



Joint Action on Networks of Expertise on Cancer

NoE on Palliative Care

WP6

12 Month Report

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EXECUTIVE SUMMARY

Palliative Care (PC) is widely endorsed in clinical guidelines and policy documents. The World Health Organization (WHO) of palliative care defines PC as “an approach that improves the quality of life of patients, adults and children, and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual”. This definition provides an overarching framework for content, delivery, professionalism and competence. Nevertheless, integration of PC into cancer care remains uneven across Europe, with substantial variation in how PC is defined, organised, financed, taught and monitored. This leads to fragmented services and unequal access to timely, needs-based PC for patients with cancer.

Within Joint Action JANE-2, work package 6 (WP6) addresses these gaps by aiming to strengthen the integration of timely, needs-based PC into standard cancer care across Europe and by establishing an EU-wide PC Network of Expertise (NoE). WP6 will deliver a shared European portfolio of services and tools for member states, cancer centres and training bodies. This includes mapping of PC organisation, delivery, education and policies. It will also develop digital care pathway models that embed PC and patient-reported outcome measures (PROMs) into routine cancer care. In addition, WP6 will provide a competence-based European framework and benchmarking tools for PC education at undergraduate, residency and specialist levels. Finally, it will produce a consensus-based indicator set and practical templates for monitoring integration and quality at national and institutional levels, all anchored in a sustainable European network.

WP6 is structured into four interlinked tasks (Task 6.1-Task 6.4) that together provide a coherent, system-level approach to integration. Building on and aligning with existing European initiatives, WP6 develops shared concepts, mapping tools, digital pathway models, educational frameworks and indicators that can be used, adapted and scaled beyond the lifetime of JANE-2.

During this reporting period, WP6 has established a stable governance structure, clarified roles and partner contributions, and developed a shared conceptual and methodological framework for all tasks.

Task 6.1 - content, understanding and organisation of palliative care - aims to appraise PC organisation and integration by developing and agreeing with working definitions of palliative care, specialised PC services and integration into routine cancer care, and by designing core surveys to map delivery and organization of palliative care.

Task 6.2 - digitalised care pathways and PROM/PRO integration - aims ultimately to assess the use of PROMS, care pathways and ultimately undertake a pilot study on digital palliative care pathways building on existing European initiatives.

Task 6.3 - education and competence across sectors- has adopted and extended European Association of PC (EAPC) Atlas–based tools for mapping PC education at undergraduate and specialisation levels, undertaken initial analyses, and is developing a consensus document that defines shared terminology, analytical pillars and a three-level mapping approach to palliative medicine education (undergraduate, residency, specialisation).

Task 6.4 - indicators for monitoring implementation and quality - aims to develop and refine indicators of PC including integration in cancer care. Using mixed methodology including a scoping review, a qualitative interview study with key opinion leaders and a Delphi process to reach international consensus on indicators of PC integration, it will meet these aims.

As a key stage in these tasks, a single survey will be delivered that includes all individual survey questions from the whole of WP6 and administered via the central JANE-2 coordinating centre.

Together, these efforts provide a coherent and complementary foundation for WP6 and create a solid basis for the next project phase, where mapping, pilot studies and consensus-based tools will be implemented and used to inform European and national strategies for integrating PC in cancer care.

INTRODUCTION

Despite decades of clinical and policy endorsement, palliative care (PC) remains inconsistently integrated into cancer care across Europe. Fragmentation in provision, accessibility, education and acceptance hinders timely access and contributes to avoidable suffering and suboptimal use of healthcare resources. The WP6 Network of Expertise (NoE) has been established to address these gaps by strengthening the integration of timely, needs-based PC into routine cancer care and by building sustainable European structures for collaboration, implementation and quality improvement.

WP6 is organised into four iterative tasks that together provide the foundation for a coherent, system-level approach to integration:

- Task 6.1 – content, understanding and organisation of palliative care
- Task 6.2 – digitalised care pathways and PROMs/PREMs integration
- Task 6.3 – education and competence across sectors
- Task 6.4 – indicators for monitoring implementation and quality

WP6 is organised in two main phases. Phase 1 (2025–2026) focuses on developing standards, care pathways and a shared educational framework for palliative care in oncology. Phase 2 (2027–2028) will concentrate on piloting these models in different European contexts, refining implementation strategies and evaluating their effectiveness. Within this structure, WP6 will deliver three deliverables:

- **D6.1 (Month 16):** Report on the prototype of patient care pathways to be piloted at selected sites.
- **D6.2 (Month 36):** Report on three pilot studies – two assessing the relevance and local applicability of palliative care pathways in 6–8 sites, and one testing and validating a prototype set of indicators in 6–8 countries.
- **D6.3 (Month 40):** Pan-European report on the level of palliative care implementation according to the developed indicators, including European educational and care standards for key palliative care professionals.

This 12-month report (covering the period November 2024–October 2025) summarises the progress of WP6 towards establishing the PC Network of Expertise (NoE) and laying the groundwork for sustainable implementation across Europe. For each of the four tasks, the report documents the main achievements, challenges, any deviations from the original work plan and justification, the contributions of partners and the use of resources during the first reporting period. In addition, the report describes how WP6 governance has been consolidated, how dissemination

activities and collaborations with European and international initiatives have evolved, and how synergies and stakeholder engagement contribute to long-term sustainability.

The report begins with the executive summary with subsequent sections presenting a summary of each task. Cross-cutting sections then describe the governance of the NoE, dissemination activities, synergies with other initiatives, collaborating stakeholders and the sustainability strategy. An appendix provides supporting documentation and a detailed overview of participating institutions.

OBJECTIVES OF THE NOE

The overall objective of the WP6 Network of Expertise in PC is to close gaps in access to and integration of PC for cancer patients across Europe. More specifically, the NoE aims to:

- Ensure that timely, need-based PC is available to cancer patients of all ages at all relevant levels of care, regardless of country or setting.
- Develop and implement shared European standards, pathways, educational frameworks and indicators that support integration of PC into routine cancer care.
- Reduce heterogeneity in organisation, delivery, education and monitoring of PC by providing comparable data, tools and guidelines to Member States and cancer centres.
- Build a sustainable European collaboration platform that links clinicians, educators, researchers, policymakers and civil society, and that can continue to support implementation beyond the lifetime of JANE-2.

TASK 6.1 – CONTENT, UNDERSTANDING AND ORGANISATION OF PALLIATIVE CARE

Leaders: Mogens Grønvold, Stine Novrup Clemmensen – Institution: REGIONH (Denmark)

Co-Leads: Eva Schildmann, Sophie Meesters, Jakob Hardt – Institution: UKA (Germany)

Overview

Task 6.1 aims to describe and assess how PC is defined, organised and delivered to patients with cancer across Europe, with a particular focus on the integration of PC into cancer care. During the reporting period, the task has developed and agreed upon working definitions of PC and integrated PC in cancer care, designed core survey instruments for mapping PC delivery and organisation, and conducted an internal mapping of PC expertise within WP6 partners. These activities establish the conceptual and methodological basis for the subsequent mapping and analysis.

