# Personalising patient education for lung cancer patients

**Master Thesis**
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**Master thesis**
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*cover image: Freepik*

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# glossary

These are a list of words abbreviations used in this report.

ASH = Albert Schweitzer Hospital, (dutch) ASZ/Albert Schweitzer Ziekenhuis
CfL = Centre for Lung Cancer, (dutch) CvL/Centrum voor Longkanker
HCP = healtchare professional
MDC/MDT = multidisciplinary consultation/multidisciplinary team
SDM = shared decision making

# table of contents

# chapter one: introduction

An important aspect of care is for healthcare professionals (HCP) to provide patient education. This information is provided in many different formats: from books to videos or during a doctor appointment. There is a massive amount of patient education on the internet, also making information accessible to everyone. This information though is provided in a 'one-size-fits-all' approach (Dekkers & Hertroijs, 2018) where everyone receives relatively the same information and in the same manner even though they may have their preferences and needs as a patient.

There are two users in the process of patient education. The one receiving education, which could be the patient themselves or their support systems and also the one giving education, which are the healthcare professionals. This report focusses on patient education from the perspective of healthcare professionals as they are the experts in their field and in how patient education is given. They also know what goes on in the hospital and which processes and procedures take place. Having worked with many patients, they are able to describe their experience of working with them and know the patients from a different standpoint. Their input is important to first understand the current situation to define insights and opportunities. Therefore, the research question will be: "How and when can healthcare professionals personalise patient education to improve the patient journey?". To answer this question literature research was performed to understand the scope of this project. These topics are lung cancer and patient-centred care, which will be explained in chapter 2.

Patient education is for patients to become knowledgeable about their health so that they can participate in decision making and build skills for self-care (Dekkers et al., 2018). Shared decision making (SDM) is where healthcare professionals and patients can make medical decisions together which takes a patient's preferences and values into account (Bot et al., 2014). Different models describe the steps and characteristics of SDM, which has been researched (Elwyn et al., 2012; Wexler, 2013; Barry & Edgman-Levitan, 2012) and further detailed in chapter 2.2. These articles explain the role of HCPs and patients in the SDM process, as it turns patient education into a dialogue where HCPs provide information on the condition, treatment options, and outcome and patients can express their preferences and values. During this, HCPs guide and facilitate the process to empower patients. Power, as described by Joseph-Williams et al. (2014), is how patients perceive their capacity to influence decisions.

Different aspects influence power and knowledge. Knowledge can be influenced by a person's health literacy. Health literacy is defined by the World Health Organisation (2019) as, "the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health". A patient's knowledge is not only their capability to process the medical information, but also being able to form their thoughts on their preferences and values and express this to others. Using patient education information also entails their ability to build skills for self-care and in understanding what needs to be done to be healthy physically and mentally.

This project furthermore focusses on patient education for lung cancer patients at the Albert Schweitzer Hospital (ASH) which is described in chapter 3 and 4. Chapter 3 focusses on the set-up of the lung cancer department at ASH, which is the Centre for Lung Cancer, and how patient education is currently given. At the moment, patient education is mainly given in a standard format. By personalising it and taking personal preferences and values into account, this could improve a patient's knowledge and experience. Interviews were held with HCPs and observations of the consultation took place to analyse the current patient journey and process of patient education. This analysis is in chapter 4.

In other industries companies are personalising their products and service, turning the purchase of products and services into an experience. For example in retail, it's not just about offering a product to a consumer, but about the whole retail experience surrounding it. Offering customers a seamless experience from being able to browse products online or in physicals stores to switching from device to device is how consumers nowadays interact with brands. Brands keep in contact with their consumers by personalising e-mails with their name, offering special deals, showing relevant content based on user history, and in many other ways. Through personalisation, brands hope to improve their interaction with customers by meeting their needs efficiently and effectively and ultimately increasing their satisfaction.

This is also changing for healthcare. What used to be healthcare professionals (HCPs) mainly performing medical procedures, the focus is now on the patient and caring for the wellbeing of the patient. Services are shifting towards personalised experiences for customers to keep them engaged and this is something healthcare can also benefit from too. Personalised experiences in a hospital setting will allow HCPs to focus on a patient's health beyond medical procedures so they provide information based on patients' preferences and needs to improve health outcomes and care experiences.

Afterwards, in chapter 5 there is a summary of the analysis and the design challenge. Chapter 6 describes a personalised version of the patient portal, a tool that can be used to provide personalised education and a conclusion in Chapter 7 which will discuss further research that can be done.

# chapter two: project context

2.1 Lung cancer
2.2 Patient-centred care

This chapter describes the context of lung cancer and patient-centred care. The following topics about lung cancer are discussed: what it is, how it is in the Netherlands, self-care skills and trends. Patient-centred care is broken down into two main topics: shared decision making and personalisation. Literature is used to define these topics and to provide theoretical background information to support this research.

## 2.1 lung cancer

Lung cancer is when there is uncontrolled cell growth in the tissue of the lungs that turns into a tumour. About 80% of people that have lung cancer is because they smoke, but it can also be caused by exposure to factors such as radiation, toxic substances, second-hand smoking, pollution or caused by genetics in the family or other lung diseases. Symptoms of lung cancer are shortness of breath, coughing (up blood), chest pains when breathing deeply or coughing, tiredness and unexplained weight loss. These symptoms usually aren't noticeable until it has spread or not until later stages of cancer. They are also similar symptoms of other problems, such as infections or long-term effects of smoking, which may delay diagnosis. Therefore, lung cancer is usually detected in later stages where lung cancer has already spread. Some earlier cases of lung cancer are diagnosed due to the testing of other medical conditions.

There are two main types: small-cell lung cancer and non-small-cell lung cancer. The difference is that small-cell lung cancer has smaller lung cells than normal and it spreads faster throughout the body. About 20% of people with lung cancer have small-cell lung cancer where usually metastasis has already occurred upon diagnosis and is treated by chemotherapy and/or radiation. Non-small-cell lung cancer grows slowly and can be treated in several ways, such as an operation, chemotherapy, radiotherapy, and other treatments. If lung cancer is diagnosed in later stages sometimes the only option is palliative treatment, which is a treatment to prolong life by reducing pain, symptoms, and stress. Treatment is decided both with healthcare professionals and patients together, where they discuss the benefits and risks of treatment.

## Lung cancer in the Netherlands

Annually there are about 13,300 people that are diagnosed with lung cancer in the Netherlands. It is one of the most common types of cancers and the number one cause of death for cancer (IKNL, 2019), wherein 2017 10,390 people have passed away from lung cancer (CBS, 2019). According to NKR (2019), there are about 28,500 people in the Netherlands that had lung cancer on January 1, 2018. The amount of people that have lung cancer has been growing each year, with a strong increase of lung cancer in women in the past 15 years, but there are slightly more men than women that have lung cancer. This can be seen in figure 1. The increase in women with lung cancer is because of a large group of women that were smoking in the 60s, which later decreased in the 80s.

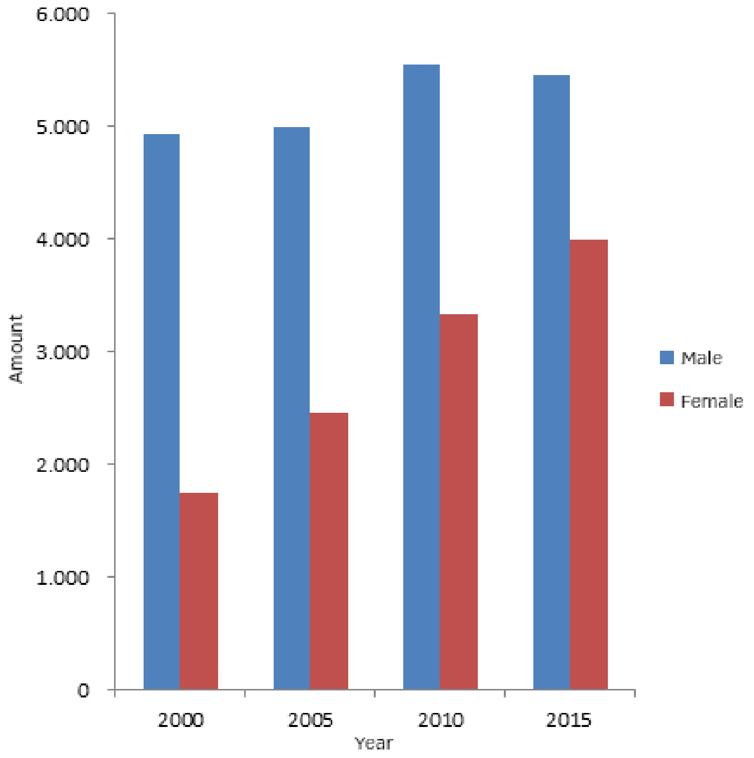


*Figure 1: New patients with non-small-cell lung cancer (kanker.nl, 2018)*

Lung cancer affects mainly elderly people and the largest group of diagnosed lung cancer patients are ages 70-74 years old. It rarely occurs that people are diagnosed with lung cancer under the age of 40, as most are above the age of 60. Since it takes time before lung cancer to grow and be diagnosed, about 50% are diagnosed at stage 4 where there is metastasis and cancer has spread to other parts of the body. About 25% of people with lung cancer are stage 1 and 2 (Longkanker Nederland, 2016). This means that for most patients an operation is not an option because cancer has spread too much. The chance of survival five years after diagnosis is 19% and this decreases to 11% after another five years. The percentages change depending on the type of lung cancer a person has, their condition and which stage it is. The later the stage of lung cancer and small-cell lung cancer have a lower rate of survival. Researchers are looking into how to detect and diagnose cancer earlier, with the possibility of using AI for example (NCI, 2018).

In the Netherlands, there are patient organisations and platforms that offer advice and support for lung cancer patients and their (surviving) relatives. The information they provide is for people to educate themselves on lung cancer, what they can expect and how they can build skills for self-care. Kanker.nl is a website that provides information on different types of lung cancer and an online platform where (ex) patients can share their experiences and come in contact with other patients. Longkanker Nederland is a patient organisation where people can find information about lung cancer and read and share experiences. They work towards improving care guidelines so that patients receive better care in hospitals and also participate in developing pamphlets and videos for lung cancer. KWF Kankerbestrijding is a foundation that finances and facilitates (lung) cancer research and provides information and support for patients.

For further support, there are guides where patients can compare hospitals and treatments. This can be through statistics and side by side comparisons. There are a few decision aids where lung cancer patients can fill in their preferences, to help them discuss with their doctor which treatment is better. There are questions such as: 'how important is it for you that there are no side-effects after treatment?' or 'how important is it for you to have certainty that the cancer is gone?'. Keuzehulp Longkanker is an online decision aid which was designed by the VU University Medical Center Amsterdam in 2015. Their research was done with a group of healthcare professionals and researchers that first discussed the comparison of the two treatments. The decision aid is only for the choice of an operation or stereotactic radiation therapy, which are treatments for non-small-cell lung cancer. These two methods of treatments were chosen because they were comparable and would be important for patients to discuss with their doctor if they were unsure. This research was subsidised by the KWF and also supported by Longkanker Nederland by bringing them in contact with patients and discussing with them together how to further develop the decision aid. There are also other companies, such as PATIENT+, that create decision aids for other organisations. This decision aid, which can be seen below in figure 2, is also for non-small-cell lung cancer treatments.

Wat is voor u belangrijk?

Voor longkanker zijn twee verschillende behandelingen mogelijk. In een overleg tussen longartsen, radiotherapeuten en verpleegkundigen wordt besproken voor welke behandelingen u in aanmerking komt. Dit hangt bijvoorbeeld af van de plek en grootte van de tumor, en of u nog andere ziektes heeft. U kunt hieronder aangeven wat u zelf belangrijk vindt. Samen met de uitkomst van het overleg komen u en uw arts tot een behandeling. Zet het schuifje bij uw mening. Als u het niet weet, laat het schuifje dan in het midden staan.

Bestraling: Ik wil niet een week in het ziekenhuis liggen.

Operatie: Ik vind het niet erg om 5-7 dagen in het ziekenhuis te liggen.

Bestraling: Ik vind het niet erg om 3 tot 5 keer naar het ziekenhuis te moeten voor een bestraling.

Operatie: Ik wil in één keer behandeld worden.

*Figure 2: PATIENT+ lung cancer decision aid*

## Self-care skills

An important part of prevention and managing lung cancer is self-care. Making small changes in one's lifestyle reduces the risk of cancer, possible complications during treatment and the time of recovery. Cancer Research UK (2018) and HealthiNation (2018) describe a list of self-care tips to prevent and fight cancer and ultimately how to keep your body in a healthy condition. First and foremost, it is important to not smoke or quit smoking. Lung cancer occurs in only about 10-15% of non-smokers and those that are diagnosed with cancer and quit smoking can improve their chances of survival by 30 to 40%. Smoking damages the health of lungs and heart, so continuing smoking may decrease the options there are for treatment.

The next self-care tip is to keep a healthy diet and weight. Keeping a balanced diet of fruits and vegetables and eating certain foods, such as apples and tomatoes, can help protect the lungs. Loss of appetite and weight loss are cancer symptoms which can cause malnutrition and make treatment less effective. Lastly, exercising regularly is important to keep the body in good condition. Especially for those that have lung cancer, making sure their body is in good condition will prepare them for treatment. Their body will: respond better to treatment, have a lower chance of complications and recover quicker. Regular exercising such as walking/running and biking are simple to do and there are also breathing exercises that patients learn to improve breathing. Patients that are educated in self-care participate more and have better health outcomes (Hasanour-Dehkordi, 2016). They can take responsibility and manage their health.

## Trends in healthcare

It is expected that the number of new cases of lung cancer will increase by 37% by 2040 in the Netherlands (Volksgezondheid, 2019). Cancer, in general, is also on the rise worldwide, mainly due to three factors (Bray et al., 2018). These factors that influence each other are growing world population, aging population and the deterioration of lifestyle. As more people are growing older, they have a higher risk of gene mutation which can cause cancer.

A change in demographics also means a change in patient behaviour and their view of healthcare. Lung cancer patients are from the Silent Generation (born in 1925-1940) and there are starting to become more Baby Boomers (born in 1940-1955). The Silent Generation tends to rely more on doctors and their expertise and want to be told what needs to be done, whereas Baby Boomers are more engaging with HCPs (Heath, 2016). Also because there is an increase in life expectancy, Baby Boomers are a generation where they are taking care of their parents and children and tend to have more health problems.

There is another shift in healthcare, the use of technology. From being able to search on your own for medical information to keeping track of your health, there has been an increase in the usage of mobile/tablet apps, electronic health records, social media, wearable technology, etc. Virtual medical services, also known as telehealth, are also becoming more popular, where patients can receive remote consultations and monitoring. Patients are seeing the advantages of using technology for healthcare and are increasingly becoming more interested in the possibilities and also sharing their information with HCPs. The use of technology in healthcare increases convenience, affordability, and quality. Younger generations are inclined to more untraditional methods of medical care in comparison to Baby Boomers and the Silent Generation. The Silent Generation and 91% Baby Boomers rely on professionals over digital devices for health monitoring in comparison to only 63% of Millennials that rely more on professionals (Accenture, 2019). Not only do consumers increasingly want to use technology to monitor their health, but HCPs also want to integrate digital tools into their practices to improve efficiency, safety and diagnostic ability (American Medical Association, 2016).

# 2.2 Patient-centred care

Constant advances are being made in the medical field, creating new techniques and tools. This leads to safer and more efficient procedures with improved outcomes, but also to a larger gap between physicians and patients and where they're left out of the decision-making process (Barry & Edgman-Levitan, 2012). Therefore a major trend in healthcare that can narrow the gap is patient-centred care, which is defined by the Health Innovation Network (2016) as "putting people and their families at the centre of decisions and seeing them as experts, working alongside professionals to get the best outcome". Patient-centred care will be further explained through the two topics of involving patients in the decision-making process and putting them at the centre of their treatment by focussing on their individual preferences and needs.

