EUonQoL

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

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Summary

Abbreviations and Definitions

AE	Adverse events
QOL	Quality of Life
PRO	Patient reported outcomes
EORTC	European Organisation for Research and Treatment of Cancer
QLG	Quality of Life Group
WHO	World Health Organisation
ICF	International Classification of Functioning, Disability and Health
CAT	Computer Adaptive Testing
HRQOL	Health related quality of life
EU	European Union
EUonQoL-Kit	European Oncology Quality of Life toolkit
WP	Workpackage

General Information

This report provides detail on the results from workpackage 4 (WP4). This workpackage is part of an EU funded project “"EUonQoL-Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe” grant agreement n° 101096362). The overall project aims to develop, pilot and validate the European Oncology Quality of Life toolkit (EUonQoL-Kit), a patient co-researcher driven, unified system for the assessment of quality of life (QoL) based on the evaluations and preferences of cancer patients and survivors. The EUonQoL-Kit will be developed from the patient perspective, administered digitally, available in all 27 European Union (EU) and associated countries languages, applicable for use in future, periodic surveys to contribute to the EU’s mission on cancer and inform health policy. Workpackage 4’s aims are to develop the toolkit using mixed methods and then present information of initial usability testing. This report describes the results of the mixed methodology and process of triangulation of results to develop the toolkit.

The table below summaries the different workpackages.

Table 1: Overview of the different workpackages

Workpackage (WP)	Workpackage Title
WP1	Ethics
WP2	Involvement of stakeholders and patients
WP3	Review of existing HRQoL databases, measures & item libraries
WP4	Development of the EUonQoL-Kit
WP5	Cross-cultural determinants of the QoL and linguistic and cultural adaptation of EUonQoL-Kit
WP6	Digital tools for data collection
WP7	EUonQoL-Kit Pilot Survey
WP8	Implementation
WP9	Dissemination
WP10	Project Management/Coordination

Study Summary

The study presented in this report describes WP4 and is aimed at developing a draft of the EUonQoL-Kit for pilot testing in the following phases of the EUonQoL project. This outcome will be achieved using mixed methods methodology to explore patient views and preferences through combining: 1) patient interviews, 2) Delphi survey for multiple stakeholders, and 3) initial usability testing. This report outlines the results from parts 1 (interviews) and 2 (Delphi survey) and describes the process of triangulation with the results from the systematic reviews (WP3) and consensus meeting and then finally the selection of items for the draft toolkit. This iterative process was carried out in parallel across seven centres in six countries (Table 2) and the final consensus meeting included representation from co-researchers, and the executive committee (ExCo) and stakeholder board.

Table 2: Participating Centres

COUNTRY	CENTRE NAME	ACRONYM
UK	Leeds Cancer Centre	LEEDS
IT	Fondazione IRCCS Instituto Nazionale Tumori-Milano	INT
FR	Institut Gustave Roussy,	GR
FR	Institut Curie	CURIE
NL	Netherlands Cancer Institute	NKI
DE	German Cancer Research Center	DKFZ
DK	Rigshopitalet, Copenhagen	RH
DK	Bispebjerg Hospital, Copenhagen	BH

Compliance

All aspects of the study were undertaken in accordance with the MRC Good Research Practice guidelines, Good Clinical Practice (GCP) guidelines, the Data Protection Act (2018), and the EU Clinical Trials Directive (although this study does not come under the scope of the directive).

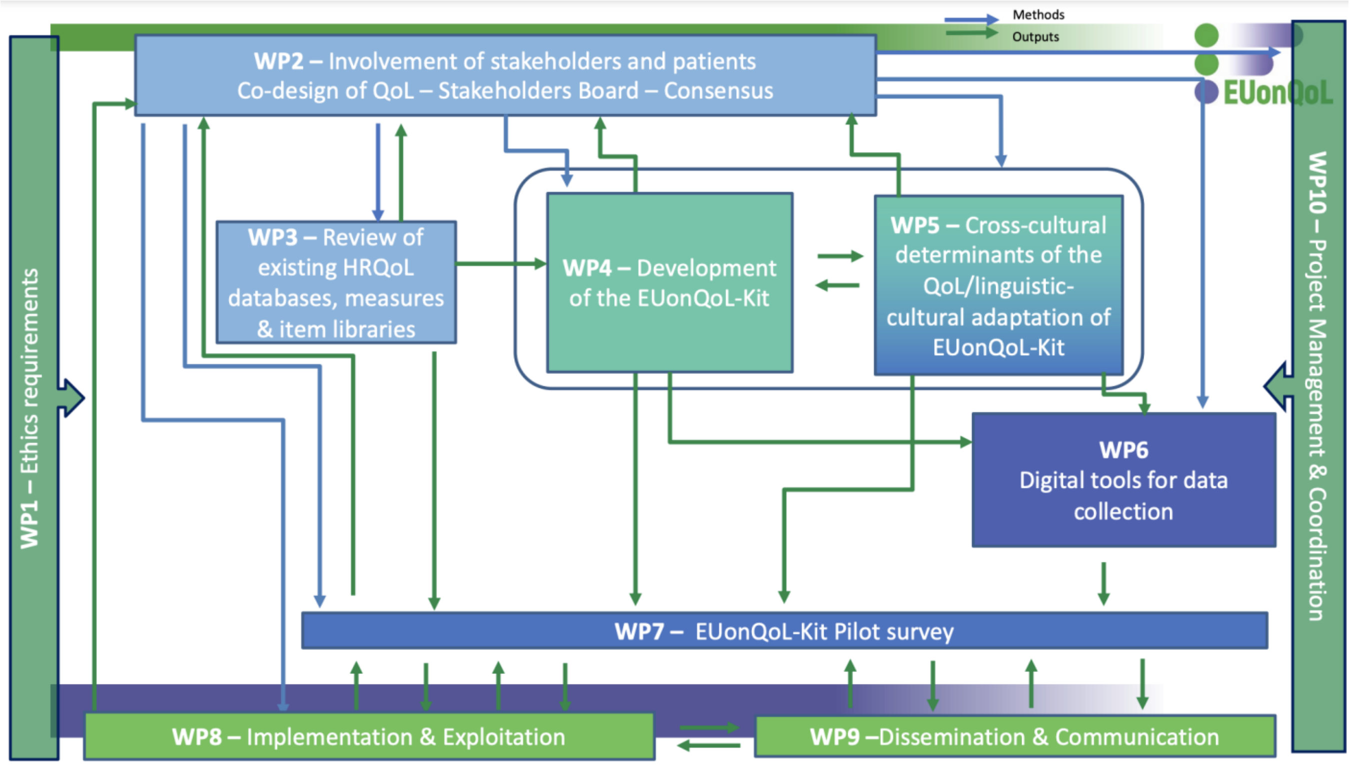
Funder

The study is funded by an EU Horizons 2020 grant (EUonQoL - 101096362 - DLV-101096362).

Flow diagram of Overall Project

This flow diagram outlines the overall EUonQoL project. This protocol outlines procedures for workpackage 4 (WP4) – development of the EUonQoL-Kit.

Figure 1: Flow of project


Methods
Outputs
EUonQoL
WP2 – Involvement of stakeholders and patients
Co-design of QoL – Stakeholders Board – Consensus
WP1 – Ethics requirements
WP3 – Review of existing HRQoL databases, measures & item libraries
WP4 – Development of the EUonQoL-Kit
WP5 – Cross-cultural determinants of the QoL/linguistic-cultural adaptation of EUonQoL-Kit
WP6
Digital tools for data collection
WP10 – Project Management & Coordination
WP7 – EUonQoL-Kit Pilot survey
WP8 – Implementation & Exploitation
WP9 –Dissemination & Communication

Report Summary

Aim

The overall aim of this project is to develop a questionnaire toolkit called the EUonQoL-Kit intended to assess quality of life (QOL) across the whole cancer continuum of patients within Europe. The toolkit will assess QOL in three target groups of patients:

(A) receiving active treatment (curative and non-curative)
(B) cancer survivors for patients aged 18 years and older
(C) receiving palliative care

This stage (WP4) of the project aims to develop a draft of the EUonQoL-Kit for initial usability testing. This study uses co-design and mixed methods approaches, working with patients and survivors as co-researchers (WP2) to explore patient preferences and priorities regarding QoL domains and subdomains in each part of the cancer continuum.

Method

The research involved an iterative process carried out in parallel across six countries (UK, The Netherlands, France, Denmark, Germany and Italy) using mixed methods methodology to explore patient views and preferences through patient interviews and a Delphi survey prior to usability testing. Existing QoL frameworks were used to structure the content of the interviews and Delphi survey.

A purposive sample of patients in target groups A, B and C, were invited to take part in semi-structured interviews. Interview data was analysed using a thematic framework analysis. Patients were asked for their views on QOL issues to cover in the toolkit, asked to rank the different subdomains, based on existing frameworks, for relevance and importance for inclusion in the toolkit and encouraged to highlight gaps where new themes/domains are needed. The percentage of patients reporting issues as essential is presented alongside illustrative verbatim examples and new themes emerging.

A purposive sample of 135 participants took part in the Delphi survey. Participants were a combination of patients and health care professionals who self-allocated to target groups A, B or C. A maximum of three rounds of the Delphi survey were planned to achieve consensus. The results of the interviews and Delphi were then combined with the results from two systematic reviews (WP3; report 3.1) using a process of triangulation. These combined results were presented at a stakeholder consensus meeting on 11th October 2023 for consensus voting using nominal technique to decide on subdomains for inclusion. Using a further process of triangulation, all results were combined, prioritising patient and stakeholder views, to decide on the subdomains for inclusion.

A modular approach to questionnaire design was agreed for the development of the EUonQoL-Kit, aiming to include common metrics of core QoL domains across the cancer continuum as well as issues specific to the target groups. Our aim is to use a computer adapted testing (CAT) model to measure subdomains if available. If a CAT approach was not available for a particular subdomain, a review of the existing validated instruments (WP3) was carried out to provide the best item(s) to describe a particular subdomain. If no high quality items exist, or novel concepts emerged, new items were developed according to EORTC module development principles. The final list was approved by the ExCo and co-researchers.

Results

71 patients were enrolled into the interview study across the six countries (A=12; B=33; C=26). 149 participants made up of patients and health care professionals (HCP) (A=54; B=68; C=27) took part in round 1 (R1) of the Delphi survey. 60.4% of respondents were patients (n=90) and 39.6% were HCPs (n=59). 82 participants took part in R2 (A=32; B=37; C=13) and 89 in R3 (A=27; B=47; C=15). Consensus after 3 rounds was achieved for 20 out of all 47 items.

Healthcare was an emerging theme from the interviews and Delphi, with participants highlighting the importance of communication, involvement in decision-making and the care pathway as key components impacting on their QoL. We integrated these results iteratively into future frameworks.

In general, the consensus views, echoed the result found in the interviews and Delphi survey. The overall results found that within the existing QoL framework concepts, for the physical health domain, pain and fatigue symptoms were rated most highly across all target groups. Other symptoms were found to be too specific to cancer-specific issues and not general across all target groups, however, overall symptom burden from treatment or disease was found to be relevant across all groups. A few symptoms were highly relevant however in the palliative care group, in particular, nausea. Physical mobility and activity did not rate as highly by was highlighted as important to include, in particular the impact of cancer on ability to carry out physical exercise, work or leisure activities. Sexual activity was rated highly only in the survivor group in the interviews.

Within the social health domain, impact on social role and work was ranked highly as well as impact on family and partner relationships. In the interviews, impact on financial circumstances was also highly rated and this was rated as highly relevant for inclusion within the consensus meeting. Within the psychological health domain, emotional function issues such as anxiety and depression ranked highly as well as fear of recurrence or cancer progression. Within the overall health domain, overall QoL, and overall health were rated highly. Within the emerging healthcare theme, communication with health care professionals, involvement in decision making and the care pathway were all rated very highly.

The list of subdomains was mapped onto 60 CAT items, 24 items from the EORTC item library and 1 novel item in the first draft of the Toolkit.

Discussion

The final list of items will be tested within WP4, within a usability study of approximately 60 patients from each of the six countries and the target groups as before.

Introduction

The improvement or preservation of quality of life (QoL) is one of the three pillars of the EU Mission on Cancer, which underpins the needs of patients from cancer diagnosis across treatment, survivorship, and advanced terminal stages of non-curable cases. The burden of cancer on quality of life is well recognised (2, 3). While clinical trials and real-world data show the positive effects of routine QoL assessment on patient wellbeing and use of health care resources, full implementation of QoL assessment in routine oncology practice is not yet part of standard of care and health care systems do not take into consideration QoL measures when devising clinical, societal, and healthcare policymaking systems (4, 5).

Validated patient-reported questionnaires or patient-reported outcomes (PROs) cover symptoms from the disease or treatment, and capture aspects of health-related quality of life (HRQoL) including patient self-reported functioning (physical, role, social function) (6-8). These terms will be used interchangeably. Within this project, we will use existing validated QoL questionnaires to develop a toolkit that is relevant for all EU cancer patients: from those on active treatment, survivors and those patients under palliative care. This project will leverage what is currently available in the literature and explore relevance and address gaps based on patients' and other stakeholders' needs. In parallel with the interview and Delphi studies that are described, a number of systematic literature reviews (WP3) have been conducted to provide a comprehensive overview of the available patient-reported outcome measurement systems in oncology and of the QoL issues described in the qualitative literature (report D3.1: Report reviews on available measurements tools). We describe a methodological process of triangulation to combine the results from the different datasets and will report these results in an expert consensus meeting to decide on the final content for the toolkit.

This study aims to inform the development of a unified PRO for the assessment of QoL in cancer patients in different phases of their disease trajectory through identifying patients' preferences and priorities through mixed methodology.

Methods

Quality of life frameworks

To structure the project, we identified a number of Health-related QoL (HRQOL) frameworks in the literature which define QoL domains for cancer patients and survivors. A systematic review of HRQOL models from 2012, recommended the use of one of three most commonly used models globally to frame research in HRQOL; WHO ICF framework; Wilson and Cleary; and Ferrans et al. update of Wilson and Cleary (9-12). Based on their analysis, they recommend the Ferrans et al. 2005 update of the Wilson and Cleary model as it includes, in addition to the original model characteristics (see Figure 2), the impact of individual and environmental factors; which in particular will be relevant when considering cultural and population diversity(11, 12).

In addition, the WHO ICF model is also highlighted as useful for use as a mapping and classification framework (10). WHO ICF specifically includes children and young adults within the framework and is used to describe the health of populations as well as individuals and therefore it may be relevant to use this framework within this study for future expansion of the work. Table 3 below describes the WHO QOL domains and facets derived from the WHOQOL development work for general assessment of population QOL (rather than cancer specific), which along with the other frameworks described have been used to structure the patient interviews to ensure comprehensive coverage (13).

