STREAMLINED **GER**IATRIC 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
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D1.1: CORE DATASETS OF HEALTH CARE PROFESSIONALS, MULTIMORBIDITY AND INTRINSIC CAPACITY FOR GERONTE MODEL

Lead Beneficiary : 5-UCD

Involved Beneficiaries : 3-DIAK, 4-OUS

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GERONTE – Transforming Patient Care

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Disclaimer and acknowledgment

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History of Changes

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V1.2	2022-02-23	Shane O'Hanlon	Addition of communication of health care professional consortium
V1.3	2022-03-07	Nelleke Seghers	Data added on ONC-OPT pilot
V1.4	2022-03-07	Marije Hamaker	Final version with all dataset links included
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V1.7	2023-01-12	Marije Hamaker	Revision after input from European Commission
V1.8	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
D1.1 *Core dataset of health professionals, multimorbidity and intrinsic capacity for the GerOnTe model*	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 describes the process that was used to develop the most important components of the Holis GV dashboard as well as the GerOnTe care pathway.

These are summarised as the following datasets made openly accessible via ZENODO GERONTE community at https://zenodo.org/communities/geronte/ (See Table 1):

Table 1: Description and DOI of core datasets defined for the GERONTE intervention

GERONTE Intervention: Core Dataset Description	DOI (all versions)
GERDAT002 - Composition of the health care professional consortium	https://doi.org/10.5281/zenodo.6334681
GERDAT001- Core multimorbidity dataset	https://doi.org/10.5281/zenodo.6334599
GERDAT003- Core intrinsic capacity dataset	https://doi.org/10.5281/zenodo.6334723

In this process, we made use of various methods, including 49 meetings with the members of the work package group, two scoping and three systematic literature reviews, patient interviews and focus groups, and finally, four survey rounds and one online meeting with an expert panel of 39 oncologic and/or geriatric health care professionals involved in the care for older patients with multimorbidity and cancer.

In this process, we developed five patient multimorbidity profiles based on the type of comorbidity, and the impact on decision-making as well as the subsequent care trajectory. These include:
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; and
       Profile 5 - Concurrent cancer.

We established a core set of four health care professionals who should be involved in the decision-making and care trajectory for every older patient with multimorbidity and cancer within the GerOnTe care pathway (cancer specialist, advanced practice nurse, geriatrician, primary care physician); as well as an additional list of health care professionals who can be included as needed. We established standardized methods of communication and decision-making within the health care professional consortium, as well as a way of communicating with health care professionals not involved in the consortium itself.

A second step was to establish the main information components that should be included in the common medical file that is used in the GerOnTe care pathway. These include:

1) a large image of the patient;
2) personal information about the living situation and current formal and informal care;
3) tumour information including recommendations of the multidisciplinary tumour board;
4) comorbidities;
5) medication and substance use;
6) non-cancer specific prognosis;
7) intrinsic capacity/frailty; and
8) patient preferences.

For comorbidities, we developed a dataset of items that have such importance to the decision-making process that they need to be highlighted in the Holis GV dashboard. After a scoping literature review, input was received from the expert panel. Through an iterative process, it was decided which comorbidities were relevant and how these were best captured in data to provide to the health care professional consortium. This resulted in a list of 16 relevant somatic/psychiatric comorbidities to be included in the dataset provided to the health care professional consortium. In addition to a clinical judgement of the comorbidities by a geriatrician, both for the severity of the comorbid condition as well its impact on daily functioning, we developed a list of objective measurements that could further complement the comorbidity information in the GerOnTe care pathway. A similar process was followed for data on intrinsic capacity and frailty resulting in the inclusion of 24 items across six domains.

For patient preferences, we focussed on three types of preference: outcome preferences, decision control preference, and information preference. In this process, three systematic literature reviews including one meta-analysis, were performed and two series of patient interviews. For outcome preferences, we developed a new outcome prioritization tool called ONC-OPT, which included the following outcomes: 1) extending life; 2) maintaining independence; 3) reducing pain and other symptoms; and 4) limiting negative effects of cancer treatment. For decision control preference, we found significant heterogeneity in the older patient population, meaning that it is important to solicit this preference for each patient individually. This led to the inclusion of the control preference scale in the Holis GV dashboard. For information preferences, we developed a prompt list of questions that patients can use to become aware of questions that they may want to discuss with their health care provider. We also developed a list of tips that patients can use to improve their information with their health care professionals.

Attainment of the objectives and explanation of deviations

D1.1 *Core dataset of health professionals, multimorbidity and intrinsic capacity for the GerOnTe model* 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 two subobjectives :

- Establish the list of key professionals to be gathered in an HPC according to the patient profile
- Determine which medical and personal data of patients are needed for the HPC to make the best informed decisions

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

We deviated from initial grant agreement on two points:

- In the Grant agreement we had stated that we would determine which five core health care professionals should be included in the decision-making or care trajectory for all older patients with multimorbidity and cancer within the GerOnTe care pathway. Additionally, eight other members would be listed that could be included depending on the patient's needs.
  We found that in our expert panel there was clear consensus on four core members, who should be involved in every patient in the GerOnTe care pathway, irrespective of the multimorbidity profile. These were cancer specialist, advance practice nurse, geriatrician and primary care physician. No consensus was reached on the fifth core member, as this was too dependent on the patient's specificities. Determining a fifth core member would therefore lead to inefficiency of care rather than optimization. For this reason, we decided to limit the core health care professional consortium to four members, with the possibility to add others if needed.
  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.

- A second deviation from the grant agreement is that we initially stated we would determine a core dataset of four frailty components and three intrinsic capacity components. However, despite coming from a different perspective, further detailed inspection of the scientific determinants of frailty and intrinsic capacity revealed significant overlap, and we felt it was not possible to allocate specific items to either frailty or intrinsic capacity. Thus, we combined these two aspects in a single overview of items relating to frailty, intrinsic capacity or both, across the domains function/locomotor, nutrition, vitality, cognition and psychological status, geriatric syndromes and sensory impairments, social support/environment; and finally, comorbidity and medication. 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 D1.1 *Core dataset of health professionals, multimorbidity and intrinsic capacity for the GerOnTe model* is part of work-package 1 which supports GERONTE objective O1: INFORMATION. Optimizing the decision-making and care trajectory for older patients with multimorbidity and cancer first of all requires that all necessary information is available and that relevant stakeholders are identified and their input is included.

This deliverable covers two sub-objectives :
- Establish the list of key professionals to be gathered in an HPC according to the patient profile
- Determine which medical and personal data of patients are needed for the HPC to make the best informed decisions

In this deliverable we describe the process in which we developed five common patient multimorbidity profiles; established the core members of the health care professional consortium, who will take on the joint responsibility of decision-making and providing care within the GerOnTe care

pathway; we also established how they should communicate with each other and with others not involved in the health care professional consortium. Additionally, we established eight essential medical information components that need to be available to all health care professionals in the GerOnTe care pathway, including information on comorbidity, frailty/intrinsic capacity components and patient preferences.

2. Methods

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, two scoping and three systematic literature reviews, patient interviews and focus groups, 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.

2.1. 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, 49 meetings took place within the Geronte consortium. A list of these meetings can be found in Annexe 1. Of these 49, 35 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, DCU). 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.

Partner	Person(s)	Contribution
DIAK	Marije Hamaker, Nelleke Seghers	Involved throughout, leader
OUS	Siri Rostoft	Involved throughout
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
DCU	Anthony Staines, Bridgit O'Sullivan	Focus groups

2.2. Scoping literature review on multimorbidity profiles, frailty and intrinsic capacity

2.2.1. Multimorbidity profiles

A scoping literature review was done to retrieve prior studies regarding multimorbidity profiles. This search was done in Pubmed and used synonyms of multimorbidity/comorbidity and profiles/patterns. The search was limited to the past 10 years. This search yielded 528 hits. As this was a scoping literature review, exact details regarding the in- and exclusions were not recorded. Fourteen papers were found to be relevant, and were analysed and discussed in more detail An overview of these papers can be found in Annexe 2. These formed the basis of further exploration of multimorbidity profiles with the expert panel.

2.2.2. Frailty and intrinsic capacity

A second scoping literature review was performed regarding studies on intrinsic capacity and frailty components that could be included for examination and/or intervention in the GerOnTe care pathway for older patients with cancer. This search was done in Pubmed and used synonyms of geriatric management and oncology. The search yielded 194 hits. As this was a scoping literature review, exact details regarding the in- and exclusions were not recorded. Thirteen papers were found to be relevant and were used as the basis of the intrinsic capacity/frailty datasets and intervention protocol. An overview of papers that were analysed can be found in Annexe 3.

2.3. 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 through the technical report of the European Commission. The decision to divert from the Delphi method did not affect the outcome of the deliverable or the objectives of the project.

2.4. 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, 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 various comorbidities, and intrinsic capacity/frailty items for decision-making and care for each of these cancer types and the treatment modalities that are available for them. They also provided input on the multimorbidity profiles, composition of the health care professional consortium, as well as symptom monitoring and self-management (described elsewhere). Answers from each survey

round were subsequently compiled, compared with findings from the literature reviews, 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 specialties (medical oncology, surgery, radiotherapy, pulmonology, urology, geriatrics, general practice). Respondents were from the following countries: Netherlands, France, Belgium, Norway, Italy, Denmark, Germany, Hungary, Cyprus, United Kingdom. Mean age was 47 years and respondents had a mean of 17 years in clinical practice. Detailed data on the composition of the expert panel in Round 1 can be found in Annexe 5.

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 6.

2.5. Patient interviews and focus groups

2.5.1. Patient interviews

We performed two series of interviews with patients aged >70 years, diagnosed with cancer or treated for cancer during the last two years, regarding quality of life and outcome preferences. Patients were recruited during a consultation with their treating oncologist or when they were receiving treatment in the outpatient clinic. After explaining the study concept to patients, they provided written informed consent.

In the first series, the subsequent interview was done by phone at a time that suited the patient. All interviews were conducted by one interviewer. Interviews lasted between 15 and 45 minutes; patients were given as much time as needed. In these interviews, patients were asked to respond to four open ended-questions: What makes life worthwhile? What does quality of life mean to you? What could improve your quality of life? What could decrease your quality of life? If they answered with broad or vague terms, they were asked to specify as much as possible. Next, patients were asked to select the top five important determinants of quality of life. For details, see section 7.2.

In the second series of interviews, with another cohort of patients aged >70 years, diagnosed with cancer or treated for cancer during the last two years, we assessed the feasibility of using the ONC-outcome prioritization tool to assess patient preferences (for details, see section 8.2.4). These interviews were performed at the oncology out-patient clinic.

2.5.2. Focus groups

We aimed to conduct focus group meetings in which the challenges faced by older patients with cancer would be discussed as well as questions relating to the Holis GV application under development. For

this purpose, we recruited non-frail or pre-frail patients aged ≥ 70 years, diagnosed with cancer (breast, lung, colorectal, prostate) in an early stage, in complete remission or in partial remission for at least 6 months; and with at least one additional comorbid condition. They were excluded if they had cognitive impairment impacting their participation, depressed mood or anxiety issues. Additionally, we set out to recruit informal caregivers for these patients. We aimed to recruit patients in a representative gender ratio (I.e. equal ratio in case of lung and/or colon cancer; equal ratio not feasible for prostate/breast cancer.

An attempt to recruit patients and caregivers through cancer patient associations did not yield any result. Next, we provided the oncologic outpatient clinics with information flyers regarding the study, which the treating physicians could then provide to potentially suitable patients. Patients were asked to contact the research team if they were interested in participating. This process ensured their voluntary participation.

