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Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe

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CHAPTER 1

Systematic review of the existing Patient Reported Outcome Measures to assess Health-Related Quality of Life in European cancer patients and survivors

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1. Introduction

Health-related quality of life (HRQoL) can be globally defined as ‘‘how well a person functions in their life and his or her perceived well-being in physical, mental, and social domains of health’’ (1). Functioning refers here to a patient’s ability to carry out some pre-defined activities, and well-being to his/her subjective feelings (1). More specifically, the framework developed by Wilson and Cleary, which is currently the most applied theoretical model of HRQoL (2), conceives HRQoL as a multidimensional construct encompassing five components: symptom status, functional status, biological and psychological variables, general health perceptions and overall quality of life. Over the past decades, there has been increasing recognition that assessing cancer patients’ HRQoL is pivotal to delivering optimal patient-centred healthcare (3,4). HRQoL is now perceived as a meaningful endpoint throughout the cancer continuum (5,6) and can serve as a valuable source of information to guide healthcare policies (e.g., Europe’s Beating Cancer plan,(7)). However, HRQoL is often inaccurately assessed by health care providers (HCPs) and poorly captured by medical procedures or tests, highlighting the need for patient involvement in reporting their outcomes (3,4,8,9). Patient-reported outcomes (PROs) are defined by the Food and Drug Administration as “a measurement based on a report that comes directly from the patient about the status of a patient’s health condition, without amendment or interpretation of the patient’s response by a clinician or anyone else” (10). Patient-reported outcome measures (PROMs) refer to the tools used to measure PROs and are now systematically used for the assessment of HRQoL in cancer care.

To assess the HRQoL of cancer patients, a wide array of PROMs is now available, ranging from generic (e.g., SF-36, EQ-5D-5L) to cancer- (e.g., EORTC QLQ-C30, FACT-G) and tumour-specific tools (e.g., EORTC QLQ-BR23, FACT-B). However, this diversity means that it has become more and more challenging to select the most appropriate PROM to be used. This choice should be made in regard to the target population, the target construct, and importantly, the PROM measurement properties (11). To support this decision and allow for the objective comparison and quality appraisal of PROMs, comprehensive overviews of the psychometric properties of PROMs are needed.

Over the past years, many systematic reviews comparing PROMs for the assessment of HRQoL in cancer patients were published. Most of them focused on PROMs measuring HRQoL in a specific type of cancer (e.g., breast cancer, prostate cancer, etc.) (12–23) or cancer population (e.g., cancer survivors, advanced cancer, palliative patients, etc.) (14,24–26). Half of these reviews focused on PROMs evaluating one specific HRQoL-related construct (e.g., depression, fatigue, pain, etc.) (12,13,27–29) and the majority did not report the psychometric properties of the PROMs under investigation per subscale (13–17,19–22,24,25,27,28,30). For the reviews reporting on the psychometric properties of PROMs, the methods used to assess both the quality of studies and results differed significantly (31). Currently, the highest methodological standards for the conduct of systematic reviews on the psychometric properties of PROMS are provided by the COnsensus-based Standards for the selection of health Measurement INstruments initiative (COSMIN,(32)). Among the reviews published to date, only half relied on the COSMIN methodology and most of them did not apply it fully. For instance, in several reviews the rating of the overall results per PROM was unclear or not performed (12,16,20,27,33) and the risk of bias assessment or the grading of the evidence were not conducted (12,13,24,27,30,33). As such, a comprehensive overview of the psychometric properties of PROMs used for the assessment of HRQoL across the cancer continuum is still missing.

The EUonQOL project aims at developing a new PROM (i.e., EUonQOL toolkit) for HRQoL assessment that will be applied across a wide variety of cancer patients over the European Union and its associated

countries. To inform the development of this PROM, it is necessary to leverage on the current state of the field and to identify, following the highest methodological standards, the best PROMs currently available to assess HRQoL in European cancer patients and survivors. This chapter reports on a systematic review of the evidence supporting the measurement properties of PROMs assessing the multidimensional construct of HRQoL throughout the cancer continuum and provides a set of evidence-based recommendations to the EUonQOL consortium for the development of the toolkit.

2. Methodology

The protocol of this systematic review is based on the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (34) and has been registered in the International Prospective Register of Systematic Reviews database (PROSPERO 2023 - CRD42023418616) prior to data extraction.

The systematic review was conducted according to the COSMIN guidelines for systematic reviews (32) and used the COSMIN taxonomy of measurement properties (Table 1). All steps of the screening process were performed using RAYYAN (35)

Table 1. COSMIN definitions of measurement properties

Measurement property	Definition
Content validity	The degree to which a PROM measures the construct(s) it purports to measure
Structural validity	The degree to which the scores of a PROM are an adequate reflection of the dimensionality of the construct to be measured
Internal consistency	The degree of interrelatedness among the items
Cross-cultural validity	The degree to which the performance of the items on a translated or culturally adapted PROM are an adequate reflection of the performance of the items of the original version of the PROM
Measurement invariance	The proportion of the total variance in the measurements which is due to "true" differences between patients
Reliability	The degree to which the measurement is free from measurement error
Reliability (extended definition)	The extent to which scores for patients who have not changed are the same for repeated measurement under several conditions: e.g., using different sets of items for the same PROM (internal consistency); over time (test-retest); by different persons on the same occasion (inter-rater): or by the same persons (i.e., raters or responders) on different occasions (intra-rater)
Measurement error	The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured
Construct validity	The degree to which the scores of a PROM are consistent with hypotheses (for instance with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups) based on the assumption that the PROM validly measures the construct to be measured
Responsiveness	The ability of a PROM to detect change over time in the construct to be measured

2.1 Literature search

A systematic search was performed in the bibliographic databases MEDLINE (through PubMed) and ELSEVIER (through Scopus) without publication date restriction. The search strategy was based on the PECO acronym (36) in which the population was represented by cancer patients and survivors, the exposure by psychometric properties and the outcome by health-related quality of life. No comparator was used. Both MesH terms and text words were used.

The search was conducted on the 28th of February 2023. Original research articles published in English (including erratum and correction articles) were considered for inclusion. Reference lists of included articles were manually searched by hand to ensure all relevant studies were considered. Additionally, the exclusion filter of Terwee et al. (37) was used. The grey literature was not considered.

The respective search strategies used for PubMed and Scopus are provided in Appendix 1.

2.2 Selection process

The selection process was twofold. First, it was determined whether the PROMs captured by the search should be in- or excluded. Second, all titles and abstracts were screened for eligibility in a blinded standardized matter. If the study seemed relevant or in case of doubt, the full-text article was retrieved and screened. Both the abstract and full-text screening were done by a minimum of two reviewers independently (K.M., M.S., L.L.). Discrepancies were resolved by discussion and/or consultation of a third reviewer (H.V.).

2.2.1 PROM selection

To be included PROMs needed to meet following criteria:

1) PROMs had to be self-administered based on a questionnaire (paper-pencil or electronic). This excluded assessment tools based (fully or partially) on hetero-assessment, interactive voice response systems, talking touch screens, drawings, or nomograms. An interview format was allowed when the study population was not able to complete the PROM independently.
2) PROMs had to assess HRQoL as a multi-domain concept (i.e., based on a multidimensional model of HRQoL) and be applicable across cancer types. This excluded tools designed to assess a specific HRQoL subdomain (e.g., exclusively assessing physical functioning) or cancer site (e.g., assessing HRQoL following breast reconstruction).
3) PROMs had to be validated for use in the target population of European cancer patients or survivors. In case no European validation[1] was found for a PROM identified through the initial search, an additional search was performed in PubMed (Appendix 3). If no evidence of validity among European cancer patients or survivors could be retrieved after the additional search, the PROM and its related articles were excluded.

2.2.2 Study selection

Studies were included when the following criteria were met:

1) Studies had to provide information on the measurement properties of the included PROMs. For this review, the development, content validity, structural validity/unidimensionality, internal consistency, cross-cultural validity, measurement invariance, reliability, measurement error and construct validity were considered. Studies reporting on criterion validity were considered to inform construct validity due to the absence of gold standard for PROMs (32). Studies reporting on criterion validity were considered to inform construct validity due to the absence of gold standard for PROMs (32). Responsiveness was not assessed in this review since the content and the number of hypotheses to assess responsiveness are inexhaustible and arbitrary, and the quality of comparator instruments (in the absence of gold standard) cannot be proven (38).
2) Studies had to provide original research data (including erratum and correction articles) and be published in English. Articles written in other languages or case studies, protocols, conference abstracts, conference reports, commentaries, opinion article and reviews were not considered.
3) Studies had to be performed in adult European cancer patients or survivors (mean age ≥ 21 years and not defined as Adolescents and Young Adults [AYA]). Articles including “mixed samples” (i.e., European cancer patients and non-cancer patients) were only included if separate results were provided for the cancer patients group. Studies involving both European and non-European cancer

[1] European Union and associated countries (for the full list of countries, please see Appendix 2)

patients, were included. Studies only reporting results within a non-European cancer sample, were excluded (except for development and content validity studies). Articles reporting on patients with benign tumours or including less than 15 cancer patients were also excluded.

Detailed information on the selection process was reported in a PRISMA flowchart.

2.3 Data extraction

During the data extraction, it was determined which measurement properties were evaluated for every included study. Data extraction was done by one reviewer and checked by a second reviewer. When available, data were extracted as follows:

1) *Study characteristics* - Authors, title, publication year, design.
2) *Study sample characteristics* - Sample size, age, gender, EU/non-EU, clinical status (general population, non-cancer patients, cancer patients undergoing curative treatment, cancer patients undergoing palliative treatment, cancer survivors), cancer stage and cancer site.
3) *PROM characteristics* - PROM specimen, original development paper, original language in which the PROM was developed, target population for whom the PROM was developed, number of subscales and items, content coverage, recall period, response options, type of scale(s), scoring and estimated duration of assessment. In case of missing data, additional information was retrieved by searching Google and ePROVIDE (https://eprovide.mapi-trust.org) or by contacting PROM developers.
4) *PROM measurement properties* – development and content validity, structural validity/undimensionality, internal consistency, cross-cultural validity and measurement invariance, reliability, measurement error and construct validity. Detailed information on the data extracted for these measurement properties is provided in Appendix 4.

Following data extraction, all PROMs and related studies were then included in the next phase of the review process for quality assessment.

2.4 PROM quality assessment

Quality assessment was performed independently by two reviewers. Discrepancies were solved by consensus. In case of disagreement, a third reviewer was involved to solve the discrepancy. As per COSMIN guidelines (32), quality assessment was conducted sequentially for each PROM in the following order: development/content validity[2], internal structure (i.e., structural validity, internal consistency, and cross-cultural validity/measurement invariance), reliability, measurement error and construct validity (i.e., criterion validity and hypotheses testing). The COSMIN group defines content validity as the most important measurement property and recommends assessing it first and excluding PROMs with high quality evidence of inadequate content validity (32,39). However, studies that would report on the poor content validity of a PROM are unlikely to be published and this requirement is unlikely to be met, which does not allow for differentiating between PROMs based on the quality of content validity. The EUonQoL project, which relies on a co-design approach, places patients and healthcare professionals at the centre of the research process. It is essential that the PROMs selected to serve as a basis for the development of the EUonQOL toolkit are supported by evidence of content validity, i.e., the items constituting these PROMs should be relevant, comprehensive, and comprehensible with respect to HRQoL and the European cancer population. Thus, it was decided not to assess the remaining psychometric properties of

[2] PROM development is not a measurement property, but is taken into account when evaluating content validity as per COSMIN guidelines

PROMs with inadequate content validity of any level of evidence or PROMs for which no evidence of content validity was found. Studies assessing structural validity based on a Multi-Trait MultiMethod approach (40) were considered to inform construct validity as this method is not appropriate for the assessment of structural validity as per COSMIN guidelines.

For all psychometric properties, the assessment was performed at a subscale level (when applicable). Quality assessment was performed for each study and measurement property as follows:

2.4.1 Risk of Bias assessment

The methodological quality of each study was evaluated using the COSMIN Risk of Bias Checklist (41), which provides a set of standards for design requirements and preferred statistical analyses per measurement property. For instance, when assessing content validity, these standards cover whether patients and/or professionals were asked about the relevance, comprehensiveness and comprehensibility of the items, response options, and instructions and how it was performed. These standards provide a framework to assess whether the results based on the methodological quality of a given study are trustworthy. Each standard was rated on a four-point rating scale as 'very good', 'adequate', 'doubtful', or 'inadequate'. Each assessment of a measurement property is considered to be a separate study. For development/content validity, the quality of each standard was first determined by retaining the highest rating across the identified studies before taking the lowest rating of each standard to determine the overall quality of the development and content validity studies. For all other measurement properties, the overall rating of the quality of each study was determined separately by taking the lowest rating of any standard. A few adjustments were made to the ratings of the COSMIN Risk of Bias Checklist, which are all listed in Appendix 5.

2.4.2 Criteria for good measurement properties

These criteria are evidence-based recommendations from COSMIN for which PROMs are assessed as good enough to be used in research or clinical practice (32).

Development and content validity

The overall content validity scoring comprised four steps (39). First, the results of both the PROM development and content validity studies were rated by two reviewers independently (Appendix 6). Each criterion was scored as "sufficient (+), insufficient (−), or indeterminate (?). Reviewers rated the content of the PROM of interest with "sufficient (+) or insufficient (−), using the same criteria. When there was no content validity study available, content validity criteria were rated with insufficient (-). The scoring indeterminate (?) was only used when there was evidence that some aspects of content validity were assessed but authors did not provide enough information to score the criterion appropriately. Second, an overall "sufficient (+), insufficient (−), indeterminate (?) or inconsistent (±) rating was calculated for relevance, comprehensiveness and comprehensibility per study applying the COSMIN guidelines (39) (Appendix 7). Third, an overall rating per PROM was calculated for relevance, comprehensiveness and comprehensibility by jointly considering the results of the PROM development and content validity studies, and the reviewer's ratings. The evidence from the content validity was weighted higher than the evidence from the development study and the reviewer's rating. Appendix 8 provides a detailed overview of this overall rating process. Last, an overall "sufficient (+), insufficient (−) or inconsistent (±) content validity rating was calculated, by aggregating the overall relevance, comprehensiveness and comprehensibility rating. Appendix 9 provides a detailed overview of the overall content validity rating process.

Other psychometric properties

Criteria for good measurement properties were applied for each individual study, resulting in a sufficient (+), insufficient (−), or indeterminate (?) rating. The evidence across studies was summarized and it was decided whether the results per psychometric property were consistent. Consistency was defined as at least 75% of individual studies being rated similarly for a given PROM and measurement property. If the threshold of 75% was not reached for any of the rating options and studies with exclusively "+" or "−" ratings were available in combination with "?" ratings, studies with a "?" were ignored and not included when summarizing the results. In all other cases, the overall rating was scored as inconsistent (±). A detailed overview of the criteria for good measurement properties, incorporating the inconsistency rating, can be found in Table 2. For construct validity, a priori hypotheses were formulated to evaluate the results (Table 3).

Table 2. COSMIN criteria for good measurement properties

Measurement property	Rating	Criteria
Structural validity	+	*CTT* CFA: CFI or TLI or comparable measure >0.95 OR RMSEA <0.06 OR SRMR <0.082 *IRT/Rasch* - No violation of unidimensionality: CFI or TLI or comparable measure >0.95 OR RMSEA <0.06 OR SRMR <0.08 AND - No violation of local independence: residual correlations among the items after controlling for the dominant factor <0.20 OR Q3's < 0.37 AND - No violation of monotonicity: adequate looking graphs OR item scalability >0.30 AND - Adequate model fit: IRT: $\chi 2$ >0.01 Rasch: infit and outfit mean squares ≥ 0.5 and ≤ 1.5 OR Z-standardized values > -2 and <2
	±	Results are inconsistent across studies
	-	Criteria for (+) are not met
	?	*CTT:* Not all information for (+) is reported *IRT/Rasch:* Model fit not reported OR only EFA was performed
Internal consistency	+	At least low evidence for sufficient structural validity AND reliability coefficient(s) ≥ 0.70 for each unidimensional scale or subscale
	±	Results are inconsistent across studies
	-	At least low evidence for sufficient structural validity AND reliability coefficient(s) < 0.70 for each unidimensional scale or subscale
	?	Criteria for "At least low evidence for sufficient structural validity" are not met: • There is only very low evidence for sufficient structural validity (e.g., because there was only 1 study on structural validity with a very low sample size) • There was (any) evidence for insufficient structural validity • There are inconsistent results for structural validity which cannot be explained • There is no information on the structural validity available
Cross-cultural validity / Measurement invariance	+	No important differences found between group factors (such as age, gender, language) in multiple group factor analysis OR no important DIF for group factors (McFadden's R2 < 0.02)
	±	Results are inconsistent across studies
	-	Important differences between group factors OR DIF was found
	?	No multiple group factor analysis OR DIF analysis performed
Reliability	+	Correlation coefficient ≥ 0.70
	±	Results are inconsistent across studies

	-	Correlation coefficient < 0.70
	?	Correlation coefficient not reported
Measurement error	+	*SDC or LoA < MIC* The MIC is defined as the smallest measured change score that patients perceive to be important. If the SDC is smaller than the MIC, it is possible to distinguish a clinically important change from measurement error with a large amount of certainty
	±	Results are inconsistent across studies
	-	*SDC or LoA > MIC* If the SDC is larger than the MIC, there is a considerable chance that the observed change is caused by measurement error
	?	MIC not defined
Construct validity	+	The result is in accordance with the hypothesis
	±	Results are inconsistent across studies
	-	The result is not in accordance with the hypothesis
	?	No hypotheses were formulated a priori

Abbreviations: + = sufficient results; - = insufficient results; ± = inconsistent results; ? = indeterminate results; CFA = Confirmatory Factor Analysis; CFI = Comparative Fit Index; CTT = Classical Test Theory; DIF = Differential Item Functioning; LoA = Limits of Agreement; IRT = Item Response Theory; MIC = Minimal Important Change; MID: Minimal Important Difference; MCID = Minimal Clinical Important Difference; RMSEA = Root Mean Square Error of Approximation; SDC = Smallest Detectable Change; SRMR: Standardized Root Mean Residuals; TLI: Tucker-Lewis Index.

Table 3. A priori hypotheses for construct validity

Type of construct validity (subtype)	Hypothesis
Between-PROM (convergent validity)	Correlations with instruments measuring similar constructs should be ≥ 0.50
Between-PROM (convergent/divergent validity)	Correlations with instruments measuring related, but dissimilar constructs should be ≥ 0.30
Between-PROM (divergent validity)	Correlations with instruments measuring unrelated constructs should be < 0.30
Within-PROM (convergent validity)	Correlations between an item and its own scale (corrected for overlap) should be ≥ 0.40
Within-PROM (divergent validity)	Correlation between an item and its hypothesized subscale (corrected for overlap) is higher than its correlation with the other subscales

2.4.3 Quality of evidence

The quality of the evidence was graded per measurement property using a modified Grading of Recommendations Assessment, Development and Evaluation approach (GRADE) (32,42) resulting in 4 quality levels: 'high', 'moderate', 'low', or 'very low' quality. The quality of the evidence was graded per measurement property using a modified Grading of Recommendations Assessment, Development and Evaluation approach (GRADE) (32,42) resulting in 4 quality levels: 'high', 'moderate', 'low', or 'very low' quality. Starting with high-quality level, quality of evidence was downgraded if applicable according to the following factors: risk of bias (methodological quality of the studies), inconsistency (of results across studies), imprecision[3] (total sample size of the studies) and indirectness (evidence comes from a different target population). When the original COSMIN modified GRADE approach did not provide clear guidance on the criteria to be used for the risk assessment, the GRADE approach was further adapted. The adapted

[3] Imprecision is not taken into account when grading the quality of evidence for content validity

GRADE approach used for this project is reported in Tables 4 and 5 for development/content validity and the remaining psychometric properties respectively. As per COSMIN guidelines (32) the quality of evidence for internal consistency started at the level of structural validity.As per COSMIN guidelines (32) the quality of evidence for internal consistency started at the level of structural validity.

Table 4. COSMIN adapted GRADE approach for development/content validity

	QUALITY OF EVIDENCE: starting point is always HIGH HIGH MODERATE LOW VERY LOW	
Risk of bias	- 1: Serious	Content validity study is of doubtful quality. The content validity rating of content validity study is insufficient (-) OR indeterminate (?) OR inconsistent (±)
	- 2: Very serious	No content validity study OR content validity study of insufficient quality (-) **AND** Development study is of doubtful quality. The content validity rating of the development study is indeterminate (?) OR inconsistent (±)
	- 3: Very serious	No content validity study OR content validity study of insufficient quality (-) **AND** No development study or development study is of inadequate quality. The content validity rating of the development study is insufficient (-)
Inconsistency	- 1: Serious	The combination of the scores for development study, content validity study and reviewer's rating is rated inconsistent (±) **(see scoring table below)**
Indirectness	- 1: Serious	Content validity study was performed in a cancer population but not representative of the population of interest (e.g. head & neck cancer patients versus cancer patients, palliative questionnaire assessed in non-palliative cancer patients)
	- 2: Very serious	Content validity study was performed in a non-cancer population.

Table 5 COSMIN adapted GRADE approach for other psychometric properties

		QUALITY OF EVIDENCE: starting point is always HIGH HIGH MODERATE LOW VERY LOW
Risk of bias (Consider the ratings of the individual studies in STEP 1)	-1	The are multiple studies of doubtful (D) quality OR there is only 1 study of adequate (A) quality available
	-2	There are multiple studies of inadequate (I) quality OR there is only 1 study of doubtful quality (D) available
	-3	There is only 1 study of inadequate (I) quality available
Inconsistency	-1	Overall rating across studies is scored with (±)
Imprecision	-1	Total sample size of the pooled or summarized studies **<100**
	-2	Total sample size of the pooled or summarized studies **<50**
Indirectness*	-1	Psychometric properties were assessed in a cancer population but not representative of the target population (e.g. head & neck cancer patients versus cancer patients, palliative questionnaire assessed in non-palliative cancer patients)
* To assess the indirectness one should look at the characteristics of the pooled population across studies.		

2.5 Recommendations

PROMs with sufficient content validity (i.e., rated "±" or higher) and at least low-quality evidence (i.e., GRADE) (32) for sufficient structural validity and internal consistency were recommended (32). A PROM fulfilling these criteria could not be recommended when there was high-quality evidence for any insufficient measurement property. As with the quality assessment, the formulation of recommendations was made at a subscale level.

3. Results

3.1 Study selection

A total of 10,488 unique references were identified across Scopus and Medline electronic databases. After screening the abstracts and titles against the predefined in- and exclusion criteria, 1,703 references were eligible for full textual review. From these 1,703 references, an additional 1,568 studies were excluded. The most common reason for exclusion was providing results on psychometric properties within a non-EU or non-cancer population. An additional 31 references were added manually by backward and forward screening. Ultimately, 166 studies were included for the final analysis. A detailed overview of the study selection process and exclusion reasons can be found in Figure 1.

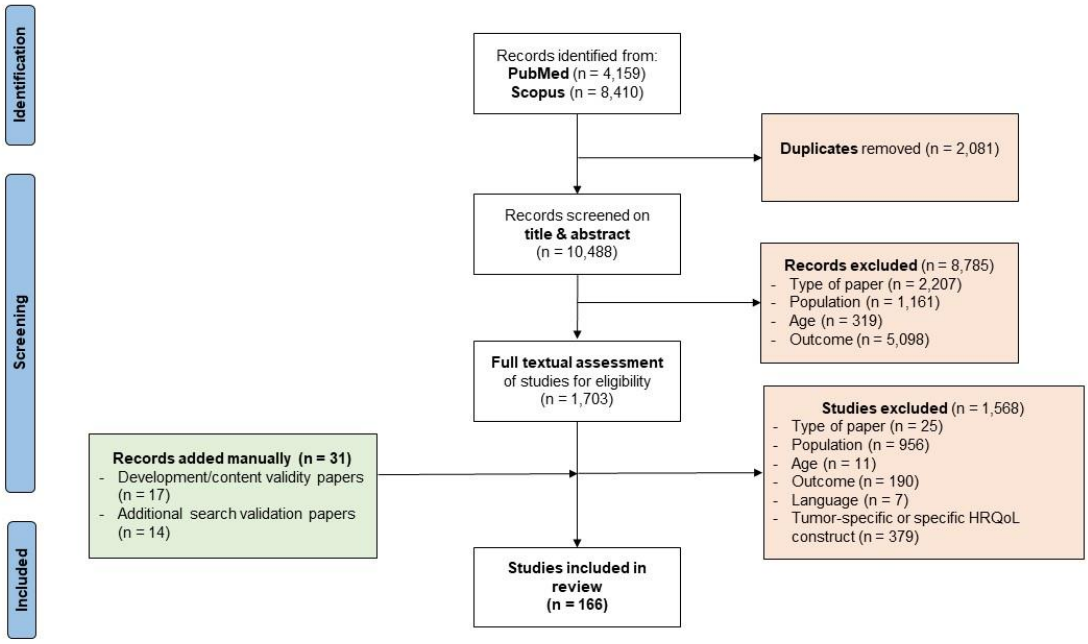

Figure 1: Flowchart of the study selection process

3.2 PROMs characteristics

Table 6 presents the PROMs (n = 37) that were included in the final analysis.

The vast majority of them (n = 35; 95.0%) were originally developed in English. The target population used for PROM development was predominantly active patients (n = 21; 56.8%), followed by palliative patients (n = 12; 32.4%), survivors (n = 6; 16.2%), and the general population (n = 6; 16.2%).

PROMs varied in length from 6 to 262 items. Items were worded to obtain information on either the frequency of the symptoms (frequency), the intensity of the symptoms or the functioning level (intensity), or how the patients' experience of cancer would interfere with their daily lives (interference). Most PROMs used a combination of items that assessed intensity and interference (n = 13; 35.1%) or a combination of

all three wording options (n = 11; 29.7%). For the remaining PROMs, item wording focused exclusively on intensity (9; 24.3%), combination of frequency and intensity (n = 2; 5.4%), exclusively on frequency (n = 1; 2.7%), and exclusively on interference (n = 1; 2.7%).

The recall period varied across PROMs, with 6 using a recall period of “week” (16.2%), 6 using “the last month” (16.2%), 5 worded to assess HRQoL “now” (13.5%), 3 using “the last two weeks” (8.1%), 2 using “today” (5.4%) and one using “the last day” (n = 1; 2.7%). The remaining PROMs (n = 13; 35.1%) used multiple recall periods and for one PROM the recall period was not specified (2.7%).

Response options also varied across PROMs, with most PROMS using different combinations of response options, including Likert scales, Visual Analog Scales (VAS), dichotomous scales, and open-ended questions (n = 17; 45.9%). The remaining PROMs used exclusively a Likert scale (n = 15; 40.5%) or numeric rating scales (n = 5; 13.5%).

The scores of 14 PROMs (37.8%) could be computed at multiple levels (item, domain, and/or global), for 13 PROMs (35.1%) the scores were exclusively computed at a domain-level, and for 10 (27.0%) exclusively at a questionnaire-level.

Table 6: General characteristics of included PROMs (n = 37)

PROM	Development paper	Original language	Population	Subscales (single item)	Items	Recall period	Response options	Items and response wording	Scoring (range)
Assessment of Quality of Life at the End of Life (AQEL)	Axelsson et al., 1999 (43)	English Swedish	Palliative	Existential Global Medical care Physical Psychological Social (Events) (Hospital stay)	22	The last week	10-point rating scale	Frequency Intensity Interference	Global score
Needs Based Biopsychosocial Distress Instrument for Cancer Patients (CANDI)	Lowery et al., 2012 (44)	English	Patients	Anxiety Depression Emotion Healthcare Physical Practical Social	39	The last two weeks	5-point Likert scale	Intensity	Global score Domain scores
Cancer Rehabilitation Evaluation System (CARES)	Schag et al. 1990 (45)	English	Patients	Marital Medical interaction Physical Psychosocial Sexual	139	The last month	5-point Likert scale Dichotomous Open-ended	Frequency Intensity Interference	Global score Domain scores
Cancer Rehabilitation Evaluation System - Short Form (CARES-SF)	Schag et al., 1991 (46)	English	Patients	Marital Medical interaction Physical Psychosocial Sexual	59	The last month	5-point Likert scale Dichotomous Open-ended	Frequency Intensity Interference	Global score Domain scores
Cancer Survivors' Unmet Needs Measure (CaSUN)	Hodginkson et al., 2007 (47)	English	Survivors	Comprehensive cancer care Existential survivorship Information Lifestyle Quality of life Relationships Return to work	46	The last month	3-point Likert scale 4-point Likert scale Dichotomous	Intensity	Global score (0-35)

Chronic Cancer Experiences Questionnaire (CCEQ)	Harley et al., 2019 (48)	English	Palliative Patients	Assessing support Clinical trials Co-ordination of care Financial advice Information and questions Key worker Limitations Making treatment decisions Managing appointments Sharing feelings with others Sustaining normality Symptom experiences Symptom non-responding Worries and anxieties	75	Now	5-point Likert scale	Frequency Intensity Interference	Global score (0-100) Domain scores
The European Organization of Research and Treatment of Cancer - Computerized Adaptive Testing (EORTC CAT)	Petersen et al., 2010 (49)	English	Patients	Appetite loss Cognitive Constipation Diarrhea Dyspnea Emotional Fatigue Financial impact Global health status and quality of life Insomnia Nausea and vomiting Pain Physical Role Social	262	The last week Not specified	4-point Likert scale 7-point rating scale	Intensity Interference	Global score Domain scores (t-score metric centered on 50)
The European Organization for Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30)	Aaronson et al., 1993 (50)	English	Patients	Appetite loss Cognitive Constipation Diarrhea Dyspnea Emotional Fatigue Financial impact Global health status and quality of life Insomnia	30	The last week Not specified	4-point Likert scale 7-point rating scale	Intensity Interference	Global score Domain scores (0-100)

				Nausea and vomiting Pain Physical Role Social					
EORTC Quality of Life Questionnaire - Elderly Cancer Patients Module (EORTC QLQ-ELD14)	Johnson et al., 2010 (51)	English	Patients	Burden of illness Maintaining purpose Mobility Worries about others Worries about future (Family support) (Joint stiffness)	14	The last week	4-point Likert scale	Intensity Interference	Global score Item scores
EORTC Quality of Life Questionnaire - Palliative Cancer Care (EORTC QLQ-C15-PAL)	Groenvold et al., 2006 (52)	English	Palliative	Appetite loss Constipation Dyspnea Emotional functioning Fatigue Insomnia Nausea and vomiting Pain Physical functioning (Quality of life)	15	The last week Not specified	4-point Likert scale 7-point rating scale	Intensity Interference	Domain scores Item scores
Edmonton Symptom Assessment System Revised (ESAS-r)	Bruera et al., 1991 (53)	English	Palliative	Anxiety Depression Drowsiness Lack of appetite Nausea Other problems Pain Shortness of breath Tiredness Well-being	10	Now	11-point rating scale	Intensity	Global score (0-100)
EuroQoL 5-Dimension 3-Level (EQ-5D-3L)	EuroQol Group, 1990 (54)	English Dutch Finnish Norwegian Swedish	General Patients (non-cancer)	Anxiety Mobility Pain Self-care Usual activities	6	Today	3-point Likert scale VAS	Intensity Interference	Domain scores (0-1) (0-100)
EuroQoL 5-Dimension 5-Level	Herdman et al., 2011 (55)	English Dutch	General Patients	Anxiety Mobility	6	Today	5-point Likert scale VAS	Intensity Interference	Domain scores (0-1)

(EQ-5D-5L)		Finnish Norwegian Swedish	(non-cancer)	Pain Self-care Usual activities					(0-100)
Functional Assessment of Cancer Therapy – General (FACT-G 2.0)	Cella et al., 1993 (56)	English	Patients	Physical Social Emotional Functional Relationship with doctor	33	The last week	5-point Likert scale	Intensity Interference	Global score Domain scores
Functional Assessment of Cancer Therapy – General (FACT-G 3.0)	Cella et al., 1993 (56)	English	Patients	Emotional Functional Physical Relationship with doctor Social	NA	The last week	5-point Likert scale	Intensity Interference	Global score Domain scores
Functional Assessment of Chronic Illness Therapy - Palliative Care 14-item version (FACIT-PAL14)	Zeng et al., 2013 (57)	English	Palliative	Emotional Palliative care Physical Social	14	The last week	5-point Likert scale	Intensity	Global score (0-56)
Functional Assessment of Chronic Illness Therapy - Palliative Care 46-item version (FACIT-PAL46)	Greisinger et al., 1997 (58)	English	Palliative	Additional concerns Emotional Functional Physical Social	46	The last week	5-point Likert scale	Intensity Interference	Global score (0-184)
Functional Living Index: Cancer (FLIC)	Schipper et al., 1983 (59)	English	Patients	Current well-being Gastrointestinal symptoms Physical Psychological Social	22	Today The last two weeks The last month	7-point Likert scale	Frequency Intensity Interference	Global score (18-126)
Impact of Cancer (IOC)	Crespi et al., 2008 (60)	English	Survivors	Altruism and empathy Appearance concerns Body change concerns Employment concerns Health awareness Life interferences Meaning of cancer Positive self-evaluation Relationships concerns - not partnered Relationships concerns – partnered Worry	50	Now	5-point Likert scale	Intensity	Domain scores

Integrated Palliative care Outcome Scale (IPOS)	Schildmann et al., 2016 (61)	English	Palliative	Anxiety or low mood Family anxieties Information needs Overall feeling of being at peace Practical concerns Symptoms	10	The last three days The last week*	4-point rating scale Open ended	Frequency Intensity Interference	Global score (0-40)
LAYA Survivorship-Related Quality of Life Measure (LAYA-SRQL)	Park et al., 2014 (62)	English	Survivors	Cognition or memory Coping Dependence Education or career Existential or spirituality Fertility Health care Intimacy or sexuality Relationship Vitality	30	Now	7-point rating scale	Interference	Domain scores
M. D. Anderson Symptom Inventory (MDASI)	Cleeland et al., 2000 (63)	English	Patients	Symptoms interference Symptoms severity	19	The last day	11-point rating scale	Intensity Interference	Domain score (0-10) Item scores
Palliative Care Outcome Scale (POS 1.0)	Hearn et al., 1999 (64)	English	Palliative	Emotional concerns Physical functioning Practical concerns Psychological functioning Psychosocial needs Spiritual considerations	12	The last three days The last day The last week The last two weeks*	3-point Likert scale 4-point Likert scale 5-point Likert scale Open-ended	Frequency Intensity	Global score (0-42)
Palliative Care Outcome Scale (POS 2.0)	Hearn et al., 1999 (64)	English	Palliative	Emotional concerns Physical functioning Practical concerns Psychological functioning Psychosocial needs Spiritual considerations	12	The last three days The last day The last week The last two weeks*	3-point Likert scale 4-point Likert scale 5-point Likert scale Open-ended	Frequency Intensity	Global score (0-42)
Assessing Quality of Life in Adult Cancer Survivors (QLACS)	Avis et al., 2005 (65)	English	Survivors	Appearance concerns Cancer benefits Cognitive problems Family distress Fatigue Financial problems Negative feelings Pain	47	The last month	7-point Likert scale	Frequency	Domain scores

				Positive feelings Recurrence distress Sexual problems Social avoidance					
Ferrans and Power's Quality of Life Index (QLI)	Ferrans et al., 1990 (66)	English	Patients	Family Health and functioning Psychological Social and economic	66	Not specified	6-point Likert scale	Intensity	Global score (0-30)
Quality of Life-Cancer Survivors (QOL-CS)	Ferrell et al., 1995 (67)	English	Survivors	Physical Psychological Social Spiritual	41	Now	11-point rating scale	Intensity Interference	Domain scores
Quality of Life at the End-of-Life Measure (QUAL)	Steinhauser et al., 2002 (68)	English	Palliative	Feeling of life completion Preparation for end of life Relationship with healthcare provider Symptom severity or impact	26	The last week The last month Not specified	5-point Likert scale Open ended	Frequency Intensity Interference	Domain scores
Rotterdam Symptom Checklist (RSCL)	Watson et al., 1992 (69)	Dutch	Patients	Activity level Overall valuation of life Physical Psychological	39	The last week	4-point Likert scale 7-point Likert scale	Intensity Interference	Global score (0-100) Domain scores
Supportive Care Needs Survey (SCNS-SF34)	Boyes et al., 2008 (70)	English	Patients	Health system and information Patient care and support Physical and daily living Psychological Sexuality	34	The last month	5-point Likert scale	Intensity	Domain scores
Short Form 20 Items Health Survey (SF-20)	Stewart et al., 1988 (71)	English	General Patients (non-cancer)	Health Perceptions Mental Health Pain Physical Role Social	20	The last month Not specified	3-point Likert scale 5-point Likert scale 6-point Likert scale Dichotomous	Frequency Intensity Interference	Domain scores (0-100)
Short Form 36 Items Health Survey (SF-36)	Ware et al., 1992 (72)	English	General Patients (non-cancer)	Bodily pain General health Mental Health Physical Role-Emotional Role-Physical Social Vitality	36	The last week The last month*	3-point Likert scale 5-point Likert scale 6-point Likert scale Dichotomous	Frequency Intensity Interference	Domain scores (0-100)

				(Reported Health Transition)					
Sheffield Profile for Assessment and Referral for Care (SPARC)	Ahmed et al., 2009 (73)	English	Palliative	Communication and information Family and social Independence and activity Personal Physical Psychological Religious and spiritual Treatment	45	The last month Not specified	4-point Likert scale 10-point rating scale Dichotomous Open-ended	Intensity	Domain scores
Short-Form Survivor Unmet Needs Survey (SF-SUNS)	Campbell et al., 2014 (74)	English	Survivors	Access and continuity of care Financial concerns Information Relationships and emotional health	30	The last month	5-point Likert scale	Intensity	Domain scores
World Health Organization Quality of Life-BREF Questionnaire (WHOQOL- BREF)	WHOQOL Group, 1998 (75)	English French Spanish Croatian Dutch Hebrew Japanese Russian Thai	General Patients (non-cancer)	Environment Physical Psychological Relationships Social (General health) (Quality of life)	26	The last two weeks	5-point Likert scale	Frequency Intensity Interference	Global score Domain scores
World Health Organization Quality of Life Questionnaire (WHOQOL-100)	WHOQOL Group, 1994 (76)	English French Spanish Croatian Dutch Hebrew Japanese Russian Thai	General Patients (non-cancer)	Dependence on medication or treatments Environment Level of independence Physical Psychological Relationships Social Spirituality or religion or personal beliefs Working capacity (Quality of life)	100	The last two weeks	5-point Likert scale	Frequency Intensity Interference	Global score Domain scores (0-20)
Three-Levels-of-Needs Questionnaire (3LNQ)	Johnsen et al., 2011 (77)	Danish	Palliative Patients	Felt needs Problem burden Problem intensity	35	Now The last week Not specified	3-point Likert scale 4-point Likert scale 7-point Likert scale Dichotomous Open-ended	Intensity Interference	Domain scores

Abbreviations: NA = no information available; VAS = visual analog scale; * PROM has multiple versions with different recall periods

3.3 Content coverage

The HRQoL domains covered by the identified PROMs are presented below. A subdivision was made between physical, mental, social, and global health domains based on the Wilson & Cleary framework (1).

3.3.1 Physical health

Pain (n = 27; 73.0%) was the most commonly covered domain, followed by energy change (n = 26; 70.2%), instrumental activity (n = 18; 48.6%), nausea and vomiting (n = 18; 48.6%), daily living (n = 18; 48.6%), and insomnia (n = 17; 46.0%). Loss of hair, sensory neuropathy, shivering, skin problems, stinging or sore eyes, swelling, and body strength were the least commonly covered, as they all appeared in only one PROM (2.7%). The overview of the physical health domains' coverage is provided in Tables 7a and 7b.

3.3.2 Mental health

Symptoms of depression and general sadness (n = 25; 67.6%) were the most commonly covered domains, followed by symptoms of anxiety and worry (n = 21; 56.8%). Participants' desire to have children was only covered by one PROM (2.7%). The overview of the mental health domains' coverage is provided in Tables 8a and 8b.

3.3.3 Social health

A detailed overview of social health domains is displayed in Table 9. PROMs most often assessed social support (n = 22; 59.5%), general financial issues (n = 17; 45.9%), patients' ability to work (n = 15; 40.5%), and worry about others (n = 12; 32.4%). Social limitations was the least evaluated domain, covered in only 3 PROMs (8.1%). The overview of the social health domains' coverage is provided in Table 9.

3.3.4 Global health

Table 10 presents global health domains addressed in PROMs, including general QoL, individuals' perception of their health, their view of and approach to health care, and their interaction with medical staff. The domain of received care was the most frequently assessed across PROMs, as it was mentioned in 12 tools (32.4%). The least explored domains were patients' honesty and dedication to the treatment (n = 3; 8.1%), satisfaction with medical devices (n = 2; 5.4%), and fear of healthcare (n = 1; 2.7%).

Table 7a: Overview of the physical health domains covered by the PROMs (n = 37)

PROM	Overall		Activity				Sexual			Body	
	Symptom interference and burden	Treatment side effects	Mobility	Instrumental	Daily living	Physical exercise	Issues	Pleasure	Fertility	Image	Strength
AQEL			X	X	X						X
CANDI		X		X			X		X		
CARES		X	X	X	X	X	X		X	X	
CARES-SF		X		X	X	X	X			X	
CaSUN		X					X		X	X	
CCEQ		X							X		
EORTC CAT	X		X	X	X	X					
EORTC QLQ-C30	X		X	X	X	X					
EORTC QLQ-ELD14	X			X	X						X
EORTC QLQ-C15-PAL	X										
ESAS-r											
EQ-5D-3L			X	X	X						
EQ-5D-5L			X	X	X						
FACT-G 2.0		X	X					X			
FACT-G 3.0		X	X					X			
FACIT-PAL14											
FACIT-PAL46		X	X				X				
FLIC	X			X	X						
IOC										X	
IPOS	X		X								
LAYA-SRQL						X		X	X		
MDASI	X			X	X	X					
POS 1.0	X										
POS 2.0	X										
QLACS	X						X			X	
QLI								X		X	
QOL-CS											
QUAL	X										
RSCL			X	X	X	X	X				

SCNS-SF34				X	X		X				
SF-20	X			X	X	X					
SF-36	X			X	X	X					
SPARC		X		X	X		X			X	
SUNS-SF										X	
WHOQoL-BREF					X	X		X		X	
WHOQoL-100	X			X	X		X	X		X	
3LNQ	X			X	X		X	X			

Table 7b: Overview of the physical health domains covered by the PROMs (n = 37) (follow-up)

PROM	Symptoms[4]														
	Nausea and vomiting	Energy change	Insomnia	Diarrhea	Constipation	Pain	Dyspnea	Appetite loss and taste changes	Weight change	Dry or sore mouth	Swallowing issues	Cough	Bladder issues	Headache	Aching muscles and joint stiffness
AQEL		X	X			X							X		
CANDI	X	X	X		X	X			X						
CARES	X	X	X	X		X		X			X		X		
CARES-SF		X	X	X		X		X	X				X		
CaSUN									X						
CCEQ	X	X	X	X	X	X	X	X		X					
EORTC CAT	X	X	X	X	X	X	X	X							
EORTC QLQ-C30	X	X	X	X	X	X	X	X							
EORTC QLQ-ELD14															X
EORTC QLQ-C15-PAL	X	X	X		X	X	X	X							
ESAS-r	X	X				X	X	X							
EQ-5D-3L															
EQ-5D-5L															
FACT-G (V2)	X	X	X			X									

[4] Loss of hair, sensory neuropathy, shivering, skin problems, stinging or sore eyes, swelling, and tingling hands or feet are symptoms covered by only one PROM

FACT-G (V3)	X	X	X			X									
FACIT-PAL14	X	X	X		X	X	X								
FACIT-PAL46	X	X	X		X	X	X		X	X					
FLIC															
IOC															
IPOS	X	X			X	X	X	X		X					
LAYA-SRQL		X													
MDASI	X	X	X			X	X	X		X					
POS (V1)	X				X	X						X			
POS (V2)	X				X	X						X			
QLACS		X				X									
QLI		X				X									
QOL-CS															
QUAL															
RSCL	X	X	X	X	X	X	X	X		X				X	X
SCNS-SF34		X				X									
SF-20						X									
SF-36		X				X									
SPARC	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
SUNS-SF		X													
WHOQoL-BREF		X	X			X									
WHOQoL-100		X	X			X									
3LNQ	X	X				X	X	X							

Table 8a: Overview of the mental health domains covered by the PROMs (n = 37)

PROM	Psychopathological states			Worry			Cognitive abilities		Other			
	Depression and sadness	Substance abuse and dependence	Anxiety and general worry	Future worry	Treatment worry	Illness worries	Memory	Concentration	Distress	Agitation and restlessness	Loneliness	Other unpleasant feelings
AQEL	X		X				X	X				
CANDI	X	X	X	X	X					X		
CARES	X		X		X	X	X	X		X		X
CARES-SF			X		X			X				
CaSUN									X			
CCEQ			X	X	X	X	X	X	X			
EORTC CAT	X		X				X	X		X		
EORTC QLQ-C30	X		X				X	X		X		
EORTC QLQ-ELD14				X		X						
EORTC QLQ-C15-PAL	X											
ESAS-r	X		X									
EQ-5D-3L	X		X									
EQ-5D-5L	X		X									
FACT-G (V2)	X		X									
FACT-G (V3)	X		X			X						
FACIT-PAL14	X					X						
FACIT-PAL46	X		X			X						
FLIC	X					X						X
IOC			X	X		X				X		
IPOS	X				X							
LAYA-SRQL							X	X				
MDASI	X						X					
POS v1					X							
POS V2	X				X							
QLACS			X			X	X					
QLI			X									
QOL-CS												
QUAL						X						

RSCL	X		X	X				X		X		
SCNS-SF34	X		X	X		X						
SF-20	X									X		
SF-36	X									X		
SPARC	X		X		X		X			X	X	X
SUNS-SF	X				X	X	X		X		X	
WHOQoL-BREF								X				
WHOQoL-100	X	X	X	X			X	X				
3LNQ	X		X								X	

Table 8b: Overview of the mental health domains covered by the PROMs (n = 37) (follow-up)

PROM	Positive affect	Positive outlook	Being at peace and spirituality	Self-efficiency and confidence	Feeling like In control	Feeling safe	Relaxing and enjoying things	Learning	Maintaining purpose, hopefulness, or motivation	Altruism and empathy	Coping	Planning	End-of-life	Desire to have children
AQEL									X					
CANDI		X	X	X	X						X			
CARES														
CARES-SF														
CaSUN			X		X				X		X			
CCEQ				X							X	X		
EORTC CAT														
EORTC QLQ-C30														
EORTC QLQ-ELD14		X							X				X	
EORTC QLQ-C15-PAL														
ESAS-r														
EQ-5D-3L														
EQ-5D-5L														
FACT-G (V2)							X				X			
FACT-G (V3)							X				X			
FACIT-PAL14							X		X					

FACIT-PAL46	X		X		X		X		X		X			
FLIC											X			
IOC	X	X	X		X					X	X			
IPOS			X											
LAYA-SRQL			X		X		X	X		X	X			X
MDASI							X							
POS v1				X										
POS V2				X										
QLACS	X	X									X			
QLI	X		X	X	X				X			X		
QOL-CS														
QUAL		X			X		X		X				X	
RSCL														
SCNS-SF34					X						X			
SF-20	X		X											
SF-36	X		X	X										
SPARC			X		X				X					
SUNS-SF		X									X			
WHOQoL-BREF		X		X		X	X		X					
WHOQoL-100	X			X		X	X	X	X					
3LNQ														

Table 9: Overview of the social health domains covered by the PROMs (n = 37)

PROM	Social			Social perceptions			Financial issues			Other domains	
	Isolation	Support	Limitations	Burden to others	Worry about others	Dependency on others	Ability to work	Insurance	General	Partner relationship	Leisure activities
AQEL		X									
CANDI	X	X			X	X		X	X		
CARES		X			X		X	X	X	X	X
CARES-SF		X			X		X	X	X	X	
CaSUN		X				X	X	X	X	X	
CCEQ	X			X	X	X	X		X		X
EORTC CAT			X	X			X		X		X
EORTC QLQ-C30			X	X			X		X		X
EORTC QLQ-ELD14		X			X						
EORTC QLQ-C15-PAL											
ESAS-r											
EQ-5D-3L											
EQ-5D-5L											
FACT-G 2.0	X	X		X			X			X	X
FACT-G 3.0	X	X		X			X			X	X
FACIT-PAL14		X		X	X						
FACIT-PAL46		X		X		X	X			X	
FLIC											X
IOC	X	X			X		X	X	X	X	
IPOS		X							X		
LAYA-SRQL		X	X			X					X
MDASI		X					X				
POS 1.0		X							X		
POS 2.0		X							X		
QLACS	X				X			X	X		
QLI		X			X	X	X		X	X	X
QOL-CS											
QUAL		X		X	X				X		
RSCL						X					

SCNS-SF34					X						
SF-20	X										
SF-36	X						X				
SPARC		X			X	X					
SUNS-SF		X						X	X		
WHOQoL-BREF		X					X		X		X
WHOQoL-100	X	X					X		X		X
3LNQ	X			X							

Table 10: Overview of the global health domains covered by the PROMs (n = 37)

PROM	Overall		Healthcare					Approach to healthcare			Medical interaction			
	QoL	Health	Hospital stay and appointments	Received care	Medical devices	Medical transport	Other	Fear	Involvement	Honesty and dedication	Accessibility and involvement	Interaction	Available information	General
AQEL	X		X	X							X			
CANDI				X				X			X	X		X
CARES					X	X				X		X		X
CARES-SF					X					X		X		X
CaSUN							X		X				X	X
CCEQ			X	X		X			X	X	X	X	X	
EORTC CAT	X	X												
EORTC QLQ-C30	X	X												
EORTC QLQ-ELD14														
EORTC QLQ-C15-PAL														
ESAS-r	X													
EQ-5D-3L		X												
EQ-5D-5L		X												
FACT-G 2.0	X	X										X		
FACT-G 3.0	X	X										X		
FACIT-PAL14	X													
FACIT-PAL46	X	X												
FLIC														
IOC		X		X										
IPOS													X	
LAYA-SRQL				X			X		X					
MDASI														
POS 1.0			X	X									X	
POS 2.0			X	X									X	
QLACS														
QLI														
QOL-CS														
QUAL									X			X		X
RSCL														

SCNS-SF34				X							X	X	X	
SF-20														
SF-36														
SPARC						X							X	
SUNS-SF			X	X							X	X	X	
WHOQoL-BREF	X	X		X		X	X						X	
WHOQoL-100	X	X		X		X	X						X	
3LNQ				X			X				X			

Abbreviations: QoL = Quality of life

3.4 Study characteristics

Out of the 166 included studies, 56 provided information on PROM development (33.7%), 58 on content validity (34.9%) and 104 on the remaining measurement properties (62.7%). The study populations included cancer patients in palliative care (n = 42; 25.3%), cancer patients undergoing active treatment (n = 102; 61.4%), and cancer survivors (n = 33; 19.9%). The demographic and clinical characteristics of the study samples are presented in Appendix 10.

3.5 Development and content validity

3.5.1 Quality of the PROM development studies

Table 11 provides a detailed overview of all ratings of the PROM development. The majority of PROMs (n = 28; 75.7%) scored very good on all general design requirements. Twenty-six PROMs (70.3%) were developed with input from patients. However, the concept elicitation of most PROMs (n = 24; 64.9%) was scored as doubtful since it was not clear whether interviewers were experienced or trained, or whether 2 researchers were involved in the coding. A total of 23 PROMs (62.2%) were pilot tested. Nevertheless, all these PROMs scored doubtful or inadequate due to the lack of a clear description of the methodology applied to assess the comprehensibility or comprehensiveness (i.e., use of skilled trainers, appropriate interview guide, appropriate approach to analyze the data, involvement of at least 2 researchers) or not having tested the final set of items. The total PROM development was rated as inadequate for 28 out of 37 PROMs (75.7%) and doubtful for 9 PROMs (24.3%). None of the included PROMs received a very good or adequate rating for the PROM development.

3.5.2 Quality and results of the content validity studies

Details on the rating of content validity studies are provided in Table 11. For 30 PROMs (81.1%) at least one aspect of content validity was assessed, 29 (78.4%) involving patients and 20 (54.1%) involving professionals. However, the majority (n = 27; 73.0%) of those studies were of doubtful quality because they did not provide a clear description of the methodology applied to assess relevance, comprehensibility or comprehensiveness (use of skilled trainers, appropriate interview guide, appropriate approach to analyze the data, recording of interviews and verbatim transcription). However, the majority (n = 27; 73.0%) of those studies were of doubtful quality because they did not provide a clear description of the methodology applied to assess relevance, comprehensibility or comprehensiveness (i.e., use of skilled trainers, appropriate interview guide, appropriate approach to analyze the data, recording of interviews and verbatim transcription). On a patient-level, the EORTC QLQ-C30 was the only PROM that scored very good on relevance, comprehensibility and comprehensiveness. On a professional-level, the EORTC CAT was the only included PROM with a very good rating on relevance and comprehensiveness.

3.5.3 Evidence synthesis

Summarizing all evidence per PROM, only 10 (27.0%) PROMs were rated as having sufficient overall content validity with high quality evidence. For the EORTC CAT, EORTC QLQ-ELD14, IPOS, SPARC and SUNS-SF, sufficient relevance, comprehensiveness, and comprehensibility were demonstrated. The CaSUN, CCEQ and EORTC QLQ-C30, on the other hand, demonstrated inconsistent results for relevance, while sufficient results were found for both the comprehensiveness and comprehensibility. Finally, the POS 1.0 and 2.0 were rated with sufficient results for relevance and comprehensibility, but insufficient results for comprehensiveness. A detailed overview of the evidence synthesis of the quality of the PROMs can be found in Table 12.

Nearly half of the PROMs (n = 17; 45.9%) obtained an inconsistent overall content validity rating with low to very low quality of evidence. For relevance, the inconsistency was often caused by the lack of a justification for the response options or recall period in the development papers, nor were patients or professionals explicitly asked about their appropriateness in the content validity papers. For comprehensibility, most of the development and content validity papers did not specifically ask the patients about the comprehensibility of the applied recall period, leading to inconsistent results.

For 10 PROMs (27.0%) insufficient results were obtained for the overall content validity rating with low to very low level of evidence. For most of these PROMs, content validity was not assessed. Since content validity is essential as it should be clear that the items of the PROM are relevant, comprehensive, and comprehensible with respect to the construct of interest and target population (32), these 10 PROMs (27.0%) were not considered further for the rating of the other psychometric properties.