Objectives are to

- Assess the organisation of PC in different countries
- Assess PC delivery to cancer patients

Achievements

Conceptual and methodological framework

- Conducted reviews on:
 - definitions of PC
 - integration of PC into cancer care
- Developed working definitions based on these literature reviews and refined them through several feedback rounds with Task 1 partners and WP6.
- Achieved a uniform working definition of integration of PC into cancer care (UKA; Q2 2025).
- Completed a scoping review and agreed document on:
 - a PC definition, and
 - a specialised PC service description (Q2 2025)

Survey development and internal mapping (Tasks 6.1.1–6.1.2)

- Designed a survey (6.1-Survey 1) to assess PC delivery to cancer patients; developed and revised iteratively in Q1–Q3 2025.
- Presented 6.1- Survey 1 to the full Task 1 group in Q4 2025 and revised based on written feedback from Task 1 members
- Started drafting 6.1-Survey 2 to assess the organisation of PC in different countries, based on the definitions document and other sources; overlaps and boundaries with Tasks 2–4 were clarified in a series of meetings (Q3–Q4 2025)

- Developed and implemented an additional questionnaire mapping PC expertise within WP6; approximately 90% of participating sites responded (Q3–Q4 2025)

Milestone-level progress

- Consented definitions and working documents (PC definition, specialised service description, and integration into cancer care) completed and made available to WP6.
- Core content and structure of 6.1-Survey 1 finalised; 6.2-Survey 2 structure in active development by the end of the period

Dissemination and synergies

- Task 6.1 activities were presented in WP6 and Task leader meetings, contributing to a shared understanding of integration, definitions and organisational aspects of PC across tasks. During the reporting period, Task 6.1 was presented at the EAPC World Congress 2025 in Helsinki and at the 14th European Palliative Care Research Centre (PRC) International Seminar 2025 in Oslo.

Challenges

- Achieving consensus on definitions and survey content required multiple iterations and extensive feedback rounds.
- Overlaps and boundaries with other tasks (particularly Tasks 2–4) required several dedicated meetings to avoid duplication and clarify scope.

Deviations in activities and justifications

- Instead of only developing one survey instrument, the task:
 - produced additional conceptual documents (working definition of integration into cancer care; PC definition and specialised service description), and
 - decided to develop two surveys (delivery and organisation) plus a third, internal mapping of expertise

Justification:

- The conceptual work was necessary to provide a robust foundation for subsequent mapping.
- Separate surveys for delivery and organisation allow more precise and methodologically sound assessments.
- The internal expertise mapping supports selection of respondents and interpretation of results.

Contribution of partners

- UKA and REGIONH led the conceptual work on definitions and integration documents and coordinated feedback rounds within Task 1 partners and WP6 participants.

- Task 1 participants contributed through:
 - recurring meetings (Q2–Q4 2025)
 - written feedback on surveys and definitions, and
 - high response rates to the internal expertise-mapping questionnaire

Use of resources

- Personnel time at UKA and REGIONH was used primarily for:
 - literature reviews
 - development of conceptual documents
 - survey design and refinement
 - participation in WP6 and Task 1 meetings
- Travel resources were used to attend WP6 and Task & co-leader meetings in Oslo (e.g. January and September 2025)
- No major deviations from planned resource use; funds have been used in accordance with the activities described. Less staff resources used than 1/4 of the total of granted resources (UKA).

Activities planned to move forward

Q4 2025 (Task 6.1.1 – Develop and prepare a digital survey)

- Finalise the survey on PC delivery (Survey 1) and the organisational survey (Survey 2), including internal testing at selected WP6 partner sites
- Adjust wording and structure based on feedback from Task 1 and WP6 meetings

Q2–Q4 2026 (Task 6.1.2 – Perform the mapping at WP6 partner sites)

- Launch Survey 1 and Survey 2 at WP6 partner sites according to the agreed sampling strategy. This will be delivered as one survey including all individual survey questions from the whole of WP6.
- Monitor response rates and follow up with partners to ensure adequate coverage across countries and settings

Q4 2025–Q2 2026 (Task 6.1.3 – Analyse and summarise mapping results)

- Clean and validate data from both surveys.
- Analyse and summarise mapping results on PC delivery and organisation and integrate findings with the internal expertise-mapping survey.

Q2 2026–Q1 2027 (Task 6.1.4 – Publish scientific paper(s))

- Prepare and submit the first scientific manuscripts based on the mapping of PC delivery and organisation

- Develop additional papers focusing on cross-country comparisons and models of integration where data allow

Q2 2027–Q3 2028 (Task 6.1.5 – Operationalise results into national implementation plans)

- Translate mapping results into practical recommendations and national implementation proposals
- Work with national representatives and relevant WPs to align with cancer plans, accreditation processes and existing policy frameworks

Q1–Q4 2028 (Task 6.1.6 – Revise results, launch)

- Refine and update guidance and tools based on feedback from early adopters and emerging evidence
- Support the launch and wider dissemination of agreed implementation plans and tools across participating countries

TASK 6.2 – DIGITALISED CARE PATHWAYS AND PROMS INTEGRATION

Leader: Marianne Jensen Hjermsstad – Institution: OUS (Norway)

Co-Lead: Anna Reyners – Institution: UMCG (The Netherlands)

Deliverables (Task 6.2):

- **D6.1 – Prototype/Protocol of PC pathways** (originally due Q1 2026; expected Q2 2026)
- **D6.2 – Pilot Studies Report** (Q4 2027)

Overview

The assessment and use of Patient Reported Outcome Measures (PROMs) is the best method to elicit the patient's voice through the disease trajectory and beyond. This approach ascertains the acknowledgement of the patient's own evaluation of symptoms, functioning, psychological state and preferences for care. Also, this is emphasized as an inherent part of cancer care in all phases of disease and treatment, and palliative and supportive care alike. The systematic use of PROMs is endorsed by international treatment guidelines for years. When coupled with treatment guidelines and systematized in patient care pathways, PROMs contribute considerably to the quality of cancer care provided. Despite this knowledge and evidence, PROMs and patient care pathways are not implemented systematically in routine cancer care, nor in palliative or supportive care.

Objectives are to:

- Leverage digital tools and launch PC pathways as a method for integrating Patient-Reported Outcome Measures (PROMs) into cancer care.
- Use hybrid or paper-based alternatives in centres that are not yet digitally mature.
- Adapt all implementations to the specific characteristics and needs of each centre.
- Develop, test, and iteratively revise the pathway content and implementation through multiple rounds, in line with the structure described in the task points.
- Give recommendations on how palliative care can be routinely implemented by means of standardised care pathways across Europe.

Achievements

Consolidation and structure (Task 6.2.1)

- Established Task 6.2 meetings every two weeks to consolidate the Task group and structure ongoing work.

- Revised and clarified the Task 2 participant list and commitment, through direct contact and follow-up with those who had registered.
- Recruited new collaborators to strengthen the Task group.
- Aligned allocated person-months (PMs) with the expected workload to clarify partner contributions

Concept and survey development (Task 6.2.1)

- Supported and collaborated with two PhD students in the national PROMISE project (Netherlands) working on:
 - use of PROMs in palliative care, and
 - technical/ICT solutions for PROM implementation
- Initiated collaboration with EUnetCCC and maintained links with MyPath-EU and related initiatives.
- Drafted a first survey (6.2 Survey 1) aiming to obtain a brief overview of:
 - PC organisation and delivery, and
 - the use of PROMs
- Currently 6.2-Survey 1 is being reviewed by the wider Task2 group.

Progress towards mapping and pilot work (Tasks 6.2.2–6.2.3)

- Defined the overall approach for mapping at the WP6 partner sites including:
 - iterative refinement of 6.2 Survey 1
- Initial discussions on protocol development and feasibility for broader mapping and pilot work have been conducted within the Task group.

Dissemination and synergies

- Q3 2025: Two oral presentations on Task 6.2 given at 14th (PRC) International Seminar 2025 in Oslo.
- Q4 2025: Task 6.2 work presented at Oslo University Hospital weekly seminars, ensuring regular internal sharing and knowledge transfer.
- Ongoing collaboration with:
 - Dutch PhD projects (OPTIMISM) on PROMs and ICT.
 - MyPath-EU and MyPath Matrix (digital patient pathways
 - EUnetCCC (European network on comprehensive cancer centres), providing a strong network and knowledge base for the development of digital pathways.

Challenges encountered

- Initial difficulty in getting enough Task 6.2 participants to actively commit to the work, leading to slower progress in the early phase.

- Uncertainty about which survey platform to use for larger-scale deployment (e.g. Google tools vs Triangulate).
- The complexity of designing surveys that adequately capture:
 - organisational aspects
 - PROM use
 - digital maturity, and
 - contextual differences (low-, middle- and high-income settings).

