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# Joint Action on Networks of Expertise on Cancer

## Milestone number. 7.1

### Annual Activity Report (M12) – Survivorship NoE

November 2025

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## 1 EXECUTIVE SUMMARY

The main goal of the JANE2 project (EU Joint Action in Networks of Expertise on Cancer, <https://jane-project.eu/>) is to establish seven Networks of Expertise (NoE) in the cancer field. This involves preparing all required structures and resources for their launch, as well as critically reviewing existing and future EU models of collaboration and networking. These networks will foster collaboration and knowledge sharing among all EU Member States, leading to the development of clinical guidelines and best practices, facilitating research and innovation, enhancing education and training, and ultimately improving health policy at both national and European levels.

Within the JANE2 work packages (WPs), WP7 aims to establish the foundation of a **Survivorship NoE**. As part of the overall objective to expand and strengthen the Survivorship NoE, the plan is to create specialized working groups. These groups of experts will deal with key aspects of survivorship care for people of all ages, and they will focus on putting these aspects into practice and ensuring that all relevant stakeholders across the EU are involved.

The aim of this document, which is the first milestone of the WP7, is to provide clear and comprehensive information on all activities and achievements of the Survivorship NoE during this first year, including tasks outlined in the Grant Agreement, activities supporting JANE2's core WPs, and in some cases additional details on supportive actions that helped ensure the NoE's objectives.

This report will have some sections that cover for overarching issues of the NoE as well as additional task-centered sections, with details into the activities conducted within each active task. Each task will have a brief description of the aim, timeline, latest updates, barriers or challenges identified and next steps planned.

## 2 GLOSSARY

### A

- **ACC (Alleanza Contro il Cancro)** – Italian national oncology network, coordinated by the Italian Ministry of Health and leading Task 7.3 on developing an Integrative Survivorship Care programme
- **AEs (Affiliated Entities)** – Organisations that are contributing to specific activities within JANE2 project. In JANE2 these are connected through a common national Beneficiary entity, who originally received the funding.
- **AECC (Asociación Española Contra el Cáncer)** – Spanish cancer patient organisation that as part of their service portfolio, conducts some survivorship-related research activities and other initiatives.
- **AIEOP (Associazione Italiana di Ematologia e Oncologia Pediatrica)** – Italian pediatric oncology association, gathering hematologist and oncologist healthcare professionals.
- **AIOM (Italian Association of Medical Oncology)** – A national professional organisation in Italy that promotes research, education, and the development of clinical guidelines in the field of medical oncology.
- **ASCO (American Society of Clinical Oncology)** – A major professional organisation in the United States dedicated to improving cancer care. It produces guidelines, conducts research, provides education, and supports oncology professionals worldwide.
- **AYA (Adolescent and Young Adult)** – In the context of cancer, this is a population group typically defined as individuals diagnosed with cancer between the ages of 15 and 39. Their cancer care needs are distinct to children and older adults due to developmental, social, and biological factors.

### B

- **BCR (Belgian Cancer Registry)** – A Belgian entity that collects and manages cancer-related data for research and surveillance.
- **Business Model Canvas** – A strategic management tool used to design, describe, and analyze a business model, often applied to plan network sustainability.

### C

- **CB (Capacity building)** – Holistic and strategic process through which organisations develop, strengthen, and sustain the skills, systems, and resources needed to implement survivorship care programmes.
- **CANCON (Comprehensive Cancer Control Joint Action)** – An EU joint action (2014–2017) producing guidance for improving cancer care pathways.
- **CAYA (Childhood, Adolescent and Young Adult)** – In the context of cancer, a population group that includes those diagnosed with cancer during childhood as well as adolescents and young adults. It is often used in survivorship research and programme design.
- **COG (Children’s Oncology Group)** – A large North American clinical trials and research organisation that develops treatment protocols and long-term follow-up guidelines for children and adolescents with cancer.
- **Clinical center** – A healthcare facility that provides comprehensive medical services, including diagnosis, treatment and sometimes research and education, often serving as a hub for clinical care and patient management.
- **Cochrane review** – A high-quality systematic review produced using rigorous standardized methods from the Cochrane Collaboration.
- **Collaborative Stakeholders** – External entities to JANE2’s initial Consortium Agreement that are invited to participate in a Network of Expertise to contribute with their expertise, resources, or support.
- **Comparative analysis** – A method that evaluates similarities and differences across studies, models, or datasets to identify patterns or contrasts.
- **Conflict of Interest (COI)** – A situation where personal, financial, or professional interests could influence—or appear to influence—objective judgment.
- **Consensus statement** – A formal agreement on a topic, developed by experts after reviewing evidence and deliberating.



- **COSA (Clinical Oncology Society of Australia)** – A professional society promoting excellence in clinical oncology and cancer care in Australia.
- **CPAC (Canadian Partnership Against Cancer)** – A national organisation coordinating cancer control efforts across Canada.
- **CPGs (Clinical practice guidelines)** – Evidence-based recommendations for diagnosis, treatment, and follow-up of patients.
- **Conditional logic** - A survey-design feature in which specific questions are shown or hidden depending on how the respondent answers previous items. It ensures that participants only see questions relevant to their situation
- **Cross-referencing** – A method used to compare, verify, or connect information from two or more sources, datasets, or sections of a document to ensure consistency, accuracy, and completeness.

## D

- **Data lock** – The point in time at which data collection for a study or survey is finalized for analysis.
- **Delphi consensus process** – A structured, multi-round survey of experts used to reach consensus while maintaining anonymity.
- **DOI (Digital Object Identifier)** – A permanent alphanumeric identifier assigned to digital publications for reliable long-term access.

## E

- **ECO (European Cancer Organisation)** – European not-for-profit organisations aimed to reduce the burden of cancer and improve outcomes and the quality of care for cancer patients.
- **EDACS (Ending Discrimination Against Cancer Survivors)** – Belgian organisation supporting and advocating for new policies that can protect cancer survivors' rights.
- **Electronic Medical Record (EMR)** – A digital system used within healthcare organisations to store patient health information.
- **EMBASE** – A major biomedical and pharmacological literature database commonly used in systematic searches.
- **EPAAC (European Partnership for Action Against Cancer)** – An EU initiative (2011–2014) aimed at coordinating cancer control strategies across Member States.
- **ePROMs (electronic PROMs)** – Digital versions of PROMs collected via online platforms, apps, or electronic health systems.
- **EUnetCCC (European Network of Comprehensive Cancer Centers)** – A Joint Action that aims to connect and create a Comprehensive Cancer Centers framework across Europe in order to provide all patients with access to high-quality cancer care services.
- **ESMO (European Society for Medical Oncology)** – A leading professional organisation for medical oncology in Europe. It develops clinical practice guidelines, organizes scientific meetings, and promotes standards for cancer care.

## F

- **FEFCI (Federación Española de Familias de Cáncer Infantil)** – Spanish federation of associations supporting families of children with cancer.
- **Financial toxicity** – In the context of cancer survivorship, this is an economic burden experienced by cancer survivors and their families due to costs of treatment, care, and loss of income.

## G

- **GDPR (General Data Protection Regulation)** – EU legislation governing the protection and lawful processing of personal data.
- **General Assembly** – The main decision-making body of the Network of Expertise, consisting of all partner institutions.



- **Governance structure** – The organisational framework defining roles, responsibilities, and decision-making processes within the Network of Expertise.
- **Grey literature** – Informal publications such as reports, training manuals, or policy documents not indexed in academic databases.

## H

- **HPP (Health Policy Platform)** – EU-level initiative to coordinate synergic health-related EU initiatives and to share and align strategies on the different areas, including survivorship.
- **High contributors** – Partners providing significant effort, expertise, or resources to a specific task or subtask.

## I

- **IGG (Istituto Gianina Gaslini)** – A scientific pediatric hospitalization and care institution leading Task 7.2 on mapping survivorship care across the EU.
- **IGHG (International Guideline Harmonization Group)** – A consortium that harmonizes guidelines for long-term care of childhood cancer survivors.
- **IKNL (Netherlands Comprehensive Cancer Organisation)** – The national institute overseeing cancer care quality, research, and data in the Netherlands.
- **INE-CSC (Implementation Network Europe for Cancer Survivorship Care)** - Cost Action initiative that aims to systematically support the sustained translation of evidence-based interventions into routine clinical to ultimately enhances the health and wellbeing of cancer survivors.
- **Informed consent** – A process ensuring participants voluntarily agree to research participation after understanding risks, benefits, and rights.
- **INT (Istituto Nazionale dei Tumori)** – Italian cancer research and treatment institution based in Milan that leads JANE2 project as the coordinating institution.
- **Integrative survivorship care** – A survivorship care programme that addresses the multiple needs identified in the cancer survivors (i.e. medical, psychosocial, educational needs).
- **iPAAC (Innovative Partnership for Action Against Cancer)** – The successor to EPAAC (2018–2021), developing innovative approaches to cancer control in Europe.

## J

- **JANE2 (Joint Action on Networks of Expertise in Cancer)** – EU initiative that aims to establish Networks of Expertise in cancer-related knowledge fields; second iteration of the JANE project.
- **Joint Action (JA)** – An EU-funded collaborative initiative in which multiple Member States work together to address a common health or policy challenge, producing shared tools, guidelines, or actions with concrete results.

## K

- **Key Performance Indicators (KPIs)** – Measurable indicators used to evaluate the performance, quality, or impact of a service or programme.
- **Kick-off meeting** – Initial meeting typically marking the start of a project, which helps at setting objectives, and establishing collaboration.
- **KOTK (Kom op tegen Kanker)** – Belgian cancer patient organisation contributing to survivorship activities.