Table 11: Quality of development and content validity studies of all included PROMs (n = 37)

PROM	DEVELOPMENT												CONTENT VALIDITY				
	PROM design							Cognitive interview (CI) study				Total quality PROM development study	Relevance		Comprehensiveness		Comprehensibility
	General design requirements					Concept elicitation	Total PROM design	General design requirements	Comprehen-sibility	Comprehen-siveness	Total CI study		Patients	Professionals	Patients	Professionals	Patients
	Clear construct	Clear origin of construct	Clear target population	Clear context of use	Sample representing the target population			Sample representing the target population									
AQEL	V	V	V	V	V	I	I	V	NA	NA	I	I	NA	NA	NA	NA	NA
CANDI	V	V	V	V	V	D	D	V	I	I	I	I	D	D	D	D	D
CARES	V	V	V	V	V	I	I	V	NA	I	I	I	D	D	D	D	D
CARES-SF	V	V	V	V	V	I	I	NA	NA	NA	I	I	D	D	NA	NA	D
CaSUN	V	V	V	V	D	D	D	V	D	D	D	D	D	NA	D	NA	D
CCEQ	V	V	V	V	V	D	D	V	D	D	D	D	NA	D	D	D	D
EORTC CAT	V	V	V	V	V	D	D	V	D	D	D	D	D	V	D	V	D
EORTC QLQ-C30	V	V	V	V	I	NA	I	I	NA	NA	I	I	V	NA	V	NA	V
EORTC QLQ-ELD14	V	V	V	V	V	D	D	V	D	D	D	D	D	D	D	D	D
EORTC QLQ-C15-PAL	V	V	V	V	V	D	D	V	NA	I	I	I	D	D	D	D	NA
ESAS-r	V	V	V	V	V	I	I	V	NA	NA	I	I	NA	NA	A	NA	A
EQ-5D-3L	V	V	V	V	V	I	I	NA	NA	NA	I	I	NA	NA	NA	NA	NA
EQ-5D-5L	V	V	V	V	V	I	I	A	D	NA	I	I	NA	NA	NA	NA	D
FACT-G 2.0	V	V	V	V	V	D	D	V	NA	D	I	I	D	D	D	D	NA

FACT-G 3.0	V	V	V	V	V	D	D	V	NA	D	I	I	D	D	D	D	NA
FACIT-PAL14	D	D	V	V	V	D	D	NA	NA	NA	I	I	D	D	NA	NA	NA
FACIT-PAL46	V	V	V	V	V	D	D	NA	NA	NA	I	I	D	D	NA	NA	NA
FLIC	V	V	V	V	D	D	D	V	D	NA	I	I	NA	NA	NA	NA	D
IOC	V	V	V	V	V	I	I	V	D	D	D	I	D	D	D	D	D
IPOS	V	V	V	V	V	D	D	V	D	D	D	D	D	D	D	NA	D
LAYA-SRQL	V	V	V	V	D	D	D	V	NA	NA	I	I	NA	NA	NA	NA	NA
MDASI	V	V	V	V	V	D	D	V	NA	NA	I	I	NA	D	NA	D	NA
POS 1.0	V	V	V	V	V	D	D	V	D	D	D	D	D	D	D	D	D
POS 2.0	V	V	V	V	V	D	D	V	D	D	D	D	D	D	D	D	D
QLACS	V	V	V	V	V	D	D	V	NA	NA	I	I	NA	D	NA	NA	NA
QLI	V	V	V	V	V	D	D	NA	NA	NA	I	I	NA	NA	NA	NA	NA
QOL-CS	V	V	V	V	V	D	D	I	NA	D	I	I	NA	NA	D	NA	NA
QUAL	V	V	V	V	V	V	V	V	D	I	I	I	D	NA	NA	NA	D
RSCL	V	V	V	V	A	I	I	A	NA	NA	I	I	NA	NA	NA	NA	NA
SCNS-SF34	V	V	V	V	V	D	D	V	D	D	D	D	D	D	D	I	D
SF-20	V	V	V	V	V	I	I	NA	NA	NA	I	I	NA	NA	NA	NA	NA
SF-36	V	V	V	V	V	I	I	A	I	NA	I	I	NA	NA	NA	NA	NA
SPARC	V	V	V	V	A	A	A	V	D	V	D	D	D	A	D	A	D
SUNS-SF	V	V	V	V	V	D	D	V	D	NA	I	I	D	D	NA	D	D
WHOQoL-BREF	V	V	I	V	D	D	I	NA	NA	NA	I	I	D	NA	NA	NA	NA
WHOQoL-100	V	V	I	V	D	D	I	D	NA	D	I	I	D	NA	D	NA	NA
3LNQ	V	V	V	V	V	D	D	V	I	NA	I	I	NA	NA	NA	NA	D

Abbreviations: V = very good; A = adequate; D = doubtful; I = inadequate; NA = no information available on this item

Table 12: Evidence synthesis of the quality of all included PROMs (n = 37)

PROM	CONTENT VALIDITY: RATING OF RESULTS				QUALITY OF EVIDENCE			
	Relevance	Comprehensiveness	Comprehensibility	TOTAL RATING OF RESULTS	Risk of bias	Inconsistency	Indirectness	TOTAL GRADE
AQEL	-	-	-	-	-3			Very low
CANDI	±	±	-	±	-1	-1		Low
CARES	±	+	-	±	-1	-1		Low
CARES-SF	±	-	±	±	-1	-1		Low
CaSUN	±	+	+	+				High
CCEQ	±	+	+	+				High
EORTC CAT	+	+	+	+				High
EORTC QLQ-C30	±	+	+	+				High
EORTC QLQ-ELD14	+	+	+	+				High
EORTC QLQ-C15-PAL	±	-	-	-	-3			Very low
ESAS-r	±	±	±	±	-1	-1		Low
EQ-5D-3L	-	-	-	-	-3	-1		Very low
EQ-5D-5L	-	-	-	-	-2			Low
FACIT-PAL14	±	±	-	±	-2	-1		Very low
FACIT-PAL46	+	±	-	±	-2	-1		Very low
FACT-G 2.0	+	+	-	±	-1	-1		Low
FACT-G 3.0	+	+	-	±	-1	-1		Low
FLIC	-	±	-	-	-2			Low
IOC	±	+	+	+	-1	-1		Low
IPOS	+	+	+	+				High
LAYA-SRQL	±	±	-	±	-2	-1		Very low
MDASI	±	+	-	±	-1	-1		Low
POS 1.0	+	±	+	+				High
POS 2.0	+	±	+	+				High
QLACS	±	-	-	-	-1			Low
QLI	±	-	-	-	-2		-1	Very low
QOL-CS	-	±	-	-	-2	-1		Very low
QUAL	±	±	+	±	-1	-1	-1	Very low
RSCL	±	-	-	-	-3			Very low

SCNS-SF34	+	-	+	**±**	-1	-1		**Low**
SF-20	-	-	-	**-**	-3			**Very low**
SF-36	-	-	-	**-**	-3			**Very low**
SPARC	+	+	+	**+**				**High**
SUNS-SF	+	+	+	**+**				**High**
WHOQoL-BREF	±	±	±	**±**	-2	-1	-2	**Very low**
WHOQoL-100	±	+	±	**±**	-1	-1	-2	**Very low**
3LNQ	±	-	±	**±**	-2			**Low**

Abbreviations: + = sufficient results; - = insufficient results; ± = inconsistent results; PROMs with sufficient ratings for content validity are presented in green.

3.6 Structural validity

Structural validity was assessed for 28 of the 35 PROMs (80.0%). However, for more than half of these PROMs (n = 15; 53.6%) the quality of the included studies was rated as inadequate due to small sample sizes or the lack of confirmatory factor analyses (Table 13). Only 8 of the included PROMs (22.9%) relied on studies of very good methodological quality for structural validity. Sufficient structural validity with high level of evidence was found for EORTC QLQ-C30 model 1 and 3 (Table 15). For the EORTC QLQ-C30 model 2, IPOS and SCNS-SF34 model 1, sufficient structural validity with moderate level of evidence was demonstrated (Table 15). High-level evidence for unidimensionality on a subscale level was only retrieved for the EORTC CAT cognitive functioning, emotional functioning and fatigue subscales (Table 15). For all the other PROMs the structural validity was rated as insufficient or indeterminate, or the level of evidence was rated as low to very low (Table 15).
A detailed overview of the different models can be found in Appendix 11.

3.7 Internal consistency

For nearly all PROMs (n = 30; 85.7%) internal consistency was assessed. However, for most of the included studies, the methodological quality was rated as doubtful since there was not at least low-quality evidence that the PROMs were unidimensional (Table 13). Therefore, the Cronbach's alpha could not be interpreted properly, leading to an indeterminate rating (78). Among the PROMs that fulfilled the prerequisite of unidimensionality, sufficient internal consistency with high level of evidence was demonstrated for EORTC CAT (subscales: cognitive functioning, emotional functioning and fatigue), EORTC QLQ-C30 model 1 (subscales: physical functioning, role functioning, emotional functioning, social functioning, fatigue, pain and global health status), EORTC QLQ-C30 model 3 (subscales: quality of life and physical health), IOC (subscales: altruism and empathy, health awareness, meaning of cancer, appearance concerns, body change concerns, life interference, worry, employment concerns and relationship concerns (not partnered)) and SCNS-SF34 model 1 (subscales: psychological, health system information, patient care and support, physical and daily living and sexuality) (Table 15). For IPOS (subscales: physical symptoms and support) and WHOQoL-BREF (subscales: physical health, psychological health and environment) sufficient internal consistency with moderate level of evidence was found (Table 15). For the subscales positive self-evaluation and relationship concerns partnered of the IOC, insufficient internal consistency with high-level evidence was demonstrated (Table 15). Therefore, these subscales should not be recommended for use

3.8 Cross-cultural validity and measurement invariance

Cross-cultural validity was only evaluated for the EORTC CAT by studies of very good methodological quality (Table 13). High-level evidence for sufficient cross-cultural validity was demonstrated for the following subscales: physical functioning, role functioning, cognitive functioning, emotional functioning, fatigue, pain and insomnia (Table 15).

Measurement invariance was assessed for 4 PROMs (11.4%) only. The methodological quality of the included studies ranged from very good to insufficient (Table 13), since for most of the included studies it was unclear whether the samples were similar for relevant characteristics except the group variable. Sufficient measurement invariance with a high level of evidence was demonstrated for EORTC CAT (subscales: physical functioning, role functioning, cognitive functioning, emotional functioning, fatigue, pain and insomnia) after assessing the group variables age, gender, tumour site, tumour stage, current treatment, cohabitation, education and work status (Table 14 & 15). For all the subscales of EORTC QLQ-C30 model 1, sufficient

measurement invariance with a moderate level of evidence was found when considering the group variables age, gender, tumour location, type of surgery, comorbidity, disease type and time (Table 14 & 15). The mode of administration was assessed as group variable for all subscales of FACT-G 2.0, resulting in sufficient measurement invariance with low level of evidence (Table 14 & 15). Finally, age, gender, cancer treatment and information were assessed for all subscales of the EORTC QLQ-C30 model 4, leading to sufficient measurement invariance with low level of evidence (Table 14 & 15).

3.9 Reliability and measurement error

None of the included studies evaluated the measurement error of any of the included PROMs. Reliability was assessed for 18 PROMs (51.4%). However, since most of the studies did not provide a proper description of similar test conditions or patients being stable between measurements, the methodological quality was rated as doubtful (Table 13). On top of that, most of the studies calculated Pearson or Spearman correlation coefficients without evidence that no systematic error had occurred. Therefore, only sufficient reliability of high-level evidence could be demonstrated for the physical functioning and cognitive functioning subscales of the EORTC QLQ-C30 model 1 (Table 15). For all the other subscales and PROMs, insufficient or inconsistent results were found for reliability, or the level of evidence was rated as low to very low (Table 15).

3.10 Construct validity

3.10.1 Construct validity with other PROM

For 25 PROMs (71.4%), the construct validity was assessed in comparison to other PROMs. A detailed overview of the comparators with their associated correlation coefficients can be found in Table 14. The methodological quality of these studies was rated as either very good, adequate, doubtful or inadequate (Table 13). The inadequate scores were due to the lack of information on the measurement properties of the comparator. The doubtful scores were due to providing information on measurement properties of the comparator in any study population. For the adequate scores, there was evidence for sufficient measurement properties of the comparator, but it was not clear whether they specifically applied to the study population. High-level evidence for sufficient construct validity was demonstrated for CANDI (total + subscales: depression, anxiety and physical), CARES-SF model 1 (total + subscales: physical and relatives & friends), CaSUN model 1 (total), EORTC CAT (total + all subscales), EORTC QLQ-C30 model 1 (total + all subscales), EORTC QLQ-C30 model 3 (subscales: quality of life and physical health), EORTC QLQ-ELD14 (subscales: mobility, burden of illness and joint stiffness), FACIT-PAL14, FACIT-PAL46 (total + subscales: physical well-being, emotional well-being and functional well-being) and POS model 2 (subscales: pain, anxiety, depression and feeling at peace) (Table 15). Moderate level of evidence for sufficient validity was demonstrated for CaSUN model 2 (subscales: physical effects, psychological effects, practical issues and relationships), QUAL (subscales: life completion and preparation for end of life), SCNS-SF34 model 1 (subscales: psychological, health system information, patient care & support and physical & daily living), SCNS-SF34 model 2 (subscales: psychological, physical & daily living and sexuality), SUNS-SF (subscale: relationship and emotional health), WHOQoL-BREF (total + subscales: physical health and psychological health) and WHOQoL-100 (total + subscales: physical and psychological) (Table 15). For POS 2.0 (total), EORTC QLQ-ELD14 (subscale: worries about others) and CARES-SF model 1 (subscales: medical and sexual) insufficient construct validity with high-level evidence was found (Table 15).

3.10.2 Convergent and divergent validity within PROM

The convergent and divergent validity within PROM was assessed for 5 PROMs (14.3%) using the multitrait item scaling. The methodological quality of all included studies was rated very good (Table 13).

After applying the criteria for good measurement properties, sufficient convergent validity with high level of evidence was found for CCEQ (subscales: coordination of care, general practioner involvement, information and questions, treatment decisions, clinical trials, symptom non-reporting, key worker, limitations, sustaining normality, financial advice, worries & anxiety and sharing feelings with others), EORTC QLQ-C30 model 1 (subscales: role functioning, emotional functioning, social functioning, fatigue, pain, nausea & vomiting, global health status, dyspnoea, appetite loss, insomnia, constipation, diarrhoea and financial impact) and EORTC QLQ-ELD14 (subscales: mobility, future worries, maintaining purpose and burden of illness) (Table 15). Additionally, high-level evidence for insufficient convergent validity was demonstrated for CARES-SF model 2 (subscales: psychological, sexual and marital) and CCEQ (subscales: managing appointments and assessing support). For divergent validity, high-level evidence for sufficient divergent validity was demonstrated for CCEQ (all subscales), EORTC QLQ-C30 model 1 (subscales: role functioning, emotional functioning, social functioning, pain, nausea & vomiting, global health status, dyspnoea, appetite loss, insomnia, constipation, diarrhoea and financial impact) and EORTC QLQ-ELD14 (subscales: mobility, future worries, maintaining purpose and burden of illness) (Table 15). Furthermore, high-level evidence for insufficient divergent validity was found for CARES-SF model 2 (subscales: physical, psychological, sexual and marital) (Table 15).

3.10.3 Known-group comparison

For 18 PROMs (51.4%) known-group comparisons were performed. A detailed overview of the known-group differences can be found in Table 14. The methodological quality of most of the included studies was rated as inadequate since they did not formulate a priori hypotheses about the expected differences between groups (Table 13). Even though these low-quality studies demonstrated multiple differences between groups, careful interpretation is warranted since no a priori hypotheses were formulated, leading to an indeterminate rating. The remaining studies were rated as very good or adequate (Table 13). The adequate scores were due to the lack of information about the handling of missing data. The MDASI model 1 (subscales interference items and symptom items) was the only PROM with sufficient known-group comparison of high-level evidence with respect to performance status (Table 14 & 15). Both the EORTC CAT (subscales: physical functioning, emotional functioning and fatigue) and the SCNS-SF34 (subscales: psychological and physical & daily living) demonstrated sufficient known-group comparison with moderate-quality evidence (Table 15).

3.11 Feasibility

Table 16 presents information on the feasibility of PROMs with sufficient content validity (n = 24; 64.9%). All PROMs are available in multiple languages, except QUAL, which can only be used by English-speaking individuals. The average completion time ranges from less than 5 minutes (FACIT-PAL14) to 30 minutes (CARES). Fourteen PROMs (58.3%) are copyrighted, two (8.3%) are not, and information is unavailable for eight PROMs (33.3%). Fourteen PROMs (58.3%) are free for academic use, while ten (41.6%) have no available information on costs for academic use. Scoring manuals are available for 15 of the included PROMs (62.5%) and reference values for 9 of the included PROMs (37.5%).

3.12 Recommendations

The EORTC CAT (subscales: role functioning, cognitive functioning, emotional functioning, fatigue, pain and insomnia), EORTC QLQ-C30 model 1 (subscales: physical functioning, role functioning, emotional functioning, social functioning, fatigue, pain and global health status), EORTC QLQ-C30 model 3 (subscales: quality of life and physical health), IOC (subscales: altruism & empathy, health awareness, meaning of cancer, appearance concerns, body change concerns, life interference, worry and relationship concerns (not partnered)) and IPOS (subscales: physical symptoms and support) demonstrated sufficient content validity, and at least low-quality evidence for sufficient structural validity and internal consistency. Therefore, they can be recommended for use in clinical practice and research. The recommended subscales are highlighted in green in Table 15.

3.13 Mapping recommended PROMs on EUonQOL HRQoL framework

A detailed overview of the mapping of the recommended PROMs based on the EUonQOL HRQoL framework can be found in Table 17.

For physical health, EORTC CAT (subscales: role functioning, pain, fatigue and insomnia), EORTC QLQ-C30 (subscales: physical functioning, role functioning, pain and fatigue), IPOS (subscale: physical symptoms) and IOC (subscales: appearance concerns, body change concerns) are recommended. For mental health, EORTC CAT (subscales: emotional functioning and cognitive functioning), EORTC QLQ-C30 (subscales: emotional functioning) and IOC (subscales: worry, meaning of cancer, altruism and empathy, body change concerns, health awareness and life interference) are advised. For social health, EORTC QLQ-C30 (subscales: physical functioning and social functioning), IPOS (subscale: support) and IOC (subscales: health awareness, life interference and relationship concerns (not partnered)) are pre-eminently considered the best subscales. Finally, for global quality of life, the use of the global health status subscale of the EORTC QLQ-C30 can be advocated. For none of the aforementioned subscales, sufficient evidence for all psychometric properties was demonstrated.

Table 13: Methodological quality of the studies assessing the remaining psychometric properties for the final set of PROMs (n = 35)

PROM	Structural validity	Internal consistency	Cross-cultural validity/ Measurement invariance	Reliability	Construct validity		
					Construct validity with other PROM	Convergent/divergent validity within PROM	Known-group comparison
CANDI	I (1)	I (1)		D (1)	V (1)		
CARES	I (1)	D (1)		D (1)	I (1)		
CARES-SF (model 1)	I (1)	D (1)		I (1)	V (1)		
CARES-SF (model 2)	I (1)	D (1)		D (1)		V (1)	I (1)
CaSUN (model 1)	I (1)	D (1)		D (1)	V (1)		
CaSUN (model 2)	V (1)	D (1)		D (1)	V (1)		
CCEQ		D (1)				V (1)	I (1)
EORTC CAT	V (4) – D (3)	V (7) – D (2)	V (7)		V (5) – A (2)		A (3)
EORTC QLQ-C30 (model 1)	V (2) – A (1)	V (21) – I (1)	D (3) – I (1)	A (2) – D (3) – I (1)	V (4) - A (6) - D (2) - I (4)	V (7)	V (2) – A (1) – I (11)
EORTC QLQ-C30 (model 2)	V (1)						I (1)
EORTC QLQ-C30 (model 3)	V (1)	V (1)			V (1)		
EORTC QLQ-C30 (model 4)	I (1)		D (1)				
EORTC QLQ-C30 (model 5)	I (1)						
EORTC QLQ-ELD14		D (3)			V (3)	V (3)	A (2) - I (1)
ESAS-r		I (1)		D (1)	I (1)		I (2)
FACIT-PAL14	I (1)	D (1)			V (1)		
FACIT-PAL46	A (1) – I (1)	D (2)			V (2)		
FACT-G 2.0	I (1)	D (2)	D (1)	D (1)			I (1)
FACT-G 3.0	I (1)	D (1)		D (1)	D (1)		I (1)
IOC	A (1)	V (3)		D (1)	I (1)		V (1) – I (1)
IPOS	V (1)	V (1) – I (1)		D (2)	V (2)		I (2)
LAYA-SRQL	V (1)	D (1)			I (1)		
MDASI (model 1)	I (1)	D (1)			D (1)		V (1) – A (1)
MDASI (model 2)	I (1)	D (1)		D (1)			I (1)
MDASI (model 3)	I (1)	D (1)					
POS 1.0				D (2)	I (1)		

POS 2.0		D (1)		D (1)	V (1)		
QUAL	I (1)	D (1)			A (1)		
SCNS-SF34 (model 1)	V (1)	V (2)		D (1)	V (1)		V (1)
SCNS-SF34 (model 2)	A (1)	D (1)		A (1)	V (1)		A (1)
SPARC	I (1)	D (1)					I (1)
SUNS-SF	D (1)	D (1)			V (1)		
WHOQoL-BREF	A (1)	V (1)			V (1)	V (1)	I (1)
WHOQoL-100		D (2)		D (1)	A (1) – D (1)		I (1)
3LNQ							

Abbreviations: V = very good; A = adequate; D = doubtful; I = inadequate; (#) = number of studies assessed; grey cells indicate data are not available.

Table 14: Rating of criteria for good measurement properties for final set of PROMs (n = 35)

PROM (subscale level)	Structural validity			Internal consistency		Cross-cultural validity/ Measurement invariance		Reliability			Construct validity						
											Construct validity with other PROM			Convergent validity within PROM	Divergent validity within PROM	Known-group comparison	
	Hypothesized model	Model fit indices	+/±/-/?	Internal consistency correlation coefficients	+/±/-/?	Group variable	+/±/-/?	Type of reliability	Correlation coefficient	+/±/-/?	Comparator	Correlation coefficient	+/±/-/?	+/ ± / - /?	+/ ± / - /?	Comparison groups	+/±/-/?
CANDI	3-factor	EFA	?	0.94	?			Test-retest	0.87	+	**BSI** **FACT-G** **HADS**	0.69 0.76 0.67	+				
CANDI DEP								Test-retest	0.83	+	**BSI** Depression **HADS** Depression	0.61 0.7	+				
CANDI ANX								Test-retest	0.84	+	**BSI** Anxiety **HADS** Anxiety	0.62 0.61	+				
CANDI PHY																	
CANDI SOC																	
CARES	5-factor	EFA	?	0.88	?			Test-retest	0.92	+	**EORTC QLQ-C30** **Distress thermometer**	0.56 0.63	+				
CARES PF				0.93	?			Test-retest	0.9	+	**Karnofsky score**	0.67	+				
CARES PSY				0.96	?			Test-retest	0.7	+	**HADS** Anxiety Depression **SSL-D**	 0.75 0.64 0.43	+				
CARES MED				0.9	?			Test-retest	0.84	+							
CARES MAR				0.92	?			Test-retest	0.91	+	**MMQ** Marital	0.48	-				
CARES SEX				0.87	?			Test-retest	0.89	+	**MMQ** Sexual	0.55	+				
CARES-SF[1]	6-factor	EFA	?	0.9	?			Test-retest	0.87	+	**Rolls Royce** General well-being	0.7	+				

CARES-SF[1] PHY				0.69-0.89	**?**			Test-retest	0.82	**+**	**Rolls Royce** Physical symptoms and activity	0.57	**+**				
CARES-SF[1] PSY				0.69-0.89	**?**			Test-retest	0.91	**+**							
CARES-SF[1] MED				0.69-0.89	**?**			Test-retest	0.85	**+**	**Rolls Royce** Medical interaction	0.15	**-**				
CARES-SF[1] SEX				0.69-0.89	**?**			Test-retest	0.85	**+**	**Rolls Royce** Sexual function	0.42	**+**				
CARES-SF[1] MAR				0.69-0.89	**?**			Test-retest	0.9	**+**							
CARES-SF[1] RAF				0.69-0.89	**?**			Test-retest	0.77	**+**	**Rolls Royce** Social relationships and work performance	0.33	**+**				
CARES-SF[2]	5-factor	EFA	**?**	0.89-0.9	**?**			Test-retest	0.91	**+**						Disease stage Performance status Treatment regime Tumour response	**4?**
CARES-SF[2] PHY				0.84-0.87	**?**			Test-retest	0.91	**+**				**±**	**-**	Disease stage Performance status Treatment regime Tumour response	**4?**
CARES-SF[2] PSY				0.8-0.82	**?**			Test-retest	0.88	**+**				**-**	**-**	Disease stage Performance status Treatment regime Tumour response	**4?**
CARES-SF[2] MED				0.61-0.74	**?**			Test-retest	0.8	**+**				**±**	**±**	Disease stage Performance status Treatment regime Tumour response	**4?**
CARES-SF[2] SEX				0.49-0.56	**?**			Test-retest	0.76	**+**				**-**	**-**	Disease stage Performance status Treatment regime Tumour response	**4?**
CARES-SF[2] MAR				0.64-0.68	**?**			Test-retest	0.72	**+**				**-**	**-**	Disease stage Performance status Treatment regime Tumour response	**4?**
CaSUN[1]	5-factor	CFI: 0.89 TLI: 0.88 RMSEA: 0.075 SRMR: 0.082	**-**	0.94	**?**			Test-retest	0.71-0.98	**+**	**HADS** Anxiety Depression **EQ-5D** **RS-14**	 0.49 0.43 0.30 0.41	**+**				
CaSUN[1] ES				0.86	**?**			Test-retest	0.71-0.98	**+**							
CaSUN[1] PES				0.88	**?**			Test-retest	0.71-0.98	**+**							

CaSUN[1] CC				0.82	**?**			Test-retest	0.71-0.98	**+**							
CaSUN[1] INF				0.71	**?**			Test-retest	0.71-0.98	**+**							
CaSUN[1] REL				0.75	**?**			Test-retest	0.71-0.98	**+**							
CaSUN[2]	5-factor	CFI: 0.93 RMSEA: 0.047	**-**	0.95	**?**			Test-retest	0.82	**+**							
CaSUN[2] PHE				0.73	**?**			Test-retest	0.74	**+**	**QLACS** Pain Fatigue	 0.55 0.51	**+**				
CaSUN[2] PSE				0.94	**?**			Test-retest	0.89	**+**	**BSI** Global symptom index **QLACS** Positive feelings Negative feelings Appearance concerns Recurrence distress	 0.67 0.64 0.59 0.47 0.46	**+**				
CaSUN[2] CCI				0.9	**?**			Test-retest	0.51	**-**							
CaSUN[2] PI				0.77	**?**			Test-retest	0.78	**+**	**QLACS** Financial problems	 0.51	**+**				
CaSUN[2] REL				0.83	**?**			Test-retest	0.83	**+**	**QLACS** Sexual problems Social avoidance	 0.55 0.51	**+**				
CCEQ																	
CCEQ MA				0.71	**?**									**-**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ COC				0.88	**?**									**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ GPI				0.78	**?**									**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ IAQ				0.77	**?**									**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ MTD				0.82	**?**									**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ CT				0.8	**?**									**+**	**+**	Type of cancer	**4?**

															Disease duration Age Education	
CCEQ SNR				0.71	**?**								**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ KW				0.78	**?**								**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ LIM				0.88	**?**								**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ SN				0.77	**?**								**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ FA				0.79	**?**								**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ WAA				0.83	**?**								**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ SFO				0.81	**?**								**+**	**+**	Type of cancer Disease duration Age Education	**4?**
CCEQ AS				0.68	**?**								**-**	**+**	Type of cancer Disease duration Age Education	**4?**
EORTC CAT											**EORTC QLQ-C30**	0.87-0.88	**+**			
EORTC CAT PF	1-factor	CFI: 0.94 TLI: 0.98 RMSEA: 0.09 Res. Corr.: >0.25	**-**	Reliability coefficient (r = 1 - SE(θ)²) >0.9-0.94	**+**	Age Gender Country Tumour site Tumour stage Current treatment Cohabitation	**+**				**EORTC QLQ-C30** Physical functioning	0.64-0.93	**+**			Age Cancer stage Employment	**3+**

						Education Work status											
EORTC CAT RF	1-factor	CFI: 0.987 TLI: 0.997 RMSEA: 0.081 Res. Corr.: <0.15 Infit: 0.93-1.03 Outfit: 0.60-0.93 S-X^2: >0.05	+	Reliability coefficient (r = 1 - SE(θ)²) 0.85	+	Age Gender Country Tumour site Tumour stage Current treatment Cohabitation Education Work status	+				**EORTC QLQ-C30** Role functioning	0.87-0.91	+				
EORTC CAT CF	1-factor	CFI: 0.903 TLI: 0.989 RMSEA: 0.095 Res. Corr.: <0.20 Infit: 0.91-1.15 Outfit: 0.73-1.20 S-X^2: >0.10	+	Reliability coefficient (r = 1 - SE(θ)²) 0.94	+	Age Gender Country Tumour site Tumour stage Current treatment Cohabitation Education Work status	+				**EORTC QLQ-C30** Cognitive functioning	>0.56-0.88	+				
EORTC CAT EF	1-factor	CFI: 0.906 TLI: 0.987 RMSEA: 0.089 Res. Corr.: <0.20 Infit: 0.93-1.07 Outfit: 0.59-0.97 S-X^2: >0.35	+	Reliability coefficient (r = 1 - SE(θ)²) >0.9	+	Age Gender Country Tumour site Tumour stage Current treatment Cohabitation Education Work status	+				**EORTC QLQ-C30** Emotional functioning	0.85-0.87	+			Age Gender Cancer stage Current treatment Employment	**4+** **1-**
EORTC CAT SF											**EORTC QLQ-C30** Social functioning	0.87-0.88	+				
EORTC CAT FAT	1-factor	CFI: 0.92 TLI: 0.995 RMSEA: 0.098 Res. Corr.: <0.15 Infit: 0.93-1.04 Outfit: 0.65-1.09 S-X^2: >0.002	+	Reliability coefficient (r = 1 - SE(θ)²) >0.95-0.96	+	Age Gender Country Tumour site Tumour stage Current treatment Cohabitation Education Work status	+				**EORTC QLQ-C30** Fatigue	0.68-0.9	+			Age Cancer stage Current treatment	**3+**

EORTC CAT PAI	1-factor	CFI: 0.977 TLI: 0.995 RMSEA: 0.147 Res. Corr.: <0.10 Infit: 0.76-1.07 Outfit: 0.71-1.03 S-X^2: >0.04	+	Reliability coefficient ($r = 1 - SE(\theta)^2$) >0.9	+	Age Gender Country Tumour site Tumour stage Current treatment Cohabitation Education Work status	+				**EORTC QLQ-C30** Pain	0.79-0.93	+				
EORTC CAT NV											**EORTC QLQ-C30** Nausea & vomiting	0.89-0.9	+				
EORTC CAT DYS											**EORTC QLQ-C30** Dyspnoea	0.82-0.83	+				
EORTC CAT AL											**EORTC QLQ-C30** Appetite loss	0.9	+				
EORTC CAT INS	1-factor	CFI: >0.99 TLI: >0.99 RMSEA: 0.08 Res. Corr.: <0.05 Infit: 0.64-0.92 Outfit: 0.49-0.91 S-X^2: >0.10	+	Reliability coefficient ($r = 1 - SE(\theta)^2$) 0.94	+	Age Gender Country Tumour site Tumour stage Current treatment Cohabitation Education Work status	+				**EORTC QLQ-C30** Insomnia	>0.72-0.9	+				
EORTC CAT CON											**EORTC QLQ-C30** Constipation	0.87-0.89	+				
EORTC CAT DIA											**EORTC QLQ-C30** Diarrhoea	0.88-0.9	+				
EORTC CAT FI											**EORTC QLQ-C30** Financial impact	0.81-0.82	+				
EORTC QLQ-C30[1]	9-factor	CFI: 0.95-0.99 TLI: 0.93-0.99 RMSEA: 0.05-0.056	+	0.95	+	Cancer type Treatment status	**1+** **1-**				**MFI** **HADS** Anxiety Depression	0.76 0.67 0.55 0.67	+				
EORTC QLQ-C30[1] **PF**				0.66-0.91	+	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**7+** **3-**	Test-retest Parallel forms	0.58-0.87 0.98	+	**SF-36** Physical functioning **FACT-LYM** Physical functioning **ECOG score** **FLIC** Physical functioning **DLQI** Symptoms & feelings	0.25-0.79 0.58 0.7 0.6 0.28	+	±	±	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Quality of life	**7+** **30?** **4-**

										ADL **IADL** **Karnofsky score**	0.31 0.28 0.43				Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	
EORTC QLQ-C30[1] RF				0.7-0.93	**+**	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**10+**	Test-retest Parallel forms	0.58-0.82 0.9	**±**	**SF-36** Role functioning **BIPQ** Consequences **FACT-LYM** Functional well-being **ECOG score** **DLQI** Daily activities Leisure **ADL** **IADL** **Karnofsky score**	0.32-0.6 0.38 0.51 0.6-0.63 0.32 0.41 0.30 0.38 0.38	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**4+** **29?** **7-**
EORTC QLQ-C30[1] CF				0.43-0.79	**±**	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**9+** **1-**	Test-retest Parallel forms	0.58-0.82 0.91	**±**	**ECOG score**	0.49-0.5	**+**	**±**	**±**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation	**6+** **29?** **5-**

															Time since surgery Relationship status Comorbidities Type of cancer	
EORTC QLQ-C30[1] EF				0.63-0.87	**+**	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**8+ 2-**	Test-retest Parallel forms	0.58-0.82 0.94	**±**	**SF-36** Role emotional Mental health **HADS** Anxiety Depression **BIPQ** Emotional representation Concerns **FACT-LYM** Emotional well-being **ECOG score** **FLIC** Emotional functioning **DLQI** Symptoms and feelings **GDS**	0.36 0.5-0.76 0.31 0.17 0.53 0.33 0.39 0.2-0.26 0.51 0.35 0.62	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Quality of life Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**4+ 30? 7-**
EORTC QLQ-C30[1] SF				0.7-0.89	**+**	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**10 +**	Test-retest Parallel forms	0.58-0.84 0.92	**±**	**SF-36** Social Functioning **FACT-LYM** Social well-being **ECOG score** **FLIC** Social functioning **DLQI** Daily activities Leisure Personal relationships **EORTC QLQ H&N35** Social contact Social eating	0.42-0.71 0.46 0.48-0.5 0.21 0.38 0.45 0.31 0.69-0.83 0.45	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Quality of life Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**5+ 30? 6-**

EORTC QLQ-C30[1] FAT				0.58-0.96	**+**	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**10** **+**	Test-retest Parallel forms	0.62-0.82 0.95	**±**	**ECOG score** **SF-36** Vitality	0.51-0.61 0.46-0.76	**+**	**+**	**±**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Quality of life Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**5+** **30?** **6-**
EORTC QLQ-C30[1] PAI				0.56-0.97	**+**	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**10** **+**	Test-retest Parallel forms	0.62-0.82 0.91	**±**	**SF-36** Pain **ECOG score** **EORTC QLQ-H&N35** Pain **FLIC** Pain **VAS**	0.64-0.71 0.34-0.38 0.49-0.53 0.44 0.72	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Quality of life Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**4+** **30?** **7-**
EORTC QLQ-C30[1] NV				0.04-0.94	**±**	Age Gender Tumour location Type of surgery Comorbidity	**10** **+**	Test-retest Parallel forms	0.43-0.82 0.96	**±**	**ECOG score** **FLIC** Nausea	0.01-0.06 0.66	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status	**2+** **30?** **9-**

						Disease type Time									Toxicity Type of lymphoma Treatment status Quality of life Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	
EORTC QLQ-C30[1] GHS				0.7-0.99	**+**	Age Gender Tumour location Type of surgery Comorbidity Disease type Time	**9+** **1-**	Test-retest Parallel forms	0.33-0.82 0.88	**±**	**SF-36** Global health **MFI** **HADS** Anxiety Depression **FACT-LYM** Total **ECOG score** **FLIC** Global health **DLQI** Total score	0.32-0.7 0.65 0.6 0.46 0.63 0.63 0.48-0.6 0.4 0.4	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**7+** **30?** **4-**
EORTC QLQ-C30[1] DYS								Test-retest Parallel forms	0.47-0.82 0.8	**±**	**ECOG score**	0.35-0.39	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education	**5+** **28?** **6-**

															Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	
EORTC QLQ-C30[1] AL							Test-retest Parallel forms	0.47-0.82 0.96	**±**	**ECOG score** **EORTC QLQ-H&N35** All subscales	0.27-0.38 0.08-0.49	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**1+** **28?** **10-**
EORTC QLQ-C30[1] INS							Test-retest Parallel forms	0.47-0.82 0.92	**±**	**ECOG score**	0.16-0.24	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities	**2+** **28?** **9-**

															Type of cancer	
EORTC QLQ-C30[1] CON							Test-retest Parallel forms	0.47-0.82 0.87	**±**	**ECOG score**	0.06-0.22	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**6+ 28? 5-**
EORTC QLQ-C30[1] DIA							Test-retest Parallel forms	0.33-0.82 0.95	**±**	**ECOG score**	0.09-0.1	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	**2+ 28? 9-**
EORTC QLQ-C30[1] FI							Test-retest Parallel forms	0.47-0.82 0.92	**±**	**ECOG score**	0.21-0.22	**+**	**+**	**+**	Disease status Weight loss Tumour site Disease stage Performance status Toxicity	**1+ 28? 10-**

																Type of lymphoma Treatment status Patient group Clinical condition Education Sex Age Extent of surgery Radiation Time since surgery Relationship status Comorbidities Type of cancer	
EORTC QLQ-C30[2]	1-factor	CFI: 0.963 TLI: 0.959 RMSEA: 0.064	**+**													Performance status Comorbidity Blood transfusion Treatment stage	**4?**
EORTC QLQ-C30[3]	2-factor	CFI: 0.985 RMSEA: 0.053	**+**														
EORTC QLQ-C30[3] QoL				0.96	**+**						**BSI** Depression Anxiety Total	0.62 0.56 0.7	**+**				
EORTC QLQ-C30[3] PH				0.88	**+**						**BSI** Depression Anxiety Total	 0.33 0.51 0.31	**+**				
EORTC QLQ-C30[4]	1-factor	RMSEA: 0.072	**-**														
EORTC QLQ-C30[4] PF						Age Gender Cancer treatment Information	**3+** **1-**										
EORTC QLQ-C30[4] RF						Age Gender Cancer treatment Information	**4+**										
EORTC QLQ-C30[4] CF						Age Gender Cancer treatment Information	**4+**										
EORTC QLQ-C30[4] EF						Age Gender Cancer treatment Information	**3+** **1-**										

EORTC QLQ-C30[4] SF						Age Gender Cancer treatment Information	**4+**										
EORTC QLQ-C30[4] GHS						Age Gender Cancer treatment Information	**4+**										
EORTC QLQ-C30[5]	6-factor	EFA	**-**														
EORTC QLQ-ELD14																	
EORTC QLQ-ELD14 MOB				0.69-0.81	**?**						**EORTC QLQ-C30** Physical functioning Role functioning	0.63-0.79 0.55-0.57	**+**	**+**	**+**	Age Disease duration Living arrangement Comorbidity Performance status Treatment status Health status	**7+** **3?** **1-**
EORTC QLQ-ELD14 WAO				0.35-0.72	**?**						**EORTC QLQ-C30** Emotional functioning	0.19-0.29	**-**	**±**	**±**	Age Disease duration Living arrangement Comorbidity Performance status Treatment status	**5+** **3?**
EORTC QLQ-ELD14 FW				0.84-0.86	**?**						**EORTC QLQ-C30** Emotional functioning	0.26-0.51	**±**	**+**	**+**	Age Disease duration Living arrangement Comorbidity Performance status Treatment intention Disease stage Health status	**4+** **5-** **3?**
EORTC QLQ-ELD14 MP				0.68-0.85	**?**									**+**	**+**	Age Disease duration Living arrangement Comorbidity Performance status Treatment status Health status	**3+** **5-** **3?**
EORTC QLQ-ELD14 BOI				0.71-0.83	**?**						**EORTC-QLQ C30** Global health status	0.46-0.51	**+**	**+**	**+**	Age Disease duration Living arrangement Comorbidity Performance status	**2+** **5-** **3?**

																Treatment status Health status	
EORTC QLQ-ELD14 JS											**EORTC QLQ-C30** Physical functioning Pain	0.42-0.50 0.48	**+**		**±**	Age Disease duration Living arrangement Comorbidity Performance status Treatment status	**2+ 3- 3?**
EORTC QLQ-ELD14 FS															**±**	Age Disease duration Living arrangement Comorbidity Performance status Treatment status	**2+ 3- 3?**
ESAS-r				0.86	**?**											Hospital status	**?**
ESAS-r INS											**ESAS Karnofsky score**	0.94 0.10-0.19	**+**				
ESAS-r DEP								Test-retest	0.44-0.66	**-**	**ESAS Karnofsky score**	0.92 0.10-0.19	**+**			Cognitive impairment	**?**
ESAS-r DRO								Test-retest	0.50-0.51	**-**	**ESAS Karnofsky score**	0.9 0.38-0.49	**+**			Cognitive impairment	**?**
ESAS-r LOA								Test-retest	0.50-0.56	**-**	**ESAS Karnofsky score**	0.88 0.38-0.49	**+**			Cognitive impairment	**?**
ESAS-r TIR								Test-retest	0.53-0.54	**-**	**ESAS Karnofsky score**	0.86 0.38-0.49	**+**			Cognitive impairment	**?**
ESAS-r PAI								Test-retest	0.51-0.53	**-**	**ESAS Karnofsky score**	0.85 0.38-0.49	**+**			Cognitive impairment	**?**
ESAS-r WB								Test-retest	0.52-0.59	**-**	**ESAS Karnofsky score**	0.85 0.38-0.49	**+**			Cognitive impairment	**?**
ESAS-r ANX								Test-retest	0.40-0.56	**-**	**ESAS Karnofsky score**	0.82 0.10-0.19	**+**			Cognitive impairment	**?**
ESAS-r NAU								Test-retest	0.42-0.55	**-**	**ESAS Karnofsky score**	0.75 0.10-0.19	**+**			Cognitive impairment	**?**
ESAS-r SOB								Test-retest	0.54-0.58	**-**	**ESAS Karnofsky score**	0.71 0.38-0.49	**+**			Cognitive impairment	**?**
FACIT-PAL14	3-factor	EFA	**?**	0.81	**?**						**EORTC QLQ-C15-PAL**	0.5	**+**				
FACIT-PAL46	5-factor	CFI: 0.939	**-**	0.75-0.93	**?**						**EORTC QLQ-C15-PAL**	0.5	**+**				
FACIT-PAL46 PWB				0.82	**?**						**ESAS** Pain Nausea Tiredness Well-being **Karnofsky score**	 0.51 0.58 0.62 0.52 0.6	**+**				

FACIT-PAL46 SWB				0.64-0.73	**?**												
FACIT-PAL46 EWB				0.76-0.78	**?**						**ESAS** Sadness Worry	0.51 0.59	**+**				
FACIT-PAL46 FWB				0.81-0.82	**?**						**ESAS** Lack of sleep	0.53	**+**				
FACIT-PAL46 AC				0.71-0.86	**?**												
FACT-G 2.0	4-factor	EFA	**?**	0.9	**?**	Mode of administration	**+**	Test-retest	0.9	**+**						Disease stage Chemotherapy	**2?**
FACT-G 2.0 PWB				0.81-0.86	**?**	Mode of administration	**+**	Test-retest	0.74	**+**						Disease stage Chemotherapy	**2?**
FACT-G 2.0 FWB				0.85-0.86	**?**	Mode of administration	**+**	Test-retest	0.85	**+**						Disease stage Chemotherapy	**2?**
FACT-G 2.0 SWB				0.78-0.83	**?**	Mode of administration	**+**	Test-retest	0.77	**+**						Disease stage Chemotherapy	**2?**
FACT-G 2.0 EWB				0.72-0.77	**?**	Mode of administration	**+**	Test-retest	0.83	**+**						Disease stage Chemotherapy	**2?**
FACT-G 3.0	5-factor	EFA	**?**	0.89	**?**			Test-retest	0.79-0.88	**+**	**EORTC QLQ-C30** Global health status **FLIC** Global	0.66 0.84	**+**			Gender Marital status Cancer type Performance status	**4?**
FACT-G 3.0 PWB				0.82	**?**						**EORTC QLQ-C30** Physical functioning Role functioning **FLIC** Role	0.54 0.71 0.61	**+**			Gender Marital status Cancer type Performance status	**4?**
FACT-G 3.0 FWB				0.8	**?**						**EORTC QLQ-C30** Physical functioning Role functioning **FLIC** Role	0.51 0.5 0.68	**+**			Gender Marital status Cancer type Performance status	**4?**
FACT-G 3.0 SWB				0.69	**?**						**EORTC QLQ-C30** Social functioning **FLIC** Sociability	0.08 0.25	**-**			Gender Marital status Cancer type Performance status	**4?**
FACT-G 3.0 EWB				0.74	**?**						**EORTC QLQ-C30** Emotional functioning **FLIC** Emotional functioning	0.71 0.75	**+**			Gender Marital status Cancer type Performance status	**4?**
FACT-G 3.0 RWD				0.65	**?**						**FLIC** Confidence in treatment	0.37	**+**				
IOC	8-factor	CFI: 0.97 RMSEA: 0.045	**+**														

		SRMR: 0.084														
IOC AE				0.67-0.8	+			Test-retest	0.66	-	**PTGI** Relating to others	0.51	+			Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status	**1-** **6?**
IOC HA				0.61-0.74	+			Test-retest	0.48	-						Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status	**1+** **6?**
IOC MOC				0.77-0.85	+			Test-retest	0.74	-	**PTGI** New possibilities Personal strength Appreciation of life	0.69 0.64 0.55	+			Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status	**1-** **6?**
IOC PSE				0.54-0.74	-			Test-retest	0.57	-	**PTGI** Personal strength	0.56	+			Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status	**1-** **6?**
IOC AC				0.73-0.85	+			Test-retest	0.57	-						Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status Education Comorbidities	**2+** **8-** **6?**
IOC BCC				0.75-0.82	+			Test-retest	0.71	+						Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status	**3+** **7-** **6?**

																Education Comorbidities	
IOC LI				0.73-0.85	**+**			Test-retest	0.63	**-**						Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status Education Comorbidities	**4+ 6- 6?**
IOC WOR				0.79-0.90	**+**			Test-retest	0.77	**+**	**SF-12** Mental health **FCRI** Psychological distress Severity Triggers	0.53 0.6 0.74 0.56	**+**			Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status Education Comorbidities	**2+ 8- 6?**
IOC EC				0.63-0.76	**±**											Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy Relationship status	**1- 6?**
IOC RCNP				0.75-0.85	**+**											Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy	**1- 5?**
IOC RCP				0.52-0.68	**-**											Time since diagnosis Age Chemotherapy Radiotherapy Surgery Hormone therapy	**1+ 5?**
IPOS	3-factor	CFI: 0.855 SRMR: 0.0002	**+**	0.77	**+**			Test-retest	0.83	**+**	**EQ-5D-3L** Self-rated health **EORTC QLQ-C15-PAL**	0.46 0.79	**±**			Cancer stage Prognosis Performance status	**3?**
IPOS PS				0.91	**+**			Test-retest	0.51	**-**	**EQ-5D-3L** Pain/discomfort Mobility	0.42 0.2	**±**			Cancer stage	**?**

IPOS EI				0.64	-			Test-retest	0.31	-	**EQ-5D-3L** Anxiety/depression	0.36	+			Cancer stage	?
IPOS SUP				0.75	+			Test-retest	0.5	-						Cancer stage	?
LAYA-SRQL	10-factor	CFI: 0.92 TLI: 0.9 RMSEA: 0.066 SRMR: 0.074	-	0.93	?						**SF-12** General health	0.56	+				
LAYA-SRQL INT				0.91	?												
LAYA-SRQL COG				0.9	?						**SF-12** Mental health	0.52	+				
LAYA-SRQL FER				0.84	?												
LAYA-SRQL EDU				0.82	?												
LAYA-SRQL VIT				0.84	?						**SF-12** Vitality Physical functioning Role physical	 0.64 0.58 0.61	+				
LAYA-SRQL HC				0.72	?												
LAYA-SRQL REL				0.78	?						**SF-12** Social functioning	0.29	+				
LAYA-SRQL DEP				0.76	?						**SF-12** Social functioning Physical functioning Role physical	 0.44 0.37 0.33	+				
LAYA-SRQL SPI				0.85	?												
LAYA-SRQL COP				0.83	?						**SF-12** Role emotional	0.6	+				
MDASI[1]	2-factor	EFA	?								**EORTC QLQ-C30** Global health status	0.6	+				
MDASI[1] **II**				0.84-0.9	?						**EORTC QLQ-C30** Physical functioning Role functioning Social functioning	 0.72 0.73 0.32	+			Performance status	+
MDASI[1] **SI**				0.82-0.85	?						**BPI** **EORTC QLQ-C30** Emotional functioning Cognitive functioning Pain Fatigue Nausea/vomiting Dyspnoea Insomnia Appetite loss	0.84 0.71 0.58 0.78 0.69 0.68 0.74 0.72 0.86	+			Performance status	+

MDASI[2]	3-factor	EFA	**?**	0.85	**?**												
MDASI[2] F1				0.85	**?**			Test-retest	0.98-0.99	**+**						Performance status	**?**
MDASI[2] F2				0.75-0.77	**?**			Test-retest	0.98-0.99	**+**						Performance status	**?**
MDASI[2] F3				0.68-0.70	**?**			Test-retest	0.98-0.99	**+**						Performance status	**?**
MDASI[3]	3-factor	EFA	**?**														
MDASI[3] GS				0.79	**?**												
MDASI[3] ECC				0.73	**?**												
MDASI[3] GIC				0.71	**?**												
POS 1.0											**RSCL** Global	0.6	**+**				
POS 1.0 PAI								Interrater Test-retest	0.33-0.54 0.6	**-**	**BPI** Pain Intensity **RSCL** Pain	0.7 0.5	**+**				
POS 1.0 OS								Interrater Test-retest	0.39-0.50 0.5	**-**	**RSCL** Physical	0.5	**+**				
POS 1.0 ANX								Interrater Test-retest	0.32-0.49 0.7	**-**							
POS 1.0 FA								Interrater Test-retest	0.11-0.41 0.5	**-**							
POS 1.0 INF								Interrater Test-retest	0.10-0.36 0.5	**-**							
POS 1.0 SUP								Interrater	0.01-0.33	**-**							
POS 1.0 LW								Interrater	0.27-0.45	**-**							
POS 1.0 SW								Interrater	0.16-0.22	**-**							
POS 1.0 WT								Interrater	0.25-0.44	**-**							
POS 1.0 PA								Interrater	0.04-0.37	**-**							
POS 2.0				0.67	**?**			Interrater Test-retest	0.56 0.72	**±**	**EORTC QLQ-C15-PAL** Global QoL	0.23	**-**				
POS 2.0 PAI								Interrater Test-retest	0.68 0.66	**-**	**EORTC QLQ-C15-PAL** Pain	0.77	**+**				
POS 2.0 OS								Interrater Test-retest	0.58 0.2	**-**	**EORTC QLQ-C15-PAL** Pain Nausea/vomiting Dyspnoea Insomnia Appetite loss Constipation	 0.3 0.41 0.04 0.18 0.32 0.26	**±**				
POS 2.0 ANX								Interrater Test-retest	0.43 0.68	**-**	**EORTC QLQ-C15-PAL** Emotional functioning	0.51	**+**				

POS 2.0 FA								Interrater Test-retest	0.26 0.59	-							
POS 2.0 INF								Interrater Test-retest	0.28 0.79	±							
POS 2.0 SF								Interrater Test-retest	0.3 0.03	-							
POS 2.0 DEP								Interrater Test-retest	0.47 0.59	-	**EORTC QLQ-C15-PAL** Emotional functioning	0.68	+				
POS 2.0 FAP								Interrater Test-retest	0.33 0.68	-	**EORTC QLQ-C15-PAL** Emotional functioning **FACIT-Sp**	0.41 0.4	+				
POS 2.0 WT								Interrater Test-retest	0.3 0.27	-							
POS 2.0 PA								Interrater Test-retest	0.23 0.17	-							
QUAL	3-factor	EFA	?	0.77	?												
QUAL RWH				0.81	?												
QUAL LC				0.77	?						**Experiences in close relationships scale**	0.54	+				
QUAL PEL				0.64	?						**Demoralization scale** **Generalized anxiety disorder questionnaire** **FACIT-Sp** **Patient Health Questionnaire** Depression	0.42 0.29 0.29 0.23	+				
SCNS-SF34[1]	5-factor	CFI: 0.98 TLI: 0.98 RMSEA: 0.052	+														
SCNS-SF34[1] PSY				0.80-0.93	+			Test-retest	>0.70	+	**EORTC QLQ-C30** Emotional functioning	0.64	+			Age Education level Children Disease status	**3+** **1-**
SCNS-SF34[1] HSI				0.80-0.93	+			Test-retest	>0.70	+	**EORTC IN-PATSAT32** Doctor's information provision Nurses' information provision Other personnel information Information exchange	0.6 0.43 0.48 0.49	+			Age Education level Children Disease status	**2+** **2-**

SCNS-SF34[1] PCS				0.80-0.93	+			Test-retest	>0.70	+	**EORTC IN-PATSAT32** Doctor's interpersonal skills Nurses' interpersonal skills	0.4 0.36	+			Age Education level Children Disease status	**4-**
SCNS-SF34[1] PDL				0.80-0.93	+			Test-retest	0.62	-	**EORTC QLQ-C30** Physical functioning Role functioning Fatigue Pain	0.56 0.46 0.57 0.53	+			Age Education level Children Disease status	**3+** **1-**
SCNS-SF34[1] SEX				0.71-0.93	+			Test-retest	>0.70	+						Age Education level Children Disease status	**2+** **2-**
SCNS-SF34[2]	4-factor	CFI: 0.567 TLI: 0.538 RMSEA: 0.278	-														
SCNS-SF34[2] PSY				0.95	?			Test-retest	0.74-0.83	+	**EORTC QLQ-C30** Emotional functioning **HADS** Anxiety Depression	0.64 0.65 0.64	+			Age Gender Treatment regime	**1+** **2-**
SCNS-SF34[2] HIP				0.95	?			Test-retest	0.74-0.83	+						Age Treatment regime Time since last treatment	**1+** **2-**
SCNS-SF34[2] PDL				0.89	?			Test-retest	0.83	+	**EORTC QLQ-C30** Physical functioning Role functioning Fatigue Pain	0.5 0.63 0.64 0.47	+			Gender Treatment regime	**1+** **1-**
SCNS-SF34[2] SEX				0.79	?			Test-retest	0.74	+	**EORTC QLQ H&N35** Sexuality	0.47	+			Age Gender	**2-**
SPARC	6-factor	EFA	?														
SPARC PS				0.68	?											Treatment location	?
SPARC PSS				0.86	?											Treatment location	?
SPARC RSI				0.65	?											Treatment location	?
SPARC IA				0.77	?											Treatment location	?
SPARC FSI				0.80	?											Treatment location	?
SPARC TI				0.62	?											Treatment location	?
SUNS-SF	4-factor	CFI: 0.924 TLI: 0.912	-														

