision-making information was presented by the treating physician during the consultation and hospital leaflets (Närhi, 2007). Now, there are forums, organization websites, published studies, applications and many more **different sources** where decision-making information can be found. These different sources are made available by different providers, varying from peers to medical researchers. The hospitals themselves are also participating in this trend by making the Electronic Health Record available for patients (Smulders & Metselaar, 2017).

On the basis of this development lies the **digitizing of the information**. Not only the amount and the different sources increases, but also the accessibility. Nowadays almost everybody has a mobile device with internet to access the world of healthcare information within a few clicks (Markovitch & Willmott, 2014). According to Car,

Colledge & Majeed (2008), it is clear, in many circumstances, alternative format resources are an effective and viable alternative to the classic printed patient information leaflet.

The power behind this increasing information provision lies in the field of **personalization**. By filling in some simple personal characteristics, appropriate personalized information can be presented that relates to the patient rather than the general population. (Fernandez-Luque, Karlsen, Bonander, 2011). This is due to **big data** sources. In recent years, large databases have been created with valuable information (Raghupathi, Raghupati, 2014). Some are; treatment outcomes, incidence and quality of life. By releasing algorithms on these databases, valuable prediction models about possible outcomes form different treatment options can be created (Winters-Miner, 2014).

From the government (Minister van Medische Zorg, 2018) (Minister van Volksgezondheid, Welzijn en Sport, 2018), the pressure is increased

to make decisions based on these models in order to prevent overtreatment, undertreatment, overdiagnosis, underdiagnosis, uncontrolled costs and budgets, medical treatment errors and wrongly placed incentives (VHBC, 2018). **Value-based healthcare** is the paradigm to maximize the quality of care while keeping healthcare affordable.

## CHANGING RELATION BETWEEN PHYSICIAN AND PATIENT

There have been major movements in medicine and the role of doctors within the immediate past and the pace is accelerating (British Medical Association, 2017). The increasing amount of information and government pressure influences both physician and patient. Due to the advancing technological possibilities, care is shifting more and more to the patient at home. However, the provision of information has not been fully optimized according to this trend. New technology, such as eHealth applications, will support this further. This development also changes the role of the care provider: in the

future, patients will increasingly approach them as coach, co-thinker or extensionist (Rijksinstituut voor Volksgezondheid en Milieu, 2018).

Health professionals are increasingly encouraged to involve patients in treatment decisions, recognizing patients as experts with unique knowledge of their own health and their preferences for treatments, health states, and outcomes. Increased **patient involvement**, a result of various socio-political changes, is an important part of quality improvement since it has been associated with improved health outcomes and enables doctors to be more accountable to their patients (Say, Thomson, 2003). However, physicians sometimes have doubts whether presenting all this information does have the right influence on the patient concerning information and cognitive overload. Physicians regularly make tacit judgments about the amount of information that patients can reasonably assimilate, how to interpret and contextualize it, how it will affect patients' and families' ability to cope with the illness and make informed decisions, and how to avoid frightening or overwhelming patients with

details (Epstein, Korones & Quill, 2010).

Apart from the impact of increasing information provision and government pressure, there are other factors that underlie the **changing role of the physician**. Some of these factors are; **healthcare is becoming more efficient** and physicians are becoming **increasingly specialized**. With the result that the information provided by the specialists to the patient is becoming increasingly complicated due to the increasing specialization (Cassel, Ruben, 2011). Which again, could ensure that patients experience an information overload. Added to that, the predication models, created from big data sources, can be used by the physician to consider treatment options for the patient and increase the efficiency of the provided care.

Nowadays, patients are better informed about their own case and matching care path because of the increasing availability of information. Internet health information seeking can improve the **patient physician relationship** depending on whether the patient discusses the information with

the physician and on their prior relationship. As patients have better access to health information through the Internet and expect to be more engaged in health decision making, traditional models of the patient provider relationship and communication strategies must be revisited to adapt to this changing demographic (Tan & Goonawardene, 2017)

Because of **internet health information seeking behavior**, patients are becoming more and more empowered. **Empowerment of patients** is defined in 2009 by the World Health Organization (WHO) as a process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation. This is already a well-known phenomenon among general practitioners (BMA, 2018).

According to Ajoulat, d'Hoore & Deccache (2007), empowerment may be defined as a complex experience of personal change. It is guided by

the principle of self-determination and may be facilitated by health-care providers if they adopt a patient-centred approach of care which acknowledges the patients' experience, priorities and fears. In order to be empowering for the patient, therapeutic education activities need to be based on self-reflection, experimentation, and negotiation. This allows the appropriation of medical knowledge and the reinforcement of psychosocial skills. As they get empowered, patients may develop a greater sense of self-efficacy regarding various disease and treatment-related behaviours, and may reflect about values and priorities in life. As a result of their empowerment process, patients are expected to better self-manage not only their illness, but their lives as well.

If patients participate better in the treatment process, the **patient experience** is improved, leading to **better care** (NRC Health, 2017). However, not all available information is equally reliable. As mentioned before, the misinterpretation of the information may lead to the opposite goal of a well-informed patient

who is equipped to discuss treatment options with their physician. This is something that may complicate the task of medical doctors, as patients approach them with wrong assumptions and emotions based upon these beliefs. Besides, radical **transparency** can lead to an information overload and an even more concerned patient. According to the British Medical Association (2017), questions were raised about how time pressured clinicians can deal with the volume of unfiltered information, some irrelevant or misleading, that can now form the backdrop to any consultation. A doctor's judgement was also increasingly weighed by patients alongside the 'wisdom of the many' including advice from other physicians, friends and from the internet.

Unlike results from diagnostic tests, **quality of life** can only be described by the individual, and must consider many aspects of life (Calman, 1984). Quality-of-life assessment could, and perhaps should, be integrated in clinical practice. During long-term treatment the perception of the patients' well-being by physicians and patients themselves can easily diverge from each

other, resulting in misunderstandings about the treatment and its contribution in relation to perceived quality of life, and may even become the base for non-compliance (Janse et al, 2003).

## SHARED DECISION MAKING

What role patients should assume in medical decision making is an issue that has stimulated much debate. A wide variety of opinions exist, ranging from the view that patients should assume at least some responsibility for their own treatment, to the position that it is unwise to encourage such participation because patients do not have the specialized knowledge required to make treatment decisions (Degner, Sloan, 1992). The difficult process of SDM, described as a process in which the physician shares with the patient all relevant risk and benefit information on all treatment alternatives and the patient shares with the physician all relevant personal information that might make one treatment, outcome or side effect more or less tolerable than others (figure 1.3) (King, Eckman, & Moulton, 2011). SDM is currently being advocated by both



healthcare professionals and patients as the ideal for decision making (Stiggelbout, Pieterse, & De Haes, 2015). The process of SDM is difficult to implement, for example because it has proven difficult and time consuming to create access to balanced and easy, outcome to understand information for patients. This indicates an opportunity to create a tool which incorporates the components in a structured way to stimulate the process of SDM.

Although SDM has the potential to **support the shifting relationship between physician and patient**, the problem of interpretation of the information remains, with the result that the specialists are wary about releasing clinical information, because they do not consider that patients are able to estimate the correct value of the clinical information (Edwards, 2004). Spiegelhalter, Pearson & Short (2011) suggest, when the information is presented according to the principles of **risk communication**, it can be made understandable for patients. Risk communication is a process of interaction and exchange of information and opinions

among individuals, groups and institutions that incorporate and respect the perceptions of the information recipients, to help people understand the risks to which they are exposed and make more informed decisions about threats to health and safety and to encourage them to participate in minimizing or preventing these risks (Damman, VUmc, & RISC, n.d.).

- 
- doctor alone
  - doctor led & patient acknowledgement (sought or offered)
  - doctor led & patient agreement (sought or offered)
  - doctor led & patient views/opinion (sought or offered)
  - shared equally
  - patient led & doctor views/opinion (sought or offered)
  - patient led & doctor agreement (sought or offered)
  - patient led & doctor acknowledgement (sought or offered)
  - patient alone

*Figure 1.3. Degrees of SDM (Makoul & Clayman, 2005)*

## CONCLUSIONS

This paragraph concludes the literature research. Many connections have been found between the components presented in figure 1.2. To describe the connections between the components, a theoretical frame work is created (figure 1.4). The goal of this framework, which is obtained by literature and therefore theoretical, is to be projected in practice and to find connections between theory and practice. These connections will serve as a fundamental basis for creating concepts.

The theoretical framework should be read as follows;

1. Because the available information is increasing, both physician and patient are influenced by this increasing provision.
2. This influence may cause the patient to be more empowered and the physician to educate him/her self with the insights gained from the big data and other information sources.
3. Empowered patients may be increasingly involved in making decisions about their own

treatment options. Physicians are always involved in making these decisions.

4. To meet the definition of the process of SDM, both patient and physician need to understand the content of the same amount of available information.
  - This means that the patient should share their personal interests and attitude towards the treatments options in an understandable and realistic way for the physician.
  - The physician should share the clinical information with the patient in an understandable way.
5. To reach the goal, to create information for both physician and patient which is understandable for both parties, the information could be transformed according to the principles of risk communication.
6. Then, the SDM process between physician and patient leads to a treatment decision to which the treatment starts.
7. When the decision was based on the process of SDM, it may have influenced the patient experience in a positive way, leading to a

better quality of life for the patient.

8. The outcome of the treatment may be positively influenced by the process of SDM, leading to a better quality of care.

In other words, Involving the patient in terms of SDM may improve the quality of life and quality of care.

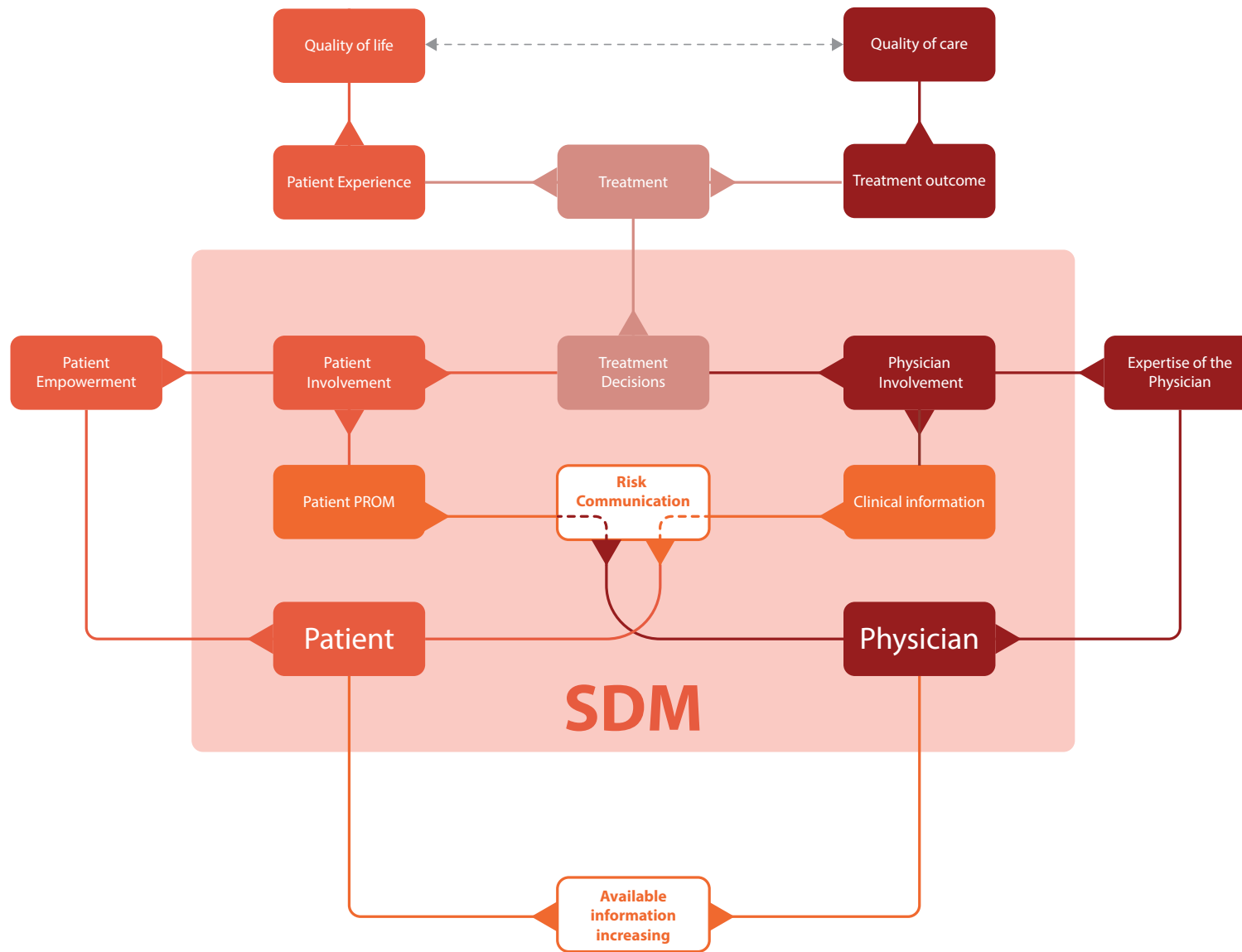
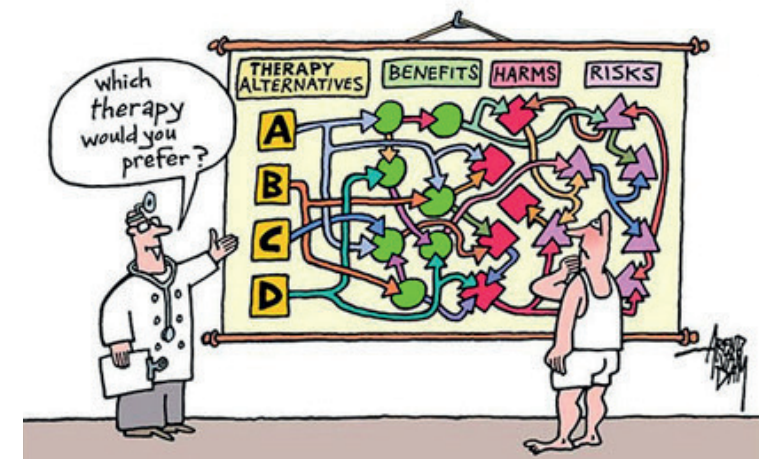


Figure 1.4. Theoretical Framework

## RELEVANCE

The scope of this project is to equip a patient and physician to make an informed shared decision. The literature showed that both the changing roles, of the patient and physician, are influenced by the increasing information provision. The gathered information about the influences of the changing role of the patient, the changing role of the physician and the increasing information provision, shows a theoretical approach on a macro level. However, to be able to create a design which facilitates the patient and physician to make an informed shared decision, a projection of this theoretical framework is needed to a concrete, realistic decision in healthcare. The client IKNL, has a database of cancer patients, meso level. The choice was made to focus on colorectal cancer patients and the treatment choices that belong to adjuvant chemotherapy, micro level. Therefore, the process of decision making concerning adjuvant chemotherapy for colorectal cancer patients needs to be investigated to fully understand the current situation. Then, a design can only be created that fits within that specific scenario. The next chapter – user research – explains how this is done.



## 1.2 USER RESEARCH



*Investigating in practice on a micro level*

The literature research provided a first understanding about decision-making, the increasing information provision and changing role of patient and physician, which resulted in a theoretical framework on a macro level. In order to define a design direction and validate a concept, the micro level; the current process of decision making in practice concerning the treatment options for adjuvant chemotherapy for colon cancer patients, must be analysed. The aim of this user research was to gather insights from the current decision-making process concerning the treatment options for adjuvant chemotherapy for colon cancer patients, to create the PPEJ. The PPEJ is a graphical representation of the current decision-making process. It provides an overview of the different phases of the current process. Within these phases the different interactions and emotions of patient and physician are shown. The goal of the PPEJ is to get a comprehension of the complete decision-making process. By means of the PPEJ, any bottlenecks within the care path were identified which can be starting points for potential design directions.

### RESEARCH QUESTIONS

Three main research questions were defined regarding the general decision-making process, the role of the patient, the role of the physician and the available information provision.

#### ***General decision-making process***

Research question 1; How is the current decision-making process regarding the treatment options for adjuvant chemotherapy for colon cancer patients organised in practice?

1. Where, in the care path of the patient, does decision-making process takes place?

2. What is the current procedure during the decision-making process?
3. What current interactions occur between patient and physician?
4. How are the decisions made about a treatment option?

#### ***Patient experience in decision-making process***

Research question 2; How does the patient experience his/her role in the decision-making process?

1. What information does the patient uses?

2. What information does the patient misses?
3. What was expected of the (chosen) treatment?
4. How do patients prepare themselves for the final decision-making moment?

#### ***Physician experience in decision-making process***

Research question 3; How does the physician experience his/her role in the decision-making process?

1. What is key in treating a patient?
2. What information does the physician uses?
3. How do physicians provide information to the patient, and what type of information do they provide?
4. What information do physicians provide to the patient about different treatment options?
5. What information does the physician misses?
6. What do physicians think of releasing predictive numerical information to patients?

## RESEARCH METHODS

Mixed research methods (figure 1.5) were used to answer the research questions. Results of the user research comprise the following:

- Entire care path of the patient (page 36)
- The current procedures during the decision-making process (page 39)
- Patient Physician Experience Journey (page 42-43)





Method	R.Q. answered
 Consultation observations N= 35	1.1, 1.2, 1.3 2.1, 2.2, 2.3, 3.1, 3.2, 3.3, 3.4, 3.5, 3.6
 MDC observation N= 1	1.1, 1.2 3.2
 Semi-structured physician interviews N= 3	1.1, 1.2, 1.3, 1.4 3.1, 3.2, 3.3, 3.4, 3.5, 3.6
 Semi-structured patient interviews N= 6	1.2, 1.4 2.1, 2.2, 2.3, 2.4

Figure 1.5. Methods and R.Q. they answered



## Research method 1 – Consultation observations

The observational study was performed to obtain insights about the physicians' and patient's interaction, behaviour and emotions during a consultation, with emphasis on making treatment related decisions, from the perspective of the researcher. It also allowed to capture the general phases of each consult.

### Participants (figure 1.6)

To find answers about the patients' and physicians' experience during their care path, observations were performed in two hospitals. The Catharina hospital in Eindhoven and the AMC in Amsterdam. 35 consultations were attended, out of the 35 patients that were observed, 22 of them suffered from colon cancer. 15 of them were diagnosed with another type of cancer.

### Procedure

The physician invited the patients to the consultation room. Permission was requested from the patient by the physician for the attendance of the researcher. When permission was granted, the researcher greeted the patients. During the presence of the researcher, there has been no verbal communication with the patients. The position taken, was sitting behind the physician which was sitting behind his/her desk. A notebook was used to make notes. The attitude taken, was to be as un-present as possible for the patients to not disturb and influence the consultation.

### Processing the information

After the consultation, the notes made during the consultation, were examined to determine how an average consultation looks like, and to look for Interesting quotes made by patient and physician. The notes were also used to capture emotions, frustrations and challenges experienced by patient and physician in the PPEJ. The obtained knowledge was used to answer the research questions. The full description of the observations can be found in appendix 3.




Hospital	Physician	Number of patients	Gender of patients	Age of patients
	Oncologist	N = 11	5 females	Avg. 65 (53-73)
			6 males	Avg. 61 (50-71)
	Oncologist	N = 3	3 males	Avg. 62 (57-70)
	Oncological surgeon	N = 21	8 females	Avg. 59 (47-76)
			13 males	Avg. 64 (41-83)

Figure 1.6. Participants of the observations



## **Research method 2 – Multi Disciplinary Consultation (MDC) observation**

The observational study was performed to get a general impression of the MDC. This is a meeting of many physicians, going through patient cases to discuss and determine how to treat each patient. Behaviour and emotions during the MDC were captured from the attendees, with emphasis on making treatment related decisions, from the perspective of the researcher. It also allowed to capture the general phases of the MDC.

### **Participants**

The physicians attending the MDO at the Catharina Hospital Eindhoven were;

- Oncological Surgeon

- Oncologist
- Gastroenterology doctor
- Nuclear medic
- Radiologist
- Pathologist
- Nursing specialists of the Surgical Oncology
- Nursing specialists of the Gastroenterology

The different specialists only spoke when their specialty was applicable for the case. During the MDC, most of the time the radiologist started with the discussion of the patient by telling what he had observed from the multiple scans that were made of the patient.

### **Procedure**

The researcher was invited by the oncological

surgeon to attend the MDC. During the presence of the researcher, there has been no verbal communication with the attendees. The position taken, was sitting next to oncological surgeon which was sitting behind his desk. A notebook was used to make notes. The attitude taken, was to be as un-present as possible for the attendees to not disturb and influence the MDC.

### **Processing the information**

After the MDC, the notes made during the MDC, were examined to determine how an average MDC looks like. The obtained knowledge was used to answer the research questions. The description of the MDC can be found in appendix 4.





### **Research method 3 – Semi structured physician interviews**

The hospital is responsible for the diagnosis of the patient. After diagnosis, the treatment is given by multiple physicians from the hospital. Therefore, interviews were conducted to obtain insights of the care path of the patient through the eyes of the treating physicians.

#### **Participants**

Multiple physicians were interviewed, 3 in total at two different hospitals. 2 physicians from the Catharina Hospital in Eindhoven and 1 physician of the AMC in Amsterdam;

- An oncological surgeon at the Catharina Hospital Eindhoven

- An oncologist at the Catharina Hospital Eindhoven
- An oncologist at the AMC Hospital Amsterdam

#### **Procedure**

The interviews were performed in the time between and after the consultations. When a consultation was finished, questions were asked to the specialist. The nature of the questions was based on what had occurred during the consultations along with some general questions. When allowed, a voice recording was made of the interview. Besides the practical nature of the recordings, the second purpose was to be able to focus on the conversation instead of being distracted due to the immediate documentation of the answers given.

#### **Processing the information**

The audio recorded interviews were used with the intention to complement the documentation of the interviews afterwards. The obtained knowledge was used to answer the research questions. The full description of the interviews can be found in appendix 5.



## **Research method 4 – Semi structured patient interviews**

Because a patients' care path is more than just the consultations at the hospital, interviews were needed with patients to be able to fully describe the patient part of the PPEJ. During the consultation observations, it became clear that the patient never stands alone and was often accompanied by their loved ones, or informal caregiver. Therefore, informal caregivers were also interviewed.

### **Participants**

6 participants were interviewed;

- Patient, male, who have been declared healed, 61 Years old at diagnosis of patient
- Patient, male, who have been declared healed, 63 Years old at diagnosis of patient
- Patient, female, who have been declared healed, 37 Years old at diagnosis of patient

- Informal caregiver, where the patient, female, died from the effects of colon cancer, 83 Years old at diagnosis of patient
- Informal caregiver, where the patient, female, died from the effects of colon cancer, 56 Years old at diagnosis of patient
- Patient/informal caregiver combination, where the patient, male, was still being treated, 61 Years old at diagnosis of patient

### **Procedure**

The interviews were performed at the patients' and loved ones' homes. First, a brief description was given by the researcher to explain what the purpose was of the interview. Then the interview started. Beforehand, a list with questions was put together. The function of the list was to serve as a guideline through the interviews. The questions were not handed over to the interviewees. If it

was not possible to interview the patient or loved ones, questions were asked about the influence of the patient or loved ones, depending on who was interviewed. When allowed, a voice recording was made of the interview. Besides the practical nature of the recordings, the second purpose was to be able to focus on the conversation instead of being distracted due to the immediate documentation of the answers given.

### **Processing the information**

The audio recorded interviews were used with the intention to complement the documentation of the interviews afterwards. The obtained knowledge was used to answer the research questions. The full description of the interviews can be found in appendix 6.

## RESULTS USER RESEARCH

### *General decision-making process*

### ***Research question 1; How is the current decision-making process regarding the treatment options for adjuvant chemotherapy for colon cancer patients organised in practice?***

#### **R.Q. 1.1 - Where, in the care path of the patient, does decision-making process takes place?**

The following steps (figure 1.7) in the care path of the patient were distinguished;

1. The individual realizes that something is wrong.
2. The individual visits the general practitioner with his/her complaints.
3. The general practitioner advises the individual to visit gastro-entrevologist physician at the hospital.
4. The first examination results are presented. When the results are negative, the individual is sent home. When the results are positive, the individual becomes a patient and needs a more thorough examination.
5. The patient undergoes a more thorough

examination.

6. Before the results of the thorough examination are shared with the patient, multiple specialists discuss the results in the MDC to define the diagnosis and prognosis.
7. The results of the MDC are shared with the patient which starts with the treatment. Dependent of the diagnosis different treatment options are applicable. These options are;
  - Surgeon, to remove a tumour.
  - Oncologist, to give chemotherapy for three applications. One application, to prevent the tumour from growing and clean the body from cancer cells before surgery so called neoadjuvant chemotherapy. The second application to remove the final cancer cells after surgery so called adjuvant chemotherapy. The last application is to extend the life of a terminal patient with palliative chemotherapy.
  - Radiotherapist, to give radiation for two applications. One application, to prevent the tumour from growing and clean the cutting edges for the surgeon before surgery. The second application is of a

palliative nature where the tumour is kept under control but with no intention to cure.

The decision-making process of colorectal cancer patients and the treatment choices that belong to adjuvant chemotherapy are covered by steps 6 and 7.1 and 7.2 (figure 1.8). These steps are in the final phase of the care path. First, the patients' case is discussed by the MDC, step 6. During the MDC different treatment options are discussed and a final treatment option is recommended. Then, the oncological surgeon discusses the test results with the patient, step 7.1. Because of bad results, the recommended treatment option is presented to the patient with the advice to make an appointment with the oncologist. Finally, the oncologist discusses the recommended treatment option with the patient and a final treatment decision is requested from the patient, step 7.2. In addition, it is of great importance, to realize that the moment that this treatment decision has to be made, the patient has already gone through a lot of misery. The uncertainty for the patient continues.

