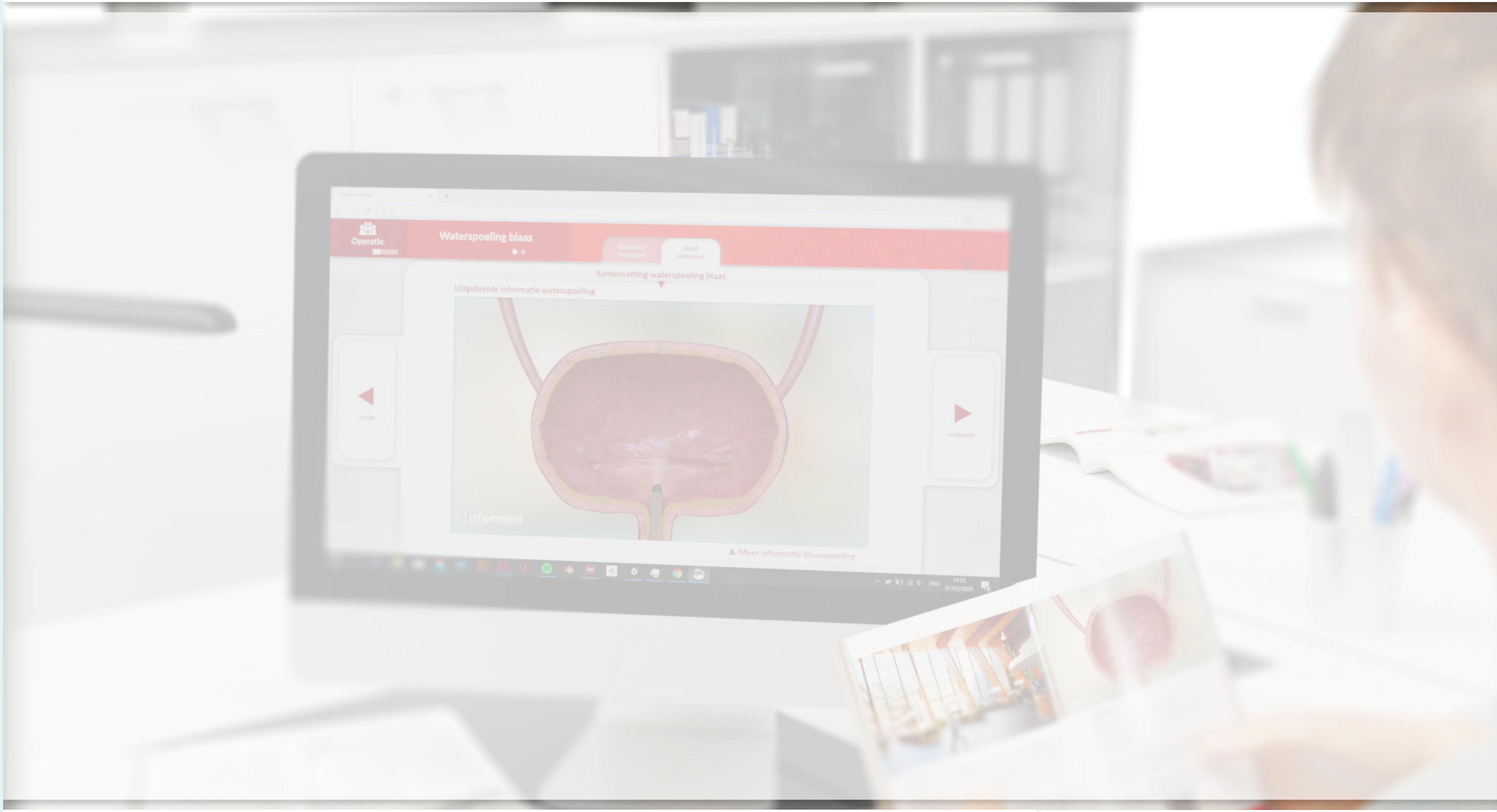

Tailored Interactive 3D animation

for NMIBC patients

TU Delft Msc. Graduation Project by
S. A. Steenbergen

PREFACE

"Because I already had the surgery, I understand and can visualize everything. However, if you use the interactive animation in advance, you'll know a lot already and be better prepared. And the medical specialists have to explain less."

This quote is the result of the last couple of months of hard work. The participant tested the tailored interactive animation and afterwards pointed out that this was something that many patients and medical specialists would benefit from. The tailored interactive animation was preferred over the current resources as a health information material. The conclusions of this project show a promising future for tailored interactive animations as a primary source for health information. For the future, I hope to play a part in the further development of tailored interactive animations, make it accessible for everyone at anytime and help many patients in understanding complex health information to reduce their anxiety and uncertainty.

Selwyn

The team members for this project:
TU Delft supervisors: dr. V. Visch and dr. ir. N. J. H. Vegt.
Informed/SFVG supervisor and urologist: dr. S. H. de Vries

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CONTEXT EXPLORATION

In this phase the context will be explored to learn about the target group and their disease. Thereby the treatment traject will be described to gain insights in the care provided by the Franciscus hospital. These findings will be accompanied by the resources the medical specialists of franciscus have to inform patients.

Problem definition

The goal of this project is to design a **tailored interactive 3D animation** that suits **non-muscle invasive bladder cancer patients** with different **patient profiles**, to increase their treatment **engagement** and reduces their **anxiety** and **uncertainty**.

INTRODUCTION

The starting point for this project is to create a better patient-focused treatment explanation animation together with Sint Francisucs Vlietland Groep and Informed.

Sint Franciscus Vlietland Groep

The Sint Franciscus Vlietland Groep (SFVG) is a hospital group as a result of the collaboration between 'het Sint Franciscus Gasthuis' in Rotterdam and 'Vlietland Ziekenhuis' in Schiedam. The SFVG is a general hospital and facilitated 574.111 outpatient clinical visits in 2019.[1] For comparison, the academical hospital, Erasmus MC, facilitated a similar number of 572.717 outpatient clinical visits in 2018.[2]

Informed

The company, Informed, creates a medical library with validated explanation videos. In collaboration with the SFVG and their medical specialists, they continuously work on 3D animations to explain patients about their medical treatment.

In the past two years the library grew to a sustainable amount of 3D animations. The library contains 100+ animations, covering specialisms as urology, gynaecology, anesthesia, surgery and more. SFVG and Informed want to investigate how the animations can be improved. They continuously research the requirements for patient-information and are interested in how the explanation videos can be improved to better meet the patient's health information needs.

RELEVANCE

The medical specialists of the SFVG inform their patients about their medical treatment to provide the best care. Exchanging information and knowledge is essential to make the best medical diagnosis and determine the best treatment plan for patients. Which information has to be exchanged is legislated by law. This law is referred to as 'informed consent'.

Informed consent

There is an ongoing trend in healthcare called 'shared decision making', which lead to a 2020 update for 'informed consent', to strengthen the patient's position.[3] This implies that the medical specialist has to inform the patient about the nature and goal of the treatment and the patient's state of health in a for the patient comprehensible manner. The medical specialist has the duty to verify the patient's understanding of the health information.[4,5]

Information loss

The information exchange between medical specialists and patients happens during consults in the hospital. The SFVG's medical specialists have ten minutes of consulting time per patient to address all the topics of informed consent. Studies showed that patient do not remember all information after consults, only 20% of the information can be recalled. The information given by the medical specialist is not processed by patients, due to attentional narrowing. This occurs if events are perceived as stressful or emotional. Patients process one central message which can become the primary focus. A message from the doctor like, 'this disease is chronical and will affect your daily life drastically'. Other information as treatment planning or lifestyle rules is not processed.[6]

Knowledge reduces anxiety and uncertainty

The most common emotional responses of patients are anxiety and uncertainty. These problematic emotional responses for patients do not only occur during the consult, but may occur throughout the complete treatment trajectory. Studies showed that the patient's anxiety can be reduced by improving their knowledge about the treatment.[7] Further research learned that the patient's uncertainty can be reduced by realistic and objective information.[8] Thus, more knowledge reduces the patient's anxiety and uncertainty.

Explanation videos

The patient is lacking medical knowledge which results in negative emotions. The medical specialist wants to provide information, but can't due to the patient's negative emotions. See fig. 1.Therefore information is shared via paper folders, so patients can process medical information at home. Research showed that real-footage explanation videos reduce the anxiety of patients before surgery and is beneficial compared to a traditional medium as a folder.[9] Furthermore, it is assumed that 3D animation is an excellent medium for patient-information communication, since it allows a wide spectrum of possibilities to optimally visualize complex health information.

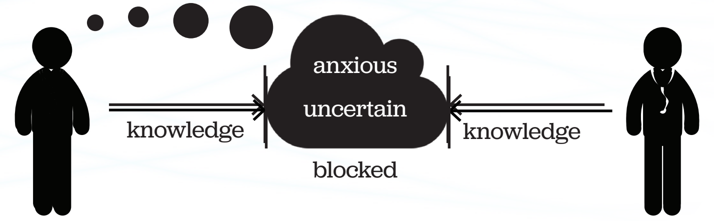


fig. 1, knowledge exhange issue

INFORMED CONSENT

BACKGROUND

The law, Wet geneeskundige behandelingsovereenkomst (WGBO), addresses the patient's rights on health information. The law is created in 1995 and the latest version dates from 2020. The WGBO describes issues as the right of the patient on information, limitation of right on information due to therapeutical exception, the patient's right on not to know and the patient's duty to provide information.[3,4,5]

In this project the law of the patient's right on information is the most relevant, since it describes all topics medical specialists have to address when providing health information.

These topics are:
- the nature and the goal of the research or treatment;
- the expected effects and risks for the health state of the patient;
- other methods of research or treatment;
- the current health state of the patient and their future prospects.

After the consult and thus all relevant information is provided, the patient and the medical specialist make an agreement. This agreement is referred to as 'informed consent'.[4]

Adjustments WGBO 2020
From the first of january, WGBO is adjusted, as a part of shared decision making in healthcare, to further strengthen the patient's position.The medical specialist has the duty to consult the patient in time, in a for the patient comprehensible manner. The specialist has to verify if the patient understood the provided information. Thereby the specialist has to examine the patient's situation and needs, and allow the patient to ask questions. [3]

TREATMENT

The SFVG offers care in many specialisms as gynaecology, orthopedics, urology, oncology and more. For many of these specialisms animations are used by medical specialists to inform patients about their medical treatment. The medical animation library covers 100+ treatments, and is still growing.

Focus on the TUR-B animation
In this project the focus will be on the TUR-B animation only. By focussing on one treatment and the corresponding animation, it allows us to dive deep and research a specific target group. The TUR-B animation covers the urological treatment, transurethral resection of the bladder, with aim to cure a patient from non-muscle invasive bladder cancer. The corresponding treatment trajectory and severity of the disease, result in a certain complexity, make this treatment the optimal example to show difficulties patients and medical specialists encounter in exchanging information.[10]

What is non-muscle invasive bladder cancer?
Non-muscle invasive bladder cancer (NMIBC) is cancer in tissue on the inner surface in the bladder. This means that the bladder muscle tissue is not involved. The severity of the cancer depends on the tumor stage and grade. The tumor stage describes how deep the tumor grows into the bladder tissue.
Tumor stages:
Ta: Tumor on the surface of the bladder
Tis: High grade cancer, flat patch on the surface of the bladder
T1: Tumor goes through the surface, but not into the muscle tissue.
T2: Tumor reached the muscle layer
T3: Tumor grows through the muscle layer into the fat tissue
T4: Tumor has spread to other surrounding organs, as prostate in men or vagina in females.[11,12]

For NMIBC patients the Ta to T1 tumor stages are relevant. The disease can be treated well, 5-year survival rates for high-grade T1 cancer are about 70-85%. Around 90% of the bladder cancer patients have tumors of these stages.[13]

Symptoms
The main indication of bladder cancer is blood in urine, this is called hematury. In most cases patients do not have pain, and the blood loss will decrease or even completely disappear. Other indications are a frequent urge to urinate or recurrent cystitis.[10]

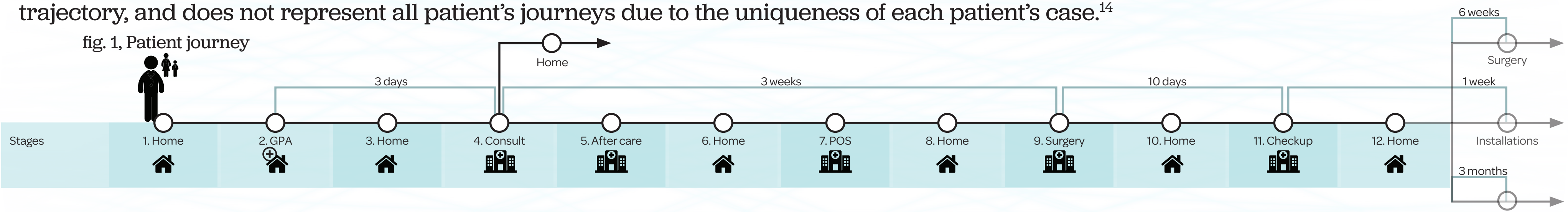
TUR-B
The Transurethral resection of bladder tumor (TUR-B or TURBT) is a surgery with the aim to remove the bladder tumor. A cystoscope or resectoscope is used to remove the tumor via the urethra and collect samples for research. This means that the body is entered via a natural orifice and no incisions are needed. The patient is under anesthesia during this surgery. After the surgery, patients can have bladder installations to prevent from recurring cancer. It is important to note, that there is no alternative treatment to remove the bladder cancer.[10]

Conclusion
The focus in this project will be on the SFVG's TUR-B treatment trajectory. This implies that the target group is patients who suffer non-muscle invasive bladder cancer who have to undergo the TUR-B surgery at the SFVG.

TUR-B PATIENT JOURNEY

How does the SFVG's TUR-B trajectory exactly looks like? The TUR-B patient journey is mapped out in the diagram below to understand where the patients have to go though within the treatment trajectory. It is important to consider that this journey is a generalization of the trajectory, and does not represent all patient's journeys due to the uniqueness of each patient's case.[14]

fig. 1, Patient journey



Description of stages

See fig. 1. The patient journey is developed in collaboration with the medical specialist

1. Home
The patient is at home and discovers there's something wrong. It could be blood in urine, frequent urge to urinate or cystitis. The patient makes an appointment with the general practitioner. The patient is asked to bring an urine sample to the appointment.

2. General practitioner
At the general practitioner's appointment the patient and the urine sample are examined. There is an indication that further research at the hospital is needed and the follow-up appointment, the consult, at the hospital is planned. The patient is asked to bring another urine sample to the hospital in advance.

3. Home
The patient is in awaiting of the consult. The patient has to take another urine sample.

4. Consult
The results of the urine sample research are discussed. The patient is examined by the urologist and diagnosed with bladder cancer. The urologist explains about the treatment trajectory. The urologist introduces the opportunity to visit the oncology nurse. The nurse will answer the patient's further questions.

5. Aftercare
The aftercare is optionally, the patient can opt to visit the oncology nurse. In this meeting the oncology nurse will have all the time to answer all the patient's questions.

6. Home
The patient is in awaiting of the pre-operative screening (POS). The patient can process the provided information and prepare for the screening.

7. POS
The patient is screened for the surgery. The screening consist of talks with the anesthetist to discuss medication and anesthesia, a talk with the doctor's assistant to share more information for the surgery and a talk with the pharmacist to further elaborate on the medication.

8. Home
The patient is in awaiting of and has to prepare for the surgery. For preparation, important topics to consider for the patient is medication and eating and drinking behavior.

9. Surgery
The patient undergoes the bladder removal surgery. And a sample of the cancer is taken. After the surgery the patient has to recover and get bladder rinsing. When the patient's urine is clean, the patient is allowed to go home.

10. Home
The patient is recovering from the surgery and in awaiting of the checkup at the hospital.

11. Checkup
The results of the surgery and cancer research are discussed to determine the follow-up treatment trajectory.

12. Home
The patient is awaiting of the next consult.

TARGET GROUP

Who are the patients that follow the TUR-B trajectory? What are their needs concerning health information during this trajectory?

Demographics
In 2018 around 6800 people are diagnosed with bladder cancer. These are invasive and non-invasive tumours.
Bladder cancer occurs **three** times more frequent by men than women.

Bladder cancer is for both men and women **top-10** most common cancers. For men it is ranked 6 and for women 7.

Age of diagnosed bladder cancer patients:

15%	27%	35%	23%
<60y	60-69y	70-79y	80+y

Bladder cancer causes
The most important risk factor for bladder cancer is smoking. **30 to 40%** of the bladder cancer patients are diseased due to smoking. Smokers have 3 times more chance of bladder cancer than non-smokers.

People who were in a lot of contact with certain **chemicals** as aromatic amines (textile and paint) tend to have more risk of bladder cancer.

Another explanation can be **genetic predisposition**, if several first-grade family members were diagnosed with bladder cancer.[15]

Contact
The NMIBC patients have the most frequent contact with the **oncology nurse** and their **urologist** during the TUR-B treatment trajectory. The analysis, based on previous research[14], to determine these stakeholders can be found in appendix A.

Conclusions
- The NMIBC patients are mostly men. (3 times more than women)
- The age of only 15% of the patients is under 60 years, and thus the target group is elderly people.
- The NMIBC patients have frequent contact with the oncology nurse and urologist, therefore their role needs to be investigated.

TARGET GROUP

Importance of health information for patients

For patients it is important to understand the treatment information to make choices and manage their conditions. Good care is not providing the facts only, but allowing patients to play a role in shared decision making. To facilitate this shared decision making, it is important not only to provide information, but whether the patient understands the information adequately, can use this information and make a good choice. If information is interactive, patients can choose to access it. Engaging patients with the information is essential to make good choices. Patients who are engaged have better health outcomes.[16] This means that, combined with informed consent, NMIBC patients need to understand the nature of the TUR-B treatment, the expected effects and risks, alternative methods, the current health state and their future prospects.[5] Then patients can participate in shared decision making and better choices can be made.

Tailored information

Every patient is different and has different needs concerning health information. There is a significant need to make the increasingly available health information more usable and useful for all consumers. Patient differ in coping styles if it comes to dealing with health information. Likewise, patients differ in the amount and type of information they need and which aspects of care they prioritize. A one-size-fits-all approach cannot address the finer details that vary from person to person and uniquely affect each individual's health-related decisions and behavior. Tailored information satisfies the individual patients needs concerning health information.[17] Since, there are many differences in patients and its characteristics, it is interesting to look for opportunities to categorize patients and making use of patient profiles.[18]

Conclusions

- It is important to let patient interact with information to support shared decision making.
- More engaged patients have better health outcomes.
- Tailored information affects each individual's health-related decisions and behavior.
- Patients can be categorized with the use of patient profiles.

PROBLEM DEFINITION

All conclusions of the exploration phase result in the following set of concepts (in mentioned order): anxiety, uncertainty, 3D animation, non-muscle invasive bladder cancer patients, interaction, engagement, tailoring and patient profiles. These concepts were combined and this leads us to the following problem definition for this project:

Problem definition

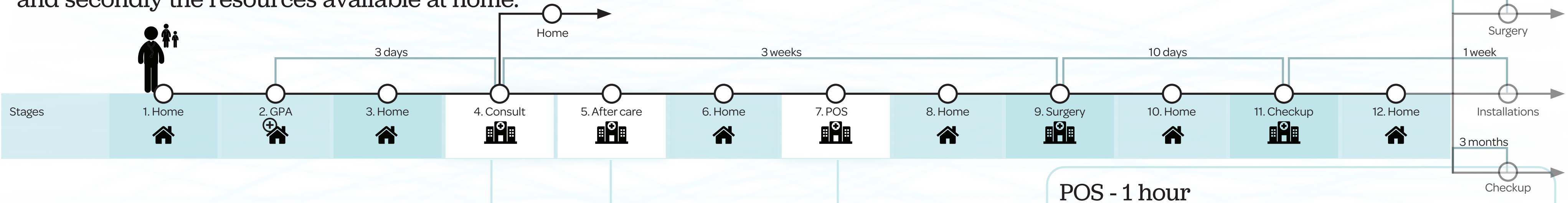
The goal of this project is to design a **tailored interactive 3D animation** that suits **non-muscle invasive bladder cancer patients** with different **patient profiles**, to increase their treatment **engagement** and reduces their **anxiety** and **uncertainty**.

SYNTHESIS

The problem definition is constructed, yet some concepts needs more investigation and clarification. In the next phase The NMIBC patient’s current resources for health information will be developed to learn what is already available during the treatment trajectory. Furthermore, the concept of tailoring will be developed to make it more comprehensible and use it to construct patient profiles.

CURRENT RESOURCES

What are the current resources for patients during the treatment trajectory? First are the resources in the hospital described and secondly the resources available at home.



Consult - 3x 10 min.

The first contact moment in the Franciscus hospital is the consult. The main goal of this moment is to determine the diagnosis of the patient. Therefore research has to be conducted to diagnose the patient. The consult consists of three parts: consult, cystoscopy and TUR-B consult.

1. Consult - 10 min.
After a brief introduction the urologist asks certain questions to learn about the patient's demographic and medical background. The results of the urine research is discussed as well.

2. Cystoscopy - 10 min.
The patient's bladder is inspected during this research. The goal is to find any suspicious deviations inside the bladder on the bladder mucosa. This research is not necessarily painful for the patient, rather uncomfortable.

3. TUR-B consult - 10 min.
The urologists discusses the results, bladder cancer, of the cystoscopy with the patient. All the informed consent topics will be covered in this part.

Aftercare - 1 hour

Due to the severity of the diagnosis and the limited time available, the hospital offers aftercare directly after the consult. In this contact moment, the oncology nurse has time to answer all patient's questions. Thereby she elaborates on the urologist's story to ensure all important information is shared. The oncology nurse is the contact person throughout the treatment trajectory. Notably, this contact moment is optionally. The patient can decide not to talk to the oncolohy nurse.

POS - 1 hour

The next contact moment is the preoperative screening (POS). This contact moment consists of conversations with several medical specialists.

1. Anesthesiologist
The main goal is to inform the patient about the anesthetics needed for the treatment. For the TUR-Bladder the anesthetist will explain about spinal anaesthesia. The specialist will use a questionnaire to gain insights in the patient's health conditions. Occasionally, blood test or ECG, heart rate monitoring, is necessary to ensure the treatment can take place safely. Lastly, all preparations like taking medication, are discussed.

2. Doctor-assistant
The doctor-assistant shares all information about the preparations for the hospitalization and what to expect that day and the days after. The home situation is discussed as well, to learn if homecare has to be arranged.

3. Pharmacist
The pharmacist discusses the patient's medication. Therefore, the patient is asked to bring his or her medication list.

CURRENT RESOURCES

SFVG's 'Verwijderen blaastumor' folder

Next to the contact moments, specialists can provide folders. These folders are created to summarize all the required information concerning the treatment programme. Franciscus has a communication department specialized in writing for low literacy to ensure that all patients can understand the information. The folder addresses all by law mentioned topics to ensure patients are well informed about the treatment. Noteworthy, all folder's information is written and it contains no visuals whatsoever.[10] See appendix B, for the folder's contents.

TUR-B animation

Next to the folder, medical specialists share the TUR-B 3D animation with the patient. This animation summarizes the most important topics of the folder. This animation is made by Informed in collaboration with the urology department to ensure the quality. All recent animations contain eight topics to support patients in processing information: introduction, indication, alternatives, preparation, treatment, complications, aftercare and results. The TUR-B animation is outdated and does not address alternative treatments, preparation, complication and results. If the by government described topics are considered, the animation is lacking information about the expected effects and risks for the health state of the patient and alternative methods of research or treatment. The last topic cannot be covered, since there is no alternative treatment. Nevertheless, this means that patients cannot fully rely on the animation only to gather sufficient information. See appendix C for the TUR-B animation's contents.

QR-code

Scan the QR-code and watch the TUR-B animation

Phone call or mailcontact with oncology nurse

The 'Verwijderen blaastumor' folder contains a chapter about when to contact the hospital. Patients can contact the oncology nurse for urgent questions via phone or mail.

E-consult

The SFVG offers e-consults to give patients another option to contact the hospital. The e-consult is a digital medical consult via internet. Patients can message their medical specialist and receive an answer within three working days.[19]

Family caregivers

Caregivers as relatives, partners, friends and neighbors, who assist the patient during the treatment trajectory cannot be overlooked, since they help patients manage and cope with illness. For patients, information provided by caregivers may be as reliable as the medical record.[20]

Dr. Google

Patients tend to search online for medical information, which is as a resource often referred to as Dr. Google. Patients seek online when they feel the urge to know, to be more informed, to find alternative treatments, to take charge of one's life and to manage self-perceived minor conditions. Patients encounter barriers for online information as limited e-health literacy (presentation of information and volume of information) and inconsistency of information between different websites.[21]

TAILORED INFORMATON

To be able to design tailored health information or eventually an interactive tailored animation, it is important to dive into what tailoring actually is.

What is tailoring?
Tailored materials are focused on one specific person, are based on the individual's characteristics unique to this person. Often the term, targeted, is interchangeably used in research. A clear distinction can be made, if targeted is defined as a material with the intention to reach a specific subgroup based on demographic characteristics.[17]

Generic versus tailored materials
Generic materials are the least expensive way to reach large audiences, contain as much information as possible and demands fewest communication. Easy to read and comprehensiveness are key for a well-designed generic material. The SFVG's 'Verwijderen blaastumor' folder is a great example of a generic material. These materials tend to meet all information consumer's needs and therefore do not consider the individual's specific characteristics. On the other hand, tailored materials are intended to reach one specific person, through considering one's characteristics that are unique to that person.[17]

Why tailor materials?
Generic materials contain a lot of information within a single material to meet all information consumer's needs. Tailored materials can be more specific to one's needs, and therefore exclude superfluous information. If information addresses the unique needs of the consumer, it will motivate them, acquire new skills and help to change lifestyles.[17]

Limitations and opportunities
Tailored communication is conceptualized as specific adjustment optimally embedded for the individual, where targeted communication adapts to groups. Tailoring is more useful if it is viewed as a process of segmentation, thus dividing a target group into subgroups. And customize communication, thus making person-specific adaptations within these subgroups. This allows a new view on tailoring, the more the communication is adapted (segmentended and customized) the more it can be seen as tailored. This definition of tailoring allows segmentation and makes tailoring not individuals specific, rather more or less tailored based on how many subgroups and customization possibilities within these groups.[22]

Conclusion
- Generic materials are intended to meet all information consumers needs, and therefore contain for the individual superfluous information.
- Tailored materials are intended to meet the individual's specific characteristics.
- The more segmentations and and the more customizations in communication within these segmentations make materials more tailored.
- The target group needs to be divided into subgroups based on the patient's characteristics which can be used to work with.

PATIENT PROFILES

The more segmentations, and thus the more a target group is divided into subgroups, the more tailored a material is. Therefore, it is interesting to explore ways to divide NMIBC patients into more characteristic-specific subgroups. These subgroups are called patient profiles. There are many sets or combinations of patient's characteristics to derive patient profiles from.[23] Within the scope of this project it is interesting to consider the patient's characteristics towards health information if it comes to a target group segmentation approach.

The profiles can be derived from a set of the patient's characteristics. Which characteristics are relevant depends on where the profiles are used for. The profiles will be used to divide the target group, NMIBC patients, into subgroups or patient profiles. The intended use of the profiles are to connect all the collected TUR-B treatment information to matching profiles. Thereby, the profiles will be used to collect new information (missing information and information interactions) from qualitative research and again connect these to the profiles.

There are many different approaches for target group segmentation based on the patient's characteristics. Several of these approaches are researched to find the best suited approach for this project. A short discription of these approaches can be found in appendix D. In the context of patient-information communication, it is important to consider the patient's health information preferences.

These preferences are investigated in Understanding Consumers' Health Information Preferences.[24] The health information seeking behaviour, health decision making and how people use this information are analysed with the purpose of segmentation for guidance in communications and delivery for health services. For this research five domains are measured: (1) self-efficacy for finding and using health information, (2) prevention orientation, (3) relationship with health care provider, (4) perceived importance of health information, (5) health information seeking behavior. This lead to four segments: independent actives, doctor-dependent actives, doctor-dependent passives and independent passives. Independents tend to have a high degree of independence in health decision making, contrary to passives who have a low degree. Actives have a high degree of engagement in health enhancement, contrary to passives who have a low degree.[24]

PATIENT PROFILES

Further investigation of these segments lead to the following descriptions:

Independent actives (IA)
This group places high value on health information and prevention efforts, and have a high degree of self-efficacy for understanding health information. Independent actives are actively trying to maintain their health. They find doctors to be reliable sources of information, work collaboratively with their doctors, however place authority in health decision making by themselves. To support their decision making, they tend to consult multiple sources as doctors, books and internet.[24]

Doctor-dependent actives (DDA)
This group also place high value on their health and having health information, although find difficulties in understanding. Likewise independent actives, they actively try to maintain their health. They work collaboratively with there doctors and rely on the doctor as their primary information source and for health decision making.[24]

Doctor-dependent passives (DDP)
This group is less involved in prevention and health information. They find understanding information very difficult (is most likely to be low health literate) and are less likely to seek information, but are open to information provided by their doctor. Rarely, they indicate to have a collaborative relationship with their doctor, rather they depend on their doctor to make health care decisions. [24]

Independent passives (IP)
This group is the least engaged in prevention than the other groups and do not feel the urge to seek health information. They are the least likely to have a collaborative relationship with the doctor and find health decision making an authority for themselves. Independ passives are driven by their attitudes and beliefs about their health and the healthcare system.[24]

Patient profiles
From these descriptions four patient profiles are derived. These profiles can be found in fig. 1.

Conclusion

- These profiles will be used to connect all collected TUR-B information to.
- These profiles will be used to connect gathered missing treatment-related information in the qualitative research to the matching profile.
- These profiles will be used to in research gathered insights about interactions and connect these to the matching profile.

PATIENT PROFILES

	Characteristics		Values
IA Independent Active	• Actively maintain their health • Desire for health information • Self-efficacious understanding health information • More likely consulting multiple sources		• Multiple health information sources
DDA Doctor-Dependent Active	• Actively maintain their health • Desire for health information • Rely on doctor as primary health information source		• Increase the doctors role in providing health information • Tailored to health literacy level (low)
DDP Doctor-Dependent Passive	• Less engaged in prevention efforts • Less likely to seek health information • More open to health information provided by doctors • Low literacy		• Special efforts are needed to make health information relevant • Tailored to health literacy level (low) • Information dissemination in primary care setting
IP Independent Passive	• Less engaged in prevention efforts • Less likely to seek health information • Less open to health information provided by doctors • Little communication with healthcare providers		• Special efforts are needed to make health information relevant • Barriers are related to their attitude and beliefs about healthcare • Find ways to make healthcare relevant is key • Information disseminated through other channels: interactive media, secondary audiences

fig. 1, Patient profiles

RESEARCH

In this phase a qualitative research will be conducted and the results will be discussed. The main goal for this research is to gather information from actual NMIBC patients about which health information they find important. Thereby insights will be gathered on how they prefer to gather health information. The TUR-B animation will be discussed to learn if the visual language matches their preferences. The participants health preferences will be identified, so the findings can be connected to the corresponding patient profile.

RESEARCH DESIGN

The main goal for this research is to learn from NMIBC patients about their health information preferences concerning the TUR-B treatment trajectory. The aim for the research is to learn for each patient profile: how should health information be visually presented? What information is of the patient's interest? How should this information be accessed?

