Exploring Strategies to Enhance The Use of PROMs in Dutch Routine Clinical Practice

Integrating PROMs in Dutch Clinical Practice: Strategies for Effective Routine Use

by

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List of Abbreviations

ABCRC PROM Assessment of Burden of Colorectal Cancer Patient-Reported Outcome Measure.
AI Artificial Intelligence.
AIFI AI for Imaging.

EHR Electronic Health Record.
EORTC QLQ-C30 European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 30.
EPIS Exploration-Preparation-Implementation-Sustainment.

GDPR General Data Protection Regulation.

HCP Health Care Practitioner.
HRQoL Health-Related Quality of Life.

ICHOM International Consortium for Health Outcomes Measurement.

MVP Minimum Viable Product.

NKI Netherlands Cancer Institute – Antoni van Leeuwenhoek.

PREM Patient-Reported Experience Measure.
PROM Patient-Reported Outcome Measure.
PROs Patient-Reported Outcomes.

QALY Quality-Adjusted Life Year.

SROI Social Return on Investment.
STAR Symptom Tracking and Reporting system.

TDF Theoretical Domains Framework.

UAVG Uitvoeringswet Algemene Verordening Gegevensbescherming (Dutch GDPR implementation).

VBC Value-Based Care.
VBHC Value-Based Healthcare.

ZIN Zorginstituut Nederland (National Health Care Institute).

Chapter 1

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Chapter 2

Executive Summary

Patient-Reported Outcome Measures (PROMs) are standardised instruments that capture patients' self-reported health status, symptoms, and quality of life, making them central to value-based and patient-centred care (McClimans&Browne, 2012). In the Netherlands, national policy under the "UitkomstsgerichteZorg" program has established PROMs sets for key conditions and promoted their routine use in shared decision-making (Ministerie van Volksgezondheid, Welzijn en Sport, 2023). However, real-world adoption remains patchy: clinicians face workflow integration hurdles and time constraints, patients often lack feedback or clear incentives to participate, and economic justifications for PROMs investments are underdeveloped (van Engen, van Lint, et al., 2024; Huberts et al., 2024). Moreover, while patient organisations are formally involved in Dutch health governance, their potential to advocate for, educate about, and co-design PROMs initiatives has not been systematically harnessed (van de Bovenkamp et al., 2010).

This study addresses the central question: How can patient organisations effectively enhance the use of Patient-Reported Outcome Measures in Dutch clinical practice to maximise value for patients? Employing a mixed-methods design, it first conducts a targeted literature review to map barriers (e.g., digital literacy gaps, lack of workflow integration, General Data Protection Regulation (GDPR)-related consent complexities) and enablers (user-friendly ICT platforms, clear clinical responsibilities, actionable feedback loops) across micro, meso, and macro levels (Sawatzky etal., 2021; Oude Voshaar et al., 2023).

Next, semi-structured interviews with representatives from leading Dutch patient organisations will explore their perspectives on these factors and investigate co-creative strategies for PROMs implementation. Finally, a Social Return on Investment (SROI) analysis, using data from a Dutch academic cancer centre and national health statistics quantifies the projected social and economic impact of prioritised interventions (Social Value UK, 2012).

Preliminary findings suggest that patient organisations can play pivotal roles in (1) advocating for the tools that will remove barriers such as language barriers and low health literacy, and (2) advocating for the voice of patients when creating and implementing PROMs in clinical practice. Moreover, (3) facilitating workshops on the PROMs to increase engagement and expand knowledge, (4) leading public awareness campaigns and collaborating with other patient organisations to emphasise the personal and system-level benefits of PROMs. Furthermore, the SROI analysis indicates that hospital-level deployment yields a modest return of €0.20 for every euro invested. However, scaling up to the national level increases the return to €4.57 per euro. This further emphasises the need for widespread, coordinated efforts to realise the full potential of PROMs.

Keywords: Patient-Reported Outcome Measures, value-based healthcare, patient organisations, barriers and enablers, Social Return on Investment.

Chapter 3

Introduction

3.1 Context

3.1.1 Patient-Reported Outcome Measures (PROMs)

Patient-Reported Outcome Measures Patient-Reported Outcome Measure (PROM) are standardized questionnaires that allow patients to report on their health status, symptoms, and quality of life during treatments (McClimans & Browne, 2012). In the field of oncology PROMs can capture patients' perspectives on key outcomes such as pain, emotional well-being, and daily functioning. For instance, in the context of head and neck (HNC) cancer, PROMs effectively capture a wide range of physical and emotional metrics, including pain and discomfort in the oral region, depression and anxiety, fatigue, and sleep disturbances. Therefore, these measures are crucial to capture in value-based and patient-centered care, as they prioritize outcomes that matter most to patients (de Oliveira Faria et al., 2021). Research proves that when integrated at the beginning of routine clinical practice, PROMs can enhance patient–clinician communication, improve quality of life, and extend patient survival. Across three RCTs involving 1,289 cancer patients, integrating PROMs into routine care led to a 16% relative reduction in mortality (HR = 0.84; 95% CI 0.72–0.98; moderate certainty). The likely reason is that PROMs act as an early-warning system: patients regularly report symptoms, often before they become severe. Therefore, it provides clinicians with a clear, structured signal for quicker intervention. This proactive approach allows side effects to be managed in a timely manner. That then can prevent minor issues from escalating into treatment-limiting complications and ultimately helps patients maintain successful cancer therapy. (Balitsky et al., 2024).

3.1.2 Value-Based Healthcare

Recognizing this potential, healthcare systems all over the world —including the Netherlands—are increasingly working to incorporate PROMs standardized care which is an alignment with value-based healthcare principles. The Value- Based Care (VBC) model that was introduced in 2006 seeks to enhance patient outcomes while managing costs (Porter & Teisberg, 2006). This system rewards providers, hospitals and doctors, based on the quality and efficiency of the care provided rather than the amount of care provided. As shown in Figure 3.1 healthcare should be organized around patients' specific medical conditions, emphasizing the accurate measurement of outcomes that matter to them while monitoring related costs. Payment models should prioritize the value of care over the volume of services. It is essential to develop networks that provide the right care, in the right settings, by competent professionals. These elements must be backed by a unified information technology infrastructure. It promotes preventive medicine, effective management of chronic disease, and personalized, coordinated care plans. By focusing on improved health outcomes, value-based care attempts to improve patient satisfaction and lower overall healthcare spending. For these reasons, it aligns perfectly with the principles of PROMs. Thanks to data gathered through PROMs, healthcare providers can personalize treatments based on each patient's needs, supporting personalized care in line with the goals of value-based care. In addition, it can contribute to a better self-understanding and awareness of one's own care, symptoms and personalized care. Additionally, incorporating PROMs into VBC encourages ongoing improvement and the efficient use of healthcare resources to deliver outcomes that are matter most to patients (van Engen, Buljac-Samardzic, et al., 2024). However, implementing PROMs in real-world Dutch clinical settings has proven challenging. Hospitals and clinics face practical obstacles such as workflow integration difficulties, questionnaire burden to both clinicians and patients, and unclear processes for acting on PROMs data (Huberts et al., 2024). A recent study in a Dutch hospital emphasized that achieving high PROM response rates remains a "widely recognized and pressing challenge," with limited knowledge on how best to engage patients (van Engen, van Lint, et al., 2024). Even when patients complete PROMs, clinicians may struggle to use the data effectively due to time constraints or insufficient training.

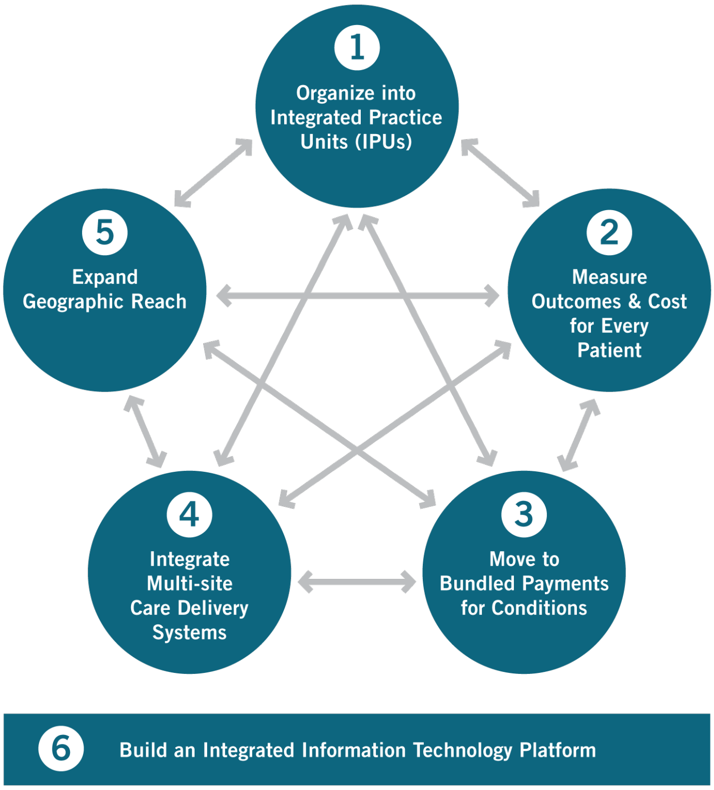


Figure 3.1: Conditions for Value-Based Care

3.1.3 Interventions to increase the use of PROMs

While multiple initiatives to implement Patient-Reported Outcome Measures (PROMs) have emerged in Dutch clinical care, their adoption remains inconsistent and has not yet become routine in many practices. To improve this, several types of interventions could be considered that would increase the use of PROMs in hospitals. These interventions include, for instance, strengthening and developing hospital policies that can guide their use by having official rules and plans to implement them in routine practice. Additionally, investing in education and training - both for patients and doctors - could help to reduce resistance to using these questionnaires. A closing example would be accelerating digitization - some of the sources say that an effective electronic system is the key to successful implementation of PROMs. (Stover et al., 2021). However, it's still unclear which types of interventions to support the better use of PROMs are seen as most relevant by patients. Given the importance of patient-centered care, incorporating patient perspectives is crucial to determine which strategies would be most effective and beneficial from their point of view and which of them could contribute to enhancing the Dutch healthcare system.

3.2 Problem statement

Both practical and research challenges contribute to the limited adoption of PROMs in Dutch healthcare. On a practical level, clinics face difficulties integrating PROMs into clinical workflows, encouraging consistent use among both patients and providers, and ensuring that PROM results meaningfully inform care decisions. For instance, clinicians often lack clear guidance on how to respond to PROM scores, and patients may not perceive any direct benefit, leading to lower engagement from their side (Cella et al., 2024).

From a research perspective, there is a lack of evidence-based strategies (interventions) for effective PROMs implementation, particularly in the Dutch context, and uncertainty about which of them would provide the most value for patients. Previous efforts have often focused on technology or clinician training in isolation, indicating mixed results. Additionally, the role of patient organizations in promoting PROMs adoption remains underexplored. Successful adoption requires continuous efforts to involve, inspire, and educate end users- which in this case are healthcare professionals and patients (Huberts et al., 2024). Therefore those organizations could help address patient engagement challenges, advocate for patient-centered implementation, and ensure that PROMs can reflect patient priorities.

3.3 Research objective

This study seeks to identify and evaluate effective intervention that patient organizations—can adopt to enhance the implementation and the use of PROMs within Dutch healthcare. Combining stakeholder perspectives with theory-driven analysis, the study will propose one targeted intervention and assess potential impact on patient outcomes and the overall value for patients using economic evaluation method. Ultimately, this research will deliver actionable recommendations to guide effective PROMs implementation into Dutch clinical practice.

3.4 Research question and sub-questions

Research question: How can patient organizations effectively enhance the use of Patient-Reported Outcome Measures in Dutch practice to maximize value for patients?

From the research question, the following sub-questions were defined.

- What are the primary barriers and facilitators influencing the implementation of PROMs in healthcare within the Netherlands?
- What do patient organizations in the Netherlands see as the primary barriers and facilitators influencing the implementation of patient-reported outcome measures (PROMs) in healthcare?
- How do the PROMs that generate the greatest value for patients align with the objectives of patient organizations?
- Which strategies can patient organizations prioritize to address the identified barriers and strengthen the use of PROMs in clinical practice?
- How can the impact and value of this patient organization-led strategy be assessed in practice?

Chapter 4

Background

4.1 Value-Based Care and PROMs

The Netherlands has adopted value-based care principles on a national level, with government policy clearly promoting outcomes-focused healthcare. Back in 2018, the Ministry of Health, Welfare and Sport rolled out a program called "Uitkomstsgerichte Zorg" ("Outcome-Oriented Care") (Ministerie van Volksgezondheid, Welzijn en Sport, 2023). The National Health Care Institute (Zorginstituut Nederland, Zorginstituut Nederland (National Health Care Institute) (ZIN)) was in charge of overseeing the program. From 2018-2022 the focus of the program was on developing the foundations of outcome-based care by creating PROM and Patient-Reported Experience Measure (PREM) sets for different conditions, designing tools and training to support shared decision-making and raising awareness among patients and professionals. As for the 2023-2026 the objective change slightly. It is no longer about the development part but more about the implementation in the routine practice. The Ministry of Health has outlined significant objectives to be achieved by this time that will cover systematic use of PROMs, PREMs, and clinical outcomes in shared decision-making, quality improvement, and healthcare purchasing. To support its goals, the plan outlines three strategic pathways, collectively referred to as the Spoorboek. The first focuses on promoting shared decision-making by training healthcare providers, increasing patient awareness, and providing institutions with practical resources—such as communication tools designed for individuals with limited health literacy. To ensure broad adoption across Dutch healthcare organizations by 2025, national roadshows and a centralized knowledge platform will be utilized. The second pathway targets condition-specific implementation, initially concentrating on four key health conditions: chronic kidney disease, knee and hip osteoarthritis, inflammatory bowel disease, and breast cancer. These were selected due to their varying levels of complexity and existing frameworks, offering valuable insights for wider implementation. Patient-reported outcome measures (PROMs) and decision points are integrated into care pathways, with national project teams supporting local customization of these initiatives. The third strategic line focuses on building the infrastructure needed for future scalability of outcome-based care, with a particular emphasis on ICT. This includes the nationwide standardization of data using ZIBs, the deployment of PROMIS (a general PROM system), and strong partnerships with EHR providers to enable seamless data collection, exchange, and reuse. As a whole, these three tracks aim to turn outcome-based care from concept into standard practice in everyday clinical settings.

One of the example of value based care in practice is the Santeon Samen Beter program (Santeon, 2024), where seven top clinical hospitals that together base their programs on Value-Based Health Care. Within improvement teams, medical professionals and caregivers define the patient group's characteristics, available treatments, and scorecard. In order to ensure that the patient's viewpoint is included, the scorecard is created in collaboration with them. This is important because patients provide important information about what results improve their quality of life the most.

Moreover, Dutch health insurers have actively supported Value-Based Care (VBC) by experimenting with new contracting models that reward high-quality outcomes. VBC is committed to providing comprehensive solutions, with bundled services as one of its pillars Figure 3.1. One of the Dutch insurer, Menzis, has implemented bundled payment contracts that incorporate outcome measures (EIT Health, 2020). Since 2017, Menzis has offered bundled payments for conditions like breast cancer, hip and knee replacements, cataract surgery, rheumatoid arthritis, heart failure, depression, and bariatric surgery in partnership with providers These contracts set a fixed price for the complete care cycle of a condition, adjusted for patient case-mix, and incorporate outcome requirements. Patient outcomes (including PROMs) are explicitly measured and used as part of the contract evaluation: for example, in Menzis' hip and knee replacement contracts, outcome indicators such as infection rates, revision surgery rates, and PROMs for patient-reported pain and function are tracked alongside costs

Grounded in the principles of value-based care, the Amsterdam PROM Implementation Strategy (Groenewegen et al., 2024) illustrates how PROM can be used to enhance healthcare by emphasizing outcomes that matter most to patients. VBC seeks to move away from a volume-driven approach, focusing instead on the effectiveness and quality of care provided. In this context, PROMs are essential for capturing health outcomes from the patient's viewpoint, allowing clinicians to personalize treatment, improve communication, and facilitate shared decision-making. For instance, the UK's National Health Service (NHS) has implemented PROMs in oncology services, enabling clinicians to tailor treatments based on patients' self-reported health statuses, thereby aligning care delivery with individual needs and improving overall outcomes. Similarly, in the United States, the Centers for Medicare Medicaid Services (CMS) have incorporated PROMs into their quality reporting programs, incentivizing providers to focus on outcomes that matter most to patients. Amsterdam University Medical Centers have systematically incorporated PROMs into everyday clinical workflows through a well-defined policy and process that guide teams from initial engagement to full integration within the electronic health record system. This approach ensures that patient-reported data not only inform one-on-one consultations but also drive broader quality improvement initiatives. By emphasizing the use of general PROMs and promoting active involvement from both clinicians and patients, the strategy embodies VBC's core aim of delivering customized, outcome-focused care that enhances value for both individuals and the health system.

4.2 Patient-Reported Outcome Measure Implementation

PROMs capture direct reports from patients about their health status during treatment. It is important to distinguish between two types of patient-reported measures: PROMs, which are the focus of this study, and PREMs (Patient-Reported Experience Measures). The key difference is that PROMs are often collected through repeated measures over time to capture health status, whereas PREMs assess patient experiences during the treatment (Zorginzicht, n.d.).

PROMs can also be categorized based on their purpose. Literature identifies two main types of PROMs (Oude Voshaar et al., 2023):

Generic PROMs, which apply to a broad patient population (e.g., PROMIS® Global02, TOPICS-SF, NRS Quality of Life). Condition-Specific PROMs, which are designed for specific patient groups (e.g., Oxford Knee Score, Oxford Hip Score). By systematically collecting PROMs, healthcare providers gain direct insights into patients' experiences and symptoms, even in cases where no visible signs are present. Research has shown that PROMs provide benefits for various stakeholder groups, supporting improved communication, informed decision-making, and enhanced care quality.

Unfortunately, patient-reported outcome measures (PROMs) are not widely utilized due to several barriers. These barriers include resource constraints, such as limited financial or human resources, which will be discussed in more detail later in this chapter. There are also technological limitations, such as insufficient technical facilities or poor integration with existing systems. A particular challenge is aligning the integration of PROMs with the General Data Protection Regulation (GDPR), mainly due to the complex administrative processes related to obtaining informed patient consent for data processing, which can be time-consuming.

To effectively integrate PROMs into clinical practice, it is essential to explore the factors that facilitate their implementation. One contributing factor may be management skills and the capacity to utilize data, as doctors may be hesitant to engage with these processes. Therefore, it is crucial to raise awareness

Patient (Martins et al., 2023)	Clinicians (McClimans & Browne, 2012)	Healthcare System
1. Enhance communication	1. Fewer ER visits	1. Better care planning
2. Overall satisfaction	2. Fewer hospitalizations	2. Better care delivery
3. Personalized care	3. Enhance treatment effectiveness	3. Better resource allocation
4. Better quality of care	3. Better quality of care	3. Better quality of care

Table 4.1: Benefits of PROMs for a selected group of stakeholders

about the value of PROMs to ensure that healthcare professionals prioritize their use (McClimans & Browne, 2012).

A successful example of PROM implementation can be seen in the My Wellness Check program at the University of Miami's Sylvester Comprehensive Cancer Center, which utilized the Exploration-Preparation-Implementation-Sustainment (EPIS) framework. Guided by EPIS, the team integrated a multilingual suite of eight computer-adaptive PROMIS® tests into the Epic electronic health record system for routine use in a high-volume gynecologic oncology clinic. Over 16 months, they achieved a 60% survey uptake (with a 70% completion rate once initiated), 85% of surveys completed through the patient portal from home, and clinician follow-up on automated alerts in over 77% of cases. These results demonstrate the feasibility and significant clinical adoption of the program.

For the implementation aspects, it is essential to gain a holistic understanding of the healthcare system and what makes it effective. According to (Sawatzky et al., 2021), effective healthcare delivery requires a multi-level approach with an alignment between all three levels. Each level For effective healthcare delivery, a holistic understanding of the system is crucial. According to (Sawatzky et al., 2021), a multi-level approach that aligns micro, meso, and macro levels is essential. Each level has distinct stakeholders, priorities, and decision-making processes, which help identify barriers and enablers for implementing new healthcare initiatives.

The micro-level focuses on direct interactions between patients and healthcare providers, emphasizing personalized care. The meso-level focuses on healthcare organizations and community systems, involving managers and department heads to support patient care. The macro-level encompasses health policy and governance influencing entire systems, with stakeholders like government officials making decisions on coverage and resources. Understanding these levels is crucial for addressing barriers and enablers in implementing healthcare initiatives.

The current use of PROMs highlights certain gaps that influence the selection of appropriate strategies. Successful strategies work to overcome these barriers, increasing the effectiveness of implementation. However, for long-term improvement, it is essential to align interventions with patients' perspectives to ensure they are relevant and acceptable. When interventions reflect patient preferences, they tend to increase engagement and the completion rate of PROMs, ultimately improving both the quality and quantity of data collected. As a result, patient-centered strategies for implementation could deliver a higher social return on investment (SROI) by directly contributing to better patient outcomes, improved quality of care, and more efficient use of healthcare resources.

4.3 Patient Organisation in Netherlands

Patient organizations play an increasing role in healthcare by advocating for patient needs, influencing policy, and collaborating on research and care improvements (Bensing, 2000). There are over 300 different organizations, about 200 of which are disease specific organizations. In the Netherlands, the healthcare system formally integrates patient organizations into various decision-making processes 4.2.

Patient organizations in the Netherlands receive part of their funding from the government, as claimed around 46% of their income. Membership fees contribute approximately 27% of their income, while donations from the pharmaceutical industry account for about 8% for some organizations (Van de Bovenkamp & Trappenburg, 2011).

Government funding for these organizations began in the 1980s and has increased significantly over time to strengthen their operations and reduce reliance on pharmaceutical companies. However, these subsidies come with requirements for accountability, which results in some government influence over how organizations manage their operations, set priorities, and pursue professional development.

In practice, Dutch patient associations help bridge information gaps by educating patients, representing their interests in policy discussions, and enhancing care quality from a patient-centered perspective. A key insight from Dutch experts is the need to better define "which subjects patients can and should contribute to, and in what way" to optimize their involvement. This study positions PROMs implementation as one such area where patient organizations could make a meaningful impact. By leveraging their close connection to patient communities, patient organizations could help adapt PROMs processes to patient needs, encourage participation, and advocate for system improvements that enhance the usefulness of PROMs in care. Therefore, it could indicate that when patient organizations are effectively engaged, they can act as catalysts for more patient-centered care delivery.

A key actor in this ecosystem is INVOLV, an independent Dutch foundation dedicated to advancing patient and public involvement across healthcare, welfare, and research. INVOLV provides tailored training and advisory services, such as the “Kickstarter for Researchers”, to support researchers in meaningfully embedding patient involvement throughout the research process. They also emphasize enhancing involvement by cultivating sustainable researcher–patient relationships, improving methods, increasing influence, and reaching underrepresented groups.

Through programs like these, INVOLV strengthens the capacity of patient organizations to serve as catalysts for patient-centered care and research. By facilitating structured and meaningful engagement, they help ensure that patient participation is not just a formality but a driver of better healthcare outcomes.

These organizations participate in guideline committees, hospital advisory boards, and insurance negotiations to ensure that the patient’s voice is represented. This Dutch model of patient participation offers significant opportunities for patient groups to contribute, leading to the institutionalization of their role (van de Bovenkamp et al., 2010).

Table 4.2: Key Areas of Participation and Influence of Dutch Patient Organizations

Domain	**Description**
Government Policymaking	Participation in ministries, parliament, and advisory bodies.
Health Research	Agenda setting, review of research proposals, involvement in research supervision.
Medical Guideline Development	Contribution to committees that create clinical care standards and protocols.
Quality Improvement Projects	Involvement in hospital-based quality initiatives, including training and feedback.
Insurance Negotiations	Negotiation of collective insurance contracts and input on health service purchasing.
Examples of Policy Influence	
Medication Distribution	Changes in drug policy driven by lobbying and media use (e.g., HIV, cancer).
Reimbursement Rules	Success in modifying insurer criteria (e.g., Per Saldo).
Quality Marks for Care	Development of criteria used by insurers in hospital negotiations.

However, the actual power of patient organizations remains limited, as their ability to influence decisions often depends on the goodwill of healthcare providers and insurers. In many cases, their participation is more symbolic than considerable which has more superficial function that is sometimes used by more powerful actors to justify predetermined decisions. Moreover their practical knowledge is officially recognised as important, it is often undervalued or not fully respected in practice (van de Bovenkamp et al., 2010).

4.4 Economic Evaluation

Economic evaluation in healthcare systems is a crucial component of the approach to innovation, as it helps decision-makers understand whether an intervention delivers sufficient value relative to its cost, ensuring that limited resources are allocated efficiently and equitably. Especially in the Netherlands, where insurers decide where to invest, evidence for a return on investment is particularly valuable (for Economic & Affairs, 2019). Among various evaluation methods, such as cost-benefit analysis, the Social Return on Investment (SROI) framework is particularly practical because it captures not only direct financial returns but also broader social, health, and patient-centred outcomes expressed in monetary terms (Social Value UK, 2012). Recent literature findings on the impact of PROMs shows that SROI can vary across treatment services and patient populations. For example, Crane et al. (2025) reported SROI ratios ranging from 5.55:1 in heart failure care to 0.85:1 in epilepsy services. These findings highlight the need to tailor Patient-Reported Outcomes Measurement (PROM) implementation to specific contexts and continuously optimize its design and delivery. Such evidence highlights not only the promise of PROMs as a means to improve patient care and system efficiency but also the extent to which economic evaluation ensures that investments deliver their intended impact and informs strategic reallocation of resources where value is low. Moreover, SROI allows stakeholders to quantify intangible benefits such as improved quality of life, patient satisfaction, and equity, which are often overlooked in traditional cost–benefit analyses. Applying SROI to PROM initiatives is especially appropriate, as PROMs are designed to capture the patient perspective on outcomes that matter most to them, such as functional status and emotional well-being, which may not immediately translate into cost savings but contribute meaningfully to overall healthcare value. By estimating the social and economic returns generated by investing in PROMs, SROI provides convincing evidence to policymakers, insurers, and providers that such investments are not only clinically justified but also economically prudent, helping to build a stronger case for their sustained implementation at scale.

4.5 Literature gap

A review of existing literature reveals two important gaps. First, while numerous studies have examined PROMs implementation barriers and facilitators such as technological challenges, clinician workload, and ambiguity around stakeholder roles, few have specifically addressed the role of patient organizations in this process. "Future studies would also benefit from more integrated stakeholder and patient and public involvement when developing and implementing PROMs in order to capture what is important to patients and healthcare providers" by Silveira Bianchim et al., 2023.Most implementation research has centered on healthcare providers or system-level interventions, with less focus on patient-led or patient-partnered initiatives. As a result, there is limited understanding of how organizations such as patient organizations can capitalize on their unique role to enhance PROM adoption—for instance, by leading patient education initiatives, collaborating on the design of PROM workflows, or ensuring that providers are held accountable for the use of PROM data. In doing so, it aligns with the call by van de Bovenkamp et al., 2010 to study more closely "which subjects patients can and should contribute to, and in what way". Secondly, there is ongoing discussion about whether routinely collecting PROMs provides enough value to justify continuing the practice. Researchers and healthcare authorities agree that there is currently a shortage of strong economic evaluations showing whether implementing PROMs in clinical settings is truly beneficial (Silveira Bianchim et al., 2023). Decision-makers want clearer proof that PROMs positively affect patient outcomes and healthcare quality before expanding their use. Therefore, examining interventions designed to increase PROM adoption can clarify if the intervention efforts lead to socially valuable outcomes and more value-based care (Crane et al., 2025). Value-driven care is recognized as a crucial component in creating a sustainable healthcare system in the Netherlands and all over the world (van Engen, Buljac-Samardzic, et al., 2024) . Evaluating the Social Return on Investment (SROI) of PROM interventions will help to close a critical evidence gap and could become more significant in promoting value-based healthcare. In order to assess the clinical impact of interventions as well as their effects on quality of life, participation, and autonomy, PROMs—which represent the outcomes that patients value most—are essential. Stakeholders can learn more about how patient-centered initiatives lead to broader societal benefits by assessing the SROI of PROMs. That way it will supports Integraal Zorgakkoord which puts value-driven care as one of the foundational pillars of future-proof healthcare. Moreover Integraal Zorgakkoord emphasis on "passende zorg" (appropriate care), which prioritizes efficacy, sustainability, and the patient experience which also encourages resource efficiency and avoids needless treatments (Ministry of Health & Sport, 2022).

Chapter 5

Methods

5.1 Research design

This study will use a mixed-methods research design, combining both quantitative and qualitative approaches. This methodology enables a comprehensive exploration of stakeholder perspectives, contextual factors, and processes related to the implementation of Patient-Reported Outcome Measures (PROMs). It aligns with a constructivist paradigm, recognizing that the experiences and beliefs of patients, clinicians, and members of the patient organization collectively shape the reality of the use of PROMs.

The qualitative case study design concentrates on the implementation of PROMs in the Netherlands and the role of various a patient organization, in this process. To strengthen the qualitative approach, concepts from implementation research were integrated. Specifically, the Theoretical Domains Framework (TDF) guided the development of interview protocols and the analytical process, ensuring a thorough examination of factors influencing implementation. The TDF functions as a comprehensive framework that supports the identification of behavior change determinants and the design of interventions (Atkins et al., 2017).

Beyond the qualitative components, the study will incorporate a quantitative action research element through Social Return on Investment (SROI) analysis. SROI is a framework for evaluating and quantifying the broader social, economic, and environmental impact of an intervention (Roberts et al., 2023). Insights derived from the interviews will guide the selection of an intervention aimed at increasing the use of PROMs in Dutch clinical practice, which will then be assessed using SROI analysis.

Table 5.1: Overview of the Research Approach

Sub-Question	Research Method	Data Collection	Data Tools
Literature Analysis			
SQ1 What are the primary barriers and facilitators influencing the implementation of PROMs in healthcare within the Netherlands?	Systematic literature review	Peer-reviewed articles, government/industry reports	Academic databases (PubMed, Scopus)
Qualitative Analysis			
SQ2: What do patient organizations in the Netherlands identify as primary barriers and facilitators influencing the implementation of patient-reported outcome measures (PROMs) in healthcare?	Qualitative interviews	Interviews with patient organization representatives	Qualitative coding tools (Excel, Atlas.Ti)
SQ3: How do PROMs generating the greatest value for patients align with patient organizations' objectives?	Qualitative interviews	Interviews with patient organization representatives	Qualitative coding tools (Excel, Atlas.Ti)
SQ4: Which interventions can patient organizations prioritize to address identified barriers and enhance the use of high-value PROMs in clinical practice?	Qualitative interviews	Interviews with patient organization representatives	Qualitative coding tools (Excel, Atlas.Ti)
Quantitative Analysis			
SQ5: How can the impact and value of patient organization-led interventions be quantitatively assessed in clinical practice?	Quantitative evaluation using SROI Analysis	Survey data and literature data	Excel

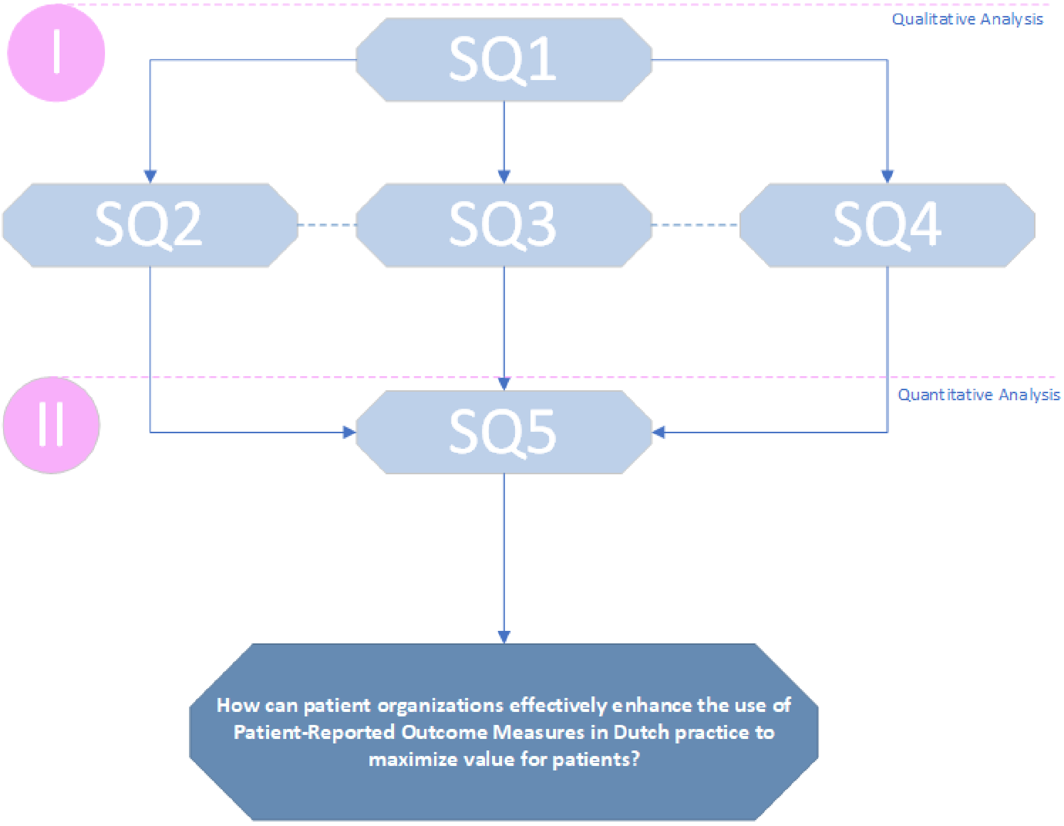


Figure 5.1: Research flow diagram.