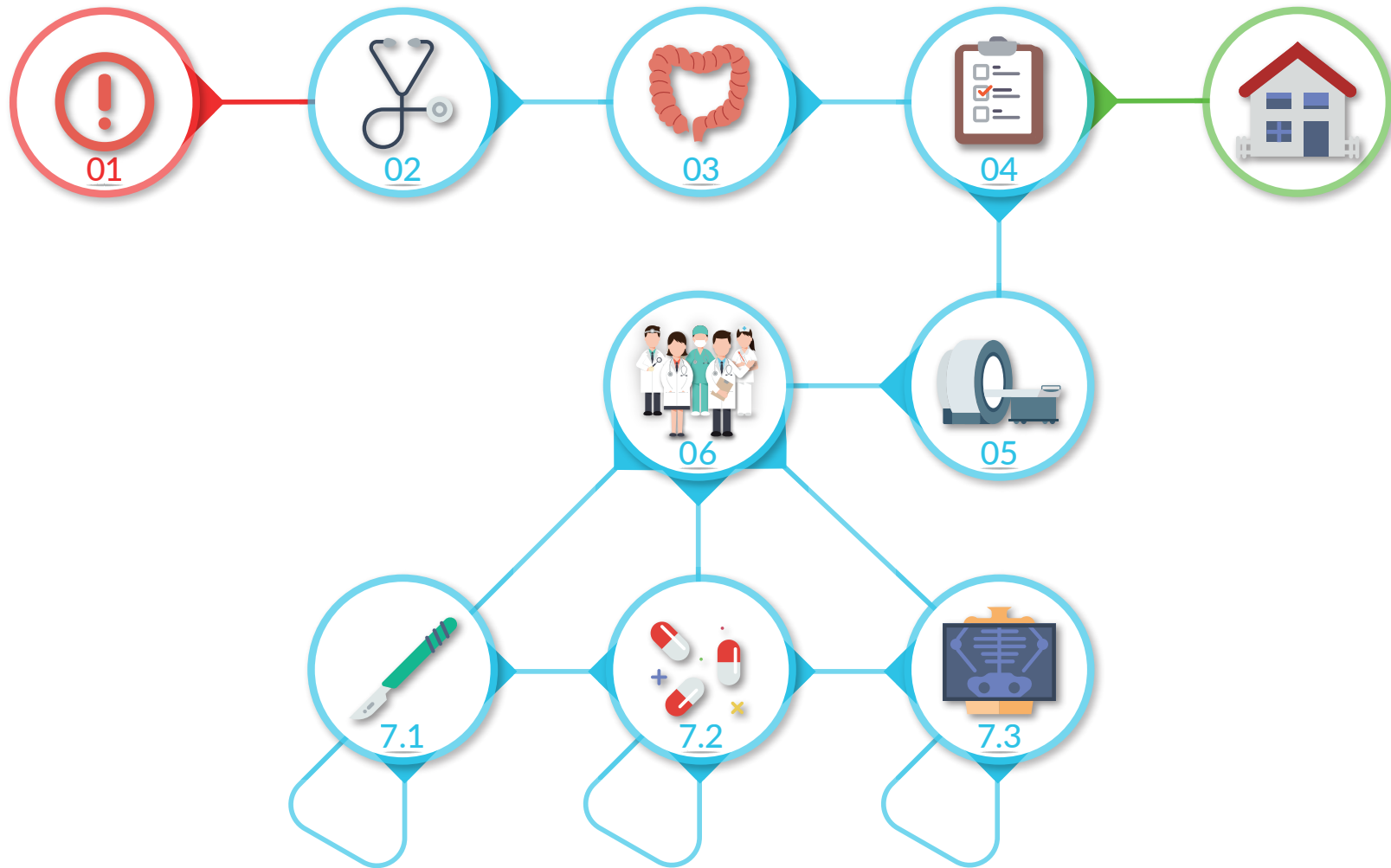
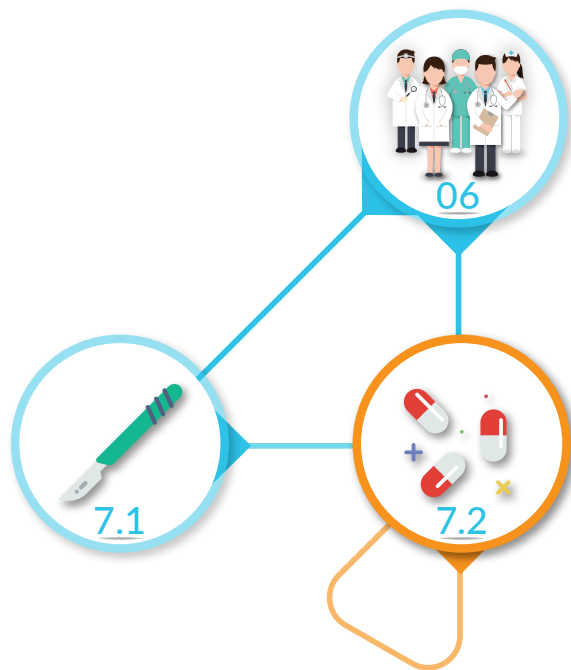


Figure 1.7. Care path of a colon cancer patient in the Netherlands



*Figure 1.8. The decision-making process of colorectal cancer patients and the treatment choices that belong to adjuvant chemotherapy*

### R.Q. 1.2 - What is the current procedure during the decision-making process?

The current procedure of decision-making, of colorectal cancer patients and the treatment choices that belong to adjuvant chemotherapy, can be divided into 5 interventions. These 5 interventions are shown in figure 1.9.

#### 1. Surgery

The first intervention is the surgery. During this intervention, the tumour is removed out of the colon of the patient. After the resection, tissue is taken and send to the pathologist for further examination. The patient is under anaesthesia, depending on what type of operation is performed (American Cancer Society1, 2018). The oncological surgeon performs the surgery, supported by his surgical team.

The basis for choosing a treatment option is laid here, because the composition of that tissue is the foundation of the decision-making process and shows whether a treatment is still needed. When a treatment is still needed, it can be determined on the basis of the composition which treatment options are possible.

#### 2. Pathology

The second intervention is the pathology of the tissue. During this intervention, the removed tissue from the resection is examined by the pathologist. The result of the examination results in a pTNM classification (American Cancer Society2, 2018). The pTNM classification is the most recent American Joint Committee on Cancer (AJCC) system (Edge & Compton, 2010) effective January 2018. It uses the pathologic stage (also called the surgical stage) which is determined by examining tissue removed during an operation. This is also known as surgical staging. This is likely to be more accurate than clinical staging, which considers the results of a physical exam, biopsies, and imaging tests, done before surgery.

The pTNM classification is the outcome of the examination by the pathologist. This outcome indicates for the oncological physicians what treatment options may be applicable., and which should therefore be discussed during the MDC and ultimately with the patient for the need of the decision-making process.

### **3. MDC**

The third intervention is the MDC. During this intervention, the entire medical team comes together to discuss the pTNM classification of the patient and the possible treatment options. The result of the MDC is, in their eyes, a suggestion for the best treatment option. The medical team consists of; Oncological Surgeon, Oncologist, Gastroenterology doctor, Nuclear medic, Radiotherapist, Pathologist, Nursing specialists of the Surgical Oncology, Nursing specialists of the Gastroenterology. The different specialists only spoke when their specialty was applicable for the case. Each case was dealt with very fast, a couple of minutes per case. When a terminally case was dealt with, you could feel the empathy in the room. They felt involved with the patient every time.

Currently, which recommendations are made during the MDC by the medical team, will largely determine which treatment options are presented to the patient by first the oncological surgeon, and then by the oncologist.

### **4. Consultation**

The fourth intervention is the consultation with the oncological surgeon. During this intervention, the pTNM classification of the patient and the suggestion for the best treatment option is shared by the oncological surgeon with the patient. In case of the decision-making process of colorectal cancer patients and the treatment choices that belong to adjuvant chemotherapy, the patient receives bad news. the oncological surgeon tells that positive glands have been found and refers the patient to the oncologist to discuss the next treatment option.

During the consultation, the patient finds out that there is actually still a treatment to be done. It is clear to the patient that a decision has to be made soon. After the patient has made an appointment with the oncologist and goes home, the possible search for information starts to prepare for the final decision-making moment that is going to take place.

### **5. Consultation**

The fifth intervention is the consultation with the oncological surgeon. During this intervention, the oncologist explains again the pTNM classification of the patient and the suggestion for the best treatment option. The purpose of this consultation is to make a final decision about the treatment option which is going to follow for the patient.

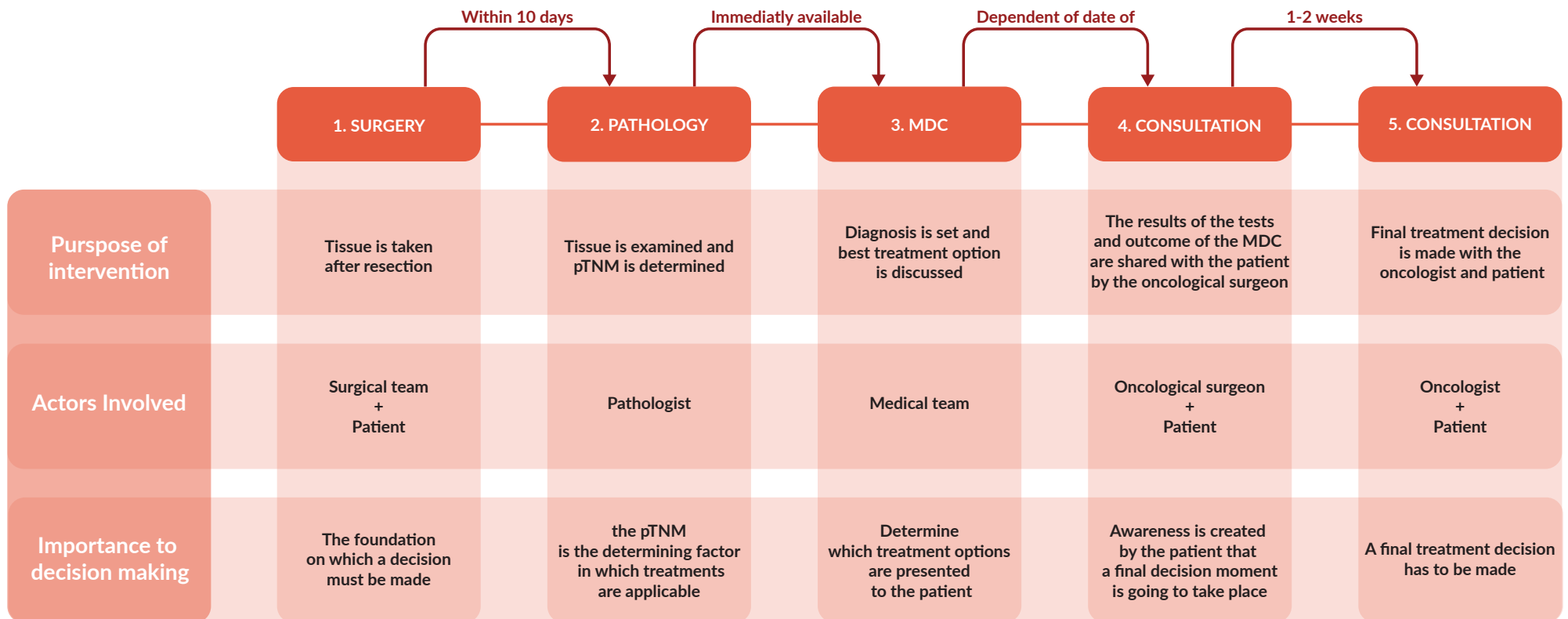


Figure 1.9. The current procedure of decision-making for colon cancer patients concerning adjuvant chemotherapy

**R.Q. 1.3 - What current interactions occur between patient and physician?**

The current steps in the decision-making process are described by figure 1.9. During the surgery, step 1, and both consultations, step 4 and 5, there is interaction between patient and physician. Despite the possible interaction between oncological surgeon and patient during the surgery step, there is no interaction about the decision-making process. In summary, only during both consultations there is interaction between patient and physician.

**Patient Physician Experience Journey (PPEJ)**

All the obtained insights of the 4 research methods that have been applied, were used to answer the research questions. Besides answering the research questions, the insights were also used to create a graphical representation of the current decision-making process; the PPEJ. Zoomed in on the 5 interventions (figure 1.10), the PEJ is an elaboration of the steps 4 and 5. Within these steps, interaction took place between patient and physician concerning the current decision-

making process. The PPEJ shows the steps that were taken from the moment of the consultation at the oncological surgeon, to the moment a final treatment decision was made (pages 42-43).

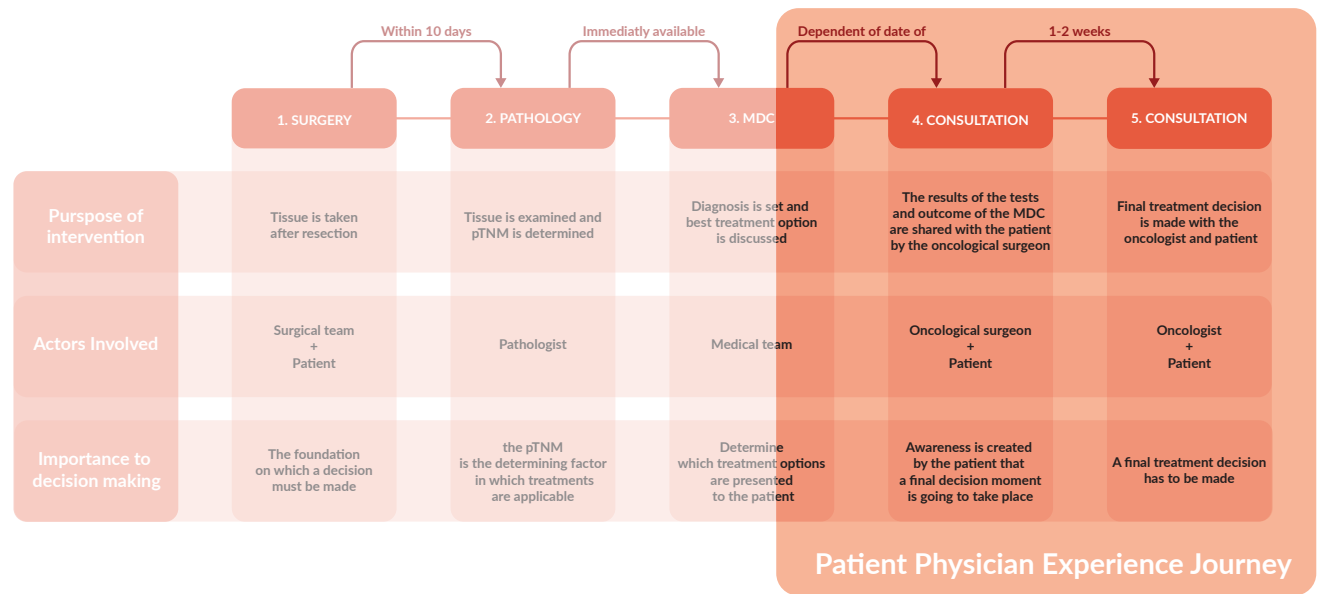


Figure 1.10. The final steps which are shown were used to create the PPEJ



### R.Q. 1.4 – How are the decisions made about a treatment option?

In the current process of decision-making, the final decision, according to the physician, is up to the patient. The opinion of the physician is irrelevant. In reality this is more nuanced. When patients are confronted with decisions (consultation observations), some experienced an information overload which made it 'impossible' to make a thorough decision at that specific moment. Most patients are not prepared when confronted with a treatment decision and they tend to decide based on the emotion. In that case, the physician takes his/her responsibility to make the final decision to prevent the patient from further harm. In some cases, the final decision-making moment is delayed. The physician considered the patient, at that time, not suitable for deciding. Followed by a call appointment a week later so the patient had time to think at home about the choice that had to be made.

*'The treatment was straightforward with 'nothing' to choose. We believed in the advice of the specialist, because of the way how he explained it.'*

*- Patient -*

*'For me, there was no real decision to be made. It is found that you have a tumour and that tumour needs to be removed, obvious.'*

*- Patient -*

*'All the 'choices' were made by us and later confirmed with the specialist that was trusted.'*

*- Patient -*

*'The decisions that were made, were all with my family and the specialist. First at home with my family and the during the consultations with the specialist.'*

*- Patient -*

*'In my case, I had the feeling that there were no decisions to make. In my situation with a young wife and 2 small children I had to take any possibility.'*

*- Patient -*

*'My opinion is that you always should respect the decisions of the patient. He or She is the one to undergo the entire trajectory.'*

*- Oncologist -*

# PATIENT PHYSICIAN EXPERIENCE JOURNEY

1 - 7 days

10 - 15 min

1 - 2 weeks

MDC

1

Consultation with Oncological Surgeon



2

At Home

Interaction



Physicians



Patient Informal Carer

TREATMENT RECOMMENDATION

Patient Experience



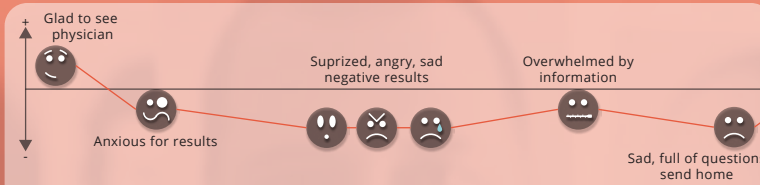
Frustrations & Challenges

**PH:** Telling and showing the patient the results of the last examinations on computer screen, together with the proposed treatment option by the MDC. Any explanation is also given when requested.

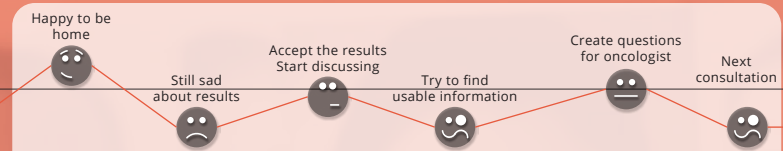
**PA/IC :** Listening to the oncological surgeon about the outcomes and the proposed treatment option. Looking at the computer screen. Asking questions if something is unclear.

**IC:** Talking to the patient about the received information from the oncological surgeon and discussing what to do next. Questions are written down together. Optional; searching for information.

**PA:** Talking to their informal carer about the received information. Wondering what to do next. Come up with questions for oncologist. Optional; searching for information.

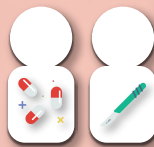


- Coping with disappointment of not being healed. No knowledge of the info on the screen of the oncologist.
- Understanding what the oncological surgeon is explaining.

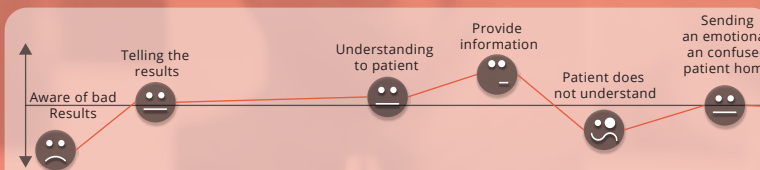


- Not able to find the right information and not knowing what the next treatment will do to them.
- Try to understand the importance and content of the next consultation and find the right information about the treatment options.

Physician Experience



Frustrations & Challenges



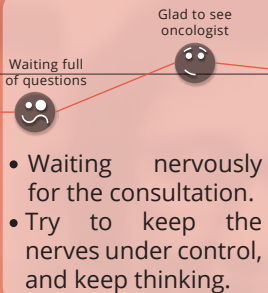
- The negative results for the patient. Not able to give sufficient answers to the patients' predictive questions.
- Inform the patient of the negative outcome of the examination results and provide information for the next step in the care path.

10 - 45 min

### 3 Waiting room

**PH:** Pick up the patient.

**PA/IC:** Waiting for the oncologist to get them.

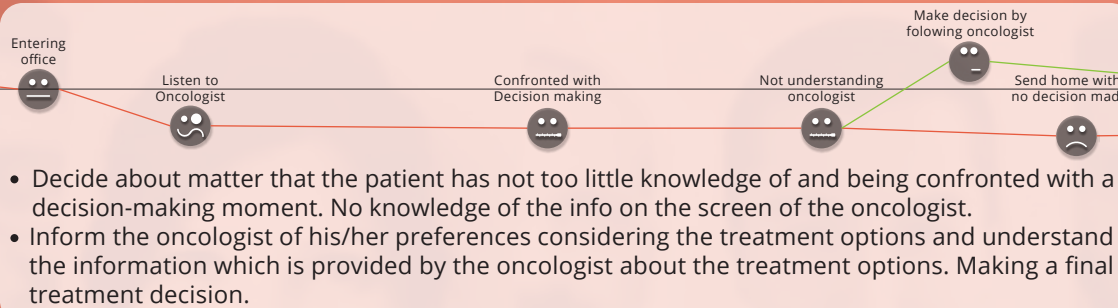


10 - 15 min

### 4 Consultation with Oncologist

**PH:** Again, telling and showing the patient the results of the last examinations on computer screen, together with the proposed treatment option by the MDC. Any explanation is also given when requested.

**PA/IC:** Listen to the oncologist. Process the information given by the oncologist. Decide about the next steps if possible.

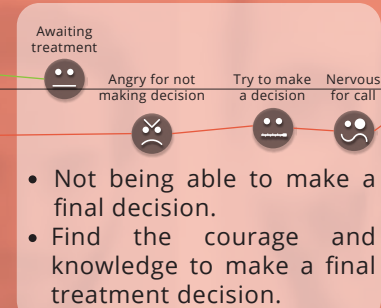


1 week

### 5 At Home

**IC:** supporting the patient in making a final decision.

**PA:** Progress the provided information by the oncologist and try to make a final decision.

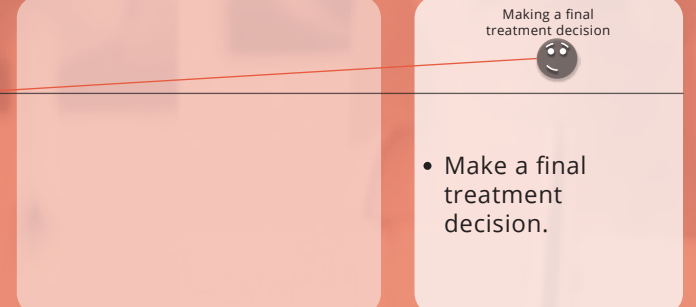
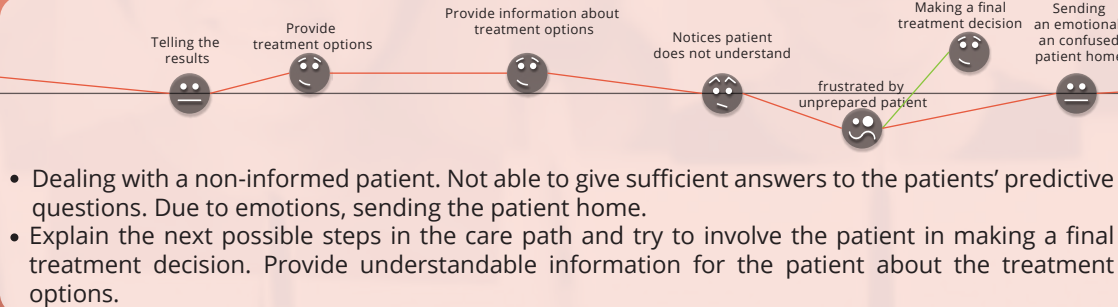
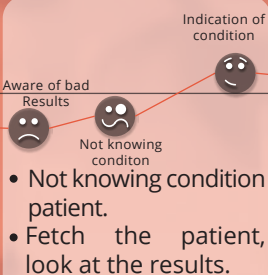
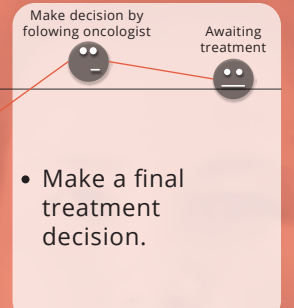


5 - 15 min

### 6 Call Meeting

**PH:** Call the patient for a final decision.

**PA:** Waiting for the oncologist to call to make the final decision.



## *Patient experience in decision-making process*

### *Research question 2; How does the patient experience his/her role in the decision-making process?*

#### *R.Q. 2.1 - What information does the patient uses?*

The information a patient uses when making a final treatment decision is dependent on each patient. Most of the information that they use, comes from the attending physician. When information is provided by the treating hospital, it is often experienced as an information overload. Patients indicated that they do want this information, but they only wanted to have the superficial amount and practical nature of information about their case. Not every patient is looking on the internet for information. They are scared of all the information that that may encounter which they do not want to know. For example, bad cases where patients died in a short time after the diagnosis. If information is sought on the internet, this is usually done by the informal caregivers. For a consultation, many patients discuss the matter with their informal caregivers. Their opinion is of high value to the patient.

*'There was no 'I' during the care path. Only 'we!'*

*- Patient -*

*'A lot of information noise was given by the people around us, unintentionally.'*

*- Patient -*

*'Once, after the result of the population screening, I have searched the internet about intestinal examination. After a couple of stories, I closed it off. It did not make me smarter but only made me more nervous.'*

*- Patient -*

*'The hospital gave a lot of information to take home, but still I started googling. You should not do that, because you see the worst-case scenarios. But still, you're going to search.'*

*- Patient -*

*'I have also read a lot of flyers in the waiting room of the hospital besides the flyers that they already had given me. And of course, the explanation from the hospital staff is an important source of information which was really useful.'*

*- Patient -*

*'Information was searched on the internet. Especially about symptoms.'*

*- Patient -*

*He searched for information about the survival chances on IKNL. 'The chances were very low but still there was a change and I grabbed that change.'*

*- Patient -*

*'They all give you advise but it is not your field of expertise so you agree to the suggestions.'*

*- Patient -*

*'I have read everything we received about the different types of chemo. About the side effects and how it actually worked etc. Our daughters have searched on the internet but we did not do that. We accepted our faith.'*

*- Patient -*

*'Percentages were mentioned quite often, but we do not feel the value in statistics about this subject. We have made decisions more based on feelings.'*

*- Patient -*

*'What would you choose?'*

*- Patient -*

*'I googled yesterday'*

*- Patient -*

*'Information is only useful if a choice can be made'*

*- Patient -*

## R.Q. 2.2 - What information does the patient miss?

The information the patient is missing varies. According to the consultation observations and the physician interviews, the information the patients asked for, was about; their life expectancy, possible side effects of the treatment, what there is to gain from the treatment, how the treatment will influence their quality of life, their prognosis and the differences between the treatment options when presented.

*'When receiving the results of the examination you know what is wrong. That is still difficult, but then you have your diagnosis and your prognosis. you know what you have.'*  
- Patient -

■ *'Uncertainty is the worst you can have'*  
- Patient -

*'Are you sure that it does not suddenly go faster?'*  
- Patient -

*'If I knew that the side effects were to be so severe I would have never done it'*  
*'Will the tingling fade away over time?'*  
- Patient -

*'If I could choose what kind of treatment I want to have. Then I want to know the pros and cons of the treatment options I can choose.'*  
- Patient -

*'The choices are very hard to make concerning my quality of life.'*  
- Patient -

*'How long do I have to live? How much longer with another chemotherapy?'*  
*'Does chemo still make sense?'*  
- Patient -

*'How long do I have to live? Why am I doing chemotherapy when it is not working? What about the quality of life I got left? Will I die from this?'*  
- Patient -

### R.Q. 2.3 - What was the expected of the (chosen) treatment?

The expectations of the (chosen) treatment are unclear, because there is a lack of knowledge about what that patient can expect. Sometimes a patient wants to be healed no matter what the consequences are, while others find their quality of life more important than a longer life. The expressions about the patient's expectations only became clear during the consultations when the results were discussed and/or a treatment decision had to be made. A few had a clear vision of what to expect, but these patients were rare.

The decision was made to not do adjuvant chemotherapy after surgery. This decision was made because of her age and condition. In addition, she was living alone and was fond of her freedom. When she would have started the chemotherapy, she was most likely to lose that freedom because she would have been admitted to a special care facility due to the chemo. We as a family, were at ease with that decision. But after a year everything has returned.'

*'Afterwards, I thought, when it had returned, if we had not made the wrong decision.'*

*- Patient -*

*'When looking back, I think it is just bad luck.' You just do not expect that the mitosis of an 84-year-old is that high which results in metastases.'*

*- Patient -*

*Hearing about the chemo. 'but the tumour does not go away?'*

*- Patient -*

*'I'd rather live a year shorter, and that I can live normally instead of adding an extra year with being sick all the time because of the chemo. Quality of life was more important than living a bit longer.'*

*- Patient -*

*'After the first surgery, the removal of the rectal carcinoma, no adjuvant chemo was suggested with the reason to maintain the current quality of life.'*

*- Patient -*

*'When the chemo started, then every time a cure was done, the nervousness raised because you did not know if it helped, besides the awful side effects that she suffered.'*

*- Patient -*

*'The time that we had left was really precious to me but it was always 'enjoying with the parking brake on'*

*- Patient -*

*'Many times, we have tried the things that were possible but the first cure was too intense because of the side effects so we had to quit. The quality of life had dropped dramatically.'*

*- Patient -*

*'As long if won't have any pain.'  
'I do not have the illusion that I will be my old self again'*

*- Patient -*

*'We have always lived in certainty and are planning to continue doing that'  
'Quality of life was finally the key in the decision. Do you need to live 8 months in agony and buy some time or do you want to live for 8 months whereof you can enjoy 6 of them?'*

*- Patient -*

*'I will do anything to be alive as long as possible'*

*- Patient -*



#### R.Q. 2.4 - How do patients prepare themselves for the final decision-making moment?

When the patients are aware that a decision about a treatment option has to be made, they prepare themselves in different ways. Some patients tend to look for information anywhere they can find it, while others do not want to know anything about it and leave the making of a decision to the physician. Almost every patient that was questioned and observed, discussed the decision-making moment with their loved ones. The loved ones often had written down questions on paper. These questions were asked during the decision-making consultation to the physician by the loved ones, while the patient was just sitting and listening.

*'You come up with questions together before consultation, and during we asked them.'*

*- Patient -*

*'Before going to the consultations, we all sat down and talked about the questions that we had. My questions, but also the questions of my husband and children. Then we went with the 3 of us to the consultation'*

*- Patient -*

*'Before we went to the consultation of the results of the surgery we had discussed everything at home with the family. Basically, the decision was made at home and then confirmed by the specialist during the consultation. Maybe the specialist, although then the obvious decision, should have informed us about the possible other treatments.'*

*- Patient -*

### *Physician experience in decision-making process*

## **Research question 3; How does the physician experience his/her role in the decision-making process?**

### **R.Q. 3.1 - What is key in treating a patient?**

Key to treat a patient, is to know what kind of patients the physician is dealing with. In order to do so it is wished by the physicians, to remain the same physician for a patient. When a patient is known by the physician, it is known what emotions and wishes that specific patient has and therefore easier to deal with and take that into consideration while treating the patient. When the physician sees the patient for the first time this is very difficult.

Another key element, is to be as clear as possible. Nobody benefits from prevaricating around the matter that needs to be told, good or bad news. When the patient knows what they have to deal with it is manageable. Not knowing what is going on is undoable for a patient.

