

Technische Universiteit Eindhoven
Industrial Design

Application Design of Decision Aid for Prostate Cancer Patients

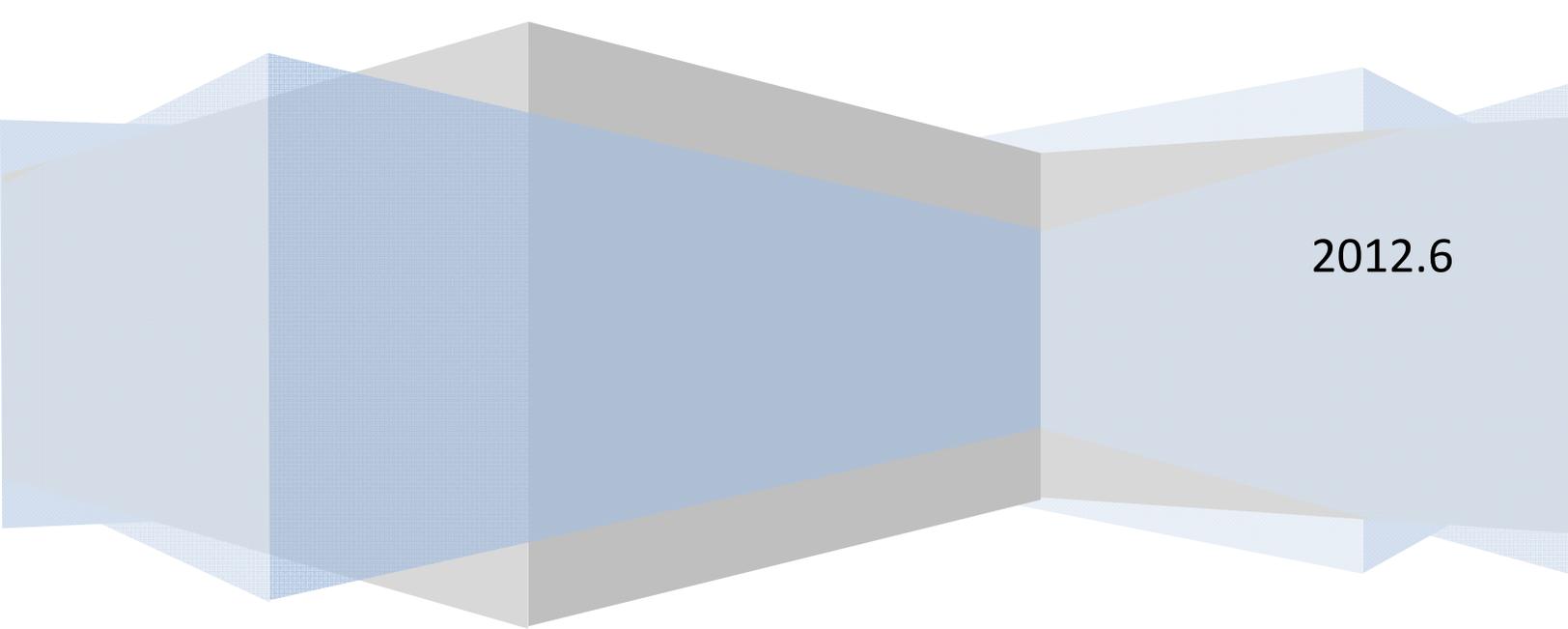
Report of Final Master Project

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Design Vision

“We are now in the middle of a transfer towards customized, ubiquitous and adaptive systems, which anticipate our needs and weave themselves into the fabric of everyday life.”

With the development of technology, humans tend to be immersed in an ubiquitous computational social world. This world will provide various approaches with people to access information and maintain a social network. Nowadays the interaction between intelligent products and users are mostly rigid, cold and bring about some side effects. For example, people get used to contacting their friends through Facebook, Twitter or MSN instead of communicating with each other in a natural way. Since people rely more on computers to solve problems, our behavior and body movements are restricted by screens. Further, overload information provided by intelligent products distracts people too much attention and wastes a lot of time. According to all these problems, I would like to conclude there is much room for exploration and improving on current products.

We designers do not only have to develop the next generation of digital systems, products and services, but also discuss in a social context what kind of life and society these products can or should support. I will keep thinking and exploring on how to smooth the boundaries between technology and natural world, and how to enrich people's subjective experience of using intelligent products and applications. Since technology is blind or at least neutral, there are opportunities and challenges for designers to add value on it and influence users' subjective experience. It is important for designers to have an insight on the intrinsic needs and desires of users at the first place, as well as the physical, mental and social capabilities of people. Then there are many factors which can be controlled by designers to influence people's experience: the formal sensory qualities, sound, smell, mass and texture and behavioral qualities, feedback, rhythm, sequence, layering and logic. What's more, intuitive behaviors can be used to support improved learning ability and more natural human form of communication.

Summary

This report describes the Final Master Project (FMP) of Leijing Zhou for Philips Research (Department of Human Interaction & Experiences). The project is coached by both Philips and the Technische Universiteit Eindhoven; the contact in Philips is Pavan Dadlani, the TU/e coach is Matthias Rauterberg. Prostaatcentrum zuidwest Nederland(PZN) is the potential client of this project. All the user research, observation study and user tests were done in PZN.

An Ipad application called Prostaïd was designed to help prostate cancer patients reach a shared decision regarding their treatments with the doctors. The application tailors personalized diagnosis information, medical evidences for patients, also takes into account of patients' personal value and preferences. The application facilitates the shared decision making process in PZN, which enhances the communication between professionals and prostate cancer patients.

The Chapter 1 of this report introduces the background and goals of the project, and also generally explains the specific medical area of this project: Shared decision making process for prostate cancer patients. Some previous user research done by Philips were used as the starting point of the project.

In Chapter 2, based on the previous research story boards were drawn to demonstrate the current situation of SDM process in PZN. Persona and competitive products analysis were made to find problems and inspirations.

In Chapter 3, based on the problems and inspirations some explorations were made to define the boundaries of the project. A blueprint of tablet application was defined to show the main directions of design.

The Chapter 4 of the report provides some literature reviews, which become the guidelines for design.

The Chapter 5 of the report explains the procedure of user research, which includes the preparatory work and the summary of observation study and interviews with doctors, nurses and prostate cancer patients.

Chapter 6 shows the iterations of design.

CHAPTER 1 INTRODUCTION

Project Background

“Let the service work around me!”

In 2010, Philips announced a strategic “Vision 2015” plan which aims at further strengthening Philips’ leadership in the domain of health and well-being. In line with this vision, several new projects are being initiated across various units of Philips, many of them focus on patient empowerment. “Patient Centric Solutions for Cancer Care” at Philips Research is one of the projects. The design team observed a need for solutions that support prostate cancer patients during their treatments. As seen in Figure 1, this project covers the areas of Diagnosis and Treatment of the whole cancer care cycle.



Figure 1 The scope of “Patient Centric Solutions for Cancer Care” –Philips (this project focus on the decision making process between Diagnosis and Treatment)

Project Goals

“The decision is yours!”

Among men, prostate cancer is the second most frequently diagnosed cancer, and the fifth most common cancer overall [1]. Once a man is diagnosed with prostate cancer, he will be involved with a lot of healthcare professionals over the course of his treatment, e.g. oncologists, urologists, radiologists, surgeon and a lot of specialist nurses. Due to the myriad of steps involved in diagnosing and treating cancer, a patient comes across a large amount of new information to absorb, communicate, manage and store, e.g., information related to their diagnosis, types of treatments, test results, treatment procedures, treatment side effects, financial issues associated with treatment, etc.

Different from other cancers, prostate cancer is usually growing slowly, and won’t necessarily cause harm[2]. Even when a patient is diagnosed, the cancer might not cause any problems immediately. There are various treatment options and enough time for the patient to choose the most suitable solution. So the decisions such as whether and when to take a treatment are mostly based on patient’s health profile and the different risk-benefit tradeoffs of each treatment option. These decisions are “preference-sensitive”-patient preferences and personal values should be the sole drivers of such decisions[3]. Most of the prostate cancer patients have to decide themselves which treatment they will go through, although they lack professional knowledge and skills.

Solutions to support this decision making process were needed. To begin with, the project goals were defined as:

- Support information needs of prostate cancer patients
- Facilitate shared decision making process between clinicians and prostate cancer patients
- Explore context of use for designed product

Terms Explanation

“what’s prostate cancer? What’s SDM?”

As this project involves a lot of medical expertise, some professional terms and background knowledge are explained at the beginning of this report:

Prostate Cancer

Prostate cancer is cancer that forms in tissues of the prostate (a gland in the male reproductive system found below the bladder and in front of the rectum). Prostate cancer usually occurs in older men[4].

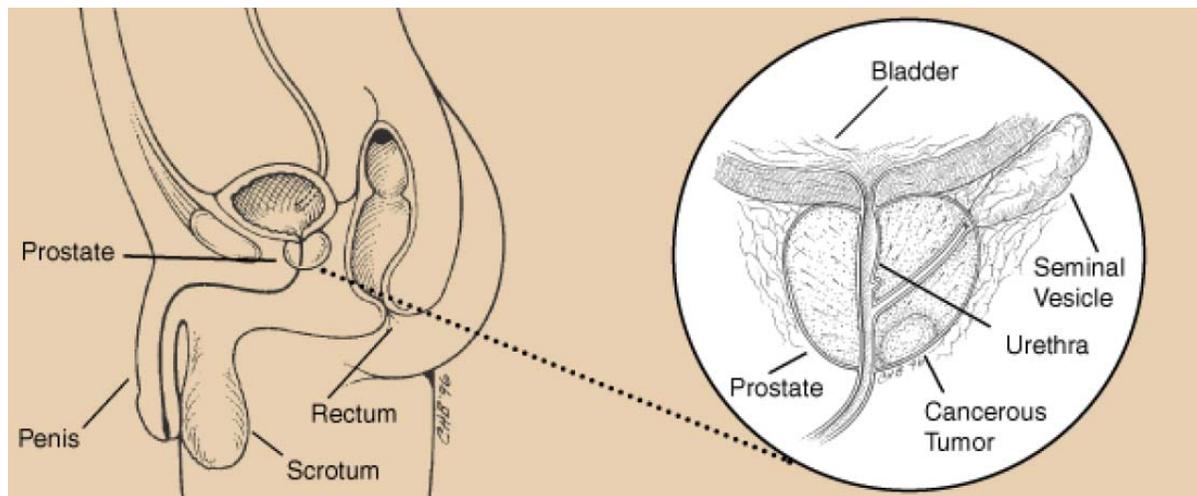


Figure 2 Anatomy of the male reproductive and urinary systems -American cancer society

Early-stage Prostate Cancer

When cancer cells are found only in the prostate, it is early-stage prostate cancer. Compared with many other cancers, prostate cancer grows slowly. This means that it can take 10 to 30 years before a prostate tumor gets big enough to cause symptoms. In fact, autopsy studies show that many older men who died of other diseases also had prostate cancer that never affected them during their lives[2].

Diagnosis of Prostate Cancer

Diagnosis of prostate cancer is the process of identifying prostate cancer, from its signs and symptoms. Early-stage prostate cancer is most often found by a prostate-specific antigen (PSA) blood test and/or Digital rectal exam (DRE)[5].

Treatment of Prostate Cancer

Men with prostate cancer have many treatment options. The traditional treatments include active surveillance, surgery, radiation therapy, hormone therapy, and chemotherapy. Patients may have a combination of treatments. The treatment that’s best for one man may not be best for another. The treatment that’s right for the patient depends mainly on his age, stage of prostate cancer, test results

and personal preferences on the risk-benefit tradeoffs of each option[4]. As most prostate cancers found in the early stages grow slowly, which means diagnosed prostate cancer patients have many weeks to months to make a treatment choice.

Shared Decision Making (SDM)

Both the clinician and the patient take steps to participate in the process of treatment decision making and sharing information as a prerequisite. They bring information and values to the process and they come together to make the decision[6].

Decision Aids

Decision aids are tools that help people understand the likely outcomes of their treatment options and think about their values and preferences as they relate to the risks and benefits of each option[7]. The terms decision aids and aids for shared decision making are used interchangeably.

Design Context

“How is SDM process working in cancer center?”

As it's shared decision making process, the input from healthcare professionals, e.g. clinicians and nurse practitioners is so important. In this project, Philips Research collaborated with Prostaatcentrum zuidwest Nederland for pilot study. Prostaatcentrum zuidwest Nederland(PZN) at Rotterdam is a result of collaboration between Erasmus Medische Centrum (EMC) and Sint Franciscus Gasthuis (SFG). Both the hospitals offer different treatments, SFG houses the consultation part of the PZN and all patient intake consultations take place here. PZN offers a comprehensive array of treatments available for Prostate Cancer. The care team at PZN is multi-disciplinary and the health professionals working in the team are listed below:

Physicians:

- Five urologists
- Two radio therapist
- One oncologist

Nurses:

- Three specialist nurses
- A research nurse

Some interviews with specialist nurses and urologists at PZN were conducted by Beant Kaur Dhillon[8] to get an overview of SDM process at PZN. Figure 3 on the next page draws the overview of treatment-related decision making process.

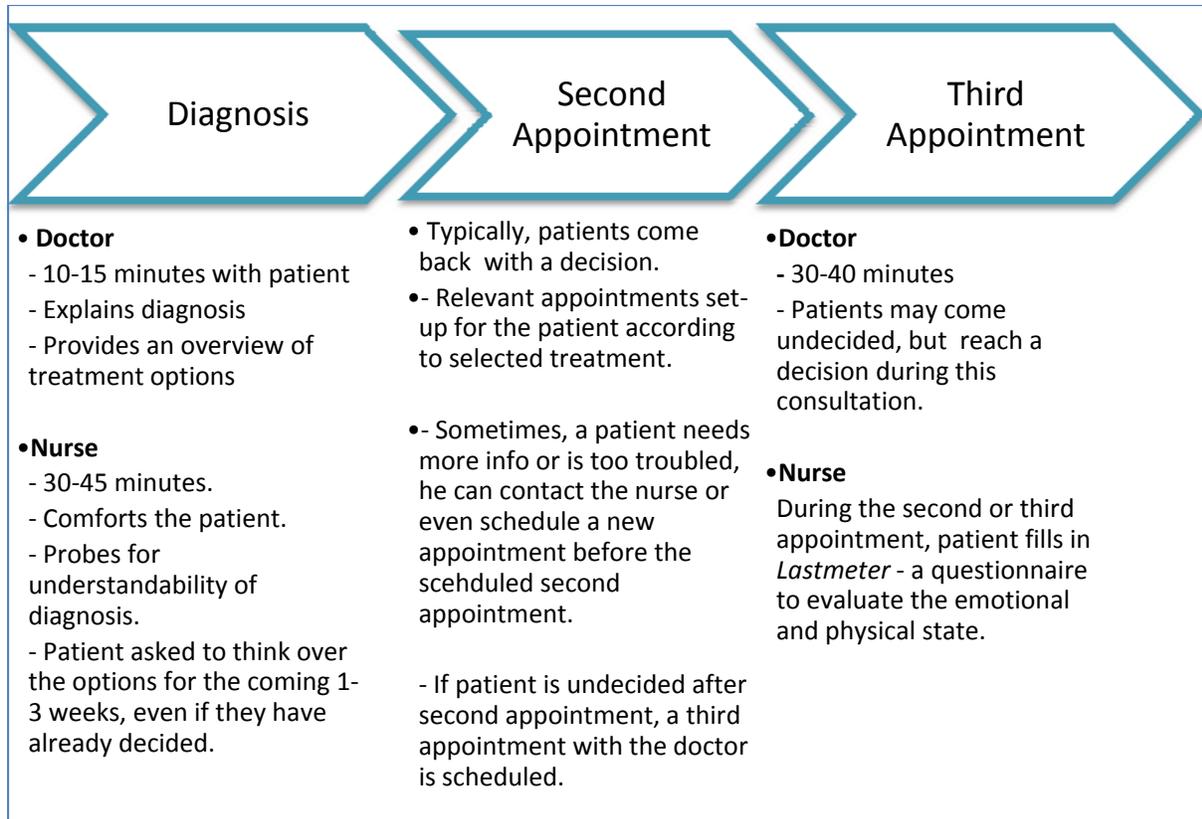


Figure 3 Overview of Treatment-related decision making process at PZN- Beant Kaur Dhillon

CHAPTER 2 NEEDS FINDING

Persona

“One man’s battle with prostate cancer”

There are many dedicated websites for blogs of cancer survivors. These blogs are used to record information, communicate, share and even inspire other cancer patients. These blogs can be a useful resource for designer to gain user insights of prostate cancer patients. What are their real situations? What are their activities when considering different treatment options? What’s the difficulty of decision making? What are their advices and reflections?

After reviewing some blogs, one weblog (<http://prostate-cancer-log.blogspot.com/>)[9] was selected for user research. It was written by a prostate cancer survivor from USA. He kept recording all the details of procedures, test results, practical tips and even personal feelings and reflections from his first abnormal PSA test until now.

“I started keeping notes on what I am going through and that is how this blog started- it helps me keep track of names, dates and so on and I hope it helps you”. He arranged his treatment-related information carefully. He concluded several practical tips for other prostate cancer patients. As seen in Figure 4, he

even made a business card to promote his blog. It is believable that he has great passion to record his prostate cancer journey and share useful information with other people.

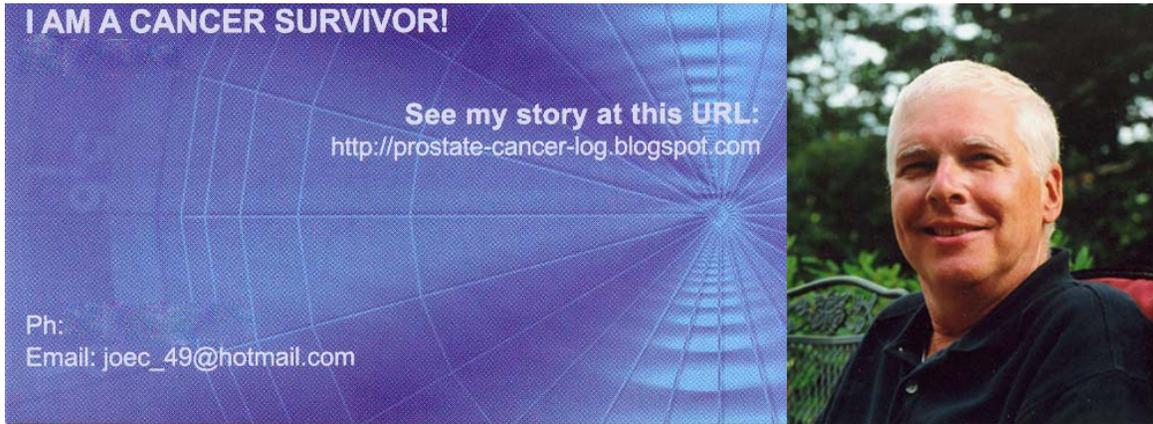


Figure 4 “I am a cancer survivor”-Prostate cancer journey

Name: Joe **Age:** 61

Cancer story:

Joe was first diagnosed at age 55 (in year 2005) with aggressive prostate cancer. He choose Surgery for his treatment option. One year later he got recurrence of prostate cancer. Now he is undergoing the chemotherapy.

Opinions on shared decision making:

(quoted from Joe’s blog[9] post on 12/27/2005) *“I placed a call to my family doctor as why do we have to decide. He left a message that I am to decide what makes sense for me- this seems silly to me as I indicated, i.e. ordinary people do not have the training, education, skills or experience to make an informed decision. But all doctors appear to ask the patient to decide- weird!”*

This sentence reveals the big need of decision aid for prostate cancer patients: patients are all ordinary people, but they have to decide themselves what kind of treatment, surgery? radiotherapy? or active surveillance? It’s such a big challenge, especially for older men.

Activities during SDM process:

Based on the information on Joe’s blog[9], I drew table 1 to trace his important activities and contact persons during the decision making period:

Time	Activity
11/3/2005	Joe met with the family doctor for annual routine physical and blood test. The doctor’s only concern was he felt a lump on Joe’s prostate during the digital rectal exam (DRE test). And the PSA score was 3.15, up from the previous 2.54. The family doctor then referred Joe to a urologist.
11/10/2005	Joe met with the urologist and did DRE test again. He was recommended a biopsy to see

	what it might be.
11/29/2005	The urologist did the biopsy and took 12 tissue samples to the lab.
12/1/2005	The urologist called Joe to say he had cancer. Bone scan and cat scan was recommended.
12/8/2005	Joe went through the bone scan and cat scan. He asked for and received (via CDROM) the copies of bone scan/cat scan and also the biopsy result.
	Joe started letting coworkers, friends, colleagues know that he had prostate cancer to see who they knew in his situation and what doctors, if any, they would recommend. It proved very helpful, because he found a very great doctor.
12/13/2005	Joe together with his wife met the urologist again. The urologist recommended surgery(Radical prostatectomy)followed by hormone therapy. He compared the survival estimate between surgery and watchful waiting. He asked for a MRI test and also referred Joe to a radiation oncologist.
12/19/2005	Joe had a two-hour MRI test. He met his family doctor discussing about the treatment options.
12/20/2005	Joe met with another senior doctor for second opinion.
12/22/2005	A college friend who was then director of surgery recommended surgery.
12/27/2005	Joe met with a radiation oncologist talking about the outcome and side effects of radiation therapy.
12/27/2005	Joe made the decision to take surgery.

Table 1 Joe's activities during SDM process

As seen in table 1, Joe consulted five clinicians: family doctor, urologist, radiation oncologist, another senior doctor, director of surgery. He asked for and received the copies of bone scan/ cat scan and also the biopsy result. Based on these doctors' opinions and the medical documents, he made the decision of treatment. Figure 5 on the next page shows Joe's health profile and the copies of test results and scans, then I made analysis and reflection on them:

[problem 1] The scans and pathology reports contain too much medical jargon, which are difficult for ordinary people to comprehend.

[inspiration 1] Based on problem 1, information visualization can be used to make the diagnosis information comprehensible, and further some interaction design can enhance patients absorb the medical information better.

