Joint Action on Networks of Expertise on Cancer

Milestone number. 43

1st AYA NoE Annual activity report

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1 EXECUTIVE SUMMARY

Adolescents and young adults (AYAs, aged 15–39 at cancer diagnosis) are identified as a unique patient group with distinct clinical and psychosocial needs necessitating specialized care. The Network of Expertise (NoE) on AYAs with cancer was defined through the Joint Action on Network of Expertise (JANE) and is intended for implementation via the Joint Action on Network of Expertise -2 (JANE-2) to enhance AYA with cancer research and care across Europe. The NoE employs a structured, collaborative approach that harmonizes national and EU-level objectives, creating a platform for professionals, patient groups, and stakeholders to advance AYA cancer care, influence policy, and mitigate disparities among Member States. Additionally, it fosters cooperation between pediatric and adult oncology services to improve care throughout the cancer continuum. This document provides an overview of the activities conducted during the first year of the NoE.

2 INTRODUCTION

2.1 Objectives of the NoE

The NoE on AYAs with cancer is the result of a consensus process reached within the Joint Action on Network of Expertise (JANE). By consensus, AYAs with cancer were identified as a complex oncological condition requiring a different approach based on collaboration between the EU and Member States, which could benefit from cross-border cooperation and EU expertise.

Addressing cancer care in AYAs is essential because this age group has specific clinical and psychological needs. Cancer in AYAs often present different biological characteristics compared to those in children or older adults, requiring tailored therapeutic strategies. Moreover, psychosocial support is crucial to cope with impacts on education, work, relationships, and fertility, improving quality of life and chances of recovery. Hence the idea of launching an NoE that can exploit expertise and experience to respond to the specific needs of AYAs with cancer.

The NoE on AYAs with cancer was therefore created to:

- align national and EU-level objectives regarding research and delivery of care on AYAs with cancer
- provide a platform for collaboration among healthcare professionals, patient groups, and other stakeholders to enhance AYA cancer care, influence healthcare policy, and reduce disparities across EU Member States
- be the method to achieve our overarching goal of fostering collaboration between pediatric and adult oncology services to improve care for AYAs across the cancer continuum.

2.2 Tasks (11.1 – 11.7)

2.2.1 Task 11.1 – NoE Organigram and Governance (Leader: ISNB)

- Achievements

A comprehensive governance model for the Network of Excellence (NoE) on Adult Oncology (AYA) with cancer was developed in the initial months of the network's activities. This model outlines the organization's structure, roles, responsibilities, and interfaces, and is detailed below.

The governance framework includes committees, boards, and transversal priority task forces, each with specific objectives, coordinators, membership profiles, meeting frequencies, reporting lines, and an evaluation framework for ongoing monitoring.

Please see chapter 3 for details.

The governance model was finalized through restricted core-board meetings (including T11.1 and NoEs leaders) to establish terms of reference and expedite decision-making procedures. Subsequently, broader meetings (including all WP11 task leaders and collaborative stakeholders) were held to ensure comprehensive stakeholder representation.

- Activities planned moving forward

The governance structure will be revisited and modified as the network evolves and MSs, along with their representatives, become involved in the coming years. Membership criteria will be discussed after the results of the ongoing mapping process are finalized.

2.2.2 Task 11.2 - Development of dedicated AYA programs (Leader: Sciensano)

- Achievements

A scoping review has been conducted to provide a concise overview of the existing care models and programs in Europe. The screening and data extraction phases have concluded, and the data synthesis phase has commenced.

A survey has been developed to complement the scoping review and identify informed stakeholders that should reply to the survey at Member States level. The survey questions were crafted and integrated with those from other WP11 tasks, such as clinical recommendations, training, clinical cancer research, monitoring indicators, and sustainability strategy. This resulted in an overarching survey that captures input from six tasks of WP11 and avoids any overlaps. Three distinct target audiences have been identified: healthcare providers, policymakers, and patient groups. To ensure a high response rate to the survey, liaison persons in each country will actively promote its distribution.

- Activities planned moving forward

1) The data synthesis has commenced and is anticipated to conclude by the end of February 2026. Preliminary findings will be presented to the contributors of the Task and will be aligned with their respective feedback.

2) Survey: A liaison person/group for each EU country will be identified and determine the target audience for the task partners and other WP11 task leaders. The survey will be finalized and shared in collaboration with Triangulate Health Ltd. Analysis results will start to be shared in April 2026. The results of all the surveys (all the other NoEs) are expected by the end of August 2026. The goal is to identify key characteristics based on country/regional specifics and best practices for AYA-focused programs.

