Uncovering the Daily Experiences of People Living with Advanced Cancer: Development, Content-Validation and Optimization of an Experience Sampling Methods Questionnaire

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Abstract

Background: Experience sampling methods (ESM), self-report methods that typically utilize multiple assessments per day, can provide detailed knowledge of cancer patients' daily experiences, potentially informing oncological care. The use of ESM among people with advanced cancer is limited and no validated ESM questionnaires currently exist in oncology.

Objective: To develop, content-validate, and optimize a digital ESM questionnaire for people with advanced breast or lung cancer (ESM-AC questionnaire), covering multidimensional domains and contextual factors.

Methods: Three-round mixed-methods design following COSMIN and EORTC guidelines, comprising semi-structured interviews with a total of 43 people with advanced breast or lung cancer and 8 healthcare professionals. Round one assessed appropriateness, relative importance, relevance, and comprehensiveness of an initial ESM item set, developed from existing questionnaires. Round two tested comprehensibility of ESM items. Round three tested usability of the digital ESM-AC questionnaire using the m-Path application. Analyses included descriptive statistics and qualitative content analysis.

Results: Following the first round, we developed an initial core set of 68 items (to be used with all patients) and a supplementary set (optional; patients select items), both covering physical, psychological, social, spiritual-existential, and global wellbeing domains, and concurrent contexts in which experiences occur. We categorized items to be assessed multiple times per day (e.g., "At this moment, I feel tired."), once a day, in the morning (e.g., "Last night, I slept well.") or once a day, in the evening (e.g., "Today, I felt hopeful."). We used participants' evaluations to optimize the questionnaire items, the digital application, and its onboarding manual. This resulted in the ESM-AC questionnaire, comprised of a digital core questionnaire containing 31 momentary items, 2 morning items and 7 evening items, and a supplementary set containing 39 items. Participants largely rated the digital questionnaire "easy to use" (M = 4.5 on a scale from 1 to 5, SD = 0.5).

Conclusions: We developed the ESM-AC questionnaire, a content-validated digital questionnaire for people with advanced breast or lung cancer. It showed good usability when administered on smartphone devices. Future research should evaluate the potential of this ESM tool to uncover daily experiences of people with advanced breast or lung cancer, its potential clinical utility and extend validation to other populations with advanced diseases.

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Keywords: instruments, measures, neoplasms, quality of life, telemedicine

Introduction

Quality of life assessment among people with cancer often relies on retrospective patient-reported outcome measures (PROMs), which typically require patients to aggregate their experience over several days or weeks into one score (e.g., "During the past week, were you tired?")[1–3]. This precludes temporally fine-grained knowledge on how cancer-related experiences such as physical or psychological symptoms and concerns change within and across days. From a research and clinical perspective, this knowledge is critical for improving patient symptom management and psychosocial support (e.g., by identifying novel intervention targets).

To bridge this gap, experience sampling methods (ESM)[4], also called ecological momentary assessment (EMA)[5], may be suitable. ESM or EMA methods involve repeatedly gathering self-report data from participants in the context of their daily life, often multiple times per day for several consecutive days through mobile devices, such as smartphones[5–7]. By asking questions about momentary experiences in their natural environment (e.g., "At this moment, I feel…"), ESM mitigates retrospective biases and improves ecological validity of findings[5]. Moreover, ESM provides the opportunity to study affect over time (i.e., experiences of feelings or emotions), as an important indicator of emotional functioning and psychological wellbeing[7–9], and to investigate patients' experiences together with concurrent contexts, such as the social environment[10]. Including contextual items can facilitate the identification of situations that alleviate or exacerbate certain experiences, thereby informing future psychosocial interventions.

Despite ESM's potential to provide novel insights into the daily experiences of people with cancer, its utilization in oncology research remains limited, especially among people with advanced stage cancer[7,10,11]. This is an important gap, as advanced cancer comes with a higher likelihood of experiencing symptoms and concerns that impact quality of life, compared to earlier stages of cancer[12,13]. There is currently no validated ESM questionnaire designed specifically for people with advanced cancer[7,11]. Validity, especially content validity is a crucial indicator of whether the content of an instrument is an adequate reflection of the construct being measured[14,15]. Yet, it is often overlooked in ESM research as a whole, leading to recent calls for more content-validation of ESM questionnaires[7,11,15,16].

This study is part of a larger project in which we aim to test the feasibility of ESM and use it to obtain novel insights into the daily experiences of people with advanced cancer. This study, reporting the development, content-validation and optimization of an experience sampling methods questionnaire is the first step in the larger ESM project. Because symptoms can vary across different advanced cancer diagnoses and our aim was to develop a questionnaire that is highly relevant to the

specific experiences of intended users, our project's scope is narrowed to people living with advanced breast cancer or advanced lung cancer. We selected these diagnoses as they are among the most prevalent cancer diagnoses with high mortality rates[17–19], are both associated with considerable risk for experiencing serious symptom burden[20–24].

In this study, we aimed to develop, validate, and optimize the experience sampling methods for people living with advanced cancer (ESM-AC) questionnaire. The digital ESM questionnaire aims to comprehensively assess relevant daily experiences (i.e., symptoms, concerns, wellbeing) of people with advanced breast cancer or advanced lung cancer, and the context in which these experiences occur, multiple times per day for several consecutive days.

Methods

Study Design

We conducted a three-round interview study with patients and healthcare professionals using a mixed-methods research design (summarized in Figure 1). To develop and validate the ESM questionnaire in the first two interview rounds, we based our design on guidelines of patient-reported outcome measures[14,25], because no specific guidelines for ESM questionnaires were available[15]. Specifically, the COSMIN methodology[14] guided the assessment of the content validity of our initial set of items in the first two rounds (i.e., covering relevance, comprehensibility, and comprehensiveness; see Table 1 for an overview of key psychometric concepts used in this study). In the first round, the item set was shortened and categorized into a core and supplementary item set based on content validity, appropriateness and relative importance, following the EORTC guidelines for module development[25–27]. The second round focused on the comprehensibility of all items, and on the relevance and appropriateness of items added after round one. In the third round, we optimized the digital (core) ESM questionnaire by assessing barriers related to its usability for patients using the dedicated ESM smartphone application (i.e., m-Path[28]).

Table 1. Key concepts with their respective definitions

Concept	Definition
Content validity	The extent to which the content of an instrument is an adequate reflection of the construct to be measured. This includes relevance, comprehensiveness and comprehensibility. (1)
Relevance	The extent to which a questionnaire item is relevant for the construct of interest within a specific population and context of use. (1)
Comprehensiveness	The extent to which all key aspects of the construct are included in the questionnaire. (1)
Comprehensibility	The extent to which a questionnaire item is understood by patients as intended. (1)
Appropriateness	The extent to which a questionnaire item is perceived as appropriate and not

	upsetting. (2)
Relative importance	The extent to a questionnaire item is deemed more important for the questionnaire's context of use than other items in the same content domain.
Usability	The extent to which a system, product or service can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use. (3)

Note. All concepts, except for usability, are recommended to be used by EORTC guidelines for module development to shorten questionnaires.

Participants and setting

For the first two rounds, we planned to interview 32 patients and 8 healthcare professionals from one university hospital and one regional hospital in Belgium. These sample sizes adhere to the COSMIN and EORTC guidelines[14,25]. In the third round, we aimed to include 8 patients from the former university hospital[29], and 4 additional patients if, after the preceding usability interviews, large changes would be made that require further testing.

Inclusion criteria:

- a diagnosis of stage III or IV lung cancer or stage IV breast cancer, and
- age 18 or older, and
- speaks and understands Dutch, and
- an Eastern Cooperative Oncology Group (ECOG) performance status of 0, 1 or 2, based on assessment by their treating physician.

Exclusion criteria:

- having major communication difficulties or insufficient cognitive abilities to take part in a semi-structured interview (as judged by their treating physician), or
- any psychiatric disorder that, in the opinion of their treating physician, might hinder participation due to expected burden or unreliable responses, or
- uncorrectable hearing or poor vision, or
- had participated in a previous part of this study.

