ExPEERience

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

Appendix - Tess Peters

Welkom terug tess!

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

Erasmus MC
Universitair Medisch Centrum Rotterdam

zorg monitor
Erasmus MC

TU Delft

CardioLab

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

Appendix Master Thesis
Delft, July 2021

Education
MSc. Design For Interaction
Medisign specialization
Delft University of Technology
Faculty of Industrial Design Engineering

Supervisory team
Chair: Prof. dr. ir. M.S. Kleinsmann
Mentor TU Delft: Prof. dr. H.M.J.J. Snelders / MSc. J. Jung
Mentor company: Dr. M. Offerman (Erasmus MC, Rotterdam)

Author
Tess Peters
Contact: tess-peters@outlook.com

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

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Appendix A.
Project Brief

Data enabled design: Empowering head and neck cancer patients — project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 01 - 03 - 2021

16 - 07 - 2021 end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

The head and neck cancer department of the Erasmus MC in Rotterdam uses a system called the Health Care monitor (de Zorgmonitor) to collect and organise personal information from patients. The system uses PROM (patient reported outcome measurements) questionnaires that are filled in by the patient two weeks prior to a consultation with the doctor. Questions relate to the physical health of the patient but also to the experienced quality of life. The answers given by patients are collected and shown to the doctor in the form of a dashboard (see figure 1). This dashboard shows the answers using colors so that the doctor can easily see which topics are red and therefore need to be adressed with the patient during the consultation. This system allows both patients and doctors to be better prepared for the consultation. The questionnaires are filled in before every consultation for 5 years after treatment.

The 3 core values the Health Care monitor creates according to research from the Value Based Healthcare Team of the Erasmus MC are; 1. Increased quality care, 2. Strengthening position of the patient, 3. Future proof healthcare.

In interviews with the different members of the Value Based Healthcare team and by observing 8 consultations with patients, some limitations of the current system were discovered. One limitation discovered was that the data currently is not continuously collected. A snapshot of the patients health and experience is made two weeks prior to the consultation. This means that it is not always reflective of how the patient felt over a longer period of time. Another limitation is that currently the patients do not have insight into their data themselves. Patient data from the filled in questionnaires can be shared by the doctor during a consultation. However not all doctors show the dashboard to the patient and patients can only have a glance during this consultation but not later on when they are at home. The Value Based Healthcare team therefore also expressed their wish for a 'patient dashboard'. This could help to increase the second value; to strengthen the position of the patient.

Next to the doctors and the Value Based Health Care team of the Erasmus MC, the patients are a very important stakeholder group in this context to consider. Therefore, in order to understand the journey of cancer patients and their concerns, blogs and forums of online cancer communities were analysed. From 715 stories from 3 different platforms a journey map was created showing both the patients and family members experiences. Important insights gathered were that patients discuss a lot about the side effects of their treatment and how they deal with them. Both physical and mental side effects are important topics to be informed about and share with others. For head and neck cancer patients, ways of dealing with side effects related to eating and drinking were often discussed and shared amongst patients. Furthermore the importance of support from family members became apparent in this analysis.

This leads us to the next stakeholder group involved; the family members of the patient. By analysing their stories on online cancer communities it was found that they can lose themselves in the process of caring for their loved one. Selfcare is therefore important for this group to consider. Because family members are also effected psychosocially by this disease and they are important support for the wellbeing of the patient, they also need to be considered in the context of this project. Therefore this project will not only look at the quadruple aim that is often used in medical design projects but at a penta aim, including the experience of family members (see figure 2).

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introduction (continued): space for images

image / figure 1: The dashboard of the Healthcare Monitor in use by a doctor

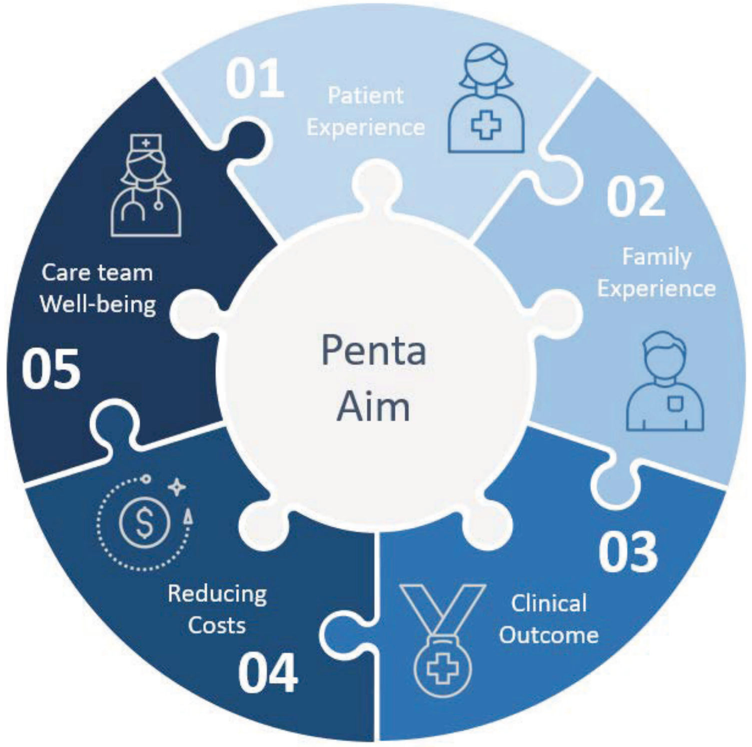

image / figure 2: The penta aim; the quadruple aim with the added aim of family experience

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

This project will adress the issue of a lack of continuous patient data and the lack of insight for head and neck cancer patients into their data and relevant information in the follow-up phase after treatment. Patients do not have a structured overview of their data when they are at home before and after their consultations and also currently do not have a way of tracking their physical and mental health experiences continuously over time. This also relates to the problem that the questionnaires at the moment are a snapshot and may not reflect a complete image of the patient.

This project aims to strengthen the second value created by the Health Care monitor as defined by the Value Based Healthcare Team; strengthening the position of the patient, or in other words; patient empowerment. Patients need to be given more control in their own health care process and need to have self efficacy in dealing with treatment side effects. Furthermore information should be provided in a personalized way and at the right time in the right frequenty.

An issue that should be adressed is what kind of experiential data should be collected continuously and how this data can be collected in a way that is unobtrusive for the patient and fits within their context. Furthermore a way of effectively communicating and showing information and data to the patient should be investigated. Since 29% of adults in the Netherlands have difficulties in communicating with health care professionals and understanding healthcare data it is important that not only the interaction of collecting data but also the interaction of showing data to patients is carefully investigated.

This project will focus on collecting data continuously in the same phase that the Health Care monitor questionnaires collect data, namely the first 5 years after treatment. This follow-up phase is also an important phase for the patient since they need to find a way to deal with the physical and mental side effects of the treatment.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

I will design a product service system linked to the Health Care monitor of the Erasmus MC that empowers head and neck cancer patients to track and view their own data and relevant information continuously over 5 years after treatment in a context-aware personalized way.

I expect to design a digital interface that allows head and neck cancer patients to track their physical and mental experiences related to their cancer process and side effects in a way that is not intruding or overwhelming but fits within their context. I will also design an interaction to communicate this collected data effectively to both patient and doctor. The way the information is communicated to the doctors should fit with their workflow in order to fulfill the penta aim. To fulfill the penta aim, my design will also include an element that considers the interaction between the patient and family members.

The focus of this project is on the patient experiences but as mentioned before, all 5 aims of the penta aim will be taken into account in order to create a solution that is effective and relevant for all stakeholders in this medical context.

Initials & Name T Peters 4772 Student number 4437144

Title of Project Data enabled design: Empowering head and neck cancer patients

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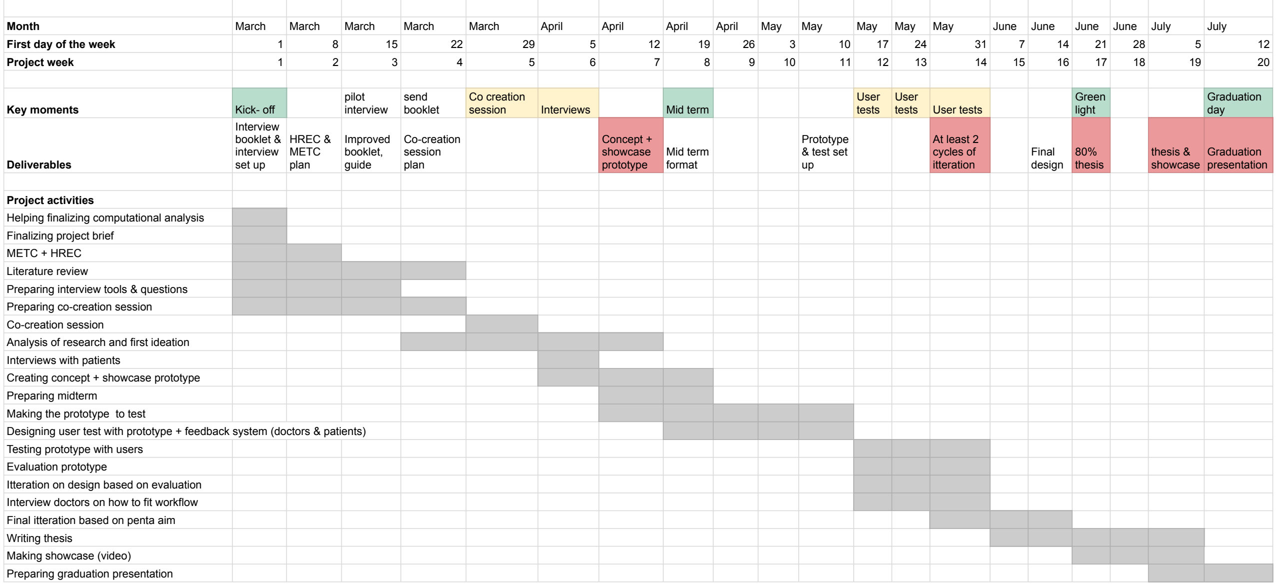
PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.

start date 1 - 3 - 2021 16 - 7 - 2021 end date



Month	March	March	March	March	March	April	April	April	April	May	May	May	May	May	June	June	June	June	July	July
First day of the week	1	8	15	22	29	5	12	19	26	3	10	17	24	31	7	14	21	28	5	12
Project week	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Key moments	Kick- off		pilot interview	send booklet	Co creation session	Interviews		Mid term				User tests	User tests	User tests			Green light			Graduation day
Deliverables	Interview booklet & interview set up	HREC & METC plan	Improved booklet, guide	Co-creation session plan			Concept + showcase prototype	Mid term format			Prototype & test set up			At least 2 cycles of itteration		Final design	80% thesis		thesis & showcase	Graduation presentation
Project activities																				
Helping finalizing computational analysis	▨																			
Finalizing project brief	▨																			
METC + HREC	▨	▨																		
Literature review	▨	▨	▨	▨																
Preparing interview tools & questions	▨	▨	▨																	
Preparing co-creation session	▨	▨	▨	▨																
Co-creation session					▨															
Analysis of research and first ideation				▨	▨	▨	▨													
Interviews with patients						▨														
Creating concept + showcase prototype						▨	▨	▨												
Preparing midterm							▨	▨												
Making the prototype to test							▨	▨	▨	▨	▨									
Designing user test with prototype + feedback system (doctors & patients)								▨	▨	▨	▨									
Testing prototype with users												▨	▨	▨						
Evaluation prototype												▨	▨	▨						
Itteration on design based on evaluation												▨	▨	▨						
Interview doctors on how to fit workflow												▨	▨	▨						
Final itteration based on penta aim														▨	▨	▨				
Writing thesis															▨	▨	▨	▨	▨	
Making showcase (video)																	▨	▨	▨	
Preparing graduation presentation																			▨	▨

Due to the need for ethical (HREC) and perhaps medical approval (METC), the planning of the interviews and user tests might change a bit in relation to the necessary approvals needed and the time it takes the commities to approve our research. A realistic amount of time for these approvals is already taken into account, but this might be subject to change.

Testing with users, evaluating and itterating is continuously done for three weeks as the prototype tested will be updated at least once during these three weeks, so multiple prototypes will be tested in this time.

Initials & Name T Peters 4772 Student number 4437144

Title of Project Data enabled design: Empowering head and neck cancer patients

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... Stick to no more than five ambitions.

My motivation for chosing this project is that it fits with my interest of designing for a medical context. I am interested in the interactions between different stakeholders in the medical environment and how design can help to increase care and wellbeing. I have done a Research Project for the CardioLab in collaboration with the Erasmus MC that has led to the formulation of this graduation project. During this research project I have become familiar with and very much interested in, the experiences of cancer patients and I believe that this project can really make a difference for these patients if executed well. It can be the start of more patient empowerment and better shared decision making for cancer patients.

Competences that I want to prove with this graduation project are;
- My ability to do user interviews and context research
- My ability to do user research with a developed prototype
- My ability to facilitate co-creation sessions with stakeholders
- My ability to design meaningful interactions

Competences that I want to learn during this graduation project are;
- To learn how to manage different stakeholders in the medical environment
- To learn how to use community data as inspiration for design
- To learn how to design for the medical context
- To learn how to apply for ethical (and medical) approval
- To learn how to make a digital prototype that is updatable during the test phase

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Initials & Name T Peters 4772 Student number 4437144

Title of Project Data enabled design: Empowering head and neck cancer patients

Appendix B. Design research project outcomes

Design research project outcomes

Answering the question: what are the major overlapping opportunities when comparing the patient and family members experience of online cancer communities with the goals of the VBHC team?

Mehod

As shown in the thesis in chapter 1.1.4, we combined the results of the first three research questions in order to answer the fourth research question and find the major overlapping opportunities. This was done by comparing the current use of the Healthcare Monitor to the expressed wished use (see figure A). By comparing these, gaps could be found for each of the values (goals) that the Health Care monitor aims to create. These gaps were then compared to the concerns expressed in the patient and family journey to find overlapping areas for improvement.

Results

Comparing the two studies let to several interesting opportunities. 3 main opportunities were defined. Each opportunity has its main focus on a different stakeholder group. The first opportunity is care-team drive (see figure B), the second is patient-driven (see figure C) and the third is family-driven (see figure D). The three opporunities defined are:

- **Shared Decision Making**: A more continuous and complete flow of patient data for more patient specific advice.
- **Patient Empowerment**: Providing more insight and access for patients to track their data and relevant information.
- **Family Support**: Involving informal caregivers (family) in the Health Care monitor to help them in caring for the patient and themselves.

More continuous and complete flow of patient data for more patient specific advice

This opportunity came from the wishes of the VBHC team to collect data more continuously and more patient specific so that better prognostic models can be created for different treatments. This can give the care-team a more complete view of the patient and help them to give more personal advice for treatments when making a shared decision. This can help in the patient concern found called 'Making a big decision', where patients want to be helped to make the best decision for their personal situation.

An example scenario of what a designed product service system could do for this opportunity is sketched in figure E. This scenario shows how this opportunity could steer improvements for the Healthcare Monitor.

More insight and access for patients to track and view their data

The main wish of the VBHC team that drove this opportunity was the wish for a patient dashboard. Also in the patient journey we found the need

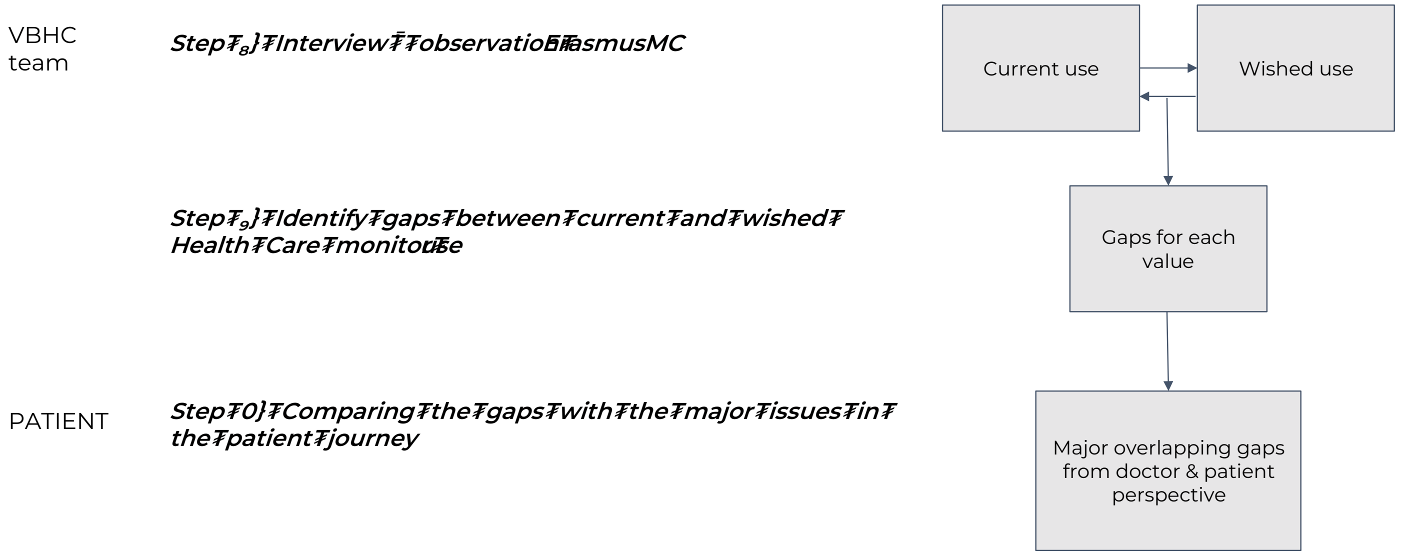


Figure A. Comparing the VBHC team perspective with the concerns expressed by patients and family members on online communities to find the major overlapping opportunities.