The research is conducted with NMICB patients of the SFVG. To set up the research a procedure has to be followed. The description of this procedure can be found in appendix E. The qualitative research contains one round and is conducted with five participants. Each session is consists of five parts and takes 25-30 minutes. The sessions are of semi-structured interview nature, are audio recorded and after research transcribed. The participants are former TUR-B patients, and now follow the subsequent bladder instillation trajectory. The bladder instillation patients have to visit the hospital frequently and are therefore easier to recruit for research. It is assumed that the participants can reflect on the previous TUR-B trajectory.

Part 1: Introduction
The participant is introduced to the scope of the research.

Part 2: Determine the participant's patient profile
The main goal of this part is to learn which patient profile (or a combination of profiles) suits the participant best. In round 1 participants are asked to rate ten (Likert scale)[25] statements. These statements (appendix F) are extracted from the Health information Preferences paper. Based on these scores the patient profile is determined. In round 2 and 3 the participants are asked to choose a persona (see appendix F) that they can identify themselves with. It is allowed to combine more personas. See fig. 1. This adaptation made this research part less intensive for participants in terms of time and concentration.

fig. 1, Example of persona

Personal info

- Naam: A. Visser
- Leeftijd: 51 jaar

Quotes

- "Ik ben zeer actief met mijn gezondheid bezig."
- "Ik probeer zelf zoveel mogelijk informatie over mijn gezondheid vergaren."
- "Naast de arts, raadpleeg ik ook veel andere bronnen. Bijvoorbeeld online." "

Part 3: TUR-B animation review
The main goal of this part is to learn more about the participants preferences if it comes to visual language for the representation of health information. In round 1 the participant is asked to choose the visual style of their preference. Three images of bladders (1-realistic, 2-medical and 3-cartoonish) are used to choose from. In round 2 and 3 the participants are asked to point out their preference on a horizontal axis from realistic (left) - medical (middle) - cartoonish (right). See fig. 2. This allows participants to point out the exact position on the axis for their preference, instead of having only three options to choose from. After the participants choose for a preference, they are asked to explain their choice and how their choice relates to the visual language of the TUR-B animation.

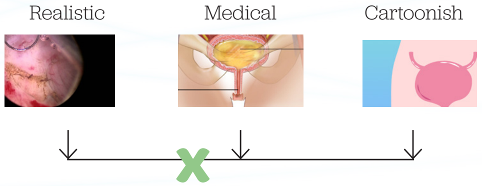


fig. 2, Visual language

RESEARCH DESIGN

Part 4: Health information preferences interview

The last part of the session has the aim to learn which health information is of interest for the participant. Is all the information from the 'Verwijderen blaastumor' folder relevant and are their gaps? Thereby it has the aim to learn how participants want to access this information. Which sources do they use to access health information? A different approach for each round is used to improve part 4 and find more useful answers. The answers on these questions are gathered via semi-structured interviews and with the usage of research tools. These tools are exchanged for another in each round.

Research tool round 1
The TUR-B patient journey and a set of cards are presented to the participant. Each card has a short description of important topics from the 'Verwijderen blaastumor' folder. See figure 3. The participant is asked to place the cards, they find especially interesting, in the patient journey. See appendix G for an overview of the cards. They are asked to further explain why and where this card should be in the journey. This will result in a patient journey with the most important topics per phase.

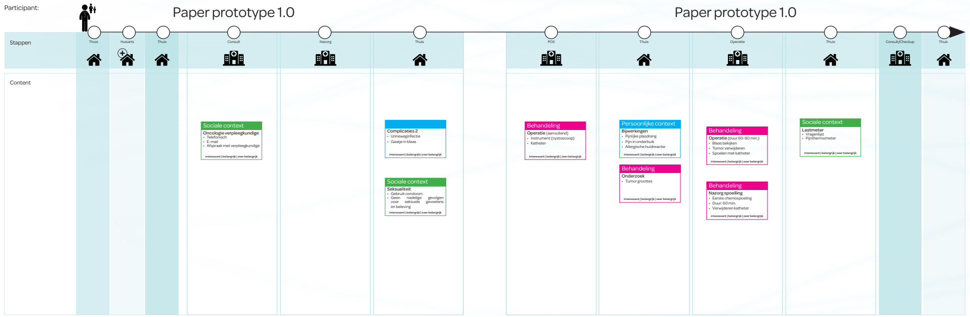


fig. 3, Patient journey and cards

Research tool round 2
A setting for the TUR-B consult is created. The participant is asked to play the role of the urologist and consult the researcher about the TUR-B treatment. Throughout this role-play we hope to learn which topics are addressed by the participant. It is assumed that these topics are important for the participant.

Research tool round 3
The patient journey is developed into a paper prototype for a digital application. This paper prototype is presented to the participants, and they are asked to explain what information should be on which screen. An example is represented in figure 4. It is assumed that this will provide information about which topics should be placed at every screen.

fig. 4, Paper prototype

RESEARCH RESULTS

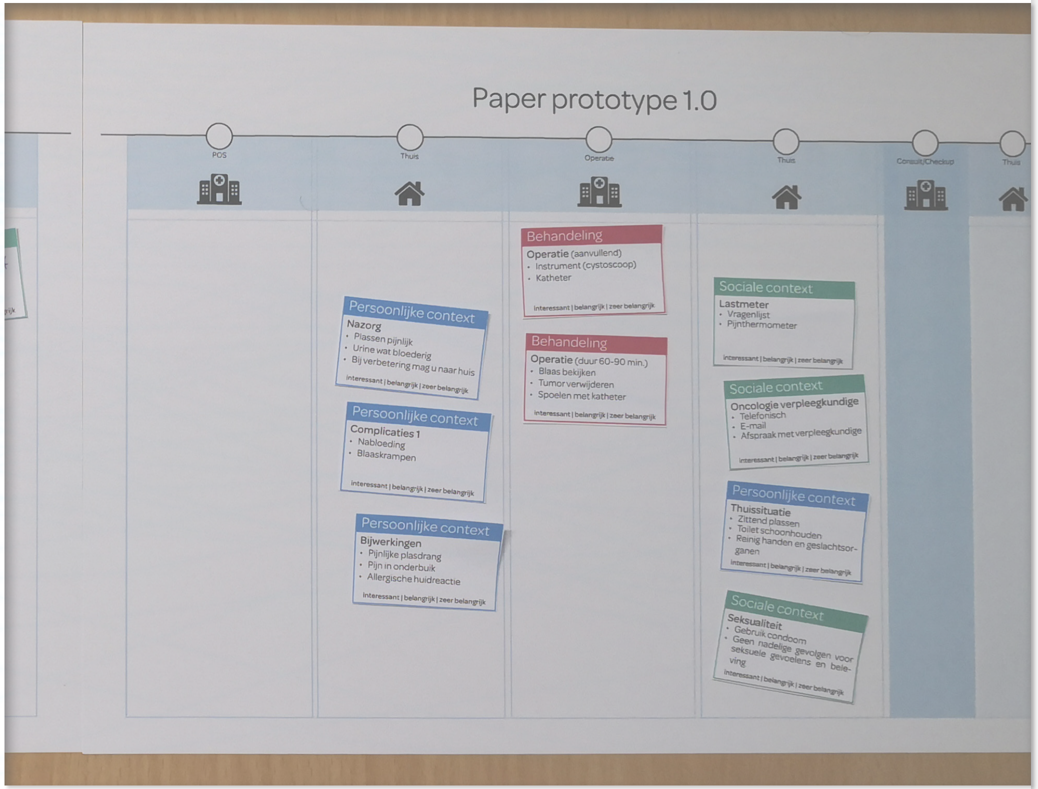
The research gave insights for each patient profile: which visual language suits the participant? what information is of the patient's interest? How should this information be accessed?

Research result analysis method
The research resulted in approximately 25 minutes of audio footage per interview session, and the audio footage is transcribed.

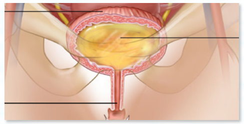
Visual language
The visual language of preference is determined during the session, the choice is noted by the researcher. Additional explanations, are extracted from the transcriptions if available.

TUR-B information issues
A derivation of Instant Data Analysis (IDA)[26] is used to analyze the transcriptions and with the aim to find issues with TUR- B information provided by current resources. For the purpose of this research analysis, issues are defined as information leaks in current resources or information that needs special attention. The IDA method is designed to reduce the labor and time for the analysis. From the transcriptions several issues with health information were extracted and ranked based on frequency and severity. This resulted in a set of information issues per patient profile.

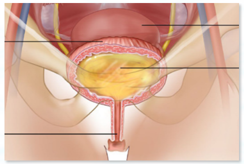
Preferred information access
The results for the preferred access options are extracted from the transcriptions.



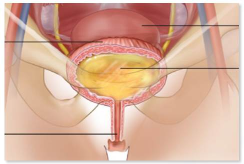
RESEARCH RESULTS

Participant	Patient profile	Visual language	TUR-B issues
1	**IA** Independent Active	 medical	Size of tumours Severity of cancers Frequent contact with oncology nurse History of immunotherapy

ROUND 1

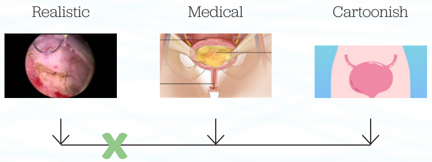
Participant	Patient profile	Visual language	TUR-B issues
2	**IP** Independent Passive	 medical	What do you experience without sedation? An animation would be relevant, especially the first time you have surgery The animation shows the ideal scenario; other scenarios would be interesting Time and planning Experience hospital rooms in advance Pain indication

ROUND 1

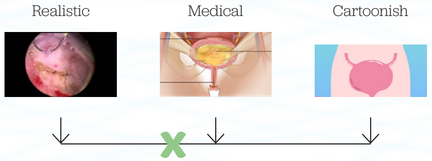
Participant	Patient profile	Visual language	TUR-B issues
3	**DDA** Doctor-Dependent Active	 medical	Pain indication Cystoscopy Urinal problems

ROUND 1

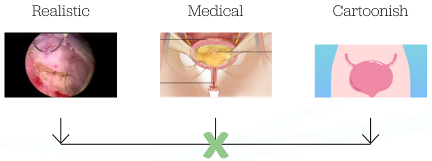
RESEARCH RESULTS

Participant	Patient profile	Visual language	TUR-B issues
4	**DDP** Doctor-Dependent Passive		Size of tumours Severity of cancers Frequent contact with oncology nurse History of immunotherapy

ROUND 2

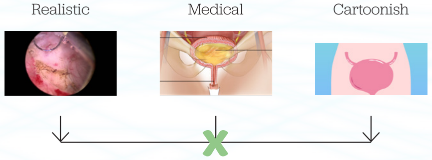
Participant	Patient profile	Visual language	TUR-B issues
5	**IA** Independent Active		What do you experience without sedation? An animation would be relevant, especially the first time you have surgery The animation shows the ideal scenario; other scenarios would be interesting Time and planning Experience hospital rooms in advance Pain indication

ROUND 2

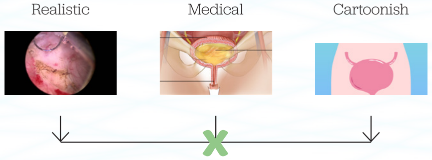
Participant	Patient profile	Visual language	TUR-B issues
6	**IP** Independent Passive		Pain indication Cystoscopy Urinal problems

ROUND 2

RESEARCH RESULTS

Participant	Patient profile	Visual language	TUR-B issues
7	DDA Doctor-Dependent Active		Got something to relax before spinal anesthesia Consequences for sport activities How to inform relatives about diagnosis Information online is not objective, doctor is Navigation to and in hospital unclear Sedation

ROUND 3

Participant	Patient profile	Visual language	TUR-B issues
8	DDA / IP Doctor-Dependent Active / Independent Passive		Hermatology Thrombocytes and consequences Pain catheter Faced problems finding objective information online

ROUND 3

Quotes

P4: “I liked the visual style, because they don’t show what isn’t necessary and you see what will happen. For a patient it is enough.”

‘P7: ’I don’t search online for medical information. Everyone online says it’s like that or that. I don’t listen to anyone, except the doctor.”

The transcriptions of the research can be found in appendix H.

RESEARCH CONCLUSIONS

All the results of the individual sessions are collected and sorted per topic (anesthetics, preparation, treatment, research, aftercare, alternatives, complications, sexuality, advices, discharge and contact us when) and treatment or contextual related, which shows a complete overview of all the information issues per patient profile. For example, the choice for sedation is mentioned by one or more IA participant(s). This choice is treatment related and is a anesthetics topic. This complete overview is presented in table 1.

Conclusions

- The preferred visual language is slightly more realistic than medical. The TUR-B animation is designed to be close to medical and from the research the assumption can be made that the visual language matches the patient's preference for all profiles.
- Most of the information of interest per patient profile is collected. To gain a more complete overview more research have to be conducted. The current overview provides sufficient patient input on information interests to include in the design of the prototype. The completeness of information of the 'Verwijderen blaastumor ' folder was found of high value, however many participants found difficulties in accessing this information. Thus, the information of the folder needs to be included in the prototype.
- All participants, regardless of the patient profile, valued the 'Verwijderen blaastumor' folder, the medical specialists and the TUR-B animation as main health information sources. This means that the prototype cannot replace the folder and medical specialists. However, it will replace the TUR-B animation, since the aim for the prototype is to be an improvement of the explanation video.

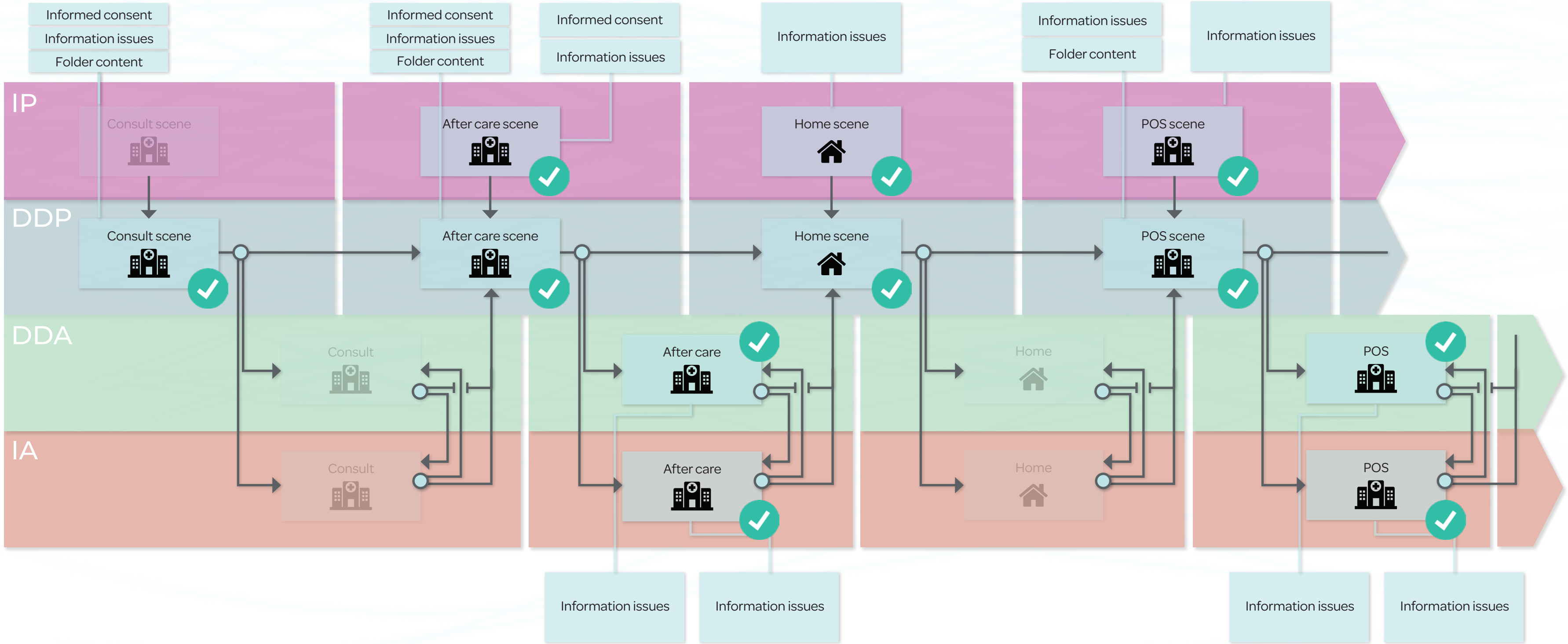
RESEARCH CONCLUSIONS

Table 1, Overview results

	Treatment			Contextual effect info			
	Folders + animation	Information issues		Folders + animation	Information issues	Folders + animation	Information issues
IA	Anesthetics	Choice: sedation or not	Planning treatment trajectory	Complications	General anesthesia	Sexuality	
	Preparation					Advices	
	Treatment	Bladder installations				Discharge	
	Research					Contact us when..	Oncology nurse
	Aftercare	Farmaceutisch kompas					kanker.nl/kanker.be
	Alternatives	Immunotherapy					
DDA	Anesthetics	Choice: sedation or not	Hospital rooms	Complications	Spinal anesthesia	Sexuality	
	Preparation		Routing hospital		Thrombocytes	Advices	Preferably by doctor
	Treatment	When allowed to go home				Discharge	
	Research					Contact us when..	
	Aftercare	Sport activity					How to inform relatives
	Alternatives	Hematology					
DDP	Anesthetics	Choice: sedation or not	Review all information	Complications	Pain cystoscopy	Sexuality	
	Preparation				Blood loss	Advices	Preferably by doctor
	Treatment				Urinary problems	Discharge	
	Research	Cystoscopy				Contact us when..	Oncology nurse
	Aftercare						
	Alternatives						
IP	Anesthetics	Choice: sedation or not	Hospital rooms	Complications	Pain catheter	Sexuality	
	Preparation	Sobriety	Routing in hospital		Fever	Advices	
	Treatment	Choice: screen or not	Routing out hospital		Urinating	Discharge	
	Research	Tumour location, sizes	Planning treatment			Contact us when..	When to call
	Aftercare	Future prospects					Taboo/shame for peers
	Alternatives						

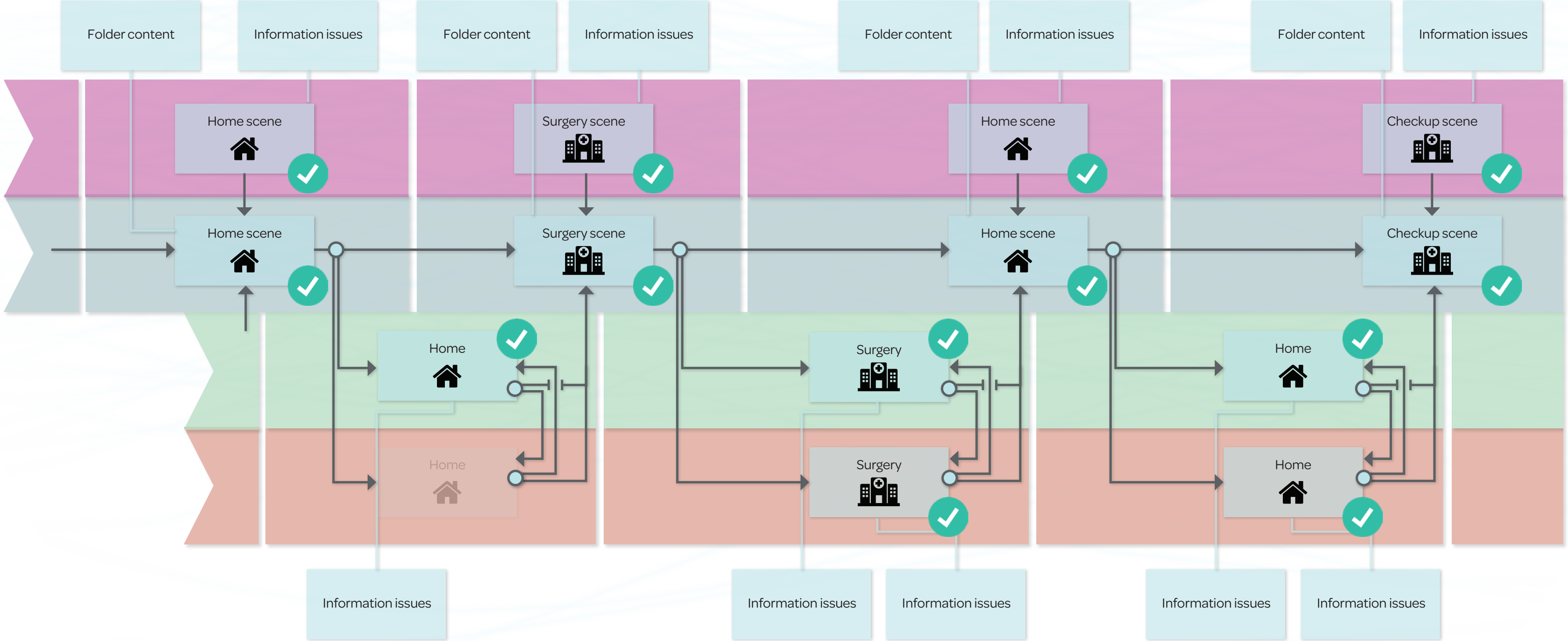
WRAP-UP

The NMIBC patient's treatment trajectory is visualized in the patient journey. This journey provides an organized overview of all the collected health information: topics of informed consent, the 'Verwijderen blaastumor' folder and the qualitative research.



WRAP-UP

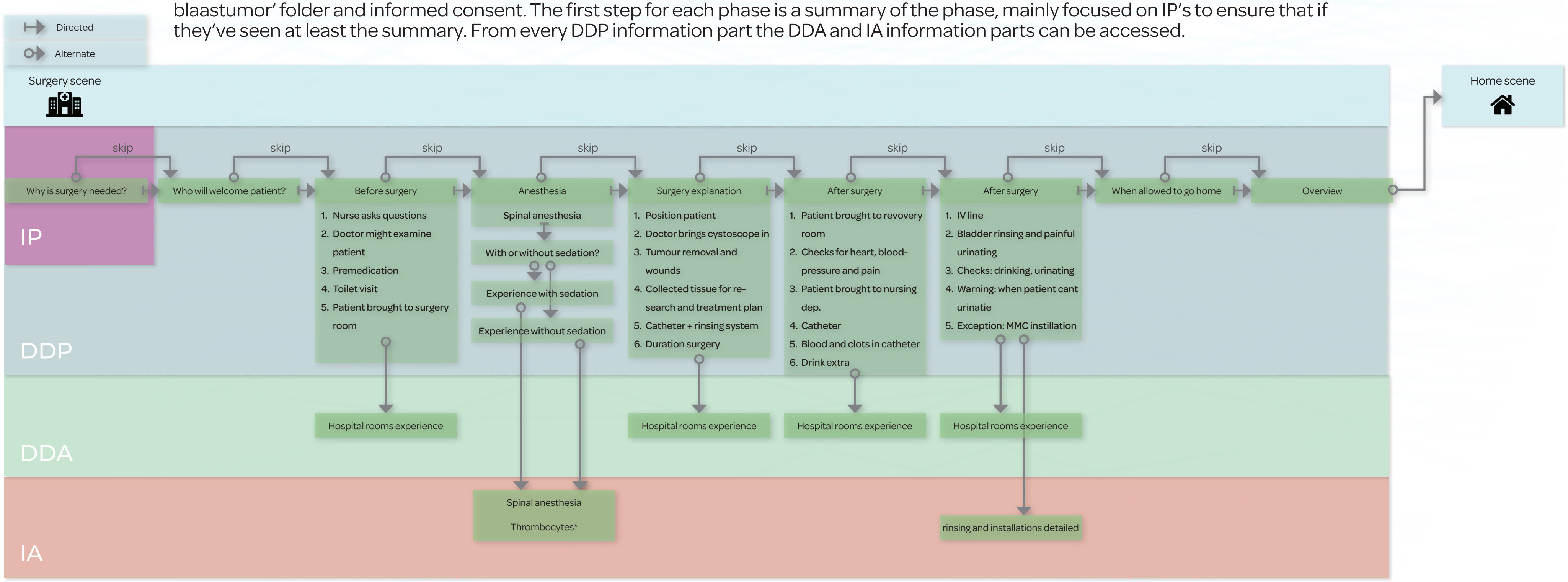
All the collected information is connected to the corresponding patient profile within the phase. The decision has been made to connect the ‘Verwijderen blaastumor’ folder content to the DDP profiles, since this content is provided by the medical specialist and the DDP’s value this the most. For some profiles no information was found, after research. These issues are greyed out. Visit appendix I to get a more detailed view on which information is exactly referred to.



WRAP-UP

For each of the individual phases storylines are defined. These storylines comprehend all collected information per phase from research. The detailed versions of all phases can be found in appendix J.

The example provided in fig. 1, provides a detailed overview of which information has to be included within the surgery phase. The decision has been made to take the DDP information as a base storyline. The DDP information contains all the required information from the ‘Verwijderen blaastumor’ folder and informed consent. The first step for each phase is a summary of the phase, mainly focused on IP’s to ensure that if they’ve seen at least the summary. From every DDP information part the DDA and IA information parts can be accessed.



WRAP-UP

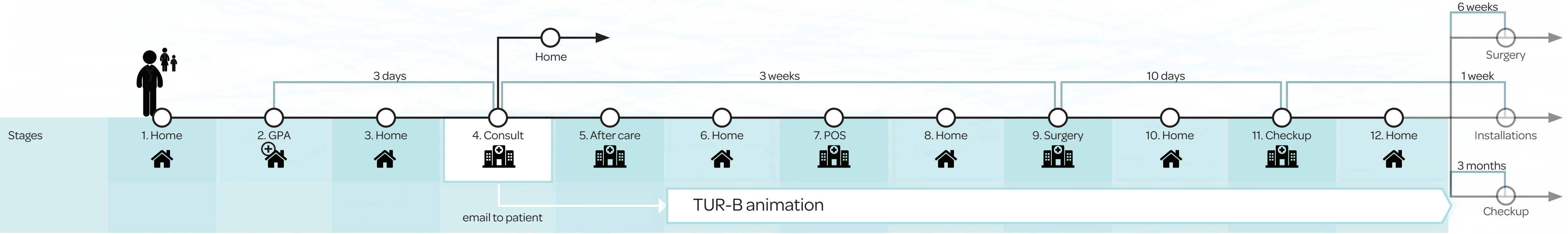
The detailing and organizing of the collected information per phase leads to this storyline overview. This overview is an abstrafied visualization of all the required information pieces. These information pieces are from now on defined as ‘steps’.

If the DDP storyline is defined as the base storyline, DDA and IA information steps have to be accessed via DDP steps. This results in many storylines one can follow throughout the complete treatment trajectory. For example, the POS (pre operative screening) phase has two options to continue the storyline in step 2. One can choose to proceed to step 3 or access the IA step.

CONCLUSION

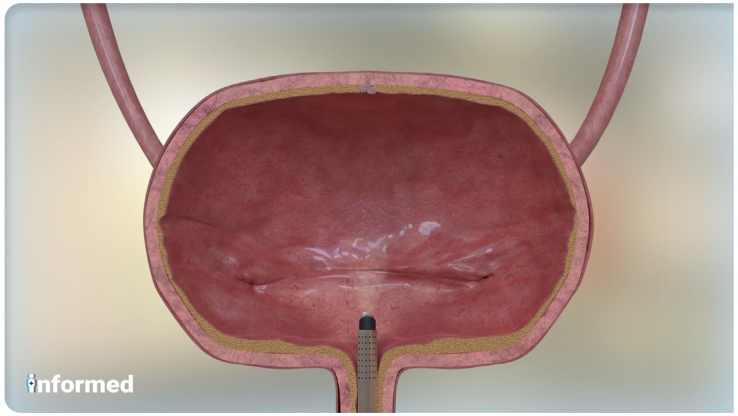
For the rest of the project the focus will be on the surgery phase of the TUR-B treatment trajectory. In this conclusion phase the tailored interactive animation will be developed. From now on the tailored interactive animation will be referred to as Tailored Interactive TUR-B (TI TUR-B) animation or prototype. The aim for the conclusion phase is to design the TI TUR-B prototype with the inclusion of findings as: information and storylines for each patient profile. Thereby extra attention is paid on how to design User Interfaces (UI) for elderly, since the target group, NMIBC patients, are assumed to be elderly people (60-80y).

GENERAL USER FLOW



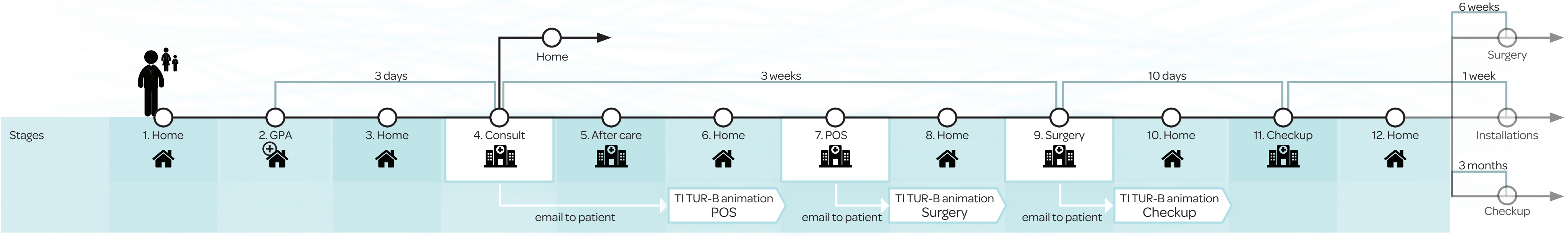
The TI TUR-B animation will replace the original TUR-B animation. Therefore it is useful to look into how exactly the TUR-B animation is shared by medical specialists and used by patients. Then the intended usage for the TI TUR-B animation is constructed.

User flow TUR-B animation
The TUR-B animation is shared with the patient after the consult. Directly after the consult the patient has to make a follow-up appointment at the desk of the outpatient clinic. Over here the patient is asked if they want to receive an email with the TUR-B animation. If yes, the desk clerk checks a box in the patient's electronic health record (EHR), HiX. This EHR features automatically generated emails for medical specialist-patient contact. The patient receives an email, where their doctor advices to click on the hyperlink and watch the TUR-B animation.



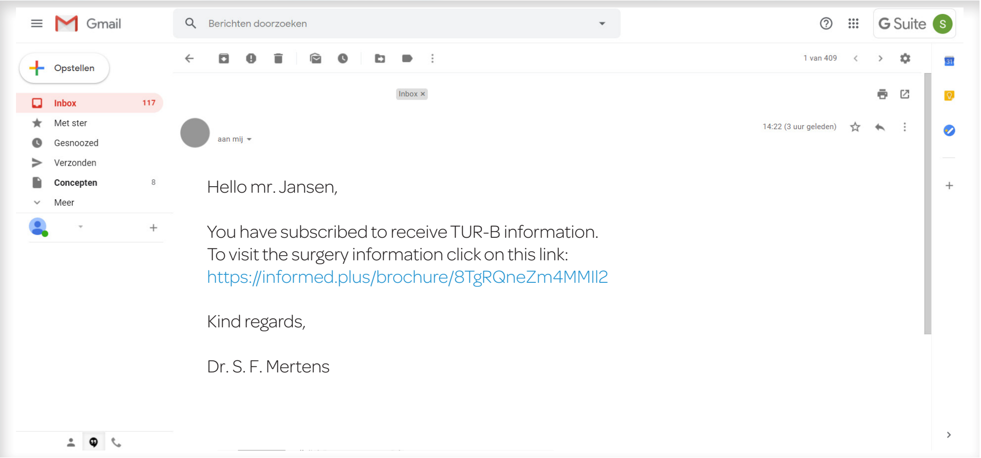
QR-code
Scan the QR-code and watch the TUR-B animation

GENERAL USER FLOW



User flow TI TUR-B animation

The TI TUR-B animation is shared the same as the TUR-B animation. This means that the patient receives an email from their medical specialist. However, the patient will receive these emails more frequently. The patient will receive an email with information to prepare themselves for the upcoming phase. For the surgery phase, the patient will receive an email directly after the preoperative screening. The patient clicks on the hyperlink and is redirected to the TI TUR-B animation for the surgery phase.



