



Joint Action on Networks of Expertise

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Implementation of a sustainable Network of Expertise on Adolescents and Young Adults with cancer

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Author(s)	Andrea Ferrari, Annalisa Trama
Deliverable lead partner	INT
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Institution	Name of recipient(s)
1 - Coord INT	Paolo G. Casali, Annalisa Trama, Joanne Fleming, Salvatore Provenzano
2 - INT	Andrea Ferrari
3 - WP11 partners	
4 - Joint Action JANE partners	

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LIST OF ABBREVIATIONS

Abbreviation	Definition
AYA	Adolescents and young adults
CCI	Childhood Cancer International
COI	Core Outcome Indicator
ENTYAC	European Network for Teenagers and Young Adults with Cancer
ERN	European Reference Network
ESMO	European Society for Medical Oncology
EURACAN	European Reference Network on Rare Adult Solid Cancers
JANE	Joint Action on Networks of Expertise
MS	Member State
NGO	Non-Governmental Organization
NoE	Network of Expertise
SIOPE	European Society for Pediatric Oncology
WP	Work Package
YCE	Youth Cancer Europe



RECIPIENTS OF THIS DOCUMENT

This document is addressed to the whole JANE consortium. It is an official deliverable for the project and shall be delivered to the European Commission and appointed experts.

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Executive summary

Adolescents and young adults (AYAs) aged 15–39 with cancer represent a unique patient population whose needs often fall between pediatric and adult oncology frameworks. Key challenges include:

- Distinct epidemiology and tumor biology
- Psychological complexities and a lack of age-appropriate care
- Limited access to specialized treatment and clinical trials
- Insufficient cancer awareness and inequities in care across Europe

While initiatives like the ESMO-SIOPE AYA Working Group and ENTYAC have made strides in addressing these challenges, there remains a pressing need for a cohesive, formally structured network to unite efforts across Europe. The JANE WP11 initiative aims to design a formal Network of Expertise (NoE) for AYAs with cancer in Europe, leveraging existing models and addressing identified gaps. The NoE will provide a platform for collaboration among healthcare professionals, NGOs, patient groups, and other stakeholders to enhance AYA cancer care, influence healthcare policy, and reduce disparities across EU Member States (MS).

The project employed a structured, collaborative approach, focusing on the interplay between national and EU-level objectives. The overarching goal of the NoE is to foster collaboration between pediatric and adult oncology services and improve care for AYAs across the cancer continuum.

The NoE governance will ensure effective organization, broad representation, and sustainability, by including a task focusing on funding, resource allocation, and integration with healthcare systems.

Participation in the NoE will prioritize European scope and national mandates, requiring centers and societies to demonstrate expertise, leadership, and capacity in AYA care. A focus will be placed on engaging underrepresented regions, particularly in Eastern Europe.

The NoE will work with scientific societies (e.g., SIOPE, ESMO), the European Reference Networks (ERNs), advocacy groups, national programs, and research organizations to align efforts and maximize impact.

In conclusion, the establishment of the NoE will create a unified and sustainable framework to address the complex needs of AYAs with cancer, foster collaboration across disciplines, and improve outcomes across Europe. This initiative will serve as a cornerstone for advancing AYA cancer care and equity in the EU.

Introduction

Adolescents and young adults (AYAs) diagnosed with cancer make up a particular group of patients whose clinical and psychological needs differ substantially from those of pediatric or older adult patients. Whilst some doubts still exist on the definition of the AYA age range, experts currently tend to agree on a broader definition, i.e. age range of 15-39 years (1).

In recent years, the international scientific community has recognized that AYAs inhabit a middle ground between the worlds of pediatric and adult oncology, and neither pediatric nor adult healthcare models have proved capable of meeting their particular needs. AYA patients are characterised by specific features, such as the unique epidemiology (with both pediatric-type and adult-type tumors occurring within the same age group), the specific tumor biology, the insufficient awareness of cancer in this population, the complex psychological sphere, the clinical challenges like the difficulty of accessing specialized care and treatment trials, the need for age-appropriate hospital environments with dedicated facilities and programs (2-5).