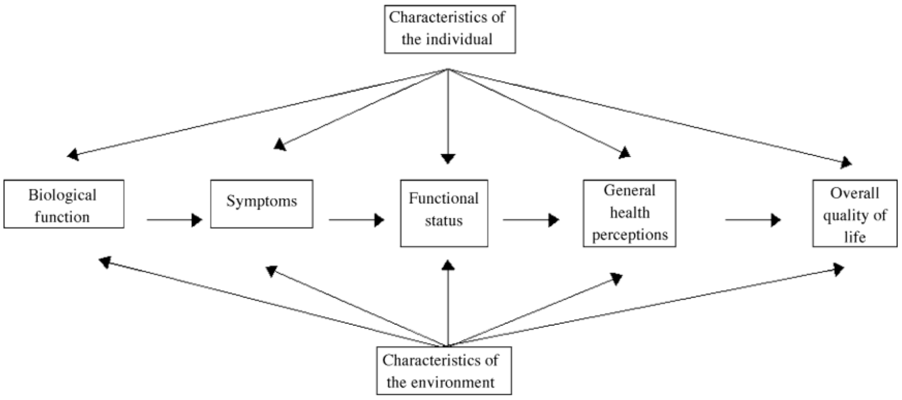


Figure 2: Adapted from Wilson and Cleary, Ferrans et al. (2005)

Table 3: WHO QOL Domains and Facets (WHO 1998)

Domain I Physical Capacity
1 Pain and discomfort
2 Energy and fatigue
3 Sleep and rest
Domain II Psychological
4 Positive feelings
5 Thinking, learning, memory and concentration
6 Self-esteem
7 Bodily image and appearance
8 Negative feelings
Domain III Level of Independence
9 Mobility
10 Activities of daily living
11 Dependence on medication or treatments
12 Work capacity
Domain IV Social Relationships
13 Personal relationships
14 Social support

15 Sexual activity	
Domain V Environment	
16 Physical safety and security	
17 Home environment	
18 Financial resources	
19 Health and social care: accessibility and quality	
20 Opportunities for acquiring new information and skills	
21 Participation in and opportunities for recreation/ leisure activities	
22 Physical environment (pollution/noise/traffic/climate)	
23 Transport	
Domain VI Spirituality/Religion/ Personal Beliefs	
Overall quality of life and general health perceptions	

In addition to these HRQOL frameworks, a recent review for the development of a survivorship module for the EORTC Quality of Life group established a number of key domains and sub-domains to consider for cancer survivors. The EORTC Quality of Life group developed an EORTC QoL cancer survivorship core questionnaire and validated the prioritized survivorship scales through a Delphi survey (IRBd20-198)(14).They used a list of QoL issues relevant to disease free cancer survivors irrespective of their cancer diagnosis (see Table 4 below).

Table 4: Survivorship domains identified within EORTC QLG Survivorship questionnaire development

Domain	Description
Physical	Ability to walk long and short distances, run, doing strenuous activities
Cognitive	Ability to concentrate, remember, think
Emotional	Feelings of anxiety, depression, anger
Role	Ability to pursue hobbies, work, recreational activities
Social	Interference of social life by cancer-related physical problems
Fatigue (4)	Tiredness, weakness, need to rest
Sleep	Problems with sleeping, falling asleep, waking up during the night
Pain (2)	Pain, interference of pain with daily activities
Symptom	Chronic side effects of various cancer treatments

Negative health outlook (7)	Worries about (health in) the future, still feeling a cancer patient, feelings of life being on hold
Work (4)	Ability to work
Health distress (3)	Worries about current health, return or spreading of cancer, another type of cancer
Body image	Perception of mental and physical functioning and physical appearance
Symptom	Being alert for symptoms and contacting doctor for these symptoms
Positive	Positive life style changes and improved self-care
Loss of	Loss of income due to cancer
Problems	Problems with insurances, loans, mortgages due to cancer
Ability to have	Worries about loss of fertility due to cancer
Worry impact	Worries about the impact of cancer on the children of the cancer survivor
Treated	Feelings of being treated differently by people around them
Social isolation (2)	Feeling that family, friends, acquaintances do not understand do not understand the impact of their cancer diagnosis on their life
Positive social	Feeling that relationships with family and friends improved, became more important
Partner	Feeling that partner relation improved
Positive impact on	Feelings about being more willing to help other, being more understanding for other people's feelings
Positive affect (4)	Feeling of increased purpose of life, life appreciation, coping, distinguishing what is important in life
Deeper	Giving a deeper meaning to the fact of having (had) cancer
Sexual problems (5)	Being uncomfortable about the idea of being sexually intimate, avoiding sexual activity, and when applicable: problems with erection/ vaginal dryness, problems during sexual intimacy, difficulties becoming sexually aroused
Sexual	Sexual interest, being sexually active
Sexual	Finding enjoyment in sexual activity

The domains and subdomains generated from the frameworks described above were used to structure the content of the patient interviews and Delphi survey to ensure comprehensive coverage (Appendix 1) (11, 15). The domains are defined as the overall higher-level concept (Social health, Psychological health and wellbeing, Physical Health and Overall QOL) and the subdomains are defined as the concepts within the high level domain (e.g. Maintaining independence, or Physical activity). For some subdomains, in particular for symptoms, further issues are outlined based on individual symptoms (e.g. fatigue and pain) which were considered as individual concepts part of a broader domain. Items (referring to questions taken from existing questionnaires) were included to illustrate a particular subdomain to assist discussion.

We updated the framework iteratively as results emerged from the Delphi survey, interviews and WP3 systematic reviews, supported by co-researchers who attended weekly WP4 meetings and the July workshop and online consensus, providing feedback on the findings.

Study Design, Measures and Analysis

Definition of the target patient population

The aim of the final toolkit is to reflect the spectrum of patients with a cancer diagnosis. Different countries have different definitions of palliative care and therefore there may be overlap and minor differences in the allocation of patients to different groups. The definitions outlined are not exhaustive of the whole cancer patient population, but they are aimed to be used in to validate the tool and to be able to distinguish three different patient populations with relative precision. There will be some overlap between the groups.

As agreed with the EUonQoL executive, the target population groups are defined throughout all stages of this study as:

A. **Active Treatment:**
    i. **curative treatment -** undergoing or recently completed curative treatment for early-stage cancers

Examples:

- Early stage 1-2 breast cancer during or up to 3 months following radiotherapy, surgery or systemic treatments

    ii. **non-curative treatment** for advanced/metastatic cancers, including disease controlling/life prolonging tumour-directed treatment (e.g. patients with metastatic disease receiving chemotherapy, immunotherapy or targeted agents)

Examples:

- Metastatic breast cancer on **1st line** palliative chemotherapy;
- Lung cancer on immunotherapy

B. **Survivors:** At least *one* year off active treatment (but can be on long-term adjuvant hormonotherapy) and being disease-free without evidence of active cancer. We will aim to recruit survivors >5 years.

Examples:

- ER/PR+ breast cancer treated with surgery, adjuvant radiotherapy and on 10 years of hormonal treatment

C. **Palliative care:** Patients with advanced cancers who meet at least one of the following criteria:

  i. Patients with projected prognosis <12 months with a Performance Status (PS)/Karnofsky (KPS) <=70 or ECOG <=2
  ii. Patients referred to a specialist palliative care team for symptom control
  iii. Patients may be receiving non-curative treatment purely for symptom control (including palliative radiotherapy and/or systemic treatment)

Examples:

- Patients with castrate-resistant prostate cancer, progressed through systemic treatment options referred for radiotherapy for bone pain;
- Metastatic breast cancer patient on **5th line systemic treatment**

Patient study population for Delphi survey and interviews

Patient were considered eligible for the study if they were:

- Age 18+, from the target groups defined above:
  - A: Active treatment; B: Survivors; C: Palliative
- Able and willing to give informed consent
- Able to read and understand local language

- Not exhibiting overt psychopathology or serious cognitive dysfunction, which would impede their being able to take part in the study.

Stage 1: Patient interviews

Patient interviews were conducted in six countries - Leeds, UK; 2 institutions in Paris, France; Copenhagen, Denmark; Heidelberg, Germany; Amsterdam, Netherlands; and Milan, Italy. A procedural overview is displayed in Figure 3. To ensure the development of a toolkit which represents the specific needs of different patient groups across the cancer trajectory we included a purposive sample of patients (Table 5), aged 18 years and older, recruited across the cancer continuum. A purposive sampling strategy was adopted to balance cancer centre, age grouping, gender, tumour group (including a proportion of rare cancers) and patient group (active treatment, palliative care, survivors). Based on previous literature, a sample size of approximately 75 patients overall was chosen to allow us to reach thematic saturation (approx. 20-25 per target group) and with an aim to enhance diversity, we aimed to recruit patients from heterogeneous backgrounds based on sociodemographic and ethnic diversity. Summarised findings were fed back via two-weekly online meetings with all centres and recruitment was stopped when emerging themes were saturated.

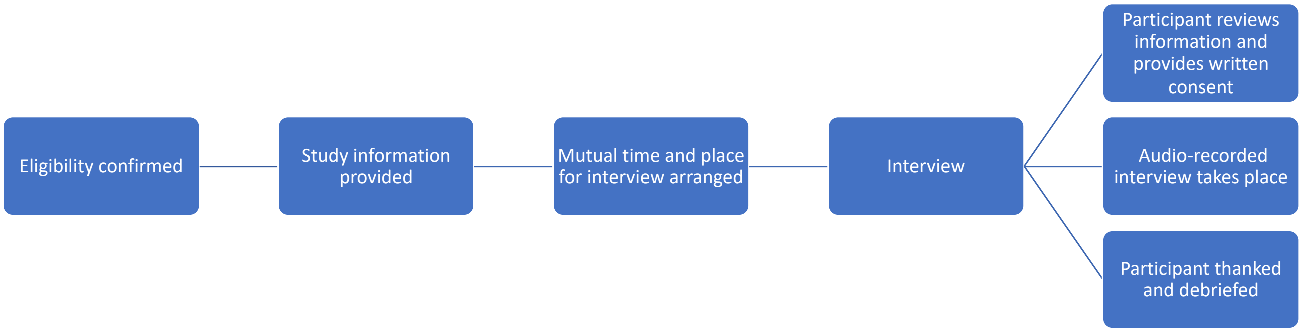


Figure 3: Flowchart for procedures: Interviews (UK)

Table 5: Purposive sampling strategy for Interviews

Disease trajectory	**Categories**	**Cancer sites**	**Institution** and number of patients enrolled in each subgroup
A: Active treatment n=25*			
Early stage, curative intent n=12/13	Surgery Radiotherapy Systemic treatments	Breast Prostate Colorectal Haematology Rare cancers	Leeds (3) INT (3) RH (2) NKI (5)
Advanced, disease control/life prolonging n=12/13	Radiotherapy Systemic treatments	Lung; Upper GI Breast/colorectal Ovarian	Leeds (3) Curie (10) RH (2)
B: Cancer survivors n=25*			
12+ months after diagnosis; treated with curative intent	12+months to <5 years; Beyond 5 years	Diverse cancer sites	Leeds (3) INT (3) GR (10) DKFZ (5) RH (3) NKI (5)
C: Palliative care n=25*			
Last 12 months of life OR Referred to specialist palliative care service	Performance status 1-2; 3-4	Range of cancers	INT (6) Curie (10) RH (3)

*Groups further balanced to account for age **18-39; 40-59; 60+;** gender, cancer centre and performance status (e.g. ECOG 0-4) with at least one patient in each grouping. We will be aspirational regarding the inclusivity and diversity (ethnic and sociodemographic) of our sample without being prescriptive and some flexibility will be allowed for recruitment in each centre (aiming overall to recruit at least 5 patients in each centre).

Existing conceptual frameworks outlined in the background section (10-12, 15), were used to develop the interview framework (Appendix 1). The different domains and sub-domains were discussed initially with open and then closed questions, and patients also provided with example questions to facilitate the discussion. Patients were asked for their preferences regarding the different domains and subdomains in terms of content, importance to them, and any missing domains. Patients were asked to consider ranking the domains and sub-domains in tiers for inclusions *(1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*.

The interviews were audio recorded for reference and the semi-structured interviews transcribed and coded by the local teams. The qualitative data produced by the interviews was analysed using a thematic framework analysis in each local language by the local coordinators. The summary of the analysis, key messages, verbatim quotes and conclusions was translated in English and the aggregated results shared for final analysis (due to data sharing restrictions). The demographics and quantitative data on importance for inclusion was summarised by descriptive statistics and summary results shared by each local team. Details on acceptability, wording and missing issues was documented for each domain.

The output of this phase is a compilation of a list of domains and subdomains for inclusion in the EUonQoL-Kit, alongside the additional issues that participants raised in the interviews.

Stage 2: Delphi survey

The same target groups of patients (A, B, C) were recruited for the Delphi survey. The participants were identified by the local researcher and those who agreed to participate were sent a link to a country specific registration page where they provided consent for the survey. Figure 4 outlines the procedure.

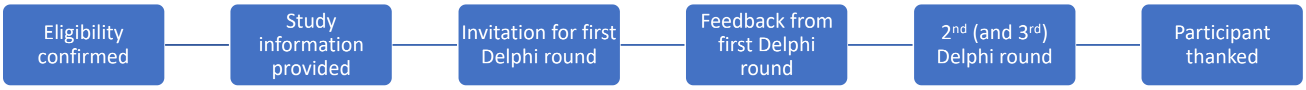


Figure 4: Flowchart for procedure: Delphi

Healthcare providers (i.e., medical specialists, primary care physicians, nurses and nursing specialists and allied health care professionals) were also invited to take part in the Delphi survey and asked to participate via local research teams. Eligible healthcare professionals were a doctor (medical, surgical, or radiation oncologist or palliative care), specialist research nurse or specialist allied health professional, or researcher involved in the care of cancer patients or involved in quality of life research.

The Delphi survey was presented in multiple languages to patients and health care professionals from six European countries (The Netherlands, United Kingdom, Germany, France, Denmark and Italy) and was circulated using the online software program DelphiManager (COMET, 2016). This software is designed to facilitate the building and management of Delphi surveys, including pseudonymisation of the data.

The sample size included approximately 135 participants overall, exceeding the target of approximately 30 participants per stakeholder group (A, B, C, HCP). Both patients and HCPs were recruited using a purposive sampling strategy similar to the interviews (Table 6) (16). The HCP's were asked to participate in the Delphi keeping in mind one specific patient group in terms of treatment phase, which resulted in their allocation to that stakeholder group during analysis

(A, B, C). As a result, each stakeholder group consisted of both patients and healthcare professionals.

Table 6. Purposive sampling strategy for Delphi.

Centre	A) Active treatment		B) Survivors	C) Palliative care	D) Health care providers	Total
	Curative	Non-curative				
LEEDS (UK)	5	5	3	0	5	18
INT (IT)	5	0	5	9	5	24
CURIE (FR)	0	0	0	0	0	0
GR (FR)	0	0	10	0	10	20
DKFZ (DE)	0	0	10	0	5	15
RH (DK)	3	2	5	5	5	20
NKI (NL)	5	0	0	10	5	20
Total						**117**

Note: if necessary, the numbers of recruited participants can be increased up to 2 units for each sub-population and centre, based on the results obtained.

*Groups further balanced to account for age **18-39; 40-59; 60+;** gender, cancer centre and performance status (e.g. ECOG 0-4) with at least one patient in each grouping. We will be aspirational regarding the inclusivity and diversity (ethnic and sociodemographic) of our sample without being prescriptive and some flexibility will be allowed for recruitment in each centre (aiming overall to recruit at least 5 patients in each centre).

The participants were invited to the first Delphi round and background information from the participants was collected via a short questionnaire. Information on age group, cancer site, treatment, gender, and sociodemographic information was collected for patients. Information on age group, gender and occupation was collected for healthcare professionals.

A maximum of three Delphi rounds was planned, irrespective of whether consensus has been reached. Each round was open for 2 weeks and one reminder was sent via e-mail after one week if the participant had not yet completed the survey round. Subsequent rounds of the Delphi were conducted after 2-4 weeks. Participants were asked to rate a list of proposed QoL domains on a

9-point Likert scale, based on the Grading of Recommendations, Assessment, Development and Evaluations (GRADE) method,(17) with scorings 1-3 representing limited importance, 4-6 important but not critical and 7-9 meaning critically important for inclusion.

The list of QoL domains used the same framework of domains and subdomains as used in the interviews and example questions were included. During the first round, participants were invited to suggest new domains that were not included in the list but considered to be important by the participant. These suggested new domains were discussed in the weekly research meetings. The research team decided that any suggested domain that was proposed more than once would be included in the second/third round of the Delphi survey.
The threshold for when consensus was reached was defined as:
At least 70% of the participants within one group rate the domain as critically important (scoring 7 to 9) and 15% or less of the participants within one group rate the scale as of limited importance (scoring 1 to 3).

If consensus was reached in one of the stakeholder groups for a particular domain, then this domain was no longer included in future surveys, even if consensus was not reached in all target populations. This decision is due to a limitation with the DelphiManager software.

For the second/third rounds, the participants were provided with a summary of the results per group for every domain, including their own responses to the QoL domains. Participants were asked to rate the domains again for which no consensus was reached in the previous round using the same scoring system.

Results from the Delphi are reported as percentage of participants who rate the domain as critically important (scoring 7 to 9) alongside the denominator for each target group (appendix 2).

