



STREAMLINED **GERIATRIC** AND **ONCOLOGICAL** EVALUATION BASED ON
IC TECHNOLOGY
 FOR HOLISTIC PATIENT-ORIENTED HEALTHCARE MANAGEMENT
 FOR OLDER MULTIMORBID PATIENTS

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

**D1.4: DATASET OF SELF-MANAGEMENT RECOMMENDATIONS FOR
 PATIENT-DRIVEN IMPROVEMENT OF INDEPENDENT LIVING**

Lead Beneficiary : 3-DIAK

Involved Beneficiaries : 1-UBx, 2-KUL, 4-OUS, 5-UCD

| | |
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GERONTE Consortium

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| 4 | Oslo University Hospital | OUS | NO |
| 5 | University College Dublin | UCD | IE |
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| 7 | MyPL SAS | MyPL | FR |
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| 9 | International Society of Geriatric Oncology | SIOG | CH |
| 10 | Dublin City University | DCU | IE |



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| V1.0 | 2022-01-10 | Marije Hamaker (DIAK) | First draft |
| V1.1 | 2022-02-14 | Marije Hamaker (DIAK) | Numbering changed |
| V1.2 | 2022-03-07 | Marije Hamaker (DIAK) | Final version with dataset links included |
| V1.3 | 2023-01-12 | Marije Hamaker (DIAK) | Revision after input from European Commission |

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Executive Summary

Deliverable work status

| Deliverable | Completion status in % | Deviation | Data complete or to be updated |
|---|---|--|--------------------------------|
| D1.4 <i>Dataset of self-management recommendations for patient-driven improvement of independent living</i> | 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) | | |
| 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 development and content of the self-management recommendations for dealing with symptoms during/after cancer treatment as well as general healthy ageing recommendations. It describes the seven steps that were undertaken to develop the self-management library, the final list of subjects and symptoms that were included, and the sources that were used to obtain this list.

Attainment of the objectives and explanation of deviations

D1.4 *Dataset of self-management recommendations for patient-driven improvement of independent living* is part of work-package 1 which supports GERONTE objective O1: INFORMATION (Gather the stakeholders and data needed for patient-centred and multi-actor complex decision-making process and management). This deliverable covers one sub-objectives: Develop a protocol for patients' self-management during the treatment trajectory.

This objective has been attained in full (deliverable 100% complete). This deliverable is now finalized, no further modifications are expected in future.

There is a minor deviation in this deliverable. In the Grant agreement, we determined that we would establish a minimum list of 15 common symptoms that were amenable to self-management. In the end, our self-management library became longer, as we included all items in the list of 27 relevant symptoms and PROMs that are included in the symptom monitoring, as well as other common symptoms that may be burdensome to older patients with multimorbidity undergoing cancer treatment. Additionally, we added 20 more general self-care recommendations for healthy ageing and dealing with cancer or its treatment. This deviation does not impact on the overall objectives of the project nor does it impact on the use of resources within the care pathway. It in fact only benefits the patient as more information is now available to them to assist them in their self-management.

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.

Introduction

1.1. GERONTE and its objectives

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

Objectives

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

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

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

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

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

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

1.2. Rationale

Deliverable D1.4 is part of work-package WP1 which supports GERONTE objective O1:

INFORMATION. This deliverable covers one sub-objectives: Develop a protocol for patients’ self-management during the treatment trajectory.

Patient empowerment by supporting self-management is an important component of the Geronte care pathway. As patients will be monitoring themselves at home, to register side-effects of treatment, decompensation of comorbidities and signs of functional decline, they will also be faced with questions about how to deal with the issues that they are having. While one important component of the care pathway is early signalling of complications to allow for early intervention by health care professionals, there is also a lot that patients can do for themselves at home to enhance their life-style, decrease burden of signs and symptoms or to improve outcomes.

This deliverable reports on the method of obtaining the self-management recommendations. The library of self-management recommendations, GERDAT005, can be found online at

<https://doi.org/10.5281/zenodo.6334779>.

1. Method

1.3. 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 colleagues in other specialties was requested as needed; formal input was obtained through the channels listed below.

For the completion of this deliverable, online 5 meetings took place within the Geronte consortium. A list of these meetings can be found in Annexe 1. The number of meetings that took place in Work package 1 as a whole, 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.

Overview of contributions

| Partner | Person(s) | Contribution |
|---------|---------------------------------|-----------------------------|
| DIAK | Marije Hamaker, Nelleke Seghers | Involved throughout, leader |
| OUS | Siri Rostoft | Involved throughout |
| UCD | Shane O'Hanlon | Involved throughout |

* For administrative reasons, explained elsewhere, UCD will not claim costs for the person months they have invested in this deliverable.

