NEJM Catalyst | Innovations in Care Delivery

CASE STUDY

The Amsterdam PROM Implementation Strategy: Policy and Pathway

Anouk Groenewegen, MSc, Maud M. van Muilekom, PhD, Cenne H.A.M. Sieben, MSc, Michiel A.J. Luijten, PhD, Sharon L. Janssen, MSc, Nynke Venema-Taat, MSc, Mira Korte, MSc, Caroline B. Terwee, PhD, Piet M. ter Wee, MD, PhD, Hedy A. van Oers, PhD, Lotte Haverman, PhD

Vol. 5 No. 7 | July 2024

DOI: 10.1056/CAT.23.0414

Patient-reported outcome measures (PROMs) are an essential tool in practicing value-based health care and patient-centered care. When used in clinical care, PROMs have shown positive effects, including better patient–clinician communication, improved quality of life, and even increased survival. Despite these promising effects, however, real-life implementation of PROMs remains challenging. Therefore, in 2019, the Amsterdam PROM Expertise Center (PEC) was initiated; this multidisciplinary team is dedicated to guiding the implementation of PROMs in the Amsterdam University Medical Centers using an Epic/MyChart electronic health record (EHR). Based on experience and scientific evidence, PEC developed both the PROM policy consisting of eight recommendations and the Amsterdam PROM Pathway, a practical guideline to implement PROMs in clinical care across diverse patient populations. The Amsterdam PROM Pathway consists of four phases (registration, design, preparation, and implementation) involving eight steps. After a clinician identifies the need for PROM use by registering at PEC (Step 0), the health care team will initially conduct a content intake session with PROM experts to identify and choose appropriate patient-reported outcomes and corresponding PROMs and to define a suitable workflow (Step 1). Second, the technical intake occurs with application specialists to establish the workflow within the EHR. In the third and fourth steps, the PROMs are integrated into the EHR, and the construction is rigorously tested. During the fifth step, the entire health care team undergoes comprehensive training in both theoretical knowledge and practical skills, preparing them for the subsequent go-live

phase with PROMs in Step 6. Finally, the seventh step involves a short-term and annual evaluation of the implementation process to identify problems that may have arisen and to provide possible solutions. The initiation of PEC and the development of the PROM policy and the Amsterdam PROM Pathway have been instrumental in overcoming hurdles on multiple levels: the hospital, the information and communications technology system, the PROMs, the clinician, and the patient. Improving PROM implementation requires an ongoing process supported by current and future research and implementation projects on, for instance, the optimization of EHR usage and inclusivity of PROMs for all patients. Since launching its Amsterdam PROM Implementation Strategy, the organization has provided PROM-specific training to hundreds of clinicians and has seen health care team PROM engagement grow from 15 when going live in 2019 to 74 in April 2024. In addition, the number of health care teams using one or more Patient-Reported Outcomes Measurement Information System measures in their PROM sets has increased from 0 in 2019 to 26 in April 2024.

KEY TAKEAWAYS

- Adopt a systematic yet flexible approach that is tailored to accommodate diverse workflows and schedules of health care teams.
- Ensure the inclusion of every team member, including supporting staff, from the outset of the implementation process for efficiency.
- Share experiences from clinicians and relevant scientific publications on generic patient-reported outcome measures (PROMs) to educate and inform other health care teams — internal and external — about their benefits.
- Conduct PROM evaluations with health care teams and use the input to optimize clinician training by emphasizing the importance of discussing PROM outcomes with patients, offering communication guidance, and showing how to access PROMs in electronic health record systems.
- Recognize low health and digital literacy as common barriers for patients completing PROMs; advocate for further studies to enhance accessibility for all patients.
- Always prioritize discussing PROM outcomes with patients, reinforcing the importance of patient involvement in understanding and addressing their health.

The Challenge

Value-based health care (VBHC) and patient-centered care (PCC) are worldwide, actively endorsed health care delivery models with a common aim of improving health outcomes important to patients.[1,2] Essential tools for measuring outcomes that matter to patients are patient-reported outcome measures (PROMs). PROMs are standardized questionnaires completed by patients to assess a range of patient outcomes, including: symptoms; physical, mental, and social functioning; and overarching health outcomes. PROMs can be used for several purposes. Originally, they were developed for scientific research to assess treatment effectiveness in clinical trials.[3] PROMs can additionally serve to gain insight into the quality of care by comparing aggregated PROM data within and across health care teams and institutions.[4] Finally, PROMs can be used on the individual patient level in clinical care.

Using PROMs in clinical care usually involves completion of PROMs before an outpatient visit, after which responses are visualized in a dashboard for both patients and clinicians. Subsequently, the clinician and the patient can discuss the PROM outcomes during consultation. In this manner, PROMs can support screening and monitoring of a patient's health status, promote PCC (by assessing patient's perspectives), and guide clinical decision-making.[5] Previous studies have shown positive effects of using PROMs in clinical care, such as better patient–clinician communication, higher quality of life and other health outcomes, and even increased survival.[6]

Even with these promising effects, real-life implementation of PROMs remains challenging. Barriers exist on multiple levels, including the hospital, the information and communications technology (ICT) system, the PROMs themselves, the clinician, and the patient.[7-10] Subsequently, PROMs are not successfully implemented and used in clinical care, by which intended effects are not reached.

Despite more than a decade and a half of experience in PROM activity, we are still faced with numerous implementation challenges across these multiple levels, which are discussed in the current case study. Adding to the complexity was the administrative merger in 2018 of two academic hospitals, the Academic Medical Center (AMC) and the VU University Medical Center (VUmc), to form Amsterdam University Medical Centers (UMC), a large tertiary hospital in the Netherlands with more than 19,500 staff members. This necessitated adjustments in clinical workflows of multiple health care teams that already were or would be using PROMs.

The Goal

To overcome the implementation challenges on multiple levels, Amsterdam UMC established a multidisciplinary PROM implementation team to both develop a PROM policy and to actively guide centralized, evidence-based implementation of PROMs into routine clinical care.

