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Deliverable no. D2.3: Overview of NavCare-EU toolkit, its materials, and tools for all RCT partners for evaluation

Part of WP 2: Standardization, adaptation, and feasibility testing of the NavCare-EU intervention

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Contact: Prof. Kenneth Chambaere (Kenneth.Chambaere@Ugent.be)



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1 BACKGROUND EU NAVIGATE

GENERAL PROJECT INFO

Acronym: EU NAVIGATE (Coordinator: VUB)
Title: Implementation and evaluation of a navigation intervention for people with cancer in old age and their family caregivers: an international pragmatic randomized controlled trial
Call: HORIZON-HLTH-2021-DISEASE-04
EU nr: 101057361
Period: 01/09 2022-31/08/2027 (5yrs)
Budget: 5 993 222.00€ (total grant amount)

EU NAVIGATE CONSORTIUM PARTNERS

1. VRIJE UNIVERSITEIT BRUSSEL (Belgium)
2. THE PROVOST, FELLOWS, FOUNDATION SCHOLARS & THE OTHER MEMBERS OF BOARD, OF THE COLLEGE OF THE HOLY & UNDIVIDED TRINITY OF QUEEN ELIZABETH NEAR DUBLIN (Ireland)
3. UNIWERSYTET JAGIELLONSKI (Poland)
4. STICHTING VUMC (The Netherlands)
5. UNIVERSIDADE DE COIMBRA (Portugal)
6. UNIVERSITEIT GENT (Belgium)
7. UNIVERSITY OF BRITISH COLUMBIA - OKANAGAN (Canada)
8. EUROPEAN CANCER ORGANISATION (Belgium)
9. EUROPEAN ASSOCIATION OF PALLIATIVE CARE (Belgium)
10. AGE PLATFORM EUROPE (Belgium)
11. LEGA ITALIANA PER LA LOTTA CONTRO I TUMORI DI MILANO (Italy)

Six partners are involved in the implementation and evaluation of the NavCare-EU intervention (see Figure 1): BELGIUM (Vrije Universiteit Brussel & Universiteit Gent), IRELAND, POLAND, NETHERLANDS, PORTUGAL, ITALY.



ABSTRACT OF THE EU NAVIGATE PROJECT

Background: Most people with cancer are older people, affecting millions of Europeans yearly. Integrating high-quality, equitable, and cost-effective care across the continuum of supportive, palliative, end-of-life, and survivorship care for both patients and family caregivers is highly relevant from a healthcare, prevention, and economic perspective.

Aims: EU NAVIGATE is an interdisciplinary, cross-country, and intersectoral project funded by the European Union and aims to evaluate the effectiveness and cost-effectiveness of a patient and family navigation intervention (NavCare-EU) for older people with cancer and their family caregivers in different healthcare systems in Europe. It focuses on reaching underserved individuals and supporting and empowering them to access their networks and available resources within their community. As the first step, the existing and promising Canadian Nav-CARE intervention will be adapted, contextualized, standardized and pilot-tested across six European countries.

Concept and methods: NavCare-EU is a person- and family-centered non-pharmacological intervention in which navigators **collaborate with patients and families** to improve quality of life and well-being, foster empowerment, and facilitate timely and equitable access to health and social care services and resources as needed, throughout the supportive and palliative care continuum. NavCare-EU is based on the existing and successfully tested Nav-CARE intervention from Canada. Effectiveness and cost-effectiveness will be evaluated through an international pragmatic randomized controlled trial among cancer patients with declining health aged 70 years and older and their family caregivers. Robust mixed-method subgroup analyses and in-depth process and implementation evaluations are also included.

Impact: EU NAVIGATE will advance the state of the art by providing **innovative solutions** to the complex **supportive and palliative care** needs to be experienced by **older people with cancer and their families**, which is implementable in the real world and diverse health care systems and contexts. User and stakeholder involvement methods are integrated throughout the whole project. EU NAVIGATE will contribute to the overall goals of the Mission on Cancer, to actions of Europe's Beating Cancer Plan, and to the UN Sustainable Development Goal of ensuring healthy lives and promoting well-being for all at all ages.

2 BACKGROUND WORK PACKAGE 2

TITLE

Standardization, adaptation, and feasibility review of the NavCare-EU intervention through user and stakeholder involvement.

OBJECTIVES

The Nav-CARE© intervention developed in Canada will be the basis for the NavCare-EU intervention in the participating countries in this project. The main aim of WP 2 is: **To prepare a standardized NavCare-EU intervention for all countries through:**

- 1) Translation, cross-country adaptation, and standardization of the Nav-CARE© intervention toolkit (i.e. its blended training and implementation manuals and tools) through user and stakeholder involvement.
- 2) Feasibility testing of the intervention toolkit with users and stakeholders in each country.
- 3) Ensuring adaptations do not compromise the functional integrity of the intervention as a whole, i.e. the extent to which the evidence-informed intervention's core functions and processes (core components) are maintained.
- 4) International blended training development using a train-the-trainer approach.
- 5) Integration of the blended training, implementation manuals, and tools into a separate page on the NavCare-EU website.

COORDINATION

The lead beneficiary of WP2 is P6 (Ghent University) with P7 (UNIVERSITY OF BRITISH COLUMBIA - OKANAGAN (CA) and the coordinator P1 (VRIJE UNIVERSITEIT BRUSSEL).

3 INTRODUCTION TO THIS REPORT

This deliverable D2.3. presents the NavCare-EU toolkit as it will be evaluated in the subsequent steps of the EU NAVIGATE project. The NavCare-EU toolkit is a linguistic and cultural adaptation of the Nav-CARE© program developed in Canada by Duggleby and Pesut, partners in the project, to the six countries where it will be implemented and evaluated.

This public document provides an overview of the Nav-Care© intervention and its adaptations for use in EU NAVIGATE, before it will be evaluated in a large-scale pragmatic randomised controlled trial. Detailed reporting of the entire toolkit per country and the adaptations are available to the trial participants and EU NAVIGATE consortium. All adaptations made concern necessary contextual adaptations that are consistent with the core components of the original interventions.

After its evaluation, the toolkit will be disseminated further, ensuring appropriate use beyond the EU NAVIGATE project. More information on the entire project can be found at www.eunavigate.com.