3) Interviews are planned to delve deeper into the findings of the scoping review and the survey. Contributors will be identified to address regional practicalities, such as obtaining approval from ethics committees. Furthermore, a working group will be established to draft interview questions and determine an identification approach for interviewees.

2.2.3 Task 11.3 - Development of clinical recommendations (Leader: HSJD/UNITO)

- Achievements

- Early Engagement of High Contributors in WP11.3 subtasks

  At the start of the project, based on the initial list of institutions involved in this task, direct email communication was established to identify each institution's contact person, their interests, and their expected level of participation in the various sub-tasks. This process provided an overall view of each team member's preferences and confirmed that all high-contributing participants were willing to engage in multiple activities. Interestingly, some low-contributing partners showed interest in specific sub-tasks, and some observers expressed enthusiasm for contributing beyond their assigned roles.

- T11.3.1 Map existing guidelines to identify a priority list of recommendations to develop.
  - Survey

    Mapping existing guidelines through a targeted survey is a crucial step in improving care for Adolescents and Young Adults (AYAs) with cancer across the European Union. This process will enable the identification of current practices, gaps, and variations in care standards within this specific population with unique needs.

    With this aim in mind, we contributed to the survey as reported in Task 11.2 In case guidelines are available we aimed

    - To identify the responsible bodies to clarify who oversees guideline development and implementation. This is essential for understanding the governance structure and for targeting future collaboration and/or harmonization efforts.
    - To assess the communication infrastructure and the identification of potential gaps in knowledge transfer, which are essential for ensuring effective dissemination and uptake of guidelines.
    - To determine whether guidelines are regularly updated and the drivers of guideline changes (e.g., new research, patient feedback, policy shifts). Assessing the availability of training opportunities ensures that guidelines are not only disseminated but also properly implemented, reflecting the level of institutional support for their adoption. To evaluate, in a straightforward way, the effectiveness of current guidelines, to highlight the strengths and the areas for improvement.
    - To determine whether supplementary resources that could enhance guideline adherence and improve patient outcomes are available.
    - To explore existing feedback mechanisms and their integration into care improvement processes.
    - To identify the most common gaps identified in the currently available guidelines and procedures

    Furthermore, a few questions were added to the survey in case no guidelines are available:

    - Plans for guideline development, assessing the readiness and institutional commitment to improve AYA cancer care, or if this remains a gap in the strategic planning.

- Current approaches used by healthcare providers to compensate for the absence of formal guidelines emphasizing existing strengths and informal practices that could potentially be standardized or scaled up.
- Mechanisms in place for listening to AYAs and whether their voices are integrated into service improvement processes.
- Barriers to guideline development, such as resource limitations, lack of awareness, or insufficient data specific to the AYA population.

By collecting and analyzing this data, we will establish a clear overview of the landscape and develop a prioritized list of recommendations tailored to the needs of AYAs with cancer.

- Bibliographical search

  A bibliographical search looking fot he state-of-the art was conducted on four databases (Pubmed, Embase, Cinahl, APA PsycInfo) following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines to ensure methodological rigor and transparency (Page et al., 2021). It was divided into two parts:

  - Bibliographic research based on a broad list of terms (95 strings) regarding the main problems for AYA with cancer
  - Bibliographic research based on four specific diseases, relatively common in the AYA population (Sarcoma, Hodgkin Lymphoma, Testicular Cancer, and Breast Cancer)

  To complete the research, we also examined repositories of scientific societies and European projects focused on AYAs.

  We found one comprehensive guideline about Adolescent and Young Adult (AYA) Oncology, Version 2.2024 (produced by the American group), and some other specific guidelines about a single topic related to this population (such as molecular testing, provision of healthcare, end-of-life, psychological well-being, and management of cancer pain). Eventually, we decided to include other types of publications similar to guidelines, such as recommendations or expert consensus, and 121 papers were included in our search.

  Based on the search results, we identified three preliminary topics for guideline development: Sexuality and Affectivity, Psychosocial and Educational Support, and Physical Rehabilitation and Sport Activity. We will decide, together with the coordinators and contributors, on one or two more topics to develop.

  These three important topics were selected based on their relevance, evident gaps, feasibility, and impact on AYA cancer care. Each represents an area central to patients' overall well-being, treatment adherence, and long-term outcomes, insufficiently addressed or standardized in current practice:

  - **Evidence Gap**: All topics show limited or fragmented evidence and a lack of specific guidelines tailored to AYA populations.

