



Utilization of patient-reported outcome measures for women with low health literacy in gynecologic oncology – A mixed-methods study

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HIGHLIGHTS

- Nearly a quarter (23.5%) of patients at our gynaecological cancer centre had self-perceived low health literacy.
- PROM-completion rates were high and completion patterns did not differ based on health literacy level.
- There were several issues with the comprehensibility of PROMs for women with low health literacy.
- Women with low health literacy indicated difficulties with digital accessibility of PROMs.
- Limited understanding of PROMs' purpose and minimal integration in daily practice led to reluctance toward completing PROMs.

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ABSTRACT

Purpose. Patient-reported outcome measures (PROMs) are used in oncology to assess patients' wellbeing. It is unclear if PROMs suit patients with low health literacy (HL). This study aimed to determine the prevalence of low HL in gynaecological cancer patients, describe associated clinical and sociodemographic factors, and explore PROMs use and comprehensibility for this group.

Methods. Patients treated for a gynaecological malignancy completed a waiting room questionnaire to assess self-perceived HL. Clinical and sociodemographic characteristics were collected via additional questions and the electronic patient file. Those with low HL, identified by the self-perceived HL screener and educational level, were interviewed, covering cognitive debriefings of a PROM-subset and semi-structured questions on attitudes toward PROMs. Patient characteristics were analyzed descriptively. Qualitative interview data were analyzed using Tourangeau's response process model and reflexive thematic analysis.

Results. In total, 136 patients completed the waiting room questionnaire. 23.5% ($n = 32/136$) had self-perceived low HL, of which 18 agreed to interviews. Cognitive debriefings revealed comprehensibility issues, particularly related to interpreting recall periods and response options. Some terms were perceived as ambiguous or emotionally charged. During semi-structured questions, participants expressed digital access issues and reluctance toward PROMs, often due to confusion about their purpose and absence of feedback on prior responses during consultations.

Discussion. Challenges with PROM comprehensibility and use among patients with low HL may hinder accurate health status reflection, impacting clinical work and research outcomes. Improvements are needed in clearly communicating PROMs' purpose and feedback on responses. To overcome comprehensibility barriers, PROMs should be developed and validated with low HL populations.

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1. Introduction

Health literacy (HL) is steadily gaining importance in clinical practice, particularly in cancer care [1,2]. People with low health literacy (LHL) experience difficulty accessing, processing, and understanding basic health information and services [3]. LHL is associated with poorer health outcomes, including higher hospitalization rates, greater reliance on emergency care, reduced participation in screening programmes, and increased mortality [4]. In Europe, nearly half of the population struggles with low or limited HL [5], for the Netherlands this accounts for more than a third of the population [6].

In cancer care, LHL presents unique challenges. This is due to the complexity of tests and treatments, and the involvement of various healthcare providers [2]. Patients with LHL often encounter barriers when engaging in medical decision-making processes, especially when it comes to time-critical decisions [7]. In gynaecological cancer care, women often report unmet needs related to understanding medical information [8]. However, literature addressing LHL in gynaecological oncology remains limited [9].

Treatment for gynaecological cancer has significant physical and psychological impacts and negatively affects quality of life (QoL) [10]. To evaluate this impact on QoL, patient-reported outcome measures (PROMs) are increasingly used. These are standardized questionnaires that capture patients' experiences and perspectives of their health and QoL [11]. PROMs can be completed at home or at the outpatient clinic. Integration of PROMs in routine care can improve communication between patients and healthcare providers, support decision-making about treatment options, and allow effective symptom and QoL monitoring [12,13].

Despite many promising findings, there are challenges in practice. It is known that the response burden of PROMs, the degree to which a respondent perceives their participation as difficult, time-consuming, or emotionally stressful, can be high [14]. This response burden is likely higher for individuals with literacy problems. However, populations with LHL are often overlooked when developing and validating PROMs. For example, the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaires (QLQ) are often used for people with cancer [15]. In development and validation studies of EORTC modules specific to gynaecological malignancies, there is no mention of the inclusion of participants with low or limited HL. To address this gap, the objective of this study was to examine how patients with LHL interpret and use PROMs in gynaecological cancer care, using a mixed-methods approach. Specific aims were:

1. To determine the prevalence of LHL in patients with gynaecological malignancies, assess their clinical and sociodemographic characteristics and explore patterns of patient-reported outcome measure (PROM) completion.
2. To evaluate the comprehensibility of PROMs for patients with LHL and explore their perspectives regarding the use of PROMs within gynaecological cancer care.

2. Material and methods

2.1. Study design and setting

This mixed-methods study consisted of two parts. The first part involved administering a waiting room questionnaire to assess LHL and PROM-completion patterns, and statistical analyses of socio-demographic and clinical data from the electronic patient portal. The second part consisted of interviews with only participants with LHL. Fig. 1 illustrates the study design and recruitment process.

The study was conducted between October 2023 and February 2024 at a Dutch gynaecological oncology centre, serving a wide referral region. As part of standard care, patients received digital invitations to complete a PROM-set via their electronic portal prior to follow-up

consultations with their gynaecological, medical or radiation oncologist. PROMs were integrated into the electronic patient system, enabling medical professionals to access responses in the file. Upon receiving the PROM-set, patients receive a short explanation that PROMs will be used in preparation for the consultation. Physicians were instructed and trained to discuss the responses during the consultation.

