STREAMLINED **GERI**ATRIC AND **ON**COLOGICAL EVALUATION BASED ON IC **TE**CHNOLOGY
FOR HOLISTIC PATIENT-ORIENTED HEALTHCARE MANAGEMENT
FOR OLDER MULTIMORBID PATIENTS

HORIZON 2020 PROGRAMME – TOPIC H2020-SC1-BHC-24-2020
Start date: 01/04/2021 - Duration: 60 months

D1.2: DATASET OF SYMPTOMS AND PROMS FOR SPECIFIC CANCER TYPES AND GENDER

Lead Beneficiary : 4-OUS

Involved Beneficiaries : 3-DIAK, 5-UCD

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Deliverable Type	Report
Dissemination Level	Public
Due Date	2022-03-31 (MONTH 12)
Pages	20
Document version	V1.5
Project Acronym	GERONTE
Project Title	Streamlined **Ger**iatric and **On**cological evaluation based on IC **Te**chnology for holistic patient-oriented healthcare management for older multimorbid patients
Grant Agreement Number	945218
Project Coordinator	Université de Bordeaux Prof. Pierre SOUBEYRAN

GERONTE Consortium

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Disclaimer and acknowledgment

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History of Changes

Version	Date	Author	Description of change
V1.0	2022-02-17	Siri Rostoft	First draft
V1.1	2022-02-24	Siri Rostoft	Revised draft
V1.2	2022-02-25	Marije Hamaker	Overview of quality of life questionnaires that were assessed added in the Annexe
V1.3	2022-03-10	Marije Hamaker	Dataset reference from ZENODO added
V1.4	2023-01-12	Marije Hamaker	Revision after input from the European Commission
V1.5	2023-02-21	Marije Hamaker	Final version after revision

Table of Content

Executive Summary

Deliverable work status

Deliverable	Completion status in %	Deviation	Data complete or to be updated
D1.2 *Dataset of symptoms and PROMS for specific cancer types and gender*	100 %	Minor deviations in content explained below; no deviation in time-line	Data complete
Associated Deliverables	D2.1 (Development of the Holis Dashboard and patient application) D4.1 (D1.1. is used as input for the new care pathway which is evaluated in the clinical trials)		
Associated Objectives	GERONTE objective O1: INFORMATION (Gather the stakeholders and data needed for patient-centred and multi-actor complex decision-making process and management).		

Description of deliverable

This deliverable reports on the development of a core dataset of symptoms and patient reported outcome measures (PROMs) for specific cancer types and gender. The dataset of symptoms and PROMs are also specific for various treatment types (such as surgery, chemotherapy, radiation therapy, and targeted therapy). Data regarding symptoms and PROMs will be reported directly from patients by the patient app Holis and made available to the health care professional consortium to support oncologic decision making and determine how the patient is best supported through their oncologic treatment trajectory and follow-up. After literature review, input was received from an expert panel of medical specialists, nurses and other health care professionals with a background in geriatric medicine or involved in cancer treatment for the four cancer types included in Geronte (breast, prostate, lung and colorectal cancer). Through an iterative process, it was decided which symptoms and PROMs were relevant and how these were best captured in data to provide to the health care professional consortium. This resulted in a list of 28 relevant symptoms and PROMs to be included in the dataset provided to the health care professional consortium based on reports from the patient. We also developed a protocol for the frequency of reporting depending on treatment type and the precise location of the patient in their treatment trajectory.

Attainment of the objectives and explanation of deviations

D1.2 *Dataset of symptoms and PROMS for specific cancer types and* is part of work-package 1 which supports GERONTE objective O1: INFORMATION (Gather the stakeholders and data needed for patient-centred and multi-actor complex decision-making process and management). This deliverable covers one subobjective:

- Determine which data are best to involve the patient in their recovery process, through real-time reporting and self-management

These objectives have been attained in full (deliverable 100% complete). This deliverable is now finalized, no further changes are expected in future.

In the Grant Agreement, we proposed to select 5 symptoms, 5 indicators of destabilized comorbidities, and 3 indicators of functional decline that would be used for monitoring. However, given the heterogeneity within the population of older patients with multimorbidity and cancer, it was not possible to allocate the set of 18 core symptoms and 10 additional symptoms depending on cancer or treatment, to one of these three categories (symptoms of cancer, indicator of destabilized comorbidity, or indicator of functional decline. Thus, the selected symptoms were clustered together without further link to their origin. However, we did achieve the minimum of 13 symptoms to be used for monitoring. This deviation does not impact on the overall objectives of the project nor does it impact on the use of resources within the project or the care pathway.

Justification for delay in deliverable submission

The objectives related to this deliverable have been achieved on time and as scheduled in Annexe 1 (Description of the Action Part A) of the Grant Agreement N°945218.

1. Introduction

1.1. GERONTE and its objectives

GERONTE is a 5-year research and innovation project (April 2021 to Mars 2026) funded by the European Union within the framework of the H2020 Research and Innovation programme, in response to the health societal challenge topic SC1-BHC-24-2020 “Healthcare interventions for the management of the elderly multimorbid patient”. The overall aim of GERONTE is to improve quality of life - defined as well-being on three levels: global health status, physical functioning and social functioning- for older multimorbid patients, while reducing overall costs of care. To this end, GERONTE will co-design, test, and prepare for deployment an innovative cost-effective patient-centred holistic health management system, hereafter referred to as the GERONTE intervention. GERONTE intervention will rely on an ICT based application for real-time collection and integration of standardised clinical and home patient-reported data. GERONTE intervention will be demonstrated in the context of care of multimorbid patients having cancer as a dominant morbidity, and be adaptable to any other combination of morbidities.

Objectives

O1: INFORMATION gather the stakeholders and data needed for patient-centred and multi-actor complex decision-making process and management

O2: **TOOLS** develop ICT tools for the GERONTE intervention to be implemented

O3: METHODS develop socio-economic methods for evaluating the impacts of the implementation of the GERONTE intervention

O4: **DEMONSTRATION** demonstrate in 16 study sites from three EU countries the feasibility and effectiveness of the GERONTE intervention

O5: **REPLICATION** develop recommendations for the replication of GERONTE best practices in all European health systems

O6: ENGAGEMENT engage all stakeholders by co-designing the GERONTE intervention

1.2. Rationale

Deliverable D1.4 is part of work-package 1 which supports GERONTE objective O1: INFORMATION. This deliverable covers one sub-objective: Determine which data are best to involve the patient in their recovery process, through real-time reporting and self-management. An important component of Geronte is to monitor symptoms and PROMs during the treatment trajectory for cancer in order to catch early signs of destabilization of the patient due to symptoms, destabilized comorbidities or functional decline. This may lead to early interventions by the APN to prevent further decline. This deliverable describes the process of developing a list of symptoms and PROMs for specific cancer types and gender that are relevant to oncology care and treatment monitoring. The list is made for patient report from the patient app.