## Shared decision making

Shared decision making, as earlier described, is a process in which both healthcare professionals and patients are involved. There are numerous models and frameworks that describe the different step of shared decision making, but there are common elements throughout. As de Silva (2012) and Probst et al. (2017) describe, it is about having an informed, engaged and motivated patient. These elements will be further described using steps from these researchers and also Elwyn et al. (2012) and Wexler (2012).

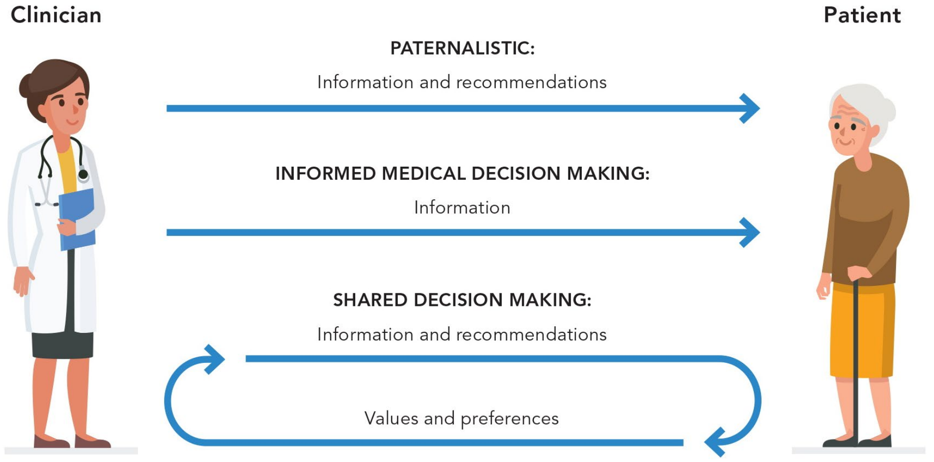


*Figure 3: Shared decision making vs. usual care (Schrager, Philips & Burnside, 2017)*

Informing a patient is about providing information and discussing this with patients. The information provided to patients is about: the issue, potential solutions and the benefit and risks of these options. Patients therefore need to be informed to understand and use the information given to them. HCPs are the expert in the medical field, there to guide a patient throughout the process, but a patient is also an expert in knowing what their preferences and needs are. Therefore patients need to be engaged in the discussion so that HCPs can understand what their goal and concerns are and can create and implement the treatment plan with them. Figure 3 shows the different between shared decision making and usual care and that information alone is not shared decision making. Involving the patient in this process motivates them to work towards the goal they've set themselves and takes into account their personal situation. Throughout this process HCPs and patients should evaluate to be able to continuously build on the treatment plan.

Through these steps, patients are to become more knowledgeable about their condition and the options they have for treatment. This allows them to engage with HCPS and become more involved in making decisions. Patients are more satisfied because they know and understand what to expect and feel confident with the knowledge they've achieved and can act upon it.

### *Barriers of shared decision making*

These guides and models may be harder to practice in reality as there are multiple barriers. One of the main barriers of shared decision making is that there is an insufficient amount of information provided to patients (Joseph-Williams, Elwyn & Edwards, 2014). SDM, in the context of cancer, definitely has room for improvement, as according to the NFK (2019) HCPs don't discuss: long term effects with about 35% of patients, what's important in their daily lives with about 45% of patients and future plans with about 55% of patients. Patients are reportedly more satisfied though when these topics are discussed. Results from their research also show that more than 80% of cancer patients want to decide about treatment together with HCPs. Professionals fail to invite and prepare patients for SDM though, which leads to different perceptions and expectations.

Another barrier is that patients have the perception that HCPs are the only experts in the decision-making process and don't feel capable of making decisions based on their knowledge. There are of course different levels of capability and willingness to participate in decision making, but that is something HCPs must discuss with patients. This may also be difficult as many professionals have not had training in interpersonal communication skills. Professionals do have (years of) experience in engaging with patients, but SDM takes information provision a step further where there is more communication between HCPs and patients. They therefore need to have a sense of who the patient is and how to best communicate with them, which leads to the next topic of personalisation.

## Personalisation

Patient education is information on patients' health condition, treatment and recovery (Shuldham, Fleming & Goodman, 2002) with the goal of patients becoming more knowledgeable about their condition to become a member of the decision-making team (Whyte & Grant, 2005). Though as earlier stated, this information is provided in a one-size-fits-all approach because it is efficient for HCPs to have a standard and organised method to their work, which includes educating patients. HCPs therefore give lung cancer patients a large amount of information about treatment and pre- and postoperative aspects. This can be overwhelming for patients, especially as the situation itself can already be stressful for patients. Therefore by providing patient education in a personalised manner, one that takes their preferences and needs into consideration, it can improve their health outcomes and care experience.

There are many different ways and aspects of patient education to personalise. The Five Ws and One H: Who, What, When, Where, Why and How, is used to describe the different aspects personalisation of patient education in the context of this project.

*For whom is patient education personalised & how can it be personalised?*

The who in this case are lung cancer patients. Each patient is different, whether it be how they go through treatment or respond to it. This could be their condition, how their body physically responds to treatment, how they mentally cope with and accept their situation, or their ability to understand and use the information. There are methods of profiling patients, based on different patient characteristics which describe similar behaviour and needs of a group of patients and how to provide care for them. Personalised care can be then provided according to the different patient groups. Patient profiles by Dekkers (2018) categorises patients on their clinical, psychological and communication characteristics to be able to provide tailored patient education. This research was done with total joint arthroplasty (TJA) patients for hip and knee replacement and resulted in three different profiles: managing, optimist and modest. Patients fill in a questionnaire which determines which profile they are.

The managing profile, which is the largest group of TJA patients, describes patients that have the lowest health and quality of life in comparison to the other groups. They have the highest communicative skills and needs which HCPs can cater to by facilitating SDM and providing extra information. They may have higher outcome expectations and when these aren't met, they are less satisfied. HCPs can manage patients' expectations to improve satisfaction. An optimistic patient does not have any strong preferences, have the highest health status and are satisfied, so the usual care works for them. What HCPs normally do is provide information and guidance in managing their condition. The third group is modest patients, which tend to be older patients with lower communication skills and a higher need for emotional support. Their lower communication skills may be a barrier to them understanding the information they receive and therefore make it difficult for them to be active during treatment. Personalised education can benefit modest patients to help them with this. By providing extra support emotionally and in building skills to communicate better, this may improve their care.

Another method of patient profiling was researched by Bloem & Stalpers (2016), which measure patients' level of control and acceptance. Control is described as how much a patient believes they're able to do to make an impact on their health. Acceptance is the level of being able to deal with the condition. By personalising care, they hope to improve the experience for patients. The model from Bloem & Stalpers for patient profiling is shown in figure 4. Patients with low control and acceptance are placed in quadrant four and are relatively passive. Guiding patients step-by-step towards their goal can help patients to become motivated and have hope in their treatment. Patients in quadrant three stand in the way of their recovery because of their low acceptance. Providing extra support from HCPs and family members will help them. The second quadrant describes patients that are motivated to change but have difficulty doing so because of their lack in certain skills. Offering patients support in planning and structuring their treatment goals, decisions and plans will help them. The first quadrant and group with the highest acceptance and control and are confident in their skills. HCPs can provide more information to increase patients' confidence.

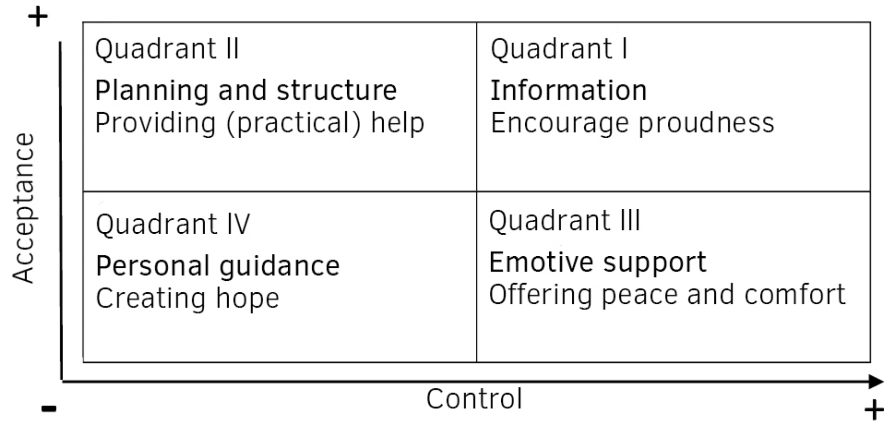


*Figure 4: Patient profile model (Bloem & Stalpers, 2016)*

These methods of profiling are researched and compared because this research was done together with Dekkers and the Albert Schweitzer Hospital is currently using the Bloem & Stalpers method in their research. There are some similarities and differences between these methods. The profiles and quadrants have some overlap in the characteristics, behaviour or on how to provide care to these groups. The main difference in these profiling methods are the objectives. The profiles from Dekkers are a method in providing tailored care based on patients' needs and preferences which may change over time. The quadrants from Bloem & Stalpers focus on improving patients' experience with care by increasing their acceptance and control.

Aside from lung cancer though, there are many other aspects of a patient that affect them, which is more than just their health, but their wellbeing. My Positive Health by Machteld Huber (2012) is a tool used to have a better conversation between HCPs and patients. The My Positive Health spider chart is shown in figure 5. It is only in Dutch because they are still testing it in different languages. This spider chart describes the different domains of wellbeing, which are: how someone feels physically and mentally, their confidence in their future, how much they enjoy life, their participation in society and their daily life. By scoring these domains, patients can reflect on how they're feeling, what they'd like to improve and discuss with HCPs how to improve these aspects. Over time, patients can fill it in again to see if progress has been made or if there are other issues.

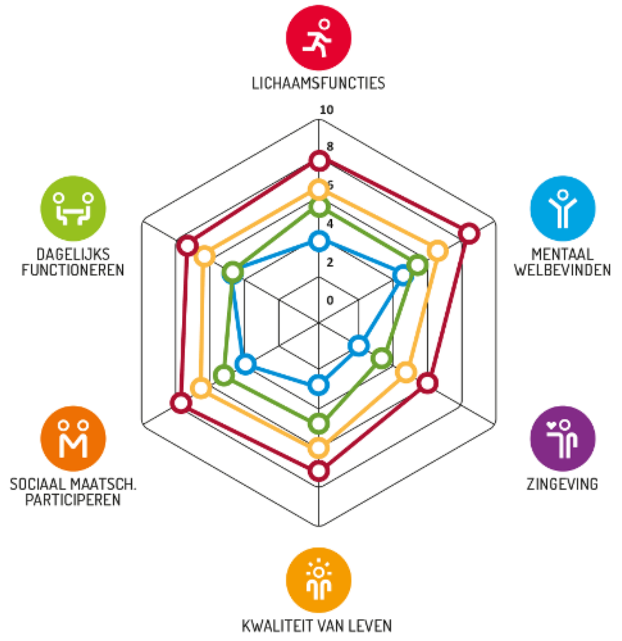


*Figure 5: Mijn positieve gezondheid conversation tool*

*What can be personalised?*

Patient education can be personalised by the method and topic. The method is how care is provided, for example changes in care based on profiles. This could be extra support or information and the format it comes in. Certain patients may prefer to read everything or others may need to see a visual representation of information to help them to remember and understand it all. Some may have less communication skills or a lower health literacy, where information can be personalised to match their level to help them understand it. The type and amount of information patients are interested in or need to make their choices also differ. There are patients that want to know everything, but also those that don't want to know anything. What they want to know more (or less) about is personal for patients. Cancer patients in general prefer more information about postoperative pain (King et al., 2014).

*When and where can personalisation take place?*

There are different moments along a patient journey where patient education is given. It can be personalised when and where they have access to it or are given patient education during the patient journey. Some patients actively search for information themselves and use different sources, whereas others rely on the expertise of HCPs to guide them. Chapter 4 shows the patient journey in detail for lung cancer patients at the Albert Schweitzer Hospital and when patient education is given.

*Why should patient education be personalised?*

Depending on how and when patients receive information, it can also affect the patient's experience and their final results (Dekkers & Hertroijs, 2018; Oswald et al., 2018). This will improve many aspects of a patient's experience, for example, their satisfaction, relationship with HCPs, anxiety, empowerment, self-management and/or clinical outcomes (Dekkers et al., 2018).

# chapter three: internal analysis

**3.1 Centre for Lung Cancer**
**3.2 Centre for Lung Cancer strategy**
**3.3 Patient education at the CfL**

The research was done at the Centre for Lung Cancer at the Albert Schweitzer Hospital. This chapter focusses on the internal analysis of the centre, therefore: the organisation and their professionals who are involved in lung cancer care, their strategy, and the current methods of patient education.

Figure 6: The Centre for Lung Cancer at the Albert Schweitzer Hospital

# 3.1 Centre for Lung Cancer

At the Centre for Lung Cancer (CfL), next to the Albert Schweitzer Hospital in Dordrecht, patients have appointments at the outpatient clinic for diagnosis and treatment of lung cancer or any lung-related operations. Pictured in figure 6 is the centre. It opened in 2016 and is located in the Radiotherapy department of the Erasmus MC. The two buildings are connected so patients can access it through the main entrance of the hospital. The Albert Schweitzer Hospital has partnered together with the Erasmus MC to be able to provide patients different treatments. Lung cancer patients used to be treated at the Pulmonary Medicine Department, where other lung-related diseases are also treated, but now have their own space where HCPs work closer together.

## Albert Schweitzer Hospital

The Albert Schweitzer Hospital (ASH) officially opened on January 1, 1999, when the Drechtsteden Ziekenhuis and Merwedeziekenhuis merged. The hospital was named after Dr. Albert Schweitzer, famous for his philanthropy and many other things, including building a hospital in West Africa in 1913. He serves as an inspiration for their vision and motto, "Zorg met hoofd, hart en ziel", which means "Care with head, heart, and soul". With this in mind, they want patients to feel welcome and safe when they are in their care and focus on patient-centered care so that a patient's healthcare needs act as a guide for HCPs actions. With over 200 medical specialists and 4.000 employees in total working at three locations, ASH is a network of hospitals providing care for the southern region of South-Holland. These hospitals are located in Dordrecht, Zwijndrecht, and Sliedrecht. The ASH provides care for many different specialisations and performs (academic) research to improve their services. The research includes testing new medical treatments and techniques, but also innovations. ASH has set up IDEASz, a team focused on turning new ideas into projects for improving healthcare. The research and projects at ASH have led to them winning awards and giving speeches, including abroad, to be able to share their knowledge and use the prize money to fund other projects.

Another important aspect of providing patient-centred care is to make sure patients are satisfied with the care provided. Hospitals provide statistics on the quality of their care to the Health and Youth Care Inspectorate and National Health Care Institute and Ziekenhuischeck uses these statistics to make it easy and accessible for civilians to compare. In 2017 ASH has received a 7.8 and had over 25,000 same-day treatments, 28,000 clinical admissions and 157,000 polyclinic appointments that year. They've also performed their own research into the patient experience by using the Consumer Quality Index (CQI) to improve the quality of the hospital. Their scores for the outpatient clinic in 2018 were 8.36 and has been slowly rising each year. They've received positive feedback on the following points: patients feel safe, communication with doctors and nurses, time taken to explain the treatment, the pain was kept in control and the hospital is accessible. Points where ASH, in general, need to improve are: the room and stay, information at discharge and information on medicine. Patients part of the patient panel at ASH have participated in the CQI and give a general overview of the satisfaction at the hospital.