## L

- **Late effects** – Long-term consequences of cancer treatment experienced by survivors.
- **Long-term follow-up** – Continuous monitoring and care of cancer survivors after completion of active treatment.



- **Low contributors** – Partners providing limited involvement or support to specific tasks or subtasks.

## M

- **Mapping** – In the context of this project, process of identifying, cataloging, or analyzing entities, programmes, or stakeholders relevant to survivorship.
- **MASCC (Multinational Association of Supportive Care in Cancer)** – An international organisation advancing supportive care for people with cancer.
- **MDTs (Multidisciplinary Teams)** – Groups of healthcare professionals from different specialties who jointly plan and deliver patient care.
- **Meta-analysis** – A statistical technique combining data from multiple studies to compute pooled effect estimates.

## N

- **Narrative review** – A qualitative, descriptive summary of existing literature that does not follow a strict systematic protocol.
- **National Coordinators Board** – Experts representing individual countries within a Network of Expertise to facilitate local engagement.
- **National Networks / Regional Networks** – Groups of institutions or organisations at the national or regional level collaborating within the survivorship field.
- **NCCN (National Comprehensive Cancer Network)** – A not-for-profit alliance of U.S. cancer centers that publishes widely used evidence-based clinical practice guidelines for cancer treatment, prevention, and supportive care.
- **NCSI (National Cancer Survivorship Initiative)** – A UK programme improving outcomes and quality of life for cancer survivors.
- **NHS (National Health Service)** – The publicly funded national healthcare system of the UK.
- **NKR (Netherlands Cancer Registry)** – The national registry collecting data on cancer incidence, treatment, and outcomes in the Netherlands.
- **NoE (Network of Expertise)** – EU-level collaborative network conformed of different types of entities (Research centers, clinics, patient associations and scientific societies) bringing together specialized institutions and stakeholders in a specific area to support a specific portion of the cancer community.
- **NKUA (National and Kapodistrian University of Athens)** – Greek public university leading Task 7.4 on developing Capacity Building programmes for survivorship.

## O

- **OUS (Oslo University Hospital)** – Public university hospital in Norway, affiliated with the University of Oslo. Co-leading together with VHIO Task 7.6 on evaluation of the survivorship care programme.
- **Observers** – Partners who follow the work and receive information from the NoE's but do not have formal responsibilities. They may participate in meetings and provide input when relevant.
- **Organigram** – A structured visual representation of the governance and internal organisation of a project, network, or institution.

## P

- **PanCare** – European initiative focusing on the care of childhood cancer survivors.
- **PanCare4AYA** – European network focusing on adolescents and young adults (AYA) cancer survivors.
- **PanCareSurFup Consortium** – A European consortium studying long-term outcomes and survivorship after childhood cancer.
- **Panel of Experts** – A group of recognized specialists convened to provide informed judgment, review evidence, or guide decisions.
- **Patient advocacy groups** – Organisations representing patients' interests, contributing insights and priorities.



- **Patient Board** – Group of patients and caregivers providing input to governance, strategy, and activities of the NoE.
- **Pilot use cases** – Selected centers used to test implementation of the survivorship programme.
- **Policymakers** – Individuals or groups responsible for creating, shaping, and implementing policies, regulations, and guidelines within governmental, regional, or institutional settings
- **Primary Care Providers (PCPs)** – Healthcare professionals providing first contact and ongoing care for survivors.
- **PRISMA flow diagram** – A visual representation of the number of records identified, screened, and included/excluded in a systematic review.
- **PROMs (Patient-Reported Outcome Measures)** – Standardized questionnaires capturing patients' direct reporting of symptoms, functioning, or quality of life.
- **PubMed** – Free online database of biomedical literature for research and evidence-based practice.

## R

- **Research centers** – Institutions conducting scientific studies on cancer care and survivorship.

## S

- **Scientific and Professional Board** – Advisory board providing expert guidance on scientific, clinical, or professional matters.
- **Sciensano** – Belgian scientific healthcare research institution co-leading, together with SJD, the WP7 (Survivorship NoE) within JANE2.
- **Scientific societies** – Professional organisations that bring together researchers, clinicians, and experts within a specific scientific or medical field.
- **SIOPE (European Society for Paediatric Oncology)** – A European organisation representing healthcare professionals in paediatric oncology.
- **SJD (Sant Joan de Déu Barcelona Children's Hospital)** – Spanish pediatric hospital in Barcelona specializing in children's health and cancer, which runs a care unit for cancer survivors. Together with Sciensano, this is the institution leading WP7 (Survivorship NoE) within JANE2.
- **Snowball sampling** – Recruitment method where existing participants help identify additional respondents for surveys or studies.
- **Steering Committee** – Operational management body responsible for coordinating network activities and strategy.
- **Stakeholder engagement** – Process of involving individuals or organisations in the planning and implementation of network activities.
- **Stakeholder mapping** – Systematic identification and classification of stakeholders relevant to a project or network.
- **Sustainability plan** – Strategic plan ensuring continuity of network services and operations beyond initial funding.
- **Subtask** – Smaller, focused component of a task, detailing specific actions or outcomes.
- **Survivor educational programmes** – Educational activities designed to empower survivors with knowledge and skills for self-management.
- **Survivorship care** – Activities and services provided to cover cancer survivors' needs, including medical, psychosocial, and supportive interventions.
- **Survivorship Holistic Needs Assessment (HNA)** – A structured assessment identifying a cancer survivor's physical, emotional, social, and practical needs.
- **Survivorship indicators** – Metrics used to monitor and assess outcomes for survivors.
- **Synergies** – Collaborative interactions between initiatives, networks, or institutions to maximize impact.
- **Synergy alignment** – Coordination of related projects or initiatives to avoid duplication and optimize outcomes.
- **Systematic review** – A structured, comprehensive, and transparent method of locating, evaluating, and synthesizing all available research on a specific question.

## T



- **Task** – Specific work package component often with defined objectives and responsibilities.
- **Task/subtask leaders/co-leaders** – Entities responsible for managing and coordinating a task or subtask.
- **Tertiary prevention** – Interventions that reduce long-term impacts, complications, or disability after a disease has occurred.
- **TYA (Teenage and Young Adult)** – A category referring to patients typically aged 13–24 with distinct cancer care needs.

## U

- **ULSSM (Unidade Local de Saúde de Santa Maria)** – Portuguese health institution leading Task 7.5 on implementing survivorship care programmes in pilot centers.

## V

- **VHIO (Vall d’Hebron Institute of Oncology)** – Spanish adult a pediatric hospital located in Barcelona. Institution leading Task 7.6 on evaluation of the survivorship care programme.

## W

- **WP (Work Package)** – A major subdivision of a Joint Action or EU-funded project.

### 3 INTRODUCTION

The JANE2 falls within the framework of the European Union's EU4Health Programme. More specifically, Joint Actions aim to foster cooperation, coordination, and knowledge sharing among Member States in various areas of health policy and practice. Its predecessor, the JANE project, started in October 2022, coordinated by Istituto Nazionale dei Tumori (INT) and it involved the participation of 16 Competent Authorities and 20 Affiliated Entities (AEs) and two Patient Associations from 16 countries around Europe. Its main aim was to set up the foundations to the establishment of Networks of Expertise (NoEs).

After completion of JANE1 in October 2024, JANE2 was launched in November 2024. This second stage of the project is also coordinated by INT and involves around 130 participants from more than 25 EU Member States.. The main objective of JANE2 is to, based on the foundational evidence collected in JANE2, establish seven NoEs related to cancer in different areas, including complex & poor prognosis cancer, palliative care, survivorship, personalized primary prevention, omics, hi-tech medical resources and adolescents & young adults with cancer.

Additionally, JANE2 is set out to support National Networks and Comprehensive Cancer Centers (CCCs), with the sister project assigned called EU Network of Comprehensive Cancer Centres (EUnetCCC). The NoEs will serve to promote collaboration and share knowledge and services with healthcare systems across all EU Member States, first to healthcare providers but also directly reaching out to patients. Some of the services that these NoEs aim to provide at the European, national, and local levels include:

- Supporting the development of CPGs and general recommendations for healthcare professionals, patients, and the public.
- Raising public awareness and engaging in advocacy and policy actions.
- Contributing to the development of effective healthcare organisation models, among other initiatives.
- Fostering research and innovation aimed at improving the quality of life of cancer patients

The Work Package 7 corresponds to the establishment of the Survivorship NoE. Throughout its first four years, this network is set to focus on developing a framework and guideline materials to support the implementation of survivorship care programmes in clinics and centers across Europe and guiding them into adopting suitable care models that work in the different cases according to regional and local circumstances.



Rather than creating entirely new resources, the project will build on existing guidelines, recommendations, training programmes, and published documents from various entities and societies. This approach will help establish a solid foundation for promoting high-quality, integrative, and holistic survivorship care, while providing a flexible reference framework adaptable to the diverse contexts of EU Member States. To ensure a comprehensive and effective approach, the initiative includes desk research and a mapping of the current landscape of survivorship care in Europe. These efforts will help identify existing best practices, gaps and the potential variability in healthcare systems regarding how survivorship care is provided across the different countries.

By fostering collaboration and knowledge-sharing, the Survivorship NoE will provide essential tools for healthcare providers looking to enhance long-term care and support for cancer survivors, ensuring a more standardized and accessible survivorship care framework across Europe.

