



The JANE- EU Joint Action on Networks of Expertise aims at shaping seven new Networks of Expertise (NoEs) in the cancer field. It started in October 2022 with the participation of sixteen European countries, represented by 16 beneficiaries and 20 affiliated entities. The Joint Action is coordinated by Fondazione IRCCS, Istituto Nazionale dei Tumori di Milano, Italy. and it is funded by the European Health and Digital Executive Agency, EU4Health Programme (Grant Agreement:101075328).



The Annual Plenary Meeting of JANE-Joint Action on Networks of Expertise was organized on 16th and 17th November 2023 in Barcelona, Spain, with the participation of all JANE partners. The meeting had the main objective of monitoring the progress of the project, the achievements to date, analyzing the problems and difficulties encountered, as well as specifying the next tasks to be completed by the partners. The Annual Plenary Meeting also served to discuss the future JANE2 Joint Action, which is presented as the continuity of this project and whose start date is scheduled for September 2024.

Additionally, a Stakeholder Forum was held on 16th November focused on: i) presenting the current status and achievements of JANE and share the main concerns of the NoEs leaders to establish solid alliances with different key agents, ii). Exploring stakeholders' needs and expectations about NoEs and how they can contribute to addressing current challenges in the cancer ecosystem, iii) discussing what NoEs can expect from civil society, academia, the private sector, and other key agents in terms of support and collaboration.

During the event, the leaders of the work packages for the seven Networks of Expertise:

- NoE-Complex & Poor prognosis cancer
- NoE-Palliative care
- NoE-Survivorship
- NoE-Personalized Primary Prevention
- NoE-Omics
- NoE-Hitech medical resources
- NoE – Adolescent and Young adults with cancer

summarized the activities and the progress in each of the networks during the first year of the project

NoE-Complex & Poor prognosis cancer

Mission of NoE on Poor prognosis cancer was established - increase survival rate of patients with PPC at least above 33%. The group decided to run a pilot NoE PPC dedicated to pancreatic cancer since the 5 year overall survival in this group is around 10%. Pancreatic cancer working group was formed and existing models of pancreatic cancer care were evaluated for current and future networking and mapping of existing initiatives dedicated to pancreatic cancers was performed.

There was consensus about building the multidisciplinary group gathering the expertise, professionals from different specializations, PAGs and societies or institutions representing the healthcare systems across Europe. The list of experts involved in model WP5 Poor Prognosis Cancers was prepared. Pancreatic cancer working group revised deliverables and set of standards on early diagnosis, guidelines and education provided by IPAAC. Four domains for pancreatic cancer NoE were defined: research and innovation, clinical care, policy and patient engagement, education & training. Pancreatic working group developed PPC governance model based on EURACAN governance model.

NoE-Palliative care

The overall objective is to establish a sustainable, high profile NoE on palliative care (PC), to support the integration of the principles underpinning evidence-based palliative care into routine cancer care across the European Union member states. To comply with these objectives, the targets of NoE in palliative care include:

- Integration of the principles of palliative care (PC) into routine cancer care, regardless of at which health care level the anti-anticancer treatment/care/follow-up is provided
- Connect and liaise to
 - ensure anchoring at the health political arena, nationally and internationally at the overall NoE level with CCCs and relevant stakeholders
 - increase visibility, collaboration and work of common identified gaps in PC provision
- Become a platform for PC experts for the discussion of excellence of care.
- Define key criteria to facilitate this integration by
 - defining the basic content of PC
 - developing indicators on how to monitor integration
 - focusing on how to implement the PC principles at different health care levels
 - using patient-centered care pathways (PCCP) as the framework for integration
 - ensuring adequate PC competence in routine CC and PC with access to PC training and implementation also in remote areas), e.g., online resources

NoE-Survivorship

NoE on Survivorship focuses on health and the physical, psychological, social and economic issues affecting people after the end of the primary treatment for cancer. Achieving comprehensive and coordinated management and care for cancer survivors requires coordination and organization across health systems. NoE should be implemented at the national or EU level in collaboration with Healthcare providers appointed by member states for survivorship and further contact directly with comprehensive cancer infrastructure in each country. The NoE sites and/or services should provide:

- Guidelines for recurrences and second primary cancers
- Guidelines for effects of primary cancer and chronic medical conditions;
- Guidelines for psychological effects of cancer;
- Guidelines for social, work, and financial effects of cancer;
- Guidelines for cancer prevention and overall health and well-being promotion

NoE-Personalized Primary Prevention

The objectives of the NoE on Personalized Primary Prevention include: Promote knowledge exchange and collaboration; Develop evidence-based guidelines and best practices; Facilitate research and innovation; Enhance education and training; Influence policy and practice.