## Healthcare professionals involved in lung cancer patient care

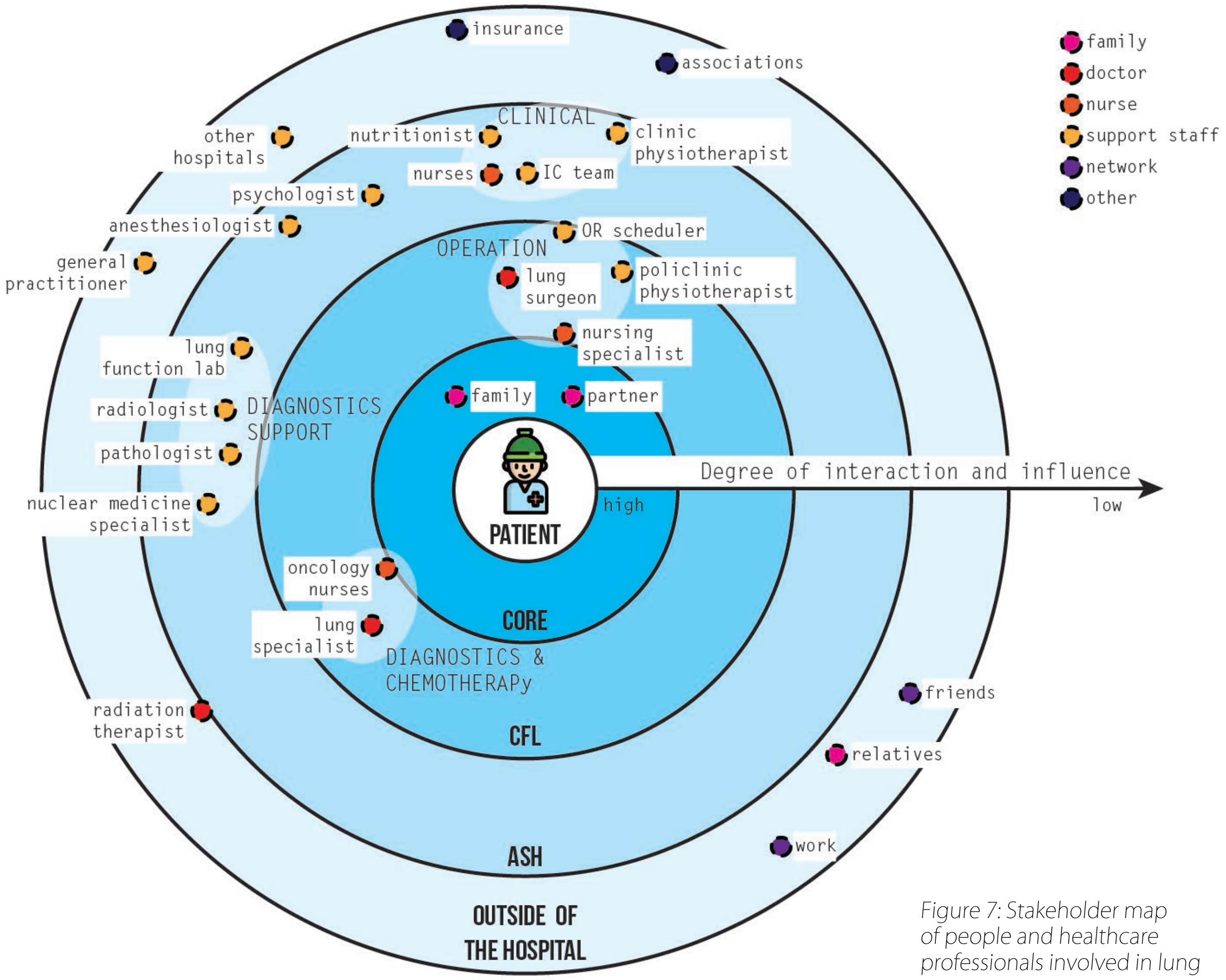


*Figure 7: Stakeholder map of people and healthcare professionals involved in lung cancer care*

There are many HCPs involved in caring for lung cancer patients and also others that are affected by it. The stakeholder map in figure 7 shows the different parties involved and their level of interaction and influence they may have on treatment. The HCPs that are grouped are the teams that work closely together to help patients during different stages throughout their treatment.

### *Core support for patients*

Closest to patients are their family members and partners that are their support systems during their treatment. These are people that see the patient the most and can support patients outside of the hospital. Almost all patients bring someone along during their appointments. It helps to have someone else at the appointment to help remember things since there is a lot of information patients receive. This core group can also help patients during recovery to keep track of their progress and stay healthy and fit. Especially because patients go through a wave of emotions and an unpredictable journey, family members and partners provide also emotional support and helping out the patient in any way can help relieve their stress and anxiety.

### *Healthcare professionals within the Centre for Lung Cancer*

The diagnostics and surgical team work closely together in the CfL. An important change in lung cancer care that the CfL provided is that these HCPs work all in one location. Patients previously had appointments in different departments and on different days, making it more difficult and troublesome for patients. By creating the CfL, HCPs can easily communicate with one another and patients can have multiple appointments in one day.

### *Diagnostics and chemotherapy team*

Patients that are suspected of having lung cancer are in the care of the oncology nurses and lung specialists. They provide information on tests and discuss results with patients. This group is also the HCPs that does chemotherapy. They are supported by the diagnostics support team, which includes the: lung function lab, radiologist, pathologist, and nuclear medicine specialist. These are the HCPs that perform the tests and research to diagnose lung cancer. They are in contact with the diagnostics team and give them the results to discuss with patients.

### *Surgical team*

The surgical team includes lung surgeons, nurse practitioners, a physiotherapist, and an operation room scheduler. There are two different lung surgeons and nursing specialists that switch off on tasks because all of the HCPs work also in different departments within the Albert Schweitzer Hospital. Here is a description of each of the HCPs roles:

| | |
|---|---|
| **Lung surgeon** | The lung surgeon provides patients with medical information, guides them through medical decisions and performs the surgery. |
| **Nursing specialist** | The nursing specialist is the case manager for the operation phase of the patient journey, which is responsible for keeping an overview of what happens to the patient and that things run on track by keeping contact with the patient and other HCPs. They provide patients with more practical information and on lifestyle changes that need to be made. Patients that have any questions or concerns can contact the nursing specialist at any time. |
| **Physiotherapist** | The physiotherapist informs patients of the exercises they need to do at home before and after the surgery and the importance of the exercises done after the surgery in the clinic. |
| **Operation room scheduler** | The operation room scheduler plans operation dates so that it fits in with the surgeon's schedule. |

These HCPs collectively are the operating team that treat lung cancer patients that receive an operation at the CfL.

### *Multidisciplinary team*

There is a multidisciplinary meeting that meets to discuss which treatment is best for patients. There are two different meetings, a medical one and a psychosocial meeting. During the medical multidisciplinary consultation the teams responsible for the different treatments, therefore the surgical team, chemotherapy team, and radiation therapist, are present and also include other professionals to determine which treatment is the best medical option for patients. At the psychosocial multidisciplinary meeting, the oncology nurses, nursing specialists, policlinic physiotherapist, psychologist, and dietitian discuss how a patient is doing and their progress during treatment. These meetings are a gathering of professionals across different teams, as can be seen in the stakeholder map, where they work together to provide the best care for patients.

### *Healthcare professionals within the Albert Schweitzer Hospital*

Within the Albert Schweitzer Hospital there are healthcare professionals that provide support to lung cancer patients. This is the diagnostics supporting team, the clinical team and other supporting HCPs.

#### *Diagnostics support*

The diagnostics supporting team consists of the lung function lab, the radiologist, pathologist and nuclear medicine specialist. They perform lab tests for patients that are in the diagnostics stage and give the results to the healthcare professionals that are in charge.They usually do not engage with patients directly.

#### *Clinical team*

After an operation, patients are in the care of the clinical team. Patients are cared for by the intensive care, nurses and nutritionist. There are also clinical physiotherapists that help patients with exercises and rehabilitation.

#### *Supporting HCPs*

| | |
|---|---|
| **Anesthesiologist** | Patients must meet with an anesthesiologist that will check their condition before surgery, their health during surgery and prescribe painkillers after surgery. |
| **Psychologist & dietitian** | They are available through the CfL for patients who need extra support. |

### *Partners & healthcare professionals oustide the Albert Schweitzer Hospital*

Outside of the ASH there are other partners and supporting HCPs that are involved in the care of patients and have influence on them. Below is a description of the role they play in a patient's treatment.

| | |
|---|---|
| **General practitioner (GP)** | Patients are referred from their GP and are kept up to date with patients' diagnosis and progress. |
| **Other hospitals** | Some patients come from a different hospital to be operated on at the ASH. |
| **Radiation therapist** | If a patient would need radiotherapy, this would be done at the Erasmus MC. |

#### *Network & other*

| | |
|---|---|
| **Insurance** | A patient's insurance is not directly involved in the treatment, but do need information from patients and HCPs for care to be provided. |
| **Associations** | Associations can provide extra support to patients, whether it be to help them out with their situation or emotional support in support groups. |
| **Relatives & friends** | Other relatives and friends can also provide emotional support. |
| **Work** | Patients that work may be affected physically and mentally, which will definitely influence how and when patients can work. |

# 3.2 Centre for Lung Cancer strategy

At the CfL different medical teams provide various treatments. Each team has a committee that is responsible for the team and together they discuss the current activities and projects at the CfL. They haven't set a specific vision or strategy, but as HCPs they have different projects all with an underlying goal. Here are a few of the projects and goals.

## Improving treatment and care

The CfL and ASH do research new medical techniques and technology to implement. For example, certain procedures may have previously needed a larger incision, but now does not require one do to the same procedure due to advancements in medical tools. Treatment nowadays means more than just the medical procedure, but also the care delivered before and afterwards. Currently, the CfL is looking to improve the prehabilitation and rehabilitation for surgery patients. During prehabilitation, HCPs want patients to get into good condition before going into surgery. To stimulate exercising, patients can come to the hospital to receive guidance and support in how to exercise. This will help patients train regularly. After the surgery is rehabilitation, where patients recover from surgery. Some patients need extra care at home, so the CfL arrange home care where HCPs visit patients' home to check on how they're doing. To also help patients with their exercises after surgery, the CfL is looking into extending the ASH Behandelpad app. Their idea is that patients will be able to watch instructional videos on exercises and keep track of their progress. HCPs will receive or be able to view patients' progress and know-how to assist patients further to improve their recovery. These are just a few of the projects that the CfL is working on, which are led by HCPs in the surgical team.

## Growing the Centre for Lung Cancer

Since specialised hospital care is being condensed in the Netherlands, the CfL is looking to grow to continue to provide care to lung cancer patients and to be able to handle the increase in patients. This is an ongoing trend where specialised care, including lung cancer care, is being reduced (RTL Nieuws, 2019). That is why it is important the CfL continuously improve their care to attract patients and other hospitals. The CfL has partnered with the Erasmus MC and the Beatrixziekenhuis in Gorinchem. It was set up together with the Erasmus MC so that patients are also able to receive radiation. This takes place in at the Erasmus MC, which is located right next door. Lung cancer patients at the Beatrixziekenhuis that need an operation are transferred to the CfL. Therefore diagnosis takes place in the Beatrixziekenhuis and after an operation, patients are then transferred back to the Beatrixziekenhuis. By continuously growing, the CfL will be able to expand and become more flexible. Currently, there are only consultation appointments once a week due to the capacity, but with more patients and HCPs they would be able to help patients any day of the week and shorten waiting times.

## Bridging silos

Within the CfL there are medical teams that are responsible for lung cancer patients' treatments, but this also includes other HCPs outside of the CfL. Though there is a network of HCPs that provide care to patients, it is a complex system that makes sharing patient information and consistent information difficult. Not only in the CfL, but healthcare is working towards breaking down the 'silo mentality' to improve overall care.

# 3.3 Patient education at the CfL

Lung cancer patients receive patient education through different methods provided by the CfL. Patients can find information on the website, in pamphlets, on the patient portal, the ASH Behandelpad app and receive information during the consultation appointment. In the waiting room, patients can also find extra pamphlets and information on workshops and meetings. The ASH has partnered with patient organisations to provide these informational meetings where the motto is, "Cancer, more than a diagnosis". Patients and their support systems are invited to learn about the (psychological) effects of have cancer and how to deal it.

## The Centre for Lung Cancer website

*Figure 8: The Centre for Lung Cancer homepage*

Most departments at the ASH have a page on the website with information. The CfL has its own website that is linked to the ASH website. They wanted to renew their website so that there would be a better overview of the information and that anyone could have easy access to it. People can visit the website to learn more about lung cancer and the procedures and also familiarize themselves with the CfL and the medical team. Most information on the website is in text, but there are also videos which are sometimes used during appointments. The HCPs hope to expand the website enough so that patients only need to visit the CfL website when searching for information.

## Lung cancer pamphlets

During appointments, patients receive paper pamphlets (in figure 9) with information to read at home. The nursing specialists explain the information in the pamphlet in short, but patients must read it for themselves in detail. By giving patients pamphlets, HCPs want to make sure that they have then given all the information to a patient. The specific pamphlets given during an appointment can also be found on the patient portal. All patient folders are also available on the ASH website and the lung cancer pamphlets are also on the CfL website. The pamphlets are updated annually together with HCPs.

## Mijn ASz - patient portal

The ASH has a patient portal called Mijn ASz. Patients can log on with their DigiD to access their patient records. Mijn ASH is connected to HiX, the system HCPs at the ASH use to view and record patient results and progress. This way the information that HCPs put in HiX is directly linked to patients' medical records on Mijn ASz. Patients can then view results and notes from HCPs. They also have an overview of their appointments in the past and future and can also make new appointments. After an appointment, there is also a short summary which the doctor has written up for other HCPs which patients can also see. The summary is very short notes, more meant for other HCPs, and therefore has medical terms which may be difficult for patients to understand. Results are posted on Mijn ASz a week after patients have taken a test. Sometimes results are posted before doctors discuss it with them, so there is a message that pops-up to warn patients about viewing their results from beforehand because results that may seem negative, may turn out to be something not so bad at all. These results also use medical terms and don't have any explanation, mainly values. There is an eConsult where patients can send their doctors a question they might have, but this is used seldom because HCPs are worried that there will be questions flooding in and that they won't have the capacity to answer them all. Patients are encouraged to call nursing specialists if they have any questions. Patients sometimes need to fill in questionnaires which also can be found on Mijn ASz.

## ASZ Behandelpad app

The Albert Schweitzer Hospital also has an app called ASZ Behandelpad (ASH care pathway) shown in figure 10. It has information about the hospital, different illnesses, and treatments. Not all departments have their information on the app yet, but the Centre for Lung Cancer does have their information for anyone to see. It's set-up in a timeline format, with information in text and video and pictures of treatment at the CfL. Patients can fill in their treatment day and a personal code to receive notifications. At this moment, there is only information on the app and as earlier stated, they are looking into extending the app use for rehabilitation exercises.

## Consultation appointment

Throughout treatment, patients have appointments at the CfL where they are informed over treatment or results. A detailed description of the consultation appoinment for patients receiving an operation is in the following chapter.

## Analysis of patient education

These methods of patient education mainly give information and require minimal interaction from users. During an appointment HCPs can respond to what patients say and do, but meetings are short and sometimes the first time HCPs and patients meet, therefore it is difficult to gauge who the patient is and how they respond to the information. HCPs do try to summarize the information given and check with patients if they understood the information by asking them. For the other methods of patient education, there is no way of checking what patients have viewed or read and if they've understood it. All the information on the website, app, in the pamphlets and given during appointments are also the same general information that all patients receive and that everyone has access to. Mijn ASz is also a way HCPs can provide patient education and communicate with patients but is not used very often.