4 METHODS USED TO TRANSLATE AND ADAPT

The Nav-CARE© program was translated and adapted from the Canadian to European context – specifically to each country’s healthcare context and populations of older cancer patients– into a **standardized European NavCare-EU intervention** (further referred to as “NavCare-EU”).

Following guidelines of the ADAPT guidance for adapting complex interventions (by Moore et al. (<https://www.bmj.com/content/374/bmj.n1679>)), the translation and adaptation of the program was done through **a step-by-step plan that had six stages**. This guaranteed that the core components and processes of the original program were kept.

STAGE 1: Translation and preparation of the Nav-CARE© intervention materials

STAGE 2: Context analysis of original and new context(s)

STAGE 3: Feasibility review of the intervention and materials *with* Local Adaptation Teams

STAGE 4: Development and delivery of International Training

STAGE 5: Pilot testing

STAGE 6: Overall summary of all adaptations per country (using the Model for Adaptation Design and Impact framework)

In this report, we provide an overview of project-specific adjustments made to the original Nav-CARE© (Duggleby & Pesut) program for the European context, followed by a presentation of cultural adaptations unique to each country involved. The appendices include the major consortium-wide adaptations and the Coordinator Job description.

5 BRIEF OVERVIEW ORIGINAL NAV-CARE© INTERVENTION

The original Nav-CARE© toolkit as used in the original Canadian project by Wendy Duggleby and Barbara Pesut from respectively UNIVERSITY OF ALBERTA and UNIVERSITY OF BRITISH COLUMBIA – OKANAGAN (Canada) is summarized in this section.

Nav-Care© is a person- and family-centred navigation intervention, developed over the past 13 years for older adults with a variety of chronic illnesses of which cancer was the most prevalent, and for people living with advanced cancer in rural areas of Canada. It is a face-to-face and tele-supported non-pharmacological intervention that aims to work in collaboration with patients, families, professionals, and communities to promote quality of life and wellbeing, reduce health-related suffering, support empowerment and social engagement, and improve timely and equitable access to health and social care services and resources as needed, throughout the care and illness continuum.

Core components of the Nav-Care© intervention are **navigators** who collaborate with patients and family caregivers throughout the continuum of supportive, palliative and End-of-Life care. Their main activities focus on connecting clients to social supports, both formal and informal, advocating for clients in meeting their quality-of-life goals, resourcing by identifying needs and negotiating access to meeting those needs, and engaging clients in what is most meaningful to them. Above all, navigators are trained to ask the question ‘What is most important to you today?’ and work alongside patients and families to help them accomplish that. Navigators are selected, trained, and mentored volunteers or professionals (licensed or unlicensed) (depending on the best fit with the health care context of the country or region of implementation). They have **face-to-face and/or telephone or IT-supported** contact with patients and family carers, every two weeks on average or in different intervals, as needed. Nav-Care has a clear and specific implementation model. Navigators are matched to patients and family carers by **navigator coordinators** who are also responsible for championing the intervention and for networking with and connecting to health and social care professionals in the community and in hospitals in the region. Navigators and coordinators are trained, coached, and mentored by a **navigation trainer** and training- and coaching-sessions are competency-based.

A Nav-CARE© intervention toolkit supports the implementations of the intervention and contains blended (part online, part in-person) training and implementation tools and manuals. The complete original Nav-CARE© toolkit comprises 22 documents and has been shared with all partners after they had signed a bilateral Memorandum of Understanding with the developers. The toolkit includes four manuals (The Implementation Manual, Volunteer Navigation Training: Learning Manual, Volunteer Coordination Manual, Volunteer Navigation Training: Facilitator’s Guide), and several supporting documents, videos, and other resources.

All Nav-CARE© resources are organised into 3 sections:

- 1) **The implementation section**
- 2) **The volunteer coordinator resources section**
- 3) **The education facilitation and training section**

SECTION 1: Implementation Section

The implementation sections contains an **Implementation Manual** and video that introduces this manual. The manual is intended to support organizations in the first and essential steps in implementing the navigation model within the constraints of their organization and provides the organization with a checklist of necessary preconditions to ensure implementation is possible and sustainable.

SECTION 2: The Volunteer Coordinator Resources Section

The volunteer coordinator resources section is organized into **four subsections** containing resources to help implement Nav-CARE in a community:

Coordinator Manual	This contains the Volunteer Coordinator Manual and a video that introduces this manual. It takes users through the steps of implementing the Nav-CARE program.
Public Education	This contains a PowerPoint (that outlines the Nav-CARE program that is designed to be used to educate groups in a community. Each slide contains a voice-over, available for use if needed. This presentation can be modified to suit various audiences and time frames.
Publicity	This contains materials to amplify the profile of Nav-CARE in a community, including a brochure, poster, and one-pager. It also includes prototypes for a prescription pad and Post-it notes. The Nav-CARE branding folder is used as an additional public-facing material. The Nav-CARE Identity Guidelines outline the Nav-CARE colours and how the logo can be used.
Evaluation	This contains the four Nav-CARE program evaluation tools in the Volunteer Coordinator Manual: Volunteer Self-Efficacy Survey, Client Engagement Questionnaire, Qualitative Interview Questions, and Volunteer Satisfaction Survey.

SECTION 3: The Education Facilitation and Training Section

The education facilitation and training folder materials aim to support in-person and online training sessions.

Facilitator's Guide	This contains the Facilitator's Guide and the video that introduces this manual.
Volunteer Navigation Training Manual	This contains the Volunteer Navigation Training Manual and a video that articulates what to expect in this manual. It also contains the quizzes used for each module.
PowerPoints	The 'Volunteer Navigation 6 weeks online plus support' PowerPoint has been constructed to support the education delivery format 'Six-Week On-Line Training with In-Person Sessions'.
Training manual videos	Each module has a brief video that articulates what the volunteer can expect to learn in that module. These videos are part of the online learning platform and can also be used during in-person training.
Appendices	If one wants to conduct an in-person training the following documents need to be given to the volunteers: Changes Toolkit and the Community Resource Guide. The folder also contains important surveys through which to evaluate the training.