  - **Centrality in AYA Care:** Each area is crucial to the holistic care of AYAs, influencing medical, psychosocial, and quality-of-life dimensions.
  - **Feasibility and Sustainability:** The selected domains are realistically implementable within existing healthcare frameworks, with moderate to high sustainability if integrated with current services.

Furthermore, the task leaders and contributors agreed not to develop disease-specific recommendations. Instead, disease-related nuances will be integrated into the recommendations for the transversal topics. This approach ensures conceptual coherence, prevents fragmentation of guidance, and facilitates the inclusion of condition-specific considerations within a unified, cross-cutting framework for AYA cancer care.

- Activities planned moving forward
- Implementation and distribution of the survey and data analysis in collaboration with Task 11.2
- Incorporation of the survey findings into the strategic plan for the development of guidelines.
- Definition of the methodological approaches for the appropriate development of the recommendations.
- Definition of the dedicated task forces for the development of the five recommendations.

2.2.4 Task 11.4 - Development of training on cancer in AYA (Leader: NKUA)

- Achievements

- A survey was designed and share with T11.2 to map the current state of education and training on cancer in AYAs across MSs.
- A preliminary curriculum syllabus has been prepared, outlining the core modules (clinical, psychosocial, survivorship, fertility, policy/access to care, and research/clinical trials).

- Activities planned moving forward
- Finalizing and prioritizing curriculum topics among partners.
- Developing the comprehensive written curriculum, including learning objectives, content outline, and target audience.
- Creating educational modules for each curriculum section, such as slides, instructor notes, self-learning materials, and case discussions.

- Risk: Delays in receiving input from all partners. Mitigation: Propose a core or mandatory set of modules to finalize first.

2.2.5 Task 11.5 - Promotion of clinical cancer research in AYA (Leader: Unicancer)

- Achievements

The task activities were organized into 4 working groups to set up the landscape:

1. Survey definition - working on survey focusing on identifying structures in place at national, European and international level to favour AYA inclusion in trial at all phase of the drug development and access to therapeutic innovation (including drug repurposing). Completion of this work in collaboration with Task 11.3.
2. Epidemiology - looking into epidemiological data to support AYA need for clinical trials. Setting up work on a publication with the data found through this data.
3. Identifying existing consortia with the potential to connect in order to avoid duplication of work and promote collaboration.
4. Working with existing initiatives - using the JANE 2 network to contribute to Labelling initiative, connecting the work of the task to existing initiatives.

- Activities planned moving forward

- Analysis and publication of survey in collaboration with other WP11 tasks;
- Work on paper to publish epidemiological data findings, informing gaps in inclusion of AYA in trials;
- Identify and include JANE 2 experts in Labelling initiative, updating figures from 2023, to 2024 and 2025;
- Identify and work with existing groups and consortia – dissemination about NoE activities, avoiding duplication of work and promoting collaboration.

2.2.6 Task 11.6 - Monitoring AYA cancer indicators (Leader: NKI)

- Achievements

This task aims to identify and define quality indicators (QIs) for use in AYA healthcare monitoring at the pan-European level.

Here, QIs are defined as standardised, evidence-based metrics of healthcare, epidemiological and clinical outcomes, and can be used as benchmarks in supporting the delivery of high-quality care across a variety of European healthcare settings. Theoretical models of healthcare will be used to ensure full coverage of healthcare systems by the QIs. To do so, this task will first identify which QIs are currently in use for this purpose and where across Europe. Furthermore, qualitative research including AYAs, their informal caregivers, and healthcare providers (HCPs) will 'fill in the gaps' to generate a broad set of AYA-centric QIs. Relevant data sources wherein these metrics may be accessible (e.g., registries and longitudinal cohort studies) will then be identified. This will build on existing best practices and ecosystems, including patient-centered Core Outcome Sets (COS) of data linked in a federated way, like those generated and described in STRONG AYA, an ongoing EU Horizon project.

Task specific objectives and achievements so far are:

1. Identifying and defining quality healthcare indicators for AYAs
    1.1. Broadly assess extant metrics for measuring quality indicators (QIs). Metrics for measuring quality, not just specific to healthcare, were broadly investigated and quality indicators were selected as a suitable measure for healthcare quality in AYA. These have been used variably elsewhere and have served a similar but different purpose to core outcome indicators, such as those described for AYAs in STRONG-AYA (Janssen et al., 2025). Two notable instances of their previous use are in research regarding healthcare systems specifically (as "system outcome indicators") and in palliative care (Mack et al., 2023; Rae, 2021; Rae et al., 2020). However, beyond this, no dedicated quality indicators are currently used for monitoring wider healthcare quality for AYAs with cancer.