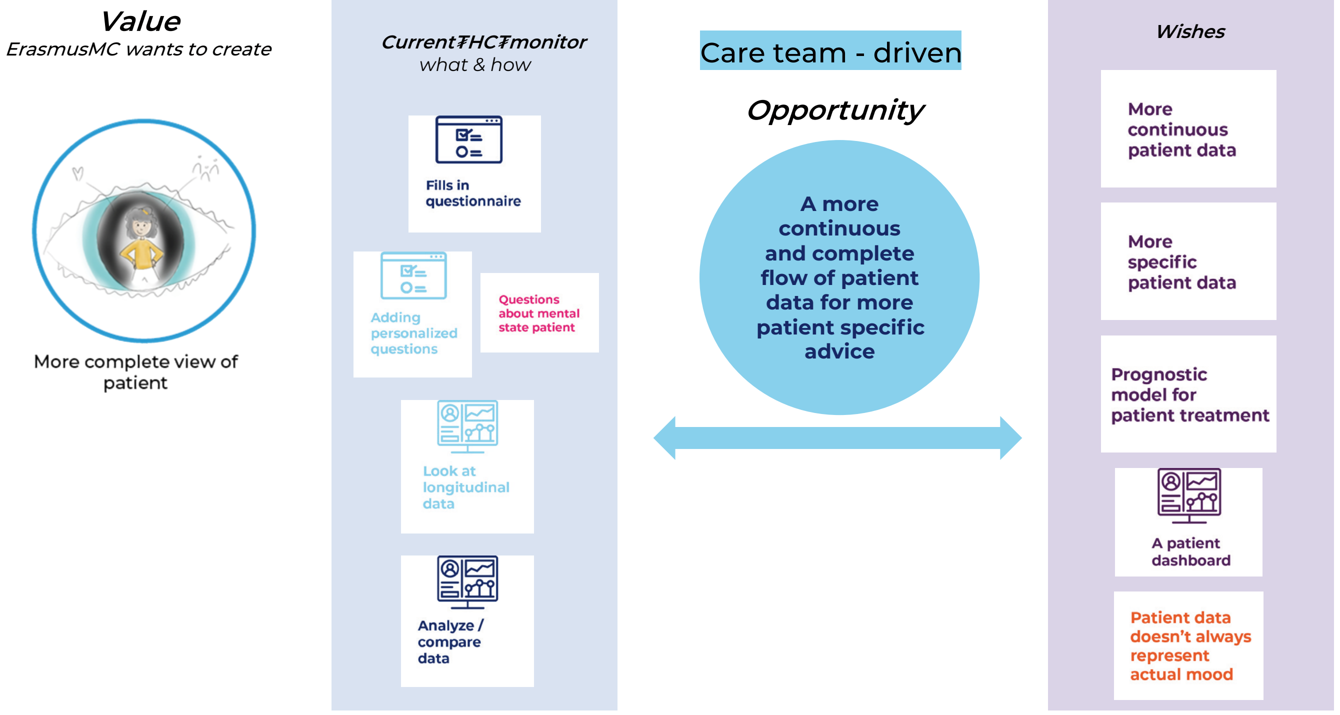


Figure B. The care team-driven opportunity found: Shared decision making

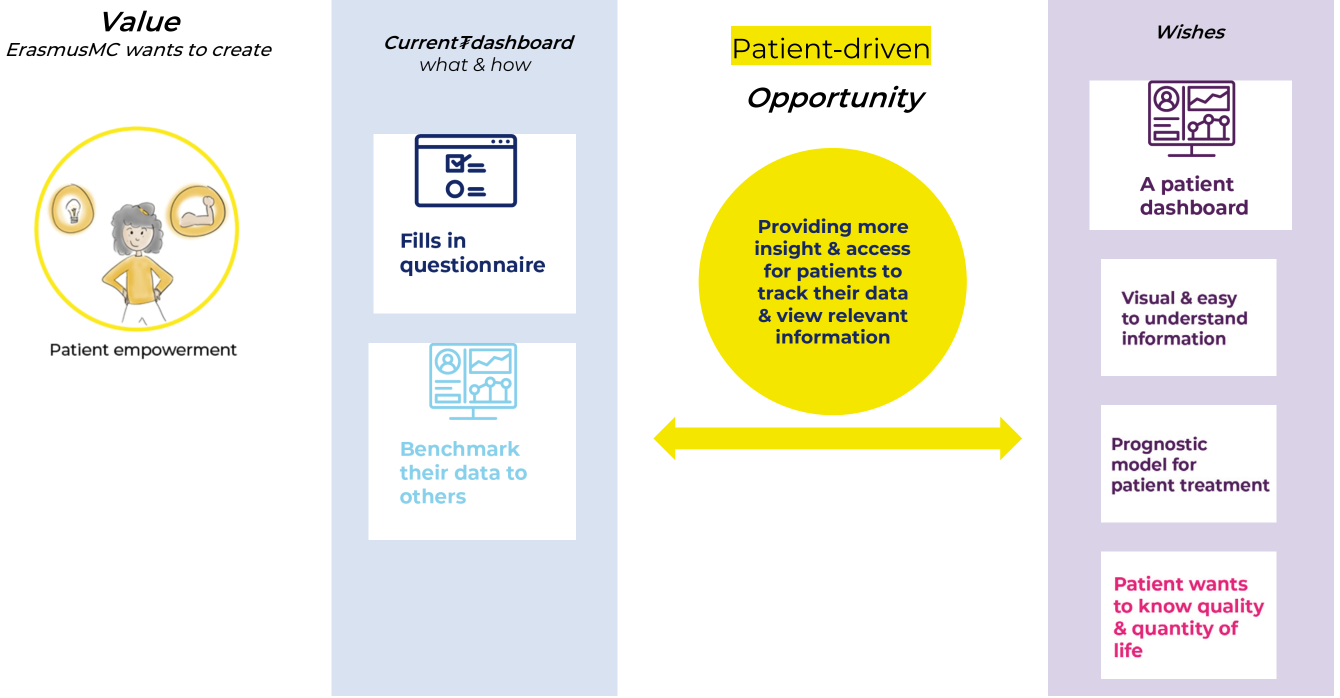


Figure C. The patient-driven opportunity found: Patient empowerment

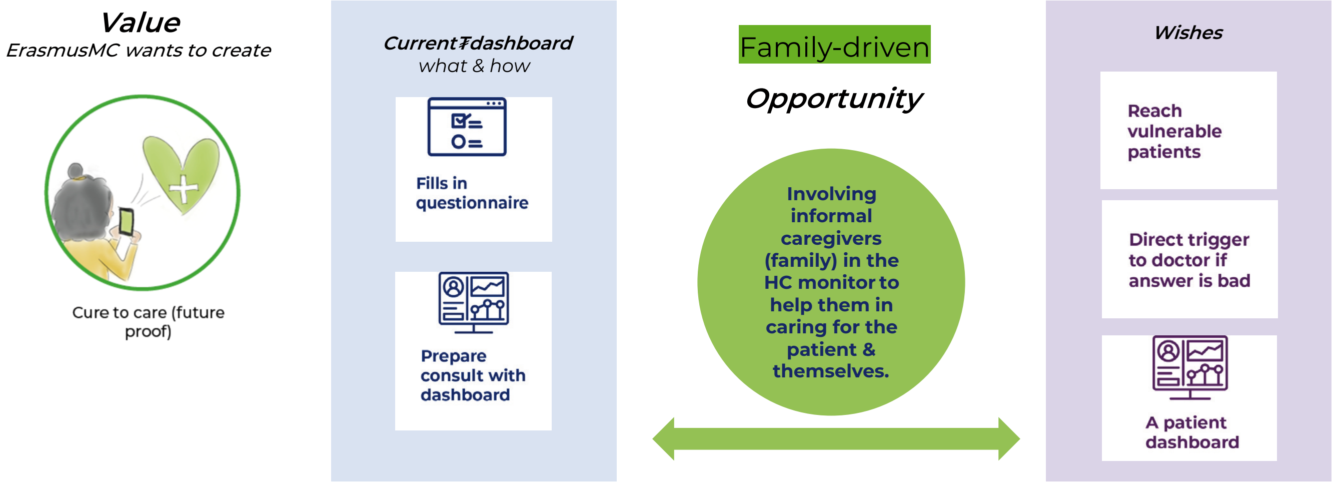


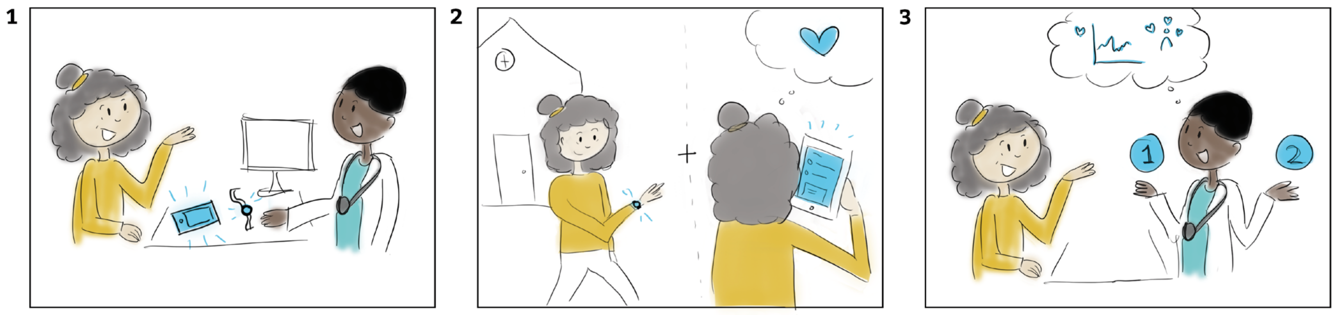
Figure D. The family-driven opportunity found: Family support of patients to be well informed and to learn how to deal with the side effects of their treatment. Patients are asking other patients about their experiences and ways of dealing with side effects. Furthermore patients expressed their troubles and tips for preparing consultations and organizing information. This opportunity can empower the patient. Making them in control of their own health care journey by providing personalized information and helping them in tracking what suits their personal lifestyle.

An example scenario for adressing this opportunity and creating a patient dashboard with a designed product service system is sketched in figure F.

Involving family in the Healthcare Monitor to help them care for the patient and themselves
This opportunity mainly derived from the biggest code group found in the family experience journey called 'self-care'. This group represents the stories of family members that lost sight of themselves in caring for their loved one and the importance to keep caring for yourself as well. The hospital wants to reach vulnerable patients and become more future proof. An opportunity to do so is to involve the family members more in the health care process by also involving them in the Healthcare Monitor. Family members already express that they want to be involved in the care process but often are not sure how to take best care of the patient. If they can be better informed and also inform the care team about the patient, all stakeholders can optimally work together to create better quality care.

In figure G you see an example scenario of how family members could be involved in the Healthcare Monitor.

Since the support from family is very important for the patient and the lifes of family members are also effected a great deal by cancer, it was decided to change the quadruple aim as seen in the discussion to a quintuple aim. This quintuple aim includes the aim of 'family experience' next to the four usual aims.



Patient receives sensory data collectors and app after being diagnosed.

Patient track their physical and mental health at home. Patient is prompted to think about lifestyle and their values in life through questionnaires.

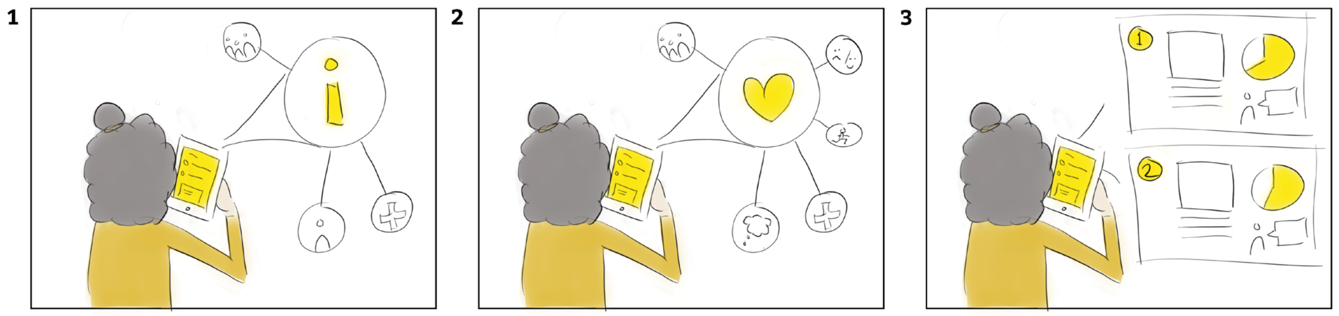
Based on the continuous experiential and sensory data collected the doctor can provide a more fitting and personalised advice for treatment.

Patient continous to track data during treatment to also measure the mental and physical side effects and their effect on the perceived quality of life.

This data can be used by the doctor for further consultations and treatment decisions.

All the collected data can be used for prognostic models based on lifestyle and patient treatment satisfaction for future patients.

Figure E. An example scenario for the shared decision making opportunity



When patient is diagnosed they can go to their own patient dashboard to see a clear overview of the disease and information discussed.

App asks patient about life goals, lifestyle and what they want to track.

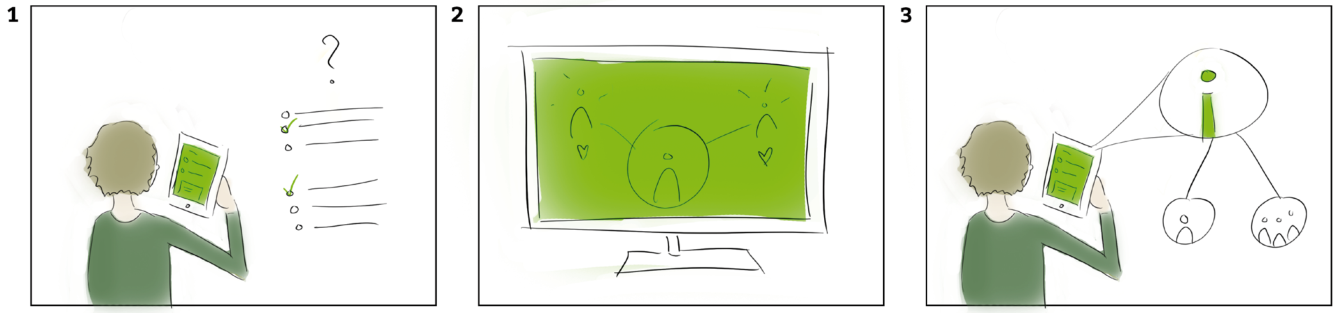
Based on reflections and tracked data the patient gets to see their treatment option suggestions. They can read about side effects and peer experiences.

Patient comes better prepared to make a treatment decision and knows what she wants to aks the doctor who also has a better view into the patient's wishes.

Patient keeps track of the data that she wants to track (in the form of a diary/sensors) and sets a plan for recovery. She can see her progress over time.

The app can suggest the patient to read peer experiences or can suggest tips about side effects/mood changes based on the input data of the patient.

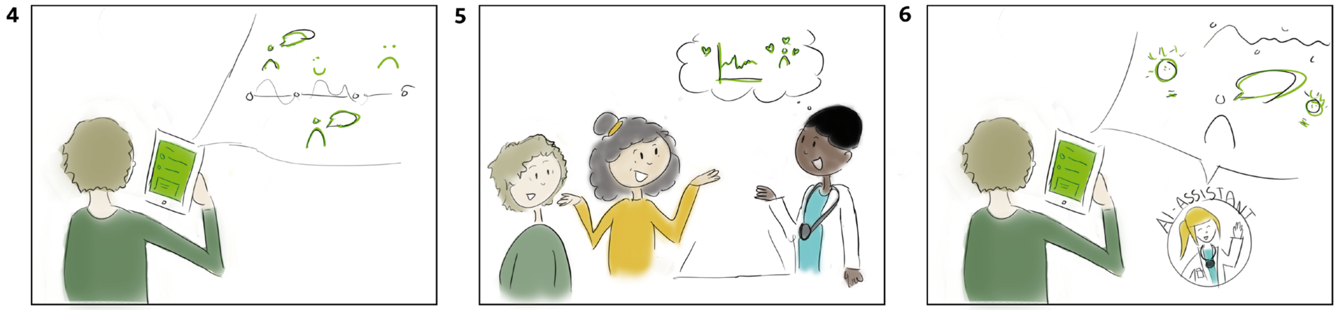
Figure F. An example scenario for the patient empowerment opportunity



Family fills in questionnaire about patient and about themselves.

This gives doctor better insight into patients social context and the families role as caretaker.

Family member receives info on how to care for the patient and for themselves in the cancer journey.



Family tracks patient and personal experiences through a diary/blog.

Data is analysed and can be used by the doctor to give better advice to both patient and family.