The PROM-set consisted of 86 questions, combining twenty self-formulated general questions on medical history and sociodemographic topics, the EORTC core QLQ (C30), a selection of items from disease-specific EORTC modules for ovarian (OV28), endometrial (EN24), cervical (CX24) and vulvar (VU34) cancer, and a selection of Patient-Reported Outcomes Measurement Information System® (PROMIS®) *Social Function: Ability to Participate in Social Roles and Activities* scale (version 2.0, Short Form 8a) [16–20]. EORTC answer options used a four-point Likert scale and PROMIS a five-point Likert scale. Some questions from EORTC referred to the patient's situation 'during the past week.'

2.2. Study population

Recruitment is summarized in Fig. 1. All patients scheduled for outpatient appointments received an information letter via post, informing them a researcher could approach them in the waiting room about the study. After written informed consent, participants completed a brief paper-based questionnaire in the waiting room (the 'waiting room questionnaire'; see 'Data Collection' for details on the questionnaire). To accommodate potential literacy or reading barriers, a researcher (AJ, DS) read the questions aloud.

For interview recruitment, purposive sampling was used. Patients with self-reported LHL were contacted by telephone to explain details about and potentially schedule an interview. They were informed that the interviews would be conducted by one of two female researchers, and were given the name of the researcher that would interview them. Administration of the waiting room questionnaire and interview conduction occurred concurrently, enabling iterative refinement of the interview guide and assessment of information power of interviews. Following Malterud et al. (2016), sample adequacy was determined by the study's focused aims, specific population (patients with LHL and gynaecological cancer), and use of established theory (See: 'Data collection') and a structured, combined qualitative analysis approach [21]. Recruitment continued until interviews yielded in-depth data, confirming information power.

2.3. Data collection

2.3.1. Part 1: health literacy, patient characteristic and PROM-completion patterns

To assess HL and PROM-completion patterns, the waiting room questionnaire was administered. It included four multiple-choice questions regarding educational attainment and self-perceived HL, and three open-ended questions about primary language, occupation and familiarity with PROMs. Self-perceived HL was assessed using the three validated questions by Chew et al. (2008) (See: 'Data analysis'; Table 1) [22]. This screening method was used due to its brevity and lower participant burden compared to performance-based HL tools. The final question was open-ended, inviting patients to explain their reasons for (non-)completion of the PROM-set.

Further clinical and sociodemographic characteristics were collected from electronic patient files. For patients who completed PROMs as part of standard care, self-reported employment status and financial burden were used to assess socioeconomic context. Employment status was drawn from the last completed PROM-set within one year before study inclusion. To assess perceived financial burden during the disease trajectory, answers to question 28 from the EORTC QLQ-C30 ("Has your physical condition or medical treatment caused you financial difficulties?") from all prior completed PROM-sets were collected. The highest reported financial burden was reported in the results.