> *Within the Amsterdam University Medical Centers, the primary goal of implementation is supporting clinical care, and secondary goals may be quality control or research practices."*

The Execution

In 2019, the board of directors of Amsterdam UMC, advised by the hospital's Department of Care Support and Strategy and Innovation, made a strategic decision to allocate resources for implementation of PROMs in clinical care as part of VBHC[11] using the electronic health record (EHR) Epic/MyChart to overcome previously mentioned barriers. A dedicated and multidisciplinary team was initiated: the Amsterdam PROM Expertise Center (PEC). Subsequently, PEC — together with various PROM, methodologic, and implementation experts — developed a PROM policy, which consists of eight recommendations. These were formulated based on the PROM cycle, the literature, and our more than 15 years of experience with implementing PROMs using the evidence-based KLIK PROM portal.[12-14] (The stand-alone KLIK PROM portal has been active since 2011, starting at Emma Children's Hospital. Currently, health care teams are using KLIK, implemented from the bottom up, in more than 40 Dutch hospitals, mainly in pediatrics. Over those years, it became clear that training and evaluation are key, hence the prominent place in our policy.)

The PROM cycle is a framework consisting of eight steps that are based on existing resources and were developed by using an iterative, user-centered design (Table 1).

After a clinician has identified the need for a PROM (Step 0), the submission is reviewed, and if the request regarding the objective and the content of the PROMs adheres to our policies, it can proceed to Step 1. Any clinician may submit an intake form, but we ask the clinician to inform the entire health care team about the request and ask for their full commitment.

In accordance with the first step of the PROM cycle (to determine the objective), our PROM policy starts with component 1: establishing the intended goal of the implementation, the target population, and the setting. Within the Amsterdam UMC, the primary goal of implementation is supporting clinical care, and secondary goals may be quality control or research practices. After Steps 2 and 3 of the PROM cycle, the patient-reported outcomes (PROs) and PROMs should be selected with input from patients, from the existing literature or focus groups; this aligns with policy component 2.[12,18] Based on the literature and our experience, we advise health care teams to select generic PROMs and only add disease-specific PROMs when necessary (policy component 3). Generic PROMs are applicable to the entire population, and they thereby reduce the burden for patients with comorbidity (who often receive multiple disease-specific PROMs per outcome), simplify the interpretation of PROM outcomes for clinicians, and make comparisons across patient populations possible.[14,15] More specifically, to reduce the patient burden (which aligns with policy component 4),[19] we advise using the generic Patient-Reported

Table 1. The PROM Cycle and the Aligned PROM Policy

PROM Cycle Phase	PROM Cycle Step	PROM Policy Component
1. Goal	1. Determine objective: (a) individual patient care, (b) quality improvement, (c) accountability	1. Start with the intended goal of implementation (clinical care), the target population, and the setting
2. Selection	2. Select PROs	2. Select PROs and PROMs with input from patients 3. Use generic PROMs (e.g., PROMIS CAT) when applicable/possible and disease-specific PROMs when necessary[14,15]
	3. Select PROMs	
	4. Test the PROM (go back if it does not work)	
3. Indicator*	5. Define the indicator	(As the policy focuses on objective 1a, we have no corresponding policy regarding the indicator)
	6. Test the indicator (go back if it does not work)	
4. Use	7. Use the PROM	4. Limit the burden for patients to approximately 30 questions or 10 minutes
	8. Maintenance and evaluation	5. Visualize outcomes on comprehensible and attractive dashboards for patients and clinicians[16]
		6. Emphasize the importance to always discuss PROMs with patients during consultation
		7. Educate both clinicians and patients in the use and administration of PROMs[17]
		8. Evaluate the PROM implementation periodically

PROM = patient-reported outcome measure, PRO = patient-reported outcome, PROMIS = Patient-Reported Outcomes Measurement Information System, CAT = Computerized Adaptive Test. *The interpretation of Phase 3 is dependent on the goal, the target population, and the setting that are determined in Phase 1.[12] Because our primary goal is to use PROMs to support daily clinical care (a), Phase 3 is not relevant to our policy; however, it may be relevant for health care teams with a secondary role to use PROMs for quality registration (b).
Source: The authors, informed by the citations within the table

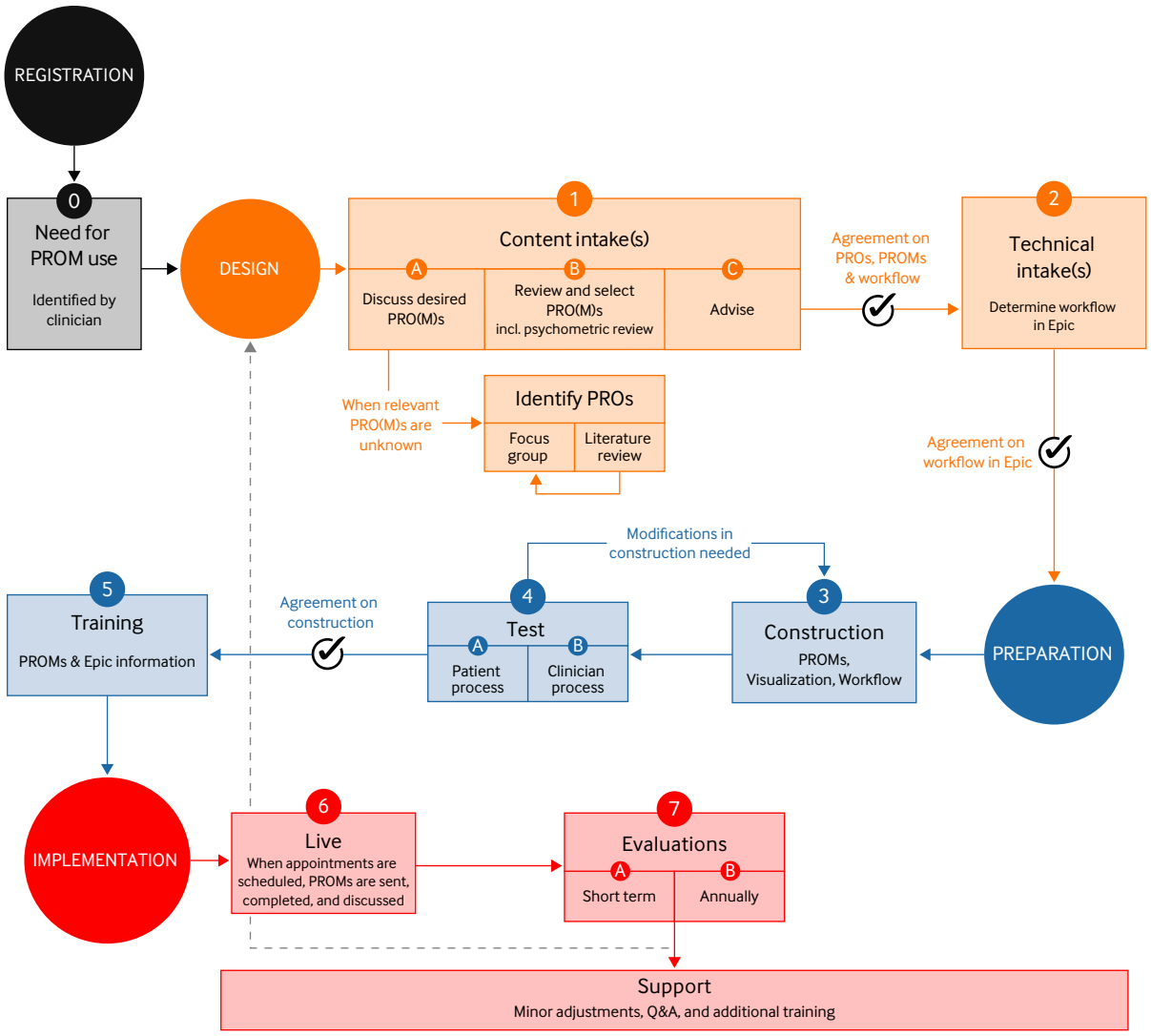
Outcomes Measurement Information System (PROMIS) Computerized Adaptive Tests (CATs) because the items administered to the patient are based on responses given to previously answered items and are more tailored to the patient's situation. Because we use the PROMs for individual patient care, we know from our experience and the literature[20] that it is essential to discuss the PROM outcomes with patients during consultations, which aligns with policy component 6. To support this discussion, we aim to visualize the outcomes in a manner as comprehensible and attractive as possible for the benefit of both the patients and the clinicians (policy component 5).[16] Educating clinicians in the use and administration of PROMs, including their visualization (which aligns with policy component 7),[17] and evaluating the PROM implementation (Step 8 of the PROM cycle, which aligns with policy component 8) are the final two essential policy components to effectively optimize the use of PROMs in clinical care.

