



# Joint Action on Networks of Expertise

## Milestone number. 10

### Sustainability strategy of NoEs

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## DOCUMENT INFORMATION

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## *Table of abbreviations*

BIOSISTEMAK	Instituto de Investigación en Sistemas de Salud (formerly Kronikgune)
BMG	Bundesministerium für Gesundheit
CCC	Comprehensive Cancer Center
CIBER	Consortio Centro de Investigación Biomédica en Red
CIPH	Hrvatski zavod za javno zdravstvo
CNAO	FONDAZIONE CENTRO NAZIONALE DI ADROTERAPIA ONCOLOGICA
CNAO	FONDAZIONE CENTRO NAZIONALE DI ADROTERAPIA ONCOLOGICA
DKFZ	Deutsches Krebsforschungszentrum
EC	European Commission
FHF	Fédération Hospitalière de France
GDPR	General Data Protection Regulation
HSJD	Hospital Sant Joan de Déu
IARC	The International Agency for Research on Cancer
ICAN	Cancer Advocacy Network
ICO	Instituto Catalán de Oncología
IDIVAL	Fundación Instituto de Investigación Marqués de Valdecilla
INCA	Institut National du Cancer
INT	Intituto Nazionale dei Tumori
INT-NA	ISTITUTO NAZIONALE TUMORI FONDAZIONE PASCALE
INT-NA	ISTITUTO NAZIONALE TUMORI FONDAZIONE PASCALE
IONC	INSTITUTUL ONCOLOGIC PROF DR ION CHIRICUTA CLUJ-NAPOCA
IOV	ISTITUTO ONCOLOGICO VENETO
IPR	Intellectual property rights
IRST	ISTITUTO ROMAGNOLO PER LO STUDIO DEI TUMORI DINO AMADORI
JANE	EU JOINT ACTION NETWORKS OF EXPERTISE ON CANCER
MHA	Ministry for Health and Active Ageing
MS	Member States
MSCI	NARODOWY INSTYTUT ONKOLOGII IM. MARII SKŁODOWSKIEJ-CURIE- PANSTWOWY INSTYTUT BADAWCZY
NCI-LT	NACIONALINIS VEZIO INSTITUTAS
NoEs	Networks of Expertise
OOI	Országos Onkológiai Intézet



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OUS	OSLO UNIVERSITETSSYKEHUS HF
SAS	Servicio Andaluz de salud
UNICEF	United Nations Children’s Fund
WHO	World Health Organization
WP	Work Package

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## 1 EXECUTIVE SUMMARY

The overall objective of the JANE Joint Action is to establish seven Networks of Expertise in the cancer field by preparing everything necessary to launch them and critically evaluating existing models of current and future EU networking. These networks will foster collaboration and knowledge sharing among all EU Member States, leading to the development of guidelines and best practices, facilitating research and innovation, enhancing education and training, and ultimately improving health policy at both national and European levels.

Within the JANE work packages (WPs), there is the WP4 related to sustainability. This WP will support the NoEs by focusing on strategies to guarantee their sustainability and aligning them with European and national policies. It will also generate policy recommendations and guidance to facilitate the sustainability of the networks, possibly extending to other health care networks in the EU.

The aim of this document, which is the first milestone of the WP4, is to provide useful information to support future leaders and members of the Networks of Expertise to develop the sustainability strategy of the NoEs. The results that are reported in this milestone are based on the results of the first task of WP4 ‘T4.1 *Mapping and analysis of existing networks*’ that have analyzed European health care networks’, organizations and networking projects and will lay the foundations of the sustainability strategy of the NoEs, which will be later validated with experts in the field to build a final set of recommendations.

The development of a successful sustainability strategy requires considering various organizational structures. This is the main reason why initially these organizational structures were described in detail and the elements to consider to be able to compare them were defined. This work resulted into a reference framework with several dimensions and sub-dimensions that is intended to serve as a basic pillar in the definition of new organizations in this field while guaranteeing their sustainability over time.



## 2 INTRODUCTION

### 2.1 JANE project summary

The JANE project (EU Joint Action in Networks of Expertise on Cancer, <https://jane-project.eu/>), falls within the framework of the European Union's EU4Health Program, specifically the Joint Actions which aim to foster cooperation, coordination, and knowledge-sharing among Member States in various areas of health policy and practice. JANE project has started in October 2022, it is coordinated by Istituto Nazionale Dei Tumori (INT) and involves the participation of 16 Competent Authorities and 20 Affiliated Entities and 2 Patient Associations from 16 countries all around Europe.

JANE aims to establish seven Networks of Expertise (NoEs) related to cancer in the areas of complex & poor prognosis cancer, palliative care, survivorship, personalized primary prevention, omics, hi-tech medical resources and adolescents & young adults with cancer.

JANE will outline and prepare these NoEs to cover these crucial areas of cancer care, bringing together the best resources available in Europe in each specific field, in order to support National Networks and Comprehensive Cancer Centers (CCCs). The NoEs will serve to promote collaboration and share knowledge and their own services with healthcare systems across all Europe, first to healthcare providers directly reaching out to patients. The NoEs will provide services to the European cancer community, these services may include, but will not be limited to the following: a) producing, or supporting, clinical practice guidelines and/or general recommendations for medical professionals, patients, the public; b) raising public awareness and carrying out advocacy/policy actions; c) developing healthcare organization models; d) developing educational activities/tools for medical professionals and patients; e) undertaking efforts to promote research; f) developing quality criteria for accreditation/endorsement mechanisms; g) engaging patients and the public; h) others.

The general goals of JANE are:

- To prepare everything necessary to launch the new Networks of Expertise; from defining their missions and objectives, studying their design and working out the selection criteria for participants, to providing all items to set up calls for expressions of interest;
- To critically evaluate existing models of current and future EU networking, research infrastructures and platforms, future networking among comprehensive cancer centers, as well as technologically relevant aspects for optimal functioning of networking in general, in order to properly shape the new NoEs.



During this Joint Action the members of the Joint Action envisage the effective functioning of the NoEs, building on previous and ongoing EU networking experiences, and finding solutions rooted in the European oncology community. This will be possible thanks to work developed by the Task Forces of JANE about current problems of EU health networks. The subject of the Transversal Task Forces are integration between health care and research; integration between EU networking and MSs; integration between information-technology infrastructures, including the use of artificial-intelligence tools; the ERN model and patient involvement.

The outputs of the discussions and the consensus made within the Task Forces about current problems of EU health networks will be shared with the European oncology community and Member States, through a green paper and a European conference at the end of the Joint Action.

The results of the work done during JANE will serve as a basis for the follow-up Joint Action (JANE-2) that will also be coordinated by INT and it is expected to start in the last quarter of 2024. JANE 2 will allow the launch of the seven NoEs in the cancer area, allowing them to start fulfilling their mission.

## 2.2 Purpose of this document

Among the work packages in the JANE project, there is one specifically aimed at sustainability (WP4). This work package aims to ensure the long-term sustainability of Networks of Expertise (NoEs) by aligning them with European and national policies, offering policy recommendations, and providing them guidance on that aspect.

The aim of this document, which is the first milestone of the WP4, is to provide useful information to support future leaders and members of the NoEs to set the sustainability strategy of the networks. This milestone conducted into the task T4.1 *'Mapping and analysis of existing network's'*, includes the development of a reference framework with several dimensions and sub-dimensions to facilitate the description between organization structures and functions.

The development of this framework provided the basis for the analysis of 15 existing healthcare networks, organizations and networking projects in the EU. This work will result in the lay the foundation of the sustainability strategy of the NoEs prior its establishment in the European ecosystem. These strategies will be later validated with experts in the field to build a final set of recommendations. That is intended to serve as a first step in the conceptualization of the NoEs and will give an overview for setting their general infrastructure in Europe.

It will also be useful for the creation of new NoEs apart from the initial seven networks that will be launched within the scope of JANE2 Joint Action.



The contents of this document are presented as follows. **Section 1** contains the executive summary of this document. **Section 2** provides the introductory aspects of the work presented in this milestone. **Section 3** describes the methodology for developing the framework, the identification, selection and prioritization of organizations and finally the strategy for the information collection and review. **Section 4** presents the lessons learned from the mapping. Finally, **Section 5** presents the conclusions of the work.