Deviations in activities and justifications

- Delayed progress in Task 6.2.1 compared with the Gantt, mainly due to:
 - time required to consolidate a committed working group, and
 - extended conceptual work on survey design and stakeholder engagement.
- As a result, related activities in Task 6.2.2 (mapping at WP6 partner sites) and Task 6.2.3 (analysis and summarising mapping results) will start later than initially planned.

Justification:

- A realistic Task structure and timeline and a well-designed initial survey are prerequisites for meaningful mapping and analysis.
- Time invested in defining and clarifying the contribution of partners, their PMs.
- Leadership investment in defining the conceptual scope to improve feasibility and data quality in later phases.

Contribution of partners

- The Task lead and co-lead have coordinated:
 - regular WP6 and Task 6.2 meetings.
 - clarification of the Task 6.2 participant list
 - contact with external networks and projects (MyPath, EUnetCCC, OPTIMISM).
- Core collaborators in Task 6.2 have:
 - contributed to survey design and conceptual discussions
 - participated in every two weeks meetings
 - supported the development of a realistic structure and timeline for survey and pilot work.

Use of resources

- Resources used during the reporting period have primarily consisted of in-kind contributions within the allocated PMs:
 - Task lead and co-lead time for coordination, meetings and conceptual work
 - Contributions from collaborators involved in survey development and stakeholder coordination

- No major additional costs beyond planned staff time are reported in this period.

Activities planned to move forward

Q4 2025 – Q1 2026: Finalise 6.2 Survey 1 and use results to prepare the pilot study protocol (supports D6.1, due Q1 2026)

- Finalise 6.2 Survey 1 based on written feedback (Q1 2026)
- Use the results from 6.2 Survey 1, together with experience from MyPath, to define the core structure and content of the digital PC care pathway
- Prepare a first draft of the prototype pathway model, including adaptations for different levels of digital maturity (digital / hybrid / paper)
- Deliver D6.1 Prototype of PC pathways in Q1 2026 (noting a slight delay from the original timeline).
- Q1 – Q2 2026: Design the pilot study protocol (D6.2)
- Develop, circulate, and finalise the pilot study protocol, using findings from 6.2 Survey 1
- Complete required legislative, data-protection and ethical approvals to allow the pilot study to start

Q3 – Q4 2026: Conduct pilot study of implementation of a digital care pathway for PC (informs D6.2)

- Undertake the pilot study of the pathway prototype in 6–8 centres, with centre-specific digital / hybrid / paper solutions

Q1–Q4 2027: Analysis, reporting and publications (towards D6.2)

- Analyse data from the pilot study and summarise the impact of the pathway models on care processes and PROMs use
- Prepare the Pilot Study Report (D6.2) on the implementation and results of the digital / hybrid palliative pathways
- Publish pilot study results

Ongoing (2025 onwards): Network and implementation support

- Contribute to establishing and strengthening national networks within WP6 countries to support implementation of digitalised PC pathways and PROM integration across care levels
- Maintain and deepen collaboration with MyPath, OPTIMISM, EUnetCCC and other relevant initiatives to ensure alignment of pathway content, digital infrastructure and quality indicators

TASK 6.3 -EDUCATION AND COMPETENCE ACROSS SECTORS

Leaders: Mari Lõhmus – Institution: PEHR (Estonia), Carlos Centeno – Institution: OUS (Norway)

Co-Lead: Greta Chlebopaseviene – Institution: LSMUL KK (Lithuania)

Centeno supports the Task 6.3 leadership group through a secondment agreement with OUS (secondment; home institution: University of Navarra (UNAV), Spain), contributing scientific expertise and methodological input.

Deliverables

- **D6.3** – Report on the level of PC implementation according to developed indicators with pan-European educational standards at all levels (Month 40), in collaboration with Task 4

Overview

Task 6.3 aims to strengthen PC education and competence across Europe by providing a structured, evidence-based overview of how PC is taught and regulated at three levels: undergraduate, residency and specialisation. During the current reporting period (Nov 2024–Oct 2025), the Task has consolidated its leadership (Estonia, Lithuania, Navarra/WHO-CC), agreed on a three-level mapping approach, aligned its methodology with international frameworks, integrated data from the EAPC Atlas of PC In Europe, and finalised a consensus document that defines shared terminology and analytical pillars for the forthcoming mapping and survey work.

Objectives

- To map the organisation, structure, and delivery of PC education across Europe at three levels (undergraduate, residency, specialisation)
- To analyse competence frameworks and assessment approaches used in different countries
- To integrate existing European data sources (e.g. Atlas 2025) into the WP6 methodology
- To design level-specific tools for residency and specialisation where no previous European instruments existed
- To prepare the scientific and methodological basis for harmonised European recommendations (Deliverable D6.3)

Achievements

Conceptual and methodological framework.

- Leadership structure consolidated (Estonia, Lithuania, Navarra/WHO-CC) and initial coordination mechanisms established
- Three-level mapping approach (undergraduate, residency, specialisation) confirmed

- Analytical structure agreed (*structure* → *competences* → *assessment*).
- Task 6.3 Consensus Document finalised (Aug 2025), establishing shared terminology, analytical pillars and the overall mapping strategy

Tools and mapping (Tasks 6.3.1–6.3.3)

- Existing survey tools for undergraduate and specialisation education, previously developed and applied by ATLANTES for the EAPC Atlas Europe 2025, were reviewed, validated and adopted for use in WP6
- Mapping of undergraduate PC education across Europe has been completed through the Atlas (data collection 2023–2024, publication 2025), and the data have been made available to WP6
- Analysis of undergraduate education is completed, including coverage, curricular models, regulatory determinants and cross-country variation
- Mapping and analysis of specialisation-level PC education are largely completed, with remaining ambiguous national cases identified and undergoing clarification
- A scientific review of residency training in PC has been initiated and advanced during the reporting period, laying the groundwork for the development of a residency-level mapping instrument

Framework for completing the mapping exercise (Nov 2024–Jul 2025)

- Task 6.3 leadership consolidated (Estonia, Lithuania, Navarra/WHO-CC).
- Methodological alignment achieved across undergraduate, residency and specialisation levels
- Atlas Europe 2025 data on undergraduate and specialisation mapping integrated into the WP6 framework
- Task 6.3 Consensus Document completed (Aug 2025).

Launch of e-surveys for residency and specialisation (Aug 2025–Apr 2026) – progress within the reporting period:

- Draft structures of e-surveys for residency and specialisation refined through WP6 discussions
- Scientific review on residency training progressed, providing the empirical basis for the design of the new residency survey

Dissemination and synergies

- In 2025, Task 6.3 had three presentations at the JANE2/PRC seminar and the 14th PRC International Seminar, September 2025 in Oslo, highlighting:

- the need for PC education in Europe
- the role of the EAPC Atlas, and
- the relevance of JANE2 for clinical cancer care and education.
- Methodological pillars, the level-based mapping structure and draft tools were shared and discussed in WP6 Task Leader meetings (online, Apr–Jun 2025)
- Throughout the reporting period, Task 6.3 has collaborated closely with the ATLANTES Global Observatory / WHO Collaborating Centre, integrating Atlas 2025 education data and aligning methodology to support the mapping and consensus work

Challenges encountered

Gantt vs real workflow

Subtask definitions in the Gantt do not fully match the actual workflow of education mapping, which is structured by educational levels and existing data sources.

Lack of residency-level tools

No existing European tool for residency-level mapping was available at the start of the Task, necessitating a dedicated review of residency training evidence and additional conceptual work before survey design.

Dependency between instruments and mapping

The start of residency mapping depends on the design and finalisation of the residency-level mapping instrument (Task 6.3.1), creating an inherent dependency that delays mapping until the tool is ready.

