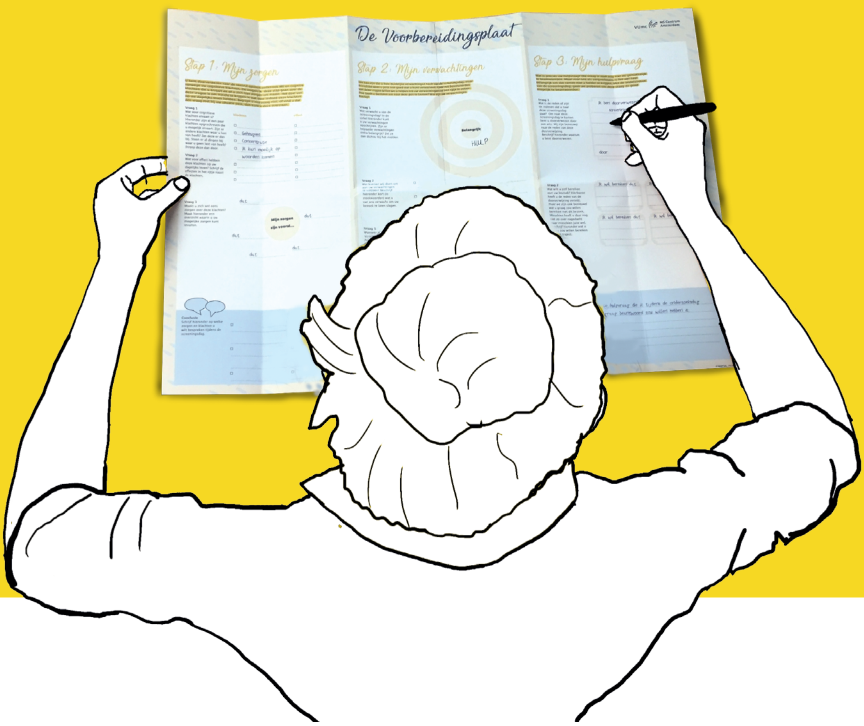
Redesigning the MS Patient Experience
- it's all about preparation



Zoé Martial

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Master thesis

by Zoé Martial

Colophon

Master thesis
Redesigning the MS Patient Experience
 - it's all about preparation
Master Design for Interaction
12 July 2018
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ABSTRACT

Yearly, 270 people in the Netherlands are diagnosed with Multiple Sclerosis (MS) and over 16.000 people are already diagnosed with MS in the Netherlands [1]. Between 40% and 70% of MS patients suffer from cognitive complaints in various stages of their disease [8, 67]. The MS Centre Amsterdam has started a new so-called Second Opinion Multiple Sclerosis and COGnition screening (SOMSCOG) outpatient clinic for MS patients suffering from cognitive problems to research these cognitive problems.

A clear definition of patient experience is defined by the Beryl Institute: "Patient experience is the sum of all interactions, shaped by an organisations culture, that influence patient perceptions across the continuum of care" [19]. A literature study researching patient centred strategies showed that patient experience has an influence on quality of life. This connection shows that it is useful to improve patient experience to create a positive effect on quality of life.
To this end, the central aim of this research was to design a service or product-service system that helps to improve the patient experience of MS patients who visit the SOMSCOG outpatient clinic at VUmc.

Different user research methodologies have been employed, with research methods including interviews, contextmapping and observations. This study showed that the needs and the underlying values of MS patients visiting the SOMSCOG outpatient clinic are fundamental values. They long for transparency, clarity and honesty. Additionally the user study exposed an interesting problem: patients have difficulties preparing for visit of the outpatient clinic. A result of this lack of preparation is that the help request - which form the basis of diagnosis - is often suboptimally formulated.

The insights gained throughout the user study resulted in a patient journey in which the current experience is depicted. By combining the insights of the literature and user study a design goal was formulated.

The aim of the design process was create a tool that will help patients prepare to for their hospital visit, that will guide them through the day and provide an overview of the whole journey. This tool should improve the overall patient experience and make a positive impact on the patient's quality of life.

Building on the patient journey and the insights from literature, a toolkit - named *De Gids* - has been developed with which patients can prepare themselves for the screening day of the SOMSCOG outpatient clinic.

De Gids encompasses a folder, an information guide and a preparation sheet. The information guide contains information of the screening day e.g. the schedule, possible outcomes and treatment options. It also contains a conversation starter which can be used by patients and a next of kin. The aim of this conversation starter is to trigger patients in sharing their concerns around cognitive problems with someone close to them. The preparation sheet contains questions which prepare patients for the consultation with a neurologist on the screening day. It also functions as a conversation aid during this consultation. By filling out the questions on the sheet, patients will reflect on their concerns, expectations and a help request is formulated. This preparation of the help request should result in a better formulated help request.

When the help request is improved, the diagnosis can have a better connection with patients' needs and the treatment options that will be offered might be more effective. This will ultimately result in better care and improved quality of life. ■

ACKNOWLEDGMENT

Many people have contributed to this project, without whom I wouldn't have been able to finish. First of all I would like to thank my supervisory team of Delft University of Technology, Marijke Melles and Gert Pasman for being supportive throughout this project. It was a little bit of a rough start, but thanks to you two I ended up with this interesting project at VUmc. Thank you for providing feedback and motivating me the last year. A special thanks to Martine de Bruijne and Brigit de Jong for initiating this assignment. And Brigit, thank you for giving me the opportunity to be completely immersed in the VUmc, this has been a wonderful experience. I would also like to thank Olga for our weekly - or not so weekly - meetings. Thank you for all the detailed proofreading and pages of comments, you really motivated me to improve. And of course I would like to thank all the medical professionals of MS Center Amsterdam for letting me observe your every move and participating with interviews. And of course a big thank you to all of the patients who helped me with my research, who spend days filling out booklets and posters and shared intimate information with me.

Next I would like to thank my ZH-1F-03 office-roommates Josephine, Quirien en Ivan. You guys made my time at VUmc, I will miss our lunches, after work drinks and our haircutting sessions.

Of course I would like to thank my friends for supporting me. Some of you deserve some extra attention: Heleen for always being critical and giving feedback even if I did not want feedback, Simone for always being there when I needed support. Janne for the coffees and motivational words, thank you. Thank you Jord, for your sharing your expertise and trying to hack my InDesign file.

Most of all I would like to thank my mum for your endless support, for letting me stay with you, for feeding me and for all your care, love and support. I would also like to thank my sister Lisa, for showing me that graduating is not all there is.

At last, I would like to thank Luuk, for your endless support during every step along the way. Thank you for keeping me fed and alive and for showing me the bright side of life. Finally I would like to thank my dad, who I know would've been the proudest of all. Although you weren't able so see this result, you pushed me to continue.

Merci.

Zoé Martial

CONTENTS

INTRODUCTION

Context

Worldwide 30 per 100.000 people suffer from Multiple Sclerosis (MS), that is about 0,03% of the world population. In the Netherlands, there are over 16.000 people with MS and yearly another 270 people are diagnosed [1]. Multiple Sclerosis is a disease that affects the central nervous system which consists of the brain and spinal cord. The optic nerves can also be affected. When suffering from MS, the immune system attacks myelin, the fatty substance that surrounds and insulates the nerve fibres, as well as the nerve fibres themselves [2].The damaged myelin forms scar tissue which becomes hard and cause a disturbed nerve conduction, which in turn can cause many different symptoms including eye problems, muscle spasms, mobility problems, problems with thinking, learning and planning, depression and anxiety [1, 3]. This is only a limited list of symptoms, there are many more. Most people with MS only have a few of these symptoms. Which ones occur and at what order varies widely per patient. The underlying mechanisms of developing MS are largely unknown. There are some genetic conditions that make it more likely to develop this disease, but MS doesn't have to be heritable. There is no cure for MS. However, some treatments can help recovery from attacks, modify the course of the disease and manage symptoms [4].

Company

The VUmc MS Center Amsterdam is one of the top five MS research groups in the world. It is an important source of information about MS for both neurologists and patients. About 50 percent of all newly diagnosed MS patients in the Netherlands visit the centre for a consultation. The centre's combination of fundamental and clinical research allows it to quickly apply new research developments in diagnostics and treatment of MS. The interdisciplinary interaction between neurology, radiology, pathology and immunology within one centre is quite unique worldwide [5]. The VU MS Center Amsterdam collaborates with the department of Public and Occupational Health within VUmc to investigate (and improve) the patient's perspective on (the quality of) the provided care.

Case

In February of 2017 the VUmc MS Centre Amsterdam has started a new so-called Second Opinion Multiple Sclerosis and COGnition screening (SOMSCOG) outpatient clinic for MS patients suffering from cognitive problems. It is called a second opinion because another medical specialist than the usual specialist sees the patient. A second opinion is commonly known as a one-time-only visit to another specialist. Aim of this one-day screening is to make a diagnosis of cognitive

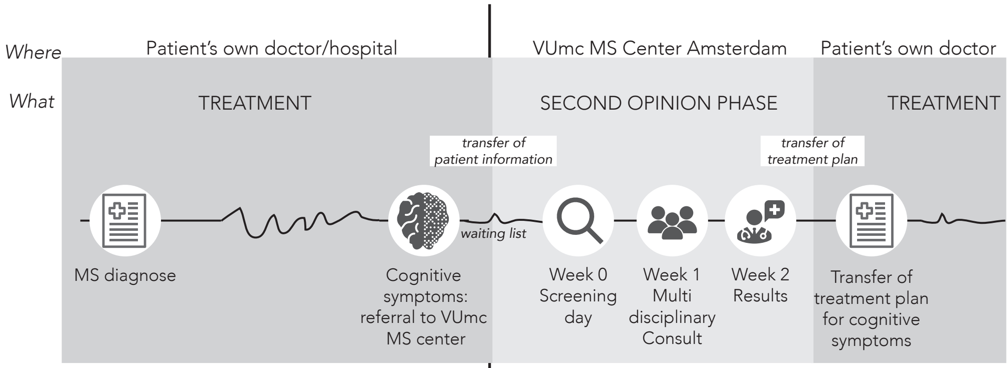


figure 1-1: The current patient journey of SOMSCOG patient, from MS diagnosis towards treatment for cognitive symptoms. The time for each step and phase varies, so the timeline in this journey is not divided in equal steps.

problems and set up a personal treatment plan for the symptoms. During that day patients undergo multiple tests and fill out many questionnaires. For this screening doctors and medical professionals from different departments work together intensively in a interdisciplinary team. The week after the screening day, results of patients of the previous week are discussed in a multidisciplinary consult. One week later the patient returns to the VUmc to receive the results of this screening day. Next, the results and a treatment plan are communicated to the patient's own doctor, who will then continue treating the patient. This process is shown in Image 1-1 above.

The one-day set-up of the SOMSCOG screening has been chosen to make it as efficient as possible for the patient. Consequentially, the screening day is packed with multiple tests, scans and questionnaires. On the one hand, it seems efficient to have all these tests on the same day. It is convenient for the patient to see all different medical professionals on one day. But on the other hand, it might be a very tiresome day especially when having cognitive issues. It is unknown how this screening day fits with the patients' perceptions and experiences. The SOMSCOG outpatient clinic is still in process of improving. So far the health care professionals of VUmc MS Center Amsterdam do not have insights in the patient experience of the second opinion phase. Therefore, the goal of this graduation assignment is to investigate and improve the patient experience of MS patients who undergo this second opinion phase.

Assignment

The aim of this assignment was to design a product, service or product-service system that helps to improve the patient experience of MS patients who visit the SOMSCOG outpatient clinic phase at VUmc. Outcomes of this assignment are aimed at improving quality of life of MS patients and quality of care of the SOMSCOG outpatient clinic at VUmc.

Objective

The objective of this study was to explore the patients' needs at the SOMSCOG visits and it aimed to identify possible design directions to improve patient experience.▶

Methods

Methods that will be used to answer the research questions are desktop literature research, observations of visits to SOMSCOG outpatient clinic, interviews with medical professionals and patients, immersion and contextmapping..

Process

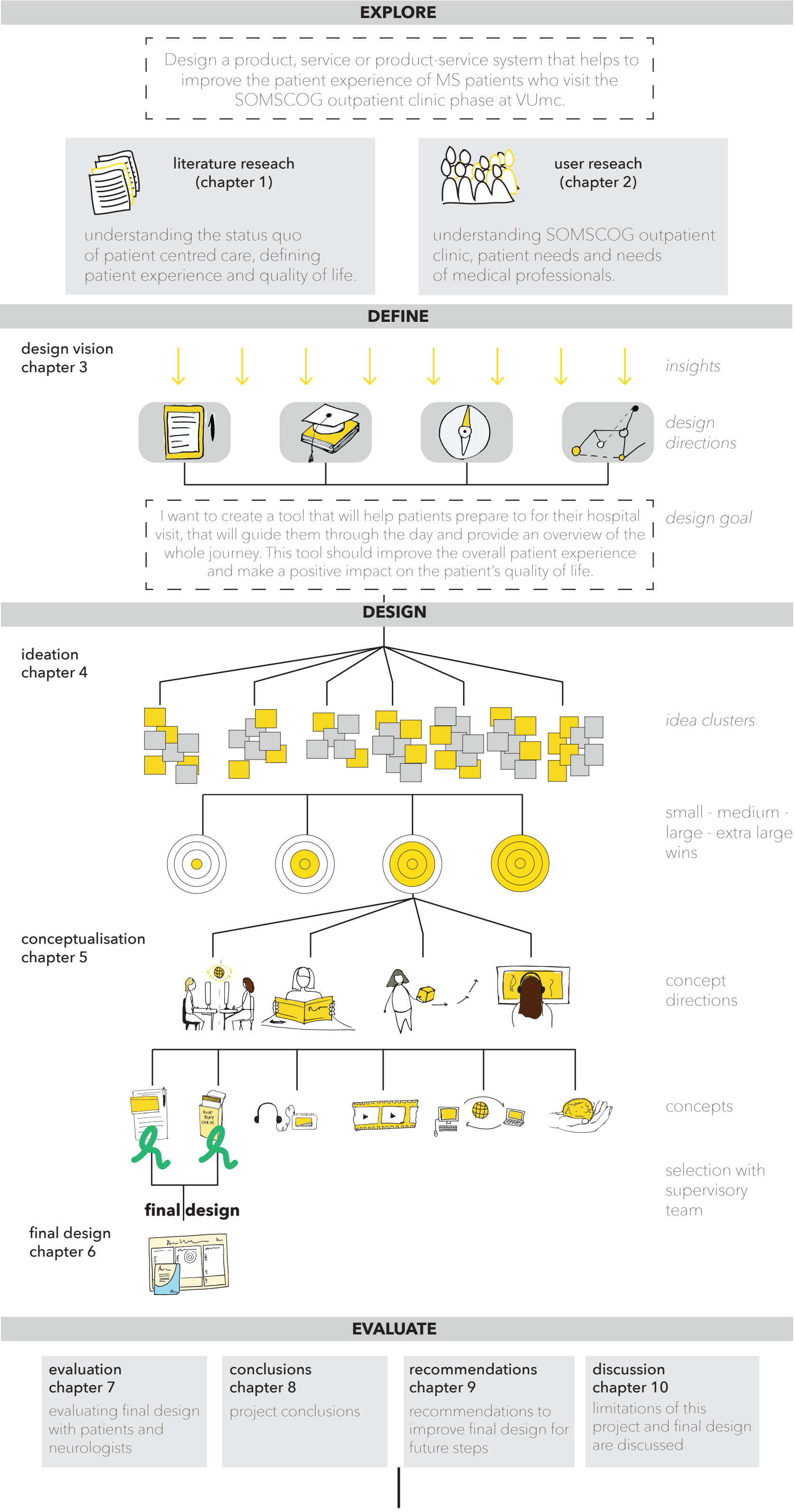
This design project can be divided into four parts: explore, define, design and evaluate. figure 1-2 on the right pages shows a visual representation of this project.

In the first part, **explore**, the problem analysis is addressed. The study pertaining to the problem analysis consists of two parts: a desktop (literature) research and a user research which entails observations and interviews. The desktop study (chapter 1) has a focus on creating definitions that are useful for this entire project and on describing what is already known about patient experiences of MS patients. One can think of the following: outlining what the concepts of patient experience and quality of life entail, what important cognitive symptoms of MS patients are. The desktop study will support the user study with theoretical information and will provide a conceptual framework for the user study. The user study (chapter 2) had a focus on investigating the actual needs of SOMSCOG patients and the needs of care providers. The focus of the observations was on the actors involved in SOMSCOG and how these actors interact with each other. These studies combined provided a wide data range with which the patient journey was created.

In the next part, **define**, eight main insights arose when combining the most important insights from the user and literature studies (chapter 3). The user studies provided important conclusions about the research questions and topics. The insights served as principles for design directions. The design directions were used to improve the current patient experience of SOMSCOG patients. Combined with a WWWWWH, a problem definition and a design goal were formulated. Subsequently a framework with criteria and an interaction vision were made to start the ideation phase. Which was the start of the third part of this project, **design**.

The patient journey (chapter 2) provided multiple design opportunities. These opportunities were combined with the insights of literature and use research and moulded into four design directions (chapter 3). Together with the design goal, this was the starting point for ideation (chapter 4).
The ideation and conceptualisation phase consisted of multiple iterations. The aim of the ideation phase was to translate the design opportunities identified in the patient journey and the design directions into concepts that will solve one or more problems. In the ideation phase, the design areas were explored by means of How-to's, ideas were generated, clustered and categorised in small wins, medium wins, large wins and extra-large wins. Finally, one category – the large wins – were chosen for fur further development
Then, six concepts were developed and together with the supervisory team two were selected to continue with (chapter 5). The two selected concepts were developed in different iterations and then evaluated with a total of 6 patients, two experts and presented to a group of medical professionals at VUmc. These evaluations led to combining the two concepts into one final design, a tool that helps patient preparing for their SOMSCOG outpatient clinic visit and that functions as a conversation aid during a consultation with a neurologist (chapter 6).

The last part of this project, **evaluate**, entailed the evaluation and validation of the final design. The final design was evaluated with patients and with neurologist (chapter7). Next, conclusions with regard to this project were drawn (chapter 8) and recommendations for further implementations were described (chapter 9). At the end, limitations of this project were written in the discussion. ■



EXPLORE

Design a product, service or product-service system that helps to improve the patient experience of MS patients who visit the SOMSCOG outpatient clinic phase at VUmc.

literature reseach
(chapter 1)

understanding the status quo of patient centred care, defining patient experience and quality of life.

user reseach
(chapter 2)

understanding SOMSCOG outpatient clinic, patient needs and needs of medical professionals.

DEFINE

design vision
chapter 3

insights

design directions

I want to create a tool that will help patients prepare to for their hospital visit, that will guide them through the day and provide an overview of the whole journey. This tool should improve the overall patient experience and make a positive impact on the patient's quality of life.

design goal

DESIGN

ideation
chapter 4

idea clusters

small - medium - large - extra large wins

conceptualisation
chapter 5

concept directions

concepts

selection with supervisory team

final design

final design
chapter 6

EVALUATE

evaluation
chapter 7

evaluating final design with patients and neurologists

conclusions
chapter 8

project conclusions

recommendations
chapter 9

recommendations to improve final design for future steps

discussion
chapter 10

limitations of this project and final design are discussed

figure 1-2: Visual overview of this graduation project.

SECTION A - EXPLORE

The section includes both the literature research and user research. It describes the methods, research questions, results and conclusions of both. It is an important starting point of the design phase.

1 LITERATURE RESEARCH

This chapter encompasses everything concerning the literature research. First an explanation of MS is given. What does it mean to have MS, what are the symptoms, age people get diagnoses, treatment possibilities and illness progression? The next part of this chapter is about cognitive symptoms in MS. This is important for the scope of this project as the patient population are all people who suffer from cognitive problems. The main cognitive symptoms are described and an overview of the patients of the SOMSCOG outpatient clinic is given.
This chapter continues with describing the definition of patient experience and other important topics related to this concept of patient experience. After this, it continues with another relevant concept for this project: Quality of Life and how this is described in literature and what it entails in relation to MS patients and in relation to cognitive problems. The chapter ends with a conclusion in which the literature research questions are answered, other important insights are summarised, and it shows the relevance of user research.

1.a Research plan

This paragraph describes method and research questions of the desktop literature research: which search engines and terms were used, how the generated information is selected, what information is used and what info isn't used.

1.a.1 Research questions

Research questions formulated for the literature research are:

1. How is the concept quality of life described in literature?

1.1 What does this concept entail?

1.2 How does this manifest for MS patients?

2. How is the concept patient experience described in literature?

2.1 What does this concept entail?

2.2 How does this manifest for MS patients?

3. What are the most important cognitive symptoms for MS patients?

3.1 How do cognitive symptoms influence each other and quality of life?

It is also interesting to look at the relation between quality of life and patient experience. Is there a relation between the two, and if so, how are these related?

1.a.2 Method

For this literature research, information was gathered, verified and used to answer the research question. This paragraph describes the search engine used, search terms that were researched and how information was selected. The next four paragraphs – 1.c, 1.d, 1.e and 1.f – are the results of the desktop literature research, and in the last paragraph of this chapter – 1.G – the conclusions are presented.

Search engine

Several search engines were used for the desktop literature research, such as Google and Google Scholar. Additionally, Pubmed was also investigated, however, the results were not fully satisfactory. Pubmed offers mostly biomedical literature but also life -, behavioural - and chemical science and bioengineering citations and abstracts are included [6]. This is of course useful for this project, but the design and interaction articles were missing. While these are the useful articles for this project, therefore Google Scholar was used primarily. Here, I could search across multiple different disciplines as well as the ones included in PubMed.

Search terms

Different search terms were used to perform a literature research. These queries vary from large terms such as: 'What is patient experience' to smaller questions such as: 'What are executive function skills?'. Appendix A shows all the used search terms.

The search was conducted between July 2017 and November 2017 by this author. The database used was Google Scholar, Google and MS International Federation. The keywords (e.g. patient experience (definition), MS patient experience, Quality of life (MS patient), cognitive impairment, cognition, cognitive symptoms, patient perception, value-based healthcare, shared decision making, patient empowerment, patient participation, health related quality of life, their plurals) were determined after an initial broad search of the literature and adapted during the process based.

Selection

In order to choose what information to use and what not, the relevance of the information was checked. With articles found through Google scholar, the abstracts were read. If an article looked promising and relevant, the method and conclusion was read. Furthermore, articles were selected when they provided new information, insights and clear definitions

For information gathered from Google, a more careful selection took place - only websites of trustworthy institutions were used. However, trustworthiness of website a is hard to determine when not much is known of a certain subject. Therefore, Google was mostly for definitions and explanations of things found in articles on Google Scholar. ■

1.b What is MS?

Multiple Sclerosis (MS) is a neurodegenerative disease that affects the central nervous system. The central nervous system contains the brains and the nerves in the spinal cord.

A neurodegenerative disease is characterised by degeneration of the central nervous system. In this process, nerve tissue deteriorates.

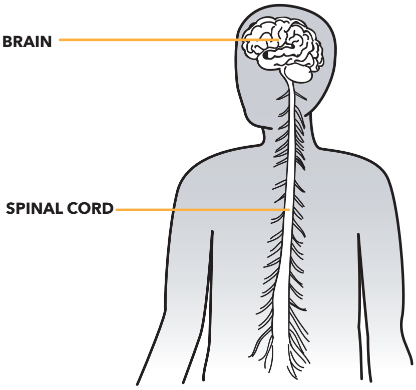
Nerves can be seen as electric wires passing signals from one end to the other. Electric wires have a core made out of copper – or another conductive metal – and is enclosed with an insulating layer of plastic. Just like electric wires, nerves have a 'conductive' core – the axons – and are insulated with a fatty protective layer: myelin. As mentioned in the introduction of this report, when suffering from MS, myelin is attacked by the immune system resulting in damaged myelin and affected nerve signal conduction. The damaged myelin forms scar tissue which becomes hard and cause a disturbed nerve conduction.

The symptoms from MS may vary widely and are both in the physical as in the mental spectrum.

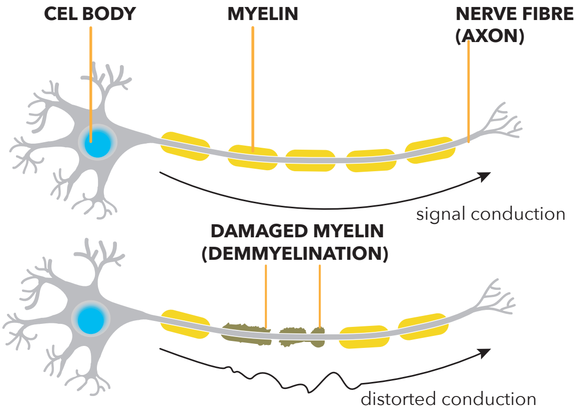
Prevalence

MS has a higher prevalence in countries located north of the equator. This means that in Sweden there are more people with MS than in the Netherlands, and in the Netherlands are more people with MS than in Spain. The Atlas of MS, published by the WHO in 2008 shows that the prevalence of MS in Africa is 0,3 patients per 100.000 people, in Eastern Mediterranean countries the prevalence is already higher with 14,9 diagnosed patients per 100.000 while in Europe there are 80 people per 100.000 people diagnosed with MS [7].

Why this is the case, is partly unknown, but scientists showed that it might be related to sun exposure, vitamin D intake and genetic background. Data show that vitamin D might have a protective effect on risk disease progression [8].



▸ ***figure 1-3:*** Central nervous system consists of the brains and spinal cord. This is affected by multiple sclerosis.



▸ ***figure 1-4:*** For multiple sclerosis demyelination is a typical symptom. The damaged myelin forms scar tissue which becomes hard and cause a disturbed nerve conduction. Resulting in a loss in function or pain.

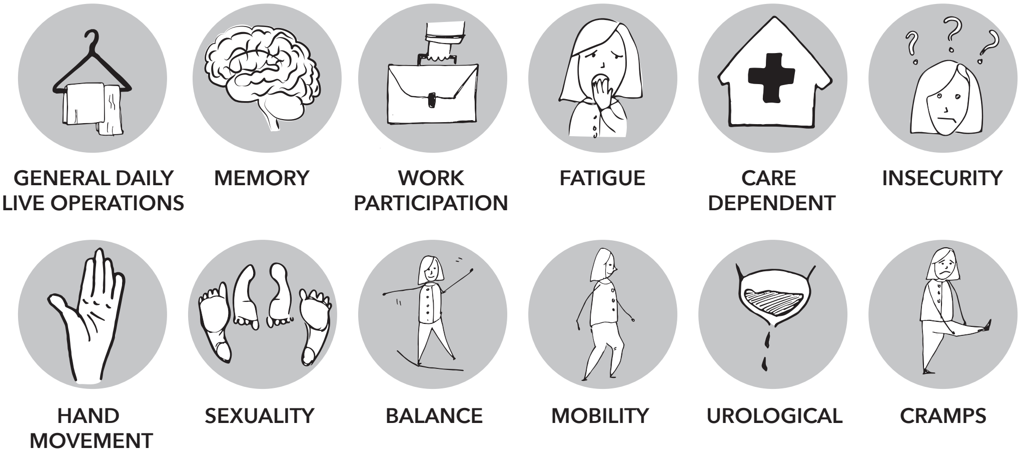
1.b.1 Impact

A patient's live is hugely impacted by MS. Not just mobility is impacted, it goes way beyond that. The outcomes of an impact survey were presented by Dr. B.A. de Jong during the MS-day at VUmc Amsterdam [9]. She showed that MS might affect twenty-five different aspects of life. The impact of MS on different domains differ per type of MS, but all the domains can be affected. The image below shows some of these domains that are most affected. Other that are affected areas include:

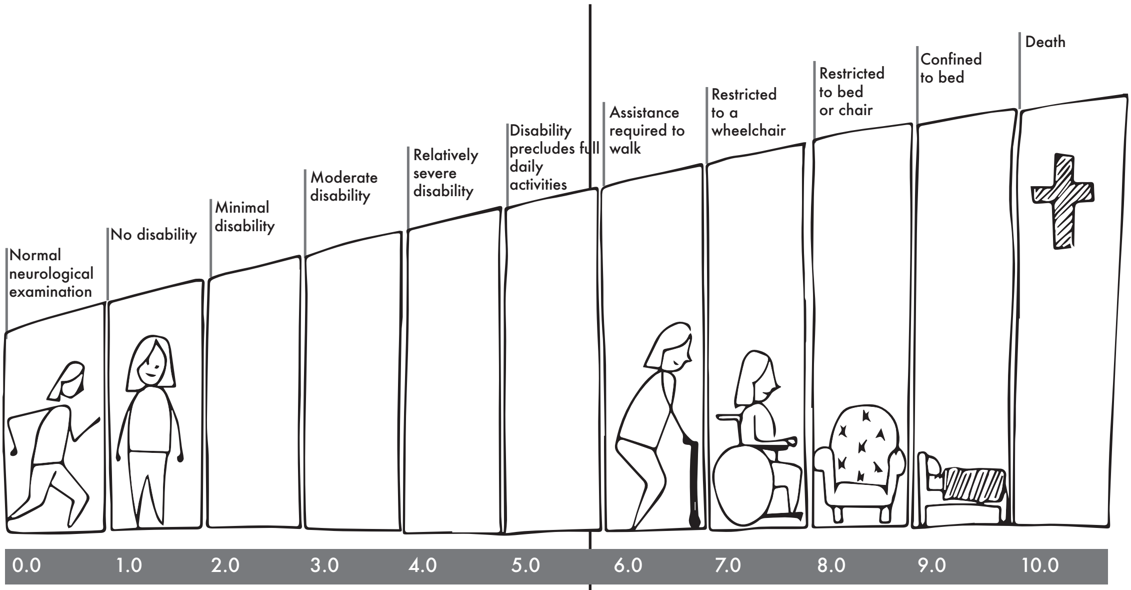
- Concentration
- Double vision and eye sight
- Anxiety
- Pain: musculos-skeletal
- Pain: neurological
- Mood/depression
- Societal participation
- Swallowing and speech
- Gastro intestinal
- Processing information

1.b.2 EDSS

As MS has such broad symptoms, it is difficult to measure the progression of the illness accurately. There is a method developed, the EDSS - Expanded Disability Status Scale, that quantifies disability in multiple sclerosis and monitors changes in the level of disability over time. It is a neurostatus scoring method on which a patient is scored for different functional systems (FS). Neurologist John Kurtzke developed this method in 1983 [10].
The EDSS scale ranges from 1 to 10 in 0,5 unit increments that represent higher levels of disability. The higher the EDSS score, the more severe the disability. Scoring is based on an examination by a neurologist. When a patient is unaware of a deficit, but when examination reveals signs of a deficit, a score higher than 0 is given [11]. A score of 1 implies that the patient is not aware of the deficit and that the deficit does not interfere with normal activities (vision, cerebral and bowel and bladder FS excluded). ▶



▶ ***figure 1-5:*** Domains that are most affected by MS. The degree of affection differs per person, disease progression and type of MS.



▸ ***figure 1-6:***Image 2c-4: Expanded Disability Status Scale: EDSS. The scale ranges from 0 – normal neurological examination – to 10 – death, with increments of 0,5 unit. Scoring is based on neurological examination by a neurologist and self-report by patient.

The functions included in the EDSS are:

1. Optic functions: visual acuity, visual fields, etc.

2. Brainstem functions: eye movement, hearing loss, facial weakness, etc.

3. Pyramidal functions: reflexes, limb strength, overall motor performance, etc.

4. Cerebellar functions: head tremor, straight line walking, truncal ataxia (standing still with eyes closed), etc.

5. Sensory functions: superficial sensations (light touch and pain), vibration sense, position sense, tingling.

6. Bowel and bladder functions: urinary hesitancy and retention, urge, bowel disfunction, sexual disfunction, etc.

7. Cerebral disfunction: decrease in mentation, fatigue.

8. Ambulation: represents walking range and the type of assistance needed for walking.

The scale of EDSS goes from 0 – no impairment up to 10 – death due to MS. With a score of >4: the outcome is usually for a huge part determined by mobility (de Jong, 2017). It is remarkable that cognitive problems are not included in the EDSS scoring system.
Image x on the previous page shows a graph of EDSS.

1.b.3 Diagnosis

It often takes often several months to years after the first symptoms until someone is diagnosed with MS. Typically, the first symptoms are vague, such as a tinkling feeling in the limbs, numbness or impaired vision. These symptoms usually disappear after a couple of days. That is why making a diagnosis is difficult. Alleman & van Oosten [8] suggest that the diagnosis MS should be considered in all patients younger than 40 years old with a neurological deficit evolving in hours to days and lasting more than 24h.
People are usually between 20 and 40 years old when being diagnosed with of MS.

McDonald criteria

The McDonald Criteria of International Panel on Diagnosis of MS [12] are the most commonly used diagnostic criteria of MS. These so-called McDonald criteria sate that to for a MS diagnosis, dissemination in space (DIS) and time (DIT) should be objectively demonstrated. In 2011 these criteria have been revised by Polman et al. [12]. They showed that imaging (MRI) can be used to demonstrate DIS and DIT by one single scan instead of multiple scans. With these simplified criteria the diagnostic sensitivity is preserved and at the same time diagnosis can be done earlier and more uniform and widespread use.

1.b.4 Types of MS

There are three types of multiple sclerosis: relapse remitting (RRMS), secondary progressive (SPMS) and primary progressive (PPMS).

Relapse remitting MS

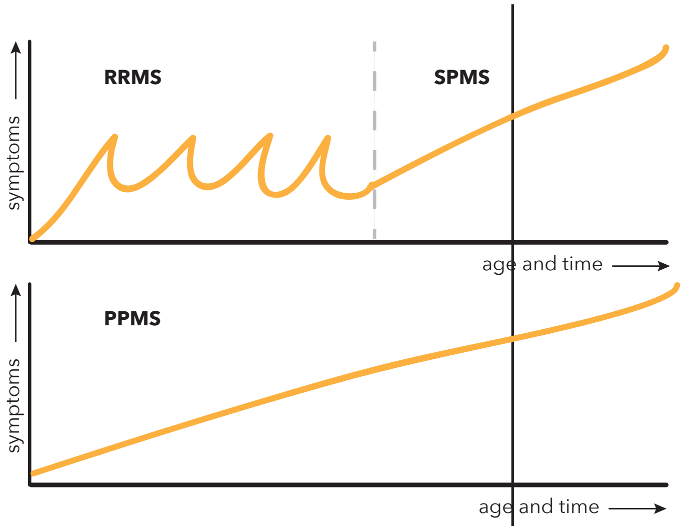
Around 85% of the people diagnosed with MS are first diagnosed with relapse remitting MS (Alleman & van Oosten, 2015). With RRMS the relapses – or attacks – are spread over the central nervous system. An attack is neurological disturbance with inflammatory lesions [13]. These inflammatory lesions cause demyelination around the axons in the myelin layer which in result can cause disturbed nerve conduction. Dependent on the severity and location of inflammation, an attack can last from 24h up to days. After an attack, the myelin layer recovers – but not to its normal condition – within weeks to months. The recovery of symptoms is typical for relapse remittent MS. After a period with relapses, the symptoms usually disappear.

Secondary progressive MS

After a having had RRMS for a longer period of time, this recovery mechanism that 'repairs' the myelin layer starts to shut down, causing degeneration of the nerves. This is a slow and gradual process. Patients notice a progressive regression without relapses. This is entitled secondary progressive MS (SPMS). It is estimated that after about twenty years of RRMS, people transfer to SPMS [8]. However, these it varies widely between individuals.

Primary progressive MS

Some people with MS, about 15%, skip the relapse remittent phase and have a progressive course of illness – primary progressive MS (PPMS). They do not have recovery between relapses. Usually these people are diagnosed with MS after their 40th birthday. PPMS is known to be caused more by neurodegeneration and less inflammation [8]. ►



▸ ***figure 1-7:***Disease progression for the different types of MS. The figure above shows RRMS – with relapses of symptoms – and how it turns into SPMS – with a more gradual progression – over time.
The figure below shows the gradual progression of PPMS over time.

1.b.5 Treatment

Three kinds of treatment options are available for MS [8].

1. **Maintenance treatment:** immunomodulating and immunosuppressive treatment. These treatments inhibit inflammation and demyelination. There is no treatment available for neurodegeneration – which is typical for PPMS and SPMS. Due to this RRMS patients mostly benefit from maintenance treatment. There are several kinds of medication available, both first - and second line treatment.

2. **Treatment of relapses:** when a patient notices a relapse and there is no improvement after a couple days methylprednisolone can be administered intravenously to speed up recovery.

3. **Symptomatic treatment:** MS causes a lot of different symptoms, and some of these symptoms can benefit from treatment. For instance, depression can benefit from psychotherapy, for cognitive problems a psychologist or an occupational therapist could help. Neuropathic pains can be treated (not solved) with medication e.g. different kinds of antiepileptic drugs or cannabinoids.

All of the treatment options mentioned above could reduce the symptoms, but none of them can cure MS.

1.c Cognitive symptoms in MS

It is commonly known that MS causes a wide variety of different physical symptoms. Less well-known is the fact that MS also has an impact on the functioning of different cognitive domains. As mentioned in the introduction of this report, the Second Opinion for Multiple Sclerosis and Cognition outpatient clinic (SOMSCOG poli) is established exactly for this reason; why, how and when do people suffer from cognitive problems and what causes these problems. Because the SOMSCOG is aimed at people that suffer from cognitive problems, it is important for me to understand more of the cognition part of MS. First, we have to understand what cognition is. The website of the MS international federation writes that: "cognition refers to the higher brain functions such as memory and reasoning" [63]. So, problems concerning memory and reasoning are called cognitive problems.
This paragraph describes the most important cognitive symptoms of MS patients and how these problems might affect quality of life. It also describes the difference between a cognitive problem and a cognitive impairment.

1.c.1 Subjective & objective complaints

During this project terms as problem, impairment, complaints and disorder are used to indicate that something is not quite right in the cognition department. Here a short description is given of what is meant with these terms.
Cognitive symptoms can be subjectively or objectively identified. The symptoms are the same, but the cause of the symptoms differ.

Subjective complaints

Both cognitive problems and cognitive complaints are things someone experiences, these are subjective. Cognitive symptoms are how these problems or complaints are manifested. Cognitive impairment is the general term of experiencing cognitive symptoms. Cognitive impairment is characterised by changes in reasoning and thinking, and can involve difficulties in remembering, learning new things, concentrating, or making decisions that affect daily life [64]. These impairments can have different underlying causes such as anxiety, medication, depression, neurological disorders, fatigue, etc.

Objective complaints

Patients talk about their cognitive complaints, and, as said before, there could be a disorder behind these complaints. But this does not have to be the case. Their complaints could also be caused by depression, anxiety or fatigue. These types of disorders can also affect cognitive functioning.
A cognitive disorder can be objectified by neuropsychological testing, which can sometimes be seen on an MRI-scan [65]. That means they are determined by neurodegenerative aspect of the disease.

Grey area

Often it is not clear whether cognitive symptoms are caused by MS or due to psychological problems, fatigue or sleeping disorders. For instance, a depression could cause similar symptoms [66]. This means that someone without an objectively identifiable cognitive disorder can still suffer from cognitive problems, with manifesting symptoms. This person might define themselves as cognitive impaired, even though there is no medical 'proof' for it. The contrary could also be the case. Someone without any complaints or symptoms could have an objectively identifiable cognitive disorder, without feeling impaired. ▶

1.c.2 Affected cognitive domains

Between 40% and 70% of MS patients suffer from cognitive complaints in different domains. These symptoms occur at any stage of their disease, both in early and later stages [8, 67]. MS has a negative impact on several cognitive domains. Affected cognitive domains include:

- Abstract reasoning
- Attention
- Being able to overview things
- Concentration
- Finding words
- Learning new things
- Memory
- Mental speed
- Planning
- Problem solving
- Process speed of (new) information
- Visual spatial abilities

[8, 64, 67, 68]. Executive functions are also affected. Executive functions are neurologically-based skills involving mental control and self-regulation[69].

Interventions

There are some intervention options available to help patients cope with their decrease in cognitive functioning, such as cognitive rehabilitation therapy. All interventions available are therapy-based. There is not a pill-like solution to 'cure' cognitive problems. Most interventions are aimed at learning new coping strategies. Interventions used to be aimed at addressing learning problems and memory issues. Recently the focus has moved to other domains such as executive function and attention, since these are the cognitive functions that have been shown to be most affected by this illness [67]. One of the treatments available is 'Niet rennen maar plannen.'This is an outpatient clinic cognitive rehabilitation treatment program. The focus of this treatment is on teaching patient new strategies to deal with mental processing speed, memory, planning and fatigue.

Also, there has been a change in focus on treating subjective cognitive complaints instead of focussing on objectively identified cognitive disorders. Currently there is a study being conducted at VUmc – Remind-MS – in which the effect of mindfulness on cognitive problems is researched. This study has subjective cognitive complaints as a starting point. Another study at VUmc, called 'Dance for health' researches the effect that learning a new choreography and moving (dancing) has on the memory (hippocampus).

1.c.3 SOMSCOG patients overview

As mentioned in the introduction, the SOMSCOG outpatient clinic started in February 2017. Up until now (June 12th), about70 people have visited the SOMSCOG outpatient clinic. For the first 58 visitors, the demographics are shown in figure 1-8 on the right pate. This table is inserted to get a better view at what kind of people visit this outpatient clinic. ■

	Total n = 58
Gender [b] (females)	33 (56,9)
Age [b] (years)	47.5 (10.8)
Education [c] (Verhage)	6 (3-7)
Disease duration diagnosis [b] (years)	13.6 (8.8)
Disease duration onset [b] (years)	15.1 (9.3)
Type of MS [a]	
RR	36 (62.1)
SP	12 (20.7)
PP	6 (10.3)
CIS	2 (3.4)
Unknown	2 (3.4)
EDSS [c]	3.5 (2.0-8.5)
Any disease modifying therapy (yes) [a]	26 (44.8)
Note: a N(%), b M (SD), c median (min-max). Abbreviations: RR = relapse remitting, SP = secondary progressive, PP = primary progressive, CIS = clinical isolated syndrome, EDSS = expanded disability scale scores.	

► ***figure 1-8:*** Table with characteristics of SOMSCOG patients

1.d Patient experience

In order to find out the current state of patient experience of MS patients that visit the SOMSCOG outpatient clinic, it is necessary to understand what patient experience entails. This paragraph describes the definition of patient experience used throughout this report.
To find a suitable definition, it was necessary to look at different definitions used and to look at patient experience in a broad sense. A patient's experience cannot be viewed in isolation of broader concerns about quality and cost of healthcare [14].
To understand the status quo of patient experience, we also needed to look at other aspects of patient centeredness e.g. patient satisfaction, expectation, preference, engagement and participation. To explore the context of patient experience, it was necessary to look at related concepts e.g. shared decision making and value based healthcare.
Patient experience is a rather contemporary phenomenon. The earliest patient experience article was published in 1993 and since then many more articles have followed [15]. There is a whole journal dedicated to patient experience: The Patient Experience Journal (www.pxjournal.org), which started in 2014 with four issues published each year. This journal is an important source for information concerning patient experience, and for this report.

1.d.1 Why is patient experience important?

It is beneficial for both healthcare organisations and patients to measure and improve patient experience. Patient experience has a strong relationship to medication adherence and self-management. Especially for chronically ill patients, healthcare providers cannot achieve positive health outcomes without commitment and action from patients. This commitment, or patient engagement, combined with good patient experience could lead to better healthcare outcomes, and reduced costs [29]. According to Browne et al. measuring patients' experiences is important to understand how to improve the quality of care [29]. It is also important as a basis for deciding on what not to improve. Often increase in quality of care is closely related to increase of income generated by care.
In the current interest of VUmc in Value Based Healthcare, patient experience is a key concept, because they can be linked. The next paragraph shows why this is important and how the two are linked.

1.d.2 How is the concept patient experience described?

