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Electronic Patient Reported Outcome Measures after palliative radiotherapy: evaluation of implementation

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Background: Radiotherapy is a frequently utilized palliative treatment for cancer patients. Electronic Patient-Reported Outcome Measures (ePROMs) offer a method for patients to communicate their symptoms and concerns to healthcare providers (HCPs) remotely. While ePROMs have demonstrated significant benefits for oncology patient care, their integration into routine clinical practice of palliative radiotherapy (PRT) poses challenges. The current study aimed to evaluate the implementation of an ePROM-intervention after PRT.

Methods: We conducted a two-phase study to evaluate the implementation of a self-developed ePROM intervention, known as the ePRomT diary, for symptom monitoring post-PRT. This diary offered automated self-management advice for mild symptoms and also guided patients to contact an HCP for severe symptoms. We assessed various implementation aspects using the RE-AIM framework and collected data through surveys, interviews, electronic health records, and field notes. Quantitative data analysis employed descriptive statistics, while qualitative data underwent thematic analysis using NVivo. Recruitment periods for both phases spanned 10 weeks.

Results: In Phase I, 37 out of 87 eligible patients (43%) participated, a number that rose to 40 out of 49 eligible patients (82%) in Phase II. Among participating patients, 93% in Phase I and 98% in Phase II reported the ePRomT diary as a valuable addition to their care. Additionally, 75% and 84% expressed willingness to reuse it, while 70% and 80% would recommend it to others in Phases I and II, respectively. In Phase I, 17 out of 39 patients (44%) completed at least one ePROM assessment, increasing to 26 out of 40 patients (65%) in Phase II. While patients found the self-management advice generally correct and relevant, they noted its somewhat generic nature. Moreover, while the advice to contact an HCP was deemed appropriate, adherence to it varied. HCPs expressed satisfaction with the intervention, deeming it valuable in patient care, and believed that integrating it into routine clinical practice would enhance patient acceptability with minimal workflow disruptions.

Conclusions: Despite certain limitations, including participant bias, our study offers valuable insights into the implementation and potential implications of an ePROM intervention for symptom follow-up post-PRT, framed within the RE-AIM framework. ePROM interventions like the ePRomT diary show promise and are well-received by both patients and HCPs. However, optimizing such interventions to better align with

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patient needs and seamlessly integrating them into clinical workflows within the context of PRT warrants further investigation.

Keywords: Palliative radiotherapy (PRT); electronic Patient-Reported Outcome Measures (ePROMs); implementation research; symptom management

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Introduction

Background

Radiotherapy is a frequently employed palliative treatment for patients with advanced cancer (1,2). In our hospital, approximately 30% of radiation treatments are given with palliative intent, equating to around 750 palliative radiotherapy (PRT) courses annually. Despite preventive measures, treatment-related symptoms or other issues can persist post-treatment, leading to a decline in patients' quality of life (QoL). Due to the short treatment courses used for PRT, these symptoms often manifest after treatment completion. Consequently, accurately capturing treatment-induced toxicities from patients is challenging, as monitoring typically only occurs during scheduled visits. Additionally, there is a lack of guidelines detailing the best practices for systematic symptom monitoring after PRT (3,4).

Highlight box

Key findings

- Electronic Patient-Reported Outcome Measures (ePROMs) after palliative radiotherapy (PRT) for symptom follow-up are feasible a well-received by both patients and healthcare providers.

What is known and what is new?

- ePROMs have been shown to be valuable in palliative cancer treatment and palliative care, but integration in clinical practice remains a challenge.
- PRT patients may use ePROMs to report their (treatment-related) symptoms from home.
- This study adds information on the implementation of ePROMs in patients receiving PRT.

What is the implication, and what should change now?

- ePROMs should be integrated into existing workflows to maximize their potential benefit for patients undergoing palliative treatment, such as radiotherapy.

Rationale and knowledge gap

Remote follow-up through web-based care is a potential strategy to enhance care for patients. Electronic Patient-Reported Outcome Measures (ePROMs) could enable patients to report symptoms and concerns from home, facilitating timely and appropriate care (5). In research settings, ePROMs have been shown to be acceptable to both patients and healthcare providers (HCPs) and are associated with improved patient-provider communication, enhanced health-related QoL, reduced emergency department visits, and even improved cancer-related survival (6-11). However, ePROM implementation in routine clinical practice has shown to be challenging, with ongoing concerns about their associated burden and workload for both patients and clinicians, limited integration of ePROMs into clinical workflows and the electronic medical record (EMR), and insufficient technical support (12-14). Limited data are available on the application of ePROM-based symptom follow-up after PRT (15).

Objective

Our team has developed an ePROM intervention for symptom follow-up after PRT, named the ePRomT diary (12,15,16). The current study aimed to evaluate the implementation of this intervention using the RE-AIM framework. In Phase I, we investigated: (I) which patients were most likely to use the ePROM intervention; (II) how patients would perceive and use the intervention; (III) which HCPs within our staff were motivated to participate in implementation and how they viewed their role; (IV) which aspects of our intervention needed modification to increase implementation and enhance patients' satisfaction; and (V) what resources HCPs require for long-term success. Based on the user feedback received in Phase I, modifications were made to the intervention and its implementation strategy, and its target audience was redefined. The impact of these

changes on relevant RE-AIM aspects was assessed in Phase II of the study (*Table 1*). We presented this article in accordance with the TREND reporting checklist (available at https://apm.amegroups.com/article/view/10.21037/apm-24-74/rc).

Methods

Study design

A mixed-method two-phase implementation evaluation of an ePROM based follow-up intervention after PRT was performed in a single, tertiary hospital, University Hospitals Leuven in Belgium.

ePROM intervention

Drawing on clinical experience, literature on ePROMs in advanced cancer and palliative care, previous ePROM diaries developed in our hospital, and our own exploratory research on ePROMs in PRT, we developed an ePROM intervention for symptom follow-up after PRT: the ePRomT diary (12,17,18).