Due to COVID restrictions and the vulnerable patient group involved, we were only able to have one group meeting. Minutes of this meeting can be found in Annexe 7. To replace the other meetings that were planned, we performed one-on-one interviews in the patients' home environment as an alternative. Although this allowed for less interaction between patients and/or caregivers, it did allow for more in depth interviews. This deviation did not impact on the objectives of the deliverable or the project as a whole.

2.6. Systematic literature reviews

In addition to the scoping literature reviews on multimorbidity profiles, frailty and intrinsic capacity, we performed three systematic literature reviews to assess patient needs and preferences:

- Patient preferences for treatment outcomes in geriatric oncology
- A meta-analysis on the role older adults with cancer favour in treatment decision-making
- Information needs of older patients newly diagnosed with cancer

Details on these systematic reviews can be found in Section 8.

3. Developing multimorbidity profiles

3.1. Defining and fine-tuning multimorbidity profiles

As part of the process of optimizing care for older patients with multimorbidity and cancer, we set out to develop multimorbidity profiles, aiming to identify clusters of comorbidities with similar care needs or similar impact on the oncologic treatment trajectory.

As a first step, a literature review was done to retrieve prior studies regarding multimorbidity profiles. An overview of the papers that were analysed can be found in Annexe 2. Some details on the search are listed in section 2.2.1.

In general, the retrieved studies used latent class analyses to determine types of illness that often co-occur. For the GerOnTe project, the primary focus was to develop profiles based on similar care needs or care impact, thus requiring a different approach. While the literature review did not yield any classifications that were useful for GerOnTe, it did help to develop a list of 52 potentially relevant comorbidities (Annexe 7) that were subsequently provided to the expert panel (Round 1, Annexe 4).

The experts were asked to state for each one how likely it is that the presence of this comorbidity would change the oncologic treatment decision or the care trajectory. Results can be found in Annexe 7. Items were carried forward to the next round of the survey (Round 2, Annexe 4) if at least 50% of respondents scored them as being likely or very likely to change either decision-making or care trajectory or 30% or higher for both.

Combining what was found in literature with the answers regarding the relevance of each comorbid condition, we proposed five multimorbidity profiles (Annexe 9), which were subsequently presented to the expert panel (Round 2, Annexe 4). Overall, 91% of respondents agreed with the categorization of the profiles. Some respondent made suggestions for fine-tuning/clarifying the categories. Based on this input, the multimorbidity profiles that will be used for the GerOnTe project are the following:

- 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.

Datasets for this part of the expert panel survey have been published at https://doi.org/10.5281/zenodo.7594684.

3.2. Relevance for oncologic decision-making

In this round of the survey (Round 2, Annexe 4), the experts were asked to confirm the relevance of each multimorbidity profile for oncologic decision-making for the treatment modality that they were involved in. Scores ranged from 1 (not relevant) to 4 (very relevant).

All profiles received an overall ranking over 3 or higher, meaning it is (very) likely that the presence of a profile will influence the treatment decision. This influence is strongest for surgery and chemotherapy; for radiotherapy, only Profile 3 was likely to be of relevance (Figure 1).

Figure 1. Relevance of profile for oncologic decision-making
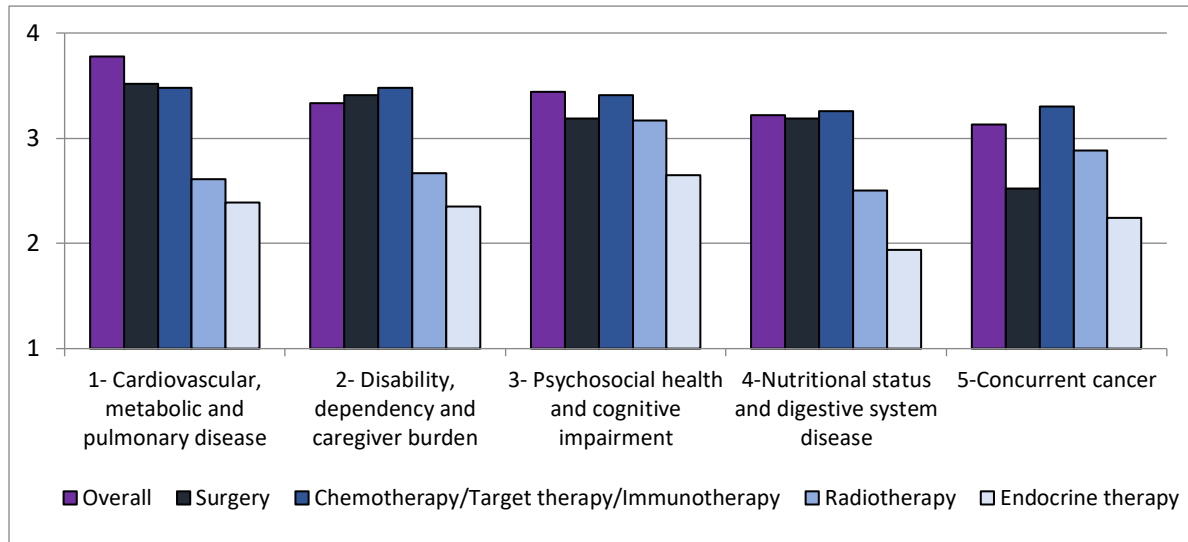
Next, respondents were asked <u>why</u> a profile would influence oncologic decision-making. These results confirm the relevance as well as distinctness of the profiles, by showing they affect decision-making in different ways. In summary, Profiles 1 and 3 were primarily considered important for determining the feasibility of surgery, systemic therapy, and to a lesser degree radiotherapy. Profile 2 and 4 were also relevant for determining feasibility of treatment but additionally, for determining the likelihood of recovery, resilience or functional/cognitive decline. Profile 5 was considered important for decision-making by affecting prognosis, treatment interactions and overall health care burden.

Datasets for this part of the expert panel survey have been published at https://doi.org/10.5281/zenodo.7594684.

3.3. Relevance for care trajectory

Figure 2 shows how each multimorbidity profile was scored in terms of their relevance to the cancer care trajectory that they are involved in, on a scale of 1 (not relevant) to 4 (very relevant).

Overall, the relevance of the morbidity profiles for the care trajectory was scored lower than for oncologic decision-making, but nonetheless, respondents thought it (very) likely that the presence of Profiles 1 to 4 would influence the care trajectory (Figure 2). For Profile 5, respondents were split with equal numbers considering it relevant as not relevant.

Again, respondents were asked why a profile would influence oncologic care trajectory. Pre-treatment optimization was thought to be necessary for Profiles 1 and 4, while all profiles (with

Profile 4 to a lesser degree) were considered to help in fine-tuning the support and care provided during oncologic treatment. Profiles 2 and 3 were also considered to affect treatment compliance, self-care capacity and the ability to understand treatment protocols.

Figure 2. Relevance of profile for the cancer care trajectory
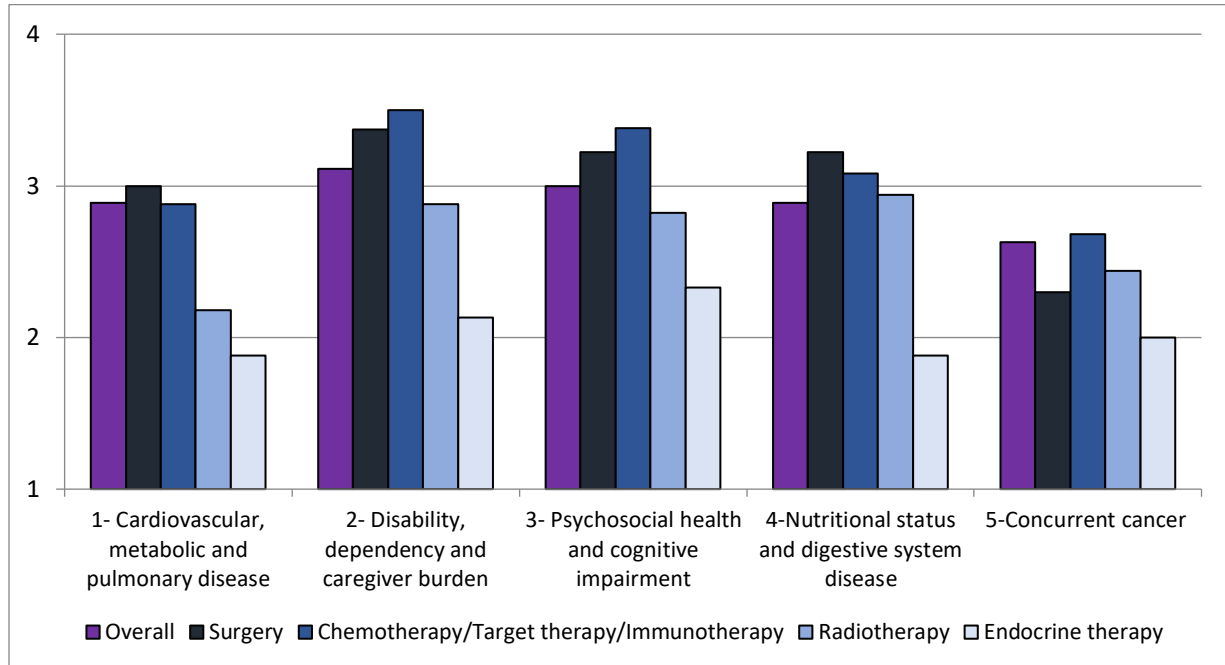
Taken together, these results demonstrate the relevance of these multimorbidity profiles for decision-making and the subsequent oncologic care trajectory. However, they also demonstrate that all patients with multimorbidity and cancer are likely to require fine-tuning in support and care, and that there is no one-size-fits-all.

Datasets for this part of the expert panel survey have been published at https://doi.org/10.5281/zenodo.7594684.

4. Health care professional consortium

4.1. Composition of the health care professional consortium

Another important component of the GerOnTe care pathway was to determine which health care professionals should be included in the health care professional consortium (HPC) providing care for the patient. Beforehand, we had considered the option of four core members and at least eight other participants depending on the patient's specificities or profile.

Based on clinical experience, we developed a list of 15 potential participants, including general practitioner, one or more oncology specialists (such as surgeons, medical oncologists, radiotherapists), geriatrician, oncology nurse, social worker, clinical pharmacist, physiotherapist, anaesthesiologist, home care nurse, dietician, occupational therapist, spiritual helpers/clerics, psychologist/psychiatrist, palliative care specialist, organ-specific physician(s) such as cardiologist, pulmonologist, nephrologist, rheumatologist etc.

This list was presented to the expert panel (Annexe 4, Round 4), and they were asked to determine whether or not these participants should be involved in decision-making and/or the subsequent oncologic care trajectory; experts could specify if these participants should be involved for all patients, only in specific situations/profiles, or did not need to be involved.

For decision-making, only three (groups of) professionals were consistently chosen: oncology specialist(s) (100% of respondents), geriatrician (100% of respondents) and general practitioner (81% of respondents). Over half of respondents (56%) felt the oncology nurse should be involved in decision-making and half (44%)of respondents felt like an organ-specific physician should be involved.

For the care trajectory, four (groups of) professionals were selected: general practitioner (97% of respondents), oncology specialist(s) (100%), oncology nurse (97%), and the geriatrician. For the latter, 53% of respondents felt the geriatrician should be involved in all patients, and 44% that the geriatrician should be involved in case of specific issues or impairments.

For all remaining groups of health care professionals, it was felt like their involvement should be tailored to the specificities of the patient; no other profession was selected by more than half of respondents as relevant for all patient while their involvement in specific situations was endorsed by over 90% of respondents for nearly all professionals.