Stage 3: Combining results: Triangulation

A narrative synthesis of the systematic review findings has been reported by WP3 previously. We combined WP3 results, along with the results of the WP4 interviews and Delphi survey at a subdomain level. The item level data, used to probe participants, was also included in the triangulation the results. This was supported by co-researchers attending the weekly WP4 meetings prior to the face-to-face consensus meeting held at NIVEL, Utrecht on 11th October 2023. Prior to the consensus meeting, WP4 including co-researchers, and WP3 agreed on a decision framework to support the presentation of results to the consensus.

Decision framework:

- Include if all 3 data sources are (+) concordant.
- If 2 are concordant – likely include.
- If 2 are concordant (-) for exclusion, domain to be discussed.
- If all three are concordant (-) for not including propose to exclude but discuss individual cases as raised within any of our working groups.
- The dimensions selected from the three classification systems need to have a corresponding psychometric validity within Systematic review 1.
- Note: Qualitative SR may not cover all domains in framework.

Thresholds for importance in the different methods:

For the thresholds, throughout the decision-making framework we use a traffic light colour scheme to highlight the decisions: GREEN highlights a subdomain/issue for inclusion, AMBER: requires more discussion, and RED is for subdomains/issues we will likely exclude.

i. Delphi Consensus =/> 70% (GREEN); =/> 60% (AMBER); <60% (RED)
ii. Interview consensus =/> 60% ranking the domain/item as ‘1-essential’ (GREEN); =/>50% (AMBER); <50% (RED)
iii. Included in qualitative systematic review (Yes; GREEN)
iv. Supplement with qualitative data from interviews

Consensus meeting: 11th October 2023

The combined results for all subdomains were presented at a face-to-face consensus meeting held at NIVEL, Utrecht on 11th October 2023. At this meeting members the stakeholder board and co-researchers had the opportunity to vote for the inclusion of subdomains based on the evidence presented from WP3 and WP4 as outlined above and their personal and professional experience. Members of the ExCo and WP4 and WP3 researchers were present to support discussions. A summary of the evidence collected for each of the QoL domains (Physical Health, Wellbeing and Mental Health, Social Health and Overall QoL and the emerging theme of Healthcare), was presented, using a PowerPoint presentation, during the meeting as shown in the results section.

The data from the systematic reviews, Delphi and Interviews was presented for each subdomain in term. Each subdomain was subsequently discussed according to its **usefulness** and **actionability**. The participants provided further insights about specific actions and strategies that can be taken based on the domain under examination to enhance patient well-being and cancer care, and also from a health policy perspective (usefulness and actionability). In addition, participants provided feedback on how comprehensive the proposed list of domain and subdomains is in capturing the various aspects of QoL of cancer patients in the three different disease phases (**comprehensiveness**). Participants voted individually on the relevance of *each subdomain for each target population* on a scale from 0 to 10 (where 0 is equal to “absolutely not relevant” and 10 is equal to “absolutely relevant”).

The results of the consensus for each subdomain were presented back to the consensus during the face-to-face meeting to allow for final discussion to support the final decision-making.

Following on from the consensus meeting, the results from WP3 systematic reviews, WP4 and the Consensus meeting were tabulated. A pragmatic decision was made to create a further decision framework to support the final inclusion or exclusion of subdomains, in order to balance the need to have excellent coverage of issues versus patient burden.

Decision framework for consensus results:

- To include if consensus rated >=8 (GREEN)
- To discuss further if consensus rated 6-7.9 (AMBER)
- To consider exclusion from the toolkit if rated <6 (RED)

Decision-making for subdomains

We opted to prioritise the consensus views for inclusion for the subdomains. For items rated lower than 8, and rated 'to discuss' or 'for exclusion' we referred back to our decision framework prior to the consensus meeting to see if our results were concordant or not. Informal notes were made regarding the discussions by WP4 researchers and included where relevant to supplement the rankings. A full report will be provided by WP2.

During this review process, the criteria could be varied on a subdomain issue-by-issue basis for inclusion or exclusion if appropriate arguments are proposed for doing so. Decisions about inclusion or exclusion related to the overall number of issues selected and balancing this with burden to patients. Transparent notes will be provided and shared with the executive prior to making the final decision for the draft toolkit for usability testing. For the sake of reducing repetition, we have presented the final decision table (Table 7) following on from the consensus.

Decision making for item selection

After the selection of subdomains for inclusion, a combination of WP3, WP4 and co-researchers discussed at an online meeting, a list of items for inclusion in the toolkit for usability testing and a draft of this report sent around with opportunities for feedback provided from all workpackages and co-researchers. The final draft list of items will be approved by the ExCo.

A decision-making framework was agreed on to prioritise the selection of items for the usability testing. Due to the decision to use CAT for the EUonQoL toolkit if available, EORTC CAT items were prioritised for those subdomains. This is because this is the only CAT tool validated in an EU population (WP3 results). Furthermore, to reduce time burden for patient responses, the selection of other items from the EORTC Item Library if an appropriate item is available was priorities (as these items use the same response categories of 'not at all', 'a little', 'quite a bit', and 'very much', as the CAT items). The EORTC Item Library items are also validated in an EU population (WP3 results). If an appropriate item is not available in these two PRO libraries, we will look alternative questionnaires, including the IPOS questionnaire and the IOC questionnaire, as an alternatives for selecting appropriate items (Schildmann et al., 2016; Crespi et al. 2008). Should an appropriate item not be available in any of the available PROs, we will develop a new item according to EORTC QLG guidance.

Table 7. Decision framework for Item selection.

Decision	Item selection
1	EORTC CAT (short forms or full CAT)
2	EORTC Item Library
3	Alternative questionnaire: including IPOS/IOC
4	New Item developed

Results

Interview results

Demographics

The recruitment of patients was conducted in seven centres across six countries, including UK, Italy, France, the Netherlands, Germany and Denmark. In total, 71 adult patients were enrolled into the interview study Table 8.

Table 8. Demographic and clinical characteristics of the sample.

Demographics	N	%
Gender		
Female	44	62
Male	27	38
Age	N	%
18-39	8	11.3
40-59	24	33.8
> 60	39	54.9
Target Group	N	%
A – Active Treatment	12	16.9
B – Survivors	33	46.5
C – Palliative care	26	36.6
Country	N	%
UK	9	12.7
Italy	12	16.9
France - Gustave Roussy	10	14.1
France - Institute Curie	20	28.2
Netherlands	10	14.1
Germany	7	9.9
Denmark	3	4.2
Total	71*	100
Employment	N	%
Employed	18	25.4
Unemployed	9	12.7
Retired	20	28.2
Disabled	8	11.3
Other:	4	5.6

Missing	13	18.3%
Education	N	%
None/ primary school only	0	0
High school	34	47.9
College or University	34	47.9
Missing	3	4.2
Clinical Characteristics		
Disease location	N	%
Breast cancer	25	35.2
Colorectal cancer	13	18.3
Prostate cancer	2	2.8
Lymphoma	3	4.2
Bladder cancer	2	2.8
Gynaecological cancer	6	8.5
Head and neck cancer	3	4.2
Lung cancer	5	7.0
Melanoma	2	2.8
Glioma	1	1.4
Other:	9	12.7

*N=4 more interviews to add data on from A: Active treatment group

The sociodemographic background of the participants included is outlined in Table 8. The sample consisted of both males and females, with female participants accounting for 62% of the total sample. Patients of various ages, including those in a younger range (18-39), middle age (40-59) and an older range (60+), were represented with the majority of the sample being aged 60 or over (55%). The sample was also inclusive of patients across the cancer continuum, for example, it included those on active treatment, survivors, and those receiving palliative care. The recruitment targets for survivors and palliative care patients were exceeded and was slightly lower than targeted for the active treatment group.

Country

Multiple languages and European cultures were captured within the diverse sample, with seven sites across six countries recruiting patients for this study. With the exception of one site, recruitment rates ranged from between 10-17%. France contributed the highest number of patients to the study due to the inclusion of two sites within this country.

Employment

The employment status of the participants was captured for 82% of the sample with a quarter of patients in some form of employment (full or part-time). A similar number were not in any form of employed either being unemployed (13%), or unable to work due to cancer related disability (11%). A slightly larger proportion of the sample were retired (28%).

Education

Overall, the education level of the sample was split evenly between those that completed high school only and those that continued their studies beyond high school, for example college or university. None of the included patients had an education lower than high school level.

Clinical characteristics

With regards to the clinical characteristics of the sample, a wide range of cancers were included. Breast and colorectal cancer were the most commonly included (36%,19% respectively). The Other category accounted for 13% of the sample and included multiple cancer types such as, Kidney, Neuroendocrine, Sclerosant rhabdomyosarcoma, Myeloma, Pancreas, GIST, Leukaemia and Liposarcoma.

Overall results

The results of the interviews, conducted as part of work package 4 and the development of the EUonQOL Toolkit, are presented in Appendix 4. These findings combine the results of both the qualitative and the quantitative assessments completed by participants during the interviews. Quality of life related issues were first freely discussed with the participants to provide qualitative data on the types of issues experienced. Secondly, the conceptual framework containing each subdomain and its associated items was presented, and subsequently ranked by the participant for their priority for inclusion in the Toolkit. A threshold of 60% was in place to determine the most essential subdomains according to participants. The qualitative data was used to support the quantitative data and expand the findings of this study.

Physical Health

Symptoms

Several symptoms were included within this subdomain covering a range of specific and generic issues. The results from the quantitative data indicated four key symptoms reported as 'essential' for inclusion within all three target groups, and included pain, fatigue, symptom worries/disease burden and overall impact of treatment side effects. The qualitative data collected during the interview supports that mentioned above, with multiple participants across each target group each spontaneously mentioning the importance of these symptoms.

The remaining symptoms, apart from 'Tingling and numbness in hands and feet', were found to reach the threshold in only the Palliative care group, this included sleeping problems (73%), change in eating habits-appetite loss (85%), nausea (62%), constipation (76%), diarrhoea (65%), and breathing problems (60%). Tingling and numbness in hands and feet did not meet the threshold across the three target groups.

Mobility and activity

The subdomain of mobility and activity, also referred to as physical function, was assessed by four key issues and 5 example items. The results indicated that mobility, physical exercise, and the ability to care for oneself were all rated as essential in the palliative care group (81%, 80% & 73% respectively). The scores across the Active Treatment and Survivor groups were lower and did not meet the target threshold, however when examining this further using the qualitative data it was identified that despite the lower ratings, participants recognised the importance of this domain and its inclusion and perhaps the lower ratings reflect the selection of item examples describing poorer physical function that would be expected for survivors and patients on active treatment where patient's performance status is likely to be good (e.g. ECOG 0-1). For example, mobility was spontaneously discussed multiple times within the survivor group, as was the necessity for including physical activity in both the active and survivor groups. An illustrative example of this was provided by a participant in the Survivor group who referenced how the impact of cancer, and its treatment, had on their mobility and activity, *"I really wanted to hike/bike to strengthen muscles, but this was hard because of impaired mobility".*

Sex life

The quantitative data for this subdomain indicates a level of inclusion limited to that of the Survivor group. Specifically, physical sexual problems were rated as essential in this group. The qualitative data for this group was also strongly in favour of including this domain, as shown by the various references to sex related problems during the interviews, this included aspects such as lower libido and sexual worries and concerns.

Patients in the Active group were shown to have very little interest in selecting this domain, this was shown in both the quantitative and qualitative data which universally show a low demand for including this domain. Within this target group, sex was reported as a low priority, an example to illustrate this is a quote from a participant receiving active treatment who reported, "*Sex is the last thing on my mind, I just want to focus on getting better*". This was a theme that echoed across the interviews for the Active treatment group.

As with the Active treatment group, the Palliative group also scored this domain as being non-essential. However, unlike those on active treatment, palliative patients were found to report more sexual problems during the interviews such as, lower libido and problems with sexual function. Perhaps this represents a loss in intimacy or closeness with partners as they enter the final stage of their life. This concept could be better captured by the questions around relationships.

Body image

This domain was not rated highly for inclusion with each target group rating it below the 60% threshold in the quantitative data. The qualitative did indicate that some participants across the three groups spontaneously discussed this domain and found it to be important, however this was not translated in the quantitative scores. Perhaps this domain is perceived as important at an individual level but not essential for inclusion in the Toolkit used at a population level.

Psychological/wellbeing and mental health

Several subdomains within the psychological wellbeing domain were found to be rated as essential by patients in all three-target group. These included 'Anxiety and worry', 'Psychological distress and stress' and 'Fear of recurrence'. These are presented in greater detail below.

Anxiety and worry

This subdomain included anxiety and depression. Anxiety was highly ranked as being essential by participants across Active treatment (75%), Survivors (78%) and Palliative care (73%). Qualitative data supports this finding with participants in each group spontaneously referencing the impact anxiety had across the cancer continuum. Depression was also ranked as being essential across all three groups (67%, 63% & 69% respectively). Qualitative data from those on active treatment and those categorised as survivors further support this domain.

Psychological distress and stress

The example item included for this subdomain related to experiencing feelings of stress. Consensus across the groups was found, with participants receiving active treatment rating this domain very highly (82%), in comparison to the survivors (63%) and palliative care (73%). Issues surrounding the translatability and comprehension of the terms stress and distress in non-English speaking countries was raised, in multiple languages. Further to this, the term stress is used colloquially in the UK to describe feelings of anxiety, and therefore may prove to be interpreted differently across the EU member states. The CAT item for emotional function includes multiple items including the item: 'Did you feel tense?' which is likely to capture this subdomain effectively and does not have the challenges of translatability mentioned.

Fear of recurrence

Both the Active treatment group and Survivors rated this domain as highly essential with scores of over 80% in each group. Interestingly, the Palliative care group also rated this domain as essential (68%) despite the clinical disparity between palliative patients and disease recurrence. (This may be due to the wording or may relate to fear of disease progression or fear of dying). Consideration should be paid to the item wording selected for this group. In the interviews, both fear of recurrence and fear of dying were spontaneously mentioned across the three target groups.

The remaining subdomains within psychological wellbeing included those related to, Future outlook, Memory and concentration, Positive impact, Life satisfaction, Spirituality and Meaning and purpose. The majority of which met the threshold in the active treatment group only. For instance, none of the aforementioned subdomains were essential in the Survivor group, and only future outlook, positive impact and meaning and purpose met the threshold in the palliative care group.

For spirituality, the qualitative data highlighted mixed views on the inclusion of this subdomain. Many patients felt that it was not relevant or appropriate to include such questions in the Toolkit, however some felt it was important. There was no consensus within the qualitative data. In addition to this, the participants raised concerns over the item wording, for example, reference to 'God" was controversial as it did not encompass all religious, or spiritual beliefs.

Social

The following subdomains were identified as essential across all three target groups, 'Social roles and activities' and 'Maintaining independence'. The remaining domains were essential in at least two of the groups, with the exception of 'Social isolation and connectivity' which was essential only to the Palliative care group.

Social roles and activities

The ability to work and complete daily activities was strongly supported across the three target groups (82%, 63% & 69% respectively). This subdomain was supported in the qualitative data whereby patients felt that many of the issues presented were important and or relevant as discussed during the interviews. Specifically, the ability to work, and ability to work flexibly, in a supportive environment were key to patients when discussing this subdomain. This was of particular relevance to those of a younger age demographic, and for those that had retired, it felt less strongly about this domain.

"I had to abandon my professional role, asking for a more mechanical job with no responsibilities that I could do today and maybe not tomorrow because of treatment time and side effects." Survivor.

Maintaining independence

Highly essential in the Active group (100%) that this domain be included, it was important to them that they were not a burden on their family, friends or people that are close to them. Survivors and those receiving palliative care also found this domain to be essential (60% & 63% respectively).

