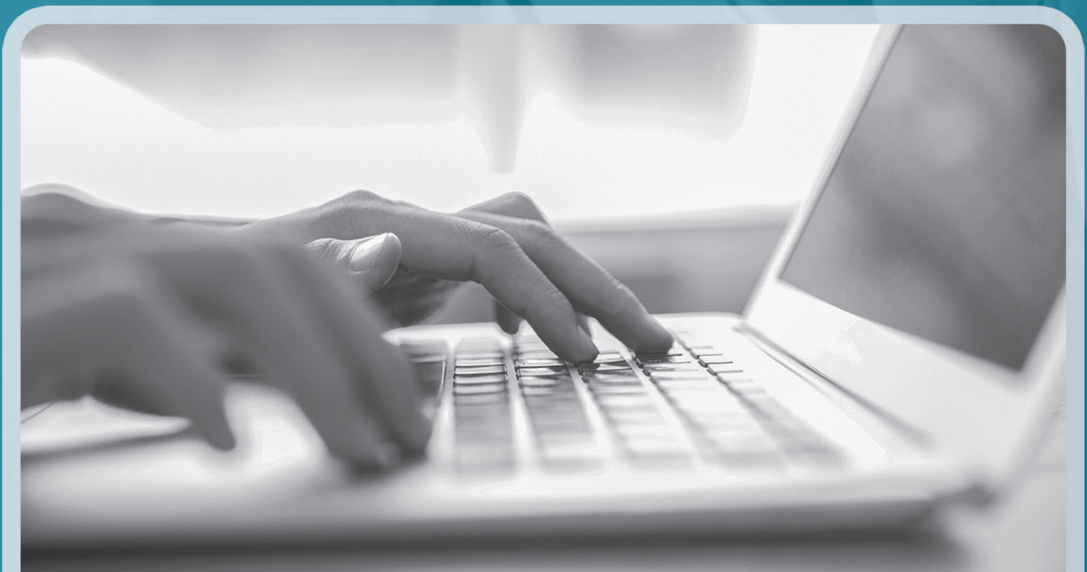
APPENDICES

SHARED DECISION MAKING

DESIGNING FOR CANCER CARE

SIEMON VAN OPSTAL
MASTER THESIS



APPENDIX 1

AJCC Stage	Stage grouping	Stage description
0	Tis N0 Mo	The cancer is in its earliest stage. This stage is also known as carcinoma in situ or intramucosal carcinoma (Tis). It has not grown beyond the inner layer (mucosa) of the colon or rectum.
I	T1 or T2 N0 M0	The cancer has grown through the muscularis mucosa into the submucosa (T1), and it may also have grown into the muscularis propria (T2). It has not spread to nearby lymph nodes (N0) or to distant sites (M0).
IIA	T3 N0 Mo	The cancer has grown into the outermost layers of the colon or rectum but has not gone through them (T3). It has not reached nearby organs. It has not spread to nearby lymph nodes (N0) or to distant sites (M0).
IIB	T4a No Mo	The cancer has grown through the wall of the colon or rectum but has not grown into other nearby tissues or organs (T4a). It has not yet spread to nearby lymph nodes (N0) or to distant sites (M0).
IIC	T4b No Mo	The cancer has grown through the wall of the colon or rectum and is attached to or has grown into other nearby tissues or organs (T4b). It has not yet spread to nearby lymph nodes (N0) or to distant sites (M0).
IIIA	T1 or T2 N1/N1c M0	The cancer has grown through the mucosa into the submucosa (T1), and it may also have grown into the muscularis propria (T2). It has spread to 1 to 3 nearby lymph nodes (N1) or into areas of fat near the lymph nodes but not the nodes themselves (N1c). It has not spread to distant sites (M0).
	OR	
	T1 N2a Mo	The cancer has grown through the mucosa into the submucosa (T1). It has spread to 4 to 6 nearby lymph nodes (N2a). It has not spread to distant sites (M0).

AJCC Stage	Stage grouping	Stage description
IIIB	T3 or T4a N1/N1c M0	The cancer has grown into the outermost layers of the colon or rectum (T3) or through the visceral peritoneum (T4a) but has not reached nearby organs. It has spread to 1 to 3 nearby lymph nodes (N1a or N1b) or into areas of fat near the lymph nodes but not the nodes themselves (N1c). It has not spread to distant sites (M0).
	OR	
	T2 or T3 N2a Mo	The cancer has grown into the muscularis propria (T2) or into the outermost layers of the colon or rectum (T3). It has spread to 4 to 6 nearby lymph nodes (N2a). It has not spread to distant sites (M0).
	OR	
	T1 or T2 N2b M0	The cancer has grown through the mucosa into the submucosa (T1), and it may also have grown into the muscularis propria (T2). It has spread to 7 or more nearby lymph nodes (N2b). It has not spread to distant sites (M0).
IIIC	T4a N2a M0	The cancer has grown through the wall of the colon or rectum (including the visceral peritoneum) but has not reached nearby organs (T4a). It has spread to 4 to 6 nearby lymph nodes (N2a). It has not spread to distant sites (M0).
	OR	
	T3 or T4a N2b M0	The cancer has grown into the outermost layers of the colon or rectum (T3) or through the visceral peritoneum (T4a) but has not reached nearby organs. It has spread to 7 or more nearby lymph nodes (N2b). It has not spread to distant sites (M0).
	OR	
	T4b N1 or N2 M0	The cancer has grown through the wall of the colon or rectum and is attached to or has grown into other nearby tissues or organs (T4b). It has spread to at least one nearby lymph node or into areas of fat near the lymph nodes (N1 or N2). It has not spread to distant sites (M0).
AJCC Stage	**Stage grouping**	**Stage description**
IVA	Any T Any N M1a	The cancer may or may not have grown through the wall of the colon or rectum (Any T). It might or might not have spread to nearby lymph nodes. (Any N). It has spread to 1 distant organ (such as the liver or lung) or distant set of lymph nodes, but not to distant parts of the peritoneum (the lining of the abdominal cavity) (M1a).
IVB	Any T Any N M1b	The cancer might or might not have grown through the wall of the colon or rectum (Any T). It might or might not have spread to nearby lymph nodes (Any N). It has spread to more than 1 distant organ (such as the liver or lung) or distant set of lymph nodes, but not to distant parts of the peritoneum (the lining of the abdominal cavity) (M1b).
IVC	Any T Any N M1c	The cancer might or might not have grown through the wall of the colon or rectum (Any T). It might or might not have spread to nearby lymph nodes (Any N). It has spread to distant parts of the peritoneum (the lining of the abdominal cavity), and may or may not have spread to distant organs or lymph nodes (M1c).

APPENDIX 2

This chapter starts with background information about colon cancer and the treatment options concerning adjuvant chemotherapy, followed by an overview about the consultation where adjuvant chemotherapy is discussed. Then, shared decision making is implemented in the healthcare context. Thereafter, the patient role in this framework is being treated. Then, the trend is discussed about blended care. The chapter ends with a section about risk communication, because risks play a role when presenting information to patients, and finally the conclusions.

Colon Cancer

Numerous people are confronted with cancer every day. Over 100000 patients were diagnosed in the year 2016 in the Netherlands (IKNL, 2017), making it still one of the most common causes of death in the Netherlands (CBS, 2017). According to the dataset from IKNL, after the gender related breast and prostate cancer, colon cancer is the most common form (Figure 1.1).

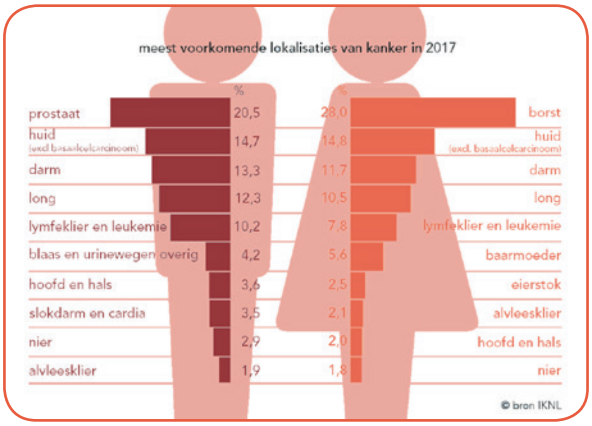


Figure 1.1. Most common localizations of cancer

According to KWF & Kanker.nl (2018), colon cancer is form of bowel cancer. Colon cancer is one of the most common cancers in the Netherlands. This type of cancer is slightly more common in men than in women. In colon cancer, the tumour is in the colon. The colon is at the end of the digestive tract (Figure 1.2). The colon passes into the rectum, which then ends in the anus. A tumour may also develop in the rectum. This is called rectal cancer.

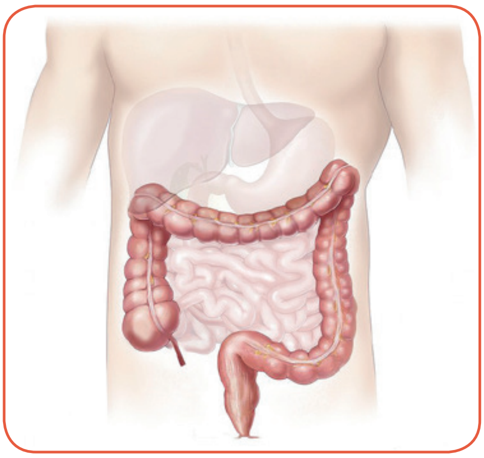


Figure 1.2. Colon and rectum

Colorectal cancer often starts with a polyp (Figure 1.3) on the inside of the intestinal wall. A polyp is a growth of the mucous membrane. Polyps are benign and usually arise spontaneously. People over 50 years are more likely to have polyps. Polyps can become malignant. Then it is called cancer or a malignant tumour. The malignant tumour can grow through the different layers of the intestinal wall. This way the tumour can end up in surrounding organs.

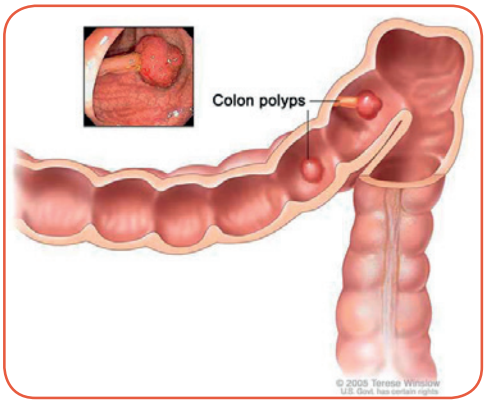


Figure 1.3. Polyp formation inside the colon

Symptoms of colorectal cancer are diverse. They also hang together with the place where the tumour is. Blood or mucus in the stool or blockage can be symptoms of a tumour in the colon. But not everyone with colorectal cancer has symptoms. In 2014 the bowel cancer screening program started. The aim of the population screening is to discover colon cancer and rectal cancer early, before symptoms develop.

Stages

To indicate the progression of tumours, these can be divided into different categories. it is popularly spoken of the different stages (Figure 1.4), in a more clinical approach the TNM classification is used.

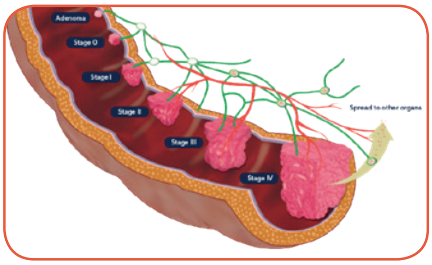


Figure 1.4. Different stages of cancer

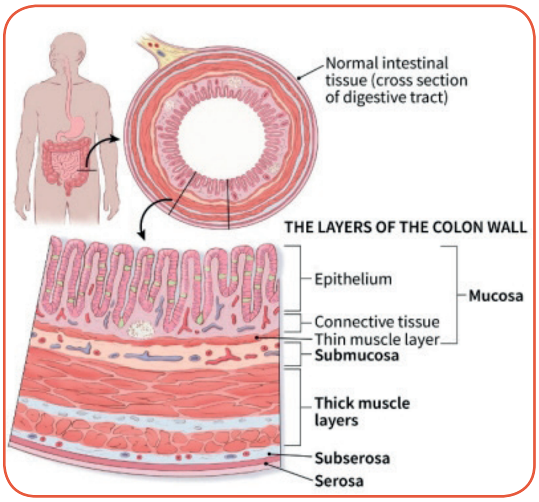


Figure 1.5. Build up of the intestinal wall

According to the American Cancer Society (2018);

- The extent (size) of the tumor (T): How far has the cancer grown into the wall of the colon or rectum? These layers, from the inner to the outer, include (Figure 1.5);
- The spread to nearby lymph nodes (N): Has the cancer spread to nearby lymph nodes?
- The spread (metastasis) to distant sites (M): Has the cancer spread to distant lymph nodes or distant organs such as the liver or lungs?

The system described in Appendix 1, is the most recent American Joint Committee on Cancer (AJCC) system (Edge & Compton, 2010) effective January 2018. It uses the pathologic stage (also called the surgical stage) which is determined by examining tissue removed during an operation. This is also known as surgical staging. This is likely to be more accurate than clinical staging, which takes into account the results of a physical exam, biopsies, and imaging tests, done before surgery.

Numbers or letters after T, N, and M provide more details about each of these factors. Higher numbers mean the cancer is more advanced. Once a person's T, N, and M categories have been determined, this information is combined in a process called stage grouping to assign an overall stage. For this project the focus lies on the AJCC stages after which adjuvant chemotherapy is applicable. The AJCC stages are; IIIA, IIIB and IIIC. (IVA, IVB, IVC)

Surgery

Surgery is often the main treatment for earlier-stage colon cancers. The type of surgery used depends on the stage (extent) of the cancer, where it is, and the goal of the surgery. Any type of colon surgery needs to be done on a clean and empty colon. You will be put on a special diet before surgery and may need to use laxative drinks and enemas to get all of the stool out of your colon. This bowel prep is a lot like the one used before a colonoscopy (American Cancer Society, 2018).The possible surgical options are;

- The inner lining (mucosa), which is the layer in which nearly all colorectal cancers start. This includes a thin muscle layer (muscularis mucosa).
- The fibrous tissue beneath this muscle layer (submucosa)
- A thick muscle layer (muscularis propria)
- The thin, outermost layers of connective tissue (subserosa and serosa) that cover most of the colon but not the rectum

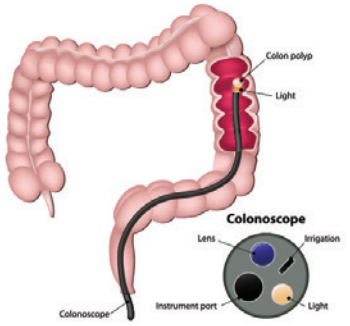


Figure 1.6. Colonscopy

Colonoscopy (Figure 1.6) - Some early colon cancers and most polyps can be removed during a colonoscopy. This is a procedure that uses a long flexible tube with a small video camera on the end that's put into the person's rectum.

and threaded into the colon. When cancer or polyps are taken out this way, the doctor doesn't have to cut into the abdomen (belly). Different versions are; Polypectomy and Local excision.