2. Developing dataset of symptoms and PROMs for specific cancer types and gender

For this deliverable: DIAK, OUS and UCD worked closely together. In the process of developing the core information components for the Holis GV dashboard as well as the core participants of the health care professional consortium, including the way they communicate, we made use of various methods. These include meetings with the four work package members, and collaboration with other work packages within the Geronte project, literature reviews, and finally, four survey rounds and one online meeting with an expert panel of oncologic and geriatric health care professionals involved in the care for older patients with multimorbidity and cancer. This section provides further details on each of these methods.

Overview of contributions

Partner	Person(s)	Contribution
DIAK	Marije Hamaker, Nelleke Seghers	Involved throughout
OUS	Siri Rostoft	Involved throughout, leader
UCD	Shane O'Hanlon	Involved throughout
UBx	Pierre Soubeyran	Multimorbidity profiles, focus groups,
MYPL	Christophe Vergne, Yousra Elmerini, Guilherme Dumas	Dashboard, focus groups, small scale pilots
BOC	Lucia Ferrera, Vittoria Ardito	PROMs and PREMs

Work package meetings

For the work package responsible for this deliverable, a working group was established from the three main partners (DIAK, OUS, UCD), consisting of 3 geriatricians (2 female, 1 male) from three different centres in three countries, and a PhD student (female) who is a resident in geriatric medicine. Informal input from colleages in other specialties was requested as needed; formal input was obtained through the channels listed below.

For the completion of this deliverable, 37 meetings took place within the Geronte consortium. A list of these meetings can be found in Annexe 1. Of these 37, 23 were meetings between the three Geronte partners responsible for this deliverable (DIAK, OUS, UCD) and 14 with one or more other Geronte partners (UBX, BOC, ESE, MYPL). Given the number of meetings, we have listed only the topics discussed per meeting in Annexe 1. Full minutes are available upon request; as this is a public deliverable and some of the information in the minutes is privacy sensitive, we choose not to deposit them publicly.

2.1 Literature review

We performed a systematic literature search to identify papers on self-management and self-monitoring interventions during cancer treatment for older patients with cancer. As a first step, a literature review was undertaken on MEDLINE and EMBASE to determine if any previous scientific publications were available that could serve as a library for the self-management recommendations. The following search was performed on January 14th 2021: self[tiab] AND (care[tiab] OR management[tiab] OR monitoring[tiab] OR efficacy[tiab]) AND (older[tiab] OR geriatric[tiab] OR multimorb*[tiab]) AND (cancer[tiab] OR oncology[tiab] OR malign*[tiab]). Searches were limited to 2000 onward.

This yielded 1058 hits in pubmed and 1766 hits in Embase. The search file was deposited online at https://doi.org/10.5281/zenodo.7540599.

While going through the search results, it was clear that this search strategy failed to identify all relevant papers, in particular because self-monitoring has mostly been performed in younger patients with cancer in previous studies, and no studies were specifically done in the older population. Studies also differed between self-monitoring and self-management, and the majority of studies on self-monitoring were in relation to cancer screening interventions. We therefore changed our strategy and based our symptoms and PROMs on (1) experiences from our partner institution in GerOnTe (Katholieke Univeristeit Leuven) which has a monitoring system in use already[1,2] and (2) key randomized trials in the field that have been published in the recent years[3-5]. Additionally, we included all relevant quality of life questionnaires that are currently in use in oncology (general, breast, colorectal, prostate lung), elderly medicine and general medicine. An overview of the literature that was included can be found in Annexe 2 and 3.

Deviation from initial plan of using Delphi method

We had intended to carry out two Delphi processes during the course of WP1, partially in surveys and partially through expert meetings. Due to COVID, we were not able to host the in-person expert meetings as planned. Furthermore, the number of items that required consensus, did not lend itself to a formal Delphi process in which one topic is discussed across multiple rounds until a full consensus is achieved. We therefore had to choose mitigation strategies, described next. Details on how this decision was made are reported in the minutes of the work package meetings and can be accessed by authorised readers in the confidential appendices. The decision to divert from the Delphi method did not affect the outcome of the deliverable or the objectives of the project.

2.2 Expert panel input

A panel of experts was established, including medical specialists, nurses and other health care professionals with a background in geriatric medicine or involved in cancer treatment for the four cancer types included in Geronte (breast, prostate, lung and colorectal cancer). We aimed to include a full range of involved specialists, from different European countries, with variation in the degree of current involvement in geriatric oncology care as well as years in practice, and a representative gender ratio.

In a series of monthly surveys, these experts were asked to provide their input on the relevance of which symptoms and PROMs were most relevant for decision making and follow-up of patients. Answers to the survey were subsequently compiled, compared with findings from literature review, and taken forward to the next survey for further fine-tuning. The questions addressed in each round are shown in Annexe 4. As the questions pertained specifically to the development of the Geronte care pathway, we could not make use of pre-existing questionnaires. Thus, for each round we included those questions necessary to take the next step in the development of the care pathway, building on the input that was provided in previous rounds, or gathered through other sources as described throughout this deliverable.

Each round included between 32 and 40 participants across a range of different backgrounds (doctors, nurses) and a range of specialisms (medical oncology, surgery, radiotherapy, pulmonology,

urology, geriatrics). Respondents were from the following countries: Netherlands, France, Belgium, Norway, Italy, Denmark, Germany, Hungary, Cyprus, United Kingdom. Mean age was 47 and respondents had a mean of 17 years in clinical practice. Composition of the expert panel in Round 1 can be found in Annexe 5.

Based on the literature review, a list of 53 symptoms and PROMS and the following questions (1) not relevant to monitor (2) relevant for all patients, both during treatment and follow-up (3) only relevant during treatment, and (4) only relevant for specific cancer types. In the next round, the experts were asked to state which symptoms and PROMs they prioritized. Results can be found in Annexe 6. Based on this feedback, a core set of 18 symptoms and PROMs were included to monitor for all patients, and additional symptoms and PROMS were collected for specific cancer types and according to gender and treatment type.

Datasets for this part of the expert panel survey ware deposited at https://doi.org/10.5281/zenodo.7594684; access is currently restricted but will be open once the data have been used for publication.

At the end of four survey rounds, an online meeting was planned with a selection of the expert panel – ensuring input from each relevant background, gender and specialty – to demonstrate how their input had been incorporated into the GerOnTe care pathway and Holis GV dashboard. The feedback they provided was included in the next steps of the development. Minutes of this meeting, which took place on 22-9-2021, can be found in Annexe 7.