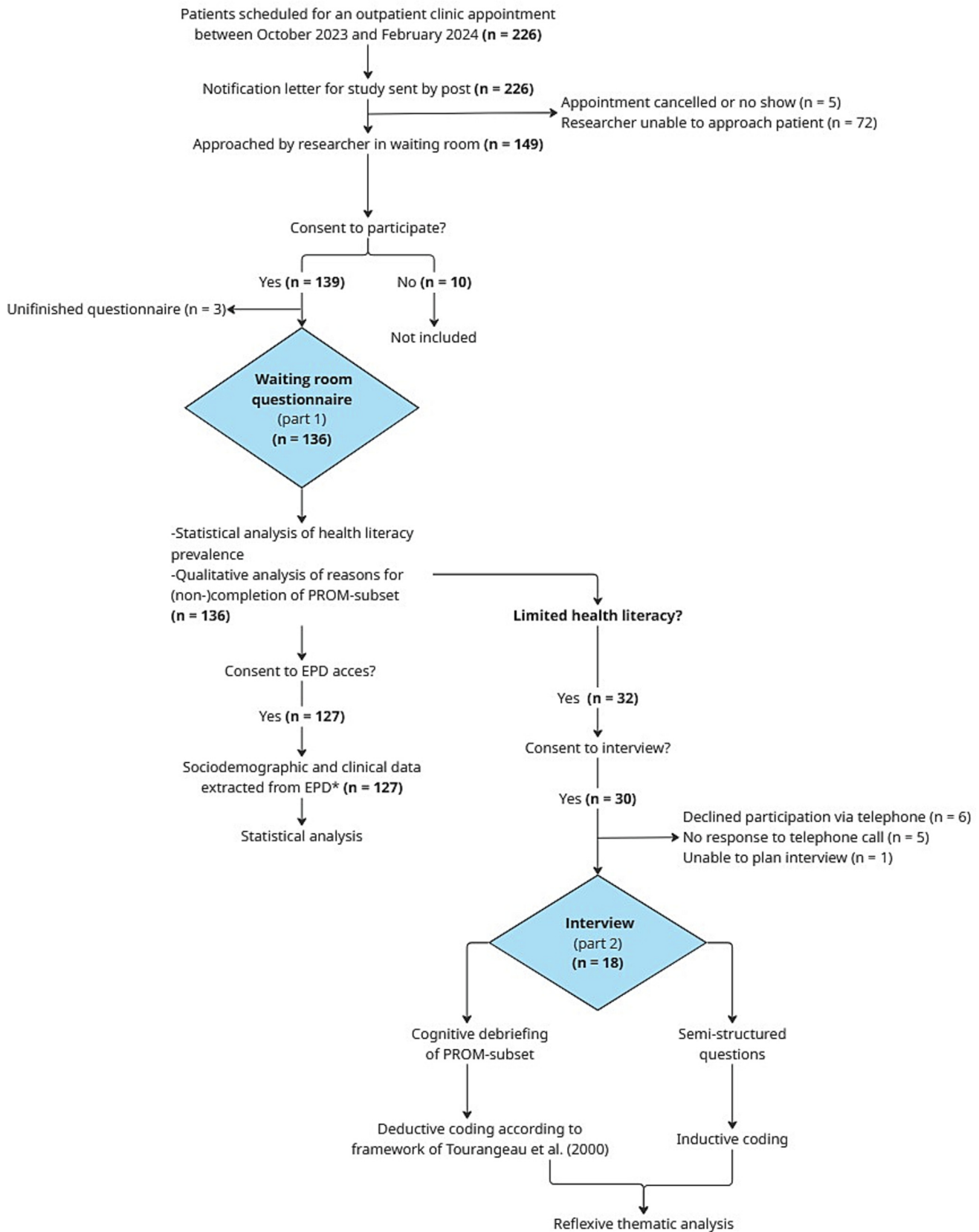


Fig. 1. Overview of the study aims and respective data collection method and participants.

Table 1
Criteria for classification as low health literacy (criteria of both domains must be met).

Domain	Item	Criteria for classification as low health literacy
Chew et al. (2008) screening questions	(1) “How often do you have someone help you read hospital materials?” (2) “How confident are you in filling in medical forms by yourself?” (3) “How often do you have problems learning about your medical condition because of difficulty understanding written information?”	“Now and then” or “often” to Q1 and/or Q3, and/or “a little” or “not sure” to Q2
Educational attainment	Dutch system	Highest educational attainment: Post-secondary vocational education/entry level (*Middelbaar Beroepsonderwijs Niveau 1* (MBO 1))
	Abroad	No more than 10 years of education abroad

2.3.2. Part 2: comprehensibility of PROMs and patient perspectives

Comprehensibility was assessed through cognitive debriefing using Willis' (2005) methods [23], focusing on the first fifteen items from the PROM-set: eight from the *PROMIS® Social Function: Ability to Participate in Social Roles and Activities scale (version 2.0) Short Form 8a* and seven from the *EORTC QLQ-C30*. Each participant reviewed the first item (PROMIS®-29: “I have trouble doing all of my regular leisure activities with others”) and two additional items, randomly selected by the interviewer. Participants were asked to rephrase questions in their own words and reflect on wording, sentence structure and response options. When participants seemed to experience difficulties, we asked further probing questions and asked them to suggest alternatives.

Using semi-structured questions, we explored participants' familiarity with PROMs, reasons for (non-)completion, perceived purpose, logistical aspects (digital access, assistance), and their thoughts on viewing prior responses.

An interview guide was developed based on literature about cognitive interviewing, PROMs and HL, and with input from the research team. It was pilot tested and adjusted iteratively. One researcher (DS or AJ) conducted 45–60 min interviews at the patient's preferred location (e.g. at home, medical centre or online), which were audio-recorded after written informed consent. At the start, the researcher explained her role and occupation.

Participants' characteristics were collected from the electronic patient file. To characterise performance-based HL, the Dutch Newest Vital Sign (NVS-D) was administered. This validated tool presents a nutrition label followed by six questions to generate a HL score from 0 to 6 [24]. A score of 0–1 indicated limited HL, 2–3 possible limited HL, and ≥ 4 adequate HL.

2.4. Data analysis

2.4.1. Part 1: health literacy, patient characteristics and PROM-completion patterns

Data from the waiting room questionnaire were extracted and combined in a secure database with the data from the electronic patient files. Participants were classified as ‘low health literate’ when they met both the criteria of the Chew et al. (2008) screening questions and the educational attainment criteria for LHL,¹ see Table 1.

¹ In line with recommendations from the Dutch expertise centre Pharos, educational level was included as a proxy measure for HL alongside the Chew et al. (2008) screener [25]. Criteria for educational attainment are in line with Pharos' guidelines.

Chi-square statistics and unpaired *t*-tests were conducted using IBM SPSS Statistics 28.0 to stratify data based on HL level. Responses to the final open-ended question regarding reasons for (not) completing PROMs were extracted from the waiting room questionnaires and compiled in a secure, de-identified spreadsheet, whereafter they were colour-coded and categorized to identify common reasons.

2.4.2. Part 2: comprehensibility of PROMs and patient perspectives

Interview recordings were transcribed verbatim and coded independently by two researchers (AJ, DS) using MAXQDA 2022. Transcript sections from the cognitive debriefings were deductively coded based on the four psychological processes for answering survey questions based on Tourangeau et al. (2000): (1) comprehension, (2) recall, (3) judgement, and (4) response [23]. Within this deductive coding framework, inductive coding was applied to further explore specific barriers within each psychological process. This combined approach allowed for the systematic organization of findings while also capturing concrete comprehension barriers. Semi-structured transcript sections were coded inductively. Coding discrepancies were resolved with the senior author (JA). Codes were grouped into themes following reflexive thematic analysis [31]. The themes were discussed within the research group and adjusted accordingly to capture nuanced insights. A thematic map was created. For this paper, quotes were selected and translated to English using DeepL, and reviewed by DS for cross-cultural validity.