### 3 METHODOLOGY

#### 3.1 Development of the reference framework for the analysis of European networks, organizations and networking projects

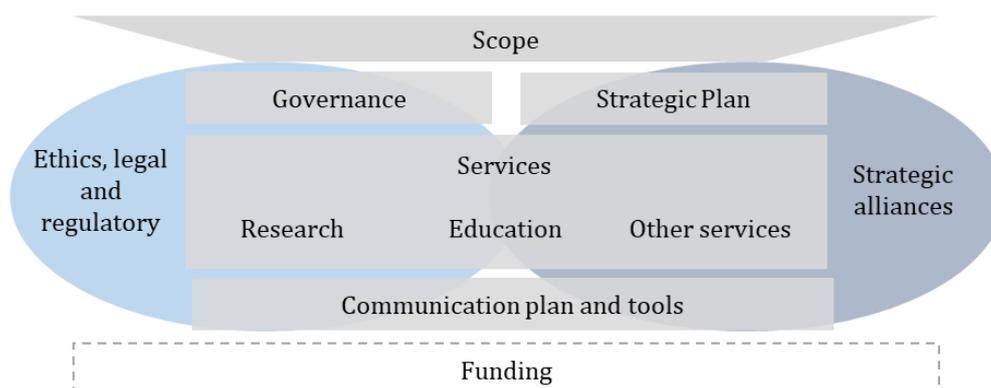
The main aim of the Task 4.1 is to gather information about key aspects of European networks, organizations and networking projects that could serve as a cornerstone to support the creation and sustainability of the NoEs over time. It is expected that this will be possible through the analysis of lessons learned from these organizations, leading to a set of strategies that will be validated with experts to finally develop recommendations for the sustainability of NoEs.

Before to the selection of the organizations to be analyzed, a previous exercise was done elaborating a document to facilitate the description and comparisons between different organization structures. This was the result of a preliminary literature review exercise where it was found that many factors could be taken into account in the development of successful sustainability strategy within organizations.

This document, entitled ‘**Reference framework for the analysis of European networks, organizations and networking projects**’, includes a number of dimensions and sub-dimensions that are intended to serve as basic pillar in the definition of existing and new organizations. On other hand, the description and analysis of the different models allows for a qualitative comparison between them, which could also serve as a basis for selecting key aspects that could guarantee the creation of sustainable organizations or networks over time.

This framework includes eight organizational dimensions that are basic for the networks and associations analyzed: (1) scope, (2) governance, (3) strategic plan, (4) services (research, education and others), (5) strategic alliances, (6) communication strategy and tools, (7) ethics legal and regulatory and (8) funding.

**Figure 1.** Dimensions and sub-dimensions of the Reference framework for the analysis of European networks, organizations and networking projects.





Below are descriptions of each of the dimensions and sub-dimensions included in the framework.

### 3.1.1 Scope

The scope of the organization, network our European networking project will be defined by all the priority areas it encompasses, and seeks to define the objectives, mission, vision and values of the network<sup>1</sup>.

- **Objectives:** "They are those purposes that the organization seeks to achieve through its existence and activities<sup>2</sup>". They are therefore a measurable result that an organization aims to achieve and that guides all members of the organization in reaching it, it also could serve as a framework for monitoring the progress towards their objectives. Objectives can be distinguished according to their nature (general/specific), their time frame (short/medium/long term), their measurability (quantitative/qualitative) and their scope of application.
- **Mission:** Is a concise explanation<sup>3</sup> of the organization's reason for existence. It describes the organization's purpose and its overall intention, as well as, how it intends to meet those goals. The mission statement supports the vision, addresses what the organization offers and serves to communicate the purpose and direction to their members and other stakeholders.
- **Vision:** A statement that creates a mental image of the ideal state which the organization wishes to achieve. It could encourage their members, customers and stakeholders in terms of what they are doing and where the organization is headed.
- **Values:** Are considered the key determinants of attitudes, work behavior and decision-making processes that guide and direct the organizations and its culture<sup>4</sup>. It also highlights the contexts in which organizations operate, as normative assumptions and goals of the institutions in everyday practice.

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<sup>1</sup> Sá-Sousa A, Rodrigues T, Fernandes S, Santos AM, Garcia-Lema I, Costa ED, Chaves Loureiro C, Boechat JL, Baía Reis A, Figueiredo D, Fonseca JA, Neves AL, Jácome C. ConectAR: Collaborative network of patients with asthma and carers actively involved in health research. A protocol for patient and public involvement. *Eur Ann Allergy Clin Immunol.* 2022 Mar 10. doi: 10.23822/EurAnnACI.1764-1489.249. Epub ahead of print. PMID: 35261226

<sup>2</sup> Jauch, Lawrence R., and William F. Glueck. *Strategic management and business policy.* McGraw-Hill, 1988.

<sup>3</sup><https://www.shrm.org/resourcesandtools/tools-and-samples/hr-qa/pages/mission-vision-values-statements.aspx#:~:text=A%20mission%20statement%20is%20a.customer%2C%20vendors%20and%20othe%20stakeholders>.

<sup>4</sup> Askeland, H., Espedal, G., Jelstad Løvaas, B., & Stephen, S. "Understanding Values Work in Organisations and Leadership" ed. Harald Askeland, Beate Løvås and Gry Espedal, *Understanding Values Work: Institutional Perspectives in Organizations and Leadership* (Palgrave Macmillan, 2020), 26.



### 3.1.2 Governance

There is a certain agreement in the literature in establishing that governance represents the efforts and processes whereby the priorities of an action are achieved<sup>56</sup>. In addition, it would also include the set of entities that participate, their roles, attributions and operating guidelines<sup>7</sup>. Based on this, each network must develop its own structure considering its context, including its stakeholders, funding, research environment, personalities, among others, to ensure that their priorities can be met.

- **Identifiable governing entity:** The governing entities may include the following bodies: General Assembly, Strategic Board, Management board, President, Coordination, Key observers, Working Groups and Specific Departments, such as Communication and Dissemination and Ethic and Legal. Furthermore, some networks could have potentially policy-making bodies, which could act as observers.
- **Organizational and functional structure:** The bodies included in the organizational structure have well-defined functions. Certain aspects of infrastructure are critical to the success of networks, such as those responsible for resource management, timing and process facilitation. A functional organizational structure should organize the network in different functions based on areas of expertise, grouping professionals by specialty, skills or roles, who are specialized in specific tasks. Some of these functions could be administration, communication, operation management, among others.
- **Capability:** Number and nature of organizations or profile of professionals involved in the organization. The diversity of profiles within organizations can facilitate their multidisciplinary approach, as well as the collaboration of agents from different sectors (industry, academia, advocacy, among others).
- **Organizational model:** The legal status and nature of the network could vary, as described below. In addition, mixed status has also been identified, even if not detailed in this section<sup>8</sup>.
  - International public organization or European Agency: A European Agency is a body governed by a European law and set up by an act of secondary legislation (regulation/joint action/decision). It has its own legal personality, financial and administrative autonomy,

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<sup>5</sup> Barbazza E, Tello JE. A review of health governance: definitions, dimensions and tools to govern. Health Policy. 2014;116(1):1-11

<sup>6</sup> Hanleybrown F, Kania J, Kramer M. Channeling change: making collective impact work. Stanf Soc Innov Rev 2012

<sup>7</sup> Marco comparativo para HDAB. 2022

<sup>8</sup> Kalra, D., Lange, M., Birov, S., Müller, S., Prodan, A., Kolitsi, Z., Nicolas, L., & Marti, T., 2022. Service Portfolio for Sustainability. [online] mHealthHUB European. Available at: <<https://mhealth-hub.org/download/d4-5-service-portfolio-for-sustainability>> [Accessed 22 February 2023].



and it is independent in the execution of the assigned mission/tasks. The Agency usually receives financial funding from the EC, and it is most often a permanent body, which has its seat in one of the Member States of the European Union. Some of these entities are United Nations Children's Fund (UNICEF), World Health Organization (WHO) and The International Agency for Research on Cancer (IARC).

- Single non-for-profit Organization: A Non-for-Profit Organization (NPO) is an organization that uses surplus revenues to achieve its goals rather than distributing them as profit or dividends. NPOs have controlling members or a board of directors. Many of these organizations employ paid staff including management profiles, whereas others employ unpaid volunteers and even executives who work with (occasionally nominal) compensation or without compensation. Some of these entities in the cancer field are International Cancer Advocacy Network (ICAN), Center for Advancement in Cancer Education and Young Survival Coalition.
- Partnership or Society: Is an entity formed by two or more individuals or entities who collaborate to achieve a common goal or to conduct business activities together. They share profits or losses and also responsibilities according to the terms outlined in the partnership or society agreement. This model could work in EC funded projects, through a new Consortium Agreement, to implement new scope as a continuation of the previous project; it may provide short-term sustainability solutions. Over time, this partnership may eventually evolve into models such as the European Economic Interest Grouping (EEIG), designed to facilitate the creation of consortia to participate in EU programs.
- **Membership**: Status or condition of being a member of a group, organization or community, typically entailing certain rights, privileges and obligations associated with the participation. Depending on the nature and purpose of the networks, the procedures to join them may vary.