A third element, is to be as understandable as

possible. There is no point in talking in a clinical language if the patient does not understand this. It is the same with numbers. For example, the chance of getting better is greater than becoming ill again. People are very creative in interpreting numbers. They come up with the strangest things. Compare the patients with everybody else. 'How many patients have the same thing'. Patients want to identify themselves. And in case of bad news, try to make the patients feel like they are the exception on the 'rule'.

*'Trust in each other is very important. Every patient is really different.'*

*- Oncologist -*

*'Doubt is intolerant, bad news is doable. When you know the results are bad, then you know at least where you are dealing with.'*

*- Oncological Surgeon -*

*'Even if patients have the exact same outcome. They still choose different things. That has to do with the attitude of the patient. Some patients just want to survive as long as possible so they feel that there are no choices for them.'*

*- Oncologist -*

*'Overall oncology is presenting the patient with choices and providing my professional opinion about the possibilities. With the given information, the patient makes the final decision. Sometimes patients would like to think about it so they return home and after some time they contact me with more questions and/or the decision that they have made.'*

*- Oncologist -*

### R.Q. 3.2 - What information does the physician uses?

The information the physician uses can be divided into 3 sections; The pTNM and the outcome of the MDC, their own experience as a physician and the input they receive from the patient. The pTNM and the outcome of the MDC and their own experience as a physician, are straight forward where they only need to depend on themselves. The input of the patient is a lot harder because this is dependent on what the patient is willing to tell, and how prepared they were for the consultation. Most of the time patients are not prepared to make a treatment decision which makes it difficult. Because the patients were not prepared, the physician needs to explain a lot. The patient experiences an information overload, which makes it 'impossible' to make a thorough decision at that specific moment.

*'I always go get the patients myself from the waiting room, this way I have 30 meters to determine the condition of the patient and to record the non-verbal communication.'*

*- Oncologist -*

*'Unfortunately, most of them are not. They base their decision on emotion or nothing at all.'*

*- Oncologist -*

*'Most of the time they are not. They have a wait-and-see attitude and let it come to itself.'*

*- Oncologist -*

### R.Q. 3.3 - How do physicians provide information to the patient, and what type of information do they provide?

The most usual way is by conducting a dialogue. When a patient comes to a consultation, most of the time is spend talking by the physician. Sometimes, the physician turns his/her computer screen with, for instance, the blood results to show the patient. On the basis of what is shown on the screen, the doctor tries to support his/her story. Once a while, physicians refer to websites and leaflets where the patient can find general information during the consultation. When a clinical trial is proposed, the physician provides the necessary information on printed paper for the patient to take home. It also occurred that the physician started to draw on a ripped piece of paper, trying to explain the different treatment options and possible burden of them to the patient, where dialogue was insufficient.

The content of the provided information by the physician, can be divided into 3 sections. The first section, the information provision of the results of examinations that the patient has

undergone. The second section, is the provision of information about the possible treatment options when a treatment decision has to be made. The third section, is providing the patient with answers when they have questions.

### R.Q. 3.4 - What information do physicians provide to the patient about different treatment options?

The information provided by the physicians about the different treatment options dependeds on what have been discussed during the MDC. When doing the consultation observations, it struck that most of the time the physician was talking and explaining about just 1 treatment option. The one that was best through the eyes of the physician, based on the pTNM. When a patient explicitly asked for other options, they were explained, but then immediately discouraged by the physician.

### R.Q. 3.5 - What information does the physician misses?

Most patients are not prepared when confronted with a treatment decision and they tend to decide based on the emotion on that specific moment. Every patient is different, so the wishes, norms and values that have to be dealt with are also always different with each consultation. This makes the profession of physician loveable, but also very difficult. because the physician has to estimate this when they see patient at the actual consultation, there is little time for this. Therefore, bonding with the patient is very important. When there is a connection, the wishes, norms and values are easier to predict. But ideally, the patient should be able to tell those themselves.

*'The specialist had given the information in an optimistic way that the change that the tumour would return within a short amount of time was most likely not going to happen. He was wrong. It did return within the year with metastases.'*

*- Informal Caregiver-*

### R.Q. 3.6 - What do physicians think of releasing predictive numerical information to patients?

The physicians that were observed and interviewed were optimistic about the provision of predictive numerical information. The main advantage is that the patient is better prepared before attending the consultation. On the physician side, there is a demand for more accurate prediction models where they can base their presumptions on.

*'Actually, I would like to have something to make the explanations more visible to make it more understandable for the patients.'*

*- Oncological Surgeon-*

*'The question is always, how you can inform patients in a better way. How much can a patient sacrifice to be living a bit longer? For the cost of what? Quality of Life?'*

*- Oncologist-*

*'I think it is very good to give this kind of information to the patients. But I do not think it is good for them to see this information for the first time when they are at home, that will only lead to a lot of questions from the patients' side.'*

*- Oncologist -*

*'If people would be better prepared when coming to my consultations than everything would be a lot easier. You have to make the decisions together. Every single patient is making different decisions. Every patient is different and they make different decisions, different things are important to them. It's about providing everyone the space to make their own decisions. People should realize that they make the decision.'*

*- Oncologist -*

*'It will also be good to be using as a supportive tool during the consultation, so a design where the patient and I both can work with. I can imagine that if you show this kind of information without any explanation that it even may backfire.'*

*- Oncologist -*

## MAIN CONCLUSIONS USER RESEARCH

### *R.Q. 1 How is the current decision-making process organised in practice?*

The current decision-making process is complex. For this project, 5 interventions were distinguished concerning the decision-making process (Figure xx). In the current decision-making process, the patient is only actively involved in the final 2 interventions, the consultation with the oncological surgeon and the consultation with the oncologist. Therefore, a more detailed PPEJ was created (Figure xx). There are a number of actors involved, as is depicted in the PPEJ. Those actors are; the informal carers, the oncological surgeon, the oncologist and the patient. Although the surgery of the patient is not included in the PPEJ this is the key step of the current decision-making process. During the surgery, tissue is taken what results in the pTNM classification determined by the pathologist. Depending on the pTNM, the treatment options become automatically known that apply to the patient. Most of the final treatment decisions are based on this classification only, and made by the oncologist with approval of the patient. From the moment the results of the examinations and the recommended treatment option is

presented to the patient, the patient experiences a lot of uncertainty and has many unanswered questions.

Although SDM is being pursued by physicians and patients in today's health care, reality shows that the process of decision-making is mostly lead by the physicians. The physician has full access to the data on which these decisions could be based, and only share this data during the short 15-min consultations, by turning their computer screen full of incomprehensible figures to the patient. Patients have limited access to their own data and most of them do not understand the pTNM classification. This makes it almost impossible to actively participate in the decision-making process, even if they want to. Physicians are aware of patient centred care and do acknowledge this, but need all their time to inform the patient about all the results and possible treatment options. Even if this information is understood by the patient, there is hardly any time to get to know the person behind the patient, including their wishes and preferences about the different treatment options. The questions that patients asked, were mostly left

unanswered because of the difficult nature of the questions, considering; life expectancy, possible side-effects and influence on their quality of life. This all results in a patient physician interaction were both parties are not satisfied. Physicians have to deal with emotional and unprepared patients and patients are left with a lot of uncertainty, an information overload and many unanswered questions.

### *R.Q. 2 How does the patient experience his/her role in the decision-making process?*

Most patients had a submissive attitude in the decision-making process. The observations and interviews have shown that this is due to various factors. Most of the time there is a lack of knowledge on the patient's side, which makes it very difficult for them to fully participate in the decision-making process. Because of the short 15-min consultations, and the big amount of information that needs to be told by the physician, there is hardly any time left for the patient to absorb the information, to then think about it, and then make a good decision within the same consultation. When in some cases

the knowledge was there, the confrontation with the bad news made them emotional and unsuitable for self-making thoughtful decisions. This resulted in following the physician's advice because 'this is not your field of expertise so you agree to the suggestions'.

Patients tend to search for information. However, because there is so many information to be found on the internet, they experience an information overload and find worst-case scenarios which scares them, what causes them to stop searching. The questions that they wanted to be answered, where of a predictive and personal nature, and could not be exactly answered by physicians and the internet.

The purpose of the treatment is different for every patient. some want to live as long as possible while others pursue their quality of life. Again, due to the short consultations full of information and the overwhelming effect of receiving bad news, ensured that these personal preferences were barely communicated with the physician.

### ***R.Q. 3 How does the physician experience his/her role in the decision-making process?***

Physicians have many consultations during a working day. They see many different patients with different physical characteristics. Before each consultation, the physician looks at the patient file to see who they are treating in the upcoming consultation. They try to approach and treat each patient personally, but due to the short contact moments with the patient this is very difficult and ensures that they fall back on the clinical information that they possess from the patient. Although, the personal preferences of the patient would be a valuable source of information for the physician to present the right treatment option, there is not enough time to get this out of the patient within the consultation. The information obtained from the patient is often based on emotions and not on well-considered thinking, because they were unprepared for the decision-making moment. Therefore, they need almost all the time to inform the patient about the possible treatment options and the suggested treatment option. Because of the time constraint, often only the suggested

treatment option is elaborated. When a patient is to emotional and considered unfit to make a final decision, the physician sends them home to overthink the matter and suggests a telephone appointment to discuss the final decision.

## LIMITATIONS USER RESEARCH

Although the results of the user research provided detailed information and insights on the current decision-making process of colon cancer patients concerning adjuvant chemotherapy, it had several limitations. First, the number of participants in the different research methods (consultation observations N=35, MDC observation N=1, Semi-structured physician interviews N=3, Semi-structured patient interviews N=6) is too low to be able to generalize for the entire population in the Netherlands. In addition, the information was mainly obtained from only one hospital (Catharina Hospital Eindhoven) and participants from the province of Noord Brabant. Demographic differences could not be observed. Another limitation was the availability of finding useful participants in a short amount of time, therefore informal cares were also used to describe the patients' experience. Finally, the interpretations of the obtained information were done by the researcher with a design background. This may have ensured that things have been differently defined than that they are in reality. Nevertheless, the obtained insights were of great value to proceed with the design process.



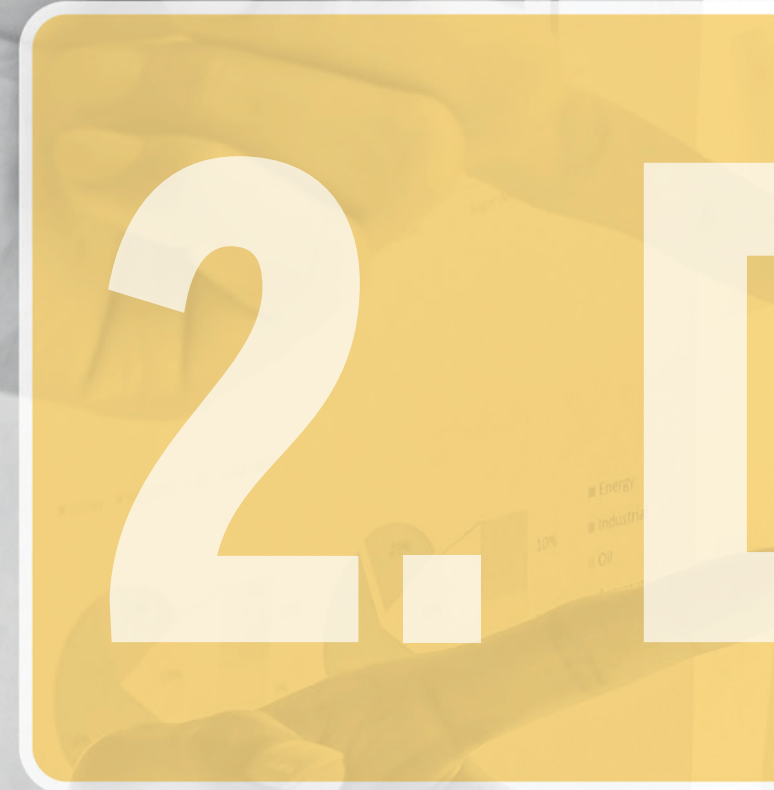


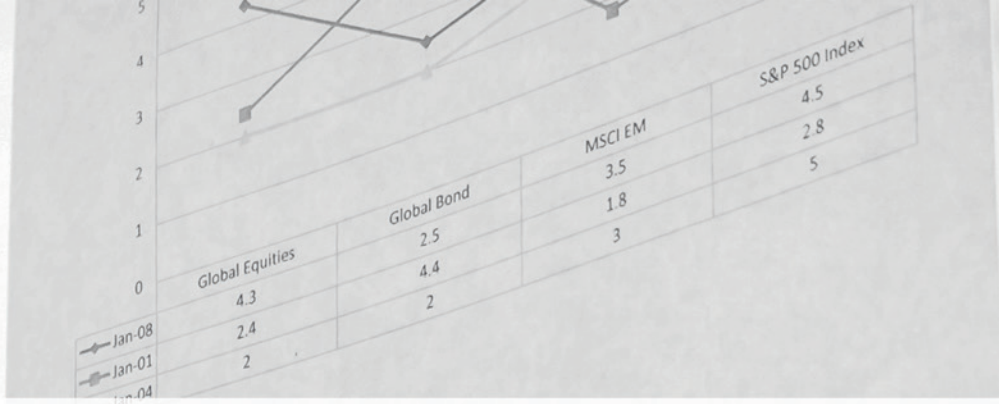
This chapter gives an overview of the convergence of literature research and user research to a final design brief with the list of requirements. First a synthesis took place making the opportunities for design emerge. Then, a design exploration was performed to fine tune the opportunities for design into a design direction. Finally, a design brief was formulated and a list of requirements was drafted. This was the starting point for the Develop phase.

## 2.1 Synthesis

## 2.2 Design Exploration

## 2.3 Design Brief





# DEFINE



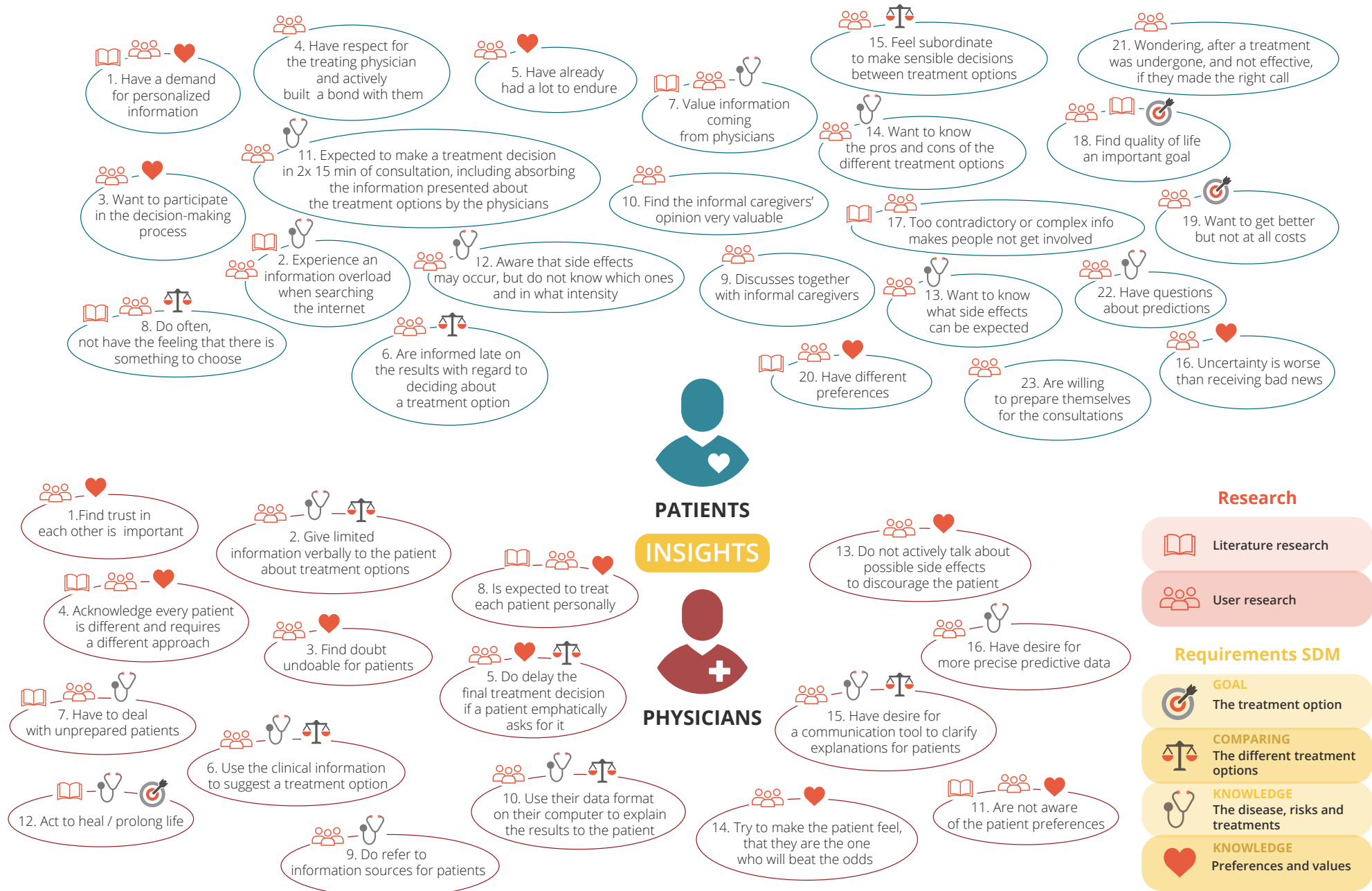


Figure 2.1. Overview of the gathered insights of both user and literature research

## 2.1 SYNTHESIS



*Merging both the user and literature research*

When the theoretical framework was projected on the user research, a long list of insights emerged (figure 2.1). Inspired by the master thesis of Karen Thomson (2016), this list was then analyzed, and four main components were distinguished with regard to the condition of SDM. These components must be met, by both the patient and physician, in order to be able to speak of a shared decision.

### The condition for shared decision making

As mentioned above, the four main components must be met. However, the analysis of the insights has shown that this is currently not the case (figure 2.2). The four main components are;

#### 1. The goal of the treatment option

When a physician is treating a patient, he/she has a clear goal in mind. The goal is to keep the patient healthy as long as possible, according to the physicians' definition of healthy. Most of the time, the predefined guidelines are used to pursue this goal. If patients have a different wish, then the physician tries to take this into account, as is observed during consultation observations. Keeping the patient healthy, is a difficult definition when it comes to quality of life, as quality of life is

different for each individual. Because patients are more and more focusing on their quality of life, but do not have the knowledge of the different treatment options, it is difficult for them to have a clear treatment goal in mind.

#### 2. Comparing different treatment options

The physician is familiar with the different treatment options, and knows the content of the differences. However, when it comes to knowing the outcome of a certain treatment option for one specific patient, like life expectancy, possible side effects and the severity of the side effects,

*'SDM is a process in which the physician shares with the patient all relevant risk and benefit information on all treatment alternatives and the patient shares with the physician all relevant personal information that might make one treatment, outcome or side effect more or less tolerable than others'*







		 PATIENTS	 PHYSICIANS
<b>GOAL</b> the treatment option		+/-	✓
<b>COMPARING</b> the different treatment options		✗	+/-
<b>KNOWLEDGE</b> the disease, risks and treatments		✗	✓
<b>KNOWLEDGE</b> preferences and values		✓	+/-

Figure 2.2. The current situation about the four components between patient and physician

the physician uses his/her own experience to estimate this. Sometimes choice aids (page 64-68) based on numerical information of the general population are used, but there is always an uncertainty when it comes to treating an individual patient. Patients often do not even know that there are multiple treatment options, let alone the content of the different options. As a result, as observed and interviewed, patients tend to follow the physician's advice when making a final decision instead of considering the options themselves.

### ***3. Knowledge about the disease, risks and treatments***

The physician is an expert on colon cancer and the treatment options concerning adjuvant chemotherapy, as it is her/his profession. The patient is a trickier case, as the knowledge about the disease, risks and treatments differs per patient. Added to that, the physician is not aware of the knowledge level of the patient about this matter.

### ***4. Knowledge of the preference and values***

The physician is aware of his/her own preferences and wishes concerning the final treatment decision, and shares this with the patient. Hereby, the patient knows what treatment option is suggested by the physician. However, the preferences and wishes of the patient often remain with the patient. In the short 15-minute consultations, there is hardly any time to share these preferences and wishes with the physician. The reason for this, is the amount of information the physician has to explain to the patient, because the patient was lacking knowledge for making a well thought through final treatment decision (consultation observations).

## Opportunities for design

The design opportunities for this graduation project lay in creating a design that enables both patient and physician to meet the four main components (figure 2.3). Combining the four main components with the wished outcome led to;

*Create a design that ensures both patient and physician are aware of;*

1. *The different possible treatment options for the patient*
2. *Understand what these personal treatment options involve concerning risks, treatment options and possible outcome*
3. *Be aware of the preferences and values of both patient and physician*

*So that patient and physician can discuss the treatment goal, during the consultation with the oncologist, according to the condition of SDM, to make a final treatment decision.*













		 PATIENTS	 PHYSICIANS
<b>GOAL</b> the treatment option 		+/-	✓
<b>COMPARING</b> the different treatment options 		✗	+/-
<b>KNOWLEDGE</b> the disease, risks and treatments 		✗	✓
<b>KNOWLEDGE</b> preferences and values 		✓	+/-
<b>CURRENT</b>			
		 PATIENTS	 PHYSICIANS
<b>GOAL</b> the treatment option 		✓	✓
<b>COMPARING</b> the different treatment options 		✓	✓
<b>KNOWLEDGE</b> the disease, risks and treatments 		✓	✓
<b>KNOWLEDGE</b> preferences and values 		✓	✓
<b>GOAL</b>			

Figure 2.3. The desired goal for this graduation project

## 2.2 DESIGN EXPLORATION



### *The exploration of the design possibilities*

When analysing the drafted design opportunities, and more specifically the three points of interest (page 63), different themes have been discovered for each point of interest. These themes are; general information, prediction information and interaction abilities. Currently, existing choice aids try to inform patients by providing general and some predication information. Interaction with the physicians is not supported. An analysis was performed concerning these existing choice aids to see and learn how they present the various information. Then, with all the information obtained, a design direction was chosen.

### Participatory analysis

The previous analyses (discover phase) show that patients find it very difficult to make decisions considering the treatment options within their care path. This stems from the lack of knowledge of the patients about the matter where choices must be made. When searching the internet multiple choice aids can be found. Because the design will be of the same nature as these choice aids, an analysis was preformed to these other 'participators'. The analysis is based on a personal designer attitude adn can be seen as the designers' opinion.

The main objective of the analysis was to learn from the existing choice aids. How they look, function

and particularly, how they present numbers to their users. Secondly, it provides a starting point in creating a new design instead of starting from scratch. Key to this analysis, is to understand that all of these choice aids were created to support the user in a non-profitable way, the same goal as IKNL. Therefore the 'participators' are more likely to be different parties with the same goal instead of a regular 'commercial competitor'.

The goal of the design is to be more user friendly and understandable for the users than the other choice aids. Although some design flaws can be determined in the existing choice aids and prevented in the new design, it is key to optimize the new design through performing user tests

and multiple iteration steps. Most important is to keep in mind for whom the design is going to be and make them part of the development of the new design.

Five providers of choice aids where analysed. Not all these choice aids are built for colon cancer patients. However, on an abstract level, they all present information to patients to help them in making decisions within the medical field considering treatment options. That is why these choice aids are part of this analysis. The analysed choice aids were;

1. Cijfersoverkanker.nl
2. Patient+ Keuzehulp
3. AMC keuzehulpen\*
4. Radboud UMC keuzehulpen\*
5. Evidencio

*\*These choice aids are practically the same but presented by different hospitals. The only thing different is the colours used in the user interface.*



## Cijfersoverkanker.nl

Cijfersoverkanker.nl (www.cijfersoverkanker.nl) (figure 2.4) is a website of IKNL. This is the current way of IKNL to present their database of numerical information about cancer patients to society. However, the way the numbers are being presented and the user-friendliness leaves a lot to be desired.

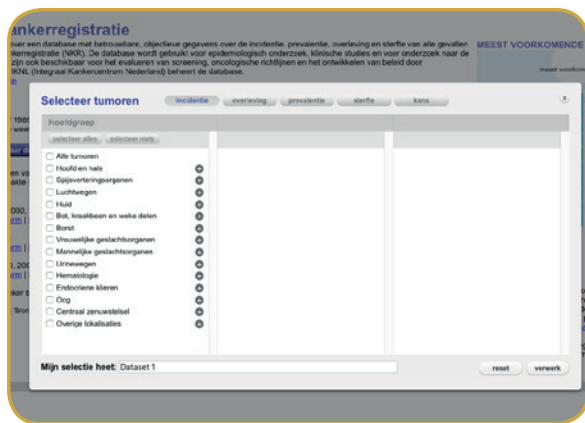


Figure 2.4. The website of cijfersoverkanker.nl

### Appearance

The appearance of the website is of an old fashion nature. The font used and the size of the font is

not appealing and small which makes it difficult to read. The amount of text presented is high which makes the website unclear and contributes to an information overload.

Although some technical terms cannot be prevented, no explanation can be found about these technical terms which makes many sentences not understandable for users whom are not familiar with these terms.

Some of the buttons are very clear while others lack appearances of a button, which may lead to misunderstandings for the user on where to click on. When getting to the results, the buttons in the section 'Selectiecriteria' have the look that they are not pressable.

The layout of the website is built up into separated boxes with each their own category, filling the page from left till right. The sentences from the presented information go across the entire screen, which creates long lines of text. When less information is presented e.g. a chart, many empty spaces occur. Then underneath all

the charts large textboxes are presented with the same left till right style, which makes the website messy and unclear to its user.

### Functionality

When clicking on the 'naar de cijfers' button, a large difficult-to-understand box opens. The user needs to fill in a lot of options before getting to the results they are looking for. Again, a lot of technical terms are used within this box without any explanation. However, when knowing how to handle this website, the functionality is not bad. The results presented are of an accurate nature depending on the data the user has entered which ensures possible personification.

### Communication of numbers

Numbers are being presented in charts and supported with long lines of text with technical terms. When not being able to read these charts, the provide information by the website is useless. Too much numbers are presented at the screen at the same time which makes it confusing and unclear.

## Patient+ Keuzehulp

Patient+ Keuzehulp is a website meant for users whom are looking for information about high risk colon cancer stadium 2 (www.keuzehulp.info) (figure 2.5). It provides information about the different chemotherapy options after surgery.

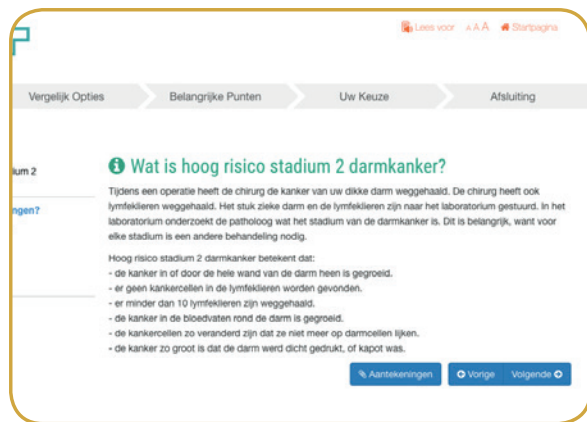


Figure 2.5. The website of Patient+ keuzehulp

### Appearance

The appearance of the website is of a modern nature. The font and font size are thin and small

which makes it difficult to read. However, the distance between the text lines is sufficient and easy to the eye. The amount of text presented is tolerable which in some cases may contribute to an information overload.

The overall language is of a good level. The sentences are written in an understandable way. Therefore, you do not have to be a specialist to understand the presented information. Some of the buttons are very clear while others lack appearances of a button, which may lead to misunderstandings for the user on where to click on.

The layout of the website is built up into separated fixed boxes with each their own category, centred on the website. The sentences from the presented information remains in these boxes. When less information is presented the layout changes which creates an easy to the eye and clean design.

### Functionality

No input is necessary of the users' side. With the 'volgende' button the user navigates though

the website and the presented information. Because of the fixed layout everything remains clear while navigating. Which each step, the user receives a limited amount of information. Although the usability is a high quality, the presented information is of an average nature with no personification. A good addition is the 'read-function'. However, this function is quite hidden and hard to find if you have no knowledge of icons.