*Figure 9: Lung cancer pamphlets*

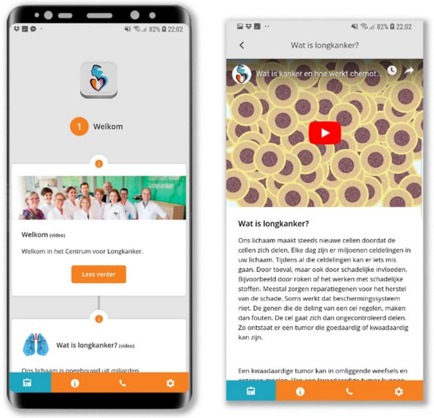


*Figure 10: ASZ Behandelpad app*

# chapter four: patient journey

## 4.1 Lung cancer patient journey
## 4.2 HCPs roles during the patient journey
## 4.3 Patient journey for patient profiles

The patient journey describes the steps patients take and which HCPs are involved in which step. The research focusses on the experience of HCPs, which is analysed to describe the opportunities and insights for the design challenge.

# 4.1 lung cancer patient journey

*Figure 11: Care pathway for lung cancer patients*

There are different treatments patients can receive at CfL for lung cancer. This could be an operation, chemotherapy, radiotherapy or a combination of treatments. Most patients that come to CfL are referred from their general practitioner after there are suspicions of lung cancer. In the figure above are the stages patients go through when they are referred to CfL. The focus of this project are lung cancer patients that are eligible for operation, therefore this is the care pathway for operation patients.

The journey lung cancer patients take is an unpredictable road. Hospitals use care pathways to describe the steps a patient goes through and the multidisciplinary process. The care pathway for lung cancer has guidelines for HCPs to treat patients within a certain amount of time. This care pathway mainly describes the patient journey from a medical standpoint, whereas a patient journey describes the actions of a patient and their experiences and feelings. The following describes the steps a patient takes, who's involved and the comparison of how this can differ for certain patients. These are the results from observations and interviews done at CfL.

The patient journey for lung cancer patients can be split into three stages: diagnosis, operation and after care as seen in figure 11. The full patient journey is in Appendix A. The timeline shows an overview and how long each step takes. The touchpoints are how patients come in contact with things related to the ASH. The colors correspond to the coloured dots on the patient journey. Uncoloured dots are steps where patients are not involved in and also shows steps that other patients not receiving surgery take. The numbered steps are described further in detail.

During the diagnosis patients go through multiple tests to check if the suspicious spots on the lung X-ray is indeed lung cancer. If it is concluded that patients have lung cancer and that they are able to be operated on, patients then go through the operation stage. This consists of prehabilitation, the operation and rehabilitation. Once patients complete this stage they return into the care of the diagnostics team. The patient journey shows the timeline of how long each stage is supposed to take and touchpoints patients have with the ASH. The touchpoints correspond to the coloured circles in the patient journey, which are the steps a patient goes through. Since there is no data into when patients use the patient education material, the touchpoints show when they are introduced to the material. There are some moments where a (surgical) patient is not present, but they are steps HCPs take that have to do with a patient. Not all patients that come to the CfL for lung cancer follow these steps. There are many possibilities depending on the severity of the cancer, the test results, and other factors.

## Diagnostics stage

Before patients come to the CfL, they've been to their doctor due to complaints of symptoms. Symptoms of lung cancer, such as coughing, tiredness, and shortness of breath, are often diagnosed as another sickness before suspicions of lung cancer, so therefore it may take a while before patients are referred to a lung specialist. Once the general practitioner suspects the symptoms of being lung cancer, patients are referred to the lung specialist to go through multiple exams. Patients are seen within a week at the CfL. (1) During the first meeting, patients meet an oncology nurse that explains what the care pathway will look like. They only explain the tests that are going to be done that day, especially because it's unsure if the patients need to complete all the tests. The oncology nurse escorts the patients to their first test directly after the appointment. This is because the tests take place at another department in the hospital and to help patients find their way throughout the hospital. (2 & 3) Along this course patients receive pamphlets which describe the different tests and are introduced to the ASH Behandelpad app. The Behandelpad app and CfL website describe the care pathway step-by-step and include videos. During this stage patients are under the care of the diagnosis team which includes the lung specialists and oncology nurses.

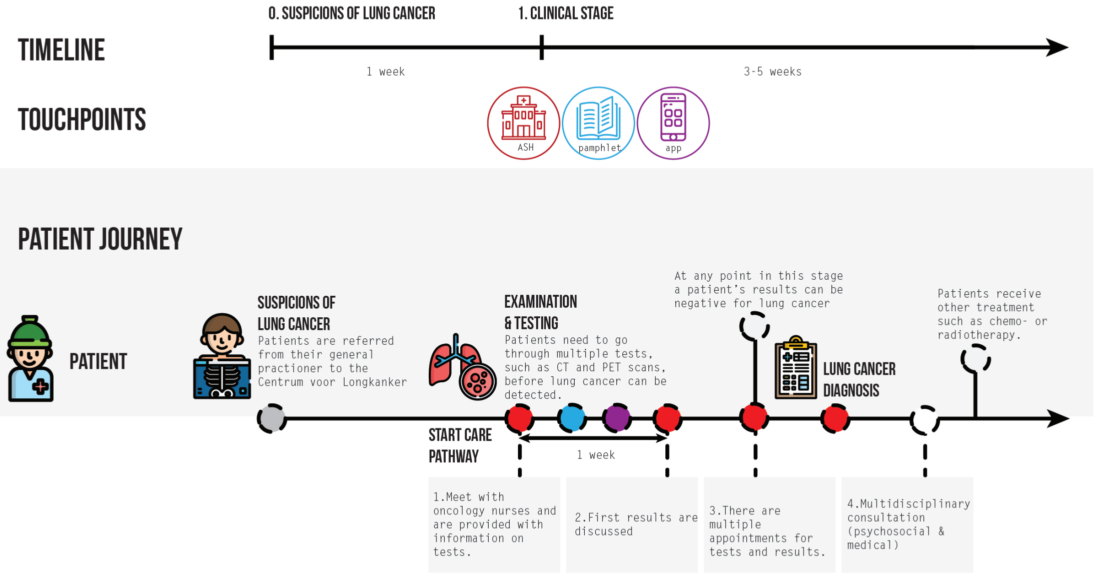


*Figure 12: Diagnostics stage of patient journey*

Oncology nurses find it important that during this first appointment is to set expectations. Many patients expect to know the outcome directly, but it's only after all the tests are done that the specialists have a better idea if it is lung cancer. This can take from three to five weeks of testing and waiting for results and if any of the test results come back negative for lung cancer, patients can be referred to another department. (4) The healthcare professionals hold a multidisciplinary consultation (MDC) where specialists from the different treatments gather to discuss the medical treatment that best suits the lung cancer patient based on the results of the tests. This happens every week on a Tuesday afternoon. Patients that qualify for an operation are called directly to make an appointment for the consultation with the surgical team. Other patients may receive treatment such as chemo or radiotherapy.

## Surgical stage (prehabilitation)

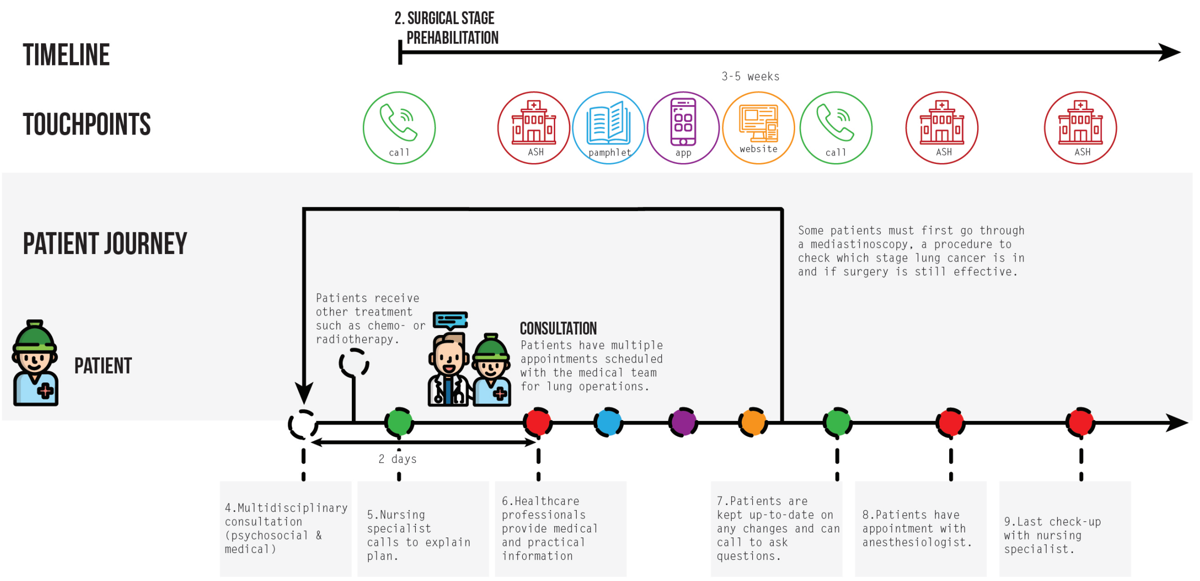


*Figure 13: Prehabilitation during surgical stage*

The surgical stage can also be broken down into three stages: prehabilitation, operation, and rehabilitation. (5) During prehabilitation (figure 13) patients are contacted by the nursing specialist for the consultation appointment, which takes place on Thursday afternoon, two days after the MDC. At this moment patients are also handed off from the diagnostics team to the surgical team.

Patients from the Beatrixziekenhuis that are diagnosed with lung cancer and need an operation are treated at the ASH. They can take the tests to receive the diagnosis at the Beatrixziekenhuis, therefore lung specialists and the surgical team keep in contact with each other about the patient and their progress of the operation.

### *Consultation appointment & prehabilitation*

Patients meet the whole team during the (6) consultation appointment where patients have one appointment after the other all at the CfL. The goal of this appointment is to educate patients of the medical and practical information regarding an operation so that patients can make an informed decision on the goals of their treatment and can engage in their treatment.

The consultation appointment, or 'carousel', has been designed for patients to meet the surgical team at one time and one location. Patients were observed during the consultation. The appointment starts with meeting the lung surgeon, then the nursing specialist, then the physiotherapist and lastly the operation scheduler. Patients meet the lung surgeon first because some want to discuss if they want to do an operation or not. Providing information to patients that are contemplating an operation is different than those that already have made their decision. The following is a more detailed description of what happens during the consultation appointment.

**Meeting with the lung surgeon**

- Patients arrive at the CfL, sign in with the assistant and wait in the waiting room until the lung surgeon calls them.
- The patient meets the lung surgeon.
- Lung surgeon gives a recap of the tests and results from previous appointments and turns their computer screen to show the X-rays and PET scans.
- By drawing the current situation of the patient's lungs, the lung surgeon describes the medical procedure that will take place. Patients can take home this drawing to show their family members.
- Patients are further educated on the risks and complications of the surgery and the lung surgeon discusses with the patients what their thoughts on the operation.
- Other information the patient receives is about what the day of the operation will look like and what happens after surgery.
- When the meeting ends, patients are led to the nursing specialist by the lung surgeon. This takes place right next door and the lung surgeon summarizes any personal issues to the nursing specialist so that they are up to date.

**Meeting with the nursing specialist**

- The patient meets nursing specialist
- The nursing specialists first asks how they're feeling and the type of symptoms they have.
- Patients are then introduced to information in the pamphlets which the nursing specialist shortly goes through and highlights the important information they need to know before surgery. An important aspect is a patient's condition and that they're in good condition before surgery.
- Patients are also introduced to the app which has information from the pamphlet and website and are encouraged to download the app and show friends and family that are following their treatment.
- Other HCP's that are also involved with the patient's treatment and their role are explained to patients.
- Patients have the chance to ask any questions and are informed to call the nursing specialists may they have any other questions or symptoms after the appointment.

**Meeting with the physiotherapist**

- Patients meet the physiotherapist.
- Patients are told about the exercises they'll do after surgery. There will be other physiotherapists in the clinic that will help them with their exercises. The exercises take place already a day after surgery, so patients are told this from beforehand to let them know it's not strange and that it's supposed to happen. The physiotherapist explains how to do different exercises, why patients need to do it and the benefit.
- The physiotherapist also encourages patients to let the nurses know if they have any physical pains and to not endure the pain.
- Patients also discuss with the physiotherapist how their condition currently is, if they do any exercises and how to best get in shape before surgery.
- The physiotherapist reminds the patients to call the nursing specialist if they have any questions.

**Meeting with the OR scheduler**

- Lastly, patients meet the operation scheduler to plan in a date for the operation and an appointment with the anaesthesiologist and lets them know of the forms they must fill in before surgery.

There are a few weeks in between the consultation and the operation where patients focus on prehabilitation. This may be to stop smoking, eating healthy and exercising to keep their body in good condition to reduce risks of complications and healing time after surgery. (7) If there any changes in appointments, the nursing specialist will call a patient to update them. The nursing specialist also keeps up to date on how patients are doing, especially those who need extra attention. (8) Patients also have an appointment with an anesthesiologist before surgery for a check-up and if necessary extra tests. (9) A day before surgery patients also come to the hospital for the last check-up with the nursing specialist.

Another possibility is that a patient receives a mediastinoscopy. A mediastinoscopy is a day treatment where the stage of lung cancer is diagnosed. Some patients need a further diagnosis and are operated on. This is a shorter process than a full operation. Within a week after the MDC patients are operated on and stay also for a shorter period in the hospital for recovery. Patients are then discussed at the MDC again to determine which treatment is the most suitable. This may be an operation in which the patients will return for another consultation appointment and wait for the full operation.

## Surgical stage (operation & rehabilitation)

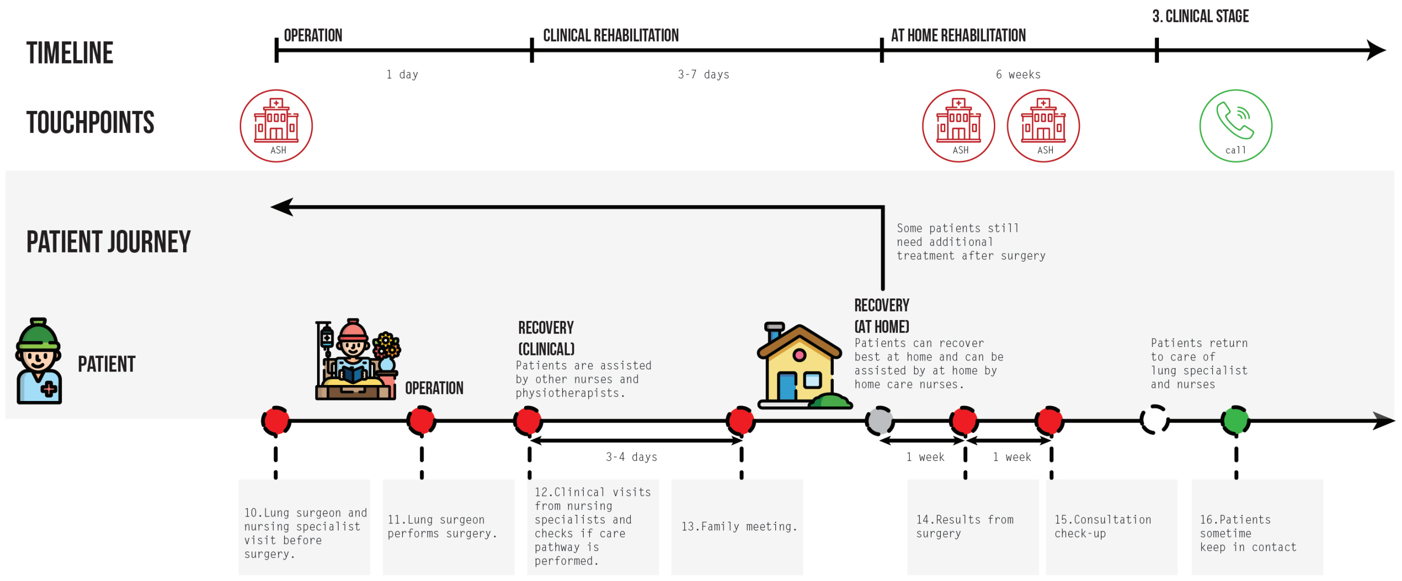


*Figure 14: Operation and rehabilitation of patient journey*

Within three to five weeks patients are operated on and begin rehabiliation (figure 14). (10 & 11) On the day of surgery, the nursing specialist and lung surgeon meet patients beforehand to check on how they're doing and also to reassure patients of how the operation will go. (12) After surgery, the lung surgeon calls the family to let them know how the surgery went while patients recover in the intensive care. When patients are stable they are moved to the clinic into the care of the nurses. During their stay they must do exercises to keep moving and this starts a day after surgery. (13) A few days after surgery there is a family meeting where patients, their support systems and the doctors discuss how the surgery went, how recuperation is going and a forecast to when patients may go home. Depending on the condition of a patient, they can be discharged from the hospital four days to about a week after surgery.