Hello mr. Jansen,

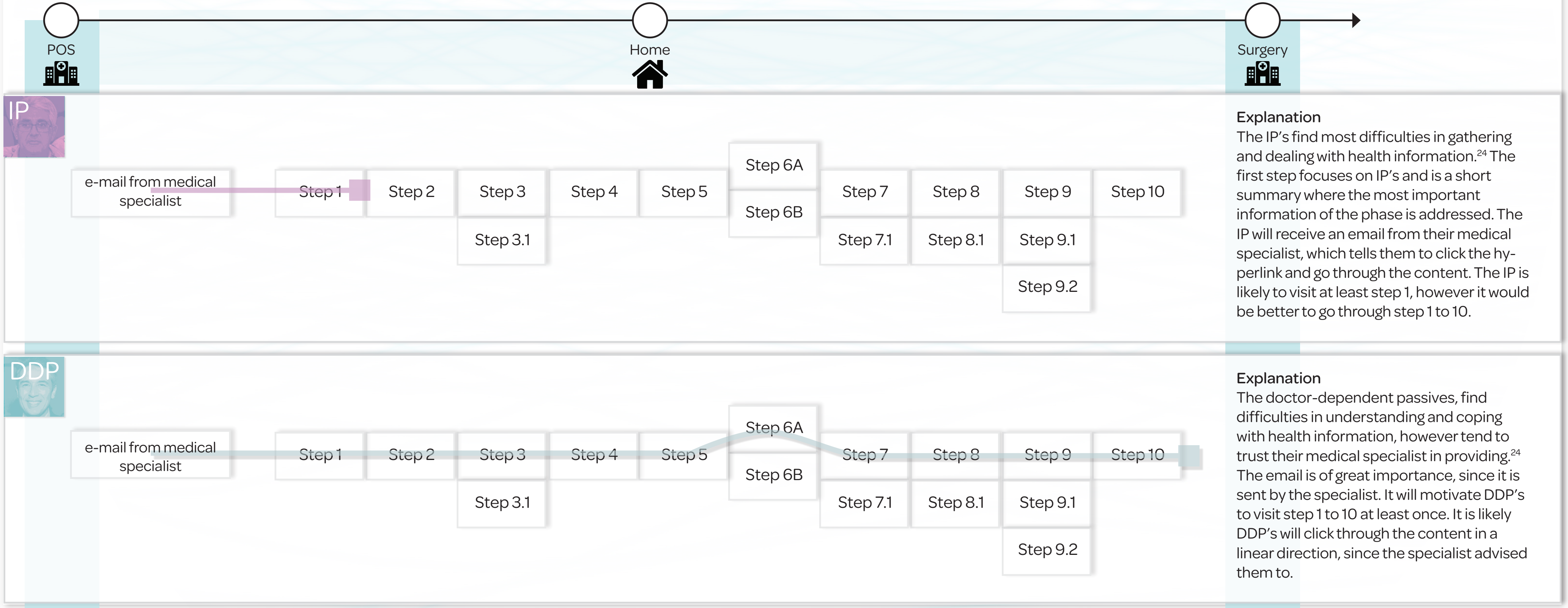
You have subscribed to receive TUR-B information.
To visit the surgery information click on this link:
https://informed.plus/brochure/8TgRQneZm4MMIl2

Kind regards,

Dr. S. F. Mertens

INTERFACE USER FLOW

Each patient type has different characteristics if it comes to understanding and coping with health information.[24] Therefore it is interesting to examine their information gathering behavior to make assumptions about their intended usages. These will help to facilitate matching usages for the user interface for users of each profile.



POS

Home

Surgery

IP

e-mail from medical specialist

Step 1 Step 2 Step 3 Step 4 Step 5 Step 6A Step 6B Step 7 Step 8 Step 9 Step 10

Step 3.1 Step 7.1 Step 8.1 Step 9.1 Step 9.2

Explanation
The IP's find most difficulties in gathering and dealing with health information.[24] The first step focuses on IP's and is a short summary where the most important information of the phase is addressed. The IP will receive an email from their medical specialist, which tells them to click the hyperlink and go through the content. The IP is likely to visit at least step 1, however it would be better to go through step 1 to 10.

DDP

e-mail from medical specialist

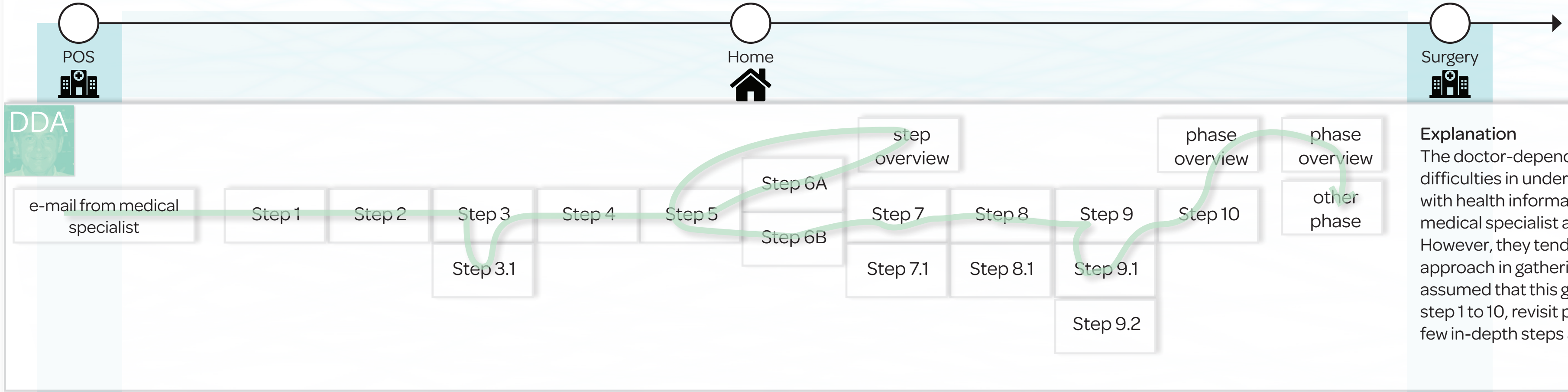
Step 1 Step 2 Step 3 Step 4 Step 5 Step 6A Step 6B Step 7 Step 8 Step 9 Step 10

Step 3.1 Step 7.1 Step 8.1 Step 9.1 Step 9.2

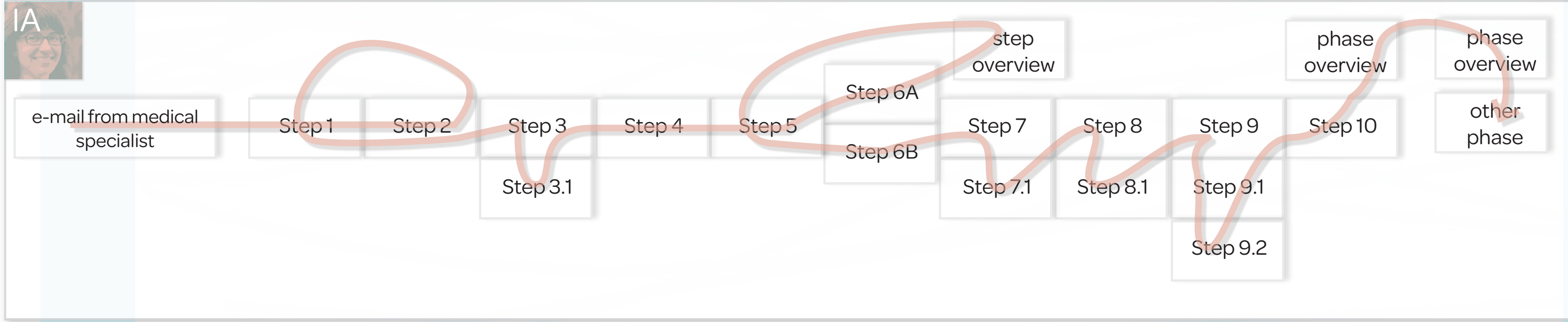
Explanation
The doctor-dependent passives, find difficulties in understanding and coping with health information, however tend to trust their medical specialist in providing.[24] The email is of great importance, since it is sent by the specialist. It will motivate DDP's to visit step 1 to 10 at least once. It is likely DDP's will click through the content in a linear direction, since the specialist advised them to.

INTERFACE USER FLOW

TI TUR-B animation surgery phase
The information for the surgery phase is divided over 10 steps. This means that the patient has to take 10 steps to go through all the recommended information for the surgery. All the required information is in step 1. The sidesteps, for example 3.1, are meant to dive deeper into a subject. The detailed user flows can be found in appendix K.



Explanation
The doctor-dependent actives, find less difficulties in understanding and coping with health information and trust the medical specialist as their main source. However, they tend to have a more active approach in gathering information.[24] It is assumed that this group will go through step 1 to 10, revisit previous steps, visit a few in-depth steps and visit other phases.



Explanation
The independent actives find the least difficulties in understanding and coping with health information. They have a intrinsic motivation to gather information, however rely less on the medical specialist, prefer open information and the ability to access all information.[24] IA's are expected to explore all the content, and thus use all interaction possibilities: revisit steps, visit in-depth steps and other phases.

INTERFACE COMPONENTS

The user needs to be able to access all the content of their preference. Therefore a user interface (UI) needs to be designed. The UI has to consist of several components to facilitate the navigation to the content: access via hyperlink, phase overview, step overview and the steps.

Access

E-mail

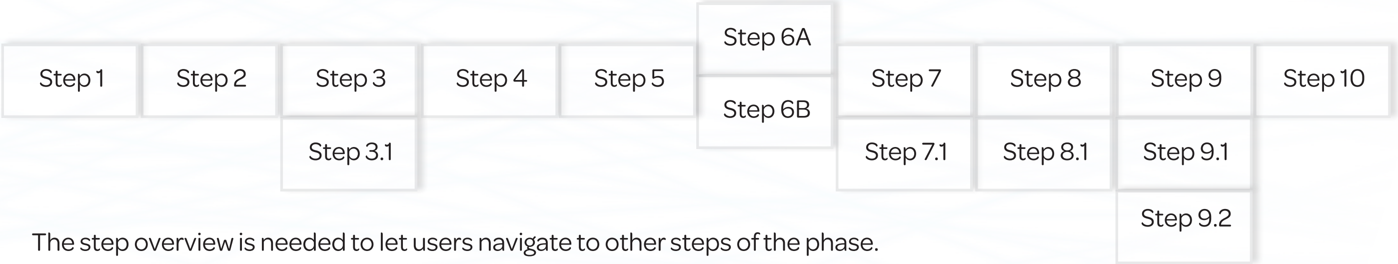
Email environment
The application will replace the 3D animation. This animation is currently accessible via an online platform, several patient applications and a link in an email. In this project the focus will be on the e-mail. This email is automatically generated and sent via Hix, Franciscus's EPD.

Phase overview

Consult | Aftercare | Home I | POS | Home II | Surgery | Home III | Checkup

The phase overview is needed to let users navigate to other phases of the treatment programme.

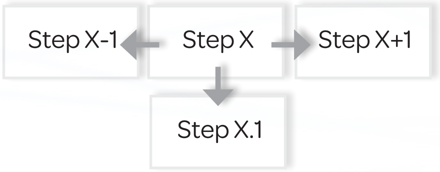
Step overview (surgery phase)



The step overview is needed to let users navigate to other steps of the phase.

Step

At every step the user needs to be able to navigate to the next step or if available, the in-depth step. Users should have the possibility to go to the previous step is well, to complete the navigation.



INTERFACES FOR ELDERLY

The target group for this project is NMIBC patients of the Franciscus hospital. This type of cancer regularly occurs by people of older age (60-80y).[15] Therefore their preferences regarding digital media cannot be overlooked. This project aims to deliver a prototype for the TI TUR-B animation, which is used online. It is of great importance, to learn about the target group's potential disabilities in digital application usages and understandings. This research will lead to a set of guidelines (interface structure, interaction and design language) for the TI TUR-B animation. The users directly interact with the user interface, and thus this can be considered as the main interaction point between user and application.

Interface structure

Menu structure

The key to structurizing interface menus for elderly is consistency. It is important to stick to the industry standard for application layouts, since users are used to it.[27] In most applications the main menu is placed on the left-hand side. Other key elements as login and search fields are placed on the top of the screen. There should be a colour distinction between visited and yet to visit links to overcome navigational problems.[28]

Menu layers

Too many menu layers or subcategories are found difficult by elderly. It is advised to stick to two layers, more layers are difficult to handle.[28]

Interaction

Double clicking issues

Previous research learned that double clicking is a problem for elderly people (sayo-go). All interactions should be made with a single click, if possible.[28]

Scrolling

Users with motor skill impairment, tend to face problems with scrolling. Especially, if tiny items are used for scrolling interactions.[28] Therefore scrolling needs to be avoided if possible.

Buttons

Hand-eye coordination and motor skills deteriorate of elderly. Small clickable items are difficult to interact with. The buttons should be at least 11mm diagonally and 2mm apart from each other.[28]

Design language

Fonts

The fonts in the application have to plain, since it has a significant positive influence on readability. A sans serif font will provide good readability. A small font size leads to less comfortable reading, therefore a bigger font size have to chosen.[28] Another solution would be that the size is adjustable to the user's preferences. Do not go lower than 12 pt font size.[28]

Contrast

A lot of contrast have to be considered as well. Black and white or light grey tend to have the most contrast which is helpful for good readability.[28]

Colour usage

Especially for elder people, it is important to stick to colour guidelines. Hereby, it is important to think of with what a colour is associated with. Avoid the color blue for not clickable interface items, since dark blue is the industry standard for web links.[28]

MEMORY LANE

BACKGROUND

Memory lane is a touchscreen device for elderly, especially focused on people suffering dementia. However, all elder people can use this product, with the benefit that no technical knowledge is needed. The device has several care features to help elderly to remember appointments, ask for any help, practice physical exercises and contact relatives. Next to these features, the device has entertainment features as radio, television shows and more.[29]

Interface structure

The screen of the device is always turned on, showing a slideshow and alerts. When the user touches the screen it directly opens the home menu. The home menu consists of six large buttons, which allows users to access all the apps features with a single tap.
Two navigation buttons are placed at the top of the screen, which allows users to go to the previous screen or directly to the home screen. The applications tends to limit the possible interactions per screen.

Interface design

The device is an android tablet covered in a photo frame. This reference to a classic elderly interior can be found in many aspects of the interface design as well.

Home menu buttons

The six home menu buttons almost fill the whole screen. Each button has a large icon of old devices, that this feature replaces. For example, polaroid pictures to represent the picture gallery and an old telephone for video calling. These icons are very close to reality and less abstrified as the icons used in regular applications.

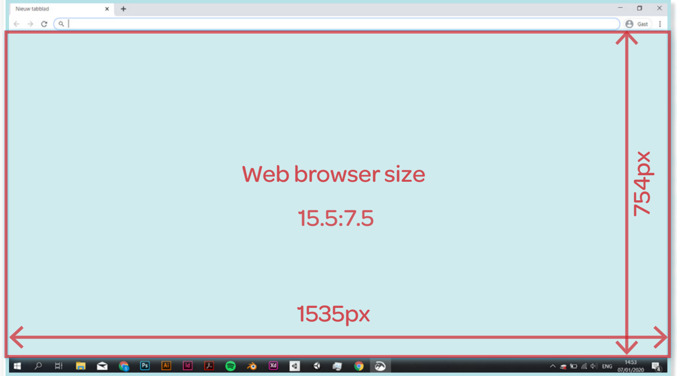
Navigation buttons

The buttons are fairly large, compared to other regular interfaces. The navigation buttons are white with black text.

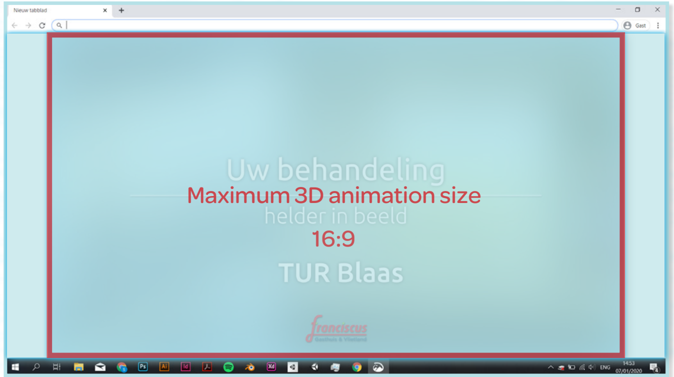
Colour usage

The homepage, agenda and help screens have a blue background with white buttons and panels. The picture gallery and entertainment screens have a more classic appearance; a lot of gradients of brown, wood and leather textures for backgrounds, panels and buttons are used.

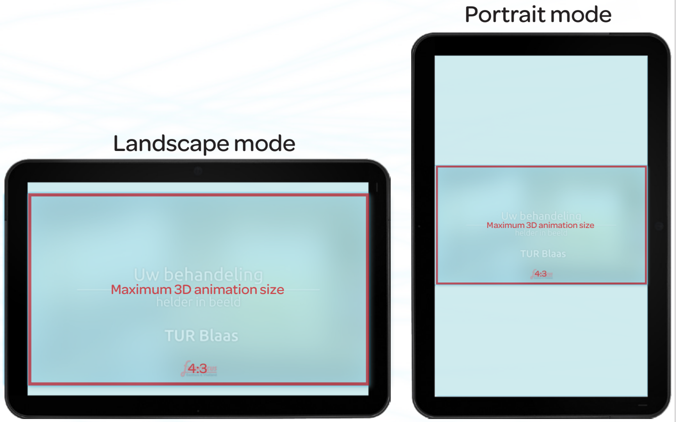
INTERFACE LAYOUT



Web implementation
The application has to be accessible via the user's web browser, since it will replace the animation. The animation is placed on a webpage. This limits the screensize to the browsers aspect ratio. The webbrowser is scalable, therefore the content needs to rescale on the web browser.



Content size
For elderly readablity is an issue, therefore the content should be as big as possible. If the aspect ratio of the content is 3D animation taken into account, 16:9, you will find the maximum size.

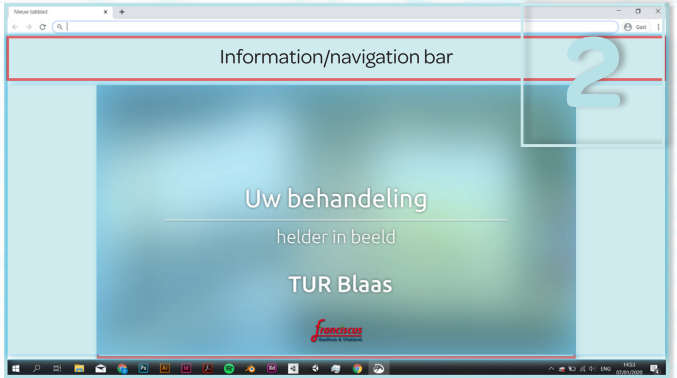


Tablet implementation
The application has to be accessible via the user's tablet device via its web browser. Tablets have the feature to have the webpage fullscreen displayed. This means that the maximum aspect ratio will be almost similar to the 3D animation. This aspect ratio is 4:3. However the tablet is rotatable, which influence the layout dramatically.

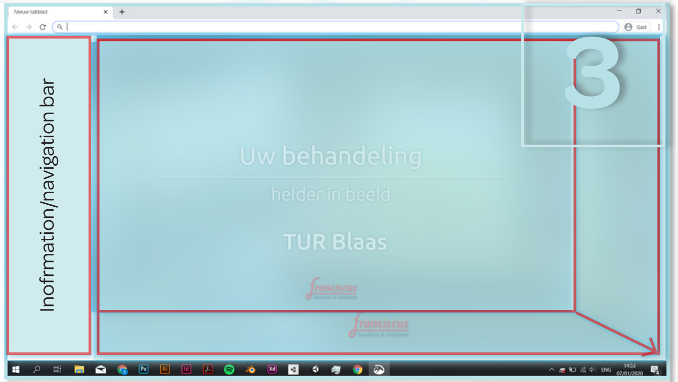
Conclusion
The current 3D animation is implemented in a webpage. This means it is accessible on any device with a webbrowser, as a laptop or tablet. Their aspect ratio's have to be considered when designing the application's layout. However, a tablet's screen is rotatable, which leads to complete new dimensions for the layout. To optimize the layout for this aspect ratio a second layout design is needed. The portrait mode will be neglected in this project. Smartphones are not taken into account as well, since their screens are significantly smaller and therefore need another structure and layout. The interface will be primarily designed for laptops and computer. And then slightly adjusted for tablets.

INTERFACE LAYOUT

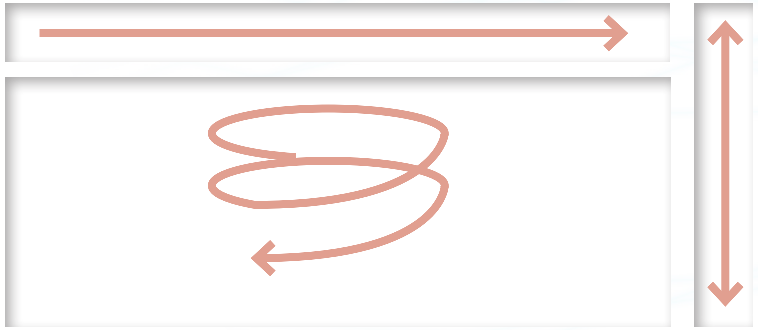
Bottom
Over here you can see that the navigation bar is placed at the bottom of the interface. Visually it looks appealing, however it is not matching the industry standards for main navigation bar placement.



Top
The top part of the interface screen is origanally used for search bars and login. Nowadays, more websites have a top positioned main navigation bar.



Left-side
The industry standard for the main navigation on user interfaces is on the left-side of the screen. Users are comfortable with this position and find less difficulties understanding where the functionalities of these buttons. Besides this, the animation panel can be enlarged as well.



Timeline for patient journey
The main navigation bar is representing the different phases of the treatment programme. The user has to navigate through the different phases over time. Timelines run from left to right, top to bottom or even 3D. Many popular websites as facebook, twitter or news use top to bottom for their timeline.

Conclusions
The industry standard for user interfaces is improtant to consider when designing for elderly. It is important to stick to interface layouts where elderly are used to. To find the best layout, all the different components need to be placed. For the timeline it is important to consider the most logical direction(s). A left-to-right direction is commonly used in timeline representations.

INTERFACE LAYOUT

The content is collected, restructured and organised; the UI user workflow is examined; guidelines for UI design for elderly are created; limitations for aspect ratio are investigated; and layout designs are explored. All of this has to come together in the application. To be able to design a user interface that actually fits the target groups, it is important to consider the lead user at every screen. This lead user, is the user who is assumed to find the most difficulties is in understanding the content and interactions on screen.

Recap patient profiles

According to Maibach, passives tend to find more difficulties in gathering health information and therefore ease of access to content is key for these groups.[24] For the passives focused layout it is important to consider the amount of components at every screen, where the challenge is to limit this amount to the bare minimum. Contrary, actives have a more positive attitude towards gathering health information.[24] For these groups it is important to facilitate their explorative nature.

Colour codes

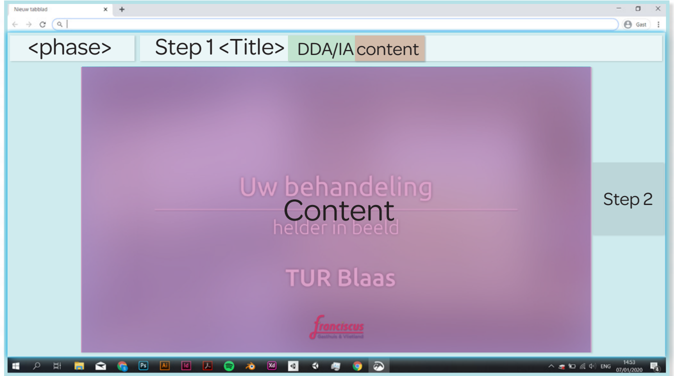
The components on all screens are colour coded according their determinant user. This does not imply that only this group can use these components. It is designed as such that the group who is assumed to find most difficulties is still capable of understanding.

- Pink components are primarily designed for independent passives (IP).
- Grey components are primarily designed for doctor-dependent passives (DDP).
- Green components are primarily designed for doctor-dependent actives (DDA).
- Orange components are primarily designed for independent actives (IA).

Step 1 screen

Used by

Lead user

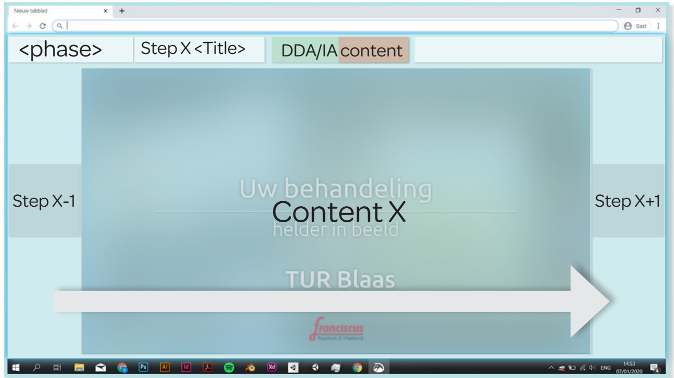


Explanation
This is the landing page of the application. All users need to understand the content at this step. IP's tend to find the most difficulties in dealing with health information. The step 2 button is focused on DDP's, since interacting with it directs users to DDP content. At the top is a 'switch' button visualized. This button lets the user switch between DDP and DDA/IA layouts.

Step X screen

Used by

Lead user



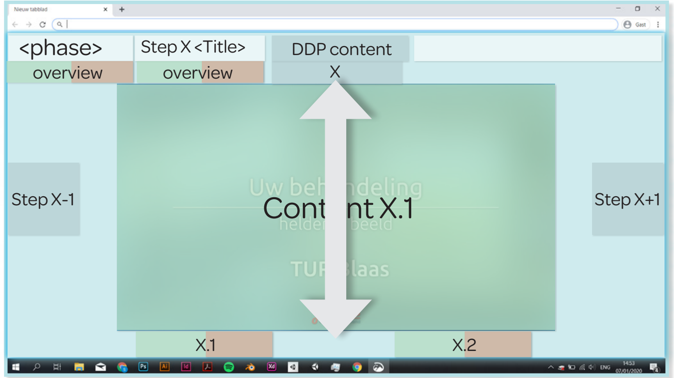
Explanation
The base storyline contains all the DDP content. The layout shows the least amount of components for DDP to be able to go through all the content. The navigation direction is from left-to-right to refer to the traditional timeline. At the top of the screen is the DDA/IA content button to switch to an interface, more focused on their preferences.

INTERFACE LAYOUT

In-depth step screen

Used by IP DDP DDA IA

Lead user DDIA



Explanation
The DDA and IA users have other health information preferences, therefore some extra components need to be added: the in-depth steps (X.1 and X.2), the phase overview and step overview buttons. However, the DDP buttons, step X-1 and step X+1, are still relevant and cannot be removed. The in-depth information has a vertical direction, since it is a in-depth step and not a step further in the timeline. The content screen needs to be slightly smaller.

Phase overview screen

Used by IP DDP DDA IA

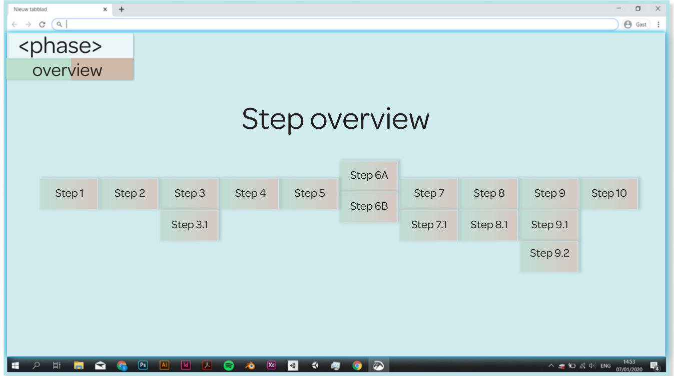
Lead user DDIA

Explanation
The user can access all phases of the treatment programme in the phase overview by clicking on it. The phases are chronological and therefore act as a timeline. For consistency, a similar direction as the DDPsteps, left-to-right, is used.

Steps overview screen

Used by IP DDP DDA IA

Lead user DDIA



Explanation
The step overview allows users to quickly navigate to the desired step and provides an overview of all the steps within each phase. The user still needs to know which phase he is currently visiting. From this overview the phase overview can be accessed as well for consistency. This overview gives insight about the left-to right ordered steps and the vertical ordered in-depth steps.

Conclusions

The challenge is to design one user interface which facilitates two contrasting usages: a usage that suits passives and one for actives. The UI has to contain many components without becoming overly complex. When considering the different profiles, the UI has to adapt to the user to sooth all user's desires; the UI will adapt to the user's preferences. Therefore the UI needs input from the user to know which user is using the application. In the near future this can be solved with an smart algorithm which is capable of gathering user data to determine the user's profile. Within the project's scope this is unachievable, and therefore an easy solution will be a switch button. The user can switch between different layouts to access all components of their interest.

DESIGN LANGUAGE

Elderly are not used to all recent user interfaces. Therefore it is important to refer in design language to familiar objects. The memory lane interface clear contrasting and fairly large buttons. The color usage is consistent throughout the complete interface, to reduce learning throughout usage.

