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# Moving beyond barriers: a mixed-method study to develop evidence-based strategies to improve implementation of PROMs in clinical oncology care

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## Abstract

**Purpose** This study aimed to identify feasible, evidence-based strategies to improve the use of Patient-reported outcome measures (PROMs) implemented in clinical oncology practice.

**Methods** A mixed-method study involving observations of consultations and semi-structured interviews with patients and healthcare professionals (HCPs) was conducted to identify facilitators and barriers for using PROMs; barriers and facilitators were structured following the Theoretical Domains Framework. For each barrier, evidence-based improvement strategies were selected using the Behaviour Change Techniques Taxonomy v1. Subsequently, improvement strategies were ranked on priority and feasibility by an expert panel of HCPs, information technology professionals, and PROMs implementation specialists, creating an implementation improvement strategy.

**Results** Ten consultations were observed and 14 interviews conducted. Barriers for implementation included that the electronic health record and PROMs did not align to the individual needs of end users, the HCPs' hesitance to advice patients about health-related quality-of-life issues, and a lack of consensus on which HCPs were responsible for discussing PROMs with patients. Forty-one improvement strategies were identified, of which 25 remained after ranking. These included: redesigning the PROMs dashboard by including patient management advice, enhancing patient support to complete PROMs, and clarifying HCPs' responsibilities for discussing PROMs. Strategies currently considered less feasible were: improving user-friendliness of the patient portal due to technical constraints, aligning PROMs assessment frequency with clinical courses, and using baseline PROMs for early identification of vulnerabilities and supportive care needs. These will be studied in future research.

**Conclusion** Evidence-based improvement strategies to ensure lasting adoption of PROMs in clinical practice were identified.

**Keywords** Patient reported outcome measures · Health-related quality of life · Quality of care · Personalized care · Germany

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## Background

Patient Reported Outcomes Measures (PROMs) represent the patient's assessment of symptoms, physical functioning, and health-related quality of life (HRQoL) without interpretation from healthcare providers (HCPs) [1]. The use of PROMs in clinical practice is increasing, with a growing body of literature recognizing its benefits. In a recent Cochrane review, Gibbons et al. [2] showed that patients are able to express symptoms and problems that otherwise might be overlooked, leading to better patient-HCP communication and timely intervention. This results in reducing emergency admissions and improves treatment adherence and HRQoL [2]. Additionally, PROMs may help to identify vulnerable patients and improve timely referral for supportive care [2].

Still, the implementation of PROMs in oncology care remains challenging and its use in daily clinical practice is therefore limited [3, 4]. There has been extensive research on barriers and facilitators for implementing PROMs in oncology care, identifying success factors. These include the integration of PROMs into electronic health records (EHR), establishing the relevance of PROMs in existing workflows, and a range of organizational and behavioral factors, such as 'readiness for an organization to implement change' [3–12]. Various strategies have been used to overcome barriers, for example: working with clinical 'change champions' (i.e. team members who support and are frontrunners in the use of PROMs and can help facilitating implementation) [3, 13, 14], aligning PROMs workflows with existing clinical workflows [13], and appointing care coordinators to prepare PROMs consultations [15]. Key considerations for designing, implementing, and managing PRO systems for use in clinical care have been summarized in implementation frameworks [16].

Despite successful practice examples, it remains unclear why certain implementation strategies are more successful than others. The lack of theoretical underpinnings and detailed descriptions of published strategies complicates determining their effectiveness [17]. Note that the applicability of specific strategies will depend on the context of implementations, which may vary widely between clinical settings [16]. As advocated by Stover et al. [18], we need theoretically guided studies to clarify how, why, and in what circumstances strategies lead to successful PROMs implementation. To guide the selection of implementation strategies, it is recommended to first identify barriers and facilitators in the specific context, and then link them to selected strategies designed and rooted in evidence to overcome specific barriers, for instance by using a Behavior Change Techniques (BCT) Taxonomy [19, 20]. Our study aimed to: (a) identify barriers and evidence-based

improvement strategies for PROMs implementation applying a BCT-taxonomy, and (b) create an improvement strategy by prioritizing the most urgent and feasible evidence-based strategies.

## Methods

### Design

A qualitative mixed-method study consisting of semi-structured interviews and clinical observations was conducted to identify facilitators and barriers for PROMs use. This study was approved by our institutional review board (IRB-21-278) and is reported following the Standards for Reporting Implementation Studies (StaRI) [21]. Participants gave informed consent for participation in this study.

### Setting

Building on a variety of existing PROMs initiatives scattered through the organization, a hospital-wide PROMs program was initiated at the outpatient clinics of the Netherlands Cancer Institute in 2021. Supported by in-house digital developments, PROMs were implemented as part of routine clinical care for advanced melanoma, curative breast cancer, surgically-treated bladder cancer, and head and neck cancer. Implementation was informed by the User's Guide to Implementing Patient-Reported Outcomes Assessment in Clinical Practice [22]. For each cancer type, questionnaires, assessment frequencies, and assessment timing (see Supplement S1 for a full overview) were based on existing standards, including those from the Dutch Institute for Clinical Auditing [23] and the International Consortium for Health Outcomes Measurement [24]. When first registered at our institute, patients give informed consent to the use of their clinical data for research purposes. PROMs are considered part of standard care; no additional PROMs-specific consent is requested.

As part of the initial implementation, HCPs were trained in the use of PROMs by the implementation team (KdL, EB, IF, EA, LvdP). Champions (IvdP, MW, MvdK, RD) at each department helped to inform the implementation process. PROMs administration was built in the EHR and EHR-associated patient portal (Hix 6.3, ChipSoft). Administration was automated for melanoma and head and neck patients, while manual administration was selected for breast cancer and bladder cancer patients, meaning HCPs actively invited patients to PROMs administration. Patients completed the PROMs in the patient portal after receiving an email that referred them to this portal. An information leaflet about PROMs was accessible through the portal as well.

Before start of this study in January 2023, 193/234 (82%) melanoma, 246/321 (77%) breast cancer, 209/283 (74%) bladder cancer, and 188/303 (62%) head and neck cancer patients had completed the PROMs at baseline (see Supplement S1). HCPs could access individual patients' PROMS scores via the EHR-integrated dashboard and discuss these with patients during clinical consultations. Scores were presented in a dashboard, where individual scores are compared to thresholds for clinical importance [25] to facilitate score interpretation (Fig. 1). At study initiation, HCP had registered they had discussed PROMs with patients during consultations in about 5% of patients who had completed PROMs.

