PROJECT

LIFECHAMPS: A Collective Intelligence Platform to Support Cancer Champions

GRANT AGREEMENT No.

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DELIVERABLE

D2.3 – Selected person outcome metrics

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30/11/2020	Dr Greg Kotronoulas Sheena McGowan

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QUALITY CONTROL

Author(s)	Dr Grigorios Kotronoulas (GK, UofG) Sheena McGowan (SM, UofG)
Contributor(s)	AUTH APC UPV HULAFE KI
Reviewed by	Zoe Valero Ramón (UPV) Antonis Billis (AUTH) Kiko Núñez (SALUMEDIA)
Approved by	Prof Panagiotis Bamidis (AUTH)

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ABBREVIATIONS LIST

Abbreviation	Meaning
ADL	Activities of daily living
CINV	Chemotherapy-induced nausea and vomiting
CIPN	Chemotherapy-induced peripheral neuropathy
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
EC	European Commission
HRQoL	Health-Related Quality of Life
IADL	Instrumental activities of daily living
ICHOM	International Consortium for Health Outcomes Measurement
ISOQOL	International Society for Quality of Life Research
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
PABAK	Prevalence-adjusted bias-adjusted Cohen's kappa
PRE	Person-reported experience
PRO	Person-reported outcome
PREM	Person-reported experience measure
PROM	Person-reported outcome measure
WP	Work package

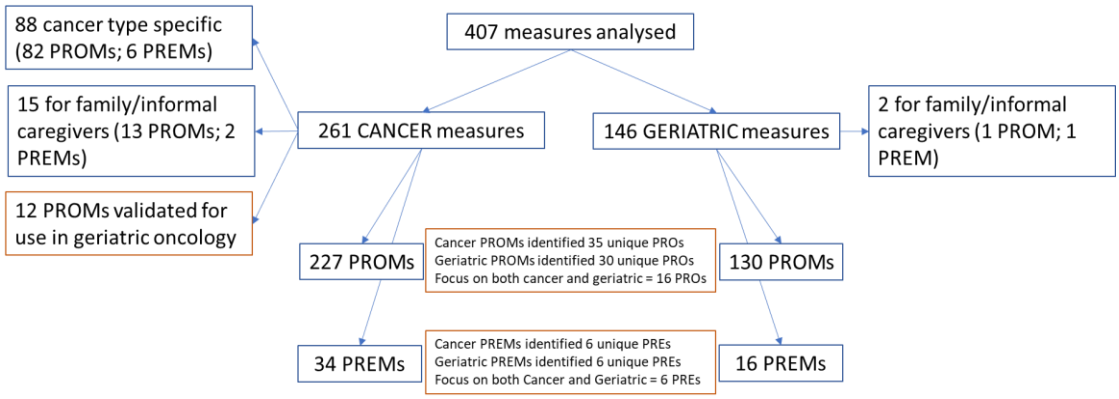
Note: For abbreviations of all PROMs and PREMs reviewed, please see **Appendix 6**: Abbreviations of all PROMs and PREMs reviewed**.**

1 EXECUTIVE SUMMARY

Background: In the past two decades, person-reported outcomes (PROs) and person-reported experiences (PREs) have been brought to the forefront of care service delivery. Health systems that aim to provide better care should be able to systematically monitor and respond to PROs and PREs. Monitoring brings in the concept of measurement, which in this context is facilitated by the use of self-reported questionnaires developed with direct patient input and enabling direct patient output (PRO and PRE data) that health professionals can act upon. These self-reported questionnaires are often referred to as PRO measures (PROMs) and PRE measures (PREMs), depending on whether the focus is on outcomes or experiences, respectively. Several measures have been developed over the past 50 years to assess healthcare matters that can be classified as PROs or PREs. It is paramount that PROMs and PREMs are selected for use in practice and research based on a thorough evaluation of their psychometric properties to ensure that valid and reliable person-reported data are captured. LifeChamps will heavily rely on the collection of PRO and PRE data. Therefore, identification of psychometrically robust PROMs and PREMs to enable accuracy in data collection has been a key part of the early developmental work of WP2, specifically assigned to Task 2.3, which is the focus of the current report. The aim of Task 2.3 was to identify existing psychometrically robust PROMs and PREMs in the fields of cancer care (breast, prostate, melanoma/skin; cancer in general), geriatrics and geriatric oncology for subsequent use in WP5 and WP7 in line with their respective objectives.

Methods: A systematic search strategy was developed and run in MEDLINE (accessed via Ovid), Cochrane Library and Google Scholar. The PROQOLID® database was also searched for additional measures and articles. Searches were limited to international research published in the English language. Eligible studies were published between January 1999 and March 2020 to retrieve the most up-to-date evidence. Studies and PROMs/PREMs included in previously published literature reviews were also considered for inclusion after applying our eligibility criteria. Four pairs of screeners were involved in the screening process. Inter-rater agreement was quantified by calculating percentage agreement, Cohen's kappa, and a prevalence-adjusted bias-adjusted Cohen's kappa (PABAK). Data from the final sample of studies was extracted onto a bespoke data extraction form created for this rapid review and inserted into an Excel spreadsheet for ease of use. Studies were further clustered per PRO/PRE. All evidence was integrated in a thematic narrative synthesis that generated summaries of key PROM/PREM elements, content domains and psychometric properties for further consideration.

Results: Of the initial 4,146 articles, 575 articles were considered for full-text evaluation, and 467 articles were retained and included in the final sample. Finally, 407 measures were fully reviewed and analysed. The flowchart below summarises characteristics of the included measures.



The identified cancer PROMs targeted 35 unique PROs; the geriatrics PROMs targeted 30 unique PROs. Sixteen PROs were the focus of both cancer and geriatrics PROMs. The cancer PREMs identified 6 unique PREs; the geriatrics PREMs targeted 6 unique PREs. Six PREs were the focus of both cancer and geriatrics PREMs.

Overall interrater percentage agreement was good at 77% (range 70%-83%). Cohen's kappa estimates were low (overall 0.31; range 0.23-0.42) indicating minimal level of agreement. The corrected PABAK estimates were more favourable (overall 0.54; range 0.39-0.66), indicating weak-to-moderate agreement among the pairs of screeners.

Wide variability in psychometric validation, measure structure (length, recall period), language availability and electronic format availability was noted. Consideration of PROMs and PREMs as 'fit for purpose' was based on the measures meeting combinations of these criteria.

Conclusions: A total of 71 cancer PROMs and 45 geriatrics PROMs (including 8 PROMs for geriatric oncology) are recommended for use as offering the best combination of features. Similarly, a total of 11 cancer PREMs and two geriatrics PREMs can be considered for use based on the aforementioned criteria. Ultimate selection of any of these PROMs and PREMs for use in research must take into account the unique requirements of the research inquiry (i.e. outcomes, end-points and frequency of measurement) as well as the unique characteristics and abilities of the patient population in geriatric oncology (e.g. respondent burden, cognitive capacity). The shortlist and copies of PROMs and PREMs will be subsequently shared during Task 2.2 consultation with end-users and stakeholders for consideration and selection/inclusion in WP5 and WP7.

2 INTRODUCTION

The field of geriatric oncology is a rapidly evolving one, bringing together current knowledge in oncology and geriatrics to enhance the standard of care provided to older people with cancer, who often present with complex and heterogeneous treatment requirements and healthcare needs. Geriatric assessment and monitoring in cancer care involves functional assessments of activities of daily living, geriatric syndromes and frailty [1]. Such assessments have historically been clinician-led, however the need to have (both) the patient's and (their) family's input throughout the process has quickly emerged as key to ensure a person-centred and person-led approach that can decisively enhance the standard of care offered.

For health systems and professionals, obtaining measures/data such as lab values, physical performance, mortality rates, length of stay, or readmissions is key and routine practice. However, what patients and caregivers focus on primarily is receiving quality care, managing symptoms, the ability to carry on with daily activities, keeping up with family or keeping mentally healthy. Such quality of life matters that come directly from the person at the receiving end of care are called person-reported and can be about either outcomes or experiences of care.

In the past two decades, person-reported outcomes (PROs) and person-reported experiences (PREs) have been brought to the forefront of care service delivery, particularly in relation to chronic conditions, such as cancer [2], and in relation to aging [3]. PROs and PREs often cause patients to seek out help. Health systems that aim to provide better care should be able to systematically monitor and respond to PROs and PREs. Example PROs and PREs that have been identified for assessment in geriatric oncology are outlined in **Table 1** below.

	Oncology specific	**Geriatrics specific**	**Geriatric oncology**
PROs	• Fear of recurrence • Symptom burden (late treatment effects)	• Frailty • Social isolation • Functional dependency/decline • Falls propensity/risk	• Quality of life/well-being • Suboptimal nutritional status • Polypharmacy burden • Multimorbidity burden • Depression • Cognitive decline • Physical ability
PREs	• Patient centredness of cancer services	• Access to care services	• Patient-clinician communication • Care processes coordination-integration • Preferences-goals of care • Quality of care environment • Care services responsiveness

TABLE 1 EXAMPLE PROS AND PRES CLASSIFIED PER CLINICAL AREA

Monitoring brings in the concept of measurement, which in this context is facilitated by the use of self-reported questionnaires developed with direct patient input and enabling direct patient output (PRO and PRE data) that health professionals can use to act upon. These self-reported questionnaires are often referred to as PRO measures (PROMs) and PRE measures (PREMs), depending on whether the focus is on outcomes or experiences, respectively. Definitions of all person-reported terms are provided in **Table 2**.

Term	Definition
Person-reported outcome (PRO)	A health outcome directly reported by the person (e.g. patient) who experienced it. It stands in contrast to an outcome reported by someone else, such as a physician-reported outcome or a nurse-reported outcome.
Person-reported experience (PRE)	A person's perceptions and experiences of interactions with the healthcare system and the degree to which his/her needs are being met directly reported by the person (e.g. patients) himself/herself.
Person-reported outcome measure (PROM)	Psychometric tools (e.g. questionnaires) that measure patients' views of e.g. health status, perceived level of impairment, disability, or health-related quality of life. PROMs are a means of measuring clinical effectiveness and safety. PROMs can be classified as either generic or disease specific.
Person-reported experience measure (PREM)	PREMs are psychometric tools (e.g. questionnaires) that measure patients' views of their experience whilst receiving care. They are an indicator of the quality of patient care, although do not measure it directly. PREMs look at the impact of the process of the care on the patient's experience e.g. communication and timeliness of assistance. PREMs can be classified as either relational (identify patients' experience of their relationships during treatment, e.g. did they feel listened to) or functional (examine more practical issues, such as the facilities available). PREMs measure whether patients have experienced certain care processes rather than their satisfaction with the care received (which may be subject to bias).

TABLE 2 DEFINITIONS OF KEY TERMS USED IN THIS REPORT

Several measures have been developed over the past 50 years to assess healthcare matters that can be classified as PROs or PREs. However, only a fraction of these measures can be thought of as actual PROMs or PREMs, in that they allow for true self-reporting by the service user and have been developed with direct service user involvement. At the same time, the psychometric development process has only been standardized in the last 15 years thanks mainly to specific initiatives, such as the COnsensus-based Standards for the selection of health Measurement INstruments

(COSMIN) initiative [4] (https://www.cosmin.nl/; see also **APPENDIX 1**: LINKS TO COSMIN GUIDELINES), the International Consortium for Health Outcomes Measurement (ICHOM) (http://www.ichom.org/), or the work published by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) [5, 6]. As such, it is paramount that PROMs and PREMs that are considered for use in clinical practice and/or research are selected based on a thorough evaluation of their psychometric properties to ensure that valid and reliable person-reported data are captured.

LifeChamps will heavily rely on the collection of PRO and PRE data. Therefore, identification of psychometrically robust PROMs and PREMs to enable accuracy in data collection has been a key part of the early developmental work of Work Package 2 (WP2), specifically assigned to Task 2.3, which is the focus of the current report.

3 AIM & RESEARCH QUESTIONS

3.1 AIM

The aim of Task 2.3 is to identify existing psychometrically robust PROMs and PREMs for subsequent use in WP5 and WP7 in line with their respective objectives. WP5 and WP7 focus on monitoring health-related quality of life (HRQoL) against gold standards to allow for the development of innovative ways to assess frailty in older cancer survivors that can lead to personalisation of health services and gains in patient HRQoL.

To address the aim of Task 2.3, we set out the following research questions.

3.2 RESEARCH QUESTIONS

Research Question 1	What PROMs and PREMs currently exist that target PROs and PREs in the fields of cancer care (breast, prostate, melanoma/skin; any cancer), geriatrics and geriatric oncology?
Research Question 2	What are the reported psychometric properties of such PROMs and PREMs, including measures of content and construct validity; internal consistency reliability, stability, and responsiveness to change?

4 METHODS

4.1 SEARCH STRATEGY

A systematic search strategy was developed in consultation with an academic librarian at UofG. Searches were run separately in the following databases:

- MEDLINE (accessed via Ovid),

- Cochrane Library, and
- Google Scholar.

The PROQOLID® database (https://eprovide.mapi-trust.org/) that houses several patient-related measures was also searched for additional measures and articles. Reference lists of all included articles were examined. Indicative search terms used for each database can be found in **APPENDIX 2**: Example Searches.

Searches were limited to international research published in the English language. Eligible studies had to be published between January 1999 and March 2020 to retrieve the most up-to-date evidence.

Studies and PROMs/PREMs included in previously published literature reviews were also considered for inclusion after applying our eligibility criteria.

4.2 ELIGIBILITY CRITERIA

Explicit, research-question-driven eligibility criteria were set out, informed by the COSMIN initiative guidelines for the selection of PROMs [4] (see also **APPENDIX 1**: LINKS TO COSMIN GUIDELINES).

4.2.1 INCLUSION CRITERIA

- Studies concerned with development/testing/implementation of a PROM or PREM (i.e. developed with direct patient input *and* developed as a self-reported measure).
- Studies developing/testing/implementing a PROM to specifically measure any PROs or PREs (either as a whole or as sub-domain/subscale) as outlined in **Table 1**.
- Studies developing/testing/implementing PROMs/PREMs for use in:
    - Geriatrics - this includes PROMs/PREMs: for older patients (≥65 years of age) irrespective of whether they have cancer or not; or for family caregivers/relatives of older patients.
    - Cancer care - this includes PROMs/PREMs: for patients with breast cancer, prostate cancer, or melanoma/skin cancers; or for generic use in cancer; or for family caregivers/relatives of older patients.
- Studies aiming to evaluate one or more psychometric properties and/or interpretability (distribution of scores, missing items, floor/ceiling effects, change scores) of the PROM/PREM under development.
- Original studies or literature reviews. Where a literature review is available for any PROs/PREs as outlined in **Table 1**, then this will form the main source of PROMs/PREMs. No additional original studies will be sought for the years covered by the literature review in question. However, additional original studies will still be sought for the period between review publication and current date (i.e. 2020).

4.2.2 EXCLUSION CRITERIA

- Studies that are not concerned with PROM/PREM development/testing/implementation (includes studies that are concerned with development/testing of an outcome measure which is not a PROM/PREM).
- Studies that develop a PROM/PREM that includes only individual items on example PROs/PREs as outlined in **Table 1**, i.e. items don't form a validated sub-domain/subscale.
- PROMs/PREMs developed for a specific cancer type that is not breast, prostate, or skin/melanoma - applies to PROMs/PREMs for patients and family caregivers/relatives.
- Studies that use the PROM/PREM only to measure its target PROs/PREs (e.g. observational studies or randomised controlled trials).
- Studies that use a PROM/PREM to validate another instrument.
- Studies concerned with development/testing of a PROM/PREM in languages other than English.
- Grey literature, commentaries, opinion papers.

4.3 SCREENING AND STUDY SELECTION

Retrieved records were transferred to Endnote® reference management software (http://endnote.com/) and de-duplicated, before they were screened on the basis of title and abstract. The screening process was the responsibility of all Task 2.3 partners. UofG divided up the retrieved records and distributed to Task 2.3 partners to enable initiation of the screening process.

Retained records were accessed in full-text and further screened against our eligibility criteria. UofG coordinated the relevant procedures with Task 2.3 partner participation until the final sample of studies was retrieved for indicative PROs/PREs outlined in **Table 1**.

Four pairs of screeners were created among the partners involved. Screeners indicated likely eligibility or not of their allocated records by choosing one of four options: include, unsure include, unsure exclude, exclude. For analysis purposes and to allow easier interpretation, the four categories were collapsed into two mutually exclusive ones, include/unsure include (1) and exclude/unsure exclude (2). Where disagreement in ratings was noted, UofG reviewed the records involved and made a final decision according to inclusion and exclusion criteria.

Inter-rater agreement was quantified by calculating percentage agreement [7], Cohen's kappa [8] and a prevalence-adjusted bias-adjusted Cohen's kappa (PABAK) [9]. The PABAK accounted for two problems. The first problem is the prevalence problem, which appears when the marginal distributions of observed ratings fall under one category of ratings at a much higher rate over another; this typically causes Cohen's kappa to be unrepresentatively low. The second problem is the bias problem, which appears

when the marginal distributions of specific ratings are substantially different between raters; this typically causes Cohen's kappa to be unrepresentatively high [10]. Interpretation of all Cohen's kappa and PABAK estimates was based on guidance by McHugh (2012) [7] and as per **Table 3**.

Value of Kappa	Level of Agreement	% of Data that are Reliable
0–0.20	None	0–4%
0.21–0.39	Minimal	4–15%
0.40–0.59	Weak	15–35%
0.60–0.79	Moderate	35–63%
0.80–0.90	Strong	64–81%
>0.90	Almost Perfect	82–100%

TABLE 3 INTERPRETATION OF KAPPA ESTIMATES

4.4 DATA MANAGEMENT AND EXTRACTION

Data from the final sample of studies was extracted onto a bespoke data extraction form created for this rapid review and inserted into an Excel spreadsheet for ease of use. Studies were further clustered per PRO/PRE.

The data extraction was performed by all Task 2.3 partners, who were allocated specific PROs/PREs. Task 2.3 partners extracted information about the PROMs/PREMs and their properties, and returned feedback to UofG to collate for the final report.

The data extraction was in line with RQ1 and RQ2 to generate information on PROM/PREM content, user-friendliness and psychometric robustness. The following areas were covered:

- Focus area (PROM or PREM)
- Target PRO or PRE
- Target field (oncology or geriatrics or geriatric oncology)
- Target population (patient or family/caregiver)
- Number of items
- Recall period
- Validation for online distribution
- Dimensionality and scoring
- Availability of translations in Greek, Spanish and Swedish (English was assumed to be the default development language)
- Process to obtain permission to use
- Psychometric robustness as per COSMIN initiative guidance (see **APPENDIX 3**: Definitions of KEY PSYCHOMETRIC TERMS for definitions of these terms):
    - Reliability - Internal consistency and stability
    - Content validity
    - Construct validity
    - Responsiveness to change.

Psychometric robustness was rated as sufficient (+), insufficient (–) or indeterminate (?) as per COSMIN initiative guidance [4]. See **Appendix 4.** Definitions of psychometric robustness ratings for definitions of these ratings.

4.5 DATA SYNTHESIS AND RECOMMENDATIONS

All evidence was integrated in a thematic narrative synthesis that generated summaries of key PROM/PREM elements, content domains and psychometric properties for further consideration.

To select, shortlist and recommend PROMs and PREMs for inclusion in a core measures set, we were informed by the COSMIN initiative's practical guideline on selecting outcome measures [11] and frameworks developed by van der Wees et al. [12] and the International Society for Quality of Life Research (ISOQOL) [13]. According to COSMIN guidance [11], developers of a core measures set must:

(1) Provisionally include a measure if there is at least high-quality evidence (defined as "consistent findings in multiple studies of at least good quality OR in one study of excellent quality AND a total sample size of 100 patients or more") for:
    - Good content validity (defined as "a (+) rating according to the criteria for good measurement properties) and
    - Good internal consistency (or evidence for test-retest or interrater reliability; defined as "a (+) rating according to the criteria for good measurement properties) and
    - If the measure is feasible, considering the measure's length, completion time, administration mode and translation availability, and the patient's comprehensibility and mental ability [14] that relate to recall period or timeframe. According to current guidance, selection of suitable measures must consider reducing respondent burden, which often is a function of measure length and comprehensibility of content [12]. Although lengthy measures have been considered problematic for use in clinical practice [15], there is no specific recommendation as to what is considered 'lengthy'. For our purposes, we considered measures as being 'very short' (1-5 items), 'short' (6-15 items), 'moderately long' (16-30 items), 'long' (31-45 items) and 'very long' (46+ items). For two or more measures with similar psychometric properties and other feasibility features, we favoured the shorter measures for use in a geriatric population. In relation to recall period, we have followed guidance developed by the ISOQOL in that "more recent recall periods more accurately capture patients' actual outcomes and experiences, although short reference periods may require more frequent assessments" [16]. Shorter recall periods (7 days or less) were generally favoured in our selection of PROMs/PREMs.