Family and relationships

This subdomain contained important example issues that met the threshold in at least two of the target groups, and included 'Impact on children/family', 'Fertility: Ability to have children' and 'Impact on partner relationship'. Despite the threshold in the Survivor group not being met for the 'impact on children/family', its importance was highlighted several times in the qualitative data. Concerns around fertility and the ability to have children were of importance to those on active treatment (73%), as well as for survivors (78%) and less relevant in the palliative group (54%). On the other hand, the inclusion of the impact of partner relationship was most relevant for the Active and Palliative care groups (73% & 88%). The higher impact on partner relations for these groups may be linked to lower levels of intimacy, whilst it was shown that sexual issues were not important, specifically in the active treatment group, the impact on their relationships may be capture better by this subdomain. This subdomain is somewhat dependent on the individual, for example their age for fertility issues and partner status in and/or family status.

“Of course it has an impact on relationships/family if you are in a bad mood or deeply sad.” - Survivor.

Social isolation and connectivity

Lowest ranking of the social health domains, however qualitative data was supportive of this sub-domain across all three target groups, particularly in the survivor group who frequently referenced isolation during the interviews. Feeling isolated was also highlighted as being important in the interviews for those on active treatment. Quantitative data indicated participants in the palliative care group rated this subdomain as essential for inclusion with their inclusion percentages around 71%.

"People start to pull away when the situation becomes more difficult." – Survivor.

Financial aspects

This subdomain was close to reaching the threshold across all three groups, Active treatment group (58%) was the only one to not reach the threshold. Qualitative data supported the importance of financial difficulties across the caner continuum, particularly in the Active and Survivor groups, with many participants spontaneously mentioning their experience of financial difficulties as a result of their cancer and/or treatment.

“I received 14 "no" answers from 14 different insurance agencies when I asked to be insured in order to build a house."

Self-efficacy

The concept of self-efficacy was somewhat difficult to define and capture with the example items provided to participants. Its actionability for inclusion within a Toolkit is limited due to these reasons. Patients within the Active treatment and palliative groups found self-confidence to be an important issue within this subdomain. Further to this, the item around self-help information provision was scored highly across all three groups, however, does not fully capture the original subdomain that is self-efficacy.

Overall health views

Three subdomains were covered within the Overall health domain and included 'Overall Quality of Life (QoL)', 'Overall health perspective' and 'Health behaviour change'. The 60% threshold was met in at least two of the target groups for each subdomain, with Overall QoL and Overall health perspective scoring highly within the Active treatment (83% & 75%) and Palliative care group (81% & 85%). Quantitative scores from the Survivor group were below the threshold for both subdomains and the qualitative data provided mixed responses. Participants in this group felt it may not be necessary to ask both the overall QOL item as well as the overall health question, however there was no consensus on which was the better option. Decisions over the inclusion of these domains should be considered based on scale structure. The inclusion of these two subdomains may demonstrate improvement within the survivor group.

The third subdomain within Overall health views was Health behaviour change. The data collected for this construct was somewhat challenging. This was due to the iterative nature of qualitative research, whereby the example items included in the original framework were revised and updated to better illustrate the health behaviour change domain. Qualitative feedback from participants highlighted the issue and once the more appropriate items were added, the qualitative results from the remaining interviews clearly highlighted both the importance of including this domain and the most appropriate item to include. It is to be noted that data on the new item was not available in the palliative care group. (this was due to the later interviews only being conducted in groups A and B). Further to this it should be noted that the appropriateness of including the recommended item, 'Since the diagnosis and treatment of your cancer: Have you made positive lifestyle changes (e.g., more exercise, healthy food, cutting down smoking)?', in the palliative group was raised.

Emerging domain - Healthcare

This domain emerged during the initial interviews conducted with palliative care patients. Issues around communication with healthcare professionals were frequently and spontaneously discussed. As the interviews progressed, it became clear that this was a new emerging theme that should be considered for inclusion in the Toolkit, despite this being outside of the existing QoL framework, and more akin to what is often tested in Patient-Reported Experience Measures (PREMs). The decision to include this new domain was agreed between the researchers and co-researchers present at the research workshop on 5th July 2023 – it was agreed that patients' views of their care experience hugely impacted on their QoL, and therefore was relevant for collection within the toolkit. It was therefore included in the conceptual framework for the remaining interviews. Within the domain of Healthcare, the three subdomains included, 'Communication with healthcare professionals', 'Involvement in decision-making' and 'Impact of care pathway'. Quantitative data on these subdomains were provided by those on active treatment and survivors, with both groups endorsing the inclusion of this domain. Qualitative data from these groups further supports this as well as the qualitative data obtained during the interviews with those receiving palliative care.

"On Monday, we first learnt that another catheter was going to be inserted to replace the infected one. Nothing was ever discussed with the medical team: who made the decision; who knows where and with whom." – Palliative

Delphi results

Table 9 below demonstrates the number of participants per group. Please note: from round 1 onwards the HCPs were allocated to one of the three possible stakeholder groups to which they were assigned.

Table 9. Number of recruited participants per country and stakeholder group at the start of the Delphi survey.

Centre	A) Active treatment	B) Survivors	C) Palliative care	HCP (allocated to A, B,C)	Total
LEEDS (UK)	**4**	**5**	**2**	**11**	**22**
INT (IT)	**1**	**4**	**1**	**7**	**22**
GR (FR)	**1**	**8**	**1**	**12**	**22**
DKFZ (DE)	**5**	**15**	**2**	**13**	**35**
RH (DK)	**1**	**7**	**4**	**11**	**23**
NKI (NL)	**7**	**9**	**4**	**5**	**25**
TOTAL RECRUITED	**28**	**48**	**14**	**59**	**149**

The number of participants that **completed** each Delphi round are shown in Table 10 below. These amounts contain the combined numbers per stakeholder group **across all participating countries.** Participants received an invitation for the second and third round if they had participated in the first round.

Table 10. Participants of the Delphi per round per stakeholder group in all six participating countries (according to DelphiManager software). Each stakeholder group contains both patients and HCPs.

Target Group	Round Number		
	R1	**R2**	**R3**
A (A + HCPA)	54	32	27
B (B + HCPB)	68	37	47
C (C + HCPC)	27	13	15
Total	**149**	**82**	**89**

Table 11 below shows participant information of the **patients only** in each stakeholder group.

Table 11. Sociodemographic details of patients per stakeholder group.

Information category		**A (n=32)**	**B (n=53)**	**C (n=14)****
Age	18-39	12.5%	15%	0%
	40-59	31.25%	28%	36%
	60+	50%	40%	57%
	No information available	6.25%	17%	7%
Gender	Female	59%	45%	50%
	Male	34%	38%	43%
	No information available	6%	17%	7%
Partner status	Widow	6%	2%	-**
	Married / living together with partner	47%	26%	-
	Partner / not living together	0%	4%	-
	Separated /divorced	6%	9%	-
	Single	13%	4%	-
	No information available	28%	55%	-
Highest level of education	None/ primary school only	0%	0%	-
	High school	25%	11%	-
	College or university	47%	34%	-
	No information available	28%	55%	-
Employment status	Full-time	28%	13%	-
	Part-time	3%	4%	-
	Unemployed	9%	2%	-
	Homemaker	0%	6%	-
	Student	0%	0%	-
	Retired	28%	19%	-
	Disabled	0%	0%	-
	Other	3%	2%	-

	No information available	28%	55%	-
Type of cancer	Breast cancer	28%	21%	-
	Colorectal cancer	0%	2%	-
	Prostate cancer	0%	4%	-
	Lymphoma	0%	2%	-
	Bladder cancer	3%	0%	-
	Gynaecological cancer	3%	4%	-
	Head and neck cancer	9%	8%	-
	Lung cancer	3%	0%	-
	Testicular cancer	0%	2%	-
	Melanoma	6%	0%	-
	Glioma	0%	0%	-
	Other	19%	4%	-
	No information available	28%	55%	-
Treatment received	Other	0%	2%	-
	None	9%	0%	-
	Chemotherapy	28%	30%	-
	Radiotherapy	16%	6%	-
	Hormonal therapy	0%	0%	-
	Surgery	9%	2%	-
	Stem cell transplantation	0%	0%	-
	Monoclonal antibodies (e.g. rituximab, cetuximab, trastuzumab)	0%	0%	-
	No information available	38%	60%	-

**Sociodemographic information is limited for stakeholder group C due to a malfunction in the DelphiManager software.

Table 12. Occupations of the HCP's in each stakeholder group.

HCP: Occupations per stakeholder group	**A**	**B**	**C**
Medical specialist	28%	32%	50%
Primary care physician	3%	0%	0%

Nurse	10%	9%	7%
Nursing specialist	7%	5%	7%
Researcher	7%	18%	21%
Exercise specialist	0%	5%	0%
Mental health specialist	10%	18%	7%
Other	24%	5%	7%
No information available	10%	9%	0%

Results of numbers of subdomains where consensus was made first round, second round and third round are presented below.

Consensus (for a subdomain to have limited importance or assessed to be critically important for inclusion) was reached over **20 out of all 47** items that were included in the Delphi.

Consensus was reached in **1 item** after one round:

1. Communication with HCP

This item was suggested multiple times during the first round, included in the second round, where consensus was reached immediately.

Consensus was reached in **14 items** after two rounds.

1. Ability to work
2. Fatigue/Lack of Energy
3. Fear of recurrence
4. Global health status
5. Impact of treatment side-effects
6. Impact of children/family
7. Insomnia
8. Maintain independence
9. Mobility

10. Overall quality of life
11. Pain/pain interference
12. Partner relations
13. Social isolation
14. Uncertain prognosis

Consensus was reached in another **5 items** after three rounds.

1. Diarrhoea
2. Instrumental activities /Daily living
3. Nausea
4. Social activity limitations
5. Symptom awareness

Please see appendix 2 for a more detailed report including the percentages of participants per stakeholder group that rated the item as critically important (scoring 7 to 9).

A number of items were **unlikely to reach consensus**, distinguished by low Delphi scores across all stakeholder groups during all rounds in which they were included.

Domain: **Physical health**

Subdomain: Sex life
- Sexual pleasure
- Sexual problems

Subdomain: Body image
- Body image
- Changes in weight

Subdomain: Symptoms
- Sensory neuropathy

Domain: **Wellbeing and mental health**

Subdomain: Meaning and purpose

- Meaning and purpose

Subdomain: Spirituality

- Spirituality
- Positive affect

Domain: **Social health**

Subdomain: Social roles and activities

- Leisure travel

Subdomain: Family and relationships

- Fertility: Ability to have children *(largely dependent on age of participant)*

Subdomain: Financial aspects

- Insurance

Triangulation – results

A full overview of the triangulated quantitative results can be found in Appendix 5.

These results show the summary of the results from WP3 and WP4 at the subdomain level and are summarised as follows:

- **Systematic Review (quantitative results)**: the number of QoL tools measuring the subdomain under examination is reported over the total number of available QoL tools (n/N: %).
- **Systematic Review (qualitative results)**: for each of the 3 target populations, the subdomain under examination is reported in qualitative studies (Yes/No). *Any new emerging domains/subdomains are also reported.*
- **Interviews with patients:** for each of the 3 target populations, the number of patients evaluating the subdomain under examination as relevant is reported over the total number of respondents (n/N: %). *Any new emerging domains/subdomains are also reported.*
- **Delphi survey (with patients and HCPs)**: for each of the 3 target populations, the number of participants evaluating the subdomain under examination as relevant is reported over the total number of surveyed people (n/N: %).
- **Co-researcher and Stakeholder Board members rating:** for each of the 3 target populations, the mean score from the consensus meeting is reported (range 0-10).
- **Decision:** for each of the 3 target populations, the decision on whether or not the subdomain is retained in the Toolkit (Yes/No).
- **Item Selection:** The Item(s) selected to assess the included subdomains.

The slides are highlighted in green/amber/red depend on thresholds of agreement: See Figure 5 for further details of the thresholds.

🟩	Interviews >60% Delphi >70% Participant rating >8
🟨	Interviews 50-60% Delphi 60-70% Participant rating 6-7.9
🟥	Interviews <50% Delphi <60% Participant rating <6

Figure 5. Decision threshold legend used in the triangulation of results.

An example from the triangulation table can be seen in Figure 6. The summarised data for each domain and subdomain were presented, coded, and analysed for its inclusion/exclusion in the Toolkit. GREEN highlights a subdomain/issue for inclusion, AMBER: requires more discussion, and RED is for subdomains/issues we will likely exclude.

	ACTIVE	**SURVIVORS**	**PALLIATIVE**
PHYSICAL HEALTH **Have you had pain?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	73% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	83% (12)	78% (32)	92% (26)
Delphi	75% (32)	76% (36)	85% (13)
Participant rating	**9.7**	**9.6**	**10**
Final decision	**Yes**	**Yes**	**Yes**
Item Selection	**CAT-Pain**	**CAT-Pain**	**CAT-Pain**

Figure 6. Triangulation of data, an example subdomain depicting the available data and decision on its inclusion.

Qualitative feedback from the consensus

A more detailed report from WP2 outlining the consensus meeting will follow. However, in general, the consensus views, echoed the result found in the interviews and Delphi survey. 13 participants took part in the voting process, made up of co-researchers and Stakeholder Board members. The overall results found that within the existing QoL framework concepts, for the physical health domain, pain and fatigue symptoms were rated most highly across all target groups. Other symptoms were found to be too specific to cancer-specific issues and not general across all target groups, however, overall symptom burden from treatment or disease was found to be relevant across all groups. A few symptoms were highly relevant however in the palliative care group, in particular, nausea. Physical mobility and activity did not rate as highly by was highlighted as important to include, in particular the impact of cancer on ability to carry out physical exercise, work or leisure activities. Sexual activity was rated highly only in the survivor group in the interviews.

Within the social health domain, impact on social role and work was ranked highly as well as impact on family and partner relationships. In the interviews, impact on financial circumstances was also highly rated and this was rated as highly relevant for inclusion within the consensus meeting. Within the psychological health domain, emotional function issues such as anxiety and depression ranked highly as well as fear of recurrence or cancer progression. Within the overall health domain, overall QoL, and overall health were rated highly. Within the emerging healthcare theme, communication with health care professionals, involvement in decision making and the care pathway were all rated very highly.

In addition, notes were made (AG) regarding the discussions from the meeting. These summarised comments are included under each domain and subdomain where additional comments outside of those mentioned previously (in interview or Delphi results) were discussed, however a full report on the consensus meeting will be provided by WP2:

Notes from Consensus discussions:

SOCIAL HEALTH

- **SOCIAL ROLE AND ACTIVITIES**

Discussion highlighted the importance of considering the ability to work less than full time, which is an issue not covered by the role function CAT. However, flexible and hybrid working practices are now commonplace and therefore acknowledgement of an employer's ability to support and finance more flexible working, support sick leave, modification of duties and periods of phased return to work, was felt to be important, actionable (as different countries will have different policies or legal frameworks to support employers), and a new item will be developed to measure this.

- **FAMILY & PARTNER RELATIONSHIPS**

The importance of including these issues was highlighted with discussion around worry and concern about cancer burden on others both in the short and long term and the increased incidence of relationship breakdown in particular if it is the women who is ill.

- **SOCIAL ISOLATION & CONNECTIVITY**

This echoed with many co-researchers experiences, with recalling how some people didn't know what to say to them and often withdrew, reflecting the social stigma around illness and a cancer diagnosis. Discussion around the importance of online forums as a way to connect was commented on and the importance of knowing if a patient is alone (which will be captured on the CRF) in determining how to interpret the questionnaire results and to develop subsequent interventions.

- **SELF-EFFICACY**

The participants commented on this subdomain overlapping other issues, including with caregiver and health care professional support, information given (measured in the healthcare emerging domain) and the level of health (and other) literacy.

- **FINANCIAL ASPECTS**

The importance of this issue was stressed, although overlap with the ability to work (measured in social function) was noted. The importance of this issue was particularly pertinent to the use of the toolkit for health policy as there is variable state financial support across the EU for cost of medicines.

PSYCHOLOGICAL HEALTH AND WELLBEING

- **ANXIETY & DEPRESSION**

The emotion burden and impact of cancer was highlighted. In addition, the importance of measurement of this area was highlighted to raise awareness of the impact of psychological health in cancer patients as an extension of reducing stigma more generally around psychological health issues.

- **PSYCHOLOGICAL DISTRESS**

WP4 highlighted challenges around translation of this item, and overlap with the emotional function CAT domain, which covers a broad range of issues. One of the members of the stakeholder board mentioned however, that should this issue be included that the distress thermometer has been translated and therefore we could look to this questionnaire to support translations.