		RMSEA: 0.064															
SUNS-SF INF				0.77	**?**												
SUNS-SF FC				0.92	**?**												
SUNS-SF ACC				0.73	**?**												
SUNS-SF REH				0.81	**?**						HADS	0.63	**+**				
WHOQoL-BREF	4-factor	CFI: 0.896 RMSEA: 0.058	**+**								**EORTC QLQ-C30** Global health status	0.67	**+**			Adverse events Adverse events with CTCAE grade 3 or 4 Performance status EORTC QLQ-C30 GHS	**4?**
WHOQoL-BREF PH				0.81	**+**						**EORTC QLQ-C30** Physical functioning Role functioning Pain Insomnia	0.73 0.73 0.62 0.49	**+**	**-**	**-**	Adverse events Adverse events with CTCAE grade 3 or 4 Performance status EORTC QLQ-C30 GHS	**4?**
WHOQoL-BREF PSH				0.77	**+**						**EORTC QLQ-C30** Emotional functioning	0.61	**+**	**-**	**-**	Adverse events Adverse events with CTCAE grade 3 or 4 Performance status EORTC QLQ-C30 GHS	**4?**
WHOQoL-BREF SR				0.57	**-**						**EORTC QLQ-C30** Social functioning	0.07	**-**	**-**	**-**	Adverse events Adverse events with CTCAE grade 3 or 4 Performance status EORTC QLQ-C30 GHS	**4?**
WHOQoL-BREF ENV				0.77	**+**									**-**	**+**	Adverse events Adverse events with CTCAE grade 3 or 4 Performance status EORTC QLQ-C30 GHS	**4?**
WHOQoL-100				0.96	**?**						**SF-36** General health	0.65	**+**			Clinical status	**+**
WHOQoL-100 PHY				0.85-0.88	**?**			Test-retest	0.78	**+**	**SF-36** Physical functioning Role limitations physical Pain Energy/fatigue	0.53 0.67 0.64 0.71	**+**			Clinical status	**+**
WHOQoL-100 PSY				0.68-0.89	**?**			Test-retest	0.8	**+**	**BDI** **BSI** **CESD** **STAI** **SF-36** Emotional well-being	0.71 0.66 0.63-0.67 0.62-0.70 0.69	**+**			Clinical status	**-**

WHOQoL-100 LOI				0.94	**?**			Test-retest	0.94	**+**						Clinical status	**+**
WHOQoL-100 SR				0.71-0.82	**?**			Test-retest	0.82	**+**	**SF-36** Social functioning	0.24	**-**			Clinical status	**-**
WHOQoL-100 ENV				0.83-0.88	**?**			Test-retest	0.86	**+**						Clinical status	**-**
WHOQoL-100 SPI				0.86	**?**			Test-retest	0.86	**+**						Clinical status	**-**
3LNQ																	
3LNQ PI																	
3LNQ PB																	
3LNQ FN																	

Abbreviations: + = sufficient results; - = insufficient results; ± = inconsistent results; ? = indeterminate; [1] = model 1; [2] = model 2; [3] = model 3; [4] = model 4, [5] = model 5; empty cells indicate data are not available **ADL** = Activities of Daily Living questionnaire; **BDI** = Beck Depression Inventory; **BPI** = Brief Pain Inventory; **BSI** = Brief Symptom Inventory; **CANDI** DEP = depression; ANX = anxiety; PHY = physical; SOC = social; **CARES** PF = physical functioning; PSY = psychological; MED = medical; MAR = marital; SEX = sexual; **CARES-SF** PHY = physical; PSY = psychological; MED = medical; SEX = sexual; MAR = marital; RAF = relatives and friends; **CaSUN** ES = existential survivorship; PES = psychological & emotional support; CC = comprehensive care; INF = information, REL = relationships; PHE = physical effects; PSE = psychological effects; CCI = comprehensive care & information; PI = practical issues; **CESD** = Center for Epidemiologic Studies Depression scale; **CCEQ** MA = managing appointments; COC = coordination of care; GPI = general practioner involvement; IAQ = information and questions; MTD = making treatment decisions; CT = clinical trials; SNR = symptom non-reporting; KW = key worker; LIM = limitations; SN = sustaining normality; FA = financial advice; WAA = worries and anxiety; SFO = sharing feelings with others; AS = assessing support; **CFA** = confirmatory factor analysis; **CFI** = comparative fit index; **DLQI** = Dermatology Life Quality Index; **ECOG** score = Eastern Cooperative Oncology Group score; **EFA** = exploratory factor analysis; **EORTC CAT** PF = physical functioning; RF = role functioning; CF = cognitive functioning; EF = emotional functioning; SF = social functioning; FAT = fatigue; PAI = pain, NV = nausea & vomiting; DYS = dyspnoea; AL = appetite loss; INS = insomnia; CON = constipation; DIA = diarrhoea; FI = financial impact; **EORTC IN-PATSAT32** = EORTC satisfaction with in-patient health care module; **EORTC QLQ-C30** PF = physical functioning; RF = role functioning; CF = cognitive functioning; EF = emotional functioning; SF = social functioning; FAT = fatigue; PAI = pain, NV = nausea & vomiting; GHS = global health status; DYS = dyspnoea; AL = appetite loss; INS = insomnia; CON = constipation; DIA = diarrhoea; FI = financial impact; QoL = quality of life; PH = physical health; **EORTC QLQ-ELD14** MOB = mobility; WAO = worries about others; FW = future worries; MP = maintaining purpose; BOI = burden of illness; JS = joint stiffness; FS = family support; **EORTC QLQ-H&N35** = EORTC head & neck cancer module; **EQ-5D-3L** = EQ-5D 3-level; **ESAS** = Edmonton Symptom Assessment Scale; **ESAS-r** INS = insomnia; DEP = depression; DRO = drowsiness; LOA = lack of appetite; TIR = tiredness; PAI = pain; WB = well-being; ANX = anxiety; NAU = nausea; SOB = shortness of breath; **FACIT-PAL46** PWB = physical well-being; SWB = social well-being; EWB = emotional well-being; FWB = functional well-being; AC = additional concerns; **FACIT-Sp** = Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being; **FACT-G 2.0** PWB = physical well-being; FWB = functional well-being; SWB = social and family well-being; EWB = emotional well-being; **FACT-G 3.0** PWB = physical well-being; FWB = functional well-being; SWB = social and family well-being; EWB = emotional well-being; RWD = relationship with doctor; **FACT-LYM** = Functional Assessment of Cancer Therapy – Lymphoma; **FCRI** = Fear of Cancer Recurrence Inventory; **FLIC** = Functional Living Index Cancer; **GDS** = Geriatric Depression Scale; **HADS** = Hospital Anxiety and Depression Scale; **IADL** = Instrumental Activities of Daily Living questionnaire; **IOC** AE = altruism and empathy; HA = health awareness; MOC = meaning of cancer; PSE = positive self-evaluation; AC = appearance concerns; BCC = body change concerns; LI = life interference; WOR = worry; EC = employment concerns; RCNP = relationship concerns (not partnered); RCP = relationship concerns partnered; **IPOS** PS = physical symptoms; EI = emotional issues; SUP = support; **LAYA-SRQL** INT = intimacy; COG = cognition; FER = fertility; EDU = education; VIT = vitality; HC = healthcare; REL = relationship; DEP = dependence; SPI = spirituality; COP = coping; MDASI II = interference items; SI = symptom items; F1 = factor 1; F2 = factor 2; F3 = factor 3; GS = general symptoms; ECC = emotional and cognitive components; GIC = gastrointestinal component; **MFI** = Multidimensional Fatigue Inventory; **MMQ** = Maudsley Marital Questionnaire; **POS 1.0** PAI = pain; OS = other symptoms; ANX = anxiety; FA = family anxiety; INF = information; SUP = support; LW = life worthwhile; SW = self worth; WT = wasted time; PA = personal affairs; **POS 2.0** PAI = pain; ANX = anxiety; FA = family anxiety; INF = information; SF = sharing feelings; DEP = depression; FAP = feeling at peace; WT = wasted time; PA = personal affairs; **PTGI** = Post-traumatic Growth Inventory; **QLACS** = Quality of Life in Adult Cancer Survivors scale; **QUAL** RWH = relationship with healthcare provider; LC = life completion; PEL = preparation for end of life; **Res. Corr.** = Residual correlation; **RMSEA** = Root Mean Square Error of Approximation; **RSCL** = Rotterdam Symptom Checklist; **RS-14** = 14-item resilience scale; **SCNS-SF34** PSY = psychological; HSI = health system information; PCS = patient care and support; PDL = physical and daily living; SEX = sexuality; HIP = health system, information and patient support; **SF-12** = Short-Form 12 items; **SF-36** = Short-Form 36 items; **SPARC** PS = physical symptoms; PSS = psychological symptoms; RSI = religious and spiritual issues; IA = independence and activity; FSI = family and social issues; TI = treatment issues; **SRMR** = Standardized Root Mean Residuals; **SSL-D** = Social Support List-Discrepancies; **STAI** = State-Trait Anxiety Inventory; **SUNS-SF**

INF = information; FC = financial concerns; ACC = access and continuity of care; REH = relationship and emotional health; **TLI** = Tucker-Lewis Index; **WHOQoL-BREF** PH = physical health; PSH = psychological health; SR = social relationships; ENV = environment; **WHOQoL-100** PHY = physical; PSY = psychological; LOI = level of independence; SR = social relationships; ENV = environment; SPI = spiritual; **3LNQ** PI = problem intensity; PB = problem burden; FN = felt need

Table 12: Summary of findings and quality of evidence for final set of PROMs (n = 35)

PROM	Development & content validity		Structural validity		Internal consistency		Cross-cultural validity/ Measurement invariance		Reliability		Construct validity							
											Construct validity with other PROM		Convergent validity within PROM		Divergent validity within PROM		Known-group comparison	
	Rating	LoE	Rating	LoE	Rating	LoE	Rating	LoE	Rating	LoE	Rating	LoE	Rating	LoE	Rating	LoE	Rating	LoE
CANDI	±	Low	?	Very low	?	Very low			+	Very low	+	High						
CANDI DEP	±	Low							+	Very low	+	High						
CANDI ANX	±	Low							+	Very low	+	High						
CANDI PHY	±	Low																
CANDI SOC	±	Low																
CARES	±	Low	?	Very low	?	Low			+	Low	+	Very low						
CARES PF	±	Low			?	Low			+	Low	+	Very low						
CARES PSY	±	Low			?	Low			+	Low	+	Very low						
CARES MED	±	Low			?	Low			+	Low								
CARES MAR	±	Low			?	Low			+	Low	-	Very low						
CARES SEX	±	Low			?	Low			+	Low	+	Very low						
CARES-SF[1]	±	Low	?	Very low	?	Low			+	Very low	+	High						
CARES-SF[1] PHY	±	Low			?	Low			+	Very low	+	High						
CARES-SF[1] PSY	±	Low			?	Low			+	Very low								
CARES-SF[1] MED	±	Low			?	Low			+	Very low	-	High						
CARES-SF[1] SEX	±	Low			?	Low			+	Very low	-	High						
CARES-SF[1] MAR	±	Low			?	Low			+	Very low								
CARES-SF[1] RAF	±	Low			?	Low			+	Very low	+	High						
CARES-SF[2]	±	Low	?	Very low	?	Low			+	Low							?	Very low
CARES-SF[2] PHY	±	Low			?	Low			+	Low			±	Moderate	-	High	?	Very low
CARES-SF[2] PSY	±	Low			?	Low			+	Low			-	High	-	High	?	Very low

CARES-SF[2] MED	±	Low			?	Low			+	Low			±	Moderate	±	Moderate	?	Very low
CARES-SF[2] SEX	±	Low			?	Low			+	Low			-	High	-	High	?	Very low
CARES-SF[2] MAR	±	Low			?	Low			+	Low			-	High	-	High	?	Very low
CaSUN[1]	+	High	-	Very low	?	Low			+	Very low	+	High						
CaSUN[1] ES	+	High			?	Low			+	Very low								
CaSUN[1] PES	+	High			?	Low			+	Very low								
CaSUN[1] CC	+	High			?	Low			+	Very low								
CaSUN[1] INF	+	High			?	Low			+	Very low								
CaSUN[1] REL	+	High			?	Low			+	Very low								
CaSUN[2]	+	High	-	Moderate	?	Very low			+	Very low								
CaSUN[2] PHE	+	High			?	Very low			+	Very low	+	Moderate						
CaSUN[2] PSE	+	High			?	Very low			+	Very low	+	Moderate						
CaSUN[2] CCI	+	High			?	Very low			-	Very low								
CaSUN[2] PI	+	High			?	Very low			+	Very low	+	Moderate						
CaSUN[2] REL	+	High			?	Very low			+	Very low	+	Moderate						
CCEQ	+	High																
CCEQ MA	+	High			?	Low							-	High	+	High	?	Very low
CCEQ COC	+	High			?	Low							+	High	+	High	?	Very low
CCEQ GPI	+	High			?	Low							+	High	+	High	?	Very low
CCEQ IAQ	+	High			?	Low							+	High	+	High	?	Very low
CCEQ MTD	+	High			?	Low							+	High	+	High	?	Very low
CCEQ CT	+	High			?	Low							+	High	+	High	?	Very low
CCEQ SNR	+	High			?	Low							+	High	+	High	?	Very low
CCEQ KW	+	High			?	Low							+	High	+	High	?	Very low
CCEQ LIM	+	High			?	Low							+	High	+	High	?	Very low
CCEQ SN	+	High			?	Low							+	High	+	High	?	Very low
CCEQ FA	+	High			?	Low							+	High	+	High	?	Very low
CCEQ WAA	+	High			?	Low							+	High	+	High	?	Very low
CCEQ SFO	+	High			?	Low							+	High	+	High	?	Very low
CCEQ AS	+	High			?	Low							-	High	+	High	?	Very low
EORTC CAT	+	High									+	High						

EORTC CAT PF	+	High	-	Low	?	Moderate	+	High			+	High					+	Moderate
EORTC CAT RF	+	High	+	Low	+	High	+	High			+	High						
EORTC CAT CF	+	High	+	High	+	High	+	High			+	High						
EORTC CAT EF	+	High	+	High	+	High	+	High			+	High					+	Moderate
EORTC CAT SF	+	High									+	High						
EORTC CAT FAT	+	High	+	High	+	High	+	High			+	High					+	Moderate
EORTC CAT PAI	+	High	+	Low	+	High	+	High			+	High						
EORTC CAT NV	+	High									+	High						
EORTC CAT GHS	+	High									+	High						
EORTC CAT DYS	+	High									+	High						
EORTC CAT AL	+	High									+	High						
EORTC CAT INS	+	High	+	High	+	High	+	High			+	High						
EORTC CAT CON	+	High									+	High						
EORTC CAT DIA	+	High									+	High						
EORTC CAT FI	+	High									+	High						
EORTC QLQ-C30[1]	+	High	+	High	+	Very low	±	Very low			+	High						
EORTC QLQ-C30[1] PF	+	High			+	High	+	Moderate	+	High	+	High	±	Moderate	±	Moderate	?	Low
EORTC QLQ-C30[1] RF	+	High			+	High	+	Moderate	±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] CF	+	High			±	Moderate	+	Moderate	+	High	+	High	±	Moderate	±	Moderate	?	Low
EORTC QLQ-C30[1] EF	+	High			+	High	+	Moderate	±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] SF	+	High			+	High	+	Moderate	±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] FAT	+	High			+	High	+	Moderate	±	Moderate	+	High	+	High	±	Moderate	?	Low
EORTC QLQ-C30[1] PAI	+	High			+	High	+	Moderate	±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] NV	+	High			±	Moderate	+	Moderate	±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1]GHS	+	High			+	High	+	Moderate	±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] DYS	+	High							±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] AL	+	High							±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] INS	+	High							±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] CON	+	High							±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] DIA	+	High							±	Moderate	+	High	+	High	+	High	?	Low
EORTC QLQ-C30[1] FI	+	High							±	Moderate	+	High	+	High	+	High	?	Low

EORTC QLQ-C30[2]	+	High	+	Moderate													?	Very low
EORTC QLQ-C30[3]	+	High	+	High														
EORTC QLQ-C30[3] QoL	+	High			+	High					+	High						
EORTC QLQ-C30[3] PH	+	High			+	High					+	High						
EORTC QLQ-C30[4]	+	High	-	Very low														
EORTC QLQ-C30[4] PF	+	High					+	Low										
EORTC QLQ-C30[4] RF	+	High					+	Low										
EORTC QLQ-C30[4] CF	+	High					+	Low										
EORTC QLQ-C30[4] EF	+	High					+	Low										
EORTC QLQ-C30[4] SF	+	High					+	Low										
EORTC QLQ-C30[4] GHS	+	High					+	Low										
EORTC QLQ-C30[5]	+	High	-	Very low														
EORTC QLQ-ELD14	+	High																
EORTC QLQ-ELD14 MOB	+	High			?	Moderate					+	High	+	High	+	High	±	Moderate
EORTC QLQ-ELD14 WAO	+	High			?	Moderate					-	High	±	Moderate	±	Moderate	±	Moderate
EORTC QLQ-ELD14 FW	+	High			?	Moderate					±	Moderate	+	High	+	High	±	Moderate
EORTC QLQ-ELD14 MP	+	High			?	Moderate							+	High	+	High	±	Moderate
EORTC QLQ-ELD14 BOI	+	High			?	Moderate					+	High	+	High	+	High	±	Moderate
EORTC QLQ-ELD14 JS	+	High									+	High			±	Moderate	±	Moderate
EORTC QLQ-ELD14 FS	+	High													±	Moderate	±	Moderate
ESAS-r	±	Low			?	Very low											?	Very low
ESAS-r INS	±	Low									+	Very low						
ESAS-r DEP	±	Low							-	Low	+	Very low					?	Very low
ESAS-r DRO	±	Low							-	Low	+	Very low					?	Very low
ESAS-r LOA	±	Low							-	Low	+	Very low					?	Very low
ESAS-r TIR	±	Low							-	Low	+	Very low					?	Very low
ESAS-r PAI	±	Low							-	Low	+	Very low					?	Very low
ESAS-r WB	±	Low							-	Low	+	Very low					?	Very low
ESAS-r ANX	±	Low							-	Low	+	Very low					?	Very low
ESAS-r NAU	±	Low							-	Low	+	Very low					?	Very low

ESAS-r SOB	±	Low							-	Low	+	Very low					?	Very low
FACIT-PAL14	±	Very low	-	Very low	?	Low					+	High						
FACIT-PAL46	±	Very low	-	Moderate	?	Moderate					+	High						
FACIT-PAL46 PWB	±	Very low			?	Moderate					+	High						
FACIT-PAL46 SWB	±	Very low			?	Moderate												
FACIT-PAL46 EWB	±	Very low			?	Moderate					+	High						
FACIT-PAL46 FWB	±	Very low			?	Moderate					+	High						
FACIT-PAL46 AC	±	Very low			?	Moderate												
FACT-G 2.0	±	Low	?	Very low	?	Low	+	Low	+	Low							?	Very low
FACT-G 2.0 PWB	±	Low			?	Moderate	+	Low	+	Low							?	Very low
FACT-G 2.0 FWB	±	Low			?	Moderate	+	Low	+	Low							?	Very low
FACT-G 2.0 SWB	±	Low			?	Moderate	+	Low	+	Low							?	Very low
FACT-G 2.0 EWB	±	Low			?	Moderate	+	Low	+	Low							?	Very low
FACT-G 3.0	±	Low	?	Very low	?	Low			+	Low	+	Low					?	Very low
FACT-G 3.0 PWB	±	Low			?	Low					+	Low					?	Very low
FACT-G 3.0 FWB	±	Low			?	Low					+	Low					?	Very low
FACT-G 3.0 SWB	±	Low			?	Low					-	Low					?	Very low
FACT-G 3.0 EWB	±	Low			?	Low					+	Low					?	Very low
FACT-G 3.0 RWD	±	Low			?	Low					+	Low						
IOC	+	Low	+	Low														
IOC AE	+	Low			+	High			-	Very low	+	Very low					?	Very low
IOC HA	+	Low			+	High			-	Very low							?	Very low
IOC MOC	+	Low			+	High			+	Very low	+	Very low					?	Very low
IOC PSE	+	Low			-	High			-	Very low	+	Very low					?	Very low
IOC AC	+	Low			+	High			-	Very low							±	Moderate
IOC BCC	+	Low			+	High			+	Very low							±	Moderate
IOC LI	+	Low			+	High			-	Very low							±	Moderate
IOC WOR	+	Low			+	High			+	Very low	+	Very low					±	Moderate
IOC EC	+	Low			±	Moderate											?	Very low
IOC RCNP	+	Low			+	High											?	Very low
IOC RCP	+	Low			-	High											?	Very low

IPOS	+	High	+	Moderate	+	Very low			+	Low	±	Moderate					?	Low
IPOS PS	+	High			+	Moderate			-	Very low	±	Low					?	Very low
IPOS EI	+	High			-	Moderate			-	Very low	+	Low					?	Very low
IPOS SUP	+	High			+	Moderate			-	Very low							?	Very low
LAYA-SRQL	±	Very low	-	Moderate	?	Very low					+	Very low						
LAYA-SRQL INT	±	Very low			?	Very low												
LAYA-SRQL COG	±	Very low			?	Very low					+	Very low						
LAYA-SRQL FER	±	Very low			?	Very low												
LAYA-SRQL EDU	±	Very low			?	Very low												
LAYA-SRQL VIT	±	Very low			?	Very low					+	Very low						
LAYA-SRQL HC	±	Very low			?	Very low												
LAYA-SRQL REL	±	Very low			?	Very low					+	Very low						
LAYA-SRQL DEP	±	Very low			?	Very low					+	Very low						
LAYA-SRQL SPI	±	Very low			?	Very low												
LAYA-SRQL COP	±	Very low			?	Very low					+	Very low						
MDASI[1]	±	Low	?	Very low							+	Low						
MDASI[1] II	±	Low			?	Moderate					+	Low					+	High
MDASI[1] SI	±	Low			?	Moderate					+	Low					+	High
MDASI[2]	±	Low	?	Very low	?	Low												
MDASI[2] F1	±	Low			?	Low			+	Low							?	Very low
MDASI[2] F2	±	Low			?	Low			+	Low							?	Very low
MDASI[2] F3	±	Low			?	Low			+	Low							?	Very low
MDASI[3]	±	Low	?	Very low														
MDASI[3] GS	±	Low			?	Low												
MDASI[3] ECC	±	Low			?	Low												
MDASI[3] GIC	±	Low			?	Low												
POS 1.0	+	High									+	Very low						
POS 1.0 PAI	+	High							-	Moderate	+	Very low						
POS 1.0 OS	+	High							-	Moderate	+	Very low						
POS 1.0 ANX	+	High							-	Moderate								
POS 1.0 FA	+	High							-	Moderate								

POS 1.0 INF	+	High							-	Moderate								
POS 1.0 SUP	+	High							-	Moderate								
POS 1.0 LW	+	High							-	Moderate								
POS 1.0 SW	+	High							-	Moderate								
POS 1.0 WT	+	High							-	Moderate								
POS 1.0 PA	+	High							-	Moderate								
POS 2.0	+	High			?	Low			±	Low	-	High						
POS 2.0 PAI	+	High							-	Moderate	+	High						
POS 2.0 OS	+	High							-	Moderate	±	Moderate						
POS 2.0 ANX	+	High							-	Moderate	+	High						
POS 2.0 FA	+	High							-	Moderate								
POS 2.0 INF	+	High							±	Low								
POS 2.0 SF	+	High							-	Moderate								
POS 2.0 DEP	+	High							-	Moderate	+	High						
POS 2.0 FAP	+	High							-	Moderate	+	High						
POS 2.0 WT	+	High							-	Moderate								
POS 2.0 PA	+	High							-	Moderate								
QUAL	±	Very low	?	Very low	?	Low												
QUAL RWH	±	Very low			?	Low												
QUAL LC	±	Very low			?	Low					+	Moderate						
QUAL PEL	±	Very low			?	Low					+	Moderate						
SCNS-SF34[1]	±	Low	+	Moderate														
SCNS-SF34[1] PSY	±	Low			+	High			+	Very low	+	Moderate					+	Moderate
SCNS-SF34[1] HSI	±	Low			+	High			+	Very low	+	Moderate					±	Low
SCNS-SF34[1] PCS	±	Low			+	High			+	Very low	+	Moderate					-	Moderate
SCNS-SF34[1] PDL	±	Low			+	High			-	Very low	+	Moderate					+	Moderate
SCNS-SF34[1] SEX	±	Low			+	High			+	Very low							±	Low
SCNS-SF34[2]	±	Low	-	Low														
SCNS-SF34[2] PSY	±	Low			?	Very low			+	Low	+	Moderate					±	Very low
SCNS-SF34[2] HIP	±	Low			?	Very low			+	Low							±	Very low
SCNS-SF34[2] PDL	±	Low			?	Very low			+	Low	+	Moderate					±	Very low

SCNS-SF34[2] SEX	±	Low			?	Very low			+	Low	+	Moderate					-	Low
SPARC	+	High	?	Very low														
SPARC PS	+	High			?	Very low											?	Very low
SPARC PSS	+	High			?	Very low											?	Very low
SPARC RSI	+	High			?	Very low											?	Very low
SPARC IA	+	High			?	Very low											?	Very low
SPARC FSI	+	High			?	Very low											?	Very low
SPARC TI	+	High			?	Very low											?	Very low
SUNS-SF	+	High	-	Very low														
SUNS-SF INF	+	High			?	Very low												
SUNS-SF FC	+	High			?	Very low												
SUNS-SF ACC	+	High			?	Very low												
SUNS-SF REH	+	High			?	Very low					+	Moderate						
WHOQoL-BREF	±	Very low	+	Low							+	Moderate					?	Very low
WHOQoL-BREF PH	±	Very low			+	Moderate					+	Moderate	-	Moderate	-	Moderate	?	Very low
WHOQoL-BREF PSH	±	Very low			+	Moderate					+	Moderate	-	Moderate	-	Moderate	?	Very low
WHOQoL-BREF SR	±	Very low			-	Moderate					-	Moderate	-	Moderate	-	Moderate	?	Very low
WHOQoL-BREF ENV	±	Very low			+	Moderate							-	Moderate	+	Moderate	?	Very low
WHOQoL-100	±	Very low			?	Very low					+	Moderate					+	Very low
WHOQoL-100 PHY	±	Very low			?	Low			+	Very low	+	Moderate					+	Very low
WHOQoL-100 PSY	±	Very low			?	Low			+	Very low	+	Moderate					-	Very low
WHOQoL-100 LOI	±	Very low			?	Very low			+	Very low							+	Very low
WHOQoL-100 SR	±	Very low			?	Low			+	Very low	-	Moderate					-	Very low
WHOQoL-100 ENV	±	Very low			?	Low			+	Very low							-	Very low
WHOQoL-100 SPI	±	Very low			?	Very low			+	Very low							-	Very low
3LNQ	±	Low																
3LNQ PI	±	Low																
3LNQ PB	±	Low																
3LNQ FN	±	Low																

Abbreviations: + = sufficient results; - = insufficient results; ± = inconsistent results; ? = indeterminate; LoE = level of evidence; [1] = model 1; [2] = model 2; [3] = model 3; [4] = model 4, [5] = model 5; empty cells indicate data are not available; subscales with sufficient ratings of high- or moderate-level evidence are presented in green; subscales with insufficient ratings of high-or moderate-level evidence are presented in red

CANDI DEP = depression; ANX = anxiety; PHY = physical; SOC = social; **CARES** PF = physical functioning; PSY = psychological; MED = medical; MAR = marital; SEX = sexual; **CARES-SF** PHY = physical; PSY = psychological; MED = medical; SEX = sexual; MAR = marital; RAF = relatives and friends; **CaSUN** ES = existential survivorship; PES = psychological & emotional support; CC = comprehensive care; INF = information, REL = relationships; PHE = physical effects; PSE = psychological effects; CCI = comprehensive care & information; PI = practical issues; **CCEQ** MA = managing appointments; COC = coordination of care; GPI = general practioner involvement; IAQ = information and questions; MTD = making treatment decisions; CT = clinical trials; SNR = symptom non-reporting; KW = key worker; LIM = limitations; SN = sustaining normality; FA = financial advice; WAA = worries and anxiety; SFO = sharing feelings with others; AS = assessing support; **EORTC CAT** PF = physical functioning; RF = role functioning; CF = cognitive functioning; EF = emotional functioning; SF = social functioning; FAT = fatigue; PAI = pain, NV = nausea & vomiting; DYS = dyspnoea; AL = appetite loss; INS = insomnia; CON = constipation; DIA = diarrhoea; FI = financial impact; **EORTC QLQ-C30** PF = physical functioning; RF = role functioning; CF = cognitive functioning; EF = emotional functioning; SF = social functioning; FAT = fatigue; PAI = pain, NV = nausea & vomiting; GHS = global health status; DYS = dyspnoea; AL = appetite loss; INS = insomnia; CON = constipation; DIA = diarrhoea; FI = financial impact; QoL = quality of life; PH = physical health; **EORTC QLQ-ELD14** MOB = mobility; WAO = worries about others; FW = future worries; MP = maintaining purpose; BOI = burden of illness; JS = joint stiffness; FS = family support; **ESAS-r** INS = insomnia; DEP = depression; DRO = drowsiness; LOA = lack of appetite; TIR = tiredness; PAI = pain; WB = well-being; ANX = anxiety; NAU = nausea; SOB = shortness of breath; **FACIT-PAL46** PWB = physical well-being; SWB = social well-being; EWB = emotional well-being; FWB = functional well-being; AC = additional concerns; **FACT-G 2.0** PWB = physical well-being; FWB = functional well-being; SWB = social and family well-being; EWB = emotional well-being; **FACT-G 3.0** PWB = physical well-being; FWB = functional well-being; SWB = social and family well-being; EWB = emotional well-being; RWD = relationship with doctor; **IOC** AE = altruism and empathy; HA = health awareness; MOC = meaning of cancer; PSE = positive self-evaluation; AC = appearance concerns; BCC = body change concerns; LI = life interference; WOR = worry; EC = employment concerns; RCNP = relationship concerns (not partnered); RCP = relationship concerns partnered; **IPOS** PS = physical symptoms; EI = emotional issues; SUP = support; **LAYA-SRQL** INT = intimacy; COG = cognition; FER = fertility; EDU = education; VIT = vitality; HC = healthcare; REL = relationship; DEP = dependence; SPI = spirituality; COP = coping; **MDASI** II = interference items; SI = symptom items; F1 = factor 1; F2 = factor 2; F3 = factor 3; GS = general symptoms; ECC = emotional and cognitive components; GIC = gastrointestinal component; **POS 1.0** PAI = pain; OS = other symptoms; ANX = anxiety; FA = family anxiety; INF = information; SUP = support; LW = life worthwhile; SW = self worth; WT = wasted time; PA = personal affairs; **POS 2.0** PAI = pain; ANX = anxiety; FA = family anxiety; INF = information; SF = sharing feelings; DEP = depression; FAP = feeling at peace; WT = wasted time; PA = personal affairs; **QUAL** RWH = relationship with healthcare provider; LC = life completion; PEL = preparation for end of life; **SCNS-SF34** PSY = psychological; HSI = health system information; PCS = patient care and support; PDL = physical and daily living; SEX = sexuality; HIP = health system, information and patient support; **SPARC** PS = physical symptoms; PSS = psychological symptoms; RSI = religious and spiritual issues; IA = independence and activity; FSI = family and social issues; TI = treatment issues; **SUNS-SF** INF = information; FC = financial concerns; ACC = access and continuity of care; REH = relationship and emotional health; **WHOQoL-BREF** PH = physical health; PSH = psychological health; SR = social relationships; ENV = environment; **WHOQoL-100** PHY = physical; PSY = psychological; LOI = level of independence; SR = social relationships; ENV = environment; SPI = spiritual; **3LNQ** PI = problem intensity; PB = problem burden; FN = felt need

Table 16: Feasibility of PROMs with sufficient content validity (n = 24)

PROM	Available languages	Copyright	Academic use	Time of completion (minutes)	Scoring manual available	Reference values available
CANDI	English, Turkish	NA	NA	NA	NA	Yes
CARES	English, Dutch, Spanish, Swedish	Yes	Free	10-30	Yes	Yes
CARES-SF	English, Turkish	Yes	Free	20	Yes	Yes
CaSUN	English, Chinese, Dutch, Japanese, Korean (2 additional languages, see Appendix 12)	No	NA	10	Yes	NA
CCEQ	NA	NA	NA	NA	NA	NA
EORTC CAT	English, French, German, Italian, Spanish (5 additional languages, see Appendix 12)	Yes	Free	12	Yes	Yes
EORTC QLQ-C30	English, French, German, Italian, Spanish (85 additional languages, see Appendix 12)	Yes	Free	11	Yes	Yes
EORTC QLQ-ELD14	English, French, German, Italian, Spanish (17 additional languages, see Appendix 12)	Yes	Free	15	Yes	Yes
ESAS-r	English, French, German, Italian, Spanish (33 additional languages, see Appendix 12)	No	Free	NA	NA	No
FACT-G	English, French, German, Italian, Spanish (67 additional languages, see Appendix 12)	Yes	Free	5-10	Yes	Yes
FACIT-PAL14	English, German, Spanish (16 additional languages, see Appendix 12)	Yes	Free	< 5	Yes	NA
FACIT-PAL46	English, German, Spanish (16 additional languages, see Appendix 12)	Yes	NA	10-15	Yes	NA
IOC	English, Dutch, French, Italian, Norwegian	NA	Free	10-15	Yes	NA
IPOS	English, German, French, Italian (10 additional languages, see Appendix 12)	Yes	Free	NA	Yes	NA
LAYA-SRQL	English, German	NA	NA	NA	NA	Yes
MDASI	English, French, German, Italian, Spanish (35 additional languages, see Appendix 12)	Yes	Free	5	NA	Yes
POS	English, Chinese, Dutch, Japanese, Norwegian (1 additional language, see Appendix 12)	Yes	Free	4-10	Yes	NA

QUAL	English	NA	NA	NA	NA	NA
SCNS-SF34	English, French, German, Japanese, Spanish (1 additional language, see Appendix 12)	Yes	NA	10	Yes	NA
SPARC	English, Korean, Polish	NA	NA	NA	NA	NA
SUNS-SF	English, Chinese, Persian	NA	NA	NA	NA	NA
WHOQoL-BREF	English, French, German, Italian, Spanish (69 additional languages, see Appendix 12)	Yes	Free	5	Yes	NA
WHOQoL-100	English, French, German, Italian, Spanish (26 additional languages, see Appendix 12)	Yes	Free	10-20	Yes	NA
3NLQ	English, Danish	NA	NA	NA	NA	NA

Abbreviations: NA = information not found; Yes = copyrighted or available; No = not copyrighted or not available

Table 17: Mapping HRQoL-framework of WP4 with best-evidence recommendations

HRQoL framework	Development & content validity	Structural validity	Internal consistency	Cross-cultural validity/ Measurement invariance	Reliability	Construct validity			
						Construct validity with other PROM	Convergent validity within PROM	Divergent validity within PROM	Known-group comparison
PHYSICAL HEALTH									
Pain/Pain interference	EORTC CAT PAI EORTC QLQ-C30 PAI IPOS PS	EORTC CAT PAI EORTC QLQ-C30 PAI IPOS PS	EORTC CAT PAI EORTC QLQ-C30 PAI IPOS PS	EORTC CAT PAI EORTC QLQ-C30 PAI		EORTC CAT PAI EORTC QLQ-C30 PAI	EORTC QLQ-C30 PAI	EORTC QLQ-C30 PAI	
Fatigue	EORTC CAT FAT EORTC QLQ-C30 FAT IPOS PS	EORTC CAT FAT EORTC QLQ-C30 FAT IPOS PS	EORTC CAT FAT EORTC QLQ-C30 FAT IPOS PS	EORTC CAT FAT EORTC QLQ-C30 FAT		EORTC CAT FAT EORTC QLQ-C30 FAT	EORTC QLQ-C30 FAT		EORTC CAT FAT
Insomnia	EORTC CAT INS	EORTC CAT INS	EORTC CAT INS	EORTC CAT INS		EORTC CAT INS			
Appetite loss	IPOS PS	IPOS PS	IPOS PS						
Nausea	IPOS PS	IPOS PS	IPOS PS						
Constipation	IPOS PS	IPOS PS	IPOS PS						
Diarrhoea									
Dyspnoea	IPOS PS	IPOS PS	IPOS PS						
Sensory neuropathy									
Symptom awareness									
Impact of treatment side-effects	IOC LI								
Mobility	EORTC QLQ C30 PH IPOS PS	EORTC QLQ C30 PH IPOS PS	EORTC QLQ C30 PH IPOS PS	EORTC QLQ C30 PH		EORTC QLQ C30 PH			
Physical exercise	EORTC QLQ C30 PH	EORTC QLQ C30 PH	EORTC QLQ C30 PH	EORTC QLQ C30 PH		EORTC QLQ C30 PH			
Activities daily living	EORTC CAT RF EORTC QLQ C30 PH EORTC QLQ-C30 RF	EORTC CAT RF EORTC QLQ C30 PH EORTC QLQ-C30 RF	EORTC CAT RF EORTC QLQ C30 PH EORTC QLQ-C30 RF	EORTC CAT RF EORTC QLQ C30 PH EORTC QLQ-C30 RF		EORTC CAT RF EORTC QLQ C30 PH EORTC QLQ-C30 RF	EORTC QLQ-C30 RF	EORTC QLQ-C30 RF	

Instrumental ADL	EORTC QLQ C30 PH	EORTC QLQ C30 PH	EORTC QLQ C30 PH	EORTC QLQ C30 PH		EORTC QLQ C30 PH			
Physical sexual problems									
Sexual pleasure									
Body image	IOC AC	IOC AC	IOC AC						
OTHERS **Sore or dry mouth** **Lack of energy** **Vomiting** **Lack of energy**	 IPOS PS IPOS PS IPOS PS IOC BCC	 IPOS PS IPOS PS IPOS PS IOC BCC	 IPOS PS IPOS PS IPOS PS IOC BCC		 IOC BCC				
MENTAL HEALTH									
Anxiety	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF		EORTC CAT EF EORTC QLQ-C30 EF	EORTC QLQ-C30 EF	EORTC QLQ-C30 EF	EORTC CAT EF
Depression	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF		EORTC CAT EF EORTC QLQ-C30 EF	EORTC QLQ-C30 EF	EORTC QLQ-C30 EF	EORTC CAT EF
Psychological distress	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF	EORTC CAT EF EORTC QLQ-C30 EF		EORTC CAT EF EORTC QLQ-C30 EF	EORTC QLQ-C30 EF	EORTC QLQ-C30 EF	EORTC CAT EF
Fear of recurrence	IOC WOR	IOC WOR	IOC WOR		IOC WOR	IOC WOR			
Uncertain prognosis	IOC WOR	IOC WOR	IOC WOR		IOC WOR	IOC WOR			
Future life plans	IOC LI								
Cognitive problems	EORTC CAT CF	EORTC CAT CF	EORTC CAT CF	EORTC CAT CF		EORTC CAT CF			
Positive affect	IOC MOC	IOC MOC	IOC MOC		IOC MOC	IOC MOC			
Life satisfaction	IOC MOC	IOC MOC	IOC MOC		IOC MOC	IOC MOC			
Spirituality									
Meaning and purpose									
OTHERS **Altruism and empathy** **Feeling misunderstood** **Being embarrassed about physical limitations** **Coping** **Increased body awareness**	 IOC AE IOC LI IOC BCC IOC HA IOC HA	 IOC AE IOC LI IOC BCC IOC HA IOC HA	 IOC AE IOC LI IOC BCC IOC HA IOC HA		 IOC BCC	 IOC AE			

SOCIAL HEALTH									
Ability to work									
Leisure activities – Hobbies	EORTC QLQ-C30 SF IOC LI	EORTC QLQ-C30 SF IOC LI	EORTC QLQ-C30 SF IOC LI	EORTC QLQ-C30 SF		EORTC QLQ-C30 SF	EORTC QLQ-C30 SF	EORTC QLQ-C30 SF	
Leisure travel	IOC LI								
Social activity limitations	EORTC QLQ-C30 SF IOC LI	EORTC QLQ-C30 SF IOC LI	EORTC QLQ-C30 SF IOC LI	EORTC QLQ-C30 SF		EORTC QLQ-C30 SF	EORTC QLQ-C30 SF	EORTC QLQ-C30 SF	
Impact on children/family	EORTC QLQ-C30 SF IOC RCNP	EORTC QLQ-C30 SF IOC RCNP	EORTC QLQ-C30 SF IOC RCNP	EORTC QLQ-C30 SF		EORTC QLQ-C30 SF	EORTC QLQ-C30 SF	EORTC QLQ-C30 SF	
Fertility									
Partner relations									
Social isolation	IOC LI	IOC LI	IOC LI						
Social support	IPOS SUP	IPOS SUP	IPOS SUP						
Self-efficacy and confidence	IOC HA	IOC HA	IOC HA						
Maintain independence	EORTC QLQ C30 PH	EORTC QLQ C30 PH	EORTC QLQ C30 PH	EORTC QLQ C30 PH		EORTC QLQ C30 PH			
Financial difficulties	IPOS SUP	IPOS SUP	IPOS SUP						
Insurance problems									
GLOBAL QUALITY OF LIFE									
Overall quality of life	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS		EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	
Health behaviour change	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS		EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	EORTC QLQ-C30 GHS	

Abbreviations: empty cells indicate data are not available

EORTC CAT RF = role functioning; CF = cognitive functioning; EF = emotional functioning; FAT = fatigue; PAI = pain; INS = insomnia; **EORTC QLQ-C30** PF = physical functioning; RF = role functioning; EF = emotional functioning; SF = social functioning; FAT = fatigue; PAI = pain; GHS = global health status; **IOC** AE = altruism and empathy; HA = health awareness; MOC = meaning of cancer; AC = appearance concerns; BCC = body change concerns; LI = life interference; WOR = worry; RCNP = relationship concerns (not partnered); **IPOS** PS = physical symptoms; SUP = support

4. Discussion

The EUonQOL project aims at developing a novel PROM for the assessment of HRQoL in cancer patients and survivors that can be used across the EU and its associated countries, while maintaining adequate measurement properties (EUonQOL toolkit). Leveraging on the body of evidence already available is a natural first step towards the completion of this aim. The systematic review presented in this chapter provides a comprehensive overview of the evidence in the published literature on the measurement properties of the PROMs currently available for the assessment of HRQoL of European cancer patients and survivors. The main objective was to identify the most appropriate PROMs to serve as a basis for the development of the EUonQOL toolkit and to provide evidence-based recommendations to the EUonQOL consortium.

This review led to the identification of 35 unique[5] PROMs and to the assessment of 166 studies using the COSMIN guidelines (32,39,79). From these, 25 PROMs demonstrated a sufficient level of content validity to be further assessed. Among them, subscales of only 4 PROMs (i.e., EORTC QLQ-C30, EORTC CAT, IOC and IPOS) met the COSMIN recommendation criteria, i.e., beyond content validity, at least low-quality evidence was found for sufficient structural validity and internal consistency in European cancer patients or survivors. Taken together, the recommended subscales cover the following HRQoL (sub)domains: physical health (appearance, body change, fatigue, insomnia, pain, physical functioning, physical health and physical symptoms), mental health (altruism and empathy, cognitive functioning, emotional functioning, health awareness, meaning of cancer and worry), social health (relationship concerns, role functioning, social functioning and support) and global health (global health status, life interference, quality of life).

This review also investigated the quality of the identified PROMs' remaining measurement properties. Among the recommended PROMs, the EORTC CAT subscales assessing role, cognitive and emotional functioning as well as fatigue, pain and insomnia were the only ones supported by high-level evidence of cross-cultural validity and measurement invariance. These subscales, together with most EORTC QLQ-C30 subscales (i.e., 12 out of 15) demonstrated sufficient construct validity with a high level of evidence. Regarding reliability, high-level evidence was found only for the physical functioning subscale of the EORTC QLQ-C30. Regarding the IOC, several subscales were rated as sufficient for construct validity (i.e., altruism/empathy, meaning of cancer, worry) and reliability (i.e., body change, meaning of cancer, worry). However, these ratings were only supported by very low-quality evidence. None of the remaining psychometric properties of the IPOS received a sufficient rating. Among the non-recommended PROMs, a high level of evidence for sufficient construct validity was found for only 13 of them (37.1%) and not for all subscales (except for the CCEQ), with no other high-level evidence found for any of the remaining psychometric properties. Further, no evidence could be found for all the psychometric properties of any of the PROMs identified in this report and no information could be retrieved on measurement error, including for the PROMs being recommended. Altogether, this systematic review demonstrates that high-quality studies on the psychometric properties of PROMs measuring HRQoL throughout the cancer continuum are scarce.

[5] In some cases, several versions of the same PROM were identified and assessed.

These results need, however, to be nuanced. First, what constitutes a valid PROM remains unclear. In this review, many publications supporting the “validity” or “validation” of a given PROM were retrieved, yet the objectives and methods underlying these terms were highly heterogeneous. COSMIN provides clearer guidance when a valid PROM, i.e., one that can be recommended, is supported by evidence of content validity and adequate internal structure (i.e., structural validity and internal consistency). Based on the current results, this seems to suggest that almost 90% of the PROMs commonly used in the European cancer field are not valid. Second, it is worth noting that the COSMIN guidelines do not directly assess the quality of the PROMs’ measurement properties but rather if the evidence supporting these properties was reported. For instance, 201 subscales could be rated across the PROMs included in this review, leading to 1809 potential ratings. Overall, 1204 (66.6%) of the ratings could not be performed because of lack of information while in only 15 cases (0.8%) high evidence of insufficient quality was demonstrated. This indicates that the evidence supporting the measurement properties of most PROMs in the European cancer field is insufficient or, in most cases, not available. As the absence of evidence is not the evidence of absence, no claim can be made regarding the validity of any of the PROMs that were not recommended. Third, the COSMIN guidelines set high standards which often lead to severe downgrades of an entire criterion due to the “worst score counts” approach. For instance, the development of most PROMs (64.9%) was scored as doubtful since it was not clear whether interviewers were experienced or trained, or whether 2 researchers were involved in the coding during the concept elicitation phase. These are only 2 requirements out of 64 others for the sole rating of the PROM development and content validity quality. It could be beneficial to update these guidelines and simplify, when possible, their application to make them more accessible and encourage their implementation to guide the field towards better practices. While these standards provide a precise framework for the development of new PROMs, it is likely that information such as the training level of the interviewer would be omitted in articles reporting on the development of a PROM, particularly if the article was published several decades ago. For instance, it is possible that the interest of scientific journals regarding the reporting of information such as content validity was less at the time, or simply that clear standards were lacking. Among the PROMs identified through this review, 25 (71.4%) were developed before the publication of the COSMIN guidelines in 2010. For instance, the development of the EORTC QLQ-C30, which was published in 1993 (50), did not report any information on content validity. This PROM would have been excluded from the current review if a content validity study (80) had not been published recently. Finally, these results are not specific to the cancer field. Other systematic reviews based on the COSMIN guidelines in patients with diabetes (81) chronic back pain (82), neck pain (83) or shoulder dysfunction (84) reported comparable results, with very few to no PROMs meeting the quality criteria set by COSMIN. A delay is, of course, expected between the publication of new methodological standards and their actual implementation in research practices. However, 13 years after the publication of the COSMIN guidelines, none of the PROMs developed since then in the cancer field fully meet their quality criteria. This discrepancy argues in favor of making such guidelines more visible, even more so when considering that a joint effort of the COSMIN and PRISMA groups is planned to provide an updated framework (85). Building on this framework to homogenize research practices would certainly allow for a better comparability of PROMs and improve overall PROM quality.

This is the first systematic review to provide a comprehensive overview of all available PROMs and their psychometric properties for the assessment of HRQoL in European cancer patients and survivors. No restrictions were applied regarding the cancer population or cancer type, allowing for a representative overview through the cancer continuum. To our knowledge, this review is also unique in reporting on the measurement properties of PROMs in the cancer field at a subscale level, which is an important pre-

requisite of such reports according to the COSMIN guidelines. Additionally, a detailed overview of all the HRQoL-domains covered by the PROMs was provided. Finally, by complying with the highest available methodological standards in terms of systematic review conduction (PRISMA) and PROM assessment (COSMIN), the current review is based on a robust and reproducible methodology.
Despite the innovative aspect of this study, several limitations should be acknowledged as well. First, the review was restricted to validation papers involving cancer patients and survivors from European countries. We acknowledge that validation studies have been published with the target population outside of Europe, which may provide further insight into the psychometric properties of these PROMs. However, within the scope of this European project, the primary focus was set on European cancer patients and survivors only. Second, the practical application of the COSMIN guidelines is complex. Assuming the evidence was available, more than 130 criteria/requirements could be assessed per PROM, excluding subscales, for some of which a clear procedure regarding how to perform the rating was lacking. Given the complexity and occasional lack of specific guidance within the COSMIN guidelines, several decisions were made in this work on how to value information within the articles, which might have led to systematic errors. However, for all deviations reported in this review, the methodology applied is transparent, allowing for the reproduction of results and their interpretation in regard to the choices that were made. Third, other guidelines on developing and validating outcome measures exist and can vary depending on the needs of various stakeholders (10,86). However, this review only focused on the COSMIN guidelines to have a benchmark based on the most comprehensive set of criteria for measurement properties of PROMs. Finally, the assessment of the studies and psychometric properties was in some instances limited by the lack of information available. Even though additional information was sought online and from the original authors, the requested information was often not supplied. This implies that relevant data, either unpublished or available in secondary databases, may have been missed, which might have led to different results for some PROMs were it considered.

In conclusion, 35 unique PROMs evaluating HRQoL across the European cancer continuum were identified in this review and the quality of the measurement properties of their 204 subscales was systematically assessed. Overall, there was a lack of high-quality evidence to support the psychometric properties of most PROMs, highlighting the need for new studies to investigate this gap, or alternatively, to develop new PROMs following the current best practices**.** On the other hand, a selection of subscales from the EORTC CAT, EORTC QLQ-C30, the IOC and the IPOS, which altogether cover a significant variety of domains, met the methodological standards defined by the COSMIN guidelines and can be recommended. In the context of the EUonQOL project, the overall content coverage of these subscales will be compared to the HRQoL domains that cancer patients and survivors reported as essential (see Chapter 2 & EUonQOL Deliverable D 4.1 (to be published)). This will allow for identifying which domains are currently not adequately covered by existing PROMs. The potential identification of gaps will guide the need to develop new sets of items and subscales for the EUonQOL toolkit and ensure its relevance and comprehensiveness. The most appropriate subscales identified in this report are recommended for implementation in the toolkit if it is concluded that the HRQoL domains they cover are essential for patients across the cancer continuum.