Information summary:

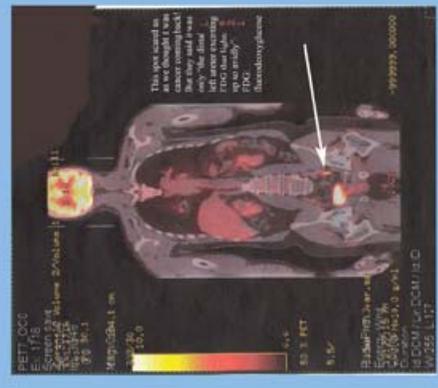
On Joe's blog, he recorded all the details of information which was useful for him during the treatment, also for the decision making process. The information is presented in different formats, e.g. verbal, videotapes, audiotapes with workbooks, booklets, CDROMs, websites and etc. Here I summarized the information involved in the process:

- Verbal exchange with health professions through call or face-to-face meeting
- Copies of bone scan, cat scan, pathology report, biopsy result and etc.
- Booklets or pamphlets about prostate cancer and decision making guidelines

Real situation of patients



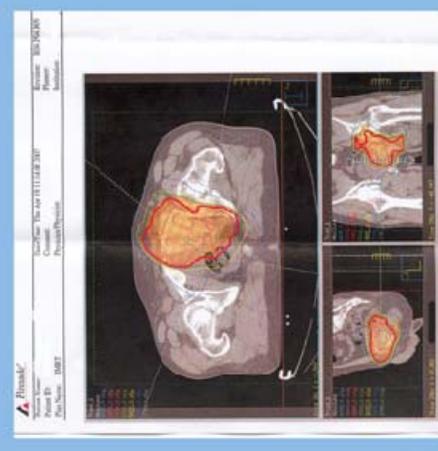
Bone scan



CT result

CT result report text detailing patient information, exam details, and findings. The report includes sections for 'EXAMINATION', 'FINDINGS', and 'IMPRESSION'.

IMRT scan



Radiation Plan

Structure Set	Volume	Material	Weighting	Priority	Order
PTV	100%	PTV	1.0	1	1
PTV	100%	PTV	1.0	1	2
PTV	100%	PTV	1.0	1	3
PTV	100%	PTV	1.0	1	4
PTV	100%	PTV	1.0	1	5
PTV	100%	PTV	1.0	1	6
PTV	100%	PTV	1.0	1	7
PTV	100%	PTV	1.0	1	8
PTV	100%	PTV	1.0	1	9
PTV	100%	PTV	1.0	1	10
PTV	100%	PTV	1.0	1	11
PTV	100%	PTV	1.0	1	12
PTV	100%	PTV	1.0	1	13
PTV	100%	PTV	1.0	1	14
PTV	100%	PTV	1.0	1	15
PTV	100%	PTV	1.0	1	16
PTV	100%	PTV	1.0	1	17
PTV	100%	PTV	1.0	1	18
PTV	100%	PTV	1.0	1	19
PTV	100%	PTV	1.0	1	20
PTV	100%	PTV	1.0	1	21
PTV	100%	PTV	1.0	1	22
PTV	100%	PTV	1.0	1	23
PTV	100%	PTV	1.0	1	24
PTV	100%	PTV	1.0	1	25
PTV	100%	PTV	1.0	1	26
PTV	100%	PTV	1.0	1	27
PTV	100%	PTV	1.0	1	28
PTV	100%	PTV	1.0	1	29
PTV	100%	PTV	1.0	1	30
PTV	100%	PTV	1.0	1	31
PTV	100%	PTV	1.0	1	32
PTV	100%	PTV	1.0	1	33
PTV	100%	PTV	1.0	1	34
PTV	100%	PTV	1.0	1	35
PTV	100%	PTV	1.0	1	36
PTV	100%	PTV	1.0	1	37
PTV	100%	PTV	1.0	1	38
PTV	100%	PTV	1.0	1	39
PTV	100%	PTV	1.0	1	40
PTV	100%	PTV	1.0	1	41
PTV	100%	PTV	1.0	1	42
PTV	100%	PTV	1.0	1	43
PTV	100%	PTV	1.0	1	44
PTV	100%	PTV	1.0	1	45
PTV	100%	PTV	1.0	1	46
PTV	100%	PTV	1.0	1	47
PTV	100%	PTV	1.0	1	48
PTV	100%	PTV	1.0	1	49
PTV	100%	PTV	1.0	1	50

Bone scan result

Bone scan result report text detailing patient information, exam details, and findings. The report includes sections for 'EXAMINATION', 'FINDINGS', and 'IMPRESSION'.

IMRT result

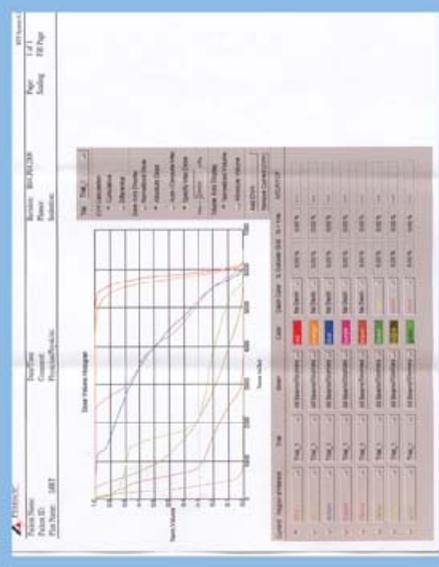


Figure 5 Joe's health profile and real situation of treatment

- Diaries ,blogs or notes written by patients to record important information
- Appointment schedule, treatment plan
- Information from internet, links of useful website

And then I made the analysis and reflection based on them:

[problem 2] The information with different formats become difficult to manage and share. For example, notes written on scraps of paper, websites links, appointments and etc.

[inspiration 2] Based on problem 2, the decision aid can play the role of storing and managing information for the patients.

Personal experience and tips:

(quoted from Joe's blog[9] post on 4/22/2007)

Joe used his blog to keep track of all the treatment-related information, also for sharing personal experience with other cancer patients.

"I list below some tips you should take to beat cancer and I hope they do help you. These steps below come from my personal experience battling prostate cancer as well as some research I have done and also conversations with doctors. Here are some specific steps I suggest you consider:

1. **Get smart on your specific cancer.** Ask the doctor what type of cancer you have. Your cancer may use a different scoring, so ask your doctor some questions (1) is this cancer confined to where she or he found it or has it spread elsewhere (2) is this cancer slow growing or aggressive (3) how does it score on a scale. Once you know, start searching the web and I suggest you start with these web sites: National Cancer Institute/ American Cancer Society National Institute for Health
2. **Tell everyone you know RIGHT AWAY.** They or someone they know may have already done the research and thus may know great doctors and/or hospitals. Don't be shy, tell everyone! I did this and found a VERY GOOD SURGEON at a VERY GOOD HOSPITAL, just because I spoke up & told many people.
3. **Pick your doctor and hospital carefully.** The nearest hospital may not be the best hospital for you. Get a doctor/hospital where they routinely do this treatment perhaps even weekly and preferably a teaching hospital.
4. **Keep a diary of everything that happens** as it WILL be a real blur after a period of time. I kept a diary and then I moved it to a web. My diary has been a lifesaver for me on many levels. I kept it with me at every meeting with the doctor, by my bedside at night and when I was in the hospital, I kept it nearby so I could write down what was going on.
5. **Ask your doctor AND the hospital for copies of all medical tests**, i.e. your biopsies, tests, blood tests, cat-scans, bone scan, pet-scans, MRIs etc. Ask for it within 3-4 weeks of having the test. They will not offer it to you - you have to ask.
6. **Whenever you meet with a doctor, have another person come with you and this person's role is to bring a notebook and write down what the doctor says.** You will be the person having a

conversation with the doctor and thus you cannot write down what he or she says (too distracting to the doctor).

7. **Keep a positive outlook.** *Say every day that you will beat cancer. Attitude is perhaps 50% of the reason people beat cancer. I know many people who beat cancer and all had a positive attitude.*
8. **Prepare a one-page summary of your health.** *put your blood type and a summary of what you have gone through thus far, including recent blood tests (and dates) as well as dates of chemo, cat scans and so on. ”*

These solutions come from a cancer survivor’s story, they are very useful for other cancer patients to store and manage their treatment-related information. At the same time, these personal experience and tips became inspirations and opportunities for my design:

[inspiration 3] Based on tips 1, cancer patients have to understand the diagnosis information firstly and then make informed decision. So the decision aid should be able to educate cancer patients how to read his health profile: What’s my tumor stage? Is this cancer growing slowly or aggressively? has it spread?

[inspiration 4] Based on tips 1, there are various websites such as National Cancer Institute, American Cancer Society, which give patients access to a wealth of information. These cancer websites and organizations can be a good starting point for me to understand prostate cancer firstly as a normal patient.

[inspiration 5] Based on tips 4, keeping diaries and notes are methods for patients to manage personal information. The decision aid can add a feature to enhance patients’ needs such as keeping diaries.

[problem 3] Based on tips 5, patient’s profile and medical tests, i.e. biopsies, blood tests, cat-scans, bone scans, MRI scans etc, are important references for patients to make decision, but they have to ask.

[inspiration 6] Based on tips 8 and problems 3, patient’s profile and medical tests are necessary if patients want a second opinion. It is nice to have these documents already in the decision aid. The decision aid can be supported by hospital, or even starts at hospital. The database of decision aid is linked to the Electronic Health Record (EHR) of cancer center, then patients don’t need to ask for test results themselves.

[inspiration 7] Based on tips 6, when the patient concentrates on conversation with professional, he cannot take notes at the same time. The decision aid may have the function to record verbal exchange between professionals and patients.

[inspiration 8] Based on tips 7, cancer patients are special user group. They need encouragement and inspiration to keep positive attitude. So the phrasing and pictures used in the decision aid should be carefully considered, which should communicate positive ideas.

Workflow

“right after diagnosis, patients ask the most questions, and then it decrease over a period of time”

PZN is one of the best prostate cancer center in Netherlands. Different from other hospitals, the emotional coping by specialist nurse- the second meeting is unique. Based on Beant’s user interviews

with urologists and specialist nurses in PZN, there are three important meetings (refer to Figure 3) in SDM process between prostate cancer patients and professionals :

The first diagnosis meeting lasts 10 to 15 minutes. The doctor will explain the diagnosis with the patient and provide an overview of treatment options. Doctors often do not volunteer information but answer questions.

Afterwards, a specialist nurse will comfort the patient and try to make sure he understand the treatment options. This meeting lasts 30 to 45 minutes. Specialist nurses use less medical jargon than doctors to explain the treatments. They talk about the potential side effects of treatments with patient and his spouse. They also offer informative like some information booklets, which contains general information for all the treatments. It is not personalized according to the patient. A specialist nurse commented that right after diagnosis, patients ask the most questions, and then it decreases over a period of time.

Then the patient can have one week or two weeks time thinking over his treatment options. Normally the patient will iteratively go through the information gathering and sharing process. After comparing the various treatment options and thinking about his personal preferences, he is able to reach a decision. Then he will have a meeting with doctor talking about his decision and the next step to do for the chosen treatment.

Story Boards

The overall SDM process is very complex, it involves medical information, opinions exchange and personal values. Patients have to communicate with different stakeholders for advices and suggestions in various contexts. The workflow of PZN (refer to Workflow in Chapter 2) explains how the cancer center works in SDM process. Persona (refer to Persona in Chapter 2) introduces patients' activities to gather information during the decision making process. Based on workflow of PZN and persona, I drew a series of story boards demonstrating current situation of shared decision making process, as seen in figure 6. Based on these story boards, the information and context analysis were made to find problems and inspirations:



Figure 6 sketch of story boards

Story Boards Demonstrating Current Situation of Shared Decision Making Process

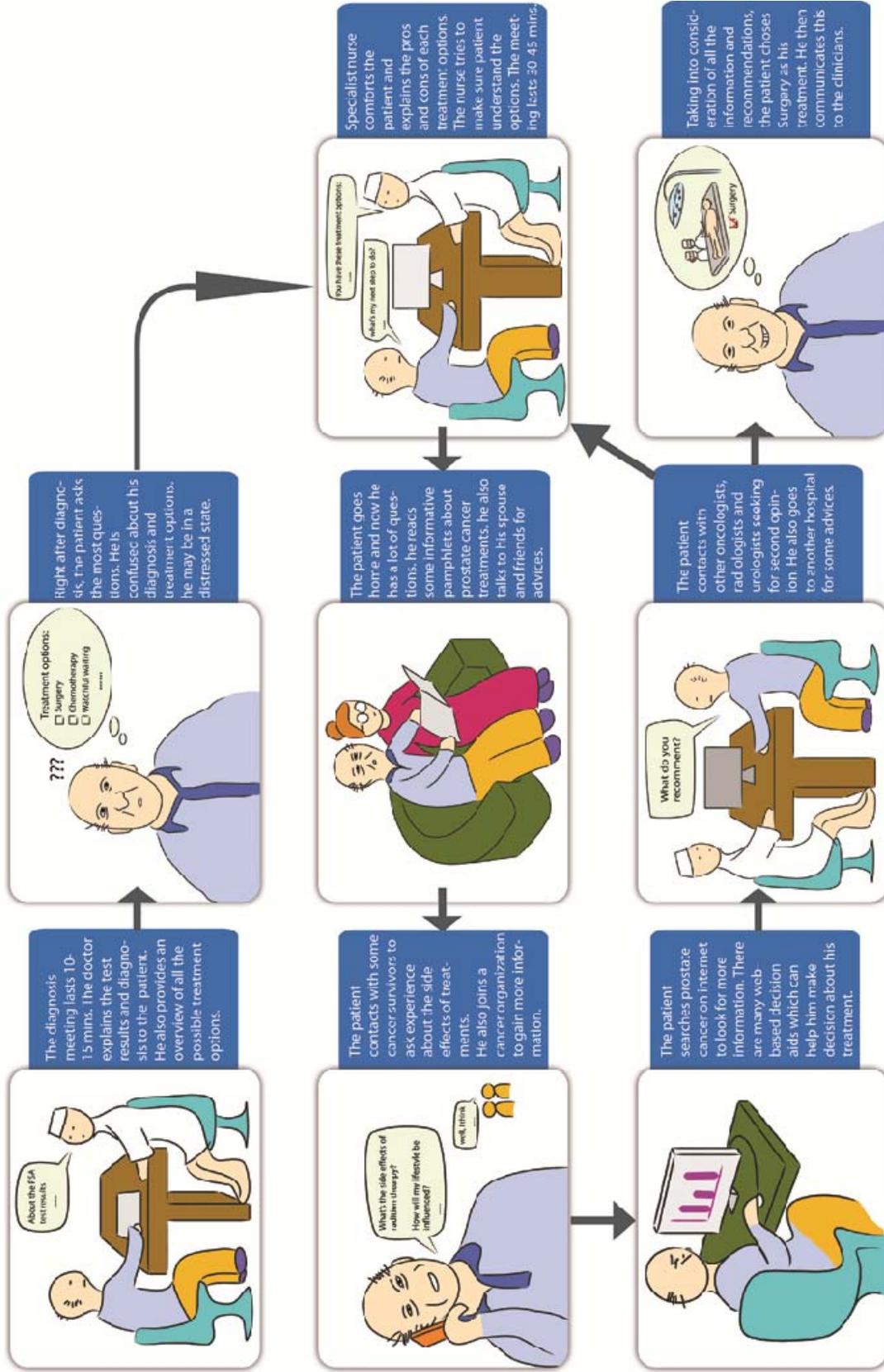


Figure 6 Story boards demonstrating the current situation of shared decision making process

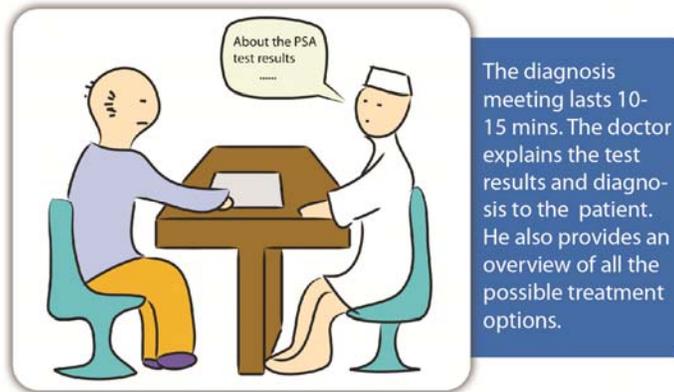


Figure 7 story board of urologist meeting

As seen in figure 7, the SDM process starts with a urologist meeting explaining the diagnosis information.

[problem 4] Professional consultants are trusted and valued[10]. Because of lack of time (10-15mins), health professionals may share incomplete information.

[inspiration 9] Based on problem 4, patients still need to learn more information about treatments before they make an informed decision. So the decision aid should cover the information which is not shared in the urologist meeting.

[problem 5] The first meeting is a bad news meeting, the information provided by professionals may not be absorbed by the patient because of his distressed emotional state. The stress and anxiety experienced during early stages by patients and pain may lead to diminished attention. This diminished attention, coupled with the usual stress of clinical environment affects comprehension as well as storage and retrieval-related aspects of information[11].

[inspiration 10] Based on problem 4 and problem 5, the decision aid may have the function to help patients store diagnosis information at the bad news meeting, and then be able to get access to the same information when they are at home.



Figure 8 story board of specialist nurse consulting

As seen in figure 8, patients then have a nurse consulting for emotional support and more information.

[inspiration 11] Specialist nurses are good at comforting cancer patients and act as a source of emotional support. Nurses' experience can be inspirations for designers to explore how to comfort cancer patients, what is the right phrasing to communicate with patients.

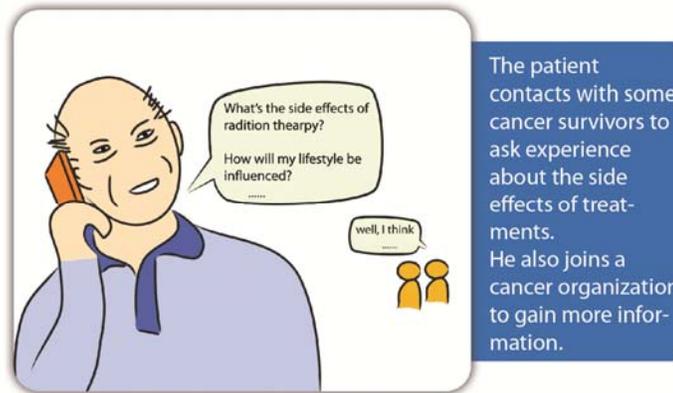


Figure 9 story board of contacting cancer survivors

As seen in figure 9, patients may contact cancer survivors to seek for more information.

[inspiration 12] Cancer survivors can provide useful tips and some practical advices with cancer patients, e.g. what to expect after surgery, how about the side effects.

[problem 6] Experience such as side effects of treatment is based on patient's own health profile, which may vary greatly from one patient to another.

[inspiration 13] Based on problem 6, A feature of tailoring cancer survivors with similar health profile for patients can be useful.

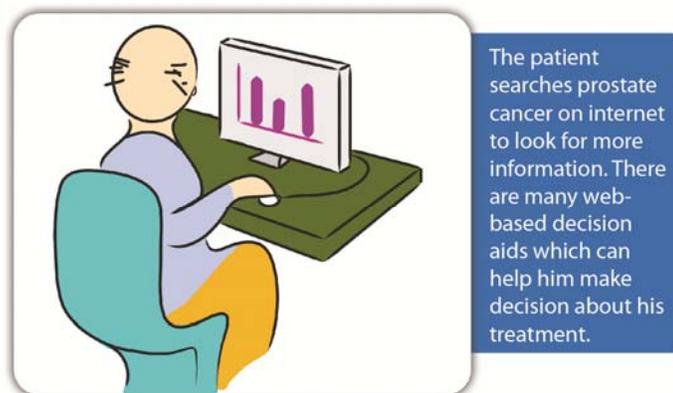


Figure 10 story board of internet searching

As seen in figure 10, most of the patients will search information on the internet. Internet is 24 hours and 7 days available, which has a wide choice of sources. While there are still some general problems:

[problem 7] Most of prostate cancer patients are elderly men, who may lack of access or unfamiliar with computers[12].

[inspiration 14] Based on problem 7, the interaction design of decision aid should be as natural as possible. So the elderly men are able to use it intuitively.

[problem 8] The biggest concerns of searching on the internet by cancer patients were getting overwhelmed with information and finding out things that they would not want to know.

[problem 9] Some websites may provide credible information but do not provide information tailored to a patients' condition and overall health profile.

[inspiration 15] Based on problem 8 and problem 9, the decision aid should provide tailored information according to patients' profile.

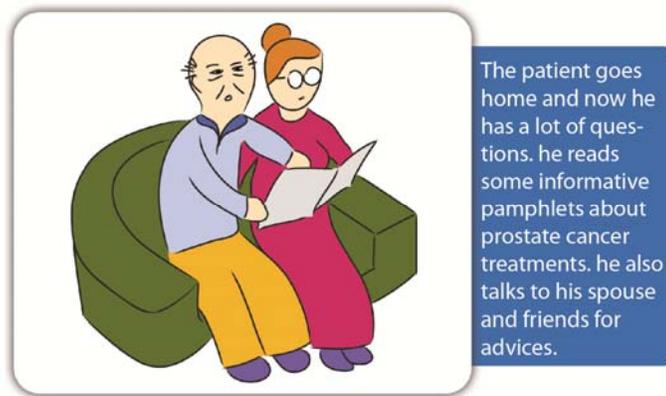


Figure 11 story board of discussing with spouse

[inspiration 16] Prostate cancer patient's spouse plays an important role in decision making process, because the outcome and side effects of treatment influences both the patient and his spouse. There is design space to facilitate cancer patient's spouse participating in the decision making process.

Competitive Landscape

"Be a prostate cancer patient!"

After analyzing the current situation of SDM process. I assumed myself as an early-stage prostate cancer patient who wants to know more about the treatment options. I searched on the internet, sought for available decision aids, and went through the materials of prostate cancer, especially the treatment-related information. These activities are helpful for design because of:

- The role of “prostate cancer patient” provides me with subjective experience and reflection on how to look for treatment-related information and what are the needs of cancer patients for decision making.
- Understanding the professional jargons and medical knowledge of prostate cancer can help me better communicate with clinicians and cancer survivors for the user research study.
- Going through as much material as possible helps me gain an insight of the competitive landscape of decision making aids, which can be the inspiration for design.

There are many websites and non-profit organizations which provide information and decision making tools for prostate cancer patients. e.g. government websites (National Cancer Institute), non-profit support organizations (cancer.org) and business organizations related to cancer care (Health Dialog company). As seen in figure 12 on the next page, there are several examples of different informative products designed for prostate cancer patients. And I also made analysis on these products:

- **Overview of treatment options:** Prostate-cancer.com[13] provides a clear overview of treatment options including the outcome, benefits and side effects of each option.
- **Interactive decision making aids:** *Prosdex*[14] is an online interactive decision making aids help patients make treatment choice.
[problem 10] The online decision aid doesn't tailor personal information based on patient's profile, and it is “one-time” event.
- **Prostate cancer survivors' stories:** The website *Blog for a Cure*[15] offers many prostate cancer survivors' stories. The information from stories is vivid and natural, easy-understandable by cancer patients.
[inspiration 17] Positive stories can comfort and inspire cancer patients. The stories also help patients cope with stress and anxiety emotions.
- **Booklets of decision guide:** National Cancer Institute provides detailed booklet *Treatment Choices for Men With Early-Stage Prostate Cancer*[16] to guide patients to make a decision.
- **Practical tips like questions to ask doctor:** Cancer.org supported by the American Cancer Society offers a book called *Questions to Ask Your Doctor About Prostate Cancer*[17]. It helps patients ask professionals the right questions at the right time. It also provides some educational videos for explaining prostate cancer.
- **Social networking sites:** There are some social networking sites for cancer patients to share their information and experience, e.g. Circle of Sharing[18] helps cancer patients and their caregivers get personalized information and share it with family and friends.
[inspiration 18] Through social networking sites, patients can have more opportunities to know professionals and cancer survivors.
[problem 11] Patients may concern about the extent of privacy of their personal information on the sites.
- **Educational videos for prostate cancer:** Many videos are available on the internet to educate patients with prostate cancer.
[inspiration 19] Audios and videos are suitable media for communicating information with prostate cancer patients, since they are mostly elderly people.