2.5. Ethical considerations

The study was exempt from review by the Amsterdam University Medical Centre (METC) on September 20th 2023 (referral number: 2023.0620) as this study was not subject to the Dutch Medical Research Involving Human Subject Act.

3. Results

An overview of the study and recruitment is detailed in Fig. 1.

3.1. Part 1: health literacy, patient characteristic and PROM-completion patterns

226 patients were listed to attend the outpatient clinic, of which 221 actually visited. 149 patients were approached by the researchers (AJ, DS). The researchers were unable to approach the other 72 patients, due to time constraint or simultaneous occupation with another patient. Of 149 patients, ten declined participation and 3 questionnaires were left unfinished, because the patient got called into the consultation room while completing the questionnaire. Eventually, 136 patients completed the waiting room questionnaire.

In total, 23.5% ($n = 32/136$) patients appeared to have self-perceived LHL based on the HL screener and their educational attainment [22]. Nine patients declined access to their electronic patient files, of whom eight with adequate HL and one with limited HL. Characteristics are presented in Table 2. Participants with LHL were significantly older than participants with adequate HL (mean 65.7 vs. 54.7 years, $p < 0.001$). Other characteristics did not significantly differ between groups.

74% of respondents ($n = 101/136$) regularly completed PROMs. The most frequently mentioned reason was that it was perceived as mandatory (e.g. “if it must be done, it must be done”). The second most common reason was to benefit the physician, for instance to prepare for the consultation, to get acquainted with a new patient or to recognize patterns. Mostly respondents with LHL reported completing PROMs to contribute to research data/statistics (14%; $n = 3/22$). Two respondents with LHL and six with adequate HL reported completing PROMs for personal benefit, citing that it lowered the threshold to discuss certain topics or

Table 2
Characteristics of patients that completed the waiting room questionnaire (part 1).

		Low HL* (n = 32) N (%)	Adequate HL (n = 104) N (%)
Age in years (mean ± SD)		65.2 (±11.7)	54.8 (±15.8)
Type of malignancy	Vulvar	10 (31)	24 (23)
	Ovarian	5 (15)	18 (17)
	Endometrial	9 (28)	13 (12)
	Cervical	7 (18)	33 (32)
	Other	1 (3)	7 (6)
Years since diagnosis	< 1 year	9 (28)	26 (25)
	1–5 years	18 (56)	50 (48)
	5–10 years	2 (6)	6 (5)
	> 10 years	2 (6)	14 (13)
Recurrence (yes)		7 (21)	17 (16)
Sociodemographic data			
Educational level (Dutch system)	No formal education	1 (3)	0
	Less than high school	15 (51)	0
	High school diploma or equivalent	10 (34)	21 (21)
	Some college / associate degree	3 (10)	24 (24)
	Bachelor's degree	0	36 (36)
	Graduate degree	0	19 (19)
Education abroad (yes)		3 (9)	6 (6)
Education when obtained abroad in total years (mean ± SD)		6.7 (±1.5)	12.6 (±4.4)
Self-reported employment status	Paid employment	6 (19)	40 (39)
	Self-employed	1 (3)	7 (7)
	Retired	14 (44)	19 (18)
	Unemployed	6 (19)	14 (14)
	Student	0	2 (2)
	Volunteer work	1 (3)	2 (2)
	Missing	4 (13)	20 (19)
Current or prior employment in health-care related profession (yes)		2 (6)	16 (15)
Self-reported financial problems	Not at all	17 (53)	61 (59)
	A little	5 (16)	11 (11)
	Quite a bit	2 (6)	5 (5)
	Very much	0	2 (2)
	Missing	8 (25)	25 (24)
Primary language other than Dutch		3 (9)	2 (1)
Smoking status	Non-smoker	10 (31)	49 (47)
	Currently smoking	15 (47)	31 (30)
	Former smoker	5 (16)	14 (14)
	Missing	2 (6)	10 (10)
PROMs completion habits			
Completed PROMs according to waiting room questionnaire (self-reported)		22 (69)	76 (73)
Completed PROMs according to electronic patient file		25 (78)	78 (75)
Completed PROMs prior to consultation of administration of the waiting room questionnaire		17 (53)	46 (44)

* Patients were classified as having LHL if they affirmed at least one screening question by Chew et al. (2008) and had education below post-secondary vocational education/entry level (Middle-level applied education level 1 (MBO 1)) or, if educated abroad, had fewer than ten years of education.

provided insight into their own health. 'Other' responses included reasons that could not be categorized in the categories described before, e.g. "it is generally important," "it will speed up the consultation", "I only complete it when my situation changes."

Among participants with adequate HL, the main reasons for not completing PROMs were perceived difficulty (25%; n = 7/28) and burden (21%; n = 6/28). For participants with LHL, the most common reason was unawareness of the existence of the PROM-set (30%; n = 3/10), followed by difficulty completing it (20%; n = 2/10), mainly due to digital access issues such as logging into the patient portal. 'Perceived burden' was caused by frequent administration of the PROM-set, perceived irrelevance of items, lengthiness of the PROM-set and repetitiveness of items. 'Other' reasons were: not getting around to it, not remembering instructions about the PROM-set, or feeling it was unnecessary as their

(health) situation does not change. Reasons were unspecified by 20% of participants with LHL (n = 3) and 11% with adequate HL (n = 2).