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6. Appendices

Appendix 1. Detailed overview of the search strategy applied for PubMed and Scopus

	PubMed	Scopus
Population: cancer patients & survivors	("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract])	((TITLE-ABS-KEY ("tumor*")) OR (TITLE-ABS-KEY ("neoplasm*")) OR (TITLE-ABS-KEY ("neoplasia*")) OR (TITLE-ABS-KEY ("cancer*")) OR (TITLE-ABS-KEY ("malignanc*")) OR (TITLE-ABS-KEY ("carcinoma*")) OR (TITLE-ABS-KEY ("postcancer")) OR (TITLE-ABS-KEY ("post-cancer"))) AND ((TITLE-ABS-KEY ("palliative care")) OR (TITLE-ABS-KEY ("palliative treatment*")) OR (TITLE-ABS-KEY ("palliative therap*")) OR (TITLE-ABS-KEY ("palliative surger*")) OR (TITLE-ABS-KEY ("palliative supportive care*")) OR (TITLE-ABS-KEY ("survivor*")) OR (TITLE-ABS-KEY ("patient*")))
Exposure: psychometric properties	AND ("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR "minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract])	AND ((TITLE-ABS-KEY ("questionnaire")) OR (TITLE-ABS-KEY ("questionnaires")) OR (TITLE-ABS-KEY ("instrument")) OR (TITLE-ABS-KEY ("instruments")) OR (TITLE-ABS-KEY ("rating")) OR (TITLE-ABS-KEY ("outcome measure")) OR (TITLE-ABS-KEY ("outcome measures")) OR (TITLE-ABS-KEY ("measurement tool")) OR (TITLE-ABS-KEY ("measurement tools")) OR (TITLE-ABS-KEY ("computer-based")) OR (TITLE-ABS-KEY ("digital")) OR (TITLE-ABS-KEY ("computer adaptive test*")) OR (TITLE-ABS-KEY ("computer-adaptive test*")) OR (TITLE-ABS-KEY ("computer-adaptive")) OR (TITLE-ABS-KEY ("computer adaptive")) OR (TITLE-ABS-KEY ("computerized adaptive test*")) OR (TITLE-ABS-KEY ("computerised adaptive test*")) OR (TITLE-ABS-KEY ("cat"))) AND ((TITLE-ABS-KEY ("chronbach*")) OR (TITLE-ABS-KEY ("cronbach*")) OR (TITLE-ABS-KEY ("psychometric properties")) OR (TITLE-ABS-KEY ("psychometric analysis")) OR (TITLE-ABS-KEY ("psychometric evaluation")) OR (TITLE-ABS-KEY ("psychometric characteristics")) OR (TITLE-ABS-KEY ("factor analysis")) OR (TITLE-ABS-KEY ("reliability")) OR (TITLE-ABS-KEY ("reliable")) OR (TITLE-ABS-KEY ("validity")) OR (TITLE-ABS-KEY ("valid")) OR (TITLE-ABS-KEY ("validation")) OR (TITLE-ABS-KEY ("minimal clinically important difference*")) OR (TITLE-ABS-KEY ("clinically meaningful change*")) OR (TITLE-ABS-KEY ("clinically meaningful difference*")) OR (TITLE-ABS-KEY ("responsiveness")) OR (TITLE-ABS-KEY ("minimal important change*")) OR (TITLE-ABS-KEY ("minimal important difference*")) OR (TITLE-ABS-KEY ("translation")) OR (TITLE-ABS-KEY ("translated")) OR (TITLE-ABS-KEY ("cross-cultural")) OR (TITLE-ABS-KEY ("development")))
Outcome: Health-related Quality of Life	AND ("quality of life"[MeSH Terms] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "life satisfaction"[Text Word] OR "well-being"[Text Word] OR "wellbeing"[Text Word] OR "patient reported outcome measures"[MeSH Terms])	AND (TITLE-ABS-KEY ("quality of life")) OR (TITLE-ABS-KEY ("life quality")) OR (TITLE-ABS-KEY ("patient-reported outcome*")) OR (TITLE-ABS-KEY ("hrqol")) OR (TITLE-ABS-KEY ("patient reported outcome*")) OR (TITLE-ABS-KEY ("perceived health")) OR (TITLE-ABS-KEY ("health status")) OR (TITLE-ABS-KEY ("well-being")) OR (TITLE-ABS-KEY ("wellbeing"))
Exclusion string Terwee et al. 2009 + English filter	AND (english[Filter]) NOT (‘‘addresses’’[Publication Type] OR ‘‘biography’’[Publication Type] OR ‘‘case reports’’[Publication Type] OR ‘‘comment’’[Publication Type] OR ‘‘directory’’[Publication Type] OR ‘‘editorial’’[Publication Type] OR ‘‘festschrift’’[Publication Type] OR ‘‘interview’’[Publication Type] OR ‘‘lectures’’[Publication Type] OR ‘‘legal cases’’[Publication Type] OR ‘‘legislation’’[Publication Type] OR	AND (LIMIT TO (LANGUAGE , "english")) AND (EXCLUDE (DOCTYPE , "le") OR EXCLUDE (DOCTYPE , "ed")) AND (EXCLUDE (DOCTYPE , "cp"))

	‘‘letter’’[Publication Type] OR ‘‘news’’[Publication Type] OR ‘‘newspaper article’’[Publication Type] OR ‘‘patient education handout’’[Publication Type] OR ‘‘popular works’’[Publication Type] OR ‘‘congresses’’ [Publication Type] OR ‘‘consensus development conference’’[Publication Type] OR ‘‘consensus development conference, nih’’[Publication Type] OR ‘‘practice guideline’’[Publication Type]) NOT (‘‘animals’’[MeSH Terms] NOT ‘‘humans’’[MeSH Terms])	

Appendix 2. List of European and associated countries in the EUonQOL project

European and associated countries		
Albania	Germany	North-Macedonia
Andorra	Greece	Norway
Armenia	Hungary	Portugal
Austria	Iceland	Romania
Azerbaijan	Ireland	Russia
Belarus	Italy	San Marino
Belgium	Kazakhstan	Serbia
Bulgaria	Latvia	Slovenia
Croatia	Liechtenstein	Slovakia
Cyprus	Lithuania	Spain
Czechia	Luxembourg	Sweden
Denmark	Malta	Switzerland
Estonia	Moldavia	Turkey
Finland	Monaco	Ukraine
France	Montenegro	United Kingdom
Georgia	Netherlands	Vatican City

Appendix 3. Additional search strategy for European validation papers

1. STEP 1:

- Define entry terms for the SPECIFIC QUESTIONNAIRE:
  - Full name (make sure to enter all the different spelling options)
  - Acronym (make sure to enter all the different spelling options)

Example:

EORTC-QLQ-C30	"European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30"
	EORTC-QLQ-C30
	EORTC QLQ-C30
	EORTC QLQ C30
	QLQ C30

- Combine all the entry terms with OR-function:
  - ("European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30") OR (eortc-qlq-c30)) OR (eortc qlq-c30)) OR (eortc qlq c30)) OR (qlq c30)

2. STEP 2:

- Enter search string for POPULATION:
  - ("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract])
- Enter search string for PSYCHOMETRIC PROPERTIES:
  - ("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR "minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract])

3. STEP 3:

- Combine search strings of POPULATION, PSYCHOMETRIC PROPERTIES and SPECIFIC QUESTIONNAIRE with the AND-function:
  - ((((("European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30") OR (eortc-qlq-c30)) OR (eortc qlq-c30)) OR (eortc qlq c30)) OR (qlq c30)) AND (("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR

"measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR "minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract]))) AND (("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract]))

4. *STEP 4:*

- Find search string (which is used to gather the articles for our systematic review but remove English filter)
    - (((((("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR "minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract])) AND ("quality of life"[MeSH Terms] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "life satisfaction"[Text Word] OR "well-being"[Text Word] OR "wellbeing"[Text Word] OR "patient reported outcome measures"[MeSH Terms])) AND (("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract])) AND (english[Filter])) NOT ((‘‘animals’’[MeSH Terms] NOT ‘‘humans’’[MeSH Terms]))) NOT ((((("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR

"minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract])) AND ("quality of life"[MeSH Terms] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "life satisfaction"[Text Word] OR "well-being"[Text Word] OR "wellbeing"[Text Word] OR "patient reported outcome measures"[MeSH Terms])) AND (("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract])) AND ((address[Filter] OR biography[Filter] OR casereports[Filter] OR comment[Filter] OR congress[Filter] OR consensusdevelopmentconference[Filter] OR consensusdevelopmentconferencenih[Filter] OR directory[Filter] OR editorial[Filter] OR festschrift[Filter] OR interview[Filter] OR lecture[Filter] OR legalcase[Filter] OR legislation[Filter] OR letter[Filter] OR news[Filter] OR newspaperarticle[Filter] OR patienteducationhandout[Filter] OR practiceguideline[Filter])))

5. STEP 5:

- Combine search string of STEP 3 (POPULATION AND PSYCHOMETRIC PROPERTIES AND SPECIFIC QUESTIONNAIRE) and STEP 4 (ENTIRE search string) with NOT-function:
    - (((((("European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30") OR (eortc-qlq-c30)) OR (eortc qlq-c30)) OR (eortc qlq c30)) OR (qlq c30)) AND (("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR "minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract]))) AND (("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract]))) NOT ((((((("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR "minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically

meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract])) AND ("quality of life"[MeSH Terms] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "life satisfaction"[Text Word] OR "well-being"[Text Word] OR "wellbeing"[Text Word] OR "patient reported outcome measures"[MeSH Terms])) AND (("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract])) AND (english[Filter])) NOT ((‘‘animals’’[MeSH Terms] NOT ‘‘humans’’[MeSH Terms]))) NOT ((((("instrument*"[Title/Abstract] OR "questionnaire*"[Title/Abstract] OR "measur*"[Title/Abstract] OR "rating*"[Title/Abstract] OR "computer*"[Title/Abstract] OR "digital*"[Title/Abstract] OR "computer-adaptive test*"[Title/Abstract] OR "computer adaptive test*"[Title/Abstract] OR "computer adaptive"[Title/Abstract] OR "computer-adaptive"[Title/Abstract] OR "computerized adaptive test*"[Title/Abstract] OR "computerised adaptive test*"[Title/Abstract] OR "CAT"[Title/Abstract]) AND ("chronbach*"[Title/Abstract] OR "cronbach*"[Title/Abstract] OR "psychometric properties"[Title/Abstract] OR "psychometr*"[Title/Abstract] OR "factor analysis"[Title/Abstract] OR "develop*"[Title/Abstract] OR "reliab*"[Title/Abstract] OR "valid*"[Title/Abstract] OR "translat*"[Title/Abstract] OR "cross-cultural"[Title/Abstract] OR "minimal clinically important difference*"[Title/Abstract] OR "minimal important change*"[Title/Abstract] OR "minimal important difference*"[Title/Abstract] OR "clinically meaningful change*"[Title/Abstract] OR "clinically meaningful difference*"[Title/Abstract] OR "responsiveness"[Title/Abstract])) AND ("quality of life"[MeSH Terms] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "life satisfaction"[Text Word] OR "well-being"[Text Word] OR "wellbeing"[Text Word] OR "patient reported outcome measures"[MeSH Terms])) AND (("patient*"[MeSH Terms] OR "Survivors"[MeSH Terms] OR "Palliative Care"[MeSH Terms]) AND ("Neoplasms"[MeSH Terms] OR "Carcinoma"[MeSH Terms] OR "post-cancer"[Title/Abstract] OR "postcancer"[Title/Abstract])) AND ((address[Filter] OR biography[Filter] OR casereports[Filter] OR comment[Filter] OR congress[Filter] OR consensusdevelopmentconference[Filter] OR consensusdevelopmentconferencenih[Filter] OR directory[Filter] OR editorial[Filter] OR festschrift[Filter] OR interview[Filter] OR lecture[Filter] OR legalcase[Filter] OR legislation[Filter] OR letter[Filter] OR news[Filter] OR newspaperarticle[Filter] OR patienteducationhandout[Filter] OR practiceguideline[Filter])))))

6. ***STEP 6: Apply “English” filter***

7. ***STEP 7: Assess and screen articles for the predefined in- and exclusion criteria***

Appendix 4. Overview of the data extraction for the PROMs measurement properties

Measurement property	Data extracted
Development/ Content validity	- Level of analysis: scale/subscale - Methodological approach for concept elicitation, PROM design, relevance, comprehensiveness and comprehensibility
Structural validity/ Unidimensionality	- Level of analysis: scale/subscale - Statistical approach and related sample size: EFA, CFA or IRT - Final model and fit indexes: CFI, TLI, RMSEA (90%CI) SRMR or WRMR
Internal consistency	- Level of analysis: scale/subscale - Statistical approach and related sample size - Internal consistency reliability coefficients: Cronbach alpha, McDonald Omega, KR-20, SE(θ)
Cross-cultural validity/ Measurement invariance	- Level of analysis: scale/subscale - Statistical approach and related sample size - Group variable under investigation (e.g. country, age, gender,...) with its observed differences
Reliability	- Level of analysis: scale/subscale - Statistical approach and related sample size - Type of reliability: test-retest, inter-rater, intra-rater, parallel forms - Correlation coefficients: ICC, Spearman, Pearson, Kappa or weighted Kappa
Measurement error	- Level of analysis: scale/subscale - Statistical approach and related sample size - Standard Error of Measurement, Limits of Agreement, Smallest Detectable Change, Minimal Important Change
Construct validity with other PROM	- Level of analysis: scale/subscale - Statistical approach and related sample size - Comparator + formulated hypotheses - Correlation coefficients or effect sizes
Convergent/ divergent validity within PROM	- Level of analysis: scale/subscale - Statistical approach and related sample size - Formulated hypotheses - Correlation coefficients
Known-group comparison	- Level of analysis: scale/subscale - Statistical approach and related sample size - Formulated hypotheses - Group variable + defined subgroups with observed differences

Abbreviations: CFA = Confirmatory Factor Analysis; CFI = Comparative Fit Index; IRT = Item Response Theory; RMSEA = Root Mean Square Error of Approximation; SDC = Smallest Detectable Change; SRMR: Standardized Root Mean Residuals; TLI: Tucker-Lewis Index; WRMR: Weighted Root Mean Residuals

Appendix 5: Overview of adjustments made to the Risk of Bias rating of COSMIN Guidelines

Psychometric property	Criteria	Adjustment made
PROM development (Box 1)	23	Inadequate rating was removed from the response options.
	25	Adequate and doubtful rating were removed from the response options.
	26	Doubtful rating was removed and inadequate was defined as “NO or not clear (SKIP items 27-35)”.
	35	Adequate and doubtful rating were removed from the response options.
Content validity (Box 2)	6	Inadequate rating was removed from the response options.
	13	Inadequate rating was removed from the response options.
	20	Inadequate rating was removed from the response options.
	25	Inadequate rating was removed from the response options.
	30	Inadequate rating was removed from the response options.
Structural validity (Box 3)	2	Adequate rating was removed from the response options.
Internal consistency (Box 4)	5	Criteria 5 was removed from the Risk of bias assessment.
Cross-cultural validity & Measurement invariance (Box 5)	4	Criteria 4 was removed from the Risk of bias assessment.
Reliability (Box 6)	1-3	Not applicable rating was added to the response options.
Measurement error (Box 7)	6	Adequate rating was removed from the response options.
Construct validity (with other PROM) (hypothesis testing) (Box 9.a)	4	Inadequate rating was removed from the response options.
	1-4	Not applicable rating was added to the response options.
Construct validity (Known-group comparison) (Box 9.b)	7	Inadequate rating was removed from the response options.
	5-7	Not applicable rating was added to the response options.
Construct validity (convergent & divergent validity)	1	Criteria 3 of Box 9.a was introduced.

Appendix 6: The 10 criteria for good content validity

		PROM development study		Content validity study		Rating of reviewers
1	**+**	Construct of interest is clearly described **(criterion 1 of box 1A = very good) AND** origin of construct is clear **(criterion 2 of box 1A = very good) AND** the is evidence from concept elicitation, literature or professionals that ≥85% of the items refer to construct of interest	**+**	Professionals rated the relevance of items for the construct of interest as sufficient **(criteria 22-26 of box 2D = very good, adequate or doubtful)** and found ≥85% of the items relevant for the construct	**+**	Reviewers consider ≥85% of the items relevant for the construct of interest
	-	Quality is inadequate (≥1 of the 3 (+)-criteria is not fulfilled)	**-**	Professionals were not involved in the content validity study OR rated <85% of the items of the PROM relevant for the construct	**-**	Reviewers consider <85% of the items relevant for the construct of interest
	?	No(t enough) information available to score a (+) or (-)	**?**	No(t enough) information available to score a (+) or (-)		
2	**+**	Target population of interest is clearly described **(criterion 3 of box 1A = very good) AND** representative patients were involved in the elicitation of relevant items **(criterion 5 of box 1A = very good or adequate) AND** concept elicitation was not inadequate **(criteria 6-13 of box 1A = very good, adequate or doubtful)**	**+**	Patients rated the relevance of items for the construct of interest as sufficient **(criteria 1-7 of box 2A = very good, adequate or doubtful)** and found ≥85% of the items relevant for them	**+**	Reviewers consider ≥85% of the items relevant for the population of interest
	-	Quality is inadequate (≥1 of the 3 (+)-criteria is not fulfilled)	**-**	Patients were not involved in the content validity study OR rated <85% of the items of the PROM relevant for them	**-**	Reviewers consider <85% of the items relevant for the population of interest
	?	No(t enough) information available to score a (+) or (-) OR doubtful whether study was performed in a sample representing the target population	**?**	No(t enough) information available to score a (+) or (-)		
3	**+**	The context of use of interest is clearly described **(criterion 4 of box 1A = very good)**	**+**	Professionals rated the relevance of items for the context of use as sufficient **(criteria 22-26 of box 2D = very good, adequate or doubtful)** and found ≥85% of the items relevant for the context of use	**+**	Reviewers consider ≥85% of the items relevant for the context of use of interest
	-	The context of use of interest is not clearly described **(criterion 4 of box 1A = doubtful)**	**-**	Professionals were not involved in the content validity study OR rated <85% of the items of the PROM relevant for the context of use	**-**	Reviewers consider <85% of the items relevant for the context of use of interest
	?	No(t enough) information available to score a (+) or (-)	**?**	No(t enough) information available to score a (+) or (-)		
4	**+**	A justification is provided for the response options	**+**	Patients or professionals rated the appropriateness of the response options as sufficient **(criteria 1-7 of box 2A or criteria 22-26 of box 2D = very good, adequate or doubtful)** and found ≥85% of the response options relevant	**+**	Reviewers consider ≥85% of the response options appropriate for the construct, population, and context of use of interest
	-	No justification was provided for the response options	**-**	Patients or professionals were not involved in the content validity study OR rated <85% of the response options of the PROM relevant	**-**	Reviewers consider <85% of the response options appropriate for the construct, population, and context of use of interest
	?	No(t enough) information available to score a (+) or (-)	**?**	No(t enough) information available to score a (+) or (-)		
5	**+**	A justification is provided for the recall period	**+**	Patients or professionals rated the appropriateness of the recall period as sufficient **(criteria 1-7 of box 2A or criteria 22-26 of box 2D = very good, adequate or doubtful)** and found the recall period relevant	**+**	Reviewers consider the recall period appropriate for the construct, population and context of use of interest for **≥85% of the items**.

	-	No justification is provided for the recall period	-	Patients or professionals were not involved in the content validity study OR rated the recall period for <85% of the items of the PROM relevant	-	Reviewers consider the recall period **only partially** (<85% of the items) **OR not** appropriate for the construct, population and context of use of interest.
	?	No(t enough) information available to score a (+) or (-)	?	No(t enough) information available to score a (+) or (-)		
6	+	Patients were asked about the comprehensiveness of the PROM in concept elicitation phase or cognitive interview **(criteria 6-13 of box 1A or criteria 26-35 of box 1B = very good, adequate or doubtful) AND** no key concepts were missing	+	Patients or professionals were asked about the comprehensiveness of the PROM **(criteria 8-14 of box 2B or criteria 27-31 of box 2E = very good, adequate or doubtful) AND** no key concepts were missing	+	Reviewers consider the PROM **comprehensive** for the construct, population and context of use of interest for **≥85% of the items**.
	-	Quality is inadequate (≥1 of the 2 (+)-criteria is not fulfilled)	-	Patients or professionals were not involved in the content validity study OR quality is inadequate (≥1 of the 2 (+)-criteria is not fulfilled)	-	Reviewers consider the PROM **only partially** (<85% of the items) **OR not comprehensive** for the construct, population and context of use of interest comprehensive (<85% of the items)
	?	No(t enough) information available to score a (+) or (-)	?	No(t enough) information available to score a (+) or (-)		
7	+	Patients were asked about the comprehensibility of the instructions (including recall period) in cognitive interview **(criteria 16-25 of box 1B = very good, adequate or doubtful) AND** problems were adequately addressed	+	Patients were asked about the comprehensibility of the instructions (including recall period) **(criteria 15-21 of box 2C = very good, adequate or doubtful) AND** no important problems were found	+	
	-	Quality is inadequate (≥1 of the 2 (+)-criteria is not fulfilled)	-	Patients were not involved in the content validity study OR quality is inadequate (≥1 of the 2 (+)-criteria is not fulfilled)	-	
	?	No(t enough) information available to score a (+) or (-)	?	No(t enough) information available to score a (+) or (-)		
8	+	Patients were asked about the comprehensibility of the items and response options (including wording of items and response options) in cognitive interview **(criteria 16-25 of box 1B = very good, adequate or doubtful) AND** problems were adequately addressed	+	Patients were asked about the comprehensibility of the items and response options (including wording of items and response options) **(criteria 15-21 of box 2C = very good, adequate or doubtful) AND** no important problems were found for ≥85% of the items and response options	+	
	-	Quality is inadequate (≥1 of the 2 (+)-criteria is not fulfilled)	-	Patients were not involved in the content validity study OR quality is inadequate (≥1 of the 2 (+)-criteria is not fulfilled)	-	
	?	No(t enough) information available to score a (+) or (-)	?	No(t enough) information available to score a (+) or (-)		
9	+		+		+	Reviewers consider ≥85% of the items and response options appropriately worded
	-		-		-	Reviewers consider <85% of the items and response options appropriately worded
	?		?			
10	+		+		+	Reviewers consider ≥85% of the response options matching the questions
	-		-		-	Reviewers consider <85% of the response options matching the questions
	?		?			

Appendix 7: Calculation of the overall relevance, comprehensiveness and comprehensibility rating per study

		PROM development		Content validity		Reviewer rating
Relevance rating	**+**	Criteria 1 and 2 are rated sufficient (+) AND ≥2 of remaining 3 items are rated sufficient (+)	**+**	Criteria 1 and 2 are rated sufficient (+) AND ≥2 of remaining 3 items are rated sufficient (+)	**+**	Criteria 1 and 2 are rated sufficient (+) AND ≥2 of remaining 3 items are rated sufficient (+)
	-	Criteria 1 and 2 are rated insufficient (-) AND ≥2 of remaining 3 items are rated insufficient (-)	**-**	Criteria 1 and 2 are rated insufficient (-) AND ≥2 of remaining 3 items are rated insufficient (-)	**-**	Criteria 1 and 2 are rated insufficient (-) AND ≥2 of remaining 3 items are rated insufficient (-)
	?	≥2 criteria are rated indeterminate (?)	**?**	≥2 criteria are rated indeterminate (?)		
	±	All other situations	**±**	All other situations	**±**	All other situations
Comprehensiveness rating		Rating of criterion 6		Rating of criterion 6		Rating of criterion 6
Comprehensibility rating	**+**	Criterion 8 = sufficient (+) AND criterion 7 = sufficient (+) or indeterminate (?)	**+**	Criterion 8 = sufficient (+) AND criterion 7 = sufficient (+) or indeterminate (?)	**+**	Criteria 9 and 10 are rated sufficient (+)
	-	Criterion 8 = insufficient (-)	**-**	Criterion 8 = insufficient (-)	**-**	Criteria 9 and 10 are rated insufficient (-)
	?	Criterion 8 = indeterminate (?)	**?**	Criterion 8 = indeterminate (?)		
	±	Criterion 8 = sufficient (+) AND criterion 7 = insufficient (-)	**±**	Criterion 8 = sufficient (+) AND criterion 7 = insufficient (-)	**±**	One criterion = sufficient (+) AND one criterion = insufficient (-)

Appendix 8: Calculation of the overall relevance, comprehensiveness and comprehensibility rating per PROM

PROM development	Content validity	Rating reviewer	Overall RELEVANCE COMPREHENSIVENES COMPREHENSIBILITY rating
+	+	+	+
+	+	±	+
+	+	-	+
+	-	+	±
+	-	±	±
+	-	-	-
+	?	+	+
+	?	±	±
+	?	-	±
+	±	+	±
+	±	±	±
+	±	-	±
-	+	+	+
-	+	±	±
-	+	-	±
-	-	+	-
-	-	±	-
-	-	-	-
-	?	+	±
-	?	±	±
-	?	-	-
-	±	+	±
-	±	±	±
-	±	-	±
?	+	+	+
?	+	±	±
?	+	-	±
?	-	+	±
?	-	±	±
?	-	-	-
?	?	+	+
?	?	±	±
?	?	-	-
?	±	+	±
?	±	±	±
?	±	-	±
±	+	+	+
±	+	±	+
±	+	-	±
±	-	+	±
±	-	±	-
±	-	-	-
±	?	+	±
±	?	±	±
±	?	-	±
±	±	+	±
±	±	±	±
±	±	-	-

Appendix 9: Calculation of the overall content validity rating

Overall RELEVANCE rating	Overall COMPREHENSIVENESS rating	Overall COMPREHENSIBILITY rating	Overall CONTENT VALIDITY rating
+	+	+	+
+	+	±	+
+	+	-	±
+	-	+	±
+	-	±	±
+	-	-	±
+	±	+	+
+	±	±	±
+	±	-	±
-	+	+	±
-	+	±	±
-	+	-	±
-	-	+	±
-	-	±	-
-	-	-	-
-	±	+	±
-	±	±	±
-	±	-	-
±	+	+	+
±	+	±	±
±	+	-	±
±	-	+	±
±	-	±	±
±	-	-	-
±	±	+	±
±	±	±	±
±	±	-	±

Appendix 10: Overview of PROMs included in the final analysis

PROM	Reference	Age (mean ± sd)	Gender	Population	Type of cancer	Cancer stage	Country	Extracted information
AQEL	Axelsson et al., 1999 (43)	NA	Female (n = 24; 33.8%) Male (n = 47; 66.2%)	Palliative (n = 71; 100%)	Breast (n = 9; 12.7%) Gastrointestinal (n = 33; 46.5%) Urological (n = 29; 40.9%)	Advanced (n = 71; 100%)	EU (n = 71; 100%)	Development Content validity Construct validity Reliability
	Henoch et al., 2010 (87)	69.0 ± NA years (range 36-85)	Female (n = 51; 48.0%) Male (n = 55; 52.0%)	Palliative (n = 106; 100%)	Lung (n = 106; 100%)	Median: 9.0 ± NA years (range 2-142) since diagnosis	EU (n = 106; 100 %)	Construct validity Content validity
CANDI	Beyhun et al., 2016 (88)	52.4 ± 12.2 years	Female (n = 98; 57.0%) Male (n = 74; 43.0%)	Patients (n = 172; 100%)	Breast (n = 70; 40.7%) Colorectal (n = 31; 18%) Endometrium (n = 5; 2.9%) Gastric (n = 17; 9.9%) Liver (n = 4; 2.3%) Lung (n = 16; 9.3%) Lymphoma (n = 9; 5.3%) Ovary (n = 5; 2.9%) Pancreas (n = 4; 2.3%) Prostate (n = 3; 1.7%) Others (n = 8; 4.7%)	NA	EU (n = 172; 100%)	Construct validity Internal consistency Reliability Structural validity
	Lowery et al., 2012 (44)	**Sample 1** (n = 50): <40 years (n = 6; 12.0%) 40-60 years (n = 26; 52.0%) >60 years (n = 18; 36.0%) **Sample 2** (n = 50): <40 years (n = 6; 12.0%) 40-60 years (n = 22; 45.0%)	**Sample 1** (n = 50): Female (n = 38; 76.0%) Male (n = 12; 24.0%) **Sample 2** (n = 50): Female (n = 35; 70.0%) Male (n = 15; 30.0%)	Patients (n = 214; 100 %)	**Sample 1** (n = 50): Breast (n = 11; 23.0%) Chronic lymphocytic (n = 5; 10.0%) Colon or rectal (n = 6; 13.0%) Lung (n = 3; 6.0%) Myeloma (n = 3; 6.0%) Ovarian (n = 7; 13.0%) Multiple (n = 3; 6.0%) Other (n = 11; 23.0%) Missing (n = 1; 2.0%) **Sample 2** (n = 50): Breast (n = 20; 40.0%)	Stage I (n = 51; 23.8%) Stage II (n = 44; 20.6%) Stage III (n = 62; 29.0%) Stage IV (n = 44; 20.6%) Missing (n = 13; 6.1%)	Non-EU (n = 214; 100 %)	Development Content validity

		>60 years (n = 22; 43.0%)			Chronic lymphocytic (n = 5; 10.0%) Colon or rectal (n = 7; 15.0%) Lung (n = 3; 6.0%) Myeloma (n = 1; 2.0%) Ovarian (n = 4; 8.0%) Multiple (n = 3; 6.0%) Other (n = 6; 13.0%) Missing (n = 1; 2.0%)			
CARES	Schag et al., 1991 (46)	NA	NA	NA	NA	NA	NA	Development
	Schouten et al., 2016 (89)	50.5 ± 7.2 years (range 30-60)	Female (n = 122; 69.3%) Male (n = 54; 30.7%)	Patients (n = 176; 100%)	Bladder (n = 1; 0.6%) Bone (n = 1; 0.6%) Brain (n = 3; 1.7%) Breast (n = 98; 55.7%) Colorectal (n = 21; 11.9%) Gynaecological (n = 6; 3.3%) Head and neck (n = 7; 4%) Kidney (n = 2; 1.1%) Liver-gall-bladder (n = 2; 1.1%) Lung (n = 3; 1.7%) Oesophagus (n = 3; 1.7%) Prostate (n = 11; 6.3%) Skin (n = 3; 1.7%) Stomach (n = 1; 0.6%) Testis (n = 5; 2.8%) Thyroid (n = 1; 0.6%) Others (n = 8; 4.5%)	1.2 ± 2 years since diagnosis	EU (n = 176; 100%)	Construct validity Content validity Internal consistency Reliability Structural validity
	Schouten et al., 2017 (90)	56.2 ± NA years (range 28-78)	Female (n = 22; 84.6%) Male (n = 4; 15.4%)	Patients (n = 26; 100%)	Brain (n = 1; 3.8%) Breast (n = 11; 42.3%) Colorectal (n = 4; 15.4%) Hodgkin lymphoma (n = 2; 7.7%) Liver (n = 1; 3.8%) Lung (n = 1; 3.8%) Malignant melanoma (n = 1; 3.8%) Non-Hodgkin lymphoma (n = 2; 7.7%) Ovarian (n = 1; 3.8%)	NA	EU (n = 26; 100%)	Content validity

					Pancreas (n = 1; 3.8%) Prostate (n = 1; 3.8%) Thyroid (n = 1; 3.8%) Uterine body (n = 1; 3.8%) Other diagnosis (n = 1; 3.8%) Total (n = 29)*			
CARES-SF	Güner et al., 2022 (91)	55.9 ± 11.3 years (range 27-84)	Female (n = 197; 65.7%) Male (n = 103; 34.3%)	Patients (n = 300; 100%)	Breast (n = 126; 42.0%) Lung (n = 106; 35.3%) Others (n = 68; 22.7%)	Stage III (n = 114; 38.0%) Missing (n = 186; 62.0%)	EU (n = 300; 100%)	Construct validity Internal consistency Reliability Structural validity (model 1)
	Schag et al., 1991 (46)	NA	NA	Patients (n = 1241; 100%)	NA	NA	Non-EU (n = 1241; 100%)	Development Content validity
	Te Velde et al., 1996 (92)	57.0 ± 12.1 years (range 22-86)	Female (n = 281; 58.0%) Male (n = 204; 42.0%)	Patients (n = 485; 100%)	Breast (n = 170; 35.0%) Colorectal (n = 117; 24.0%) Lung (n = 150; 31.0%) Other (n = 48; 10.0%)	Local (n = 92; 19.0%) Regional (n = 204 ; 42.0%) Metastatic (n = 189; 39.0%)	EU (n = 485; 100%)	Construct validity Internal consistency Reliability Structural validity (model 2)
CaSUN	Hodgkinson et al., 2007 (47)	59.6 ± NA years (range 26-99)	Female (n= 286; 81.0%) Male (n = 67; 19.0%)	Survivors (n = 353; 100%)	Breast (n = 209; 59.2%) Colorectal (n = 32; 9.1%) Gynecologic (n = 60; 16.9%) Prostate (n = 43; 12.2%) Other (n = 9; 2.6%)	2.3 ± NA years since diagnosis (range 1-15)	Non-EU (n = 353; 100%)	Development Content validity
	Martinez et al., 2021 (93)	56.0 ± 9.6 years	Female (n = 566; 100%)	Survivors (n = 566; 100%)	Breast (n = 566; 100%)	≤ 12 months after treatment (n = 149; 26.3%) 19-59 months after treatment (n = 210; 37.1%) ≥ 60 months after treatment (n = 176; 31.1%) Other (n = 31; 5.5%)	EU (n = 566; 100%)	Internal consistency Reliability Structural validity (model 2)
	Mirošević et al., 2022 (94)	57.3 ± 12.6 years	Female (n = 233; 79.0%) Male (n = 62; 21.0%)	Survivors (n = 295; 100%)	Breast (n = 148; 50.0%) Colon (n = 18; 6.1%) Lymphoma (n = 19; 6.4%) Melanoma (n = 9; 3.1%) Others (n = 93; 31.5%) Missing (n = 8; 3.0%)	6.7 ± 12.6 years after treatment	EU (n = 295; 100%)	Construct validity Internal consistency Reliability Structural validity (model 1)
CCEQ	Harley et al., 2019 (48)	NA (range 41-90)	Female (n = 209; 50.2%) Male (n = 207; 49.8%)	Patients (n = 416; 100%)	Breast (n = 98; 23.6%) Colorectal (n = 72; 17.3%)	NA	EU (n = 416; 100%)	Development Construct validity

					Gynaecological (n = 79; 19.0%) Prostate (n = 117; 28.1%) Renal (n = 51; 12.3%) Total (n = 417)*			Content validity Internal consistency
EORTC CAT	Dirven et al., 2017 (95)	61.0 ± NA years	Female (n = 552; 50.5%) Male (n = 541; 49.4%) Missing (n = 1; 0.1%)	Patients (n = 1094; 100%)	Breast (n = 224; 20.5%) Gastrointestinal (n = 116; 10.6%) Gynecological (n = 151; 13.8%) Head and neck (n = 128; 11.7%) Lung (n = 46; 4.2%) Urogenital (n = 237; 21.7%) Other (n = 190; 17.4%) Missing (n = 2; 0.2%)	Stage I-II (n = 580; 53.0%) Stage III-IV (n = 485; 44.3%) Missing (n = 29; 2.7%)	EU (n = 990; 90.5%) Non-EU (n = 104; 9.5%)	Construct validity Internal consistency Measurement Invariance Structural validity
	Dirven et al., 2017 (96)	63.0 ± NA years (range 26-97)	Female (n = 542; 52.6 %) Male (n = 488; 47.4%)	Patients (n = 1030; 100%)	Breast (n = 237; 23.0%) Gastrointestinal (n = 144; 14.0%) Genitourinary (n = 171; 16.6%) Gynecological (n = 99; 9.6%) Head and neck (n = 87; 8.4%) Hematological (n = 51; 5.0%) Lung (n = 33; 3.2%) Other (n = 208; 20.2%)	Stage I–II (n = 615; 59.7%) Stage III-IV (n = 409; 39.7%) Missing (n = 6; 0.6%)	EU (n = 1030; 100%)	Development Content validity
	Dirven et al., 2021 (97)	61.0 ± NA years	Female (n = 552; 50.5%) Male (n = 541; 49.4%) Missing (n = 1; 0.1%)	Patients (n = 1094; 100%)	Breast (n = 224; 20.5%) Gastrointestinal (n = 116; 10.6%) Gynecological (n = 151; 13.8%) Head and neck (n = 128; 11.7%) Lung (n = 46; 4.2%) Urogenital (n = 237; 21.7%) Other (n = 190; 17.4%) Missing (n = 2; 0.2%)	Stage I-II (n = 580; 53.0%) Stage III-IV (n = 485; 44.3%) Missing (n = 29; 2.7%)	EU (n = 990; 90.5%) Non-EU (n = 104; 9.5%)	Development Construct validity Content validity Internal consistency Measurement invariance Structural validity
	Gamper et al., 2014 (98)	63.5 ± 11.7 years (range 29-82)	Female (n = 22; 53.7%) Male (n = 19; 46.3%)	Patients (n = 41; 100%)	Anus (n = 1; 2.4%) Breast (n = 8; 19.5%) Colorectal (n = 11; 26.9%) Gynaecological (n = 2; 4.9%) Head and neck (n = 4; 9.8%) Kidney (n = 1; 2.4%) Lung (n = 4; 9.8%) Pancreatic (n = 2; 4.9%) Peritoneal (n = 1; 2.4%) Pleura Mesothelioma (n = 1; 2.4%)	Stage I–II (n = 13; 31.7%) Stage III–IV (n = 23; 56.1%) Missing (n = 5; 12.2%)	EU (n = 41; 100%)	Development Content validity

					Pulmonal synovial (n = 1; 2.4%) Stomach (n = 1; 2.4%) Testicular (n = 2; 4.9%) Missing (n = 2; 4.9%)			
	Gamper et al., 2016 (99)	61.6 ± 12.7 years	Female (n = 540; 52.8%) Male (n = 483; 47.2%)	Patients (n = 1023; 100%)	Breast (n =130; 12.7%) Gastrointestinal (n = 199; 19.4%) Gynecological (n = 97; 9.5%) Head and neck (n = 74; 7.2%) Lung (n = 90; 8.8%) Urogenital (n = 104; 10.2%) Other (n = 235; 23.0%) Missing (n = 94; 9.2%)	Stage I-II (n = 456; 44.6%) Stage III-IV (n = 420; 41.1%) Missing (n = 147; 14.4%)	EU (n = 1023; 100%)	Development Internal consistency Measurement invariance Structural validity
	Giesinger et al., 2011 (100)	57.4 ± NA years (range 32-80)	Female (n = 29; 56.9%) Male (n = 23; 43.1%)	Patients (n = 52; 100%)	Bladder (n = 3; 5.8%) Breast (n = 14; 26.9%) Colorectal (n = 8; 15.4%) Gynaecological (n =5; 9.6%) Laryngeal (n = 3; 5.8%) Lung (n = 10; 19.2%) Other (n = 9; 17.3%)	Stage I-II (n = 17; 33.3%) Stage III-IV (n = 33; 64.7%) Unknown (n = 2; 2.0%)	EU (n = 52; 100%)	Development Content validity
	Petersen et al., 2010 (49)	58.0 ± NA years (range 27-88)	Female (n = 24; 56.0%) Male (n = 19; 44.0%)	Patients (n = 43; 100%)	Breast (n = 10; 23.0%) Gastrointestinal (n = 6; 14.0%) Gynaecological (n = 5; 12.0%) Head and neck (n = 2; 5.0%) Prostate (n = 2; 5.0%) Urogenital (n = 5; 12.0%) Other (n = 5; 12.0%) Missing (n = 8; 20.0%)	Stage I-II (n = 5; 12.0%) Stage III-IV (n = 31; 72.0%) Unknown (n = 7; 16.0%)	EU (n = 43; 100%)	Development Content validity
	Petersen et al., 2013 (101)	59.0 ± NA years (range 18-99)	Female (n = 778; 58.9%) Male (n = 537; 40.7%) Missing (n = 6; 0.5%)	Patients (n = 1321; 100%)	Breast (n = 299; 22.6%) Gastrointestinal (n = 191; 14.5%) Gynecological (n = 167; 12.6%) Hematological (n = 150; 11.4%) Head and neck (n = 113; 8.6%) Lung (n = 87; 6.6%) Urogenital (n= 150; 11.4%) Other (n = 156; 11.8%) Missing (n = 8; 0.6%)	Stage I–II (n = 612; 46.3%) Stage III–IV (n = 538; 40.7%) Missing (n = 171; 12.9%)	EU (n=1199; 91.0%) Non-EU (n = 122; 9.0%)	Development Construct validity Content validity Internal consistency
	Petersen et al., 2013 (102)	58.0 ± NA years (range 18-91)	Female (n = 648; 55.1%) Male (n = 524; 44.6%) Missing (n = 4; 0.3%)	Patients (n = 1176; 100%)	Breast (n =150; 12.6%) Gastrointestinal (n = 135; 11.5%)	Stage I–II (n = 399; 33.9%) Stage III–IV	EU (n=1076; 91.5%) Non-EU	Development Construct validity Content validity

					Gynaecological (n = 180; 15.3%) Head and neck (n = 163; 13.7%) Lung (n = 52; 4.4%) Urogenital (n = 181; 15.4%) Other (n = 124; 10.5%) Missing (n = 191; 16.2%)	(n = 583; 49.6%) Missing (n = 194; 16.5%)	(n = 100; 8.5%)	Measurement invariance Structural validity
	Petersen et al., 2016 (103)	60.0 ± NA years (range 19-90)	Female (n = 619; 56.0%) Male (n = 484; 44.0%)	Patients (n = 1103; 100%)	Breast (n = 199; 18.0%) Gastrointestinal (n = 131; 11.9%) Gynaecological (n = 179; 16.2%) Head and neck (n = 165; 15.0%) Lung (n = 33; 3.0%) Other (n = 191; 17.3%) Missing (n = 205; 18.6%)	Stage I–II (n = 536; 49.0%) Stage III–IV (n = 518; 47.0%) Missing (n = 49; 4.4%)	EU (n=1000; 90.7%) Non-EU (n = 103; 9.3%)	Development Construct validity Content validity Internal consistency Measurement invariance Structural validity
	Petersen et al., 2016 (104)	62.0 ± NA years (range 22-88)	Female (n = 540; 53.0%) Male (n = 483; 47.0%)	Patients (n = 1023; 100%)	Breast (n =130; 12.7%) Gastrointestinal (n = 199; 19.4%) Gynaecological (n = 97; 9.5%) Head and neck (n = 74; 7.2%) Lung (n = 90; 8.8%) Urogenital (n = 104; 10.2%) Other (n = 235; 23.0%) Missing (n = 94; 9.2%)	Stage I-II (n = 456; 44.6%) Stage III-IV (n = 420; 41.1%) Missing (n = 147; 14.4%)	EU (n=1023; 100%)	Development Content validity Measurement invariance Structural validity
	Petersen et al., 2018 (105)	58.8 ± NA years	Female (n = 233; 53.8%) Male (n = 193; 44.6%) Total (n = 426; 100%) **	Patients (n = 399; 100%)	Breast (n = 78; 18.0%) Gastrointestinal (n = 109; 25.2%) Gynaecological (n = 50; 11.5%) Head and neck (n = 41; 9.5%) Lung (n = 32; 7.4%) Urogenital (n = 40; 9.2%) Other (n = 69; 15.9%) Total (n = 419; 100%)**	Stage I-II (n = 147; 33.9%) Stage III-IV (n = 252; 58.2%)	EU (n = 399; 100%)	Content validity
	Petersen et al., 2020 (106)	60.6 ± 12.0 years	Female (n = 391; 55.9%) Male (n = 296; 42.4%) Total (n = 687; 100%) **	Patients (n = 867; 100%)	Breast (n = 213; 30.5%) Lung (n = 83; 11.9%) Ovary (n = 38; 5.4%) Prostate (n = 45; 6.4%) Stomach (n = 36; 5.2%) Other (n = 256; 36.7%) Total (n = 671; 100%) **	Stage I–II (n = 207; 23.9%) Stage III–IV (n = 360; 41.5%) Other (n = 300; 34.6%)	EU (n = 867; 100%)	Construct validity
	Puskulluoglu et al., 2022	65.0 ± NA years	Female (n = 17; 55.0%) Male (n = 14; 45.0%)	Patients (n = 31; 100%)	Breast (n = 3; 10.0%) Gastrointestinal (n = 10; 32.0%)	Stage I-II (n = 14; 45.0%) Stage III-IV	EU (n = 31; 100%)	Development Content validity

	(107)				Genitourinary (n = 2; 6.0%) Gynaecologic (n = 7; 23.0%) Head and Neck (n = 2; 6.0%) Hematologic (n = 2; 6.0%) Lung (n = 2; 6.0%) Other (n = 3; 10.0%)	(n = 15; 48.0%) Unknown (n = 2; 7.0%)		
	Thamsborg et al., 2015 (108)	NA	Female (n = 28; 57.0%) Male (n = 21; 43.0%)	Patients (n = 49; 100%)	Breast (n = 8; 16.0%) Gastrointestinal (n = 10; 20.0%) Genitourinary (n = 5; 10.0%) Gynaecological (n = 6; 12.0%) Head and neck (n = 5; 9.0%) Lung (n = 3; 6.0%) Other (n = 9; 18.0%) Missing (n = 3; 6.0%)	Stage I-II (n = 18; 37.0%) Stage III-IV (n = 25; 51.0%) Unknown (n = 6; 12.0%)	EU (n = 49; 100%)	Development Content validity
EORTC QLQ-Q30	Aaronson et al., 1988 (109)	NA	NA	Patients (n = 750; 100%)	NA	NA	EU (n = NA) Non-EU (n = NA)	Development
	Aaronson et al., 1993 (50)	NA	NA	Patients Palliative (n = 305; 100%)	Lung (n = 305; 100%)	Local (n = 60; 19.7%) Loco-regional (n = 147; 48.2%) Metastatic (n = 87; 28.5%) Other (n = 9; 3.0%) Missing (n = 2; 0.6%)	EU (n = 212; 67.9%) Non-EU (n = 101; 32.3%) Total (n=313; 100%)**	Development
	Arraras et al., 2002 (110)	Median: 60.0 ± NA years (range 21-90)	Female (n = 22; 11.0%) Male (n = 179; 89.0%)	Patients (n = 141; 70.1%) Survivors (n = 60; 29.9%)	Head and neck (n = 201; 100%)	**Patients:** Local (n = 77; 38.0%) Regional (n = 110; 55.0%) Metastatic (n = 14; 7.0%) **Survivors:** 1-3 years after treatment	EU (n = 201; 100%)	Construct validity Internal consistency
	Arraras et al., 2008 (111)	70.9 ± 5.2 years	Male (n = 137; 100%)	Patients (n = 137; 100%)	Prostate (n = 137; 100%)	Local (n = 137; 100%)	EU (n = 137; 100%)	Construct validity Internal consistency
	Bjordal et al., 2000 (112)	Median: 63.0 ± NA years (range 22-91)	Female (n = 117; 19.0%) Male (n = 505; 81.0%)	Patients (n = 262; 42.1%) Survivors (n = 360; 57.9%)	Head and neck (n = 622; 100%)	**Patients** (n = 204): Stage I (n = 67; 33.0%) Stage II (n = 43; 21.0%) Stage III (n = 46; 23.0%) Stage IV (n = 48; 24.0%)	EU (n = 529; 85.0%) Non-EU (n = 93; 15.0%)	Construct validity Internal consistency

						Survivors: 1-3.5 years after treatment		
	Brunelli et al., 2000 (113)	Median: 66.0 ± NA years (range 59-74)	Female (n = 25; 25.0%) Male (n = 73; 74.0%)	Palliative (n = 98; 100%)	Oesophagus (n = 92; 94.0%) Others (n = 6; 6.0%)	Advanced (n = 98; 100%)	EU (n = 98; 100%)	Internal consistency
	Calderon et al., 2022 (114)	58.9 ± 12.2 years	Female (n = 569; 61.0%) Male (n = 362; 39.0%)	Patients (n = 931; 100%)	Breast (n = 320; 34.4%) Colorectal (n = 393; 42.2%) Others (n = 218; 23.4%)	Stage I-II (n = 525; 56.4%) Other (n = 406; 43.6%)	EU (n = 931; 100%)	Construct validity Internal consistency Structural validity (model 3)
	Cankurtaran et al., 2008 (115)	49.1 ± 13.6 years	Female (n = 69; 59.6%) Male (n = 45; 40.4%)	Patients; Palliative (n = 114; 100%)	Breast (n = 46; 59.6%) Gastrointestinal (n = 17; 14.9%) Head and neck (n = 8; 7%) Lung (n = 13; 11.7%) Others (n = 30; 26.1%)	Loco-regional (n = 112; 98.2%) Metastatic (n = 2; 1.8%)	EU (n = 114; 100%)	Construct validity Internal consistency Reliability
	Cavaletti et al., 2013 (116)	Median: 63.9 ± NA years (range 29-85)	Female (n = 135; 48.0%) Male (n = 146; 52.0%)	Patients (n = 281; 100%)	Breast (n = 40; 14.2%) Colorectal (n = 118; 42.0%) Lung (n = 17; 6.0%) Multiple myeloma (n = 35; 12.5%) Ovarian (n = 21; 7.4%) Others (n = 50; 17.8%)	NA	NA	Reliability
	Cocks et al., 2023 (80)	63.5 ± NA years (range 23-89)	Female (n = 51, 45.0%) Male (n = 62, 55.0%)	Patients (n = 65; 57.5%) Palliative (n = 43; 38.1%) Missing (n = 5; 4.4%)	Breast (n = 19; 17.0%) Colorectal (n = 15; 13.0%) Haematological (n = 12; 11.0%) Lung (n = 19; 17.0%) Prostate (n = 19; 17.0%) Skin (n = 8; 7.0%) Other (n = 21; 19.0%)	Metastatic (n= 43; 38.1%) Locally advanced (n = 37; 32.7%) Localised (n = 28; 24.8%) Missing (n = 5; 4.4%)	EU (n = 85; 75.2%) Non-EU (n = 28; 24.8%)	Content validity
	Conroy et al., 2004 (117)	53.0 ± 11 years	Female (n = 196; 63.0%) Male (n = 114; 37.0%)	Patients (n = 270; 87.0%) Palliative (n = 40; 13.0%)	Breast (n = 163; 52.6%) Colorectal (n = 60; 19.4%) Head and neck (n = 87; 28.0%)	NA	EU (n = 310; 100%)	Internal consistency Reliability
	Costa et al., 2015 (118)	NA	Female (n = 969; 50.8%) Male (n = 937; 49.2%)	Patients (n = 1906; 100%)	Breast (n = 537; 28.1%) Colorectal (n = 502; 26.3%) Gynaecological (n = 128; 6.7%) Head and neck (n = 121; 6.3%) Lung (n = 198; 10.3%) Oesophagus (n = 124; 6.5%) Prostate (n = 296; 15.5%)	NA	EU (n = NA) Non-EU (n = NA)	Measurement invariance Structural validity (model 1)

	Demirci et al., 2011 (119)	Median: 50.0 ± NA years (range 30-75)	Female (n = 127; 100%)	Patients (n = 127; 100%)	Breast (n = 127; 100%)	NA	EU (n = 127; 100%)	Internal consistency
	Efficace et al., 2019 (120)	51.5 ± 14.5 years	Female (n = 925; 43.6%) Male (n = 1196; 56.0%) Missing (n = 8; 0.4%)	Patients (n = 2134; 100%)	Blood (n = 2,134; 100%)	NA	EU (n=2120; 99.3%) Non-EU (n = 14; 0.7%)	Construct validity Structural validity (model 2)
	Fischer et al., 2017 (121)	NA	Female (n = 264; 100%)	Patients (n = 264; 100%)	Breast (n = 264; 100%)	Stage I (n = 50; 18.9%) Stage II (n = 169; 64.0%) Stage III (n = 34; 12.8%) Missing (n = 11; 4.2%)	EU (n = 116; 43.9%) Non-EU (n = 148; 56.1%)	Construct validity Internal consistency
	Georgakopoulos et al. 2013 (122)	40.6 ± 14.8 years	Female (n = 35; 43.7%) Male (n = 45; 56.3%)	Patients (n = 80; 100%)	Lymphoma (n = 80; 100%)	Stage I-II (n = 44; 55.0%) Stage III-IV (n = 36; 45.0%)	EU (n = 80; 100%)	Construct validity Internal consistency
	Hiçsönmez et al. 2007 (123)	57.0 ± NA years (range 15-72)	Female (n = 25; 28.4%) Male (n = 63; 71.6%)	Palliative (n = 88; 100%)	NA	Local advanced (n = 11; 12.5%) Metastatic (n = 77; 87.5%)	EU (n = 88; 100%)	Construct validity Internal consistency
	Hinz et al. 2012 (124)	60.3 ± 12.1 years	Female (n = 624; 40.8%) Male (n = 905; 59.2%)	Patients (n = 1529; 100%)	Brain (n = 70; 4.6%) Breast (n = 173; 11.3%) Colon (n= 63; 4.1%) Gastrointestinal (n = 294; 19.2%) Gynaecological (n = 193; 12.6%) Head and neck (n = 119; 7.8%) Lung (n = 54; 3.5%) Prostate (n = 287; 18.8%) Urological (n = 161; 10.5%) Others (n = 118; 7.7%) Total (n = 1532)*	NA	EU (n = 1529; 100%)	Construct validity Internal consistency
	King-Kallimanis et al., 2012 (125)	63.0 ± 12.6 years	Female (n = 60; 38.7%) Male (n = 95; 61.3%)	Patients (n = 155; 100%)	Bladder (n = 6; 3.9%) Breast (n = 24; 15.6%) Cervical (n = 6; 3.9%) Colorectal (n = 19; 12.3%) Endometrial (n = 7; 4.6%) Esophageal (n = 16; 10.4%) Lung (n = 13; 8.4%) Prostate (n = 33; 21.4%) Other (n = 31; 20.0%)	NA	EU (n = 155; 100%)	Measurement invariance Structural validity (model 4)
	Koller et al., 2021 (126)	62.2 ± 12.3 years	Female (n = 209; 46.4%) Male (n = 241; 53.6%)	Patients (n = 450; 100%)	Blood (n = 36; 8.0%) Bone (n = 2; 0.4%)	Local (n = 176; 39.1%) Local advanced	EU (n = 450; 100%)	Construct validity Internal consistency

					Breast (n = 45; 10.0%) Eye, Brain, CNS (n = 4; 0.9%) Gastrointestinal (n = 93; 20.7%) Gynaecological (n = 29; 6.4%) Oral (n = 32; 7.1%) Respiratory and chest organs (n = 50; 11.1%) Skin (n = 68; 15.0%) Soft tissue (n = 2; 0.4%) Urogenital (n = 70; 15.6%) Others (n = 19; 16.0%)	(n = 123; 27.3%) Metastatic (n = 133; 29.6%) Missing (n = 18; 4%)		
	Kontodimopoulos et al., 2011 (127)	52.7 ± 11.5 years	Female (n = 105; 100%)	Patients (n = 105; 100%)	Breast (n = 105; 100%)	NA	EU (n = 105; 100%)	Construct validity Internal consistency
	Koukouli et al., 2009 (128)	60.4 ± 11 years	Female (n = 99; 52.7%) Male (n = 89; 47.3%)	Patients (n = 188, 100%)	Breast (n = 59; 31.0%) Colorectal (n = 67; 36.0%) Lung (n = 62; 33.0%)	Local (n = 61; 32.4%) Locoregional (n = 49; 26.1%) Metastatic (n = 78; 41.5%)	EU (n = 188, 100%)	Construct validity Internal consistency
	Kuenstner et al., 2002 (129)	57.6 ± 13.6 years	Female (n = 122; 52.1%) Male (n = 112; 47.9%)	Patients (n = 234; 100%)	Breast (n = 86; 36.8%) Gastrointestinal (n = 37; 15.8%) Leukemia (n = 22; 9.4%) Lung (n = 26; 11.1%) Lymphoma (n = 44; 18.8%) Others (n = 19; 8.1%)	NA	EU (n = 234; 100%)	Construct validity Internal consistency Reliability
	Kyrgidis et al., 2012 (130)	Sample 1 60.8 ± 9.6 years Sample 2 57.6 ± 11.1 years Sample 3 65.7 ± 11.7 years	Female (n = 64; 100%)	Patients (n = 64; 100%)	Breast (n = 42; 65.6%) Oral (n = 22; 34.4%)	Locoregional (n = 22; 34.4%) Metastatic (n = 42; 65.6%)	EU (n = 64; 100%)	Construct validity Internal consistency
	Marzorati et al., 2019 (131)	66.7 ± 7.7 years	Female (n = 67; 40.1%) Male (n = 100; 59.9%)	Patients (n = 167; 100%)	Lung (n = 167; 100%)	NA	EU (n = 167; 100%)	Structural validity (model 1) Measurememnt variance
	Müller et al., 2017 (132)	Median: 70 ± NA years (range 63-75)	Female (n = 80; 46.5%) Male (n = 92; 53.5%)	Patients (n = 172; 100%)	Non-melanoma skin (n = 172; 100%)	NA	EU (n = 172; 100%)	Construct validity Internal consistency
	Mystakidou et al., 2001 (133)	62.7 ± NA years (range 38-87)	Female (n = 74; 61.7%) Male (n = 46; 38.3%)	Palliative (n = 120; 100%)	Breast (n = 16; 13.3%) Cervical (n = 12; 10.0%) Lung (n = 30; 25.0%)	NA	EU (n = 120; 100%)	Construct validity Internal consistency