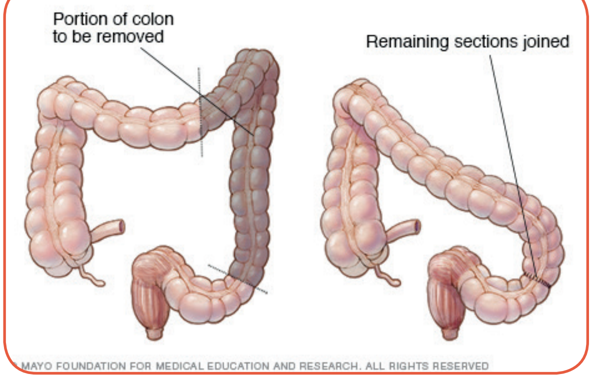


Figure 1.6. Colectomy

Colectomy (Figure 1.7) - A colectomy is surgery to remove all or part of the colon. Nearby lymph nodes are also removed. Different versions are; Partial colectomy and Total colectomy. These two versions can be done by open colectomy or laparoscopic-assisted colectomy.

Colostomy (Figure 1.8) – This is the same type of colectomy that's done to remove the cancer, but instead of reconnecting the ends of the colon, the top end of the colon is attached to an opening (called a stoma) made in the skin of the abdomen. Stool then comes out this opening. When this principle is done to relieve the blockage without removing the part of the colon it is called diverting colostomy. The colon is then cut above the tumor and attached to a stoma to allow stool to come out. When the end of the small intestine (the ileum) instead of the colon is connected to a stoma in the skin is called an ileostomy

Adjuvant chemotherapy

Adjuvant chemo is given after surgery. The goal is to kill any cancer cells that might have been left behind at surgery because they were too small to see, as well as cancer cells that might have escaped from the main tumour and settled in other parts of the body but are too small to see on imaging tests. This helps lower the chance that the cancer will come back (American Cancer Society, 2018).

More than 100 chemotherapy or chemo drugs are used to treat cancer – either alone or in combination with other drugs or treatments. These drugs are very different in their chemical composition, how they are taken, their usefulness in treating specific forms of cancer, and their side effects. Chemotherapy is divided into 6 categories (KWF,2016), these categories are:

- Alkylating agents
- Antimetabolites
- Antimitotic cytostatic
- Antitumor antibiotics
- Topoisomerase inhibitors
- Other cytostatic

According to the guidelines (IKNL, 2014), In patients with stage III colon cancer there is an indication for adjuvant chemotherapy, consisting of a fluoropyrimidine (capecitabine or 5-fluorouracil / leucovorin) plus oxaliplatin (CAPOX or FOLFOX). In contraindications to oxaliplatin the treatment should consist of capecitabine monotherapy, or possibly 5FU / LV. Since the effect of adjuvant chemotherapy using fluoropyrimidine monotherapy is questionable in patients with MSI carcinoma, it is recommended that these patients only receive oxaliplatin-containing chemotherapy with fluoropyrimidine.

Chemotherapy affects not only cancer cells (IKNL, 2014), but also healthy cells. Especially healthy cells that grow rapidly can respond to chemotherapy. For example;

- Bone marrow cells that make blood
- Hair follicles
- Mucosal cells of the mouth
- Mucosal cells of the gastrointestinal tract
- Mucosal cells of the vagina (women)

This can cause you to suffer from side effects. In the rest periods of the chemotherapy healthy cells have the time to recover. Most healthy cells do that. This way the side effects disappear again. Sometimes this happens after a few days, sometimes it takes longer. You cannot predict how you react to chemotherapy. Some people suffer from

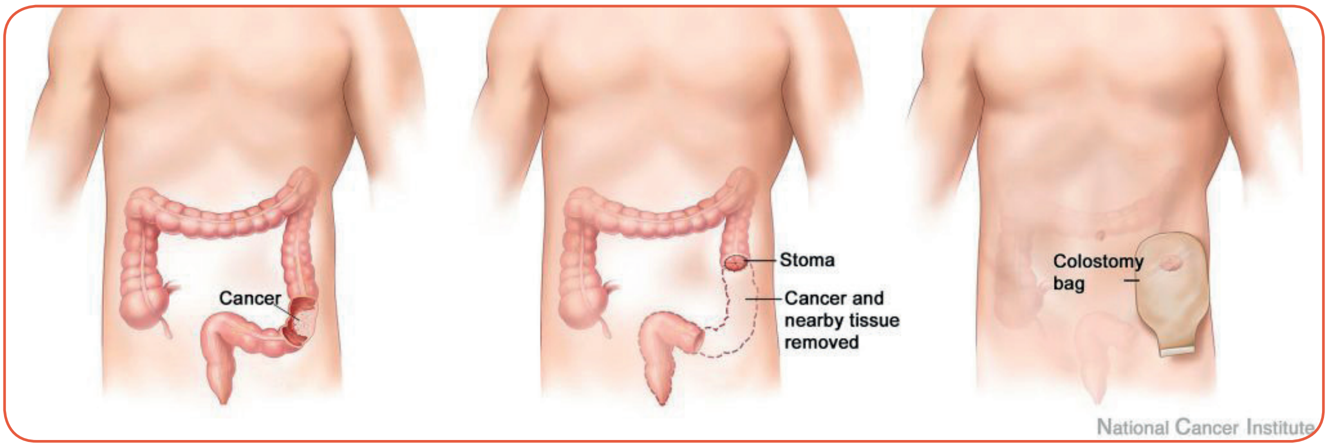


Figure 1.8. Colostomy

side effects, others notice less.
What side effects may occur depends on;

- Type of chemotherapy
- Dose
- Combination with other medications and / or treatments
- Combination with other types of chemotherapy
- Way of administration
- Duration of treatment
- Your physical condition

Usually the doctor looks after 2 or 3 chemotherapy cures whether the treatment has an effect. The best message is that the chemotherapy causes the tumour to shrink. The disease may also have stalled or progressed less quickly. But it can also show that the chemotherapy does not work.

APPENDIX 3

Observations Catharina Hospital 23-01-2018 – Ignace de Hingh, oncological surgeon

During the observations attention will be paid to the following points;

- Emotional status of the patient, medical specialist, (loved ones).
- The types of questions that might be asked by the patients, (loved ones)
- Experience the vibe within the room during the appointments.
- Possible categorization of different types of patients based on;
  - Behaviour
  - Questions being asked
  - Acceptation
  - Hope
  - Interest in numerical information
- Determine in what stage of the care path they are.
- Try to speak to as many specialists as possible of the care path
  - Oncologist
  - Oncological surgeon
  - Case manager / nurse
  - Stoma nurse
  - Radiologist
  - Gastrointestinal doctor

General

All the patients had received surgery or where going to have surgery. That is why they were at this particular consultation appointment.

Number of patients;

- 21 patients
  - 13 Males
  - 8 Females

Age of patients

- Average 62 years old (41 - 83)
  - Male average of 64 years old
    - 41 – 83
  - Female average of 59 years old
    - 47 – 76

Patient 1 – Male, 69 – Follow up

This patient came for the follow up appointment. Through the drain, placed after surgery, moisture kept running. After checking by the specialist, everything looked normal and there was no reason for another appointment soon. At the moment, the patient was undergoing chemotherapy that responded well and was nearly cured.

Questions asked by patient

- Are those sutures soluble?
- What about that drain, how does is stays in place?

Comments/quotes by patient

- ‘I am now no longer afraid of anything’
- ‘Chemo goes well, I do not feel anything about it’

Attitude of patient

The patient was relaxed and calm.

Things that stood out

This patient had no demand for information. This was because it went well with the patient.

Patient 2 – Male, 60 – Follow up
This patient came for the follow up appointment. He underwent an intense surgery and came for the results. The results were good but the conclusion of the surgeon was that the removed tissue was not malicious and therefore the surgery was not necessary.

Questions asked by patient
Too many to write down

Comments/quotes by patient
- 'Not sleeping destroyed me completely'
- 'I did not expect that the days after the surgery were going to be so intense and awful'

Attitude of patient
In the beginning the patient was nervous about the outcome of the surgery. After hearing the good news, it changed to a critical but relieved attitude.

Things that stood out
This patient wanted to know everything about what the surgeon had to tell. He told that he lived up to the surgery in suspense. He did not expect that the days after the surgery where going to be this rough on him. He did not sleep for 14 days which 'destroyed' him physically.

Patient 3 – Male, 63 – Follow up
This patient came for the follow up appointment. Surgery was done and the chemo afterwards took care of the rest. He received good news.

Questions asked by patient
No questions were asked

Comments/quotes by patient
No comments were given

Attitude of patient
Nervous at first, but after hearing the good news relieved and relaxed.

Things that stood out
After hearing the good news, there was no demand for information. Because of the successful treatment he received, he felt like he was in good hands and that there was nothing to worry about anymore. Weighing things up and making choices is up to the doctor.

Patient 4 – Female, 76 – Follow up
This patient came for the follow up appointment. Surgery was done and the chemo afterwards took care of the rest. She received good news.

Questions asked by patient
No questions were asked

Comments/quotes by patient
- 'Taking someone with me reassures me, you never know'

Attitude of patient
Nervous at first, but after hearing the good news relieved and relaxed.

Things that stood out
After hearing the good news, there was no demand for information. Because of the successful treatment she received.

Patient 5 – Female, 47 – Follow up

This patient came for the follow up appointment. After screening, a suspicious spot was seen on the MRI-scan. Chemotherapy was started to reduce the dimensions of the tumour. The result was positive. The tumour was not progressive and stayed the same size, which was not the news she was hoping for. Surgery was postponed because of this result until the tumour grows bigger.

Questions asked by patient

No questions were asked

Comments/quotes by patient

No comments were given

Attitude of patient

Relieved but still disappointed because nothing was going to happen. She hoped it could have been removed soon.

Things that stood out

She had a lot on her mind. Besides the good-natured tumour in the abdomen, al lot of bad things happened to her in the past few years. This explained her disappointment.

Patient 6 – Male, 72 – Follow up

This patient came for the follow up appointment. He had surgery and was recovered enough to start with chemotherapy. The follow up was after he started with the chemo.

Questions asked by patient

No questions were asked

Comments/quotes by patient

- 'You can get angry and worried, but it does not solve anything'
- 'We'll see'

Attitude of patient

Acceptance about his current situation

Things that stood out

His attitude was most striking. But it helped the patient to deal with his situation.

Patient 7 – Female, 59 – Follow up

This patient came for the follow up appointment.

Questions asked by patient

No questions were asked

Comments/quotes by patient

No comments were given

Attitude of patient

No typical attitude

Things that stood out

Nothing

Patient 8 – Male, 41 – Follow up

This patient came for the follow up appointment. After surgery, chemotherapy was necessary. The patient responded to the treatment and was given the positive result during the consultation. He was part of a cancer treatment study.

Questions asked by patient

No questions were asked

Comments/quotes by patient

- 'You are n=1'
- 'I had nothing to choose'
- 'Information is only useful if a choice can be made'
- 'If I could choose what kind of treatment I want to have. Then I want know the pros and cons of the treatment options I can choose from'.

Attitude of patient

He was very nervous when walking in. After the good news he was relieved and became happy and relaxed.

Things that stood out

He told that a week before and after the surgery he was very nervous. Before, of what was going to happen and after because of the fear of the outcome. He said a very interesting thing as mentioned in the 'quotes by patient'.

Patient 9 – Male, 51 – Follow up

This patient came for the follow up appointment. He was a polish man who has had surgery. The results of him were good but the surgeon wanted to perform a lookup to check if everything was okay.

Questions asked by patient

No questions were asked

Comments/quotes by patient

No comments were given

Attitude of patient

He was a bit nervous when coming in. When the surgeon started to explain he wanted to do the lookup he became very anxious and refused. After a thorough explanation, provided by his wife over the phone in polish, he agreed. The nervousness remained.

Things that stood out

He walked in on his own with a poor command of the Dutch language. When the surgeon tried to explain what the result was, it was not clear for him. After some silence the surgeon asked if his wife was reachable by phone so she could translate it for him. Then, a hands-free conversation, with his telephone on speaker lying on the table, was performed. Although a translator was used, it was not possible to fully explain everything that was going to happen with him.

Patient 10 – Male, 74 – Follow up

This patient came for the follow up appointment.

Questions asked by patient

No questions were asked

Comments/quotes by patient

No comments were given

Attitude of patient

No typical attitude

Things that stood out

Nothing stood out

Patient 11 – Female, 58 – Follow up

This patient came for the follow up appointment. She was part of a cancer treatment trial.

<u>Questions asked by patient</u>

No questions were asked

<u>Comments/quotes by patient</u>

- ‘It is what it is’

<u>Attitude of patient</u>

Nervous when walking in. very relieved when hearing the good news.

<u>Things that stood out</u>

Nothing stood out

Patient 12 – Female, 47 – Follow up

This patient came for the follow up appointment. She is under treatment for the last 8 years by the surgeon. Her tumour stayed the same which is a good thing. The surgeon advised her to start with a trail treatment.

<u>Questions asked by patient</u>

- Starting with another chemotherapy, what is the purpose of it?
- Asking about her quality of life when starting another chemotherapy

<u>Comments/quotes by patient</u>

- I will do it for the feeling, but I do lend quality

<u>Attitude of patient</u>

She was a bit annoyed with the feeling of ‘here we go again’. Especially when the outcome was presented to her and when the surgeon advised the treatment trial.

<u>Things that stood out</u>

Because of her long treatment she had seen it all and started to wondering; why am I doing this. Nothing happened with her tumour except the sickness she got from the chemotherapy. She said that there is a lot of talking without imaging.

Patient 13 – Male, 68 – Follow up

This patient came for the follow up appointment. Metastases were found. The patient was left with a difficult choice. Option 1 was to start with chemotherapy immediately. Option 2 was to wait for at least 3 months (when another appointment was made) to see how the metastases were developed and then maybe start with chemotherapy.