An overview of reasons for (not) completing PROMs is shown in Fig. 2.

3.2. Part 2: comprehensibility of PROMs and patient perspectives

18 of 32 participants with LHL consented and completed an interview. Two declined participation while completing the waiting room questionnaire, six declined during the telephone contact mentioning limited time or lack of interest, five did not respond to the telephone call, and for one it was not possible to arrange a mutually suitable date and time.

Based on educational level, five participants did not classify as LHL according to our waiting room questionnaire. However, they were included in interviews because these patients reported having a lot of difficulty with medical information in the HL screener. Characteristics of interview participants are detailed in Supplementary material 3. Based on the NVS-D, six interviewees had low, five limited, and seven adequate performance-based HL levels. Ten participants had previously completed PROMs as part of their care.

The main observations of the cognitive debriefings are presented in Table 3 according to the four psychological processes of survey response based on Tourangeau et al. (2000) [23]. The comprehension process was strongly influenced by word knowledge and semantic connotations. Recall was affected by variability in participants' conceptualization of the timeframe used in many EORTC-QLQ items, 'during the past week.' Regarding the judgement process, response scales were sometimes perceived as restrictive, and interpretation was strongly influenced by word knowledge and personal convictions. Response processes were further influenced by perceived item relevance related to age and comorbidities, and the current health status of participants. Consequently, some mentioned not responding to or rushing through items.

Based on the semi-structured questions, three key themes were developed: (1) Challenges with navigating the PROMs process; (2) Overall feeling of reluctance; and (3) Clarification of the purpose for using PROMs.

3.3. Theme 1: Challenges with navigating the PROMs process

Participants experienced barriers with receiving, completing, and interpreting the PROM-set. Participants mentioned barriers related to digital accessibility and difficulties with comprehensibility. Comprehensibility issues are described in Table 2. Issues with digital accessibility included: trouble logging into the patient portal or finding the PROM-set. Some participants mentioned having no or little prior experience with computers and the Internet. Many participants required assistance from family members when completing PROMs. A few participants intentionally chose not to complete PROMs, driven by avoidance of the electronic patient portal, as seeing medical results evoked a sense of restlessness for them.

To improve comprehensibility, participants were asked if they would appreciate the use of images in the questionnaire. Opinions were mixed: some felt that it would make the questionnaire longer or appear childish, others thought it would be beneficial for some, such as non-native Dutch speakers. Participants suggested shortening the questionnaire or adding a read-aloud function.

3.4. Theme 2: Overall feeling of reluctance

Participants generally stated an overall feeling of reluctance toward completing PROMs, mainly caused by a lack of clarity about the purpose of PROMs and poor integration into the consultation with their physician. 16 out of 18 participants expressed a generally negative view of PROMs, mostly caused by the length and repetitiveness of the PROM-set. Some thought they had to complete PROMs too often or labelled

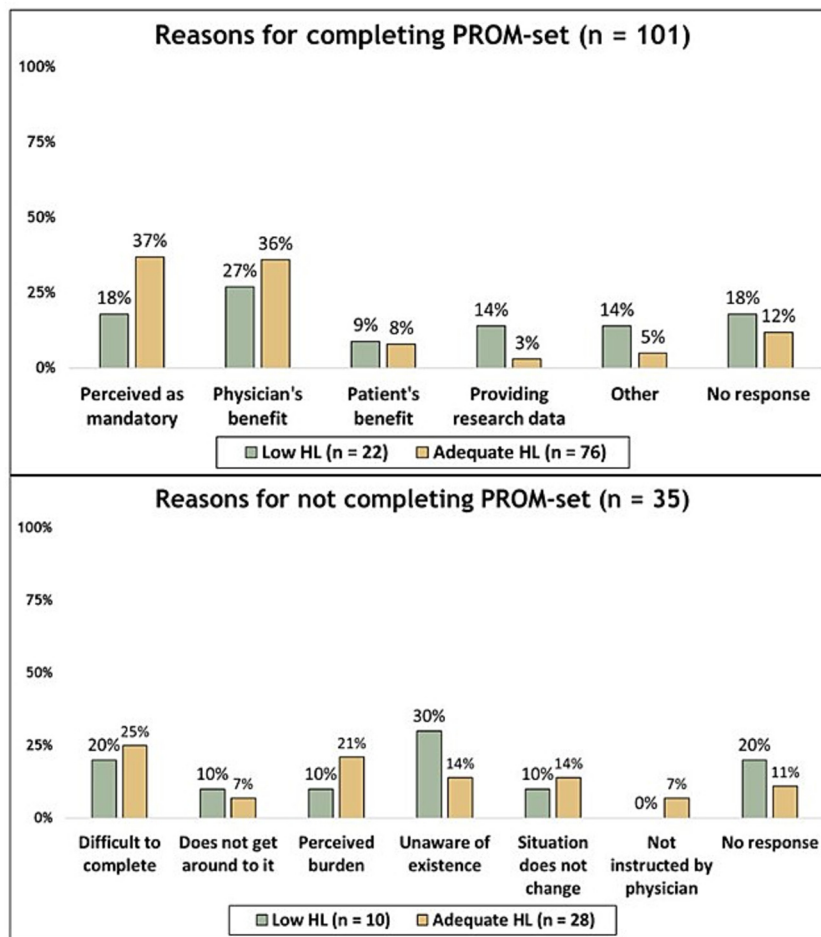


Fig. 2. Reasons for (not) completing the PROM-set.

the PROM-set as difficult. A minority of these participants preferred conversing about the topics of the PROM-set, rather than completing questions. It was mentioned that repeating similar questions during consultations increased reluctance.