Based on the diary content the app can suggest relevant info, support group or experiences from peers.

Figure G. An example scenario for the family support opportunity

Appendix C.

Code groups manual analysis general cancer community data

Time	Groups	Code groups	Nr. Codes	
Diagnosis	The ground falls away beneath you when you get the diagnosis, your life is set to change	Shocked about the diagnosis	6	91
		Felt unprepared for diagnosis	1	
		Not knowing how to react to the diagnosis	1	
		The impact when hearing the diagnosis of cancer	14	
		Fear of what is going to happen	2	
		Feeling losing control of life	1	
		Belonging to the 'cancer' group	3	
		Losing control over life	9	
		Life can be turned upside down in one short moment	6	
		Getting the diagnosis gives a shock to patient and family	8	
		Adverse reaction to news of cancer is common	1	
		Cancer was discovered unexpectedly and patient is not really preparec	1	
		Life changes drastically between diagnosis and treatment very quickly	3	
		Patient talks about their diagnosis and extra complications / waiting inv	16	
		Patient tells about diagnosis	19	
	Cancer often starts with small health complaints	Cancer often starts with small health complaints	4	39
		Before cancer diagnosis patient often has other health complaints	3	
		Cancer starts through exhibiting another problem	3	
		Symptoms and pre-health	6	
		Unclear symptoms	5	
		Suspecting something is wrong	18	
	The importance of information availability and transparency for the patient	Overwhelmed by information	3	141
		It is hard to grasp all information at once	9	
		Inadequate information from healthcare professionals creates confusio	11	
		Patients are looking for confirmation an information online	9	
		Self-seeking more information	4	
		Many questions - searching for answers	14	
		Patients want to know and understand everything there is to know	8	
		Actively seeking information by yourself	3	
		Long process of finding information by yourself	2	
		When patients and family members have very little information they ge	1	
		Mistrust and fear of missing out on information	11	
		It is important in what setting you get the news you have cancer	1	
		Doctor gives advice to patient	9	
		People are unsure when going to a doctor is necessary	6	
		Patients want to know what to expect	8	
		It is important that medical information is available for patient	8	
		Being well informed helps cancer patients in dealing with all	34	
	It takes time to process the diagnosis and the emotions that come with it, it feels unfair and unreal	Confusing diagnosis	1	40
		Experience of misdiagnosis	5	
		Uncertainty of the dianosis	1	
		Had a healthy life before, not understanding why getting cancer	7	
		Denying the diagnosis	2	
		Patients don't understand why they are in this situation, it feels unfair	8	
		Takes time come over shock and first wave of emotions	7	
		Denying your situation	4	
		Feeling unreal, need time processing	5	
	Telling others	Difficult to deliver the news to family or others	9	19
		It can be difficult to inform family/friends about cancer	5	
		Worried for family and telling about cancer	5	
Tests & scanning	Waiting for results is stressful you need to find a way to make the waiting time more bearable	Concerns and ways to deal with stressful long waiting time	8	119
		The afflicting moments before the test results	13	
		Patient appreciate short waiting times	3	
		Patients annoyed with long waiting times	10	
		Patients are very stressed for results and control appointments	17	
		There is a lot of waiting in the process	14	
		Long process and waiting creates suspense build up	3	
		Mental stress and anxiety related to waiting and questions	15	
		Worry about results	3	
		Waiting is hard	9	
		Suspecting something is wrong	18	
		Patients try to stay calm and sober	6	
	Being well informed and thinking about pro's and con's (Quality vs quantity) helps patients to make tough decisions in which they want to have a say in	Decision of going for or changing treatment	7	242
		Challenges of breast surgery	3	
		Decision making of breast surgery	4	
		Importance of shared decision making	4	
		Being in a dilemma	5	
		Difficult knowing low chances of survival	2	
		Hate of not knowing	4	
		Being well informed helps cancer patients in dealing with all	34	
		Experiencing doubt throughout the process	4	
		Hormonal medication decisions	3	
		Important factors of choosing a facility	4	
		Difficult decisions to make	4	
		It is important to balance life extension and quality of life	12	
		Patient doesn't want to make big decisions herself	1	
		Patient want a say in their treatments and examinations	7	
		Patient wanting control of own life	11	
		Possible side effect of treatment can scare patient	5	
		Wanting a good quality of life	9	
		Having to chose between quality of life or treatment	20	
		Patient does not want any more treatment	9	
		Patient wanting to be in control of own process	3	
		Common dilemma for family between suffering through treatment or sp	1	
		Decision making is challenging due to stress	1	
		It is crucial to understand who takes the decision for the patient	1	
		Patients want information and transparent communication with doctors	15	
		Can help to leran from experiences from others but people still respond	2	
		Difficulty making a decision on treatment, wanting to know what to exp	7	
		The uncomfortable and scary consequences of treatment influence dec	21	
		Patient wants their voice to be heard	2	
		Seeking guidance in decision making and need to share your own opin	29	
		Patients want to know what to expect	8	
	Stepping aboard the fast moving train of hospital tests	After testing everything suddenly moves fast	2	36
		Go into the mill of the hospital	16	
		Did not expected needing more testing	2	
		Felt vulnerable needing to be tested again	4	
		A lot needs to happen in a short time	4	
		Quick examinations after each other	4	
		Scans and other forms of research can be experienced as unpleasant	4	
Treatment & side effects	Working while being in treatment can help with the mental health but it is important to be flexible to deal with challenges of treatment	Being pressured to return to work	4	85
		Challenges returning to work	7	
		Concern of working during treatments	5	

		Unhappy be advised not to return to work	2	
		Helpful tricks to return to work	1	
		Perks of returning to work	2	
		Mixed feelings back to work	5	
		Working while going through chemo therapy	16	
		Patients struggle to go back to work	6	
		Having bad experiences in getting back to work process	9	
		It is pleasant to have a good relationship with your employer	3	
		Not being able to work due to cancer	10	
		Working takes much energy from patient	6	
		Being able to work with flexibility of time and space helps patient be m	2	
		Cancer takes away time from work and causes stress and frustration	1	
		Having regular work with cancer is challenging and fatigue hits on the l	2	
		Need to be flexible with work	4	
	Getting sucked into a dark place, and how to get out	Negative thoughts	2	304
		Giving up thoughts	5	
		Having suicidal thoughts	6	
		Different ways dealing with anxiety	16	
		Different ways dealing with depression	6	
		How to overcome depression	36	
		CBD & cancer	7	
		It is scary to live in unertainty	16	
		Patients can feel lonely	3	
		Patients feel empty	7	
		Patients struggle to stay positive	15	
		Feeling restless about situation	8	
		Patient felling lonely	7	
		Patient feeling sad about situation	13	
		Patient not feeling part of society	4	
		Patient being afraid of own health and future	10	
		Patient feeling emotional about the situation	7	
		Cancer makes life uncertain	10	
		Depression and uncertainty is common for cancer patients	3	
		Patients feel frustration and anger for having cancer	2	
		Emotional and mental health of patient are effected, need to find a way	20	
		Confusion and uncertainty	3	
		Dealing with mental health	2	
		Being afraid of the unknown	9	
		Feeling depressed, anxious and alone	51	
		Cancer has a big influence on the emotional state of the patient, it can	13	
		Fear and insecurity are part of daily life of patient	23	
	Need to find a way to deal with unpleasant side effects that influence the QoL during/after treatment	Cancer and therapy can be a tough process	33	478
		Side effects treatment reduce QoL	65	
		Unpleasant experience of pain, symptoms or side effects	13	
		Addiction to pain killer	4	
		Different attitude dealing with hair loss	9	
		Dealing with hair loss / hair issues	9	
		Dealing with nausea	4	
		Dealing with side effects	24	
		Different hacks to manage drinking water	10	
		Hormonal medication dealing with side effects	4	
		Side effects of therapy	42	
		Skin side-effects	6	
		Cancer & side effects brings pain and uncomfort	44	
		Patient doesn't want to become bald	4	
		Patients have memory problems	2	
		Patients struggle to deal with side effects	12	
		Complications from treatment can be permanent	13	
		Having concentration problems after treatment	9	
		Patient experiencing much pain during cancer process	2	
		Patient not knowing how to deal with the situation	4	
		Patient suffering from side effects of cancer treatment	38	

		Patient suffering memory loss due to treatment	7	
		Treatment is changing the body of patient	3	
		Using music as a medicine	1	
		Using humor as a medicine	5	
		Using pain medicine		
		Cancer brings new problems in each phase	5	
		Insecurity attached to new look	3	
		Side effects of treatment influence patient life	10	
		Mental stress from side effects and dealing with them	19	
		Preparing oneself for treatment	4	
		Worry about side effects and symptoms	5	
		Patient undergoing treatment and dealing with side effects (mental and	32	
		Dealing with side effects	33	
	The importance and difficulty of having a healthy diet, active lifestyle and doing what you wan to do while dealing with less energy / fatigue	Difficulty of keeping healthy lifestyle, activity level or diet	2	223
		Constantly feeling exhausted and fatigue	4	
		Important to feel good	1	
		Dietary changes	10	
		Sleeping difficulties and remedies	2	
		Diets/eating problems	25	
		Dealing with fatigue	7	
		Exercise has major benefits on the patient's wellbeing	18	
		Nutrition & lifestyle	18	
		Sleeping issues/experiences during the cancer journey	6	
		Keep doing important activities, whatever it takes	8	
		Being tired is often in the way of being able to do whatever patients wa	23	
		Patient need intrinsic motivation	7	
		Patients want to stay fit	2	
		Not being able to do things patient wants due to cancer	11	
		Patient has very low energy level	17	
		Physical exercise benefits recovery of patient	19	
		Wanting to prepare for treatment	2	
		Patient is feeling tired most of the time	11	
		Accepting that daily life needs to change is difficult	2	
		Physical fitness is a big part of cancer and is encouraged	1	
		Pain and sleeplessness comes together and often interupts daily routi	1	
		Treatment effects tastes buds, changing the diets of patient drastically	1	
		Quiting smoking and bad habits	8	
		Dealing with fatigue	8	
		Diet and physical activities during cancer	9	
	Recovery takes time, you need to find your own way and pace of recovering	Recovering from cancer takes time	27	115
		Concerns toward recovery	1	
		Difficulties during recovery	2	
		Healing process after treatment can be a challenge	1	
		Creating an own recovery plan	7	
		Recovering in a safe environment	3	
		Patients are impatient in their recovery	2	
		Patient need to find their own pace of doing things	31	
		Patients tend to start too fast when building up their life again	4	
		Patient has to take it slow during recovery process	6	
		Patient listens to body	6	
		Patient looking for guidance during cancer and recovery process	10	
		Period after treatment is very heavy	4	
		Living with cancer is chaotic, you need to find a routine and adapt	7	
		patient focusses on recovering	4	
	Patient discussing treatment	Surfacing of other health problems	3	74
		Patient can have unexplicable side effects	5	
		Patient talks about progress of treatment/illness	41	
		Getting additional treatment to reduce/solve residual complaints	9	

		Alternative medication / clinical trials	14	
		Some medicine is hard to get	2	
	COVID makes the cancer journey even more difficult	Concerned for COVID precaution in hospital	5	74
		COVID is worst than cancer	5	
		COVID isolation being alone / no accompany challenges	9	
		COVID messing up treatment schedules	6	
		Worried of getting COVID due to hospital visits and low immune systen	10	
		Knowing what to do with COVID is a relief	4	
		Covid impacts on cancer patients	6	
		Importance of face-to-face contact	3	
		Patients appointments get postponed	5	
		Patients are extra careful with corona	7	
		Beside of cancer, another problem	8	
		Corona makes it even harder	6	
	Moods can change very fast	Moods can change very fast	13	65
		Emotional rollercoaster	31	
		The journey of cancer is an emotional rollercoaster	8	
		Bad news has a big role in the process	13	
	Importance mental health	Importance of mental health & wellbeing	13	70
		Losing the connection with your body/feelings	20	
		Help of psychologist can be very valuable	2	
		Patient's head are often overflowing with thoughts	6	
		The mental part is perceived even harder than the physical part of havi	2	
		Cancer and treatment influences patients mental state	9	
		Patient needs psychological help in recovery process	5	
		Cancer has a big influence on the emotional state of the patient, it can	13	
	Fighting cancer	Patients feel like they fail when they don't beat cancer	2	27
		Patients are determined to survive	9	
		Seeing cancer as a fight	6	
		Patients attack cancer like it is a person they hate	2	
		Cancer is about fighting and surviving	8	
	Staying positive and hopeful, enjoying the little things and victories	Be positive	35	296
		Hopes during treatments	8	
		Getting better after treatment	4	
		Inner-strength to stick through cancer journey	5	
		Focus on the positive things	28	
		Enjoying the little things in life	11	
		Positive memories help the patient	2	
		Small improvements give a lot of hope to hold on to	15	
		Being outdoors is somethings patients enjoy	3	
		Cancer made patients more emotional and aware of beautiful (little) thi	17	
		Humour is important	3	
		Patients are looking for hope	6	
		Patient live day by day	4	
		Patients look for positivity in the negativity	10	
		Patient looking forward to surgery	1	
		Small steps forward feel like big achievements	12	
		Being happy with what is still possible	6	
		Feeling grateful to be/feel healthy	7	
		Patient and family living in the moment	2	
		Patient being happy with current treatment	5	
		Patient enjoying last part of life	11	
		Patient feeling happy with recovery progress	6	
		Patient hoping on further recovery in the future	5	
		Patient keeping up a positive attitude	12	
		Using humor as a medicine	5	
		Falling sick makes people revalue life and behave better	2	
		Stying positive and humoristic is important	8	

		Positive attitude	10	
		Patient learned that he/she needs to enjoy what's still there, positive ar	53	
	Seeking distraction	Moments of relief	2	38
		Taking a break from cancer	1	
		Looking for distraction to not think about the illness	9	
		Patients are looking for distraction	12	
		Patient looking for distracting activities	3	
		Trying to find distractions from horribe situation	9	
		Important to keep occupied and distracted	2	
	Patient wants to be normal	Patient still wants to be self-reliant	4	48
		Patient want to live like and be treated like a normal person	17	
		Patient find it complicated to deal with labels like brave	2	
		Patients want to feel useful	3	
		Patient can lose oneself during cancer process	7	
		Need to be treated normaly and normalise things	3	
		Patient longs to return to normal life	12	
	Accepting the new you	Accepting the new you	23	63
		Reaching a moment of realisation and acceptance	3	
		Patience is needed to adapt to new life	18	
		Patient needs to accept the situation	13	
		Advice to deal with life when on a time limit	1	
		Patient acknowledges and accepts the effects of cancer	1	
		Being prepared for what's to come	4	
	Putting things in perspective to make the situation more bearable	Patients compare themselves with others to put their situation in perspe	7	45
		Putting the situation into perspective to make it less sad	8	
		Trying to put things in perspective to make situation bearable	14	
		Moments of reflection	16	
	Patient worries about others and about what others think of them, therefore they hide feelings while it is important to show your emotions to others	Patient worries about suffering of others	12	103
		Patients don't want to bother anyone with their stories	8	
		Patient feel like they are complaining	3	
		Patients struggle to deal with expectations of others	3	
		Patients don't want to bother anyone with their stories	8	
		Patient feeling guilty towards environment about being ill	5	
		Patient hiding feelings from family/environment	12	
		It is important to show your emotions during the process	6	
		Patients want to ignore their situation	4	
		Avoiding the confrontation	6	
		Patients tend to bottle up their feelings	7	
		Patient trying to make family feel good	3	
		Sudden dependence on other people	2	
		Patient feels guilt for putting family through stress	1	
		Protecting family, concerned for them	8	
		Worried for family and telling about cancer	5	
		Feeling guilty for others	4	
		Feeling guilty for others	6	
Living on	Cancer changes you and your attitude in life, but also in a positive way	Traumatic experience both mentally and physically	2	83
		Cancer changing perspective in life	3	
		Cancer impacts your daily life	39	
		Change in attitude in life	10	
		Patients have to rediscover themselves after they are cancerfree again	8	
		Cancer can enrich your life	11	
		Find more meaning in life	3	