(14) A week after being discharged from the hospital, the lung specialist discusses the results from surgery with the patient. There is a possibility that another treatment is also needed or due to complications another surgery is needed where patients then must go through the surgical stage again. (15) Another week after meeting with the lung specialist, the patient has a consultation appointment with the surgical team again to discuss how things went and how recovery is going. After about six weeks, when patients are fully recovered, they return into the care of the diagnostics team where they will get regular check-ups. (16) Some patients like to keep in contact with the surgical team by calling the nursing specialists.

## Analysis of patient journey

In an interview, HCPs were asked how they experience the patient journey and their pains and gains along the care pathway regarding patient education. The interview guide and tools can be found in Appendix B. The consultation in the carousel format works well for HCPs and patients. Working at the CfL allows HCPs to work closer together where they can easily communicate with each other during consultations by simply walking next door. Since they've worked on creating the carousel together, the concept is well thought out. They discussed the order patients see HCPs, what each HCP will tell patients and how they'll provide treatment as a team. This works well for HCPs because they understand each other and after working together for a few years, they know what to expect from each other and their interaction goes in a natural flow. Interestingly, HCPs mention the fact that it's kind of become a routine in how they provide patient education and that they already know what the others will say. This means that patient education is standardised for all patients and by working this way, the HCPs slowly work less like a team, because patient education has become an ingrained routine instead of working together. The carousel format has had a big impact on patients and is an improved method of patient education, but HCPs still see room for improvement.

HCPs notice that if things go as planned then it goes well, but some things make it difficult. There are times when the consultation appointment starts later because HCPs are busy working in other departments. They don't stick to the order in which their story is supposed to be told then, which makes it more difficult for HCPs to deliver information and have an overview of where patients are and when. They do have a system where they can see where patients are and who they're talking to, but it isn't used very often and they sometimes lose sight of patients.

Other problems that occur during the patient journey is that inconsistent information is sometimes given to patients. This is because several HCPs treat a patient, some that know a patient and care pathway less. This causes miscommunications where patients become confused and will ultimately lead to more stress for patients. In the clinic, several HCPs don't only work with the lung cancer patient, so sometimes certain steps take longer or are forgotten. For example, a physical therapy appointment may be skipped or it takes longer than normal for certain tubes and drains to be taken out. The CfL HCPs try to visit to keep track of this to make sure everything goes as planned, but it is inefficient to keep checking if the care pathway is being executed correctly.

### *Patient experience*

There are things HCPs try to do to improve the care they provide to patients and what they see that has a positive impact on patients and their experience. What HCPs do during a consultation is talk about lung cancer and the operation from their own perspective as an expert. To help patients understand and remember everything, HCPs repeat a lot of things and check afterwards to make sure they've understood it. This helps to manage expectations and reduce stress when patients have other expectations. There may be longer waiting times because of staff shortage or some tests may take longer than normal and this can be disappointing for patients. This makes them unhappy, especially when they are told it would have already been done, but also makes them worried about their situation and that their health might have worsened within that time. It affects their mood and the relationship they then have with HCPs and any negative emotions affect their condition and recovery. During the diagnostics stage, HCPs also explain things step-by-step to not overwhelm patients with information. By giving information step-by-step and repeating thing

Being at the CfL and seeing how the team works together, shows patients that they can be trusted and that they're invested in doing their very best for patients. Patients see the teamwork and effort which gives them a sense of security to put their trust in the team to treat them. At appointments, when the HCPs bring patients to the next HCP in the carousel format, HCPs repeat what patients have told them and either communicate with one another directly or through Hix so that HCPs are up to date and that patients know that someone is listening to what they're saying and are being cared for. It also shows when HCPs are prepared and know who they're treating. It makes treatment more efficient and reassures patients that treatment will go smoothly. By getting to know patients, they in turn also get to know HCPs so that they trust them and are comfortable enough to ask questions and know who they can go to to tell how things are going.

# 4.2 HCPs roles during the patient journey

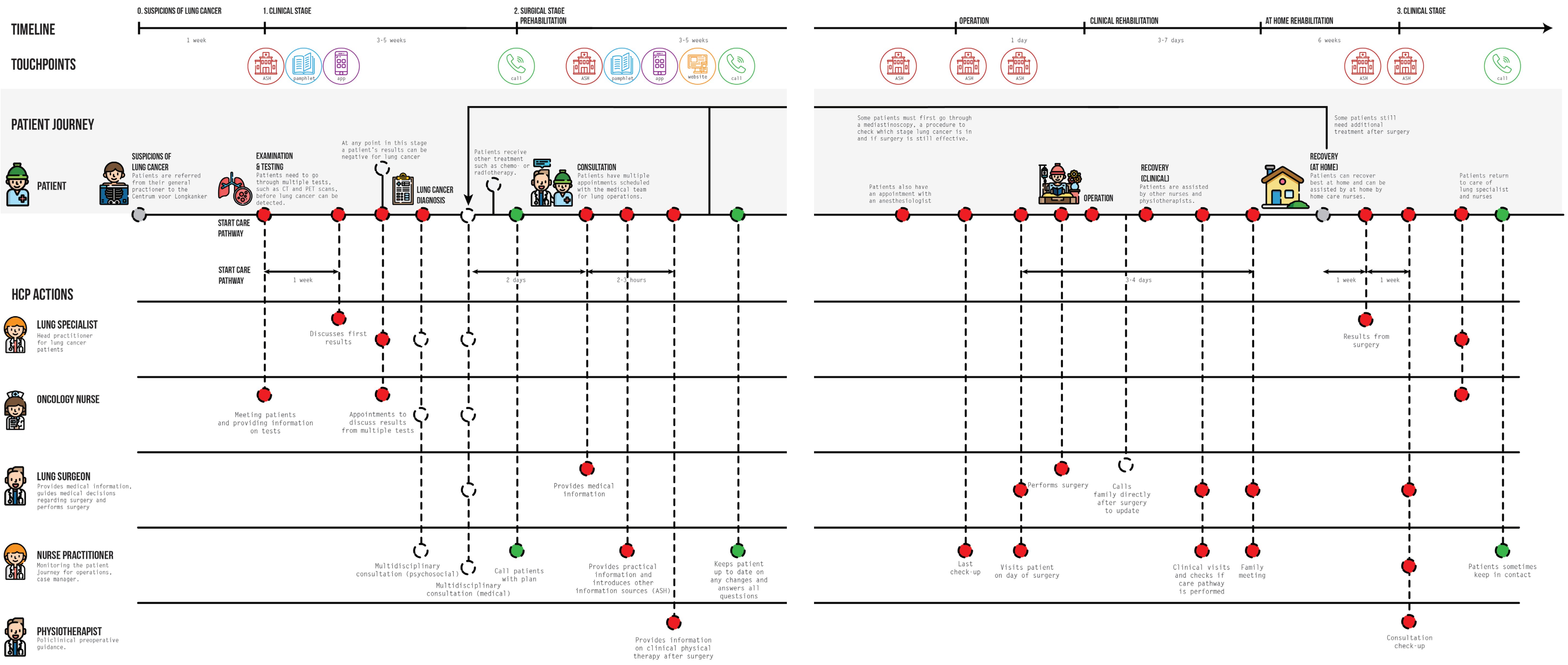


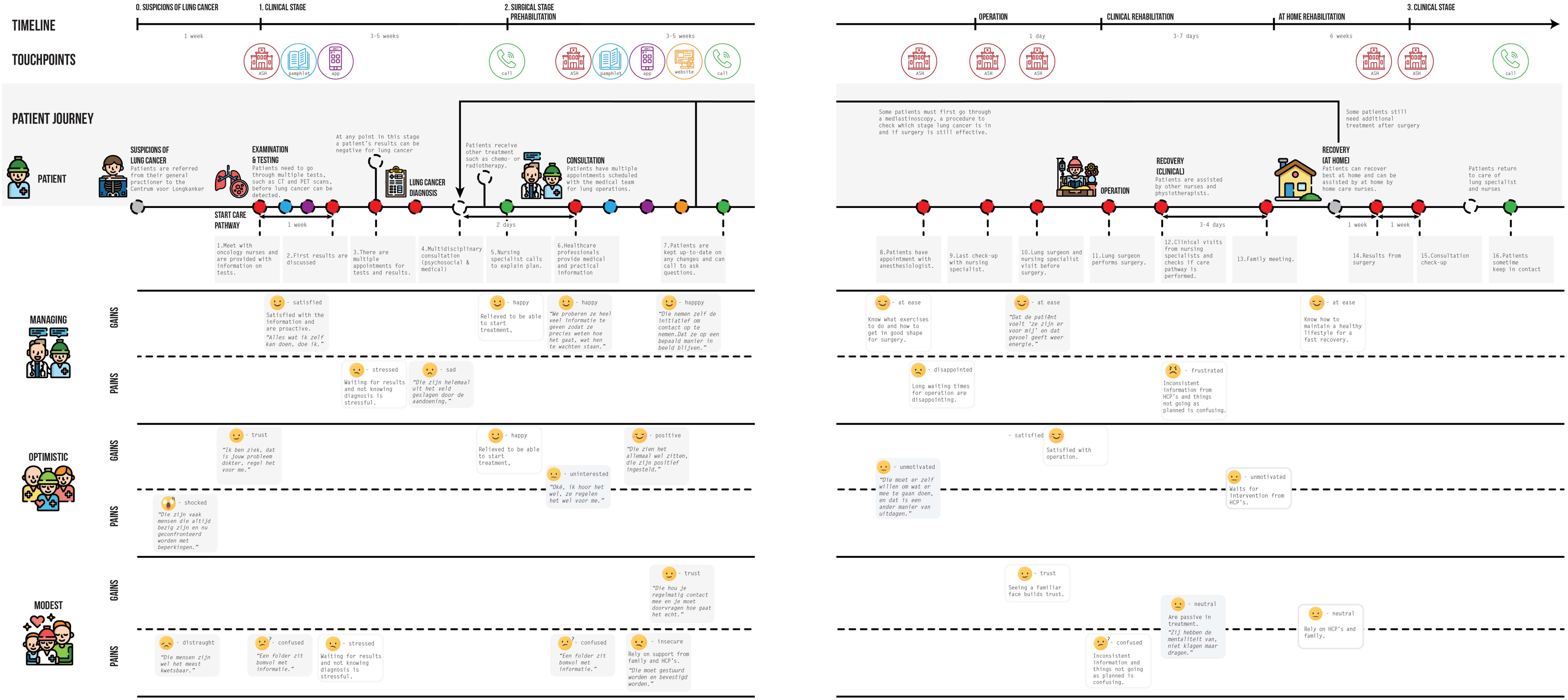
*Figure 15: HCPs involvement in the patient journey*

Many HCPs are involved in caring for a patient. The two medical teams that work closest with surgical lung cancer patients are the diagnostics and surgical team at the CfL. They don't interact with patients all at the same time but are all responsible for different aspects of care. In figure 15 are the steps where HCPs are involved during the patient journey and which HCPs are involved. This shows the different jobs within the CfL, but there are multiple HCPs per job. They do try to plan in patients with the same HCPs so that patients know the members of their treatment team better and can become comfortable with them, but it is not always possible.

In this version of the patient journey, it shows a few things:

- There is an overlap between the medical teams during the MDC and after that point that surgical patients go into the care of the surgical team. Due to the change and amount of different HCPs that care for patients, they therefore need to communicate well with each other, and with the patient, to keep up to date on a patient's progress. It makes it difficult for everyone to know who the patient is and how they respond to treatment.
- During the surgical stage, the nursing specialist, which is the case manager, has the most contact with patients. They have an overview of what is happening with patients by keeping in contact with other HCPs, the patient and their support systems.
- Being in good condition is important for going into surgery and recovery, but the physical therapist changes during the course of treatment which makes it difficult for them to become involved with a patient's care. The physical therapist only sees the patient for polyclinical appointments but would prefer to become more involved. The physical therapist is now part of the psychosocial MDC and working on a project to set up prehabilitation training for patients.

# 4.3 Patient journey for patient profiles



Patients are referred from their general practioner to the Centrum voor Longkanker

Patients need to go through multiple tests, such as CT and PET scans, before lung cancer can be detected.

At any point in this stage a patient's results can be negative for lung cancer

Patients receive other treatment such as chemo- or radiotherapy.

Patients have multiple appointments scheduled with the medical team for lung operations.

Some patients must first go through a mediastinoscopy, a procedure to check which stage lung cancer is in and if surgery is still effective.

Patients are assisted by other nurses and physiotherapists.

Some patients still need additional treatment after surgery

Patients can recover best at home and can be assisted by at home by home care nurses.

Patients return to care of lung specialist and nurses

1.Meet with oncology nurses and are provided with information on tests.

2.First results are discussed

3.There are multiple appointments for tests and results.

4.Multidisciplinary consultation (psychosocial & medical)

5.Nursing specialist calls to explain plan.

6.Healthcare professionals provide medical and practical information

7.Patients are kept up-to-date on any changes and can call to ask questions.

8.Patients have appointment with anesthesiologist.

9.Last check-up with nursing specialist.

10.Lung surgeon and nursing specialist visit before surgery.

11.Lung surgeon performs surgery.

12.Clinical visits from nursing specialists and checks if care pathway is performed.

13.Family meeting.

14.Results from surgery

15.Consultation check-up

16.Patients sometime keep in contact

- satisfied
Satisfied with the information and are proactive.
*"Alles wat ik zelf kan doen, doe ik."*

- happy
Relieved to be able to start treatment,

- happy
*"We proberen ze heel veel informatie te geven zodat ze precies weten hoe het gaat, wat hen te wachten staan."*

- happpy
*"Die nemen zelf de initiatief om contact op te nemen.Dat ze op een bepaald manier in beeld blijven."*

- at ease
Know what exercises to do and how to get in good shape for surgery.

- at ease
*"Dat de patiënt voelt 'ze zijn er voor mij' en dat gevoel geeft weer energie."*

- at ease
Know how to maintain a healthy lifestyle for a fast recovery.

- stressed
Waiting for results and not knowing diagnosis is stressful.

- sad
*"Die zijn helemaal uit het veld geslagen door de aandoening."*

- disappointed
Long waiting times for operation are disappointing.

- frustrated
Inconsistent information from HCP's and things not going as planned is confusing.

- trust
*"Ik ben ziek, dat is jouw probleem dokter, regel het voor me."*

- happy
Relieved to be able to start treatment,

- uninterested
*"Oké, ik hoor het wel, ze regelen het wel voor me."*

- positive
*"Die zien het allemaal wel zitten, die zijn positief ingesteld."*

- satisfied
Satisfied with operation.