### 3.1.3 Strategic plan

Strategic plans promote thinking, acting and learning that lead to improvements in organizational performance and better decision making. In a way, they show what can be done, how, where and when, in pursuit of achieving the network's goals<sup>9</sup>. It is necessary that the Strategic Plan takes into account possible adjustments over time in order to ensure the sustainability of the network. These

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<sup>9</sup> Bryson, John M., Barbara C. Crosby, and John K. Bryson. "Understanding Strategic Planning and the Formulation and Implementation of Strategic Plans as a Way of Knowing: The Contributions of Actor-Network Theory." *International Public Management Journal* 12.2 (2009): 172-207. Web. Feb 14, 2023



considerations could include a plan for a transitional period<sup>10</sup> that considers the full development and achievement of activities or services that can provide benefits to the network and encourage its self-financing.

### 3.1.4 Services

The provision of services by the organization could contribute to its continuity and sustainability.

- **Research:** Interdisciplinary research could enhance complex problem solving. In that sense, collaborative networks are an opportunity for both professionals and society to foster multicenter research with greater impact and extent. It is particularly important that every time a collaborative project ends, the network creates a space for exploration of the advantageous initiatives, the barriers encountered, and the identification of strategies for improvement.
- **Education and training:** Initiatives aimed at training both organization members and/or external participants, as well as the existence of exchange or twinning opportunities that foster the generation of knowledge or new competencies<sup>11</sup>. There is a value opportunity and a business opportunity for the organizations to organize conferences that highlight success stories and disseminate learnings, as well as deeper dive workshops to explore specific topics and to develop strategies<sup>12</sup>.
- **Other services:** Include the provision of other kind of resources that benefit contribute to the organization, such as the matchmaking services, knowledge exchange activities, among others.

### 3.1.5 Strategic alliances

- **Key stakeholders:** A key stakeholder is an individual, group or organization that has a vested interest in a particular project, organization or system. Promote the dialogue with these agents it is important for the organizations to guarantee that their objectives meet the perceived needs in the thematic area of the network and are aligned with European policies and initiatives. The assumption of strategic alliances can guarantee a continued service and financial sustainability beyond the first stage of life of networks, often related with the existence of funds for a project. To do this, it is necessary to identify the target stakeholders that can benefit from the objectives of

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<sup>10</sup> Kalra, D., Lange, M., Birov, S., Müller, S., Prodan, A., Kolitsi, Z., Nicolas, L., & Marti, T., 2022. Service Portfolio for Sustainability. [online] mHealthHUB European. Available at: <<https://mhealth-hub.org/download/d4-5-service-portfolio-for-sustainability>> [Accessed 22 February 2023].

<sup>11</sup> Godwin N, P, Peck E, Freeman T, Posaner R. Managing across diverse networks of care: Lessons from other sectors. Report to the National Co-ordinating Centre for the NHS Service Delivery and Organisation R&D. London, Co-ordinating Centre for NHS Delivery and Organisation. 2004

<sup>12</sup> Kalra, D., Lange, M., Birov, S., Müller, S., Prodan, A., Kolitsi, Z., Nicolas, L., & Marti, T., 2022. Service Portfolio for Sustainability. [online] mHealthHUB European. Available at: <<https://mhealth-hub.org/download/d4-5-service-portfolio-for-sustainability>> [Accessed 22 February 2023].



the network, establishing networks of work and collaboration with them and drawing up individualized action plans for them.

- **Networking, matchmaking and knowledge exchange:** This dimension includes the activities aimed at the promotion of collaboration between the stakeholders of the network and its members through events, collaboration in projects or exchange of good practices in twinning format (owner of a good practice transfers knowledge to one or more adopters, leading to a replication or adaptation of the practice in another context)<sup>13</sup>.

### 3.1.6 Communication strategy and tools

It includes the communication strategy and tools that the organization has to increase the awareness of its activities, to promote training and research and other opportunities for active members to attract new people or entities to join the network<sup>14</sup>. It is recommended that the organization has its own brand entity, as well as a dissemination pack that can be used in all its communications.

### 3.1.7 Ethics, legal and regulatory

Regarding research activities, two aspects that might be specially considered are data privacy and personal data protection<sup>15</sup>. Specially, topics as **secondary use of data and data security** are very remarkable: including privacy, confidentiality, integrity and availability. The organization must be aware of these issues and the related regulations, as well as aspects related to international collaboration and the development of projects and initiatives that may affect or be linked to the development of activities within their organization.

In some cases, it may be necessary for organizations to develop their own legal **and regulatory frameworks** for exchange activities, participation in collaborative projects or during the design of documentation of public interest, which may lead to issues related to intellectual property, among others. In the case of international collaborations, models of care processes as well as the use of common infrastructures may also be subject to legal or regulatory issues.

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<sup>13</sup> Kalra, D., Lange, M., Birov, S., Müller, S., Prodan, A., Kolitsi, Z., Nicolas, L., & Marti, T., 2022. Service Portfolio for Sustainability. [online] mHealthHUB European. Available at: <<https://mhealth-hub.org/download/d4-5-service-portfolio-for-sustainability>> [Accessed 22 February 2023].

<sup>14</sup> Sá-Sousa A, Rodrigues T, Fernandes S, Santos AM, Garcia-Lema I, Costa ED, Chaves Loureiro C, Boechat JL, Baía Reis A, Figueiredo D, Fonseca JA, Neves AL, Jácome C. ConectAR: Collaborative network of patients with asthma and carers actively involved in health research. A protocol for patient and public involvement. *Eur Ann Allergy Clin Immunol.* 2022 Mar 10. doi: 10.23822/EurAnnACI.1764-1489.249. Epub ahead of print. PMID: 35261226

<sup>15</sup> Sá-Sousa A, Rodrigues T, Fernandes S, Santos AM, Garcia-Lema I, Costa ED, Chaves Loureiro C, Boechat JL, Baía Reis A, Figueiredo D, Fonseca JA, Neves AL, Jácome C. ConectAR: Collaborative network of patients with asthma and carers actively involved in health research. A protocol for patient and public involvement. *Eur Ann Allergy Clin Immunol.* 2022 Mar 10. doi: 10.23822/EurAnnACI.1764-1489.249. Epub ahead of print. PMID: 35261226

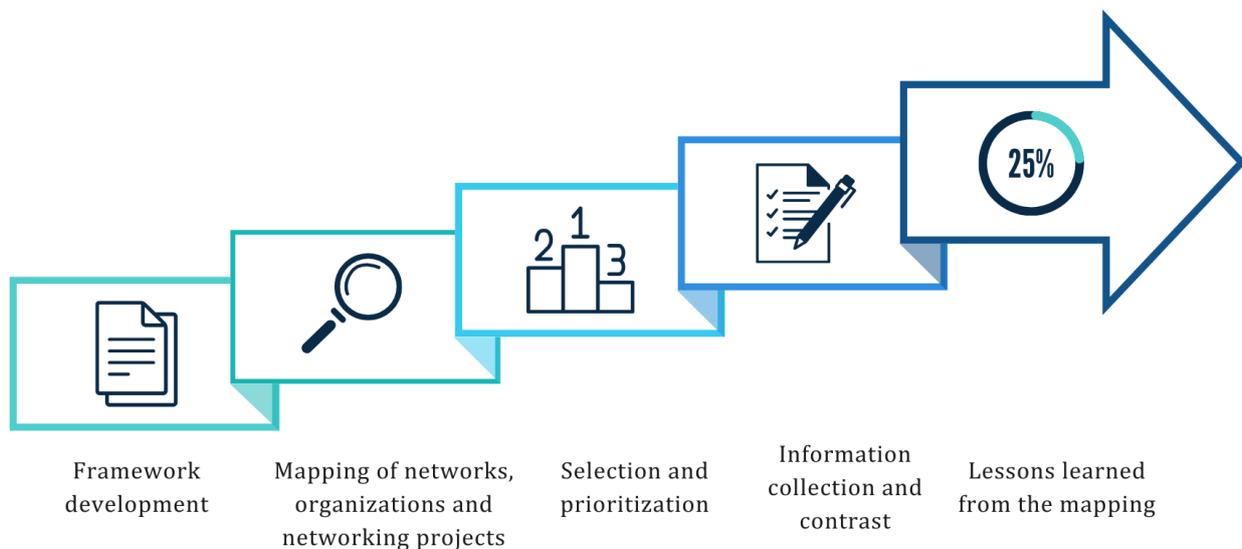
### 3.1.8 Funding

The availability of funds is fundamental and a necessary requirement for the sustainability of the organization and the promotion of activities that foster the exchange and generation of knowledge<sup>16</sup>. In order to guarantee the financial sustainability of the organization after the initial funding sources dedicated to their implementation, three different sources of economic input can be distinguished: income generated by the network, members' own investments (in-kind and/or financial) and potential external funding<sup>17</sup>.

## 3.2 Identification, selection and prioritization

After the development of the reference framework, an identification, selection and prioritization of European networks, organizations and networking projects in the cancer field was conducted. A general overview of the process is represented in the figure below.

