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IMPROVING **PATIENT-REPORTED OUTCOME MEASURES** OPTIMIZING AND RESTRUCTURING PROMS THROUGH DESIGN

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PREFACE

This master thesis is the final part of my Industrial Design Engineering studies at the University of Twente. Over the past ten months, I worked on this project in collaboration with Panton, designers for healthcare.

I would like to thank Jasper Brands for giving me the opportunity to do my thesis at Panton and for his guidance throughout the process. I also want to thank my colleagues at Panton for creating a welcoming and supportive environment; I have never felt alone during the past ten months.

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Jinte Pomper, June 2025

ABSTRACT

Patient-Reported Outcome Measures (PROMs) are increasingly used in healthcare to incorporate the patient's perspective into clinical decision-making and to support the broader goals of Value-Based Healthcare (VBHC). PROMs are standardized questionnaires that collect data directly from patients about their symptoms, quality of life, and functional status. While PROMs can theoretically improve individual care, support internal and external quality control, and contribute to scientific research, their current implementation often fails to meet these goals. Common issues include low patient engagement, poor integration into clinical workflows, limited relevance to individual consultations, and a lack of meaningful use by healthcare professionals (HCPs).

This thesis explores how PROMs can be redesigned to increase their value for patients, care organizations, and the healthcare system, specifically focusing on their use in Shared Decision Making (SDM). Using the Values that Matter design approach, the research identifies key stakeholder values (patient-centeredness, quality, and efficiency) and translates these into concrete design criteria. Three concept directions were developed and evaluated through a combination of literature review, expert interviews, and two rounds of co-design sessions with Multiple Sclerosis (MS) patients and their HCPs.

The final concept, a digital consultation preparation tool named Coprio, was selected for further development. This tool allows patients to report symptoms, identify important discussion topics, and receive a consultation summary. The tool is integrated into the existing patient app and electronic health record systems, ensuring that patients and healthcare professionals can prepare for consultations effectively. Coprio also includes features such as symptom severity tracking and Al-generated consultation notes, which aim to enhance communication, engagement, and relevance for SDM.

The tool was evaluated against a set of design criteria and stakeholder values. It was considered to support SDM by helping patients voice their concerns, symptoms and preferences, enabling HCPs to conduct consultations more effectively, and improving SDM. The tool also addresses key barriers identified in literature, such as usability challenges and the lack of integration into existing workflows.

The thesis demonstrates how a value-based design approach can lead to more meaningful and effective healthcare tools. By aligning the design process with the real-world needs and values of both patients and professionals, the proposed solution offers a promising alternative to traditional PROMs. It improves the patient's experience and supports the broader goals of VBHC by enhancing the quality and efficiency of care.

This research contributes to the growing field of design for healthcare by showing how co-design and value-based methodologies can address complex challenges. The final concept has the potential to be adapted for other patient groups and clinical contexts, offering a scalable and sustainable approach to improving patient-centered care.

AI	Artificial Intelligence
DMT	Disease Modifying Treatment
НСР	Healthcare professional
MS	Multiple Sclerosis
PRO	Patient Reported Outcome
PROM	Patient Reported Outcome Measure
RQ	Research Question
SDM	Shared Decision Making
UI	User Interface
VBHC	Value Based Healthcare
VtM	Values that Matter

LIST OF ABBREVIATIONS

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Chapter 1 INTRODUCTION



1.1 BACKGROUND

1.1.1 PATIENT-REPORTED OUTCOME MEASURES

Traditionally, in healthcare, much attention has been given to scanning results or objective measurements about a patient's physical state . Based on this, physicians would decide how patients were doing (Krogsgaard et al., 2021). In the past decades, patient-centered care has become increasingly important (Gibbons et al., 2016). This links to the Value-Based Healthcare model (VBHC) that aims to increase value for patients and care organizations (Teisberg et al., 2020). This is done by using resources efficiently and sustainably, as they become less freely available due to increases in people who need care and decreases in available healthcare professionals (HCPs), time, and money. Within the VBHC model, it is essential for the quality of healthcare to include the patient's perspective (Teisberg et al., 2020). A Patient-Reported Outcome Measure (PROM) is a tool that can facilitate this demand. PROMs are standardized questionnaires that gather data directly from patients, without interpretation or interference from care professionals or others (Krogsgaard et al., 2021). This data can include symptoms, guality of life, and functional status (Churruca et al., 2021). PROMs are conducted in different ways, such as on paper or by phone. Nowadays, however, they are often conducted using digital guestionnaires, which could be considered part of the realm of digital health technologies.

PROMs have not always been used in healthcare. The first PROMs were introduced in the 1960s and were directed towards mental health (Churruca et al., 2021). However, these were not intended to measure patients' perspectives on their health routinely, but rather for use in research, such as in clinical trials that assess the effectiveness of treatments ("Guidance for Industry: Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims: Draft Guidance," 2006). Currently, PROMs, clinical tests, and objective measurements gather complementary data and all add unique information about a patient's health situation (Krogsgaard et al., 2021). Over time, PROMs have become more routinely used for supporting clinical decision making, comparing results between health-care organizations and to use as a base for quality improvement and evaluations (Black, 2013).

Although PROMs are currently being implemented in almost all areas of healthcare, their value and impact are increasingly becoming a point of discussion. A range of problems is reported on, such as usability issues, low compliance rates, and non-use by HCPs (Silveira Bianchim et al., 2023).

EXAMPLE

Janine is a 71-year-old woman recovering from a hip replacement surgery (Figure 1). Traditionally, her HCPs would focus on scanning results and movement constraints. However, Janine experiences the impact of her surgery in a way that goes beyond these clinical metrics. She felt that her day-to-day challenges were overlooked. This is where PROMs could add value. A holistic view of her recovery could be constructed by directly asking the patient about her quality of life and ability to perform certain activities.



Figure I, Janine filling in a PROM question about daily activities

Janine also experienced some problems (Figure 2). Although Janine filled in the PROMs when asked, the results were never discussed with her. Janine's care team still only focused on the clinical outcomes and did not integrate her PROM data into her treatment plan, leaving Janine feeling unheard.

1.2 RESEARCH QUESTION

In this Master thesis, problems related to PROMs will be identified and tackled from a design perspective. The thesis topic was initiated by Panton. Panton is a design agency that designs products, systems, and services for and with healthcare partners. Panton has close relations with healthcare organizations and professionals to better design for them. Concerns related to PROMs from the healthcare field were brought up to Panton, leading to this assignment.

WHY USE A DESIGN APPROACH?

A design approach would be suitable for this problem related to PROMs. Digital health technologies, such as monitoring applications and PROMs, have a low chance of successful integration with the healthcare system, often caused by a mismatch in needs and values (Birnbaum et al., 2015; Pagliari, 2007). Where healthcare has traditionally focused on understanding illnesses and the effectiveness of care processes and medication, design, and usercentered design specifically, is a discipline that has developed methods and tools to understand needs and values of stakeholders. Design and healthcare have always had an overlap in interest in the design of healthcare products and technologies. More recently, the two disciplines have increasingly worked together on designing digital health technologies, care practices, and services. A notable example of this in the Netherlands is the work of design agency Panton. However, the integration of design methodologies in the design for the healthcare sector remains difficult. New healthcare technologies must be based on Evidence-Based Design, where the evidence is mainly based on randomized controlled trials (Smits, Kim, et al., 2022). Design research typically does not include randomized controlled trials, but has various other ways to collect valuable insights, focusing more on wellbeing and experience of patients and healthcare professionals, using for example interviews or diary studies. This thesis will consider these different views and presents a case that shows the opportunities and challenges of a design-based approach to a healthcare problem.

In this thesis, the following research question (RQ) will be answered: **RQ1: How can PROMs be redesigned to increase their value for patients, care organizations, and the care system?**

1.3 METHODOLOGY

From the perspective of the healthcare domain, there is a need for VBHC. This can be seen in several policies and an increase in scientific publications about this framework (Damman et al., 2020). PROMs are meant as a way to implement VBHC. However, it can be challenging to implement VBHC if it is unclear which values are at stake. The large number of different applications of PROMs in healthcare increases this challenge. Therefore, to find the value of PROMs, we need to know what value entails for patients, HCPs, and the care system. The next section will explain in more detail what types of values could play a role.

1.3.1 A METHODOLOGY COMBINING HEALTHCARE, VALUES AND DESIGN

As the topic of this thesis is to research and improve the value of PROMs for patients, care organizations, and the care system, an approach that includes both digital health and values would be appropriate. Such a method was created by Smits et al. (Smits, Ludden, et al., 2022), called "Values that Matter" (VtM). This method aims to capture the values that stakeholders experience and allow the designer to evaluate the impact of the introduction of a new technology. Central to the approach is the construction of value frameworks. Value frameworks can be described as the view a group of people in a specific context have on their morals, including their values and how these values are experienced (Smits, Ludden, et al., 2022). The impact of introducing a new technology can then be observed based on the changes in a value framework. This impact is measured in the moral mediation of technology, based on Mediation Theory (Verbeek, 2015). Moral mediation means that technology shapes our values and moral choices, acting as a mediator between humans and the world (Verbeek, 2015). Therefore, the VtM approach gives us insight into the values at stake, how a new technology possibly influences these values, and concrete tools to design with values in mind.

DEFINING VALUE

The triple value healthcare model of VBHC can be used to define the types of values that will be used to represent values of the care system (Jani et al., 2018).



Personal Value

The first value that should be considered is Personal Value, which is the direct value for the patient (Jani et al., 2018). Needs and expectations of the patient should be taken into account when delivering care. Thereby, it is important to not only consider objective clinical outcomes, but also subjective outcomes, for example retrieved from PROMs, to find out what is most important to the patient (Jani et al., 2018).



Technical Value

The second value is Technical Value. This means that the outcomes and costs of any (technical) intervention should be considered: the absolute and relative value of it (Jani et al., 2018). For example, if a solution is as cost-effective as possible.

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Allocative Value

The third value concerns the total population: the Allocative Value. Here, it is important to consider and divide resources in order to meet the needs of the entire population as much as possible (Jani et al., 2018). Therefore, individual and population needs should be balanced. It often is not possible to provide an individual with everything they need, when the rest of the population needs to use resources as well (Jani et al., 2018).

1.3.2 STRUCTURE



Figure 3, Values that Matter framework (Smits et al., 2022)

This thesis will use the VtM approach, and its structure will be based on the design phases specified in this approach. VtM uses three phases: Explore, Conceptualize, and Anticipate, which can be used multiple times in a design process in a way that best fits the design process (Figure 3).

In the **explore phase**, the current value framework is investigated through several questions related to value change:

- 1. What values are important for the actor?
- 2. What definition is given to each value?
- 3. What is the relative importance of each value?
- 4. How is each value specified in norms?
- 5. How is each value experienced?

Questions directly retrieved from (Smits, Ludden, et al., 2022)

The answers to these questions can be found by conducting several types of empirical research recommended for value-sensitive design, such as interviews, context mapping, and diaries (Smits, Ludden, et al., 2022). When answering these questions, it is good to have definitions of the terminology that is used. First of all, "values" can be defined as: the beliefs people have, especially about what is right and wrong and what is most important in life, that control their behavior (VALUES | English Meaning - Cambridge Dictionary, n.d.). Secondly, "norms" are defined as everything that is necessary to be able to realize a value in practice (van de Poel, 2013).

In the **conceptualize phase**, the value framework is considered while designing a new technology. This can be done in two ways: by considering the established value framework or creating a preferred value framework to inform the new design. Based on the values in the framework, norms should be constructed or gathered from the empirical research. Then, design criteria can be constructed based on the norms, which results in a list of criteria that can be used to design new technologies that fit to the values of its stakeholders (Smits, Ludden, et al., 2022).

In the **anticipate phase**, the soft impacts of technology are investigated. This can be done in a pilot study where a prototype of the new technology is used in the same context as researched in the explore phase. Instead of a prototype, visuals or other ways to describe the concept can also be used. The same five questions as in the explore phase should be asked, in order to be able to compare the value frameworks (Smits, Ludden, et al., 2022). After the empirical research, the initial value framework can be compared with the value framework impacted by the introduced technology. Based on this, insights on the moral mediation of technology can be found.

Following the VtM approach, it is necessary to know the values of all stakeholders (patients, care organizations and the care system) before we start designing a solution to one of the problems with PROMs. Therefore, the project started with several explore phases. Subsequently, the use of PROMs was redesigned in a conceptualize phase and it was evaluated how stakeholders are influenced by the introduction of possible solutions in an anticipate phase. As PROMs are already used in practice, the value framework that was discovered in the explore phase reflects the impact of this technology and allows us to see how current PROMs fit into the VBHC model. In this thesis, an alternative or improved solution based on current PROMs will be introduced, which allows comparing the value framework of the new solution with the existing PROM technology.

Figure 4 shows the structure of this thesis . As can be seen, a double diamond model was used for the process. Since the research question is very broad, a broad explore phase was started to identify the most important topics to focus on and redefine the research question. This allowed the research to be feasible and thorough where it mattered most. The conceptualize phase again took a broadening perspective to find possible answers to the research question. Through co-design sessions, the process could narrow to present a prototype and answer to the research question at the end of this thesis.



Chapter 2 **EXPLORE PHASE** PART 1 - BROAD CONTEXT

The first explore phase aims to gain insight into the use and application of PROMs and identify problems in a broad context. This will be done by a literature review and several interviews with PROM experts. Four main goals of PROMs will be identified. Existing solutions are briefly discussed. A value analysis will be done on the literature and expert interviews to find the current impact of PROMs and identify the most important issues. This chapter will end with a value framework that can be used to refine the research question and choose a focus in one of the four PROM goals.



2.1 LITERATURE REVIEW



Figure 5, Patient reported outcomes in generic PROMs, based on Kharroubi et al., 2022

This section aims to understand the context and impact of PROMs. For this, a literature search was conducted through Google Scholar, using keywords such as "PROM", "problems", "goals", "development", "use", "compliance", "impact", "value", and "VBHC". A broad view was considered, but specific attention was given to Dutch studies to make later comparisons of value frameworks of Dutch participants more reliable. The Dutch life cycle of PROMs and relevant problems will be mapped out. This section will conclude with an overview of the PROM life cycle and corresponding problems.

2.1.1 GOALS AND FEATURES

A | Types of PROMs

PROMs are used in almost all areas of healthcare, ranging from PROMs that prepare patients and HCPs for a recurring clinical visit to PROMs that evaluate a short hospital stay. This also means that many different PROMs are used in healthcare. Nevertheless, these PROMs can be split up into two groups: generic and condition-specific PROMs.

Generic PROMs gather data relevant to multiple patient groups, making it possible to compare a large group of patients in different conditions (Churruca et al., 2021). A well-known example of a generic PROM is the EQ-5D, developed by the Dutch organization EuroQol ("EuroQol--a New Facility for the Measurement of Health-Related Quality of Life," 1990). This PROM has five questions that evaluate a patient's health, mobility, self-care, activities, pain, and mental state. Figure 5 gives an overview of all patient-reported outcomes (PROs) that can be asked in a generic PROM (Kharroubi et al., 2022).

Condition-specific PROMs are used to gather data about specific patient groups. An example of a condition-specific PROM is the EORTC QLQ-30. This PROM was developed by the European Organization for Research and Treatment of Cancer. This PROM can be used for all patients with cancer, but also for specific types of cancer by adding modules to the questionnaire (Churruca et al., 2021). Other examples of disease groups that use condition-specific PROMs are respiratory, cardiovascular, and mental health illnesses (Churruca et al., 2021).

B | PROM goals

PROMs can have different purposes within generic and condition-specific PROMs. PROMs are generally used for four different goals (Figure 6). Sometimes, a PROM is used simultaneously for multiple goals. This section will explain the four types of goals.



Figure 6, PROM goals

By being aware of the different goals of PROMs, it is possible to see that the value of PROMs is likely different for each goal. Although needs may be different for PROMs used for scientific research compared to PROMs used for individual care improvement, the tool, being PROMs, stays the same. When reviewing problems related to PROMs in the next chapter, it is good to keep in mind that a distinction in goals is not always made when reporting these problems in the literature.

IMPROVING INDIVIDUAL CARE

PROMs contribute to improving individual care. They can help patients understand their health status and progress and encourage them to actively participate in **self-management**. HCPs can use the same information to gain insight into a patient's health status and use this to **monitor** them better and to **diagnose** diseases better (Field et al., 2019; Porter et al., 2016). During consultations, PROMs can be used to identify topics of conversation and to facilitate **shared decision making** (SDM) (Quik, 2022). When used for individual care improvement, PROMs can be implemented before, during, and after a treatment, or for a more extended period during a complete care path (Quik, 2022).

INTERNAL QUALITY CONTROL

PROMs are used for internal quality control, for example to evaluate treatments and inform policy on a care organization and care system level (Churruca et al., 2021). Furthermore, care organizations can use PROM outcomes about internal quality to compare departments or teams or compare themselves to other care organizations (Quik, 2022). Policies inside the care organization can also be evaluated for quality improvement, and best practices can be identified (Quik, 2022).

EXTERNAL QUALITY CONTROL

PROMs are used for external quality control. In those cases, PROMS can be used for external transparency by comparing results nationally (Quik, 2022). The outcomes of these PROMs are shared with the public. **Care insurance companies** can then decide based on these outcomes and contract specific care organizations. Next to care insurance companies, healthcare inspectors or policymakers also look at PROM outcomes for decision-making, and **patients can make an informed decision** about which hospitals they want to be treated in (Quik, 2022).

SCIENTIFIC RESEARCH

PROMs play a role in scientific research. For example, PROMs have been used to assess treatment effectiveness, care pathways, and care delivery models (Churruca et al., 2021). If appropriate PROMs are used, different outcomes between two treatments can be noticed, which can be used in the assessment of those treatments (Krogsgaard et al., 2021). For example, the Patient-Centered Outcomes Research Institute (PCORI) uses data from PROMs to research best practices and treatments in the health care sector (Schamber et al., 2013). PROM data can also be used for making guidelines within care organizations and to generally contribute to knowledge about certain types of diseases (Quik, 2022).

2.1.2 PROM LIFE CYCLE, IMPACT AND PROBLEMS

This section outlines the PROM life cycle, discussing its phases, impacts, and challenges. The insights presented are based on recent review papers (Figure 7), supplemented by additional literature and official reports from the Netherlands to capture the most prevalent and pressing issues. The PROM life cycle, including its impact and problems, is summarized in Figure 7. This section helps to get a basic understanding of the PROM process and gives insight into relevant issues.

A | Development Phase

The development phase occurs at the start of the PROM life cycle. Typical of this phase is the care and effort that is being put into ensuring the creation of validated, scientific PROMs. Partly, this is because PROMs are often developed for scientific purposes, with patient and HCP involvement being critical to ensuring their relevance and validity (Quik, 2022; Terwee et al., 2018). Including a representative sample of the target population helps to ensure the PROM is comprehensive and comprehensible. HCPs further refine its relevance and comprehensiveness during the development process (Terwee et al., 2018).

Validation is a vital step in the development phase. A widely used method for validation is the Consensus-based Standards for the selection of health status Measurement Instruments (COSMIN) (Mokkink et al., 2019). This method includes evaluating content, structure, consistency, and responsiveness, as well as defining methodological requirements for the research validating PROMs (Mokkink et al., 2019). Once validated, PROMs are stored in databases like the COSMIN database, PROMIS, and PubMed, where they are accessible for research and clinical use (COSMIN, n.d.). So overall, PROMs are constructed in a structured and controlled way during the development phase.

However, the development phase is not without its challenges. One significant issue is the growth in the variety of PROMs. New PROMs are frequently created for different patient groups or conditions, without reusing existing PROMs. This leads to an unnecessary variety of PROMs, complicating standardization and integration efforts (Quik, 2022).

B | Implementation Phase

The second stage, the implementation phase, is also conducted in a careful and controlled manner. The implementation of PROMs involves selecting and integrating them into care workflows. Care organizations must first define their goals and the PROs they wish to

measure. Tools such as the Dutch "Zorginstituut Nederland" toolbox assist with PROM preparation and application. Additionally, validated databases provide organizations with a wide range of options to choose from (Quik, 2022). After a PROM is selected, PROMs are tested, often through pilot studies, to ensure their suitability for the intended purpose.

After selecting a PROM, there is an integration step. This step involves creating indicators that translate PROM outcomes into meaningful data for healthcare providers. For instance, a scoring system must define thresholds for acceptable results, which are then tested before full-scale implementation takes place (Quik, 2022).

Nevertheless, there are some problems connected to the implementation phase. PROMs are not always used as intended, with some applied to populations or conditions for which they were not validated, reducing their effectiveness (Krogsgaard et al., 2021; Wiering et al., 2017). Additionally, the high implementation costs, including IT systems and supplier fees, are significant barriers for healthcare organizations (Quik, 2022).

C | Use Phase

In the third phase, the use phase, PROMs are used to gather patient data. How data is administered varies, ranging from paper-based methods to digital platforms and interviews, either in-person or via phone (Silveira Bianchim et al., 2023). Digital methods, such as email or app-based questionnaires, are increasingly popular for their efficiency and ease of use (Rutherford et al., 2016). Regardless of the mode of delivery, studies show no significant differences in the quality of data collected (Rutherford et al., 2016). Therefore, the most cost-effective option is often chosen.

However, many issues often hinder the use of PROMs. There are barriers inherent to the design and procedure of PROMs, such as unreliable internet access or inaccessible designs (Silveira Bianchim et al., 2023). Additionally, the length and complexity of the questionnaires, repetitiveness in questions, or overlapping PROMs cause participation rates to drop (Porter et al., 2021; Silveira Bianchim et al., 2023). Furthermore, differences in PROM compliance rates are present across different demographic groups. This is influenced by factors such as age, ethnicity, and socioeconomic status (Hutchings et al., 2012; Schamber et al., 2013). This could be due to the design and procedure of PROMs.

IDENTIFIED PROBLEMS	There are too many different PROMs, leading to unwanted variety (Quik, 2022) PROM Developm	nent		PROMs are being used in the incorrect patient group (Krogsgaard et al., 2021)	The costs of implementing a new PROM are very high (Quik, 2022)	PROMs are too long or use difficult words (Silveira Bianchim et al., 2023) Patients get too little time to finish FROMs (Silveira Bianchim et al., 2023) Patient feel too ill and do not want to be occupied with PROMs (Unni et al., 2024) The content of PROMs confuses or emotionally upsets patients (Silveira Bianchim et al., 2023) PROMs are not always suitable for people with reduced cognitive or physical abilities (Silveira Bianchim et al., 2023)	PROMs are too bureaucratic and take up too much time (Silveira Bianchim et al., 2023) Technical issues occur, such as unreliable internet (Silveira Bianchim et al., 2023) Caregivers are uninterested in using PROMs (Quik, 2022) Caregivers forget to ask for consent in using PROMs (Quik, 2022)	Patients do not know why they have to fill in PROMs (Silveira Bianchim et al., 2023) Patients with multiple health problems have to fill in too many PROMs (Silveira Bianchim et al., 2023)	PROMs are considered to be effective , but they are not in practice (Silveira Bianchim et al., 2023) PROM outcames are biased, beccuse of response bias (Quik, 2022) PROM Evaluatio	In practice, PROM data is rarely used to tailor treatments or improve services (Damman et al., 2019)
STEP	A new PROM is developed	A study is set up to validate the PROM	The validated PROM ends up in a PROM database 3	The hospital selects a PROM	The PROM is integrated in existing systems	Patients fill in a PROM	Caregivers look at the PROM data	PROM results are discussed with patients 8	Patient group PROM results are discussed internally 9	Treatments or policies are improved
IDENTIFIED IMPACT	Figure 7. PROM/life or	le with impacts and prof	blems		More data, without ircrease in workload (Silveira Bianchim et al., 2023)	More likely to share symptoms (Silveira Bianchim et al., 2023) Better manage own health (Silveira Bianchim et al., 2023) Prepare for appointments better (Silveira Bianchim et al., 2023)	Tailor treatment to potients (Silveira Bianchim et al., 2023) Less hospital admissions (Basch et al., 2016; Demedts et al., 2021) Get feedback of health status between appointments (Silveira Bianchim et al., 2023)	Improved health outcomes in some situations (Silveira Bianchim et al., 2023) Better treatment outcomes (Basch et al., 2016; Demedts et al., 2021) Detect healh problems better (Porter et al., 2016) Facilitate communication with care professionals (Silveira Bianchim et al., 2023)	Possibly reduces healthcare costs due to less hospital days, emergency department visits and hospitalisations (Basch et al., 2016; Demedts et al., 2021) Evaluate treatment effectiveness, care pathways and care delivery models (Churruca et al., 2021) Inform policies (Churruca et al., 2021)	Improve quality of care (Porter et al., 2016) More effective treatments (Porter et al., 2016)

Other problems are connected to the motivation of patients. It is not always made clear to patients what the relevance of filling in PROMs is (Silveira Bianchim et al., 2023). Other patients simply feel too ill to fill in questionnaires (Unni et al., 2024). Furthermore, the content of PROMs can emotionally upset patients, leading to negative feelings surrounding the completion of PROMs (Silveira Bianchim et al., 2023).