		You, your life and relationships change	7	
	Cancer stays in someones life for a long time, need to find a way to continue	Going to check ups	5	46
		Cancer stays in someones life for a long time	5	
		Hard to move from survival mode to living mode	1	
		It is hard for patient to have trust in own health again	7	
		End of treatment is not always a happy ending and patients feel anti-cli	1	
		Challenging to recover from cancer	2	
		Life goes on, getting back on track	7	
		Wanting to return to normal life after treatment	16	
		Choosing (new) activities to indicate that life continues	2	
	Fear of cancer coming back	Worried of recurence of cancer	7	46
		Fear of cancer coming back	10	
		Fear of relapse	6	
		Feeling afraid of cancer in the future	10	
		The worry about cancer never stops	7	
		Fear of recurrence	6	
General	Importance of a trusting, empathic and informative relation with medical team	Being refused by healthcare system/professional	4	260
		Disappointment and distrust towards medical system/ professionals	15	
		Felt not well-informed by health care professionals	2	
		Silos in medical teams	3	
		Felt reassured and built trust with healthcare professional	9	
		Supportive medical system/professional	7	
		Communicating with medical team	4	
		Medical staff is important in the patient's cancer journey	10	
		Patient expect pro-active approach from hospitals	2	
		Patients appreciate friendly, human doctors and assistants	10	
		Patients don't like doctors to be too formal	1	
		Patients get annoyed with doctors	4	
		Patient need help from others because they cannot understand and rei	2	
		Patients value expertise of doctors and hospitals	7	
		Way of communicating results is important	4	
		A good relationship with the doctor is important	6	
		Information is not well communicated by doctor/hospital	14	
		Not trusting hospital and doctors	11	
		Patient feeling abandoned by doctors	8	
		Patient has more trust in experienced hospitals	4	
		The hospital has communication errors	3	
		The process involves multiple doctors and hospitals	9	
		Wanting more attention of doctors for side effects of complications	2	
		Experienced hospital staff gives trust in situation	6	
		Friendly and genuine hospital staff is apreciated by family	22	
		If doctors do not take the time to communicate clearly, the family and patient lose trust in advice	14	
		Doctor-patient relationship is crucial, a level of comfort is needed	4	
		Negligence during the treatment can add to the stress of cancer	1	
		Multiple specialists involved in the treatment	1	
		Involving a trusting and empathic healthcare professional is important	10	
		Doctors and nurses are important for providing professional assurance	14	
		Importance of doctor taking patient seriously	5	
		Patient talks about medical staff, need for them to be empathic in their	42	
	Fear of the hospital	Uncomfortable hospital stay	2	32
		Scary first time hospital visit or treatment experience	5	
		Gint to the hospital can be a complex journey	1	
		Intense memories arise when coming back to certain settings from earl	2	
		Patient feeling afraid of hospital checkups	10	
		Hospital visits are always tense	12	

	Patient is not understood by the environment which creates a change in social life, patient needs to discover how to communicate with others about cancer	Finding difficulties in sharing feelings	3	160
		Not being understood by others	1	
		How to comfort or communicate with patients	6	
		Unhelpful comments from others	5	
		Ways of talking about cancer to other people	26	
		Social life when having cancer	2	
		Not being understood by the environment	14	
		Don't try to relate to the patient as if you understand	5	
		Offers to help should be specific	4	
		Patients feel that people don't know how to respond to their situation	4	
		Cancer changes the way people look at patient	4	
		Environment forgetting patient is still ill	10	
		Environment has no understanding for patient's situation	17	
		Environment is confronting patient with cancer	2	
		Environment is discouraging the recovery of patient	4	
		Environment not knowing how to deal with situation	8	
		Feeling socially excluded during and after cancer process	4	
		Cancer is affecting patient's private and social life	5	
		Cancer patients feel invisible and detached from society	1	
		Patient finds priority in people in their lives	4	
		Patient does not feel understood or supported by family and friends	11	
		Not being understood by environment and effect on relationships	11	
		Less social interaction	4	
		people around patient can say bad things	5	
	The importance of supporting family and friends	Feeling loved	2	183
		Importance of having a close support system	10	
		Friends, family & community support	13	
		Activities and support from family and friends is important	15	
		Empathy and understanding from others is very important	11	
		Acts of friends and family are heartwarming	11	
		Family and friends are most enjoyable things in patient's life	10	
		Friends and family are biggest support	14	
		Patient appreciates everyone who sends a message	3	
		Close family taking care of patient	3	
		Patient feels supported by the family/environment	20	
		Patient appreciates support from family	6	
		Cancer is not a solo journey but sharing with loved ones makes it easy	1	
		Important to have support of family and friends	3	
		Importance of family support	3	
		Communication and understanding between family and patient is impo	17	
		Patient does not feel understood or supported by family and friends	11	
		Patient is happy with family and friends, gets supported	30	
	Importance of communicating and sharing with peers	Feel resonated seeing others with same experience	2	268
		Getting support from online forums	7	
		Power of peer support	3	
		Eager to seek others opinion or advice	1	
		Sharing information and story	33	
		Forum community	10	
		Friends, family & community support	13	
		Urge to share with/help other patients	33	
		Cancer patients in similar situations support each other	5	
		Patients are looking for confimration and recognition form other patient	6	
		Patients look for interaction with other patients	10	
		Patients share their experiences very detailed to help others	13	
		Reading and writing blogs help patients to come to terms with themsel	11	
		Explaining about current state of cancer	7	
		Patients often share poems to express their feelings	3	
		Explaining about treatment process	16	
		Patient looking for advice how to approach situation	13	
		Patient looking for fellow sufferers	12	

		Patient needs outlet for feelings	6	
		Patient recognizing themselfs in other patients stories	7	
		Showing support to other patients	19	
		Looking for support from other families of patients	15	
		Wanting to be there for others that go through cancer process	3	
		Sharing helps in dealing with cancer	5	
		Connection with peers and talking is important	15	
Family	Family is worried about patient and fears the future	Difficult knowing friends or family getting cancer	1	101
		Family feeling worried and sad about situation of patient	5	
		Family is concerned about patient	22	
		Family member feeling afraid of future of patient	22	
		Having doubt about the process	9	
		It is hard to think about the future or make future plans with cancer in fa	18	
		The worry about cancer never stops	7	
		Fear of losing is prominent	1	
		Fear of future and losing patient	13	
		Family is concerned for patient	3	
	Family needs to deal with loss	Difficulties griefing for loss	19	68
		Helpful ways dealing with loss	8	
		Family remembering deceased patient	10	
		Families have different ways of coping with loss	1	
		Family slowly says goodbye to patient during process	6	
		Losing someone is painful and takes time to process	11	
		Important to remember the good times	2	
		Hard to have family with cancer and say goodbye	11	
	Family takes care of patient and wants to do anything to help/comfort patient	Family is care taker of patient	10	56
		Role and experience of caregiver	3	
		Family wanting to do anything to help and comfort patient	21	
		Wanting patient close by all the time	9	
		Family want to know what they can do for patient, they gather informati	13	
	Cancer also has a big (emotional/mental) impact on the lives of family members. They need to find a way to deal with the situation and not lose themselves (not always put the patient first)	Family and friends also get dragged into the rollercoaster	17	264
		Cancer controls families and patients lives	3	
		Cancer has impact on the whole family of patient	6	
		Family member feeling alone	4	
		Family needs professional psychological help to deal with the situation	11	
		Family not knowing how to deal with the situation	16	
		Hospital visits are always tense	12	
		It is hard for family members to keep up with normal life	7	
		Cancer takes up a lot of family members' time	7	
		Family wishing everything went back to normal	12	
		Going to work is difficult for family member	6	
		Hard to get back on track after cancer process	11	
		Taking care of patient affect mental and physical health of family memb	19	
		Family member hiding own feelings	15	
		The process is emotionally tough for family members	40	
		Family members go through emotional rollercoaster	3	
		Balance helping yourself (personal hapiness) and caring for partner, de	34	
		Mental health of family is also important to take into account, they nee	37	
		Mental health of family is also effected	4	
	It is imporant to talk about feelings and situation	Talking about it helps to cope with situation	11	67
		Family member hiding own feelings	15	
		The importance of staying positive and supporting each other, transpar	24	

		Communication and understanding between family and patient is impo	17	
	Family feels powerless	Feeling like being in a terrible period	17	87
		Feeling sad angry and powerless	36	
		It is hard for family member to see patient in pain	22	
		Traumatic for family members to witness their loved ones with cancer	2	
		Family feels helpless/ powerless	10	
	Family is involved in the medical process and hospital visits of the patient	Family is involved in hospital process	4	81
		Being unable to get a hold of a doctor	2	
		Family describing events happening during and around the hospital	20	
		Family is involved in medical process of patient	7	
		Feeling disasapointed to get delay in the process	3	
		Feeling left out of or not understanding medical information	7	
		If doctors do not take the time to communicate clearly, the family and patient lose trust in advice	14	
		There is a lot of waiting in the process	14	
		Involving a trusting and empathic healthcare professional is important	10	
	Family looking for information and education on cancer and how to help patient	Family member wanting to educate about cancer	10	35
		Family wanting to know and learn all information about cancer	12	
		Family want to know what they can do for patient, they gather informati	13	
	Family is in shock by unexpected diagnosis, need to find a way to deal with bad news	Cancer diagnosis often comes unexpected	8	42
		Family feeling in shock	14	
		Ignorant of cancer untill it happens to someone close	4	
		Family shocked from news	3	
		Family dealing with receiving bad news	7	
		It is hard to tell bad news to family/friends	6	
	Also for the family a lot happens when going into the hospital mill	A lot of events happen/need to happen in a short time period	12	14
		Some hospital investigations are going to feel like a routine	2	
	Family wants to talk about the treatment of patient and how the patient is doing	Patient undergoing chemotherapy	6	34
		Family member wants to tell how patient is doing	21	
		Additional complaints/side effects cause setback in treatment process	7	
	Cancer puts tension on relation between family members	Cancer is changing behaviour of patient	16	121
		Cancer puts tension on relation between family members	15	
		Patient acting ignorant about the situation	10	
		Patient not wanting to accept help	1	
		Family as emotional outlet	2	
		Patient's personality changes drastically	1	
		Change in relationship, due to behaviour change patient and lack of ap	31	
		Patient changes perspective in life and can become negative	18	
		Stained relationships	12	
		Cancer has a negative impact on family relationship	15	
	Cancer causes beautiful moments between family members	Cancer causes beautiful moments between family members	21	42
		Cancer changes perspective on life	8	
		Family being happy and grateful for the time they still have with patient	13	
	Frustration with environment that does not understand their situation	Environment is confronting family with cancer	13	32
		Family feeling not being understood by environment	9	

		Family member getting frustrated with people in environment	4	
		Not many people are fully supporting the patient	6	
	Positivity and hope, wanting the best for patient	Family admires patient being strong and positive	14	87
		Family always hopes for patient healing	10	
		Family encouraging themself to stay strong in the situation	9	
		Family feels happy when treatment is working	15	
		Feeling relieved about events happening in process	9	
		The importance of staying positive and supporting each other, transpar	24	
		Family wants the best for patient and want to enjoy time left	6	
	Family are a team with the patient	Family and patient accepting what needs to be done to treat cancer	8	16
		Family makes important decisions together	5	
		Cancer is not a solo journey but sharing with loved ones makes it easy	1	
		Fighting cancer as a team	2	
	For families it is also important to communicate with peers and seek support	Wanting to be there for others that go through cancer process	3	53
		Looking for support from other families of patients	15	
		Importance of support from extended families and their responsibilities	5	
		The importance of communicating with peers and support groups for th	19	
		Reaching out for help is important and is stimulated when there are kid	4	
		The importance of connecting to people who know how to help	7	
	Family tries to find ways to distract themselves and put things in perspective	Trying to find distractions from horribe situation	9	23
		Trying to put things in perspective to make situation bearable	14	
	Financial burden on family members	Family members need to make tough decisions and are under financia	4	19
		Insurance and finance worries of family	9	
		Mental stress from finances	6	

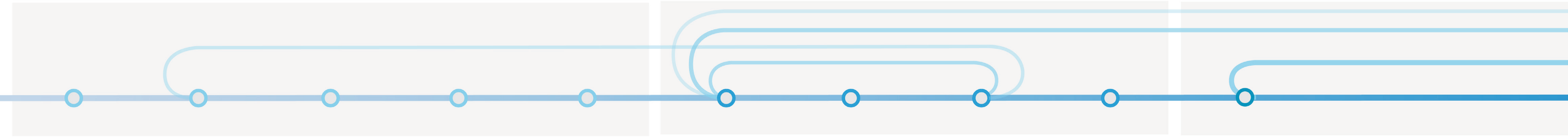
Appendix D.

General cancer patient concern journey

Cancer Patient Experience

	Diagnosis					Testing					
Journey steps	The start	Hearing the diagnosis	Seeking more information	Processing	Telling others	Doing tests	Waiting for results	Hearing results	Making a decision on treatment	Undergoing treatment	
Environment	🏠 🏥	🏥	🏠	🏠	🏠	🏥	🏠	🏥	🏠 🏥	🏥	

Journey Flow



Quantified patient experience

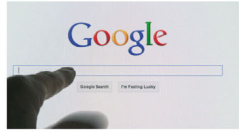
Small health complaints 39

Cancer often starts with small health complaints.

The big change 91

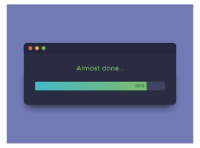
The ground falls away beneath you when you hear the diagnosis, life is set to change.

Information 141



The importance of information availability and transparancy in a way that is not overwhelming.

Processing 41



It takes time to process the information and the emotions that come with it

Delivering the bad news 19

Difficult to deliver the news to family or others.

Inside a fast moving train 36

Stepping aboard the fast moving train of different hospital tests.

Stress while awaiting results 119

Waiting for the test results is stressfull you need to find a way to make the waiting time more bearable.

Making a big decision 242

Being well informed and thinking about pro's and con's (quality vs quantity of live) helps patients to make tough decisions in which they want to have a say in.

Talking about treatment 74

Patient discusses treatment and talks about procedures.

Fighting cancer 27

Seeing cancer as a fight you need to win.

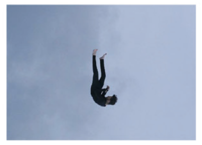
Dealing with side effects 478

You need to find your own way to deal with the unpleasant side effects caused by the treatment.

Emotional Journey Patient

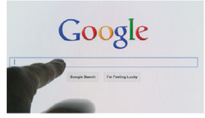
Quantified family experience

The shock 42



Family is in shock by unexpected diagnosis, need to find a way to deal with bad news.

Information 35



Family looks for information and education on cancer to know how to help patient.

Inside a fast moving train 14

Also for the family a lot happens when going into the hospital mill.

One team 16

Family is a team with the patient and want to help with the decision.

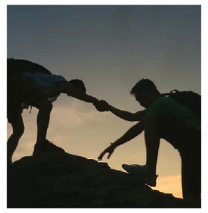
Involved in medical process 81

Family is involved in the medical process and goes to the hospital visits together with the patient.

Talking about treatment 34

Family wants to talk about the treatment of patient and how the patient is doing

Family as caretaker 56



Family takes care of patient and wants to do anything to help comfort the patient.

Self care

Cancer also has a big (emotional/mental) impact
lives of family members. Th
need to find a way to deal v
the situation and not lose
themselves (not always put
patient first).

Treatment and side effects

Dealing with side effects and recovery

Life after cancer

From surviving to living

Check ups

Dealing with side effects
478

You need to find your own way to deal with the unpleasant side effects caused by the treatment.

Diet & physical activity
242

Patients find it important but difficult to have a healthy diet and active lifestyle while dealing with less energy and fatigue.

It takes time
115

Recovery takes time you need to find your own way of doing this and taking the time.

Seeking distractions
38

Patient looks for distraction in nature, hobbies or people.

Working
85

Working while being in treatment can help with the mental health but it is important to be flexible to deal with challenges of treatment.

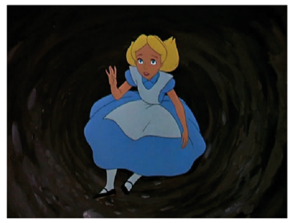
Stay positive
296

Patients tries to stay positive and hopeful, enjoys the little things and small victories.

Mental health
70

It is important for the patient to be mentally healthy and to seek help if needed.

Dark thoughts
304

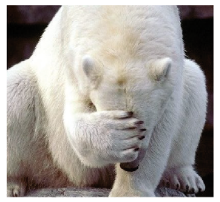


Getting sucked into a dark place, and how to get out. Patient has feelings of depression, anxiety, sadness and loneliness.

Emotional rollercoaster
65

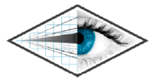
Moods of patient can change very fast from positive to negative.

In hiding
103



Patient worries about others and about what others think of them, therefore they hide feelings while it is important to show your emotions to others.

Perspective
45



Putting things in perspective to make the situation more bearable.

Normal
48

Patient wants to be normal and go back to how things were.

The new you
63

Need to accept the new you, new limitations but also possibilities.

Change
85

Cancer changes you but also in a positive way.

Fear
46

Patient keeps fearing that cancer comes back.

Cancer stays in life
46

Cancer stays in your life for a long time even if you don't see it on the surface. You need to find a way to continue.

n/ discomfort

Positive / inventive

Fatigue

Motivated

Frustrated

Distracted

Happy

Depressed

Anxious

Hopeful

Alienated

Acceptance

Peace

Fear

Family as caretaker
56

Family takes care of patient and wants to do anything to help comfort the patient.

Self care
264

Cancer also has a big (emotional/mental) impact on the lives of family members. They need to find a way to deal with the situation and not lose themselves (not always put the patient first).

Social tension
121

Cancer puts tension on relation between family members. Need to deal with change of patient.

Importance of talking
67

It is important for family members and patients to talk about their feelings and the situation.

Seeking distractions
23

Family tries to find ways to distract themselves and put things in perspective

Financial burden
19

Family members have to worry about the financial affairs.

Positivity
87

The family is positive and hopes the best for the patient.

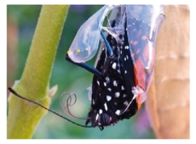
Powerless
87

The family feels powerless. Their family member is in pain and they cannot or don't know how to help.

Fear for the future
101

Family is worried about the patient and fears the future.

Beautiful moments
42



Cancer causes beautiful moments between family members.