1.4. Determining which subjects to provide recommendations for

Selection of signs and symptoms for which to provide self-management recommendations was based on several factors

- Symptoms selected for home monitoring (see deliverable 1.2)
- Commonly occurring signs and symptoms of cancer or in relation to cancer-treatment, based on validated questionnaires for assessing symptom burden and quality of life (see deliverable 1.2)
- General healthy ageing recommendations encountered during online search
- Supplemented with additional subjects encountered during literature and online searches

In the Grant agreement, we determined that we would establish a minimum list of 15 common symptoms that were amenable to self-management. In the end, our self-management library became longer, as we included all items in the list of 27 relevant symptoms and PROMs that are included in the symptom monitoring, as well as other common symptoms that may be burdensome to older patients with multimorbidity undergoing cancer treatment. Additionally, we added 20 more general self-care recommendations for healthy ageing and dealing with cancer or its treatment.

This deviation does not impact on the overall objectives of the project nor does it impact on the use of resources within the care pathway. It in fact only benefits the patient as more information is now available to them to assist them in their self-management.

1.5. Literature search

To provide useful self-management recommendations, we first looked for any previous scientific publications were available that could serve as a library for the self-management recommendations. Therefore, a literature review was undertaken on MEDLINE and EMBASE. The following search was performed on January 14th 2021: self[tiab] AND (care[tiab] OR management[tiab] OR monitoring[tiab] OR efficacy[tiab]) AND (older[tiab] OR geriatric[tiab] OR multimorb*[tiab]) AND (cancer[tiab] OR oncology[tiab] OR malign*[tiab]). Searches were limited to 2000 onward.

This yielded 1058 hits in pubmed and 1766 hits in Embase. While this search retrieved several studies on home-monitoring applications, none provided a complete library with self-management recommendations.

1.6. Local sources

As the second step, patient information leaflets and booklets available at the Diaconessenhuis Utrecht, the Netherlands, and the Catholic University Leuven, Belgium were consulted to retrieve recommendations already provided to patients undergoing cancer treatment at the moment.

This yielded input on the following subjects:

- UZ Leuven guidelines concerning your chemotherapy treatment
 - Diarrhoea, vomiting, nausea, poor appetite, pain, fever/feeling ill, fatigue, feeling depressed/irritable, feeling worried/nervous/uncertain, sore/dry mouth, tingling, rash/skin issue, constipation, hair loss, teary eyes, sexuality and intimacy, muscle/joint pain, change in taste/smell
- Diaconessenhuis patient leaflets
 - Hair loss, change of skin, burning eyes, change in smell/taste, sore/dry mouth, fatigue, intimacy and sexuality, bleeding and bruising, urinary symptoms, trouble sleeping, wound problems, ostomy issues, incontinence, faecal incontinence.

1.7. Online search

As the third step, an online search was performed in google using search terms “health ageing”. In addition, three cancer information websites were consulted.

- Kwf.nl
- Kanker.nl
- wcrf.org

For any remaining topics that were identified for which no sources for recommendations had thus far been retrieved, specific online searches were performed to identify any available information.

1.8. Expert opinion

As the fourth step, for any topics still without recommendations, expert opinion was sought from advance practice nurses, (para)medical experts and/or other health care professionals with expertise pertaining to the subject. Professionals were recruited from the participating Geronte partners, based on their expertise and/or role in the development of the care pathway.

1.9. Expert review

As the final step, all recommendations were gathered in one document which was subsequently reviewed by five medical specialists (3 geriatricians, 2 oncologists) and three advance practice nurses to achieve consensus on the content of the self-management library. Professionals were recruited from the participating Geronte partners, based on their expertise and/or role in the development of the care pathway. Any disagreement was resolved through a consensus discussion. The final document was approved by all eight reviewers.

1.10. Translation

Once the English version of the document was agreed upon, it was translated to both Dutch and French to allow for inclusion in the patient applications.

2. Conclusion

This document reports on the process of developing the self-management recommendation library for patients undergoing cancer treatment and optimizing healthy life-style. Based on the information found in literature, and on expert opinion, no differentiation was made in self-management recommendations based on age or gender.

A full overview of the included subjects and symptoms, as well as the sources from which the self-management recommendations were retrieved can be found in Annexe 2. The full self-management recommendation library, GERDAT005, can be found online at <https://doi.org/10.5281/zenodo.6334779>.

This deliverable primarily focused on Objective 1 of the GERONTE project: INFORMATION - Gather the stakeholders and data needed for patient-centred and multi-actor complex decision-making process and management. In particular, this deliverable address subobjective 1.4: Develop a protocol for patients' self-management during the treatment trajectory.