"A lot of things are being asked in the same way, but just with different words, and that starts to annoy me, because you're dealing with something [cancer] that's pretty intense" – Patient 16.

Questions with static answers, such as the date of their last menstruation, also contributed to feelings of reluctance, especially as these were always repeated at the start of each PROM-set. One participant distinctively mentioned not understanding why it was necessary to ask about this topic.

Some participants mentioned feeling frustrated when questions felt irrelevant to them, influencing their willingness to complete PROMs. They suggested adapting the set to their disease stage, adding a skip function, or including an open text box for remarks when unsure about the response options.

3.5. Theme 3: Clarification of the purpose for using PROMs

Participants indicated lacking clarity about the purpose of PROMs. None of the participants remembered having received prior explanation about its purpose or how their answers would be used in daily practice.

"Well, I thought it was strange, because I didn't know I had to fill it in, so I'm just waiting and then all of a sudden you are called to fill in a

questionnaire. I thought: 'well a few questions,' but I didn't know there would be that many [questions]." – Patient 1.

The majority regularly completed PROMs for similar reasons as given in the waiting room questionnaire (Fig. 2). Only one participant saw PROMs as meaningful in her cancer journey.

"It is very pleasant for myself to... That's what I just said... to just pause and think again: (...) How do I actually feel? So yes, I think it is very pleasant for that." – Patient 4.

The majority mentioned that their responses had not been discussed during the consultation, which caused reluctance and evoked anxiety. Some assumed doctors reviewed responses privately. Feeling reassured by the physician was seen as most important in their care, also related to PROM responses.

"(...) because basically, of course, all the answers to that questionnaire are good, because it's about someone personally. (...) if at the bottom you can say: 'it will be looked at by the doctor and discussed,' but yes, then it has to be discussed." – Patient 12.

One participant mentioned that providing clear explanations go beyond mere words and highlighted the importance of a good doctor-patient relationship and non-verbal communication.

"If there is a good connection, he [gynaecologist] can see it on my face when he tells me something that I don't understand (...) if he

Table 3
Main findings of cognitive debriefing of PROM-questions according to the model of Tourangeau et al. (2000).

Cognitive process	Main observations	Example	Quote(s)
Comprehension	Terms that included adjectives that were perceived as vague and broad caused confusion or elicited emotions.	'Important work' was interpreted variably: • Paid work • Household work • Hobbies or other activities 'Usual' caused confusion: • Some thought 'usual' referred to their pre-illness state and had trouble comparing their current state with their pre-illness state. Questions on walking ability showed variable interpretation: • 'Short' versus 'long' distance • It was suggested to specify timeframes and/or distances	"Uhm, I think that one is difficult too, because what is doing all the work that is important to me? I consider work to be housework, for example. Do they define that as 'all the work' too? Look, housework is of course not really important to me." – Participant 16 "Yes, I do indeed find that 'usual' emphasises that it should actually be usual, yes... But that it currently is well yes... no longer usual for well, say patients." – Participant 16 "Maybe yes... That people would prefer a time commitment with it. A long walk of an hour or more or less than an hour." – Participant 3
	Word knowledge and connotation influenced negative (emotional) reactions to terms.	Negative associations with specific wording: • 'Having trouble with' or 'being limited in' carry different meanings in Dutch. 'Being limited' also carries the meaning of being disabled. Interpretations differed: • Some used distinct point of references, e.g. national holidays or the weekend • Some considered their situations during the past few weeks or preceding weekend	"Yes, this [limited] feels more unpleasant (...) it makes me emotional. Yeah, I, I'm not limited, I mean I am, but naming it is a bit difficult [interviewer: confronting, yes..]" – Participant 16
Recall	Participants showed diversity in conceptualizing time frames, such as 'during the past week' (as instructed for EORTC QLQ-questions).	Interpretations differed: • Some used distinct point of references, e.g. national holidays or the weekend • Some considered their situations during the past few weeks or preceding weekend	Interviewer: "It's Wednesday today, how far back do you look when it comes to 'during the past week'?" Participant: "Well... New Year's Eve or something, right?" – Participant 13 Interviewer: "Is it clear to you what the past week entails?" Participant: "Yeah, I think a few weeks before this week." – Participant 8
Judgement	Participants mentioned that the response scales forced them to choose one option, even when they felt it did not perfectly fit their reality.	• Some thought their current situation was somewhere between response options • Some thought their situation fluctuated a lot and thus could not choose one option	"I do know that sometimes I thought that the answer I actually wanted to give was not listed (...) and I would like to be in between." – Participant 5
	Interpreting response options and choosing a fitting response was influenced by several factors.	Most participants used frequencies to interpret both intensity ('not at all' to 'very much') and frequency ('never' to 'always') response scales. Personal convictions played a role: • "Never" and "always" were perceived as extremes and therefore deemed inappropriate Word knowledge influenced response choice.	"Well, 'not at all,' thus you never run into anything. And I do run into [things] once every 2 days, 3 days (...), so I think that is 'a little.' And 'quite a bit' is if you have it every day and 'very much' is if you have it with everything." – Participant 7 Interviewer: "And would you have an idea of what is a bad answer to this question?" Participant: "From the answers you gave for it? Oh yes, 'never' and 'always.' Because those are so very extreme." – Participant 5 "I wouldn't say 'quite a bit,' I would say 'a little.' (...) For myself, I understand that [a little] better than 'quite a bit' yes." – Participant 18
Response	Response styles were influenced by the current health status.	Participants rushed through when: • their health status was improved • they experienced limited to no symptoms	"Yes, that one also has a lot [of questions] and we actually usually go through those at lightning speed. (...) Yes, that could be, but then you think: 'Oh, I don't have any difficulties and you know, do that so quickly, yes...' – Participant 13
	Response styles were influenced by whether participants felt questions related to their personal and/or clinical situation and felt questions were necessary for the trajectory of their gynaecological malignancy. Response styles were influenced by comprehensibility.	Comorbidities or age influenced perceived relevance of items and response choice. Items were skipped when not understood.	"Because I have a bad gait, but that has nothing to do with gynaecology. (...) If you asked this: do you have difficulty taking a long walk? Yes, because my back hurts, yes, but then I can... You can't write that in a digital questionnaire of course." – Participant 7 "If the questions are easy, I'll fill them in. And otherwise I skip them." – Participant 18