In literature, various definitions are used to describe patient experience. It is useful to have a distinct definition of patient experience, but according to Silvera & Jason (2015), this is not easy to come up with [15]. Each journal, website or institution has a different way of looking at it. Different terms are used inter variably. Together with the evolution of the patient experience movement, professional disciplines and new definitions of patient experience appear [16].
Some definitions are short, easy to understand and clear. Others are long and complicated to grasp.
In the latter category belongs the definition used by the World Health Organisation (WHO). The WHO is an organisation focused on international public health that is established in 1948 by the United Nations. The WHO states that: "Patient experience is intended to capture the responsiveness of the health system" [17]. This health system refers to the way people are treated and environment of treatment when they look for healthcare. With this definition, it seems to be implied that responsiveness is the way this system is able to react to patient's needs, and the way it can adapt to an individual's preference. However, this is only implied, and not certain. It is quite difficult to understand this definition and important issues, e.g. quality and values of a healthcare institution and preferences of patients, are not embedded. Therefore, I chose to

not use this definition.
The definition used during this project has been formulated by the Beryl Institute. The Beryl Institute, founded in 2006, describes themselves as “the global community of practice dedicated to improving the patient experience through collaboration and shared knowledge.”[18]
This is done by executing research and funding scholarships. In order to come up with a universal definition of patient experience, they formed a work group of patient experience leaders from a cross-section of healthcare organisations. Together, they shared their perspectives, insights and backgrounds on what patient experience means to them and created the following definition.

“Patient experience is the sum of all interactions, shaped by an organisations culture, that influence patient perceptions across the continuum of care” [19]

- The Beryl Institute

This definition covers a broad range of information, it includes all the interactions experienced during a patient’s journey. It includes an organisation’s culture which includes their employees, vision and values. It also covers how the interactions influence the patient’s perception over the whole range of care. So not just where the patient is literally in touch with a hospital, but also before and afterwards. This definition is also used by The Patient Experience Journal as their standard definition for future references [16].

Other definitions that were considered for this project can be found in the Appendix B.
Now a definition has been established to use in this report, the question arose what does this definition exactly entail?

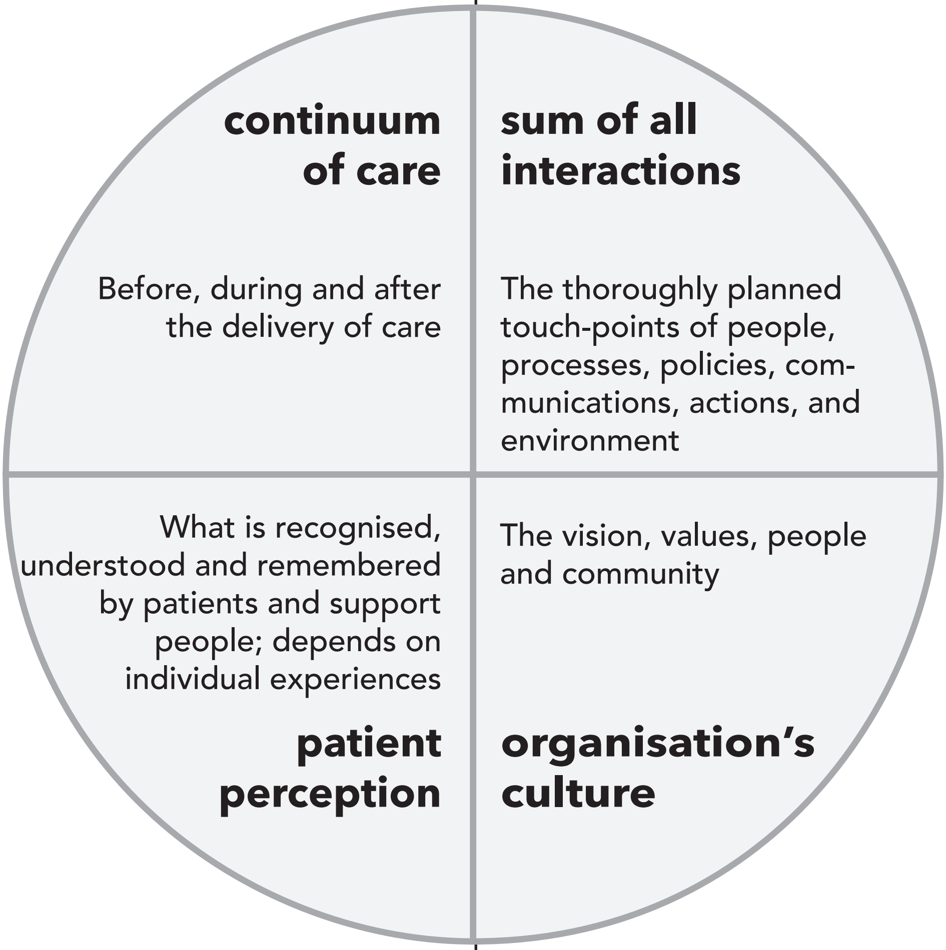
1.d.3 What does the concept patient experience entail?

On their website, The Beryl Institute explains this definition in four steps. Here, the definition is also divided in four pieces in order to explain it.
“Patient experience is the sum of all interactions, shaped by an organisation’s culture, that influence ▶

patient perceptions across the continuum of care" [19].

Continuum of care: "Before, during and after the delivery of care" [19]. This means that all the steps patients taken concerning a patient's care are included in the experience, e.g., being put on a waiting list, phone calls with the hospital, the drive over, duration of treatment, and time after treatment waiting for the results are all included — i.e. the whole patient journey

The sum of all interactions: "The thoroughly planned touch-points of people, processes, policies, communications, actions, and environment" [19]. This means that a wide range of interactions is included. Online and offline channels are included, such as the people from the care facility, the policies concerning this care, the processes within a facility, the facility itself, the treatment, being in touch the desk employees, etc. These are all part of the patient experience.



▶ ***figure 1-9:*** Definition of patient experience as used and defined by The Beryl Institute. It entails four elements: the sum of all interactions around a care visit, the influence of an organisation's culture, the perception of patients, across the continuum of care.

Organisations culture: “The vision, values, people (at all levels and in all parts of the organisation) and community” [19]. The culture of a care facility is an important factor of the patient experience. Although parts of this are present in the background, i.e., vision and value, these have an influence on all the interactions. The vision and value of a facility shape the policies and the way people are allowed to act. It influences e.g. the time reserved per patient, but also the way a facility is acting in a community. It has a big impact on the employees. And in this culture, people have to do their jobs. Not just the doctors and nurses but also the people that keep a care facility running: the cleaners, the desk employees, the people that handle the stock, the security guards, the assistants, the lunch ladies. All the people involved in running a care facility.

Patient perception: “What is recognised, understood and remembered by patients and support people. Perceptions vary based on individual experiences such as beliefs, values, cultural background, etc.” [19]. Often patient experience is mixed up with patient perception. I think these two are closely related, but not the same. According to LaVela & Gallan (2014) the view of the patient determines subsequent evaluations of an experience [14]. This view, or perception, is based on previous experiences and personal i.e. beliefs, values and background.

1.d.4 Concepts related to patient experience

There are some relevant concepts related to that of patient experience. These are described shortly here, how they are connected to patient experience and why they are relevant.

Patient perception: The patient’s perception determines the way something is experienced and is influenced by internal and external factors. As can be seen in the patient experience definition, the patient’s perception is part of the patient experience. According to LaVela & Gallan (2014) it is the only factor that influences the experience [14]. But as the definition of patient experience shows, the experience is defined by three other factors as well. Therefore, one cannot interchange patient experience and patient perception.

Patient satisfaction: is a patient’s affective and cognitive assessment of a healthcare interaction if his/her expectations were met [14, 20]. These expectations are formed by previous experiences, beliefs, values and other internal and external factors.

Perceived quality: shows how a healthcare interaction is perceived. It is not about what is remembered, but how it is remembered: a valuation can be added. ▶

Patient experience is the sum of all interactions, shaped by an organisation’s culture, that influence patient perceptions across the continuum of care.

Patient satisfaction and perception are not the same. **Patient satisfaction** shows how and if expectations are met. **Patient perception** shows how something is experienced. Satisfaction can be measured by aspects such as how satisfied, pleased happy patients are about an aspect of healthcare. Perception is about what is remembered, understood and recognised by the patient.
In short: patient perception is about what happened, perceived quality is about how it happened, and patient satisfaction shows how it made the patient feel.

Patient engagement: is the (emotional) involvement of a patient into their health and well-being. This concept is clearly distinct from satisfaction, experience and perception, but it is an interesting related concept to discuss. The idea is that engaged patients are better in making informed decisions about their healthcare possibilities [21]. Research conducted by Mulley et. al (2012) has the same outcome [22].
LaVella & Gallan (2014) describe an engaged patient "as one who is emotionally involved to their health and well-being" [14]. Synonymously to this, is **patient activation:** is defined as 'an individual's knowledge, skill, and confidence for managing their health and health care' [23].

Healthcare organisations can benefit from activated patients, writes Laundro (2014) in The Wall Street Journal. She states that: "Patients who are highly activated have better health outcomes and incur lower costs" [24]. Patient engagement can be influenced by a healthcare organisation's plans or actions, but the execution of it lies in the hands of the patients [14]. A cross sectional study performed by Greene & Hibbard (2012) found that patient activation is strongly and positively related to a broad range of health-related outcomes, which suggests improving activation has great potential [25].

According to the MSIF Quality of Life Principles Work Group [26](2017) making life affecting decisions independently and being empowered to do so can improve quality of life. In order to empower patients, they have to be engaged first [27]. In the next paragraph the concept Quality of Life is explained.
Patient participation: is how participative a patient is during healthcare interactions. It includes how willing a patient is in sharing information, answering the questions asked, doing what is needed or asked [14]. It is related to patient engagement. When a patient is involved in their health and well-being, it is most likely that this patient will also participate actively in healthcare interactions.

Positive and negative experiences

In order to create an optimal patient experience, it is important to understand patient's preferences, perceptions and expectations. It is also important to understand patient's negative preferences, to prevent negative experiences. According to Oliver (1993) negative experiences are more pertinent and perceived with greater intensity and are expressed with greater variety than positive experiences [28]. This indicates that it is useful to invest in a positive patient experience.

Example: A patient's expectations about a medical event were met. Her patient satisfaction was measured, and she was pleased. Her patient perception of that event could be measured in what she remembered, such as: "The doctor asked me about side effects, I did not expect that and was pleasantly surprised."

1.d.5 Patient-centred care

Currently patient experience is at the point of attention in the healthcare industry. This is also the case for related patient-centred methods and approaches such shared decision making and value-based healthcare. Indirectly patient experience is about creating value for patients, as is value based healthcare.

Shared Decision Making

In shared decision making (SDM), clinicians and patients work together to understand the patient's situation and to determine how best to address it [30].

Patients are encouraged to think about the available treatment possibilities concerning the approach and the likely benefits and harms of each option [31]. This way patients can communicate their preferences and co-select the best course of action for them. Shared decision making respects patient autonomy and stimulates patient engagement.

Stiggelbout et al. (2015) distinguished four steps in the SDM process [32]:

1. Clinician informs the patient that a decision is to be made and that the patient's opinion is important;
2. Clinician explains the options and their pros and cons;
3. Clinician and the patient discuss the patient's preferences and the professional supports the patient in deliberation;
4. Clinician and patient discuss the patient's wish to make the decision, they make or defer the decision, and discuss follow-up.

Patient Decision Aids

It is important that an informed decision is made. To achieve this, patients can be supported with patient decision aids (PDAs) – these aids have been developed to provide patients with evidence-based information. There are different tools and interventions available, varying from flowcharts define and express preferences, to information booklets, videos or web tools. These tools are usually designed for situations where there is some uncertainty about the best treatment option and provide information about the harms and benefits in as balanced a way as possible [31]. Many of these interventions are consulted before meeting with a medical professional. The patient is already informed before making a decision. When a patient hears about the different options for the first time when meeting his clinician, there has not been much time to let the information settle. These PDAs can be valuable to prepare patients (and medical professionals) for their consultation, but they do not necessarily support their conversation. And, according to Kunneman et al. (2016) only a small portion of patients use these PDAs distributed to them [30]. ►

► ***figure 1-10:*** Four steps of shared decision making as distinguished by Stiggelbout et al. (2015).

Montori and Kunneman therefore argue that PDAs should demand little or no work prior of the patient prior of meeting a clinician. When properly designed, these tools offer only the information necessary to support the patient-clinician conversation (the clinician can supplement information as needed) [33]. New tools – conversation aids – have been developed by Kunneman and her peers (2016), to support the dialogue patients and clinicians must establish to determine the patient situation and the actions required to address this situation [30]. This dialogue between patient and clinician is the most important part of shared decision making.

PDAs have been associated with improved decision quality and decision-making processes without worse patient or health system outcomes [34].

> "The underlying goal of SDM is to fundamentally care for the patient in a manner that resolves each person's situation by virtue of its effectiveness, consistency with what matters to this person, and fit with the contexts in which treatment and condition play out." [30]

Value based healthcare

According to Michael Porter (2010), value based healthcare is about delivering the best possible outcome - this is called value - to patients at the lowest costs [35].

This model is not about reducing costs, but about increasing value. That is where it differs from current strategies in healthcare. Porters says that we should move away from a supply-driven health care system which is mainly organized around what physicians do. Instead we should move toward a patient-centred system organized around what patients need [36].

The system moves from volume to value. It is not about how many patients are treated, how much money is made, but it is about achieving value for patients.

The following equation shows how health outcomes are divided by costs, resulting in patient value [37, 38].

$$Patient\ value = \frac{health\ outcomes}{costs}$$

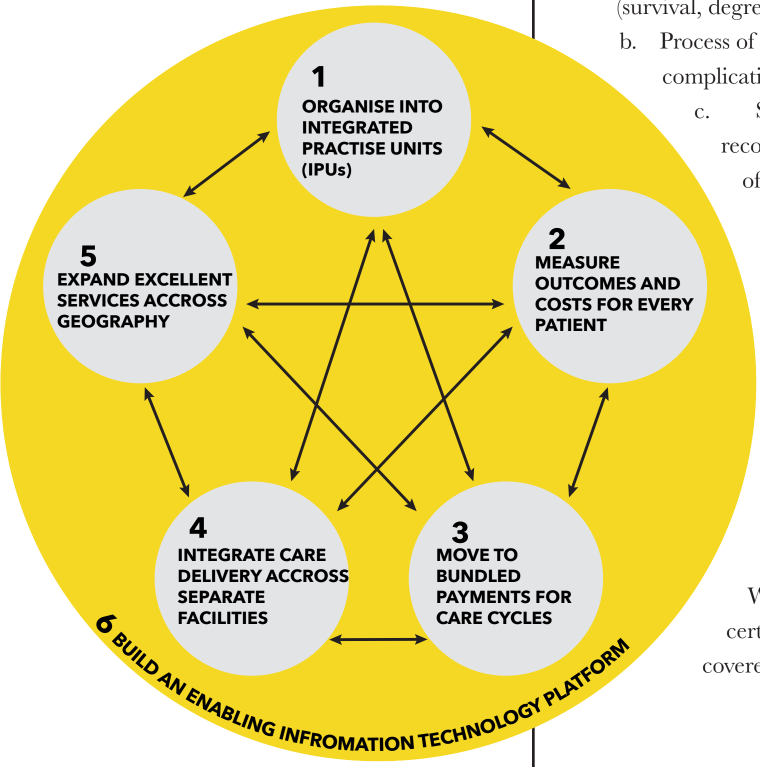
Since value is defined as outcomes relative to costs, it encompasses efficiency [35]. But cost reduction for the sake of cost reduction, without keeping in mind the health outcomes is dangerous according to Porter (2010). He says that this could potentially limit effective care [35].

The ultimate goal of health care delivery, in the value based healthcare approach, is to achieve high value for patients. Obviously, this is what is most important for patients. But it also brings the different actors in the health care system together. If value improves, patients, payers, providers, and suppliers can all benefit while the economic sustainability of the health care system increases [35].

The strategy

Porter suggest that there are six components in the value based healthcare strategy that can help an organisation improve value to patients. The image below shows the six components. Underneath each component is explained briefly. The explanations are adapted versions from an article by Porter & Lee (2013) published in the Harvard Business Review [39].

1. **Organise into integrated IPU's**
   First, the healthcare system should be organized around the customer (i.e. the patient) and its needs. An Integrated Practice Unit (IPU) brings together the full range of providers and support staff who address a specific disease or clinical condition, e.g. headache or epilepsy [40]. An IPU is constructed around a medical condition or related conditions, and care is provided by a multidisciplinary team.



▶ ***figure 1-11:*** Porter's strategy of value based healthcare consists of six components. The five-pointed star that is based on a strong elaborate ICT foundation.

This first component already shows a clear connection with patient experience and patient satisfaction and shared decision making. It is a good example of patient centred care.

2. **Measure outcomes and costs for every patient**
   Value is calculated by health outcomes and costs; these factors should be measured. Expenses should be measured at the medical condition level over the full cycle of care. Health outcomes should be measured over time and comparing outcomes to peers is crucial for teams to improve. It is important to measure outcomes that matter to patients, which shows again that this is linked to patient experience, patient perception and patient satisfaction. Outcomes that should be measured are:
   a. Health status achieved or retained (survival, degree of health or recovery).
   b. Process of recovery (time to recover, complications, side effects)
   c. Sustainability of health or recovery (long term consequences of therapy)

   Patient reported outcome measures (PROMs) are a way to do this. What these are, is explained in paragraph 1.e.3. Also, the patient experience can be seen as an outcome and could therefore be measured.

3. **Move to bundled payment for care cycles**
   With this payment method a certain identified care cycle is covered by one payment. This could ▶

mean: a bundled payment that covers for the full care cycle for acute medical conditions, the overall care for chronic conditions for a defined period (usually a year), or primary and preventive care for a defined patient population (healthy children, for instance).

4. **Integrate care delivery across separate facilities**
   With integrated systems, fragmentation and duplication of care can be eliminated and the types of care delivery can be optimised in each location. This will improve the value provided to patients.

5. **Expand excellent services across geography**
   Medical centres, even academic ones, mostly serve patients in their immediate surroundings. By expanding their services for particular medical conditions with excellent IPU's, value is likely increased on a larger scale. But, it is important to focus on improving value when expanding geographically, not just increasing volumes.

6. **Build an enabling information technology platform**
   The right kind of IT system can help the parts of an IPU work with one another, enable measurement and new reimbursement approaches, and tie the parts of a well-structured delivery system together. A supportive IT system can also help to improve patient engagement.

Triple Value Model

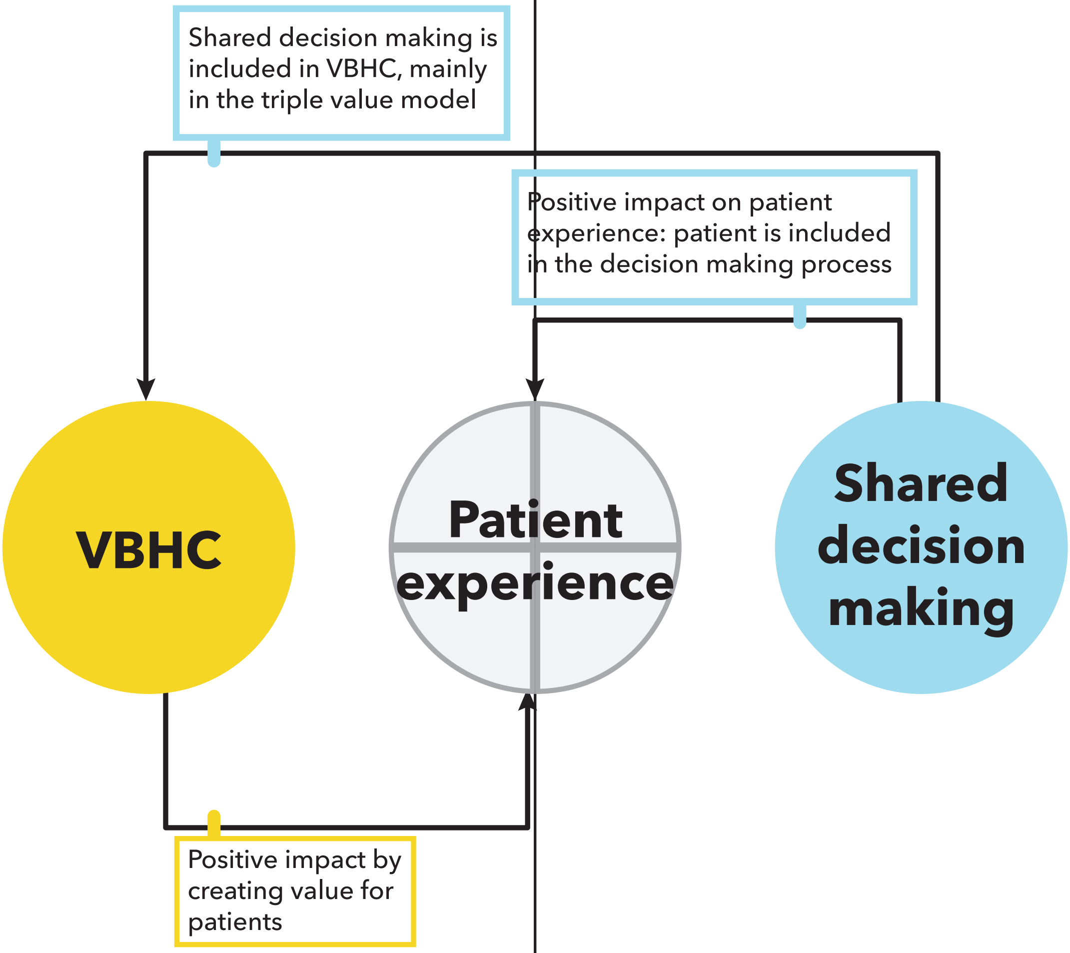
There is another value based healthcare model that also includes public health more broadly, instead of only institutionalized care in hospitals, the Triple Value Model (TVM). This model, developed by Muir Gray and colleagues, is based on three kinds of values: allocative, technical and personal. The first, allocative, is concerned with how assets are divided amongst subgroups of a population. The second, technical, is concerned with how resources are used for each subgroup. The latter, personal is all about the delivery of services informed by what matters to each individual of subgroups [41].

TVM works different than Porter's strategy does. The main difference in emphasis is that in TVM shared decision making is emphasised, while this remains somewhat underemphasised in Porter's strategy. Instead, in Porters model there is very much emphasis on measurement of outcomes such as PROMs (i.e. quality of life). However, in TVM, PROMs are also used.

I would suggest that a combination of these two models: follow the steps of Porter, and make sure that within and patient-clinician-consultations, the focus lies on shared decision making. This way, the most value is created for patients.

1.d.6 Connecting different patient centred methods

When reviewing all the patient centred care concepts related to patient experience, it appeared that in literature these different concepts - shared decision making, value based healthcare and patient experience - have never been combined.
To understand the similarities and differences of the concepts, it was necessary to find a link. As, in my opinion, the concepts patient experience, value based healthcare and shared decision making are related, but have their differences. I tried to combine the three patient centred care concepts in one image to show their relation.
The image below shows how shared decision making, value based healthcare and patient experience follow and influence each other. ■



▶ ***figure 1-12:*** Patient centred care concepts united and linked together. Value based healthcare influences patient experience. Shared decision making influences both patient experience and value based healthcare.

1.e Quality of Life

This paragraph describes how the concept quality of life is described in literature, what it entails and how this is applicable for MS patients.
Quality of life became more important in health care as medical treatment was able to extend the length of life. Sometimes, this has a negative impact on of quality of life, other times, it has a positive impact on quality of life, without extending length of life. One of the first times quality of life was mentioned was in literature was in 1966 by Elkinton [42]. He calls it "the harmony within a man, and between a man and his world to which the patient, the physician, and society aspires." It is particularly important, mentioned Elkinton (1966), to be able to answer questions regarding the goals and values of daily human life as the knowledge and power of medical science is growing. This was back in 1966, so now - fifty years later, it is just as important, or maybe even more than it was back then. As medical science, nowadays is able to do things that were unimaginable in 1966, life can be prolonged drastically, but quality of life (QoL) is not always priority.

1.e.1 (Health Related) Quality of Life in literature

Quality of life is a subjective term, that is influenced by different kinds of internal and external factors [43]. Similar to patient experience, multiple terms are used throughout literature. To make a first separation, here the focus lies on quality of life and not on health-related quality of life (HRQOL). These terms are being used interchangeably, but their definitions do not differ greatly [44]. Both of them are subjective and influenced by internal and external factors. Carr et al. (2001) considers "health related quality of life as a discrepancy between the expectations of health and the experience" [45]. Quality of life entails more than just the difference between expectations of health and the experience. This difference is part of QoL, but there is more to it. I think it is important to have a broader look at it, particularly for MS patients who will be a patient for their whole life. Therefore, this definition of the HRQoL is not broad enough to cover their QoL.

1.e.2 How is Quality of life described in literature?

When looking at what is described about quality of life in literature, definitions include different internal and external factors, also subjective and objective factors of both the physical and psychological kind— it is multidimensional [46]. The impact on quality of life of each factor differs per person [45, 47].

A list of mentioned factors that might determine QoL are: values, beliefs, experiences, expectations, culture, life-domains, work, and physical-, emotional- and social well-being, mood and self-efficacy [43, 45, 47-50].The WHO created a definition of quality of life in 1997, and it has been used in a lot of their documents on QoL and measurement tools and methods, often combined with specified measurement tools developed by the WHO such as WHOQOL-100 and WHOQOL-BREF [51-54].

"An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment."[52]

For this project I will use this definition. It includes multiple factors and it entails both the individual's perception and expectations, features of their environment, and even the context of culture.
As defined by the WHO, quality of life is an

individual's perception, it differs from person to person. Therefore, subjective evaluations of QoL are needed to define more precisely the patient's experience of life [46]. That, is why QoL should be measured from the patient's perspective [47].

1.e.3 PROMS

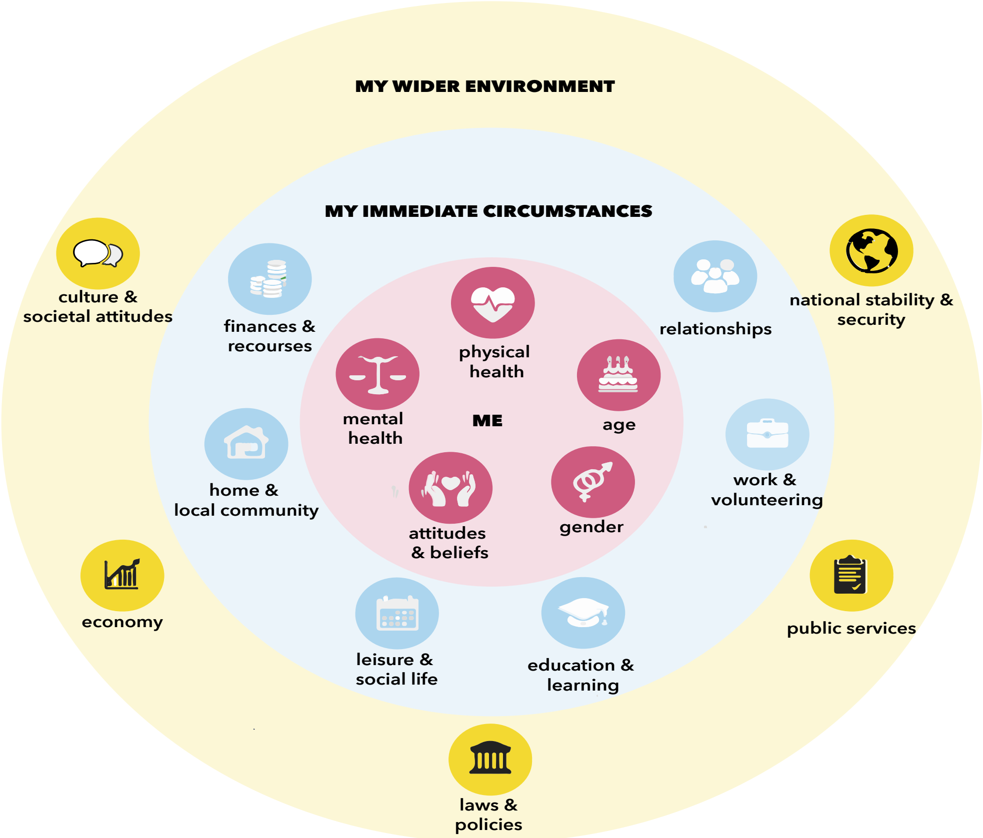
There are different ways to measure quality of life. Patient Reported Outcomes (PROMS) are often used. These are standardised, validated questionnaires that are completed by patients and used to measure their perception of their functional well-being and health status. Patients rate their health by scoring the severity or difficulty in completing certain tasks or routine activities.
The aim of PROMs is to get patients' own assessment of their health and health-related quality of life. PROMs questionnaires do not ask about patients' satisfaction with or experience of health care services. The also do not ask for their opinions about how successful their treatment was. The main thing about a PROM is that health is assessed by the person experiencing it, not by a doctor or anyone else [55].
The MSQOL-54 is an example of a multidimensional health related QoL measure that combines both generic and MS-specific topics in a single PROMS [56]. It is developed specifically for MS patients. The MSQOL-54 consist of 52 questions concerning both physical and psychological topics [57].

1.e.4 QoL and MS patients

According to Karimi & Brazier (2016) the importance of QoL rose simultaneously with the ability of life extension [44]. Particularly for people suffering from a chronic disease, medical treatment is not just about surviving or prolonging life, but also about improving the quality of it.
MS has a dramatic negative impact on quality of life [49]. Specifically, cognitive symptoms, mood, depression and fatigue have a big impact on the QoL [8, 58]. One of the aims of MS treatment is to lower the negative impact of the disease on quality of life [59]. As this disease will, up until now, never be cured, it is necessary to make living with it as comfortable as possible. During this project, it is therefore important to keep QoL in mind in order to be able to create a positive impact. figure 1-13 on page 40 shows all the domains that affect quality of life in MS patients.

Benedict et al. (2005) found some parameters to predict both physical Health Related QoL as Mental HRQOL [60]. As mentioned before, for this report the WHO definition of Quality of Life is used and not a definition of HRQOL. But what Benedict et al. (2005) researched is also useful for QoL in relation with MS [60]. For the first time physical HQOL is predicted by fatigue, depression and physical disability. At first sight, it seems remarkable that physical HQOL is predicted by depression, but depression and a lack of physical activity are linked [61]. A lack of physical exercise is linked with depressed mood. But also, the other way around is possible: depression is a significant risk factor of decreased physical activity [62].

Benedict et al. (2005) also reported that mental HRQOL is mainly associated with depression and fatigue [60]. They concluded that self-report HQOL are most strongly predicted by measures of depression.
This indicates that treating co-morbid depression is likely to improve the well-being and quality of life of patients with physical illnesses. As MS patients suffer both from physical and mental symptoms, treating depression is also likely to improve the QoL of MS patients and have a positive impact on their physical well-being [61]. ►



▸ ***figure 1-13:*** Factors that affect quality of life of MS patients. The factors are divided in three sections: (1) me, (2) my immediate environment and (3) my wider environment and

Seven principles to improve quality of life

The MS international federation formulated seven principles to improve quality of life. These principles are based on the insights and experience by people affected by MS. These principles are slightly modified from the booklet: Seven principles to improve quality of life with MS (2015) by the MSIF Quality of Life Principles Work Group [26].

- Empowerment, independence and a central role for people affected by MS in decisions that affect their lives. Shared decision making could be used.

- Access to comprehensive and effective treatments and care for the changing physical and mental health needs of life with MS

- Support for the network of family, friends, loved ones and informal caregivers

- Work, volunteering, education and leisure opportunities that are accessible and flexible

- Accessible public and private spaces, technology and transport

- Financial resources to meet the changing needs and costs of living with MS

- Supportive attitudes, policies and practices that promote equality and challenge stigma and discrimination

1.e.5 Quality of life and patient experience

As mentioned before, there are several factors that determine quality of life. One of them which hasn't been mentioned is patient experience, which can be placed under the mental and physical health factor in the 'Me' section.

Patient experience can have an influence on quality of life. Both can be seen as a result of care. I reckon patient experience has the biggest impact on QoL when a certain experience is experienced repeatedly. This impact could either be negative or positive. When a patient is a frequent visitor of hospitals, the effect of the patient experience on his/her quality of life is bigger than a one-time hospital visitor. Chronic patients such as MS patients visit hospitals quite often. The sum of all those visits will definitely impact their QoL. In the context of this project: the visits of SOMSCOG patients will probably only have a small effect on their quality of life. They visit the outpatient clinic only once or twice for the screening day(s) and once to get the diagnosis. But, we should keep in mind that the final result of their visit of SOMSCOG clinic: a diagnosis of their cognitive well-being, can have a big influence on their QoL. This means that in this project, there is an implicit effect of patient experience on quality of life.

Speaking of the scope of the project: improving the patient experience will not impact the quality of life. But improving the preparation, resulting in a better help request will make a better diagnosis. Which will positively impact quality of life.

1.e.6 Quality of life and cognitive complaints

As mentioned before internal and external factors have an impact on quality of life. Critical internal factors that impact quality of life are cognitive impairment, depression and fatigue [8, 49].

When looking at figure 1-13 on the left pag**e**, you can see these factors are divided into three sections.

1 Me
2 My immediate circumstances
3 My wider environment

Cognitive impairment can be scaled under the domain: Me. However, it seems like its impact reaches much further than just this section. As cognitive impairment has an impact on people's ability to work, it also influences the second section: My immediate circumstances [70]. Not only the 'Work and Volunteering' part of this domain is impacted, also 'Education and Learning' can be impacted. It does not stop here. When looking at all the affected functions and domains mentioned before, nearly each part of the two sections can be affected. That indicates that cognitive disorders indeed have a huge impact on quality of life.

Mitolo et al. (2015) state that due to their cognitive impairment, MS patients participate in fewer social and professional activities, are less likely to be employed, have greater difficulties in doing routine household tasks and are more vulnerable to psychiatric illness than people with a purely physical disability [67]. Minden et al. (2013) also state that MS patients suffer more often from major depressive disorders than the general population.
It is important to know that depression is not a cognitive impairment, but it affects cognitive functions. One study shows that depression may influence subjective reports of cognitive impairment[71]. This means that without further research it is not possible to know whether a patient suffers from cognitive disorders or whether a patient is cognitive impaired due to depression.
In all, we are sure that MS can negatively impact different cognitive domains. Not just because there is an underlying cognitive disorder, also depression and fatigue play their part. ■

1.f Conclusions literature research

This paragraph concludes the desktop literature research. Conclusions are drawn about quality of life, its definition and its impact. Also, it draws conclusions about patient experience and related topics i.e. shared decision making and value based healthcare. These topics are not just about patient experience but go a little further.
Furthermore, a patient centred framework that connects patient experience, quality of life, with value based healthcare and shared decision making.

1.f.1 Quality of life

Research question 1: How is the concept quality of life described in literature?
Quality of life is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It affected the individual's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

Research question 1.1: How does this manifest for MS patients?
MS has a has a dramatic negative impact on quality of life [49]. Currently, medical care is not just about prolonging one's life, but also about improving its quality. This is especially important with chronic diseases such as MS.

1.f.2 Patient experience

Research question 2: How is the concept patient experience described in literature?
Patient experience is the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care [19].

Research question 2.1: How does this manifest for MS patients?
For the scope of this project, it is important to find out the needs of patients who visit the SOMSCOG outpatient clinic in order to improve the patient experience of the clinic. These needs were not found during the literature research. That is why this sub question cannot be answered.

Shared decision making

Shared decision making (SDM) is about collaboration between clinicians and patients to understand the patient's situation and to determine what the best option is to address it [30]. This way patients can communicate their preferences and co-select the best course of action for them. Shared decision making respects patient autonomy and stimulates patient engagement.
"The underlying goal of SDM is to fundamentally care for the patient in a manner that resolves each person's situation by virtue of its effectiveness, consistency with what matters to this person, and fit with the contexts in which treatment and condition play out" [30].

Value based healthcare

Value based healthcare (VBHC) is about delivering the best value to patients at the lowest costs. It is important to know that increasing value is the highest goal, not reducing costs.

1.f.3 The patient centred framework

figure 1-14 below shows the connection between value based healthcare, patient experience, shared decision making and quality of life.
Here is a guide through of the image. First it is important to see that both value based healthcare and shared decision making impact the patient experience. Respectively, value is created for patients, which has a positive impact on their experience. And being included in the decision making process also impacts the patient experience. But this connection goes further. Shared decision making can also be seen part of the value based healthcare. That is indicated by the arrow from SDM to VBHC.

When we move on to the right side of the image, you can see that QoL has three arrows pointed towards it. The (results of the) different patient centred approaches influence the quality of life. Of course, the results of decisions impact quality of life - either positively or negatively - depending on the consequences of the decision. One of the principles to improve quality of life is the empowerment and central role of a patient. This is exactly what shared decision making is about. So, when a patient is ▶

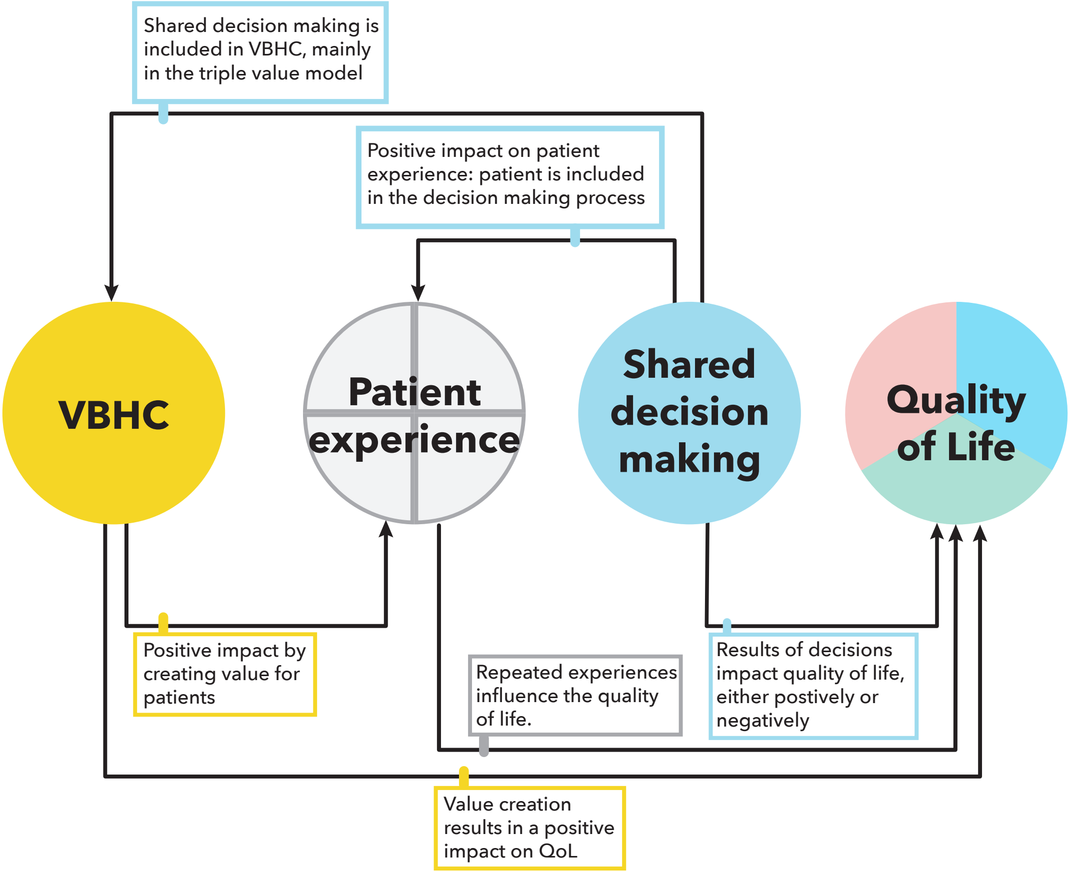


figure 1-14: The influence of patient centred concepts. Value based healthcare influences patient experience. Shared decision making influences both patient experience and value based healthcare. All three concepts of patient centred care have an impact on patients' quality of life.

included in the decision making process, the quality of life benefits from it.

The patient experience also impacts quality of life. If a patient has certain experiences repeatedly, the impact is bigger. But one should keep in mind, that something seemingly meaningless can have a large impact on the patient experience and consequently on the QoL.

When value is created, quality of life is most probably positively impacted. One of the seven principles of improving quality of life is the access to comprehensive and effective treatment and care, well this can be achieved by creating value for the patient, thus having a positive impact on quality of life.

1.f.4 Cognitive symptoms in MS

Research question 3: What are the most important cognitive symptoms in MS? How do cognitive symptoms influence each other and quality of life? The most important cognitive symptoms in MS are symptoms related to the memory, information processing and concentration. These symptoms have a huge impact on quality of life. Cognitive impairment impact people's ability to work, but also impact their general daily life activities and the overall mental well-being [8, 64, 67, 68].

1.f.5 Relevance

The scope of this project is to improve the patient experience and ultimately quality of life of SOMSCOG patients. The literature study showed that both patient experience and quality of life are affected by different factors.

When gathering information on patient experience of MS patients in hospitals, it was difficult to find relevant articles for this project. There are many articles published concerning patients experiencing fatigue or cognitive impairment. But not much could be found concerning their experience with healthcare. That is why this project is relevant. During the user study what impacts the patient experience is investigated. It is necessary to find out the needs of MS patients and if their needs are fulfilled and if their expectations are met. This is something that cannot be found in literature, and where the user study will help fill in the gaps.
In this project, the focus lies on the experience around the visits to the outpatient clinic for cognitive symptoms in VUmc. For this, all interactions with all actors of the whole SOMSCOG phase will be included. The next chapter - user research - explains how this is done. ■

2 USER RESEARCH

The literature study of chapter 2 provided an essential understanding of patient experience, quality of life and MS in general. It also provided insights in what kind of cognitive problems patients encounter.
Now it is necessary take a closer look at what happens at the SOMSCOG outpatient clinic. How do medical professionals interact with patients? How do patients behave during their visit? What are their needs and expectations? For this project it is needed to find answers to these questions (and see if the theory is applied in practice).
At this point, it is important to gain understanding of the patient's perspective. However, it important to realise that whatever is designed and implemented, the medical professionals are the ones to execute this. Therefore, their input is needed for this design process. Four different research methods are used to answer the two main research questions and eight research topics.

2.a Introduction

Finding possibilities to improve the patient experience of SOMSCOG outpatient clinic requests a clear overview of the current process and experience. What steps are taken, and which actors are involved in this process. By making a patient journey with its touch points and a visualisation of the emotions experienced, possible points of improvement can be found. The goal of the patient journey is to get a comprehension of the complete SOMSCOG process, from the moment of referral up to when the patient returns to its own clinician. But, creating a patient journey is of this process does not provide enough insight in the patient needs. Also, the behaviour of patients, healthcare professionals and informal care provider are observed as well as the typical information provision to patients and exchange between patient and healthcare staff.

2.b Research questions

Research questions and research topics have been created to find the missing information of the general SOMSCOG process, the needs of patients, and the interaction between patients and medical professionals. For each research question and topic between brackets is indicated which research method was used to answer the question/topic. Research method 1 is indicated as [RM1], research method 2 as [RM2], etc.

Research questions

The research questions formulated for the user research are:

1. What are the needs of MS patients regarding the care provided during SOMSCOG visits and how is the care pathway affected by their needs? [RM 4]

1.1 What are the values and preferences underlying these needs of MS patients? [RM4]

2. What are the needs of health care professionals regarding the care provided during SOMSCOG care giving and how does this impact the care giving? [RM2]

Research topics

Some extra research topics have been formed. Especially during observations, these topics were used to focus on.

The main research topic is defined as:

- How do the actors of SOMSCOG outpatient clinic interact with each other? [RM1 RM2]

In order to find out, first we need to establish:

- What actors are involved in the care provided at the SOMSCOG outpatient clinic? [RM1 RM2]

Next, the following research topics are used during user research. These topics are all embedded under the main research topic.