- **FEAR OF RECURRENCE/DYING**

As previously noted, choice of wording for this issue and relevance was discussed. For active and palliative groups could use the words: Fear of progression/dying versus survivors: recurrence or relapse. Wording of this issue was noted to be specific to the different target groups.

- **SPIRITUALITY**

Cultural differences in religion highlighted and the importance not to mention ‘God’ in an item measuring this issue.

- **POSITIVE ASPECTS**

Differences in opinion in the room about the positive aspects of having a cancer diagnosis. 'Post traumatic growth' was discussed and some co-researchers talked about their own change in outlook and how other patients talk about this being an important experience, However, it was noted this was not a universal experience, and may perhaps depend on the prognosis of a patient.

- **CONCENTRATION & MEMORY**

Low scores from the data noted. 'Chemo brain' mentioned as a side effects of treatment. Recognised as being 'important' and to be discussed further.

PHYSICAL HEALTH

- **SYMPTOMS**

Side effects/burden symptoms were felt to be very important to capture the overall treatment/symptom burden of cancer patients when it was not possible to include all specific symptoms issues. The discussion was around inclusion of individual cancer specific versus more generalised symptoms and overall number of items on the questionnaire. A balance is needed. The impact of sleeping problems on psychological health was commented on as well as the ongoing burden of side effects for patients on, in some cases, 10 years of hormonal therapy.

- **MOBILITY & ACTIVITY**

Physical activity was not ranked highly in the consensus, however, on further discussion it was clear that the ranking had been affected by the presentation of results from a particular item: "Do you need to stay in bed or a chair during the day?" which would not reflect the majority of patients in an active treatment or survivor group. With further discussion, the participants felt confident it was important to include this item but that the use of the CAT items would ensure the items included would be more representative.

- **SEX LIFE**

Commented on the overlap of this issue with impact on partner relationships. Therefore, it was considered that it is essential to cover impact on partner relationships and perhaps sex life can be captured in those target groups where more relevant.

- **BODY IMAGE**

Very important to some patients, in particular the survivors group. The participants commented on perhaps more around attractiveness and that this could be treatment and gender specific.

- **OVERALL HEALTH**

The participants were in strong support of including these summarising dimensions and raised the question, if there might be an opportunity for patients to rank priorities. Further investigation of this suggestion will be carried out within the usability study.

- **OVERALL QOL**

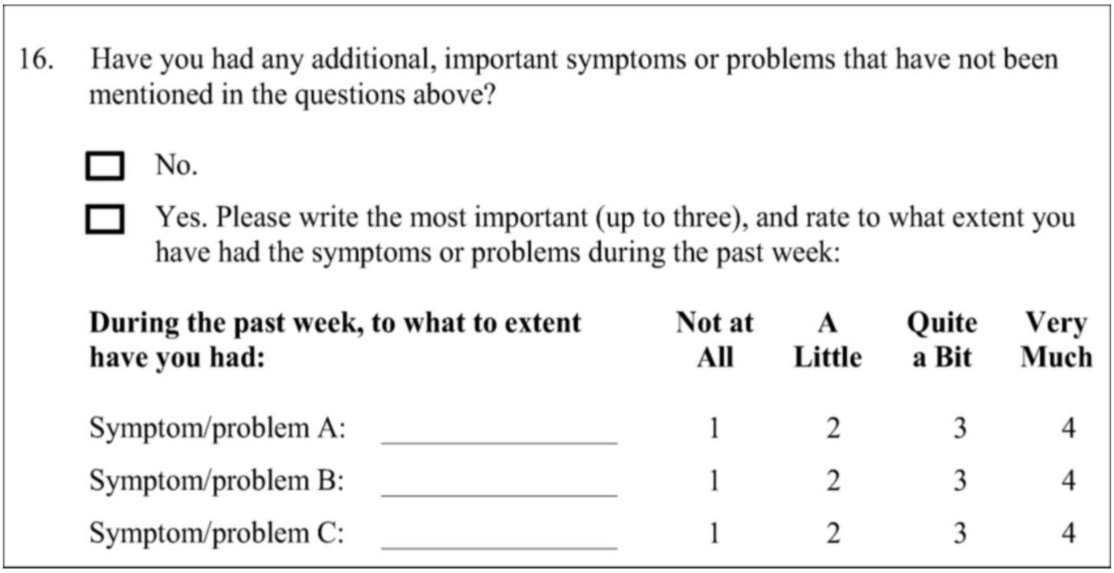
The short (one week) duration of the time frame was mentioned as potentially having less relevance for survivors, but this consideration needs to reflect the issues of recall bias, and for survivors, that it is a positive result to have a goof quality of life (i.e. it is as important to capture a good result as a poorer one).

HEALTHCARE: COMMUNICATION with HCPs, SHARED DECISION-MAKING AND IMPACT OF THE CARE PATHWAY

All agreed this was important area to measure from a policy perspective and that this has an impact on patients' QOL and therefore is important to measure. Participants felt strongly that it was important to cover communication, and shared decision-making in the toolkit as this was important for patient empowerment. In addition, the inclusion of 'information support' was highlighted as a potential issue for inclusion and how this was important for self-care e.g. "Has the information given about your physical condition and treatment been adequate?" For the more complex measurement of the impact of the care pathway, it was raised that the wording would need to include all healthcare providers, not just hospitals.

WISP: HOW TO COVER ADDITIONAL ISSUES

The participants were keen to consider how an open question could be added to the toolkit and this will be covered by the addition of WISP (see figure) to ensure the toolkit is comprehensive in its coverage but also allows flexibility.



16. Have you had any additional, important symptoms or problems that have not been mentioned in the questions above?

☐ No.

☐ Yes. Please write the most important (up to three), and rate to what extent you have had the symptoms or problems during the past week:

During the past week, to what to extent have you had:		**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
Symptom/problem A:	________________	1	2	3	4
Symptom/problem B:	________________	1	2	3	4
Symptom/problem C:	________________	1	2	3	4

In addition, a suggestion was made as to whether it would be possible to rank patients QOL priorities using the toolkit. This option will be explored during the usability testing.

Item selection

After the final decision about subdomains for inclusion for the different target population were agreed, in collaboration with WP3 items were selected in line with the recommendations from WP3 systematic review, prior to final confirmation by ExCo.

Where CAT was available, this is highlighted in the results – (see 'Item Selection' Figure 6. Triangulation of data, an example subdomain depicting the available data and decision on its inclusion. In addition, to the dynamic version of the questionnaire, we also produced static short forms of the questionnaire which are available for a range of severity – mild, moderate and severe (see example Table 13). Following the recommendations from the EORTC CAT team, for the short form versions of the CAT we agreed to include the mild versions for target group B – survivors (based on the decision that for the majority of issues patient issues are likely to have resolved to some extent, supported by our own findings in the interview study); and for target groups A – active treatment, and B – palliative care, to select the moderate option, as patients are likely to have a higher burden of issues. Based on the CAT teams' experience, the severe version of the CAT is at a more extreme end of the spectrum. However, this decision will be tested prospectively within the usability study and can be modified.

Table 13. Example of the CAT-Pain short form and its items for mild, moderate, and severe symptoms.

	CAT Scale	Item Code	Mild	Moderate	Severe
PHYSICAL HEALTH Symptoms - Pain					
Did pain interfere with your daily activities?	CAT Short Form - Pain	PA14	X	X	X
Have you had pain?	CAT Short Form - Pain	PA16	X	X	X
Has pain interfered with your social activities?	CAT Short Form - Pain	PA10	X	X	X
Has pain made it difficult for you to do the jobs that you usually do around the house?	CAT Short Form - Pain	PA2	X		
Have you had severe pain?	CAT Short Form - Pain	PA11		X	X
Have you had extreme pain?	CAT Short Form - Pain	PA3			X

The decision framework for the selection of items to assess each domain is presented in Table 7. Table 14 presents the results of the selection process, for the first draft, as mapped to the framework. EORTC CAT short forms were included where possible (60 items), items from the EORTC Item library (25 items) and novel items (1). No items were selected from other questionnaires.

Table 14. Overview of the items categorised by the decision framework.

Type	Domain	Number of items
CAT		60
	Physical Function SF	8
	Role Functioning SF	5
	Pain SF	5
	Fatigue SF	7
	Sleep SF	4
	Appetite SF	3

	Nausea/Vomiting SF	4
	Emotional Functioning SF	7
	Cognitive Functioning	5
	Social Function	8
	Financial Difficulties – SF	4
EORTC		25
	Item Library items	24
	Write in three symptoms (WISP)	1
New		1
	Novel item	1

Table 15 highlights the draft list of items identified for inclusion across the Toolkits. It is expected that the Active Treatment Toolkit (Group A) will consist of around 65 items, Survivor Toolkit (Group B) around 60 items and Palliative care Toolkit (Group C) around 67 items. The first draft of the Toolkit is provided in Appendix 6.

Table 15. The proposed list of items identified for inclusion across the Toolkits.

	Item (Note the answer stems for the majority of these items are: not at all; a little; quite a bit; very much (N/A)	ACTIVE (Group A)	SURVIVORS (Group B)	PALLIATIVE (Group C)
1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	Y	Y	Y
2	Do you have any trouble taking a long walk?		Y	
3	Do you need help caring for your feet (e.g. cutting your toenails)?		Y	
4	Do you have any trouble carrying a heavy bag upstairs?	Y	Y	Y
5	Do you have any trouble taking a long walk carrying a heavy pack on your back (e.g. a filled rucksack)?		Y	
6	Do you have any trouble taking a short walk outside of the house?	Y		Y
7	Do you need help undressing?	Y		Y
8	Do you have any trouble walking for 30 min.?	Y		Y
	<u>During the past week:</u>			

9	Have you been limited in doing light housework (e.g. dusting or making the bed)?	Y		Y
10	Have you been limited in doing physically demanding recreational activities (e.g., swimming or cycling)?		Y	
11	Were you limited in doing either your work or other daily activities?	Y	Y	Y
12	Have you been limited in doing heavy housework (e.g., washing floors or vacuuming)?	Y		Y
13	Were you limited in pursuing your hobbies or other leisure time activities?	Y	Y	Y
14	Did pain interfere with your daily activities?	Y	Y	Y
15	Have you had pain?	Y	Y	Y
16	Has pain interfered with your social activities?	Y	Y	Y
17	Has pain made it difficult for you to do the jobs that you usually do around the house?		Y	
18	Have you had severe pain?	Y		Y
19	Were you tired?	Y	Y	Y
20	Have you felt weak?	Y	Y	Y
21	Have you felt exhausted?	Y	Y	Y
22	Have you become easily tired?		Y	
23	Have you lacked energy?		Y	
24	Have you required frequent or long periods of rest?	Y		Y
25	Have you had a feeling of overwhelming and prolonged lack of energy?	Y		Y
26	Have you had trouble sleeping?	Y	Y	Y
27	Have you had trouble getting a good night's sleep?	Y	Y	Y
28	Have you had trouble staying asleep?		Y	
29	Have you woken up for long periods during the night?	Y		Y
30	Have you forced yourself to eat?			Y
31	Have you lacked appetite?			Y
32	Have you lacked interest in eating?			Y
33	Have you felt nauseated?	Y		Y
34	Have you vomited?	Y		Y

35	Has nausea or vomiting been a problem for you?	Y		Y
36	Has nausea or vomiting interfered with your physical activities like taking a walk?	Y		Y
37	Have you been constipated?			Y
38	Have you been dissatisfied with your physical appearance?		Y	
39	Have you been short of breath?			Y
	<u>During the past 4 weeks:</u>			
40	Has the treatment affected your sexual activity?	Y	Y	
41	Have you been watching yourself closely for any new symptoms?	Y	Y	Y
	<u>During the past week:</u>			
42	To what extent have you been troubled with side-effects from your treatment?	Y	Y	Y
43	Did you feel tense?	Y		Y
44	Have you felt vulnerable?	Y	Y	Y
45	Have you felt that nothing could cheer you up?	Y		Y
46	Have you felt miserable?	Y	Y	Y
47	Did you feel depressed?	Y	Y	Y
48	Did you worry?		Y	
49	Have you felt sad?		Y	
50	Have you worried about recurrence of your disease?		Y	
51	Have you been afraid of tumor progression?	Y		
52	Have you worried about your health in the future?	Y	Y	Y
53	How much has your disease been a burden to you?	Y		Y
	<u>Because of your experience with cancer:</u>			
54	Have you had to limit your life plans or goals?	Y	Y	Y
	<u>During the past week:</u>			
55	I have felt at peace with myself			Y
56	Have you had difficulty remembering things?	Y	Y	Y

57	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	Y	Y	Y
58	Have you been forgetful?		Y	
59	Have you had difficulty remembering what someone just told you?	Y		Y
60	Have you had difficulty maintaining concentration even when doing something important?	Y	Y	Y
61	As a result of your physical condition or medical treatment, have you preferred to spend time alone?		Y	
62	As a result of your physical condition or medical treatment have you been less able to see your family or friends?	Y		Y
63	As a result of your physical condition or medical treatment, have you spent less time with your family or friends?	Y	Y	Y
64	As a result of your physical condition or medical treatment, have you felt isolated from your family or friends?	Y	Y	Y
65	As a result of your physical condition or medical treatment, have you found it hard to make contact with people?	Y	Y	Y
66	Has your physical condition or medical treatment interfered with your family life?	Y	Y	Y
67	Has your physical condition or medical treatment interfered with your social activities?	Y	Y	Y
68	Has your physical condition or medical treatment interfered with your relationships with your family or friends?	Y		Y
69	Have you worried about your ability to have children?	Y	Y	
70	Have you worried that you are a burden to other people?	Y	Y	Y
71	Have you worried about becoming dependent on others?	Y	Y	Y
72	Has your physical condition or medical treatment caused you financial difficulties?	Y	Y	Y
73	Has your physical condition or medical treatment caused you financial difficulties leading to changes in your lifestyle?	Y	Y	Y

74	As a result of your physical condition or medical treatment, have you had less money to spend on yourself (e.g., for buying yourself something that you would like to have but don't necessarily need)?	Y	Y	Y
75	As a result of your physical condition or medical treatment, have you had difficulties paying any of your regular expenses (e.g. rent, insurance, phone)?	Y		Y
76	Have you had problems with obtaining insurance, loans, and/or a mortgage?		Y	
77	NEW. Have you been satisfied with the support received from your employer e.g. arranging flexible working?	Y	Y	Y
78	Since the diagnosis and treatment of your cancer: Have you made positive lifestyle changes (e.g., more exercise, healthy food, cutting down smoking)?	Y	Y	
	We are interested in your MOST RECENT experience of the care you have received and the communication you have had with the professional(s) who treat you.			
79	Have you been satisfied with your communication with your professional(s)?	Y	Y	Y
80	Have you felt that you and your professional(s) had a shared understanding of your disease and treatment?	Y	Y	Y
	How would you rate the services and care organisation of the most recent care you have received, in terms of:			
81	The provision of follow-up by the different caregivers (doctors, nurses, physiotherapists, psychologists, etc.) after treatment?	Y	Y	Y
	During the past week:			
82	Have you felt satisfied with the care you have received?	Y	Y	Y
83	Have you felt satisfied with the information you have received (e.g. about the disease and its treatment)?	Y	Y	Y
	For the following questions please circle the number between 1 and 7 that best applies to you.			
84	How would you rate your overall quality of life during the past week?	Y	Y	Y

85	How would you rate your overall health during the past week?	Y	Y	Y
86	Have you had any additional, important symptoms or problems that have not been mentioned in the questions above?	Y	Y	Y
	<u>Yes, please write in the most important (up to three), and rate to what extend you have had the symptoms or problems during the past week:</u>			
	Symptom/problem A: Symptom/problem B: Symptom/problem C:			
	Total items	65	60	67

Discussion

This report provides an overview of the initial studies within WP4 and describes the process of triangulation of results (along with relevant WP3 data) as well as quantitative results and notes made from the consensus process. In particular, it describes the inclusion of Healthcare as an emerging theme from the work, which is outside of traditional QoL conceptual models, based on the high importance and relevance placed on these issues by the patients and stakeholders involved in the work.