We aimed to include four equally-sized subgroups based on primary tumor site (breast or lung cancer) and age (younger than 70 or older than or equal to 70)[30,31].

As for healthcare professionals, we aimed to include a specialist in respiratory oncology, an oncologist specialized in breast cancer, a radiotherapy specialist, an oncology nurse, an onco-psychologist, a health sciences researcher, and two specialist palliative care providers (i.e., a physician and a nurse affiliated with a palliative home care team).

Measurement instruments and procedures

Initial Item Set. The questionnaire aimed to comprehensively measure and evaluate daily experiences of people with advanced cancer and the context in which they occur. More specifically, we conceptualized daily experiences as symptoms, concerns, and wellbeing across physical (including physical symptoms and functioning), psychological (including positive and negative affect, psychological symptoms, and cognitive complaints), social, spiritual-existential, and global wellbeing domains (Figure 2). Context was conceptualized as the person's current location, activity, social company, significant events, medication use, and sleep quality.

We created an initial item set capturing in-the-moment experiences based on (1) the items of questionnaires identified in the van Roij et al.'s (2018) review of PROMs in advanced cancer patients[1] and (2) an existing ESM item repository from the field of mental health sciences[32]. From van Roij's review, we selected three questionnaires: the EORTC QLQ-C30, FACIT-Pal and IPOS[33–35], as they relate to our target population, have sufficient content validity, and have a comprehensive symptom coverage (i.e., did not focus on one specific symptom or experience). After excluding overlapping items and items with low expected within-day variability (e.g., "I have family members who will take on my responsibilities"), we retained 43 items suitable for the measurement of symptoms, concerns, and wellbeing across various subdomains (Figure 2).

From the ESM item repository, we purposively selected 12 items measuring affect, spanning across valence and arousal dimensions (i.e., levels of pleasantness and physiological activation, respectively) and 13 items to measure context. We additionally selected items to measure the patient's experience while completing the ESM questionnaire (i.e., meta-experience items). We obtained official Dutch translations for all items and rephrased them to reflect in-the-moment experiences (e.g., changing "during the past 7 days, I felt…" to "in this moment, I feel…" or "since the last beep, I felt…", with beep referring to the assessment prompt). For less frequent experiences or events, we used the phrasing "since the last beep" instead of "in this moment", such as for "I have had diarrhea". One item measuring sleep quality was developed for the first assessment of the day (i.e., "Last night, I slept well."). All English translations of items presented in this paper are phrased analogous to their existing PROM counterparts, or, if no such counterparts were available, we presented forward translations of the Dutch versions used in this study.

Content validity and usability assessments. In all study rounds, we conducted individual semi-structured interviews with advanced breast or advanced lung cancer patients. One round also included interviews with healthcare professionals, as outlined in Figure 1. These interviews served to assess content validity, to shorten the initial item list and divide it into a core and supplementary set, and to optimize the digital ESM questionnaire based on its usability. At the start of all interviews,

patients completed a baseline questionnaire on sociodemographic characteristics. In round three the baseline questionnaire additionally assessed cognitive complaints and smartphone use. We conducted interviews at patients' homes or in quiet hospital rooms. Patients' close others were allowed to be present during the interviews.

During round one, we interviewed patients and healthcare professionals to evaluate the relevance and comprehensiveness of symptoms, concerns, and wellbeing items. We aimed to create a core item set of 33 items, which was the foreseen number of items needed to cover all subdomains, and a supplementary set with no item limit, and to improve its comprehensiveness by adding items deemed relevant but missing by the participants. Participants were asked to rate each item's relevance ("Not at all", "A little", "Quite a bit", "Very Much"), select the most important items for each subdomain (Figure 2 displays the number of items to select per subdomain, as instructed by the interviewer), suggest missing concepts, and to mark inappropriate items. Participants were prompted for reasons for categorizing items as inappropriate or "Not at all" or "A little" relevant.

In round two, we interviewed patients on the comprehensibility of items resulting from the first round (as the last part of content validation), the relevance and appropriateness of newly added items, and the appropriateness and comprehensiveness of context and meta-experience items, and their response options (assessed analogous to round one). To assess comprehensibility, patients completed the pen-and-paper questionnaire while thinking out loud[36].

In round three, we optimized the ESM questionnaire by assessing its usability when patients responded to it in the m-Path application. M-Path is an online platform that provides "an intuitive and flexible framework to conduct smartphone-based ecological momentary assessment and intervention studies […]"[37]. Patients were each provided with a Motorola E20 smartphone device with the digital ESM questionnaire available in m-Path. They were instructed on how to use the application and asked to complete the digital questionnaire on the provided device, while thinking out loud. The researcher prompted patients when difficulties were observed. Afterwards, a brief semi-structured interview assessed the usability of the questionnaire, through an adapted version of the System Usability Scale (5-point Likert scale; 1 = Totally do not agree, 5 = Totally agree)[38,39]. Usability outcomes included readability, comprehensibility, ease-of-use, reasons for encountered difficulties, and expected burden of multiple daily assessments for six days. Lastly, patients completed the digital ESM questionnaire a second time without thinking out loud to estimate completion times. All interviews were recorded and transcribed verbatim. More details on procedure and instruments have been reported in the protocol of this study[40].

Data Analyses and Continuous Adaptations of the Questionnaire

Following the EORTC guidelines for module development, as applied in Groenvold et al. (2006)[25,27], we transformed item relevance ratings into a 0-100 scale, with 'not at all' corresponding to 0 and 'very much' to 100. We calculated mean relevance scores and standard deviations per item. Additionally, we calculated the percentages of respondents who rated an item as inappropriate or upsetting, who listed an item among the top *n* most important items per subdomain (*n* was the approximated number of items to retain in the final questionnaire for each subdomain, see Figure 2), and who found an item incomprehensible. We calculated descriptive statistics for usability.

By using conventional content analysis[41] on the interview transcriptions, we inductively developed content categories for participants' reasons of lack of item relevance (provided by participants who judged an item as "Not at all" or "A little" relevant), inappropriateness, problems with comprehensibility, and themes of novel items to add[41]. Furthermore, we developed content categories for difficulties or conveniences in the user-experience or comprehension of the digital questionnaire. We added items to the list if at least two participants suggested adding it to the questionnaire.

The questionnaire was adapted after each of the three rounds. After round one, we used descriptive statistics of relevance, importance and appropriateness ratings from patients and healthcare professionals to guide item exclusion and categorization into core and supplementary sets (see Supplementary material 1 for an overview of the categorizations). We assigned items to the core item set if they ranked among the top *n* most important per subdomain (see Figure 2 for *n* values), were judged "Quite a bit" or "Very much" relevant by half of participants, and were deemed appropriate (or amenable to rewording). The authors discussed removal of items that were rated as "Not at all" or "A little" relevant by half of participants, or participants provided recurring reasons for lack of relevance or the inappropriateness of items and the item could not be appropriately reworded or changed to resolve those reasons. Items that were not removed or categorized into the core set were assigned to the supplementary set. Note that the decision to use core and supplementary sets was made after analysis of round one.

After round two, we made necessary and feasible item revisions based on descriptive statistics of comprehensibility and inappropriateness, and content categories for reasons of items' low comprehensibility and inappropriateness.

After round three, we used descriptive statistics of usability outcomes and content categories of difficulties when using the digital questionnaire to improve the usability of the questionnaire in m-Path. Following general recommendations in ESM research[42,43], we used a mean questionnaire

completion time threshold of three minutes to consider the questionnaire too long.

Results

Participant characteristics

In round one, 15 patients and 8 healthcare professionals participated; in round two new 18 patients; and in round three new 10 patients (Table 2). The overall mean age was 67.3 (*SD* = 10.3). Overall, 53.5% of patients had a stage III or IV lung cancer diagnosis and 46.5% of patients had a stage IV breast cancer diagnosis. Close others were present during four interviews in round one, seven in round two, and seven in round three.