Competitive Landscape of Informative Products for Prostate Cancer Patients

Prostate cancer survivors' stories
(Blog For A Cure)



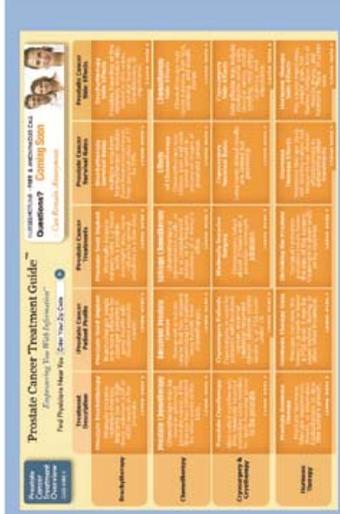
Booklets of decision guide
(A Decision Guide by
Centers for Disease Control and Prevention)



Educational videos of prostate cancer
(Prostate Cancer Videos by
American Cancer Society)



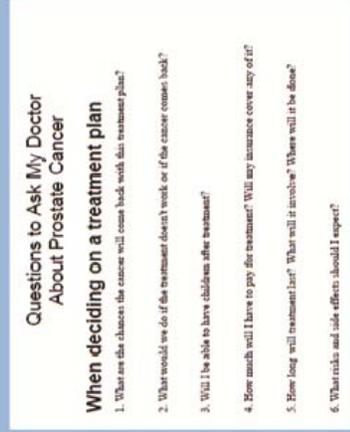
Overview of treatment options
(Prostate Cancer Treatment Guide)



Interactive decision making aid
(Prosdex)



Practical tips
(Questions to Ask My Doctor About Prostate Cancer
by American Cancer Society)



Social networking sites for sharing information
(Circle of Sharing by American Cancer Society)



Figure 12 Competitive landscape of informative products for prostate cancer patients

Summary

Based on Persona, Workflow and Competitive Landscape, a summary of needs finding was made : Table 2 (refer to Appendix 1) summarizes the problems in current SDM process. Table 3(refer to Appendix 1) summarizes the inspirations for future design.

CHAPTER 3 BOUNDARIES DEFINING

Design Directions

Based on the summary of needs finding, I grouped all the problems and inspirations to generate the main design directions. As seen in table 4, there were six main topics:

Key words	Design directions	Sources
Information visualization	Information visualization and interaction design can be used to make the medical jargons comprehensible, especially the diagnosis information (e.g. stage of cancer, biopsy result) and treatment explanations.	Problems 1,4 Inspirations 1,3,9
Personalization	The decision aid should play an important role as storing and managing personal information for the prostate cancer patients. There can be some features such as keeping diaries, recording verbal exchange between professionals during meetings and etc.	Problems 2,10,11 Inspirations 2,5,7,10
Collaboration with hospital	The decision aid might be supported by hospital, or even starts at hospital. The database of decision aid is linked to the Electronic Health Record (EHR) of cancer center, then patients don't need to ask for test results themselves.	Problems 3 Inspirations 6
Usability	The target user group is quite special: elderly people and at the same time cancer patients. So the phrasing and information used in the decision aid should be carefully considered to communicate positive attitudes, e.g. positive cancer survivor's story. And the interaction design of decision aid should be as natural as possible. So the elderly men are able to use it intuitively. Audios and videos are suitable media for communicating information with prostate cancer patients.	Problems 7 Inspirations 8,14,17,19
Shared decision	The decision aid may consider the different stakeholders and scenarios in SDM process: patient, patient's spouse, doctor, nurse and even patient's friend or cancer survivors. The roles of these stakeholders in SDM process can be explored later.	Problems 5 Inspirations 11,12,16,18
Tailoring mechanism	The decision aid should tailor personalized information for patients to avoid information overloaded.	Problems 6,8,9 Inspirations 13,15

Table 4 design directions based on summary of needs finding

Explorations

Based on the key words of design directions, I brainstormed and explored some ideas. The ideas vary from tangible product to user interface, treatment navigation to treatment rating system, ambient experience to information design.

Idea 1: cancer robot

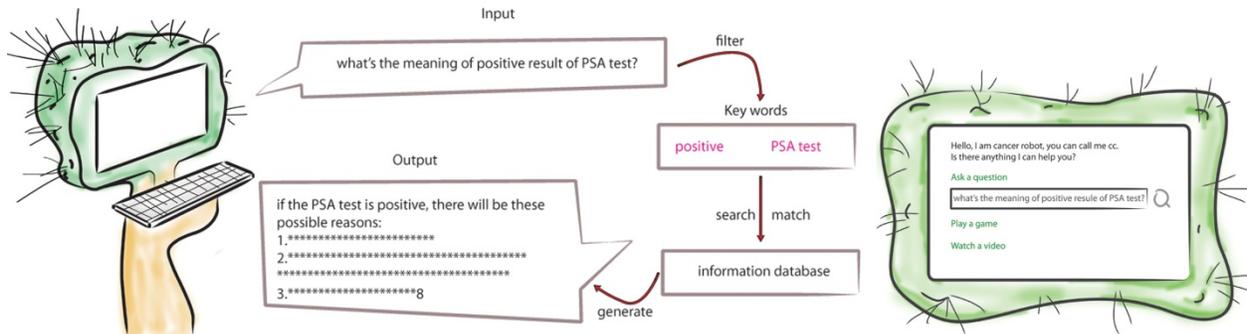


Figure 12 Sketch of cancer robot

Design Inspiration: conversational interaction

Description: the idea is to create a cancer robot in the waiting area of cancer center. The cancer robot has a strong database supported by cancer clinical sites. It is interactive and interesting, with the appearance as cancer cell. Patients can ask questions ,play task-based games to gain a general overview of prosatate cancer. Patients can also watch informative videos and movies.

Idea 2: treatment navigation tool

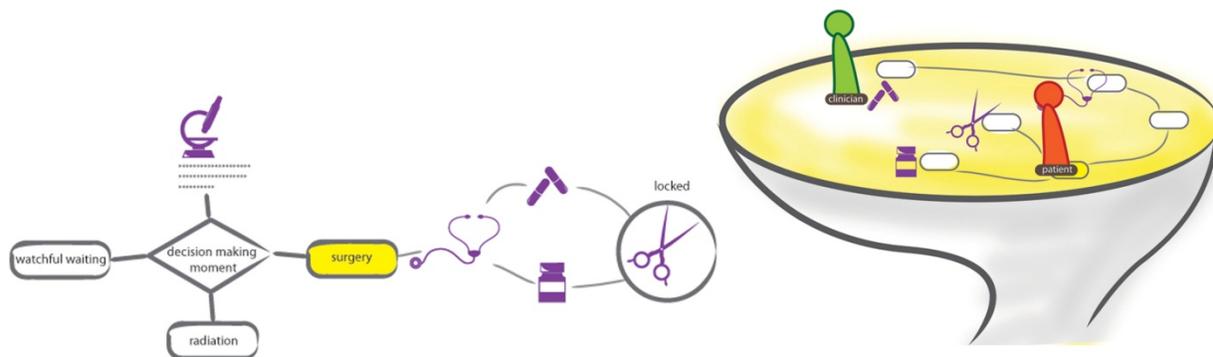


Figure 13 Sketch of treatment navigation tool

Design Inspiration: information visualization/ tangible interaction

Description: the main idea is to use natural and visual language to transform the professional medical information. The intelligent table visualizes the branches of patients' choices. It helps patients follow the clinical procedure step by step and provides right information at right time. The toys on the table

represent doctor and patient. So the system can be used by both clinicians and patients at the same. This idea facilitates the interaction between clinicians and patients during the consulting meeting.

Idea 3: web-based decision making tool

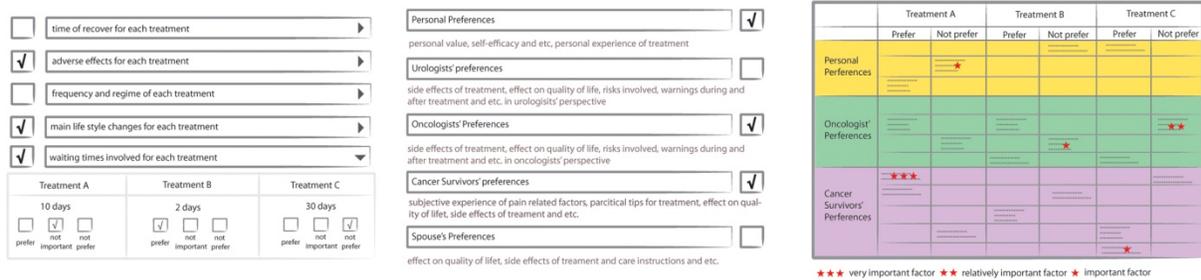


Figure 14 Sketch of decision making tool

Design Inspiration: user interface/ tailoring mechanism

Description: the main idea is to give cancer patients the decision-making empowerment to choose what factors will be taken into account and also how important they are. This tool helps patients tailor the decision-related information step by step (tailor stakeholders involved— tailor factors taken into consideration— rate the importance of factors). The tool also helps patients reach a decision with rational reasons. The reasons provided in the summary help patients be confident about his own decisions and better communicate with clinicians during the decision making meeting.

Idea 4: memory disk & template form

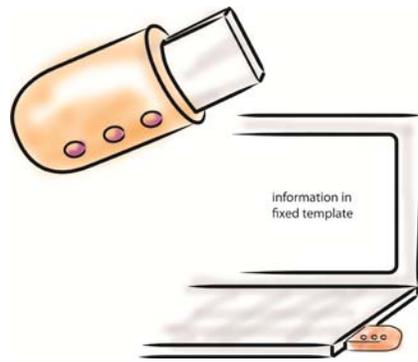


Figure 15 Sketch of memory disk

Design Inspiration: information template/ Electronic health record

Description: the main idea is to use a product to store all the verbal information and electronic health record(EHR). The innovative point is that all the information collected by patients will be transformed automatically to a fixed template, which is easier for communicating and sharing. The product is a kind of memory disk, patients use it to record the verbal information from clinicians during the meetings. They can also bring it home and get access to the information on their own computer.

Idea 5: Dedicated consulting room

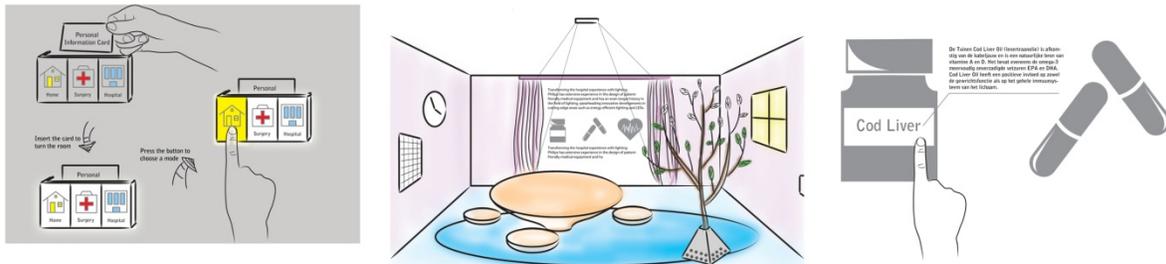


Figure 16 Sketch of dedicated consulting room

Design Inspiration: ambient experience

Description: the idea is creating a dedicated space, so that professionals and patients can sit together and go through the different treatment options. The information is immersed in the space, patients can have some tangible interaction to obtain the treatment-related information.

Review: These broad ideas were reviewed by my supervisor Pavan. Some ideas and explorations were kept for further design, such as information visualization, use of Electronic Health Record (EHR). The directions of tangible interaction and ambient experience were given up because they are limited in the consulting room. The decision aid should be flexible enough to facilitate the whole process (cancer center's work flow & patients' needs when they are at home). What's more, in order to build a high-quality prototype before the deadline of FMP, it is a realistic idea to start with user interface. So after discussion, the boundaries of project were defined.

Blueprint

As seen in Figure 17 on the next page, I drew the blueprint of decision aid for prostate cancer patients in SDM process. It would be an Ipad application, as Ipad application is flexible to facilitate the whole SDM process: The Ipad can be embedded in the consulting room, provides enriched user experiences, records verbal information during consulting and etc. The application can be operated by both doctor and patient during the meeting. And when the patient leaves the cancer center, he can still get access to the same application through PC. The application contains patient's electronic health record and it is used to store and manage personal information by prostate cancer patients during the whole SDM process. The application include the main components of SDM process: treatment options overview, comparison of treatment options, value clarification, checking for understanding of facts and perspectives and decision summary.

Blueprint of Application Design

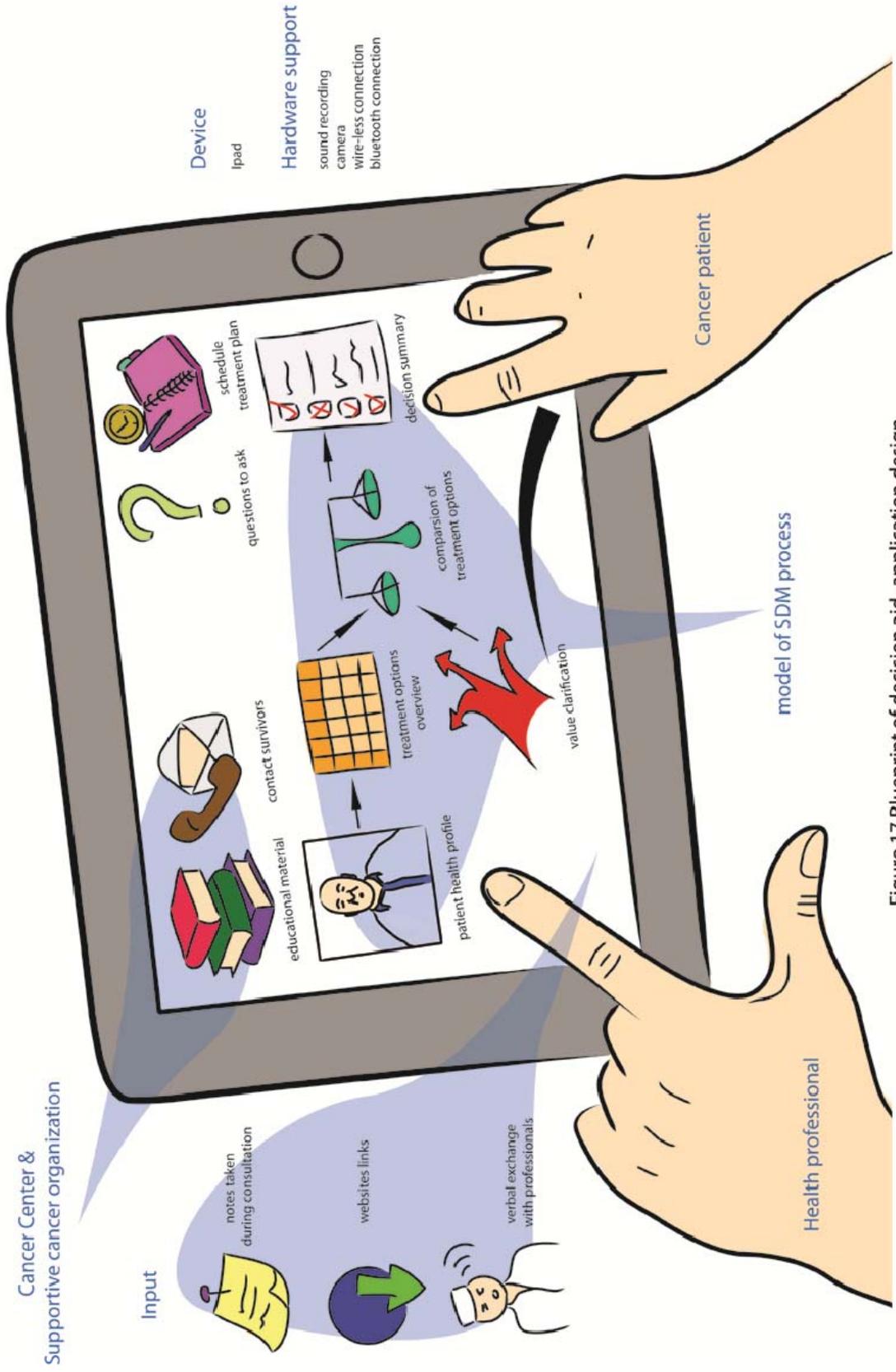


Figure 17 Blueprint of decision aid -application design

CHAPTER 4 DESIGN GUIDELINES

Model of SDM Process

Ottawa Health Research Institute (OHRI) is a front-runner in research and design for SDM. OHRI provides an integrated model of SDM [19], which has five main components. The existing decision aids may have one or more of these components:

Comparison of treatment options shows how the treatment options differ across different parameters, i.e. pros and cons of all options.

Value clarification is one of the most important steps for shared decision making and this is what separates SDM from other decision making models. This step involves drawing out the values important for a patient and enabling them to communicate their preferences. This initiates a negotiation between the clinician and the patient where the clinician provides his recommendation and the patient weighs the attributes that are personally important to her/him[20].

Checking for understanding of facts and perspective ensures that the patient understood the information provided correctly and that the clinician has a clear view on patient's preferences.

Decision Summary provides overview of the choices made by the patient, if any. It could present all the information input by the patient and then make it available for discussion during consultations with health professionals.

Usability Guidelines for Elderly People

The usability of interfaces plays a major role in the user experience of an application. It is important that the user finds the application easy to use and understand; this is particularly challenging, but very important for elderly users[21]. One of the most difficult problems in adopting technology has been that of user interfaces which are often not well-suited for elderly users, as growing old inevitably changes the physical and cognitive capabilities of humans [22].

When a website is designed and developed, it is recommended to make use of a set of guidelines to improve usability of the site [23]. Based on the World Wide Web Consortium (W3C: an international community that develops standards and guidelines that when adhered to improve accessibility and usability of websites Guidelines) , a set of research-derived ageing-centered Web design guidelines which take into consideration the needs of older adults were made. As seen in table 5 on the next page, the source column of the table identified the scholars whose research produced or supported the guideline.

Id	Guideline	Source
1	Target Design	
1.1	Provide larger targets	[27] [25]
1.2	There should be clear confirmation of target capture, which should be visible to older adults who should not be expected to detect small changes	[27]
1.3	The older adult should not be expected to double click	[27]
1.4	It should be obvious to older adults what is clickable and what is not	[28][29]
2	Use of Graphics	
2.1	Graphics should be relevant and not for decoration. Minimal to no animation should be present	[27][30][28]
2.2	Images should have alt tags	[27]
2.3	Icons should be simple and meaningful; text incorporated with the icon when possible	[27][30][24]
3	Navigation	
3.1	Extra and bolder navigation cues should be provided	[27]
3.2	Clear navigation should be provided	[27][24][28]
3.3	Provide location of the current page	[27][24]
3.4	Avoid pull down menus	[27][30][25]
3.5	Do not have a deep hierarchy and group information into meaningful categories	[27][25]
3.6	Make all functionality available from a keyboard	[28]
4	Browser Window Features	
4.1	Avoid scroll bars	[27][28][29]
4.2	Provide only one open window e.g. pop up/ animated advertisements or multiple overlapping windows should be avoided	[27]
5	Content Layout Design	
5.1	Language should be simple, clear, uses the active voice and uses positive phrasing	[27][30][28][29]
5.2	Avoid irrelevant information on the screen	[27]
5.3	Important information should be highlighted	[27]
5.4	Important information should be concentrated mainly in the centre	[27]
5.5	Screen layout, navigation and terminology used should be simple, clear and consistent	[27][30][24]
6	Links	
6.1	There should be differentiation between visited and unvisited links	[27][30][29]
6.2	Links should be clearly named and no link with the same name should go to a different page	[27]
6.3	Links should be in a bulleted list and not tightly clustered	[27][25]
7	User Cognitive Design	
7.1	Provide ample time to read information	[27][28]
7.2	Reduce the demand on working memory by supporting recognition rather than recall and provide fewer choices to the user	[27][24][28]
8	Use of Colour and Background	
8.1	Colours should be used conservatively	[27]
8.2	Blue and green tones should be avoided	[27][30]
8.3	Background screens should not be pure white or change rapidly in brightness	[27]

	between screens.	
8.4	A high contrast between the foreground and background should exist.	[27][30][28]
8.5	Content should not all be in colour alone (colour here is denoted by all colours other than black and white)	[27]
8.6	Avoid using background patterns	[27][30]
9	Text Design	
9.1	Avoid moving text	[27][30][28]
9.2	Text should be left justified	[27][30]
9.3	There should be double spacing between the lines	[27][30]
9.4	Main body of the text should be in sentence case and not all capital letters	[27][30]
9.5	Text should have clear large headings	[27]
9.6	Use medium or bold face type e.g. san serif type font i.e. Helvetica, Arial of 12-14 point size. Avoid other fancy font types	[27][30][25][29][28]
9.7	Provide text alternatives for any non-text content so that it can be changed into other forms people need, such as speech, large print or simpler language	[28][30][29]

Table 5 Web design guidelines for elderly people

Chapter5 Field Study

Some user research (refer to Design Context in Chapter 2) were already done to get an overview of the workflow of PZN in SDM process, while there was still a lot of information missing. In order to gain a deeper understanding about the clinical workflow and patient experiences within the stages of diagnosis and treatment of the prostate cancer care cycle, The research team of Philips conducted field study in PZN, including observation study and interviews with different stakeholders.

Workshop

In order to prepare for the field study, a workshop within the research team was organized by Pavan Dadlani. At the beginning, A medical consultant explained the general flow of prostate cancer, e.g. what happens to the patient before the diagnosis meeting, what's the special point to indicate a patient becomes involved in SDM process, what are the tests a patient may go through and etc. As shown in figure 18 on the next page, a complete Prostate flow from Philips Design was used to explain the medical information.



Figure 18 Workshop- medical consultant explaining the Prostate flow

Afterwards, based on the story boards (refer to Story Boards in Chapter2) demonstrating patient's experience flow, the research team brainstormed the questions related to the scenarios. Figure 19 shows the questions on post-its in the the workshop.