2.5 Monitoring of symptoms and PROMs in the cancer treatment trajectory

In the Grant Agreement, we proposed to select 5 symptoms, 5 indicators of destabilized comorbidities, and 3 indicators of functional decline that would be used for monitoring. However, given the heterogeneity within the population of older patients with multimorbidity and cancer, it was not possible to allocate the set of 18 symptoms that were selected by the expert panel specifically to one of these three categories (symptoms of cancer, indicator of destabilized comorbidity, or indicator of functional decline. For example, dyspnea could be a symptom of lung cancer, but also an indicator of destabilized heart failure. Fatigue could be a symptom, a sign of destabilized heart failure and an indicator of functional decline. The symptoms and PROMs were linked to the established comorbidity profiles. See illustration below.

			Signs of destabilized comorbidity				
	Cancer- or treatment-related symptoms	Signs of functional decline	Profile 1 Cardio-vascular, metabolic & pulmonary disease	Profile 2 Disability, dependency and caregiver burden	Profile 3 Psychosocial health and cognitive impairment	Profile 4 Nutritional status and digestive system disease	Profile 5 Concurrent cancer
ALL PATIENTS							
Dyspnoea	X		X				X
Diarrhoea	X					X	X

Vomiting	X					X	
Nausea	X					X	
Daily activities limited by bowel/urinary problems	X	X		X		X	
Poor appetite	X					X	X
Weight change	X	X	X			X	
Pain	X			X			
Fever/feeling ill	X						
Fatigue	X	X	X	X	X	X	X
Trouble sleeping	X				X		
Trouble remembering/thinking; confusion	X	X			X		
Feeling depressed or irritable	X				X		
Feeling nervous, worried or uncertain	X				X		
Change in mobility	X	X		X			
Unsteady on your feet/falls	X	X		X			
Forced to spend time in bed	X	X	X	X	X		
Need help with daily activities	X	X		X			

Additionally, specific cancer types and treatment warrant specific monitoring:

Chemotherapy Sore/dry mouth Tingling hand/feet Rash/skin issue	*After surgery/radiotherapy* Wound problems Rash/skin issues Bloody stools or mucus (colorectal and prostate only)	*After ostomy:* Ostomy issues	*Lung cancer* Cough Cough up blood

An important comment received in asserting the relevance of symptoms and PROMs was that only the presence of the symptom/PROM was not sufficient; additional information on the severity of a symptom as well as symptom development may affect an oncological decision or the treatment trajectory. During the expert meeting, we therefore discussed which cut-offs to use for symptoms and PROMs and the frequency of monitoring. We based our grading of symptom severity on the study by Basch and colleagues[3]. Because of multiple possible combinations in individual patients, we decided that we need to tailor the list of symptoms to the individual patients with regards to cancer type, treatment type, and gender. Furthermore, the frequency of monitoring will vary according to the location of the patient in the treatment trajectory. It was therefore decided that the monitoring will be customized by the advanced practice nurse (APN) in the patient app based on the individual cancer- and treatment types. The symptoms and PROMs are linked to self-management recommendations in the app, as described in deliverable 1.4. – DATASET OF SELF-MANAGEMENT RECOMMENDATIONS FOR PATIENT-DRIVEN IMPROVEMENT OF INDEPENDENT LIVING.

The final symptoms and PROMs and cut-off values for notification to contact the APN are specified in Annexe 7, 8, 9 and 10. There are separate list: one for symptoms, one for destabilized comorbidities, and one for functional decline, as well as specific lists for treatment trajectory, treatment type and cancer type. These can also be found in the dataset GERDAT006 “Dataset of symptoms and proms for specific cancer types and gender” (published online at https://doi.org/ 10.5281/zenodo.6342645. Annexe 11 shows how they will be monitored in the Geronte care pathway.

In the Grant Agreement, we proposed to select 5 symptoms, 5 indicators of destabilized comorbidities, and 3 indicators of functional decline that would be used for monitoring. However, given the heterogeneity within the population of older patients with multimorbidity and cancer, it was not possible to allocate the set of 18 core symptoms and 10 additional symptoms depending on cancer or treatment, to one of these three categories (symptoms of cancer, indicator of destabilized comorbidity, or indicator of functional decline. Thus, the selected symptoms were clustered together without further link to their origin. However, we did achieve the minimum of 13 symptoms to be used for monitoring. This deviation does not impact on the overall objectives of the project nor does it impact on the use of resources within the project or the care pathway.

2.6 Symptoms and PROMs for gender

Based on the feedback from the survey and the discussion about symptoms and PROMs for gender in the group of experts, we decided to not make a distinction for gender in the monitoring of patients with colorectal cancer or lung cancer. For prostate cancer the symptoms and PROMs will be specific for males, and for breast cancer the vast majority of patients will be women. However, even for these cancer types the symptoms and PROMs cannot be considered to be gender specific. For signs of destabilized comorbidities and functional decline there is also no distinction for monitoring according to gender. When capturing destabilization or increase of symptoms, the patients are their own controls, and destabilization is related to their baseline functional status which is independent from gender.

3 Conclusion

This document reports on the development of a core dataset of symptoms and PROMs data that need to be reported by patients and monitored by the HPC during the treatment trajectory to support oncologic decision making and determine how the patient is best supported through their oncologic treatment trajectory and follow-up. The dataset will be tailored to cancer type, treatment type, and gender. Gender will be taken into account as some cancers are more prevalent in female patients (breast cancer) while prostate cancer affects only male patients. The list of symptoms and PROMs overlap with regards to monitoring of symptoms, destabilized comorbidities, and functional decline.

D1.1 *Dataset of symptoms and PROMS for specific cancer types and* is part of work-package 1 which supports GERONTE objective O1: INFORMATION (Gather the stakeholders and data needed for patient-centred and multi-actor complex decision-making process and management). This deliverable covers one subobjective:

- Determine which data are best to involve the patient in their recovery process, through real-time reporting and self-management

These objectives have been attained in full (deliverable 100% complete). This deliverable is now finalized, no further changes are expected in future.

This deliverable was also used to inform and obtain other objectives and subobjectives in the project.

- Objective 2 is to develop the HolisTM GV tool for the GerOnTe model to be implemented. The first subobjective of this objective is to develop an ICT tool useful for health professionals (presenting patients' quality data on digital dashboards, helping shared decision-making, and enhancing communication inside the HPC and with patients). Deliverable 1.2 provided the information that should be included in the ICT tools for both the HPC as well as the patients.
- Finally, Deliverable 1.2 aided in the development of the Geronte care pathway, which is the foundation of Objective 4 of the GERONTE project (Demonstrate in 16 study sites from three EU countries the feasibility and effectiveness of the GerOnTe model). In particular, the deliverable 1.2 was used to develop the care pathway and trial protocol for subobjective 4.1 (Establish the protocol for two RCT (FRONE in France, TWOBE in both Belgium and the Netherlands) to demonstrate the clinical relevance of GerOnTe).