Table 2. Sociodemographic and clinical characteristics of patients per interview round

Characteristics	Round 1 (N = 15)[a]	Round 2 (N = 18)[b]	Round 3 (N = 10)[c]
Age (years)			
M (*SD*)	68 (8.5)	68.7 (11.3)	63.8 (11.1)
Range	56-78	44-86	45-78
Gender (% female)	73.33%	77.78%	60%
Living situation (n)			
Home, alone	2	4	2
Home, with partner/children/other	13	14	8
Marital Status (n)			
Married	13	8	-
Living together, but not married	0	6	-
Widowed	1	1	-
Divorced	1	3	-
Educational level (n)			
Primary	2	0	1
Secondary	8	10	4
Tertiary	5	8	5
Employment status (n)			
Professionally active	2	1	1
Not professionally active	13	17	9
Religious denomination (n)			
Catholic Christian	6	8	6
Not religious	5	9	4
Not specified	4	1	0
Cancer diagnosis			
Stage III or IV lung cancer	7	10	6
Stage IV breast cancer	8	8	4
Treatment(s) received, as reported by patient[d]			
Chemotherapy	14	13	9
Radiotherapy	13	10	5
Surgery	12	3	7
Hormonal therapy	4	5	2
Immunotherapy	6	9	4
EORTC QLQ-C30 concentration problems (n)	-	-	
Not at All			7
A Little			2
Quite a Bit			1
Very Much			0

EORTC QLQ-C30 memory problems (n)	-	-	
Not at All			5
A Little			3
Quite a Bit			2
Very Much			0
Smartphone ownership in years, *M* (*SD*)	-	-	10.2 (4.4)
Daily time spent on smartphone in hours, *M* (*SD*)	-	-	3.2 (2.8)
Confidence using smartphone (1 = "Not at all confident", 5 = "Very confident"), *M* (*SD*)	-	-	4.1 (0.7)

Abbreviations. *M* = mean, *SD* = standard deviation

[a]Due to an oversight, we did not collect participation rates and reasons for non-participation in this round.

[b]Out of 25 invited patients. Reasons for non-participation included no interest, as indicated by patient or partner (n = 5), inability to find an appropriate interview location (n = 1), experiencing distress (n = 1), or no reasons provided (n = 1).

The following sections present the results per interview round and relevant adaptations made to the ESM questionnaire based on these findings.

Interview Round 1

Relevance. Most items received positive relevance ratings, with no unanimous low relevance ratings across all participants (Table 3). The most frequent reasons for considering an item lacking in relevance were: overlapping content with other items, not experiencing the measured construct, not perceiving the measured construct as bothersome, and having doubts about the question formulation. After discussion among the project team, we removed 12 items that at least half of participants indicated as having "A little" relevance or less, or participants stating that the item had considerable overlapping content with other items. For instance, we removed the item "At this moment, I feel sick" due to overlap with specific symptoms such as nausea and removed the item "At this moment, I feel capable of making decisions" due to low reported relevance, as patients reported not having to make decisions.

Some items were considered irrelevant by participants because they measured stable constructs within a day. To address this, we deviated from the planned approach to develop in-the-moment items only and instead developed several items for designated morning and evening assessments. One and eleven item(s) from the initial item list were dedicated to morning and evening assessments, respectively. For instance, the in-the-moment item "At this moment, I feel moral support by my close ones" was revised to the evening item "Today I felt supported by others". Items excluded before round one based on little expected within-day variability were reconsidered for inclusion in the once-daily questionnaires. Hence, we added eight initially removed items to the evening list for further testing in round two (e.g., "Today, I was able to openly discuss my concerns with my close ones.").

Table 3. Inappropriateness frequencies, relevance means, and proportions of relative importance ratings of experience sampling method items

Subdomain	Item	No. of participants judging item as inappropriate		Relevance, mean (standard deviation)			Proportion of participants who selected item as one of most important in subdomain		
		Pt	HCP	Pt	HCP	/2[a]	Pt	HCP	/2[a]
Initial items at round 1									
Global Well-Being	At this moment, I am content with the quality of my life.	0	0	82.2 (27.8)	79.2 (39.6)	80.7	0.87	0.75	0.81
Physical Functioning	Did this pain interfere with your daily activities?	1	0	57.8 (40.8)	91.7 (23.6)	74.7	0.6	0.5	0.55
	Since the last beep, I was limited in pursuing my hobbies or other leisure time activities.	1	0	76.2 (30.5)	75 (34.5)	75.6	0.13	0.25	0.19
	Since the last beep, I had trouble meeting the needs of my family because of my physical condition.	1	0	64.4 (40.8)	83.3 (25.2)	73.9	0.33	0.25	0.29
	Since the last beep, I needed help with eating, dressing, washing myself or using the toilet.	2	0	57.8 (38.8)	95.8 (11.8)	76.8	0.27	0.75	0.51
	Since the last beep, I was affected by poor mobility.	1	0	71.1 (27.8)	54.2 (43.4)	62.6	0.4	0.25	0.32
	Since the last beep, I had trouble doing strenuous activities, like carrying a heavy shopping bag or suitcase.	1	0	55.6 (32.5)	58.3 (15.4)	56.9	0.27	0	0.13
Physical Symptoms	At this moment, I am short of breath.	0	0	78.6 (21.1)	87.5 (35.4)	83	0.33	0.5	0.42
	At this moment, I have the need to rest.	0	0	76.2 (20.4)	54.2 (39.6)	65.2	0.27	0.12	0.2
	At this moment, my mouth and throat are dry.	0	0	37.8 (35.3)	70.8 (27.8)	54.3	0.07	0	0.03
	At this moment, I lack appetite.	0	0	77.8 (20.6)	91.7 (23.6)	84.7	0.33	0.38	0.35

Subdomain	Item	No. of participants judging item as inappropriate		Relevance, mean (standard deviation)			Proportion of participants who selected item as one of most important in subdomain		
		Pt	HCP	Pt	HCP	/2[a]	Pt	HCP	/2[a]
	At this moment, I am bothered by side effects of treatment.	0	0	80 (24.6)	70.8 (41.6)	75.4	0.6	0.5	0.55
	At this moment, I am constipated.	2	0	73.3 (25.8)	87.5 (24.8)	80.4	0.27	0.25	0.26
	At this moment, I have pain.	1	0	77.8 (24.1)	100 (0)	88.9	0.73	0.88	0.8
	At this moment, I have a lack of energy.	0	0	80 (21.1)	83.3 (30.9)	81.7	0.4	0.25	0.32
	At this moment, I feel nauseated.	0	0	75.6 (23.46)	87.5 (17.3)	81.5	0.33	0.62	0.48
	At this moment, I feel tired.	0	0	80 (21.1)	100 (0)	90	0.4	0.5	0.45
	At this moment, I feel weak.	0	0	60 (31.4)	41.7 (49.6)	50.8	0.07	0.12	0.1
	At this moment, I feel drowsy.	0	0	51.1 (27.8)	37.5 (41.6)	44.3	0.07	0	0.03
	At this moment, I feel ill.	0	0	69 (35.7)	37.5 (37.5)	53.3	0.27	0.25	0.26
	At this moment, I have swelling in parts of my body.	0	1	59 (27.7)	58.3 (29.6)	58.7	0.07	0.12	0.1
	Since the last beep, I have had diarrhea.	2	0	66.7 (30.9)	83.3 (25.2)	75	0.2	0.12	0.16
	Since the last beep, I have had to vomit.	0	0	68.9 (34.4)	58.3 (38.8)	63.6	0.07	0.25	0.16
Negative Affect	At this moment, I feel anxious.	0	0	76.2 (33.2)	100 (0)	88.1	0.53	0.88	0.7
	At this moment, I feel lonely.	0	0	78.6 (24.7)	91.7 (15.4)	85.1	0.27	0.5	0.38
	At this moment, I feel irritated.	0	0	40 (28.7)	54.2 (39.6)	47.1	0.07	0	0.03
	At this moment, I feel tense.	0	0	48.9 (35.3)	45.8 (43.4)	47.4	0.07	0.12	0.1
	At this moment, I feel stressed.	0	0	57.8 (32)	58.3 (42.7)	58.1	0.2	0	0.1
	At this moment, I feel listless.	0	0	46.7 (35.2)	75 (29.6)	60.8	0.2	0	0.1
	At this moment, I feel	0	0	62.2	66.7	64.4	0.07	0.12	0.1