<u>Questions asked by patient</u>

- After hearing the news, how can I take a decision. Based on what?

<u>Comments/quotes by patient</u>

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

<u>Attitude of patient</u>

Nervous when walking in. Devastated when hearing the news. Full of questions when the new treatment options where explained.

<u>Things that stood out</u>

Because of the difficult choice the patient had to make he was eventually send home to think about it and discuss this with his loved ones. The surgeon would call him in a week to make a decision. The surgeon tried to let he patient feel like he was the exception concerning his life expectancy. The patient was in doubt because of his remaining quality of life.

Patient 14 – Male, 68 – New

This patient was new to the surgeon. At the scans a spot was found. It could be a stone or tumour. The patient was relieved when hearing that it could be a stone. When realising that it also might be cancer, a lot of questions arisen. The surgeon told him, that even if it is a stone, that there is still a possibility of 1:1000 that the might die of it.

Questions asked by patient

- If it is not cancer, what is going to happen?
    - What kind of surgery do I need to have
- If it is cancer, what is going to happen?
    - What kind of surgery do I need to have
- What do you think? (directed to the surgeon)
    - If it is malicious?
    - Sown?

Comments/quotes by patient

- I just want to know what is going to happen

Attitude of patient

Nervous when walking in. Relieved when hearing the news. Full of questions when the possible treatment options where explained depending on what it was.

Things that stood out

The positive attitude despite the news that something was wrong.

Patient 15 – Male, 58 – New

This patient was new to the surgeon. Because the real patient was recovering from the examination. His daughter and 2 sons attended the consultation. It was a Turkish family. The surgeon was very sure that there was a tumour in the colon, and possibly one in his liver. If this was true, the patient had a maximum of 2 years to stay alive because the tumour was spread through the patients' blood.

Questions asked by patient/loved ones

- Can't you do surgery on him?

Comments/quotes by patient/loved ones

- How is this possible, he was healthy a year ago.
- How are we going to tell this to him, it will break him.

Attitude of patient/loved ones

Nervous and hopeful at first, when hearing the news confused. After explaining the news very sad and angry.

Things that stood out

The fact that the two sons walked out really angry and devastated, slamming with the door was remarkable. The daughter stayed calm but was very sad. After some time 1 of the sons came back and asked the surgeon if he would not give this news to his father (the patient) because he will suffer from this news potentially shorten his life even more because of stress.

The amount of chaos in the room was remarkable.

Patient 16 – Female, 66 – Follow up
This patient came for the follow up appointment. After been fully treated, she found some blood in her stool. It was harmless and the cancer had not returned.

Questions asked by patient
No questions were asked

Comments/quotes by patient
No comments were given

Attitude of patient
No typical attitude

Things that stood out
Nothing

Patient 17 – Male, 83 – Follow up
This patient came for the follow up appointment but was treated somewhere else. Therefore, it was a new patient to the surgeon. Despite the chemotherapy, the tumour was progressive. The patient was terminally.

Questions asked by patient
- How long do I have to live?
- How much longer with another chemotherapy?

Comments/quotes by patient
- Does chemo still make sense?

Attitude of patient
Devastated

Things that stood out
The struggle of acceptance that he was going to die ‘soon’ and asking if there is really nothing the surgeon could do.

Patient 18 – Female, 65 – Follow up
This patient came for the follow up appointment and was cured

Questions asked by patient
No questions were asked

Comments/quotes by patient
- ‘I googled yesterday’

Attitude of patient
Nervous when walking in. Very happy and relieved when hearing the good news.

Things that stood out
After all the bad news the surgeon became really enthusiastic and happy when seeing the outcome of this patient because he could finally deliver some good news again.

Patient 19– Male, 61 – Follow up

This patient came for the follow up appointment. He had surgery 5 years ago and was back for the results of a check up.

Questions asked by patient

No questions were asked

Comments/quotes by patient

No comments were given

Attitude of patient

No typical attitude

Things that stood out

Nothing

Patient 20 – Female, 56 – New, pre-treated

This patient came for the follow up appointment but as treated before somewhere else. Therefore, a new face to the surgeon. On the scan metastases were found. She was dying.

Questions asked by patient

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

Comments/quotes by patient

- ‘the chemo is really very intense’

Attitude of patient

Angry and devastated

Things that stood out

She said that the previous medical specialist had given her different news (or at least in another way) which gave her hope of getting better. The surgeon had seen the same scans and he was very sure that this was not going to happen.

Patient 21 – Male, 63 – New, pre-treated

This patient came for the first time with an interesting case. He had a rare disease and was therefore an outlier. He had visited many hospitals in the Netherlands and Belgium with his story.

Questions asked by patient

Too many to write down

Comments/quotes by patient

Too many to write down

Attitude of patient

Well informed and judicial

Things that stood out

The surgeon was prepared sending the patient papers with the treatment options and the testing results to inform the patient even more. He felt understood and decided to get treated here in this hospital many because of the attitude and the service the surgeon provided.

Observations Dirkje Sommeijer, Kees Punt, 06-02-18
Oncologists at the AMC Hospital Amsterdam

During the observations attention will be paid to the following points;

- Emotional status of the patient, medical specialist, (loved ones).
- The types of questions that might be asked by the patients, (loved ones)
- Experience the vibe within the room during the appointments.
- Possible categorization of different types of patients based on;
  - Behaviour
  - Questions being asked
  - Acceptation
  - Hope
  - Interest in numerical information
- Determine in what stage of the care path they are.
- Try to speak to as many specialists as possible of the care path
  - Oncologist
  - Oncological surgeon
  - Case manager / nurse
  - Stoma nurse
  - Radiologist
  - Gastrointestinal doctor

General

Number of patients;

- 3 patients
  - 3 Males

Age of patients

- Male average 62 years old (57 - 70)

Patient 1 – Male, 57 – Kees Punt

This patient has been under treatment by Kees Punt for the past 6 years. His tumour started in the colon but now he has metastases in the liver as well.

Questions asked by patient

Because of the long history with this patient, he became an expert on his own case. Therefore, no questions were asked by the patient.

Comments/quotes by patient

No comments were given

Attitude of patient

The patient had a relaxed attitude during the consultation. He had accepted his condition.

Things that stood out

The calm attitude of the patient despite the seriousness of his disease.

Patient 2 – Male, 70 – Dirkje Sommeijer

This patient underwent chemotherapy and came back for the results. Before he was treated in a different hospital. Unfortunately, the tumour was progressive despite the chemotherapy.

Questions asked by patient

The questions asked by the patient were all based on getting the approval to do the alternative treatment in Germany and if there was a combination possible of the regular treatment and the alternative treatment.

Comments/quotes by patient

"I will do anything to be alive as long as possible"

Attitude of patient

During the consultation the patient was first hopeful but, in the end, irritated and he felt let down by the oncologist. This was due to his overall attitude of 'I want to do anything possible to stay a live as long as possible'

Things that stood out

After hearing the bad news, the patient was blaming the previous hospital for the inefficient treatment, which was understandable. When he started talking about the alternative treatment in Germany, he was constantly searching for consent of the oncologist. The oncologist was very strict and could not give him the consent he was looking for which resulted that the patient was turning towards me for confirmation of his treatment plans.

Patient 3 – Male, 60 – Dirkje Sommeijer

This patient came for a follow-up appointment. This was made because of the severe side effects this patient had due to the chemotherapy. He was constantly shaking, incontinent, and in a lot of pain in the throat area. The decision was made together with the patient to stop the chemotherapy and recover first with a prescription of increased medicines. If the patient was not recovering fast, admission to the hospital is necessary. The current blood values showed that it was not necessary yet.

Questions asked by patient

'Can you not increase the dose?'

Comments/quotes by patient

'The pain is breaking me up'

Attitude of patient

The patient was scared and in a lot of pain which made it hard to concentrate for him during the consultation.

Things that stood out

Because of the pain he was constantly focussing and asking about his pain medication and if this could be increased. The rest which was mentioned went right past him. It was very obvious that the quality of life of this patient was decreased to rock bottom.

Observations Jeltje Cnossen, Frederik Wesseling, 13-02-18
Radiotherapists at the Catharina Hospital Eindhoven

During the observations attention will be paid to the following points;

- Emotional status of the patient, medical specialist, (loved ones).
- The types of questions that might be asked by the patients, (loved ones)
- Experience the vibe within the room during the appointments.
- Possible categorization of different types of patients based on;
  - Behaviour
  - Questions being asked
  - Acceptation
  - Hope
  - Interest in numerical information
- Determine in what stage of the care path they are.
- Try to speak to as many specialists as possible of the care path
  - Oncologist
  - Oncological surgeon
  - Case manager / nurse
  - Stoma nurse
  - Radiologist
  - Gastrointestinal doctor

General

Number of patients;

- 2 patients
  - 1 Male
  - 1 Female

Age of patients

- Male 73 years old
- Female 56 years old

Patient 1 – Female, 56 – Jeltje Cnossen

This Patient has a rectal carcinoma and was treated with chemotherapy. The minor side effects were that she was a bit tired and that she had some tingling in her hands and feet, but overall, she did not suffer much from it. In order to remove the tumour, radiotherapy was suggested. During this consultation the patient received the information about the radiotherapy through an outdated booklet. The radiologist manually with pen highlighted the useful parts of the booklet for the patient.

Questions asked by patient

'CT-scan, that's that tunnel?'

Comments/quotes by patient

'Well, we are here anyway'

Attitude of patient

During the consultation the patient came in relaxed and positive. When it became clear that she had to undergo a CT-Scan, she first turned anxious but after explaining it was not the MRI-scan she was relieved and relaxed again. Still she was a bit annoyed that she had to spent more time in the hospital that day and that she had to drink the special fluid for the CT-scan.

Things that stood out

Although it was known for the patient that she started radiotherapy, she was not prepared for the CT-scan. When the radiologist started talking about the MRI-scan, although it was difficult for a patient to understand, it helped to show the MRI scan with the explanation about what was found on the MRI-scan.

The old-fashioned booklet with information about radiotherapy for the patient which was used by the radiotherapist.

Patient 2 – Male, 73 – Frederik Wesseling
This patient has a stadium 4 tumour. The by the MDO suggested radiotherapy was of a palliative nature. The patient has troubles swallowing due to the tumour with an unusual production of mucus. He had lost a significant amount of weight.

<u>Questions asked by patient</u>
'Do I need to get a probe?'

<u>Comments/quotes by patient</u>
No comments were given

<u>Attitude of patient</u>
The patient had a submissive attitude during the consultation just listening and nodding to what the radiologist had to say.

<u>Things that stood out</u>
This patient is also suffering from a bone marrow disease. In the beginning in a different hospital the complaints where all assigned to this disease. After many complaints a look was taken in the throat of the patient with the tumour as consequence.

The way the radiotherapist was explaining everything was very clear which led to hardly any questions on the patients' side.

The old-fashioned booklet with information about radiotherapy for the patient which was used by the radiotherapist. Again, the information needed for the patient within the booklet was manually marked with a pen.

Observations Geert Jan Creemers, 14-02-18
Oncologist at the Catharina Hospital Eindhoven

During the observations attention will be paid to the following points;

- Emotional status of the patient, medical specialist, (loved ones).
- The types of questions that might be asked by the patients, (loved ones)
- Experience the vibe within the room during the appointments.
- Possible categorization of different types of patients based on;
  - Behaviour
  - Questions being asked
  - Acceptation
  - Hope
  - Interest in numerical information
- Determine in what stage of the care path they are.
- Try to speak to as many specialists as possible of the care path
  - Oncologist
  - Oncological surgeon
  - Case manager / nurse
  - Stoma nurse
  - Radiologist
  - Gastrointestinal doctor

<u>Number of patients;</u>

- 11 patients
  - 5 Males
  - 6 Females

<u>Age of patients</u>

- Average 64 years old (50 - 73)
  - Male average of 61 years old
    - 50 – 71
  - Female average of 65 years old
    - 53 – 73

Patient 1 – Male, 57
This patient has a rectal carcinoma with 2 metastases in the liver which is curable. During the consultation the treatment options were presented and explained by the oncologist. First chemotherapy of 3 courses, then if necessary radiotherapy and finally surgery.

Questions asked by patient

- Hearing about the chemo – 'but the tumour does not go away?'
- After realizing that the oncologist did not guarantee him from overcome the cancer – 'you understand that this will get into my head, right?'
- 'How long will I live?'

Comments/quotes by patient
'it remains strange that it was not seen at the hospital in Uden'

Attitude of patient
Anxious when walking in. Then devastated when hearing about the metastases. A bit relieved when told that it can be cured but in the end he had a lot of doubt when the being told that there is no certainty of being fully cured.

Things that stood out
The overall consultation was again supported by showing the images of the MRI scan.

Patient 2 – Male, 67
This patient had a stage 4 tumour. Only palliative care is the remaining option. After the bad news in a previous consultation this was the follow-up. The patient was feeling good despite the diagnosis. Therefore, there was no need for treatment yet.

Questions asked by patient
'can't I come earlier on the next appointment?'
'are you sure that it does not suddenly go faster?'

Comments/quotes by patient
No specific comments

Attitude of patient
Positive but still insecure about not treating.

Things that stood out
The kind of negotiating between patient and oncologist to decide when the next appointment was going be (patient wanted it earlier than the oncologist suggested). Again, the oncologist had to tell the patient that he could not know it for sure about what was going to happen.

Patient 3 – Female, 70
This patient has a gastric carcinoma with metastases in the peritoneum. Her wish is to make it until her 50-year anniversary of her marriage. Previous she started with chemotherapy, although the oncologist had suggested not to do any chemo, but after 2 cures she quitted because of the drastic drop in her quality of life. She had 'recovered' from that and was feeling quit 'fine'. Therefore, the decision was made to stop the treatment.

Questions asked by patient
'Will I make it?'

Comments/quotes by patient
'you expose yourself to the side effects'
'If I knew that the side effects where to be so severe I would have never done it'

Attitude of patient
Submissive and curious about what the oncologist had to tell. Relieved that she most probably would make it until her anniversary.

Things that stood out
The patient was missing imaging and was asking about it. Making choices based on uncertainty is very difficult.

Patient 4 – Female, 67
This was a patient with colon cancer and metastases in the peritoneum. She had started with 4 cures of chemo before the surgery. Then had the surgery and now came for the post-treatment with chemo. There were quit some options for her that where explained by the oncologist. The choice was up to her.