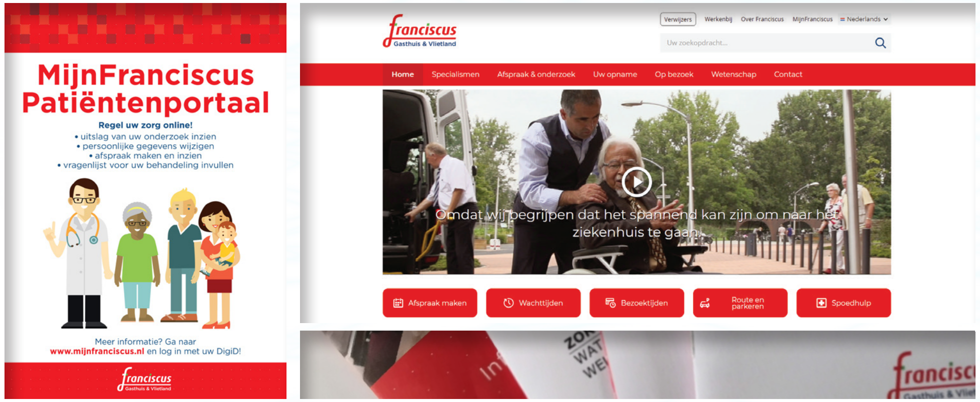
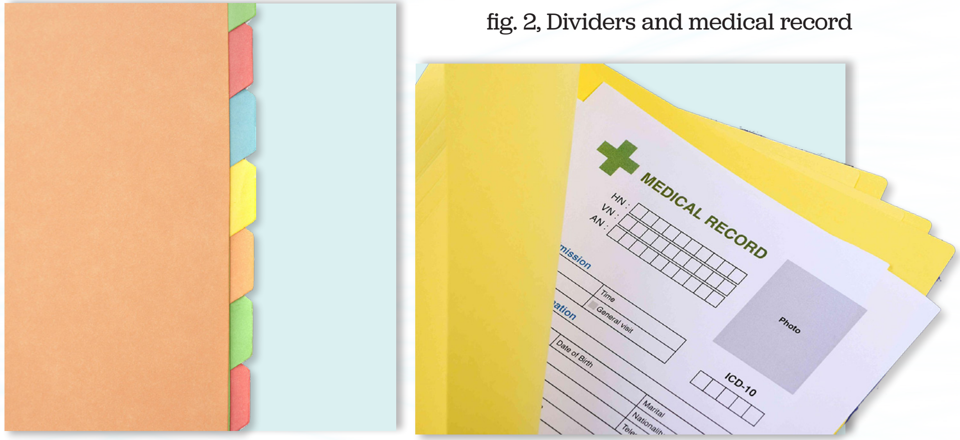


fig. 1, SFVG branding

SFVG branding
The patients follow the treatment traject at the SFVG, and to make sure this application is designed in collaboration with the hospital it is important to stick to the branding. This will contribute to a consistent information sharing throughout the complete treatment traject. Patient will recognize the hospitals branding and know it is qualitative information. The branding contains a gradient of red colours in combination with white. A square pattern can be found on many folders. See fig. 1.

fig. 2, Dividers and medical record



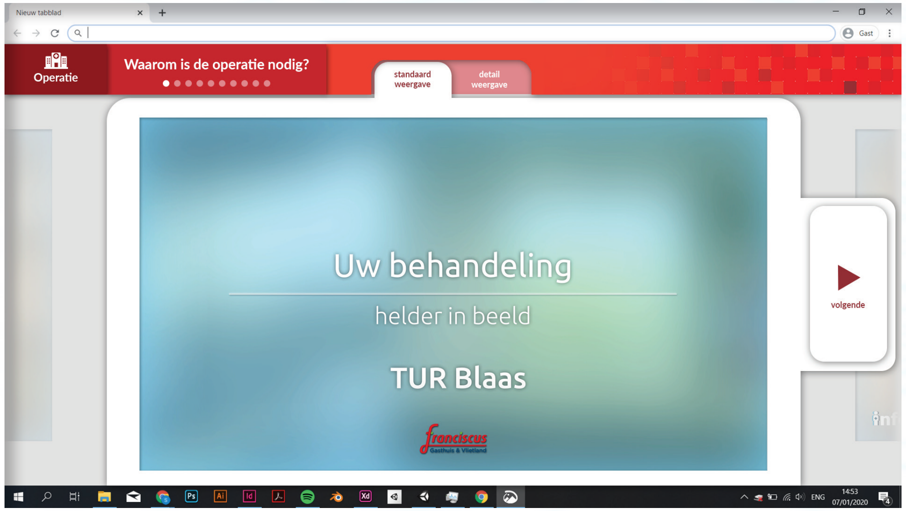
Metaphor paper medical record and folder dividers
For this project it is interesting to look at what physical objects elderly encounter during the treatment programme. Elderly grew up with the paper version of the medical record and experienced this paper version for large part of their lives. It is interesting to explore how the digital prototype can refer to the classic paper medical record. To organise the different phases of the treatment programme, it might be useful to investigate how physical folders are structured. Dividers help users to navigate easily to the part they want to. See fig. 2.

Conclusions
The application should fit the branding of SFVG to ease recognizability and overcome any concerns about reliability. Therefore colour usage and other design elements needs to be implemented in the final design. Certain elements need to refer to physical objects, to help elderly understanding its features. Therefore it is interesting what role folders and dividers can play to clarify the design.

FINAL DESIGN

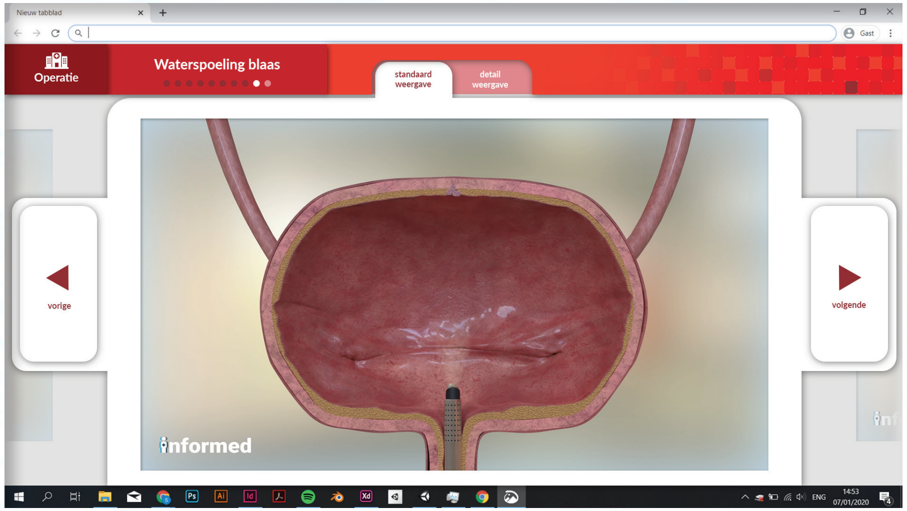
After several iterations (see appendix L), and the implementation of the design language, the final design for the TI TUR-B prototype is created. In the next part are the most important details explained, to give an overview of the final design.

Step 1 screen Used by IP DDP DDA IA Lead user IP



Explanation
The start screen of each phase contains the independent passive content. This content is primarily focused on the IP users, however it is still used by all other users. The group who finds most difficulties in coping with health information needs to understand what is on the screen. This content is centralized and scaled as large as possible to ensure the user is capable of understanding what is shown in the content panel. All the buttons are fairly large and contain text (and icons) to ensure consistency in all interactions. The fonts are sans-serif and larger than 16 pt to contribute to readability.

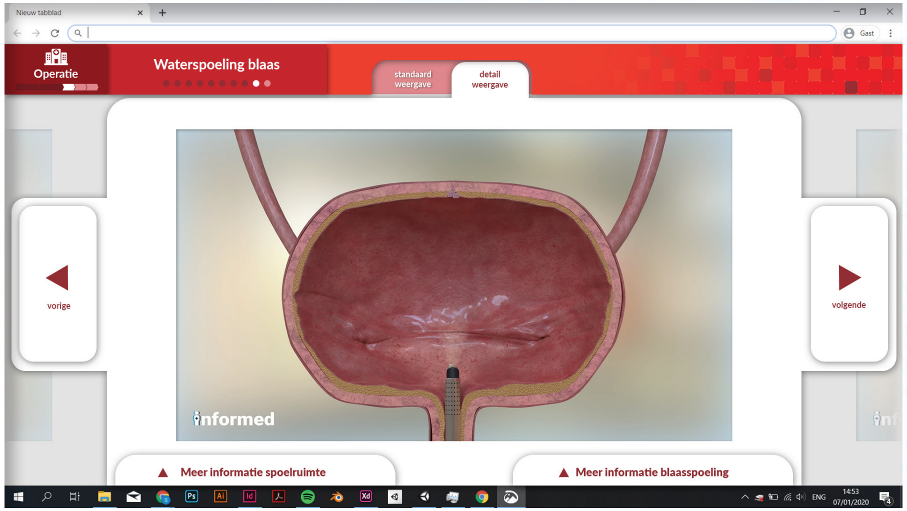
Step X screen Used by IP DDP DDA IA Lead user DDP



Explanation
This screen is primarily focused on doctor-dependent users. All users need to understand this screen except the independent passive. In the top left corner is all the relevant nagivation information: the surgery phase, and the step within the phase (waterspoeling blaas). The buttons next to the content, are used to navigate to other steps within the phase. The switch-button at the top of the screen is implemented to let users switch to a more detailed layout. This detailed layout contains information, more relevant for doctor-dependent and independent actives.

FINAL DESIGN

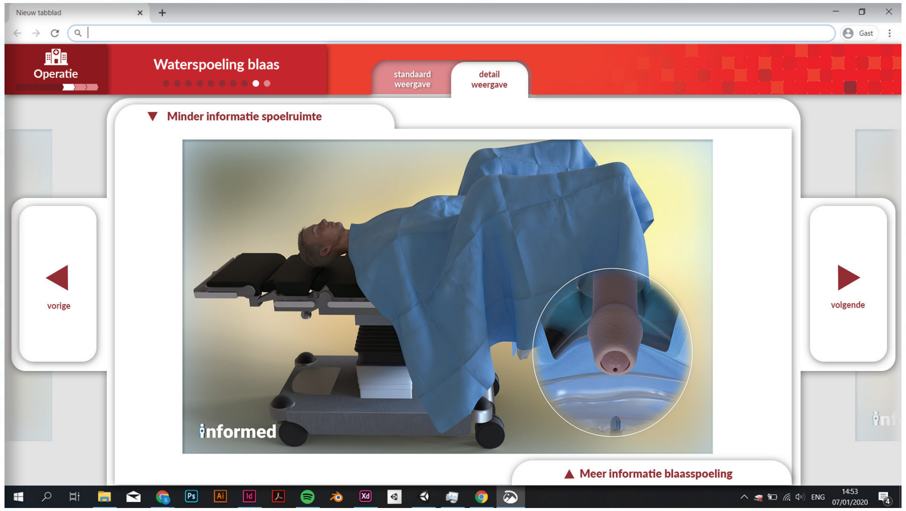
Step X screen detail Used by IP DDP DDA IA Lead user DDIA



Explanation

The screen above shows how the detailed mode looks like. This mode is primarily focused on both the active groups. The layout is quite similar to the basic version, however there is more information added. The phaseblock on the left-corner has an indication, to inform the user which phase he is currently visiting and how this phase relates to the others. Two buttons are added to let users access the in-depth content.

In-depth step screen Used by IP DDP DDA IA Lead user DDIA



Explanation

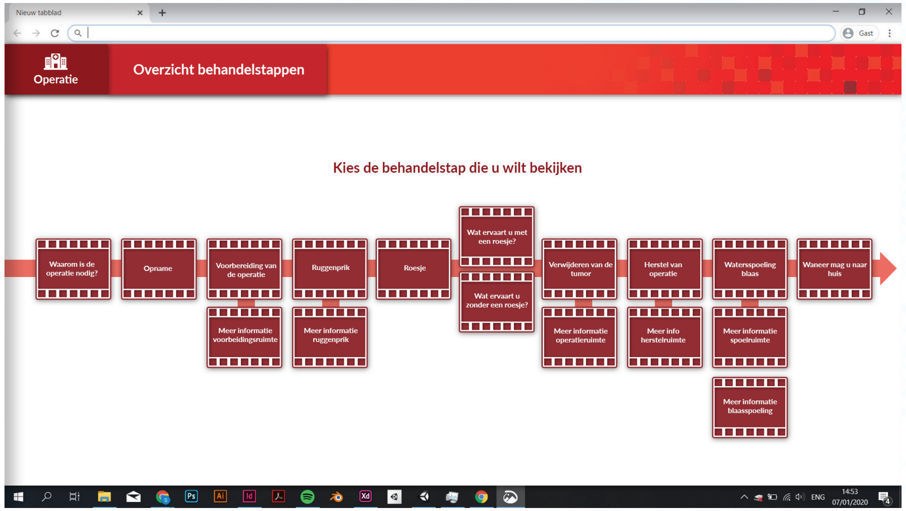
This example shows what the user will experience when one of the in-depth buttons is clicked. A layer with in-depth information will slide over and cover the main content. The text on the button changes from ‘more information’ to ‘less information’. The user can use this button to slide the in-depth information layer down and access the main content again.

FINAL DESIGN

Step overview screen

Used by IP DDP DDA IA

Lead user DDIA



Overzicht behandelstappen

Kies de behandelstap die u wilt bekijken

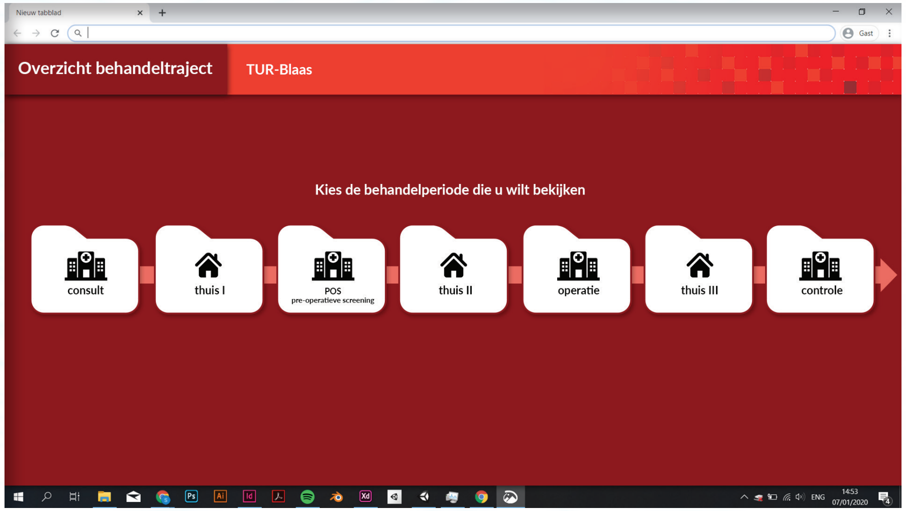
Explanation

This screen illustrates how the step overview looks like. This menu is primarily used by both active users and allows them to easily access a step with one click. Thereby it gives users an overview of all available steps within the phase.

Phase overview screen

Used by IP DDP DDA IA

Lead user DDIA



Overzicht behandeltraject

TUR-Blaas

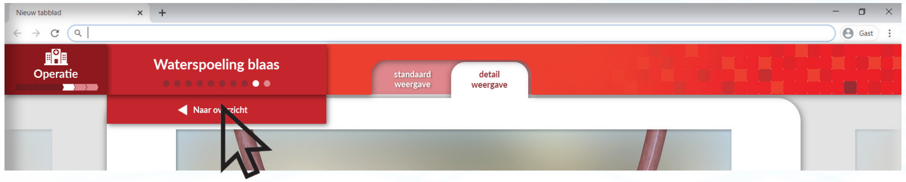
Kies de behandelperiode die u wilt bekijken

Explanation

This screen contains the overview of all the phases within the treatment traject. The user can access a phase by clicking on the icon. A distinct colour contrast is used, compared to the step overview, to overcome any confusion about which overview the user is visiting.

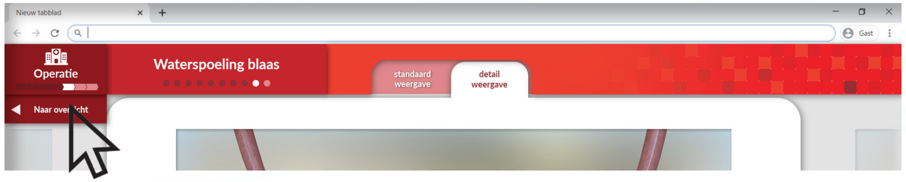
FINAL DESIGN

Access step overview | Used by IP DDP DDA IA | Lead user DDIA



Explanation
To access the step overview, the user has to click on the step to access the dropdown button. The user can click this 'naar overzicht' button to access the overview. The two-click process prevents users from missclicks.

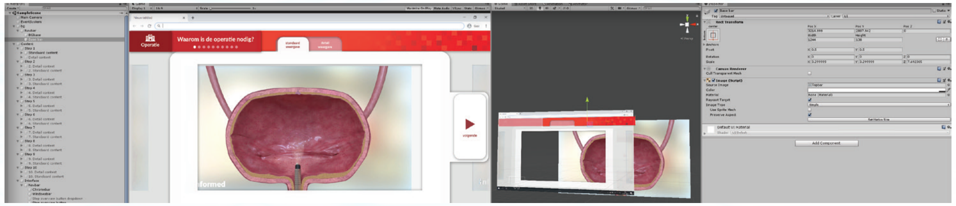
Access phase overview | Used by IP DDP DDA IA | Lead user DDIA



Explanation
To access the step overview, the user has to click on the phase to access the dropdown button. The user can click this 'naar overzicht' button to access the overview. The two-click process prevents users from missclicks.

TI TUR-B digital prototype

The TI TUR-B digital prototype is developed with Unity. This semi-open source game-engine allows unlimited possibilities for web application. With unity it is possible to implement video footage, video players, 3D models, user interfaces and more, all in one application.[30] This makes this engine not only suitable for the current prototype, it allows future development as well.



QR-code
Scan the QR-code and watch
the TI TUR-B prototype demo

Conclusions

- The user interface structure and design language are implemented in the final design for the TI TUR-B prototype.
- The TI TUR-B prototype is developed in unity, since this software allows the required features for the prototype.
- The TI TUR-B prototype is ready for evaluation research.

EVALUATION

The TI TUR-B prototype is ready for testing. The prototype will be used in the evaluation research to learn if the prototype is an improvement. It can be considered as an improvement, if research shows that participants prefer the TI TUR-B prototype, compared to the current resources based on five topics: anxiety, uncertainty, completeness of information, visual language and ease of use.

RESEARCH DESIGN

The main goal for the evaluation research is to learn if the TI TUR-B animation prototype, matches to the health information preferences of the four patient profiles of NMIBC patients and is an improvement of the current resources based on five topics: anxiety, uncertainty, completeness of information, visual language and ease of use.

The qualitative research contains one round and is conducted with five participants. Each session is consists of five parts and takes 25-30 minutes. The sessions are of semi-structured interview nature, are audio recorded and after research transcribed. The participants are former TUR-B patients, and now follow the subsequent bladder instillation trajectory. The bladder instillation patients have to visit the hospital frequently and are therefore easier to recruit for research. It is assumed that the participants can reflect on the previous TUR-B trajectory.

Part 1 Introduction
The participant is introduced to the research' topic: improving the health information resources for NMIBC patients. Thereby, the participant is asked to go back in time, to where they prepare for the upcoming TUR-B surgery.

Part 2 Testing the TI TUR-B animation prototype
The main goal for this part is to let the participant experience the prototype, learn which storylines are followed and if the user interface is clear. The exact context for using the prototype is created for the participant. The participant is asked to prepare for the TUR-B surgery, by using the prototype. During the usage, the participant is asked to think aloud.

Part 3 Reflect on current resources
The main goal for this part is to let participants recall their experiences with current resources, the 'verwijderen blaastumor' folder and the TUR-B animation, so they can compare them in the next part. The participant is asked to reflect on their experiences with the current resources; the folder and the animation. The following question and sub questions are asked:

Can you tell me about how you prepared yourself for the TUR-B surgery?
- How did you go through the folder's contents?
- How clear was the folder's information to you?
- How did you watch the TUR-B animation? All in once? How often?
- How clear was the animation to you?

Part 4 Comparison
The main goal for the comparison part is to learn if the TI TUR-B prototype is an improvement, compared to the current resources based on five topics: anxiety, uncertainty, completeness of information, visual language and ease of use . The participant is asked to fill in a questionnaire. The questionnaire consists of 5 statements; each statement has to be rated (Likert scale)[25] for both the current resources ('verwijderen blaastumor' folder and TUR-B animation, and TI TUR-B prototype). Each statement comprehends one of the five topics.

Part 5 Determine the patient profile
The main goal of this part is to learn which patient profile (or a combination of profiles) suits the participant best. The participants are asked to choose a persona that they can identify themselves with. It is allowed to combine more personas.

Evaluation research results
The results of the evaluation research are presented in the following tables.
- **First** column: the participant.
- **Second** column: the participant's patient profile of part 5.
- **Third** column: the prototype's user flow(s) participant followed in part 2.
- **Fourth** column: the scores for the comparison of part 4.

RESEARCH RESULTS

Participant | Patient profile | User flow | Comparison results

ROUND 4

9

DDA Doctor-Dependent Active / **IA** Independent Active

The participant initially followed the IP user flow. After suggesting there is more than step 1, the DDP user flow was followed.

	Reassurance	Certainty	Information preference	Visual language	Usage
TI TUR-B prototype	5	5	5	4	5
Folder and TUR-B animation	3	3	3	3	3

*scores: 1-5, higher is better

Participant | Patient profile | User flow | Comparison results

ROUND 4

10

DDP Doctor-Dependent Passive

The participant followed the DDP user flow, without any suggestions.

	Reassurance	Certainty	Information preference	Visual language	Usage
TI TUR-B prototype	5	5	5	5	5
Folder and TUR-B animation	3	5	5	5	5

*scores: 1-5, higher is better

Participant | Patient profile | User flow | Comparison results

ROUND 4

11

DDA Doctor-Dependent Active / **IA** Independent Active

The participant followed the DDA user flow, navigated exploratively through the prototype and no suggestions were needed.

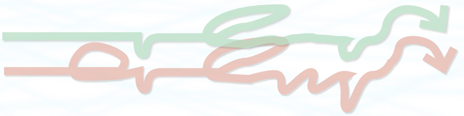
	Reassurance	Certainty	Information preference	Visual language	Usage
TI TUR-B prototype	5	5	5	5	5
Folder and TUR-B animation	4	5	4	5	4

*scores: 1-5, higher is better

RESEARCH RESULTS

ROUND 4

Participant	Patient profile	User flow	Comparison results
12	**IA** Independent Active	The participant initially followed the DDA user flow. The 'switch' is used, the phase and step overviews were used after a hint.	

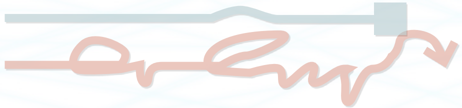


	Reassurance	Certainty	Information preference	Visual language	Usage
TI TUR-B prototype	5	5	5	5	5
Folder and TUR-B animation	5	5	5	5	5

*scores: 1-5, higher is better

ROUND 4

Participant	Patient profile	User flow	Comparison results
13	**IA** Independent Active	The participant initially followed the DDP user flow, after a hint (try to click on everything and see what happens) the IA user flow was followed.	



	Reassurance	Certainty	Information preference	Visual language	Usage
TI TUR-B prototype	5	5	5	5	5
Folder and TUR-B animation	5	5	5	5	5

*scores: 1-5, higher is better

Quotes

P10: "Because I already had the surgery, I understand and can visualize everything. However, if you use the interactive animation in advance, you'll know a lot already and be better prepared. And the medical specialists have to explain less."

P12: "If the information (via the TI TUR-B prototype) is provided by your urologist, it makes it clearer for you. Nice application!"

The transcriptions of the research can be found in appendix M.

RESEARCH CONCLUSIONS

The TI TUR-B prototype is tested and compared to the current resources, the 'Verwijderen blaastumor' folder and the TUR-B animation, thus the evaluation research conclusions can be made.

IP participant
The research is conducted with five participants: two IA's, one DDP and two mixtures of IA and DDA. There is no information gathered from an IP participant. However, participant 9 showed characteristics of an independent passive, contrary to the result of part 5 (combination of DDA and IA). The participant told, she had neglected the 'Verwijderen blaastumor' folder.

"Oh, the folder. So, I did not read it. I was reproved, because I didn't read it."

Thereby, the participant showed a passive attitude during the prototype testing. The participant asked if she was done halfway step 1 (IP information). Furthermore, the participant did not show any explorative or active behavior. This insinuates that participant 9 can provide valuable information for IP's.

User flows
Four out of five participants followed the intended user flow as described in the conclusion phase. Notably, some hints or instructions were needed to show the features of the prototype. Hints or instructions like: 'try to click in the screen and see what happens' or 'the phase indicator is actually a button.' More detailed information on these design flaws are addressed next.

Comparison results
The folder plus the TUR-B animation were compared with the TI TUR-B prototype based on five topics: reassurance, certainty, information of preference, visual language and usage. All resources scored well. The average score for each of the compared resources:

	Reassurance	Certainty	Information preference	Visual language	Usage
TI TUR-B prototype	5	5	5	4.8	5
Folder and TUR-B animation	4	4.6	4.4	4.6	4.4

*scores: 1-5, higher is better

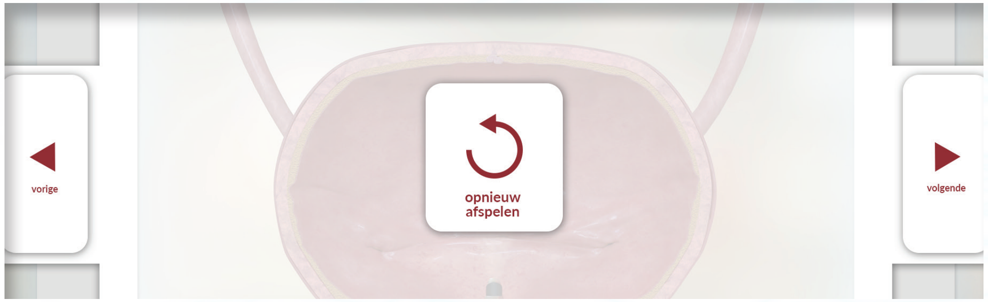
Based on these scores the indication can be made that the TI TUR-B prototype is an improvement compared to the 'Verwijderen blaastumor' folder and TUR-B animation. The evaluation research learned that TI TUR-B prototype better meet the NMIBC patient's needs concerning health information for at least the DDP's, DDA's and IA's. Thereby participant 9 provided valuable information for IP's, which shows that the prototype is pointing in the right direction. This research is on a such small scale that it cannot count for all patients, nevertheless it illustrates that Tailored Interactive 3D animation is promising for patient-health information communication with the aim to reduce the patient's anxiety and uncertainty.

RECOMMENDATIONS

The TI TUR-B prototype needs more development until it can replace the TUR-B animation. Firstly, some changes should be made to the design to overcome any user's confusions. These changes are all user interface-design related.

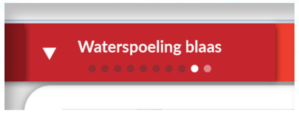
Animations loops

The animations in the prototype loop in the prototype. Several participant were confused and thought they had to rewatch the animation. An easy solution for this problem is to disable the loop feature and implement a rewatch button at the animation's end screen.



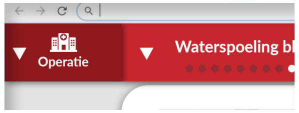
Step indication button

At first, it was not clear for all participants that the step indication, actually is clickable. Without a hint, they would not know of the step overview's existence and never use it. Therefore an icon needs to be added to the design of the button to show its clickable feature.



Phase indication button

The phase overview was not accessed at first for the same reason as the step overview. The participant did not recognize the phase indication button as a button. An icon needs to be added as well.

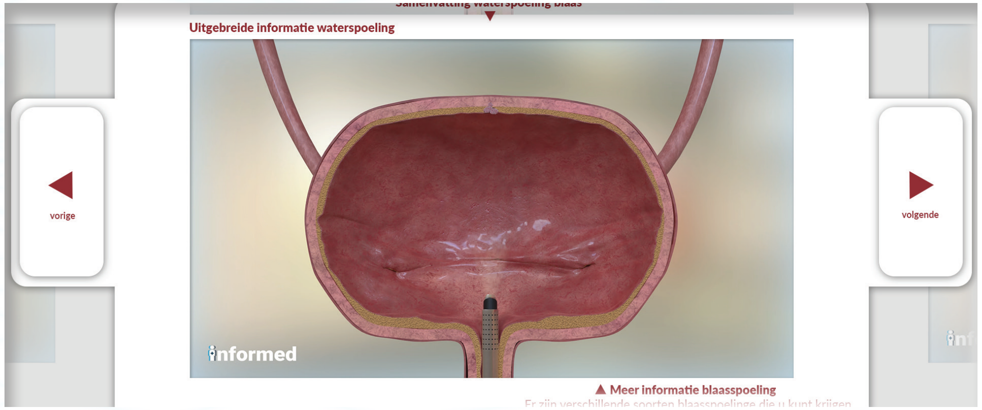


Switch button

The button at the mid-top of the screen allows users to switch between the basic and the detailed layout. Users can access in-depth information in the detailed layout. The participants recognized the switch-button, but did not experience many changes. Therefore a larger distinction in design between the basic and detailed layout has to be made.

In-depth steps

Some of the in-depth steps have an extra interactive feature. Users can rotate the view of the scene by using two rotation buttons. At first, the feature of these button was not recognized. The design or interaction needs to be improved.
Some of the participants did not understand whether a in-depth step is opened or not. Thus, more distinction needs to be made between the base step and the in-depth step.



Step overview

The step overview shows all the steps within the surgery phase. The unvisited steps are semi-transparent and the visited steps have no transparency at all. For readability reasons another distinction has to be made. A solution is a colour difference between visited and unvisited steps.

RECOMMENDATIONS

The previous recommendations need little time and effort to solve and implement in the design, compared to the following issues. The evaluation research showed interesting opportunities for future improvements of the design. Further research need to conducted to investigate these issues and design a satisfying result.

IP research
Previous research learned that independent passives need special attention for designing health information materials. The evaluation research did not include a self-determined IP. Therefore future research need to be conducted to learn more about the IP's attitude towards the TI TUR-B animation.

Translation for other treatments
In this project only the TUR-B treatment is researched. It is interesting how other treatments are constructed, so the TI TUR-B animation can be redesigned for another treatment. Then a complete digital library with tailored interactive animations can be developed to inform patients with other diagnoses as well.

Traditional folder and TI TUR-B animation
The evaluation research learned that participants preferred the TI TUR-B animation as their main information source, however still wanted something on paper to read. Therefore, future research has to conducted to learn how the interactive animation and the traditional folder or reference work can be combined into one coherent product family.

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APPENDICES

Context exploration

A Stakeholder analysis
B Verwijderen blaastumor folder
C TUR-B animatie
D Patient profile analysis
E SFVG research procedure
F Statements and personas
G TUR-B information cards

Context exploration

H Qualitative research transscript
I Wrap-up in detail
J Wrap-up in detail
K User flow in detail
L UI iterations
M Evaluation research transscript

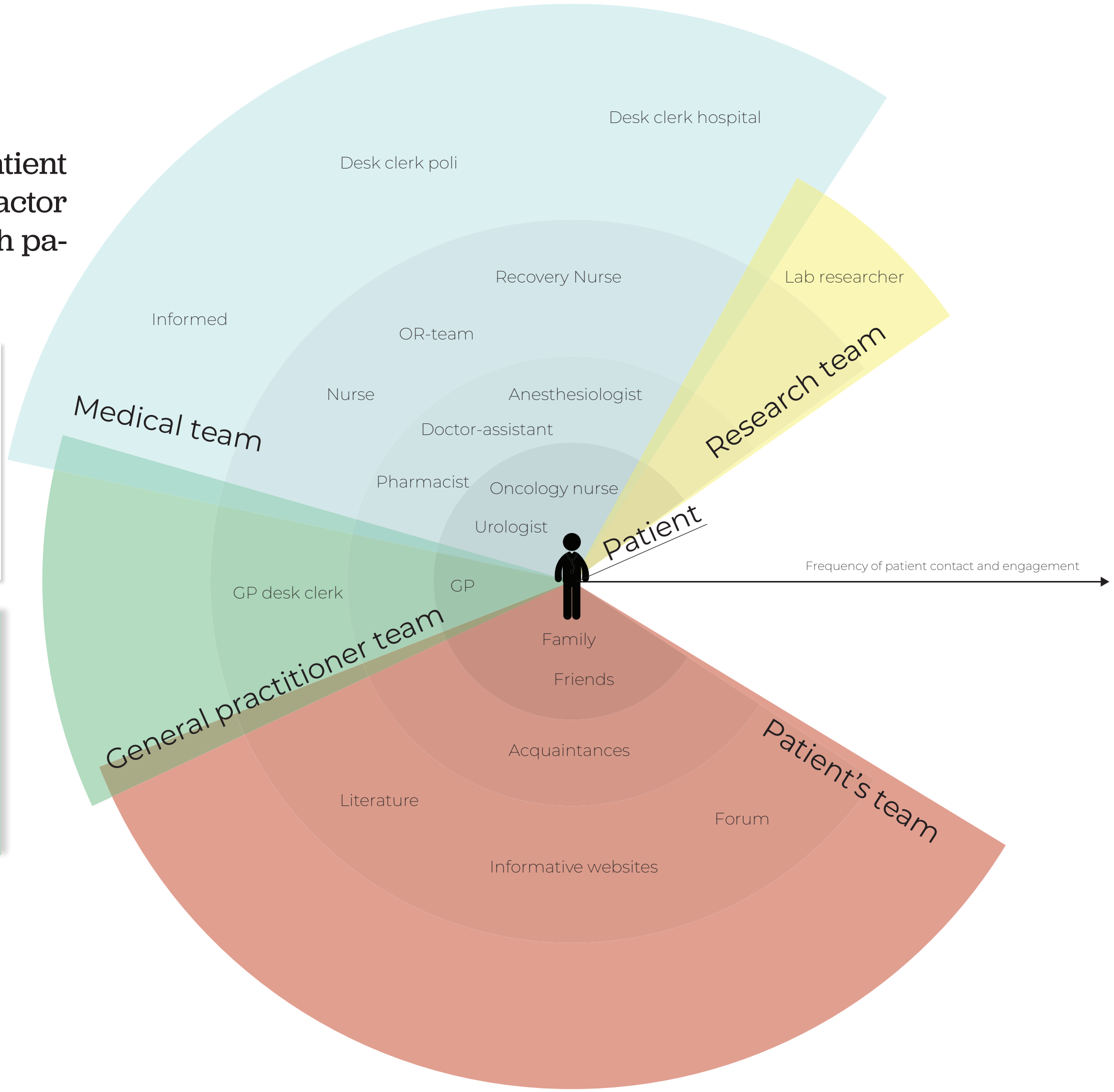
A

Stakeholder analysis

The actor map helps to give insight in all actors related the patient during the treatment traject. This map helps to determine which actor belongs to which ‘team’ and how frequent they are in contact with patients and how engaged they are during the traject.