### 3.1 Objectives of the WP7

The first four years of WP7 will focus on achieving the key objectives necessary to establish the foundation of the Survivorship NoE:

1. **Establish the foundation** for a dedicated Survivorship Network of Expertise (NoE).
2. **Expand and consolidate** the Survivorship NoE as part of the broader JANE2 initiative.
3. **Guarantee the involvement of all relevant stakeholders**, including patients, professionals, researchers, and policymakers.
4. **Support transversal collaboration with other JANE2 WPs** through communication and knowledge exchange, **as well as synergies with other related EU-initiatives.**
5. **Conduct complementary actions**, even beyond the original roadmap, to strengthen survivorship care networks, such as participation in out of JANE2 survivorship research initiatives, attend events centered on survivorship that could facilitate new contacts, etc.
6. **Monitor and report on progress** through task-based documentation, including aims, timelines, updates, barriers, and next steps.

### 3.2 Timeline

As shown in the timeline, out of the six tasks within the NoE activities, four have already been initiated and are currently active (Figure 01). Therefore, this document will primarily compile the activities and progress related to Tasks 7.1, 7.2, 7.3 and 7.4 during these first 12 months.



Task	From month	To month
T7.1	1	48
T7.2	1	12
T7.3	4	21
T7.4	10	21
T7.5	21	33
T7.6	21	44

TASK	2024-2025				2025-2026				2026-2027				2027-2028			
	Nov-Jan	Feb-Apr	May-Jul	Aug-Oct												
	M1-3	M4-6	M7-9	M10-12	M13-15	M16-18	M19-21	M22-24	M25-27	28-30	M31-33	M34-36	M37-39	M40-42	M43-45	M46-48
<b>Task 7.1</b> NoE organigram, governance and synergies				MS27				MS28				MS29				MS30
<b>Task 7.2</b> Landscape analysis on current survivorship care across Europe																
<b>Task 7.3</b> Development of integrative survivorship care programme							D7.1									
<b>Task 7.4</b> Capacity-building programme on integrative cancer survivorship care																
<b>Task 7.5</b> Implementation of cancer survivorship care programme																
<b>Task 7.6</b> Evaluation of cancer survivorship program, scaling-up, dissemination and sustainability															D7.2	

Figure 01. Timeline of tasks for the Survivorship NoE

## 4 TASKS

### 4.1 Task 7.1

#### 4.1.1 Key information

- **Objective: NoE organigram, governance and synergies**
- **Task leaders and co-leaders:** SJD and Sciensano
- **Subtasks:**

T7.1.1- Define the structure of the Survivorship NoE

T7.1.2- Assure synergies with other JANE2 NoEs such as AYA and EUnetCCC

T7.1.3- Identify and establish collaborations with other EU initiatives including European networks, projects and research groups

T7.1.4: Define the Survivorship NoE's dissemination plan, performance evaluation framework, and sustainability plan

- **Timeline:** November 2024 – October 2028

#### 4.1.2 Achievements

##### 1. Organigram and governance of the NoE

The Task 7.1 leadership has worked on an initial draft scheme of the organigram and governance operational approach for the NoE (more info in section 4, *Governance*).

##### 2. Strategic priorities

In agreement with the JANE2 Coordination Team, the strategic priorities and the means by which those priorities would be covered were defined on the first few months of the Joint Action landing. Find the full preliminary list below (Table 01). The WP7 leadership intends to use this initial list as a foundation to be refined according to the progress made during this first year, with an updated version to be issued at the beginning of the second year.

Priority	Means
1. Identification & mapping (Task 7.2)	1. Collaboration, research, reviews
2. Inclusive (Task 7.2)	1. Health economics considerations 2. Cost-effective determinants: evidence-based health, lifestyle habits and psychosocial, environmental medicine

<b>3. Development &amp; implementation (Task 7.3, Task 7.5)</b>	<ol style="list-style-type: none"> <li>1. Follow-up determinants</li> <li>2. Consensus meetings</li> <li>3. Development of CPGs</li> <li>4. Pilot settings: track enrollment and participation</li> </ol>
<b>4. Health care providers &amp; patient's education and training (Task 7.4)</b>	<ol style="list-style-type: none"> <li>1. Map training and education programmes</li> <li>2. Coordinate with primary care healthcare professionals</li> <li>3. Patient education – empowerment</li> </ol>
<b>5. Innovation</b>	<ol style="list-style-type: none"> <li>1. Survivors digital information (i.e. EU Passport)</li> </ol>
<b>6. Patient engagement</b>	<ol style="list-style-type: none"> <li>1. Consensus meetings with survivors</li> <li>2. “Right to be forgotten”</li> </ol>
<b>7. Transition to adult care (Task 7.3)</b>	<ol style="list-style-type: none"> <li>1. Consensus meetings with paediatric and adult healthcare systems</li> </ol>
<b>8. Evaluation (Task 7.6)</b>	<ol style="list-style-type: none"> <li>1. Monitor cancer survivorship programme indicators</li> <li>2. Health economics consideration</li> </ol>
<b>9. Dissemination and sustainability (Task 7.6)</b>	<ol style="list-style-type: none"> <li>1. Collaboration with WP2 and WP4</li> </ol>

**Table 01.** Overview of the Survivorship NoE's key priorities and the corresponding means proposed to address them.

### 3. Survivorship NoE's meetings and coordination

As part of the management of the activities and progress of the tasks within the NoE, Task 7.1 is responsible of organizing meetings as well as joining events organized by the JANE2 Coordination Team or by any of the leaders of the core WPs. Part of the role of supervising and aiding in the progress of the tasks is related to identifying synergic projects, policy initiatives or relevant entities or networks that could have a positive impact in the Survivorship NoE. This entails communicating and organizing sessions to present the Survivorship NoE and to bring related initiatives closer together.

This is a list of some of meetings organized and managed as part of Task 7.1 activities in this first year:

- **Internal Survivorship NoE KoM (November 2024):** This was the first event organized among WP7 leaders and coleaders to discuss on the initial plan and vision of the network
- **Assistance to JANE2 KoM Milan (January 2025):** The leaders (SJD) and co-leaders (Sciensano) were actively involved throughout the preparation activities leading up to the Kick-off Meeting (KoM), as well as during the meeting itself, to encourage the participation of all relevant stakeholders attending the event.



- **Monthly meetings with WP7 task leaders (third Monday of each month):** These sessions are conceived to reunite task leaders and have them present the latest updates as well as issues identified in the ongoing activities. The sessions are also leveraged to communicate any relevant information from the NoE leadership (new synergies, updates from the core WPs, etc.).
- **Meetings with Coordination Team and other WPs (first Monday of each month):** Meeting organized by JANE2 coordination team to coordinate and monitor work of the different NoEs and to inform on any relevant information to NoE leaders and coleaders.
- **Ad-hoc sessions:** As the activities within the NoE have started progressing, numerous meetings have been scheduled to address urgent matters related to task advancement.
- **NoE in person meeting (May 2025):** This session aimed to strengthen collaboration among task leaders, identify challenges, and engage all WP7 partners. It gathered 18 representatives from European institutions, and a key outcome was the proposal of a flexible “working definition” of a cancer survivor for the NoE.
- **Synergies:** Since the start of the project, the leader and coleaders of WP7 have been very attentive to any potential identification of synergic projects at the European level and have conducted communications and sessions to help bring these initiatives to collaborate with the NoE in the cases that was required (more info in section 6, *Synergies with the NoE*).
- **Collaborative Stakeholders:** As part of the work within Task 7.1, the task’s leadership has conducted meetings with different entities to introduce them to the NoE’s purpose and activities and to request their interest to join as Collaborative Stakeholders (more info in section 7, *Collaborating stakeholders of the NoE*).

#### 4. First in-person meeting of the Survivorship NoE

During the JANE2 KoM event in Milan, an additional meeting spontaneous between partners of the WP7 was organized in between sessions. At this meeting it was agreed within this group that the NoE would benefit from organizing an in-person meeting during the first year.

The selected day was May 9<sup>th</sup> and the event was hosted in Barcelona by the SJD institution (leaders of the WP7). It brought together 18 representatives from European institutions participating in the NoE and the task leaders and coleaders (Figure 02). The day’s agenda was structured into task-specific sessions in the morning, followed by an open online session in the afternoon, to which all the WP7 partners were invited.

The main objective of the event was to facilitate collaboration among task leaders, identify challenges and barriers, and engage the broader group of partners conforming the General Assembly of the network. One of the key outcomes of the event was the proposal of a “working definition” for a cancer survivor: **“Individuals who have had cancer and have completed active anti-tumor treatment (excluding hormonal therapy).”**

This definition is intended to remain flexible and susceptible to adjustments in the future, while providing a clear and pragmatic basis for establishing a common care framework that can be applied across Europe.



Figure 02. Picture taken at the 1st in-person of the Survivorship NoE event hosted in Barcelona

### 4.1.3 Challenges encountered

In terms of general challenges for the Survivorship NoE and for the Task 7.1, this is the list of the ones identified so far:

- **Fragmentation across initiatives**

The large number of EU-funded projects and initiatives in the field makes it difficult to engage stakeholders effectively and to design a coherent and efficient collaboration plan.

- **Engagement at task level**

Engaging partners at the task level has proven to be time-consuming and complex, requiring significant coordination efforts.

- **Varying levels of preparedness**



There are noticeable differences in partners' experience with Joint Actions, particularly in understanding methodology, timelines, and how to build synergies. These discrepancies also affect how partners approach the generation of materials and outcomes as described in the Grant Agreement.

- **Defining sustainability**

One of the key challenges remains outlining a realistic and viable sustainability plan for the network beyond the initial funding period.