(2) Select only one measure for each outcome (i.e., constructs or domains).
    - For the purposes of D2.3, we shortlisted more than one measure per outcome to provide alternative options for consideration in a subsequent consultation with stakeholders; however, measures considered 'most suitable' and measures considered as 'alternative options' were indicated separately per target outcome/experience to allow for easier reference.

(3) Use a consensus procedure to get final agreement on the selected measures among relevant stakeholders, including patients [11].

4.6 TIMELINES

The total duration of Task 2.3 was 12 months, with rapid review procedures requiring about 6 months of work. Timelines attached to Task 2.3 are as per **Figure 1** below.

ACTIVITY	START	END	DURATION
Preparatory work	**1**	**3**	**3**
Task 2.3 activities protocol	1	3	3
Rapid review activities	**1**	**18**	**18**
Database searches (UofG)	4	4	1
Records screening & selection (all 2.3 partners)	5	5	1
Data extraction per PRO/PRE area (all 2.3 partners)	6	7	2
Data synthesis (UofG)	8	9	2
Final report writing-up (UofG with all 2.3 partners)	10	12	3
D2.3 report delivery	12	12	1

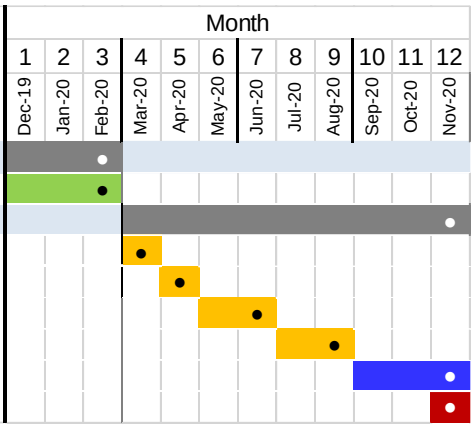


FIGURE 1 PROJECTED TIMELINES FOR TASK 2.3

5 RESULTS

5.1 RESULTS OF THE ELECTRONIC SEARCHES

The initial searches returned 4,146 articles, which were screened for eligibility based on title. Of these, 1,394 articles were subsequently shortlisted and further screened based on abstract. Of these, 575 articles were considered for full-text evaluation, and 467 were retained and included in the final sample. **Figure 2** presents a PRISMA flow diagram [17] that details all screening and selection activities.

The final sample of articles comprised both original studies (n=414) and literature reviews (n=53). Careful consideration of the measures resulted in 407 measures retained for analysis and evidence synthesis. Most of the measures in the final sample were PROMs (n=357; 87.7%).

Overall interrater percentage agreement was 77%, ranging from 70%-83% across the four pairs (**Table 4**). The corresponding Cohen's kappa estimates were considerably low. The overall Cohen kappa was 0.31, indicating only minimal level of agreement. Across pairs, Cohen kappa estimates ranged from 0.23 (minimal agreement) to 0.42 (weak agreement). Correcting for prevalence and bias problems, all PABAK estimates were more favourable compared to Cohen's kappa estimates. The overall PABAK was 0.54, indicating weak agreement. PABAK estimates across groups ranged from 0.39 (minimal agreement) to 0.66 (moderate agreement).

	Percentage agreement	Cohen's kappa	PABAK
Pair 1	76%	0.31	0.52
Pair 2	83%	0.37	0.66
Pair 3	70%	0.23	0.39
Pair 4	80%	0.42	0.60
Overall	77%	0.31	0.54

Notes:
PABAK - prevalence-adjusted bias-adjusted Cohen's kappa.
Estimate interpretation: 0–0.20 (no agreement); 0.21–0.39 (minimal agreement); 0.40–0.59 (weak agreement); 0.60–0.79 (moderate agreement); 0.80–0.90 (strong agreement); >0.90 (almost perfect agreement).

TABLE 4 PERCENTAGE AGREEMENT, COHEN'S KAPPA AND PABAK ESTIMATES

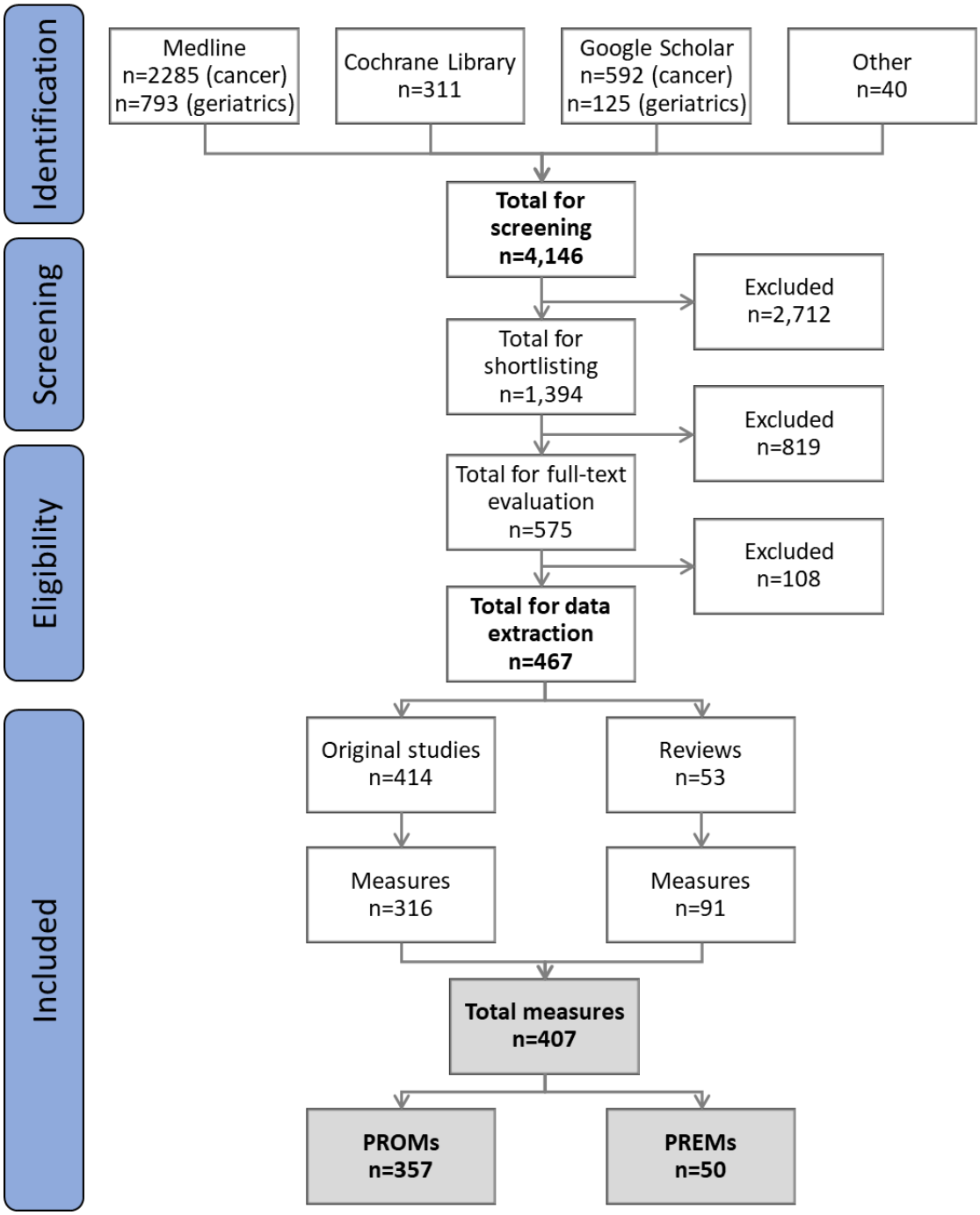


FIGURE 2 PRISMA FLOW DIAGRAM OF SEARCH RESULTS AND SELECTION PROCESS (ADAPTED FROM MOHER ET AL. 2009 [17])

5.2 THE PROMS/PREMS DATASET

The data extraction form was created in MS Excel with a view to host extracted data on PROMs and PREMs akin a searchable dataset, also harnessing Excel's filter function for individual columns. The final dataset comprises three parts, 35 columns and 408 rows in total, and contains just over 14,000 entries.

The three parts in the final dataset are as follows:

- Part A. Bibliographic information of shortlisted PROMs/PREMs and papers
- Part B. Basic characteristics of shortlisted PROMs/PREMs
- Part C. Psychometric properties of shortlisted PROMs/PREMs.

See **Appendix 5**: SCREENSHOTS OF the PROMs/PREMs DataSET for example screenshots of the three parts.

The goal is for the dataset to be a 'live' document that is regularly updated as new information comes through about existing PROMs/PREMs or about newly developed/adapted ones. Therefore, the current version is expected to be updated both during and after the lifetime of this project.

The 'live' dataset will be uploaded onto the LifeChamps website and become publicly available for consultation by the scientific community on top of serving its purpose within the LifeChamps project.

5.3 ANALYSIS OF PROMS WITH RECOMMENDATIONS

Of the 357 PROMs identified, 227 (63.6%) were developed or adapted for primary use in oncology, while the remaining 130 (36.4%) were geriatrics-specific PROMs.

Of the 227 PROMs developed or adapted for use in oncology, 145 PROMs (64%) were not cancer type specific and 82 PROMs (36%) were cancer type specific. The breakdown of cancer type specific PROMs was as follows:

- Breast cancer specific PROMs (n=38)
- Prostate cancer specific PROMs (n=34)
- Skin cancer specific PROMs (n=10).

The 357 identified PROMs covered a wide range of target PROs, which are highlighted in **Table 5**, separately for oncology PROMs, geriatrics PROMs and geriatric oncology PROMs. Unsurprisingly, oncology PROMs mainly target symptom burden and HRQoL/well-being, whereas the main targets for geriatrics PROMs are HRQoL/well-being and physical activity.

Target PRO (alphabetical order)	n Oncology PROMs (Total=227)	n Geriatrics PROMs (Total=130)	n Geriatric oncology PROMs (Total=12)[d]
Body image / sexual functioning	10	-	-
Cognitive decline	3	3	-
Emotional / psychological responses	32	13	4
• Fear of cancer recurrence	4	-	-
• Depression	6	11	3
• Anxiety	3	-	-
• Anxiety and depression	4	-	1
• Other	15	2	-
Falls propensity and risk	-	8	-
Frailty	-	7	1
Functional status / dependency	4	12	1
HRQoL / Well-being	56[a]	20	1
Multimorbidity burden	-	1	-
Nutritional status / cachexia	4	4	1
Healthcare needs	13[b]	2[c]	-
Physical activity / ability / mobility	11	29	1
Polypharmacy	-	3	-
Social isolation	3	6	1
Symptom burden/distress	78	9	-
• Multisymptom burden	28	3	-
• Fatigue	26[e]	-	-
• CINV	2	-	-
• CIPN	5	-	-
• Pain	7	1	-
• Sleep	3[e]	1	-
• Appetite and oral health	2	-	-
• Anaemia	1	-	-
• Diarrhoea	1	-	-
• Dyspnoea	1	-	-
• Treatment toxicity	3	-	-
• Dysphagia	-	1	-
• Nocturia	-	2	-
• Sarcopenia	-	1	-
Other PROs	13[c,f]	13[g]	2[h]

Notes:
CINV - Chemotherapy-induced nausea and vomiting; CIPN - Chemotherapy-induced peripheral neuropathy.
**Darker shading indicates higher frequency.*
[a] Includes 6 PROMs developed for family members / informal caregivers.
[b] Includes 4 PROMs developed for family members / informal caregivers.
[c] Includes 1 PROM developed for family members / informal caregivers.
[d] Included in the total oncology PROMs and total geriatrics PROMs.
[e] Includes one PROM that assesses both sleep and fatigue (PROMIS-S/F #283)
[f] Attitudes towards cancer diagnosis; Self-efficacy; Health Literacy; Health state / Utility; Geriatric assessment; Skin self-examination; Financial distress; Impact of cancer on life; Parenting.

[g] *Self-efficacy; Acceptance; Occupational competence; Sense of coherence; Mortality; Resourcefulness; Illness behaviour; Hearing loss/ability; Will to live; Geriatric assessment; Health utility / status.*
[h] *Geriatric assessment.*

TABLE 5 BREAKDOWN OF TARGET PROS PER CLINICAL FIELD (ONCOLOGY V. GERIATRICS V. GERIATRIC ONCOLOGY)

Tables in sections 5.3.1 and 5.3.2 highlight PROMs that have been categorised according to their development for use in oncology and geriatric populations, respectively, and by target outcome. Tables in sections 5.3.3 and 5.3.4 highlight PROMs that have been developed for family/informal caregivers and geriatric oncology, respectively.

Within each table, those PROMs highlighted in blue are those that have been identified and rated as 'most suitable', i.e. they have the most robust psychometric properties, availability in most or all four target languages (English, Greek, Spanish and Swedish), availability in electronic format, length most likely to promote completion of the measure (generally, the shorter the better), and a short recall period most compatible with retention/recall of the participant. Alternative PROMs (but with less favourable properties) are highlighted in light blue.

5.3.1 ONCOLOGY SPECIFIC PROMS BY TARGET PRO AND CANCER TYPE

5.3.1.1 Multisymptom burden/distress

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#028	BSI-18	Any	18	7d	Yes	Yes	No	Yes	No	+	?	?	?	?
#074	ESAS-r	Any	10	Now	No	Yes	No	Yes	Yes	+	+	+	+	+
#444	FLIC	Any	22	2w	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#457	CCM	Any	42	Now	Yes	Yes	No	No	No	+	+	+	+	?
#173	MDASI	Any	26	24h	Yes	Yes	No	Yes	Yes	?	?	+	?	?
#479	MUDI	Any	27	Now	No	Yes	No	No	No	+	+	+	?	+
#522	RSCL	Any	30	1w	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#523	SDS	Any	13	Lately	No	Yes	No	Yes	Yes	+	+	+	?	?
#022	BCTOS-12	BC	12	Now	No	Yes	No	No	No	+	+	+	?	?
#024	BCTRI	BC	27	Now	No	Yes	No	No	No	+	?	-	?	?
#115	NFBSI-16	BC	16	7d	No	Yes	No	No	No	+	?	+	+	?
#174	MDASI-BCM	BC	21	24h	No	Yes	No	No	No	?	?	?	?	?
#087	EORTC PR25	PC	25	7d	No	Yes	Yes	Yes	Yes	+	+	-	-	?
#098	FAPSI-8	PC	8	7d	Yes	Yes	Yes	Yes	Yes	+	-	+	?	+
#175	MDASI-PC	PC	19	24h	No	Yes	No	No	No	?	+	+	+	+
#465	PCSISDS	PC	46	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#468	PSSR	PC	11	Now	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#471	RSSSA-PC	PC	48	Now	No	Yes	No	Yes	Yes	-	-	?	+	?

#472	UCLA-PCI	PC	20	Now	No	Yes	No	Yes	No	+	+	+	+	+
#473	DALE	PC	32	Now	No	Yes	No	No	No	+	+	+	?	?
#474	CLARK	PC	29	Now	No	Yes	No	No	No	+	+	+	?	?
#475	EPIC CP	PC	16	Now	No	Yes	No	Yes	Yes	+	+	+	?	?
#476	ESCAP-CDV	PC	36	Now	No	Yes	No	No	No	+	+	+	?	?
#477	FACT-P	PC	12	Now	Yes	Yes	Yes	Yes	Yes	+	+	-	?	+
#480	NCCN/FACT-P SI-17	PC	17	Now	No	Yes	Yes	Yes	Yes	-	-	+	?	?
#482	PSM	PC	36	Now	No	Yes	No	No	No	+	+	+	?	?
#485	QII	PC	19	Now	No	Yes	No	No	No	+	+	+	?	?
#487	STAR	PC	15	Now	Yes	Yes	No	No	No	+	+	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 6 BREAKDOWN OF 28 PROMS FOR MULTISYMPTOM BURDEN

Analysis: Twenty-eight PROMs were identified that targeted multisymptom burden; 8 were cancer generic, 4 targeted breast cancer and 16 targeted prostate cancer. Wide variability in language provision is noted with only three PROMs (#098, #468 and #477) available in all four target languages. Six PROMs (#028, #098, #173, #457, #477 and #487) offer online availability.

The strongest cancer generic measure is the ESAS-r (#074), offering excellent across the board psychometric robustness, short question length (10 questions) and is conducted within the present time. The questionnaire is available in English, Spanish and Swedish. The FLIC (#444) also has good psychometric properties except for responsiveness to change. The FLIC is relatively short (22 questions) with a 2-week recall and is available in all 4 languages. Additionally, the SDS (#523) has strong content and construct validity, relatively good language availability and a short timeframe for recall.

Of the breast cancer specific PROMs, the BCTOS-12 (#022) is the strongest PROM, with strong construct and content validity and short length (12 questions). Alternatively, the NFBSI-16 (#115) can be considered, mainly due to good content validity and reliability measures and a short length.

Of the prostate cancer specific PROMs, the PSSR (#468) and the UCLA-PCI (#472) offer the best combination of characteristics, although no electronic version is available for the PSSR (#468) and no evidence on stability and responsiveness. Alternatively, a few other PROMs can be considered, particularly the FACT-P (#477) and the FAPSI-8 (#098) if a longer recall is required (past 7 days). The remaining highlighted PROMs offer less robust psychometric evaluation.

Recommendation for use: Cancer generic: **#074**, followed by #444 and #523. Breast cancer specific: **#022**. Prostate cancer specific: **#468 or #472**, followed by #098 and #477.

5.3.1.2 Fatigue / Cancer-related fatigue (CRF)

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#084	EORTC QLQ-FA	Any	12	7d	No	Yes	No	Yes	Yes	?	?	-	?	-
#106	FSI	Any	14	7d	No	Yes	No	No	Yes	+	+	+	-	?
#152	IPQ-CRF	Any	58	24h	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#192	MFI-20	Any	20	Now	No	Yes	No	No	No	?	?	+	?	?
#193	MFSI-SF	Any	30	Now	No	Yes	No	No	No	?	+	+	+	?
#268	PP-CRF	Any	12	Now	No	Yes	No	Yes	No	?	?	+	+	?
#280	PROMIS-S/F	Any	13	Now	Yes	Yes	No	No	No	+	?	?	?	?
#284	PQ	Any	13	2w	No	Yes	No	No	No	+	+	+	?	?
#320	SCFS	Any	28	NS	No	Yes	No	No	No	+	?	?	?	?
#325	SMSFS-A	Any	17	1w	No	Yes	No	No	No	?	?	?	?	?
#369	WCFS	Any	16	24h	No	Yes	No	No	No	+	+	+	?	?
#374	BFI	Any	9	24h	Yes	Yes	Yes	No	No	+	+	+	?	?
#378	FSS	Any	9	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	+	-
#379	FIB-72	Any	72	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	?	?
#380	LFS	Any	18	Now	Yes	Yes	No	No	No	-	+	+	?	+
#381	MAF	Any	16	Now	Yes	Yes	No	No	Yes	+	+	+	?	?
#383	HCFS	Any	15	Now	No	Yes	No	No	No	+	+	+	+	?
#440	PFS-R	Any	22	Now	No	Yes	Yes	Yes	Yes	+	?	+	?	?
#384	CRFDS	Any	20	Now	Yes	Yes	No	No	No	+	+	+	?	?
#441	FACIT-F	Any	13	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#499	GFS	Any	7	NS	No	Yes	Yes	No	No	+	+	+	+	?
#502	SOFI	Any	25	Now	No	Yes	No	Yes	Yes	+	+	+	?	?
#045	CRFAI	BC	22	Now	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#287	PFS-R	BC	40	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#377	FAS	BC	10	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	+	-
#382	CFS	BC	15	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	+	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 7 BREAKDOWN OF 26 PROMS FOR FATIGUE

Analysis: Twenty-six PROMs targeted fatigue, four of which were breast cancer specific targeted. Of the cancer generic PROMs, the FSS (#378), the HCFS (#383), the FACIT-F (#441) and the GFS (#499) offer the most robust psychometric measures, although responsiveness was not ascertained in any of these measures. Within these measures, length ranged between 9-15 questions, with time frame for recall placed at 'present time'. Only the FSS (#378) and the FACIT-F (#441) are available in all four target languages, while the FSS (#378) is also available in electronic format. The MAF (#381) can also be considered as a short alternative that is available in electronic format.