					Ovarian (n = 10; 8.3) Pancreas (n = 16; 13.3%) Others (n= 36; 30.1%)			Structural validity (model 5)
	Shuleta-Qehaja et al. 2015(134)	50.0 ± 10.9 years	Female (n = 62; 100%)	Patients (n = 62; 100%)	Breast (n = 62; 100%)	Stage 0-I (n = 7; 11.3%) Stage II (n = 19; 30.6%) Stage III-IV (n = 36; 58.1%)	EU (n = 62; 100%)	Construct validity Internal consistency
	Singer et al. 2009 (135)	65.1 ± 9.6 years	Female (n = 27; 8.4%) Male (n = 296; 91.6%)	Patients (n = 323; 100%)	Head and neck (n = 323; 100%)	Stage I (n = 90; 28.0%) Stage II (n = 45; 14.0%) Stage III (n = 52; 16.0%) Stage IV (n = 68; 21.0%) Missing (n = 68; 21.0%)	EU (n = 323; 100%)	Construct validity Internal consistency
	Sommer et al., 2020 (136)	Median: 51.5 ± NA years (range 41-60)	Female (n = 897; 42%) Male (n = 1174; 55%) Missing (n = 63; 3%)	Patients (n = 2134; 100%)	Blood (n = 2134; 100%)	NA	EU (n = 2134; 100%)	Measurement invariance Structural validity (model 1)
	Terret et al., 2011 (137)	Median: 76.0 ± NA years (range 68-86)	Male (n = 72; 100%)	Patients (n = 72; 100%)	Bladder (n = 14; 19.0%) Prostate (n = 53; 74.0%) Renal (n = 5; 7.0%)	NA	EU (n = 72; 100%)	Construct validity Internal consistency
	Uwer et al., 2011 (138)	Median: 64.0 ± NA years	Female (n = 46; 36.0%) Male (n = 81; 64.0%)	Patients (n = 127; 100%)	Colorectal (n = 127; 100%)	Non-metastatic (n = 80; 63.0%) Metastatic (n = 45; 35.0%) Unknown (n = 2; 2.0%)	EU (n = 127; 100%)	Reliability
	van Leeuwen et al., 2017(139)	**Prostate**: 75.0 ± 5.8 years **Testicular**: 43.1 ± 8.8 years	Male (N = 142; 100%)	Survivors (N = 142; 100%)	Prostate (n = 116; 47.9%) Testicular (n = 126; 52.1%)	**Prostate**: 13 ± 2.1 years since treatment allocation **Testicular:** 11.9 ± 3.8 years since treatment allocation	EU (N = 142; 100%)	Construct validity Internal consistency
	Wallwiener et al. 2017 (140)	51.0 ± 11.31 years	Female (n = 106; 100%)	Patients (n = 106; 100%)	Breast (n = 106; 100%)	Metastatic (n = 30; 28.3%) Adjuvant treatment (n = 76; 71.7%)	EU (n = 106; 100%)	Reliability
EORTC QLQ-ELD14	Arraras et al., 2019 (141)	74.5 ± 6.6 years	Female (n = 87; 100%)	Survivors (n = 87; 100%)	Breast (n = 87; 100%)	11.8 ± 8.1 years since diagnosis	EU (n = 87; 100%)	Construct validity Internal consistency
	Johnson et al., 2020 (51)	NA	Female (n = 94; 51.6%) Male (n = 88; 48.4%)	Patients (n = 182; 100%)	Breast (n = 49; 26.9%) Colorectal (n = 47; 25.8%) Lung (n = 38; 20.9%) Prostate (n = 26; 14.3%)	Local treated for cure (n = 69; 38.8%) Locally advanced (n = 81; 44.2%)	EU (n = 164, 89.6%) Non-EU (n = 9, 10.4%)	Development Content validity

					Ovarian (n = 11; 6.0%) Upper GI (n = 11; 6.0%)	Metastatic (n = 33; 10.8%) Total (n = 183; 100%)**	Total (n=183; 100%)**	
	Wheelwright et al. 2013 (142)	77.3 ± 4.9 years (range 70-96)	Female (n = 264; 51.1%) Male (n = 253; 48.8%) Missing (n = 1; 0.1%)	Patients (n = 288; 60.4%) Palliative (n = 189; 39.6%) Total (n = 477; 100%)**	Blood (n = 54; 10.3%) Breast (n = 91; 17.6%) Colorectal (n = 87; 16.8%) Lung (n = 63; 12.2%) Ovary (n = 23; 4.4%) Prostate (n = 75; 14.5%) Upper GI (n = 21; 4.1%) Other (n = 104; 20.1%)	Local (n = 190; 41.6%) Local advanced (n = 99; 21.7%) Metastatic (n = 168; 36.8%) Total (n = 477; 100%)**	EU Non-EU (n = 518, 100%)	Development Construct validity Content validity Internal consistency
	Wrazen et al., 2014 (143)	76.4 ± 5.7 years	Female (n = 41; 63.1%) Male (n = 24; 36.9%)	Patients (n = 65; 100%)	Breast (n = 16; 24.6%) Prostate (n = 13; 20%) Colorectal (n = 12; 18.5%) Head and neck (n = 12; 18.5%) Lung (n = 6; 9.2%) Other (n = 6; 9.2%)	NA	EU (n = 65, 100%)	Construct validity Internal consistency
EORTC QLQ-C15-PAL	Arraras et al., 2014 (144)	66.8 ± 12.2 years (range 32-92)	NA	Palliative (n = 116; 100%)	Bone (n = 116; 100%)	Advanced (n = 116; 100%)	EU (n = 116; 100%)	Construct validity Internal consistency
	Bjorner et al., 2004 (145)	Below 40 years (n = 843; 10.2%) 40-49 years (n = 1531; 18.6%) 50-59 years (n = 1645; 20.0%) 60-69 years (n = 1965; 23.8%) Above 69 years (n = 2044; 24.8%) Unknown (n = 214; 2.6%)	Female (n=4678; 56.8%) Male (n=3453; 41.9%) Missing (n=1111; 13.4%)	Palliative (n = 904; 11.0%) Survivors (n = 143; 1.7%) Other (n=5287; 67.8%) Missing (n=1608; 19.5%)	Breast (n = 3129; 38.0%) Lung (n = 692; 8.4%) Prostate (n = 1323; 16.1%) Other (n = 2849; 34.6%) Unknown (n = 249; 3.0%)	Advanced (n = 904; 11.0%) Stage I-II (n=4381; 53.2%) Stage III (n = 1206; 14.6%) Missing (n= 1751; 19.5%)	EU (n = 8242; 100%)	Development
	Golčić et al. 2018 (146)	72.7 ± 9.57 years	Female (n = 68; 45.1%) Male (n = 83; 54.9%)	Patients Cancer (n =137; 90.7%) Non-cancer (n = 14; 9.3%)	Colorectal (n = 19; 13.9%) Lung (n = 34; 24.8%) Pancreas (n = 13; 9.5%) Other (n = 71; 51.8%)	NA	EU (n = 151; 100%)	Construct validity Internal consistency
	Groenvold et al. 2006 (52)	Median: 73 ± NA years (range 41-86)	NA	Palliative (n = 41; 100%)	Breast (n = 6; 14.6%) Colorectal (n = 3; 7.3%) Prostate (n = 4; 9.8%) Stomach (n = 7; 17.1%)	Advanced (n = 41; 100%)	EU (n = 41; 100%)	Development Content validity

					Other (n = 13; 31.7%) Unknown (n = 8; 20.0%)			
	Leppert et al., 2013 (147)	67.30 ± 12.3 years (range 33-94)	Female (n = 58; 45.0%) Male (n = 71; 55.0%)	Palliative (n = 129; 100%)	Breast (n = 9; 6.98%) Cervix (n = 4; 3.10%) Colon (n = 19; 14.73%) Endometrium (n = 3; 2.33%) Head and neck (n = 8; 6.20%) Kidney (n = 12; 9.30%) Liver (n = 2; 1.55%) Lung (n = 26; 20.16%) Oesophagus (n = 2; 1.55%) Ovary (n = 7; 5.43%) Pancreas (n = 7; 5.43%) Prostate (n = 12; 9.30%) Stomach (n = 4; 3.10%) Urinary bladder (n = 2; 1.55%) Vulva (n = 2; 1.55%) Other locations (n = 10; 7.75%)	Advanced (n = 129; 100%)	EU (n = 129; 100%)	Construct validity Interal consistency Reliability
	Ozcelik et al., 2016 (148)	52.76 ± 14.55 years	Female (n = 83; 55.3%) Male (n = 67; 44.7%)	Palliative (n = 150; 100%)	Breast (n = 29; 19.3%) Gastrointestinal (n = 49; 32.7%) Genitourinary (n = 21; 14.0%) Lung (n = 8; 5.3%) Osteosarcoma (n = 15; 10.0%) Skin (n = 2; 1.3%) Other (n = 26; 17.3%)	Advanced (n = 150; 100%)	EU (n = 150; 100%)	Internal consistency
	Petersen et al., 2006 (149)	NA	NA	Palliative (n =267; 100%)	NA	Advanced (n =267; 100%)	EU (n =267; 100%)	Development
	Pilz et al., 2021 (150)	64.5 ± 9.6 years (range 27-90)	Female (n = 117; 52.0%) Male (n = 107; 47.6%) Missing (n = 1; 0.4%)	Palliative (n = 225; 100%)	Brain (n = 6; 2.7%) Breast (n = 44; 19.6%) Colorectal (n = 27; 12.0%) Gynecologic (n = 16; 7.1%) Head and neck (n = 10; 4.4%) Hematological (n = 5; 2.2%) Lymphoma (n = 6; 2.7%) Lung (n = 44; 19.6%) Prostate (n = 22; 9.8%) Stomach (n = 10; 4.4%) Other (n = 35; 15.6%) Total (n = 215; 100%)**	Stage III (n = 31; 14.5%) Stage IV (n = 179; 83.6%) Missing data (n = 4; 1.9%) Total (n = 214; 100%)**	EU (n = 225; 100%)	***

ESAS-r	Bruera et al., 1991 (53)	65.0 ± 13.0 years	Female (n =57; 56.4%) Male (n = 44; 43.6%)	Palliative (n = 101; 100%)	Breast (n = 15; 14.9%) Gastrointestinal (n = 23; 22,8%) Genitourinary (n = 20; 19.8%) Haematological (n = 3; 3.0%) Head and neck (n = 6; 5.9%) Lung (n = 30; 29.7%) Unknown (n = 3; 3.9%)	Advanced (n = 101; 100%)	Non-EU (n = 101; 100%)	Development
	Carvajal et al., 2013 (151)	54 ± NA years (range 18-84)	Female (n = 46; 70.0%) Male (n = 20; 30.0%)	Palliative (n= 66; 100%)	Breast (n= 12; 18.0%) Gastrointestinal (n = 24; 36.0%) Genitourinary (n = 16; 24.0%) Lung (n = 3; 5.0%) Others (n = 11; 17.0%)	Advanced (n= 66; 100%)	EU (n= 66; 100%)	Construct validity Internal consistency
	Ekström et al. 2020 (152)	62.9 ± 12.1 years	Female (n = 570; 54.4%) Male (n = 477; 45.6%)	Palliative (n = 1047, 100%)	Breast (n = 226; 21.6%) Digestive (n = 279; 26.6%) Genitourinary (n = 107; 10.2%) Gynaecological (n = 63; 6.0%) Lung (n = 222; 21.2%) Others (n = 150; 14.4%)	Advanced (n=1047, 100%)	EU (n = NA) Non-EU (n = NA)	Construct validity Reliability
	Sætra et al. 2016 (153)	Median: 67.0 ± NA years (range 31-87)	Female (n = 27; 50.0%) Male (n = 27; 50.0%)	Palliative (n = 54; 100%)	Breast (n = 4; 7.0%) Colorectal (n = 12, 22.0%) Lung (n = 9, 17.0%) Multiple myeloma (n = 9, 17.0%) Ovary (n = 4; 7.0%) Pancreatic (n = 5, 9.0%) Prostate (n = 4; 7.0%) Rare types (n = 7; 13.0%)	Advanced (n = 54; 100%)	EU (n = 54; 100%)	Content validity
	Watanabe et al., 2009 (154)	56.0 ± NA years (range 41-74)	Female (n =10; 50.0%) Male (n = 10; 50.0%)	Palliative (n = 20; 100%)	Breast (n = 1; 5.0%) Genitourinary (n = 7; 35.0%) Gastrointestinal (n = 5; 25.0%) Haematological (n = 3; 15.0%) Head and neck (n = 1; 5.0%) Lung (n = 3; 15.0%)	Advanced (n = 20, 100%)	Non-EU (n = 20; 100%)	Content validity
	Watanabe et al., 2012 (155)	61.0 ± NA years	Female (n =80; 50.0%) Male (n = 80; 50.0%)	Patients Cancer (n= 155; 97.0%) Non-cancer (n = 5; 3.0%)	NA	NA	Non-EU (n = 160; 100%)	Content validity
EQ-5D-3L	Brooks et al., 1996 (156)	NA	NA	NA	NA	NA	NA	Development

	Devlin et al., 2017 (157)	NA	NA	NA	NA	NA	NA	Development
	EuroQol, 1990 (54)	NA	NA	NA	NA	NA	EU (n = 592; 100%)	Development
	Kimman et al., 2009 (158)	55.8 ± 10.1 years (range 23-79)	Female (n = 192; 100%)	Patients Survivors (n = 192; 100%)	Breast (n = 192; 100%)	Stage I (n = 99; 51.6%) Stage II (n = 61; 31.8%) Stage III (n = 17; 8.6%) Unknown (n = 15; 7.8%)	EU (n = 192; 100%)	***
EQ-5D-5L	Davies et al., 2020 (159)	60.4 ± 11.5 years	Female (n=1498; 72.5%) Male (n = 567; 27.5%)	Patients (n = 2065; 100%)	Hypopharynx (n = 75; 3.6%) Larynx (n = 377; 18.3%) Nasal (n = 25; 1.2%) Nasopharynx (n = 41; 2.0%) Oral (n = 470; 23.8%) Oropharynx (n = 766; 37.1%) Sinuses (n = 11; 0.5%) Thyroid (n = 111; 5.4%) Other (n= 180; 4.7%) Unknown primary (n = 9; 4.5%)	Stage I (n = 460; 22.2%) Stage II (n = 321; 15.6%) Stage III (n = 280; 13.6%) Stage IV (n = 892; 43.2 %) Missing (n = 112; 5.4%)	EU (n = 2065; 100%)	***
	Herdman et al., 2011 (55)	<40 (n = 36; 46.8%) > 40 (n = 39; 50.1%) Missing (n = 2; 2.6%)	Female (n = 43; 55.8%) Male (n = 34; 44.2%)	NA	NA	NA	EU (n =77; 100%)	Development Content validity
FACT-G 2.0	Cella et al., 1993 (56)	**Sample 1:** Median: 60 ± NA years (range 27-76)	NA	Patients (n = 680; 100%)	**Sample 1**: Breast (n = 15; 33.3%) Colorectal (n= 15; 33.3%) Lung (n = 15; 33.3%) **Sample 2**: Breast (n = 30; 33.3%) Colorectal (n= 30; 33.3%) Lung (n = 30; 33.3%) **Sample 3** (n = 545): Breast (n = 213; 39.0%) Colorectal (n = 65; 12.0%) Head and neck (n = 44; 8.0%) Leukemia and lymphoma	**Sample 1:** Stage III-IV (n =45; 100%)	Non-EU (n = 680; 100%)	Development Content validity

					(n = 44; 8.0%) Lung (n = 82; 15.0%) Ovarian (n = 11; 2.0%) Prostate (n = 32; 6.0%) Other (n = 54; 10.0%)			
	Costet et al., 2005 (160)	56.0 ± 12.3 years (range 19-91)	Female (n = 357; 72.4%) Male (n = 130; 26.4%) Missing (n = 6; 1.2%)	Patients (n = 493; 100%)	Brain (n = 11; 2.4%) Blood (n = 18; 3.8%) Breast (n = 271; 57.9%) Digestive (n = 31; 6.6%) Ear or nose or throat (n = 41; 8.8%) Gynecological (n = 16; 3.4%) Lung (n = 24; 5.1%) Skin (n = 11; 2.4%) Urology (n = 26; 5.6%) Others (n = 19; 4.1%) Total (n = 468)**	Local (n = 291; 59.0%) Metastatic (n = 117; 23.7%) Remission (n = 49; 9.9%) Missing (n = 36; 7.3%)	EU (n = 493; 100%)	Construct validity Internal consistency Reliability
	Fumimoto et al., 2001 (161)	Age < 39 (n = 3; 1.7%) 40–49 (n =11; 6.1%) 50–59 (n = 43; 23.9%) 60–69 (n = 67; 22.3%) 70–79 (n = 49; 37.2%) >80 (n = 5; 2.8%) Missing (n = 2; 1.1%)	Female (n = 44; 24.4%) Male (n = 136; 75.6%)	Patients (n = 180; 100%)	Lung (n = 180; 100%)	Stage I–II (n = 12; 6.7 %) Stage III (n = 74; 41.1%) Stage IV (n = 86; 47.8%) Missing (n = 8; 4.4%)	Non-EU (n = 180; 100%)	Content validity
	Smith et al., 2007 (162)	Female 55.7 ± 12.4 years Men 60.8 ± 13.0 years	Female (n = 323; 69.5%) Male (n = 138; 29.7%) Missing (n = 4; 0.9%)	Patients (n = 465; 100%)	Breast (n = 99; 21.3%) Colorectal (n = 72; 15.5%) Gastrointestinal (n = 27; 5.8%) Genitourinary (n = 132; 28.4%) Lung (n = 22; 4.7%) Melanoma (n = 21; 4.5%) Renal (n = 44; 9.5%)	NA	EU (n = 465; 100%)	Internal consistency Measurement invariance Structural validity

					Sarcoma (n = 19; 4.0%) Others (n = 23; 4.9%) Missing (n = 7; 1.5%)			
FACT-G 3.0	Conroy et al., 2004 (117)	53 ± 11 years	Female (n = 196; 63.0%) Male (n = 114; 37.0%)	Patients (n = 270; 87.0%) Palliative (n = 40; 13.0%)	Breast (n = 163; 52.6%) Colorectal (n = 60; 19.4%) Head and neck (n = 87; 28.0%)	NA	EU (n = 310; 100%)	Construct validity Internal consistency Reliability Structural validity
FACIT-PAL14	Moldón-Ballesteros et al. 2022 (163)	78.9 ± 11.7 years	Female (n = 69; 52.7%) Male (n = 62; 47.3%)	Palliative (n = 131; 100%)	Brain(n = 5; 3.8%) Breast(n = 11; 8.4%) Colorectal(n = 32; 24.2%) Gynaecological(n = 7; 5.3%) Head and neck(n = 6; 4.5%) Prostate(n = 5; 3.8%) Stomach(n = 10; 7.6%) Others(n = 11; 8.3%) Missing (n = 4; 3.0%)	Advanced (n = 131; 100%)	EU (n = 131; 100%)	Construct validity Internal consistency Structral validity
	Zeng et al., 2013 (57)	65.6 ± 13.01 years (range 38-88)	Female (n = 23; 38.0%) Male (n = 37; 62.0%)	Palliative (n = 60; 100%)	Breast (n = 11; 18.3%) Colorectal (n = 2; 3.3%) Lung (n = 7; 11.6%) Oesophagus (n = 3; 5.0%) Prostate (n = 20; 33.3%) Renal cell (n = 5; 8.3%) Unknown (n = 2; 3.3%) Others (n = 10; 16.6%)	Advanced (n = 60; 100%)	Non-EU (n = 60; 100%)	Development Content validity
FACIT-PAL46	Bagcivan et al., 2019 (164)	51.9 ± 15.3 years	Female (n = 120; 51.7%) Male (n = 112; 48.3%)	Patients (n = 232; 100%)	Breast (n = 25; 10.8%) Blood (n = 50; 21.6%) Genitourinary (n = 44; 19.0%) Gastrointestinal (n = 42; 18.1%) Lung (n = 31; 13.3%) Others (n = 22; 9.4%) Missing (n = 18; 7.7%)	Stage I (n = 18; 7.8%) Stage II (n = 14; 6.0%) Stage III (n = 29; 12.5%) Stage IV (n = 24; 10.3%) Unspecified (n = 147; 63.4%)	EU (n = 232; 100%)	Construct validity Internal consistency Structural validity
	Greisinger et al., 1997 (58)	NA	NA	Palliative (n = 120; 100%)	NA	Advanced (n = 120; 100%)	non-EU (n = 120; 100%)	Development Content validity
	Lyons et al., 2009 (165)	65.4 ± 10.9 years	Female (n = 100; 39.0%) Male (n = 156; 61.0%)	Palliative (n = 256; 100%)	Breast (n = 29; 11.0%) Gastrointestinal (n = 106; 42.0%) Genitourinary (n = 37; 14.0%) Lung (n = 84; 33.0%)	Advanced (n = 256; 100%)	Non-EU (n = 256; 100%)	Content validity

	Moldón-Ballesteros et al. 2022 (163)	78.9 ± 11.7 years	Female (n = 69; 52.7%) Male (n = 62; 47.3%)	Palliative (n = 131; 100%)	Brain (n = 5; 3.8%) Breast (n = 11; 8.4%) Colorectal (n = 32; 24.4%) Gynecological (n = 7; 5.3%) Head and neck (n = 6; 4.6%) Kidney (n = 9; 6.9%) Lung (n = 19; 14.5%) Neurologic (n = 5; 3.8%) Pancreas (n = 7; 5.3%) Prostate (n = 5; 3.8%) Stomach (n = 10; 7.6%) Others (n = 11; 8.4%) Missing (n = 4; 3.1%)	NA	EU (n = 131; 100%)	Construct validity Internal consistency Structural validity
FLIC	Bektas et al., 2008 (166)	49.8 ± 12.12 years (range 19-65)	Female (n = 48; 43.6%) Male (n = 62; 56.4%)	Patients (n = 110; 100%)	Breast (n = 36; 32.7%) Colorectum (n = 21; 19.1%) Lung (n = 19; 17.3%) Other (n = 34; 30.9%)	Local (n = 62; 56.4%) Metastatic (n = 48; 43.6%)	EU (n = 110; 100%)	Content validity Internal consistency
	Goh et al., 1996 (167)	NA	NA	NA	NA	NA	Non-EU (n = 246; 100%)	Content validity
	Schipper et al., 1984 (59)	NA	NA	Patients (n = 837; 100%)	NA	NA	EU (n = 837; 100%)	Development Content validity
IOC	Blanchin et al., 2015 (168)	57.3 ± 11.3 years	Female (n = 243; 100%)	Survivors (n = 243; 100%)	Breast (n = 243; 100%)	5.2 ± 4.7 years since diagnosis	EU (n = 243; 100%)	Construct validity Internal consistency Structural validity
	Crespi et al., 2008 (60)	66.3 ± 10.1 years (range 34-89)	Female (n = 1188; 100%)	Survivors (n = 1188; 100%)	Breast (n = 1188; 100%)	NA	Non-EU (n = 1188; 100%)	Development
	Muzzatti et al., 2013 (169)	Median: 60.0 ± NA years (range 28-79)	Female (n = 244; 80.3%) Male (n = 60; 19.7%)	Survivors (n = 304; 100%)	Breast (n = 192; 63.2%) Colorectal (n = 16; 5.3%) Genitourinary (n = 10; 3.3%) Gynaecological (n = 7; 2.3%) Lymphoma (n = 60; 19.7%) Others (n = 18; 5.9%) Missing (n = 1; 0.3%)	9 ± NA years since diagnosis (range 5-33 years)	EU (n = 304; 100%)	Content validity Internal consistency Reliability
	van Leeuwen et al. 2017 (139)	**Prostate**: 75 ± 5.8 years **Testicular**: 43.1 ± 8.8 years	Male (n = 242; 100%)	Survivors (n = 242; 100%)	Prostate (n = 116; 47.9%) Testicular (n = 126; 52.1%)	**Prostate**: 13 ± 2.1 years since treatment allocation **Testicular**:	EU (n = 242; 100%)	Construct validity Internal consistency

						11.9 ± 3.8 years since treatment allocation		
	Zebrack et al., 2006 (170)	61.5 ± 14.3 years	Female (n = 84; 44.0%) Male (n = 109; 56.0%)	Survivors (n = 193; 100%)	Breast (n = 47; 24.4%) Colorectal (n = 39; 20.2%) Lymphoma (n = 49; 25.4%) Prostate (n= 58; 30.0%)	7.67 ± 1.9 years since diagnosis	Non-EU (n = 193; 100%)	Development Content validity
IPOS	Beck et al., 2017 (171)	Median: 70 years (range 50-94)	Female (n = 8; 61.5%) Male (n = 5; 38.5 %)	Palliative (n = 13; 100%)	Malignant (n = 7; 53.8%) Non-malignant (n = 6; 46.2%)	Advanced cancer (n = 13; 100%)	EU (n = 13; 100%)	Content validity
	Hocaoglu et al. 2020 (172)	58.2 ± 12.5 years	Female (n = 172; 73.5%) Male (n = 62; 26.5%)	Patients (n = 234; 100%)	Breast (n = 113; 48.3%) Colon (n = 16; 6.8%) Lymph nodes (n = 16; 6.8%) Lung (n = 9; 3.8%) Prostate (n = 14; 6.0%) Thyroid (n = 9; 3.8%) Uterus (n = 7; 3.0%) Others (n = 50; 21.4%)	Stage I (n = 16; 6.8%) Stage II (n = 71; 30.3%) Stage III (n = 80; 34.2%) Stage IV (n = 44; 18.8%) Unknown (n = 23; 9.8%)	EU (n = 234; 100%)	Construct validity Internal consistency Structural validity
	Schildmann et al. 2016 (61)	NA (range 22- 85)	Female (n = 17; 68.0%) Male (n = 8; 32.0%)	Palliative (n = 25; 100%)	Malignant (n = 21; 84.0%) Non-malignant (n = 3; 12.0%) Missing (n = 1; 4.0%)	Advanced (n = 25; 100%)	EU (n = 25; 100%)	Development Content validity
	Szeliga et al., 2022 (173)	70.1 ± 9.9 years	Female (n = 90; 50.0%) Male (n = 90; 50.0%)	Palliative (n = 180; 100%)	Breast (n = 20; 11.1%) Gastrointestinal (n = 41; 22.8%) Genitourinary (n = 39; 21.7%) Head and neck (n = 15; 8.3%) Respiratory (n = 34; 18.9%) Others (n = 31; 17.2%)	Advanced (n = 180; 100%)	EU (n = 180; 100%)	Construct validity Internal consistency Reliability
LAYA-SRQL	Park et al., 2014 (62)	33.0 ± 7.0 years	Female (n = 303; 78.3%) Male (n = 84; 21.7%)	Survivors (n = 387; 100%)	NA	NA	Non-EU (N = 387; 100%)	Development Content validity
	Richter et al., 2018 (174)	Median: 30 ± NA years (range 16-39)	Female (n = 186; 79.5%) Male (n = 48; 20.5%)	Survivors (n = 234; 100%)	Blood (n = 125; 53.4%) Breast (n = 57; 24.4%) Sarcoma (n = 13; 5.6%) Others (n = 39; 16.6%)	2.7 ± NA years since diagnosis	EU (n = 234; 100%)	Construct validity Internal consistency Structural validity
MDASI	Cleeland et al., 2000 (63)	NA	Female (n = 171; 25.5%) Male (n = 499; 74.5%)	Patients (n = 670; 100%)	Breast (n = 48; 7.2%) Gastrointestinal (n = 20; 3.0%) Gynecologic (n = 38; 5.7%) Genitourinary (n = 20; 3.0%) Head and neck/thyroid (n = 17; 2.5%) Leukemia acute(n = 29; 4.3%)	NA	Non-EU (n = 670; 100%)	Development Content validity

					Leukemia chronic (n = 23; 3.4%) Lymphoma (n = 41; 6.1%) Lung and mesothelioma (n = 14; 2.1%) Other (n = 50; 7.5%) Missing (n = 370; 55.2%)			
	Guirimand et al. 2010 (175)	60.5 ± 12.8 years	Female (n = 94; 58.0%) Male (n = 68; 42.0%)	Palliative (n = 162; 100%)	Breast (n = 39; 24.0%) Gastrointestinal (n = 63; 39.0%) Genitourinary (n = 2; 1.0%) Gynaecological (n = 6; 4.0%) Head and neck (n = 4; 2.0%) Leukemia (n = 9; 6.0%) Lung (n = 14; 9.0%) Lymphoma (n = 5; 3.0%) Myeloma (n = 10; 6.0%) Others (n = 10; 6.0%)	Advanced (n = 162; 100%)	EU (n = 162; 100%)	Construct validity Internal consistency Structural validity (model 3)
	Mystakidou et al. 2004 (176)	NA	Female (n = 89; 59.3%) Male (n = 61; 40.7%)	Palliative (n = 150; 100%)	Breast (n = 30; 20.0%) Gastrointestinal (n = 19; 12.7%) Genital (n = 32; 21.3%) Lung (n = 22; 14.7%) Lung and breast (n = 2; 1.3%) Lung and other (n = 2; 1.3%) Prostate (n = 22; 14.7%) Urinary (n = 7; 4.7%) Other (n = 14; 9.3%)	Metastatic (n = 99; 66.0%) Other (n = 51; 44.0%)	EU (n = 150; 100%)	Construct validity Internal consistency Reliability Structural validity (model 2)
	Schmidt et al., 2015 (177)	60.6 ± 12.9 years	Female (n = 349; 50.1%) Male (n = 348; 49.9%)	Patients (n = 697; 100%)	Brain (n = 6; 0.9%) Breast (n = 97; 13.9%) Gastrointestinal (n = 194; 27.8%) Genitourinary (n = 65; 9.3%) Gynaecological (n = 58; 8.3%) Head and neck (n = 52; 7.5%) Pulmonary (n = 62; 8.9%) Other (n = 136; 19.5%) Missing (n = 27; 3.9%)	NA	EU (n = 697; 100%)	Construct validity Internal consistency Structural validity (model 1)
POS 1.0	Bausewein et al. 2005 (178)	63 ± NA years (range 27-94)	Female (n = 74; 63.0%) Male (n = 44; 37.0%)	Palliative (n = 118; 100%)	Breast (n = 27; 23.0%) Gastrointestinal (n = 21; 18.0%) Genitourinary (n = 30; 25.0%) Lung (n = 22; 19.0%) Lymph/blood (n = 2; 2.0%) Others (n = 16; 14.0%)	Advanced (n = 118; 100%)	EU (n = 118; 100%)	Content validity Reliability

	Hearn et al., 1999 (64)	NA	Female (n = 66; 45.0%) Male (n = 82; 55.0%)	Palliative Cancer (n = 146; 100%) Non-cancer (n = 2; 1.4%)	Breast (n = 20; 13.9%) Digestive (n = 44; 30.6%) Genitourinary (n = 33; 22.9%) Lymph/haemato (n = 3 ; 2.1%) Respiratory (n = 26; 18.1%) Other (n = 20; 13.9%)	NA	EU (n = 148; 100%)	Development Content validity
	Pelayo-Alvarez et al., 2013 (179)	69.4 ± 11.5 years	Female (n = 47; 40.0%) Male (n = 70; 60.0%)	Palliative (n = 117; 100%)	Breast (n = 5; 4.3%) Gastrointestinal (n = 37; 31.6%) Larynx (n = 7; 6.0%) Lung (n = 29; 24.8%) Prostate (n = 10; 8.5%) Others (n = 29; 24.8%)	NA	EU (n = 117; 100%)	Construct validity Reliability
POS 2.0	Costantini et al., 2016 (180)	18-55 years (n = 18; 12.0%) 56-65 years (n = 28; 18.7%) 66-75 years (n = 45; 30 %) 76-85 years (n = 46; 30.7%) >85 years (n = 13; 8.7%)	Female (n = 73; 48.7%) Male (n = 77; 51.3%)	Palliative (n = 150; 100%)	Blood (n = 6; 4%) Breast (n = 14; 9.3%) Gastrointestinal (n = 64; 42.7%) Genitourinary (n = 19; 12.7%) Head and neck (n = 4; 2.7%) Lung (n = 35; 23.3%) Others (n = 8; 5.3%)	NA	EU (n = 150; 100%)	Construct validity Content validity Internal consistency Reliability
QLACS	Andreu Vaillo et al. 2022 (181)	59.2 ±12.2 years (range 18-92)	Female (n=1094; 58.8%) Male (n = 753; 41.2%) Total (n = 1847)**	Survivors (n=1823; 100%)	Breast (n = 673; 36.8%) Colorectal (n = 250; 13.7%) Gynaecologic (n = 97; 5.3%) Head and neck (n = 106; 5.8%) Hematologic (n = 108; 5.9%) Melanoma (n = 80; 4.4%) Multiple (n = 95; 5.2%) Prostate (n = 288; 15.8%) Others (n = 130; 7.1%) Total (n = 1827)**	4.5 ± 4.5 years since primary treatment (range 0.1-30)	EU (n = 1823; 100%)	Construct validity Internal consistency
	Ashley et a., 2014 (182)	60.87 ± 10.47 years (range 24-85)	Female (n = 221; 54.3%) Male (n = 186; 45.7%)	Survivors (n = 407; 100%)	Breast (n = 187; 45.9%) Colorectal (n = 107; 26.3%) Prostate (n = 113; 27.8%)	NA	EU (n = 407; 100%)	Internal consistency
	Avis et al., 2005 (65)	64.9 ± 14.5 years (range 34-91)	Female (n = 32; 55.0%) Male (n = 26; 45.0%)	Survivors (n = 58; 100%)	Bladder (n = 6; 10.3%) Breast (n = 12; 20.7%) Colorectal (n = 11; 19.0%) Gynecologic (n = 10; 17.2%) Head and neck (n = 9; 15.5%) Prostate (n = 10; 17.2%)	NA years since diagosis (range 5-18)	Non-EU (n = 58; 100%)	Development Construct validity Content validity Internal consistency Reliability Structural validity

	Escobar et al., 2015 (183)	65.1 ± 11.0 years (range 30-91)	Female (n = 422; 59.7%) Male (n = 285; 40.3%)	Survivors (n = 707; 100%)	Breast (n = 354; 50.1%) Colorectal (n = 193; 27.3%) Prostate (n = 160; 22.6%)	NA	EU (n = 707; 100%)	Construct validity Internal consistency Structural validity
	Fathollahi-Dehkordi et al. 2021 (184)	NA	Female (n = 150; 100%)	Survivors (n = 150; 100%)	Breast (n = 150; 100%)	NA years since diagnosis (range 1.5-5)	Non-EU (n = 150; 100%)	Content validity
QLI	Can et al., 2011 (185)	**Sample 2** (n = 154): 20-29 (n = 10; 6.5%) 30-39 (n = 29; 18.8%) 40-49 (n = 52; 33.8%) 50-59 (n = 53; 34.4%) 60-69 (n = 10; 6.5%)	**Sample 2** (n = 154): Female (n = 24; 15.6%) Male (n = 130; 84.4%)	Patients (n = 174; 100%)	Lung (n = 174; 100%)	**Sample 2** (n = 154): Stage II (n = 12; 7.8%) Stage III (n = 40; 26.9%) Stage IV (n = 54; 35.1%) Limited (n = 18; 11.7%) Extensive SCLC (n = 30; 19.5%)	EU (n = 174; 100%)	Internal consistency
	Ferrans et al., 1985 (186)	**Sample 1:** 33.1 ± 6.73 years (range 23-52) **Sample 2:** 50 ± 14.18 years (range 24-75)	**Sample 1**: Female (n = 85; 97.0%) Male (n = 3; 3.0%) **Sample 2:** Female (n = 10; 28.0%) Male (n = 27; 72.0%)	**Sample 1:** General (n = 88; 100%) **Sample 2**: Non-cancer patients (n=37; 100%)	NA	NA	Non-EU (n = 125; 100%)	Development Content validity
	Ferrans, 1990 (66)	49.7 ± 11.7 years (range 27-76)	Female (n = 111; 100%)	Patients (n = 23; 20.9%) Survivors (n = 88; 79.1%)	Breast (n = 111; 100%)	7.93 ± 5.24 years (range 2.0-32.2) since diagnosis	Non-EU (n = 111; 100%)	Content validity
	Rannestad et al. 2011 (187)	General 57 ± NA years (range 32-75) Survivors 58 ± NA years (range 32-75)	Female (n = 653; 100%)	General (n = 160; 24.5%) Survivors (n = 493; 75.5%)	Gynaecological (n = 493; 100%)	NA	EU (n = 653; 100%)	Construct validity Internal consistency
	Rustøen et al. 1999 (188)	52 ± 12.98 years (range 19-78)	Female (n = 99; 76.0%) Male (n = 32; 24.0%)	Patients (n = 131; 100%)	Breast (n = 48; 36.6%) Colon (n = 17; 13.0%)	NA	Non-EU (n = 131; 100%)	Internal consistency Relaibility

					Gynaecological (n = 24; 18.3%) Prostatic (n = 13; 9.9%) Other (n = 28; 21.4%) Missing (n = 1; 0.8%)			
QOL-CS	Ferrell et al., 1995 (67)	49.6 ± 12.3 years	Female (n = 556; 81.0%) Male (n = 130; 19.0%)	Survivors (n = 686; 100%)	Breast (n = 294; 42.9%) Cervical (n = 30; 4.3%) Colon (n = 25; 3.7%) Leukemia (n = 25; 3.7%) Lymphoma (n = 59; 8.6%) Hodgkins (n = 53; 7.7%) Ovarian (n = 53; 7.7%) Other (n = 139; 20.3%) Missing (n = 8; 1.1%)	6.7 ± 6.2 years (range 0.3-44.8)	Non-EU (n = 686; 100%)	Development Content validity
	Van Dis et al., 2006 (189)	<70 (n = 192; 24.0%) 70-74 (n = 212; 27.0%) 75-79 (n = 248; 32.0%) >80 (n = 132; 17.0%)	Male (n= 784; 100%)	Survivors (n= 784; 100%)	Prostate (n= 784; 100%)	Stage I (n =164; 21.0%) Stage II (n = 428; 55.0%) Stage III (n = 96; 12.0%) Stage IV (n = 45; 6.0%) Missing (n = 51; 6.0%)	EU (n= 784; 100%)	Construct validity Content validity Internal consistency Reliability
QUAL	Grünke et al. 2018 (190)	57.7 ± 11.7 years (range 29-81)	Female (n = 110; 60.1%) Male (n = 73; 39.9%)	Palliative (n = 183; 100%)	Breast (n = 24; 13.1%) Digestive (n = 53; 29.0%) Gynecological (n = 21; 11.5%) Lung (n = 24; 13.1%) Urogenital (n = 19; 10.4%) Others (n = 42; 23.0%)	Advanced (n = 183; 100%)	EU (n = 183; 100%)	Construct validity Internal consistency Structural validity
	Lo et al., 2011 (191)	61 ± 12 years (range 28-88)	Female (n = 256; 55.0%) Male (n = 212; 45.0%)	Palliative (n = 468; 100%)	Breast (n = 67; 14.0%) Gastrointestinal (n = 143; 31.0%) Genitourinary (n = 86; 18.0%) Gynaecological (n = 71; 15.0%) Lung (n = 101; 22.0%)	Advanced (n = 468; 100%)	Non-EU (n = 468; 100%)	Development
	Steinhauser et al. 2002 (68)	62 ± NA (range 34-84)	Female (n = 53; 26.5%) Male (n = 147; 73.5%)	Patients Cancer (n = 128; 64.0%) Other (n = 72; 36.0%)	NA	NA	Non-EU (n = 200, 100%)	Development Content validity
RSCL	Agra et al., 1998 (192)	**Sample 1**: NA years	**Sample 2**: Female (n = 40; 34.0%)	**Sample 2**: Patients	**Sample 2**: Colon (n = 10; 8.5%)	NA	**Sample 2**: EU	Construct validity Internal consistency

		(range 35-75) **Sample 2**: 67.1 ± 12.7 (range 31-92)	Male (n = 78; 66.0%)	(n = 118; 100%)	Gynaecological (n = 9; 7.6%) Lung (n = 31; 26.3%) Other (n = 67; 57.6%) Missing (n = 1; 0.8%)		(n = 118; 100%)	Reliability
	De Haes et al., 1998 (193)	42.9 ± 5.0 years (range 24-51)	Female (n = 689; 100%)	Patients (n = 689; 100%)	Breast (n = 689; 100%)	Stage II (n = 689; 100%)	EU (n = 654; 95.0%) Non-EU (n = 35; 5.0%)	Cross-cultural validity Internal consistency
	De Haes et al., 1990 (194)	NA	**Sample 1**: Female (n = 86; 100%)	**Sample 1**: Patients (n = 86; 100%) **Sample 2**: Patients (n = 56; 100%) **Sample 3**: (n = 20; 100%) **Sample 4**: Patients (n = 165; 34.7%) Survivors (n = 167; 35.1%) Health (n = 144; 30.3%)	NA	NA	EU (n = 771; 100%)	Internal consistency
	Kearsley et al. 1998 (195)	NA (range 30-80)	Female (n = 48; 40.2%) Male (n = 72; 59.8%)	Patients (n = 120; 100%)	Breast (n = 21; 17.6%) Lung (n = 41; 34.1%) Lymphoma (n = 9; 7.5%) Ovary (n = 3; 2.5%) Prostate (n = 25; 20.8%) Other (n = 20; 16.7%) Missing (n = 1; 0.8%)	NA	EU (n = 120; 100%)	***
	Paci, 1992 (196)	Sample 1: 60.7 ± 13.2 years	Female (n = 180; 100%)	Patients (n = 180; 100%)	Breast (n = 180; 100%)	NA	EU (n = 180; 100%)	Construct validity Internal consistency
	Watson et al., 1992 (69)	Sample 1:	Female (n = 278; 60.0%) Male (n = 156; 40.0%)	Patients (n = 434; 100%)	Bladder (n = 6; 1.4%) Breast (n = 130; 30.0%)	NA	EU (n = 434; 100%)	Development Construct validity

		55 ± 14.3 years (range 16-86) Sample 2: 52 ± 12.3 years (range 19-74)			Gastrointestinal (n = 15; 3.5%) Gynecological (n = 28; 6.5%) Head and neck (n = 14; 3.2%) Leukemia (n = 7; 1.6%) Lung (n = 84; 19.3%) Melanoma (n =15; 3.4%) Myeloma (n = 15; 3.4%) Non-Hodgkin's lymphoma; Hodgkin's disease (n = 82; 18.9%) Prostate (n = 8; 1.8%) Others (n = 30; 7.0%)			
	Witteveen et al. 1999 (197)	NA	NA	Palliative: Cancer (n = 81; 100 %) Non-cancer (n = 31; 27.7%)	Breast (n = 15; 18.5%) Digestive (n = 15; 18.5%) Head and neck (n = 7; 8.6%) Ovarian (n = 23; 28.5%) Other (n = 21; 25.9%)	Advanced (n = 81; 72.3%) Other (n = 31; 27.7%)	EU (n = 112; 100%)	Construct validity Internal consistency
SCNS-SF34	Aydin Avci et al. 2018 (198)	53.2 ± 16.0 years	Female (n = 244; 42.6%) Male (n = 329; 57.4%)	Patients (n = 573; 100%)	NA	NA	EU (n = 573; 100%)	Internal consistency Structural validity (model 1)
	Bonevski et al., 2000 (199)	NA	Female (n = 484; 56.8%) Male (n = 357; 42.0%) Missing (n = 10; 1.2%)	Patients (n = 851; 100%)	Breast (n = 280; 32.0%) Colon and rectum (n = 150; 17.0%) Lung (n = 67; 8.0%) Prostate (n = 80; 9.0%) Skin (n = 43; 5.0%) Unknown (n = 14; 2.0%) Other (n = 217; 24.0%)	NA	Non-EU (n = 851; 100%)	Content validity
	Boyes et al., 2009 (70)	NA	**Sample 1** (n = 444): Female (n = 228; 51.0%) Male (n = 189; 43.0%) Missing (n = 27; 6.0%) **Sample 2** (n = 444): Female (n = 256; 58.0%) Male (n = 168; 38.0%)	Patients (n = 1138; 100%)	**Sample 1**: Breast (n = 137; 31.0%) Colorectal (n = 74; 17.0%) Lung (n = 31; 7.0%) Prostate (n = 39; 9.0%) Other (n = 137; 31.0%) Missing (n = 26; 5.0%) **Sample 2**:	NA	Non-EU (n = 1138; 100%)	Development

			Missing (n = 20; 4.0%) **Sample 3** (n = 250): Female (n = 89; 36.0%) Male (n = 161; 64.0%)		Breast (n = 139; 32.0%) Colorectal (n = 70; 16.0%) Prostate (n = 35; 8.0%) Lung (n = 32; 7.0%) Other (n = 142; 32.0%) Missing (n = 26; 5.0%) **Sample 3**: Breast (n = 14; 6.0%) Colorectal (n = 21; 8.0%) Prostate (n = 82; 33.0%) Lung (n = 23; 9.0%) Other (n = 110; 44.0%)			
	Brédart et al., 2012 (200)	54.0 ± 11.3 years	Female (n = 384; 100%)	Patients (n = 384; 100%)	Breast (n = 384; 100%)	Local (n = 310; 80.7%) Metastatic (n = 74; 19.3%)	EU (n = 384; 100%)	Construct validity Internal consistency Reliability Structural validity (model 1)
	Jansen et al., 2016 (201)	18-60 years (n = 63; 31.3%) >60 years (n = 138; 68.7%)	Female (n = 67; 33.3%) Male (n = 134; 66.7%)	Patients/Survivors (n = 201; 100%)	Head and neck (n = 201; 100%)	Patients Stage 1 (n = 56; 27.9%) Stage 2 (n = 27; 13.4%) Stage 3 (n = 33; 16.4%) Stage 4 (n = 74; 36.8%) Unknown (n = 11; 5.5%) Survivors Time since last treatment: <1 year (n = 78; 38.8%) 1-2 years (n = 60; 29.9%) >2 years (n = 63; 31.3%)	EU (n = 201; 100%)	Construct validity Internal consistency Reliability Structural validity (model 1 and 2)
	Zeneli et al., 2016 (202)	59.0 ± 14.0 years	Female (n = 21; 52.5%) Male (n = 19; 47.5%)	NA	Breast (n = 10; 25.0%) Gastrointestinal (n = 9; 22.5%) Head and neck (n = 2; 5%) Hematologic (n = 7; 17.5%) Lung (n = 5; 12.5%) Urogenital (n = 7; 17.5%)	NA	EU (n= 40; 100%)	Content validity
SF-20	Stewart et al., 1988 (71)	47.0 ± NA years (range 18-103)	Female (n = 6936; 62.0%)	Non-cancer patients (n = 11186;100%)	NA	NA	Non-EU	Development Content validity

			Male (n= 4250; 38.0%)				(n = 11186; 100%)	
	Tchen et al., 2002 (203)	Median: 74 ± NA years (range 65-86 years)	NA	Patients (n = 63; 100%)	Large cell lymphoma (n = 63; 100%)	NA	EU (n = 63; 100%)	Construct validity Internal consistency Structural validity
SF-36	Aaronson et al., 1998 (204)	57.3 ± 12.1 years (range 22-86)	Female (n = 281; 58.0%) Male (n = 203; 42.0%)	Patients (n = 286; 59.0%) Palliative (n = 199; 41.0%)	Breast (n = 169; 35.0%) Colorectal (n = 116; 24.0%) Lung (n = 150; 31.0%) Other (n = 49; 10.0%)	Local (n = 286; 59.0%) Metastatic (n = 198; 41.0%)	EU (n = 484; 100%)	Construct validity Internal consistecy
	Bunevicius, 2017 (205)	55.8 ± 14.4 years	Female (n = 157; 69.0%) Male (n = 70; 31.0%)	Patients (n = 227; 100%)	High-grade glioma (n = 44; 19.0%) Low-grade glioma (n = 19; 8.0%) Meningioma (n = 91; 40.0%) Metastatic (n = 2; 1.0%) Pituitary adenoma (n = 27; 12.0%) Vestibular schwannoma (n = 20; 9.0%) Other (n = 24; 10.0%)	NA	EU (n = 227; 100%)	Construct validity Internal consistency
	Mosconi et al., 2010 (206)	64 ± 9.2 years	Male (n = 157; 95.7%) Missing (n = 8; 4.3%)	Patients (n = 165; 100%)	Laryngeal (n = 165; 100%)	NA	EU (n = 165; 100%)	Internal consistency Construct validity
	Reulen et al., 2006 (207)	NA	NA	Survivors (n = 8934; 100%)	NA	NA	EU (n = 8934; 100%)	Internal consistency
	Ware et al., 1992 (72)	NA	NA	NA	NA	NA	NA	Development
SPARC	Ahmed et al., 2009 (73)	NA	NA	Survivors (n = 1; 50.0%) Other (n = 1, 50.0%)	NA	NA	EU (n = 2; 100%)	Development Content validity
	Leppert et al., 2012 (208)	64.2 ± 11.3 years	Female (n = 32; 55.0%) Male (n = 26; 45.0%)	Palliative (n = 58; 100%)	Breast (n = 6; 10.3%) Cervix (n = 2; 3.4%) Colon (n = 8; 13.8%) Kidney (n = 4; 6.9%) Larynx (n = 3; 5.0%) Lung (n = 12; 20.7%) Ovary (n = 3; 5.0%)	Advanced (n = 58; 100%)	EU (n = 58; 100%)	Construct validity Content validity Internal consistency Structural validity

					Prostate (n = 6; 10.3%) Thyroid gland (n = 3; 5.0%) Others (n = 11; 19.6%)			
	Pyo et al., 2021 (209)	55 ± NA years (range 41-69)	Female (n=14; 93.3%) Male (n = 1; 6.7%)	Patients (n = 15; 100%)	Breast (n = 12; 79.9%) Liver cell (n = 1; 6.7%) Pancreatic (n = 1; 6.7%) Stomach (n = 1; 6.7%)	Stage II (n = 4; 26.6%) Stage III (n = 3; 20.1%) Stage IV (n = 8; 53.3%)	Non-EU (n = 15; 100%)	Content validity
SUNS-SF	Campbell et al., 2014 (74)	NA	Female (n = 814; 51.0%) Male (n = 775; 49.0%)	Survivors (n = 1589; 100%)	Breast (n = 356; 22.0%) Colorectal (n = 230; 14.0%) Lung (n = 67; 4.2%) Non-Hodgkin's lymphoma (n = 84; 5.3%) Prostate (n = 338; 21.0%) Other (n = 514; 32.0%)	NA	Non-EU (n = 1589; 100%)	Development
	Campbell et al., 2011 (210)	NA	Female (n = 310; 56.4%) Male (n = 240; 43.6%)	Survivors (n = 550; 100%)	Breast (n = 142; 25.8%) Colorectal (n = 75; 13.6%) Lung (n = 34; 6.2%) Lymphoma (n = 31; 5.6%) Prostate (n = 100; 18.2%) Other (n = 168; 30.6%)	NA years since diagnosis (range 1-5)	Non-EU (n = 550; 100%)	Development
	Hall et al., 2014 (211)	NA	Female (n = 329; 45.0%) Male (n = 403; 55.0%)	Survivors (n = 732; 100%)	**Sample 1**: Non-Hodgkin's lymphoma (n = 10; 58.0%) Missing (n = 7; 42.0%) **Sample 2**: Leukemia (n = 129; 19.0%) Myeloma (n = 108; 16.0%) Non-Hodgkin's lymphoma (n = 397; 59.0%) Other (n = 42; 6.2%)	Median: 2.9 ± NA years since diagnosis	Non-EU (n = 732; 100%)	Content validity
	Pereira et al., 2021 (212)	67.40 ± 10.52 years	Female (n = 106; 49.8%) Male (n = 107; 50.2%)	Patients (n = 213; 100%)	Myeloma (n = 213; 100%)	Stage I (n = 76; 35.7%) Stage II (n = 59; 27.7%) Stage III (n = 53; 24.9%) Stage IV (n = 25; 11.7%)	EU (n = 213; 100%)	Construct validity Internal consistency Structural validity

WHOQoL-BREF	De Mol et al., 2018 (213)	63.4 ± 9.2 years	Female (n =70; 45.8%) Male (n = 83; 54.2%)	Patients (n =153; 100%)	Adenocarcinoma (n = 141; 92.2%) Large cell (n = 4; 2.6%) Large cell neuroendocrine (n = 1; 0.7%) Mesothelioma (n = 7; 4.6%)	Locally advanced (n = 19; 12.4%) Metastatic (n = 119; 77.8%) Other (n = 14; 9.2%) Unknown (n = 1; 0.7%)	EU (n =153; 100%)	Construct validity Internal consistency Structural validity
	WHO Group, 1998 (75)	NA	NA	NA	NA	NA	EU Non-EU (n = NA)	Development
WHOQoL-100	Den Oudsten et al., 2009 (214)	**Breast cancer**: 54.9 ± 0.6 years (range 19-87) **Benign**: 58.7 ± 9.5 years (range 34-87) **Survivors**: 56.6 ± 11.4 years (range 26-85)	Female (n = 496; 100%)	Patients (n = 356; 71.8%) Survivors (n = 140; 28.2%)	Breast (n = 496; 100%)	NA	EU (n = 496; 100%)	Construct validity Internal consistency
	Paredes et al., 2010 (215)	41.5 ± NA years	Female (n = 36; 44.4%) Men (n = 45; 55.6%)	Patients (n = 81; 100%)	Bone (n = 43; 53.1%) Soft tissue (n = 28; 34.6%) Missing (n = 10; 12.3%)	Diagnostic (n = 13; 16.1%) Treatment (n = 36; 44.4%) Follow-up (n = 32; 39.5%)	EU (n = 81; 100%)	Construct validity Content validity Internal consistency Reliability
	Power et al., 1998 (216)	43.4 ± 16.0 years	Female (n=2583; 53.8%) Male (n= 2219; 46.2%)	General (n = 912; 19.0%) Non-cancer patients (n = 3890; 81.0%)	NA	NA	EU (n = 2846; 59.3%) Non-EU (n=1956; 40.7%)	Development Content validity
	WHO Group, 1994 (76)	NA	NA	General (n = 50; 16.7 %) Patients (n = 250; 83.3%)	NA	NA	EU (n = NA) Non-EU (n = NA)	Development
3LNQ	Johnsen et al., 2011 (77)	63.0 ± 13 years	Female (n = 44; 59.5%) Male (n =30; 40.5%)	Patients (n = 74; 100%)	Brain (n =2; 2.7%) Breast (n =17; 23.0%) Gastrointestinal (n =24; 32.4%)	Stage III (n = 38; 51.4%) Stage IV (n = 30; 40.5%) Missing (n = 6; 8.1%)	EU (n = 74; 100%)	Development Content validity

					Genitourinary (n =6; 8.1%) Gynecological (n =10; 13.4%) Head and neck (n =5; 6.8%) Hematological (n =5; 6.8%) Lung (n =2; 2.7%) Other (n =3; 4.1%)			

Abbreviations: SD = standard deviation; n = sample size; EU = participants recruited from countries from the European Union and associated countries; Non-EU = participants recruited from countries outside the European Union and associated countries; * = the total differs from the total for the rest of the calculations in the study because some patients suffer from multiple cancer types; ** = the total differs from the total for the rest of the calculations in the study; *** = only information on development and content validity was assessed

Appendix 11: Detailed overview of different models per PROM

PROM	Model number	Hypothesized model	Factors (number of items)
CARES-SF	Model 1 (91)	6-factor model	Physical (11) Psychological (5) Medical interaction (4) Sexual (3) Marital (6) Relatives & friends (4)
	Model 2 (92)	5-factor model	Physical (10) Psychological (17) Medical interaction (4) Sexual (3) Marital (6)
CaSUN	Model 1 (94)	5-factor model	Existential survivorship (7) Psychological & emotional support (7) Comprehensive care (7) Relationships (3) Information (3)
	Model 2 (93)	5-factor model	Physical effects (4) Psychological effects (11) Comprehensive care & information (9) Practical issues (6) Relationships (5)
EORTC QLQ-C30	Model 1 (118,131,136)	9-factor model	Physical functioning (5) Role functioning (2) Cognitive functioning (2) Emotional functioning (4) Social functioning (2) Fatigue (3) Pain (2) Nausea/vomiting (2) Global health status (2)
	Model 2 (120)	1-factor model	Quality of life (29)
	Model 3 (114)	2-factor model	Quality of life (30) Physical health (9)
	Model 4 (125)	1-factor model	Functioning HRQoL (17) encompassing: Physical functioning (5) Role functioning (2) Cognitive functioning (2) Emotional functioning (4) Social functioning (2) Global health status (2)
	Model 5 (133)	6-factor model	Factor 1 (NA) Factor 2 (NA) Factor 3 (NA) Factor 4 (NA) Factor 5 (NA) Factor 6 (NA)
MDASI	Model 1 (177)	2-factor model	Interference items (6) Symptom items (13)
	Model 2 (176)	3-factor model	Factor 1 (6) Factor 2 (6) Factor 3 (6)
	Model 3 (175)	3-factor model	General symptoms (7) Emotional & cognitive components (3) Gastrointestinal component (3)
SCNS-SF34	Model 1 (198,200,201)	5-factor model	Psychological (10) Health system & information (11) Patient care & support (5) Physical & daily care (5) Sexuality (3)
	Model 2 (201)	4-factor model	Psychological (10) Health system, information & patient support (16) Physical & daily care (5) Sexuality (3)

Abbreviations: NA = no information available

Appendix 12: Overview of available languages

PROM	Available languages
CaSUN	Slovenian, Spanish
EORTC CAT	Danish, Polish, Swedish, Taiwanese, Dutch
EORTC QLQ-C30	Afrikaans, Albanian, Amharic, Arabic, Armenian, Assamese, Azerbaijani, Belarusian, Bengali, Bosnian, Bulgarian, Burmese, Cantonese, Catalan, Cebuano, Chichewa, Creole, Croatian, Czech, Danish, Dutch, Estonian, Farsi, Finnish, Ganda, Georgian, Greek, Greenlandic, Gujarati, Hebrew, Hiligaynon, Hindi, Hungarian, Icelandic, Ilokano, Indonesian, Japanese, Kannada, Kazakh, Khasi, Khmer, Korean, Latvian, Lithuanian, Luganda, Macedonian, Malay, Malayalam, Maltese, Mandarin, Marathi, Montenegrin, Nepali, Northern Sotho/Sepedi, Norwegian, Oriya, Pangasinan, Polish, Portuguese, Punjabi, Romanian, Russian, Serbian, Setswana/Tswana, Sinhalese, Slovak, Slovenian, Sotho/Sesotho, Spanish, Swahili Swedish, Tagalog, Tamil for India, Telugu, Thai, Turkish, Ukrainian, Urdu, Uzbek, Vietnamese, Welsh, Xhosa, Yoruba, Zulu
EORTC QLQ-ELD14	Bulgarian, Chinese Mandarin, Croatian, Danish, Dutch, Greek, Japanese, Korean, Lithuanian, Norwegian, Polish, Portuguese, Russian, Slovenian, Spanish, Swedish, Turkish
ESAS-r	Afrikaans, Albanian, Algonquin, Arabic, Armenian, Burmese, Chinese, Cree, Croatian, Czech, Farsi, Greek, Hebrew, Hindi, Hungarian, Inuktitui, Japanese, Korean, Mandarin, Oji Cree, Polish, Portuguese, Punjabi, Russian, Serbian, Somali, Swedish, Tagalog, Tamil, Turkish, Ukrainian, Urdu, Vietnamese
FACT-G	Afrikaans, Albanian, Arabic, Armenian, Bengali, Bosnian, Bulgarian, Burmese, Catalan, Cebuano, Chinese, Croatian, Czech, Danish, Dutch, Estonian, Farsi, Finnish, Georgian, Greek, Gujarati, Hebrew, Hiligaynon, Hindi, Hungarian, Icelandic, Ilokano, Indonesian, Japanese, Kannada, Kazakh, Korean, Latvian, Lithuanian, Macedonian, Malay, Malayalam, Maltese, Marathi, Montenegrin, Northern Sotho/Sepedi, Norwegian, Odia, Oriya, Polish, Portuguese, Punjabi, Romanian, Russian, Sepedi, Serbian, Setswana/Tswana, Sinhalese, Slovak, Slovenian, Sotho/Sesotho, Swahili, Swedish, Tagalog, Tamil, Telugu, Thai, Turkish, Ukrainian, Urdu, Vietnamese, Wolof, Xhosa, Zulu
FACIT-PAL14	Bengali, Burmese, Chinese, Dutch, Hindi, Indonesian, Japanese, Malay, Malayalam, Portuguese, Sinhalese, Tamil, Telugu, Thai, Turkish, Vietnamese
FACIT-PAL46	Bengali, Burmese, Chinese, Dutch, Hindi, Indonesian, Japanese, Malay, Malayalam, Portuguese, Sinhalese, Tamil, Telugu, Thai, Turkish, Vietnamese
IPOS	Chinese, Greek, Israeli, Japanese, Polish, Portuguese, Romanian, Swedish, Turkish
MDASI	Afrikaans, Amharic, Arabic, Bosnian, Chinese, Croatian, Czech, Danish, Dutch, Estonian, Filipino, Finnish, Greek, Hebrew, Hindi, Hungarian, Icelandic, Japanese, Korean, Malay, Marathi, Norwegian, Polish, Portuguese, Romanian, Russian, Serbian, Slovak, Swedish, Taiwanese, Tamil, Thai, Turkish, Ukrainian Vietnamese
POS	Portuguese
SCNS-SF34	Mandarin
WHOQoL-BREF	Afrikaans, Albanian, Amharic, Arabic, Assamese, Bahasa, Bangla, Bulgarian, Cebuano, Chichewa, Chinese, Croatian, Czech, Danish, Dari, Dutch, Estonian, Farsi (Persian), Filipino, Finnish, Ganda, Gichuka, Greek, Gujarati, Hausa, Hebrew, Hiligaynon, Hindi, Hungarian, Indonesian, Japanese, Kannada, Kazakh, Khmer, Kikuyu, Kiswahili, Korean, Laotian, Latvian, Lithuanian, Luganda, Macedonian, Malay, Malayalam, Maltese, Marathi, Mongolian, Nepali, Norwegian, Odia, Polish, Portuguese, Romanian, Russian, Serbian, Shona, Sinhalese, Slovak, Somali, Swedish, Tamil, Thai, Tibetan, Turkish, Ukrainian, Urdu, Vietnamese, Yoruba
WHOQoL-100	Arabic, Cantonese, Croatian, Czech, Danish, Dari, Dutch, Greek, Hebrew, Hindi, Hungarian, Japanese, Kiswahili, Korean, Lithuanian, Malay, Norwegian, Persian, Polish, Portuguese, Russian, Serbian, Sinhalese, Swedish, Thai, Turkish

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CHAPTER 2

Systematic review of the needs and Health Related Quality of Life domains relevant to European cancer patients and survivors.