## Theoretical underpinnings

This study was guided by the Theoretical Domains Framework [26] and Behavior Change Techniques Taxonomy v1 (BCTTv1) [27]. The taxonomy was developed to build international consensus for reporting behavior change interventions and to support the creation of theory-informed implementation interventions [28]. It has been used to guide different implementation projects in health care [29–32], including implementation of PROMs in multidisciplinary community rehabilitation [33], and can be altered to specific situations. The BCTTv1 classifies 93 BCTs clustered in different groups (e.g. *shaping knowledge, goals and planning, social support*, etc.) [27]. We linked BCTs to barriers and facilitators obtained from the observations and interviews, clustered by 14 Theoretical Domains Framework

### PROM - Patient Score

VRAGENLIJST

PROMs EORTC QLQ-C30

PATIENTNR

21702533

Patiëntnummer

21702533

'In de kolom 'Scores' worden de PROM scores vergeleken met drempelwaarden (gebaseerd op scores van andere mensen die ook kanker hebben of hebben gehad). Is de score beter dan de drempelwaarde, kleurt het getal groen. Is de score gelijk aan de drempelwaarde, dan kleurt het getal blauw. Bij een score onder de drempelwaarde, wordt het getal rood.

In de kolom 'Verloop' wordt de huidige score vergeleken met de meest recente vorige score. Indien de huidige score 10 punten of meer afwijkt van de meest recente, is er sprake van een klinisch relevante verbetering of verslechtering. Indien de score minder dan 10 punten afwijkt, is het verloop gelijk.

#### Globale Gezondheid - Scores

#### Verloop

Globale gezondheid 50

#### Functioneren - Scores

#### Verloop

Cognitief Functioneren	17	Slechter
Emotioneel Functioneren	50	Slechter
Fysiek Functioneren	60	Slechter
Rol Functioneren	83	Slechter
Sociaal Functioneren	83	Slechter

#### Symptoom - Scores

#### Verloop

Gebreken aan eetlust	100	Slechter
Constipatie	67	Slechter
Diarré	100	Slechter
Kortademing	67	Slechter
Vermoeidheid	22	Slechter
Financiële problemen	67	Slechter
Misselijkheid	17	Slechter
Pijn	67	Slechter
Slapeloosheid	33	Slechter

#### Summary Score - Scores

#### Verloop

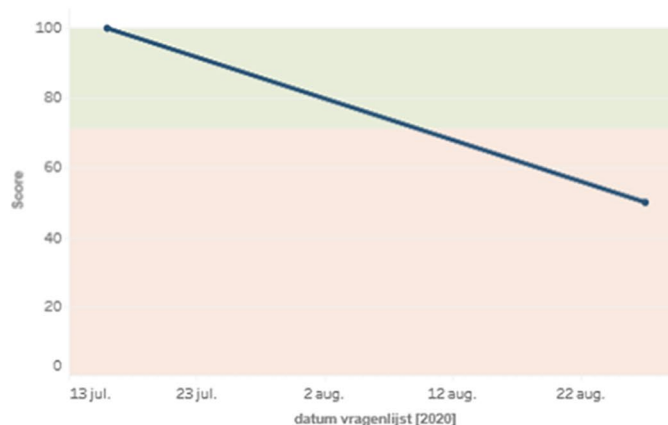
Summary Score 48

Uw laatste vragenlijst is van 27-8-2020.

Met emotioneel functioneren wordt bedoeld in welke mate u zich zorgen maakt of zich gespannen, prikkelbaar of neerslachtig voelt.

U scoorde 50 op het domein Emotioneel Functioneren. Als de score onder de 71 komt, heeft u dit domein aandacht nodig.

Uw vorige score was 100, waardoor uw functioneren nu Slechter is.



**Fig. 1** PROMS dashboard in the electronic health record as presented to healthcare practitioners. On the left side: table with questionnaire domains, followed by a score in red or green for scores worse or better than the clinical threshold values set by Giesinger et al. respectively, and an arrow indicating the change in score compared to the

previous score (arrow up = better, arrow down worse, arrow to the left = same). On the right side: A graph with the trend over time, green area indicating scores above the threshold, red indication scores below the threshold

(TDF)-domains (e.g. *knowledge, goals, and social influences*). For example: the TDF-barriers *knowledge* is linked to the BCT *Shaping knowledge* and *Feedback & Monitoring*. Figure 2 presents TDF definitions and all possible links between the TDF and BCTTv1.