Faced with these challenges, the scientific community should adapt to the needs of AYA patients with cancer by involving diverse health professionals from different disciplines, patient advocates, and stakeholders, possibly engaging on an international level. At European level, various initiatives dedicated to AYAs have been developed. One example is the Working Group on AYAs developed by the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE). This Working Group was initially founded for mainly educational purposes; among its initiatives, it is worth mentioning a survey which described the underprovision and inequity of specialized cancer care for AYAs across Europe, and the publication in 2021 of a position paper which summarizes the challenging aspects of managing AYAs with cancer and illustrates the vision shared by the two scientific societies on the subject (6). Another initiative developed at European level is the European Network for Teenagers and Young Adults with Cancer (ENTYAC), a sort of federation in which existing professional societies, national groups of professionals concerned with AYA patients with cancer, nongovernmental organizations, patients, and family groups can cooperate and grow. ENTYAC has a long history, it was able to involve people from various disciplines across Europe and facilitate interactions, but still has an informal executive group and informal members, and no formal structure or recognition from institutional parties.

With this background, the aim of the JANE WP11 dedicated to AYAs with cancer was to prepare everything necessary to launch a new Network of Expertise (NoE) on AYAs, that will address the special challenges of this population throughout the EU, taking into account the existing models of networking. The NoE on AYAs will be promoted by the European Health and Digital Executive Agency, and will have

a formal organigram and governance, different tasks, a defined sustainability program, partners defined by Members States, and EU funds.

Methodology used (i.e. to design the NoE)

The two first activities of the JANE WP11 dedicated to AYAs were:

1. To analyse the different already existing European projects dedicated to AYAs. Among them, in particular, the WP identified the SIOPE (European Society for Paediatric Oncology) AYA committee, the ESMO (European Society for Medical Oncology)-SIOPE AYA Working Group, ENTYAC (European Network for Teenagers and Young Adults with Cancer), and Non-Governmental Organisations (patients, advocates and their families) CCI Europe (Childhood Cancer International), and Youth Cancer Europe.
2. To create the WP core group involving key people from the different already existing European projects dedicated to AYAs

The core group and the whole WP met every two months by online calls.

With the planned timing, the group worked on the different tasks (1. Definition of the scope of the NoE; 2. Identification of participants; 3. Sites identification; 4. Definition of the NoE core deliverables; 5. NoE governance development) and different milestones (a. Definition of the scope of the NoE; b. Endorsement criteria; c. Expression of interest; d. NoE deliverables; e. NoE governance).

In the definition of the objectives of the NoE, major discussions were related to the interplay between the national and the EU level. Objectives were identified and then revised. To address them, 7 possible tasks to be included in the future NoE on AYAs were described. Endorsement criteria by type of partners categories were defined, with the European scope as the major criterion. According to these, the possible synergies with potential stakeholders (according to the different objectives) were discussed.

Scope of the NoE

The overarching scope of the NoE on AYAs is to be the network where healthcare professionals collaborate with Non-Governmental Organizations (NGOs), patient groups and relevant stakeholders about AYA with cancer and where collaboration between pediatric and adult cancer services will be strengthened to improve AYA care, from prevention to survivorship. With its activities, the NoE on AYAs aims to influence healthcare policy.

As major aims, the NoE will focus on the implementation of national AYA dedicated programme in different EU MS, and on the development of multilevel actions to address the gap of AYA patient survival across the different EU MS.

More precisely, various specific objectives have been identified to address the different challenges of AYAs with cancer, i.e.

- To support the development of an AYA-dedicated program
- To develop specific clinical recommendations on AYA-specific topics (e.g. age-specific psychosocial support, fertility) and different types of cancer across age groups
- To promote cancer research in AYAs
- To raise awareness of cancer in AYAs
- To monitor AYA cancer epidemiology, leveraging what is available or underway
- To define and promote dedicated training on cancer in AYA
- To support Patient and Public Involvement and Engagement

Governance of the NoE

The NoE's governance defines the organisation and management structure of the network, the legal basis, the funding sources, the operational procedures with the definition of roles, responsibilities, and specific strategies to ensure the interplay with external experts and stakeholders and with MSs, other EU networks, patients. The governance ensures broad representation of NoE partners and an adequate management system (Figure 1). In addition, it implies also to define the best way to enlarge the network in order to involve all relevant experts/projects, how to ensure adequate patients' representation and engagement in the NoE, and how to increase awareness of the NoE and AYA.