The final cause of problems in the use phase of PROMs is the involvement, or lack of involvement, of HCPs. Many HCPs are uninterested in using PROMs or forget to invite patients to use PROMs (Quik, 2022). Furthermore, results from PROMs are not always discussed with patients, reducing their possible positive impact and demotivating patients to fill in more PROMs (Silveira Bianchim et al., 2023).

D | Evaluation Phase

The last step in the PROM life cycle is the evaluation phase. This phase assesses the relevance, validity, and effectiveness of PROMs and what the PROM outcomes mean for quality management. In the Netherlands, the "Zorginstituut Nederland" toolbox provides guidelines for evaluating the validity of PROMs, ensuring that PROMs continue to meet their goals and provide reliable data (PROM-toolbox: Tools Voor de Selectie En Toepassing van PROMs in de Gezondheidszorg, n.d.).

Challenges in this phase include a limited understanding of how PROMs achieve their intended outcomes and the lack of systematic integration into care systems. Bureaucratic problems and technical complexities further make it more difficult to tailor treatments or improve care services (Damman et al., 2019; Silveira Bianchim et al., 2023). Additionally, low response rates and demographic differences in PROM participation can introduce bias, which could affect decision-making and treatment evaluations (Unni et al., 2024). While some studies suggest that PROMs can reduce healthcare costs, evidence of their economic benefits remains inconsistent (Basch et al., 2016; Silveira Bianchim et al., 2023).

E | Conclusion

While PROMs have the potential to transform healthcare by enhancing patient engagement and improving outcomes, significant challenges exist throughout their life cycle. What becomes clear from this literature search is that there are many problems related to PROMs at different stages. To find a solution to increase the value of PROMs, it is necessary to focus on a goal or a problem that is important to patients, HCPs, and the care system. Therefore, a value analysis and expert interviews will be held to help determine this focus.

2.1.3 EXISTING SOLUTIONS

The challenges identified in the previous section are widely recognized within the healthcare sector. Therefore, solutions have been proposed and implemented to address these issues. This section explores existing approaches to solving the problems connected to PROMs based on a short review of relevant literature and reports, utilizing keywords such as "PROM," "Design," "Usability," "Relevance," "Improvement," "Solution," and "Innovation". Learning from existing solutions aids the design process by providing insight into effective strategies and points of improvement.

A | Guidelines and technological advancements

One prominent issue in PROM implementation is the oversupply of different PROMs, leading to overlap in questionnaires. Zorginstituut Nederland developed a PROM toolbox to address this problem, as mentioned in the previous section (Quik, 2022). The toolbox encourages care institutes to limit the number of PROMs in use, promote standardization in ICT and data exchange, and facilitate sharing results among care organizations to reduce overlapping PROMs (Quik, 2022). It includes a general guide, an implementation cycle, and a web application designed to streamline PROM integration. The toolbox emphasizes that it is important to apply patient involvement throughout the process, from selection to evaluation, and stimulates the use of user-centered design principles to enhance accessibility and usability (Quik, 2022).

Similarly, the Linnean Initiative, a national group promoting Value-Based Healthcare, provides tools such as a selection guide for generic PROMs to standardize and streamline their use. This initiative puts emphasis on collaboration of HCPs to accelerate the implementation of PROMs.

Technological advancements also address PROM challenges, notably through Computerized Adaptive Testing (CAT) PROMs (Churruca et al., 2021). CAT-based systems, such as the widely used Patient-Reported Outcome Measure Information System (PROMIS, or PROMIS-CAT), use Item Response Theory to adapt questions based on patients' prior responses (Churruca et al., 2021; "Handbook of Modern Item Response Theory," 1997). This approach reduces unnecessary questions while maintaining diagnostic accuracy. COSMIN supports CAT-based PROMs as they enhance patient experience by offering fewer but more relevant questions (I'm Looking for Available Outcome Measurement Instruments • COSMIN, n.d.).

Although these guidelines and technological advancements are useful, they only aim to solve problems in the development and implementation steps of the PROM life cycle. Therefore, they are not enough to address the most important challenges surrounding PROMs.

B | Design improvements

A second type of solution is design improvements. These often aim to increase the response rates, for example by improving usability. Bartas, a master's student at TU Delft, focused on improving PROM use for HIV patients through a card game that educated patients about PROMs and their benefits (PROMis for Quality Care | TU Delft Repository, 2023). While the game showed potential for increasing motivation and response rates during small-scale evaluations, its long-term effects and applicability to other patient groups remain uncertain (PROMis for Quality Care | TU Delft Repository, 2023).

Another design solution is a Multimedia PROM (mPROM). mPROMs incorporate visual and auditory elements, reducing reliance on text. Azad et al. developed the Multimedia Adaptation Protocol (MAP) to guide the creation of mPROMs (Azad et al., 2024). Their prototype included images and audio narration, aiming to reduce patient anxiety and increase engagement. However, the prototype has yet to undergo extensive evaluation (Azad et al., 2024). Patients preferred completing PROMs at home and stressed the importance of not increasing time investment, while HCPs expressed concerns about increased workload and emphasized the need for a more standardized solution (Azad et al., 2024).

Other strategies to improve response rates include notifications, personalized invitations, reminders, and incentives, which have been shown to enhance participation in web surveys (Sammut et al., 2021). In clinical settings, integrating PROMs into patient workflows has shown promise. For instance, a touchscreen interface in an Australian oncology clinic allowed patients to complete PROMs in waiting rooms. Their responses would then be integrated into clinical reviews. Participation rates were influenced by factors such as

interface placement, wait times, and the quality of HCP-patient relationships (Unni et al., 2024).

Although these design improvements aim to solve important problems of PROMs, they primarily focus on increasing compliance rates. It is questionable whether increasing compliance rates increases the value of PROMs, because it does not solve underlying issues. Therefore, other solutions should be explored.

C | Conclusion

Despite these efforts, most solutions address isolated aspects of PROM-related challenges rather than covering the complete picture. They focus on aspects of the PROM life-cycle or on individual stakeholders. It is uncertain if these solutions correspond with the values and needs of all stakeholders involved. Therefore, there is an opportunity to investigate how a broad and value-based approach to the problem might provide a more holistic solution.

2.2 VALUE ANALYSIS LITERATURE

The literature review in this chapter will conclude with a value analysis and an overview of identified issues. This helps to identify themes in the literature and can therefore guide the process of selecting a focus topic within the context of PROMs. Schwartz's theory of values provided a foundational understanding for extracting values from the literature review. Schwartz (2012) identifies six key characteristics of values: they are beliefs tied to emotions, refer to desirable goals, transcend specific actions and contexts, serve as decision-making criteria, are ordered by importance, and guide behavior when relevant. These characteristics were used to identify values in the literature review.

2.2.1 CODING PROCESS

An inductive coding process was used for the value analysis, based on the review of 30 papers in Section 2.1. To identify values within VBHC, Personal Values, Technical Values, and Allocative Values were taken into account. The text was scanned for sentences that explained reasons for implementing PROMs and explanations of benefits and implications. The literature review was coded using an inductive coding process with Taguette software, followed by axial coding to group labels into three overarching values: **patient centeredness, quality, and efficiency**. These overarching values encompass sub-values and norms, highlighting needs in PROMs (Figure 8).

2.2.2 KEY VALUES

Figure 8 shows three identified value themes, with their corresponding sub-values. For each sub-value, it is indicated which stakeholder holds these values, if this was mentioned in the reviewed literature. The three identified value themes are patient-centeredness, quality, and efficiency. Some sub-values are relevant within multiple value themes.

A | Patient Centeredness

The first value, patient-centeredness, emphasizes benefits for patients, care institutions, and the broader healthcare system by taking a patient-centered stance. This theme corresponds with the Personal Value type of the VBHC model, as these values mainly reflect direct value for patients.

Patient-centeredness is achieved by incorporating several sub-values linked to the main value, including autonomy, engagement, and equality.

Autonomy is an important value, as Quik (2022) describes. To reach this sub-value, patients should have the ability to have a say in decision-making (shared responsibility) and self-manage their disease (self-reliance) (Quik, 2022). This autonomy is furthermore supported by transparency and clear communication between care professionals and patients (Quik, 2022; Teela et al., 2021). Furthermore, engagement must be high to realize autonomy (Printza, 2022). Other aspects necessary to reach the value of patient-centeredness are that activities must be relevant to the patient and have a clear purpose (Terwee et al., 2018).

Equality is another important sub-value in the overarching value of patient-centeredness. When the patient group is well represented, the care system gets a better overview of healthcare effectiveness and quality (Silveira Bianchim et al., 2023). To realize this equality, values such as accessibility, safety, and usability need to be taken into account as well (Azad et al., 2024; Silveira Bianchim et al., 2023; Terwee et al., 2018).

B Quality

The second value theme is quality. Quality ensures PROMs enable preventive and holistic care (Krogsgaard et al., 2021; Porter et al., 2016). This theme corresponds with the Allocative Value type of the VBHC model because this value allows the healthcare system to apply a solution to a group of patients rather than individuals.

Quality is reached through important values such as scientific integrity and engagement. Scientific integrity is important for quality when PROMs are used for research (Mokkink et al., 2019). Similar to realizing equality for patient-centeredness, the same sub-values apply for realizing quality based on PROM implementation. Any PROM or future alternative to PROM needs to be accessible and have good usability, and it needs to be relevant in order to get useful data that can be used to realize good quality (Mokkink et al., 2019; Silveira Bianchim et al., 2023; Unni et al., 2024).

Engagement is also important in realizing quality because it leads to more data. Transparency and good communication are also important sub-values that contribute to reaching quality throughout the care system.



Figure 8, Overview of values retrieved from the literature review, black means identified in the literature review

C | Efficiency

The last value theme, efficiency, underpins quality and patient-centered care by reducing resource waste. This theme corresponds with the Technical Value type of the VBHC model, because it focuses on measurable values such as time and costs.

Important sub-values of efficiency are cost-effectiveness, usability, and accessibility. Most importantly, implementations of PROMs or future alternatives need to be cost-effective and relevant (Porter et al., 2016; Unni et al., 2024). In order to have efficient PROMs or alternatives to PROMs, their use needs to be effective as well and lead to good engagement. For this, accessibility and usability are again important. To reach good engagement, communication between HCPs and patients is also necessary (Teela et al., 2021).

2.2.3 PROBLEM CATEGORIES

During the analysis of values in the literature, problems related to PROMs were also identified. Figure 9 presents a categorization of these problems, dividing them into three groups: the design and procedure of the PROMs, HCP involvement, and factors related to the patient's internal motivation. The overview also shows which values are negatively impacted, which are sub-values mainly related to patient-centeredness and efficiency.

2.2.4 CONCLUSION

The literature highlights neglected values in PROM design and implementation, particularly in patient-centeredness and efficiency. Looking at the identified values, PROMs must become more relevant, purposeful, and accessible, with greater focus on communication, transparency, and shared responsibility. For efficiency, PROMs must improve usability, accessibility, engagement, and cost-effectiveness. Finally, enhancing quality should focus on strengthening engagement and scientific integrity, particularly among HCPs.

It is important to note that these factors are associated with the broad view on PROMs and are, therefore, still at risk of only identifying problems that lie at the surface of the situation. Furthermore, the relative importance of each value is difficult to find in the literature. Therefore, expert interviews are needed to discover this.

PROBLEMS INHERENT TO PROM PROCESS AND DESIGN

The wording of PROMs is too upsetting	Empathy
Patients do not understand the content of PROMs	Accessibility
Filling in PROMs is more difficult for specific groups	Equality
Patient has to fill in too many PROMs	Relevance
PROMs are being used in the wrong patient group	Scientific integrity
Unneccesary variety of PROMs	Cost-effectiveness
PROMs are very expensive	Cost-effectiveness
Technical issues occur	Accessibility
Current way of PROMs are not accessible	Accessibility
Patient has to answer the same questions	Engagement
PROMs are too long or too complex	Usability

PROBLEMS INHERENT TO CAREGIVER ENGAGEMENT

HCP does not motivate patient	Engagement
Patients do not get enough support from HCPs	Communication
PROM outcomes are not discussed with patients	Shared responsibility
HCP is not motivated about PROMs	Engagement

PROBLEMS INHERENT TO PATIENT ENGAGEMENT Patients do not feel the need to fill in PROMs Purpose Patients feel too ill to fill in PROMs Self-reliance Patients do not know what happens with their data Transparency

Figure 9, Overview of problems, with problem categories and values

2.3 EXPERT INTERVIEWS

To compare the findings from the literature research to PROM use in practice and identify which topics are most relevant to address, semi-structured interviews with experts were conducted. The aim of the interviews was to learn about PROM use in practice, identify problems related to PROMs, and confirm important values of experts, including their relative importance.

2.3.1 METHOD

The interview questions were prepared with the VtM approach in mind (Smits, Ludden, et al., 2022). Different questions were prepared for each interview to match the participants' expertise. The questions could be categorized into three categories: PROM use in practice, value-related questions, and vision of the future. The interview questions can be found in Appendix A.

Four semi-structured interviews were conducted through video calls with six experts from four different hospitals. An overview of participants is given in Table 1. Ethical approval was given by the ethical committee NES UT – nr 240781. Participants were sent a digital information sheet and consent form, which can be found in Appendix B. If consent was not yet given digitally at the beginning of an interview session, oral consent was asked for and given. Participant 3 did not give permission to use direct quotes in the thesis. The interviews were annotated during the sessions.

The interviews were transcribed in Microsoft Word and deductively coded using ATLAS.ti. The coding labels were based on those retrieved from the literature review's value analysis. Additional labels were added where necessary. Anonymized quotes were translated from Dutch to English using ChatGPT.

2.3.2 FINDINGS

Figure 10 shows an overview of the findings. The grey areas indicate how often a value was mentioned in relation to the other values. The outer circle shows the exact number of mentions. The inside of the circle shows which values were mentioned in relation to each

PARTICIPANT	EXPERTISE	HOSPITAL
P1	Researcher on the topic of VBHC	St. Antonius Hospital
P2	PROM coordinator	St. Antonius Hospital
Р3	Researcher on the topic of Decentralized Clinical Trials	UMCU
P4	Researcher on the topic of VBHC	Amsterdam UMC
P5	PROM coordinator	Amsterdam UMC
Pó	VBHC advisor	MST

Table 1, Participants expert interviews

other, and the thickness of the line shows how often this relation was made. 286 labels were assigned in total. Similar to the literature review, patient-centeredness, quality, and efficiency were identified as the main themes. Codes in the theme "**Patient-centeredness**" were mentioned most often (n=45), followed by "**Quality**" (n=36) and "**Efficiency**" (n=30).

A | Patient-centeredness

"Relevance" (n=26) and "Shared responsibility" (n=23) were mentioned most within this theme. According to P1, P2, P4, P5, and P6, the most important goal of PROMs was or should be improving individual patient care. An important context where this is done is for SDM during consultations. P1 explained, "I would like to say that, for the hospital, PROMs are primarily intended for use in the consultation room. The PROMs that are being implemented are focused on shared decision-making." - P1.

SDM falls in the category of shared responsibility in this analysis. Shared responsibility can be defined as a situation where patients and HCPs both show initiative during a consultation. Patients are responsible for voicing important topics and preparing for SDM, while HCPs are responsible for asking about important topics and stimulating SDM. Patients and HCPs can use PROMs in consultation rooms to know more about what is important for the patient. Furthermore, patients are encouraged to think about what they want to discuss beforehand and are expected to participate more in the decision-making process. However, in practice, this does not seem to be the case. Pl explained, "We see that patients still have doubts about whether they are even allowed to ask questions during the consultation. [...] It seems so obvious that you can do that, but not everyone understands that." – Pl

In addition to using PROMs for SDM, experts talked about the general procedure and benefits of PROMs. Patients get sent a PROM several days before their hospital visit, which they have to complete. Patients are asked questions about their quality of life, pain levels, medication, and more. If these results are used during consultations, SDM can be improved, and HCPs can have a more holistic view of the patient's health status, leading to a better quality of care. P1 illustrated this advantage of PROMs: *"PROMs encourage patients and doctors to think ahead about certain issues. They come into the consultation better prepared. Healthcare providers can also prepare for the consultation more effectively in advance." - P1.*

However, there are many examples where PROMs currently hinder the experience of the identified values. P6 describes two examples of problems related to relevance: "For a trauma center, it is mandatory to collect EQ-5D-5L data one year after the trauma. We do this because it is required, for quality control purposes. While this is useful, we know that many patients do not actually complete the survey since they have long moved on. [...] For patients with prostate cancer, a PROM is often requested. Sometimes, the patient is treated in a different hospital but still receives the questionnaire. However, the survey is not intended for use in the consultation room; its main purpose is benchmarking." – P6. In these cases, data from PROMs is not used to improve individual care, but patients are still burdened with the questionnaires. This hurts the main value of patient-centeredness.

2

30

B Quality

"Quality" (n=36), "Relevance (n=26), "Engagement" (n=19) and "Holistic Care" (n=16), were mentioned most often in the category "Quality". Regarding relevance and holistic care, P2 mentioned: *"The primary goal [of PROMs] is shared decision-making, but it is actually an essential part of diagnostics, just like blood values and imaging. If that is not the case at all, the question is whether you should even use a PROM for that condition." -P2.* With this quote, P2 explains that PROMs add unique information about a patient's health status, allowing HCPs to get a more holistic view. However, P2 also believes that PROMs should not be used in every situation; each condition must be checked to determine if the PROM is relevant.



Figure 10, Values found during expert interviews

The quality of the data of PROMs also depends on who is able to fill it in. When accessibility is bad, some patient groups are excluded from the data generation, leading to biased data and decision-making. HCPs also have their concerns about the quality and validity of data. They like clinical data more, as P6 explains: "[Implementing PROMs] is not a priority. Home monitoring is, because it helps reduce the burden on healthcare and clinical measurements are more in demand. With everything going on, this has not been given priority, so it is not a focus within the professional association." - P6. This mindset also influences engagement, as HCPs are not motivated to implement and send PROMs to patients.

C | Efficiency

In the category "Efficiency" (n=30), "Relevance" (n=26), and "Engagement" (n=19) are also mentioned often. Efficiency and relevance are closely related, with examples around PROM design and HCP involvement. P6 highlights that there are currently too many PROMs, which burden patients and HCPs. Therefore, P6 suggests: "*With generic PROMs, you need far fewer PROM questionnaires. This simplifies many things, such as dashboard maintenance. It takes much less time and burdens patients much less.*" - P6.

Although engagement and quality are connected, as previously explained, engagement and efficiency are also closely connected, especially when looking at it from an HCP perspective. Several participants mentioned that implementing and using PROMs takes up much time and effort from HCPs. Consequently, their engagement is relatively low. P4 says, "Healthcare providers already have a lot on their plate, and shared decision-making adds extra pressure. If you could offer training that discusses when it is truly beneficial, you can see where it should be applied. This way, you are not giving providers the impression that they are constantly being asked to do more, but rather showing them how to deliver more appropriate care to the patient. [...]. Currently, it is a collection of fragmented tasks that take time and create pressure for healthcare providers." – P4.

However, engagement from HCPs differs within functions. P6 explains: "Through the nurse, you can also hold consultations, and this is where PROMs fit in perfectly. [...] The nurse specialist conducts the consultation, so there is no additional step where the patient must also see the internist. You can tell that the nurse specialist approaches discussing the questionnaires differently, with a more holistic view, whereas the internist focuses on what they find most important."-P6.

According to P4 and P5, engagement is influenced by usability issues. HCPs can use

PROMs to prepare the consultations, but this takes time and is not easy if they just look at existing PROM dashboards. During consultations, HCPs often do not show patients the PROM results, making it more difficult to discuss them. HCPs indicate that they find it challenging to use PROMs and that they also find it difficult to use them for SDM. Time also plays an important role. P6 emphasizes this in the following quote: "[PROM results] should be very easy to review. You should be able to see it at a glance, without needing to go over it beforehand. That way, you avoid the issue of not having enough time during the consultation." - P6

2.3.3 IMPLICATIONS

Experts talked about the values patient centeredness, quality, and efficiency. Regarding patient centeredness, relevance and shared responsibility are important. Simultaneously, there are several barriers that prevent the presence of relevance and shared responsibility. Experts, therefore, would like to see these values improved. Quality is an important value as well, because it ensures that PROMs add Allocative Value to the care system. PROMs can add value by being an essential part of diagnostics and giving insight into a patient's health status. But because HCPs have a limited view of what PROMs can be used for, and they question the validity of the data, PROMs are limitedly used by them. The interviewed experts therefore want to change this attitude of HCPs. Finally, efficiency can be improved. The experts expect changes to be made to the workflow of PROMs from a HCP's perspective.

Figure 11 gives an overview of all problems identified during the expert interviews. They are linked to the value labels found in the literature review and expert interviews. The problems can again be divided into three groups: the design and procedure of the PROMs, HCP involvement, and factors related to the patient's internal motivation.

Expert insights reaffirmed that PROMs could significantly enhance consultation value by facilitating preparation and SDM. However, barriers such as limited HCP involvement, insufficient training, and usability issues undermine their effectiveness.

Improving PROM use around consultations could benefit individual care and enhance data quality for broader applications like quality control and research. Notably, HCP involvement, a critical factor influencing patient motivation, remains underexplored in the literature and warrants closer attention.

PROBLEMS INHERENT TO PROM PROCESS AND DESIGN

PROMs burden for patients and cause emotional confrontations	Empathy
Patients have trouble filling in PROMs and accessing results	Accessibility
Some patient groups have difficulties with digital PROMs	Equality
Patients have to fill in too many PROMs	Relevance
There are many clicks when trying to gain insight into results	Usability
PROM results can not be shcred during scientific studies	Scientific integrity
Not all patient groups can fill in PROMs, leading to biased results	Accessibility
$PROMs\xspace$ are used in situations where they are not relevant	Relevance
PROMs are very expensive to implement and takes time	Cost-effectiveness
Dashboards for HCPs are not accessible	Accessibility
PROMs are too long	Usability

PROBLEMS INHERENT TO CAREGIVER ENGAGEMENT

PROMs are almost never discussed during consultations	Communication
Sometimes PROMs are not used to improve individual care	Holistic care
There is no insight into what goes on during consultations	Transparency
65% participation is seen as nothing to worry about	Engagement
HCPs are not used to looking at PROM dashboards	Usability
There is little insight into what happens during consultations	Communication
HCP PROM training is only effective on the short term	Engagement
New employees do not get informed about PROMs	Communication
HCPs are unaware of the value of PROMs	Relevance

PROBLEMS INHERENT TO PATIENT ENGAGEMENT

Patients do not know that they can ask questions during consults	Autonomy
Only 65% of patients complete PROMs	Engagement
Patients do ${\bf not}\ {\bf know}$ why they have to fill in PROMs	Purposeful
Patients find it difficult to prepare for a consultation	Self-reliance
Patients feel at \ensuremath{unease} when filling in PROMs in the hospital	Safety
PROM outcomes are not discussed with patients	Shared responsibility

Figure 11, Problems found during expert interviews

2.4 CONCLUSION

To conclude Explore Phase Part 1, a value framework was constructed based on the information from Explore Phase Part 1, using the five questions of the VtM-approach:

- 1. What values are important for the actor?
- 2. What definition is given to each value?
- 3. What is the relative importance of each value?
- 4. How is each value specified in norms?
- 5. How is each value experienced?

Questions directly retrieved from (Smits, Ludden, et al., 2022)

Creating a value framework allows us to assess stakeholders' values that reflect the current state and use of PROMs. By reflecting on the relative importance of these values and how they are currently experienced, a preferred value framework can be built that should match a new PROM solution. Findings from both the literature and interviews were used. The framework is depicted in Figure 12.

While these values and norms offer a clear value framework, the current implementation of PROMs often fails to meet them. Patient-centeredness is hindered by usability challenges and insufficient HCP involvement. Quality is compromised by data biases and poor engagement, and efficiency suffers from fragmented communication and suboptimal workflows.

A challenge of this framework is that it highlights many different values, making it difficult to identify the root problem of PROMs that needs to be addressed to increase its value. The problems are rooted in factors related to the design and procedure of PROMs, HCP involvement, and patients' motivation, but are also spread over the four different PROM goals. However, the expert interviews provided a clear focus within these goals. Individual care improvement was seen as the most important goal of PROMs. Therefore, the goal of individual care improvement will be the focus of the next chapter.

PATIENT CENTEREDNESS

Care that is tailored, relevant, and aligned with the patient's needs and preferences. It is achieved when autonomy, accessibility, and empathy are upheld.



QUALITY

Defined by the delivery of evidence-based, holistic care that is transparent and equitable. High-quality care relies on unbiased and relevant data.

	Equality Equal access to care for all patients.	Evidence-based Holistic, evidence-based treatments tailored to individual needs.	Data collection Transparent communication and unbiased, inclusive data collection.	Cost-effective Cost-effective and preventive care solutions to reduce unnecessary burden.	Usability Accessible, usable systems promoting HCP and patient engagement.
	Responsibility	Relevance		Communication	
9	Shared responsibility between patients	All care activities and data are relevant and		Clear communic- ation between stakeholders to	
nal	and caregivers.	beneficial to patients.		optimize care processes.	