- **Incorporating patient perspective**

The challenge of effectively incorporating the patient's perspective is common across all tasks. Each task remains committed to developing a plan that ensures patient input is meaningfully integrated and aligned with the specific objectives and context of the work.

#### 4.1.4 Deviations in activities and justifications

None identified yet.

#### 4.1.5 Contribution of partners

Task 7.1 leaders have been engaging with the other WP7 Task leaders and helping support their activities as well as identifying all the contacts within the NoE and establishing an initial communication with all of them to request to confirm their participation in the NoE's activities.

Task 7.1 leaders have planned to present the final draft of the NoE's governance structure to both high and low contributors during an interactive meeting. This session will actively involve participants in the decision-making process regarding the configuration of the NoE's organigram, as well as the definition of the roles and functions of the NoE and its constituent bodies.

#### 4.1.6 Activities planned moving forward

1. Continue to support, monitor and evaluate regularly the work conducted by Task leaders in the Survivorship NoE and address any issues promptly
2. Ensure alignment across task leaders with other JANE2 WPs and/or other EU initiatives, also through establishment of Health Policy Platform subgroup on Survivorship
3. Complete the Governance structure and present a plan for functions and role of the NoE
4. Present the plan and governance to HC to involve them in the decision process



5. Identify current gaps in cancer survivorship care, research, and policy across EU Member States and define the added value, roles, and functions for the NoE
6. Develop a plan for setting up national networks that can strengthen regional or local initiatives while aligning them with the broader European objectives
7. Develop a plan to engage patients in all WP7 tasks, ensuring their perspectives are integrated into the development of each task's outcomes

## 4.2 Task 7.2

### 4.2.1 Key information

- **Objective:** Landscape analysis on current survivorship care across EU
- **Task leaders:** IGG
- **Subtasks:**

T7.2.1: Map existing survivorship programmes across EU countries

T7.2.2: Chart age, tumour- and treatment-specific current guidelines for survivorship care

T7.2.3: Perform a health economics study on the financial toxicity of cancer survivors and their families

- **Timeline:** November 2024 – October 2025

### 4.2.2 Achievements

#### 1. Defining methodology and plan for the task

Following a preliminary literature review aimed at identifying previous studies with objectives aligned to those of this task, a number of relevant works were analyzed. Based on this assessment, it was determined that the most appropriate approach to perform a comprehensive landscape analysis in a timely approach would be the development of a structured questionnaire designed to collect targeted information on survivorship care programmes currently active across different organisations, as well as on related research activities and potential existing survivorship within regions/countries and across Europe. For this task it was determined that the best way to perform a landscape analysis would be to use a survey with questions related to survivorship care, as well as research in the area and potential existing survivorship networks across Europe. Since the respondents, identified among JANE2 partner institutions (high and low contributors, observers and stakeholders) will include four types of entities—research centers, clinics, patient advocacy groups, and scientific societies—it was decided to prepare a general introductory section with questions aimed at identifying the respondent and their



affiliated organisation. This will be followed by four tailored blocks of questions, each specifically designed for one of the four entity types.

## 2. Survey preparation and EUnetCCC synergy

From the very start of this effort, a potential synergy with a task within the sister Joint Action EUnetCCC was identified. As a result the IGG team established a collaboration plan to align efforts where possible. At the time of the first communications between projects, EUnetCCC team leading of Task 8.2.7 within WP8 was configuring a survey around survivorship care to be sent across the participants of the task. Given the shared focus of the surveys and also the fact that some entities were present in both JAs, it was agreed to develop similar content and to avoid sending it twice to entities involved in both projects. However, since some of the more detailed objectives differed between the projects, it was decided to develop two separate surveys per Joint Action. One survey, for EUnetCCC, is shorter and specifically focuses on survivorship care and services at clinical centers. The other, for the JANE2 Survivorship NoE, is more comprehensive but includes the same Clinical Center questions as those in the EUnetCCC survey. This approach allowed both initiatives to benefit from the results. To develop this coordinated plan and ensure both initiatives remained aligned, several joint meetings were scheduled between the teams. However, according to the respective Gantt Charts, the EUnetCCC deadline preceded that of JANE2, thus concordance between the two surveys was not 100%.

As per the surveys structure the following 5 sections (structured in 15 modules) were included:

1. General Information (common to both EUnetCC and JANE2 surveys)
2. Organisation specific
  - Clinical center (common to both EUnetCC and JANE2 surveys)
  - Research Center
  - Scientific Society
  - Patient Advocacy Group
3. Survivorship Networks
4. Challenges & Barriers (common to both EUnetCC and JANE2 surveys)
5. Health Economic Study (financial toxicity)

Before distributing the JANE2 survey with the partners, the Task 7.2 leaders conducted a meeting with 25 high and low contributors to their task. The purpose of the session was to present the draft survey and gather feedback. All input received was consolidated into a document and taken into account to generate the finalized version. This last version was presented to all task leaders and finalized during the first in-person meeting of the NoE held in Barcelona in May 2025.



The survey was developed in English to ensure consistency across participating countries and organisations. It was implemented using the LimeSurvey platform, an open-source online survey tool that enables the design of structured questionnaires featuring a wide range of question types and logic options. LimeSurvey was selected for its flexibility and compliance with data protection requirements. The platform was kindly provided by the WP co-leader, Sciensano. The complete structure of the survey comprised a total of 201 questions with conditional logic applied according to respondents' answers. This facilitated the creation of a user-friendly interface for respondents from diverse organisational backgrounds and countries, as well as the systematic collection and export of data in standard formats for subsequent analysis. An invitation letter was prepared to accompany the survey link when shared with partners. The survey was officially launched on the 15<sup>th</sup> May 2025.

### **3. Circulation of the survey**

Given the absence of an official mailing list and the difficulty of obtaining contact details of survivorship experts across Europe due to privacy constraints, the initial sample was drawn from institutions participating in JANE2 WP7. The subsequent recruitment relied on the logarithmic expansion characteristic of the snowball sampling method.

Eligible for participation in the survey were:

- JANE2 WP7 institutions (69 organisations)
- Additional candidates suggested by WP7 partners (snowball sampling, theoretically unlimited)

The survey was distributed via an invitation letter sent by email, followed by three reminder messages to maximize participation.

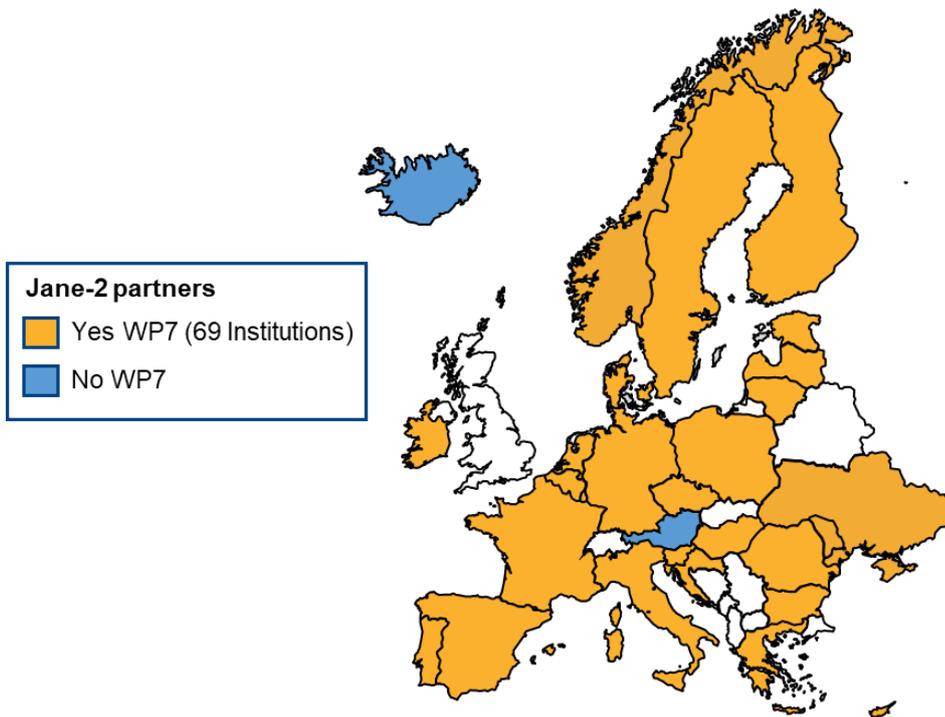


Figure 03. Map of EU countries with at least one institution represented in WP7

After the official launch of the survey on 15<sup>th</sup> May 2025 and the third and final reminder sent on 17<sup>th</sup> July 2025, the questionnaire was officially closed on 31<sup>st</sup> August 2025, in accordance with the timeline established in the project Gantt chart.

#### 4. Analysis of participation rate

Responses were recorded in real time (for both JANE2 partners and “snowball” institutions) through the LimeSurvey platform, allowing for coordinated tracking of reminders and follow-up with non-respondents. Preliminary data on response rates were presented monthly during WP7 leaders’ meetings, enabling continuous monitoring and timely actions to ensure adequate coverage.

Upon completion of the data collection phase, responses were exported in Excel format. Both fully completed questionnaires and those only partially completed (but with >50% of questions answered) of the total items were included in the dataset for subsequent analysis. This approach maximised the use of available data while maintaining an acceptable level of completeness.