- How is information provided to patients at the SOMSCOG outpatient clinic? And vice versa; how do patients provide information to professionals? [RM1 RM2 RM3 RM4]
- How do care professionals work together? [RM1 RM2 RM3]
- What is the role of the informal care provider during the visits? [RM1 RM2 RM3 RM4]

Furthermore, the waiting rooms are observed, the topic used for this is:

- How are the waiting rooms set up? [RM1]

2.c Methods

Four research methods were applied for user research. First the procedure and participants of each method is described. Then, in a later paragraph, the analysis of the methods is described.

1. Observations
To get a first, understanding of the context, observations were performed.

2. Interviews medical professionals
To dig deeper in the context and subject, interviews with medical professionals were held.

3. Immersion
The opportunity to fully immerse in the context was offered - I became a hostess of the outpatient clinic, became part of the evaluation team of the outpatient clinic and participated in a few MS-group activities.

4. Contextmapping with patients
Contextmapping research was performed, by means of sensitising booklets followed by individual interviews with patients to gather insights in the user's needs and behaviour.

The time spend for each method is shown in the table in figure 2-15 on the next page. Each research method is divided into different activities. An estimation of time spent per activity is shown. ▶

Method and activity	**Time** Total: 129,7 H
1. Observations	**65,5 hours**
Screening day	45 H
Diagnosis consultation	2 H
Neurologist consultation	4 H
MS meetings	9 H
MS day	4,5 H
SOMS MDM	12H
2. Interviews medical professionals	**6,5 hours**
Medical professionals	6,5 H
3. Immersion	**47 hours**
Being a hostess	32 H
Multidisciplinary meetings (MDM)	14 H
Evaluation SOMSCOG	1 H
4. Contextmapping	**10 hours**
Introduction meeting	1,5 H
Interviews	8,5 H

figure 2-15: Specification of user research time

2.c.1 Research method
1 – Observations

Observing during the screening day at VUmc outpatient clinic was done to generate data from the researcher's perspective. It helped to identify the different steps of the process and captured the atmosphere during the different parts of the day. The aim was to map all the steps patients take during their visits of the outpatient clinic and what actors are involved in all these steps. Also, the behaviour of patients, healthcare professionals and informal care providers were observed as well as the typical information provision to patients and exchange between patient and healthcare staff.

Participants

Different observations were performed at the SOMSCOG outpatient clinic during the screening day, result meetings and at VUmc hospital in general.

Patient and professional observations

- Around 45 hours of observations of the screening day took place between May and November 2017; resulting in 12 patients being observed with three different hostesses.

- Three diagnosis consults were observed (2H). appendix D shows the notes taken after the consultations.

- Seven neurological consults during the screening day (4H), with two different neurologists were observed.

Activity observations

- To get a better understanding of MS, around eight second opinion MS multidisciplinary meetings were attended. During these meetings, patients who wanted a second opinion concerning their MS diagnosis, medication or other questions were discussed.

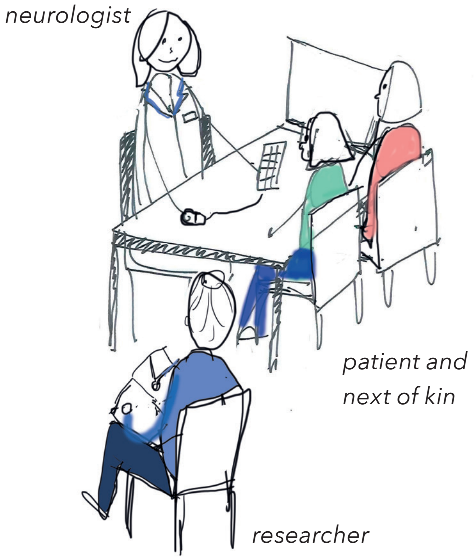
- The annual MS day of VUmc MS Center Amsterdam, on October 10th was an afternoon filled with presentation about MS. Some were so specific and therefore hard to understand: detailed subjects of advanced optical microscopy, functional network dynamics of the brain and ultra-sensitive detection technology for biomarkers. In Appendix "E Attending MS day" a summary of the presentations is described.

Procedure patient observations

Before each contact with patients, the researcher was introduced by the neurologist or hostess. Then the researcher introduced herself. Permission was asked if the researcher could tag along and observe during the screening day. All twelve patients gave their permission. During these observations, there was a lot of contact with the patients and their next of kin as they had often had to wait. Informal questions were asked during the day.

With the consultation observations (both the neurological consult and the diagnosis consult) the neurologist asked the patient permission whether the researcher could observe. Then the researcher introduced herself. All five patients gave their permission. The researcher sat down next to the patient, a little bit to the back and the side, to not intervene with the consultation,

This worked quite well, the patients ignored the researcher and it seemed as if they forgot she was there. During observations, the researcher did not record any audio or video, due to privacy reasons. She also did not take notes because this felt inappropriate. Sometimes, the researcher scribbled some notes directly afterwards, but often there was not time to do this. Often, there was an appointment immediately afterwards, or conversations started. Notes that were taken, tried to capture the emotions of the patients and professionals, quotes and described the interactions between them. See appendix F for some of the notes taken after patient observations. ►



► ***figure 2-16:*** Observation situation during consultation

2.c.2 Research method 2 – Interviews with healthcare professionals

Interviews with healthcare professionals working at or for the SOMSCOG outpatient clinic were held to get a feeling with the hospital, understand the different procedure executed during the screening day and find points of improvements in this process. This research was not aimed at acquiring a complete overview, but it mainly performed as a source of inspiration and to find themes and design directions for a patient centred design. Insights were used to formulate the design framework (chapter 5) and to create the patient experience journey.

Participants

A total number of ten medical professionals from VUmc were interviewed which provided useful data. The professionals were from different disciplines:

- Four medical researchers
- One neurologist
- Two neuropsychologists
- One health scientist/neuroscientist
- One cognitive neuropsychologist PhD candidate (follows education to become an epidemiologist)
- Neuroscientist and anatomy PhD candidate

All of the medical professionals, except one, had more than two years of work experience in the medical field.

Including participants

To ask the medical professionals to participate with this research, emails were sent to professionals who work for the SOMSCOG. The aim was to include a representative cross-section of the people involved in the SOMSCOG outpatient clinic. Not all disciplines were interviewed, some were hard to reach. When the number of ten participants was reached, inclusion of participants stopped. This was already more than enough.

With most of the participants, the contact was already good and friendly, so they were willing to participate. Only two people (of the twelve) that were approached did not want to participate. One professional declined my interview because: he “had once decided to just never participate in this kind of research.” One professional ignored the invitation email altogether.

Procedure

The interviews lasted between 25 and 55 minutes, depending on the timeslot available and the amount of information participants wanted to share. The interviews usually took place in the offices of the participants, three exceptions: one participant preferred to be interviewed outside during a walk and two preferred to do the interview in the hospital restaurant Het Plein. Before the interview started, participants were asked to sign an informed consent form. This secured and enabled the participants to talk more freely. Each interview was voice-recorded

and during the interview some additional notes were taken.
A semi-structured interview guide was used to conduct the interview (appendix G). First, the participants were asked to introduce themselves and tell about their professional background. Then questions concerning their tasks at the SOMSCOG were asked. Finally, the researcher asked if the participant missed something to perform their jobs comfortably and if something could help them.

2.c.3 Research method 3 – Immersion

Immersing myself in the SOMSCOG (and MS) team provided me with practical understanding in how the team operates, the relations between the team-members and also how people in the team behave.
Being a hostess at the outpatient clinic provided useful insights of the behaviour of patients during the day.

Activities

I participated in different activities during my time in VUmc. The ones described here are part of a participatory research – immersion. The goal of this method was to get a good understanding of how the hospital functions. Immersion is often used to gain the best understanding of a topic, by becoming part of the group or topic of study [72]. Of course, for someone without MS it is not possible to become part of a patient population. Thus, I became part of the MS team, and in particular the SOMSCOG team.

Hostess

Four different days, 32 hours in total, I acted as the hostess of the SOMSCOG outpatient clinic during the screening day. My role was to guide the two visiting patients of that day during their visit. I brought them to all their examinations and when possible accompanied them with some of them. This was a whole different experience than shadowing a hostess.

SOMSCOG multidisciplinary meeting

During the last year, as a researcher, I attended twenty multidisciplinary meetings (MDM) of the SOMSCOG. These meetings usually lasted between 20 and 40 minutes. Two patients from the previous week were discussed and a diagnosis was made. Medical professionals attending this MDM included: neurologist, rehabilitation specialist, neuroscientist, PhD candidate/psychologist, neuropsychologist, MRI researcher, MEG researcher. During the first meetings, I was merely an observer, but as experience came, I was more involved in the process, asked questions and shared what patients told me during the screening day.

SOMSCOG evaluation

During the first evaluation of the SOMSCOG outpatient clinic, on September 25th, the researcher shared her first insights. Each discipline of the SOMSCOG team had one or more slides with points to evaluate. The researcher was included as a team member. Here, insights from an outside perspective and insights from the hostess's point of view were shared.

MS Team meeting

Every Monday from 16H-17H there is a team meeting with the whole MS team. Every week someone else presents their current research or other things they are working on. I have attended this meeting 10 times. Very specific research topics were discussed. It was interesting to see what everybody is working on, but the subjects were sometimes hard to follow. Sometimes, the topics involved very specific statistical analyses, or medical experiences. Nonetheless, it was a nice way to get a feeling of how hospitals work and what people are doing. These meetings were a nice way to learn ▶

more about MS and the medical field in general during my time here. For me, it was also a good opportunity to present my findings and design (on May 28th).

2.c.4 Research method 4 - Contextmapping

Contextmapping is a user-centred design method where the user is treated as the expert of his or her experience. By providing the user with design tools and approaches, he or she can express a particular experience [73]. The methodology is developed at Delft University of Technology and is nowadays spread in design practice worldwide. Exploration techniques are used to learn about the needs, wishes, motivations and experiences of everyday people. Contextmapping uses qualitative research, analysis and conceptualisation methods and supports empathy with the end-users and inspiration for better solutions [74, 75]
Interviews with patients were conducted to identify the patients' needs and the underlying values. An essential part of these interviews was the use of sensitizing booklets to unravel needs and underlying values. This research was not aimed at acquiring a complete overview, but it mainly performed as a source of inspiration and to find themes and design directions for a patient centred design.

Participants

This research included six participants, if which two were male and four female. They were aged 35, 36, 38, 40, 50 and 59, diagnosed with MS and a visitor of the SOMSCOG outpatient clinic. Furthermore, all of them have signed an informed consent form. 5 out of 6 participants spoke Dutch, one participant received English versions of the materials provided. Six participants are already enough to base conclusions on. As the aim of the user research was qualitative research, this number of participants was sufficient. It is expected that with this amount of people sufficient insight and information will be gathered. Research by Molich et al. (2004) shows that 85% of the possible answers are given when performing a user research with five participants [76]. Their conclusions are based on a mathematics model developed by Nielsen & Landauer in 1993 [77].

Including participants

Patients of SOMSCOG clinic were asked to participate in this research during the screening day. First was explained what participating in this research includes. When a patient was willing to participate, an information letter was handed out, for them to read at home. After a week, the participant was contacted by the researcher (by phone) and were asked if he/she still wanted to participate. When the participant was still positive about participation, a date was planned to sign the informed consent and to hand over the sensitising booklet. At the same time an interview date and time was planned.

Procedure

The contextmapping research consists of two parts. Participants fill out a diary (part A) and are interviewed (part B). Appendix H shows the research protocol written for the METc request.

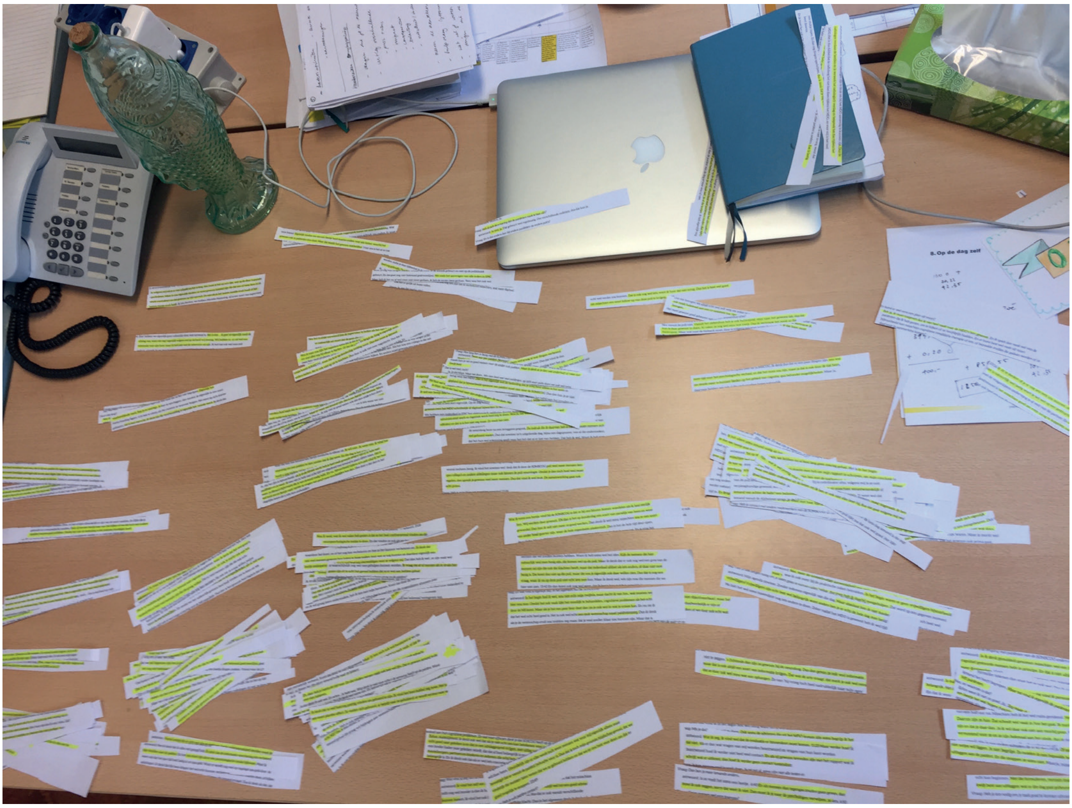
Sensitising booklet

Part A – prequel to the interviews – is the sensitising phase where sensitising booklets in the shape of a diary were filled out. These booklets were used to sensitise patients: make them think about the subject of the interview. Questions about their experiences with the SOMSCOG visit, their expectations prior to their visits are asked. Also, a time-line around their visits and a map of help around their well-being were included. To check whether patients would be inclined to use the booklet, three pilot tests were done. One SOMSCOG visitor and two recovering cancer patients were included in this pilot test. They provided some useful tips to improve the booklet. Appendix I shows the setup and results of the pilot tests. The filled-out booklets additionally gave valuable insights in the patients' contexts and needs (Appendix J shows some examples of the filled-out booklets).

Interview

The interviews (part B) took place at patients' homes, all over the Netherlands: Amsterdam (2x), Utrecht, Almere, Gouda and Etten-Leur. The interviews usually took place a couple weeks after the participants had visited the SOMSCOG outpatient clinic, but all within 42 days of their visit. When interviews are conducted longer than 42 days afterwards, their memories will be recall inaccuracies and bias may occur [14]. The duration of the (recorded) interviews varied from 59 minutes to 105 minutes, depending on the amount the participants spoke and how much they needed to share their story.

The interviews were conducted according to the interview guide - see Appendix K - a semi structured interview. It started with the introduction of the researcher, the goal of the research, the plan of the interview. Most of the times, the informed consent forms were signed when the packages were given to the patients, but in two occasions these forms were signed during the interview appointment. All the interviews were recorded – audio only – with permissions of the participants, also notes were taken. Only one participant wanted to say things off the record, and this was done respectfully. ▶



▶ ***figure 2-17:*** Cut out quotes from targeted search

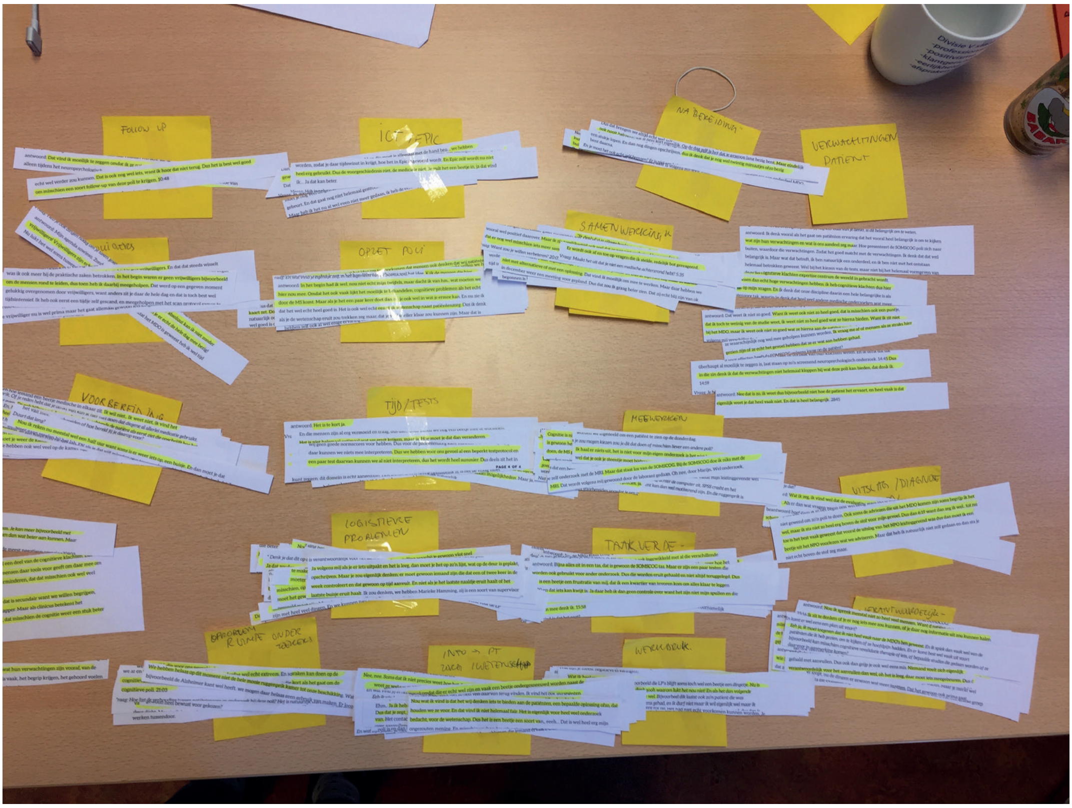
The interviews were set-up in two parts: during the first part the sensitising booklet was used as a guideline. Additional questions were asked to find out patients' needs. The second part of the interview was reserved to gather feedback on the developed concepts.

2.c.5 Analysis

This paragraph describes the analyses performed for all the user research methods.
The first step in the analysis started with analysing the observations. This was done by first rereading the notes taken and by adding other remembered, interesting facts that were not noted. Then the different actors were identified, and different phases distinguished, resulting in a team map (chapter 3.d). Next, the audio recordings of all the interviews – both with patients and medical professionals – were transcribed (see appendix L). Notes taken during the interviews were included in the transcriptions. Not everything the participants said was transcribed. During the transcription process, small talk was excluded when it was irrelevant for this research. Also, for better understanding some sentences were paraphrased slightly.

Then, the data analysis continued with analysing the interviews with medical professionals. This was done by means of a targeted search.
Aim of this targeted search was:

- Find wishes and requirements for the design brief



▶ ***figure 2-18:*** Clustering the quotes

- Identify the steps taken by medical professionals and patients
- Identify problems during the screening day
- Find the needs of patients in the SOMSCOG journey
- Provide inspiration for ideation

The transcriptions were printed, interesting quotes were highlighted and cut out. This pile of insights was then organised and clustered into overarching themes.
Subsequently, a targeted search through the transcripts of the interviews with patients was performed. This targeted search was done to find overlapping themes and to complement the insights found in the interviews with professionals. The insights of all these observations interviews and notes were combined and clustered into bigger clusters. The results – paragraph 3.d – shows these themes. Special attention was paid to quotes concerning preparation, the expectation of patients around the SOMSCOG journey and quotes concerning patients' and professionals' needs. These kinds of quotes were mostly selected.

The filled-out sensitising booklets used during contextmapping were inspected, but most of the things written in it were already mentioned during the interviews. Therefore, these booklets were merely used as inspiration for the design process. Next, the notes and insights of the observations were examined to see whether the same themes reoccurred.

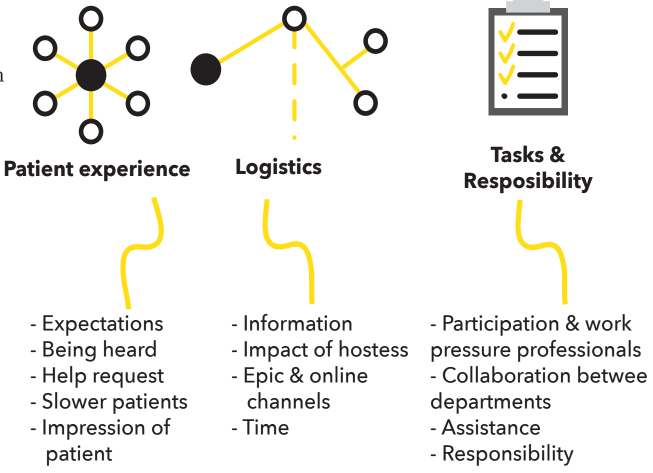
The insights and quotes, both from patients and medical professionals, were used to answer the research questions. Also, a visual qualitative overview of the SOMSCOG journey was made – a patient experience journey. The different phases and steps the patient undertakes and goes through, how these steps and phase are experienced and the most promising design opportunities are included in this journey (see chapter 4). Quotes were added to support the results (chapter 3.e).

Analysis immersion

The analysis of the immersion has not been an active analysis. Along the way, interesting facts and insights were picked up. Therefore, insights of this research method cannot be pointed out. There are results, but immersion provided mostly a good idea of how the hospital environment works, how patients and professionals behave. Combined with the observations and interviews, a complete image of the context was drawn. ■

2.d Results

When listening to the recordings, reading the transcriptions of the interviews, and interpretation looking at observations notes, etc., different obstacles and remarkable situations during the screening day were found. This paragraph first describes the actors involved in SOMSCOG outpatient clinic and how they interact with each other. Then, results for the four research methods are shown. These results can be clustered in three categories: 1) logistics, 2) tasks & responsibility, 3) patient experience. For each category, sub-themes are identified. Ffigure 2-19 on the right, shows all the categories and sub-themes.



Patient experience

- Expectations
- Being heard
- Help request
- Slower patients
- Impression of patient

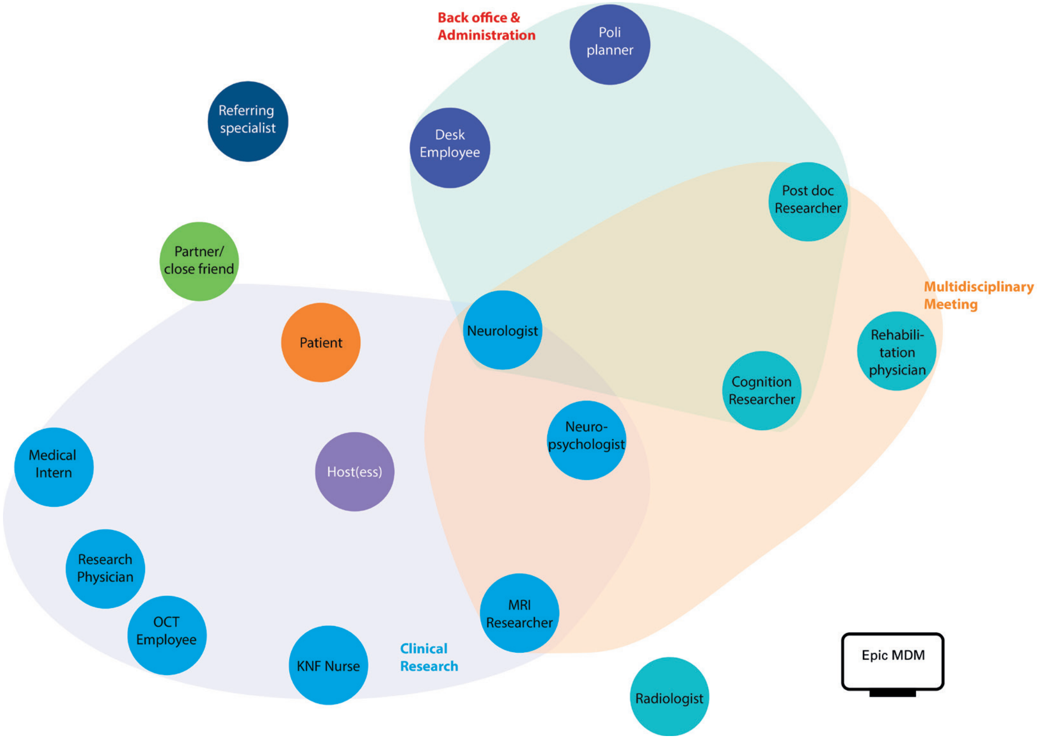
Logistics

- Information
- Impact of hostess
- Epic & online channels
- Time

Tasks & Resposibility

- Participation & work pressure professionals
- Collaboration betwee departments
- Assistance
- Responsibility

▶ ***figure 2-19:*** Categories and sub-themes of user research



▶ ***figure 2-20:*** Team map of actors involved in SOMSCOG outpatient clinic

2.d.1 Team map

Many different actors of the SOMSCOG outpatient journey were identified. Appendix N shows a list of all the actors involved. This team map shows all the identified human actors of the SOMSCOG outpatient clinic.

What actors are involved in the care provided at the SOMSCOG outpatient clinic? [RM1, RM2]

There is a large number of actors involved in the SOMSCOG outpatient clinic, both human and non-human actors. For clarity, it is decided to only show the human actors here, except for Epic, the electronic patient files. The human actors are shown in the team map in figure 2-21.

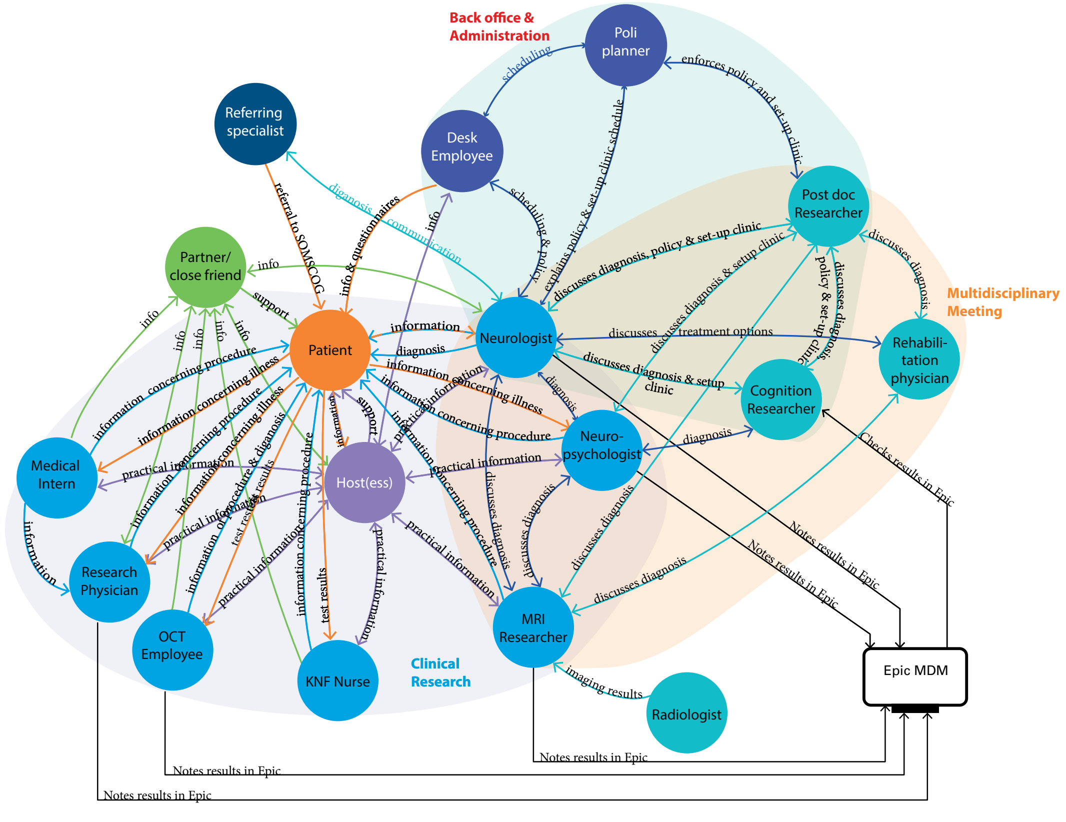
The team map is divided in three segments:

1. Back office and administration (green)
2. Multidisciplinary meeting (orange),
3. Clinical research (lilac).

Each actor plays a part in one or more of the segments. As you can see, in the middle of the map is the neurologist. This neurologist is active in each segment of the map. For most actors in clinical research, there are multiple people playing their part. I have decided to only include one representative actor.

How do these actors interact with each other? [RM1 RM2]

figure 2-21 shows how these actors interact with each other. Each line represents an interaction. The arrows indicate the direction of interaction. When two actors are connected with a double arrowed line, the interaction goes both ways. ►



▶ ***figure 2-21:*** Team map showing the interaction between actors involved in SOMSCOG outpatient clinic.

The hostess interacts with all care providers in the clinical research segment. Young hostesses can be frightened to interact with the neurologist. There is no contact between the different care providers during the screening day, the MDM not included. Care providers don't need help from other care providers, except when there is no intern available to assists, then the medical-researcher help each other out. When there is a delay in the schedule the hostess and cognition researcher take actions to resolve this. Medical professionals who do not attend the MDM do not really feel part of a team, everybody does their own little part and that's it. They do not see the results from what they do.

> "Wij zijn eigenlijk een beetje een eilandje in het geheel." – Professional

2.d.2 Patient experience

Patient expectations of screening day

Medical professionals are unsure whether the expectations of the patients are met. Often patients do not have an objectively identified disorder, but still suffer from cognitive complains. Especially research physicians sometimes feel like the patients' problems are not always solved. Although patients appear to have a different view on this. It appears to be important for patients to get reassurance on their cognitive functioning, e.g. suffering from Alzheimer disease. Their expectations are met and even surpassed sometimes. Patients expect clarity of their cognitive issues and they get this out of the SOMSCOG clinic.

> "Uiteindelijk is wel vaak de conclusie dat er niet zo veel mee/met ze gedaan kan worden."
> - Professional

> "Ik vraag me af of menen als ze hier straks gezien zijn of ze er echt het gevoel hebben dat ze er wat aan hebben gehad."
> - Professional

For medical professionals it can be difficult to cope with the fact that they could not give a distinct diagnosis. They were unsure how the patient would react to the non-diagnosis, whether they would be satisfied. There are also questions whether all the patients that need to come to this clinic are reached, how the ones that are not familiar with this clinic reached?

> "Nou wat ik vind is dat het wij denken iets te bieden aan de patiënten, een bepaalde oplossing ofzo, dat houden we ze voor. En dat vind ik niet helemaal fair. Het is eigenlijk voor heel veel onderzoek bedacht, voor de wetenschap"
> - Professional

Although patients are often not diagnosed with a cognitive disorder, they still receive advise that might help their cognitive well-being. Often, they need psychological help. During observations, it appeared that this is not what patients expected, but it stills help them understand their issues.

> "Een doel is gewoon meer een objectieve beoordeling van je cognitie. Het is lastig om echt duidelijk in beeld te brengen, wat is er mis met mij?"
> – Patient

> "Door de uitslagen ben ik gerustgesteld."
> – Patient

Patients have the feeling of being heard

One of good things of SOMSCOG journey is that patients feel heard: finally, they get thorough examinations and insights in their cognitive functioning. Patients are very pleased with the whole SOMSCOG journey. They feel treated with respect, they feel heard and understood and they are glad somebody finally acknowledges their cognitive issues. Some walk around with this for a long time. For several, this is the first time a specialist asks them about their cognitive issues. They are not all diagnosed with cognitive disorders but being heard and examined and reassured is what some need. The medical professionals are glad they can be part of this, as they see that patients are thankful for being there.

Especially the combination of NPT's and MEG-scans and fMRI-scans are highly valued by the patients.

> "Het is goed dat je zo multidisciplinair kijkt naar iemand met cognitieve problemen. En ook, je merkt ook aan het aanbod dat er heel veel mensen zijn die dit graag willen."
> - Professional

> "Ook voor mantelzorgers, partners en kinderen en iedereen die erbij betrokken is. Ik denk dat duidelijk heel belangrijk is."
> - Professional

Formulation of help requests

> "Ik vind het heel goed dat er een duidelijke hulpvraag geformuleerd wordt aan het begin. Die dan ook beantwoord kan worden"
> - Professional

Observations showed that patients often do not have a clear question they want to have answered during the screening day. Some do not realise this is a second opinion phase. That this is not the place for questions regarding their regular care. Some patients have questions for which this is not the right second opinion clinic, such as: Do I have MS?

> "Dat zie af en toe ook bij patiënten terug, dat ze een hulpvraag hebben die niet helemaal aansluit bij de SOMSCOG. Soms heb je iemand die vraagt, heb ik wel echt MS?"
> - Professional

Interviews with medical professional show that they feel the same. The aim of the day is to answer a patient's help request. During the first consult with the neurologist, patients are asked for what question they seek answers. In the MDM, the different disciplines work together to find that answer. However, if the question is not 'right' the answer will never fit the question. Some patients just want to participate with scientific research and do not have a help request at all.

> "Ik denk dat het heel erg belangrijk is met de beeldvorming van de SOMSCOG poli, de verwachtingen van de patiënt, en de hulpvraag van de patiënt. En dat wij dan weer kunnen ingaan op de verwachtingen en de hulpvraag. Ik denk dat dit een belangrijk onderdeel is."
> – Professional

Patients of SOMSCOG are slower than regular MS patients

As patients come to the clinic for cognitive problems, it is very logical that they have some issues with information processing. Observations and interviews showed that the patients are often quite slow in performing tasks. The NPT often take longer because otherwise not all the tests will have been finished.

> "Binnen de anderhalf uur zouden niet alle testen af zijn. Omdat die mensen gewoon wat trager zijn."
> - Professional ▶

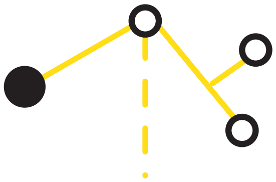
Impression of patient

The day is long and overwhelming for patients, but they are grateful to be examined VUmc. They value the opinions of the specialists in the academic hospital. Patients are impressed with how professional everything and everyone is. Some things can be confronting, such as the NPTs, and many are afraid for the MRI and the LP. However, most patients cooperate very well with all the examinations. At the end of the day, they are usually exhausted. Some have experienced severe post puncture headaches, for up to a week. Two patients interviewed for this research were very unhappy with this. They said they were misinformed about the risks of the LP and if they would have known, one wouldn't have done it. The other still would've had the LP but would've made arrangements with extra help afterwards.

> "Als jullie mij dit van tevoren hadden gezegd, nog voor de onderzoeksdag, had ik ervoor gezorgd dat ik hulp had. Maar nu kan ik dat niet meer stante pede regelen in het weekend. Dus ik voelde me aan mijn lot overgelaten en was echt heel erg boos"
> – Patient

One patient that suffered from post puncture headaches said she was warned by the medical professionals about this.

2.d.3 Logistics and set- up of outpatient clinic



Information provision for patients

As mentioned before, the SOMSCOG is a new outpatient clinic, and start-up problems come along with a new clinic. What was found during the user research is that the information provision to patients was not always optimal. For example, for patients it was not clear that the clinic is partly used as scientific research and partly for diagnosis.

> "De scheidslijn tussen zorg en wetenschap is ook heel ingewikkeld." - Patient

Some are looking for a clear distinction or want to know how this is divided. Actually, most of the examinations are done for both purposes. During observations it appeared that several patients and their next of kin, had a lot of questions concerning this research part. The information provided beforehand does not offer them enough clarity.

> "Het wordt nu natuurlijk gebracht als second opinion poli, maar dat vooral ook wel heer erg gericht is op onderzoek. Want bijvoorbeeld een MEG, ja dat heeft nu voor de patiënt echt geen klinische waarde. Maar dat wordt nu wel een beetje onder dat kopje verkocht, voor second opinion."
> – Professional

> "Ten eerste omdat het eigenlijk het protocol wat summier is, dus veel meer screenend is, waarin je niet heel duidelijk kunt zeggen: dit domein is echt aangedaan."

> - Professional

The amount of information the patients receive is huge, and this can cause confusions. Over the last months, there are some improvements realised and documents added or revised to make things clearer for patients.
Documents patients receive are:

- Invitation letter
- Information booklet
- Questionnaire for patient (21 pages)
- Questionnaire for next of kin (4 pages)
- Two informed consents, one for the patient, one for the next of kin
- Two forms to withdraw the consent, one for the patient, one for the next of kin
- MRI consent form, concerning metal objects in the body
- Biobank information letter
- Visitor information about parking around VUmc

Patients receive all the documents mentioned above in a large envelope. The envelope often rips open in an undesired way, halfway through the middle. Most patients keep all the documents in the envelope. As it is torn down the middle, it appears quite unorganised.

> "En mijn envelop was wel helemaal vreemd kapotgescheurd. Een dikke haal zat er aan."
> - Patient

The information letter sent to the patient is also not clear about the time they should be there. One letter says a certain time, but the information booklet says something else. This is very confusing.

Patients, for whom the screening day is spread out over two days, receive the same invitation letter as the one-day patients. The only difference is that some notes scribbled on it, to indicate that they have to be there the day before. Half of the patients do screening day in two days. They do not receive accurate info. This is very confusing for them.

> "Negatief vond ik de uitnodiging die ik thuis kreeg van het VUmc, over de dagen. Dat briefje, daar staat dan iets bijgeschreven. Dan denk ik: oh jongens, dit komt wel heel onprofessioneel over. Er staat voor de eerste dag een tijd dat ik er moest zijn, maar geen eindtijd."
> - Patient

During observations and interviews it was noticed that patients are often late. Furthermore, patients come across as if they have not prepared for the screening day. It seems like have not read all the information and don't know what time they have to be present for the first consultation.

This could have to do with the fact that they do not always understand and remember the information they have read. One neurologist mentioned that sometimes it takes him fifteen minutes of his consult (which is 30 minutes in total) to explain the informed consent and have the patient sign it.

> "Met die formulieren, de mensen snappen het niet. Dat moet je uitleggen. Dat je veel tijd kwijt bent aan het uitleggen wat er die dag gaat gebeuren. Dat is het grootste bezwaar denk ik."
> - Professional

Patients often feel like they have prepared very well, they filed out the questionnaires and read the information letters they said. However, when they arrive at the hospital, often late, they seem unprepared and blanc.

> "De mensen zijn vrij… eehh… ze zien wel wat er op hun afkomt."
> - Professional

After the diagnosis consultation, there is a lack in information provision. Patient stated that they had trouble remembering what the neurologist had said. They are very tense before this diagnosis consultation. ▶

> "Ik vind het heel spijtig dat je geen a4tje krijgt met een toelichting op de uitslag. Want je hebt een gesprek en alles draait om dat ene gesprek. Waar je al 1,5h voor in de auto hebt gezeten met een spanningsboog. Ik verwacht dan nog een samenvatting mee te krijgen. Want het is er al, het staat al zwart op wit in de computer."
> - Patiënt

Impact of the hostess on screening day

The hostess (or hosts) are an invaluable part of the SOMSCOG outpatient clinic. Most of the interviewees interacting with the hostess acknowledged their role. During observations and interviews, their part in the screening day is highly valued by both the medical professionals and the patients. Especially when a hostess is unavailable they are greatly missed. The people that have to take over their roles are the ones that notices this the most.

> "In het begin waren er geen vrijwilligers om de mensen rond te leiden, dus toen heb ik daarbij meegeholpen. Dat werd op een gegeven moment gelukkig overgenomen door vrijwilligers, want anders zit je daar de hele dag en dat is toch best wel tijdsintensief."
> - Professional

Most of all, as a hostess it is very important to keep track of the time. There is not a lot of time and some examinations take longer than planned. In particular with the MRI it is very important to be on time, otherwise the timeslot will be used by someone else. Furthermore, the patients are often not familiar in the VUmc, so they follow the hostess around without intervening in the process. The hostesses are the ones that guide the patient around and the ones that make sure everything runs smoothly. Patients share a lot of personal information with the hostesses. One thing that is remarkable is that not all the hostesses know the procedures very well.
All the patients that were interviewed (18 in total) were also pleasantly surprised by the presence of the hostesses. They said that they did not expect them to be there, and that they were glad that the hostess brought them everywhere. Doing it themselves, would have caused stress, cost a lot of energy and they most likely they would have got lost.

> "Ik had een chaperonne toegewezen gekregen. En dat vond ik wel echt heel fijn. Ik zag mezelf al zoeken naar waar ik nu weer naar toe moet, al die dingen. Nu was er gewoon iemand waar je op kon vertrouwen."
> - Patiënt

During observations and immersion, it was remarkable that when the hostess introduces herself, patients hand over all responsibility to the hostess.

Epic and the use of online channels

Online channels are not optimally used, both by patients and professionals. Not all the appointments are inserted in Epic, so when a digital active patient checks his appointments, he cannot see the entire schedule of the day. There has been a case that a patient planned more appointments during the screening day because he saw empty time slots. This caused a lot of trouble finding the patient and making sure all the examinations of the screening day could be continued. Furthermore, from the medical professional side, Epic can also be used more efficiently. Placing orders in epic can be tedious task, the medical history of a patient is not always properly inserted, etc. Ultimately, the digital opportunities are not always used: all the documents are sent by physical mail, all the questionnaires are physical, all the tests during the NPT are filled out on paper and inserted in by hand by medical professionals.

> “Dat kan echt wel efficiënter technisch wat handiger in elkaar gezet worden, zodat je daar tijdswinst in krijgt, hoe het in Epic ingevoerd wordt. En Epic zelf wordt nu niet heel erg gebruikt. Dus de voorgeschiedenis niet, de medicatie niet. Je vult het een beetje in, ja dat vind ik… Ja dat kan beter. ”
> - Professional

Lack of time

During the research it appeared that healthcare professionals need, as expected, more time than they have now, to do their jobs. Especially the neuropsychologists feel as if they do not have enough time to make an optimal conclusion. They find the test battery too short.

> “Puur vanuit patiëntenzorg gekeken, dus niet vanuit wetenschappelijke kant, zouden wij bepaalde tests eruit gooien en een andere test erin gooien.”
> - Professional

> “Omdat je geen echte uitspraken kan doen op de cognitieve domeinen maar meer op testniveau. En dat voelt een beetje te kort als het gaat om de cognitieve poli.”
> - Professional

For the medical researchers participating in the SOMSCOG outpatient clinic has a big impact on their schedule. The time needed to see one patient takes up to 2,5 hours.

> “De rompslomp eromheen: daarom heb ik eigenlijk geen zin om het te doen. Want ik ben heel lang bezig voor een patiënt.”
> - Professional

There is a lot of time needed to prepare everything for the LP and phlebotomy. This is due to the fact that there is no designated room with all the tools needed for these examinations. They have to run around to gather everything, often it is unclear where to find stock when they’ve run out of e.g. tubes or needles. This logistics part is not yet organised and costs a lot of time.

> “Het loopt niet helemaal gestroomlijnd.”
> - Professional

Some say that it would be good if someone took the time to make a clear checklist of everything you need for their examination, and to organise the stock, etc, but no one really wants to make time for it. So, they just continue the way things are, and nothing changes. It seems as if no one feels responsible to improve it, as working at SOMSCOG is just an extra task to their normal activities. Now, they even have to leave the examination room when they forgot something during the consult with the patient.