Dealing with loss
68

When the patient does not make it the family are left and need to deal with this loss.

General factors that influence journey

Important relationships

Quantified patient experience

Medical team
260

It is Important to have a trusting, empathic and informative relation with your medical team. Patients talk about good and bad examples..

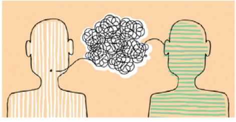
Peers
268

Patients stress the importance of communicating with peers. Both for sharing your story and hearing stories from others.

Family & friends
183

Support from family and friends is very important for the patient.

Misunderstood
160



Patient is not understood by the environment which creates a change in social life, patient needs to discover how to communicate with others about cancer.

Quantified family experience

Family peers
46

For families it is also important to communicate with peers and seek support.

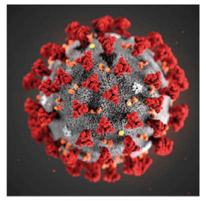
Misunderstood
46

Family feels frustrated with the environment that does not understand their situation.

Extra barriers

Quantified patient experience

Corona
74



COVID makes the cancer journey even more difficult for patients.

Hospital fear
74

Some patients fear the hospital and are reluctant to go to the hospital.

Appendix E.
Topic descriptions and formation HNC computational analysis

topic_distrbution

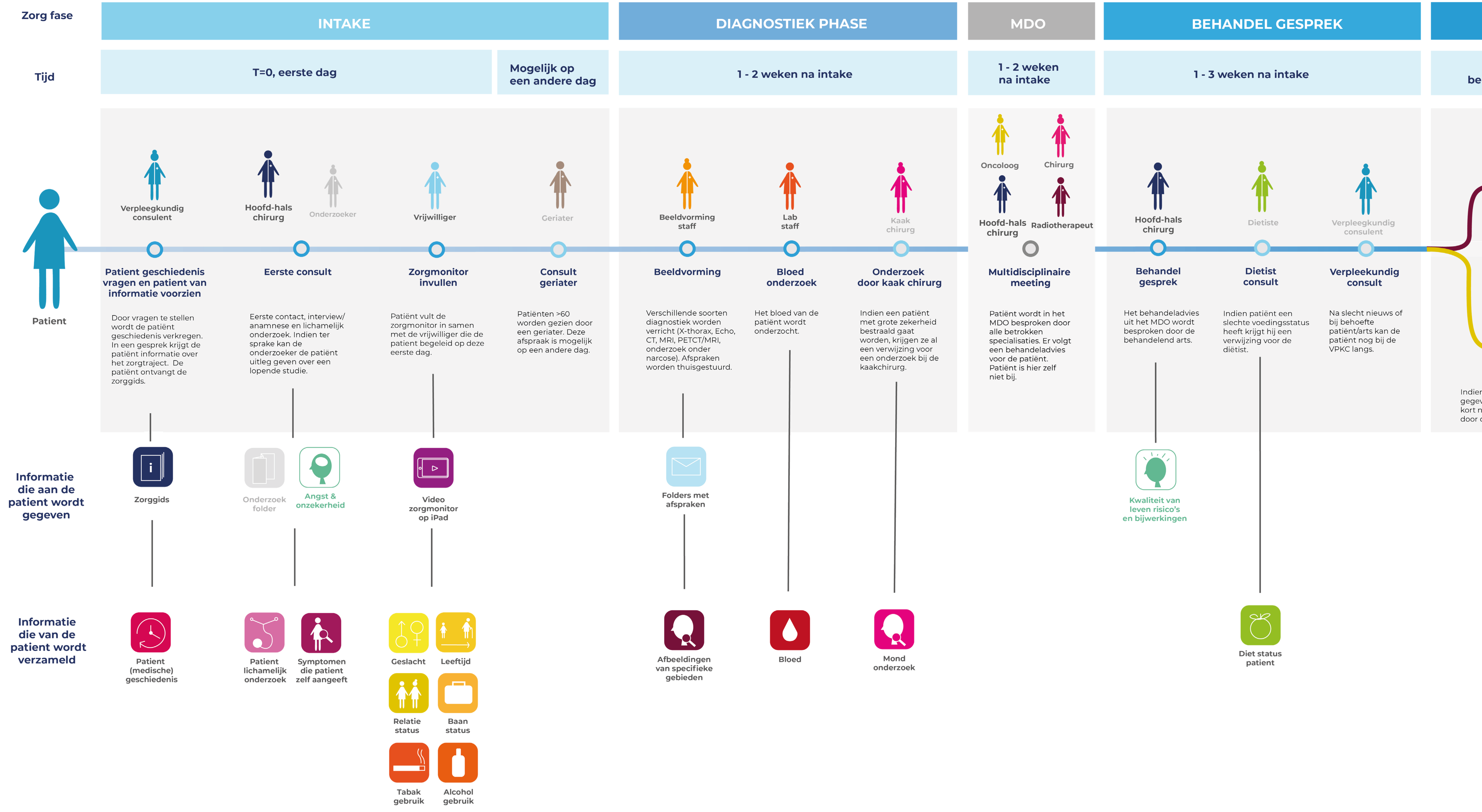
Topic	Topic_Keywords	Num_Texts	Perc_Texts	Topic description
1.0	soup, soft, calorie, dietician, meal, ensure, add, diet, milk, cream	1790	0.0596	**Questions and tips for what you can eat in your recovery phase and how you can make it eatable**
17.0	saliva, mucus, ulcer, buy, burn, cough, mouthwash, rinse, spray, product	1705	0.0568	**Tips for doing mouth care and what products to use for a dry/sensitive mouth and to deal with the mucus problem**
7.0	wife, man, fight, daughter, son, child, strength, age, heart, young	1554	0.0517	**Effect on and support from loved ones**
3.0	symptom, specialist, nose, test, worried, refer, ent, blood, voice, concern	1543	0.0514	**Experiencing symptoms that might be cancer creates worry. Patients are referred to ent specialists to do diagnostic testing. This stage makes them feel anxious and worried (need guidance here)**
6.0	spread, lymph_node, primary, mri, left, sign, large, cell, gland, lung	1518	0.0505	The type of cancer, spread, primary tumor place and the treatment process differ from person to person. Patients undergo diagnostic tests to get personal information on their disease.
2.0	information, forum, party, join, link, line, number, member, thread, medical	1494	0.0497	**Patients are looking mostly for information on treatment, side effects and late effects of treatment. The forum is where they find most information on this.**
13.0	skin, exercise, heal, scar, speech, flap, arm, muscle, shoulder, swell	1476	0.0491	**Dealing with side effects of surgery: Doing exercises (physio suggested) and discussing healing process of scar.**
0.0	regard, suggest, kind, story, carcinoma, book, dissection_reconstruction, flap_postoperative, holiday, co	1388	0.0462	Patients discuss holiday and how to arrange it with travel insurance (money matters). Patients sharing cancer stories and suggestions.
14.0	return, dani_squamous, continue, update, progress, hpv, fingers_crosse, pleased, quick, therapy	1202	0.04	Discussing HPV specific concerns
9.0	rest, half, tired, walk, step, fatigue, road, ready, plenty, sense	1192	0.0397	**Dealing with fatigue: slowly increasing the amount of exercise/walks, get enough rest**
16.0	write, message, phone, chat, forget, contact, add, profile, ring, detail	1193	0.0397	**Keeping peers updated on your own terms. Making new peer friends.**
8.0	bed, eye, minute, sit, spend, watch, close, drive, listen, move	1186	0.0395	**Preparing for treatment and ways to pass the time in the hospital.**
12.0	relief, morphine, drug, painkiller, painful, hurt, prescribe, tablet, dose, liquid	1168	0.0389	**Questions and tips on how to relief pain and what painkillers to use**
5.0	pay, job, local, health, lucky, nhs, form, medical, system, benefit	1136	0.0378	**Job related issues and financial questions**
20.0	sick, rig, stomach, med, nausea, admit, ensure, awful, nutrition, fluid	1135	0.0378	**Feeling sick (from feeding tube/pump) and ensuring you still get enough nutrition**
10.0	type, option, decide, explain, outcome, decision, cure, chance, info, discuss	1071	0.0357	**Making a decision between treatment options is not always possible but it is important to be informed on the potential outcomes and side effects**
21.0	yesterday, meet, touch, honest, date, guy, lol, bring, totally, lovely	1072	0.0357	**It is a positive experience to meet peers, share stories and help each other.**
23.0	partner, infection, feeling, turn, fear, scary, situation, scare, stress, horrible	1071	0.0357	**Experiencing negative feelings of fear and stress. Partner being worried for patient.**
22.0	dentist, low, top, jaw, dental, bone, mine, oral, leg, bite	985	0.0328	**Experiencing dental/mouth Issues (after jaw surgery). Concerns on reconstruction of jaw and some appearance changes.**
19.0	realise, nice, amazing, light, wonderful, lovely, cold, share, lucky, wear	949	0.0316	**Giving practical clothing tips for what to wear against the cold and against sunburn.**
18.0	affect, afraid, floor, concern, extremely, main, person, procedure, reaction, depend	901	0.03	Procedures and reactions depend per person
4.0	stuff, slowly, tip, stick, lack, improvement, appetite, eating, hot, slow	897	0.0299	**Tips for eating issues and lack of appetite**
15.0	advise, chemotherapy, cisplatin, loss, complete, difference, ear, due, hair, short	815	0.0271	**Dealing with hearing loss and hair loss due to treatment**
24.0	quickly, guess, move, imagine, ahead, grateful, process, prepare, begin, shock	754	0.0251	**The shock of getting diagnosed with cancer and the rollercoaster process of having cancer**
11.0	word, metastatic_scc, run, fact, learn, load, pass, describe, wake, bother	842	28	**Peer support and understanding in dealing with physical and psychosocial side effects**

Final topics

Eating problems	Follow-up	Treatment
Dry mouth	Follow-up	
Muccus problem	Follow-up	
Effect on and support from loved ones	Follow-up	
Guidance with fear/worry		First consult
Quality of life and treatment/ side effects		Before treatment
Physical effects and recovery surgery	Follow-up	
Dealing with fatigue	Follow-up	Treatment
Physical activity	Follow-up	
Support from peers	Follow-up	
Ways to pass the time		Treatment
Relieving pain	Follow-up	Treatment
Job issues	Follow-up	
Feeding tube	Follow-up	Treatment
Dental issues	Follow-up	
What to wear (against cold/sunburn)		Treatment
Hearing loss	Follow-up	
Negative feelings	Follow-up	Treatment
Feeling sick	Follow-up	Treatment

Appendix F.
HNC patient care trajectory and information journey

Hoofd-halskanker patient zorgtraject en informatie reis



Zorg fase

Tijd

Patient

Informatie die aan de patient wordt gegeven

Informatie die van de patient wordt verzameld

INTAKE

T=0, eerste dag

Patient geschiedenis vragen en patient van informatie voorzien

Door vragen te stellen wordt de patiënt geschiedenis verkregen. In een gesprek krijgt de patiënt informatie over het zorgtraject. De patiënt ontvangt de zorggids.

Eerste consult

Eerste contact, interview/ anamnese en lichamelijk onderzoek. Indien ter sprake kan de onderzoeker de patiënt uitleg geven over een lopende studie.

Zorgmonitor invullen

Patiënt vult de zorgmonitor in samen met de vrijwilliger die de patient begeleid op deze eerste dag.

Mogelijk op een andere dag

Consult geriater

Patiënten >60 worden gezien door een geriater. Deze afspraak is mogelijk op een andere dag.

DIAGNOSTIEK PHASE

1 - 2 weken na intake

Beeldvorming

Verschillende soorten diagnostiek worden verricht (X-thorax, Echo, CT, MRI, PETCT/MRI, onderzoek onder narcose). Afspraken worden thuisgestuurd.

Bloed onderzoek

Het bloed van de patiënt wordt onderzocht.

Onderzoek door kaak chirurg

Indien een patiënt met grote zekerheid bestraald gaat worden, krijgen ze al een verwijzing voor een onderzoek bij de kaakchirurg.

MDO

1 - 2 weken na intake

Multidisciplinaire meeting

Patiënt wordt in het MDO besproken door alle betrokken specialisaties. Er volgt een behandeladvies voor de patiënt. Patiënt is hier zelf niet bij.

BEHANDEL GESPREK

1 - 3 weken na intake

Behandel gesprek

Het behandeladvies uit het MDO wordt besproken door de behandelend arts.

Dietist consult

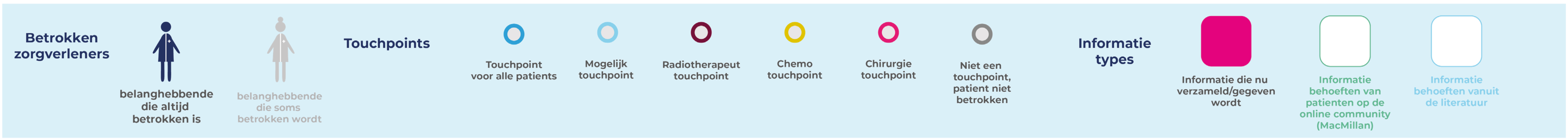
Indien patiënt een slechte voedingsstatus heeft krijgt hij een verwijzing voor de diëtist.

Verpleekundig consult

Na slecht nieuws of bij behoefte patiënt/arts kan de patiënt nog bij de VPKC langs.

Indier
gegev
kort n
door

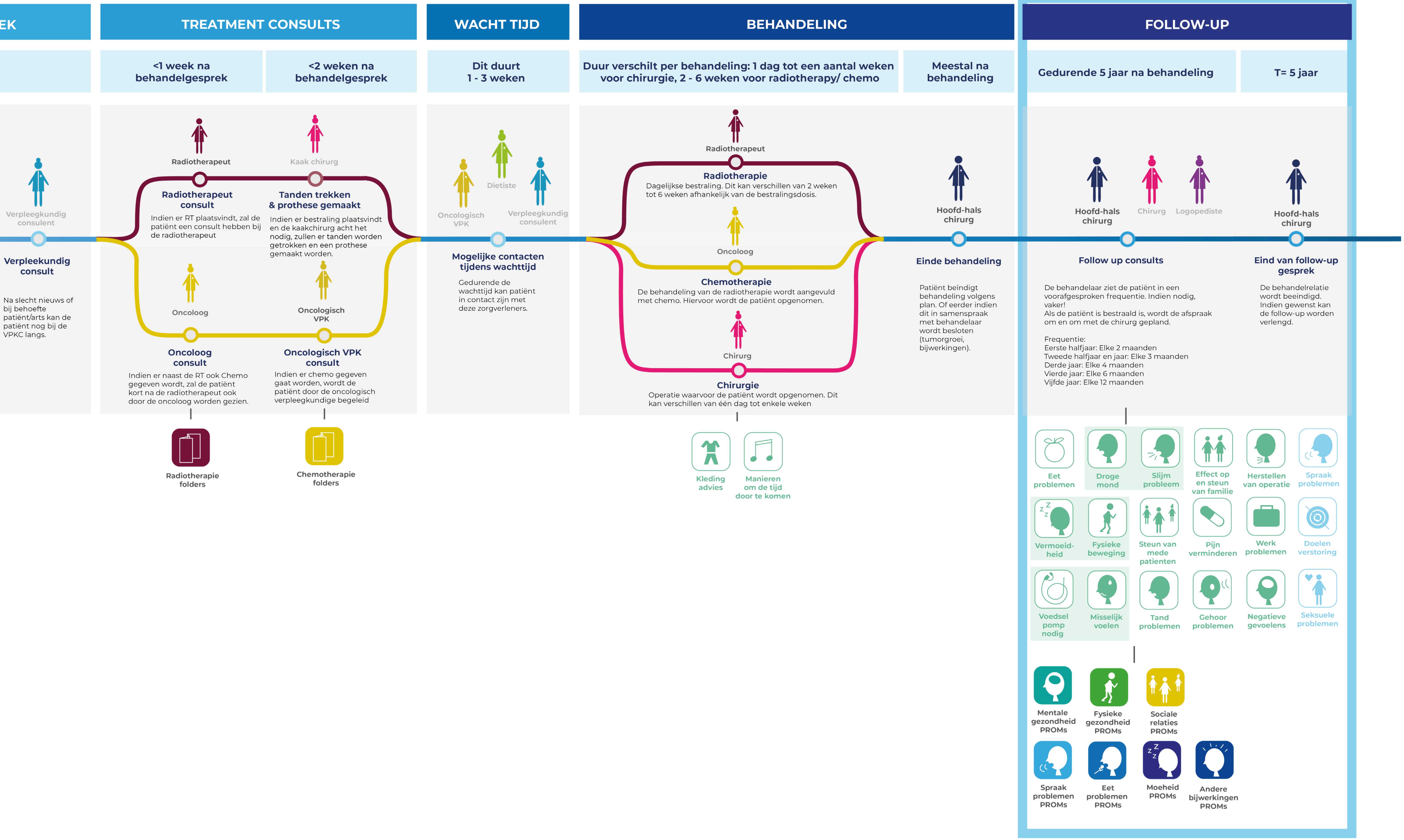
Legenda



Betrokken zorgverleners

Touchpoints

Informatie types



EK

Verpleegkundig consulent

Verpleekundig consult

Na slecht nieuws of bij behoefte patiënt/arts kan de patiënt nog bij de VPKC langs.