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1 Introduction

As already mentioned in Chapter 1 of this report, the burden of cancer on Health-related quality of life (HRQoL) is well recognized (1, 2), and clinical trials and real-world data show the positive effects of routine quality of life assessment on patient wellbeing and use of health care resources (3). However, full implementation of Patient-reported outcome measures (PROMs) for the assessment of HRQoL in routine oncology practice is not yet part of standard of care. Currently, health care systems and cancer control programs usually do not take into consideration PROMs when devising clinical, societal, and healthcare policymaking systems.

Nowadays, when technology allows for a larger use of PROMs with a considerably low burden of administration (4), some of the reasons for their limited use in routine clinical practice may be related to the content of the existing instruments.

The available HRQL questionnaires were developed a few years ago mainly to be used in the context of research studies, to assess efficacy, effectiveness or tolerability of treatments or interventions (5). The **content of these instruments may not consider the new situation of cancer survivors and cancer patients under new therapies**, such as intensive protocols over extended periods of time.

Moreover, HRQoL instruments were developed by health professionals and researchers to meet their own information needs. Better use of research evidence in health systems **requires partnerships between researchers and those who contend with the real-world needs and constraints of health systems, including patients**. In order to improve HRQoL assessment relevance, uptake, and impact, an increase in community and stakeholder participation is then needed.

So, although plenty of generic and either disease- or treatment-specific questionnaires have been developed and validated to measure HRQoL in oncology, **the ambition of the EUonQoL project** is to review existing scales and develop a new one (EUonQoL toolkit) overcoming the mentioned limitations.

The identification of emerging needs related to new cancer treatments, along with societal developments, require not only a revision of traditional HRQoL assessment tools (Chapter 1 of WP3), but also a summary of the most recently published evidence regarding the needs and concerns of oncological patients; and the opinion of all stakeholders related to this new framework.

This chapter (Chapter 2 of WP3) summarizes the methods and results of a systematic review on qualitative studies focused on the needs and concerns of European oncological patients and survivors. Conclusions from this summary of the evidence will help in the identification of domains, usually unmet in the traditional HRQoL conceptual models, and will be presented for discussion within the EUonQoL Stakeholders Board, in order to decide about their inclusion on the new EUonQoL-toolkit.

2 Methodology

2.1 Protocol and registration

The systematic review of the literature on the needs, preferences, concerns and general HRQoL domains relevant to European cancer patients and survivors is registered in the International Prospective Register of Systematic Reviews database (CRD406320 in https://www.crd.york.ac.uk/PROSPERO), and was designed following the methodological standards of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (6).

2.2 Information sources and search

The search was conducted in the MEDLINE bibliographic databases (specifically PubMed) on March the 6th of 2023. The search strategy included both MeSH and text word terms, and had 4 sections: one focused on the type of population (survivors, patients under treatment or palliative patients), a second one the pathology (neoplasm), a third section regarding the construct of interest (needs, concerns related to quality of life), and a last one referring to the importance or relevance of those constructs to patients. The search was limited to English publications within the last decade.

Several search strategies were tested (Appendix 1), for making decisions not only on the terms included (or excluded), but also regarding how they should be searched (as MeSH, Title/Abstract, or Text Word). Also, some tests were conducted with different approximations for referring to 'quality of life', and with the use of * when including both singular and plural. The use of the terms neoplasm and carcinoma was also tested.

The final decision (Table 1) was made based on two simple sensitivity analysis strategies: results about the inclusion of well-known studies in the area of interest (i.e. van Leeuwen M, et al Health Qual Life Outcomes. 2018, 7); and comparison of the potentially included and excluded articles, after a quick screening of a percentage of the results from two different strategies.

Table 1. Search Strategy used for the literature review in PubMed

(("Patient*"[Mesh] OR "Survivor*"[Mesh] OR "Palliative Care"[Mesh])
AND ("Neoplasms"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract])
AND ("Quality of Life"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh] OR "health-related quality of life"[Text Word] OR "health related quality of life"[Text Word] OR "patient-reported outcome*" [Text Word] OR "patient reported outcome*" [Text Word])
AND ("relevan*"[Text Word] OR "import*"[Text Word] OR "preferences"[Text Word] OR "feelings"[Text Word] OR "needs"[Text Word] OR "issues"[Text Word] OR "concerns"[Text Word] OR "worries"[Text Word] OR "difficulties"[Text Word] OR "limitations"[Text Word] OR "experiences"[Text Word] OR "problems"[Text Word]))
FILTERS: English; Publication Date last 10 years

2.3 Eligibility criteria

We considered as inclusion criteria: studies focused on Patient-Reported Outcomes, Needs, Preferences, Concerns, Worries; in samples of cancer patients in treatment, survivors or in palliative care; from the European Union (UK) or associated countries and the United Kingdom (UK) (see Appendix 2 in Chapter I); gathered through quantitative designs, or using mixed approaches including qualitative methods.

Studies were excluded if samples were composed by children, adolescents and young adults; very specific populations (rare tumours, second malignancy, tumour location specific treatments, LGTB…); patients with multimorbidity (with and without cancer); partners, caregivers or health professionals. Study designs excluded were randomized clinical trials, evaluation of interventions or e-platforms, assessment of usability or feasibility, development or validation of questionnaires, those focused on COVID impact on cancer patients, and non-original research articles (protocols, comments, guidelines, editorials…).

2.4 Selection process

Four researchers (MF, OG, CL, CA) independently reviewed titles and abstracts in two pairs using the Covidence® software (www.covidence.org).

A pilot test was conducted to standardize criteria among reviewers. The same four researchers (MF, OG, CL, CA) reviewed the articles' full text, to select the articles for data extraction. Disagreements in all phases were resolved through discussion with the participation of third-party reviewers.

2.5 Data collection process and data items

Data extraction and verification was carried out by 7 researchers (MF, OG, CL, CA, LR, MT, YP). We designed a predefined data collection form within Covidence® with the information to extract: author and year of publication, country in which the study was performed, aim of the study, study design (ranking, review, qualitative, scores, mixed-methods, other), year of data collection, recruitment methodology (consecutive, purposive, random, does not specify, other), cancer population type (survivors, under treatment, palliative), tumour location, inclusion and exclusion criteria, information of the sample (size, age, sex). Table 2 shows detailed information on the data extracted.

Furthermore, the following specific information on qualitative studies' characteristics was also extracted: theoretical approach (phenomenology, ethnography, grounded theory, action research, does not specify, other), qualitative approach (in-depth interviews, semi-structured interviews, focus groups, consensus meetings, Delphi, does not specify, other), use of guidelines for qualitative research, saturation of information, and themes, subthemes and quotations.

An example of the matrix used for data extraction is included in Appendix 2.

Table 2. Predefined data collection form.

General information
COVIDENCE ID
Country in which the study was conducted
Characteristics of included studies
Aim of the study
Methods
Study design (ranking, review, qualitative, scores, mixed-methods, other)
Qualitative approach (in-depth interviews, semi-structured interviews, focus groups, consensus meetings, Delphi, does not specify, other)
Theoretical approach (phenomenology, ethnography, grounded theory, action research, does not specify, other)
Year data was collected
Recruitment methodology (consecutive, purposive, random, does not specify, other)
Participants
Population type (survivors, under treatment, palliative)
Tumour location
Number of participants
Age of participants
Percentage of females
Inclusion criteria
Exclusion criteria
Quality
Appropriate qualitative guidelines followed
Reached saturation
Content
Themes
Subthemes
Quotations

2.6 Quality Assessment of the Studies

To assess the risk of bias of the included studies we used the Specialist Unit for Review Evidence (SURE) checklist (8). This checklist was developed for the quality appraisal of qualitative studies from an adapted and updated version of the NICE Public Health Methods Manual (2012) (9) and the Critical Appraisal Skills Programme (CASP) (10) checklists. The research team decided to use this checklist after an extensive review of the current tools used for quality appraisal of qualitative studies (11) to find the best tool that matched the needs of the present review. Moreover, the researchers mapped the dimensions of the SURE, CASP and NICE checklist prior to choosing the SURE checklist (Table 3.1).

The SURE checklist (Table 3.2) is composed of 10 items: clear aim/hypothesis, appropriateness of choice of qualitative method, description of sampling strategy, description of data collection, exploration of relationship between researchers and participants, discussion of ethical issues, description and justification of the data analysis and interpretation, credibility of findings, report of sponsorship or conflict of interest, and limitations and conclusions.

The risk of bias arising from each item is classified for the SURE checklist as: ‘Yes’, ‘Can’t tell’, or ‘No’. An example on the matrix used for SURE appraisal is included in Appendix.

Table 3.1 Mapping of the CASP, SURE, and NICE checklists.

CASP (10 items)	SURE (10 items)	NICE (14 items)
Was there a clear statement of the aims of the research?	Does the study address a clearly focused question/hypothesis	Is the study clear in what it seeks to do?
Is a qualitative methodology appropriate?	Is the choice of qualitative method appropriate?	Is a qualitative approach appropriate?
Was the research design appropriate to address the aims of the research?		How defensible/rigorous is the research design/ methodology?
Was the recruitment strategy appropriate to the aims of the research?	Is the sampling strategy clearly described and justified?	
Was the data collected in a way that addressed the research issue?	Is the method of data collection well described?	How well was the data collection carried out?
Has the relationship between researcher and participants been adequately considered?	Is the relationship between the researcher(s) and participants explored?	Is the role of the researcher clearly described?
Have ethical issues been taken into consideration?	Are ethical issues explicitly discussed?	How clear and coherent is the reporting of ethics?
Was the data analysis sufficiently rigorous?	Is the data analysis/interpretation process described and justified?	Is the data analysis sufficiently rigorous?
Is there a clear statement of findings?	Are the findings credible?	Are the findings convincing?
How valuable is the research?		
	Is any sponsorship/conflict of interest reported?	
	Finally… consider: Did the authors identify any limitations? Are the conclusions the same in the abstract and the full text?	Is there adequate discussion of any limitations encountered?
		Is the context clearly described? Were the methods reliable? Is the data 'rich'? Is the analysis reliable? Are the findings relevant to the aims of the study?

Table 3.2 Specialist Unit for Review Evidence (SURE) checklist.

#	Item
1	Does the study address a clearly focused question/hypothesis
	-Setting? -Perspective? -Intervention or Phenomena -Comparator/control if any -Evaluation/Exploration?
2	Is the choice of qualitative method appropriate?
	-Is it an exploration of e.g. behavior/reasoning/ beliefs)? -Do the authors discuss how they decided which method to use?
3	Is the sampling strategy clearly described and justified?
	-Is it clear how participants were selected? -Do the authors explain why they selected these particular participants? -Is detailed information provided about participant characteristics and about those who chose not to participate?
4	Is the method of data collection well described?
	-Was the setting appropriate for data collection? -Is it clear what methods were used to collect data? -Type of method (e.g., focus groups, interviews, open questionnaire etc.) and tools (e.g. notes, audio, audio visual recording). -Is there sufficient detail of the methods used (e.g. how any topics/questions were generated and whether they were piloted; if observation was used, whether the context described and were observations made in a variety of circumstances? -Were the methods modified during the study? If YES, is this explained? -Is there triangulation of data (i.e. more than one source of data collection)? -Do the authors report achieving data saturation?
5	Is the relationship between the researcher(s) and participants explored?
	-Did the researcher report critically examining/reflecting on their role and any relationship with participants particularly in relation to formulating research questions and collecting data). -Were any potential power relationships involved (i.e. relationships that could influence in the way in which participants respond)?
6	Are ethical issues explicitly discussed?
	-Is there sufficient information on how the research was explained to participants? -Was ethical approval sought? -Are there any potential confidentiality issues in relation to data collection?
7	Is the data analysis/interpretation process described and justified?
	-Is it clear how the themes and concepts were identified in the data? -Was the analysis performed by more than one researcher? -Are negative/discrepant results taken into account?
8	Are the findings credible?
	-Are there sufficient data to support the findings? -Are sequences from the original data presented (e.g. quotations) and were these fairly selected? -Are the data rich (i.e. are the participants' voices foregrounded)? -Are the explanations for the results plausible and coherent? -Are the results of the study compared with those from other studies?
9	Is any sponsorship/conflict of interest reported?
10	Finally… consider: Did the authors identify any limitations? Are the conclusions the same in the abstract and the full text?

2.7 Summary measures

Articles were first divided by the type of population they were studying (cancer survivors, patients under treatment, and palliative patients).

The primary outcome was defined as the themes and subthemes arising from each study, or the specific verbatims when necessary.

A thematic analysis was undertaken separately for the three groups of patients, in which the researchers who conducted the extraction discussed how to group the information form different studies using WhiteBoard. Each theme from each study was individually analysed and grouped with similar themes (from the same or a different study) into the same category. Categories (Table 4) were stablished based on Wilson & Cleary framework on HRQoL in oncology (12).

New categories were created for themes that did not fit in any of the predefined categories.

Working screenshots of the WhiteBoards are included in Appendix 4.

Table 4. Categories used for grouping relevant themes reported at the qualitative studies.

Physical
Social
Emotional/Mental
Global
Work
Death
Coping
Other

2.8 Synthesis of results

A table with all the themes aggregated into the different predefined categories was created stratifying by patient group (survivors, under treatment, and palliative). The number of studies in which each specific theme raised, was included in brackets. To avoid researchers' interpretation bias on what patients really meant by a specific term, the criteria applied was leaving the label of the themes as they were, instead of pooling them with ‘similar ones’. Sensitivity analysis was planned by selecting those studies of good quality according to the SURE checklist.

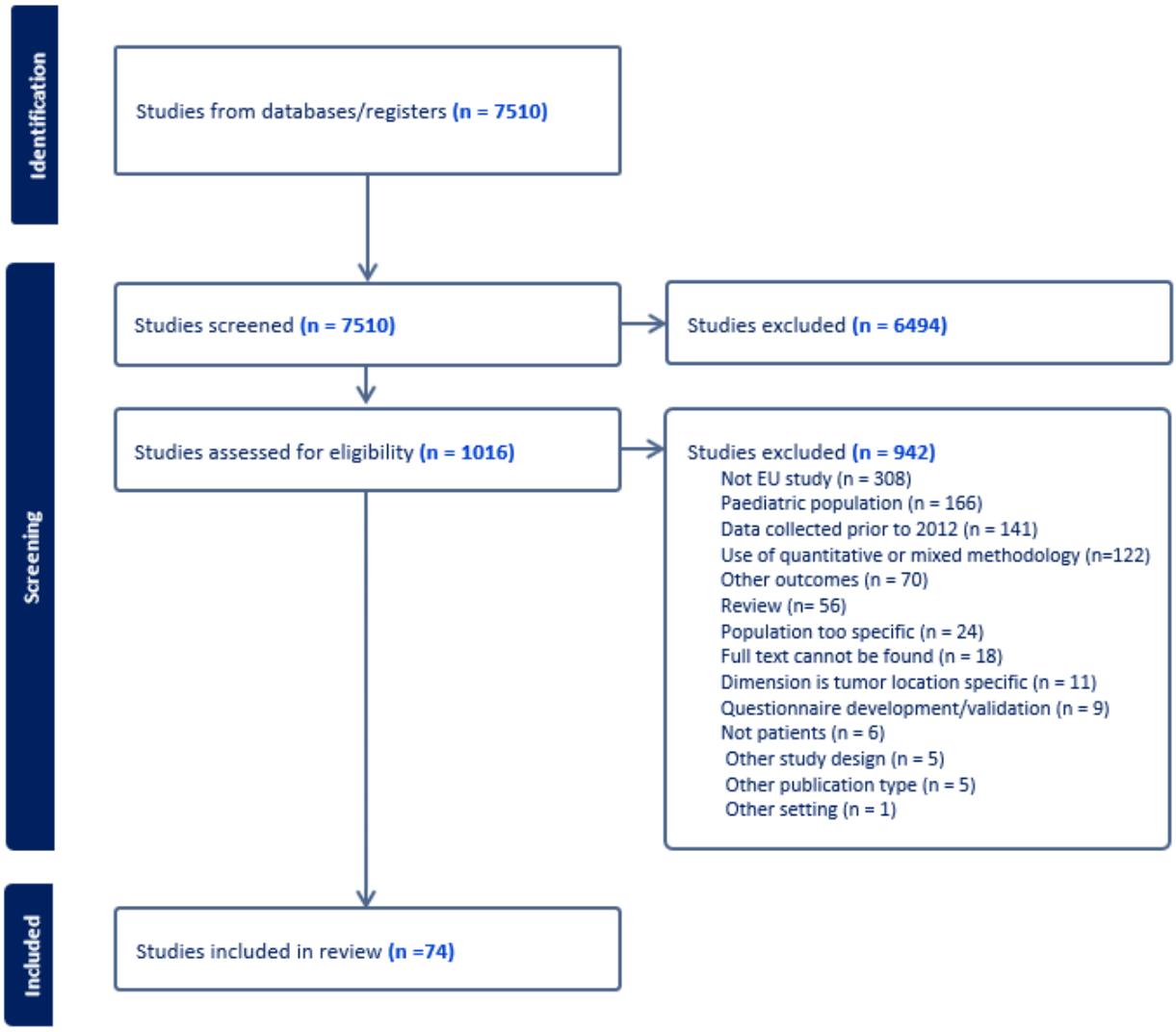
3 Results

3.1. Selection of studies

A total of 7510 articles were identified across PubMed. After screening all titles and abstracts, a complete full-text review of 1016 manuscripts was carried out. Of those, 308 were excluded because they didn't include European population (30.3%), 166 only included paediatric patients (16.3%), and in 141 studies data was collected prior to 2012 (13.8%). Other reasons for study exclusion were use of quantitative or mixed methodology (n=122), other outcomes (n=170), review studies (n=156), studies with very specific populations (n=124), dimension was specific of one tumour location (n=111), questionnaire validation or development (n=19), participants were not patients (n=16), other study design, publication type, or setting (n=111). Finally, 74 qualitative studies fulfilled the inclusion criteria and went to the following phase for data extraction.

More detailed information of the study selection process is described in the PRISMA flow-chart (Figure 1).

Figure 1. Selection process overview – PRISMA flow-chart.



3.2 Characteristics of the included studies

Of the 74 qualitative studies included (13-86) in this review, 30 studies focused on cancer survivors, 23 on cancer patients undergoing treatment at the time of the study, and 21 on palliative cancer patients.

A summary of these studies' characteristics is shown in Table 5; detailed fundamental information of each study can be found in Tables 5a, 5b, and 5c, according to population (survivors, under treatment, and palliative); and methodological information can be found in Appendix 5.

The countries in which more studies had been conducted were UK (n=19), Denmark (n=10), Sweden (n=9), The Netherlands (n=8), Norway (n=7), Germany (n=4), Turkey (n=4), France (n=3) and Ireland (n=2). The qualitative approaches most often used were semi-structured interviews, with 42 studies, followed by in-depth interviews, with 13 studies. The majority of the studies included patients with different tumour locations (n=22). Among those with specific tumour location samples, the most frequent locations were colorectal cancer (10 studies), prostate and breast cancer (9 studies each), and lung cancer (4 studies).

The 30 qualitative studies focusing on cancer survivors (Table 5a) were published between 2013 and 2022, their sample size ranged from 4 to 196 participants, and most of them were conducted on specific tumour location samples (7 studies of survivors of prostate cancer, 6 of breast cancer and 6 of colorectal cancer). The most common aim was to explore the existential experiences of patients who had undergone treatment with curative intent, but the specific purposes of some studies also included exploring: common language of cancer, critical reflections of information received and needs experienced during their trajectory, factors influencing adherence to treatment and healthy lifestyle, remaining treatment side effects, or return to work.

The 23 qualitative studies focused on cancer patients undergoing treatment at the time of the study (Table 5b) were published between 2014 and 2022, their sample size ranged from 3 to 5364 participants, and most of them were conducted among multiple tumoral locations. The most common aim was to explore perceptions and experiences of patients during treatment with curative intent, but specific purposes of some studies also included exploring: pain management, inpatient and outpatient settings and transitions between them, cancer rehabilitation, needs of support and information, communication with health professionals, decision-making processes, patients' preferences for receiving prognostic information, and work resumption and retention.

The 21 qualitative studies focused on cancer patients undergoing palliative treatment (Table 5c) were published between 2015 and 2022, their sample size ranged from 6 to 55 participants, and most of them were conducted among multiple tumoral locations. The most common aim was to explore the needs, experiences, and meaning of living with advanced cancer at the end of life, but specific purposes of some studies also included exploring: motives and perceptions of late lines of palliative oncologic treatment, preferences for home care to enable home death, and spiritual well-being.

Table 5. Characteristics of the Qualitative Studies

	Total	Survivors	under treatment	Palliative
Number of articles	74	30	23	21
Country				
United Kingdom	19	10	5	4
Denmark	10	3	4	3
Sweden	9	2	4	3
Netherlands	8	4	4	-
Norway	7	5	-	2
Germany	4	-	-	4
Turkey	4	2	2	-
France	3	3	-	-
Ireland	2	1	-	1
Others	8	-	4	4
Qualitative approach				
Semi-structured interviews	42	17	12	13
In-depth interviews	13	4	6	3
Focus groups	5	4	1	-
More than one approach	5	3	1	1
Others	9	2	3	4
Tumor location				
Multiple locations	22	3	9	10
Colorectal	10	6	2	2
Prostate	9	7	1	1
Breast	9	6	2	1
Lung	4	-	1	3
Head & neck	3	2	1	-
Multiple myeloma	3	1	2	-
Brain	2	2	-	-
Others	13	4	5	4
Sample size (n)	3-5364	4-196	3-5364	6-55

Table 5a. Characteristics of the qualitative studies that included survivors.

Author Year, Country	**Qualitative approach**	**Tumor location** Total participants (n)	**Aim of study**
Appleton 2013, Denmark	Semi-structured interviews	Colorectal 13	To explore in-depth the lived experience of colorectal cancer survivors.
Appleton 2014, UK	Focus groups	Multiple locations 18	To gain an insight into how survivors experience the common language and metaphor of cancer.
Aunan 2021, Norway	Focus groups	Prostate 16	To explore and analyse prostate cancer survivors' experiences and critical reflections of information received during their cancer trajectory.
Burden 2016, Sweden	Semi-structured interviews	Colorectal 25	To explore people's relationships with food and nutrition throughout their colorectal cancer journey.
denBakker 2018, Netherlands	Focus groups	Colorectal 22	To gather participants' experiences with their full recovery in the different treatment phases and identifying their needs experienced during these phases.
Dunne 2018, Ireland	Semi-structured interviews	Head & Neck 26	To identify survivors' perceptions of barriers to their active self-management after completing primary treatment for Head & Neck Cancer.
Harji 2015, UK, Australia	Focus groups	Colorectal 21	To identify HRQoL issues relevant to patients undergoing surgery for locally recurrent rectal cancer, with the aim of developing a conceptual framework of HRQoL specific to locally recurrent rectal cancer.
Harrow 2014, UK	Semi-structured interviews	Breast 39	To explore women's experiences of taking adjuvant endocrine therapy; their understandings and reasons for taking or not taking medication and the factors which influenced adherence or non-adherence and the information and support they received or desired.
Jakobsen 2018, Norway	In-depth interviews, Semi-structured interviews	Breast 11	To describe the everyday life in breast cancer survivors experiencing challenges.
KammingaNCW 2022, Netherlands	Focus groups, In-depth interviews	Multiple myeloma 20	To gain an in-depth understanding of metastatic melanoma survivors' experiences of resuming life after immune checkpoint inhibitors and their associated survivorship care needs.

Author Year, Country	**Qualitative approach**	**Tumor location** Total participants (n)	**Aim of study**
Koutoukidis 2017, UK	Semi-structured interviews, Focus groups	Endometrial 16	To examine the perceived importance of health behaviours after endometrial cancer treatment, and the factors influencing adherence to a healthy lifestyle after treatment and to explore the information that endometrial cancer survivors obtain after treatment, and their preferred method of information delivery.
Lagerdahl 2014, UK	Semi-structured interviews	Multiple locations 8	To explore the existential experiences of patients who have undergone treatment with curative intent for a range of cancers, and are considered to be in complete remission.
Liaset 2018, Norway	In-depth interviews	Brain 4	To explore individual experience after undergoing treatment for brain cancer and the return to work process.
Matheson 2020, UK	Semi-structured interviews	Prostate 27	To explore the experiences of men identified as having psychological distress, drawn from the total sample of interviewed men with Prostate Cancer.
Piil 2022, Denmark	Semi-structured interviews	Brain 13	To address perspectives on the daily life experiences of Long-Term Survivors with High grade Glioma and their caregivers.
Puppo 2020, France	Semi-structured interviews	Ovarian 16	How ovarian cancer survivors give meaning to their cancer experience and how the latter has an impact on their QoL.
RegnierDenois 2017, France	In-depth interviews	Breast 36	To understand the barriers to using supportive care services among breast cancer survivors under the age of 50 and to find out how this can contribute to inequalities.
Samsøe 2022, Denmark	Semi-structured interviews	Head & Neck 6	To gain insight into men's experience concerning the quality of life one year after completing radiation therapy for head and neck cancer to contribute to radiographers' and RTT's understanding of patients' experiences during treatment.
Şengünİnan 2019, Turkey	Semi-structured interviews	Breast 12	To explore Turkish breast cancer survivors' experiences related to Fear of Recurrence.
Şengünİnan 2020, Turkey	Semi-structured interviews	Breast 12	To explore experiences of Turkish breast cancer survivors about returning or continuing to work.
Stamataki 2015, UK	Semi-structured interviews	Melanoma 15	To explore the impact of melanoma diagnosis on the supportive care needs of patients with cutaneous melanoma.
Stuhlfauth 2018, Norway	Semi-structured interviews	Colorectal 9	To gain insight into how persons who have undergone surgery for colon cancer experience changes in their everyday life in general and in their sexual life in particular.

Author Year, Country	**Qualitative approach**	**Tumor location** Total participants (n)	**Aim of study**
Torp 2020, Norway	Semi-structured interviews	Colorectal 7	Explore how self-employed people experience their working situation during and after cancer treatment.
Treanor 2016, UK	Semi-structured interviews	Multiple locations 16	To investigate the nature and onset of late effects experienced by survivors and the manner in which late effects have affected their lives.
Trusson 2016, UK	In-depth interviews	Breast 24	In depth consideration of ongoing disruptions to identities, bodies and elationships, from diagnosis of breast cancer to the end of treatment, and well beyond.
vanEe 2018, Netherlands	Semi-structured interviews	Prostate 22	To gain more insight into the experiences of men 70 years old or older with prostate cancer and the care received from health-care professionals, family members and other informal carers.
Wagland 2019, UK	In-depth interviews	Prostate 97	To explore the experience of treatment decision making amongst men diagnosed with stage I-III prostate cancer.
Wennick 2017, Sweden	Semi-structured interviews	Prostate 19	To illuminate how men under 65 years of age experience their everyday life one year or more after a radical prostatectomy for localised prostate cancer, when the remaining side effects are likely to be permanent.
Wollersheim 2021, Netherlands	Recording of visits	Prostate 32	To investigate the supportive care and information needs of prostate cancer survivors during routine follow-up care.
Zanchetta 2016, France	Blog entries	Prostate 196	To explore issues of QoL as reported by French Prostate Cancer survivors in a public blog, and had two objectives: (a) to identify the salient aspects and issues of the experience of living with PC from the perspective of PC survivors based on textual data from their posted testimonies; and (b) to analyze the ideas in the posted testimonies about perceived and lived impacts of PC on QoL.

Table 5b. Characteristics of the qualitative studies that included patients under treatment.

Author Year, Country	**Qualitative approach**	**Tumor location** Total participants (n)	**Aim of study**
Björnsdóttir 2021, Iceland	Semi-structured interviews	Multiple locations 21	To explore patients' perceptions and experiences of cancer rehabilitation in rural areas in northern Iceland.
Boman 2018, Sweden	Semi-structured interviews	Breast 16	To explore how patients experience participation during treatment and care for breast cancer related to their understanding.
Çömez 2016, Turkey	In-depth interviews	Breast 14	To investigate women with breast cancer and their spouses' experiences with surgery, radiotherapy, chemotherapy, and hormone therapy from the diagnosis of breast cancer to the end of treatment.
Erol 2018, Turkey	Semi-structured interviews	Multiple locations 16	To explore the pain experiences of patients with advanced cancer and how they manage with pain, and to present a view of pain management approaches of nurses from the perspectives of the patients.
Fraterman 2022, Netherlands	Semi-structured interviews	Melanoma 13	To investigate the supportive care and information needs and how these needs can be supported by eHealth applications.
Giesinger 2018, Six European countries	Semi-structured interviews	Multiple locations 83	To investigate what makes a symptom or functional impairment clinically important.
Graffigna 2017, Italy	Narrative medicine	Chronic myeloid leukemia 158	To explore patients' experiences of their illnesses by investigating (i) the impact of the latter on patients' emotions and QoL, and (ii) how they react to the ideas of healing from their disease and interrupting their treatment.
Hajdarevic 2022, Sweden	Semi-structured interviews	Breast; Prostate; Colorectal 27	To describe perceived needs of support among patients close to discharge from the hospital and at the end of primary curative radiotherapy for breast, colorectal or prostate cancer.
He 2021, UK, Germany and France	Semi-structured interviews	Multiple myeloma 30	To conduct an exploratory investigation into concepts that could form attributes that influence treatment choices for patients with multiple myeloma and to identify trade-offs that patients are willing to make between treatment attributes.
Hoesseini 2020, Netherlands	Focus groups	Head & Neck 17	To explore head and neck cancer patients' preferences for receiving prognostic information.
Jakobsson 2017, Sweden	In-depth interviews	Colorectal 10	To describe the lived experience of recovery during the first 6 months after colorectal cancer surgery.

Author Year, Country	**Qualitative approach**	**Tumor location** Total participants (n)	**Aim of study**
JepsenLØ 2016, Denmark	Semi-structured interviews	Acute leukemia 26	How patients with acute leukemia experience the different conditions of the inpatient and outpatient settings and how they reflect on these transitions in order to create meaning in and keep up everyday life.
Millet 2022, UK	Semi-structured interviews	Cervical 37	To explore the recovery experience in the short and long term and associated patterns of recovery amongst those treated with surgery and/or chemoradiotherapy from a biopsychosocial perspective.
Netsey-AfedoMML 2020, Denmark	In-depth interviews	Prostate 113	To explore how patients with advanced prostate cancer experience the communication with health professionals as well as to explore their experiences of the decision-making processes during their course of treatment.
Petri 2015, Denmark	Open qualitative interviews	Lung 3	To explore and describe the essential meaning of the phenomenon: Everyday life during curative radiotherapy in patients with NSCLC.
vanDongen 2022, Netherlands	Semi-structured interviews	Multiple locations 14	To investigate (1) the challenges and controversies patients experience in managing vaginal, vulvar, penile or anal cancer; their unmet needs; and how this affects their psychosocial functioning and (2) the gaps HCPs experience in providing psychosocial support and potential improvements in care.
Wagland 2016, UK	Coding of free-text responses collected by using a PROM	Colorectal 5364	To develop and tested a learning-based text-mining approach to facilitate analysis of patients' experiences of care and develop an explanatory model illustrating impact upon HRQoL.
Osborne 2014, UK	Semi-structured interviews, focus groups	Multiple myeloma 51	To (1) explore the issues important to QoL from the perspective of people with multiple myeloma, and (2) explore the views of patients and clinical staff on existing QoL questionnaires and their use in clinical practice.
Appleton 2018, UK	Semi-structured interviews	Lung; Colorectal; Head & Neck 30	To explore how cancer services promote and support patients' well-being throughout their cancer treatment.
BeerdaDCE 2022, Netherlands	Semi-structured interviews	Multiple locations 15	To explore the experiences and perspectives of patients with advanced cancer, regarding work resumption and work retention.
Jespersen 2022, Denmark	In-depth interviews	Multiple locations 7	To explore the multifaceted symptoms of pain in older patients with advanced gastrointestinal cancer while receiving palliative chemotherapy.
AlanderMEJ 2021, Sweden	In-depth interviews	Does not specify 8	To explore the lived experience of young adults.
Shilling 2017, UK	In-depth interviews	Multiple locations 24	To explore the impact of extended cancer survival on broader aspects of life and wellbeing such as occupational, financial and family life for patients with advanced cancer and their nominated informal caregivers.

Table 5c. Characteristics of the qualitative studies that included palliative patients.

Author Year, Country	**Qualitative approach**	**Tumor location** Total participants (n)	**Aim of study**
Aumann 2016, Germany	Semi-structured interviews	Lung 18	To ascertain a range of experiences of patients with lung cancer and to make recommendations regarding the improvement of treatment based on their preferences.
Balmer 2015, UK	Symbolic interactionism	Multiple locations 30	To explore the experiences of living after cancer for people diagnosed with a poor prognostic cancer and contextualise it within the social and cultural representation of cancer in contemporary UK society.
Beernaert 2016, Belgium	Semi-structured interviews	Multiple locations 18	To explore how patients with a life-limiting illness experience certain care needs related to their condition from diagnosis onward.
Bergqvist 2017, Sweden	Cognitive debriefings	Breast 20	To investigate breast cancer patients' motives, perceptions, and experiences of late lines of palliative oncologic treatment.
Dobrina 2016, Italy	Semi-structured interviews	Multiple locations 11	To explore needs and wishes in the last week of life of patients at home and seek out the views of the family caregivers.
Doveson 2020, Sweden	Semi-structured interviews	Prostate 16	To explore the perspectives of men when facing life-prolonging treatment of metastatic castration resistant prostate cancer.
Drury 2022, Ireland	Semi-structured interviews	Colorectal 22	To explore the prevalence of colorectal survivorship issues and their impact on survivors' QoL.
Dunham 2017, UK	In-depth interviews	Multiple locations 9	To consider how the older person constructs the experience of cancer pain and how this is informed by expectations and experiences.
Håkanson 2015, Sweden	Narrative interviews and supplementary participating observation	Multiple locations 9	To enhance the depth of existing knowledge about meanings and experiential outcomes of bodily care in the context of an inpatient specialist palliative setting.
Hofheinz 2016, Germany	In-depth interviews, Choice-based conjoint surveys	Stomach, Oesophageal 55	To assess patient preferences for a new hypothetical palliative CT (chemotherapy) of gastric cancer in Germany, using a Choice-based conjoint (CBC) analysis approach, in patients with previous or ongoing CT exposure
IvzoriErel 2022, Israel	In-depth interviews	Does not specify 20	To explore the experience of a sense of place among individuals at the end-of-life receiving care at home via home-hospice or in a hospital.
Laursen 2019, Denmark	Semi-structured interviews	Oesophageal 17	To illuminate the ways in which incurable oesophageal cancer disrupts the patients' lives and how the patients experience and adapt to life with the disease in order to suggest palliative care interventions.

Loughran 2019, UK	Semi-structured interviews	Multiple locations 6	To address this paucity of information by recording and describing the lived experiences of people living with incurable cancer, the effects on their lives, their views on rehabilitation, and their perceived rehabilitation needs in palliative care setting.
Madsen 2019, Denmark	Semi-structured interviews	Multiple locations 10	To explore patients' experiences of transitions during the course of incurable cancer.
Maersk 2018, Denmark	Semi-structured interviews	Multiple locations 28	To explore how the identity of people with advanced cancer is influenced by their experiences of living at home.
Nysæter 2022, Norway	Semi-structured interviews	Does not specify 9	To explore the preferences for home care over time to enable home death among adult patients with cancer in the late palliative phase.
Reynolds-Cowie 2021, UK	Focus groups	Multiple locations 27	(1) to investigate the impact of insomnia on cancer survivors' lives, (2) to provide insight into the strategies used by cancer survivors to self-manage insomnia, (3) to explore the attention given to sleep difficulties throughout the cancer care trajectory, and (4) to consider the availability of support or interventions for sleep that are available to cancer survivors.
Rodríguez-Prat 2022, Spain	Semi-structured interviews	Multiple locations 8	To explore how patients with advanced cancer understand control, in terms of underlying beliefs, attitudes, and expectations consistent with self-efficacy, in different dimensions of their life, their illness, and their healthcare.
Rohde 2017, Norway	Semi-structured interviews	Colorectal 20	To explore spiritual well-being in colorectal cancer patients in the palliative phase undergoing chemotherapy.
Stanze 2019, Germany	In-depth interviews	Lung 17	To understand the needs, explore the experiences and meaning of living with advanced cancer at the end of life, and develop strategies for improved patient-centered care in Germany.
Villalobos 2018, Germany	Semi-structured interviews	Lung 9	To explore the patients' and relatives' experiences over the trajectory of disease.

3.3 Quality of the qualitative studies included

Table 6 shows a summary of the quality of the included studies, assessed following SURE checklist, and stratified by population type (survivors, under treatment, and palliative). The majority of the studies included addressed a clearly focused question/hypothesis (96%-100%), made an appropriate choice of the qualitative methodology used for their aim (86%-91%), clearly described their sampling strategy (60%-70%), described well the method used for data collection (73%-83%), explicitly discussed ethical issues (83%-91%), described and justified the data analysis and interpretation (81%-91%), reported if having any conflict of interest or not (86%-87%), presented credible findings (86%-87%), and correctly identified the study's limitations (76%-87%). Only the 'relationship between the researcher and the participant' item caused frequently downgrading of the studies' quality, reported in 10% of studies on survivors, in 39% of studies on patients under treatment, and in 24% of studies on patients in palliative care.

Among the 30 studies conducted with survivors, 27 fulfilled at least 5 of the 10 items on the SURE list; and so did 22 of the 23 studies with patients under curative treatment and 20 of the 21 under palliative treatment.

Table 6. Summary of the included studies' quality following SURE checklist

SURE checklist questions	Survivors (n=30)	Under treatment (n=23)	Palliative (n=21)
D1. Does the study address a clearly focused question/hypothesis	100%	96%	100%
D2. Is the choice of qualitative methodology appropriate	87%	91%	86%
D3. Is the sampling strategy clearly described and justified	60%	70%	62%
D4. Is the method of data collection well described	73%	83%	76%
D5. Is the relationship between researcher & participants explored	10%	39%	24%
D6. Are ethical issues explicitly discussed	83%	91%	90%
D7. Is the data analysis/interpretation process described /justified	83%	91%	81%
D8. Are the findings credible	87%	87%	86%
D9. Is any sponsorship/conflict of interest reported	87%	100%	76%
D10. Did the authors identify any limitations	87%	87%	76%

Of the 21 studies that involved palliative patients, 4 were of the highest quality (completed and reported each item of the checklist). This was only the case for 1 of the 30 studies on survivors, and for 7 of the 23 studies carried out with patients under treatment. Details on the appraisal of the 10 SURE items for each study can be found in Tables 6a, 6b, and 6c by population type (survivors, under treatment, and palliative).

Table 6a. Quality appraisal of qualitative studies that included *survivors*.

Author (Year)	D1 Does the study address a clearly focused question/hypothesis	D2 Is the choice of qualitative methodology appropriate	D3 Is the sampling strategy clearly described and justified	D4 : Is the method of data collection well described	D5 Is the relationship between the researcher(s) and participants explored	D6 Are ethical issues explicitly discussed?	D7 Is the data analysis/interpretation process described and justified?	D8 Are the findings credible?	D9 Is any sponsorship/conflict of interest reported?	D10 Did the authors identify any limitations?
Appleton (2013)	+	+	–	+	–	+	+	+	–	+
Appleton (2014)	+	+	–	–	–	+	+	+	+	–
Aunan (2021)	+	+	+	+	?	+	+	+	+	+
Burden (2016)	+	+	+	+	–	+	+	?	+	+
denBakker (2018)	+	+	+	+	?	+	+	+	+	+
Dunne (2018)	+	?	–	–	–	+	–	?	+	+
Harji (2015)	+	+	?	+	–	?	?	+	–	+
Harrow (2014)	+	+	+	+	?	+	+	+	+	+
Jakobsen (2018)	+	+	+	+	?	+	+	+	+	+
KammingaNCW (2022)	+	+	+	+	?	+	+	+	+	+
Koutoukidis (2017)	+	+	?	+	–	+	+	+	+	+
Lagerdahl (2014)	+	?	?	+	–	+	?	+	–	+
Liaset (2018)	+	+	+	+	–	+	+	?	+	+
Matheson (2020)	+	+	+	+	+	+	+	+	+	+
Piil (2022)	+	+	+	+	–	+	+	+	+	?
Puppo (2020)	+	+	?	?	?	?	+	?	+	–

RegnierDenois (2017)	+	+	+	?	–	?	+	+	+	+
Samsøe (2022)	+	+	–	+	–	?	+	+	+	+
ŞengünİnanA (2019)	+	+	+	+	–		+	+	+	+
ŞengünİnanA (2020)	+	+	+	+	?	+	+	+	+	+
Stamataki (2015)	+	+	+	?	?	+	+	+	+	+
Stuhlfauth (2018)	+	+	–	+	?	+	+	+	?	+
Torp (2020)	+	+	+	+	–	+	+	+	+	?
Treanor (2016)	+	+	–	+	?	+	+	+	+	+
Trusson (2016)	+	+	+	?	+	+	?	+	+	+
vanEe (2018)	+	+	+	+	?	+	+	+	+	+
Wagland (2019)	+	+	+	+	?	+	+	+	+	+
Wennick (2017)	+	+	+	+	+	+	+	+	+	+
Wollersheim (2021)	+	?	?	?	–	+	+	+	+	+
Zanchetta (2016)	+	?	?	?	–	+	?	+	+	+

+ Dimension graded as 'Yes'

? Dimension graded as 'Can't tell'

– Dimension graded as 'No'

Table 6b. Quality appraisal of qualitative studies that included *patients under treatment*.

Author (Year)	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10
AlanderMEJ (2021)	–	+	–	–	–	+	+	+	–	–
Appleton (2018)	+	+	+	+	+	+	+	+	+	+
BeerdaDCE (2022)	+	+	+	+	+	+	+	+	+	+
Björnsdóttir (2021)	+	+	+	+	?	+	+	+	+	+
Boman (2018)	+	+	+	+	–	+	+	+	+	+
Çömez (2016)	+	+	+	+	–	+	+	+	+	+
Erol (2018)	+	+	?	+	–	+	+	+	+	+
Fraterman (2022)	+	+	+	+	?	+	+	+	+	+
Giesinger (2018)	+	+	+	+	+	+	+	+	+	+
Graffigna (2017)	+	+	–	+	–	+	+	+	+	+
Hajdarevic (2022)	+	+	+	+	+	+	+	+	+	+
He (2021)	+	?	+	+	+	+	+	+	+	+
Hoesseini (2020)	+	+	+	+	+	+	+	+	+	+
Jakobsson (2017)	+	+	+	+	+	+	+	+	+	+
JepsenLØ (2016)	+	+	+	+	–	+	+	+	+	+
Jespersen (2022)	+	+	?	+	–	+	+	+	+	?
Millet (2022)	+	+	?	?	+	+	+	+	+	+
Netsey-AfedoMML (2020)	+	+	+	+	+	+	+	+	+	+
Osborne (2014)										
Petri (2015)	+	+	?	+	+	+	?	+	+	+
Shilling (2017)	+	+	?	?	–	?	+	+	+	+
vanDongen (2022)	+	+	+	+	–	+	+	+	+	+
Wagland (2016)	+	+	+	+	?	+	+	+	–	+

Table 6c. Quality appraisal of qualitative studies that included *palliative patients*.

Author (Year)	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10
Aumann (2016)	+	+	+	+	–	+	+	+	+	+
Balmer (2015)	+	?	–	+	?	+	+	?	+	?
Beernaert (2016)	+	+	+	?	–	+	+	+	+	–
Bergqvist (2017)	+	+	?	+	–	+	+	+	+	+
Dobrina (2016)	+	+	+	+	–	+	+	+	–	+
Doveson (2020)	+	+	+	–	–	+	+	+	+	+
Drury (2022)										
Dunham (2017)	+	?	–	–	?	+	?	?	–	?
Håkanson (2015)	+	+	+	+	+	+	+	+	+	+
Hofheinz (2016)	+	+	+	+	?	+	?	?	+	+
IvzoriErel (2022)	+	+	+	+	+	+	+	+	+	+
Laursen (2019)	+	+	?	+	+	+	+	+	+	+
Loughran (2019)	+	+	+	+	+	+	+	+	+	–
Madsen (2019)	+	+	–	?	?	+	?	+	+	+
Maersk (2018)	+	+	+	+	?	+	+	?	–	+
Nysæter (2022)	+	+	+	+	?	+	+	+	+	+
Reynolds-Cowie (2021)	+	+	?	+	–	–	+	+	+	+
Rodríguez-Prat (2022)	+	+	?	+	–	+	+	+	+	+
Rohde (2017)	+	+	+	+	+	+	+	+	+	+
Stanze (2019)	+	+	+	+	–	+	+	+	+	+
Villalobos (2018)	+	+	+	+	?	+	+	+	+	+

3.4 Synthesis of the evidence from published qualitative research

The evidence on the needs, concerns, worries, or any HRQoL domain relevant for oncological patients was reflected on the themes and verbatims raised in the included studies. The themes, subthemes, and quotes extracted from each study are shown in Appendix 6.

Table 7 presents a mapping of all the themes aggregated into the different predefined categories (adaptation from Wilson & Cleary framework), according to population group (survivors, under treatment, and palliative). The number of studies (if more than one) in which each specific theme is raised is included in brackets.

After the thematic analysis working sessions, 19 themes were extracted from the 30 studies conducted with survivors. It can be observed that a high number of studies identify as a concern the 'Symptoms & Physical functioning' and 'Psychological & Emotional wellbeing' derived from the pathology or the treatment received. Among the social issues, those that emerged more frequently were 'Change in Social Life & Relationships', and 'Life Disruption'. Among coping strategies, those related to fear of recurrence and body image are the ones more frequently identified. Returning to work was also identified as a very relevant issue for survivors; as well as health management and communication with health professionals among the other categories not included as predefined ones that emerged in this group of patient survivors.

Thirty-four themes were identified to be relevant for patients undergoing treatment at the time of the study. The Symptoms & Physical functioning issues raising in this group were very heterogeneous, from pain or gastrointestinal symptoms, to physical powerlessness. In this group of patients, relationships and support were the most common social concerns. The most prominent coping issues were those associated with changes in body image and difficulty in planning for the future. In the work area, financial consequences are of concern to patients under treatment. Again, health management and communication with health professionals were other categories not included as predefined that emerged in this group of patients under treatment.

Finally, from the 21 qualitative studies conducted with palliative patients, 20 themes were identified to be relevant. The main physical concerns are referred to the loss of physical capacities and energy; similarly, the loss of identity and loss of concentration, memory or sleep, were identified in the emotional area. The palliative group stands out for developing strategies that allow them to adapt to the new reality. As expected, the topic of death is the most explicitly mentioned one in studies with palliative patients, which identify relevant aspects such as being able to have privacy at home, fear of death, what life will be like after death, and existential issues. Finally, again health management is one of the issues among the other categories not included as predefined that emerged in this group of palliative patients.

Table 7. Mapping of themes by population type, aggregated into the predefined categories adapted from the Willson framework. # of studies in brackets, if more than one.

SURVIVORS	UNDER TREATMENT	PALLIATIVE
PHYSICAL		
Symptoms & Physical functioning (13)	Pain (2)	Pain (2)
	Fatigue	Fatigue
	Gynaecological S	Nauseas
	Urological S	Functional Difficulties
	Gastrointestinal S (2)	
	Locomotor S	
	Treatment S (2)	
	Difficulties with food intake	
		Losing body capability (3)
	Physical Powerlessness (2)	Powerlessness
EMOTIONAL		
		Loss of identity (4)
	Challenges to identity	Loss of concentration, memory, and sleep
Psychological & Emotional Wellbeing (7)		
	Psychosocial functioning	
SOCIAL		
Changes in Social Life & Relationships (10)	Social Relationships (8)	Social shifts/needs (5)
Social Support & Stigma (3)	Social Support (5)	
	Perceptions & Reactions to Disease	
Social Groups (2)		
	Needs and Counselling	
Sexuality/Sexual Function (4)	Sexual Intercourse	
Life Disruption (9)		
	Acceptance of an altered everyday life	
	Balancing before with present	
		Practical Needs
	Self-efficacy and dependence	

SURVIVORS	UNDER TREATMENT	PALLIATIVE
Coping (12)	Coping (3 + being resilient + preservation or return to normality + Holding on to normalcy)	
		Adapting to new reality (7)
Reminders (4)		
Body Image (6)	Appearance and Body Image (2)	
Fear of Recurrence (7)	Recurrence	
	Fear	Fear
Changes in Life style (4)	Health promoting behaviours	
Future Perspectives (2)		
	Not planning for the future (2)	
	Long-term worries	
		Maintaining privacy at home (2)
		Loss of control (2)
	Mortality and Death (2, Spiritual pain)	Death (6)
		Life without me (2)
		Existential issues (5)
QoL in general (2)	General Quality of Life (2)	
Work (8)	Work and Finances (3)	Work
		Financial worries (2)
	Treatment as life priority	
Understanding disease and treatment (3)		
Management (9)	MANAGEMENT (10)	Management (5)
Communication (8)	COMUNICATION (6)	
Location specific issues (3)		
	e-Health (1)	
	Patient Involvement (3)	

4 Discussion

The present systematic review was designed with the initial aim of providing the EUonQoL Stakeholder Board with evidence on the relevant HRQoL domains complementary to that coming from the standardized questionnaires. Results show how, besides traditional domains covered by these HRQoL instruments, qualitative studies identify other needs, worries, or preferences that are relevant for oncological patients. We synthetized the themes and subthemes that emerged in a total of 74 qualitative studies that met the inclusion criteria. Most of the studies (n=30) were focused on the cancer survivors, followed by the studies in cancer patients undergoing treatment at the time of the study (n=23), and those on palliative cancer patients (n=21). These qualitative studies, which explore how the cancer experience impacts patients' quality of life, identified from 19 to 34 themes, according to population. These themes have been mapped into the previously 8 defined categories (physical, social, emotional/mental, global, work, death, coping, and other relevant aspects).