Figure 19 Workshop- brainstorming on the story boards to generate questions

After workshop, all the questions were summarized to set the interview guidelines. I generated a list of questions in terms of context and content:

Questions about the context

Before the decision meeting, there are two main scenarios in SDM process: meeting with professionals in cancer center and searching information at home. Table 6 shows the interview questions in terms of context are based on these two scenarios:

During the diagnosis & consulting meeting:
<ol style="list-style-type: none"> 1. Who will participate the meeting normally and what are their roles? 2. What's the information do patients receive during the meeting? 3. What's the extent do patients understand the information? 4. What are the forms of communication during the meeting? 5. Is there any problem of communication? If yes, how can patients and clinicians solve these problems?
After the meeting, when patients are at home:
<ol style="list-style-type: none"> 1. What are the forms and sources of information do patients receive after the diagnosis meeting? 2. Who will search the information? Patients themselves or their family? 3. What are the problems of them? (here interviews may give some examples such as booklets, cancer organization, on-line library and etc.)

Table 6 Interview questions about context

Questions about the content

In terms of content, it is important to know what is the exact medical information shared between patients and other stakeholders in the SDM process, because the decision aid is information-based. Table 7 shows the interview questions related to the content.

About the diagnosis:
<ol style="list-style-type: none"> 1. What's the knowledge of patients about prostate cancer before and after the diagnosis meeting? 2. Do patients understand their PSA result, Gleason score, stage of prostate cancer and biopsy result and etc.? If yes, how do they get the education of these tests?
About the treatment decision:
<ol style="list-style-type: none"> 1. When thinking about the treatment options, whose opinions have you taken into account? And can you explain the order of importance? And why? (For example: oncologist / radiation oncologist / urologic oncologist / surgeon / specialist nurse / cancer survivor/ spouse and family) 2. When thinking about the treatment options, which factors have influenced your decision of treatment? And can you explain the order of importance? And why? (For example: <ol style="list-style-type: none"> 1) The procedure of treatment: Time of hospital stay/ required hospital visits/ time of recover 2) The subjective experience of treatment: Pain and discomfort during treatment/ what happens to the body 3) Some available evidences of treatment: Survival rate / survival years / chance of recurrence / probability of side effects 4) Long-term quality of life of treatment: The side effects after treatment/ influence on life style)

Table 7 Interview questions about content

Interviews

The interviews were led by a research consultant, and seven designers participated. According to the interview guides (refer to appendix 2), the aim of interviews and observations were:

- Get insight into the person’s mindset, motivations, emotional experiences, experience needs, all related to decision making.
- Get a deeper understanding of the experience of the stakeholders within the selected spaces.
- Get insight into relevant activities and experiences that cannot be observed in the hospital, such as family life at home, looking for information etc.

For three days, the whole research team interviewed most of the staff in PZN:

- 2 Urologists
- 2 Oncologists
- 2 Nurses
- 1 Psychologist, involved in cancer patient care
- 1 Receptionist

and some prostate cancer patients and their partners:

- 6 patients that face decision making: (*watchful waiting, active surveillance, treatment*).
- 4 patients that are in treatment / have decided

After the interviews, the research consultant concluded all the notes and made a flow for PZN-figure 20. Compared with the work flow in chapter 2 it has more enriched information. There are four main scenarios happen in the cancer center:

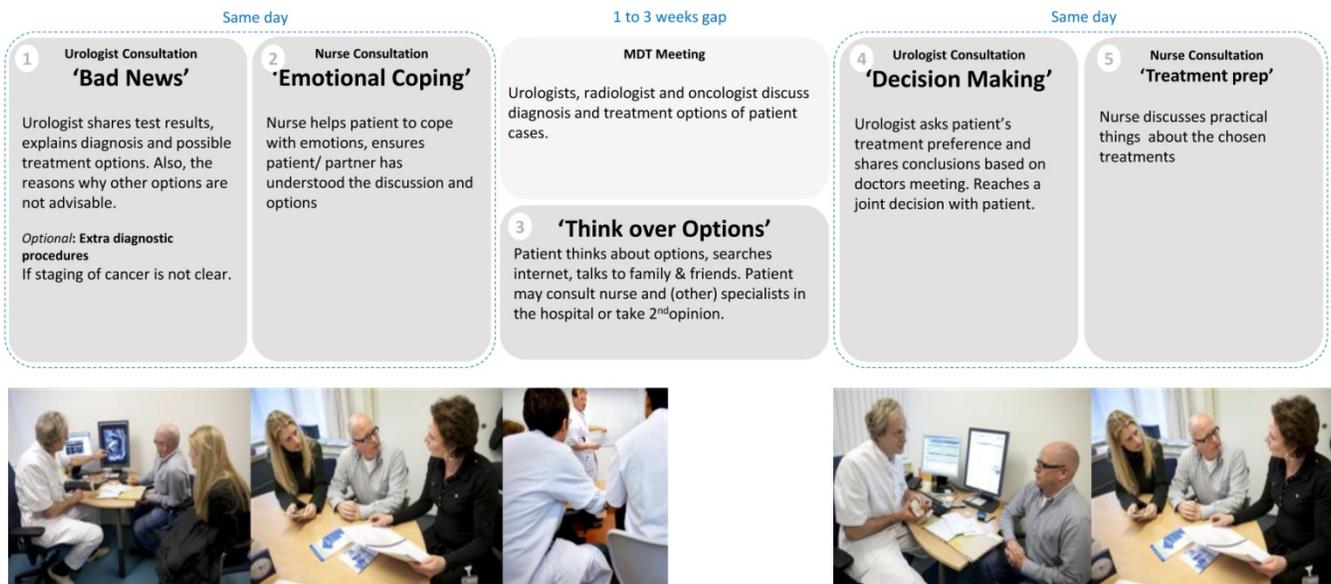


Figure 20 shared decision making process in PZN—Jeanine Kierkels

Bad news meeting:

At the bad news meeting, the urologist shares test results, explains diagnosis and possible treatment options as well as the reasons why other options are not advisable. The patient is stressed and nervous, who does not know on forehand whether it will be a good or bad news.

Emotional coping:

Nurse helps patient cope with emotions, ensures patient and his partner has understood the discussion and option. Nurse explains things verbally and may provide information handouts. Information is repeated, because patient and partner often don't completely remember what has been discussed with urologist. She also explains the treatment in detail in "easy language" such as what would happen with patient's body if he would do surgery. The specialist nurses also answer patients' mails and calls.

MDO meeting:

The MDO stands for Multi Disciplinair Overleg in dutch, which is an internal meeting of PZN. It happens at the lunch time every working day. Normally if a doctor thinks a patient needs to be discussed in the MDO, he then puts patient's record on a list. During the MDO, all patients on the list will be discussed one by one. The urologists, radiologists and oncologist will all participate. They discuss the best option for patient's further treatment. Treating physician states his opinion, then other doctors give their opinions and discuss the relevancy and strength of the arguments. All the doctors are very open for discussion, they are not hesitant to give or defend their opinions. Based on patient's profile, they take into account of these factors:

- Age
- General health and other medical problems
- Psychology
- Quantity and quality of life
- Preferences of the patient

The options are presented as a priority list rather than fixed decision.

Decision making meeting:

The decision making meeting is normally one week or two weeks after the bad news meeting. The urologist asks patient's treatment preference and shares conclusions based on MDT meeting, then they reach a joint decision about treatment. A urologist explained the meeting in these words *"It is a common commitment to a certain goal. Patients need to be stimulated to take their own decision and responsibility, because then the compliance with their treatment and their follow up is better."* Patient may prepare himself for the meeting a lot of questions and the urologist also has to correct the information patient has collected from e.g. newspaper, but misinterpreted.

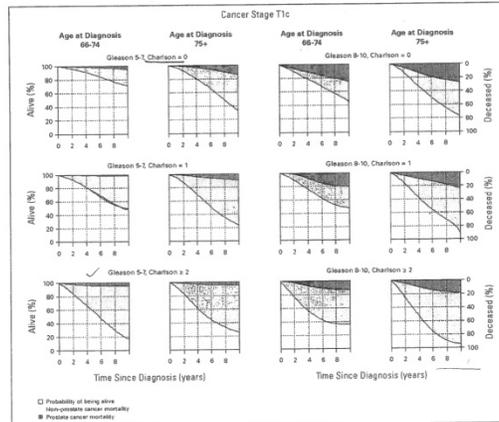
Most of the nurses and all the patients speak Dutch. Because of the language problem, I only attended the interviews with the two urologists. Here are the specific questions and answers of the interviews below. Some photos taken in the PZN are used to explain the urologists' answers.

Are patients receptive to have cancer?

Usually not, then the urologist tries to catch the patient to say *"you have cancer, but don't worry, you won't die of it. We will treat it!"* The patient is always not alone, with spouse next to him. Figure 21 is

the table of risk of mortality used by urologist to explain that for localized prostate cancer patients the chance of prostate cancer mortality is quite low. *“you have cancer but you will die of something else.”*

Competing risk of mortality by age at diagnosis, cancer stage, grade, and comorbidity: cancer stage T1c.



Albertsen P C et al. JCO 2011;29:1335-1341

American Society of Clinical Oncology

JOURNAL OF CLINICAL ONCOLOGY

Figure 21 table of risk of mortality-PZN

What kind of information does urologists share with patients?

The urologists explain the tailored and customized information verbally with the help of on-screen images, and sometimes with hand drawn sketches. Urologists also use facts and statistics to explain the diagnosis information and treatment options, e.g. 8 of 10 patients experience these side effects.

As shown in figure 22, There are two screens in the urologist consulting room, the colored one is used by urologist to input data and calculate some predictive probabilities. The black& white screen with high resolution is good for showing the scans. *“people are interested when you point out where the prostate is, where the problem lies and where metastasis are. They feel more recognized. They have to see the same thing with what I talk about.”* Patients usually don't want to have the scans because they don't see what the urologist can see. Sometimes patients want the copies especially when they want a second opinion, then they can have it in the CD. But it is not common. All the information is transparent, there are only technical reasons for not sharing the original file with patients. e.g. for MRI scan people need special equipment to show it and the report is difficult to be interpreted.



Figure 22 B&W screen specifically for showing the scans in urologist consulting room

As seen in figure 23 on the next page, sometimes the urologist will draw sketches on paper to show where the tumor is.



Figure 23 Sketch drawn by urologist to explain the tumor

One of the urologist has an Ipad, he uses an app called Draw MD Urology to demonstrate the tumor stage and surgery during consulting. But he mentioned the problem: many patients ask for the images, then he has to suspend the conversation, type the email address and then send, which is not very convenient. Figure 24 is the screenshot of this app.

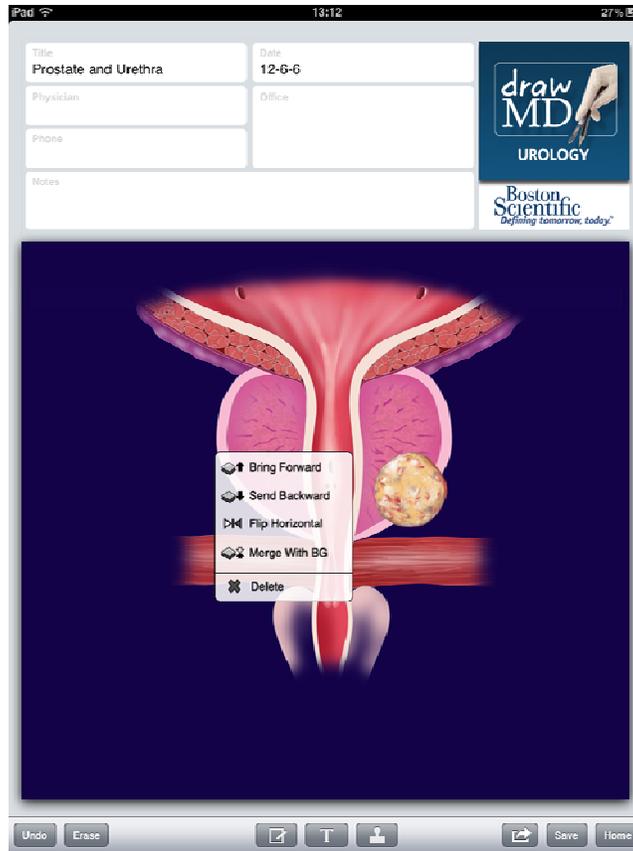


Figure 24 screenshot of Ipad app- Draw MD Urology

Do patients take notes?

Sometimes they take notes, and even record.

What is the challenge of communication in the bad news meeting?

It is difficult to find whether the patients really understand what the urologist has told. *“that is the art of being a doctor: to see from their facial expressions and from their questions if they understand it or not at all. Sometimes you have a professor or a laborer.”*

The urologist tries to have maximum time face to face. As time is always limited, he has to balance the time needed to be on screen to read the diagnosis data.

How do the urologist capture patients’ preferences?

“you try to make the contact to understand what kind of man it is. Whether he is a very technical person or resolute, whether he wants something done or not, whether he wants aggressive treatment or not”. For example, there are two patients with the same tumor stage, a pilot patient will say *“doctor, this is cancer ,fix it for me!”*; a reverend patient will respond *“Do I need treatment? Are you sure? Ok, if I really need treatment, let’s do radiotherapy”*

How does the environment support the interaction between urologists and patients?

“It works better to have patient and his spouse around the table instead of across because it is easier to show them the screen.” The urologist tries to have more interaction between patients. The room is not luxurious, it is functional and clean. Figure 25 shows the normal scenario of urologist consultation.



Figure 25 urologist consultation

What is the spouse’s role in SDM process?

One of the urologist explained that in seventy percentages of situations the woman is the boss. They are always worried of losing their partners, they seldom care about the technical directions. *“I want you to be alive, so don’t take any risk, get the thing out!”*. For other cases, there is balanced relationship between patient and his partner.

How about the decision making meeting? When the treating urologist goes to MDO to discuss the patient’s case, then the patient comes back with a best option in his mind, how does that go?

The disagreement doesn’t happen that often because at the moment of diagnosis the clinicians already direct some directions. The directions are based on patients’ age, comorbidity, stage of cancer, Gleason score and etc.

Do patients regret their decisions?

When patient has made an informed decision, which means he made his own decision, he will always be satisfied with his choice.

CHAPTER 6 ITERATIVE DESIGN

In this chapter, iterative design were conducted based on the design directions (refer to chapter 3) and design guidelines (refer to chapter 4). For each iteration, there was a prototype built for discussing and receiving feedbacks.

The First Iteration

The goal of the first iteration was to determine the type of information to display. At this point, the focus of the project was the type of information being displayed; the interaction aspects would be detailed in the later iterations. For this iteration, I read a lot of literatures and books about prostate cancer, and then organized the medical information based on the model of SDM process. The information sources of the figures and prototype mainly came from:

- The book *Prostate Cancer* written by American Cancer Society
- The book *Questions to Ask My Doctor About Prostate Cancer* written by American Cancer Society
- The booklet *What You Need To Know About Prostate Cancer* written by National Cancer Institute
- The booklet *Prostate Cancer Treatment (PDQ)* written by National Cancer Institute
- The booklet *Treatment Choices For Men With Early-stage Prostate Cancer* written by National Cancer Institute
- The on-line decision aid *Clinically Localized Prostate Cancer* supported by Agency for Healthcare Research and Quality

Information organization

Based on the information source, I combined the relevant information and then summarized three overview maps of the content: Figure 26 presents the different decisions a prostate cancer patient has to make after diagnosis. Firstly, a patient has to choose between active surveillance or taking treatment to remove cancer immediately. If he prefers active surveillance, some routine tests will be tracked until he decides to undergo any treatment. If he chooses taking treatment now, several options with different risk-benefit trade-offs are provided. It's up to the patient to decide which treatment to take. Sometimes, different treatments can be combined. e.g. Hormone Therapy after a Surgery. In the end, the hospital or location for the treatment should be carefully considered about.

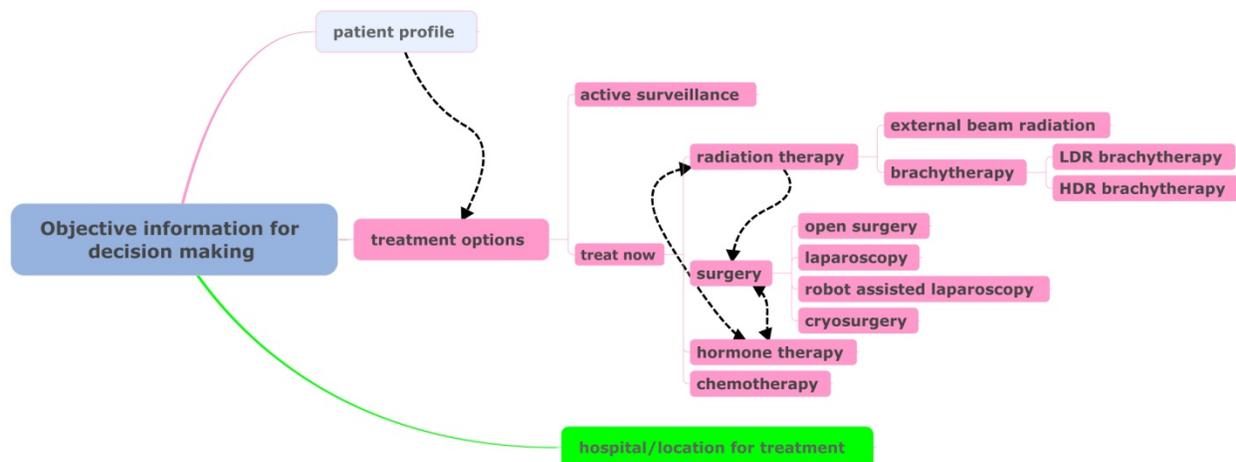


Figure 26 map of treatment options

Figure 27 shows the evidences or values related to the decisions. The values with pink lines are connected to the decision for treatment options, while the values with green lines are related to the decision for hospital/location of treatment.

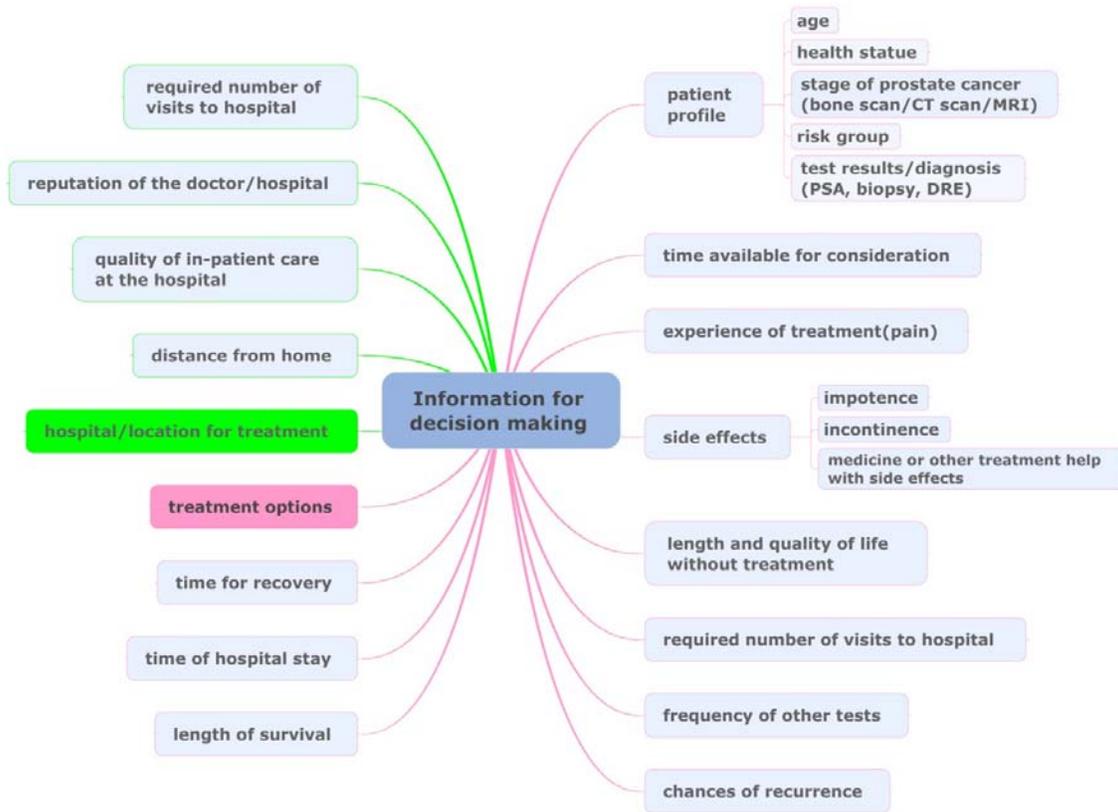


Figure 27 values related to the decisions

Figure 28 lists all the stakeholders involved in the SDM process, whose suggestions or preferences will influence the final treatment decision.

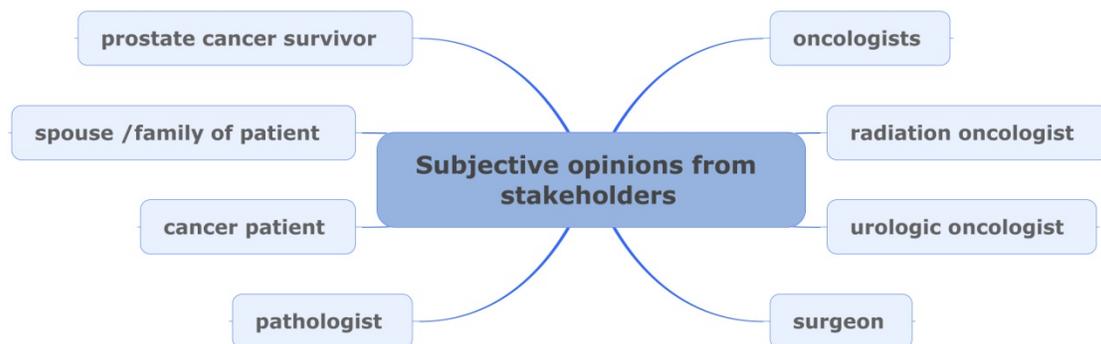


Figure 28 stakeholders involved in the SDM process

Information visualization

Based on figure 27, I made an analysis of all the influencing factors patients may take into consideration. Table 8 below shows how the factors are classified the factors according the nature of information.

Influencing factors:	Category
Experience of treatment (pain)	 
Time available for consideration	 
Length and quality of life without treatment	   
Side effects (impotence/ incontinence/ Medicine or other treatment help with side effects)	 
Required number of visits to hospital	
Frequency of other tests	  
Chances of recurrence	
Length of survival	 
Time of hospital stay	  
Time for recovery	  
Explanations:	
	The factors with conversation mark relate with subjective information such as personal feelings and experience. Patients can get this kind of information from nurses, cancer survivors. The media of information can be storytelling, audios or videos.
	The factors with calculator mark relate with data information which can be ready for tailoring model.
	The factors with clock mark relate with time information. It is possible to use timeline, schedule, calendar and other similar forms to present these information.
	The factors with heart mark relate with patients' values. Patients can clarify their personal preferences and values according to the evidences.