5.2 Data collection

5.2.1 Search Strategy- Theoretical Background (MR, R3, R4, R5)

I have chosen a targeted literature review as my search strategy. A targeted literature review involves identifying and synthesizing literature that is directly relevant to specific aspects of the research topic, rather than attempting to capture all available studies in a broad or systematic way. This approach enables to focus on the publications most related to value-based care, PROMs implementation, patient organisations in the Netherlands, and economic evaluation methods. By concentrating on these core areas, the targeted literature review provides a thorough answer to one of main research questions, while also establishing a strong foundation for exploring the other research questions addressed later in the thesis.

5.2.2 Selecting Literature

The literature examined in this chapter was carefully chosen to provide a thorough and current overview of each core concept. Priority was given to peer-reviewed journal articles, systematic reviews, and key policy reports with a focus on the Dutch healthcare system, value-based care, the implementation of PROMs, patient organisations, and methods of economic evaluation in healthcare. Essential sources were identified through databases such as Scopus and PubMed using specific keywords, as well as by reviewing the reference lists of foundational studies. This method ensures that each subsection is supported by the most credible and relevant evidence available, forming a strong foundation for addressing the central research question.

5.2.2.1 Search Topics and Keywords

The keywords for literature serach in PubMed, Web of Science and Scopus.

Table 5.2: Scopus Search Strategy for Literature Review

Search Component	Details
Search Fields	**TITLE-ABS-KEY** (Title, Abstract, Keywords); **AFFIL** (Affiliation); **LIMIT-TO** (Limitation to) **PUBYEAR** (Publication year)
PROMs Terms	"Patient Reported Outcome Measures" OR proms OR eproms OR "patient-reported outcomes"
Implementation Terms	"implementation" OR "adoption" OR "integration"
Healthcare Context	"healthcare" OR "clinical practice" OR hospital OR "primary care" OR "clinical care"
Geographic Filter	"netherlands" OR "dutch"
Publication Year	> 2014 AND < 2026
Language Filter	"English"
Affiliation Country	"Netherlands"

Table 5.3: PubMed Search Strategy for Literature Review

Search Component	Details
Search Fields	Title/Abstract
PROMs Terms	"Patient Reported Outcome Measures"[Title/Abstract] OR PROMs[Title/Abstract] OR ePROMs[Title/Abstract] OR "patient-reported outcomes"[Title/Abstract]
Implementation Terms	implementation[Title/Abstract] OR adoption[Title/Abstract] OR integration[Title/Abstract]
Healthcare Context	healthcare[Title/Abstract] OR "clinical practice"[Title/Abstract] OR hospital[Title/Abstract] OR "primary care"[Title/Abstract] OR "clinical care"[Title/Abstract]
Geographic Filter	Netherlands[Title/Abstract] OR Dutch[Title/Abstract]
Publication Year	2015–2025
Language Filter	English

Table 5.4: Scopus Search Strategy for Literature on Patient Organisations and PROMs in the Netherlands

Search Component	Details
Patient Organisation Terms	"patient organization" OR "patient organisation" OR "patient association" OR "patient advocacy"
PROMs Terms	"patient reported outcome" OR "patient-reported outcome" OR PROM OR PROMs OR ePROM OR ePROMs
Geographic Terms	Netherlands OR Dutch OR Nederland
Combined Strategy	(*Patient Organisation Terms*) AND (*PROMs Terms*) AND (*Geographic Terms*)

Table 5.5: PubMed Search Strategy for Literature on Patient Organisations and PROMs in the Netherlands

Search Component	Details
Search Fields	Title/Abstract
Patient Organisation Terms	("patient organization"[Title/Abstract] OR "patient organisation"[Title/Abstract] OR "patient association"[Title/Abstract] OR "patient advocacy"[Title/Abstract])
PROMs Terms	("patient reported outcome"[Title/Abstract] OR "patient-reported outcome"[Title/Abstract] OR PROM[Title/Abstract] OR PROMs[Title/Abstract] OR ePROM[Title/Abstract] OR ePROMs[Title/Abstract])
Geographic Terms	(Netherlands[Title/Abstract] OR Dutch[Title/Abstract] OR Nederland[Title/Abstract])
Combined Strategy	(Patient Organisation Terms) AND (PROMs Terms) AND (Geographic Terms)

The inclusion criteria (Table 5.6) ensured that only English-language studies from the Netherlands, published between 2015 and 2025, and directly addressing PROMs implementation barriers or facilitators in healthcare settings were considered. Conversely, the exclusion criteria (Table 5.7) filtered out non-English or non-Dutch studies, works without an implementation focus or empirical evaluation, grey literature without peer review (unless specifically justified), and any duplicate or outdated publications. This rigorous screening framework guarantees that our review remains both geographically and thematically relevant while maintaining methodological robustness.

Table 5.6: Inclusion Criteria

Criterion	Description
Geographical scope	Studies conducted within the Netherlands.
Settings	Implementation of PROMs in healthcare settings.
Content focus	Discussion of barriers and/or facilitators.
Publication period	Published between 2015 and 2025.
Language	English.

Table 5.7: Exclusion Criteria

Criterion	Description
Language	Non-English publications.
Geographical scope	Studies conducted outside the Netherlands.
Implementation focus	Studies not addressing PROMs implementation.
Publication type	Non-peer-reviewed literature (unless specifically justified grey literature).
Study design	Editorials, opinion pieces, abstracts without full papers, and other non-empirical works.
Evaluation	Lack of assessment of PROMs implementation effectiveness or impact.
Duplicates	Duplicate publications.
Publication period	Published before 2015.
Content focus	Studies not discussing barriers or facilitators.

The literature review followed a four-stage screening process to ensure both relevance and rigor. In the Title stage, studies were rapidly excluded if their topics, populations, or focus areas did not align with PROMs implementation. During the Abstract screening, we confirmed that remaining articles addressed implementation of PROMs within the Dutch healthcare context. At the Introduction and Conclusion stage, we evaluated whether each paper offered conceptual insights, barriers, or facilitators pertinent to our research questions. Finally, the Full-Text review applied stringent methodological criteria—such as empirical robustness and depth of analysis—to select only those studies that could meaningfully inform our SROI framework.

Table 5.8: Screening Stages and Filtering Criteria During Literature Review

Stage	Action	Typical Criteria Used
Title	Quickly exclude irrelevant studies	Topic mismatch, wrong population, not about PROMs, etc.
Abstract	Assess fit with research scope	Implementation focus? PROMs context? Netherlands?
Introduction and Conclusion	Assess conceptual relevance and findings	Does it provide useful barriers/enablers, insights, or models?
Full Text	In-depth evaluation	Methodological quality, depth of analysis, empirical evidence, etc.

5.2.3 Interviews- RQ2, RQ3, RQ4

Using a purposive sampling strategy, there semi-structured interviews were conducted with representatives of patient organizations in the Netherlands and experts involved in PROMs implementation or advisory work related to patient organizations. This aspect of the research was essential, as it provided valuable insights from patient representatives, incorporating the much-needed patient perspective and informing the development of the strategy. Data were be collected cross-sectionally, with all interviews conducted within the span of two weeks.

5.2.4 RQ5

For the Social Return on Investment (SROI) analysis, data on PROMs completion and discussion rates were gathered from a Dutch cancer hospital, provided by one of the interview participants. A core step in the SROI process is engaging stakeholders to identify outcomes most relevant to the intervention. Following best practice, stakeholders (Expert 1, Expert 3, Org 1B) shared their perspectives on anticipated and experienced changes from the AI agent's implementation. These insights shaped the selection of both health and non-health outcomes, preceding the mapping outcomes stage where indicators and proxy values are assigned. The remaining data were obtained from public databases, such as (Integraal Kankercentrum Nederland (IKNL), 2025), as well as from literature and company websites, for example to estimate AI development costs.

5.3 Data analysis

5.3.1 RQ1

To analyze the data and provide foundation on the landscape of implementation of PROMs in clinical practice thematic analysis was conducted. This process helped identify and interpret key patterns and themes in this area of knowledge. The reserach question aimed to idnefied barriers and enablers in PROMs implemention, therfore an open coding approach was used, utilizing ATLAS.ti as the analytical tool to capture all insights from literature Each article out of 49 was carefully read to identify the main barriers and enablers with key details documented in a structured Excel table, including the country, study type, PROMs focus, identified barriers and enablers, involvement of patient organisations, and overall relevance to this research. This helped to ensure that findings were collected consistently and allowed for easy comparison across sources. As patterns began to emerge during the review of the literature, the next step was to refine a coding system that could consistently group similar types of barriers and enablers. This process began with manually reviewing and coding each entry in Excel. Initially, a set of predefined categories based on early reads of the literature and prior knowledge was applied to label each barrier and enabler identified in the studies. Once the full Excel table was populated and reviewed, the data was further analyzed using inductive approach ATLAS.ti to validate the codes, identify recurring patterns, and explore broader themes across studies. Barriers were categorized in themes that reflected , while enablers were categorized based on EPIS framework that guided the analysis of enablers to see when an enabler mattered most and where leverage points actually sit.

The combination of manual and software-assisted coding ensured consistency, depth, and traceability throughout the analysis. After iterating through each row and sketching the Barriers and Enablers codes, the code frequency table was reviewed to merge similar codes into more descriptive categories. After reducing the number of code, similar codes were grouped into larger clusters for a clearer understanding of the patterns occurring in this dataset. Lastly, a final check of assigned codes was concluded, and the codebook has been exported into a spreadsheet file. This two-step approach structured coding in Excel followed by thematic analysis in ATLAS.ti provided a strong foundation for answering one of the core research questions and informed the next stages of the thesis.

5.3.2 RQ2, RQ3, RQ4

The first step in the analysis was to review the full interview transcripts and organise the narrative responses into a structured table, guided by the Theoretical Domains Framework Theoretical Domains

Framework (TDF). This process made sure that all the questions and answers were in the right categories, which created a clear and organised set of data ready for the detailed thematic coding.

After the initial structuring of the interviews, the process of thematic analysis has began. Key concepts within each transcript were systematically coded against the Theoretical Domains Framework (TDF), with specific labels being assigned to identify and categorise various barriers and enablers. After the initial coding, it became clear that the first pass had produced a large number of granular and often overlapping codes. Therefore, a second iteration was necessary to refine the codebook and ensure consistency. To illustrate behavior change in a patient organization regarding the implementation of patient-reported outcome measures (PROMs) in the Netherlands, the researcher coded the responses from each interview according to various domains and assigned a score to each Table 5.9, Figure 7.2.

Score	Label
+2	strong facilitator
+1	moderate facilitator
0	neutral
–1	moderate barrier
–2	strong barrier

Table 5.9: Facilitator and Barrier Scoring Scale

This created a comparative 'heatmap' of challenges and strengths that provided a clear picture of the overall awareness, engagement, and understanding of PROMs implementation among patient organisations in the Netherlands. It also shed light on the specific barriers and facilitators these organisations perceive in the implementation of PROMs within Dutch clinical practice. By systematically coding and scoring each organisation's responses across the TDF domains, the analysis revealed specific strengths (facilitators) such as strong commitment to patient engagement, and uncertainties or hesitations (barriers) such as limited knowledge of PROMs data interpretation. Identifying these domain-specific facilitators and barriers is essential for understanding what enables or hinders PROMs implementation from the perspective of patient organisations, directly addressing RQ2.

Parallely, themes were derived for RQ3 and RQ4. For RQ3, we consolidated categories related to PROMs' value into broader themes—such as "Patient Voice"—and, at the same time, these themes were also identified independently across the data. For RQ4, we aggregated every interview code that implied a strategy, calculated their frequencies to reveal which approaches patient organizations might prioritize, and thus transformed our qualitative insights into a quantitative summary. This multi-stage process—moving from thematic interpretation to frequency analysis—provided the comprehensive evidence base needed to answer our core research questions.

To bridge the gap between the idea of PROMs and their practical implementation, the interviews revealed a clear path forward. Firstly, there is a shared agreement on what makes a PROM useful: it must be specific to a disease, consider the whole person by incorporating mental and social well-being, and be designed with direct patient input. To achieve this, the problem must be addressed from several angles: educating both patients and doctors, pushing for systemic changes such as improved IT systems, and developing the specific, high-value PROMs that patient communities require.

5.3.3 RQ5

For the Social Return on Investment Social Return on Investment (SROI) analysis, the author refers to established examples from the literature and apply the standard model commonly used to calculate SROI. The beginning of the analysis is with using the PICOT framework and aligns each element: population, intervention, comparison, outcome, and timeframe. It also presents specific figures, assumptions, and metrics employed in both the hospital-level pilot and the national rollout. Next, the author has used Excel calculation tool with the input from the template for SROI (Social Value UK, 2025) with input from the guide for SROI (Social Value UK, 2012). Furthermore the author has performed a two-tiered SROI analysis—first at the hospital level and then at the national level—by systematically identifying and costing all relevant implementation inputs, mapping key outcome domains (health-related quality of life, health literacy, and patient experience), and drawing on published evidence and expert estimates to assign monetary proxies for each benefit. We then applied standard SROI adjustments for deadweight, attribution, and benefit drop-off, projected net benefits over a multi-year horizon with discounting, and calculated the social return ratio by comparing discounted benefits to initial investment. Finally, we examined the robustness of our findings through one-at-a-time sensitivity testing and scenario comparisons, all while grounding our assumptions and parameter choices in the peer-reviewed literature and industry reports.

Chapter 6

Research Question 1

Barriers and Enablers to PROMs Implementation in the Netherlands

6.1 Results

A total of 276 sources were identified in Scopus, and 68 sources were found in PubMed, resulting in a total of 344 results that were uploaded to Covidence. After removing 59 sources, 285 remained for screening. The screening process focused on the titles and abstracts of these sources. Any source that clearly did not relate to the implementation of Patient-Reported Outcome Measures (PROMs) in Dutch healthcare was discarded.

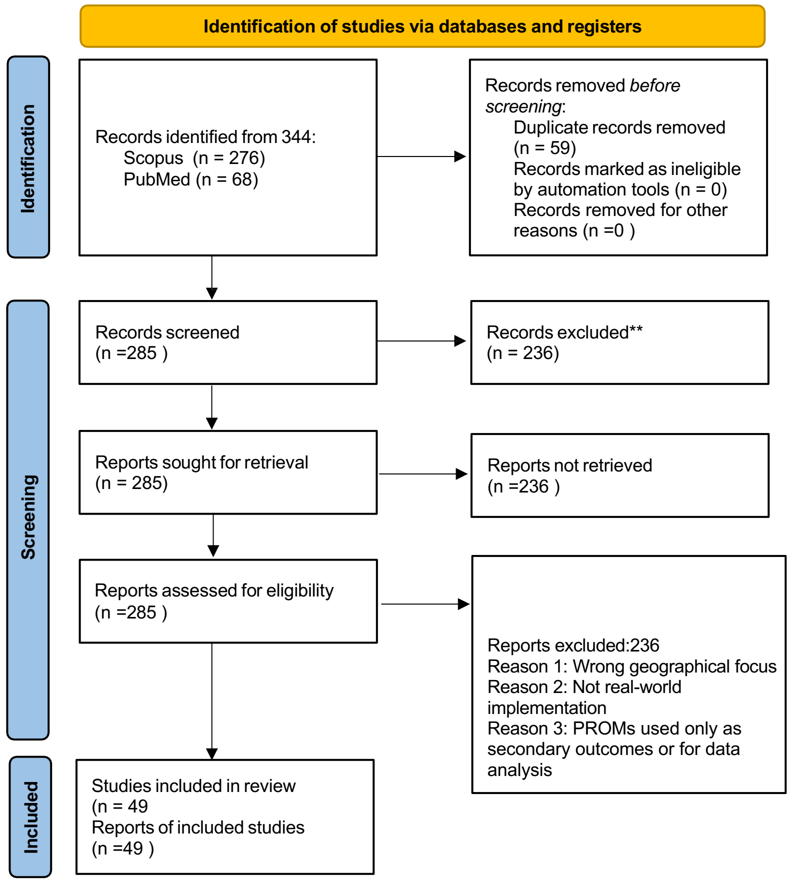
As a result, 231 sources were immediately removed because they did not address the real-world implementation of PROMs within the Dutch healthcare context. Following a thorough review of the titles and abstracts, entries that did not fit into the designated categories were grouped under "No." One of the reasons was that a significant number of studies were conducted outside of the Netherlands (e.g., in the UK, Belgium, Uganda, or Kenya), which resulted in their exclusion from the literature review. Other studies have centered on the development of instruments or the establishment of instruments, as an example, core outcome sets (COS), standardized collections such as International Consortium for Health Outcomes Measurement (ICHOM), or psychometric instruments rather than their use. Some sources have covered Delphi processes or consensus exercises that have not been implemented in clinical practice. Additionally, protocols, planning documents, reviews, and editorial pieces were excluded since they had no outcomes measured. Furthermore, clinical and feasibility studies were excluded if patient-reported outcome measures (PROMs) were used solely as secondary outcomes without a clearly defined implementation framework. Lastly, observational and registry studies were excluded if PROMs data were used only for analysis and not to evaluate their integration into clinical practice.

For more detailed analysis, there were 54 articles that passed to the second round of full-text literature review. After thorough analysis, only 49 of them were used to answer the first research sub-question Appendix B. The analysis of the review of the literature can be seen in the Figure 7.1

6.2 Findings

Patient-reported outcomes (PROs) were gradually implemented into the Dutch healthcare system between 2015 and 2025. In this chapter, I will provide a comprehensive overview of the relevant PROMs implementation processes. A total of 49 studies were conducted to identify the barriers and enablers experienced during the implementation process. The initial segment of the chapter outlines the various barriers and enablers that can be addressed at multi-level. The chapter provides examples of micro, meso, macro, levels to offer a visual representation of their appearance. The second part of the chapter discusses all the barriers and enablers that were identified during the literature review, indicating which ones are most significant and relevant.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

Source: Page MJ, et al. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

Figure 6.1: Literature Review

6.2.1 Explanation of the Levels

The micro-meso-macro framework draws from systems theory and organizational science, recognizing that healthcare systems operate as nested, interconnected levels where decisions and actions at one level influence and are influenced by other levels (Krawczyk et al., 2019) . This approach acknowledges that healthcare is not simply a collection of individual interactions but rather a complex system where patient care (micro), organizational processes (meso), and policy environments (macro) are linked together Table 6.1.

6.2.2 Micro Level

In the study by van Cranenburgh et al., 2016 researchers reflected the barriers at micro level by examining the day-to-day logistics of how, when, and by whom PROMs are used within a single care setting. The context of the study was set in academic, general hospital, and private practice settings. The evaluation process covered the assessment of the tool designed to assess HRQoL, treatment satisfaction, and disease severity. They have identified several obstacles that make it challenging to integrate PROM completion with standard practices. It was observed that PROM results were addressed in only a third of consultations. Therefore, a discussion gap was created, which had a limiting impact on the care. There are other issues that have come to light regarding the unclear responsibilities of the staff. The lack of clarity regarding who should inform patients, assist with login, and follow up on PROM results created workflow inefficiencies. It is important to note that only three out of six clinics agreed to participate, citing lack of time, personnel, or infrastructure as the reasons for their nonparticipation. This further illustrates a significant barrier, which is a resistance to the broader implementation of PROMs. As for enablers both patients and healthcare professionals agreed that completing Patient-Reported Outcome Measures (PROMs) at home helps reduce the burden on clinic staff. PROM results could be made available instantly, with options to print or save them for clinical use. The system interface was found to be user-friendly by both patients and clinicians, with patients experiencing minimal technical difficulties. Motivated patients were both willing and able to complete PROMs, achieving a completion rate above 95% and typically finishing in under five minutes.

Another study that emphasizes the microlevel process was by Thomassen et al., 2024 while describing the ABCRC-tool in colorectal cancer follow-up. One of the barriers was that some patients would have preferred more tailored or additional options in the questionnaire, which could decrease their engagement if their personal concerns are not fully addressed. When in comes to PROMs content Patients and HCPs sometimes found it difficult to initiate discussions on sensitive subjects (e.g., intimacy, sexual functioning). This unfamiliarity or discomfort can lead to important topics being overlooked in consultations. Consultations using the tool initially took longer, in part because time had to be spent explaining the tool. While this may decrease with experience, it can act as a barrier in busy clinics, potentially discouraging HCPs from using PROMs consistently. Patients who were further out from treatment and experiencing few symptoms saw little added value in using the PROM, reducing their motivation to engage with the tool. Patients felt more involved and “heard” because they were directly asked which topics they wanted to discuss. This increases patient activation and satisfaction. Patients appreciated receiving actionable advice, especially those with a higher burden of symptoms.

As for enablers both patients and Health Care Practitioner (HCP) found the Assessment of Burden of Colorectal Cancer Patient-Reported Outcome Measure (ABCRC PROM) easy to use, clear, and not time-consuming. The digital invite and interface were generally considered user-friendly, “The questions are relevant, yes, complete as well from the mental state to the physical state.”. Another enabler was that completing the PROM before consultations prompted patients to reflect on their health and prepare questions for their provider, adding structure and agency, Quote: “As preparation for the consultation, it makes me think about how things are going. What are questions I would like to ask the physician? So it, it adds structure and I appreciate that.” In addition, patients appreciated receiving actionable advice, especially those with a higher burden of symptoms, and patients felt more involved and ’heard’ because they were directly asked which topics they wanted to discuss which increases patient activation and satisfaction.

6.2.3 Meso Level

At the meso level, (de Jel et al., 2023) examined the use of patient-reported outcome measures (PROMs) in head and neck oncology at all 14 Dutch expert centers. The study involved aligning PROMs with interdisciplinary workflows, standards, and values across multiple providers. One objective highlighted in this study was improving patient and healthcare provider (HCP) participation by effectively aligning the goals and experiences of both stakeholders. The study partnered with the Head and Neck Cancer patient society, which included patients who were familiar with PROMs. One of the challenges highlighted was the absence of discussion concerning PROM results. Many patients indicated that a primary reason for not participating in PROMs, or for not seeing value in them, is the absence of feedback and a "call to action" based on their results. At the organisational (meso) level, a "call to action" is the workflow alarm that goes out when the average PROM scores drop below a certain level, indicating that quick follow-up is needed. This highlights the interconnection between micro and meso levels: when patients do not see their responses being acknowledged or leading to meaningful actions during consultations, their motivation tends to decline. The study revealed that only approximately two-thirds of healthcare professionals actively encourage patients to complete PROMs. This may often be due to a lack of clarity regarding how PROMs benefit their workflow or how they may really improve patient outcomes. Likewise, patients may be reluctant to complete PROMs because they do not perceive a clear benefit, particularly if past experiences demonstrated minimal to no influence on their care. This issue is influenced by how the organization prioritizes and supports PROMs, through training, meetings, and expectations, therefore barriers on this level appears. The value of PROMs to enablers was evident. Digital literacy has been identified as a key factor in enabling patients to adequately complete PROMs. Patients who have sufficient resources and computer skills have demonstrated a positive response. Furthermore, 50% of the participants indicated a preference for receiving the PROMs invitation prior to their consultation. Alerting patients to this change in advance, an adjustment that clinicians would need to build into their workflows, could increase patient engagement with PROMs and foster deeper dialogue during clinic visits. Moreover, to have successful PROMs integration, the technological and logistical infrastructure is still very important in the implementation process. It's worth noting that patients are generally willing to put more time into filling out questionnaires when they see that this effort improves care.

Another article that can represent implementation on the meso level is (Boomstra et al., 2025), which is focusing on patient and healthcare professional (HCP) experiences. As one of the barriers was when HCPs step upon non-resposne issues often found that patients had not completed PROMs, or were not included for follow-up, which demotivated them to check for the next patient. Quote: "Sometimes I do think to use the PROMs, but then when I open the dashboard, almost none of the patients completed them." (HCP 03). Discussing all indicated issues in PROMs was not feasible within the short consultation time. PROMs were often reviewed at the end, making them feel redundant. Quote: "You just have 10 min to discuss everything and then all those issues about quality of life, you just don't have the time."Some doctors did not feel equipped or saw it as their role to discuss HRQoL topics (e.g., fatigue, sexual functioning), expecting nurse practitioners to handle them. Quote: "I am more treatment-focused; ...the nurse practitioner can talk about the effect of the disease on someone's life."Digital and Health Literacy Barrier: Patients with low digital skills, language barriers, or low literacy had trouble accessing or understanding PROMs in the patient portal. Barrier: Patients often did not understand why they were asked to fill PROMs, sometimes thinking it was for research and not their care. Quote: "Honestly, I thought the questionnaires were for research." When HCPs did not refer to PROMs in the consultation, patients lost motivation to complete them in the future. Quote: "I have once completed those questionnaires, but then [during consultations] the doctor just asked me the same questions again. What is the point then to complete those questionnaires?"

As for enablers when PROMs dashboards were integrated into EHRs, access was easier, which supported review during consultations. Furthermore, meetings to clarify who should discuss PROMs at what time and with which patients fostered accountability and integration. Another enabler that was pointed out was hospital-based support infrastructure , such as help desks or tablets in waiting rooms. This helped patients complete PROMs if they struggled at home, provided clearer instructions about the purpose and value of PROMs.

6.2.4 Macro Level

(**voshaar2023**) examined implementation at the macro level. This study represents a national-scale implementation initiative of how the standard set of generic PROMs should be used and further developed by specialist care providers in the Netherlands. The study highlighted barriers such as existing PROMs that varied widely in content, timing, and format. This made it impossible to compare outcomes across studies. That led to hospitals, clinicians, and researchers held differing opinions about which PROMs were appropriate at the end. This led to tension during the consensus-building process. Some providers questioned whether standardized PROMs would actually improve quality or just add administrative burden. As for enablers, hospitals can use different patient feedback tools while still making sure their results can be compared. This is possible because multiple proven Patient-Reported Outcomes Patient-Reported Outcomes (PROs)measures can be linked to the same type of outcome, like Health-Related Quality of Life (HRQoL). The PROM-cycle is a structured method that helps hospitals select the most suitable tools by ensuring they are valid, practical, and comparable to other instruments. Eight national patient organizations voted on the most important patient-reported outcome (PRO) domains and participated in webinars and reviews. Interestingly, patients raised concerns about the readability and complexity of many PROMs. As a result, the Pharos readability test was applied to the candidate PROMs, and those that failed the literacy/accessibility criteria were excluded. Patient feedback emphasized the importance of selecting PROMs that are meaningful in real-life care conversations, not just for data collection or benchmarking.

Another article that covered macro level was (van Engen, Buljac-Samardzic, et al., 2024) which studied a decade-long process at Erasmus MC, a Dutch university hospital. One of the barriers pointed out was the transition towards Value-Based Health Care Value-Based Healthcare (VBHC), with PROMs at its core, that was found to be inherently complex and resistant to linear or uniform solutions. Standard change management models fell short in capturing this complexity. Dutch hospitals, including Erasmus MC, are traditionally organized in specialty-based silos, lacking integration around patient pathways. This fragmentation hindered the adoption of PROMs and VBHC principles. The lack of a centralized national Electronic Health Record (EHR) system, limited IT support, and insufficient integration of PROMs into existing hospital systems slowed progress. Volume-based reimbursement remained the norm, while VBHC (and PROMs) aimed for value-based models. This misalignment created conflicting incentives. Establishment of a Central Support Team (CST) and later, integrated IT teams, coordinated PROMs implementation and helped overcome departmental silos. Increased Executive Board involvement (e.g., requiring departments to report VBHC activities, acknowledging high performers) created stronger organizational expectations and accountability. National learning networks connected stakeholders across hospitals, facilitating exchange of knowledge, best practices, and joint problem-solving. At the macro level, PROMs implementation is shaped by national policy, organizational structures, IT and data infrastructure, leadership engagement, and cultural alignment. The most significant challenge is balancing deep, meaningful local change with scalable, system-wide adoption—requiring adaptive strategies, sustained investment, and integration into core policies and routines.

Table 6.1: Barriers and Enablers of PROMs Implementation Across System Levels

	Micro	**Meso**	**Macro**
Barriers	Low discussion rates; unclear responsibilities; time pressure; sensitive topics avoided.	Lack of follow-up; unclear roles; time constraints; digital/language gaps.	Fragmented PROMs; no national EHR; siloed systems; misaligned incentives.
Enablers	Easy tools; home completion; high motivation; structured consultations.	EHR integration; team clarity; support tools; early PROMs invitation.	PROM-cycle; patient input; readability checks; national coordination.

6.2.5 Analysis of Barriers and Enablers in PROMs Implementation

This section summarizes findings from 49 academic sources to reveal recurring patterns of challenges and facilitators for patient-reported outcome measures (PROMs) in healthcare. We identified key organizational, professional, and patient-level factors that prevent or further accelerate PROM adoption.

Rather than focusing on individual case studies, overarching trends were examined across diverse contexts and stakeholder perspectives. The goal is describe adoption barriers and highlight conditions for successful PROM integration. These insights pinpoint where interventions are most needed and which strategies offer the greatest promise.

6.2.6 Analysis of Barriers in PROMs Implementation

The literature reviewed highlights a range of barriers to the implementation of PROMs in Dutch clinical practice Figure 6.2. In the included studies, organizational barriers were discussed most often (28.2% of mentions), followed by IT & accessibility barriers (24.5%) and patients' barriers (21.9%). These three categories were thus the most frequently reported in the reviewed literature, suggesting that both systemic and user-facing challenges are prominently described as hindering PROMs implementation. Clinician-related barriers (15.7% of mentions) were also identified, focusing primarily on engagement issues (34.5%), limited eligibility or use cases (27.3%), and perceived burden (20%). While the frequency of these mentions in the literature cannot directly indicate their prevalence or significance in practice, these findings do reflect recurring themes and concerns raised in the research on PROMs implementation.