Annexe 1: *Work package meetings*

Meetings were already started prior to the official start of the project.

Members of the work package team were Siri Rostoft (SR) from OUS, Shane O'Hanlon (SO) from UCD, and Marije Hamaker (MH) and Nelleke Seghers (NS) from DIAK. Any additional persons who joined will be listed below.

Date	Present	Topics discussed
7-1-2021	All	Multimorbidity profiles, PROMS, information needs, self-monitoring, self-management
14-1-2021	SR, MH, NS	Input from KUL+UBX on multimorbidity profiles, symptom monitoring
21-1-2021	All + Christophe Vergne MYPL	Introduction dashboard, what data can be included, what are the technical possibilities. Explanation of timeline for development.
9-2-2021	SR, MH, NS	Information needs, PROMs, minimal datasets
17-2-2021	All	Development process, ethics requirements, patient focus groups, multimorbidity data, selection of expert panel
4-3-2021	All	Self-monitoring and self-management, patient preferences, information needs, expert panel, expert surveys
17-3-2021	All	Planning expert surveys (timeline and content)
10-5-2021	MH NS + ESE	Focus groups
12-5-2021	NS MH + Lucia Ferrara, Vittoria Arditto (BOC)	Alignment WP1 and WP3
20-5-2021	All	Symptom monitoring
27-5-2021	SR, MH, NS	Preliminary results survey round 2, symptom monitoring, health care professional consortium
10-6-2021	All	Results survey round 2, core data sets
16-6-2021	MH NS SR+ ESE + MYPL	Workshop preparation focus groups
17-6-2021	All	Focus groups preparation
25-6-2021	All	Symptom monitoring, health care profession consortium, preparation survey round 3
28-6-2021	MH NS SR + ESE + MYPL	Workshop preparation focus groups
29-6-2021	MH NS + MYPL	Focus groups preparation
7-7-2021	MH NS SR + ESE + MYPL	Workshop preparation focus groups
12-7-2021	All	Symptom monitoring, core datasets, focus groups, results survey round 3
4-8-2021	All	Preparation expert panel survey round 4, health care professional consortium, expert panel meeting, core dataset
12-8-2021	All	Focus groups
16-8-2021	All	Dashboard and symptom monitoring, patient focus groups, expert meeting
18-8-2021	MH NS + ESE + MYPL	Workshop preparation focus groups
3-9-2021	All+Geronte consortium	WP1 results presentation
8-9-2021	MH NS + BOC	Prems and Proms
14-9-2021	All	Expert panel meeting, patient preferences using ONC OPT
20-9-2021	All	Finalizing plans for expert meeting
29-9-2021	All+ expert panel	Expert panel meeting (minutes see: Annexe 6)
30-9-2021 + 1-10-2021	MH, NS, MYPL	Meeting in Paris with MYPL for dashboard development
1-10-2021	All + MYPL + Pierre Soubeyran (UBX)	Demonstrating how WP1 translates to dashboard and patient application
13-10-2021	All	Symptom monitoring, measurement objective physical functioning, health literacy, HPC decision making process
28-10-2021	NS MH	Patient focus group meeting (minutes see Annexe 7)
10-11-2021	All	Symptom monitoring, medication adherence, patient application
19-11-2021	All	Symptom presentation in dashboard
21-12-2021	All	Symptom monitoring, small scale pilots
22-12-2021	MH NS + MYPL	Small scale pilots
10-1-2022	All	Preparation for Dublin meeting

26-1-2022	All	Writing of deliverables and possibilities for publication

Annexe 2: Papers assessed in symptoms and PROMs literature review

1. Coolbrandt A, Muylaert K, Vandeneede E, Dooms C, Wildiers H. Real-time symptom management in the context of a remote symptom-monitoring system: prospective process evaluation and cross-sectional survey to explore clinical relevance. *Support Care Cancer* 2021; **29**(6): 3401-8.
2. Coolbrandt A, Muylaert K, Vandeneede E, Dooms C, Wildiers H. Remote System for Daily Symptom Monitoring During Systemic Anticancer Treatment: Patient Acceptance, Usability, and Compliance. *Cancer Nurs* 2021.
3. Basch E, Deal AM, Kris MG, et al. Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *J Clin Oncol* 2016; **34**(6): 557-65.
4. Maguire R, Fox PA, McCann L, et al. The eSMART study protocol: a randomised controlled trial to evaluate electronic symptom management using the advanced symptom management system (ASyMS) remote technology for patients with cancer. *BMJ Open* 2017; **7**(5): e015016.
5. Maguire R, McCann L, Kotronoulas G, et al. Real time remote symptom monitoring during chemotherapy for cancer: European multicentre randomised controlled trial (eSMART). *Bmj* 2021; **374**: n1647.

Annexe 3: Quality of life questionnaires used to compile the list and method for symptom monitoring

General quality of life questionnaires for patients with cancer
Functional living with cancer
Functional assessment of cancer therapy (FACT) – general
European organisation of Research and Treatment of Cancer – QLQ-C30

Quality of life questionnaires for older patients with cancer
European organisation of Research and Treatment of Cancer – ELD14

Quality of life questionnaires for patients with prostate cancer
Functional assessment of cancer therapy (FACT) – prostate
European organisation of Research and Treatment of Cancer – PR25

Quality of life questionnaires for patients with breast cancer
Functional assessment of cancer therapy (FACT) – breast
European organisation of Research and Treatment of Cancer – BR23

Quality of life questionnaires for patients with lung cancer
Functional assessment of cancer therapy (FACT) – Lung
European organisation of Research and Treatment of Cancer – LC13

Quality of life questionnaires for patients with colorectal cancer
Functional assessment of cancer therapy (FACT) – Colorectal
European organisation of Research and Treatment of Cancer – CR29

Quality of life questionnaires for patients undergoing radiotherapy
European organisation of Research and Treatment of Cancer – PRT23

General quality of life questionnaires
36-Item Short Form Survey (SF-36)
12-Item Short Form Survey (SF-12)
EQ5D
Edmonton symptom assessment scale (ESAS)

Annexe 4: *Questions asked each round of the Expert panel surveys*

As the questions pertained specifically to the development of the Geronte care pathway, we could not make use of pre-existing questionnaires. Thus, for each round we included those questions necessary to take the next step in the development of the care pathway, building on the input that was provided in previous rounds, or gathered through other sources as described throughout this deliverable.