Of the breast cancer specific PROMs, the FAS (#377) is the best match across the range of criteria, followed by the CFS (#382).

Recommendation for use: Cancer generic: **#378**, followed by #441. Breast cancer specific: **#377**, followed by **#382**.

5.3.1.3 Chemotherapy-induced nausea and vomiting (CINV)

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#171	MAT	Any	8	12-24h	No	Yes	No	Yes	No	+	?	?	?	?
#443	INVR	Any	8	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 8 BREAKDOWN OF 2 PROMS FOR CINV

Analysis: Only two PROMs were found that targeted CINV. Psychometric properties of the MAT (#171) were deemed indeterminate based on current data available. The INVR (#443) is a short measure (8 questions) that assesses CINV in the present time, with robust psychometric properties (except for responsiveness to change) and is available in all four target languages.

Recommendation for use: **#443**.

5.3.1.4 Chemotherapy-induced peripheral neuropathy (CIPN)

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#053	CIPNAT	Any	64	CTx start	No	Yes	No	No	No	+	+	+	?	?
#061	CAS-CIPN	Any	15	7d	No	Yes	No	No	No	+	+	+	?	?
#079	EORTC QLQ-CIPN20	Any	20	7d	No	Yes	No	No	No	+	+	+	+	?
#261	CIPN-R-ODS	Any	28	Now	No	Yes	Yes	Yes	No	?	+	+	+	?

#354	TNAS	Any	13	Now	No	Yes	No	Yes	No	+	?	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; CTx - Chemotherapy. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 9 BREAKDOWN OF 5 PROMS FOR CIPN

Analysis: Five cancer generic PROMs for CIPN were identified. The EORTC QLQ-CIPN20 (#079) has solid psychometric measures, is relatively short with 20 questions and has a 1-week recall period. The CAS-CIPN (#061) is relatively shorter and also has reasonable psychometric measures, although no data is available on stability or responsiveness to change. The CIPN-R-ODS has good psychometric properties (although content validity is unclear) and is available in most target languages (except for Swedish) but it can be considered lengthy.

Recommendation for use: **#079**.

5.3.1.5 Pain

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#019	BAT	Any	14	7d	No	Yes	No	Yes	No	+	+	-	+	?
#016	BQ-27	Any	13	Now	No	Yes	No	No	No	+	+	-	-	-
#039	CPI	Any	19	Now	No	Yes	No	No	No	+	+	?	?	?
#060	CPIndex	Any	4	1d	No	Yes	No	No	No	+	+	-	+	+
#279	PROMIS-Pain	Any	10	7d	Yes	Yes	No	Yes	No	+	+	+	+	+
#435	BPI	Any	9	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	+	?
#436	MPQ	Any	78	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 10 BREAKDOWN OF 7 PROMS FOR PAIN

Analysis: All seven PROMs for pain are cancer generic. Length ranges from 4 to 78 items, although most PROMs comprise fewer than 20 items (BPI #435 and CPIndex #060: <10 items). Use of the MPQ (#436; 78 items) can be highly impractical. Recall period for most PROMs is either 'present time' or 'past 7 days'. Electronic versions are available for the PROMIS-Pain (#279) and BPI (#435) only. Wide variability in language availability is noted, with the BPI (#435) and MPQ (#436) being the only two PROMs

available in all four target languages. Content and construct validity have been established for all PROMs. Internal consistency and stability have only been established for 3 and 4 PROMs, respectively, while responsiveness to change is confirmed for only the CPIndex (#060) and PROMIS-Pain (#279).

***Recommendation for use:* #435,** followed by **#279** and **#060**.

5.3.1.6 Sleep

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#280	PROMIS-S/F	Any	13	Now	Yes	Yes	No	No	No	+	?	?	?	?
#288	PSQI	Any	19	4w	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#442	ISI	Any	7	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 11 BREAKDOWN OF 3 PROMS FOR SLEEP

Analysis: Of the three cancer generic measures identified, the PSQI (#288) and the ISI (#442) both have robust psychometric properties (although no data on responsiveness to change for the ISI). The PSQI (#288) assesses overall sleep quality, whereas the ISI (#442) specifically targets insomnia. Both PROMs are of adequate length, however the recall period of the PSQI (#288) at 4 weeks may increase the risk of recall/memory bias. Both PROMs are available in all four target languages.

***Recommendation for use:* #442** (for insomnia) or **#288** (for overall sleep quality).

5.3.1.7 Appetite and Oral health

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#031	CASQ	Any	12	2d	No	Yes	No	No	No	+	?	+	?	?
#092	EORTC QLQ-OH17	Any	17	7d	No	Yes	Yes	Yes	Yes	+	?	-	+	-

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 12 BREAKDOWN OF 2 PROMS FOR APPETITE AND ORAL HEALTH

Analysis: The CASQ (#031) assesses appetite, while the EORTC QLQ-OH17 (#092) measures overall oral health. Although content validity has been established for both PROMs, they both present gaps regarding all other psychometric properties. There is no electronic version available for either PROM, although the EORTC QLQ-OH17 (#092) is available in all target languages.

Recommendation for use: Nil - If use is necessary, use with caution.

5.3.1.8 Anaemia

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#009	AIM	Any	38	7d	Yes	Yes	No	No	No	+	?	?	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 13 BREAKDOWN OF 1 PROM FOR ANAEMIA

Analysis: Only the AIM (#009) was identified to assess anaemia. Poor psychometric data, no availability in any language other than English, and being moderately lengthy (38 questions) render use of this PROM potentially problematic.

Recommendation for use: Nil - If use is necessary, use with caution.

5.3.1.9 Diarrhoea

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#348	STIDAT	Any	12	Now	No	Yes	No	No	No	+	+	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 14 BREAKDOWN OF 1 PROM FOR DIARRHOEA

Analysis: The STIDAT (#348) offers reasonable psychometric properties, although stability and responsiveness to change are yet to be confirmed. The PROM is available in English only, its short length (12 questions) and recall period (present time) make it potentially useful for ongoing assessments of diarrhoea.

***Recommendation for use:* #348**.

5.3.1.10 Dyspnoea

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#445	CDS	Any	12	Now	No	Yes	No	No	Yes	+	+	+	+	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 15 BREAKDOWN OF 1 PROM FOR DYSPNOEA

Analysis: The CDS (#445) is a generic cancer PROM of short length that measures dyspnoea in present time with very good psychometric properties, although responsiveness to change remains unknown.

***Recommendation for use:* #445**

5.3.1.11 Treatment toxicity

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#164	LENT/SOMA-Prostate	PC	28	NS	No	Yes	No	No	No	?	?	?	?	?
#295	PCRT	PC	29	4w	No	Yes	No	No	No	+	+	+	?	?
#483	LENT/SOMA	PC	41	Now	No	Yes	No	No	No	-	-	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 16 BREAKDOWN OF 3 PROMS FOR TREATMENT TOXICITY

Analysis: Three prostate cancer specific PROMs were identified that assess treatment toxicity with variable recall timeframes. Two PROMs have inadequate psychometric data. Only the PCRT (#295) has been relatively well validated for use in the radiotherapy setting and is at the limit in terms of acceptable length, although it has a recall period of a month which may be too long.

Recommendation for use: Nil - If use is necessary, use with caution.

5.3.1.12 Patient HRQoL

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#121	FACT-G	Any	27	7d	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#122	FACT-G7	Any	7	7d	No	Yes	Yes	Yes	Yes	+	+	-	+	+
#125	FACIT-PAL14	Any	14	7d	No	Yes	No	Yes	No	+	+	-	?	?
#138	HF-QOL	Any	38	NS	No	Yes	No	No	No	+	+	+	?	+
#139	HSF-14	Any	14	Daily	No	Yes	No	No	No	+	?	+	-	?
#153	IOCv2	Any	50	NS	No	Yes	No	No	No	+	+	+	?	?
#054	CCEQ	Any	75	NS	No	Yes	No	No	No	+	+	+	+	?
#062	COST	Any	11	7d	No	Yes	No	No	No	+	+	+	?	?
#071	DIC-2	Any	33	NS	No	Yes	No	No	No	+	+	-	?	+
#088	EORTC QLQ-ELD15	Any	14	7d	No	Yes	Yes	Yes	Yes	+	-	-	-	-

#090	EORTC QLQ-C30	Any	30	NS	Yes	Yes	Yes	Yes	Yes	?	+	?	?	-
#176	MYCaW	Any	9	Now	No	Yes	No	No	No	+	?	?	?	?
#267	PGI	Any	18	Now	No	Yes	No	No	No	?	?	?	?	?
#305	PSSCAN	Any	21	60d	No	Yes	No	No	No	+	+	+	+	?
#331	SF-36	Any	36	4w	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#334	SF-12v2	Any	12	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#417	LASA	Any	5	1w	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#458	FACT-BRM	Any	17	Now	No	Yes	Yes	Yes	No	+	+	+	?	?
#460	HFS-14	Any	14	Now	No	Yes	No	No	No	+	+	+	?	?
#495	CPILS	Any	29	5y	No	Yes	No	No	No	+	+	+	-	-
#498	QoL-CS	Any	41	Now	No	Yes	No	Yes	No	?	-	+	+	-
#025	BREAST-Q	BC	216	2w	Yes	Yes	No	Yes	Yes	+	+	+	+	?
#081	EORTC QLQ-BR23	BC	23	7d	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#117	FACT-B	BC	37	NS	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#118	FACT-B+4	BC	40	7d	Yes	Yes	No	Yes	No	+	+	+	+	+
#168	LTQOL-BC	BC	28	20y	No	Yes	No	No	No	?	?	?	?	?
#249	BREAST-Q-NSS	BC	14	Now	No	Yes	No	No	No	?	?	?	?	?
#306	QLACS	BC	47	6m	No	Yes	No	No	No	+	+	+	-	?
#307	QOL-BCS-15	BC	15	Now	No	Yes	No	No	No	-	-	-	-	?
#318	SLDS-BC	BC	92	10d	No	Yes	No	No	No	+	?	+	+	?
#359	ULL QLQ	BC	14	2w	No	Yes	No	No	No	+	+	+	+	+
#415	ULDQ	BC	80	Now	No	Yes	No	No	No	?	?	?	?	-
#416	WINGATE	BC	10	Now	No	Yes	No	No	No	?	?	?	?	+
#123	FACT-P	PC	39	7d	No	Yes	Yes	Yes	Yes	+	+	+	?	+
#075	EPCLQ	PC	36	NS	No	Yes	No	No	No	+	+	+	+	+
#096	EPIC-26	PC	26	1m	No	Yes	No	Yes	No	+	-	-	+	+
#296	PROSQOLI	PC	11	24h	No	Yes	No	No	No	?	?	?	?	+
#297	PCSS	PC	18	Now	Yes	Yes	No	No	No	+	+	+	+	+
#357	ULCA-PCI	PC	20	Now	No	Yes	No	No	No	?	?	?	?	?
#462	EORTC QLQ-PR25	PC	25	Now	No	Yes	Yes	Yes	Yes	+	+	-	?	?
#463	IPSS	PC	7	Now	No	Yes	No	Yes	Yes	-	-	?	?	?
#464	PC-QOL	PC	52	Now	No	Yes	No	Yes	No	+	+	+	+	?
#467	PCTO-Q	PC	44	Now	No	Yes	No	No	No	-	-	?	+	?
#097	FACE-Q SCM	SC	56	7d	Yes	Yes	No	Yes	No	+	+	+	+	+
#408	Skindex-29	SC	29	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#409	DLQI	SC	10	1w	Yes	Yes	Yes	Yes	Yes	+	+	+	+	?
#410	DQOLS	SC	41	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#116	FACT-M	SC	51	NS	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#423	SCQoL	SC	9	Now	No	Yes	Yes	Yes	Yes	+	+	-	?	+
#337	SCQOLIT	SC	10	7d	No	Yes	No	No	No	+	+	+	+	+

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 17 BREAKDOWN OF 50 PROMS FOR HRQOL

Analysis: Fifty PROMs were identified that assess HRQoL and/or well-being. Twenty-one were cancer generic, 12 were breast cancer specific, 10 prostate cancer specific, and 8 skin cancer specific. PROM length varied widely from 1 to 216 items.

Among the cancer generic PROMs, the FACT-G (#121), the FACT-G7 (#122), the SF-36 (#331), the SF12v2 (#334) and the LASA (#417) were the best validated ones, with availability in all four target languages. The FACT-G7 (#122), the SF12v2 (#334) and the LASA (#417) were the shortest PROMs (<15 items). Recall period varied, however a shorter timeframe of 7 days or less would be more favourable for ongoing assessment.

Of the breast cancer specific PROMs, the EORTC QLQ-BR23 (#081), the FACT-B (#117), the FACT-B+4 (#118) and the ULL QLQ (#359) emerged as the best validated ones. The EORTC QLQ-BR23 (#081) and the FACT-B (#117) are also available in all target languages. The ULL QLQ (#359) is the shortest PROM (14 items), however is only available in English. The EORTC QLQ-BR23 (#081) is relatively short (23 items).

Of the prostate cancer specific PROMs, the EPCLQ (#075), the PCSS (#297) and the PC-QOL (#464) have good psychometric data (although only English versions exist), followed by the EORTC QLQ-PR25 (#462) and the FACT-P (#123). The PCSS (#297) and the EORTC QLQ-PR25 (#462) are of reasonable length (25 items or fewer). While the PCSS (#297) is available in electronic format, it is only available in English. The opposite is true for the EORTC QLQ-PR25 (#462).

Of the skin cancer specific PROMs, the DLQI (#409) fits all criteria (including availability in electronic format), followed by the Skindex-29 (#408) and the SCQoL (#423). These three PROMs are short (or relatively short), thus enhancing uptake by patients.

Recommendation for use: Cancer generic: **#122 or #334 or #417**, followed by #121 and #331. Breast cancer specific: **#081**, followed by #117 and #359. Prostate cancer specific: **#297**, followed by #462. Skin cancer specific: **#409**, followed by #408 and #423.

5.3.1.13 Functional status / dependency

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#366	WHO-DAS	Any	36	30d	No	Yes	Yes	Yes	Yes	?	+	+	+	+
#434	SIP	Any	136	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#277	PROMIS-PF	Any	10	7d	Yes	Yes	No	Yes	No	+	+	+	+	+
#170	Lymph-ICF DK	BC	29	Now	No	Yes	No	No	No	+	?	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 18 BREAKDOWN OF 4 PROMS FOR FUNCTIONAL STATUS / DEPENDENCY

Analysis: Four PROMs were found that assess functional status and/or dependency, three cancer generic and one breast cancer specific. Of these, only the Lymph-ICF DK (#170) has questionable psychometric properties. The SIP (#434) is rather lengthy, although it is available in all four target languages. The WHO-DAS (#366) and the PROMIS-PF (#277) have reasonable psychometric data, although content validity of the former is unclear. The PROMIS-PF (#277) has a 7-day recall period (compared to 30 days for the WHO-DAS), while it is the only available in electronic format.

***Recommendation for use:* #277**, followed by #366.

5.3.1.14 Nutritional status / Cachexia

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#029	CAS	Any	13	2w	No	Yes	No	No	No	+	?	+	+	+
#073	EAT-10	Any	10	NS	Yes	Yes	Yes	Yes	Yes	+	+	+	+	+
#083	EORTC QLQ-CAX24	Any	14	7d	No	Yes	No	No	No	?	?	-	-	?
#114	A/CS-12	Any	2	NS	No	Yes	No	No	No	+	?	+	?	+

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 19 BREAKDOWN OF 4 PROMS FOR NUTRITIONAL STATUS / CACHEXIA

Analysis: Four cancer generic PROMs were found that assess a patient's nutritional status, of which only one (EAT-10, #073) is brief (10 items), has robust psychometric data and is available in all languages.

***Recommendation for use:* #073**

5.3.1.15 Fear of cancer recurrence

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#044	CWS	Any	6	Now	Yes	Yes	No	Yes	No	+	+	+	?	?
#108	FCRI-SF	Any	9	NS	No	Yes	No	No	No	+	+	+	+	?
#063	CARS	BC	30	NS	No	Yes	No	No	No	+	+	+	-	?
#315	IPQ-BCS	BC	35	18d	No	Yes	No	No	No	+	+	+	+	?
Notes: *BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.*														

TABLE 20 BREAKDOWN OF 4 PROMS FOR FEAR OF CANCER RECURRENCE

Analysis: Two cancer generic and two breast cancer specific PROMs were identified that assess fear of cancer recurrence. Availability of translated versions is poor across all four PROMs. The CWS (#044) is the shortest cancer generic PROM, also available in electronic format, although evidence on stability and responsiveness to change is lacking. The FCRI-SF (#108) is slightly longer (9 items) and is well validated.

The breast cancer specific PROMs are overall reasonably validated (particularly the IPQ-BCS, #315), however they both are quite lengthy (30/35 questions).

Recommendation for use: Cancer generic: **#044**, followed by #108. Breast cancer specific: Nil - If use is necessary, use with caution.

5.3.1.16 Depression

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#451	CES-D	Any	20	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#517	BDI-SF	Any	13	1m	No	Yes	No	No	No	?	?	+	+	?
#518	BEDS	Any	6	7d	No	Yes	No	Yes	No	?	+	+	?	?
#520	MEQ	Any	33	Now	No	Yes	No	No	No	+	?	+	?	?
#521	POMS-SF	Any	37	1w	No	Yes	No	No	No	+	+	+	?	?
#421	POS-H/N	SC	15	Now	No	Yes	No	No	No	+	?	+	-	-
Notes:														

BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 21 BREAKDOWN OF 6 PROMS FOR DEPRESSION

Analysis: Six PROMs assessing depression were found, 5 of them being cancer generic. Only two cancer generic PROMs demonstrated sufficient psychometric validation, i.e. primarily the CES-D (#451) and secondarily the POMS-SF (#521). The latter is a moderately long PROM with 37 items and a 1-week recall period. The CES-D (#451) is available in all languages, is relatively short (20-items) and assesses depression in the present time. No PROM is available in electronic format.

Recommendation for use: Cancer generic: **#451**. Skin cancer: Nil - If use is necessary, use with caution.

5.3.1.17 Anxiety

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#450	STAI	Any	40	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#516	BAI	Any	21	1m	No	Yes	No	Yes	Yes	?	?	+	?	?
#179	MAX-PC	PC	18	1w	No	Yes	No	No	No	+	?	+	?	?

Notes:

BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 22 BREAKDOWN OF 3 PROMS FOR ANXIETY

Analysis: Two cancer generic PROMs and one prostate cancer specific PROM were found that assess anxiety. The STAI (#450) is the best validated PROM in this area, with a very short recall period and extensive language availability, albeit relatively long (40 items). However, the STAI consists of two subscales, one for trait anxiety (20 items) and one for state anxiety (20 items), which can be used separately depending on the nature of the inquiry.

Recommendation for use: **#450**

5.3.1.18 Anxiety and Depression

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#149	HADS	Any	14	NS	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#278	PROMIS-DAA	Any	86	7d	Yes	Yes	No	Yes	No	+	+	+	+	+
#332	PSYCH-6	Any	6	Now	No	Yes	No	No	No	+	?	+	+	?
#300	POT-BC	BC	14	7d	Yes	Yes	No	No	No	+	+	?	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 23 BREAKDOWN OF 4 PROMS FOR ANXIETY AND DEPRESSION

Analysis: Four PROMs were found that assess both anxiety and depression, three of which are cancer generic. The PROMIS-DAA (#278) has the most robust psychometric validation data, however it is quite lengthy which makes its use impractical. The HADS (#149) is relatively well validated and available in all four languages, with no specific recall period. The PSYCH-6 (#332) is the shortest PROM (6 items) with a very short recall period (present time) but only available in English.