6 OVERVIEW OF MOST SIGNIFICANT CHANGES TO NAV-CARE©

A. SUMMARY OF ADAPTATIONS

The most noticeable differences between the original Nav-CARE© (Duggleby & Pesut) program vs. the NavCare-EU program are shortly described in Table 1.

Table 1: Most noticeable differences between the original Nav-CARE© vs NavCare-EU

	Nav-CARE©	NavCare-EU
Brief intervention summary	Nav-CARE is a free volunteer navigation program that supports people with declining health to live as well and independently at home for as long as possible. Specially trained volunteer navigators help clients access resources and services in their community, while providing companionship and emotional support.	NavCare-EU is a European project investigating navigation programmes in different EU countries. Navigation programmes support older people with cancer and declining health throughout their trajectory to live as well as possible at home. Specially trained navigators help older people, and their families access needed resources and services, while providing companionship and support.
Most significant differences	While the original Nav-CARE program focused on supporting people with declining health, the NavCare-EU intervention focused on older adults with cancer and in declining health. Additionally, the Canadian socio-economic, political, and cultural context differs from the European context and from each country's context individually. These two important differences result in the necessity for adaptations to the original toolkit, beyond language translations, to ensure that the program works well and can be used in other regions and organisations.	

The NavCare-EU toolkit (Table 2) is similar to the original Nav-Care toolkit. The depth of the adaptation and whether it is a European or a country-specific adaptation has been indicated by a colour code (legend below). The following section illustrates the document-specific adaptations, with an example of a country-specific adaptation.

Table 2. Overview of the NavCare-EU Toolkit, including all intervention materials

	Name of the document	Length	Type of document
	Implementation folder		
1	Coordinator job description	1 page	Word
2	Implementation manual tutorial	1min54'	Video
3	Nav-CARE implementation manual	25 pages	Word
	Volunteer Coordinator resources folder		
	Manual		
1	Nav-CARE Volunteer Coordinator Manual	51 pages	Word
2	Volunteer Coordinator Manual tutorial	1min45'	Video
	Public Education		
3	Public Education_long version_annotated	45 slides	PPT
4	Nav-CARE Talking Points for Community Members	3 pages	Word
5	Nav-CARE Talking Points for Healthcare Providers	3 pages	Word
	Publicity		
6	Nav-CARE brochure	2 pages	PDF
7	Nav-CARE HCP1Pager	4 pages	PDF
8	Nav-CARE Identity Guidelines	12 pages	PDF
9	Nav-CARE NotePad_print	1 page	PDF
10	Nav-CARE Poster	1 page	PDF
11	Nav-CARE Post It Note_print	1 page	PDF
	Education Facilitation and Training folder		
	Facilitators guide		
12	Facilitators Guide tutorial	2min13'	Video
13	Nav-CARE Facilitators guide	37 pages 37 pages	PDF Word
	Volunteer Navigation Training Manual		
14	Volunteer Navigation Training Manual tutorial	2min43'	Video
15	Nav-CARE Volunteer Navigation Training Manual	127 pages	Word
	PowerPoints		
16	Volunteer Navigation Education_PPT for 6 weeks online plus support	64 slides	PPT
	Training Manual Videos		
17	Training Manual Videos -> introduction, modules 1-6, conclusion	/	Video's
	Appendices		
18	Changes Toolkit_Appendix 1_Training Manual	74 pages	PDF
19	Nav-CARE community resource guide	26 pages	Word
20	Module Quiz 1 through 6	/	Word
21	Module Quizzes_ANSWER KEY	4 pages	Word
22*	Nav-CARE Health Care Navigator Training Manual	91 pages	Word

Legend colour codes

Green= used by all 6 countries and slight European project-specific and cultural country-specific adaptations

Orange= used by all 6 countries and considerable project-specific and cultural country-specific adaptations

Purple= used for inspiration for similar documents/ materials by some of the participating countries or by the international trainer or national trainers

Red= Not used in any country

As indicated in the table above, the original materials are either ‘for inspiration only’ (as indicated in purple), ‘translated but slightly modified’ (as indicated in orange) or ‘considerably adapted’ (as indicated in green). All green and orange materials were fully translated into the official language of the implementation region.

The materials that are not used in any country (as indicated in red) exclusively consist of tutorial videos in English or publicity material for the original Nav-CARE project. The tutorial videos in English are for most countries not useful as their official language differs from English and original publicity material is not used as new publicity material for the European project has been created. The materials that are not used (as indicated in red) will not be mentioned in the document-specific overview below.

The materials utilized for inspiration in creating similar documents or resources, either by certain participating countries, the international trainer, or national trainers (as indicated in purple), serve either public education and publicity aims or are used as sources of inspiration for training materials. Public education and publicity materials differ due to the numerous differences in the original and implementation context, as for instance the logos and project identity styles. Most trainers use the purple training materials as an initial foundation, encompassing all relevant content and being tailored to the specific local context of the region and the implementing organization.

There are only 2 materials that were used by all 6 countries and underwent considerable project-specific and cultural country-specific adaptations (as indicated in orange), namely the appendices ‘Changes Toolkit’ and ‘Community Resource Guide’. Each country uses these but are considerably adjusted to fit the region and organisation of implementation, and the local materials and tools already available. Typically, similar existing materials from the implementation organization or local community are integrated into the format and objectives of the original appendices.

All 6 countries used all four manuals and underwent slight European project-specific and cultural country-specific adaptations (as indicated in green). As the four manuals form the foundation of the toolkit, all of them are translated and adapted in each country. Before the country-specific adaptations, especially the Volunteer Navigation Manual and the Facilitators Guide were adapted to fit the European context instead of the original Canadian context.

B. CONSORTIUM-WIDE ADAPTATIONS

As mentioned in the introduction, the toolkit needed international and national adaptations beyond translations due to two significant differences between the Nav-CARE and NavCare-EU intervention. The notable consortium-wide adaptations are listed below in Table 3.

The International Adaptation Oversight Group (IAOG), consisting of the original developers of the intervention, the WP 2 UGent team, and the VUB coordination team, discussed all major adaptations to the program, to maintain the core components. An overview of the feedback and the proposed action to the major adaptations is provided as **Appendix 1** to this deliverable.