What is in the actor map?
In the middle of the circle is the target group, the NMIBC patient, visualized. All actors are classified in teams: patient’s team, general practitioner team, medical team and research team. The size of the circle the actors are in depends on the frequency of patient contact and engagement. The actors in the smallest circle have the most patient contact and are most engaged.

Conclusion
The actors in the smallest circle have to be included during the project, since they have the most contact and are most engaged during the treatment traject. This means that the patient’s family and friends, urologist and oncology nurse will definitely taken into account.The general practitioner, will be left out since he is not part of the TUR-B treatment traject.



B

Verwijderen blaastumor folder

Introduction

As discussed with your urologist, a bladder tumour is found. Bladder tumours are all growths inside the bladder wall. These can be good-natured or malignant. Pathological research is needed to determine the best diagnosis. In this folder you can find all information discussed with your urologist.

Topics

- What is a bladder tumour?
- Types of bladder tumours
- Pathelogical research

Tumour removal

In collaboration with you, is suggested to remove the tumour. This happens in your case via the urethra with a special instrument (transurethral resection). This is a keyhole surgery via the urethra, where tumour tissue or the complete tumour is removed.

Topics

- Nature of surgery

Anesthesia

When undergoing surgery, the urologist refers you to the polyclinic preoperative screening (POS), Anesthesia. All relevant information concerning the anesthesia will be discussed. Usually, this surgery will be done under spinal anesthesia.

The anesthetist numbs your lower body via an injection in your back. The advantage of this technique is that it your lower body is completely numb, but you are conscious and no respiration is needed. In general you will recover faster after these type of anesthesia. If you are uncomfortable being conscious during the surgery, you can discuss a sleeping aid with the anesthetist.

It is important to stop well ahead with blood thinners as Ascal, Aspirine, Marcoumar, Sintrommitis, Acenocoumarol, Acetosal, Persantin and similar. Generally, this is already discussed at the polyclinic Urology. If you forgot about this, please inform as soon as possible.

Topics

- Pre-operative screening
- Spinal anesthesia
- Sleeping aid
- Stop with bloodthinners

Hospitalization

The hospitalization will be at the day of the surgery vor the day before. If the surgery will take place on the same day, you are allowed to drink clear fluids, as tea, juice or water, till two hours before the surgery. Till six hours before the surgery, you are allowed to eat biscuits or crackers. At the day of hospitalization the nurse will show you around the Urology department. She will ask a few questions and discusses the course of events concerning the surgery. If necessary, the doctor will examine you.

An hour before the surgery, you will get your premedication as discussed with the anesthetist. These meds will prepare your body for the anesthesia. The nurse ask you to visit the toilet. Thereafter, she will bring you to the surgery department.

Topics

- When is the hospitalization?
- When to stop drinking?
- When to stop eating?
- Who will take care of the patient?
- What will happen before the surgery?
    1. Nurse asks questions
    2. Doctor might examine patient
    3. Premedication
    4. Toilet visit
    5. Patient brought to surgery room

Surgery

The bladder tumour will be removed, because it causes complications, as bleedings. In addition, not all bladder tumours are good-natured. This can not be determined during bladder examination.

The surgery is as follows:

- U lie on your back with your legs in supports;
- The doctor brings the cystoscope (an hollow instrument) in the urethra to examine your urethra and bladder;
- The bladder tumour and/or tumours will be removed layer for layer with an electrical loop. This causes an internal wound. Small bleedings will be scorched, using this loop.
- The collected tissue will be used for pathological research. There will be determined if the tumour is malignant. We determine the treatment plan based on these results.
- A catheter will be left in the bladder, since urine can be bloody after the surgery.

The complete surgery lasts one till one and a half hour.

Topics

- Why is the tumour removed?
- Surgery explanation:
    1. Position patient
    2. Doctor brings cystoscope in
    3. Tumour removal and wounds
    4. Collected tissue for research and treatment plan
    5. Catheter
    6. Duration surgery

Scientific research

If urine, blood or tissue samples are taken, there is a the opportunity that certain body material is left over. This material can be used for scientific research. Hereby, insights in the cause and treatment of diseases will be gathered. Research has to meet strict legislation, as the anonymization body material.

All research related important information, you can find at www.pathology.nl/voorlichting. If you are against collecting samples of your body material, than you can read in the folder how to protest.

Topics

- What will happen with leftover body material.

After surgery 1

You will be brought to the recovery room after the surgery. Your heart rate, blood pressure and pain will be checked. When these checks are stable, you will be brought to the nursing department. These checks will be repeated a few times at the nursing department.

You will have a catheter after the surgery. This catheter cleans the bladder continuously. This overcomes clots and small tissue particles blocking the catheter. When the fluid remains clear, the instillation can be stopped.

When the catheter is removed, there will be some blood and clots in your urine. This decreases gradually. Still it can take up to a few weeks until all clots are disappeared. It is possible that the crots reoccur. This is normal. If you drink extra on that day, the blood will disappear.

Topics

- Patient brought to revovery room
- Checks for heart, bloodpressure and pain
- Patient brought to nursing dep.
- Catheter
- Blood and clots in urine
- Drink extra

After surgery 2

You will have an infuse in your arm, it will removed when your sickness is over, the flushfluid is clear and you can eat and drink.

When the flush fluid is clear, the nurse will provide the first bladder instillation (chemo or cytostatica). This instillation remains for one hour in you bladder. Afterwards the catheter can be removed. At first, urinating can be painful. The urine is bloody. If you drink well. it will get better soon.

The nurse notes and checks your drinking, how much you urinate and how much is left in the bladder. This will be determined using an echo device. If you urinate well, you can go home.

You have to warn the nurse if you have to urinate, but you can't.

Sometimes no insitillation is given after surgery. This occurs when there is doubt about damage in a inner bladder layer or during the surgery a little gap is caused.

Topics

- Infuse
- Bladder instillation and painful urinating
- Checks: drinking, urinating
- Warning: when patient cant urinatie
- Exception: no instillation

Complications

- Blood loss

The bladder will be flushed after the surgery, til the flush fluid is clear. It may take longer than usually. Sometimes we have to use a syringe to remove the clots. Rarely, blood loss occurs that has to be treated in the surgery room.

- Catheter problems

An irritated bladder occurs frequently, due to the catheter. This result in bladder cramps. These cramps can be cured with medicines.

- Ureteral infection

A ureteral infection can occur after the surgery. Antibiotics can help to cure the infection.

- Bladder puncture during surgery

A small puncture recovers naturally. The catheter has to remain a couple of days.

The bladder instillation can have the following side effects, since the chemo can influence healthy cells. These can be:

- Severe pain and painful urge to urinate
- Pain in the under belly
- Allergic skin reactions

When these complains last longer, contact the polyclinic Urology.

Topics

- Complications:
  1. Blood loss
  2. Catheter problems
  3. Ureteral infection
  4. Bladder puncture
- Side effects:
  1. Pain and painful urge urinating
  2. Pain in underbelly
  3. Allergic skin reactions
- Contact polyclinic Urology

Home advice

Since you've had chemo/cytostatica, some advices counts to protect your family or inmates:

- Men have to sit down the first two days while urinating to overcome spraying;
- We advise to clean the toilet immediately after spilling;
- Clean your hands and genitals after toilet use for the first two days;
- It is recommended to use a condom having sexual intercourse for the first week after the bladder instillation.

Topics

- Due to chemo:
  1. Men sit down urinating
  2. Clean toilet
  3. Clean hands and genitals
  4. Use condom

Effect on sexuality

A lot of men have the believe that one will become impotent after the transurethral surgery. This is not the case. Such a surgery has no negative influence on an erection and sexual feelings and experience do not decrease.

Topics

- Sexuality: not impotent

Dismissal

In general, everyone will leave the hospital one day after the surgery. This is when you can urinate after the catheter removal.

There are some general rules of life after the surgery:

- To overcome clots in the bladder, you have to drink a lot;
- Avoid physical labour;
- Avoid pressure, when defecating. If necessary, the feces can be made less tough using laxatives;
- You are allowed to drive, not to cycle;
- The first two weeks you have to relax. Thereafter, you can pick up your daily routine.

After dismissal we arrange an appointment for the polyclinical checkup. This appointment takes place a week after the dismissal. We ask you about problems and examine your urine. We discuss the results of the bladder tumor tissue as well. Based on this, we make new appointments.

Topics

- When leave the hospital?
- Rules of life:
  1. Drink a lot
  2. Avoid physical labour
  3. Avoid pressure ; defecating
  4. Driving alowed, cycling not
  5. Relax for two weeks
- Schedule checkup for:
  1. Urine examination
  2. Results tissue research
  3. New treatment programme

Contact us

You have to contact use when you:

- urinate blood clots or blood loss will not decrease;
- hav a fever above 38,5;
- have severe burning pain while urinating or when you can't urinate;
- suddenly have a severe stomachache, even with paracetamol (dose: 4 times a day - every six hours - two tablets paracetamol of 500mg)

Topics

- Contact when:
  1. Clots and blood in urine not decreases
  2. fever; 38,5
  3. Burning pain or can't urinate
  4. Sever stomachache; dose paracetamol

C

TUR-Bladder 3D animation

Next to the folder, medical specialist share the TUR-B 3D animation with the patient. This animation summarizes the most important topics of the folder. This animation is made by Informed in collaboration with an urologist to ensure the quality. Studies showed that 3D animations help patients in understanding health information.

Uw behandeling

helder in beeld

TUR Blaas

IC - A

Introduction

Bij U is onlangs een afwijking ontdekt in de blaas.

IC - D

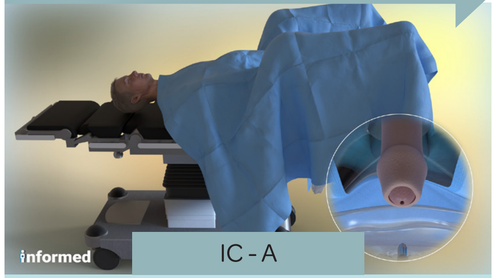
Indication

Alleen door het verkrijgen van weefsel kan de juiste diagnose gesteld worden en een persoonlijk behandel advies gemaakt worden.

IC - C

Alternatives

Preparation



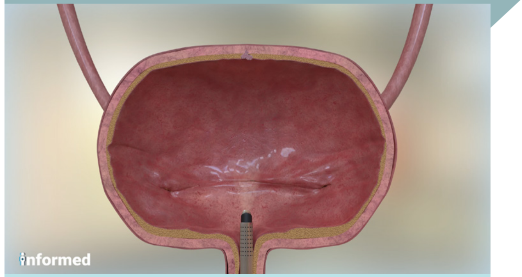
IC - A

Treatment

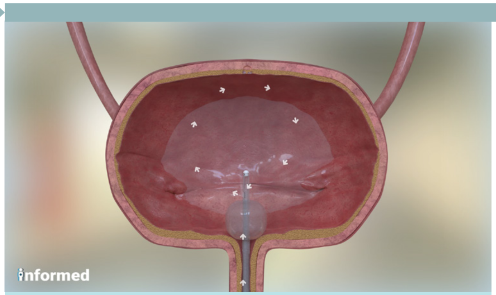
Onder verdoving wordt een buisje door de plasbuis in de blaas gebracht. Door dit buisje gaat een camera en de zogenaamde resectoscoop waarmee weefsel verwijderd kan worden. Aan de resctorscoop zit een metalen draad, de lis, waarmee elke afwijking kan worden weggesneden en bloedvaatjes worden dichtgebrand. Tijdens de operatie stroomt er continue spoelvloeistof in en uit de blaas. De weggesneden stukjes worden met de spoelvloeistof die door de resectoscoop de blaas inspoelt afgevoerd en opgevangen voor microscopisch onderzoek. Meestal wordt

About the animation

The latest animations of Informed comprehend eight chapters: introduction, indication, alternatives, preparation, treatment, complications, after care and results. Unfortunately, this animation is outdated and does not address alternatives, preparation, complications and results. This means that the animation is incomplete and does not guarantee informed consent. It lacks information about alternatives for the TUR-B (informed consent C) and information about effects and risks for the patient’s health state (informed consent B).



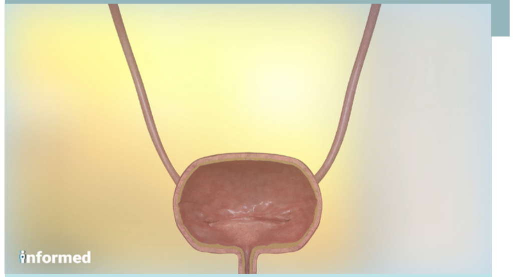
uit de bodem van te afwijking ook nog een hapje genomen met een scherpe biopsie tang, die het weefsel afsnijd zonder stroom waardoor het weefsel minder beschadigd en betrouwbaarder microscopisch onderzoek kan plaatsvinden om te bepalen hoe diep de afwijking groeit. Als al het afwijkende weefsel verwijdert is en er geen bloeding zichtbaar is wordt de blaas gevuld en het hele instrument verwijderd. Als laatste wordt een spoelcatheter ingebracht. Nu wordt een slangetje, de spoelcatheter, door de plasbuis tot in de blaas gebracht. Door de ballon



op te blazen blijft de catheter in de blaas. Nu wordt een slangetje, de spoelcatheter door de plasbuis tot in de blaas gebracht. Door de ballon aan het einde van de cathteter op te blazen blijft de cathteter in de blaas. Via de catheter loopt de spoelvloeistof in en uit de blaas. Door de kleur van de spoeling kan een eventuele nabloeding snel ontdekt worden. Meestal kan de snelheid van inlopen van de spoelvloeistof snel worden afgebouwd. Als de urine helder blijft, de verdoving is uitgewerkt wordt de cathetern verwijderd.

IC- B

Complications



After care

Zodra u heeft aangetoond dat u leegplast mag u naar huis.

Results

D

Patient profiles analysis

Some examples of segmentation based on the patient's characteristics are presented in the PROFILe project and the Tailored Healthcare project. The PROFILe project assesses patient's characteristics based on glycaemic control trajectories for adult patients with type 2 diabetes. Researcher hypothesized that patients with different trajectories have different preferences for diabetes care and support. The tailored healthcare project approach is to assess older patients, undergoing lower limb joint replacement surgery, based on their coping style, anxiety and communication preferences. The PROFILe approach is difficult to translate to NMIBC patients, since the nature of both treatments are very different and a factor as glycaemic control trajectories is hard to find. The tailored healthcare project is closer to the project since it assesses the patient's coping styles, anxiety and communication preferences.

Another approach is examined in Tailored Health Communication, where total hip arthroplasty patients are divided into three subgroups: patients of subgroup A are individuals with poor preoperative clinical status, who have a diverse set of coping styles and strong preferences towards communication. Patients of subgroup B have good preoperative clinical status and quality of life, have limited coping strategies and find patient-provider communication of lesser importance, except a need for open information. Patients of subgroup C are older and more anxious, have other coping behaviour (religious) and are less skilled and self-efficacious in communication about health. This approach is closer to health information preferences of patients. Nevertheless, this set of characteristics might trouble segmentation of NMIBC patients when considering demographics as age, since most of them are assumed to fit subgroup C.

E

SVFG research procedure

The SFVG research procedure consists of several steps until the research can be conducted. This procedure is constructed to ensure the relevance and quality of research.

Step 1

Firstly, the researcher has to be enrolled and approved as a researcher at the SFVG. For an external researcher an introduction is needed by a representative of the SFVG. This reprensative is responsible for the researcher's actvities.

Step 2

Account needs to be created to gain access to the SFVG's digital platforms: HiX (electronic health record platform) and Castor (digital study environment). Likewise, an account needs to be created to gain access to the SFVG's mail environment and computer login to gain access to their computer facilities. Furthermore, an access pass needs to be created for entering and for identification purposes in several facilitities .

Step 3

The research protocol has to be described, handed-in and approved by the SFVG's research department. This contents of the protocol can found below.

Bijlagen	*E1. Patiënteninformatie met Franciscus logo en lokale gegevens (indien van toepassing)* *E2. Informed consent mét Franciscus logo* *F1. Vragenlijsten* *I3. CV Franciscus-hoofdonderzoeker* *I4. CV Franciscus-coördinerend onderzoeker*

Inhoud

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Onderzoeksdoel(en) 4
Studie design 4
3. Populatie 4
Inclusie criteria 4
Exclusie criteria 4
Aantal proefpersonen/ sample grootte 4
Duur van de studie 5
4. Procedures van onderzoek en evt. behandelingen 5
Studie procedure 5
5. Variabelen en meetmethoden 5

Versiedatum 19-11-2018 *Pagina 1 van 9*
Printdatum 26-11-2018 *(uitgeprinte versie van SOP 24 uur houdbaar – alleen digitale versie gebruiken)*

Format onderzoeksprotocol Niet WMO-plichtig onderzoek (november 2018)

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Secundaire uitkomstmaat 5
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6. Analyses 6
Statistische analyses 6
7. Ethische aspecten 6
Motivatie niet WMO plichtig onderzoek 6
Belasting voor de proefpersoon 6
Risico voor de proefpersoon 6
8. Administratieve aspecten 7
Privacy en databeheer 7
Publicatiebeleid 9
9. Financieel 9
Overige opmerkingen 9
Referenties 9

Step 4

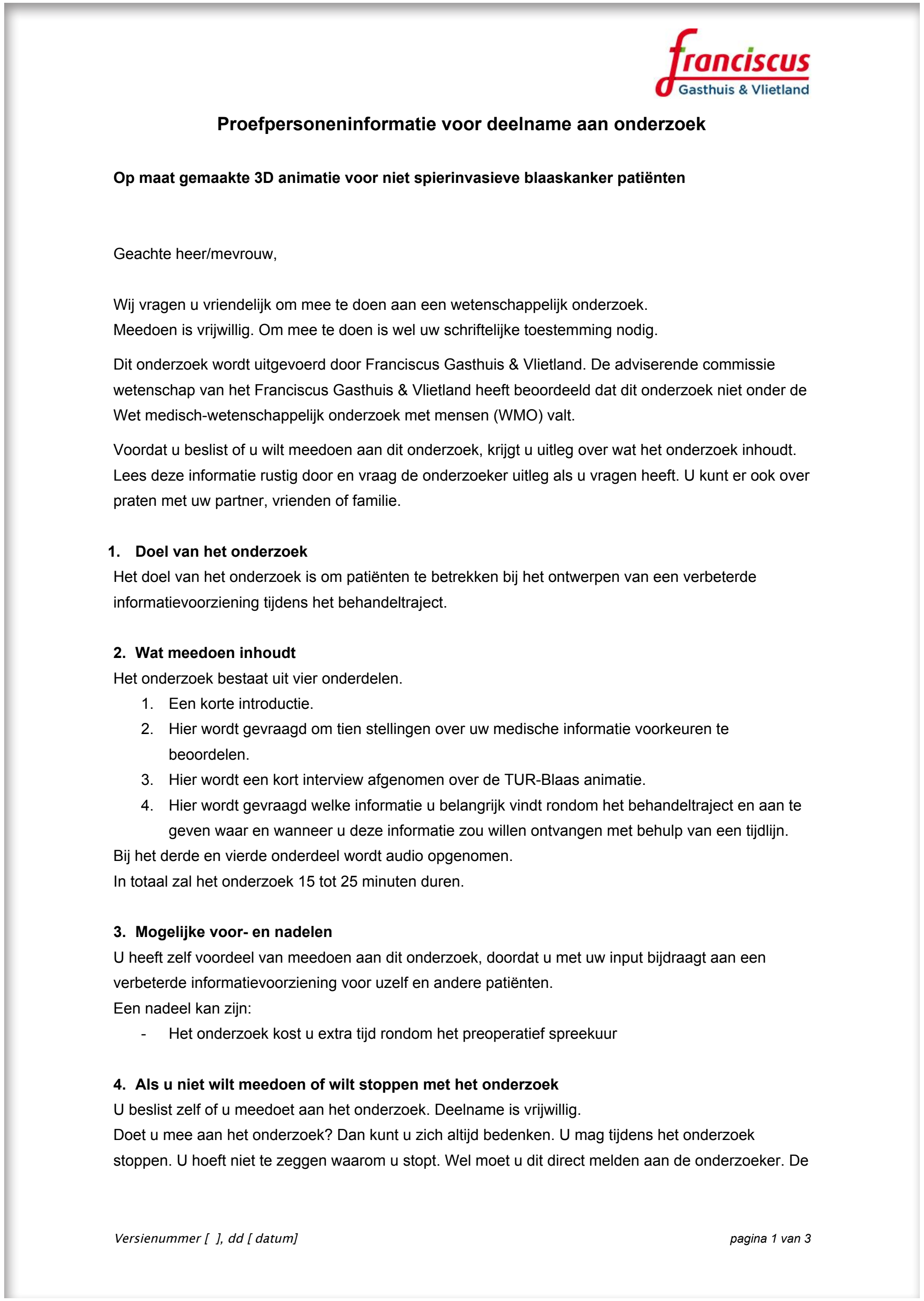
The patient information folder (PIF), can be found over here. These forms are used to inform the participant about the research. If the participants agree on the terms, as described in the PIF, they have to sign.

The PIF has to be handed in and approved by the SFVG's research department before the research can take place.

Step 5

The urology department has to be informed about the researcher's activities. Thereby they helped to arrange research rooms and reqruit participants.

All these steps were taken for the Qualitative Research and Evaluation Research.



franciscus
Gasthuis & Vlietland

Proefpersoneninformatie voor deelname aan onderzoek

Op maat gemaakte 3D animatie voor niet spierinvasieve blaaskanker patiënten

Geachte heer/mevrouw,

Wij vragen u vriendelijk om mee te doen aan een wetenschappelijk onderzoek.
Meedoen is vrijwillig. Om mee te doen is wel uw schriftelijke toestemming nodig.

Dit onderzoek wordt uitgevoerd door Franciscus Gasthuis & Vlietland. De adviserende commissie wetenschap van het Franciscus Gasthuis & Vlietland heeft beoordeeld dat dit onderzoek niet onder de Wet medisch-wetenschappelijk onderzoek met mensen (WMO) valt.

Voordat u beslist of u wilt meedoen aan dit onderzoek, krijgt u uitleg over wat het onderzoek inhoudt. Lees deze informatie rustig door en vraag de onderzoeker uitleg als u vragen heeft. U kunt er ook over praten met uw partner, vrienden of familie.

1. Doel van het onderzoek

Het doel van het onderzoek is om patiënten te betrekken bij het ontwerpen van een verbeterde informatievoorziening tijdens het behandeltraject.

2. Wat meedoen inhoudt

Het onderzoek bestaat uit vier onderdelen.

1. Een korte introductie.
2. Hier wordt gevraagd om tien stellingen over uw medische informatie voorkeuren te beoordelen.
3. Hier wordt een kort interview afgenomen over de TUR-Blaas animatie.
4. Hier wordt gevraagd welke informatie u belangrijk vindt rondom het behandeltraject en aan te geven waar en wanneer u deze informatie zou willen ontvangen met behulp van een tijdlijn.

Bij het derde en vierde onderdeel wordt audio opgenomen.
In totaal zal het onderzoek 15 tot 25 minuten duren.

3. Mogelijke voor- en nadelen

U heeft zelf voordeel van meedoen aan dit onderzoek, doordat u met uw input bijdraagt aan een verbeterde informatievoorziening voor uzelf en andere patiënten.
Een nadeel kan zijn:

- Het onderzoek kost u extra tijd rondom het preoperatief spreekuur

4. Als u niet wilt meedoen of wilt stoppen met het onderzoek

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig.
Doet u mee aan het onderzoek? Dan kunt u zich altijd bedenken. U mag tijdens het onderzoek stoppen. U hoeft niet te zeggen waarom u stopt. Wel moet u dit direct melden aan de onderzoeker. De

Versienummer [ ], dd [datum] *pagina 1 van 3* gegevens die tot dat moment zijn verzameld, worden gebruikt voor het onderzoek. Als u wilt, kan wel het verzameld opnamemateriaal dat nog niet is gebruikt, worden vernietigd.

5. Gebruik en bewaren van uw gegevens

Voor dit onderzoek is het nodig dat uw antwoorden op de vragenlijst worden verzameld en uw stem wordt opgenomen. Elke proefpersoon krijgt een code die op de gegevens komt te staan. Dit heet gecodeerd. Uw naam wordt dan niet meer gebruikt.

Uw gegevens

Al uw gegevens blijven vertrouwelijk. Alleen de onderzoeker weet welke code u heeft. Voor het onderzoek worden uw onderzoeksgegevens gecodeerd gedeeld met de TU Delft. De onderzoeksgegevens zijn bij publicatie in een (wetenschappelijk) tijdschrift en bij de TU Delft niet te herleiden naar u.

Als u de toestemmingsverklaring ondertekent, geeft u toestemming voor het verzamelen, bewaren en inzien van uw persoonsgegevens.
De onderzoeker bewaart uw gegevens 15 jaar. Daarna worden de persoonsgegevens vernietigd.

Uw lichaamsmateriaal

Al het opgenomen geluidsmateriaal wordt bewaard binnen de veilige digitale omgeving van het Franciscus tot en met ten minste 1 Maart. Het materiaal wordt gebruikt om te analyseren hoe het prototype verbeterd kan worden.

6. Geen vergoeding voor meedoen

Voor het meedoen aan dit onderzoek krijgt u geen onkostenvergoeding.

7. Heeft u vragen?

Bij vragen kunt u contact opnemen met de onderzoeker.

<u>Contactgegevens</u>

- Selwyn A. Steenbergen. E-mail: s.steenbergen@franciscus.nl, Tel: 06-18144017

Dank voor uw aandacht.

Bijlage: Toestemmingsformulier proefpersoon
Op maat gemaakte 3D animatie voor niet spierinvasieve blaaskanker patiënten

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens op de manier en voor de doelen die in de informatiebrief staan. Ik geef toestemming om mijn gegevens nog 15 jaar na dit onderzoek te bewaren.
- Ik wil meedoen aan dit onderzoek.

Naam proefpersoon:

Handtekening: Datum : __ / __ / __

Ik verklaar dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek. Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de proefpersoon zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker:

Handtekening: Datum : __ / __ / __

De proefpersoon krijgt een volledige informatiebrief mee, samen met een kopie van het getekende toestemmingsformulier.

F

Statements and personas

These statements and personas were used to determine the patient’s profile.

	volledig oneens	oneens	neutraal	eens	volledig eens
Stellingen	1	2	3	4	5
1. Het is belangrijk om geinformeerd te worden over gezondheidskwesties.					
2. Het is noodzakelijk om geinformeerd te worden over gezondheidskwesties, om gezond te zijn en blijven.					
3. Wanneer ik ziek ben, probeer ik informatie te vinden over mijn ziekte.					
4. Voordat ik een gezondheids gerelateerde keuze maak, probeer ik zo veel mogelijk uit zoeken over de kwestie.					
5. Ik werk samen met de arts om mijn gezond te blijven.					
6. Ik laat het aan de arts over de juiste keuzes over mijn gezondheid te maken.					
7. Ik zou meer controle over mijn gezondheidstoestand hebben.					
8. De meeste gezondheidskwesties zijn erg moeilijk voor mij om te begrijpen.					
9. Ik heb moeite met het begrijpen van gezondheidsinformatie die ik lees.					
10. Ik vertrouw op de arts, dat mij alles verteld wordt wat ik nodig heb om gezond te blijven.					

Quotes

- Naam: A. Visser
- Leeftijd: 51 jaar

- “Ik ben zeer actief met mijn gezondheid bezig.”
- “Ik probeer zelf zoveel mogelijk informatie over mijn gezondheid vergaren.”
- “Naast de arts, raadpleeg ik ook veel andere bronnen. Bijvoorbeeld online.” “

- Naam: T. J. van Lent
- Leeftijd: 63 jaar

- “Ik doe er veel aan om zo gezond mogelijk te blijven.“
- “Ik heb behoefte aan informatie over mijn gezondheid.”
- “Ik vertrouw op de arts dat hij mij zo goed mogelijk inlicht over mijn gezondheid.”

- Naam: N. P. de Groot
- Leeftijd: 55 jaar

- “Ik zoek zelf niet naar informatie over mijn gezondheid.”
- “De artsen en de verpleegkundigen verstrekken mij alle informatie die ik nodig heb.”

- Naam: V. Warmerdam
- Leeftijd: 71 jaar

- “Heel eerlijk, ik ben eigenlijk niet zo heel veel bezig met mijn gezondheid.”
- “Ik heb niet zo veel behoefte aan veel communicatie met de medisch specialisten.”