Details can be found in the dataset GERDAT002: "Composition of the health care professional consortium" published online at https://doi.org.10.5281/zenodo.6334681.

Based on these findings, we determined that the core of the HPC should consist of one or more oncology specialists, a geriatrician, an oncology nurse and the general practitioner. To adequately reflect real life care and multidisciplinary practice, no specifications were made or deemed necessary to address the gender composition of the HPC or the number of years in practice. Participants of the HPC need to be competent in their specific specialization, but this is a general requirement for any person delivering patient care and therefore does not need to be specified in more detail for the purpose of the HPC. The heterogeneity of patient issues within the population of older patients with multimorbidity and cancer did not allow us to include a fifth core member as we had intended in the grant proposal. This heterogeneity, even within the multimorbidity profile groups, as well as the

possibility that patients fit within more than one profile, also means that additional members should be added as needed based on the specificities of the patient and that it was not possible to point out specific additional members that should always be included in a specific profile. This does not allow for a one-size-fits-all and thus requires careful tailoring.

To facilitate this tailoring process, the possibility of adding a specific health care professional to the health care professional consortium was included in the intervention protocol detailed in Deliverable 1.3.

4.2. Communication of the health care professional consortium

4.2.1. Communication within the health care professional consortium

In order to facilitate transfer of information between the stakeholders, we worked on guidance for how relevant input for the HPC meetings is gathered, discussed and reported to ensure that communication was effective. Three of the HPC members are normally physically present in the same location (advanced practice nurse, oncology specialist and geriatrician) and one is normally in a different physical location (general practitioner). As part of the expert panel meeting, this topic was discussed, and different options were presented. After consideration of the pros and cons, it was agreed that an asynchronous approach to communication was the most feasible. This involves the GP providing information to the other members before the HPC meeting, and the remaining three members discussing this information together (either in person or virtually). Figure 3 shows how the information is communicated into the HPC – the general practitioner is represented here by the logo "specialist advice", which can also include other medical specialists as needed.

Figure 3: Overview of information communication to the HPC
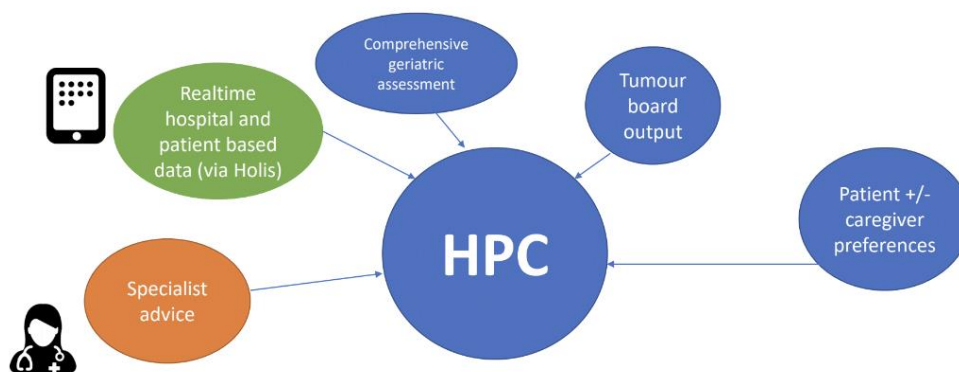
Involving the GP in the HPC ensures that relevant background information can be used as part of the decision-making process. Our expert panel agreed that it would not be necessary to ask the GP for input on oncological decisions *per se*, but rather information that helps provide wider context about the patient and their suitability for different treatment options. This will be achieved by the APN contacting the GP in advance of the first HPC meeting. The GP will be requested to provide information with a uniform structure following these questions:

1- How well do you know this patient and their caregivers? Are they adequate in seeking medical advice?
2- How many times did you see the patient during the past year?
3- What is your impression of their overall fitness level? Do you think they are fit enough to undergo cancer treatment?
4- Can you help us to identify any issues that need support? E.g. cognition, functional, adherence, social, distress, transport, environment

4.2.2. Process of the HPC meeting for decision-making

At the HPC meeting, the advanced practice nurse, oncology specialist and geriatrician discuss patients within the Geronte pathway, using the Holis application as a structured prompting system. Holis facilitates an accessible representation of the most relevant patient information that will be used within the decision-making process. We have not been prescriptive about who leads the meeting, but generally the advanced practice nurse will present patients for discussion as they provide regular input into Holis about the patients, including the initial set-up and completion of baseline data.

At the initial meeting (HPC decision making meeting), all the previously mentioned information topics will be reviewed and discussed, for example tumour type, co-morbidities, social and demographic factors, patient preferences and intrinsic capacity (see section 5). The Holis GV dashboard ensures this process is driven by holistic information which also permits patient involvement in their own decisions. The APN can ensure that all relevant information has been taken into account as part of the decision-making process. In order to achieve this, a structured information flow will also be a feature of the meeting. Each of the following questions will be considered:

1- What would the life expectancy of this patient be without cancer?
2- What is the life expectancy with the cancer left untreated?
3- What is the burden of the cancer if left untreated?
4- Does the cancer treatment add to the patient's life expectancy?
5- Does the patient have physical complaints that are likely to be resolved by the cancer treatment?
6- What is the burden of the cancer treatment (hospital admissions and visits, complication risk)?
7- What are the alternative treatment options (including best supportive care) and how would these alternative options differ with regards to expected outcomes?
8- What is the influence of the proposed cancer treatment on the patients' goals?
9- What is the cancer treatment recommendation?
10- What other (non-cancer) interventions are recommended?

The group of questions above was finalised at the expert panel meeting, having presented an initial list of questions obtained from a previous study by Festen et al (J Geriatr Oncol. 2019 Nov;10(6):951-959. doi: 10.1016/j.jgo.2019.04.006). The purpose of the original list was to provide a step-wise approach to decision making for any treatment. We modified this list to ensure it was applicable to older patients with cancer. The final list was agreed by all members of the expert panel.

As previously mentioned, patient input is a core part of the Geronte care pathway and one of the reasons why this is a novel patient-centred approach to decision making in older people with cancer. Once the initial meeting has concluded, the APN (with a physician as needed) will meet with the patient to discuss the outcome and the final treatment decision will be made together with the patient.

4.2.3. HPC meetings during treatment and follow-up

At three, six and nine months, the HPC will convene again for an evaluation meeting and take stock of the treatment plan and how it has affected the patient. The following structure will be used to discuss this in a standardised way:

HPC evaluation-meeting questionnaire (3, 6 and 9 months)

1- Is the current treatment plan still suitable? Does this treatment plan still fit the personal goals of the patient?
2- What issues have arisen (if any) since the last review? Are there any worrisome symptoms or signs of functional decline?
3- Is any extra support or intervention needed now, or likely to be needed before the next review?

The above process will continue with treatment and patient symptom reporting until the 12 month point of the timescale. Again, there will be a structured meeting to discuss progress with the following questions decided:

HPC- evaluation meeting questionnaire (12 months)

1- In your opinion, how successful has the patient's treatment been for meeting their priorities? (Likert scale, 1-5)
2- Are there any further recommendations for the patient or the treating team at this time?

During our discussions with stakeholders it was also pointed out that while the structured timeline above is appropriate for most patients, there was also a need to facilitate an additional meeting where this was felt to be necessary. Any member of the HPC can trigger this, and the following structure will be provided for discussion of the issue(s):

Additional HPC meeting – evaluation questions

1.   Why is an additional HPC meeting organised?

2.   What issues have arisen since the last review? Are there any worrisome symptoms or signs of functional decline?

3.   What new treatment plan is considered? Does this treatment plan still fits the personal goals of the patient?

4.   Is any extra support or intervention needed now, or likely to be needed before the next review?

4.2.4. Health care professional consortium reporting

Finally, the process needs to complete the information feedback loop by bringing the general practitioner into the equation. At each meeting, there is an information outflow by providing a summary of the meeting and any decisions made. This written report will be communicated to the GP by default, and to any other relevant stakeholders as needed. For example, it might be considered that a patient is having new symptoms suggestive of heart failure during the treatment programme. As a result, the HPC may decide to make a referral to a cardiologist and this information will be transmitted both to that specialist and the patient's GP.

5. Core medical components

Another task of our work package was to establish at least five medical data components that need to be made available in the common medical file (i.e. the Holis GV dashboard) for all patients.

As a first step, we asked the expert panel open-ended questions (Annexe 4, Round 2) about what they felt were the biggest challenges in caring for older patients with multimorbidity and cancer (Table 1) and in what ways comorbidity/multimorbidity profiles could impact on the cancer treatment trajectory (Table 2). Datasets for this part of the expert panel survey will be used for publication. After this has been completed, the datasets will be deposited in Zenodo.

Table 1. Challenges in caring for older patients with multimorbidity and cancer

Challenges	Explanation
To select the best suited treatment for the individual, balancing the uncertain benefits and risks and including patient preferences and goals	• Lack of scientific evidence in this population • Best suited treatment depends on preferred outcomes • Risk of overtreatment and undertreatment • Focus still too much on the disease instead of the patient
To increase the awareness and inclusion of relevant non-tumour parameters/frailty/IC throughout the process	• During the decision-making process • And during follow up • Also implement non-oncologic interventions
To maintain quality of life, functioning and independence	• Organize care (p)rehabilitation • Implement geriatric interventions
To overcome organizational challenges and improve coordination of care	• Coordination of multiple HCP involved • One central healthcare professional • Organize support for the patient • Lack of time and financing
To monitor interaction and destabilization of both cancer(treatment) and multimorbidity	• Higher risk and more impact of adverse events • Quick decline in functioning when conditions are destabilized • Monitoring cancer treatment tolerance and comorbidities frequently

Table 2. Impact of comorbidity/multimorbidity on the cancer treatment trajectory

Reasons mentioned	% of respondents
Establishing the feasibility of treatment and the risk of complications/toxicity	90%
Tailoring of support and care during treatment	83%
Estimating resilience and functional/cognitive outcomes	77%
Possibility for pre-treatment optimization	67%
Interactions between treatment for cancer and for comorbidity	63%
Predicting prognosis, competing causes of death	57%
Risk of decompensation of comorbid conditions due to cancer treatment	47%
Patient's ability to understand treatment protocols and self-care recommendations; compliance	47%
Need for post-treatment rehabilitation/additional discharge care	43%
Impact on decision-making capacity	37%
Acceptability of overall health care burden	33%

These challenges and issues include organisational, interventional, research and information aspects. For determining the medical data components that need to be included in the common medical file, the information aspects were of primary importance. Table 3 lists the eight data components that were included in the Holis GV dashboard, based on the input of the expert panel.

In the online expert panel meeting, these eight components were discussed and agreed on by the panel. In the next sections, we will discuss in more detail the core datasets that have been developed for comorbidity and intrinsic capacity/frailty, as well as the way in which patient preferences were incorporated in the Holis GV dashboard.