understands you, he says it in your words. (...) Because sometimes he tells me something, then I think: do I get subtitles?" – Patient 2.

4. Discussion

This study provides insight into how patients with LHL interpret and use PROMs in gynaecological cancer care. Nearly a quarter of patients at our gynaecological cancer centre had self-perceived LHL. Besides age,

there were no significant differences in characteristics. According to the electronic patient file, nearly 80% of the study population completed PROMs. PROM-completion patterns did not differ based on HL level. Most patients that we included in this study completed PROMs because they saw them as mandatory or helpful to their physician. Among LHL patients, the main reason for non-completion was said to be unawareness and difficulty to complete. Notably, adequate-HL participants more often cited perceived burden as a reason for non-completion than those with LHL.

In interviews with 18 women with LHL several challenges emerged regarding both the use and comprehensibility of PROMs. Comprehensibility difficulties were particularly related to use of vague terms (e.g. long distance), emotionally charged questions, recall periods (e.g. “during the past week”), and discrimination between response options. Participants indicated difficulties with digital accessibility of PROMs. Moreover, an overall feeling of reluctance toward completing PROMs was mentioned, due to lack of understanding of its purpose and integration in the consultation by the physician, length of the PROM and repetitiveness of questions.

4.1. Integration with prior work and implications

Our study highlights several areas for improving PROM completion rates within LHL populations. Clear communication about the purpose of PROMs and feedback on responses appear essential, as supported by prior research demonstrating improved implementation when patients receive adequate instruction and feedback [25–27]. Another improvement area is addressing digital barriers [27,28]. Many participants required assistance to complete PROMs, echoing Meirte et al. (2020) on the digital divide and need for tailored support for patients with limited access to or familiarity with digital tools [29]. Targeted interventions, such as instructional videos or on-site assistance, may enhance accessibility for LHL populations [30].

In line with Tuinenberg et al. (2024), the only Dutch study to date assessing PROM comprehensibility, our results highlight that among others questionnaire length and interpreting response options hinder comprehension [25]. Additionally, our participants struggled with interpreting recall periods, a challenge not reported by Tuinenberg et al. (2024). Recall periods in PROMs are intended to support population-level metrics, such as quality-adjusted life years, and to enhance the accuracy of the collected data [31]. However, if patients with LHL misinterpret recall periods, these estimates may be biased and unrepresentative. While Cocks et al. (2023) considered variable adherence to recall periods irrelevant to PROM content validity [18], our findings call into question the appropriateness of including them for LHL populations.

Participants with adequate HL more often cited physician benefit as a reason for completing PROMs, whereas those with LHL more often cited personal benefit, possibly reflecting greater trust in physician guidance [32]. It is possible that reluctance toward PROM completion, as mentioned by interview participants, is linked to stress, for example related to the use of unfamiliar terminology. Patients with LHL may initiate the completion of PROMs due to their belief in its perceived benefits (Fig. 2), yet experience stress during completion, whereas adequate-HL individuals might opt out earlier, deeming them too time-consuming for example. This aligns with waiting-room questionnaire data, where 23% of adequate-HL participants abstained from completion due to perceived burden, compared to 11% of LHL participants.

In interviews, reluctance was expressed caused by PROM length and perceived irrelevance to their personal situation. In part informed by this study, the PROM-set used at our department has been revised by the Amsterdam PROM Expertise Center to enhance patient-friendliness by reducing the number of questions and repetitiveness [33]. While this may lower perceived burden, improving inclusivity requires more than shortening questionnaires; it demands fundamental re-evaluation of PROM design. It requires co-developing and validating PROMs with LHL populations. Many validation and reliability studies of PROMs exclude people with LHL and mostly include patients with higher educational attainment [34]. For example, Cocks et al. (2023) stated in their inclusion criteria that ‘*Patients had to be literate and fluent in the local language*’ [15]. Given that comprehensibility directly impacts content validity [25], these type of criteria suggest limitations in the generalizability of findings to LHL-populations. A strategy to potentially lower patient burden is through PROM item libraries, enabling flexibility in measurement of only context-specific items [35].