To execute the PROM policy and to guide the implementation of PROMs in clinical care, PEC developed the Amsterdam PROM Pathway as a practical guideline. With the pathway, we aim to implement PROMs in clinical care (following the recommendations of the PROM policy) in a centralized way across diverse patient populations throughout the entire Amsterdam UMC. The Amsterdam PROM Pathway consists of the following phases: registration, design, preparation, and implementation (Figure 1 and Table 2).

FIGURE 1

The Amsterdam PROM Pathway

This figure depicts the Amsterdam Patient-Reported Outcome Measure (PROM) Pathway process from phase 0 (registration), with the single step in which the original need for a PROM is identified by a clinician, to the two-step design phase to address, first, the clinical workflow and content of the patient-reported outcomes (PROs)/PROMs and second, the technical workflow of the PROM request. The pathway then proceeds to the three-step preparation phase to address construction, testing, and training and, finally, the two-step implementation phase to address and support the live process and evaluations. The time from registration to implementation optimally ranges from 3 to 4 months, but that can vary based on the individual case.



incl. = including, Q&A = question and answer.
Source: The authors

Table 2. The Four Phases of the Amsterdam PROM Pathway with a Detailed Description of the Eight Steps, the People Involved, and Associated Tasks

Phase	Steps		Involved People	Tasks/Actions
1. Registration	0. The need for PROM use is identified		• Clinician (champion)* • PEC: coordinator • OCIT**	Clinicians are asked to complete an intake form about the objective of the request, preferred PROs and PROMs, and details about the patient group and workflow.
2. Design	1. Content intake(s)	1a. Discuss desired PROM(s) and PRO(s)	• Clinician (champion/ health care team) • PEC: coordinator and PROM implementation expert • OCIT	The preferred PROs and PROMs are discussed with clinicians during a first meeting. When the preferred PROs are known, the preferred PROMs are discussed, and the clinical workflow is clarified, including which outpatient clinic visits should be linked to the PROMs and how often the PROMs need to be administered.
		1b. Identify PROs, review and select PROMs	• PEC: PROM implementation expert, psychometrician • Clinician (champion/ health care team)	When relevant PROs are not yet known, focus groups with patients are organized (e.g., Furumaya et al.[18]), or a literature search is performed to identify these PROs. Based on the relevant PROs, PROMs are selected, in line with the PEC policy (Table 1), to conform to the recommended standard set of generic PROMs.[16] Psychometric properties (validity and reliability), availability of a Dutch translation of the PROM and reference values, the burden for the patient, and the license of PROMs are important aspects.
		1c. Advise	• Clinician (champion/ health care team) • PEC: PROM implementation expert	A comprehensive written report is prepared by PEC, outlining advice on the recommended PROs and PROMs tailored to the specific patient group. This report undergoes approval by the health care team, ensuring alignment and agreement on the chosen PROs and PROMs for implementation.
	2. Technical intake(s)		• Clinician (champion/ health care team) • PEC: coordinator and application specialists • OCIT	The incorporation of the PROMs within the workflow of Epic EHR is discussed as well as the possibilities of the PROM construction and visualization. This discussion is supported by a document that is completed beforehand by the health care team.
3. Preparation	3. Construction		• PEC: application specialists • Clinician (champion)	The PROMs, their visualization, and their workflow are constructed in the Epic EHR. The construction process is expedited when the preferred PROMs are already integrated into Epic EHR for use by other health care teams, reducing the time required for setup and configuration.

Table 2. The Four Phases of the Amsterdam PROM Pathway with a Detailed Description of the Eight Steps, the People Involved, and Associated Tasks (cont.)

Phase	Steps		Involved People	Tasks/Actions
	4. Test	4a. Patient process 4b. Clinician process	• PEC: coordinator, PROM implementation expert, and application specialists • Clinician (champion)	The construction of the patient and clinician process in the Epic EHR is tested to check whether all questions and the scoring of the PROMs are built in correctly as well as the visualization of PROM outcomes.
	5.Training		• PEC: coordinator, PROM implementation expert, and application specialists • Health care team	The training is mandatory for the entire health care team to prepare them to work with the PROMs.[17] This training encompasses several aspects: a background on what PROMs are and how they are used, an explanation about the selected PROMs, how these PROMs can be sent to the patients via the Epic EHR, how the outcomes can be viewed and interpreted, and suggestions for discussing PROMs with patients. Afterward, supportive documents are available.
4. Implementation	6. Live		• PEC: application specialists • Health care team • Patients	The PROMs go live. From this moment, the PROMs are available in the Epic EHR and can be used by the health care team.
	7. Evaluations	7a. Short term 7b. Annually	• PEC: coordinator, PROM implementation expert, and application specialists • Health care team	Short-term (within a few months after the start) and long-term (annual) evaluations with the health care team are held. In these meetings, problems with the implementation can be identified, and satisfaction with the content of the PROMs is evaluated. Moreover, insights into experiences are valuable to optimize the Amsterdam PROM Pathway.
	Support (ongoing)		• Clinician (health care team) • PEC: PROM implementation experts and application specialists • OCIT	Slight modifications can be executed, inquiries can be addressed, and supplementary training sessions can be organized.