Table 3. Data components for the common medical file (Holis GV Dashboard)

Component	Motivation
Large image of the patient	This is to remind the health care professionals involved in decision-making and care trajectory about the person they are caring for and to maximize the focus on the person and not the disease
Personal information about the living situation and current formal and informal care	The patient has a context and this context is important for the cancer care trajectory. Being informed about the patient's personal situation and current care availability provides both insight in resources and vulnerabilities as well as opportunities for optimizing support
Tumour information including treatment recommendation of the multidisciplinary tumour board	Decision-making about cancer treatment is not possible without understanding the details of the disease. Multidisciplinary input is needed to determine treatment options, including alternatives, that can be discussed in meeting of the health care professional consortium
Comorbidities	Understanding the multimorbidity burden is essential in determining feasibility of treatment, risks of oncologic treatment-related complications or decompensation of comorbidities, as well as prognostication
Medication and substance use	Interactions between medication for multimorbidity and for cancer can be a significant complicating factor in geriatric oncology. This also applies for substance (ab)use. Furthermore, polypharmacy evaluation can assist in optimizing the patient's health status prior to initiating oncologic treatment.
Non-cancer specific prognosis	Estimating the remaining life expectancy of the patient – separate from the cancer-related prognosis – can help in choosing a suitable patient, taking into account time-to-benefit as well as time to cancer-related complications
Intrinsic capacity/frailty	This information is necessary for understanding the patient's capacity to tolerate treatment, resilience, vulnerabilities as well as for providing interventions aimed at optimizing support and health status
Patient preferences	Knowing the patient's priorities and preferences is essential for process and treatment tailoring, and for keeping the focus on the patient.

6. Comorbidity dataset

6.1. Developing dataset of comorbidities for the GerOnTe care pathway

In the Holis GV dashboard, information about comorbidities will be included in two ways. First, the dashboard provides space for listing the prior medical history in the way it is currently common practice in medical files. However, the Holis GV dashboard will also include an Avatar – an image of the patient with the opportunity to highlight specific comorbidities that have a high relevance for oncologic decision-making and/or the subsequent care trajectory. The Avatar will also include more detail about the severity and impact of the comorbid condition.

To determine which comorbidities should be highlighted in the Avatar (if present), we used the list of 52 comorbidities that was developed based on the prior literature review. We asked the expert panel (Annexe 4, Round 1) to state for each one how likely it is that the presence of this comorbidity would change the oncologic treatment decision or the care trajectory. Results can be found in Annexe 5. Items were considered important enough for inclusion in the Avatar if at least 50% of respondents scored them as being likely or very likely to change either decision-making or care trajectory or 30% or higher for both. Based on these results, the following comorbidities were considered relevant for including in the Holis GV dashboard (Table 4). Items in black are included in the comorbidity overview, items in red are incorporated in the intrinsic capacity overview, and green items are included in both.

Table 4: Items from the comorbidities list selected by the expert panel for the Holis GV Dashboard

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

Datasets for this part of the expert panel survey will be used for publication. After this has been completed, the datasets will be deposited in Zenodo.

6.2. Determining relevant variables to capture comorbidity severity and impact

An important comment received from our expert panel in asserting the relevance of comorbidities was that the mere presence of the comorbidity was not sufficient. Additional information on the severity of a comorbid condition is needed to know if it impacts an oncologic decision or a treatment trajectory. Therefore, as a next step, we asked the experts to state for the sixteen somatic/psychiatric comorbidities considered important in the previous round, whether or not the presence itself is sufficient information or if they needed extra information quantifying the severity; if so, we also asked which information (Annexe 4, Round 3). Detailed responses can be found in Annexe 9. Datasets for this part of the expert panel survey will be used for publication. After this has been completed, the datasets will be deposited in Zenodo.

Based on this input, it was decided that in the GerOnTe care pathway, that for each relevant comorbidity the patient has (thus included in the Avatar), the geriatrician should provide a clinical judgement regarding its severity (mild/stable, moderate or severe/unstable) and impact on daily functioning (none, limited, significant). In addition, a Core Multimorbidity Dataset of objective variables (measurements, classifications etc.) was extracted from the expert suggestions (GERDAT001 published online at https://doi.org/10.5281/zenodo.6334599).

A similar process was undertaken for geriatric comorbidities and impairments; results of this are reported in Section 7 which describes frailty and intrinsic capacity.

6.3. Monitoring and self-management of comorbidities in the treatment trajectory

A final step in this process was to determine which comorbidities warrant symptom monitoring during the treatment trajectory and which lend themselves to self-management. Results of the work regarding symptom monitoring are reported in Deliverable 1.2 – DATASET OF SYMPTOMS AND PROMS FOR SPECIFIC CANCER TYPES AND GENDER. With regards to self-management, recommendations were linked to specific symptoms which could be caused by a range of comorbidities. The process of developing these symptom-specific recommendations can be found in Deliverable 1.4. – DATASET OF SELF-MANAGEMENT RECOMMENDATIONS FOR PATIENT-DRIVEN IMPROVEMENT OF INDEPENDENT LIVING. The self-management recommendations itself can be found online in the Dataset of Self-management Recommendations GERDAT004 published at https://doi.org/10.5281/zenodo.6334770.

7. Developing dataset of relevant intrinsic capacity variables

7.1. Intrinsic capacity, frailty and the geriatric assessment

In the grant proposal, we set out to determine at least four frailty components and three intrinsic capacity components to be included in the common medical file/Holis GV dashboard.

Intrinsic capacity can be defined as the composite of all the physical and mental capacities that individuals can draw on at any point in their life.[1] It is a dynamic construct: lifestyle, injuries, events at different points across the life course will have a significant impact on the intrinsic capacity

trajectory, as will health-related or social interventions. While there is a general tendency for intrinsic capacity to decline from mid-adulthood onward, there will be significant variation between individuals. Furthermore, intrinsic capacity may wax and wane as an individual experiences various setbacks and potential recoveries in their life course.

While intrinsic capacity focuses on the evolution of reserves over time, a frailty assessment can be seen as snapshot taken at a specific moment. Through an evaluation of geriatric domains, a patient's vulnerabilities are uncovered and used as input for modifying treatment as well as implementing interventions to optimally support the patient.

For clinical utility, intrinsic capacity has been decomposed into subdomains that can inform clinical responses, including mobility/locomotor, cognitive, sensory, psychosocial and vitality/energy domains. In geriatric oncology, the most commonly assessed geriatric domains to assess frailty include the ability to perform basic and instrumental activities of daily living (ADLs and IADLs), mobility, nutritional status, cognition, mood and social support, and geriatric syndromes, in addition to comorbidity and related medication use. Thus, there is significant overlap between these two constructs, and ultimately, we decided that it was not useful to try to separate them into items pertaining only to one or the other. Thus, instead of providing at least four frailty and three intrinsic capacity components, we decided to combine this, and provide a minimum of at least seven components across the following domains:

- Function/locomotor
- Nutrition/vitality
- Cognition and psychological status
- Geriatric syndromes and sensory impairments
- Social support/environment
- Comorbidity and medication

7.2. Initial literature review and expert panel input

As discussed in Section 6, we asked the expert panel to state for each comorbidity from a list of 52 items, including not only somatic but also functional, psychological, social and nutritional comorbidities – how likely it is that the presence of this comorbidity will change the oncologic treatment decision or the care trajectory (Annexe 4, Round 1). Again, comorbidities were carried

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[1] Islene Araujo de Carvalho, Finbarr C Martin, Matteo Cesari, Yuka Sumi, Jotheeswaran A Thiyagarajan, John Beard. Operationalising the concept of intrinsic capacity in clinical settings .WHO Clinical Consortium on Healthy Ageing 21–22 November 2017

forward if at least 50% of respondents scored them as being likely or very likely to change either decision-making or care trajectory or 30% or higher for both (Annexe 3, Round 2). Results can be found in Annexe 4. In addition to the comorbidity items identified by the expert panel, additional impairments were identified through literature review and the expert opinion of five geriatricians with expertise in geriatric oncology. These items were identified as being potentially relevant for assessing resources and predicting course of treatment or care needs (Table 4, details in Core Intrinsic Capacity Dataset, GERDAT003 published online at https://doi.org/10.5281/zenodo.6334723). Aspects marked with an asterix were derived from our expert panel as being important. The other items (without an asterix) were added based literature review on intrinsic capacity and geriatric assessment in geriatric oncology (Annexe 3) and the expert opinion of five geriatricians involved in geriatric oncology.

Table 4: Intrinsic capacity data set

Items of the geriatric assessment
Frailty screening (Clinical Frailty scale)
Patient priorities (ONC-OPT)
Prognosis (Lee-index)
Somatic: fatigue *
Functional status
Dependence for ADLs *
Dependence for instrumental ADLs *
Previous falls *
Impaired mobility, gait or balance*
Performance status *
Faecal Incontinence*
Urinary incontinence
Impaired vision or hearing
Usage of walking aid
Nutritional status
Malnutrition and/ or involuntary weight loss*
Sarcopenia, anorexia or cachexia *
Cognition and psychological status
Dementia and other neurodegenerative disease*
Delirium risk or previous delirium *
Anxiety, depression and other mood disorders *
Loneliness *
Health literacy
Social support and environment
Who is the primary caregiver
Caregiver burden *
Living situation and partner status*
Transportation issues*
Use of (informal) care
Social network
Polypharmacy
Adherence problems

7.3. Assessing and grading of impairments included in the intrinsic capacity dataset

Details on how the items of the intrinsic capacity dataset may be evaluated and graded for incorporation in the GerOnTe Dashboard can be found in the Intrinsic Capacity Evaluation and Intervention protocol, GERDAT005 published online at https://doi.org/10.5281/zenodo.6334779. The process of developing this protocol is described in Deliverable 1.3.

8. Developing dataset of patient preferences

8.1. Challenges faced by older patients with multimorbidity and cancer

In the patient focus group (Annexe 7), we asked older patients with multimorbidty and a history of cancer, as well as caregivers of these patients, what they had found the biggest challenges within their cancer treatment trajectory. These are summarized in Table 5.

Table 5. Challenges faced by older patients with multimorbidity in the cancer treatment trajectory

Decision-making challenges	- How to take your role as stakeholder - How to set realistic goals
Emotional challenges	- Uncertainty and worries - Psychological impact
Social challenges	- Impact on family - Impact on caregivers and other caregiver issues
Information challenges	- Dealing with all the information - Keeping track of all appointments and medical requirements - Lack of information about what can be expected during and after treatment as well as long-term effects
Multimorbidity challenges	- Lack of attention for health care needs and illnesses aside from the cancer trajectory - Overall health care burden - Coordination between health care providers
Medical challenges	- How to deal with symptoms and side-effects - Interaction between treatments

Again, these challenges include organisational, intervention and information aspects. For the patient preferences dataset, we decided to focus on three aspects of patient preferences: outcome preferences including goal setting, communication preferences including decision-making control, and information preferences.

8.2. Outcome preferences and goal setting

8.2.1. Systematic literature review of outcome preferences

A first step to understanding patient preferences in oncology was to perform a systematic literature review on outcome preferences in oncology. The systematic Medline and Embase search yielded 7321 hits (2042 from MEDLINE and 5279 from EMBASE). Details of the search are deposited in https:// doi.org/10.5281/zenodo.7194756, a flow diagram is provided on the next page. Studies were eligible if they reported some form of prioritization of outcome categories relative to each other in patients with cancer and if they included at least three outcome categories. Subsequently, for each study, the highest or second highest outcome category was identified and presented in relation to the number of studies that included that outcome category.

In total, 4374 patients were asked for their priorities in the 28 included studies. Of this group, 79% identified quality of life as the highest or second highest priority, followed by overall survival (67%), progression- and disease- free survival (56%), absence of severe or persistent treatment side-effects

Study selection for outcome preferences

All studies	n= 7321
MEDLINE	n= 2042
EMBASE	n= 5279

Duplicates	n= 2072

Study selection for outcome preferences

Exclusion	n= 5222	
Not original research		n= 179
Not cancer or not adult		n= 374
Wrong outcome		n= 4584
No extractable data		n= 44
Insufficient number of categories		n=11
No full text		n= 30

Search	n= 27
Cross-referencing	n=1
Included total	n=28

(54%), and treatment response 50%. Absence of transient short-term side-effects was prioritized in only 16%.