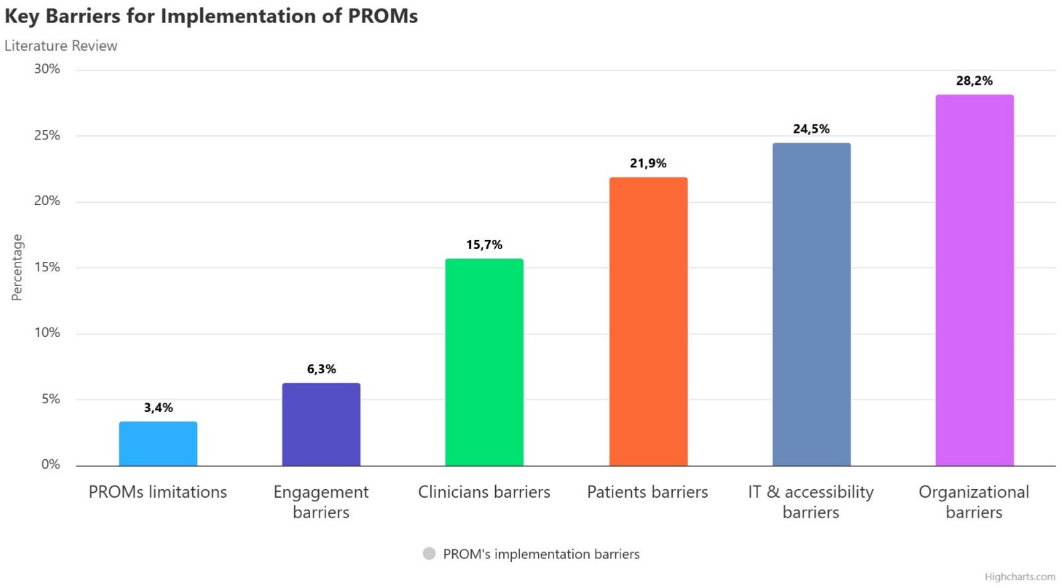


Figure 6.2: Key Barriers

6.2.6.1 Organisational barriers

Above all, the literature reviewed most frequently discusses challenges on the organisational side. Organisational barriers accounted for 28.2% of occurrences in the reviewed studies, underlining that stakeholder management and managerial support are central themes in research on PROMs implementation Figure6.3.

Time-related barriers and organisational issues were mentioned in 24.2% of cases, reflecting widespread concern in the literature about the potential increase in workload that implementing PROMs might entail. This aligns with reported perceptions that PROMs add time to consultations and that healthcare providers often lack dedicated time for interpreting and using PROM results effectively. Related to this, several studies noted that although PROMs are routinely collected, they are often not reviewed prior to patient consultations, undermining their potential to support shared decision-making.

A recurring issue identified in the reviewed literature is a lack of role clarity: for example, Boomstra et al., 2025 reported that it was often unclear who bore responsibility for discussing PROMs results, leaving the task unaddressed in practice. Workflow misalignment and staffing limitations also emerged as notable themes, reported in 16.2% and 11.1% of articles, respectively. The absence of dedicated personnel for reviewing results, integrating them into consultations, or maintaining PROMs workflows points to structural gaps that may hinder effective implementation.

Finally, the literature also describes lack of supportive policy as a barrier. As one study noted: "Although there were plans for incorporating PROMs into daily life, there was little support or system-level motivation to do so" (Veltkamp et al., 2022). This highlights how institutional and system-level priorities influence the extent to which PROMs are integrated into routine practice.

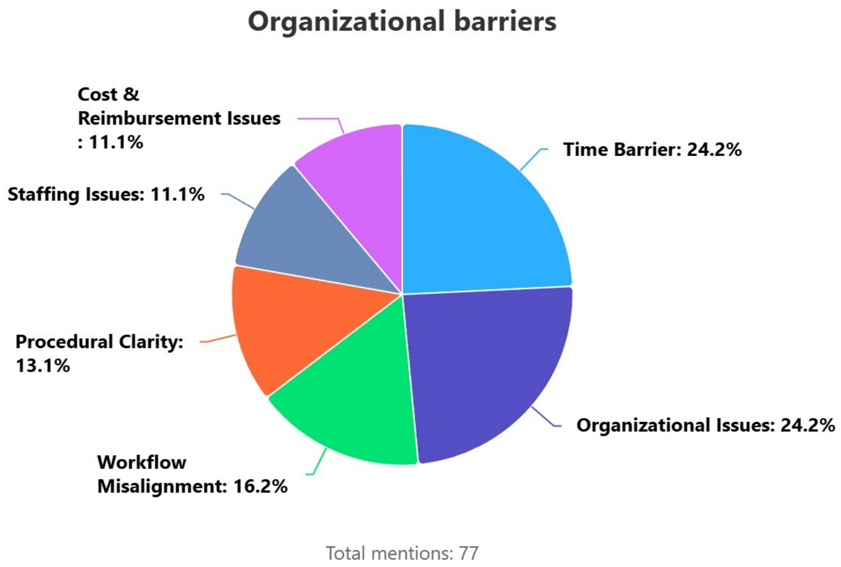


Figure 6.3: Organisational Barriers

6.2.6.2 IT and Accessibility Barriers

This identified theme is in line with other research that highlight how crucial a solid technology infrastructure is to the efficient application of PROM as illustrated in the pie chart Figure 6.4. Some of the issues were including EHR in technical issues with PROM extraction. The fact that these problems keep happening means that healthcare organizations should make it a priority to set up reliable IT systems and strong technical support before implementing PROM

The challenge of integrating these platforms with current EHR systems is a big reason why these systems haven't been widely adopted.

For instance, the KLIK portal demonstrates how inadequate integration with electronic health records (EHRs) can create additional operational burdens. Because KLIK requires clinicians to access a separate website to view the ePROfile, it adds extra steps to their workflow (Schepers et al., 2017). Many healthcare organisations still rely on outdated IT systems that are not compatible with data collection tools, which complicates the whole integration process. Importantly, interoperability is just one of several technical requirements: successful implementation also depends on user-friendly interfaces, data security and real-time access to data. To address these challenges, technical infrastructure should be carefully assessed before choosing PROMs platforms, ensuring potential integration issues are considered in advance. The findings highlight four main technical concerns reported in the literature: fragmented systems (de Jel et al., 2023), persistent bugs and lack of integration, slow technical support (van Engen, van Lint, et al., 2024), difficulties in extracting PROMs data, and problematic dashboards.

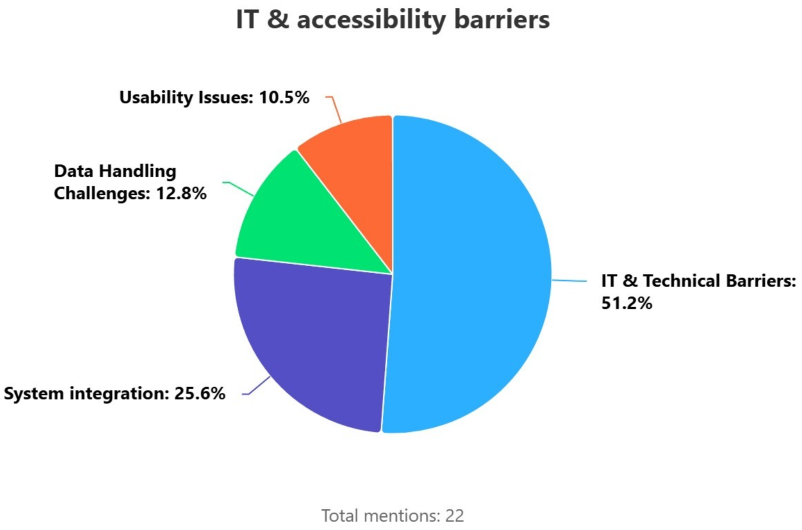


Figure 6.4: It and Accessibility Barriers

6.2.6.3 Clinician barriers

34,5% of clinician barriers are related to clinician engagement, showing that healthcare professionals still find it challenging to adopt PROMs completely Figure 6.5. One of the main reasons for this is that they have not received adequate training or support (Verburg et al., 2019). Without an understanding of how PROMs can help them in their daily work, some doctors either ignore them or complete them only because they are required to do so. For instance, clinicians said that using PROMs means more work because preparing before a consultation and discussing the results during the appointment takes extra time. Additionally, some aren't sure if PROMs help make better decisions, while others see them as just more paperwork.

These problems worsen when there isn't enough time, the PROMs system doesn't work well, or PROMs aren't part of the normal routine (Wiegel et al., 2023). Time pressure and technical issues make PROMs feel more like a burden than a useful tool. Training is another issue. Depla et al., 2023 In mentioned that training hasn't been part of the PROMs program since 2020. Moreover, it was pointed out that the training needs need to be more tailored to the needs of the professionals. All of this shows that, without the right support, it's difficult for clinicians to embrace using PROMs.

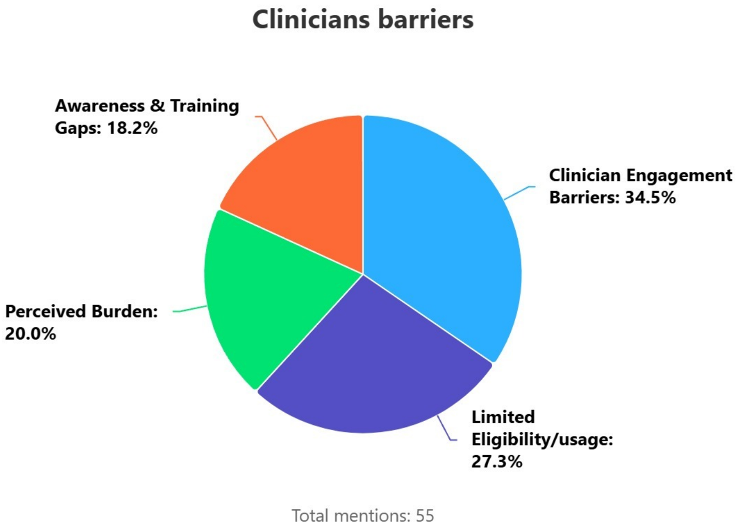


Figure 6.5: Clinician barrier

6.2.6.4 Patient barriers

This theme of barriers shows the substantial challenge that hinder patients from believing and using PROMs barrier in this group is lack of feedback, stated as 26% (Mourits et al., 2024), (van Egdom et al., 2019), (Hays & Quigley, 2025) Figure 6.6. Patients often fill out PROMs but receive no follow-up or explanation of how their responses are used. When patients don't see any results or changes based on their input, they may lose interest and motivation, feeling that their voices are not being heard or valued. Th reason for that could directly linked to lack of awareness and training gaps in clinical context that limits the understanding of PROMs and their added value in everyday clinical practice, combined with uncertainty about how to apply this data during consultations. On the top of that there is also time factor meaning that insufficient time to analyze PROM results, which stands for an organizational issue. This makes the tool meaningless and poorly used. Healthcare providers have to make sure tha when using and developing the workflow around PROMs the feedback loop should be included.

Digital skills and language barriers came up as second most mentioned barrier. Language was mentioned in 8 articles, which made it 6,5%. In a country as diverse as the Netherlands, this is a real concern. As of 2023, about 26% of the Dutch population had a migration background. The largest groups originated from Turkey, Morocco, and Suriname. This multicultural fabric is further enriched by the significant presence of EU nationals (Centraal Bureau voor de Statistiek, 2024). Three studies even excluded participants who were not fluent in Dutch (Schepers et al., 2017),(van Engen, van Lint, et al., 2024), (Boomstra et al., 2025). This highlights the need to provide translated versions of PROMs to ensure all patients can take part in the process.

Another frequently mentioned barrier is patient engagement, which includes patient indifference, meaning some patients lack motivation or don't see the need to complete PROMs. For example, some patients don't feel it's urgent or necessary because they already have regular, personal contact with their healthcare providers (Sipma et al., 2023). Another reason could be questionnaire fatigue. During interviews, patients showed little interest in filling out yet another questionnaire. Some studies also noted that while PROMs support patient-centered care, they don't always impact actual communication practices. This might explain why there weren't significant changes when comparing pre- and post-implementation scores.

Other barriers include the doubt in PROMs Value. Patients reported that the forms were too confusing, caused anxiety (Thomassen et al., 2024), or simply felt overwhelming. Some needed extra support to complete them (Thomassen et al., 2024). Others mentioned privacy concerns or lack of Internet access as reasons for not participating (Schepers et al., 2017). One said "It's unclear what happens with the answers: "can the government use them against me?" There were also comments about unclear tools, for instance, in (van Oers et al., 2021), patients said a better explanation of OncoQuest at the start of treatment would help, and Wiegel et al., 2023 mentioned that some said the email invitation wasn't motivating or appealing.

Moreover, many patients felt PROMs were irrelevant when their condition was stable (Boomstra et al., 2025). One said, "Filling out KLIK feels useless when things are going well," Others said they expected care discussions to focus on what could be done about their symptoms, not just how they felt (van Dalen et al., 2025). Some even preferred sharing feedback directly with their provider instead of through PROMs or PREMs (Teela et al., 2021), while others with more negative experiences found it easier to open up through the questionnaire.

The last barrier established is the "psychosocial" barrier. Both patients and healthcare providers often resist change due to emotional discomfort with unfamiliar systems. This discomfort may occur from a fear of losing control, uncertainty about added value, or a reluctance to shift away from familiar routines. Boomstra et al., 2025 mentioned that teleconsultations can be a barrier to discussing PROMs because, although they seem efficient, they can reduce the sense of personal connection and empathy in patient-provider interactions.

This can weaken trust and limit honest communication. Another psychosocial barrier is dropout due to fear of stigma or shame may occur when sensitive or taboo topics, such as mental health or sexuality, are addressed, preventing patients from fully engaging with PROMs. Additionally, negative prior healthcare experiences can leave a lasting emotional impression, which can lower a patient's motivation to participate or belief that their input will be taken seriously. Addressing these social and emotional dynamics is essential for building a safe and trusting environment in which PROMs can succeed.

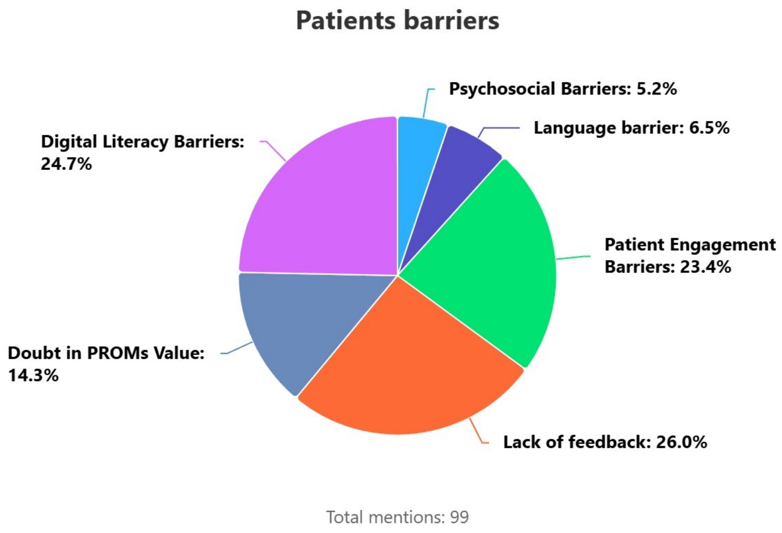


Figure 6.6: Patient barriers

6.2.6.5 Other

The other identified themes were PROM limitations, where the codes identified were inadequate PROMs, ranging from not fitting the content of the PROMs to the needs of the patient and limited treatment options that could be offered after the PROM discussion. Another theme was engagement barriers. Codes that were captured included low competition rates and engagement dropout due to lack of follow-up from the clinician side.

6.2.7 Analysis of Enablers in PROMs Implementation

6.2.7.1 EPIS Framework

This section outlines the enablers identified in the literature that can be applied at each step of the Exploration-Preparation-Implementation-Sustainment (EPIS) framework. Most of these enablers are particularly evident in step 3, which focuses on implementation, clinical use, and decision-making. This may further suggests that factors in this step should be further considered to ensure a successful overall implementation process Figure6.7.

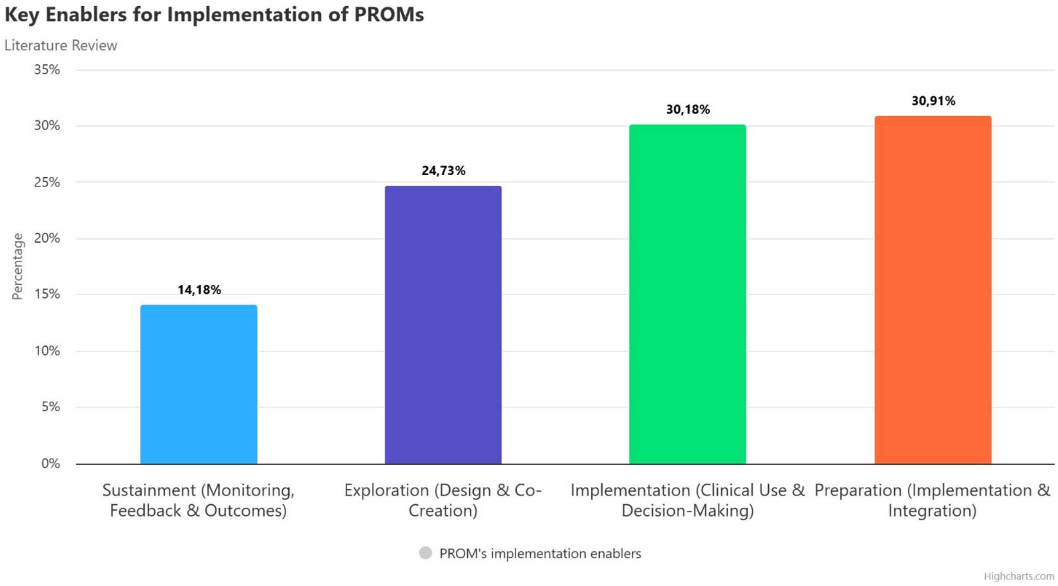


Figure 6.7: Key Enablers

6.2.7.2 Preparation (Implementation & Integration)

Preparation (30.91%) is the most frequently cited enabler. The pie chart shows that this stage depends on several identfied themes that can be interpreted as foundational elements such as a strong implementation strategy (20%), stakeholder engagement (16.5%), and robust IT infrastructure and training (each 15.3%) Figure 6.8. These factors suggest that effective planning, clear guidance, and buy-in from both technical and clinical stakeholders are critical to creating a solid foundation for PROMs integration.

One of the study's by Oude Voshaar et al., 2023 patient-reported outcome measures (PROMs) was directly integrated into the electronic health records. This allowed for automated distribution of questionnaires, which patients and parents could complete securely through a patient portal linked to the EHR. Therefore, healthcare providers could directly view the PROM results completed within the electronic health record. A colour-coded dashboard (green, orange, red) was built within the EHR to aid in the interpretation of scores (normal, slightly elevated, highly elevated), facilitating discussions with patients and parents while informing decisions about referrals to psychological healthcare.

Moreover, (Bennink et al., 2023) highlights the importance of training as an enabler and concludes that sustainable PROM implementation necessitates "multicomponent organisational strategies covering training and guidance". This is crucial because a primary barrier to implementation is limited PROMs awareness among clinicians and patients" and insufficient, skill levels of clinicians in interpreting and responding to PROM data. Therefore, developing training programmes or guidelines for clinicians in terms of the processing involved in PROMs collection and interpretation directly addresses these skill and knowledge deficits.

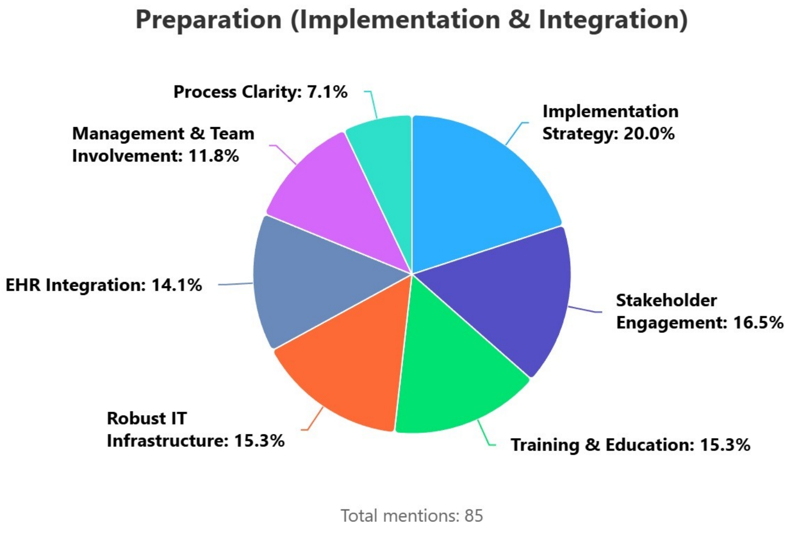


Figure 6.8: Preparation (Implementation & Integration
)

6.2.7.3 Implementation (Clinical Use & Decision-Making)

Implementation (30.18%) focuses on how PROMs are used in clinical decision-making. Its success hinges on professional and patient support (25.3%), clear visual reporting (26.5%), and wide adoption (12%) Figure 6.9. Additional factors like real-time alerts and improved communication reflect the operational enablers needed to turn PROM data into actionable insights during care.

First, strong management support and a clear vision for value-based healthcare are crucial (Thomassen et al., 2024). This top-down strategic alignment demonstrates organizational commitment and priority, providing the necessary mandate and resources for change. Second, active involvement from the entire care team, including care providers, patients, and key staff such as medical specialists and nurses, is crucial. Their participation, especially in selecting PROMs, ensures that the measures are clinically relevant. This fosters essential buy-in and ownership, which translates strategic goals into practical adoption and sustained use. Moreover van Egdom et al., 2019 emphaizess on champion per deparment which made it easier to spread the awarness and motivation on PROMs uptake. For the successful PROMs implementation requires more than just selecting the right measures, it demands alignment with patient needs, thoughtful planning for data collection and interpretation, and a clear path for integrating results into clinical decision-making (Hays & Quigley, 2025). Impact arises not only from the tools themselves, but from their meaningful integration into workflows that have purpose, structure, and relevance.

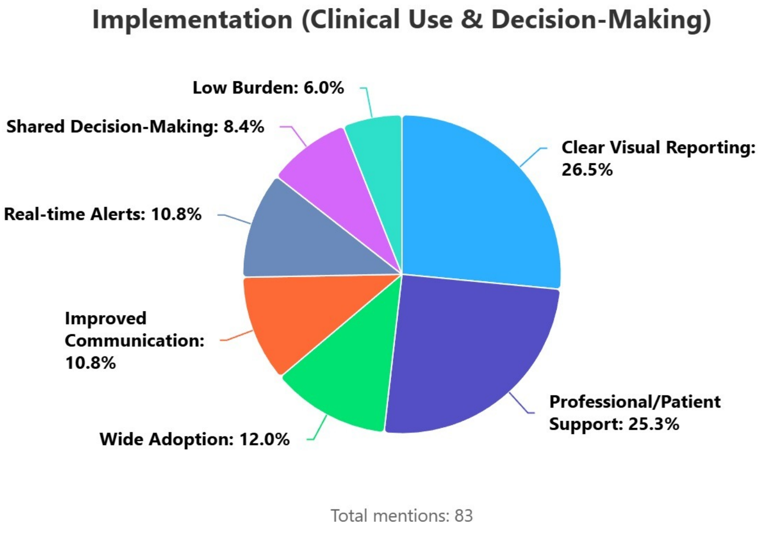


Figure 6.9: Implementation (Clinical Use & Decision-Making)

6.2.7.4 Exploration (Design & Co-Creation)

Exploration (24.73%) covers the theme of co-creation and design process. This phase emphasizes personalized care (27.9%), shared vision on patient care (17.6%), and patient preparation and perceived benefits, demonstrating that involving patients early in the design and making PROMs relevant to their individual care journey is key to long-term engagement and trust Figure 6.10.

The exploration phase should begin with meaningful co-creation, directly involving patients in identifying relevant outcomes and shaping the content of PROMs. Partnering with patient organizations can foster trust, provide practical support, and offer user-centered insights that can improve the design and initial implementation of these measures (de Wit et al., 2019)

The approach should assure an intuitive and straightforward use of PROMs. It is essential to provide clear visual feedback to reduce cognitive load for patients. Moreover clinicians must effectively communicate how PROMs will be used, aligning expectations to enable patients to prepare for more focused and collaborative consultations (Abma et al., 2019).

Furthermore, effective implementation Patient-Reported Outcome Measures (PROMs) indicates a collective commitment among healthcare professionals towards active patient involvement and shared decision-making in treatment. That already starts in the beginning of the process, in the exploration phase.

Enabler Shared Vision on Patient Care expands the scope of care beyond purely medical issues to include psychosocial aspects. Nurses emphasized this by stating it is "another way of gathering information to obtain different insights: " Not just medical, but also psychosocial" (van Muilekom et al., 2022). This alignment on how patients should be involved, what information is important, and how decisions should be made, fosters an environment where PROMs are seen not merely as a data collection tool but as an integral part of a holistic, patient-centered approach to care.

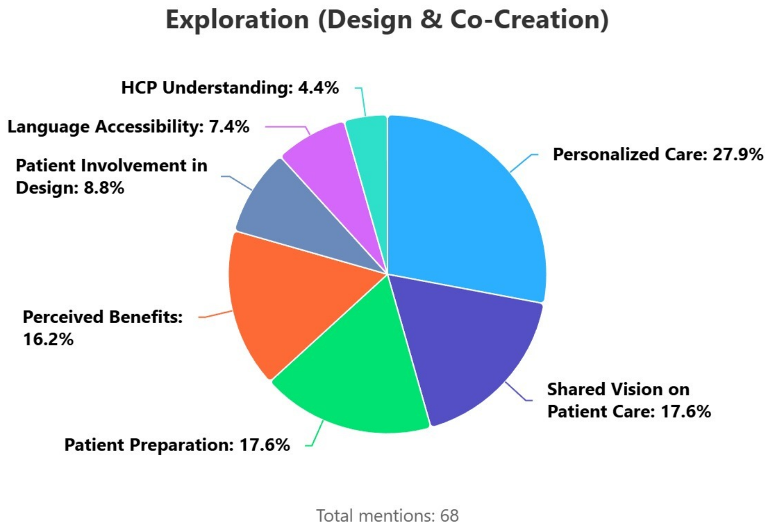


Figure 6.10: Exploration (Design & Co-Creation)

6.2.7.5 Sustainment (Monitoring, Feedback & Outcome)

Sustainment (14.18%), though cited less frequently, is essential for long-term value. It focuses on outcomes like patient satisfaction (30.8%), research/benchmarking support (30.8%), and data quality (20.5%) Figure 6.11. While sustainment ranks lowest in percentage, it is crucial for proving PROMs' ongoing relevance and effectiveness, encouraging continued investment and adaptation.

To ensure the continued use of PROMs over time it is important to highlight their real-world benefits in improving patient outcomes and the overall care experience. Studies show that PROMs are more likely to be adopted in the long term when they help manage symptoms, lead to earlier clinical interventions, and improve quality of life, which was evident in lung cancer care and post-treatment scenarios, where the study showed a 16% improvement in Health-Related Quality of Life (HRQoL) compared to usual care and highlighted how PROM (3). However, maintaining this effectiveness requires also access to reliable and high-quality data. To minimize administrative tasks and support timely clinical decisions, PROMs must be consistently collected, remain complete, and automatically integrated into electronic health records (3). Furthermore, patient satisfaction tends to remain high when patient feedback is valued, particularly when reviewed during appointments and used to guide treatment plans (Abma et al., 2019). Finally, sustaining the use of PROMs requires integrating them into daily healthcare routines with strong infrastructure, continuous feedback mechanisms, and collective recognition of their importance.

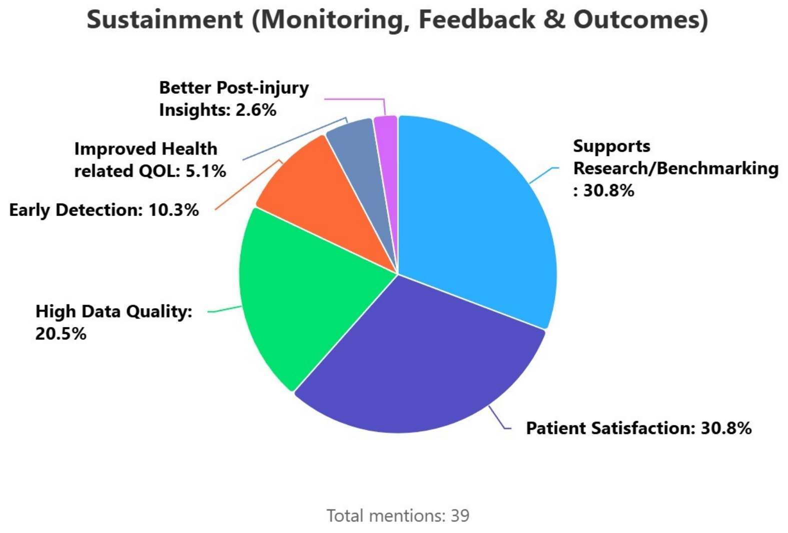


Figure 6.11: Sustainment (Monitoring, Feedback & Outcome)

Chapter 7

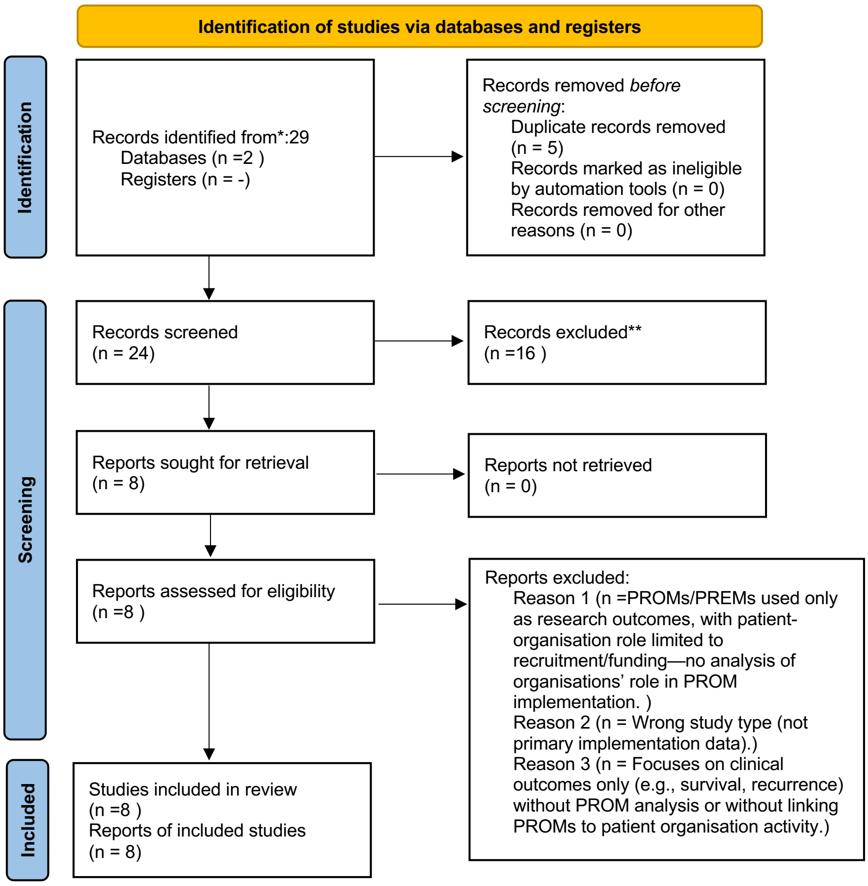
Research Question 2

Barriers and Enablers to PROMs Implementation in the Netherlands according to patient organisations

7.1 The current status of patient organisations and patient-reported outcome measures

A total of 24 sources were identified in Scopus, and 5 sources were found in PubMed that were duplicates from the Scopus search. The screening process focused on the titles and abstracts of these sources to assess their relevance to the research question. Any source that clearly did not relate to patient organisations and their connection to PROMs was excluded. This process resulted in the identification of 8 sources that met the inclusion criteria, as they explicitly addressed the involvement, role, or impact of patient organisations in the development, implementation, or use of PROMs. These 8 sources were retained for full-text analysis to extract detailed insights on current status, barriers, and facilitators. The list of those articles can be found in the Appendix B and in the Figure 7.1.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

Source: Page MJ, et al. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

Figure 7.1: Literature Review

7.1.1 Findings

Several studies highlight the important and varied ways in which patient organizations are involved in initiatives related to Patient-Reported Outcome Measures (PROMs). De Jel et al. (2023) conducted a survey involving Dutch patients with head and neck cancer and their clinicians. It was found that while both groups valued PROMs patients expressed a need for greater involvement in acting on the results, indicating a need for a more proactive approach. This underscores the crucial role of patient organizations in translating PROM feedback into actionable follow-up.