At the closure of the questionnaire, of the 69 partner organisations included in the Survivorship NoE, 54 responded, resulting in a 78% response rate. Both JANE2 and EUnetCCC partners achieved full participation (19 out of 19, 100%). Among “only JANE” partners, response rate varied by level of contribution to T7.2. In more detail it was 100% (10/10) for HC, 63% (7/11) for LC and 60% (6/10) for Observers and 100% (5/5) for Stakeholders. Moreover 7/14 (50%) of non-task 7.2 contributors



provided responses. Following this initial step, an additional 30 responses were collected through snowball sampling, resulting in a total of 84 organisational responses.

## 5. Survey results

Survey results started to be analyzed by Task 7.2 at the beginning of September 2025. The survey explored how respondents define cancer survivorship in practice, the scope and organization of survivorship care, and the frameworks guiding service delivery. It also examined the age groups addressed, the professional profiles involved, and the general alignment with international, national, or institutional guidance.

The results outlined the landscape of survivorship programmes in clinical cancer centers, highlighting variations in organization, multidisciplinary involvement, and service availability across the life course. Core clinical follow-up emerges as a central component, complemented by a range of supportive services addressing psychosocial, rehabilitative, and preventive needs. Regarding the survivorship research activity, the survey results showed the thematic areas of focus and the role of scientific societies in supporting and collaborating on this work. Many of the responses evidenced the discrepancies between pediatric and adult survivorship models, reflecting historical developments and structural factors within oncology. As part of the responses retrieved, there was information to help understand the role of patient advocacy groups within the survivorship community, by conducting educational and training activities, and promoting the establishment of survivorship networks. Collectively, the survey results provided a high-level overview of current survivorship efforts, emphasizing scope, themes, and organizational approaches and identified areas where coordination, education, and structured support remain underdeveloped.

### 4.2.3 Challenges encountered

In terms of challenges identified for the Task 7.2:

- **Lack of access to a comprehensive mailing list**

At the moment of deciding about the dissemination list for the survey, Task 7.2 leaders recognized there was no comprehensive one including most of the European clinical centers. Ideally, this process might have been facilitated through collaboration with national or European scientific societies, which could have provided access to their mailing lists or identified institutions actively involved in survivorship. However, time constraints and privacy and informed consent regulations impeded us to access an already established mailing list. Hence, it was decided to first circulate the survey among JANE2 partners counting on an exponential increase of contacted centers through the snowball sampling method, which however allowed only 30 additional responses. This fact led to

a possible uneven country representation having received sometime only one answer from very large and populated countries, and many more from small and less populated ones.

- **Survey Inconsistencies Between JANE2 and EUnetCCC**

Certain questions included in the JANE2 survey were not present in the EUnetCCC version. As a result, the team had to re-contact some of the JANE2 centers participating in EUnetCCC to try to collect the missing data from some of the survey sections (Survivorship Networks and Health Economic Study).

- **Ambiguity in the Definition of “Network”**

In the process of drafting this landscape analysis questionnaire, the definition of “network” as reported in the JANE2 application (“a NoE provides services to the cancer community, first to health care providers directly reaching out to patients. NoEs should formally incorporate other entities in addition to health care providers, i.e. scientific and professional societies, patient advocacy groups, research institutes devoted to items such as molecular biology, public health, health economics, etc.”) was considered as too stringent. It was then decided to leave to the interpretation of the respondents their understanding of a network. This ambiguity may have affected how respondents interpreted and answered related questions within the survey. For example, some respondents referred to the International Guidelines Harmonization Group as a survivorship network, but it was concluded that a more appropriate definition for this group would be of a scientific working group aiming to provide guidelines to be adopted by networks.

- **Technical issues, Data Cleaning and Harmonization Delays**

The process of cleaning, aligning, and harmonizing survey responses for further analysis took more time than initially anticipated. The raw data extracted from the LimeSurvey platform required extensive cleaning, particularly in the free-text fields, where responses often needed to be standardized or manually coded for consistency.

In addition, it was necessary to align the responses obtained from the EUnetCCC questionnaire, as some questions were structured slightly differently compared to those in the survey. This step required careful cross-referencing to ensure the comparability of datasets.

Finally, during the distribution phase, a technical issue was identified in the design of some tables, which initially did not allow for multiple answers. Although this issue was corrected, it led to a

temporary misalignment in the database, further delaying the data harmonization and validation process.

- **Incorporating patient perspective**

The challenge of effectively incorporating the patient's perspective is common across all tasks. Each task remains committed to developing a plan that ensures patient input is meaningfully integrated and aligned with the specific objectives and context of the work.

#### 4.2.4 Deviations in activities and justifications

No major deviations occurred in T7.2 related activities. Regarding the health economics study described in the grant agreement, Task 7.2 leaders could only rely on answers to the economic-specific section of the questionnaire (S5) and to an additional specific question targeted to Patients advocacy groups. Due to time constraints it was not possible to go into more detail regarding this part, and more importantly the lack of survivor-specific participants, which would have entailed an approval of an ethics committee, limited the capacity to collect more specific information. While the level of detail may be limited, the findings are still expected to offer valuable insights into the current landscape of health economics in survivorship care at the EU level. This can contribute to a broader understanding of the economic implications and inform future, more targeted analyses.

#### 4.2.5 Contribution of partners

The task 7.2 leader, IGG, worked in close collaboration with leaders of the Survivorship NoE (SJD and Sciensano), as well as with leaders of the Survivorship task in EUnetCCC. After several consultation rounds, during monthly web conferences, the final draft was approved in the Barcelona meeting with all task leaders, with the addition of few questions addressing training and education programmes to be included in Task 7.4.

Regarding active participation in the survey, the response rate among High Contributors and Stakeholders was 100%, and 70% among Low Contributors.

#### 4.2.6 Use of resources

Sciensano provided the LimeSurvey platform used to design, host, and distribute the questionnaire which was developed by IGG.

#### 4.2.7 Activities planned moving forward

1. Complete the data analysis of the survey responses received

2. Present data to the rest of task leaders during one of the upcoming NoE's Monthly meeting
3. Engage with Tasks 7.3 and 7.4 to ensure that survey results are effectively communicated and incorporated where beneficial to their outcomes
4. Explore the possibility of developing a scientific publication from the survey results
5. Assess gaps and identify areas for further investigation

### 4.3 Task 7.3

#### 4.3.1 Key information

- **Objective:** Development of integrative survivorship care programme
- **Task leaders:** ACC
- **Timeline:** February 2025 – July 2026

#### 4.3.2 Achievements

##### 1. Development of the Task methodology

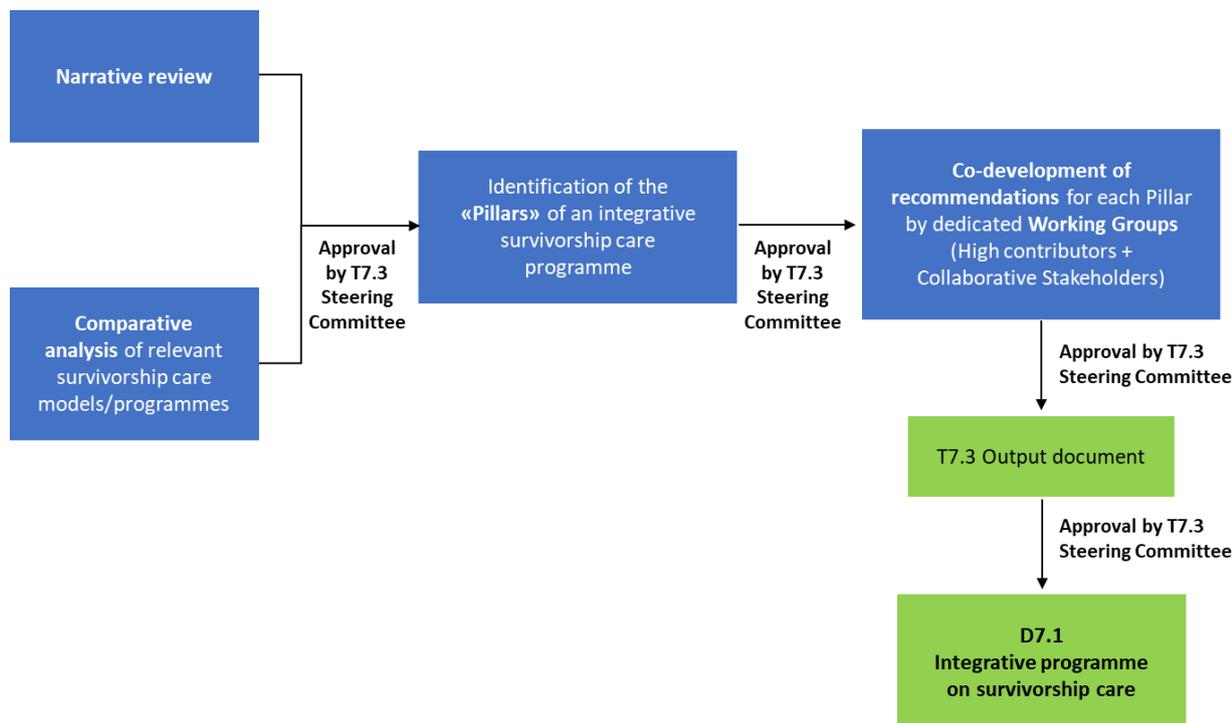
As a first approach to Task 7.3, the task leaders defined the scope and objectives of the task. The main objectives outlined were:

- a. Gather evidence about existing frameworks of survivorship care worldwide by conducting a narrative review from diverse sources of information, to inform the structure and content of an integrative survivorship care programme.
- b. Co-develop recommendations/statements outlining a comprehensive and flexible programme on survivorship care. Such activity will extensively involve the NoE high contributors and collaborative stakeholders in a co-creation approach.
  - Achieve a consensus on the proposed recommendations among survivorship care experts representing both European patient advocacy associations covering all survivors' age groups (children, AYA, adults) and European scientific societies (such as ESMO and SIOPE).