Table 8 Influencing factors analysis

Visualize treatments: time line

Based on the analysis,  the factors with clock mark relate with time information. It is possible to use timeline, schedule, calendar and other similar forms to present these information.

As seen in figure 29, the idea is to use some icons to represent the key steps of treatments, e.g. different tests, hospital care, medicines, surgery, radiation, accessories and etc. then based on the real information of treatments, the medical icons help explain the procedures of treatments.

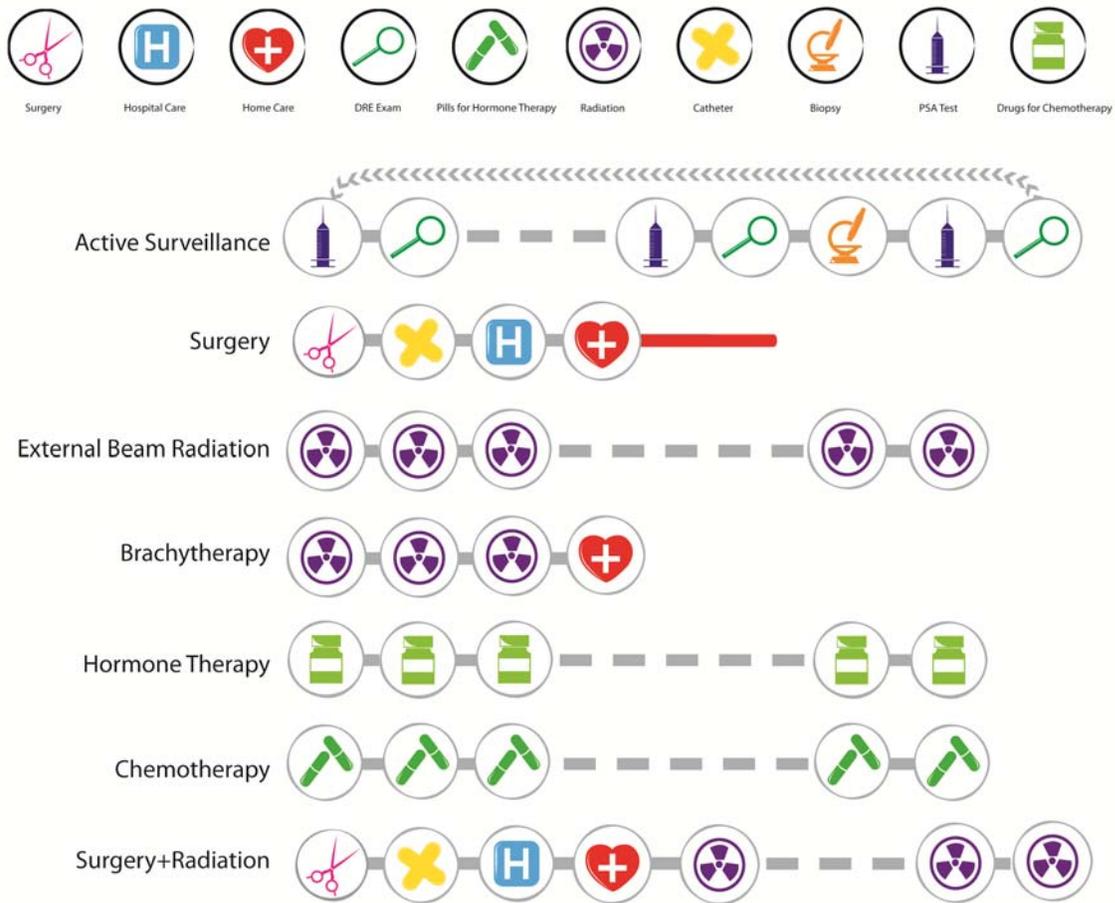


Figure 29 visualize the treatment procedures with icons

Figure 30 is an advanced version compared with figure 29. I still used the icons to explain the significant step of treatments, the time line is more accurate here. So that it is possible to compare the factors such as “required number of visits to hospital” “frequency of other tests” “time of hospital stay” and etc.

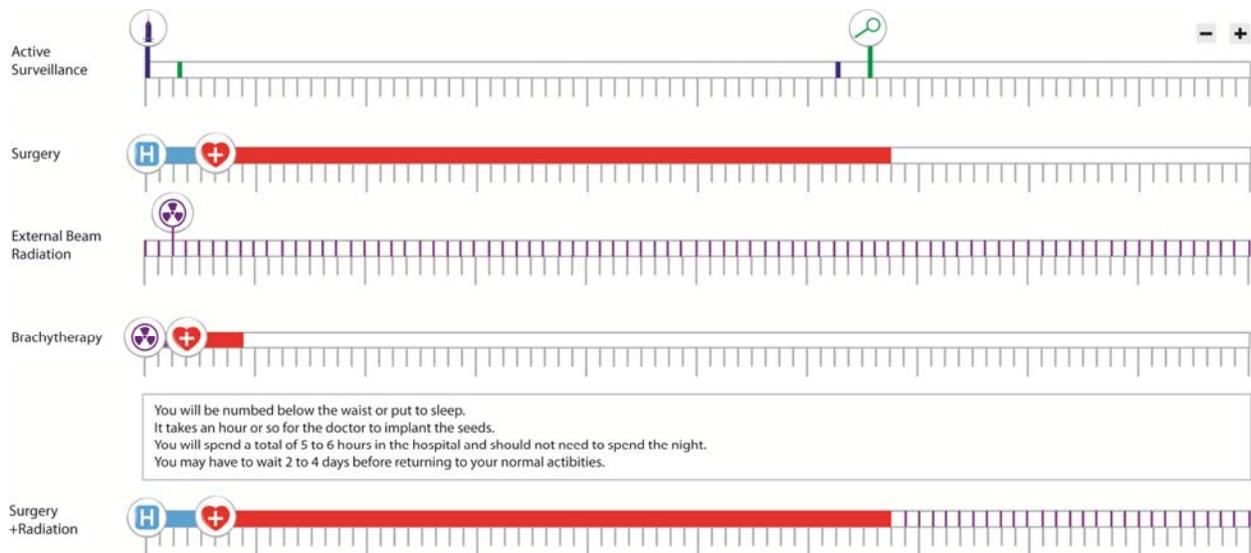


Figure 30 time line idea explaining procedures of treatments

Prototype1: fast facts booklet

The first iteration (refer to appendix 3: prototype 1) was much driven by the competitive landscape (refer to chapter 2) of web-based products help prostate cancer patients understand their health profile and then make an informed decision. From the needs finding [problem 8], The biggest concerns of searching on the internet by cancer patients were getting overwhelmed with information and finding out things that they would not want to know.

For example, only the book *Prostate Cancer* written by American Cancer Society is 77 pages long. The information is complete but overloaded for patients. And the various products provide redundant information with different formats, e.g. most of the booklets explain the same medical information such as PSA tests and Gleason score, but they use different phrasings and pictures.

So the first iteration is like a “fast facts booklet” of prostate cancer. It is a combined and improved version of the current booklets. It is used as the database of later iterations of design. The information is organized based on the integrated model of SDM (refer to chapter 4):

- Treatment options overview
- Comparison of treatment options
- Value clarification
- Checking for understanding of facts and perspective
- Decision summary

As seen from figure 31-the content of the fast facts booklet, it shows how the information is organized. The order is linear, it starts at “education of background information and diagnosis”, then introduces the

“treatment options”, there are some questionnaires help patients “clarify personal values and preferences”, and finally patients consider all the influencing factors and “make the informed decision of treatment”.

Education of background information	3
What is prostate?	3
What is prostate cancer?	3
What are the symptoms of prostate cancer?	3
Understand the diagnosis	4
How is prostate cancer found?	4
Digital rectal exam.....	4
PSA blood test	4
Biopsy	4
Gleason score	4
Has the prostate cancer spread?	4
Bone scan	5
CT scan	5
MRI	5
What are the stages of prostate cancer?	5
What is prostate cancer risk group?	6
Understand treatment options	6
Treatment options overview.....	6
Active surveillance	6
Surgery	7
Radiation	9
Hormone therapy.....	11
Chemotherapy.....	11
Compare treatment options	
What can you expect during treatment?	
What are the side effects?	
What can be done to help side effects?.....	
Will you have pain?	
Clarify personal values and preferences	12
Evaluate the importance of related values	12
What do you concerned about?	13
What are you preferences?.....	13
Make choices	13
What are the factors which influence the choice of treatment?.....	13
What are the recommendations from professionals?	14

Figure 31 content of prototype 1

The Second Iteration

The first iteration is just some preparation work for later design, so the second iteration is the starting point of design of user interface.

Information organization

As seen in figure 32, the order of information of prototype 2 is still similar to the prototype 1, which is based on the SDM model. The big difference is that prototype 2 combines patients' personal information with the medical information. For example, in step 2, my diagnosis information (the test results and scans) are combined with education of DRE test, blood test, biopsy, Gleason score and etc. figure 32 shows the flow of prototype 2, it is still linear but personalized.

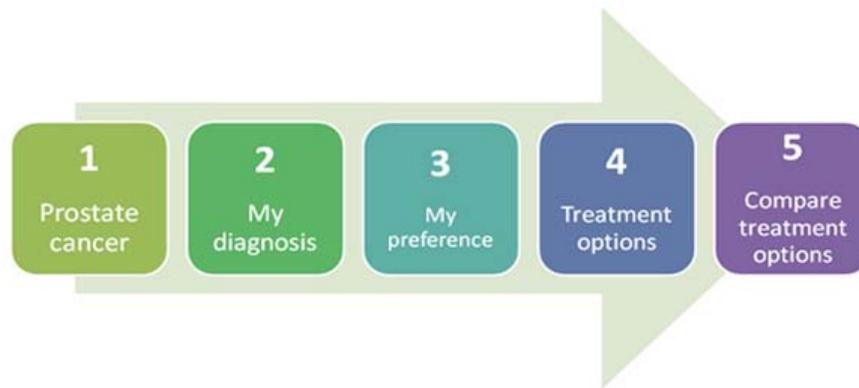


Figure 32 flow of prototype 2

Information visualization

Based on the design directions (refer to chapter 3), I generated ideas on the topic of information visualization:

Information visualization	Information visualization and interaction design can be used to make the medical jargons comprehensible, especially the diagnosis information (e.g. stage of cancer, biopsy result) and treatment explanations.	Problems 1,4 Inspirations1,3,9
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Visualize diagnosis information:

From the needs finding [problem 1], the scans and pathology reports contain too much medical jargon, which are difficult for ordinary people to comprehend. Based on the medical information, I visualized most of the test results to communicate what do the results and numbers mean to a patient. For example, figure 33 firstly introduces what is Gleason score and then explains what is the exact meaning if a patient has the Gleason score 7.

My Gleason Score: 7

The Gleason Score, as it is referred to, will help to ensure that physicians are aware of the prostate cancer's stage. Utilizing the Gleason Score will enable the physician to make an accurate decision call on management options, and the possibility of a cure for the patient's prostate cancer. A Gleason score is the sum of two grades which helps determine how aggressive the cancer is. It can fall anywhere between 2-10. A score of 2 would be taken as almost normal, while a 10 would suggest cancer that is wildly and aggressively malignant.

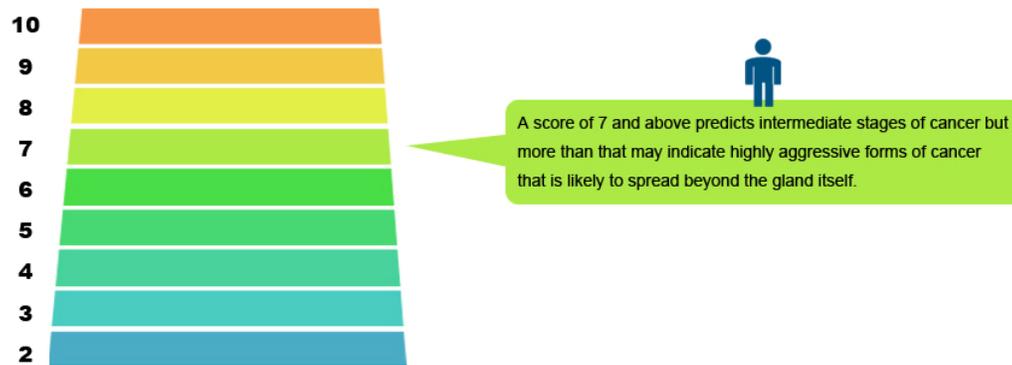


Figure 33 visualization of personalized Gleason score- prototype 2

Visualize treatments:

Figure 34 shows the idea of using story boards to explain the procedures of treatments. The story boards can be used during the nurse consultation, then nurses can just pick some important scenarios.

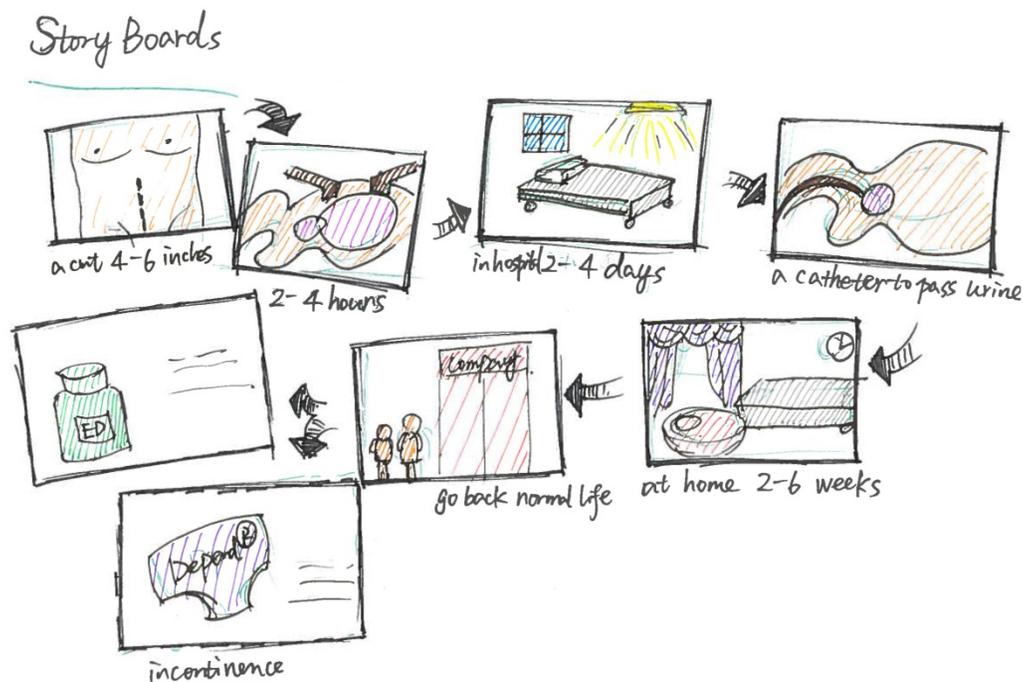


Figure 34 use story boards explaining the procedure of treatments

Visualize statistics:

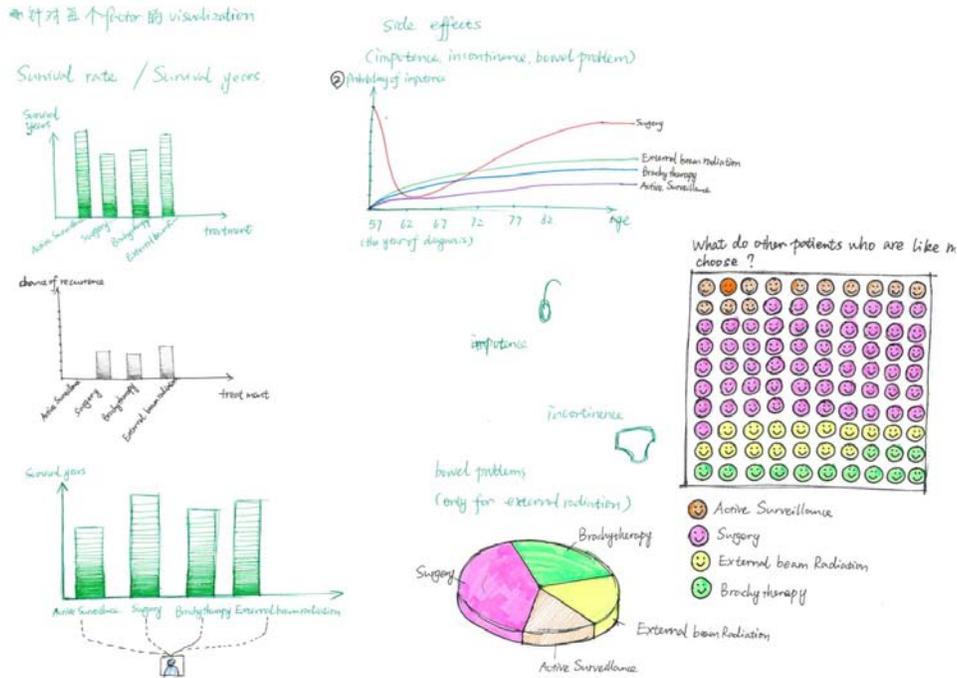


Figure 35 sketches of visualizing the statistics

There are some statistics helpful for patients to compare treatment options, e.g. survival rate, life expectancy, chance of recurrence and probability of side effects. Figure 35 shows the explorations of visualizing and simplifying the statistics. Different color, size, chart style are explored to communicate the abstract data information.

For example, on the page “what do other patients like me choose” –figure 36, I used 100 smiley faces to communicate the number of patients with similar health profile choose each treatment option. It is more natural than pie chart.

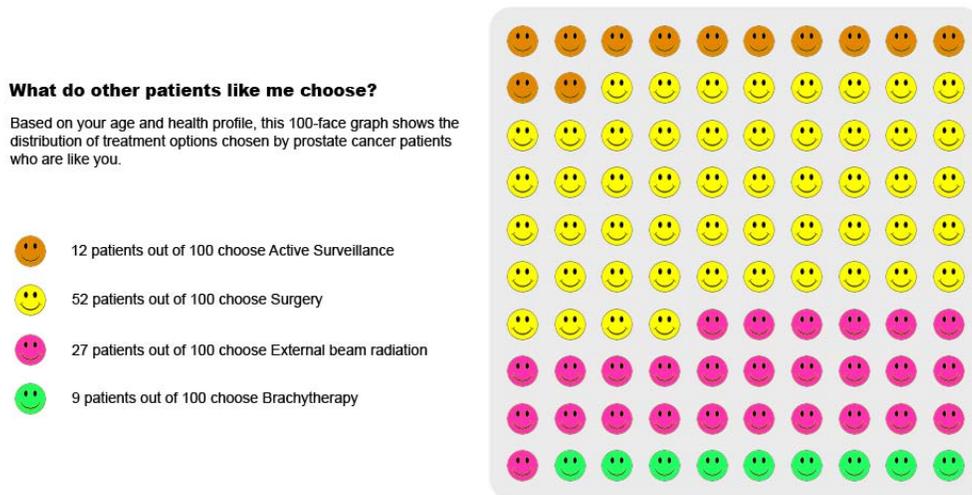


Figure 36 100-face explaining what do other patients like me choose- prototype 2

Another example is figure 37, I used pie chart and different colors indicate the numbers, which is clear and self-explanatory.

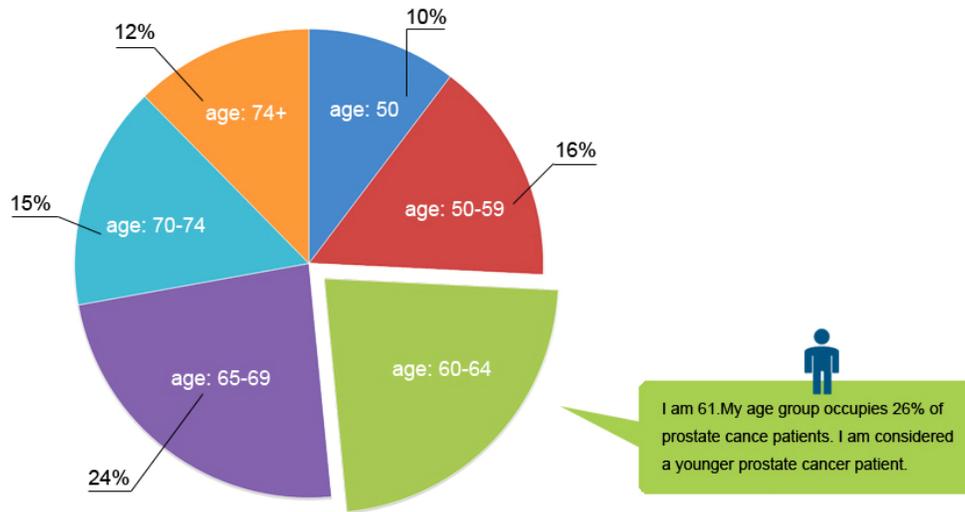


Figure 37 age group –prototype 2

Personalization

Based on the design directions (refer to chapter 3), I generated ideas under the topic of personalization:

Personalization	The decision aid should play an important role as storing and managing personal information for the prostate cancer patients. There can be some features such as keeping diaries, recording verbal exchange between professionals during meetings and etc.	Problems 2,10,11 Inspirations 2,5,7,10
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The Problems & Inspirations (refer to chapter 3) already provided some concret ideas of personalization. For example, keeping diaries, recording verbal exchange and etc. Figure 38 shows the design of “My information” page, the application has these features for personalization:

- Personalized health profile
- Feature of recording doctors’ verbal information
- Feature of keeping notes
- Feature of adding patients’ own questions
- Personal preferences and values
- Personalized treatment comparison report
- Personalized treatment plan
- Contact information with cancer center



My INFORMATION



Figure 38 “My information” page- prototype 2

As seen in the figure 39- “treatment options” page of prototype2, the options are tailored based on patient’s personal information, only the suitable choices are present. This page was added before explaining the details of each treatment. It is used to describe the reasons why a specific treatment option is suitable for a patient.

What are my options based on my profile and preferences?