In a systematic review of melanoma clinical registries, (Blood et al., 2021) identified the Dutch Melanoma Registry. This can be served as an example where PROMs and Patient-Reported Experience Measures (PREMs) have improved transparency, audits, and research. However, they also noted challenges such as, for example, collection bias. Their findings state that the role of patient advocacy can be significant in promoting the inclusion of PROMs within creation of this kind of registries.

(Hays & Quigley, 2025) further highlight the benefits of structured involvement by patient organizations. Their research shows that patient and family advisory councils, as well as co-design processes in ambulatory care, can enhance the uptake and integration of PROMs into quality improvement efforts.

Collaboration between researchers and patient organisations is well illustrated by (Bootsma et al., 2024), who partnered with the Dutch Crohn's and Colitis patient organisation to identify patient-prioritised complaints related to perianal fistula. This partnership ensured that the resulting PROM content was directly aligned with the lived experiences and priorities of patients.

At the national level, (Oude Voshaar et al., 2023) showed how genuine collaboration can work in practice by co-creating a standard set of generic PROMs together with umbrella patient organisations, professional societies, and other key stakeholders. In addition, similarity (Hek et al., 2022) described the BRIMM infrastructure, which links EHR data with PRO for overactive bladder, developed hand in hand with a pelvic health patient association. Both examples highlight how patient organisations can play an active role not only in shaping the design of PROM tools, but also in making sure the feedback from these tools is meaningful and actionable.

The literature underscores that patient organisation engagement with PROMs is highly variable and often inconsistent. In the Netherlands, there are existing examples that patient organisations can possibly be in active participation in co-developing PROM instruments, setting outcome priorities, advising on implementation. For example, Crohn's and Colitis NL, the pelvic health group mentioned (Bootsma et al., 2024), and various umbrella patient organisations noted in (Oude Voshaar et al., 2023) show that, when included in structured processes, patient organisations can significantly influence PROM content, ensure it aligns with patient priorities, and support its integration into clinical practice.

However, there are significant gaps in the literature. Studies, such as (Lowry et al., 2024) demonstrate that many patient organisations, especially those outside well-established national quality frameworks, have low awareness of PROM tools, limited capacity for engagement, and are rarely consulted in policy or program design. Even in cases where PROMs are collected, patient organisations often have minimal influence on decision-making or feedback processes.

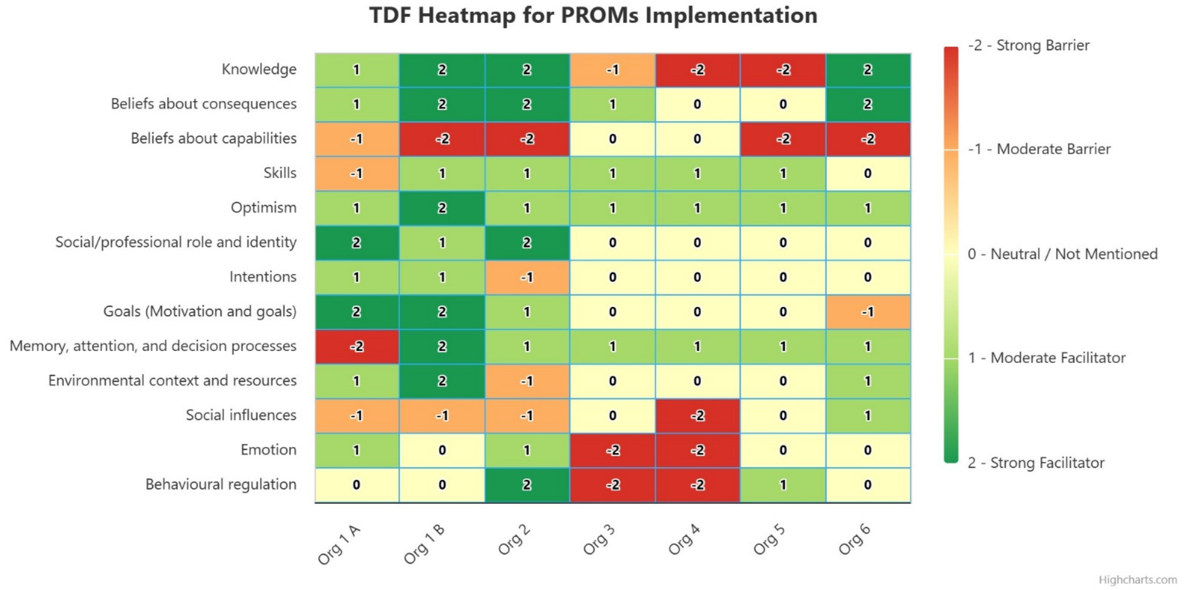
Overall, the current landscape is fragmented: there are pockets of strong collaboration, mainly in settings where patient organisations have formal structures for patient involvement, but in many contexts, patient organisations remain under-engaged in PROM initiatives. The literature consistently calls for more systematic inclusion, training, and capacity-building to enhance the role of patient organisations as partners in making PROMs truly patient-centred.

7.2 Theoretical Domains Framework

Using the Theoretical Domains Framework, author formulated questions across 13 domains to effectively address the research questions. These domains also revealed the actual knowledge and awareness levels related to patient organizations. This chapter presents an overview of eight interviews conducted with representatives from the patient organization and three experts, incorporating their perspectives that help establish barriers and enablers to PROMs implementation in Dutch clinical practice.

7.3 Results

This led to the completion of 11 interviews, which included three experts and eight representatives from different patient organizations. All interview transcripts can be found in Appendix D. To illustrate behavior change in a patient organization the researcher coded the responses from each interview according to various domains and assigned a score to each which resulted in Figure 7.2.



	Org 1 A	Org 1 B	Org 2	Org 3	Org 4	Org 5	Org 6
Knowledge	1	2	2	-1	-2	-2	2
Beliefs about consequences	1	2	2	1	0	0	2
Beliefs about capabilities	-1	-2	-2	0	0	-2	-2
Skills	-1	1	1	1	1	1	0
Optimism	1	2	1	1	1	1	1
Social/professional role and identity	2	1	2	0	0	0	0
Intentions	1	1	-1	0	0	0	0
Goals (Motivation and goals)	2	2	1	0	0	0	-1
Memory, attention, and decision processes	-2	2	1	1	1	1	1
Environmental context and resources	1	2	-1	0	0	0	1
Social influences	-1	-1	-1	0	-2	0	1
Emotion	1	0	1	-2	-2	0	0
Behavioural regulation	0	0	2	-2	-2	1	0

Figure 7.2: Heat Map

The interview was conducted with both larger and smaller patient organisations. From the heat map, it is visible that larger organisations can have both strong facilitators and substantial barriers. This is because it has PROM implementation in its guidelines, more resources, and experience with PROMs. Smaller organisations face those barriers at a moderate level, as well as facilitators. They also identified knowledge domains as substantial barriers, as some participants were unfamiliar with PROMs before the interview. One key learning from the interview process is that raising awareness can shift mindsets. This is evidenced by the more positive attention paid by all patient organizations to the PROMs implementation after the interviews were conducted with them.

7.3.1 Knowledge

Most of the organisations in the study show an increasingly thoughtful grasp of patient-reported outcome measures (PROMs), viewing them not merely as data-collection tools but as a way to align care with what truly matters to patients. One participant captured this shift neatly: “We conduct [PROMs] research because we want new knowledge and product development to be adjusted to the needs of patients.”

A handful of organisations demonstrate a particularly mature engagement with PROMs, grounded in both academic research and patient advocacy. One of the participants, who completed a PhD on PROM implementation at Amsterdam UMC, explained:

“I’m very, very familiar—my PhD focused on introducing PROMs into everyday clinical practice.” (D.8)

Within the organization of this participant, PROMs are routinely recommended on the basis of patient surveys. She cited a recent study on sexuality after cancer treatment:

“In interpreting the findings we suggest: use PROMs to find out if any problems are present.”

Although some organisations admit they still lack detailed knowledge, they are keen to explore PROMs further, even without a fully structured implementation plan. As one interviewee noted about colleagues’ day-to-day practice:

“They do use them, but I don’t think they would call them ‘PROMs’ (D.4)

Yet this enthusiasm is not always matched by organisational support. Asked directly whether their organisation backs PROM use, one respondent replied simply, “Do not support.” (D.9)

Another organisation emphasised that PROMs are only as valuable as the conversations they catalyse:

“I don’t regard PROMs as the Holy Grail, you still need a good, trustworthy conversation between clinician and patient. PROMs can help focus on what’s important for the patient.” (D.8)

Across all organisations, the common thread is clear: PROMs are valued not as ends in themselves, but as instruments to ensure that care, research and innovation remain centred on the lived experience and priorities of patients .Participants stressed that meaningful outcomes extend well beyond traditional clinical indicators such as seizure frequency or medication side-effects. PROMs draw attention to issues often overlooked—fatigue, depression, concentration difficulties, or social participation—that profoundly affect quality of life.

7.3.2 Beliefs about consequences

This domain revealed how patient organisations in the Netherlands perceive the benefits and consequences of implementing Patient-Reported Outcome Measures (PROMs) in clinical practice. Drawing on their experiences and perspectives, the organisations highlighted the potential of PROMs to make care more patient-centred, foster shared decision-making, and provide concrete evidence of what truly matters to patients. At the same time, they emphasised the importance of how PROM results are used and communicated during consultations, to ensure they genuinely support patients’ preferences and autonomy.

One participant noted that “you can really design the therapy towards the needs of the patients,” highlighting PROMs as a tool to personalise care and ensure treatment aligns with patient priorities.

Similarly, (D.8) observed that “it can help focus on what’s important for the patient,” underscoring the role of PROMs in centring discussions on what truly matters to individuals during care planning.

Another participant added nuance by stressing that how PROM results are used in consultations is equally important: “So it’s also very important how the results of the PROMs are fed back in the consultation and of course also ask the patient if they want to discuss it, because not every patient wants to discuss everything with their doctor.” This underscores the need to respect patient preferences and autonomy when integrating PROMs into clinical encounters.

Org 5 (D.9) reflected more critically on current practice, stating, “We have a good healthcare but professionals think what’s good for patients and it’s time patients have to think more.” This points to a perceived paternalism in care and the potential of PROMs to empower patients and shift the dynamic toward shared decision-making.

Finally, Org 1A highlighted the evidentiary value of PROMs, explaining: “So once we have a list of PROMs, we know what’s important to the patients. So I think it’s very easy for doctors to think they know what patients want or what they need. But once we have a PROM set that actually proves what the patients really want.” This emphasises that PROMs can challenge assumptions and provide concrete evidence of patient priorities to guide care.

7.3.3 Beliefs about capabilities

Despite the enthusiasm many organisations express for PROMs, they also acknowledge a practical stumbling block: patients (and clinicians) quickly lose faith if the questionnaires seem like an extra chore with no obvious pay-off. As one interviewee warned:

“If patients feel they spent time filling it in and the doctor never mentions it, they’ll stop doing it.” (D.2)

“I think we should. . . see if it’s really helpful for our patients. Otherwise, we’re not looking for more work.” (D.4)

To prevent that drop-off, the (D.2) now campaigns for tighter integration of PROM data into the care pathway—embedding it in shared-decision-making conversations and in professional training—so both patients and caregivers experience its value.

From the interviews, it can be seen that cost and time is heavy obstacles to PROMs implementation.

"If you want to make it part of daily care. . . it's going to be more expensive," one respondent conceded, noting that staff time and IT upgrades rarely come free. (D.8)

Moreover, the substantial barrier is also fragmented technology:

"The biggest barrier is implementing it in our systems," they said, pointing out that PROM data often sits in a separate portal instead of the electronic health record (EHR). (D.3)

"A huge barrier when I was in the prom research was that every hospital had their own system... It has to be all in the same." (D.8)

Another organisation made the same point more bluntly:

"No matter how well-designed PROMs are, if the care system is complex, it's hard to use them successfully." (D.7)

Moreover, they believe they have the power to shape policies that will advance the use of PROMs. Org 1 (D.5) actively collaborates with research institutions to identify the most relevant PROMs for people with the disease they are advocating for, aiming to bring these into consultations and healthcare evaluations. They view their role as "shouting the message," advocating for better patient-centred data in clinical care:

"What we need is to inform patients that their information and their stories are of importance to get the right PROMs, but also to get the right care," (D.7)

They think that patient organisations can can help in advancing PROM uses in Netherlands,

And the one way to do it is by co-creation.

"Always do this together with patient organisations." (D.8)

Ultimately, they advocate for structural investment in implementation:

"While their outlook is cautious, they remain committed to "keep on doing what we are doing"—repeating the message wherever possible and pushing PROMs into the spotlight. (D.8)

Another organisation stresses the step-by-step approach, where being visible and present at key decision-making tables is the first move. "Being visible is, I think, the first step. The next step is to be at the table and discuss this kind of topic," they explained. (D.6)

7.3.4 Skills

In the interviews, several participants highlighted the critical skills and competencies needed to effectively implement PROMs in clinical practice and to support patients in using them meaningfully. One key insight was that systematically uncovering what patients need, value, and worry about demonstrates that providers and organisations truly listen to and care about their communities. This requires expertise in structured needs assessment, ensuring that patients' concerns are captured comprehensively and translated into actionable insights.

Qualitative research skills were also seen as indispensable: knowing how to collect meaningful patient input, analyse it, and facilitate discussions based on the findings is a core competency for anyone working with PROMs. As one participant summarised, "You need somebody dedicated to implement it in the hospital. . . slowly teach the clinicians and nurses," underlining the need for a dedicated role and strong communication and training abilities to support staff.

Org 4 (D.4)further reinforced this point, stating, "Well, good. A good education for medical persons. And good implementation in the hospital," highlighting the dual need for both education and organisational readiness to make PROMs work in practice.

Finally, one expert reflected on the role of patient organisations in building patient skills, explaining, “If patient organisations are going to educate patients, then I think what patients need is to understand how to interpret their scores and how to start a discussion with the physician.” This underscores that empowering patients with interpretive skills and communication confidence is just as important as training clinicians, making PROMs a shared endeavour between both sides of the consultation.

7.3.5 Optimism

Across the interviews, there was a clear sense of enthusiasm for PROMs—rooted above all in their ability to amplify the patient’s voice in healthcare. As one participant put it, “It’s important to focus on the opinions of patients and their relatives... It’s time patients have more say” (D.4).

This optimism was echoed in different ways by others. Org 1A described PROMs as “a necessity,” noting that an ageing population makes patient-centred metrics indispensable for sustainable care. Another organisation expressed a “mildly positive” view, seeing clear promise while remaining mindful of practical challenges. (D.6) offered an equally hopeful perspective: “We’re optimistic; PROMs will help us—and, ultimately, the people we care for.”

Together, these reflections paint a consistent picture: while levels of confidence vary, there is strong agreement that integrating patient-reported outcomes is a crucial step toward delivering better, more responsive care.

7.3.6 Social/professional role and identity

Organisational support for PROMs varies widely across the landscape. Leading the way are Org 6 (D.8) and Org 2 (D.2), both of which have already established formal guidelines and demonstrated a strong commitment as advocates. Close behind is Org 1, which is actively collaborating with research institutions to identify, select, and pilot the most relevant PROMs for its patient population.

By contrast, several other organisations have yet to formalise their approach to PROMs—but they express a clear willingness to change. As Org 4 described, their organisation sees a simple yet impactful starting point: “We could launch a social media campaign, post real-life examples on our website, and ask, ‘What did you like? What could be improved?’ and keep that feedback loop open.”

In essence, while some organisations have already moved from interest to concrete action, others remain in the early stages, focused on raising awareness, engaging patients, and building momentum as a foundation for future support.

7.3.7 Intentions

Most organisations agreed that healthcare providers genuinely want to incorporate PROMs into routine practice. However, they also stressed that how well this happens largely depends on how the organisation itself is structured and resourced.

As one interviewee noted, “I think the big ones do see this and put effort into it,” (D.7)

This view contrasts them with smaller organisations that often struggle to prioritise PROMs due to limited capacity:“...smaller patient organisations... they have limited time, so perhaps they don’t emphasise it that much.” (D.7) Another participant highlighted the unevenness across the field, observing simply: “It differs so much. There’s such a big variety. Some do, some don’t.” (D.2)

This reflects a broader challenge: while the intention to use PROMs is widespread, the ability to follow through varies significantly depending on size, resources, and organisational focus.

7.3.8 Goal and Motivation

When asked which aims matter most for PROMs (see Chapter RQ3 for a full breakdown), participants consistently identified three priorities: aligning care with what patients truly value, making outcomes more visible to drive quality improvement, and strengthening the patient’s voice in decision-making.

At the same time, interviewees stressed the need for PROMs to become simpler and more inclusive. As Org 6 (D.8) pointed out, “Use one language level—short, plain questions that everyone in the Netherlands can understand. Language is still a barrier; we’re not reaching everyone we should.”

Participants also noted that PROMs need to evolve to better reflect real-life concerns often overlooked by standard instruments. Org 6 highlighted gaps in generic questionnaires: “The standard European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire – Core 30 (EORTC QLQ-C30) form has no items on sexuality or on how you’re managing day-to-day social life.” Keeping these issues visible and part of routine care, they argued, requires persistent advocacy: “It doesn’t help when you only mention it once. When people are trained to be a doctor, it should be part of the system.”

Org 4 (D.4) underscored the value of structure that PROMs bring to healthcare: “It is nice to have a common structure. You cannot compare when there is no standardisation.” However, they also cautioned against reducing PROMs to a checklist, noting the importance of pairing quantitative scores with qualitative insights: “Listen to the things which are not explicitly said. . . What is behind this? Is this the real problem?”

This emotional and psychosocial dimension, they added, is especially crucial in the context of rare diseases, where standardised PROMs often fall short: “The general PROM is nice, but it might not apply to [specific disease]. . . You deal with fairly different issues.” Together, these reflections illustrate the nuanced expectations that patient organisations have for PROMs—valuing their structure and standardisation, but also urging adaptation and depth to truly capture what matters most to patients.

7.3.9 Memory, attention, and decision processes

Opinions varied when the conversation turned to whether patient organisations should actively remind patients to complete their PROMs. Most organisations felt that issuing direct reminders falls outside their mandate, as each patient follows a personal care journey. Instead, they see their primary role as advisers and educators, raising awareness of why PROMs matter through website articles, social media posts, and workshop discussions.

As one participant suggested, “Maybe we can simply highlight how important it is—not just for you, but for fellow patients too” (D.4). Another participant from Org 4 agreed, noting that gentle nudges through online channels “can definitely happen.” Similarly, Org 6 reflected on a more indirect approach, adding, “Maybe not directly reminding them, but indeed, explaining why it could help.”

Together, these perspectives suggest that patient organisations are willing to support PROM completion through awareness and education, while respecting patients’ autonomy and individual care paths.

7.3.10 Environmental context and resources

Organisations recognised that collecting and acting on PROMs* can be labour-intensive, yet many also felt that smart use of technology could lower the burden and even add value. A case in point is the Federation’s experiment with short animated explainer videos, which introduce PROMs to patients in an engaging, low-cost format.

Technologically, the Org 2 (D.2)is likewise exploring more sophisticated data dashboards. While they stress that “technology should never become a hurdle, you can always work from a simple list,” they also acknowledge that clear visualisations make PROM results easier for clinicians and patients to interpret. Looking ahead, particpant from (D.5) sees great potential in technology, particularly Large Language Models (LLMs), to transform how PROMs are developed and use. They believe that AI can bridge the gap between narrative patient experiences and structured clinical data. “Artificial intelligence, large language modelling helps us to structure unstructured data,” the participant noted, adding that these tools could soon enable clinicians to understand patient needs and tailor consultations better accordingly. In their view, combining advanced AI tools with improved patient understanding and engagement can drive the sustainable and meaningful integration of PROMs into routine care.

They therefore see a key role for patient organisations in co-designing these tools, ensuring that the features highlighted—well-designed dashboards (Org 2), condition-specific score indicators (Leon Danique), or voice-assisted completion aids (D.8)—match what truly matters to patients.

7.3.11 Social influences

Interviewees agreed that credible ambassadors, enthusiastic doctors or nurses, can create a gentle but effective form of peer pressure. As one participant put it, “When colleagues see them using PROMs, they start thinking, ‘Maybe we should use them too.’” (D.8)

Looking ahead, many organisations see untapped potential in digital channels to reinforce that social influence. AI-powered chatbots, targeted social-media campaigns and even simple feedback forms or website banners could keep PROM-thinking “top of mind,” as Org 4 explained: “Awareness is something we deal with all the time.” By weaving these micro-nudges into everyday workflows, organisations hope to normalise PROMs without adding extra burden.

Yet several respondents admitted they had not considered how professional norms or peer expectations shape attitudes toward PROMs—evidence that, for now, the practice remains outside mainstream routine in many settings.

One participant shared an insightful example of how peer dynamics and transparency can drive better use of PROMs:

“What sometimes helps is when departments give insight into how often the PROMs were discussed by each individual physician. Then a little competition started between physicians—because they’re quite competitive people—to see who could reach the top score in discussing PROMs with patients. That’s a bit like the pink ribbon example I mentioned before—using quality indicators.” (D.3)

This example illustrates how making PROM-related performance visible can tap into professional pride and competitiveness to improve patient-centred practices. By framing PROM discussion rates as a quality indicator and sharing them internally, organisations can create positive peer pressure that motivates clinicians to prioritise meaningful conversations with patients.

7.3.12 Emotion

All of the organizations stressed the importance and need for Proms, but they also indicated that there is still a lot of work to be done. As one representative from put it:

"We feel it’s important, but... The job has only just started." (D.2)

Some of the organizations confirmed that this is not their priority. It’s not at the top of their minds, but they will take it into account after this interview.

"I will take lessons from this interview and talk about it." (D.9)

7.3.13 Behavioural regulation

Here some of the organisation ahd guidelines have in place. One of the organisations We do several surveys among patients regarding their needs and their experience in quality of life and quality of care, and then the findings regularly points to PROMs "On a national level, we all agreed on this general PROMs and then. So we also did our organisation to implement general problems and then supplemented by PROMs on the specific" (D.2)

Some of the organisations already have guidelines in place.

One of them explained:

“We regularly conduct surveys among patients about their needs, their quality of life, and their experience with the care they receive — and the results consistently point us toward the importance of PROMs.” (D.8)

At the national level, there is a shared agreement on the general commitment to using PROMs. Building on that, one organisationn (D.2) decided to implement a general set of PROMs as a foundation, and then supplemented them with more specific, condition-focused PROMs tailored to each federation. This approach allowed align with national goals while also addressing the unique needs of each patient group.

7.3.14 Concluson

The use of PROMs in clinical practice is shaped across multiple behavioural domains, where different barriers and enablers influence the process as can be seen in 7.1. Knowledge gaps remain, as clinicians often view PROMs primarily as research tools and lack clarity on follow-up actions; however, familiarity with guidelines and patient organisation input facilitates adoption. Perceived consequences, such as added workload and risks of unmet patient expectations, are balanced by recognition of PROMs' potential to structure care and broaden discussions. Capability constraints, especially among patients with lower health literacy, contrast with the enabling role of clinical champions and supportive leadership. Skills in qualitative research, communication, and empowering patients are crucial yet underdeveloped. While stakeholders express optimism about this systemic change, progress is seen as slow and often driven by individual rather than organisational support. There is still a need to change mindsets and attitudes to give patients more power and recognise the critical role of patient organisations, which already act as key supporters and voices for patients. Environmental and organisational factors, such as rigid EHRs, lack of standard procedures, and insufficient financial incentives, undermine the sustainability of the PROMs implementation. However, technological infrastructure, dedicated staff, and innovative tools like AI and dashboards are promising facilitators. Social influences, emotions, and behavioural regulation further highlight the importance of ambassadors, shared belief in PROMs' value, and internal policies and targets.

Overall, the findings show that while there are still many challenges, there is also evident progress toward using PROMs in a more patient-focused and organised way. This highlights the need for better support from the whole healthcare system, a shift in attitudes and culture, and ongoing education and advocacy to keep moving forward.

Table 7.1: Facilitators and Barriers to PROMs Implementation Categorized by TDF Domain

TDF Domain	Barriers	Facilitators	Supporting Quotes
Knowledge	Primary use seen as research; non-medical outcomes missed; follow-up actions poorly embedded	Familiarity via research; patient orgs identify outcomes; awareness and use of national guidelines	"Clinicians here are quite interested in using the PROMs, but mainly to figure out the quality of life. . . " (expert 1), "How do I measure if a patient family is happy?" (D.4), "Yes. So we are really aware of the guidelines within the Netherlands and we also implemented the guidelines in our own policy. . . " (D.1)
Beliefs about consequences	Too time-consuming; risk that patients feel ignored; conflict between patient and clinician views; lack of follow-up	Standardized structure; earlier symptom recognition; broader conversations beyond medical topics	"It's mainly that the follow up actions are not that well embedded currently." (D.3), I filled in the questionnaire and I never heard something back from the professional. (Org 5) "Oh well, first of all, it's nice to have a common structure." (Org 4), "The benefit is that you can really design the therapy towards the needs of the patients." (D.5)
Beliefs about capabilities	Adds to workload; digital PROMs widen equity gap for low literacy patients	Champion clinicians; patient orgs push via quality indicators; leadership support	". . . not everybody speaks the Dutch language and we only kind of offer PROMs in Dutch. . . " (Skills
Clinicians lack soft skills for difficult conversations; patients unsure how to bring up PROMs	Expertise in qualitative research; strong communication skills; patient orgs educate and empower patients	"You have to have expertise in qualitative research." (D.5)	
Optimism	Progress is slow	Belief that healthcare is becoming more patient-centered and systemic change is coming	"I think things are progressing, but just very slow." (D.3), "Well, I think I'm optimistic." (D.4), "I am optimistic, otherwise I shouldn't do this work." (D.5)
Social/professional role and identity	Patients not empowered to question doctors; clinician skepticism of patient orgs	Patient orgs bridge gap and help patients advocate for themselves	"I think patients also need a cultural shift in terms of standing up for their rights. . . " (D.3)
Intentions	Driven by individuals, not systems; commitment varies	Seen as a means to patient-centered care	"I wouldn't say specifically for the PROMs as a goal, but maybe as a means towards more patient centred care." (expert 1), "Smaller patient organisations. . . have limited time, so that's perhaps they don't emphasise it that much." (D.5)
Goals (Motivation and goals)	Lack of financial incentives; PROMs must use simple, accessible language; language barriers persist	Modular, adaptive questionnaires reduce burden; patient involvement in PROM selection ensures value	"There's currently something going on in France. . . where they are reimbursing clinicians to discuss PROMs. . . " (expert 1), "I think you can translate it in any language, but you still need this doctor and this patient to be able to talk to one another." (D.8)

TDF Domain	Barriers	Facilitators	Supporting Quotes
Memory, attention, and decision processes	Reminders seen as provider's responsibility; fragmented patient pathways	Patient orgs raise awareness with educational tools like videos	"Yeah, yeah, that's what we are doing with improving health literacy. If patients don't know what they can encounter, they don't think of it themselves." (Org 1B), ". . . for individual patients it will be very difficult because there are a lot of different hospitals and every patient has like a very own path. . . " (D.1)
Environmental context and resources	PROM initiatives unsustainable; rigid EHRs; insurer influence	National infrastructure and collaboration; dedicated staff; AI for data structuring	"The EHR is not going well because. . . it's just a bit rigid." (D.3), "One way to achieve that is making sure that these PROM sets are incorporated in the healthcare guidelines." (D.5), "Large language modeling helps us to structure unstructured data. . . " (D.4), "Dashboard. . . easy to understand with green, orange, and red light." (D.6)
Social influences	Limited insight into norms	Ambassador clinicians; internal competition; patient orgs as PROM ambassadors	"I do think it helps when you have some ambassador, doctors or nurses." (D.8), "[Patient organisations]. . . they should be the ambassadors for it [PROMs]." (D.10)
Emotion	Frustration at slow pace; job has only just started	Strong shared belief in benefits of PROMs among advocates	"We all struggle with. . . the way it is not working or not going fast enough." (D.3), "We are enthusiastic. Yeah, yeah, yeah. But we also see it's challenging." (D.1)
Behavioural regulation	Lack of standardized procedures; many orgs still creating guidelines	Internal policies developed through project work; internal targets within clinical teams	"They have now discussed among each other. . . that they have set a target for discussing 80% of the PROMs that are completed by patients." (D.3), "We don't have formal guidelines. . . that's sort of almost where we are creating by working on these projects, right." (D.7), "Yeah. So we made this policy and pathway ourselves within the PROMs Centre. . . " (D.1)

Chapter 8

Research Question 3

PROMs that deliver the greatest value to patients and align with the objectives of patient organizations

Patient-reported outcome measures (PROMs) are only as valuable as the extent to which they capture what truly matters in patients' lives. By shifting the focus from narrow clinical endpoints to broad, patient-centered domains—physical function, emotional well-being, social participation, and overall quality of life—PROMs can transform care conversations and decision making. However, not all Patient-Reported Outcome Measures (PROMs) equally represent the patient perspective. Below, the author explores which types of PROMs from the perception of patient organisation deliver the greatest value for patients, drawing on expert insights and patient voices, and explain why they matter.

These sections in this chapter represent themes such as patient voice, adaptive design, generic and disease-specific PROMs and underrepresented topics, which were derived from interviews with patient organisations. As mentioned in Chapter 7 In one of the domains **??**, interviews were conducted to gather participants' opinions on which PROMs matter the most to them.

8.0.1 Patient Voice

This subsection explores the theme of patient voice, which emerged from the interviews as a critical determinant of PROMs' meaningfulness and impact. Highlighting patient voice is essential, because PROMs by definition aim to capture patients' lived experiences, yet without patient involvement, they risk becoming just another top-down clinical tool divorced from actual needs.

Several respondents emphasized that PROMs should not be designed in isolation but instead co-created with patients and actively discussed in clinical settings to close the feedback loop: "How do you think about them? Were they useful for you? Did the doctors talk about it with you?" (Org 4)

"Patient-reported outcome measures should be embedded in every medical process and care pathway—they're a crucial element of shared decision-making." (Org 2)

Organizations reported directly involving patients in selecting PROM sets and even conducting online questionnaires where patients vote on which outcomes they find most important:

"Patient-reported outcome measures should be embedded in every medical process and care pathway—they're a crucial element of shared decision-making." (Org 3) "To determine the value of PROMs from a patient perspective, we directly involve patients in selecting PROM sets, ensuring the outcomes truly matter to them. Additionally, we conduct online questionnaires where patients vote on the outcomes they find most important." (Org 1A)

This approach provides a clear foundation for improving healthcare and quality of life: "I think that's knowing the most valuable PROMs for patients. Gives us the foundation on which topics to work on and where we can improve healthcare and quality of life." (Org 6)

PROMs are most powerful when they're not just administered to patients but designed with them as one of the experts mentioned:

"To determine the value of PROMs from a patient perspective, we directly involve patients in selecting PROM sets, ensuring the outcomes truly matter to them." (Expert 1)

This quote is supported by another participant conclusion: "If the PROMs meet the needs of a patient, that means it's valuable." (Org 1B)

"They are not aligned with the objectives of patient organizations. . . They are not working with PROMs, so they don't have it in their daily focus." (Expert 3)

Respondents also stressed the importance of aligning PROMs with patient organizations, because these organizations are deeply aware of patient realities:

"They should be aligned. . . they are in the practical situation all the time. They know what's going on in the patient communities, in patients themselves." (Org 4)

These insights collectively underscore that the meaningfulness of PROMs depends on continuous patient involvement and dialogue, ensuring that the measures reflect patients' priorities and truly guide improvements in care and quality of life. The theme of patient voice is therefore not just a nice-to-have but a condition for PROMs to fulfill their promise of patient-centered care.