Table 3. Brief overview of consortium-wide adaptations

Adaptation theme	Reason for need for adaptation	Proposed decision/action formulated by the IAOG
Adaptations specific to the project aims of EU NAVIGATE	To fit the aims and specific population focus of the EU NAVIGATE project	This includes changes to materials to entail more informative paragraphs on cancer, its common treatments and symptoms.
Medical Assistance in Dying (MAID) & Advanced Care Planning (ACP)	Legal regulations differ from Canada and in each country individually	Adapt to country-specific legal context. However, to safeguard the core components, navigators must be able to talk with people that have End-of-Life care conversations/ concerns. The navigator role includes conversations about

		what is important to quality of life. He/she does not include discerning wishes about medical scope of treatment.
Cases/roleplays in Volunteer Navigation Manual & Facilitators Guide	Not compatible with socio-economic, cultural and geographic context	IAOG adapted cases in the Volunteer Navigation Manual. International trainer & the original developers adapted the cases/roleplays in the Facilitators Guide.
Additional information/materials on cancer (treatment) in the Volunteer Navigation Manual	Sample of the original intervention differs from the EU intervention	Agree to include this extra information on a very basic level, although as a separate and supplementary module to NavCare-EU. Team Ireland forwarded their existing materials to the VUB coordination team, who transformed them into a module
Institution and concept differences. E.g., hospices, palliative care, spiritual guide, dignity therapy, etc.	Not always compatible with socio-economic and cultural context	Adapt to country-specific institutions and concepts that are similar and be sure to report to the IAOG to see whether the core components of the intervention and of the message remain the same.
Change of the word Volunteer Navigator	Not always compatible with country-specific linguistic preferences	Agree to change to 'navigators' or 'volunteers' as needed in each context. Need to be consistently used throughout all materials.
Publicity material, Logo's, acknowledgments, disclaimer and dedication	Different intervention with different sponsors, implementation organisations and legal requirements	Agree to change according to the European standards and agreed upon project identity style and always refer to the original intervention.

C. OVERVIEW OF MOST IMPORTANT COUNTRY-SPECIFIC ADAPTATIONS

As mentioned in the introduction, the toolkit needed international and national adaptations beyond translations due to two significant distinctions between the Nav-CARE and NavCare-EU intervention. The notable adaptations are summarized below per country. Analysis of these adaptations is based on the Country Adaptation Reporting Sheets which every country submitted to the WP 2 Team and which are added as appendices to the extended report (for internal use only).

Country	Most significant country-specific adaptation(s) to Nav-Care©
Belgium	The Belgian team suggested modifications only for the Volunteer Navigator Learning Manual. These adaptations exclusively concerned content and involved the removal or replacement of paragraphs/elements with more country-specific alternatives, aiming for improved contextual alignment. All adaptations occurred pre-implementation and were consistent with the core components of the intervention.
The Netherlands	The Netherlands proposed overall adaptations and some specific adaptations to the Volunteer Coordinator Manual. The overall adaptations concerned mainly cultural fit and consortium wide adjustments such as regulatory compliance. The adaptations to the Volunteer Coordinator Manual concern adjustments to make a better fit with the local region and multiple implementation organisations as to make it more concise and clearer to their coordinators.
Italy	The Italian team proposed overall modifications and some specific alterations for the Volunteer Navigation Manual. The overall adjustments consist out of concept or term replacements to a more culturally appropriate term. As for instance the term Navigator was changed into 'voluntaria Virgilio' which refers to the guide of Dante in Divina Commedia. This term is a better fit to the Italian context. All

	adaptations were made pre-implementation considering professional experiences which were shared between team members. These modifications were made to prevent miscomprehension and consequently the possibility of a misleading aim of the project.
Poland	Poland proposed overall adaptations and specific adaptations to each manual. Overall changes mainly concerned terminology, regulatory compliance and changes in services and institutions that do not exist in Poland, as for example hospices. The adjustments to the Facilitator's Guide concern content related changes to make it more compatible with the polish context. The main alteration to the Volunteer Navigation Manual was switching the volunteer role to that of a social worker in Poland. This change was necessary because of specific limitations in the country that prevent volunteer work from being feasible, leading to social workers taking on the role of navigators. The coordinator manual is made more concise and more applicable to the polish context with polish alternatives for the resources in the local communities. Furthermore, all changes were made in the pre-implementation phase and in consultation with the entire research team and the Local Adaptation Team.
Portugal	All proposed modifications of the Portuguese team are content related and appear in all materials. Most changes concern different use of terms, concepts and services. As for instance, the word client is used in the context of paid services, which implies one party offering a service and the other party paying for it. Therefore, it was changed to 'pessoa adcompanhada' or 'beneficiario do programa'. All term related changes were discussed with the research team and translators during the pre-implementation phase. Changes were made to make the materials being perceived as more appropriate and helpful. A particular change to the Volunteer Navigation Training Manual involves the section on digital navigation. Since certain software isn't accessible in Portugal, they plan to replace it with more commonly used software
Ireland	Ireland has the most similar context to the Canadian context of all participating European countries, so they had to make the least change in language and content-wise. The adaptations thus mainly consist of simplifications, making some paragraphs more concise and some minor changes that make the manuals more context appropriate. For example, the research team feels that home visit is somewhat intrusive and that it would be more appropriate for the Volunteer Coordinator to connect with the patient and family via video or telephone. All adaptations are made within the research team during the pre-implementation phase.