**Figure 2.** Step process methodology overview.



As a second step in the development of this procedure, between December 2022-January 2023, Biosistemak (BS) as leader of WP4, asked WP4 partners (BMG, CIBER, CIPH, CNAO, DKFZ, FHF, HSJD, ICO, IDIVAL, INCA, INT-NA, IOV, NCI LT, OIL, OOI, SAM LT, SAS, and UNICANCER) and the leaders of the 7 NoEs of JANE (MSCI, OUS, IOCN, Sciensano, UNICANCER, and INT) to provide examples of networks,

<sup>16</sup> Héon-Klin, V. European Reference networks for rare diseases: what is the conceptual framework?. Orphanet J Rare Dis 12, 137 (2017). <https://doi.org/10.1186/s13023-017-0676-3>

<sup>17</sup> Kalra, D., Lange, M., Birov, S., Müller, S., Prodan, A., Kolitsi, Z., Nicolas, L., & Marti, T., 2022. Service Portfolio for Sustainability. [online] mHealthHUB European. Available at: <<https://mhealth-hub.org/download/d4-5-service-portfolio-for-sustainability>> [Accessed 22 February 2023].



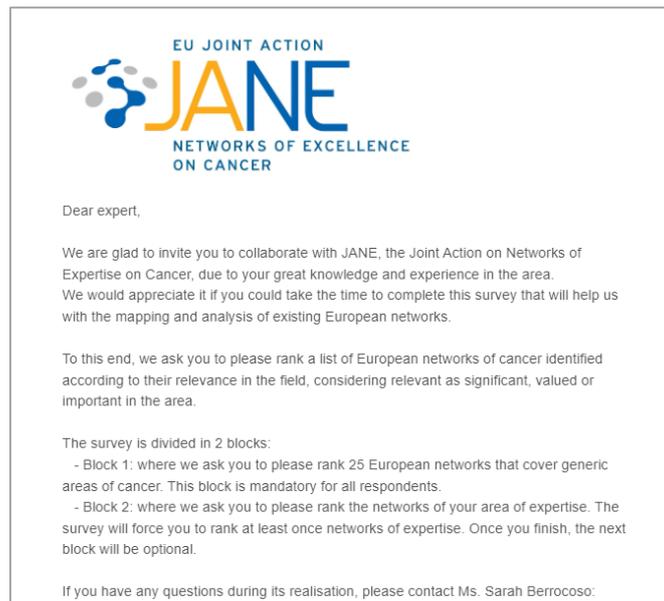
organizations and networking projects could potentially serve as a reference in the development of a sustainability model for the NoEs. As a result, **62 entities were mapped** (the complete list of the organizations included in this activity can be found in



## Annex 1).

From 6 February to 3 March 2023, the same JANE partners were asked to prioritize these 62 initial organizations according to their relevance by JANE through the completion of an online questionnaire developed on the [Qualtrics](#) platform (**Annex 2**).

**Figure 3.** Welcome message of the online questionnaire previewed in Qualtrics.

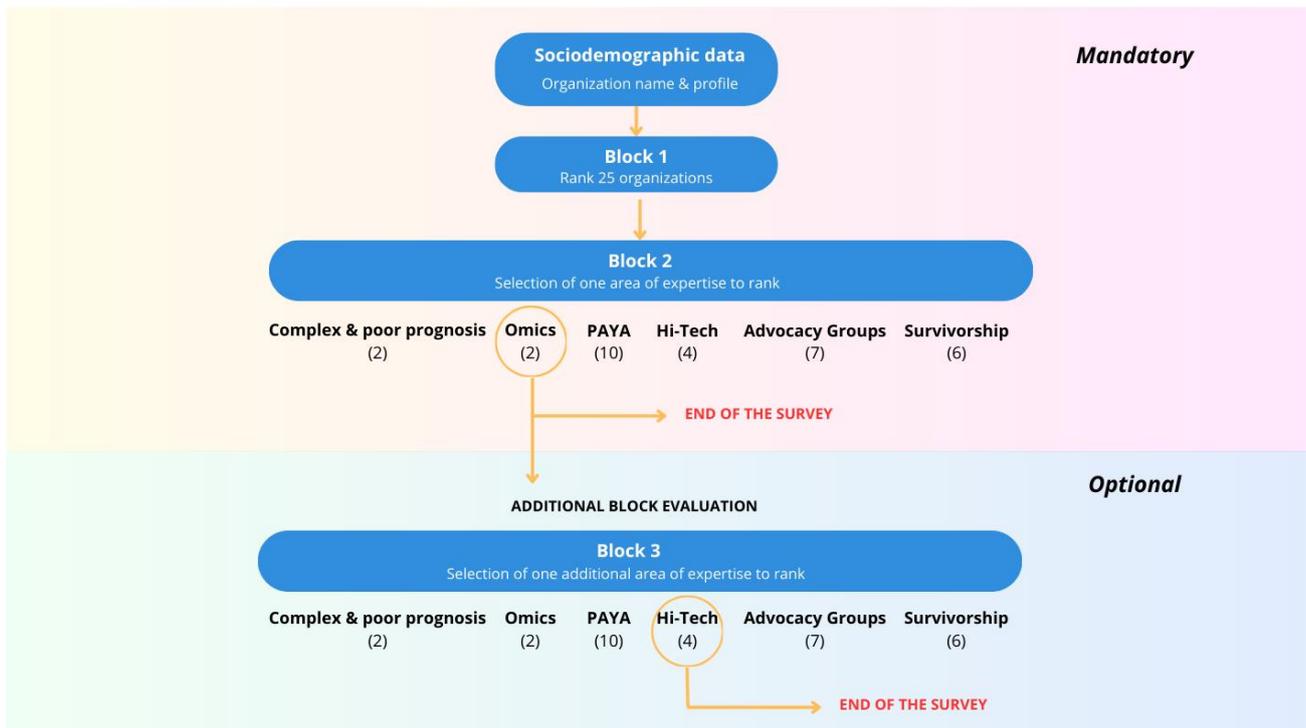


During this process, participants were also asked to prioritize organizations related to their area of expertise. For this purpose, the 62 organizations were provisionally divided into two blocks in the survey. The first block included organizations that covers generic cancer areas or areas that couldn't be included in the block two. The second block included organizations that are related with the domain areas of the NoEs (complex and poor prognosis cancers, survivorship, omics, hi-tech medical resources and pediatric, adolescents & young adults) or with advocacy groups.

It should be noted that this classification into general or domain areas was only used to facilitate the prioritization activity to experts. As some of the organizations may belong to more than one domain area (e.g. PAYA and survivorship) this initial classification should not be considered for any further discussion.

The survey flow of the questionnaire was set up once this initial classification had been established (Figure 4).

**Figure 4.** Survey flow.



In the mandatory part of the questionnaire participants were asked to provide the name of their organization and their profile. Then, they were asked to rank the organizations included in the first block of the questionnaire. During the evaluation a short description of each of the mapped organizations were included. Participants were asked to rank the organizations according to their relevance, by dragging each of the organizations in the list and dropping them in order of most to least importance to respondents. This system was selected to facilitate the evaluation process, as other systems such as Likert scale could be more difficult due to the large number of organizations included in the list.

**Figure 5.** Screenshot of the drag and drop system of the online survey for the prioritization activity.





*Note.* A short description of the general scope of each organization was included before the ranking activity.

At the end of the block 1 the participants were required to evaluate the organizations in block 2. In this block participants were asked to rank the networks in their area of expertise, with a possible choice between: PAYA, survivorship, hi-tech medical resources, complex and poor prognosis, advocacy groups or omics. After that, they could finalize the questionnaire or complete another domain area optionally (block 3).

The final part of the questionnaire allowed participants to suggest additional organizations that had not been included in the initial mapping.

### **3.3 Information collection and contrast**

It was decided to study in detail information from a total of 15 organizations among all those mapped. Biosistemak was in charge to gather the information of the dimensions in the reference framework for the 15 networks, organizations and networking projects prioritized in the previous exercise.

In order to complete the information for each dimension, a series of questions were defined to check whether the entities to be studied made this information publicly available on their websites or in their documentation. The questions to be answered for each of the dimensions and sub-dimensions of the reference framework are presented below.

#### **1. Scope**

- What are the objectives of the organization?
- What is the mission of the organization? What is the organization's purpose? Why does the organization exist?
- What is the vision of the organization? What problem is the organization seeking to solve? Where is the organization going? Where will the organization be in the future?
- What are the values of the organization? What are the values that distinguish the organization? What values should guide the decision-making in the organization?

#### **2. Governance**

- Does the organization have an identifiable governing entity?
- Does the organization have a well-defined organizational and functional structure?
- What is the nature of the organizations or profiles of the professionals involved?
- What is the organization's model?