These insights collectively underscore that the meaningfulness of PROMs depends on continuous patient involvement and dialogue, ensuring that the measures reflect patients' priorities and truly guide improvements in care and quality of life. The theme of patient voice is therefore not just a nice-to-have but a condition for PROMs to fulfill their promise of patient-centered care.

However, PROMs tend to be most useful in clinical settings when they generate actionable insights for health professionals, and those insights don't always align with the outcomes that resonate most with patients (Bain et al., 2018).

8.0.2 Adaptive design

Interviews highlighted that technology could significantly address the current mismatch between PROM data and actionable, patient-centered care. This mismatch arises because many PROMs, particularly standardized or generic instruments, are designed to enable comparability across patients and settings. While this standardization supports population-level benchmarking and research, it often comes at the cost of specificity and relevance for individual patients. As a result, clinicians may find that patient-reported outcome measure (PROM) results lack the nuance necessary for making immediate treatment decisions. Additionally, patients may feel that the questions do not capture the aspects of their lived experience that are most important to them, or they may view the questions as burdensome because they do not relate to their specific situation at all. Additionally, the potential for design capability in interpreting PROM scores remains. In this context, adaptive design could be beneficial.

"Currently, patients receive a standard questionnaire that often includes redundant questions, such as asking if they can walk a long distance followed by whether they can walk a short distance. If a patient can walk a long distance, they can obviously walk a short one as well. In computer adaptive testing, these redundant questions are skipped." (expert 1)

"I'm quite fond of the computer adaptive testing, even though we don't have that here because it's not supported here technically." (expert 1)

Such computer adaptive tools could streamline questionnaires and ensure that results directly inform care, by linking specific scores to clear next steps:

'If you have a certain score, you could redirect patients to certain resources or referrals, or just a step is missing from 'OK, now we have completed the questionnaires'. (expert 1)

This underscores the current gap between collecting PROM data and integrating it meaningfully into the care process. Expert 1 further explained that ideally, scores should guide patients onto appropriate care pathways: "If I have a score of this, then I should be doing that. . . hopefully that helps to. . . [create] a care pathway patients can go onto."

Participants also stressed that presenting outcomes in a more patient-centred way could make them more meaningful and actionable:

“The way we present the outcomes to patients could be more patient-centred.” (expert 1)

"I just think that the electron patient records need to be more user friendly and I think that would help so much because we often hear that clinicians struggle with finding how to send the PROMs or finding the answers of the PROMs and then if they cannot find the answers, they will not discuss it with the patient"3 (expert 2)

This idea extends beyond data collection to how outcomes are communicated, suggesting more intuitive, accessible formats, such as traffic light–style indicators: “The scores would be presented in [an] intuitive way which is easy to understand. . . maybe something like a green and an orange and a red light or something like that” (Org 3). Together, these insights highlight the potential of technology not only to improve the efficiency of PROMs, but also to translate results into clear, actionable, and patient-friendly care pathways, an area for further development.

Applying technology, like computer-adaptive testing and intuitive result presentation, could potentially make PROMs way actionable and more patient-centred, turning scores into, for example, clear care pathways that patients can easily understand and follow.

8.0.3 Generic vs disease specific

One recurring theme highlighted by the organizations is the tension between generic and disease or patient group–specific PROMs. As Org 3 points out, tailoring PROMs to specific diseases or patient groups is often necessary: “[PROMs that bring value to patients] should be a disease or patient group specific.”

The choice between generic and disease-specific PROMs can also influence how burdensome they feel to patients. Generic PROMs, while useful for comparisons across conditions, sometimes include questions that feel irrelevant to patients, potentially increasing frustration and reducing engagement. In contrast, disease-specific PROMs can feel more targeted to patients’ actual experiences and priorities, which may help reduce perceived burden. Still, in populations with chronic conditions, completing any PROMs—whether generic or specific—can feel overwhelming when patients’ focus is simply on survival:

“It’s challenging because of the patient group—people with chronic diseases. At some point, we stop burdening them with lists and questionnaires, as their focus shifts entirely to survival.” (Org 3)

Disease-specific PROMs excel at relevance, they ask about symptoms and concerns that matter most to a given group, which can reduce frustration and boost engagement. But this focus comes at a cost, where you lose the ability to compare results across different conditions, populations, and health systems. Each new condition requires its own instrument development, testing, translation, implementation, training, and ongoing maintenance—efforts that quickly multiply administrative burden and cost across a health system. Generic PROMs, by contrast, provide a common metric for benchmarking and policy decisions, even if some questions feel irrelevant to individual patients.

Org 4 underscores that generic tools may be especially ill-suited for rare diseases:

“I think the general is nice, but it might not be applicable to rare diseases because you might deal with fairly different issues.”

As one of the experts highlighted: "PROMs questionnaire should be tailored to [...] per illness, even extra because it’s nowadays too general (expert 3)"

Purely disease-specific PROMs fail to capture broad outcomes and make it impossible to benchmark performance across clinics, regions, or entirely different patient groups. They also require a separate instrument (and validation) for every new condition.

Recognizing these competing needs, Org 5 recommends a hybrid approach:

“It will be a combination of specific and generic measures, because when we talk about recovery for people with this condition, there are particular symptoms . . . and we also need that universal language to compare and learn.”

As contractdion one of the experts explained that by designing a generic PROM around universally important areas—such as physical functioning, social participation, emotional health (including anxiety and depression), pain, fatigue, and overall quality of life—you ensure two things. First, every patient is asked about the aspects of health that truly matter to them, regardless of their specific condition. Second, because all respondents answer the same core questions, clinicians and researchers can directly compare outcomes across different diseases, settings, and patient groups. In this way, the core PROM both remains relevant to individual experiences and establishes a consistent framework for evaluating health and well-being at a broader level.

"So Netherlands, there was a a study in developing a generic PROMs set and this was done with various patients populations. Outcomes that are found to be important for the general population and patients as well, and these include physical functioning, social functioning, mental well-being, including depression, anxiety symptoms and pain, fatigue, and general quality of life So I think it is important to include these because this is what patients and people generally mention to find important.(expert 2)

Together, these insights underscore the need to carefully balance specificity and feasibility, ensuring PROMs are meaningful and relevant to patients experiences, without adding unnecessary burden—an area that warrants further attention and thoughtful design.

To be truly valuable, PROMs need to balance broad and disease-specific measures, capturing what matters most to each patient group, while keeping the burden low, particularly for those with chronic or rare conditions.

8.0.4 Accessible, inclusive language

Finally, inclusivity is crucial for making PROMs both meaningful and effective.

As Org 6 reminds us, "[a good PROM] should be simple . . . understandable for all people in the Netherlands, even when they are not highly educated," because a questionnaire that no one can understand cannot drive improvements in care.

However, simplicity alone does not guarantee equity. It has to be ensured that PROMs reach and serve patient groups who have historically been disadvantaged, whether because of limited education, language proficiency, or cultural barriers. For example, a recent survey of around 4,000 respondents found that about 95 percent spoke Dutch, underscoring how non-Dutch speakers are routinely left out of these measures.

As Org 6 respondent explained, "Language is a problem, so we don't reach all the people we want to reach, and that's the same for PROMs."

Low health literacy and language barriers, which can affect anyone, regardless of educational attainment—are well-documented limits on patient-reported measures and can widen health disparities (van der Heide et al., 2013).

As respondent from Org 1A said: "...my role as a patient organisation, I think improving health literacy and increasing patient empowerment is the way to implement PROMs"

More inclusive approaches, such as plain-language design, multilingual versions, and culturally sensitive outreach are therefore essential to ensure PROMs truly capture the experiences and priorities of all patients, not only those who are native Dutch speakers or highly educated.

8.0.5 Underrepresented Topics

Respondents consistently highlighted that PROMs should reflect the full spectrum of patients' lived experiences, extending beyond clinical symptoms to include social participation, mental well-being, and sexuality. As Org 1A pointed out: "I feel like a lot of patients want more psychological outcomes. . . also things like societal participation. . . those are underrepresented."

This sentiment was echoed by Org 1B: "It's about. . . that social activities like an inclusion in society," and further reinforced by Org 6: "Your social life. How do you do in your daily life?" These comments show how deeply patients value their ability to stay connected to their communities and sustain meaningful social roles during illness. Mental well-being also emerged as a critical, yet often overlooked domain: “Pushing PROMs beyond pain scores to include mental well-being” (Org 1A),

“Well, I guess it’s more like the emotional part of things” (Org 2),

“It’s about side effects of medication. It’s about mental well-being so depression” (Org 1B), reflecting patients’ desire to have emotional struggles acknowledged and addressed.

Sexual health, another highly personal but often invisible dimension, was flagged as a gap by Org 6:

“In the generic EORTC questionnaire, there is no sexuality item,” with Lex adding: “The girls might be feeling very insecure.”

Which was also mentioned by one of the experts:

“Sexual functioning and satisfaction are often overlooked, but experienced to be important. . . Including this outcome in a PROM set can help to get the conversation about this sensitive topic started.” (Expert 2)

Taken together, these insights make clear that PROMs risk being perceived as incomplete if they fail to include what patients themselves see as central to their quality of life. Social participation, mental and emotional well-being, and sexuality are not peripheral, they are fundamental aspects of living with dignity, connection, and confidence.

8.0.6 Conclusion

Perspectives from the interviews reveal an essential difference between experts and patient organisations regarding Patient-Reported Outcome Measures (PROMs). While experts advocate for more generic measures that reflect broad quality-of-life outcomes. Patient organisations tend to favour disease-specific and tailored PROMs. The experts value simplicity and wide applicability, whereas patient organisations emphasise the need for precision and relevance to specific conditions.

This disagreement highlights the necessity for dialogue and alignment between healthcare professionals and patient advocates to find the right balance between generic and disease-specific PROMs in routine care.

Another key takeaway from the interviews is that patient organisations want to be involved in the design and co-creation of PROMs. It is essential to consult with them not only during the design phase but also periodically to assess the relevance of the questionnaires over time.

An additional point that stood out from the interviews is the technological aspect. Technology can simplify processes, so approaches such as adaptive design and score indication should be explored further in future research.

Chapter 9

Research Question 4

Which strategies can patient organizations prioritize to address the identified barriers and strengthen the use of PROMs in clinical practice?

Based on in-depth interviews with representatives from patient organisations and experts, author has identified several strategies to effectively integrate PROMs into everyday care, which can be seen in the Figure9.1. One key observation is that these organisations see themselves as a bridge between patients and clinicians. They aim to translate what truly matters to patients into simple, co-created guidelines and procedures that medical associations, insurers, and hospitals can follow.

Having a dedicated PROM advocate from a patient organisation could be one effective strategy to pursue. Having someone who has the time to oversee the implementation process. Of course, this would need to be considered in conjunction with a budget. However, following a conversation with the patient organisation, there could be a starting point for discussing this position. This could highlight the need for staff training, reminding doctors of the importance of patient feedback and maintaining accountability, which can help transform good intentions into routine practice. Another idea to boost engagement, derived from the interviews, was providing small incentives such as gift cards, which would increase engagement.

Moreover, it has been observed that animations, social media posts, and engaging website features can spark curiosity and clearly explain how completing a PROM can contribute to better, more personalised care. Incorporating these tools into training for both patients and healthcare professionals is crucial to making PROMs feel meaningful and accessible. That is something that definitely can be on the hands of a patient organisation. As one organisation mentioned in the interviews, they are developing the PROMs animation video for educational purposes, explaining to patients why it is important and encouraging them to discuss this with their clinical team during treatment. That is the beginning of creating awareness from the patient organisation side regarding that idea.

What was interesting is that, from the interviews, some representatives really thought about collaboration, combining it with a workshop. The first step to change is raising awareness and knowledge. Therefore, patient organisations that could bring themselves together for a topic, exchange expertise, provide fundamental workshops, and support those organisations that can play a role in implementation, just as they are lacking resources, knowledge, etc.

One interviewee highlighted the value of collaborative events where patients and organizations come together, describing them as ideal opportunities to exchange information, raise awareness, and align efforts. As they put it: "I feel like just consider events where different patients, organisations get together, I think. That's just a great place to talk about 'What you're doing'? To get more awareness of these things" (Org 1A).

They further reinforced this point, stating: "I think once we get together and sort of create awareness and we're all on the same page about these things" (Org 1A).

Finally, many organisations are excited and see actual value in the potential of technology. Tools such as AI that convert free-text comments into structured scores, or chatbots that guide patients through surveys, can significantly scale the impact and help close the loop between patient feedback and care delivery. Patient organisations can advise on this idea because, ultimately, it serves the patients well.

Input from interviews and thorough analysis of barriers and enablers, based on the literature helped to choose a strategy to increase the use of PROMs in clinical practice. As mentioned in 6 section6.4, 7 Section 7.3.10, 8 and Section 8.0.2, technology plays a key role in successfully implementing PROMs. Additionally, examining patient-related barriers reveals interconnected challenges that span both technological and patient-perceived domains.

One solution that stood out from the interviews is the increasing use of artificial intelligence (AI) in healthcare. About half of the interviewees believe that AI could help support the implementation of PROMs Figure 9.1.

This can be supported by one of the particpants: “If you’re looking at PROMs, all those validated questionnaires are structured data. AI—particularly large language models helps us convert unstructured data into structured data.” (Org 1B)

“It’s impossible for us to manually sift through all the articles and data anymore—AI can rapidly analyze everything, surface the key highlights, and organize them into focused PROMs, giving us the confidence to know exactly which outcome measures matter most" (Org 4)

“As for the doctor, it would be ideal to present the information in a dashboard format—much like AI tools used in research" (Org 3)

With that in mind, this chapter will explore this idea further. It will look at how AI might be used, while also considering ethical and privacy concerns. This will lay the groundwork for Chapter 5, where the feasibility of this strategy will be evaluated through an economic analysis.

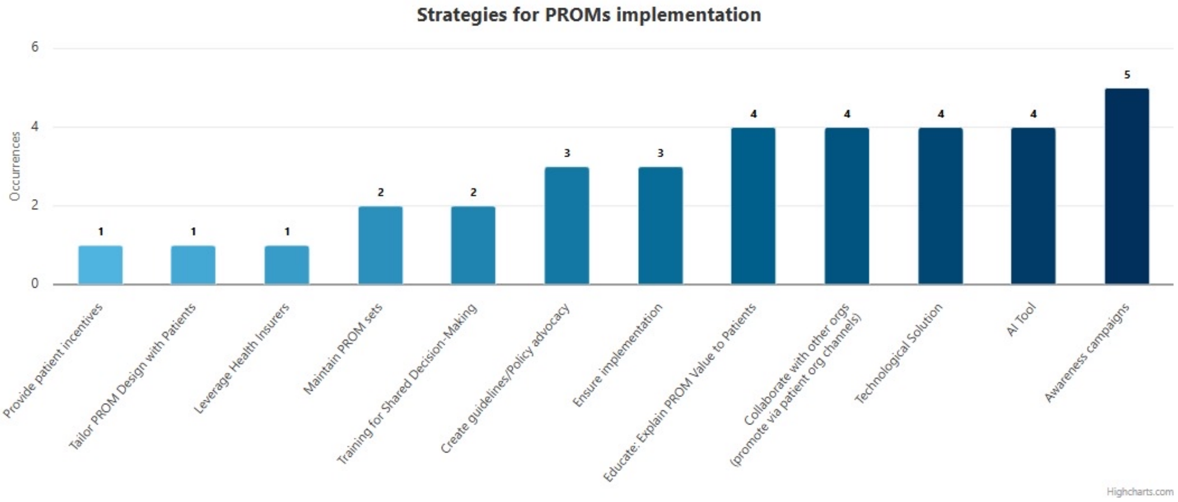


Figure 9.1: Strategies based on interviews with patient organisations

9.1 Current Technological Landscape for PROMs in Netherlands

To propose a solution effectively, I conducted an additional literature review. In this review, I examined a small case study to understand the current technological landscape for PROMs in the Netherlands and the role AI plays in this context. Therefore, I present the results of my findings, which provide a logical foundation and inspiration for the proposed solution.

The technological landscape of healthcare in the Netherlands is currently undergoing a major transformation aimed at improving the accessibility, usability, and interoperability of health data. Electronic health records (EHRs) have been fragmented among providers, which has made it difficult for patients and professionals to access complete health profiles. The Dutch national strategy envisions shifting towards a patient-centered "life-course dossier," in which data follows the individual and is accessible across networks. Artificial intelligence (AI) is expected to play a critical role in supporting care by simplifying documentation, enhancing decision-making, and reducing administrative burdens through technologies such as text mining and voice interfaces. On eof the exmaples is AI for Imaging (AIFI) project for five Dutch hospitals, focusing on making AI software accessible for medical diagnostics through shared national infrastructure (Nederlandse Vereniging voor Radiologie, 2025) The strategy aims to establish an integrated health information system by 2035, where patients and healthcare professionals can collaborate in real time with the support of secure, standardized data flows and intelligent digital services (Ministry of Health, Welfare and Sport (VWS), 2023)

Patient-reported outcome measures (PROMs) are closely aligned with the Dutch national vision for a future-proof health information system. As instruments that capture patient-reported outcomes on symptoms, functioning, and well-being, PROMs are vital for personalised and preventive care, which are cornerstones of the envisioned "passende hybrid zorg."- appropriate care (Zorginstituut Nederland, n.d.-a) (Zorginstituut Nederland, n.d.-b). To function effectively within a system based on interoperability, data reuse, and citizen-centred governance, PROMs must be standardised, digitally integrated, and accessible across all healthcare settings. Moreover, the topic of making medical data more patient-friendly is important to enable patients to understand and use their electronic health records (Amsterdam UMC – Amsterdam Public Health, 2023)

As an example, Dutch hospitals have made significant strides in integrating PROMs directly into Electronic Health Record (EHR) systems. A notable example is Medisch Spectrum Twente (MST), which successfully transitioned from eight different web-based PROM applications to a fully integrated system within ChipSoft (Medisch Spectrum Twente, n.d.). ChipSoft is a leading a company with ICT systems in healthcare, for example, through Electronic Patient File HiX, which supports complete medical standard content (ChipSoft, n.d.). This standard content includes user-friendly solutions, such as workflow support, intelligent registration forms, care pathways, and decision support.

The Netherlands Cancer Institute Netherlands Cancer Institute – Antoni van Leeuwenhoek (NKI) represents a leading example of comprehensive PROM integration in clinical practice. There PROMs are not collected on paper or in isolated systems but they are fully integrated into the Electronic Health Record (EHR). Patients receive automatic prompts through the hospital's patient portal (such as MijnAVL MyAVL is your personal patient portal that gives you access to your appointments, medical records, information and questionnaires anytime, anywhere) before appointments (Antoni van Leeuwenhoek (AVL) / Netherlands Cancer Institute, n.d.). Once completed, the PROMs are immediately synchronized with the EHR, allowing care providers to access, review, and act on patient-reported data in real time during consultations.

However it is not sufficient. Experts believe there is potential for improvement in the area of innovation (appendix-interviews). One example from the literature of an innovative way to further foster PROM uptake is the use of multimodal Patient-Reported Outcomes Measures (PROMs), as presented by Thumboo et al., 2006 and highlighted by de Ligt et al., 2025. Instead of depending only on written words, this approach presents each question through a coordinated combination of video, audio, and visual cues. Patients watch a clip of an interviewer reading the question out loud, with the text displayed in sync with the spoken words. Moreover, the recording speed can be adjusted to suit the user's pace.

Not only does this solution reframe how questions are communicated, but it also makes them more accessible. If applied more broadly, multimodal PROMs could transform the way patients participate in and interpret their role in reporting outcomes.

Therefore, one of the way of incorporating multi-model PROMs is AI Agent that could tackle the barriers such as health language, health literacy, summary of PROMs score and recommendation prep for consultation. To improve completion rates, existing PROMs should be revised to use simple, concrete language, avoiding jargon and negations, and eliminating distracting information.

(de Ligt et al., 2025), a researcher at NKI, states that conversational agents supported by AI could help patients who complete Patient-Reported Outcomes Measures (PROMs) by using natural speech on everyday devices, such as phones or tablets, eliminating the need for typing or reading. They state that the approach could be efficient when combined with the multimodal approach mentioned earlier, with audio-enabled interfaces that can read questions, which could be the next version of the proposed AI Agent, making PROM completion more accessible, particularly for patients with limited literacy. They also noted that the conversational agent helps bridge language gaps by offering multilingual support, thereby enhancing inclusivity for individuals who are not native speakers, which is consistent with the AI Agent concept proposed in this chapter.

9.2 Proposed Solution

As a solution to overcome barriers such as low patient engagement, limited health literacy, language barriers, and—indirectly—the lack of follow-up, as identified through interviews and confirmed by the literature review, I explore certain things about a minimum viable product Minimum Viable Product (MVP) of a digital artificial intelligence (AI) agent. This agent would support both patients and clinicians throughout the patient-reported outcome measurement (PROM) process.

The MVP focuses on four core capabilities:

9.2.0.1 Intelligent Language Support (Detection & Translation)

The agent automatically detects the patient's preferred language (based on patient records or initial user selection) and delivers the PROM in that language. The option to have it original would also be possible. The AI-agent could use high-quality machine translation to present the questions in the patient's language and capture responses in a format that clinicians can interpret easily. This feature would then lower the language barrier, therefore eliminating the need for Dutch proficiency. For example, a Polish-speaking patient could receive a PROM in Polish and respond, and the system would then translate the answers back to Dutch or English for the care team. Furthermore, the agent could converse in multiple languages. For example, through a chat interface, it could clarify a question in the patient's language if it senses confusion. Advanced AI language models can preserve the meaning of medical terms in translation, making real-time translation possible. Recent research highlights that atients accept AI translation for interactions, with satisfaction rates among patients reported between 84-96.6% (Genovese et al., 2024).

9.2.0.2 Simplified Reading Level and Explanations

To assist patients with limited health literacy, the AI agent would offer a "simplified language" mode. This would indicate presenting PROM's questions and answer options in plain, everyday language A2 level, which is recommended for low-literacy audience (Stichting Lezen en Schrijven, n.d.).

For instance, instead of asking," Rate the severity of your dyspnea during exertional activities in the past 2 weeks," the toolt might ask, "How difficult was it to breathe when you were active in the last 2 weeks?" The agent could also provide examples of "active" activities, such as walking or doing housework, to ensure understanding. The agent can also be interactive. If a patient does not understand a term, they can ask the agent for clarification via text or voice. Because it is AI-driven, the agent can understand the patient's query and explain it in simpler terms or even use an analogy. This solution would provide real-time support for health literacy. By simplifying the language in PROM questionnaires, we remove a major hurdle that can cause patients to misunderstand or abandon them, making it far more likely they'll complete each item accurately. Behind the scenes, every plain-language question is linked to its original, validated counterpart through a "cross-walk" table created by PROM developers, clinicians, and psychometric experts. Once those mappings are defined, for example, a response of "often" to "In the last seven days, did you feel tired?" translates to the same numeric score as the formal fatigue question, the survey platform applies these rules automatically, delivering a dataset that uses the original PROM codes and scoring.

9.2.0.3 Web & Mobile Interface

This MVP would work seamlessly in their browser or app, regardless of whether they are using a computer, tablet, or smartphone. To ensure it is easy for everyone to use, including those with visual or motor impairments, the interface will follow accessibility best practices, such as using high-contrast colours, readable fonts, and ensuring compatibility with screen readers.

9.2.0.4 Automated Follow-Up and Analytics Dashboard:

Once patients complete their PROMs, the tool continues to work behind the scenes. The MVP updates a dashboard that care teams can access, ideally integrated into existing EHR systems, such as HiX or Epic. The dashboard could show patient scores and flag any concerning changes, such as abnormal spikes in pain or signs of worsening mood, that could indicate depression. It could also track trends over time. If something requires urgent attention, such as severe nausea in a cancer patient, the agent can notify the care team or send a supportive message to the patient. Importantly, clinicians would set all alerts and thresholds in the system to avoid notification overload.

9.2.0.5 System Diagram

To bring clarity to the complex ecosystem in which our AI agent for PROMs must operate, the researcher visually mapped the critical inputs, such as policies, funding, IT infrastructure, and staff training, alongside the external enablers and constraints of EHR cooperation. By illustrating digital infrastructure and privacy regulations, the diagram highlights critical dependencies and potential bottlenecks.

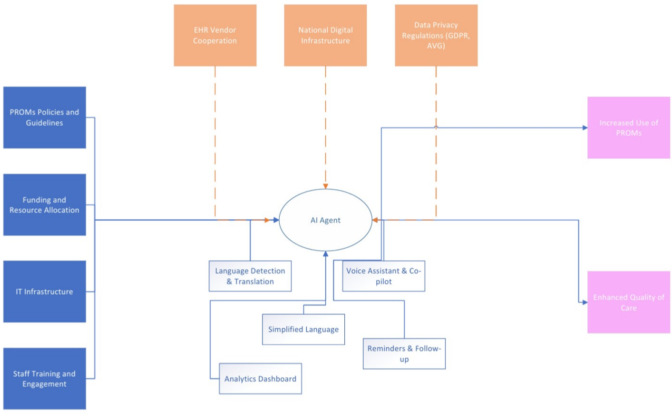


Figure 9.2: System Diagram

The system diagram places an AI Agent at its core, showing how four key organisational inputs, PROMs policies and guidelines, funding and resource allocation, IT infrastructure, and staff training and engagement, directly feed into the design and deployment of an AI-powered PROMs platform. Above the AI Agent are three external enablers and constraints, such as EHR vendor cooperation, national digital infrastructure, and data privacy regulations (e.g., GDPR/AVG). Once activated, the AI Agent delivers a suite of integrated functions, language detection and translation (with results surfaced via an analytics dashboard), a voice assistant and clinical co-pilot, patient-friendly simplified language, and automated reminders and follow-up. This all leads to two primary outcomes: increased use of PROMs across diverse patient populations and, therefore, enhanced quality of care through richer feedback, timely interventions, and data-driven insights.

9.3 Ethical Issues Dillemas

However, the integration of AI agents into PROM systems can raise ethical dilemmas that can go far beyond technical functionality. These challenges cross with fundamental principles of biomedical ethics: autonomy, beneficence, non-maleficence, and justice (Varkey, 2020).

9.3.1 Autonomy

Patient autonomy requires that individuals maintain meaningful control over their healthcare decisions and their health data. However, AI agents in PROM administration often operate as "black boxes," making decisions about content adaptation, question sequencing, and response interpretation without a transparent explanation of their reasoning processes.

To safeguard autonomy, any AI-driven PROM system must offer clear explanations of its decision logic, allow patients to review and amend their responses before submission, and provide an easy way to pause or decline AI-guided features altogether.

At the same time, respecting autonomy demands full compliance to data-protection standards, where patients must give explicit, informed consent for each use of their health information, and they should know exactly where and how their data will be stored and who can access it.

By combining transparent AI processes with robust privacy-by-design measures—such as data minimization, purpose limitation, and compliance with GDPR and the Dutch Uitvoeringswet Algemene Verordening Gegevensbescherming (Dutch GDPR implementation) (UAVG)—PROM platforms can empower patients to participate on their own terms and maintain genuine control over their personal health narratives.

Moreover, research indicates that patients have significant privacy concerns about electronic PROM systems, with 30% expressing worries that substantially influence their willingness to participate (Meirte et al., 2020)

Given that PROMs involve sensitive health data, any AI-driven solution must ensure data minimization, purpose limitation, and explicit patient consent. Concerns arise, particularly around how and where data is stored and whether third-party AI providers have access to identifiable health information.

By combining transparent AI processes with robust privacy-by-design measures—such as data minimization, purpose limitation, and compliance with GDPR and the Dutch UAVG—PROM platforms can empower patients to participate on their own terms and maintain genuine control over their personal health narratives.

9.3.2 Beneficence

The principle of beneficence demands that healthcare interventions promote patient well-being.

The exploraed AI agent in PROM systems fits into this principle. AI tool can do more good for patients, as was discuused before by making questionnaires easier to access for people who speak different languages, helping collect complete information about how patients feel, and spotting health problems earlier using intelligent analysis.

9.3.3 Non-maleficence

However, the principle of non-maleficence—"do not harm", raises critical concerns about potential negative consequences. AI systems can perpetuate or amplify existing biases present in training data, resulting in systematically biased interpretations of patient responses based on factors such as race, ethnicity, gender, age, or socioeconomic status.

Research demonstrates that nearly 75% of machine learning algorithms in healthcare contexts generate biased outcomes, predominantly affecting disadvantaged groups.(Colacci et al., 2025) The bias operates through multiple mechanisms, including biased training data, algorithmic design choices, and differential performance across demographic groups.AI systems can sometimes repeat or even worsen unfair patterns found in the data they were trained on. This can lead to biased results when describing phenomena such as pain or emotional distress.

9.3.4 Justice

Procedural justice means that decisions in healthcare should be made through fair and respectful processes. As PROMs lead to shared decision-making with AI agents, there needs to be assurance that they not only provide fair results but also operate in a manner that is transparent, accountable, and respects patients' rights. This includes ensuring patients understand how the AI works, providing them with the opportunity to question or correct what the AI says, and enabling them to reach a real person when needed.

9.4 Conclusion

An Artificial Intelligence (AI) agent can be a significantly more effective solution than general tools, such as Google Translate, for addressing issues like health literacy and language barriers (Bahrami & Rubulotta, 2025). In comparison to basic translation tools that only convert text, an AI agent can interpret medical information within its context, simplify complex medical terminology, and adjust the level of communication according to a patient's literacy and needs. AI agents can tailor PROM content to meet patient needs, such as language requirements, and detect critical information. AI Agent can also propose recommendations for consultation, including further steps that may need to be taken after receiving a specific score. An AI agent tailored for PROM use in clinical contexts can interpret medical context accurately, connect to EHR systems, operate securely under privacy regulations, engage dynamically with patients, and integrate training support. Those are all essential capabilities that general-purpose tools cannot match. This enables more effective, trustworthy, and clinically integrated patient-reported outcome processes.

The AI tool has great potential to contribute to the broader implementation of PROMs in Dutch clinical practice. However, it has to be acknowledged that users are more likely to complete PROMs with an AI Agent when their awareness and understanding are at a sufficient level. Therefore, adequate training is necessary to ensure that people do not feel discomfort, unease, or lack of trust throughout the PROM process.

Regarding the presented solution, people who could benefit most from self-management tools, such as those with limited health literacy or higher health risks, often face the most significant challenges in using them. Therefore, through personalised communication and a user-friendly digital platform PROMs can be made more inclusive and accessible. Making the content of PROMs and their results more straightforward to understand could boost completion rates and guarantees that PROMs influence patient care for all.

Chapter 10

Research Question 5

Impact and value of this patient organization-led strategy be assessed in practice

10.1 SROI analysis on AI Agent

This chapter outlines the estimated results of the SROI analysis for an AI Agent intervention designed to improve health literacy, PROMs completion, and patient satisfaction. The analysis explores the potential impact of implementing this intervention at two levels of scope: a hospital-level pilot, covering 1,269 cancer patients, and a national-level forecast, covering the Dutch cancer patient population across nine specialised centres that account for 207,528 cancer patients. For more details of the analysis, see Appendix C and the Excel document attached to the report. According to the Dutch Guideline for Economic Evaluations in Healthcare (Zorginstituut Nederland, 2024), the SROI method is not considered the standard for formal health economic evaluations, which typically favour cost–utility analysis (CUA) or cost-effectiveness analysis (CEA).