<ul style="list-style-type: none">  I don't mind have frequent testing to monitor cancer (PSA test, biopsy).  I can accept that the cancer will remain in my body.  I cannot adjust to the loss of ability to have an erection. 		<div style="background-color: #0070C0; color: white; padding: 5px; border-radius: 5px; display: inline-block;">Active Surveillance</div>
<ul style="list-style-type: none">  I am 61. I am younger prostate cancer patients, so surgery is suitable for me.  My Gleason score is 7. A score of 7 and above predicts intermediate stages of cancer.  I am in the Middle-risk group of prostate cancer. It is less likely to be cured by surgery alone. I may still need radiation therapy after surgery.  I am on the T2 stage of prostate cancer. The cancer hasn't spread to the bones, but I had better to remove it as soon as possible. 		<div style="background-color: #0070C0; color: white; padding: 5px; border-radius: 5px; display: inline-block;">Surgery</div>
<ul style="list-style-type: none">  I may develop incontinence after surgery. It is small adjustment for me to wear an absorbent pad during my daily activities.  My Gleason score is 7. A score of 7 and above predicts intermediate stages of cancer.  I am in the Middle-risk group of prostate cancer. It is less likely to be cured by surgery alone. I may still need radiation therapy after surgery.  This is a good time in my life to take care of my cancer right away, I have enough time. 		<div style="background-color: #0070C0; color: white; padding: 5px; border-radius: 5px; display: inline-block;">Radiation therapy</div>

Figure 39 treatment options match- prototype 2

Figure 41 is an idea of tailoring mechanism build on the explorations of figure 40. It is inspired by “short-board effect”: the possible treatments (with the metaphor of water) for patients depend on the measurement of answers (with the metaphor of laths).

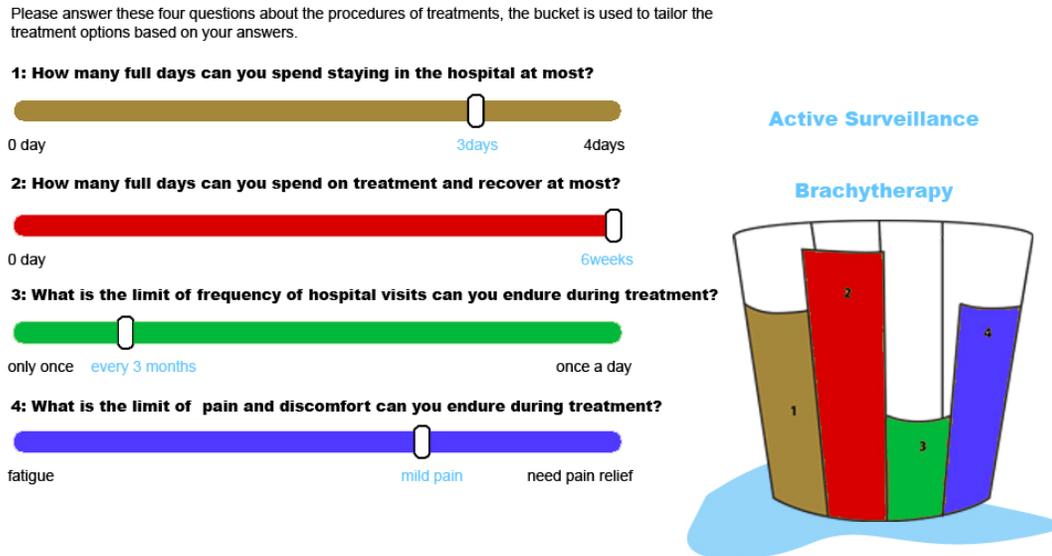


Figure 41 tailoring treatments based on treatment involvement

A Philips colleague who is working on mathematics models provided a time trade-off model for comparing different treatments. The original question is very technique, difficult to understand. As seen in figure 42, then I visualized the questions, and also add some animations to guide patients understand and fill in the questionnaire step by step.

The scale below shows what you have chosen about importance of impotence:



Figure 42 visualize the time trade-off model- prototype 2

Figure 43 is the sketch of making patients' own comparisons. I used the medicine bottles with tangible feeling to represent the treatments, which is simple and natural. the interaction style is also suitable for Ipad application.



Figure 43 sketch of make my own comparison

Figure 44 shows the digitalized page in prototype 2. Patients can drag the treatments they like and select the influencing factors which they think is important and relevant for them. Then the application will tailor a personalized report for the patients.

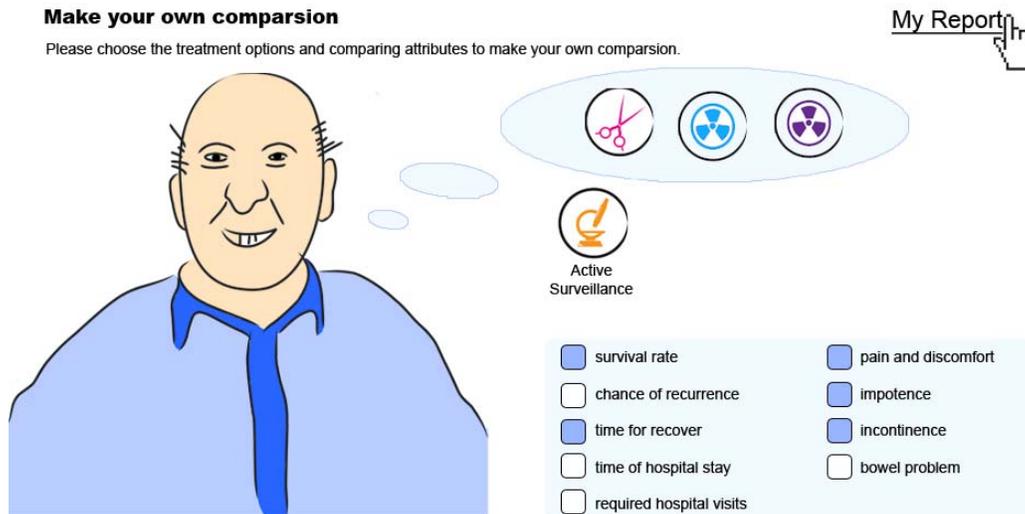


Figure 44 page of making my own comparison- prototype 2

Prototype 2: linear-order user interface

Compared with prototype 1, prototype 2 was improved much on the aspects of information visualization and personalization, the complete version can be found in appendix 4.

Feedbacks

Prototype 2 was reviewed by my supervisors and other stake holders in the team of Philips, it was presented at the final exhibition of M2.1 semester. Here are the feedbacks received for further iterations:

1. It is an “all in one” version, which means all the content is put in one layer. It makes users feel tired to go through all the pages one by one.
2. Phrasing needs to be improved to show more empathy of cancer patients.
3. There are two kinds of navigation: linear order based on SDM process and “my information” portal. A Clearer can combined navigation and more guidance to the user is needed.

The Third Iteration

The third iteration was made after the field study. A fellow designer joined the team and brainstormed the ideas with me together.

Information organization

Based on the feedback 1 and 2 of prototype 2, I brainstormed to find more cues of how to link different topics and how to group information. Figure 45 shows the sketches of brainstorming.

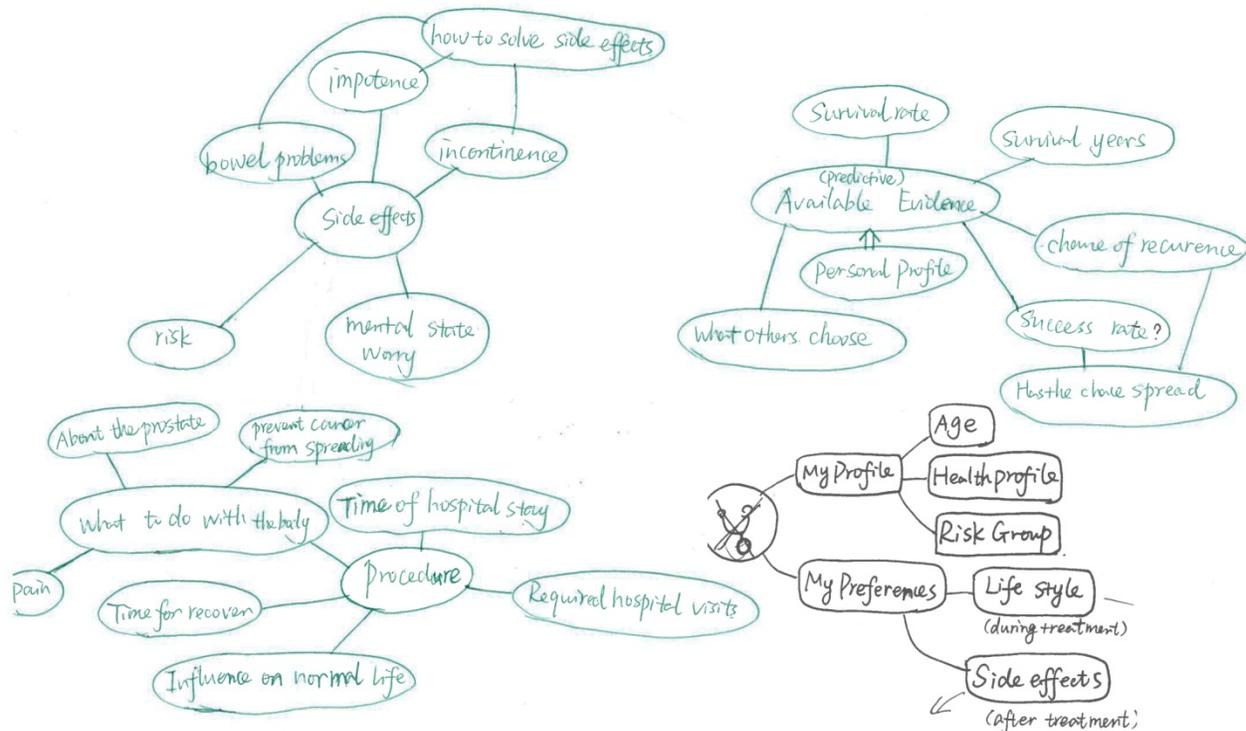


Figure 45 group information

My diagnosis page:

My diagnosis page is very important because normally it is the first step patient uses the application. Based on the information of figure 27 (refer to the first iteration), the page contains patient's personal information (age/ health profile), test results (PSA/ gleason score/ tumor stage/ MRI scan) and the information from the cancer center (doctor's report/ risk of mortality/ prostate anatomy). The risk group is used as a label of the prostate cancer patient and the prostate anatomy is highlighted on this page because patients like visual language to explain their problems. In order to keep the diagnosis information simple and clear, the detailed information is hidden behind the icons.

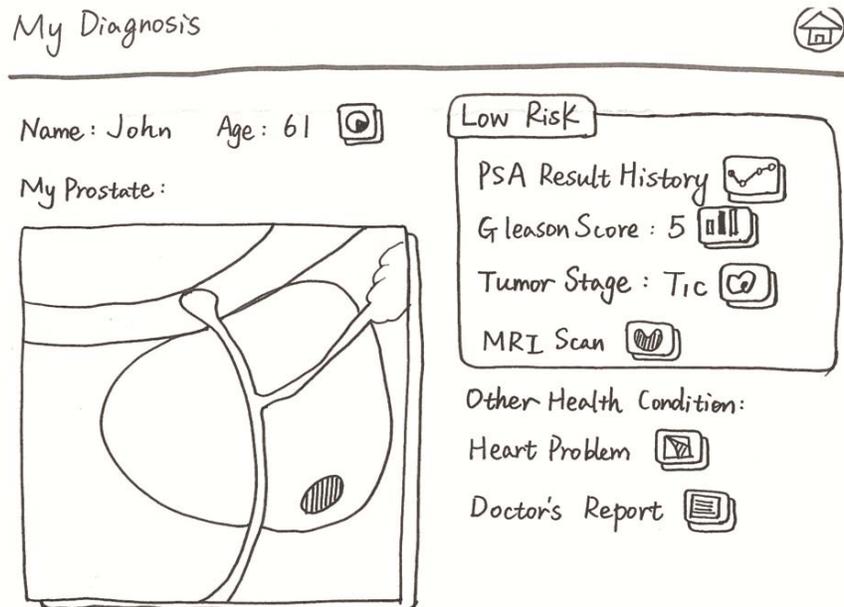


Figure 46 diagnosis page- prototype 3

My preferences page:

 Based on the influencing factors extracted from table 8, these are the factors which can be chosen by patients. so these topics were included in the “my preferences” page.

- Experience of treatment
- Length and quality of life without treatment
- Side effects (impotence/ incontinence/ Medicine or other treatment help with side effects)
- Frequency of other tests
- Required number of visits to hospital
- Time of hospital stay

Then we grouped the information within three main topics:

- Quality of life: includes side effects (impotence/ incontinence/ Medicine or other treatment help with side effects) and experience of treatment
- Mind set: includes patient’s mental state/ Length and quality of life without treatment
- Involvement: includes Frequency of other tests /Required number of visits to hospital/Time of hospital stay

Figure 47 shows the page for my preferences. It has three topics of questionnaires. The layout is simple and focused:

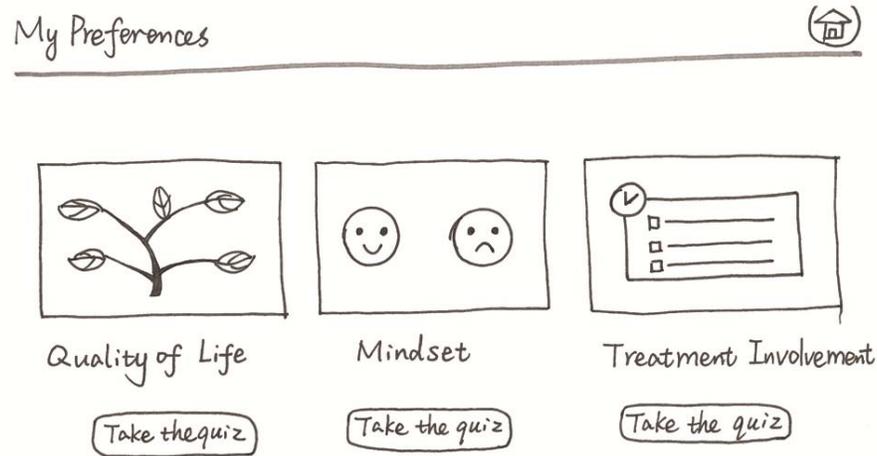


Figure 47 my preferences page- prototype 3

My decision page:

Get the inspiration from user research, “It is a common commitment to a certain goal. Patients need to be stimulated to take their own decision and responsibility, because then the compliance with their treatment and their follow up is better.” There is a clear step for making the final decision.

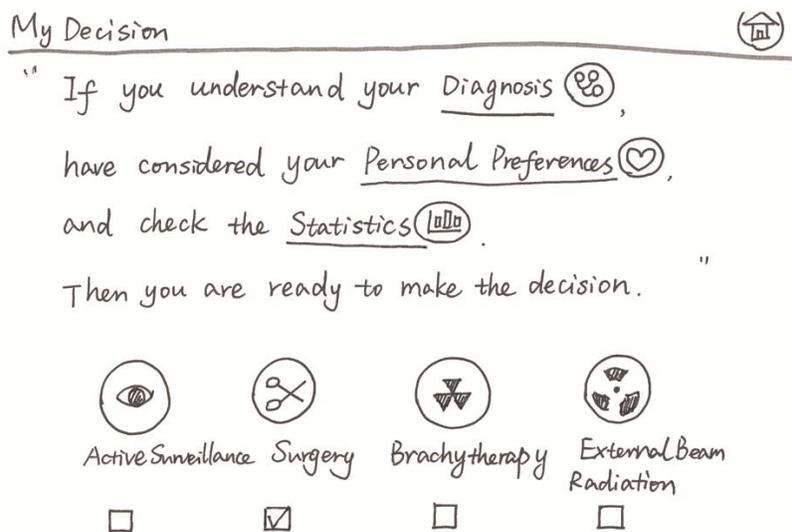


Figure 48 my decision page- prototype 3

As figure 48 shows, only after patient went through all the information, he is able to make an informed decision.

Statistics page:

In prototype 2, there are some charts explaining the data related to me based on the treatments, such as survival rate, chance of recurrence, patients like me choose and life expectancy. Here figure 49 shows the explorations of statistics page. The idea is to find a good solution to present all the data on one page, so that patients can use the numbers to easily compare the treatments.

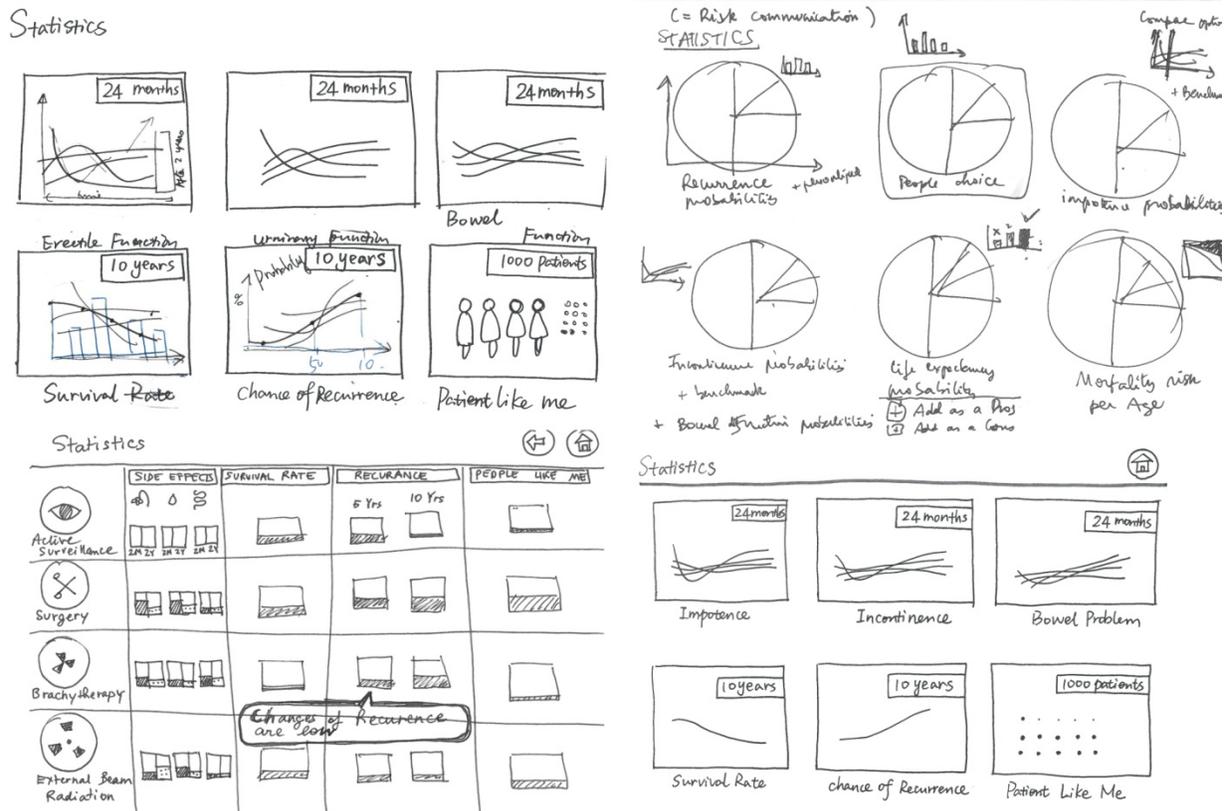


Figure 49 sketch of statistics page

Figure 50 shows the final effect of statistics like page after discussion. In this page, there is only one chart style, so that patients only need to learn one visual style.

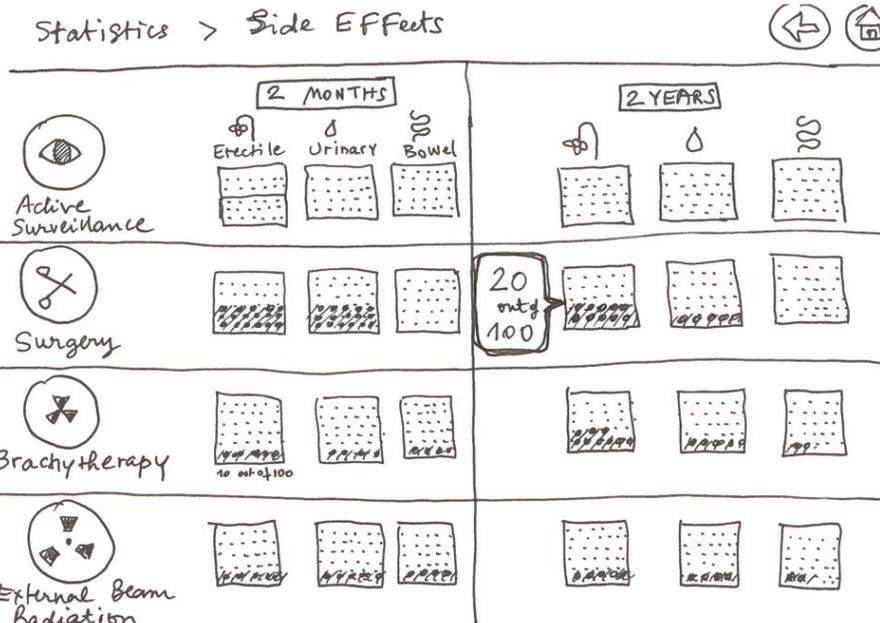


Figure 50 sketch of statistics page- prototype 3

Treatment option page:

In order to explain the procedures of treatment options, there were already some ideas generated before, e.g. the time line idea in the first iteration and the story boards idea in the second iteration. Here I explored the layout of treatment option page. the idea is too keep all the key information in one page, some detailed information is organized behind the story boards or links.

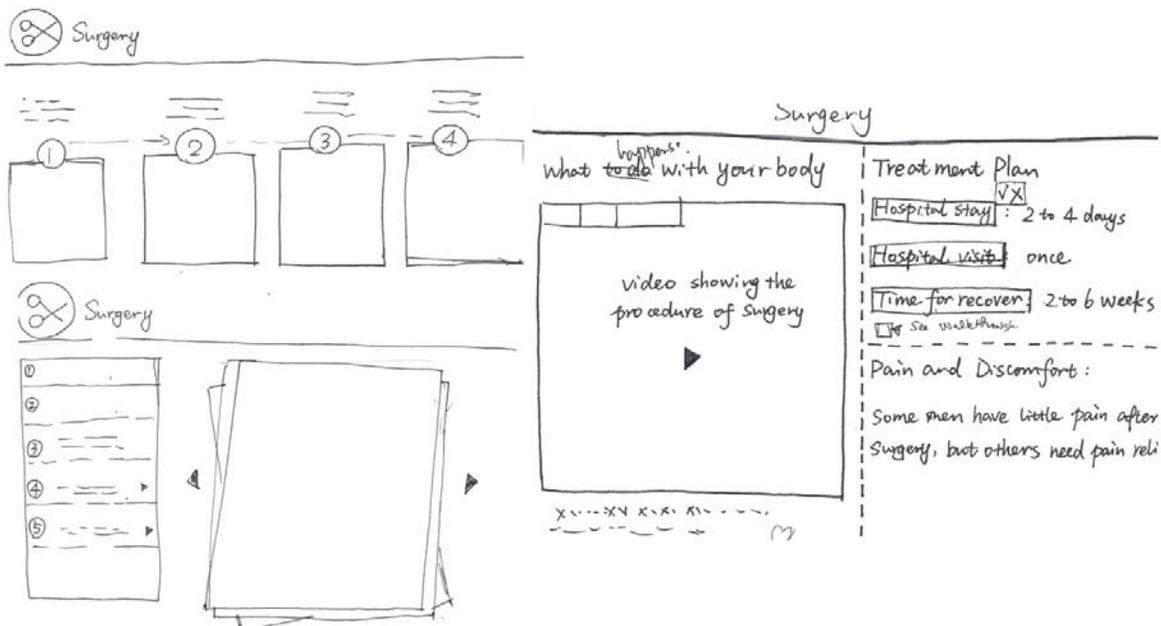


Figure 51 sketch of treatment option page

Home page:

When my diagnosis page, my preferences pagen, my decision page, treatment option page and statistics page were ready, it is not difficult to make the navigation page. The diagnosis, preferences and statistics related with me was grouped as my profile. The main idea is using branches to represent patient’s options. Figure 52 shows the sketches during brainstorm.