TREATMENT CONSULTS

<1 week na behandelgesprek

<2 weken na behandelgesprek

Radiotherapeut

Radiotherapeut consult

Indien er RT plaatsvindt, zal de patiënt een consult hebben bij de radiotherapeut

Kaak chirurg

Tanden trekken & prothese gemaakt

Indien er bestraling plaatsvindt en de kaakchirurg acht het nodig, zullen er tanden worden getrokken en een prothese gemaakt worden.

Oncoloog

Oncoloog consult

Indien er naast de RT ook Chemo gegeven wordt, zal de patiënt kort na de radiotherapeut ook door de oncoloog worden gezien.

Oncologisch VPK

Oncologisch VPK consult

Indien er chemo gegeven gaat worden, wordt de patiënt door de oncologisch verpleegkundige begeleid

Radiotherapie folders

Chemotherapie folders

WACHT TIJD

Dit duurt 1 - 3 weken

Oncologisch VPK

Dietiste

Verpleegkundig consulent

Mogelijke contacten tijdens wachttijd

Gedurende de wachttijd kan patiënt in contact zijn met deze zorgverleners.

BEHANDELING

Duur verschilt per behandeling: 1 dag tot een aantal weken voor chirurgie, 2 - 6 weken voor radiotherapy/ chemo

Meestal na behandeling

Radiotherapeut

Radiotherapie

Dagelijkse bestraling. Dit kan verschillen van 2 weken tot 6 weken afhankelijk van de bestralingsdosis.

Oncoloog

Chemotherapie

De behandeling van de radiotherapie wordt aangevuld met chemo. Hiervoor wordt de patiënt opgenomen.

Chirurg

Chirurgie

Operatie waarvoor de patiënt wordt opgenomen. Dit kan verschillen van één dag tot enkele weken

Kleding advies

Manieren om de tijd door te komen

Hoofd-hals chirurg

Einde behandeling

Patiënt beindigt behandeling volgens plan. Of eerder indien dit in samenspraak met behandelaar wordt besloten (tumorgroei, bijwerkingen).

FOLLOW-UP

Gedurende 5 jaar na behandeling

T= 5 jaar

Hoofd-hals chirurg

Chirurg

Logopediste

Follow up consults

De behandelaar ziet de patiënt in een voorafgesproken frequentie. Indien nodig, vaker!
Als de patiënt is bestraald is, wordt de afspraak om en om met de chirurg gepland.

Frequentie:
Eerste halfjaar: Elke 2 maanden
Tweede halfjaar en jaar: Elke 3 maanden
Derde jaar: Elke 4 maanden
Vierde jaar: Elke 6 maanden
Vijfde jaar: Elke 12 maanden

Hoofd-hals chirurg

Eind van follow-up gesprek

De behandelrelatie wordt beeindigd. Indien gewenst kan de follow-up worden verlengd.

- Eet problemen
- Droge mond
- Slijm probleem
- Effect op en steun van familie
- Herstellen van operatie
- Spraak problemen
- Vermoeid-heid
- Fysieke beweging
- Steun van mede patienten
- Pijn verminderen
- Werk problemen
- Doelen verstoring
- Voedsel pomp nodig
- Misselijk voelen
- Tand problemen
- Gehoor problemen
- Negatieve gevoelens
- Seksuele problemen

- Mentale gezondheid PROMs
- Fysieke gezondheid PROMs
- Sociale relaties PROMs
- Spraak problemen PROMs
- Eet problemen PROMs
- Moeheid PROMs
- Andere bijwerkingen PROMs

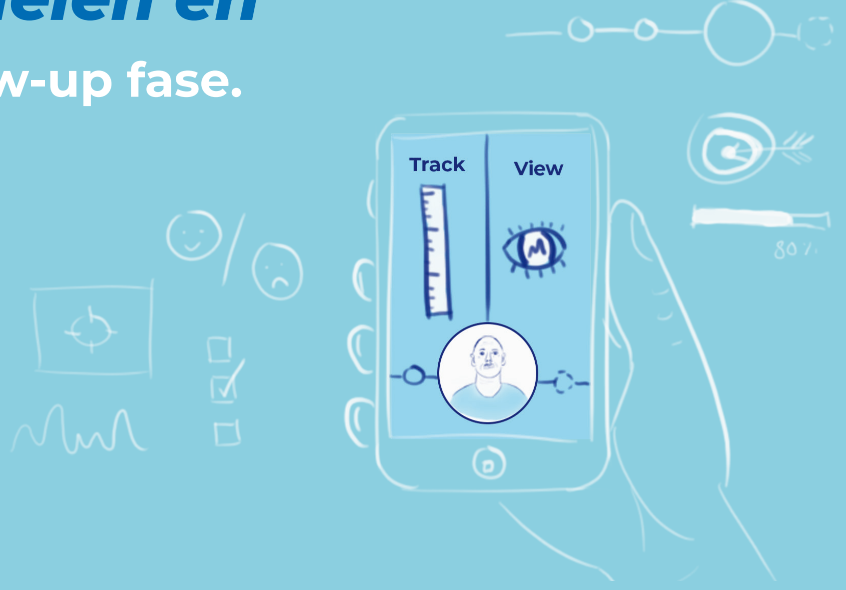
Appendix G.
Focus group care professionals booklet

Co-creatie sessie
25 Maart Boekje

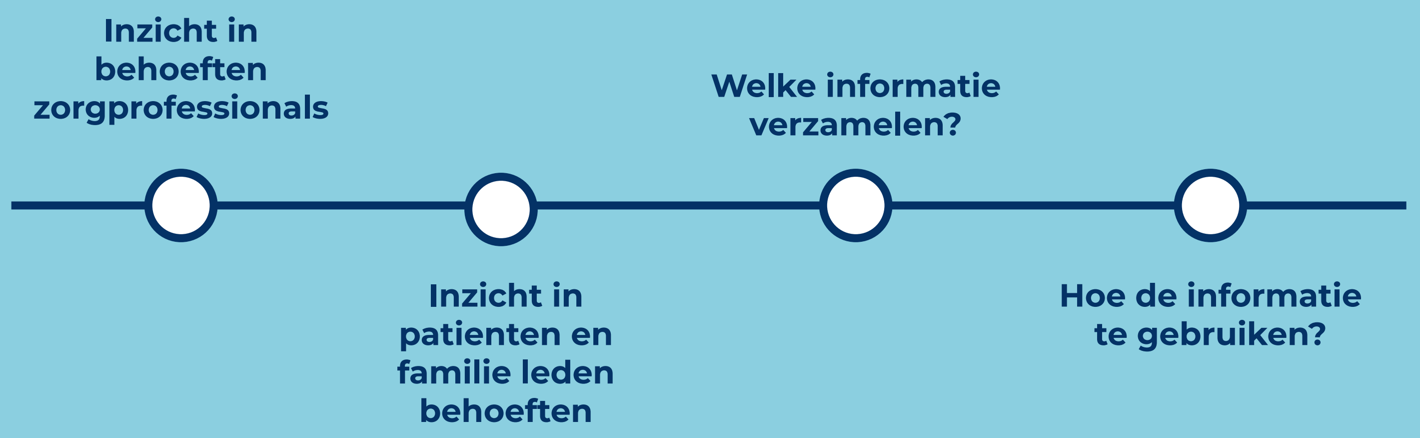
Zorgprofessionals co-creatie sessie voor het ontwerpen van een aanvullende service voor hoofd-halskanker patiënten binnen de Zorgmonitor

Co-creatie sessie doel

De **behoeften en meningen van zorgprofessionals** verkennen omtrent een ***nieuwe vorm van patiënten informatie verzamelen en gebruiken*** in de follow-up fase.



Co-creatie sessie outline



Inzicht in behoeften zorgprofessionals

Inzicht in patienten en familie leden behoeften

Welke informatie verzamelen?

Hoe de informatie te gebruiken?

Inzicht in jouw behoeften als zorgprofessional

Stap 1: Schrijf op de behoeften kaart hiernaast je **naam, functie en jaren ervaring** die je hebt binnen je functie.

Stap 2: Schrijf **2 behoeften** die jij ervaart als zorgprofessional in de follow up fase op de behoeften kaart in de spreekwolkjes.

Stap 3: Schrijf in het vak hieronder eventueel **waarom** deze 2 behoeften voor jou van belang zijn.

Stap 4: Haal de behoefte kaart uit het boekje en **zet hem op je bureau**.

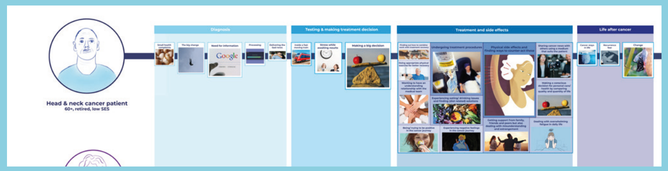
Naam: ....

Functie: ....

Aantal jaar ervaring: ....

Inzicht in de patient en familie

Stap 1: Verken de algemene reis van een kanker patient en familie lid in de **online omgeving** die is gedeeld via de Teams meeting.



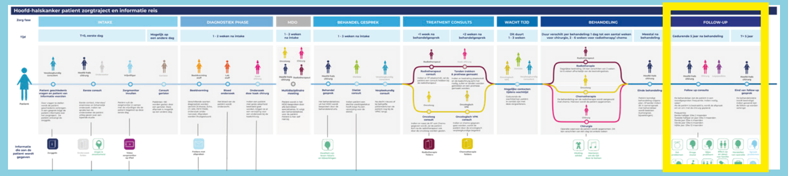
Stap 2: Schrijf **2 inzichten** op de inzichten kaart hiernaast die je inspireren en die je mee wilt nemen tijdens de rest van deze sessie.

Stap 3: Schrijf in het vak hieronder eventueel **waarom** deze 2 inzichten volgens jou van belang zijn/ jou aanspraken.

Stap 4: Haal de inzichten kaart uit het boekje en **zet hem op je bureau**.

Welke informatie verzamelen?

Stap 1: Bekijk de online hoofd-halskanker reis PDF en bestudeer in het specifiek de **informatiebehoefte vanuit de patiënt en vanuit de literatuur** in de follow up fase die hiernaast ook op stickers staan.



Stap 2: Teken/schrijf eventuele **nieuwe informatie punten** die er nog niet tussen staan en die nuttig zouden zijn om continu te verzamelen in deze fase op een lege sticker hiernaast.

Stap 3: Schrijf in het vak hieronder eventueel **waarom** deze nieuwe informatie nuttig zou zijn om te verzamelen.

Eet problemen
Droge mond
Pijn verminderen
Tand problemen
Vermoeidheid
Spraak problemen

Slijm probleem
Herstellen van operatie
Negatieve gevoelens
Werk problemen
Fysieke beweging
Doelen verstoring

Voedsel pomp en misselijkheid
Steun van mede patienten
Gehoor problemen
Effect op en steun van familie
Seksuele problemen

Mentale gezondheid PROMs
Fysieke gezondheid PROMs
Sociale relaties PROMs
Spraak problemen PROMs
Eet problemen PROMs
Moeheid PROMs
Andere bijwerkingen PROMs

Welke informatie verzamelen?

Stap 4: Kies en prioriteer de informatiepunten die jij het belangrijkst vindt om te verzamelen in het overzicht hiernaast van 1 (meest belangrijk) tot 5 (minst belangrijk). Dit kun je doen door de stickers van de vorige pagina in de vakjes te plakken.

Neem in je keuze de volgende dingen mee:
De context van het project:

- Het gaat om het verzamelen van continue data
- In de follow-up fase: na behandeling tot 5 jaar na behandeling
- Met als doel patient empowerment

De verschillende belangen en behoeften:

- De 2 inzichten op je patient-famlie inzichten kaart
- Je eigen ervaring als zorgprofessional en jouw 2 behoeftes

Stap 5: Beschrijf **waarom** je de informatiepunten op deze manier hebt geprioriteerd.

1

2

3

4

5

Hoe de informatie te gebruiken?

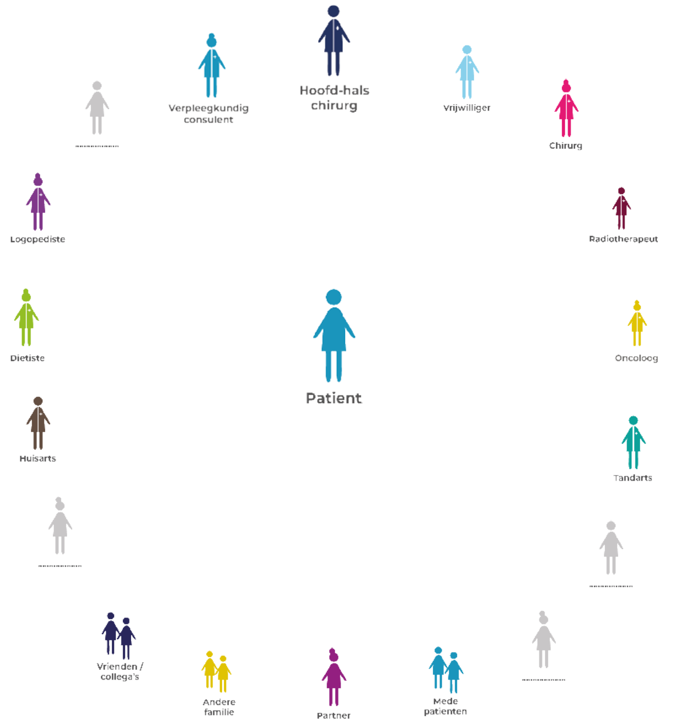
Stap 1: Kies een of meerdere van de geprioriteerde informatie punten waarvoor je een systeem opzet wilt ontwerpen.

Stap 2: Check of alle belangrijke stakeholders voor dit informatietype zijn weergegeven in de stakeholder kaart, **schrijf de stakeholders erbij** die er nog niet tussen staan maar wel van belang zijn in de communicatie.

Stap 3: Teken interactie pijlen tussen de stakeholders die volgens jou betrokken moeten zijn bij het inzien van/delen van de gekozen informatie en schrijf erbij wat de betekenis is van de interactie.

Stap 4: Schrijf eventuele **extra uitleg** onder de interactie kaart.

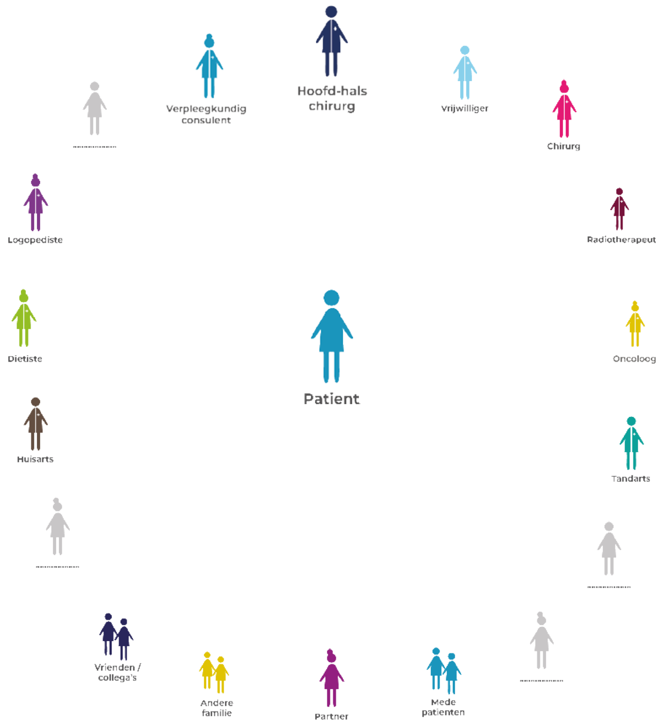
Gekozen informatie punt(en): ....



Extra uitleg/opmerkingen bij de getekende interactiekaart:

A3 vellen systeem kaarten zie appendix 8

Gekozen informatie punt(en): ....