From the standpoint of welfare economics, SROI does not attempt to capture societal welfare in the same way as well-known utility-based frameworks do. Instead, it assigns monetary values to selected outcomes using proxies. Therefore it involves a process that captures judgment and relies heavily on the chosen proxies, underlying assumptions, and attribution methods. Within this research, SROI is applied as an exploratory and complementary tool, rather than a substitute for recommended evaluation methods. The purpose is to investigate whether SROI can shed light on wider societal value, particularly non-health outcomes such as patient experience and health literacy that are often omitted from QALY-based assessments.

Table 9.1 organises the findings from the SROI study using the PICOT structure: population, intervention, comparison, outcome, and timeframe. The table aligns each element of the PICOT framework with the corresponding inputs for the economic evaluation, presenting population sizes, AI agent specifications, comparator benchmarks, cost and benefit estimates, and the five-year analysis horizon side by side. In the following chapter, the researcher will investigate the calculation and estimation of each parameter.

Table 10.1: The PICOT Framework with Chapter-Specific Data

Element	Chapter-Specific Details	Reference
Population	• Hospital pilot: 1269 cancer patients ($n_{\text{breast}} = 438$, $n_{\text{melanoma III/IV}} = 224$, $n_{\text{bladder}} = 335$, $n_{\text{head\&neck}} = 272$). • National forecast: 679200 total Dutch cancer patients (≈393300 in active hospital follow-up and 207 528 across 9 specialised centres).	10.1.1.1
Intervention	• AI-agent integrated into EHR to drive: – +20% PROMs completion – +10% uptake in new feature for PROMs discussion – Improved health literacy and patient satisfaction • Base-case investment (hospital): €1 209 165 (development, EHR integration, cloud, compliance, cybersecurity, maintenance, training 40 staff). • National rollout cost: €8 838 925.	10.1.1.3
Comparison	• Usual care PROMs workflow without AI: – Baseline discussion rates: breast 15%, melanoma III/IV 2%, bladder and head&neck similarly low. • Serves as "business as usual" deadweight (75% of post-intervention discussions).	10.1.1.3.3
Outcome	**Costs:** • Perspective: hospital/provider (direct implementation costs); societal perspective for health-literacy and satisfaction proxies. • Investment: €1.21 M (pilot), €8.84 M (national). **Effects:** • QALYs: 0.0050 QALY per PROM report → valued at €50 000/QALY → €250 per discussion. • Health literacy: €620 annual savings per patient (24.5% prevalence 310.9 beneficiaries in pilot). • Patient satisfaction: €300 per patient-year (15% WTP uplift; €25 per visit × 12). • Base-case SROI (pilot): PV benefits €233.6 k; NPV –€975.5 k; return €0.19/€. • National SROI (€80 k/QALY): PV benefits €40.35 M; NPV +€31.52 M; return €4.57/€.	10.1.1.3.5
Timeframe	• Horizon: 5 years post-implementation. • Discount rate: 3% p.a. • Drop-off: 10% p.a.; attribution: 100	10.1.1.5

These results are based on calculations and assumptions informed by available evidence and expert input. They provide an exploratory assessment of the intervention's social value intended to guide future evaluation and decision-making.

10.1.1 Base Case

To estimate the SROI for the AI Agent, the author applied a base-case scenario while also examining alternative scenarios. The complete set of calculations is provided in the Appendix C and the Excel file attached to the report.

10.1.1.1 Stakeholders

Through interviews the author identified a range of outcomes that stakeholders considered most relevant to evaluating the impact of the AI agent. These outcomes reflected both direct health- related effects and broader non-health benefits. The most frequently mentioned outcomes included improved patient understanding of their health information, greater confidence in communicating with healthcare providers, and enhanced satisfaction with care processes. Stakeholders also emphasised indirect effects such as reduced administrative burden for clinicians and more efficient use of consultation time. These insights directly shaped the scope of the SROI analysis by ensuring that only outcomes with stakeholder relevance were carried forward to the mapping and valuation stages. For the base case of the study, the author examined a Dutch hospital that has implemented PROMs into its workflow.

10.1.1.2 Cost Input

Initially, 1,269 patients were sent PROMs. These patients were diagnosed with breast cancer, melanoma stages III and IV, bladder cancer, and head and neck cancer. This research will examine the current PROMs results collected at this hospital and investigate how integrating AI could influence these outcomes. PROMs are administered multiple times during treatment—typically in 3, 4, or 6 follow-up rounds, allowing changes to be tracked over the course of care..

Table 10.2: Number of Patients at Baseline by Disease

Disease	Number of Patients at Baseline
Breast cancer	438
Melanoma stage III/IV	224
Bladder cancer (surgically treated)	335
Head and Neck cancer	272
Total	1 269

As shown in Table 10.3, the estimated costs of deploying AI in a healthcare setting are converted to euros at the June 2025 rate (1 USD = 0.8672 EUR) and vary widely between different categories. The largest expense is AI development itself, with industry estimates ranging from approximately €43,400 to €434,100, depending on the project's scope and the vendor selected.

Integrating AI with existing electronic health records also displays significant variability, costing between €92 and €607,800, reflecting the difference between lightweight add-ons and comprehensive system overhauls. Cloud hosting costs are relatively modest, ranging from €28,000 to €56,000. Ongoing maintenance and support can cost between €10,400 and €130,200 annually.

Compliance and cybersecurity measures each require approximately €43,400 to €434,100 to meet regulatory and data protection standards. Furthermore, training for 40 staff members adds another €4,300 to €8,700 per person.

In total, these expenses culminate in a base-scenario investment of roughly €1,209,165.

Table 10.3: Estimated Costs of AI Implementation in Healthcare
(June 2025: 1 USD = 0.8672 EUR)

Action	Cost (EUR)	Source
AI Development	€ 69 400–€ 303 900	Master of Code, 2025
	€ 43 400–€ 73 700	Biz4Group, 2025
	€ 86 800–€ 434 100	TopFlight Apps, 2025
EHR Integrations	€ 92–€ 280	Callin.io, 2025
	€ 130 200–€ 434 100	Eglobal India, 2025
	€ 86 800–€ 607 800	Aalpha, 2025
Cloud Costs	€ 28 000–€ 56 000	Simbo.ai, 2025
Maintenance & Support	€ 10 400–€ 86 800	Oyelabs, 2025
	€ 43 400–€ 130 200	Eglobal India, 2025
Compliance	€ 173 600–€ 434 100	Eglobal India, 2025
Cybersecurity	€ 43 400–€ 130 200	Eglobal India, 2025
Training & Development (40 employees)	€ 4 300–€ 8 700 per emp.	Master of Code, 2025
Total (Base Scenario)		**€ 1 209 165**

10.1.1.3 Mapping Outcomes

The intervention was designed to generate three primary outcomes, each directly experienced by stakeholders. First, the intervention improves QALYs, reflecting gains in health-related quality of life. This was estimated based on a 20% increase in completion rates, adjusted for discussion rates, and calculated using evidence-based estimates of QALY gain per PROM report (0.0050 QALY per form), as documented by (Basch et al., 2016). Second, the intervention improves health literacy, with an estimated annual economic benefit of €620 per patient, based on published research quantifying the societal and healthcare cost savings associated with higher health literacy levels (Truong & Fenton, 2022). Finally, the intervention improves patient satisfaction, valued as a 15% improvement, corresponding to €300 annually per patient, based on patient-reported willingness-to-pay and improved experience metrics (Versluis et al., 2025). These outcomes were selected to reflect both individual-level and system-level benefits and were quantified using robust, published indicators to enable consistent and transparent valuation.

10.1.1.3.1 Patient satisfaction Evidence suggests that around 61% of patients would be willing to pay more for an improved hospital experience (DistilINFO Hospital IT, 2025). For this analysis, a conservative benchmark of 15% was used, assuming that patients would accept paying 15% more than the standard hospital consultation fee if it offered better service (e.g., shorter waits, friendlier staff, more transparent communication). This 15% premium falls within the range observed in hospital markets and aligns with self-reported willingness-to-pay (WTP) for quality improvements (Jiang et al., 2023).

The monetary gain from improved patient satisfaction was calculated by applying this 15% premium to the average annual out-of-pocket spending on hospital consultations, estimated at €1,952 per patient (€160 per monthly visit × 12 months) (Meijer et al., 2025). The €300 per patient per year figure represents only the portion of this spending (specifically the 15% improvement) that can be attributed to the intervention.

Consequently, the valued improvement is calculated as:

$$0.15 \times 1{,}952 = 292.8 \approx 300 \quad (\text{€ per patient per year})$$

To translate this into a per-visit benefit, the €300 is divided across an anticipated 12 outpatient visits per year, resulting in approximately €25 per consultation. This approach distributes the patient satisfaction benefit over the expected frequency of care interactions, aligning the economic value with the likely point at which it is realised.

10.1.1.3.2 Health Literacy Improved health literacy has a measurable impact on healthcare utilization and costs. Patients with low health literacy are known to have worse disease management, more avoidable hospital admissions, lower adherence to treatment, and overall poorer outcomes, which translates into higher healthcare costs. The cited study (Truong & Fenton, 2022) estimates that improving a patient's health literacy reduces healthcare expenditures by approximately €620 per year per patient. This figure comes from cost-effectiveness research quantifying the savings from interventions that improve a patient's ability to understand and engage with their care.

In addition, data from the ("Improving the communication of outcome-data to patients with lower health literacy/numeracy", 2022) show that 24.5% of patients have low health literacy. This prevalence rate indicates the proportion of the population that stands to benefit most from interventions targeting health literacy.

$$\frac{24.5 \times 1269}{100} = 310.905$$

10.1.1.3.3 QALYS At baseline, the number of completed PROMs and the number of discussions following completion showed considerable variation across cancer types 10.4.

Table 10.4: Key Indicators by Cancer Type and Follow-Up Point

Indicator	Definition
Completed PROMs	Number of completed Patient-Reported Outcome Measures per cancer type and follow-up point.
PROMs Discussions	Number of discussions about PROMs per cancer type and follow-up point.
Discussion Rate	Ratio of PROMs discussions to completions (discussions / completions).

In breast cancer, 279 PROMs were completed, of which 42 were discussed with patients, resulting in a discussion rate of approximately 15%. In melanoma stage III/IV, 192 PROMs were completed, but only three were discussed, corresponding to a discussion rate of just 2%. Similar variability was observed in other cancer types, with discussion rates generally declining over follow-up measurements in most groups. To estimate the potential impact of the AI Agent intervention, two assumptions were applied: a 20% improvement in completions, based on evidence that improved health literacy increases patient willingness and ability to complete PROMs; and a 10% uplift in discussions, reflecting evidence that higher completion and clearer PROMs increase their clinical use during consultations.

10.1.1.3.4 Calculation of change with AI After estimating the improved completion rates with the assumed +20% uplift (to reflect the expected increase in PROMs completion due to improved health literacy), and an additional +10% uplift in discussions (to reflect improved clinical engagement), the final discussion rates were derived using observed Completion-to-Discussion (C/D) ratios for each cancer type and follow-up point.

These C/D ratios represent the historical proportion of completed PROMs that were actually discussed with patients, specific to each cancer type and timepoint. For example, in breast cancer at baseline, the C/D ratio was 0.15, indicating that approximately 15% of completed PROMs were discussed with patients. In contrast, the ratio for melanoma stage III/IV at baseline was considerably lower, at just 0.02. These ratios also varied across follow-up measurements, reflecting fluctuations in clinical practice patterns over time.

The baseline C/D ratios represent the proportion of completed PROMs that were actually discussed with patients under existing, routine practice essentially the behavior without intervention. Since the intervention is designed to increase PROMs completion (+20%) and improve discussion behavior (+10%), these improvements build on top of the current clinical norms rather than assuming a complete change in practice patterns. Therefore it assume uplifts on the observed baseline C/D ratio, where analysis acknowledges the existing clinical context and ensures that projections remain realistic. Using baseline data avoids overestimating the impact of the intervention and keeps the estimates grounded in observed behavior.

10.1.1.3.5 Calculation of QALYS To estimate the value of each patient discussion enabled by the AI Agent intervention, we reviewed published evidence on digital PROMs and symptom monitoring systems. Across all four articles, the reported QALY gains per patient ranged from 0.003 to 4.58. When calculated on a per-discussion or per-report basis, the QALY gain ranged from 0.00013 to 0.0763 per interaction. 10.5 summarizes the QALY gains per individual discussion or report reported across these studies.

For example, the French multicenter lung cancer study attributed approximately 0.0763 QALY per additional consultation, while the Symptom Tracking and Reporting system (STAR) trial in chemotherapy patients estimated 0.0050 QALY per self-report. These findings informed the sensitivity analysis of the social value attributed to each patient discussion.

For the base case scenario, the author will use the estimated intervention by (Basch et al., 2016), which resulted in an annual QALY gain of approximately 0.0583 per patient. Patients were scheduled for 16 visits per year, with an average adherence of 73%, resulting in approximately 11.7 completed PROM reports per patient annually.

The number of completed PROM reports per patient per year was calculated as $16 \times 0.73 \approx 11.7$.

Dividing the total annual QALY gain per patient by the number of reports completed yields the estimated QALY gain per report:

$$\frac{0.0583}{11.7} \approx 0.0050 \text{ QALY per report.}$$

These calculations demonstrate how evidence-based estimates of QALY gains can be translated into per-report values, forming a foundation for the SROI analysis by linking individual patient interactions to meaningful improvements in quality of life.

Table 10.5: QALY Gain per Discussion or Report by Study

Cancer Type / Context	QALY Gain per Discussion / Report	Source
Lung cancer, PRO monitoring	0.0763	https://pubmed.ncbi.nlm.nih.gov/30776447/
Chemotherapy, STAR system	0.0050	https://pubmed.ncbi.nlm.nih.gov/26644527/
Mixed cancers, EHR-integrated advice	0.00027 – 0.00045	https://ascopubs.org/doi/10.1200/OP.23.00498
Breast and prostate, symptom app	0.00013	https://cancer.jmir.org/2025/1/e53539

10.1.1.4 Valuing Outcomes – QALYs, Health Literacy, and Patient Satisfaction

To estimate the monetary and social value of the intervention, a proxy value was applied to the QALY gains observed for each cancer type. This approach follows the methodology proposed by Zorginstituut, which assigns an approximate monetary value per QALY based on established cost-effectiveness thresholds and prior evidence from the literature.

The base case analysis considered scenarios, representing the middle reasonable willingness-to-pay (WTP) for a QALY, which is €50,000 on hospital level.

The valuation of our three key outcomes—improved QALYs, enhanced health literacy and higher patient satisfaction relies on a common set of assumptions. Researcher assumes that each benefit begins in the period after the AI Agent is implemented and lasts for five years, reflecting the nature of literacy gains, behaviour change and sustained satisfaction improvements. All outcomes are weighted at 10/10 for

Table 10.6: Willingness-to-Pay per QALY by Cancer Type

Cancer Type	WTP (EUR)	EUR/QALY per discussion
Breast cancer	50 000	250
Melanoma stage III/IV (A)	50 000	250
Bladder cancer (surgically treated) (A)	50 000	250
Head and Neck cancer (A)	50 000	250

stakeholder importance. Monetary proxies were drawn from the literature: scenario 1- €50 000 per QALY (the middle bound of Dutch willingness-to-pay) €620 annual savings per patient with improved health literacy (Truong & Fenton, 2022), and a €25 per-patient value for consultation experience, which stands for 15% of satisfaction. For example, the improved QALYs outcome is calculated as:

Base case scenario:

$$0.005\ \left[\text{QALY/discussion}\right] \times 50{,}000\ \left[\text{€/QALY}\right] = 250\ \text{€}$$

The health literacy gain for 310.905 patients yields

$$310.905 \times 620\,\text{€} = 192\,761\,\text{€}$$

For patient satisfaction is

$$1\,269 \times 25\,\text{€} = 31\,725\,\text{€}$$

10.1.1.5 Valuing Outcomes- Deadweight, Attribution, Dropoff

The researcher set the deadweight at 75% because, of the 92.5 discussions recorded post-intervention, 70 (approximately 75%) would have occurred regardless, reflecting the "business as usual" baseline. Conservatively, only the remaining 25% is attributed to new impact. Attribution is set to 100% because no other concurrent programmes or external factors targeted PROMs discussions during the study period, allowing us to credit 100% of the observed uplift to our intervention. Finally, the researcher applied a 10% annual drop-off rate—a mid-range assumption commonly used in SROI practice—to capture the gradual decline in sustained discussion levels over subsequent years without overstating long-term benefits.

Table 10.7: Assumptions for Deadweight, Attribution, and Drop-off

Parameter	Value	Rationale
Deadweight	75%	Of the 92.5 discussions post-intervention, 70 ($\approx$ 75%) would have occurred "business as usual", so we conservatively attribute only the remaining 25% to our activity.
Attribution	100%	No other concurrent programmes or external factors targeted PROMs discussions during the study period, allowing us to credit 100% of the observed uplift to our intervention.
Drop-off	10% p.a.	A mid-range annual decay rate commonly used in SROI practice, reflecting a realistic gradual decline in sustained discussion levels without overstating long-term benefits.

10.1.1.6 SROI – Base-Case Results and Improvement Strategies

This base-case evaluation, conducted at a single hospital using PROMs baseline data, examines three benefit streams—QALYs gained, health-literacy improvements, and patient satisfaction—as shown in Table 10.8. It is assessed over a five-year horizon with a 3% annual discount rate. Year 1 benefits of approximately ≈ €61.9 k decline to about €40.6 k by Year 5, yielding a total present value of €233.6 k. Against an initial outlay of €1.209 M, the net present value remains deeply negative at ≈ −€975.5 k, equating to just €0.19 of social benefit per euro invested. While the intervention clearly improves health outcomes and patient experience, its high upfront cost overwhelms the discounted returns.

Table 10.8: Base Case Scenario: Calculating Social Return (Discount rate = 3%)

	Year 0	**Year 1**	**Year 2**	**Year 3**	**Year 4**	**Year 5**
Improved QALYs	0	5 781.25	5 203.13	4 682.81	4 214.53	3 793.08
Improved Health Literacy	0	48 190.28	43 371.25	39 034.12	35 130.71	31 617.64
Improved Patient Satisfaction	0	7 931.25	7 138.13	6 424.31	5 781.88	5 203.69
Total	0	61 902.78	55 712.50	50 141.25	45 127.12	40 614.41
Present value of each year	0	60 099.78	52 514.37	45 886.34	40 094.86	35 034.35
Total PV						233 629.71
NPV (PV – investment)						–975 535.29
Social Return (per € invested)						0.1932

To improve the social return, potential strategies include cutting implementation expenses (e.g., streamlining training), scaling the intervention nationally to convert the AI agent into a fixed cost, or focusing on patient subgroups or outcomes that yield greater QALY gains and improvements in health literacy.

10.1.2 Sensivity Analysis

Table 10.9 presents a univariate (one-at-a-time) sensitivity analysis in which each key parameter is varied individually while all others remain at their base-case values.

The first two cases vary the total investment by applying all cost categories at their lower-bound or upper-bound estimates. The last two cases vary only the assumed QALY gain per PROM report, holding all other inputs constant. For each case, the table reports the investment, present value (PV) of benefits, net present value (NPV), and social return (€ benefit per € invested).

Table 10.9: Univariate sensitivity analysis (one-at-a-time) for the AI-agent SROI. **Base case:** one Dutch hospital with 1 269 patients; total investment €1 209 165; PV of benefits €233 630; NPV –€975 535; social return 0.193€/€.

Variant	**Investment (€)**	**PV benefits (€)**	**NPV (€)**	**Social return (€/€)**
Base case	1 209 165	233 630	–975 535	0.193
Low-cost build	546 250	233 630	–312 620	0.428
High-cost build	1 922 080	233 630	–1 688 450	0.122
Low QALY/report	1 209 165	212 378	–996 787	0.176
High QALY/report	1 209 165	544 772	–664 393	0.451

In the low-cost build, reducing all expenses to their lower-bound estimates decreases the investment by €662 915 and nearly doubles the social return from €0.19 to €0.43 per euro invested, although the project remains net-negative. In contrast, applying upper-bound costs increases the NPV shortfall to –€1.69 million and reduces the return to €0.12 per euro. Changing the QALY gain per PROM report has a similarly strong effect: using the upper-bound value (0.0763 QALY) more than doubles the social return to €0.45 per euro, while the lower-bound value (0.00013 QALY) reduces it slightly to €0.18. Overall, investment size and the estimated health-quality gain per PROM report are the primary drivers of the AI agent's social return.

10.1.3 Scenario Analysis

In this section, scenario analysis takes place to illustrate the conditions under which our AI-agent investment shifts from a theoretical concept to a socially valuable intervention in Table 10.12. Rather than presenting a single point estimate, researcher compares the economics of deploying the solution in one Dutch hospital versus rolling it out nationally, and test conservative and ambitious valuations of health gains by varying the willingness-to-pay threshold for QALYs. Examining the hospital-level scenarios at both €20 000 and €80 000 per QALY helps to understand whether, even with generous health-value metrics, the fixed implementation costs can ever be justified at a small scale. In contrast, the national scenarios reveal how spreading those costs across many more patients can transform a net loss into a substantial positive return, regardless of the Quality-Adjusted Life Year (QALY) price tag. These comparative analyses demonstrate not only which assumptions drive social return but also where strategic focus, on scale, expense control, or value measurement, will most effectively unlock the promise of AI Agent in healthcare.

10.1.3.1 Population size

The figure of 679,200 represents everyone in the Netherlands who has been diagnosed with cancer in the past ten years and is still alive today, according to the Netherlands Cancer Registry (iknl.nl). But not all of these survivors are hospitalized or need care in highly specialized clinics, where PROMs will be avaiable, many continue their follow-up in primary or secondary care or not at all. According to patients who receive curative cancer treatment remain under hospital-based surveillance for the first five years post-treatment to monitor for recurrence, manage late effects, and coordinate ongoing care.

The figure of approximately 393 300 cancer survivors in active hospital-based follow-up is derived by applying the five-year crude prevalence rate for cancer to the Netherlands' population (OECD & European Observatory on Health Systems and Policies, 2023). Specifically:

$$\underbrace{393\,300}_{\substack{\text{Survivors in}\\\text{active follow-up}}} = \underbrace{\left(\frac{2\,210}{100\,000}\right)}_{\substack{\text{Five-year crude}\\\text{prevalence rate}}} \times \underbrace{17\,780\,000}_{\substack{\text{Population of}\\\text{the Netherlands}}}$$

Not all of this patient will be treated in hospitals that are specualized, have proms etc. For the purpose of this study there were idenfied 9 hospitals that are specializing in oncological care.

Centre	Unique patients per year	Source
NKI-AVL (Amsterdam)	41 139 (2021)	Netherlands Cancer Institute
Erasmus MC Cancer Institute (Rotterdam)	33 623 (2024)	Erasmus MC, 2024
UMCG Comprehensive Cancer Center (Groningen)	27 892 (2024)	Universitair Medisch Centru
Maastricht UMC+ Comprehensive Cancer Center	23 374 (2024)	Maastricht UMC+, 2024
Radboudumc Centre for Oncology (Nijmegen)	22 110 (2024)	Radboudumc, 2024
Rijnstate Oncology Center (Arnhem)	30 885 (2024)	Rijnstate, 2024
Princess Máxima Center for Pediatric Oncology (Utrecht)	∼ 600 (annual)	Prinses Máxima Centrum, 20
Maastro Clinic (Maastricht)	4 500 (new per year)	Maastro Clinic, 2025
Catharina Cancer Institute (Eindhoven)	23 405 (2024)	Catharina Ziekenhuis, 2024
Total across all centres	**207 528**	—

Table 10.10: Annual unique patients treated at major Dutch cancer centres.

In this national-scale example, which uses a valuation of €80,000 per QALY, we start by calculating the undiscounted benefits for each year. We do this by multiplying the total units of impact—15,144 extra QALY-equivalent interactions, 50,844 literacy-improved patients, and 207,528 satisfaction-enhanced visits, by their respective per-unit values: €400 per QALY, €620 per literacy gain, and €25 per satisfaction event. We also apply a net attribution rate of 25%. In Year 1, this yields approximately €1.51 million from the QALY interactions, €7.88 million from improved literacy, and €1.30 million from enhanced satisfaction visits. Adding these figures together gives a total annual benefit of €10.69 million. We then discount this amount at a rate of 3% per year, resulting in a five-year present value total of €40.35 million. After deducting the national implementation cost of €8.84 million, the net present value is +€31.52 million. This corresponds to a social return of €4.57 for every euro invested.

$$\text{Impact (QALYs)} = 15{,}144 \times 400 \times 0.25 = 1{,}514{,}400$$

$$\text{Impact (Health Literacy)} = 50{,}844.36 \times 620 \times 0.25 = 7{,}880{,}875.80$$

$$\text{Impact (Patient Satisfaction)} = 207{,}528 \times 25 \times 0.25 = 1{,}297{,}050.00$$

Table 10.11: Discounted Value of Outcomes and Returns over 5 Years National Scale, WTP=€80000 (Discount rate: 3%)

Outcome	Year 0	Year 1	Year 2	Year 3	Year 4	Year 5
Improved QALYs	0	1,514,400	1,362,960	1,226,664	1,103,998	993,598
Improved Health Literacy	0	7,880,876	7,092,788	6,383,509	5,745,158	5,170,643
Improved Patient Satisfaction	0	1,297,050	1,167,345	1,050,611	945,549	850,995
Total Value	0	10,692,326	9,623,093	8,660,784	7,794,706	7,015,235
Present Value (each year)	0	10,380,899	9,070,688	7,925,844	6,925,495	6,051,403
Total PV						40,354,329
Net Present Value (NPV)						31,515,404
Social Return (per euro invested)						4.57

To illustrate the effects of different scales and willingness-to-pay (WTP) thresholds, an option-scenario analysis was conducted Table 10.12.

In the base case—single hospital deployment with a WTP of €50 000 per QALY—the €1 209 165 investment generates €233 630 in present-value benefits, yielding an NPV of –€975 535 and a social return of €0.19 per euro invested. Lowering the WTP to €20 000 in Scenario A reduces benefits to €220 538, deepens the NPV loss to –€988 627, and decreases the return to €0.18/€. Increasing the WTP to €80 000 in Scenario B raises benefits to €246 721, narrows the NPV deficit to –€962 444, and improves the return to €0.20/€.

Scaling nationally under the conservative €20 000 threshold in Scenario C requires a higher total investment of €8 838 925, but boosts benefits to €36 067 662, turning the NPV positive at +€27 228 737 and lifting the return to €4.08/€. With an €80 000 threshold in Scenario D, national benefits increase further to €40 354 329, the NPV rises to +€31 515 404, and the return reaches €4.57/€.

This comparison shows that while adjusting the WTP threshold has only modest effects at the single-hospital scale, scaling nationally transforms the AI agent from a net cost into a strong social investment.

Table 10.12: Scenario Analysis Comparing Hospital vs. National Deployment

Scenario	**Scale**	**Investment (€)**	**PV Benefits (€)**	**NPV (€)**	**SROI (€/€)**
A. Hospital, €20k WTP	Hospital	1 209 165	220 538	– 988 627	0.182
B. Hospital, €80k WTP	Hospital	1 209 165	246 721	– 962 444	0.204
C. National, €20k WTP	National	8 838 925	36 067 662	+27 228 737	4.081
D. National, €80k WTP	National	8 838 925	40 354 329	+31 515 404	4.566

10.1.4 Discussion

These findings underscore that modest adjustments to the willingness-to-pay threshold alone are insufficient to make the AI-agent economically viable at a single-hospital level, where it remains a net cost with low social returns. In contrast, scaling the intervention nationally unlocks significant economies of scale, transforming the AI agent into a high-impact social investment with strong positive returns. Therefore, the value of the AI-agent lies not in the deployment but in its strategic implementation at a national scale to fully realise its societal benefits.

Chapter 11

Discussion

This chapter presents findings and aims to address how patient organizations can effectively enhance the use of Patient-Reported Outcome Measures (PROMs) in Dutch practice to maximize value for patients. Based on the results of Research Questions 1, 2, 3, and 4, the author identified barriers and enablers from the patient perspective and compared these with findings from the literature. From this analysis, strategies for increasing the use of PROMs were proposed, including one that was economically evaluated using the SROI method. Author then will examine implications of these findings, address the study's limitations, and outline recommendations for future research.

11.1 Research question 1

What are the primary barriers and facilitators influencing the implementation of PROMs in healthcare within the Netherlands?

The analysis has revealed that organisational barriers, cited in 28.2% of studies, are the single most-reported obstacle to PROM integration in Dutch practice. Time pressures and unclear staff roles frequently undermine the use of PROM data where many healthcare providers collect but rarely discuss results during consultations, where at the same time their responsibilities for discussing scores are left vague. This mirrors Boomstra et al.'s finding that, without explicit favour of leadership and dedicated "owners" for PROM workflows, initiatives quickly lose momentum.

Technical and accessibility barriers were nearly as dominant (24.5%), with EHR interoperability issues and fragmented dashboards repeatedly diminishing clinician trust in PROM tools (van Oers et al., 2020). The KLIK portal example, requiring clinicians to navigate to an external website, adds steps that reduce review points by up to 40% in some settings. While prior studies have highlited these interoperability gaps, this review strengthen the span of their impact where nearly half of implementations report persistent bugs or unsupported features. Clinician engagement barriers (15.7%), showed increased workload and insufficient training (34.5% of clinician-related mentions). This aligns with (van Cranenburgh et al., 2016), where ongoing skill-building and feedback loops proved essential to sustained use. Therefore I advocate shifting from one-off workshops to learning-health-system models that embed continuous support to keep clinicians engaged with inclusion of patient organisation perspective. Patient-facing barriers (21.9%) center on a lack of feedback and follow-up (26%), digital-literacy gaps, and language obstacles. When patients receive no explanation of their PROM scores or see their input ignored during consultations, motivation can fall. In a multicultural context like the Netherlands, where over a quarter of residents have a migration background, untranslated or poorly explained PROMs risk excluding vulnerable groups. It has to be ensured that patients receive clear, personalized feedback and multilingual, low-threshold completion options are critical to reversing disengagement. This barrier aligns with findings from literature and therefore author had chosen to focus on exploring solution to eliminating them in Chapter 9. As for enablers, the analysis shows that successful implementation of PROMs can reflect an iterative cycle across the EPIS phases. First, we focus on exploration, where we work closely with patients to create meaningful solutions. Next is the preparation phase, which involves strategic planning, engaging stakeholders, and building a strong IT foundation, like integrating Electronic Health Records (EHR) and creating visual dashboards. Then comes implementation, where we encourage supportive leadership and clinical champions and use automated feedback systems to help put plans into action. Finally, in the sustainment phase, we continuously monitor data quality, set benchmarks, and show patient-centered results to ensure long-term use and investment.

Taken together, these findings illustrate that barriers operate at micro (clinician workflow), meso (organizational policy and IT), and macro (system-wide standardization) levels and that solutions specified to a single layer are unlikely to succeed. As was observed in (Groenewegen et al., 2024), this multi-level tension reflects that aprroach on many levels has to be in considered in the same time to sucssefuly impkement PROMs in clinical practice. This study contributes to the field by providing the comprehensive, Dutch-specific mapping of how barriers and enablers pinpointing exactly where a coordinated approach to leadership, technology co-development, continuous training, and patient feedback loops can facilitate the sustained adoption of PROMs.

11.2 Research Question 2

What do patient organizations in the Netherlands see as the primary barriers and facilitators influencing the implementation of patient-reported outcome measures (PROMs) in healthcare?