Usability

Autonomy Patients exercise

care decisions.

Relevance Care activities a

purposeful, and minimize emotio

Usable and facilitate safe

Figure 12, Value framework Explore Phase Part 1

3

EFFICIENCY

Achieving high-quality outcomes with optimal

use of resources. While it occasionally conflicts

with patient-centeredness, efficiency ensures

sustainable and effective care delivery.

EXPLORE PHASE - BROAD CONTEXT

2.5 REFINED RESEARCH QUESTION

Reflecting on the introduction of this thesis, the research question that needed to be addressed was:

How can the value of PROMs be improved for patients, care organizations, and the care system?

This question is very broad and does not guide towards a clear root problem that needs to be solved to increase the value of PROMs. However, based on insights from the literature review and expert interviews, the research question can be refined. Through this research, the context of PROM use was examined, along with the values they currently support, gaps in their effectiveness, and challenges in implementation and use.

INDIVIDUAL CARE IMPROVEMENT PATIENT POPULATION CARE





omparing data of Writing reports on patient groups treatment effectiveness

ong-term Evaluating teams opulation and treatments



The identified values, Patient-Centeredness, Quality, and Efficiency, highlight the critical importance of using PROMs for individual care improvement (Figure 13), one of the four identified PROM goals which is both relevant to patients and prioritized by healthcare systems.

However, several issues persist: unclear responsibilities for discussing PROMs, patients' lack of awareness about using PROMs in consultations, limited use of PROM data by HCPs, and design shortcomings that hinder patient engagement and understanding. These challenges reduce the Patient-Centeredness, Quality, and Efficiency of PROMs. Three main factors influence this: the design and procedure of PROMs, HCP involvement, and internal patient factors. Thus, the refined research question is:

RQ2: How can the design and procedure around PROMs, HCP involvement, and internal patient motivation be improved to increase the value of PROM use for individual care improvement?

RQ2 outlines key areas for intervention and specifies the context for improving PROM use. The following section will investigate the factors influencing PROM value for individual care improvement.

Figure 13, Individual care improvement versus patient population care

Chapter 3 **EXPLORE PHASE** PART 2 - INDIVIDUAL CARE

Based on the refined research question, the second part of the explore phase can be started. This part will dig deeper into the context of PROMs surrounding individual care improvement and medical consultations. Results from the expert interviews will be used. Additionally, literature research will be done to find important factors related to this context. To conclude part 2 of the explore phase, a new value framework will be made, and the research question will be further refined.



3.1 PROM CONTEXT FOR INDIVIDUAL CARE IMPROVEMENT

There are several sub-goals within the goal of PROMs used for individual care improvement, which will be explained in this section. This detailed overview will help understand how PROMs are used for individual care improvement and can help identify a further focus within the context of PROMs.

3.1.1 GOALS AND FEATURES



Figure 14, PROM goal: improving individual care

When PROMs are used for individual care improvement, there are four subgoals for which they are used: diagnostics, Shared Decision-Making, remote monitoring, and self-management (Figure 14).

A | Diagnostics

The first sub-goal is diagnostics. Patients fill in the first PROM before or during the first consultation to facilitate this goal. Information from this data can be used for the first assessment and is used in combination with clinical outcomes (Field et al., 2019). In this stage, PROM data can also be used to find underlying issues that need to be addressed. PROMs can be used for screening in this case and can therefore contribute to a better diagnosis (Field et al., 2019). In the long term, insights from routinely answered PROMs can give insight into the progression of a disease as well (Field et al., 2019).

B Shared Decision Making

PROMs are also used to facilitate SDM, which is the second sub-goal. In this situation, PROMs are used before and during consultations to identify important factors for patients (Field et al., 2019). This makes it possible to choose treatments that are of the most value to the patient, therefore contributing to VBHC. Most of all, PROMs facilitate communication between patients and HCPs (Field et al., 2019; Quik, 2022). By clearly showing the impact of the illness on the patient's life, HCPs could be encouraged to consider the patient's perspective when discussing treatment options (Field et al., 2019; Teela et al., 2021). PROMs can also provide an opportunity to talk about expectations of treatment outcomes and help HCPs and patients to set realistic goals together (Field et al., 2019).

C | Monitoring

The third sub-goal is patient monitoring. Gathering data over a more extended period helps to gain insight into the progression of a disease, or even a lack of progression (Porter et al., 2016). Especially for chronically ill patients, this could be a good approach to tailor treatments to the needs of a patient. Therefore, PROMs could be a valuable tool to make adjustments to a treatment plan when necessary (Field et al., 2019).

D | Self-management

The final sub-goal is self-management of patients. PROMs could assist patients in learning more about their health condition (Field et al., 2019; Silveira Bianchim et al., 2023). Patients could have access to their health status between consultations, which may improve self-management (Field et al., 2019). Self-management entails that patients follow self-management advice, comply with treatment plans, and visit HCPs when needed (Field et al., 2019).

In conclusion, there are very different uses of PROMs even within the primary goal of individual care improvement. Diagnostics, SDM, monitoring, and self-management all use PROMs for different purposes. In the next section, problems related to PROM use for individual care improvement will be mapped out, and the sub-goals that could benefit the most from a redesigned use of PROMs will be evaluated.

3.2 PROBLEMS IN PRACTICE

This section enriches the findings from the expert interviews with literature on the perspectives of patients and HCPs with PROM use for medical consultations. This section aims to identify problems with PROM use for individual care improvement in practice. Literature was searched using the keywords "caregiver," "patient," "perspective," "experiences," "PROM," and "consultation."

3.2.1 HCPS' POINT OF VIEW

HCPs recognize the value of PROMs but also experience problems during the use of PROMs for consultations. For example, HCPs frequently do not review PROM overviews before consultations or fail to share the results with patients during visits. This limits the potential of PROMs as a tool to initiate conversations on topics important to the patient (Damman et al., 2019). Furthermore, a disconnect often arises; HCPs expect patients to bring up their PROM results, while patients anticipate that their HCP will lead the discussion (Damman et al., 2019; Trillingsgaard et al., 2016).

Research on a PROM dashboard called KLIK (see example) suggests that while approximately 70% of HCPs discuss PROM results with patients, these discussions often fall short due to barriers such as time constraints, forgetfulness, or because PROM results do not have priority (Teela et al., 2021). Although HCPs acknowledge the value of PROMs in providing evidence for treatment decisions, many remain reluctant to engage in discussions, caused by skepticism about data quality and concerns about patients' ability to understand the information (Damman et al., 2019).

During consultations lasting between 10 and 50 minutes, approximately 15% of the time is spent discussing PROM results, which most HCPs consider satisfactory (Teela et al., 2021). However, many patients are not invited to participate in KLIK due to various factors, including the absence of a chronic condition, mental disabilities, illiteracy, language barriers, or HCPs' lack of awareness regarding their responsibility to invite patients (Teela et al., 2021). Despite the benefits of KLIK, such as improved communication, earlier problem detection, and better preparation for both HCPs and patients, barriers persist. HCPs report low patient response rates, the time-consuming nature of the process, the

EXAMPLE

Platforms like KLIK have been implemented in the Netherlands to support the integration of PROMs into clinical practice (Teela et al., 2021; van Muilekom et al., 2022). KLIK displays patients' PROM responses in a structured format (Figure 15), aiming to make the data more accessible and interpretable for HCPs.

PROfiel Overzicht sessies Afspraken Deelname protocollen Invulmomenten Invulmomenten en afspraken Acties

ANNE (V / 10-09-1998) 18-09-2015 Hoe vaak waren er in de afgelopen week problemen met ichameliik 18-09-201 Het is voor mij moeilijk om meer dan één straat op en neer te lopen Nooit • Het is voor mij moeilijk om te rennen Vaak • Het is voor mij moeilijk om te sporten of lichamelijke oefeningen te doer Vaak • Het is voor mij moeilijk om iets zwaars op te tiller Het is voor mij moeilijk om zelfstandig een bad of douche te nemer Nooit • Het is voor mij moeilijk om kanveities in en om het huis te doer Soms o Ik heb wondies of piin Ik heb weinig energie Bijna altijd • 18-09-2015 Emotioneel Ik voel me angstig of bang Nooit • Ik voel me verdrietig of sombe Soms o Ik voel me boos Bijna nooit Ik heb moeite met slapen Vaak e Ik maak me zorgen over wat mij zal overkomen Soms a 18-09-2015 Sociaal Ik heb moeite om met andere tieners op te schieten Bijna nooit • Andere tieners willen mijn vriend(in) niet zijn Nooit • Andere tieners pesten mij Nooit • Ik kan dingen niet die andere tieners van mijn leeftijd wel kunner Soms • Het is moeilijk om mee te bliven doen met tieners van mijn leeftijd 18-09-2015 School Het is moeilijk om op te letten tijdens de les Ik vergeet dingen Bijna altijd 🛛 Ik heb moeite om bij te blijven met mijn schoolwerk (waaronder huiswerk Soms a Ik ga niet naar school, omdat ik me niet lekker voe Soms • Ik ga niet naar school, omdat ik naar de dokter of het ziekenhuis moe Soms • Profiel afdrukken

Figure 15, Example of the KLIK platform

irrelevance of certain PROM questions, and technical difficulties as key obstacles (Teela et al., 2021).

The literature suggests several improvements to enhance the effectiveness of PROMs in clinical practice. These include regular training for HCPs on interpreting and discussing PROM results, more straightforward guidelines on responsibilities related to patient participation, shorter and more relevant PROMs to reduce patient burden, and the promotion of positive examples from other care teams to encourage greater acceptance of PROM use (Damman et al., 2019; Teela et al., 2021). Additionally, HCPs require sufficient time both to motivate patients to engage with PROMs and to review results before consultations (Teela et al., 2021). While generic PROMs provide valuable insights, their lack of personalization limits their ability to reflect individual patient contexts (Ashworth et al., 2007). Incorporating free-text responses may help address this issue, as evidenced by a study where over half of the patients contributed new, relevant information through open-ended answers (Ashworth et al., 2007). However, such responses are less suitable for quality control purposes (Field et al., 2019).

3.2.2 PATIENTS' POINT OF VIEW

Patients experience several benefits from discussing PROMs during consultations, including enhanced patient-centered communication, improved self-management, and a better understanding of the relationship between their symptoms and health condition (Trillingsgaard et al., 2016). Discussing PROMs can contribute to more effective symptom management, optimized treatment, and improved lifestyle adjustments. However, 10 to 30% of patients have difficulties to interpret PROM results (Damman et al., 2019). This shows the importance of presenting data in an accessible and meaningful way.

Other than symptom management, PROM discussions help to highlight emotional wellbeing, quality of life, and other sensitive issues. This contributes to the early diagnosis of psychological problems related to chronic conditions. Additionally, visual representations of treatment outcomes support SDM by making the data easier to understand (Damman et al., 2019; Trillingsgaard et al., 2016). However, this is only the case if patients have access to their PROM results and are actively involved in discussing them. Many patients remain unsure about how their data is used, and they often assume that PROMs primarily serve the needs of HCPs rather than their own. Some also perceive PROMs as impersonal tools and express frustration over the inability to provide more detailed responses (Trillingsgaard et al., 2016).

While some patients value PROM discussions, others prefer to focus on different issues during consultations or find the results irrelevant to their concerns. Comparative PROM data, used to illustrate treatment effects in similar patient groups, can also lead to confusion, because patients struggle to interpret and contextualize the information (Damman et al., 2019).

A lack of awareness about the benefits of PROMs further contributes to their underuse for self-reflection and self-management. Many patients do not expect to play an active role in SDM during consultations, which is often due to time constraints and a reluctance to take up too much of their clinician's time (Trillingsgaard et al., 2016).

3.2.3 CONCLUSION

While PROMs have the potential to enhance patient-centered care, improve selfmanagement, and facilitate SDM, significant barriers hinder their effective use in clinical practice. HCPs recognize the value of PROMs but often struggle with time constraints, skepticism about data quality, and practical challenges in integrating results into consultations. Similarly, patients benefit from PROM discussions when they are accessible and meaningful, yet many remain unaware of their purpose, consider them impersonal, or struggle to interpret comparative data. Digital platforms like KLIK aim to address some of these challenges, but their success depends on consistent patient engagement, HCP training, and improved usability. To improve PROMs, efforts could focus on improving data presentation, reducing patient burden, and encouraging a culture where both HCPs and patients actively engage in PROM-driven discussions.

3.3 VALUES

A second, smaller reflection on values during consultations can be made based on Section 3.2. Five papers were used for this analysis and a deductive coding process was used. The problems described by HCPs and patients were compared to the values identified and used in Section 2.3. It was counted how many times each value was mentioned, and visualized which values were related by counting how many times they were mentioned in relation to each other. This visualization can be seen in Figure 16.

N

9

One aspect that becomes clear from the visualization is the importance of the value communication (n=15) related to PROM use for consultations. When PROMs are discussed during consultations, it provides the opportunity for patients to explain how they feel and how their condition impacts their life. Furthermore, it helps HCPs to take the patient's perspective into account. However, problems that were experienced were mainly related to the communication of PROMs. One example is the hesitation of HCPs to discuss PROMs with patients. Furthermore, the patient's attitude towards communication caused that PROMs were not always discussed.

As seen in Figure 16, communication was most often mentioned concerning shared responsibility (n=7), which is closely connected to SDM. The importance of communication in SDM can explain this, as talking is central to the process. Problems related to communication, therefore, also impact SDM.

Engagement (n=11) was mentioned most often in relation to the role of HCPs. HCPs did not engage well with PROMs for individual care improvement. For instance, they forgot to discuss them or did not prioritize them. Other reasons were that they expected patients to take the initiative, or did not have enough time to discuss PROMs. On the other hand, patient engagement was also mentioned, as patients did not always fill in PROMs or were hesitant to discuss them during consultations. Therefore, improvements are needed on the HCPs' and patients' sides.



Figure 16, Value overview of patients' and caregivers' perspectives on PROMs during consultations

Summarizing, effective communication is important for integrating PROMs into consultations. However, both HCP and patient hesitations often hinder discussions. Communication is closely linked to shared responsibility, which highlights its role in SDM. Engagement remains a challenge, as HCPs often deprioritize PROMs while patients may hesitate to complete or discuss them. Addressing these barriers requires improvements on both sides to enhance PROM use and patient-centered care.

3.4 CONCLUSION

To conclude explore phase part 2, the values of patients and HCPs can be described, based on PROM use for individual care improvement. The three main values could still be applied to the analysis of patients and HCPs: Patient Centeredness (n=59), Quality (n=47), and Efficiency (n=45). The most important sub-values identified are communication, engagement, shared responsibility, and relevance. These sub-values are connected to the three central values. The focus was placed on the subvalues to get a more detailed value framework and to clearer describe norms (Figure 17).

Currently, many PROM-related problems prevent patients and HCPs from experiencing these values. Therefore, an alternative to PROMs that allows patients and HCPs to experience these values should be found. These values can be reached if the solution promotes communication, shared responsibility, engagement, and relevance, as sub-values of patient-centeredness, quality, and efficiency.

COMMUNICATION

PATIENT CENTEREDNESS, QUALITY, EFFICIENCY

Patients are informed about the choices and options that they have, and HCPs are open to listen to the patient's perspective.

SUB-VALUES



ENGAGEMENT

PATIENT CENTEREDNESS, QUALITY, EFFICIENCY

The way HCPs and patients actively use and get value out of PROMs.

NOKMS	Perspective Caregivers listen to the patient's perspective	Impact Patients are able to communicate what the impact of a condition is on their life	Initiating Caregivers initiate the discussion about patient-reported outcomes	Participation Patients actively participate in consultations and activities around the consultation



SHARED RESPONSIBILITY

PATIENT CENTEREDNESS

3

SUB-VALUES The way HCPs and patients share responsibility in making decisions about the patients care path.

> SDM part in a Shared

VORMS

RELEVANCE

PATIENT CENTEREDNESS, QUALITY, EFFICIENCY

Filling in PROMs is of added value to the patient and improves their individual care noticeably by the patient.

Understanding
Patients understand
why they have to
participate in a
certain activity

Beneficial

The activity is beneficial to a patients individual care path

Figure 17, Value framework explore phase 2
3.5 REFINED RESEARCH QUESTION

Based on the information gathered in this section, it is possible to refine the research question further. It can be concluded that PROMs currently routinely act as a tool to provide context about a patient's health status. It aids in diagnosing illnesses and acts as a conversation starter between patients and HCPs to inform treatment plans. It can also be used to know when to adjust a treatment plan and assist patients in self-management. A design vision that would support all these goals for individual care improvement can be written:

To design a tool that routinely collects information about the context of a patient's health status and shares this with patients and HCPs.

In theory, such a tool could be used for diagnostics, SDM, monitoring, and self-management. Current PROMs fulfill this description. However, they are not used optimally because of many limitations, as discussed in the previous chapters. As PROMs are currently used for a wide variety of goals, it may be possible that they are too generic to be used well for every goal. There may be no single solution that can address all functionalities PROMs currently aim to have but fail to fulfill. To illustrate: generic PROMs are used to improve individual care, while it has been proven that individualized PROMs that allow patients to have free-text responses gather more relevant information for individual care improvement (Ashworth et al., 2007). Perhaps it is likely that the generic PROM solution that currently aims to solve many goals is not the most suitable option for solving individual goals.

From the expert interviews, it became clear that PROMs are mainly used for diagnostics and monitoring, and less for SDM and self-management. Nevertheless, SDM was seen as the most important goal of PROMs. Explore phase part 2 also shows the important role of PROMs in SDM. Therefore, to increase the value of PROMs, I have decided to focus this research on improving a situation where PROMs are used for the goal that holds the most value: PROMs to assist SDM. To make a tailored solution, the design vision can be rewritten into one that takes SDM as its most important goal:

RQ3.1: To design a tool that provides context for and stimulates Shared Decision Making.

The next chapter will dive deeper into the role of PROMs in SDM to add more detail to this goal and will adopt a case study that allows for a tailored solution to be made.

Chapter 4 **EXPLORE PHASE** PART 3 - SHARED DECISION MAKING

Based on RQ3, the final part of the explore phase can be started. This part will dig deeper into the context of PROMs used for Shared Decision Making (SDM). The SDM process and the role of PROMs in SDM will be explained. A case study is selected to illustrate and test the proposed solutions in Chapter 6. Multiple Sclerosis patients and their HCPs will participate in this. Therefore, context about MS will also be given in this section. To conclude the explore phase, the research question will be refined one more time, and results of the complete explore phase will be used to generate a list of design criteria that will be used to inform the design phase.



4.1 PROM CONTEXT FOR SHARED DECISION MAKING

4.1.1 SHARED DECISION MAKING PROCESS

To design an alternative to PROMs that can support SDM, it is essential to gain more insight into the concept. So, what is SDM?

SDM is a process that happens during medical consultations. If, in a consultation, a decision needs to be made that involves the context, concerns, and preferences of a patient, SDM can be applied. For SDM, information provided by both the patient and the HCP is important. For example, the patient provides information about their context, concerns, and preferences by filling in a PROM. HCPs provide information about the options available to the patient, such as possible treatments. This is often described as the essence of SDM (Elwyn et al., 2017).

There are several benefits to SDM. SDM allows patients to gain insight into their health situation and ask for care that is more fitting to their context (Wiegant et al., 2017). It can also make care more efficient, as tailored decisions could lead to treatments that fit better to the patient's life, therefore reducing unnecessary treatments or operations (Wiegant et al., 2017). Therefore, SDM contributes to VBHC, which aims to individualize care to improve patient value and reduce costs and resources.

There are also some barriers related to SDM. Although it is a goal of hospitals to apply SDM more, it is not yet standard practice. This is caused by problems, such as a lack of time, difficulties in integrating into existing workflows, and inadequate information supply to patients (Joseph-Williams et al., 2017). But the most difficult challenge is the attitude of HCPs, who are reluctant to apply SDM (Joseph-Williams et al., 2017).

ASPECTS OF A SHARED DECISION MAKING PROCESS



Figure 18, Aspects of a shared decision making process, showing the use of PROMs. Based on Damman et al., 2020, with adaptations based on the findings in this thesis.

4.1.2 THE ROLE OF PROMS IN SDM

Elwyn et al. (2017) established a three-talk model to divide the process of SDM to make it easier to implement during consultations. In the Netherlands, a four-talk model is used more often to describe the SDM process. This model consists of the steps: Team talk, Option talk, Choice talk, and Decision talk (Figure 18).

- During the **Team talk**, the HCP explains that there are options, offers support, and asks about goals (Elwyn et al., 2017; Stiggelbout et al., 2015). During this phase, HCPs and patients are stimulated to work together to inform each other about context and options.
- During the **Option talk**, the HCP explains the options in more detail. For each option, the HCP explains the pros and cons. To support this talk, option grids can be given to the patient that also show all options in a structured way (Elwyn et al., 2013).
- During the **Choice talk**, patients and HCPs discuss the patient's needs and preferences. This aids the patient in forming a choice about the treatment options (Elwyn et al., 2017; Stiggelbout et al., 2015).
- During the **Decision talk**, the HCP asks the patient about their preferences and whether the patient is ready to decide. If the patient needs more time or information, the HCP should supply this (Elwyn et al., 2017; Stiggelbout et al., 2015).

PROMs can be used to support the SDM process (Figure 18). First of all, they provide context about the impact of a patient's health condition on their life (Field et al., 2019). PROMs used for individual care give insight into the severity and frequency of occurrence of symptoms that are otherwise difficult to remember by patients (Field et al., 2019). Secondly, patients gain insight into their health symptoms through PROMs, which allow them to think about their preferences (Field et al., 2019). Finally, PROMs that have been used in research can provide insight into which treatments are most effective for specific patient groups (Damman et al., 2020).

PROMs could especially play an important role during the Option and Choice talk (Groenewegen et al., 2024). During these phases, PROMs provide information about the context of the patient, but they can be used for goal setting as well (Damman et al., 2020; Groenewegen et al., 2024). Besides the ability of PROMs to provide information,

their presence can also motivate HCPs to take the patient's perspective into account and initiate the Team talk (Damman et al., 2020; Field et al., 2019). However, currently, this is not enough to ensure that SDM is sufficiently applied (Damman et al., 2020). Damman et al. suggest that the role of PROMs during the choice talk should be stimulated more, for example by introducing decision aids (Damman et al., 2020).

4.2 CURRENT PROM USE FOR MS PATIENTS

Although PROM use for SDM is quite a specified goal, its implementation in practice can differ significantly depending on different types of patients or hospitals. Therefore, it is helpful to select a case study. This makes it possible to gather enough details for the design process. The selected case study is the use of PROMs for SDM for Multiple Sclerosis (MS) patients in the St. Antonius Hospital in the Netherlands. These patients were selected because they often have multiple SDM moments every year and are expected to benefit from an alternative solution to PROMs. This section will explain relevant details of the condition, the care trajectory, and the current use of PROMs for these patients.

4.2.1 CONTEXT AND CARE TRAJECTORY

MS is a chronic neurological disorder that usually starts between the ages of 20 and 40 (Multiple Sclerosis | National Institute of Neurological Disorders and Stroke, n.d.). There are different types of MS. One of the most common types of MS is Relapsing-Remitting MS (RRMS). People with this type of MS suffer from recurring periods with symptoms, after which a period of disease inactivity, remission, takes place (Multiple Sclerosis | National Institute of Neurological Disorders and Stroke, n.d.). It is unclear when a period of remission will end. When symptoms remain steady over time, patients are diagnosed with Secondary-Progressive MS (SPMS).

People with MS can suffer from various symptoms. These include vision problems, muscle weakness, numbness and pain, balancing problems, bladder control problems, and dizziness (Figure 19). Furthermore, mental or physical fatigue, mood changes, and cognitive changes can be experienced (Multiple Sclerosis | National Institute of Neurological Disorders and Stroke, n.d.). Women are two times as likely to develop MS as men (Multiple Sclerosis | National Institute of Neurological Disorders and Stroke, n.d.).



Figure 19, Example of MS symptoms

There is no cure for MS. However, there are treatments based on medication that can reduce how often and how severely attacks happen. These are disease-modifying treatments (DMTs). These treatments also aim to slow down the progression of the disease (Multiple Sclerosis | National Institute of Neurological Disorders and Stroke, n.d.). There are different types of DMTs, all of which differ in timing, location of administration, safety, tolerability, and side effects (Ubbink et al., 2022). DMTs have different effects on different patients. Therefore, they need to be closely monitored. This also causes the need to try out and switch to other types of DMTs (Ubbink et al., 2022). Next to DMTs, there are also treatments and therapies for specific symptoms. These symptoms can range from vision problems to sexual dysfunction (Multiple Sclerosis | National Institute of Neurological Disorders and Stroke, n.d.). This is why a patient is usually treated by a team of HCPs.

Usually, patients who are diagnosed with MS have yearly consultations with a neurologist. However, depending on the patient, there are also consultations with other HCPs. An MS team often consists of a neurologist, a nurse, a physiotherapist, an occupational therapist, a speech therapist, a psychologist, and a dietitian (MS Centrum | St. Antonius Ziekenhuis, n.d.).