The POT-BC (#300) is a relatively short PROM with a 1-week recall period and available in electronic format, however data on reliability and responsiveness to change is scarce.

Recommendation for use: Cancer generic: **#149**, followed by #332. Breast cancer specific: Nil - If use is necessary, use with caution.

5.3.1.19 Psychological responses

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#072	DT[1]	Any	1	7d	No	Yes	Yes	Yes	Yes	+	+	?	?	+
#078	ET[1]	Any	5	7d	No	Yes	Yes	Yes	Yes	+	+	?	?	+
#033	CBI-B[2]	Any	14	Now	No	Yes	No	No	No	+	+	+	?	?
#036	CCQ[2]	Any	21	2w	Yes	Yes	No	No	No	+	+	+	+	?
#455	WCQ[2]	Any	68	Now	Yes	Yes	No	Yes	Yes	?	+	?	-	?
#301	POST[3]	Any	65	1w	No	Yes	No	No	No	+	+	+	?	?
#302	PAIS-SR[3]	Any	46	30d	No	Yes	No	No	No	+	+	?	?	?

#519	IES-R[3]	Any	15	7d	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#184	MMACS[3]	Any	29	Now	No	Yes	Yes	No	No	?	?	+	+	?
#251	NEIS[3]	Any	15	Now	No	Yes	No	No	No	?	?	+	?	?
#453	MAC[3]	Any	40	Now	No	Yes	Yes	Yes	Yes	+	+	+	-	?
#185	MUIS-C[4]	Any	23	Now	No	Yes	No	Yes	Yes	?	+	+	?	?
#526	MUIS-SF[4]	Any	5	Now	No	Yes	No	Yes	Yes	?	+	+	+	?
#283	PSS[1]	BC	10	30d	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#304	PDQ-PC[3]	PC	38	Now	No	Yes	No	No	No	-	+	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs. 1 Stress or distress; 2 Coping; 3 Adjustment; 4 Uncertainty.

TABLE 24 BREAKDOWN OF 15 PROMS FOR PSYCHOLOGICAL RESPONSES

Analysis: Fifteen PROMs were identified targeting psychological responses; two PROMs were breast cancer specific, one was prostate cancer specific, while the rest were cancer generic PROMs. Psychological responses involved stress/distress, coping, adjustment or uncertainty.

The DT (#072) is the best cancer generic PROM for a rapid assessment of stress/distress, while it is available in all four target languages. The CCQ (#036) appears to be well-validated and it is available in electronic format, although a 2-week recall period increases the risk of recall bias. The IES-R (#519) is a short measure (15 items) of adjustment that has reasonable validity and reliability, and language availability. In terms of PROMs assessing uncertainty, the MUIS-SF (#526) can reasonably be deemed most adequate, although its content validity is questionable.

Regarding breast cancer specific PROMs, the PSS (#283) is a well-validated and easily applicable PROM of stress/distress. The PDQ-PC (#304) can be deemed relatively lengthy and with poor language availability, and its validity is yet to be confirmed.

Recommendation for use: Cancer generic: **#072** (stress distress), followed by #078. **#036** (coping). **#519** (adjustment). Breast cancer specific: **#283** (stress distress). Prostate cancer specific: Nil - If use is necessary, use with caution.

5.3.1.20 Social isolation

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#308	QRI	Any	22	90d	No	Yes	No	No	No	+	+	+	+	+
#339	SCS	Any	15	1m	No	Yes	Yes	No	No	?	+	+	+	?
#340	SDI-21	Any	21	Now	No	Yes	No	No	No	+	+	+	+	?

Notes:

BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 25 BREAKDOWN OF 3 PROMS FOR SOCIAL ISOLATION

Analysis: The SCS (#339) has questionable content validity and thus cannot be considered. The QRI (#308) is a proxy measure of social isolation that assesses a patient's quality of relationships. This PROM offers excellent psychometric data and is of good length (22 questions), but with a rather lengthy recall period of 3 months and available only in English. The SDI-21 (#340) is a short and direct measure of current social difficulties, with favourable psychometric properties and a very short recall timeframe.

***Recommendation for use:* #340**

5.3.1.21 Cognitive function / decline

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#120	FACT-Cog	Any	37	7d	Yes	Yes	No	Yes	Yes	+	+	+	?	?
#057	CSC-W21	BC	21	Now	Yes	Yes	No	No	No	+	+	+	?	?
#181	MCQ-30	BC, PC	30	Now	No	Yes	Yes	Yes	No	?	+	?	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 26 BREAKDOWN OF 3 PROMS FOR COGNITIVE FUNCTION / DECLINE

Analysis: The FACT-Cog (#120) offers reasonable psychometric validation data, although evidence on stability and responsiveness to change is lacking. With 37 questions and a 7-day recall period, the PROM can become burdensome for people with or at risk of cognitive decline, increasing the risk of recall bias.

The CSC-W21 (#057) is a good alternative to FACT-Cog, specifically for patients with breast cancer. With only 21 questions and a very short recall timeframe, this PROM can reliably measure cognitive functioning in this patient subgroup, although language availability is poor.

The MCQ-30 suffers from poor validation and a rather lengthy format.

Recommendation for use: Cancer generic: Nil - If use is necessary, use with caution. Breast cancer specific: **#057**.

5.3.1.22 Physical ability / activity

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#095	EBSE	Any	14	Now	No	Yes	No	No	No	+	+	+	+	?
#135	GSLTPAQ	Any	4	7d	No	Yes	No	No	No	+	?	?	+	?
#148	HLQ-Cancer	Any	18	NS	No	Yes	No	No	No	+	+	+	+	?
#159	IPAC-SF	Any	7	7d	No	Yes	Yes	Yes	Yes	?	?	?	?	?
#286	PASE	Any	12	7d	No	Yes	No	No	No	+	+	+	+	+
#290	PActS-W	Any	12	Now	No	Yes	No	No	No	+	+	+	?	?
#309	QuickDASH	BC	11	14d	No	Yes	No	No	No	+	+	+	+	+
#358	UEFI	BC	20	2w	No	Yes	No	No	No	?	?	?	+	?
#363	WHI-BPAQ	BC	9	7d	No	Yes	No	Yes	No	?	?	?	+	?
#412	DASH	BC	30	1w	Yes	Yes	Yes	Yes	Yes	?	+	+	?	+
#413	KAPS	BC	13	Now	No	Yes	No	Yes	No	?	?	?	?	-

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 27 BREAKDOWN OF 11 PROMS FOR PHYSICAL ABILITY / ACTIVITY

Analysis: Six cancer generic PROMs were found for patients to self-report physical ability or physical activity. Primarily the PASE (#286) and secondarily the EBSE (#095) and the HLQ-Cancer (#148) have been well validated, are of short length and offer a short recall period (7 days or less). No translations of these PROMs exist.

Of the breast cancer specific PROMs, only the QuickDASH (#309) appears to meet all criteria, with excellent psychometric measures, short length (11 items), and a recall period of 2 weeks. Of the remaining PROMs, the original DASH (#412) is well validated and available in all languages and in electronic format, but incomplete psychometric testing and length are barriers for use.

Recommendation for use: Cancer generic: **#286**, followed by #095 and #148. Breast cancer specific: **#309**, followed by #412.

5.3.1.23 Patient healthcare needs

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#037	CaNDI	Any	23	2w	Yes	Yes	No	No	No	+	+	+	+	?
#038	CNQ	Any	32	Now	Yes	Yes	No	No	No	+	+	+	?	?
#040	CARES	Any	139	Now	Yes	Yes	No	No	No	+	+	+	+	?
#041	CASUN	Any	43	1m	No	Yes	No	Yes	No	+	+	+	+	?
#248	NEQ	Any	25	Now	No	Yes	No	No	No	?	+	+	+	?
#271	PRRS	Any	29	7d	Yes	Yes	No	No	No	+	?	?	?	?
#345	SPUNS	Any	118	Now	No	Yes	No	No	No	+	+	+	+	?
#346	SCNS-SF34	Any	34	1m	No	Yes	Yes	Yes	No	+	+	+	?	?
#347	SNST	Any	40	Now	No	Yes	No	No	No	+	?	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 28 BREAKDOWN OF 9 PROMS FOR PATIENT HEALTHCARE NEEDS

Analysis: Patient healthcare needs refers to patient need for supportive care services to meet their physical, emotional, social, psychological, informational, spiritual and practical needs [18]. Several PROMs in this area have been well-validated (see #037, #040, #041, #345), although the nature of the PRO means that most measures are quite lengthy. Of note, no evidence on responsiveness to change is available for any of the nine PROMs. On balance, the CaNDI (#037) offers the best combination of psychometric properties and user-friendliness; the CaNDI (#037) has a recall timeframe of 2 weeks that can make information more relevant in repeated measurements. Alternatively, the longer SCNS-SF34 (#346) or the CASUN (#041) can be considered despite a relatively long recall period of 4 weeks.

Recommendation for use: **#037**, followed by #346 and #041.

5.3.1.24 Body image / sexual functioning

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#018	BIS[1]	Any	10	Now	No	Yes	Yes	Yes	No	+	+	+	+	?

#446	DISF-SR[2]	Any	26	Now	Yes	Yes	No	No	Yes	+	+	+	+	?
#447	SFQ[2]	Any	31	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	+	?
#448	IIEF-EF[2]	Any	15	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?
#017	BIBCQ[1]	BC	45	Now	No	Yes	No	No	No	+	+	+	+	?
#020	BCPCI[1]	BC	55	1w	No	Yes	No	No	No	+	?	?	?	?
#327	SABIS[1]	BC	28	Since Dx	No	Yes	No	No	No	?	+	+	+	?
#515	FSFI[2]	BC	32	4w	No	Yes	No	No	No	+	+	+	?	?
#328	SAQ[2]	PC	37	3m	No	Yes	No	No	No	?	?	+	+	?
#329	SDS[2]	PC	12	Now	No	Yes	No	No	No	?	?	+	+	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; Dx - Cancer diagnosis. "+"=sufficient, "–"=insufficient, "?"=indeterminate. 1 Body image; 2 Sexual functioning. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 29 BREAKDOWN OF 10 PROMS FOR BODY IMAGE / SEXUAL FUNCTIONING

Analysis: Ten PROMs were identified targeting body image or sexual functioning; five were breast cancer specific and two were prostate cancer specific. Four PROMs specifically targeted body image.

Of the four cancer generic PROMs, psychometric validation is very good on all measures with the exception of responsiveness to change. The BIS (#018) is a short measure of current body image changes. The DISF-SR (#446) and the SFQ (#447) can be used as relatively short, generic measures of sexual functioning, whereas the IIEF-EF (#448) is a measure of erectile dysfunction and thus relevant to male patients only.

Of the breast cancer specific PROMs, the BIBCQ (#017) has reasonable psychometric properties for the measurement of body image concerns, although its length can be problematic.

Both PROMs available for prostate cancer have mixed / poor psychometric validation, a wide recall period (present time to 3 months), and a range of questionnaire length (12-37 questions.

Recommendation for use: Cancer generic: **#018** (body image) **or #447** (sexual function), followed by #446. Breast cancer specific: Nil - If use is necessary, use with caution. Prostate cancer specific: Nil - If use is necessary, use with caution.

5.3.1.25 Other cancer PROs

Dataset ID	PROM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#032	CAI[1]	Any	41	Now	No	Yes	No	No	No	+	+	+	+	?
#058	CASE-cancer[2]	Any	12	Now	No	Yes	No	No	No	+	+	-	?	?

#429	PAM-18[2]	Any	18	Now	Yes	Yes	No	No	No	+	+	+	-	?
#142	HLCS-C[3]	Any	88	NS	No	Yes	No	No	No	+	?	?	?	?
#143	HLHO-10[3]	Any	10	NS	No	Yes	No	No	No	+	?	+	+	?
#093	EQ-5D-5L[4]	Any	6	Now	Yes	Yes	Yes	Yes	Yes	+	?	-	+	?
#317	SAKK C-SGA[5]	Any	20	Now	No	Yes	No	No	No	+	?	?	?	?
#385	PFW[7]	Any	10	Now	No	Yes	No	No	No	+	+	+	?	?
#264	PCQ[9]	Any	15	Now	No	Yes	No	No	No	?	?	+	?	?
#021	BCSES[2]	BC	14	Now	No	Yes	No	No	No	+	+	+	+	?
#494	BCIA[8]	BC	16	2y	Yes	Yes	Yes	No	No	+	+	+	-	-
#273	PORPUS[4]	PC	49	2w	No	Yes	No	No	No	+	+	?	?	?
#324	SE-SSE[6]	SC	5	Now	No	Yes	No	No	No	+	+	?	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs. 1 Attitudes towards cancer diagnosis; 2 Self-efficacy; 3 Health Literacy; 4 Health state / Utility; 5 Geriatric assessment; 6 Skin self-examination; 7 Financial distress; 8 Impact of cancer on life; 9 Parenting.

TABLE 30 BREAKDOWN OF 13 PROMS FOR OTHER CANCER PROS

Analysis: Thirteen PROMs were identified that target a wide range of other cancer-related PROs, including attitudes towards cancer diagnosis; self-efficacy; health literacy; health state/utility; geriatric assessment; skin self-examination; financial distress; impact of cancer on life; and parenting concerns. Four PROMs are cancer specific.

Of all PROMs, the CAI (#032) and the BCSES (#023) offer the best psychometrics, followed by the PFW (#385), the PAM-18 (#429) and the BCIA (#494). The CAI (#032) is a measure of patients' attitudes towards cancer, however it can be deemed as lengthy (41 items). The BCSES (#023) is a short measure of self-efficacy specifically for patients with breast cancer. The PAM-18 (#429) offers an alternative, cancer generic option for measuring self-efficacy, with the only caveat being unfavourable data on stability.

The PFW (#385) is a short measure of financial distress, applicable to any type of cancer. Despite being well-validated, the BCIA (#494) has a very long recall period (2 years) that render it impractical. Where health utility/status is the target PRO, the EQ-5D-5L (#093) offers a relatively good option. The same can be said for skin self-examination among patients with skin cancer (SE-SSE, #324).

Recommendation for use: Cancer generic: **#429** (self-efficacy), followed by #032 (attitudes towards cancer diagnosis), #093 (health state/utility), #385 (financial distress). Breast cancer: #021 (self-efficacy). Skin cancer: #324 (skin self-examination).

5.3.2 GERIATRICS SPECIFIC PROMS BY TARGET PRO

5.3.2.1 Physical activity / physical ability / mobility

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#003	ACSort	82	Now	No	Yes	No	No	No	+	?	?	?	?
#007	ASCQ	22	Now	No	Yes	No	No	No	+	+	+	+	?
#052	CHAMPS PAQ	41	1m	No	Yes	No	Yes	No	+	+	?	+	?
#067	DEMMI	15	Now	Yes	Yes	No	No	No	+	+	?	?	?
#127	GMF	21	NS	No	Yes	No	No	Yes	+	+	-	+	?
#137	Hand 10	10	1w	No	Yes	No	No	No	+	+	+	+	+
#150	HAP	94	NS	No	Yes	No	No	No	?	+	+	+	?
#157	IFIS	5	NS	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#158	IPAQ-E	27	7d	No	Yes	Yes	Yes	Yes	+	+	?	+	?
#166	LSA	9	7d	No	Yes	No	No	No	?	+	+	?	?
#169	LSCS	56	Now	No	Yes	No	No	No	+	+	+	?	?
#186	MAT-W	104	7d	No	Yes	No	No	No	?	+	?	?	?
#189	mGES	10	Now	No	Yes	No	No	No	?	+	+	+	?
#257	OEE	9	Now	No	Yes	No	No	No	?	+	+	+	?
#294	PPFV	1	7d	No	Yes	No	No	No	+	?	?	?	?
#312	RAPA	9	7d	No	Yes	No	No	No	-	?	?	?	?
#323	SASE	17	NS	No	Yes	No	No	Yes	+	?	+	+	?
#335	SPADI	13	3m	No	Yes	No	No	No	?	+	?	?	+
#349	TSE	19	Now	No	Yes	No	No	No	+	+	+	?	?
#350	TAPA	12	1w	No	Yes	No	No	No	?	?	?	?	?
#362	VADL	28	Now	No	Yes	No	No	No	?	?	?	+	?
#370	YPAS	41	1m	No	Yes	No	Yes	No	?	?	?	+	?
#373	ICECAP-O	5	Now	No	Yes	No	Yes	Yes	+	+	+	?	?
#387	7 Day Recall PAR	7	1w	No	Yes	Yes	Yes	Yes	+	+	?	?	?
#388	MBQ	21	12m	No	Yes	Yes	Yes	Yes	+	+	?	+	?
#400	SBAS	2	1d	No	Yes	No	Yes	Yes	-	-	?	-	?
#403	IPAQ-LF	27	7d	No	Yes	Yes	Yes	Yes	?	+	+	?	?
#404	AEOP	43	1m	No	Yes	No	No	No	+	+	+	+	?
#405	IPEQ	10	1w	No	Yes	No	No	No	+	+	+	+	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 31 BREAKDOWN OF 29 PROMS FOR GERIATRIC PHYSICAL ACTIVITY / ABILITY / MOBILITY

Analysis: Twenty-nine geriatric PROMs were identified that assess physical activity / ability / mobility. In terms of psychometric robustness, the Hand 10 (#137) and the IFIS (#157) have been fully validated, followed by ASCQ (#007), the AEOP (#404) and the IPEQ (#405). The ICECAP-O (#373) and the IPAQ-E (#158) also are well-validated

measures of physical capability and physical activity, respectively. PROM length and recall period vary widely across PROMs.

Recommendation for use: Physical ability: **#157 or #137**, followed by #373, #007 and #349. Physical activity/mobility: **#405 or #158**, followed by #404.

5.3.2.2 HRQoL

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#027	OPQOL-brief	13	Now	No	Yes	No	No	No	+	+	+	?	?
#066	CASP-19	19	NS	Yes	Yes	Yes	Yes	Yes	+	+	+	+	?
#077	EQOLI	139	NS	No	Yes	No	No	No	+	?	?	?	?
#109	FS	8	NS	No	Yes	Yes	Yes	No	+	+	+	-	?
#111	FHSQ	13	7d	Yes	Yes	No	Yes	No	+	+	+	+	+
#141	HELP-Screener	15	NS	Yes	Yes	No	Yes	No	?	?	-	+	?
#147	IHEAR-IT	73	NS	No	Yes	No	No	No	+	+	+	?	?
#160	ICECAP-O	5	Now	No	Yes	No	Yes	Yes	+	?	?	-	?
#180	MENQOL	29	1m	No	Yes	Yes	Yes	No	?	+	?	?	?
#252	NHP	38	Now	No	Yes	Yes	Yes	Yes	?	+	+	?	?
#262	OTC-MIS	12	Now	No	Yes	No	No	No	?	+	+	+	?
#292	PU-QOL	87	1w	No	Yes	Yes	No	No	+	-	?	?	?
#310	QuiLL	27	2w	No	Yes	No	No	No	+	+	+	?	+
#361	VEINES-QOL	26	Now	No	Yes	No	No	Yes	?	+	+	+	+
#364	WHO-5	5	Now	No	Yes	No	No	No	?	?	+	?	?
#367	WHOQOL-OLD	24	Now	No	Yes	No	No	No	?	?	+	?	?
#368	WHOQOL-BREF	26	Now	No	Yes	No	No	No	?	+	+	+	?
#397	SF-8	8	Now	Yes	Yes	Yes	Yes	Yes	+	+	?	+	+
#513	AQoL-8D	35	1w	No	Yes	No	Yes	No	+	+	+	?	?
#514	QWB	76	3d	Yes	Yes	No	Yes	Yes	+	-	+	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 32 BREAKDOWN OF 20 PROMS FOR HRQOL

Analysis: Twenty PROMs were found that evaluate HRQoL in older people. The FHSQ (#111) and the VEINES-QOL (#361) have robust psychometric properties, although they target HRQoL that is condition-specific (i.e. foot health and deep vein thrombosis, respectively) rather than global. Of the PROMs that evaluate global HRQoL, the CASP-19 (#066) and the SF-8 (#397) are short in length, have good psychometric properties and a very short recall timeframe, and are available in electronic format and across the target languages. Alternatively, the QuiLL (#310), the OPQOL-brief (#027) and the

AQoL-8D (#513) can be considered, with less favourable psychometric properties and longer recall periods.