The TDF based interview findings with patient organisations map closely onto the barriers and enablers identified in the broader PROM implementation literature (RQ1). Still, they add a crucial stakeholder perspective that literature reviews alone have often overlooked. First, organisational barriers around unclear roles, lack of follow-up, and absence of dedicated ownership confirm findings of McClimans and Browne, 2012. The observation by van Oers et al., 2020 highlights the importance of having designated "owners" and formal incentives in promoting the effectiveness of PROM workflows. Establishing clear responsibilities and motivating factors can significantly enhance their success. Patient organisations described exactly this gap when nobody feels responsible for discussing or acting on PROM results, both clinicians and patients lose faith in the process. Their call for embedding PROM tasks into job descriptions and care pathways reinforces Boomstra et al., 2025 finding that top-down roadmaps must be paired with micro-level workflow redesign in Research Question 1 6. Secondly, the IT and accessibility challenges raised by patient repentances where fragmented portals, language barriers, and gaps in digital literacy mirror the technical obstacles documented by Depla et al., 2023. What's new here is patient organisations' insistence that technology co-development include end-user training and multilingual, plain-language design from day one, rather than as an afterthought. This perspective extends the literature by highlighting how technical solutions must be co-created with patient voices to ensure equitable access.

Third, clinician engagement barriers in the literature (perceived burden, insufficient training) find strong resonance in TDF domains around "Beliefs about capabilities" and "Skills." Patient organizations stressed that unless both patients and clinicians see immediate, meaningful feedback, ideally discussed during consultations, PROMs quickly become "just another form". This underscores the conclusions of van Cranenburgh et al., 2016 and Boomstra et al., 2025 that without follow-up PROMs, they do not exist. Moreover, from the input of one of the hospitals it was stated that the discussion rates were around 10% compared to the completion rates that were over 50%. This could indicate that future work should focus on activating clinicians to improve the completion rate. Finally, patient organisations highlighted the social and emotional aspects. Professional norms, peer influence, and the need for credible ambassadors are often under-emphasised in quantitative barrier surveys. Their examples of friendly competition (publishing individual PROM discussion rates) illustrate a low-cost enabler that literature on value-based care is only beginning to explore.

Moreover, there is a visible lack of cooperation on PROMs with each other. It could be interesting to propose an engagement in this matter for patient organisations, such as a training conference where they can exchange their expertise and knowledge to tackle PROMs implementation. However, some participants mentioned that it would be crucial to survey on a larger scale, where patient organisations could share their opinions.

By incorporating these stakeholder insights with the RQ1 insights , I not only validate known barriers and enablers but also enrich our understanding of how patient organisations can act as bridging gaps between policy, technology, and clinical practice to drive sustainable PROM integration.

11.3 Research Question 3

How do the PROMs that generate the greatest value for patients align with the objectives of patient organizations?

I have explored which Patient-Reported Outcome Measures (PROMs) can potentially provide the most value to patient organizations. When questioned about their goals, patients expressed that PROMs generally emphasize patient well-being and shared decision-making, precise the areas that patient organisation prioritze. Therefore PROMs naturally align with their objectives such as serving as the voice of the patients, where PROMs reflect this voice, highlighting the importance of collaboration between patients and clinicians. This collaborative aspect is a key focus for patient organizations.

Further research is needed to gain a more comprehensive understanding of this topic. Patient organizations emphasized that PROMs deliver meaningful value only when they are co-created with patients and integrated into care pathways. This finding supports the argument made by De Wit et al. (2019) for the active involvement of patients and the principles of value-based care as outlined by (Stover et al., 2021). However, larger, quantitative studies that compare specific PROMs and directly involve patient organizations in their design and evaluation would shed further light on best practices in this emerging field. Participants also suggested that computer-adaptive testing can significantly reduce the burden of redundant questions and personalize assessments for each individual echoing our RQ1 literature technical readiness.

The well-documented tension between generic and disease-specific instruments led them to recommend a hybrid model, combining a universal core of broad domains (physical function, mental well-being, social participation, pain, fatigue) with condition-specific add-ons, mirroring (Oude Voshaar et al., 2023) tiered measurement framework. They emphasized that, to promote equity, PROMs should be written in clear, everyday language and made available in multiple languages, thereby including non-Dutch speakers and individuals with limited literacy a concern raised by (Groenewegen et al., 2024).

Finally, patient groups called for routine inclusion of under-represented topics like social participation, emotional health, sexuality thereby answering (Balitsky et al., 2024) request to expand PROMs beyond just symptom checklists. Collectively, these insights point to five imperatives: continuous patient engagement in PROM design, adaptive and user-centered technology, a balanced generic-plus-specific measurement strategy, inclusive language practices, and systematic capture of the full spectrum of patient-valued outcomes steps essential for PROMs to truly strengthen patient voices and drive personalized, impactful care.

11.4 Research Question 4

Which strategies can patient organizations prioritize to address the identified barriers and strengthen the use of PROMs in clinical practice?

Patient organisations play a unique role in translating patient experiences into practical clinical tools, and both interviews and the literature highlight clear strategies they can champion to embed PROMs in daily care. They significantly impact patients, leading the author to recognise the potential for raising awareness through their activities. This influence could affect competition rates and ultimately the discussion rates among clinicians.

One of the solutions could be acting as mediators between patients and clinicians, as mentioned by de Wit et al., 2019, can make suggestions on dedicated PROM advocates who could then oversee the PROMs process from a patient organisation perspective. That could help remind clinicians and maintain accountability to make patient feedback a routine part of their practice. Of course, this role would be more advisory than executive in nature. There should be a champion like this from the clinical side, but having one from the patient side could create an impact.

As some of them are now participating in consultations about PROMs, the author proposes a more structured approach to their role in this matter. Co-creating clear, jargon-free guidelines and offering small incentives, such as gift cards, can also boost participation without incurring significant costs. This is consistent with findings that improve patient engagement ((J-PAL), 2009).

Digital engagement offers another powerful lever. Social media campaigns, animations, videos and interactive web tools can make PROMs approachable and relevant for patients, while short clinician training modules could potentially help on how patient-reported data improves care. This an approach supported by evidence showing that digital outreach and education can normalize PROMs as meaningful, not just administrative (De Gagné et al., 2019)

Many interviewees also see AI as a breakthrough for scaling adoption. AI agents that simplify language, translate in real time, and process free-text feedback could overcome literacy, language, and time barriers, aligning with emerging research on AI's potential in health data collection and real-time analytics (Stichting Lezen en Schrijven, n.d.). Embedding such tools in existing EHRs, like HiX or MyAVL, could help turn patient feedback into actionable dashboards that highlight trends and prompt timely care.

However, as the literature cautions, rolling out AI demands careful attention to ethics, transparency, and equity (Weiner et al., 2025). Patient organizations can take part in co-organizing and co-design workshops with clinicians, technologists, and regulators, piloting prototypes, and gathering evidence that reflects calls for patient-centered, co-created AI solutions, which aligns with the recommendation by Canfell et al., 2024. Patient organisations being the primary stakeholders in this context, should be actively engaged in the joint development and oversight of AI-driven PREMs analysis processes. Finally, by developing ready-to-use toolkits, governance templates, and integration checklists, and by building broad coalitions with clinical and tech partners, they can help move AI from pilot to practice, ensuring the patient voice is not just heard but acted upon in care.

11.5 Research Question 5

How can the impact and value of this patient organization-led strategy be assessed in practice?

The findings of this SROI analysis show that the patient organization–led AI strategy may generate meaningful improvements in PROMs completion, health literacy, PROMs completion, and patient satisfaction, but its cost-effectiveness depends heavily on scale. At the hospital level, the intervention's benefits are outweighed by high implementation costs, resulting in a modest return of about €0.20 per euro invested—even under generous willingness-to-pay assumptions. This aligns with the implementation science literature, which often highlights the challenge of achieving sustainable returns for digital innovations when deployed in small-scale pilots (McCool et al., 2020).

In contrast, scaling the intervention to the national level significantly improved outcomes, yielding returns of €4.57 per euro invested. Such scale effects are consistent with broader findings that health IT investments tend to show positive returns only when fixed costs are amortized across large populations (Bahuguna et al., 2025).

These results also support existing evidence on the value of PROMs and patient-centered technologies in improving care quality. Prior studies have documented how PROM use enhances shared decision-making and quality of life by van Muilekom et al., 2021, Amini et al., 2021 and that digital PROM tools can improve patient outcomes at acceptable cost-effectiveness thresholds However, concerns about equity, transparency, and unintended biases with AI applications in healthcare remain widely documented. This underlines the importance of the ethical safeguards and co-design processes built into the strategy evaluated here.

Additionally, the potential role of patient organizations in leading such initiatives is highlighted by findings from Dewit et al. (2019), who argue that these organizations effectively mediate patient perspectives and advocate for more equitable and patient-centered changes in the health system. Furthermore, using economic evaluations to support their initiatives allows patient organizations to validate their positions and persuade other stakeholders on issues that are truly important to patients. Therefore, the example of Social Return on Investment (SROI) can be further leveraged by patient organizations to advocate for various causes.

The recommendation to develop toolkits, coalitions, and focus on national-level rollout echoes lessons from implementation frameworks by van Oers et al., 2020, which emphasize the need for stakeholder alignment, scalability, and sustainability planning in digital health innovations.

11.6 Main Research Question

How can patient organizations effectively enhance the use of Patient-Reported Outcome Measures in Dutch practice to maximize value for patients?

Patient organizations can enhance the routine use of Patient Reported Outcome Measures (PROMs) in Dutch clinical practice by focusing on three interconnected areas: stakeholder engagement and advocacy, digital outreach and capacity building, and technology deployment. From a technological perspective, they can address barriers such as low health literacy, language difficulties, and patient engagement. These barriers are particularly significant to the researcher, who believes they can be effectively overcome using current technology. As a result, patient organizations can advocate for the development of an AI-powered "PROM agent."

This agent would provide intelligent language support, simplified reading modes, an accessible web and mobile interface, and automated follow-up with analytics dashboards. Such features would address persistent issues, including language gaps, low literacy, administrative burdens, and lack of feedback, while integrating seamlessly with hospital Electronic Health Records (EHRs). These barriers were identified through interviews with representatives of patient organizations.

Moreover, the role of patient organizations can extend beyond that. By leveraging their resources, they can aid in the general implementation of PROMs by co-designing workshops for patients. These workshops would raise awareness and knowledge, laying the groundwork for meaningful change. Ongoing advocacy at the levels of insurers and government ensures that PROM content, workflows, and policy support reflect real-world needs and incorporate the patient voice in decision-making.

Furthermore, targeted social media campaigns, educational modules, patient-friendly guides, and "PROM champions" within clinical settings can help build digital health literacy, increase patient activation, and translate good intentions into daily practices. By combining these elements, patient organizations can personalize and scale PROM delivery, enhance clinician engagement with real-time insights, and achieve a projected social return of approximately €4.57 for every euro invested, thereby embedding patient-centered outcome measurement into the core of Dutch healthcare.

In summary, this study contributes to the growing body of evidence that AI-enhanced PROM strategies can improve patient-centered care, but also reinforces the need for careful scaling, stakeholder engagement, and ethical oversight to fully realize their social value. Patient organizations are uniquely positioned to champion such initiatives, ensuring that technological innovations serve meaningful patient needs rather than adding to administrative burden or inequity.

11.7 Strengths and limitations

This study combines a qualitative case study, guided by the Theoretical Domains Framework (TDF), with a quantitative Social Return on Investment (SROI) analysis. This approach provides both in-depth insights from stakeholders and a measurable assessment of social value. By drawing on both the EPIS and TDF frameworks, the study was able to systematically identify and categorize barriers and enablers, integrating insights from the literature with firsthand perspectives gathered through interviews. Involving patient organization representatives in the interviews ensured that the proposed AI-agent strategy was grounded in real-world needs, thereby enhancing its relevance and acceptability. Addi- tionally, conducting scenario analyses at both hospital and national scales quantified the economic trade-offs of the AI agent across various willingness-to-pay thresholds, highlighting the importance of scale in achieving positive social returns.

Despite its strengths, this study has several important limitations. First, our barrier mapping relied on 49 academic sources of varying recency and methodological rigor. Many of these studies excluded non-Dutch-speaking participants, which limits the applicability of our findings to the increasingly diverse migrant population in the Netherlands. Second, although GDPR-related consent and data-protection requirements were identified as potential obstacles, we did not empirically assess these administrative burdens, leaving unresolved the question of how legal processes might impede or reshape PROMs implementation timelines.

However, because our qualitative data come from only a handful of patient organizations. Therefore, due to the large number and variety of patient organizations, it was not possible to include every perspective. Many groups' unique insights on PROMs implementation could not be incorporated into our analysis. Moreover, PROMs identified as "most valuable" may reflect the specific priorities of these organizations rather than those of the broader community of patient advocates. Strategies that these organizations prioritize may therefore lack relevance or feasibility for groups operating in different clinical or policy environments. Future studies should purposely sample a more diverse range of organizations, combine qualitative feedback with quantitative validation of PROM performance, and rigorously test proposed strategies in varied settings to overcome these shortcomings.

Furthermore, dual-coding of barriers and facilitators, though structured by the Theoretical Domains Framework, depends on researcher judgment and may not be fully reproducible across contexts. The study did not include hands-on testing or pilot deployments of the proposed AI agent within live clinical workflows. The study did not include hands-on testing or pilot deployments of the proposed AI agent within live clinical workflows. As such, it remains fundamentally uncertain whether a usable interface can be designed, whether integration with electronic health records is technically and organizationally feasible, and whether sustainable training outside a controlled research setting can be achieved.

Moreover, from the perspective of welfare economics, SROI doesn't measure societal welfare in quite the same way as utility-based methods do. Instead, it turns selected outcomes into monetary values using proxy measures, which can introduce a level of subjectivity due to the inherent choices, assumptions, and attribution factors involved. This method provides most value when aiming to when it's applied under certain conditions: (1) to provide a comprehensive view of social and non-market outcomes, (2) to aid in exploratory prioritization rather than making formal reimbursement decisions, and (3) to use proxies that have credible empirical backing and are relevant to stakeholders.

Although this study meets these conditions, it is important to interpret the findings within the context of these methodological limitations.

11.8 Future recommendation

In conclusion, this study highlights that while implementing PROMs in Dutch clinical practice faces persistent organisational and system-level barriers, such as unclear ownership of PROMs, fragmented IT infrastructures, and insufficiently defined workflows.

Patient organisations are uniquely positioned to overcome these challenges by acting as proactive co-designers and advocates who embed explicit PROM responsibilities into care pathways and job descriptions, drive the development of plain-language and multilingual systems, and champion end-user training. The interviews revealed what representatives from patient organisations care about, highlighting persistent resource disparities (with larger groups often facing more complex barriers despite their greater capacity) and outlining their perceived role as ambassadors in working with clinicians.

Future research should focus on confirming these findings on a larger scale with a broader representation of patient organisations. Then it can be measured and compared between organisations to see which PROMs bring value to them.

Furthermore, this study did not assess whether involving these organisations in co-design changes stakeholders' awareness or attitudes toward Patient-Reported Outcome Measures (PROMs). These outcomes still require further evaluation in future research. Participants discussed their role in fostering friendly competition by promoting transparent discussions about PROM completion rates, which helps create gentle peer pressure and address the "last mile" of implementation.

Finally, interviewees envisioned using AI-powered digital tools, chatbots, and dynamic dashboards, along with ongoing leadership advocacy at the decision-making level. The pilot study would shed more light on the feasibility and agreement with patient organisations on this tool in collaboration with the hospital.

Lastly, these insights underscore the importance of cross-sector collaboration, bringing together patient organisations, policymakers, clinicians, and IT partners to develop, implement, and maintain PROM initiatives on a national scale. This fosters a patient-centred, value-based healthcare system in the Netherlands. While interviews reveal important themes regarding barriers, facilitators, and the roles patient organisations envision for themselves, they do not—and were not designed to—provide conclusive evidence that PROMs actually improve clinical outcomes or quality of life. In fact, the literature on whether routine PROM collection translates into measurable patient benefit remains inconclusive. Before committing substantial public funds to AI-driven PROM tools at a national scale, we need rigorous, real-world research that links increased completion rates to demonstrable improvements in care processes, health outcomes, or patient experience. Only with that evidence in hand can policymakers confidently decide whether the potential gains justify the cost. Furthermore, the SROI analysis indicates that hospital-level deployment yields a modest return of €0.20 for every euro invested. However, scaling up to the national level increases the return to €4.57 per euro. Further research, conducted in collaboration with hospitals, should be undertaken to test these implications in real-world settings. However, scaling up to the national level increases the return to €4.57 per euro.

Chapter 12

Conclusion

In conclusion, this study highlights that implementing PROMs in Dutch clinical practice faces persistent organizational and system-level barriers, such as unclear PROM ownership, fragmented IT infrastructures, and insufficiently defined workflows.

Patient organizations are uniquely positioned to overcome these challenges by acting as proactive co-designers and advocates who embed explicit PROM responsibilities into care pathways and job descriptions, drive plain-language and multilingual system design, and champion end-user training.

The interviews demonstrated that engaging organisations in the co-design process not only surface resource disparities, where larger groups contend with more barriers despite greater capacity, but also catalyzes a positive shift in awareness and attitudes toward PROMs across all stakeholders . Participants described their ambassadorial role in leveraging credible clinicians and fostering friendly competition through transparent PROM discussion rates to generate gentle peer pressure and bridge the “last mile” of implementation . They further emphasized the need for adaptive measures combining a core set of physical, mental, and social domains with condition-specific add-ons to capture underrepresented outcomes like sexuality and social participation.

Finally, interviewees envisioned the deployment of AI-powered digital nudges, chatbots, automated follow-up prompts, and dynamic dashboards, alongside sustained leadership advocacy at decision-making tables as essential to transforming PROMs from static data collection tools into meaningful, value-driven conversations embedded in routine care.

Lastly, these insights underscore the importance of cross-sector collaboration, bringing together patient organizations, policymakers, clinicians, and IT partners, to develop, implement, and maintain PROM initiatives on a national scale. This fosters a patient-centered, value-based healthcare system in the Netherlands.

Furthermore, the SROI analysis shows that hospital-level deployment yields a modest return of €0.20 per euro invested. However, scaling up to the national level increases the return to €4.57 per euro. This further emphasizes the need for widespread, coordinated efforts to realize the full potential of PROMs.

In summary, by combining the strengths of patient organizations with strategic policy support, technological innovation, and national-scale collaboration, the Netherlands can transform PROMs from an underused tool into a cornerstone of truly patient-centered, value-based healthcare.

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Appendix A

AI Use- Reflection

Throughout this thesis, large language models were used to assist researchers with specific aspects of the master's thesis. Artificial intelligence (AI) tools, such as ChatGPT, assisted with outlining the chapters and refining the language where necessary to enable the reader to frame their main points and propose a correct grammatical structure. Moreover, those tools helped with finding synonyms and rephrasing text. ChatGPT was also used as a search engine, making it easier to find some data such as, for example, the cost of AI development for SROI. As for the layout AI, we were used to brainstorming certain aspects of table contents as well as the input for Overleaf, where the report was created. ChaGPT also helped with structuring tables in LaTeX in a concise, readable way.

Appendix B

Literature review

Table B.1: Included Articles on PROMs Implementation in the Netherlands (1–24)

No.	Citation (APA)	Summary
1	Sipma et al. (2023)	Early PROM implementation in Dutch dialysis care
2	Van Muilekom et al. (2022)	KLIK portal use in over 20 hospitals
3	Billingy et al. (2024)	SYMPRO-Lung ePRO rollout across 14 centres
4	Abma et al. (2019)	PROM integration in Dutch sleep centres
5	Van der Hout et al. (2020)	RCT of Oncokompas in survivorship care
6	De Wit et al. (2019)	National rollout of Oncokompas
7	Mourits et al. (2024)	Routine stroke PROMs in 2 hospitals
8	Rausch-Koster et al. (2024)	CAT-EyeQ PROM study using CFIR
9	Voshaar et al. (2023)	Developed a national standard set of generic PROMs for Dutch specialist care to unify outcome measurement.
10	Van Dalen et al. (2025)	PROM screening in paediatric IBD clinic
11	Scheibe et al. (2020)	PROM implementation in multicenter cancer care programs across Europe.
12	Peeters et al. (2023)	PROM use in neuro-oncology consultations
13	Looijen et al. (2023)	ePROMs in Erasmus MC IMID registry
14	Van Engen et al. (2024a)	Longitudinal PROM integration in VBHC
15	Graupner et al. (2021)	Barriers/facilitators in oncology PROM use
16	Van Egdom et al. (2019)	PROM implementation in breast cancer care
17	Boomstra et al. (2025)	Strategies to improve PROM usage
18	Van Engen et al. (2024b)	EHR-based analysis of PROM response
19	Depla et al. (2023)	PROM/PREM use in obstetric networks
20	Van Cranenburgh et al. (2016)	ePROM pilot in dermatology clinics
21	Van Oers et al. (2021)	CFIR analysis of KLIK portal use
22	Duman-Lubberding et al. (2017)	5-year PROM + nurse consult follow-up
23	Meerhoff et al. (2021)	PROMs for QI in Dutch physiotherapy
24	Wiegel et al. (2023)	RA ePRO registry data analysis
25	Huberts et al. (2024)	PROM adoption barriers in Erasmus MC
26	Veldhuizen et al. (2024)	PROM use in district nursing
27	Klootwijk et al. (2023)	Postpartum PROM/PREM follow-up
28	Brinkman et al. (2019)	PROM uptake in physiotherapy registry
29	Verburg et al. (2021)	Development of outcome indicators
30	Van Engen et al. (2024c)	Clinician use of PROMs in hospital

Table B.2: Included Articles on PROMs Implementation in the Netherlands (25–47)

No.	Citation (APA)	Summary
31	Thomassen et al. (2024)	PROM pilot in colorectal cancer follow-up
32	Amini et al. (2021)	Survey on PROM barriers in academic hospitals
33	Dronkers et al. (2020)	PROM system evaluation in head and neck cancer
34	Depla et al. (2022)	PROM implementation in perinatal networks
35	Schepers et al. (2017)	Real-world KLIK PROM use in paediatric oncology
36	Teela et al. (2021)	National survey on KLIK usage
37	Laureij et al. (2020)	ICHOM PROM applicability in perinatal care
38	Blood et al. (2021)	PROM/PREM use in melanoma registries and related implementation challenges.
39	Van Eenbergen et al. (2019)	Usability of BijKanker ePRO portal
40	Veltkamp et al. (2022)	PROM use in paediatric nephrology
41	Maas et al. (2024)	PROMs in young-adult cancer survivorship
42	Meerhoff et al. (2017)	PROM registry strategy in physiotherapy
43	De Jel et al. (2023)	PROM improvement in head and neck cancer
44	Bennink et al. (2023)	PROM-driven care in multiple myeloma
45	Van Kalsbeek et al. (2023)	PanCareFollowUp PROM rollout (includes NL)
46	Anderson et al. (2024)	An Umbrella Review. Mapping of enablers and barriers to PROMs integration in routine care
47	Groenewegen et al. (2024)	Development and application of Amsterdam PROM Pathway (4 phases, 8 steps)
48	Hays & Quigley (2025)	Challenges and benefits of PREMs and PROMs in ambulatory care.
49	Kidanemariam et al. (2024)	PROM pathway in vestibular-schwannoma care

Table B.3: Current Status on Patient Organisations and PROMs

No.	Citation (APA)	Summary
1	de Jel et al. (2023)	PROM use in Dutch head and neck cancer care; patients want more involvement in acting on results.
2	Blood et al. (2021)	PROM/PREM use in melanoma registries; patient advocacy drove inclusion.
3	Hays & Quigley (2025)	Role of patient councils and co-design in ambulatory PROM/PREM uptake.
4	Sipma et al. (2023)	Early PROM implementation in Dutch dialysis; patient organisation involved in set development.
5	Nguyen et al. (2024)	Limited PROM awareness and use among patient organisations in Quebec.
6	Bootsma et al. (2024)	Crohn's & Colitis NL collaboration to identify patient-prioritised complaints.
7	Hek et al. (2022)	BRIMM EHR–PRO infrastructure co-developed with pelvic health patient association.
8	Oude Voshaar et al. (2023)	National PROM set co-created with umbrella patient organisations.

Appendix C

SROI

Table C.1: Estimated costs for AI in healthcare (June 2025, 1 USD = 0.8672 EUR)
Exchange rate: https://www.exchange-rates.org/exchange-rate-history/usd-eur-2025?utm_source=chatgpt.com

Action	Cost (USD)	Cost (EUR)	Low	Base	High	Source
AI Development	$80,000–$350,000	€69 400–€303 900	43 400.00	217 400.00	434 100.00	https://masterofcode.com/blog/cost-of-ai-in-healthcare
	$50,000–$85,000	€43 400–€73 700	—	—	—	https://www.biz4group.com/blog/healthcare-ai-agent-development
	$100,000–$500,000+	€86 800–€434 100	—	—	—	https://topflightapps.com/ideas/cost-of-ai-in-healthcare/
EHR Integrations	€92–€280	€92–€280	34 700.00	217 400.00	434 100.00	https://callin.io/cost-of-implementing-ai-in-healthcare/
	$150,000–$500,000+	€130 200–€434 100	43 400.00	—	—	https://www.eglobalindia.com/cost-of-building-an-ai-agent-for-healthcare/
	$100,000–$700,000	€86 800–€607 800	—	—	—	https://www.aalpha.net/blog/cost-of-implementing-ai-in-healthcare/?utm_source=chatgpt.com
Cloud Costs	€28,000–€56,000	€28,000–€56,000	28 000.00	42 000.00	56 000.00	https://www.simbo.ai/blog/understanding-the-cost-factors-associated-with-ai-in-healthcare-a-
Maintenance & Support	15–20% of initial development	€10 400–€86 800	6 510.00	38 045.00	86 820.00	https://oyelabs.com/guide-to-ai-development-costs/?utm_source=chatgpt.com
	$50,000–$150,000/year	€43 400–€130 200	—	—	—	https://www.eglobalindia.com/cost-of-building-an-ai-agent-for-healthcare/
Compliance	$200,000–$500,000	€173 600–€434 100	173 440.00	347 200.00	434 100.00	https://www.eglobalindia.com/cost-of-building-an-ai-agent-for-healthcare/
Cybersecurity	$50,000–$150,000	€43 400–€130 200	43 360.00	86 720.00	130 080.00	https://www.eglobalindia.com/cost-of-building-an-ai-agent-for-healthcare/
Training & Development (40 employees)	$5,000–$10,000 per emp.	€4,300–€8,700 per emp.	173 440.00	260 400.00	346 880.00	https://www.openxcell.com/blog/cost-of-ai-in-healthcare/?utm_source=chatgpt.com
Total	—	—	546 250.00	1 209 165.00	1 922 080.00	https://www.eglobalindia.com/cost-of-building-an-ai-agent-for-healthcare/

Table C.2: Cost-effectiveness of PRO symptom-monitoring in oncology: QALY gains per discussion/report

Summary	Years life saved	QALYs per patient	Value of discussion	Adjusted years	Source
A French multicenter randomized trial evaluated web-based PRO surveillance versus standard CT-centered follow-up after lung-cancer treatment. Annual follow-up costs were €941 per patient in the PRO arm vs €1 304 in control, and the PRO strategy yielded an incremental 4.6 QALYs at lower cost, giving an ICER of €20 912 per QALY and a 97% probability of being "very cost-effective" at the €30 000/QALY threshold. In short, online symptom self-reporting both cut surveillance spending and delivered meaningful survival–quality gains, making it a cost-effective alternative to conventional monitoring.	19.0 months versus 12.0 months in control	$35.09 - 30.51 = 4.58$ QALYs	$193 - 133 = 60$ extra consultations; $4.58/60 = 0.0763$ QALY	$0.0763 \times 365 = 27.9$ days	https://pubmed.ncbi.nlm.nih.gov/30776447/
766-patient RCT at Memorial Sloan Kettering compared routine chemotherapy with and without the STAR electronic symptom-monitoring system. At 6 months the PRO arm showed better HRQoL (EQ-5D decline 1.4 vs 7.1), higher proportions with improved HRQoL (34% vs 18%), fewer ER visits (34% vs 41%) and hospitalizations (45% vs 49%), and longer chemo exposure (8.2 vs 6.3 months). One-year OS was higher (75% vs 69%, P = .05) and mean QALY survival rose from 8.0 to 8.7 months (P = .004).	8.7 versus 8.0	$0.7/12 = 0.0583$ QALY	16 visits × 73% ≈ 11.7 reports; $0.0583/11.7 = 0.0050$ QALY	$0.0050 \times 365 = 1.83$ days	https://pubmed.ncbi.nlm.nih.gov/26644527/

Table C.2 continued

Summary	Years life saved	QALYs per patient	Value of discussion	Adjusted years	Source
In a 508-patient UK RCT, the eRAPID platform—weekly online self-reports with automated self-management advice integrated into the EHR—was compared with usual care over 18 weeks. Across all tumour types it delivered a small QALY gain (+0.003 per patient) and slightly lower costs (–£25), giving a 55–58% probability of being cost-effective at NICE's £20–30 k/QALY threshold. Benefits were more pronounced in the early-stage subgroup (63% of participants), where eRAPID saved £727 per patient and increased QALYs by +0.005, clearly dominating usual care.	not mentioned	0.003 (overall) and 0.005 (early)	13.5 × 0.82 = 11.1 "discussions"; 0.003/11.1 = 0.00027 QALY; 0.005/11.1 = 0.00045 QALY	0.00027 × 365 = 0.099 day (2.4 h); 0.00045 × 365 = 0.164 day (4.0 h)	https://ascopubs.org/doi/10.1200/OP.23.00498
Two Swedish open-label RCTs tested the Interaktor app in 149 breast-cancer and 150 prostate-cancer patients. Participants logged symptoms every weekday; high-severity entries triggered nurse callbacks. Mapping EORTC QLQ-C30 to EQ-5D showed an extra 0.0076 QALY per breast patient and 0.0002 QALY per prostate patient at €92 and €43 implementation cost, respectively.	not mentioned	0.0076 (breast)	15 × 5 = 75 reports; ×0.80 = 60; 0.0076/60 = 0.00013 QALY	0.00013 × 365 = 0.0463 day ≈ 1.11 h	https://cancer.jmir.org/2025/1/e53539
Sensitivity Analysis:		**Low:** 0.00013	**Base:** 0.005	**High:** 0.0763	

Table C.3: National Scenario (WTP = €20,000) — Social Return over 5 Years (Discount rate: 3%)

Outcome	Year 0	Year 1	Year 2	Year 3	Year 4	Year 5
Improved QALYs	0	378,600	340,740	306,666	275,999	248,399
Improved Health Literacy	0	7,880,876	7,092,788	6,383,509	5,745,158	5,170,643
Improved Patient Satisfaction	0	1,297,050	1,167,345	1,050,611	945,549	850,995
Total Value	0	9,556,526	8,600,873	7,740,786	6,966,707	6,270,037
Present Value (each year)	0	9,278,180	8,107,148	7,083,916	6,189,829	5,408,589
Total Present Value (PV)						36,067,662
Net Present Value (NPV)						27,228,737
Social Return (per euro invested)						4.08

Table C.4: Hospital Scenario (WTP = €20,000) — Social Return over 5 Years (Discount rate: 3%)