Subdomain	Item	No. of participants judging item as inappropriate		Relevance, mean (standard deviation)			Proportion of participants who selected item as one of most important in subdomain		
		Pt	HCP	Pt	HCP	/2[a]	Pt	HCP	/2[a]
	depressed.			(27.8)	(43.6)				
	At this moment, I feel nervous.	0	0	53.3 (30.3)	58.3 (42.7)	55.8	0.13	0.12	0.13
	At this moment, I feel irritable.	0	0	51.1 (30.5)	70.8 (21.4)	61	0.13	0	0.07
	At this moment, I feel down.	0	0	60 (33.8)	54.2 (46.9)	57.1	0.07	0	0.03
	At this moment, I feel sad.	0	0	68.9 (23.5)	91.7 (15.4)	80.3	0.13	0.25	0.19
Positive Affect	At this moment, I feel energetic.	2	0	57.1 (33.2)	70.8 (27.8)	64	0.4	0.5	0.45
	At this moment, I feel enthusiastic.	4	1	40.5 (32.5)	54.2 (43.4)	47.3	0.2	0	0.1
	At this moment, I feel calm.	1	0	40.5 (29.8)	70.8 (27.8)	55.7	0.27	0.38	0.32
	At this moment, I feel relaxed.	2	0	61.9 (34.2)	79.2 (30.5)	70.5	0.27	0.38	0.32
	At this moment, I feel cheerful.	2	3	60 (31.4)	62.5 (37.5)	61.3	0.13	0.25	0.19
	At this moment, I feel satisfied.	2	0	69 (20.5)	79.2 (35.4)	74.1	0.47	0.5	0.48
Cognitive Complaints	At this moment, my thinking is clear.	0	0	57.1 (33.2)	75 (38.8)	66.1	0.2	0.12	0.16
	Since the last beep, I have had difficulty in concentrating on things, like reading a newspaper or watching television.	0	0	66.7 (32)	100 (0)	83.3	0.47	0.75	0.61
	Since the last beep, I have had difficulty remembering things.	0	0	64.4 (32)	95.8 (11.8)	80.1	0.33	0.12	0.23
Psychological Well-being	At this moment, I am satisfied with how I am coping with my illness.	0	1	86.7 (16.9)	70.8 (41.6)	78.8	0.87	0.75	0.81
	At this moment, I have peace of mind.	0	0	73.3 (28.7)	58.3 (42.7)	65.8	0.33	0.62	0.48
	At this moment, I am able to enjoy life.	2	0	77.8 (30)	70.8 (33)	74.3	0.8	0.5	0.65
	At this moment, I	0	0	75.6	87.5	81.5	0.8	1	0.9

Subdomain	Item	No. of participants judging item as inappropriate		Relevance, mean (standard deviation)			Proportion of participants who selected item as one of most important in subdomain		
		Pt	HCP	Pt	HCP	/2[a]	Pt	HCP	/2[a]
	worry.			(29.5)	(17.3)				
Sleep Quality	Last night, I slept well.	0	0	86.7 (21.1)	95.8 (11.8)	91.3	0.93	1	0.97
Social Well-being	At this moment, I feel like a burden to my family.	1	1	73.8 (26.7)	87.5 (35.4)	80.7	0.87	0.88	0.87
	At this moment, I get emotional support from the people close to me.	1	0	95.2 (12.1)	91.7 (23.6)	93.5	1	0.88	0.94
Spiritual and Existential Well-being	At this moment, I accept my illness.	0	0	88.9 (27.2)	95.8 (11.8)	92.4	0.87	0.38	0.62
	At this moment, I am able to make decisions.	2	0	44.4 (27.2)	41.7 (42.7)	43.1	0.07	0.12	0.1
	At this moment, I feel hopeful.	0	0	73.3 (31.4)	95.8 (11.8)	84.6	0.53	0.5	0.52
	At this moment, I feel useful.	2	0	54.8 (33.6)	83.3 (25.2)	69.0	0.27	0.5	0.38
	At this moment I feel independent.	2	0	71.1 (30.5)	70.8 (45.2)	71	0.27	0.5	0.38
Items added after round 1									
Physical Functioning	Today I did everything that I wanted to do.	0	0	64.6 (31)	-	-	-	-	-
Physical Symptoms	The neuropathy I experience is located at:	0	0	77.1 (35.9)	-	-	-	-	-
Physical Symptoms	At this moment, I am experiencing neuropathy (e.g., tingling or pain).	0	0	81.3 (34.4)	-	-	-	-	-
Negative Affect	At this moment, I feel angry.	0	0	56.3 (33.8)	-	-	-	-	-
Positive Affect	At this moment, I feel cheerful.	0	0	54.2 (40.1)	-	-	-	-	-
Professional Life	At this moment, I feel capable of working.	0	0	85.7 (21.5)	-	-	-	-	-
Psychologic	At this moment, I have	0	0	82.2	-	-	-	-	-

Subdomain	Item	No. of participants judging item as inappropriate		Relevance, mean (standard deviation)			Proportion of participants who selected item as one of most important in subdomain		
		Pt	HCP	Pt	HCP	/2[a]	Pt	HCP	/2[a]
al Well-being	negative thoughts or feelings.			(21.3)					
Psychological Well-being	Today, my work (including household chores) has given me satisfaction.	0	0	62.5 (26.9)	-	-	-	-	-
Sleep Quality	Last night, I woke up ... times. [0 - 1-2 - 3-4 - 5-6 - More than 6]	0	0	54.2 (40.1)	-	-	-	-	-
Sleep Quality	Last night, I had trouble falling back asleep after waking up.	0	0	70.8 (31.9)	-	-	-	-	-
Social Well-being	I am satisfied with the level of intimacy I experienced yesterday.	0	0	68.8 (28.5)	-	-	-	-	-
Social Well-being	Today, I felt that my family appreciates me.	0	0	64.6 (37.5)	-	-	-	-	-
Social Well-being	Today, I worried about my loved ones.	0	0	68.8 (25.7)	-	-	-	-	-
Social Well-being	Today, I was able to openly discuss my concerns with my loved ones.	0	0	68.8 (31)	-	-	-	-	-
Social Well-being	Today, someone in my family or friends felt anxious or concerned about me.	0	0	60.4 (40.8)	-	-	-	-	-
Social Well-being	Today, my physical condition or treatment disrupted my social activities.	0	0	83.3 (24.4)	-	-	-	-	-
Social Well-being	Today, my physical condition or treatment disrupted my family life.	0	0	71.1 (37.5)	-	-	-	-	-
Social Well-being	Today, I was satisfied with the communication about my illness with my loved ones.	0	0	62.5 (34.2)	-	-	-	-	-
Spiritual and Existential	Today, I felt connected to my faith.	0	0	35.7 (38)	-	-	-	-	-

Subdomain	Item	No. of participants judging item as inappropriate		Relevance, mean (standard deviation)			Proportion of participants who selected item as one of most important in subdomain		
		Pt	HCP	Pt	HCP	/2[a]	Pt	HCP	/2[a]
Well-being									
Spiritual and Existential Well-being	Today, I made the most of my day.	0	0	72.9 (34.9)	-	-	-	-	-
Spiritual and Existential Well-being	Today, I found life meaningful.	0	0	72.9 (32.7)	-	-	-	-	-

Abbreviations. Pt = Patient, HCP = Healthcare professional
[a]The mean of the values for patients and healthcare professionals

Appropriateness. Twenty-two out of 55 items were deemed inappropriate by between one to five participants (Table 3), with twelve items deemed inappropriate by at least two participants. Reasons included privacy concerns, content overlap, confronting questions, infrequent experiences, question formulation, clinical utility, and bad subdomain fit (Supplementary material 2). We removed the most inappropriate item "At this moment, I feel enthusiastic" as four patients and one healthcare professional marked it as inappropriate due to content overlap and patients not experiencing this feeling.