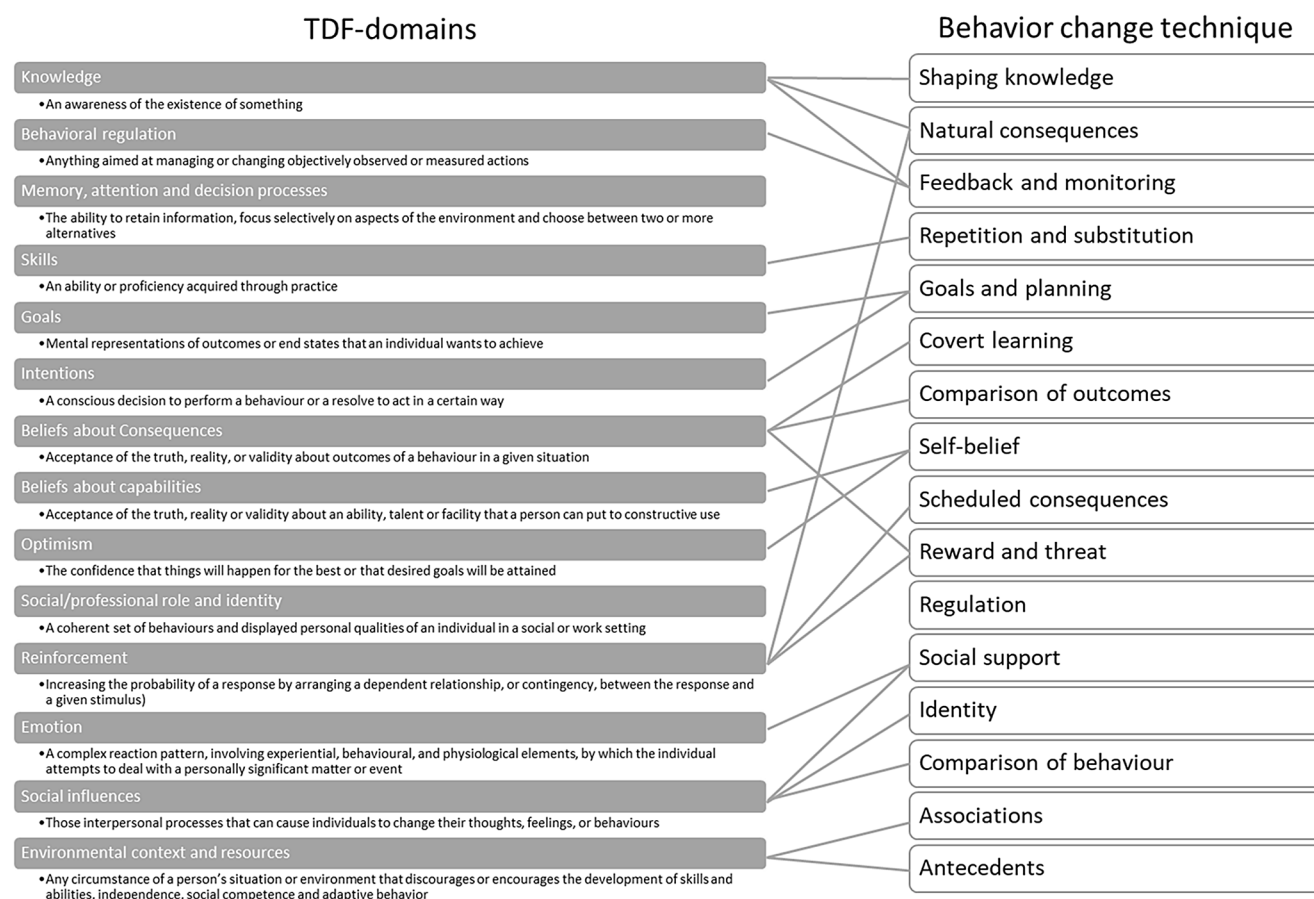
## Study population

HCPs who regularly treat melanoma, breast, bladder, head and neck cancer were eligible to participate in the observations and/or interviews. Purposive sampling was used to ensure a mix of early adopters and/or champion HCPs, and HCPs who rarely used PROMs during clinical care. Eligible patients had been included in the PROMs administration and were proficient in Dutch. Purposive sampling was used to select a mix of patients who did and did not complete PROMs. Saturation was defined as when no new barriers or facilitators were presented during the interviews or consultations.

## Procedure and materials

The study was carried out by the PROMs implementation team (EB, KdL, LvdP). EB observed regular clinical consultations and conducted the interviews. EB is an experienced interviewer and had no treatment relationship to the patients. KdL and LvdP reviewed all materials.

An observation guide (Supplement S2) informed by Trillingswaard-Majdahl's observation guide for observing patient-HCP interaction during PROMs-based consultations [34] was used to observe clinical consultations. After each observed consultation, both patients and clinicians were invited to participate in a semi-structured interview to discuss the observations and their experiences with PROMs. The interview guides (Supplement S3) were based on TDF-domains and a general questionnaire about barriers and facilitators (Supplement S4). This questionnaire had been sent to the HCPs in all departments to gain a general impression of barriers and facilitators. It covered topics such as knowledge about the PROMs implementation, the degree in which HCPs were expected to use PROMs, and perceived competition from other innovations. After each interview,



**Fig. 2** Links between the Theoretical Domains Framework (TDF) and grouped Behaviour Change Techniques Taxonomy v1, adapted from Cane et al



EB wrote a summarizing memo. All interviews lasted between 10 and 25 min and were recorded and transcribed verbatim.

## Data analysis

A deductive rapid analysis approach was used [35, 36]; see Gale et al. [37] for a full description of this approach. First, EB coded barriers and facilitators based on the TDF-domains in the memos and interview transcripts. Second, a list of barriers was formed by EB, and discussed with KdL and LvDP. In deliberation they decided on which barriers were duplicate or overlapping, that could be combined or removed to decrease redundancy. Third, to create fitting improvement strategies, two authors (EB and KdL) independently selected improvement strategies from the BCTTv1 taxonomy [26, 27] for each listed barriers, conflicting decisions were discussed with a third author (LvDP), whose judgment was final. Finally, to prioritize barriers and matching improvement strategies, department champions (IvdP, MW, MvdK, RD) and a representative from the IT department (MP) rated each strategy for priority (1–5) and feasibility (1–5) during a consensus meeting. Following Kwok et al. [38], strategies were classified as highly prioritized or feasible if scored  $> 2.5$ .

## Results

### Participants characteristics

Between February and June 2023, 9 patients (2 melanoma, 2 breast cancer, 3 bladder cancer, and 2 head and neck cancer)

**Table 1** Participants characteristics

Characteristics	Patients ( $n=9$ )	HCP ( $n=9$ )
<b>Department/cancer type</b>		
Melanoma	2	2
Breast cancer	2	3
Bladder cancer	3	2
Head and neck cancer	2	3
<b>PROMS use</b>		
Yes	5	5
No	4	4
<b>Clinical discipline</b>		
Nurse practitioners		3
Surgeons		3
Medical oncologist		2
Speech therapist		1
<b>Years of working experience</b>		9.3
<b>(Mean, SD)</b>		<b>(3.0)</b>

Abbreviations: HCP: healthcare practitioners; PROMs: patient-reported outcome measures

and 9 HCPs (4 nurse practitioners, 3 surgeons, and 2 medical oncologist) participated. Five (56%) of nine patients had completed PROMs; almost half (44%) of the clinicians had more than once used PROMS during routine clinical care (Table 1).

Following saturation, thirty-one barriers and facilitators were identified; see Table 2 for a detailed description and supportive quotes.

### Barriers as perceived by health care professionals

The main resource for HCPs, the PROMs dashboard in the EHR, insufficiently supported HCPs. That is, HCPs found it difficult to interpret PROMs as scoring principles were not uniformly presented for different PROMs (i.e. different score ranges and directionality; *Barrier 1*) and HCPs were unfamiliar with definitions of domains (*Barrier 10*). Access to the PROMs dashboard via the EHR facilitated its use, but information about which patients had been included in and/or completed PROMs was presented on a different EHR page (*Barrier 3*). This led to HCPs navigating to the dashboard, only to find out that the patient had not been included and thus had not completed PROMs, which demotivated them to check the dashboard for the next patient (*Barrier 4*). The lack of overview also led to HCPs forgetting to include patients in follow-up measures (*Barrier 5*). If patients had completed PROMs, reporting about HRQoL was hindered as results from the dashboard could not be copied to the clinical report in the EHR (*Barrier 6*). In general, HCPs missed feedback and/or instructions about the PROMs and the status of implementation, and/or where to find this information (*Barrier 11–13*).