    1.2. Explore theoretical models of healthcare to ensure all aspects of healthcare systems are considered when developed quality indicators. Theoretical models of healthcare were researched to ensure the entirety of healthcare systems are considered during quality monitoring exercises. Initially, the Donabedian model of healthcare (structure-process-outcome) was considered (Donabedian, 2005, 1988), but academic criticism of its linearity guided our thinking towards revised models of healthcare (Mitchell et al., 1998). More recent Donabedian-based models of quality healthcare have been proposed for use in specific aspects of cancer care, such as in radiology (Harden et al., 2022). However, no specific models of all-encompassing quality healthcare for AYAs with cancer currently exist. The Quality Healthcare Outcomes Model (QHOM) was ultimately selected owing to it being comprehensive, yet broad enough to cover all aspects of healthcare (Boyle and Baernholdt, 2021; Mitchell et al., 2018, 1998). Therefore, all QIs proposed will be categorised by QHOM domain to ensure that all aspects of healthcare systems are represented and addressed during future monitoring exercises.

    1.3. Define "quality indicator for quality healthcare". "Standardised, evidence-based metrics of healthcare, epidemiological and clinical outcomes for use in benchmarking exercises and in supporting the delivery of high-quality care across a variety of healthcare settings."

    1.4. Identify contributing/supporting partners. A mailing list was created with all contributing and observing consortium members, as self-identified in the wider consortium spreadsheet. Further, all task members were invited to individual 1-hour meetings to discuss their potentially contribution to the task. Synergies were identified with T11.2 and T7.6. Plus, an official "launch meeting' involving all contributing task members was hosted on the 30th of May, describing the project background, upcoming sub-tasks and roles.

1.5. Create a survey for completion by task contributors and their networks aimed at establishing 1) if QIs are currently used in their country/healthcare setting and 2) stakeholder recruitment/how individuals may contribute to JANE2 task 11.6.

1.6. Create a detailed survey aimed at identifying which QIs (or any metrics) are currently used for evaluate/monitor healthcare for AYAs with cancer within each European country. A detailed survey has been created and shared with T11.2 leaders. This now awaits dissemination.

1.7. Define and recruit stakeholders and participant groups in qualitative and quantitative research.

1.8. Generate a publishable protocol for JANE2 T11.6. The protocol has been revised based on suggestions and outcomes in the activities previously described, with an aim to submit for publication by the end of 2025.

1.9. Conduct a scoping review on global AYA cancer indicators. By the end of July, librarians at EMC and the NKI were consulted on creating a search string for use in creating a scoping review of quality indicators for AYAs at the global level. Since then, the string has been completed, and double-blind screening activities are underway.

1.10. Conduct semi-structured interviews to 'complete' the preliminary list of QIs for the monitoring of AYA cancer quality healthcare, adding to those identified in the scoping review.

1.11. Assemble an international advisory group to consult on language and cultural considerations when addressing the feasibility and implementation of QIs at the pan-European level. Have them review the preliminary list of generated AYA QIs.

1.12. Conduct a Delphi study to define a finalised list of QIs for AYAs with cancer.

1.13. Network/framework analyses.

1.14. Consult policymakers for QI implementation strategies at the pan-European level.

1.15. Dissemination.

Note: alongside the above, similar work will begin on defining and utilising "network indicators" i.e., indicators of the success of the AYA NoE. This will take place progressively throughout the project lifestyle.

2. Identifying relevant data repositories and selecting international benchmarks
   - To be refined on completion of the above dependencies.
3. Making the data accessible Europe-wide via a federated learning system
   - To be refined on completion of the above dependencies

- Activities planned moving forward

- Scoping review completion
- Protocol manuscript submission
- Analysis of survey results.

2.2.7 Task 11.7 - Definition of the sustainability strategy for the AYA with cancers NoE (Leader: UKE)

- Achievements

According to the timetable in the application for T11.7, the actual activity will not start until 2026, so the time available so far has been used effectively to find collaborations and carry out preliminary work.