Comprehensiveness. Participants suggested adding several constructs to improve comprehensiveness, leading to the addition of thirteen items to the item list (Supplementary material 3). Among these, two were conditional items administered only if certain responses are given during the same assessment, such as reporting moderate pain levels or poor sleep. These questions included "The pain is located in these parts of the body: ..." and "I think I didn't sleep so well, because: ...". Examples of other added items included "At this moment, I feel capable of working" and "At this moment, I have negative thoughts or feelings". Additionally, we included three items to the questionnaire as the research team thought them to be necessary for comprehensive measurement of the psychological domain ("At this moment, I feel restless" and "At this moment, I feel depressed") and an open question concerning other contextual factors ("If there is anything else you want to mention about the period since last beep, you can do that here:").

Relative importance. We assigned 46 items with the highest relative importance of their

subdomain to the core questionnaire and 38 items to the supplementary list (see Table 3 for the proportions of how many times items were chosen as among the top most important).

Interview round 2

Comprehensibility. Between 1 to 5 participants provided remarks for 31 out of 79 items (Supplementary material 4). Reasons for marking items as incomprehensible included unclear word meanings, different interpretations from the intended meaning, situational content, response options misalignment, and other issues. In response to this feedback, we changed the wording of some items and response options and removed some items (Supplementary material 5). For instance, we replaced the response option "On the move" under the item "What am I doing?" to "En route (e.g., on the bus)" for clarity. Another example is the core questionnaire item "Today I felt supported by others", which we changed to "Today I received the support I needed from my loved one(s)", as some patients indicated not needing or seeking support all the time.

Relevance of added items. On average, most added items were rated as, at least 'a little' relevant, with mean ratings typically exceeding "quite a bit" relevant (Table 3).

Appropriateness of added items. No items were considered as inappropriate by the participants.

Additional findings and changes made. Three patients reported frequently experiencing muscle cramps, leading to the addition of the item "Since the last beep, I had muscle cramps" to the supplementary list. Based on research team consensus, we improved the comprehensiveness of the "Where am I?" item by adding an "outside" response option. Figure 3 displays the resulting questionnaire in the m-Path application.

Interviews Round 3

Usability. On a scale ranging from 0 = "Totally do not agree" to 5 = "Totally agree", participants generally expressed positive sentiments about using the ESM-AC questionnaire in their daily lives (M = 3.6, SD = 0.8;), finding it easy to use (M = 4.5, SD = 0.5), and expecting no need for support with the questionnaire or the smartphone device in their daily lives (M = 1.6, SD = 0.7, and M = 1.5, SD = 0.7, respectively). They also indicated that there was no inconsistency in the questionnaire (M = 1.6, SD = 0.7), they expected that most people would quickly learn to use the questionnaire (M = 4.0, SD = 1.1), felt confident using it (M = 4.2, SD = 1), did not require a lot of knowledge to complete it (M = 1.3, SD = 0.5), items and response options were clear (M = 4.3, SD = 0.5, and M = 4.0, SD = 0.9, respectively), the response options were comprehensive (M = 4.1, SD = 1), and the

lay-out was satisfying (*M* = 4.2, *SD* = 0.6). Moreover, participants did not experience it as burdensome to complete the questionnaire (*M* = 1.5, *SD* = 0.7), and did not think it was too long (*M* = 1.9, *SD* = 0.9). However, as reflected by neutral mean scores with higher variance, participants were more divided regarding the simplicity of item phrasings (*M* = 2.2, *SD* = 1.2) and the readability of items (*M* = 3.9, *SD* = 1.4). Moreover, most participants anticipated that completing the questionnaire ten times per day on six consecutive days would be burdensome (*M* = 3.7, *SD* = 1.1).

Perceived difficulties. Participants reported various barriers with using the digital ESM-AC questionnaire and device, and we observed some difficulties when participants used the questionnaire. For some patients, response formats and the option to skip open-ended items were initially not clear, the momentariness of items (i.e., "at this moment, I feel …") required further instructions (e.g., participants would give higher pain scores due to previous pain episodes, when currently not experiencing pain), interpretations of some complex items were unintended (e.g., concentration problems were interpreted as wider cognitive problems), the purpose of the study and of specific questionnaire content domains were unclear (e.g., context items), and the device went into standby during the interview. All the changes we made to the ESM-AC questionnaire, smartphone device settings, and onboarding instructions are reported in Table 4. See Table 5 for the resulting core ESM questionnaire. We also created a manual for researchers to provide patients with instructions where needed (Supplementary material 6).

Table 4. Changes made to different ESM-AC questionnaire properties after the usability interviews of round 3.

Property	Observed or reported barriers	Changes made
ESM Questionnaire	Momentariness of item unclear	The phrasing "at the moment the beep went off" was added to the multiple-choice context items. For example: *"Who am I with?"* → *"Who was with me at the moment of the beep?"*
	Momentariness of item unclear	In-the-moment phrasings were added to items that did not previously include it. For example: *"I'm in bed or on the couch"* → *"I was in bed or sofa when the beep went off"*
	Meaning of "place I was at" wrongly associated with bed or sofa	*"I was happy with the place I was at"* was reordered to be between *"Where was I at the moment of the beep?"* and *"I was in bed or sofa when the beep went off"*
	Unclear what was measured with substance item	"Since last beep, I have used the following" → "Since last beep, I have used the following substance(s)" (response option "Other" was changed to "Other substance(s)")
	-	An m-Path feature was selected for the multiple-choice items that allows participants to directly type new categories when the "other" option is selected. This replaced the need for conditional open-ended items when participants used the respective response option.
Smartphone device settings	Device screen darkened while completing the questionnaire	The time-to-standby settings on the devices was changed from 30 seconds to 60 seconds.
Onboarding instructions	Response formats and option to skip open-ended items were not	A formal interview guide was developed for the training at the onboarding session, which included instructions

	initially clear; momentariness of items required instructions; unintended interpretations of some complex items; purpose of study and some study domains (e.g. context items) unclear; reported expectations of missing assessments; difficulty unlocking smartphone	on how to explain the different response option formats and how to use them, skipping open-ended items, temporality of questions (i.e. in-the-moment, since last beep), content of more complex items (e.g. concentration as separate from memory problems), the purpose of the study and some question domains, acceptability of missing assessments, unlocking the smartphone.

Completion times. During the second time of filling in the digital ESM-AC questionnaire (i.e., without thinking out loud), it took participants on average 3.8 minutes (SD = 1.1) to complete the questionnaire.

Table 5. Final core ESM-AC questionnaire

Assessment schedule	Subdomain	Item	Response options
Momentary	Physical symptoms	1. At this moment, I have pain.	Slider: 0 = Not at all, 100 = Very much
		1'. If pain > 10: The pain is located at these body parts.	Multiple-choice: o Head o Back o Hands or fingers o Stomach o Hips o Knees o Feet or toes o Other body parts
		2. At this moment, I feel tired.	Slider: 0 = Not at all, 100 = Very much
		3. At this moment, I feel nauseated.	Slider: 0 = Not at all, 100 = Very much
		4. At this moment, I'm experiencing breathing problems (shortness of breath, difficulty breathing).	Slider: 0 = Not at all, 100 = Very much
	Negative affect	5. At this moment, I feel restless.	Slider: 0 = Not at all, 100 = Very much
		6. At this moment, I feel sad.	Slider: 0 = Not at all, 100 = Very much
	Positive affect	7. At this moment, I feel content.	Slider: 0 = Not at all, 100 = Very much
		8. At this moment, I feel relaxed.	Slider: 0 = Not at all, 100 = Very much
		9. At this moment, I feel energized.	Slider: 0 = Not at all, 100 = Very much
	Cognitive	10. Since last beep, I had trouble	Slider: 0 = Not at all,