In principle, the General Assembly represents the main body of the NoE. The General Assembly will include all members and Affiliated Partner representatives, as well as all the Collaborating Stakeholders. The General Assembly will be governed by a Steering Committee that includes NoE coordinators, the Leaders of the seven thematic tasks, Patient Groups and a limited number of selected Stakeholders whose role is considered essential; National Coordinators may be eventually included. An Executive Committee of few people is identified for strategic purposes.

An external Advisory Board may be considered.

Alongside the different thematic tasks, a few selected cross-cutting "operational areas" may be identified, e.g. on policy, synergies, Patient and Public Involvement.

To ensure the implementation of an adequate governance plan within the NoE, a specific task responsible for governance has been created.

In addition, the NoE has also a specific task on the sustainability strategy, addressing key factors such as resource allocation and funding mechanisms, EU collaborations, implementation of the different achievements at country level (integration with the health care system).

Endorsement criteria for NoE participants

The main endorsement criterion for NoE participants should be the European scope. For centers/health care providers, this means, for example, participation in EU projects or EU collaborative groups/consortia.

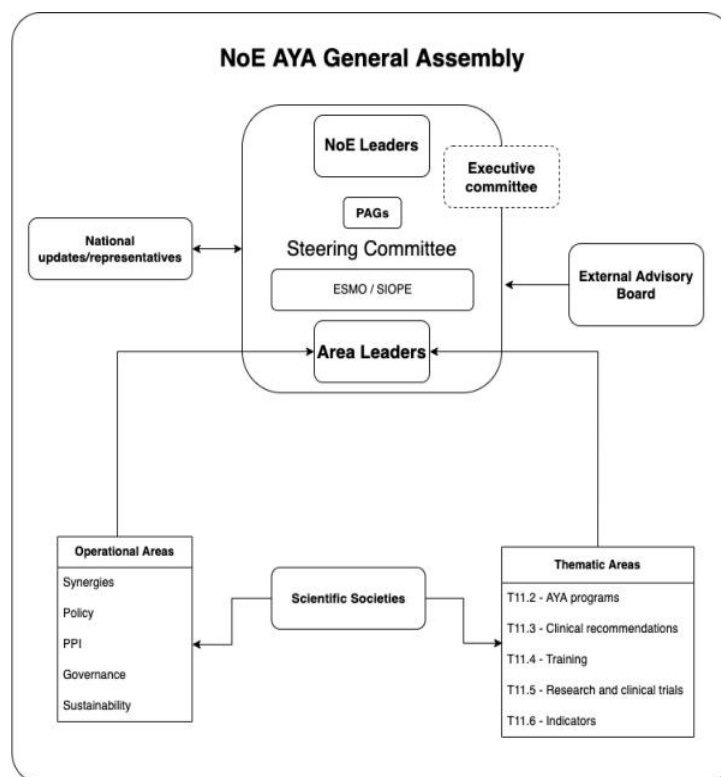


FIGURE 1 SCHEMATIC DIAGRAM OF THE AYA NOE GOVERNANCE STRUCTURE

Further endorsement criteria are:

- national mandate – centers need to have a national leadership or mandate on AYA, and the capacity and resources to participate in the NoE with the goal to lead/guide the implementation of NoE recommendations at the national level.
- specific competence/expertise on AYA, proven by coordination/participation in national programmes, or in AYA dedicated research/studies.

To ensure that the network is adequately manageable, the number of cancer centers directly involved as partners in the NoE must be limited. Both centers focusing on childhood cancers and centers focusing on adult cancers must be involved.