7 OVERVIEW NAVCARE-EU TOOLKIT BEFORE FURTHER EVALUATION

The NavCare-EU toolkit which will be used for the implementation and evaluation study (in a pragmatic randomised controlled trial in 6 EU countries) consists of the following materials:

1. **Materials for the Navigators/Volunteers:** **A VOLUNTEER LEARNING MANUAL** including all information for volunteers to act as navigators:
 - *Module 1:* The Navigator Role
 - *Module 2:* Addressing Cancer and Quality of Life Concerns
 - *Module 3:* Advocating for Patients and Families, and Promoting Active Engagement
 - *Module 4:* Facilitating Community Connections
 - *Module 5:* Wellbeing and Support for Navigators
 - *Module 6:* Supporting Virtual Navigation
2. **Materials for the Navigation Coordinators:** **The full NAVIGATOR COORDINATOR RESOURCES FOLDER** consists of subfolders containing several resources to help implement NavCare-EU into the local community. The partners translated all these materials and adapted them to their local setting. This folder entails **A coordinator manual, public education materials (e.g. PowerPoints and Talking points), Publicity (flyers and posters), and Evaluation materials**. Most of these documents are also included in the Facilitator's Guide.
3. **Materials for the implementation sites:** **An IMPLEMENTATION MANUAL** that describes what the project entails, what the role of volunteers is whether an organization is ready to implement the NavCare-EU, and the necessary preconditions to do so. It contains an implementation checklist and an exemplary memorandum of understanding. We have provided a **COORDINATOR JOB DESCRIPTION** in **Appendix 2**, of which the details are specific to each country and implementation site. This was again adapted for each implementing organization in each country (hospital setting versus palliative care home care service). This differs from Canada, where coordinators typically share similar backgrounds due to their hospice work experience, unlike in Europe, where not every country has hospices.
4. **Materials for the Country Trainers and Coordinators:** **A FACILITATOR'S GUIDE** for country trainers was specially designed in close consultation with the NavCare© developers. This includes supportive **training materials** (slides, a community resource guide, assessments, ...).
 - *Section 1:* EU NAVIGATE Nav-Care Training Considerations (i.e. how to select a trainer and essential training techniques and assessment strategies)
 - *Section 2:* Overview of the Nav-CARE Volunteer Navigation Learning Program (i.e. training objectives, required competencies, curriculum package and delivery model)
 - *Section 3:* Nav-Care Training Delivery (i.e. delivery format, supplies, agenda)
 - *Section 4:* Continuing Education and Mentorship (i.e. techniques to work together)
 - *Section 5:* Evaluation (i.e. module quizzes, self-evaluation, volunteer self-efficacy questionnaire)

A specific training week was set up for the **INTERNATIONAL TRAINING** of country trainers as part of the EU NAVIGATE project. The agenda for this training week is added to **Appendix 3**. Materials were developed by the International Training Team (involving the developers, Duggleby and Pesut, from the original Nav-Care© intervention).

8 FUTURE EVALUATION OF NAV-CARE EU NAVIGATION PROGRAM

In the next five years, the NavCare-EU research project aims to contribute high-quality evidence on navigation programmes for older people with cancer and their families in six European countries. We aim to evaluate and implement NavCare-EU to examine its effectiveness and cost-effectiveness in improving the quality of life and well-being of older people with cancer and their family caregivers and how it is implemented in practice.

Eager to discover more about the project, its results, and its potential impact across the EU?

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9 APPENDICES

**APPENDIX 1: OVERVIEW
FEEDBACK INTERNATIONAL
ADAPTATION OVERSIGHT
GROUP**

TOPIC	PARTNER INPUT on proposed changes to the Nav-Care© original	IAOG FEEDBACK & PROPOSED ACTION
Medical Assistance in Dying (MAID): delete or adapt to country regulations	<ul style="list-style-type: none"> - Euthanasia and Medical Assistance in Dying are forbidden in Poland, therefore we have to delete this part in the manuals (Poland) - Not relevant in Ireland (Ireland) - Euthanasia and MAID are not legal in Italy, therefore we have decided to remove paragraphs regarding volunteers' supporting role in this kind of decision. However, we decided to maintain some important paragraphs regarding MAID to give further information about it. It is important to discuss this topic with patients, despite it is not possible for them to decide for MAID in Italy. Furthermore, it is fundamental to prepare volunteers to be able to deal with sensitive situations as this one, but also to prepare them to help patients comprehend his/her options. (Italy) - The question of euthanasia is currently in the process of being legalised. This is a topic that may undergo significant changes until the intervention starts. We would like to discuss with LAT how to approach this topic and how to include it the materials in a way that will be relevant independently of the evolution of the process in Portugal. (Portugal) - In Belgium euthanasia is legal. + we thought it would be more understandable and easier to speak about euthanasia instead of MAID. (Belgium) 	<p>Agree to adapt to country-specific legal context.</p> <p>However, also in countries without MAID legislation, there is still the need for volunteers to be prepared to have a conversation when a client expresses a wish to die and/or to discontinue treatment. Volunteers need to be able to have a conversation in which they can hear the suffering story of the client and to work with the client to determine further action (e.g., assisting client to speak to primary care physician regarding discontinuing treatment or ACP or to implement action plan if there is a concern regarding suicide).</p>
ACP, power of attorney, advance directives: adapt to country regulations	<ul style="list-style-type: none"> - We may introduce information on Advanced Care Planning, medical attorney and end of life wishes/will – in the extend is allowed by Polish law. (Poland) - Contextual fit to assure appropriateness of the materials: In Portugal we have a document defined by legislation called "Diretiva Avancada de Vontade", an advance directive or living will. This is a document in which person states, with conscious volition, their preferences regarding healthcare they wish to receive should they find themselves in a medical condition where they are unable to express their wishes. It is a document that is registered in National Register of Living Wills. To explore other less formal tools of exploring preferences for advanced care planning, we will consult LAT. (Portugal) - There are different ACP tools, which we mentioned in the manual. (Belgium) 	<p>Agree to adapt to country-specific legal context.</p> <p>To be clear: the NavCare volunteer role is limited to listening to clients as they make their wishes known and helping them to communicate those wishes to whomever needs to know. The volunteer role includes conversations about what is important to quality of life. The volunteer role does not include discerning wishes about medical scope of treatment.</p>
Emergency situations: adapt to country regulations/conventions?	<ul style="list-style-type: none"> - We foresee the possibility of volunteer facing emergency situation, as is also acknowledged in the materials. This implies having a clearly defined, described and tested out "distress or serious event protocol" in relation to how to respond to the situation with person with cancer/family member, who and how to inform later (research team, for example) and how to keep record of these events. (Portugal) 	<p>Agree to this adaptation.</p> <p>In NavCare there are two directives:</p> <ol style="list-style-type: none"> 1) the volunteer coordinator is typically the first line of reporting for non-urgent situations (e.g., client seems more confused) 2) there is a protocol that the client agrees to in the event of immediate distress (e.g., client does not answer the door)