In line with the aforementioned objectives, the Task methodology was structured around two subtasks:

T7.3.1: Review of the existing frameworks on cancer survivorship care and comparative analysis

T7.3.2: Co-development of recommendations for a European integrative programme on survivorship care with experts among JANE-2 contributors, collaborative stakeholders, patient advocacy associations and scientific societies with a European scope. Overall, the methodology underlying the work plan of Task 7.3 will follow the steps highlighted in the representation below (Figure 04).



**Figure 04.** Schematic outlining Task 7.3 methodology.

A **T7.3 Steering Committee** was established according to the following criteria:

#### Membership

Members of the Steering Committee will include:

- The Task Leaders of the JANE-2 Work Package 7 (NoE on Survivorship);
- Representatives of European Patient Advocacy Associations covering all age groups (children, AYA, adults): CCIE, YCE, and the former president of ECPC.
- Representatives of European Scientific Societies (ESMO and SIOPE).

#### Roles and responsibilities

The Steering Committee will be involved in all stages of the consensus document preparation. Its responsibilities will include:

- Reviewing the relevant evidence collected by the Task 7.3 leader (ACC) and the Task methodology;
- Reviewing the preliminary framework and key pillars of a European survivorship care programme proposed by ACC;
- Reviewing and refining the initial set of statements drafted by the Task 7.3 High Contributors under the coordination of ACC;
- Reviewing and approving the final version of the survivorship care programme (T7.3 output).

The recommendations outlining the survivorship care programme will be formulated in a collaborative fashion by establishing dedicated **Working Groups** for each identified “pillar” (or core component) of

the survivorship care programme. Task 7.3 high contributors were assigned to specific Working Group(s) according to the preferences they expressed in a dedicated survey circulated by ACC. The work of the Working Groups is proceeding in parallel on each pillar and is being coordinated by ACC, who is providing a preliminary structured document (with bibliographic references) to be discussed and refined. The documents resulting from the different Working Groups will be submitted to the Steering Committee for revision and approval.

## **2. Narrative review of the existing frameworks on cancer survivorship care**

This subtask consisted of a narrative review integrating clinical guidelines, consensus statements, peer-reviewed literature, and national survivorship care programmes. A structured search was conducted to identify international clinical guidelines and European consensus documents on survivorship care, drawing primarily from major oncology and supportive care societies (ESMO, ASCO, MASCC) and European collaborative initiatives (EPAAC, iPAAC, CANCON, PanCareSurFup), supplemented by expert-suggested references. Guidelines and consensus statements published within the last 15 years were selected, resulting in the inclusion of 10 key documents that collectively represent the main international policy and professional guidance shaping survivorship care between 2011 and 2025. To complement this grey literature, a systematic search of EMBASE was performed using a predefined query focused on national survivorship care programmes and models, limited to high-level evidence. After screening 345 records and applying inclusion and exclusion criteria, 33 studies were retained for analysis, with the selection process documented through a PRISMA flow diagram. Finally, a reference-based mapping approach was applied to identify and compare established national survivorship care programmes across different health system contexts. In total, 11 national programmes were identified and analysed to highlight common frameworks, strengths, and limitations in the organisation of survivorship care worldwide.

## **3. Comparative analysis across different national survivorship care programmes**

Task 7.3 leaders analysed 11 national cancer survivorship care programmes, highlighting substantial variation in scope, organisation, and maturity across countries. The UK, Australia, Canada, the USA, and the Netherlands emerged as the most advanced frameworks, characterised by integrated, patient-centred survivorship models linking oncology, primary care, and supportive services. These programmes emphasise personalised survivorship care plans, multidisciplinary coordination, psychosocial support, patient education, and systematic quality monitoring. The UK and the Netherlands stand out for their highly systematised approaches, supported by centralised governance, risk-stratified follow-up, digital tools, and routine use of patient-reported outcomes. Australia and Canada have robust national guidelines and shared-care models, but implementation remains

heterogeneous due to federated health systems and regional variability. The USA pioneered survivorship care planning and patient navigation models, yet delivery is fragmented and influenced by institutional and insurance-based differences. Other countries, including New Zealand, Denmark, Singapore, Ireland, Germany, and Japan, have implemented partial or programme-specific initiatives, often lacking comprehensive national coordination or consistent access. Overall, while there is strong convergence around core principles of survivorship care aligned with international guidelines, substantial divergence persists in governance, resource allocation, and real-world implementation across health systems.

#### 4. Identification of seven pillars for the development of the Survivorship Care Programme

Building on the previous steps, seven core elements—or “pillars”—of survivorship care were identified and defined. These pillars represent the essential components consistently highlighted across advanced national frameworks and professional guidance as critical to high-quality survivorship care. From an implementation perspective, these seven pillars were categorised into four overarching types to facilitate practical application:

- **Care pillars** outlining what care services and support mechanisms are needed to address survivors’ needs.
- **Infrastructure pillars** addressing how the services should be delivered.
- **Enabler pillars** focusing on the tools that could enhance the programme’s implementation by facilitating documentation, follow-up adherence, and accessibility in underserved areas.
- **Evaluation pillar**, ensuring that the programme addresses survivors’ needs in an accountable and transparent fashion, by providing measurable key performance indicators which allows for monitoring and improvement of the services.

##### 4.3.3 Challenges encountered

- **Conceptual Divergences:**

Early discussions revealed differing interpretations of key terms such as “model” versus “programme,” highlighting the need for shared conceptual clarity before progressing to content development. Such different views were openly discussed during monthly NoE meetings and Steering Committee meetings. Explanatory documents were shared by ACC as the Task was progressing, and comments and suggestions from Task leaders were further discussed and integrated.

- **Initial difficulty to involve High and low contributors in the first months, before the Task methodology was clarified**

The complexity of the outcome that Task 7.3 aims to deliver made it difficult to plan a clear strategy to involve high and low contributors to the task in the first months. After dedicating time to brainstorm on this issue a specific plan that organized the work and the involvement of the partners at different levels was outlined and launched.

- **Difficulty in envisioning the task's output**

Given the ambitious nature of its objectives, defining the final output requires careful consideration as it needs to avoid duplicating existing initiatives. The added value of the outcome is that the recommendations should remain pragmatic and designed to enable the piloting of the reference programme as part of Task 7.5 implementation.

- **Incorporating patient perspective**

The challenge of effectively incorporating the patient's perspective is common across all tasks. To ensure patient input is meaningfully integrated and aligned with the specific objectives and context of the work:

- Major European patient associations (CCIE, YCE) were invited to join the Steering Committee;
- National patient associations (KOKT, AECC) were invited to join the Working Groups as collaborative stakeholders. The Italian patient association FAVO (among the NoE's observers) is participating in the Working Groups as well.

#### 4.3.4 Deviations in activities and justifications

None identified yet.

#### 4.3.5 Contribution of partners

Initially, an internal survey was sent to Task 7.3-contributing partners (high & low contributors, as well as observers) to assess in which specific subtasks they wished to contribute and how. For that survey and overview of all Task 7.3 subtasks was provided. The survey was launched on March 28th and closed on April 25th. A total of 22 responses were collected and used in the following months to plan out the methodology of the task and the involvement of the contributing partners.

After Task 7.3 leaders had completed the initial steps of the first subtask, they scheduled a first online meeting with all contributors in September 2025. During the meeting, Task 7.3 leaders gave an update

on the task's timeline, work plan and initial findings. During the meeting, the inputs made by partners were gathered.

The involvement of partners is expected at different levels:

- **High contributors and Collaborative Stakeholders:** Active participation in update meetings; Engagement in Working Groups delving into each pillar to co-develop the statements outlining the survivorship care programme; Review the final document. As previously mentioned, Task leaders and some collaborative stakeholders (European scientific societies and patient associations) were also invited to join the Task Steering Committee.
- **Low contributors** will participate in the meetings organized to share updates on the task advancement and will be asked to review the final output document.
- **Observers** will also participate in the meetings organized to share updates on the task advancement.

#### 4.3.6 Activities planned moving forward

1. Continue developing the recommendations regarding each Pillar of the survivorship care programme within the established Working Groups.

Get the approval of the Steering Committee established within the scope of the Task.

### 4.4 Task 7.4

#### 4.4.1 Key information

- **Objective:** Capacity-building programme on integrative cancer survivorship care
- **Subtasks:**

T7.4.1: Map training and education programmes for pediatric and adult cancer survivors, their caregivers and healthcare professionals.

T7.4.2: Elaborate capacity-building programme and provide training for healthcare professionals across the EU for survivors of all ages and cancer types

T7.4.3: Elaborate capacity-building programme and enhance health literacy of patients and caregivers. To empower them with knowledge for an improved, integrative and more comprehensive survivorship care.