> “Voor ons het grootste struikelblok is dat het logistiek niet goed geregeld is. Of door onszelf of door iemand anders.”
> - Professional

> “Ja dat zouden we zelf wel kunnen verbeteren. Ik dat het ook wel een beetje komt omdat het initiatief komt van iemand anders voor de poli. En dat eigenlijk niemand er heel veel zin in heeft om er echt tijd in te gaan steken om het even goed te doen.”
> - Professional ▶

2.d.4 Tasks and responsibility professionals

Participation and work pressure professionals

What was remarkable of the user research is that most of the people participating in the SOMSCOG outpatient clinic did not choose to work here but were assigned to do so. This may impact their sense of responsibility. Important to know is that all the medical professionals really do the best they can for the patient. Most of the medical researchers/PhD candidates, six in total, mention that they like to work in the clinic and stay informed and in touch with patients. But they also mention that working at SOSMCOG does not benefit their research. Most of their research topics are not linked with SOMSCOG.

All the medical professionals were, at first sight, pleased with the way everybody worked together. They were positive about the collaboration of all the disciplines and did not have anything to complain. “Ik heb niks te klagen.” They said the MDMs went smoothly, people knew where to find each other for questions. But, when asked for elaborations on their answers, some did mention issues about collaborating with other departments. When going deeper into the topic of collaboration, some issues did arise. It was remarkable to see how different departments do not have a clue about how other departments in the hospital function. They do not understand each other’s workload, tasks and responsibilities.

For instance, one department was not happy with the content of a test, they kind of expected someone else to solve this. This someone else, wanted them to work together.

> ”Ze zijn daar wel passief in. Ze zijn niet blij, maar komen niet met alternatieven of een oplossing.”
> - Professional

What is also interesting to see is how tasks are divided. This outpatient clinic is only one year old, but habits have already developed. In the beginning of this clinic, there was some misunderstanding with the availability of test materials, so two PhD candidates made sure all the printed materials were ready in a bag for the neuropsychologists to find. But now, when they run out of printed materials, they call these PhD candidates instead of printing it themselves.

> ”En als er vragen vanuit de neuropsychologen zijn voor testmateriaal ofzo, dan print ik dat uit. De NPO testen, daar heb je testformulieren nodig.” - Professional

> ”Hij zorgt er altijd voor dat een bepaalde neuropsychologische test er is want die gebruiken zij ook voor onderzoek. Dus die ligt altijd ergens anders.” - Professional

Collaboration with other departments

It has been difficult to get all the members of such an elaborate multidisciplinary team on the same page, but overall this seems to work quite well. Each department had their own interests in this clinic and in the data generated. Of course, there were some struggles between departments e.g. concerning the use of generated data, but by communicating each other’s expectations this was resolved.

> ”Ik denk dat het wel heel knap is om één dag met zoveel onderzoeken in een dag te krijgen en dat het goed loopt. Dat niet als een ding uitloopt het hele schema in de war loopt, maar ze de dag zo kunnen doorlopen.”
> - Professional

The members of the clinic are proud to be a part of it and think it is of added value to MS patients and to the VUmc MS Center Amsterdam.

> "En ik denk ook wel dat het MS centrum zich ook wel op de kaart zet. Door dat te doen, wij zijn ook wel de enige die dit aandachtsgebied hebben."
> – Professional

In September, the outpatient clinic was evaluated with the whole team. This was a good way to hear everyone out and to start making some changes. Appendix M shows the recommendations that were made for this evaluation.

> "Ik denk dat je elkaar heel erg nodig hebt."
> - Professional

Some miscommunications were resolved, but another problem arose. Who is responsible for implementing the changes? These tasks are either not assigned, or some people volunteered in doing them, on top of their daily activities. This results in a slow process of implementing changes. At the moment of writing – April 25th – some small changes still have not been made.

> "Ik had alleen wel graag al wat dingen verbeterd. Bijvoorbeeld de patiënt informatiebrief."
> - Professional

Assistance with procedures

When assistance is needed for procedures, assistance is not always available due to conflicting schedules. For example, when performing a lumbar puncture, a medical researcher needs assistance. This is usually done by a medical intern. Interns are often absent on Thursdays because of education obligations. That means that the medical researchers have to help each other. This is a burden for them. They made a planning where everybody has a designated number of shifts in the clinic, and when an intern is missing, they have to help each other out, and pick up extra shifts.

Similar is the case with the presence of a supervisor of SOMCOG outpatient clinic. When a medical-researcher doesn't succeed with a lumbar puncture, after two attempts, he/she calls the supervisor. The supervisor can take over the LP, or advice the medical-researcher what to do. However, on Thursday afternoons there is no supervisor available. This of course, is not very practical, because it can be unclear who to call.

> "Onze hoofd SOMSCOG, is er op donderdagmiddag nooit. Dus dan moet je iemand anders bellen als de LP niet lukt, die er ook niet op zit te wachten."
> - Professional

Feeling responsible for patients

This research showed that sometimes there is a lack in the sense of responsibility. It could be caused by the fact that people see the patient for a short amount of time and then never again. Only the neurologists see the patients a second time, during the diagnosis consult. The other medical professionals do not hear back from the patient or the diagnosis. A reason for this is that not the care givers that see the patients at the clinic, visit the MDM. That is due to a lack of time, some they have to see the a SOMSCOG patient during the MDM, others have other things to do during that time. Some medical professionals would like to know how the patient responded to the advice and would like to hear back from them.

> "Je hebt geen behandelrelatie met ze. Je moet gewoon even je testen doen en daarna zie je ze niet meer. Je hoeft niks voor ze te betekenen en geen inhoudelijke vragen te beantwoorden."
> - Professional ►

The same lack of responsibility is noticed during the transfer of patients' files. No one is responsible for this transfer. Patients that are referred to VUmc from other expect that their files are automatically send to their own neurologist. They find it very important for their own neurologist to have both the results of the NPT's and other tests and the files of the scans (such as the MRI-scans). The results are important for the referring neurologist to know what the conclusions are. The NPT's are important to track over a longer period of time, same is for the MRI-scans. The patients want them to build their files and keep track of disease progression.

> "Dossieroverdracht!! Dat is toch waarvoor je komt."
> - Patient

Furthermore, patients realise that MRI-scans cost a lot of money, so they want their original neurologist to have the scans. That way, there is no need to redo the scans shortly after visiting SOMSCOG outpatient clinic. During interviews, it became apparent that there are a lot of issues with the transfer of files. This does not happen automatically. Sometimes the referring neurologist does not even receive a letter with the diagnosis, only the GP receives it. Patients and their referring neurologists have to put in a lot effort to make it happen.

> "Het dossier niet doorgestuurd naar mijn eigen neuroloog. Toen heb ik de MS-verpleegkundige gebeld en die reageerde een beetje geïrriteerd en ze zei dat het gestuurd was. Toen ik bij mijn eigen neuroloog was, waren de dossiers er niet."
> – Patient ■

▶ ***figure 2-22:***These pictures show the interior of the waiting room. The pictures are taken at night when there were no patients around, as it is not allowed to take pictures of patients. 1) One of the two hallways leading to the waiting room, different art works are displayed on the wall, changing regularly. 2) different chairs with a coffee table and reading material. 3) Overview of the tables in the waiting room. 4) Close up of regular tables with fake leather chairs and reading materials. (5) Panorama of the waiting room.

2.e Conclusions user research

The user research that has been conducted provided a lot of new information, insights and remarks. In this paragraph the research questions and topics are answered.

2.e.1 Research questions answered

Research question 1: What are the needs of MS patients regarding the care provided during SOMSCOG visits and how do these impact their care pathway? [RM 4]

The contextmapping research, observations and immersion showed that patients have basic needs when visiting the SOMSCOG outpatient clinic. Here the most important needs are listed, with a short explanation why this is important for the patients and how it influences their care pathway.

- Feeling heard and being taken seriously
  One of the most important needs of the patients visiting the SOMSCOG outpatient clinic is to feel heard and understood. Patients expect to be treated professionally, which means that they and their complaints should be taken seriously. Often, they have had a long journey before getting diagnosed with MS and a similar experience for their cognitive problems. Some patients did not receive much attention from their neurologist or specialist concerning their cognitive problems. Not all specialists are open to talk about these concerns. As the cognitive problems are not visible and all happening in their heads, they have difficulties explaining it to others. This makes them feel alone and as if no one sees what they suffer from.
- Concretely, this means that patients want to be able to ask all the questions that pop up, without feeling as if the medical professionals do not take them seriously. They want the professionals to answer sincerely and tell them the truth.
  - ▹ An effect on the care pathway is that when patients do not feel like they can ask anything they want, there will be lack in patient participation. Also, patient will look up information themselves. Which is not always desired, as information online can be biased.
  - ▹ Furthermore, an effect is that patients at the outpatient clinic feel like finally there is someone who is interested in their cognitive problem. They have high expectations of the clinic. They hope that finally, there might be something that can improve their situation. They want to participate with more scientific researches taking place at VUmc because they want to find a solution for MS and all the problems related to it, helping future MS patients.

- Take the time
  Coherent with being taken seriously, patients need some time to tell their story. The patients interviewed admired how much time was invested in them during the screening day. This made them feel valued and important.

- Insight in cognitive functioning
  Patients primary need of their visit is to get insight in their situation and complaints. They want to know if something is wrong, what that is and how it can be improved. The effect on their care pathway is that they have high expectations. They expect a lot from their visit and do not think about what to do after the SOMSCOG visit.

- Overview and information
  Patients need overview of the visit. They want to know the schedule of the visit beforehand, what time the visit starts and ends. Also, they

are interested in knowing beforehand what kind results they could expect and the available treatment options.

▹ Effect of this need for overview before the visit is that they look up a lot of information themselves on the internet. Some patients do this very thoroughly and see themselves as experts on cognition. Other state that they do not look for information on purpose: they are afraid to end up deep down the internet where the horror scenarios are found.

- File transferring and results
  An expressed need of the patients is that they wish to receive a summary of the test results on paper. They often have troubles remembering the information told during the diagnosis consultation, and when they travel back home, questions arise: “What was it again that he told?” Also, more questions arise a while after their visit. Therefore, it would be recommended to have some kind of follow-up where these questions can be asked.

- Furthermore, for patients who are from another hospital, it is important that the files created at the SOMCOG outpatient clinic are transferred to their own doctor. At the moment, this transfer does not go smoothly. Patients and their neurologists really have to keep calling and mailing the VUmc before the files are sent.

▹ An effect of this need for a document after the visit, is that patients are quite disappointed that they do not receive any information concerning their diagnosis on paper. They have troubles with their memory, so they state that they cannot remember everything the neurologists say. They really need something they can read afterwards.

▹ tAnother effect on their patient journey is that there are extra steps to be taken that were not foreseen by the patients. They have to put a lot time and effort in getting the files from VUmc sent to their own hospital. This creates a negative effect on their experience.

Research question 1.1: What are the values and preferences underlying these needs of MS patients? [RM4]

- When you take a look at the needs of the patients, you can see these are quite basic. The values underlying the needs of MS patients are fundamental values i.e. transparency, clarity and honesty.

- Preferences of individual patients were identified, but these varied widely. No recurring pattern could be established. Therefore, preferences are not listed.

Research question 2: What are the needs of health care professionals regarding the care provided during SOMSCOG care giving and how does this impact the care giving? [RM2]

- De needs of the medical professionals differ per discipline. Sometimes these needs interfere with each other’s.

- The needs of healthcare professionals are similar to patients’ needs very fundamental: they need time and resources to do their jobs. What did stand out was that sometimes the needs of different healthcare providers interfere with each other. On the one hand there is a group that stands out for patient care, but on the other hand there are some people that see the added value of scientific research. Most of the time, these two fields can both be served, but sometimes one field gets less attention than wanted. An example is with the neuropsychological testing (NPT). There is limited time, 90 minutes, to perform all the tests. When developing the test battery for this clinic, a deliberate decision has been made to include both patient care related tests and tests that can be used for scientific research. For the ▶

neuropsychologists this test battery feels sparse in terms of patient care. A little bit of extra time (30min) would be sufficient for them to include one or two extra tests and adapt it to the patients' situation: better diagnosis. Impact is not enough information to make a clear diagnosis.

▹ The care giving is not really affected by this as the medical professionals are still able to do their jobs. What is affected most is that some professionals as if they do not provide the best care they can. This is of course not a pleasant feeling.

- Another need of the medical professionals is some structure in the logistic part of the SOMSCOG clinic. This need has been repeated multiple times. One can think of a way to organise the stuff that is needed for a LP and phlebotomy. Also, a clear schedule of who is the supervisor of the clinic in case an LP doesn't go well.

▹ An effect of this lack in structure and suboptimal logistics is that some professionals get a negative feeling towards the clinic. However, when they are in a consultation with a patient, they can easily let go of their negative feelings.

- During the observations of consultations of neurologists and patient it was remarkable that patients often do not have a clear idea why they are at the outpatient clinic. The neurologists ask what their help request is, but most of the time, the patients did not have one ready. A great part of the day is based on finding an answer to this question, so it is important that the help request is formulated properly. And often, the question is not relevant for this outpatient clinic (do I have MS?), or too vague.

- Medical professionals could use better prepared patients. Because when this help request is formulated better, the medical professionals can answer a more relevant question, and this will eventually result in better patient care.

▹This indicates that the care provision can be improved if the formulation of the help request is improved. The care pathway of patients is therefore highly affected by this lack in preparation.

- Remarkable is that some medical professionals feel the need to have a follow up with the patients they see. As this is an outpatient clinic, most of the time they only see the patient just once (the neurologist sees them twice, other professionals only when follow up research required).

▹ The care giving is not affected by this, but some professionals would like to see how the diagnosis has affected the patients.

2.e.2 Research topics answered

Additional research topics that have been formulated for observations are answered here.

How do care professionals work together? [RM1 RM2 RM3]

Overall the interaction between actors runs smoothly. The professionals know where and when to find each other, they communicate sufficiently and in a professional but friendly way.
There were some struggles with the approval of the test battery by the neuropsychologists, but after an evaluation this has improved better. The neuropsychologists did not feel included in the set-up of the SOMSCOG outpatient clinic and they feel as if the patient care is overwhelmed by scientific research. For them, more time is needed for the NPT. However, everybody is impressed in how the SOMSCOG outpatient clinic functions and satisfied with how the patients are helped. They realise that it is an unknown field they are operating

in, and they know that everybody in this process is needed.

The hostesses play an invaluable part of the screening day. Both the patients as the medical professional mentioned how important they are. They guide the patients around and are the go-to person for questions. However, there is a lack of information provision for the hostesses. Patients ask questions that cannot be answered accurately by the hostesses. This could be resolved by an information booklet or guide especially aimed at the hostess. This way, their expertise can be broadened, and they will be able to be an even bigger help during the screening day.

The division of tasks can be improved. The results showed that the MRI researcher and the cognition researcher are responsible for printing the test materials of the NPT's for the neuropsychologists. I would recommend that the neuropsychologists are responsible for their own (printed) test materials. This may mean that some extra materials will have to be purchased, but it seems as if this is an investment that is worth wile. The time it takes now to run back and forth to bring the LLT (location learning test), will make up for it very quickly. Furthermore, it would be wise to free up a couple of hours per week, two to three, for someone to work on improving the outpatient clinic. Points of improvement discussed in the evaluation are still not implemented due to a lack of time.

How is information provided to patients at the SOMSCOG outpatient clinic? And vice versa; how do patients provide information to professionals? [RM1 RM2 RM3 RM4]

Professional to patient

Most of the information patients receive before their visit is provided on paper. Patients receive a large amount of information before visiting the outpatient clinic in different folders, booklets and letters.

During their visit patients receive a schedule of the day on paper. The rest of the information provision is all shared orally.

Even after the diagnosis consultation, patients do not receive their results and diagnosis on paper. For a lot of patients, it would be good to receive the diagnosis on paper. They have trouble understanding and remembering what has been told.

Results of the blood and liquor tests are visible in mijndossier (the online patient record) before the diagnosis consultation. But most patients do not understand what these results mean.

What is remarkable is that during all the observed consultations, there was only one patient that had somebody take notes and one patient that recorded the diagnosis consultation. Taking notes, or recording the consultation should be stimulated. Patients are nervous for the results and suffer from cognitive problems. Therefore, it is very likely that they will remember everything that is being told.

Patient to professional

The information provided to professionals is done both on paper orally. The patients fill out questionnaires before their visit. During their visits, information is shared by telling their story to the care providers. Patients answer a lot of questions. During the day, patients repeat their story a couple of times. Different care providers ask the same questions. Important details are left out at different care providers (due to repetitive questions). Some patients share lots of unimportant details, they seem be glad somebody finally listens to their story.
The hostess is the go-to person for the patient to share the story. Sometimes important details and questions are shared with her and not with the neurologist. It would be good if this information could somehow be shared with the neurologist or medical-researcher. ▶

What is the role of the informal care provider during the visits? [RM1 RM2 RM3 RM4]

First of all, the name informal care provider – mantelzorger – should not be used for people accompanying patients to SOMSCOG outpatient clinic. Both the patients and the so-called informal care providers feel offended by this term. Most of them state that they are not a care provider and patients state that they do not need an informal care provider. It is therefore very important to change the name mantelzorger to naaste (next of kin). The role of the next of kin during the screening day is in the first plate to provide moral support and to make the day less lonely. The next of kin also there to support the patients in sharing their story and to help the patients answer questions during consultations (when needed). Of course, the support is not just during the screening day, also for transport to and from VUmc and during the diagnosis consult.

Sometimes, the informal care provides is too involved and interferes too much when the patient tries to tell his/her story. They over control of the patient. Some patients look relieved when the next of kin take over control, but often the patient does not seem to like this. Overall, it is of added value when someone close comes along with the patient. For support and for an extra point of view on the cognitive problems.

How are the waiting rooms set up? [RM1]

The waiting rooms are as expected in a hospital: stuffy, boring and beige. There are no windows to look outside, no plants. There are some (old) magazines, there are three different kind of chairs and there is a coffee machine. Overall, the atmosphere is outdated, but it does feel rather pleasant. figure 2-22 on page 67 shows how the waiting rooms look like.

Some waiting rooms, at OCT for instance, are very crowded and a bit overwhelming for the patient (especially right after a lumbar puncture).

The standard waiting room where lunch is also served, can also be pretty crowded. This creates a lack of privacy when patients want to discuss something with their companions or want to ask the hostess something (personal) about the day. For some patients, the presence of other people is a nice add-on. They converse with other people waiting and they seem to enjoy this. It makes the day less dull, especially for the companions of the patients. For other patients, the presence of other patients can be overwhelming.

One waiting room, at the MEG, is completely different from the others: it is newly renovated, so it seems. The furniture is up-to-date, there is different lighting which gives is a whole different atmosphere. Much fresher and less stuffy. It would be interesting and worthwhile to try something similar with the waiting room of the SOMSCOG clinic.

2.f Patient journeys

A patient journey is made from the observations and updated with the insights from the interviews with patients. This journey shows the steps the patients take, from the moment of being referred to the outpatient clinic, up until they get back to their regular neurologist. As the SOMSCOG outpatient journey is a large and complex journey, several versions are depicted. figure 2-25 on page 78 shows the total SOMSCOG outpatient clinic journey.

Total SOMSCOG patient journey

The horizontal axis depicts the time line. On the vertical axis the different actors that are directly involved in the care pathway are listed. Beneath that, the emotion line of the patient is shown (in yellow). This line varies per person, but overall, they follow the course shown here. As can be seen, the emotions are quite positive at the start, right after referral. Patients have high hopes and are keen to find a solution for their problems. During the screening day, the line improves as well, the start is messy and with low emotions. During the day the emotions rise and fall, due to fatigue.

In this journey an extra time line is added in light grey. The steps on this time line show steps that are only taken by medical professionals. Patients are not involved in these steps. These steps are added for the completeness, but patients are not included.

The total patient journey is a good tool to see the whole journey, but details are missing in this image. Therefore, two separate journeys are shown. figure 2-24 on page 76 shows the stages **before and after the screening day** (stage 1 and 2 and 4, 5 and 6). Ffigure 2-23 on page 74 shows all the steps of **the screening day** (stage 3).

Before and after screening day journey

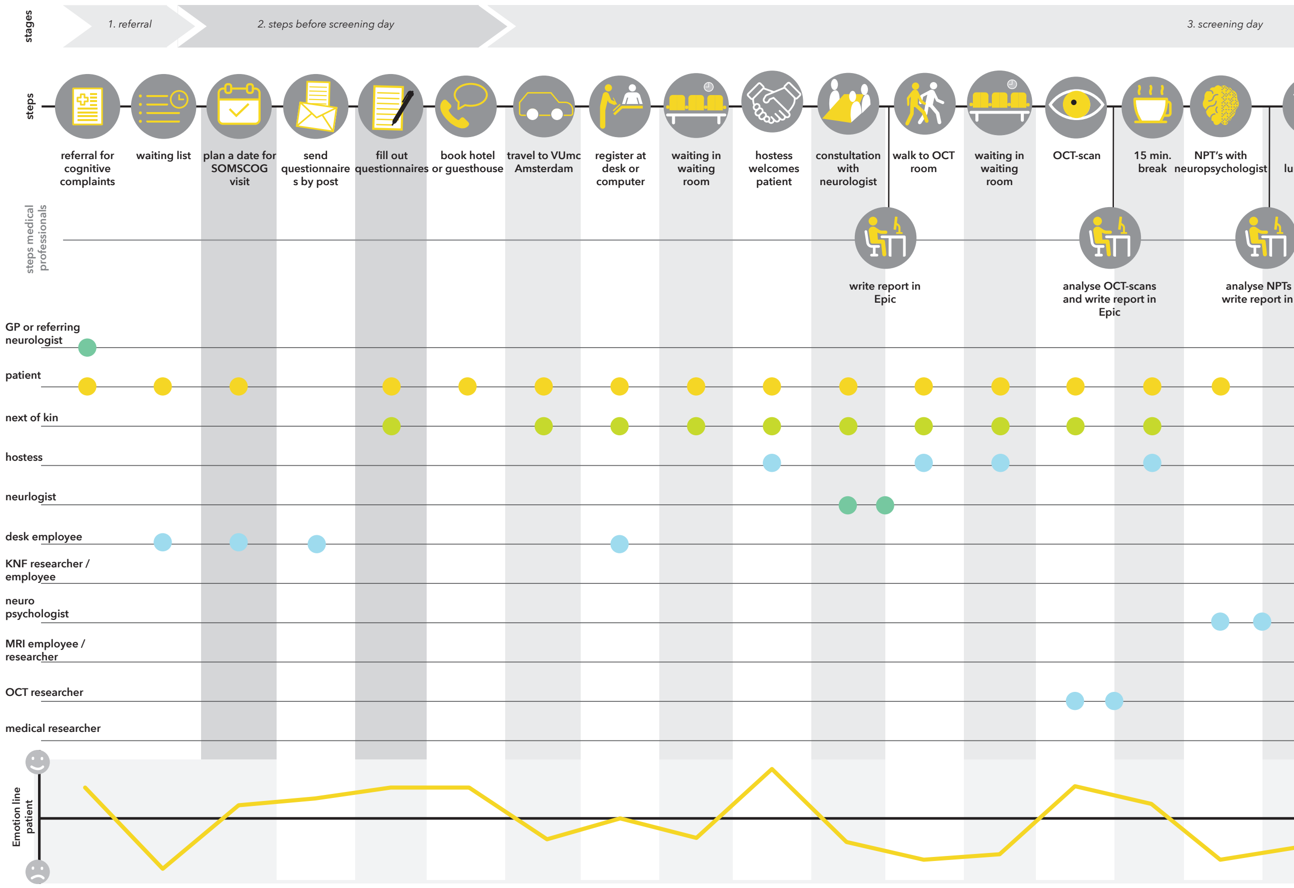
In figure 2-24 on page 76 it is interesting to see how a lack of information affects the emotions of patients. In the first part of the journey, after being referred to VUmc, the patient has to wait a while before a date can be set. The insecurity of how long this takes has a negative effect: patients feel insecure and don’t know when they can go to the outpatient clinic. The same can be seen in the last part of this journey, in stage 5 - diagnosis consultation. After diagnosis, patients expect to receive a document with the results and the diagnosis which they don’t get. This has a negative effect on their emotions and the patient experience. The same thing is the case with files of VUmc not being transferred to a patient’s hospital: this has a negative effect on the patient experience.
However, overall it can be said that patients are reassured by the diagnosis. This is often paired with an upwards (positive) emotion line.
Actors who do not play a part in this part of the journey are omitted from this image for a clearer overview.

Screening day journey

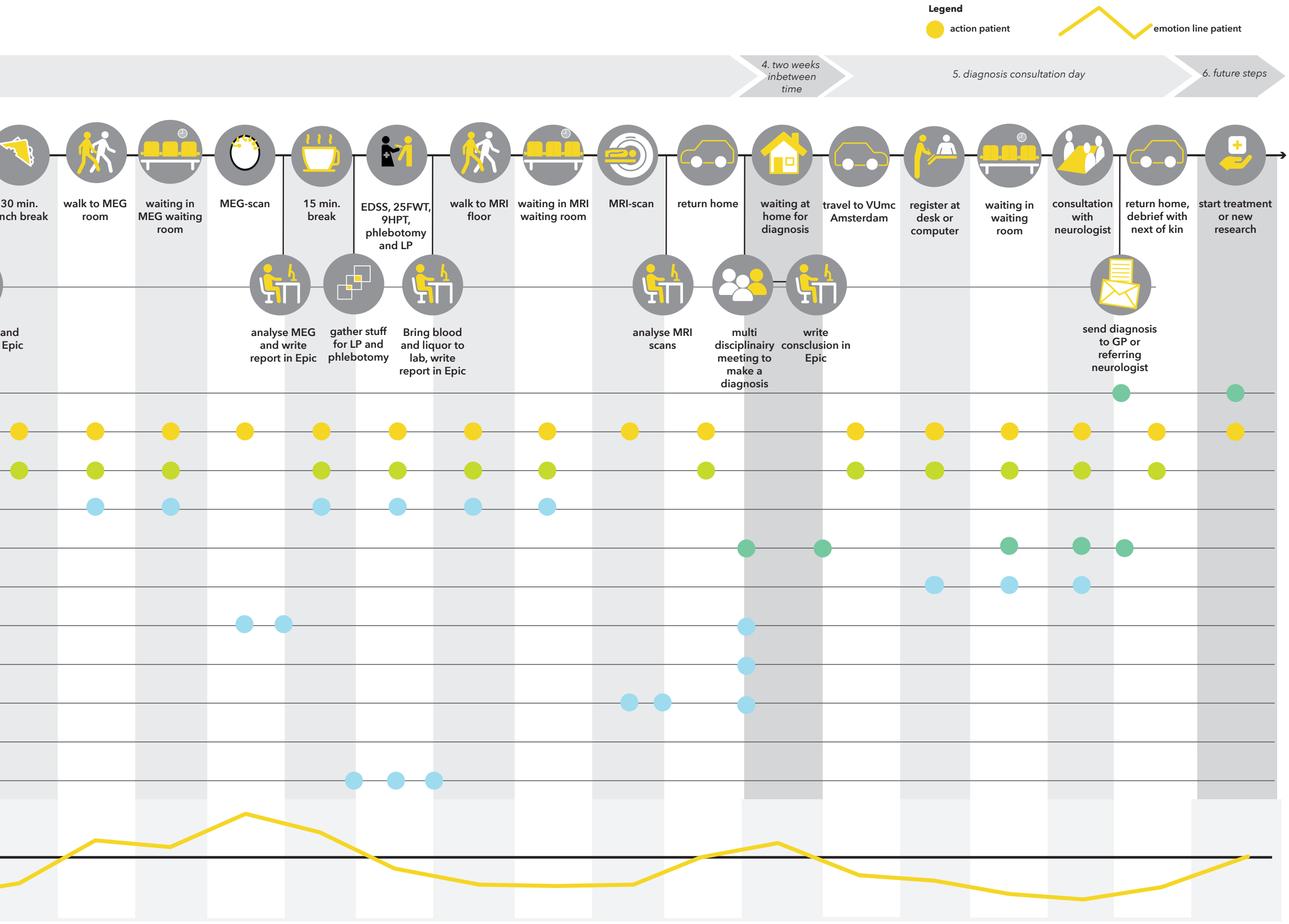
The screening day journey shows the steps taken on the screening day. All the different examinations are depicted but also the steps taken to get to and from VUmc.
Interesting it this journey is the huge positive effect the hostess has. Patients don’t expect someone that leads them around all day. When the hostess introduces herself, patients are relieved.
Overall patients are satisfied with this day, there emotions vary widely but that is mostly due to the fact that it’s long and tiresome. The procedures also play a role in the emotion line: for instance the NPTs are often experienced as heavy and difficult. The LP is something many patients fear, that is shown by the dip in the emotion line.
The GP/referring neurologist is omitted from this image as he does not have a role in this part of the journey. ■

Total patient journey SOMSCOG outpatient clinic

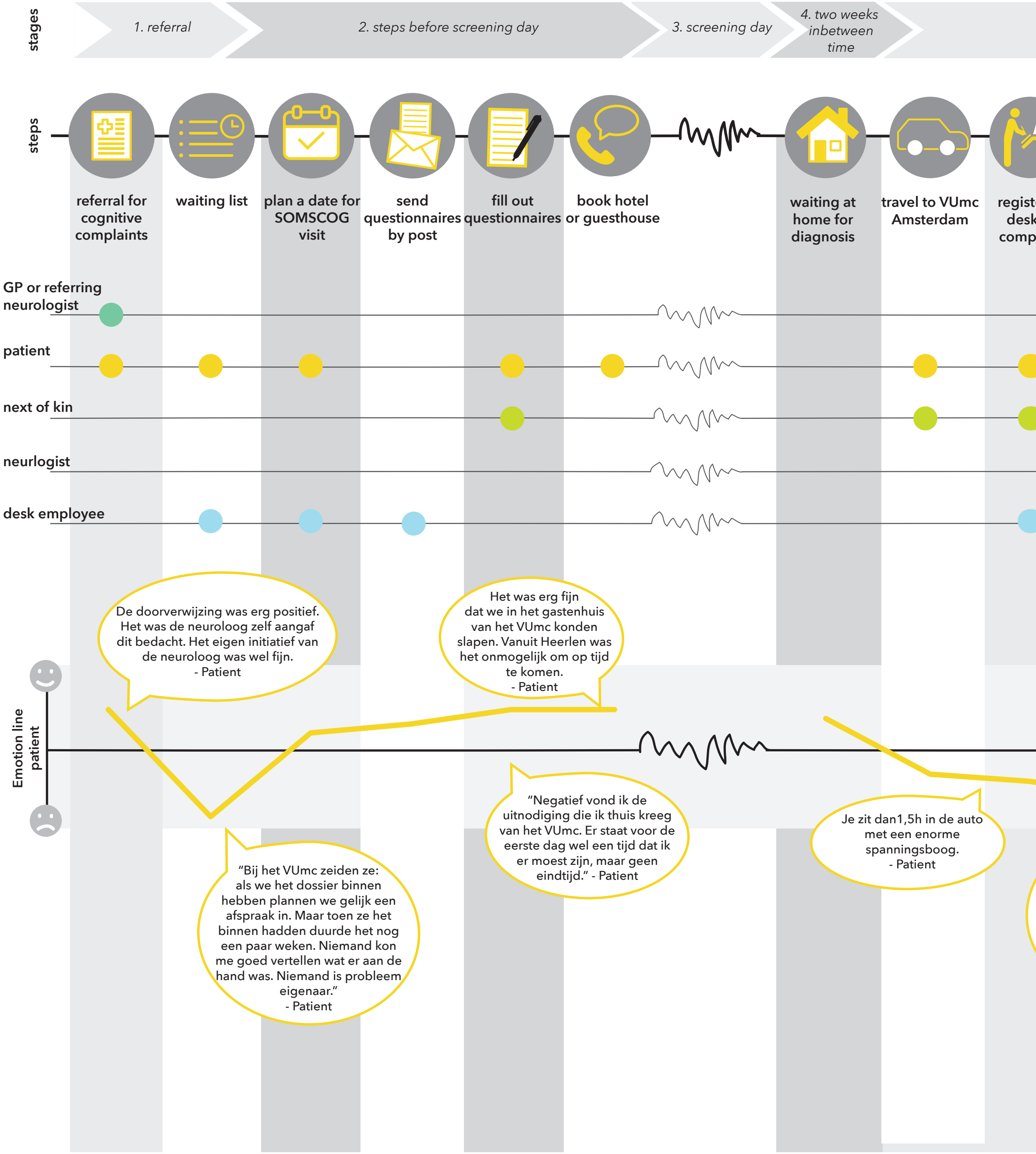
Patient journey SOMSCOG outpatient clinic



▶ ***figure 2-23:*** Complete SOMSCOG outpatient clinic patient journey. The journey is divided in six stages: 1) referral, 2) steps before screening day, 3) screening day, 4) two weeks in between time, 5) diagnosis consultation day, and 6) future steps. The steps in each stage are depicted with images. The yellow line on the bottom of the journey is the emotion line of the patient, it shows how the emotions develop over time.


Legend
action patient
emotion line patient
4. two weeks inbetween time
5. diagnosis consultation day
6. future steps
30 min.
nch break
walk to MEG room
waiting in MEG waiting room
MEG-scan
15 min. break
EDSS, 25FWT, 9HPT, phlebotomy and LP
walk to MRI floor
waiting in MRI waiting room
MRI-scan
return home
waiting at home for diagnosis
travel to VUmc Amsterdam
register at desk or computer
waiting in waiting room
consultation with neurologist
return home, debrief with next of kin
start treatment or new research
and
Epic
analyse MEG and write report in Epic
gather stuff for LP and phlebotomy
Bring blood and liquor to lab, write report in Epic
analyse MRI scans
multi disciplinairy meeting to make a diagnosis
write consclusion in Epic
send diagnosis to GP or referring neurologist

Patient journey SOMSCOG outpatient clinic before & after scree



▸ ***figure 2-24:*** Part one of the patient journey. This image shows the steps before and after the screening day. The yellow line on the bottom of the journey is the emotion line of the patient, it shows how the emotions develop over time. Quotes of patient interviews are added for more details. Quotes above the line are positive quotes; quotes below the emotion line are negative quotes.

ning day

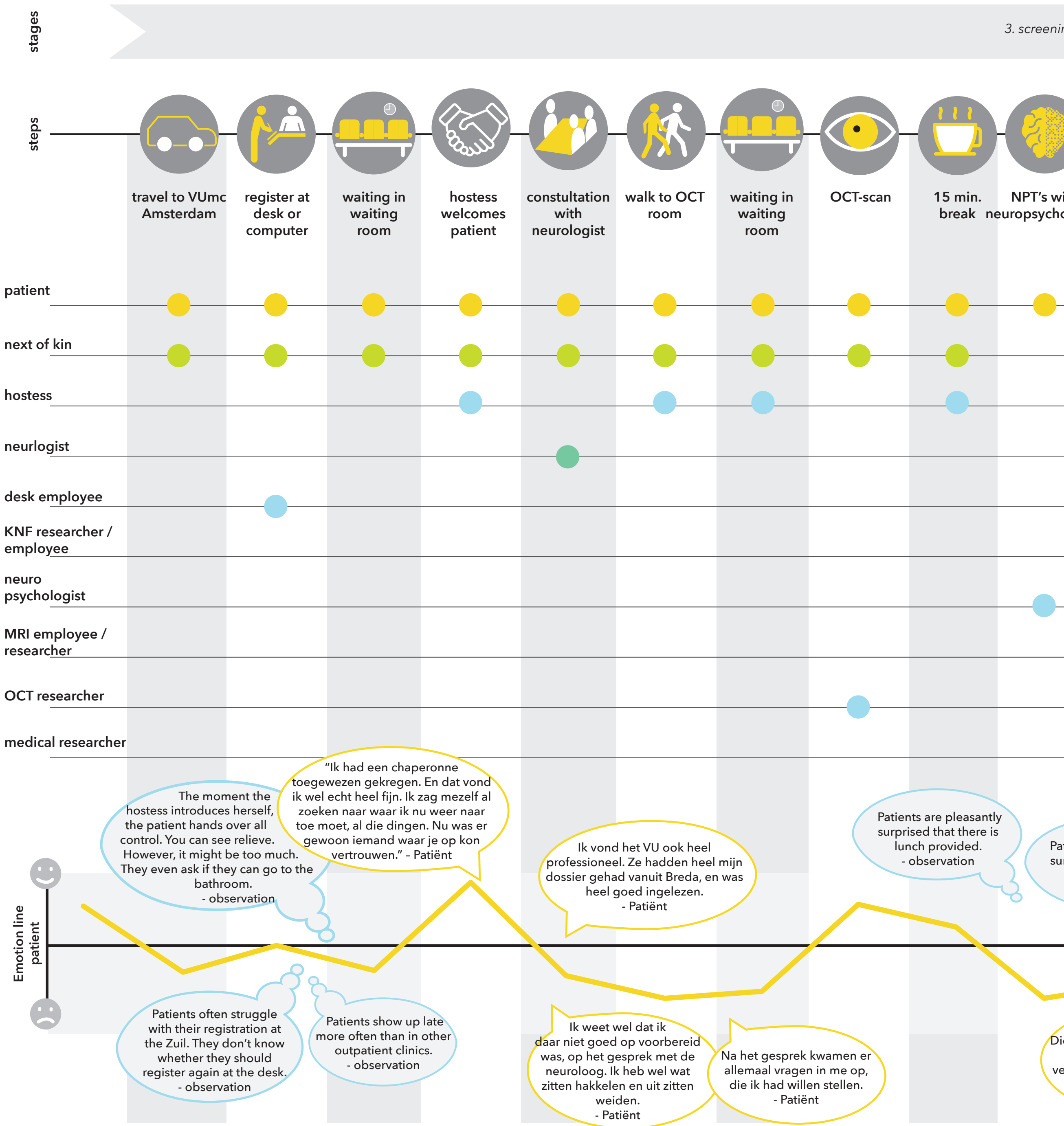
"Door de uitslagen ben ik gerustgesteld."
– Patient.

De wachtruimte nu vind ik heel onduidelijk. Moet je voorin de groene ruimte wachten, of juist achterin bij de tafels? Waar ga je zitten? Is helemaal niet duidelijk. De neuroloog kon me niet vinden, want ik zat achterin.
- Patient

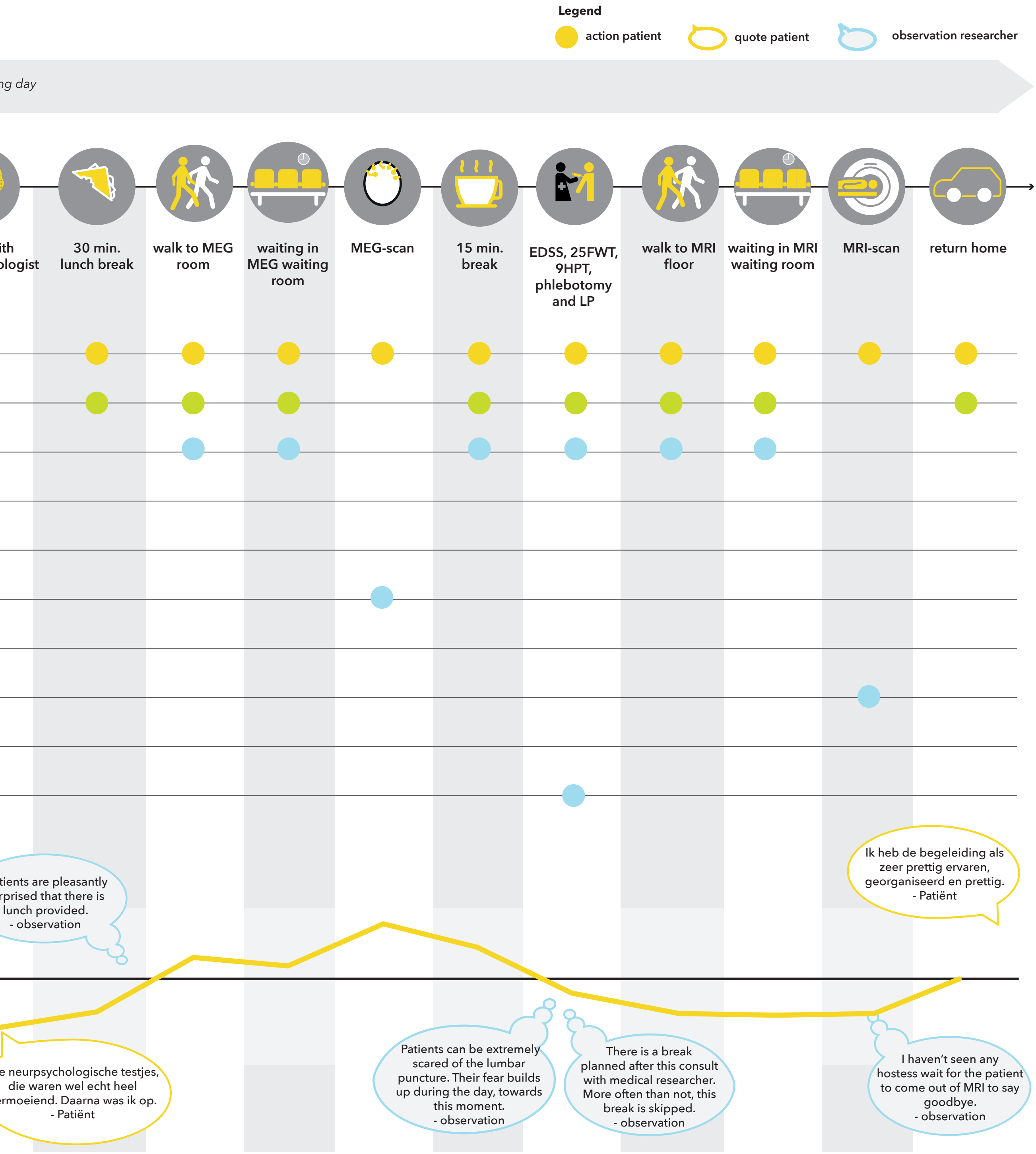
"Ik vind het heel spijtig dat je geen a4tje krijgt met een toelichting op de uitslag. Ik verwacht dan nog een samenvatting mee te krijgen. Want het is er al in de computer."
- Patient

"Het dossier was niet doorgestuurd naar mijn eigen neuroloog. Toen heb ik de MS-verpleegkundige gebeld en die reageerde een beetje geïrriteerd en ze zei dat het gestuurd was. Toen ik bij mijn eigen neuroloog was, waren de dossiers er niet."
– Patient

Patient journey screening day



▶ ***figure 2-25:*** The patient journey of the screening day. This image shows the third stage of the total SOMSCOG journey. It involves all the steps of the screening day. The yellow line on the bottom of the journey is the emotion line of the patient, it shows how the emotions develop over time. Quotes of patient interviews are added for more details. Furthermore, observations from the user research have been added.


Legend
● action patient
quote patient
observation researcher
ng day
ith
ologist
30 min. lunch break
walk to MEG room
waiting in MEG waiting room
MEG-scan
15 min. break
EDSS, 25FWT, 9HPT, phlebotomy and LP
walk to MRI floor
waiting in MRI waiting room
MRI-scan
return home
tients are pleasantly rprised that there is lunch provided. - observation
e neurpsychologische testjes, die waren wel echt heel rmoeiend. Daarna was ik op. - Patiënt
Patients can be extremely scared of the lumbar puncture. Their fear builds up during the day, towards this moment. - observation
There is a break planned after this consult with medical researcher. More often than not, this break is skipped. - observation
Ik heb de begeleiding als zeer prettig ervaren, georganiseerd en prettig. - Patiënt
I haven't seen any hostess wait for the patient to come out of MRI to say goodbye. - observation

SECTION B - DEFINE

This section describes the translation from the literature and user research to a design brief. It shows the eight most important insights which are translated into four design directions. These two combined were the start of a problem definition (made with the use of a WWWWWH). The chapter ends with a design brief, a design goal and interaction visions.