Regulatory complexity and harmonisation

Considerable variability of regulatory systems across countries makes harmonisation difficult. Adapting a shared framework and indicators to diverse national educational structures is both a conceptual and practical challenge.

Deviations in activities and justifications

Task 6.3.1 – Instrument structure

- Planned: a single generic tool for mapping PC education
- Actual: instruments structured by educational level (undergraduate, residency, specialisation)

Justification:

- Undergraduate and specialisation tools were already fully developed and applied by ATLANTES for the Atlas and could be directly used by WP6
- No prior European instrument existed for residency; a quick review was required to inform tool design

- The level-based approach ensures better methodological accuracy and is consistent with WP6 decisions and international frameworks

Task 6.3.2 – Timing of mapping

- The Gantt foresees that mapping will start in 2026.
- In practice, undergraduate and specialisation mapping were completed earlier (through the Atlas, data collection 2023–2024, publication 2025)

Justification:

- Work conducted by ATLANTES and shared with WP6 accelerated progress for these levels
- Residency mapping is not delayed in itself but is logically dependent on completion of the residency instrument (Task 6.3.1)

Task 6.3.3 – Timing of analysis

- The Gantt foresees analysis starting in 2026
- Analysis of undergraduate and specialisation levels started earlier (2024–2025), based on existing Atlas data

Justification:

- Early access to Atlas data enabled Task 6.3 to complete analyses ahead of schedule, accelerating WP6 progress overall
- Residency analysis can only begin once residency mapping has been conducted (Task 6.3.2)

Task 6.3.5 – Publication activities

- Publications were planned for later stages (post-2027)
- Preliminary manuscripts based on undergraduate analysis and the residency training review are already being prepared (2024–2025)

Justification:

- Early completion of undergraduate and specialisation analyses naturally led to earlier manuscript work, without negatively affecting other tasks

Contribution of partners

Leadership and coordination

- Mari Lõhmus assumed formal Task leadership; Greta Chlebopasevičienė confirmed as co-lead.

- Planned improvement: strengthen division of responsibilities and maintain a structured workflow for survey development and mapping.
- Jan 2025: Carlos Centeno (UNAV / WHO-CC / ATLANTES) joined the leadership group at WP6 request, bringing methodological expertise and integrating Atlas data.

Scientific support and methodology

- Feb–Jun 2025: Estonia, Lithuania and Spain jointly developed the analytical pillars (*structure* → *competences* → *assessment*) and the three-level mapping strategy.
- Apr–Jun 2025: Task 3 partners contributed to shared drafts, reviewed structures for level-based mapping and provided feedback during WP6 Task Leader meetings.

Consensus building and cross-country expertise

- Jun–Aug 2025: All Task 6.3 partners validated the Synthesised Consensus Document (Aug 2025), agreeing on terminology, pillars and mapping approach
- Throughout 2025: Partners from Finland, Slovenia, Cyprus and Hungary provided examples of national educational structures and regulatory environments, improving the realism and relevance of the mapping framework.

Synergies with other networks & dissemination roles

- 2025 (ongoing): Estonia, Lithuania and Spain coordinated exchanges with CODE-YAA and WHO-CC structures to avoid overlap and harmonise indicators.
- NEMC (Estonia), UNAV / ATLANTES–WHO CC (Spain) and Kauno klinikos (Lithuania) contributed through PRC seminars and JANE2 meetings in Oslo September 2025, presenting the need for PC education, the role of the Atlas, the clinical relevance of JANE2 education work and empirical findings on undergraduate education.

Use of resources

During the reporting period, resources used by Task 6.3 have been aligned with its scientific and technical objectives:

- Staff time from Estonia, Lithuania and Spain supported:
 - development of the methodological framework
 - preparation of the consensus document
 - consolidation of the three-level mapping approach (undergraduate, residency, specialisation)
- Participation in onsite WP6 meetings in Oslo contributed to coordination, harmonisation and shared planning across partners

Deviations in resource use

- No major deviations in resource use have occurred
- The main development has been the strengthened scientific contribution from the University of Navarra (WHO-CC / ATLANTES), enabled by Carlos Centeno's formal affiliation with the Head Office under the institutional collaboration agreement between the University of Oslo and the University of Navarra. This has facilitated additional methodological work and further integration of Atlas education data into Task 6.3

Activities planned to move forward (Task 6.3)

Q4 2025 (Oct–Dec 2025)

- Complete the conceptual work for the residency-level mapping instrument, based on the rapid review of residency training.
- Identify and close remaining gaps in the specialisation module so that it fully aligns with the agreed analytical pillars (structure → competences → assessment).

Q1–Q2 2026 (Jan–Jun 2026)

- Conduct internal pilot testing of the residency and specialisation surveys within the Task 6.3 group (small adjustments to items, formats and length).
- Finalise the national engagement and communication plan, including the role of national champions and supporting materials.
- Launch the residency and specialisation e-surveys across participating WP6 countries, with ongoing support to national contact points.
- Finalise the data collection framework and integrate Atlas undergraduate data as the first layer of a three-level European mapping dataset.

Q2–Q4 2026 (Apr–Dec 2026)

- Complete data collection for residency and specialisation surveys and carry out data cleaning and validation.
- Begin residency-level analysis and integrate findings across undergraduate, residency and specialisation levels.
- Draft and refine the *Draft European Consensus Document on PC education and competences across levels* as the scientific basis for WP6 reporting (core contribution towards Deliverable D6.3).

2027–2028

- Deepen cross-level analyses (undergraduate, residency, specialisation), including cross-country comparisons and links to regulatory frameworks.

- Develop guidance, recommendations and implementation pathways for harmonised PC education in Europe (linked to Task 6.3.4).
- Prepare and submit additional scientific papers based on the three-level mapping and competence framework (Task 6.3.5).
- Contribute to the overall WP6 synthesis on the level of PC implementation and pan-European educational standards (Deliverable D6.3, in close collaboration with Task 6.4).

Governance

- Task 6.3 was formally initiated under NEMC leadership in early 2025; co-leadership was consolidated between Estonia and Lithuania after Liutkauskienesteped down for personal reasons.
- Central scientific support was strengthened by integrating Carlos Centeno (UNAV / WHO-CC / ATLANTES) into the leadership team to reinforce methodological rigour and cross-European coordination.
- Regular WP6 online meetings were used to refine analytical pillars, harmonise scope and confirm methodological steps; shared documents and minutes support transparency and follow-up.
- Task 6.3 activities are anchored in existing European structures (WHO-CC, ATLANTES, CODE-YAA, EAPC education networks), with plans to further involve national representatives and develop a central repository for shared documents and templates to ensure sustainability.

TASK 6.4 – INDICATORS FOR IMPLEMENTATION

Leader: Jesús González Barboteo with Miguel Mateu Sanz – Institut Català d'Oncologia (ICO), ES

Co-Lead: Pedro Antunes Meireles – Direção-Geral da Saúde (DGS), PT

Deliverables:

- **D6.2 – Pilot Studies Report** planned Q4 (Month 36) 2027)
- **D6.3 – Report on the Level of PC Implementation** (planned Q1 (Month 40) 2028)

4.1 Overview

Task 6.4 responds to the urgent need for validated indicators that can track the integration of PC into standard cancer care and assess both progress and quality of implementation. Integration is understood as the delivery of cancer care and PC in close collaboration, combining cancer-directed therapies with interdisciplinary care that addresses physical, psychological, emotional and spiritual needs of patients and their support networks. Such integration aims to ensure coordinated, efficient care and improved patient outcomes from diagnosis until the end of life.

During the current reporting period, Task 6.4 has restructured its governance, revised its methodological approach, and initiated two complementary studies: a scoping review and a qualitative interview study with key opinion leaders. In parallel, the Task has drafted a Delphi study protocol to reach consensus on a core set of indicators for PC integration.