Questions asked by patient
All the questions where about the side effects of the different types of chemo and what to choose.

Comments/quotes by patient
‘what would you choose?’

Attitude of patient
Quite positive in the beginning but a bit feared for the unknown because of the decision that she had to make about the chemo treatment.

Things that stood out
She was constantly referring to here Quality of Life when the options where discussed. Again, imaging was lacking which would have helped this patient in making decisions.

Patient 5 – Male, 71
This patient, ‘who should not have been here anymore’, suffered from pancreatic cancer and had received a chemo treatment after surgery.

Questions asked by patient
All questions where about the side effects that the patient underwent during the last period.

Comments/quotes by patient
‘Can’t we do a scan just to be sure?’

Attitude of patient
Optimistic but critical and accurate.

Things that stood out
The patient had written everything down what he felt between the appointments with the oncologist. He was recording the entire conversation on paper and asked for a copy of the blood results to take home. To comfort the patient a scan was planned for over 3 weeks. At this point the doses of his chemo was adjusted due to the amount of side effects.

Patient 6 – Female, 73
This patient had a stage 4 tumour. Despite the chemo the tumours where progressive.

Questions asked by patient
Because the oncologist asked the questions there were no real questions asked by the patient (also due to the fact that the oncologist was familiar with this patient)

Comments/quotes by patient
‘we have always lived in certainty and are planning to continue doing that’

Attitude of patient
Let everything come about but wanted to be in charge of the decisions.

Things that stood out
The oncologist asked the patient how to continue. The decision of the oncologist to treat the symptoms and not the tumour itself (palliative care). He described prednisone to increase the appetite of the patient to gain weight and strengthen a bit.

Oncologist: ‘How can we make sure to maintain a good level of Quality of Life for as long as possible by treating the symptoms?’

Patient 7 – Male, 68

This was a routine patient. He was suffering from prostate cancer which had metastases. He had received 3 cures of chemo and came for a check-up. He had nearly no side effect of the chemo and everything looked alright.

Questions asked by patient

Because of the ‘positive’ news there were no questions.

Comments/quotes by patient

No specific comments were given

Attitude of patient

The patient was satisfied and calm. He felt understood when the oncologist suggested him to go to the dermatologist.

Things that stood out

The screen of the oncologist was turned to show and explain the blood values to the patient. Because the leg of the patient was quite swollen, the oncologist suggested to make an appointment with the dermatologist for a support stocking.

Patient 8 – Female, 71

This patient was diagnosed with uterine cancer. She had given chemo cures before the necessary surgery. The oncologist suggested chemo afterwards but the patient was not sure of that at the time.

Questions asked by patient

‘Will the tingling fade away over time?’

Comments/quotes by patient

‘Alright then, if the tingling stays at the same level I am fine with it’

Attitude of patient

The patient was touchy but overall calm.

Things that stood out

Due to the touchiness of the patient, the oncologist had to be strict with her for the upcoming treatments. Just to make important decisions to fully cure her of the disease despite the minor side effects.

Patient 9 – Female, 58

This patient had a stadium 4 tumour and was undergoing chemo.

Questions asked by patient

No questions were asked

Comments/quotes by patient

‘it’s going very well so let’s continue’

Attitude of patient

Very positive throughout the short consultation

Things that stood out

Because it was very short nothing really stood out.

Patient 10 – Female, 53

This patient has a colon carcinoma with metastases.

Questions asked by patient

No questions were asked

Comments/quotes by patient

‘I am very relieved, you know...’

Attitude of patient

Nervous at first, but relieved when hearing the good blood values.

Things that stood out

The screen was again used to show the numbers to explain the blood values.

Patient 11 – Male, 50

This patient was diagnosed with a colon carcinoma with metastases and was undergoing chemo cures.

Questions asked by patient

No questions were asked

Comments/quotes by patient

‘Let’s continue with the chemo because I have not suffered a bit. I even walked in two parades

‘I have nothing to say’

Attitude of patient

Positive attitude throughout the entire consultation

Things that stood out

Again, the turning of the screen to show the patient the blood values.

APPENDIX 4

Observations Catharina Hospital 23-01-2018 – Multi Disciplinary Consultation

During my day at the Catharina Hospital in Eindhoven I attended the MDC. This is a meeting of many specialists going through patient cases to discuss and determine how to treat each patient. The specialists attending the MDC were;

- Oncological Surgeon
- Oncologist
- Gastroenterology doctor
- Nuclear medic
- Radiotherapist
- Pathologist
- Nursing specialists of the Surgical Oncology
- Nursing specialists of the Gastroenterology

The different specialists only spoke when their specialty was applicable for the case.

Things that stood out
Each case was dealt with very fast, only a couple of minutes. When a terminally case was dealt with, you could feel the empathy in the room. They felt with the patient each time.

APPENDIX 5

Interview Ignance de Hingh , 23-01-18
Oncological Surgeon at the Catharina Hospital Eindhoven

During the observations with oncological surgeon Ignace de Hingh, questions were asked to get more insights about the Patient Journey.

What is key in treating a patient besides the method of treatment you apply?
To give the right attention to the patient to try to build a bond with them. Having a connection and a certain feeling with the patient is very important. Trust in each other is very important. Every patient is really different.

How do you create this bond?
With small talk you try to build up your bond with the patients and try to make them feel as comfortable as possible.

What does an average consultation look like?
First, you ask them how they are feeling, let them give their own 'diagnose'. Then you address to the results of the scans. Finally, the lab results are used to give a complete diagnose.

To advise patients what to do, I first explain the possibilities. Then, I try so discuss the possibilities. Actually, I would like to have something to make the explanations more visible to make it more understandable for the patients.

How do you deliver good/bad news?
Many times, I explain things with an approach. For example, that chance of getting better is greater than becoming ill again. In my opinion, providing exact numbers to the patient has no use. People are not able to see the right value in the numbers. People are very creative in interpreting numbers coming up with the strangest things. Compare the patients with everybody else. 'How many patients have the same thing'. Patients want to identify themselves. And in case of bad news, try to make the patients feel like they are the exception on the 'rule'.

We have seen a lot of patients that have had chemo at your consultation. Why did they come here, and did not went to the radiologist/oncologist?
Radiologists never do follow up appointments, they only investigate. Surgeons almost do every follow up when the patient had received surgery. Oncologists do the follow up with patients who did not had surgery. It can be different in other countries but these are the discussed in mutual agreements.

When during surgery a stoma is placed, are the patients being informed in front and by whom?
In front of the surgery and it is done by the stoma nurse. Of course, we introduce the matter first during the consultation if we see the possibility that a stoma is necessary. Most of the time only if the tumour is at the left side of the colon.

The voice recordings of this appendix are available upon request.
Please send an email to; siemonvanopstal@gmail.com

Which parties are involved during the MDO?

- Oncological Surgeon
- Oncologist
- Gastroenterology doctor
- Nuclear medic
- Radiotherapist
- Pathologist
- Nursing specialists of the Surgical Oncology
- Nursing specialists of the Gastroenterology

Interview Jeltje Cnossen, 13-02-18
Radiotherapist at the Catharina Hospital Eindhoven

During the observations with radiotherapist Jeltje Cnossen, questions were asked to get more insights about the Patient Journey.

How does the care path of a patient look like in the Catharina?
See interview Ignace de Hingh. This is the same hospital and the care path drawn by him was confirmed by Jeltje Cnossen.

How often does decision making moments occur during a consultation?
The guidelines and protocols are very clear, and most of the time the patient fits these guidelines and protocols. But it is always discussed with the patient. They have the choice to do the treatment or not. It is also possible to only do a part of the treatment, so they do radiation but not the recommended chemotherapy.

So, when the patient has a very distinct case, most of the time they follow our advice. But sometimes a patient decides not to be treated and takes the risks of that choice for granted. But our job is to inform the patient in the best way possible about the consequences if not being treated. When everything is explained, then of course the patient has some time to think about it.

What the patient decides depends on a couple of things, but older people often take their Quality of Life in mind when making decisions about these treatments. When being older, 80 years old, they tend to focus more on the life that they are currently having and do not want to be treated in spite of everything. But a patient of 50 years old, with a husband and a couple of kids, will make different choices with the future in mind.

What is key in treating a patient besides the method of treatment you apply?
To guide the patient as good as possible so that they can make the right decision for themselves. Motivate patients to make a deliberate choice. It does not have to be my choice, because that is not what it is about.

One patient understands the given information better than the other. The same amount of information is not always suitable for every patient. Some patients have the need for a simple trajectory or an elementary amount of information where you explain what is going to happen but they do not need to know all possible options. Other patients want to know absolutely everything about what is going to happen and what the different options are to discuss this with many people before making a decision. This varies for each patient. Every patient is a different case.

I think that there is a group of patients that really need to think about the added value and the consequences of the treatment options with regarding to their Quality of Life when making a decision. And there is a group where it is very obvious that there is a lot to gain from certain treatment options. This is not just age related but it also depends on the actual tumour. If there is a chance of radical resection, when the cutting edges are free of tumour, that is very decisive for the risk of a recurrence or survival. That is what you pursue.

What does an average consultation look like?
Depending on what the purpose is of the visit of the patient. Some patients I see for the first time while others come for results and a follow-up.

How do you deliver good/bad news?
By being to the point. The results are the results and it is my job to tell them. Being direct is the best for the patient.

Do you think the explained proposal of what I am planning to do is going to be helpful for patients?
I think it would be helpful, but only in the beginning when the treatment has not been decided yet. When it is already clear what we are going to do as treatment I do not think it is going to be of any value.

When my design is going to be ‘successful’ would you use it during your consultations?
Yes, absolutely. Adjuvantonline.nl and mskcc.org I am using already for breast cancer patients. For the rectal carcinoma there is nothing yet. I would especially use it to explain to the patient what the profit is of the certain treatment.

If you apply radiation therapy for patients with breast cancer and a piece of the lungs is also being radiated (because it is inevitable) and the patient also smokes, the chance of lung cancer increases dramatically. So, what is there to gain with the primary target to radiate the breast if you get lung cancer in return. And what do patients find acceptable.

It would be nicer to have a more accurate prediction of what the chances are for one patient instead of constantly speaking in a very abstract level of the possible chances.

Despite everything that is findable on the internet, I think this idea is very desirable. I am happy that there is somebody who is willing to create something for this problem.

What is the reason to give more or less information during a consultation?
Depending on the patient I adjust the amount of information I am going to give to the patient. Not everybody wants to know everything. Some patients just come in to listen what I have to say. But it is not the case that I hold something back for the patient. It has also to do for which appointment the patient comes, when it is just a follow-up then the patients know everything already so les information is needed. But you notice whom is sitting across the table and what they want to know.

Other interesting things that were mentioned

- Induction chemotherapy (specialty of Catharina, not always used in other hospitals), then radiation and chemo at the same time, then surgery, then optionally radiation in the after-care.
- When you have a change of 2% to get back the disease and unfortunately you get the disease back, you have it not just for 2%, you have it for the full 100%.
- Check mskcc.org and adjuvanonline.nl
- We see only patients that we can treat, we always try to improve their Quality of Life.

Interview Geert Jan Creemers, 14-02-18
Oncologist at the Catharina Hospital Eindhoven

During the observations with oncologist Geert Jan Creemers, questions were asked to get more insights about the Patient Journey.

How does the care path of a patient look like in the AMC?
See interview Ignace de Hingh. This is the same hospital and the care path drawn by him was confirmed by Geert Jan Creemers.

How often does decision making moments occur during a consultation?
There are always choices to make. Making decisions is a thing you do together with the patient. Always. Of course, when the treatment has started than there is nothing to choose anymore, but that treatment was based on a decision. Each time a treatment has ended, new decision moments occur depending on how the patient is feeling.

Some time ago a patient told me that he wanted to stop with his chemotherapy after cure 1. He said this is no quality of life. And I think that is admirable. However, it raises the question, where is this decision based on. For example, the previous patient that we have seen is a simple man. I did not know where his decision was based on, but I understand it completely. The possible gain of the treatment was significantly low in comparison to the side effects. And that makes it hard, with one patient you really need to talk and act semi-intellectual, and with the other patient it is about small talk in a very informal way.

Are the patients prepared for the decision-making moments?
Unfortunately, most of them are not. They base their decision on emotion or nothing at all.

What is key in treating a patient besides the method of treatment you apply?
To know with what kind of people/patients you are dealing with. When you know the person you are treating, you can help them in the best way possible. That is very hard when I see patients for the first time. When you know them, you know what their emotions are and how to deal with them.

What does an average consultation look like?
The patients come here after a scan has been made. This is discussed ate the MDO wherever a treatment plan is made. I only do the 'special' cases. When a patient fits the guidelines and protocols and the treatment plan is straightforward I let them be taking care by the specialized nurse. They undergo their treatment and afterwards I see them to check whether everything went according plan. This is the piece of care with minor decision moments because it is straightforward. Mainly the choice is to treat or not to treat. When treated there is only one option. The other cases, where the patient can choose what to do, then they come to me. But even if it is a straightforward case, they would like to see me at some point. The one who is actual treating them.

How do you deliver good/bad news?
To the point, so the patients know what they are dealing with.

Do you think the explained proposal of what I am planning to do is going to be helpful for patients?
If people would be better prepared when coming to my consultations than everything would be a lot easier. You have to make the decisions together. Every single patient is making different decisions. Every patient is different the make different decisions, different things are important to them. It's about getting everyone the space to make their own decisions. People should realize that **they** make the decision. It is not the case that everything is obligatory what we suggest. Nothing is obligatory.

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

<u>Other interesting things that were mentioned</u>

- Doubt is intolerant, bad news is doable. When you know the results are bad, then you know at least where you are dealing with.
- 'I always go get the patients myself from the waiting room, this way I have 30 meters to determine the condition of the patient and to record the non-verbal communication.'