G
TUR-B information cards

Behandeling

Onderzoek
- Tumor groottes

interessant | belangrijk | zeer belangrijk

Behandeling

Anesthesie
- Ruggenprik
- Eventueel slaapmiddel

interessant | belangrijk | zeer belangrijk

Behandeling

Anesthesie gevolgen
- Ruggenprik
- Slaapmiddel

interessant | belangrijk | zeer belangrijk

Behandeling

Voorbereiding
- Geen bloedverdunners
- Tot 2u voor operatie drinken
- Tot 6u voor operatie eten

interessant | belangrijk | zeer belangrijk

Behandeling

Operatie (duur 60-90 min.)
- Blaas bekijken
- Tumor verwijderen
- Spoelen met katheter

interessant | belangrijk | zeer belangrijk

Behandeling

Operatie (aanvullend)
- Instrument (cystoscoop)
- Katheter

interessant | belangrijk | zeer belangrijk

Behandeling

Onderzoek (pathologisch)
- Weefselonderzoek
- Doel: aard tumor bepalen

interessant | belangrijk | zeer belangrijk

Behandeling

Diagnose
- Blaastumor vastgesteld

interessant | belangrijk | zeer belangrijk

Behandeling

Nazorg
- Uitslaapkamer
- Verpleegafdeling

interessant | belangrijk | zeer belangrijk

Behandeling

Nazorg controles
- Hartslag, bloeddruk en pijn
- Naspoelen met katheter
- Infuus

interessant | belangrijk | zeer belangrijk

Behandeling

Nazorg spoeling
- Eerste chemospoeling
- Duur: 60 min.
- Verwijderen katheter

interessant | belangrijk | zeer belangrijk

Behandeling

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Anesthesie Ruggenprik
- Onderlichaam gevoelloos
- Wel bewustzijn
- Sneller herstel

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Anesthesie Slaapmiddel
- Niet 'bewust' operatie bijwonen

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Nazorg
- Plassen pijnlijk
- Urine wat bloederig
- Bij verbetering mag u naar huis

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Complicaties 1
- Nabloeding
- Blaaskrampen

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Complicaties 2
- Urineweginfectie
- Gaatje in blaas

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Bijwerkingen
- Pijnlijke plasdrang
- Pijn in onderbuik
- Allergische huidreactie

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Thuissituatie
- Zittend plassen
- Toilet schoonhouden
- Reinig handen en geslachtsorganen

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Leefregels 1
- Veel drinken
- Vermijd zware arbeid
- Bij poepen, persen vermijden

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Leefregels 2
- Wel autorijden, niet fietsen
- Eerste 2 weken, rustig aan doen

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Contact opnemen bij 1
- Duidelijke bloedstolsels
- Bloedverlies vermindert niet
- Koorts boven 38,5°

interessant | belangrijk | zeer belangrijk

Persoonlijke context

Contact opnemen bij 2
- Brandende pijn bij plassen
- Niet meer kunnen plassen
- Hevige aanhoudende buikpijn

interessant | belangrijk | zeer belangrijk

Persoonlijke context

interessant | belangrijk | zeer belangrijk

Sociale context

Seksualiteit
- Gebruik condoom
- Geen nadelige gevolgen voor seksuele gevoelens en beleving

interessant | belangrijk | zeer belangrijk

Sociale context

Blogs
- Verhalen lotgenoten

interessant | belangrijk | zeer belangrijk

Sociale context

Lastmeter
- Vragenlijst
- Pijnthermometer

interessant | belangrijk | zeer belangrijk

Sociale context

E-consult
- Digitaal contact met medisch specialist

interessant | belangrijk | zeer belangrijk

Sociale context

Oncologie verpleegkundige
- Telefonisch
- E-mail
- Afspraak met verpleegkundige

interessant | belangrijk | zeer belangrijk

Sociale context

interessant | belangrijk | zeer belangrijk

Sociale context

interessant | belangrijk | zeer belangrijk

Sociale context

interessant | belangrijk | zeer belangrijk

Sociale context

interessant | belangrijk | zeer belangrijk

Persoonlijke context

interessant | belangrijk | zeer belangrijk

Persoonlijke context

interessant | belangrijk | zeer belangrijk

Behandeling

interessant | belangrijk | zeer belangrijk

H
Qualitative Research transcriptions

Participant 1

IA
Gesprekken met oncologie, goed geïnformeerd.
Medisch best
Geen text in beeld
De informatie was al duidelijk door de oncologieverpleegkundige
Opgezocht: grootte tumoren, hoe kwaadaardig.
Veel contact gehad met oncologie verpleegkundige
Hoe was het voordat de immunotherapie er was, hoe therapie ontdekt is.

Participant 2

Part 1
IP
Medisch, "dan zie je echt hoe het gaat"
Vooral belangrijk de eerste keer een animatie bekijken.

Part 2:
"Als je geen roesje krijgt kun je zien wat er allemaal gebeurd, je kan alles zien dat is erg interessant.''
Ik heb de eerste keer drie weken met een zak om mijn poot gelopen omdat ik niet kon plassen.
Bij mij zat hij niet netjes tegenover, maar in een hoekje. Dan werd ie groot, ging ie hangen en douwde hij mijn plasbuis dicht. Katheter gehad.
Meer variaties op het 'ideale' getoonde scenario.

Part 3
Koorts gehad, want verkeerde antibiotica. Operatie ging niet door, door koorts. Hoe lang gaat het nu nog duren? Als het maar blijft opschuiven, gaat het ellende geven.
Je krijgt een ruggenprik. daar is iedereen in paniek over, maar dat stelt eigenlijk niet heel veel voor. Je voelt echt niks.
"De watjes hadden ze wel even warm mogen maken, die waren ijskoud door de alcohol."
'Dan waarschuwen ze je: als je uit de operatie komt, moet je niet schrikken. Want er staan hele stellages om je heen. En dat zien die hele grote spoelzakken natuurlijk'' Sommigen raken dan helemaal in de stress.
"Dat is ook wat met de chemo. Dan zie je ze staan, helemaal in pak, haar weggebonden, mondkapje op. En ik kan gewoon zo blijven liggen zeker? Hun staan helemaal ingepakt en de patiënt zelf niet. " "je ligt daar en denkt, nou het zal wel goed gaan''
Van BCG werd ik een beetje ziek, grieperig, en had wat stemmingswisselen, maar bij mij valt het wel mee.
Na de katheter, doet het wel erg zeer, maar dat is logisch.
''Nou da's wel leuk, dan zeggen ze: als je kleinkinderen langskomen moeten ze op een ander toilet. Waar moeten ze dan als je 1 toilet hebt? Bij de buren?'
Dan zeggen ze : als je stolsels in je urine hebt, moet je bellen. Dus ik bel; zeggen ze van ja het is wel goed, laat zo zitten. Wat is het nou, moet ik nou bellen of goed veel water drinken dan gaat het over..
Je ken ook de eerste keer praten met iemand over dat gedrang, nou dat heb ik ook niet gedaan joh. Misschien zijn er mensen die er wel behoefte aan hebben te praten. Maar ik niet.

Participant 3

DDA
Medisch
De contactmomenten zijn me af en toe niet duidelijk
Een keuze voor wel of niet een roesje
Ik wilde naar huis gaan, daar slaap ik het fijnst. Maar ik moest vanwege mijn leeftijd nog een nachtje slapen. Dat vond ik onplezierig.
Ik had last van het naspoelen met de katheter.

Participant 4

Part 1

DDP

Part 2

Realistisch-medisch

Ik hoef de animatie niet nogmaals te kijken. Erg duidelijk. Alleen met m'n man gekeken.

De oncologisch verpleegkundige heeft hem laten zien.

"De stijl beviel me eigenlijk wel, omdat ze weglaten wat niet nodig is en je ziet wat er gaat gebeuren. Meer heb je niet nodig als patiënt."

De animatie ging erg over de operatie, maar waar ik persoonlijk veel last van had was de cystoscopie. Je had ook nog de CT-scan en toen de cystoscopie.

Part 3

Ik werd opgebeld en ze vertelden dat ze een poliep hadden gezien. En toen moest ik veel sneller.

Ik had niet verwacht, want ik had blaasontsteking- geen last, dat ik daarna echt pijn, bloed, vervelend, urine niet kunnen ophouden. Dat was misschien duidelijker geworden met een animatie.

De huisarts heeft overlegd met de uroloog over mijn blaasontsteking. Daar zat ik niet tussen en de verzekering ook niet.

Ik heb alleen maar 'ja' gezegd als patiënt, dat vond ik ook voldoende.

Ik ben geen vraagtekens tegengekomen. Die ik wel had kon ik neerzetten bij de oncologisch verpleegkundige.

Andere opties? Nee, die zijn me niet voorgehouden.

Wel gevraagd: vind je dat goed? Maar de stappen zelf zijn me als patiënt onbekend. Ze zijn mij goed uitgelegd.

Ik vind het erg prettig dat je oncologisch verpleegkundige kan bellen.

Ik heb s morgens gebeld en dat wordt je s middags teruggebeld, maar dat duurt wel lang.

Je kan nooit alles in een keer opnemen en je komt altijd dingen tegen die je of niet snapt of waar je het niet mee eens bent. Soms moet je het eerst een plekje geven en soms blijf je met vragen zitten.

Ik had de keuze wel of geen roesje.

De operatie is een vaststaand traject, ik had daar geen keuzes.

Ze hebben 90 minuten op mij moeten wachten, maar als je patient heb ik daar niks van gemerkt. Ze hadden geen haast of boosheid of iets in die trant.

Met de operatie had ik geen keuze, dat is in het franciscus. Met de spoeling nu wel, dat vind ik op zich wel prettig. Keuzes zijn mij niet voorgelegd en daar heb ik niet naar gevraagd.

Ik vertrouw de arts op de keuzes; ik ga ervanuit dat iemand z'n vak kent.

Het is allemaal een vloeiend geheel, er zal vast wel iets fout gaan, maar dat merk je niet.

Ze geven je rust.

Participant 5

Part 1

IA

Part 2

Medisch- realistisch

Ze moesten een dunne slangetjes gebruiken, want het was te nauw.

De type van narcose of verdoving wil je wel mee nemen.

Bij mij ging de ruggenprik niet goed, dus heb ik volledige narcose gehad.

De spoeling na de operatie wordt niet genoemd, het kan een immuno, een chemo myosine zijn. ..dat er preventief een medicatie in de spoeling kan zitten.

Het is wel leuk dat hoe die katheter nou zichtbaar werd gemaakt, want dat was me nou nooit duidelijk hoe die vastgehouden werd.

Misschien wel ondertiteling toevoegen voor mensen die slechthorend zijn. Een optie voor aan of uit.

Part 3

De keuze is wel of niet behandelen op ieder moment, die keuze heb je telkens.

In juli hebben we die cystoscopie gedaan. Was te groot, dus een operatie.

Noot: planning erg belangrijk voor patiënt.

Immunotherapie is na de operatie vrij vlot begonnen. Daarna veel contact met Jolanda.

Ik probeerde mijn spieren soepel te houden met fysiotherapie. Toen vertelde (jolanda) ze me: wat jij nou probeert te doen gaat niet. je hebt griep en je probeert sportprestaties te doen. Dus hebben we de fysio op een laag pitje gezet.

Ik heb de folders goed doorgenomen. En heb me aangemeld bij kanker.nl, een profiel aangemaakt. En recentelijk kanker.be.

Ik ben hier en daar wat verder naar de bijwerkingen gaan kijken. Op farmaceutisch kompas.

Participant 6

Part 1

IP

Part 2

Medisch

Ja, dat heb ik allemaal gehad he. Dit is heldere taal hoor, dat begrijp ik.

Ik heb zo'n lange lijst joh, duurt dat allemaal zo lang? (over planlijst spoelingen)

Ik heb nu medicijnen gehad, om het wat wijder te maken en dat gaat wel beter.

Ik heb ook wel 's gehad, thuis heb ik een emmer, dat het helemaal rood was. Dat het niet goed was.

Het is een hele cyclus, die je af moet gaan. Dat is nog wel he.

Het is voor mij duidelijke taal. Begrijpelijke taal, zal ik het zo zeggen.

Part 3

Er zijn hier zo'n rij urologen. Ik dacht dat dezelfde uroloog de behandelingen deden, maar het is elke keer een andere. Ik kwam het ziekenhuis in en het was zo'n lijst. Ik kon zo

aanwijzen. Die heb ik gehad, die heb ik gehad..
Anesthesist ben ik ook geweest. Moeten ze kijken of je hart goed is.
En dan heb je hier nog een afdeling en daar ga je dan heen voor nieronderzoek.
Ben ik thuis, neem ik m'n medicijnen en en dan goed..
Ik had niet gedacht dat ik er zoveel bij kreeg. Zoveel ziekenhuizen en zo veel daarheen en dan weer daarheen. Dat valt me tegen.
Dan wordt je hier geholpen in Vlietland, maar dan word je geopereerd in Rotterdam. Dat vind ik een beetje traumatisch. Kleiweg is niet zo makkelijk te vinden. Ik vind het een beetje een doolhof. Ook daar naar toe gaan. Mijn zoon haalt me op en rijdt natuurlijk helemaal verkeerd. Hij begreep er geen reet van.
Dat zijn dingen.. Je krijgt zoveel informatie.. Ook informatie met die boekjes allemaal. Moet je nuchter komen.. Dan denk ik ik voel me al niet zo lekker, dus neem ik een beschuitje. Jaaa, maar niet opereren he. Ik werd daardoor later geopereerd. Dat vond ik hectisch.
Je krijgt zoveel informatie, dat het allemaal wel een beetje stokt. Moet je daarheen en daarheen.. Je ken te veel informatie ook krijgen he.
Het gaat allemaal wel goed, maar je moet het goed op een rijtje zetten. Je weet wel hoe dat gaat thuis, het gaat wel eens makkelijk. Het zal wel goed wezen. En dan lees je het nog niet goed genoeg..
Ze zeggen: wilt u televisie? Ik zeg: ja ik wil wel zien of hoe dat gaat. Nou dat vond ik een hele schrapperij hoor. Het was net alsof ie aardappels zat te schillen..
Nou en toen had je dat ik savonds terug naar de kamer kon. En toen naderhand had je die zak, moet helder zijn. Was het niet bleef rood. Kwam de uroloog zeggen, dat ik nog een keer snachts geopereerd kon worden.
Die hele zak met papier, dat vind ik een beetje… pfoe.. Ken dat niet simpeler? Ken der geen zuster thuis komen? Ik moet een kwartier hier wezen. Moet ik weer een taxi bellen.
In Maasluis staan de oude mannen op een bruggetje te praten. En ze hebben het nooit over blaaskanker. Het wordt een soort verbloemd.
Maar waarvoor is het zo'n taboe? Schaamte?
Dat water drinken he. Moet je je glas helemaal leegdrinken en dan meten ze dat. Dan zit er te veel in je blaas, maar dan mag je nog niet weg. Hoe komt dat dat je nooit leegplast? Nou ik die pillen heb om je plasbuis wijder te maken, gaat het wel goed.
En die katheter zat een keer niet goed en daar heb ik me een pijn aan gehad.
Als je nou die grote tumoren ziet he. Heb je dan nog een kans op leven?

Participant 7

DDA
Medisch
Te gespannen voor ruggenprik, iets in infuus gedaan en toen ging de ruggenprik wel goed
Ik heb nergens last van. Je kan beter zittend plassen als staand.
Ben je moe, afgevallen, slaap je goed, eet je goed, heb je pijn. We wandelen veel.
Sporten, mag maar liever niet. Ik badminton, een beetje fanatiek. Ik wil graag weten of ik dat nog mag. De dokter vertelde me daar even mee te wachten.
Patiënt hield urinepotje 'achter' voor vrouw, had gelijk door dat het foute boel was
Ik zoek niets op op internet. Iedereen zegt zus en zo en . Ik luister nergens naar. Het enige waar ik naar luistert is de dokter. Internet interesseert mij niets voor zo iets.
IK kreeg thuis de uitslag van de scan. 'Ik dacht die kreeg ik toch van de dokter' Ik schrok mij helemaal de …" Thuis via de telefoon..
Ik heb zoveel naar me toe gehad. Moest ik op ene dag daar en daar naar toe. Ik zeg schrijf het maar op een brieffie. Ik ken het niet meer volgen.
Ik heb wel es gehad (red. ander ziekenhuis) van ja ga maar effe liggen daaro joh, ik kom zo bij je
De arts bepaalt toch wat er gaat gebeuren. Als de arts zegt van dit en dat, kan ik toch niet zeggen van het moet zo.
Ik ga niet gauw tegen een arts in
Kijkt u maar op het scherm. Ik ken wel op het scherm kijken, maar hoefde ik niet. Ik weet toch niet waar ik naar kijk. Geen behoefte aan. (artsen boden aan uit te leggen wat er gebeurd, maar patiënt had geen behoefte)
Mijn vrouw moet in het franciscus wezen ik niet veel later hier (Vlietland)
Ze luisteren hier naar je.
Als ik de animatie gehad had, had ik m gekeken. Want hij is van de arts

Participant 8

DDA/IP
Medisch
Ik heb zelf gewoon mee liggen kijken. Het is mijn eigen lichaam, ik kijk gewoon mee
Ik heb zelf wat opgezocht over bestralen met hematologie, kwam ik bij de hematoloog zegt ie: 'ja, dat doen we niet hier' Je krijgt gewoon prednison en klaar. Die was een beetje verbolgen erover, dat ik had zitten googlen.
Ja googlen is wel leuk. Het is A of B, maar je hoort niet exact, wat je wil zien of horen. Allemaal een slag om de arm houden.
Ik kan niet meer geopereerd worden door trombocyten. Of het moet levensbedreigend zijn.

I
Wrap-up in detail

The diagram on the next pages provides overview of all the collected content in relationship to the patient journey.

Green items

The green items contain all the collected content:

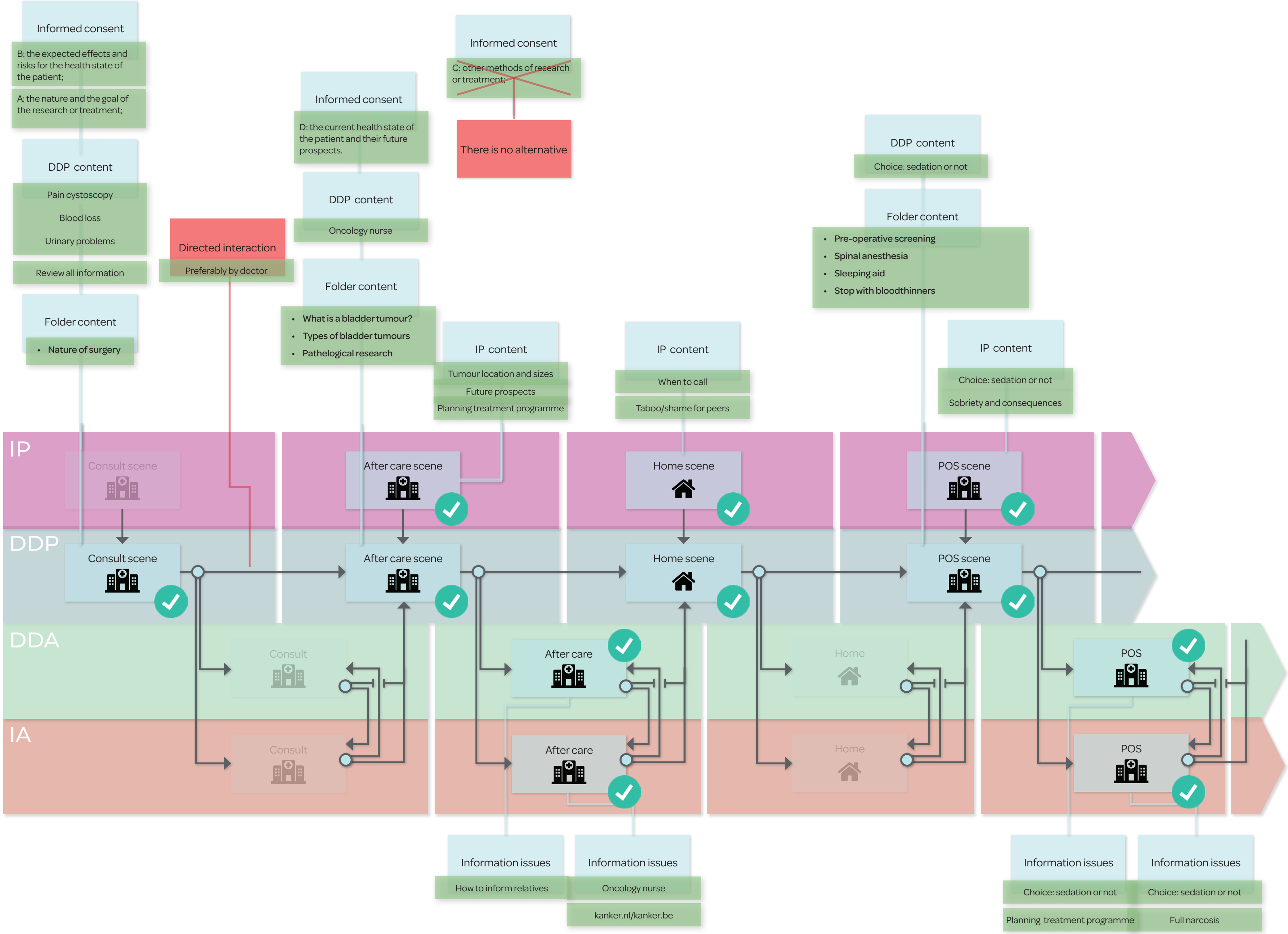
- labeled ‘informed consent‘, information described by law’;
- labeled ‘Folder conten‘, all content of the folder and animation;
- labeled ‘IP content‘, all relevant content for independent passives gathered from research;
- labeled ‘DDP content‘, all relevant content for doctor-dependent passives gathered from research;
- labeled ‘DDA content‘, all relevant content for doctor-dependent actives gathered from research;
- labeled ‘IA‘, all relevant content for independent actives gathered from research;

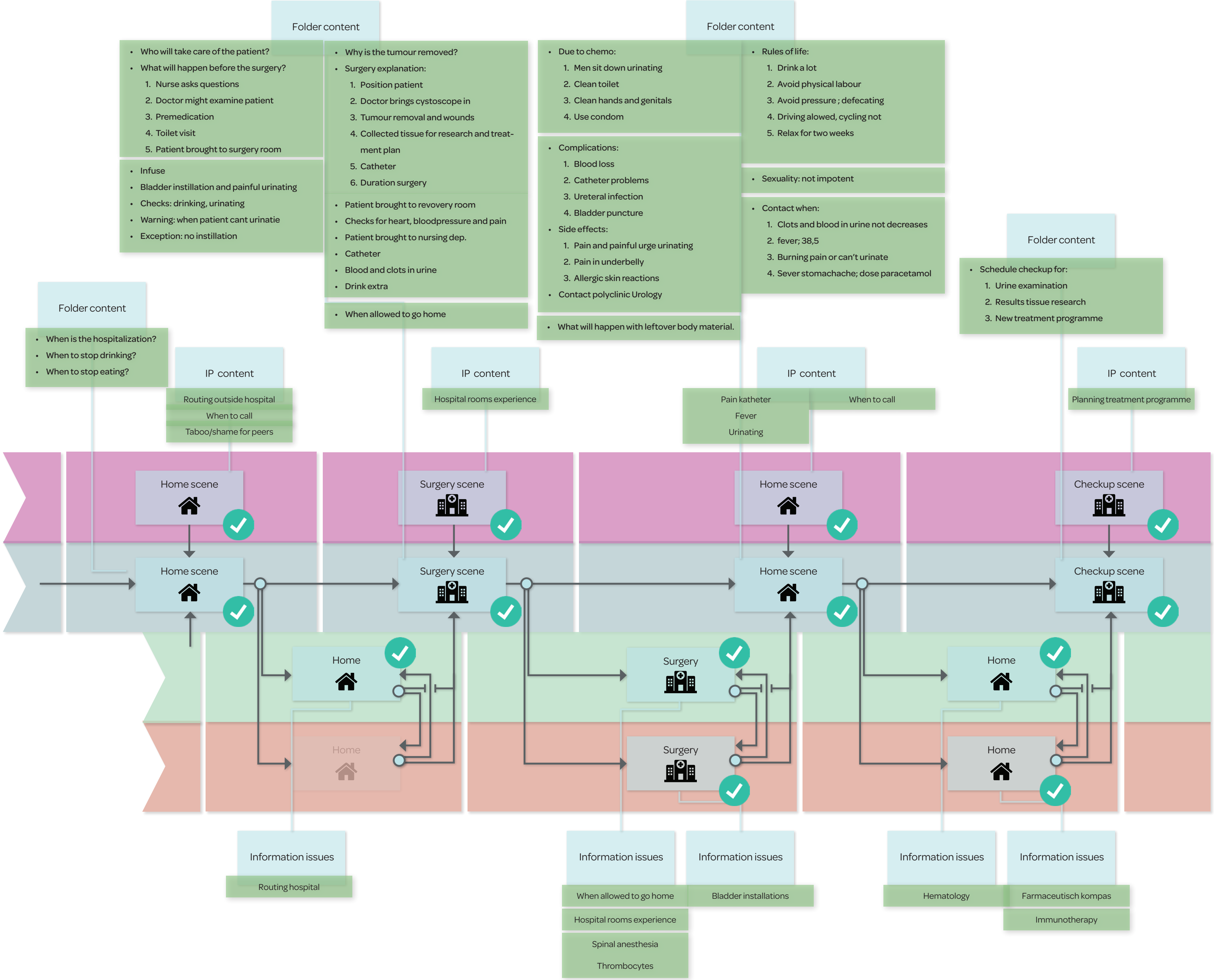
Links

The green items are linked to the corresponding block (of IP,DDP,DDA or IA) within a phase of the patient journey.This helps to understand which content is relevant in a certain phase. Thereby it tells which content is interesting for which audience. A block is greyed out when no content can be linked, and thus no matching content is found during the project.

Arrows

The arrows represent how to move from block to block. There is a directed interaction or an alternate interaction. The directed interaction is the basic path to follow, this content is recommended to go through by medical specialists. The alternate paths are sidesteps with in-depth information.


Informed consent
B: the expected effects and risks for the health state of the patient;
A: the nature and the goal of the research or treatment;
DDP content
Pain cystoscopy
Blood loss
Urinary problems
Review all information
Folder content
Nature of surgery
Directed interaction
Preferably by doctor
Informed consent
D: the current health state of the patient and their future prospects.
DDP content
Oncology nurse
Folder content
What is a bladder tumour?
Types of bladder tumours
Pathelogical research
Informed consent
~~C: other methods of research or treatment;~~
There is no alternative
IP content
Tumour location and sizes
Future prospects
Planning treatment programme
IP content
When to call
Taboo/shame for peers
DDP content
Choice: sedation or not
Folder content
Pre-operative screening
Spinal anesthesia
Sleeping aid
Stop with bloodthinners
IP content
Choice: sedation or not
Sobriety and consequences
IP
Consult scene
After care scene
Home scene
POS scene
DDP
Consult scene
After care scene
Home scene
POS scene
DDA
Consult
After care
Home
POS
IA
Consult
After care
Home
POS
Information issues
How to inform relatives
Information issues
Oncology nurse
kanker.nl/kanker.be
Information issues
Choice: sedation or not
Planning treatment programme
Information issues
Choice: sedation or not
Full narcosis



Folder content

- When is the hospitalization?
- When to stop drinking?
- When to stop eating?

IP content

Routing outside hospital

When to call

Taboo/shame for peers

Folder content

- Who will take care of the patient?
- What will happen before the surgery?
  1. Nurse asks questions
  2. Doctor might examine patient
  3. Premedication
  4. Toilet visit
  5. Patient brought to surgery room

- Infuse
- Bladder instillation and painful urinating
- Checks: drinking, urinating
- Warning: when patient cant urinatie
- Exception: no instillation

- Why is the tumour removed?
- Surgery explanation:
  1. Position patient
  2. Doctor brings cystoscope in
  3. Tumour removal and wounds
  4. Collected tissue for research and treatment plan
  5. Catheter
  6. Duration surgery

- Patient brought to revovery room
- Checks for heart, bloodpressure and pain
- Patient brought to nursing dep.
- Catheter
- Blood and clots in urine
- Drink extra

- When allowed to go home

IP content

Hospital rooms experience

Folder content

- Due to chemo:
  1. Men sit down urinating
  2. Clean toilet
  3. Clean hands and genitals
  4. Use condom

- Complications:
  1. Blood loss
  2. Catheter problems
  3. Ureteral infection
  4. Bladder puncture
- Side effects:
  1. Pain and painful urge urinating
  2. Pain in underbelly
  3. Allergic skin reactions
- Contact polyclinic Urology

- What will happen with leftover body material.

- Rules of life:
  1. Drink a lot
  2. Avoid physical labour
  3. Avoid pressure ; defecating
  4. Driving alowed, cycling not
  5. Relax for two weeks

- Sexuality: not impotent

- Contact when:
  1. Clots and blood in urine not decreases
  2. fever; 38,5
  3. Burning pain or can't urinate
  4. Sever stomachache; dose paracetamol

IP content

Pain katheter

Fever

Urinating

When to call

Folder content

- Schedule checkup for:
  1. Urine examination
  2. Results tissue research
  3. New treatment programme

IP content

Planning treatment programme

Home scene ✓

Surgery scene ✓

Home scene ✓

Checkup scene ✓

Home scene ✓

Surgery scene ✓

Home scene ✓

Checkup scene ✓

Home ✓

Home

Surgery ✓

Surgery ✓

Home ✓

Home ✓

Information issues

Routing hospital

Information issues

When allowed to go home

Hospital rooms experience

Spinal anesthesia

Thrombocytes

Information issues

Bladder installations

Information issues

Hematology

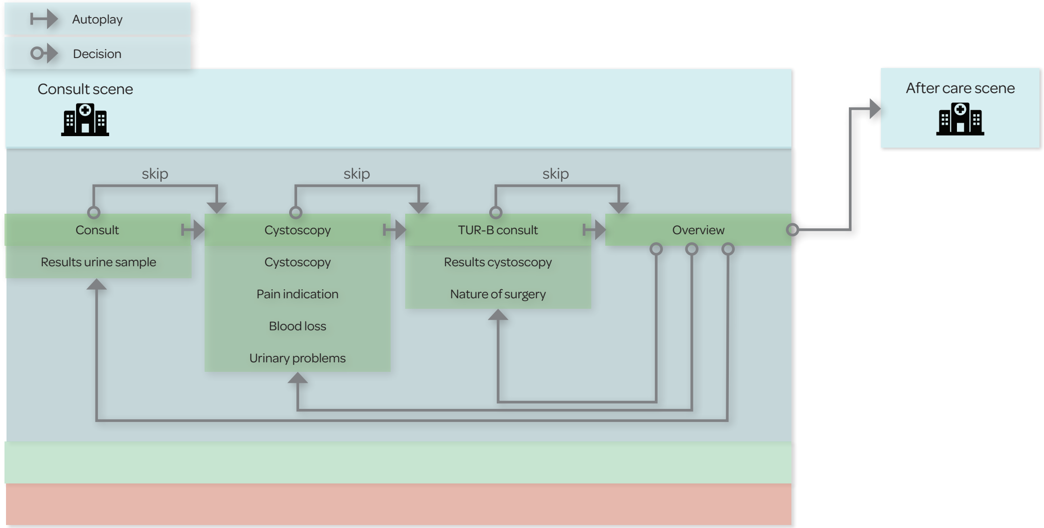
Information issues

Farmaceutisch kompas

Immunotherapy

J

Wrap-up in detail



Autoplay

Decision

Consult scene

After care scene

skip

skip

skip

Consult

Results urine sample

Cystoscopy

Cystoscopy

Pain indication

Blood loss

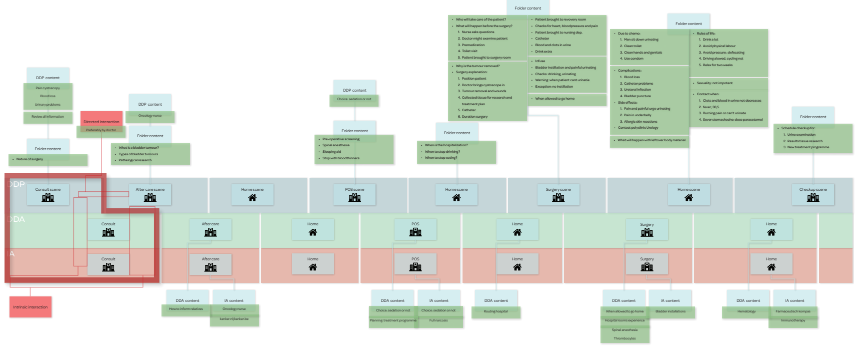
Urinary problems

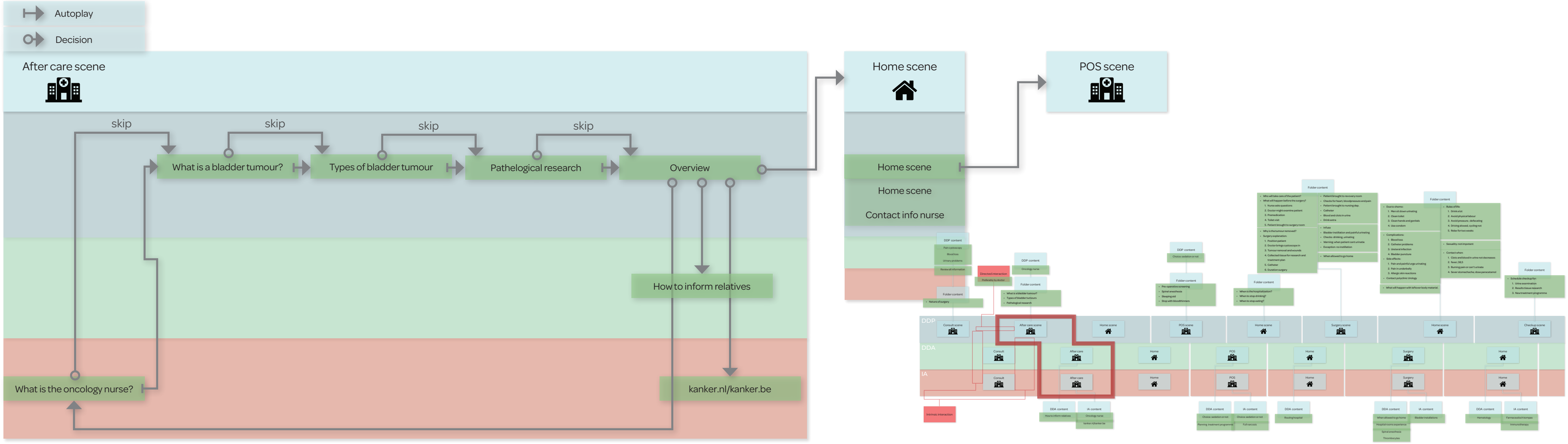
TUR-B consult

Results cystoscopy

Nature of surgery

Overview





Autoplay

Decision

After care scene

Home scene

POS scene

skip

skip

skip

skip

What is a bladder tumour?