- Has the organization a well-defined process to join it? Are there any inclusion requirements to be part of the organization, such as, being an entity with legal representation and/or being a natural person? Who are the members of the organization (organization, individuals, both)?

### 3. Strategic plan

- What aspects does the strategic plan include? Does it refer to aspects such goals, strategic lines, budget, a quality assessment and/or monitoring plan with measurable performance indicators?
- How is the Strategic Plan it formulated - which bodies or professionals are involved in its elaboration?
- How long is the Strategic Plan valid?
- How often is the network's progress/performance reviewed?
- Has it an impact evaluation and/or performance monitoring assessment?
- Is there any sustainability strategy or plan included?

### 4. Services

#### 4.1. Research

##### 4.1.1. Strategic research goals

- Is there a Scientific Advisory Board?
- Is there a research strategic plan?
- Is there research working groups?

##### 4.1.2. Peer reviewed publications

- Does the organization participate in international peer-reviewed publications?

##### 4.1.3. Scientific events

- Does the organization participate in scientific congresses or events?
- Does the organization participate in the organization of scientific events?

##### 4.1.4. Clinical trials

- Does the organization participate in clinical trials?



#### 4.1.5. European projects

- Does the organization participate in European projects?

#### 4.1.6. Others

- Does the organization participate in other activities such as, guidelines, white papers, recommendations for prevention, diagnosis, follow up or others?

### 4.2. **Education**

- Does the network organize educational activities such as webinars, workshops, events (matchmaking, congresses, conferences or seminars) or training courses?

### 4.3. **Other services**

- Does the organization have a matchmaking service?
- Does the organization organize knowledge exchange activities?
- Does the organization offer consultancy services?
- And any other type of services?

## 5. **Strategic alliances**

### 5.1. **Key stakeholders**

Provide a description of this type of alliance where assets of different nature could be found such as<sup>18</sup>:

- a) Patients and citizens
- b) Health and care professionals
- c) Health and care provider organizations
- d) Non-profit and charitable health organizations
- e) Health and care payers
- f) Public health agencies
- g) Policymakers
- h) Innovation sponsors
- i) Industry associations

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<sup>18</sup> Kalra, D., Lange, M., Birov, S., Müller, S., Prodan, A., Kolitsi, Z., Nicolas, L., & Marti, T., 2022. Service Portfolio for Sustainability. [online] mHealthHUB European. Available at: <<https://mhealth-hub.org/download/d4-5-service-portfolio-for-sustainability>> [Accessed 22 February 2023].



j) Industry

k) eHealth ecosystem

- Does the organization have a matrix/mapping of key stakeholders? (e.g., on its website there is a section of collaborators or entities or foundations that support the network).
- Does the organization have initiatives to raise awareness about their impact among stakeholders? (e.g., dedicated webinars on the impact of the network assessing Europe priorities in cancer research).
- Does the organization show its relevance to connect with relevant stakeholders? (e.g., facilitating networking in events, or the dissemination of tools, educational material, or good practices for stakeholders.)

## 5.2. Networking, matchmaking and knowledge exchange

- Does the organization include aspects related with networking opportunities and collaboration between different systems (industry, ends users, among others); use of the twinning scheme; matchmaking events or services; providing access to experts; providing experiences from patient advocacy groups and dissemination activities?

## 6. Communication strategy and tools

- Does the organization have a public communication plan or strategy?
- Does the organization have a website? (e.g., the website contains information about the values and mission of the network, about its members and activities, as well as education resources accessible on a continuous basis).
- Does the organization have a news page? (e.g., the network updates the content related to their activities or on aspects related to the work of the network).
- Does the organization send a newsletter?
- Does the organization have social networks? Which ones? Are they active enough?

## 7. Ethics, legal and regulatory

- Is there any reference to aspects related with ethic, legal or regulatory in the organization website or publications?



## 8. Funding

### 8.1. Income generated by the organization

- Does the organization have a business model for ensuring its financial sustainability, such as subscription/membership rates, service portfolio (training and education activities, consultancy, etc.)?

### 8.2. Member's own investments (in-kind and/or financial)

- Does the organization have a membership fee?
- Does the organization have a paying system to obtain certain resources? (e.g., open databases)
- Does the organization have in-kind contributions? (e.g., sponsoring students for internships; workshops and conference participation; providing specific areas of content to supplement and update guidelines or to create new areas of content; and promoting the network amongst its own stakeholder networks).

### 8.3. Potential external funding

- Does the organization have a funding entity or entities? (e.g., grants from national health ministries and other policy-makers; grants from healthcare payers and associations; annual membership fees from participant organizations and fees for services as performing assessments or consultancy activities).
- Does the organization support donations? (e.g., donations from sponsoring organizations as industry).
- Does the organization have sustainable funding instruments or participation in competitive funding calls? (e.g., R&D grants as EC programs).

It should be noted that the final section of the document includes a summary table with all the dimensions and sub-dimensions of the framework.

Once the information for each organization was completed, WP4 members or JANE associated partners (representatives from the analyzed organizations) were contacted between June and September 2023 and given one month to review the information about the organization assigned to them.



As part of this process, each of the 15 organizations were peer-reviewed by two members as shown in Table 1. This initial information was cross-checked and supplemented, when necessary, by them.

**Table 1.** JANE members responsible in the peer-review.

Organization	Peer reviewer 1	Peer reviewer 2
EURACAN	UNICANCER: Muriel Rosagik	CNAO: Chiara Marazzi
ESMO	IOV: Lorenzo Businaro	CIPH: Petra Cukelj
EORTC	CIPH: Petra Cukelj	IOV: Lorenzo Businaro
GENTURIS	INCA: Thomas Dubois	OIL: Mateja Krajc
OECI	FHF: Thomas Dubois	DKFZ: Tanja Jutzi
UNCAN.eu	CIBER: Aina Castell	OOI: Edit Marosi
PCE	BMG: Selamawit Woldai	INCA: Thomas Dubois
EAPC	FHF: Thomas Dubois	ICO: Jesús González Barboteo
TRANSLACORE	INT-NA: Maria Carmela Piccirillo	OOI: Edit Marosi
PANCARE	DKFZ: Tanja Jutzi	NCI-LT: Audrius Dulskas
EU-CAYAS-NET	BMG: Selamawit Woldai	BIOSISTEMAK: Yhasmine Hamu
ESTRO	SAS: Miguel Giraldez Álvarez	UNICANCER: Jean-Yves Blay
PAEDCAN	HSJD: Cristina Larrosa Espinosa	BIOSISTEMAK: Yhasmine Hamu
SIOPE	HSJD: Cristina Larrosa Espinosa	BIOSISTEMAK: Yhasmine Hamu
CCI	IDIVAL: Carlos López	NCI-LT: Audrius Dulskas

*Note.* Where possible, reviewers were assigned to organizations in which they were actively involved.

In addition to reviewing the text, were asked to provide comments and feedback about the following aspects:

- To identify if there was any missing information or reference about the organizations and include it if necessary.
- To confirm if the summary table at the end of the document summarizes appropriately the key information referred to each dimension of analysis.
- To highlight one key feature and one weakness of the organization analyzed.

Regarding the last point, this feedback was given considering the information available in the document; to collect aspects considered of interest and/or questions for improvement to be studied.



The comments and feedback of the peer reviewers gathered in this phase were considered and incorporated into the final version of the information about the organizations.

The last step in the mapping was the global analysis of the information gathered that helped to identify key elements for the generation of recommendations for the sustainability of the NoEs. This global analysis comprised a **comparison of the eight dimensions** of the framework of the organizations under study and drawing the **main conclusions for the sustainability of the future NoEs**.



## 4 LESSONS LEARNED FROM THE MAPPING

CIBER, CNAO, ICO, IDIVAL, INT-NA, IRST, MHA, MSCl, SAS and other JANE partners, who did not include the name of their organization in the questionnaire, have participated in selection and prioritization activity and as a result, the following 15 networks were selected to be further in-deep analyzed:

- EURACAN - European Reference Network on Rare Adult Cancers (solid tumors): <https://euracan.eu/>
- ESMO - European Society for Medical Oncology: <https://www.esmo.org/>
- EORTC - European Organization For Research And Treatment of Cancer: <https://www.eortc.org/>
- OECI – Organisation of European Cancer Institutes: <https://www.oeci.eu/>
- GENTURIS - European Reference Network (ERN) for all patients with one of the rare genetic tumour risk syndromes: <https://www.genturis.eu/>
- UNCAN.eu - European Initiative to UNderstand CANcer: <https://uncan.eu/>
- PCE – PANCREATIC CANCER EUROPE – The European Multi-Stakeholder Platform on Pancreatic Cancer: <https://pancreaticcancereurope.eu/>
- EAPC\* – European Association for Palliative Care: <https://eapcnet.eu/>
- PANCARE – Pan-European Network for Cancer of Survivors after Childhood and Adolescent Cancer: <https://www.pancare.eu/>
- EU-CAYAS-NET – EU Network of Youth Cancer Survivors: <https://beatcancer.eu/>
- TRANSLACORE – Translational control in Cancer European Network: <https://translacore.eu/>
- ESTRO – The European Society for Radiotherapy and Oncology: <https://www.estro.org/>
- CCI Europe – Europe Childhood Cancer International: <https://ccieurope.eu/>
- PAEDCAN – European Reference Network for Paediatric Cancer (haemato-oncology): <https://paedcan.ern-net.eu/>
- SIOPE – The European Society for Paediatric Oncology: <https://siope.eu/>

\*The EAPC association was not included in the initial mapping and was suggested for inclusion in the final list.