The alignment of PROMs administration frequency with clinical courses importantly impacted the relevance of PROMs. For instance: PROMs for melanoma patients were administered every three months. This was useful for the surgeons' follow-up consultations, but not the oncologists' consultations: the oncologists reported not using PROMS due to week-by-week variation of symptoms during systemic treatment (*Barrier 7*). Additionally, baseline PROMs were administered after the first consultation. Although HCPs stated seeing value in using baseline PROMs to inform treatment decisions or early referral to supportive care, these could thus not be used to do so. With the next consultation planned weeks after baseline, the results were outdated by the time these were discussed. (*Barrier 8*). The relevance of PROMs was affected by patient's priorities, which were not always reflected by the PROMs dashboard, especially for the bladder cancer and head and neck cancer patients. Specifically, patients generally stated they considered only a few issues to be relevant, even if the dashboard indicated multiple clinically relevant complaints items

**Table 2** Barriers and facilitators for HCP and patients classified by theoretical domains Framework

TDF domain	Barrier	Observation [number of observation]	Quote from interviews [participant]*	
Barriers for health care professionals				
Environmental context and resources	1	The interpretation of the dashboard is hard due to difference in scaling and format, and use of unclear definitions	It takes a long time for the clinician to figure out the meaning of the domains. Functioning scores are scaled 100-0, symptom scales are score 0-100. [1] IIEF scores range 1–14, HCP does not know what to make of the scores. [2]	
	2	Patients do not always experience burden or want to do something about clinically relevant issues		When asked about the clinically relevant PROMs, patient answers: Oh, I was never so fit that I could walk the stairs; it is not a problem for me. [3]
	3	It is unclear which patients have been included in the PROMs		When preparing a consultation, the HCP has to go to the main page and see if the patients was included for the PROMs. Many patients are not (yet) included. There is no quick overview of who is included. [1,4,6]
	4	Non-response rate demotivates HCP to check the dashboard		HCP clicks on the dashboard, and the patient did not complete (most recent) PROMs, this happens in 6/8 patients. [1,2,3,7,9]
	5	Patients are not included for the follow-up measures		Patients who meet the criteria and completed the baseline are not included for the follow-up. [1,5]
	6	Information from the dashboard cannot be copied into free-text fields in the EHR		In the EHR, the HCP reports quality of life issues in free-text fields. The HCP needs to retype the results from the dashboard, because its content cannot be copied. [3,9]
	7	PROMs frequency is not aligned with consultations in the internal medicine department		Patient describes their fatigue, different from the week before. [1,2,6] Baseline questionnaire is reviewed, but at present consultation, the patient represents a new range of complaints due to systemic treatment. HCP quickly reviews the baseline questionnaire but decides not to use it in the consultation because it is outdated. [6,8,10]
	8	Baseline questionnaire is not used due to short time-frame between administration and start of treatment		The first consultation with the patient is months after baseline, supportive care interventions have already been proposed in the multidisciplinary team meeting, and treatment has already started. [1,2,3]
	9	There is overlap between the questionnaires from the PROMs administration and other projects		A self-developed questionnaire is used to prepare consultations for head and neck cancer patients. [4] Another app is used to monitor symptoms during treatment. [9]
	10	The definition of the domains presented in the dashboard is unclear		HCP explains Social functioning as ‘if you are able to walk the stairs’. [2]

**Table 2** (continued)

TDF domain	Barrier	Observation [number of observation]	Quote from interviews [participant]*
<b>Barriers for health care professionals</b>			
Knowledge	11 Not all staff members are up to date about PROMs or do not know what to do	Researcher needed to show the location of the dashboard and tell who was included in the PROMs administration. HCP did not know where to find information about PROMs. [1,2,10]	
	12 Not all HCP know where to find instructions about PROMs (who is included, where is the dashboard)	Researcher needed to show the location of the dashboard and tell who was included in the PROMs administration. HCP did not know where to find information about PROMs. [1,2,10]	
	13 Not all HCP know the status of the PROMs implementation and miss feedback on the progress		<i>"I know you once introduced it, but is the program still running? Where could I find the information again? I did not know if the program was still running, or if patients still filled the questionnaires in."</i> [HCP 07]
Goals	14 There are too many items to discuss in one consultation	When reviewing the dashboard, 8/10 items are indicated in red. Discussing fatigue already takes two minutes, and also the treatment needs to be discussed. Other items are not discussed. [6] When reviewing the dashboard, 6 items are indicated in red. HCP asks the patients to choose the most relevant items, patients indicates only 2 relevant items. [2]	<i>"You just have 10 min to discuss everything and then all those issues about quality of life, you just don't have the time."</i> [HCP 02]
	15 PROMs are not incorporated in the consultation	Consultation as regular; PROMs dashboard is reviewed in the final minutes. [2, 6, 3]	<i>"It just not in my system, I ask the questions I want to know, and afterwards see on the dashboard if there is anything else I need to discuss, but mostly all the issues have been discussed and it is just something extra I need to do. If I would use the dashboard as a guideline, it would feel as an added value."</i> [HCP 04]
Professional role and identity	16 Doctors do not consider themselves equipped to talk about HRQoL	HRQOL is not discussed during the consultations. [8]	<i>"I am more treatment-focused; we alter the consultations between surgeon and nurse practitioner, so the nurse practitioner can talk about the effect of the disease on someone's life."</i> [HCP 08]
Beliefs about consequences & skills	17 HCP find it hard to give advice on subjects as fatigue or when to refer to allied health care professionals	Fatigue is discussed, concluding that fatigue is part of the treatment. No referral or self-management advice is given. [2,5]	<i>"Yeah, this patient is fatigued, but that's normal with this treatment. I am not sure if a referral would be appropriate for this patient. [...] It makes more sense to discuss those items months after treatment."</i> [HCP05] <i>"Fatigue is complex, you only have 10 min to discuss everything."</i> [HCP01]
Beliefs about consequences & goals	18 HCP do not see added value of PROMs for referring to supportive care	Speech therapist easily incorporates MDADI answers into consultation and advises about specific problems. [10] PROMs dashboard is reviewed, but is not referred to during the consultation. Supportive care is discussed when the patient mentions they experience a lot of anxiety about the next scan. [3] In the consultations, quality of life is not discussed. [2,7,8]	<i>"We already discuss quality of life and psychosocial care during our consultation, so PROMs feel like something extra to discuss."</i> [HCP 03] <i>"If I could have used it to say for example 'it's better in your situation to go for the chemotherapy', then you truly use it for shared decision making, now it's just individual numbers."</i> [HCP 08]
	19 HCP forgets to discuss PROMs because they are not used to it	PROMs dashboard is not reviewed. [2]	<i>"I have so many things to discuss, I do find it important, but I just forget it."</i> [HCP 02]