### Communication of numbers

Numbers are being presented in a figurines diagram and supported with lines of text. Which is a good way. However, there are a lot of figures and they are very small which makes it a bit unclear. In different sections of the website the colours are changed which may be unclear to its users. Using the colours green and red is not good with regards to the colour blinds.

The nature of the given information is not of the actual case, but a similar case due to a lack of information at the creators of the choice help.

## AMC keuzehulpen & Radboud UMC Keuzehulpen

As stated before, the choice aids of AMC ([www.amc.keuzehulp.online](http://www.amc.keuzehulp.online)) (figure 2.6) and Radboud UMC ([www.radboud.keuzehulp.online](http://www.radboud.keuzehulp.online)) are practically the same. The only difference is the used colours in the user interface and the content. These aids support the user in finding information about;

- Enchondromas and atypical cartilage tumours and knee and hip wear (Radboud)
- Haemangiomas, Malignant (child) bone tumours and Reflux disease under 18 months (AMC)

### Appearance

The appearance of the website is of a clean and modern nature. The font used and the font size is appealing and sufficient which makes it easy to read. The amount of text presented is sufficient which makes the website clear and quiet.

Difficult technical terms are used but explained with images. Buttons are very clear and consistent. However, they are put at the bottom of the

information page. When the page is longer than the screen the user is watching on they have to scroll all the way down to go to the next or previous page.

The layout of the website is built up into one stroke from top to bottom, centred on the website. The sentences from the presented information remains in this stroke which prevents long sentences. When less information is presented the layout changes which creates an easy to the eye and clean design.

### Functionality

No input is necessary of the users' side. With the 'volgende' button the user navigates through the website and the presented information. Because of the fixed layout everything remains clear while navigating. Which each step, the user receives a limited amount of information. Although the usability is a high quality, the presented information is of an average nature with no personification.

### Communication of numbers

Numbers are being presented in a figurines

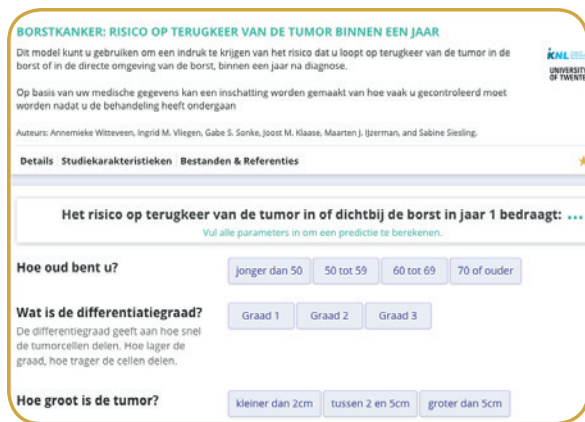
diagram and supported with lines of text. Which is a good way. However, there are a lot of figures and they are very small which makes it a bit unclear. In different sections of the website the colours are changed which may be unclear to its users. Using the colours green and red is not good with regards to the colour blinds.



Figure 2.6. The website of AMC keuzehulp

## Evidencio

Evidencio is a library where all kinds of healthcare models are published, also for breast cancer (www.evidencio.com) (figure 2.7). The model they present can be used to determine the possible change that the tumour may return after a year of diagnose. Evidencio has been working together with IKNL to create this choice aid.



The screenshot shows a web interface for a breast cancer risk assessment tool. The title is "BORSTKANKER: RISICO OP TERUGKEER VAN DE TUMOR BINNEN EEN JAAR". Below the title, there is a brief explanation of the model's purpose and a list of authors. The main heading is "Het risico op terugkeer van de tumor in of dichtbij de borst in jaar 1 bedraagt: ...". There are three input sections: "Hoe oud bent u?" with buttons for "jonger dan 50", "50 tot 59", "60 tot 69", and "70 of ouder"; "Wat is de differentiatiegraad?" with buttons for "Graad 1", "Graad 2", and "Graad 3"; and "Hoe groot is de tumor?" with buttons for "kleiner dan 2cm", "tussen 2 en 5cm", and "groter dan 5cm".

Figure 2.7. The website of Evidencio

## Appearance

The appearance of the website is of a clean and modern nature. The font and font size differ in

quality. The titles are good and big enough but the explanation text is very small. The amount of text presented is high which makes the website unclear and contributes to an information overload. However, the differences in font sizes and colours counters the possible information overload.

Difficult technical terms are used but explained with some extra lines of text. Still in the explanation some difficult technical terms are used which makes some sentences not understandable for users whom are not familiar with these terms. Buttons are very clear and consistent.

The layout of the website is built up into one stroke from top to bottom, centred on the website. The sentences from the presented information remains in this stroke which prevents long sentences.

## Functionality

The user can click on the predefined boxes to create a selection. The selection is then used by the model behind the choice aid to produce

an answer. The information is presented in just one stroke and does not switch to different screens. This makes the entire model very clear but can be found to long. Scrolling is needed for the navigation of the page. Some level of personification is possible but still categories are asked instead of the exact numbers e.g. age.

## Communication of numbers

The communication of the numbers is done in percentages and supported with lines of text. The problem lies in understanding percentages. When the user does not understand or how to interpret percentages, the entire outcome is useless.

## Conclusion

The new design;

- Should contain a clean and clear font with a proper size for users to read the information.
- Should not contain too much text in one glance.
- When technical terms are used, provide the user with the proper explanation to make the information understandable.
- Should use simple text in short sentences to make it understandable for as many users as possible.
- Should have a user-friendly interface with an obvious structure.
- Should have a clean and clear layout.
- Should have the ability to personalize the presented information.
- Should not be demanding to many actions by the user.
- Should present the numbers in an understandable way for most of the population by means of a combination of text and visuals.

## Design direction

To determine the design direction for this graduation project, the options and their resources of each of the three themes were put together in a graphic overview (page 70-71). The overview shows the chosen options by which the purpose of the theme can be attributed together with the resources needed to implement the option. The resources needed for the option to be implementable, were used as a weighting factor to determine what the best option is to facilitate all three themes. The themes were;

1. Providing general information about the disease, treatments and risks
2. Providing personalized prediction information, based on the numerical information database from IKNL
3. Enable interaction between physician and patient to inform each other about individual preferences and wishes.

The chosen options were;

1. Using printed versions like leaflets and letters
2. Using email
3. Chat service

4. Electronic Medical Record
5. Telling through dialogue
6. Web application

The resources of the options were;

- Parties needed at the same time
- Quick access to desired information
- Possibility to reread the information
- Independent of consultations
- Extra actions in the current activities of the physician

Finally, the decision was made, based on the analysis of the graphic overview, to go with option 6. A design for a web application (figure 2.8).



*Figure 2.8. The chosen design direction*

# THEMES



## Printed variants

## Email

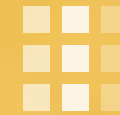
1. Providing general information	✓	✓	✓	✓	✓	✓	✗	✓	✓	✗
2. Providing personalized prediction information	✓	✗	✓	✓	✗	✓	✗	✓	✓	✗
3. Enable interaction	✗	No	✓	Yes	✗	✓				

## OPTION 1

## OPTION 2

# RESOURCES

Parties needed at the same time	✗	Yes	✓	No
Quick access to desired information	✗	No	✓	Yes
Possibility to reread the information	✗	No	✓	Yes
Independent of consultations	✗	No	✓	Yes
Extra actions in current activities of the physician	✗	Yes	✓	No



### Chat service

### Electronic Medical Record

### Telling through dialogue

### Web Application\*

✗	✓	✓	✓	✗	✗	✗	✗	✗	✗	✗	✓	✗	✗	✓	✓	✓	✓	✓	✓
✗	✓	✓	✓	✗	✓	✓	✓	✓	✓	✗	✓	✗	✗	✓	✓	✓	✓	✓	✗
✓					✗					✓					✓				

## OPTION 3

## OPTION 4

## OPTION 5

## OPTION 6

Option 1 and option 6 were ranked as the best design directions. However, the power of the client, IKNL, lies in the delivery of personalized figures. Although this is doable through a printed version, the problem lies in that a single personalized print is still necessary for each patient. When this print has to be delivered by the hospital, this will add several steps to the current work process of the physician. In addition, before the print can be made, the data of an individual patient must still be retrievable. The design direction of a web application supports the immediate question of the representativeness of different figures for an individual patient. To combine the best of both options, the decision was made to go with option 6, where a print function is integrated so that if patients need a printed version, they can do this themselves.

\* The reason for a web application is based on influencing the physician's current process as little as possible. since there is a computer with internet in the consultation room, no further adjustments are needed to the consultation room to facilitate the design when a web application is used.

## 2.3 DESIGN BRIEF



### *Determining the design challenge*

Combining all the gathered information from the discover and define phase, the following design challenge and list of requirements emerged, to where the design had to comply;

Create a **User Interface for a web application** that ensures that **both patient and physician** are aware of the **different possible treatment options**, understand what these treatment options **involve** concerning risks, treatment options and possible outcome, **according to the principles of risk communication**, and that **interaction** can take place, so that the **preferences and values of both patient and physician can be shared**, to support the process of SDM concerning adjuvant chemotherapy for colon cancer patients.



# LIST OF REQUIREMENTS - THE DESIGN SHOULD...



## Emerged out of the insights

1. Present the numerical information of IKNL, when requested, to both patient and physician
2. Be used by both patient and physician in a supportive way to prepare themselves for the final treatment decision during the oncologists' consultation
3. Prevent an information overload, especially at the patients' side
4. Be usable for elderly people, since the disease is more common in later life
5. Enable the patient and physician to share their preferences and values



## Emerged out of the patient

1. Be able to present personalized prediction information of the patient as; life expectancy, influence on their quality of life, possible intensity of the side effects
2. Be able to present general information to the patient about the possible treatment options and side effects that may occur



## Emerged out of the physician

1. Present the personal prediction information in the presence of a physician
2. Be usable within the physicians' consultation office
3. Trigger the patient to think about their quality of life before coming to the consultation



## In need of conceptualisation

1. Contain a clean and clear font with a proper size for users to read the information.
2. Provide the user with the proper explanation to make the information understandable, when technical terms are used
3. Use simple text in short sentences to make it understandable for as many users as possible.
4. Have a user-friendly interface with obvious buttons and structure.
5. Have the ability to personalize the presented information.
6. Not be demanding to many actions by the user.
7. Present the numerical information in an understandable way for most of the population.

This chapter gives an overview of the creation of the final concept. First the conceptualisation took place. Through multiple iterations the concept was optimized to a final concept. Then a prototype was created and tested with multiple potential users in an iterative way. All the insights obtained from this chapter were used to create the final design in the next phase.

### 3.1 Conceptualization

### 3.2 Prototype

### 3.3 User test Optimizations

# 3.1





# DEVELOP



# 3.1 CONCEPTUALISATION

*Creating a design for both patient and physician*



Due to the decision to make a web application, the strict boundaries and a clear goal that emerged out of the define phase, the decision was made to start designing a concept. The concept was optimized through multiple iterations. After that, the possible scenarios were investigated along the timeline of the current procedure of decision-making (page 39). Finally, a concept took shape, which was the starting point for the prototyping phase.

## Conceptualisation process

First a concept was created by means of a block diagram (figure 3.2) (appendix 7), in which the three basic elements; providing general information, providing prediction information and enable interaction, were incorporated. Thereafter, the concept was developed through multiple iteration steps with multiple parties

(figure 3.1). During the meetings with the different parties an explanation was given about the concept, supported with a presentation. Feedback was received and used to improve the concept. Finally, all the different iteration steps led to a final concept, which was ready for prototyping.

Within the block diagram, the kanker.nl logo appears. Kanker.nl ([www.kanker.nl](http://www.kanker.nl)) works closely with IKNL in the interest of the population. Where IKNL has the large data base on cancer patients, kanker.nl is more concerned with informing cancer patients by providing general information and bringing patients together to share their experiences. Because of the close collaboration, it was decided to implement the general information from kanker.nl in the concept. if adjustments to this information are necessary in the future, this can be adjusted quickly and efficiently.

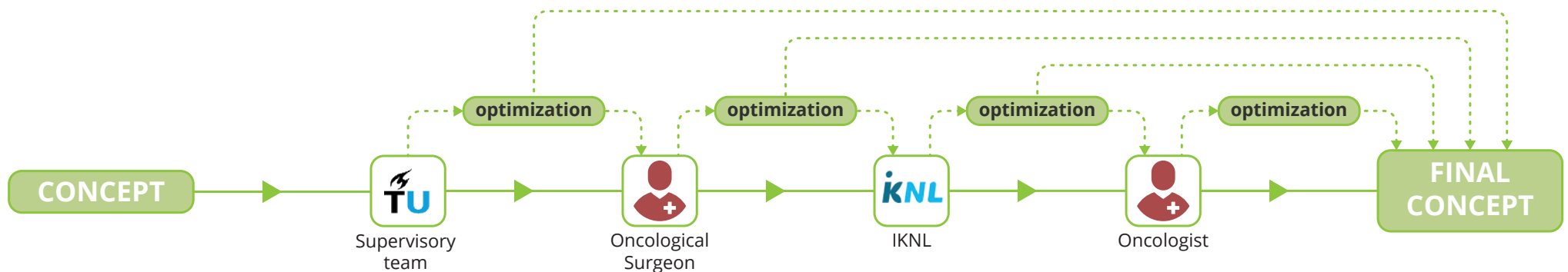
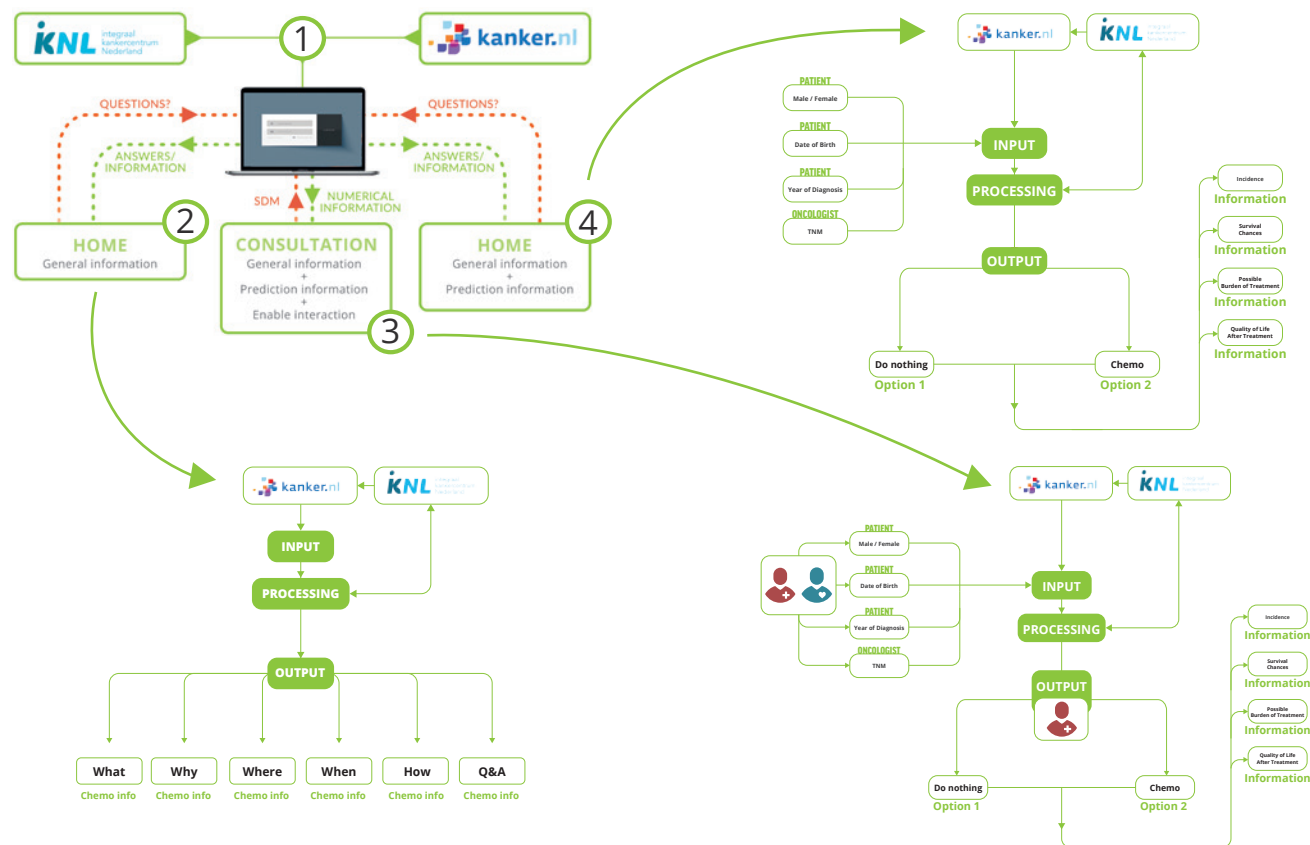


Figure 3.1. Graphic representation of the conceptualisation process

① The information provision comes from IKNL and kanker.nl, transformed by the web application into easy to understand information for specifically the patient.

② Before the consultation the patient can use the web application to find information about the general nature of adjuvant chemotherapy. By providing the information, the patient is triggered to think about the upcoming decision and their preferences and hopefully prepares him/her self for the consultation.

③ During the consultation, in cooperation with the physician, the pTNM can be entered in the web application. The web application processes this input, and provide the users with the asked personalized prediction information about the different treatment options. This prediction information triggers the conversation between patient and physician concerning the decision of a treatment option. During this conversation, the preferences of both parties are shared to have the same understanding, of the same amount of information, which is needed for a shared decision. Finally, a shared decision is made.



④ When during the consultation no choice could be made, the patient is sent home with the prediction information and the provided information by the physician to overthink the matter. The patient is not enabled to change the entered pTNM. Then, a call appointment or another consultation is needed to make a final shared treatment decision.

Figure 3.2. Block diagram of the start concept before the iterations (appendix 7)

## Concept iterations

### *Iteration with supervisory team*

During the meeting with the supervisory team, both TU Delft coaches, the IKNL coach and the VUmc expert on risk communication and SDM were attending. The block diagrams were used to explain the concept, supported by a presentation. During the discussion, notes were made by the researcher. The following points of feedback have been used to optimize the concept;

- Be aware that you are the designer, and do not let physicians or patients tell you what to do with the numerical information.
- Try to figure out why physicians do not want patients to be receiving this kind of information without the presence of them.
- Determine the goal of the design, do you want to inform patients and physicians or do you want to tell them what to do
- Think about what SDM is and how you want to contribute to this process with a design.
- Presenting different types of chemotherapy might be too complex for the patient. Again, what is the goal you are trying to reach.

### *Iteration with IKNL*

During the meeting with IKNL, ten employees were attending. The backgrounds of the employees varied from communication expert to clinical data scientist. The block diagrams were used to explain the concept, supported by a presentation. During the discussion, notes were made by the researcher. The following points of feedback have been used to optimize the concept;

- Think carefully about when you want to present which information and to whom.
- Physicians need different information than patients.
- An Electronic Medical Record is too much information for a patient, think about how you want to present numbers.
- Make sure that a doctor recommends the web application
- Could the quality of life preferences of the patient perhaps be shared before the MDC  
It might be an idea to prepare a patient for what might happen before surgery because the cTNM is already known. Despite the fact that the pTNM is more accurate.

### *Iteration with physicians*

During the meetings with the physicians, an oncologist and an oncological surgeon were asked to provide feedback. The meetings took place on two separate days at the Catharina Hospital. The block diagrams were used to explain the concept, supported by a presentation. During the discussion, notes were made by the researcher. The following points of feedback have been used to optimize the concept;

- The patient must decide between to treat or not to treat. Presenting the different types of chemotherapy is too specified and lies with the oncologist to match that as best as possible for the patient. Things like dosing is really up to the oncologist. (Surgeon / Oncologist)
- Categorize the patients in age groups of 5 years to get the figures from a larger group. (Surgeon)
- Show and explain the incidence of which the figures are part of, so that the correct value of the figures can be seen. (Surgeon / Oncologist)

- Do not show personalized numerical information for patients at their home. Do this in the presence of a physician so that they can go through the numbers together and no misconceptions can arise because that only makes it more annoying for the patient. In doing so, you also suggest that the personal characteristics cannot be filled in incorrectly by the patient. (Surgeon / Oncologist)
- The general information should be based on what adjuvant chemotherapy means, together with what the patient has to invest in time, number of visits to the hospital and possible side effects in relation to what can be gained with it. (Surgeon / Oncologist)
- What the exact pTNM value is, is not important for the patient. They want to know what it means. Am I cured or not, do I need another treatment or not. (Surgeon)
- Try to trigger the patient to make them think about their quality of life and what they want to achieve with the possible treatment before coming to the consultation. (Oncologist)

## Realization in the current procedure of decision-making

During the iteration steps along with the points of feedback that were obtained, it became clear that both the patient and physician had their own interests in the current process of decision-making. These interests are different with regard to the information they want to have, but also

when the information is desired. Therefore, a closer look was taken at the current procedure of decision making (page 39) and different moments of implementation of the different interests of patient and physician where identified (figure 3.3).

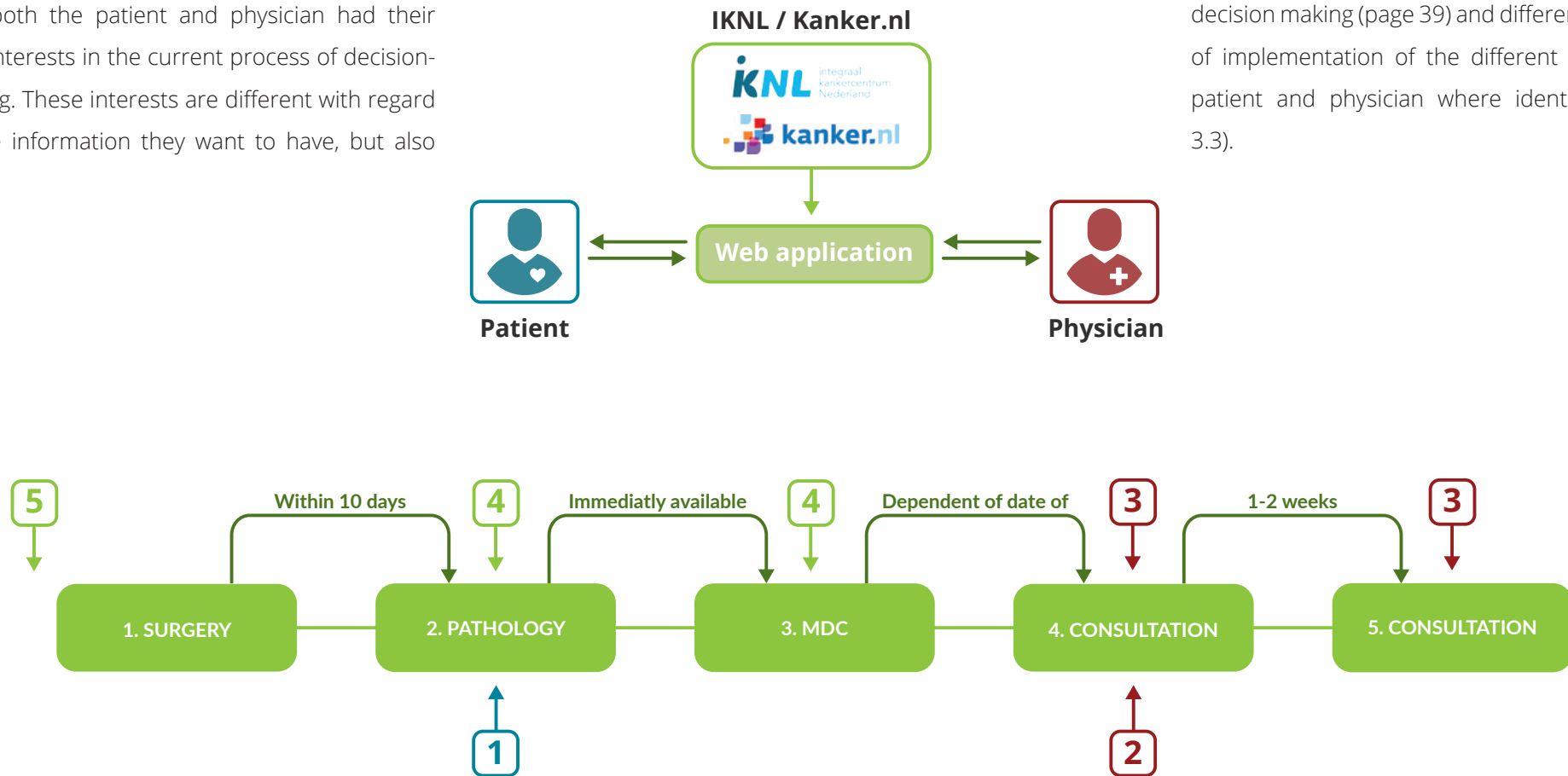


Figure 3.3. Graphic representation of the different moments of implementation of the different interests of patient and physician



### **Moment 1**

From the patients' side, it is known that leaving them in doubt is worse than actually receiving bad news. Therefore, the possibility is presented to give the outcome of the diagnosis along with the personal prediction information, immediately when this is released by the pathologist without the presence of a physician. This gives the patient the opportunity to think about his or her quality of life well before the consultation of the final decision, and to communicate this with the physicians through the web application before the final decision-making moment.

### **Moment 2**

From the oncological surgeons' side, it is known that presenting personal numerical prediction information about the possible treatment options is unwanted. Therefore, the possibility is presented to give the diagnosis at the same time as the current process, during the consultation with the oncological surgeon. After the diagnosis is known by the patient along with the personal prediction information, they can start thinking about their quality of life and communicate this through the web application.

### **Moment 3**

From the oncologists' side, it is known that presenting numerical prediction information about the possible treatment options is unwanted. Therefore, the possibility is presented to give the diagnosis at the same time as the current process, during the consultation with the oncological surgeon but not with prediction information. After the diagnosis is known by the patient, they can start thinking about their quality of life and communicate this through the web application. When the final treatment decision has to be made during the consultation with the oncologist, the personal numerical prediction information is presented and discussed together.

### **Moment 4**

From the side of IKNL and kanker.nl, it is known that they serve the interests of the patient. Therefore, the possibility is presented to give the outcome of the diagnosis along with the personal prediction information, immediately when this is released by the pathologist without the presence of a physician. This gives the patient the opportunity to think about his or her quality of life well before the consultation of the final decision.

However, the patient must communicate this with the physicians through the web application before the MDC, so that all the specialists can think about the best treatment option, and recommend this to the patient during the consultations.

### **Moment 5**

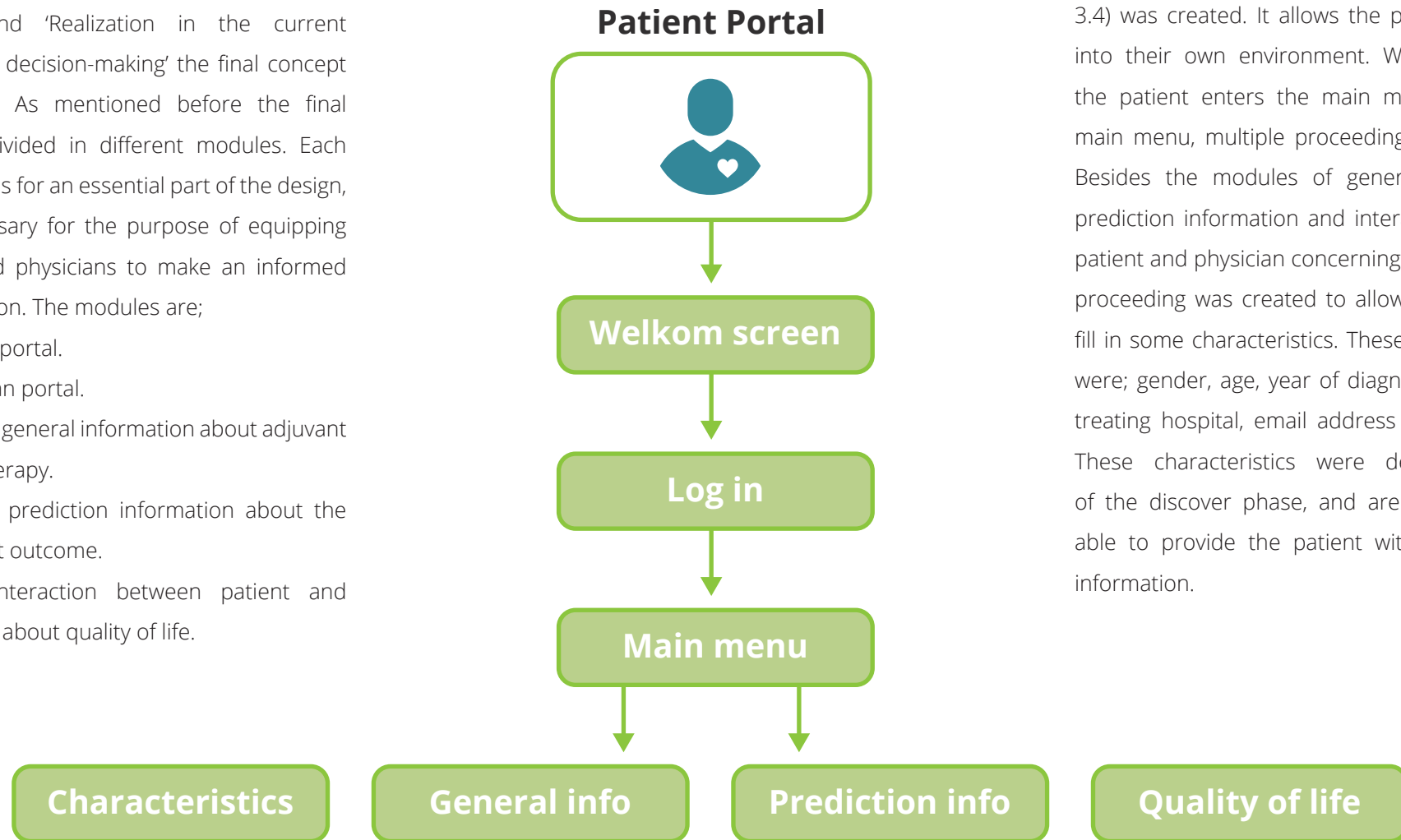
The fifth moment, which is presented from the side of IKNL and kanker.nl, is similar to moment 4 except, it was suggested to use the clinical TNM instead of the pathology TNM. The cTNM is known before the surgery which gives the patient even more time to think about his or her preferences and quality of life and communicate this through the web application before the MDC.