Objectives

- To identify indicators that can effectively monitor the integration of PC within standard cancer care practices, capturing both structural and process-related aspects
- To assess the progress and quality of implementation of PC integration, including its impact on patient outcomes, healthcare provider performance and continuity of care
- To develop a context-sensitive, consensus-based indicator set for integration of PC in cancer care that is compatible with national evaluation systems across Europe

Achievements

Conceptual and methodological shift (Task 6.4.1)

Task 6.4.1 was originally conceived as the development of a digital survey to map the use of PC indicators. Early discussions with group leaders showed that:

- although several indicators exist in the literature, they are not applied consistently across studies or health systems

- implementation of PC has evolved substantially in recent years, making older literature only partially representative
- a survey alone would not capture the multidimensional and complex nature of PC integration

Based on these considerations, the workplan was redefined to include two complementary methodological components:

Scoping review

Aim: to identify up-to-date and cancer care - specific indicators of PC integration, including those from:

- the scientific literature.
- consensus documents from relevant organisations (ESMO, OECl, etc.), and
- national PC strategic plans across European countries.

Key achievements:

- 07.07.2025 – A scoping review protocol was written and registered in PROSPERO: “Indicators of integration of PC in cancer care 2025” (CRD420251087390)
- An initial search identified 517 articles after removing duplicates.
- Selection by one reviewer included:
 - 112 scientific articles, and
 - 50 grey literature documents
- Extraction and thematic grouping of indicators from selected documents yielded over 100 indicators, which were merged and grouped thematically
- An internal consultation among T6.4 partners was initiated to reach consensus on indicator formulations and definitions

Qualitative interview study with key opinion leaders (KOLs)

- Aim: to identify unpublished or practice-based indicators reflecting current PC integration for cancer patients
- Key achievements:
 - A draft interview protocol was completed
 - A preliminary list of stakeholders was compiled, including KOLs, patient representatives and NGO representatives:
 - approximately 50 contacts collected initially, plus
 - an additional 60 contacts suggested by T6.4 contributors and WP6 leaders and co-leaders

Together, these two strands provide a comprehensive basis for an updated, practice-relevant indicator set.

Delphi study for indicator applicability (Task 6.4.5)

- Recognising that indicators are diverse and inconsistently applied across Europe, Task 6.4 decided to **advance Task 6.4.5** ahead of schedule
- The initial “digital survey for applicability of indicators” was redefined as a **Delphi study** to reach international consensus on the **relevance and applicability** of candidate indicators

Governance and internal organisation

- An internal survey was sent to T6.4 participants to:
 - identify their profile
 - determine their level of participation, and
 - establish working groups to distribute subtasks
- A member from the Task leader’s institution (PAM – DGS) joined the team to share responsibility for leadership and coordination

Dissemination and synergies

Task 6.4 has been presented and discussed at key scientific meetings including the 14th PRC seminar in Oslo and the 5th Research Conference of the Portuguese Association of Palliative Care. These activities have helped raise awareness of the indicators’ work, present the objectives of JANE2, WP6 and Task 6.4, and position the indicator development within the broader European PC community. Participation in the first EUnetCCC Annual Meeting in Paris has strengthened links between JANE2/WP6 and comprehensive cancer centre initiatives, ensuring that future indicators can be aligned with emerging quality and accreditation standards. A formal collaboration process with EUnetCCC WP6 on “Strengthening Capacities and Quality Improvement” has been initiated, creating a structured platform for future joint work on indicator development, implementation and benchmarking.

Challenges encountered

Governance restructuring

- The initial Task Leader was unavailable for an undefined period. This temporarily affected workflow and required the co-leader (JGB – ICO) to assume full leadership duties
- Governance structures had to be redefined, and a new representative from DGS (PAM) joined the leadership team

Partner engagement and representation

- Identifying representatives from all contributor countries, especially those expected to have a high level of participation, proved challenging
- Only around 40% responded to the initial internal survey on roles and responsibilities
- Multiple reminders were needed, and in some cases, representatives from lower-contributing countries volunteered to take on additional responsibilities

Methodological complexity of indicators

- Wide variability in indicator formulations and descriptions across literature and grey sources made thematic grouping and harmonisation difficult
- An internal consultation process was needed to refine formulations and reach agreement on core definitions

Data protection and ethics for interviews

- Uncertainty arose around identifying the responsible entity for data protection in the interview study
- This required consultation with ethics committees and consideration of whether ICO's data protection office would assume responsibility

Deviations in activities and justifications

Task 6.4.1 – From single digital survey to scoping review + interviews

Planned: development of a digital survey mapping the use of PC indicators.

Actual: task redefined to include:

- a scoping review of indicators and relevant documents (scientific and grey literature, strategic plans, consensus documents), and
- a qualitative interview study with KOLs to identify unpublished and practice-based indicators
- **Justification:**
- Existing indicators are heterogenous and inconsistently used, and the literature does not fully reflect recent developments in PC integration
- A survey alone would not be sufficient to capture the complexity and multi-dimensionality of PC integration

The chosen approach provides a more robust, evidence-based foundation for indicator selection

Tasks 6.4.2–6.4.4 – Delays and re-sequencing

Tasks affected:

- 6.4.2 – Perform the partner mapping at WP6 partner sites
- 6.4.3 – Analyse and summarise mapping results
- 6.4.4 – Operationalise results into pan-European and national indicators

Deviation:

- These tasks have been delayed relative to the Gantt chart due to the later start and expanded scope of Task 6.4.1 and the need to establish governance
- No substantive activity has been reported yet for these tasks within the current period
- **Justification:**
- Consensus on which indicators to use is a prerequisite for meaningful mapping, analysis and operationalisation
- It was therefore necessary to complete the scoping and consensus phases first

Task 6.4.5 – Advancement of the Delphi study

- **Planned:** Task 6.4.5 (digital survey for applicability of indicators) originally scheduled for 2027–2028
- **Actual:** work on the Delphi study (redefined digital survey) started much earlier (from Oct 2025)
- **Justification:**
- Consensus on indicator relevance and applicability is needed before partner mapping and operationalisation
- Advancing the Delphi process ensures that later tasks (6.4.2–6.4.4) use a validated and agreed indicator set.

Contribution of partners

Governance and coordination

- An internal survey (10.04.2025) was used to determine contributions and responsibilities in Task 4; about 40% of partners responded
- Periodic T6.4 meetings (28.02.2025, 07.06.2025, 26.06.2025, 20.10.2025) helped maintain coordination; one meeting in August was cancelled due to summer break, highlighting the need for improved meeting planning

Methodology and protocol development

- 07.07.2025 – **Protocols:** VUB, IKNL, Charité and UNICANCER contributed to writing the scoping review protocol

- 10.10.2025 – **Scoping review:** UNICANCER contributed as reviewer for the scoping review
- 10.11.2025 – **Delphi protocol:** DGS contributed to the Delphi study protocol

Indicator formulation and consultation

- 10.11.2025 – WP6 leaders, co-leaders and T6.4 contributors participated in consultations on indicator formulation and definitions, supporting thematic grouping and refinement of the indicator list

Planned improvements

- Increase partner engagement through more personalised follow-up (individual emails).
- Improve meeting planning to ensure continuity despite holiday periods
- A formal collaboration process with EUnetCCC WP6 on “Strengthening Capacities and Quality Improvement” has been initiated, creating a structured platform for future joint work on indicator development, implementation and benchmarking

Use of resources

Staff (16.12.2024–16.12.2025)

- Funding supported the hiring of a Research Project Manager for the first year of the project. Hiring is expected to continue for the full project duration

Travel (01.01.2025–30.11.2025)

- Travel funds used to attend:
 - WP6 Kick-off meeting in Oslo (January 2025)
 - Annual JANE2 Meeting in Milan (January 2025)
 - WP6 Meeting during the 14th PRC Seminar in Oslo (September 2025),
 - Joint EUnetCCC–JANE2 meeting in Paris (November 2025)