**Table 2** (continued)

TDF domain		Barrier	Observation [number of observation]	Quote from interviews [participant]*
<b>Barriers for health care professionals</b>				
Social influences	20	HCP do not expect from each other to discuss PROMs; it not clear who should be responsible for discussing PROMs at which time points	PROMs dashboard is not reviewed. [2,8]	<i>"I just forget, and it also not something we regularly discuss or hold each other accountable for."</i> [HCP 02]
<b>Barriers for patients</b>				
Skills	21	Patients with low literacy or digital skills find it hard to complete PROMs or navigate the patient portal	HCP clicks on the dashboard, patient did not complete PROMs. [1,2,3,7,9]	<i>"I did not know how to find the questionnaire in the patient portal."</i> [Pt03]
	22	Patients find BreastQ lengthy and hard to fill in		<i>"All those questions about my breasts, and this all while I haven't even started treatment. It just a lot."</i> [Pt02]
	23	Patients find the interpretation of the PROMs hard		<i>"When I see the numbers [on patient portal], I do not know what they mean, what should I do with them?"</i> [Pt01]
Goals	24	The goal of completing PROMs is not clear	HCP clicks on the dashboard, patient did not complete PROMs. [1,2,3,7,9]	<i>"I have once received an email with "Questionnaires are made available to you", but honestly, I thought the questionnaires were for research."</i> [Pt02]
	25	Patients find questions about their sex life not aligned with their experiences and life goals	PROM about sexual functioning is not completed. [7,9]	<i>"The questions about your sex life, I do not like the way they phrase those questions. I do not have sex the way those questions assume I should have sex. So when I read those questions, I stopped [completing the PROM]."</i> [Pt07] <i>"The way I have sex now is different than before the surgery, I am just intimate with my wife, and that is fine by me, but the questions indicate there is a problem."</i> [Pt09]
Environmental context and resources	26	Patients experiencing language barriers are not able to complete PROMs	Patients experiencing language barriers are not included for the PROMs. [1, 9]	
	27	Patients do not know what to do about a deteriorated score		<i>"Okay, I have a lower score on fatigue or appetite; it would be helpful to know what to do. Do I contact my GP? Or can I myself do something to improve it?"</i> [Pt05]
	28	Patients are not able to review their results in the patient portal in an appropriate format		<i>"Completing the questionnaire helped me to prepare for the consultation, but I could not find the answers in the patient portal, so I did not know what to do with it."</i> [Pt05]
	29	Patients find it hard to navigate through the PROMs system/patient portal	HCP clicks on the dashboard, patient did not fill in the questionnaire. [1,2,3,7,9]	<i>"I clicked on the link, but then I got lost, then I logged out."</i> [Pt07]
	30	PROMs frequency is not aligned with consultations and course of HRQoL issues during treatment		<i>"I have completed the questionnaire 3 months ago, now I have started immunotherapy and it differs day by day. Sometimes I am really fatigued, but a week later I am fine again. So the results are really not relevant anymore if discussed today."</i> [Pt02]
Reinforcement	31	Patients stop completing PROMs because HCP do not refer to them	In the consultations, quality of life is not discussed. [2,7,8] HCP clicks on the dashboard, patient did not complete PROMs. [1,2,3,7,9]	<i>"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?"</i> [Pt02]

Abbreviations: TDF: Theoretical Domains Framework; HCP: healthcare professional; HER: electronic health record; MDADI: M.D. Anderson Dysphagia Inventory; GP: general practitioner; HRQoL: health-related quality of life

\*Quotes from the original interviews in Dutch were translated

to discuss (*Barrier 14*). Also, HCPs tended to review the PROMs at the end of consultations instead of incorporating them into their anamnesis, which made discussing PROMs feel redundant (*Barrier 15*).

It was observed that HRQoL was infrequently discussed during consultations. Some doctors stated they considered that ‘discussing HRQoL is the job of the nurse practitioners (NPs)’ and felt NPs are better equipped to talk about this. Others found it challenging to interpret PROM results and hard to determine when to refer to appropriate supportive care (*Barrier 16*) and which advice to give on issues such as fatigue; they expected patients would feel fatigued during chemotherapy treatment and were unsure about what to advise, when to refer, and where to refer to (*Barrier 17*). In contrast, speech therapists felt equipped to deal with the HRQoL issues for head and neck cancer patients, as they were accustomed to discussing these topics (*Barrier 16, 17*).

Although HCPs expressed that they saw added value in discussing PROMs during consultations, they stated it was not something they expected from each other to do. Furthermore, they stated it was unclear who was responsible for discussing PROMs, so nobody felt responsible (*Barrier 20*). In some departments, PROMs were considered irrelevant, since supportive care interventions were already part of usual care. It was stated that PROMs are only relevant if they provided extra information or contributed to a specific goal (like cancelling consultations when no clinically relevant complaints have arisen, or for treatment decision-making; *Barrier 18*).

### Barriers as perceived by patients

Patients could not always complete PROMs, reporting difficulties for navigating the patient portal (*Barrier 21, 27*). Breast cancer patients considered the BreastQ questionnaire particularly lengthy and difficult to complete (*Barrier 22*). The goal of completing PROMs was unclear to patients, who often assumed it was for research purposes (*Barrier 24*). Additionally, not all PROMs questions felt relevant or appropriate to them. Patients felt especially discouraged to answer questions about their sex life, noting their view on sex had changed post-treatment (*Barrier 25*). It was noted that some patients were unable to complete PROMs due to language barriers (*Barrier 26*) or lack of access to the patient portal.

Patients expressed the need to review their own results and retrieve self-management advice in preparation for consultations. However, although patients had access to a table of numeric scores, they were unable to view their results in the PROMs dashboard (*Barrier 28*). Therefore, results

were considered difficult to interpret (*Barrier 23*), and without subsequent guidance, patients did not know how to act on deteriorated scores (*Barrier 27*). Consequently, patients relied on HCPs to show, interpret, and/or discuss scores and come up with subsequent (self-) management actions. Also, patients stated they would lose motivation to complete the PROMs if these were left undiscussed during consultations or not properly communicated to them (*Barrier 31*).

### Strategies for improvement

In total, 43 strategies were composed and related to the following BCT-domains: *Shaping Knowledge, Feedback and monitoring, Goals and planning, Comparison of behavior, Social Support, Associations and Antecedents*. Table 3 gives an overview of the considered strategies classified by the BCT with feasibility and priority ratings administered during the consensus meeting. Twenty-five strategies were prioritized and considered highly feasible, forming the final improvement strategy.