This objective has been attained in full (deliverable 100% complete). This deliverable is now finalized, no further modifications are expected in future.

This deliverable also provided the information that should be included in the ICT tools for both the HPC as well as the patients to fulfill Objective 2 of the GERONTE project. Objective 2 is to develop the Holis™ 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). Deliverables 1.4 provided the information that should be included in the ICT tools for the patients.

Annexe 1: Work package meetings

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

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

| Date | Present | Topics discussed |
|------------|---------|--|
| 7-1-2021 | All | Multimorbidity profiles, PROMS, information needs, self-monitoring, self-management |
| 4-3-2021 | All | Self-monitoring and self-management, patient preferences, information needs, expert panel, expert surveys |
| 22-10-2021 | All | Preparation presentation for Dublin consortium meeting, patient monitoring and self-management, input general practitioner |
| 10-1-2022 | All | Preparation for Dublin meeting |
| 26-1-2022 | All | Writing of deliverables and possibilities for publication |

Annexe 2: Symptoms and sources of information

Overview of signs and symptoms for which recommendations have been made available in the self-management library, and the sources from which recommendations were collected. The actual recommendations, GERDAT005, can be found online at <https://doi.org/10.5281/zenodo.6334779>.

2a. Topics on general recommendations for healthy ageing and health lifestyle

| | Topic | Source |
|----|-------------------------|---|
| 1 | FLUID INTAKE | ageuk.org.uk |
| 2 | ALCOHOL | British Geriatric Society healthy ageing |
| 3 | HEALTHY DIET | ageuk.org.uk fda.gov www.voedingenkankerinfo.nl |
| 4 | ADJUST DIET | UZ Leuven guidelines concerning your chemotherapy treatment www.voedingenkankerinfo.nl |
| 5 | SMOKING | ageuk.org.uk |
| 6 | ORAL HYGIENE | ageuk.org.uk |
| 7 | MEDICATION SAFETY | fda.gov |
| 8 | MEDICATION FOR SYMPTOMS | UZ Leuven guidelines concerning your chemotherapy treatment |
| 9 | EXERCISE | ageuk.org.uk |
| 10 | FALLS PREVENTION | Beteroud.nl |
| 11 | FEET | ageuk.org.uk |
| 12 | MENTAL ACTIVITY | Mayo clinic |
| 13 | SLEEP | ageuk.org.uk Trimbos instituut Diakonessenhuis patient booklet/leaflet: adviezen om beter te slapen |
| 14 | REST AND ACTIVITY | UZ Leuven guidelines concerning your chemotherapy treatment |
| 15 | ENERGY | UZ Leuven guidelines concerning your chemotherapy treatment |
| 16 | SOCIAL | ageuk.org.uk Trimbos instituut |
| 17 | LONELINESS | loketgezondleven.nl (from the Dutch ministry of Health) |
| 18 | GRATITUDE | Trimbos instituut |
| 19 | URINATION | Diakonessenhuis patient information |
| 20 | DEFECATION | Diakonessenhuis patient information |

2b. Topics of recommendations related to symptoms in the daily/weekly/monthly symptom reporting checklists

| | | |
|---|--|--|
| 1 | DYSPNOEA | KWF patient booklet/leaflet: als de dood nabij is |
| 2 | DIARRHOEA | UZ Leuven guidelines concerning your chemotherapy treatment |
| 3 | VOMITING | UZ Leuven guidelines concerning your chemotherapy treatment |
| 4 | NAUSEA | UZ Leuven guidelines concerning your chemotherapy treatment |
| 5 | DAILY ACTIVITIES LIMITED BY BOWEL/URINARY PROBLEMS | Diakonessenhuis patient booklets/leaflets Incontinence/Fecal incontinence |
| 6 | POOR APPETITE | UZ Leuven guidelines concerning your chemotherapy treatment |
| 7 | UNINTENTIONAL WEIGHT LOSS | World Cancer Research Fund: Tijdens kanker, goed eten en omgaan met klachten |

| | | |
|---|---------------------------|--|
| 8 | UNINTENTIONAL WEIGHT GAIN | World Cancer Research Fund: Tijdens kanker, goed eten en omgaan met klachten |
|---|---------------------------|--|