This initial draft list of items presented here (following potential further modifications based further comments from co-researchers and stakeholders), will be tested within WP4, performed on a purposive sample of approximately 60 patients from each of the six countries and in the target patient groups as before. Participants will be administered the EUonQoL-Kit, using an online or paper version, with subsequent cognitive debriefing interview to establish acceptability and perspectives regarding the dimensions included in the EUonQoLKit. Patient's preferences, facilitators, and barriers regarding digital methods of distributing QOL questionnaires will be explored as well as the option for ranking of QOL priorities as emerged from the October consensus meeting. Along with input from co-researchers, the findings from the usability testing will enable further refinement to the toolkit prior to defining the final set of questions for inclusion in the EUonQoL-Kit for pilot testing (WP7).

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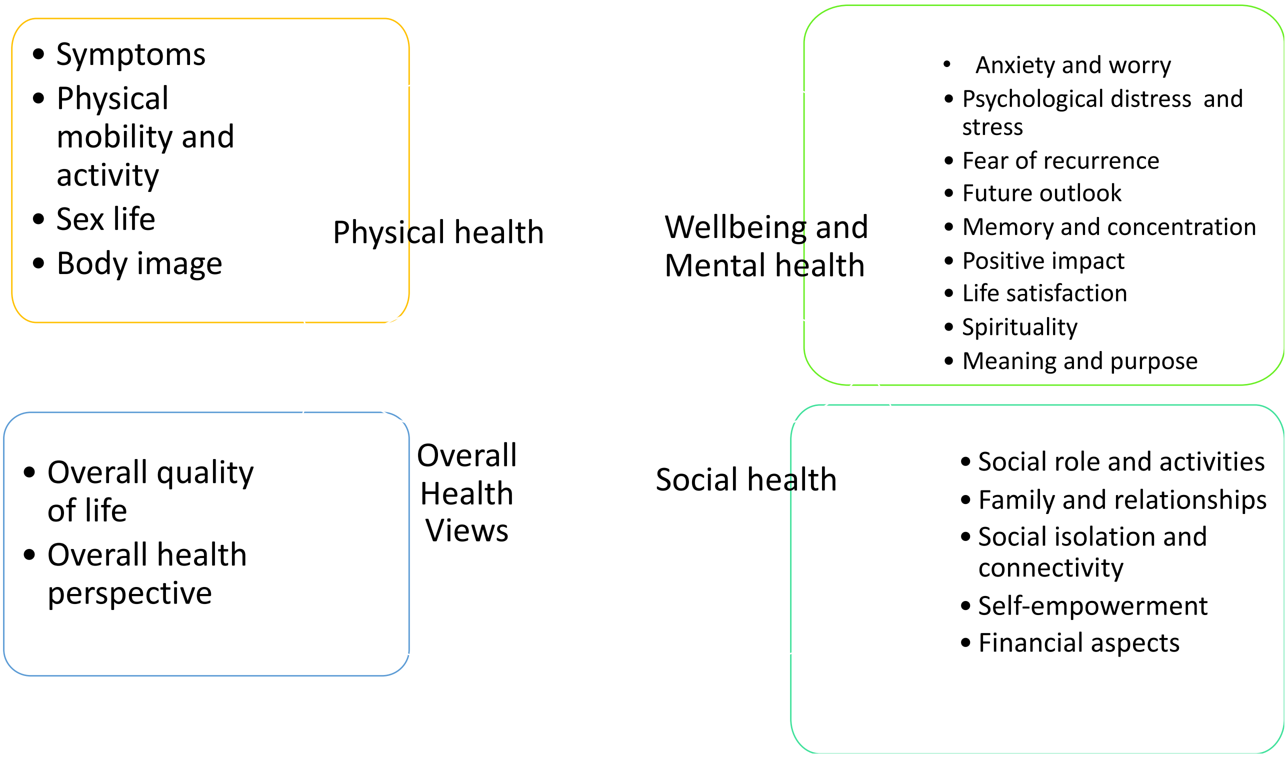
APPENDICES

1. *Health related quality of life domains*

For use within the interview study and framework analysis of this data and in the Delphi Survey (all reviewed and modified with co-researcher input)

Diagram to use as a prompt to discuss domains and subdomains:



Physical health

- Symptoms
- Physical mobility and activity
- Sex life
- Body image

Wellbeing and Mental health

- Anxiety and worry
- Psychological distress and stress
- Fear of recurrence
- Future outlook
- Memory and concentration
- Positive impact
- Life satisfaction
- Spirituality
- Meaning and purpose

Overall Health Views

- Overall quality of life
- Overall health perspective

Social health

- Social role and activities
- Family and relationships
- Social isolation and connectivity
- Self-empowerment
- Financial aspects

2. Overview of Delphi results per outcome

The results below demonstrate the percentages of participants per stakeholder group that rate an item as critically important (score 7-9) **(A = active treatment / B = survivors / C = palliative).** Percentages in the table reflect the results of R3 unless consensus was reached in R2.

Item	Participants that rated item as *critically important* *Percentages reflect R3 unless consensus was reached in R2			Consensus: At least 70% of the participants within <u>one</u> group rate the domain as critically important (scoring 7 to 9) and 15% or less of the participants within <u>one</u> group rate the scale as of limited importance (scoring 1 to 3). *Consensus reached if marked with an X
Example question	**A** Active treatment (%)	**B** Survivors (%)	**C** Palliative (%)	
Ability to Work (consensus R2) *Were you limited in doing either your work or other daily activities?*	**61**	**73**	**62**	**X**
Activities Daily Living *Do you need help with eating, dressing, washing yourself or using the toilet?*	69	32	58	
Anxiety *Did you worry?*	63	64	54	
Appetite loss *Have you lacked appetite?*	23	32	59	
Body image *Have you been dissatisfied with your physical appearance?*	41	52	33	
Changes in weight *Have you been concerned about changes in your weight?*	27	47	42	
Cognitive problems *Have you had difficulty remembering things?*	63	64	54	
Communication with HCP (consensus R2) *Have you been satisfied with the communication with your healthcare professional?*	**53**	**73**	**69**	**X**
Constipation *Have you been constipated?*	41	35	58	
Depression *Did you feel depressed?*	64	51	54	
Diarrhoea *Have you had diarrhoea?*	**46**	**35**	**76**	**X**
Distress *Have you felt stressed?*	55	49	46	
Dyspnoea *Were you short of breath?*	64	36	66	

Fatigue/Energy (consensus R2) *Have you lacked energy?*	**69**	**59**	**92**	**X**
Fear of recurrence (consensus R2) *Have you worried about recurrence of your disease?*	**72**	**74**	**85**	**X**
Fertility: Ability to have children *Have you been concerned about your ability to have children?*	32	24	25	
Financial difficulties *Has your physical condition or medical treatment caused you financial difficulties?*	59	46	51	
Future Life plans *Have you had to limit your life plans or goals?*	69	50	54	
Global health status (consensus R2) *How would you rate your overall health during the past week?*	**69**	**73**	**60**	**X**
Impact of treatment side-effects (consensus R2) *To what extent have you been troubled with side-effects from your treatment?*	**72**	**68**	**85**	**X**
Impact on children/family (consensus R2) *Has your physical condition or medical treatment interfered with your family life?*	**75**	**59**	**85**	**X**
Insomnia (consensus R2) *Have you had trouble sleeping?*	**49**	**65**	**92**	**X**
Instrumental Activities Daily Living *Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?*	**72**	**39**	**58**	**X**
Insurance *Have you had problems with obtaining insurance, loans, and/or a mortgage?*	28	30	33	
Leisure activities -Hobbies *Were you limited in pursuing your hobbies or other leisure time activities?*	57	48	67	
Leisure travel *Have you been limited in your ability to travel?*	30	27	24	
Lifestyle changes *Have you made positive lifestyle changes (e.g. more exercise, healthy food, cutting down smoking)?*	68	55	54	
Maintain independence (consensus R2)	**69**	**73**	**62**	**X**

Have you worried that you are a burden to other people?				
Meaning and purpose *Do you feel that your life has more purpose?*	52	32	34	
Mobility (consensus R2) *Do you need to stay in bed or a chair during the day?*	**63**	**59**	**85**	**X**
Nausea *Have you felt nauseated?*	**59**	**45**	**76**	**X**
Overall quality of life (consensus R2) *How would you rate your overall quality of life during the past week?*	**78**	**68**	**87**	**X**
Pain/pain interference (consensus R2) *Have you had pain?*	**75**	**76**	**85**	**X**
Partner relations (consensus R2) *Is your relationship with your partner stronger?*	**69**	**65**	**92**	**X**
Physical exercise *Do you have trouble taking a long walk?*	68	52	66	
Positive affect *Has the experience of cancer helped you to distinguish between important and unimportant things in life?*	41	45	50	
Positive life outlook *Have you had a positive outlook on life in the last week?*	39	45	41	
Self-efficacy *Have you lacked self-confidence?*	69	50	66	
Sensory neuropathy *Have you had tingling or numbness in your hands or feet?*	50	37	33	
Sexual pleasure *Was sexual activity enjoyable for you?*	23	25	33	
Sexual problems (physical) *Has the treatment affected your sexual activity?*	41	32	42	
Social activity limitations *Has your physical condition or medical treatment interfered with your social activities?*	**77**	**54**	**83**	**X**
Social isolation (consensus R2) *Have you felt isolated from those close to you (e.g. family, friends)?*	**75**	**65**	**77**	**X**
Social support *I have felt able to share thoughts about life with people who are close to me.*	63	57	59	
Spirituality *I have felt at peace with myself.*	24	17	8	

Symptom awareness	**73**	**40**	**66**	**X**
How much has your disease been a burden to you?				
Uncertain prognosis (consensus R2)	**78**	**76**	**62**	**X**
Have you been worried about your health in the future?				

3. QOL domains with examples from EORTC Item Library

Health domains v1.4	Examples of questions v1.4	Examples of importance	Response
Physical health			1-4
Physical symptoms			
Pain/pain interference	Have you had pain? Not at all, A little, Quite a bit, Very much	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Energy	Have you lacked energy?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Sleeping problems	Have you had trouble sleeping?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Changes in eating habits/Loss of appetite	Have you lacked appetite? Have you had problems with your sense of taste? Have you had acid indigestion or heartburn?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Nausea	Have you felt nauseated?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Constipation	Have you been constipated?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Diarrhoea	Have you had diarrhoea?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Breathing problems	Were you short of breath?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

Tingling and numbness with hands and feet	Have you had tingling or numbness in your hands or feet?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Symptom worries	How much has your disease been a burden to you? Have you been watching yourself closely for any new symptoms?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Impact of treatment side-effects	To what extent have you been troubled with side-effects from your treatment?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Mobility and activity			
Mobility	Do you need to stay in bed or a chair during the day?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Physical exercise	Do you have any trouble taking a short walk outside of the house? Do you have any trouble taking a long walk?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Ability to care for yourself	Do you need help with eating, dressing, washing yourself or using the toilet?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Lifting and housework	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Sex life			
Sexual problems (physical)	Has the treatment affected your sexual activity?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

	Have you worried about your ability to have sexual intercourse?		
Sexual interest	Has sexual activity been enjoyable for you? Have you had problems becoming sexually aroused? Have you been interested in sex?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Body Image			
	Have you been dissatisfied with your physical appearance?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Wellbeing and Mental Health			
Anxiety and worry			
Anxiety	Did you worry? Have you felt panic?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Depression/Sadness	Did you feel depressed? Have you felt sad?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

	Have you felt motivated to continue with your normal hobbies and activities?		
Psychological distress and stress			
Distress /Stressed	Have you felt stressed?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Fear of recurrence - Not applicable if cancer has already recurred			
	Have you worried about recurrence of your disease?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Future outlook			
Future health outlook	Have you worried about your health in the future? Have you felt positive about your health?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Future Life plans	Have you had to limit your life plans or goals? Have you worried about not being able to continue working or your education?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

	I have felt able to plan for the future.		
Memory and concentration			
Memory and concentration	Have you had difficulty remembering things? Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Positive impact			
	Has the experience of cancer helped you to distinguish between important and unimportant things in life?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Life satisfaction			
Positive life outlook	Have you had a positive outlook on life in the last week? I have felt able to plan for the future	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Spirituality			
	I have felt at peace with myself	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
	I feel connected to God or to someone or something greater than myself	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

Meaning and purpose			
	Do you feel that your life has more purpose?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Social Health			
Social roles & activities			
Ability to Work	Were you limited in doing either your work or other daily activities? N/A for some	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Leisure activities - Hobbies	Were you limited in pursuing your hobbies or other leisure time activities?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Leisure travel	Have you been limited in your ability to travel?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Social activity limitations	Has your physical condition or medical treatment interfered with your social activities?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Family and Relationships			
Impact on children/family	Has your physical condition or medical treatment interfered with your family life?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Fertility: Ability to have children	Have you been worried about your ability to have children?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Partner relationship	Is your relationship with your partner stronger? N/A for some	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

Social isolation and connectivity			
	Have you felt isolated from those close to you (e.g. family, friends)? Are your relationships with family and/or friends stronger?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
	I have felt able to share thoughts about life with people who are close to me.	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Self-efficacy			
	Have you lacked self-confidence? Have you taken better care of yourself? During your current disease or treatment, how much information have you received on: Things that you can do to help yourself get well (rest, contact with others..)?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
	Have you worried that you are a burden to other people?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

Financial aspects			
Financial difficulties	Has your physical condition or medical treatment caused you financial difficulties?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Access to financial support and information	Have you had problems with obtaining insurance, loans, and/or a mortgage?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant N/A*	
Overall health views			
Overall QOL	How would you rate your overall quality of life during the past week? Very poor (1) – Excellent (7)	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	
Overall health perspective	How would you rate your overall health during the past week? Very poor (1) – Excellent (7)	1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant	
Health behaviour change	My feelings about life have changed since I have felt less well Have you worried about changes in your daily life?	*1) essential; (2) desirable; (3) optional; and (4) to be excluded as irrelevant*	

4. Interview results table

Domains - Framework v1.5	Example items presented in Framework v1.5	Active treatment	Active treatment	Survivors	Survivors	Palliative care	Palliative care
		NB1% (n)	Qualitative summary	NB1% (n)	Qualitative summary	NB1% (n)	Qualitative summary
Physical health	**Physical health**	**Physical health**	**Physical health**		**Physical health**	**Physical health**	**Physical health**
Symptoms							
Pain/pain interference	Have you had pain? Not at all, A little, Quite a bit, Very much	83 (12)	Pain	78 (32)	Pain (4)	92% (26)	Pain (2)
Energy	Have you lacked energy?	67 (12)	Fatigue (4)	69 (32)	Fatigue (5)	85% (26)	Fatigue (2)
Sleeping problems	Have you had trouble sleeping?	50 (12)	Important (2)	53 (32)	Sleeping problems (3)	73% (26)	
Changes in eating habits/Loss of appetite	Have you lacked appetite?	44 (9)	Appetite loss (2)	57 (14)	Appetite loss (2)	85% (20)	
Changes in eating habits/Loss of appetite	Have you had problems with your sense of taste?	43 (7)		56 (27)	Problems with taste	17% (6)	
Changes in eating habits/Loss of appetite	Have you had acid indigestion or heartburn?	57 (7)		42 (26)	indigestion/heart burn (2)	17% (6)	
Nausea	Have you felt nauseated?	58 (12)	Important	45 (31)	Nausea (2)	62% (26)	
Constipation	Have you been constipated?	42 (12)	Important	26 (31)	Important	76% (25)	
Diarrhoea	Have you had diarrhoea?	42 (12)	Diarrhoea (2)	31 (32)	Diarrhoea (3)	65% (26)	
Breathing problems	Were you short of breath?	58 (12)	Breathing problems (2)	35 (31)	Breathing problems (2)	60% (25)	