- shocked
*"Die zijn vaak mensen die altijd bezig zijn en nu geconfronteerd worden met beperkingen."*

- unmotivated
*"Die moet er zelf willen om wat er mee te gaan doen, en dat is een ander manier van uitdagen."*

- unmotivated
Waits for intervention from HCP's.

- trust
*"Die hou je regelmatig contact mee en je moet doorvragen hoe gaat het echt."*

- trust
Seeing a familiar face builds trust.

- neutral
Are passive in treatment.
*"Zij hebben de mentaliteit van, niet klagen maar dragen."*

- neutral
Rely on HCP's and family.

- distraught
*"Die mensen zijn wel het meest kwetsbaar."*

- confused
*"Een folder zit bomvol met informatie."*

- stressed
Waiting for results and not knowing diagnosis is stressful.

- confused
*"Een folder zit bomvol met informatie."*

- insecure
Rely on support from family and HCP's.
*"Die moet gestuurd worden en bevestigd worden."*

- confused
Inconsistent information and things not going as planned is confusing.

*Figure 16: Patient journey for patient profiles*

The patient journey explains how patients experience their treatment, and because each patient is different, they experience it differently. Based on the patient profiles from Dekkers (2018), the patient journey, in figure 16, shows the pains and gains these different profiles experience during their journey. As previously explained, these patient profiles were researched with TJA patients and describe different patient groups for these patients. For this project it is assumed that these same patient groups exist for lung cancer patients to be able to evaluate how different types of patients experience care pathway and patient education. To understand how the patient profiles from Dekkers relate to lung cancer patients, HCPs were interviewed on how they see patient profiles from their point of view. These HCPs are from the surgical team, therefore there is mainly information during the surgical stage. There is less information on the diagnostics stage and how the different profiles experience the patient journey outside of the CvL. The quotes used in this emotional patient journey are from the interview and italicised and in the grey boxes. Assumptions based on the interview and literature are in the grey outlined boxes.

## Managing patients' experience

Patient that are managing have the highest communication skills between the other profiles. They find it important to have information about the different treatments so they are able to make their own decision on which treatment they receive. As many of the HCPs stated, they provide a lot of information to patients during an appointment and other forms of information are general information. Managing patients are satisfied with this as they prefer having more information. Their communication skills make them capable of being able to organise the information they receive and filter out what they need to be able to make decisions on their treatment. Therefore the appointments when they receive information, managing patients are satisfied and happy. They are also active in searching for information and come prepared to an appointment. They are also active in seeking contact with HCPs and are in control of their health by staying healthy. During their treatment they also expect HCPs to be active in providing treatment, and things such as visiting patients before surgery will assure them that things will go well. If things don't go as planned or said though, this makes managing patients frustrated and unsatisfied with the care. This could be due to long waiting times or miscommunications with other HCPs. After surgery they are capable of recovering due to the fact that they've learned certain skills to build self-care. Even though patient education is provided to patients as if they're managing, HCPs believe that this is the smallest group for lung cancer patients.

## Optimistic patients' experience

The conclusion Dekkers describes optimistic patients are slightly different to how some HCPs see and experience treating optimistic lung cancer patients. Optimistic patients may have lower self-esteem and the diagnosis or even possibility of having lung cancer is devastating for them to hear, as any lung cancer patient might feel when hearing about lung cancer, but for an optimistic patient that was once capable of doing anything, this would be a negative experience. The difference also in the patient profiles for TJA patients and lung cancer patients may be that TJA patients want to keep track of their progress. Optimistic lung cancer patients though want to know just enough information to make important decisions together with their doctor. The amount of information given now to patients may be more than an optimistic patient is interested in and finding the information that interests them and motives them may be more important as they trust doctors to take care of them.

## Modest patients' experience

The CfL notice that most lung cancer patients are like modest patients. They prefer to receive more support from family and guidance throughout treatment from HCPS. Modest patients are a bit more passive in their treatment and less communicative, therefore they tend to ask questions and endure pain. With the current methods of patient education, they are overwhelmed with the amount of information they receive and don't know how to use all the information they've received. Therefore the appointments are stressful moments for patients when they receive all the information. The patient journey is stressful for them and HCPs keep contact regularly with them to see how they're doing and make sure they're making progress in their health. HCPs keep contact by calling patients, visiting before surgery and after surgery in the clinic. In the clinic, different HCPs are busy caring for other patients and may not know the patient and clinical pathway as well as others, which may result in giving wrong information or certain tasks that may be skipped or will take longer than usual. This is confusing for modest patients and makes them worried about their recovery. Since they are also more passive, they will rely more on HCPs and their family for support during recovery.

## Other patients' experience

Not all patients fit exactly into these three profiles, but these are the more generalised groups. Another way HCPs would group patients are in the amount of information patients want to know. Some patients want to know everything and stay on top of their health by being an active participant in their treatment. Other patients don't want to know anything, which makes recovery difficult if they don't know what to do and how to reduce chances of complications. Other patients receive too much information and aren't able to comprehend everything they're told, so the care pathway still comes as a surprise for them even though they were told everything from beforehand. Another difference between patients is their support systems and who accompanies them during appointments. As an HCP described, partners are more supportive in reassuring the patient that they'll go through it together. The younger generation, like grandchildren, is more supportive and encouraging or a daughter/son are on top of things. They listen carefully to instructions and stimulate the patient to do things.

# chapter five: design challenge

This chapter gives a summary of the insights and opportunities from research and how this ties in with the research question. The design brief will further describe the design direction.

The research question for this project is, 'How and when can HCPs personalise patient education to improve the patient journey.' Research was done at the Albert Schweitzer Hospital to have a clear overview of how patient education is currently given to lung cancer patients that can receive an operation. This was done through interviews with the surgical team and observations during consultations. Currently, when lung cancer patients are referred to the lung cancer department at the hospital they receive information and support up until their surgery to help them prepare for it, which is called prehabilitation. Patient education is mainly given during the first consultation appointment patients have with the surgical team. Other tools used for patient education are the website, pamphlet, and app. Their method of the 'carousel', where patients have multiple appointments and meet the surgical team all in one day at the Centre for Lung Cancer, works well for the surgical team and patients and is an improvement from how appointment previously ran. Patients can meet the surgical team and see their teamwork which creates a safe atmosphere where patients can trust the medical professionals. HCPs find it important that through this meeting patients are informed and can be engaged in decision making and self-care.

These methods of patient education, however, are given to the patient in the same manner and does not consider the different needs and preferences that a patient has as to when and how they receive this information. The website, pamphlet, and app are mainly a one-way provision of information and takes little consideration of a patient's unique personality and situation. This may not be an effective way to keep patients informed and engaged in their treatment. Through the consultation and keeping in contact with patients, HCPs do try to get to know a patient better, but this sometimes proves difficult as the surgical team meets patients for the first time when they also give patients information on the operation. They also have limited time with patients to get to know patients, provide a large amount of information and also do administrative work which creates a barrier for HCPs.

## Design challenge

The focus of this project is lung cancer patients receiving surgery and the patient education they receive about this treatment. Through personalising patient education, patients will ideally become more knowledgeable about their situation and actively involved during treatment. Patients that are engaged can participate in decision making and self-care, which will increase satisfaction and health outcomes. Personalisation can be achieved if HCPs have a better understanding of the patient they're treating. Therefore to be able to personalise they would need to understand the person in front of them and how they want to be communicated with so that they can provide information in the right way and time.

Patient education can be personalised by providing information using the method patients respond to most, for example through video's or text. The type of information should also be personalised based on the patient's personal situation and at which moment of the patient journey they are in. Patients should also receive information relevant to their interest or concerns. This way patients are more inclined to look into it and will help them to make decisions about their treatment. This information should be easily accessible for patients and personalisation should begin right at the moment the patient journey begins. For the professionals especially, it is important for them to understand the patient's preferences and their goal, so that they can make this into consideration and provide the correct information and make them the focus of their treatment.

# chapter six: personalised profile

**6.1 Online personalised profile**
**6.2 Benefits of a personalised profile**
**6.3 Implementing personalised profiles**

This chapter describes how patients and HCPs can use a personalised profile, the benefits of the tool for all stakeholders and how it can be implemented in the future.

## 6.1 Online personalised profile

*Figure 17: Personalised profile on Mijn ASz*

Providing personalised patient education can be done by combining Mijn ASz and the Behandelpad app as shown in figure 17. On the patient portal patients can create their personal profile to receive information catered to their needs and follow their care pathway. This platform can be used on the computer, tablet or phone. Currently, patients can log in to Mijn ASz to find their medical records and plan in an appointment. Patient education is given during a consultation and is also provided in pamphlets, the website, and the Behandelpad app. These methods of patient education provide standard information for all patients and have minimal interaction with patients. Therefore providing a platform where patients have easy access to the information they're looking for will help patients to make an informed decision and become active in their treatment.

## How patients use the personalised profile

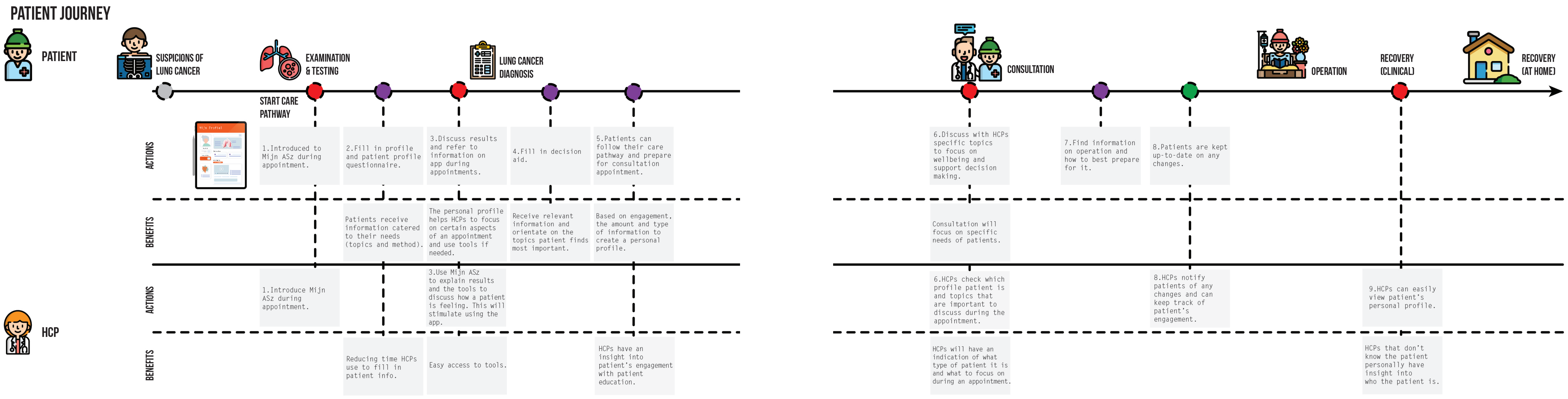


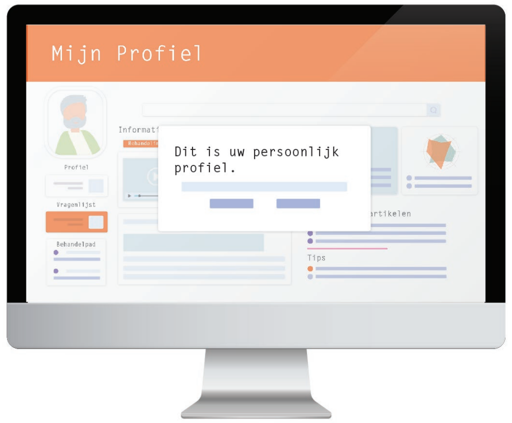
*Figure 18: Steps and benefits for patients and HCPs using the personalised profile*

In figure 18 is the patient journey including using a personalised profile. It describes the steps and benefits for patients and HCPs. (1) When patients have their first appointment with the oncology nurses at the CfL to have their first diagnostic tests, they will be introduced to their personal profile on Mijn ASz. The oncology nurses can explain in short what it is, which is where patients can find their medical records, results, and information on the tests. They can encourage patients to complete their profile so that they can receive personalised information. Information is personalised by type of information and the method it is presented in. Patients that therefore choose not to fill in questionnaires can still view the information, but don't receive personalised information. (2) By logging in with their digiD they'll be able to view and complete their profile. All patients at the ASH already have an account and can log onto Mijn ASz to view their medical records. Patients will be prompted to fill in a series of questions to complete their profile. There are two different questionnaires patients need to fill in to receive personalised information. The first questionnaire determines what type of patient they are and the second questionnaire is a decision aid to provide relevant information.


Mijn ASz

Welkom naar uw profiel!

*Figure 19: Welcome page*


Mijn Profiel

Dit is uw persoonlijk profiel.

*Figure 20: Option for personalisation*

When patients first log in they're welcomed and shown what they can find on their profile (figure 19). Patients that are in the diagnostics stage only need to complete their profile and fill in the first questionnaire. If patients are later diagnosed with lung cancer, they are then prompted to fill in the second questionnaire.

Personal information is already linked to digiD accounts and patients only need to fill in additional personal information to complete their profile. To complete the profile there are standard questions that HCPs regularly ask lung cancer patients, such as, 'do you smoke?' and 'how often do you exercise?'. These answers will help determine what type of information patients receive and provide relevant information. For example, if a patient doesn't smoke, then they won't see information to stop smoking. Patients are given the option to not fill in any information and also to change their profile back to the standard profile if they have filled in information. Patients can customise their profile in the settings, but personalisation provides extra benefits. Not all patients know how they want to be interacted with, especially during treatment. Customising their own profile takes extra time and providing a personalised profile based on other patients groups, makes it easy for patients to use.

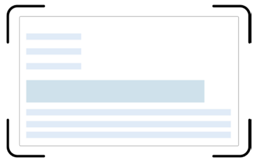


Figure 21: Scan medication list

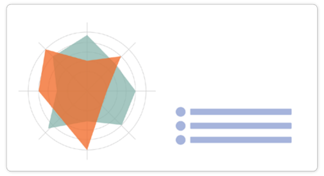


Figure 22: Online tools

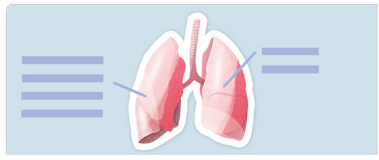


Figure 23: Online visuals

Adding a simple function where patients can take a picture or type the list of medication they use (figure 21), can also change the type of information they see and HCPs don't have to ask for the list and allows patients to fill it in themselves. Patients can fill these questionnaires in pretty much anywhere, as long as they have internet. Patients can fill it in on the go, at home or directly in the hospital lobby or waiting room.

The first questionnaire indicates what type of profile a patient is. This can be managing, optimistic or modest. The patient profiles differ in how the information is presented because the patient groups vary in the amount of interest patients have in information and their capability to comprehend the information provided. Information from the CfL is currently in video and text form, which includes a few visuals. Based on engagement with the platform, it will be able to provide more information in those formats, making it easier and more attractive for patients to find information in the format that is most suitable for them. Therefore the more engagement a patient has with their profile, the more personalised it will become.

(3) HCPs can use the platform during appointments to familiarize patients with their profile. Instead of using the printed pamphlets, they can show the information on the platform and encourage patients to take a look after the appointment. Tools HCPs use during an appointment to discuss with patients can also be added to the platform, giving HCPs easy access to them and where they can easily keep track of previously used tools for patients. Tools are for example the distress thermometer and 'My Positive Health' (which may be used in the future). Patients can look into them (figure 22) and be prompted to fill them in at their leisurely to then discuss during the next appointments. There are also tools that HCPs use that can be digitalised. For example, HCPs use drawings to explain the medical procedure. By adding a picture of a lung on the platform that they can draw on (figure 23), patients can have a digitalised version. Patients can also follow their care pathway through the platform and see which information has been given in previous appointments and also receive notifications on upcoming ones.