Types of bladder tumour

Pathelogical research

Overview

How to inform relatives

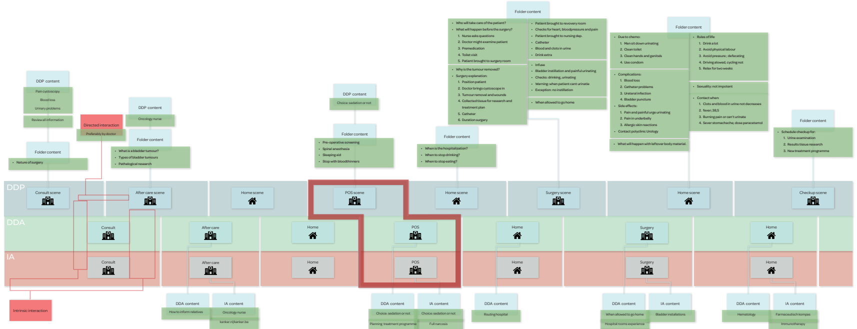
What is the oncology nurse?

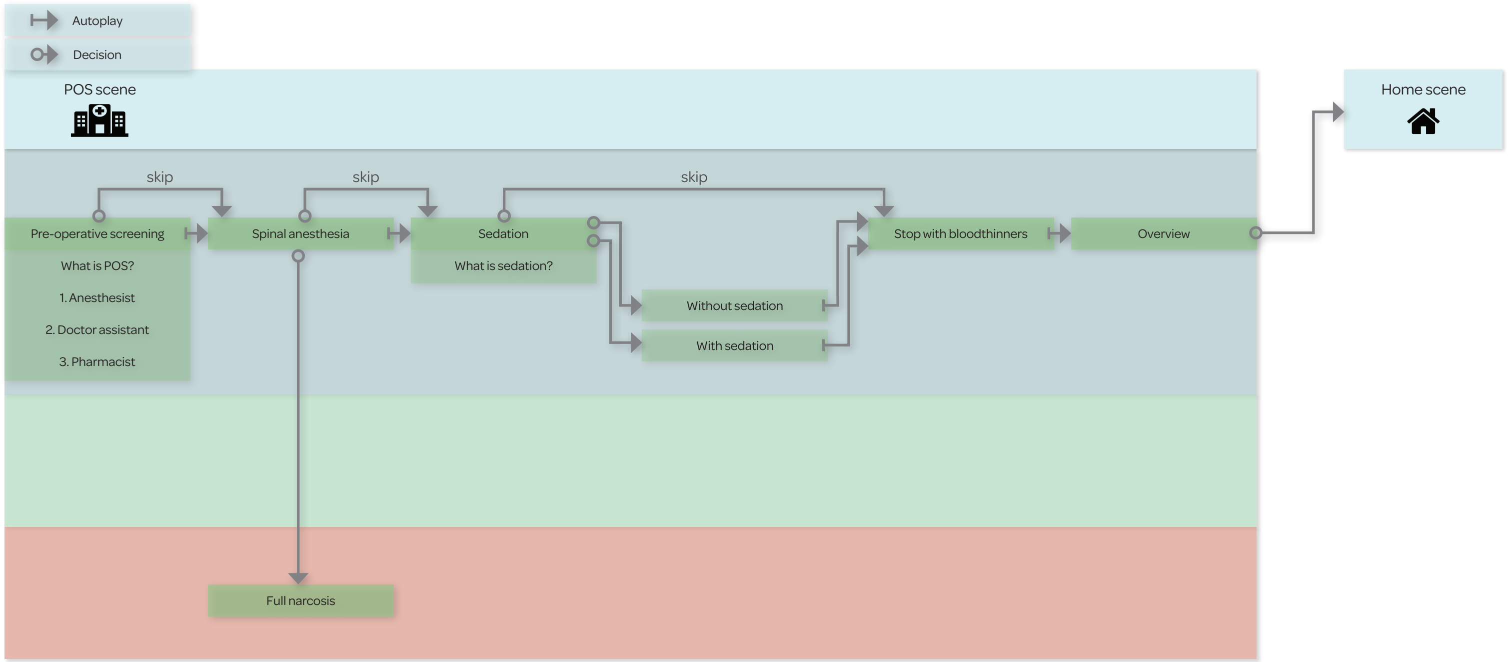
kanker.nl/kanker.be

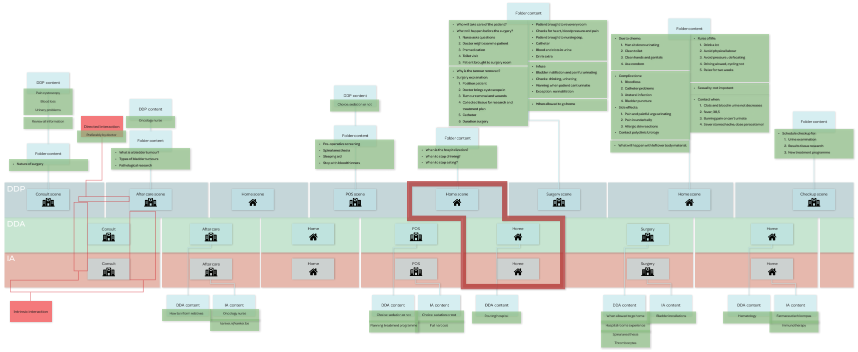
Home scene

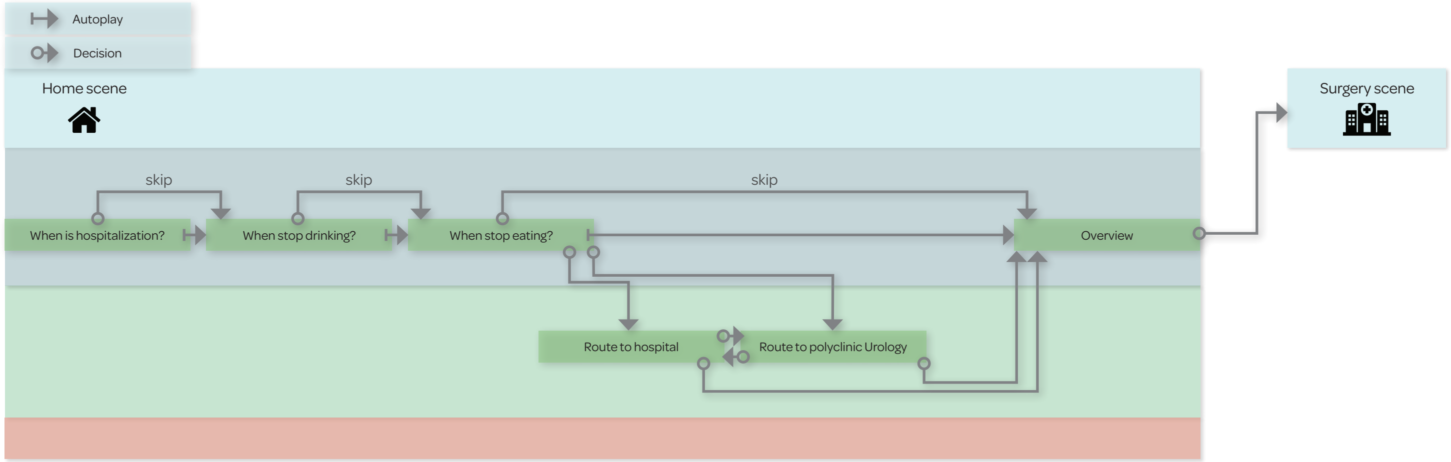
Home scene

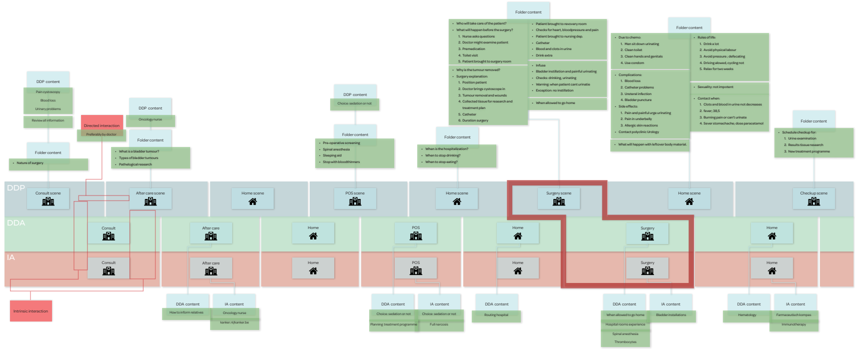
Contact info nurse

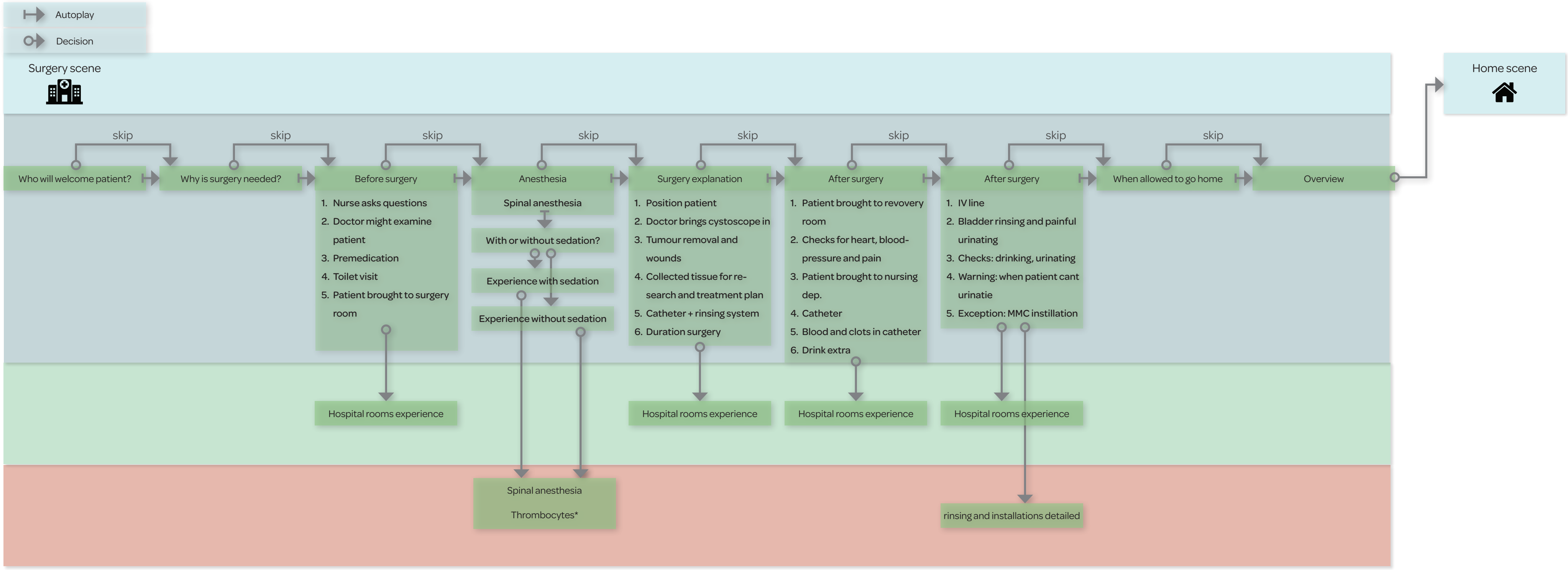

DDP
DDA
IA

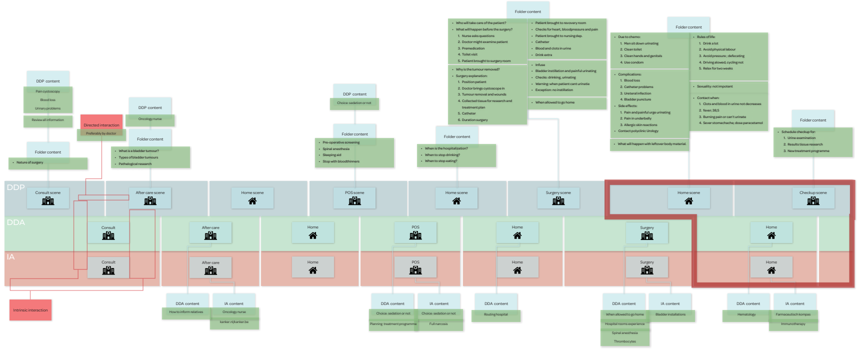

Autoplay
Decision
POS scene
Home scene
skip
skip
skip
Pre-operative screening
What is POS?
1. Anesthesist
2. Doctor assistant
3. Pharmacist
Spinal anesthesia
Sedation
What is sedation?
Without sedation
With sedation
Stop with bloodthinners
Overview
Full narcosis

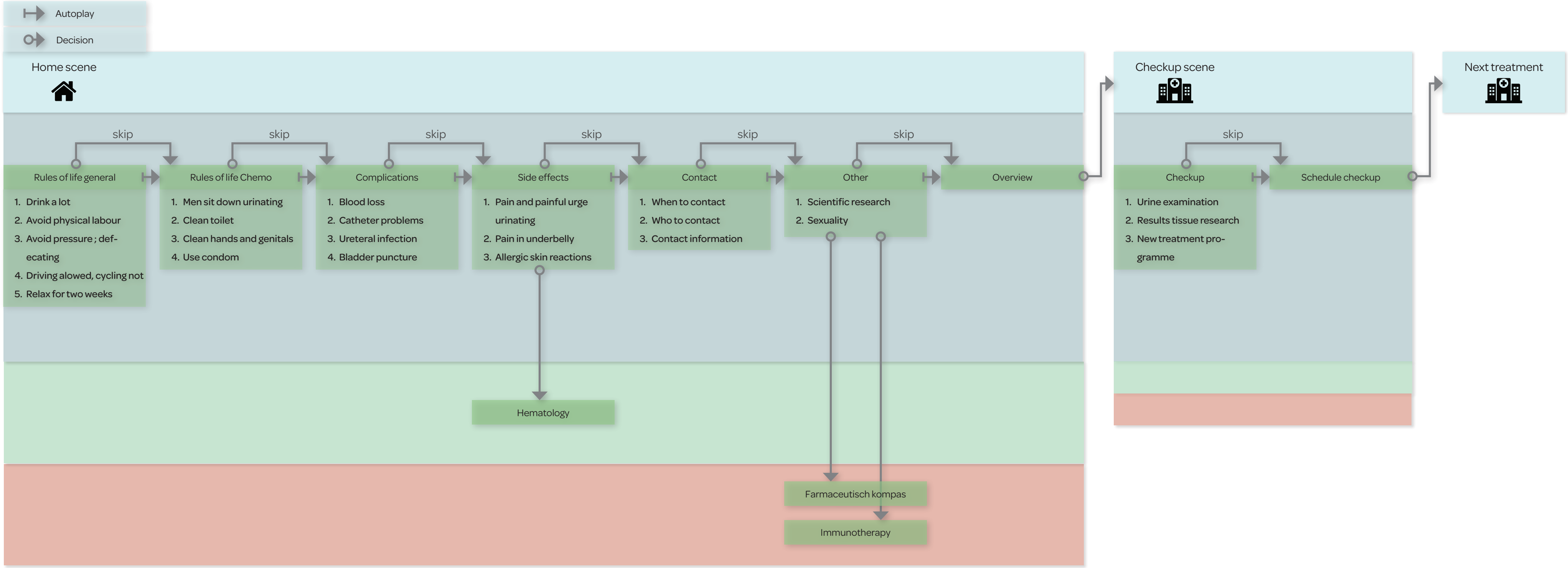



Autoplay
Decision
Home scene
skip
skip
skip
When is hospitalization?
When stop drinking?
When stop eating?
Overview
Route to hospital
Route to polyclinic Urology
Surgery scene


DDP
DDA
IA


Autoplay
Decision
Surgery scene
Home scene
skip
skip
skip
skip
skip
skip
skip
skip
Who will welcome patient?
Why is surgery needed?
Before surgery
1. Nurse asks questions
2. Doctor might examine patient
3. Premedication
4. Toilet visit
5. Patient brought to surgery room
Anesthesia
Spinal anesthesia
With or without sedation?
Experience with sedation
Experience without sedation
Surgery explanation
1. Position patient
2. Doctor brings cystoscope in
3. Tumour removal and wounds
4. Collected tissue for re-search and treatment plan
5. Catheter + rinsing system
6. Duration surgery
After surgery
1. Patient brought to revovery room
2. Checks for heart, blood-pressure and pain
3. Patient brought to nursing dep.
4. Catheter
5. Blood and clots in catheter
6. Drink extra
After surgery
1. IV line
2. Bladder rinsing and painful urinating
3. Checks: drinking, urinating
4. Warning: when patient cant urinatie
5. Exception: MMC installation
When allowed to go home
Overview
Hospital rooms experience
Hospital rooms experience
Hospital rooms experience
Hospital rooms experience
Spinal anesthesia
Thrombocytes*
rinsing and installations detailed





Autoplay

Decision

Home scene

skip

Rules of life general

1. Drink a lot
2. Avoid physical labour
3. Avoid pressure ; defecating
4. Driving alowed, cycling not
5. Relax for two weeks

Rules of life Chemo

1. Men sit down urinating
2. Clean toilet
3. Clean hands and genitals
4. Use condom

Complications

1. Blood loss
2. Catheter problems
3. Ureteral infection
4. Bladder puncture

Side effects

1. Pain and painful urge urinating
2. Pain in underbelly
3. Allergic skin reactions

Contact

1. When to contact
2. Who to contact
3. Contact information

Other

1. Scientific research
2. Sexuality

Overview

Hematology

Farmaceutisch kompas

Immunotherapy

Checkup scene

Checkup

1. Urine examination
2. Results tissue research
3. New treatment programme

Schedule checkup

Next treatment

K

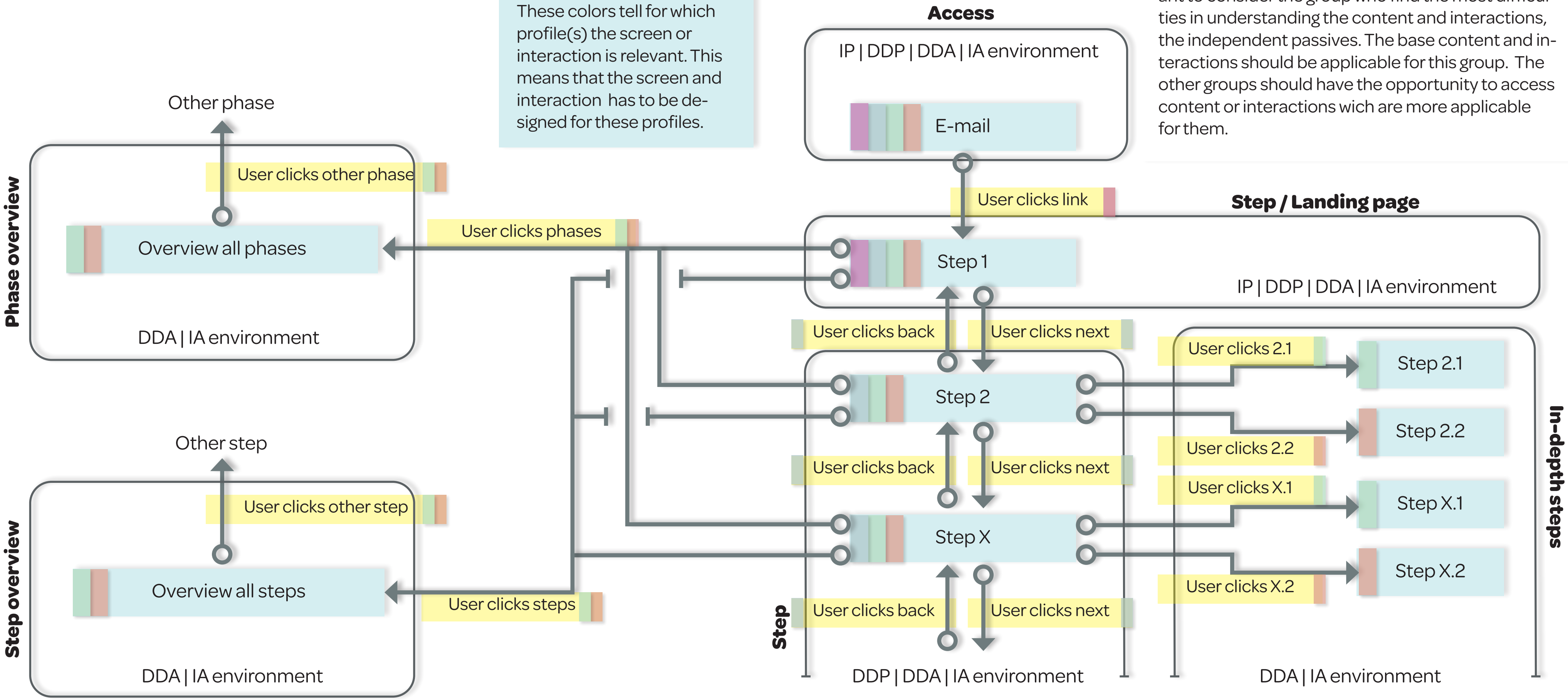
User flow in detail

The flowchart illustrates how the user will go through the user interface. The user interface is multi-layered to suit all patient types. To be able to do so, the choice is made to focus on the most determined user within the environment.

IP DDP DDA IA

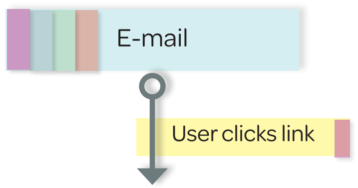
These colors tell for which profile(s) the screen or interaction is relevant. This means that the screen and interaction has to be designed for these profiles.

For example, in step one patients of all profiles have to be able to use this screen. Therefore it is important to consider the group who find the most difficulties in understanding the content and interactions, the independent passives. The base content and interactions should be applicable for this group. The other groups should have the opportunity to access content or interactions wich are more applicable for them.



E-mail account

IP | DDP | DDA | IA environment



The user receivers an e-mail from the medical specialist. The content of the mail:
- Let the user know there's new information available
- It is important to go through the information before this phase starts
- Provides a link to access the module.

Hello <patient name>,

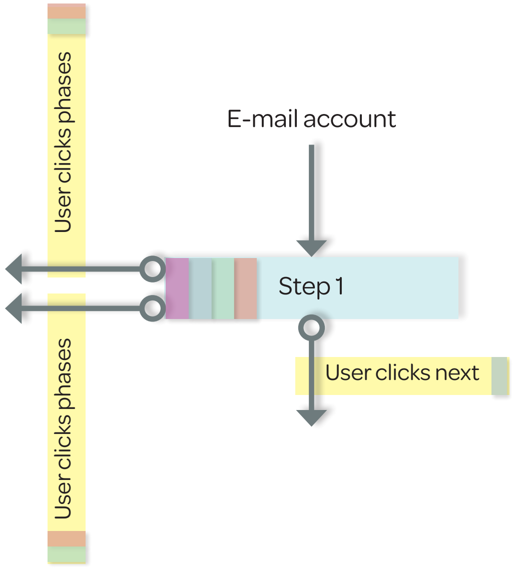
Hereby, I want to let you know that there is new information available about the phase of the treatment programme you're currently in. You gain access via the link.
<Link>

Regards,

<medical specialist>

Step/ Landing page

IP | DDP | DDA | IA environment



The user is directed to the landing page of the phase, step 1.

Content targeted for
IP, DDP, DDA and IA. IP is leading since this group is assumed to find the most difficulties in understanding the content.

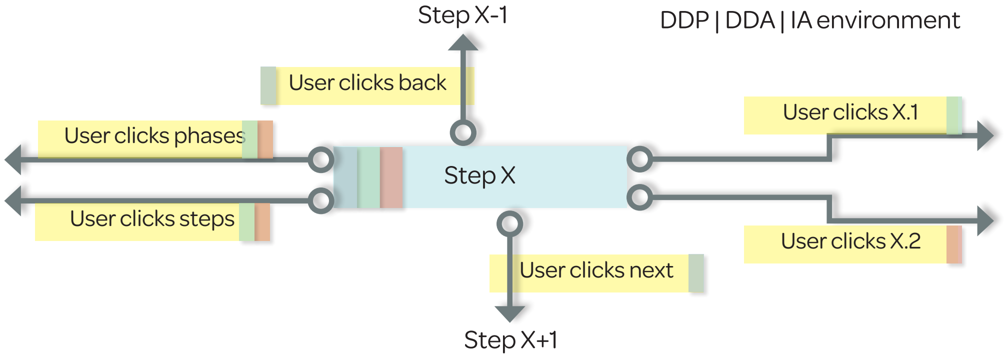
Content
This step contains:
- Introduction animation surgery phase

As mentioned, the content of the step is mainly designed for independent passives.

Possible interactions
The interactions have different groups as a target group.
- The navigation to the next step is considering doctor-dependent passives. This step is primarily targeted for DDP.
- The navigation to the phase and step overview is relevant for doctor-dependent actives and independent actives. This step is primarily targeted for DDA and IA.

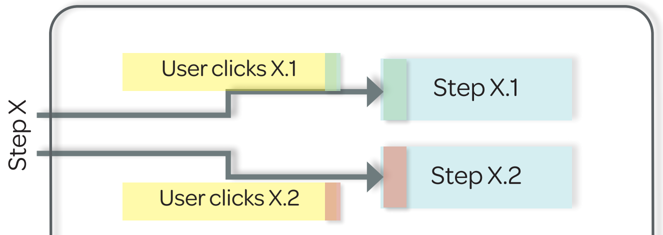
Step

DDP | DDA | IA environment



Content targeted for
DDP, DDA and IA. DDP leading since this group is assumed to find the most difficulties in understanding the content.
Content
The user can go through the base content, mainly designed for doctor-dependent passives, within the step.
Possible interactions
If the user is finished, there are several options to navigate to.
- The user can navigate to the next step. This is the doctor-dependent passive flow. This interaction is primarily targeted for DDP.
- The user can navigate to the in-depth informations steps. These steps contain content focussing on doctor-dependent actives and/or independent actives. This interaction is primarily targeted for both DDA and IA.
- The navigation to the phase and step overview is relevant for doctor-dependent actives and independent actives. This interaction is primarily targeted for both DDA and IA.

In-depth steps



Step X

User clicks X.1

Step X.1

User clicks X.2

Step X.2

DDA | IA environment

Content targeted for
DDA and IA. The content matches the interests of DDA and/ or IA.

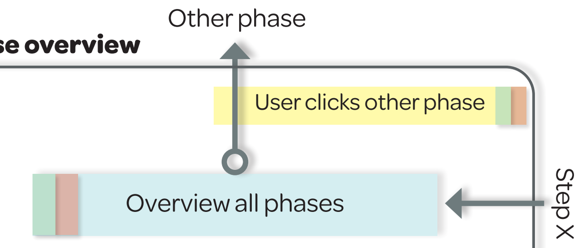
Content
The user can go through the in-depth content of the step X.

Possible interactions
If the user is finished with this content, he can navigate to the:

- other related in-depth step;
- back (to step X);
- next (to step X+1).

All interactions are targeted for both DDA and IA.

Phase overview



Other phase

User clicks other phase

Overview all phases

Step X

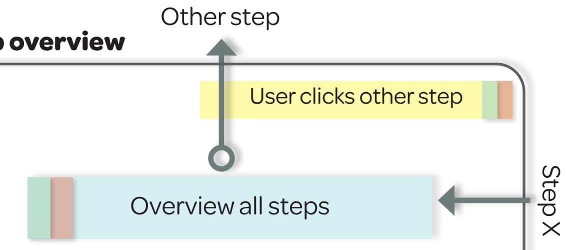
DDA | IA environment

Content targeted for
DDA and IA

Content
The user sees an overview of all the phases of the treatment programme.

Possible interactions
The user can access a phase by clicking on it.
All interactions are targeted for both DDA and IA.

Step overview



Other step

User clicks other step

Overview all steps

Step X

DDA | IA environment

Targeted for
DDA and IA

Content
The user gains access to the in-depth content.
This content is considered for doctor-depenedent actives and/or independent actives.

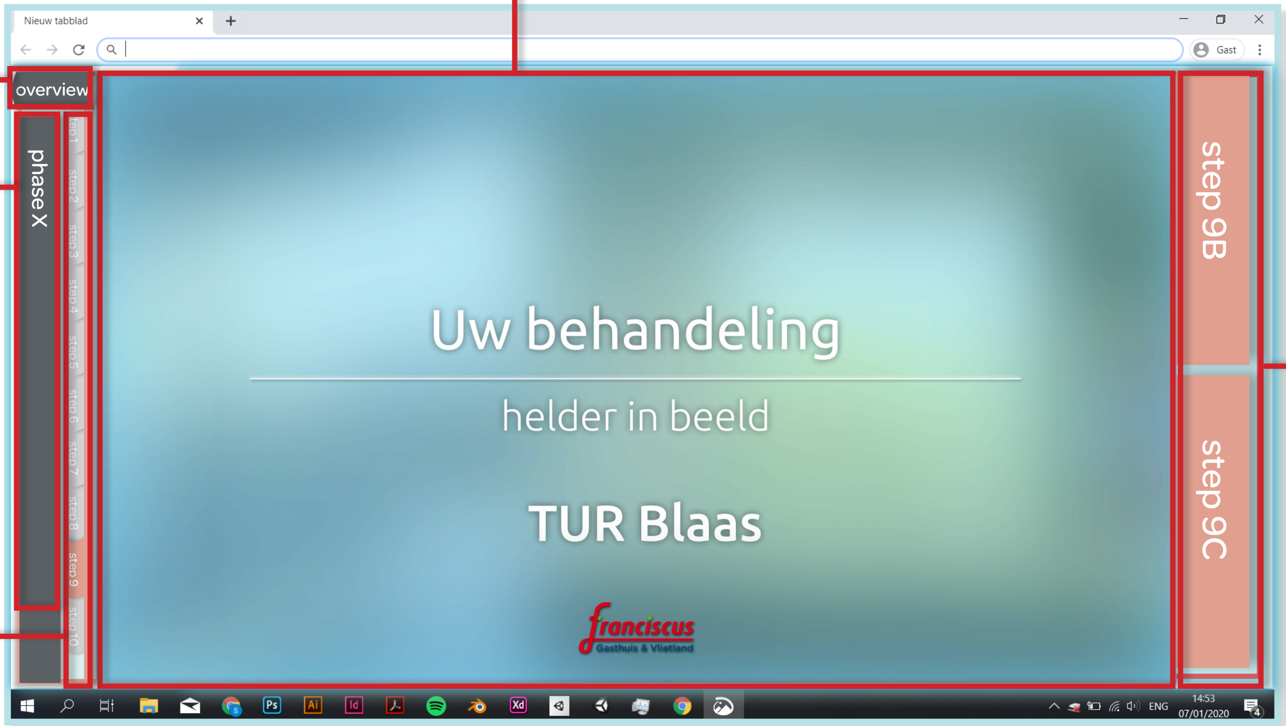
Possible interactions
If the user is finished with this content, he can navigate to the:

- other related in-depth step;
- previous step;
- next step.