- **Timeline:** August 2025 – July 2026



## 4.4.2 Achievements

### 1. Development of the methodology

As part of Task 7.4 initial work, leaders of the task defined the methodology, which followed the steps according to the defined subtasks:

- I. Identify and map education programmes on survivorship: The team is planning to conduct an initial literature review, including non-published local-level initiatives, patient/caregiver experiences in combination with the analysis of the answers of the CB section within the Task 7.2 survey
- II. Evaluate the identified programmes: This step will include analyzing the materials found to identify strengths and limitations, scalability, and adaptability across the different settings/countries. This review phase will also seek to understand the cancer-specific coverage of any of the identified CB programmes.
- III. Highlight general gaps and facilitators in the education programmes identified that could be useful to use as reference at the EU-level: Once the previous analysis is performed the team will identify most common gaps and facilitators present in the identified CB programmes.
- IV. Provide recommendations to build CB programme: For this end, the team will compile a repository of publicly available educational programmes, and then provide recommendations (essential elements for the educational programmes for the NoE's). Lastly the team is planning to test implementation (options: cancer-specific, age-specific, modular formats, suggested curriculum)

### 2. Initial literature review and selection of the relevant materials

The first bibliographic searches to identify educational programmes for healthcare professionals and PCPs were conducted in the Pubmed and Google Scholar databases. The article types selected were Review, Systematic Review, Meta-Analysis and Clinical Trial Strategy. In addition to this search, Task 7.4 leaders collaborated with Task 7.3 leaders to identify additional materials that covered educational programmes for PCP and Survivors. The final list of items identified was 31 (24+7).

## 4.4.3 Challenges encountered

- **Limited Availability of Survivorship-Focused Educational Programmes**

A major challenge was the limited number of existing educational or training programmes specifically addressing cancer survivorship, particularly for primary care providers and other healthcare professionals involved in follow-up care.



- **Grey literature**

The literature searches were conducted exclusively within the PubMed and Google Scholar database, which, while comprehensive in terms of peer-reviewed biomedical publications, inherently limits the scope of materials identified. Many educational programmes—especially those developed by professional associations, non-governmental organisations, patient advocacy groups, or local healthcare systems may not be formally published in academic journals. As a result, potentially valuable grey literature or practical, field-tested training programmes were not captured in this review.

- **Need to agree how the CB programme should be defined and configured**

For the Survivorship NoE, and given that different centers, clinics, and organisations may conceive and organize capacity building in diverse ways, Task 7.4 needs to reach an agreement on the precise definition of the Capacity Building (CB) Programme to be delivered, as well as the levels that will form part of it.

- **Incorporating patient perspective**

The challenge of effectively incorporating the patient’s perspective is common across all tasks. Each task remains committed to developing a plan that ensures patient input is meaningfully integrated and aligned with the specific objectives and context of the work.

#### **4.4.4 Deviations in activities and justifications**

During the initial discussions with partners, the team identified the need to define the CB programme to be developed. This definition would serve as a base to work on the different levels of the programme and to reach consensus on this topic Task 7.4 leaders will plan on a session with partners of the task.

In parallel, since a good number of CB programmes might not be found through the traditional academic or commercial publishing channels, the task will be looking at the grey literature through the collaboration with contributors of their task. The team expects that health centers with well-established survivorship care services will potentially have CB materials that can serve as good reference and would not be found otherwise on a bibliographic search.

#### **4.4.5 Contribution of partners**

Task 7.4 leaders scheduled a meeting on September with their tasks high contributors, to present and discuss the methodology envisioned for the task. During the meeting the Task 7.4 leadership presented the materials identified after the Pubmed literature review in two excel spreadsheets: one for the publications related to survivorship training programmes for health providers and other for publications related to survivor educational programmes. In addition, the session included a Q&A



session to respond to some questions by the partners and incorporated their feedback into the methodology or the outcome.

After that initial meeting, Task 7.4 leaders sent a communication to task's high contributors to explain the next steps and request each of the partners to review a set of publications.

#### 4.4.6 Activities planned moving forward

- Complete the review process of the articles identified in the Literature review
- Plan a strategy for collecting grey literature, through Task 7.2 survey and directly through inquiring Task 7.4 partners
- Analyze the list of different CB materials collected to identify gaps/facilitators of the different CB programmes identified that can serve as good reference at EU-level, also, in alignment with Task 7.3 initial outcomes

### 4.5 Task 7.5 (not initiated yet)

#### 4.5.1 Key information

- **Objective:** Implementation of cancer survivorship care programme
- **Task leaders:** ULSSM
- **Subtasks:**

T7.5.1: Define pilot use cases for implementation of survivorship programme

T7.5.2: Define the guidelines for adoption and implementation

T7.5.3: Define guidelines for data collection procedures

- **Timeline:** May 2026 – July 2027

### 4.6 Task 7.6 (not initiated yet)

#### 4.6.1 Key information

- **Objective: Evaluation of cancer survivorship programme**
- **Task leaders and co-leaders:** VHIO and OUS
- **Subtasks:**

7.6.1: Define the variables and evaluation criteria of the integrative survivor care programme and its implementation

T7.6.2: Monitor cancer survivorship indicators in use cases



T7.6.3: Generate an updated health-economic assessment

T7.6.4: Dissemination of the survivor care programme among healthcare professionals, patients and caregivers

- **Timeline:** May 2026 – July 2028



## 5 GOVERNANCE OF THE NOE

One of the key elements to conform the Survivorship NoE is to define its organigram and its governance. As a network that is aiming to represent at a pan-European level the expertise around survivorship but considering also the national level networks to sustain it, there are several elements that need to be included to facilitate the organisation's structure and functions.

We are considering that the Survivorship NoE will be governed through several interconnected bodies. The General Assembly, composed of all members of the NoE, will be the main decision-making forum, contributing to the roadmap, governance and strategic plans, and meeting annually. The Steering Committee will oversee the management, coordination and implementation of activities. Advisory support will be provided by different specific advisory boards such as a Scientific and Professional Board and a Patient Board. As mentioned in Task 7.1 section, the governance structure is currently being developed and will be further discussed in the coming months between the WP7 leadership teams and the Task 7.1 partners, with the goal of producing an updated and refined version.

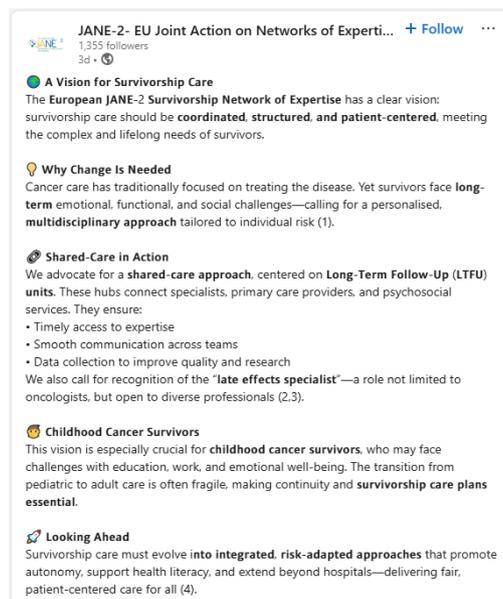


## 6 DISSEMINATION ACTIVITIES

Effective dissemination and communication strategies are essential components of any EU-funded Joint Actions such as JANE2, ensuring that outcomes, objectives, and impacts reach relevant stakeholders and the broader public. In this context, the Survivorship NoE leadership within JANE2 has actively engaged in a range of dissemination activities to enhance visibility and outreach.

On the day of the project's Kick-off Meeting, WP7 leadership helped with the conduction of several dissemination actions, including conducting video interviews and preparing dedicated posts for LinkedIn and Bluesky to highlight the event and its significance. Beyond the Kick-off Meeting, the NoE has worked on drafting content to be published on both platforms. These publications often featured the latest developments within the NoE, such as the first in-person meeting of the Survivorship NoE, in an attempt to reach out to partners and potential stakeholders (access post [here](#)).

More recently, on October 2025, the NoE created and shared content to outline the NoE's vision and perspective on survivorship care and the expected EU-level impact of these collaborative efforts (access post [here](#), Figure 05).



**References**

1. Loonen JJ, Bijllevens NMA, Prins J, et al. *Int J Integr Care*. 2018.
2. Van Kalsbeek RJ, Mulder RL, Haupt R, et al. *Eur J Cancer*. 2022.
3. Oeffinger KC, McCabe MS. *J Clin Oncol*. 2006.
4. Jankovic M, Haupt R, Spinetta JJ, et al. *J Cancer Surviv*. 2018.

#JANE2 #EU4Health #HaDEA #EUHealthNetworks

Model of Personalized Cancer Survivorship Care  
(modified from Loonen JJ et al., 2018)