The global analysis and comparison of the main characteristics of the organizations presented in the section before, leads to the identification of the key aspects to be considered for establishing sustainable



organizations in the European cancer field. This aims to offer insights into the diverse approaches identified in this analysis and to explore their implications for future developments in the field. A descriptive summary and lessons learned from the mapping will be presented following the dimension and sub-dimension structure of the reference framework. It should be noted that the learnings presented in this document will be based on the information that have been found publicly on mapping organizations. A table with the summary of all the dimensions of the organizations can be found in **Annex 3**.

## 4.1 Scope

All the entities mapped have clearly defined their objectives, while the mission, vision and values have been described in 60% of the cases.

On the other hand, almost all organizations include information about their mission and vision, while the explicit definition of the values is not found in a specific section of their website or documentation in the 26.7% of the entities.

The values serve as guiding principles for the organizations and shape their culture. They also illuminate the contexts of the organizations, representing the assumptions and objectives in their everyday operations. Thus, the values of organizations, although not explicitly stated in the description of the entity, can be implicitly defined within their own objectives and mission.

The description of these aspects (objectives, mission, vision, and values) are pillars for the constitution of the organization, network or project and help to define its action plans and future activities. This should also apply to the constitution and launch of the NoEs.

## 4.2 Governance

The **governance system** of the mapped organizations is defined for the 86.7% of the organizations except two. However, it must be noted that, that the main difference between these two organizations and other entities, is that the latter are articulated and function as networks of organizations as they are two funded projects. This implies that its governance structure is equivalent to that of a research project.

This type of structure and division of functions can be also found in the NoEs at the moment of preparation of this document. While this organization is evolving towards the definition of a governance model, this is an open question that should be defined and implemented in the future.

**The most predominant bodies and organizational structures found in the mapping** are described below, which may also be of interest for the NoEs model.

- The General Assembly is a body mostly represented by members of the organization at all levels (directors, members, associated partners...). Its aim is usually associated with decision-making



processes in the organization, such as the definition of the budget, governance model, or strategic plans. Half of the organizations analyzed include a General Assembly or General Board in their structure or include the responsibilities of this body under the name of Board of Directors, General Boards or Action Chairs (20%).

- The Executive Board/Committee is responsible for the management and administration of the organization and is represented by leading roles. A 73.3% of the mapped networks included this organism in its governance. Due to the fact that this Board has managerial responsibilities, in some cases additional dependent departments could be also found, such as, communication offices.
- Council / Advisory boards: support and advice other leadership bodies and propose strategic topics for discussion. The 26.7% of organizations included a Council in its governance the same percentage included an advisory board.

In addition, some entities described specific advisory boards, such as an Ethics Advisory Committee in PAEDCAN, and an Educational, Professional & Partnership and Scientific Councils in ESTRO. The 60% of the organizations have a specific Scientific Advisory Board.

- Groups, group domains, task forces' teams or focus groups, committees are usually divided in specialized workforces lead by experts. The 73.3% of the organizations analyzed included these groups in their structure.
- The Communication office oversees all the dissemination and communication efforts in the organization. Only the 13.3% of the organizations in the mapping include an exclusive communication department, although the functions of this department are taken over by other structures such as the Executive Board.

Finally, about this section, it should be noted that some organizations create structures with their own functions, related to the organization's objectives. This is the case for example for OECI and its Accreditation and Designation programme, or for TRANSLACORE which has an awards department.

### **Organizational models**

On 9 May 2023, a workshop dedicated to this issue and its potential impact for NoEs was held during the second JANE plenary meeting. The detailed information presented on this aspect is included in **Annex 4**. The main findings in the mapping about this aspect are included below.

Regarding the **type of organizational model**, half of the entities (53.3%) are legal non-profit organizations (in white in the Figure 5), while 40% are non-for-profit or collaborative networks but are not legal entities (in pink and green in the Figure 5). Among the latter, the 20% are ERNs and the 20%



European funded projects. Finally, only one organization has the denomination of EEIG (yellow in the Figure 5).

**Figure 6.** Main characteristics of the organizational models of the 15 organizations analyzed

Organization	Organizational Model
EURACAN	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
ESMO	Non-profit organization, trade unions and professional associations, legal entity, non-political under Swiss law
EORTC	Non-profit organization (AISBL), legal entity, under Belgian law
OECI	European Interest Grouping, non-governmental Organisation under the Belgian law
GENTURIS	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
UNCAN.eu	Non legal entity, is not a formal organization but rather a initiative that fosters collaboration
PCE	Non-profit network (ASBL), under Belgian law
EAPC	Non-profit organization, legal entity, under Belgian law
PAN CARE	Non-profit network
EU-CAYAS-NET	Non legal entity, is a collaborative network funded by the EU4Health Programme
TRANSLACORE	Non legal entity, is a collaborative network funded by the COST Programme
ESTRO	Non-profit organization, legal entity, under Belgian law
CCI Europe	Non-governmental organisations, platforms and networks and similar/ legal branch
PAEDCAN	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
SIOPE	Non-profit association (ASBL), legal entity, under Belgian law

ERN
  Non-profit
  European Interest Grouping
  Non-legal entity (project)

*Note.* In some cases, the organizations are structured as networks of institutions rather than as single entities.

The **Annex 4** provides more information on the definition between non-profit organizations, EEIGs and ERNs, while the table below summarizes the advantages and disadvantages that these organizational models could have for the NoEs.

**Table 2.** Organizational models advantages and disadvantages summary

Organizational model	Pros	Cons
For-profit	Potential for high profits and growth	Profit motive may conflict with social or environmental goals; pressure to prioritize stakeholder interests over other stakeholders
Non-profit	Mission-driven focus; tax-exempt status and ability to receive grants and donations	Dependence on donors and grants for funding
Government agency	Public accountability and transparency; access to public funding and resources	Bureaucratic and slow decision-making; susceptibility to political influence and budget constraints
European Economic Interesting Grouping	Cross-economic activity; improves economic sustainability	Legal and regulatory requirements; maintenance

Moreover, all the models included in the mapping may be legal entities or not. Becoming a legal entity involves registering the relevant government authority or regulatory body, following the prescribed procedures, and fulfilling any specific requirements for establishing the organization's legal structure,



such as drafting articles of incorporation or a constitution. The 53.3% of the organizations are legal entities declared under the regulations of different countries that are referred in the Figure 5.

Regarding the administrative issues, the establishment of the legal status of the organizations could be one of the main challenges of some entities to ensure their sustainability. This is a key aspect as the nature of the organization may define the possibility to participate as beneficiary in funding calls. Nevertheless, entities which do not have a legal personality under their national law (groups, networks, etc.) may exceptionally participate in programs such as Horizon Europe, “provided that their representatives have the capacity to undertake legal obligations on their behalf and offer guarantees to protect the EU’s financial interests equivalent to those offered by legal persons.” [See Article 197\(2\)\(c\) EU Financial Regulation 2018/1046](#). The mechanisms to demonstrate or to acquire this equivalent could vary in different European countries, and therefore should be consulted with legal experts.

Although lacking this legal status appears to be a handicap for some organizations such as ERNs<sup>19</sup>, it does not seem to be a barrier for participating in funding calls. Another option for these networks would be to participate in consortiums as individual entities.

The final choice of an organizational model should be based **on the specific goals, resources and requirements** of the network. The results of the analysis, together with the existence of other models in Europe<sup>20</sup>, demonstrates that network models are becoming increasingly common and could support the exchange of knowledge and resources in the European ecosystem.

Having all this in mind, the models that seem to be more aligned at present with the objectives of the NoEs is the one for ERNs. The ERNs were created under the 2011 Directive on Patient Rights' in Cross-Border Healthcare<sup>21</sup>. They are based on the voluntary cooperation of Member States that contribute to the ERNs' activities in accordance with their national legislation. ERNs are not legal entities, but they work as a collaborative network within the framework of the ERN initiative supported by the EC.