Extra uitleg/opmerkingen bij de getekende interactiekaart:

Ruimte voor overige opmerkingen/suggesties:

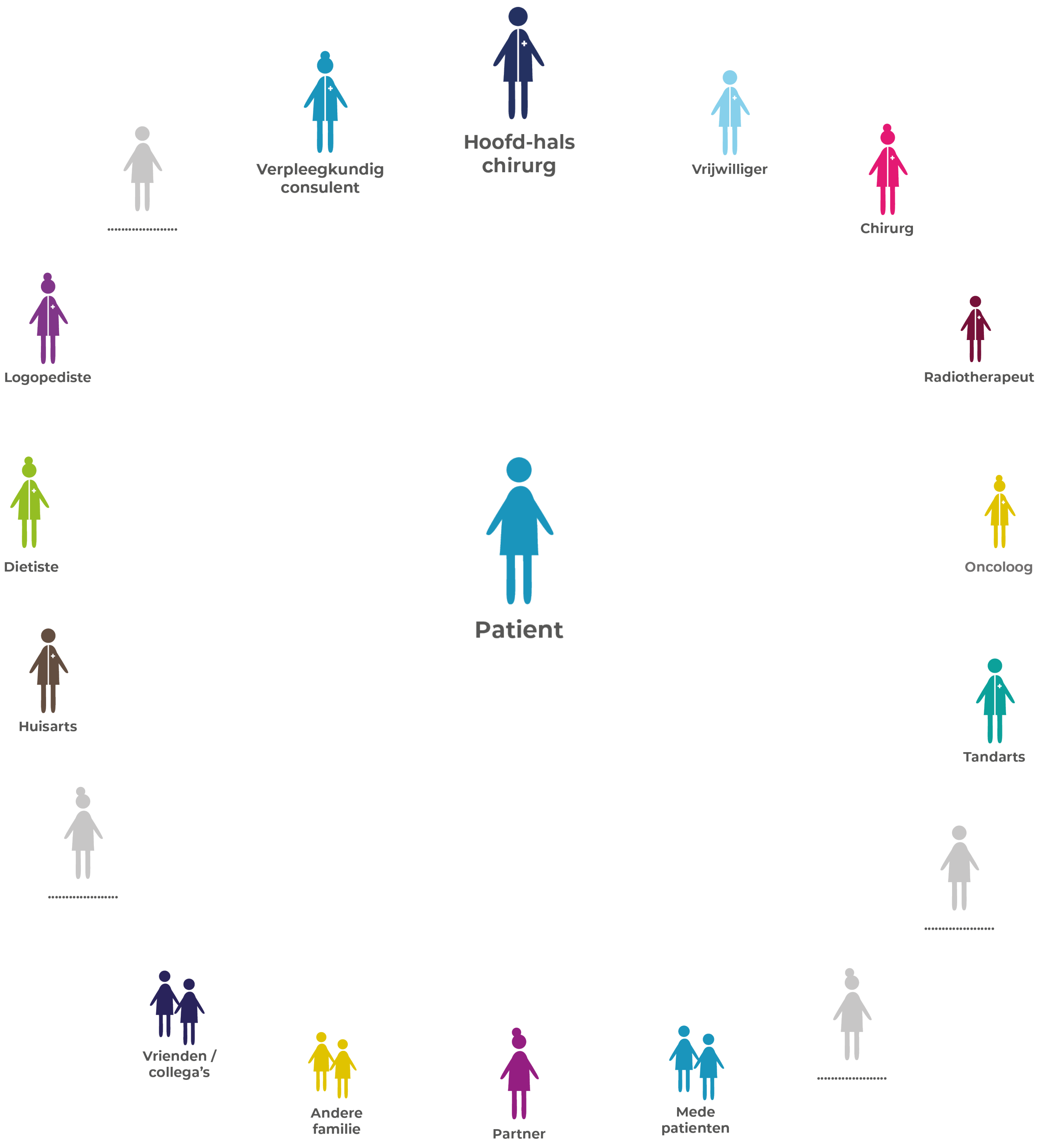
Dankjewel voor je deelname!

Jouw inzichten zullen worden gebruikt tijdens het ontwerpen van de nieuwe service.
Bewaar alsjeblieft dit boekje en bijhorende documenten. Ik haal deze op na de sesie.

Tess Peters

Appendix H.
System map focus group

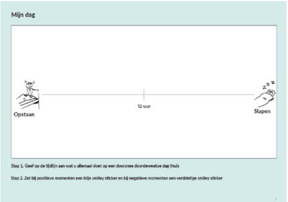
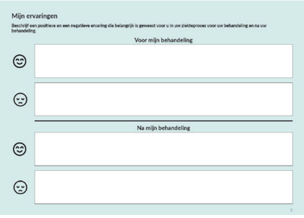
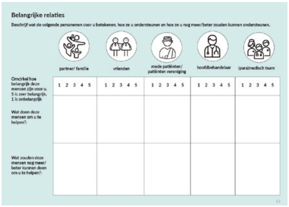
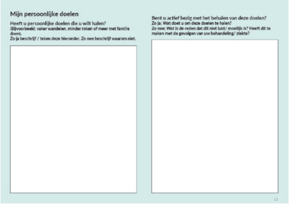
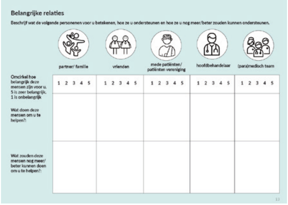
Gekozen informatie punt(en): ....



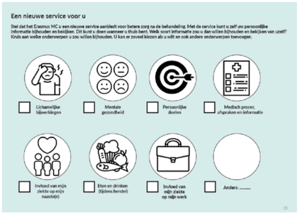
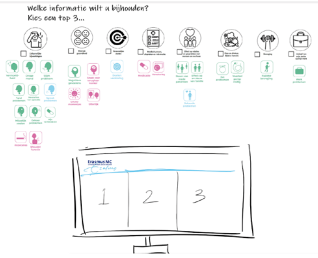
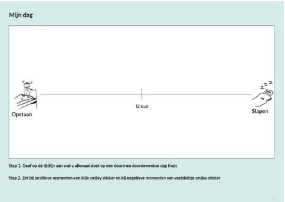
Extra uitleg/opmerkingen bij de getekende interactiekaart:

Appendix I.
First relation overview theory and context mapping

Patient empowerment conceptual model with practical relation to the preperation booklet

Concept	Indicator	Page preperation booklet
Patient abilities / knowledge / perception	**Self efficacy**: The confidence to manage cancer and its side effects in daily life	Page 7 booklet 
	Emotional wellbeing: Understanding psychological consequences of treatment and how to reduce negative feelings	Page 5 booklet 
	Feeling supported: Understandable and empathic communication that makes the patient feel respected and in control	Page 13 booklet 
Patient actions	**Control over treatment decisions**: making informed decisions about personal care/health	Page 9 booklet 
	Control over treatment management: Having an active role in consultations and a clear overview of the planning	Page 9 booklet 
	Goal re-engagement: Setting up new adapted goals and taking steps to achieve these	Page 11 booklet 
	Active in finding/giving support: Communicating with family members and peers to get/give support	Page 13 booklet 

Service system design choice model with practical relation to the preperation booklet and interview steps

Design choice	Options	Page preperation booklet or/& interview steps
Type of data/ information to collect	**Physical side effects** (fatigue, pain, speech, swallowing, body disfigurements etc), **Mental state** (emotions, stress, self-efficacy), **Personal goals, Medical process, Relations and support, Health behaviour** (diet & physical activity)	Page 7 booklet  Step 1 of Part B interview 
When to collect / show information	**Certain time on a day, certain place, during a certain activity, in a certain social context etc...**	Step 3 of Part B interview based on page 7 booklet 
How to collect data	**Voice message, questionnaire, writing, typing, sensors etc.**	Step 2 of Part B interview 
Who can have insight into the data	**Medical team, family doctor, family, friends, peers, employer**	Step 2 of part B interview 
How to show the information	**Graph, video, photo, drawing, text, sound, colors etc.**	Not covered in the interview, will be tested in prototype.

Appendix J.

Sensitizing booklet ex-patient interviews

Voorbereidende boekje interview

Voor het meedenken over een nieuwe service voor hoofd-halskanker patiënten in de fase na behandeling.

TU Delft

Erasmus MC

Kanker Instituut

Even voorstellen...

Teken/beschrijf wat u gelukkig maakt

- Wat zijn uw hobbies?
- Wat vindt u leuk om te doen?
- Met wie bent u graag samen?

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Mijn ervaringen

Beschrijf een positieve en een negatieve ervaring die belangrijk is geweest voor u in uw ziekteproces voor uw behandeling en na uw behandeling.

Voor mijn behandeling

😊

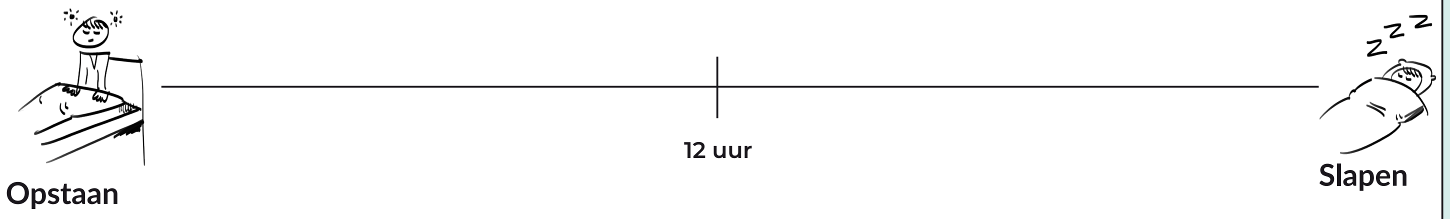
🙁

Na mijn behandeling

😊

🙁

Mijn dag



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

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

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Mijn grip op mijn gezondheid

Heeft u er vertrouwen in dat u kunt omgaan met bijwerkingen van uw behandeling? (bijvoorbeeld een droge mond) Leg uit.

Heeft u genoeg informatie gekregen over hoe u kunt omgaan met bijwerkingen van uw behandeling? Leg uit.

Hoe bereidt u zich voor op een gesprek met de arts? (bijvoorbeeld vragen / klachten van tevoren opschrijven)

Mijn persoonlijke doelen

Heeft u persoonlijke doelen die u wilt halen?

(Bijvoorbeeld; vaker wandelen, minder roken of meer met familie doen).
Zo ja beschrijf / teken deze hieronder. Zo nee beschrijf waarom niet.

Bent u actief bezig met het behalen van deze doelen?

Zo ja; Wat doet u om deze doelen te halen?
Zo nee; Wat is de reden dat dit niet lukt/ moeilijk is? Heeft dit te maken met de gevolgen van uw behandeling/ ziekte?

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Belangrijke relaties

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

	partner/ familie	vrienden	mede patiënten/ patiënten vereniging	hoofdbehandelaar	(para)medisch team
Omcirkel hoe belangrijk deze mensen zijn voor u. 5 is zeer belangrijk. 1 is onbelangrijk	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
Wat doen deze mensen om u te helpen?:					
Wat zouden deze mensen nog meer/ beter kunnen doen om u te helpen?:					

Een nieuwe service voor u

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

☐ **Lichamelijke bijwerkingen**

☐ **Mentale gezondheid**

☐ **Persoonlijke doelen**

☐ **Medisch proces, afspraken en informatie**

☐ **Invloed van mijn ziekte op mijn naaste(n)**

☐ **Eten en drinken (tijdens herstel)**

☐ **Invloed van mijn ziekte op mijn werk**

☐ **Anders: ....**

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Ruimte voor het opschrijven van extra gedachten/ opmerkingen:

Dank u wel voor het invullen van dit voorbereidende boekje. Ik wil u vragen om deze te verzenden in de bijgevoegde envelop naar het adres wat erop staat.

Ik spreek u bij het interview!

Tess Peters, Ontwerp Studente TU Delft
email: t.peters-1@student.tudelft.nl

Kanker Instituut

Appendix K.
Ex-patient interview guide

INTERVIEW GUIDE

INTRODUCTIE (5 min): Project en doel kort uitleggen (presentatie) en checken informatie gegeven in brief en toestemmingsformulier:

- U kunt altijd kiezen om een vraag niet te beantwoorden, u hoeft hier geen reden voor te geven)
- Het interview wordt opgenomen en zal alleen door mij, de onderzoeker bekeken worden om terug te zien en na gebruik worden vernietigd. Alle data die gebruikt wordt zoals bijvoorbeeld een quote zal geanonimiseerd worden.

Introductie vragen:

- Welke behandelingen heeft u ondergaan?
- Hoelang geleden is uw behandeling geëindigd?

DEEL A (15 min): Verder ingaan op boekje

PDF ingevuld boekje delen op scherm

- Wat vond u ervan om het boekje in te vullen? Is er in het algemeen iets wat u is bijgebleven/opgevallen tijdens het invullen, een idee of inzicht?

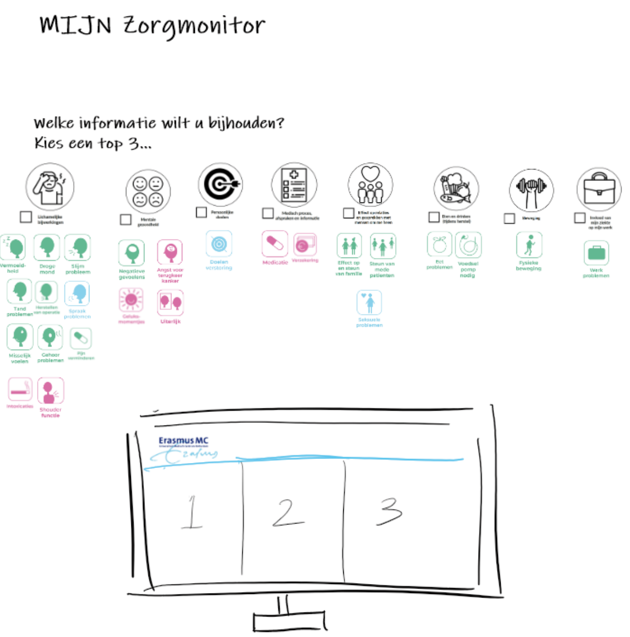
Mogelijke vragen (wordt gebaseerd op wat is ingevuld in het boekje, wat interessant is om op door te vragen bij de betreffende ex-patiënt):

- Waarom heeft u .... ervaren als positief/negatief?
- Hoe kon het dat deze negatieve ervaring gebeurd is? Wat zijn de achterliggende oorzaken?
- Waarom is dit moment op de dag negatief?
- Wat is de manier die het meeste bij u past in het omgaan met de gevolgen van uw ziekte en behandeling? (coping stijl voorbeelden! :)
- Voelt u zich goed genoeg voorbereid voordat u een gesprek in gaat met de arts?
- Vindt u doelen stellen belangrijk? (evt. kleine doelen vb) Zou u meer doelen willen zetten voor uzelf? Zou u meer willen doen om uw doelen te halen?
- Welke zorgen zou u met welke mensen willen delen?
- U heeft gekozen voor de onderwerpen; … om zelf te willen bijhouden en inzien. Waarom deze onderwerpen? Waarom zijn ze belangrijk voor u?

Deel B (35 min): Samen service ontwerpen

(Introductie (5 min): Een voorbeeld service systeem laten zien in de vorm van een storyboard. Alleen als nodig voorbeeld laten zien)

Stap 1 (15 min): Samen de gekozen onderwerpen prioriteren. **WAT bijhouden**



Samen door de onderwerpen heen gaan.

- Mist er voor u nog een subcategorie die voor u belangrijk zou zijn die er niet tussen staat?
- Welke informatie zou u willen dat deze service bijhoudt?
    - Beschrijf een top 3. Dit kan van de grotere categorieën zijn of al specifiekere sub categorieën.
    - Waarom hebben deze voor u de prioriteit?
    - Welke specifieke dingen zou u bij willen houden binnen deze categorie? (bv. bij lichamelijke bijwerkingen kiezen voor moeheid, en bij moeheid hoeveel u slaapt, beweegt, energie op een dag…)
- Welke waarde heeft het bijhouden van deze onderwerpen voor u? (geruststelling, voorbereiding etc.)
- Zou u over de tijd verschillende informatie behoeftes hebben. (Bv kort na behandeling (half jaar) versus een aantal jaar (4 jaar) na behandeling?
    - Wat zou dit verschil zijn?

Stap 2 (15 min): Hoe de informatie verzamelen en inzien? **HOE gebruiken?**

- Wat zou u willen dat er met de informatie gebeurt die u verzamelt? Welke acties zijn eraan gekoppeld?
    - Wat zou u ermee willen doen?
    - Wat zou u willen dat de zorgprofessional met de data doet?
        - Hoe zou u informatie willen delen met de zorgprofessional? Zelf kiezen om informatie te sturen of bv bij een bepaalde meting rechtstreeks een alert naar de behandelaar
        - Bij wie ligt de bal; bij u of bij het ziekenhuis
    - Met wie zou u nog meer verhalen willen uitwisselen? (laat plaatje zien)
        - Wat voor informatie zou u met deze mensen willen uitwisselen/bespreken?


(para)medisch team


hoofdbehandelaar


verpleegkundig consulent


Mijn huisarts

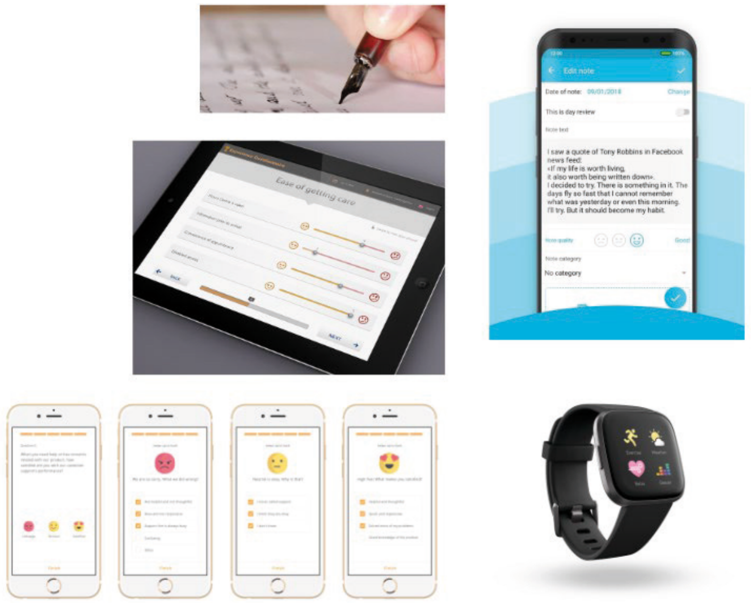

partner/ familie


vrienden


mede patiënten/ patiënten vereniging

- Wat zou de beste manier zijn om deze informatie te verzamelen? Multiple choice vragen, schaal van 1-5, dagboek, slimme sensoren. App, schrijven, sensoren. Multiple choice vragen, schaal, meting aanzetten, gewoon schrijven.