Studies on surviving patients frequently identified concerns in 6 of the 7 predefined categories adapted from Wilson & Cleary framework: physical, emotional, social, coping, global HRQoL, and work. Among these categories, evidence highlights themes such as life disruption experiences, changes in social relationships, and coping strategies related to fear of recurrence, to changes that have occurred in their body and to elements that remind them of the situation they have experienced. Further to these predefined categories, it is important to remark the emergence in this group of patient survivors of the new issues of health management, communication with health professionals, and understanding disease and treatment.

Similarly, in patients undergoing treatment, the predefined categories of physical, emotional, social, coping, global HRQoL and work covered the most frequently identified issues, and health management and communication with health professionals are some of the new emergent issues not covered by the Wilson & Cleary adapted framework. However, in this population concerns were also identified in the predefined category of death (specifically mortality, death and spiritual pain), as well as, treatment as life priority and e-health as new emergent issues beyond traditional ones.

Studies in palliative oncological patients identified concerns in all the predefined categories, from physical and emotional to work, but with a remarkable lower intensity in the social one, and the concentration of coping strategies for adaptation to the new reality and for fear. As expected, these patients make explicit their thoughts about death or what life will be like after death, as well as existential aspects. Finally, health management appears also in this group of palliative patients as a prominent emergent need.

Although a sensitivity analysis was defined to compare results before and after deleting low quality studies, it has not been conducted yet due to the low number of studies classified in this category. It is worth mentioning that the majority of the studies included fulfilled 50% or more of the items from the SURE checklist. Very few did not reach this threshold: 3 studies, among the 30 with survivors, and just 1 of the studies with patients in treatment or palliative (among 23 and 21, respectively). Surprisingly, the item with worst results in the studies conducted with any of the three populations (less than 40%) was 'relationship between the researcher and the participant' which is not one of the new items proposed at the SURE checklist, but an item also present in the previous NICE and CASP quality appraisal checklists for qualitative studies.

The results presented in this report should be interpreted carefully. Firstly, considering publication bias that may exclude studies reporting traditional domains (e.g. pain, fatigue, anxiety) as relevant, because they may not be considered new scientific findings. Secondly, many of the included studies had a specific

aim, not necessarily to widely identify HRQoL issues relevant to oncological patients. Some aimed to explore specific patients' worries, needs, or preferences (such as those unmet in standard management, social issues, returning to work or fear of recurrence). Therefore, some of the domains which could be relevant for assessing how the cancer experience impacts patients' quality of life can be underrepresented in our results. Finally, the studies that fulfilled the inclusion criteria do not represent all the EU-27 countries, nor the associated ones. There is published evidence on only 11 among the EU-27 countries, two of the associated countries (Sweden, and Turkey) and UK. Oncological patients from 59% of the EU-27 countries, and from 90% of the associated are therefore not represented in the published evidence collected in this systematic review.

Otherwise, as most of the identified studies are from the last 5 years, a strength of this systematic review is that the results capture the current situation of oncological patients (new therapies, new periods, or new management procedures in specific units). This situation is specially marked in the group of patients undergoing treatment at the time of the study, with 65% of the articles published in the last 5 years. This proportion was of 57% for the other two populations (survivors and palliative patients).

In conclusion, results on this Chapter II of D3.1 confirm the relevance of domains included in the pre-defined framework adapted from Wilson & Cleary, such as fatigue, anxiety, coping, or work; and they also add the identification of specific issues, like changes in social relationships for survivors or existential aspects for palliative patients. Concerns related to disease and treatments' management emerged in the three groups of oncological patients as relevant domains that impact their quality of life. These aspects, usually unmet in the exiting PROMs, understood as content of Patient-Reported Experience Measures, appear now as a potential domain of HRQoL in the current patient-centered care approach. The inclusion of these new emerging domains, together with the rest of identified preferences, needs, and concerns for European oncological patients, will be discussed within the EUonQoL Stakeholder Board. Assuring the content of the EUonQoL-toolkit to cover all the relevant aspects for oncological patients nowadays, will promote its use for devising clinical, societal, and healthcare policymaking systems.

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6 Appendices

Appendix 1. Search Strategies tested.

(("Patient*"[Mesh] OR "Survivors"[Mesh] OR "Palliative Care"[Mesh]) AND ("Neoplasms/diagnosis"[Mesh] OR "Neoplasms/pathology"[Mesh] OR "Neoplasms/psychology"[Mesh] OR "Carcinoma/diagnosis"[Mesh] OR "Carcinoma/pathology"[Mesh] OR "Carcinoma/psychology"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh]) AND (“relevan*”[Title/Abstract] OR “import*”[Title/Abstract] OR “preferenc*”[Title/Abstract] OR “feelings”[Title/Abstract] OR “needs”[Title/Abstract] OR “issues”[Title/Abstract] OR “concerns”[Title/Abstract] OR “worries”[Title/Abstract] OR “difficulties”[Title/Abstract] OR “limitations”[Title/Abstract] OR “experienc*”[Title/Abstract]) AND (“qualitative”[Text Word] OR “focus group”[Text Word] OR “interview”[Text Word] OR “rating”[Text Word])) English Publication Date From 2013.---- 22/02/2023 _ 535 Result of sensitivity analysis / van Leeuwen M 2018 NOT INCLUDED
(("Patient*"[Mesh] OR "Survivors"[Mesh] OR "Palliative Care"[Mesh]) AND ("Neoplasms/diagnosis"[Mesh] OR "Neoplasms/pathology"[Mesh] OR "Neoplasms/psychology"[Mesh] OR "Carcinoma/diagnosis"[Mesh] OR "Carcinoma/pathology"[Mesh] OR "Carcinoma/psychology"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh]) AND (“relevan*”[Title/Abstract] OR “import*”[Title/Abstract] OR “preferenc*”[Title/Abstract] OR “feelings”[Title/Abstract] OR “needs”[Title/Abstract] OR “issues”[Title/Abstract] OR “concerns”[Title/Abstract] OR “worries”[Title/Abstract] OR “difficulties”[Title/Abstract] OR “limitations”[Title/Abstract] OR “experienc*”[Title/Abstract]) AND (“qualitative”[Title/Abstract] OR “focus group”[Title/Abstract] OR “interview”[Title/Abstract] OR “rating”[Title/Abstract])) English Publication Date From 2013.---- 22/02/2023 _ 474 Result of sensitivity analysis / van Leeuwen M 2018 NOT INCLUDED
(("Patient*"[Text Word] OR "Survivors"[Text Word] OR "Palliative Care"[Text Word]) AND ("Neoplasms/diagnosis"[Mesh] OR "Neoplasms/pathology"[Mesh] OR "Neoplasms/psychology"[Mesh] OR "Carcinoma/diagnosis"[Mesh] OR "Carcinoma/pathology"[Mesh] OR "Carcinoma/psychology"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh]) AND (“relevan*”[Title/Abstract] OR “import*”[Title/Abstract] OR “preferenc*”[Title/Abstract] OR “feelings”[Title/Abstract] OR “needs”[Title/Abstract] OR “issues”[Title/Abstract] OR “concerns”[Title/Abstract] OR “worries”[Title/Abstract] OR

“difficulties”[Title/Abstract] OR “limitations”[Title/Abstract] OR “experienc*”[Title/Abstract]) AND (“qualitative”[Title/Abstract] OR “focus group”[Title/Abstract] OR “interview”[Title/Abstract] OR “rating”[Title/Abstract])) English Publication Date From 2013.---- 22/02/2023 _ 670 Result of sensitivity analysis / van Leeuwen M 2018 NOT INCLUDED
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Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
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Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
((“Patients”[Text Word] OR “Survivors”[Text Word] OR “Survivors/psychology”[Text Word] OR “Palliative”[Text Word]) AND (“neoplasms”[Mesh] OR “Carcinoma”[Mesh]) AND (“quality of Life”[Mesh] OR “patient-reported outcomes” OR “health-related quality of life” OR “wellbeing” OR “well-being”) AND (“relevan*”[Text Word] OR “import*”[Text Word] OR “preferenc*”[Text Word] OR “feelings”[Text Word] OR “needs”[Text Word] OR “issues”[Text Word] OR “concerns”[Text Word] OR “worries”[Text Word] OR “difficulties”[Text Word] OR “limitations”[Text Word] OR “experienc*”[Text Word]) AND (“qualitative” [Text Word] OR “focus group” [Text Word] Or “interview” [Text Word] OR “scale” [Text Word] OR “questionnaire” [Text Word] OR “measure” [Text Word] OR “rating” [Text Word])) English Publication Date From 2013.---- 22/02/2023 _ 5192
Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
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~~OR "focus group" [Text Word] OR "interview" [Text Word] OR "scale" [Text Word] OR "questionnaire" [Text Word] OR "measure" [Text Word] OR "rating" [Text Word]))~~

English

Publication Date From 2013.----

22/02/2023 _ 4602

Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED

(("Patient*"[Mesh] OR "Survivors"[Mesh] OR "Palliative Care"[Mesh]) AND ("Neoplasms"[Mesh] OR "Carcinoma"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh] OR "quality of life"[Text Word] OR "patient-reported outcome" [Text Word] OR "patient reported outcome" [Text Word]) AND ("relevan*"[Text Word] OR "import*"[Text Word] OR "preferenc*"[Text Word] OR "feelings"[Text Word] OR "needs"[Text Word] OR "issues"[Text Word] OR "concerns"[Text Word] OR "worries"[Text Word] OR "difficulties"[Text Word] OR "limitations"[Text Word] OR "experienc*"[Text Word])) ~~AND ("qualitative" [Text Word] OR "focus group" [Text Word] OR "interview" [Text Word] OR "scale" [Text Word] OR "questionnaire" [Text Word] OR "measure" [Text Word] OR "rating" [Text Word]))~~

English

Publication Date From 2013.----

22/02/2023 _ 9528

Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED

(("Patient*"[Mesh] OR "Survivors"[Mesh] OR "Palliative Care"[Mesh]) AND ("Neoplasms"[Mesh] OR "Carcinoma"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh] OR "health-related quality of life"[Text Word] OR "health related quality of life"[Text Word] OR "patient-reported outcome" [Text Word] OR "patient reported outcome" [Text Word]) AND ("relevan*"[Text Word] OR "import*"[Text Word] OR "preferenc*"[Text Word] OR "feelings"[Text Word] OR "needs"[Text Word] OR "issues"[Text Word] OR "concerns"[Text Word] OR "worries"[Text Word] OR "difficulties"[Text Word] OR "limitations"[Text Word] OR "experienc*"[Text Word])) ~~AND ("qualitative" [Text Word] OR "focus group" [Text Word] OR "interview" [Text Word] OR "scale" [Text Word] OR "questionnaire" [Text Word] OR "measure" [Text Word] OR "rating" [Text Word]))~~

English

Publication Date From 2013.----

22/02/2023 _ 5318

Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
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Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
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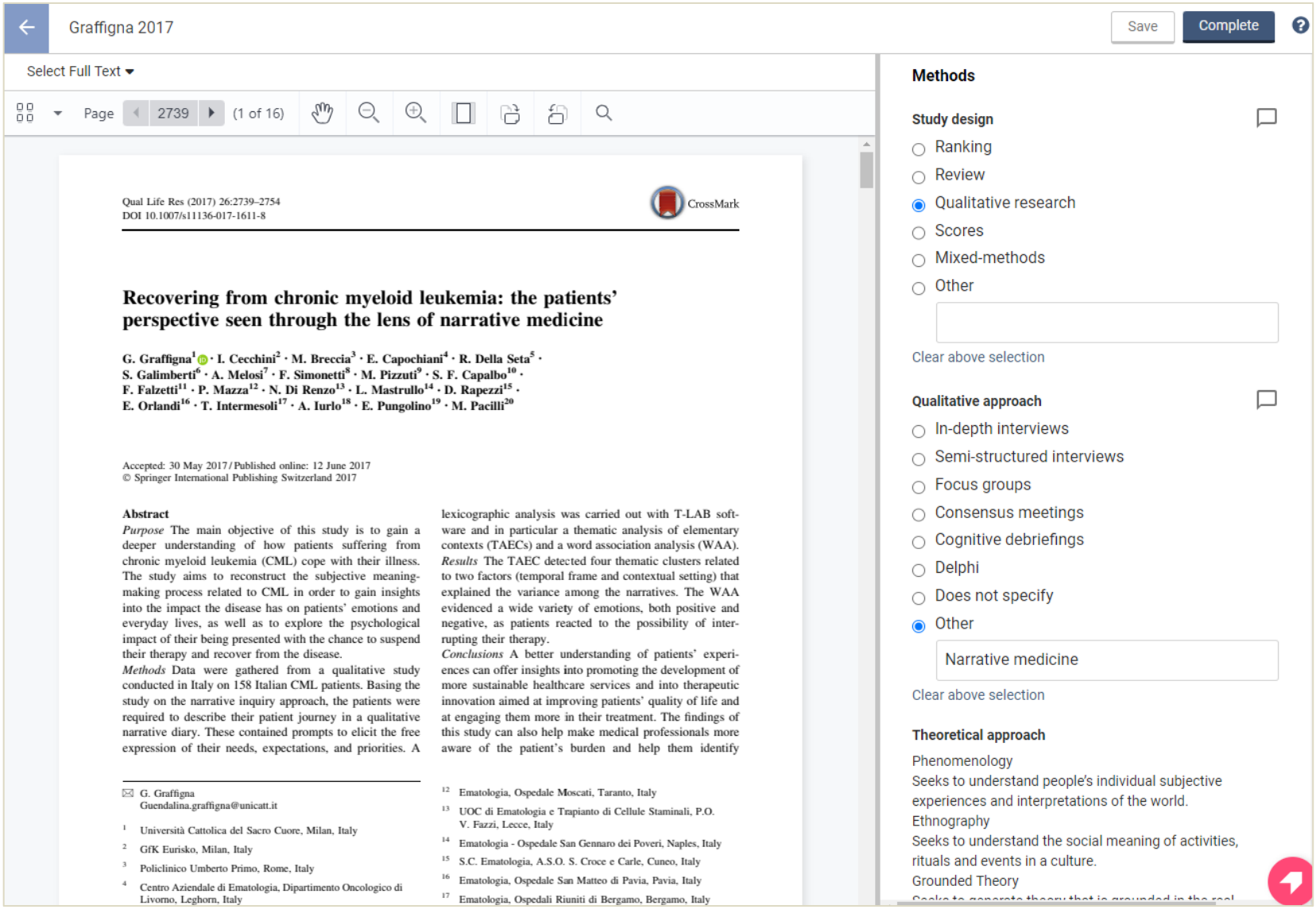
Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
(("Patient*"[Mesh] OR "Survivors"[Mesh] OR "Palliative Care"[Mesh]) AND ("Neoplasms"[Mesh] OR "Carcinoma"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh] OR “health-related quality of life”[Text Word] OR “health related quality of life”[Text Word] OR “patient-reported outcome” [Text Word] OR “patient reported outcome” [Text Word]) AND (“relevan*”[Text Word] OR “import*”[Text Word] OR “preference”[Text Word] OR “feeling”[Text Word] OR “need”[Text Word] OR “issue”[Text Word]

OR “concern”[Text Word] OR “worr*”[Text Word] OR “difficult*”[Text Word] OR “limitation”[Text Word] OR “experience”[Text Word] OR “problem”[Text Word])) English Publication Date From 2013.---- 23/02/2023 _ 4848 (PubMed) 01/03/2023 _ 4,864 (PubMed)   Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
(("Patient*"[Mesh] OR "Survivors"[Mesh] OR "Palliative Care"[Mesh]) AND ("Neoplasms"[Mesh] OR "Carcinoma"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh] OR “health-related quality of life”[Text Word] OR “health related quality of life”[Text Word] OR “patient-reported outcome” [Text Word] OR “patient reported outcome” [Text Word]) AND (“relevan*”[Text Word] OR “import*”[Text Word] OR “preferences”[Text Word] OR “feelings”[Text Word] OR “needs”[Text Word] OR “issues”[Text Word] OR “concerns”[Text Word] OR “worries”[Text Word] OR “difficulties”[Text Word] OR “limitations”[Text Word] OR “experiences”[Text Word] OR “problems”[Text Word])) English Publication Date From 2013.---- 01/03/2023 _ 4,711 results results (PubMed)   Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED
(("Patient*"[Mesh] OR "Survivors"[Mesh] OR "Palliative Care"[Mesh]) AND ("Neoplasms"[Mesh] OR "post-cancer" [Title/Abstract] OR "postcancer" [Title/Abstract]) AND ("Quality of Life/psychology"[Mesh] OR "perceived health"[Text Word] OR "health status"[Text Word] OR "well-being" [Text Word] OR "wellbeing"[Text Word] OR "Patient Reported Outcome Measures"[Mesh] OR “health-related quality of life”[Text Word] OR “health related quality of life”[Text Word] OR “patient-reported outcome” [Text Word] OR “patient reported outcome” [Text Word]) AND (“relevan*”[Text Word] OR “import*”[Text Word] OR “preferences”[Text Word] OR “feelings”[Text Word] OR “needs”[Text Word] OR “issues”[Text Word] OR “concerns”[Text Word] OR “worries”[Text Word] OR “difficulties”[Text Word] OR “limitations”[Text Word] OR “experiences”[Text Word] OR “problems”[Text Word])) English Publication Date From 2013.---- 01/03/2023 _ 4711 results (PubMed)   Result of sensitivity analysis / van Leeuwen M 2018 INCLUDED

Appendix 2. Example of the matrix used at COVIDENCE for data extraction. Screen shots.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Page 2739 (1 of 16)
Qual Life Res (2017) 26:2739–2754
DOI 10.1007/s11136-017-1611-8
CrossMark
Recovering from chronic myeloid leukemia: the patients' perspective seen through the lens of narrative medicine
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Accepted: 30 May 2017 / Published online: 12 June 2017
© Springer International Publishing Switzerland 2017
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Methods Data were gathered from a qualitative study conducted in Italy on 158 Italian CML patients. Basing the study on the narrative inquiry approach, the patients were required to describe their patient journey in a qualitative narrative diary. These contained prompts to elicit the free expression of their needs, expectations, and priorities. A lexicographic analysis was carried out with T-LAB software and in particular a thematic analysis of elementary contexts (TAECs) and a word association analysis (WAA).
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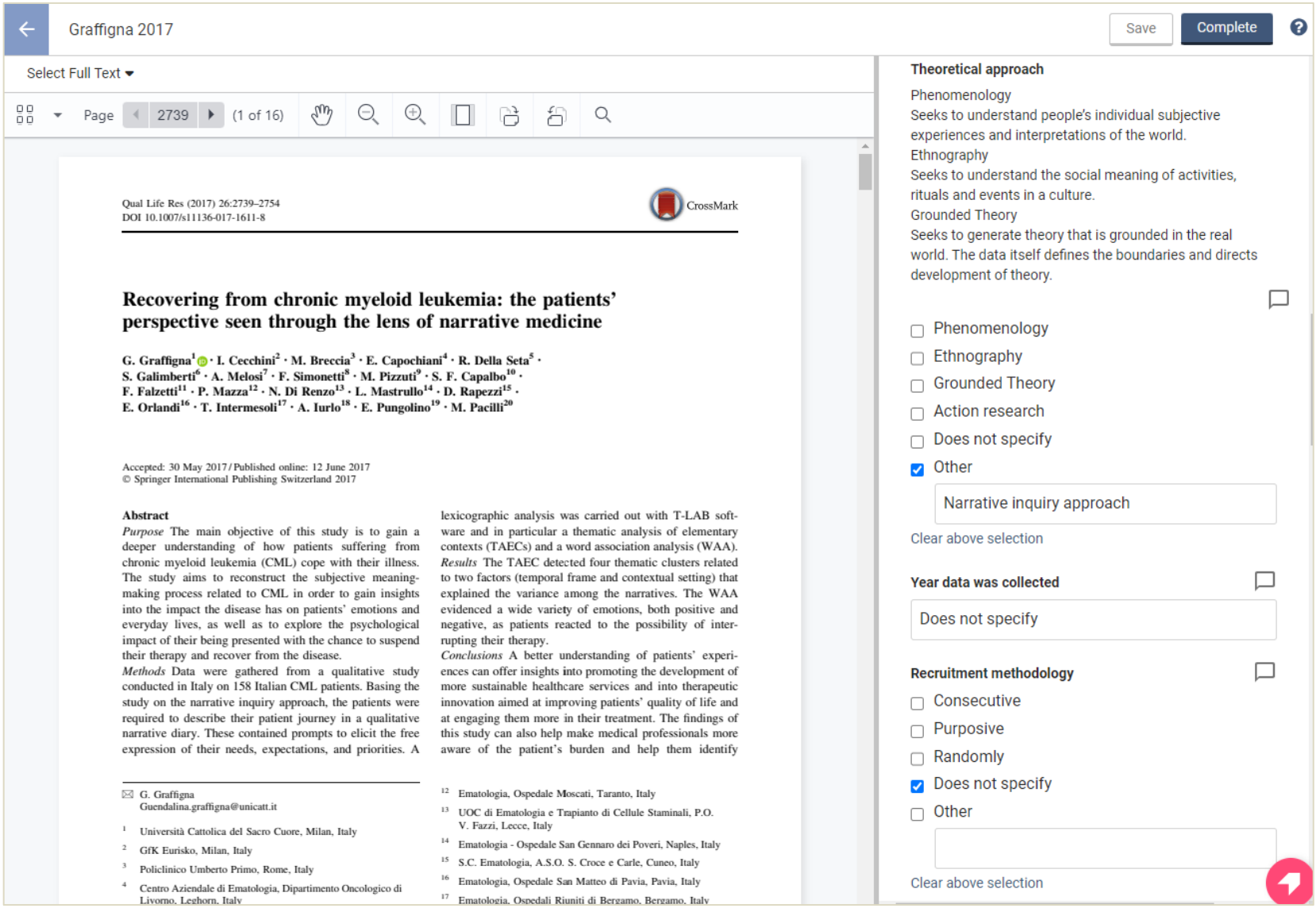
16 Ematologia, Ospedale San Matteo di Pavia, Pavia, Italy
17 Ematologia, Ospedali Riuniti di Bergamo, Bergamo, Italy
Methods
Study design
Ranking
Review
Qualitative research
Scores
Mixed-methods
Other
Clear above selection
Qualitative approach
In-depth interviews
Semi-structured interviews
Focus groups
Consensus meetings
Cognitive debriefings
Delphi
Does not specify
Other
Narrative medicine
Clear above selection
Theoretical approach
Phenomenology
Seeks to understand people's individual subjective experiences and interpretations of the world.
Ethnography
Seeks to understand the social meaning of activities, rituals and events in a culture.
Grounded Theory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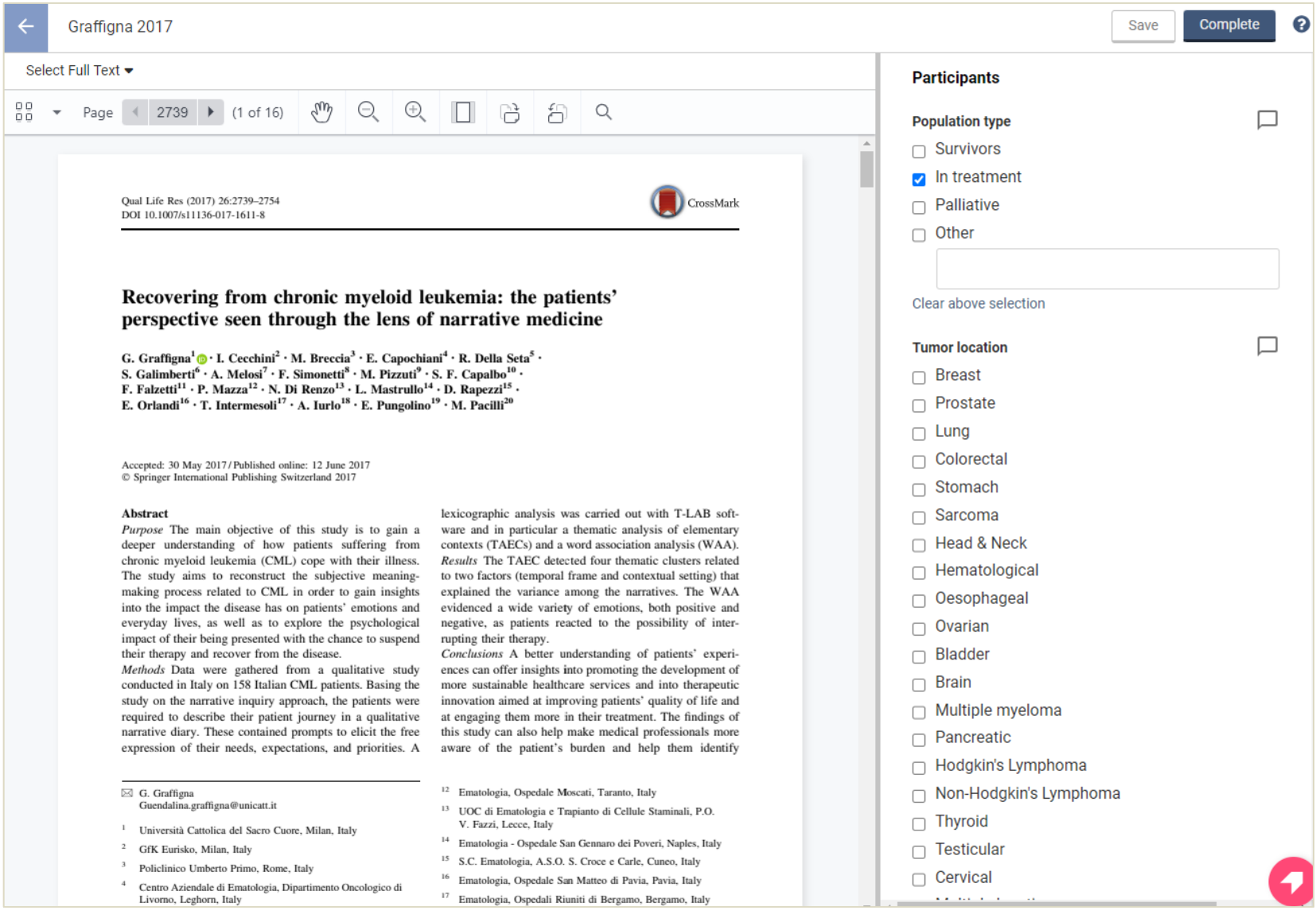
Ethnography
Seeks to understand the social meaning of activities, rituals and events in a culture.
Grounded Theory
Seeks to generate theory that is grounded in the real world. The data itself defines the boundaries and directs development of theory.
Phenomenology
Ethnography
Grounded Theory
Action research
Does not specify
Other
Narrative inquiry approach
Clear above selection
Year data was collected
Does not specify
Recruitment methodology
Consecutive
Purposive
Randomly
Does not specify
Other
Clear above selection



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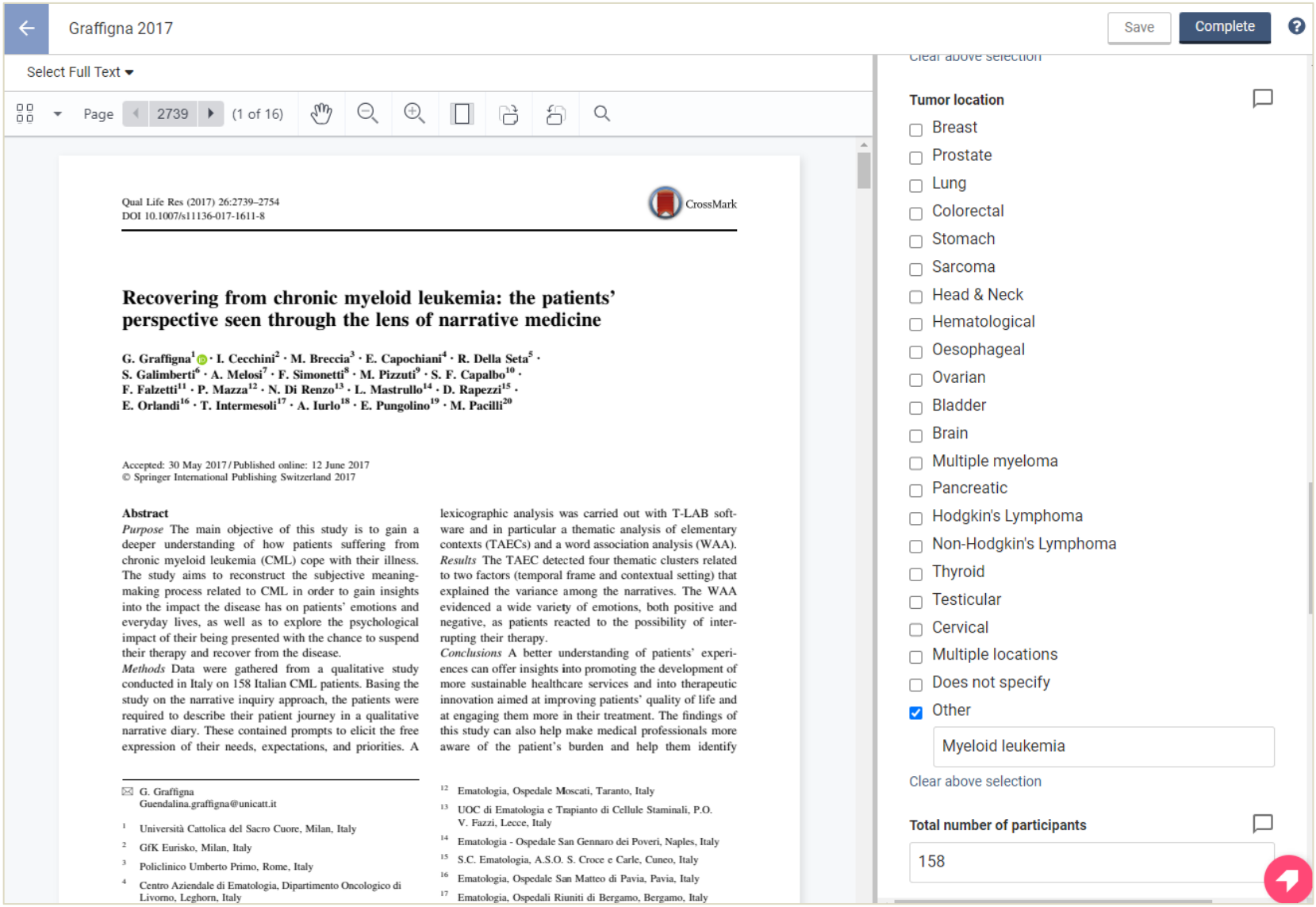
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17 Ematologia, Ospedali Riuniti di Bergamo, Bergamo, Italy
Clear above selection
Tumor location
Breast
Prostate
Lung
Colorectal
Stomach
Sarcoma
Head & Neck
Hematological
Oesophageal
Ovarian
Bladder
Brain
Multiple myeloma
Pancreatic
Hodgkin's Lymphoma
Non-Hodgkin's Lymphoma
Thyroid
Testicular
Cervical
Multiple locations
Does not specify
Other
Myeloid leukemia
Clear above selection
Total number of participants
158


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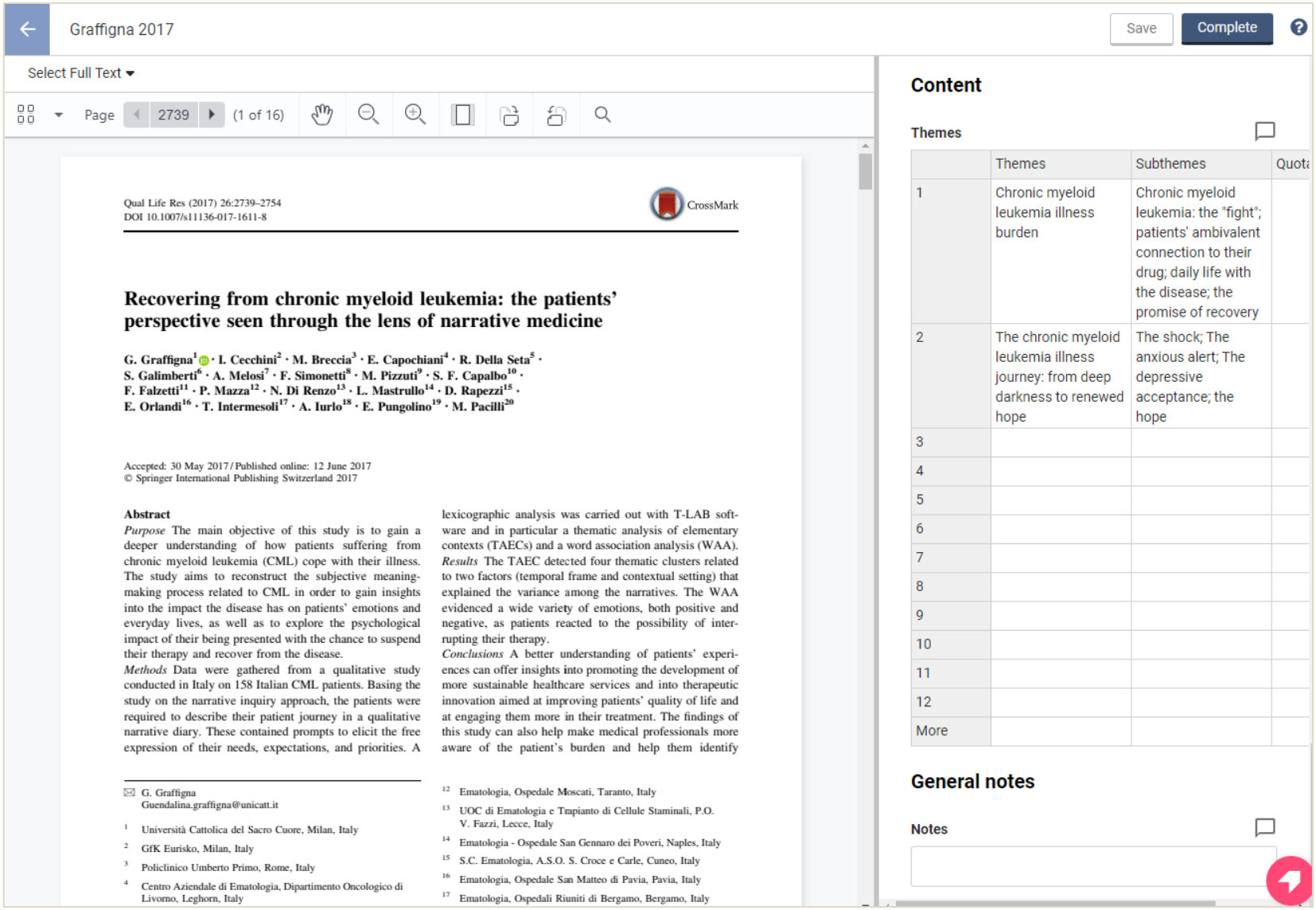
16 Ematologia, Ospedale San Matteo di Pavia, Pavia, Italy
Age of participants
Does not specify
Percentage of females
Does not specify
Inclusion criteria
(1) patients diagnosed with CML, (2) patients undergoing a target therapy treatment for their CML
Exclusion criteria
Does not specify
Quality
Appropriate qualitative guidelines followed
Yes
Does not specify
Clear above selection
Reached saturation
Yes, evidence is provided
Yes, assumed that saturation was reached
Evidence suggests saturation was not reached
It is not mentioned wheter or not it was reached
Other
Clear above selection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17 Ematologia, Ospedali Riuniti di Bergamo, Bergamo, Italy
Content
Themes
Themes
Subthemes
Quota
1 Chronic myeloid leukemia illness burden Chronic myeloid leukemia: the "fight"; patients' ambivalent connection to their drug; daily life with the disease; the promise of recovery
2 The chronic myeloid leukemia illness journey: from deep darkness to renewed hope The shock; The anxious alert; The depressive acceptance; the hope
3
4
5
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10
11
12
More
General notes
Notes

Appendix 3. Example of the matrix used at COVIDENCE for the quality assessment of the included studies. Screen shots.


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Is the choice of qualitative methodology appropriate?
Is it an exploration of eg behaviour/reasoning/ beliefs)?
Do the authors discuss how they decided which method to use?
Yes
Can't tell
No
Supporting text
Enter supporting text about your judgement
Is the sampling strategy clearly described and justified?
Is it clear how participants were selected?
Do the authors explain why they selected these particular participants?
Is detailed information provided about participant characteristics and about those who chose not to participate?
Yes
Can't tell
No


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Is the method of data collection well described?
Was the setting appropriate for data collection?
Is it clear what methods were used to collect data?
Type of method (eg, focus groups, interviews, open questionnaire etc) and tools (eg notes, audio, audio visual recording).
Is there sufficient detail of the methods used (eg how any topics/questions were generated and whether they were piloted; if observation was used, whether the context described and were observations made in a variety of circumstances?
Were the methods modified during the study? If YES, is this explained?
Is there triangulation of data (ie more than one source of data collection)?
Do the authors report achieving data saturation?
Yes
Can't tell
No
Supporting text
Enter supporting text about your judgement
Is the relationship between the researcher(s) and participants explored?
Did the researcher report critically examining/reflecting on their role and any relationship with participants particularly in relation to formulating research questions and collecting data).


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Did the researcher report critically examining/reflecting on their role and any relationship with participants particularly in relation to formulating research questions and collecting data).
Were any potential power relationships involved (ie relationships that could influence in the way in which participants respond)?
Yes
Can't tell
No
Supporting text
Enter supporting text about your judgement
Are ethical issues explicitly discussed?
Is there sufficient information on how the research was explained to participants?
Was ethical approval sought?
Are there any potential confidentiality issues in relation to data collection?
Yes
Can't tell
No


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Is the data analysis/interpretation process described and justified?
Is it clear how the themes and concepts were identified in the data?
Was the analysis performed by more than one researcher?
Are negative/discrepant results taken into account?
Yes
Can't tell
No
Supporting text
Enter supporting text about your judgement
Are the findings credible?
Are there sufficient data to support the findings?
Are sequences from the original data presented (eg quotations) and were these fairly selected?
Are the data rich (ie are the participants' voices foregrounded)?
Are the explanations for the results plausible and coherent?
Are the results of the study compared with those from other studies?
Yes
Can't tell
No


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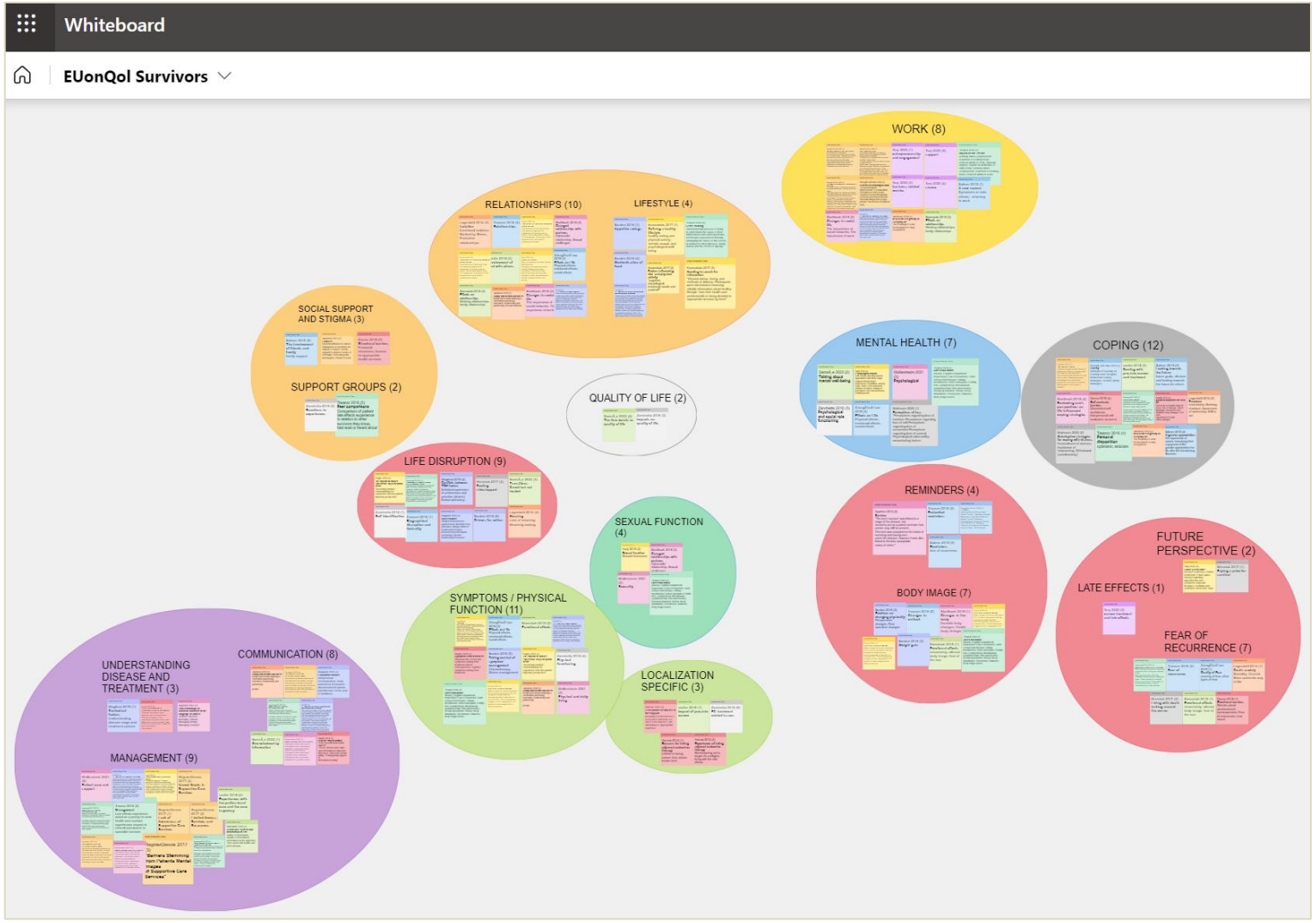
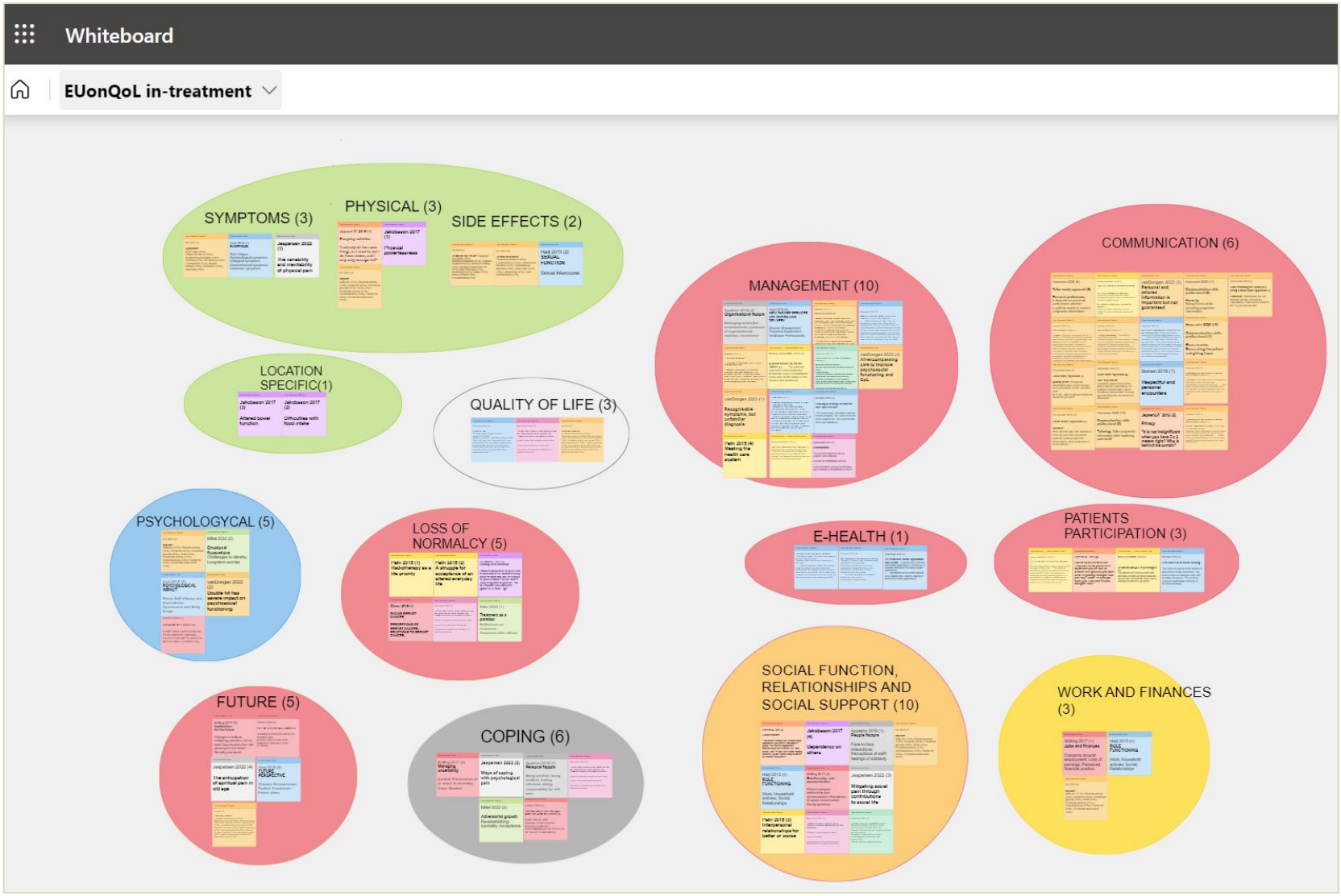
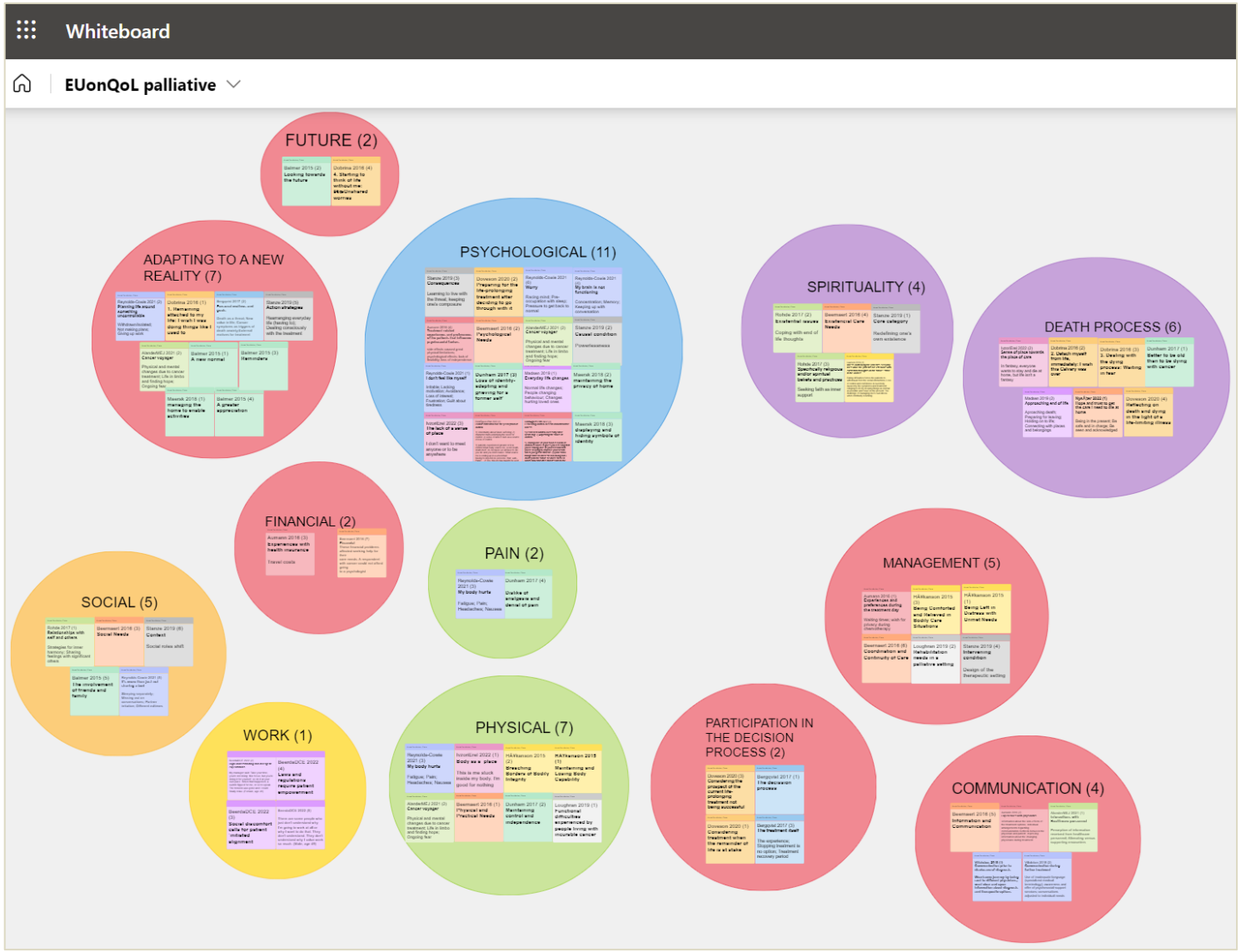
Is any sponsorship/conflict of interest reported?
Yes
Can't tell
No
Supporting text
Funding This study was liberally funded by Novartis Italia.
Conflict of interest All authors declare that they have no conflict of interest to be
Finally...consider: Did the authors identify any limitations? Are the conclusions the same in the abstract and the full text?
Yes
Can't tell
No
Supporting text
Enter supporting text about your judgement

Appendix 4. WhiteBoards from the thematic analysis working sessions.




Whiteboard
EUonQoL in-treatment
SYMPTOMS (3)
PHYSICAL (3)
SIDE EFFECTS (2)
LOCATION SPECIFIC(1)
QUALITY OF LIFE (3)
MANAGEMENT (10)
COMMUNICATION (6)
PSYCHOLOGYCAL (5)
LOSS OF NORMALCY (5)
E-HEALTH (1)
PATIENTS PARTICIPATION (3)
FUTURE (5)
COPING (6)
SOCIAL FUNCTION, RELATIONSHIPS AND SOCIAL SUPPORT (10)
WORK AND FINANCES (3)



EUonQoL
Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe
Funded by the European Union

Appendix 5. Specific characteristics of the studies included.

5a. Methodological characteristics of the qualitative studies that included survivors.

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
Appleton (2013) Phenomenology	Purposive (Does not specify)	Completed curative treatment 6 months to 5 years prior with no further treatment pending	Do not specify	Not reported No
Appleton (2014) Phenomenology	Purposive (Does not specify)	Course of active treatment for cancer had ended.	Do not specify	Not reported No
Aunan (2021) Phenomenology	Purposive (2019)	Prostate cancer survivors.	Do not specify	Yes No
Burden (2016) Phenomenology	Does not specify (2012)	Undergone surgery within the previous 3 years for CRC; could provide their informed consent.	Do not specify	Not reported Yes
denBakker (2018) Phenomenology	Purposive (2016)	>18 years; colon cancer survivors; undergone colon surgery between 2014 - 2016; finished complementary chemotherapy (multimodal treatment); master the Dutch language fluently.	Receiving neoadjuvant chemo radiation.	Yes Yes
Dunne (2018) Does not specify	Purposive (Does not specify)	8 - 60 months post-diagnosis; >18 years old; spoke sufficient English.	Undergoing or awaiting treatment, or receiving palliative care.	Not reported No
Harji (2015) Does not specify	Purposive (2010-2012)	> 18 years old; with an existing resectable LRRC or surgically treated for a LRRC within the last 2 years; able to provide informed written consent to participate; able to read and write in English.	Undergone non-surgical palliative treatment of their LRRC; were cognitively impaired; unable to speak/read and/or write English or unable to provide informed consent.	Not reported No
Harrow (2014) Does not specify	Purposive (2014)	Primary breast cancer; attending outpatient clinics for routine surgical or oncology follow-up between 1 and 5 years after diagnosis.	Do not specify	Not reported Yes

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
Jakobsen (2018) Phenomenology	Purposive (2016)	Breast cancer survivor; described a challenging everyday life in a seven-day diary.	Metastatic disease; inability to provide informed consent; inability to read or understand Norwegian.	Not reported Yes
KammingaNCW (2022) Grounded Theory	Purposive (Does not specify)	Stage IV melanoma; achieved a tumour response to treatment with ICIs.	Do not specify	Yes Yes
Koutoukidis (2017) Does not specify	Purposive (2014)	Endometrial cancer survivors within five years post active treatment.	Do not specify	Yes Yes
Lagerdahl (2014) Does not specify	Does not specify (Does not specify)	Working age; completed first-line treatment within the previous 12 months; complete remission; not have been diagnosed with any other life-threatening illness within the previous five years.	Do not specify	Not reported No
Liaset (2018) Does not specify	Purposive (Does not specify)	Have received treatment for brain tumors; employed prior to and after treatment.	Linguistic problems prior to treatment (e.g aphasia).	Not reported Yes
Matheson (2020) Phenomenology	Purposive (Does not specify)	Psychological distress.	Do not specify	Yes Yes
Piil (2022) Pragmatic paradigm	Consecutive (2017)	>18 years old; diagnosed with HGG for a minimum of 3 years; ability to speak and understand Danish. Caregivers were eligible if the patient named them as a very close relative.	Do not specify	Not reported No
Puppo (2020) Does not specify	Does not specify (2016)	Received optimal treatment (surgery and chemotherapy) for OC, irrespective of cancer stage at diagnosis; >18 years old; no documented relapse for at least 3 years after first-line treatment; had no other cancer.	Do not specify	Not reported No
RegnierDenois (2017) Phenomenology	Purposive (Does not specify)	< 50 years old; had been treated by surgery, adjuvant chemotherapy and radiotherapy for non-metastatic breast cancer; experienced life after treatment for 6 months to 2 years.	Do not specify	Not reported No

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
Samsøe (2022) Phenomenology	Does not specify (Does not specify)	Head and neck cancer survivors who attended one year of control after finishing radiation therapy at Herlev Hospital, Denmark.	Do not specify	Not reported Yes
Şengünİnan (2019) Phenomenology	Purposive (Does not specify)	>18 years old; completing primary treatment of breast cancer lasting for at least 3 months, with a maximum of 2 years.	Survivors known to have recurrent or metastatic cancer.	Not reported Yes
Şengünİnan (2020) Phenomenology	Does not specify (2016-2017)	>18 years old; employed at the time of diagnosis, completed hospital-based treatment a minimum of 6 months and a maximum of 3 years; full-time employment for the last 6 months.	Rejected to participate in the interviews (after contacted by phone by the physician).	Yes Yes
Stamataki (2015) Does not specify	Purposive (Does not specify)	Invasive melanoma of the skin; with any metastases present being limited to lymph nodes; diagnosis at least 3 months and no more than 5 years previously.	Less than 3 months post-diagnosis; distant metastases beyond lymph nodes; previous cancer diagnosis (not melanoma) less than 5 years ago; on active treatment or those ending treatment less than 3 months ago.	Not reported No
Stuhlfauth (2018) Biopsychosocial model	Does not specify (2014-2015)	Colon cancer; metastasis in lymph nodes; undergone surgery; received chemotherapy (FLOX regimen); speak Norwegian.	Do not specify	Not reported Yes
Torp (2020) Does not specify	Purposive (Does not specify)	Working in their own business at the time of the cancer diagnosis; having their main income from this business; having finished their cancer treatment; and not having had a cancer relapse.	Do not specify	Not reported No
Treanor (2016) Phenomenology	Purposive (Does not specify)	No significant cognitive impairment that would limit their verbal communication; not be in receipt of end-of-life care; not have any other health reason that a GP would deem it inappropriate to be contacted.	Death; started palliative care; did not reply survey.	Yes No
Trusson (2016) Does not specify	Purposive (2009-2012)	Treated for early stage breast cancer in the UK between 6 months and 29 years previous.	Do not specify	Not reported No

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
vanEe (2018) Does not specify	Systematic (2015)	≥70 or older; completion of hospital-based treatment 3-24 months or watchful waiting; able to understand and speak Dutch; physically and mentally able to converse for an hour.	Inclusion in a clinical trial in university cancer center.	Not reported Yes
Wagland (2019) Does not specify	Purposive (2015-2016)	Stage I-III prostate cancer 18-42 months after diagnosis; purposive sampling stratified by treatment; without or have one or more physical and emotional problems; Black, Asia and Minority groups.	Do not specify	Not reported No
Wennick (2017) Does not specify	Consecutive (Does not specify)	> 65 years old; 12-18 months previously had undergone an open or a robotic radical prostatectomy at either one of two hospitals in southern Sweden.	Not fluent in Swedish.	Not reported No
Wollersheim (2021) Does not specify	Does not specify (2014)	Diagnosed with prostate cancer, who had a radical prostatectomy as primary treatment (including men who went on to have additional therapies like salvage radiotherapy); with or without lymph node dissection; under active routine (at any time during follow-up); specialist-centered (urologist or nurse practitioner) follow-up care.	Unable to understand the Dutch language; actively followed by a cancer specialist for another primary cancer.	Not reported Yes
Zanchetta (2016) Ethnography	Blog entries (2013)	Do not specify	Do not specify	Not reported No

5b. Methodological characteristics of the qualitative studies that included patients under treatment.