A consultation also takes place when decisions about treatments should be made. This happens when starting, switching, or stopping a treatment, whether it is about DMTs or treatment and therapy to deal with symptoms of MS (Ubbink et al., 2022). Usually, there first is a big decision moment about whether or not a DMT should be used. After this decision, smaller decisions need to be made, which are dependent on the context of a patient (Damman et al., 2024).

4.2.2 SHARED DECISION MAKING AND MS

The symptoms and experiences of MS patients vary considerably among individual patients, as do their preferences and needs regarding treatment options. This variability makes SDM an essential part of MS patient care. However, due to the complex nature of MS symptoms, special attention must be paid to how SDM is applied in practice (Ubbink et al., 2022).

A | Possible improvements

As MS is a chronic condition that results in routine care management, PROMs can give insight into changes in context and preferences, which is used to inform choices (Damman et al., 2024). A benefit of using PROMs compared to other decision aids is that they contain information about the patient's health context. This allows SDM to be more adapted to individual patients.

An important consideration in the implementation of SDM is usability. In providing information to patients through tools, it is important to think about their usability for people with lower digital literacy and health literacy (Ubbink et al., 2022). Because MS patients can suffer from cognitive dysfunction and fatigue, special attention needs to be given to how information is provided. If PROMs are used, they should therefore be visible during a consultation and designed so that it is easy and quick to understand them (Ubbink et al., 2022).

B Challenges in practice

A study by Damman et al. (2024) explored how SDM and PROMs are applied for MS patients in the Netherlands. The study included consultation observations and interviews with patients and HCPs. While PROMs can support SDM by providing context, barriers were also identified.

SDM was not routinely practiced. Firstly, choices were rarely explicitly presented and were often briefly outlined, with HCPs emphasizing their preferred option (Damman et al., 2024). Secondly, HCPs often found it challenging to translate PROM data into treatment decisions and viewed PROMs as cumbersome or lacking value (Damman et al., 2024). Conversely, patients valued PROMs for insights into the impact of MS on their lives, but lost trust in their utility if results were ignored during consultations (Damman et al., 2024). Thirdly, while patients' experiences and priorities were discussed, they were seldom used to initiate SDM. Instead, HCPs quickly provided advice based on their own preferences (Damman et al., 2024).

Furthermore, practicalities like arranging tests or referrals took significant consultation time (Damman et al., 2024). Patients often requested summaries or visual overviews, which could help interpret PROM outcomes. Finally, differences in health literacy were notable: patients with lower health literacy were less prepared, asked fewer questions, and were less frequently offered choices. They also reacted more emotionally to individual

outcomes, requiring more reassurance, but HCPs tended to discuss these outcomes in less detail with them (Damman et al., 2024).

Barriers specific to MS patients included the complexity of PROM data, which neurologists found harder to interpret than direct patient interactions (Reitzel et al., 2022). Additionally, cognitive and functional impairments from MS may reduce the accuracy of self-reported data, which makes HCPs question their validity (Reitzel et al., 2022). Some neurologists suggested involving loved ones or personal HCPs in completing PROMs or considered consultations themselves as effective PROMs, as they allow reading subtle cues absent in standardized tools (Reitzel et al., 2022).

C | Effectiveness of PROMs for SDM

Miller et al. (2019) did a study to investigate if PROMs would bring up most important discussion topics for MS patients. They found that specifically asking patients what they found most important to discuss captured patient information that could not directly be retrieved from PROMs. This happened for a third of the patients, and brought up information in the domains of physical, mental, or social aspects (Miller et al., 2019). This information was gathered before the consultation by asking: "What is the most important thing you want your clinician to know today?". This question is based on the specific questionnaire: Most Important Patient Concern (MIPC) (Miller et al., 2019). Therefore, it seems likely that PROMs need to be altered to accurately capture important discussion topics for MS patients.

4.2.3 CONCLUSION

While PROMs can potentially enhance SDM for MS patients, their implementation comes with several challenges. The complexity of MS symptoms, cognitive impairments, and differing levels of health literacy among patients make it important to design PROMs that are both accessible and relevant in consultations. Studies highlighted that PROMs are not always effectively integrated into SDM, with barriers such as difficulties in interpretation and limited use of patient priorities in consultations. To improve the use of PROMs for SDM in MS care, addressing these challenges is essential.

4.3 REFINED RESEARCH QUESTION

Previous chapters identified SDM as one of the primary goals of PROMs. In theory, PROMs help patients monitor how their condition affects their daily lives, providing valuable insights for patients and HCPs. These insights are used as a foundation for SDM, and the overview of PROM results during consultations can encourage discussions about treatment options. However, findings from Explore Phase Parts 1 and 2 identified several issues with PROMs that hinder their ability to stimulate SDM. As a result, an alternative approach is necessary to achieve the goal described in Section 3.5. Based on the findings in this section, the phrasing of this goal is slightly adapted:

RQ3.2: To design a tool that identifies the impact of a disease on a patient's life and facilitates discussions about treatment options



Figure 20, Design goal with sub-goals and first set of requirements

The values of the value framework identified in Section 3.4 (communication, engagement, and relevance, (see Figure 17) should guide the development of concepts that meet this goal and align with these core values (Figure 20).

4.4 DESIGN CRITERIA

In addition to the defined goal and core values, design criteria are essential to address stakeholder needs. These criteria are based on identified norms and derived from other insights gathered in Chapter 2, 3 and 4. Figure 21 shows the criteria and outlines their source and section of origin.

A distinction can be made between three types of design criteria:

- **Design Requirements**: Fundamental functions the solution must have in order to be operational.
- **Design Principles**: Aims that could improve the effectiveness of the solution.
- **Design Guidelines**: Concrete guidelines drawn from literature that apply specifically to developing an alternative to PROMs.

By structuring the design criteria in this way, they can be used to build a solution that meets the needs and values of stakeholders.

4.5 CONCLUSION

The redefined design goal, "To design a tool that identifies the impact of a disease on a patient's life and facilitates discussions about treatment options", serves as a direct response to the overarching research question:

"How can PROMs be redesigned to increase their value for patients, care organizations, and the healthcare system?"

This was determined through several explore phases. Firstly, Chapter 3 revealed that SDM is considered the most important goal of PROMs, while its current shape hinders this achievement. Secondly, Chapter 4 showed which aspects of PROMs are necessary to allow for SDM. The design goal, together with the core values and design criteria, provides many pointers to start the conceptualize phase, in which concepts to achieve the design goal will be proposed.

DESIGN REQUIREME	NTS	
Section	Design requirement	Source
4.1	The solution should identify individual problems that patients experience	(Damman et al., 2024), Interviews
4.1	The solution should stimulate caregivers to initiate the Team talk	(Damman et al., 2024), Interviews
4.2	The solution should allow patients to identify which health aspects are most important to them	(Damman et al., 2024)
4.2	The solution should be able to be used by MS patients, taking into account possible physical and psychological impairments	(Ubbink et al., 2022)

DESIGN PRINCIPLES		
Section	Design principle	Source
3.2	Improve patient and caregiver communication	(Trillingsgaard et al., 2016)
3.2	Present information without overwhelming patients	(Damman et al., 2019)
3.2	Encourage and prepare patients to have an active role in SDM	(Trillingsgaard et al., 2016), Interviews
4.1	Integrate the solution into existing workflows	(Joseph-Williams et al., 2017), Interviews
4.1	Reduce the time it takes to use the solution for a caregiver	(Joseph-Williams et al., 2017), Interviews
4.2	Reduce the time and burden for patients to use the solution	(Reitzel et al., 2022), Interviews
4.2	Take usability for people with lower health literacy into account	(Ubbink et al., 2022)

DESIGN GUIDELI	INES	
Section	Design guideline	Source
3.2	Give caregivers confidence in conversation techniques	(Trillingsgaard et al., 2016)
3.2	Only ask information that is relevant to the patient and the caregiver to not overload patients	(Trillingsgaard et al., 2016)
4.2	Ask patient an open question about what is most important to them	(Miller et al., 2019)
4.2	Allow loved-ones and personal caregivers to help identify individual problems that the patients experience	(Reitzel et al., 2022)
4.2	Provide patients with a visual overview of what is discussed during a consultation to help them interpret outcomes	(Damman et al., 2024)
4.2	Make solutions visible during a consultation to stimulate conversation	(Ubbink et al., 2022)

Chapter 5 CONCEPTUALIZE

This chapter presents several concepts based on the insights gathered during the explore phases and the redefined design goal. The conceptualize phase consists of ideation and conceptualization. This phase aims to generate concepts that will be further refined during the anticipate phase, where they will be evaluated and codeveloped with MS patients and their HCPs. As such, the concepts developed here are designed to elicit diverse reactions and perspectives rather than providing finalized, ready-to-implement solutions.





Figure 22, Simplified visualization of the ideation process

5.1 IDEATION

The ideation phase started after Explore Phase Part 2. It was structured around the core functionalities of PROMs, which served as themes for brainstorming sessions. Several rounds of ideation were conducted to generate diverse ideas. A focus was placed on generating many fundamentally different concepts that could evoke different reactions during a testing phase with users.

Following two weeks of ideation, all generated ideas were collected and categorized, of which a complete overview can be found in Appendix C. Ideas were sorted by theme and concept category, allowing for a comparative analysis of different concept directions and their potential. Figure 22 provides a simplified visualization of this process.



A | Demonstration of ideation process through an example

Concept 1, as illustrated in Figure 22, emerged from two primary concept directions: AI Pre-Consultation and Improved Training & Education.

Figure 23 showcases various ideation sketches created using Procreate. In total, 72 sketches were made, each visualizing different ideas. To organize these ideas, the sketches were printed, cut out, and mixed at the start of the sorting process. Ideas with conceptual similarities, such as Artificial Intelligence (AI) or educational components, were grouped and assigned distinct colors and concept direction labels. Additionally, ideas fulfilling similar functions were categorized and labeled based on functionality, which was noted on the back of each sketch.

Once categorized, these sketches were sorted into their respective concept directions (Figure 24). The AI Pre-Consultation direction comprised ten sketches spanning eight functionality themes, while the Training & Education direction included four sketches covering three functionality themes.



Figure 24, Grouped ideation sketches

Figure 23, Example of ideation sketches



CONCEPT: A.I. PRE-CONSULTATION





 Patients get training about the value of PROMs and how to participate in a consultation

CONCEPT: TRAINING & EDUCATION

Figure 25, Example of initial concept directions





 Caregivers get training with practise and exercises about the value of PROMs and how to use them during a consultation Using these grouped sketches, concept directions were translated into conceptual drawings (Figure 25). Each concept was evaluated against three key problem areas: HCP involvement, PROMs process and design, and patient engagement.

Figure 26 illustrates the evaluation of the AI Pre-Consultation and Training & Education concepts, revealing complementary strengths between them. Consequently, these concepts were integrated into a single, more comprehensive solution.

Figure 27 presents a storyboard demonstrating the combined concept of Pre-Consultation and Training & Education. After these concepts were combined, they were further developed based on the additional findings in Explore phase part 3 and the requirements outlined in Section 4.4, leading to slight refinements before finalizing the concepts that will be explained in the next chapter.



Figure 26, Evaluation of concept Pre-consultation (top) and Training & Education (bottom)











Figure 27, Storyboard of combined concepts: Pre-consultation and Training & Education

Caregiver

5.2 CONCEPTS

This section provides an in-depth explanation of the developed concepts. These concepts will be refined through co-design sessions with patients and HCPs (Chapter 6). At this stage, they are not finalized designs but initial concept proposals intended to gather feedback on their functional and conceptual aspects.

Storyboards, which are low-fidelity prototypes, were used to present the concepts users in the next chapter. Research by Van Nifterik et al. (2021) suggests that such prototypes reduce participants' hesitation to suggest modifications and could encourage more open feedback. Each concept is focussed on different core values to ensure that they evoke varied reactions, emotions, and insights during co-design sessions. These core values, together with expected reactions are shown in Figures 29, 31 and 33.



5.2.1 CONCEPT 1: A.I. PRE-CONSULTATION

Patients participate in a pre-consultation with an AI assistant that asks PROM questions and helps them prepare for hospital consultations (Figure 28).

Before an in-person consultation, patients engage in a pre-consultation with their HCP's AI assistant, scheduled approximately a week in advance. During this session, the AI assistant asks the patient PROM questions, stores their responses, and shares them with the HCP. After completing the questions, the AI assistant summarizes the responses and prompts the patient with reflective questions to help them identify discussion topics for their upcoming consultation.

A report summarizing the pre-consultation is generated and shared with both the patient and HCP. During the actual consultation, the Al assistant listens in and suggests relevant follow-up questions to the HCP. Additionally, it generates a summary of the consultation, which is shared with the patient along with links to useful resources.

This concept retains the content of existing PROMs but transforms their delivery into a digital, speech-based format. Replacing long text-based questionnaires with an Alfacilitated consultation aims to improve usability and engagement while increasing the likelihood of PROM completion.

Figure 29, Expected values and reactions from stakeholders concept 1



Concept 1 : Consultation with a digital assistant before hospital visit

Figure 28, Storyboard Concept 1

5.2.2 CONCEPT 2: PROM DIARY

Patients take ownership of PROMs by using a personalized diary to track symptoms over time (Figure 30).

When an HCP activates a PROM for a patient, a personalized PROM diary device is sent to their home. The diary can be customized based on patient preferences, such as adjusting font size or enabling text-to-speech. The diary is meant to integrate into the patient's daily routine and is placed in a location that the patient routinely visits, such as a nightstand. Every day, at a time set by the patient, the diary lights up to remind the patient to complete their PROM.

This process begins three weeks before the consultation, using the PROMIS CAT system (Section 2.1.3) to reduce the number of required questions. One week before the consultation, the patient reviews their responses and selects key discussion topics for their HCP. During the consultation, the patient brings the diary to facilitate discussions about their health, priorities, and treatment preferences, stimulating SDM.

The concept puts more responsibility of answering PROMs on patients. Therefore, this concept enhances self-reliance and ensures that PROMs reflect patient priorities. The focus is on improving the relevance of PROMs in daily life and encouraging SDM discussions with HCPs.



Figure 31, Expected values and reactions from stakeholders concept 2

Self-reliance



Concept 2 : Digital diary to keep track of symptoms

Figure 30, Storyboard Concept 2

5.2.3 CONCEPT 3: CONVERSATION GUIDE

PROMs are replaced with a structured conversation tool used during consultations to gain insight into health context and facilitate SDM (Figure 32).

Patients receive a conversation guide containing condition-specific scenarios and treatment options before their consultation. The guide encourages patients to reflect on relevant experiences and potential treatment choices in advance.

The conversation tool is structured with two key sections. On the left side, disease-specific scenarios are sorted into physical, psychological, and social aspects. Patients review these scenarios and identify the ones they recognize. On the right side, disease-specific treatment options are displayed. These options provide an overview of potential interventions to discuss with a nurse specialist.

During the consultation, the patient and HCP discuss the scenarios together. This conversation gives the HCP deeper insight into the patient's health context and better voices the patient's concerns, which could stimulate SDM. After the consultation, details of the treatment options can be further explored in a follow-up consultation with a nurse or reflected upon by the patient at home using the guide.

This concept restructures PROM content, instead of only its process, to align with SDM. Instead of filling out standardized questionnaires, patients can remember experiences related to their illness and discuss them with HCPs. This aims to improve communication and engagement.



Figure 33, Expected values and reactions from stakeholders concept 3





Figure 32, Storyboard Concept 3

5.3 CONCLUSION

Each concept aligns with different core values identified in the explore phases. Concept 1 keeps the structure of existing PROMs but improves efficiency and engagement through the Al assistant. Concept 2 shifts responsibility to patients, which stimulates self-management and adds relevance for patients. Concept 3 moves away from traditional PROMs by replacing them with an interactive discussion tool to enhance SDM.

To refine these concepts further and to anticipate values, they will be tested in co-design sessions in the next phase. The results of this evaluation will be used to construct a value framework and will guide the selection and adaptation of the concept that fits best to the values of stakeholders.

Chapter 6 ANTICIPATE

In the anticipate phase, the impact of the three proposed concepts on the values of HCPs and patients will be evaluated. Interviews and co-design sessions with these user groups will be held to identify which values are affected by the concepts, and how the concepts could be changed to better match the values of HCPs and users. Besides values, it will also be evaluated if the proposed concepts meet users' needs through the list of requirements. Ultimately, the input from users will lead to a final value framework and final concept, presented in Chapter 7.



HOW TO DO CO-DESIGN?

Having well-structured co-design sessions could stimulate brainstorming sessions that lead to more innovation (Garde, 2013). It could encourage better participation and attention of participants and more idea diversity (Paulus et al., 2002). To achieve this, careful preparation and design of the sessions are essential.

Firstly, timing and organization play an importantl role. It is important to consider the timing of introducing solutions, so that unintentionally influencing participants' thoughts and ideas is avoided (Heinemann, 2011). Group size also matters. If there are more than three participants, it may be more efficient to divide them into smaller subgroups (Heinemann, 2011).

Secondly, selecting and designing tools and materials for the sessions should be done carefully. One commonly used tool is a scenario, which typically describes the user, the product, the product's goal, the context, and a sequence of actions and events (Garde, 2013). Scenarios are practical for evaluating ideas because they allow participants to envision themselves in the context of using the product. These can be visualized in various ways, including storyboards, animations, or videos. Participants can also draw or validate scenarios (Garde, 2013).

A second example is participatory prototyping. Here, future users are actively involved in developing and evaluating concepts (van der Velden & Mörtberg, 2014). This can involve techniques such as sketching, making paper mock-ups, or using digital prototypes.

Lastly, several aspects need to be considered before choosing any tool or technique. When selecting tools for co-design sessions, it is important to clearly define the objective of the session, and to formulate guiding questions (Garde, 2013). Individual and group input should be balanced. For this, an initial individual reflection could help to identify diverse perspectives (Garde, 2013). Additionally, the level of fidelity should be considered. High fidelity prototypes represent the actual context more accuratly, while more ambiguous representations may stimulate exploration on a more conceptual level (Garde, 2013).

6.1 FIRST ROUND OF CO-DESIGN

6.1.1 METHOD

Co-design sessions were conducted to test the hypothesis and further refine the concepts to align with the values and needs of stakeholders. Two key stakeholder groups were involved: four healthcare providers from an MS team and two MS patients from the St. Antonius Hospital. Each group participated in three activities: one semi-structured interview and two co-design sessions (Figure 34). All sessions were held at St. Antonius Hospital, with scheduling coordinated in consultation with participants to accommodate their availability. Ethical approval was given by METC MEC-U and the local R&D department of St. Antonius. Consent forms are stored at the St. Antonius Hospital.

A Interviews

From the HCP group, a neurologist and a rehabilitation physician were interviewed. Each interview lasted approximately 30 minutes. HCPs were asked how they prepared for consultations with MS patients, how they initiated SDM discussions, and about their experiences and opinions regarding PROMs. Two patients were also interviewed. They answered questions about how they prepared for consultations, whether and how they experienced SDM, and their familiarity with PROMs.

The interviews were recorded and transcribed using Microsoft Word. These transcriptions were then analyzed to describe current practices in MS patient visits to the clinic. The insights gained from the interviews informed the preparation of the co-design sessions, ensuring that the activities closely reflected real-world clinical practice. The interview data was not further analyzed.



B | **Co-design session 1** HCP SESSION

Four HCPs participated in the first co-design session: two neurologists, one rehabilitation specialist, and one MS nurse. The session focused on exploring and improving three conceptual designs, which were introduced using printed storyboards, as presented in Section 5.2. To support the activities, various materials were prepared, including large-format storyboards, blank storyboard frames, dilemma cards, and drawing tools (Figure 35 & Appendix D).

The session started with mutual introductions from both the researchers and the participants. Following this, the three concepts were introduced and explained using a large roll of paper displayed on the wall, which served as a visual aid throughout the session. In the first part of the session, participants were invited to reflect on the three concepts by identifying opportunities and challenges for each. Using colored Post-it notes, they wrote down their thoughts and placed them directly onto the relevant storyboard frames. While doing so, participants were encouraged to engage in open discussion with one another. Once the notes were placed, the group engaged in a plenary discussion to reflect collectively on the findings.

The second part of the session was carried out individually. Each HCP was given a set of cards containing opposing statements related to the concepts. They were asked to select the side of each card that best reflected their perspective and place it face up in front of them. Although this assignment was not discussed as a group, it served as a means for participants to articulate their preferences and could be referenced in the final assignment. In the last part of the session, participants selected the storyboard that resonated most with their professional experience or personal preference. They were then asked to propose modifications or improvements to the chosen concept by drawing or writing on blank storyboard frames. To support their creative process, they could reference the Post-it notes from earlier in the session and the statement cards from the second assignment. Depending on their pace, some participants could apply their changes to multiple concepts. At the end of the session, the results were briefly discussed.

To conclude the session, participants were thanked for their input and asked to provide feedback on the session. Their suggestions and comments were considered when preparing the next co-design session.



ENVELOPE WITH EMPTY STORYBOARD FRAMES AND DILEMMA CARDS



Figure 35, Materials for co-design session 1 HCPs

A3 CONCEPT STORYBOARDS



ENVELOPE WITH EMPTY STORYBOARD FRAMES AND DILEMMA CARDS



Figure 36, Materials for co-design session 1 patients

PATIENT SESSION

The first co-design session with patients involved two participants, both women aged 54. While the overall format of the patient session was similar to that of the HCP session, several adaptations were made to better support the patients in expressing their thoughts and experiences.

After the three concepts were introduced and explained, participants began with the first assignment. To facilitate engagement, each participant received a binder containing A3 printouts of the three concept storyboards, a set of emotion stickers, a selection of statement cards, and empty storyboard frames (Figure 36). As part of the PrEmo method (Desmet, 2018), the emotion stickers represented 14 different validated emotions. PrEmo helps participants express their emotions by comparing their feelings to validated illustrations. These emotional responses can inform concept development and evaluate the emotional impact of proposed concepts (Desmet, 2018).

Participants opened the relevant storyboard page for each concept and placed an emotion sticker on each frame to express how that particular moment or feature made them feel. After placing all stickers, they were asked to reflect on and share their strongest positive and negative emotional responses for each concept. This approach allowed participants to express their feelings visually and intuitively, making it easier to communicate complex emotional reactions.

In the second and third assignments, participants reviewed a set of statement cards and then proposed modifications to the concepts using the empty storyboard frames provided. Similar to the HCP session, participants could draw or write their ideas for improvement. Patients were encouraged to look at the emotion stickers and statement cards for inspiration. This could help them to communicate their preferences and ideas for improvement.

At the end of the session, the participants were thanked for their involvement and invited to provide feedback not only on the organization of the session but also on the physical and emotional burden it may have imposed. This feedback was used to improve the design and execution of the second session.

6.1.2 RESULTS

Figure 37 and Figure 38 illustrate all values identified during the first co-design sessions with HCPs and patients. In total, 242 labels were assigned in the HCP analysis, and 155 in the patient analysis. The grey areas in the visualizations indicate the relative frequency with which each value was mentioned. The exact number of quotations is displayed on the outer edge of the circle. The inside of the circle shows how values were experienced in relation to the three concepts. If a value was experienced positively, the curves move toward the inside of the circle, while a negatively experienced value moves toward the outside. Detailed figures showing the values experienced for each concept, including identified problems, can be found in Appendix E.

A | Values - HCPs

Two key themes emerged during the HCP co-design session: **efficiency** (n=51) and **patient-centeredness** (n=38). Efficiency was the most frequently discussed theme and was often associated with time-saving and relevance. For instance, concept 1 was perceived as increasing efficiency by allowing patients to prepare before consultations, thus reducing unnecessary discussion. One participant noted, however, "*I can imagine that it is faster to read [PROM questions] than to have someone read them to you*" - *P3, concept 1*. Concept 3 was on the other hand praised for avoiding irrelevant topics: "*Efficient, does not discuss too many unnecessary things*" -*P*2.

Among the three concepts, concept 1 generated the most discussion regarding efficiency (n=9). Positive feedback focused on the anticipated time savings due to better patient preparation and reduced administrative burden for HCPs: *"Patients can indicate what they want to discuss, so they are well prepared" – P1*. Participants appreciated the idea of automatically generated reports and summaries, which could streamline communication and documentation. However, concerns were raised about the inclusion of an Al assistant that listens to conversations and provides real-time advice, with several participants describing it as a distraction that could hinder the efficiency of the consultation.

Concepts 2 and 3 also received positive comments related to efficiency (n=4 and n=6). Concept 2 was praised for integrating the PROMIS-CAT system, because patients would have to answer fewer questions. Concept 3 was liked for allowing symptom reporting without long questionnaires. Nevertheless, a concerns were raised regarding concept 2. One HCP suggested that the PROM diary could be less efficient if it includes excessive information. Patient-centeredness (n=38) emerged as the second dominant theme, with subthemes of accessibility (n=29) and self-reliance (n=19). These values were highlighted both during discussions and the dilemma card exercise. Patient-centeredness was described as the overarching goal of the concepts, as one HCP expressed: "In the end, it is all about the patient's care request" - P4.