Because of the many possibilities to implement the different interests of patient and physician, the decision was made to divide the concept into modules. The different modules are the basis for the final concept (page 82). When each module will be implemented, was dependant of the outcome of the user test optimizations (page 98). The final moments of implementation will be presented and explained in the chapter '4.1 Final design' in the evaluate phase.

## Final concept

Using the insights gathered from the 'Concept iterations' and 'Realization in the current procedure of decision-making' the final concept was created. As mentioned before the final concept is divided in different modules. Each module stands for an essential part of the design, that is necessary for the purpose of equipping a patient and physicians to make an informed shared decision. The modules are;

1. A patient portal.
2. A physician portal.
3. Providing general information about adjuvant chemotherapy.
4. Providing prediction information about the treatment outcome.
5. Enable interaction between patient and physician about quality of life.



## Patient portal

A block diagram of the patient portal (figure 3.4) was created. It allows the patient to log in into their own environment. When logged in, the patient enters the main menu. From the main menu, multiple proceedings are possible. Besides the modules of general information, prediction information and interaction between patient and physician concerning quality of life, a proceeding was created to allow the patient to fill in some characteristics. These characteristics were; gender, age, year of diagnosis, city of the treating hospital, email address and password. These characteristics were determined out of the discover phase, and are needed to be able to provide the patient with personalized information.

Figure 3.4. Block diagram of the patient portal of the final concept

### Physician portal

A block diagram of the physician portal (figure 3.5) was created. It allows the physician to log in into their own environment. Within this environment an overview is provided of the patients who are being treated by them. This overview shows the characteristics of the different patients in a glance. The physician has the ability to add the pTNM score to each patient by pressing the 'enter' button. By clicking on the patients' name, the modules of prediction information and interaction between patient and physician concerning quality of life become visible.

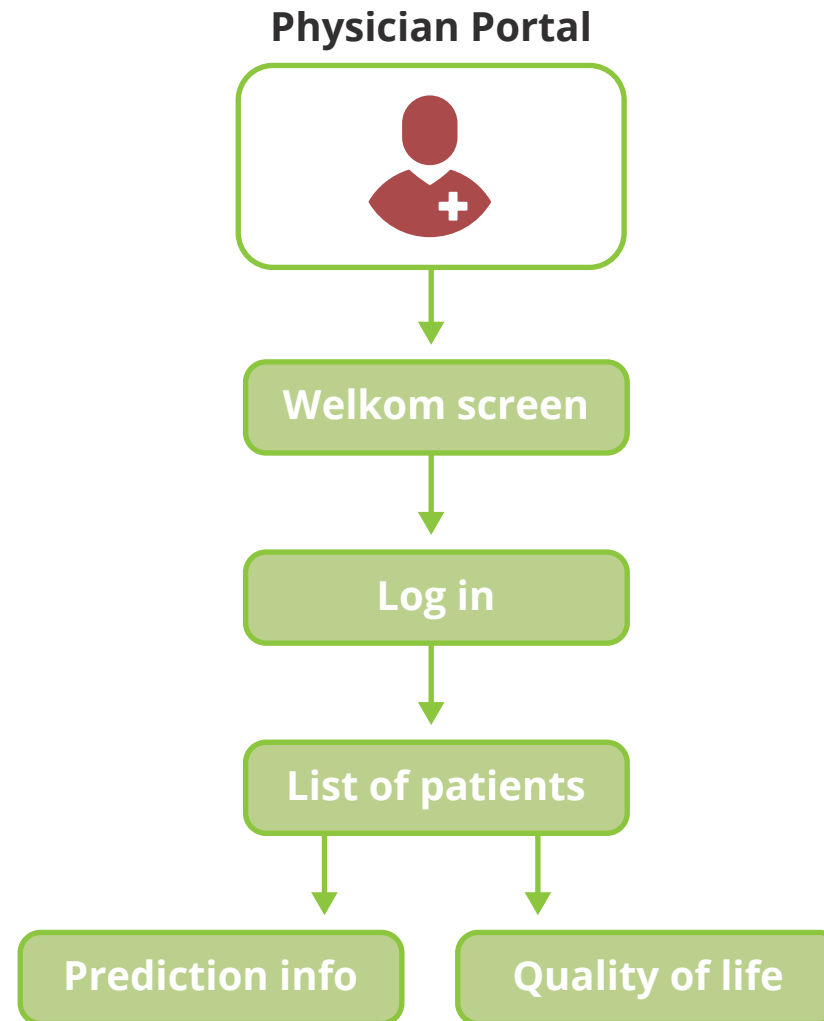
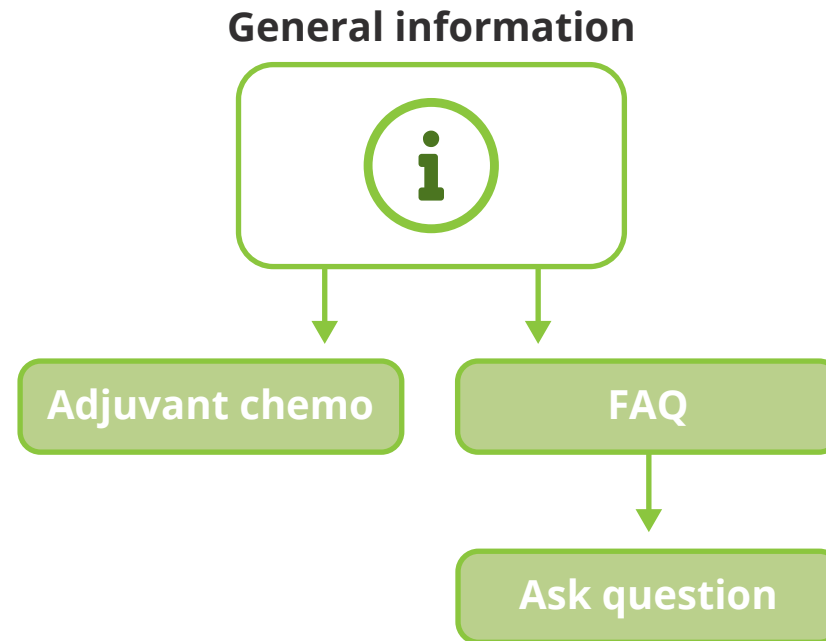


Figure 3.5. Block diagram of the physician portal of the final concept

### **Providing general information**

A block diagram of the general information portal (figure 3.6) was created. This is a straight forward 'information push' type of module. Information about the contents of adjuvant chemotherapy can be found here. The emphasis will be on practical information such as; how often a patient has to go to the hospital, how long the whole cure will last, what the potential side effects can be, etc. In addition, a FAQ has been established where patients can find answers to the most frequently asked questions by patients. If there are any other questions, these can be entered. If that specific question is asked several times by the patients, the FAQ will be adjusted and the specific question, including answer, will be added to the FAQ.



*Figure 3.6. Block diagram of the general information module of the final concept*

### Providing prediction information

A block diagram of the prediction information (figure 3.7) was created. This section shows the predictions about, in particular, the chance of survival for a specific individual. this prediction is displayed according to the principles of risk communication in order to prevent misconceptions and make it as understandable as possible for all patients. In addition, it is possible to see the forecast over a period of 2, 5 and 10 years. The incidence is also shown here, so that the user can see on how many patients the figures are based, so that the correct value can be considered by the user.

### Prediction information

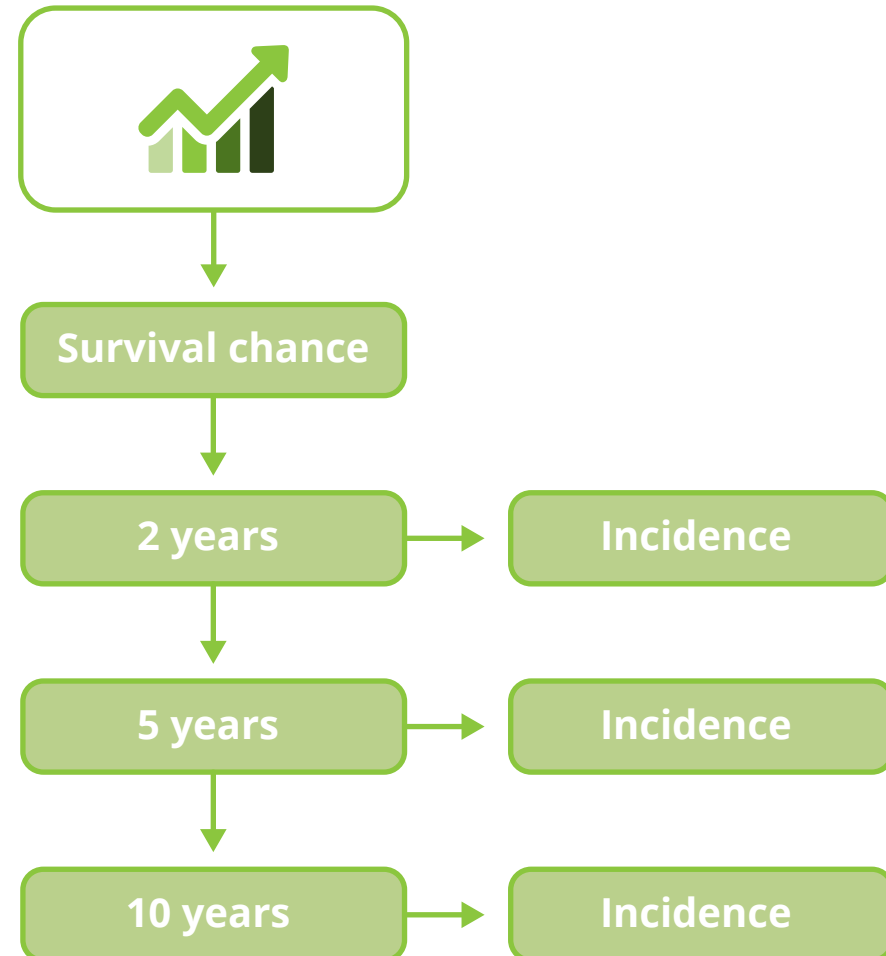


Figure 3.7. Block diagram of the prediction information module of the final concept

### Enable interaction concerning quality of life

A block diagram of the interaction between patient and physician concerning quality of life (figure 3.8) was created. This module shows the patient a list of subjects related to quality of life, arising from the IKNL databases which was obtained through questionnaires (appendix 8). Here, the patient has the opportunity to slide it into position, by means of the ball on the beam, that applies to them. This overview of quality of life is also shared with the physician, so that he/she is aware of the interests of the various issues regarding quality of life of the patient, so that this can be included in recommending a treatment option.

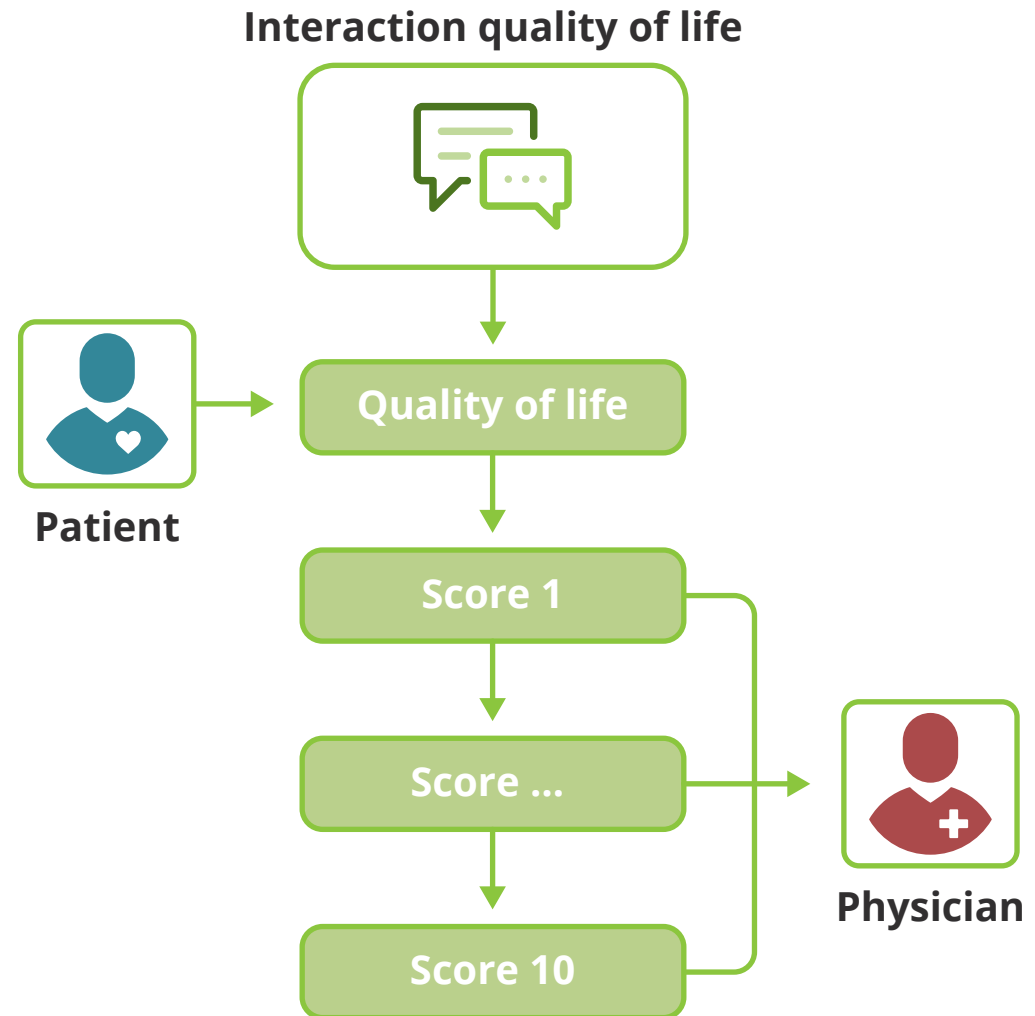


Figure 3.8. Block diagram of the interaction concerning quality of life module of the final concept

## 3.2 PROTOTYPE



### *Creating a prototype to test the design*

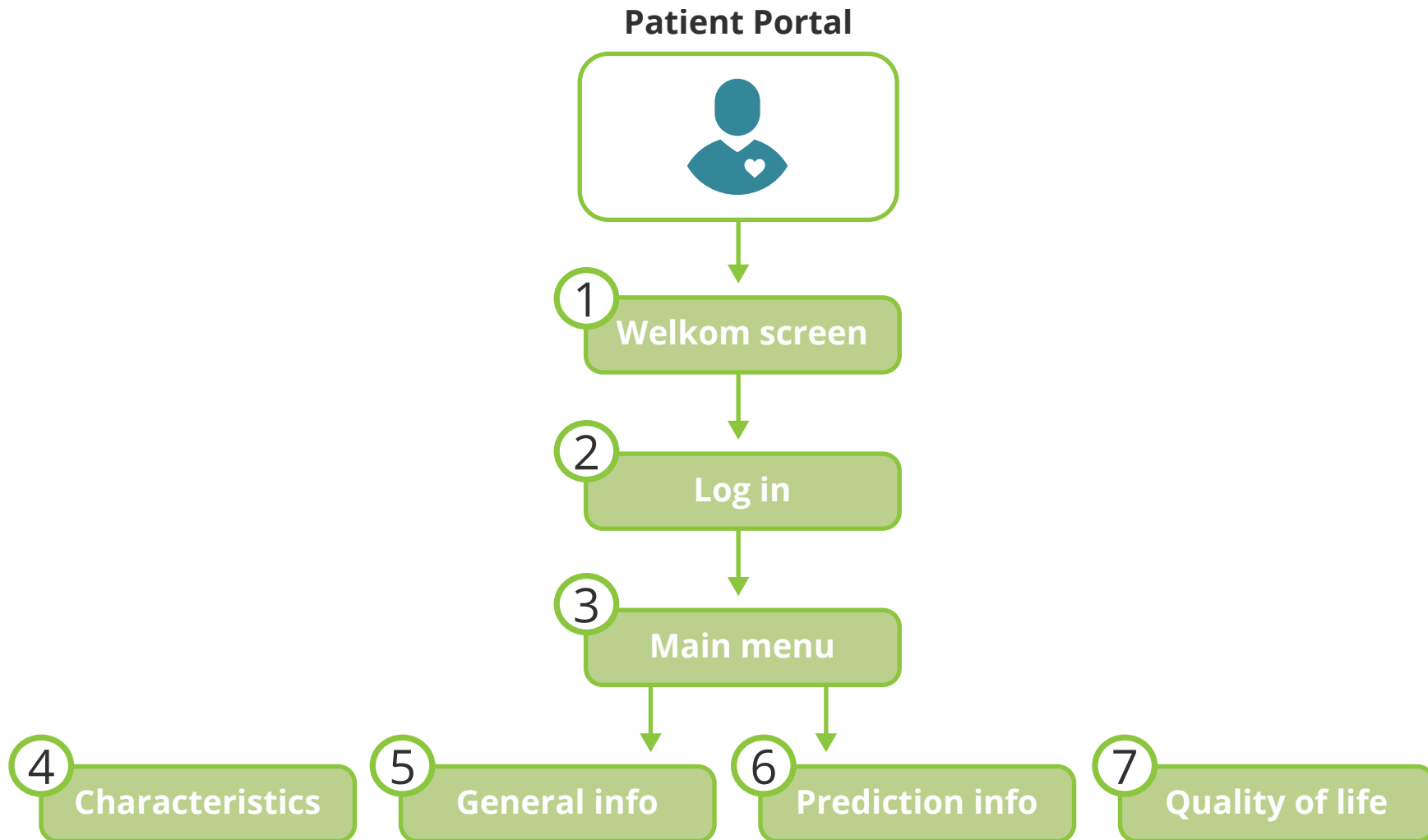
Based on the block diagrams of the final concept, the first prototypes were created. The prototypes were created using Adobe Photoshop, Adobe Illustrator and Adobe XD Design. The prototypes were tested and optimized for the user, as is describe in the next section. Before the prototyping started, a closer look was taken at the list created by Spiegelhalter, Pearson & Short (2011). They have described how risk communication can be implemented when creating informal graphics based on uncertainty about the future. This list was;

- Use multiple formats, because no single representation suits all members of an audience.
- Illuminate graphics with words and numbers.
- Design graphics to allow part-to-whole comparisons, and choose an appropriate scale, possibly with magnification for small probabilities.
- To avoid framing bias, provide percentages or frequencies both with and without the outcome, using frequencies with a clearly defined denominator of constant size. Helpful narrative labels are important.
- Compare magnitudes through tick marks, and clearly label comparators and differences.
- Use narratives, images, and metaphors that are sufficiently vivid to gain and retain attention, but which do not arouse undue emotion. It is important to be aware of affective responses
- Assume low numeracy of a general public audience and adopt a less-is-more approach by reducing the need for inferences, making clear and explicit comparisons, and providing optional additional detail.
- Interactivity and animations provide opportunities for adapting graphics to user needs and capabilities.
- Acknowledge the limitations of the information conveyed in its quality and relevance. The visualization may communicate only a restricted part of a whole picture.
- Avoid chart junk, such as three-dimensional bar charts, and obvious manipulation

through misleading use of area to represent magnitude.

- Most important, assess the needs of the audience, experiment, and test and iterate toward a final design.

*Prototype of the patient portal*

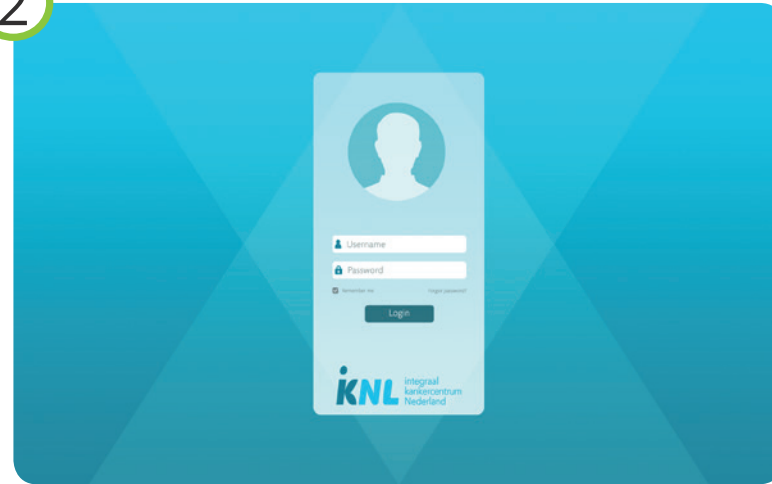




1



2



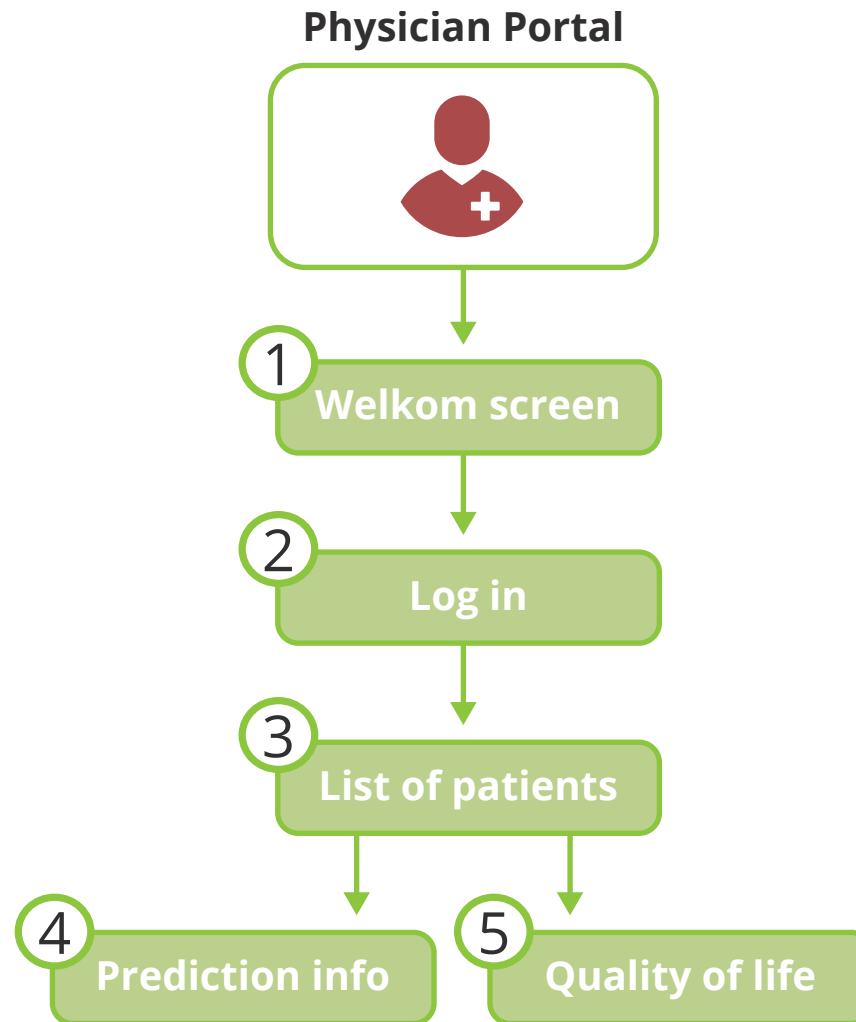
3



4



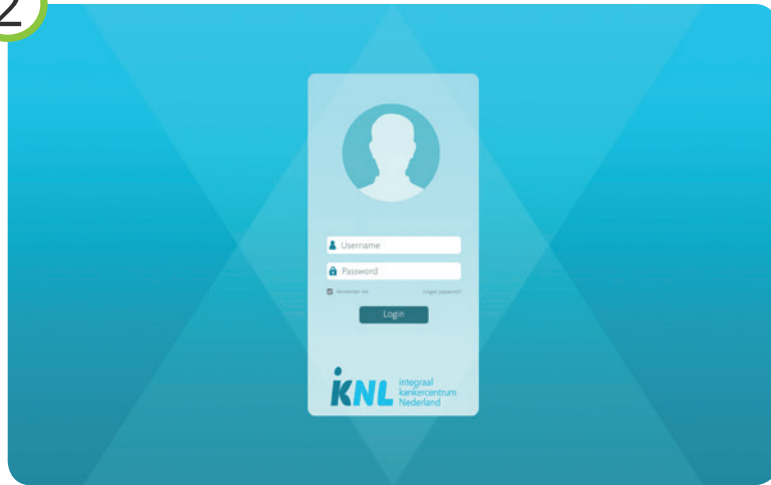
*Prototype of the physician portal*



1



2



3

Dhr. G.J. Creemers Log uit

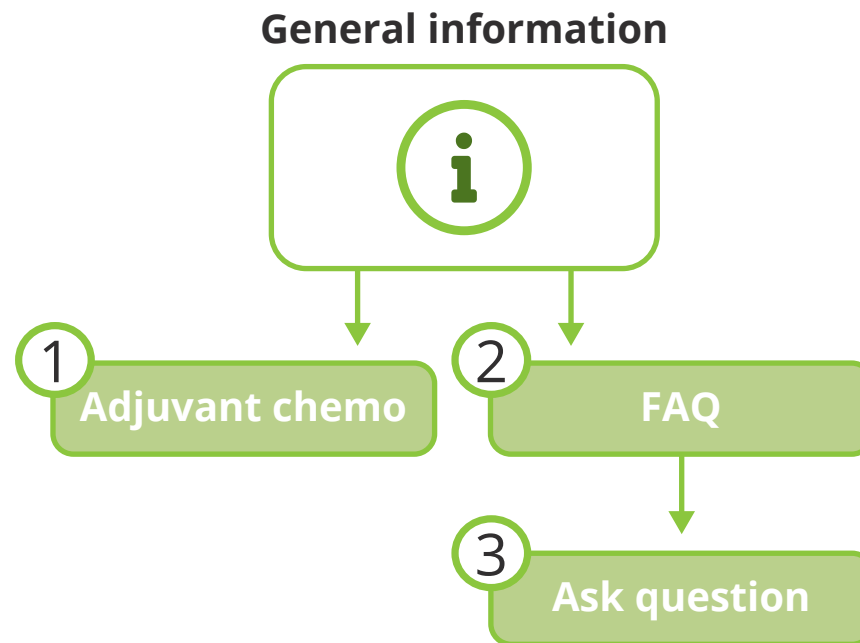
Patient	Geslacht	Leeftijd	Diagnosejaar	pTNM	QoL
1. Dhr. Janssen	Man	68	2014	T4bN0M0	Voorspelling ✓
2. Mevr. Schippers	Vrouw	72	2017	T4aN0M0	Voorspelling ✓
3. Mevr. van Gils	Vrouw	54	2018	T3N0M0	Voorspelling ✓
4. Dhr. Diepstraten	Man	78	2018	Invoeren	Voorspelling ✗
5. Dhr. Bruininks	Man	89	2017	Invoeren	Voorspelling ✓
6. Dhr. Feskens	Man	67	2018	Invoeren	Voorspelling ✗