		<p>or a phone call for a pre-arranged visit)</p> <p>If this is insufficient, countries may adapt/add directives according to local context directives</p>
Case descriptions (patient stories): use own examples?	<ul style="list-style-type: none"> - There are some cases descriptions (patient's stories) which have to be adjusted to the Polish context – we may give more suitable examples. - The example with sandwich with meat is unacceptable – we need to think about something different (will discuss it with a psychologist). (Poland) 	<p>Agree to use context-specific cases, as long as they address the underlying competencies where they are cited.</p> <p>May we ask partners to keep a record of own case descriptions, as this would yield relevant information regarding context and adaptation.</p>
Additional information/materials on cancer (treatment)	<ul style="list-style-type: none"> - Our idea for face-to-face training / inclusion in training manual was to focus on: - Common treatments – e.g. what is radiotherapy, what is it used for, what does it involve for the patient (lying on hard table in isolation for short period of time) - Common side effects – e.g. what are typical side effects of radiotherapy, what are the timescales, what can the patient / family do to mitigate side effects - Red flags – i.e. symptoms / problems that warrant urgent medical attention: a) fever > 38C; b) bleeding / bruising; c) loss of power in legs; d) loss of sensation in legs / elsewhere; e) reduced consciousness; f) other acute changes in symptoms / general condition - We intend to use oncology colleagues to support this aspect of the training. The Irish Cancer Society has multiple sources of information re specific cancers, specific treatments, and specific cancer-related problems – we would signpost these resources to the navigators (to highlight to patients). Amanda is looking at what is available / suitable now. (Ireland) – <i>see also appendix 'What is chemotherapy?'</i> 	<p>Agree to include this information, albeit as a separate and supplementary module to NavCare.</p> <p>Important to consider that navigators are lay individuals, so best to have information at a basic level (ie that you would also share with the public). We do not want to scare them off in their role.</p> <p>Perhaps the resource can include links to national information sites that the volunteers can consult if they like to dive deeper.</p> <p>Also, this information is for signposting only, navigators should not be expected to educate clients or act on this information themselves.</p>
Change to specific target group: older people with cancer?	<ul style="list-style-type: none"> - Study only involves older patients with cancer (Poland, Ireland, Netherlands) 	<p>Agree to change throughout</p>
Suggestions to restrict navigator tasks, eg practical help, initiate ACP talks	<ul style="list-style-type: none"> - Criterion will restrict recruitment of volunteers, and research team do not feel this is an appropriate task for navigators. [We need to ensure clear boundaries in terms of role of navigators] (Ireland) 	<p>The boundaries of the volunteer role should be adapted to each context. The list in the manual could act as a point of discussion regarding whether this fits your volunteer role.</p> <p>It is important to emphasize here:</p> <p>(1) volunteers seek out resources to help with practical tasks rather than doing them.</p> <p>(2) a role that is too constrictive for the volunteers makes it difficult to be creative and to develop relationships and has led to volunteer dropout as well.</p>
Support Virtual Engagement module: still relevant in post-COVID times?	<ul style="list-style-type: none"> - The Support Virtual Engagement module will be removed / replaced. Relevant content will be included in other modules. COVID-19 is less of an issue at the moment. (The research team feel that there are more important topics to cover 	<p>This module should not be removed.</p> <p>COVID 19 is just one reason for its importance; there are others:</p> <ul style="list-style-type: none"> - Home visits may be difficult for various reasons (eg

	during training, e.g. navigator wellbeing) (Ireland)	<p>immunocompromised populations, overly fatigued clients, very remote populations.</p> <ul style="list-style-type: none"> - Module includes telephone contact, and finding info on the web. <p>We also want to make sure all competencies are developed in all countries for consistency. Also, Roeline has developed her evaluative questionnaires based on the presence of all modules (the competency questions are structured by module).</p>
Remove repetition/irrelevant info to shorten Volunteer Navigation manual	<ul style="list-style-type: none"> - The research team feel that the original document is too big / overwhelming, and so want to reduce repetition / remove irrelevant text (for EU-Navigate study / Irish population) (Ireland) 	<p>The original document is mostly there for reference and as support for the training, as well as for ongoing debriefing/ mentoring. It should include all necessary and the same information, across countries.</p> <p>If any content is removed the IAOG needs to judge its effect on standardization of the training.</p>
Mention about 'hospice'/'palliative care': avoid or keep?	<ul style="list-style-type: none"> - In many places there is information about hospice, palliative care although it is written that we should not mention about it – so I would suggest avoiding these words. (Poland) - word 'hospice': changed to either palliative care or removed or kept (depending on the sentence, kept when hospice is referred to as the home base of the organisation) (Netherlands) 	<p>There is a difference between communication to healthcare providers and to the public. Palliative care (hospice) can be used when addressing the former but should be avoided when addressing the latter. The wording toward both can be tailored according to the country-specific context.</p>
Do volunteers require experience (in PC)?	<ul style="list-style-type: none"> - Volunteers will not be required to be experienced volunteers, or to have previous hospice / palliative care experience. Criterion will restrict recruitment of volunteers (Ireland) 	<p>Agree to also recruit volunteers without PC experience. However, these persons will need some key basic orientation and competencies.</p> <p>We prepared a pre-orientation competency checklist that each country can fill out in relation to their volunteers. We will work with each country to identify what additional competencies they may need to provide to their volunteers.</p> <p>The trainers/volunteer coordinators should be aware that there might be individual volunteers that will need more orientation and ongoing support.</p>
Do coordinators need to do a home visit?	<ul style="list-style-type: none"> - The Volunteer Coordinator will not conduct a home assessment prior to the volunteer engaging with the patient. The research team feel that home visit is somewhat intrusive, and that it would be more appropriate for the Volunteer Coordinator to connect with the patient and family either via a video or telephone call (Ireland) 	<p>The physical home visit is crucial. One may not pick up on certain challenges via video or telephone call. Also, the coordinator needs to ascertain the safety conditions for navigators to come to clients' homes, cf. for liability issues.</p>
'volunteers' vs 'navigators'	<ul style="list-style-type: none"> - In Poland, the intervention will be conducted by paid navigators (not volunteers) therefore we need to use word navigators (not volunteers). At the beginning of the manual, we may write that this intervention may be run by paid or unpaid (volunteer) navigators. (Poland) 	<p>Agree to change to 'navigators' or 'volunteers' as needed in each context. Need to use consistently throughout all materials.</p>