In this diary, symptoms were assessed using the Dutch translation of the Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE), with the exception of pain, which was measured using a numeric rating scale ranging from 0–10 (19-22). The symptoms evaluated were selected based on clinical experience, patient feedback, and existing literature, as specific PRO-CTCAE items have not yet been established for PRT (4,23,24). In Phase I of the study, nine general symptoms were evaluated. Additionally, patients could report any other relevant symptom(s) they experienced in a 'free text' box. In Phase II, treatment region-specific items were added to the general symptoms on patient request (*Table 2*).

The ePRomT diary was integrated into the online patient portal of the hospital's EMR, MyNexUZHealth (25). This platform allows patients to view appointments, consultation reports, scans, and other health-related information. Importantly, patients already receive ePROMs, Patient Reported Experience Measures, diaries, and other questionnaires through this platform.

Patients were automatically prompted daily to complete the ePRomT diary, for a period of 21 days following PRT. Upon completion of the diary, immediate automatic feedback was provided based on the input: reporting of limited symptom severity resulted in online self-management advice (e.g., references to specific hospital information folders and leaflets, general self-care instructions), while reporting severe symptoms led to advice to contact an HCP. There was no active follow-up of the diary by HCPs. However, when patients received advice to contact an HCP, an automatic email was also sent to researcher E.O. for research purposes.

In Phase II, one hour per week was allocated for telephone consultations with the clinical support managers (CSMs), based on patients' feedback. CSMs are nurses and radiotherapy technologists (RTTs) with several years of experience who see patients after their consultation with the physician for additional support and education. Information about the role of the CSM and their availability was added to the study materials. Patients were explicitly encouraged to contact a CSM or HCP of choice in case of questions or concerns during the study.

Implementation plan

The RE-AIM framework was used to evaluate the implementation and to identify factors for sustainable adoption of this intervention (*Table 1*). RE-AIM is an acronym for five domains: (I) *reach* of the target population; (II) *effectiveness* on key outcomes; (III) *adoption* by individuals responsible for delivery; (IV) barriers, facilitators, and resources necessary for *implementation*; and (V) potential for *maintenance* of the intervention (26-28).

Given that residents in radiation oncology (N=9) and CSMs (N=4) would be the primary recruiters for the study, they received additional training on the eligibility criteria, the ePRomT diary, and MyNexUZHealth.

All staff in the Department of Radiation Oncology were educated about (e)PROMs, their potential benefits and current use in oncology, the ePRomT diary and the study objectives via presentations, flyers, meetings, and emails. HCP from outside the department were informed about the study through a trial notification in the patients' EMR, which included information about the ePRomT diary as well as PRT, its side effects, and potential supportive measures.

The implementation strategy was discussed in advance with the medical staff, a resident representative, the head nurse, and one of the CSMs to ensure that the intervention was seamlessly incorporated into routine clinical practice as much as possible.

Both implementation phases had a recruitment period

Table 1 RE-AIM features reviewed during implementation

RE-AIM construct	Definition	Question addressed
Reach	Who will benefit from the initiative?	(I) What is the number of palliative patients referred to the Department of Radiation Oncology?
	Number, proportion and representativeness of patients willing to participate in the program, and reasons why or why not	• In an ambulatory setting • Dutch speaking • KI ≥50/WHO score ≥3[‡]
		(II) What is the number/proportion of eligible patients offered the ePRomT diary?
		(III) What is the number/proportion of eligible patients participating in the ePRomT diary?
		(IV) Why are patients motivated to participate in the ePRomT diary? Why not?
Effectiveness	What are the (individual-level) outcomes of the intervention?	(I) What is the patient satisfaction with the ePRomT diary?
	Individual impact of the intervention (including negative effects)	(II) What is the impact of the ePRomT diary on patients' experience of their symptoms?
		(III) What aspects of the ePRomT diary were experienced in a negative way?
Adoption	Who will deliver the initiative and do they have the skills and time?	(I) What are the key characteristics in the target setting?[†]
	Organizational support to deliver the ePRomT diary	(II) What are the level of expertise and characteristics of the staff members who deliver the intervention?[†]
		(III) What is the difference between staff who do and do not participate in the intervention?
		(IV) What external/organizational opportunities and threats are there?[†]
Implementation	(I) How will the initiative be delivered? Including adjustments and adaptations?	(I) What are the key elements of the intervention that must be delivered successfully?[†]
	(II) To what extend will the key aspects of the initiative be delivered as intended?	(II) What is the impact on the number of patients with symptoms contacting the Department of Radiation Oncology?
	(III) What costs need to be considered? (including time and burden)	(III) What are likely implementation challenges that need to be overcome?[†]
	The extent of implementation of the ePRomT diary	(IV) Are there competing projects or programs to consider?[†]
Maintenance	What will happen over the long run?	(I) What is staff feedback on ePROM implementation for routine clinical practice?
	Chances/necessities of ePRomT diary successfully being implemented in clinical care over time	(II) What infrastructure will be needed to sustain the ePRomT diary?[†]

[†], only reviewed in phase I; [‡], only applicable in phase II. KI, Karnofsky Index; WHO, World Health Organization; ePROM, electronic Patient-Reported Outcome Measure.

Table 2 PRO-CTCAE items of the ePRomT diary

Phase I
General symptoms after palliative radiotherapy
General pain
Nausea
Vomiting
Constipation
Diarrhea
Dyspnea
Skin reaction
Fatigue
Anxiety/sadness/discouragement
Phase II
Symptoms related to irradiation of the head & neck region
Headache
Decreased appetite
Dry mouth
Difficulty swallowing
Hair loss
Symptoms related to irradiation of the thoracal area
Difficulty swallowing
Shortness of breath
Cough
Symptoms related to irradiation of the abdominal/pelvic area
Urinary frequency
Urinary urgency

The ePRomT diary in implementation phase I included general symptoms and a free text box to add an additional symptom. In implementation phase II, site-specific PRO-CTCAE were added to these general symptoms. Note that pain was assessed by a numeric rating scale. PRO-CTCAE, Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events.

of 10 weeks, with Phase I conducted in late spring 2021 and Phase II in late spring 2022. The research group met regularly during these periods to discuss the implementation findings.