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
AlanderMEJ (2021) Phenomenology	Does not specify (Does not specify)	Does not specify	Does not specify	Yes No
Appleton (2018) Phenomenology	Purposive (2014-2015)	Patients with a diagnosis of colorectal, head and neck or lung cancer being treated with curative or palliative intent	Does not specify	Yes No
BeerdaDCE (2022) Phenomenology	Purposive (2021)	Patients diagnosed with advanced cancer and aware of the incurability of their disease; >18 years of age; working in paid employment at time of diagnosis and the year prior to diagnosis; in paid employment, or (partly) on sick leave, or receiving (partial) disability benefit/unemployment benefits at time of the interview; having the intention to return to paid employment, if not at work; able to speak Dutch	Severe psychological symptoms	Yes Yes
Björnsdóttir (2021) Does not specify	Purposive (2017)	In possession of cognitive and communicative abilities to understand and express themselves in Icelandic and; >18 years of age	Does not specify	Yes Yes
Boman (2018) Interpretative	Purposive (2014-2015)	Women diagnosed with primary breast cancer; fluent in Swedish	Women with advanced breast cancer	Not reported Yes
Çömez (2016) Phenomenology	Does not specify (2012-2013)	Patients diagnosed with breast cancer at least 1 year prior to study enrollment; volunteering to participate in the study; fluent in Turkish, not having any hearing or speech problems; and being a graduate of primary school or higher	Does not specify	Not reported No
Erol (2018) Phenomenology	Purposive (2015)	>18 years of age; within at least 6 months of diagnosis; without communication difficulties; who volunteered to participate in the study; a diagnosis of non-small cell lung cancer stage IIIB/IV or advanced gastric and colorectal cancer with stage III/IV; and with a ECOG performance score of 3 and 4	Does not specify	Not reported No

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
Fraterman (2022) Phenomenology	Purposive (2020-2021)	Patients diagnosed with high-risk or advanced melanoma during or after systemic treatment with ICIs; >18 years of age; and sufficient understanding of the Dutch language	Does not specify	Yes Yes
Giesinger (2018) Grounded Theory	Consecutive (Does not specify)	Cancer patients with any diagnosis, stage or treatment; aged >18 years	Does not specify	Not reported No
Graffigna (2017) Phenomenology	Purposive (Does not specify)	Patients diagnosed with CML; undergoing a target therapy treatment for their CML	Does not specify	Not reported No
Hajdarevic (2022) Inductive approach focusing on both manifest and latent content.	Purposive (2017-2018)	Patients diagnosed with breast, colorectal or prostate cancer who were close to be discharged from the hospital	Do not understand Swedish language; have any visual, auditory or cognitive impairment	Yes No
He (2021) Does not specify	Purposive (2019)	Physician-confirmed multiple myeloma diagnosis	Primary amyloid light chain amyloidosis, monoclonal gammopathy of undetermined significance, or smoldering Multiple Myeloma	Not reported Yes
Hoesseini (2020) Grounded Theory	Consecutive (Does not specify)	Patients that had undergone treatment for head and neck cancer 6 to 18 months before selection	Aged 80 years or older; a carcinoma in situ; Korsakoff syndrome or dementia; severe alcohol and/or drugs abuse; possible recurrent or metastatic disease; recent hospitalization; simultaneous tumor outside of the head and neck region.	Yes Yes
Jakobsson (2017) Phenomenology	Purposive (2012-2013)	Patients that had the lived experience of recovering from colorectal cancer surgery and could participate in an interview to describe their experiences verbally	Does not specify	Not reported No

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
JepsenLØ (2016) Phenomenology	Consecutive (2013-2014)	Patients had to match the standard requirements for outpatient management in the home unit; understand and speak Danish	Declined to participate; died before second assessment and withdraw informed consent	Not reported No
Jespersen (2022) Does not specify	Purposive (2017-2018)	Participants >70 years; diagnosed with gastrointestinal cancer and referred to an outpatient clinic for oncologic treatment; starting first-line palliative chemotherapy or proceeding to further treatment lines during their trajectory of receiving palliative chemotherapy	Does not specify	Not reported No
Millet (2022) Does not specify	Purposive (2019-2020)	Women treated for cervical cancer between the ages of 18 and 60 years; living in the United Kingdom	Treated for pre-malignant lesions (cervical intra-epithelial neoplasia) only	Not reported No
Netsey-AfedoMML (2020) Phenomenology	Consecutive (2017-2018)	Patients with advanced prostate cancer; initiated androgen deprivation therapy	Not advanced disease	Not reported Yes
Osborne (2014) Does not specify	Purposive (Does not specify)	>18 years; confirmed diagnosis of multiple myeloma; having been told the diagnosis; and capacity to give written informed consent	Those too unwell, symptomatic or distressed to participate (as judged by the clinical team); severe neutropenia where contact with researcher may pose a risk; unable to understand written and spoken English; and those for whom myeloma was not the most important health problem (as judged by the patient)	Yes Yes
Petri (2015) Phenomenology	Purposive (2014)	Completion of radiotherapy treatment within the last 2-3 weeks at the time of the interview; ability to speak and understand Danish; lived in their own home during the radiotherapy treatment	Does not specify	Yes No
Shilling (2017) Does not specify	Purposive (Does not specify)	>18 years old; able to read and speak English and; give fully informed consent	Could not nominate an informal caregiver who was also willing to take part in the study	Not reported No

Author (Year) Theoretical approach	Recruitment methodology (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
vanDongen (2022) Does not specify	Purposive (Does not specify)	Patients diagnosed with vaginal, vulvar, penile or anal cancer in the past 6 years and; they did not have any severe psychological problems	Does not specify	Yes Yes
Wagland (2016) Phenomenology	Consecutive (2013)	Individuals >16 years in England; survived 12-36 months following diagnosis of colorectal cancer in 2010 or 2011	They were not known to have a UK address	Not reported No

5c. Methodological characteristics of the qualitative studies that included palliative patients.

Author (year) Theoretical approach	Recruitment (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
Aumann (2016) Phenomenology	Consecutive (2013)	Small or non-small-cell lung cancer patients; undergone palliative chemotherapy at the time of the study; at least one cycle of chemotherapy.	Adjuvant chemotherapy	Yes Yes
Balmer (2015) Does not specify	Purposive (Does not specify)	Diagnosis of cancer carrying a poor prognosis, defined by Cancer Research UK (2014) as a 5-year survival estimate of less than 50%.	Does not specify	Yes Yes
Beernaert (2016) Does not specify	Purposive (2012)	Cancer which was expected to lead to death in the short or long term; clinical diagnosis of COPD, heart failure, and/or mild to moderate dementia capable of doing an interview.	People living in a nursing home.	Yes No
Bergqvist (2017) Phenomenology	Does not specify (Does not specify)	18 years old; Swedish speaking; patients with on-going (at least their second line) palliative chemotherapy.	Cognitively impaired; non-Swedish speaking.	Not reported No
Dobrina (2016) Phenomenology	Purposive (Does not specify)	Patients affected by advanced cancer who recently ended/refused further treatment, or for whom no treatment was available; 18 years of age; sufficiently fluent in Italian; provided informed consent were eligible to participate.	Does not specify	Not reported Yes
Doveson (2020) Does not specify	Purposive (2016-2017)	Men with metastatic Castration Resistant Prostate Cancer who were about to start; were currently undergoing or had finished their first life-prolonging treatment.	Does not specify	Not reported No
Drury (2022) -	- (2015)	-	-	-
Dunham (2017) Phenomenology	Purposive (2013-2014)	Older people with a diagnosis of cancer and in receipt of community based specialist palliative care services.	Does not specify	Not reported No
Håkanson (2015) Phenomenology	Purposive (2012-2013)	Various metastasized cancers; enrolled in inpatient specialist palliative care; representation of a variety of ages; equal representation of sexes; having bodily-care needs; able to speak and understand Swedish; and having the strength to participate.	Does not specify	Not reported No

Author (year) Theoretical approach	Recruitment (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
Hofheinz (2016) Phenomenology	Purposive (Does not specify)	Adult patients (>18 years) with cytologically or histologically confirmed diagnosis of mGC or mGEJ-Ca who had received at least 2 cycles of palliative CT in first or later lines of therapy; physically and mentally capable to participate in a 45-60 min interview.	Does not specify	Yes No
IvzoriErel (2022) Phenomenology	Purposive (2016)	Individuals with stage IV cancer; life expectancy of 6 months or less; who were not receiving any life-prolonging care the in-patient; > 18 years old; sufficient Hebrew language skills; for the in-patient individuals: being hospitalised for at least 10 consecutive days during the last month and not being accompanied by home-hospice teams at home; for the home-hospice group: receiving care from a home-hospice team at home	Individuals with cognitive decline or significant psychiatric illness; those who could not participate in the interview due to their physical condition	Not reported No
Laursen (2019) Phenomenology	Does not specify (2017)	Patients treated for incurable oesophageal cancer	Does not specify	Not reported No
Loughran (2019) Phenomenology	Purposive (2016)	Using the specialist community palliative care service during the study period; adults; diagnosis of cancer that was not expected to be cured with treatment and a prognosis greater than six months; undergoing supportive or palliative treatment only; physical difficulties relating to their cancer; able to communicate in verbal English or use adaptive equipment allowing an interview to take place within an hour timeslot; aware and understood their prognosis	Does not specify	Not reported No
Madsen (2019) Phenomenology	Does not specify (2015)	Adults living with incurable cancer; able to speak and understand Danish; cognitively well-functioning; assessed by healthcare professionals; energy to participate in interview	Does not specify	Not reported No
Maersk (2018) Grounded Theory	Purposive (2017)	8 years or older; living at home; receiving homecare; and identified (by nurses, doctors, and/or themselves) as having advanced cancer	People living in hospices or nursing homes	Not reported No

Author (year) Theoretical approach	Recruitment (Data collection)	Inclusion criteria	Exclusion criteria	Guidelines[1] Saturation[2]
Nysæter (2022) Grounded Theory	Purposive (2018-2019)	>18 years old; cancer in the late palliative phase; informed and aware of their state of illness and prognosis; no cognitive impairment; understand and speak Norwegian; living in their own home alone or with relative(s); had an expressed wish to die at home documented in the patient record	Patients living in nursing homes	Yes Yes
Reynolds-Cowie (2021) Phenomenology	Does not specify (Does not specify)	Diagnosis of breast, colorectal, prostate, or gynaecological cancer; chronic insomnia; completion of active cancer treatment by at least 1 month with no further anticancer therapy planned (thus excluding transient sleep effects associated with cancer treatment); ≥18 years old	Short-term or acute insomnia, <3-month duration; evidence of another sleep disorder (e.g., sleep apnoea)	Not reported No
Rodríguez-Prat (2022) Phenomenology	Purposive (2016-2018)	≥18 years old; fluency in Spanish or Catalan; outpatients diagnosed with advanced cancer; Eastern Cooperative Oncology Group (ECOG) 0-3; considered to have control over their illness and circumstances according to their responsible physician; signed informed consent; judged by their physician or nurse to be emotionally stable to participate in the study	Ongoing severe psychiatric disorder; cognitive impairment with score>5 on the SPMSQ	Yes Yes
Rohde (2017) Does not specify	Does not specify (2012-2013)	≥18 years; metastatic colorectal cancer; referral to first- or second-line noncurative chemotherapy; expected life expectancy > 6 months; written informed consent	Significant comorbidity that could compromise life expectancy; treatment with an investigational agent; inability to understand or read Norwegian; conditions that the physician believed could affect the patient's ability to understand or cope with the questions were not considered eligible	Not reported Yes
Stanze (2019) Grounded Theory	Purposive (2013-2014)	Stage IIIB or IV small cell or non-small cell lung cancer	Does not specify	Yes Yes
Villalobos (2018) Does not specify	Does not specify (2015)	Primarily metastatic lung cancer	Does not specify	Not reported Yes

Appendix 6. Extracted data of each included study.

6a. Themes, Sub-themes and quotations from included studies with survivors.

Author (year) Theme	Subthemes	Quotes
Appleton (2013)		
Partnership with the multidisciplinary team	Partnership between members of the team and the patient through the recovery process; Openness from the team supported individual adjustment at the psychological and practical level; Easy access to information from the team.	
Enablers	Societal attitudes to cancer; Willingness to demystify the stigma of cancer; Social support to achieve sense of normality; Personal goals and targets; Return to work	
Self beyond cancer	Altered concept of self; Sense of resilience; Actions to regain roles and identity; Assumption of psychological approaches to living with cancer; Developing expert knowledge; Altruistic actions, empathize with other's situations; Willingness to participate in research	
Appleton (2014)		
Understandings of common concepts in the language of cancer	Journey; Survivor; Normality; Patient; Managing identity; Managing emotions	
Survivor		The term 'survivor' was linked to a stage of the disease, but served to act as a potent reminder that cancer may still be present. The term was accepted on the basis of surviving and having overcome the disease, however it was also linked to the less acceptable status of victim.
Aunan (2021)		
Help me stay in control	To be met with interest and support	To see, listen to and make sure information is tailored to their need; Hope and predict ability; To bring along support to information meeting.

Author (year) Theme	Subthemes	Quotes
	Enough knowledge to understand what is happening	Tailored information about treatment and consequences; Tailored information from specialists and peers about side effects and how to prevent them; HCPs to contact when in need for more information (re-informed)
	A plan to build/base the new life	Someone to contact when in need; Use of humour, direct language; Accept the new situation, body changes; Use own experiences to help fellow stranger.
Burden (2016)		
Appetite swings		
Emotions on changing physicality	Preoperative changes; Post-operative changes	
Weight gain		
Medicalisation of food		
Taking control of symptom management	Chemotherapy; Stoma management	
Drivers for action		
denBakker (2018)		
Perioperative phase	Getting clarity about the diagnosis as soon as possible; Receiving adequate guidance before operation; Receiving adequate guidance during in-hospital stay; Adequate transition from the surgeon to oncologist; met needs	
	Receiving tailored, dosed and understandable information - unmet need	There is only one thing that matters if you just hear that diagnosis, it's like receiving a slap in the face. If the doctor then tells you all that information, you no longer hear it. Because you're so busy with yourself and the cancer diagnosis, fortunately my wife was sitting next to me.

Author (year) Theme	Subthemes	Quotes
	The need of a central contact person in case of complications - unmet need	What I missed in the period after surgery and before the start of chemotherapy is actually still a kind of central control over what was happening to me. The urologist is mainly busy with the bladder, the oncologist who wants start chemotherapy but cannot start it yet due to the complications with the bladder and the surgeon has to do many other things. So I felt that I had to really take care of myself and what happened to me and that I had to intervene myself not knowing whether it was necessary or not.
	Receiving nutrition-related / stool-related advice - unmet need	After surgery I had a dietician, she said you can basically just eat everything but limited processed meat or nothing at all. Which was clear to me. But I still have to go very often to the toilet. Often to defecate. Sometimes it's just that urge to defecate and then nothing happens. And then you'll go back thinking has that to do again with food? I try to keep it to myself, and see if it happens with specific food more often. Well then I see some pattern in it. At one point I felt a little bit alone with these problems.
	Receiving advices regarding resumption of normal activities - unmet need	I went grocery shopping by foot, using a bag, which I expected that I could do. However, this clearly was not yet possible, so I had to ask several times to a bystander if they could help. If someone had told me when I would have been able to do this after surgery I would have known what to expect.
During chemotherapy phase	Receiving guidance during treatment with chemotherapy - met need	
	Monitoring of their particular situation during chemotherapy - unmet need	The oncologist seems a bit too busy to me, because he starts asking questions in the waiting room and then you walk with him to his Consulting room. And when you're in that room you can almost go home again, with him looking at his watch. He is always ahead of his schedule. And then you think you better can make a list with questions in advance, otherwise it will not be useful. The doctor is often talking to you towards the door.

Author (year) Theme	Subthemes	Quotes
	Receiving information about the minimum amount of chemo needed to overall survival - unmet need.	You assume what the internist says is the best option and he explains the options and tells me that I do not have to say 'yes'. 'What do you think about it?', Of course I say 'yes', you accept everything. You can't say 'no'. I think you have no choice.
After chemotherapy phase	Receiving a longer aftercare period - unmet need	But I miss the aftercare. Occasionally I think I'd like to take that phone and just like during the process where I could talk very well with the oncology nurse specialist. What would I still like to have feedback from her again. Then you lose the negative tension and then you'll be able to resist it again.
	Receiving information about the total duration of side effects - unmet need.	And I feel like I'm beginning now and that I start to find some kind of balance between accepting that my life will never be the same as 2 years ago and that things have deteriorated. However I'm still building a valuable life again.
	Receiving emotional support - unmet need	The interesting thing is that we get medical examinations every six months 5 to 7 years long, but psychologically nothing is offered. While that's your biggest problem.
	Getting support for relatives - unmet need	I personally think that it is also good for family to have a conversation after or during chemotherapy, without the patient. To explain what is going on and what happens to your partner. During the conversation I was also anxious, it was uncomfortable. I think it is important that for the husband or wife or friend, there is also an opportunity that they can express themselves as well.
Dunne (2018)		
Emotional barriers	Worries about posttreatment consequences; Fear of recurrence; Low mood;	
Symptom-related barriers	Physical side effects and symptoms arising from treatment and its consequences; cognitive symptoms arising from treatment	
Structural barriers	Financial resources; Access to appropriate health services	
Self-evaluate barriers	Diminished self-confidence; Interpersonal self-evaluative concerns	

Author (year) Theme	Subthemes	Quotes
Harji (2015)		
Symptoms	Pain; Fatigue; Gynaecological symptoms; Locomotor symptoms; Urological symptoms; Gastrointestinal symptoms	Location, pain severity, frequency and interference; Lack of energy and lethargy; Bleeding, discharge, pain, interference and bother; Mobility, Lower limb paraesthesia and lower limb pain; Incontinence urgency and interference Urological stoma; Flatulence, rectal discharge, interference, gastrointestinal stoma.
Sexual function	Sexual intercourse	
Psychological impact	Self-efficacy and dependence; Appearance and Body Image	Surprise/Shock/Anger, Depression, Frustration, Anxiety, Hope, Relief; Self-confidence, reliance on others, change in perception; Self-consciousness, embarrassment.
Role functioning	Work; Household activities; Social; Relationships	Change in occupational status, finance; General activities, housework; Social activities, leisure activities and hobbies; change in roles, dependence on partner, communication with partner.
Future perspective	Disease recurrence; Further treatments; Future plans	Anxiety regarding appointments and symptoms; Adjuvant therapies, morbidity and restriction; Short term, hope.
Healthcare services utilization and delivery	Disease management; Treatment expectation; Healthcare professionals	Obtaining a diagnosis, intensity of diagnostic imaging, progression of disease, follow-up intensity, travel; Hope of cure, prolongation of life, limited options, length of recovery; Confidence in decision making and disease management, communication and support.
Harrow (2014)		
Reasons for taking adjuvant endocrine therapy	Lifeline to being cancer-free; doctor knows best	
Experiences of taking adjuvant endocrine therapy	Remembering not to forget; it's a religion; living with the side effects	
Perceptions of and need for support	Keeping it to themselves - everyone's different; no one's ever asked if I am still taking it; appropriate expertise	

Author (year) Theme	Subthemes	Quotes
Jakobsen (2018)		
Bodily and mental loneliness	Bodily and mental challenges	Resting needs; Exhausted; Bad sleep; Less energy.
	Information and timing mismatch	Searching for relevant information; Follow up requested; Hyperactive.
	Relationship and partnership	Bodily changes affect attractiveness; Reduced sex life; Relations to partner and other people.
New center of gravity in everyday life	The meaning of work	Trials and job experiences; Work capacity reduced; Identity and work
	Reorientation of daily occupations	Upholding bodily fitness; Creating new routines; Adjustment of daily occupations to capacity.
KammingaNCW (2022)		
Dealing with a switch in prognosis	Mixed feelings and emotions regarding prognosis switch; Facing an uncertain future	Feelings of gratitude; Difficult to understand and/or believe; Feelings of anger; Stress caused by uncertain future; Loss of trust in body; Fear of recurrence and dying; Lack of understanding by close relatives.
Challenges to proceed with life as prior to metastatic cancer	Demands and expectations to resume life again; Persistent complaints and new problems in different life domains	High demands in several life domains; High expectations of oneself; Assumptions about being 'cured' by surroundings; Persistent physical and psychological complaints; Late effects of treatment; Issues in returning to work; Negative influence on social life; Problems felt by close relatives.
Finding a new balance	Coping with uncertainty; Changed perspective on life, re-evaluation of close relationships and changed personality; Towards no longer being a patient	Concerns about living with limitations; Trust in body needs to be regained; Staying hopeful and optimistic; Enjoy life more fully; Stronger connection with religion; Re-evaluating the importance of close relationships; Friendlier and less worried about little things in life; More easily irritated; Not knowing who you are.
Needs regarding (medical) information and care	Need for tailored patient information, available at one location; Need for periodic and additionally flexible follow-up	Information tailored to individual's situation; Information tailored to individual's needs; Information in understandable language; Periodic follow-up checks provide reassurance; Additional flexible follow-up when needed.

Author (year) Theme	Subthemes	Quotes
Falling between two stools: need for broader supportive care	Need to know where to go and whom to turn to; Need for psychosocial support; Need for support for close relatives	Information about available care options; Information about whom to turn to with questions and problems; Practical and personal information; Psychological information and support; Access to peer support; Work-related information and support; Support in dealing with consequences of disease.
Koutoukidis (2017)		
Defining a healthy lifestyle;	Healthy eating and physical activity; mental, sexual, and psychological well-being	
Factors influencing diet and physical activity	Cognitive; physiological; emotional; social; and practical	
Needing to search for information	Desired advice, timing, and methods of delivery; Participants were interested in receiving reliable information about healthy lifestyle from their health care professionals or being directed to appropriate services by them	
Lagerdahl (2014)		
Death anxiety	Mortality; Control; More authentic way of life	
Freedom	Uncertainty; Seeking structure; Awareness of authorship; Will to act	
Isolation	Emotional isolation; Marked by illness, Protective relationships	
Meaning	Loss of meaning; Meaning making	
Liaset (2018)		
Back at work 100% after a couple of months	Expectations of RTW	Then I was a little like; everything like before? Then I'll be back at work 100%, after a couple, three months.
To be a minus	Reduced confidence in work life	(I)... am sort of a minus
Adjustments of work tasks is everything	Adjustments	To get the adjustments in (...) really is everything (...) in relation to the job.

Author (year) Theme	Subthemes	Quotes
Those who are closest have a lot to say - hard without	Support from relatives	It's clear that those who are closest to me; wife, parents. It means an awful lot to say that you have a support system around you. You need to have that... If not ... it becomes terribly hard.
Matheson (2020)		
Perceptions of loss	Perceptions regarding loss of function; Perceptions regarding loss of self; Perceptions regarding loss of connection; Perceptions regarding loss of control; Psychological vulnerability: exacerbating factors	
Maladaptive strategies for coping with distress	Concealment of distress; Avoidance of help-seeking; Withdrawal (social/activity)	
Piil (2022)		
Searching for meaningful activities.	Ongoing time points for treatment evaluation as the most distressful events; When the clinicians told them that they were called 'long-term survivors', the patients tended to feel that they were more fortunate than others, yet continued to feel vulnerable due to their uncertain prognosis; impaired health due to the disease, often leading to a working disability that also caused psychological vulnerability; The patients faced various obstacles when trying to returning to work	
Selecting information that enhances self-management strategies.	The survivors included in this study preferred to limit the amount of prognostic information they received; Once patients lived longer than the predicted statistical survival rate, they acknowledged that the individual disease trajectory cannot be determined with any certainty; The survivors sought to increase their chances for a prolonged period of life, or to ease symptoms, for example, nausea, by using complementary and alternative therapies; Other LTSs searched for literature describing positive patient cases written by cancer survivors	

Author (year) Theme	Subthemes	Quotes
Protection for safety reasons.	The survivors described a heavy symptom burden and a variety of late complications, including fatigue and reduced cognitive capacity, for example, impaired memory and reduced concentration; The effects of the patients' profound symptom burden negatively influenced their social relationships with their network and caregivers; Patients and the caregivers explained that their family roles changed	
Puppo (2020)		
Body and physical issues	Major surgery for minor symptoms: OC survivors' perception that the therapeutic measures are disproportionate; A reduction in physical QOL: The consequence of age or of OC treatments?; OC impact on body image and on feminine identity	
The impact of cancer experience on social life	The evolution of social activities: The impact of age and OC treatments; Providing care to others: Social adjustments after OC experience; The impact of OC experience on participants' professional careers	
The impact of cancer experience on perception of life	'Becoming mindful'; Understanding OC experience from the patient trajectory perspective	
RegnierDenois (2017)		
Lack of Awareness of Supportive Care Services		
Limited Access to Services and Resources		
Barriers Stemming from Patients' Mental Images of Supportive Care Services		

Author (year) Theme	Subthemes	Quotes
Unmet Needs in Supportive Care Services		
Samsøe (2022)		
Overwhelmed by information		
Talking about mental well-being		
Transitions - Cured but not healed		
The fine details to quality of life		
Şengünİnan (2019)		
Quality of Fear	Severity of fear; other types of fear	
Triggers	Hearing People Talking About Breast Cancer; Treatment-Related Memories; Long-Term Effects of Breast Cancer Treatment; Posttreatment Hormone Therapy and Follow-Ups; Changing Lifestyle; Attitudes of the People Around Them; Life Stressors	
Effects on Life	Physical effects; emotional effects; social effects	
Coping	Strategies Focusing on Feelings and Thoughts; Behavioral Coping Strategies; Social Coping Strategies	
Şengünİnan (2020)		
Decision making for returning to work	(1) uncertainty; (2) facilitators	1) It returning to work was a sign of healing, and I proved myself. I decided to work for a few months and then to get retired, but I didn't get retired since I felt better; 2) My breasts were removed. After that, I became anxious about my physical appearance. I wondered about how my colleagues would treat me about it.

Author (year) Theme	Subthemes	Quotes
Difficulties in work life	(1) burden of symptoms; (2) inability to modify lifestyle; (3) negative attitudes of employers and colleagues	1) One difficulty I experienced at work was the effort I had to make to prevent swelling in my arm likely to be due to removal of the lymph nodes. I also feel weak and tired - I experience a great difference now compared with the time before the cancer; 2) The doctor told me to go for a walk. I can't do it; 3) I felt good when I returned to work, but many people have heard about my disease, and I got a bit bored with having to tell the things again and again.
Sources of motivation for continuation of work life	(1) familial support; (2) having a supportive workplace atmosphere; (3) what cancer has taught	1) My family says that I was more withdrawn and quieter before returning to work, but that I became more active and took care of myself better. This has a positive influence on me; 2) I was allowed to have some flexibility in working hours. Sometimes I can be late for work, and they (employers) show tolerance for it. When I want to leave, no one objects to it; 3) I used to be reserved. I used to keep silent not to make my boss upset. Now I want to tell what I like without hurting people. I don't want to get distressed anymore because I have one life and want to live it happily and peacefully.
Benefits of returning to work	(1) psychological improvement; (2) socialization	1) It improves one's mood. It relaxes me psychologically; 2) You become involved in life. You learn things from people around. You become socialized more.
Stamataki (2015)		
Emotional effects	Uncertainty; altered body image; fear of the sun	
Effects on relationships	Working relationships; family relationships	
Functional effects		
Health care system and information needs	Clarity of information; Quality of information; Information at the right time; Time spent with health care professionals	
Stuhlfauth (2018)		

Author (year) Theme	Subthemes	Quotes
Changes in the body	Invisible body changes; Visible body changes	
Changes in social life	The importance of social networks; The importance of work	
Changed relationships with partners	Vulnerable relationship; Sexual challenges	
Reviewing one's perspectives on life-influenced coping strategies		
Changed relationships with partners	Vulnerable relationship	
Sexual challenges		
Reviewing one's perspectives on life-influenced coping strategies		
Torp (2020)		
Entrepreneurship and engagement		
Cancer treatment and late effects		
Business related worries		
Shame		
Support		
Treanor (2016)		
Onset and nature	Anxiety; Cognitive impairment; Depression; Fear of recurrence; Graft versus Host Disease; Urinary incontinence; Aches and pains; Fertility loss; Lymphedema; Menopausal symptoms; Pain; Pins and needles; Sexual dysfunction; Stoma; Sleep disturbance; Recurrence; Diabetes; Body image issues	
Management	Late effects experience acted as a prompt to seek health-care contact; experiences respect to referral and access to specialist services	
Impact of late effects	working status (employment, reduction of working hours, reduced ability to work, financial impact); Impact on activities of daily living	
Personal disposition	optimism; stoicism	

Author (year) Theme	Subthemes	Quotes
Peer comparisons	Comparison of patient late effects experience in relation to other survivors they know, had read or heard about	
Sense making	intra-individual process of trying to understand the cause of their initial cancer and subsequent late effects and experienced difficulty untangling the cause of late effects in relation to other illnesses, family history and the effects of ageing	
Trusson (2016)		
Biographical disruption and liminality		
Fear of recurrence		
Embodied reminders		
Relationships		
vanEe (2018)		
Impact of prostate cancer		
Dealing with prostate cancer and treatment		
Involvement of and with others		
Experiences with the professional care and the care trajectory		
Wagland (2019)		
Contextual factors	Understanding disease stage and treatment options;	
Driver factors	Intrapersonal process; wanted more direction from clinicians; taking control of treatment decisions increased psychological well-being; specific treatment preferences	
Facilitator factors	Interpersonal communication; easily understood information about treatment options; potential side effects; lack of facilitators	

Author (year) Theme	Subthemes	Quotes
Conflicts between TDM factors	Inhibited expression of preferences and priorities (drivers) limited autonomy	
Wennick (2017)		
Paying a price for survival		
Feeling sidestepped		
Living with death lurking around the corner		
Wollersheim (2021)		
Health system and information	Information about test results; Information about impotence treatment; Information about follow-up appointments; Information about additional prostate cancer treatment; Information about the initial treatment for prostate cancer	
Physical and daily living		
Psychological		
Sexuality		
Zanchetta (2016)		
Self-identification		
Reactions to experiences		
Impacts on quality of life		
Physical functioning		
Psychological and social role functioning		

6b. Themes, Sub-themes and quotations from included studies with patients under.

Author (year) Theme	Subthemes	Quotes
AlanderMEJ (2021)		
Interactions with Healthcare personnel	Perception of information received from healthcare personnel; Alienating versus supporting encounters	
Cancer voyager	Physical and mental changes due to cancer treatment; Life in limbo and finding hope; Ongoing fear	
Appleton (2018)		
People factors	Face-to-face interactions; Perceptions of staff; feelings of solidarity	
Organisational factors	Managing unfamiliar environments; presence of organisational routines and schedules	
Personal factors	Being positive; being resilient; feeling informed; taking responsibility for self-care	
BeerdaDCE (2022)		
Holding on to normalcy		I think it would have helped a lot if work had been included in my process from day one as a topic of conversation. I mean, that is such a big part of your life, for me anyway, you can't just ignore it. (Female, age 64).
High understanding and divergent expectations		My manager said: 'Take your time, you're not doing this for us, but you're doing it for yourself, so do it at your own pace'. When that happened, a switch flipped for me, or so to speak. The tension was gone and I could finally relax. (Female, age 48).
Social discomfort calls for patient initiated alignment		The moment you mention the words 'cancer' and 'terminal', well in this case palliative, then yes, all the doors at the Employee Insurance Agency open. (Female, age 40).

Author (year) Theme	Subthemes	Quotes
Laws and regulations require patient empowerment		
Björnsdóttir (2021)		
Rehabilitation-the need for improved access, support, and continuity	Security in rehabilitation service; Survival instinct, general functionality, and continuity in rehabilitation service	
Coping, and quality of life, balancing life as it was before cancer against the present situation to achieve normality	A task to complete, acceptance and hope; living in the present and valuing life; the impact of disease and treatment on patient's well-being	
Satisfaction, encountering caring behaviours enhances satisfaction and well-being	Fulfilment of psychological needs; support for family; the interaction of caring encounters, establishment of a good relationship;	
Boman (2018)		
Respectful and personal encounters		
Part-owner in decision-making	The women expect to be informed and staff to make decisions; The women have a dialogue with staff to make decisions; The women expect to participate actively in decision-making	
Striving to manage treatment, care and self-care	The women are compliant with the treatment plan; The women do not know what to do; The women take their own initiatives	
Çömez (2016)		
Facing breast cancer	Perceptions of breast cancer; reactions to breast cancer	
Treatment process	Symptoms experienced; fear; understanding each other's worth; needs and counselling;	
Coping with the disease and treatment process	Body image and sexuality; religious beliefs; support systems; negative effects of society and media;	

Author (year) Theme	Subthemes	Quotes
Life after breast cancer	Changes in roles; health-promoting behaviors; living for oneself and not for others	
Erol (2018)		
Pain perception and patient experiences	The meaning of pain; thoughts about the reason of pain; past experiences about pain	
Effects of pain on daily life	Fatigue/tiredness; powerlessness; restrictions	
Pain management and management strategies	Non-pharmacologic approaches; pharmacologic approaches	Non-pharmacologic approaches; pharmacologic approaches.
Patients' perspectives about nurses' approaches to pain	Perspectives about the nurses' pain assessment; perspectives about the nurses' pain management	
Fraterman (2022)		
Patient experience and cancer journey	Treatment; Response; Side effects; Psychosocial state; Interpersonal relationships; Social support system; Relationship with HCP; Patient autonomy and empowerment	Patient comments: "Yes you know. In the end, it comes down to the fact that you just want a bit of security (in the cancer journey) and that no one is actually giving you that security. I'm realistic enough to see how that works of course."
Quality of life	Positive impact; Negative impact; Impact COVID-19	Patient comments: "Good quality of life? That I just, yes, that I have as much fun as possible and that I can mean something for someone else. So that I can also make others happy. And that I do not have to sit passively behind the geraniums like a greenhouse plant."
Use of internet, mobile applications, and eHealth	General use of internet and mobile applications; Current use of eHealth; Motivation for using eHealth applications	All patients accessed the internet on a regular basis, and the majority of them used mobile applications.
Information needs - educational topics and interventions	Educational topics; Interventions; Fellow patients/peer support	Patient comments: "Everything is in the forms, you read them in five minutes, you sign them. I think there could be more attention towards that [information provision]. And of course it's not positive to mention to the patient everything that can happen [adverse events], you know, as much more can happen. This was enough for me but much more can happen."

Author (year) Theme	Subthemes	Quotes
Needs for remote patient monitoring	Feedback; Input; Use of sensors	Patient comments: "Yes, I think so. Especially on days when things are not going so well. That you, then you know, if it is implemented in [the mobile app] of course, but that if there really is something that they [healthcare professionals] look at your side effects of, there is something, and then they will contact me, you know that - that you need to worry a little less if they don't."
Requirements for eHealth applications	Availability; Ease of use; Evidence-based information; Functionalities Information architecture; Information presentation; Integration with current applications; Notifications; Privacy (compliance to privacy laws)	A crucial requirement for eHealth applications, as noted by nine patients, is ease of use.
Facilitators and barriers for eHealth	Information needs; Perceived user needs of an app; Use of sensors Remote patient monitoring; Frequency of app use	Patient comments: "I catch myself forgetting everything [symptoms] that I experienced. So it might be nice to have an overview for yourself... And to keep track of everything you experience and it might be that the physician finds something useful."
Giesinger (2018)		
Problem limits everyday life or daily functioning		
Problem causes other problems		
Emotional impact of the problem		
Duration/frequency		
Not normal /unexpected/change from normal		
Help or treatment is needed		
Emotional impact on family or partner		
Graffigna (2017)		
Chronic myeloid leukemia illness burden	Chronic myeloid leukemia: the 'fight'; patients' ambivalent connection to their drug; daily life with the disease; the promise of recovery	

Author (year) Theme	Subthemes	Quotes
Patients' ambivalent connection to their drug	Generally deep and positive feelings; issue of adherence	
Daily life with the disease	Problems and resources experienced by patients in their daily lives; interpersonal relationships; informal caring; give up hobbies and commitments; reconfigure life projects and dreams	
Promise of recovery	Possibility of interrupting CML therapy	
Emotive ambivalence related to the promise of recovery: a focused word association analysis	Positive and negative emotions expressed	
The CML illness journey': from deep darkness to renewed hope	The 'shock'; the 'anxious alert'; the 'depressive acceptance'	
Hajdarevic (2022)		
Personal support to reach a sense of control	Requiring adapted support	Various and continually changing needs of close conversations.
		Adapted instead of standardised support.
		Accessible and responsive care to reduce stress.
	Developing trust-based relationships	Personal involvement to get answers.
Social support for personal growth	Becoming enabled through mutuality	Social support facilitates daily life.
	Engaging in meaningful activities	Distraction by engaging in activities.
		Encouragement to discover new opportunities.
		Time for rest and piece to recover.
He (2021)		
Symptoms	Bone pain (90%); Fatigue/tiredness (87%); Peripheral neuropathy (30%); Infection (27%); Sleepiness (13%); Constipation (13%); Muscle cramps (10%); Headache (10%); Insomnia (10%)	

Author (year) Theme	Subthemes	Quotes
Impacts	Daily life (77%); Physical activity (73%); Social life (63%); Emotional general (50%); Work (33%); Emotional anxiety (27%); Insomnia/sleep (20%); Family life (20%); Emotional depression (10%)	
Treatment benefits	Increased life expectancy (87%); Remission/response (80%); Reduced fatigue (80%); Reduced worry (73%); Independence (70%); Increased time to recurrence (70%); Reduced bone pain (70%); Time to response (67%); Improved social life (60%); Planning for the future (60%); Improved ability to work (40%); Health-related quality of life (33%); Reduced self-care (33%)	
Treatment side effects	Peripheral neuropathy (90%); Diarrhea/constipation (83%); Cognitive impairment (83%); Nausea/vomiting (77%); Swelling of hands and feet (77%); Risk of infection (77%); Hematologic (60%); Fatigue (57%); Kidney infection (10%); Fevers/infections (7%)	
Treatment burden	Treatment duration (80%); Location/travel (73%); Intravenous injection (43%); Subcutaneus injection (20%); Other side effect (20%); Monitoring (10%); Oral administration (7%)	
Hoesseini (2020)		
Understanding the concept & using a tailor-made approach	Unknown: Participants are not familiar with the concept life expectancy	I have never heard of the 5-year survival rate.
	Confusing: Participants don´t understand the different terms that are used alternatively. This can be confusing	But what is actually meant by life expectancy? Do they mean survival chances, cure or life expectancy after treatment? Or quality of life?
	Wrong / negative formulation: The 5-year survival term sounds negative. When talking about survival rates it should be emphasized that we are talking about chances, not certainties	It really should be said differently, but I do not know how... When you get home you only hear 'five years'.

Author (year) Theme	Subthemes	Quotes
Tailor-made approach	Content: Prognostic information can be divided in 1) qualitative information: general terms without numbers or percentages, like 'the cancer is curable'; and 2) quantitative information: numbers or percentages, like months, years or survival rates. All patients wanted to receive information in general terms. However, quantitative information was not desired by all patients. Some felt empowered by prognostic information expressed in numbers or percentages, and others were in doubt or did not want to receive quantitative information at all	1) If you say 'well treatable' I do not think that life expectancy is important. Well treatable is well treatable. Therefore that means the end result is also good. In that case I do not need to hear a percentage; 2) I want to know what my chances are and find the percentages important. If you say 'it is 3%', it becomes somewhat more difficult. If I would hear 80% then I would think 'all right, I'm definitely going to make it'.
	Situation dependent: The need for quantitative prognostic information depends on the situation. In case of a poor prognosis patients have a strong preference for receiving quantitative prognostic information, while in case of a relatively good prognosis patients are equally divided between wanting or not wanting to receive this information	
	Quality of life: Prognostic information alone is not enough. Also information on the expected quality of life, with or without treatment, should be provided.	
	Time-dependent: If patients want to know more about their life-expectancy, for example survival rates, when should we discuss this? Overall, patients think this should not be discussed shortly after receiving the cancer diagnosis, because receiving the diagnosis is already an incredibly stressful event that first needs to be processed	
	Personal preferences. It depends on personal preferences whether a patient wants to receive prognostic information	

Author (year) Theme	Subthemes	Quotes
	Initiator: Who should take the initiative? How do you find out which patients want prognostic information, and what kind of information? Some patients will take the lead, while others aren't capable or don't want to, as they trust the doctor to do the right thing being the expert	
Communication skills professional	Reassurance: Reassuring the patient and giving hope	
	Honesty: Being honest while providing prognostic information	
	Tailoring: Tailor prognostic information after exploring patients' needs and preferences or decide not to share prognostic information at all when a patient isn't ready for it	
Jakobsson (2017)		
Physical powerlessness		
Difficulties with food intake		
Altered bowel function		
Dependency on others		
JepsenLØ (2016)		
Everyday activities		Patient comments: "'I actually do the same things as I used to, but I do them slower, and I may only manage half"
Privacy		Patient comments: "it is not insignificant when you have 5 x 2 meters right? Who is behind the curtain"
Social relations		Patient comments: "You form a family-like relationship with those you meet. Oftentimes you've met as inpatients and then you meet in the HU, and well... it's like it is a little family out here (in the Home unit) because we follow each other"

Author (year) Theme	Subthemes	Quotes
Patient involvement in care		Patient comments: "You have to do your bed as inpatient if you are able to because it is good to your arms. In the beginning I thought: now just stop. That's your [the nurse] job. But I had second thoughts since"
Jespersen (2022)		
The variability and inevitability of physical pain		
Ways of coping with psychological pain		
Mitigating social pain through contributions to social life		
The anticipation of spiritual pain in old age		
Millet (2022)		
Treatment as a paradox	Reflections on treatment; Treatment after-effects	
Emotional fluctuations	Challenges to identity; Long-term worries	
Adversarial growth	Re-establishing normality; Acceptance	
Netsey-AfedoMML (2020)		
Fast track diagnosing and treatment	An effective and intense routine course	The patients experience the diagnostic phase as being routine, effective, and intense. The diagnosis is given as soon as possible in a straightforward way.
	A quick follow-up on the status	The patients experience that during the treatment course consultations focus only on the status of the disease and treatment.
Off course I should have this treatment	Doctors independently decide regarding ADT throughout the course	The patients experience that doctors make all decisions regarding ADT. Often, the treatment is perceived as being pre-arranged with no consideration of patients' preferences or needs and without the patients having an opportunity to influence the course.
	Treatment with ADT is prearranged	The patients are not presented with alternative treatment options than the chosen ADT nor that the choice not to undergo treatment is an option.

Author (year) Theme	Subthemes	Quotes
They don't ask about existential issues	Focus on disease and treatment	The patients experience that health professionals mainly focus on disease and treatment-related issues.
	No interest in feelings or existential issues	Almost no health professional show interest in patients' feelings or existential issues.
	Unmet needs	Hence, patients had unmet needs and dissatisfaction.
Osborne (2014)		
Biological Status	Symptoms Status	
Treatment Factors		
Activity & Participation		
Emotional Status		
Support Factors		
Expectation		
Adaptation & Coping and Spirituality		
Petri (2015)		
Radiotherapy as a life priority		
A struggle for acceptance of an altered everyday life		
Interpersonal relationships for better or worse		
Meeting the health care system		
Shilling (2017)		
Jobs and finances	Concerns around employment; Loss of earnings; Perceived financial position	
Relationships and communication	Patient-caregiver relationship and communication; Prevalence of cancer conversation; Family dynamics	

Author (year) Theme	Subthemes	Quotes
Implications for the future	Changes in outlook, realigning priorities; Life on hold; Opportunities lost; Not planning for the future; Mortality and death	
Managing uncertainty	Control; Preservation of or return to normality; Hope; Mindset	
vanDongen (2022)		
Recognisable symptoms, but unfamiliar diagnosis		
Double hit has severe impact on psychosocial functioning		
Personal and tailored information is important but not guaranteed		
All-encompassing care to improve psychosocial functioning and QoL		
Wagland (2016)		
Positive experiences	Timeliness of diagnosis; Good quality post-treatment care	Patient comments: "The early diagnosis of cancer and treatment has been essential to my excellent recovery. It was discovered after giving blood. I have returned to work a year ago and I have had no time off at all since despite going back early."
Negative experiences	Delayed diagnosis; Inadequate post-treatment care; Poor in-patient care; Lack of coordinated care; Lack of emotional support; Lack of information on treatment side-effects; Lack of information concerning possible psychological impact of cancer and treatments; Lack of information on self-management strategies; Lack of GP involvement	Restricted opportunities for emotional support example: "I did and still do feel 'abandoned' following surgery and treatment for colon cancer. I appreciate that the oncology and surgical departments are very busy but I would have liked some form of counselling following discharge. The anxiety doesn't go away, it just gets worse."

6c. Themes, Sub-themes and quotations from included studies with palliative patients.

Author (year) Theme	Subthemes	Quotes
Aumann (2016)		
Experiences and preferences during the treatment day	Waiting times; wish for privacy during chemotherapy	
Experiences with physicians	Information about the side-effects of the treatment options; Individual arrangements regarding communication methods between the physician and patient; Improving information about the changing physicians during treatment	
Experiences with health insurance	Travel costs	
Treatment-related experiences and preferences of the patients that influence psychosocial factors	Side-effects caused great physical limitations; psychological effects; lack of flexibility; loss of independence	
Balmer (2015)		
A new normal	Symptoms or side effects; returning to work	
Looking towards the future	Future goals; altruism and looking towards the future for others	
Reminders	Fear of recurrence	
A greater appreciation	The experience of cancer increasing their enjoyment of life; greater appreciation for life after life-threatening illnesses	

Author (year) Theme	Subthemes	Quotes
The involvement of friends and family	Family support	
Beernaert (2016)		
Physical and Practical Needs		
Psychological Needs		
Social Needs		
Existential Care Needs		
Information and Communication		
Coordination and Continuity of Care		
Financial	These financial problems affected seeking help for their care needs. A respondent with cancer could not afford going to a psychologist	
Bergqvist (2017)		
The decision process		
Personal motives and goals	Death as a threat; New value in life; Cancer symptoms as triggers of death anxiety; External motives for treatment	
The treatment itself	The experience; Stopping treatment is no option; Treatment recovery period	
Dobrina (2016)		

Author (year) Theme	Subthemes	Quotes
Remaining attached to my life: 'I wish I was doing things like I used to'		
Detach myself from life, immediately: 'I wish this Calvary was over'		
Dealing with the dying process: 'Waiting in fear'		
Starting to think of life without me: 'Unshared worries'		
Doveson (2020)		
Considering treatment when the remainder of life is at stake		
Preparing for the life-prolonging treatment after deciding to go through with it		
Considering the prospect of the current life-prolonging treatment not being successful		
Reflecting on death and dying in the light of a life-limiting illness		
Drury (2022)		

Author (year) Theme	Subthemes	Quotes
Dunham (2017)		
Better to be old than to be dying with cancer	Better to be old than to be dying with cancer	
Maintaining control and independence'		
Loss of identity-adapting and grieving for a former self'		
Dislike of analgesia' and 'denial of pain'		
Håkanson (2015)		
Maintaining and Losing Body Capability		
Breaching Borders of Bodily Integrity		
Being Comforted and Relieved in Bodily Care Situations		
Being Left in Distress with Unmet Needs		
Hofheinz (2016)		
Quality of life in terms of ability of self-care	Factor level 1: No assistance required for activities of daily living; Factor level 2: Little assistance required for activities of daily living; Factor level 3: A lot of assistance required for activities of daily living; Factor level 4: Complete assistance required for activities of daily living; bed-ridden	

Author (year) Theme	Subthemes	Quotes
Treatment tolerability	Factor level 1: No or mild adverse reactions possible; no hospitalization required; Factor level 2: Moderate adverse reactions possible; manageable without hospitalization; Factor level 3: Severe adverse reactions possible, hospitalization for 3-4 days may be required; Factor level 4: Very severe to life threatening adverse reactions possible; hospitalization for ≥5 days may be required.	
Additional survival benefit	Factor level 1: No additional survival benefit; Factor level 2: Survival benefit of approximately 1 additional month; Factor level 3: Survival benefit of approximately 2 additional months; Factor level 4: Survival benefit of approximately 3 additional months	
IvzoriErel (2022)		
Body as a place		This is me stuck inside my body. I'm good for nothing.
Sense of place towards the place of care		In fantasy, everyone wants to stay and die at home, but life isn't a fantasy.
The lack of a sense of place		I don't want to meet anyone or to be anywhere.
Laursen (2019)		
Illness controlling the patients' everyday lives while the patients are left alone with existential thoughts on the future: 'table in the corner'	Eating difficulties forces the patients to withdrawal from the social interactions; Loss of control and confidence in own body caused by the symptoms and treatment; Clinging to life by keeping things as normal as possible and focus on the present; The challenge of managing one's own illness when continuity is lacking	table in the corner'; 'sense of isolation'; 'being in a zombie-like state'; 'one day at a time'; 'at sea'.

Author (year) Theme	Subthemes	Quotes
Loughran (2019)		
Functional difficulties experienced by people living with incurable cancer		
Rehabilitation needs in a palliative setting		
Madsen (2019)		
Everyday life changes	Normal life changes; People changing behaviour; Changes hurting loved ones	
Approaching end of life	Approaching death; Preparing for leaving; Holding on to life; Connecting with places and belongings	
Maersk (2018)		
Managing the home to enable activitie		
Maintaining the privacy of home		
Displaying and hiding symbols of identity		
Nysæter (2022)		
Hope and trust to get the care I need to die at home	Being in the present; Be safe and in charge; Be seen and acknowledged	
Reynolds-Cowie (2021)		

Author (year) Theme	Subthemes	Quotes
I don't feel like myself	Irritable; Lacking motivation; Avoidance; Loss of interest; Frustration; Guilt about tiredness	
Planning life around something uncontrollable	Withdrawn/Isolated; Not making plans; Giving up work	
My body hurts	Fatigue; Pain; Headaches; Nausea	
My brain is not functioning	Concentration; Memory; Keeping up with conversation	
It's more than just not sharing a bed	Sleeping separately; Missing out on conversations; Partner irritation; Different bedtimes	
Worry	Racing mind; Pre-occupation with sleep; Pressure to get back to normal	
Rodríguez-Prat (2022)		
Factors that influence the perception of control	Uncertainty about future suffering	Patients experienced greater or less control: 'What really scares me, is not death, death itself, no, because we all have to die, you die and you don't realize. What scares me is ending up in a wheelchair, having to depend on someone, that, wah - Panic!'
	Character traits underlying the need for control	Yes, this life has taught me a lot. And I have managed to get over anything, from any complicated situation, and I have dealt with things with common sense, as I have always believed... and, okay... my children are proud of me.

Author (year) Theme	Subthemes	Quotes
	Sense of lack of care as a source of loss of control	Everyone said they couldn't see anything... some of them gave me a bit of medication or some said that, it's an inflammation [...] but everyone told me that I was senselessly worrying about it.
Perceiving control over an uncontrollable illness.	Perceived control over subjective wellbeing;	Taking care of your food is a kind of control [...] because it gives you a feeling that you're taking care of yourself and that you're helping to improve your health when you get treatment.
	Adjusting the focus of control	I plan small things that I'm interested in doing but I don't plan the future... because then I'd worry now and later and [...] it's not in my power to change the course of events.
Rohde (2017)		
Relationships with self and others	Strategies for inner harmony; Sharing feelings with significant others	
Existential issues	Coping with end of life thoughts	
Specifically, religious and/or spiritual beliefs and practices	Seeking faith as inner support	
Stanze (2019)		
Core category	Redefining one's own existence	
Causal condition	Powerlessness	
Consequences	Learning to live with the threat; keeping one's composure	
Intervening condition	Design of the therapeutic setting	

Author (year) Theme	Subthemes	Quotes
Action strategies	Rearranging everyday life (having to); Dealing consciously with the treatment	
	Dealing consciously with the treatment	
Context	Social roles shift	
Villalobos (2018)		
Communication prior to disclosure of diagnosis	Wearisome journey by being sent to different physicians; want clear and open information about diagnosis and therapeutic options	
Communication during further treatment	Use of inadequate language (specialized medical terminology); awareness and offer of psychosocial support services; conversations adjusted to individual needs	