Assessment schedule	Subdomain	Item	Response options
	complaints	concentrating on things like reading a newspaper, watching television or following a conversation.	100 = Very much
	Psychological well-being	11. At this moment, I feel worried.	Slider: 0 = Not at all, 100 = Very much
		12. At this moment, I feel depressed.	Slider: 0 = Not at all, 100 = Very much
		13. At this moment, I feel anxious.	Slider: 0 = Not at all, 100 = Very much
	Social well-being	14. At this moment, I feel lonely.	Slider: 0 = Not at all, 100 = Very much
	Global well-being	15. At this moment, I feel …	Slider: 0 = Very bad, 100 = Very good
		16. If there is anything else you want to note about the period since last beep, you can do it here:	Open question
	Social company	17. Who was with me at the moment of the beep?	Multiple-choice: o Partner o Child(ren) o Other family members o Friend(s) o Acquaintance(s) o Healthcare provider o Co-worker(s) o Online contact (like Whatsapp) or phone call o Others o Nobody (I am alone)
	Social company (Appraisal)	*18a. If not 'Nobody (I am alone)':* I think this company is pleasant.	Slider: 0 = Not at all, 100 = Very much
		18b. If 'Nobody (I am alone)': It feels okay to be alone.	Slider: 0 = Not at all, 100 = Very much
	Location	19. Where was I at the moment of the beep?	Multiple-choice: o At home o At someone else's home o Store

Assessment schedule	Subdomain	Item	Response options
			o Hospital o Work o Outside o Somewhere else
	Location (Appraisal)	20. I'm content with the place I was at.	Slider: 0 = Not at all, 100 = Very much
	Location (Bed/Couch)	*21. If 'At home', 'At someone else's home', or 'Hospital':* I was in bed or on the couch when the beep went off.	Yes-No
	Activity	22. What was I doing at the moment of the beep?	Multiple-choice: o Active leisure (walking, cycling, odd jobs, …) o Passive leisure (watching tv, internet, something quiet, …) o Work o Households, groceries, home administration o En route (e.g., on the bus) o Self-care, personal hygiene (washing, dressing, …) o Eating, drinking o Taking care of my (grand)child o Conversation, interaction o Sleeping o Nothing o Something else
	Activity (Appraisal)	*23. If not 'Nothing':* I liked the activity I was doing right before the beep.	Slider: 0 = Not at all, 100 = Very much

Assessment schedule	Subdomain	Item	Response options
		24. If not 'Nothing': I felt limited doing the activity right before the beep.	Slider: 0 = Not at all, 100 = Very much
	Medication	25. Since last beep, I have used the following substance(s):	Multiple-choice: o Medication o Cigarettes o Alcohol o Caffeine (e.g., coffee) o Nothing o Other substances
		25'. If 'Medication': I used medication against:	Multiple-choice: o Pain o Nausea o Anxiety or restlessness o Others
	Meta (disturbance)	26. I thought it was disturbing to fill in this questionnaire	Slider: 0 = Not at all, 100 = Very much
	Meta (difficulty)	27. It was difficult for me to complete this questionnaire.	Slider: 0 = Not at all, 100 = Very much
	Meta (attention)	28. I completed the questions attentively.	Slider: 0 = Not at all, 100 = Very much
Morning	Sleep quality	29. This night, I slept well.	Slider: 0 = Not at all, 100 = Very much
		29'. If sleep > 10: I think I slept less well, because:	Open question
Evening	Physical functioning	30. Today, due to my physical condition, I had difficulty performing my daily activities.	Slider: 0 = Not at all, 100 = Very much
	Psychological well-being	31. I feel like I was able to enjoy my day today.	Slider: 0 = Not at all, 100 = Very much
	Social well-being	32. Today I received the support I needed from my loved one(s).	Slider: 0 = Not at all, 100 = Very much
		33. Today I felt like I was a burden to my loved one(s).	Slider: 0 = Not at all, 100 = Very much
	Spiritual-Existential well-being	34. Today I felt hopeful.	Slider: 0 = Not at all, 100 = Very much
	Meta (non-response)	35. Today I deliberately did not respond to a beep.	Yes-No
	Meta (non-response)	35'. *If 'yes':* I did not respond to that beep because:	Multiple-choice: o I could not react (on time)

Assessment schedule	Subdomain	Item	Response options
			o I was sleeping or resting o I did not feel like it o I was too stressed o The questionnaire would take me too much time o I experienced the beep as burdensome o Other

Discussion

We developed, content-validated, and optimized the ESM-AC questionnaire, a digital ESM questionnaire covering multidimensional domains to capture the experiences of people with advanced breast or advanced lung cancer. Overall, patients found the questionnaire items comprehensible and appropriate, and had positive views towards using the questionnaire in the m-Path application. As all items in the initial set were relevant to at least some patients, we primarily used the perceived importance of items to categorize them into a core questionnaire for use with all patients and a supplementary item set from which patients can select items to tailor the ESM questionnaire to their needs and experiences.

As a novel and promising tool to assess patients' symptoms, concerns, and overall wellbeing, the ESM-AC questionnaire supplements existing measurement methods in oncology, a field that has traditionally relied on retrospective PROMs[1–3]. ESM uniquely enables the measurement of experiences in-the-moment in the patient's everyday life, and, using multiple assessments per day, the investigation of how these experiences change and unfold over time, including their correlations and temporal precedence[43]. The repeated within-day assessments of ESM can also supplement more traditional daily diary measures in oncology that assess patients once per day, to uncover fine-grained fluctuations of symptoms. This can be important to better understand the complexity and dynamics of patient experiences from a research point of view. Moreover, from a clinical standpoint, ESM can be used to improve understanding of symptoms or concerns of individual patients identified using transitional once-daily or weekly administered patient-reported outcome measures

(PROMs).

To the best of our knowledge, the ESM-AC questionnaire is the first of its kind in oncology in several respects. Firstly, the limited number of ESM studies in oncology populations have never determined the content validity of their questionnaire items to be assessed in a repeated in-the-moment context[7,11]. Secondly, in cancer ESM research, the ESM-AC questionnaire is among the first to incorporate items on context and context appraisal[7,10]. By including items on concurrent location, activity, and social company, it will be possible to better understand fluctuating symptoms and their interactions with contextual factors. ESM research in other fields has shown how different contexts such as social company, concurrent activities, and location can influence patients' mental and physical experiences[44–46]. Thirdly, by dividing items into a core and supplementary list, item selection can be adapted or tailored to a particular patient or a population of patients, i.e. by adding relevant supplementary items such as "At this moment, I feel capable of working". This makes our ESM measurement highly relevant for people with advanced breast or advanced lung cancer.

Using the m-Path application[37], results showed that the ESM-AC questionnaire was easy to use for all patients, and patients had positive views towards the questionnaire presented on the device. This is crucial given the need to keep potential burden of frequent daily administrations to a minimum. This is especially true when working with populations vulnerable due to increased symptoms and reduced physical functioning related to cancer and related treatments. Additionally, although the questionnaire took on average longer than the generally recommended three minutes to complete in ESM research[42,43], participants indicated that it was not too long. We therefore deviated from our initial 3-minute threshold and did not further shorten the questionnaire[40]. As we purposively sampled people above and below the age of 70 years old (M = 63.8, SD = 11.1, range = 45-78), we were able to conclude that the system questionnaire was usable for older age groups (up to 78 years old) that are typically thought to have less smartphone experience, as indicated by their positive views on usability of the system.

Implications for future research

The next step in the development of the ESM-AC questionnaire is to evaluate it in a detailed pilot ESM study. Such a study needs to evaluate the optimal number of daily assessments among people with advanced lung or advanced breast cancer. As most participants indicated that they expected ten assessments per day for six consecutive days, as is often used in ESM research[43], to be potentially burdensome, the burden of completing such an intensive assessment schedule should be carefully investigated in real-life. This burden needs to be weighed against the necessary resolution to measure

change in the construct of interest. Additionally, further research is needed regarding the acceptability of the questionnaire length, and clarity of the instructions, items, and response options if researcher help is not immediately available. If further research confirms the feasibility and optimal features for a larger-scale ESM study, this will pave the way towards a substantial improvement of our knowledge of how symptoms, concerns, and wellbeing across multiple domains fluctuate in the everyday life of people with advanced breast or advanced lung cancer.