Participants

Patients were recruited during appointments and bedside consultations, with about 50% of patients referred for PRT seen in each setting. Patients were eligible for the ePRomT diary if they (I) could give informed consent; (II) could speak/read and write Dutch; (III) started PRT; (IV) were ambulatory or assumed to be ambulatory after treatment; (V) were willing and able (computer and internet access) to complete ePROMs (themselves or with assistance); (VI) were not enrolled in another study that required the completion of (e)PROMs. Patients treated in oligometastatic setting could not participate.

In Phase II, we excluded patients with a Karnofsky Index (KI) of ≤50/World Health Organization (WHO) score ≤3.

Data collection

To assess the proportion and representativeness of participating patients and their characteristics compared to the total patient group referred for PRT, patient data such as age, primary tumor, treatment localization, performance status, and all ePROM data (number of completed ePROMs, reported symptoms, and reported number of contacts triggered by the diary) were extracted from the EMR (*reach*, *implementation*) (*Tables 3*,*4*).

All patients who agreed to take part in the study, completed a survey (Appendix 1) and participated in a semi-structured interview 3–6 weeks after completing their treatment (i.e., 0–3 weeks after completing the diary), regardless of ePROM completion. Themes explored were reasons for (non-)use of the diary, satisfaction with the intervention, and suggested changes (*effectiveness*, *implementation*). Three to four weeks after each inclusion period, CSMs and residents participated in semi-structured interviews to review the recruitment and implementation process as well as other feedback (*implementation*, *adoption* and *maintenance*).

In addition to the surveys and interviews, field notes were taken about implementation success, HCPs' comments, and other relevant information during the recruitment period.

Analyses

Quantitative data from the patient surveys were analyzed using (descriptive) statistics. Qualitative data from field notes and interviews were thematically analyzed, focusing on themes associated with (non-)use of intervention using NVivo.

All interviews were conducted by researcher E.O., a radiation oncologist working in the department, during a

Table 3 Patient characteristics of the participating patients for both phases of the implementation

Patient characteristics	ePRomT diary—Phase I		ePRomT diary—Phase II	
	Reference cohort palliative patients (n=128)	Eligible & participating patients (n=42)	Reference cohort palliative patients (n=109)	Eligible & participating patients (n=40)
Age (years)				
Mean [range]	63 [33–87]	60 [42–83]	67 [34–103]	66 [37–86]
Median	63	59	68	67
Sex, n				
Male	69	22	78	28
Female	59	20	31	12
KI (%)				
Mean [range]	80 [30–100]	80 [50–100]	80 [40–100]	90 [60–100]
Median	80	80	80	90
Primary tumor, n				
Breast	29	12	7	2
Lung	32	9	39	16
Prostate	9	4	9	2
Rectum	5	0	7	4
Other	53	17	47	16
Site of irradiation, n				
Bone	75	31	51	14
Brain	26	8	19	12
Other	27	3	39	14
First palliative radiotherapy treatment, n				
Yes	81	25	63	24
No	47	17	46	16
Ambulatory status during treatment, n				
Hospitalized	32	11	24	1
Ambulatory	96	31	85	39

KI, Karnofsky Index.

scheduled appointment. All interviews were audio recorded, transcribed verbatim, coded and analyzed by E.O. Two additional researchers (A.C. and S.I.) independently read several transcripts, to help generate initial codes with discrepancies resolved through discussion and consensus. Coding and analysis was done using NVivo.

Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Permission for this study was obtained from the Ethics Committee Research UZ/KU Leuven (No. B3222021000603). All participants in this study signed an informed consent form (ICF). The Standards

Table 4 Reasons for non-completion of the ePRomT diary, despite participation in the study

Patient information	Phase I	Phase II
Patients who agreed to participation	42	40
Patients who completed ePROMs (at least once)	17	26
Patients who did not complete ePROMs	25	14
Reasons for non-completion		
Exclusion from trial	3	0
Too burdensome	11	7
Due to health decline	5	3
Due to no/limited symptom burden	1	2
Due to hospitalization	5	2
Difficulty with completion (technical issues)	1	1
Other	0	2
No longer interested in ePROM intervention	10	4

ePROM, electronic Patient-Reported Outcome Measures.

for Reporting Implementation Studies of Complex Interventions (StaRI) were followed (29).

Results

Reach

In Phase I, 128 patients were referred to our department for PRT (*Table 3*). Of these patients, 87 (68%) met the eligibility criteria for the ePROM intervention, and 42 patients (33%) agreed to participate. Forty-five patients (35%) declined participation for various reasons. The primary reason for refusal by 25/45 (or 56%) patients was the electronic completion of the PROMs. Three patients were offered ePROMs during systemic treatment shortly after completing PRT, which was an exclusion criterion. Consequently, their ePRomT diary was discontinued after a telephone discussion, resulting in 39 participants (30% of the total patient population or 45% of eligible patients).

Phase I revealed that four patients with a KI of ≤50 were either hospitalized or received palliative care at home with daily visits from a home care nurse (HCN) after their PRT. These patients either did not complete the ePROMs and/or found them relatively burdensome; with two patients dying during the intervention period. This resulted in 37 patients that could be analyzed. Based on these findings, it was decided to only include ambulatory patients with a KI of >50 in Phase II (*Tables 3*,*4*).