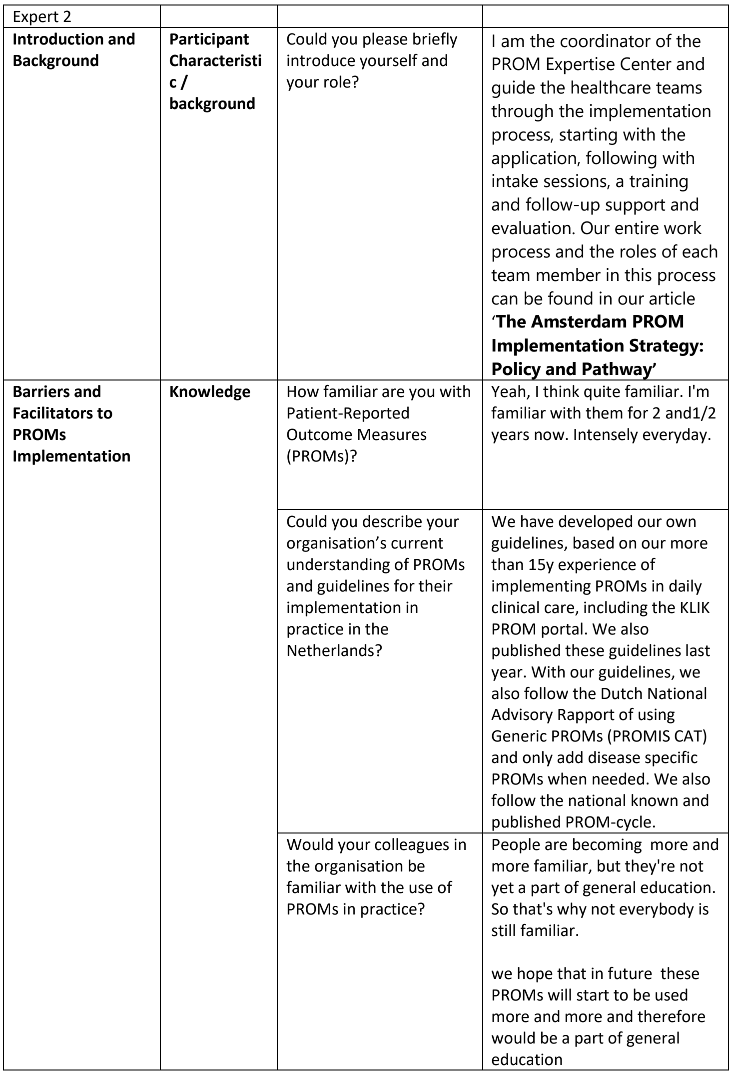
Outcome	Year 0	Year 1	Year 2	Year 3	Year 4	Year 5
Improved QALYs	0	2,313	2,081	1,873	1,686	1,517
Improved Health Literacy	0	48,190	43,371	39,034	35,131	31,618
Improved Patient Satisfaction	0	7,931	7,138	6,424	5,782	5,204
Total Value	0	58,434	52,591	47,332	42,598	38,339
Present Value (each year)	0	56,732	49,572	43,315	37,848	33,071
Total Present Value (PV)						220,538
Net Present Value (NPV)						-988,627
Social Return (per euro invested)						0.18

Table C.5: Hospital Scenario (WTP = €80,000) — Social Return over 5 Years (Discount rate: 3%)

Outcome	Year 0	Year 1	Year 2	Year 3	Year 4	Year 5
Improved QALYs	0	9,250	8,325	7,493	6,743	6,069
Improved Health Literacy	0	48,190	43,371	39,034	35,131	31,618
Improved Patient Satisfaction	0	7,931	7,138	6,424	5,782	5,204
Total Value	0	65,372	58,834	52,951	47,656	42,890
Present Value (each year)	0	63,468	55,457	48,458	42,342	37,998
Total Present Value (PV)						246,721
Net Present Value (NPV)						-962,444
Social Return (per euro invested)						0.20

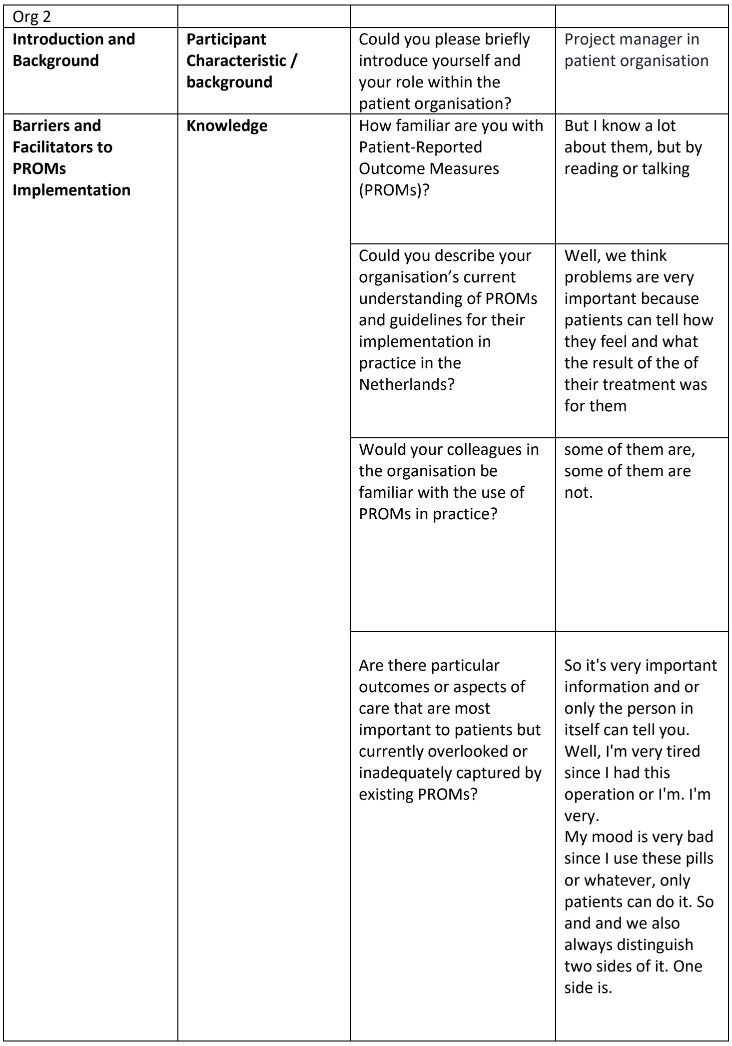
Appendix D

Transcripts



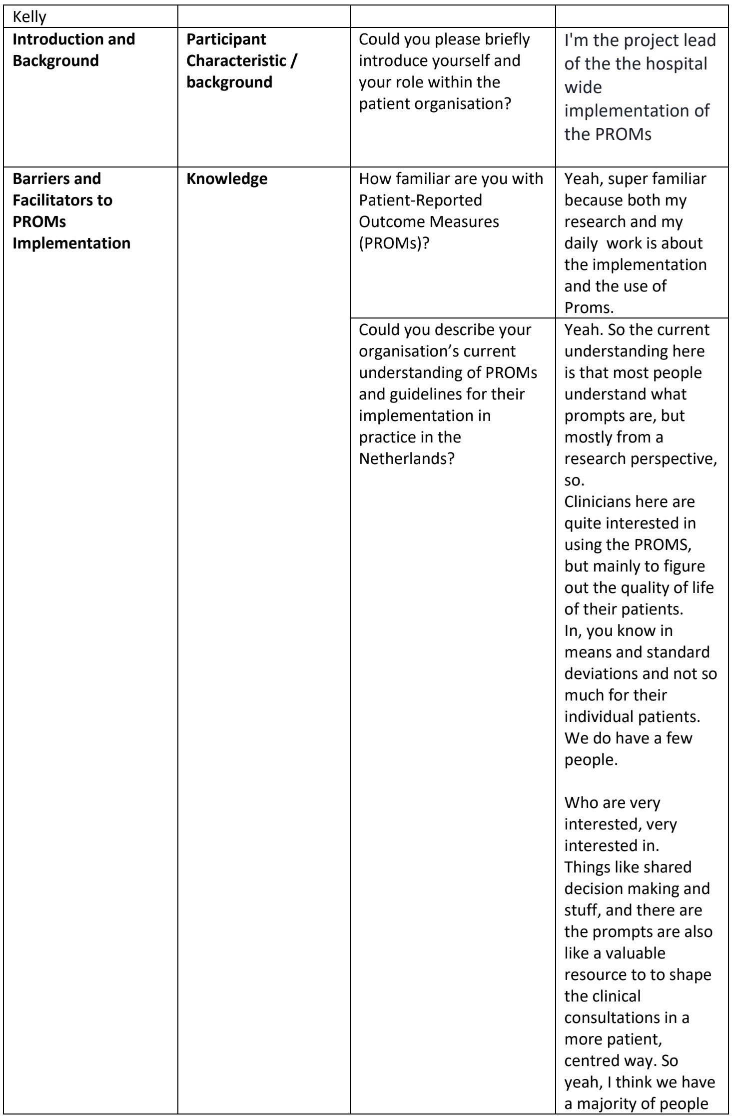
Expert 2			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role?	I am the coordinator of the PROM Expertise Center and guide the healthcare teams through the implementation process, starting with the application, following with intake sessions, a training and follow-up support and evaluation. Our entire work process and the roles of each team member in this process can be found in our article **'The Amsterdam PROM Implementation Strategy: Policy and Pathway'**
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	Yeah, I think quite familiar. I'm familiar with them for 2 and1/2 years now. Intensely everyday.
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	We have developed our own guidelines, based on our more than 15y experience of implementing PROMs in daily clinical care, including the KLIK PROM portal. We also published these guidelines last year. With our guidelines, we also follow the Dutch National Advisory Rapport of using Generic PROMs (PROMIS CAT) and only add disease specific PROMs when needed. We also follow the national known and published PROM-cycle.
		Would your colleagues in the organisation be familiar with the use of PROMs in practice?	People are becoming more and more familiar, but they're not yet a part of general education. So that's why not everybody is still familiar. we hope that in future these PROMs will start to be used more and more and therefore would be a part of general education

Figure D.1: Interview Transcript Expert 2



Org 2			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role within the patient organisation?	Project manager in patient organisation
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	But I know a lot about them, but by reading or talking
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	Well, we think problems are very important because patients can tell how they feel and what the result of the of their treatment was for them
		Would your colleagues in the organisation be familiar with the use of PROMs in practice?	some of them are, some of them are not.
		Are there particular outcomes or aspects of care that are most important to patients but currently overlooked or inadequately captured by existing PROMs?	So it's very important information and or only the person in itself can tell you. Well, I'm very tired since I had this operation or I'm. I'm very. My mood is very bad since I use these pills or whatever, only patients can do it. So and and we also always distinguish two sides of it. One side is.

Figure D.2: Interview Transcript Org 2

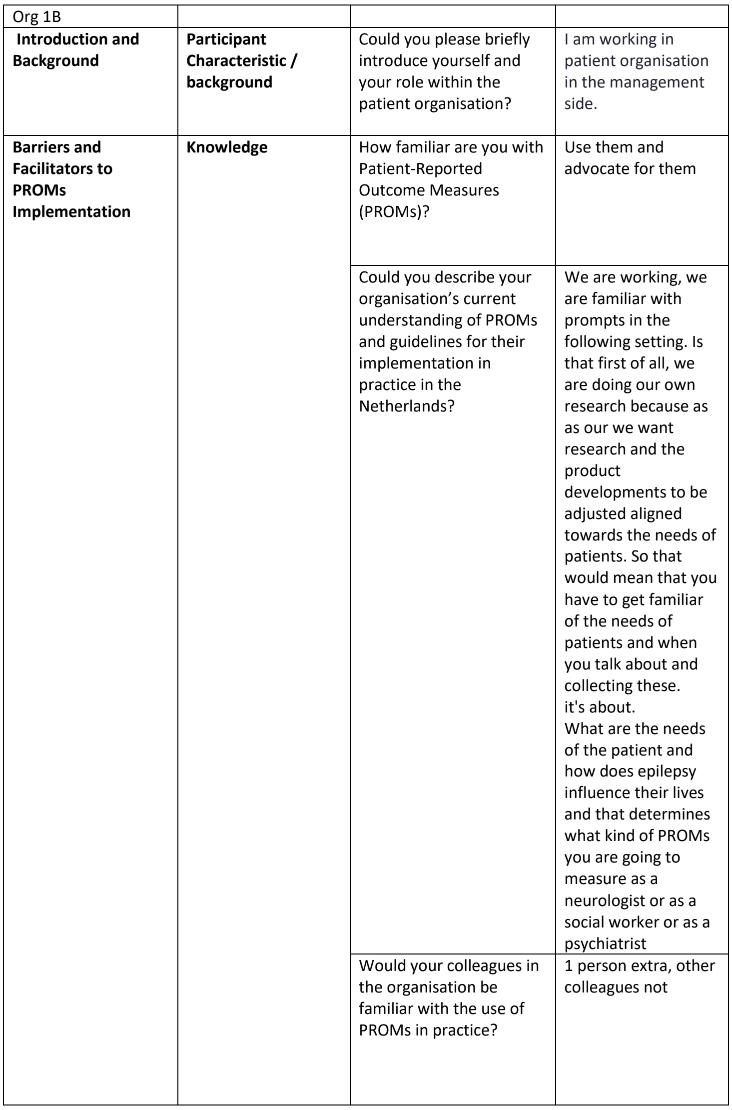


Kelly			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role within the patient organisation?	I'm the project lead of the the hospital wide implementation of the PROMs
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	Yeah, super familiar because both my research and my daily work is about the implementation and the use of Proms.
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	Yeah. So the current understanding here is that most people understand what prompts are, but mostly from a research perspective, so. Clinicians here are quite interested in using the PROMS, but mainly to figure out the quality of life of their patients. In, you know in means and standard deviations and not so much for their individual patients. We do have a few people. Who are very interested, very interested in. Things like shared decision making and stuff, and there are the prompts are also like a valuable resource to to shape the clinical consultations in a more patient, centred way. So yeah, I think we have a majority of people

Figure D.3: Interview Transcript Expert 1

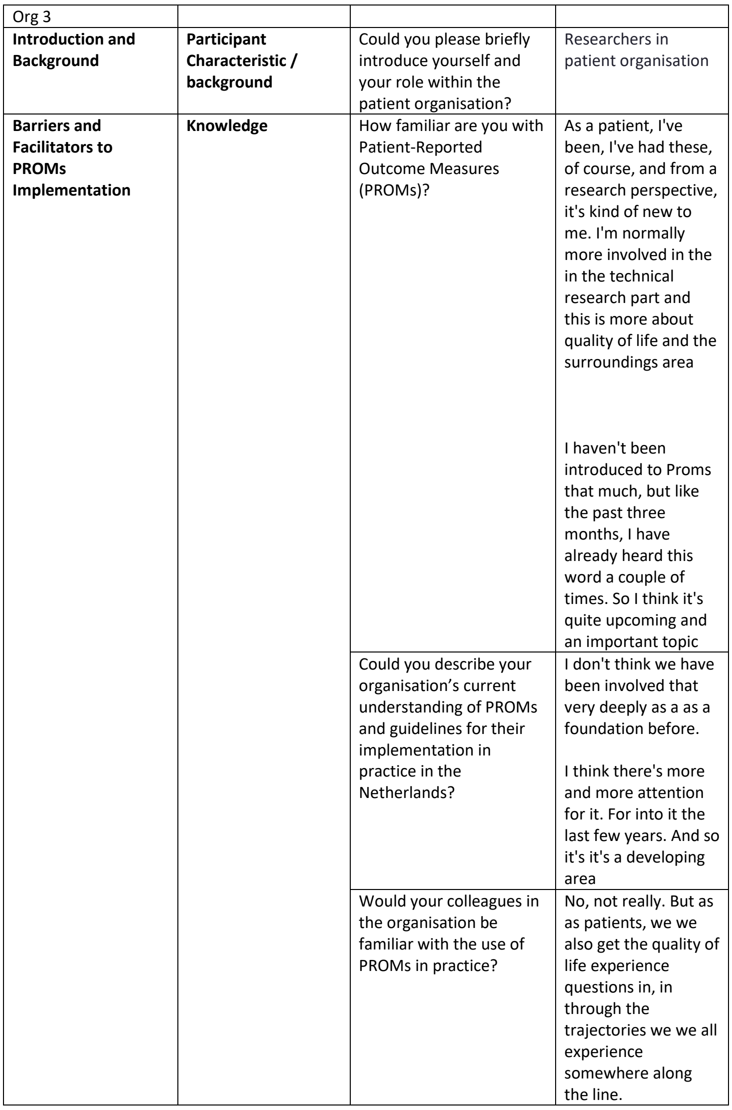
Org 5			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role within the patient organisation?	President of the patient organisation
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	Relatively well, I say average we have we have also worked on the on on the grid project.
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	Not very understanding
		Would your colleagues in the organisation be familiar with the use of PROMs in practice?	In practice they do but I don't think they will call them PROMs
		Are there particular outcomes or aspects of care that are most important to patients but currently overlooked or inadequately captured by existing PROMs?	how do I measure if a if a patient family's happy or not?
Beliefs about consequences		From your perspective, what are the benefits to the implementation of PROMs in the Netherlands?	Oh well, first of all, it's nice to have a common structure. Instead of everybody doing something else, and how do you compare them? Things you cannot compare when there's no standardisation. So I

Figure D.4: Interview Transcript Org 4



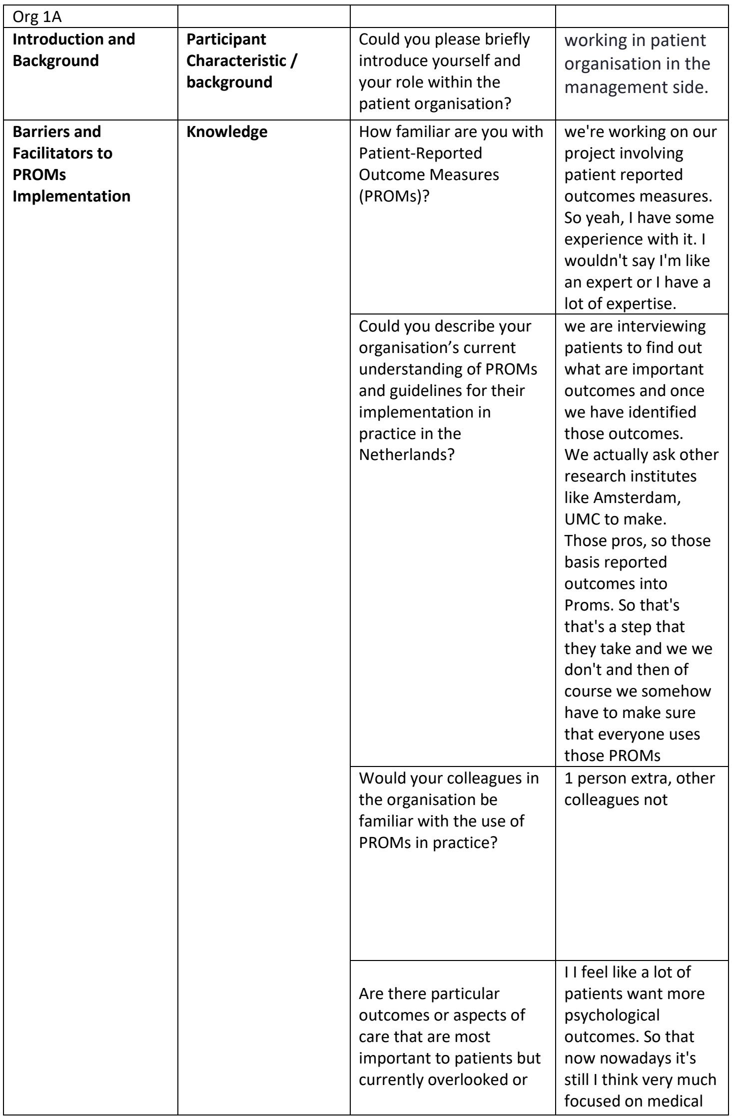
Org 1B			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role within the patient organisation?	I am working in patient organisation in the management side.
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	Use them and advocate for them
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	We are working, we are familiar with prompts in the following setting. Is that first of all, we are doing our own research because as as our we want research and the product developments to be adjusted aligned towards the needs of patients. So that would mean that you have to get familiar of the needs of patients and when you talk about and collecting these. it's about. What are the needs of the patient and how does epilepsy influence their lives and that determines what kind of PROMs you are going to measure as a neurologist or as a social worker or as a psychiatrist
		Would your colleagues in the organisation be familiar with the use of PROMs in practice?	1 person extra, other colleagues not

Figure D.5: Interview Transcript Org 1B



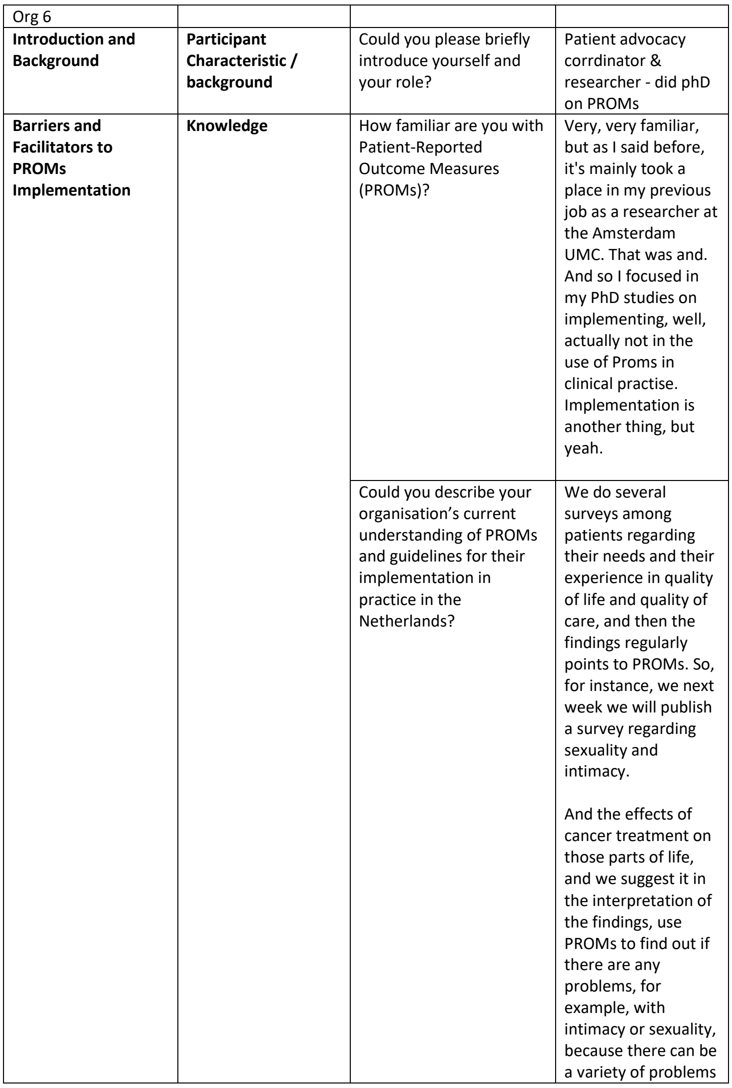
Org 3			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role within the patient organisation?	Researchers in patient organisation
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	As a patient, I've been, I've had these, of course, and from a research perspective, it's kind of new to me. I'm normally more involved in the in the technical research part and this is more about quality of life and the surroundings area I haven't been introduced to Proms that much, but like the past three months, I have already heard this word a couple of times. So I think it's quite upcoming and an important topic
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	I don't think we have been involved that very deeply as a as a foundation before. I think there's more and more attention for it. For into it the last few years. And so it's it's a developing area
		Would your colleagues in the organisation be familiar with the use of PROMs in practice?	No, not really. But as as patients, we we also get the quality of life experience questions in, in through the trajectories we we all experience somewhere along the line.

Figure D.6: Interview Transcript Org 3



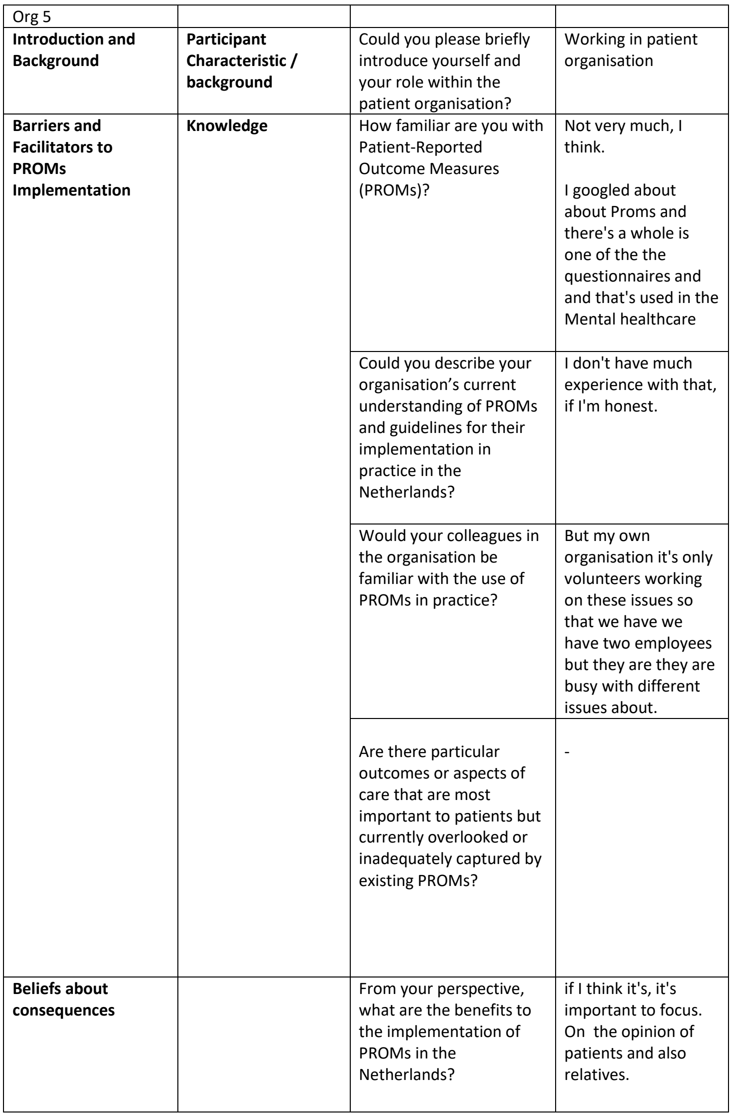
Org 1A			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role within the patient organisation?	working in patient organisation in the management side.
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	we're working on our project involving patient reported outcomes measures. So yeah, I have some experience with it. I wouldn't say I'm like an expert or I have a lot of expertise.
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	we are interviewing patients to find out what are important outcomes and once we have identified those outcomes. We actually ask other research institutes like Amsterdam, UMC to make. Those pros, so those basis reported outcomes into Proms. So that's that's a step that they take and we we don't and then of course we somehow have to make sure that everyone uses those PROMs
		Would your colleagues in the organisation be familiar with the use of PROMs in practice?	1 person extra, other colleagues not
		Are there particular outcomes or aspects of care that are most important to patients but currently overlooked or	I I feel like a lot of patients want more psychological outcomes. So that now nowadays it's still I think very much focused on medical

Figure D.7: Interview Transcript Org 1A



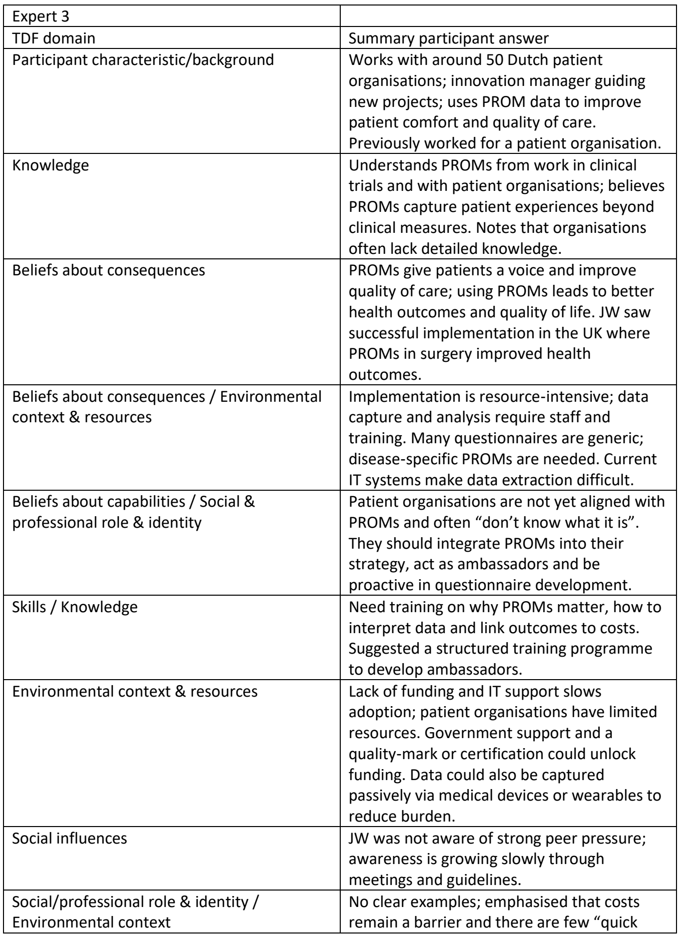
Org 6			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role?	Patient advocacy corrdinator & researcher - did phD on PROMs
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	Very, very familiar, but as I said before, it's mainly took a place in my previous job as a researcher at the Amsterdam UMC. That was and. And so I focused in my PhD studies on implementing, well, actually not in the use of Proms in clinical practise. Implementation is another thing, but yeah.
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	We do several surveys among patients regarding their needs and their experience in quality of life and quality of care, and then the findings regularly points to PROMs. So, for instance, we next week we will publish a survey regarding sexuality and intimacy. And the effects of cancer treatment on those parts of life, and we suggest it in the interpretation of the findings, use PROMs to find out if there are any problems, for example, with intimacy or sexuality, because there can be a variety of problems

Figure D.8: Interview Transcript Org 6



Org 5			
Introduction and Background	**Participant Characteristic / background**	Could you please briefly introduce yourself and your role within the patient organisation?	Working in patient organisation
Barriers and Facilitators to PROMs Implementation	**Knowledge**	How familiar are you with Patient-Reported Outcome Measures (PROMs)?	Not very much, I think. I googled about about Proms and there's a whole is one of the the questionnaires and and that's used in the Mental healthcare
		Could you describe your organisation's current understanding of PROMs and guidelines for their implementation in practice in the Netherlands?	I don't have much experience with that, if I'm honest.
		Would your colleagues in the organisation be familiar with the use of PROMs in practice?	But my own organisation it's only volunteers working on these issues so that we have we have two employees but they are they are busy with different issues about.
		Are there particular outcomes or aspects of care that are most important to patients but currently overlooked or inadequately captured by existing PROMs?	-
Beliefs about consequences		From your perspective, what are the benefits to the implementation of PROMs in the Netherlands?	if I think it's, it's important to focus. On the opinion of patients and also relatives.

Figure D.9: Interview Transcript Org 5



Expert 3	
TDF domain	Summary participant answer
Participant characteristic/background	Works with around 50 Dutch patient organisations; innovation manager guiding new projects; uses PROM data to improve patient comfort and quality of care. Previously worked for a patient organisation.
Knowledge	Understands PROMs from work in clinical trials and with patient organisations; believes PROMs capture patient experiences beyond clinical measures. Notes that organisations often lack detailed knowledge.
Beliefs about consequences	PROMs give patients a voice and improve quality of care; using PROMs leads to better health outcomes and quality of life. JW saw successful implementation in the UK where PROMs in surgery improved health outcomes.
Beliefs about consequences / Environmental context & resources	Implementation is resource-intensive; data capture and analysis require staff and training. Many questionnaires are generic; disease-specific PROMs are needed. Current IT systems make data extraction difficult.
Beliefs about capabilities / Social & professional role & identity	Patient organisations are not yet aligned with PROMs and often "don't know what it is". They should integrate PROMs into their strategy, act as ambassadors and be proactive in questionnaire development.
Skills / Knowledge	Need training on why PROMs matter, how to interpret data and link outcomes to costs. Suggested a structured training programme to develop ambassadors.
Environmental context & resources	Lack of funding and IT support slows adoption; patient organisations have limited resources. Government support and a quality-mark or certification could unlock funding. Data could also be captured passively via medical devices or wearables to reduce burden.
Social influences	JW was not aware of strong peer pressure; awareness is growing slowly through meetings and guidelines.
Social/professional role & identity / Environmental context	No clear examples; emphasised that costs remain a barrier and there are few "quick

Figure D.10: Interview Transcript Expert 3