ROUND 1. Relevant data for decision making and care in geriatric oncology

Demographic data

What is your age?
What is your gender?
What is your profession?
Which specialty?
In which cancer types are you involved (actively in its treatment, or in the decision making?
Which treatments do you provide to patients yourself?
How many years have you been in clinical practice?
Are you involved in oncologic decision making?

Comorbidity, polypharmacy and nutritional status

For each of the following items, could you state how likely it is that its presence in a patient's medical history could lead you to alter the oncologic treatment decision?

And how likely its presence will lead you to alter the subsequent care trajectory for an older patients with cancer?

… dependence for ADLs
… dementia and other neurodegenerative disease
… concurrent cancer disease
… performance status (e.g. ECOG, Karnofsky)
… congestive heart disease
… sarcopenia, anorexia or cachexia
… malnutrition and/ or involuntary weight los
… impaired mobility, gait or balance
… severe neuropathy
… Parkinson's disease or parkinsonism
… schizophrenia or other psychotic disorders
… dependence for instrumental ADLs
… delirium risk or previous delirium
… pulmonary hypertension
… ischaemic heart disease
… renal disease
... previous falls
… caregiver burden
… COPD or other lung disease
… cerebrovascular disease, including TIA
… liver disease
… diabetes mellitus with complications
… fatigue
… living situation and partner status
… faecal Incontinence
… morbid obesity
… travel distance to treatment centre
… cardiac arrhythmia
… heart valve disease

… anxiety, depression and other mood disorders
… visual impairment
… loneliness
… an intellectual disability
… social network
… severe or complicated hypertension
… pain syndrome
… anaemia
… inappropriate medication use
… substance abuse, any kind (including smoking)
… seizure disorder
… pulmonary embolism or deep venous thrombosis
… peripheral vascular disease or aortic aneurysm
… hearing impairment
… urine incontinence
… polypharmacy
… patients' financial worries
… spinal stenosis or other conditions of the spine and spinal cord
… osteoporosis and low energy fractures
… sexual dysfunction
… gastro-intestinal ulcer disease
… arthropathy or arthritis
… sleep disorders

ROUND 2. Patient profiles

In the first round we eliminated those multimorbidities and impairments that received a low score from the participants. In multimorbid patients it is a challenge to collect enough relevant information for decision making and care while avoiding an excess of information during multidisciplinary meetings and losing the overview of the patient.

With the remaining items we made 5 different patient profiles. In these profiles we combined comorbidities with (geriatric) impairments. Items were grouped together into a profile when patients having these items:

- need the same healthcare professionals to be involved,

- have similar consequences for the treatment decision or

- would need a similar care trajectory

The comorbidities and impairments are therefore not grouped aetiologically. The aim of these profiles is to make it possible to develop a care pathway for the multimorbid patient. Including those comorbidities and impairments that are common in older patients with cancer.

PATIENT PROFILE - combining impairments in the geriatric domains and comorbidities

1. Cardiovascular- metabolic comorbidities including lung disease
2. Functional and social dependency including diseases that impair mobility
3. Psychiatric/psychologic disorders and cognitive impairment
4. Malnutrition including liver disease
5. Concurrent cancer (treatment)

B: Relevance of the patient profiles per treatment modality

Now we will ask you the relevance for the different patient profiles per treatment modality.

How relevant (on a scale of 0 to 4) is each patient profiles in surgery…?

… For the oncologic decision making

… For the care trajectory

How relevant (on a scale of 0 to 4) is each patient profiles in chemotherapy…?

… For the oncologic decision making

… For the care trajectory

How relevant (on a scale of 0 to 4) is each patient profiles in radiotherapy…?

… For the oncologic decision making

… For the care trajectory

How relevant (on a scale of 0 to 4) is each patient profiles in endocrine therapy…?

… For the oncologic decision making

… For the care trajectory

C. This category is for physicians, nurses and other healthcare providers that don't provide tumour specific/cancer specific therapies, but that are involved and provide their own treatments / assessments.

What kind of assessment/treatment do you provide? (e.g. geriatric assessment, prehabillitation...etc)

...and then similar questions as the others

D. General questions about the multimorbidity profiles

Do you agree on these five patient profiles, why or why not?

Is there a patient group/ issue that is not sufficiently covered / missing?

E. Challenges

What is currently the biggest challenge when treating older patients with multimorbidity and cancer?

What do you think patients and/or caregivers consider the biggest challenge in their trajectory?

ROUND 3. Severity assessment of the comorbidities and symptom monitoring

In the first round we received feedback several times, that you needed more information on the severity of a comorbidity to know if it impacts an oncologic decision or a treatment trajectory.

Could you therefore tell us, regarding the following 16 comorbidities, if the presence itself is sufficient information or if you would need extra information to quantify the severity. If you need extra information, we will ask you in the next question, what extra information you would need.

e.g. maybe the mere presence of severe neuropathy is enough to know, but knowing how severe "congestive heart disease " is, is necessary before you decide what treatment to advise to your patient.

1. What do you need from the following comorbidities to decide if they are important for the oncologic trajectory?

	only presence/absence	extra information (severity)
… concurrent cancer disease		
… congestive heart disease		
… severe neuropathy		
… Parkinson's disease or parkinsonism		
… schizophrenia or other psychotic disorders		
… pulmonary hypertension		
… ischaemic heart disease		
… renal disease		
… COPD or other lung disease		
… cerebrovascular disease		
… liver disease		
… diabetes mellitus with complication		
… morbid obesity		
… cardiac arrhythmia		
… heart valve disease		
… substance abuse, any kind (including smoking)		

We will now ask the comorbidities that you answered with "Extra information (Severity)" again.

2. What extra information do you need? What commonly used indicator to quantify the severity of the comorbidity do you suggest us to use?

3. For your specialty what disease would you like to add as an extra besides the overall-minimum core data set?

some examples; auto immune disease, previous surgery

Symptom monitoring

In further developing this care pathway we will continue to the next step after the decision making.

We want to know which of the following symptoms are important to you (as healthcare professional) to monitor a patient at home in between hospital visits for adverse events, functional decline or destabilisation of their comorbidity. By monitoring we hope to find these problems earlier, so we can prevent further harm.

You can choose whether these symptoms are…

1. Not relevant to monitor (these will be excluded)
2. Relevant for all patients, both during treatment and follow up
3. Only relevant during ongoing oncologic treatment
4. Only relevant for specific cancer- or treatment types

We would like to reduce the list to enhance feasibility and to not overburden the patient or the healthcare profession. So would you please only consider those symptoms that would actually help you with early detection of problems.

We are not looking for symptoms that are important to patients themselves, e.g. bothersome symptoms or symptoms they worry about. We will ask patients themselves about that later on. Then we will also ask them what exact terminology to use.