### Feasible and prioritized improvement strategies aimed at health care professionals

Strategies aimed at improving user-friendliness and comprehensibility of the EHR PROMs system included: rescaling all domains to 0 = bad and 100 = good (*Strategy 1*), labelling domains with laymen terms, facilitating the identification of whether patients have completed PROMs (*Strategy 4*), and streamlining the transfer of PROMs results to the EHR free text fields (*Strategy 6*). Furthermore, enriching the dashboard with cues about allied HCPs to refer to (*Strategy 16*) and reference of patient-like-me data (*Strategy 20*) were included.

To help HCPs incorporate changes, the implementation team and department champions should (better) train HCPs in using patient management advice or referrals and incorporating the PROMs into their consultations on-site during and after consultations (*Strategy 14*).

Strategies aimed to reshape norms around what HCPs expected from each other included: scheduling consensus meetings where staff members reach agreement on who is responsible for discussing PROMs during which treatment phase and setting specific goals (e.g. % of consultations where PROMs should have been discussed; *Strategy 24*). During such consensus meetings, the PROMs implementation team can inform HCPs about the progress of implementation (*Strategy 13*) and compare progress in different departments during these meetings (*Strategy 22*).

**Table 3** Improvement strategies classified by theoretical domains Framework-domain and Behaviour Change technique

TDF-domain		Barrier	Behaviour Change Technique		Improvement strategy	Responsible for executing strategy	P	F
Environmental context and resources	1	The interpretation of the dashboard is hard due to difference in scaling and format, and use of unclear definitions	Antecedents: Restructure the physical environment	1	Rescale all scales into '0=bad – 100=good'; add questions per domain to dashboard	BI team, Impl. Team	5	5
	2	Patients do not always experience burden or want to do something about clinically relevant issues	Antecedents: Adding objects to the environment	2	Add question after each PROM: 'What are your top priorities to discuss with your HCP? (please select max. 3)'	IT-team	5	5
	3	It is unclear which patients have been included in the PROMs	Antecedents: Adding objects to the environment	3	Integrate completing PROMs as standard procedure for patients to prepare for a consultation	Impl. Team, front desk team lead	5	3
	4	Non-response rate demotivates HCP to check the dashboard	Associations: Prompts and cues	4	Show who has completed PROMs on the HCP's clinical schedule	IT- team	5	3
	5	Patients are not included for the follow-up measures	Antecedents: Restructure the physical environment	5	Re-evaluate the inclusion process	IT-team	5	4
	6	Information from the dashboard cannot be copied into free-text fields in the EHR	Antecedents: Restructure the physical environment	6	Make PROMs scores available in the free text fields of the EHR	IT-team	4	4
	7	PROMs frequency is not aligned with consultations in the internal medicine department	Antecedents: Restructure the physical environment	7	Link PROMs to consultations or increase frequency to biweekly	IT-team	5	2
	8	Baseline questionnaire is not used due to short timeframe between administration and start of treatment	Antecedents: Restructure the physical environment	8	Develop referral pathways for baseline questionnaire for treatment decisions or early supportive care referral	Impl. Team, research team	5	2
	9	There is overlap between the questionnaires from the PROMs administration and other projects	Antecedents: Restructure the physical environment	9	Re-evaluate other questionnaires	IT-team, department leads	4	1
	10	The definition of the domains presented in the dashboard is unclear	Antecedents: Restructure the physical environment	10	Add questions per domain to dashboard	BI team, Impl. Team	2	5
Knowledge	11	Not all staff members are up to date about the PROMs or do not know what to do	Shaping knowledge: Instruction on how to perform behavior	11	Appoint champions who regularly informs other staff members and regularly train HCPs	Impl. Team, department leads	4	5
	12	Not all HCPs know where to find information on PROMs (who is included, where is the dashboard)	Shaping knowledge: Instruction on how to perform behavior	12	Appoint champions who regularly informs other staff members and regularly train HCPs	Impl. Team, department leads	4	5
	13	Not all HCP know the status of the PROMs project and miss feedback on the progress	Feedback and monitoring: feedback on outcome	13	Regularly update the departments on the updates and progress of PROMs project	Impl. Team, department leads	4	5
Goals	14	There are too many items to discuss in one consultation	Antecedents: Adding objects to the environment	14	Add question after each PROM: 'What are your top priorities to discuss with your HCP? (please select max. 3)'	IT-team	5	5
Professional role and identity	16	Doctors do not consider themselves equipped to talk about HRQoL	Identity: Framing & reframing + Self-belief: focus on past success	15	Train doctors and nurse practitioners in addressing HRQoL as part as their job description and appoint role models	Impl. Team	3	3
Beliefs about consequences & skills	17	HCP find it hard to give advice on subjects as fatigue or when to refer to allied health care professionals	Antecedents: Prompts and cues	16	Add cues to the dashboard with advice about allied HCPs to refer to	BI team, Impl. Team	3	4
			Repetition and substitution: Behavioral practice and rehearsal	17	Train HCPs in giving advice about fatigue and provide prompts to triage required referral to allied HCPs	Impl. Team	3	4