3 DESIGN VISION

The user studies provided important conclusions about the research questions and topics. Eight main insights arose when combining the most important insights from the user and literature studies. These insights served as principles for design directions. The design directions were used to improve the current patient experience of SOMSCOG patients. They also formed the basis of the design goal. Combined with a WWWWWH, a problem definition and a design goal was formulated. Subsequently design criteria and an interaction vision were made to start the ideation phase.

3.a Synthesis

When combining the findings of the literature research and the findings of the user research, eight main insights can be formulated. These insights functioned as the starting point of the design directions. Appendix N shows the underlying findings of the user and literature research.

3.a.1 Insights

The main insights from the user and literature study that were used as inspiration and starting point of the design process are shown here.

1. Supervision and assistance is not always available for medical professionals during the screening day. **Logistics are sometimes chaotic and task division can be improved**. As professionals see the patient only once, **there can be a lack of responsibility amongst the professionals.**

2. **The hostess has a large impact on the screening day.** She makes the patient feel at ease which can result in a lack of initiative on the patient's side. Patients also share intimate information with the hostess.

3. **Patients feel understood at the outpatient clinic.** This **positive patient experience is important for self-**

management. Some patients have high expectations of the diagnosis, while these exactions are often not realised.

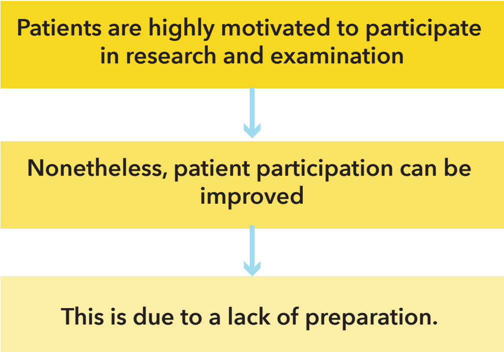
4. The s**creening day is long, tiresome and sometimes overwhelming** for patients. Afterwards, they need a couple of days to recover.

5. The use of **ICT at the outpatient clinic can drastically be improved to stimulate patient engagement.** There is no information available online and Mijndossier does not always work for patients.

6. **Patients are highly motivated to participate with studies and research** and do their best to be a good patient, which is important for good health outcomes.

7. Although patients are motivated, t**hey often have trouble expressing their needs and help request** and are quite slow when performing tests and tasks. This results in a lack of time for professional to finish the protocol.

8. The **information channels from the hospital can be improved:** there is no hierarchy in the documents sent to patients. Patients are not properly prepared for the screening day. The result of these two facts is that a lot of time of the neurologist consultation was spent explaining obvious details to patients.



Patients are highly motivated to participate in research and examination

↓

Nonetheless, patient participation can be improved

↓

This is due to a lack of preparation.

3.a.2 Design directions

Part of the synthesis phase is the formulation of design directions. These directions were made by using the main insights from the previous paragraph. Most of all, the patient journey provided a lot of inspiration for the design directions. The four formulated design directions are:

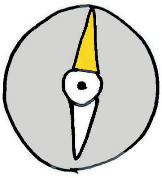
1. **Patient preparation**

The user research showed that patients are often unprepared for their outpatient clinic visit. They feel prepared, but don't quite know what to expect and what is expected from them. An actual preparation phase can be added.

2. **Information and educating**

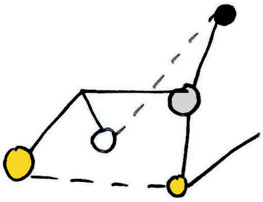
Both patients and professionals can learn a great deal from each other. Starting with the information provision to patients: they receive a lot of information with different sheets of paper, a booklet, a hand out, etc. This is can be chaotic for patients. Also, information after the diagnosis consultation can be improved. This direction offers room for exploration. ▶

3. Morale during the screening day



The screening day is very long and tiresome and the patients' behaviour can lack initiative. As Cesar Milan would say it "they are calm and submissive." For some parts of the screening day this is not the desired state of mind. Especially during consultation with the neurologist, it is important that patients can share their feelings, explain what problems they encounter concerning their cognitive symptoms and can ask questions. Observations showed that there is plenty of room for their input, but patients don't take the opportunity. This moral during the screening day can be explored and is an interesting direction for ideation.

4. Infrastructure around SOMSCOG journey

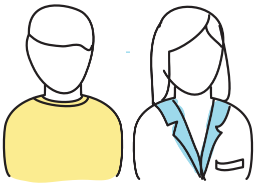


The setup of the day is very well thought through. However, there are still points of improvement possible. Especially the role of the hostess should be explored, also the mode of communication of medical professionals and shared decision-making implementation are interesting directions to explore.

3.a.3 WWWWWH

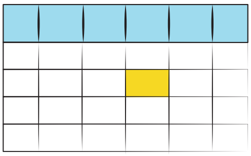
A WWWWWH helped to understand the current situation, to detect a bigger problem behind the issues arisen from the patient journey. A WWWWWH is a kind of problem analysis that can be one of the first steps in a design process. The aim is to a thorough understanding of the problem, its stakeholders and the facts and values involved [78]. The problem is deconstructed in figure 3-26, and one has to asks oneself questions about stakeholders, facts, etc. This systematic approach helped to review the project assignment and to set priorities. ■

WHO?



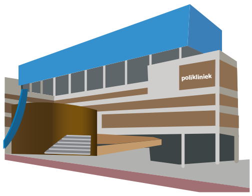
All the actors participating in the patient journey are involved in this problem. But the ones that are really affected are: patient, neurologist, partner or next of kin and the MDM participants

WHEN?



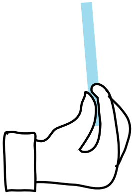
This has the most impact during the first consultation with the neurologist, when the help request should be articulated.

WHERE?



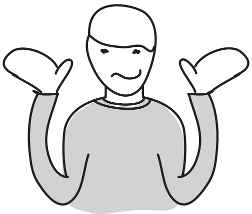
At the VUmc second opinion MS and cognition outpatient clinic.

WHAT?



Patients tend to have little or no preparation before visiting SOMSCOG outpatient clinic. Currently there is a booklet with information sent to the patient before their visit. It includes tips and tricks. There is no importance hierarchy in which parts needs more emphasis or attention than other parts

WHY?



The lack of clearly structured information results in patients showing up late, without a clear help request or an inappropriate help request. Patients behave passively, they provide little input in the consultations with medical professionals. It is also difficult for them to make a deliberate decision concerning their treatment options

HOW?

This problem is tried to be solved by asking more questions during consultations to help the patient formulate a help request. Also, extra information is provided to the patient to distress the importance of being on time. Furthermore, multiple treatment options are presented to the patients for them to have a choice in what is suitable for them. And at last, medical professionals explain things multiple times, in different ways hoping and trying to make patients understand the things they say.

Problem definition: There is lack of preparation before visiting the SOMSCOG outpatient clinic.

▶ ***figure 3-26:*** WWWWWH: the problems deconstructed in six questions. (1) who are the actors or stakeholder? (2) when does the problem occur? (3) where is it this happening? (4) what is the problem? (5) why is it a problem? (6) how has been tried to solve this problem?

3.b Design brief

A design brief was created to give the design phase direction and to set boundaries for this part of the project. The design brief provides outlines of the deliverables and scope of the project.

3.b.1 Design goal

The extensive literature research, user research, insights and a WWWWWH, are translated a design goal had been formulated. The design goal for this project is:

I want to create a tool that will help patients prepare to for their hospital visit, that will guide them through the day and provide an overview of the whole journey. This tool should improve the overall patient experience and make a positive impact on the patient's quality of life.

Rationale behind the design goal

The design should change how the patient behaves during the consultation with the neurologist: from being passive and timid, to be a more active and involved patient. It should help the patient to express their worries and problems and help them formulate their help request.
Looking at the insights and design directions, it shows that the lack of preparation has a big influence on the screening day. Improving the patients' preparation will therefore positively impact the patient journey. It affects the patient journey multiple times. Also, when patients can prepare themselves properly, the feeling of being in control can be improved, hopefully making them less submissive.

Boundaries

This design goal narrowed down the scope of ideation: from trying to solve problems on the whole patient journey, towards the start of the patient journey: the preparation phase and the first consultation. On the one hand, this helped to keep a focus during ideation and conceptualisation phase. On the other hand, it did reveal new challenges: patients might now be asked to prepare the consultation with the neurologist - something they have never done before - for a hospital which they might have never visited before.
That means that the tool should be inviting to use, look friendly but also professional as it could be one of the first things the patients will see from VUmc. It is also desired that the tool is tangible and portable: the patient can use it before their visit, and preferably also during the screening day. But it should not interfere with the examinations during the day and it cannot cost too much energy. As the screening day is already long and tiresome, an energy consuming tool is not desired.

▶ ***figure 3-27:*** Simplified patient journey

3.b.2 Criteria

Next to the design goal five important criteria are formulated. These criteria are organised based on importance. Number 1and 2 are most important. Followed by number 3 and 4. The fifth criteria is a bonus criterion, it would be nice if this could be achieved. The design must…

1. … Help with preparation of SOMSCOG visit

2. … Improve patient participation during consultation

3. … Stimulate self-reflection patient

4. … Offer guidance during hospital visit

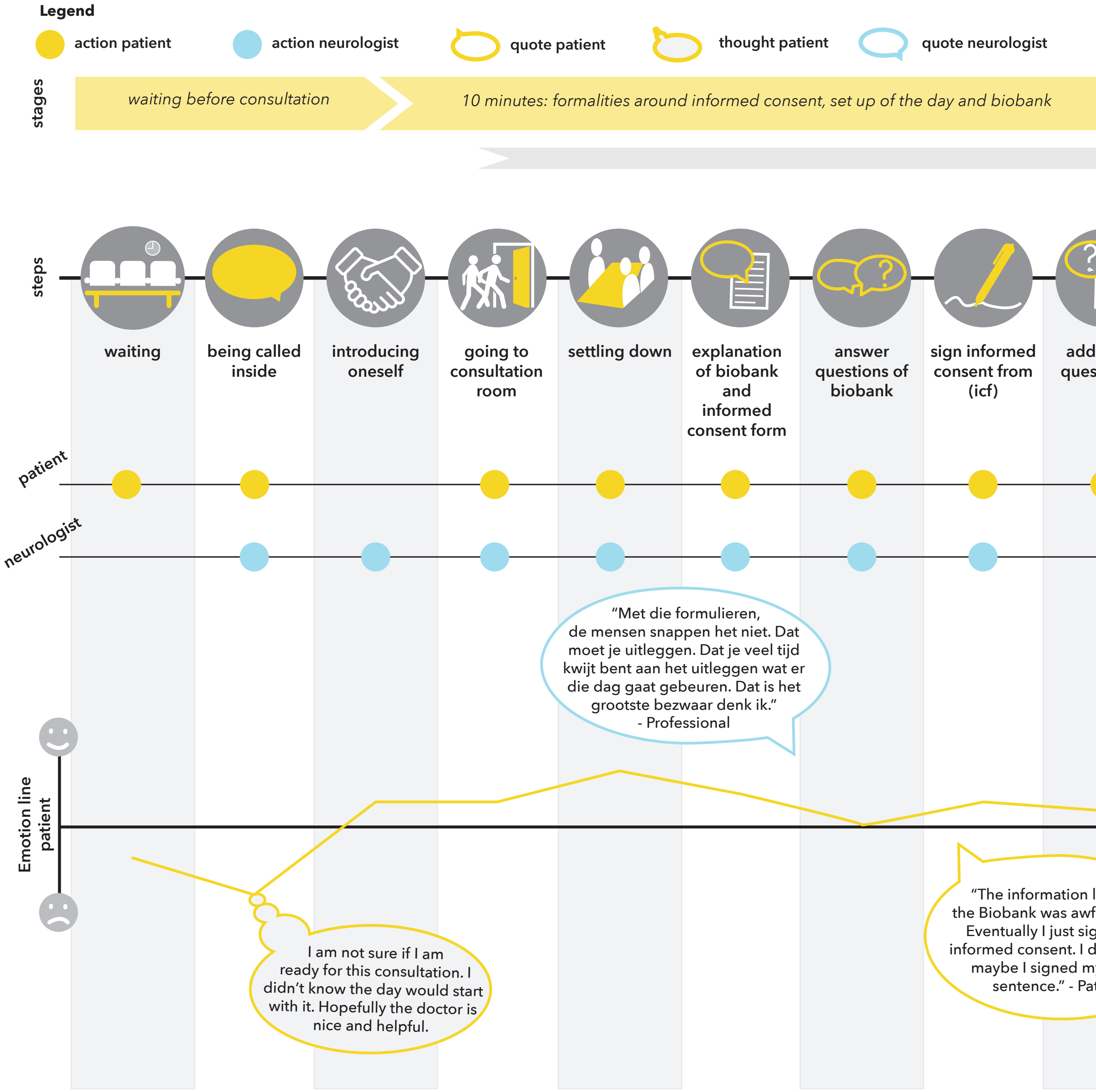
5. … Stimulate co-operation of next of kin

In appendix Q - Requirements, some other requirements are shown which formed the basis of these criteria.

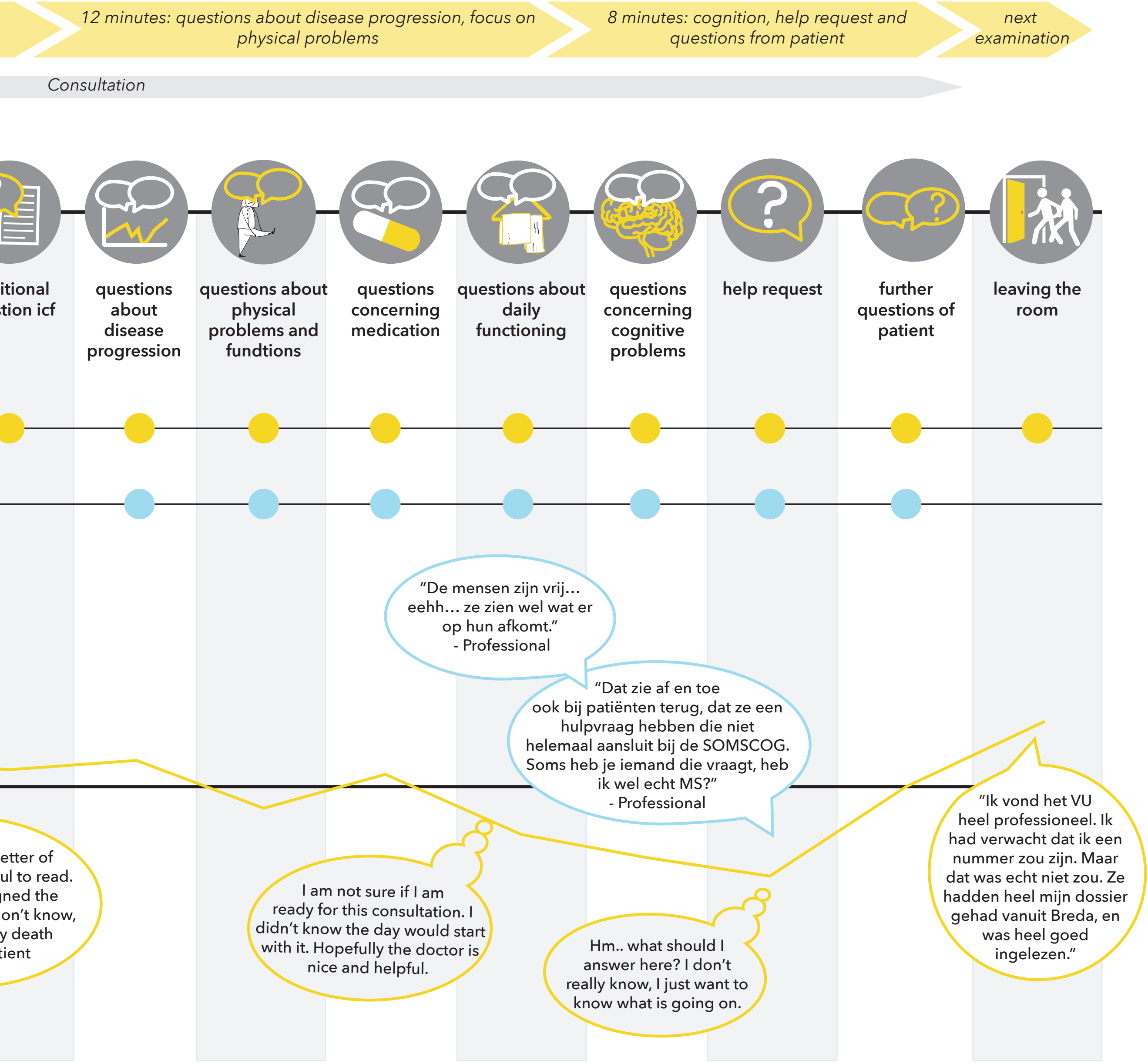
3.b.3 Consultation journey

On the next page, the current patient journey of a consultation with a neurologist is shown in figure 3-28. In this consultation three stages can be identified: 1) formalities around biobank and informed consent form, 2) question about disease progression and physical state, 3) questions about cognition and the help request.

As can be seen in figure 3-28, the consultation journey already starts in the waiting room. Here, the patient is quite nervous - which is shown with the negative emotion line. Once the neurologist has introduced her-/himself, the patient calms down, shown by the upwards emotion line. During question around the biobank, the emotion of the patient is neutral. When going into detail about their disease and especially when discussing their cognitive problems, the emotions go downwards. After the help request has been shared, the emotions turn more positive. This positive emotion at the end of the conversation is due to the fact that patients feel understood and heard by the neurologist. ■



▸ ***figure 3-28:*** Patient journey of a consultation with neurologist on screening day of SOMSCOG outpatient clinic. The steps and interactions of patients (yellow dots) and neurologist (blue dots) are shown. The emotion line in the bottom of the image shows the emotions of patients. The yellow text boxes are thoughts and quotes from patients. The blue text boxes are quotes from neurologists.



12 minutes: questions about disease progression, focus on physical problems

8 minutes: cognition, help request and questions from patient

next examination

Consultation

itional tion icf

questions about disease progression

questions about physical problems and fundtions

questions concerning medication

questions about daily functioning

questions concerning cognitive problems

help request

further questions of patient

leaving the room

"De mensen zijn vrij… eehh… ze zien wel wat er op hun afkomt."
- Professional

"Dat zie af en toe ook bij patiënten terug, dat ze een hulpvraag hebben die niet helemaal aansluit bij de SOMSCOG. Soms heb je iemand die vraagt, heb ik wel echt MS?"
- Professional

etter of ul to read. gned the on't know, y death tient

I am not sure if I am ready for this consultation. I didn't know the day would start with it. Hopefully the doctor is nice and helpful.

Hm.. what should I answer here? I don't really know, I just want to know what is going on.

"Ik vond het VU heel professioneel. Ik had verwacht dat ik een nummer zou zijn. Maar dat was echt niet zou. Ze hadden heel mijn dossier gehad vanuit Breda, en was heel goed ingelezen."

3.c Interaction

The interaction of the current situation has been analysed during the user research. Below take aways of the current and desired situation are listed. Also, interaction qualities representing these situations are listed.

Current situation

- Questioning by neurologist
- Not much input from patient
- Patient seems overwhelmed by the day. Did not expect the consultation with neurologist at the beginning of the day.
- Passive patient - does not know what to expect from this conversation

The current interactions can be identified with the following qualities:

1. insecure
2. distant
3. tense
4. reserved
5. submissive
6. passive

Desired situation

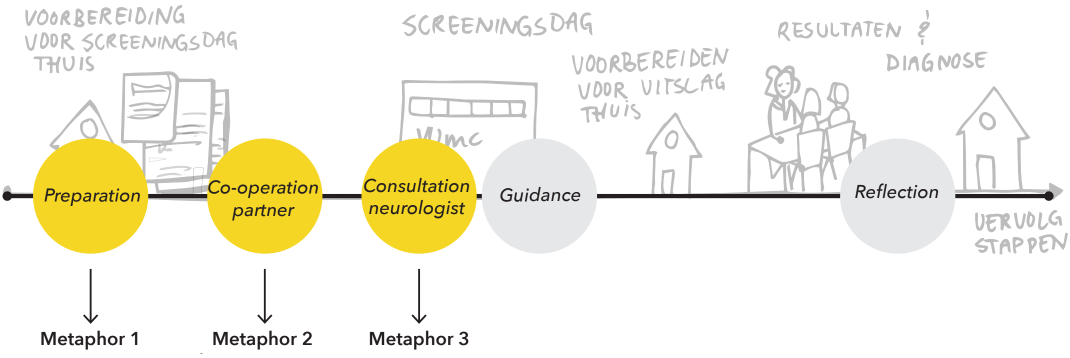
- Engaged patient
- Prepared patient, one that asks questions
- A conversation, not an oral questionnaire
- Active patient
- Open consultation

Interaction qualities that connect the desired situation and the design goal are:

1. open
2. explorative
3. safe
4. trusted

3.c.1 Interaction visions

As the criteria might show, the tool that will be designed is multifaceted: it will affect the patient journey several times. These interactions cannot be grasped by a single interaction vision. Nonetheless, the desired qualities are applicable in each situation. The desired qualities can be captured in three metaphors. The first metaphor envisions the preparation of the patient. The second metaphor visualises the co-operation of the next of kin. The third metaphor should envision the patient participation during consultation.



▶ ***figure 3-29:*** Simplified patient journey with touch points derived from the design criteria and the metaphors of the interaction visions.

Metaphor 1. Intimate conversation with close friend

The metaphor that grasps the interaction is the experience of having an intimate conversation with a close friend. A friend that asks the right questions and stimulates you to contemplate and approach topics step-by step. This friend also makes you curious.

The tool must therefore be friendly and reassuring. It should help you along the way, not disclosing everything all at once, but gradually. With a conversation, one does not tell everything at once. But when discussing things, the information is shared in little chunks.

Metaphor 2. Bedtime sleep over conversation in the dark

The metaphor envisioning the interaction between patient and partner should feel like that one conversation with a friend during a sleep over. When the lights are already out, you want to go to sleep, but finally you can discuss those subjects you were hesitating to talk about before. In the safety of the darkness, without having to look at each other, you feel safe to open up. Similar to the first metaphor, full disclosure does not happen at once, step-by-step.

Metaphor 3. Guess who

The interaction between the patient, tool and neurologist can be explained by the following metaphor.

It is like “guess who”, where both participants want to get something from the other. They are designated to cooperate and gather knowledge about something. For the neurologist it is about getting the desired information about the help request and problems. The patient wants answers to his questions, and insight in the plan of the day. The information is shared in turns, and by using a game as a mean, both get to know each other without having to look at each other all the time. ■

SECTION C - DESIGN

After the design brief was created, the design directions were inspected, and the ideas reviewed. This ideation and concept development phase was an iterative process: after progressing a few steps, regression of a couple of steps took place. This process included various design decision, some were made based on the designer’s intuition, others were inspired by patients and experts evaluations. This section describes this iterative process: from the design brief, through ideation and conceptualisation phases towards the final design. In the last chapter of this section, the result of this process is presented: the final design.

4 IDEATION

The ideation and conceptualisation phase consisted of multiple iterations. The aim of the ideation phase was to translate the design opportunities identified in the patient journey and the design directions into concepts.
The patient journey provided multiple design opportunities. These opportunities were combined with the insights of literature and user research and moulded into the four design directions. Combined with the design goal, this was the starting point for ideation.
In the ideation phase, the design directions mentioned in chapter 4 were explored. The "How-to" methodology was applied to generate ideas. These were clustered and categorised in small wins, medium wins, large wins and extra-large wins to make sure to identify ideas of the same size. This way, the small wins that are easy to solve are separated from the larger wins for which a designer is needed. Finally, one category – the large wins – were chosen for fur further development.

4.a How to's

When examining the patient journey, six how to's were made to start the ideation process. Based on the opportunities from the patient journey, the insights and de design directions. How to's (H2's) are problem statements which start with: "How to…". These statements are most helpful at the start of idea generation. The problems are reformulated in different ways, resulting in easy idea generation [79].
The H2's used are listed below.

How to How to prepare/make people (be) prepare(d) for a hospital visit?

How to activate people during a hospital visit?

How to make people in charge of their SOMSCOG/hospital visit?

How to make people come on time?

How to activate people during a consult with a neurologist?

How to help people make a(n) (informed) decision about their treatment or research?

With the help of these H2's and while keeping the patient journey in mind, 150 ideas were generated (see appendix O – Ideas for an overview of ideas).

These ideas were clustered multiple times (appendix P shows the clusters).
Two different sessions with design students and graduates provided some guiding in how to continue with the ideas. These sessions and the evolving design implications are described in appendix P – reviewing the clusters.

4.b Small – medium – large – extra large clusters

After these two sessions, all the clusters and 150 ideas were looked at again. The promising ones were selected. Selection was based on the criteria from the design brief and appendix R, combined with likeability, feasibility and relevance of each idea.
The question asked when selecting ideas was: "What has the most potential to solve a problem". One concept could solve more than one problem.

The ideas (and corresponding clusters) were divided into four categories, based on the extent of their impact, importance and the amount of work needed to implement them.
The categories are:

Small wins, medium wins, large wins and extra-large wins. The ideas in these four categories are showed in Appendix J – S-M-L-XL ideas. This appendix also shows some of the disregarded ideas.

1. Small

Quick wins, are easy changes that can be made immediately without the help of a designer. The VUmc can implement these ideas on their own. There are no changes to the current infrastructure or process needed.

2. Medium

Redesigns of current information and system. A designer could help to realise these changes, but it is not necessary. To implement these ideas, more investment of energy is needed than with the small wins.
With these ideas, something will be added to the existing process. It is important to realise that some thinking has to be done to form these ideas into changes. This can and should be done with the help of external parties. The SOMSCOG department cannot do this on their own.

3. Large

These idea directions were translated into concepts and led to new designs. The help of a designer is needed to create these designs. This was the décor in which improvement possibilities were explored.

4. Extra Large

This cluster forms the future scenario, a vision for the future. The tool that I designed, will bring us closer to this situation, but it will take time, effort, and small steps to get to this ultimate scenario.

Design implications

- The first two categories were not explored in this project, as these are small changes for which a designer is not needed.
- The last category, extra-large changes, is a futuristic scenario. This is also not in the scope of this project. So, the category that was further explored in the conceptualisation phase is Large wins. ■

5 CONCEPTUALISATION

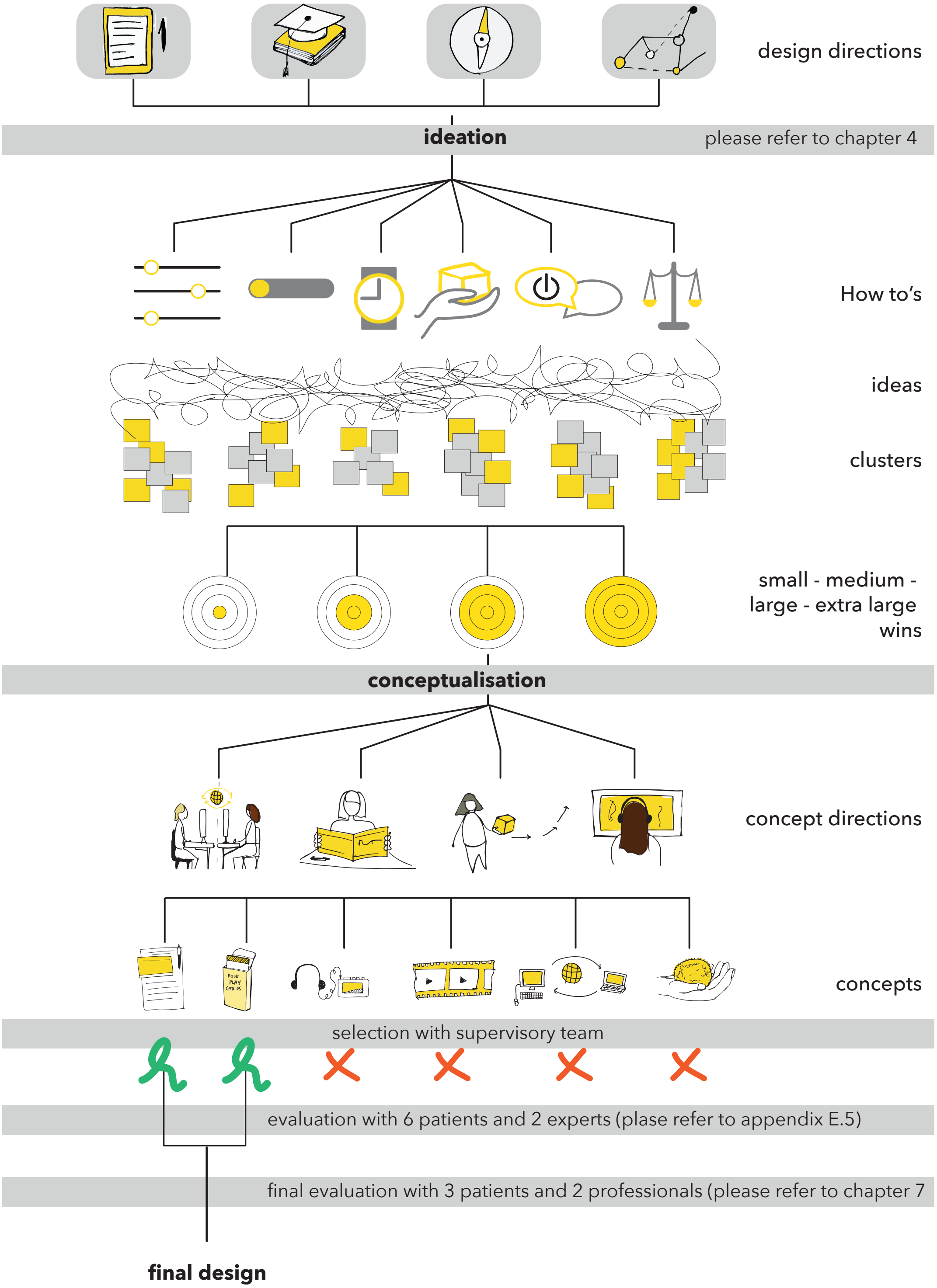
The chapter design vision set the boundaries for the design process. An overview of the ideation and conceptualisation process is visualised in figure 5-31.

From the ideation phase, the concept direction of the Large wins category was further explored in the conceptualisation phase. The aim of this was to derive concepts from the ideas. This chapter describes the process from concept direction to detailing the concept.

Six concepts were developed and together with the supervisory team two were selected to continue with. These concepts were chosen for their relevance and impact the patient journey. The two selected concepts were developed in different iterations and then evaluated with a total of 6 patients, two experts and presented to a group of medical professionals at VUmc. These evaluations led to combining the two concepts into one final design. The final evaluation sessions with 3 patients and two medical professionals led to the final design which is shown in the next chapter. The evaluation can be found in chapter 8.

This chapter describes the process and choices that were made when going from the large category to the final design.

▶ **figure 5-30:** Trains stopped running: idea selection took place in a McDonalds in Breukelen.



▶ ***figure 5-31:*** Visualisation overview of design phase of this project.

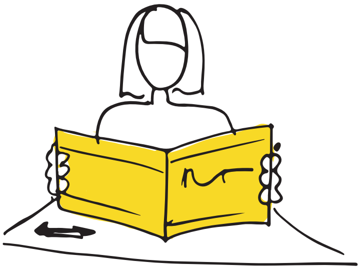
5.a From concept directions to concepts

The ideas and clusters from the large wins categories were further explored and elaborated. This resulted in four concept directions. The first rough concepts and ideas of these iterations can be seen in Appendix S – Concept directions.

1// Online sharing platform

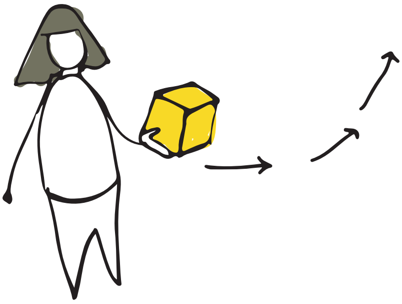
An online platform where patients can share their experiences concerning the SOMSCOG outpatient clinic. Tips can be shared, questions can be asked.

2// Sensitising as preparation for screeningday



A sensitising phase to prepare patients for their visit of the screeningday. By sensitising them beforehand, patients know what to expect and will have a smoother experience.

3// Tangible guiding during screeningday



During the day, some extra tangible guiding can provide a more smooth experience. By giving something tangilbe, patients might get a feeling of being in control.

4// Audiovisual preparation and information methods

By providing the inormation through multiple channels (and stimuli), patients might remember the infomation better. Audio and video can be used to give information to patients.

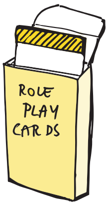
▶ ***figure 5-32:*** Four concept directions, derived from the Large Wins.

These concept directions were further explored; six concepts were the result of this process. Ffigure 5-33 below shows a short summary of these concepts. In appendix T- Concepts, the full explanation of each concept can be found. ■

c1// Preparation book

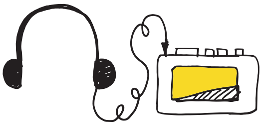
This concept is basically a sensitising booklet. The booklet is sent to the patient as preparation for the SOMSCOG visit. It will helpformulate help request, manage expectations and provide information.

c2// Role play cards



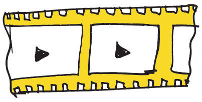
The main key of this concept is a playful way to prepare for the SOMSCOG visit. This game is meant to be played by two people. The patient and its partner or other next of kin who accompanies her visit.

c3// SOMSCOG podcast



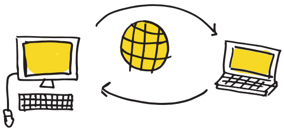
The SOMSCOG podcast is a five-episode podcast with everything a patient needs and wants to know about the SOMSCOG. It introduces the doctors, gives insights in the examinations and provides an overview of the day.

c4// The collection



The collection is a collection of instruction videos that explain what can be expected from a SOMSCOG visit. There are several short movies, of maximum 3 minutes each.

c5// Experience experts



To help patient get a grip on their SOMSCOG visit, it would be useful to make use of experience experts. This online platform provides this opportunity. Patient can get in touch with other patients

c6// Bollie

Bollie gives the patient personal guidance during the SOMSCOG visit. It is a small fluffy electronic ball that vibrates and is able to talk. Bollie can ask questions and can tell fun facts during the hospital visit.

▸ ***figure 5-33:*** The six concepts which were the results of the conceptualisation process. These concepts were evaluated and two were chosen to continue with.

5.b Concept selection

Together with the supervisory team of this project, two concepts were selected to continue with: Preparation book and Roleplay cards.

The selection was made based on the five criteria from the design brief, combined with the impact on the patient journey and financial feasibility. figure 5-34 shows the concepts with a rating for each criterion. Appendix U shows an overview of all the concepts with the rating of each criteria and an estimation of the financial investments needed to implement each concept.

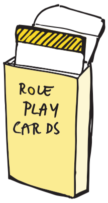
As can be seen in figure 5-34, the Preparation book and the Roleplay have different scores on the criteria. Where the Preparation book lacks in score on the co-operation scale, the Roleplay cards complements the score.

Combining the Preparation book and Roleplay cards resulted in an all-round concept with high potential. That is why these concepts were selected for continuation of development.
This was done in an iterative process, of which some important steps are explained in the next paragraph.

c1// Preparation book

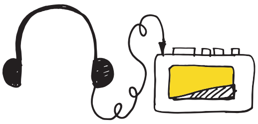
Preparation	●●●
Patient participation	●●●
Self-reflection	●●○
Guidance	●●●
Partner cooperation	●○○

c2// Role play cards



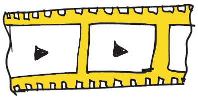
Preparation	●●○
Patient participation	●●○
Self-reflection	●○○
Guidance	○○○
Partner cooperation	●●●

c3// SOMSCOG podcast



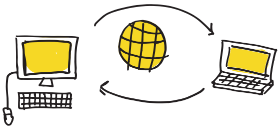
Preparation	●●○
Patient participation	●○○
Self-reflection	○○○
Guidance	●○○
Partner cooperation	●○○

c4// The collection



Preparation	●●○
Patient participation	●○○
Self-reflection	○○○
Guidance	○○○
Partner cooperation	●○○

c5// Experience experts



Preparation	●●○
Patient participation	●●○
Self-reflection	●○○
Guidance	○○○
Partner cooperation	●○○

c6// Bollie

Preparation	●○○
Patient participation	●○○
Self-reflection	●○○
Guidance	●●●
Partner cooperation	○○○

▶ ***figure 5-34:*** Concept selection with the design criteria used as selection criteria

5.b.1 The preparation book

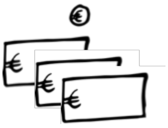
This concept is basically a sensitising booklet. The booklet is sent to the patient as preparation for the SOMSCOG visit.
Things that should be included in this booklet:

Example question that will be asked

- Help to formulate help request
- What does the patient expect?
- What is expected of the patient
- What are the problems the patient encounters?
- Schedule

Patient journey

This concept intervenes multiple times in the patient journey. As this preparation book is used before each visit of the outpatient clinic (before the screening day(s) and result consultation) and during each visit, it has a lot of impact on the patient journey.

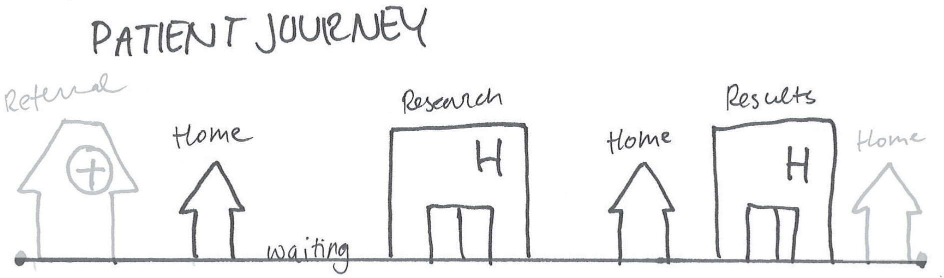


Investments

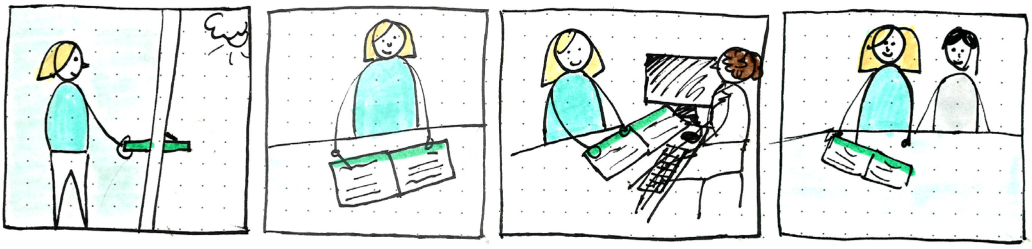
Because this concept is analogue, the costs mostly consist of printing costs. This can be done at VUmc print shop. Of course, there are also investments needed to develop this concept.

Pros and cons

+ can be used at different clinic
+ easily adaptable when SOMSCOG changes
+ possibility to make an app version for whole neurology department
- Relies on self-motivation of patient
- In this concept, partner is not included ►



► ***figure 5-35:*** Impact and touch points of the preparation book on the simplified patient journey



Het pakketje met een boekje wordt naar de patiënt thuis gestuurd. Het kan haar helpen met voorbereiden op het bezoek aan de SOMSCOG.

De patiënt neemt de informatie door en beantwoordt de vragen die in het boekje staan.

Tijdens het gesprek met de neuroloog worden de voorbereide vragen gesteld. Ook schrijft de patiënt gedurende de dag dingen op in het boekje.

Voor het uitslaggesprek pakt de patient het boekje er weer bij. Er staan wat vragen in die de patiënt beantwoordt, ter voorbereiding. Ook worden mogelijke behandelingen in het boekje uitgelegd.

► ***figure 5-36:*** Scenario of how the preparation book is used

5.b.2 Role play cards

The main key of this concept is a playful way to prepare for the SOMSCOG visit. This game is meant to be played by two people. The patient and its partner or other next of kin who accompanies her visit.

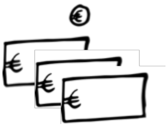
This game stimulates the cooperation of the partner. This might be helpful for a more pleasant visit.

Patient journey

The Role play cards are only used in the beginning of the patient journey, after referral before going to the screening day. The impact on the patient's journey is therefore small. However, when combined with the Preparation book, the impact on the journey is increased and the criteria

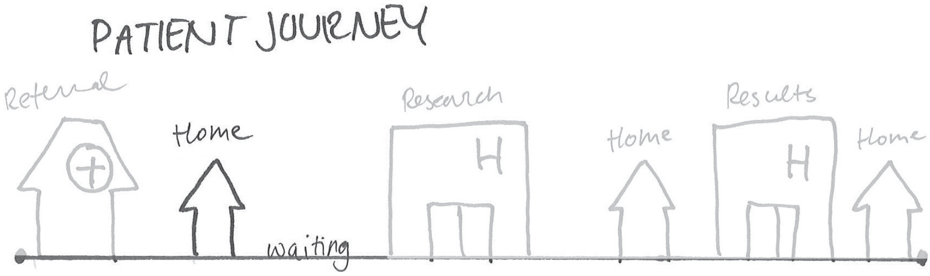
Investments

The investments for this concept are limited. Most of the costs are in the development and printing of the cards.

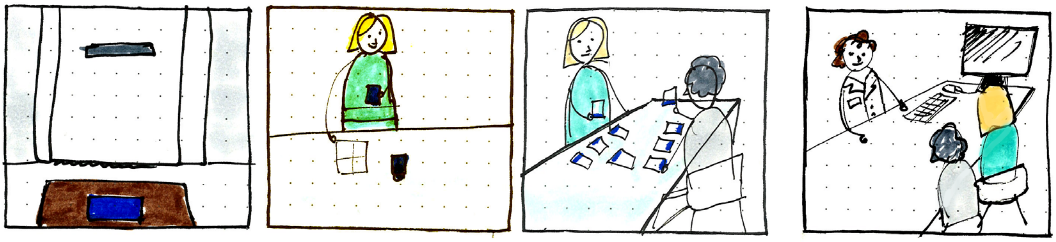


Pros and cons

- \+ inclusion of partner makes preparation a responsibility of two people
- \+ low threshold to prepare
- \- no room for exploration
- \- single people need to ask somebody to help



▶ **figure 5-37:** Impact and touch points of the role-play cards on the simplified patient journey



Het pakketje met het kaartspel wordt naar de patiënt thuis gestuurd.

De patiënt leest de spelregels en instructies door voordat ze begint met het spelen van het spel.

De patiënt en partner of andere naaste spelen het spel. Door te spelen oefenen ze alvast op vragen en het gesprek met de neuroloog. Om de beurt wisselen ze van rol.

Tijdens het gesprek met de neuroloog weet zowel de patiënt als de partner wat ze kunnen verwachten. Doordat de partner mee geoefend heeft, kan hij ook inspringen als de patënt het even niet weet.

▶ **figure 5-38:** Scenario of how the role-play cards are used

5.c Concept development

The preparation book and roleplay cards were developed into more substantial concepts. This process was done in multiple steps and iterations. These iterations consisted of an explorative creative session with design students, evaluations with patients and consultations with two experts.
These iterations are described shortly in the next few paragraphs. The aim of these iteration was to further develop the preparation book and roleplay cards into viable concepts.
The main design implications of these iterations are mentioned here. For the full insights of the sessions, please refer to appendix E6 and E7.

5.c.1 Exploration session with design students

To explore the content and function of the role play cards, a creative session was held.

Method

Aim of the creative session was to come up with substantial ideas of how the roleplay cards could be designed so they will be used by both patients and their next of kin. How could the next of kin be involved in the preparation of the screening day.