Tingling and numbness with hands and feet	Have you had tingling or numbness in your hands or feet?	55 (11)	Tingling H&F (3)	44 (32)	Tingling H&F (3) Skin sensitivity heat (2)	44% (25)	
Symptom worries	How much has your disease been a burden to you?	67 (12)		69 (32)		77% (26)	Symptom worries
Symptom worries	Have you been watching yourself closely for any new symptoms?	43 (7)	Symptom worries	70 (27)	Symptom monitoring (2)	62% (26)	
Symptom worries	How much has your treatment been a burden to you?	50 (4)		88 (8)	Treatment burden (2)		Symptom worries
Impact of treatment side-effects	To what extent have you been troubled with side-effects from your treatment?	75 (12)	Impact of side effects	69 (32)	Impact of side effects (3)	85% (26)	Impact of side effects (2)
Mobility and activity							
Mobility	Do you need to stay in bed or a chair during the day?	25 (12)	Not relevant	34 (32)	Mobility (2)	81% (26)	Mobility (2)
Physical exercise	Do you have any trouble taking a short walk outside of the house?	33 (12)	Physical exercise (3)	41 (32)	Physical exercise	80% (25)	
Physical exercise	Do you have any trouble taking a long walk?	0 (7)	Not important, Important	44 (27)	Important	84% (25)	
Ability to care for yourself	Do you need help with eating, dressing, washing yourself or using the toilet?	50 (12)	Important	41 (32)	Important	73% (26)	Ability to care for self
Lifting and housework	Do you have any trouble doing strenuous activities,	25 (12)	Lifting/house work, Not relevant	25 (32)	Lifting/house work (3)	54% (26)	Lifting/house work

	like carrying a heavy shopping bag or a suitcase?						
Sex life							
Sexual problems (physical)	Has the treatment affected your sexual activity?	42 (12)	Not relevant (2)	63 (32)	Sexual problems (4)	48% (25)	Sexual problems
Sexual problems (physical)	Have you worried about your ability to have sexual intercourse?	29 (7)	Not relevant (2)	59 (27)	Worry Sexual (2)	42% (24)	
Sexual problems (physical)	Has the disease or treatment affected your sex life (for the worse)?	0 (4)	Not relevant (2)	75 (8)	Important		Sexual problems
Sexual interest	Has sexual activity been enjoyable for you?	42 (12)	Not relevant (2)	47 (32)	Not enjoyable (2)	38% (24)	
Sexual interest	Have you had problems becoming sexually aroused?	29 (7)	Not relevant (2)	52 (27)	Lower libido (2)	36% (22)	Lower libido
Sexual interest	Have you been interested in sex?	29 (7)	Not relevant (2)	48 (27)	Lower libido (2)	0% (6)	Lower libido
Body Image							
Body Image	Have you been dissatisfied with your physical appearance?	33 (12)	Body image (3)	47 (32)	Body image (4)	44% (25)	Body image
Body Image	Have you worried about your appearance?	0 (4)		38 (8)	Body image (2)		Body image
Weight	Have you been concerned about changes in your weight?	25 (4)	Important	50 (8)	Weight management (2)		
Wellbeing and Mental Health							

Anxiety and worry							
Anxiety	Did you worry?	75 (12)	*Anxiety (2)*	78 (32)	*Anxiety (4)*	73% (26)	*Anxiety*
Anxiety	Have you felt panic?	57 (7)		48 (27)	*Panic*	33% (6)	
Depression/Sadness	Did you feel depressed?	67 (12)	*Important*	63 (32)	_Depression* (7)_	69% (26)	
Depression/Sadness	Have you felt sad?	43 (7)		59 (27)		33% (6)	
Depression/Sadness	Have you felt motivated to continue with your normal hobbies and activities?	71 (7)	*Good item*	62 (26)	*Important (2)*	33% (6)	
Psychological distress and stress							
Distress /Stressed	Have you felt stressed?	82 (11)	*Essential*	63 (32)	*Stress (3), Distress*	72% (25)	*Distress (2)*
Fear of recurrence							
Fear of recurrence	Have you worried about recurrence of your disease?	82 (11)	*Fear of recurrence (2)*	81 (32)	*Fear of recurrence (4)*	68% (25)	*Fear of recurrence*
Fear of recurrence	Have you been worried about dying?	33 (3)		88 (8)	*Worry of dying*		*worry of dying*
Future outlook							
Future health outlook	Have you worried about your health in the future?	90 (11)	*Uncertian prognosis*	53 (32)	*Future health worries (2)*	72% (25)	*Fear of future/treatment failure*
Future health outlook	Have you felt positive about your health?	83 (6)	*Felt positive*	48 (27)	*Important (2)*	50% (6)	*Important (2)*
Future Life plans	Have you had to limit your life plans or goals?	45 (11)	*Unable to plan for future*	47 (32)	*Important (2)*	81% (26)	
Future Life plans	Have you worried about not being able to continue working or your education?	83 (6)		41 (27)	*Worried about ability to work post treatment (2)*	72% (25)	
Future Life plans	I have felt able to plan for the future.	67 (6)	*Unable to plan for future (2)*	44 (27)	*Unable to plan for future (4)*	50% (6)	

Memory and concentration							
Memory and concentration	Have you had difficulty remembering things?	60 (10)	*difficulty remembering (2)*	38 (32)	*difficulty remembering (4)*	48% (25)	*difficulty remembering*
Memory and concentration	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	50 (6)	*difficulty in concentrating (2)*	37 (27)	*difficulty in concentrating (2)*	42% (24)	*difficulty in concentrating*
Positive impact							
Positive impact	Has the experience of cancer helped you to distinguish between important and unimportant things in life?	82 (11)		41 (32)	*Essential (4)*	72% (25)	*Benefits of disease*
Life satisfaction							
Positive life outlook	Have you had a positive outlook on life in the last week?	82 (11)	*Loss of postive outlook (4)*	47 (32)	*Important (2)*	50% (26)	*Finding positives*
Positive life outlook	I have felt able to plan for the future	67 (6)		41 (27)	*Important (2)*	33% (6)	
Spirituality							
Spirituality	I have felt at peace with myself	64 (11)	*Supported acceptance of dying, Not relevant*	16 (32)	*Important (2), Not relevant to all (2)*	58% (26)	*Important (2)*
Spirituality	I feel connected to God or to someone or something greater than myself	67 (6)	*Not relevant to all*	12 (26)	*Important, Not relevant to all (2)*	56% (25)	*Religious support*
Meaning and purpose							

Meaning and purpose	Do you feel that your life has more purpose?	64 (11)		19 (32)	*Important (2)*	62% (26)	*Important (2)*
Meaning and purpose	Because of your experience with cancer: Do you feel that your life has more purpose?	100 (3)	*Preferred item*	25 (8)	*Linked to 'future domain'*		
Social Health							
Social roles & activities							
Ability to Work	Were you limited in doing either your work or other daily activities? N/A for some	82 (11)	*Essential (3)*	63 (32)	*Essential (5)*	69% (26)	*Important (2)*
Leisure activities - Hobbies	Were you limited in pursuing your hobbies or other leisure time activities?	82 (11)	*Important (2)*	50 (32)	*Important (3)*	77% (26)	
Leisure travel	Have you been limited in your ability to travel?	73 (11)	*Important (2)*	28 (32)	*Important (3)*	69% (26)	
Social activity limitations	Has your physical condition or medical treatment interfered with your social activities?	64 (11)	*Essential*	41 (32)	*Essential (3)*	73% (26)	*Important*
Family and Relationships							
Impact on children/family	Has your physical condition or medical treatment interfered with your family life?	64 (11)	*Important (2) - impact on partner*	53 (32)	*Important (4)*	81% (26)	*Important (2)*
Fertility: Ability to have children	Have you been worried about your	73 (11)	*Important, Not relevant*	78 (32)	*Important*Age dependent (2)*	54% (24)	

	ability to have children?						
Partner relationship	Is your relationship with your partner stronger? N/A for some	73 (11)		53 (32)	*Important (2)*	88% (26)	*Important*
Partner relationship	Since the diagnosis and treatment of your cancer: Is your relationship with your partner stronger?	33 (3)	*Preferred item*	100 (3)	*Preferred item (2)*		
Social isolation and connectivity							
Social isolation and connectivity	Have you felt isolated from those close to you (e.g. family, friends)?	55 (11)	*Important (2)*	50 (32)	*Important (6)*	73% (26)	*Important*
Social isolation and connectivity	Are your relationships with family and/or friends stronger?	33 (6)	*Not important*	48 (27)	*Important*	50% (6)	*Important*
Social isolation and connectivity	I have felt able to share thoughts about life with people who are close to me.	45 (11)	*Not important*	50 (32)	*Important (3)*	69% (26)	*Important*
Self-efficacy							
Self-efficacy	Have you lacked self-confidence?	73 (11)	*Essential*	53 (32)	*Important (4), Not relevant*	60% (25)	*Important*
Self-efficacy	Have you taken better care of yourself?	50 (6)		56 (27)	*Important, Not relevant*	78% (23)	*Unable to take care of self (3)*
Self-efficacy	During your current disease or treatment, how much information have you received on: Things that you can do to help yourself get well	83 (6)	*Very important*	63 (27)	*Important (4)*	72% (25)	*Access to financial info*

	(rest, contact with others..)?						
Self-efficacy	Because of your experience with cancer: Have you been better able to cope with problems?	33 (3)		38 (8)	*Important (2)*		
Self-efficacy	Have you needed social support (e.g. family, friends, or relatives) to undergo therapy or to cope with the disease?	67 (3)	*Essential*	75 (8)	*Important*		*Important*
Maintain independence							
Maintain independence	Have you worried that you are a burden to other people?	100 (9)	*Important*	60 (25)	*Important (3)*	63% (19)	*Important (2)*
Financial aspects							
Financial difficulties	Has your physical condition or medical treatment caused you financial difficulties?	58 (12)	*Important*	69 (32)	*Important (4)*	60% (25)	*Important*
Access to financial support and information	Have you had problems with obtaining insurance, loans, and/or a mortgage?	50 (12)	*Important (2)*	71 (31)	*Important (6)*	56% (25)	
Overall health views							
Overall QOL	How would you rate your overall quality of life during the past week? Very poor (1) – Excellent (7)	83 (12)	*Essential*	50 (32)	*Mixed response (2)*	81% (26)	*Important**
Overall health perspective	How would you rate your overall health	75 (12)	*important, Essential*	44 (32)	*Mixed response (2)*	85% (26)	*Important**

	during the past week? Very poor (1) – Excellent (7)						
Health behaviour change	My feelings about life have changed since I have felt less well	43 (7)	*Wrong domain (2)*	41 (27)	*Not a good item (2)*	58% (17)	
Health behaviour change	Have you worried about changes in your daily life?	25 (4)	*Wrong domain*	20 (10)	*Preferred item*	100% (4)	
Health behaviour change	Since the diagnosis and treatment of your cancer: Have you made positive lifestyle changes (e.g., more exercise, healthy food, cutting down smoking)?	75 (4)	*best item (3), Spontaneously mentioned (2)*	75 (8)	*Preferred item (3)*		
Health behaviour change	Because of your experience with cancer: Do you take better care of yourself?	25 (4)	*Wrong domain, Important*	25 (8)	*Mixed response (2)*		
Healthcare							
Communication with HCPs	Have you been satisfied with your communication with your professional(s)?	75 (4)	*Important (2)*	75 (8)	*Spontaneously mentioned (3)*		
Involvement in decision-making	Have you felt that you and your professional(s) had a shared understanding of your disease and treatment?	75 (4)	*Important*	63 (8)	*Spontaneously mentioned (3)*		
Involvement in decision-making	In this hospital, how would you rate doctors in terms of:	75 (4)	*Important*	63 (8)	*Spontaneously mentioned (2)*		

	The attention they gave to your opinion about the choice of your treatment (in case of possible choices)?					
Impact of care pathway – more or less hospital visits vs primary care etc	The provision of follow-up by the different caregivers (doctors, nurses, physiotherapists, psychologists, etc.) after treatment?	75 (4)	*Important*	63 (8)	*Spontaneously mentioned (2)*	
Impact of care pathway – more or less hospital visits vs primary care etc	How would you rate the care received in this hospital?	50 (4)	*Important for improving healthcare*	75 (8)	*Spontaneously mentioned (3)*	

5. Triangulation analysis

The traffic light colour scheme highlight the decisions made: GREEN highlights a subdomain/issue for inclusion, AMBER: requires more discussion, and RED is for subdomains/issues we will likely exclude.

	ACTIVE	SURVIVORS	PALLIATIVE
PHYSICAL HEALTH Have you had pain?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	73% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	83% (12)	78% (32)	92% (26)
Delphi	75% (32)	76% (36)	85% (13)
Participant rating	**9.7**	**9.6**	**10**
Final Decision	**Include**	**Include**	**Include**
Item Selection	**CAT**	**CAT**	**CAT**
Symptoms - Energy Have you lacked energy?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	70% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	67% (12)	69% (32)	85% (26)
Delphi	69% (32)	59% (37)	92% (13)
Participant rating	**7.9**	**8**	**8.2**
Final Decision	**Include**	**Include**	**Include**
Item Selection	**CAT - Fatigue**	**CAT - Fatigue**	**CAT - Fatigue**
Symptoms – Sleeping problems Have you had trouble sleeping?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	46% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	50% (12)	53% (32)	73% (26)
Delphi	49% (32)	65% (37)	92% (13)
Participant rating	**7.6**	**7.5**	**8.2**
Final Decision	**Include****	**Include****	**Include**
Item Selection	**CAT**	**CAT**	**CAT**
Symptoms – Appetite			

Have you lacked appetite?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	32% (37)		
Systematic review - Qualitative	No	No	No
Interviews	44% (9)	57% (14)	85% (20)
Delphi	23% (22)	32% (40)	59% (12)
Participant rating	**5.3**	**5.2**	**5.8**
Final Decision	**Exclude**	**Exclude**	**Include****
Item Selection	**N/A**	**N/A**	
Symptoms – Nausea **Have you felt nauseated?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	49% (37)		
Systematic review - Qualitative	Yes	No	Yes
Interviews	58% (12)	45% (31)	62% (26)
Delphi	59% (22)	45% (40)	76% (12)
Participant rating	**6.3**	**4.8**	**7.5**
Final Decision	**Include****	**Exclude**	**Include**
Item Selection		**N/A**	
Symptoms – Constipation **Have you been constipated?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	32% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	42% (12)	26% (31)	76% (25)
Delphi	41% (22)	35% (40)	58% (12)
Participant rating	**6**	**4.3**	**6.5**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**
Symptoms – Diarrhoea **Have you had diarrhoea?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	19% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	42% (12)	31% (32)	65% (26)
Delphi	46% (22)	35% (40)	76% (12)
Participant rating	**6.1**	**4.6**	**6.7**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**

Symptoms – Breathing problems Were you short of breath?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	32% (37)		
Systematic review - Qualitative	No	No	No
Interviews	58% (12)	35% (31)	60% (25)
Delphi	64% (22)	36% (40)	66% (12)
Participant rating	**5.5**	**4.5**	**6.2**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**
Symptoms – Tingling and numbness Have you had tingling or numbness in your hands or feet?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	3% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	55% (11)	44% (32)	44% (25)
Delphi	50% (22)	37% (40)	33% (12)
Participant rating	**6.2**	**5.8**	**5.3**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**
Symptoms – Symptom worries How much has your disease been a burden to you?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	42% (37)		
Systematic review - Qualitative	No	Yes	No
Interviews	67% (12)	69% (32)	77% (26)
Delphi	73% (22)	40% (40)	66% (12)
Participant rating	**8.4**	**7.7**	**7.9**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Symptoms – Side effects To what extent have you been troubled with side-effects from your treatment?			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	24% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	75% (12)	69% (32)	85% (26)
Delphi	72% (32)	68% (37)	85% (13)