- When a patient responds to an explanation; I did not know that. That the information that you are trying to tell after that moment is useless. Sometimes, I send patients away and ask them to make an appointment for the next day. They are so full of emotion I cannot communicate with them. So, if patients are better informed in advance, because you need to make the decisions together, then everything would go a lot smoother.
- The guidelines of the care path are very useful. When the patient fits the predefined care path then we do not think about what the gain is of the offered treatments. We just execute them. We do not give the patient the feeling that there is something to choose. But what to do if the patient is 80. What is there to gain. If we proceed with the guidelines and right after surgery give chemotherapy then we would kill the patient. There are a lot of nuances within this grey area. The question is there to ask; to what point can you include the patient in making decisions. In the case of curate, it is very difficult.
- Many people state; if you can, do it. But in our profession; you could do but is it something that we must do. That is very difficult.
- Care paths or meant for patients where there is a lot to gain. They are not for the patients who only have a couple of months left.
- In the palliative care, how can we give in formation I the best way. That is something that we do not know.
- I do not care what a patient chooses, in the end it is not op to me. My task is to provide the patient with the right amount of information where they can base their decision on. That is very difficult and sometimes it takes a lot of time to do so.
- The one patient comes here so often that they see this as just a place they need to go with no emotion, they can make good decisions. Some patients, mostly that come for the first few times that need to make decisions, are so emotional that they cannot make the decision.

APPENDIX 6

Interview questions for (ex)patients with colon cancer and informal caregivers

About consultations

- How did/do you experience the consultations at the hospital?
- Could you describe how a consultation looked like?
- Could think of anything the specialist said to you that you still remember that had an impact on you?
- How did you feel before, during, after the consultations?
- How did you feel through the entire care path?

About the specialists

- Did/do you have a connection with the treating specialists?
  - No, why not?
  - Yes, how did it develop?
- Who was most valuable for you during the care path?

About SDM moments

- Did/do you had the feeling that you had something to choose during the care path?
  - When did those choosing options occur?
  - With whom did you make those decisions? (elaborate)
    - Alone
    - With the specialist
    - With your family
    - Other
  - When did you make the final decision?
    - At home, when?
    - In the Hospital, when?
    - Somewhere else?
  - How did you make the decisions?
    - Impulsive on emotion
    - Following the specialist's advice
    - considered
- Should these decision moments be adjusted for fellow sufferers?
  - How?

About information

- Did you search for information during the care path?
  - Where did you obtained this information?
    - Websites
    - Books
    - Flyers
    - Told by the specialist
- Did you looked for something but could not find it?
- Could you describe what the best 'package' of information could have been for you?

The voice recordings of this appendix are available upon request.
Please send an email to; siemonvanopstal@gmail.com

Conclusions Patient / Informal Carer interviews

Interviewee(s) 1

Interviewee(s)	Patient & IC
Age of patient at diagnosis	61
Gender of patient	Male
Year of Diagnose	2017
Reason of diagnosis	Population screening
In active treatment	Yes, aftercare because of inflammation complications
Maximum stadium of patient	II
Place of treatment of patient	Amphia Hospital Breda

Consultations

- There is a difference in feeling in the different consultations
    - Before the final diagnose, tensive
    - During the treatment, tensive in the beginning because it is all new. After a while resigned.
    - After the treatment. Tensive again with all the scans that needed to be made. What if it has returned? When a wound is healing you can feel that, but if a tumour is growing, you have no idea.
- They talked a lot about the disease at home. How he was feeling etc. There was no 'I' during the care path. Only 'we'. You come up with questions together before consultation, and during we asked them.
- Depending on what there need to be discussed during the consultation your emotion and feeling takes shape.
- The feeling before, during and after a consultation is very dependent on what there is to discuss during that specific consultation.
    - 'Maybe you are going to the hospital to collect your own death warrant'
- Nothing was said specifically about the stadium of the tumour.

Specialist

- 'the first 1,5 year after treatment is very important'
- There was a good connection with the oncological surgeon. He was clear in his communication and about the changes that I had. He could elaborate very well on his opinion and way of treatment. He felt very well how to respond to my questions.
- Communication is key.

SDM

- The treatment was straightforward with 'nothing' to choose. We believed in the advice of the specialist, because of the way how he explained it.
- All the 'choices' were made by us and later confirmed with the specialist that was trusted.
- The decisions that occur were made directly at the hospital during the consultations.

Information

- A lot of information noise was given by the people around us, unintentionally.
- No information was searched for, besides the flyers that was presented by the hospital during the treatment.
- Information was not given about the long-term side effects of the radiation. If they had known that it was going to be like this. Than the decision was not changed but then, he could have been prepared for this. Dealt with it a bit better.
- Hardly any information was given about any possible complications that may occur after surgery. It overtook them.

Other

- The attitude and character of the person is very dependent on how they deal with the care path and the decisions that comes with it.
- Not being aware of something bad, that could happen, and it happens, is a setback.
- Expectation pattern is key to the experience and feeling of the patient. Placing treatment options and the side effects in perspective contributes to this.
    - ‘I do not have the illusion that I will be my old self again’

Interviewee(s) 2

Interviewee(s)	Patient
Age of patient at diagnosis	63
Gender of patient	Male
Year of diagnosis	2017
Reason of diagnosis	Population screening
In active treatment	No
Maximum stadium of patient	I
Place of treatment of patient	Amphia Hospital Breda, (intestinal examination at PoliDirect in Eindhoven)

Consultations

- Nothing was said specifically about the stadium of the tumour.
- ‘Apparently, when being diagnosed with colon cancer, there is still something that can be done. So, let’s go for it ‘.
- Because of the first consultation with the oncological surgeon, almost all the fear I had built up till this point was taken away.’ That was a liberation’. This was done by him by telling me what the plan was. Knowing exactly what was going to happen took away the fear of the uncertainty. After that, you know which route you go into.
- ‘Uncertainty is the worst you can have’
- There is a difference in feeling in the different consultations
    - Before the final diagnose, tensive. You do not know what is inside of your body.
    - When hearing the treatment plan, you become relieved because there is something that they can do. There is a clear plan.

    - After the treatment.
- The GP talked about percentages and a very small change that I had cancer. This was before I went to Eindhoven to the MDL Doctor at Poli-Direct.

Specialist

- With both the MDL doctor and the surgeon I had comfortable conversations. The MDL doctor was from Belgium, which made hem very clear about what he had to tell. He really took the time to tell me everything that I needed to know. If I did not get his answers he tried to explain it in a different way. When everything was clear, only then he ended the consultation. The surgeon did the same thing.
- Besides these 2 specialists there was also a case manager (nurse) who was compassionate and of great value. After the consultations with the specialists we (my wife and I) sad down with her to talk about the day of the surgery, how it was going to be, what to expect etc.

SDM

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

Information

- Once, after the result of the population screening, I have searched the internet about intestinal examination. After a couple of stories, I closed it off. It did not make me smarter but only made me more nervous.
- ‘I’d rather go cycling to clear my head instead of looking for information on the internet’
- When the chances were told by the GP I did a quick look on the internet through google before going to Eindhoven with the feeling that everything was okay. But it wasn’t. ‘Then I thought, Sh*t, why am I the patsy. And then very quickly I though why should it not be me.’ It made me really sad… also because I retired recently.

Other

- The need for a check-up after the dismission by the hospital was desired. The patient had built up so much tension between the time of the diagnosis and the surgery, that he wanted to be checked after a couple of months. Just to be sure. However, the specialist had told him that it was not necessary.
- No pre-treatment before the surgery was performed.
- The period between the population screening results and the intestinal examination is very difficult. When receiving the results of the examination you know what is wrong. That is still difficult, but then you have your diagnosis and your prognosis. ‘you know what you have’.
- The second time, after surgery, again, a percentage was told what the change was of the tumour to return. But the way how it was said gave me a lot of confidence.
- Before the diagnosis you do not feel sick at all, but when you hear it, then all of a sudden you start feeling things inside of your abdominal.

which is of course very strange.

- ‘I think the attitude of the patients, in the area of decision making, has to do with age. The older the patient gets, the more willing they are to listen to the doctor and accept what the doctor suggests. While younger patients want to know more about the different options that they have. But I am not sure of that.’

Interviewee(s) 3

Interviewee(s)	Patient
Age of patient at diagnosis	61
Gender of patient	Female
Year of Diagnose	2007
Reason of diagnosis	Bowel complaints
In active treatment	No
Maximum stadium of patient	I
Place of treatment of patient	Amphia Hospital Breda

Consultations

- Nothing was said specifically about the stadium of the tumour.
- I had a special meeting with the MDL doctor for the results of the examination. This was not on a typical day when normally these consultations occur. However, because I was feeling insecure to wait so long for the results, he suggested that I could come at this specific day.
- When the word ‘cancer’ was mentioned everything stopped. I felt myself sinking. You know that something is wrong, otherwise you would not be in that place but when confronted with cancer that is something completely different and totally ‘out of this world’ at that moment. This is the end of the world I thought. I Just received my death warrant. That is what I felt. Of course, this was not the case but I did not know that back then.
- Before going to the consultations, we all sat down and talked about the questions that we had. My questions, but also the questions of my husband and children. Then we went with the 3 of us to the consultation. Me and my husband were one. My daughter, which of course is still very close to me, stood a bit further away so she had more questions about practicalities which I was not aware of at that time.
- I even thought at a moment that if I ask something carefully then I will get a careful answer. This is of course not true. The specialists are very straight forward with their answers.
- Tension was build up every time before a consultation about the results of an examination. Very relieved when hearing the good news. He mind was set on the next appointment which was 3 months further.

Specialist

- The MDO doctor made a special appoint for me to talk about the results of the first examinations, which took a couple of hours. He answered all our questions. We talked about many things not only about the disease. He did this to comfort me which was very pleasant.
- After the special consultation with the MDL doctor I had meeting with my case manager (specialised nurse). During this conversation we discussed how the treatment would look like and what to expect. They prepared me for the entire ‘journey’ which was really pleasant.

- The surgeon was also a nice person, not a friend, but still a nice and helpful person.
- The specialists were very important to me when it came down to making decisions. Being diagnosed with cancer shocks you. There is no way you are prepared for that news, let alone making decisions about the thing that shocked you. You need the professional to help you with that. Listen to them, undergo it, and then make your own decision. I needed them to give clarity about the different options that I had.

SDM

- The decisions that were made were all with my family and the specialist. First at home with my family and the during the consultations with the specialist.
- I have chosen for the ‘big surgery’ when they just ‘open up my abdomen’ and removed a piece of my colon instead of a partial removal with a lookup. I felt more reassured with the total removal. This decision was made at home with my family and then we went to the surgeon to tell him my preference.

Information

- The hospital gave a lot of information to take home, but still I started googling. You should not do that, because you see the worst-case scenarios. But still, you’re going to search.
- I have also read a lot of flyers in the waiting room of the hospital besides the flyers that they already had given me. And of course, the explanation from the hospital staff is an important source of information which was really useful.
- Everything I had questions about could be found or were answered by the specialists.
- I was looking for information about stoma’s and what kind of surgery’s I could choose from.
- Most of the questions arisen after the consultations back at home. You take the conversation in your head with you, then you start to think about it. When you sit there, you can’t think. Then you start talking about it with your family and then the questions arise.

Other

- There was always someone at my side during the appointments. My husband of course in the beginning and later my children. They are always there for me. Later we went with the 3 of us to the consultations.
- We, as a family, have talked a lot about my diagnosis.
- People not so close to the patient downplayed her case and said ‘it will be alright’ while she was feeling quite nervous about it. ‘Afterwards they were all right. But I will never do that to somebody else. Everybody has their own worries and fear about it, and you should respect that. That is different for each individual.’
- Only after 3 years of the surgery I became convinced that everything was healed and dealt with. It took me a long time. Every time I felt something in my abdomen, I became worried. The cancer left his mark on me. A whole lot less than before but still.
- ‘I would not be the first were after 10 years the cancers comes back.’

Interviewee(s) 4

Interviewee(s)	IC
Age of patient at diagnosis	83
Gender of patient	Female
Year of Diagnose	2011
Reason of diagnosis	Bowel complaints, could not eat anymore due to clocking of the colon
In active treatment	No, the patient has passed away
Maximum stadium of patient	IV
Place of treatment of patient	Amphia Hospital Breda

Consultations

- Nothing was said specifically about the stadium of the tumour.
- During the consultation after the surgery 1 positive gland was found. The specialist suggested not to do chemotherapy because of her condition and age. He also told that the growing tissue of older people is very slow. So, if it was growing, that she most likely would die of old age instead of the tumour. The risk that she would die from the tumours was much smaller than another cause of death. She agreed with the surgeon.
- The decision was made during the MDO that no after treatment was necessary because of the age and condition of the patient.
- She reacted very sober to the care path. Took it as it was. 'We'll see when the time has come.'

Specialist

- The specialist had given the information in an optimistic way that the change that the tumour would return within a short amount of time was most likely no going to happen. He was wrong. It did return within the year with metastases.
- The doctor and the hospital were not blamed for the consultant that they have done with the tragic outcome.
- A connection was there between the oncological surgeon and the patient and with the family. He was devastated about the unfortunate outcome in that short time.

SDM

- The decision was made to not do adjuvant chemotherapy after surgery. This decision was made because of her age and condition. In addition, she was living alone and was font of her freedom. When she would have started the chemotherapy, she was most likely to lose that freedom because she would have been admitted to a special care facility due to the chemo. We as a family, were at ease with that decision. But after a year everything has returned.
- Me and my 2 brothers have discussed thoroughly what the chemo could do to her. We found it irresponsible to treat her with it. Because she was living alone.
- Before we went to the consultation of the results of the surgery we had discussed everything at home with the family. Basically, the decision was made at home and then confirmed by the specialist during the

consultation. Maybe the specialist, although then the obvious decision, should have informed us about the possible other treatments.

- She was very sober in making decisions. Almost to sober. She did not was emotional about it. At least she did not show them. When she did, it was expressed in anger. Not in self-pity.
- The daughter (interviewee) of the patient has been working in the hospital for over 25 years. She was aware of the possibilities of making decisions. She had a very active attitude in this.
- It was decided, with the family, that she remained home for the final phase of her live.
- The decision was made well thought, not impulsive. Not based on emotions.

<u>Information</u>

- Information was searched on the internet. Especially about symptoms.
- Could not remember exactly what she looked for. But she did search for ‘answers’.
- According to the interviewee, patients should be aware of

<u>Other</u>

- The patient could not eat any more. The tumour was that big that it blocked everything. The diagnose was made in October but she could only be operated in December. But it was not sufficient which resulted in a visit to the acute care where she was treated immediately. Approximately, a week before the surgery was planned a ‘temporary’ stoma was the result of that surgery. Later, another surgery was done to remove the tumour.
- The patient itself was unaware of the weight loss and the decreasing condition. ‘But I noticed that it was not good, so I took her to see the GP (she didn’t want to go). I think she was afraid.’
- Due to the blocked colon an immediate surgery was necessary. Therefore, no pre-treatment of radiotherapy and chemo was applied.
- She thought that she had remembered the treatment steps but said; ‘there is nothing so deceitful as the human brain.’
- The patient had accepted the prognosis very quick.
- Afterwards, I thought, when it had returned, if we had not make the wrong decision.
- The patient was caring about the quality of life. She said; ‘as long if won’t have any pain’. But always being sick, lying in a bed was not the future she wanted.
- ‘When looking back, I think it is just bad luck.’ You just do not expect that the mitosis of an 84-year-old is that high which results in metastases. You just don’t expect that.
- He talked about a risk of 5%. Then we thought; 5 % at her age, nothing will happen. But looking back we should have done the chemotherapy.
- She said; ‘I’d rather live a year shorter, and that I can live normally instead of adding an extra year with being sick all the time because of the

chemo. Quality of life was more important then living a bit longer.