Understanding how patients prioritize potential outcomes of oncologic treatment and the trade-offs they are willing to make is an important component of shared decision-making. Our systematic review shows that quality of life, overall survival, progression- and disease- free survival, and avoiding severe and persistent side effects of treatment are the outcomes that receive the highest priority in patients with cancer. These items were taken forward to the next steps of determining outcome preferences to include in the GerOnTe care pathway.

This systematic review was published in the Cancers: Seghers PAL, Wiersma A, Festen S, Stegmann ME, Soubeyran P, Rostoft S, O'Hanlon S, Portielje JEA, Hamaker ME. Patient preferences for treatment outcomes in geriatric oncology – a systematic review. Cancers 2022 [in print]. The paper can be found in https://doi.org/10.3390/cancers14051147.

8.2.2. Patient interviews on quality of life and outcome preferences

The treatment of cancer can have a significant impact on quality of life in older patients and this needs to be taken into account in decision-making. However, quality of life can consist of many different components with varying importance between individuals. We set out to assess how older patients with cancer define quality of life and which components are most significant to them.

Due to COVID, larger scale focus group research was not considered possible, particularly given the fact that the target population for our research consisted of vulnerable, older patients. Instead, we performed individual interviews.

We performed a single-centre, qualitative interview study. Patients aged 70 years or older with current or recent cancer diagnosis were asked to answer open-ended questions: What makes life worthwhile? What does quality of life mean to you? What could affect your quality of life? Subsequently, they were asked to choose the five most important determinants of quality of life from a predefined list: cognition, contact with family, or with community, independence, staying in your own home, helping others, having enough energy, emotional well-being, life satisfaction, religion and leisure activities. Afterwards answers of the open-ended questions were independently categorized by two authors. The proportion of patients mentioning each category in the open-ended questions were compared to the predefined questions. The dataset from these interviews can be found at https://doi.org/10.5281/zenodo.7062211.

Overall, 63 patients (median age 76 years) were included. When asked "What makes life worthwhile?", patients identified social functioning (86%) most frequently. Moreover, to define quality of life, patients most frequently mentioned categories in the domains of physical functioning (70%) and physical health (48%). Maintaining cognition was mentioned in 17% of the open-ended questions but it was the most commonly chosen option from the list of determinants (72% of respondents).

To conclude, physical functioning, social functioning, physical health and cognition are important components in quality of life. When discussing treatment options, the impact of treatment on these aspects should be taken into consideration. Because quality of life is highly individual, simply asking

patients to fill out a questionnaire is not enough to understand their definition of quality of life. It is therefore important that the healthcare provider has an actual conversation about what really matters to the patient, in which they verify what components are important and why.

This study was published in Cancers: Seghers PAL, Kregting JA, van Huis-Tanja LH, Soubeyran P, O'Hanlon S, Rostoft S, Hamaker ME, Portielje JEA. What defines quality of life for older patients diagnosed with cancer? A qualitative study. Cancers 2022 [in print]. It can be found in https://doi.org/10.3390/cancers14051123.

8.2.3. Development of the ONC-OPT patient preference tool

The systematic review on outcome preferences in oncology yielded information on several methods of inquiring about patient's preferences, including discrete choice elicitation (n=15), followed by conjoint analysis (n=5), the Outcome Prioritization Tool (OPT, n=3) and various types of rating scales. For GerOnTe , we wanted an instrument that could be used in various treatment settings (curative, palliative) and that could be used in all tumour types. For this purpose, the OPT seemed the most useful. The OPT allows for an actual conversation on why a patient prioritizes certain aspects and therefore would be most suited for assessing what the various answer options mean to the individual patient.

In the original version of the OPT, a patient is asked to rate each outcome relative to other outcomes without having two values on the same level. This uses a trade-off principle: by prioritizing one outcome, patients are willing to accept the deterioration of other outcomes. The outcomes that are assigned priorities in the OPT conversation are (1) extending life, (2) maintaining independence, (3) reducing pain and (4) reducing other symptoms. During this conversation, the healthcare professional verifies if he or she understands the trade-offs correctly and invites the patient to explain why outcomes are important and how they were interpreted.

Although this tool has been used in oncology patients before, the four outcomes that are included are broad and not specific to cancer patients. Based on the information that was gathered from the systematic review and patient interviews, we decided to adapt this tool specifically for cancer patients. This was done in collaboration with the University Medical Centre Groningen (UMCG), who developed the original version of the OPT. The adapted version was given the name ONC-OPT. In this new instrument, designed specifically with GerOnTe in mind, the four outcomes for which to assign priority are: (1) extending life, (2) maintaining independence, (3) reducing pain and other symptoms, and (4) limiting negative effects of cancer treatment. We wanted to include the negative effects of cancer treatment, because it was prioritized in our systematic review after quality of life and survival as an important factor in treatment decisions.

In collaboration with UMCG, we also developed a conversation guide to assist health care professionals wanting to use the ONC-OPT tool in how to approach this. The conversation guide can be found in Annexe 10.

8.2.4. Pilot study of goal-setting using the ONC-OPT patient preference tool

In February 2022, a pilot study was launched to assess the feasibility and usability of the ONC-OPT tool in clinical practice. For this, a series of 15 minute interviews were performed with seven patients aged 70 years and older with current or recent cancer diagnosis. In addition, five health care providers using the new instrument in clinical practice received a survey to assess their experience, test the feasibility and fine-tune the conversation guide.

Patients were recruited during a consultation with their treating oncologist or advanced practice nurse or when they were receiving treatment in the outpatient clinic. All patients provided written informed consent after explaining the study concept. It was explained to patients that their answers would not influence their treatment journey and would not be given back to their treating physician. Afterwards patients were asked to fill out a form in which they rated the complexity of the method. The health care providers were asked about their experiences with the new ONC-OPT, whether all goals that patients mentioned fit in the method and whether prioritizing these goals would aid the future treatment decision. Also information on the clearness of the instructions and examples of the symptoms and negative treatment outcomes that patients wished to avoid were collected. For health care providers who had experience with the original OPT, we asked them to evaluate the difference between the new and the original tools.

Patients did not find the ONC-OPT difficult to use, but some unsure whether this tool would benefit the conversation they would have with their treating physician to choose a new treatment.

In total the ONC-OPT was tested by five different healthcare providers (all active in geriatric medicine). Of these healthcare providers four did already use the regular OPT before. All health care providers felt that they could use these new ONC-OPT to elicit patient priorities for treatment goals and most were able to fit all treatment goals mentioned by patients into one of the four categories. Sometimes, an extra explanation on the various goals was needed, particularly with regards to potential negative treatment outcomes.

In the preliminary results it thus seems that both the healthcare providers and the patients think the new ONC-OPT tool is feasible and valuable addition to the decision making process. Once the full dataset for this pilot study is available, it will be used for publication. After this has been completed, the datasets will be deposited in Zenodo.

8.3. Systematic literature review of decision control preferences

In addition to understanding patient preferences regarding outcomes of oncologic treatment, it is important to understand patient preferences regarding decision control during the decision-making process. In the complex setting of oncologic treatment decision-making, balancing professional guidance while respecting patient involvement can be a significant challenge. We performed a systematic review and meta-analysis to assess the role adults with cancer favour in treatment decision-making (TDM), including differences across age groups and change over time.

For this, a systematic search was performed in MEDLINE and Embase, for studies on role preference of (older) adults with cancer in oncological treatment decision-making. A meta-analysis was conducted based on Control Preference Scale (CPS) data, a questionnaire on patient role preference in TDM. The literature search identified 4,036 reports (2,071 from MEDLINE and 1,965 from EMBASE) of which 1,686 were duplicates. The remaining 2,350 records were screened based on title and abstract and a subset of 219 full text articles were further assessed for eligibility in accordance with our in- and exclusion criteria. Ultimately, 33 publications reporting CPS data were included in this meta-analysis, comprising 15,700 adults with cancer. Details of the search can be found in https://doi.org/10.5281/zenodo.7308287. The flow diagram is shown below.

PRISMA flow of literature selection for this review including reasons for exclusion of studies
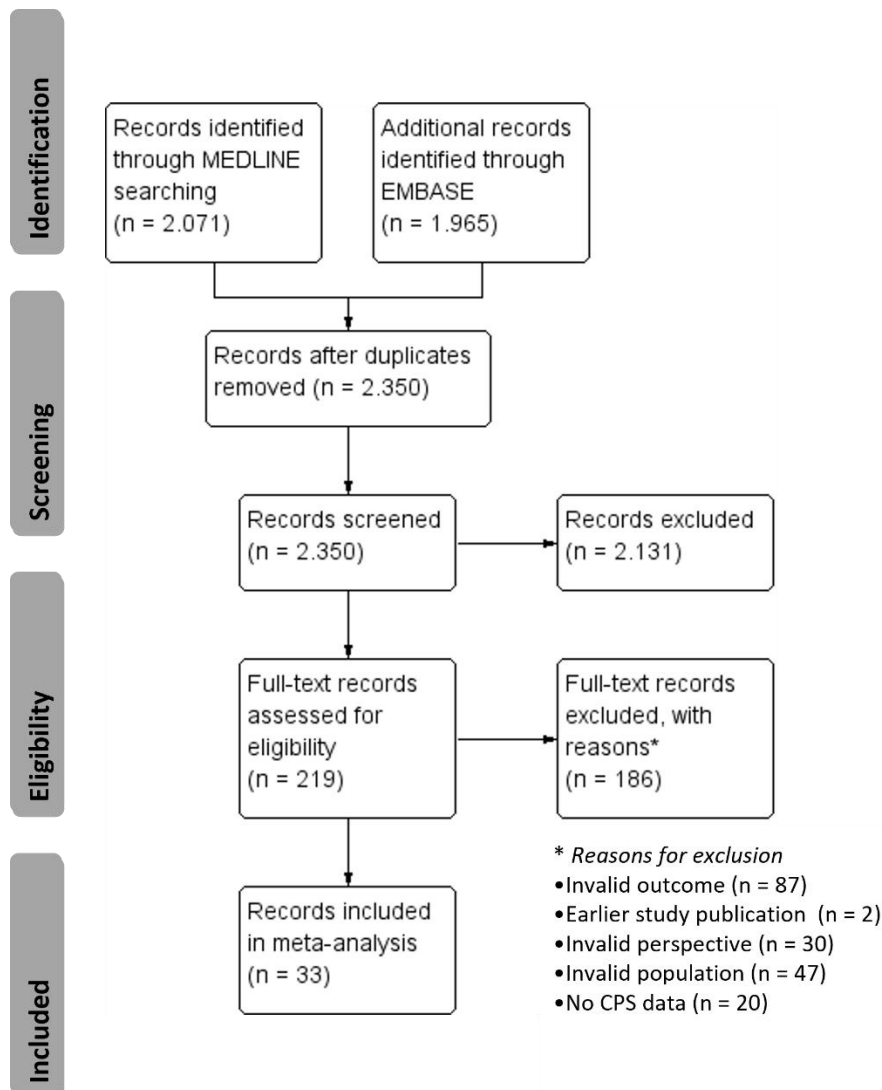
The results show that in current cancer care, patients' role preference has shifted towards significantly more active involvement in decision-making. No age dependent subgroup differences have been identified, as both younger and older adults with cancer favour an active treatment decision-making role. Of all adults with cancer who prefer an active decision-making involvement, two-thirds favour a collaborative role, in which they share decision responsibility with their physician.