***Recommendation for use:* #066 or #397**, followed by #310, #027, #513, #111 or #361.

5.3.2.3 Functional status / dependency

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#001	ADL-4	4	Now	No	Yes	No	No	No	?	?	+	?	?
#004	AlphaFIM	18	Now	No	Yes	No	No	No	+	+	+	+	?
#011	ASAS-R	15	Now	No	Yes	No	No	Yes	+	+	-	-	?
#094	ECQ	17	Now	No	Yes	No	No	No	+	+	+	+	?
#112	FEFA	19	Now	No	Yes	No	No	No	+	+	?	+	+
#113	FSES	13	NS	No	Yes	No	No	No	?	?	+	?	?
#126	GADL	13	NS	No	Yes	No	No	No	+	+	+	+	?
#134	GALI	1	6m	No	Yes	No	No	No	+	+	?	+	?
#145	HRA-E	269	NS	Yes	Yes	No	No	No	+	?	?	+	?
#165	Lawton IADL	8	Now, 6m	No	Yes	No	Yes	No	+	+	+	?	+
#391	IADL	22	Now	No	Yes	No	Yes	No	+	+	+	?	?
#492	SPQ	21	1y	No	Yes	No	No	No	?	?	?	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 33 BREAKDOWN OF 12 PROMS FOR FUNCTIONAL STATUS / DEPENDENCY

Analysis: Twelve PROMs were identified that targeted functional status / dependency. The GADL (#126), the ECQ (#094) and the AlphaFIM (#004) have good psychometric validation, with measure length ranging between 13 and 18 questions, and a very short recall period. Alternatively, the Lawton IADL (#165), the FEFA (#112) and the IADL (#391) can be considered, which are also available in Spanish. Across PROMs, availability in electronic format was rather poor.

***Recommendation for use:* #126 or #094 or #004**, followed by #165, #112 and #391.

5.3.2.4 Depression / psychological responses

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#056	CISD[2]	29	NS	No	Yes	No	No	No	+	+	+	+	?
#128	GAD-7[1]	7	2w	No	Yes	No	Yes	Yes	+	+	+	+	?
#129	GAI[1]	20	NS	No	Yes	Yes	Yes	Yes	+	+	+	+	+
#130	GAI-SF[1]	5	NS	No	Yes	Yes	Yes	Yes	+	+	+	?	+
#132	GHS[1]	30	NS	No	Yes	No	No	No	?	+	-	-	?
#289	Positive VOL[1]	17	Now	No	Yes	No	No	No	?	?	?	?	?
#321	SRQ-20[1]	20	Now	No	Yes	Yes	Yes	Yes	+	+	?	-	?
#371	ZSDS[1]	20	Now	No	Yes	Yes	Yes	No	?	?	?	?	?
#399	PHQ-9[1]	9	Now	No	Yes	Yes	No	Yes	+	+	+	+	+
#426	GDS-30[1]	30	Now	No	Yes	Yes	Yes	Yes	+	-	+	-	?
#493	BDI[1]	21	2w	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#489	GHQ-60[2]	60	Now	No	Yes	Yes	Yes	Yes	+	+	?	?	?
#528	GDS-15[1]	15	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs. 1 Depression; 2 Psychological responses.

TABLE 34 BREAKDOWN OF 13 PROMS FOR DEPRESSION / PSYCHOLOGICAL RESPONSES

Analysis: Of the thirteen PROMs that target depression/psychological responses, only two assess psychological responses (distress): the CISD (#056) and the GHQ-60 (#489). The CISD (#056) offers a better combination of psychometric and design characteristics, although it can still be considered moderately long (29 items).

Of the PROMs that assess depression, the PHQ-9 (#399), the GAI-SF (#130) and the GAD-7 (#128) are very short and well-validated measures. Of them, the GAI-SF (#130) additionally offers a combination of short recall period and language availability. Additionally, the GDS-15 (#528), the GAI (#129) and the BDI (#493) can be used for a more comprehensive assessment.

Recommendation for use: Depression: **#399 or #130 or #128**, followed by #528, #129 and #493. Psychological responses: Nil - If use is necessary, use with caution.

5.3.2.5 Symptom burden

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#012	ASPE[1]	40	7d	No	Yes	No	No	No	+	?	?	?	+
#070	DBMA[1]	21	NS	No	Yes	No	No	No	+	-	?	?	?
#398	CMSAS[1]	14	Now	No	Yes	No	No	No	+	+	+	?	?
#172	MISA-DK[2]	43	Now	No	Yes	No	No	No	?	+	+	?	?
#250	NNES-Q[3]	12	Now	No	Yes	No	No	No	?	+	?	+	?
#260	OAB-q[3]	33	7d	No	Yes	Yes	Yes	Yes	?	+	+	+	+
#263	PACSLAC[4]	60	Now	No	Yes	No	No	No	?	+	+	+	?
#274	SarcoPRO[5]	14	7d	No	Yes	No	No	No	+	?	?	?	?
#276	PROMIS SDS[6]	6	7d	No	Yes	No	No	No	+	+	+	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs. 1 Multisymptom burden; 2 Dysphagia; 3 Nocturia; 4 Pain; 5 Sarcopenia; 6 Sleep.

TABLE 35 BREAKDOWN OF 9 PROMS FOR SYMPTOM BURDEN

Analysis: Nine PROMs were identified that assess symptom burden, all with varying degrees of psychometric validation. Of the three PROMs assessing multisymptom burden, the CMSAS (#398) is brief, with good psychometric properties and a short recall timeframe. Of the symptom specific PROMs, only the PROMIS SDS (#276) can be considered for patient self-reporting of sleep disturbance. Language availability and electronic format availability was rather poor across the group.

Recommendation for use: Multisymptom burden: **#398**. Symptom specific: **#276** (sleep).

5.3.2.6 Frailty

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#055	CFS	12	1m	No	Yes	Yes	Yes	Yes	+	+	?	+	+
#107	FRAIL scale	5	1m	No	Yes	No	Yes	No	+	+	?	?	?
#136	GFI	15	NS	No	Yes	No	No	No	+	+	-	?	?
#188	mFI	14	Now	No	Yes	No	No	No	?	?	?	?	?
#293	PRISMA-7	7	Now	No	Yes	No	Yes	No	+	+	?	?	+

#343	Strawbridge Q	16	Now	No	Yes	No	No	No	?	?	?	?	?
#406	TFI	25	Now	No	Yes	No	No	No	+	+	+	+	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 36 BREAKDOWN OF 7 PROMS FOR FRAILTY

Analysis: Of the seven frailty-specific PROMs, the CFS (#055) and the TFI (#406) have been most extensively validated. The TFI (#406) comprises 25 items, which might increase respondent burden. The CFS (#055) has a relatively long recall period (past month), which can increase recall bias. Alternatively, the PRISMA-7 (#293) can be used for rapid frailty assessments with a very short recall timeframe. No PROM is available in electronic format, and language availability is scarce.

Recommendation for use: **#055 or #293**, followed by #406.

5.3.2.7 Falls propensity / risk

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#002	ABC	6	Now	No	Yes	Yes	Yes	No	+	+	+	+	?
#099	FRB&PS	20	1y	No	Yes	No	No	No	?	?	-	?	?
#100	FRQ	12	6m, now	No	Yes	No	No	No	+	+	-	?	-
#101	FES-I	16	Now	Yes	Yes	Yes	Yes	Yes	+	+	+	+	+
#102	FRAQ	28	NS	No	Yes	No	No	No	+	+	+	+	?
#131	GFFM	15	NS	No	Yes	No	No	No	+	+	+	+	?
#187	MFES	14	12m	No	Yes	No	No	No	?	+	?	?	?
#407	CTI	44	Now	No	Yes	No	No	No	+	+	+	-	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 37 BREAKDOWN OF 8 PROMS FOR FALLS PROPENSITY / RISK

Analysis: The FES-I (#101) is ideal to assess falls risk. It displays excellent psychometric validation, is of short duration (16 questions) and is available in all four target languages and in electronic format. Alternative PROMs, in ascending order of length, include the ABC (#002), the GFFM (#131) and the FRAQ (#102), which also reflect strong psychometric validation. All four PROMs have a recall period in the present time.

Recommendation for use: **#101**, followed by #002, #131 and #102.

5.3.2.8 Social isolation / support / adjustment

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#059	CCS	12	NS	No	Yes	No	No	No	+	+	-	?	?
#155	IESS	20	6m	No	Yes	No	No	No	+	+	+	?	?
#178	MOS-SSS	19	NS	No	Yes	No	Yes	No	+	+	+	?	?
#190	MLSNS	12	Now	Yes	Yes	No	No	No	?	?	+	+	?
#341	SEQ	24	2w	No	Yes	No	No	No	?	?	+	+	?
#342	SPRQ	53	Now	No	Yes	No	No	No	?	+	?	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 38 BREAKDOWN OF 6 PROMS FOR SOCIAL ISOLATION

Analysis: Psychometric validation of PROMs that target social isolation is overall moderate-to-poor. The only two PROMs that seem to offer good psychometric properties are the IESS (#155) and the MOS-SSS (#178), both of which are relatively brief (~20 questions). Compared to the MOS-SSS (#178) which assesses social isolation in the present time, the IESS (#155) has a rather long recall period which potentially renders it impractical for frequent repeated measurement.

***Recommendation for use:* #178**

5.3.2.9 Nutritional status

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#110	FFQ	110	1m/y	No	Yes	Yes	Yes	Yes	+	?	?	+	?
#182	MNA	18	Now	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#183	MNA-SFs	6	Now	No	Yes	Yes	Yes	Yes	+	?	+	?	?
#336	SNAQ	4	Now	No	Yes	Yes	Yes	No	+	+	+	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 39 BREAKDOWN OF 4 PROMS FOR NUTRITIONAL STATUS

Analysis: The SNAQ (#336) and the MNA (#182) have good evidence of psychometric validation to assess nutritional status. The MNA-SFs (#183) derives from the MNA (#182) and, despite poorer validation, can be considered for rapid nutritional assessments instead of the SNAQ (#336). No PROM is available in electronic format; however, language availability is very good.

Recommendation for use: **#336**, followed by #183 and #182.

5.3.2.10 Polypharmacy

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#316	rPATD	14	NS	No	Yes	No	No	No	+	+	+	+	?
#427	BMQ	18	Now	No	Yes	No	No	No	+	+	+	+	?
#527	MedUseQ	24	3m	No	Yes	No	No	No	+	+	+	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 40 BREAKDOWN OF 3 PROMS FOR POLYPHARMACY

Analysis: Of the three PROMs targeting polypharmacy, the rPATD (#316) and the BMQ (#427) are brief, with strong psychometric properties (except for responsiveness to change) and a short recall period. The MedUseQ (#527) is more comprehensive but has slightly weaker psychometric properties and a longer recall timeframe. All three PROMs are only available in English.

Recommendation for use: **#316 or #427**

5.3.2.11 Other geriatric PROs

Dataset ID	PROM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness

#030	CANE[2]	5	Now	No	Yes	No	No	No	?	?	?	?	?
#051	CRES[3]	49	Now	No	Yes	No	No	No	+	+	+	?	?
#151	IALHP[4]	20	NS	No	Yes	No	No	No	?	?	?	?	?
#253	OSA[5]	21	Now	Yes	Yes	Yes	No	No	?	+	?	?	?
#256	OLQ-11[6]	11	Now	No	Yes	Yes	Yes	Yes	?	?	+	+	?
#275	PROMPT[7]	30	4w	No	Yes	No	No	No	+	+	+	+	?
#314	RSOA[8]	28	NS	No	Yes	No	No	No	+	+	+	?	?
#319	SAIB[9]	25	NS	No	Yes	No	No	No	?	+	?	?	?
#333	HHIE-S[10]	1	Now	No	Yes	No	No	No	+	?	?	?	?
#365	WTL[11]	5	Now	No	Yes	No	No	No	?	+	+	+	?
#394	VES-13[12]	13	NS	No	Yes	No	No	No	+	+	+	+	+
#372	ASCOT[13]	8	Now	No	Yes	No	No	No	+	+	+	?	?
#146	HUI2[13]	7	NS	No	Yes	Yes	Yes	Yes	+	?	?	?	?
#512	HUI3[13]	8	Now	No	Yes	Yes	Yes	Yes	+	+	+	?	+
#529	MTBQ[14]	10	Now	No	Yes	No	No	No	+	+	+	?	+

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs. 1 Amotivation towards exercise; 2 Healthcare needs; 3 Self-efficacy; 4 Acceptance; 5 Occupational competence; 6 Sense of coherence; 7 Mortality; 8 Resourcefulness; 9 Illness behaviour; 10 Hearing loss/ability; 11 Will to live; 12 Geriatric assessment; 13 Health utility / status; 14 Multimorbidity burden.

TABLE 41 BREAKDOWN OF 15 PROMS FOR OTHER GERIATRIC PROS

Analysis: Fifteen PROMs were identified that target a wide range of other geriatric PROs. The VES-13 (#394) has excellent psychometric properties that allow for a quick geriatric assessment. The CRES (#051) and the PROMPT (#275) are well-validated measures of self-efficacy and perceived mortality, respectively, however can be deemed lengthy. The RSOA (#314) is a measure of resourcefulness with reasonable psychometric properties, albeit again lengthy for a geriatric population. The HUI3 (#512) is a preferences-based, brief and well-validated measure of health utility that can be effectively used in health economic evaluations of different interventions to estimate quality adjusted life years. Finally, the MTBQ (#529) is a brief measure of multimorbidity burden, with a very good psychometric profile.

Recommendation: Geriatric assessment: **#394**. Health utility: **#512**; Multimorbidity burden: **#529**.

5.3.3 PROMS FOR CAREGIVERS BY CLINICAL AREA AND TARGET PRO

The vast majority of PROMs were developed for use by patients. However, 13 PROMs (3%) specifically targeted outcomes of family members or informal caregivers (**Table 42**), mainly of patients with cancer (n=12).

Dataset ID	PROM Acronym	Target field	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#010	ACS[1]	Cancer	27	Now	No	Yes	No	No	No	+	+	-	?	?
#015	BCOS[2]	Cancer	15	NS	No	Yes	Yes	No	No	+	+	+	+	+
#176	MYCaW[2]	Cancer	9	Now	No	Yes	No	No	No	+	?	?	?	?
#042	CaSPUN[3]	Cancer	42	1m	No	Yes	No	No	No	+	+	+	-	?
#047	CarGOQoL[3]	Cancer	29	1m	Yes	Yes	No	No	No	+	+	+	+	?
#048	CQOLC[3]	Cancer	35	1w	No	Yes	No	Yes	No	+	+	+	+	+
#049	CRAS[4]	Cancer	24	Now	No	Yes	No	Yes	Yes	+	?	+	?	?
#050	CRRS[4]	Cancer	41	Now	Yes	Yes	No	No	No	+	+	+	+	+
#104	FCFI[5]	Geriatrics	25	NS	No	Yes	No	No	No	+	+	-	?	?
#105	FIN[5]	Cancer	20	Now	No	Yes	No	No	No	+	+	+	-	?
#524	HCNS[5]	Cancer	90	Now	No	Yes	No	No	No	+	+	+	?	?
#525	NAFC-C[5]	Cancer	27	Now	No	Yes	No	No	No	-	+	-	?	?
#142	HLCS-C[6]	Cancer	88	NS	No	Yes	No	No	No	+	?	?	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs. 1 Psychological responses-coping; 2 Caregiver's quality of life / well-being; 3 Caregiver's quality of life; 4 Caregiver's well-being; 5 Caregiver's needs; 6 Caregiver's health literacy.

TABLE 42 THE 13 PROMS DEVELOPED FOR USE BY FAMILY MEMBERS OR CAREGIVERS

Analysis: The 13 PROMs identified for use by family members or caregivers targeted psychological responses (coping), quality of life / well-being, healthcare needs, and health literacy. Psychometric validation is good for some PROMs, however, regardless of target PRO, most PROMs are quite long. One exception is the BCOS (#015) which is fully validated to measure caregivers' quality of life / well-being. For a more comprehensive assessment of the same PRO, the CRRS (#050) can offer the same level of psychometric validation. In terms of healthcare needs, the FIN (#105) can be used for reliable assessments without being burdensome to the respondent (20 items). Language availability is rather poor across the group.

Recommendation for use: Quality of life / well-being: **#015**, followed by #050. Healthcare needs: **#105**.

5.3.4 PROMS FOR USE IN GERIATRIC ONCOLOGY

Twelve PROMs (3%) were found that were developed or adapted for use in geriatric oncology (**Table 43**). The main target areas of these PROMs were:

- Health-related quality of life (HRQoL), activities of daily living (ADL) or instrumental ADL (IADL) (n=2),
- Depression (n=4),
- Frailty (n=1),
- Social support (n=1),
- Nutritional status (n=1),
- Physical activity (n=1),
- Onco-geriatric assessment (n=1), and
- Multimorbidity burden (n=1).

Dataset ID	PROM Acronym	Target field	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#088	EORTC QLQ-ELD15[1]	Cancer	14	7d	No	Yes	Yes	Yes	Yes	+	-	-	-	-
#391	IADL[2]	Geriatrics	22	Now	No	Yes	Yes	Yes	No	+	+	+	?	?
#136	GFI[3]	Geriatrics	15	NS	No	Yes	No	No	No	+	+	-	?	?
#178	MOS-SSS[4]	Geriatrics	19	NS	No	Yes	No	Yes	No	+	+	+	?	?
#182	MNA[5]	Geriatrics	18	Now	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#286	PASE[6]	Cancer	12	7d	No	Yes	No	No	No	+	+	+	+	+
#317	SAKK C-SGA[7]	Cancer	20	Now	No	Yes	No	No	No	+	?	?	?	?
#394	VES-13[7]	Geriatrics	13	24m	No	Yes	No	No	No	+	+	+	+	+
#149	HADS[8]	Cancer	14	NS	No	Yes	Yes	Yes	Yes	+	+	+	?	?
#399	PHQ-9[9]	Geriatrics	9	Now	No	Yes	Yes	No	Yes	+	+	+	+	+
#426	GDS-30[9]	Cancer	30	Now	No	Yes	Yes	Yes	Yes	-	-	-	-	?
#451	CES-D[9]	Cancer	20	Now	No	Yes	Yes	Yes	Yes	+	+	+	+	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs. 1 Quality of life / well-being in older people; 2 Functional status / dependency; 3 Frailty; 4 Social isolation; 5 Nutritional status; 6 Physical activity; 7 Geriatric assessment; 8 Depression/anxiety; 9 Depression.

TABLE 43 THE 12 PROMS DEVELOPED / ADAPTED FOR USE IN GERIATRIC ONCOLOGY

Analysis: As per previous analysis, the PHQ-9 (#399) (target area: geriatrics) and the CES-D (#451) (target area: oncology) have a strong psychometric profile, with the CES-D (#451) being available in all four languages. Equally, the HADS (#149) can be used for a combined assessment of depression and anxiety as necessary, offering similarly psychometric properties. The VES-13 (#394) offers an excellent validated option for geriatric assessments. The PASE (#286) is a strong self-reported measure of physical activity in geriatric oncology. The MOS-SSS (#178), the MNA (#182) and the IADL (#391) are good candidates for the assessment of social isolation, nutritional status and functional status, respectively. Full language availability is noted for the MNA (#182), the HADS (#149) and the CES-D (#451).

***Recommendations for use:* #149, #178, #286, #394, #399, #451**, followed by #182 and #391.

5.4 ANALYSIS OF PREMS WITH RECOMMENDATIONS

Of the 50 PREMs identified, 34 (68%) were developed or adapted for primary use in oncology, while the remaining 16 (32%) were geriatrics specific PREMs. No PREMs were found specifically developed or adapted for use in geriatric oncology.

Of the 34 PREMs developed or adapted for use in oncology, 28 PREMs (82%) were generic measures and 6 PREMs (18%) were cancer type specific. The breakdown of cancer type specific PREMs was as follows:

- Breast cancer specific PREMs (n=1)
- Prostate cancer specific PREMs (n=5).

No PREMs specific to the experiences of patients with skin cancer were found.

The 50 identified PREMs covered a wide range of target PREs, which are highlighted in **Table 44**, separately for oncology and geriatrics PREMs. The main target area for both oncology and geriatrics PREMs was quality of care environment. The second most frequent target area for oncology PREMs was patient centredness of care services. Care process co-ordination was another popular target area irrespective of clinical field.