PROM = patient-reported outcome measure, PEC = PROM Expertise Center, OCIT = outpatient clinic implementation team, PRO = patient-reported outcome, EHR = electronic health record. *A champion is the initiator and contact person of the health care team during the PROM implementation process. **The OCIT provides hands-on assistance for the implementation of various innovations at the outpatient clinic. Source: The authors, informed by the citations within the table

Here, we offer detail on the phases of the Amsterdam PROM Pathway process:

- **Phase 1: Registration.** The PROM Pathway starts with Step 0, when the clinician (champion) contacts PEC or the Outpatient Clinical Implementation Team (OCIT) to express their interest in using PROMs in clinical care.

- **Phase 2: Design.** Subsequently, the design phase starts, consisting of the content and technical intakes. During the content intake, the champion and PROM implementation experts discuss the clinical workflow and decide on the preferred PROs and PROMs. When PEC and the health care team have reached agreement on the chosen PROs and PROMs, the

technical intake takes place, during which the workflow of PROMs in the Epic EHR system as well as the PROM construction and visualization possibilities are discussed.

- **Phase 3: Preparation.** When the PROs, PROMs, workflow, and technical aspects are agreed on, the preparation phase is initiated. This phase starts with the construction of the PROMs, the visualization, and the workflow in the Epic EHR. The construction is subsequently tested, and the mandatory training for the health care team is planned and executed.

> *"The Patient-Reported Outcome Measure Pathway process optimally takes approximately 3 to 4 months from registration to go live."*

- **Phase 4: Implementation.** After the preparation phase, the implementation phase starts. From this moment, the team is live; the PROMs are available in the Epic EHR and can be used by the health care team. The final step of the implementation is a short-term (within a few months after start) evaluation and a long-term (annual) evaluation with the health care team. To facilitate the implementation, PEC and OCIT are always available for ongoing support.

The Amsterdam PROM Pathway process optimally takes approximately 3 to 4 months from registration to go live. The design phase can be finalized within 4 weeks, construction takes approximately 6 weeks, testing and modifications take about 4 weeks, and, finally, preparing and carrying out the training to go live take 1 week. However, these phases can take more or less time depending on, for example, the chosen PROMs, the availability and responsiveness of the health care team, the workload of the PEC, and the complexity of the workflow in the Epic EHR. In addition, implementation differences among various patient groups are present regarding the PROM administration frequency (e.g., once a year or every visit) and timing (e.g., before and after surgery), the mode of administration (automatic or manual), and which clinician discusses the PROMs.

Hurdles

During the real-world implementation of PROMs in clinical care, we faced several barriers, similar to those in other PROM implementation initiatives.[7] These barriers can be categorized as occurring at the hospital, ICT, PROM, clinician, or patient level (Table 3).[8-10]

Since its establishment in 2019, PEC has made significant steps through the implementation of the PROM policy and pathway protocols. Although many barriers have been successfully addressed, several persist. In the following subsections, we delineate both the resolved barriers and those that continue to challenge our efforts.

Hospital

The Amsterdam UMC was originally divided into two university medical centers (AMC and VUmc) with the same EHR system (Epic) and partly overlapping clinical divisions; however,

Table 3. PROM Implementation Barriers in Clinical Care on Multiple Levels

Level	Barriers
Hospital	• Other priorities, resulting in no provision of financial support and resources[7,10] • Lack of knowledge on how to fit PROMs into the workflow[7,8]
ICT	• Nonautomated PROM data collection[7,8] • Low user friendliness of PROM data collection system; difficult workflow and suboptimal PROM visualization[7,8] • No interconnectedness between PROM data collection systems • EHR only accessible for native (Dutch) speakers
PROMs	• Long (burdensome) PROMs with irrelevant questions[8] • High number of different PROMs recommended for different patient groups, resulting in a high burden for (comorbid) patients and a high financial and ICT burden to maintain and sustain[8] • PROM scores not comparable due to different scoring methods
Clinician	• Time and resources[7,8] • Lack of knowledge on how to utilize and interpret PROMs[8,9] • Insufficient training and hands-on support[8,10]
Patient	• Lack of knowledge about the goal of PROMs[8] • Lack of knowledge on how to utilize and interpret PROMs[8] • Lack of focus on appropriate PROMs for patients with communication vulnerabilities

PROM = patient-reported outcome measure, ICT = information and communications technology, EHR = electronic health record. Source: The authors, informed by the citations within the table

there were different clinical and technical workflows. Until 2019, there were many isolated initiatives for administering PROMs in the Amsterdam UMC as well as an abundance of PROMs used. Centralization and knowledge to implement PROMs in existing clinical workflows were lacking. In addition, due to existing functional specialization and distinction of two university medical centers (AMC and VUmc) — which merged into one entity (Amsterdam UMC) in June 2018 — there had been a lack of priority to implement PROMs. This changed in 2019 when the board of directors supported the initiation and continuous financial security of PEC, by which they increased resources and facilitated centralizing knowledge on PROM implementation. Also, they actively endorse using PROMs in our hospital for individual patient care and quality improvement, by which PROMs gained attention and importance across all managers of the hospital's health care teams.

> *"Disease-specific patient-reported outcome measures are only added when they touch upon patient-reported outcomes that are not covered by the generic patient-reported outcome measures and are proven to be important for the specific patient population."*

Information and Communications Technology

PEC implements PROMs through the Epic EHR, enabling an integrated and automated PROM data collection system. However, we do experience some ICT barriers that we hope to resolve in the future:

- There is a wide array of options within the Epic EHR system for clinicians to access PROM outcomes, providing flexibility, but also causing some confusion. To address this, we are focusing on delivering more personalized guidance and comprehensive explanations regarding PROM visualization options during our training sessions.

- From the literature, there is an evidence-based optimal visualization of PROM outcomes available.[16,21] Over the years, parts of this visualization have been integrated within Epic (e.g., colors to individual items). However, several visualization options (e.g., graphs with colors and reference lines) will hopefully be realized in the near future.