Concept 3 had the most consistently positive impact on patient-centeredness (n=7). HCPs emphasized its potential to improve accessibility, particularly for patients who are very ill, have low health literacy, or speak limited Dutch. One participant remarked, "*This is good for people with low literacy, because it uses visualizations instead of plain text*" - P4. The concept also promoted self-reliance by giving patients control over what they want to discuss. Notably, no negative remarks were made regarding patient-centeredness concerning concept 3.

In contrast, concept 2 was perceived to negatively affect patient-centeredness (n=8). HCPs expressed their concern that the concept might confront patients too frequently and intensely with their illness. This could cause psychological distress or burdern patients too much. Furthermore, they questioned whether the level of effort required from patients was proportional to the benefits. Still, some positive aspects were seen, particularly regarding self-reliance and improving insight into the patient's health status.

Concept 1 generated mixed responses. HCPs could see that the concept enhanced selfreliance by encouraging patients to identify discussion topics ahead of time, but they also raised concerns about accessibility. For example, one participant questioned its suitability for patients with speech difficulties, a common symptom in MS: *"I am not sure if this is suitable for people who cannot speak well, which some MS patients cannot" - P3*.

B | Problems and suggestions - HCPs

Participants identified various problems for each concept and proposed corresponding improvements. For concept 1, concerns were caused by the presence of an AI assistant during the consultation. It was considered potentially distracting and could reduce the quality of HCP-patient interactions, because too much attention might go toward the screen, instead of the patient. To address this, participants suggested removing the conversation tips or having them appear as pop-ups that could be dismissed easily.

Concerns were also raised about the solution being too technologically advanced or burdensome for certain patients. A widely supported suggestion was to offer the Al assistant as an optional feature, existing alongside more traditional PROM-based approaches, thereby giving patients a choice in their preferred method.

16

51

Concept 2 was criticized for its potential to negatively impact patient well-being. Having patients filling in PROMs every day, and the physical placement of the device, were seen as overly intrusive. Suggestions to reduce the burden included changing the physical device into a mobile application and reducing the frequency, such as limiting them to once per week instead of daily.

The most significant downside of concept 3 was considered to be the lack of HCP preparation. Although patients would arrive well-prepared, HCPs would not have prior access to this information and could be caught off guard during consultations. Additionally, concerns were raised about the practicality and sustainability of a paper-based design. One participant said, *"Paper is not sustainable, I have concerns about that. But patients do want it on paper, I hear it all the time" - P2.* Suggested improvements included developing a digital version of the concept that would allow patients' preparatory notes to be shared in advance with HCPs. Participants also expressed enthusiasm for combining concept 3 with concept 1, envisioning a solution in which patients use the visual interface of concept 3 to prepare, supported by the Al features of concept 1.



Figure 37, Caregiver's values during co-design session 1

C | Values - Patients

During the patient session, **patient-centeredness** (n=22) emerged as the overarching theme, with **empathy** (n=20), **self-reliance** (n=17), and **accessibility** (n=14) identified as the most important underlying values. These values were also highlighted as central during the dilemma cards exercise.

Empathy was a recurring theme throughout the session and was mentioned beyond the discussion of individual concepts. Participants repeatedly mentioned that they wanted to be heard and taken seriously by their HCPs, indicating that this aspect of care was currently lacking. One participant said that she felt abandoned due to the absence of contact with their HCP between consultations: *"I have not spoken to [my doctor] since my last consultation ... It would be on top of my list [to discuss] that I actually felt quite abandoned" – PI. Discussing the concepts brought up these concerns.*

Of the three concepts, concept 3 had the most positive influence on empathy (n=1). Although no direct comments were made linking the concept to this value, participants were satisfied with the communication possibilities it introduced, which they felt could strengthen the HCP-patient relationship. In contrast, empathy was perceived to be undermined by concept 1 (n=3). The digital assistant proposed as part of the solution was seen as a replacement for human contact, which participants found troubling: *"From the perspective of too many people and budget cuts, I think this will be efficient. But personally, I believe the human element should stay" – P2.* Empathy was not discussed in relation to concept 2.

Self-reliance was strongly and positively associated with all three concepts. Participants indicated that each concept offered tools that allowed them to take more control over their healthcare experience. In particular, concepts 1 and 2, which provided summaries of consultations and health-related data, were seen as empowering. Patients appreciated the ability to reflect on their health independently and felt that this promoted a sense of ownership and autonomy: *"What I like about this is that it is possible to be self-reliant. Because you have an overview of what happened" – P1, concept 2.*

In the discussion of concept 3, participants shared that they already prepare for consultations by making lists of what they want to discuss. They saw the conversation guide as a practical alternative to these list, because it could help to ensure their concerns were addressed during appointments without requiring extra preparation. One participant

said, *"I am the lady of lists, but that is not necessary anymore [for this concept]" - PI*. The concept thus supported self-reliance, even among individuals who might not otherwise take the initiative to prepare.

Accessibility was another value that was mentioned often in the patient session. However, it was discussed more in relation to other users, such as elderly or digitally inexperienced patients, than to the participants themselves. Concerns were particularly brought up when discussing concept 1. Patients thought that the Al assistant could be difficult to use for people who are unfamiliar with digital tools, such as elderly patients. Participants therefore questioned whether the solution would be inclusive enough to serve the full patient population. In contrast, concept 3 was perceived as highly accessible, mainly because of its visual format. One participant emphasized the strength of visual communication in overcoming language barriers and accommodating different levels of health literacy: "If you use visual elements, it is accessible for everyone. There are no language barriers" – P2.

The fact that this concept is a non-digital solution was also seen as a significant advantage, particularly for patients who might struggle with digital interfaces. Interestingly, accessibility was not discussed in the context of concept 2. There, the focus of the conversation shifted more towards values such as self-reliance (n=3) and engagement (n=3).

D | Problems and suggestions - Patients

Although fewer in number compared to HCPs, the patient participants also discussed several concerns and potential improvements. Concept 1 was criticized for being impersonal and possibly overwhelming for patients with limited accessibility. As one participant expressed, *"That it has come to this, that the human aspect is simply being cut away... that is what it is all about" - P2.* To avoid this, they suggested combining concept 1 with the visual elements of concept 3, although no specific ideas were offered to enhance the human aspect of the solution directly.

Concept 2 was viewed as too burdensome, both emotionally and in terms of time. Participants were concerned about being confronted too frequently with their illness and wondered if patients would actually use the solution. Suggested improvements included reducing the length and frequency of PROMs, sending reminders, and potentially integrating the system with concept 1. One idea was to replace daily PROMs with brief phone interactions using an Al assistant, asking one or two questions daily to monitor patient wellbeing without becoming intrusive. Concept 3 did not generate any significant complaints, though participants had some ideas for improvement. While both digital and paper-based formats were considered acceptable, they saw benefits of making it into a digital version so that it would be more efficient. Additional features, such as open-ended response fields and the ability to add custom scenarios, were also suggested.

Beyond the three proposed concepts, patients expressed a need for more direct and informal communication with HCPs between consultations. The patients wanted to have an easy, low-threshold method, such as a "panic button" or brief questionnaire within an app, that would allow them to signal urgent concerns or receive reassurance without needing to call or write an email.



6.1.3 IMPLICATIONS FROM FIRST CO-DESIGN ROUND

The problems and suggestions discussed during the co-design sessions were translated into user needs, which were then further refined into concrete design criteria (Figure 39). In the figure, criteria not mentioned during the sessions are indicated in grey, while confirmed needs are presented in black. The evaluation shows how well each concept aligns with the identified needs.

Based on this evaluation, concept 1 currently appears to be the most promising solution. This is reflected in the HCP session, where most participants indicated a preference for this concept. However, a different picture emerges when the evaluation is based on values (Figure 37 & Figure 38). Concept 3 best supported the key values identified by both stakeholder groups: efficiency and patient-centeredness for HCPs, and patient-centeredness, empathy, self-reliance, and accessibility for patients. Importantly, concept 3 elicited fewer negative associations with these values compared to the other concepts. This suggests that it aligns more closely with their values. Indeed, concept 3 was favored as the most preferred solution during the patient co-design session.

This leads to an apparent tension between user values and user needs, particularly within the HCP group. While concept 3 was the most positively received regarding value alignment, most HCPs still perceived concept 1 as the more viable solution. This inconsistency can be understood by examining the newly established design criteria (Figure 39). Among the six key functional requirements, concept 3 fell short in one critical area: consultation preparation. Because the concept does not currently enable HCPs to prepare for consultations, it cannot serve as a full replacement for existing PROM-based processes.

Interestingly, many of the modifications proposed by HCPs and patients for concepts 1 and 2 appear to bring these concepts closer to the existing approach of PROMs. For example, HCPs expressed a desire for concept 1 to be implemented as an optional feature, allowing patients to choose whether they want support from an AI assistant when completing PROMs or prefer to complete them independently. Similarly, suggestions for concept 2 included eliminating the separate device, reducing the frequency of PROMs, increasing the number of reminders, and enabling completion in a location of the patient's choosing. However, these changes bring the concept back to the traditional PROMs. These changes were not suggested for concept 3, showing a good balance between innovation and acceptance.

6.1.4 CONCLUSION

Because concept 3 aligns most strongly with the core values of both HCPs and patients, it has been selected for further development. Nevertheless, for this concept to become an accepted solution, it must also meet the needs outlined in the newly defined criteria. The suggested improvements will serve as important design considerations in the next steps of concept development. These include exploring a digital version of the solution, enabling consultation preparation for patients and HCPs, and exploring the integration of the Al assistant with the visual conversation guide. By addressing both values and needs, concept 3 has the potential to evolve into an innovative and more user-centered solution.

DESIGN REQUIREMENTS	A		
Design requirement	Concept 1	Concept 2	Concept 3
The solution should identify individual problems that patients experience	yes	yes	yes
The solution should stimulate caregivers to initiate the Team talk	yes	yes	yes
The solution should allow patients to identify which health aspects are most important to them	yes	yes	yes
The solution should be able to be used by MS patients, taking into account possible physical and psychological impairments	somewhat	no	yes
Requirements from session 1			
The solution should allow patients and caregivers to prepare the consultation	yes	yes	no
The solution should allow patients to bring up difficult to discuss topics	yes	somewhat	yes

DESIGN PRINCIPLES

Design principle			
Improve patient and caregiver communication	somewhat	somewhat	yes
Present information without overwhelming patients	yes	yes	yes
Encourage and prepare patients to have an active role in SDM	somewhat	yes	yes
Integrate the solution into existing workflows	somewhat	somewhat	no
Reduce the time it takes to use the solution for a caregiver	yes	yes	yes
Reduce the time and burden for patients to use the solution	yes	no	yes
Take usability for people with lower realth literacy into account	somewhat	somewhat	yes
Principles from session 1			
Patients should feel heard by caregivers	somewhat	somewhat	yes
Patients should feel safe and secure	somewhat	yes	somewhat
The relevance of using the solution should be clear for patients and caregivers	somewhat	no	yes

DESIGN GUIDELINES

Design guideline			
Give caregivers confidence in conversation techniques	yes	no	yes
Only ask information that is relevant to the patient and the caregiver to not overload patients	yes	yes	yes
Ask patient an open question about what is most important to them	yes	yes	yes
Allow loved-ones and personal caregivers to help identify individual problems that the patients experience	no	no	yes
Provide patients with a visual overview of what is discussed during a consultation to help them interpret outcomes	yes	yes	yes
Make solutions visible during a consultation to stimulate conversation	yes	yes	yes
Guidelines from session 1			
A.I. generated content is accurate and correct	somewhat	-	-

Figure 39, Evaluation of design criteria

6.2 SECOND ROUND OF CO-DESIGN

After the feedback and insights on values gathered in the first round of co-design, a second round could be started. The goal of the second round of co-design was to further develop a concept to meet the needs and values of participants better and test a prototype of this concept to gain insights into user interactions.

Concept 3, conversation guide, was further developed and adapted to fit better to the stakeholders' values and needs, and to be used as material for the second round of codesign. This led to reframing concept 3 as the "digital consultation preparation tool" (Figure 41). The updated concept was hypothetically integrated into the existing patient application of the St. Antonius Hospital "MijnAntonius," where patients already have access to an overview of past and upcoming consultations. A new feature was added: patients can access a preparation module before each upcoming consultation (Figure 40). In this module, patients can indicate physical, mental, and social symptoms they have experienced and select which of these they would like to discuss. Upon completion, a one-page visual summary is generated, which patients can save, print, and review. This summary is also sent to the HCP before the consultation and displayed on the HCP's screen during the appointment. Alternatively, patients can bring a printed version.

Additionally, the digital consultation preparation tool includes an overview of possible treatment options with corresponding risks and benefits. HCPs can mark which treatments were discussed, so that patients can read more about the options after their consultation.

If an important topics was not discussed during the consultation, the summary can also be used during appointments with other specialists. All summaries are stored in the patient's electronic health record for future reference.



To show the functionality of the digital consultation preparation, wireframes were prepared (Figure 40). The wireframes are accessible in Figma by scanning this QR code and can be found in Appendix F After the consultation, patients can evaluate the conversation using a consultation evaluation module in the app. Here, they can reflect on whether their selected discussion points were addressed and write additional notes. The treatment options marked by HCPs are also accessible with further information. Lastly, a dashboard shows trends over time, displaying which symptoms and discussion points patients have prioritized in previous consultations. This dashboard is available to patients and HCPs and supports longitudinal insight into patient-reported outcomes and priorities.

Consultvoorbereiding					
Introductie Fysiek	e symptomen Mentale symp	tomen Sociale symptomen	Overig	Prioriteiten	Overzicht
Fysieke symptomen Waar heeft u de afgelopen 3 w u Selecter alles wat van toepassing is	Fysieke symptomen Waar heeft u de afgelopen 3 weken moette mee gehad? Selecteer alles wat van toepassing is				
Lichamelijke inspanning	Dingen pakken en tillen	Evenwicht behouden	Verplaatsen binnenshuis		
Stijfheid	Last van armen of benen	Onwel voelen	Plassen of ontlasting		
Seksueel functioneren	Zicht	Slikken of spreken	Anders:		
Vorige			Volgende		

Figure 40, Excerpt of consultation preparation module UI wireframes



Refined concept | Digital consultation preparation tool and conversation guide

Figure 41, Storyboard of refined concept

6.2.1 METHOD

HCP SESSION

The second co-design session involved the same four HCPs from the first session: two neurologists, one rehabilitation specialist, and one MS nurse. This session aimed to evaluate the refined concept through a series of interactive assignments. Materials prepared for the session included a concept storyboard, blank storyboard frames, a printed user interface (UI) prototype, patient information cards, empty graphs, empty dashboards, Post-it notes, and drawing tools (Figure 42 & Appendix F).

The session started with a recap of the key outcomes from the first session, particularly the three central values identified by HCPs: efficiency, patient-centeredness, and accessibility. Participants were asked to reflect on these findings and confirm their relevance. After the recap, the refined concept was introduced via the storyboard, followed by a discussion on how well the concept aligned with the identified values and any areas for further improvement. Participants could use the printed storyboard and empty storyboard frames to write down any adjustments.

In the second assignment, participants engaged with the printed UI prototype displayed on a large roll of paper on the wall. HCPs were invited to annotate the prototype with opportunities and areas for improvement using color-coded Post-it notes. During the session, however, the Post-it notes were not used, and reactions to the concept were communicated verbally.

The final assignment focused on designing a dashboard. Each participant independently identified the types of patient information they would like to access before a consultation, and wrote these down on cards. The cards were then discussed as a group and sorted together. Using the grouped information, participants individually developed a dashboard using empty graph templates and arranged these on an empty dashboard layout. Results were discussed, and participants received a gift card as a token of appreciation to conclude the session.



Figure 42, Materials for co-design session 2 HCPs



ENVELOPE WITH EMPTY STORYBOARD FRAMES AND 5 TYPES OF ILLUSTRATIONS



Figure 43, Materials for co-design session 2 patients

PATIENT SESSION

The same two patients from the first co-design session participated in the second session. This session included two assignments, designed to elicit feedback on the refined version of the concept.

As in the HCP session, the first assignment began with a recap of the findings from the previous session, including the values of empathy, self-reliance, and accessibility. Participants were asked to reflect on whether these still resonated with them. The updated concept was then presented using the storyboard, and participants discussed how the revised design addressed their values and proposed changes where needed.

The second assignment involved an in-depth evaluation of the UI prototype, which was again presented on a large printed format. Feedback was gathered through structured discussion and the use of dot-shaped stickers to identify strengths and opportunities for improvement. The prototype was reviewed in three thematic parts: consultation preparation, the consultation itself, and consultation evaluation. During the first part, patients were also asked to contribute to the visual design by selecting preferred images from a set of options (Figure 43 & Appendix F). Similar to the HCP session, results were discussed, and participants received a gift card as a token of appreciation to conclude the session.

6.2.2 RESULTS

Figure 44 and Figure 45 illustrate all values identified during the second co-design sessions with HCPs and patients. 105 labels were assigned for the HCP analysis, and 106 for the patient analysis. The grey areas in the visualizations indicate the relative frequency with which each value was mentioned. The exact number of quotations is displayed on the outer edge of the circle. The inside of the circle shows how values were experienced in relation to the three concepts, similar to the results of the first co-design session. Detailed figures showing the values experienced for each concept, including identified problems, can be found in Appendix G.

A | Values - HCPs

Four key values emerged during the HCP co-design session: **patient-centeredness** (n=23) was mentioned most frequently, followed by **efficiency** (n=15), **quality** (n=15), and **holistic care** (n=15), which were discussed equally often.

Patient-centeredness was raised in relation to time burden and perceived benefit to the patient. Several participants 4 noted that current practice is time-consuming and does not always focus on what is most important to the patient. For example, P1 stated: "We are asking the patient so many questions [...] I could be talking for 10 minutes already about something that is not important to the patient. It is just not patientcentered enough" -P1. Participants expressed that existing PROMs already offer potential to improve patient-centeredness by making consultations more efficient and focused. Concerning the refined concept, patient-centeredness was mostly seen as positively influenced (n=9). Participants were enthusiastic about the concept's ability to steer consultations toward patient priorities. They also recognized the value of patient preparation in helping patients become more aware of their needs. However, some concerns were raised. P3, in particular, believed that limiting the number of discussion points could cause stress: "I can imagine, as a person who finds it difficult to make choices, that this can cause stress. Maybe I want to discuss additional topics, but I can only choose a few" – P3.


Efficiency was primarily mentioned in connection with time investment and workflow optimization. All participants recognized that patient preparation could save time during consultations. P3 illustrated this: "There is a lot of efficiency to gain. If you see beforehand where there are no problems, you can skip that [...] you can ask about what is key in that moment." – P3. Therefore, there were only positive remarks about efficiency (n=5).

Quality and holistic care were often discussed together. Participants described holistic care as ensuring that consultations gather complete and high-quality information that can be used for diagnostics and decision-making. Initially, the concept was perceived to positively impact quality by focusing on what truly matters to patients. For example, neurologists often see patients they have treated for over ten years, leading to habitual consultation patterns. Without structured preparation, these consultations risk becoming less thorough. Participants believed that the consultation preparation could help to counteract this risk. However, concerns emerged regarding symptom registration. Since the preparation only asks patients to indicate experienced symptoms without quantifying severity, HCPs feared missing important information compared to existing PROMs. P1 remarked: *"Here you select what symptoms you have experienced, but you do not select what went well. You will miss symptoms that way" – P1*. This also influences long-term monitoring of the patient, because the consultation preparation holds less detail: *"It is very 'yes', 'no', I think that we will miss a lot and that it is not sufficient to have a red thread in this way." – P1*. These issues were considered crucial by HCP participants.

B | Problems and suggestions - HCPs

Several suggestions were made to improve the refined concept. The most prominent recommendation was to continue using existing PROMs, such as the MSIS-29, alongside the consultation preparation. Participants worried that important symptoms might otherwise be missed. Another suggestion was to send follow-up PROMs after patients complete the consultation preparation. In this approach, patients would complete a brief preparation and receive a PROM only if additional information was needed.

Alternatively, participants suggested to integrate elements of existing PROMs into the consultation preparation, for example by using a symptom severity scale, possibly with descriptive wording. To reduce the time burden for patients, P4 suggested that after the completing the tool once, patients should only update their responses if changes occur. This way, previous answers would be reviewed and adjusted, saving time.

Regarding accessibility and usability, participants recommended maintaining the visualizations in the concept but adding intuitive actions such as sliding or swiping to select symptoms or rate severity. HCPs also suggested that treatment options should be available on paper to reduce focus on the computer screen during consultations.

Two final suggestions on how to create a functional solution were to create a good visual dashboard containing all outcomes and integrate the solution across all departments a patient sees. For example, the patient could visit a neurologist and a rehabilitation doctor, but currently, the departments do not work together, so the patient has to fill in duplicate PROMs. Participants would like to see this improved in the future.

C | Values - patients

Among the two patient participants, **accessibility** (n=30) was the most prominent theme during the second co-design session, with **usability** (n=16) also frequently discussed. Other values mentioned were **self-reliance** (n=7), **quality** (n=7), and **efficiency** (n=7).

Patients expressed a strong concern for accessibility, even before the refined concept was introduced. They shared that accessibility was a significant topic among peers: "I had an MS-themed day with webinars together with other patients. You could chat with each other and share videos. There, everyone talked a lot about accessibility as well." – P1. The elements they found important regarding accessibility were to use clear language, large font sizes, good color contrast, and enough space between elements. The participants thought the existing patient app in which PROMs can be filled in was inaccessible: "I notice that a questionnaire is often very confusing for me, for example if the information is very clustered" – P2. Although they had few specific comments about the refined concept, participants stressed that accessibility must remain a priority in further development.

Regarding usability, patients made some remarks about the presented UI mock-up (n=3). The participants expressed that everything should be very clear to understand to achieve good usability. They expressed strong negative feelings about numeric symptom scales: "What I do not like is that you have to give it a grade. I despise it. Do not touch on that. Never do it, I'll say. It always is very confusing" – P2. Both participants preferred explaining symptoms in words, as different individuals could interpret numbers differently.

On quality, participants stressed the importance of accurate information in consultation preparations and evaluations. They trusted their neurologists to ensure quality. Summaries of the consultation should contain information that the neurologist provides. Especially when an Al assistant makes such a summary, participants would like to have the accuracy checked by their neurologist: "To what extent could an Al



Figure 45, Values of patients co-design session 2

identify topics that are important to me? I am not sure if it alone can decide what should be put in a consultation summary " – P2. Despite this concern, they welcomed having an official consultation summary as a significant improvement to the quality of care and self-reliance: "It helps to think for yourself what you want to discuss. Some people do not do that currently" – P1. "You help people to become more self-reliant, even if they aren't" – P2. The participants also saw the opportunity for self-reliance for themselves through the summary they receive after the consultation.

Finally, regarding efficiency, participants recognized the limited time available to neurologists and MS nurses. They supported using consultation preparation to save time: they acknowledged that completing full PROMs during consultations would be unrealistic and that preparing beforehand would be beneficial.

D | Problems and suggestions - patients

In addition to the previously mentioned concerns, participants identified potential challenges for other patients. The refined concept relies on using the existing patient app "MijnAntonius", but not all patients use this app. During the session, patients indicated that they would like an Al assistant to summarize the consultation. They appreciated this aspect of concept 1 in the previous session and believed it could also be of value in the refined concept. However, the participants thought that some other patients might not want to engage with an Al assistant due to privacy concerns.

To address these issues, participants suggested giving patients a choice about whether an Al assistant is used to create consultation summaries. Regarding patients not using the app, MS nurses could offer alternatives, such as conducting the preparation over the phone or sending a paper version to complete and return before the consultation.

Patients also offered accessibility and usability recommendations for the user interface, including maintaining a clear layout with adequate spacing, strong contrast, large fonts, and simple language. They requested the ability to write additional explanations on each page during preparation, enabling them to generate a clearer and more personalized consultation summary.

6.2.3 IMPLICATIONS FROM SECOND ROUND OF CO-DESIGN

The values, problems, and suggestions identified by HCPs and patients indicate that the concept already largely meets the values and needs required for a good solution. This is particularly true for patients, who did not raise any negative remarks regarding the core values and focused mainly on enhancing accessibility. HCPs, however, would like to improve the impact of the concept on quality and holistic care.

For HCPs to adopt and integrate the solution into practice, it is necessary to gather more detailed information about patients' symptoms. Specifically, the extent to which symptoms are experienced must be captured to avoid missing important issue and ensure accurate diagnoses, but also to refer patients appropriately, and enable long-term monitoring of patients' health. The current concept does not yet fulfill this requirement (Figure 46). The overall flow of the concept, as presented in the storyboard (Figure 41), only needs to be adjusted slightly by including an Al assistant that provides the patient with a summary at the end of the consultation. Additionally, a long-term dashboard should be developed to present outcome data over time, supporting HCPs in their consultation preparation and follow-up. For patients it is considered important that accessibility guidelines are taken into account.

6.2.4 CONCLUSION

The consultation preparation tool should be further developed to meet user needs and values. Incorporating a scale and accessibility guidelines should be the primary focus of the next phase of concept development. The concept will be refined into a prototype that demonstrates how accessibility considerations are integrated, with patients' suggestions and additional research on accessibility incorporated to enhance the overall user experience.