**Table 3** (Continued)

Beliefs about consequences & goals	18	HCP do not see added value of PROMs for referring to supportive care	Comparison of behavior: Social comparison	18	Plan update meetings, in which referral rates to supportive care between departments and HCPs are presented	Impl. Team, department leads	3	5
			Comparison of outcomes: Credible source	19	Plan update meetings, in which (missed) referrals to allied HCPs are presented	Impl. Team, department leads	3	5
			Antecedents: Restructure the physical environment	20	Incorporate 'patients-like-me' data in the PROMs dashboard	BI team, Impl. Team	3	4
Reinforcement	19	HCP forgets to discuss PROMs because they are not used to it	Prompts and cues; future punishment	21	Install a feature in the EHR that you cannot complete other tasks before indicating "PROMs discussed"	IT team	3	2
Social influences	20	HCP do not expect from each other to discuss PROMs; it not clear who should be responsible for discussing PROMs at which time points	Identity: Identification of self as role model	22	Show good examples of departments' use of PROMs instead of appointing individual HCPs as PROMs champions	Impl. Team	3	4
			Goals and planning: goal setting outcome, action planning	23	Set agreements with each department about who is responsible for discussing PROMs for each time point	Impl. Team, department leads	5	5
			Goals and planning: review behavior goal, Discrepancy between current behavior and goal;	24	Plan update meetings, in which is reflected on % consultations in which PROMs are discussed and set goals.	Impl. Team, department leads	5	5
			Feedback and monitoring: feedback on behavior					
			Social support: Social support	25	Appoint champions in all departments and define their tasks (NP, internal medicine departments)	Impl. Team, department leads	4	5
			Comparison of behavior: Information about other approval	26	Board of directors should show repeated support for the PROMs	Board of directors	4	3
Skills	21	Patients with low literacy or digital skills find it hard to fill in the questionnaires or navigate through to patient portal	Social support: Social support	27	Install a support desk where patients can ask assistance for navigating the patient portal	Impl. Team, IT team, front desk team lead	5	3
			Antecedents: Adding objects to the environment	28	Provide tablets in the waiting room to complete PROMs	Impl. Team, IT team, front desk team lead	5	4
			Comparison of behavior: demonstration of behavior	29	Extent patient information with practical tips, screenshots, and videos to navigate through patient portal	Impl. Team, Patient Support Team	4	5
	22	Patients find BreastQ lengthy and hard to fill in	Antecedents: Restructure the physical environment	30	Re-evaluate the use of PROMs, specifically the BreastQ, and implement CAT.	Impl. Team, department lead of breast cancer, IT team	2	2
	23	Patients find the interpretation of the PROMs hard	Antecedents: Adding objects to the environment	31	Add patient-friendly PROMs dashboard to the patient portal	IT team	5	2
Goals	24	The goal of completing PROMs is not clear	Antecedents: Adding objects to the environment	32	Add question after each PROM: 'What are your top priorities to discuss with your HCP? (please select max. 3)'	IT team	5	5
	25	Patients find questions about their sex life not aligned with their experiences and life goals	Goals & planning: Review outcome goals	33	Change the language in patient information: from 'filling in the questionnaire' to 'prepare for your consultation'.	IT team	4	5
			Antecedents: Restructure the physical environment	34	Change the wording of questions about sex life, enable to tailor questions about sex life to specific preferences	Impl. Team, research team	3	1



**Table 3** (Continued)

Environmental context and resources	26	Patients experiencing language barriers are not able to complete PROMs	Antecedents: Adding objects to the environment	35	Add questionnaires in different languages to the patient portal	IT team	4	2
	27	Patients do not know what to do about a deteriorated score	Antecedents: Adding objects to the environment	36	Add self-management advice for deteriorated scores to the PROMs dashboard	BI team, Impl. Team	5	3
			Antecedents: Adding objects to the environment	37	Add self-management advice for deteriorated scores to the patient portal	IT team, Impl. Team	4	2
	28	Patients are not able to review their results in the patient portal in an appropriate format	Antecedents: Adding objects to the environment	38	Add patient-friendly PROMs dashboard to the patient portal	IT team	5	2
	29	Patients find it hard to navigate through the PROMs system/patient portal	Antecedents: Adding objects to the environment	39	Make navigation in the patient portal more patient friendly and adjustable to specific needs (pictures, spacing, font size etc.)	IT team	5	2
	30	PROMs frequency is not aligned with consultations and course of HRQoL issues during treatment		40	Link PROMs to consultations or increase frequency to by weekly	IT team	5	2
Reinforcement	31	Patients stop completing PROMs because HCP do not refer to them	Goals and planning: Goal setting	41	Set agreements with each department about who is responsible for discussing PROMs for each time point	Impl. Team, department lead	5	5
			Rewards & threats: Reward	42	Add self-management advice for deteriorated scores to the patient portal	IT team, Impl. Team	4	2
			Rewards & threats: Reward	43	Train HCPs to acknowledge that patients completed the PROMs and to ask specific follow-up questions	Impl. Team, department lead	4	3

**Legend:** Green shading: considered strategies (both P and F > 2.5), orange shading: strategies currently not considered (P or F < 2.5).

**Abbreviations:** TDF-domain: Theoretical Domains Framework; P: Priority; F: Feasibility; PROMs: patient-reported outcome measures; Impl. Team: PROMs implementation team; EHR: Electronic health record; HCP: Healthcare professional; HRQoL: health-related quality of life; BI: Business Intelligence; IT: information technology; NP: Nurse Practitioner; CAT: Computer adaptive testing

### Feasible and prioritized improvement strategies aimed at patients

Hospital-based support could assist patients who could not successfully complete PROMs in their home environment. This includes establishing help desks (*Strategy 27*) and handing out tablets in the out-patient waiting room (*Strategy 28*). Other strategies related to improving patient information (*Strategy 29*), including clear instructions about the goal of PROMs. For instance, to clarify that PROMs are about patients' own health and could inform their healthcare, we rephrased the instruction in the e-mail from 'please fill in the questionnaire' to 'prepare for your consultation' (*Strategy 33*), and aim to add an additional question after each PROM completion that asks about what patients wants to discuss with their HCP (*Strategy 32*).

### Strategies (currently) not feasible and/or prioritized

Strategies 7–9, 15, 31, 34, 35, 37–40, and 42 that had been prioritized during the consensus meetings were currently deemed to be unfeasible. This included for instance: linking PROMs to specific clinical consultations, increase assessment frequency e.g. during systemic treatment, being able

to select a different language or format to complete PROMs, and showing a patient-friendly version of the PROMs results through the patient portal. Those strategies were considered infeasible due to restrictions in the EHR-software, requiring large or complicated changes in the EHR for which no IT staff was available, lack of validated options to tailor PROMs to specific patient needs (e.g. omitting questions about their sex life), or due to the complexity of the change and the involvement of multiple stakeholders (inside and outside the hospital). Sometimes, clinical time windows made it difficult to align PROMs with clinical care. For instance, baseline PROMs could not be administered before the multidisciplinary team meetings.

Strategies that were classified as feasible but of low priority were: adding all separate PROMs items to the score dashboard (*Strategy 10*) and obligatory registration in the EHR of whether HCPs have discussed PROMs with their patient (*Strategy 21*). Strategies considered both unfeasible and not prioritized were: implementing computer adaptive testing to shorten PROMs and improve their relevance to patients (*Strategy 30*) and adjusting the PROMs to account for patient characteristics like sexual preferences (*Strategy 34*).

## Discussion

In this study, a multi-faceted evidence-based approach was applied to enhance PROMs implementation in routine oncology care. Summarized, the main barriers identified within our institution were: the insufficient alignment of PROMs, the patient portal, and EHR with patients' and HCPs' needs with the clinical context, HCPs' hesitancy in providing guidance to patients about HRQoL, and the lack of consensus regarding which HCPs are responsible for discussing PROMs. The wide variety of barriers once more underscores the complexity of implementing PROMs in oncology care, revealing many interacting components. By selecting appropriate strategies from the BCT Taxonomy and ranking these, we have provided practical guidance on where to start to ensure long-term adoption of PROMs.