Researchers aspiring to apply similar methods to other oncology or serious illness populations are encouraged to further adapt the methods to their target population. We recommend the ESM-AC questionnaire as a starting point for adaptations towards the target population and context. The core ESM questionnaire can be used in its entirety or researchers can select the domains of interest, possibly supplemented by items selected from the supplementary item set. Determining the questionnaire's content validity through semi-structured interviews will help to optimize and ensure its relevance, comprehensiveness, and comprehensibility for intended research.

Furthermore, ESM data can be compared to retrospective patient-reported outcome data to confirm and obtain more evidence on the added value of ESM and the different experiences it captures, and to investigate the ecological validity of such data. Another important area of future ESM research in oncology can be to explore its clinical value and utility, for instance, by providing clinicians with timeseries visualizations of their patients and comparing these with information gathered through traditional consultations.

Strengths and limitations

This study is among the first studies to test the content validity of an ESM questionnaire in any scientific field and resulted in the first content-valid ESM questionnaire in the field of oncology, thereby answering to recent calls for more questionnaire validation in ESM research[7,10,11]. Strengths of this study include, firstly, the close collaboration with people with cancer and healthcare professionals in multiple phases of questionnaire development, ensuring its relevance for the target population. Secondly, relevance was further ensured by adapting items from existing validated PROMs[33–35]. Thirdly, we included an equal number of patients below and above the age of 70, ensuring the inclusion of the latter as an often-underrepresented group in cancer studies. Finally, this study's relatively good participation rate reduces the risk of selection bias.

Several limitations should be noted. First, the study was limited to Dutch-speaking patients from two study sites, possibly limiting the extent to which the ESM-AC questionnaire's content validity can be generalized to patients with socio-demographic characteristics different from our sample. However, the ESM questionnaire will be further tested among new patients recruited from

different hospitals. Second, the relatively high functional status of patients in our sample (i.e., ECOG scores between 0 and 2) may lead to limited generalizability of the results to patients with advanced cancer who have more functional limitations. Third, as no people participated with an age over 78 years, the usability of our ESM method is unknown for older populations.

Conclusion

We successfully developed the ESM-AC questionnaire, the first content-valid digital ESM questionnaire in oncology to study the daily experiences of people with advanced breast or advanced lung cancer in their everyday environments. If the method proves feasible in future research on advanced cancer, and in other patient groups, it paves the way towards gaining novel insights into the daily lives of oncology patients, possibly informing, and facilitating patient-centered care.

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Conflicts of interest

The authors declare no conflicts of interest.

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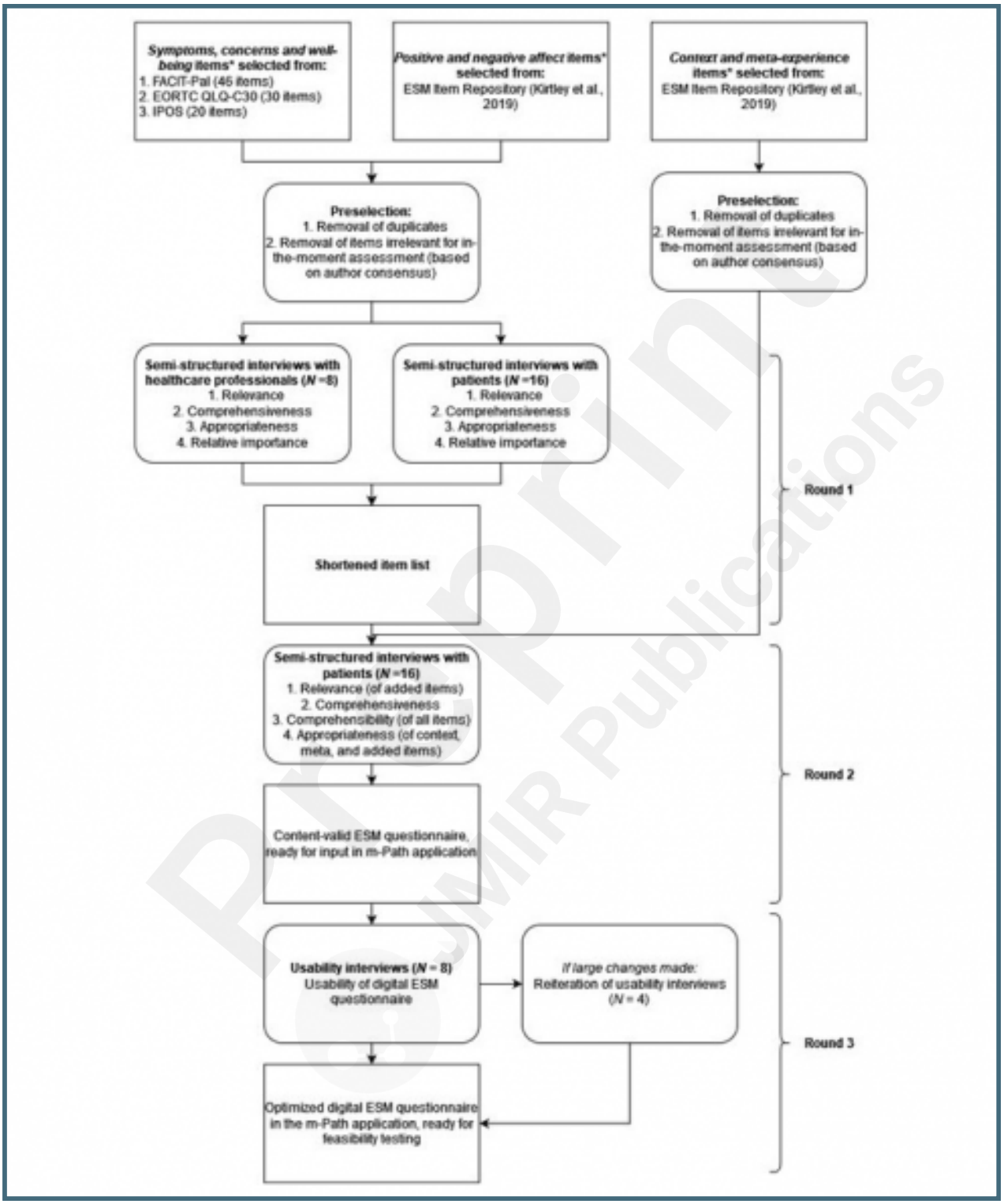
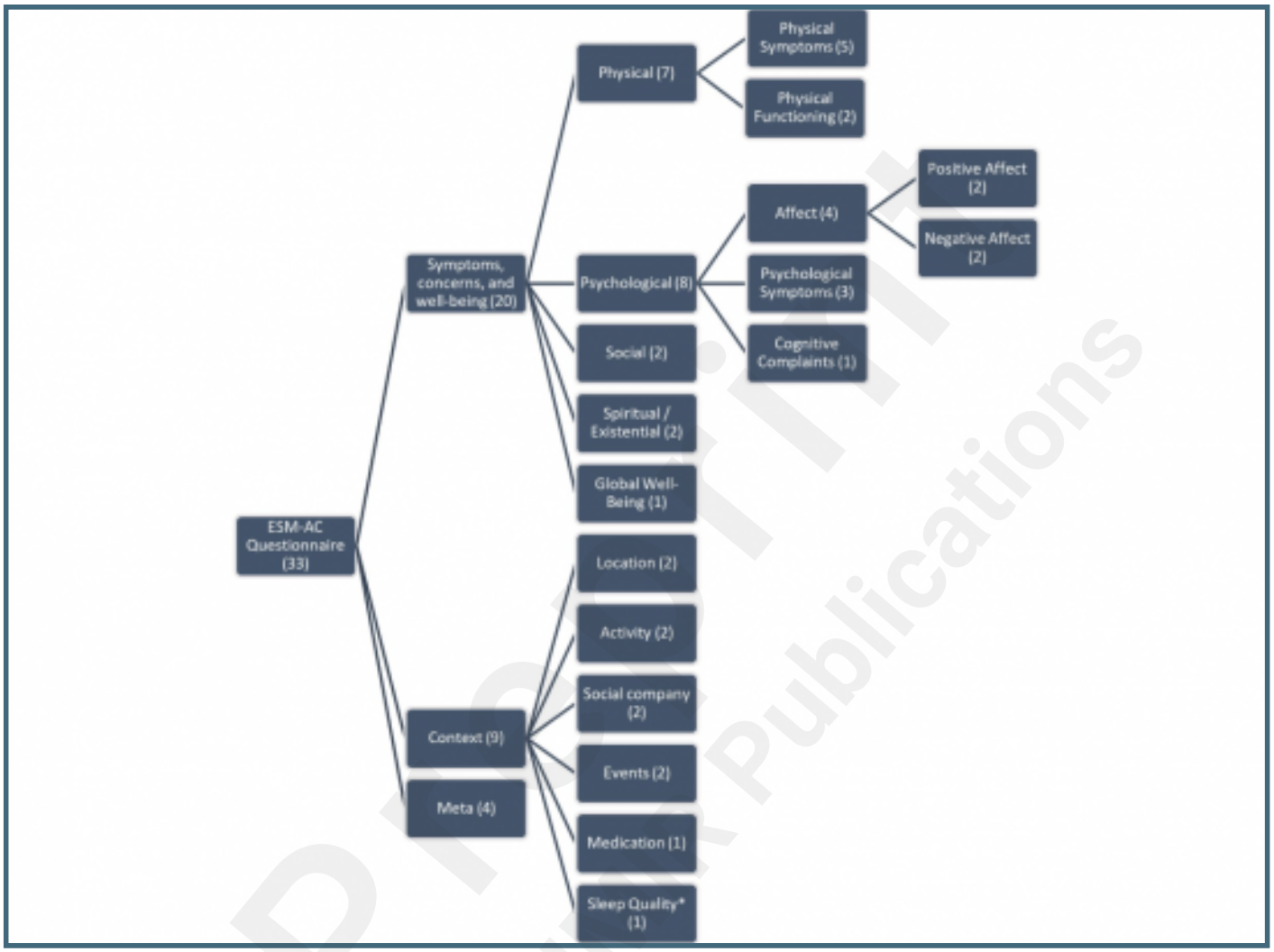
Supplementary Files