- She was very stubborn, when there was need for 24-hour care. She hated it. She lost all her freedom.
- The IC was constantly talking about the treatment team of the hospital and what they suggested. This indicates for me that she was guessing herself about the decision that was made back then.

Interviewee(s) 5

Interviewee(s)	Patient
Age of patient at diagnosis	37
Gender of patient	Male
Year of Diagnose	2002
Reason of diagnosis	Bowel complaints
In active treatment	No
Maximum stadium of patient	IV
Place of treatment of patient	Amphia Hospital Breda

Consultations

- Nothing was said specifically about the stadium of the tumour. However, he had the report of the hospital so he could see what his stadium was.
- When hearing what you have every emotion passes by, anger, sad, emotional, etc. You start asking yourself why me at this specific age? Everybody around you is shocked by your diagnosis even the specialists.

Specialist

- ‘The most important thing for me with a specialist is that you have confidence in what the specialist is telling you’. I literally asked the specialist ‘why should you treat me, what makes you the best?’.
- ‘Trust in a specialist is key for your care path,’
- After the first surgery, the removal of the rectal carcinoma, no adjuvant chemo was suggested with the reason to maintain the current quality of life.

SDM

- ‘In my case, I had the feeling that there were no decisions to make. In my situation with a young wife and 2 small children I had to take any possibility that may helped.
- There was no I in this care path, everything was discussed with my wife.
- The decisions were all made immediately during the consultations. There was nothing to think about.
- ‘My opinion is that you always should respect the decisions of the patient. He or She is the one to undergo the entire trajectory.’

Information

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

<u>Other</u>

- This patient was a nurse who has worked in the OR. Because of the medical background he knew a lot about all the things that are not naturally to other patients.
- Because of his background he knew a lot of people who could suggest him the best specialists. I was willing to go to the best place. If it was in Groningen, then I would have gone there. I used this to my advantage of knowing a lot of people.
- Specialists are not aware of what time can do to a patient. When I started with my treatment, they told me that I could receive radiotherapy as a pre-treatment before the surgery. However, there was no place for me until 5 weeks later in Tilburg. First, they give you your death warrant with the news that you have cancer, and then they expect you to sit quit for 5 weeks, that is absurd. So, I started calling and after 2 weeks I received my first radiation in Vlissingen. I could not image how horrible this must be for other patients who do not have the same connections as I did.
- Your young age is the main motivator to start fighting the cancer. You are full in life with 2 small children and a wife. No matter what, you want to fight for it. Even when the opportunities are very small. Luckily for me, there was always something they could do.
- When hearing the diagnosis, your future becomes very short. It becomes riding to Vlissingen to be radiated. The next future is the day of the surgery.
- Multiple surgeries were performed,
    - First to remove the tumour, but during the surgery the gall bladder was hit. Because of this he stayed sick.
    - Therefore, after a couple of weeks, he needed surgery to his gall bladder. But then his lungs gave up due to the stress arisen from the surgeries. He was put 12 days on breathing support on the intensive care. Can’t remember a thing of that. He stayed at the hospital for 7 weeks.
    - After a couple of follow-ups metastases were found in the liver. This was removed by laser ablation
    - 2 months later the metastases had returned in the liver and 70% of the liver was removed.
- 10 minutes after receiving the bad news that he had colon cancer, he needed to see the stoma nurse for the explanation about how to deal with that. ‘That was absurd, even unrealistic at that time. Everything that was said in that room went right past me.’
- Overall, I had the feeling that the hospital had taken excellent care of me. Also, because you are a special case. Young, just married, 2 small children.
- After the word cancer, everything else becomes subordinate.
- I did not what to expect from my body after all these surgeries. When do I need to get worried and when is it the result and feeling of the surgery.

Interviewee(s) 6

Interviewee(s)	IC
Age of patient at diagnosis	56
Gender of patient	Female
Year of Diagnose	2014
Reason of diagnosis	Bowel complaints
In active treatment	No, the patient has passed away
Maximum stadium of patient	IV
Place of treatment of patient	Amphia Hospital Breda and VUMC Amsterdam

Consultations

- ‘When hearing the results of the endoscopy, it dropped like a bomb.’
- The consultations were fine. But in the beginning, there was a lot of uncertainty which is not nice at all. When the chemo started then every time a cure was done the nervousness raised because you did not know if it helped any besides the awful side effects that she suffered.

Specialist

- We had a very nice oncological surgeon for the colon carcinoma and we had a good surgeon for the liver metastases.
- In the beginning with the oncologist between my wife and him was a kind of tension. But this was cleared quit quickly. At the final consultation he gave her 3 kisses and told her that she was a nice patient and you did so well. ‘She felt proud of that.
- The oncologist of the VUMC was a perfect doctor. We had a quick connection.
- The Amphia suggested us to go to the VUMC because of the collaboration between the 2 hospitals. And we trusted out oncologist. We never regretted that decision.
- I think a fixed specialist is needed during care path. If there is no connection with the doctor it would be nice to change doctors. Our oncologist at the Amphia was perfect for us. In the end I wrote him a letter of gratitude of the care that he has given us.

SDM

- When we got the diagnosis, we have decided that we have to deal with this together. Our daughters need to keep going with their lives, study etc. Because I am retired I was always with her at every appointment.
- Many times, we have tried the things that were possible but the first cure was too intense because of the side effects so we had to quit. The quality of life had dropped dramatically.
- When the option was offered by the VUMC with a 0,01% change of success but guaranteed of becoming ill we decided to nothing for a while and enjoy our summer.
- After declining the cure at the VUMC we went back in October to the Amphia and they offered us another cure. We accepted but the cure did

not do anything.

- There are no decisions to make, I see them as distorted facts. The specialists suggest you a type of cure and after 6 cures the side effects become so severe that there is no other option to not continue with this type cure.
- They all give you advise but it is not your field of expertise so you agree to the suggestions.
- Many people around us gave us advice like go to Belgium, go to there. But that was based on a case which had success which is of course not realistic. We gave our trust in the doctors that we had.
- She wanted to enjoy the summer instead of being in agony of the side effects and in and out of the hospital. I was very proud of her when she said that because it was not an easy decision to make.
- Quality of life was finally the key in the decision. Do you need to live 8 months in agony and buy some time or do you want to live for 8 months whereof you can enjoy 6 of them?
- Almost every time we went to see the oncologist during the consultation we knew what we wanted. We had discussed this at home. Most of the time we follow the recommendations of the oncologist.
- All the decisions were made well thought and together. And we always received the respect of the specialists which each decision that was made despite it was most of the time their preference as well.

Information

- I have read everything we received about the different types of chemo. About the side effects and how it actually worked etc. Our daughters have searched on the internet but we did not do that. We accepted our faith.
- When we started the care path at the VUMC, we made the immediate decision to do the trail. The oncologist told us to let him know finally a couple of days from now. So, we started talking about it at home and finally, after reading the entire book work, we made the decisions to do the cure.
- The second trial went the same way but we had decided to not do that cure.
- The oncologist was aware what information we needed to be able to make the decisions. He did not overload us with information that we did not wanted to have.

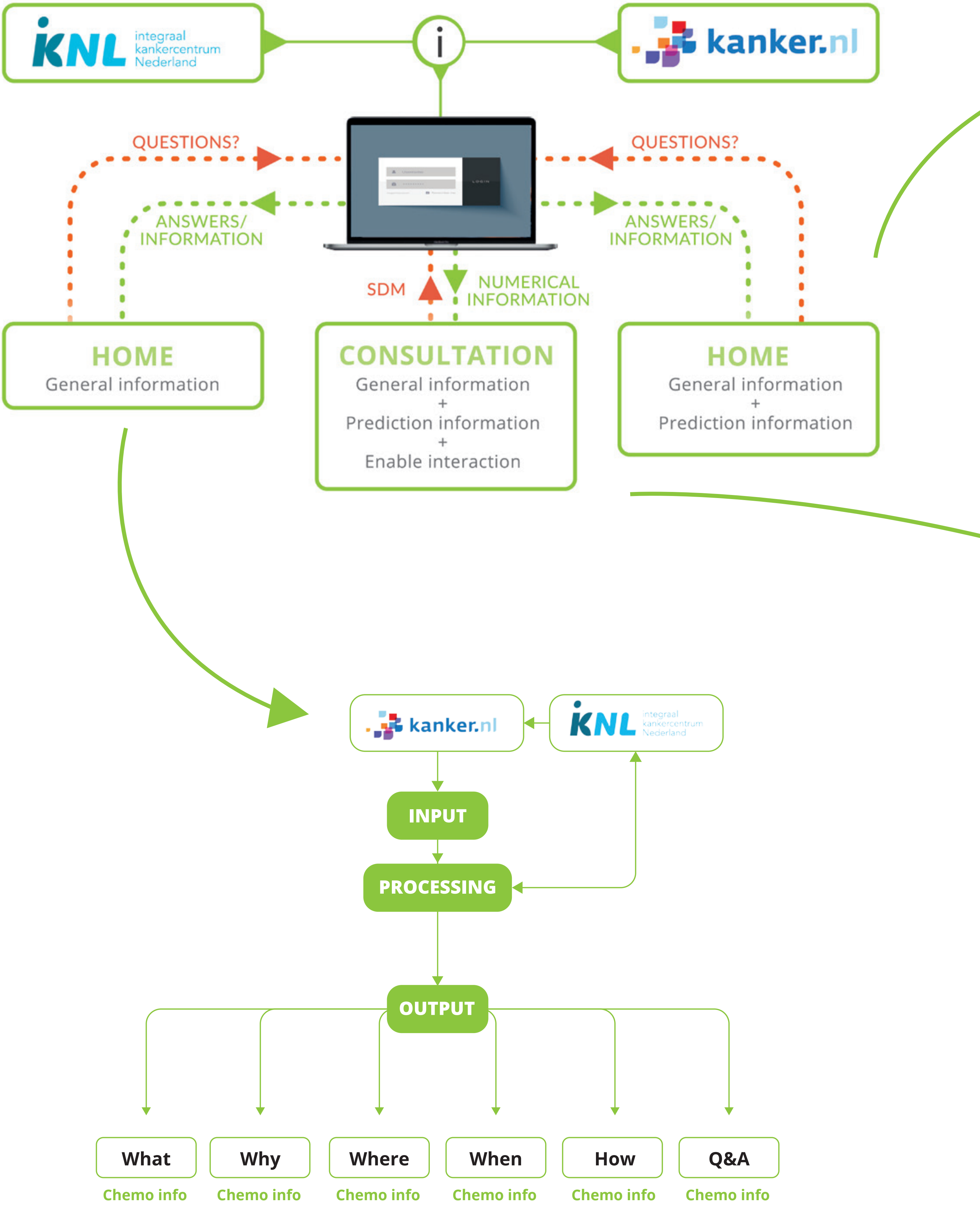
Other

- ‘We accepted the prognosis. She said; this happens to me, so let’s make something out of it. We need to discuss everything with each other on how to continue from here.’
- The time that we had left was really precious to me but it was always ‘enjoying with the parking brake on’.
- From the moment we know what was going on, I have never seen her on any picture in the way before we knew it.
- ‘I was very lucky to have known her for 42 years.’
- The first cure did something but was undoable due to the side effects,

tingling in the fingers and feet. The second cure did almost nothing. Then we were send to the VUMC because the Amphia could not do anything more for her.

- At the VUMC there were some options for different trials which was explained very well by the oncologist. A decision was made but the cure did not do anything. Then you enter experimental phase 1. They gave us a big pile of papers with information, which says you got 0,01% change that the cure is going to do something but that you will become ill… guaranteed.
- They were very clear about the amount of information they wanted to receive. This was the superficial amount.
- Percentages were mentioned quite often, but we do not feel the value in statistics about this subject. We have made decisions more based on feelings.
- The awareness of being ill is in your head, because you have been ill for a long time without knowing this.