- In the Netherlands, health care institutions independently selected their EHR and PROM data collection systems, which makes it difficult to exchange data between hospitals. Although more possibilities are becoming available to exchange basic patient information between different systems, the options for exchanging PROM data remain limited.

- In our hospital, the Epic EHR patient platform — MyChart — is only available in Dutch, which excludes patients with low proficiency in the Dutch language.

Patient-Reported Outcome Measures

PEC's strategy of prioritizing generic PROMs (more specifically, PROMIS CATs) and selectively adding disease-specific ones when necessary has significantly mitigated barriers at the PROM level. To elucidate, disease-specific PROMs are only added when they touch upon PROs that are not covered by the generic PROMs and are proven to be important for the specific patient population. Moreover, when a health care team is already making use of PROMs via other modes of administration (e.g., pen and paper), we collaboratively discuss whether to digitalize, replace, or remove these PROMs. Aside from lowering the patient burden and enabling comparison across patient populations, using a limited number of generic PROMs also reduces costs of ICT to maintain and sustain the electronic PROMs. However, certain health care teams continue to exhibit reluctance in adopting PROMIS CATs. This hesitation stems from ingrained habits, considerations rooted in research practices, or a preference to adhere to national quality registries' recommendations regarding alternative PROMs.

The introduction of a standard set of generic PROMs in 2022, supported by the Dutch Ministry of Health, presents a promising opportunity for change in the future.[15] In addition, the ongoing development of crosswalks between traditional PROMs and PROMIS measures via platforms, such as PROsetta Stone, aims to establish a universal, standardized metric, potentially easing the transition and encouraging broader adoption.

Clinicians

To educate and motivate the health care teams, PEC ensures the identification of a team champion to take the lead in the PROM implementation process. This individual takes the lead, offering guidance and fostering enthusiasm within the team from the start (in Step 1 of the

Amsterdam PROM Pathway). In the fifth step of the Amsterdam PROM Pathway, all members of the health care team participate in a 1-hour training session before integrating PROMs into clinical care. This training ensures comprehensive understanding and readiness among the team for effective PROM utilization, overcoming the knowledge barrier within the team by teaching theory and practical skills on what PROMs are. In addition, the training covers how PROM outcomes can be interpreted and discussed with patients, what PROMs can add to the care that clinicians deliver, and where the PROMs can be found in the Epic system. Despite training efforts, clinicians still encounter challenges, such as time constraints for discussing PROMs and uncertainty regarding handling poor PROM outcomes during consultations. Therefore, we are implementing hands-on support at the outpatient clinic and optimizing the PROM training by adding specific PROM communication guidance and advice on using PROMs in the shared decision-making process.

> *"Despite training efforts, clinicians still encounter challenges, such as time constraints for discussing patient-reported outcome measures and uncertainty regarding handling poor patient-reported outcome measure outcomes during consultations."*

Patients

PROM completion is important for monitoring individual patient progress as well as for obtaining reliable aggregated PROM data (e.g., for evaluating and predicting outcomes and outcome trajectories).[15] Achieving a high response rate can, however, be a challenging endeavor. To encourage patients to complete PROMs, PEC provides instructions and explanations within the patient's information letter and the EHR, highlighting the importance and benefits of completing PROMs. Moreover, patients are increasingly involved in research and implementation projects aimed at pinpointing relevant PROs and identifying appropriate PROMs. PEC is currently performing a project to optimize patient education about PROMs by developing digital informative flyers and educational videos and by exploring the possibility of showing information about PROMs in the waiting room. Also, we aim to develop PROMs for patients with communication vulnerabilities, such as low health literacy (affecting one in four Dutch adults[22]), who are currently underrepresented.

The Team

The PEC is a multidisciplinary team (Figure 2).

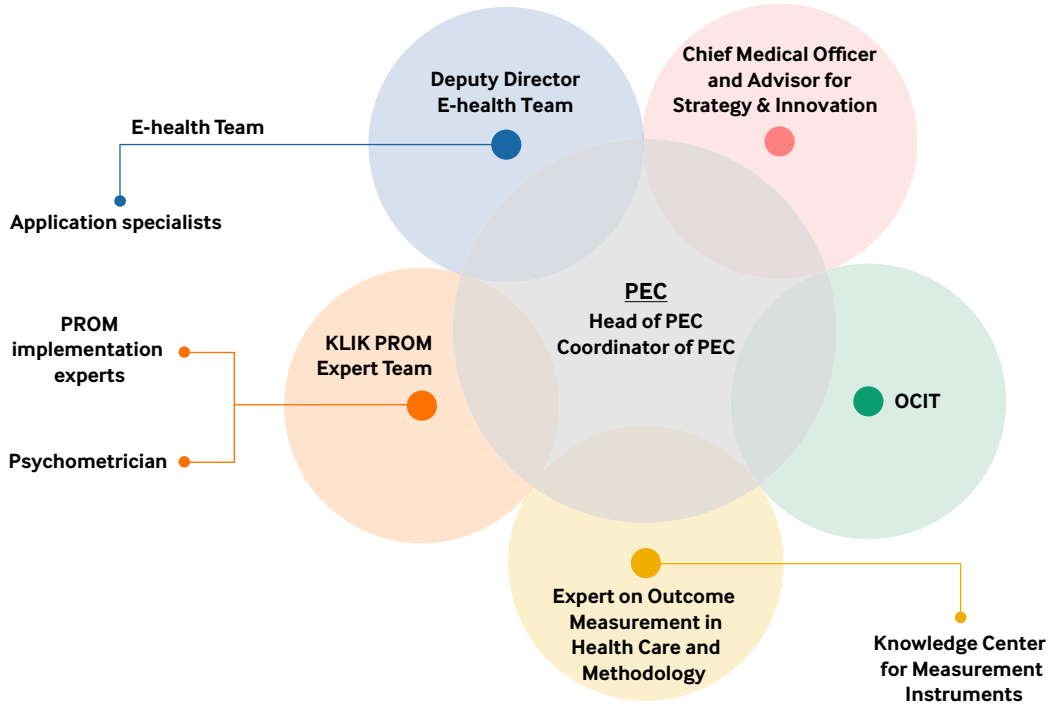
PEC is led by an expert in implementing PROMs (L.H.) and includes the following disciplines:

- Experts from the KLIK PROM expert team (M.M.v.M., M.A.J.L., H.A.v.O., and L.H. — total 0.7 full-time equivalent [FTE]), a team with more than 15 years of experience in implementing PROMs using the evidence-based KLIK PROM portal (https://www.hetklikt.nu/).[13] This team

FIGURE 2

The PROM Expertise Center

A multidisciplinary patient-reported outcome measure (PROM) implementation team is illustrated.