Participants

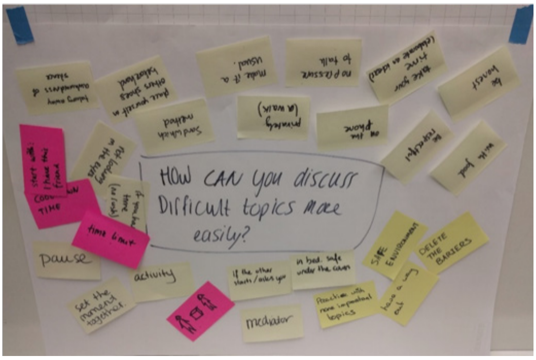
In a creative session with 5 DfI students who follow the course creative facilitation, and one facilitator, the function of the Roleplay cards was explored. The entire session lasted around 210 minutes.

Procedure

The initial topic of this session was: How might one involve a next of kin in preparation of a hospital visit? During the session, the participants and facilitator found out that a more relevant topic would be: How can one discuss a difficult topic with a next of kin. Therefore, this was the problem addressed in the session. The results of this session were two new concepts ideas. At this point in the conceptualisation process that was not useful, but this session did provide me with new insights. Appendix U shows the results of the brainstorm sessions and the concept ideas.

Results

- Answering questions can be used to understand each other's points of view for both patient as next of kin
- It would be good if not all conversation topics are shown at once, show one topic after another.
- Topics that should be included are: feelings, the future, worries and technicalities
- Having a break during conversations helps the process of talking about difficult subjects, e.g. by answering one question a day these breaks are inserted naturally.
- The patient and next of kin should be guided in the preparation process ▶



▶ ***figure 5-39:*** Interim results of a creative session with five design students and a facilitator.

5.c.2 Evaluation with patients

To improve the concepts, evaluation with patients was needed. As the research and design phase were performed simultaneously, the patient interviews from the user research phase were also used to evaluate the concepts.

Method

The goal of this evaluation was to find out what patients think of the preparation book and role-play cards and to generate input and feedback to adjust the concepts to their needs.

Participants

Six participants were individually asked to evaluate the designs. The participants were the same as the participants from contextmapping research. Six women and two men with ages ranging from 35 to 59 years old participated in the evaluation. The evaluation took place in the participants' homes and was part of the user research. At the end of the user research, about twenty minutes was spent discussing the concepts.

Procedure

First the two concepts were explained to the participants. The scenarios from each concept was shown, the reason behind the concept and interesting features of the concepts were told. Patients asked some questions to better understand the concepts. Most importantly, prototypes of the concepts were handed over. This way, the patients could really browse through the concepts.
With each participant, a different version of the preparation book and roleplay cards was shown. After each evaluation, the concepts changed, so the latest version was used for the next interview.
figure 5-40 shows different versions of the concept that were evaluated.

Results

The main results and design implication of these two consultations are shown here. Appendix E.5 shows a more detailed list of insights.

- Improved information and the addition of the schedule is highly appreciated

- Keep it small, don't overwhelm patients

- Images can provide a lot of information, so use images when possible.

- MS patients often have difficulties reading, so make the font large and provide plenty of white space

- Patients could really use the reflection after the diagnosis consultation. By filling out the sensitising booklet, they really reflected on their journey. This made them realise things: sometimes they needed more information
  Two patients mentioned that they wouldn't just use the conversation cards as preparation for the SOMSCOG visit, but also to explain to friends and colleagues what impact MS has on their lives.

- Most patients were really curious about the cards and all but one, said they would like to have the cards once they are finished.

5.c.3 Evaluations with two experts

Two experts were consulted on the content and lay out of the Preparation book and the Roleplay cards

Method

The goal of this evaluation was to improve the content of the Preparation book and Roleplay cards. Furthermore, the layout of both concepts needed improvement

Participants and procedure

Prof. Dr. Pieter Jan Stappers was consulted about the content of the two concepts. Prof. Dr. P.J. Stappers is specialised in design tools and techniques for the early phases of design. He shared his experience about how to discuss difficult topics with next of kin. But most of all, prof. Dr. P. J. Stappers provided valuable tips on how to trigger people into answering questions in the Preparation book.

Graphic designer, Jord de Kat Angelino was asked for advice on the concepts' appearance. De Kat Angelino has 15 years of experience in graphic design and has worked for several large companies such as Ahold Delhaize and Heineken.

Results

The main results and design implication of these two consultations are shown here. Appendix E.6 shows a more detailed list of insights.

- Arm the patients for the consultation. The questions in the preparation book should lead towards the consultation. > The questions in the booklet are organised in three steps. For each day the questions lead up to what should be shared in the consultation.

- The concepts should look inviting, friendly and professional. Keep this in mind when designing the concepts.

- For better acceptance at VUmc, the concepts should use features of the VUmc layout. The use of Lucida sans helps this.

- To improve readability of the booklet, separate the information and preparation parts.

- To increase the effect of being a notebook, the paper of the book should be off white. Also, the corners should be rounded, the size is changed from a5 to b5. The finishing will be folded and stapled, making it similar to a Moleskine notebook. ■

▶ **figure 5-40:** The different versions of the preparation book. Each version was evaluated with patients, and then changed. (1) first version of the book, (2) spread of the first version, (3) different versions in one overview.

6 FINAL DESIGN

In this chapter, the final design of the designed tool is shown. The aim of this assignment was to design a tool that helps to improve the patient experience of MS patients who visit the SOMSCOG outpatient clinic phase at VUmc. Therefore, De Gids was created. This tool includes a preparation sheet and information guide that can be used before, during and after visiting the SOMSCOG outpatient clinic. Patients prepare for the anamnesis consultation with questions on the preparation sheet. This preparation sheet functions as a guideline and mnemonic during the consultation.

The different features, added value for stakeholders and the use of De Gids are shown in this chapter. Furthermore, important design decisions of the design process are described and the link with the De Gids are shown.

6.a De Gids

De Gids (translated The Guide) is a preparation and information tool consisting of a physical paper guide and a preparation poser enclosed in a folder, that helps patients prepare for their SOMSCOG outpatient clinic visit. More specifically, it helps them to prepare for the consultation with the neurologist. figure 6-41 on page 107 shows the three parts of *De Gids*.

6.a.1 Features

De Gids encompasses a folder, an information guide and a preparation sheet. The information guide contains information of the screening day, the schedule, possible outcomes and treatment options. It also contains a conversation starter which can be used by patients and a next of kin to share their worries. Furthermore, it has two pages with reflecting questions that can be filled out after their SOMSCOG journey. The content of current information folder has been transformed into the new information guide. The information was structured, organised, important elements were added and images were inserted for more clarity. The preparation sheet contains questions that prepare the patient for the consultation with a neurologist on the screening day. The topics of these questions are: concerns, expectations and help request. ▶

De Voorbereidingsplaat

VUmc MS Centrum Amsterdam

Stap 1: Mijn zorgen

U bent doorverwezen naar de second opinion polikliniek MS en cognitie vanwege uw cognitieve klachten. De vragen in deze stap gaan over de klachten die u ervaart en of u zich hier zorgen om maakt. Het doel van deze vragen is om inzicht te krijgen in wat voor invloed deze klachten op uw dagelijks leven hebben. Begrijpt u een vraag niet, of vind u dat een vraag niet bij uw situatie past, dan kunt u deze overslaan.

Vraag 1. a
Wat voor cognitieve klachten ervaart u? Hieronder zijn al een paar klachten opgeschreven die u mogelijk ervaart. Zijn er andere klachten waar u last van heeft? Zet deze er dan bij. Staan er al dingen bij waar u geen last van heeft? Streep deze dan door.

Vraag 1.b
Wat voor effect hebben deze klachten op uw dagelijks leven? Schrijf de effecten in het rijtje naast de klachten.

klachten	effect
☐	☐
☐ Geheugen	☐
☐ Concentratie	☐
☐ Ik kan moeilijk op	☐
☐ woorden komen	☐
☐	☐
☐	☐
☐	☐

Vraag 2
Maakt u zich wel eens zorgen over deze klachten? Maak hieronder een overzicht waarin u uw mogelijke zorgen kunt invullen.

Mijn zorgen zijn vooral...

dat:

dat:

dat:

dat:

dat:

Stap 2: Mijn verwachtingen

Het kan zijn dat u hele duidelijke verwachtingen heeft van de screeningsdag, maar misschien weet u juist niet goed wat u kunt verwachten. Door het beantwoorden van deze vragen willen we u helpen om uw verwachtingen op een rijtje te zetten. Hoe heeft u besloten om naar deze poli te komen? Wat zijn uw verwachtingen hierbij?

Vraag 1
Wat verwacht u van de screeningsdag? In de cirkel hieronder kunt u uw verwachtingen opschrijven. Zijn er bepaalde verwachtingen extra belangrijk? Zet ze dan dichter bij het midden.

Belangrijk

Vraag 2
Wat kunnen wij doen om aan uw verwachtingen te voldoen? Beschrijf hieronder kort (in steekwoorden) wat u van ons verwacht om uw bezoek te laten slagen.

☐

☐

☐

Vraag 3
Wanneer is de screeningsdag geslaagd? Probeer te bedenken wanneer de screeningsdag voor u geslaagd is. Wat kan ervoor zorgen dat u straks tevreden bent? Beschrijf dit in het vak hieronder. Wanneer vindt u het bezoek niet geslaagd? Probeer ook dit te omschrijven.

Mijn bezoek is geslaagd wanneer

want

ezoek is niet geslaagd wanneer

graag vertellen:

Stap 3: Mijn hulpvraag

Wat is precies uw hulpvraag? Die vraag is vaak nog niet zo gemakkelijk te beantwoorden. Maar voor ons als zorgverleners is het wel heel belangrijk om dat samen met u helder te krijgen. Met de onderzoeken van de screeningsdag, gaan we proberen om deze vraag zo goed mogelijk te beantwoorden.

Vraag 1
Wat is de reden of zijn de redenen dat u naar deze screeningsdag gaat? Om naar deze screeningsdag te komen bent u doorverwezen door een arts. Wij zijn benieuwd naar de reden van deze doorverwijzing. Beschrijf hieronder waarom u bent doorverwezen.

Ik ben doorverwezen naar deze screeningsdag omdat:

door:

Vraag 2
Wat wilt u zelf bereiken met uw bezoek? Hierboven heeft u de reden van de doorverwijzing verteld, maar we zijn ook benieuwd wat u graag zou willen bereiken met dit bezoek. Misschien heeft u daar nog niet zo over nagedacht maar misschien juist wel. Beschrijf hieronder wat u graag zou willen bereiken met dit traject.

Ik wil bereiken dat

Ik wil bereiken dat

Ik wil bereiken dat

Ik wil bereiken dat

Conclusie
Wat is de hulpvraag die u beantwoord wil hebben tijdens deze screeningsdag? Probeer uw vraag zo duidelijk mogelijk te maken. Als u niet goed weet wat u te weten wilt komen, kunt u bekijken wat u hiervoor heeft opgeschreven. De antwoorden op de vragen van stap 1 en 2 kunnen u misschien helpen bij het formuleren van een hulpvraag.

De hulpvraag die ik tijdens de onderzoeksdag graag beantwoord zou willen hebben is:

Informatie map

Screeningsdag
MS en Cognitie

VUmc MS Centrum Amsterdam

MS en Cognitie

Alstublieft, voor u ligt een boek om u voor te bereiden op de screeningsdag op de polikliniek. Het bestaat uit twee delen: voorbereidende vragen en informatie. Lees het rustig door en vul de vragen in. Onze zorgverleners vinden het belangrijk dat u de vragen invult, zodat u goed voorbereid bent. We vragen u dan ook dit boek mee te nemen op de screeningsdag van de **second opinion MS en cognitie polikliniek van het VUmc (SOMSCOG).**

VUmc MS Centrum Amsterdam

▶ ***figure 6-41:*** De Gids encompasses a folder, an information guide and a preparation poster.

The total package is supplemented with information documents and informed consent forms which are currently in use at the outpatient clinic – chapter 3.d.3 shows a list of these documents. These documents were not redesigned, but they will also be included in the folder.

Overview of *De Gids*
- Folder
- Information guide
- Preparation sheet
- Pen

Furthermore, an instruction leaflet of how to use the preparation sheet during consultation is part of the final design. This leaflet is aimed to be used by neurologist who have consultations at the SOMSCOG outpatient clinic.

Extra
- Instruction for neurologists

6.a.2 How does it work?

De Gids is sent to patients when they have been referred to SOMSCOG outpatient clinic and after an appointment has been made. For the most optimal use of *De Gids*, it should be sent to the patients two weeks prior of the screening day.
The patients read the information in the guide and answer the questions on the preparation sheet. The questions on the sheet are divided in three steps, which can be answered in three days. In paragraph 7.c.3 the questions are explained. Next, the patients can discuss their cognitive issues with a next of kin, using a spread of information guide as a conversation starter.

During the visit of SOMSCOG outpatient clinic, patients take *De Gids* (information guide and preparation sheet) with them. In the consultation with the neurologist, the sheet is spread out on the table, serving as a mnemonic for the patients. It helps them to share their story. The information guide can be used to take notes during the screening day.
After the screening day patients can reread what they have written on the preparation sheet as preparation for the diagnosis consult. Again, they take the information guide and preparation sheet with them. This time, the neurologist should stimulate the patients to take notes.
When the whole journey is over, the patients can fill out the last pages of the information guide to reflect on their SOMSCOG outpatient clinic journey.
Finally, when patients return to their original neurologist, they can take *De Gids* with them and share what they have learned from their journey.

In the next paragraphs the context of use is visualised (with touch points) followed by the scenario of use in which the complete system around *De Gids* is explained.

6.a.3 Raison d'être

As was shown in the results of the user research, patients have difficulties preparing for the screening day. A result of this lack of preparation is that the help request formulated by the patients is often suboptimal. When the help request is improved, the diagnosis can have a better connection with patients' needs and the treatment options that will be offered might be more effective. This will ultimately result in better care and will positively influence quality of life.

6.a.4 Added value for the stakeholders

De Gids benefits multiple stakeholders in different ways. There are short term effects: patients feeling heard and neurologist having a more efficient consultation. A long-term effect is that the diagnosis will have a better fit with the patient and the possible treatment will improve the patients' situation. Also, the referring neurologist could benefit from *De Gids*.

However, it is suggested that the focus of *De Gids* should remain as a preparation method and supportive tool for communication during consultation at the SOMSCOG outpatient clinic. Adding more features would overwhelm patients and could distract from the main functionality. The added value for each stakeholder is described below.

MS patient with cognitive problems

By using the *De Gids*, MS patients are triggered to prepare themselves for the screening day. This preparation affects the way patients behave during the consultation with a neurologist. It is expected that patients will be more participative and show more initiative resulting in a conversation between patient and neurologist. If the neurologist responds to their provided information during consultation, patients will feel included in the conversation.
MS patients who visit the SOMSCOG are motivated patients. Often, they have walked around with these problems for a long time. So, they are eager to do something. When they formulate a fitting help request by using the preparation sheet, this could lead to better healthcare outcomes.

Neurologist of screening day

The use of *De Gids* by patients leads to better prepared patients. It is expected that this will be noticed during consultation. Patients will show more initiative and patient participation will be improved. Due to this, it would hopefully mean that getting the right information from patients will be a smoother process. Instead of 'interviewing' the patient, a conversation will occur between patient and participant.

Referring neurologist

Patients who use *De Gids* and fill out all the questions in *De Gids* will have a good overview of their cognitive problems and situation. They will have a well defined help request and will get a diagnosis that fits with this help request. Patients take the filled out preparation poster and information guide with them to their next visit. The referring neurologist will get a better insight in what complaints, effects of these complaints on daily life and concerns the patients' have. This could be beneficial for the long-term treatment.

VUmc

With better informed patients, the consultation with the neurologist could be more effective and efficient. Less time would be needed to get to the core of the problem and the formulation of the help request.
If this help request is better aimed at the core problems, the diagnosis will have a better fit. ■

6.b Context of use

As explained before De Gids can be used as a preparation tool before visiting the outpatient clinic, but it can also be used as a communication tool during consultation with a neurologist. This paragraph shows the use of De Gids. The use can be divided in eight main touch points. These touch points are the moments the user used De Gids.

6.b.1 Touch points

In the use of De Gids, eight different touch points can be distinguished, figure 6-42 on page 112 shows this in a visualisation. In each touch point, the patient is using De Gids. This can either be alone, with a next of kin or with a neurologist. On the next pages the touch points are visualised over time. In this situation, the MS patient is female and she has a male partner who will accompany her to the SOMSCOG outpatient clinic.
First, these touch points are described shortly. In the next paragraph 6.b.2 Scenario of use on page 114, a more detailed scenario of use is shown.

Two weeks prior to the screening day, the patient receives De Gids, it is sent by mail to her house. It is used as a preparation tool (touch point 1 and 2), then during the screening day as a conversation aid and guiding tool (touch point 3 and 4). After the screening day the patient uses De Gids as a revising and preparation tool (touch point 5), during diagnosis consultation it is a conversation aid and notebook (touch point 6). After diagnosis, De Gids can be used as a reflection tool (touch point 7) and when returning to her own referring neurologist it is used as a conversation aid (touch point 8).

1. The patient uses de Gids to prepare for the screening day. It functions as a preparation tool. The patient receives De Gids by mail. She reads the instructions and fills out the preparation sheet spread out over multiple days.

2. The conversation starter - De Gesprekswiel - is used by the patient and her partner. Explanation of the conversation starter can be found on

3. The patient uses the preparation sheet to share her story

4. During the screening day, the information guide functions as a notebook

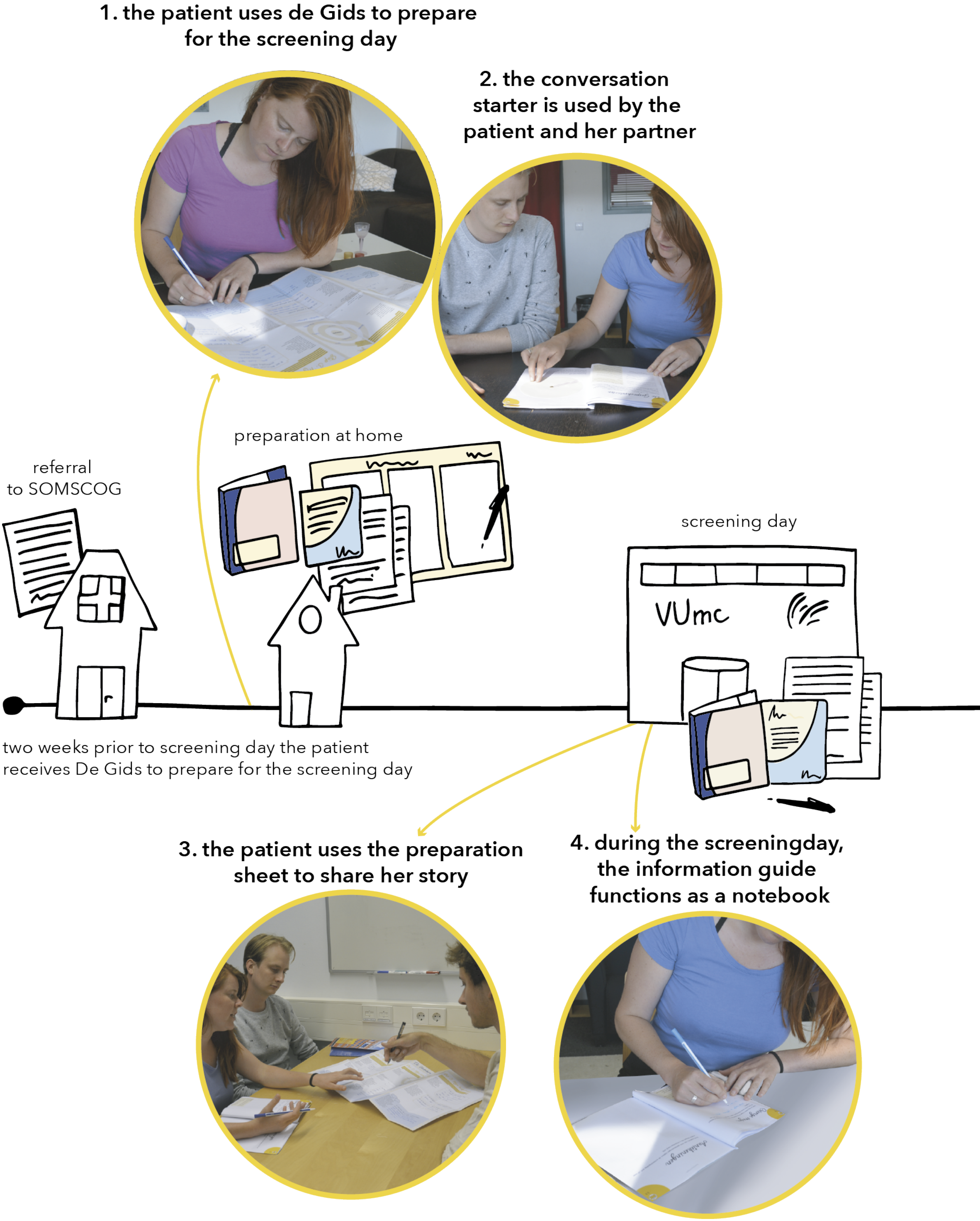
5. The patient prepares diagnosis consultation by reviewing the preparation sheet and notes taken during the screening day.

6. During diagnosis consultation with neurologist, the information guide is used to take notes and as a mnemonic tool. Questions prepared by the patient are shared with the neurologist

7. After diagnosis, the patient fills out the reflection

8. When the patients returns to her own neurologist she takes De Gids with her ►

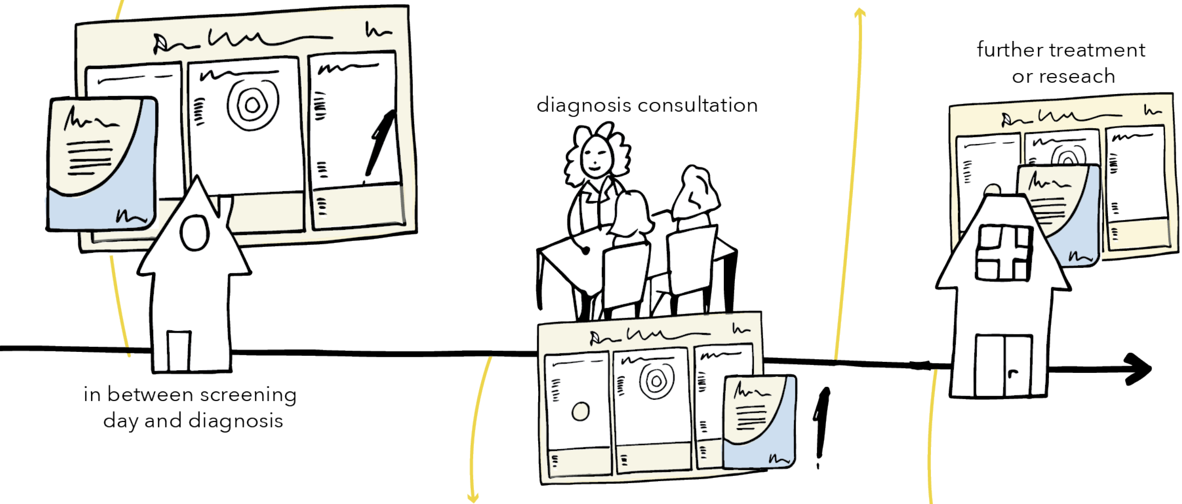
Touch points explained over time



▶ ***figure 6-42:*** Touchpoints of the interactions with De Gids shown on a simplified patient journey time line.

5. the patient prepares diagnosis consultation by reviewing the preparation sheet and notes

7. after diagnosis, the patient fills out the reflection spread



6. during diagnosis consultation the information guide is used to take notes and as a mnemonic tool

8. when the patients returns to her own neurologist she takes De Gids with her

6.b.2 Scenario of use

The next pages show how and by whom De Gids is used in different scenarios.

1: The patient uses *De Gids* to prepare for the screening day and the

Patient opens the envelop and takes De Gids out of it. .

The patient explores the content of th and finds the information guide.

She reads the instructions and is ready to start to use it

First, she has to take the poster out of the information guide.

Then , the questions poster are explored

2: The patient uses De Gespreksiel to share her cognitive problems and her concerns with her p

Later that week, the patients invites her partner to sit down with her. She wants to share her feelings concerning her cognitive problems using the conversation starter.

First they read the instructions of how De Gesprekswiel should be used.

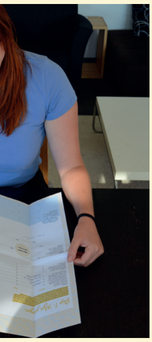
The patient s topic she 'pi tells what kir her partner c

e consultation with the neurologist

he folder

Patient takes a first glance at the information guide to see what is expected of her.

The patient moves to sit down at the table, she read that she has to write stuff.



s on the
....

... and the patient starts writing her answers. For some, she needs more time to think about the answers.

A few days later, the patients has thought about the questions. She is ready to fill out the rest of the poster.

partner.

starts with turning the wheel. The
cks' to talk about is support. She
nd of support she needs and how
could support her.

Then it's the partner's turn spin the wheel. The topic he lands on is acceptance. He shares how it is difficult for him to see her struggling with accepting her situation.

After they have shared their concerns and worries, the patient feels like she can explain her partner what she has written on the preparation sheet.

3: The preparation sheet and the information guide are used in the anamnesis consultation of the

During the anamnesis consultation, the neurologist asks about several topics on the preparation sheet.

The patient answers the questions, using the sheet as guideline. It also functions as a mnemonic device, when she forgets something.

The patient tries to answer the question of the neurologist, but is distracted. She starts another story and has many more somewhat irrelevant topics she wants to discuss.

The neurologist carefully steers the conversation in a more useful direction with help of the preparation sheet. He helps her to share the important parts of her story.

.. after a while she finds it too distracting from the conversation, so her partner takes over.

screening day.

The patient points out a question she wants to discuss with the neurologist. The partner supports the patient in sharing her story.

The neurologist answers her question and then asks her something.

By answering each others questions and by asking each other questions, a conversations has been established between the neurologist and the patient. This way, everybody gathers the knowledge they need.

Patient takes notes during the consultation...

4: The patients uses the information guide as a notebook to write notes of things she wants to remember.

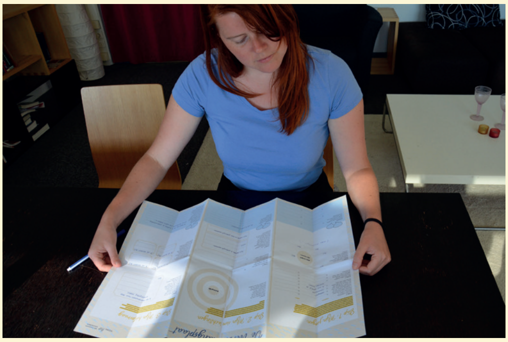
During the day, the patient writes some notes in the note section of the information guide.

6: During consultation with neurologist – diagnosis it functions as a notebook, and questions prepared by patient, are shared with neurologist.

The patient and her partner are nervous for the diagnosis. During this consultation the information guide with her prepared questions is open on the table.

Sometimes the patient looks at her questions to ask the neurologist. She writes the answers in the guide.

5: Reviewing the preparation sheet and notes taken during consultation and screening day



The patient reviews what she has written on the preparation sheet as preparation for the diagnosis consultation. Then she looks at the notes taken during the screening day.

Furthermore, the patient prepares the diagnosis consultation with her partner. Some questions arose after the screening day, so she writes them down to make sure she won't forget to ask them.

The neurologist refers back to the preparation sheet and the help request during this consultation.

At the end of the consultation, when all questions of the patient and her partner have been answered, the neurologist points out the reflection sheet. He recommends the patient to fill out this sheet. He says it can help her see if her help request has been answered.

7: Reflection after diagnosis

A few days after the diagnosis consultation the patient opens the information guide again. She looks at the questions on the reflection spread pointed out by the neurologist.

The patient fills out the reflection questions. These helps her reflect on her goals of the SOMSCOG outpatient clinic and the results she received. This way, she can review what has happened and the consequences of her visit.

8: Return to own neurologist, showing the process of the SOMSCOG using De Gids - the preparations sheet and information guide - as a guideline.

After the whole SOMSCOG journey is finished, the patient returns to her own neurologist. She takes De Gids with her.

The patient uses the preparation sheet to share her concerns and help request. She also tells her neurologist what was done at the outpatient clinic, with help of the information guide

6.c Design

During ideation and conceptualisation, ideas were developed into concepts in order to realise the design goal. The criteria were implemented in the design. This process has been influenced by the user and literature study. Some of the results of these studies can be easily recognised, others are more subtly implemented. This paragraph shows the most important design decisions that have been made along this process.

6.c.1 Style

The help of a graphic designer was used to make a style guide for *De Gids*. Together with this graphic designer some style decisions were made. A few of these decisions are listed here.

Inviting, professional and friendly

The lay out of De Gids can be described as inviting, professional and friendly. For patients to start using De Gids, it has to look inviting, to trigger patients to start. The VUmc is a professional and trustworthy establishment, therefore De Gids should also look professional. Patients need to trust De Gids and they should that the VUmc takes them seriously. That is why De Gids should have a professional appearance. During patient interviews it appeared that patients have some anxious feelings towards the VUmc, it is such a large and renown hospital. To take away their fears, the documents sent from VUmc should have a friendly feel to it. That is why De Gids should look friendly as well.

Professional

For a good fit with the VUmc style guide, the general font of De Gids is Lucida Sans MS which is the font used for VUmc communication materials. Also other parts of the VUmc style guide are used:

- An official picture of VUmc on the cover of the folder and information guide
- The cover of the folder has the blue gradient bow on it
- The cover also has the yellow text box with the official transparency.

However, some parts are slightly changed. A different, warmer yellow colour is used as the VUmc yellow is quite harsh and cold.

Friendly

To increase the friendly feel of De Gids, the corners are rounded. This makes it feel less ‘hard’. Furthermore it is decided that an extra font is used in the book. The handwritten calligraphy font makes De Gids look less like a hospital tool and therefore less intimidating.

Inviting

The trigger patients to write in De Gids, the paper should be off white. This makes it look like a notebook.

figure 6-43 on page 123 provides an overview of these design decisions on a spread of the information guide.

6.c.2 Usability

Physical instead of digital

The decision to make De Gids from paper is based on the number of people visiting the SOMSCOG outpatient clinic on a yearly basis. The maximum capacity of patients is 100 patients per year.
But this is in the most optimal situation; a more realistic number is around 60 patients per year. To make a digital version of this design, e.g. a phone application, would be a very costly procedure. Therefore, it is decided to make an analogue version. ►

Furthermore, when writing down one's thoughts, the thoughts are slowed down by the writing process. Often people type faster than they can write. So, when writing ones thought, there is more time to think and contemplate. This could result in better reflections. It would be interesting to research this phenomenon, to find out if this is true.

Separation of functions

The different functions of the information guide and preparation sheet are separated for clarity. The actual functions are explained in paragraph 6.d on page 124 and further.

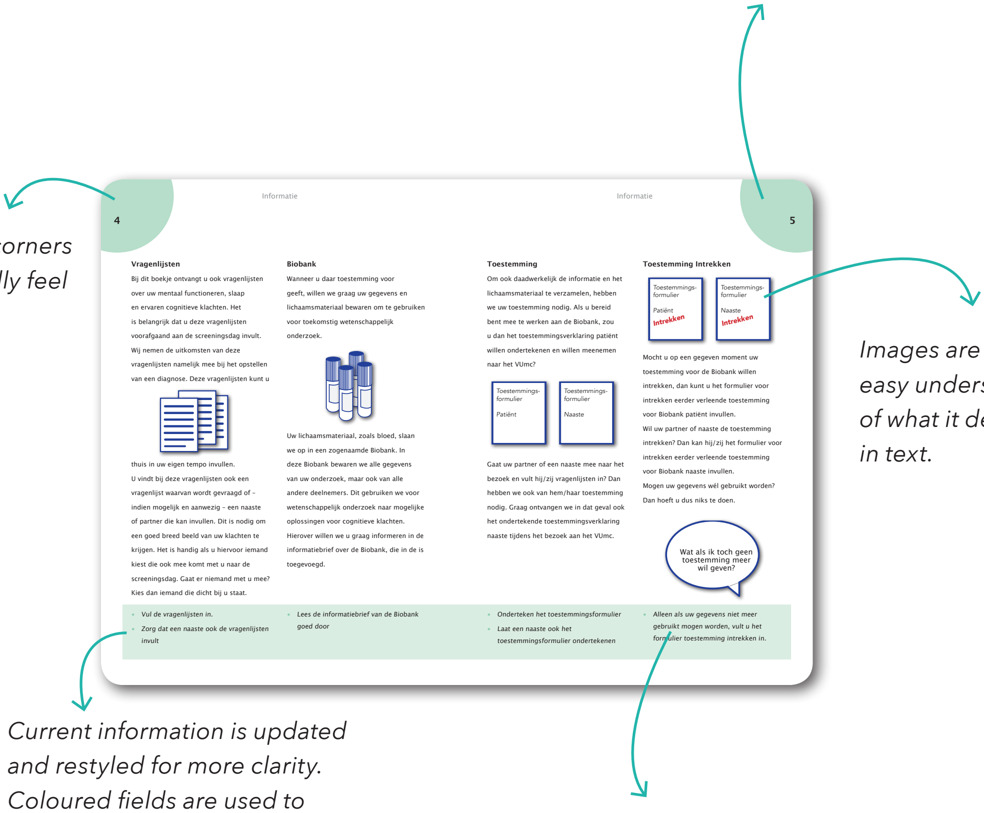
The information part - containing information the different procedures performed during the screening day - is placed at the end of the information guide. As this part will always be read by patients, they have to browse through the whole guide to get there. Which means that patients have to go past the preparation part. This way, patients will not accidentally miss (or skip) the preparation part.

Additional preparation sheet

During the design process, the decision has been made to add a preparation sheet instead of having the preparation questions in the guide. This makes the preparation phase more interactive. Patients will be triggered to use the sheet. Furthermore, the use of this sheet is more convenient during consultations than using a book with questions. Patients do not have to lip through pages to share their story. Now it is all visible in one glance in a single overview.

Conversation starter

A conversation started is inserted in the preparation guide. The previous versions of this design had a separate stack of cards that supported patients in sharing their story. For usability reasons, it was decided to have the conversation starter inserted in the guide. Having everything included in the same guide would make it easier to use. Patient already get so many documents, adding an extra item would make it confusing. Furthermore, a turning wheel is always a inviting to be touched and turned which should trigger patients to used it. And an extra motivation to have this wheel instead of a deck of cards is a financial one. It will be cheaper to have this wheel in the guide than to add a deck of cards to the package. ■



Different colours are used for different parts of the information guide, for easy distinction between parts.

Rounded corners for a friendly feel

Images are added for easy understanding of what it described in text.

Current information is updated and restyled for more clarity. Coloured fields are used to emphasise important parts.

The official VUmc font is used, to touch upon the VUmc style guide.

Informatie

4

Vragenlijsten

Bij dit boekje ontvangt u ook vragenlijsten over uw mentaal functioneren, slaap en ervaren cognitieve klachten. Het is belangrijk dat u deze vragenlijsten voorafgaand aan de screeningsdag invult. Wij nemen de uitkomsten van deze vragenlijsten namelijk mee bij het opstellen van een diagnose. Deze vragenlijsten kunt u thuis in uw eigen tempo invullen.

U vindt bij deze vragenlijsten ook een vragenlijst waarvan wordt gevraagd of – indien mogelijk en aanwezig – een naaste of partner die kan invullen. Dit is nodig om een goed breed beeld van uw klachten te krijgen. Het is handig als u hiervoor iemand kiest die ook mee komt met u naar de screeningsdag. Gaat er niemand met u mee? Kies dan iemand die dicht bij u staat.

Biobank

Wanneer u daar toestemming voor geeft, willen we graag uw gegevens en lichaamsmateriaal bewaren om te gebruiken voor toekomstig wetenschappelijk onderzoek.

Uw lichaamsmateriaal, zoals bloed, slaan we op in een zogenaamde Biobank. In deze Biobank bewaren we alle gegevens van uw onderzoek, maar ook van alle andere deelnemers. Dit gebruiken we voor wetenschappelijk onderzoek naar mogelijke oplossingen voor cognitieve klachten.

Hierover willen we u graag informeren in de informatiebrief over de Biobank, die in de is toegevoegd.

- *Vul de vragenlijsten in.*
- *Zorg dat een naaste ook de vragenlijsten invult*

- *Lees de informatiebrief van de Biobank goed door*

Informatie

5

Toestemming

Om ook daadwerkelijk de informatie en het lichaamsmateriaal te verzamelen, hebben we uw toestemming nodig. Als u bereid bent mee te werken aan de Biobank, zou u dan het toestemmingsverklaring patiënt willen ondertekenen en willen meenemen naar het VUmc?

Toestemmings-formulier
Patiënt

Toestemmings-formulier
Naaste

Gaat uw partner of een naaste mee naar het bezoek en vult hij/zij vragenlijsten in? Dan hebben we ook van hem/haar toestemming nodig. Graag ontvangen we in dat geval ook het ondertekende toestemmingsverklaring naaste tijdens het bezoek aan het VUmc.

Toestemming Intrekken

Toestemmings-formulier
Patiënt
Intrekken

Toestemmings-formulier
Naaste
Intrekken

Mocht u op een gegeven moment uw toestemming voor de Biobank willen intrekken, dan kunt u het formulier voor intrekken eerder verleende toestemming voor Biobank patiënt invullen.

Wil uw partner of naaste de toestemming intrekken? Dan kan hij/zij het formulier voor intrekken eerder verleende toestemming voor Biobank naaste invullen.

Mogen uw gegevens wél gebruikt worden? Dan hoeft u dus niks te doen.

Wat als ik toch geen toestemming meer wil geven?

- *Onderteken het toestemmingsformulier*
- *Laat een naaste ook het toestemmingsformulier ondertekenen*

- *Alleen als uw gegevens niet meer gebruikt mogen worden, vult u het formulier toestemming intrekken in.*

▶ ***figure 6-43:*** Design decisions applied pointed out on a spread of the information guide

6.d Functions and contents of De Gids

This paragraph shows an overview of the pages of the information guide and the preparation sheet. During the design process functions were added, removed and adjusted. The input for these alterations were the evaluations with patient and experts.
The information guide is divided in three parts: an introduction, an information part and a preparation part. Appendix G.1 - Final design shows larger pages of the information guide.

Introduction part

The introduction part tells how De Gids should be used and it shows what patients should do before going to the screening day. figure 6-44 on page 125 shows the spread of the introduction part.
The first two pages (1 and 2) contain a table of content and an introduction. The table of content should provide a first overview of the content of the guide. It should guide the reader through the information guide. The current information folder does not provide information hierarchy. With De Gids it is tried to make chunks of information, to cluster subjects that serve the same goal. Furthermore, extra information that was missing in the original guide is added. The introduction explains the contents of De Gids. The deliberation of what to add and what not to add was based on the user research interviews.

The next spread, (3) of image figure 6-44 on page 125, is a part that has been added based on the user research. The goal of the screening day is explained here, combined with possible outcomes and possible treatments that might be offered. This information is new info that patient have not received before. This spread is inserted to let patients know what they can expect of the screening day, of the outcomes and of the possible treatments.

On the next spread (4) a checklist is added of what has to be done before visiting the SOMSCOG outpatient clinic. This is a new part of the information. It explains that patients should read the information letter of the Biobank, sign informed consent forms if they agree that their data is used for scientific research. It also explains what to do it they want to withdraw their consent.

The last spread of this section (5) has practical information concerning their visit. It explains what they should bring to their visit of the screening day, whom to bring and whom to call for more information. ▶

1

Inhoud van dit boek

De zorgverleners van het MS Centrum Amsterdam

2

Inleiding

Dit boek bevat helpt u bij het doorlopen van de screeningsdag bij de second opinion polikliniek voor MS patiënten met cognitieve klachten. Het helpt u bij het voorbereiden op de screeningsdag, en er is ruimte om aantekeningen te maken tijdens de dag zelf. Dit boek is verdeeld in twee delen:
1) de voorbereiding en 2) informatie.

Met het eerste deel van dit boek bereidt u zich voor op de screeningsdag. We willen u vragen om de komende dagen de vragen die op de Voorbereidingsplaat staan in te vullen. De vragen bestaan uit drie stappen, en het duurt ongeveer 15 minuten om de vragen te beantwoorden. Voor alles wat u invult, geldt dat er geen goed of fout antwoord is.

Het tweede deel bevat alle informatie rondom de screeningsdag. U kunt hier het schema van de screeningsdag vinden, de verschillende onderzoeken staan uitgelegd en andere praktische zaken, zoals wat u mee moet nemen, etc..

Komt de datum u niet goed uit?
Mocht de geplande datum niet uitkomen neem dan zo spoedig mogelijk contact op:
020 – 4441162
Maandag – vrijdag van 10:00 – 16:00 uur

3

U bent doorverwezen, en nu

Tijdens de screeningsdag onderzoeken we cognitieve klachten: onder andere problemen met aandacht, geheugen en concentratie. Op deze dag vinden veel verschillende onderzoeken plaats. Houd er rekening mee dat het een drukke dag is. We raden u daarom aan om iemand uit uw directe omgeving mee te nemen: een naaste. Uw naaste kan ook informatie geven over uw klachten aan de zorgverleners.

Het doel van deze screeningsdag is om uw cognitieve problemen in kaart te brengen en we gaan op zoek naar mogelijke oorzaken voor uw klachten. Ook bespreken we passende behandelingen of onderzoeken met u die uw klachten mogelijk kunnen verlichten. De onderzoeken hiervoor zijn zowel fysieke onderzoeken, zoals bloedafname, een lumbaal punctie, oog testen, een MEG scan en MRI scan. Maar ook psychische testen, zoals een neuropsychologisch onderzoek worden tijdens de screeningsdag gedaan. We kijken ook naar andere mogelijke oorzaken van uw klachten zoals bijvoorbeeld vermoeidheid, stemmingsklachten en angsten. Dit kan allemaal van invloed zijn op uw cognitief functioneren.

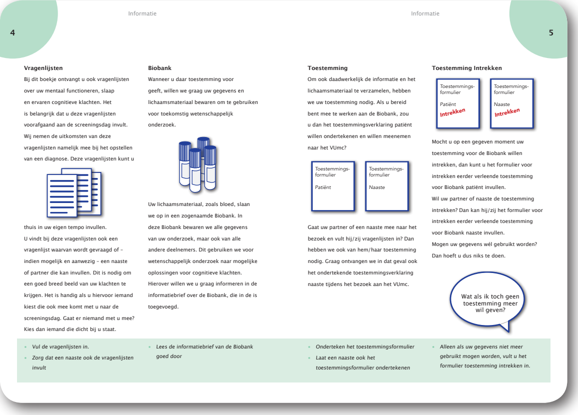
U komt alleen voor de screeningsdag en uitslaggesprek naar het VUmc. Dat betekent dat u onder behandeling blijft bij uw gebruikelijke neuroloog en ziekenhuis. Bent u normaal gesproken ook bij het VUmc onder behandeling? Dan verandert er niks. Na screeningsdag keert u gewoon terug naar uw eigen neuroloog. Vragen over medicatie of andere lopende zaken rondom MS kunt u dan ook het beste met uw eigen neuroloog bespreken en niet tijdens de screeningsdag.

Mogelijke uitkomsten
Er zijn verschillende uitkomsten van de dag mogelijk. Het kan zijn dat er een cognitieve stoornis gevonden wordt, maar het is ook mogelijk dat we niets vinden.