Target PRE (alphabetical order)	n Oncology PREMs (Total=34)	n Geriatrics PREMs (Total=16)
Care process co-ordination / continuity	6[a]	3[a]
Patient-clinician communication	6	-
Patient centredness / empowerment in care services	7	3
Preferences of goals of care	2	2
Quality of care / satisfaction with care	13	5
Other	-	2
Notes: **Darker shading indicates higher frequency.* *[a] Includes one PREM developed for family/informal caregivers.*		

TABLE 44 BREAKDOWN OF TARGET PRES PER CLINICAL FIELD (ONCOLOGY V. GERIATRICS)

Tables in sections 5.4.1 and 5.4.2 highlight PREMs that have been categorised according to their development for use in oncology and geriatric populations, respectively, and by target outcome. The table in section 5.4.3 highlight PREMs that have been developed for family/informal caregivers.

Within each table, those PREMs highlighted in blue are those that have been identified and rated as 'most suitable', i.e. they have the most robust psychometric properties, availability in most or all four target languages (English, Greek, Spanish and Swedish),

availability in electronic format, length most likely to promote completion of the measure (generally, the shorter the better), and a short recall period most compatible with retention/recall of the participant. Alternative PREMs (but with less favourable properties) are highlighted in light blue.

5.4.1 ONCOLOGY PREMS BY TARGET PRE AND CANCER TYPE

5.4.1.1 Quality of care / satisfaction with care

Dataset ID	PREM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#043	CTSQ	Any	16	1m	No	Yes	Yes	Yes	Yes	+	+	+	-	?
#080	EORTC IN-PATSAT32	Any	32	NS	No	Yes	No	Yes	Yes	+	+	+	+	?
#086	EORTC QLQ-SAT32	Any	32	NS	No	Yes	No	Yes	Yes	?	?	?	-	?
#124	FACIT TS	Any	29	NS	No	Yes	No	Yes	No	+	+	+	-	?
#255	OPPQNCS	Any	58	Now	No	Yes	No	No	No	?	?	+	?	?
#259	VSSDC	Any	29	3-5d	No	Yes	No	No	No	?	+	+	+	?
#508	EORTC PATSAT-C33	Any	33	NS	No	Yes	Yes	Yes	Yes	+	-	+	-	-
#509	APECC	Any	33	12m	No	Yes	No	No	No	-	?	+	?	?
#510	CIISS	Any	24	NS	No	Yes	No	No	No	+	?	+	?	?
#511	PSCC	Any	18	NS	No	Yes	No	Yes	No	+	+	+	?	?
#530	EORTC OUT-PATSAT7	Any	7	NS	No	Yes	Yes	Yes	Yes	+	-	+	-	-
#392	PPCQ-P	PC	35	Now	No	Yes	No	No	No	+	+	+	+	?
#507	CaPSURE Satisfaction	PC	15	3m	No	Yes	No	No	No	?	?	+	+	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.

TABLE 45 BREAKDOWN OF 13 PREMS FOR QUALITY OF CARE / SATISFACTION WITH CARE

Analysis: Overall 13 PREMs were identified assessing quality of care / care environment and patient satisfaction. No PREM is available in electronic format. Eleven PREMs were cancer generic. The CTSQ (#043) appears to offer the best combination of psychometric validation, length and language availability, although recall period is set to 'last month', which can increase recall bias. Alternatively, the FACIT TS (#124) and the PSCC (#511) can be considered for shorter recall timeframes.

Of the two prostate cancer specific PREMs, the PPCQ-P (#392) offers good psychometric validation data and can be completed in the present time, although it is moderately long (35 items) and only available in English.

Recommendation for use: Cancer generic: **#043**, followed by #124 and # 511. Prostate cancer specific: #392.

5.4.1.2 Patient centredness / empowerment in care services

Dataset ID	PREM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#068	DES-10	Any	10	Now	Yes	Yes	No	No	No	+	+	+	?	?
#266	PES	Any	28	Now	No	Yes	No	No	No	?	?	+	?	?
#272	PCCMCC	Any	87	3m	No	Yes	No	No	No	+	+	+	+	?
#355	TiOS-SF	Any	18	1w	No	Yes	No	No	No	+	?	+	?	?
#505	HEIQ	Any	25	NS	No	Yes	No	No	Yes	+	+	+	?	?
#506	CIDES	Any	7	NS	Yes	Yes	No	No	No	-	+	+	?	?
#504	CEQ	Any	40	NS	No	Yes	No	No	No	+	+	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.

TABLE 46 BREAKDOWN OF 7 PREMS FOR PATIENT CENTREDNESS OF CARE / SERVICES

Analysis: Of the seven PREMs targeting patient centredness of care / services, the DES-10 (#068) is a brief measure of patient centredness with good psychometric properties. For more comprehensive assessments of patient empowerment in care, the HEIQ (#505) and the CEQ (#504) can be considered.

***Recommendation for use:* #068**, followed by #505 and #504.

5.4.1.3 Care process co-ordination / continuity

Dataset ID	PREM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#034	CCCQ	Any	20	3m	No	Yes	No	No	No	+	+	+	-	?

#177	MCQ	Any	21	NS	No	Yes	No	No	No	?	?	?	?	?
#428	CAHPS Cancer	Any	VAR	NS	No	Yes	No	Yes	No	+	+	?	?	?
#431	PSN-1	Any	34	Now	No	Yes	No	Yes	No	+	+	+	?	?
#299	PCQ-P	PC	116	NS	No	Yes	No	No	No	+	+	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years. VAR - Variable. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.

TABLE 47 BREAKDOWN OF 5 PREMS FOR CARE PROCESS CO-ORDINATION / CONTINUITY

Analysis: Five PREMs were cancer generic and one PREM was prostate cancer specific in this group. Only the CCCQ (#034) and the PSN-1 (#431) appear to have reasonable psychometric properties (no data available on stability or responsiveness to change) and a reasonable length. Recall periods differ: 'past 3 months' for the CCCQ (#034) and 'present time' for the PSN-1 (#431) and can be used depending on the requirements of research inquiry.

***Recommendation for use:* #034 or #431**

5.4.1.4 Patient-clinician communication

Dataset ID	PREM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#035	CCAT-PF	Any	18	NS	No	Yes	No	No	No	+	+	-	-	?
#064	CCCI	Any	26	NS	No	Yes	No	No	No	+	+	+	-	?
#082	EORTC QLQ-INFO25	Any	25	NS	No	Yes	No	Yes	Yes	+	?	+	-	-
#085	EORTC QLQ-INFO26	Any	26	VAR	No	Yes	No	Yes	No	+	?	?	?	?
#531	EORTC QLQ-COMU26	Any	26	Now	No	Yes	Yes	Yes	Yes	+	-	-	-	-
#282	PECHSAE	BC	12	CTx	Yes	Yes	No	No	No	?	?	?	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years; CTx - Chemotherapy; VAR - Variable. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PROMs, light blue rows indicate 'alternative' recommended PROMs.

TABLE 48 BREAKDOWN OF 6 PREMS FOR PATIENT-CLINICIAN COMMUNICATION

Analysis: Overall, none of these PREMs reflects solid validation data. They are however of short length. The CCCI (#064) and the CCAT-PF (#035) can be considered where necessary.

Recommendation for use: Nil - If use is necessary, use with caution.

5.4.1.5 Preferences of goals of care

Dataset ID	PREM acronym	Cancer type	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#281	PPRHC	Any	123	NS	No	Yes	No	No	No	-	-	-	-	-
#163	KUJ	PC	18	Now	No	Yes	No	No	No	?	?	+	?	?

Notes:
BC – Breast cancer; Any – Developed or adopted for use with any cancer type; NS – Not specific; PC – Prostate cancer; SC – Skin cancer; d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.

TABLE 49 BREAKDOWN OF 2 PREMS FOR PREFERENCES OF GOALS OF CARE

Analysis: Both these PREMs have insufficient psychometric data, while the PPRHC (#281) is extremely lengthy.

Recommendation for use: Nil - If use is necessary, use with caution.

5.4.2 GERIATRICS SPECIFIC PREMS BY TARGET PRE

5.4.2.1 Quality of care / satisfaction with care

Dataset ID	PREM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#133	GerINCQ	67	NS	Yes	Yes	No	No	No	+	+	+	+	+
#140	HCSQ	26	NS	No	Yes	No	No	No	?	?	?	?	?
#265	PACT-M	16	7d	No	Yes	No	No	No	+	?	?	?	?
#313	RSQ	50	14d	No	Yes	No	No	No	-	+	?	?	?
#353	TC	11	3m	No	Yes	No	No	No	?	+	+	+	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.

TABLE 50 BREAKDOWN OF 5 PREMS FOR QUALITY OF CARE / SATISFACTION WITH CARE

Analysis: Five PREMs were identified that assess quality of care / satisfaction with care from the older patient's perspective. Only the GerINCQ (#133) has sufficient psychometric validation data; however, it is quite lengthy (67 items) and measures perceptions of inpatient care only. The TC (#353) is a brief measure of care transitions in the geriatric population, with relatively good psychometric properties. However, it has only been tested in the Australian context, has questionable content validity and a rather long recall period. On balance, the PACT-M (#265) can be cautiously considered for rapid assessments of the quality of transition from hospital to home; however, evidence on psychometric performance is lacking.

Recommendation for use: Nil - If use is necessary, use with caution.

5.4.2.2 Preferences of goals of care

Dataset ID	PREM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#291	PELI	55	Now	No	Yes	No	No	No	-	-	?	?	?
#326	SHAPE	110	1-2w	No	Yes	No	No	No	?	?	?	+	?
Notes: *NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.*													

TABLE 51 BREAKDOWN OF 2 PREMS FOR PREFERENCES OF GOALS OF CARE

Analysis: Neither of the two PREMs can be considered due to evident insufficiencies in their development, structure or availability.

Recommendation for use: Nil - If use is necessary, use with caution.

5.4.2.3 Care process co-ordination / continuity

Dataset ID	PREM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness

#069	DICARES	10	1m	No	Yes	No	No	No	+	+	-	+	?
#395	CANHELp-LITE patient	20	1m	No	Yes	No	No	No	+	+	+	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.

TABLE 52 BREAKDOWN OF 2 PREMS FOR CARE PROCESS CO-ORDINATION / CONTINUITY

Analysis: Both PREMs are reasonably short and available in English only. The CANHELp-LITE patient (#395) has only been tested in Canada, and therefore its applicability to the European context can be questioned. The DICARES (#069) offers the only option for the measurement of care process co-ordination and continuity in the geriatric context. Although no data are available on internal consistency and responsiveness to change, it can be cautiously considered for a quick assessment of the relevant processes.

Recommendation for use: Nil - If use is necessary, use with caution.

5.4.2.4 Patient centredness / empowerment in care services

Dataset ID	PREM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#156	ICS-PREM	16	NS	No	Yes	No	No	No	+	?	?	?	?
#285	P-CAT	39	Now	No	Yes	No	Yes	Yes	+	?	+	+	?
#356	UCLA-GA	14	Now	No	Yes	No	No	No	?	+	+	+	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs.

TABLE 53 BREAKDOWN OF 3 PREMS FOR PATIENT CENTREDNESS OF CARE / SERVICES

Analysis: The P-CAT (#285) is a relatively long, albeit well-validated, PREM in this area, with a very short recall timeframe and good language availability. The ICS-PREM (#156) offers a short alternative measure of intermediate care services for older people, although it is lacking psychometrically. The UCLA-GA (#356) suffers from poor content validity and thus cannot be considered.

***Recommendation for use:* #285**

5.4.2.5 Other geriatric PREs

Dataset ID	PREM acronym	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#006	APQ[1]	32	Now	No	Yes	No	No	No	+	+	+	?	?
#046	CRVCRES[2]	12	Now	No	Yes	No	No	No	+	+	-	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended PREMs. 1 Perceptions of aging; 2 Satisfaction with caregiver.

TABLE 54 BREAKDOWN OF 2 PREMS FOR OTHER GERIATRIC PRES

Analysis: Where perceptions of aging is the target PRE, the APQ (#006) is a good candidate measure with reasonable psychometric data. The questionnaire length (32 items) is within the acceptable range and assessment is conducted in the present time. The CRVCRES (#046) has questionable psychometric properties and indeterminate language availability for assessments of patient satisfaction with their caregiver.

Recommendation for use: Perceptions of aging: **#006**

5.4.3 PREMS FOR CAREGIVERS BY CLINICAL AREA AND TARGET PRO

Most PREMs were developed for use by patients. However, five PREMs (13%) specifically targeted experiences of family members or informal caregivers (**Table 53**).

Dataset ID	PREM Acronym	Target field	Length	Recall period	e-version available?	Available in English?	Available in Greek?	Available in Spanish?	Available in Swedish?	Content validity	Construct validity	Internal consistency	Stability	Responsiveness
#103	FAMCARE[1]	Cancer	20	NS	No	Yes	No	Yes	No	+	+	+	?	?
#298	PCQ-C[2]	Cancer	64	Now	No	Yes	No	No	No	+	+	+	+	+
#396	CANHELp-LITE caregiver[3]	Geriatrics	21	1m	No	Yes	No	No	No	+	+	+	?	?

Notes:
NS – Not specific. d – days; w - weeks; m - months; y - years. "+"=sufficient, "–"=insufficient, "?"=indeterminate. Blue rows indicate 'most suitable' recommended PREMs, light blue rows indicate 'alternative' recommended

PREMs. 1 Care process coordination, family satisfaction with advanced cancer care; 2 Caregiver's experiences; 3 Care process coordination, quality of care environment.

TABLE 55 THE 3 PREMS DEVELOPED FOR USE BY FAMILY MEMBERS OR CAREGIVERS

Analysis: Two PREMs target care process coordination and one PREM evaluates caregiver experiences. In relation to the latter PRE, the PCQ-C (#298) has strong psychometric properties but is only available in English and is rather long (64 items). The FAMCARE (#103) is a short PREM of care process coordination and family satisfaction, with good psychometric validation; however, the FAMCARE (#103) specifically targets caregivers of patients with advanced cancer only. The CANHELp-LITE caregiver (#396) could be a good candidate measure of care process coordination in the geriatric setting, but it has been used in the Canadian context only.

Recommendation for use: Caregiver's experiences: **#298**. Care process coordination: **#103**.

6 CONCLUSIONS

Of these, 261 measures (227 PROMs and 34 PREMs) were developed or adopted for use in cancer care. Eighty-eight of the cancer measures (82 PROMs and 6 PREMs) were cancer type specific. Fifteen of the cancer measures (13 PROMs and 2 PREMs) were specifically developed for use by family members or caregivers. The remaining 146 measures (130 PROMs and 16 PREMs) were developed for use in geriatric care. Two geriatric measures (1 PROM and 1 PREM) were specifically developed for use by family members or caregivers. Twelve measures (all PROMs) were specifically validated for use in geriatric oncology.

The identified cancer PROMs targeted 35 unique PROs; the geriatrics PROMs targeted 30 unique PROs. Sixteen PROs were the focus of both cancer and geriatrics PROMs. The cancer PREMs identified 6 unique PREs; the geriatrics PREMs targeted 6 unique PREs. Six PREs were the focus of both cancer and geriatrics PREMs. Wide variability in psychometric validation, measure structure (length, recall period), language availability and electronic format availability was noted. Consideration of PROMs and PREMs as 'fit for purpose' was based on the measures meeting combinations of these criteria.

A total of 71 cancer PROMs and 45 geriatrics PROMs (including 8 PROMs for geriatric oncology) are recommended for use as offering the best combination of features. Similarly, a total of 11 cancer PREMs and two geriatrics PREMs can be considered for use based on the aforementioned criteria.

Table 56 and **Table 57** summarise all recommended measures and their target PROs/PREs as these have emerged from the previous analysis.

Ultimate selection of any of these PROMs and PREMs for use in research must take into account the unique requirements of the research inquiry (i.e. outcomes, end-points and frequency of measurement) as well as the unique characteristics and abilities of the patient population in geriatric oncology (e.g. respondent burden, cognitive capacity).

Role	Target PRO	Recommended PROMs (Dataset ID)		
		Oncology	**Geriatrics**	**Geriatric oncology**
Patient	Multisymptom burden/distress	**#074**, #444, #523. BC: **#022**. PC: **#468 or #472**, #098, #477.	**#398**	N/A
	Fatigue / Cancer-related fatigue	**#378**, #441. BC: **#377**, **#382**	N/A	N/A
	CINV	**#443**	N/A	N/A
	CIPN	**#079**	N/A	N/A
	Pain	**#435,** #279, #060	Nil	N/A
	Sleep	**#442**, **#288**	**#276**	N/A
	Appetite, Oral health	Nil	N/A	N/A
	Anaemia	Nil	N/A	N/A
	Diarrhoea	**#348**	N/A	N/A
	Dyspnoea	**#445**	N/A	N/A
	Treatment toxicity	Nil	N/A	N/A
	HRQoL	**#122 or #334 or #417**, #121, #331. BC: **#081**, #117, #359. PC: **#297**, #462. SC: **#409**, #408, #423.	**#066 or #397**, #310, #027, #513, #111 or #361	Nil
	Functional status / dependency	**#277**, #366	**#126 or #094 or #004**, #165, #112, #391	#391
	Nutritional status / Cachexia	**#073**	**#336**, #183, #182	#182
	Fear of cancer recurrence	**#044**, #108. BC: Nil	N/A	N/A
	Depression	**#451**. SC: Nil	**#399 or #130 or #128**, #528, #129, #493.	**#399, #451**
	Anxiety	**#450**	N/A	
	Anxiety, Depression	**#149**, #332. BC: Nil	N/A	**#149**
	Psychological responses	**#072**, #078. **#036**. **#519**. BC: **#283**. PC: Nil	Nil	N/A
	Social isolation	**#340**	**#178**	**#178**
	Cognitive function / decline	Nil. BC: **#057**.	Nil	N/A
	Physical ability / activity	**#286**, #095, #148. BC: **#309**, #412.	**#157 or #137**, #373, #007, #349. **#405 or #158**, #404.	**#286**
	Healthcare needs	**#037**, #346, #041	Nil	N/A
	Body image / sexual functioning	**#018 or #447**, #446. BC: Nil. PC: Nil	N/A	N/A
	Frailty	N/A	**#055 or #293**, #406	Nil
	Falls propensity / risk	N/A	**#101**, #002, #131, #102	N/A
	Polypharmacy	N/A	**#316 or #427**	N/A
	Geriatric assessment	Nil	**#394**	**#394**
	Self-efficacy	**#429**. BC: #021	Nil	N/A
	Attitudes towards cancer diagnosis	#032	N/A	N/A
	Health state/utility	#093	**#512**	N/A
	Skin self-examination	SC: #324	N/A	N/A
	Financial distress	#385	N/A	N/A

Role	Target PRO	Recommended PROMs (Dataset ID)		
		Oncology	**Geriatrics**	**Geriatric oncology**
	Multimorbidity burden	N/A	**#529**	N/A
	Amotivation towards exercise	N/A	Nil	N/A
Caregiver	Psychological responses	Nil	N/A	N/A
	HRQoL	**#015**	N/A	N/A
	Well-being	#050	N/A	N/A
	Healthcare needs	**#105**	Nil	N/A

Notes:
BC - Breast cancer; PC - Prostate cancer; SC - Skin cancer; Nil - No recommendation can be made. N/A - Not applicable. Dataset ID titles and acronyms of all PROMs can be found in Appendix 6: **Abbreviations of all PROMs and PREMs reviewed**. *Entries in bold type indicate 'most suitable' PROMs; entries in normal type indicate 'alternative' PROMs.*

TABLE 56 SHORTLIST OF RECOMMENDED PROMS

Role	Target PRE	Recommended PREMs (Dataset ID)		
		Oncology	**Geriatrics**	**Geriatric oncology**
Patient	Quality of care / satisfaction with care	**#043**, #124, #511. PC: #392	Nil	N/A
	Patient centredness / empowerment in care services	**#068**, #505, #504	**#285**	N/A
	Care process co-ordination / continuity	**#034 or #431**	Nil	N/A
	Patient-clinician communication	Nil	N/A	N/A
	Preferences of goals of care	Nil	Nil	N/A
	Perceptions of aging	Nil	**#006**	N/A
Caregiver	Caregiver's experiences	**#298**	Nil	N/A
	Care process coordination	**#103**	Nil	N/A