Following the model of the ERNs, EURACAN has been recognized by WP4 partners as an entity with a well-articulated governance. The governing entity is identifiable, clear and reachable. The division of the leadership into specific tasks, such as research and quality control, allows a smaller loss of focus and could be a good strategy when it comes to achieving the network's objectives and goals. They also ensure the representation of all MSs in their board. We can find other organizations that ensure the representation of MSs in their leadership panels such as TRANSLACORE, where the governance model

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<sup>19</sup> Deliverable 4.1 EURACAN Sustainability Report, 2019. Available at: <https://ec.europa.eu/research/participants/documents/downloadPublic?documentIds=080166e5c3355ca1&appId=PPGMS>

<sup>20</sup> [Executive Master in Management of research infrastructure \(EC\) of 3 june 2017](#)

<sup>21</sup> [https://health.ec.europa.eu/system/files/2019-07/integration\\_healthcaresystems\\_en\\_0.pdf](https://health.ec.europa.eu/system/files/2019-07/integration_healthcaresystems_en_0.pdf)



proposed by COST could also be useful for NoEs in establishing the link between European and national levels.

Other structures that is proposed in the EURACAN governance model and also found in other organizations in the mapping is the Scientific Advisory Group. This structures could be useful for NoEs as far as it drives the scientific agenda of the organization and ensures and the research interests to fulfill the organization's mission. It could also works as facilitator ensuring the common functioning across research groups and its management, and also to serve as the link between the research workforces and other governance bodies. In other cases, the scientific committee oversees the scientific activities and the alignment with the organization's Strategic Plan.

## Membership

The 86.67% of the organizations included some form of membership to be part of the organization. The analysis showed that there are different ways to become a member. 13.3% of the organizations only accept expressions of interest from individuals, 26.7% from organizations, while, more than the half of the entities allow a hybrid model of participation (both individuals and organizations).

Moreover, different profiles of membership have been identified, the most predominant have been the distinction into 'full members' (66.7%) or 'associated members' (53.3%). The associated members do not account on a full membership, either because they do not have the necessary expertise to be considered a 'full member', or because they are entities outside the European Union or simply external collaborating partners. The functions and responsibilities of the members vary widely among the organizations analyzed. The members often have an impact on decision-making and participation (e.g. participation in general assemblies).

The membership system of some entities includes a fee to join them. Nevertheless, discounts or no fees for students is also identified. In addition, the fees often allow to access certain resources or services of the organization, such as reducing fees for attending conferences or courses or eligibility for grants and awards.

## 4.3 Strategic plan

The strategic plan has been reported for 73.3% of the organizations, bearing in mind that all of them describe the **responsible of elaborating this document**. The **average duration of the strategic plan** is 3.91 years, although it varies between one year (13.3%) and 8-9 years (6.7%). The most reported length is 3 to 5 years (26% of the organizations), followed by 4 years (20%).

During the life of an organization, network, or project there may be changes e.g. in its objectives or activity, therefore it is important to set periods for the review of the strategic plan. In the mapping exercise the **average time for reviewing the strategic plan** is 4.43 years, with a variation between 1



year (13.3% of the organizations analyzed) and 8-10 years (6.7%). The most common length is 5 years (26.7%), but this information could not be found in 26% of the cases.

The results show that 60% of the organizations include a **performance monitoring assessment or an impact evaluation**. Monitoring the strategic plan is crucial for identifying deviations and implementing containment measures when necessary. It is key for the Strategic Plan to anticipate potential adjustments over time to guarantee the network's sustainability.

Finally, regarding the availability of a **sustainability plan or strategy**, 40% of them reported it. Organizations that reported a plan for sustainability either referred to it or specified actions within different working groups on this variable (e.g. CCI Europe). These activities may include, investigating funding possibilities and financial partnerships, ensuring sufficient human resources, and evaluating any further develops in the governance structure of the organization in collaboration with superior Committees.

It would therefore be important that NoEs also define their overall strategic plan and specific sustainability measures for each network. The time for the performance assessment, evaluation mechanisms, and general and specific indicators should also be defined.

#### 4.4 Research

The analysis about the definition of a **Scientific Advisory Board, research strategy plan and applied working groups** was especially important, as these structures have shown to reinforce the capability in research infrastructures. 40% of the entities analyzed include these three aspects. On an individual basis, 66.7% of the organizations include research working groups, the 46.7% a research strategy plan and the 33.4% a Scientific Advisory Board.

In terms of research outputs, the existence and number of **scientific peer-published publications** was evaluated. The 86.7% of the mapping entities included this type of publication with a wide difference in the number of publications found. ESMO and EORTC are the organizations with the highest number of reported publications, with more than 1,000 in sum. This demonstrates the long track record of these organizations in the European cancer ecosystem.

Secondly, the results show that the 93.33% of the organizations analyzed have published **other type of resources** such as white papers, guidelines, recommendations, development of European standards and clinical criteria, infographics, public policy publications, or other valuable literature for the field. An example of this is the work that PAEDCAN is carrying out for the elaboration of Consensus-based Clinical Guidelines through the collaboration with specialist from different Member States. These guidelines aim to standardize the care provided to pediatric cancer patients across Europe, ensuring consistent and high-quality treatment approaches.



Thirdly, the **number of coordinated scientific events or the participation** in such events was evaluated. The analysis showed that all the organizations have participated in various events, such as annual meetings, congresses, scientific conferences, etc. The results and advances in knowledge of these organizations and their work could be also made visible both through these events, facilitating the knowledge transfer.

Other research-related aspects such as participation in clinical trials and participation in funded research projects were also explored. Information about the **participation in clinical trials** was only found for EORTC, which reported more than 200 clinical trials. However, the 73.37% of the mapped organizations have participated in **European funded projects**, both as beneficiaries and in some cases also as coordinators in these projects. These dimensions were not applicable for three organizations as they are European funded projects.

It must also be noted that **participation in networks favors the generation of research opportunities** thanks to the exchange of knowledge, and the ease of access to competitive funding. There are examples of how the collaboration of entities in some of these has led to the generation of new projects (UNCAN.eu or EU-CAYAS.net). On the other hand, in the programme which has funded TRANSLACORE (COST), many successful cases of thematic networks that have managed to obtain competitive funding at the end of the programme could be found.

The mapping has shown how **some organizations provide its members with established structures for collaborative research**, such as infrastructure for data sharing (e.g. EAPC). Other organizations, like ESMO include a Clinical Research Observatory with potentially useful functions such as providing views and recommendations to rationalize and streamline the bureaucracy associated with clinical research. Trying to work towards a favorable environment for innovative and high-quality basic, translational, and clinical cancer research.

Also, with **other types of resources** such as reference groups or task forces that could act as a focal point for discussion and exchange of knowledge, support the development and learning of early career researchers; or also by supporting the dissemination of information about competitive funding calls or direct grants for research and education for its members.

The integration between health care and research is one of the task forces in JANE and therefore one of the active discussions on the challenges facing European health networks.

The results of the mapping highlight the good work that these organizations are carrying out not only to promote research opportunities, but also to monitor their progress and the dissemination of results to the scientific and clinical community, to facilitate their implementation in the healthcare setting.



JANE NoEs could be inspired by some of the models described above to establish research collaborative opportunities.

## 4.5 Education

The 93.33% of the organizations show a strong emphasis on the production and dissemination of educational content to their members and the cancer community, offer a **regular programme of education activities**. The educational contents include online and onsite events such as **workshops, trainings, and webinars**. As an example, PAEDCAN has developed a series of educational webinars accessible to all Member States, which aim is to encourage the participation of young oncologists, enhancing training opportunities and promoting adherence to standardized care practices.

On the other hand, the 26.67% have specific **training schools**, such as the ESTRO school teaching programme, or the organization of **knowledge exchange activities** (40%), such as exchange programmes, peer visit trainings or scientific stays (e.g. SIOPE, EURACAN and EU-CAYAS-NET). The concept of these trainings is based on observational research, allowing project participants to observe healthcare professionals and other service providers in their natural working environment. This form of peer learning is designed to stimulate interaction, collaborative learning and solution-building. The peer visits aim to provide valuable feedback to the collaborating institution and actionable insights for peers to support health policy initiatives in their respective home countries. The promotion of research or clinical stays seems to be a mechanism to foster interaction, collaborative learning (sharing practices), generation of solutions and the specialization in different techniques or working models.

In addition to the education opportunities themselves, other written materials can also be included under this heading and are also examples that addresses basic and **continuing medical education** needs, emphasizing evidence-based clinical application as well as fundamental, translational, and clinical research. A clear example of this could be ESMO, which publishes handbooks, scientific meeting reports, medical oncology training guidelines and also offers an internal exam and provides with interactive practice and self-assessment tools available online at OncologyPRO.

Considering the domain areas of the NoEs it is feasible that one of its main services will be to provide **diverse educational content** ranging from written materials like guidelines to specialized courses and continuous medical education.