This meta-analysis shows that the majority of adults with cancer wishes to share decision-making responsibility with their physician. However, there is heterogeneity in the individual role preferences in TDM. A minority of adults with cancer prefers to have someone else take treatment decision-making responsibility. While at the time of decision-making this may seem desirable, studies showed that a passive role in TDM, even when preferred, is associated with poorer outcomes. Patients who prefer passive TDM involvement were shown to be less content with information and communication and felt unequipped to share responsibility when it comes to making impactful treatment decisions. Thus, although it might require additional effort to elicit an active role in TDM, this effort likely yields greater patient satisfaction. A preference for a passive role in treatment decision-making should not be the resultant of a patient feeling there is a lack of time, information or space to reach their own decision. That said, the ultimate goal is not that all patients take an active decision-making role, as a passive role preference can be an active choice for the patient, and this should be respected.

This meta-analysis shows the heterogeneity within patient preferences regarding decision control. Thus, it is important to inquire about this with each individual patient. To incorporate decision control preference in the GerOnTe care pathway, the control preference scale was included in the Holis GV Decision-making dashboard, to be completed by the patient in collaboration with the advance practice nurse.

This study has been published at https://doi.org/10.1016/j.jgo.2022.09.012.

8.4. Systematic literature review of information preferences

Understanding what information patients with cancer want and need when they are newly diagnosed and faced with making oncologic treatment decision, is an important step in optimizing care. Therefore, we set out to collect all available evidence about the information that is most important to older patients with a new cancer diagnosis and whether or not these information needs are sufficiently addressed. For this, we performed a systematic literature review of Embase and Medline.

The search yielded 4137 studies (1985 from Medline, 2152 from Embase), of which 1541 were duplicates and 2569 were excluded for other reasons. Details on the search can be found at https://doi.org/10.5281/zenodo.7143704. The flow diagram is shown on the next page. Therefore, 27 studies were included in this systematic review: eighteen studies addressing the importance of information topics and thirteen addressing the sufficiency of information provided (four addressed both). On a scale from 1-10, patients ranked information about prognosis and the chance of cure as the most important category (median ranking 10, interquartile range (IQR) 8-10), followed by information on cancer itself (median 9, IQR 5.5-9), and treatment options (median 8, IQR 8-9). Information on side-effects of treatment (median 7, IQR 6-8), and practicalities (median 6, IQR 5-7.5) were also considered important. Patients rated information about the practicalities of treatment as the most insufficiently addressed (median 9.5), followed by self-care at home (median 9), and information about prognosis and side-effects (median 8 for both).

Search results and study selection

All studies	n= 4137	
Medline		n= 1985
Embase		n= 2152

Duplicates	n= 1541

Exclusion	n= 2569	
Not original research	n=	41
Not oncology	n=	95
Not study population of interest	n=	223
Not outcome of interest	n=	2124
Not in English	n=	45
Conference abstract only	n=	30
No extractable data	n=	11

Inclusion: 27 publications

Cross referencing yielded no additional studies

This systematic review demonstrates that information provision about the cancer itself and about treatment options is generally satisfactory to patients, while information about prognosis, practicalities of treatment and self-care at home could be improved. However, there is significant heterogeneity among older patients regarding which information is most important to them, thus requiring an ongoing dialogue between patients and health care providers about which information is most needed at any given time.

This systematic review was published in the Journal of Geriatric Oncology: Hamaker ME, van Walree IC, Seghers PALN, van den Bos F, Soubeyran P, O'Hanlon S, Rostoft S. **Information needs of older patients newly diagnosed with cancer.** https://doi.org/10.1016/j.jgo.2021.09.011

To incorporate information preferences in the GerOnTe care pathway, we provide older patients with multimorbidity and cancer with a list of questions that may be relevant to them, and that could be used as prompts to improve conversations between patients and their health care providers. These questions are incorporated in the Holis GV patient application. In addition, tips for optimizing communications were also provided as part of the self-management library in the patient application. These communication tips and question list can be found in Annexe 12.

9. Conclusion

This deliverable describes the process in which we developed five common patient multimorbidity profiles; established the core members of the health care professional consortium, who will take on the joint responsibility of decision-making and providing care within the GerOnTe care pathway; and how they should communicate with each other and with others not involved in the health care professional consortium. Additionally, we established eight essential medical information components that need to be available to all health care professionals in the GerOnTe care pathway, including information on comorbidity, frailty/intrinsic capacity components and patient preferences. These aspects form the foundation of the Holis GV dashboard and the GerOnTe care pathway.

D1.1 *Core dataset of health professionals, multimorbidity and intrinsic capacity for the GerOnTe model* 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 two subobjectives :
- Establish the list of key professionals to be gathered in an HPC according to the patient profile
- Determine which medical and personal data of patients are needed for the HPC to make the best informed decisions

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 1.1 provided the information that should be included in the ICT tools for both the HPC as well as the patients.

- Deliverable 1.1 was used in Task 3.4 and Deliverable 3.1 to develop the QKPIs which are part of Objective 3 of the project (Develop socio-economical methods for evaluating the impacts of the implementation of the GerOnTe model. Subobjective 3.2 of this objective is to develop social and economic QKPIs to have a solid comparison base between countries and medicine specialties. Information form Deliverable 1.1 was able to provide information that could be used for the QKPIs.

- Finally, Deliverable 1.1 led to 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 theGerOnTe model). In particular, the deliverable 1.1 were used to develop the care pathway and trial protocol for subobjective 4.1 (Establish the protocol for twoRCT(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
22-10-2020	All	Multimorbidity literature search and multimorbidity profiles
27-11-2020	SO, MH, NS	Defining multimorbidity profiles, how to determine profile per patient, when to include comorbidity in profile
2-12-2020	All	Defining severity of comorbidty, foundation of multimorbidity profiles based on care needs
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.
29-1-2021	SR, MH, NS	Care pathway 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)
23-3-2021	All	Content expert panel surveys, geriatric interventions/ management

6-4-2021	All	Collaboration with WP6, survey round 1 development
13-4-2021	All	Survey round 1, intrinsic capacity/frailty
20-4-2021	All	Connection WP1 outcomes with WP2 dashboards.
29-4-2021	All	Preliminary results survey round 1, patient profiles, stakeholder interview discussion, multimorbidity in avatar
7-5-2021	All	Results survey round 1, preparation round 2
10-5-2021	MH NS + ESE	Focus groups preparation
12-5-2021	NS MH + Lucia Ferrara, Vittoria Arditto (BOC)	Alignment WP1 and WP3
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
9-7-2021	ALL + Pierre Soubeyran (UBX)	Focus groups preparation, minimal oncologic dataset, privacy concerns
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 preparation
13-8-2021	MH NS + MYPL	Datasets for dashboard
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
6-10-2021	All	Health literacy
13-10-2021	All	Symptom monitoring, measurement objective physical functioning, health literacy, HPC decision making process
22-10-2021	All	Prepation presention for Dublin consortium meeting, patient monitoring and self-management, input general practitioner
28-10-2021	NS MH	Patient focus group meeting (minutes see Annexe 7)
10-11-2021	All	Symptom monitoring, medication adherence, patient application
26-11-2021	All	Minimal oncologic dataset, patient evaluation questions, caregiver input
6-12-2021	MH NS, + Bridget O'Sullivan and Anthony Staines (DCU)	How to optimally make use of the data each partner is gathering
8-12-2021	NS SR	Objective physical functioning, institutionalization
10-1-2022	All	Preparation for Dublin meeting
26-1-2022	All	Writing of deliverables and possibilities for publication

Subsequent communications regarding publications primary took place via email

Annexe 2: *Papers assessed in scoping multimorbidity literature review*

This search was done in Pubmed and used synonyms of multimorbidity/comorbidity and profiles/patterns. The search was limited to the past 10 years. This search yielded 528 hits. As this was a scoping literature review, exact details regarding the in- and exclusions were not recorded. Fourteen papers were found to be relevant, and were analysed and discussed in more detail.

Classifications based on types of comorbidities and most common health problems in patients with cancer

- Karen Barnett, Stewart W Mercer, et al. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. Lancet 2012 Jul 7;380(9836):37-43.
- Helen Fowler, Aurelien Belot, Libby Ellis, Camille Maringe, Miguel Angel Luque-Fernandez, Edmund Njeru Njagi, Neal Navani, Diana Sarfati, Bernard Rachet. Comorbidity prevalence among cancer patients: a population-based cohort study of four cancers. BMC Cancer 2020 Jan 28;20(1):2.
- Diana Sarfati, Jason Gurney, Bee Teng Lim, Nasser Bagheri, Andrew Simpson, Jonathan Koea, Elizabeth Dennett. Identifying important comorbidity among cancer populations using administrative data: Prevalence and impact on survival. Asia Pac J Clin Oncol 2016 Mar;12(1):e47-56.
- Grant R Williams, Amy Mackenzie, Allison Magnuson, Rebecca Olin, Andrew Chapman, Supriya Mohile, Heather Allore, Mark R Somerfield, Valerie Targia, Martine Extermann, Harvey Jay Cohen, Arti Hurria, Holly Holmes. Comorbidity in older adults with cancer. J Geriatr Oncol 2016 Jul;7(4):249-57.

A. Classifications based on types of comorbidities and most common health problems in patients in general
- Mercedes Clerencia-Sierra, Amaia Calderón-Larrañaga, et al. Multimorbidity Patterns in Hospitalized Older Patients: Associations among Chronic Diseases and Geriatric Syndromes. PLoS One. 2015 Jul 24;10(7):e0132909.

B. Classifications based on comorbidity clusters in patients with cancer
- Erin E Hahn, Michael K Gould, Corrine E Munoz-Plaza, Janet S Lee, Carla Parry, Ernest Shen Understanding Comorbidity Profiles and Their Effect on Treatment and Survival in Patients With Colorectal Cancer. J Natl Compr Canc Netw 2018 Jan;16(1):23-34.
- Michael K Gould, Corrine E Munoz-Plaza, Erin E Hahn, Janet S Lee, Carly Parry, Ernest Shen. Comorbidity Profiles and Their Effect on Treatment Selection and Survival among Patients with Lung Cancer. Ann Am Thorac Soc 2017 Oct;14(10):1571-1580.
- Kelly M Kenzik, Erin E Kent, Michelle Y Martin, Smita Bhatia, Maria Pisu. Chronic condition clusters and functional impairment in older cancer survivors: a population-based study. J Cancer Surviv 2016 Dec;10(6):1096-1103.

D. Classifications based on comorbidity clusters in patients in general
- Mercedes Clerencia-Sierra, Amaia Calderón-Larrañaga, Nicolás Martínez-Velilla, Itziar Vergara-Mitxeltorena, Pablo Aldaz-Herce, Beatriz Poblador-Plou, Mónica Machón-Sobrado, Nerea Egüés-Olazabal, Gabor Abellán-van Kan, Alexandra Prados-Torres. Multimorbidity Patterns in Hospitalized Older Patients: Associations among Chronic Diseases and Geriatric Syndromes. PLoS One. 2015 Jul 24;10(7):e0132909
- Beatriz Poblador-Plou, Marjan van den Akker, Rein Vos, Amaia Calderón-Larrañaga, Job Metsemakers, Alexandra Prados-Torres. Similar multimorbidity patterns in primary care patients from two European regions: results of a factor analysis. PLoS One 2014 Jun 23;9(6):e100375.
- Alexandra Prados-Torres, Amaia Calderón-Larrañaga, Jorge Hancco-Saavedra, Beatriz Poblador-Plou, Marjan van den Akker. Multimorbidity patterns: a systematic review. J Clin Epidemiol 2014 Mar;67(3):254-66.
- Sanne Pagh Møller, Bjarne Laursen, Caroline Klint Johannesen, Janne S Tolstrup, Stine Schramm. Patterns of multimorbidity and demographic profile of latent classes in a Danish population-A register-based study. PLoS One 2020 Aug 11;15(8):e0237375

- Ljoudmila Busija, Karen Lim, Cassandra Szoeke, Kerrie M Sanders, Marita P McCabe. Do replicable profiles of multimorbidity exist? Systematic review and synthesis. Eur J Epidemiol 2019 Nov;34(11):1025-1053.