The NoE on AYAs should have a special focus in countries where AYA dedicated programmes do not exist (i.e. small countries, countries from Eastern Europe). The involvement of centers from these EU MS is warranted, as a first step to create a local national specific project based on the model discussed in the NoE.

The same main endorsement criterion – the European scope – must be applied to scientific/professional societies/networks/research groups, and patient advocacy groups (see below under “*Collaborating stakeholders of the NoE*”).

Services provided by the NoE

The NoE is conceived as a network of experts that provides services, ideas, and models to be developed in synergy with already existing groups/societies, and other ongoing initiatives.

To address the specific objectives of the NoE, seven possible initial tasks have been identified for the future NoE on AYAs:

1. Task 1 - Governance – this task will define the structure of the NoE including committees, roles, responsibilities, and relationships (with stakeholders and other NoEs).
2. Task 2 - Development of AYA dedicated programs – the task will map existing experiences (and lessons learned) for AYA cancer care in EU to identify key characteristics according to country/regional specificities, and share best practices on models of AYA-dedicated programme, models for bringing organisations together, for collaboration between pediatric and adult wards, for outreaching first-line treatment, communication strategies for awareness-building campaigns, model of financial sustainability. As its main service, the task will define the most appropriate models according to country/regional specificities, based on implementation research approaches (needs assessment, context analyses, identification of enablers/barriers, discussion with stakeholders, including consultation of patient organisations, recommendations). Specific concrete deliverable will be country-specific use cases and AYA programme development.
3. Task 3 - Development of clinical recommendations on AYA-specific topics and different types of cancer across age groups – the task will map existing guidelines to identify a priority list of recommendations to develop; determine the methodological approaches for defining recommendations; develop recommendations in synergies with existing expert groups and advocacy groups; explore innovative approaches for guideline implementation, such as digital

tools, decision support systems; define a plan to develop a system for monitoring the impact of the recommendations.

4. Task 4 - Development of training on cancer in AYA – the task will develop training courses addressed to different multidisciplinary stakeholders (GPs, experts, patients, etc) considering EU- and national specificities; the goal will be to create a curriculum on AYA with cancers, considering different contexts (e.g., countries with an AYA-dedicated programme and countries without an AYA programme).
5. Task 5 - Promotion of AYA/trans-age clinical cancer research (with a specific focus on access to clinical trials) – the task will support the development of new collaboration across disease specific and paediatric oncology scientific societies to promote AYA/trans-age research. A specific service of the task will be the promotion of access to clinical trial (e.g., early-phase) for AYA patients by reinforcing joint actions of medical and pediatric oncologists. A specific goal will be the creation of task forces with European pediatric/medical oncology societies per disease of interest in AYA or which are disease agnostic to promote trans-age trials, considering the early to the late phases of drug development.
6. Task 6 - Monitoring of AYA cancer indicators – the task will define Core Outcome Indicators (COIs) for AYA research and clinical care, identify relevant data sources (e.g., registries, longitudinal cohort studies) to collect these COIs, and ultimately build federated national ecosystems and a pan-European ecosystem with the identified relevant data sources including these COIs.
7. Task 7 - Definition of the sustainability strategy. This task will define a sustainability strategy for the NoE addressing key factors such as resource allocation, funding mechanisms, scalability, EU collaborations, implementation of achievements at country level (integration with the health care system).

Collaborating stakeholders and synergies of the NoE

Different collaborating stakeholders have been identified and need to be considered for the potential contribution to the NoE on AYAs. As an example, possible synergies between the NoE and identified stakeholders are depicted in Figure 2.

Scientific societies:

- SIOPE - European Society for Paediatric Oncology: SIOPE has a Committee specifically dedicated to AYA patients, and together with ESMO has founded the ESMO-SIOPE AYA Working Group. The