In Phase II, 109 patients were referred for PRT (*Table 3*). Sixty (55%) were unable to participate, of which 25 were not offered the ICF. In 19/25 (or 76%) of these patients, this was due to workflow changes during coronavirus disease 2019 (COVID-19). Additionally, 3 patients were not offered the ICF due to uncertainty regarding their treatment setting (palliative or curative), and at the request of a supervisor: in one case because of the patient's age, in the other two for unknown reasons. Of the remaining 49 patients, 40 (37% of the entire patient population or 82% of eligible patients) participated in the ePRomT diary (*Table 3*), and 9 (18%) declined participation, all citing a lack of interest in increased symptom follow-up (*Table 4*). All of the 40 patients who participated in the trial agreed to complete the study survey and were interviewed.

In both phases, reasons for participation included the opportunity for additional symptom follow-up beyond standard-of-care, self-management support associated with increased independence and patient-centered care, and the fact that the ePRomT diary was introduced as a potentially important addition to their care (*Table 5*). In the interviews, even patients who did not complete any ePROMs reported being pleased to have been invited to participate.

Patients generally expressed high satisfaction with the information provided about the study and its objectives as well as the intervention itself in the survey (Tables S1,S2). A limited number of patients gave a neutral answer to the survey question regarding their satisfaction with written information provided. In the interviews, it became clear that these patients referring to the ICF, which they found hard to understand. The information provided to them about how to use the app, the goal of the ePROmT diary etc. was regarded clear and complete by all patients.

Both CSMs and residents mentioned that the ICF acted as a barrier for recruitment. The ICF was considered disruptive in the consultation and patients were put off by the size of the ICF. Additionally, the terms 'palliative' and 'palliative radiotherapy' deterred several patients from participating, as they did not identify with these labels.

Effectiveness

In both phases, patients responded neutrally when asked if the diary met their expectations in the survey (Tables S1,S2). When asked about this in the interviews, all of these patients indicated that they had never used an ePROM diary before

Table 5 Representative quotes from ePRomT diary participants structured according to the RE-AIM framework

RE-AIM construct	Quote
Reach	"*Some patients seem to be surprised or even insulted that the study is offered, so sometimes I doubt myself about the palliative status of the patient. It makes for a difficult conversation sometimes*"—CSM 1, Phase I
	"*[…] and then all these questions about being palliative. Can't that just be removed [from the ICF], it would make it so much easier to offer the study*"—Resident 2, Phase I
	"*I think in general patients were open to be included in a study, even patients that I thought were in too poor condition to participate*"—CSM 3, Phase II
	"*Being offered the diary by someone who was enthusiastic about it was [important] for me. It made me feel that this was something that was viewed as beneficial for me and my treatment*"—Patient 7, Phase I
	"*While I ultimately did not complete your diary questions, I was very pleased to be offered [the intervention]. I felt that I by participation could complete it if I experienced issues or had unmet needs*"—Patient 9, Phase I
Effectiveness	"*I experienced some pain and was advised to make a call, but I had this appointment anyway so… I wouldn't want to disturb, especially as I have finished [my treatment] […] here I was going to discuss it anyway, it wasn't that big of a problem*"—Patient 7, Phase I
	"*The questions were good, I can't fault that… […] The amount of hair loss, I didn't expect that. It would have been nice to have understood that better, but the diary didn't ask about it either. Maybe such things could be added*"—Patient 34, Phase I
	"*You know, it is difficult to determine when [your] symptoms warrant a call. If you have a severe problem, you go to the emergency department; if it is a small issue you handle it yourself. It is difficult to determine when you can't fix it yourself anymore*"—Patient 3, Phase II
	"*My GP, I haven't talked to her in about two years now, how could she help me? Here they know what's going on, what I'm going through*"—Patient 3, Phase II
	"*One treatment is finished, the other one has not started yet. Who do I contact? The one who has finished his job? I've been on the oncology ward many times, I know them? I don't know, I just find it difficult to bother someone who has finished his task, you know?*"—Patient 21, Phase II
	"*It's easier to remember what you've experienced if it's written down somewhere. I used to write it down on paper, but with the diary it is immediately available for you in my file, so I don't have to think about it anymore*"—Patient 19, Phase II
	"*The advice in the diary is good, I've read it all. However, when they say you should optimize your [pain] I never know what they mean. It would really help me if they [HCP] and the diary would be more specific: when and which medication to take and when to stop it again. It would be nice to discuss that with someone, but can I contact someone for that? [..] I feel obliged to discuss those things during consultations and not make additional contact*"—*Patient 4, Phase II*
	"*I thought a lot of aspects were positive about the diary: it's short, you get daily reminders and immediate feedback in case of problems. It would have been nice to have more of those free text [boxes], so you can add certain things*"—Patient 40, Phase II
	"*It makes me feel more secure, the diary. You can look at it and follow the evolution of my symptoms. I know it's not actively monitored, but still, the data is there for review*"—Patient 6, Phase II
Adoption	"*What was difficult for me was not knowing how our patients were doing. There is not a lot of interaction with the other wards. That would demotivate me in the long run*"—CSM 1, Phase II
	"*While doing bedside consultations, discussing the [ePRomT diary] is difficult. Not the diary itself per se, most people know the app and symptom diaries, but the study. You have to bring all this stuff with you, remember who was potentially willing to participate and will need to be asked for their ICF …*"—Resident 2, Phase I
	"*I support ePROMs, I do. I think it's very good for our residents to use, as a teaching tool. We should just offer it to everybody*"—Supervisor 1 (field note)

Table 5 (*continued*)

Table 5 (*continued*)