Participant rating	9.2	7.9	8.8
Final Decision	Include	Include	Include
Item Selection			
Mobility & Activity Do you need to stay in bed or a chair during the day?			
Original framework	Yes	Yes	Yes
Systematic review - Quantitative	30% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	25% (12)	34% (32)	81% (26)
Delphi	63% (32)	59% (37)	85% (13)
Participant rating	6.1	6.6	7.9
Final Decision	Include	Include	Include
Item Selection	CAT-PF	CAT-PF	CAT-PF
Sex Life Has the treatment affected your sexual activity?			
Original framework	Yes	Yes	Yes
Systematic review - Quantitative	32% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	42% (12)	63% (32)	48% (25)
Delphi	41% (22)	32% (40)	42% (12)
Participant rating	6.5	8	5.9
Final Decision	Exclude	Include	Exclude
Item Selection	N/A		N/A
Body Image Have you been dissatisfied with your physical appearance?			
Original framework	Yes	Yes	Yes
Systematic review - Quantitative	27% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	33% (12)	47% (32)	44% (25)
Delphi	41% (22)	52% (40)	33% (12)
Participant rating	6	7.2	4.9
Final Decision	Exclude	Include**	Exclude
Item Selection	N/A		N/A
ANXIETY AND WORRY Did you worry?			
Original framework	Yes	Yes	Yes
Systematic review - Quantitative	59% (37)		

Systematic review - Qualitative	Yes	Yes	Yes
Interviews	88% (8)	77% (30)	73% (26)
Delphi	63% (22)	64%(40)	54% (13)
Participant rating	**8.9**	**8.2**	**7.5**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
ANXIETY AND WORRY (2) **Did you feel depressed?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	70% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	67% (12)	63% (32)	69% (26)
Delphi	64% (22)	51% (40)	54% (13)
Participant rating	**7.9**	**8.1**	**8.1**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Psychological distress **Have you felt stressed?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	8% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	82 (11)	63 (32)	72% (25)
Delphi	55% (22)	49% (40)	46% (13)
Participant rating	**7.8**	**7.5**	**7.1**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection			
Fear of recurrence **Have you worried about recurrence of your disease?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	30% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	75% (8)	74% (38)	85% (13)
Delphi	72% (32)	74% (38)	85% (13)
Participant rating	**8.4**	**9.4**	**6**
Final Decision	**Include**	**Include**	**Exclude**
Item Selection			**N/A**
Future outlook 1 - Health **Have you worried about your health in the future?**			

Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	30% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	90% (11)	81% (32)	68% (25)
Delphi	78% (32)	76% (38)	62% (13)
Participant rating	**8.6**	**8.4**	**6**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Future outlook 2 – Life plans **Have you had to limit your life plans or goals?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	30% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	45% (11)	47 %(32)	81% (26)
Delphi	69% (22)	50% (40)	54% (13)
Participant rating	**7.4**	**7.3**	**6.2**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Spirituality **I have felt at peace with myself**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	27% (37)		
Systematic review - Qualitative	No	No	Yes
Interviews	64% (11)	16% (32)	58% (26)
Delphi	24% (21)	17% (40)	8% (12)
Participant rating	**5.3**	**5.5**	**6.5**
Final Decision	**Exclude**	**Exclude**	**Include****
Item Selection	**N/A**	**N/A**	
Positive impact **Has the experience of cancer helped you to distinguish between important and unimportant things in life?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	19% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	82% (11)	41% (32)	72% (25)
Delphi	41% (22)	45% (40)	50% (12)
Participant rating	**4.8**	**6**	**4.5**
Final Decision	**Exclude**	**Exclude**	**Exclude**

Item Selection	**N/A**	**N/A**	**N/A**
Meaning & Purpose **Do you feel that your life has more purpose?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	30% (37)		
Systematic review - Qualitative	No	Yes	Yes
Interviews	64% (8)	20% (30)	62% (26)
Delphi	52% (21)	32% (40)	34% (12)
Participant rating	**3.8**	**4.5**	**4.3**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**
Concentration & Memory **Have you had difficulty remembering things?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	38% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	50% (8)	40% (30)	48% (25)
Delphi	63% (22)	64% (40)	54% (13)
Participant rating	**6.8**	**7.1**	**4.8**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**
Life satisfaction **Have you had a positive outlook on life in the last week?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	N/A		
Systematic review - Qualitative	No	Yes	No
Interviews	82 (11)	47 (32)	50 (26)
Delphi	39% (21)	45% (40)	41% (21)
Participant rating	**N/A**	**N/A**	**N/A**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**
Social role & Activities **Were you limited in doing either your work or other daily activities?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	41% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	75% (8)	60% (30)	69% (26)

Delphi	61% (33)	73% (37)	62% (13)
Participant rating	**7.8**	**9.1**	**7.2**
Final Decision	**Include**	**Include**	**Include**
Item Selection	**RF CAT**	**RF CAT**	**RF CAT**
Family and Relationships (1) **Has your physical condition or medical treatment interfered with your family life?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	70% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	64% (11)	53% (32)	81% (26)
Delphi	75% (32)	59% (37)	85% (13)
Participant rating	**8.9**	**8.1**	**8.8**
Final Decision	**Include**	**Include**	**Include**
Item Selection	**SF CAT**	**SF CAT**	**SFCAT**
Family and Relationships (2) **Is your relationship with your partner stronger?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	22% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	73% (11)	53% (32)	88% (26)
Delphi	69% (32)	65% (37)	92% (13)
Participant rating	**7.8**	**7.6**	**8.9**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Social isolation and connectivity **Have you felt isolated from those close to you (e.g. family, friends)?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	24% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	55% (11)	50% (32)	73% (26)
Delphi	75% (32)	65% (37)	77% (13)
Participant rating	**8.2**	**7.6**	**8.8**
Final Decision	**Include**	**Include**	**Include**
Item Selection	**CAT-SF**	**CAT-SF**	**CAT-SF**
Self-efficacy **Have you needed social support (e.g. family, friends, or relatives) to undergo therapy or to cope with the disease?**			
Original framework	**Yes**	**Yes**	**Yes**

Systematic review - Quantitative	24% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	73% (11)	53% (32)	60% (25)
Delphi	69% (22)	50% (40)	66% (12)
Participant rating	**7.5**	**7.4**	**7.2**
Final Decision	**Exclude**	**Exclude**	**Exclude**
Item Selection	**N/A**	**N/A**	**N/A**
Maintain independence **Have you worried that you are a burden to other people?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	27% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	100% (9)	60% (25)	63% (19)
Delphi	69% (32)	73% (37)	62% (13)
Participant rating	**7.6**	**7.5**	**7.8**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Financial aspects **Has your physical condition or medical treatment caused you financial difficulties?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	46% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	58% (12)	69% (32)	60% (25)
Delphi	59% (22)	46% (40)	51% (12)
Participant rating	**8.9**	**8.8**	**7.7**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
OVERALL QOL **How would you rate your overall quality of life during the past week?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	27% (37)		
Systematic review - Qualitative	Yes	Yes	No
Interviews	83% (12)	50% (32)	81% (26)
Delphi	78% (32)	68% (38)	87% (15)
Participant rating	**9**	**8.5**	**8.8**
Final Decision	**Include**	**Include**	**Include**
Item Selection			

Overall health perspective **How would you rate your overall health during the past week?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative	27% (37)		
Systematic review - Qualitative	No	No	No
Interviews	75% (12)	44% (32)	85% (26)
Delphi	69% (32)	73% (37)	60% (15)
Participant rating	**8.3**	**8.1**	**8.2**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Health behaviour change **Since the diagnosis and treatment of your cancer: Have you made positive lifestyle changes (e.g., more exercise, healthy food, cutting down smoking)?**			
Original framework	**Yes**	**Yes**	**Yes**
Systematic review - Quantitative			
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	75% (4)	75% (8)	
Delphi	68% (22)	55% (40)	54% (13)
Participant rating	**7.9**	**8.5**	**6.3**
Final Decision	**Include**	**Include**	**Exclude**
Item Selection			**N/A**
Emergining Themes			
Communication with HCPs **Have you been satisfied with your communication with your professional(s)?**			
Original framework	**No**	**No**	**No**
Systematic review - Quantitative	38% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	75% (4)	75% (8)	
Delphi	53% (32)	73% (37)	69% (13)
Participant rating	**8.8**	**8.7**	**9**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Involvement in decision making **Have you felt that you and your professional(s) had a shared understanding of your disease and treatment?**			

Original framework	**No**	**No**	**No**
Systematic review - Quantitative	19% (37)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	75% (4)	63% (8)	
Delphi			
Participant rating	**8.7**	**8.5**	**8.5**
Final Decision	**Include**	**Include**	**Include**
Item Selection			
Impact of care pathway **The provision of follow-up by the different caregivers (doctors, nurses, physiotherapists, psychologists, etc.) after treatment?**			
Original framework	**No**	**No**	**No**
Systematic review - Quantitative	100% (18)		
Systematic review - Qualitative	Yes	Yes	Yes
Interviews	75% (4)	63% (8)	
Delphi			
Participant rating	**7.7**	**7.8**	**7.5**
Final Decision	**Include**	**Include**	**Include**
Item Selection			

6. *The proposed items identified for inclusion across the Toolkits.*

		N/A*	Not at all	A little	Quite a bit	Very much
1	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?		1	2	3	4
2	Do you have any trouble taking a long walk?		1	2	3	4
3	Do you need help caring for your feet (e.g. cutting your toenails)?		1	2	3	4
4	Do you have any trouble carrying a heavy bag upstairs?		1	2	3	4
5	Do you have any trouble taking a long walk carrying a heavy pack on your back (e.g. a filled rucksack)?		1	2	3	4
6	Do you have any trouble taking a short walk outside of the house?		1	2	3	4
7	Do you need help undressing?		1	2	3	4
8	Do you have any trouble walking for 30 min.?		1	2	3	4
	<u>During the past week:</u>					
9	Have you been limited in doing light housework (e.g. dusting or making the bed)?		1	2	3	4
10	Have you been limited in doing physically demanding recreational activities (e.g., swimming or cycling)?		1	2	3	4
11	Were you limited in doing either your work or other daily activities?		1	2	3	4
12	Have you been limited in doing heavy housework (e.g., washing floors or vacuuming)?		1	2	3	4
13	Were you limited in pursuing your hobbies or other leisure time activities?		1	2	3	4
14	Did pain interfere with your daily activities?		1	2	3	4
15	Have you had pain?		1	2	3	4
16	Has pain interfered with your social activities?		1	2	3	4
17	Has pain made it difficult for you to do the jobs that you usually do around the house?		1	2	3	4
18	Have you had severe pain?		1	2	3	4
19	Were you tired?		1	2	3	4

20	Have you felt weak?		1	2	3	4
21	Have you felt exhausted?		1	2	3	4
22	Have you become easily tired?		1	2	3	4
23	Have you lacked energy?		1	2	3	4
24	Have you required frequent or long periods of rest?		1	2	3	4
25	Have you had a feeling of overwhelming and prolonged lack of energy?		1	2	3	4
26	Have you had trouble sleeping?		1	2	3	4
27	Have you had trouble getting a good night's sleep?		1	2	3	4
28	Have you had trouble staying asleep?		1	2	3	4
29	Have you woken up for long periods during the night?		1	2	3	4
30	Have you forced yourself to eat?		1	2	3	4
31	Have you lacked appetite?		1	2	3	4
32	Have you lacked interest in eating?		1	2	3	4
33	Have you felt nauseated?		1	2	3	4
34	Have you vomited?		1	2	3	4
35	Has nausea or vomiting been a problem for you?		1	2	3	4
36	Has nausea or vomiting interfered with your physical activities like taking a walk?		1	2	3	4
37	Have you been constipated?		1	2	3	4
38	Have you been dissatisfied with your physical appearance?		1	2	3	4
	During the past week:					
39	Have you been short of breath?		1	2	3	4
	During the past 4 weeks:					
40	Has the treatment affected your sexual activity?	N/A*	1	2	3	4
41	Have you been watching yourself closely for any new symptoms?		1	2	3	4
	During the past week:					
42	To what extent have you been troubled with side-effects from your treatment?		1	2	3	4
43	Did you feel tense?		1	2	3	4
44	Have you felt vulnerable?		1	2	3	4
45	Have you felt that nothing could cheer you up?		1	2	3	4
46	Have you felt miserable?		1	2	3	4
47	Did you feel depressed?		1	2	3	4

48	Did you worry?		1	2	3	4
49	Have you felt sad?		1	2	3	4
50	Have you worried about recurrence of your disease?		1	2	3	4
51	Have you been afraid of tumor progression?		1	2	3	4
52	Have you worried about your health in the future?		1	2	3	4
53	How much has your disease been a burden to you?		1	2	3	4
	Because of your experience with cancer:					
54	Have you had to limit your life plans or goals?		1	2	3	4
	During the past week:					
55	I have felt at peace with myself		1	2	3	4
56	Have you had difficulty remembering things?		1	2	3	4
57	Have you had difficulty in concentrating on things, like reading a newspaper or watching television?		1	2	3	4
58	Have you been forgetful?		1	2	3	4
59	Have you had difficulty remembering what someone just told you?		1	2	3	4
60	Have you had difficulty maintaining concentration even when doing something important?		1	2	3	4
61	As a result of your physical condition or medical treatment, have you preferred to spend time alone?		1	2	3	4
62	As a result of your physical condition or medical treatment have you been less able to see your family or friends?		1	2	3	4
63	As a result of your physical condition or medical treatment, have you spent less time with your family or friends?		1	2	3	4
64	As a result of your physical condition or medical treatment, have you felt isolated from your family or friends?		1	2	3	4
65	As a result of your physical condition or medical treatment, have you found it hard to make contact with people?		1	2	3	4

66	Has your physical condition or medical treatment interfered with your family life?		1	2	3	4
67	Has your physical condition or medical treatment interfered with your social activities?		1	2	3	4
68	Has your physical condition or medical treatment interfered with your relationships with your family or friends?		1	2	3	4
69	Have you worried about your ability to have children?		1	2	3	4
70	Have you worried that you are a burden to other people?		1	2	3	4
71	Have you worried about becoming dependent on others?		1	2	3	4
72	Has your physical condition or medical treatment caused you financial difficulties?		1	2	3	4
73	Has your physical condition or medical treatment caused you financial difficulties leading to changes in your lifestyle?		1	2	3	4
74	As a result of your physical condition or medical treatment, have you had less money to spend on yourself (e.g., for buying yourself something that you would like to have but don't necessarily need)?		1	2	3	4
75	As a result of your physical condition or medical treatment, have you had difficulties paying any of your regular expenses (e.g. rent, insurance, phone)?		1	2	3	4
76	Have you had problems with obtaining insurance, loans, and/or a mortgage?		1	2	3	4
77	NEW. Have you been satisfied with the support received from your employer e.g. arranging flexible working?	N/A	1	2	3	4
78	Since the diagnosis and treatment of your cancer: Have you made positive lifestyle changes (e.g., more exercise, healthy food, cutting down smoking)?		1	2	3	4
	<u>We are interested in your MOST RECENT experience of the care you have received and the communication you have had with the professional(s) who treat you.</u>					

79	Have you been satisfied with your communication with your professional(s)?		1	2	3	4
80	Have you felt that you and your professional(s) had a shared understanding of your disease and treatment?		1	2	3	4

	How would you rate the services and care organisation of the most recent care you have received, in terms of:	Poor	Fair	Good	Very good	Excellent
81	The provision of follow-up by the different caregivers (doctors, nurses, physiotherapists, psychologists, etc.) after treatment?	1	2	3	4	5
	During the past week:		Not at all	A little	Quite a bit	Very much
82	Have you felt satisfied with the care you have received?		1	2	3	4
83	Have you felt satisfied with the information you have received (e.g. about the disease and its treatment)?		1	2	3	4

	For the following questions please circle the number between 1 and 7 that best applies to you.	Very poor						Excellent
84	How would you rate your overall quality of life during the past week?	1	2	3	4	5	6	7
85	How would you rate your overall health during the past week?	1	2	3	4	5	6	7

86	Have you had any additional, important symptoms or problems that have not been mentioned in the questions above?		No	Yes		
	Yes, please write in the most important (up to three), and rate to what extend you have had the symptoms or problems during the past week:					
			Not at all	A little	Quite a bit	Very much
	Symptom/problem A:	___________	1	2	3	4
	Symptom/problem B:	___________	1	2	3	4
	Symptom/problem C:	___________	1	2	3	4