E. Classifications based on care needs and/or functioning in patients in general

- Mieke Rijken, Iris van der Heide. Identifying subgroups of persons with multimorbidity based on their needs for care and support. BMC Fam Pract 2019 Dec 27;20(1):179.

Annexe 3: *Papers assessed in the scoping intrinsic capacity and frailty literature review*

A second scoping literature review was performed regarding studies on intrinsic capacity and frailty components that could be included for examination and/or intervention in the GerOnTe care pathway for older patients with cancer. This search was done in Pubmed and used synonyms of geriatric management and oncology. The search yielded 194 hits. As this was a scoping literature review, exact details regarding the in- and exclusions were not recorded. Thirteen papers were found to be relevant and were used as the basis of the intrinsic capacity/frailty datasets and intervention protocol.

Araujo de Carvalho I, Martin FC, Cesari M, Sumi Y, Thiyagarajan JA, Beard J. Operationalising the concept of intrinsic capacity in clinical settings. WHO clinical consortium on health ageing meeting report. November 21-22 2017. Geneva, Switzerland

Beard JR, Jotheeswarean AT, Cesari M, Araujo de Carvalho I. The structure and predictive value of intrinsic capacity in a longitudinal study of ageing. BMJ Open 2019;9:e026119

Cesari M, Belloni G. Frailty and intrinsic capacity: Two distinct but related concepts. Frontiers in Medicine 2019;6 :a133.

Derman BA, Kordas K, Ridgeway J, Chow S, Dale W, Lee SM, Aguada E, Jakuwbosiak AJ, Jasielec J, Kline J, Kosuri S, Larson RA, Liu Hongtao, Mortel M, Odenike O, Pisano J, Riedell P, Stock W, Bishop MR, Artz AS. Results from a multidisciplinary clinic guided by geriatric assessment before stem cell transplantation in older adults. Blood Adv. 2019 Nov 26; 3(22): 3488–3498.

Integrated care for older people (ICOPE): Guidance for person-centred assessment an pathways in primary care. Geneva: World Helath Orgnisation; 2010 (WHO/FWC/ALC/19.1). Licence : CC BY-NC-SA 3.0 IGO

Integrated care for older people:guidelines on community-level interventions to manage declines in intrinsic capacity. Geneva: World Health Organisation; 2017. Licence: CC BY-NC-SA 3.0 IGO

Kalsi T, Babic-Illmann G, Ross PJ, Maisey NR, Hugnes S, Fields P, Martin FC, Want Y, Harari D. The impact of comprehensive geriatric assessment interventions on tolerance to chemotherapy in older people. Br J Cancer. 2015 Apr 28; 112(9): 1435–1444.

Magnuson A, Lemelman T, Pandya C, Goodman M, Noel M, Tejani M, Doughtery D, Dale W, Huuria A, Janelsins M, Vankee F, Heckler C, Mohile S. Geriatric Assessment with Management Intervention in Older Adults with Cancer: A Randomized Pilot Study. Support Care Cancer. 2018 Feb; 26(2): 605–613.

Mohile SG, Dale W, Somerfield MR, Sconberg MA, at al. Practical Assessment and Management of Vulnerabilities in Older Patients Receiving Chemotherapy: ASCO Guideline for Geriatric Oncology. J Clin Oncol. 2018 Aug 1;36(22):2326-2347.

Ommundsen N, Wyller B, Nesbakken A, Bakka O, Jordhoy MS, Skovlund E, Rostoft S. Preoperative geriatric assessment and tailored interventions in frail older patients with colorectal cancer: a randomized controlled trial. Colorectal Disease 2018;20 :16-25

Sattar S, Alibhai SM, Brennenstuhl AS, et al.. Health status, emergency department visits, and oncologists' feedback: An analysis of secondary endpoints from a randomized phase II geriatric assessment trial. Clinical Trial J Geriatr Oncol. 2019 Jan;10(1):169-174. doi: 10.1016/j.jgo.2018.06.014. Epub 2018 Jul 21.

Van der Heide I, Snoeijs S, Melchiorre MG, Quattrini S, Boerma W, Schellevis F, Rijken M, on behalf of the ICARE4EU project team. Innovating care for people with multiple chronic conditions in Europe : an overview. Nivel report 2015

Wildiers H, Heeren P, Puts M, Topinkova E, et al. International Society of Geriatric Oncology consensus on geriatric assessment in older patients with cancer. J Clin Oncol. 2014 Aug 20;32(24):2595-603.

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.

The results of the expert panel surveys will be deposited in ZENODO once the relevant publications have been made.

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, ROUND 1)*

	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: 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 7: Minutes of the patient focus group meeting 18-10-2021

Focus group participants

We had a group of 4 older patients (3 male and 1 female) with various cancer types (prostate, rectal and breast) and various stages of disease. None of them had received chemotherapy and they were all relatively fit. Aged 74-84. All arrived either by car that they drove themselves or by bike.

Treatments that they had received or received were radiation therapy, surgery, targeted therapy and hormonal therapy.

Maze

The program is too difficult to test in this population, they forget the questions, every screen needs a short question, and they don't realize that the actual app is different from Maze. They expressed mainly the problems with this testing environment, not with the app.

Due to time limitations caused by the fact that our participants wanted to know each other before we could continue, we only spend 45 minutes and most patients ended after the symptoms.

Observations during the test

Patients could easily navigate between the various screens.

If we read out loud the questions of adding symptoms they could click on the right screens and could indicate how severe the symptom was

It is not clear that "daily check-up" leads to adding symptoms

It didn't work to start with the test before they knew what the program would do. They had no idea what it was for or why they would fill it out

They were happy to see that their "mission was completed"

After every mission, they thought nice, now I am finished.

Even though they told us beforehand that they were unlikely to use such an app, they expressed that they now use pen and paper to store the same information that we plan to have in the app

Difficult features like possibilities of enlarging a screen shouldn't be in the actual app, they did not know how to navigate back to the test

Possible pitfalls the patients mentioned:

- The idea that it disappears in a black box and that no one looks at it
- They are pro-active people, so they will get in touch themselves if necessary
- Limit the time to fill it out. One person told us; he only wants to spend 4 clicks if he has no problems

- They don't want to feel sick all the time, one person had filled out symptom lists before and stopped after a week because she didn't like it and because she felt well capable of alarming herself in case something was wrong
- They already have their own systems on paper and excel on the computer

Positive reactions/ suggestions

- Graphs
- They all look for more information on their disease on the internet, so they are interested in getting more recommendations about how to deal with symptoms
- Consultation was not discussed, but most patients reported that they keep a record of what was discussed in every single consult since their diagnosis, either on paper in a word document/ excel sheet, so it would be good provide the opportunity to save these notes in the app.
- Have an "I am worried about my symptoms" button
- They will mainly use it on their computer

Ideas for adherence

Some of them already set an alarm to take their medication

It needs to be part of their routine

What are topics of self-management that you look for?

Hard to answer. They now call the hospital, ask their home care organization or look on the internet

-What exercise am I allowed to do even though I have pain due to my cancer (not feasible)

-Are these symptoms normal and part of the treatment, or do I need to contact someone (not feasible)

What rewards would you like to receive after you have completed your task?

Hard to answer in an open question. But indirectly we noticed that they were sensitive to the positive feedback in the maze environment

Practical tips for next usability testing:

No open text boxes/ questions

We need to minimize the amount of questions and we need to better combine and align the usability testing (knowing how to navigate in the app) with the content testing (do the questions that we ask them, make sense to them and are similar to the problems they experience). It is not only the

screens that we are testing, but also whether they understand our questions and understand the purpose.

If we ask them questions on how they would like to have questions asked, we need to show the examples and ask, what do you prefer. Like show 2 screens.

No possibility to enlarge the picture, they don't know how to get back to the test

Easy and well understood examples (now the content didn't make sense, if you are nauseous, you also don't sleep well and you also have poor appetite)

The questions need to remain visible at all times

Instruct patients that they need to fill it out as if they are currently receiving chemotherapy or therapy, to go back to that part of their disease. We also need to instruct them that they are representatives of other older patients who might be less fit and less active and have more problems.

Only ask about features that will be in the actual app, because that will already take quite some time

Introduction takes time, because they all have a serious disease and want to know each others stories

Things to consider in the trial:

Important to make patients understand that the reason for monitoring and explain the relevance

Show this system at the beginning of the trajectory, before they find their own system

WP-1 results

Symptoms: important to mention the 24 hours in the daily questions otherwise the time window is not clear (possibly also caused by the test environment and the delay between showing that it is a daily check-up and question)

Patients would rather have all symptoms present and click on those that they have.

Re-phrase the question on the severity at its worst in Dutch

Annexe 8. *Relevance of comorbidity for cancer treatment decision-making and the care trajectory.*

Percentages represent the proportion of participants stating that the comorbid condition would likely or very likely change the treatment decision or the care trajectory. Items were carried forward to the next round of the survey if they scored 50% or higher for either item or 30% or higher for both; items that fulfilled neither of these criteria are marked in grey.

	Treatment decision	Care trajectory
… dependence for ADLs	92%	81%
… dementia and other neurodegenerative disease	89%	78%
… concurrent cancer disease	84%	66%
… performance status (e.g. ECOG, Karnofsky)	82%	64%
… congestive heart disease	76%	66%
… sarcopenia, anorexia or cachexia	76%	94%
… malnutrition and/ or involuntary weight los	73%	91%
… impaired mobility, gait or balance	71%	67%
… severe neuropathy	68%	63%
… Parkinson's disease or parkinsonism	67%	57%
… schizophrenia or other psychotic disorders	66%	64%
… dependence for instrumental ADLs	66%	78%
… delirium risk or previous delirium	63%	67%
… pulmonary hypertension	63%	51%
… ischaemic heart disease	54%	40%
… renal disease	54%	51%
... previous falls	53%	50%
… caregiver burden	53%	61%
… COPD or other lung disease	51%	60%
… cerebrovascular disease, including TIA	49%	40%
… liver disease	49%	38%
… diabetes mellitus with complications	46%	60%
… fatigue	42%	50%
… living situation and partner status	42%	64%
… faecal Incontinence	37%	33%
… morbid obesity	35%	57%
… travel distance to treatment centre	32%	53%
… cardiac arrhythmia	30%	37%
… heart valve disease	30%	31%
… anxiety, depression and other mood disorders	29%	64%
… visual impairment	29%	25%
… loneliness	29%	56%
… an intellectual disability	26%	50%
… social network	26%	44%
… severe or complicated hypertension	24%	31%
… pain syndrome	24%	49%
… anaemia	24%	40%
… inappropriate medication use	24%	49%
… substance abuse, any kind (including smoking)	24%	53%
… seizure disorder	22%	26%
… pulmonary embolism or deep venous thrombosis	22%	31%
… peripheral vascular disease or aortic aneurysm	22%	18%
… hearing impairment	21%	22%
… urine incontinence	21%	22%
… polypharmacy	19%	50%
… patients' financial worries	16%	36%
… spinal stenosis or other conditions of the spine and spinal cord	11%	14%
… osteoporosis and low energy fractures	11%	23%
… sexual dysfunction	5%	3%
… gastro-intestinal ulcer disease	3%	6%
… arthropathy or arthritis	3%	11%
… sleep disorders	3%	26%