	<ul style="list-style-type: none"> - Change 'Volunteer Navigator' to 'Navigator' for simplification (Ireland) - We modified the term "navigator" into "volontario Virgilio". The term "navigator" does not have the same sense in Italian that it has in English. We decided for the name Virgilio to refer to the guide of Dante in Divina Commedia. We thought all participants would better understand the volunteer's role. (Italy) - We modified the verb "navigate" into "accompagnare". Same problem here as "navigate" in Italian could mean to ride the sea or surf the internet. We decided for the word "accompagnare" literally meaning "accompany". It resulted to be the best fit to comprehend the meaning of navigation. (Italy) - volunteer navigators: changed to 'navigators', more fitting to Dutch context (Netherlands) 	
'patient' vs 'client'	- "Client" not culturally appropriate (Ireland)	'Patient' would likely be too medical a term for non-professional volunteers. Which term is otherwise preferred by the team? This is dependent on the specific context
Unclarity of term 'resources'	- We had problem with the word: resources which is not explained clearly. Therefore, we suggest at the beginning to add the sentence that whenever it is used we think of: services, benefits, personal support. what else should we list?. (Poland)	OK
Unclarity of term 'community'	- other wording, more culturally fitting, see Dutch 'woordenlijst': literally 'gemeenschap' but chose 'regio' (region) (Netherlands)	OK
Unclarity of term 'family' (and variations)	- family (and variations) changed to 'those next to them' (in Dutch 'naaste')	OK
Info re rural areas does not apply	- Rural areas do not exist in Flanders (especially not in our implementation regions). Changed to remote areas or people with bad mobility (Belgium)	OK
What to do with Canada-specific websites, digital tools, guides, videos, videocall software, contact information, organisations?	<ul style="list-style-type: none"> - On the informative pages providing website, address of authors, where the reader should refer to for more information should we keep Canadian data or introduce Polish data (ex. Our University, our website etc.) or both: Canadian and Polish. (Poland) - Propose to delete resources not in Dutch: eg dignity therapy (pg37), Family caregiver decision guide (pg 41), website living with hope (pg. 45), internet safety (pg 111) - video call software (Belgium) - Because not all video calling software mentioned is often used in Belgium. (Belgium) - About the authors' citation of Italian manuals - how do we cite them? Can we insert our names? We would really appreciate to be cited in these works. (Italy) - In the implementation manual the Program Sustainability Assessment Tool (PSAT) is cited to analyse the sustainability of the program for organizations. 	<p>Agree that Canadian specific resources should be replaced by locally developed, used or implemented resources (if existing).</p> <p>Dignity Therapy, The living with hope website and internet safety can be deleted. Regarding the family caregiver decision guide: we are unsure about this as some partners may be translating this?</p> <p>About citation: any modifications can add <i>"translated and/or adapted from Pesut & Duggleby [full reference information] by [insert local authors] and EU navigate consortium."</i></p> <p>The PSAT is copyrighted, so would need permission to translate. If there is no resource available like this to replace it, it would be best to delete reference to it.</p>

	<p>There is no validated translation in Italian. Should we either work to validate it or can we translate it ourselves? (Italy)</p> <ul style="list-style-type: none"> - Remove mention of “Community Toolbox” and “Windshield Survey”: Canadian resource – not relevant to Ireland. Research team will provide an initial list of local resources, and navigators will be asked to add to the list as needed: the local resource list will be a live document available to navigators via the Irish-specific website (Ireland) - Remove mention of “Speak Up” and “Changes Toolkit”: Canadian resource – not relevant to Ireland. Research team will provide information / Irish resources for navigators on advance care planning. The research team feel that navigators should not initiate advance care planning discussions themselves, but that they should be able to support patients that want to pursue ACP (Ireland) - Content: Websites, videos, references to canadian NGOs, services and other resources (e.g., Dignity Therapy): skipping or substituting (Portugal) - In the "What video-calling software is best for you and your client?" some of the advantages and disadvantages need to be updated. Some of the software is not available in Portugal, on the other hand there are others that have been used frequently among the population. (Portugal) 	
What to do with copyright, disclaimer, acknowledgments?	<ul style="list-style-type: none"> - disclaimer; not modified yet, we have to see what is in line with Dutch law. (Netherlands) - up for discussion, do we refer to the Canadian original manual, or to the one from our current project (Netherlands) 	Do not remove Canadian disclaimer or acknowledgements but you are free to add anything that does not imply copyright or intellectual property.

APPENDIX 2: NAVCARE-EU COORDINATOR PROFILE AND ROLE DESCRIPTION

Profile description of Navigation Coordinators

Aim of this profile description:

This document is to guide countries in selecting/recruiting a Navigator Coordinator and to guide them throughout the EU NAVIGATE project. The document has 3 parts: (1) Key criteria for appointment of 'navigator coordinators' (2) the role and key responsibilities; and (3) Person specification.

Who's this profile description for:

Each country's PI and his/her delegates.

Recruitment and time of employment:

Coordinators are ideally hired part-time for 2 to 2,5 years (please consult your country's budget). Training and support is continuously offered by the Country Trainers throughout the project.

Sources: (1) PACE EU FP7 project; (2) Appendix 2 Nav-CARE Implementation Manual; (3) consultation with the international training team (Wendy Duggleby, Barbara Pesut, Gloria Purveen and Else-Gien Statema).; (4) Pesut, B., Duggleby, W., Warner, G., Kervin, E., Bruce, P., Antifeau, E., & Hooper, B. (2020). *Implementing volunteer-navigation for older persons with advanced chronic illness (Nav-CARE): a knowledge to action study*. BMC Palliative Care, 19(1), 1-16; (5) Masquillier Caroline, Cosaert Theo en Wouters Edwin (2022), *Community health workers in België – rapport 2021*, Universiteit Antwerpen: Antwerpen, 150 p., ISBN:9789057287343

Part I: Key Criteria for appointment of Navigator Coordinators

- **Understanding of the local community, health and social care system:**
The intervention is about navigating older persons with cancer and their family caregivers in the local health and social care system.
- **Ability to collaborate:**
The NavCare-EU project focuses on different actors related to the well-being and quality of life of older persons with cancer and their family caregivers. The navigator coordinator needs to have a natural ability to get alongside navigators as well as encourage the cooperation and collaboration of other actors to be part of the intervention. Ideally, the Navigation Coordinator has a wide local network and is already well connected locally with a variety of social, community and healthcare services to whom the patients/families will be navigated to.
- **Coaching navigators:**
A core skill of the Navigator Coordinator will be the ability to coach the navigators during the NavCare-EU project. The navigator coordinator must be able to motivate the navigators even when the work appears difficult – perhaps due to change of staff, low morale within the volunteering group. Ideally, he/she has prior experience as a volunteer him/herself or worked with volunteers before.
- **Good communication and networking skills:**
They have a public role in which they are tasked with raising awareness of NavCare-EU in the local community. Therefore, it is required that they are comfortable with connecting with various stakeholders

through presentations and networking. The navigator coordinator will collaborate and interact with multiple stakeholders.