DESIGN REQUIREMENTS	
Design requirement	Refined concept
The solution should identify individual problems that patients experience	no
The solution should stimulate caregivers to initiate the Team talk	yes
The solution should allow patients to identify which health aspects are most important to them	yes
The solution should be able to be used by MS patients, taking into account possible physical and psychological impairments	somewhat
The solution should allow patients and caregivers to prepare the consultation	yes
The solution should allow patients to bring up difficult to discuss topics	yes

DESIGN PRINCIPLES

Design principle	
Improve patient and caregiver communication	yes
Present information without overwhelming patients	somewhat
Encourage and prepare patients to have an active role in SDM	yes
Integrate the solution into existing workflows	somewhat
Reduce the time it takes to use the solution for a caregiver	yes
Reduce the time and burden for patients to use the solution	yes
Take usability for people with lower health literacy into account	somewhat
Patients should feel heard by caregivers	yes
Patients should feel safe and secure	somewhat
The relevance of using the solution should be clear for patients and caregivers	somewhat

DESIGN GUIDELINES

Design guideline	
Give caregivers confidence in conversation techniques	yes
Only ask information that is relevant to the patient and the caregiver to not overload patients	yes
Ask patient an open question about what is most important to them	yes
Allow loved-ones and personal caregivers to help identify individual problems that the patients experience	somewhat
Provide patients with a visual overview of what is discussed during a consultation to help them interpret outcomes	yes
Make solutions visible during a consultation to stimulate conversation	yes
A.I. generated content is accurate and correct	somewhat

Figure 46, Evaluation of design criteria refined concept

6.3 CONCLUSION

The two rounds of co-design provided insight into the values, needs, and expectations of both HCPs and patients. This guided the development of a digital consultation preparation tool. In the first round, concept 3 emerged as the most promising option, demonstrating strong alignment with users' core values, especially patient-centeredness, empathy, and accessibility. Despite this alignment to values, HCPs initially preferred concept 1, particularly because it supported the need of consultation preparation. This revealed a key tension between values and needs.

In response, concept 3 was refined and reframed as a digital consultation preparation tool for the second round of co-design. Feedback from the sessions showed that the refined concept addressed many earlier concerns, especially for patients, who appreciated its clarity, support for self-reliance, and potential to improve accessibility. HCPs also recognized its potential to enhance patient-centeredness and efficiency. However, they raised concerns about the concept's ability to capture detailed symptom information necessary for clinical quality and holistic care.

The co-design process therefore highlighted a lesson: designing for healthcare requires balancing innovation with the realities of clinical practice. While patients emphasized values like accessibility, usability, and autonomy, HCPs stressed the importance of actionable, structured data for decision-making and long-term monitoring, much like traditional PROMs should provide. These insights will shape the next phase of development, focused on improving the consultation preparation with more detailed symptom reporting, integrating Al assistance, and presenting outcomes through a user-friendly dashboard.

Chapter 7 CONCEPTUALIZE FINAL DESIGN

Input from the co-design sessions was used to start a second conceptualize phase and make a final design proposal. For this final design, three components were developed that together support SDM: consultation preparation, the consultation itself, and consultation summary. Based on the concept presented during the second co-design sessions, changes were made, user flows were developed, wireframes were created, and a design system was set up, which led to a final design proposal that is shown in this chapter.



Final concept | Consultation preparation tool



Figure 47, Storyboard final concept

7.1 CHANGES TO REFINED CONCEPT

Before creating a prototype of the final concept, feedback from the second co-design session was incorporated. This led to adjustments in the user experience captured in the storyboard, and two key changes to the user interface of the consultation preparation tool: the introduction of a symptom severity scale and a redesigned prototype layout. Additionally, accessibility guidelines for patients with MS were reviewed and considered.

A | User experience: storyboard

The storyboard in Figure 47 presents the flow of the final concept. Patients can access the consultation preparation tool through the hospital's existing patient app or website. Within the tool, they are guided through a series of symptom questions based on existing PROMs, indicating the extent to which they have experienced each symptom. After completing this step, patients can select which symptoms or other health-related topics they want to discuss during their upcoming consultation. These selections are summarized in a preparation overview that is visible to both the patient and their HCP.

During the consultation, the overview is accessible within the patient's electronic health record through a dedicated consultation module. The HCP can view the patient's input, record the consultation, and automatically generate a summary using an Al assistant. There is also a separate page within the module that presents treatment options and possible referrals to other specialists. This page can be used during the consultation to guide the conversation about treatment decisions. After the consultation, both the summary and the discussed treatment options remain accessible to the patient through a consultation summary module in the app. Over time, data from multiple consultations feed into a long-term dashboard that helps both patients and HCPs monitor symptom trends and discussion topics.

The consultation preparation tool is built around three interconnected parts: a preparation module that supports patients in getting ready for their consultation, a consultation module that facilitates the actual conversation and treatment planning, and a summary module that provides a record for future reference and reflection. From this point on, the concept will be referred to as Coprio; a wordplay on <u>consultation</u>, <u>cooperation</u>, and <u>prioritization</u>.

B | User interface: Scale

To translate the concept into a functional prototype suitable for further testing and development, it is necessary to design a user interface. The wireframes used during the second co-design session required several updates, beginning with the implementation of a scaling feature. Based on feedback from healthcare providers during that session, multiple approaches were explored to integrate a scale into the tool that allows patients to indicate symptom severity. The objective was to gather more detailed information without compromising usability or screen space. Figure 48 illustrates the different options considered for implementing the scale.

The first option presents a five-point severity scale with an illustrated symptom placed next to it. The second option displays the symptom in a fixed position on the scale, which the user can then slide to answer. A third approach integrates the scale into the same box used for displaying the symptom, which saves space but reduces usability due to limited room for explanation. A fourth option uses a two-step process: patients first indicate whether they experienced a symptom, and if so, a severity scale appears for that specific symptom.



Figure 48, Different approaches to scale interactions

Among these options, the two-step approach emerged as the most promising. It strikes a balance between screen space efficiency and usability by showing the scale only when it is relevant. This approach reduces visual clutter while still providing the necessary detail, and was therefore selected for further development.

C | User interface: Layout

While adding a scale can enhance symptom tracking, it also introduces the risk of visual cluttering, especially on mobile devices. In 2023, over 90% of the Dutch population owned a smartphone, compared to 75% with a laptop (Centraal Bureau voor de Statistiek, 2023), indicating a higher likelihood of Coprio being used on smaller screens.

To address this, the layout was optimized for mobile screens. As shown in Figure 49, the process begins with the patient indicating whether they have experienced a symptom. This is done using a card swiping motion, similar to those used in existing mobile applications like Tinder. Although this interaction style is more familiar to younger users, research shows a swipeable element can be suitable for older adults if it is at least 17.5 millimeters in size (Leitao & Silva, 2012). An example of this interaction is illustrated in Figure 49.



Figure 49, Swiping interaction on a mobile device

D Accessibility

Knowledge about accessibility guidelines needs to be gathered before further developing the prototype. As the prototype is developed around the MS case study, accessibility guidelines directed toward improving web accessibility for MS patients will be incorporated.

The National MS Society is an organization aimed at improving the lives of patients with MS. They provide information regarding several topics, including accessibility, based on professional advice and opinions, and published experiences (Who We Are: Our Mission and Values | National MS Society, n.d.).

The MS society advises using four guiding principles to ensure good accessibility for people with MS:

- **Perceivable**: All content should be recognizable and usable for different types of users. Best practices for this are to use images accompanied by text and use a minimum of AA contrast (Accessibility Principles | Web Accessibility Initiative (WAI) | W3C, n.d.).
- **Operable**: Different interactions are possible. People should be able to choose whether to interact with an interface using a mouse, touchscreen, or keyboard.
- **Understandable**: Content should be easy to understand, which is especially important in language and layout. Instructions should be available, and errors should always be explained.
- **Robust**: The design should work on different devices and browsers and function well with assistive technologies like screen magnifiers. However, a mobile-first design is considered a best practice (Accessibility: Highlights & Guidelines | National MS Society, n.d.).

This means that contrast should be checked, and images should be accompanied by text. It also needs to be considered how content can be made understandable and which instructions are necessary. Operability and robustness will receive more attention if the prototype is further developed.

7.2 UI PROTOTYPE DEVELOPMENT

7.2.1 USER FLOWS

Building on the storyboard in Figure 47 and the concept refinements, user flows were created for the preparation module, consultation module, and summary module. These are available in Appendix H. The user flows outline user goals and the necessary screens and interactions to achieve them. Figure 50 presents an excerpt from the preparation flow, demonstrating how symptom registration is handled. Such flows provide a clear direction for developing screens and elements.



Figure 50, Excerpt of preparation module user flow

7.2.2 WIREFRAMES

After all the user flows have been set up, wireframes were created to show how elements from the user flow can be displayed and used. A selection of the wireframes can be accessed in Appendix I. The final wireframes for the preparation module, consultation module, and summary module are accessible through the QR code on the right.



7.2.3 MOODBOARD

After creating the wireframes, a mood board showing the preferred style was created based on images from the design platforms Behance and Dribbble (Figure 51). Key elements that can be retrieved from the mood board are rounded buttons, light colors, and the overall modern aesthetic.

9 In the second	9.43 at a f a f a f a f a f a f a f a f a f	Rounded corners	Hein Again! Whether the
Colored cards	White space	RD	Modern aesthetics

Figure 51, Moodboard for Coprio

7.2.4 DESIGN SYSTEM

A design system containing colors, typography, icons, grids, and buttons was created prior to making graphical user interfaces of the consultation preparation tool.

A | Colors

The design system uses two colors for backgrounds and buttons, and two colors for icons and text (Figure 52). The colors for background and buttons are used in several shades and tints to maintain visual hierarchy and clarity. Figure 52 also shows which color combinations pass the WCAG AA contrast guidelines. Only those color combinations have been used.

AA Graphical Objects AA Large text #279A95
AA Large text
#7A8580
AA Normal text AA Large text
#FFFFFF
AA Normal text
#034052

Figure 52, Color system

B | Typography

Segoe UI was used as the typeface. It is a set of sans serif fonts with many weights and styles. According to Microsoft, it is an accessible and readable font at different sizes (Typography - Fluent 2 Design System, n.d.).

C | Grids

Grids can be used to create consistent and responsive interfaces where elements are neatly organized. The grids used for small screens in this design system have four columns, a margin of 32px, and a gutter of 8px (Figure 53). The grids for larger screens must be aligned with the existing grids of patients' electronic health record systems to ensure consistency.



D | Icons

Consistency in icon style and colors gives the design an organized look. Material Symbols, a set of Google icons, was used because of its consistent look, ability to customize, and availability of many icons. A subset of rounded, filled icons, with a weight of 400, was used. A preselection of icons was made for the design system based on symptoms retrieved from PROM MSIS-29 (Figure 54).







Figure 55, Example of primary buttons (left) and secondary buttons (right)

E | Buttons

The buttons were created based on all design system elements to ensure consistency and legibility. A primary button was designed with several states: enabled, pressed, disabled, and selected (Figure 55). The secondary button was based on the primary button, but uses an outline instead of a fill. For each button, a large and a smaller version were created.

7.3 GRAPHICAL USER INTERFACE

The wireframes and design system were used to develop the final designs of the preparation, consultation, and summary modules. Prototypes of these designs can be accessed via the QR code provided and are shown in Appendix J. The preparation module prototype demonstrates how symptoms are reported, how discussion topics are selected, and what the final overview looks like. The consultation module prototype illustrates how the tool could be integrated into existing electronic health record systems. The summary module prototype shows how a patient could review the consultation summary. The three models are described in this section to illustrate the functionality and design of the prototype.



The final prototype can be accessed through this QR code and is shown in Appendix J

7.3.1 PREPARATION MODULE

A Symptom reporting

The symptom reporting screens are a central component of the consultation preparation (Figure 56). Users access the module from their existing patient app. Before beginning, users are shown an instruction that explains how symptom reporting works. Swiping left indicates that a symptom was not experienced, while swiping right marks it as experienced. Users can also press "YES" or "NO" instead of swiping. If the user swipes left, the next symptom is presented. If the user swipes right, a pop-up asks the user to specify the extent to which the symptom was experienced. This pop-up can be closed or dismissed by clicking outside the frame. If a symptom is rated "quite much" or "very much," follow-up questions based on other PROMs can be given to gather more detailed information. These questions are not asked if the patient has not experienced the symptom or only to a low extent. This reduces the number of unnecessary questions asked of the patient. The patient can answer the additional questions immediately or postpone them until after the consultation preparation. Users can undo actions by pressing a labeled text button that





Figure 56, Symptom reporting screens



 Ongewenst thuis zitten Ċ, T Stiifbeid Hulpmiddelen Typ hier een toelichting of vraag O Zicht Ŭ0 Medicati Conwel voeler Tamelijk ver Zwangerschap د (Slikken of spreken / Aanpassen / Aanpassen Overview screen All discussion topics All symptoms

Figure 57 (top row), Priority selection screens and Figure 58 (bottom row), Overview screens

explains the action. This button is intentionally less visually prominent to prevent accidental or unconscious interaction. The consultation preparation includes a progress bar that estimates how long the process will take. Additionally, the symptom reporting screens show progress by indicating how many symptoms are to be reported and how many are already answered. This numerical feedback helps users better understand their progress.

B | Priority selection

Once symptom reporting is completed, the user is taken to the prioritization screen (Figure 57). Here, they can select discussion topics by clicking on an empty discussion topic field. A pop-up displays all symptoms previously marked as experienced. Symptoms marked as more severe are listed first, which makes it easier to find them. Additionally, symptoms not experienced are excluded, because they are unlikely to be interesting for discussion.

Users may also choose to discuss topics unrelated to their symptoms. These are listed under the "Other" category in the pop-up and typically include issues common to the patient group. If a topic is not listed, users can enter their own topics. Selected discussion topics then appear in the main list. Icons, colors, and symptom descriptions remain consistent throughout the consultation preparation tool to ensure a cohesive user experience. Users can add or modify topics by clicking on an existing or empty discussion slot. Filling all four topic slots is optional. When satisfied with their selections, users can proceed to the next screen.

C | Overview

After completing symptom reporting and selecting discussion topics, the preparation module is finished. A summary overview is then presented (Figure 58). By clicking on discussion topics, users can review and modify their choices. All symptoms, including those not experienced, are listed in the overview, and users may make adjustments if needed. There is also a section where patients can add personal remarks or questions, which will be included in the summary sent to the HCP.

An export button is available if the user wishes to print or share the overview. The user presses 'Close and Send' to complete the preparation process. After completion, a screen explains who will receive the summary and what will be done with the submitted information.

	Consult neurologie 12 Juni 2025 10:00	Start Al transcriptie 🌵	Patient view	
A. N. Tonius suw, 56 jr., 18-12-1963 MDN: 3432087 nimatie: Geen geg. opg.	Consultvoorbereiding	Behandelopties		
eken .	Bespreekpunten patiënt	PROMs-HADS	Schups vragenlijst	PROMs-Neurologie-Mfis-5
ng: Geen 1: Geen gegevens en	😽 Evenwicht behauden	15 Angst 个 9 Depressie 个	1 Schups score -	5 Fysieke subschaal 个 4 Cognitieve subschaal 个
EEKUURBEZOEK	Hulpmiddelen			1 Psycho. subscheal —
	R Zwangerschap	PROMs-MSIS 29		10 Totaal Mris-5 🤟
E OPERATIE rugische	Behandelopties	53 Psychologische schaal ↑		
eningen W LAATSTE BEZOEK lige ge swiltaten	Opmerkingen en vragen ik heb heel veel moeite om goed te kunnen articuleren en dat vind ik heel vervelendi. Het beperkit me in mijn dagelijks leven en ik zou het graag oplossen.			

Consultation screen

	12 Juni 2025 10:00	Start Al transcriptie 🌵	Patient view	
A. N. Tonius www, 56 jr., 18-12-1963 MDN: 3432087 nimatie: Geen geg. opg.	Consultvoorbereiding	Behandelopties		
ken Gaen	Medicatie	Doorverwijzingen	Medicijnen	Fumaraat-esters
n gegevens n	Medicatie keuzekaart →	Keuzekaart \rightarrow	Hoa gebruik je het?	2x dag
EKUURBEZOEK	Fumaraat-esters	Fysioloog	Waar moet je op letten?	Je laat 2,3 of 4 keer per jaar bloed prikken.
	Glatirameer	Revalidatie-arts	Voordelen	50% minder kans op MS-aanvallen
OPERATIE	Interferon-bèta	Uroloog	Nadelen	Diarree
eningen W LAATSTE BEZOEK	S1P receptor modulatoren	Psycholoog		الله Buikpijn/misselijk ن Blozen
ige ge ssultaten	Teriflunomide		Voor zwangeren geschikt?	Nee
			Voor auto rijden geschikt?	Ja

Treatment options screen

Figure 59, Consultation screens

7.3.2 CONSULTATION SCREENS

During the consultation, the HCP can access the consultation module within the electronic patient record. Figure 59 illustrates how this module would appear when integrated into EPIC, the electronic patient record system used by St. Antonius. The module consists of two main pages: a consultation preparation page and a treatment options page. On the consultation preparation page, HCPs can view the results of the patient's symptom reporting and discussion topics. In Figure 59, the outcomes of symptom reporting are presented as scores that indicate whether symptoms have increased, decreased, or remained stable. On the left side of the screen, discussion topics and questions prepared by the patient are displayed. The scores and indicators help HCPs to quickly interpret changes during the consultation. Since patients may not be familiar with these scores, HCPs can toggle to a patient view during discussions to aid communication. This view mirrors the preparation module's layout and displays all registered symptoms.

Within the same consultation module, the HCP also has the option to start an audio recording to generate an Al-based summary. When the recording function is selected, a pop-up appears reminding the HCP to obtain permission from the patient before starting the recording. At the end of the consultation, the HCP has to check the summary and make any necessary changes.

The second page of the consultation module focuses on treatment options, which are different depending on the patient group. For example, in the case of MS patients, treatment options are categorized into medications and referrals, which can also be seen in the treatment page layout. When the HCP clicks on a particular treatment option, detailed information becomes available, such as potential side effects or risks. Additionally, the module provides an overview of information for all treatment groups. Patients and HCPs can use this to compare treatments. The HCP can tailor or update this information to better align with the specific needs of the patient. During the consultation, the HCP can select which treatment options are suitable, and the patient can later read more about the options in the summary module.

7.3.3 SUMMARY SCREENS

The summary module represents the final component of Coprio. It summarizes everything that was prepared and discussed during the consultation into a set of summary screens, as illustrated in Figure 60. Patients can access the summary module through the existing patient application. After opening the module, patients view an overview screen that allows them to navigate between sections for treatment options, discussion topics, and a consultation summary.

Since treatment options may require active decision-making by the patient, this section is prominently placed at the top left of the screen. When accessed, the treatment options are displayed as a carousel of buttons. If a patient clicks on a treatment button, they are redirected to a corresponding page on the hospital's website that provides more detailed information about the selected treatment. The discussion topics page lists the topics the patient had prepared for discussion. Patients can click on each topic to indicate whether it was discussed during the consultation and whether they wish to revisit it in a future appointment. If a topic is marked for further discussion, it will be automatically suggested during the patient's next consultation preparation.

In the consultation summary section, patients can read the Al-generated summary of their appointment. Additionally, if they have any remaining remarks or follow-up questions, they can make a note of that directly within the summary module. These notes are saved and are visible to the HCP during the next consultation.

7.3.4 CONCLUSION

The preparation module, consultation module, and summary module together form the complete consultation preparation tool, Coprio. This tool is designed to support patients and HCPs by allowing them to prepare for consultations and offers insights into the impact of illness on the patient's daily life. The graphical user interface has been developed to ensure an accessible and user-friendly experience, featuring intuitive interactions and adherence to established accessibility standards. Across all three modules, patient screens are kept consistent to support recognition and usability, while still delivering sufficient detail and functionality to meet the needs of HCPs.



Figure 60, Summary screens

DESIGN REQUIREMENTS	
Design requirement	Final design
The solution should identify individual problems that patients experience	yes
The solution should stimulate caregivers to initiate the Team talk	yes
The solution should allow patients to identify which health aspects are most important to them	yes
The solution should be able to be used by MS patients, taking into account possible physical and psychological impairments	yes
The solution should allow patients and caregivers to prepare the consultation	yes
The solution should allow patients to bring up difficult to discuss topics	yes

DESIGN PRINCIPLES

Improve patient and caregiver communication	yes
Present information without overwhelming patients	yes
Encourage and prepare patients to have an active role in SDM	yes
Integrate the solution into existing workflows	yes
Reduce the time it takes to use the solution for a caregiver	yes
Reduce the time and burden for patients to use the solution	yes
Take usability for people with lower health literacy into account	yes
Patients should feel heard by caregivers	yes
Patients should feel safe and secure	somewhat
The relevance of using the solution should be clear for patients and caregivers	yes

DESIGN GUIDELINES

Design guideline	
Give caregivers confidence in conversation techniques	yes
Only ask information that is relevant to the patient and the caregiver to not overload patients	yes
Ask patient an open question about what is most important to them	yes
Allow loved-ones and personal caregivers to help identify individual problems that the patients experience	somewhat
Provide patients with a visual overview of what is discussed during a consultation to help them interpret outcomes	yes
Make solutions visible during a consultation to stimulate conversation	yes
A.I. generated content is accurate and correct	somewhat

Figure 61, Evaluation of final design by design criteria

7.4 CONCEPT EVALUATION

An evaluation of the design criteria can now be conducted to assess whether Coprio meets stakeholder needs. This section outlines how the identified requirements, principles, and guidelines have been addressed, and offers insight into the solution's likely effectiveness and adoption in practice.

7.4.1 REQUIREMENTS

The design requirements consist of six key prerequisites necessary for the solution to fulfill, improve, and ultimately replace the role of current PROMs in individual care, as described in Section 4.4. Coprio fulfills all six design requirements (Figure 61).

1. The solution should identify individual problems that patients experience

The consultation preparation concept asks patients to reflect on which symptoms they have experienced, similar to the current PROMs. However, it also encourages patients to consider which symptoms are worth to discuss, distinguishing between unimportant symptoms and significant problems. For example, a patient may respond to a PROM question about walking by indicating that they cannot walk more than ten meters, which might seem severe. However, if the patient has used a wheelchair for over ten years, the situation may not be as concerning. By allowing patients to indicate which symptoms and topics matter most to them, the tool facilitates personalized care tailored to individual needs.

2. The solution should initiate HCPs to start the Team talk

The Team talk phase in the SDM process involves HCPs explaining available options and discussing patient goals (Elwyn et al., 2017; Stiggelbout et al., 2015). Coprio supports this in several ways. First, it enables patients to prepare by considering what is important to discuss. This helps them identify goals ahead of the consultation. During the consultation, HCPs are presented with an overview of all treatment options, designed to be shared with the patient. This shared visual aid can facilitate the presentation of options, encouraging HCPs to initiate the Team talk.

3. The solution should allow patients to identify which health aspects are most important to them

A key functionality of Copriol is allowing patients to identify which health aspects are most important to them. In addition to health aspects, patients can indicate which other topics they find important and want to discuss during their consultation, such as nutrition or pregnancy.

4. The solution should be able to be used by MS patients, taking into account possible physical and psychological impairments

During development, accessibility guidelines specific to individuals with MS were considered to enhance perceivability and comprehension. Icons are consistently accompanied by text, and all color combinations were checked for adequate contrast. Most screens include instructions, and key interactions are supported with examples. Nonetheless, more user testing with MS patients is necessary to confirm if the solution is in fact suitable for the target group.

5. The solution should allow patients and caregivers to prepare the consultation

Coprio is framed around consultation preparation rather than simply filling out a preconsultation questionnaire. Patients are encouraged to reflect on what they want to discuss, which makes the purpose of symptom reporting more clear. They can use their symptom reports to inform their discussion points. Similarly, HCPs can review these reports and the selected discussion topics to prepare. Therefore, the tool supports both patients and HCPs in effective consultation preparation.

6. The solution should allow patients to bring up difficult to discuss topics

All symptoms common to a specific illness are asked in the symptom section of the preparation module. Sometimes, especially for MS, that includes complex or sensitive topics such as sexual functioning or defecation. If a patient indicates experiencing a symptom to a significant extent, it appears higher in the list of potential discussion topics. By presenting difficult subjects as common and placing them prominently, patients may feel more comfortable selecting them. Suppose a patient selects a sensitive topic but does not raise it during the consultation. In that case, HCPs can refer to the discussion topic list and still initiate the conversation about difficult-to-discuss topics.

Overall, the conversation preparation tool fulfills the design requirements well, suggesting that it can meet the most important needs of both HCPs and patients.

7.4.2 PRINCIPLES

While meeting the design requirements is essential, it does not guarantee that the solution will be accepted. The design principles offer additional guidance to ensure the solution is likely to be used.