Questions that you will answer with “only relevant for specific cancer- or treatment-types" will be asked again in the following question so you can specify in what patient group it is important

1.What is true for the following symptoms considering home monitoring to early detect problems;

	1.Not relevant to monitor	2.Relevant for all patients, both during treatment and follow-up	3.Only relevant during ongoing oncologic treatment	4.Only relevant for specific cancer or treatment types
diarrhea nausea vomiting constipation daily activities limited because of bowel or urinary problems fecal incontinence urinary incontinence problems with incontinence aid/stoma care Stoma leakage Sore skin stoma frequent bowel movements/urination Bloated feeling Bloody stools or mucus Release of gas dysuria poor appetite				

weight loss weight gain edema/swelling dyspnea cough up blood cough palpitations fever/shivering/feeling ill headache sweats fatigue trouble sleeping pain worrying/upset uncertainty depressed/feeling low anxiety/feeling nervous feeling irritable trouble thinking/concentrating trouble remembering confusion stomatitis/sore mouth/dry mouth Trouble swallowing tingling hand/feet teary eyes rash/skin issues hair loss satisfied with sexual life dissatisfied with body wound problems (healing, bleeding) unsteady on your feet/dizziness falls Preforming strenuous activities decreased/change in mobility (walk, rise from chair, stairs) forced to spend time in bed need help with self care (dressing, washing, toileting) need help with household chores, groceries, medications				

Only those questions answered with “only relevant for some cancer/treatment types” are asked again.

2.Could you please specify for which cancer or treatment types it is relevant?

3. Is there a difference in the above mentioned symptoms between men and women?

Yes
no

4. Are there other symptoms or outcomes that are missing that need to be monitored?

ROUND 4. Symptom monitoring, health care professionals and outcomes

A: Symptoms for monitoring

Below is a list of symptoms that were selected in round 3 as being potentially relevant for home monitoring during the treatment trajectory, irrespective of treatment or cancer type.

The purpose of home monitoring is to allow for early signalling and subsequent early intervention for complications of treatment, decompensation of comorbidities or functional decline.

However, we believe it is not feasible nor necessary to monitor each of these symptoms every day throughout the treatment trajectory.

Which five symptoms would you recommend for daily monitoring? Which five for weekly monitoring and which five for monthly monitoring during ongoing oncologic treatment?

- Dyspnoea
- Diarrhoea
- Vomiting
- Nausea
- Daily activities limited by bowel or urinary problems
- Poor appetite
- Weight change
- Pain
- Fever/feeling ill
- Fatigue
- Trouble sleeping
- Trouble remembering/thinking; confusion
- Feeling depressed or irritable
- Feeling nervous, worried or uncertain
- Change in mobility
- Unsteady on your feet/falls
- Forced to spend time in bed
- Need help with daily activities

Are any symptoms missing that you believe are essential for daily or weekly monitoring during ongoing cancer treatment in this patient population?

For each of the symptoms selected for daily or weekly monitoring during ongoing cancer treatment. Potentially, the frequency of monitoring can be decreased once treatment has been completed.

What frequency would you recommend for these symptoms during follow-up (within the first year)?

(Only showing the weekly/daily again)

B: Which healthcare professionals need to be involved

In the next section we will discuss which health care professionals you would recommend us to involve in the care trajectory of older people with both cancer and significant comorbidity that fit into the multimorbidity profiles we made before (see below):

Profile 1- Cardiovascular, metabolic and pulmonary disease

Profile 2- Disability, dependency and caregiver burden

Profile 3- Psychosocial health and cognitive impairment

Profile 4- Nutritional status and digestive system disease

Profile 5-Concurrent cancer

Which of the following health care professionals should be involved in the care trajectory of older patients with multimorbidity receiving treatment for cancer? And when should they be involved:

- involvement in all patients,

- no involvement necessary

- only involvement in case of a specific impairment/disease?

- Oncology specialist(s) (including surgeons, radiotherapists and medical oncologists etc.
- Geriatrician
- General practitioner
- Oncology nurse
- Palliative care specialist
- Other organ-specific specialist (e.g. cardiologist, pulmonologist, nephrologist, urologist etc
- Anaesthesiologist
- Pharmacist
- Psychologist/psychiater
- Physiotherapist
- Dietician
- Occupational therapist
- Social worker
- Home care nurse or care home staff
- Clerics (or spiritual helper)
- Other, please specify...

If you have indicated that you believe the following health care professionals have a role in the care trajectory (either for all patients or in case of specific impairments), do you think they also have an active role during the initial decision-making regarding oncologic treatment?

C. What are important outcomes in older patients with comorbidity?

In GerOnTe our aim is to develop a new care pathway for older people having both comorbidity and cancer in which we specifically take patient priorities, intrinsic capacity and comorbid conditions into account to improve the care for this specific patient group.

1. Which disease-specific and what patient-reported outcomes would you suggest we use to evaluate this care trajectory in older patients with multimorbidity and cancer?

2. Which outcomes do you think could be most improved using this holistic approach?

3. When would you define the new care pathway to be a success?

4. In the previous round one of the challenges that was mentioned in caring for this patient group, is the lack of information on outcomes that matter in this specific patient group. Which outcomes would you especially be interested in?

In addition to the patient reported and cancer-specific outcomes, we would also like to evaluate the care trajectory itself.

1. To achieve good service quality and positive patient experiences, what items on patient-reported experience would you suggest to measure in this patient group?

E.g. amount of information and explanation given and questions answered, involvement in decisions, empathy, consultation length, listening, continuity of care and coordination

Annexe 5: *Demographic data of the expert panel (total 39 respondents)*

	n=	%
Male	16	41%
Mean age	47 years	
Years in clinical practice	17.1 years	
Profession		
Nurse	4	10%
Physician	33	85%
Other (research)	3	8%
Speciality		
Surgery	8	21%
Medical oncology	12	30%
Primary care	3	8%
Geriatrics	9	23%
Other hospital-based specialist /organ specialist	4	10%
Other specialty...	9	23%
Cancer type involved with*		
Breast cancer	9	23%
Colorectal cancer	13	33%
Lung cancer	7	18%
Prostate cancer	8	21%
All cancer types	12	31%
Which treatments do you provide to patients yourself?*		
Surgery	12	31%
Radiation therapy	5	13%
Chemotherapy	14	36%
Targeted and/or immune therapy	14	36%
Hormone therapy	14	36%
None	9	23%
Other, namely	7	18%

* multiple answers per participant possible

Annexe 6: Relevance of symptoms and PROMs for monitoring according to expert panel

Percentages represent the proportion of participants stating that the symptom/PROM condition would likely or very likely be relevant to monitor during the care trajectory. Items were not carried forward to the next round of the survey if they scored less than 50% or higher.