APPENDIX 7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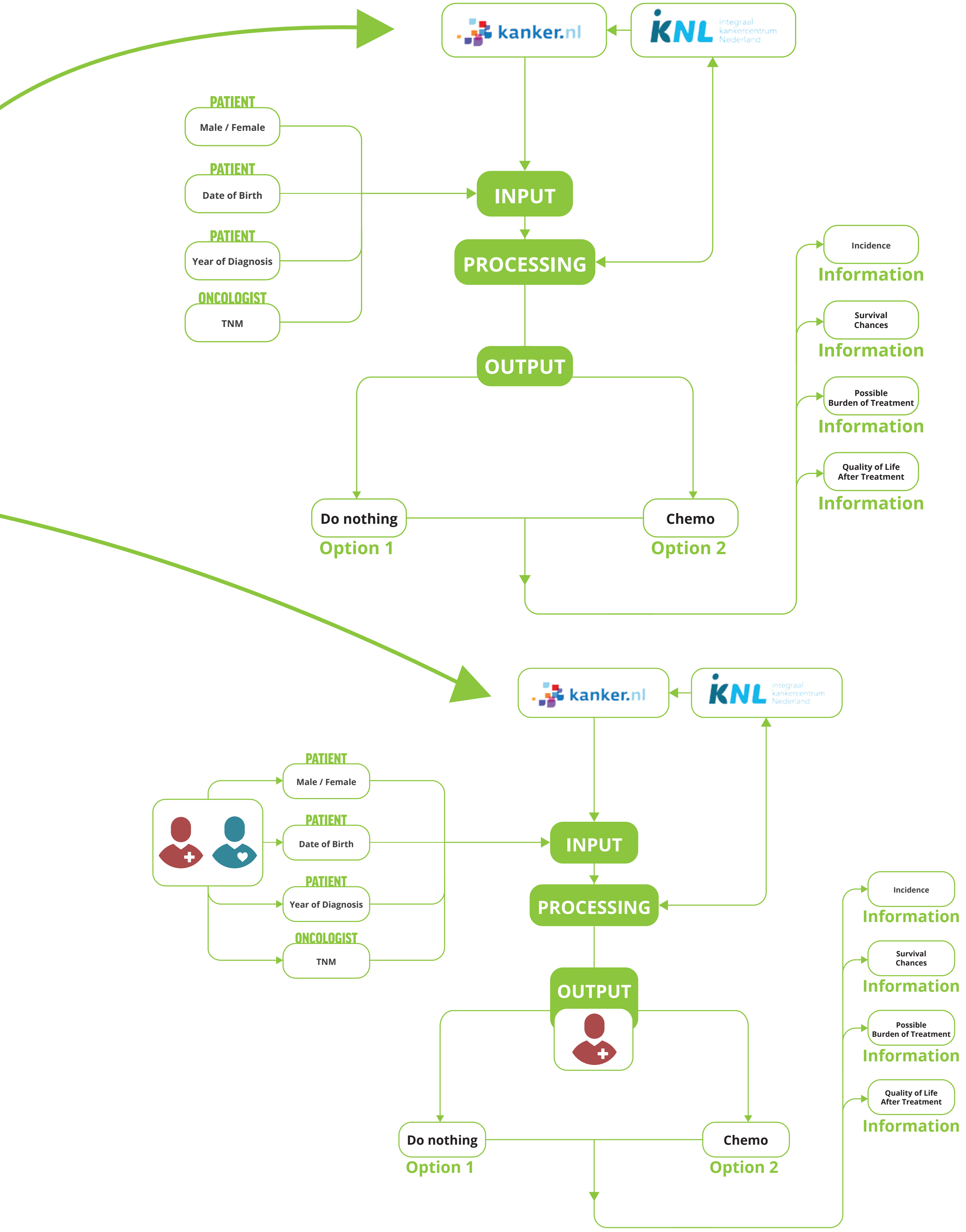
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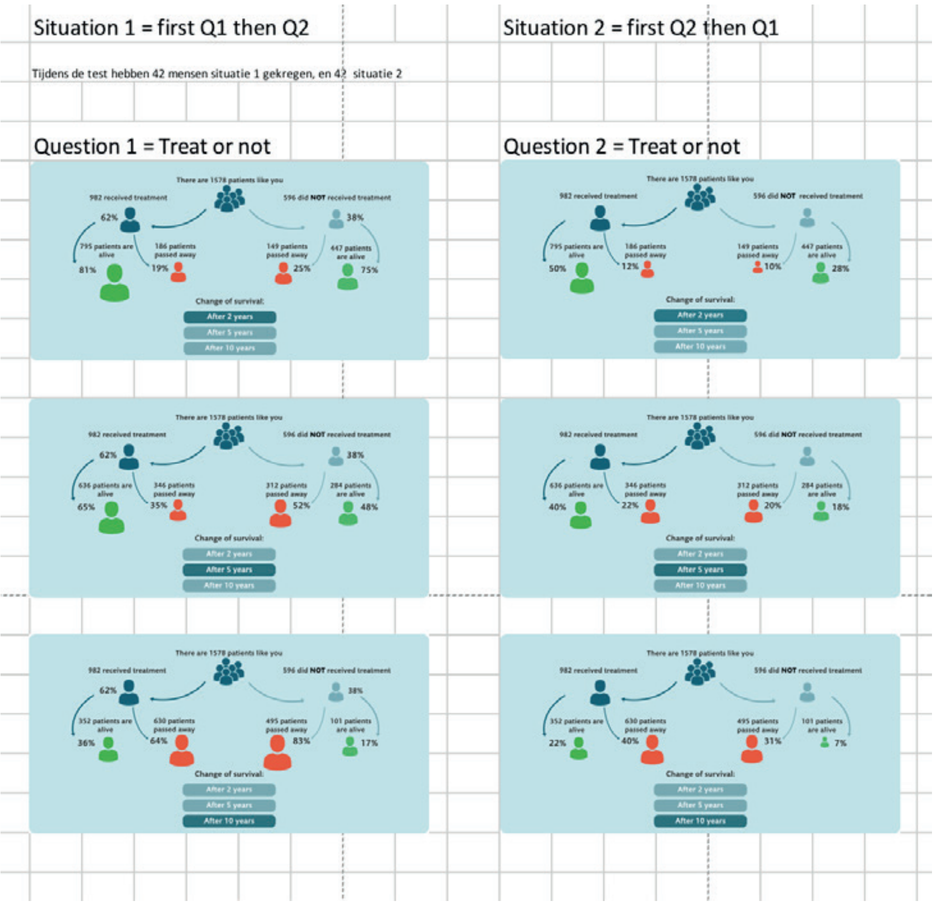
APPENDIX 8



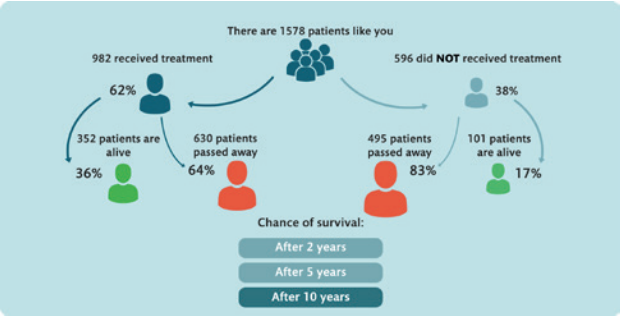
Situation 1 = first Q1 then Q2

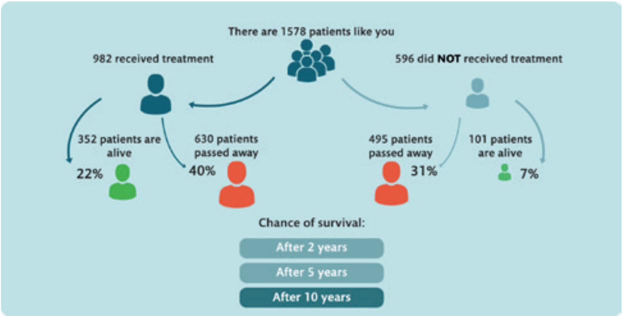
Situation 2 = first Q2 then Q1

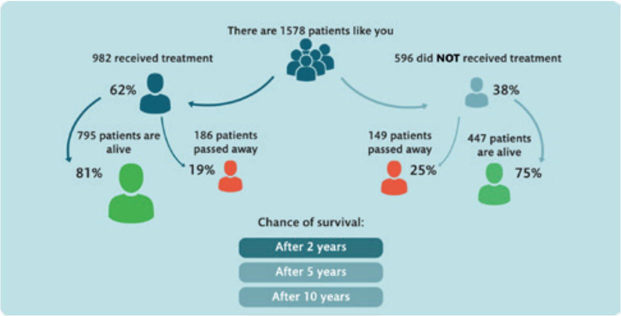
Tijdens de test hebben 42 mensen situatie 1 gekregen, en 42 situatie 2

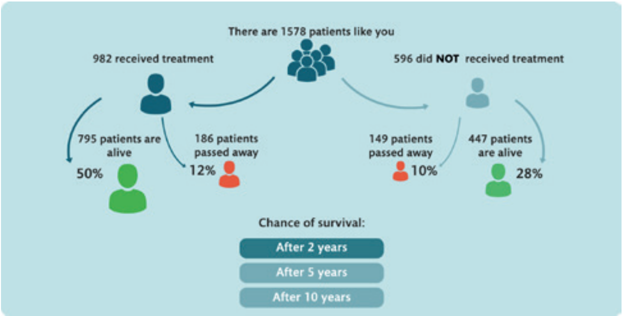
Question 1 = Treat or not

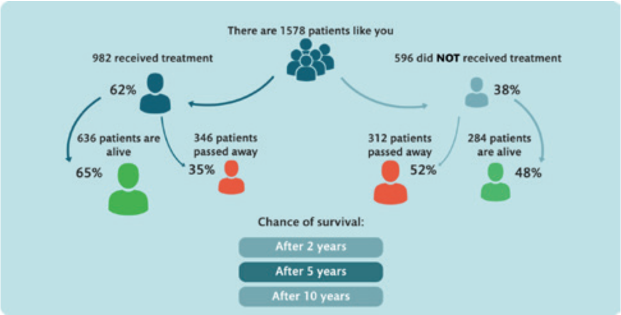
Question 2 = Treat or not

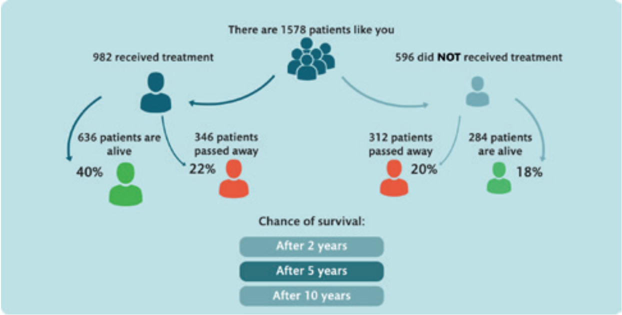












Situation 1 = first Q1 then Q2

Situation	Number of respondant	Man/Vrouw	Leeftijd	Question 1 = Wat kies je?	Question 2 = Wat kies je?
1	1	Vrouw	27	Wel behandelen	Wel behandelen
1	2	Vrouw	29	Wel behandelen	Wel behandelen
1	3	Vrouw	18	Niet behandelen	Wel behandelen
1	4	Vrouw	24	Wel behandelen	Wel behandelen
1	5	Man	26	Wel behandelen	Wel behandelen
1	6	Man	27	Niet behandelen	Niet behandelen
1	7	Man	20	Wel behandelen	Niet behandelen
1	8	Vrouw	22	Wel behandelen	Wel behandelen
1	9	Man	23	Niet behandelen	Niet behandelen
1	10	Vrouw	32	Wel behandelen	Wel behandelen
1	11	Man	27	Niet behandelen	Niet behandelen
1	12	Man	27	Wel behandelen	Wel behandelen
1	13	Vrouw	25	Wel behandelen	Niet behandelen
1	14	Man	39	Wel behandelen	Wel behandelen
1	15	Man	29	Wel behandelen	Wel behandelen
1	16	Vrouw	46	Niet behandelen	Niet behandelen
1	17	Vrouw	63	Niet behandelen	Niet behandelen
1	18	Vrouw	31	Niet behandelen	Wel behandelen
1	19	Man	48	Wel behandelen	Wel behandelen
1	20	Vrouw	52	Wel behandelen	Wel behandelen
1	21	Man	32	Wel behandelen	Wel behandelen
1	22	Vrouw	26	Wel behandelen	Wel behandelen
1	23	Man	32	Wel behandelen	Wel behandelen
1	24	Vrouw	45	Wel behandelen	Wel behandelen
1	25	Vrouw	59	Niet behandelen	Niet behandelen
1	26	Vrouw	62	Wel behandelen	Wel behandelen
1	27	Vrouw	24	Wel behandelen	Wel behandelen
1	28	Man	26	Wel behandelen	Wel behandelen
1	29	Man	21	Wel behandelen	Wel behandelen
1	30	Man	27	Niet behandelen	Niet behandelen
1	31	Vrouw	27	Wel behandelen	Wel behandelen
1	32	Man	32	Niet behandelen	Niet behandelen
1	33	Man	61	Wel behandelen	Wel behandelen
1	34	Man	24	Wel behandelen	Wel behandelen
1	35	Vrouw	28	Wel behandelen	Wel behandelen
1	36	Man	37	Wel behandelen	Niet behandelen
1	37	Man	27	Wel behandelen	Wel behandelen
1	38	Vrouw	29	Wel behandelen	Niet behandelen
1	39	Man	60	Wel behandelen	Wel behandelen
1	40	Vrouw	31	Wel behandelen	Wel behandelen
1	41	Vrouw	32	Niet behandelen	Wel behandelen
1	42	Vrouw	30	Wel behandelen	Wel behandelen
1	43	Vrouw	24	Wel behandelen	Niet behandelen
1	44	Man	24	Wel behandelen	Wel behandelen
1	45	Man	23	Niet behandelen	Niet behandelen
1	46	Man	57	Wel behandelen	Wel behandelen
1	47	Man	36	Wel behandelen	Niet behandelen
1	48	Vrouw	45	Wel behandelen	Niet behandelen
1	49	Vrouw	34	Wel behandelen	Wel behandelen
1	50	Man	54	Wel behandelen	Wel behandelen

Situation 2 = first Q2 then Q1

Situation	Number of respondant	Man/Vrouw	Leeftijd	Question 1 = Wat kies je?	Question 2 = Wat kies je?
2	1	Vrouw	26	Wel behandelen	Wel behandelen
2	2	Man	28	wel behandelen	wel behandelen
2	3	Man	27	Wel behandelen	wel behandelen
2	4	Vrouw	32	Wel behandelen	Wel behandelen
2	5	Vrouw	32	Wel behandelen	Wel behandelen
2	6	Man	58	Niet behandelen	Niet behandelen
2	7	Vrouw	25	Wel behandelen	Wel behandelen
2	8	Man	34	Wel behandelen	Wel behandelen
2	9	Man	46	Wel behandelen	Wel behandelen
2	10	Man	29	Wel behandelen	Wel behandelen
2	11	Vrouw	24	Wel behandelen	Wel behandelen
2	12	Vrouw	64	Wel behandelen	Wel behandelen
2	13	Vrouw	23	Wel behandelen	Wel behandelen
2	14	Vrouw	30	Wel behandelen	Wel behandelen
2	15	Man	27	Wel behandelen	Wel behandelen
2	16	Vrouw	43	Wel behandelen	Wel behandelen
2	17	Vrouw	42	Niet behandelen	Niet behandelen
2	18	Man	26	Wel behandelen	Wel behandelen
2	19	Vrouw	48	Wel behandelen	Wel behandelen
2	20	Man	64	Wel behandelen	Wel behandelen
2	21	Vrouw	71	Wel behandelen	Wel behandelen
2	22	Man	26	Wel behandelen	Wel behandelen
2	23	Vrouw	53	Wel behandelen	Wel behandelen
2	24	Vrouw	24	Wel behandelen	Wel behandelen
2	25	Vrouw	32	Niet behandelen	Niet behandelen
2	26	Man	61	Wel behandelen	Niet behandelen
2	27	Vrouw	62	Wel behandelen	Wel behandelen
2	28	Vrouw	68	Niet behandelen	Niet behandelen
2	29	Vrouw	25	Wel behandelen	Wel behandelen
2	30	Man	27	Niet behandelen	Wel behandelen
2	31	Vrouw	0	Niet behandelen	Niet behandelen
2	32	Vrouw	55	Wel behandelen	Wel behandelen
2	33	Man	55	Wel behandelen	Wel behandelen
2	34	Man	56	Wel behandelen	Wel behandelen
2	35	Man	56	Wel behandelen	Wel behandelen
2	36	Vrouw	37	Niet behandelen	Niet behandelen
2	37	Man	53	Wel behandelen	Wel behandelen
2	38	Vrouw	60	Wel behandelen	Wel behandelen
2	39	Man	37	Wel behandelen	Wel behandelen
2	40	Vrouw	28	Wel behandelen	Wel behandelen
2	41	Vrouw	28	Wel behandelen	Wel behandelen
2	42	Man	24	Wel behandelen	Wel behandelen
2	43	Man	33	Wel behandelen	Wel behandelen
2	44	Vrouw	30	Wel behandelen	Wel behandelen
2	45	Vrouw	57	Wel behandelen	Wel behandelen
2	46	Vrouw	28	Wel behandelen	Wel behandelen
2	47	Vrouw	55	Wel behandelen	Niet behandelen
2	48	Vrouw	56	Wel behandelen	Wel behandelen
2	49	Vrouw	55	Wel behandelen	Wel behandelen
2	50	Man	28	Wel behandelen	Niet behandelen