All interactions are targeted for both DDA and IA.

L

User interface iterations



Overview button
This button opens the phase menu. In this menu users can navigate to all the different phases of the treatment programme

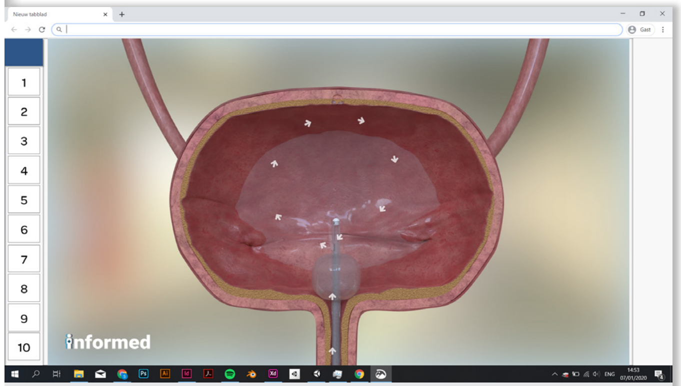
Content panel
The content for the active step is centralized on the screen.

Phase indicator
Over here is space to inform the user over the phase he's currently visiting.

In-depth buttons
At this place, in-depth buttons can be positioned, which allow users to access in-depth information concerning the step he's currently visiting.

Submenu | step navigation
The user can navigate through all the steps within the phase.

Iteration step 1

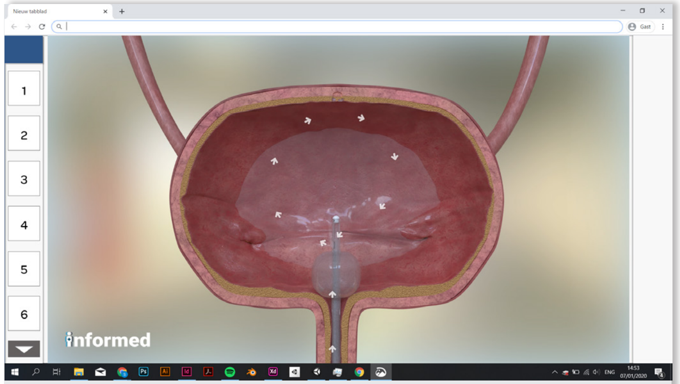


10 buttons on screen

The surgery phase consists of ten steps, according the archetype. The image above shows how these steps can be placed in the reserved spot for the stepline per phase. This amount of buttons might be overwhelming for the user. Thereby the buttons have to be fairly small and close to eachother to fit the design.

Conclusion

This design has dis- and advantages:
+ A complete overview of all the steps per phase
- Too many buttons on screen
- Buttons have to be scaled down drastically

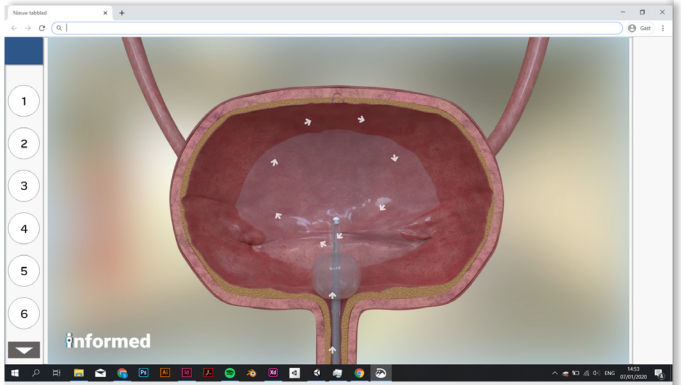


Scrolling

The steps can be divided into three different subphases of the surgery: pre-surgery, surgery and post-surgery. This decreases the maximum of steps onscreen to six, for pre-surgery. A scroll element is needed to navigate to the next subphase, surgery. Scrolling tend to be very difficult for elderly, however if a button is used for scrolling less effort is needed.

Conclusion

This design has dis- and advantages:
+ Less buttons on screen
+ Steps are divided over subphases
+ More space for larger buttons and space between buttons
- Less overview of all steps



Button design

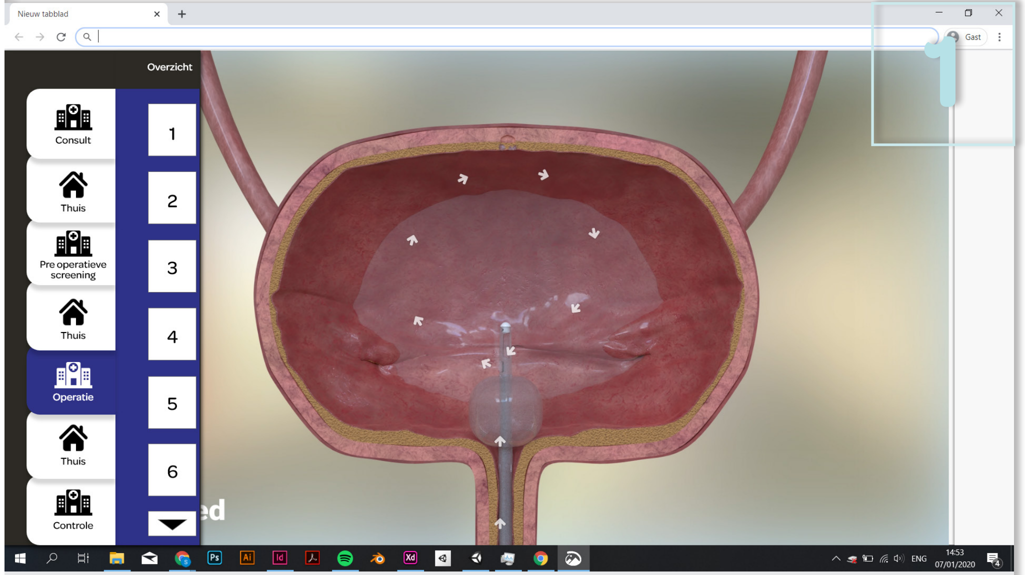
The previous button designs, where squared. If the buttons are of a circular shape, more there's more space between the buttons. This might prevent miss clicks. The downside is that the button's clickable surface is significanly smaller.

Conclusion

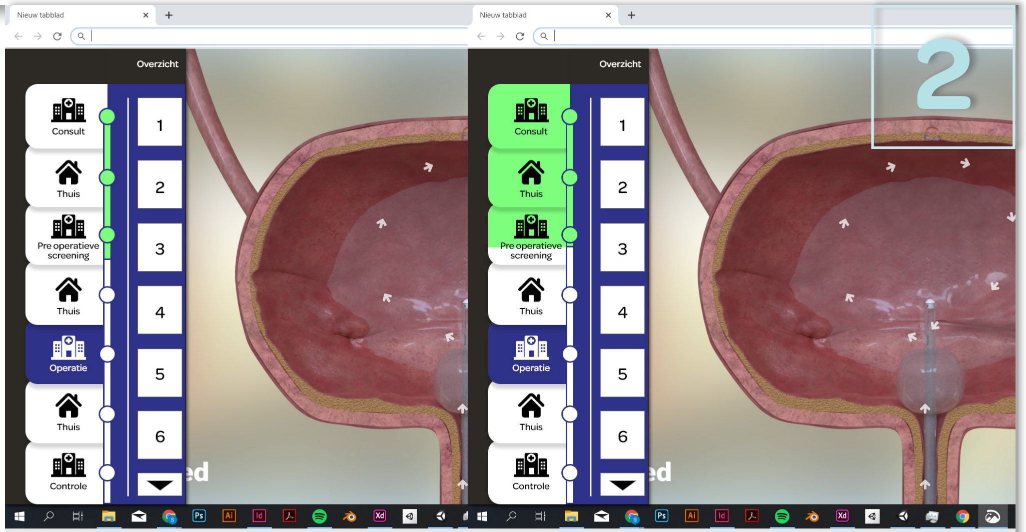
The best choice for the button shape relies on the final design of the buttons. It is important to consider what information is actually in and around the buttons to decide the best shape.

Iteration step 2

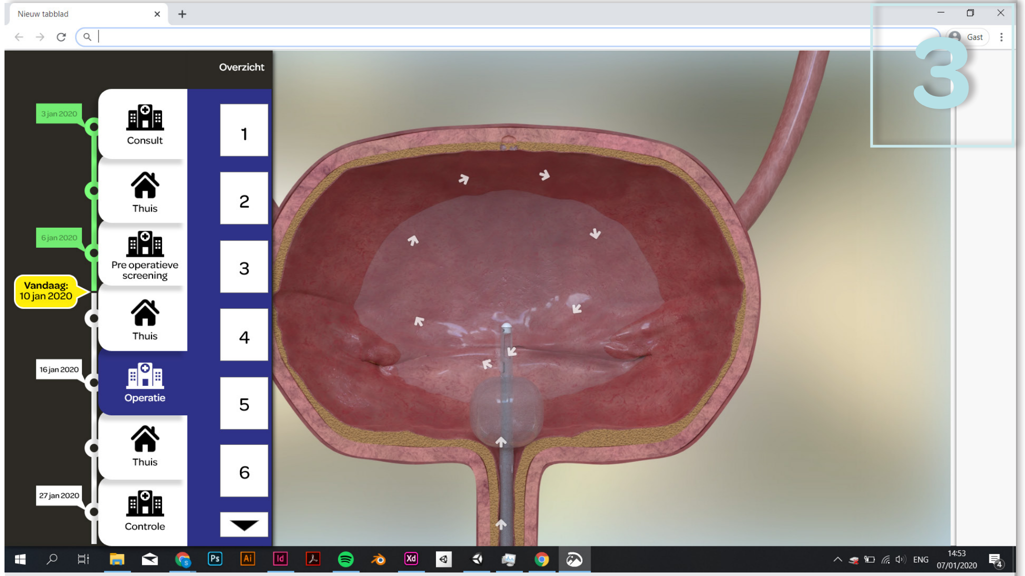
Iteration step 3



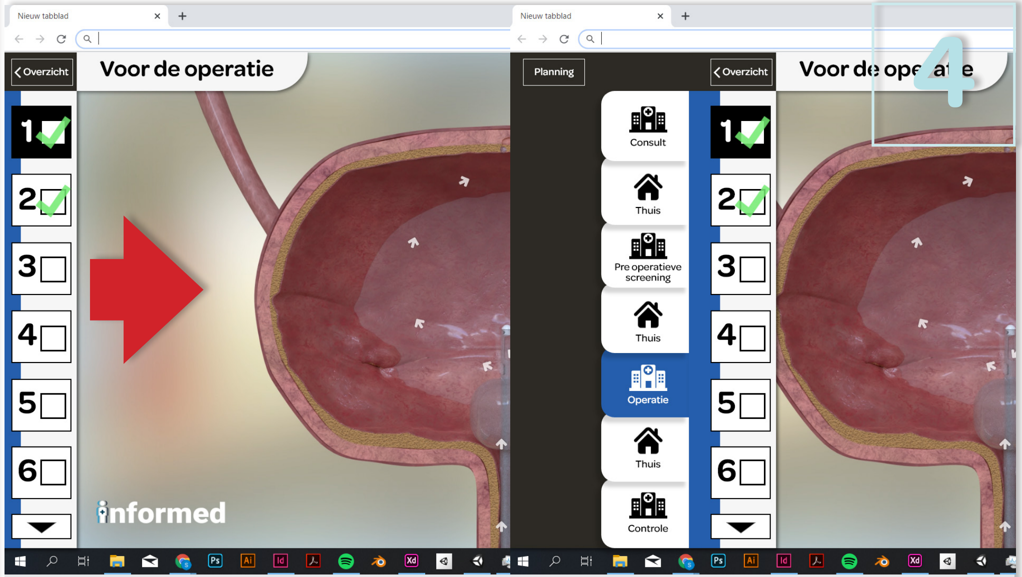
Folder with dividers methaphore
Each phase of the treatment programme is assigned to a divider in the overview. This overview is accessible via the 'overzicht' button in the left upper corner. The 'active' phase should have a contrasting colour difference.



Timline at of right of dividers
The timeline has a prominent place in the layout of the navigation menu. However, it is unclear if this timeline belongs to the phases or the steps within the phases.



Timline at left of dividers
If the timeline is positioned at the left of the dividers, it becomes more clear for the users that this timeline belongs to the phases instead of the steps. Still a downside of the timeline and planning is that there is a lot of information on the screen.

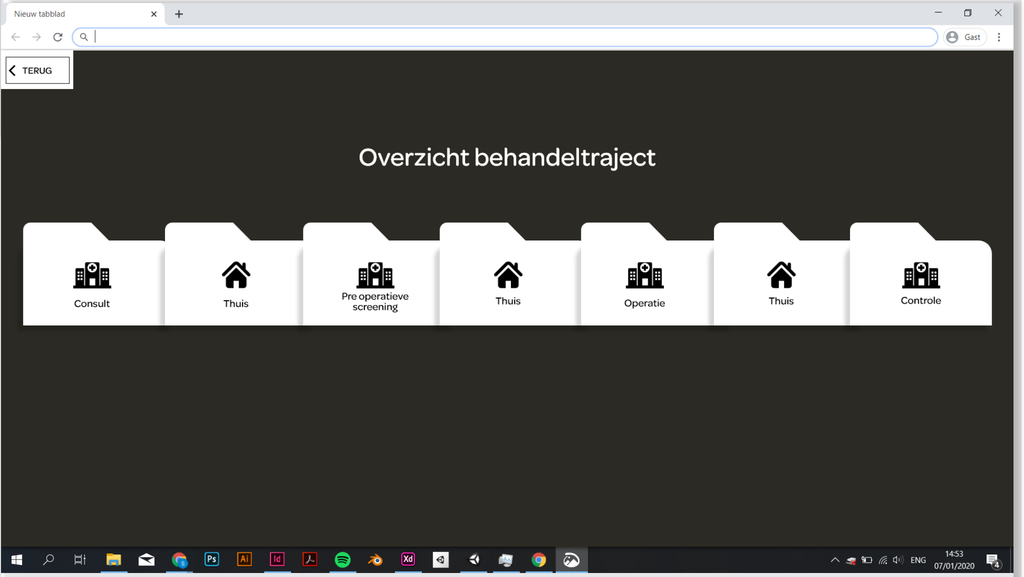


Stepmenu design

When the user opens the 'overzicht' menu only the phases are shown. An extra button is added to open the planning. This reduces the amount of content on the screen.

Conclusion

The unfoldable menu allows the user to gain access to other phases of the treatment programme. It does slightly hides parts of the content, nevertheless it does not contribute to a clear layout. There is a lot of different buttons and content on the screen. A new and better solution for the phasemenu has to be designed.



Overview page

This page replaces the previous overview menu. This menu can be opened via the same button as the old design. This overview menu blocks all the content, to help users in understanding what is on the screen.

Contrast

The overview page has a contrasting design to differentiate this menu as much as possible from the phase pages. The back button, labeled as 'TERUG', is replacing the overview button.

Iteration step 3

Tile structure
All content is placed in tiles of different sizes. These represent the main chapters within each phase. To 'current' chapter is central positioned.

More information button
This button let te user open the storyline panel.

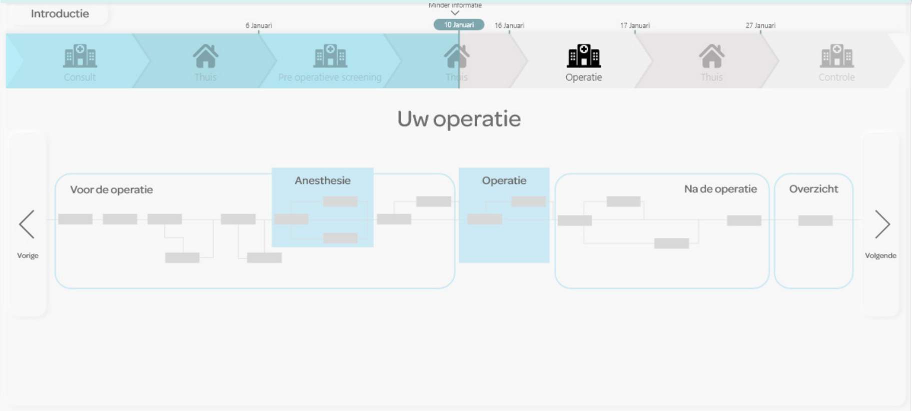
Dates
These dates help users to gain insights in when each phase is scheduled.

Introduction button
At all times the introduction should be accessible to help users understand the prototype.

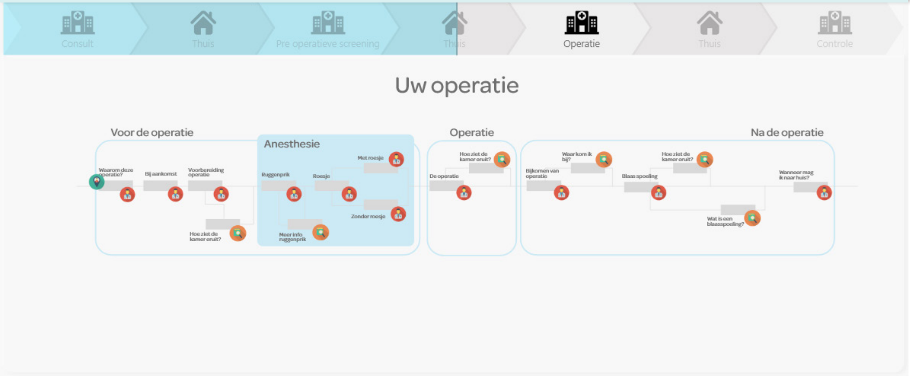
Navigation bar
This menu allows users to navigate trough the prototype. Each button refers to a phase in the treatment programme.
When the phase icon is black, the phase is active; the user is currently visiting the content of this phase.

Today bar
This bar shows in which phase the user is. For example, this user is halfway the treatment programme.

Previous design



Redesign



Iteration step 4

M
Evaluation Research transcriptions

Participant 9

Part 1
- Ik heb het bewust een keer gezien, ik weet wat er gebeurd is. Het moet gebeuren, dus je gaat het gelaten. Ik vind het heel duidelijk. Ik kan gewoon klikken, op volgende?
- Moet ik dit allemaal afzien?
- Ik moet zeggen daar hing toch een geweldige sfeer. De mensen onderling is zon geweldige sfeer. Dat zie ik niet terug, het is puur zakelijk. (voorbereiding stap)
- Ik vind het allemaal wel heel duidelijk hoor, ja. (over de animatie)
- Moet ik iets doen omdat ie stil staat? (een stap zonder animatie en voiceover, maar een still)
- Dus als je in de toekomst wat wil weten over hoe dat gaat, dan kan je dat op de website helemaal zien? Onderzoeker: 'Ja'. Participant: 'Ik vind het briljant.'
- Dan krijg je nog ijsje, dat vond ik ook zo geestig. (Na de operatie stap).

Part 2
- Ik zou dat (digitale folder) prettiger vinden, want dit (folder) is best veel als je dat boekwerk krijgt. Daar begin je niet zo gauw aan. En dan krijg ik achteraf wel eens op mn donder, dan zeggen ze ja dat staat in de folder. Ik vind het duidelijker hoor.
- Maar ik weet niet of iedereen digitaal gaat, of mensen dat wel doen. Ik ben 80 en ik doe het hoor. Mensen moeten zich schamen als ze dat niet doen.
- Een keer moeten we toch helemaal daar naartoe (wijst naar digitale folder). Want dat is allemaal slecht voor het milieu (wijst naar papieren folder) enzo.

Part 3
- Oh, de folder. Ik heb hem dus niet gelezen. Ik heb een standje gekregen, dat ik hem niet gelezen had
- Als ze tegen mij zeggen, dat ik de digitale folder kan bekijken, wil ik het sowieso een keer proberen.
- Ik vind dat ook duidelijker (digitale folder), dan weet ik hierin lees (folder)
- Ik heb het natuurlijk al eens meegemaakt, dus dit komt me bekend voor. Misschien voor iemand waarvoor dit allemaal nieuw is, dat iemand toch zn vragen heeft.
- Wat bedoel je met mijn manier? Als je het programma start, krijg je direct dat (de eerste stap)

Part 4
- IA en DDA*

Participant 10

Part 1
- Ik ben niet zon ster hoor met de computer..
- Dit is allemaal hetzelfde, alleen had ik een grotere monitor volgens mij.
- Af en toe deed ik mn ogen dicht, het zal wel goed zijn. Ze hebben het gereedschap en kunnen doorgaan.
- Als je dit vooraf krijgt, is het nog makkelijker om te weten wat ze gaan doen doen, zeg maar. Ze zeggen het ook wel, ze vertellen het ook wel, maar dit zou best wel een voordeel kunnen zijn. Of het voor iedereen is weet ik niet hoor. Sommige kunnen bang worden.
- Maar ik denk dat het voor een hele hoop mensen wel erg goed is.
- Omdat ik het gehad heb, dan kan ik een beeld vormen. Maarja als je dit vooraf allemaal ziet, dan weet je al een hoop. En hoeven ze jou niet zo veel meer te vertellen.

Part 2
- Ik heb het foldertje gelezen. Niet op internet gekeken, ja het moet toch gebeuren. Ze hebben er voor geleerd, dus eh.. wij weten weer andere dingen.
- Ik denk dat dit wel goed is, zeg maar.
- Het was met kerst, en het was nog niet helder. Ze zullen wel gedacht hebben, hij is veel liever thuis. Dus ik mocht naar huis. en thuis kon ik niet plassen, er zat waarschijnlijk een klein flubbeltje. En moest ik weer terug naar het ziekenhuis. (Wanneer contact opnemen..)
- Part 3
- Ik denk dat het allebei nuttig is, want de een wil het op papier hebben en de ander wil de animatie.
- Ik vind dat je het digitaal en op papier moet hebben. Dat je dus twee mogelijkheden hebt, dat is eigenlijk voor elke patiënt anders.
- Mensen moeten een leren, wij zijn niet met schermen opgegroeid. Dit moet je ook leren je, hoe dit scherm werkt.
- Ah ja, je kan allemaal zien wat er gaat gebeuren. (onderzoeker laat stappenoverzicht zien). Maar je hebt mensen en die willen het niet zien. Die willen alleen een folder hebben.

Part 4
- DDP

After research
- Als ik hem van de arts krijg, zou ik m wel openen en kijken van hoe of wat. Maar nu ik onder behandeling ben, ga ik nog niet op internet zitten zoeken en kijken. Je hebt mensen die alles gaan zitten uit pluizen. Als je daar behoefte aan hebt moet je het doen.
- Je kan er zo weinig aan doen, je laat het maar op je af komen. Meer kan je niet. Je kan je eigen nog zo druk maken, ik kan dit en dat.. Je weet toch niet wat er morgen gebeurd. En dit (digitale folder) kan je dan bekijken, als je dat wil.
- Je kan je er meer een beeld bij vormen. Anders heb je het gevoel van oeh wat zal het wezen.
- Wife participant: Ik vind dit op zich wel een goed systeem.
- Het is een goede aanvulling op enkel het papier, zonder meer. En ik denk dat als je op een gegeven moment het ingevoerd is, je ook meer mensen zal krijgen, die naar internet gaan kijken, dan op papier. Maar je zal altijd een gedeelte hebben die op papier willen.
- Participant: Ik denk dat als ik voor de operatie even snel wat wil kijken, dan ga ik voor papier. Vrouw: maar dit is even sneller te bekijken dan als je zo'n blad leest..

Participant 11

Part 1
- Ik heb snel last van een lage bloeddruk, bij de ruggenprik werd ik helemaal licht in mijn hoofd. En de tweede keer werd ik helemaal naar. Nou de volgende keer wil ik een roesje.
- Oh, dit is al geweest. Oh, kijk volgende.
- Dat weet ik, dat is ook voor iedereen verschillend. (Spinaal)
- Spoeling: soms duurt het langer dan de andere keer. Het zal wel aan wat ze ingespoten hebben liggen. Tja, weet ik veel.
- Ja, wat moet ik verder klikken. Even kijken, standaard weergave, detail. Oh dat is ook van het spoelen. (unclear, the appearance changed.)
- Ah, meer informatie verpleegafdeling. Laten we dat eens kijken. (rotation interaction, unclear.) After tip: oo ja, dat is voor het spoelen zeg maar.

- tip: oo ja, dat is voor het spoelen zeg maar.

Part 2
- Ik heb geen animatie gekregen, alleen de folder met alleen tekst.
- Ik vind het wel fijn hoor om te hebben een animatie.
- Wij hebben ook een computer en als ik iets wil weten dan kijk ik wel hoor.
- Bijvoorbeeld ik kreeg een MRI scan, daar vond ik wel spannend hoor, daar kreeg ik wel een beetje claustrofobie van. Ik heb het wel opgezocht hoor. Want ik vond het zo eng, ik moet erop voorbereid zijn. Het moet toch.

Part 3
- De folder lees ik ook altijd. Je hoort zoveel en het is fijn dat je het even kan nalezen naderhand.
- Ik heb het idee dat blaaskanker vooral bij ouderen voorkomt, en niet iedereen heeft de beschikking over een computer.
- Ik vind het allemaal heel duidelijk, de informatie.
- En dat ik dan op de mail een berichtje krijg met de informatie, dat vind ik ook fijn om dan even door te kijken.

Part 4
- IA en DDA

After research
- Ik vraag het vaak aan de oncologieverpleegkundige, wanneer ik wat wil weten. (Tijdens een blaasspoeling is de patiënt een tijd met de verpleegkundige en heeft alle tijd om vragen te stellen.) Dan hoef ik niet nog een keer online te kijken, want je wil niet altijd met je ziekte bezig zijn.
- Gingen we naar de camping, na in het ziekenhuis geweest te zijn, ging ik gewoon weer fietsen. Achteraf hoor ik dat dat helemaal niet mag. Had misschien ook in de folder kunnen staan. Als ik iets wil weten vraag ik het gelijk aan haar (onc.verpleegkundige).
- Precies eender als met een bijsluiter, dat heeft iemand een keer gehad en komt het erop. Als je daar allemaal aan moet gaan denken..
- Online daar kijk ik niet zo.
- Dat heb ik ook heel erg he, dat ik de artsen vertrouw. Want ja als je dat niet hebt, wat moet je dan he.

Participant 12

Part 1
- Oh, den dan mag ik naar de pijl toe, neem ik aan. (over de volgende knop)
- (De interface is niet direct duidelijk voor de participant, na een korte uitleg wel en gaat de participant de navigatie gebruiken).
- (Participant gebruikt het stappenoverzicht na tip, en klikt direct op een stap waarin hij geïnteresseerd is.)
- (Participant gebruikt het stappenoverzicht nogmaals als navigatie naar stap)
- (Participant gebruikt de rotatieknoppen bij de operatiestap)
- Oja, zo is het ja. Dan lig je zo in de stijgbeugels (over operatietafel).

Part 2
- Na wat gesprekken met de mensen (artsen) voel je je wel vertrouwd.
- Ik heb ook een review geschreven: mensen zijn dusdanig begeesterd met hun werk.. en het verpleegkundig personeel trouwens ook

Part 3
- Heb je dan wel eens mensen die zeggen dat ze het oneens zijn?
- Als je iets hebt, moet je iets wel goed lezen en in je op kunnen nemen. Of je nou een analytisch vermogen hebt of niet, dat scheelt wel een beetje.
- Lezen en schrijven, je neemt het 5x beter op dan dat je op dat ding zit te kijken.

Part 4
- IA

Participant 13

Part 1
- Ik heb het allemaal op papier wel gekregen, maar dit is wel duidelijker dan de folder die ik kreeg
- Roesje. Oh dat is de stap welke je mee bezig bent.
- De precieze operatie, had ik niet voor me kunnen halen. Maar zoals ze dat daar uitleggen, vind ik het wel fijn om te weten hoe ze dat doen.
- De speakover daar eh, ben je veel meer alert op dan alleen maar plaatjes. (sommige stappen hebben geen voiceover in het prototype)
- (Het verschil tussen detail en standaard weergave is onduidelijk. Een tip nodig om het verschil te laten inzien.) (Waar wel en niet verdiepingsstappen zijn, is onduidelijk)
- Oja, en dan zie je hier de operatieruimte, want daar heb je geen idee van hoe dat allemaal eruit ziet.
- (Heeft uitleg nodig om het stappenoverzicht en het faseoverzicht te bekijken. Maar heeft het daarna direct door en gebruikt het)

Part 2
- Ik heb wel op internet gekeken voor informatie enzo. En dat is over het algemeen allemaal schriftelijk. Dus ja zoveel mogelijk lezen. En op een gegeven moment heb je zo veel gelezen dat het niet allemaal blijft zitten. Maar ik denk als je het ziet en je hebt iets wat persoonlijk op jouw situatie is gericht, dan is dat natuurlijk allemaal wel veel duidelijker.
- R: Wat bedoelt u met persoonlijke situatie? P: op wat er voor jou gaat gebeuren. De operatie en wat er vooraf gaat gebeuren. Je kan het wel lezen, maar deze site geeft dat en die site geeft dat. En wat je meekrijgt van het ziekenhuis wijkt net af van het internet. Als dat voor jou beschikbaar is vanuit jouw uroloog, dan is dat natuurlijk voor jou veel duidelijker. Mooi ding (over digital prototype).

Part 3
- De papieren folder was wel informatief.
- Met de papieren folder, was ik nog een beetje zenuwachtig van (voor de operatie). Niet dat de folder mij zenuwachtig maakte, maar het gaf me niet het gevoel dat ik helemaal op mijn gemak naar de operatie zou gaan.
- Als je zo ziet hoe ze de operatie precies uitvoeren, dat zou ik vinden: veel duidelijker, veel begrijpelijker.
- Het zijn toch allemaal enge dingen die je te horen hebt gekregen. Het onbekende is altijd eng.

Part 4
- IA

ABSTRACT

In 2020 the law 'informed consent' is renewed, with the aim to strengthen the patient's position in the field of shared health decision making. Research showed that patients only recall 20% of the information provided by their medical specialist.Therefore other information materials are offered, to ensure the patient can comprehend the other 80% of health information. Nevertheless, these materials do not satisfy all patient's needs concerning health information preferences.

A qualitative research is conducted to gather knowledge of the health information preferences of non-muscle invasive bladder cancer patients. Based on these findings a tailored interactive animation is developed. The animation is used in a second qualitative research to learn if this material better meets the patient's needs, compared to current resources as a traditional folder and 3D animation.

QR-code
Scan the QR-code and watch
the tailored interactive animation demo