Data support (01.01.2025–30.11.2025)

- Annual subscription to software purchased to manage the systematic/scoping review process

Deviations in resource use

- No major deviations have been reported
- Resources have been used in line with the methodological shift (scoping review, interviews, Delphi) and governance needs of Task 6.4

Activities planned to move forward

Q4 2025 to Q12026

- Finalise formulations and definitions of the indicator list based on internal consultation
- Finalise the Delphi study protocol and seek necessary approvals
- Implement engagement strategy to strengthen participation of contributors and stakeholders (e.g. targeted invitations, follow-up emails)
- Submit the interview protocol to the ethics committee and clarify data protection responsibilities (e.g. ICO data protection office)

Q1 2026

- Complete the scoping review:
 - second reviewer selection of documents
 - resolution of discrepancies by a third reviewer
 - drafting of the scoping review manuscript
- Finalise the stakeholder list and start conducting interviews with KOLs, patient representatives and NGOs
- Begin drafting the scoping review paper and interview-based manuscript

Subsequent phases (beyond current reporting period, linked to Gantt)

- Conduct the Delphi study to reach consensus on indicator relevance and applicability
- Once consensus is achieved, carry out mapping at WP6 partner sites (Task 6.4.2), analyse and summarise mapping results (Task 6.4.3), and operationalise results into pan-European and national indicators (Task 6.4.4)
- Prepare and publish a scientific paper on guidelines and indicators (Task 6.4.6)

Governance and Sustainability

- Governance for Task 6.4 has been consolidated after the initial leader's absence, with the co-leader (ICO) assuming leadership and a DGS representative joining the core team
- Internal surveys and periodic meetings have been used to define roles, distribute subtasks and strengthen accountability
- Collaboration with EUnetCCC and engagement in key European meetings support sustainability and alignment of indicators across related initiatives
- Purchase of dedicated tools (Rayyan) and the creation of a structured methodology (scoping review, interviews, Delphi) contribute to a robust and reproducible process that can be maintained and further developed over the project period.

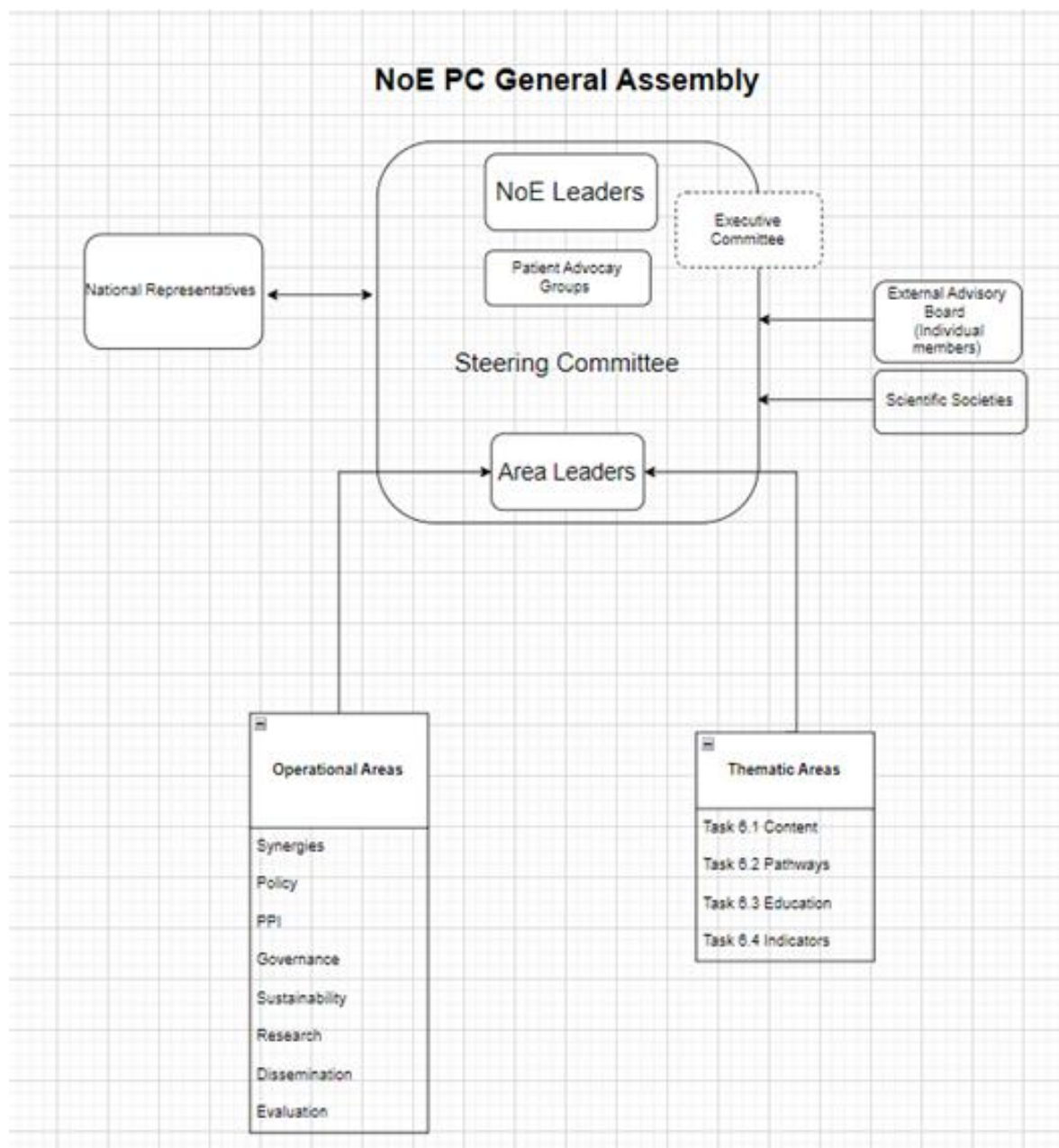
GOVERNANCE OF THE NOE

WP6 is led by Oslo University Hospital (European Palliative Care Research Centre, PRC), with Istituto Nazionale dei Tumori (INT), Milan, as co-lead. The WP6 management team coordinates scientific and operational activities, including planning, reporting and liaison with the JANE-2 coordination. WP6 is organised into four interlinked tasks that structure the thematic work of the Network of Expertise: content, understanding and organisation of PC (Task 6.1), digitalised care pathways and PROMs integration (Task 6.2), education and competence across sectors (Task 6.3), and indicators for implementation (Task 6.4).

To ensure legitimacy and practical relevance, the NoE builds on a broad stakeholder base, bringing together representatives from clinical practice, academia, public health institutes, competent authorities and ministries, as well as patient and carer organisations, professional societies and key European and international networks

The governance model of the PC Network of Expertise (NoE PC) is organised around a General Assembly, a Steering Committee and Area Leaders. Together, these structures connect national representation, overall coordination and cross-cutting operational areas with the four thematic WP6 tasks. The overall governance set-up, including the links between national representatives, leadership groups, operational areas and Tasks 6.1–6.4, is illustrated in Figure 1.

Figure 1. Governance model of the Network of Expertise on Palliative Care



The core governance of the PC NoE is provided by the WP6 management team with WP6 lead and co-lead, who act as the executive leadership and coordinate activities across Tasks 6.1–6.4. Since November 2024 they have held regular every two weeks online meetings with the WP6 Task Leaders to monitor progress, align work across tasks and prepare deliverables.

The wider NoE currently includes around 120 participants from 48 partner institutions in 27 European countries, representing comprehensive cancer centres, university hospitals, public health institutes, competent authorities, ministries, professional societies and primary care organisations. A complete list of institutions is provided in the Appendix.