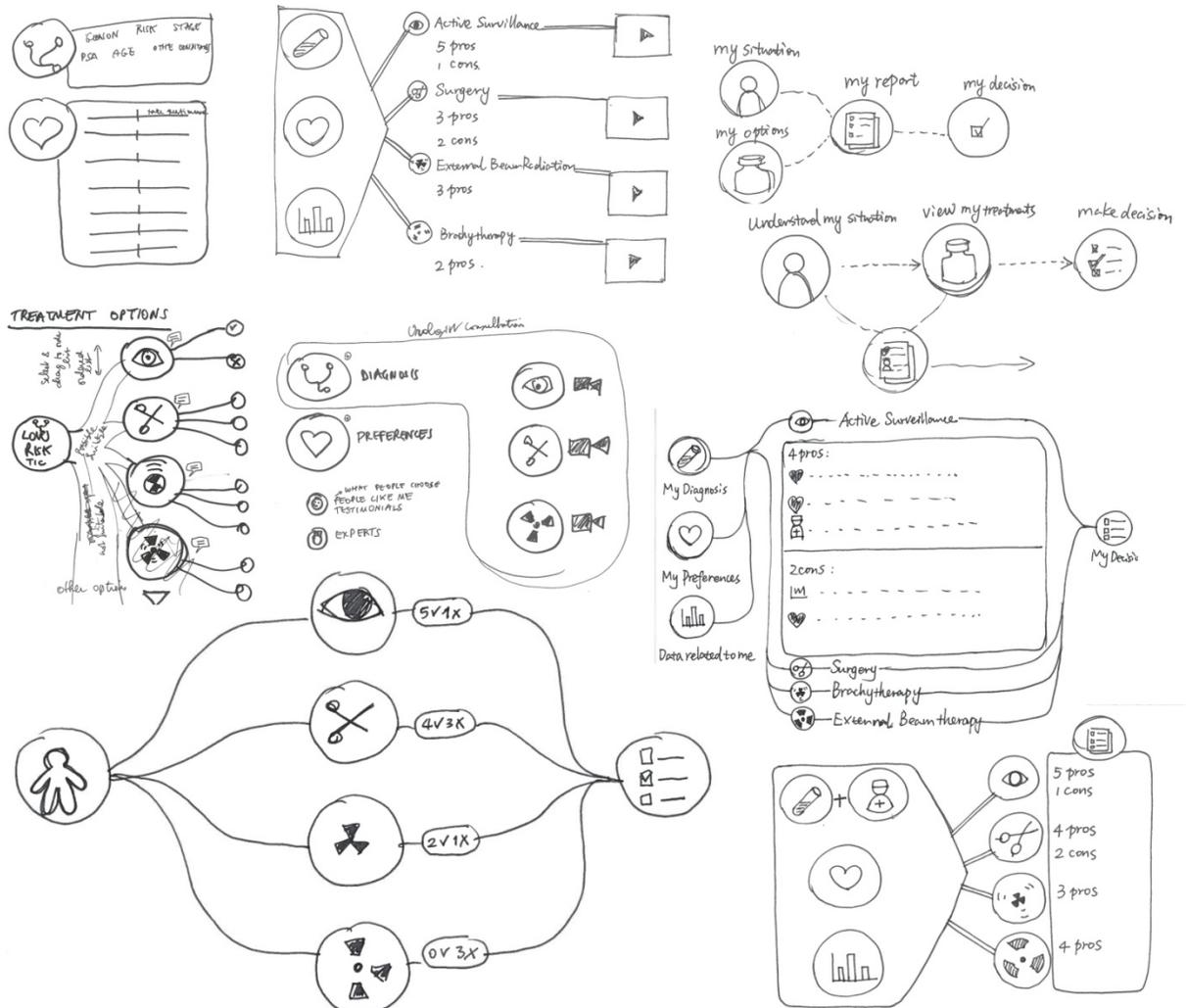


Figure 52 sketches of home page

Collaboration with hospital

Based on the design directions (refer to chapter 3), I generated ideas on the topic of collaboration with hospital:

Collaboration with hospital	The decision aid might be supported by hospital, or even starts at hospital. The database of decision aid is linked to the Electronic Health Record (EHR) of cancer center, then patients don't need to ask for test results themselves.	Problems 3 Inspirations 6
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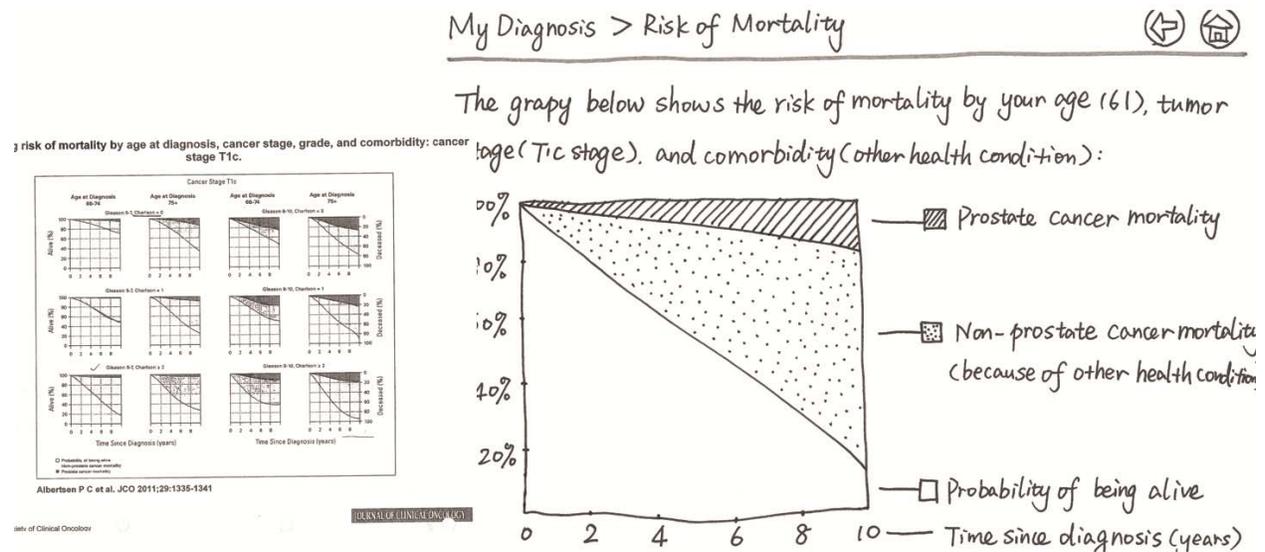
There are three main directions of ideas on the topic of collaboration with hospital:

Simply the information of cancer center:

Firstly, the application starts at the bad new meeting, the urologist introduces the application to the patient and explains the diagnosis information. There is an assumption that the electronic health record of cancer center is linked to the application. So when patients get access to the application, the information is already personalized to himself.

From the observation and interviews of field study (refer to chapter 5), the urologist normally uses the table of risk of mortality to explain that for localized prostate cancer patients the chance of prostate cancer mortality is quite low. "you have cancer but you may die of something else."

The table on the left side of figure 53 is the original file from PZN, but it is the overview of all the situations. Actually for each patient, only one small chart is relevant. The idea here is tailoring the relevant information for patient based on his health profile. So the information is blended in the application.



Enhance communication between doctors and patients:

1. All the medical information used during the consultation is included in the application, so that doctors avoid looking at the PC screens instead of interacting with patients and their partners face to face.
2. The application has some features which can be used during consultation, e.g. typing notes, drawing on prostate anatomy. The figure 54 explains where the idea comes from. The two pictures on the left side of figure 54 are the photos taking in PZN. From the interviews, sometimes the urologist will draw sketches on paper to show where the tumor is. One of the urologist has an Ipad, he uses an app called Draw MD Urology to demonstrate the tumor stage and surgery during consulting. The sketch on the right side of figure 54 is the original idea of prostate anatomy. This page is under the my diagnosis page.

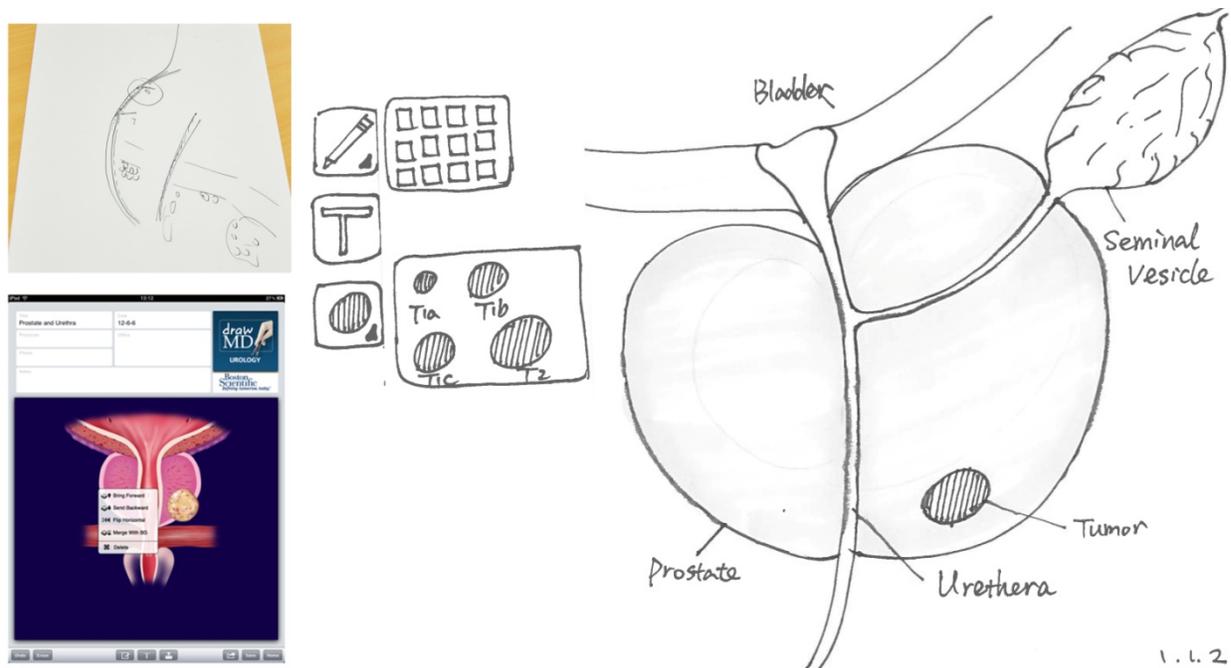


Figure 54 feature of drawing on prostate anatomy- prototype 3

Prototype 3: sketch version

The prototype 3 can be found in appendix 5. In order to blend the work flow of PZN, I and another fellow designer brainstormed the scenarios of using the application. So the prototype 3 is introduced by scenarios. We discussed and drew the script of the scenarios. It starts at the urologist consultation, then nurse consultation. Some days later when patient calm down and at home, some notification function is embedded in the design to remind patients fill in questionnaire and read the doctors' report. Finally, it is the decision making meeting.

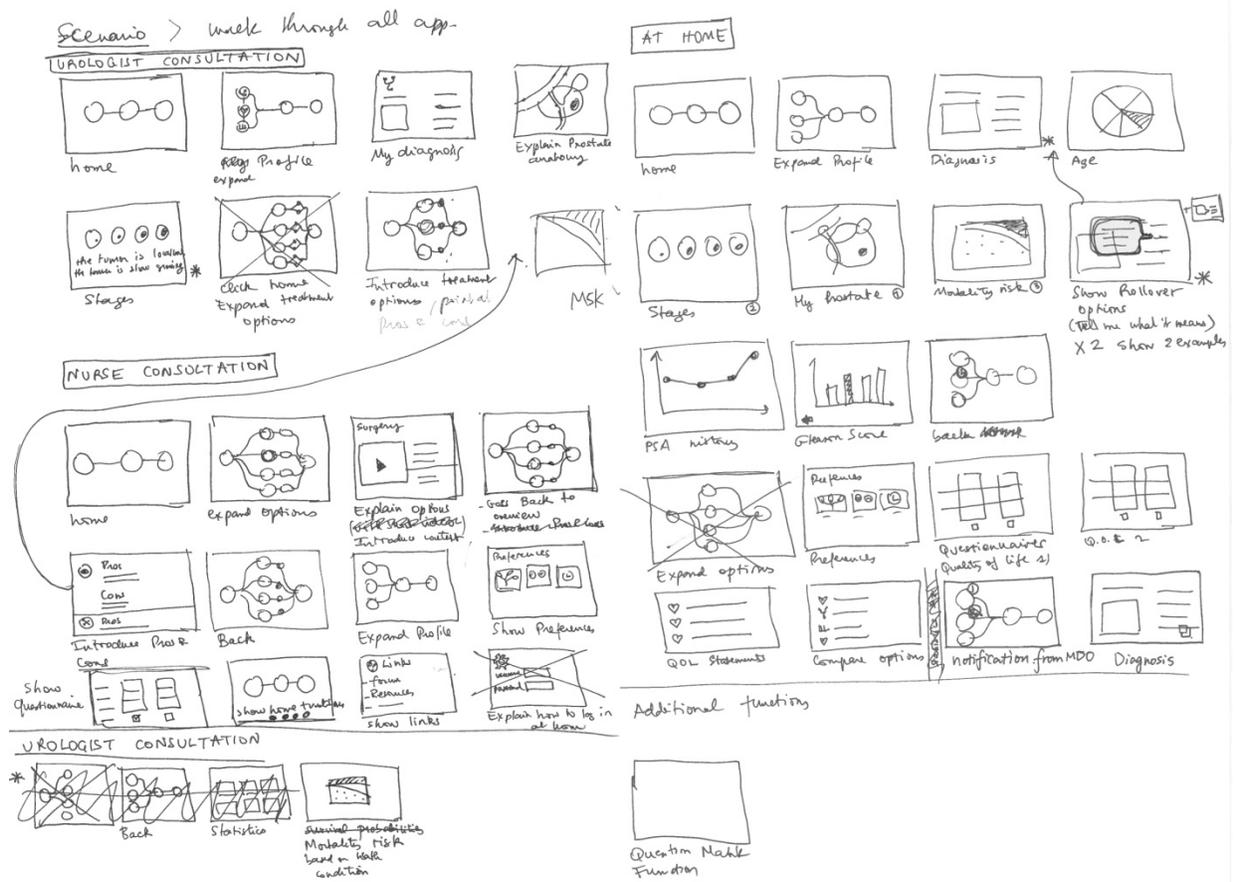


Figure 55 script of scenarios

Feedbacks

Prototype 3 was reviewed by the design team and nurses at PZN. There were these main problems:

1. The navigation is much clearer.
2. The non-interactive version of prototype makes the user interface hard to understand.
3. The hand-written visual style is not formal to share with non-designers.

The Forth Iteration

The fourth iteration is an interactive wire frame prototype. This prototype has working hyperlinks and more accurate content and icons. The design of prototype 4 built directly on prototype 3. The biggest input came from the usability guidelines for elderly people. At the end, user tests with doctors and nurses were organized in PZN, which is used to receive feedbacks.

Information organization

Figure 56 shows the architecture of prototype 4. Compared with prototype 3, there are jumping links. For example, on the summary of my preferences page, patients can jump to pros and cons page to check how the preferences impact on the treatment options. So the red links indicate the logical order of information.

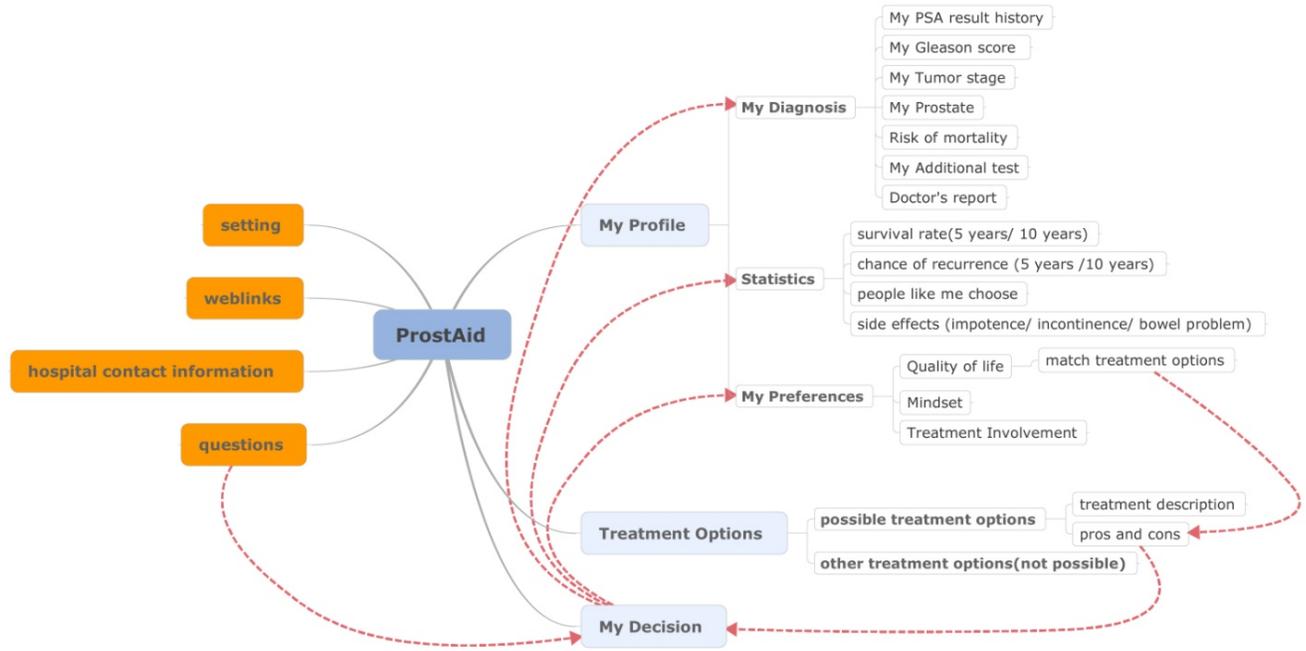


Figure 56 architecture of user interface

Usability

Based on the design directions (refer to chapter 3), I modified the user interface on the topic of usability and also aligned it with the usability guidelines for elderly people(refer to chapter 4):

<p>Usability</p>	<p>The target user group is quite special: elderly people and at the same time cancer patients. So the phrasing and information used in the decision aid should be carefully considered to communicate positive attitudes, e.g. positive cancer survivor's story. And the interaction design of decision aid should be as natural as possible. So the elderly men are able to use it intuitively. Audios and videos are suitable media for communicating information with prostate cancer patients.</p>	<p>Problems 7 Inspirations 8,14,17,19</p>
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The details of the user interface are explained according to the usability guidelines:

Target design

1.1 In prototype 4, the smallest target is 58 pixels wide (20.46 mm), the main buttons are 188 pixels wide (66.32 mm). For systems using touch screens, the ISO [31] recommends that the size of the touch-

sensitive area should be at least equal to the breadth of the index finger distal joint for the ninety-fifth percentile male. The EIA [32] recommends that the minimal touch-sensitive size should be 19.05 mm [32]. Larger spacing resulted in fewer errors, but increased the reaction time. Based on these guidelines the targets are big enough.

1.3 There is no double click in the user interface.

Use of graphics

2.1 & 2.3 All the icons were brainstormed again to reach the best effect, especially the icons for treatment options. I brainstormed and explored the different styles of images. Figure 57 shows the sketches of treatment options, each icon has its specific meaning.

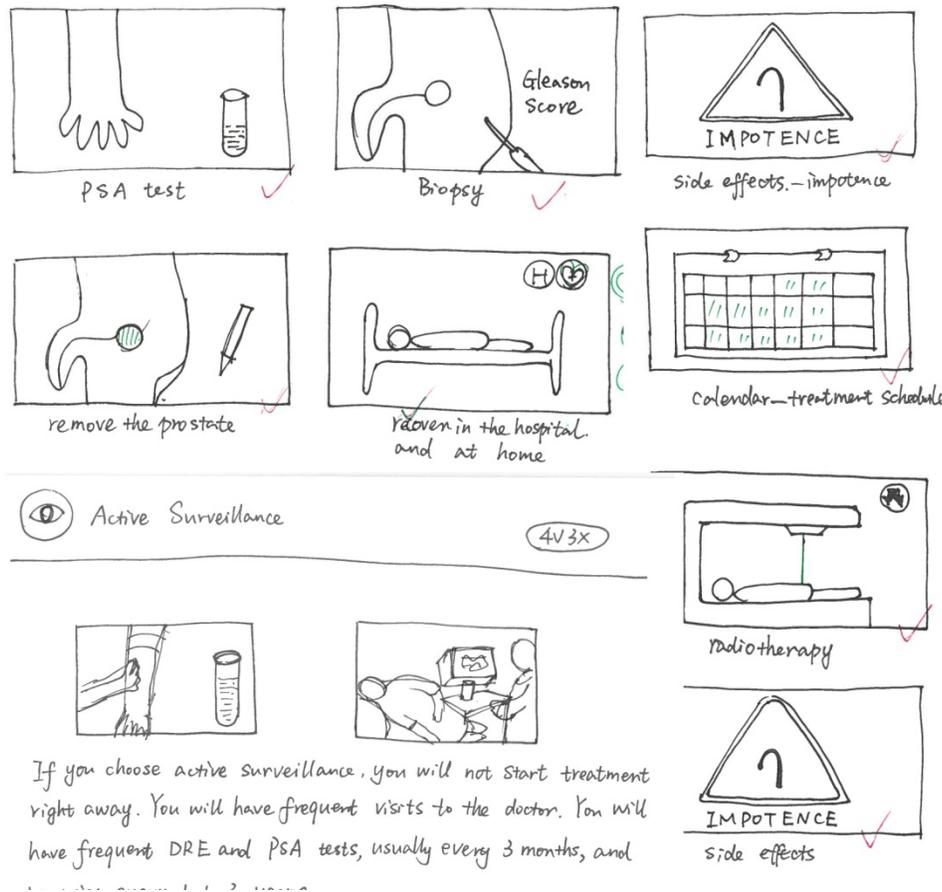


Figure 57 sketches of treatment options

Then I digitalized the icons, figure 58 on the next page shows the final effect of icons of prototype 4.