4

5



*Prototype of providing general information*

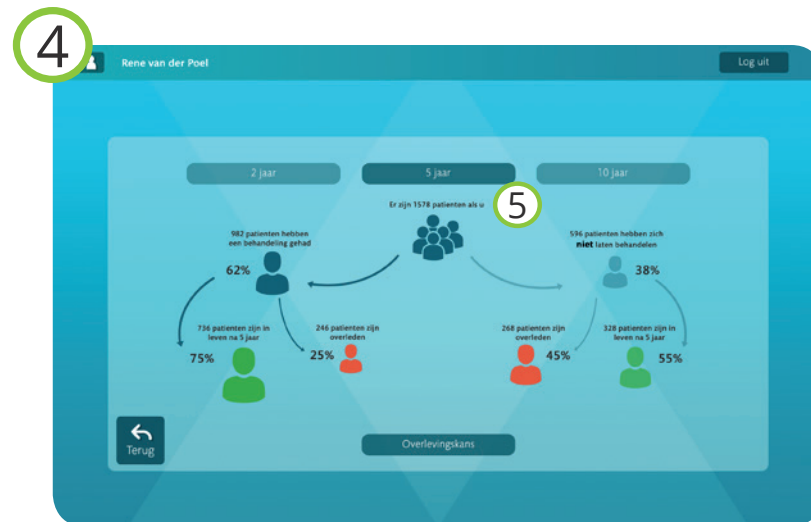
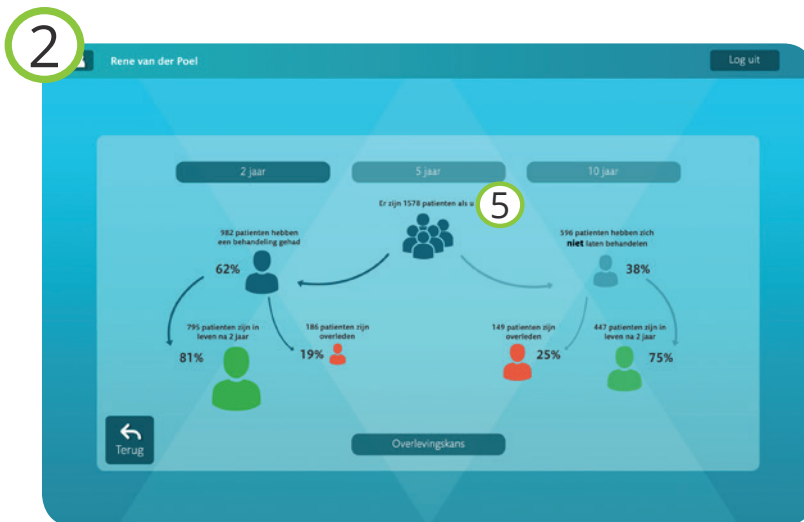
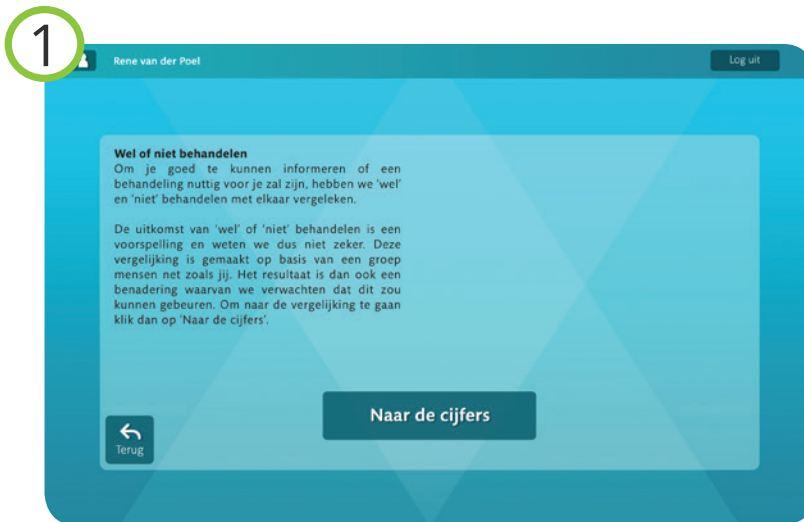




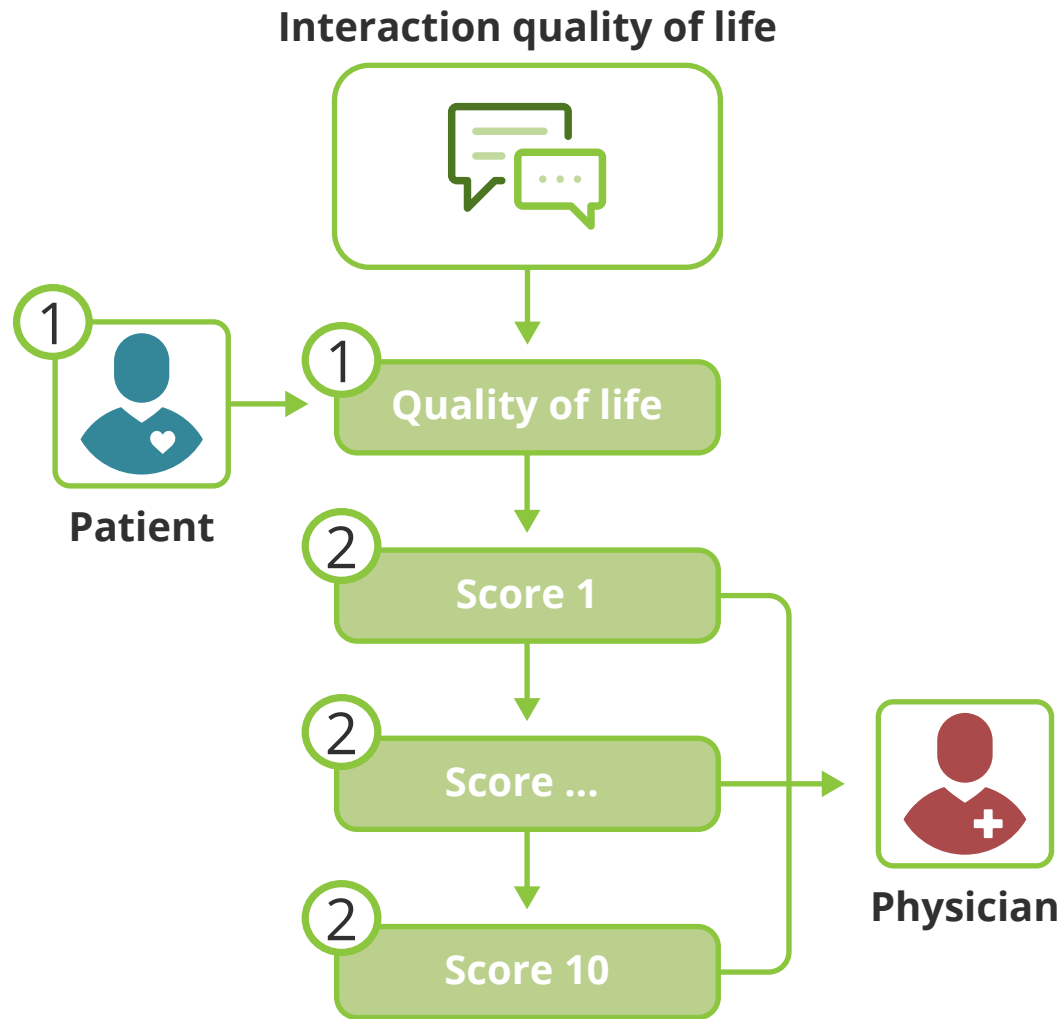
*Prototype of providing prediction information*

**Prediction information**

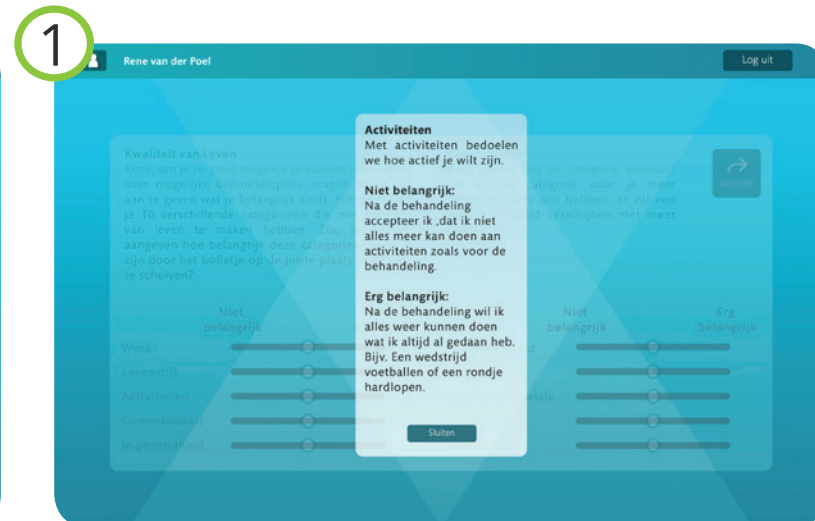
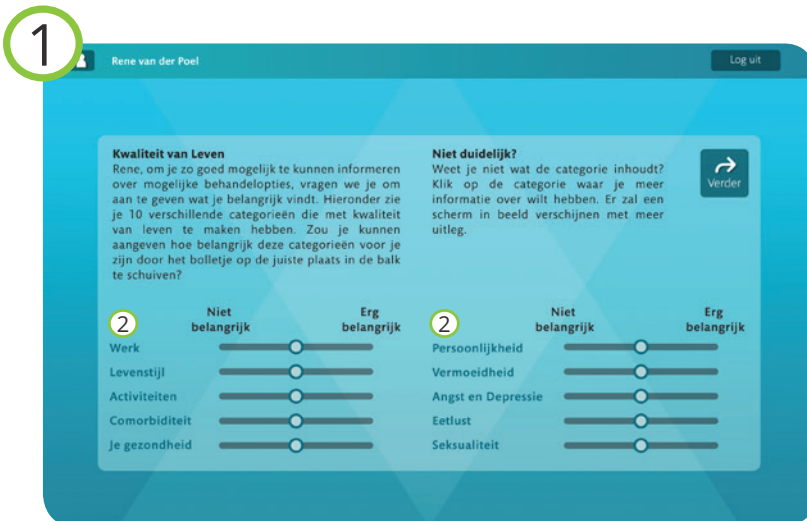




*Prototype of enabling interaction concerning quality of life*










## 3.3 USER TEST OPTIMIZATIONS



### *Optimizing the prototype through iteration steps*

To improve the prototype, multiple iterations were performed. First, a user test was carried out, then a questionnaire was sent around and finally an optimization step was performed with an oncologist. All the insights gathered were used to create the final design, which is described in the next chapter; Evaluate. During the different methods that were used to optimize the final design, the emphasis was on; improving the usability of the user interface of the web application, checking if the provided information was understandable for the users and, finding out the moment the information is requested and finding out if there was information missing which was considered crucial in making a final treatment decision.

Method	
	User test N= 8
	User questionnaire N= 100
	Semi-structured oncologist interview N= 1

### Research methods

Mixed methods (figure 3.9) were used to obtain insights about the points of interest. Besides the points of interest, more information was gathered, which was spontaneously presented by the participants during the different research methods.

### Potential patients

From the develop phase, the decision was made to use 'potential patients' instead of actual patients. Unfortunately, anyone could get cancer. That is why the current healthy population can be seen as a potential patient. The reason behind this choice, has to do with the fact that the researcher does not want to be another burden for the current patients with questions about a design, while they are in the process of fighting against this terrible disease.

Figure 3.9. User test optimization research methods



### **Research method 1 - User test**

The user test was performed to see if the created prototype functioned properly, and to discover points of improvement for the final design. Besides the usability of the user interface, the content and appearance of the application were also examined.

### **Participants**

The user test was performed with 8 potential patients from both genders, 6 females and 2 males. The age was ranging from 27 till 78 years old. There was 1 participant (male 62) who was actually a colon cancer survivor. Another participant (female 78) has lost several family members and friends by the effects of cancer. All participants were visited at their homes (figure 3.10 - 3.11). By doing so, the participants were in the environment where the design will be used in the future, when implemented.

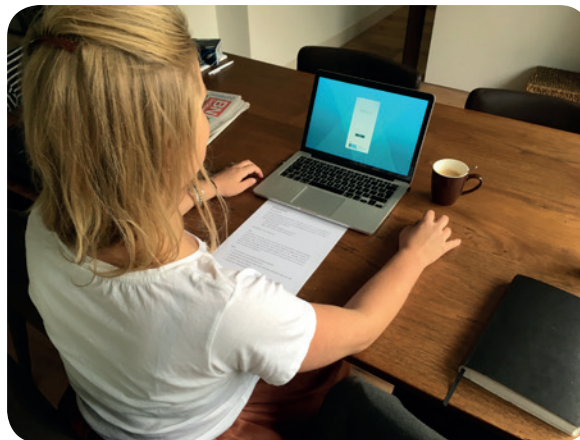
### **Procedure**

The participants received a case (appendix 9) which described a specific patient. Four tasks were asked to perform using the prototype of the web application. Each task covered a different function of the user interface. While performing the tasks, the participant was asked to think out loud and provide the researcher with any comments and questions if they had any. During the completion of the tasks, the researcher was observing the navigation behaviour on the computer screen on which the participant was working. Afterwards some questions were asked about the content of the user interface, the moment they would like to receive this kind of information during the

procedures of decision-making, and if there was information missing which was considered crucial in making a final treatment decision.

### **Processing the information**

During the test, voice recordings of all tests were made, so that the researcher was able to focus on the participants and the observations of the tasks, instead of writing everything down. However, quick notes were made during the user test. Afterwards the voice recording was listened back, and the notes were completed. After analysing the notes, points of improvement were identified and used for the final design.



*Figure 3.10. Performing the user test*



*Figure 3.11. Performing the user test*



## **Research method 2 - Questionnaire**

Due to the mixed feedback which was received about the understanding of the prediction information, the decision was made to create a questionnaire (appendix 8) to test this with a wider audience. The insights gathered from this method were used to decide if the format of the presentation of the prediction information should be changed for the final design.

### **Participants**

The participants used for this questionnaire were reached through social media. By posting the questionnaire on Facebook, a hundred participants were reached within 2 days. Both males and females reacted. The age varied from 18 till 71 years old.

### **Procedure**

Two questions were asked at the participants (figure 3.12 – 3.13) using google docs. Each question was based on the same numerical prediction

information about the survival change of a patient based on a larger group of patients similar to the characteristics of that specific patient. The only difference between the questions was the way how the percentages were presented. Both questions could be answered with 'to treat' or 'not to treat'. The participants could also give a small explanation with the chosen answer. 50 participants first got question 1 and then question 2. The other 50 participants first received question 2 and then question 1. This was done to prevent a learning curve among the participants before they came to the second question that was asked to them, to get more reliable results.

### **Processing the information**

A large data sheet was obtained. This datasheet was then analysed and the insights, arising from the answers to whether or not to treat, were used to decide if the format of the presentation of the prediction information should be changed for the final design. All the explanations next to the given answers were read, and useful insights and comments were used to optimize the final design.

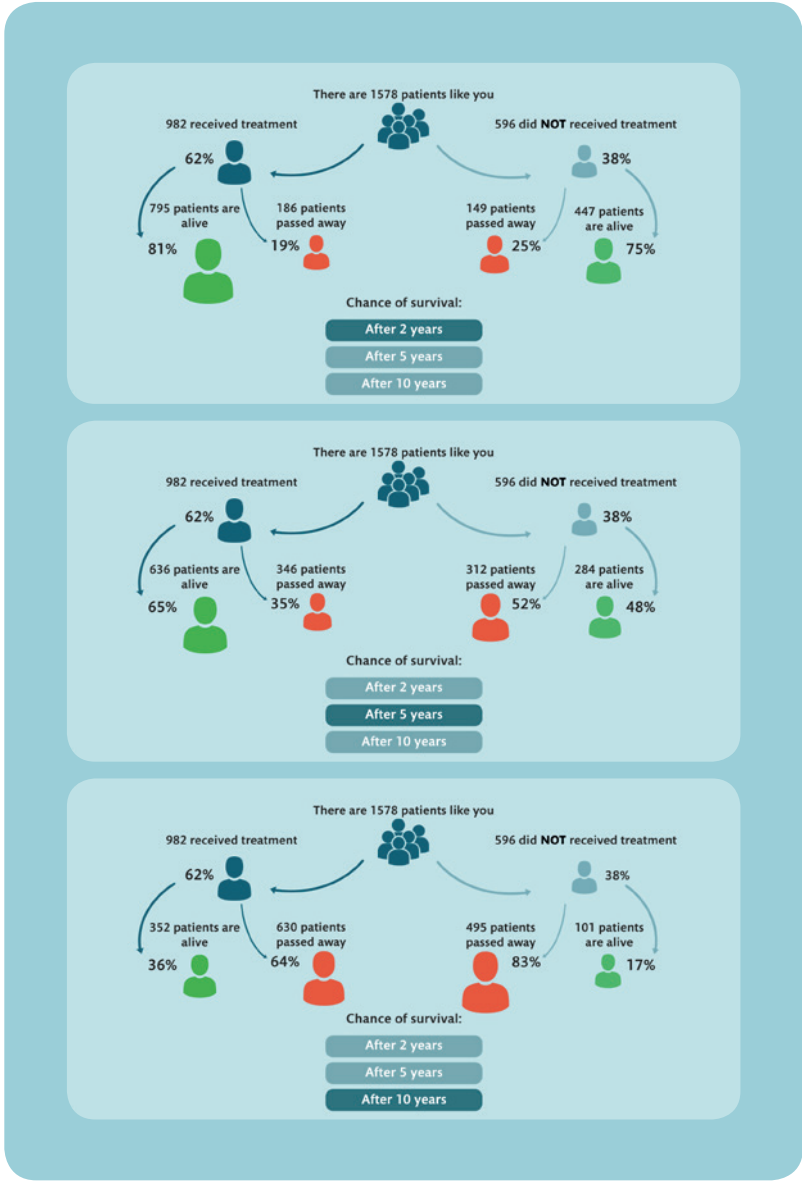


Figure 3.12. Situation of the first question of the questionnaire



Figure 3.13. Situation of the second question of the questionnaire



### ***Reserach method 3 - Semi structured interview***

Because the final design is going to influence the current process and actions of the oncologist, in treating a patient with colon cancer concerning adjuvant chemotherapy, a semi-structured interview was conducted with an oncologist. If the oncologist does not like the whole design, he/she will not recommend it to patients, which is very important for the success of the final design.

#### **Participants**

The same oncologist was interviewed of the Catharina Hospital in Eindhoven, with whom the observations also took place.

#### **Procedure**

The prototype was shown and explained to the oncologist, to which his opinion was asked. During the interview, when allowed, a voice recording was made of the interview. Besides the practical

nature of the recordings, the second purpose was to be able to focus on the conversation instead of being distracted due to the immediate documentation of the answers given.

#### **Processing the information**

The audio recorded interviews were used with the intention to complement the documentation of the interviews afterwards. The obtained knowledge was used to optimize the final design. The full description of the interview can be found in appendix 10.

## Results user test optimization

### Results user test

The results of the user test can be divided into two parts. Part one is the usability of the user interface of the web application and part two is about the content of the application.

### Usability of the user interface

1. Presenting the quality of life screen immediately after the log in, causes a lot of confusion among the users.
2. It was not clear that the quality of life subjects was pressable, to obtain more information about each subject.
3. When the quality of life screen was reached through the main menu, there was a 'further' button instead of a 'back' button which several participants asked how to get back to the main menu.
4. The screen where the personal characteristics could be filled in was presented with both a 'back' button and a 'save' button. All users expected to be leaving the screen by pressing the 'save' button. After several attempts they used the 'back' button.

5. The general information screen had a 'what is there to win' button. This button allowed the user to go to the prediction information. When this button was pressed, the participants did not understand where in the user interface they were located.
6. When the prediction information was shown, the 2,5,10-year buttons were seen as columns. This made the visual very difficult to read. After some explanation, the visual was clear to the participants.
7. It became clear that, although there was text which explained everything, the participants did not read this and made mistakes during the performance of the tasks

### Content of the user interface

1. All participants thought it was unwise to present the outcome of the tissue examination without the presence of a physician.
2. Six out of the eight participants saw that there was a bigger change to stay alive when being treated. Without hesitation they said to treat, because if there is a change 'I'll take it'. The other two had a well thought through

motivation to choose differently.

3. No elements were missed by the participants to be able to make a treatment decision. As a researcher it was found, that when something is not presented, it is not missed.
4. All participants were talking about their loved ones and that the decision could not be made without them.
5. As a researcher, it did not seem that the participants were unable to use and understand the prediction information.

### Results questionnaire

The results of the questionnaire can be divided into two parts. Part one is the difference between 'to treat' and 'not to treat' and part two is about the explanation given by the participants.

### To treat or not to treat

1. 71% of the participants want to be treated and 15% do not want to be treated independently of the infographic.
2. Only 14% changes their mind between question one and question two.

## Explanations

1. The participants suggested to use the infographic of question 1.
2. Independently of the decisions, quality of life is often mentioned as an important factor to take into consideration with regard to this kind of decisions.
3. There is a great urge to survive. 'life is too beautiful'.

## Results semi structured interview

1. Only provide a quality of life comparison against a treatment when these two are on the same level. 'When you can be cured of cancer, then I think that a patient should take the fall in quality of life during the treatment. When the patient has a very small chance of recovery or is in the palliative phase, it is a different story and it is good to weigh this against quality of life'.
2. It would be nice if patients have thought about their quality of life before they walk into my consultation room. Discussing treatment options can be linked to their opinion about quality of life, and would enhance the

discussion about what to do.

3. The way the quality of life screen is now presented is very crowded and I do not like it.
4. The ability to have more precise prediction information is always helpful, not only for the patient, but especially for the physicians. However, I do not think it is wise to present the personal prediction information to the patient at home without the presence of a physician.

## Conclusions user test

### optimization

#### *Improving the usability of the user interface of the web application*

Multiple point of improvement has been found during the research methods. These points will be used to improve the final concept.

#### *Checking if the provided information was understandable for the users*

Based on the user test and the questionnaire, it can be concluded that the way the information was present, was understandable. However, it occurred to the researcher that the potential patients find it often very difficult to imagine themselves in the situation of someone who just had surgery and then again, receive bad news. When an answer was given, every time was mentioned; 'but I do not know what I would choose if the case was actually applicable to me'.

#### *Finding out the moment the information is requested*

During the user tests, all participants said it



was unwise to provide bad news in another way than the current consultation. They would like a physician to give them the news so that questions can be asked immediately, and to be in the hands of a professional. They do would like to have the prediction information during the first consultation with the surgeon, so that they can take this home and discuss the matter before going to the oncologist.

***Finding out if there was information missing which was considered crucial in making a final treatment decision.***

More research is needed with physicians, to determine what the perfect amount and content of information is, to present to the patient. When information was not shown by the web application, it was not missed by the participants.

## **Limitations**

The tests used to optimize the prototype also knew their limitations. these restrictions are described below per applied method.

### ***User test***

Only eight participants were used for this test and provided optimizations for the final design. Although this was sufficient for the optimization process as a necessity for usability, these eight participants were not sufficient to be able to conclude anything about the entire population. Potential patients were also used, and only 1 real patient. In short, the outcomes were used in the design process, but are not valid for the design of all patients with colon cancer and the decision about adjuvant chemotherapy.

### ***Questionnaire***

Although 100 participants participated in this questionnaire, here too, the results were obtained from potential patients and not from real patients. Furthermore, it was not possible to observe how the participants made the test, and

how seriously they dealt with it. Nevertheless, the results provided insights that were useful for optimizing the prototype to a final design.

### ***Semi structured interview***

Only one oncologist was interviewed from one hospital. As a result, the insights gained from this interview are useful for the optimization of the prototype to a final design, but the obtained insights are not applicable for all oncologists in the Netherlands. To get an understanding about this design from the world of Dutch oncology, more oncologists from different hospitals should be questioned.

This chapter gives an overview of the final design. A comprehensive elaboration is presented of the final design. There is explanation about the functions and the moment of implementation. Finally, answers are given to the research questions in the conclusions section, and recommendation are presented to IKNL.

- 4.1 Final Design**
- 4.2 Implementation**
- 4.3 Conclusions**
- 4.4 Recommendations**

# 4.4



**EVALUATE**



## 4.1 FINAL DESIGN



After the prototype iterations by means of a user test, questionnaire and a semi-structured interview with an oncologist, the final design was developed. This chapter provides an overview of; the user scenario, the screen interfaces and functions and the added value for the patient and physician of the final design.

### The IPD

The name of the application, IPD, derived from the master course, Integrated Product Design. Because the main functions of the web application are to inform, prepare and decide, this was a perfect fit for the name IPD. The logo of the IPD was designed to capture the changing role of patient and physician into a more collaborative cooperation, and shows that by the icon of the patient and physician overlapping. The colour which occurred in the overlapping part, was used for the title IPD to indicate that the process of decision-making is shared.

The IPD is an application used by both patient and physician before, during, and if applicable after the consultation. The core functions of the web application are;

- Providing general information about

adjuvant chemotherapy and its contents.

- Triggering the patient to think actively about their preferences and quality of life before the consultation, to be prepared in making a final treatment decision during the consultation.
- Providing the opportunity to share the thoughts about quality of life with the physician before the consultation, so this can be taken into consideration by the physician during the final treatment decision making procedure.
- Providing value prediction information about life expectancy for a specific patient for both the patient and physician.

The application focuses on the procedure of decision-making concerning adjuvant chemotherapy for colon cancer patients, from the moment of the follow-up consultation at the

surgeon after surgery, till the moment the final treatment decision has been made with the oncologist. The main goal of the application is to shift the current decision-making procedure from the classic procedure (literature research) to a shared decision procedure. The first step to reach this goal is to involve both parties, but especially the patient, in making this final treatment decision, by sharing relevant information of both patient and physician. Currently, no tools exist to create this new relationship between patient and physician. Patients enter the consultation room with little to no knowledge of the subject, which results, most of the time, in a submissive attitude towards the physician, with little say on what is going happen (user research). With this web application, the patient will be more involved and triggered to think about their own preferences, so that the consultation takes the form of a conversation instead of a lecture from the physician.

## Touchpoints

Within the decision-making procedure, multiple touchpoints with the IPD were identified. A touchpoint is a moment, interaction takes place with the web application. Five touchpoints are prescribed for the use of the IPD.



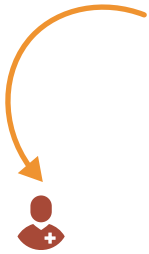
### ***Touchpoint 1 – Oncological surgeons' consultation***

The first touchpoint is the moment during the consultation with the oncological surgeon. During this consultation the patient receives the results from the surgery and examinations. Unfortunately, the patient has not been cured yet, and the oncological surgeon tells the patient that adjuvant chemotherapy is suggested. The oncological surgeon notifies the patient about the existence of the IPD. Together with the patient the email address of the patient is filled in. When the 'send' button is pressed, an email is sent to the patient with login credentials.



### ***Touchpoint 2 – At the home of the patient***

When the patient comes home from the consultation with the oncological surgeon, the patient opens his/her email when he/she has let the bad news sink. This email contains login data for the patient to log in to the IPD. When logged in, the IPD provides the information needed to prepare the patient for the upcoming consultation with the oncologist to finally make a treatment decision. At the quality of life part of the application, the patient enters their preferences. These preferences will be sent to the oncologist. Furthermore, prediction information is shown to enable the patient to be able to visualize what might happen in the event of a certain decision.



### ***Touchpoint 3 – Oncologists' consultation***

Before the consultation, the oncologist examines the patient's preferences concerning quality of life. Knowing what is important for the patient and knowing the pTNM of that specific patient, the oncologist is able to see a more accurate life expectancy prediction through the IPD. Now that the oncologist is in possession of all the necessary information, he/she can present a good treatment option to the patient, in order to have a good conversation about the final treatment decision.



### ***Touchpoint 4 – Oncologists' consultation***

First, the oncologist starts with showing the accurate life expectancy prediction by means of the IPD to the patient. Both oncologist and patient have now worked with the IPD, and therefore both are aware of the same amount of information, and understand this amount of information. The rest of the consultation the patient and oncologist will talk about the information and decide together what the treatment option will be. Sometimes it happens that no decision can be made because there is still too much doubt on the patients' side. Then, the oncologist prints the more accurate life expectancy prediction, and gives it along with the patient.