Symptom/PROM	Not relevant to monitor	Relevant for all patients
dissatisfied with body	67%	33%
performing strenuous activities	54%	38%
satisfied with sexual life	50%	50%
sweats	46%	31%
trouble remembering	36%	64%
trouble thinking/concentrating	36%	50%
uncertainty	36%	50%
trouble sleeping	29%	64%
anxiety/feeling nervous	29%	57%
worrying/upset	29%	57%
fatigue	21%	71%
need help with household chores, groceries, medications	21%	71%
unsteady on your feet/dizziness	21%	57%
depressed/feeling low	14%	86%
decreased/change in mobility (walk, rise from chair, stairs)	14%	79%
need help with self care (dressing, washing, toileting)	14%	79%
poor appetite	7%	86%
weight loss	7%	93%
dyspnea	0%	100%
falls	0%	100%
pain	0%	93%
confusion	0%	93%
fever/shivering/feeling ill	0%	79%
daily activities limited because of bowel or urinary problems	21%	64%
forced to spend time in bed	14%	71%
feeling irritable	46%	31%
teary eyes	46%	8%
palpitations	23%	38%
bloated feeling	58%	25%
hair loss	43%	7%
headache	36%	43%
cough	36%	36%
trouble swallowing	7%	64%
nausea	0%	64%

vomiting	0%	64%
tingling hand/feet	23%	23%
stomatitis/sore mouth/dry mouth	8%	31%
bloody stools or mucus	0%	69%
rash/skin issues	8%	25%
frequent bowel movements/urination	43%	29%
diarrhoea	0%	36%
edema/swelling	0%	64%
release of gas	62%	8%
dysuria	38%	31%
urinary incontinence	43%	29%
constipation	14%	36%
cough up blood	0%	71%
wound problems (healing, bleeding)	0%	54%
fecal incontinence	29%	29%
weight gain	21%	43%
problems with incontinence aid/stoma care	29%	29%
Stoma leakage	21%	36%
Sore skin stoma	14%	43%

Annexe 7: Minutes of the expert meeting 22-9-2021

Expert meeting with 11 experts from the expert panel. Names not listed here for privacy reasons.

TOPICS DISCUSSED

Geriatric assessment:

- Does the Lee index add enough extra information when everything else is already available? Will it be confusing to MDT because they are not familiar with this index?
- How to deal with medication?
    - Is number of medication not simply a measure of comorbidity?
    - Move to prior medical history?
    - Indicate only "appropriate or inappropriate" for comorbidities? (But then, if inappropriate, this will immediately be addressed in the CGA, so how relevant to keep on dashboard?

  For now we only include medication, no section on polypharmacy, because if inappropriate it will be altered during the CGA

- We need an overview of medication on the primary dashboard: how to keep up to date? Or only for during decision making?
- For each of the main GA items, allow to double click to open all items, to show full assessment, because the absence of impairment on these items also indicates that a patient is very fit.
- maybe all items could be shown, using green and red colours, then it gives an immediate overview, and only the red items will be read. >this is now how it is done
- Rather than travel distance, rename as transportation issues, which can include issues with distance but also a broader sense

ACTIONS: Nelleke will look what this looks like for 5 patients + work together with MyPL

Preferences:

- agreement on these 4 outcomes
- important to know whether curative or palliative setting (but no more details this is not for decision making, more a conversation)
- important to use this tool not as a decision making-tool specifying the survival benefit and the toxicity risk for the tumour type and treatment type and using the percentages, but as a tool to explore patient preferences for the shared decision making conversation.
- this is relevant to know in the HPC meeting, ideally the person (APN) who had the conversation is then also present to further specify, since sometimes only a specific side effect of the treatment is the reason why a person sets this high, e.g. neuropathy in piano players.
- how to reassess preferences in practice? (about 50% change their goals in studies)
-

ACTIONS: Nelleke pilot study, add reassessment to the study protocol?

Communication model

- Should be mandatory to go through the questions in the trial, including phrasing an answer which will be included in communication to GP and others involved
- Leave out question 1, limit question 9 only to the second part of the question
- For question 8, also include how these alternative options would differ with regards to expected outcomes. Include not only palliative care but also best supportive care
- No need for GP input for these questions; not enough oncologic knowledge
- However, GP input regarding background/context of patient could be very useful. Aim to get this for every patient prior to decision making, role for APN

ACTIONS: Shane to meet with GP to discuss content of summary letter. Also to edit questions as above.

Symptom monitoring

- Some debate about which way to phrase; in simple option risk that patients interpret differently.
- Do we know about reproducibility for 4 point scale? Ask Ethan Basch for input (Siri will do this)
- Personalize alerts: important to register change rather than simple the rating; this would also mean that the difference in interpretation between patients is less relevant. Avoid daily warning to contact health care provider for something that has already been present for longer time! Maybe decrease alert frequency after 1 or 2 warnings?
- Also an option to include question regarding burden or concern from the patient? But that would lead to lack of signalling for patients that tend to minimize their complaints anyway
- Option to use 4 point scale but to provide suggestions/details per symptom for what it means to score 3 (so more elaborate phrasing accessible with clicking on symptom or something?
- Patients are unlikely to fill out a weekly follow-up measurement if this is only looked at once every three months. Decrease frequency of monitoring during follow-up? Or plan telephone meetings with APN for example every month
- Ask in focus groups: would it bother them to keep filling it out during follow-up? Would it be empowering/feel supportive/feel like they are being taken care of? Or would it feel like a constant reminder that they were or are sick?

ACTIONS: Siri, check with Ethan Basch about monitoring and how to phrase, after FG adapt it to patient preferences

Annexe 8: List of symptoms and PROMs that were considered relevant to monitor for all patients, frequency of monitoring during treatment and cut-offs for when the patient is recommended to contact the APN

Symptom	Frequency of monitoring	Cut-off for notification
Dyspnoea	Daily	2 days grade 3 Any rise of 2 points
Diarrhoea	Daily	2 days grade 3
Vomiting	Daily	2 days grade 3
Nausea	Weekly	2 weeks grade 3
Daily activities limited by bowel/urinary problems	Weekly	2 weeks grade 3
Poor appetite	Weekly	2 weeks grade 3
Weight change	Weekly	+/- ≥ 2 kg or change in fit of clothes
Pain	Daily	2 days grade 3
Fever/feeling ill	Daily	2 days grade 3 Any temp >38C
Fatigue	Weekly	2 weeks grade 3
Trouble remembering/thinking; confusion	Monthly	Any grade 3 Any rise of 2 points
Forced to spend time in bed	Weekly	2 weeks grade 3
Need help with daily activities	Monthly	Any grade 3 Any rise of 2 points

Annexe 9: List of symptoms and PROMs that are indicators of destabilized comorbidities for all patients