PEC = PROM Expertise Center, OCIT = outpatient clinic implementation team.
Source: The authors

consists of PROM implementation experts (psychologists/researchers) and a psychometrician. They perform the content intakes, offer advice on PRO and PROM selection, evaluate the psychometric properties of the desired PROMs, and provide the training.

- The E-health team of the EHR department, consisting of a deputy director (N.V.-T.) and application specialists (S.L.J. and five others — total 1.5 FTE) who perform the technical intakes, build the PROMs in MyChart/Epic, and provide the training.

- A chief medical officer (P.M.t.W.) and an advisor (M.K.) from the Department of Strategy & Innovation who decide on PROM policy issues (consultancy role — 2 hours per month).

- An expert on outcome measurement in health care and methodology (C.B.T.) who advises on PROM policy and the use of PROMIS (consultancy role — 2 hours per month).

- Advisors of the OCIT. OCIT is a team of advisors who provide hands-on assistance for the implementation of various innovations at the outpatient clinic for all the clinical departments of the Amsterdam UMC. One of their tasks is supporting the implementation of PROMs.

- A coordinator is involved in all steps and essential to guide the process (A.G. — total 0.5 FTE).

Metrics

From November 2019 to April 2024, PEC has supported 74 health care teams (e.g., HIV, diabetes, multiple sclerosis, lung cancer) to implement PROMs as part of their clinical care. Over the past 5 years, this number has shown continued growth (Table 4), which is especially visible in the Departments of Internal Medicine (including HIV, diabetes, and lung cancer, among others), Women/Child, and Neurology/Head–Neck (including multiple sclerosis, among others).

In addition to this number of health care teams using PROMs through Epic, we have implemented PROMs in clinical practice through the KLIK PROM portal in 51 health care teams in our hospital since 2011, mainly in pediatrics. As further depicted in Table 4, increasing numbers of health care teams are using one or more PROMIS measures as part of their PROM set. As of May 2024, a total of 26 (35%) of 74 health care teams are using PROMIS, and 9 (50%) of 18 of the teams that go live will use PROMIS measures. As per our policy, we anticipate this number to increase further in the future.

Overall, a rise in PROM usage can be found from 2019 to 2023, with an average response rate of 24.2% (Table 5). However, to complete PROMs, patients first need to activate their patient portal of the EHR themselves. In 2019, around 44% of patients and in 2023, around 25% of patients could not complete the PROMs due to a nonactivated patient portal. The reported response rate is, therefore, an underestimation. Fortunately, the percentage of patients with an activated patient portal of the EHR has increased largely over the years, due to a hospital-wide activation

Table 4. Health Care Teams Using PROMs and Using PROMIS Measures in Their PROM Sets

Departments	2019	2020	2021	2022	2023	April 2024	Cumulative
Internal Medicine	2	6	5	4	4	2	23
Surgical Specialisms	0	1	2	2	2	1	8
Women/Child	8	1	5	2	0	7	23
Neurology/Head–Neck	5	3	3	2	2	2	17
Intensive Care/Surgery	0	1	0	1	0	0	2
Imaging	0	0	1	0	0	0	1
Teams annual net growth	15	12	16	11	8	12	74
Teams using PROMIS measures	0	4	3	3	7	9	26

Since the launch of the Amsterdam Patient-Reported Outcome Measure (PROM) Expertise Center, the total number of health care teams that have gone live with PROMs (overall and per department) has increased at a rate of about 12 teams per year, reaching 74 teams in April 2024. In addition, the number of health care teams using one or more Patient-Reported Outcomes Measurement Information System (PROMIS) measures in their PROM set has increased from 0 in 2019 to 26 in April 2024. Source: The authors

Table 5. Number of PROMs Sent to and Received from Patients per Year

PROMs	2019	2020*	2021	2022	2023
PROMs sent, all	45,848	36,844	95,650	194,084	249,391
PROMs completed	14,755	6,411	24,330	45,528	55,819
Response rate**	32.2	17.4	25.4	23.5	22.4

*The notable decline in patient-reported outcome measures (PROMs) sent and received in 2020 is largely attributed to care delivery disruptions associated with the Covid-19 pandemic. **The response rates are adversely affected because in each year, some number of patients were unable to complete and submit their responses to the PROMs surveys because they had not activated their patient portal account. Source: The authors

campaign (percentage of the entire Amsterdam UMC/percentage of patients receiving PROMs): 41%/56% in 2019, 48%/62% in 2020, 58%/69% in 2021, 64%/72% in 2022, and 71%/75% in 2023.

> *"As of May 2024, a total of 26 (35%) of 74 health care teams are using the Patient-Reported Outcomes Measurement Information System, and 9 (50%) of 18 of the teams that go live will use Patient-Reported Outcomes Measurement Information System measures."*

Due to different barriers at the level of the patient, including unfamiliarity with the Dutch language, physical or psychological difficulties, or lack of resources, a 100% activation rate of the patient portal is not expected. We do, however, make it a part of our mission to also serve these patients by striving toward a multilinguistic EHR, by opening a patient help desk for EHR concerns at the start of 2024, and by offering in-house facilities (e.g., tablets and personal computers) for patients to access their patient portal.

Finally, since the start, PEC has trained more than 300 of the organization's 7,000 clinicians in using PROMs via Epic (Table 6). These include doctors, nurses, researchers, and paramedical, psychosocial, and supporting staff. For the future, we aim to integrate PROM training into the curriculum of medical students to ensure a 100% training rate.

In most health care teams, the doctors are the main PROM users. However, nurses are increasingly being involved as well depending on the wishes and workflow of the health care team involved. In addition, we have trained 721 clinicians in using PROMs via the KLIK PROM portal from 2011 until the end of 2023.