We reported improvement strategies quite similar to Jolliffe et al. [33], including the integration of PROMs into text fields or forms in the EHR, sending out reminders, improving insight in PROMs inclusion and completion, providing information to HCPs about the status of the PROMs implementation and education how to use the PROMs, appointing champions, and assigning HCPs responsible for addressing PROMs. As the authors developed hypothetical improvement strategies, the feasibility of their strategies was not considered. Based on our priority ranking, aligning PROMs administration and clinical consultations was an important strategy due to the differences in the frequencies of consultations per treatment pathway [6, 14]. Yet, this strategy was currently deemed infeasible due to technical restrictions; the lack of integration of PROMs in clinical workflows is a commonly reported barrier [4, 7].

In contrast to existing literature [33], we interviewed patients who did and did not complete PROMs, and reported strategies like installing a help desk and providing tablets in the waiting room to assist completing PROMs, which has been described in previous work [14]. As patients often lack understanding about why and when they should complete PROMs and how this will benefit their care [8, 39–41], we improved patient information to clarify the goal of PROMs [42]. Last, presenting self-management strategies was aimed at improving patient engagement with PROMs [43]. Unfortunately, an important strategy, adding a patient-friendly score dashboard to the EHR, was currently deemed unfeasible. The inability to adjust the EHR-associated patient portal to patients' needs is often described [44–47]: even though EHR-vendors offer patient portals, EHR-systems are commonly designed with HCPs as end-users [48], causing a potential mismatch between user design and patients' needs and preferences. Consequently, potentially vulnerable patients including elderly, patients with lower (digital) health illiteracy, and non-native speakers are often unable

to participate in digital PROMs [15, 49]. Therefore, even though literature describes the embedding of PROMs in the EHR as a main facilitator for implementation [3, 50, 51], we believe the EHR may not be the optimal platform for PROMs.

Training HCPs about PROM goals, tasks, and responsibilities is crucial in motivating their engagement with PROMs [6, 52]. HCPs in the study by Jolliffe et al. [33] expressed concerns about consequences based on PROMs data, such as funding restrictions. Although not specified, PROMs may have been implemented for the purpose of outcome evaluation. This may explain why these concerns were not expressed by our respondents, who have always been informed that PROMs were implemented aimed at enabling personalized supportive care for cancer patients. Furthermore, as echoed by our study, one third of studies in the literature review Anatchkova et al. [53] described that HCPs feel unsure in their advice about HRQoL and referral to supportive care interventions. As HCPs consider it challenging to interpret PROM results [7], we have redesigned the PROMs dashboard by rescaling domains, adding laymen descriptions of domains and indicators for which treatment phase patients were in, and referencing scores to 'patients-like-me' data. Other studies have also described the enriching of the PROMs dashboard with clinical information [54] and changing directionality of PROMs scales [55] to enhance comprehensibility and support clinical decision-making. Additionally, we have rescaled all scores to scales of 0 to 100. Although presenting outcomes in a different format does not change the underlying structure of the validated PROMs, it does counteract with the practice of not modifying validated PROMs, which may explain why literature did not describe this alteration.

Furthermore, there is a lack of clear supportive care referral pathways for PROMs in supportive oncology care [14, 56]. The patient management advice that we added to the PROMs dashboard was based on existing sources of patient information available at our institute and reviewed by the institute's supportive care professionals. Although these patient management advices have not been validated in ways patient management guidelines usually get validated, we expect these lower the bar for HCPs to provide patients information and guidance on HRQoL issues [7]. Future research should focus on developing evidence-based recommendations for supportive care that align with PROMs scores for different treatment phases. Similar to our findings, Lopez et al. [50] describe that HCPs do not expect from each other to discuss PROMs. Like Jolliffe et al. [33], we aimed to reach consensus about HCPs' responsibilities for discussing PROMs. Furthermore, we aim to drive change by setting goals (e.g. % of consultations where PROMs should have been discussed), presenting performance measures,



and comparing performance between clinical teams; the latter strategy was found successful to motivate breast cancer surgeons to engage with PROMs [13].

The ranking of improvement strategies also showed the infeasibility of some strategies. These findings are important, as these point the way for future research and development. First, improving the user-friendliness of the EHR-based PROMs system was limited by the EHR's technical restrictions; aligning the administration frequency with specific treatment phases required large infrastructural changes to the EHR that are currently deemed infeasible. We need platforms with more advanced technical opportunities that can communicate in a safe way with the EHR [6, 57]. Secondly, improving the user-friendliness of PROMs by for instance adjusting wording and questioning means that these need to be revalidated: changing the wording may mean changing the meaning. As validation studies are labor-intensive, alternatives may be necessary to support patient-orientated communication of PROMs [58].

## Strengths and limitations

Including multiple data sources and end-users with different perspectives has provided a thorough understanding of the implementation process and extensive knowledge on specific strategies to ensure sustainable adoption of PROMs was gained. That said, this study may have the following limitations. First, even though deductive framework analysis is a valid approach for implementation research, we might have overlooked underlying deeper, less tangible constructs that influence PROMs implementation. These constructs, including beliefs and hospital culture, may not have been addressed by our more technical recommendations, leaving people to behave like 'they always have'. Addressing these constructs would require cultural changes in our institute, healthcare, and our society. Second, by inviting the department champions to prioritize the improvement strategies, strategies that are important to non-users and patients may have been under-prioritized. The now prioritized improvement strategies are expected to offer a larger base for support of PROMs implementation, creating support in the institute to invest in less feasible strategies and further include non-users; especially patients with lower health literacy levels may have been overlooked. Last, we applied the BCT Taxonomy to account for different roles of doctors and nurses regarding PROMs and a range of patient characteristics affecting PROMs use [49]. However, the usefulness of other existing taxonomies should be explored; specifically the Expert Recommendations of Implementation Change (ERIC) could be complementary to the BCT, providing contextual examples of how more broadly defined BCTs could be operationalized for implementation [59].

## Conclusion

This study sets an example of how to use a theory-driven approach to develop detailed improvement strategies and can contribute to uncovering why certain PROMs implementation projects work and others do not. Moving beyond identifying barriers and facilitators, this study provided detailed evidence-based strategies for improvement of implementation, aiming for lasting adoption of PROMs in routine oncology care. After implementing all proposed improvement strategies, we will redistribute the questionnaire that informed the interview guides to see whether barriers have been resolved.

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## Declarations

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