APPENDIX 9

Gebruikersonderzoek

Beste deelnemer,

Tijdens dit onderzoek word je gevraagd om wat taken uit te voeren met de applicatie die je voor je hebt. Voor je begint, zal er een case worden beschreven van een fictieve patiënt. Jij bent deze patiënt, en je zal dus vanuit zijn beleving antwoorden moeten geven op de vragen.
Tijdens het onderzoek wil ik je vragen om;

- Hardop na te denken
- Op of aanmerkingen te plaatsen als je deze hebt
- Vragen stellen indien er dingen onduidelijk zijn

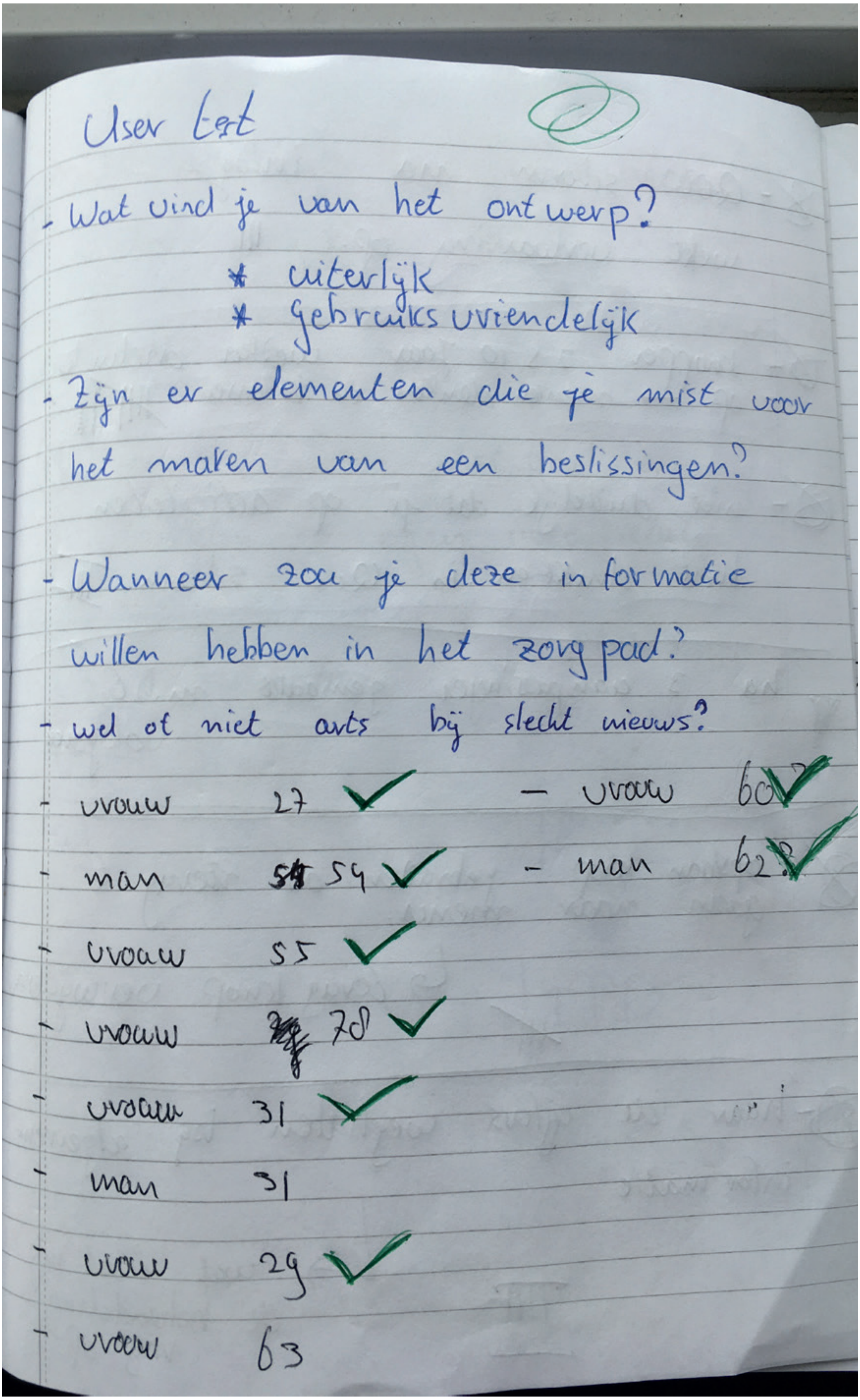
Alvast bedankt voor je deelname!

Case
Je bent René van der Poel. Een man van 64 jaar oud. René heeft een operatie ondergaan waarbij de tumor uit zijn dikke darm is verwijderd. Nadat het weggenomen weefsel was onderzocht, bleken er wat positieve klieren gevonden te zijn, waardoor adjuvante chemotherapie is aangeraden door de oncoloog. Aangezien dit een advies is, en je zelf moet bepalen of je je laat behandelen, ga je gebruik maken van deze applicatie om een keuze te maken tussen wel niet behandelen.

Taken

1. René is 64 jaar oud, kun je kijken of dit juist is ingevuld?
2. Hoeveel weken duurt de totale chemokuur?
3. Met betrekking tot kwaliteit van leven, kun je wat meer informatie vinden over wat ‘activiteiten’ nou precies inhoud?
4. Laat je je wel, of niet behandelen?

The voice recordings of this appendix are available upon request.
Please send an email to; siemonvanopstal@gmail.com



User test

- Wat vind je van het ontwerp?
  * uiterlijk
  * gebruiks vriendelijk
- Zijn er elementen die je mist voor het maken van een beslissingen?
- Wanneer zou je deze informatie willen hebben in het zorgpad?
- wel of niet arts bij slecht nieuws?

- vrouw 27 ✓
- man 54 ✓
- vrouw 55 ✓
- vrouw 78 ✓
- vrouw 31 ✓
- man 31
- vrouw 29 ✓
- vrouw 63

- vrouw 60 ✓
- man 62 ✓

① - QoL scherm na inlog
wekt verwarring op. |||

② - knoppen 2, 5, 10 Jaar wekken onduidelijkheid op → mensen denken in kolommen ~~||||~~ ||

③ - niet duidelijk dat je op activiteiten kunt drukken. in QoL scherm. ||||

! na 3 aanpassingen gemaakt m.b.t. volgorde.

---

④ - opslaan knop gebruiken om terug te gaan naar menu.
↳ terug knop verwijderen.
~~||||~~

---

⑤ - "naar de cijfers weghalen" bij algemene informatie
↳ wat levert mij de behandeling mij op
||||

Zal de verder knop vervangen door terug knop. III

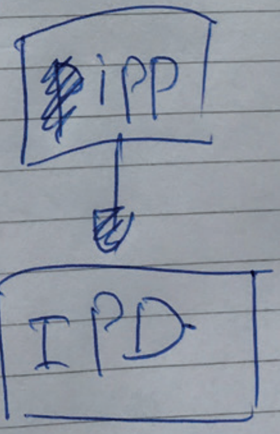
- ~~Algemen~~

menser lezen niet goed en handelen op eigen interpretatie.

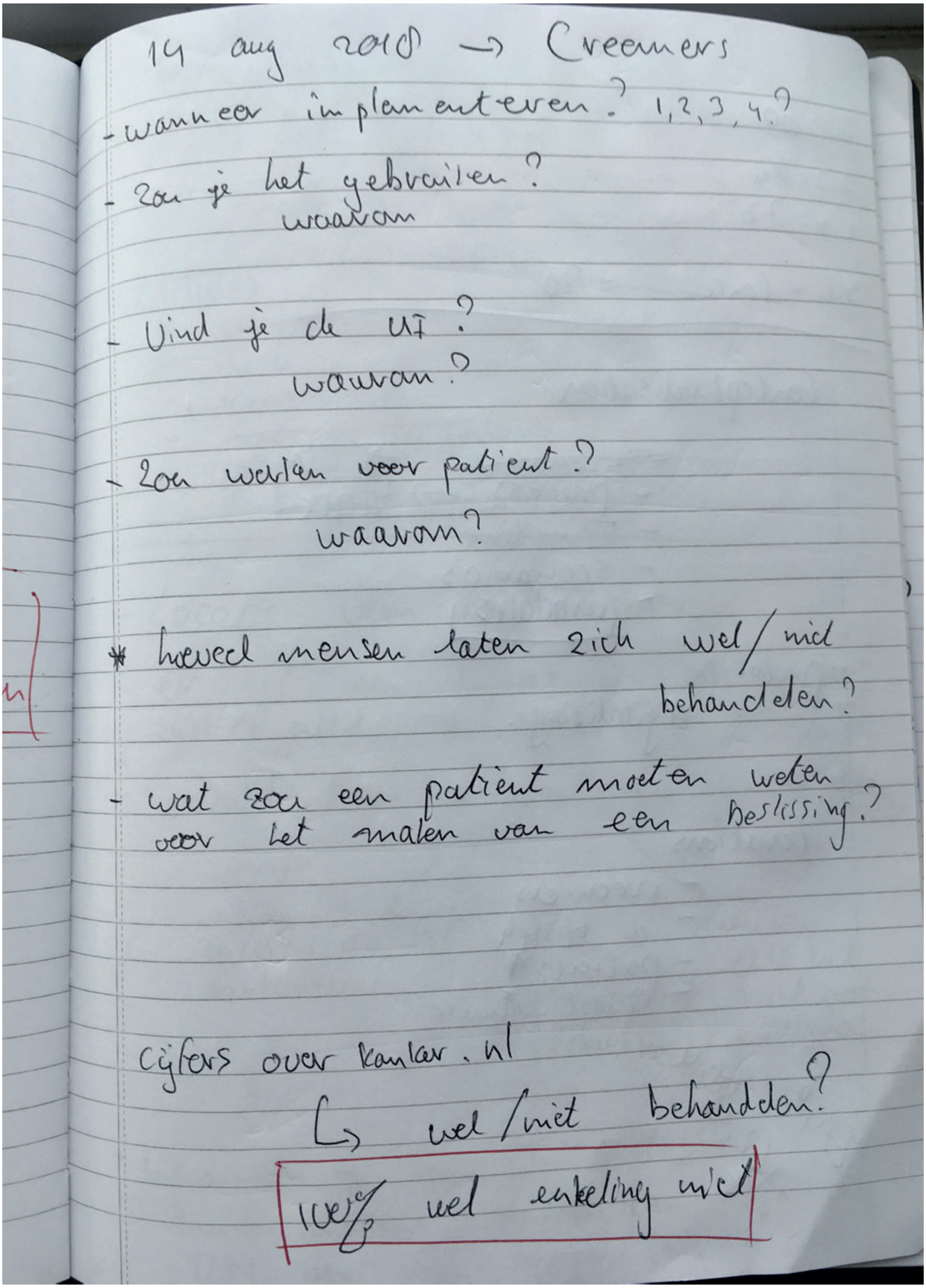
3.2	87
3.3	98
4.	106
4.1	108

inf. voorber.

info. prep. pr.



APPENDIX 10



14 aug 2018 → Creemers

- wanneer implementeren? 1,2,3,4?
- Zou je het gebruiken?
  waarom
- Vind je de UI?
  waarom?
- Zou werken voor patient?
  waarom?

* hoeveel mensen laten zich wel/niet behandelen?

- wat zou een patient moeten weten voor het maken van een beslissing?

cijfers over kanker.nl

↳ wel/niet behandelen?

100% wel enkeling niet

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- Final design

modules
- ~~arts~~
- QoL
- ~~general~~
- ~~outcome general~~
- ~~out come personalized~~.

- Locatie van de Tumor

- er zit een by-as in de cijfers
zuid-Af = test → niet Nederlands

- verschil tussen wel en niet

mensen die het aankunnen

mensen die het niet aan kunnen

↔ misleidend beeld

- ~~wanneer~~ op basis CTNM = lastig
kan een andere vorm van kanker zijn na pTNM met veel betere prognose dan

waar de patient mee naar huis is gestuurd.

- presenteer ook literatuur?

- wat is nodig van general info.
  - wat is ac
    - wat houdt het in
    - 3 weken in huis
    elke dag tabletten
    1week rust
    4x acht elkaar

hoelang duurt het process

wat zijn de verwachte bijwerking

- wat kost het mij
  - in tijd
  - hoevaak ziekenhuis
  - welke bijwerkinge
  - opbrengst?
    ↳ predictie

- 2 podcas

patient / arts

↓ algemeen
[wat houdt het in]

↓ diepte in
getallen bespreken

pTN.M = klinisch
↳ niet relevant voor patiënt
↳ meer de uitleg van stadium is belangrijk
ipv dat het stadium
1
2
3
is.

- kans wel of niet volhouden chemo.

- Q&A vs. chat
↘ te veel werk druk.
↓
wel vraag in kunnen vallen.

vraag vanuit patient

↓

praktisch niet haalbaar.

Sturing → bereidt om daar te wijzen!

- patient portal
- physician portal
- general info
- prediction info
- interaction QOL.