45 10 reposts

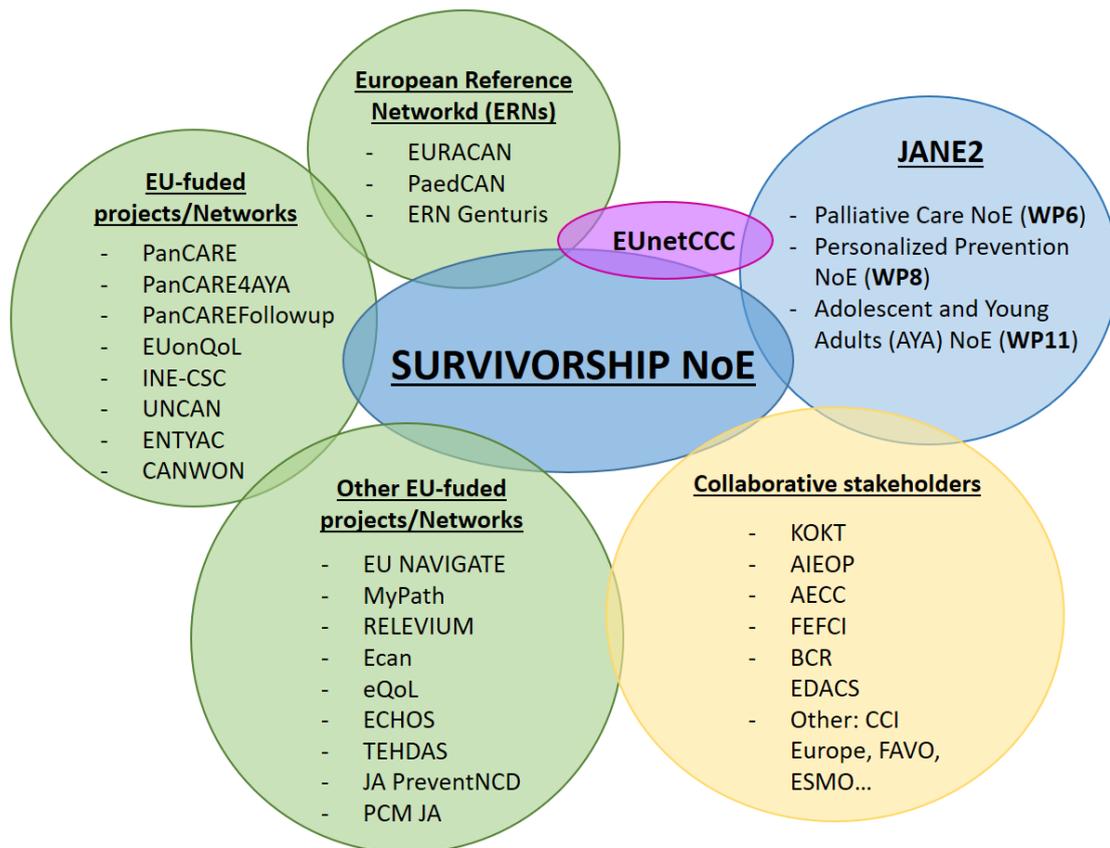
Celebrate Comment Repost Send

Figure 05. Post published in LinkedIn on October 2025

Finally, the WP7 leadership has contributed with tailored content about the NoE’s latest advancements to the JANE2 Newsletter, further reinforcing the NoE’s commitment to clear, strategic, and continuous communication across multiple channels.

## 7 SYNERGIES WITH THE NOE

As the JANE2 project started its progress into the different activities of the tasks and meetings with the different partners started to take place, ongoing and new initiatives started to be identified and the first connection with them took place. As of September 2025, there have been a total of around 18 EU-initiatives that are somehow related with the Survivorship NoE (Figure 06).



**Figure 06.** Representations of synergies with the Survivorship NoE

In this first 12 months, WP7 leadership has conducted meetings with representatives from many of these projects. In some cases, a collaboration on specific tasks and activities between the teams was established. Find below summarized some of the most relevant synergies established.

1. **EUnetCCC:** Facilitated through Sciansano, this synergy prompted a collaborative preparation between both Joint Actions on the survey to be circulated as part of task 7.2.
2. **Pancare and PanCare4AYA:** Facilitated by the IGG and OUS teams, this synergy has established a collaboration to send PanCare4AYA leaders any outcomes derived from the NoE's activities
3. **INE-CSC:** Facilitated through ULSSM, this synergy has a great potential to facilitate the work to be performed by Task 7.3 and Task 7.4.



4. **WP6, WP8 and WP9 within JANE2:** These synergies, especially with WP8, has a great potential of collaboration with Task 7.3 and Task 7.5.

## 8 COLLABORATING STAKEHOLDERS OF THE NOE

As per the Grant Agreement, inclusion of Collaborative Stakeholders was foreseen since the beginning of JANE2 to ensure participation of entities that were not included in the consortium but that would have a very positive impact if incorporated to the NoE. As part of the work within Task 7.1, leaders of the task have conducted meetings with different associations reflected in table to ensure their participation in the NoE as Collaborative Stakeholders. Their inclusion required clarifying the details of their participation at the task-level and also supporting their assessment to request fundings.

To date, the list of Collaborative Stakeholders contacted and requested to join the Survivorship NoE is summarised in Table 02.

Name of entity	Acronym	Country	Involvement in tasks
Ending Discrimination Against Cancer Survivors	<b>EDACS</b>	Belgium	All tasks
Associazione Italiana di Ematologia e Oncologia Pediatrica	<b>AIEOP</b>	Italy	T7.2, T7.3, T7.4, T7.5
Belgian Cancer Registry	<b>BCR</b>	Belgium	T7.5, T7.6
Kom op tegen Kanker	<b>KOKT</b>	Belgium	T7.2, T7.3, T7.4
Federación Española de Familias de Cáncer Infantil	<b>FEFCI</b>	Spain	T7.1, T7.2, T7.4, T7.5
Asociación Española Contra el Cáncer	<b>AECC</b>	Spain	T7.2, T7.3, T7.6

**Table 02.** List of Collaborative Stakeholders incorporated to the Survivorship NoE

## 9 SUSTAINABILITY

Sustainability is a key aspect of any initiative, and this principle equally applies to the project to establish a Network of Expertise (NoE) in Cancer Survivorship. One of the main challenges is to understand how the services offered within the NoE can provide the greatest benefit and ensure that all the activities are firmly grounded in meeting the needs of the survivorship community. To achieve this, it is essential to engage all relevant stakeholders, including healthcare professionals, cancer scientific societies, and—most importantly—cancer survivors themselves. The rationale and future direction of the NoE will be shaped through a consultative and interactive process involving Task 7.1 partners and patient representatives, ensuring that the network’s services reflect real and prioritized needs.

This approach will also build on the ongoing work of WP4, which aims to support NoE leaders in applying methodologies based on the previous knowledge and facilitating processes to help networks implement recommendations. The steps that are being followed in collaboration with WP4 team are:

### 1. Mapping and assessing stakeholder needs

The Survivorship NoE’s leadership worked on the identification of all potential stakeholders from the survivorship community that could at some point benefit, collaborate or contribute to the NoE’s activities.

Once the list of 40 stakeholders was refined, each entity was categorized by type, including patients and the public, healthcare professionals and providers, public health agencies, policymakers, industry representatives, and others. Within these categories, the specific roles of stakeholders were defined, distinguishing between users, partners, and customers of the NoE.

As a next step, the WP4 team has begun the assessment of the needs of the stakeholders included in the list, to prioritize the NoE’s potential service rollout according to the needs of end-users. After this step, an initial version of the NoE service portfolio will be drafted, reflecting the expectations and requirements identified through this stakeholder mapping process.

### 2. Validating the NoE service portfolio

For this step, a validation workshop with Survivorship NoE leaders and co-leaders will be conducted to refine the service portfolio, align services with stakeholder needs, map partners’ capacities, and assess feasibility to ensure practical implementation across cancer networks and institutions.

### 3. Defining sustainable business models

WP4 team will support the Survivorship NoE in developing a sustainable business plan following a procedure that includes the use of Business Model Canvas, the analysis of stakeholder contributions and



the review of the infrastructure, customers and financial aspects that will ensure service continuity beyond the project.

**4. Exploring strategic partnerships to support the implementation of the NoE's business plans.**

This task will identify and explore key partnerships to support the Survivorship NoE sustainability through investment and collaboration, using interviews with leaders and structured engagement with representatives from the EU Member States, industry, associations, and other existing cancer networks to maximize synergies and implement the outlined business plans.



## 10 USE OF RESOURCES

The use of resources during this reporting period for the different entities participating in the Survivorship NoE aligns with the project's planned objectives and expected progress. Overall, the distribution of efforts across partners has remained consistent with the approved work plan, with one notable exception related to the leadership of Task 7.6. Following a specific request from the original Task 7.6 leaders to step down from this role, the WP7 leaders initiated a search for suitable candidates. By January 2025, both VHIO and OUS expressed their readiness to jointly assume leadership of this task. Consequently, the WP7 leadership collaborated closely with the JANE2 coordination team to reorganize the budget distribution among partners, decreasing the allocation initially planned for the former Task 7.6 leader and increasing the budget for VHIO and OUS. These changes will be reflected in an upcoming amendment.

For all other entities involved in WP7, no deviations from the initially planned resource allocations have been made, and current use of resources remains aligned with the expected progress within the Survivorship NoE.

Of note, the JANE2 coordination team has offered a dedicated funding amount per NoE (100,000 EUR) to facilitate the incorporation of external Collaborative Stakeholders, and several are expected to be integrated during this first year (more info in section 8, *Collaborative Stakeholders of the NoE*). Since this additional funding only became available after the signing of the Consortium Agreement, the NoE leadership teams (SJD and Sciensano) have been facilitating the process of assigning and transferring the allocated budget to those Collaborative Stakeholders who requested financial support.

## DOCUMENT INFORMATION

**Milestone lead partner: SJD & Sciensano**

**Contributing partner(s): IGG, ACC, NKUA**

**Work Package: WP7 (Survivorship NoE)**

**Task: Annual activity report**

**Due delivery date: M12 – November 30th**

**Actual delivery date: M12 – November 30th**

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### Revision History

Version no.	Date of issue	Author(s)	Brief description of change
<b>0.1</b>	14.10.2025	Ío Rivera	Drafting of the first document
<b>0.2</b>	20.10.2025	Ana Carolina Izurieta	Review of the first draft
<b>0.3</b>	22.10.2025	Régine Kiasuwa, Sofie Theys	Review of the second draft
<b>0.4</b>	21.11.2025	Task leaders: IGG, ACC, NKUA	Review and modification of the tasks 7.2, 7.3 and 7.4 specific sections
<b>0.5</b>	26.11.2025	Ío Rivera	Consolidated draft
<b>0.6</b>	28.11.2025	All	Final document
<b>0.7</b>	14.01.2026	SJD, Sciensano, ACC	Publishable version