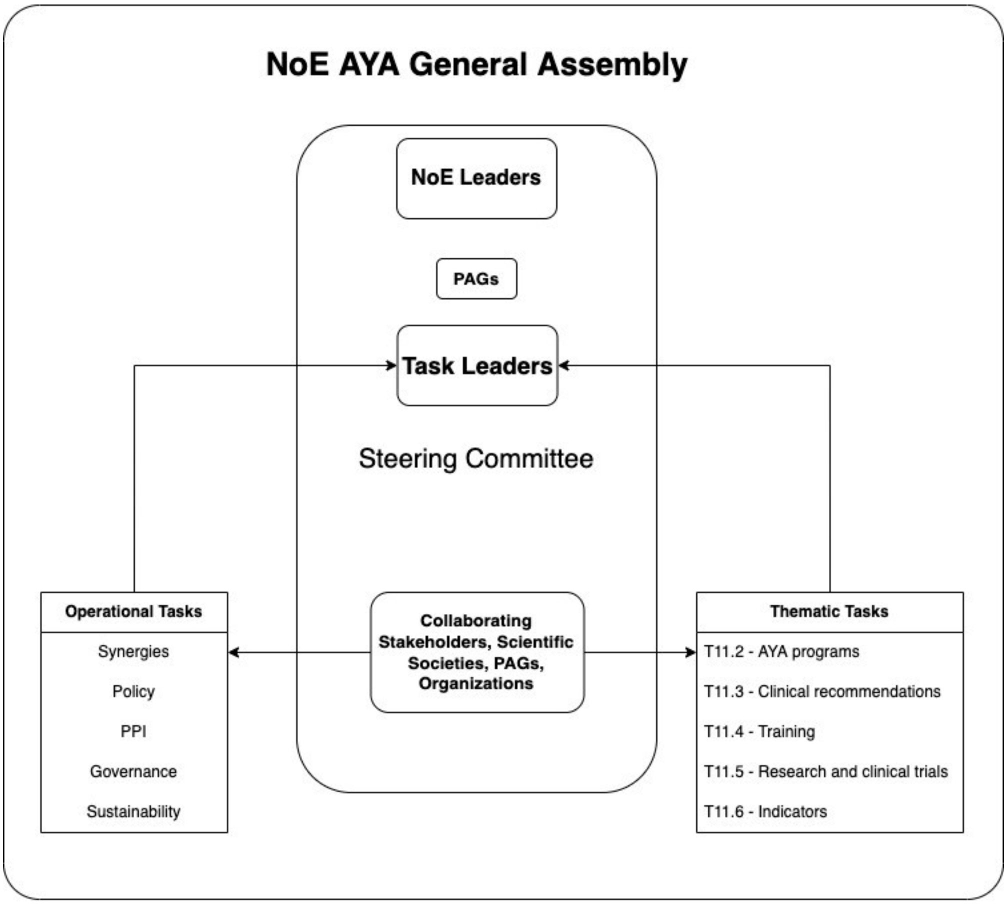
- Preliminary research for own work in T11.7 on possible stakeholders helping to address the following question:
    - What is the landscape for AYA (AYA programs, AYA wards etc.)?
    - Implementation of sustainability questions in the overarching survey in plan for the whole NoE.

- Activities planned moving forward

To define a strategy for AYA in cancers both in terms of content-related and financial sustainability, it is pivotal to first gain an understanding of the current landscape of AYA programmes, AYA wards, clinical trials, trainings and so on. These questions have been addressed by the other subtasks of the NoE within the overarching survey in plan of dissemination. We have implemented AYA-specific questions on financial sustainability regarding the general funding, resource allocation, scalability, EU collaborations and achievements of programs into health care systems to this survey. These questions mostly address policy and health care professionals, but should also be expanded to patient representatives/advocacy groups. Analyzing this survey will provide initial insights into existing AYA care structures across Europe and highlight potential aspects to sustain. These points will be discussed at several meetings to be held in 2026. All interested collaborators, representatives of major stakeholders, such as SIOPE and ESMO, networks like EUnetCCC, as well as patient advocacy groups, including CCIE and YCE, will be invited to attend. This analysis of the contents and financial backgrounds of AYA in cancers should eventually result in the definition of a sustainability strategy, that should be ultimately discussed using the Delphi method and/or circulation procedures within the entire AYA NoE.

3 GOVERNANCE OF THE NOE

The Governance structure of the AYA NoE is currently organized as follows in the Figure.



The NoE AYA Steering Committee (SC) provides strategic direction, ensuring alignment with objectives, and making key decisions to address challenges and risks.