Where to Start

A multidisciplinary expert team (described in the Team section) is key to guide the PROM implementation process within a complex organization, such as an academic hospital. The existence of this team (approximately 2.5 FTE) and their resources (e.g., PROMIS CAT user license) stands with strategic and financial support from the board of directors. Therefore, the

Table 6. Number of Clinicians Receiving PROMs Training per Discipline, 2020–2023

Professions	2020	2021	2022	2023	Cumulative
Doctors	67	58	37	58	220
Nurses	14	12	22	9	57
Psychosocial Staff	4	4	1	2	11
Paramedical Staff	9	12	2	4	27
Supporting Staff	7	9	2	3	21
Researchers	0	6	1	0	7
Annual training completed	101	101	65	76	343

Since 2020, the Amsterdam PROM Expertise Center trains all health care team members involved in sending and/or discussing patient-reported outcome measures before going live. Over the course of 4 years, 343 health care team members have been trained. Doctors represent the largest group of team members trained. However, over the years, nurses and paramedical staff members are increasingly involved as well. Source: The authors

first step to initiate such an effort is to motivate the board of directors to see the importance of using PROMs and the need to have a centrally guided implementation process. This can be supported by the scientific literature on the effects of and experiences with using PROMs,[6,20,23] case examples of implementation, and a pre-established PROM policy and pathway. Once this is arranged, we recommend starting with one or two pilot teams, comprising enthusiastic team champions and members. These teams can serve as front-runners to test the clinical working method and to inspire and support other health care teams. In addition, we advise the timely organization of evaluation sessions with the health care teams (after the first few months and annually) to continuously optimize the implementation process. Furthermore, it is essential to develop a sustainable embedment plan from the beginning to ensure long-term success. Finally, to prevent foreseen hurdles within the different levels of PROM implementation, we advise the following evidence-based recommendations:

- Hospital: Develop a PROM policy and secure support from the board of directors to implement PROMs within the organization.
- ICT: Engage application specialists in the team to construct the PROM workflow within your EHR/PROM portal, and use evidence-based visualization methods.[16,21]
- PROMs: Prioritize the utilization of generic PROMs to reduce patient, clinician, and ICT burden.
- Clinicians: Identify a team champion and arrange training and evaluation sessions to ensure comprehensive understanding and seamless integration of PROMs into clinical care.
- Patients: Clearly communicate the significance of PROMs to patients and provide support to facilitate their completion, emphasizing the value for their care and outcomes.

Anouk Groenewegen, MSc
Doctoral Candidate/Coordinator PROM Expertise Center, Amsterdam UMC Location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands

Doctoral Candidate, Amsterdam Public Health, Mental Health and Personalized Medicine, Amsterdam, The Netherlands

Doctoral Candidate, Amsterdam Reproduction and Development, Child Development, Amsterdam, The Netherlands

Maud M. van Muilekom, PhD
Assistant Professor, Amsterdam UMC Location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands

Assistant Professor, Amsterdam Public Health, Mental Health and Personalized Medicine, Amsterdam, The Netherlands

Assistant Professor, Amsterdam Reproduction and Development, Child Development, Amsterdam, The Netherlands

Cenne H.A.M. Sieben, MSc
Master of Science, Amsterdam UMC Location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands

Michiel A.J. Luijten, PhD
Postdoctoral Researcher, Amsterdam UMC Location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands

Postdoctoral Researcher, Amsterdam Reproduction and Development, Child Development, Amsterdam, The Netherlands

Postdoctoral Researcher, Amsterdam Public Health, Methodology, Amsterdam, The Netherlands

Postdoctoral Researcher, Amsterdam UMC, Vrije Universiteit, Epidemiology and Data Science, Amsterdam, the Netherlands

Sharon L. Janssen, MSc
Application Specialist/Scrummaster, Amsterdam UMC Location University of Amsterdam, EvA Servicecentrum, Electronic Health Record Department, Amsterdam, The Netherlands

Nynke Venema-Taat, MSc
Deputy Director EvA Servicecentrum, Amsterdam UMC Location University of Amsterdam, EvA Servicecentrum, Electronic Health Record Department, Amsterdam, The Netherlands

Deputy Director EvA Servicecentrum, Amsterdam UMC Location Vrije Universiteit, Department of Care Support and Strategy and Innovation, Amsterdam, The Netherlands

Mira Korte, MSc
Advisor for Strategy and Innovation, Amsterdam UMC Location Vrije Universiteit, Department of Care Support and Strategy and Innovation, Amsterdam, The Netherlands

Caroline B. Terwee, PhD
Professor of Outcome Measurement in Healthcare, Amsterdam UMC, Vrije Universiteit, Epidemiology and Data Science, Amsterdam, The Netherlands

Professor of Outcome Measurement in Healthcare, Amsterdam Public Health, Methodology, Amsterdam, The Netherlands

Piet M. ter Wee, MD, PhD
Chief Medical Officer and Professor in Nephrology, Amsterdam UMC Location Vrije Universiteit, Department of Care Support and Strategy and Innovation, Amsterdam, The Netherlands

Hedy A. van Oers, PhD
Assistant Professor, Amsterdam UMC Location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands

Assistant Professor, Amsterdam Reproduction and Development, Child Development, Amsterdam, The Netherlands

Assistant Professor, Amsterdam Public Health, Mental Health and Quality of Care, Amsterdam, The Netherlands

Lotte Haverman, PhD
Associate Professor and Director PROM Expertise Center, Amsterdam UMC Location University of Amsterdam, Emma Children's Hospital, Child and Adolescent Psychiatry & Psychosocial Care, Amsterdam, The Netherlands

Associate Professor and Director PROM Expertise Center, Amsterdam Reproduction and Development, Child Development, Amsterdam, The Netherlands

Associate Professor and Director PROM Expertise Center, Amsterdam UMC Location Vrije Universiteit, Department of Care Support and Strategy and Innovation, Amsterdam, The Netherlands

Associate Professor and Director PROM Expertise Center, Amsterdam Public Health, Mental Health and Digital Health, Amsterdam, The Netherlands

Acknowledgments

We thank Kim van Wilgenburg, Marije van der Steen, Puck Scheltens, Ilse Matthijsen, and Liesbeth Rieter for their support in establishing the PROM Expertise Center in the Amsterdam University Medical Centers. We also thank Marian Smeulers for our close collaboration on various projects and our colleagues of the E-health team of the PROM Expertise Center: Evelien Wijker-Kok, Sabine Super, Katinka Lit, Tim van Lieshout, Mathilde de Nood, and Wycher Smits.

Disclosures: Anouk Groenewegen, Maud M. van Muilekom, Cenne H.A.M. Sieben, Michiel A.J. Luijten, Sharon L. Janssen, Nynke Venema-Taat, Mira Korte, Caroline B. Terwee, Piet M. ter Wee, Hedy A. van Oers, and Lotte Haverman have nothing to disclose.

References

1. Porter ME, Lee TH. From volume to value in health care: the work begins. JAMA 2016;316:1047-8 https://jamanetwork.com/journals/jama/article-abstract/2552189 https://doi.org/10.1001/jama.2016.11698.