Part II: The role and key responsibilities of a (volunteer) Navigator Coordinator

The overall role of a navigator coordinator is to champion and provide leadership for the EU NAVIGATE project (NavCare-EU). This role can be divided into 6 key responsibilities to which different tasks are related:

- 1. Recruiting and screening Navigators**
- 2. Orientating and Mentoring Navigators**
 - Screen navigators to determine suitability for NavCare-EU
 - Facilitate NavCare-EU volunteer education, with the support of Country Trainers
 - Match navigators with older persons
 - Provide ongoing education and support for navigators
 - Evaluate navigator satisfaction
- 3. Identifying EU-Nav Persons**
 - Determine the population in need and their family
 - Educate healthcare providers about NavCare-EU
 - Provide easy referral for 'social care'
 - Determine suitability of persons for the NavCare-EU service
 - Conduct intake of NavCare-EU
 - Monitor persons' satisfaction, access to services, and engagement
- 4. Providing Public Education**
 - Determine community groups who might have an interest in NavCare-EU
 - Give presentations to interested groups
 - Provide the public with updates of the NavCare-EU program
- 5. Supporting Capacity**
 - Determine hospice societies in the geographic region interested in starting EU-Nav
 - Provide advice on implementation issues
 - Support volunteer education and ongoing development
 - Share resources
- 6. Raising the visibility of NavCare-EU in the local community**

Part III: Person Specification

	ESSENTIAL	DESIRABLE
Education and Qualifications	<ul style="list-style-type: none"> • Post-secondary education (Bachelor's degree) or equal in experience • Speaks target/country language fluently 	
Experience	<ul style="list-style-type: none"> • Experience working in local/regional nonprofit organization, health community or social care organization(s) • Expertise in/with aging or palliative care 	<ul style="list-style-type: none"> • Experience of working with multiple stakeholders • Experience of working with small & large groups in an educational capacity • Experience of working as/with volunteer(s) • Experience working with variety of local organizations that might be involved in the Nav-CARE project as well
Skills, Knowledge and abilities	<ul style="list-style-type: none"> • Excellent written and oral communication skills • Being comfortable giving public presentations • Excellent interpersonal skills, including developing and maintaining partnerships with other community organizations, conflict management, problem solving and diplomacy are required • Able to demonstrate effective working with members of a variety of professional groups • Computer literacy with knowledge of Windows-based applications • Excellent leadership skills 	<ul style="list-style-type: none"> • A valid driving licence
Aptitude, Personal Characteristics	<ul style="list-style-type: none"> • Ability to work independently in an organised and methodical way – manage time & meet deadlines • Innovative approach & ability to inspire • An ability to work with people at all levels of an organisation. • Negotiation & problem-solving skills • Approachable and adaptable • Ability to manage the impact of ‘working with’ different stakeholders 	

APPENDIX 3:
AGENDA
INTERNATIONAL
TRAINING

Overview International Training week

April 24th to April 28th 2023

Day 1	Introduction day
9:00	<p>Introductions / Program /Getting to know each other and each other's contexts</p> <ul style="list-style-type: none"> <input type="checkbox"/> Background Nav-CARE (prof. Barb Pesut) <input type="checkbox"/> Overview EU Navigate study (prof. Lieve Van den Block) <input type="checkbox"/> Organizational chart: Roles, responsibilities and learning/follow up activities <input type="checkbox"/> Week program: way of working per module
until 17:00	<p>Wrap up day 1</p>
Day 2	Train the Trainer Module 1 and 2
9:00	<p>Module 1: Volunteer role</p> <ul style="list-style-type: none"> <input type="checkbox"/> Introductory roleplay and discussion - Schematic overview module <input type="checkbox"/> Country-moderated interactive learning activity + follow up discussion <input type="checkbox"/> Contextualization by prof. Barb Pesut <input type="checkbox"/> Discussion on cultural adaptations
until 17:00	<p>Module 2: Addressing Quality of life (Structured as above)</p> <p>Wrap up day 2</p>
Day 3	Module 3 and 4 + Coördinator role
9:00	<p>Module 3: Advocating for Clients and Families (Structured as above)</p> <p>Module 4: Facilitating Community Connections (Structured as above)</p> <p>Coordinator Role</p> <ul style="list-style-type: none"> <input type="checkbox"/> Specificities coördinator role <input type="checkbox"/> Coördinator-trainer dyad
until 17:00	<p>Wrap up day 3</p>
Day 4	Module 5 and 6 + Context analysis and cultural adaptations
9:00	<p>Module 5: Promoting Active Engagement (Structured as above)</p> <p>Module 6: Supporting Virtual Navigation (Structured as above)</p> <ul style="list-style-type: none"> <input type="checkbox"/> Interviews context analysis <input type="checkbox"/> Working on cultural adaptations and country timelines
until 17:00	<p>Wrap up day 4</p>
Day 5	Research, pre-assessment and pre-requisites, Wrap up
9:00	<ul style="list-style-type: none"> <input type="checkbox"/> Research aspects of intervention (Prof. Lara Pivodic, prof. Roeline Pasman) <input type="checkbox"/> Pre-assessment learner needs
until 14:30	<p>Training Wrap up: Q&A and Evaluations</p> <p>Wrap up day 5 - Lunch</p>

Location: BIP Meeting Center, Rue Royale 2-4, Brussels