Even though HL is not directly linked to a specific socio-economic position, social factors can influence HL levels [36]. A recent review by Ryman et al. (2024) identified associations between sociodemographic factors and HL in cancer populations [37]. Similarly, our findings suggest a possible link: women with adequate HL were generally younger and more often employed than those with LHL. No substantial differences were found in perceived financial burden. While not statistically significant, smoking was more prevalent among women with LHL. Studies suggest that the likelihood of completing PROMs may also be influenced by LHL or socioeconomic background [38]. In our study we did not observe a difference in completion rates by HL level.

4.2. Strengths and limitations

This study’s key strength is its comprehensive assessment of challenges and perspectives of patients with LHL by combining cognitive and semi-structured interview methods. Administering the Chew et al. (2008) HL screener with a researcher helped mitigate intimidation and ensured reliable results by confirming patients understood the questions of the waiting room questionnaire properly.

However, several limitations should be noted. Although the Chew et al. (2008) screener is validated to assess HL, the self-reported nature of this tool may introduce measurement and selection bias. Moreover, instruments such as the Chew et al. (2008) screener and NVS-D do not measure the multidimensional construct of HL, which could cause our classification of HL to not fully capture the broader, multidimensional nature of HL. Additionally, we combined the Chew et al. (2008) screener with educational attainment to classify HL, following guidance from knowledge centre Pharos and clinical experience [39]. While this approach may have increased specificity, it likely led to a lower observed prevalence of LHL compared to the general Dutch population, where HL is typically assessed with the HLS-EU-Q16 without considering education. Furthermore, we did not directly observe patients as they completed PROMs; such real-time observation could have provided a more objective assessment of digital barriers and comprehension issues. Another limitation is that Dutch PROM translations may have nuanced differences in the emotional charge of words and terms when compared with other languages, limiting the generalizability of our findings to other language versions. Another limitation is that our study population was a heterogeneous group of patients with gynaecological cancer, both from disease site and interval of time since treatment. This could cause challenges in translating research findings into clinical practice.

5. Conclusion

This study highlights the challenges patients with LHL face with PROMs in gynaecological cancer care. Diversity in interpreting and responding to PROM-items raises concerns about whether responses reflect their intended purpose. Comprehension challenges and digital aspects of accessing PROMs can pose barriers, as well as a lack of understanding of their purpose and manner of integration into daily care. Generally, participants indicated an overall feeling of reluctance toward PROMs. Participants of this study emphasised the importance of clearly conveying the purpose of PROMs and acknowledging responses in subsequent consultations. Collaborative PROM development with and PROM validation by limited HL populations is crucial for the inclusivity and validity of PROMs in daily practice and research.

Reflexivity of authors that were responsible for the analysis of qualitative data

Dachel Seeratan is a female researcher, born and raised in Amsterdam, the Netherlands. At the time of the undertaking of this study Dachel was an MD/PhD-student, in which she combined medical school clerkships with PhD-research. In September 2024, Dachel

graduated medical school and started as a full-time PhD-researcher. Thus, at the time of manuscript preparation Dachel was working full-time. Relevant prior research experience includes undertaking other qualitative interview studies. Dachel's inspiration for undertaking research with limited health literacy and/or disadvantaged populations stems from her personal background as a second-generation migrant and experiences with medical care of family members. During this project, she focused on setting aside her personal experiences and remaining in a neutral position as a researcher. She is however aware that her personal experiences could influence her view on certain interview data.

Anne Jongkind is a female master's degree student in medicine in the Netherlands. This research project marked the beginning of Anne's master's program, starting as a thesis project in September 2023. Prior to this, Anne completed a bachelor's degree in psychology alongside a bachelor's degree in medicine, which aligned closely with the interdisciplinary nature of this study. Her background in psychology provided a unique perspective, particularly in analysing the cognitive interviews generated during the research. Anne's inspiration for pursuing this research stems from her deep interest in addressing limited health literacy and exploring how healthcare systems can be made more inclusive for diverse populations. This interest, coupled with her academic background, allowed her to approach the research with a psychological lens, enriching the study's understanding of cognitive and health-related behaviours.

CRedit authorship contribution statement

D.D. Seeratan: Writing – review & editing, Writing – original draft, Visualization, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **A. Jongkind:** Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **L.R.C.W. van Lonkhuijzen:** Writing – review & editing, Conceptualization. **M.M. van Muilekom:** Writing – review & editing, Conceptualization. **N.P.M. Ezendam:** Writing – review & editing, Methodology. **O.C. Damman:** Writing – review & editing, Supervision, Methodology, Conceptualization. **J.W.M. Aarts:** Writing – review & editing, Supervision, Project administration, Methodology, Formal analysis, Conceptualization.

Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. The medical ethics committee of the Amsterdam University Medical Centre (METC) approved this study on September 20th 2023 (referral number: 2023.0620).

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: D. D. Seeratan reports financial support was provided by Amsterdam University Medical Centres. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ygyno.2026.01.009>.

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