2. Baker A. Crossing the quality chasm: a new health system for the 21st century. BMJ 2001;323:1192 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1121665/pdf/1192.pdf https://doi.org/10.1136/bmj.323.7322.1192.

3. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Health Technol Assess 1998;2:1-74 https://www.journalslibrary.nihr.ac.uk/hta/hta2140#/abstract https://doi.org/10.3310/hta2140.

4. Greenhalgh J, Dalkin S, Gibbons E, et al. How do aggregated patient-reported outcome measures data stimulate health care improvement? A realist synthesis. J Health Serv Res Policy 2018;23:57-65 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5768260/ https://doi.org/10.1177/1355819617740925.

5. Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why? Qual Life Res 2009;18:115-23 https://link.springer.com/article/10.1007/s11136-008-9430-6 https://doi.org/10.1007/s11136-008-9430-6.

6. Gibbons C, Porter I, Gonçalves-Bradley DC, et al. Routine provision of feedback from patient-reported outcome measurements to healthcare providers and patients in clinical practice. Cochrane Database Syst Rev 2021;10:CD011589 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8509115/ https://doi.org/10.1002/14651858.CD011589.pub2.

7. Stover AM, Haverman L, van Oers HA, Greenhalgh J, Potter CM. Using an implementation science approach to implement and evaluate patient-reported outcome measures (PROM) initiatives in

routine care settings. Qual Life Res 2021;30:3015-33 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8528754/ https://doi.org/10.1007/s11136-020-02564-9.

8. Hsiao C-J, Dymek C, Kim B, Russell B. Advancing the use of patient-reported outcomes in practice: understanding challenges, opportunities, and the potential of health information technology. Qual Life Res 2019;28:1575-83 https://link.springer.com/article/10.1007/s11136-019-02112-0 https://doi.org/10.1007/s11136-019-02112-0.

9. Porter I, Gonçalves-Bradley D, Ricci-Cabello I, et al. Framework and guidance for implementing patient-reported outcomes in clinical practice: evidence, challenges and opportunities. J Comp Eff Res 2016;5:507-19 https://becarispublishing.com/doi/10.2217/cer-2015-0014 https://doi.org/10.2217/cer-2015-0014.

10. Foster A, Croot L, Brazier J, Harris J, O'Cathain A. The facilitators and barriers to implementing patient reported outcome measures in organisations delivering health related services: a systematic review of reviews. J Patient Rep Outcomes 2018;2:46 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6170512/ https://doi.org/10.1186/s41687-018-0072-3.

11. Heijsters FACJ, van Breda FGF, van Nassau F, et al. A pragmatic approach for implementation of value-based healthcare in Amsterdam UMC, the Netherlands. BMC Health Serv Res 2022;22:550 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9040233/ https://doi.org/10.1186/s12913-022-07919-1.

12. van der Wees PJ, Verkerk EW, Verbiest MEA, et al. Development of a framework with tools to support the selection and implementation of patient-reported outcome measures. J Patient Rep Outcomes 2019;3:75 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6937349/ https://doi.org/10.1186/s41687-019-0171-9.

13. Haverman L, Van Oers HA, Limperg PF, et al. Implementation of electronic patient reported outcomes in pediatric daily clinical practice: the KLIK experience. Clin Pract Pedia Psychol 2014;2:50-67 https://psycnet.apa.org/doiLanding?doi=10.1037%2Fcpp0000043 https://doi.org/10.1007/s12456-013-0048-4.

14. Terwee CB, Zuidgeest M, Vonkeman HE, Cella D, Haverman L, Roorda LD. Common patient-reported outcomes across ICHOM Standard Sets: the potential contribution of PROMIS®. BMC Med Inform Decis Mak 2021;21:259 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8420145/ https://doi.org/10.1186/s12911-021-01624-5.

15. Oude Voshaar M, Terwee CB, Haverman L, et al. Development of a standard set of PROs and generic PROMs for Dutch medical specialist care: recommendations from the Outcome-Based Healthcare Program Working Group Generic PROMs [published correction appears in Qual Life Res 2023;32:1607]. Qual Life Res 2023;32:1595-605 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10172289/ https://doi.org/10.1007/s11136-022-03328-3.

16. Snyder C, Smith K, Holzner B, Rivera YM, Bantug E, Brundage M. Making a picture worth a thousand numbers: recommendations for graphically displaying patient-reported outcomes data.

Qual Life Res 2019;28:345-56 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6363861/ https://doi.org/10.1007/s11136-018-2020-3.

17. Santana MJ, Haverman L, Absolom K, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. Qual Life Res 2015;24:1707-18 https://www.jstor.org/stable/44849466 https://doi.org/10.1007/s11136-014-0903-5.

18. Furumaya A, Nooijen LE, Haring MPD, et al. Development of a set of patient reported outcome measures for patients with benign liver tumours and cysts: patient focus groups and systematic review. J Patient Rep Outcomes 2022;6:124 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9733760/ https://doi.org/10.1186/s41687-022-00531-1.

19. Bodart S, Byrom B, Crescioni M, Eremenco S, Flood E. Perceived burden of completion of patient-reported outcome measures in clinical trials: results of a preliminary study. Ther Innov Regul Sci 2019;53:318-23 https://link.springer.com/article/10.1177/2168479018788053 https://doi.org/10.1177/2168479018788053.

20. van Muilekom MM, Teela L, van Oers HA, van Goudoever JB, Grootenhuis MA, Haverman L. Patients' and parents' perspective on the implementation of patient reported outcome measures in pediatric clinical practice using the KLIK PROM portal [published correction appears in Qual Life Res 2022;31:255-6]. Qual Life Res 2022;31:241-54 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8800898/ https://doi.org/10.1007/s11136-021-02950-x.

21. van Muilekom MM, Luijten MAJ, van Oers HA, et al. From statistics to clinics: the visual feedback of PROMIS® CATs. J Patient Rep Outcomes 2021;5:55 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8272760/ https://doi.org/10.1186/s41687-021-00324-y.

22. Willems AEM, Heijmans M, Brabers AEM, Rademakers J. Gezondheidsvaardigheden in Nederland: Factsheet Cijfers 2021. Ulrect: Nivel. 2022. Accessed December 8, 2023. https://www.nivel.nl/nl/publicatie/gezondheidsvaardigheden-nederland-factsheet-cijfers-2021.

23. Teela L, van Muilekom MM, Kooij LH, et al. Clinicians' perspective on the implemented KLIK PROM portal in clinical practice. Qual Life Res 2021;30:3267-77 https://doi.org/10.1007/s11136-020-02522-5.