### ***Touchpoint 5 – At home of the patient***

At home, the patient uses the IPD and the printed version of the prediction information to think about the final treatment decision. When the patient is ready, a call appointment or a new consultation will follow to make the final treatment decision.

# USER SCENARIO'S

## 1. Oncological surgeon consultation



The patient is waiting for the consultation with the oncological surgeon. The patient is nervous for the results of the surgery examinations.

## 1. Oncological surgeon consultation



The oncological surgeon tells the patient the bad news that positive glands have been found and that adjuvant chemotherapy is recommended.

## 1. Oncological surgeon consultation



The oncological surgeon tells about the IPD and invites the patient. In addition, the patient is requested to make an appointment with the oncologist.

## 3. Oncologist preparation



Before the consultation with the patient, the oncologist logs in into his own environment of the IPD. Then the oncologist studies the quality of life score of the patient.

## 3. Oncologist preparation



Then, by going to the next screen, the oncologist is bale to fill in the pTNM of the patient.

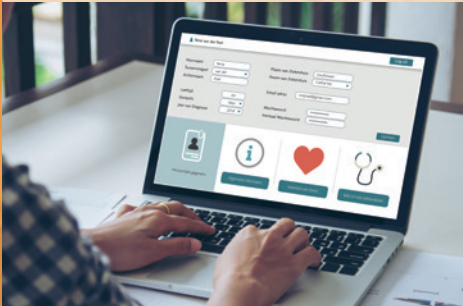
## 3. Oncologist preparation



Accurate life expectancy prediction of the patient is presented. This enables the oncologist to prepare the recommended treatment options based on all the information received from the patient and the IPD.



## 2. Patient at home



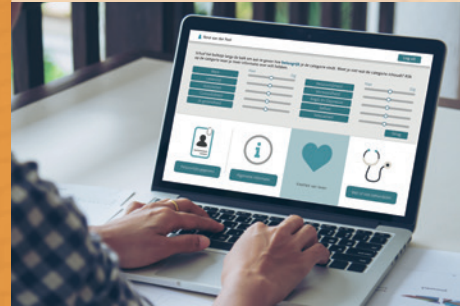
The patient has received the login credentials, and opens the IPD. First the personal information is finished by the patient.

## 2. Patient at home



Then, the patient starts reading the general information about adjuvant chemotherapy.

## 2. Patient at home



Thereafter, the patient thinks about their quality of life and fills in the score sheet, which is shared with the oncologist.

## 2. Patient at home



Finally, the patient studies the prediction information to get a understanding about the content of the treatment decision.

## 4. Oncologist consultation



The patient is waiting well prepared in the waiting room of the hospital until called for by the oncologist.

## 4. Oncologist consultation



Because of all the information that was provided to both the patient and the physician, a lot is known about each other and the conversation starts about what the treatment option is going to be.

## 4. Oncologist consultation



Finally, the more accurate life expectancy prediction information is shared with the patient, based on the pTNM. Finally, a finale treatment decision is made together with the oncologist.

## Design

During the conceptualization phase, the design brief and the list of requirements were used to create a final design. This was performed through iterative steps with multiple participants from multiple backgrounds. This section of the report provides the reader with an overview of the final design with its functionalities and how the user interface is used. In this section, orange boxes with white text can be found, which describe the most important decisions which were taken considering the final design.

The final design exists out of three portals. A patient portal, an oncological surgeon portal and an oncologist portal. Each portal will be explained, as described above, with an addition of a flowchart of all screens involved within the portal which that is being elaborated.




	When this icon is shown on a screen, this means that the area is clickable
	When this icon is shown on a screen, this means click and drag is applicable
	When this icon is shown on a screen, this means that typing is required

Figure 4.1. List of gestures for the user interface

### Login screen

First the login screen is explained. The login screen is for all the portals the same. With your personal credentials you have the possibility to log in into your own IPD environment. After logging in, the interface is different for each of the three portals.






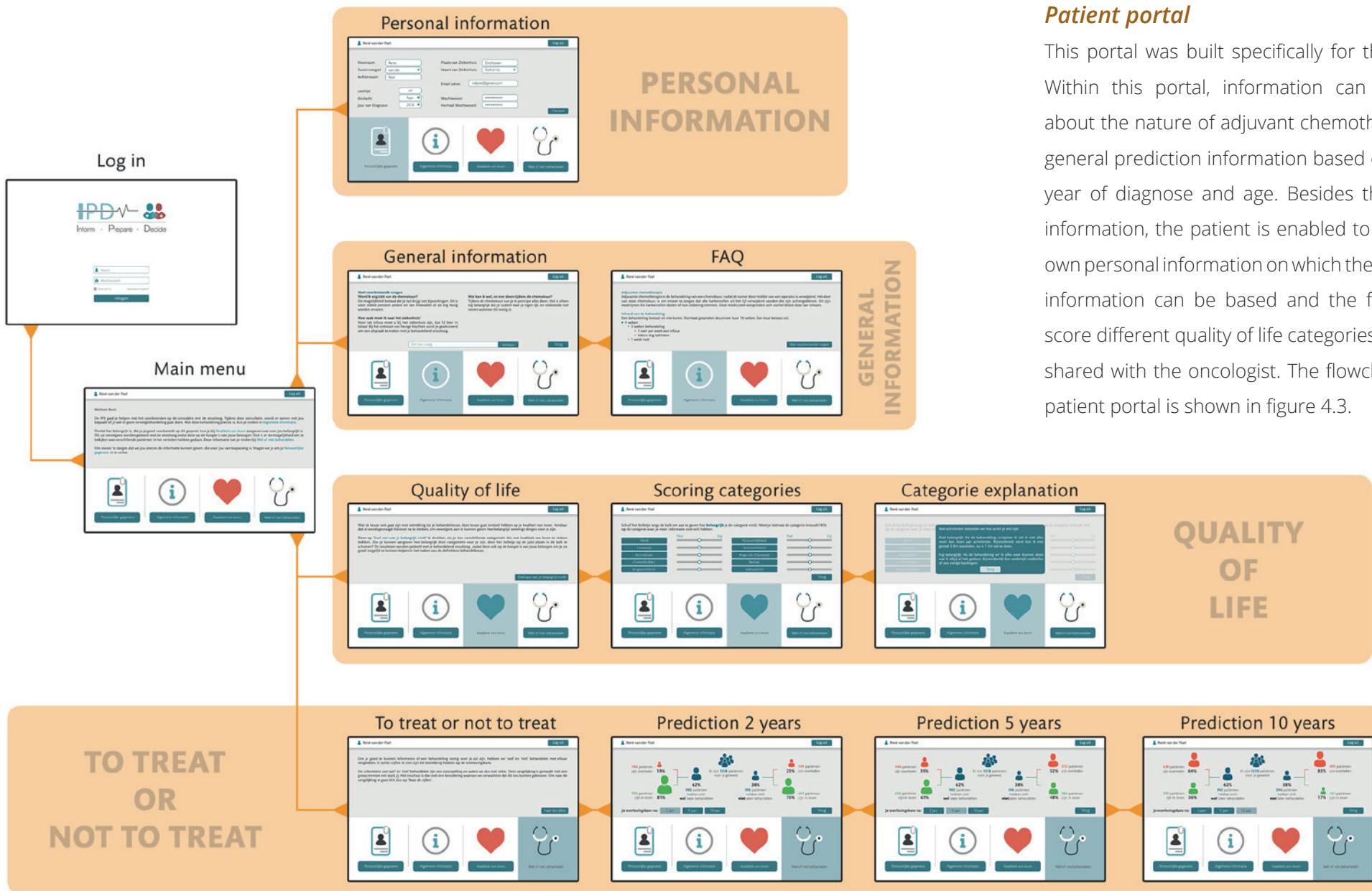
-   Click in the bar, and type in the username
-   Click in the bar, and type the password
-  Click the log in button to login after step 1 and 2 are performed.



Figure 4.2. The log in screen of the IPD web application



## Patient portal

This portal was built specifically for the patient. Within this portal, information can be found about the nature of adjuvant chemotherapy and general prediction information based on gender, year of diagnose and age. Besides the pushed information, the patient is enabled to fill in their own personal information on which the prediction information can be based and the function to score different quality of life categories which are shared with the oncologist. The flowchart of the patient portal is shown in figure 4.3.

Figure 4.3. The flowchart of the patient portal

## Main menu

The main menu (figure 4.4) exists out of three parts. First the upper beam, which shows the name of the patient who is logged in. On the right top corner, the user has the ability to log out from the IPD. The second part is located in the middle of the IPD. This area of the user interface is used to show the requested information/actions to the user, and will change when another function was requested. In this specific screen, the middle area shows a welcome message to the user with a brief explanation of what can be found in the application. The third part is the bottom beam with the four large icons. When the blue button is pressed underneath the logo, the interface changes its middle area according to the requested function.

The decision was made to leave the upper and lower beam mostly unchanged when the user switches functions. The reason behind this decision was obtained during the user tests, where apparently the users became lost in within the application. By presenting constantly where they are, this problem should be solved.



Click on the button, to log out and return to the log in screen.



Click on the button, to go to the personal information.



Click on the button, to go to the general information.



Click on the button, to go to the quality of life categories.



Click on the button, to go to the prediction models.

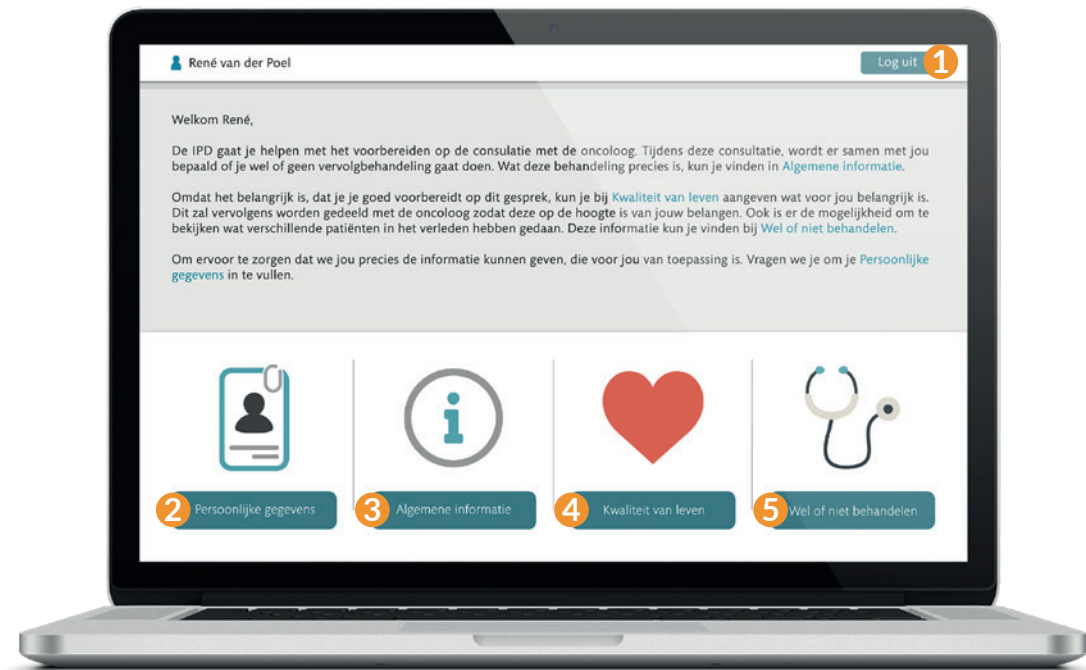


Figure 4.4. Main menu screen of the IPD web application of the patient portal

## Personal information

The personal information screen (figure 4.5) allows the user to fill in more data about themselves. Most important of this screen, is that the age, gender and year of diagnosis is filled in correctly. These values will determine the prediction information in another section of the web application. In the bottom beam, it can be observed that the personal information button was pressed. It changes colour and the button disappears to inform the user that they are in this specific function of the web application. When changes have been made by the user, it can be saved by pressing the save button on the right side of the screen. The reason for asking the town and name of the treating hospital, is to provide the opportunity for the oncologist to find the user if something went wrong with the invitation, or if the user has found this application before being invited but did create an account.



Click on the button, to log out and return to the log in screen.



Click on the button, to save the changes made.



Click on the button, to go to the general information.



Click on the button, to go to the quality of life categories.



Click on the button, to go to the prediction models.



Click in the bar, and click again on the subject you want to enter.



Click in the bar, and type within the bar.



Figure 4.5. Personal information screen of the IPD web application of the patient portal

## General information

The general information screen (figure 4.6) allows the user to find information about adjuvant chemotherapy about what it is, and how long the cure is going to take. Besides the general information, what is displayed by default, it also allows the user to go to the frequently asked questions (FAQ), by pressing the 'to the most asked questions' button on the right side of the screen.



Click on the button, to log out and return to the log in screen.



Click on the button, to go to the personal information.



Click on the button, to go to the quality of life categories.



Click on the button, to go to the prediction models.



Click on the button, to go to the FAQ.



Figure 4.6. General information screen of the IPD web application of the patient portal

## Frequently asked questions

The frequently asked questions screen (figure 4.7) allows the user to find answers about the most common questions asked by other patients. Besides what is displayed by default, the user is allowed to send a question through the 'send' button after the patient has typed a question. This question will be screened, and if it appears that the questions has been asked a couple of times, it will be included in the FAQ.



Click on the button, to log out and return to the log in screen.



Click on the button, to go to the personal information.



Click on the button, to go to the quality of life categories.



Click on the button, to go to the prediction models.



Click on the button, to go back to the general information.



Click in the bar, and type within the bar.



Click on the button, to send the question.

The decision has been made to work with the FAQ instead of a life chat. This would, according to the physicians, bring too much workload. But the FAQ still enables the patient to ask questions instead of the pushed information by the physicians.



Figure 4.7. FAQ screen of the IPD web application of the patient portal

## Quality of life

The quality of life screen (figure 4.8) provides the user with a small introduction text about the quality of life and that this most probably is going to be influenced by any treatment option that is going to be made. The main goal is to trigger the user to think about the quality of life before going to the consultation with the oncologist to make a final treatment decision. To make this task more specific, the user has the ability to click on the 'indicate what you think is important' button. The next screen enables the user to fill in their preferences on ten categories considering the quality of life.



Click on the button, to log out and return to the log in screen.



Click on the button, to go to the personal information.



Click on the button, to go to the general information.



Click on the button, to go to the prediction models.



Click on the button, to go to the quality of life categories.



Figure 4.8. Quality of life screen of the IPD web application of the patient portal



### Scoring quality of life

The scoring the quality of life screen (figure 4.9) enables the user to shift the circles along the bars to indicate how important this specific category about quality for life is for them. Ten categories were listed. These categories emerged out of the existing questionnaire which is used by IKNL to let patients fill in retrospectively their experience of their quality of life after a specific treatment option. If the category is not clear, an explanation screen can be called by clicking on the button of the category. The score that is ranked by the user for each category will be pushed to the portal of the oncologist. In this way, the oncologist receives valuable information about the preferences and interests of the patient before the consultation takes place, to choose a definitive treatment option.

- 1 
- 2 
- 3 
- 4 

Click on the button, to log out and return to the log in screen.

Click on the button, to go to the personal information.

Click on the button, to go to the general information.

Click on the button, to go to the prediction models.

- 5 
- 6 
- 7 

Click on the button, to go back to the quality of life introduction

Click on the button, to go to more information about the category

Click on the circle, then drag to place the circle to wished position



Figure 4.9. Scoring quality of life screen of the IPD web application of the patient portal

## Explanation of the categories

The explanation of the categories screen (figure 4.10) allows the user to find more information about one specific category when pressed on the button. A blue box appears on the screen with the extra information. Along with a brief explanation, some examples are shown to indicate to the user how the category should be ranked. By clicking the 'close' button, the blue box disappears, and put the user back in the scoring of quality of life screen.



Click on the button, to log out and return to the log in screen.



Click on the button, to go to the personal information.



Click on the button, to go to the general information.



Click on the button, to go to the prediction models.



Click on the button, to go back to the scoring quality of life categories.



Figure 4.10. Explanation of the category screen of the IPD web application of the patient portal

### To treat or not to treat

The treat or not to treat screen (figure 4.11) is the main screen of the prediction information for the patient and provides the user with a small description about what to expect when clicked on 'to the numbers' button. Within the description, a typical sentence is used to communicate to the user how the numerical information should be interpreted according to the principles of risk communication.

The decision was made to only provide the life expectancy prediction information of IKNL for the patient, although more types of prediction information are available. When talking about adjuvant chemotherapy, healing is still possible in most cases. Actual quality of life predictions are, according to the oncologist and the researcher, not of the same nuance when it comes to making a decision, and therefore not presented to the patient. When healing is not possible anymore (palliative care), then a life 'expectancy - quality of life' consideration is well desired.



Click on the button, to log out and return to the log in screen.



Click on the button, to go to the personal information.



Click on the button, to go to the general information.



Click on the button, to go to the quality of life.



Click on the button, to go to the numerical prediction information.



Figure 4.11. To treat or not to treat screen of the IPD web application of the patient portal

## 2-year prediction

The 2-year prediction screen (figure 4.12) provides the user with the semi-personalized life expectancy prediction after 2 years. In the bottom part of the middle area, the user has the ability to switch to 'after 5 years' and 'after 10 years' prediction. By pressing the 'back' button, the user goes back to the main screen of the prediction information with the small description.

The visual in the middle area shows, in this case, the life expectancy based on a group of 1578 patients. 596 patients did not receive any treatment, while 982 patients did. After 2 year, 81% of the treated patients were still alive, 75% of the untreated patients were still alive. By presenting these figures, the patient obtains insights an what he or she is going to decide about and what the consequences might be. Still this is a prediction based on other patients, therefore the outcome is not guaranteed.

The working principle of the 'after 5 years' (figure 4.13) and 'after 10 years' (figure 4.14) screens are the same. Only the figures changes within the user interface of the IPD.



Click on the button, to log out and return to the log in screen.



Click on the button, to go to the personal information.



Click on the button, to go to the general information.



Click on the button, to go to the quality of life.



Click on the button, to go back to the description.



Click on the button, to go to the 5-years prediction



Click on the button, to go to the 10-years prediction.



Figure 4.12. 2-year prediction screen of the IPD web application of the patient portal

The decision was made to provide the semi-personalized prediction information to the patient through the IPD. There are a couple of reasons why this decision has been made to present this 'general information' instead of the possible personalized information;

1. By presenting, more or less, general prediction information, based on gender, age and year of diagnose, the patients' pTNM value is left untreated. A minor error in entering this value may lead totally different results which may unnecessarily worry the patient. Because the pTNM is a clinical value which is understood by the physicians and not by the patients, they do not know the difference in certain values.

2. The physicians, think it is very unwise to provide the patient with accurate personalised prediction information, without the presence of a physician who is able to provide proper explanations and to answer questions. As a compromise, the general prediction information is provided for the patient, to get familiar with the way in which the information is presented. When the more accurate prediction information is shown by the oncologist, this will be understood more quickly.
3. Standard models can be created by IKNL, which are pushed to the patient. No big real-time calculations are needed, and therefore the patient portal is independently working of high-speed internet connections.



Figure 4.13. 5-year prediction screen of the IPD web application of the patient portal



Figure 4.14. 10-year prediction screen of the IPD web application of the patient portal

## Oncological surgeon portal

This portal was built specifically for the oncological surgeon. The purpose of this portal is to invite patients to the IPD. During the consultation, when the results of the surgery examinations are presented to the patient. The patient is informed, by the oncological surgeon, of the existence of the IPD. The patient only receives an invitation if positive glands were found and adjuvant chemotherapy is suggested. The flowchart of the oncological surgeon portal exists out of the log in screen and the main menu, therefore it is not presented. The main menu screen (figure 4.15) is basically a list of patients. Some general information is presented about the patient, along with the options which have been described before. The search bar allows the user to search for a patient when needed.

The decision was made to keep the oncological surgeon portal as small as possible to be as less invasive as possible for the oncological surgeons' work activities.



Click on the button, to log out and return to the log in screen.



Click in the bar, and type within the bar.



Click on the button, to send an invitation.



Click in the bar, and type within the bar to search a patient.



Click on the button, to search for the patient after typing.

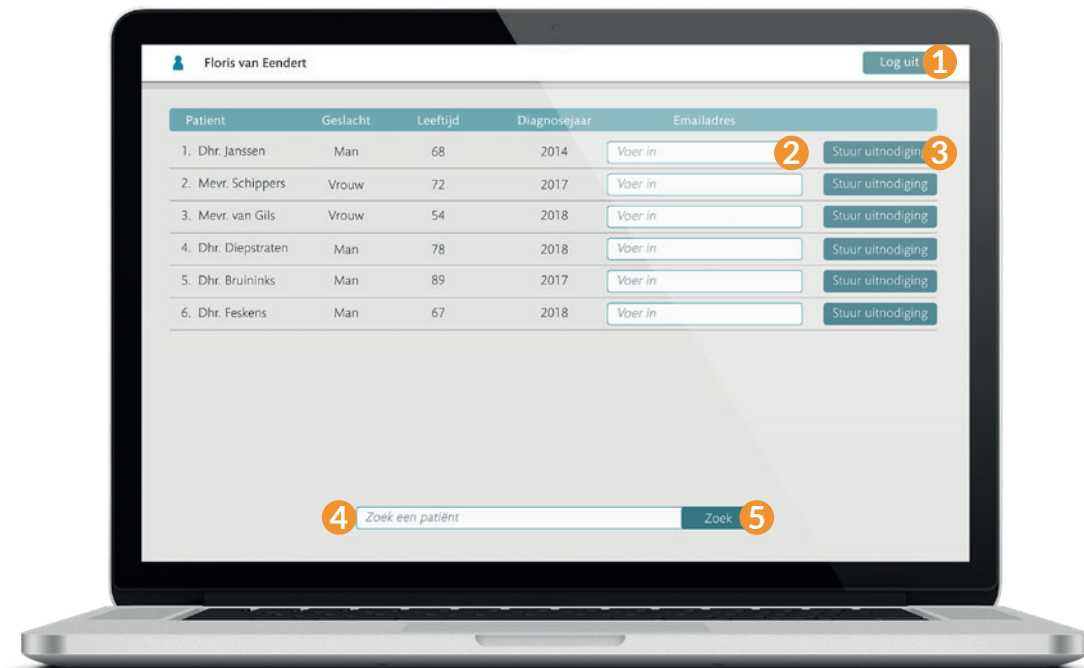


Figure 4.15. The main menu screen of the IPD web application of the oncological surgeon portal

## Oncologist portal

This portal was built specifically for the oncologist. Within this portal the oncologist has the ability to enter the patients' pTNM value into the IPD. By going to the prediction screen, an overview of the patients' score of the quality of life categories, and a life expectancy prediction, based on the pTNM, is presented to the oncologist. With this overview, the oncologist has all the information

which is needed to suggest the best treatment option for that specific patient during the consultation. During the consultation the more precise life expectancy prediction is shared

with the patient, which will be the beginning of the SDM process, resulting in a final treatment decision. The flowchart of the oncologist portal is shown in figure 4.16.

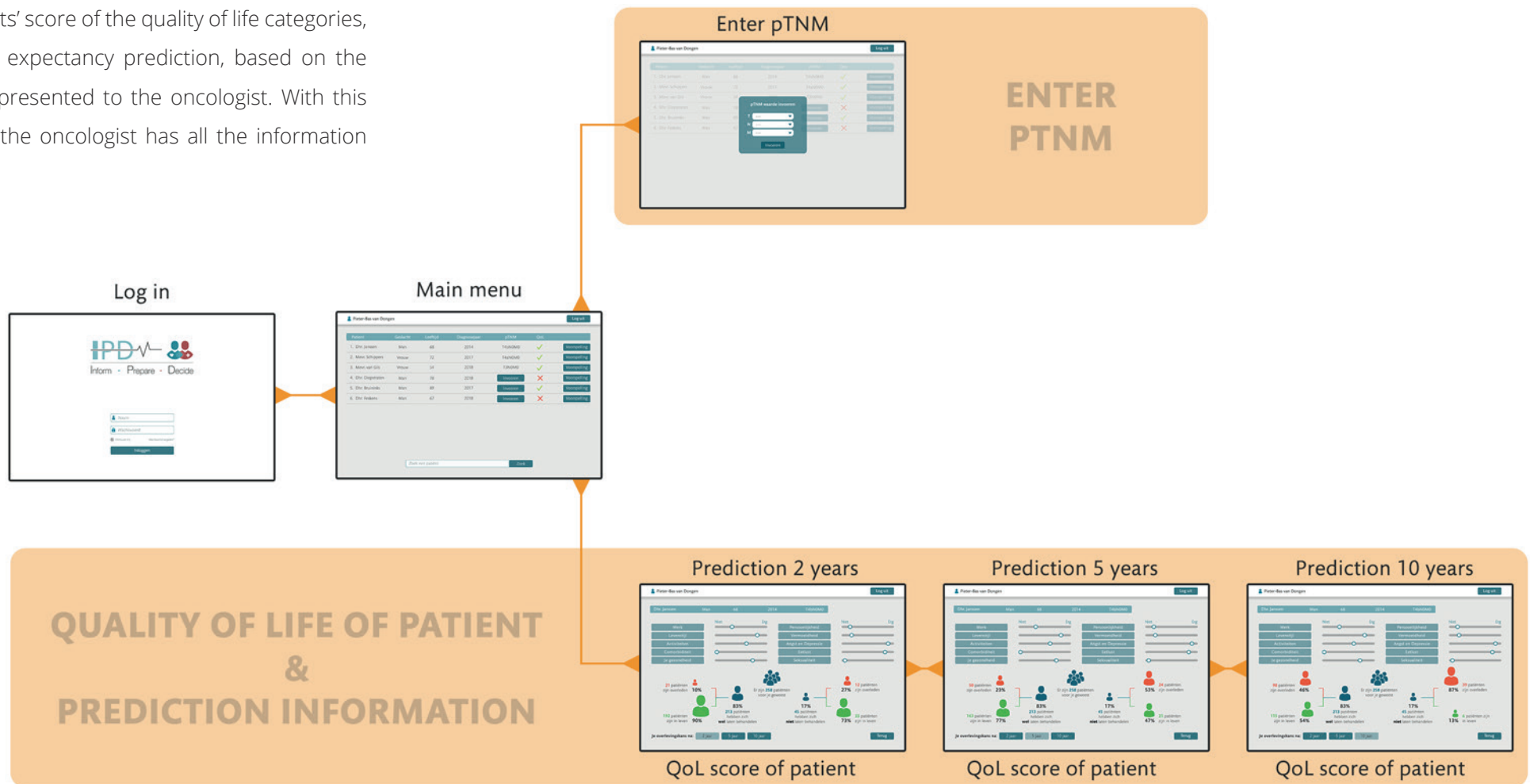


Figure 4.16. The flowchart of the oncologist portal

## Main menu

The main menu screen (figure 4.17) is a list of patients, besides the personal information which is presented, on the right side of the beam two options are available for the oncologist. The first option is to enter the patients' pTNM value on which the prediction is based. Secondly, by pressing the 'prediction' button, the oncologist is sent to the accurate personal prediction screen. The search bar allows the user to search for a patient when needed.

Between the two action options, feedback is provided to the oncologist if the patient has entered their quality of life score. The green 'V' is visible when that patient has filled in the score. The red 'X' is shown when the patient has not filled in the score yet.



Click on the button, to log out and return to the log in screen.



Click on the button, to enter the patients' pTNM.



Click on the button, to go to the prediction screen.



Click in the bar, and type within the bar to search a patient.



Click on the button, to search for the patient after typing.