Hoe bijhouden



  - Wat zijn de voor en tegens van de verschillende manieren om informatie te verzamelen voor u?

Stap 3 (5 min): **WANNEER** informatie bijhouden en inzien
Gebruik ingevulde dagreis

Wanneer bijhouden en wanneer inzien

Mijn dag

Opstaan

Slapen

Stap 1. Geef op de tijdlijn aan wat je allemaal doet en meemaakt op een doorsnee dag thuis

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

- Op welk moment van de dag zou u informatie over de aangegeven onderwerpen willen bijhouden? (bv. op het moment dat een zorg/pijn bij u opkomt, of juist op een vast moment bv bij de koffie).
  - Waarom?
  - Heeft u een herinnering nodig of zou naar de app grijpen wanneer u iets voelt?
- Hoe vaak zou u informatie willen bijhouden? (bv. zo vaak het voorkomt, ongeveer 1 x per week etc.)
  - Waarom?
- Op welk moment van de dag zou u informatie willen terugzien? (bv. direct na het invullen/bijhouden, op het einde van de dag/week)
  - Waarom?

WRAP UP (5 min): Dank u wel, uitleggen wat hiermee gedaan gaat worden. Vragen of geïnteresseerd om later in het project het prototype te testen (eind mei). Scenario laten zien wat de prototype test inhoud.

Appendix L.
Miro Board link codes and clusters

The following link refers you to the miro board that includes the codes of both the ex-patient interviews as well as the prototype test with ex-patients. The codes are also clustered showing the code groups that are presented in the thesis.

https://miro.com/welcomeonboard/MmI4NE9zVzhPRG-hJUnl2R2U5S2NBRWhSRUFGMFN3V1lIYjlzTXhYRj-Z1MTZSNGhuTnY2UnRZU01EU21QNjljbXwzMDc0N-DU3MzUwMTQ3Njk3MDU0

Appendix M. Prototype test introduction conversation

15 minuten intro interview nieuwe ex-patiënten

INTRODUCTIE (3 min): Project en doel kort uitleggen (presentatie) en checken informatie gegeven in brief en toestemmingsformulier:

- U kunt altijd kiezen om een vraag niet te beantwoorden, u hoeft hier geen reden voor te geven)
- Het interview wordt opgenomen en zal alleen door mij, de onderzoeker bekeken worden om terug te zien en na gebruik worden vernietigd. Alle data die gebruikt wordt zoals bijvoorbeeld een quote zal geanonimiseerd worden.

Vragen 10 min

Introductie vragen:

- Welke behandelingen heeft u ondergaan?
- Hoelang geleden is uw behandeling geëindigd?
- Beschrijf een positieve en negatieve ervaring in de fase na uw behandeling.
- Wat had u willen bijhouden/weten in deze fase na behandeling?

Afsluiting 2 min
Indien nog niet gepland lange prototype test inplannen en afspreken fysiek/online.

Appendix N.
Prototype test protocol with questions

Test protocol

Intro

- **Prototype**; nog niet volledig af. Sommige dingen werken wel, andere nog niet. Bedoelt als gesprekstarter om samen na te denken over wat voor waarde een app kan brengen aan patiënten in de fase na behandeling en wat er verbeterd/veranderd/toegevoegd kan worden om nog meer te kunnen betekenen voor patiënten in de fase na behandeling.
- **Toestemmingsformulier**. Opnemen van het gesprek. Foto's/filmpjes maken. Quotes gebruiken. U kunt het altijd aangeven als u een vraag niet wilt beantwoorden/wilt stoppen met het onderzoek. Samen tekenen.

Test opzet

Uitproberen van de app gevolgd door een gesprek over de app.

- Instaleren app.
- Voordat we beginnen wil ik u vragen om terug te denken aan de periode na behandeling. Situatie schetsen…

- Terwijl u de app gebruikt en verkent wil ik u vragen om hardop te denken door te vertellen wat u denkt. Ik kan u tussendoor vragen stellen. Het kan heel goed zijn dat u niet alle onderdelen van de app vind, in dit geval zal ik u op het eind nog wijzen op deze onderdelen zodat u alle onderdelen heeft verkent en we een goed gesprek kunnen hebben over het volledige idee van de app.
- Gesprek over de app. Aantal vragen voor u over de waarde, passendheid en verbeterpunten van de app.
- Samen kijken naar een aantal onderwerpen van patient empowerment en hoe deze wel/nog niet door de app naar voren komen adhv kaarten.
- Afsluiting, cadeautje + wat wordt er gedaan met de resultaten

Vragen Prototype test

Algemene vragen waarde en passendheid van het concept

1. Wat vindt u van de applicatie
2. Welke waarde zou deze applicatie u kunnen brengen als patiënt in de follow up fase (wat zou deze app voor een patiënt in de follow up fase kunnen betekenen?)
    a. Welke behoeftes in de follow up fase worden beantwoord?
    b. Hoe worden deze beantwoord?
    c. Hoe vaak zou u deze functie gebruiken?
    d. Wat vindt u van de manier waarop uw behoefte word beantwoord? Past dit bij jouw situatie/dagelijks leven?
    e. Hoe zou het op een passendere manier kunnen?
3. Welke waarde mist u in de app die u zou willen in de follow up fase?
    a. Welke behoeftes worden nog niet of onvoldoende beantwoord?
    b. Wat zou u willen toevoegen/verbeteren aan de app?
4. Wat vindt u van de metafoor die wordt gebruikt in de applicatie van iemand die soms in een turbulente en soms in een rustige stroom vaart? Klopt dit met uw ervaringen in de fase na behandeling?
    a. Zo ja: waarom?
    b. Zo nee: hoe zou u uw ervaringen omschrijven? (eventueel met een metafoor)

Vragen gericht op patient empowerment kaarten

Het uiteindelijke doel van deze app is bedoelt om de positie van de patiënt te versterken. Hier bedoelen we mee dat patiënten in staat worden gesteld om meer invloed uit te oefenen op hun individuele gezondheid door hun mogelijkheden te vergroten om meer controle te krijgen over zaken die zij zelf als belangrijk beschouwen.

Om dit te doen zijn een aantal zaken nodig en worden er een aantal uitkomsten verwacht.

Nodig:

- Relevant voor mij
- Motivatie om mee te doen
- Sociale ondersteuning
- Kennis en skills omtrent gezondheid in de follow-up
- Mogelijkheid om vragen te stellen

Verwachte uitkomsten:

- Zelfbeeld & zelfvertrouwen
- Gevoel van controle
- Actie ondernemen op gezondheid
- Omgaan met veranderingen

Graag kijk ik samen naar deze onderwerpen door ze op een schaal te plaatsen om te kijken hoe deze al wel of nog niet voldoende gestimuleerd worden door het ontwerp van de app en het gesprek aan te gaan over hoe de app deze onderwerpen beter kan vertegenwoordigen.

Appendix O.
System map summaries care professional focus group

Stakeholder map results focus group summaries

The summaries created from the different stakeholder maps can be found in figures 1-3.

The summaries are created for three different scenarios. They show the envisioned interactions that should be in place between different stakeholders in these three scenarios.

System map for the physical side effects

In the different drawings of the participants of the focus group it became clear that for the physical issues the treating ENT physician was the most important contact person (see figure 1). Patients could get into contact first with the nurse consultant but the ENT physician is mostly the one that takes action for physical concerns of the patient related to their treated cancer. If necessary the ENT physician will refer the patient to the right expert such as a dietician for eating problems, a speech therapist for speaking issues, a dentist for teeth problems or a physiotherapist for issues with the functioning of the shoulder. Other stakeholders mentioned were the general practitioner that might be contacted in some cases and the expert that makes the prosthesis if needed.

System map for psychosocial side effects

For the psychological or social consequences of the disease the nurse consultant was seen as the most important contact person that could link to the right psychologist (see figure 2). Furthermore the partner and peers play an important role for helping to deal with the mental issues after cancer.

System map for setting and reaching goals

For the more action based topics such as setting new goals and taking steps to achieve these, also the friends and family were included in the picture (see figure 3). These were seen to be able to help the patient with reaching their goals. The nurse consultant was still seen as the important bridge to discuss goals with the patient and refer to the right specialist if needed to help reach these goals.

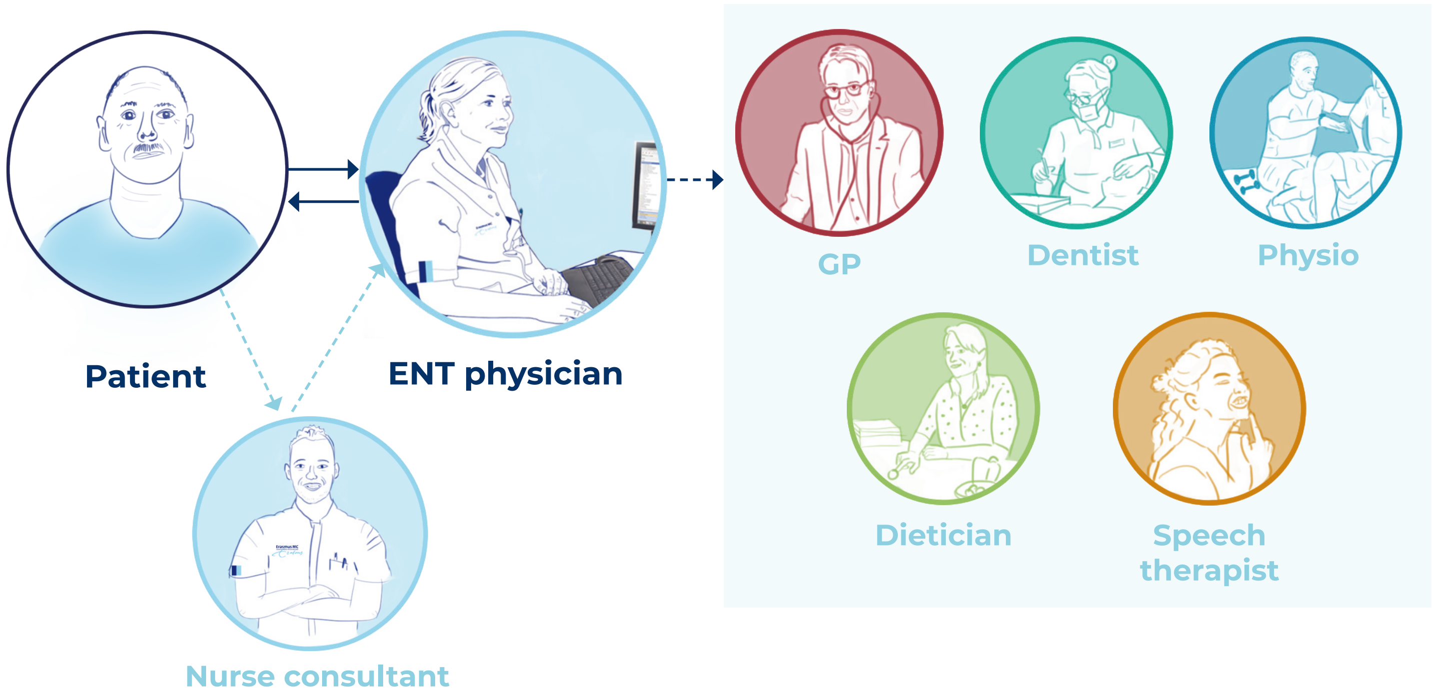


Figure 1. The interactions as envisioned by the health care professionals in the system for physical concerns

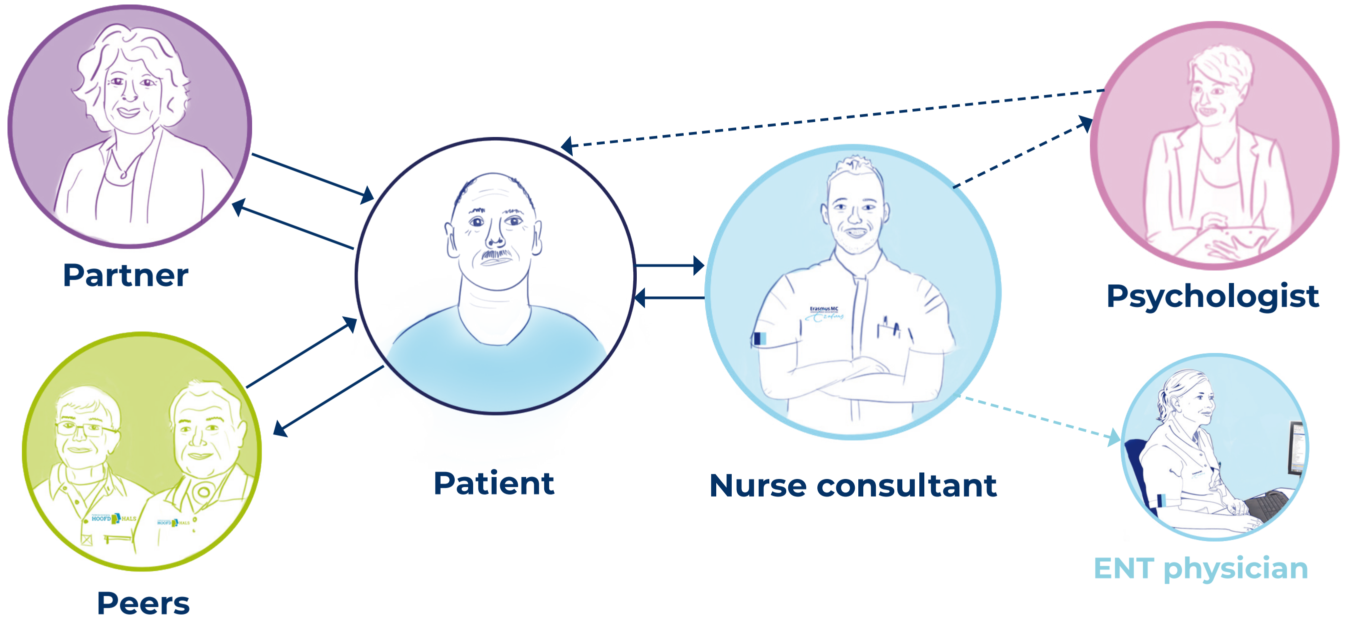


Figure 2. The interactions as envisioned by the health care professionals in the system for psychosocial concerns

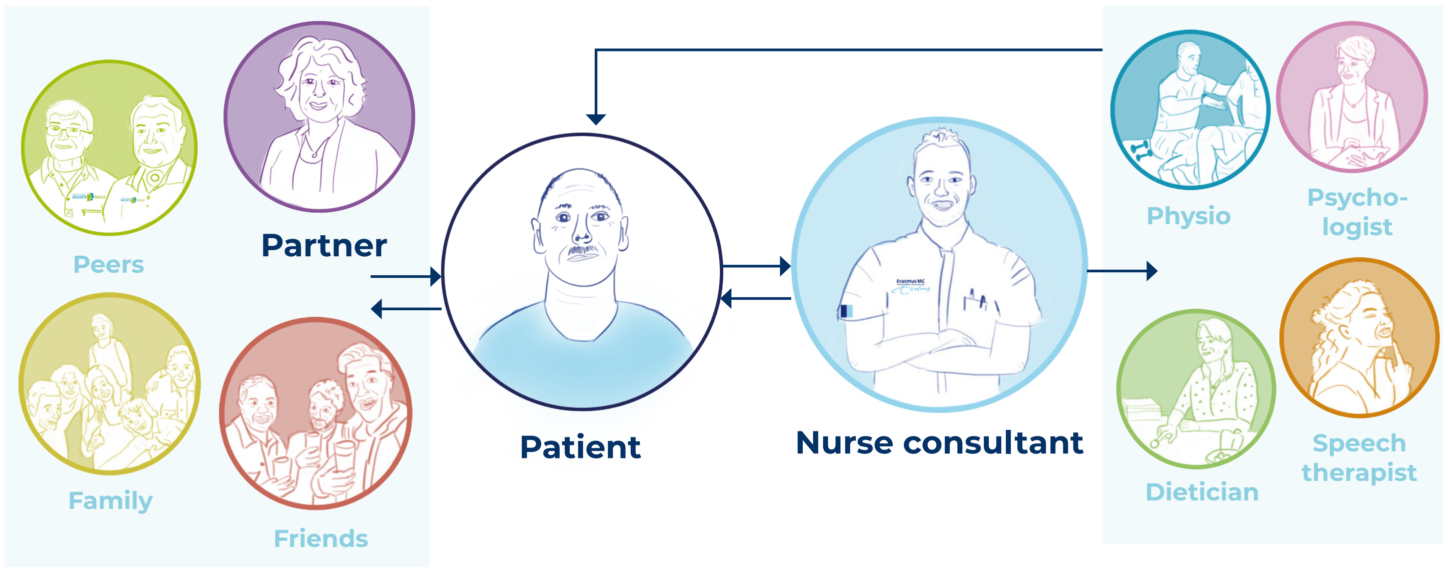


Figure 3. The interactions as envisioned by the health care professionals in the system for setting goals