In detail, the SC's main roles include:

- Defining the priorities of the NoE
- Reviewing progress and providing strategic guidance
- Addressing risks, obstacles, and stakeholder concerns
- Ensuring compliance with governance, legal, or ethical standards
- Ensuring information exchanges with JANE2 coordination bodies
- Approving new NoE partners
- Approving NoE collaborations
- Creating and supporting synergies with other JANE2 WPs and other stakeholders

- Ensuring clear communication with stakeholders, often through updates, newsletters, or reports in collaboration with the head of communication.
- Scheduling 2 annual meetings (one as a General meeting hybrid and one as a Stakeholders forum face to face)
- Other roles may become necessary by agreement, over time

The SC includes partners who bring expertise, decision-making authority, and stakeholder representation. Key members include:

- NoE lead and co-leads
- Task leaders of thematic and operational areas
- Patients representatives
- Collaborating stakeholders representatives

Meetings of the SC are held online on a bi-monthly basis to start and last 2 hours.

The General Assembly consists of all NoE partners and is responsible for key question decisions. It meets once a year (hybrid event). The first General Assembly was held Nov 5th, 2025, in Paris.

4 DISSEMINATION ACTIVITIES

- Kick-off meeting – 16 Jan 2025 - Online
- Presentation of the AYA NoE at the 2025 SIOP Europe Annual Meeting, Budapest (HU) 12-15 May 2025
- Presentation of the AYA NoE at the 5th National Scientific Forum of the Romanian Young Oncologists, Brasov (RO) 15-17 May 2025
- First Annual Meeting of the AYA NoE, Paris (F), 5 Nov 2025
- Contribution to WP2 – Dissemination newsletters and social media
- Introduction to the AYA NoE manuscript in submission in peer review scientific journal

5 SYNERGIES WITH OTHER NOES

The AYA NoE has already initiated cooperation with the NoE on Survivorship. A representative of the AYA NoE has been includeded in the SC organized within the scope of the NoE on Survivorship, to develop an integrative survivorship care programme by mid-2026, as a flexible reference programme that can be adapted across European countries. To this aim, it is planned to conduct a Delphi process to achieve a consensus among experts on a set of pragmatic recommendations on the main pillars of the programme. The SC is in charge of reviewing the initial proposal of statements developed within the NoE on Survivorship and draft a final document to be submitted to the Panel of Experts for voting throughout the Delphi process.

Collaboration with the NoE on Palliative Care and Complex and Poor Prognosis Cancer are foreseen.

6 COLLABORATING STAKEHOLDERS OF THE NOE

The AYA NoE aims to explore and gather the existing initiatives, working groups and stakeholders in the scope of AYAs with cancer.

The process of identification of potential stakeholders is ongoing.

The following collaborating stakeholders have been already engaged in the network and are actively contributing to the NoE activities:

- European Network for Teenagers and Young Adults with Cancer (ENTYAC): a collaborative European network dedicated to improving care, research, and policy for adolescents and young adults (AYA) with cancer. It brings together clinicians, researchers, and patient advocates to promote age-appropriate oncology services and reduce disparities in AYA cancer outcomes across Europe
- Childhood Cancer International (CCI) Europe: the regional branch of Childhood Cancer International, the largest global network of childhood cancer parent organizations, survivors, and advocacy groups. It works to ensure equitable access to high-quality treatment and psychosocial support for children and adolescents with cancer, while amplifying the voices of families and survivors in European policy and research initiatives.
- Youth Cancer Europe (YCE): a patient-led network representing young people aged 18–39 with cancer across Europe. It advocates for better standards of care, long-term survivorship support, mental health resources, and meaningful involvement of young patients in shaping cancer policies, research, and national strategies.
- Global Cancer Strategies (GCS): an emerging initiative focused on developing and supporting comprehensive, evidence-based approaches to cancer control worldwide. Once operational, it will collaborate with international stakeholders to strengthen national cancer strategies, promote innovation, and advance equitable access to quality cancer care and prevention globally.
- European Hematology Association (EHA): the leading organization for hematology professionals in Europe. EHA promotes excellence in patient care, research, and education across malignant and non-malignant blood disorders, facilitating collaboration through scientific congresses, training programs, and guideline development.
- European Society for Pediatric Oncology (SIOP Europe): the pan-European organization representing all professionals involved in childhood and adolescent cancer care. It works to harmonize treatment standards, drive collaborative research, and advocate for better policies to improve survival and quality of life for young cancer patients across Europe.

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1.0	25/11/2025	All	Draft
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