RE-AIM construct	Quote
Implementation	"*I started using the diary and thought it looked good. However, I had no real complaints so I didn't see the need to keep doing it*"—Patient 2, Phase I
	"*I could not find it, I looked everywhere for a diary. In the end, my daughter helped me. […] It would really help if 'Radiotherapy' would be mentioned in the title*"—Patient 7, Phase I
	"*Between all the different diaries and questionnaires, the diary got a bit lost. The title [ePRomT diary] didn't really help in finding it. Couldn't you just call it radiotherapy diary or something?*"—Patient 17, Phase I
	"*The diary itself is ok, but a bit general. For example, I experienced a lot more hair loss than I expected. It would have been nice to have the app ask me questions about this, in order to prepare me for wat could happen*"—Patient 22, Phase 1
	"*It's a lot: this diary, the one from the chemotherapy and now I see that they have send me more stuff to fill out because I'm currently in a study. You should look [at the data I have to complete]. And a lot of these questions are the same or very similar*"—Patient 13, Phase I (field note during telephone call to cancel the ePRomT diary)
Maintenance	"*It would be great if we could play a central role in patient follow-up and the ePRomT diary. I think we could really make a difference: we see a lot of patients both during consultation and follow-up and we may be easier to contact than a physician*"—CSM 1, Phase II
	"*Part of our job is implementing initiatives for patient quality, so I think this project Is right up our alley. However, we do need time for projects like this*"—CSM 3, Phase II

ICF, informed consent form; CSM, clinical support manager; GP, general practitioner; HCP, healthcare provider; ePROM, electronic Patient-Reported Outcome Measures.

and therefore did not really have any expectations about the ePROM diary or how it would work.

Patients generally found the questions in the diary to be relevant and concise (Tables S3,S4). In the interviews, patients were highly positive about the free-text box, with many suggesting the inclusion of more such boxes to individualize the diary. In Phase I interviews, some patients mentioned missing questions related to their specific situation and recommended adding additional questions specific to the treatment area, as they found the symptom list too generic (*Table 5*). This feedback was incorporated into Phase II, after which the questionnaire being 'too generic' was no longer mentioned (*Table 2*). However, providing more than one free-text box was requested by several patients in Phase II as well.

In Phase I, about two-thirds of patients indicated that the diary made them more aware of their symptoms; in Phase II, this was about half of the patients (Tables S3,S4). In the interviews, several patients mentioned that they would want to use the diary questions as a sort of checklist to know which symptoms to look out for. In Phase I, this was one of the reasons patients requested questions related to their specific symptoms, as mentioned above.

The automatic feedback was generally viewed as important, relevant, and useful. However, in the survey, a portion of patients did not associate the diary and the feedback it provided with a feeling of independence (Tables S3,S4). In the interviews, however, patient indicated that the self-management strategy enabled them to be active participants in their care, which they appreciated (*Table 5*). The feedback was considered "helpful", making patients feel "supported" and more "secure".

Some patients expressed a desire for self-management information more tailored to their specific situation. They found the advice provided on the feedback pages to be useful but rather generic. Some even indicated a preference for receiving a personalized email or message with personalized information instead of automatically generated feedback (*Table 5*).

All patients who received advice to contact an HCP considered this necessary and appropriate (Tables S5,S6). However, this advice did not seem to motivate patients to contact an HCP or make them more secure to do so. In Phase II, the motivation to contact an HCP was higher than in Phase I (Tables S5,S6). In both phases, patients perceived a barrier to reaching out. Several patients expressed a preference for being contacted by an HCP, especially when experiencing more severe symptoms. The primary reason

for this preference was the fear of inconveniencing HCPs with their concerns and questions, particularly because they lacked a specific contact person (*Table 5*). Consequently, many patients mainly used the diary and its advice to guide discussions on their most severe symptoms during face-to-face consultations, such as scheduled appointments or day ward visits. In Phase I, two patients suggested specifying a recommended time or period for contacting the hospital to further facilitate communication. In Phase II one hour per week was allocated for telephone consultations with the CSMs. This was very positively perceived and reviewed in the interviews, as most patients preferred discussing their symptoms directly with a hospital HCP and were reluctant to schedule a (telephone) appointment with their general practitioner (GP) as recommended in the diary.

In Phase II, three patients in very poor condition found three weeks of (daily) ePROMs too burdensome. One answered in their survey that 3 weeks was too long and suggested that an alternative follow-up method might be more suitable for patients in their situation during the interview. The two other patients indicated that a duration of 3 weeks was no problem, but maybe a lower frequency of ePROMs would decrease completion burden (*Table 5*). However, no negative effects related to the ePRomT diary or participation in the study were reported by these or other patients.

Overall, only one patient from Phase I indicated being disappointed with the intervention (Tables S1,S3,S5). The diary did not meet his expectations, and he was not happy with the questions asked nor the feedback provided. During the interview, he mentioned that his wife was a registered nurse in the department of oncology, and that he would discuss his symptoms and questions with her, so the diary did not provide any additional information or benefit.

In Phase I, 93% of patients using the ePRomT diary found it to be of added value in their care, 75% were willing to use it again for retreatment, and 70% would recommend the diary to others. In Phase II, these figures increased to 98% finding it valuable, 84% willing to reuse it, and 80% recommending it to others (Tables S1,S2). Using the diary did not result in a subjective impact on the duration, intensity, or overall impact of their symptoms. Nevertheless, patients in both phases mentioned feeling "safer" with the diary, despite the fact that their entries were not actively monitored.

Adoption

CSMs generally expressed satisfaction with recruitment for the study. They believed they had ample time to introduce the study, explain the diary, and assist patients with installing the software on their phones/demonstrating the diary if needed. They also felt that they were able to enroll a proper number of patients in the study. In contrast, residents, who introduced the ePRomT diary during bedside consultations in hospital and day wards, found it more challenging to discuss the study or offer assistance with the diary. They felt that considering the study and eligibility criteria was disruptive amidst their hectic schedules. Additionally, carrying ICFs during their clinical rounds was seen as burdensome. Residents also noted the difficulty of recruiting patients in shared rooms, which compromised privacy. Furthermore, they frequently encountered patients who had not anticipated being referred for PRT, making it challenging to discuss topics such as research and enroll patients in the trial.

The same CSMs were involved in the two phases of the study, so limited time in education of ePROMS or the trial was necessary. However, several residents had changed between Phase I and II and several requested information and education on an individual basis.

Despite these (perceived) challenges, the recruitment rates for the study were comparable between residents and CSMs.