Mogelijke uitkomsten zijn:
- U heeft een cognitieve stoornis die direct te maken heeft MS
- U heeft geen cognitieve stoornis, maar wel klachten. Er is meer onderzoek nodig om uit te vinden wat deze klachten veroorzaakt.
- U heeft een cognitieve stoornis die niet direct met MS te maken heeft, maar waarschijnlijk een andere oorzaak heeft.
- U heeft last van psychische klachten, zoals somberheid, angsten of vermoeidheid
- Er spelen andere dingen mee zoals ADD, ADHD etc.
- Het is ook mogelijk dat we een combinatie van oorzaken vinden.

Mogelijke aangeboden behandelingen
Het is belangrijk om te weten dat er meestal niet een pil is die u kunt nemen om de cognitieve klachten te verhelpen of verbeteren. Er is dus geen kant en klare oplossing die we u kunnen bieden. Wel zijn er verschillende soorten behandelingen die kunnen helpen. Denk hierbij aan cognitieve revalidatie therapie, psychische ondersteuning van een psycholoog. Daarnaast is het mogelijk om mee te doen aan wetenschappelijke studies.

4



Vragenlijsten
Bij dit boekje ontvangt u ook vragenlijsten over uw mentaal functioneren, slaap en ervaren cognitieve klachten. Het is belangrijk dat u deze vragenlijsten voorafgaand aan de screeningsdag invult. Wij nemen de uitkomsten van deze vragenlijsten namelijk mee bij het opstellen van een diagnose. Deze vragenlijsten kunt u thuis in uw eigen tempo invullen.
U vindt bij deze vragenlijsten ook een vragenlijst waarvan wordt gevraagd of – indien mogelijk en aanwezig – een naaste of partner die kan invullen. Dit is nodig om een goed breed beeld van uw klachten te krijgen. Het is handig als u hiervoor iemand kiest die ook mee komt met u naar de screeningsdag. Gaat er niemand met u mee? Kies dan iemand die dicht bij u staat.

Biobank
Wanneer u daar toestemming voor geeft, willen we graag uw gegevens en lichaamsmateriaal bewaren om te gebruiken voor toekomstig wetenschappelijk onderzoek.

Uw lichaamsmateriaal, zoals bloed, slaan we op in een zogenaamde Biobank. In deze Biobank bewaren we alle gegevens van uw onderzoek, maar ook van alle andere deelnemers. Dit gebruiken we voor wetenschappelijk onderzoek naar mogelijke oplossingen voor cognitieve klachten. Hierover willen we u graag informeren in de informatiebrief over de Biobank, die in de is toegevoegd.

Toestemming
Om ook daadwerkelijk de informatie en het lichaamsmateriaal te verzamelen, hebben we uw toestemming nodig. Als u bereid bent mee te werken aan de Biobank, zou u dan het toestemmingsverklaring patiënt willen ondertekenen en willen meenemen naar het VUmc?

Gaat uw partner of een naaste mee naar het bezoek en vult hij/zij vragenlijsten in? Dan hebben we ook van hem/haar toestemming nodig. Graag ontvangen we in dat geval ook het ondertekende toestemmingsverklaring naaste tijdens het bezoek aan het VUmc.

Toestemming Intrekken
Mocht u op een gegeven moment uw toestemming voor de Biobank willen intrekken, dan kunt u het formulier voor intrekken eerder verleende toestemming voor Biobank patiënt invullen.
Wil uw partner of naaste de toestemming intrekken? Dan kan hij/zij het formulier voor intrekken eerder verleende toestemming voor Biobank naaste invullen.
Mogen uw gegevens wél gebruikt worden? Dan hoeft u dus niks te doen.

- *Vul de vragenlijsten in.*
- *Zorg dat een naaste ook de vragenlijsten invult*

- *Lees de informatiebrief van de Biobank goed door*

- *Onderteken het toestemmingsformulier*
- *Laat een naaste ook het toestemmingsformulier ondertekenen*

- *Alleen als uw gegevens niet meer gebruikt mogen worden, vult u het formulier toestemming intrekken in.*

5

Praktische zaken

Wat mee te nemen?
- Zorgverzekeringsbewijs of – pas;
- Geldig legitimatiebewijs;
- Medicatie overzicht van afgelopen drie maanden. Dit geldt ook voor de medicijnen die u zelf bij apotheek of drogist heeft gekocht.
- De ingevulde vragenlijsten
- De toestemmingsformulieren van de Biobank
- Dit boek

Wie neemt u mee?
De screeningsdag is een volle en drukke dag met onderzoeken en gesprekken. Wij adviseren u op deze dag iemand mee te nemen die u goed kent. Bij voorbeeld een familielid. Die kan u helpen met het beantwoorden van vragen en aanvullende informatie geven over uw klachten. Als u het prettig vindt is het ook mogelijk dat hij of zij bij de onderzoeken aanwezig is. Laat deze persoon ook dit boek lezen.

Op de screeningsdag zelf
Trek gemakkelijke kleding aan, want u moet zich omkleden. Neem iets te lezen of te doen mee. Dit geldt ook voor degene die u begeleidt, want die moet soms op u wachten. Neem uw leesbril mee als u die heeft.

Op de dag van het onderzoek meldt u zich een kwartier voor het afgesproken tijdstip bij de receptie van de polikliniek neurologie in het VU medisch centrum. Een routebeschrijving vindt u in de folder: "Wegwijzer VU medisch centrum"

Een medewerker of gastvrouw haalt u op bij de receptie. Deze legt u uit hoe de dag zal verlopen en brengt u naar alle onderzoeken.

De uitslag
Ongeveer twee weken na het bezoek aan het MS centrum krijgt u de uitkomsten van de onderzoeken. Dit gebeurt tijdens een gesprek met de neuroloog. Dit gesprek duurt ongeveer twintig minuten.

Behalve de uitslagen hoort u ook de eventuele behandelmogelijkheden. Uw huisarts en/of verwijzend specialist krijgen een schriftelijk verslag van het onderzoek en de uitgebrachte adviezen. Wanneer u in aanmerking komt voor wetenschappelijk onderzoek wordt u hierover geïnformeerd door uw neuroloog.

Heeft u nog vragen?
Voor vragen over de screeningsdag kunt u bellen met de MS-verpleegkundige:
(020)– 444 0775
Maandag – donderdag van 10:00 – 11:30
en vrijdag van 11.30 – 13.00 uur.

Komt de datum u niet goed uit?
Mocht de geplande datum niet uitkomen neem dan zo spoedig mogelijk contact op:
020 – 4441162
Maandag – vrijdag van 10:00 – 16:00 uur

▶ ***figure 6-44:*** Introduction parts of De Gids. (1) table of contents of information guide, (2) introduction, (3) aim of the screening day, (4) checklist , (5) practical information

Preparation part

The next part of the information guide is aimed at the preparation phase. figure 6-45 on page 126 shows the spreads of this section of the guide. This part is all new, and is designed during this project. The results from both user and literature research are used as input.

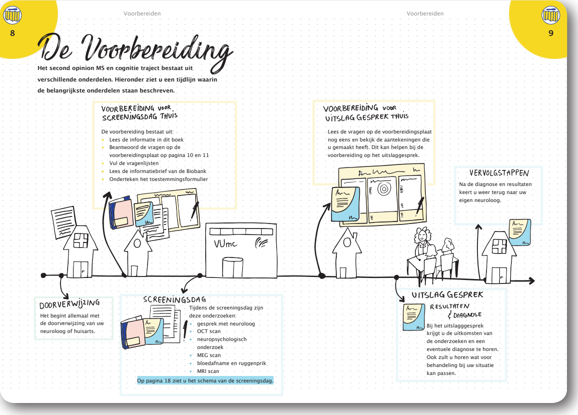
The first spread (6) shows a short version of the patient journey of SOMSCOG outpatient clinic. It is a time line on which the most important steps of the process are shown, a visual summary. The time line is added to show what is expected of the patients, It starts with the referral to go to the outpatient clinic. Next it shows what patients should do to prepare for the screening day. Then it lists the different examinations of the screening day. Next it explains how patients can prepare for the diagnosis consultation and how De Gids can be used during that consultation.

The information guide continues with a spread that explains and contains a compartment for the preparation sheet (7). The preparation sheet is shown on figure 6-46 on page 127. In paragraph - Preparation sheet on page 128 the questions of the preparation sheet are explained.

After the preparation sheet a conversation starter - De Gesprekswiel - is inserted in the guide (8). The content and use of the conversation starter is explained in the paragraph - Conversation starter on page 128.

The next page of the information guide (9) is meant for writing down question that arise during the preparation phase and to prepare questions for the consultation with the neurologist. It also contains example questions. This is done to trigger patients to prepare questions. User research showed that patients are not prepared for the screening day and in particular for the consultation with the neurologist. By showing example questions it should be easier for patients to come up with their own questions. ▶

6



Voorbereiden

8

De Voorbereiding

Het second opinion MS en cognitie traject bestaat uit verschillende onderdelen. Hieronder ziet u een tijdlijn waarin de belangrijkste onderdelen staan beschreven.

VOORBEREIDING VOOR SCREENINGSDAG THUIS

De voorbereiding bestaat uit:
- Lees de informatie in dit boek
- Beantwoord de vragen op de voorbereidingsplaat op pagina 10 en 11
- Vul de vragenlijsten
- Lees de informatiebrief van de Biobank
- Onderteken het toestemmingsformulier

DOORVERWIJZING

Het begint allemaal met de doorverwijzing van uw neuroloog of huisarts.

SCREENINGSDAG

Tijdens de screeningsdag zijn deze onderzoeken:
- gesprek met neuroloog
- OCT scan
- neuropsychologisch onderzoek
- MEG scan
- bloedafname en ruggenprik
- MRI scan

Op pagina 18 ziet u het schema van de screeningsdag.

Voorbereiden

9

VOORBEREIDING VOOR UITSLAG GESPREK THUIS

Lees de vragen op de voorbereidingsplaat nog eens en bekijk de aantekeningen die u gemaakt heeft. Dit kan helpen bij de voorbereiding op het uitslaggesprek.

VERVOLGSTAPPEN

Na de diagnose en resultaten keert u weer terug naar uw eigen neuroloog.

UITSLAG GESPREK

RESULTATEN & DIAGNOSE

Bij het uitslagggesprek krijgt u de uitkomsten van de onderzoeken en een eventuele diagnose te horen. Ook zult u horen wat voor behandeling bij uw situatie kan passen.

7

Voorbereiden

10

De Voorbereidingsplaat

In het vakje hiernaast zit de voorbereidingsplaat. Hierop staan de vragen die u helpen bij de voorbereiding van de screeningsdag.

We vragen u om de komende dagen deze vragen in te vullen. Het doel hiervan is om inzicht te krijgen in uw klachten, zorgen en verwachtingen en om een hulpvraag te formuleren.

De vragen zijn verdeeld in drie stappen:
- Stap 1: Mijn zorgen
- Stap 2: Mijn verwachtingen
- Stap 3: Mijn hulpvraag

Het duurt ongeveer 10 tot 15 minuten om de vragen van de drie stappen te beantwoorden.

De laatste vraag van elke stap is het belangrijkst, deze vragen bespreekt de neuroloog tijdens de screeningsdag. U kunt deze vraag herkennen aan de licht blauwe balk en de tekstballon die erbij staat.

11

Voor alles wat u invult geldt: er is geen goed of fout antwoord. U mag het invullen naar eigen inzicht, want u bent de expert van uw ervaringen.

De Gesprek starter (pagina 12-13)

We hebben gemerkt dat sommige mensen met MS het lastig vinden om hun cognitieve klachten met een naaste te bespreken. Daarom staat op de volgende pagina een Gespreksstarter. Deze kunt u gebruiken om uw (cognitieve) klachten met iemand te bespreken. De Gespreksstarter kan u helpen om het gesprek op gang te brengen.

Overige vragen

Heeft u nog andere vragen? Op pagina 14 kunt u deze opschrijven, zodat u ze niet vergeet.

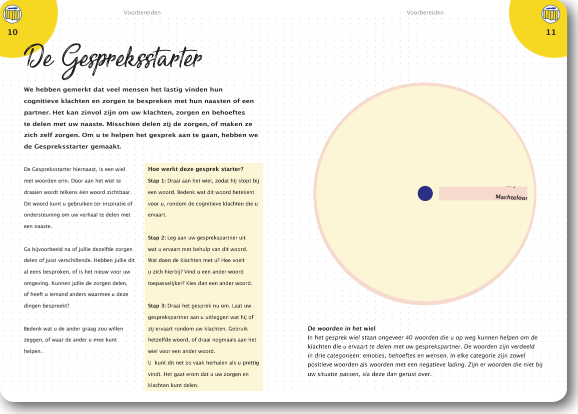
Aantekeningen

Op pagina 15-17 is ruimte om aantekeningen te maken tijdens de screeningsdag.

Het is goed om te weten dat alle vragen bedoeld zijn om u te helpen bij de voorbereiding op de screeningsdag. Als er dingen onduidelijk zijn, of als u zich niet geholpen voelt door de vragen, kunt u ze gerust overslaan. Ze zijn er om u te helpen en u kunt ze dus naar eigen inzicht invullen.

De dingen die u opschrijft hoeft u niet aan iemand te laten zien als u dat niet wil. De neuroloog zal tijdens het eerste consult op de screeningsdag wel een aantal vragen stellen die ook op de voorbereidingsplaat staan. Daarom is het nuttig om de vragen in ieder geval te lezen, zo komt u goed voorbereid op de screeningsdag.

8



Voorbereiden

10

De Gespreksstarter

We hebben gemerkt dat veel mensen het lastig vinden hun cognitieve klachten en zorgen te bespreken met hun naasten of een partner. Het kan zinvol zijn om uw klachten, zorgen en behoeftes te delen met uw naaste. Misschien delen zij de zorgen, of maken ze zich zelf zorgen. Om u te helpen het gesprek aan te gaan, hebben we de Gespreksstarter gemaakt.

De Gespreksstarter hiernaast, is een wiel met woorden erin. Door aan het wiel te draaien wordt telkens één woord zichtbaar. Dit woord kunt u gebruiken ter inspiratie of ondersteuning om uw verhaal te delen met een naaste.

Ga bijvoorbeeld na of jullie dezelfde zorgen delen of juist verschillende. Hebben jullie dit al eens besproken, of is het nieuw voor uw omgeving. Kunnen jullie de zorgen delen, of heeft u iemand anders waarmee u deze dingen bespreekt?

Bedenk wat u de ander graag zou willen zeggen, of waar de ander u mee kunt helpen.

Hoe werkt deze gesprek starter?

Stap 1: Draai aan het wiel, zodat hij stopt bij een woord. Bedenk wat dit woord betekent voor u, rondom de cognitieve klachten die u ervaart.

Stap 2: Leg aan uw gesprekspartner uit wat u ervaart met behulp van dit woord. Wat doen de klachten met u? Hoe voelt u zich hierbij? Vind u een ander woord toepasselijker? Kies dan een ander woord.

Stap 3: Draai het gesprek nu om. Laat uw gesprekspartner aan u uitleggen wat hij of zij ervaart rondom uw klachten. Gebruik hetzelfde woord, of draai nogmaals aan het wiel voor een ander woord.

U kunt dit net zo vaak herhalen als u prettig vindt. Het gaat erom dat u uw zorgen en klachten kunt delen.

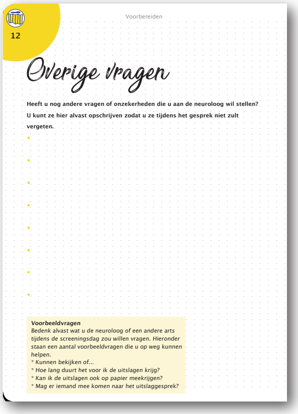
Voorbereiden

11

De woorden in het wiel

In het gesprek wiel staan ongeveer 40 woorden die u op weg kunnen helpen om de klachten die u ervaart te delen met uw gesprekspartner. De woorden zijn verdeeld in drie categorieën: emoties, behoeftes en wensen. In elke categorie zijn zowel positieve woorden als woorden met een negatieve lading. Zijn er woorden die niet bij uw situatie passen, sla deze dan gerust over.

9



Voorbereiden

12

Overige vragen

Heeft u nog andere vragen of onzekerheden die u aan de neuroloog wil stellen? U kunt ze hier alvast opschrijven zodat u ze tijdens het gesprek niet zult vergeten.

Voorbeeldvragen

Bedenk alvast wat u de neuroloog of een andere arts tijdens de screeningsdag zou willen vragen. Hieronder staan een aantal voorbeeldvragen die u op weg kunnen helpen.
** Kunnen bekijken of...*
** Hoe lang duurt het voor ik de uitslagen krijg?*
** Kan ik de uitslagen ook op papier meekrijgen?*
** Mag er iemand mee komen naar het uitslaggesprek?*

▶ ***figure 6-45:***

Preparation part of De Gids. (6) time line of patient journey, (7) explanation of preparation sheet, (8) preparation sheet, (8) conversation starter De Gesprekswiel, (9) additional questions, (10), room for thought

The questions are divided in three steps and each step should be filled out over a period of three days.

The steps are: 1 My concerns
2 My expectations
3 My help request

Each step has two or three questions that explore the topics (concerns, expectations and help request). The questions' lay out differ per step, to make it appealing to fill out.

De Voorbereidingsplaat

VUmc MS Centrum Amsterdam

Stap 1: Mijn zorgen

U bent doorverwezen naar de second opinion polikliniek MS en cognitie vanwege uw cognitieve klachten. De vragen in deze stap gaan over de klachten die u ervaart en of u zich hier zorgen om maakt. Het doel van deze vragen is om inzicht te krijgen in wat voor invloed deze klachten op uw dagelijks leven hebben. Begrijpt u een vraag niet, of vind u dat een vraag niet bij uw situatie past, dan kunt u deze overslaan.

Vraag 1. a
Wat voor cognitieve klachten ervaart u? Hieronder zijn al een paar klachten opgeschreven die u mogelijk ervaart. Zijn er andere klachten waar u last van heeft? Zet deze er dan bij. Staan er al dingen bij waar u geen last van heeft? Streep deze dan door.

Vraag 1.b
Wat voor effect hebben deze klachten op uw dagelijks leven? Schrijf de effecten in het rijtje naast de klachten.

klachten	effect
☐	☐
☐ Geheugen	☐
☐ Concentratie	☐
☐ Ik kan moeilijk op	☐
☐ woorden komen	☐
☐	☐
☐	☐
☐	☐

Vraag 2
Maakt u zich wel eens zorgen over deze klachten? Maak hieronder een overzicht waarin u uw mogelijke zorgen kunt invullen.

Mijn zorgen zijn vooral...

dat:
dat:
dat:
dat:
dat:

Conclusie
Schrijf hieronder op welke zorgen en klachten u wilt bespreken tijdens de screeningsdag.

☐ ☐
☐ ☐
☐ ☐

Stap 2: Mijn verwachtingen

Het kan zijn dat u hele duidelijke verwachtingen heeft van de screeningsdag, maar misschien weet u juist niet goed wat u kunt verwachten. Door het beantwoorden van deze vragen willen we u helpen om uw verwachtingen op een rijtje te zetten. Hoe heeft u besloten om naar deze poli te komen? Wat zijn uw verwachtingen hierbij?

Vraag 1
Wat verwacht u van de screeningsdag? In de cirkel hieronder kunt u uw verwachtingen opschrijven. Zijn er bepaalde verwachtingen extra belangrijk? Zet ze dan dichter bij het midden.

Belangrijk

Vraag 2
Wat kunnen wij doen om aan uw verwachtingen te voldoen? Beschrijf hieronder kort (in steekwoorden) wat u van ons verwacht om uw bezoek te laten slagen.

☐
☐
☐

Vraag 3
Wanneer is de screeningsdag geslaagd? Probeer te bedenken wanneer de screeningsdag voor u geslaagd is. Wat kan ervoor zorgen dat u straks tevreden bent? Beschrijf dit in het vak hieronder. Wanneer vindt u het bezoek niet geslaagd? Probeer ook dit te omschrijven.

Mijn bezoek is geslaagd wanneer
want

Mijn bezoek is niet geslaagd wanneer

Conclusie
Wat wilt u ons vertellen. Bedenk welke van de dingen in deze stap u wilt vertellen aan de neuroloog.

Dit wil ik graag vertellen:

Stap 3: Mijn hulpvraag

Wat is precies uw hulpvraag? Die vraag is vaak nog niet zo gemakkelijk te beantwoorden. Maar voor ons als zorgverleners is het wel heel belangrijk om dat samen met u helder te krijgen. Met de onderzoeken van de screeningsdag, gaan we proberen om deze vraag zo goed mogelijk te beantwoorden.

Vraag 1
Wat is de reden of zijn de redenen dat u naar deze screeningsdag gaat? Om naar deze screeningsdag te komen bent u doorverwezen door een arts. Wij zijn benieuwd naar de reden van deze doorverwijzing. Beschrijf hieronder waarom u bent doorverwezen.

Ik ben doorverwezen naar deze screeningsdag omdat:
door:

Vraag 2
Wat wilt u zelf bereiken met uw bezoek? Hierboven heeft u de reden van de doorverwijzing verteld, maar we zijn ook benieuwd wat u graag zou willen bereiken met dit bezoek. Misschien heeft u daar nog niet zo over nagedacht maar misschien juist wel. Beschrijf hieronder wat u graag zou willen bereiken met dit traject.

Ik wil bereiken dat
Ik wil bereiken dat
Ik wil bereiken dat
Ik wil bereiken dat

Conclusie
Wat is de hulpvraag die u beantwoord wil hebben tijdens deze screeningsdag? Probeer uw vraag zo duidelijk mogelijk te maken. Als u niet goed weet wat u te weten wilt komen, kunt u bekijken wat u hiervoor heeft opgeschreven. De antwoorden op de vragen van stap 1 en 2 kunnen u misschien helpen bij het formuleren van een hulpvraag.

De hulpvraag die ik tijdens de onderzoeksdag graag beantwoord zou willen hebben is:

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The first two (or three) questions in each step are meant to reflect on the topic of that step. For almost every question a beginning of a sentence is provided, to trigger the patient to finish the sentence and fill out the questions.

Every step finishes with a conclusion, which is emphasised by the blue field. These conclusions are discussed in the consultation with the neurologist on the screening day.
The questions lead up to the this consultation.

▶ ***figure 6-46:*** The preparation sheet

Preparation sheet

The questions on the preparation sheet are divided in three topics: (1) My concerns, (2) My expectations and (3) My help request. These topics were carefully selected based on the user research. Appendix G .2 - Final Design, shows a larger image of the coversation starter.

The questions of My concerns are included to make the patient think about what cognitive problems they have, how these affect their daily life. Next is asked what concerns they have in relation to these problems. Often, the problems and the effect on daily life are discussed in a consultation with neurologist, but the concerns and worries these problems (and effect) cause are left out. It is important for patients to discuss these concerns with the neurologist. The neurologist can reassure the patient based on their concerns. In the diagnosis consultation the neurologist can refer back to these concerns. This way patients will have a better grip on the situation.
The questions of *My concerns* are:

- What kind of cognitive problems do you suffer from?
- How do these problems affect your daily life?
- What are your worries concerning these problems and effect?
- Conclusion: Write down which concerns and problems you wish to discuss during the screening day.

The questions of the topic My expectations are added for the patients to realise what they expect from the outpatient clinic. The time line of the information guide is added to show what is expected of the patients, but it is even more important that patients realise what they expect from their visits to the outpatient clinic. They should be aware of their expectations. Discussing them is part of the expectation management. Patients expressing their expectations will help the neurologist realise whether these expectations are reasonable or unrealistic. Unrealistic expectations can then be managed by the neurologist. Which in the end, will result in more satisfied patients. As they know what to expect and this expectations can be realised.

The questions of *My expectations* are:

- What are your expectations of the screening day?
- What can we do to make your expectations come true?
- When will the screening day be successful for you?
- When will the screening day be unsuccessful for you?
- Conclusion: What do you want to tell us ?

The topic My help request is added to make patient think about their help request for the screening day. During the user research it appeared that often thee request are poorly formulated as patients come up with them on the spot. They have not thought about the help request and have not prepared it. Therefore, this topic is added on the poster. When the help request is well thought through, it will be of better use.

The questions of *My help request* are:

- What are the reasons you are referred to this screening day?
- What would you like to achieve with this screening day?
- Conclusion: What is the help request you wish to have answered with the screening day?

Conversation starter

This conversation starter is aimed at creating a conversation between a patient and his/her partner or a close friend. During the user research it appeared that many patients feel ashamed and scared to talk about their cognitive problems. They do not know how to discuss this with a next of kin. The conversation starter is circle containing 40 words. These words are both positive and negative emotions, needs and wishes. On top of this circle, a wheel is placed with a cut-out, that can reveal one word at a time. The wheel can be spun around

by the patient or the next of kin. When they spin the wheel, one word is shown. The purpose of this wheel is that patients can spin it and use the revealed word as inspiration to share her/his concerns, worries, problems with her/his partner. The other words are covered intendedly. This way, patients will not be overwhelmed by the amount of words. The spinning wheel is added to lower the threshold of starting a conversation. It is inviting to turn the wheel! During user observations it appeared that everybody still wanted to peek underneath the wheel, to see the other words. This makes it a bit of a playful interaction.
This conversation starter is inserted to raise awareness that problems can be discussed and it offers guiding in how to discuss them.

Information

The information part of the information guide entails four spreads. The first spread (10) has been added based on the user research and concept evaluations. This spread contains the schedule of the screening day and pictures of some of the medical professionals involved in the outpatient clinic. The user research showed that patients do not know what to expect of the screening day and this is partly caused by the fact that they do not know the schedule beforehand. Inserting the schedule in the information guide, should give patients an overview of the day. Pictures of the professionals are added to make the day less frightening and intimidating.
The information section continues with the actual information of the consultations and procedures performed during the screening day (11, 12, 13). The text has been modified to make it more patient friendly and images have been inserted for clarity. ▶

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Overzicht screeningsdag

Tijd	Onderzoek	Meekijken naaste
9:00 - 9:15	Welkom door vrijwilliger. Uitleg over het verloop van de dag.	👁
9:15 - 9:45	Gesprek met de neuroloog. Uitvragen van klachten, bespreken van hulpvraag.	👁
9:45 - 10:15	OCT: CT-scan van de oogzenuwen	👁
10:15 - 10:30	Pauze	👁
10:30 - 12:00	NPO: Neuropsychologisch onderzoek, door neuropsycholoog. Verschillende testen. Hier levert u de vragenlijsten in.	
12:00 -12:30	Lunchpauze	👁
12:30 - 13:30	MEG-scan	
13:30 - 15:00	Neurologisch onderzoek, bloedafname, hersenvocht afname (LP)	👁
15:00 - 15:30	Pauze	👁
15:30 - 16:15	MRI-scan	
16:15 - 16:30	Afsluiting met vrijwilliger	👁

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Zorgverleners

Zoals u in het schema heeft kunnen zien, zult u een heel aantal onderzoeken ondergaan tijdens de screeningsdag. Op deze pagina's staan een aantal zorgverleners van de MS en cognitie polikliniek afgebeeld. U zult niet met al deze artsen en zorgverleners te maken krijgen, maar een aantal zult u zeker tegenkomen.

Een aantal zorgverleners die u tijdens de screeningsdag kunt zien

Neurologen

Dr. B.M.J. Uitdehaag
Dr. B.A. de Jong
Dr. J. Killestein
Dr. B. van Oosten

Neuropsychologen

Drs. I.E.W. Reuling
Drs. S. Driessen

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Informatie

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De onderzoeken

De volgende pagina's beschrijven de verschillende gesprekken en onderzoeken van de onderzoeksdag. In het Overzicht screeningsdag op pagina 19 staat de volgorde van de onderzoeken beschreven.

Gesprek met neuroloog

Tijdens het gesprek met de neuroloog bespreken we uw hulpvraag. Ook zal hij/zij vragen naar uw ziektegeschiedenis, medicijngebruik en vragen of er in uw familie neuro-degeneratieve ziektes voorkomen.
Verder zal de neuroloog met u het verzoek tot deelname aan de biobank doornemen (de SOMSCOG biobank) en eventuele vragen hierover beantwoorden. Dit duurt ongeveer 30 minuten.

OCT

Om informatie te krijgen over de conditie van uw ogen wordt een OCT gemaakt (Optische Coherentietomografie). Met OCT-apparatuur kunnen we de zenuwen in het oog in beeld brengen. De dikte van de zenuwlaag in het netvlies wordt gemeten. Dit onderzoek duurt voor beide ogen ongeveer een minuut. Het is niet gevaarlijk en het doet geen pijn.

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Neuropsychologisch onderzoek

De neuropsycholoog zal een gesprek met u voeren en een aantal neuropsychologische tests doen om uw cognitief functioneren te testen. Onder andere concentratievermogen, reactiesnelheid, werktempo, geheugen, leren, taal, planning en ruimtelijk inzicht. Dit onderzoek duurt ongeveer 90 minuten.

De vragenlijsten die u thuis heeft ingevuld kunt u aan de neuropsycholoog overhandigen.
Indien u vragen heeft over het invullen van deze lijsten kunt u die stellen bij de neuropsycholoog, zodat hij/zij u kan helpen.

MEG

Een manier om de hersenen in beeld te brengen is met een MEG scan (Magneto-EncephaloGram). MEG is een apparaat waarmee de werking van de hersenen wordt onderzocht. De hersencellen produceren namelijk magnetische signalen. De MEG meet deze signalen en wij slaan ze op met behulp van een computer. Van het meten van uw hersenactiviteit voelt u niets. Het onderzoek duurt ongeveer 45 minuten. Ook dit onderzoek is niet gevaarlijk en doet geen pijn.
Omdat de signalen die een MEG apparaat meet erg klein zijn, zijn de sensoren die de hersensignalen opvangen heel gevoelig. Metalen voorwerpen zoals sleutels kunnen de MEG metingen verstoren. Dit geldt zeker ook voor elektronische apparatuur. Ook signalen uit de omgeving kunnen de MEG-metingen verstoren. Daarom bevindt het apparaat zich in een afgesloten kamer met een dikke deur. Stoorsignalen kunnen hier niet binnendringen. Het MEG-apparaat zelf is een grote helm. Daarin bevinden zich de sensoren die de signalen opvangen.

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Eerst plakt de MEG verpleegkundige een aantal sensoren op verschillende plekken op uw hoofd. Daarna betreedt u de kamer van de MEG scanner. Wanneer u op de onderzoeksbank gaat liggen, schuift u een stukje omhoog, zodat u met uw hoofd in de helm komt. De sensoren in de helm, zijn dan zo dicht bij uw hoofd dat zij via de opgeplakte sensoren op uw hoofd uw hersensignalen opvangen. Uw ogen, neus en mond blijven daarbij vrij. Het is belangrijk dat u comfortabel ligt. Als u goed ligt, krijgt u uitleg over wat u tijdens het onderzoek moet doen. Meestal moet u eerst langere tijd rustig liggen met de ogen gesloten. Soms moet u bepaalde bewegingen maken met uw handen en/of voeten.

Tijdens het onderzoek gaat de deur dicht, maar niet op slot. De MEG verpleegkundige kan u via een camera zien en u kunt via een intercom met hem/haar praten. Van de metingen zelf merkt u niets. Als het onderzoek klaar is, schuift u uit de helm, en kunt u afgeschermde kamer verlaten.
Daarna verwijdert de MEG verpleegkundige de sensoren die op uw hoofd zijn geplakt.

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Het lichamelijk neurologisch onderzoek

De arts-assistent doet een lichamelijk neurologisch onderzoek bij u. Door dit onderzoek kunnen lichamelijke neurologische functies, en eventuele stoornissen en beperkingen in kaart worden gebracht. Om de fijne handmotoriek beter in kaart te brengen wordt een "9 hole peg test" uitgevoerd. Tijdens deze oefening vragen wij u om zo snel mogelijk 9 staafjes uit een bakje pakken en deze in de openingen van een bord steken en ze daarna weer zo snel mogelijk terug te leggen.
De arts-assistent onderzoekt u, doet een ruggenprik en neemt bloed af. Dit duurt alles bij elkaar ongeveer 75 minuten.

Ruggenprik

Een ruggenprik (lumbaalpunctie) is een onderzoek waarbij een hoeveelheid (ongeveer 25 ml) hersenvocht (= liquor) wordt weggehaald.
Rond de hersenen en het ruggenmerg zitten vliezen. Tussen deze vliezen zit de liquor dat werkt als een soort stootkussen om de hersenen en het ruggenmerg te beschermen.

De ruggenprik wordt in het onderste gedeelte van de wervelkolom uitgevoerd. Met een hele dunne naald prikt de arts-onderzoeker in de liquorruimte om zo wat liquor weg te halen. In het gedeelte

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waar geprikt wordt bevindt zich geen ruggenmerg, alleen liquor. Het is dus niet gevaarlijk voor het ruggenmerg.
Bij dit onderzoek ligt u zit u met opgetrokken knieën. U moet uw neus zoveel mogelijk naar uw knieën brengen. De bolling van uw rug is nodig omdat op deze manier de ruimte tussen de ruggenwervels van de wervelkolom zo groot mogelijk wordt, zodat de arts-onderzoeker ruimte heeft om te kunnen prikken.

De arts-onderzoeker smeert uw rug in met jodium. Vervolgens prikt hij/zij met een hele dunne naald in het onderste gedeelte van de wervelkolom, tussen de lendenwervels. Dit prikken is meestal niet pijnlijker dan een bloedprik in uw arm. Een enkele keer lukt het niet de juiste plaats direct te vinden. De naald wordt dan opgeschoven. Soms geeft dit heel even een pijnlijk gevoel.
Als de naald goed zit duurt het een paar minuten voor er voldoende liquor is afgenomen. Het afnemen van liquor doet geen pijn. Wanneer voldoende liquor is afgenomen (minimaal 10 cc) verwijdert de arts-onderzoeker de naald. Heel soms kan het voorkomen dat u hoofdpijn krijgt na het onderzoek. Deze hoofdpijn is onschuldig en verdwijnt meestal als u gaat liggen. Het kan voorkomen dat de hoofdpijn enige dagen duurt.

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MRI hersenen

Bij een MRI-scan (MRI = Magnetic Resonance Imaging) worden de hersenen in beeld gebracht. Het onderzoek doet geen pijn en is niet gevaarlijk. We maken een gewone MRI-scan van de hersenen en ook een functionele MRI-scan. Deze scan lijkt erg op de andere MRI-scan, maar met deze functionele MRI kijken we ook naar de verbindingen binnen de hersenen.

Het MRI apparaat ziet eruit als een kleine tunnel die aan het hoofd- en voeteneinde open is. Voor het onderzoek ligt u op een verschuifbare tafel in deze tunnel. Rustig ademhalen, stilliggen en ontspannen is heel belangrijk.

Het onderzoek duurt ongeveer een half uur en het doet geen pijn. Tijdens het maken van de afbeeldingen hoort u een kloppend, tikkend en ratelend geluid van de MRI. Dat is normaal. Het geluid is niet continu, maar in sessies van enkele minuten en het verschilt in sterkte en tempo. De radiologisch laborant kan u tijdens het gehele onderzoek zien en u kunt met hem of haar praten.
Tijdens het onderzoek mag u geen metalen voorwerpen dragen.

▶ ***figure 6-47:*** Information part of De Gids. (10) Schedule screening day and pictures of care providers, (11, 12 and 13) explanation of the consultations and procedures performed during the screening day.

Additional functions

There are two functions that have not been discussed yet: the pages that function as a notebook (14) and the reflection spread (15), these are shown in figure 6-48 on page 130. The notebook pages can be used at any point: during the preparation or during the screening day. They are there to serve the patients needs.

The last spread of this guide contains questions with which patients can reflect on their SOMSCOG journey. These questions are added based on the contextmapping research. Part of the sensitising booklet were questions about patients' expectations of the screening day and the diagnosis consultation. The aim of these questions were to find out if patients expectations were met, but it appeared that these questions had a side effect. With the help of these questions patients realised what they wanted to get out of the SOMSCOG outpatient clinic, and whether that was achieved or not. It provided them with valuable insights. Therefore, these questions are inserted in De Gids.

The questions of the reflection are divided in two parts, and are shown here:

1. The questions are about your expectations of the screening day
    - I went to the screening day and my goal for this day was:
    - This is what I expected of the screening day
    - This was in line with my expectations:
    - This differed from my expectations

2. These questions are about your expectations of the diagnosis (consultation)
    - This is what I expected from my diagnosis consultation visit:
    - This was in line with my expectations
    - This differed from what I expected:

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Aantekeningen

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Aantekeningen

Deze pagina's zijn voor aantekeningen tijdens de screeningsdag zelf, of voor andere dingen die u misschien kwijt wilt.

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achteraf

Vragen achteraf

Deze vragen zijn bedoeld om na uw bezoeken en uitslaggesprek na te denken of uw bezoek geslaagd was.

De vragen op deze pagina gaan over de screeningsdag. Bedenk eerst waarom u ook alweer naar de screeningsdag bent gegaan.

1. Ik ben naar de screeningsdag gegaan met als doel:

2. Dit verwachtte ik van de screeningsdag:

3. Dit kwam overeen met mijn verwachtingen:

4. Dit was anders dan ik verwachtte:

achteraf

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De vragen op deze pagina over gaan over uw uitslag bezoek aan het VUmc (de dag waarop u de uitslagen van de onderzoeken kreeg) van de SOMSCOG poli.

1. Dit verwachtte ik van mijn uitslag bezoek:

2. Dit kwam overeen met mijn verwachtingen:

3. Dit was anders dan ik verwachtte:

Heeft u nog vragen?

Zijn er nog onduidelijkheden, of heeft u toch nog vragen na het uitslaggesprek?

Neem dan contact op met de MS-verpleegkundige: (020)- 444 0775

Maandag - donderdag van 10:00 - 11:30 en vrijdag van 11.30 - 13.00 uur.

Via MijnDossier kunt u ook uw vragen stellen.

▶ ***figure 6-48:*** Additional functions of De Gids. (14) notebook, (15) reflection.

6.e Future steps

Some steps have to be taken to start using De Gids in the SOMSCOG outpatient clinic. This paragraph describes shortly what actions should be taken for implementation of De Gids. Furthermore, an estimation of production costs are shown.

6.e.1 Implementation

To implement De Gids in the current set up of SOMSCOG outpatient journey the following steps have to be taken

- Final review of content and lay out
- Find a publisher/printer who can print the guide and sheet and folder. Make sure the publisher also provides finishing services. Two spreads of the guide have to be glued together: one spread has to be partially glued to insert the preparation guide. One spread has to be glued together for extra stability. In the current version of the conversation starter, a cotter pin is used to turn the wheel. Inserting this pin and glueing the pages together is an expensive procedure. Therefore a stick-on pin should be considered, this would make the production of the conversation starter more feasible.

- The neurologists of the SOMSCOG outpatient clinic need to be informed of the preparation sheet. A short workshop should be provided to explain the use of the sheet in the consultation.
- Together with this workshop, the SmartFrase (consultation protocol in Epic) should be updated, implementing the use of the sheet in the consultation.

- -The desk employees should be instructed about how the different parts of De Gids need to be assembled, including the questionnaires, information letter and informed consents. Furthermore, sending all the information and De Gids should be done two weeks prior to the screening day.

Other steps that need to be considered before implementation of De Gids are shown in chapter 9 Recommendations on page 148.

6.e.2 Costs

An estimation of production costs are shown here. Keep in mind that these are very rough estimations and costs differ per publisher. The estimation of printing and finishing are based on a short research with different online printers and publishers. Further explanation and nuances of the costs can be found chapter Discussion on page 152.

- Printing cost guide based on 36 pages and batch size of 100 pieces: **€350,- excl. VAT**
  This includes cutting the corners, folding and stapling

- Finishing costs of glueing pages to create compartment for preparation sheet. And for a batch of 100 pieces: **€200,- excl. VAT**

- Printing and folding of preparation sheet, batch size of 100 pieces: **€150,- excl. VAT**

- Costs of a designer to finalise the design and order the different parts of De Gids: **€1.200,- excl. VAT**
  These costs are based on a rate of €60,-/h, and 20 hours are needed.

- Unforeseen costs: **€500,- excl. VAT**

Total investments needed to implement De Gids in the current SOMSCOG outpatient clinic:
€2.400,- excl. VAT ■

SECTION D - EVALUATE

7 EVALUATION

During the conceptualisation phase different design decisions have been made. The design goal was to design a tool that will help patients prepare for their hospital visit, that will guide them through the day and provide an overview of the whole journey. This tool aimed to improve the overall patient experience and make a positive impact on the patient's quality of life.
De Gids was designed to change the current preparation and information of the SOMSCOG outpatient clinic.
An evaluation study was conducted to review De Gids, and to find ways to improve this design. Both patients as neurologists were included in this study, as they are both users of De Gids.

7.a Goal

The goal of the evaluation study was to collect feedback on the design, the design goal, criteria and the interaction visions. Therefore, the following research questions have been formulated.

Patient specific

- Does De Gids help patients to prepare for their visit to SOMSCOG outpatient clinic and does it help them formulate a help request? (patient participation)

Neurologist specific

- To what extent does De Gids support the patient to share their story and become a more active conversation partner?

General

- How is De Gids appearance and usability experienced?
- How would De Gids be integrated in the current patient journey and consultation?
- How does De Gids influence the interaction between patient and neurologist during the consultation?
- How are the design criteria met?

7.b Method

The evaluation study was spread out over one week and encompassed interviews with two neurologists and three patients who had visited the SOMSCOG outpatient clinic.

It was unfortunately not possible to include new patients who had not been to the screening day yet, due to METc regulations and use De Gids as a real preparation tool and in a real consultation.

Participants

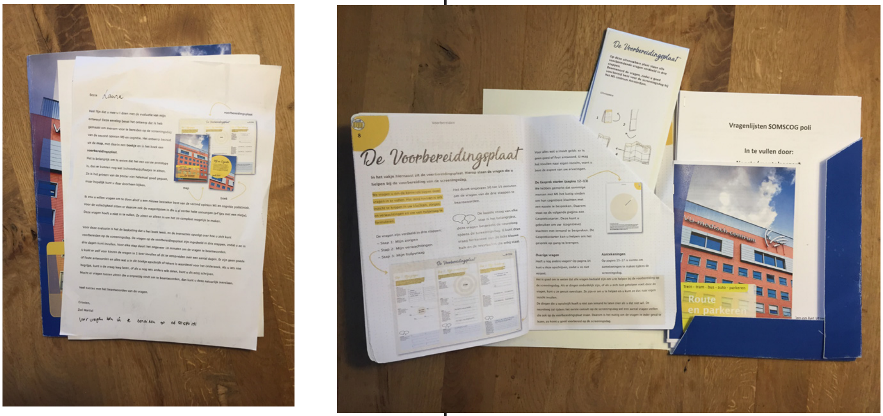
Three patients and two neurologists participated in this evaluation study. The patients were participants of the previous user study and indicated on their informed consent form that they could be asked for future research. The participant were three women, aged 59, 50 and 36 living in different parts in the Netherlands. They were contacted by phone and were asked if they wanted to participate in this evaluation study.
The neurologists work at the SOMSCOG outpatient clinic and responded to an email sent to in which they were asked to participate. One of them has also been a participant in the medical professional interviews, the other has not been part of this project.

Procedure patient interviews

A few days prior to the interview, De Gids was sent to the patients. Included in De Gids were the folder, the information guide, the preparation sheet and a pen. Furthermore, the questionnaires and an information booklet of the VUmc that SOMSCOG patients receive were included to make it as realistic as possible. On top the folder an instruction letter and an information letter of this evaluation were added. figure 7-49 shows the package that was sent to patients. This evaluation letter was obligatory according to METc regulations.

The instruction letter was to explain what was expected from the patients. Both can be found in Appendix F.1 and F.2 – Evaluation study.
Patients were asked to read the information guide as if they were new to the outpatient clinic, and they were asked to fill out the preparation sheet.
A few days after the package was sent and before the interview, the researcher called the patient to see if everything was clear.