At a certain point during the diagnostics stage, patients are either diagnosed with lung cancer or possibly referred to another department in the hospital. Patients that are referred to a different department, also including returning patients, can still use their profile to view results and find information, although not all department have their information online or on an app yet. (4) Patients diagnosed with lung cancer can then fill in the second questionnaire, the decision aid. A decision aid is a tool used for shared decision making. When the lung specialist discusses different treatments with the patient, this can be used as a starting point to engage with patients and discover what they find important. Moreover, patients can receive information they didn't know was relevant to their concerns. For example, a patient may be concerned about the pain after surgery and find out that there are treatments that have less pain or things that they can do before surgery to reduce the amount of pain they might have.

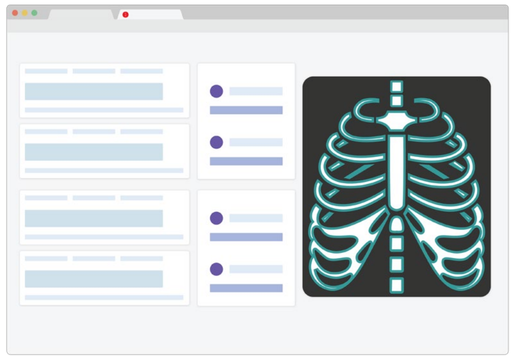


Figure 24: Extra tab on HiX

Figure 25: Personalised patient profile

## How the platform is personalised for different patient groups

HCPs can engage with patients based on their profile and use Mijn Behandelpad as a tool to interact with patients and provide information. Patient records are currently stored on HiX, which HCPs can look at when treating a patient. The focus is mainly on medical information, but storing information about patient engagement on the platform can be on a separate tab (figure 24). HCPs can quickly view which profile a patient is and what topics are of interest to the patient (figure 25). How the platform differs for each profile and the interaction HCPs have with these patients are explained in further detail. These patient profiles are generalised groups that have similar behaviour and needs. Not all 'managing', 'optimistic', or 'modest' patients are the same, this just gives an indication of how a patient may act based on data.

### *Personalised profile for managing patients*

Figure 25: Personalised profile for managing patients

For managing patients, there is an emphasis on information (figure 25). Since they have higher communication skills, they can navigate through this information and understand it. They can read related articles to find topics that may also be relevant to what they're searching for. The information provided will help them prepare for their appointments. There are also extra tips and call to actions to encourage patients to do certain things. The call to actions could be: 'Check out extra pamphlets and workshop flyers in the waiting room' or 'Read the information on the operation before your consultation appointment'. HCPs can discuss the topics they see patients have viewed to make sure they have understood everything correctly and know what to expect.

*Personalised profile for optimistic patients*

Figure 26: Personalised profile for optimistic patients

Optimistic patients appreciate the proivision of information and want to keep track of their progress. Usual care is suitable for them, therefore, their profile is a standard profile (figure 26) that has a balance of information and tools. They can follow along their care pathway and see information that is relevant to them. HCPs can provide the normal patient education of informing patients so they become active in decision making and in their own care.

*Personalised profile for modest patients*

Figure 27: Personalised profile for modest patients

Modest patients need more emotional support and can be overwhelmed by the situation and amount of information given to them. They also have lower communication skills which makes it difficult to understand and use all the information. Their personalised profile (figure 27) has summarised information and question mark button for topics they don't completely understand. HCPs can cover these specific topics during a consulation. Tools also use different and questionnaires are visualised differently, making it easier for modest patients to fill in and disucss with HCPs. HCPs need to focus on providing emotional support to modest patients. Creating a treatment plan with them based on their preferences and needs, can help them to be more motivated in achieving their goals.

# 6.2 Benefits of a personalised profile

## Benefits for patients

A personalised profile will benefit patients by providing information based on their preferences and needs. The more patients engage with their profile, the content will adapt. This means that the format in which patients interact with (video or text) and topics they're interested in will either appear more or less. Based on their profile, the platform also provides extra tools that are useful for certain patient groups. Currently, patients also have to search for their own information by topic but a decision aid could filter out topics patients didn't know were relevant to their interests or concerns. The platform can also be used on any device, making it easily accessible for patients to use. Patients would not have to go to the website for their patient records and then the app to keep track of their progress.

## Benefits for HCPs

HCPs often found it difficult to know the type of patient that's sitting in front of them. Using personalised profiles give them insight into how they can provide patient-centred care. Getting patients to become more engaged, by for example filling in their own medication list, can save HCPs time. Other tool on the platform can reduce administrative and paperwork for HCPs. They can use this time to focus on certain aspects of care.

## Benefits for CfL

Currently, there is no method of gaining data on the use of patient education materials that the CfL provides. There are paper pamphlets which cannot be checked if they're read. The website is open for anyone to read and the app is not connected to their eletronic patient records. By combining MijnASz and the Behandelpad app, the CfL can gain data into how patients engage. Connecting the two also connects the patient data and information. The data could be analysed to know how the different patient groups interact with the platform and adjust the personalisation accordingly. Since the information is also on a digital platform, it can be easily updated instead of have to print new pamphlets or having to update both the website and app.

The patient portal and app both already exist and are in use. Personalisation can renew its format. By personalising information, patients will engage more with patient education aside from the consultation. It is important that if patient engagement increases, that HCPs act accordingly, otherwise this may affect a patient's journey.

# 6.3 Implementing personalised profiles

There are two main focusses for implementation: the personalised platform and patient groups. The patient portal and app need to be connected to gather patient data. According to Marcel, the head of innovation at the ASH, connecting the two would cost a lot of money. Since these platforms are made from two different companies, they don't want the features to be combined. It is important though that these platforms are able to exchange data in the future. Especially if the HCPs are looking into expanding the app, there is a lot of data that could be used to improve their care. It would be easier for HCPs to see the data linked to the personal profile and patients can easily use multiple devices. HCPs should start making more use of the patient portal and also encourage patients to do so to. This will ease them into getting use to the platform. The methods of patient education at the CfL should also include more visuals, which could help patients understand the lengthy texts.

User research on the patient groups are also important. Understanding the patient groups within lung cancer is essential to providing personalised care. Tools and and interview guide for user research is in Appendix C. Based on the patient groups, HCPs can discuss which information is important for which patient group and how they can adapt their care. HCPs may also need training on interpersonal communication skills. There aren't any set guidelines on how to personalise their care. Patients won't be the only 'modest' or 'optimistic' even if their profile says they are, so HCPs will need to adapt to the situation and must know how to communicate with patients.

# chapter seven: conclusion

7.1 Discussion
7.2 Conclusion

This chapter describes the results, limitations, recommendations of future research that should be executed, and a conclusion.

## 7.1 Discussion

The goal of patient education is for patients to become knowledgeable so that they can be involved in making decisions and building skills for self-care. Personalisation is essential to achieving this goal, but the current methods of patient education are standardised. The results of this research are visualisations of the current process of patient education, insights and opportunities to improve patient education, and a proposal on how to personalise patient education. Personalising patient education at the CfL can improve patients' experience and can be done using patient profiles. Patient education should be personalised by personalising the methods, information and dialogue. The method is which format patients receive information in. Patients can choose what type of format they view the information in, making it easier for patients to understand and use. Personalised information will keep patients engaged and HCPs can provide personalised care based on their characteristics. This will create a dialogue between patients and HCPs to make shared decisions.

### Limitations

This research mainly focusses on the HCP perspective of patient education. Patients were not directly contacted due to hospital regulation and ethical measures. Information on patient satisfaction and their experience are either from the Consumer Quality Index questionnaire or from an HCP point of view. Patients experience their journey from a different standpoint and will have different needs than HCPs. Also, due to time constraint, the proposal was not fully tested with HCPs and users.

### Recommendation & future research

The following research should be carried out to be able to provide personalised patient education. User research is needed to understand how patients experience patient education currently. The CfL can then improve their patient education based on the feedback given. Furthermore, there should be research on the type of patient groups within lung cancer and their behaviour. Patient profiles for lung cancer patients could give HCPs a bit more information on patients and how to care for them.

## 7.2 Conclusion

Patient education can be personalised by personalising the methods, information and dialogue. This should start right at the beginning of the patient journey so that HCPs can focus on putting the patient's goal as the priority throughout care. Through personalising the engagement between HCPs and patients, they can build a relationship where patients trust HCPs and HCPs know the preferences and needs of a patient. From the information they received, they can use this to participate in decision making and building skills for self-care. Patients that have participated in decision making will be motivated to work on their set goal and understand what to expect, which will improve their satisfaction. They can become active in their treatment by using the self-care skills they have learned, which are: not smoking, eating healthy and exercising.

Personalising patient education is an important aspect that is needed for patients to actually become active in decision making and their treatment. Standardised methods are not enough in this day and age and personalisation can make an improvement in healthcare by focussing more on the patient .

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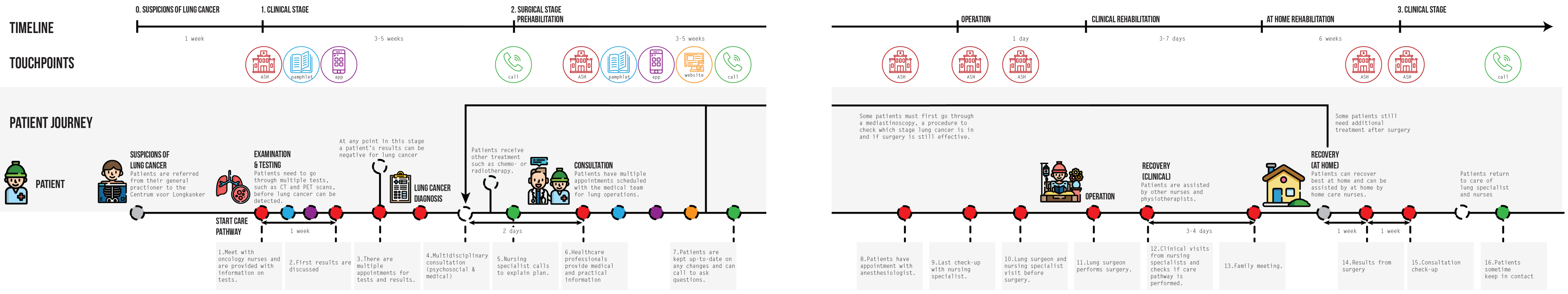
# appendix

A. Patient journey for lung cancer patients
B. Interview guide and tools
C. Interview guide for user research

## A: Patient journey for lung cancer patients



Patients are referred from their general practioner to the Centrum voor Longkanker

Patients need to go through multiple tests, such as CT and PET scans, before lung cancer can be detected.

At any point in this stage a patient's results can be negative for lung cancer

Patients receive other treatment such as chemo- or radiotherapy.

Patients have multiple appointments scheduled with the medical team for lung operations.

Some patients must first go through a mediastinoscopy, a procedure to check which stage lung cancer is in and if surgery is still effective.

Patients are assisted by other nurses and physiotherapists.

Some patients still need additional treatment after surgery

Patients can recover best at home and can be assisted by at home by home care nurses.

Patients return to care of lung specialist and nurses

1.Meet with oncology nurses and are provided with information on tests.

2.First results are discussed

3.There are multiple appointments for tests and results.

4.Multidisciplinary consultation (psychosocial & medical)

5.Nursing specialist calls to explain plan.

6.Healthcare professionals provide medical and practical information

7.Patients are kept up-to-date on any changes and can call to ask questions.

8.Patients have appointment with anesthesiologist.

9.Last check-up with nursing specialist.

10.Lung surgeon and nursing specialist visit before surgery.

11.Lung surgeon performs surgery.

12.Clinical visits from nursing specialists and checks if care pathway is performed.

13.Family meeting.

14.Results from surgery

15.Consultation check-up

16.Patients sometime keep in contact

## B: Interview guide and tools

*Goals:*

- What is the goal/value of the consultation appointment for patients?
  - Goal/values
- What role do the different HCP's play to achieve this goal?
  - Tasks, encounters, touchpoints (experience)
  - Constraints
  - USP's
- What role do HCP's want patients to play to achieve this goal?
  - Relationship
- What changes can be made to improve patient education (short and long term)?
  - Personalisation

*Introduction:*

*"Graag wil ik door middel van dit gesprek beter begrijpen wat jouw rol is binnen de Centrum voor Longkanker voor longkanker patiënten. Waar we op focussen is patiënten educatie voor longoperaties. Ik wil erachter komen hoe jij de patient journey ervaart op dit moment, jouw ervaring in het verleden en hoe het in de toekomst eruit kan zien."*

*Questions:*

1. Hebben jullie een strategie (doel) opgesteld voor de spreekuur/longoperaties dat jullie willen behalen in de komende jaren?
- Wie zijn betrokken bij het besluiten van dit doel?
- Hoe hebben jullie dit besloten?
- Wat zijn de stappen nodig om dit doel te behalen?

2. Werkt de Centrum voor Longkanker (CvL) samen met andere partners betreft patiënten education rondom operaties voor longkanker? Er hangen bijvoorbeeld flyers in de wachtruimte over workshops en groepssessies?

3. In hoeverre mag een patiënt kiezen in welke ziekenhuis ze willen behandeld zijn? Merken jullie dat patiënten specifiek voor het Albert Schweitzer Ziekenhuis (ASZ) kiezen of juist op zoek zijn naar een andere? Waarop baseren ze hun keuze? (Afstand of zorg?)

4. Zien jullie andere ziekenhuizen als concurrent?

5. Waarin is ASZ beter dan de concurrent?

*"Om te beginnen wil ik eerst beginnen met een algemene blik op patiënten educatie."*

1. Wat is het doel van patiënten educatie voor jou als longchirurg?
- Wat is voor jou het doel van patiënten educatie voor het patiënt?

2. Wat wil je dat het patiënt eruit haalt/doet met de informatie?
- Wat zijn je verwachtingen van een patiënt?

3. Zijn er specifieke taken die je uitvoert om deze doelen te behalen?

The following questions are about how HCPs experience the patient journey. The patient journey tool on the following page was used.