The first design principle is to improve communication between patients and HCPs. Coprio supports this by ensuring that the modules are recognizable and clear to understand for patients and HCPs. Patients' priorities are made visible to both patients and HCPs, encouraging active participation in SDM. By having the discussion topics visible, patients are encouraged to express their concerns, while HCPs are reminded to consider those concerns.

There are several accessibility and usability principles in the list of criteria. For patients, it is important to present information so that it does not overwhelm the patient, is understandable for patients with lower health literacy, and the relevance of the information is clear. The tool addresses this by breaking long questionnaires into smaller segments, initially using simple "yes" or "no" questions. Symptoms are supported by icons, which makes it more accessible. Azad et al. (2024) argues that using multimedia in PROMs improves accurate completion by people with low health literacy (Section 2.1.3). The solution also aims to improve relevance for patients, because reported symptoms can be used to indicate discussion topics. In this way, symptom reporting is relevant for patients and HCPs in their consultation preparation.

For HCPs, it is important that the solution does not take up too much time. Results of the preparation should be easily accessible. Coprio aims to do this by adding a consultation screen into the HCP's existing workspace. On that screen, the HCP can view the preparation results at a glance and easily switch to discussion topics with one click. However, it is unlikely that integrating the consultation screen into the HCP's existing workspace will be easy or without adaptations. For the solution to be effectively integrated into existing workspaces, it is necessary to talk to the developers and discuss possible integration.

Patients indicated during the co-design sessions that they felt the need to feel safe and secure between consultations. This means that if a patient suddenly feels unwell or has a question, they want a quick response from their HCP. Coprio might not fully fulfill this need. While the solution allows patients to indicate their symptoms and ask questions, these questions will not be answered until the consultation itself. If a patient has an urgent question or symptom, they can emailing or call their HCPs. Some patient apps also already have the option to contact an HCP.

7.4.3 GUIDELINES

The guidelines are concrete elements that can be integrated into the design. These guidelines aim to enhance the design but are not strictly essential for the tool's functionality. Most have been incorporated into Coprio. For instance, patients can submit open-ended questions or write their own discussion topics. Additionally, a visual summary is provided, and HCPs are given concrete tools to use in a conversation, such as the consultation screen with treatment options.

Not all guidelines have been fully implemented. The design does not explicitly invite loved ones to help with the consultation preparation. It is up to the patient to ask for help when filling in the preparation module, because HCPs indicated during the co-design sessions that they want to receive information from patients directly. Therefore, it is possible to do the consultation preparation with a loved one, but it is not specifically encouraged. Another guideline states that Al-generated content must be accurate and reliable. This depends on the Al model in use and will require testing to confirm if the guideline is met. In Coprio, however, HCPs are responsible for reviewing Al summaries before they are sent, which helps to ensure that patients receive accurate information.

7.4.4 CONCLUSION

The consultation preparation tool mostly meets the design requirements, principles, and guidelines identified in this thesis. This indicates that the solution fits the needs of patients and HCPs. It theoretically supports the core goals of consultation preparation and encourages SDM. While the solution shows strong potential, further improvements are needed, particularly regarding integration into existing work-flows and ensuring Al accuracy. This will be further reflected upon in Chapter 8.

7.5 EXPECTED VALUE FRAMEWORK

Besides evaluating how the concepts fulfill the needs of patients and HCPs, a value framework should again be made to show what values become important surrounding the final concept, following the VtM method. In Figure 62, values of HCPs and patients are shown, based on the discussion during the second co-design sessions. HCPs mostly expressed the three main value themes (patient-centeredness, efficiency, and quality), while patients focused more on sub-values, such as accessibility and self-reliance. For each value, norms retrieved from the results of the second co-design sessions are described.

Coprio aims to improve HCPs' values by incorporating the indicated norms. It also clearly communicates the perspective of patients to both patients and HCPs, supporting the main value of patient-centeredness. Furthermore, the tool aims to reduce patient burden by improving the usability of symptom reporting and reducing the time it takes to complete questionnaires. Regarding efficiency, the tool structures the consultation and is integrated into existing workflows, which HCPs value. Quality of care is also supported, because patients are still asked to provide detailed information about their health context and priorities. This can be used for holistic care, as a complete picture of the patient's health context can be sketched.

Patients' primary concern with using the solution was accessibility. If accessibility is not supported, this value likely becomes more important. Coprio aims to consider accessibility by following MS-specific accessibility guidelines. Patients also value self-reliance. The final concept supports this by encouraging patients to prepare for the consultation, even when they usually do not. Furthermore, patients are supported with information and can do their own research at home, based on the actual conversation during the consultation. Finally, patients value quality, which is primarily linked to the information they receive. Since the final concept delivers additional information to the patient, which currently is not the case, special focus should be given to how this information is provided to ensure that this value for patients is sufficiently supported.





PATIENT CENTEREDNESS

EMPATHY

Focus on what is important for the patient to discuss, and make sure the solution does not unnecessary burden the patient.

EFFICIENCY

EFFICIENCY

2

A solution saves time during the consultation and saves resources. Workflows are optimized.



Information that is gathered and used is accurate and evident-based.

NORMS	Perspective Caregivers listen to the patient's perspective	Reduce burden Patient's time and energy is valued and taken into consideration	Time investment A solution should be quick to use and understand	Workflow It is easy for caregivers to incorporate the solution into existing workflows	Scientific integrity Information should be gathered in an evidence-based way	Holistic care Very detailed data is needed to gain insight into the complete picture	
JES					3		
VALL			SELF RE	LIANCE	QUALITY		
╘	PATIENT CENTEREDNES	s, quality, efficiency	PATIENT CEN	ITEREDNESS	COMMUNICATION Information that is communicated is accurate and of good quality. It is clear to the patient where information comes from.		
PATIEN	Clear language is used color contrast, and eno elements is used.	l, large font sizes, good ugh space between	Patients are able and er reliant. People who are supported to become m	ncouraged to be self less self reliant are ore self reliant.			

ACCESSIBILITY

SELF RELIANCE

Communication communicated and Support People who are

Source

Figure 62, Value framework of final design

7.6 CONCLUSION



Figure 63, Design goal with sub-goals

As described in Chapter 1, PROMs are currently used in various situations, categorized into four main goals: individual care improvement, internal and external quality control, and scientific research. Using PROMs for individual care improvement, specifically for supporting SDM, was identified as the primary goal. The design objective to reach this goal is illustrated in Figure 63: to design a tool that provides context for and stimulates SDM while enhancing communication, engagement, and relevance.

The evaluation of the concept, using both the list of design criteria and the value framework, demonstrates that the final concept theoretically meets this goal. Communication is facilitated by a list of discussion topics, which serves as a conversation guide during consultations and helps patients express their concerns. Engagement is supported by actively involving patients and giving them a clear purpose in preparing consultations. Relevance is enhanced by clearly communicating this purpose to patients and HCPs, and by ensuring that the results are actively discussed during the consultation.

Therefore, the consultation preparation tool addresses the needs and values identified in the co-design sessions and fulfills the overarching design goal.

Chapter 8 DISCUSSION & CONCLUSION

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8.1 DISCUSSION

8.1.1 RESEARCH QUESTIONS

In this thesis, three research questions have been presented. This discussion will reflect the extent to which these research questions have been answered. This section starts with the most specific research question and ends with the broadest, showing how the research applies at different levels.

RQ3: To design a tool that identifies the impact of a disease on a patient's life and facilitates discussions about treatment options

As concluded in Chapter 7, the consultation preparation tool, Coprio, is a promising alternative to traditional PROMs to support SDM during consultations. This is achieved in two ways. First, Coprio makes it possible to identify the impact of a disease on a patient's life. This is done by asking patients to share which symptoms they have experienced, from a patient's perspective. The impact of this can be seen by allowing patients to indicate which of these symptoms or other health-related issues they find important to discuss. During the consultation itself, the symptoms and discussion topics can be used as a starting point to further identify the impact of the disease.

The second part of RQ3 mentiones that the solution should facilitate discussions around treatment options. Coprio supports this in several ways. Before the consultation, patients can already think about what is important to discuss by tracking their symptoms and filling in discussion topics. During the consultation, these discussion topics can give an indication about what is important to the patient, which should be taken into account in the SDM process. Furthermore, treatment options are presented in a clear and structured manner during the consultation, which reminds the HCP and patients that decisions can be made. Finally, after the consultation, patients are able to review treatment options independently and are actively encouraged to compare them. These features all aim to effectively facilitate the discussion about treatment options and encourage SDM.

However, the effectiveness of Coprio also relies on its use. Existing PROMs are used before consultations, but also after treatments, during check-ups or at other moments. For Coprio, it is essential that it is only asked to complete before an upcoming consultation. This is a non-negotiable element of the design. The discussion of results during the consultation is

central to the added value of Coprio compared to existing PROMs, because it increases relevance for patients.

It is important to note, however, that this conclusion is based on a case study involving patients with MS. Coprio's applicability to other patient groups has not yet been validated. Nonetheless, Coprio is likely suitable for broader use. The tool's method of symptom reporting is adapted from existing PROMs, which suggests that similar adaptations could be developed for other conditions that also already use PROMs. Moreover, the app itself is not disease-specific and could therefore be adapted to other patient groups. Additionally, the consultation module screens used during consultations are integrated into the electronic health record system and are accessible to HCPs across all departments, also not dependent on patient groups.

Finally, the solution was presented during a meeting at the UMCG Hospital, including HCPs, researchers, and implementation experts. The concept received positive feedback, and attendees also saw opportunities for applying Coprio to other patient groups. Based on this response, it is likely that RQ3 has been successfully met, even beyond the case study of MS.

RQ2: How can the design and procedure around PROMs, HCP involvement, and internal patient motivation be improved to increase the value of PROM use for individual care improvement?

During the course of this thesis, a deliberate decision was made to focus on SDM, identified as the most critical goal of PROMs. This focus enabled to take a bottom-up approach to the development of an alternative to traditional PROMs. However, SDM represents only one component of individual care improvement. RQ2 initially explored this overarching goal before narrowing the focus to SDM in RQ3. Has this broader research question also been met?

Although experts consistently highlighted SDM as the primary purpose of PROMs, HCPs participating in the co-design sessions frequently emphasized the importance of diagnostics and monitoring as well. When a concept that exclusively focused on SDM was introduced, concerns emerged regarding the inability of the concept to fulfill other essential functions. This feedback showed that it was still necessary to include additional sub-goals, because HCPs would not otherwise not accept the solution. As a result, the refined concept was adjusted to also support self-management, monitoring, and diagnostics.

Therefore, a scaling system was implemented that captures detailed information about symptoms experienced by patients. By incorporating this feature, Coprio can be used for all goals within individual care improvement and effectively addresses RQ2.

Since the tool collects information on patients' symptoms in a structured manner similar to existing PROMs, it could theoretically also be applied toward other PROM goals such as internal and external quality control, and scientific research. However, these goals should never be the primary goal of Coprio. A core principle of the tool is that patients engage with it to prepare for upcoming consultations and participate in SDM. This increases relevance, engagement, and communication and makes sure that Coprio adheres to important values. If the tool is not used for individual care improvement, then results are not discussed and it does not provide benefit for the patient. So, patients should only be asked to complete the consultation preparation in the context of a scheduled consultation, and never with the primary aim of fulfilling other PROM goals.

To address the other PROM goals, healthcare organizations can analyze the existing data collected through the consultation preparation process. If additional data is required, traditional PROMs can be distributed. In that case, it is essential that patients are clearly informed about the purpose of the questionnaire and how their data will be used.

RQ1: How can PROMs be redesigned to increase their value for patients, care organizations, and the care system?

This thesis explored how PROMs can be redesigned to improve their value for patients, care organizations, and the broader healthcare system. The final value framework, introduced in Chapter 7 (Figure 62), can now be compared to the initial framework from Chapter 2 (Figure 12) to evaluate whether the implementation of Coprio increases the overall value of PROMs for these stakeholders.

INITIAL VALUE FRAMEWORK

The initial framework identified three core values: **patient-centeredness**, **quality**, and **efficiency**. These align closely with the key components of the VBHC model: **personal value**, **allocative value**, and **technical value**, outlined in Chapter 1. Among the three, patient-centeredness was found to be the most important, followed by quality, and then efficiency.

A review of challenges experienced with existing PROMs showed that most problems were tied to patient-centeredness. Within this core value, there were issues related to autonomy, equality, relevance, responsibility, and usability. This highlights the central role of patientcenteredness and shows that it is currently insufficiently experienced. For quality, the main concerns included the availability of evidence-based information, how data is collected, and how relevant it is. Efficiency issues were mostly related to cost-effectiveness, usability, and communication.

So, the initial value framework highlights the importance of these three core values and shows that existing PROMs cause them to be often experienced in a negative way.

FINAL VALUE FRAMEWORK - HCPS

In the final value framework, a clearer distinction was made between values relevant to HCPs and those relevant to patients. The same three core values remained central for HCPs, but their meaning and relative importance changed. **Patient-centeredness** was still considered as most important and kept a definition similar to the initial value framework. However, **efficiency** became more important, especially during the design phase and the first co-design session, where inefficiencies in current practices became more apparent. In the final value framework, efficiency was still an important value. However, it was now mostly experienced in a positive way, because Coprio could guide the consultation and make it more time efficient. The focus therefore shifted to time efficiency, rather than resource efficiency, which was the case in the initial value framework. **Quality**, while initially seen as second most important, did not raise many concerns in the first co-design session. However, in the second session, reduced patient data made some users question the quality of information, which increased its perceived importance. Quality continued to be defined as the presence of unbiased, evidence-based, and relevant information.

So, compared to the initial value framework, the final value framework of HCPs has become more focussed on efficiency compared to quality, while the value of patient-centeredness remains unaffected.

FINAL VALUE FRAMEWORK - PATIENTS

From the patient's perspective, the final value framework confirms **patient-centeredness**, **efficiency**, and **quality** as core values, but places particular emphasis on the sub-values of **accessibility** and **self-reliance**, both of which mainly fall under the umbrella of patient-centeredness. This suggests that patient-centeredness is not only the most important value for patients but also the most strongly influenced by the introduction of new technology, as the focus on sub-values show that change is experienced.

For instance, the introduction of Coprio did not significantly alter HCPs' value priorities. However, for patients, it brought up the sub-values of accessibility and self-reliance. Accessibility became especially important in the context of using a digital tool, and the focus on self-reliance increased because patients recognized the tool's potential to better manage their symptoms. In this way, the experience of patient-centeredness is explored deeper on the patient side compared to the value framework of HCPs.

COPRIO'S FIT TO THE VALUE FRAMEWORK

The evaluation of the final concept suggests that it better aligns with the three core values of patient-centeredness, efficiency, and quality than current PROMs. This is due to better accessibility and relevance, more time-efficient consultations, and having more detailed data about a patient's health context. Since the final framework aligns well with VBHC values, it is reasonable to expect that Coprio could deliver more value at the care system level as well. Because the initial framework did not separate patient values explicitly, it is hard to measure the exact change for patients. However, analysis of the final value framework suggests that these values were enhanced rather than reduced. This could indicate an improvement in how patients experience PROMs.

The change that can be observed in the relative importance of the values and the shift to sub-values for patients underscores the concept of moral mediation through technology, as described by the VtM approach. This thesis demonstrates how technology affects which values are experienced in healthcare by different stakeholders. Not only does it confirm that values are indeed affected, it also shows the possibility to affect the values in a positive way, in order to improve healthcare. This could be reached by investigating and incoporating stakeholders' values, and actively involving them in the design process. Therefore, the research question," How can PROMs be redesigned to increase their value for patients, care organizations, and the care system" is answered.

8.1.2 FEASIBILITY

The extent to which the proposed solution in this thesis can deliver value also depends on feasibility, which is determined by the willingness of organizations to adopt the solution.

First, the values that Coprio supports should allign with values of the care system. The final value framework aligns closely with values of the VBHC model, indicating that Coprio matches the view the care system has on improving healthcare. This alignment suggests that implementing Coprio could fit to strategies of care organizations. Expert interviews also highlighted a shared sense of urgency to solve current problems of PROMs, which furthermore shows that Coprio would fit into strategies to improve healthcare.

However, there are more uncertainties surrounding practical aspects of implementation. For example, the costs and efforts needed to implement the solution should be considered. Integrating Coprio into existing patient applications and electronic health records is a large operation and might present significant challenges. A first step could therefore be to develop a standalone solution where Coprio is accessed through links in the existing patient apps and electronic health records. This might increase feasibility of the solution. However, it could also negatively affect usability on the HCPs' side, because more steps will be required to access the tool, which reduces efficiency. Still, it would be a suitable option to implement the tool with lower required efforts and costs, and would allow care organizations to test its effectiveness in practice.

The resources required to develop and implement the solution also depend on the availability of existing PROMs for a patient group. When such PROMs exist, their questions can be relatively easily translated into symptom categories for use in the tool. In cases where no appropriate PROMs are available, a more extensive development process, similar to that used in the creation of traditional PROMs, would be necessary to ensure that data is valid and relevant.

In summary, while implementing Coprio into existing technology might not be immediatly feasible, there are steps that can be taken to already increase the value of PROMs for patients, care organizations, and the care system. The value framework shows that there are reasons for the care system to want to implement Coprio, which is further supported by the experts and HCP participants in this thesis.

8.1.3 LIMITATIONS

This thesis has limitations, mainly in the initial literature review, co-design sessions, and final design.

The literature review at the start of the research aimed to identify problems and existing solutions surrounding PROMs. A value analysis was made based on this review. Although recent literature reviews and other studies were used, it was not a full systematic review and probably did not identify all problems and existing solutions described in literature. However, combining this literature review with the expert interviews helped to identify the most important problems. Another limitation of the literature is that during the literature review, no clear distinction was made between values experienced by HCPs and patients. This made it more difficult to compare the final value framework to existing values.

The co-design sessions were deductively coded and evaluated based on values identified in the literature review and expert interviews. This method could have influenced which values were found in the analysis. It would also have been interesting to have used an inductive coding process for the co-design sessions, which could have led to a slightly different value framework. However, a deductive approach was the better option for this project because it allowed for comparing the value frameworks.

During the actual co-design sessions, participants' values were influenced by the concepts shown, as the Value that Matters approach describes. However, the way information was presented and the co-design activities could also have influenced the values that were discussed. For example, patients focused extensively on accessibility during the second co-design session. This could have been caused by the presence of a UI mock-up that did not show clearly how accessibility was incorporated. While it showed that accessibility was important to the participants, other materials about the same concept could have provoked different reactions. Additionally, only a small number of participants were present during the sessions. Therefore, it is uncertain if the value framework of the final design paints an unbiased picture of the values the concept provokes. So, before the solution is implemented, a pilot study that mimics the actual use context should be held to find a more representative value framework.

8.1.4 ETHICAL CONSIDERATIONS

During this thesis, users were involved through expert interviews and co-design sessions. For the expert interviews, ethical approval has been given by NES UT – nr 240781. For the co-design sessions, ethical approval was given by METC MEC-U and the local R&D department of St. Antonius.

The potential ethical impact of the Coprio should also be discussed. First of all, Coprio is designed to support patients in preparing for consultations, which aims to increase their autonomy and self-reliance. However, care must be taken to ensure that the tool does not place too much responsibility on patients, especially when there is a risk of excluding some. The consultation preparation tool is a primary a digital tool. Therefore, it may create barriers for individuals who have limited access to technology, have low digital skills, or face cognitive or physical challenges. This makes it even more important to consider accessibility guidelines.

Secondly, Coprio, in a way, is a data collection tool that collects sensitive health information. Therefore, data security and informed consent should be ensured. It should be clear to patients how their information will be used. Furthermore, integrating Al to generate consultation summaries raises ethical questions related to data security, but also about reliability of information provided to the patient. Patients and HCPs must understand the limitations of Al-generated content and it must be clear that HCPs are still responsible for any information that is sent to patients.

Finally, the effect of Coprio on patients' experiences with their disease should be carefully considered. The consultation preparation asks patients to translate health experiences into short yes-or-no answers, each supported by an icon. The technology could therefore influence how they view the symptoms they have experienced. This influence is caused by the phrasing of the questions and the use of icons that symbolize a symptom. In this way, the tool frames symptoms through a certain lens, one that may differ from how patients actually experience their illness. Therefore, Coprio should not replace clinical judgement. There is a risk that the provided symptom overview could oversimplify complex patient experiences or limit the discussion about what is important to the patient. HCPs must therefore always be open to hearing the patient's perspective during the consultation itself.

8.2 RECOMMENDATIONS

To increase the value of PROMs and to successfully implement the Coprio consultation preparation tool into practice, further research and development is needed. Although user feedback has been positive in this thesis, there are still some aspects that should be tested and further refined to ensure that Coprio supports the values and needs of patients and HCPs.

One important next step is to further investigate the final value framework to ensure that it accurately reflects the values of HCPs and patients. Coprio can also be evaluated through the values of the VBHC model to see whether the care system sees potential in further developing it. In this context, it is especially important to test the Technical Value. Although Coprio appears to be a promising and efficient solution, the costs are not yet clear. By calculating and comparing the costs of Coprio with those of existing PROMs, hospitals and care organizations can decide whether to invest in further development of the tool.

To ensure that Coprio can be used beyond MS patients, it should be adapted for use with other PROMs. A good first step would be to integrate generic PROMs, such as the EQ-5D, which can be applied to many patient groups. Since this PROM includes only five questions, it is even more important for patients to have the option to add their own discussion topics. This ensures that individual concerns are not overlooked during consultations.

User tests are also necessary to evaluate how patients experience Coprio. In particular, it should be assessed whether patients feel stressed by the limited number of discussion topics they can select, as hypothesized by HCPs during the second co-design session. The design should also be tested for compliance with accessibility guidelines, including whether the language used is clear. Since icons are used to represent symptoms, they require special attention in user testing to ensure they convey the intended meanings.

Another important task is to test the new way of presenting PROM questions. Traditional PROMs are carefully constructed and validated. Since Coprio uses symptom-based yesor-no questions instead of original PROM questions, it is important to check whether this affects the accuracy of the results. A case study can help determine whether Coprio gathers the same kind of information as current PROMs. If it does, this approach can be extended to other PROMs. If not, the wording of symptoms or the way results are calculated may need to be adjusted.

The tool itself can also be further developed, as only a prototype is currently available. This prototype can be expanded with additional screens and features based on the current user flows. For example, interactions that show how reported symptoms and discussion points can be adjusted should be further explored, and the overview of treatment options can be made more detailed.

In addition to digital development, it is important to explore what a physical or paper version of Coprio could look like. This would ensure that patients with low digital skills can still benefit from the tool. The role of the nurse specialist should therefore also be further defined. These professionals could help guide patients during the consultation preparation process and support the use of Coprio in clinical practice also for patients with lower health literacy.

Next to improvements on the patient's side of Coprio, development on the HCP's side is needed. A long-term dashboard could be developed to monitor patient responses over time, using insights from the second HCP co-design session as a starting point. Finally, for Coprio to be used effectively in healthcare settings, it must be properly integrated into existing workflows and systems. The compatibility of the tool with systems like EPIC should be further explored to ensure it fits well into current clinical routines. Additionally, Coprio should be optimized for use across different departments so that patients are not asked to answer the same questions more than once, as is currently often the case with PROMs.

8.3 CONCLUSION

Incorporating the patient's perspective is increasingly important as care organizations move toward Value-Based Healthcare. PROMs aim to capture this perspective to improve individual care, support quality assessments, and contribute to research. However, current PROMs face significant challenges in design, implementation, and user engagement from both patients and HCPs.

This thesis used a design-oriented approach to explore and design alternatives to PROMs. While existing solutions often focus on isolated issues, such as accessibility, this research addressed underlying problems by involving patients and HCPs in co-design sessions. The goal was to develop a solution that improved PROM design and usability while aligning with user needs and values. This increases the likelihood of adoption in practice. The Values-that-Matter approach made it possible to research and design for these values. It revealed that aligning with user values, not just needs, is critical and can steer the design process into innovative directions that would otherwise be overlooked.

This research also highlights the challenges of innovation within a healthcare context. Initial concepts deviated from standard PROMs on purpose, but HCPs showed resistance to change. When a concept that aligned to user values, but moved away from existing PROMs was presented, it was rejected despite its patient benefits. Ultimately, a solution that closely aligned with existing workflows had to be developed to gain the acceptance of HCPs. Therefore, the acceptance of a solution depends not only on innovation but also on alignment with clinical practice. These findings show that design for healthcare must consider the needs, values, and practical constraints of all stakeholders. A design approach, such as that used in this thesis, can overcome these challenges.

The consultation preparation tool developed in this thesis, Coprio, provides a concrete outcome of a design approach. Coprio was designed to make PROMs more relevant to patients, improve communication between patients and HCPs, and encourage stronger engagement in the consultation process to ultimately improve their value. Coprio addresses challenges of traditional PROMs by offering a solution that aligns with the values of both patients and professionals, while also fitting within the existing care structures. This thesis demonstrates that when innovation considers both values, needs, and practical realities, it can lead to solutions that are not only more usable but also more meaningful in practice.