Implementation

In Phase I, 17 of the 37 included patients (46%) completed at least one assessment, with an average of 10 assessments per patient (range, 1–20). Of these 17 patients, 10 received self-care advice at least once. The primary reason for limited ePROM completion was a low symptom burden, leading to a perceived lack of need for self-management or HCP advice. Twenty-two patients (56%) did not complete any assessments for various reasons (*Table 4*). Ten of these patients indicated a loss of interest in the intervention after completion of their radiotherapy.

Of the 10 patients that received self-management advice, reported reading this and implementing (some of) it. Eight patients were advised to contact an HCP. Six of these patients indicated that this advice motivated them to contact an HCP (Table S3); however, only four followed this advice to some degree: three discussed their symptoms during a scheduled consultation, and one discussed his symptoms when the hospital contacted him to reschedule an appointment. This could be because only 3 patients replied 'Yes' to the survey question if they felt more confident to

contact an HCP after being advised to do so by the diary (Table S2).

Key aspects of the ePRomT diary, according to both patients and HCPs, included the use of the hospital's platform for the diary. This familiar platform enabled patients and HCPs to focus on the ePRomT diary without the need to familiarize themselves with a new medium. The (daily) completion reminders were also considered essential by many patients to ensure consistent ePROM completion. However, especially patients in poorer condition or those who did not perceive side-effect burden, mentioned that modification of the completion reminder frequency would motivate them to use the ePRomT diary in the future. However, the daily reminders were not perceived as bothersome by patients who did not want daily ePROM completion.

The focus of the diary on self-care was viewed positively by all patients, with several patients feeling empowered by this approach (*Table 5*).

One modification made after Phase I was a change in the title of the intervention. Several patients encountered difficulties finding the ePRomT diary under its original title, "ePROM PROGRAM", with one patient failing to complete any ePROMs as a result (Tables S3,S5). Based on patient feedback, the title was changed to "ePRomT diary—radiotherapy diary" for Phase II. Another adjustment was the inclusion of treatment site-specific radiotherapy-related symptoms (*Table 2*). While the general questions were deemed highly relevant and were retained, the request to add more free-text boxes was not implemented. Adaptations to the frequency of eRPOMs (once-daily) could not be made due to software restrictions.

During Phase II, 26/40 patients (65%) completed at least one assessment, with an average of 10 assessments per patient (range, 1–21). The main reason for discontinuing ePROM completion was once again a limited symptom burden. Of these 26 patients, 16 received self-care advice at least once. Fifteen patients reported reading the advice, and nine implemented some of the recommendations. Five patients discussed their symptoms and self-care management during a day ward consultation. Five patients were advised to contact an HCP, of which two followed this advice due to experiencing pain. Among the remaining patients, one felt a barrier to contacting an HCP between scheduled visits, while the other two did not consider their reported symptoms severe enough to warrant additional HCP contact. There were no patients who contacted the CSMs during the allocated telephone consultation hour. One patient mentioned that it felt odd to contact an HCP who was no longer responsible for his care, as the radiotherapy was finished (*Table 5*).

Maintenance

The initiation of the ePRomT diary was reported to be easier by CSMs compared to residents. Furthermore, CSMs expressed interest in an active role in further ePROM implementation, as they believed the ePRomT diary enhanced clinical service. However, they emphasized the need for dedicated time to follow-up on ePROM data. Residents recognized the potential benefits of ePROMs and hoped that discussing them outside of a study context would be less disruptive to their workflow. They suggested that having a flyer about the ePRomT diary, similar to other departmental flyers, would aid *maintenance*. Residents also believed that integrating ePROMs into the clinical workflow would eliminate the need for an ICF and, more importantly, remove the 'palliative' label that some patients perceived so negatively (*Table 5*).

However, CSMs mentioned in their interviews that the lack of feedback on patients' well-being after treatment could potentially demotivate them from recruiting patients for ePROMs, as they would not observe the effects of the ePROM interventions. This was confirmed by the residents interviewed, who considered receiving feedback from or about patients after treatment as a very valuable learning opportunity.

Discussion

We conducted a two-phase implementation evaluation of ePROMs for symptom follow-up after PRT. Despite the recognized benefits of ePROMs, integrating them into routine clinical care remains challenging, with a lack of guidance on successful implementation in standardized, evidence-based multidisciplinary care pathways (30). However, having ePROMs become more established in routine clinical practice may increase operational efficiencies, reduce traveling time for patients, and increase the willingness of patients to enroll in clinical trials, especially in local intervention trials with the intent of symptom control (31).

The intervention in this study was designed based on previous ePROM research and our own data, in alignment with the European Society for Medical Oncology (ESMO) recommendation on ePROMs (32). The objective of

this paper was to evaluate the implementation of this intervention using the RE-AIM framework, to guide other researchers and clinicians in their implementation efforts.

An important factor affecting *reach* was the research set-up requiring an ICF. This ICF, which consisted of several pages of complex information, acted as a barrier to participation, which is a known problem (33). Eliminating the research aspect and incorporating ePROMs into routine care for advanced cancer patients would likely improve *reach*. Additionally, the term 'palliative' used in the ICF posed a challenge for several patients, who did not consider themselves palliative or did not wish to be labeled as such, a finding consistent with previous studies (34,35). Even patients who did agree to participate in the study mentioned having difficulties with this label.

Currently, our hospital offers ePROMs in many cancer care trajectories, either for follow-up or benchmarking. Developing a comprehensive ePROM-based follow-up system across the cancer trajectory could familiarize both patients and HCPs with ePROMs, and potentially enhance their use and benefits. By offering ePROMs throughout the cancer trajectory, terms like 'curative' or 'palliative' can be avoided, alleviating the emotional burden associated with these terms and possibly further improve *reach*.