Indicator	Frequency of monitoring	Cut-off for notification
Dyspnoea	Daily	2 days grade 3 Any rise of 2 points
Diarrhoea	Daily	2 days grade 3
Vomiting	Daily	2 two days in a row/more than 3/7 per week
Nausea	Weekly	2 days grade 3
Daily activities limited by bowel/urinary problems	Weekly	2 weeks grade 3
Poor appetite	Weekly	2 weeks grade 3
Weight change	Weekly	+/- ≥ 2 kg or change in fit of clothes
Pain	Daily	2 days grade 3
Fatigue	Weekly	2 weeks grade 3
Trouble sleeping	Weekly	2 weeks grade 3
Trouble remembering/thinking; confusion	Monthly	Any grade 3 Any rise of 2 points
Feeling depressed or irritable	Monthly	Any grade 3
Feeling nervous, worried or uncertain	Monthly	Any grade 3
Change in mobility	Monthly	Any grade 3 Any rise of 2 points
Unsteady on your feet/falls	Monthly	Any grade 3 Any rise of 2 points
Forced to spend time in bed	Weekly	2 weeks grade 3
Need help with daily activities	Monthly	Any grade 3 Any rise of 2 points

Annexe 10: List of symptoms and PROMs that are indicators of functional decline for all patients

Indicator	Frequency of monitoring	Cut-off for notification
Daily activities limited by bowel/urinary problems	Weekly	2 weeks grade 3
Weight change	Weekly	+/- ≥ 2 kg or change in fit of clothes
Fatigue	Weekly	2 weeks grade 3
Trouble remembering/thinking; confusion	Monthly	Any grade 3 Any rise of 2 points
Change in mobility	Monthly	Any grade 3 Any rise of 2 points
Unsteady on your feet/falls	Monthly	Any grade 3 Any rise of 2 points
Forced to spend time in bed	Weekly	2 weeks grade 3
Need help with daily activities	Monthly	Any grade 3 Any rise of 2 points

Additionally, specific cancer types and treatment types warrant specific monitoring:

Chemotherapy	*After surgery/radiotherapy*	*After ostomy:*	*Lung cancer*
Sore/dry mouth Tingling hand/feet Rash/skin issue	Wound problems Rash/skin issues Bloody stools or mucus (colorectal and prostate only)	Ostomy issues	Cough Cough up blood

Annexe 11: Symptoms and PROMs in patient app according to treatment trajectory and cancer and treatment type

1) App daily during treatment

Asked in all patients during "active treatment", except for hormal treatment patients	
Core symptoms	**Contact health care provider**
Dyspnoea	Any very severe 1 day, AND/OR severe 2 days AND/OR any rise of ≥2 points
Diarrhoea	Any almost constantly 1 day, AND/OR frequently 2 days
Vomiting	Any very severe 1 day, AND/OR severe 2 days
Pain	Any very severe 1 day, AND/OR severe 2 days
Fever/feeling ill	Any temperature >=38 C
only asked in chemotherapy patients	
Chemotherapy	
Sore/dry mouth	Any very severe 1 day, AND/OR severe 2 days

2 App weekly during treatment

Asked in all patients during active treatment	
Core symptoms	**Contact health care provider**
Nausea	Any very severe 1 week, AND/OR severe 2 weeks
Daily activities limited by bowel/urinary problems	Any very severe 1 week, AND/OR severe 2 weeks
Poor appetite	Any very severe 1 week, AND/OR severe 2 weeks
Weight change	Change of +/- 2 kg in 2 weeks
Fatigue	Any very severe 1 week, AND/OR severe 2 weeks
Trouble sleeping	Any very severe 1 week, AND/OR severe 2 weeks
Forced to spend time in bed	Any almost constantly 1 week, AND/OR frequently 2 weeks
only asked in chemotherapy patients during active treatment	
Chemotherapy	
Tingling hand/feet	Any very severe 1 week, AND/OR severe 2 weeks

Rash/skin issues	Any very severe 1 week, AND/OR severe 2 weeks

3) App monthly during treatment

Core symptoms	Contact health care provider
Trouble remembering/thinking; confusion	Any severe/very severe
Feeling depressed or irritable	Any severe/very severe
Feeling nervous, worried or uncertain	Any severe/very severe
Change in mobility	Any severe/very severe
Unsteady on your feet	Any severe/very severe
Falls	Any occasionally, frequently or almost constantly
Need help with daily activities	Any frequently or almost constantly

Test

4) App weekly after treatment

Core symptoms	Contact health care provider
Dyspnoea	Any severe/very severe, any rise of ≥2 points
Diarrhoea	Any almost constantly 1 week, AND/OR frequently 2 weeks
Vomiting	Any very severe 1 week, AND/OR severe 2 weeks
Daily activities limited by bowel/urinary problems	Any very severe 1 week, AND/OR severe 2 weeks
Poor appetite	Any very severe 1 week, AND/OR severe 2 weeks
Pain	Any very severe 1 week, AND/OR severe 2 weeks

4) App monthly after treatment

Core symptoms	Contact health care provider
Fatigue	Any severe/very severe
Trouble sleeping	Any severe/very severe
Trouble remembering/thinking; confusion	Any severe/very severe
Feeling depressed or irritable	Any severe/very severe
Feeling nervous, worried or uncertain	Any severe/very severe
Change in mobility	Any severe/very severe
Unsteady on your feet	Any severe/very severe
Falls	Any occasionally, frequently or almost constantly
Forced to spend time in bed	Any frequently or almost constantly

Need help with daily activities	Any frequently or almost constantly
Weight change	Change of +/- 3 kg in 1 month

5) Other symptoms specific for cancer types and treatment types

Treatment options			
Stoma	yes/no		
Surgery	yes/no		
Radiotherapy	yes/no		
Chemotherapy	yes/no		
Immunotherapy	yes/no		
Hormone therapy (active treatment? No daily symptoms)	yes/no		>during active treatment no daily symptoms
Targeted therapy	yes/no		
Other therapy	yes/no		
Disease or treatment specific symptoms			
	Asked in which patients?	**During treatment**	**After treatment**
Bloody stools	[CRC] OR [prostate AND radiation]	weekly	Monthly
Mucus in stool	[CRC] OR [prostate AND radiation]	weekly	Monthly
Skin issues/rash	[Chemotherapy] OR [radiation therapy]	weekly	
Cough	Lung cancer	weekly	Monthly
Cough up blood	Lung cancer	weekly	
Hot flushes	Removed		
Wound problems	[Surgery] OR [Stoma]	weekly	
stoma issues	[Stoma AND CRC]	weekly	Monthly

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This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement 945218. The sole responsibility for the content of this project lies with the authors. It does not necessarily reflect the opinion of the European Union. The European Commission is not responsible for any use that may be made of the information contained therein.