To support joint work and build the NoE, WP6 has organised an in-person WP6 kick-off meeting in Oslo (January 2025), bringing together Task Leaders, co-leads and participants from 11 countries and 14 institutions, followed by a digital WP6 consortium kick-off meeting (18 February 2025) and further online plenary meetings with around 60 participants. Task-specific working groups have been established in each of the four tasks, with partners allocated according to expertise, and by the first quarter of 2025 all tasks had initiated regular meetings with participating partners. WP6 has also adopted a network-in-network model, in which the European NoE is linked to emerging national and regional networks that support implementation and context adaptation.

Methodologically, WP6 draws on and contributes to existing frameworks, including the European Pathway Association and the EU-funded MyPath consortium for digital care pathways, the SECPAL-led Palliative University Mapping Education (PUME) framework and WHO educational indicators for competence development, and WHO and EAPC indicator sets for monitoring PC integration.

Patient and caregiver engagement is embedded across all tasks: from experiences of organisation and provision of care (Task 6.1) to the relevance and usability of digital pathways (Task 6.2), and perceptions of professional competence and education (Tasks 6.3 and 6.4).

Strategic European and international collaborations are embedded in the governance model to ensure complementarity and sustainability:

- *Horizon Europe / EU projects* – MyPath (digital care pathways and PROMs) and EUonQoL (quality-of-life measurement), the OPTIMISM project, inform work on digital pathways, patient follow-up and indicators (particularly Tasks 6.2 and 6.4); COST Action CODE-YAA supports Task 6.3 on education, competence development and benchmarking; and EUnetCCC links PC to comprehensive cancer centre standards and accreditation processes.
- *Professional and policy bodies* – Collaboration with EAPC, ESMO and WHO-related structures helps align definitions, conceptual frameworks and advocacy messages. WP6 has held strategic meetings with these organisations, and an online event with EAPC to present the JANE-2 PC NoE is under preparation. Collaboration with UEMS – European Union of Medical Specialists – includes an overview of national medical associations and dialogue on EU-level palliative medicine specialty accreditation.
- *Intra-JANE collaboration* – Meetings, cooperation and coordination with WP5 (poor-prognosis cancers), WP7 (survivorship) and WP11 (AYA) will ensure continuity of care along the cancer trajectory and support consistency, and avoid duplication, in pathways, indicators and implementation strategies.

Through these structures, WP6 is establishing a European Network of Expertise in PC that connects clinicians, educators, researchers, policymakers and professional organisations, with a particular emphasis on oncologists and PC physicians, and supports participating countries in adapting and implementing integrated PC within their own health systems.

Services Provided by the PCNetwork of Expertise:

As part of its governance and mandate, PC NoE will deliver a concrete portfolio of services to Member States, cancer centres, training bodies and other stakeholders:

Mapping, knowledge synthesis and guidance on integrated palliative care

- Mapping of PC organisation, delivery and policies across WP6 partner sites and countries
- Shared working definitions of PC and of integration of PC into cancer care, as common reference points in Europe
- Conceptual and practical guidance on how to introduce timely, needs-based PC across the cancer continuum, clarifying roles, responsibilities and service models

Support for digitalised care pathways and PROM/PRO implementation

- Mapping of paper-based and digital PROM/PRO use, institutional readiness and structural barriers to digital tools in cancer and palliative care
- Development and piloting of adaptable digital care pathway models that embed PROMs and PC into routine cancer care follow-up, with variants for different levels of digital maturity
- Practical recommendations and examples of how PROMs and digital tools can be integrated into clinical workflows to support patient-centred, palliative-oriented care

Education, competence frameworks and benchmarking tools

- Comprehensive mapping of PC education using EAPC Atlas data and new e-surveys, covering undergraduate, residency and specialist levels
- Analysis and alignment of competence frameworks (WHO, EAPC, UK, Canada, Australia, etc.) and development of a harmonised, competence-based framework for PC education with particular focus on cancer care pathways
- Development of benchmarking tools and indicators for PC education, in collaboration with CODE-YAA and ATLANTES, to support universities, training programmes and regulators

Indicators and tools for monitoring integration and quality

- A context-sensitive, consensus-based set of indicators for the integration of PC into standard cancer care, developed through a scoping review, key opinion leader interviews and a Delphi process
- Tools and templates for using these indicators in national and local quality monitoring and accreditation, helping institutions and authorities to measure levels of integration, identify gaps and monitor change over time
- A European-level mapping of indicator uses and compliance once the indicator set is finalised

Networking, expert consultation and peer support

- A structured European network of centres and experts in palliative care, cancer care, digital health, education and quality improvement, anchored in regular WP6 leadership meetings, WP6 plenary meetings and task-specific working groups
- Opportunities for peer support, mentoring and exchange of good practices across countries and institutions, including thematic workshops and joint activities with other WPs and EU projects
- A growing network for clinicians (including oncologists and PC physicians), educators and policymakers working to integrate PC in cancer care

Policy and system-level support

- Policy-relevant summaries and recommendations to inform national cancer control plans and strategies on the integration of palliative care
- Contributions to European efforts on accreditation and specialty recognition (e.g. via UEMS, EAPC, ESMO and WHO-related initiatives) using evidence from WP6 tasks
- Alignment with comprehensive cancer centre standards (via EUnetCCC) to ensure that PC integration is reflected in quality criteria and evaluation frameworks

DISSEMINATION ACTIVITIES

WP6 has prioritised dissemination from the outset to establish the PC NoE as a visible and credible actor in the European cancer field.

Scientific publications and position papers

- The WP6 paper “*EU JOINT ACTION: Integrating Palliative Care in the EU Cancer Agenda: Insights from JANE-2*” is being considered by The Journal of Pain and Symptom Management (JPSM) and is undergoing a revision. The paper sets out the rationale, structure and ambitions of WP6 and serves as a shared reference for internal activities and external policy dialogue

Major conferences and congresses

14th International PRC Seminar

WP6 (through PRC/Oslo) organised and hosted the 14th International Seminar of the European Palliative Care Research Centre (PRC) in Oslo, 16–19 September 2025. The seminar focused on digitalisation and transformation in PC and included a dedicated JANE meeting on day 1 and a JANE session on day 2 of the seminar. The seminar brought together more than 120 participants from across Europe (clinicians, researchers, policymakers). All WP6 Task Leads presented their ongoing work and discussions focused on key system barriers to early integration, how digitalised care pathways can embed PC into routine cancer care, a common European competence framework, EU-level indicators for monitoring integration, alignment of Atlas data with WP6 indicators, and a networks-in-networks model with national focal points.

EAPC 2026

WP6 leaders and partners have submitted four abstracts to the 20th World Congress of the European Association for PC (EAPC 2026, Prague), covering:

1. A rapid review of training future clinical oncologists in PC (education and competence)
2. The role of binding regulation in driving undergraduate PC integration across Europe (EAPC Atlas / education / policy)
3. Implementation of patient-centred pathways with a PC focus (digital pathways, PROMs, implementation)
4. Building the European Network of Expertise in PC through JANE-2 (overall WP6/NoE concept and progress)

National and regional events and networks

- June 2025: WP6 supported the launch of the Regional Physician Network for PC in South-Eastern Norway (HSØ), with backing from the Ministry of Health and the regional health authorities (RHF). This network serves both as a dissemination channel and as a prototype for the network-in-network structure in WP6
- Following the EAPC congress in Helsinki (2025), a *Nordic Corner* forum was initiated under Finnish leadership. Together with WP6, the Nordic countries are establishing a joint forum to collaborate on PC and integration. Each country will nominate 2–3 representatives for a core group to plan network activities and strengthen the connection with JANE-2 WP6
- 14 November 2025 (planned): WP6 contributes to the Symposium on Needs-Based Integration of PC at the annual German PC physician meeting, with presentations by WP6 leadership (Kaasa and Caraceni) and Task 1 lead Grønvold, highlighting models and future directions in integration and digitalisation
- 19–21 November 2025 (planned): WP6 will participate in Onkologisk Forum 2025 in Trondheim, Norway's main cancer care congress, together with MyPath-EU, to present European perspectives on integration of palliative and cancer care and share early results

SYNERGIES WITH THE NOE

The PC NoE is explicitly designed to work with and through existing European initiatives and structures.