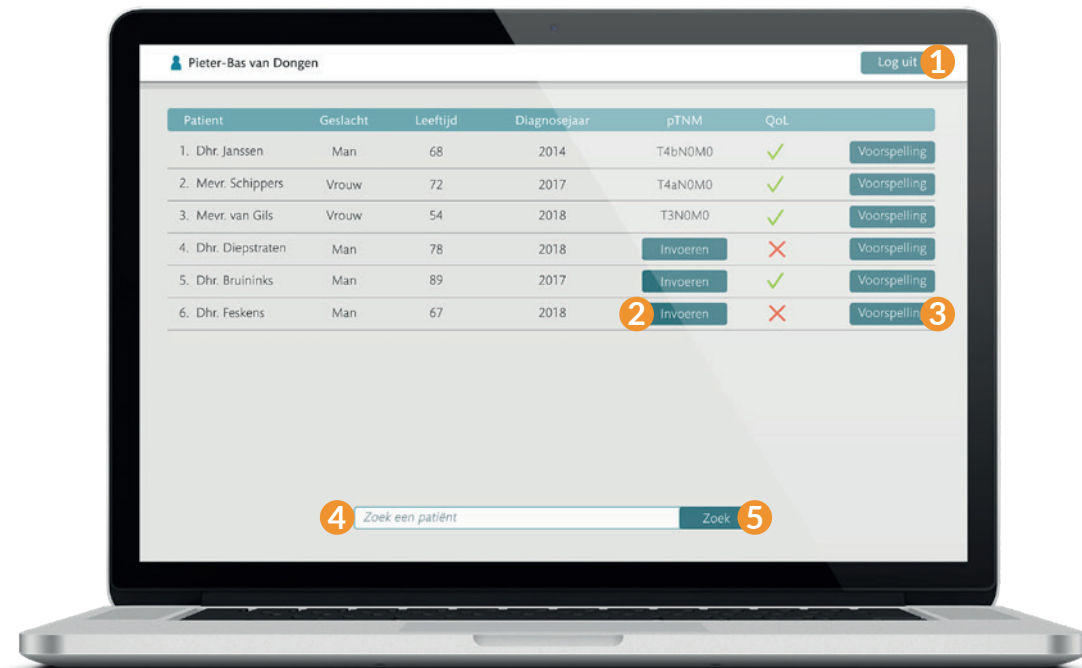


Figure 4.17. The main menu screen of the IPD web application of the oncologist portal



## Entering pTNM

The entering pTNM screen (figure 4.18) allows the oncologist to enter the specific pTNM value of the patient. Each beam stands for one of the T, N or M value. By clicking on the triangles, a dropdown menu appears with the possible values that can be entered. After all three values have been filled in, the oncologist can click the 'enter' button. When 'enter' has been pressed, the user is sent back to the main menu. The changed pTNM value is noticeable behind the patients' name.



Click on the button, to log out and return to the log in screen.



Click on the button, to enter the drop-down menu, then click again on the wished option.



Click on the button, to go to back to the main menu screen.

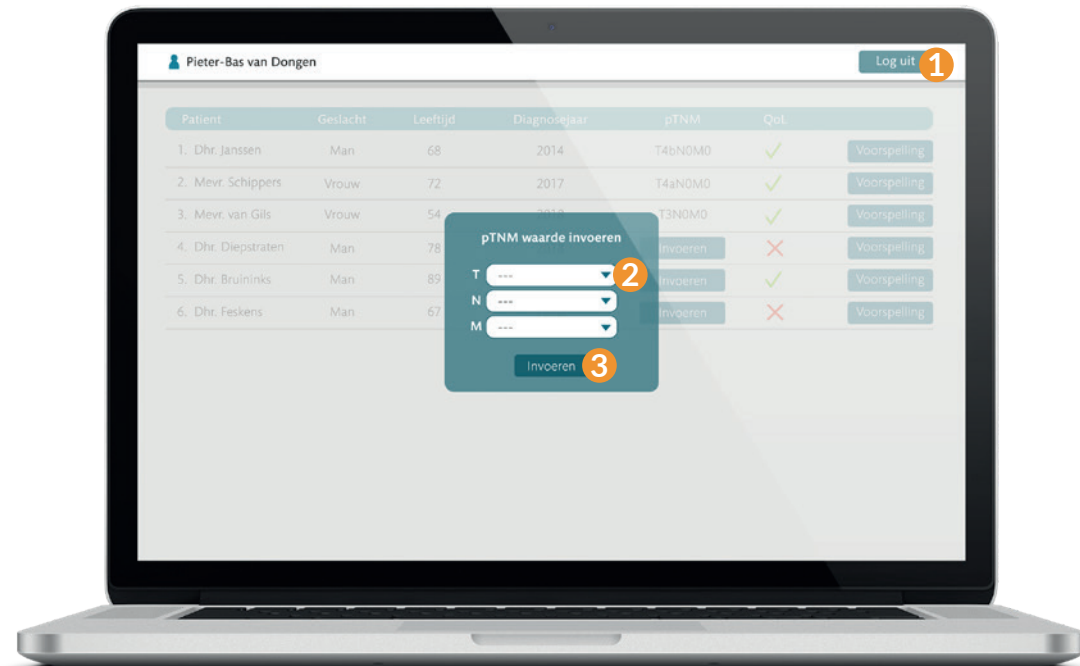


Figure 4.18. The entering pTNM screen of the IPD web application of the oncologist portal

### Accurate personal 2-year prediction

The 2-year prediction screen (figure 4.19) provides the user with the accurate personalized life expectancy prediction after 2 years, in the bottom part of the user interface. The graphical presentation is similar to the patient's portal.

By presenting these figures, the oncologist obtains insights, about what the best treatment option might be for this patient. Still, this is a prediction based on other patients, therefore the outcome is not guaranteed. Besides the graphical presentation of the prediction information, the oncologist sees the scored categories of the quality of life, filled in by the patient. Combining this information with the prediction information and the expertise of the oncologist, provides everything needed to make the best treatment suggestion for the patient.

The working principle of the 'after 5 years' (figure 4.20) and 'after 10 years' (figure 4.21) screens are the same. Only the figures changes within the user interface of the IPD.

When the consultation starts, this screen will also be used with the values to show this to the patient as a tool to support the final decision-making conversation.



Click on the button, to log out and return to the log in screen.

Click on the button, to go to the 5-years prediction

Click on the button, to go to the 10-years prediction.

Click on the button, to go back to the main menu



Figure 4.19. The 2-years prediction screen of the IPD web application of the oncologist portal



Figure 4.20. The 5-years prediction screen of the IPD web application of the oncologist portal



Figure 4.21. The 5-years prediction screen of the IPD web application of the oncologist portal



### **Patient with colon cancer**

With the help of the IPD web application, colon cancer patients are triggered to become more actively involved in the current decisions-making process concerning adjuvant chemotherapy, turning the treatment decision into a shared treatment decision. When patients become more actively involved, it does not mean that the final treatment option may change, but it does give the patient control of the decisions concerning their own body. Ideally, it will ensure that they see the doctor as more equal, whom is open to discussion instead of being an authority. All these separate components contribute to better care, resulting in a better quality of life, despite the terrible disease they are dealing with.



## **Oncological surgeon & Oncologist**

With the help of the IPD web application, physicians are provided with valuable information from and about the patients' side. With this obtained information a more personal suggested treatment option can be presented by the physician to the patient. Working with patients whom are more involved in their own case, and prepared before coming to the consultation to make the final treatment decision, is desired by the physicians. The IPD has the potential to contribute to all of these interests. However, if the IPD is accepted by the world of healthcare. By meeting these points of interest, the outcome of the treatment option will hopefully be perceived as better, leading to better care.

## 4.2 IMPLEMENTATION



The final design is an advanced concept in terms of implementation. This section provides an overview of the different elements which are dependent of the feasibility of the IPD divided into two parts. The first part is about several elements that need to be taken care of before the IPD can be operational. The second part provides insights on how the IPD, which is created on a micro level, can be projected on a meso level, and therefore on the entire database of all types of cancer of IKNL.

### Substantive text

The text which is implemented in the IPD, is partially created by the designer, and partially from existing sources. Because there is a close cooperation between IKNL and Kanker.nl it is suggested to screen the information through a communicative expert from Kanker.nl before the application is launched. When creating the text for the application, to reach as many patients as possible without the invite of a physician, the principles of search engine optimisation (SEO) should be applied.

### Calculation model for the figures

From IKNL, a clinical data scientist is needed to built the calculation model for the prediction

information, which is provided to patient and physician. As mentioned before, real-time calculations are not necessary in the current design of the patient portal of the IPD. However, at the oncologists' side, this is desired.

### Various collaborations

To make the IPD a success, various stakeholders needs to be involved. Besides IKNL and Kanker.nl, the physicians and patients must be willing to work with this application. When there is no demand for the IPD, the feasibility is unrealistic.

### Application management

To create the application, an application creator and manager are necessary. With the provided flowcharts and interaction usage explanation,

the web application could be built. When the first full functioning version is created, the application manager is able to perform iterative optimizations based on user experience.

### Providing data concerning privacy law

By implementing the IPD in the current care path of the patient, and because no clinical values are leaving the hospital, the privacy legislation should be of no concern in the current design of the IPD. When an upgraded version is created where the patient is being able to fill in the pTNM by themselves, it becomes a different case, and should be checked according the privacy legislation.

## From micro to meso

From the beginning of the project it was known that IKNL is searching for the best way to use their numerical information to help patients during their care path. For this project, it is zoomed in on colon cancer patients concerning adjuvant chemotherapy, the discussed micro level. The creation of the IPD was not just performed for this micro level, but also for the macro level. The framework behind the application can be projected on other types of cancer as well.

By creating different modules in the conceptualisation phase, separate frameworks arose which can be combined to create the applicable application for each situation. In the final design phase, it is shown how these different modules can take shape into an actual web application.

In the future, more modules can be built with other types of predictive information to provide insights to patient and physician within their care

path. A good example was already mentioned in the final design phase about palliative care. The expected quality of life can be shown to patients to make them question themselves if chemotherapy is the right option for them. Figure 4.22 shows how this prediction of quality of life could look

like when applied on the patients' portal of the current IPD. The coloured balls are the average score of patients who have been before you. In this way, you can estimate how bad you have to admit to the different categories of quality of life, with regard to choosing a treatment option.

René van der Poel Log uit

Schuif het bolletje langs de balk om aan te geven hoe **belangrijk** je de categorie vindt. Weet je niet wat de categorie inhoudt? Klik op de categorie waar je meer informatie over wilt hebben.

Categorie	Rating (Niet to Erg)
Werk	~10%
Levensstijl	~40%
Activiteiten	~30%
Comorbiditeit	~10%
Je gezondheid	~30%
Persoonlijkheid	~10%
Vermoeidheid	~70%
Angst en Depressie	~80%
Eetlust	~40%
Seksualiteit	~10%

Terug

Persoonlijke gegevens | Algemene informatie | Kwaliteit van leven | Wel of niet behandelen

Figure 4.22. The possible quality of life prediction screen of the IPD web application

## 4.3 CONCLUSIONS



In the introduction of this master thesis, the starting point was described in the introduction. With this starting point, a main research question was defined, along with three sub questions. In this part of the report answers will be given to the research questions. Besides the answers to the questions, other main conclusions will also be described.

### **How to equip patients and physicians to make an informed shared decision?**

#### ***What information is needed to make an informed decision?***

The information needed for patient and physician to make an informed shared decision, is obviously divided into two parts. The patient wants to have general information about what adjuvant chemotherapy contains, and what the treatment ultimately yields. What the treatment ultimately yields, can be described by the life expectancy prediction information provided by IKNL in an understandable way. Although this information provides the patient with the insights needed to choose if they want to be treated or not, they also want to know what it will cost them, in terms of quality of life. Because healing is still a possibility

concerning adjuvant chemotherapy, the decision was made to not provide the prediction information about quality of life, because these equations do not have the right nuance. When talking about palliative care, these equations do apply. Instead, categories concerning quality of life, where provided to the patient to trigger them to think about their own quality of life and their preferences. The information about what the treatment might cost them is taken care of by the treating physicians, as was desired.

The physician needs to know his/her patient to provide the right care. Knowing the patient is a difficult thing to achieve, because of the short 15-min consultations. By providing a platform on which the patient can share his/her thoughts about their quality of life, the physician is provided with the information needed. Therewithal, the

numerical prediction information, based on the patients' pTNM, provides the physician with all insights necessary to propose the right treatment option for a specific patient.

Most important, as the literature describes, is that both parties are aware of the same information, and understand this information, in order to make a shared informed decision.

#### ***How can the information be made understandable for the patients and physicians?***

Information can be made understandable by using the 'right language' the patient and physician speak. In practice, this is more difficult. Every patient and physician are different and speaks therefore another 'language'. To make each individual understand the same amount of information, for this project, the principles of risk communication, described by Spiegelhalter, Pearson & Short (2011), were applied. This resulted in a user interface with simple text and multiple visuals. After testing, the way the



user interface presented the different types of information, was found sufficient by the multiple participants.

### ***How can the information be transferred in a user-friendly way?***

The nature of the user interface design of the IPD, shows a user-friendly way, which was obtained through multiple iteration steps. The most important issues that needed to be considered during this project were; navigation, font size, usability and the meaning of colour. Again, by performing multiple iteration steps, the IPD evolved to a point by which all participants could work with, and understand, the user interface of the application.

### ***Conclusions to design for healthcare***

During this project multiple obstacles were encountered. These encounters were solved as good as possible by the researcher, leading to two important conclusions;

1. Each patient is a person with their own norms and values and different wishes. Even in the

exact same case and the same prediction of life expectancy, patients still make different decisions.

2. Potential patients, do not act and think the same way as an actual patient does. When confronted with a question about 'to treat or not to treat', potential patients approach this in a sober way and try to solve this question systematically. When actual patients are confronted with the same question, emotions rise and other things matter to them. One thing rises above all, the will to survive.

### **How to equip patients and physicians to make an informed shared decision?**

When the case is about colon cancer patients concerning adjuvant chemotherapy, by implementing the IPD of course.

## 4.4 RECOMMENDATIONS



To give structure to the recommendations, the different phases of the master thesis were used to describe the recommendations.

### Discover

During the literature research the decision was made to focus on the three elements of patient, physician and information provision. The assumption was made that the changing role of the patient and physician was caused by this information provision. In reality, more elements influence this change. Therefore, it is recommended that more literature research should be done to capture more points of influence and broaden the theoretical framework.

During the user research, most of the observations were performed at one hospital, and the patients that were interviewed were all treated also at the same hospital. Therefore, the results were useful for the project, but not representable for colon cancer patients in the Netherlands. It is suggested to perform more observations and interviews at different hospitals in the Netherlands.

### Define

During the design exploration, only five participators were analysed. To obtain a better result in the analysis, more participators should have been researched. Therefore, it is suggested to do more research to other participators to learn and strengthen the position of the IPD.

During the design direction, only the most common ways of communicative options have been used in the consideration of the design direction. Added to that, only a few resources were tested. To identify the best opportunities for design, the different options and resources needs to be increased. Therefore, this analysis is suggested to perform again with more resources and options.

### Develop

During the concept iterations, patients had little influence. Also, the participants that were used, were of a small number and therefore, the concept could have been stronger if more participants were used during these iteration steps, especially patients and physicians. It is recommended to discuss the concept with more patients and physicians, so that the concept will be optimized for the end users. The same applies to the user tests with the prototype.

## Evaluate – Final design

As mentioned in the implementation, before the IPD can be made fully functional, a couple of steps are still needed. It is recommended to execute these steps to have a functioning application which can be of use for many patients and physicians.

The design was created on a micro level, and a suggestion was given on how to apply this for the meso level. However, this is a theoretical approach and needs practical execution to see if the translation is possible.

The final recommendation, is the last bullet point of a list that was put together by Spiegelhalter, Pearson & Short (2011); 'Most important, assess the needs of the audience, experiment, and test and iterate toward a final design'.



# 5.8

- 5.1 References
- 5.2 Appendices

# SOURCES

## 5.1 REFERENCES

American Cancer Society. (2018, February 21). Chemotherapy for Colorectal Cancer. Retrieved June 18, 2018, from <https://www.cancer.org/cancer/colon-rectal-cancer/treating/chemotherapy.html>

American Cancer Society1. (2018, February 21). Surgery for Colon Cancer. Retrieved June 18, 2018, from <https://www.cancer.org/cancer/colon-rectal-cancer/treating/chemotherapy.html>

American Cancer Society2. (2018, February 18). Colorectal Cancer Stages. Retrieved June 18, 2018, from <https://www.cancer.org/cancer/colon-rectal-cancer/detection-diagnosis-staging/staged.html>

Aujoulat, I., d'Hoore, W., Deccache, A. (2007). Patient Empowerment in theory and practice: Polysemy or cacophony? *Patient Education and Counseling*, 66: 13-20. Advanced online publication. DOI: 10.1016/j.pec.2006.09.008

BMA. (2018, April 20). Patient empowerment

and self-care. Retrieved July 14, 2018, from <https://www.bma.org.uk/advice/employment/gp-practices/quality-first/patient-empowerment>

British Medical Association. (2017). The changing face of medicine and the role of doctors in the future. Retrieved from <https://www.bma.org.uk/-/media/files/pdfs/collective%20voice/policy%20research/education%20and%20training/the-changing-face-of-medicine-june-2017.pdf?la=en>

Calman, K.C. (1984). Quality of life in cancer patients: An hypothesis. *Journal of Medical Ethics* 1984;10:124-127. Advanced online publication. <http://dx.doi.org/10.1136/jme.10.3.124>

Car, J., Colledge, A., Donnelly, A., Majeed, A. (2008). Health information for patients: time to look beyond patient information leaflets. *Journal of the royal society of medicine*. Advance online publication. DOI: 10.1258/jrsm.2008.080149

Cassel, C.K., Reuben, D.R. (2011). Specialization, Subspecialization, and Subsubspecialization

in Internal Medicine. *New England Journal of Medicine*. Advanced online publication. DOI: 10.1056/NEJMs1012647

Centraal Bureau voor de Statistiek. (2017, December 28). Overledenen; belangrijke doodsoorzaken (korte lijst), leeftijd, geslacht [Dataset]. Retrieved January 4, 2018, from [http://statline.cbs.nl/statweb/publication/?vw=t&dm=slnl&pa=7052\\_95&d1=0-1,7,34,42,49,63,71,79&d2=a&d3=0&d4=\(1-2\)-1&hd=080703-1543&hdr=t&stb=g2,g1,g3](http://statline.cbs.nl/statweb/publication/?vw=t&dm=slnl&pa=7052_95&d1=0-1,7,34,42,49,63,71,79&d2=a&d3=0&d4=(1-2)-1&hd=080703-1543&hdr=t&stb=g2,g1,g3)

Damman, O., VUmc, & RISC. (n.d.). Risk Communication [College-slides]. Retrieved August 5, 2018, from <http://www.emgo.nl/team/1102/olgadaman/presentations/>

Degner, L.F., Sloan, J.A. (1992). Decision making during serious illness: what role do patients really want to play. *J Clin Epidemiol*, 45(9), 941-950. Advance online publication, from [https://www.jclinepi.com/article/0895-4356\(92\)90110-9/pdf](https://www.jclinepi.com/article/0895-4356(92)90110-9/pdf)

Edge, S. B., & Compton, C. C. (2010, February 24). The American Joint Committee on Cancer: the 7th Edition of the AJCC Cancer Staging Manual and the Future of TNM. Retrieved June 18, 2018, from <https://link.springer.com/content/pdf/10.1245%2Fs10434-010-0985-4.pdf>

Edge, S. B., & Compton, C. C. (2010, February 24). The American Joint Committee on Cancer: the 7th Edition of the AJCC Cancer Staging Manual and the Future of TNM. Retrieved June 18, 2018, from <https://link.springer.com/content/pdf/10.1245%2Fs10434-010-0985-4.pdf>

Edwards, A. (2004, June 2). Flexible rather than standardised approaches to communicating risks in health care. Retrieved July 19, 2018, from <https://qualitysafety.bmj.com/content/13/3/169>

Epstein, R.M., Korones, D.N., Quill, T.E. (2010). Withholding Information from Patients – When Less is More. *New England Journal of Medicine*. Advanced online publication. DOI: 10.1056/NEJMp0911835

Fernandez-Luque, L., Karlsen, R., Bonander, J. (2011). Review of Extracting Information from the Social Web for Health Personalization. *Journal of Medical Internet Research*. Advanced online publication. DOI: 10.2196/jmir.1432

Ik heb buikklachten, is dit darmkanker? (n.d.). Retrieved March 28, 2018, from <https://www.stopdarmkanker.nl/darmkanker/ik-heb-buikklachten-is-dit-darmkanker/>

IKNL. (2014, April 16). Adjuvante chemotherapie coloncarcinoom. Retrieved June 18, 2018, from [https://www.oncoline.nl/index.php?pagina=/richtlijn/item/pagina.php&id=37117&richtlijn\\_id=933](https://www.oncoline.nl/index.php?pagina=/richtlijn/item/pagina.php&id=37117&richtlijn_id=933)

IKNL. (2017, February 2). Incidence | All tumors; Rural; Man Woman; Invasive [Dataset]. Retrieved January 9, 2018, from [http://www.cijfersoverkanker.nl/selecties/Dataset\\_1/img5a551ea812e75](http://www.cijfersoverkanker.nl/selecties/Dataset_1/img5a551ea812e75)

IKNL. (n.d.). multidisciplinair overleg. Retrieved

June 11, 2018, from <https://www.iknl.nl/oncologische-zorg/diensten/multidisciplinair-overleg>

IKNL. (n.d.). Retrieved December 27, 2017, from <https://www.iknl.nl/over-iknl/about-iknl>

IKNL. (n.d.). Retrieved January 4, 2018, from <http://iknl.nl/>

Janse, A.J., Gemke, R.J.B.J., Uiterwaal, C.S.P.M., van der Tweel, I., Kimpen, J.L.L., Sinnema, G. (2003) Quality of life: patients and doctors don't always agree: a meta-analysis. *Journal of Clinical Epidemiology*. 57 (2004) 653-661. Advanced online publication. DOI: 10.1016/j.jclinepi.2003.11.013

Kaba, R., Sooriakumaran, P. (2007). The evolution of doctor-patient relationship. *International journal of surgery*. Advance online publication. DOI: <https://doi.org/10.1016/j.ijsu.2006.01.005>

Kanker.nl. (2015, July). Stadium-indeling bij

dikke darm kanker. Retrieved March 29, 2018, from <https://www.kanker.nl/bibliotheek/dikkedarmkanker/onderzoek-en-diagnose/19-stadium-indeling-bij-dikkedarmkanker>

King, J. S., Eckman, M. H., & Moulton, B. W. (2011). The Potential of Shared Decision Making to Reduce Health Disparities. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/21309892>

KWF, & Kanker.nl. (2018, March). Dikke darm kanker. Retrieved June 15, 2018, from <https://www.kanker.nl/bibliotheek/dikkedarmkanker/wat-is/2-dikkedarmkanker>

KWF. (2016, December). Soorten chemotherapie. Retrieved June 18, 2018, from <https://www.kanker.nl/bibliotheek/chemotherapie/behandeling/9927-soorten-chemotherapie>

Makoul, G., Clayman, M.L. (2005). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(2006)301-312. Advanced online publication. DOI: 10.1016/j.pec.2005.06.010

Markovitch, S., & Willmott, P. (2014, May). Accelerating the digitization of business processes. Retrieved July 19, 2018, from <https://www.mckinsey.com/business-functions/digital-mckinsey/our-insights/accelerating-the-digitization-of-business-processes>

Minister van Volksgezondheid, Welzijn en Sport. (2018). Ontwikkeling Uitkomstgerichte zorg. Retrieved from <https://www.rijksoverheid.nl/regering/bewindspersonen/bruno-bruins/documenten/rapporten/2018/07/02/ontwikkeling-uitkomstgerichte-zorg-2018-2022>

Minister voor Medische Zorg, B. B. (2018, July 2). Uitkomstgerichte zorg 2018-2022 [Letter to De voorzitter van de Tweede kamer der Staten-Generaal].

Närhi, U. (2007). Sources of medicine information and their reliability evaluated By medicine users. *Pharm World Sci*, 29:688-694. Advanced online publication. DOI: 10.1007/s11096-007-9131-1

NRC Health. (2017, May 12). The Impact of Improved Patient Experiences. Retrieved July 23, 2018, from <https://nrchealth.com/impact-improved-patient-experiences/>

Oncoguide. (n.d.). Retrieved January 4, 2018, from <https://www.oncoguide.nl/#!/guidelines>

Ortiz, E., Clancy, M.C. (2003). Use of information Technology to improve the Quality of Health Care in the United States. *Health Services Research*. Advanced online publication. DOI: 10.1111/1475-6773.00127

Raghupathi, W., Raghupathi, V. (2014). Big data analytics in healthcare: promise and potential. *Health information Science and Systems*. Advanced online publication. DOI: 10.1186/2047-2501-2-3

Rijksinstituut voor Volksgezondheid en Milieu. (2018). Een gezond vooruitzicht. Retrieved from [https://www.rivm.nl/Documenten\\_en\\_publicaties/Wetenschappelijk/Rapporten/2018/](https://www.rivm.nl/Documenten_en_publicaties/Wetenschappelijk/Rapporten/2018/)



Juni/Volksgezondheid\_Toekomst\_Verkenning\_2018\_Een\_gezond\_vooruitzicht\_Synthese

RIVM. (n.d.). Bevolkingsonderzoek darmkanker. Retrieved March 29, 2018, from [https://www.rivm.nl/Onderwerpen/B/Bevolkingsonderzoek\\_darmkanker](https://www.rivm.nl/Onderwerpen/B/Bevolkingsonderzoek_darmkanker)

Sanderson, David & Busquets, Dídac & Pitt, Jeremy. (2012). A Micro-Meso-Macro Approach to Intelligent Transportation Systems. Proceedings - 2012 IEEE 6th International Conference on Self-Adaptive and Self-Organizing Systems Workshops, SASOW 2012. 77-82. 10.1109/SASOW.2012.22.

Say, R.E., Thomson, R. (2003). Challenges for doctors. The Importance of patient preferences in treatment decision. Advanced online publication. <https://doi.org/10.1136/bmj.327.7414.542>

Smulders, Y., & Metselaar, S. (2017, June 1). Direct inzage in epd niet in belang van patiënt. Retrieved July 14, 2018, from <https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/direct-inzage-in-epd-niet-in-belang-van-patient.htm>

nl/nieuws/laatste-nieuws/artikel/direct-inzage-in-epd-niet-in-belang-van-patient.htm

Spiegelhalter, D., Pearson, M., & Short, I. (2011). Visualizing uncertainty about the future. *Sciencemag*, 333(6048), 1391-1400. Retrieved from <http://science.sciencemag.org/content/333/6048/1393>

Srini Pillay, M. D. (2010, May 3). The dangers of Self Diagnosis. Retrieved January 15, 2018, from <https://www.psychologytoday.com/blog/debunking-myths-the-mind/201005/the-dangers-self-diagnosis>

Stiggelbout, A. M., Pieterse, A. H., & De Haes, J. C. J. M. (2015). Shared decision making: Concepts, evidence, and practice\$. Retrieved from <https://www.researchgate.net/publication/281818876>

Stiggelbout, A.M., Kiebert, G.M. (1997). A role for the sick role: Patient preferences regarding information and participation in clinical decision-making. *Can Med Assoc / 1997*; 157:383-9

Tan, S.S.L., Goonawardene, N. (2017). Internet Health Information Seeking and the PatientPhysician Relationship: A Systematic Review. *Journal of Medical Internet Research*. Advanced online publication. DOI: 10.2196/jmir.5729

Truog, R. D. (2012). Patients and Doctors - The evolution of a relationship. *The new England journal of medicine*, Med 2012(366), 581-585. DOI: 10.1056/NEJMp1110848

UICC. (2010). TNM-Classificatie en PTNM. Retrieved June 11, 2018, from [https://www.oncoline.nl/index.php?pagina=/richtlijn/item/pagina.php&id=37849&richtlijn\\_id=946](https://www.oncoline.nl/index.php?pagina=/richtlijn/item/pagina.php&id=37849&richtlijn_id=946)

Van Boeijen, A. G. C., Daalhuizen, J. J., Zijlstra, J. J. M., & Van der Schoor, R. S. A. (2013). *Delft Design Guide*. Amsterdam, Netherlands: BIS publishers.

Van Eenbergen, M. C. H. J. (2018, March 13th). Het ontsluiten van kankergetallen voor patiënten en naasten [pptx]. Retrieved from IKNL.

vbhc.nl. The Value Based Healthcare concept. 2018 [cited 2018 July 17]; Available from: <http://www.vbhc.nl/what-is-value-based-healthcare>.

VUmc. (n.d.). Missie, visie en kernwaarden. Retrieved June 11, 2018, from <https://www.vumc.nl/afdelingen/over-vumc/missie-visie-kernwaarden/>

Winters-Miner, L. A. (2014, October 6). Seven ways predictive analytics can improve healthcare. Retrieved July 19, 2018, from <https://www.elsevier.com/connect/seven-ways-predictive-analytics-can-improve-healthcare>

World Health Organization. (2009). WHO Guidelines on Hand Hygiene in Health Care: First Global Patient Safety Challenge Clean Care Is Safer Care. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK144022/>

## 5.2 APPENDICES

The appendices are available upon request.

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