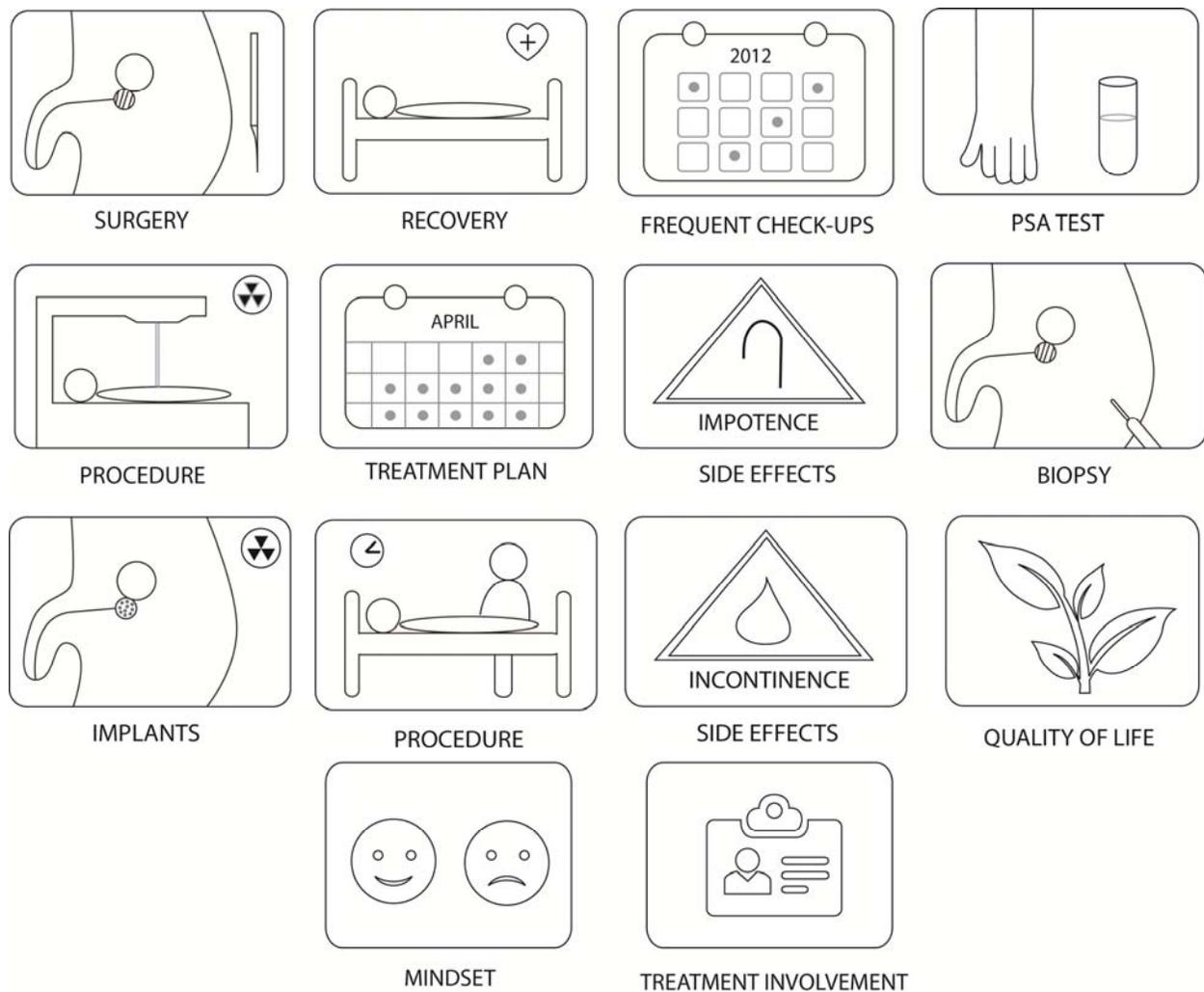


Figure 58 icons –prototype 4

Navigation

3.2 clear navigation

3.3 always have the name of the page on the top middle part of the screen

3.4 no pull down menus

Browser window features

4.2 one full screen one time.

Content layout design

5.1 language is simple, clear and uses positive phrasing

5.5 screen layout, navigation and terminology used is simple, clear and consistent

Links

6.2 links are clearly names and no link with the same name go to a different page

Text design

9.1 no moving text

9.2 text is left justified

9.3 the smallest text size is 15 points. In particular, text size should be 12 to 14 points font[33]. So it is big enough.

Prototype 4: wire frame version

The details of prototype 4 can be found in appendix 6.

Feedbacks

We made user tests both with doctors and nurses, and then received the feedbacks:

1. The risk of mortality chart is difficult to understand
2. The pros and cons page lose some explanation, especially the icon is abstract
3. Add a feature of cleaning questions on the my decision page
4. Explain the meaning of gleason score somewhere of the interface
5. Statistics page is too full, which makes people feel information overloaded

The Fifth Iteration

During the fifth iteration, a professional graphic designer visualized all the wire frame pages. And the content was also refined according to the feedbacks received from the prototype 4. Based on the high-quality screens, I edited a animation explaining the interaction design. The ideas were aligned with the usability guideline for elderly people.

Interaction design

Direct and indirect interaction types need to be considered as each involves a different form of manipulation. A representation of a direct interaction on a touch-based interface is the user touching an object on the screen and manipulating it through physical interaction including tapping, dragging, sliding, flicking, pinch or spread, and holding.

Prototype 5: high-fidelity version

Detailed pages of prototype 5 can be found in appendix 7.

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Appendix 1: Summary of Problems & Inspirations

In this appendix, there are two tables explaining the summary of needs finding. Table 2 summarizes the problems in current SDM process. Table 3 summarizes the inspirations for design, which are based on the Persona, Workflow and Competitive Landscape of Chapter 2.

ID	Source	Problems
1	Persona	The scans and pathology reports contain too much medical jargon, which are difficult for ordinary people to comprehend.
2	Persona	The information with different formats become difficult to manage and share. For example, notes written on scraps of paper, websites links, appointments and etc.
3	Persona	Based on tips 5, patient's profile and medical tests, i.e. biopsies, blood tests, cat-scans, bone scans, MRI scans etc, are important references for patients to make decision, but they have to ask.
4	Story Boards	Professional consultants are trusted and valued[10]. Because of lack of time (10-15mins), health professionals may share incomplete information.
5	Story Boards	The first meeting is a bad news meeting, the information provided by professionals may not be absorbed by the patient because of his distressed emotional state. The stress and anxiety experienced during early stages by patients and pain may lead to diminished attention. This diminished attention, coupled with the usual stress of clinical environment affects comprehension as well as storage and retrieval-related aspects of information[11].
6	Story Boards	Experience such as side effects of treatment is based on patient's own health profile, which may vary greatly from one patient to another.
7	Story Boards	Most of prostate cancer patients are elderly men, who may lack of access or unfamiliar with computers[12].
8	Story Boards	The biggest concerns of searching on the internet by cancer patients were getting overwhelmed with information and finding out things that they would not want to know.
9	Story Boards	Some websites may provide credible information but do not provide information tailored to a patients' condition and overall health profile.
10	Competitive Landscape	The online decision aid doesn't tailor personal information based on patient's profile, and it is "one-time" event.
11	Competitive Landscape	Patients may concern about the extent of privacy of their personal information on the sites.

Table 2 Summary of problems in current SDM process

ID	Source	Inspirations
1	Persona	Based on problem 1, information visualization can be used to make the diagnosis information comprehensible, and further some interaction design can enhance patients absorb the medical information better.
2	Persona	Based on problem 2, the decision aid can play the role of storing and managing information for the patients.
3	Persona	Based on tips 1, cancer patients have to understand the diagnosis information firstly and then make informed decision. So the decision aid should be able to educate cancer patients how to read his health profile: What's my stage? Is this cancer slow growing or aggressive? has it spread?
4	Persona	Based on tips 1, there are various website such as National Cancer Institute, American Cancer Society, which give patients access to a wealth of information. These cancer websites and organizations can be a good starting point for me to understand prostate cancer firstly as a normal patient.
5	Persona	Based on tips 4, keeping diaries and notes are methods for patients to manage personal information. The decision aid can add a feature to enhance patients' needs such as keeping

		diaries.
6	Persona	Based on tips 8 and problems 3, patient's profile and medical tests are necessary if patients want a second opinion. It is nice to have these documents already in the decision aid. The decision aid can be supported by hospital, or even starts at hospital. The database of decision aid is linked to the Electronic Health Record (EHR) of cancer center, then patients don't need to ask for test results themselves.
7	Persona	Based on tips 6, when the patient concentrates on conversation with professional, he cannot take notes at the same time. The decision aid may have the function to record verbal exchange between professionals and patients.
8	Persona	Based on tips 7, cancer patients are special user group. They need encouragement and inspiration to keep positive attitude. So the phrasing and pictures used in the decision aid should be carefully considered, which should communicate positive ideas.
9	Story Boards	Based on problem 4, patients still need to learn more information about treatments before they make an informed decision. So the decision aid should cover the information which is not shared in the urologist meeting.
10	Story Boards	Based on problem 4 and problem 5, the decision aid may have the function to help patients store diagnosis information at the bad news meeting, and then be able to get access to the same information when they are at home.
11	Story Boards	Specialist nurses are good at comforting cancer patients and act as a source of emotional support. Nurses' experience can be inspirations for designers to explore how to comfort cancer patients, what is the right phrasing to communicate with patients.
12	Story Boards	Cancer survivors can provide useful tips and some practical advices with cancer patients, e.g. what to expect after surgery, how about the side effects.
13	Story Boards	Based on problem 6, A feature of tailoring cancer survivors with similar health profile for patients can be useful.
14	Story Boards	Based on problem 7, the interaction design of decision aid should be as natural as possible. So the elderly men are able to use it intuitively.
15	Story Boards	Based on problem 8 and problem 9, the decision aid should provide tailored information according to patients' profile.
16	Story Boards	Prostate cancer patient's spouse plays an important role in decision making process, because the outcome and side effects of treatment influences both the patient and his spouse. There is design space to facilitate cancer patient's spouse participating in the decision making process.
17	Competitive Landscape	Positive stories can comfort and inspire cancer patients. The stories also help patients cope with stress and anxiety emotions.
18	Competitive Landscape	Through social networking sites, patients can have more opportunities to know professionals and cancer survivors.
19	Competitive Landscape	Audios and videos are suitable media for communicating information with prostate cancer patients, since they are mostly elderly people.

Table 3 Summary of inspirations based on the problems and current situation of SDM process

Appendix 2: Interview Guides

Interview Guide - Patient & loved one

Before you start

- › Introduce yourself and inform them about the goal of the session
 - › Mention that there is always a 'way out' to stop.
 - › Fill in the consent form with them
 - › Ask them permission to record the session, turn on audio recorder
 - › Keep asking why
 - › Always ask for example and anecdotes to explain certain values etc.
 - › At the end: ask permission to take her / their photograph
 - › Check timing
-

Personal story

1. Who are you?
2. Where do you come from?
3. How would you characterize each other? (if with partner) What does the other mean to you?
4. Can you describe why you came to this hospital visit alone / together?

Disease story

5. *Can you tell us a bit more about your health situation?*
 - *check stage: screening, diagnose, treatment, follow-up etc*
 - *Active surveillance/watchfull waiting? How long in the loop?*
 6. *Can you describe the people involved and your relationships with them along your care process?*
 - *Clinical staff, family and friends, other patients?*
- › Make selection of relevant topics to discuss depending on patients' disease story & stage in SDM process.
7. What are your expectations of today's visit at PZN? How did you prepare yourself for this consultation?
 8. What are you typically thinking about? What's on your mind?
 9. What do you talk about? (if with loved one) Why?

Impact daily life

10. At the moment, how does a typical day in your life look like
11. How did your health situation changed your daily life?
 - *What do you miss most from your life before you had (signs of) prostate cancer?*
 - *What are your biggest concerns?*

Diagnosis & information

12. What was on your mind when you first heard your diagnosis?
13. Did you understand all the info the urologist shared with you?
 - *What would you like to know more about? Check understanding PSA result, Gleason score, stage of prostate cancer and biopsy result and etc.?. If yes, how do they get the education of these tests)*
14. What information topics were most important to you? Why?
 - *Did you miss any information: wish to hear more technical info or get more emotional support? access information shown in the hospital at home?*
15. Did you look for additional information yourself? Why, why not?
16. What info, which sources, what did you like about it??
17. How do you keep track of your prostate cancer, what do you do with all the info?
18. Are you more receptive to read information while at home or in a hospital setting? Why? What about trust?

Extra: Are you familiar with PCs, smartphone apps or tablets? If so would you invest time on a digital tool to better manage your health?

Treatment decision

19. Do you know what the next steps will be? What treatment?
20. Are you involved in choosing a treatment? Why and how, or why not?
21. What do you find the most difficult about this next (decision) step?
22. What is the role of your family and friend in this process?
23. If you could improve 3 things in the process of selecting your treatment, what would those be?
24. Were there times during your treatment selection that you wished you would have had some extra support? In what way/from whom? At home or in hospital?
25. What made you finally decide to go for this treatment? Which factors have influenced your decision? (Gradual process or clear defining moment?)

Future

26. What do you realistically think your future will be like? What are your dreams?
27. What would help you to feel like you did before?
28. Which advice would you give to someone, after being diagnosed with (prostate) cancer?
 - *Deciding on which treatment to choose? Where to look for information?*

Interview Guide - Urologist

Before you start

Are there additional topics to cover based on shadowing/observations?

Do you need to validate any findings and/or assumptions from the other team?

- › Introduce team and objectives
 - › Check how much time they have available
 - › Mention that if they need to step out we can arrange to continue later
 - › Ask permission for recording, turn on audio recorder,
 - › For the first questions, mainly listen and let them tell their story, with remaining questions start to probe for interest areas
 - › Keep asking why / ask for examples
 - › Check timing
-

Personal information

1. For the record: could you please tell me who you are and what you do?
2. What made you choose this profession?
3. How would you describe your job/role?
4. What are your responsibilities? How do you feel about them?
5. What do you like most from your job? Why?
6. Are there things that make you like your job a little less?

Diagnosis – treatment flow

7. What kind of activities do you perform within your day-to-day work?

Focus on activities related to the patients' diagnosis to treatment stage > share & discuss flow-framework.

8. *Assess map: what are the missing activities? Go into more detail: what happens before and after the main appointments?*
9. From your perspective, which activities do you consider most important? Why?

10. Who are the stakeholders you interact with? *Assess map: are there missing stakeholders?*
11. How about the interaction with other staff members? When, where, what, how?
12. What are the moments you interact with the patient & family? When, where, what, how?

Prostate cancer diagnosis

13. Could you tell us more about diagnosing prostate cancer? (Is it difficult to confirm? Inconclusive? Staging? And its relation to decision making?)
14. When do you label the health status 'cancer'?
15. Do patient with different stage of cancer/stage in diagnosis process follow a different flow? *Relate to map.*
16. In case patient is in watchful waiting or active surveillance stage, is this diagnosis meeting the same appointment set up as in previous screening results or different?
17. Is there an indication for patient it is going to positive/negative news? How much does the patient already know?
18. At this diagnosis meeting: How do you estimate the ratio: patients in watchful waiting/active surveillance vs 'new patients'?
19. How do you prepare yourself for a diagnosis appointment?
20. Do you assess (e.g. intuitively, structure, not at all) patients before the appointment?
21. How do patients prepare themselves?

22. How do you stay professionally up to date?

Shared decision making

23. SDM: at what point in the process does the 'shared decision making start'? treat or not? or what treatment? Relate to map
24. What decisions do you make, and how do you advice patients and loved ones? What tools, knowledge and experience do you need?
25. What information do you share with patients / how do you filter this? Why?
26. Transparency of info: Are there things you know, but you don't share with the patient immediately? How willing are you to share data/documents with patients? Why, or why not?
27. What patient info do you need to know in order to advice them?
28. Do you already use any tools/calculators for diagnosis / decision making? What, why?
29. How do think patients perceive having to make to choice themselves rather than trusting a professional to make the choice for them? Why? What are the differences between people?
30. What role do relatives (should) play?
31. Are there any challenges that you face while managing information related to a patient?
32. Are there any challenges you face while helping a patient reach a decision?

Aspirations

33. Have you seen changes in your profession with regards to diagnosis and treatment decision over the years? How did it impact you?
34. Are there any changes you foresee? How could they impact you in your work?
35. How about the technology, supporting you in your work? (e.g. mobile applications etc.)
36. What are your aspirations?
37. What motivates you? Why?

Interview Guide – Nurse

Before you start

Are there additional topics to cover based on shadowing/observations?

Do you need to validate any findings and/or assumptions from the other team?

- › Introduce team and objectives
 - › Check how much time they have available
 - › Mention that if they need to step out we can arrange to continue later
 - › Ask permission for recording, turn on audio recorder,
 - › For the first questions, mainly listen and let them tell their story, with remaining questions start to probe for interest areas
 - › Keep asking why / ask for examples
 - › Check timing
-

Personal information

1. For the record: could you please tell me who you are and what you do?
2. What made you choose this profession?
3. How would you describe your job/role?
4. What are your responsibilities? How do you feel about them?
5. What do you like most from your job? Why?
6. Are there things that make you like your job a little less?

Diagnosis – treatment flow

7. What kind of activities do you perform within your day-to-day work?

Focus on activities related to the patients' diagnosis to treatment stage > share & discuss flow-framework.

8. Assess map: what are the missing activities? Go into more detail: what happens e.g. before and after the main appointments?
9. From your perspective, which activities do you consider most important? Why?
10. Who are the stakeholders you interact with? Assess map: are there missing stakeholders?
11. How about the interaction with other staff members? When, where, what, how?

12. What are the moments you interact with the patient & family? When, where, what, how?
Assess map (do we miss anything?)

Patient support - profiling

13. Do recognize differences between patients (and loved ones) in how they handle their diagnosis? And how they are involved in their treatment diagnosis. Can you please describe?
14. How do you 'identify' one type of patient from the other? (Role of control and masculinity)
15. Do you adjust your support / communication style / type of info to the type of patient? How?
16. Why do you think this important (or not)?
17. How do you take into account patients' behaviours, fears, habits, culture, beliefs, values?
18. What role do / should relatives play? Do you address the partner equally as the patient, or more or less? Why?

Shared decision making

19. SDM: at what point in the process does the 'shared decision making start'? treat or not? or what treatment? Relate to map
20. How do patients perceive having to make to choice themselves rather than trusting a professional to make the choice for them? Why? What are the differences between people?
21. What about patients who don't want to make a decision? (1out of 5?) How does that influence the process?
22. Do you have an idea how patients reach a decision? Rational vs. emotional process, thinking vs feeling: are decision made intuitively or based weighing pros and cons?
23. Are there any challenges you face while helping a patient reach a decision? What do you think are the main challenges of the patient and loved one?
24. Patients that felt 'good' about the decisions they've made, what process did they go through??

Lastmeter vraag: 'zou u met een deskundige willen praten over uw problemen': wie is die deskundige, en hoe gaat dit in zijn werk?

Aspirations

- Have you seen changes in your profession with regards to diagnosis and treatment decision over the years? How did it impact you?
- Are there any changes you foresee? How could they impact you in your work?
- What are your aspirations?
- What motivates you? Why?

Interview Guide – Other Specialists

Before you start

Are there additional topics to cover based on shadowing/observations?

Do you need to validate any findings and/or assumptions from the other team?

- › Introduce team and objectives
 - › Check how much time they have available
 - › Mention that if they need to step out we can arrange to continue later
 - › Ask permission for recording, turn on audio recorder,
 - › For the first questions, mainly listen and let them tell their story, with remaining questions start to probe for interest areas
 - › Keep asking why / ask for examples
 - › Check timing
-

Personal information

1. For the record: could you please tell me who you are and what you do?
2. What made you choose this profession?
3. How would you describe your job/role?
4. What are your responsibilities? How do you feel about them?
5. What do you like most from your job? Why?
6. Are there things that make you like your job a little less?

Diagnosis – treatment flow : Shared decision making

Focus on activities related to the patients' diagnosis to treatment stage > share & discuss flow-framework.

7. How would you describe your role / involvement in the patient's shared decision decision making process?
8. From your perspective, which 'activities' do you consider most important? Why?
9. When do patients come to you for advise, and why? How does this process work?
10. How would you describe the type of patient that comes to you to orient himself on choices?
11. What do you discuss in such an appointment, what questions do patients have?
12. What (patient) info, knowledge, tools and experience do you need to advice patients?
13. How do you think patients perceive having to make to choice themselves rather than trusting a professional to make the choice for them? Why?
14. What role do (should) relatives play?

15. Who are the clinical stakeholders you interact with?

16. How would you describe this interaction? (incl. sharing of patient info)
17. Are there any challenges that you face while managing information related to a patient?
18. Are there any challenges you face while helping a patient reach a decision?
19. How do you stay professionally up to date?

Aspirations

20. Have you seen changes in your profession with regards to diagnosis and treatment decision stage over the years? How did it impact you?
21. Are there any changes you foresee? How could they impact you in your work?
22. What are your aspirations?
23. What motivates you? Why?

Observations – Points of Attention

General

Issues to explore: people, places, processes and interactions

Processes steps of the clinical workflow

- What are the steps? And when do they occur?
- What issues and/or challenges do you see/hear relating to delivering care?
- What issues and/or challenges do you see/hear relating to shared decision making?

Stakeholders

- Who is involved in each step? (care givers, patients, loved ones)
- What are their roles/responsibilities?
- How does clinical staff interact with each other?
- How is their interaction with patients and their families?

Context

- What does the context look like?
- What is the atmosphere/pace/rhythm of the space?
- What elements make up the space?
- What context-related factors do you notice that impact care / interactions?

Product and technology Interaction

- What technology, tools, products and services are used by the staff (and patients) and when?
- How does the staff interact with it?

Information flow

- How is information communicated and shared between staff?
- How is information communicated to and shared with patient & loved ones?
- How is it captured? Shared?
- Who knows what at which point?
- What information does the patient receive?

Consultations

- What are the main differences between the consultations with different patients? Why?
- What is similar for every consultation?
- What is communicated, or discussed?
- What questions do patients and loved ones ask?
- Understand role patient vs loved one in process

Waiting room & other patient areas

- How long are patients waiting between all appointments
- How do patients and loved ones fill this time?
- How is the interaction with other patients? What are the things typically (not) talked about?