1. Wat is jouw ervaring van de patiënt journey?

2. Wanneer zie je de patiënt of doe je iets voor de patiënt?

3. Wat voor informatie geef je aan de patiënt?

4. Hoe zorg je ervoor dat de informatie die je geeft aansluit op wat de andere zorgverleners zegt?

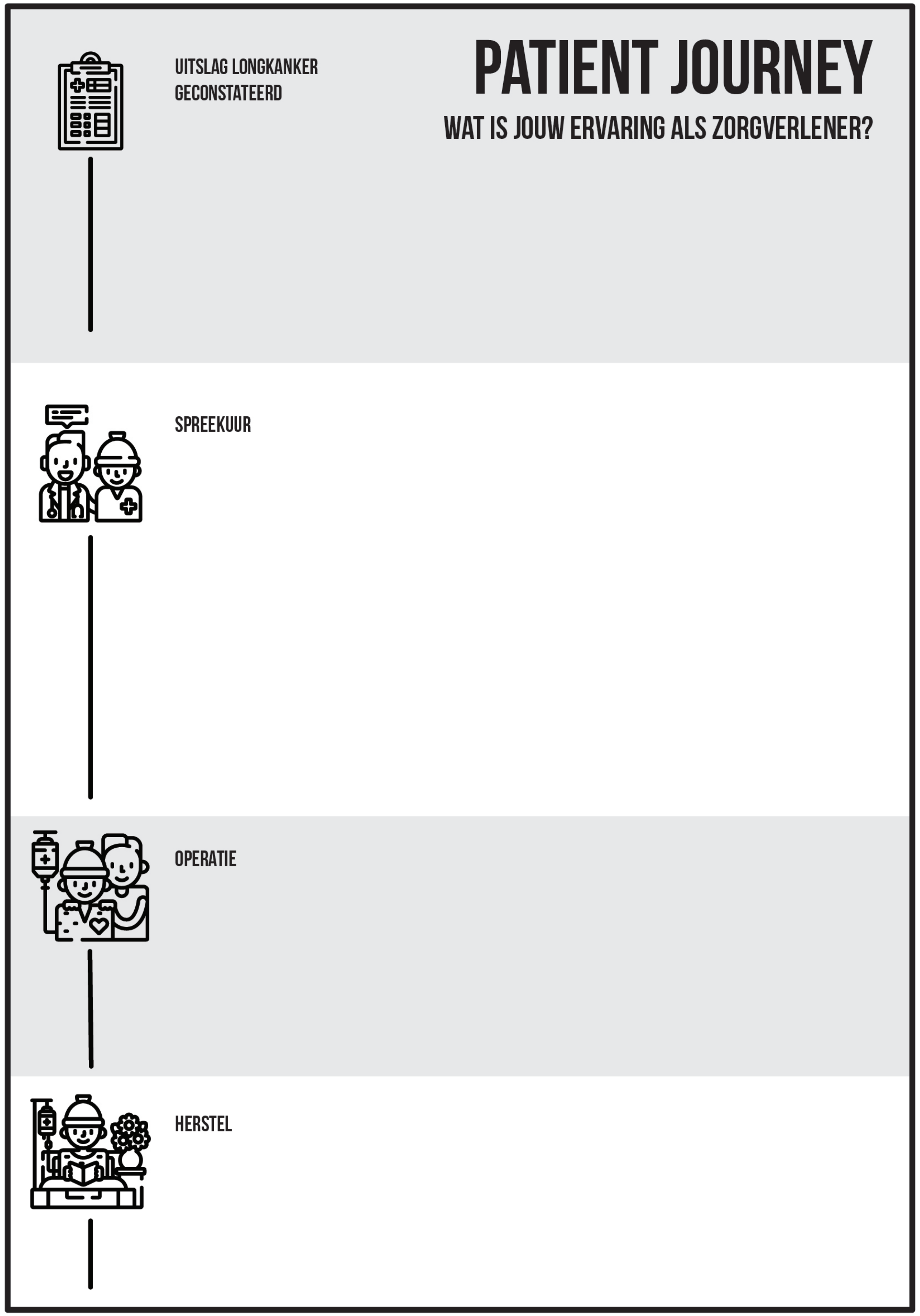
5. Wat is het resultaat van het spreekuur? Hoe gaan patiënten om met de informatie die jij aan ze hebt gegeven?

The list below are probing questions that were asked if HCPs talked about any of the topics.

- Hoe bereid je voor op een gesprek?
  Wat zijn dingen waar jij rekening moet houden?

- Hoe betrek je een patiënt bij het gesprek?

- In hoeverre mogen patiënten keuzes maken tijdens hun behandeling?/Wanneer worden patiënten erbij betrokken in het maken van keuzes?



# PATIENT JOURNEY

## WAT IS JOUW ERVARING ALS ZORGVERLENER?

**UITSLAG LONGKANKER GECONSTATEERD**

**SPREEKUUR**

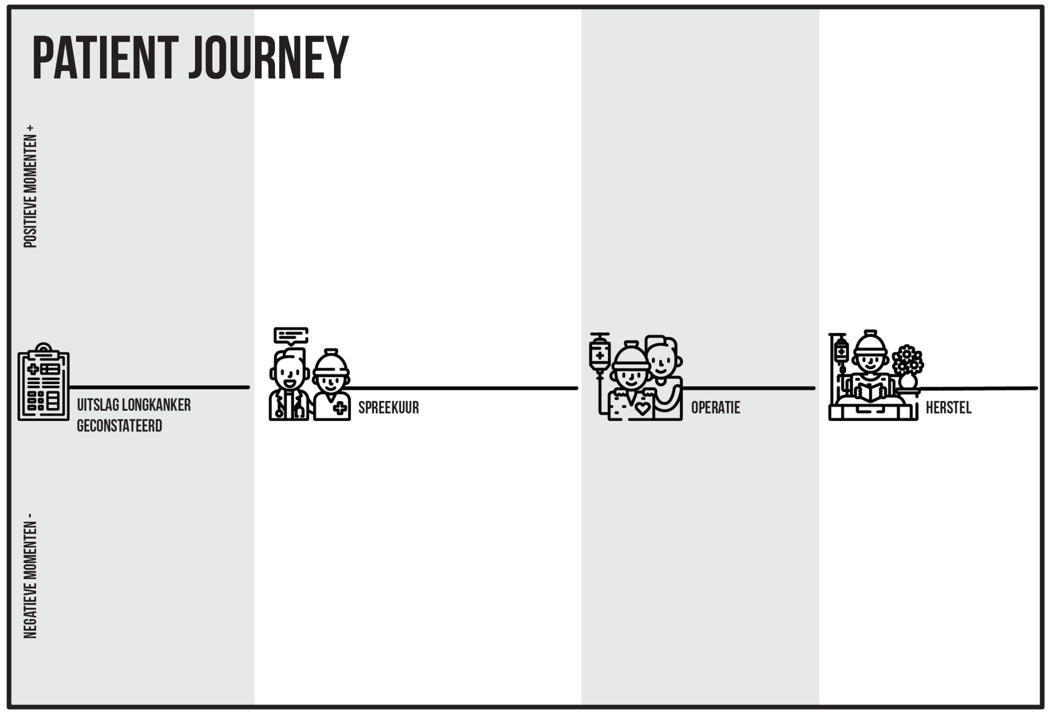
**OPERATIE**

**HERSTEL**

- In hoeverre betrek je familieleden/vrienden bij de conversatie? Of in het prehabilitation van de patiënt?
  Zie je mogelijkheden hiervoor, dat familieleden/vrienden vaker worden betrokken bij het prehabilitation/herstel van een patiënt?
  Zo ja/nee wat zou er dan moeten veranderen? Waarom is dit volgens jou nodig?
- Wat vind jij dat de CvL goed doet voor de patiënten (tov andere ziekenhuizen)?
- Welke problemen loop je tegenaan tijdens dit proces?
- Vind je dat het doel is behaald? Waaruit blijkt het dat het doel (niet) is behaald?

*"Als je terugdenkt aan je slechtste ervaring met een patiënt, het hoeft niet per se dat de patiënt het ziekst was, maar een ervaring dat voor jou gevoel minder goed ging. Hier heb ik een patient journey dat beschrijft de stappen die een patiënt samen met jou doorloopt. "*

The tool below is the patient journey again, but this time space above and below for HCPs to write their pains and gains.



1. Kan je nu je ervaring delen? Hoe ging je om met deze patiënt?

*"Hiervoor heb ik de positieve gezondheid spinnenweb, waarbij je een patiënt op verschillende aspecten van gezondheid kan beschrijven. "*

1. Kan je de patiënt beschrijven die je aan het behandelen was?
2. Kan je vertellen waarom je een bepaald cijfer geeft voor ________?
3. Hoe schat je in hoeveel mensen willen meedenken?
4. Kan je met deze stickers met de bijbehorende kleur aangeven hoe deze (zes) pijlers zijn veranderd over tijd voor de patiënt?

The next questions are about patient groups within lung cancer.

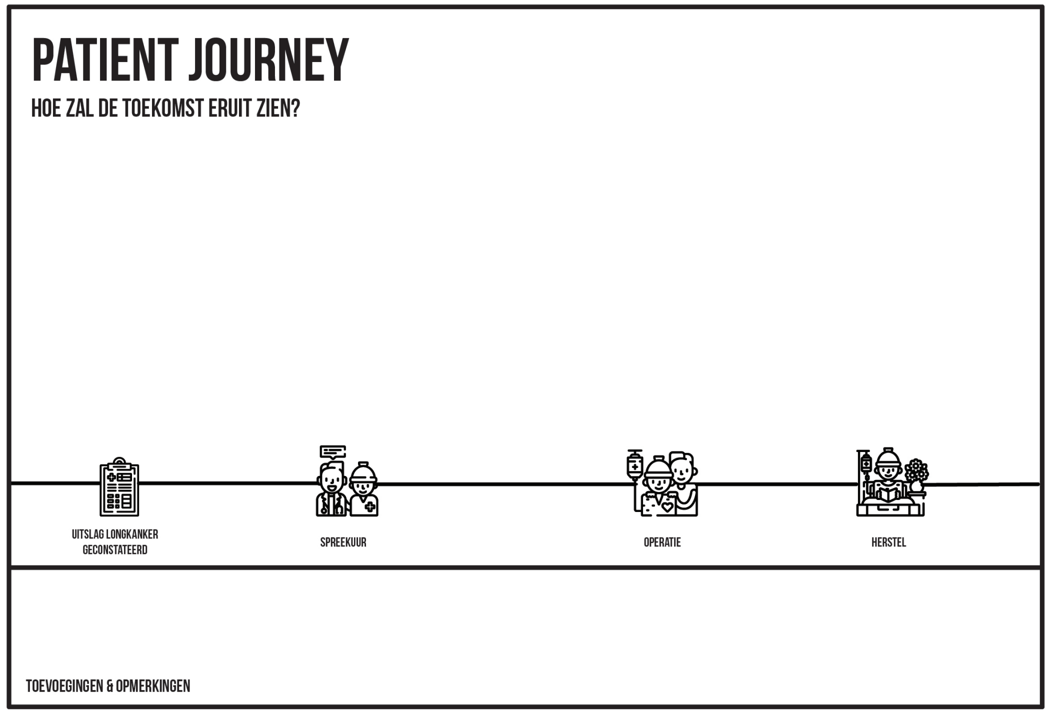
1. Merk je grote verschillen tussen patiënten? (Ziekte, levensstijl, stress…?)

2. Kan je de verschillende “soorten” patiënten beschrijven?
- Hoe ga je om met de verschillen in … ?
- Hoe belangrijk is personalisatie voor jou? Op welke manier merk je dat?
- Wat zou je willen weten van een patiënt om te kunnen personaliseren?
- Vind je personalisatie een taak van de zorgverlener? Vind je dit een taak van het systeem?

3. Herken je deze groepen patiënten ook bij longkanker patiënten?

4. Wat vinden jullie van patiënten profielen en het gebruik van personaliseren op groepen?

*“Als we nu kijken naar de toekomst.”*



1. Hoe zou personaliseren een rol kunnen spelen bij het CvL?

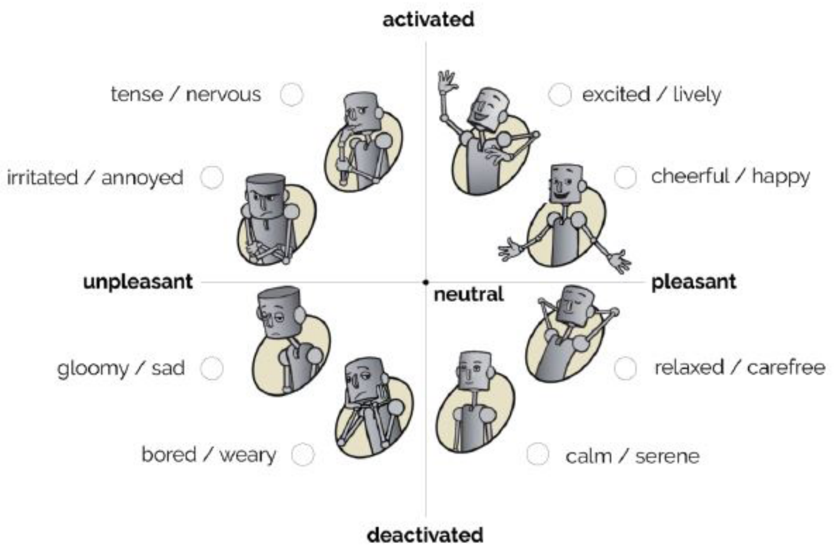
2. Zijn er nu andere manieren waardoor het spreekuur verbeterd worden? Wat is hiervoor nodig?

3. Hoe kunnen jullie ervoor zorgen dat de informatie dat gegeven wordt aansluit op elkaar en consistent blijft?

## C: Interview guide for user research

Doel: Begrijpen welke stappen patiënten doorlopen tijdens hun behandeling en hoe ze dat ervaring (gekoppeld aan hun profiel)

*“Bedankt dat u mee wilt doen aan het onderzoek over uw ervaring bij het Centrum voor Longkanker. Voor dit onderzoek gaat het specifiek over de informatie dat u ontvangt rondom het spreekuur. Om te begrijpen wat u heeft ervaren gaan we samen stap voor stap door het process lopen vanaf het moment dat u door de verpleegkundig specialist werd gebeld voor een afspraak voor het spreekuur. Daarnaast vraag ik u om ook te beschrijven welke emotie u voelde op dat moment met betrekking tot het wat u heeft ervaren. Hierbij is een emotie chart, dit kunt u gebruiken om u te helpen met het beschrijven van hoe u voelde toen”*



Patients are asked to fill in their journey during the interview in the experience card on the next page. The questions are asked to better understand their experience.

*Voor het spreekuur*

1. Als eerst bent u gebeld door de verpleegkundig specialist om een afspraak te maken voor
- het spreekuur. Kunt u mij vertellen hoe dit is gegaan?
- Wat was er besproken? Wat voor informatie heeft u gekregen?
- Wist u al van tevoren wat het spreekuur inhield?
- Had u bepaalde verwachtingen van het spreekuur?
- Was alles duidelijk?
- Had u bepaalde vragen (die niet zijn beantwoord)?

2. Kunt u mij vertellen hoe u daarbij voelde? Waarom?

3. Hoeveel tijd was er tussen het telefoongesprek en de afspraak? Hoe voelde uw daarbij?

4. Heeft u voor het spreekuur nog informatie opgezocht over uw gezondheid?
Hoe heeft u uw informatie opgezocht?
Heeft u informatie van andere mensen gekregen? Zo ja, wie?

5. Heeft u bepaalde dingen veranderd aan uw levensstijl na de uitslag/het opzoeken van informatie?
Zo ja, wat voor verandering en op welk moment bent u begonnen?
Waardoor ben u begonnen met uw levensstijl veranderen?

# PATIËNT ERVARING

FASES

UITSLAG

SPREEKUUR
CHIRURG

VERPLEEGKUNDIG
SPECIALIST

FYSIOTHERAPEUT

ACTIVITEITEN

ERVARING

POSITIEVE
GEVOELENS

NEUTRAAL

NEGATIEVE
GEVOELENS

*Tijdens het afspraak*

1. Bent u op tijd geholpen? Hoe lang moest u wachten? Hoe voelde in het wachtruimte?

2. Tijdens het afspraak heb je met verschillende HCP's gesproken zoals: de poli-assistenten, longchirurg, verpleegkundig specialist, fysiotherapeut en de OK-planner. Met wie heeft u als eerste gesproken?

3. Hoe verliep het gesprek met de chirurg/verpleegkundig specialist/fysiotherapeut? Wat voor informatie heeft u ontvangen?

4. Wat vond u fijn aan het gesprek?

5. Wat vond u minder fijn aan het gesprek?

6. Hoe voelde u tijdens het gesprek met de chirurg/verpleegkundig specialist/fysiotherapeut?

7. Had u iemand meegenomen naar het spreekuur?
   Wie was het?
   Waarom is diegene meegekomen?

*Algemene vragen*

1. Heef u de ASZ website gebruikt?
- Hoe heb je de website gebruikt?
- Wat vond er ervan?

2. Heeft u de ASZ Behandelpad app gebruikt? Zo nee, waarom niet?
- Zo ja, vanaf welk moment heeft u de app gebruikt?
- Hoe heeft u de app gebruikt?
- Wat vindt u ervan?
- Wanneer had u voor het eerst over de app gehoord?
- Had u eerder over de app willen horen?