STATEMENT ON THE USE OF AI AND OTHER TOOLS

During the preparation of this work, I used ChatGPT, Grammarly, and Word to enhance grammar and text flow, but never to generate original text (Figure 64). ChatGPT was also used to translate anonymized quotes during the interviews and co-design sessions. Word was used to write original text in, and to transcribe interviews and co-design sessions

automatically. Adobe Firefly was used to generate Figure 19 and Image selection (patients) shown in Appendix F. Google Scholar was used as a search engine, and Mendeley Cite was used as a reference manager. ATLAS.ti and Taguette were used for the coding process, but the Al features were not used. Adobe Illustrator, Photoshop, and InDesign were used for the graphical elements of this thesis. Figma was used to develop the Coprio prototype and wireframes. Procreate was used to make ideation sketches. After using all these tools/services, I thoroughly reviewed and edited the content as needed, taking full responsibility for the final outcome.



Figure 64, Statement on the use of AI

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APPENDICES

APPENDIX A – INTERVIEW QUESTIONS EXPERT INTERVIEWS

Onderzoeksvraag: Hoe kan de waarde van PROMs worden verbeterd voor patiënt, zorginstelling en zorgsysteem vanuit een ontwerpperspectief?

Doel interview: Identificeren problemen en waarde van PROMs

Deel 1: Introductievragen

- 1. Wat is jouw functie en wat houdt dat in?
- 2. Hoe kom jij in aanraking met PROMs?
- 3. Wat voor problemen heb je ondervonden met PROMs?

Deel 2: Context

- 1. Waarom zetten jullie PROMs in?
- 2. Sinds wanneer worden PROMs ingezet?
- 3. In welke situaties zetten jullie PROMs in?
- 4. Hoe vaak worden PROMs ingezet? Krijgt elke patiënt ermee te maken?
- 5. Hoe worden PROMs aan patiënten aangeboden?
- 6. Naast patiënten, wie hebben er allemaal te maken met PROMs?
- 7. Hoe gaan zorgverleners om met PROMs?
- 8. Krijgen zorgverleners trainingen over PROMs?
- 9. Hoe kiezen jullie geschikte PROMs?
- 10. Hoe worden de uitkomsten van PROMs ingezet?
- 11. Wat voor beslissingen worden er gemaakt op basis van PROMs?
- 12. Wat is de huidige meerwaarde van PROMs?
- 13. Vinden jullie dat PROMs op dit moment effectief zijn? Wat maakt ze effectief, of juist niet?
- Deel 3: Normen en waarden
- 1. Wat is er belangrijk voor jou in jouw baan?
- 2. Hoe zie je dat terug in de praktijk?
- 3. Zijn er conflicten tussen wat jij belangrijk vindt en wat je doet in jouw baan?

- 4. Weet je iets over wat belangrijk is voor de patiënt?
- 5. Weet je iets over wat belangrijk is voor de zorgverlener?

Deel 4: Toekomstbeeld

- 1. Wat hoop je dat in de toekomst belangrijk wordt in de gezondheidszorg?
- 2. Wat denk jij dat de toegevoegde waarde van PROMs kan zijn in de toekomst?
- 3. Wat zijn volgens jou mogelijkheden om PROMs te verbeteren?
- 4. Als je nu de mogelijkheid had om iets te veranderen en dat zou direct toegepast worden, wat zou je dan voorstellen?
- 5. Wat zou er gebeuren als er morgen opeens geen PROMs meer worden ingezet?

Deel 5: Afronding

- 1. Ken je nog mensen waarmee ik verder in gesprek kan? Bijvoorbeeld zorgverleners of patiënten? Zo ja, wat voor type patiënten? Wat voor type PROMs?
- 2. Heb je interessante artikelen of rapporten die ik zou kunnen raadplegen?

APPENDIX B – CONSENT FORM

Informatieblad voor onderzoek 'PROMs in de praktijk'

Doel van het onderzoek

Dit onderzoek wordt geleid door Jinte Pomper. Het doel van dit onderzoek is om uit te zoeken wat de huidige waarde is en problemen zijn van Patient Reported Outcome Measures in de praktijk.

Hoe gaan we te werk?

U neemt deel aan een onderzoek waarbij we informatie zullen vergaren door u te interviewen en uw antwoorden te noteren.

Uitsluitend ten behoeve van het onderzoek zullen de verzamelde onderzoeksgegevens worden gedeeld met de Universiteit Twente en Panton, beide gevestigd in Nederland.

Potentiële risico's en ongemakken

Er zijn geen fysieke, juridische of economische risico's verbonden aan uw deelname aan deze studie. U hoeft geen vragen te beantwoorden die u niet wilt beantwoorden. Uw deelname is vrijwillig en u kunt uw deelname op elk gewenst moment stoppen.

Vertrouwelijkheid van gegevens

Wij doen er alles aan uw privacy zo goed mogelijk te beschermen. Er wordt op geen enkele wijze vertrouwelijke informatie of persoonsgegevens van of over u naar buiten gebracht, waardoor iemand u zal kunnen herkennen.

Voordat onze onderzoeksgegevens naar buiten gebracht worden, worden uw gegevens zoveel mogelijk geanonimiseerd, tenzij u in ons toestemmingsformulier expliciet toestemming heeft gegeven voor het vermelden van uw naam, bijvoorbeeld bij een quote.

In een publicatie zullen anonieme gegevens of pseudoniemen worden gebruikt. De aantekeningen en andere documenten die in het kader van deze studie worden gemaakt of verzameld, worden opgeslagen op de persoonlijke opslag van de onderzoeksleider. De onderzoeksgegevens worden bewaard voor een periode van 10 jaar. Uiterlijk na het verstrijken van deze termijn zullen de gegevens worden verwijderd of worden geanonimiseerd zodat ze niet meer te herleiden zijn tot een persoon. De onderzoeksgegevens worden indien nodig (bijvoorbeeld voor een controle op wetenschappelijke integriteit) en alleen in anonieme vorm ter beschikking gesteld aan personen buiten de onderzoeksgroep.

Tot slot is dit onderzoek beoordeeld en goedgekeurd door de ethische commissie van de faculteit BMS(domain Humanities & Social Sciences).

Vrijwilligheid

Deelname aan dit onderzoek is geheel vrijwillig. U kunt als deelnemer uw medewerking aan het onderzoek te allen tijde stoppen, of weigeren dat uw gegevens voor het onderzoek mogen worden gebruikt, zonder opgaaf van redenen. Het stopzetten van deelname heeft geen nadelige gevolgen voor u.

Als u tijdens het onderzoek besluit om uw medewerking te staken, zullen de gegevens die u reeds hebt verstrekt tot het moment van intrekking van de toestemming in het onderzoek gebruikt worden.

Wilt u stoppen met het onderzoek, of heeft u vragen en/of klachten? Neem dan contact op met de onderzoeksleider.

Jinte Pomper Jinte.pomper@panton.nl +31 6 10746449

Als u klachten heeft over het onderzoek, kunt u deze richten aan de secretaris van de Ethische Commissie Natuur- en Technische Wetenschappen van de Universiteit Twente, P.O. Box 217, 7500 AE Enschede (NL), telefoon: +31 (0) 53 489 5607; e-mail: ethicscommitte-nes@utwente.nl. Dit onderzoek wordt uitgevoerd vanuit de Universiteit Twente, faculteit Behavioural, Management and Social Sciences. Indien u specifieke vragen hebt over de omgang met persoonsgegevens kun u deze ook richten aan de Functionaris Gegevensbescherming van de UT door een mail te sturen naar dpo@utwente.nl.

Tot slot heeft u het recht een verzoek tot inzage, wijziging, verwijdering of aanpassing van uw gegevens te doen bij de Onderzoeksleider.

APPENDIX B

Consentformulier

Door dit toestemmingsformulier te ondertekenen erken ik het volgende:

- 0 Ik ben voldoende geïnformeerd over het onderzoek door middel van een separaat informatieblad. Ik heb het informatieblad gelezen en heb daarna de mogelijkheid gehad vragen te kunnen stellen. Deze vragen zijn voldoende beantwoord.
- 0 Ik neem vrijwillig deel aan dit onderzoek. Er is geen expliciete of impliciete dwang voor mij om aan dit onderzoek deel te nemen. Het is mij duidelijk dat ik deelname aan het onder- zoek op elk moment, zonder opgaaf van reden, kan beëindigen. Ik hoef een vraag niet te beantwoorden als ik dat niet wil.

Naast het bovenstaande is het hieronder mogelijk voor verschillende onderdelen van het onderzoek specifiek toestemming te geven. U kunt er per onderdeel voor kiezen wel of geen toestemming te geven. Indien u voor alles toestemming wil geven, is dat mogelijk via de aanvinkbox onderaan de stellingen.

- 0 Ik geef toestemming om de gegevens die gedurende het onderzoek bij mij worden verzameld te verwerken zoals is opgenomen in het bijgevoegde informatieblad.
- 0 Ik geef toestemming dat er tijdens het interview aantekeningen gemaakt worden.
- 0 Ik geef toestemming om mijn antwoorden te gebruiken voor quotes in de onderzoekspublicaties.
- 0 Ik geef toestemming om de bij mij verzamelde onderzoeksdata te bewaren en te gebruiken voor toekomstig onderzoek en voor onderwijsdoeleinden.
- 0 Ik geef toestemming voor alles dat hierboven beschreven staat.

Naam Deelnemer:

Naam Onderzoeker:

Handtekening:

Handtekening:

Datum:

Datum:

Dit informatieblad en formulier is digitaal beschikbaar gemaakt via Google Forms: https://docs.google.com/forms/d/1Yo337s_E7qd8L3864-iQL5gJExlKraHwYThLL9TeAB8/edit

APPENDIX C – IDEATION SKETCHES AND GROUPINGS



Sorted by CONCEPT: Automated data gathering



Sorted by CONCEPT: Managing health symptoms



Sorted by CONCEPT: Training & Education



Sorted by CONCEPT: Physical PROM device


Sorted by CONCEPT: App improvement



Sorted by CONCEPT: No PROMs



Sorted by CONCEPT: Step by step consultation



Sorted by CONCEPT: Pre-consultation (AI)

APPENDIX C



Sorted by CONCEPT: Patient prepares consultation



Sorted by FUNCTION: Longitudinal data gathering



Sorted by CONCEPT: Other



Sorted by FUNCTION: Shared responsibility



Sorted by FUNCTION: Informed decisions



Sorted by FUNCTION: Discussion points



Sorted by FUNCTION: Patient preparation



Sorted by FUNCTION: Saves time



Sorted by FUNCTION: Stimulates communication



Sorted by FUNCTION: Caregiver preparation



Sorted by FUNCTION: Data before consultation



Sorted by FUNCTION: Other

APPENDIX D - CO-DESIGN MATERIALS SESSION 1

Dilemma cards patients



PREMO stickers patients





APPENDIX E – ANALYSIS CO-DESIGN SESSION 1

LIST OF PROBLEMS & SUGGESTIONS	AMOUNT OF TIMES MENTIONED
Problems	
Distracting during consultations	5
Technology might not work properly	4
Too burdening for patients	2
Too modern for some patients	2
Relevance of tips during consultations is unclear	1
HCP looks too much at screen	1
Patients need to have a choice in using this solution	1
Relevance is unclear to patients	1
Too unpersonal	1
Might give unreliable data	1

Suggestions	
Patients need to be given the choice if they want to use this solution	10
Allow this solution to be adjusted to the individual patient	7
Use PROMIS-CAT	5
Combine concept 1 with concept 3	5
Use visualizations to make it more clear	3
HCP checks summary before it is sent to patients	3
Remove the advice during consultations	2
If patient has cognitive problems, loved ones are asked about symptoms	2
Keep the summaries short	2
Use a person instead of A.I. assistant	2
Ask open questions before consultation	2
A.I. assistant reminds caregiver when they forget to ask about important symptoms	1
Prepare patients for the consultation with an unschooled person	1
Use an app	1
Let frequency of PROMs be dependent on clinical relevance studies	1
Use pop-up to guide conversation	1
Make a dashboard to show outcome PROMs	1



LIST OF PROBLEMS & SUGGESTIONS	AMOUNT OF TIMES MENTIONED
Problems	
Takes too much time for patients	1
Too burdening for patients	1
Too unpersonal	1
Suggestions Use visualizations to make it more clear	3
Suggestions	
Combine concept 1 with concept 3	3
Ask open questions before consultation	1
Combine concept 1 with concept 2	1
Use this concept to have routine check-ups through	phonecalls with A.I. assistent 1



Problems	
Patients get too confronted with illness	9
Too burdening for patients	7
Too modern for some patients	2
Frequency of measuring is too high	2
Takes too much time for patients	1
HCP looks too much at screen	1
Suggestions Use and instead of additional device	5
Use app instead of additional device	5
	2
Let trequency of PKOMs be dependent on clinical relevance studies	
Make this concept replace yearly check-ups	1
Don't place it in bedrooms	1
Use automated data gathering	1

AMOUNT OF TIMES MENTIONED

LIST OF PROBLEMS & SUGGESTIONS



LIST OF PROBLEMS & SUGGESTIONS	AMOUNT OF TIMES MENTIONED
Problems	
Too burdening for patients	5
Takes too much time for patients	3
Too little obligation to fill it in	3
Patients get too confronted with illness	2
Suggestions	
Remind patient of filling in PROM	3
Use PROMIS-CAT	2
Combine concept 2 with concept 1	1
Have routine phonecall with A.I. assistent instead o	f diary 1
Reduce frequency of measurement	1



LIST OF PROBLEMS & SUGGESTIONS	AMOUNT OF TIMES MENTIONE
Problems	
No preparation possible	
Difficult to generalize	
Patient loses conversation guide	
Suggestions	
Make concept also digitally available	
Combine concept 3 with concept 1	
Incoporate the conversation guide during nurse co	nsultations as well
Input on paper should be easily translated to digita	l information
Allow concept to be brought to next consultation (v	vith nurse)
Patient can indicate what they want to discuss befo	rehand
Visualizations make it more clear	



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Autonomy FFICIENCY Relevance C	CONCEPT 3 PATIENTS	Holistic care Scientific integrity Transparency
Communication Communication Cx Usobility Cx Espagase	Cost-effectiveness Cost-effectiveness ALITYPND Cost-effectiveness Cost-effectivene	Contracting the set of

LIST OF PROBLEMS & SUGGESTIONS	AMOUNT OF TIMES MENTIONED
Problems	
Suggestions	
Combine concept 3 with concept 1	5
Visualizations make it more clear	5
Make concept also digitally available	4
Allow for open answers	2
Personalize to individual patient's needs	1

APPENDIX F - CO-DESIGN MATERIALS SESSION 2

UI mock-up (patients and HCPs)



Dashboard mock-up with assets (HCPs)



Image selection (patients)

Fysieke inspanning











Medicatie







Zicht

Angstig of gespannen gevoel

Last van armen of benen

Afhankelijkheid van anderen

Plassen of ontlasting

















0

APPENDIX G – ANALYSIS CO-DESIGN SESSION 2

LIST OF PROBLEMS & SUGGESTIONS AMOUNT OF TIMES MENTIONS Problems Problems Patients might feel stressed when deciding which topics to choose Formed habits make consultations less thorough Consultation preparation does not explicitly ask what goes well Suggestions Suggestions Suggestions Still send out MSIS-29 Ink to necessary PROMs from the consultation preparation. Make a dashboard to show outcomes Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show ther atment options separately (on paper) States of the separately (on paper)					
Problems Patients might feel stressed when deciding which topics to choose Formed habits make consultations less thorough Consultation preparation does not explicitly ask what goes well Suggestions Still send out MSIS-29 Link to necessary PROMs from the consultation preparation Make a dashboard to show outcomes Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	IST OF PROBLEMS & SUGGESTIONS AMOUNT OF TIM	es mentioned			
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Consultation preparation does not explicitly ask what goes well Suggestions Still send out MSIS-29 Link to necessary PROMs from the consultation preparation Make a dashboard to show outcomes Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics. Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	ormed habits make consultations less thorough	1			
Suggestions Still send out MSIS-29 Link to necessary PROMs from the consultation preparation Make a dashboard to show outcomes Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	Consultation preparation does not explicitly ask what goes well	1			
Still send out MSIS-29 Link to necessary PROMs from the consultation preparation Make a dashboard to show outcomes Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	ugaestions				
Link to necessary PROMs from the consultation preparation. Make a dashboard to show outcomes Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	till send out MSIS-29	8			
Make a dashboard to show outcomes Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics. Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	ink to necessary PROMs from the consultation preparation	6			
Visualization makes it clearer Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	Aake a dashboard to show outcomes	4			
Integrate the solution across all departments Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	isualization makes it clearer	4			
Patient fills in consultation preparation once, in the future only makes changes Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	ntegrate the solution across all departments	3			
Use a scale (with words) for registering symptoms Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	atient fills in consultation preparation once, in the future only makes changes	3			
Another consultation is planned if there is not enough time to discuss all important topics Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	Jse a scale (with words) for registering symptoms	3			
Show other specialists in treatment options Explicitly ask patient what goes well Show treatment options separately (on paper)	nother consultation is planned if there is not enough time to discuss all important	t topics 2			
Explicitly ask patient what goes well Show treatment options separately (on paper)	how other specialists in treatment options	2			
Show treatment options separately (on paper)	xplicitly ask patient what goes well	1			
	how treatment options separately (on paper)	1			
Swipe or slide symptoms	wipe or slide symptoms	1			
Add links to more health information in the consultation evaluation	dd links to more health information in the consultation evaluation	1			
Send out PROMs more often	end out PROMs more often	1			
Add pregnancy to list of discussion topics	ndd pregnancy to list of discussion topics	1			

LIST OF PROBLEMS & SUGGESTIONS	AMOUNT OF TIMES MENTIONED
Problems	
Numeric scales are confusing	4
Only measures one point in time	2
Generated summary might be unreliable	T
People don't want to use an AI assistant because of p	rivacy 1
MS nurse has too little time	1
Not every patient has MijnAntonius	1
Suggestions	
Use enough space and contrast	6
Make a feature for additional explanation	5
Use a large font size	4
Patients can choose if they want an AI assistant during	the consultation 3
Make it clear if and when you still can make changes	3
Make automated summary with AI	2
Patient fills in consultation preparation together with nu	urse 2
Use icons as images	2
Indicate during consultation if you need an additional	consultation with MS nurse 1
Additional discussion topics are added to consultation	n evaluation 1
Patient can choose to receive consultation preparation	n at home 1
HCP checks summary	1
Keep summaries short	1
Differentiate between chronic and temporary symptom	ns l
Use accessible language	1
Check the concept with a neurologist for scientific inte	grity 1
Visualization makes it clearer	Ĩ
Investigate how many patients use MijnAntonius	1
Use short description under images	1
Use a scale based on words	1



APPENDIX H – USER FLOWS

Consultation preparation user flow





Consultation user flow





View a dashboard with all results of patient's tests and preparations.

Consultation summary user flow









Consultation wireframes



AT	←→ Dossier Neu	rologie Resultaten	Consult Beoordeling	Formulier		AT	←→ Dossier Ne	urologie Resultaten	Consult Beoorde	ling Formulier
	12 Juni 2025 10:00	Start Al transcriptie 🔮 🕘	Patient view				12 Juni 2025 10:00	Start Al transcriptie 🔍 🌒	Patient view	
A. N. Tonius Vrouw, 56 jr., 18-12-1963 MDN: 3432087 Reanimatie: Geen geg. opg.	Consultvoorbereiding	Behandelopties				A. N. Tonius Vrouw, 56 /r., 18-12-1963 MDN: 3432017 Reanimatic: Geen (eg. opg.	Consultvoorbereiding	Behandelopties		
oeken	Medicatie	Doorverwijzingen				O Zoeken	Medicatie	Doorverwijzingen	Mediciinen	Fumaraat-esters
ing: Geen n: Geen gegevens en	Medicatie keuzekaart \rightarrow	Keuzekaart \rightarrow				Verzekering: Geen Allergielen: Geen gegeves opgeslagen	Medicatie keuzekaart \rightarrow	Keuzekaart \rightarrow	Hoe gebruik je het?	2x dag 🔗
EEKUURBEZOEK	Fumaraat-esters	Fysioloog				9-2 SPREEKUURBEZCEK	Furmaraat-esters	Fysioloog	Waar moet je op letten?	Je laat 2,3 of 4 keer per jaar bloed prikken.
R.	Glatirameer	Revalidatie-arts				Lengte: - Gewicht: - BMI: -	Glatirameer	Revalidatie-arts	Voordelen	50% minder kans op MS-aanvallen
OPERATIE	Interferon-bèta	Uroloog				LAATSTE OPERATIE	Interferon-bèta	Uroloog	Nadelen	Diarree
gische ningen	S1P receptor modulatoren	Psycholoog				Zie chirugische aantekeningen SINDS UW LAATSTE #EZOEK	S1P receptor modulatoren	Psycholoog		D Buikpijn/misselijk 送 Blozen
ge ge sultaten	Teriflunomide					Inwendige ge Geen resultaten	Teriflunomide			
									Voor zwangeren geschikt?	Nee
									Voor auto rijden geschikt?	Ja
					Opstaan		-			Opsiaan

	~-7	Dossier	Neurologie	Resultation	Consult	beoordening FC	onnuner
AT	Consult r 12 Juni	teurologie 2025 10:00	Start Al tra	nscriptie	Patient view		
A. N. Tonius	0.			1			
rw, 56 jr., 18-12-1963 MDN: 3432087	CO	risultvoorbereid	ing Be	enandelopties			
natie: Geen geg. opg.	÷	Terug				Keu	zekaart medicatie
: Geen Geen gegevena		Medicijnen	Fumaraat-esters	Glatirameer	Interferon-bèta	S1P receptor modulatoren	Teriflunomide
KUURBEZOEK		Hoe gebruik je het?	2x dag 🔗	***	機	1x dag 🔗	1x dag
		Waar moet je op letten?	Je laat 2,3 of 4 keer per jaar bloed prikken.		Je laat 2 keer per jaar bloed prikken.	Je laat 2 keer per jaar bloed prikken. In het begin vaker	Je laat 2 keer per jaar bloed prikken. In het begin vaker
		Voordelen	50% minder kans op MS-aanvallen	33% minder kans op MS-aanvallen	33% minder kans op MS-aanvallen	50% minder kans op MS-aanvallen	33% minder kans op MS-aanvallen
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iltaten				- natkioppingen	prikplek	Hoofdpijn of diarree	
		Voor zwangeren geschikt?	Nee	Ja	Ja	Nee	Nee
		Voor auto rijden geschikt?	Ja	Ja	Ja	Ja	Ja
		Markeon als ontin					

Consultationsummary wireframes

	Consultevaluatie ≡		
	Consult neurologie 12 Juni 2025 10:00		
	Symptomen: Heel erg		
	Zicht Ontlasting		
	Angsi Dila been		
	Stemmingswisselingen		
	Terug		
	Consultevaluatie		
	Consult neurologie 12. Juni 2025 10:00		
	Opmerkingen		
	Geen		
	Terug		
Consultevaluatie =	Consultevaluatie ≡	Consultevaluatie =	Consultevaluatie ≡
Consult neurologie	Consult neurologie	Consult neurologie	Consult neurologie
12 Juni 2025 10:00	12 Juni 2025 10:00	12 Juni 2025 10:00	12 Juni 2025 10:00
Consultvoorbereding →	Bespreckpunten	Medicatie	Consult samenvatting Spraw's see the bianrylik onderwerp sport of a writer. Dar spreadnas headt
	Spraak		voor up punette. De reutoloog meet uilgeleg dat alt een verveloorkonnend symptoom is bij MS. De arts stelt voor de revalidatie arts of specholoog te
	Sporten	Fumaraat-esters Fumaraat-esters	ezceken. Een vervidgatspraak met de MS verpleeglaundige is ingepland om de overige besprekepurten van de patient te bespreken.
Consult samenvetting $ ightarrow$	+ Verkoudheid	Doorverwijzingen	
Klik hier om eigen notities toe te	🛨 Energie		
voegen		Revalidatie arts Psycholoog	

Opstaan als PDF	Terug	lerug	Terug

APPENDIX J – GRAPHIC USER INTERFACES





Heeft u moeite gehad me dingen pakken en tillen, bijvoorbeeld tijdens het oppakken van uw tas, telefoon of kopje koffie?

NEE JA





Vergetower gewig Heat erg Conservent their atten Conservent their atten Conservent Con	regeneration (outer sequence) Sequence * Schalle *						
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U kunt nu kiezen wat u wit bespreken tjedens uw volgende consult Venter klachten aanpassen	Veter	New Inspiringunt	Hulproblem Hulproblem Warder Urader Orgedaan maken	U kunt nu uw owericht angassen voordat deze wordt winstaard Verder begreefspunten angassen	Typ her een toeksteing ef vezag	Interviewent Image: state s	 Stiphed Zicht Onvertiveten Tamatijk verd Diskland of sporken Manazona et anderatore Anpassen

symptomen overig

Heel erg
Ongewenst thuis zitten

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Zicht

Tamelijk veel

G Onwel voelen

≩i) Slikken of spreken

Bevestigen

symptomen overig

Suggesties

🔊 Schubs

00 Medicatie

Voeding

di Hulpmiddelen Bevestigen

G Kwaliteit van leven

Consultation GUI





Consultation summary GUI


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