2c. Topics of recommendations related to symptoms in the daily/weekly/monthly symptom reporting checklists

| | | |
|----|--|--|
| 1 | DYSPNOEA | KWF patient booklet/leaflet: als de dood nabij is |
| 2 | DIARRHOEA | UZ Leuven guidelines concerning your chemotherapy treatment |
| 3 | VOMITING | UZ Leuven guidelines concerning your chemotherapy treatment |
| 4 | NAUSEA | UZ Leuven guidelines concerning your chemotherapy treatment |
| 5 | DAILY ACTIVITIES LIMITED BY BOWEL/URINARY PROBLEMS | Diakonessenhuis patient booklets/leaflets Incontinence/Fecal incontinence |
| 6 | POOR APPETITE | UZ Leuven guidelines concerning your chemotherapy treatment |
| 7 | UNINTENTIONAL WEIGHT LOSS | World Cancer Research Fund: Tijdens kanker, goed eten en omgaan met klachten |
| 8 | UNINTENTIONAL WEIGHT GAIN | World Cancer Research Fund: Tijdens kanker, goed eten en omgaan met klachten |
| 9 | PAIN | UZ Leuven guidelines concerning your chemotherapy treatment KWF patient booklet/leaflet: Pijn bij kanker |
| 10 | FEVER/FEELING ILL | UZ Leuven guidelines concerning your chemotherapy treatment |
| 11 | FATIGUE | UZ Leuven guidelines concerning your chemotherapy treatment Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |
| 12 | TROUBLE SLEEPING | Diakonessenhuis patient booklet/leaflet: adviezen om beter te slapen |
| 13 | TROUBLE REMEMBERING/ THINKING; CONFUSION | KWF patient booklet/leaflet: Ouderen en kanker No sources found, expert opinion/consortium partners |
| 14 | FEELING DEPRESSED OR IRRITABLE | UZ Leuven guidelines concerning your chemotherapy treatment |
| 15 | FEELING NERVOUS, WORRIED OR UNCERTAIN | UZ Leuven guidelines concerning your chemotherapy treatment |
| 16 | CHANGE IN MOBILITY | No sources found, expert opinion/consortium partners |
| 17 | UNSTEADY ON YOUR FEEL/FALLS | No sources found, expert opinion/consortium partners |
| 18 | FORCED TO SPEND TIME IN BED | No sources found, expert opinion/consortium partners |
| 19 | NEED HELP WITH DAILY ACTIVITIES | No sources found, expert opinion/consortium partners |
| 20 | SORE/DRY MOUTH | UZ Leuven guidelines concerning your chemotherapy treatment Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |
| 21 | TINGLING HAND/FEET | UZ Leuven guidelines concerning your chemotherapy treatment |
| 22 | RASH/SKIN ISSUES | UZ Leuven guidelines concerning your chemotherapy treatment Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |
| 23 | WOUND PROBLEMS | Diakonessenhuis patient booklet/leaflets Naar huis na een darmoperatie/ borstamputatie/borstsparende operatie |
| 24 | BLOODY STOOLS OR MUCUS | No sources found, expert opinion/consortium partners |
| 25 | OSTOMY ISSUES | Diakonessenhuis patient booklet/leaflet: Darmstoma |

| | | |
|----|----------------|--|
| 26 | COUGH | No sources found, expert opinion/consortium partners |
| 27 | COUGH UP BLOOD | No sources found, expert opinion/consortium partners |

2d. Topics of recommendations for other common issues related to cancer, its treatment or their sequelae

| | | |
|---|----------------------------|---|
| 1 | CONSTIPATION | UZ Leuven guidelines concerning your chemotherapy treatment |
| 2 | SEXUALITY AND INTIMACY | UZ Leuven guidelines concerning your chemotherapy treatment Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH Kanker.nl |
| 3 | HAIR LOSS | UZ Leuven guidelines concerning your chemotherapy treatment Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |
| 4 | DRY, BURNING OR TEARY EYES | UZ Leuven guidelines concerning your chemotherapy treatment Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |
| 5 | MUSCLE OR JOINT PAIN | UZ Leuven guidelines concerning your chemotherapy treatment |
| 6 | CHANGES IN TASTE OR SMELL | UZ Leuven guidelines concerning your chemotherapy treatment Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |
| 7 | URINARY PROBLEMS | Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |
| 8 | BLEEDING OR BRUISING | Diakonessenhuis patient booklet/leaflet Chemotherapie op het DBOH |

2e. Sources used for recommendations regarding communication and how to prepare for your next consultations

- www.rijnstate.nl/tips
- KWF patient booklet/leaflet: kanker, in gesprek met je arts
- www.kanker.nl/sites/default/files/library_files/Studie%203%20Gespekswijzer%20start%20pdf.pdf
- Literature review prepared for Geronte to address this topic:

Hamaker ME, van Walree IC, Seghers PAL (Nelleke), van den Bos F, Soubeyran P, O'Hanlon S, Rostoft. S. **Information needs of older patients newly diagnosed with cancer**. J Geriatr Oncol 2021 Sep 23;S1879-4068(21)00212-5. doi: 10.1016/j.jgo.2021.09.011.



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