The criteria for participation in the future network for centers, experts and health care providers include: Expertise and experience; Reputation and track record; Collaborative approach; Innovation and adaptability; Geographic scope and coverage; Compliance and regulatory requirements; Resources and capacity; Alignment with Network Objectives; Continuous Professional Development; Ethical considerations These endorsement criteria help establish a framework for assessing the quality, expertise, and patient-centeredness of centers, experts, and healthcare providers in oncology.

The participants in the network should include a diverse group of stakeholders, such as:

- Researchers and scientists specializing in personalized cancer prevention
- Geneticists and genetic counselors involved in genetic testing and risk assessment.
- Patient advocacy groups and representatives to ensure patient-centered perspectives.
- Oncologists and healthcare providers with expertise in cancer prevention
- Public health professionals and policymakers focusing on cancer prevention strategies.
- Representatives from relevant organizations and institutions involved in cancer research or healthcare delivery.

NoE-Omics & NoE-Hitech medical resources

Although NoE-Omics & NoE-Hitech medical resources remain separate, they have decided to work closely together due to their similar characteristics and common challenges.

The scope of the future network on Omics focuses on fostering the integration of omics technologies into all EU healthcare systems in order to improve clinical decisions in precision medicine in oncology (genetic susceptibility, diagnosis, treatment, follow-up, palliative care) The scope of the future network on Hi-tech medical resources includes 5 domains considered as priorities: innovative radiotherapies, interventional radiology, innovative nuclear medicine, cell therapies and ex-vivo testing of agents.

As omics and hi-tech medical resources are innovative, very expensive and rather rare resources in the European cancer area, the future NoEs will have to respect the following principles: equal access to excellence and high quality services, fast integration of innovation into care and flexibility given the Member States' specificities. The objectives of the future NoEs are being defined in synergy with other existing stakeholders, networks and projects at the EU and national levels. As omics and hi-tech medical resources evolve fast, the future network could act as an innovation observatory, warning of new innovative practices that are "ready" for use.

The endorsement criteria of NoEs on Omics and Hitech medical resources come under the following headings:

- Type and volume of activity
- Infrastructure, resources, capability
- Workflow, accessibility, collaboration

The endorsement participation criteria were defined in order to allow 3 categories of healthcare providers all around Europe to benefit from the future network. Those criteria needed to apply to care and had to remain simple, with a prerequisite of quality, inclusivity and a twinning approach.

NoE-Adolescent and Young adults with cancer

The endorsement criteria and identification of participants were defined as following:

1) Health care providers, comprehensive cancer centers: The centers must have European scope (e.g. participation to EU projects/EU collaborative groups etc.)

- National leadership/mandate: centers need the capacity, capability and resources to participate at the European level in order to then lead/guide the implementation of recommendations of the NoE at the national level
- Specific competence/expertise on AYA proven by coordination/participation in national networks/programmes; AYA dedicated research/study; publication track on AYA with cancers
- Proven collaboration between paediatric and adult oncology
- Proven collaboration with national AYA programme/activities/associations

2) Scientific and professional societies/networks/research groups: The endorsement criteria must be the European scope (e.g. involved in EU projects on health care organization, public policy, clinical practice guidelines, etc.)

- Scientific societies (SIOPE, ESMO, EHA, EONS, ECO, ESTRO, ESSO, OECI)
- European Reference Networks (EURACAN, PaedCan, EuroBloodNet, Genturis)
- Research organization (EORTC, European Network of Cancer Registries)
- Collaborative groups AYA focused (ENTYAC)

3) Patient advocacy groups

The NoE must include patient and public involvement (PPI) groups as active members. The PPI is considered a key component of the whole project, to ensure that patients' needs are really met, and each results leads to a real benefit for the patient. The major endorsement criteria remain the European scope. The NoE should involve Youth Cancer Europe, Childhood Cancer International (CCI) – Europe and European Cancer Patient Coalition (ECPC).

The following months will be vital to continue working on the NoEs and to define the new JANE2 Joint Action that will bring together the challenges in the European health ecosystem related to the approach to cancer. The aim will be to present the results of this analytical work to the **European Parliament at the final JANE event.**