Notes:
Nil - No recommendation can be made. N/A - Not applicable. Dataset ID titles and acronyms of all PROMs can be found in Appendix 6: **Abbreviations of all PROMs and PREMs reviewed**. *Entries in bold type indicate 'most suitable' PREMs; entries in normal type indicate 'alternative' PREMs.*

TABLE 57 SHORTLIST OF RECOMMENDED PREMS

7 REFERENCES

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8 APPENDIX

8.1 APPENDIX 1: LINKS TO COSMIN GUIDELINES

- https://www.cosmin.nl/wp-content/uploads/COSMIN-syst-review-for-PROMs-manual_version-1_feb-2018.pdf
- https://www.cosmin.nl/wp-content/uploads/COSMIN-study-designing-checklist_final.pdf#
- https://www.sciencedirect.com/science/article/pii/S0895435610000909?via%3Dihub
- https://www.cosmin.nl/wp-content/uploads/COSMIN-definitions-domains-measurement-properties.pdf

8.2 APPENDIX 2: EXAMPLE SEARCHES

MEDLINE (Ovid)

1. cancer.mp. or exp *Neoplasms/
2. geriatric.mp. or exp Geriatrics/ or geriatric assessment.mp. or exp Geriatric Assessment/ or *Aged/ or *Health Services for the Aged/ or *Middle Aged/ or elder$.mp.
3. *Outcome Assessment, Health Care/ or patient reported outcome measure.mp. or exp Patient Reported Outcome Measures/ or *"Surveys and Questionnaires"/ or patient outcome assessment.mp. or *Patient Outcome Assessment/ or patient reported experience.mp. or prom.mp or prem.mp. or patient experience.mp.
4. (validation or development or implementation or testing).mp
5. 1 and 3 and 4
6. 2 and 3 and 4
7. Limit 5 and 6 to (English language and humans and yr="1999 -Current")

Cochrane Library

1. Validation or development in All Text
2. Cancer or oncolog* or geriatric* or old* in All Text
3. Patient NEXT reported NEXT outcome in All Text
4. Patient NEXT reported NEXT experience in All Text
5. Measure or assessment or questionnaire in All Text
6. 3 OR 4
7. 1 AND 2 AND 5 AND 6
8. Limit to publication date from Jan 1999 to Apr 2020, in Cochrane Reviews (word variations have been searched)

Google Scholar

Cancer	validation development "patient reported outcome measure" OR "patient reported experience measure" intitle:cancer

Geriatrics	validation development intitle:elderly OR intitle:older OR intitle:geriatric "patient reported outcome measure" OR "patient reported experience measure"

8.3 APPENDIX 3: DEFINITIONS OF KEY PSYCHOMETRIC TERMS

Psychometric property	**Definition**
Internal consistency	Internal consistency refers to whether several items that propose to measure the same general construct produce similar scores. Measurement of this property relies on calculation of two sets of metrics.
Cronbach's alpha	⩾0.80 indicates good internal consistency
Inter-item, item-to-total or inter-scale correlations	Absence of extremes values <0.10 and >0.90 indicates absence of redundancy and thus good internal consistency
Stability (test-retest)	Stability or test-retest reliability refers to the closeness of the agreement between the results of successive measurements of the same measure, carried out under the same conditions of measurement. Investigation may include calculation of parametric/non-parametric correlation coefficients or intraclass correlation coefficients, percentage agreement, or test-retest mean differences.
Intraclass correlation coefficients	≥0.75 indicates good stability.
Percentage agreement	Higher % indicate higher level of agreement.
Test-retest mean differences	Absence of significant differences indicates good stability.
Content validity	Content validity refers to the extent to which a measure represents all facets of a given construct.
Construct validity	Construct validity refers to the degree to which a test measures what it claims, or purports, to be measuring. Investigated as part of scale analysis and/or known-groups validity.
Scale analysis	Scale analysis refers to a set of exploratory and confirmatory analyses, used for item reduction and investigation and confirmation of the dimensionality (constructs) of a measure.
Known-groups validity	Known-groups validity (or extreme-groups validity) refers to when a measure can discriminate between two or more groups known to differ on the variable of interest.
Criterion validity	Criterion validity refers to the extent to which a measure is related to an outcome that is measured at the same time (concurrent validity) or at a later time (predictive validity). Concurrent validity is investigated via convergent and/or discriminant validity.
Convergent validity	Convergent validity refers to the degree to which two measures of constructs that theoretically should be related, are in fact related.
Discriminant validity	Discriminant validity refers to whether concepts or measurements that are not supposed to be related are actually unrelated.

Psychometric property	Definition
Predictive validity	The extent to which a score on a scale or test predicts scores on some criterion measure.
Floor/ceiling effects	Ceiling effects occur when respondents' scores cluster towards the high end (or possible upper limit) of the measure or item. The opposite is the floor effect. The problem is that variance is not measured or estimated above or below a certain level.
Responsiveness to change	The ability of an instrument to detect change over time in the construct to be measured.

8.4 APPENDIX 4. DEFINITIONS OF PSYCHOMETRIC ROBUSTNESS RATINGS

Psychometric properties	Comment / guidance
Number of subscales / domains	If there are confirmed subscales/domains, please type in the number of subscales or domains of the PROM or PREM.
Subscales / domains	If there are confirmed subscales/domains, please list the names of the subscales or domains of the PROM or PREM.
Content validity confirmed? "+"=sufficient "–" =insufficient "?"=indeterminate	Content validity refers to the extent to which a measure represents all facets of a given construct. Content validity is usually confirmed by a thorough literature review to create a pool of items and by direct consultation with patients and/or experts in the field. Sufficient content validity is where direct consultation has taken place on top of a literature review. Indicate as indeterminate if no information at all exists. Please look across papers identified in Part A and Part B -- detailed information might be in a literature review paper.
Construct validity confirmed? "+"=sufficient "–" =insufficient "?"=indeterminate	Construct validity refers to the degree to which a test measures what it claims, or purports, to be measuring. Investigated as part of scale analysis (known as factor analysis) and/or and/or criterion validity and/or known-groups validity. Sufficient construct validity is where scale analysis has taken place and confirmed construct validity of the PROM or PREM (plus or minus criterion or known-groups validity). Indicate as indeterminate if no information at all exists. Please look across papers identified in Part A and Part B -- detailed information might be in a literature review paper.
Internal consistency confirmed? "+"=sufficient "–" =insufficient "?"=indeterminate	Internal consistency refers to whether several items that propose to measure the same general construct produce similar scores. Measurement of this property relies on calculation of two sets of metrics: Cronbach's alpha and inter-scale correlations. Target Cronbach's alpha >=0.80. Target inter-scale correlations between 0.10 and 0.90. Sufficient internal consistency is where at least target Cronbach's alpha is met. Indicate as indeterminate if no information at all exists. Please look across papers identified in Part A and Part B -- detailed information might be in a literature review paper.

Psychometric properties	Comment / guidance
Stability confirmed? **"+"=sufficient** **"–" =insufficient** **"?"=indeterminate**	Stability or test-retest reliability refers to the closeness of the agreement between the results of successive measurements of the same measure, carried out under the same conditions of measurement. Investigation may include calculation of correlation coefficients (target >=0.75), percentage agreement (target 80%), or test-retest mean differences (target no statistically significant differences). Sufficient stability is where at least one target is met. Indicate as indeterminate if no information at all exists. Please look across papers identified in Part A and Part B -- detailed information might be in a literature review paper.
Responsiveness to change confirmed? **"+"=sufficient** **"–" =insufficient** **"?"=indeterminate**	The ability of an instrument to detect change over time in the construct to be measured. Target is statistically significant changes in PROM or PREM scores from baseline to follow up points in a longitudinal study. Sufficient responsiveness to change is where longitudinal performance of the PROM/PREM has been tested and the target has been met. Indicate as indeterminate if no information at all exists. Please look across papers identified in Part A and Part B -- detailed information might be in a literature review paper.

8.5 APPENDIX 5: SCREENSHOTS OF THE PROMS/PREMS DATASET

Part A. Bibliographic information of shortlisted PROMs/PREMs and papers						
1. ID	**2. PROM/PREM (title)**	**3. PROM/PREM (abbreviation)**	**4. PROM or PREM?**	**5. Target field**	**6. Core publication from rapid review**	**7. URL to core publication**
#001	4-item self-report activities of daily living	ADL-4	PROM	Geriatrics	International Urology &	https://pubmed.ncbi.nlm.nih.gov/2
#002	Activities specific Balance Confidence	ABC	PROM	Geriatrics	Archives of Gerontology &	https://pubmed.ncbi.nlm.nih.gov/2
#003	Activity Card Sort	ACSort	PROM	Geriatrics	Australian Occupational	https://pubmed.ncbi.nlm.nih.gov/2
#004	adult Alpha Functional Independence Measure	AlphaFIM	PROM	Geriatrics	Journal of Neuroscience	https://pubmed.ncbi.nlm.nih.gov/2
#005	Age-Related Muscle Loss Questionnaire	ARMLQ	PROM	Geriatrics	Journal of the American	https://pubmed.ncbi.nlm.nih.gov/2
#006	Aging Perceptions Questionnaire	APQ	PREM	Geriatrics	Health & Quality of Life	https://hqlo.biomedcentral.com/art
#007	Ambulatory Self-Confidence Questionnaire	ASCQ	PROM	Geriatrics	Gerontology. 53(6):373-81,	https://pubmed.ncbi.nlm.nih.gov/1
#008	Amotivation Toward Exercise Scale	ATES	PROM	Geriatrics	Journal of Aging & Physical	https://pubmed.ncbi.nlm.nih.gov/1
#009	Anemia Impact Measure	AIM	PROM	Cancer	Kleinman L, Benjamin K,	https://pubmed.ncbi.nlm.nih.gov/2
#010	Appraisal of Caregiving Scale	ACS	PREM	Cancer	Lambert SD, Yoon H, Ellis KR,	https://www.ncbi.nlm.nih.gov/pmc

Part A.	Part B. Basic characteristics of shortlisted PROMs/PREMs						
1. ID	1. Target outcome or experience of PROM/PREM	2. Target population of PROM/PREM	3. Is PROM/PREM cancer type specific?	4. Number of questions on PROM/PREM	5. PROM/PREM recall period	6. Is PROM/PREM validated for online/electr	7. Does PROM/PREM give total score?
#001	Functional dependency/decline	Non-cancer	Not applicable	4	Present time	No	Yes
#002	Falls propensity	Non-cancer	Not applicable	6	Present time	No	Yes
#003	Activity engagement and participation in	Non-cancer	Not applicable	82	Present time	No	Yes
#004	Functional dependency/decline	Non-cancer	Not applicable	18	Present time	No	Yes
#005	Sarcopenia, Physical ability, uboptimal	Non-cancer	Not applicable	14	Past 7 days	No	Yes
#006	Perceptions of aging	Non-cancer	Not applicable	32	Present time	No	Yes
#007	Physical ability, Ambulation	Non-cancer	Not applicable	22	Present time	no	Yes
#008	older adults' reasons t	Non-cancer	Not applicable	12	Past 6 months	No	Yes
#009	Symptom burden for patients with anemia	Generic cancer	No	38	Past 7 days	Yes	Yes
#010	individuals' perception	Generic cancer	No	27	Present time	No	Yes

Part A.	Part C. Psychometric properties of shortlisted PROMs/PREMs						
1. ID	Number of subscales/ domains	Subscales/domains	Content validity confirmed?	Construct validity confirmed?	Internal consistency confirme	Stability confirmed? "+"=sul	Responsiveness to change confirm
#001	3	personal care, mobility, and eating.	?	?	+	?	?
#002	1	Balance confidence	+	+	+	+	?
#003	4	instrumental activities; low demand leisure	+	?	?	?	?
#004	1	functional ability	+	+	+	+	?
#005	2	functional impacts of reduced muscle strength	+	?	?	?	?
#006	7	timeline chronic, timeline cyclical, consequence	+	+	+	?	?
#007	1	walking confidence home or community	+	+	+	+	?
#008	4	Outcome beliefs; capacity beliefs; effort	+	+	+	+	?
#009	2	symptom-severity questions, symptom	+	?	?	?	?
#010	3	general Stress, threat, benefit	+	+	-	?	?

8.6 APPENDIX 6: ABBREVIATIONS OF ALL PROMS AND PREMS REVIEWED

Dataset ID	PROM/PREM Title	Abbreviation
#001	4-item self-report activities of daily living	ADL-4
#002	Activities specific Balance Confidence	ABC
#003	Activity Card Sort	ACSort
#004	adult Alpha Functional Independence Measure	AlphaFIM
#006	Aging Perceptions Questionnaire	APQ
#007	Ambulatory Self-Confidence Questionnaire	ASCQ

Dataset ID	PROM/PREM Title	Abbreviation
#009	Anemia Impact Measure	AIM
#010	Appraisal of Caregiving Scale	ACS
#011	Appraisal of Self-care Agency Scale-Revised	ASAS-R
#012	Assessment Symptoms Palliative Elderly	ASPE
#015	Bakas Caregiving Outcomes Scale	BCOS
#016	Barriers Questionnaire-27	BQ-27
#017	Body Image After Breast Cancer Questionnaire	BIBCQ
#018	Body Image Scale	BIS
#019	Breakthrough Pain Assessment Tool	BAT
#020	Breast Cancer Specific Patient Concerns Inventory	BCPCI
#021	Breast Cancer Survivor Self-Efficacy Scale	BCSES
#022	Breast Cancer Treatment Outcome Scale - short form 12	BCTOS-12
#024	Breast Cancer Treatment Response Inventory	BCTRI
#025	BREAST-Q for breast surgery	BREAST-Q
#026	Brief Cognitive Assessment tool - sweet 16.	Sweet 16
#027	Brief Older People's Quality of Life Questionnaire	OPQOL-brief
#028	Brief Symptom Inventory-18	BSI-18
#029	Cachexia Assessment Scale	CAS
#030	Camberwell Assessment of Need for the Elderly	CANE
#031	Cancer Appetite and Symptom Questionnaire	CASQ
#032	Cancer Attitudes Inventory	CAI
#033	Cancer Behavior Inventory-Brief	CBI-B
#034	Cancer Care Coordination Questionnaire	CCCQ
#035	Cancer Communication Assessment Tool for Patients and Families	CCAT-PF
#036	Cancer Coping Questionnaire	CCQ
#037	Cancer Needs Distress Inventory	CaNDI
#038	Cancer Needs Questionnaire	CNQ
#039	Cancer Pain Inventory	CPI
#040	Cancer Rehabilitation Evaluation System	CARES
#041	Cancer Survivor Unmet Needs Measure	CASUN
#042	Cancer Survivors' Partners Unmet Needs Measure	CaSPUN
#043	Cancer Therapy Satisfaction Questionnaire	CTSQ
#044	Cancer Worry Scale	CWS
#045	Cancer-related fatigue ambulatory index	CRFAI
#046	Care Receiver View of Caregiver Role Enactment Scale	CRVCRES
#047	CareGiver Oncology Quality of Life	CarGOQoL
#048	Caregiver Quality of Life Index-Cancer	CQOLC
#049	Caregiver Reaction Assessment Scale	CRAS
#050	Caregiver Roles and Responsibilities Scale	CRRS
#051	Care-Receiver Efficacy Scale	CRES
#052	CHAMPS Physical Activity Questionnaire for Older Adults	CHAMPS PAQ
#053	Chemotherapy-Induced Peripheral Neuropathy Assessment Tool	CIPNAT
#054	Chronic Cancer Experiences Questionnaire	CCEQ
#055	Clinical Frailty Scale	CFS
#056	Cognitive Inventory of Subjective Distress	CISD
#057	Cognitive Symptom Checklist-Work 21	CSC-W21
#058	Communication and Attitudinal Self-Efficacy Scale for Cancer	CASE-cancer
#059	Community Commitment Scale	CCS
#060	Composite Pain Index	CPIndex
#061	Comprehensive Assessment Scale for Chemotherapy-Induced Peripheral Neuropathy in Survivors of Cancer	CAS-CIPN
#062	Comprehensive score for financial toxicity	COST
#063	Concerns About Recurrence Scale	CARS
#064	Construction of the Considerations Concerning Cancer Information	CCCI

Dataset ID	PROM/PREM Title	Abbreviation
#066	Control, Autonomy, Self-realization, and Pleasure Questionnaire-19	CASP-19
#067	De Morton Mobility Index	DEMMI
#068	Decisional Engagement Scale	DES-10
#069	Discharge Care Patient Experiences Survey	DICARES
#070	Disease Burden Morbidity Assessment	DBMA
#071	Distress Inventory for Cancer-v2	DIC-2
#072	Distress Thermometer	DT
#073	Eating Assessment Tool	EAT-10
#074	Edmonton Symptom Assessment System-Revised	ESAS-r
#075	Effects of Prostate Cancer upon Lifestyle Questionnaire	EPCLQ
#077	Elderly Quality of Life Index	EQOLI
#078	Emotion Thermometer	ET
#079	European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire-Chemotherapy-Induced Peripheral Neuropathy	EORTC QLQ-CIPN20
#080	European Organisation for Research and Treatment of Cancer In-patient Satisfaction With Care Questionnaire	EORTC IN-PATSAT32
#081	European Organisation for Research and Treatment of Cancer Quality of Life Group - Breast cancer 23	EORTC QLQ-BR23
#082	European Organisation for Research and Treatment of Cancer Quality of Life Group-Information 25	EORTC QLQ-INFO 25
#083	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - Cachexia 24	EORTC QLQ-CAX24
#084	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - Fatigue	EORTC QLQ-FA
#085	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - Information 26	EORTC QLQ-INFO26
#086	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - Inpatient Satisfaction 32	EORTC QLQ-SAT32
#087	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire & Prostate Module	EORTC QLQC-30+PR25
#088	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Module for Older People With Cancer	EORTC QLQ-ELD15
#090	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Core 30	EORTC QLQ-C30
#092	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Oral Health 17	EORTC QLQ-OH17
#093	EuroQoL Five dimensions	EQ-5D-5L
#094	Everyday Competence Questionnaire	ECQ
#095	Exercise barriers self-efficacy-Cancer related lymphedoema	EBSE
#096	Expanded Prostate Cancer Index Composite - Short Form	EPIC-26
#097	FACE-Q Skin Cancer Module	FACE-Q SCM
#098	FACT Advanced Prostate Symptom Index-8	FAPSI-8
#099	Fall Risk Behaviors and Perceptions Scale	FRB&PS
#100	Fall Risk Questionnaire	FRQ
#101	Falls Efficacy Scale-International	FES-I
#102	Falls Risk Awareness Questionnaire	FRAQ
#103	FAMCARE	FAMCARE
#104	Family Caregiving Factors Inventory	FCFI
#105	Family Inventory of Needs	FIN
#106	Fatigue Symptom Inventory	FSI
#107	Fatigue, Resistance, Ambulation, Illness and Loss of weight Scale	FRAIL scale
#108	Fear of Cancer Recurrence Inventory-Short Form	FCRI-SF
#109	Flourishing Scale	FS
#110	Food Frequency Questionnaire	FFQ