Patients' satisfaction with intervention (*effectiveness*) was high. Patients did not feel that using the diary affected their perception of symptom intensity, duration, or impact on their lives neither positively nor negatively. It should be noted that the majority of patients did not report significant side-effects. On the other hand, patients did report satisfaction with the self-management tools provided, which made them feel empowered, in control, and "safe". Additionally, no patients reported negative experiences with either the diary or the self-management advice. We found no differences in the opinions on self-management between patients of different age groups or performance statuses. However, we did not assess the extent to which the self-management advice was actually used. Self-management in patients with advanced cancer is highly personal and multifaceted. Self-management support can benefit from an individualized approach embedded in strong partnerships with relatives and HCPs (36). Some patients expressed a desire to tailor the ePRomT diary to their specific capabilities and needs and several patients did not wish to initiate or discontinued the intervention due to its intensity, with daily ePROMs for three weeks. Patients also would have preferred individualized feedback. However, individualized feedback would likely entail active follow-up of the ePROMs by an HCP, resulting in a significant increase in workload. A potential alternative could be the use of health chatbots for patients who prefer more individualized information. While data are still limited, patients' willingness to interact with these chatbots appears to be high (37,38). Nevertheless, even with the use of chatbots, adequate human resources to address ePROM data should be allocated to this responsibility (32).

A recent study found no difference in health-related QoL between ePROM symptom monitoring via a reactive approach, where patients receive alerts to contact an HCP, or an active approach, where the HCP receives an alert to contact the patients (39). However, we found that patients who were prompted to contact an HCP still faced barriers to doing so. Patients who received an alert tended to delay discussing their symptoms, waiting for a planned hospital appointment, typically at the medical oncology department. This could partly be due to the difference in rapport patients have with their HCPs in medical oncology compared to radiation oncology. It has been shown that sufficient time with HCPs in radiotherapy is critical for developing trust and reducing anxiety and stress. However, the shorter treatment schedules of palliative patients may hinder the development of the patient-professional relationship, while the symptoms, added disease burden, and existential distress associated with a palliative outlook may actually demand enhanced support, interpersonal engagement, and communication (40). Improving rapport with HCPs in radiotherapy and motivating patients to contact them will certainly aid in the *implementation* and *effectiveness* of ePROM-based PRT symptom follow-up. This is especially relevant as our CSMs are very willing to play an active role in supporting these patients, during and after their treatment.

Despite challenges, both CSMs and residents were willing to offer patients ePROMs, which is a crucial finding. Staff in organizations with higher readiness are more likely to initiate change, be collaborative and cooperative, and willing to implement new evidence-based practices, essential for the *adoption* and *maintenance* (30,41,42). Several studies have highlighted the benefit of having project managers or coordinators skilled in both knowledge translation and facilitating practice changes (14,42). Furthermore, the presence of local staff champions to advocate for ePROMs usage has been shown to be an important facilitator in *implementation*, *adoption*, and *maintenance* (42). As CSMs are responsible for optimizing clinical care and implementing care initiatives, their positive evaluation of our intervention

and willingness to take up an active role in further ePROM endeavors is encouraging. Their willingness to play an active role in supporting these patients can also enhance the *effectiveness* and *reach* of the ePRomT diary, thereby promoting patient-centered care and improving the overall quality of care provided. Where CSMs see patients during initial consultation and sometimes during their treatment, they are not very often informed about the patients' wellbeing after treatment is completed as it is the resident that is contacted for deliberation or re-referral to the department. This organizational factor could be a potential *maintenance* issue.

It should be noted however, that about half of patients were recruited by residents. Whereas CSMs have extensive experience in oncology care pathways and can act as local champions, residents have varying levels of experience with radiation oncology in general, PRT and patient care. Additionally, they rotate between different care paths every few months and do not complete their entire residency in our hospital. Continued education on PRT and its symptoms as well as their use, benefits and the ePRomT diary intervention will be necessary for *maintenance*.

For this study, we had access to an established hospital-based online platform, that made it possible to integrate ePROM data in the EMR. Limited integration has been shown to be a significant barrier for *implementation* (42). Many hospitals may not have our resources, making the interpretation of our results for other applications challenging.

A potential limitation of this study is the representativeness of the patients who participated. While those who took part were highly satisfied with the intervention, it's crucial to acknowledge that only one-third of all patients referred for PRT met the eligibility criteria for our implementation evaluation study, for various reasons. Another limitation could be the role of the main researcher, E.O., who serves as a radiation oncologist and palliative care physician at the hospital where the study was conducted. Although none of the patients included in the study were treated by E.O., her position in the hospital may have influenced the responses of both patients and HCPs who participated in the interviews, potentially introducing bias into the study. Additionally, since we did not audio-record, transcribe, and analyze the research team meetings, there might be some nuances in these discussions that were missed. Nonetheless, we believe this would not have significantly impacted the decisions made during the study.

Conclusions

This study indicates that the ePRomT diary is feasible and well-received. However, further research is required to address the challenges related to patient recruitment and commitment to the intervention, optimize the frequency and duration of ePROMs, and integrate ePROMs into existing workflows to maximize the potential benefits of ePROM-based symptom follow-up after PRT.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by The Ethics Committee Research UZ/KU Leuven (EC Research, No. B3222021000603) and informed consent was obtained from all individual participants.

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Supplementary

Appendix 1

Patient questionnaire

Dear Sir, Madam,

Thank you for participating in this electronic Patient Reported Outcome Measure (ePROM) study and agreeing to an interview.

This interview will focus on the ePROM diary you were offered after your palliative radiotherapy.

In preparation of your interview, we would like to ask you some questions about your experiences with and opinion about the ePROM diary. In the interview we would like to explore your experiences further.

Please don't hesitate to answer honestly, your opinion will only help us improve future care.