Annexe 9: *Multimorbidity profiles proposal and final categorisation after expert panel input*

Part 1- initial proposed multimorbidity profiles

	1	2	3	4	5
Old	1. Cardiovascular, metabolic and pulmonary disease	Disability and dependency	Psychosocial health and cognitive impairment	Nutritional status and digestive system	Concurrent cancer treatment
NEW	1.Cardiovascular, metabolic and pulmonary disease	2.Disability, dependency and caregiver burden	3.Psychosocial health and cognitive impairment	4. Nutritional status and digestive system	5. Concurrent cancer
Including these items of round 1:	… congestive heart disease … pulmonary hypertension … ischaemic heart disease … renal disease … COPD or other lung disease … cerebrovascular disease, including TIA … diabetes mellitus with complications … morbid obesity … cardiac arrhythmia … heart valve disease	… severe neuropathy * … Parkinson's disease or parkinsonism … dependence for ADLs … performance status (e.g. ECOG, Karnofsky) … impaired mobility, gait or balance … dependence for instrumental ADLs … previous falls … fatigue … faecal Incontinence … caregiver burden … ~~living situation and partner status~~ … travel distance to treatment centre	… dementia and other neurodegenerative disease … schizophrenia or other psychotic disorders … delirium risk or previous delirium … anxiety, depression and other mood disorders … substance abuse, any kind (including smoking) … loneliness New: … living situation and partner status	… sarcopenia, anorexia or cachexia … malnutrition and/ or involuntary weight loss … liver disease	… concurrent cancer disease
Other comorbidities		Rheumatologic diseases (including PMR and auto-immune disease) **		Colitis (auto-immune disease) **	

Part 2- Final multimorbidity profiles after expert panel input

	1	2	3	4	5
Name	Cardiovascular, metabolic and pulmonary disease	Disability and dependency	Psychosocial health and cognitive impairment	Nutritional status and digestive system	Concurrent cancer treatment
Included items from round 1	… congestive heart disease … pulmonary hypertension … ischaemic heart disease … renal disease … COPD or other lung disease … cerebrovascular disease, including TIA … diabetes mellitus with complications … morbid obesity … cardiac arrhythmia … heart valve disease	… severe neuropathy … Parkinson's disease or parkinsonism … dependence for ADLs … performance status (e.g. ECOG, Karnofsky) … impaired mobility, gait or balance … dependence for instrumental ADLs … previous falls … fatigue … faecal Incontinence … caregiver burden … living situation and partner status … travel distance to treatment centre	… dementia and other neurodegenerative disease … schizophrenia or other psychotic disorders … delirium risk or previous delirium … anxiety, depression and other mood disorders … substance abuse, any kind (including smoking) … loneliness	… sarcopenia, anorexia or cachexia … malnutrition and/ or involuntary weight loss … liver disease	… concurrent cancer disease
New		Rheumatologic disease			

Annexe 10: – *Variables suggested to describe severity of comorbidity*

Comorbidities	% stating presence alone is sufficient	Examples of suggested variables for capturing severity			
Anxiety, depression and other mood disorders	20%	medication	current or history	compliance	current symptoms
Cardiac arrhythmia	41%	type of arrhythmia	treatment required		
Cerebrovascular disease	27%	frequency of CVA's	cognitive function	affecting ADL-iADL	
Concurrent cancer disease	10%	(previous) treatment	stage of disease	prognosis	
Congestive heart disease	24%	LVEF	NYHA (symptoms)	Recent hospitalisation	
COPD or other lung disease	17%	GOLD	symptoms/ impact on ADL		
Diabetes mellitus with complication	60%	many different answers	hba1c	severity of symptoms-impact on ADL	
Heart valve disease	24%	severity (unspecified)	impact on ADL	LVEF	
Ischaemic heart disease	20%	similar as congestive heart disease	LVEF	past treatment	symptomatic/stable
Liver disease	17%	child pugh	billirubin and"liver function tests"	cause of liver disease	
Morbid obesity	83%	BMI			
Parkinson's disease or parkinsonism	34%	cognitive function	severity of symptoms	functional impairment	prognosis
Pulmonary hypertension	49%	different answers	symptoms/NYHA	impact on ADL	
Renal disease	17%	GFR			
Schizophrenia or other psychotic disorders	33%	stable or not	severity of symptoms	adherence	interference with treatment
Severe neuropathy	65%	functional impairment-impact on ADL			
Substance abuse, any kind (including smoking)	47%	quantification	what abuse		

Annexe 11: *Conversation guide for the ONC-OPT tool*

Background

The Outcome Prioritization Tool (OPT) is a conversation guide/method that can assist you when discussing preferences for treatment goals and outcomes with patients. This information can be used to provide tailored recommendations for oncologic treatment choices. The ONC-OPT is an adaption of the OPT tool, tailored to the oncologic setting.

Using the ONC-OPT, patients are asked to rank and prioritize treatment goals from most to least important. Included goals are extending life, maintaining independence, reducing or eliminating pain or other symptoms, and preventing negative treatment effects. Patients are asked to rate each goal with a number between 0 and 100, representing the importance of the goal. The exact number is not important, what matters is the difference in rating between the various goals.

Being asked to prioritize will help the patient understand that there are trade-offs to be made. Prioritizing one goal could be at the cost of another. The health care provider will gain more insight into what matters most to the patient, and which concessions they are or are not willing to make, as well as their reasons. For health care providers, it is important to understand how the patient interprets each goal, for example, what maintaining independence means to them in their particular circumstances. The ONC-OPT is a conversation guide to discuss what matters to patients; it is not a decision aid. The results of the ONC-OPT conversation will be taken into consideration in the shared-decision making discussion the oncologic specialist will have with the patient (and caregivers).

Instructions for patients

As a nurse/physician, it is important to me to understand what matters to you. This can help in choosing the most appropriate treatment for you.. In the conversation we are going to have now, we will not be choosing a specific treatment option. We will try to clarify what is most important to you in your life. A treatment option can have positive or negative effects. This could be a reason you don't want to choose that treatment. For example, a treatment that may help you live longer, could be so tough that it means your physical condition declines so that you need more help from others to cope.

Now I am going to go through the different goals with you.

1.   Extending life: Aiming to live as long as possible

2.   Maintaining independence: Aiming to be as independent as possible in your daily activities

3.   Reducing or eliminating pain and other symptoms.

Are there any specific symptoms you would like to reduce or avoid?

(If the patient doesn't name any symptoms, you can give examples: pain, dizziness, fatigue, shortness of breath)

4.   Preventing negative effects of treatment: Aiming for a treatment that has the least chance of having negative effects.

Are there specific side-effects or other negative effects of treatment that you would like to avoid if at all possible?

(If the patient doesn't mention any examples, you could mention: loss of feeling in your fingers, incontinence, increased risk of infection, cognitive decline, hair loss.)

Looking at these goals, which is most important to you?

Where would you rate this goal on a scale of 0 to 100? The higher you place the goal, the more important it is to you. The exact number is not important, what matters is which goals you prioritize and how close together or far apart the different goals are. As you are thinking about this, I would like to ask you not to place two goals on the same level, but to really make a choice about which is the most important. There is no wrong or right answer, it is about what matters most to you.

So for you … is the most important. What does that mean to you? What are you trying to avoid?

Sometimes, a treatment could benefit one goal but could have a negative effect on another goal. That is why it's important for you to realize that if you prioritize …. this may mean you need to accept a less positive effect on another goal. For example, if you give highest priority to maintaining independence, this means you should also be willing to possibly live less long in order to maintain your independence as much as possible.

Let's look at the second highest priority. What is the next one for you, after …

(Continue like this until all goals have been given a ranking)

Annexe 12: *Communication tips for patients and questions prompt list*

Communication tips to prepare for your next consultation with your health care provider

To make the most of your health care providers, it is a good idea to prepare for your next consultation.

- Take some time to think about what you want to know about your disease, symptoms and possible treatments. It will help both you and your health care providers if you are clear about what you want to know (and what you don't want to know).
- Write down any questions you may have beforehand. This list may give you some ideas of questions you might want to ask (LINK TO QUESTIONS LIST). Think about which questions have the highest priority for you, so you can ask those questions first.
- Bring someone with you to the consultation. If you are afraid to ask a question, your family member, friend or caregiver can do this for you. Two people will remember more than one person, and being in the consultation together will make it easier to discuss what was said. You can consider recording the conversation with your health care provider, but be sure to ask permission for this first.
- Ask your health care provider how much time they have; it may be necessary to plan a second consultation.
- Always bring a medication list to the consultation
- If you have trouble understanding what is being said or if you are feeling unsure about something, ask questions. Also ask your health care provider to explain medical terms that you don't understand. If they speak too quickly, ask them to slow down.
- Repeat what was said in your own words, so you can check if you have understood and your health care providers knows if everything is clear
- It may be a good idea to take some notes, so that you can reread what was said later on.
- If you need to make a difficult decision, ask for time to consider your options. Also ask how much time you can take to think about it.
- Ask if there is any written information or useful websites you could consult to get more information on paper
- Ask who you should contact if you have any further questions.

Questions list

Cancer itself	• What is my diagnosis? • How did I get this?
Prognosis	• What can you tell me about my prognosis? • Will treatment make me feel better? • Will treatment make me live longer? • What can I expect for the future? Will I get other complaints? • How will I know if the treatment was successful? • How will I know if the cancer came back? • What will happen to me if the cancer cannot be cured? • With whom can I discuss my advance directives? • What happens if I find the treatment too burdensome?
Decision-making	• Where can I find more information? • Is there a patient support group I can contact? • Should I get a second opinion? • Who can help me if I am struggling to make a treatment decision?

	• Did you inform my primary care physician about my diagnosis?
Treatment options	• What can you or another health care provider do about this illness? • Do I have a choice regarding treatment? • Why is this treatment the best option? • What is the goal of this treatment? • What are the expected benefits of this treatment? • What are the risks of this treatment? • What happens if I do not get treatment? • What are the advantages and risks of postponing treatment? • Are there any other treatment alternatives and what are the risks and benefits? • What happens if I change my mind and want to stop the treatment? • Are there other treatment options available if the first treatment does not work or the cancer comes back?
Practicalities	• Will the treatment or test be painful? • When will I get the results of the test? • May I take someone to accompany me to the test/treatment? • How long will the treatment take? • Where will the treatment take place? • What does my follow-up look like? Will I keep getting check-ups? • Are there any specific signs or symptoms I need to watch for during follow-up? • Will you remain my health care provider? • Which health care providers are available for my living situation? • Which hygiene measure do I need to take? Where can my partner/family go for more information? • Who can I contact if I have problems or questions?
Side-effects	• What side-effects should I expect from this treatment? • When will side-effects occur and how long will these side-effects last? • Are there any side-effects that I should pay particular attention to or report during treatment? • Who can I contact if I have side-effects? • I am suffering from a specific complaint, is there anything you or I can do to alleviate my complaints? • Are there any preventive measures I can take?
Self-care at home	• What is the best way to care for myself before or during treatment? • What can I do to recover more quickly?
Functioning and quality of life	• How long will it take me to recover from this test/treatment? • How will this treatment affect my life now and in the future? • Will I be able to still do my normal daily activities after the treatment, both in the short and the long term? • How will this treatment affect my quality of life? • Is there anything you or I can do to improve my functioning or quality of life?
Dealing with after-effects	• Where can I get coping support if I am struggling with emotional after-effects? • What can be done to deal with physical after-effects? What can I do myself? Can I get professional help?

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