Two of the patient interviews were at their own house. One patient offered to come to a community house with working spaces, to save the researcher travel time. The interviews lasted between 68 and 90 minutes, following the semi-structured interview guide from appendix F.4. Each patient was asked to sign an informed consent form and was asked for permission to audio-record the interview.
All patients gave permission. Then the goal of ►



► **figure 7-49:** The package sent to patients (1) the folder with the information letter and explanation, (2) the content of the folder the study was explained, and it was emphasised that they could share any thoughts and points of improvement of the design. During the interview notes were taken, to shorten the transcription time afterwards. The focus of the interview was on the preparation sheet because this is a new element that has been added to the current process. The new elements of the information guide were also evaluated.

Interviews with neurologists were done at the hospital, following the semi structured interview guide from Appendix F.5 and they lasted for twenty minutes. Each interview started with thanking them for their time and the explanation of De Gids. Notes were taken during the interviews.

At the end, the participants were thanked for their time and feedback.

Data
Data collected during evaluation included:

- Notes from both patient and neurologist interviews
- Audio recordings patient interviews
- Notes and feedback written on De Gids

7.c Results

Important quotes of the audio-recordings were transcribed and analysed. A targeted search was conducted to find answers to the research questions. The outcomes of this analysis can be divided in five categories, which are based on the research questions:

1. Triggering patient activation
2. Influence on current interaction of consultation
3. Integration in current consultation
4. Appearance and usability
5. Design criteria

From these conclusions some recommendations were drawn which are shown in chapter 10. What was remarkable is that overall, all neurologists and patients gave positive feedback on De Gids and specifically on the preparation sheet.

7.c.1 Triggering patient activation

De Gids and the preparation sheet is inviting to use as a preparation tool.

> “Ik vind het ontzettend leuk dit. Als ik dit krijg kan ik er zo mee aan de slag. Het dwingt me om na te denken.”
> – Patient 3

Patients state that it is important to come prepared to the consultation. Because the consultation is where their cognitive symptoms are discussed.

> “Dit is voor de mensen zelf, om goed voorbereid daar te komen. En dat is natuurlijk superbelangrijk.” - Patient 3

During the evaluation study, only one patient filled out the preparation sheet. Two patients did not understand the instructions and hadn’t filled out the questions. They did carefully inspect the sheet and gave feedback on the questions.

> “Goh, je zal dit toch krijgen, als je onderzoek moet laten doen. Ik zou dat fijn vinden als je zo wordt voorbereid. Ik heb dat nog nooit meegemaakt.”
> - Patient 1

When the patients prepare themselves for the

consultation with the preparation sheet, they want to share the conclusions of the sheet with the neurologist. They state they will use the sheet as a mnemonic and guideline for their story.
Both patients and neurologists highly value the first step of the preparation sheet. This step – My concerns – addresses both the complaints, the effect of the complaints and the concerns of the patients.

> “Bij stap 1 moet hij dan doorgaan op de effecten en vragen wat de patiënt erbij voelt. Dat hij dus meer in die patiënt duikt, dus dat die zorgen dat hij daarin duikt.
> - Patient 1

Two patients said it was important to share their concerns with the neurologist. One patient did not know whether the SOMSCOG outpatient clinic was the place to do this, but she would share it with her own neurologist. This indicates that not all patients are willing to share their concerns about their cognitive issues with the neurologist of the screening day.

The buildup of the questions was also evaluated as good. The first questions in each step were seen as personal reflections and evaluations and these lead to more specific conclusions. All patients stated that it was important to discuss those conclusions in the consultation.

Conclusions triggering patients

The appearance of De Gids and specifically the preparation sheet triggers patients to fill out the questions. Patients are keen to fill out the sheet and to bring it to the consultation. Things that should be discussed during the consultation are the conclusions of the questions and the concerns from step 1.
Neurologists feel like the preparation sheet can have a positive influence on the consultation. Especially the questions regarding symptoms, effects of the symptoms and the patient concerns are highly valued. Currently questions about their worries are not asked in the consultation. Patients find it pleasant that the questions on the sheet lead up to conclusions, which will be shared with the neurologist. When asked about bringing the sheet to the consultation, they all said it would be very useful as a mnemonic tool, and a guideline for the conversation.

The extra time that is needed to fill out the sheet was not seen as a barrier. Patients fill like this would provide some grip on the situation.

7.c.2 Influence on current interaction of consultation

Both neurologists said that it could help the patients to share more than they currently do. Now patients often say ‘yes’ but they do not show a lot of initiative. In an ideal scenario, using the preparation sheet during consultation could save time as the patient knows what to tell and expect from the consultation.

> “In het ideale geval komen we doordat ze deze plaat hebben ingevuld sneller ter zake, het kan tijd besparen.”
> - Neurologist 1

However, it could also have the opposite effect. When patients expect the neurologist to discuss every detail of what they have written down.

> “Als patiënten denken: ik ga de avond ervoor er eens lekker voor zitten. Dat ze alle punten opschrijven, en al deze punten ook willen bespreken tijdens het consult. Dan zou het wel langer kunnen gaan duren.”
> – Neurologist 1

Neurologist can imagine how the sheet is used during consultation and they are open to it. They see that this could be a helpful tool for the patient. ▶

> "Ik denk dat het voor de patiënt best een hulpmiddel kan zijn."
> - Neurologist 1

Both neurologists also mentioned that it was very good that patients' concerns are explicitly mentioned. This could be beneficial for the diagnosis consultation.

> "Expliciteren van zorgen, lijkt met ook goed. Ook is het belangrijk voor het uitslag gesprek om te weten wat de zorgen zijn. Dan kun je daarop teruggrijpen bij het uitslag gesprek of de zorgen terecht zijn, of dat het niet nodig is."
> - Neurologist 2

Expectations are important to address during the first consultation according to the neurologists. One neurologist mentioned that the difference between expectations and help request is small currently the topics of the two overlap.

> "Het is zinvol om op de verwachtingen in te spelen tijdens het gesprek. Dat is wel belangrijk, dan kun je onrealistische verwachtingen wegnemen."
> – Neurologist 2

Patients mentioned that the use of the preparation sheet during the consultation would help to have a conversation. By using a tool, a conversation will be established instead of being interviewed.

> "Doordat er iets op tafel ligt komt er meer een gesprek op gang, omdat het tastbaar is. Het wordt meer een communicatie in plaats van een vragenvuur. Dat bereikt dit ding volgens mij wel, mits de neuroloog ook de patiënt de ruimte geeft om tot een gesprek te komen."
> – Patient 1

Conclusions influence

The preparation sheet could positively influence the consultation. It could even have an influence on the diagnosis consultation when concerns are discussed in the first consultation. During diagnosis the neurologist can refer to the concerns and either confirm on invalidate these concerns. The preparation sheet could help in having a balanced conversation between patient and neurologist.

A risk of the sheet is that patients wish to discuss every detail of what they have written on the sheet. This could make the consultation last longer, which is an undesired situation. That means that the neurologist should play an active role as conversation leader. Currently this is also the case, but often the neurologist has to pull information out of the patient. With the use of the preparation sheet it could be the case that this leader role changes from pulling information to guiding the patient to important details. It is important to make it clear to the patient that only parts of the preparation sheet will be discussed during the consultation.

7.c.3 Integration in current consultation

For the most optimal use of De Gids, it should be sent to the patients two weeks prior of the screening day. This way there is plenty of time to prepare in steps. Patients recognise that it would be best to fill out the preparation sheet over a longer period of time.

> "Als je het echt goed wil doen, dan moet je het even wegleggen en dan zie weer iets nieuws. Dan ga je erover nadenken en denk je: ohja."
> - Patient 2

To properly integrate the use of the preparation sheet in the current consultation, neurologists should be aware of the existence of the sheet. Patients all state it would be useful to bring the sheet to the consultation. They indicate that the protocol of the consultation should be adapted to the use of the preparation sheet.

> "In de vraagstelling moet de arts het ook gaan volgen, het moet eigenlijk wel synchroon gaan lopen. Zo'n arts volgt ook een protocol, een gespreksopbouw."
> – Patient 2

Next to being aware of the existence of the sheet, the neurologist should use the same words as used on the sheet. Otherwise, patients might not be aware they are addressing the same topic.

> "Dan moeten de vragen ook niet anders klinken dan dat het hier staat. Het zal voor haar hetzelfde zijn, maar ze moeten ook hetzelfde klinken. De vragen moeten op dezelfde manier gesteld worden. "
> – Patient 3

Patients legitimately asked whether De Gids could also help them prepare for the diagnosis consultation. In the current version this is not the case. They also mention that at the end of the second opinion journey, they still had some questions regarding the diagnosis. They did not know where they could address these questions.

Overall, patients think that using the preparation sheet in a consultation would lead to an organised conversation in which both patient and neurologist get the information they need from the other.

> "Als de vragen van de plaat gesteld worden, dan heb je een heel gestructureerd gesprek en kan je in een half uur een heleboel."
> – Patient 3

Conclusions integration

Both patients and neurologists see the added value of the De Gids. Patients were most optimistic about integrating De Gids in the current SOMSCOG outpatient clinic. They even stated that it would be good to make a more generic version for other situations. The neurologists were also enthusiastic, and one even thought a trial would start to put this in practice.

To integrate the preparation sheet in the current consultation, the Smartfrase used by neurologist should be slightly adapted. Smartfrase is the consultation protocol in Epic used by neurologists. The topics that should be addressed during consultation are listed. Some extra topics from the preparation sheet should be included.

Currently it is not indicated in De Gids that patients should fill out the preparation sheet in steps. It would be good to mention this. A distinct preparation step for the diagnosis consultation could be added. This would improve the diagnosis consultation from the patient's perspective. Furthermore, the neurologist should mention the last pages with questions. Patients can fill this out to find out if questions arise after consultation.
To have a good ending of the second opinion journey, a MS-nurse should call two weeks after the diagnosis. This gives patients time to reflect on the diagnosis and provide them with a possibility to ask the last questions.

7.c.4 Appearance and usability

Overall the appearance of De Gids was described as appealing and inviting to use. All patients said the preparation sheet and information guide looked very appealing and they were eager to fill it out.

> "Ik vond de plaat best wel leuk. Ik vond het overzicht fijn en goed dat je kan schrijven."
> – Patient 2

Patients thought the sheet was much better than those "boring forms" they usually get. It triggers them to start. Also, the neurologists mentioned ►

that they could imagine patients would be triggered to use the sheet.

> "Ik kan me voorstellen dat het er aantrekkelijk uitziet voor een patiënt."
> – Neurologist 2

The preparation sheet was seen as organised and structured. The steps of the sheet were clear and easy to understand. For certain questions extra room was needed to write down the answers.

> "Het ziet eruit of het makkelijk in te vullen is, wel een goeie."
> – Neurologist 1

The questions in My expectations could be interpreted in various ways. Some patients thought it was about what they expected from the day itself, other thought it meant what they wanted to get out of the day.

> "Verwachtingen lijkt me goed dat het betekent wat ze van de poli, de afspraken en de SOMSCOG verwachten. Wat heb je aan de hele SOMSCOG, wat heb je eraan om ernaartoe te gaan."
> – Neurologist 2

Overall, both the patients and neurologists appreciated De Gids and saw its positive effects.

> "De onzekerheid is enorm als je hier heen gaat, en het is toch fijn om deze leidraad te hebben. Dat is dit, een leidraad."
> – Patient 1

Conclusions appearance & usability

Patients indicated that they are triggered to prepare for the screening when they receive De Gids. It looks appealing and it invites them to use it. A final review is needed and then De Gids is ready to be used.

7.c.5 Design criteria

Patients were asked to rate the design criteria of De Gids. The image below shows how the criteria were rated.

As you can see, the patients rate the first criteria quite high. The think De Gids would help them to prepare for their visit to SOMSCOG outpatient clinic.

> "Ik denk dat het voor de voorbereiding heel erg kan helpen."
> – Patient 2

The second and third criteria are also reached. Patients said it would offer guidance during the day, as the schedule of the screening day is inserted in the information guide. By answering the questions on the preparation sheet, self-reflection is stimulated, according to the patients in this evaluation.

The fourth criteria - stimulate cooperation with next of kin - is not achieved by De Gids. Patients did not really use the Gesprekswiel because either they did not have anybody to use it with or they felt like they did not need it.

> "Hij is superhandig als je er iemand voor hebt om het echt mee door te nemen. Nu heb ik dat niet. "
> – Patient 3

However, even if the Gesprekswiel hasn't been used, patients liked that it was inserted in the booklet.

> "Hoe dan ook is het bijna leuk om uit te brengen zonder boekje. Meer voor een MS gesprekspartner. Je zou hem eens moeten aanmelden bij het MS -fonds ofzo. In het boekje is het meer een leuke toevoeging."
> – Patient 2

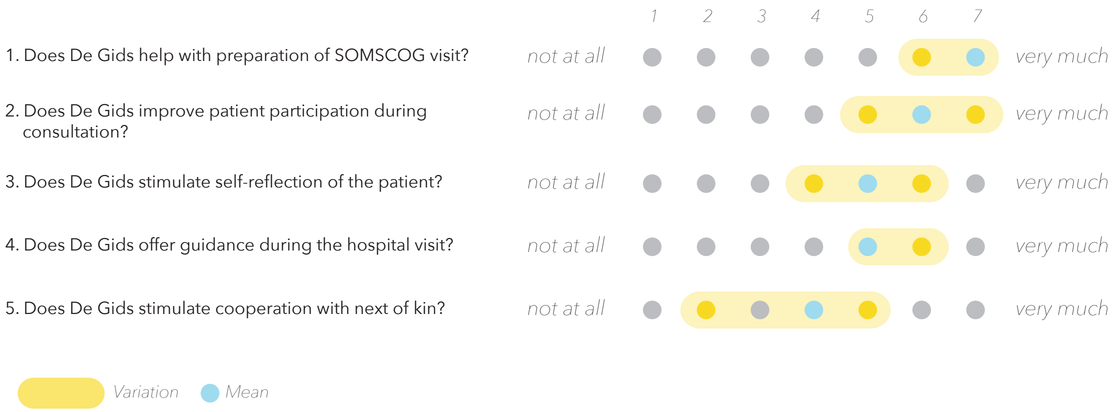
The last criteria, improve patient participation is evaluated good. Patients feel like this will be the case when the neurologist is also involved in using the preparation sheet.

> "De neuroloog gaat ook vanuit die plaat uit, zij moet ook van die plaat uitgaan. Het moet ook haar leidraad zijn om het gesprek te voeren."
> – Patient 3

Conclusions design criteria

Overall, most of the criteria are reached up to a certain point. Especially offering help in preparation and improving patient participation is recognised by the patients. There is a lack in stimulation of cooperation with next of kin. This is something that could be improved.

The next chapter shows recommendations of how De Gids can be improved. ■



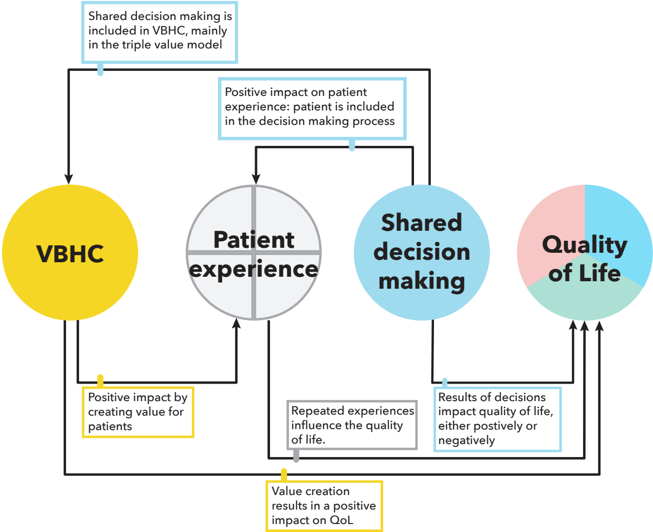
▶ ***figure 7-50:*** De Gids rated on the five design criteria. It shows that the first and most important two criteria get the highest score. Please note that only three participants were asked to rate the criteria. Therefore, one cannot made conclusions based on this figure.

8 CONCLUSIONS

At the start of this project a project aim was formulated. The aim of this assignment was to design a product, service or product-service system that helps to improve the patient experience of MS patients who visit the SOMSCOG outpatient clinic phase at VUmc.

The first section of this thesis – Explore entailed the research part of this assignment. Chapter 1 – literature study – provided an overview of the research, setting the objective concerning and explaining the relevance of the user study.

It included information on MS and cognitive problems, as well as patient experience and quality of life. A model was created to link patient centred strategies together. figure 8-51 below shows this model where the different patient centred care methods are combined.



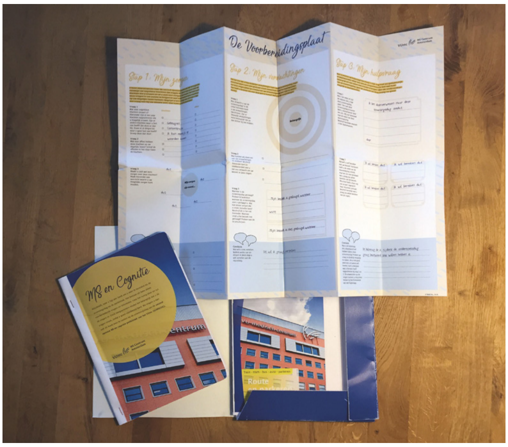
▶ ***figure 8-51:*** Patient centred care strategies combined in one model.

The user study – chapter 2 – provided insights in the current situation. It uncovered the needs of patients visiting SOMSCOG outpatient clinic, showed the actors involved in the outpatient clinic and their interactions. The user study concluded with a patient journey map which showed all the steps patients go through in their SOMSCOG outpatient clinic journey - see figure 2-23 on page 74. The main conclusions from the user study are that the needs of SOMSCOG outpatient clinic patients are fundamental such as transparency, clarity and honesty.

In section 2 – Define – the transition from the research phase to the design phase is made by finding overarching insights and design directions. To develop a tool a more accurate design goal was formulated:

I want to create a tool that will help patients prepare to for their hospital visit, that will guide them through the day and provide an overview of the whole journey. This tool should improve the overall patient experience and make a positive impact on the patient's quality of life.

In the third section – design – this design goal was explored, and it resulted with the final design: De Gids. De Gids is a physical, paper guide with a preparation poser, that helps patients prepare for their SOMSCOG outpatient clinic visit. More specifically, it helps them to prepare for the consultation with the neurologist. De Gids encompasses a folder, an information guide and a preparation sheet. The information guide contains information of the screening day, the schedule, possible outcomes and treatment options. It also contains a conversation starter which can be used by patients and a next of kin to share their worries. The preparation sheet contains questions that prepare the patient for the consultation with a neurologist on the screening day.



▶ ***figure 8-52:*** Impression of De Gids

The final evaluations showed that both patients and neurologist valued the use of De Gids. Patients think De Gids and the preparation sheet can positively influence the consultation with the neurologist. It could establish a balanced conversation between the two. Neurologists value the fact that the preparation sheet can be a helpful tool for patients to share their story and to show more initiative during consultation. However, it was mentioned that they should not have too much initiative, because then the consultation could take too long. Neurologist should be made aware of this risk.

An important feature of De Gids is the conversation starter in the information guide. This conversation starter was aimed to invite patients to talk about their cognitive problems with a partner or a next of kin. However, evaluations showed that people were not inclined to use it. The reasons for this varied, but it clearly showed that changes should be made for the conversation starter to work.
The use of De Gids can be extended for other consultations in healthcare. Especially the preparation sheet could be used in other consultations. Of course, now there is a clear focus on cognitive problems. However, if the questions on the sheet are more generic, it can be used in multiple MS consultations.

Addressing the aims and goals of this project

The aim of this project was to improve the patient experience of MS patients visiting the SOMSCOG outpatient clinic.

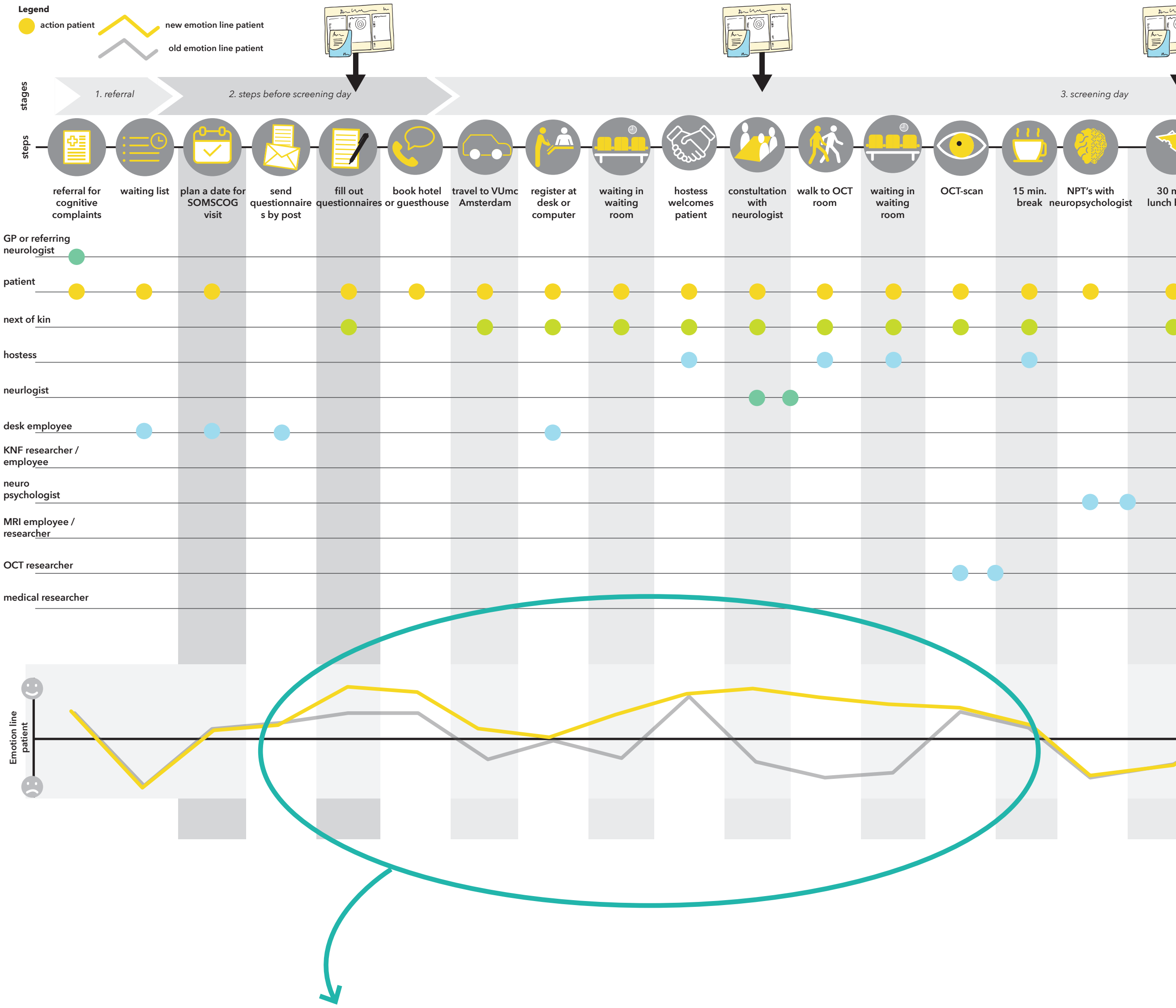
Furthermore, the design goal stated that a tool had to be created to that will help patients prepare to for their hospital visit, that will guide them through the day and provide an overview of the whole journey. I can conclude that De Gids does help patients to prepare for the outpatient clinic visit, it also guides them, and it gives them an overview of the journey. The second part of the design goal was: This tool should improve the overall patient experience and make a positive impact on the patient's quality of life. I would say that with De Gids, I have succeeded in improving the patient experience of MS patients visiting the SOMSCOG outpatient clinic. However, not the whole experience was improved by De Gids. It is limited to the experience of the first stage – the preparation phase. I would imagine that this does impact further experience, but that cannot be concluded from the evaluations that were performed. figure 8-53 on page 146 shows the impact of De Gids on the current patient journey. It shows point in time when De Gids is used and it shows how the emotion line changes by the use of De Gids.

It is difficult to say whether De Gids has a positive influence on the quality of life of patients. In chapter 1 is explained that quality of life is influence by many internal and external factors. The SOMSCOG outpatient clinic visit is one of many other hospital visits. The use of De Gids would be just another external factor. However, when looking at the reactions from patients during the ▶

evaluations, I see that especially the preparation sheet has a lot of potential to be successful in creating a positive impact on patients' quality of life. Further research is needed to validate this claim. In chapter 5 – ideation, the idea clusters were grouped in four categories: small wins, medium wins, large wins and extra-large wins. It was then decided to continue with the large wins category. When looking at the influence of De Gids on the patient journey, it can be concluded that one direction of the extra-large category has also been reached. The direction was: Educate the patients to show the importance of patient participation. One might say that by using De Gids, patients are getting prepared and inherent to this, patients are silently getting educated and patient participation is improved. De Gids does not have an educative approach, an effect of using De Gids is that patient learn how to prepare for a consultation, and improved patient participation is a beneficial consequence.

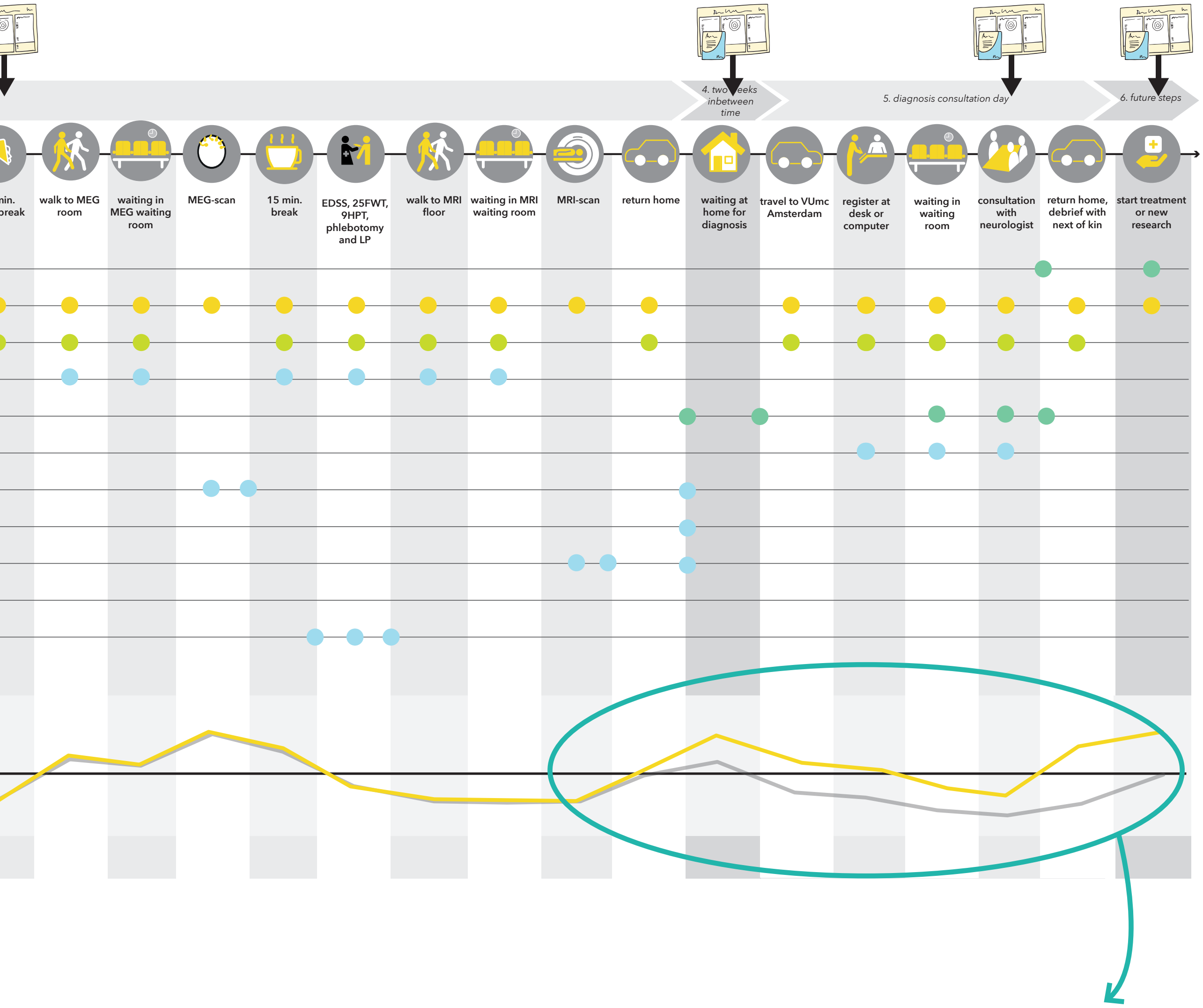
The next chapter lists recommendations for improvements and implementation of De Gids. The limitations of this project and contributions of this project are discussed in the last chapter of this thesis. This chapter also discusses how the interaction vision and design criteria are evaluated. ■

Patient journey SOMSCOG outpatient clinic: Impact of De Gids



The emotion line of the patient is expected to be more positive in the beginning of the patient journey. By using De Gids, patients are more prepared and feel more in control. This is reflected on the emotion line, by feeling more positive emotions.

▶ ***figure 8-53:*** The impact of De Gids on the patient journey. This image shows six points where De Gids impacts the journey. It also shows how the emotion line changes by the use of De Gids. The grey emotion line is the old line, the yellow emotion line is when De Gids is used.



At the end of the patient journey, patients are also expected to have a more positive feeling, which is reflected in the emotion line. Again, this is due to the preparative but also due to the reflective character of De Gids.

9 RECOMMENDATIONS

The recommendations are divided in three topics: De Gids, SOMSCOG process and project. The first topic consists of recommendations concerning De Gids. The chapter continues with recommendations to improve the SOMSCOG from patients' perspective. In the last paragraph of this chapter recommendations concerning this project are described.

9.a De Gids

An extra step could be added in De Gids that helps patients prepare for the diagnosis consultation. Clear instructions are needed of how they can prepare for this conversation. This could be included in the information guide. I wouldn't recommend including this extra step on the preparation sheet as this would interfere with the current overview of the sheet.
Furthermore, the conversation protocol of the diagnosis consultation (SmartFrase) should contain a reminder to emphasise the importance of filling out the last questions in the information guide. These questions can help patients to reflect on what is achieved with the SOMSCOG outpatient clinic. Also, it can help them finding out what questions might arise after the diagnosis consultation.

The order of information in the information guide can be improved. The chapter praktische zaken (page 17-18) should be moved after page 5. Praktische zaken contains patients need to see at first glance and multiple times.

The text of the information guide and preparation sheet should have one final review. Aim of this review is to make the text as clear and correct as possible. Furthermore, het Taalpunt, the illiteracy centre of VUmc, should be asked to review the text. The aim of this is to make the text better suited for people who have literacy problems.

Some information needs improvement, such as risks of post puncture headache (PPH) after the lumbar puncture. There are numbers available from research of prevalence of PPH, but these are not mentioned in the information guide. During user observations it became apparent that many patients suffer from PPH, and some feel misinformed with the current information guide. From risk communication perspective it would be wise to include these numbers

It is not clearly mentioned in De Gids, that the questions on the preparation sheet should be answered in multiple days. Therefore, an additional comment needs to be added in the information guide or on the preparation sheet that the questions should be answered over a in multiple days e.g. three days. To stimulate this, it also needs to be included in the overview of the journey on page 6 and 7 of the information guide.
The pictures of the medical professionals working at SOMSCOG outpatient clinic should look identical. Now there is a clear distinction between neurologists and neuropsychologists. Furthermore, the way they are presented in the information guide is quite static. An iteration should be made to make it more interesting.

User observations showed that the goal of the screening day is not always clear to patients. For some patients the difference between scientific research and patient care is unclear. It appeared that some would like to know which parts of the day are for research and which are for patient care. This could be better indicated in the information guide. However, now that the SOMSCOG outpatient clinic is up and running, all the examinations of the screening day serve both purposes.

The current version of the Gesprekswiel should be improved. At the moment it does not trigger patients to use it. Evaluations showed that patients value this conversation starter, but none of them has used it. They all had their reasons not to use it. But this shows that the current Gesprekswiel does not work for these patients. Therefore, it should be revised. Further testing is necessary to improve the Gesprekswiel.

As can be seen in the cost specification of chapter 7.d.2, there are quite some investments needed to produce De Gids. Especially adding De Gespreksweil in the information guide is an expensive feature. Therefore, a minimum viable product could be considered. In this minimum viable product, the Gesprekswiel could be excluded. This would make the information guide less expensive and still useful. A result of excluding the Gesprekswiel is that the last criteria will not be achieved. But as this is the least important criterion, the design goal will still be reached. Furthermore, to reduce costs, a generic folder of VUmc or Amsterdam UMC could be used.

In the final phase of this project, VUmc merged with AMC into one hospital: Amsterdam UMC. A consequence of this merge is that the corporate style changed. To make De Gids ready for use, the lay out should change to fit in the new style. Logos of and references to VUmc should be replaced by Amsterdam UMC and the style rules of Amsterdam UMC should be applied.
An ideal situation is one in which the website of the MS Center Amsterdam (due to the merge the name is no longer VUmc MS Center Amsterdam) contains a lot valuable of information. If this would be the case, there should be references to the website in the information guide. These should refer to videos explaining the different procedures, showing patients' experiences with the day (both positive and negative experiences) and provide an insight in the screening day. However, at the moment, this is not possible with the current website. In Appendix G -Recommendations, some recommendations of how the website could be improved are shown. These recommendations are shared with the communication department of MS Center Amsterdam.

In order for De Gids and more specifically the preparation sheet to work properly, the current ►

SmartFrase of the anamnesis consultation should be updated. In appendix x.2 an outline of how this should be, is included. Important parts are: asking about concerns (step 1, question 2), ask patients to share their conclusions of each step. At the end of the consultation, ask patients whether everything that they wanted to discuss has been discussed.

9.b SOMSCOG outpatient clinic processes

To make the SOMSCOG outpatient clinic even better and to respond to patients' needs some changes should be made. Patients really miss receiving a summary of the results and diagnosis. They would really like to receive a document with the results of each examination, so they can re-read the results after the consultation. They have trouble remembering the diagnosis and results.
An important improvement of the SOMSCOG outpatient clinic is that an extra step should be added in the patient journey. I would recommend having a follow up with the patient, two weeks after the diagnosis consultation. Because, after the diagnosis consultation patients are left with (many) questions and no idea whom to ask.
This is wat should be done:
The patient fills out the questions on the last spread of the information guide. One of these questions should be: "Do you have any further questions?" Example questions will be included, to make it easier for the patient to come up with their own questions. Then, two weeks after diagnosis consultation, the MS nurse will call the patient.
If indeed, the patient had some extra questions, needed some explanations, etc. then the MS-nurse can answer them. If there are questions the MS nurse cannot answer, then she will set up a phone call with a neurologist. Adding this step to the patient journey, will have a positive effect on the patient experience. The journey below shows the extra step, with the alteration of the emotion line. The grey line is the current emotion line, the yellow line is the new emotion line. As you can see on the patient journey, another addition has been made.

Someone should be responsible for sending the files of patients from other hospitals to their own neurologist. The user interviews showed that most often this file transfer does not happen unless the patient and their original neurologist ask for it repeatedly. Someone should get the task of doing this for patients that are referred from other hospitals than VUmc. Patients find it really important that the information that is gathered during the screening day is shared with the referring neurologist. As the SOMSCOG outpatient clinic is promoted as a second opinion clinic (it's even in the name) this is a logical consequence and inevitable step that should be taken.

Currently there are two very good and pragmatic hostesses, but this has been different. Therefore, I would suggest making an instruction document for the hostess of the outpatient clinic. This document should include the examinations that are done, and some extra information such as why these examinations are done, frequently asked questions, etc. This way, patients can get helpful answers to their questions. Observations and interviews showed that some hostesses are not always properly informed and unable to answer patients' questions correctly. Sometimes wrong information was provided. To prevent this, an instruction handout should be made.

If possible, make sure that medical care providers who see SOMSCOG outpatient clinic patients come to the MDM. This would be good for a complete overview on which diagnosis is based.
A less pressing recommendation that I wanted to make in this section, was updating the outdated waiting rooms of the neurology outpatient clinic. And funny enough, the waiting rooms are currently being renovated. Great!

During the user study it appeared that everybody but people working at VUmc have difficulties with the name SOMSCOG. Patients don't remember or even recognise the name and some even say it sounds like a disease. Therefore, I would recommend to only use SOMSCOG as an internal working title and come up with a more inviting and user-friendly name to communicate to the outside world. A suggestion would be: cognition outpatient clinic (cognitie poli).

9.c Interaction vision

One of the metaphors of the interaction visions does not cover the interaction properly. This is the case for the interaction vision of next of kin cooperation (metaphor 2). I did not realise that using the Gesprekswiel is something one plans to do. People take the time to settle down and use the conversation starter. The interaction vision shows an interaction which happens gradually, it is an interaction which arises from a certain situation. It is not a conversation one intended to have. Therefore, the interaction vision should be revised. The current vision does not complement the interaction and is not useful to improve the use of the conversation starter. ■

10 DISCUSSION

This project provided some valuable insights and resulted in a design supplemented with recommendations. But, there are some points of discussion. This chapter entails these considerations.

7 principles of quality of life and MS

In the literature research, the seven principles of quality of life for MS patients were mentioned (chapter 2.e). These seven principles show that quality of life is impacted by many factors. It is interesting to see how the use of De Gids can be viewed in respect of these principles. Here, the 7 principles are shown.

1. **Empowerment, independence and a central role for people affected by MS in decisions that affect their lives.**
2. **Access to comprehensive and effective treatments and care for the changing physical and mental health needs of life with MS**
3. Support for the network of family, friends, loved ones and informal caregivers
4. Work, volunteering, education and leisure opportunities that are accessible and flexible
5. Accessible public and private spaces, technology and transport
6. Financial resources to meet the changing needs and costs of living with MS
7. Supportive attitudes, policies and practices that promote equality and challenge stigma and discrimination

When looking at the seven principles with De Gids in mind, it seems like the first two principles are touched upon with the use of De Gids. The first principle states that empowerment of people affected by MS in decisions that affect their lives. This indicates that, for instance, when deciding about a treatment for cognitive symptoms it is important for the person with MS to play a central role in this decision-making process. The second principle: access to effective treatment for changing mental health, is also touched upon with the use of De Gids. Both of these principles can only be applied when this person affected by MS, is well informed. De Gids, is not the ultimate information tool, but it does provide slightly more information than before. Furthermore, by using De Gids, it is expected that the help request can be improved. The diagnosis is based on this help request. So, by preparing the patients to formulate a help request, they are empowered a little bit more to make decisions concerning their treatment.

Cognitive affected people

During the course of this project, I started realising how cognitive problems affected people with MS. As many of them told me, it is not visible for others, it is all in their head. Often, things that are normal for me, cost people suffering from cognitive problems a lot of energy. Even the interviews I had with patients affected their energy. Some told me they had to plan a free afternoon or day after the interviews to rest.

For the evaluation interviews, I considered doing a role play activity. Although I thinks the participants would have been able to do this, I thought it would cost too much energy. Therefore, I decided to have a more regular interview. When writing this, I realise that I have done exactly the same thing I have judged people working is hospitals: thinking for the patients without asking whether assumptions are true. That brings me to the next point of this discussion.

Limited number of participants

The user research and evaluation in this thesis only included a small number of participants.

The contextmapping research included just six people. These six people did provide valuable information and insights in their journey. The emotion line is based on their experiences but also on observations. This is of course not very accurate. Therefore, one should keep in mind that the emotion lines showed are rough estimations of situations. One cannot value these with numbers.

The interviews with medical professionals were done with ten different people. Of which, four were medical researchers – arts onderzoekers. One could say they were over-represented in this research. The goal was to interview everybody working at SOMSCOG outpatient clinic. But this was way too much. I did not realise at first how many people were involved in the outpatient clinic. Therefore, the plan changed into trying to interview at least one person of each discipline. With the tenth participant, it was decided that it would be enough for this project.

Goal of the screening day

Interviews showed that some medical professionals had some concerns about the goal of the screening day. They were worried that patient care was secondary to scientific research. This has not been a point of focus in this project as I think it was one of the start-up problems of the outpatient clinic. As the clinic runs for over a year now, these concerns have been resolved due to the fact that each procedure is now also used for patient care.

For instance, the beginning of the outpatient clinic, the MEG-scans were only made for research. Now these are analysed, and the results are provided to the patients.

Feeling heard and screening day

One of the result of the user study was that it is very important for the patients to feel heard and understood. One could therefore ask the question: why bother then, to have them follow all these medical procedures, if all they need is being heard? Well, they do not only need to be heard, but also be reassured. And this reassurance is only possible when having the results of the MRI-scan, NPT's, blood and liquor analysis. Therefore, it is very important for patients to have all these procedures done.

Costs

The estimated costs of printing De Gids are rough estimations. Publishers have been contacted to get an impression of the costs. I have not asked for official quotations. Making a good quotation costs quite some time for the publishers, and as it is not sure whether De Gids will be used, I decided to make my own estimations, based on internet publishers. I increased prices of the online printing services by a minimum of 10% to be on the safe side. Furthermore, prices of finishing (such as glueing and inserting the cutter pin) are based on the experience of the graphic designer consulted in the conceptualisation phase. He estimated the costs of glueing a page at 50 cent per page per document. So the price mentioned in the costs paragraph are higher, to be on the save side.

Criteria

During the final evaluation study, the criteria ►

formulated in the design brief were evaluated. As stated in the design brief, the criteria were organised based on importance: number 1and 2 are most important. Followed by number 3 and 4. The fifth criteria is a bonus criterion, it would be nice if this could be achieved.

The evaluation study and my personal evaluation showed that most of the criteria are achieved. De Gids scores quite high on the first two criteria: offering help in preparation and improving patient participation. The next two - stimulate self reflection of the patient and offer guidance during the hospital visit - are also attained, although not as much as the first two. The last criterion - stimulate cooperation with next of kin is unfortunately not successfully achieved. There is a lack in stimulation of cooperation with next of kin. This is something that could be improved.

Interaction vision

In the design brief three interaction visions were formulated for different interactions of the design, see paragraph 3.c.1 on page 90. These visions were represented by three metaphors. With the evaluation I realised that two of the interaction visions representative for the interactions between the patient and De Gids. The first metaphor - having an intimate conversation with a close friend that asks the right questions - is something that is established with De Gids. This metaphor is applicable when the patient uses De Gids alone to prepare for the screening day.

The second metaphor - having a conversation during a sleep over right before going to sleep - is not achieved. This metaphor needs refining. This has already been discussed in further discussed in paragraph 9.c Interaction vision on page 151 of the recommendations.
The last metaphor, when the design is used by the patient and the neurologist is established with the use of De Gids. This metaphor was like playing ‘guess who’ where two people ask questions in return. The patient and neurologist have a conversation which is less scary because the preparation poster on the table. This mnemonic device serves as a conversation aid, making the consultation less scary and establishing a conversation. The metaphor of playing a game is not achieved, as this consultation is not a game. But that was not the aim of this metaphor. This metaphor represented the conversation, questions are alternately asked: patient - neurologist - patient - neurologist. ■

11 IMPACT

I participated in the evaluation of SOMSCOG in September. Some of my points of improvement were implemented during the course of this project. One thing that was changed is that patients now receive the schedule of the day beforehand. Furthermore, current patients receive an overview of what is expected of them during preparation. Appendix X shows the overview I made, which is in use now.

Together with Hanneke Hulst, I made a video to participate in the team price of VUmc. This video can unfortunately not be attached to this report. It was shown to the board of VUmc and during the new year's gathering. In this gathering the team price was awarded. Unfortunately, it was another team that won. ■

SECTION E - REFERENCES

12 REFERENCES

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12 July 2018