General study-related questions

1. The oral explanations I received about the diary were clear

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

2. The information material I received about the diary was clear

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

3. The purpose of the diary was clear to me

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

4. The diary met my expectations

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

If you have used the diary, please complete the following questions. If you did not use the diary, please continue with question 22

5. I found the diary easy to use

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

6. I was able to complete the diary independently

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

7. I found the questions asked in the diary relevant

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

8. I found the time taken daily to complete the diary acceptable

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

9. I found the period after radiotherapy (3 weeks) that the diary is offered acceptable

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

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10. I found it important that self-care tips are offered in the diary

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

11. I read the self-care tips offered through the diary

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

12. To what extent did you find the self-care tips from the diary useful?

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

13. To what extent did you find the self-care tips important for you feeling independent?

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

14. Did the diary motivate you to become more aware of your symptoms/complaints?

Yes	No

15. Did the self-care tips make you feel more confident about contacting a healthcare provider?

Yes	No

16. Did you discuss the diary's self-care tips with a healthcare provider?

Yes	No

If you were advised to contact a healthcare provider through the diary, please complete the following questions. If you did not receive this advice, please continue with question 22

17. I think it is important that the diary gives the advice to contact a healthcare provider

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

18. The advice to contact a healthcare provider is correctly given

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

19. The advice from the diary motivated me to contact a healthcare provider

Yes	No

20. The advice from the diary made me feel more confident about contacting a healthcare provider

Yes	No

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21. Did you discuss the advice from the diary with a healthcare provider?

Yes	No

General diary-related questions

22. I believe a diary after palliative radiotherapy adds value

Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree

23. I would use the diary (again) in any subsequent radiotherapy session

Yes	No	I'm not sure

24. I would recommend using the diary to other patients.

Yes	No	I'm not sure

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Table S1 Questionnaire data of all evaluable patients in Phase I of the implementation evaluation

Question/answer options	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Yes	No	I don't know
The oral information was clear	0	0	1	36	0	–	–	–
The study material was clear	0	0	3	37	0	–	–	–
The purpose of the diary was clear	0	0	1	35	1	–	–	–
The diary met my expectations	0	1	16	20	0	–	–	–
The diary is of value	0	1	2	32	2	–	–	–
I would use the diary again	–	–	–	–	–	28	2	7
I would advise the diary to others	–	–	–	–	–	26	1	10

Table S2 Questionnaire data of all evaluable patients in Phase II of the implementation evaluation

Question/answer options	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Yes	No	I don't know
The oral information was clear	0	0	2	37	1	–	–	–
The study material was clear	0	0	2	36	2	–	–	–
The purpose of the diary was clear	0	0	1	38	1	–	–	–
The diary met my expectations	0	0	13	25	2	–	–	–
The diary is of value	0	0	1	34	5	–	–	–
I would use the diary again	–	–	–	–	–	34	0	6
I would advise the diary to others	–	–	–	–	–	32	0	8

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Table S3 Questionnaire data of all patients who completed the diary in Phase I of the implementation evaluation

Question/answer options	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Yes	No
Questions completed by patients who used the diary (N=17)							
The diary is easy to use	0	1	3	13	0	–	–
I could complete the diary independently	0	2	2	13	0	–	–
The questions are relevant	0	1	1	15	0	–	–
The diary completion time is acceptable	0	0	7	10	0	–	–
The diary period is acceptable	0	2	2	11	2	–	–
Self-care tips are important	0	1	2	10	4	–	–
Questions completed by patients who received self-care advice (N=10)							
I've read the self-care tips	0	1	0	9	0	–	–
The self-care tips are useful	0	1	2	7	0	–	–
The self-care tips made me feel independent	0	1	3	6	0	–	–
Questions completed by patients who used the diary (N=17)							
The diary made me aware of my symptoms	–	–	–	–	–	11	6
Questions completed by patients who received self-care advice (N=10)							
Self-care tips made me more confident to contact an HCP	–	–	–	–	–	4	6
I discussed the self-care tips with an HCP	–	–	–	–	–	0	10

HCP, healthcare provider.

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Table S4 Questionnaire data of all patients who completed the diary in Phase II of the implementation evaluation

Question/answer options	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Yes	No
Questions completed by patients who used the diary (N=26)							
The diary is easy to use	0	0	1	23	2	–	–
I could complete the diary independently	0	0	2	24	0	–	–
The questions are relevant	0	0	2	20	4	–	–
The diary completion time is acceptable	0	0	1	25	0	–	–
The diary period is acceptable	0	1	4	21	0	–	–
Self-care tips are important	0	0	1	23	2	–	–
Questions completed by patients who received self-care advice (N=16)							
I've read the self-care tips	0	0	1	13	2	–	–
The self-care tips are useful	0	0	2	12	2	–	–
The self-care tips made me feel independent	0	0	6	9	1	–	–
Questions completed by patients who used the diary (N=26)							
The diary made me aware of my symptoms	–	–	–	–	–	13	13
Questions completed by patients who received self-care advice (N=16)							
Self-care tips made me more confident to contact an HCP	–	–	–	–	–	11	5
I discussed the self-care tips with an HCP	–	–	–	–	–	2	14

HCP, healthcare provider.

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Table S5 Questionnaire data of all patients who received advice to contact an HCP in Phase I of the implementation evaluation

Question/answer options	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Yes	No
The advice to contact an HCP is important	0	1	0	5	2	–	–
The advice to contact an HCP is correct	0	0	1	7	1	–	–
I was motivated to contact an HCP	–	–	–	–	–	6	2
I was more confident to contact an HCP	–	–	–	–	–	3	5
I discussed the advice with an HCP	–	–	–	–	–	0	8

HCP, healthcare provider.

Table S6 Questionnaire data of all patients who received advice to contact an HCP in Phase II of the implementation evaluation

Question/answer options	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Yes	No
The advice to contact an HCP is important	0	0	0	4	1	–	–
The advice to contact an HCP is correct	0	0	0	5	0	–	–
I was motivated to contact an HCP	–	–	–	–	–	2	3
I was more confident to contact an HCP	–	–	–	–	–	1	4
I discussed the advice with an HCP	–	–	–	–	–	0	5

HCP, healthcare provider.

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