Figures

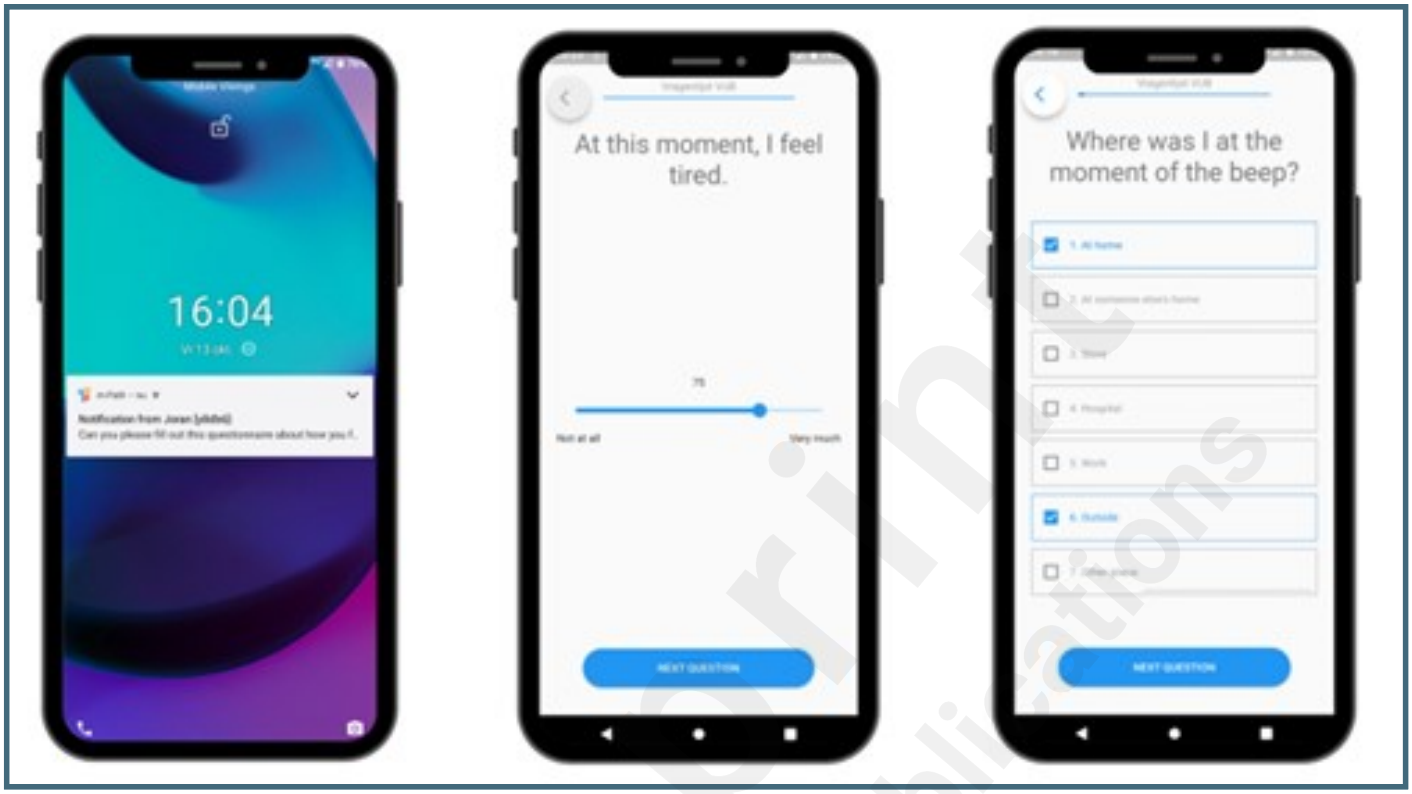
Flowchart of development and validation procedure. *We used Dutch translations of these questionnaires.



Subdomains that the ESM-AC questionnaire intended to cover. Note. The between-bracket numbers after each domain name indicate the approximate number of items that we aimed to retain per domain and the number of most important items that participants had to choose for each right-most subdomain. *Not asked at every ESM assessment.



Screenshots of the ESM-AC questionnaire in the m-Path application. Notes. Left: Receiving a notification; Middle: Example of slider response scale; Right: Example of multiple-choice response scale.



Multimedia Appendixes

Supplementary material 1. Figure on criteria for categorization into the core questionnaire, supplementary set or items to be removed.
URL: http://asset.jmir.pub/assets/1795b3334a4e3222d1db9a485dc9cf86.docx

Supplementary Material 2. Frequency table of categorized reasons for deeming item inappropriate.
URL: http://asset.jmir.pub/assets/729b45d2ba01ef0db71c01853f045f49.docx

Supplementary Material 3. Content categories of patient and healthcare professional responses to the open-ended question on what content was missing from the item sets.
URL: http://asset.jmir.pub/assets/5490e8bfc0e8fe350cac5df657391119.docx

Supplementary material 4. Proportions of participants that had no difficulties with comprehensibility of item per item, ordered by subdomain.
URL: http://asset.jmir.pub/assets/d36fa6d596314db2203290872ce13387.docx

Supplementary Material 5. Resulting Dutch item versions before and after the first two interview rounds.
URL: http://asset.jmir.pub/assets/2ab2ba2d991bb191aedcc33ee7221443.docx

Supplementary material 6. Dutch onboarding session manual created after interview round three.
URL: http://asset.jmir.pub/assets/31cc82f4f9d8bc37e8241ec4ddf4d411.docx