Dataset ID	PROM/PREM Title	Abbreviation
#111	Foot Health Status Questionnaire	FHSQ
#112	Frail Elderly Functional Assessment Questionnaire	FEFA
#113	Function Self-Efficacy Scale	FSES
#114	Functional Assessment of Anorexia and Cachexia Therapy	A/CS-12
#115	Functional Assessment of Cancer Therapy - Breast Cancer Symptom Index	NFBSI-16
#116	Functional Assessment of Cancer Therapy - Melanoma	FACT-M
#117	Functional Assessment of Cancer Therapy-Breast	FACT-B
#118	Functional Assessment of Cancer Therapy-Breast+4	FACT-B+4
#119	Functional Assessment of Cancer Therapy-Cognitive Function	FACT-CF
#120	Functional Assessment of Cancer Therapy-Cognitive Function	FACT-Cog
#121	Functional Assessment of Cancer Therapy-General	FACT-G
#122	Functional Assessment of Cancer Therapy-General 7 item	FACT-G7
#123	Functional Assessment of Cancer Therapy-Prostate	FACT-P
#124	Functional Assessment of Chronic Illness Therapy Treatment Satisfaction	FACIT TS
#125	Functional Assessment of Chronic Illness Therapy-Palliative Care 14	FACIT-PAL14
#126	General Activities of Daily Living Scale	GADL
#127	General Motor Function Assessment	GMF
#128	Generalized Anxiety Disorder scale-7	GAD-7
#129	Geriatric Anxiety Inventory	GAI
#130	Geriatric Anxiety Inventory-short form	GAI-SF
#131	Geriatric Fear of Falling Measure	GFFM
#132	Geriatric Hopelessness Scale	GHS
#133	Geriatric In-hospital Nursing Care Questionnaire	GerINCQ
#134	Global Activity Limitation Indicator	GALI
#135	Godin-Shephard Leisure-Time Physical Activity Questionnaire	GSLTPAQ
#136	Groningen Frailty Indicator	GFI
#137	Hand 10	Hand 10
#138	Hand-Foot Skin Reaction and Quality of Life Questionnaire	HF-QOL
#139	Hand-Foot Syndrome QOL Questionnaire 14	HSF-14
#140	Health Care Satisfaction Questionnaire	HCSQ
#141	Health Enhancement Lifestyle Profile-Screener	HELP-Screener
#142	Health Literacy of Caregivers Scale – Cancer	HLCS-C
#143	Health Literate Health Care Organization 10 Item Questionnaire	HLHO-10
#144	Health of the Nation Outcome Scales for Elderly People	HoNOS65+
#145	Health Risk Appraisal for the Elderly	HRA-E
#146	Health Utility Index Mark 2	HUI2
#147	Hearing Loss Inventory Tool	IHEAR-IT
#148	Herdecke Quality of Life Questionnaire	HLQ-Cancer
#149	Hospital Anxiety and Depression Scale	HADS
#150	Human Activity Profile	HAP
#151	Ideas About Long-Standing Health Problems	IALHP
#152	Illness Perception Questionnaire-Cancer Related Fatigue	IPQ-CRF
#153	Impact of Cancer Scale v2	IOCv2
#154	Informant Questionnaire on Cognitive Decline in the Elderly	IQCODE
#155	Instrumental Expressive Social Support Scale	IESS
#156	Intermediate Care Services PREM	ICS-PREM
#157	International Fitness Scale	IFIS
#158	International Physical Activity Questionnaire modified for the elderly	IPAQ-E
#159	International Physical Activity Questionnaire-Short form	IPAC-SF
#160	Investigating Choice Experiments for the Preferences of Older People Capability measure for Older people	ICECAP-O
#163	Knowledge, Understanding and Judgement Scale	KUJ

Dataset ID	PROM/PREM Title	Abbreviation
#164	Late Effects of treatment on Normal Tissue – Subjective, Objective, Management, and Analytic - Prostate	LENT/SOMA-Prostate
#165	Lawton Instrumental Activities of Daily Living Scale	Lawton IADL
#166	Life-Space Assessment	LSA
#168	Long Term Quality of Life-Breast Cancer	LTQOL-BC
#169	Lorensen's Self-care Capability Scale	LSCS
#170	Lymphoedema Functioning, Disability and Health Questionnaire	Lymph-ICF DK
#171	MASCC Antiemesis Tool	MAT
#172	McGill Ingestive Skills Assessment	MISA-DK
#173	MD Anderson Symptom Inventory	MDASI
#174	MD Anderson Symptom Inventory - Breast Cancer Module	MDASI-BCM
#175	MD Anderson Symptom Inventory - Prostate Cancer	MDASI-PC
#176	Measure Yourself Concerns and Wellbeing	MYCaW
#177	Medical Care Questionnaire	MCQ
#178	Medical Outcomes Study Social Support Survey	MOS-SSS
#179	Memorial Anxiety Scale for Prostate Cancer	MAX-PC
#180	Menopause Specific Quality of Life Questionnaire	MENQOL
#181	Metacognitions Questionnaire 30	MCQ-30
#182	Mini Nutritional Assessment	MNA
#183	Mini Nutritional Assessment short-form	MNA-SF
#184	Mini-Mental Adjustment to Cancer Scale	MMACS
#185	Mishel Uncertainty in Illness Scale-Community	MUIS-C
#186	Mobility Assessment Tool for Walking	MAT-W
#187	Modified Falls Efficacy Scale	MFES
#188	modified Fried Index	mFI
#189	modified Gait Efficacy Scale	mGES
#190	Modified Lubben Social Network Scale	MLSNS
#192	Multidimensional Fatigue Inventory-20	MFI-20
#193	Multidimensional Fatigue Symptom Inventory-Short Form	MFSI-SF
#194	Multidimensional Functional Health Scale	MFHS
#248	Needs Evaluation Questionnaire	NEQ
#249	Nipple-Specific Scale for the BREAST-Q	BREAST-Q-NSS
#250	Nocturia, Nocturnal Enuresis and Sleep-interruption Questionnaire	NNES-Q
#251	Northwestern Ego-integrity Scale	NEIS
#252	Nottingham Health Profile	NHP
#253	Occupational Self Assessment for Elderly Individuals	OSA
#255	Oncology Patients' Perceptions of the Quality of Nusing Care Scale	OPPQNCS
#256	Orientation to Life Questionnaire	OLQ-11
#257	Outcome Expectations for Exercise Scale	OEE
#259	Outpatient, Visit-Specific Satisfaction With Doctor Questionnaire	VSSDC
#260	Overactive Bladder questionnaire	OAB-q
#261	Overall Disability Scale for Patients With Chemotherapy-Induced Peripheral Neuropathy	CIPN-R-ODS
#262	Over-the-Counter Medication Impact Scale	OTC-MIS
#263	Pain Assessment Checklist for Seniors with Limited Ability to Communicate	PACSLAC
#264	Parenting Concerns Questionnaire	PCQ
#265	Partners at Care Transitions Measure	PACT-M
#266	Patient Empowerment Scale	PES
#267	Patient Generated Index	PGI
#268	Patient Perceptions of Cancer-Related Fatigue	PP-CRF
#271	Patient Roles and Responsibilities Scale	PRRS
#272	Patient-Centered Communication Measures for Cancer Care	PCCMCC
#273	Patient-Oriented Prostate Utility Scale	PORPUS

Dataset ID	PROM/PREM Title	Abbreviation
#274	Patient-Reported Outcome measure of Sarcopenia	SarcoPRO
#275	Patient-Reported Outcome Mortality Prediction Tool	PROMPT
#276	Patient-Reported Outcomes Information System Sleep Disturbance Scale	PROMIS SDS
#277	Patient-Reported Outcomes Measurement Information System (PROMIS) Physical Function Short Form	PROMIS-PF
#278	Patient-Reported Outcomes Measurement Information System-Depression, Anxiety, and Anger	PROMIS-Depression, Anxiety, and Anger
#279	Patient-Reported Outcomes Measurement Information System-Pain	PROMIS-Pain
#280	Patient-Reported Outcomes Measurement Information System-Sleep/Fatigue	PROMIS-Sleep/Fatigue
#281	Patients' Preferences With Regard to Health Care	PPRHC
#282	Patients' Experience of Communication and Handling of Symptomatic Adverse Events	PECHSAE
#283	Perceived Stress Scale	PSS
#284	Perform Questionnaire	PQ
#285	Person-centered Care Assessment Tool	P-CAT
#286	Physical Activity Scale for the Elderly	PASE
#287	Piper Fatigue Scale Revised	PFS-R
#288	Pittsburgh Sleep Quality Index	PSQI
#289	Positive Valuation of Life Scale	Positive VOL
#290	Possibilities for Activity Scale for Women Encountering Cancer	PActS-W
#291	Preferences for Everyday Living Inventory	PELI
#292	Pressure Ulcers Quality of Life scale	PU-QOL
#293	Program of Research to Integrate Services for the Maintenance of Autonomy - 7 item	PRISMA-7
#294	Project to Prevent Falls in Veterans	PPFV
#295	Prostate Cancer Radiation Late Toxicity	PCRT
#296	Prostate Cancer Specific Quality of Life Instrument	PROSQOLI
#297	Prostate Cancer Symptom Scale	PCSS
#298	Prostate Care Questionnaire for Carers	PCQ-C
#299	Prostate Care Questionnaire for Patients	PCQ-P
#300	Psychooncological Treatment Need in Breast Cancer Patients	POT-BC
#301	Psycho-Oncology Screening Tool	POST
#302	Psychosocial Adjustment to Illness Scale-Self report	PAIS-SR
#304	Psychosocial Distress Questionnaire-Prostate Cancer	PDQ-PC
#305	Psychosocial Screen for Cancer	PSSCAN
#306	Quality of Life in Adult Cancer Survivors	QLACS
#307	Quality of Life-Breast Cancer Survivors-15	QOL-BCS-15
#308	Quality of Relationship Inventory	QRI
#309	Quick disability of shoulder, arm and hand questionnaire	QuickDASH
#310	QuiLL	QuiLL
#312	Rapid Assessment of Physical Activity	RAPA
#313	Resident Satisfaction Questionnaire	RSQ
#314	Resourcefulness Scale for Older Adults.	RSOA
#315	Revised Illness Perceptions Questionnaire-Breast Cancer Survivors	IPQ-BCS
#316	revised Patients' Attitudes Towards Deprescribing	rPATD
#317	SAKK Cancer-Specific Geriatric Assessment	SAKK C-SGA
#318	Satisfaction With Life Domains Scale for Breast Cancer	SLDS-BC
#319	Scale for the Assessment of Illness Behavior	SAIB
#320	Schwartz Cancer Fatigue Scale	SCFS
#321	Self Reporting questionnaire-20	SRQ-20

Dataset ID	PROM/PREM Title	Abbreviation
#322	Self-Awareness of Falls in Elderly Scale Among Elderly Inpatients.	SAFE
#323	Self-care Ability Scale for the Elderly	SASE
#324	Self-Efficacy for Skin Self-Examination Scale	SE-SSE
#325	Self-efficacy in Managing Symptoms Scale-Fatigue Subscale for Patients With Advanced Cancer	SMSFS-A
#326	Self-maintenance Habits and Preferences in Elderly	SHAPE
#327	Sexual Adjustment and Body Image Scale	SABIS
#328	Sexual Adjustment Questionnaire	SAQ
#329	Sexual Distress Scale	SDS
#331	Short Form Health Survey 36	SF-36
#332	Short Scale for Detecting Anxiety and Depression	PSYCH-6
#333	Shortened Hearing Handicap Inventory for Elderly	HHIE-S
#334	Short-Form 12v2	SF-12v2
#335	Shoulder Pain and Disability Index	SPADI
#336	Simplified Nutritional Appetite Questionnaire	SNAQ
#337	Skin Cancer Quality of Life Impact Tool	SCQOLIT
#339	Social Constraints Scale	SCS
#340	Social Difficulties Inventory-21	SDI-21
#341	Social Environment Questionnaire in Chinese Older Adults.	SEQ
#342	Social Participation Restrictions Questionnaire	SPRQ
#343	Strawbridge questionnaire	Strawbridge Q
#344	Stroke Self-Efficacy Questionnaire	SSEQ
#345	Support Person Unmet Needs Survey	SPUNS
#346	Supportive Care Needs Survey Short Form 34	SCNS-SF34
#347	Supportive Needs Screening Tool	SNST
#348	Systemic Therapy Induced Diarrhea Assessment Tool	STIDAT
#349	Task Self-efficacy Scale	TSE
#350	Telephone Assessment of Physical Activity	TAPA
#353	Transition Care	TC
#354	Treatment Induced Neuropathy Assessment Scale	TNAS
#355	Trust in Oncologist Scale-Short Form	TiOS-SF
#356	UCLA Geriatrics Attitudes scale	UCLA-GA
#357	University of California, Los Angeles Prostate Cancer Index	ULCA-PCI
#358	Upper Extremity Functional Index	UEFI
#359	Upper Limb Lymphedema Quality of Life Questionnaire	ULL QLQ
#361	Venous Insufficiency Epidemiological and Economic Study	VEINES-QOL
#362	Vestibular Disorders Activities of Daily Living Scale	VADL
#363	WHI Brief Physical Activity Questionnaire	WHI-BPAQ
#364	WHO Well-Being Index	WHO-5
#365	Will-to-Live scale	WTL
#366	World Health Organization Disability Assessment Schedule	WHO-DAS
#367	World Health Organization Quality of Life-Old people	WHOQOL-OLD
#368	World Health Organization Quality of Life-Short form	WHOQOL-BREF
#369	Wu Cancer Fatigue Scale	WCFS
#370	Yale Physical Activity Survey	YPAS
#371	Zung Self-Rating Depression Scale	ZSDS
#372	Adult Social Care Outcomes Toolkit	ASCOT
#373	ICEpop CAPability measure for Older people	ICECAP-O
#374	Brief Fatigue Inventory	BFI
#377	Fatigue Assessment Scale	FAS
#378	Fatigue Severity Scale	FSS
#379	Fatigue Items Bank-72	FIB-72
#380	Lee Fatigue Scale	LFS
#381	Multidimensional Assessment of Fatigue	MAF

Dataset ID	PROM/PREM Title	Abbreviation
#382	Cancer Fatigue Scale	CFS
#383	Hirai Cancer Fatigue Scale	HCFS
#384	Cancer Related Fatigue Distress Scale	CRFDS
#385	Personal Finance Wellness Scale(formally known as the 'Incharge Financial Distress/Financial Well-Being Scale IFDFW scale	PFW
#387	Seven day physical activity recall	7 Day Recall PAR
#388	Modified Baecke Questionnaire	MBQ
#391	Instrumental Activities of Daily Living Scale	IADL
#392	prostate cancer questionnaire	PPCQ-P
#394	Vulnerable Elders Survey-13	VES-13
#395	Canadian Healthcare Evaluation project questionnaire for patients	CANHELp-LITE patients
#396	Canadian Healthcare Evaluation project questionnaire for caregivers	CANHELp-LITE caregiver
#397	Short-form 8 (SF-8)	SF-8
#398	Condensed Memorial Symptom Assessment Scale (CMSAS).	CMSAS
#399	Patient Health Questionnaire-9	PHQ-9
#400	Stanford Brief Activity Survey:	SBAS
#403	International Physical Activity Questionnaire-Long Form	IPAQ-LF
#404	Adherence to exercise for older patients	AEOP
#405	Incidental and Planned Exercise Questionnaire (IPEQ)	IPEQ
#406	Tilburg Frailty Indicator	TFI
#407	CAREFALL Triage Instrument	CTI
#408	Skindex General Dermatological Questionnaire	Skindex-29,
#409	Dermatologic Life Quality Index	DLQI
#410	Dermatology quality of life scales	DQOLS
#412	Disabilities of Arm, Shoulder and Hand	DASH
#413	Kwan's Upper extremity/Shoulder Problem Scale	KAPS
#415	Upper Limb Disability Questionnaire	ULDQ
#416	Wingate questionnaire	WINGATE
#417	Linear Analogue Self Assessment	LASA
#421	Patient Outcome of Surgery – Head/Neck	POS-H/N
#423	Skin Cancer Quality of Life	SCQOL
#424	Skin Cancer Quality of Life Impact Tool	SCQOLIT
#426	Geriatric Depression Scale-30 item	GDS-30
#427	Beliefs about Medicines Questionnaire	BMQ
#428	Consumer Assessment of Health Plans Study	CAHPS Cancer
#429	Patient Activation Measure	PAM-18
#431	Patient Satisfaction with Navigation-Interpersonal scale	PSN-1
#434	Sickness Impact Profile- physical function	SIP
#435	Brief Pain Inventory- 9	BPI
#436	McGill Pain Questionnaire	MPQ
#440	Piper Fatigue Scale -R	PFS-R
#441	Functional Assessment of Chronic Illness Therapy-Fatigue	FACIT-F
#442	Insomnia severity Index	ISI
#443	Index of nausea and vomiting	INVR
#444	Functional living index Cancer	FLIC
#445	Cancer Dyspnea Scale	CDS
#446	Derogatis Interview for Sexual Functioning-Self report	DISF-SR
#447	Sexual Function Questionnaire	SFQ
#448	International Index of Erection Dysfunction	IIEF-EF
#450	Spielberger State Trait Anxiety Scale	STAI
#451	Centre for Epidemiological Study (CES)-Depression Scale	CES-D

Dataset ID	PROM/PREM Title	Abbreviation
#453	Mental Adjustment to Cancer	MAC
#455	Ways of Coping Questionnaire	WCQ
#457	Cancer Care Monitor	CCM
#458	Functional Assessment of Cancer Therapy- Biological Response Modifiers	FACT-BRM
#460	Hand foot syndrome -14	HFS-14
#462	European Organisation for Research and Treatment of Cancer (EORTC)-Prostate cancer 25	EORTC QLQ-PR25
#463	International Prostate Symptom Score	IPSS
#464	Prostate Cancer Quality of Life Instrument	PC-QOL
#465	Prostate Cancer Symptom Indexes and Symptom Distress Scales	PCSISDS
#467	Prostate Cancer Treatment Outcome Questionnaire	PCTO-Q
#468	Prostate Symptom Self-Report	PSSR
#471	The Radiumhemmets Scale of Disease-Specific Symptom Assessment—Prostate Cancer	RSSSA-PC
#472	University of California Los Angeles-Prostate Cancer Index	UCLA-PCI
#473	Dale: Symptom Scale	DALE
#474	Clark: Symptom Indexes	CLARK
#475	EPIC for Clinical Practice	EPIC CP
#476	Estudio sobre la Calidad de Vida en el Cáncer de Próstata-Calidad de Vida (ESCAP-CDV)	ESCAP-CDV
#477	Functional Assessment of Cancer Therapy- Prostate	FACT-P
#479	Male Urogenital Distress Inventory	MUDI
#480	National Comprehensive Cancer Network (NCCN)/FACT-P Symptom Index-17	NCCN/FACT-P SI-17
#482	German prostate specific module	PSM
#483	Late effects on normal tissue	LENT/SOMA
#485	QII	QII
#487	STAR questionnaire	STAR
#489	General Health Questionnaire-60	GHQ-60
#492	Sherbrooke Postal Questionnaire	SPQ
#493	Beck Depression Inventory-21	BDI
#494	Brief Cancer Impact Assessment	BCIA
#495	Cancer Problems in Living Scale	CPILS
#498	Quality of Life Cancer Survivors	QoL-CS
#499	General Fatigue Scale	GFS
#502	Swedish Occupational Fatigue Inventory	SOFI
#503	Hirai Cancer Fatigue Scale	HCFS
#504	Cancer Empowerment Questionnaire	CEQ
#505	Health Education Impact Questionnaire	HEIQ
#506	Cyber Info-Decisional Empowerment Scale	CIDES
#507	Patient Satisfaction with Healthcare for Prostate Cancer	CaPSURE Satisfaction
#508	European Organisation for Research and Treatment of Cancer satisfaction with cancer care core questionnaire	EORTC PATSAT-C33
#509	Assessment of Patient Perspectives on Cancer Care	APECC
#510	Cancer Information Importance/Satisfaction Scale	CIISS
#511	Patient Satisfaction With Cancer Care	PSCC
#512	Health Utility Index Mark 3	HUI3
#513	Assessment of Quality of Life-8 Dimensions	AQoL-8D
#514	Quality of Wellbeing-Self administered	QWB
#515	Female Sexual Function Index-Breast Cancer	FSFI
#516	Beck Anxiety Inventory	BAI
#517	Beck Depression Inventory–Short Form	BDI-SF

Dataset ID	PROM/PREM Title	Abbreviation
#518	Brief Edinburgh Depression Scale	BEDS
#519	Impact of Event Scale-Revised	IES-R
#520	Mood Evaluation Questionnaire	MEQ
#521	Profile of Mood States-Short form	POMS-SF
#522	Rotterdam Symptom Checklist	RSCL
#523	Symptom Distress Scale	SDS
#524	Health Care Needs Survey	HCNS
#525	Needs Assessment of Family Caregivers-Cancer	NAFC-C
#526	Mishel Uncertainty in Illness Scale-Short form	MUIS-SF
#527	Medication Use Questionnaire	MedUseQ
#528	Geriatric Depression Scale-15 item	GDS-15
#529	Multimorbidity Treatment Burden Questionnaire	MTBQ
#530	European Organisation for Research and Treatment of Cancer satisfaction with cancer care - Outpatient satisfaction complementary module 7	EORTC OUT-PATSAT7
#531	European Organisation for Research and Treatment of Cancer satisfaction with cancer care - Communication26	EORTC QLQ-COMU26

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