SYNERGIES

EAPC Atlas / ATLANTES Global Observatory / WHO Collaborating Centre

- Provide education and system-mapping expertise, underpinning Task 3 and informing broader NoE activities on policy and organisation
- Facilitate alignment between JANE-2 outputs and existing European monitoring frameworks

MyPath-EU and EUonQoL

- Offer methodological and technical foundations for digital care pathways and PROM/PRO integration, central to the NoE's services on digitalised patient-centred care and quality-of-life assessment

COST Action CODE-YAA

- Supports the development of educational standards and competence frameworks, enhancing WP6's work on education and benchmarking

EUnetCCC

- Ensures that PC is embedded in comprehensive cancer centre standards and quality improvement efforts, creating direct synergies for the NoE's work on indicators, accreditation and system-level change

WHO, EAPC, ESMO, UEMS

- Provide a bridge between WP6 evidence and broader European and global advocacy, guidelines, accreditation processes and specialty recognition in palliative medicine and cancer care

Intra-JANE synergy (WP5, WP7, WP11)

- Joint work with WP5, WP7 and WP11 ensures that PC is integrated across the cancer continuum (poor-prognosis cancers, survivorship, AYA), and that pathways, education and indicators developed in WP6 are coherent with the needs and outputs of other WPs

Emerging national and regional networks (networks in networks)

- Networks such as the Regional Physician Network for PC in South-Eastern Norway and the Nordic Corner collaboration, provide concrete platforms for implementation, context adaptation and peer support within and across countries. These networks operationalise the NoE at country and regional level and help translate European frameworks into locally owned structures and practices.



These synergies reinforce the NoE's scientific credibility, avoid duplication, enhance uptake and create a coherent framework in which Member States and centres can use WP6 outputs.

COLLABORATING STAKEHOLDERS OF THE NOE

The PC NoE brings together a broad and diverse group of stakeholders at different levels:

- **Clinical stakeholders**
 - Oncologists, PC physicians, nurses, psychologists, social workers and other members of multidisciplinary teams from comprehensive cancer centres, university hospitals and primary care
- **Academic and research institutions**
 - Centres of excellence in palliative care, cancer care, health services research, digital health and education – including PRC/Oslo, INT Milan, ATLANTES/University of Navarra, and others
- **Public health and policy stakeholders**
 - Public health institutes, competent authorities and ministries of health engaged in cancer control planning, service organisation and regulatory frameworks
- **Professional and scientific organisations**
 - European and national societies (EAPC, ESMO, national PC and oncology societies), education networks and accreditation bodies (e.g. UEMS sections, national medical associations)
- **European networks and projects**
 - MyPath-EU, EUonQoL, CODE-YAA, EUnetCCC and related EU initiatives functioning as collaborating platforms for pathways, QoL assessment, education and quality improvement
- **Patients, carers and civil society**
 - Patient and carer representatives (Salute Donna Salute Uomo), NGOs and advocacy groups are involved in co-production processes in WP6 tasks (e.g. pathways, indicators, education), ensuring that the NoE services are grounded in lived experience and public expectations

This broad stakeholder base is key to the NoE's legitimacy, practicality and long-term impact.

SUSTAINABILITY

WP6 is structured in two phases: an initial mapping and development phase followed by refinement and implementation, with pilot studies in multiple countries to test feasibility, relevance and clarity of proposed pathways, education frameworks and indicators. A core premise for sustainability is that all models, tools and indicators are adapted to the specific settings in which PC is provided and continuously improved through an enduring Network of Expertise and international collaboration. Prototype indicator sets will be tested and validated in multiprofessional pilot studies across centres and levels of care, before being scaled up to pan-European mapping and longer-term monitoring.

Sustainability is embedded in the design of the PC NoE at several levels:

Anchoring in existing structures

- WP6 is built on and linked to durable European and international structures (EAPC, ESMO, WHO-related entities, EUnetCCC, EAPC Atlas/ATLANTES, CODE-YAA), increasing the likelihood that its models, tools and indicators will remain in use beyond the lifetime of JANE-2

Network-in-network model

- By fostering national and regional networks – such as the Regional Physician Network for PC in South-Eastern Norway and the emerging Nordic Corner collaboration – the NoE creates local ownership and implementation capacity, rather than relying solely on a central European structure

Integration into standards and policy

- The NoE explicitly targets the integration of PC into:
 - National Cancer Control Plans and strategies
 - comprehensive cancer centre standards (via EUnetCCC), and
 - education and accreditation systems (via UEMS, EAPC, ESMO, national medical associations)
- Once embedded in these frameworks, WP6 outputs (pathways, indicators, competence frameworks) can drive sustainable change

Capacity-building and competence development

- Through mapping, education frameworks, benchmarking tools and training activities, WP6 contributes to building a skilled workforce that can sustain integrated PC locally and nationally

Scientific foundation and continuous learning

- Systematic reviews, surveys, indicator development and pilot projects provide a strong evidence base

- Publications, congress contributions and ongoing evaluation will support refinement, scaling and adaptation of the NoE's outputs over time

Ongoing visibility and engagement

- Strategic presence at European and national meetings, the organisation of the annual PRC International Seminar, and collaboration with EU projects, stakeholders and partners ensure continued attention, uptake and support for the NoE's work

Together, these elements position WP6 as the basis for a lasting European Network of Expertise in Palliative Care, supporting Member States and cancer services in integrating PC into routine cancer care across the EU. By combining shared frameworks, digital pathways, education standards and indicators with a networks-in-networks model, WP6 creates practical capacity for implementation.

DOCUMENT INFORMATION

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Appendix 1. Participating institutions in WP6 by country

Country	Institution(s)
Austria	Medical University of Vienna / Vienna General Hospital
Belgium	Vrije Universiteit Brussel
Bulgaria	National Association of General Practitioners in Bulgaria
Cyprus	Bank of Cyprus Cancer care Centre
Croatia	Sestre Milosrdnice University Hospital Center
Czechia	Masaryk Memorial Cancer Institute
Denmark	Aarhus University Hospital (Region Midtjylland); The Capital Region of Denmark – Bispebjerg and Frederiksberg Hospital
Estonia	North Estonia Medical Centre
Finland	Finnish Cancer Center (FICAN); Helsinki University Hospital
France	UNICANCER
Germany	Charité – Universitätsmedizin Berlin; University Hospital Augsburg
Greece	National and Kapodistrian University of Athens
Hungary	National Institute of Cancer care; National Koranyi Institute for Pulmonology
Ireland	Health Service Executive; Trinity College Dublin
Italy	Fondazione IRCCS San Gerardo dei Tintori; Fondazione IRCCS Istituto Nazionale dei Tumori; IRCCS Azienda Ospedaliero-Universitaria di Bologna
Latvia	Riga East University Hospital
Lithuania	Hospital of Lithuanian University of Health Sciences Kauno Klinikos; Ministry of Health of the Republic of Lithuania; National Cancer Institute
Moldova	Institute of Cancer care
Netherlands	Netherlands Comprehensive Cancer Organisation; University Medical Center Groningen
Norway	Oslo University Hospital
Portugal	Directorate-General of Health; Portuguese Cancer care Institute of Lisbon Francisco Gentil
Romania	OncoHelp Association – Cancer care Center
Slovenia	University of Ljubljana, Faculty of Medicine; Institute of Cancer care Ljubljana
Spain	Andalusian Health Service; Catalan Institute of Cancer care; Ministry of Health of the Valencian Government; Vall d'Hebron Institute of Cancer care
Sweden	Region Östergötland (Linköping University); National Board of Health and Welfare
Ukraine	National Cancer Institute
United Kingdom	The Royal Marsden NHS Foundation Trust



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