- synergies between the NoE on AYA and SIOPE can involve different objectives (and different tasks), including the development of AYA-dedicated programs, the development of clinical recommendations, training on cancer in AYA, and promotion of clinical cancer research in AYA.
- ESMO - European Society for Medical Oncology and ESMO/SIOPE AYA Working Group: possible synergies on the development of AYA-dedicated programs, the development of clinical recommendations, training, and promotion of research.
 - EHA - European Hematology Association: development of clinical recommendations
 - EONS -European Oncology Nursing Society: development of clinical recommendations
 - ESTRO - European Society for Radiotherapy and Oncology: development of clinical recommendations
 - ESSO - European Society of Surgical Oncology: development of clinical recommendations
 - IPOS - International PsychoOncology Society: development of clinical recommendations
 - OECI - Organisation of European Cancer Institutes: development of clinical recommendations, monitoring AYA cancer indicators
 - ECO - European Cancer Organization

European Reference Networks

- EURACAN - European Reference Network on Rare Adult Solid Cancers: possible synergies in the development of clinical recommendations and training.
- PaedCan - ERN for Paediatric Oncology: development of clinical recommendations and training.
- EuroBloodNet – ERN on Rare Hematological Diseases: development of clinical recommendations and training.
- Genturis – ERN on GENetic TUmour RIsk Syndromes: development of clinical recommendations and training.

Research organisations

- EORTC - European Organisation for Research and Treatment of Cancer: promotion of clinical cancer research in AYA
- European Network of Cancer Registries: promotion of research

Collaborative groups/research projects, AYA focused

- ENTYAC - European Network for Teenagers and Young Adults with Cancer: the synergies between the NoE on AYA and ENTYAC can involve different objectives, including the development of AYA dedicated programs, development of clinical recommendations, training on cancer in AYA, monitoring of AYA cancer indicators.

Synergies

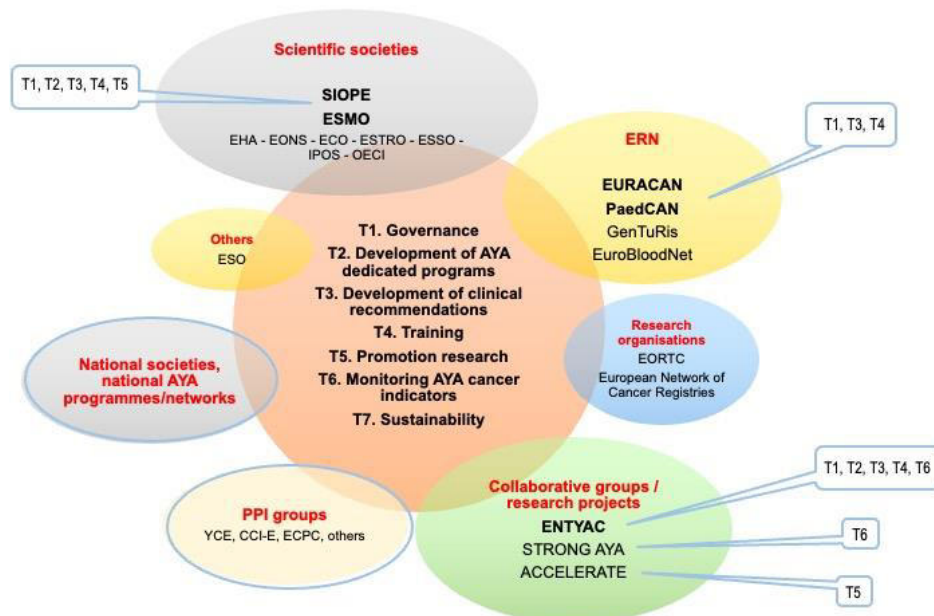


FIGURE 2 SYNERGIES BETWEEN THE NOE AND ITS STAKEHOLDERS

- STRONG AYA: promotion of research, monitoring of AYA cancer indicators.
- ACCELERATE platform: promotion of clinical cancer research

Patient and Public Involvement (PPI) groups

- YCE (Youth Cancer Europe), CCI-E (Childhood Cancer International – Europe), ECPC (European Cancer Patient Coalition), others: possible synergies on the development of AYA dedicated programs, the development of clinical recommendations, promotion of research, monitoring of AYA cancer indicators.

National societies, national AYA programmes/network

- synergies on the development of AYA dedicated programs

Others

- ESO – European School of Oncology: synergies in the development of training on cancer in AYA.

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