Some specific platforms for sharing such materials have been described in the mapping. The need for the establishment of a digital platform to host such content and its requirements should be considered in the future.



## 4.6 Other services

The analysis revealed a variety of internal and external services offered by the organizations. In particular, the 26.67% have **matchmaking services** aimed at supporting members to identify projects or to find partners for their proposals. Regarding the **knowledge exchange activities**, in the previous section activities related to clinical or research stays were reported, but a variety of content could be also included under this umbrella. In this sense, 80% of the organizations include services related to the exchange of knowledge. Only 20% of the organizations analyzed offer **consultancy** services, it is the case of GENTURIS that offers consultancy services for patients.

Finally, **other type of services** was described in 60% of the cases, some of them will be mentioned below in case they can be used as an inspiration for future services of NoEs.

Among the most outstanding services is the Accreditation and Designation Programme of OECI, is the only cancer accreditation global programme which evaluates comprehensive cancer care and translational care. This program assesses various aspects of cancer care and research, including clinical services, research activities, education programs, and organizational structures. Institutes that meet the rigorous standards set by the programme receive an accreditation, that recognizes their commitment to providing high-quality cancer care and conducting cutting-edge cancer research. This accreditation enables to bundle expertise and competence for the development of concrete affordable and realistic solutions to effectively combat cancer in a harmonized and standardized way across Europe.

Another important resource is the EURACAN e-tool, an electronic platform to support the management and coordination of rare cancer patient cases in Europe. This tool provides a centralized platform for expert consultation, clinical information exchange, and treatment progress tracking for patients with rare cancers. It enables more efficient collaboration between healthcare professionals across Europe, facilitating access to specialized expertise and resources needed to improve the care of patients with rare cancers.

Other organizations, like EORTC also offers interesting services such as a clinical trials database and a data and sample sharing service.

It should be noted that the NoEs are intended to serve the cancer community by first addressing healthcare providers and then extending support to patients.

These networks will provide a range of services, such as producing or supporting clinical practice guidelines and recommendations, raising public awareness and advocating for policy action, developing models of healthcare organization, creating educational initiatives and tools for both health professionals and patients, promoting research efforts, establishing quality criteria for accreditation mechanisms, involving patients and the public, and other potential activities.



Although some services are already envisioned for NoEs, it will be important to consider in the future their adequacy and the capacity of NoEs' experts to provide these services.

#### 4.7 Strategic Alliances

In the analysis, it was observed that **all the organizations actively foster dialogue with partners, citizens, and broader stakeholders**. All of them define the list of their collaborating stakeholders and develop activities to raise the awareness among them. It has also been noted that it is important to demonstrate the connection between different organizations, for example through dissemination tools or educational materials.

One of the organizations in the mapping includes an agreement with an external consultancy service that support and advise the coordinator and its members so that European policy makers understand the value of the organization in the European Union.

Fostering dialogue with partners, citizens, and wider stakeholders within the field of interest is essential to ensure that the organization's objectives are aligned with the perceived needs of the thematic area and the related European policies. Strategic alliances ensure the continuity of the service and financial sustainability beyond the initial project phase, which is typically dependent on project funding. This requires identifying target stakeholders and other beneficiary groups, building collaborative networks and developing tailored action plans.

Key partnerships will be crucial for the NoEs, also to ensure the interplay with MSs, and other EU cancer networks and structures such as CCCs (such as CraNE), CCN and ERNs.

The mapping has demonstrated different strategies to transfer the results to a wider audience. These could serve as models for NoEs, and it will also be necessary to define different strategies to engage stakeholders from different backgrounds and keep them active and involved with NoEs.

#### 4.8 Communication strategy and tools

Only 60% of the organizations have a communication plan, although it is possible that the remaining organizations have one and that it is not publicly available.

Later, the modality of communication-related content that the organizations produce was studied. In this regard, it was found that all the organizations have a **website** and a **news section**, 93.3% have a **newsletter**, while a big disparity was found when analysing the existence of **social media accounts**. While all the organizations have an account on some platform, only 13.3% of them have one or two social media accounts, 26.7% have accounts on 3 platforms, and 60% on 4 or more. The most frequent social media is LinkedIn (100% of the organizations analyzed), followed by, Twitter (93.3%), Facebook (86.7%), Instagram (60%) and YouTube (33.3%).



The number of accounts in social networks the results do not seem to be very significant to determine the communicative impact of the organizations. In this sense, and as indicated in communication guidelines as those of the EC, variables such as the frequency of publications, the quality of the content and its suitability for the target audience and the platform itself determine the impact of these entities to a greater extent than the mere fact of having more accounts on different platforms.

Taking LinkedIn as a reference, one of the most used social networks by all organizations, the organizations have publications in different formats (videos, pdf's, photographs...) that help to make visible content that they develop, such as specific webinars, opportunities, as well as useful information for the general population. In addition, having a clear visual identity that helps to differentiate it from other publications on the social network seems to be key in this area.

It would be important for the NoEs in the future to tailor a communication strategy, following reference guidelines such as those developed by the EC, or by including good practices from other known organizations or projects.

#### 4.9 Ethics, Legal and Regulatory

The results show that 80% of the organizations analyzed include some reference related to ethics, law and regulation in their website or publications. All of them refer information about the **General Data Protection Regulation (GDPR)**, mainly related to the management of data in their websites. In addition, the 6.7% refers information about the management of **Intellectual property rights (IPR)**.

The analysis revealed a diversity of regulations, codes of conduct, and ethical frameworks tailored to the specific domains of work of the organizations. Specifically, the 13.3% of the organizations mention information about **regulations**, for example, about medicine or human rights. The 26.7% have specific information on **clinical trials**, while 20% include **legal frameworks** for different areas such as ERNs, euthanasia and physician assisted suicide. Finally, the 26.7% include information on various **codes of conduct**, such as, ethics in fundraising, standards for the protection of human subjects in research and the use of biomedical technologies, among others.

Although this was not a specific result of the analysis, the issue of **data integration and interoperability** has proven to be a great challenge within the ERNs. These challenges are not only technological dilemmas, but also involve the sharing of data across different countries with different regulations and legislation and are therefore related to this dimension. Interoperability issues are coming to the fore in different projects, and specific actions such as the EU4Health Joint Action on integration of European Reference Networks (ERNs) into national healthcare systems (JARDIN) will include the study of specific aspects such as this in order to increase the sustainability of ERNs.



This could also be a difficulty for the NoEs in the future, therefore, there is a need to address legal and ethical considerations, in addition to those already identified in this analysis in relation to GDPR, IPR and other regulations specific to the scope and services of each network.

On the other hand, it will be necessary for NoEs to be informed of new developments in relation to these issues related to regulation, as there are currently different initiatives to respond to these challenges.

#### 4.10 Funding

The results show that 60% of the entities have defined **processes or business models for ensuring their financial sustainability**.

Regarding the **member's own investments**, the results show that the 86.7% have in-kind contributions from their members, such as supporting internships, workshop and conferences participation, among others.

Finally, the **potential external funding** was found in 93.3% of the organizations, including different sources, such as donors (33.3%), sponsors (20%), grants (26.7%) or through a membership system (33.3%). For the 60% of the organizations, EU fundings was one of the main sources of their financial sustainability.

At this point, it is worth noting a possible limitation of this analysis, as the payment of a membership fee has been counted as both in-kind contribution and external contribution, as it is an external income to the organization. However, this information has mainly been reported in the section on potential external funding, where the main sources come from European funding, and to a lesser extent from sponsors or donations.

Moreover, it was not possible to obtain specific economic data for all the organizations, and therefore they were not specifically included in this analysis, as this information is not public in all cases. It would be interesting to explore this aspect further when designing a specific business model, as well as analyzing the cost of maintaining other resources/services (e.g. event organization, preparation of materials, etc.).

Sponsors and donations come from different fields such as industry or foundations. As mentioned above, both participation in calls for projects and the generation of this type of contributions could be means to be valued in the business model of the NoEs.

To this end, it would be necessary to analyze the viability of this type of income in the structure that the NoEs may have in relation to their organizational model.



## 5 CONCLUSIONS

The global analysis and comparison of the main characteristics of the organizations presented in the section before, leads to the identification of the key aspects to be considered for establishing the sustainability strategy of the NoEs. This conclusions aims to offer insights into the diverse approaches identified in this analysis and to explore their implications for future developments. These findings should be validated with experts in the field to build a final set of recommendations.

The key findings in relation to NoEs are presented below:

- The definition of the **objectives, mission, vision and values** could support the definition of action plans and future activities of the NoEs.
- The choice of an organizational model for NoEs should be based on **the specific goals, resources and requirements** of the network. The final decision should be assessed in all cases by **legal and financial experts to ensure compliance with laws and regulations**.
- The establishment of **suitable governance structures is pivotal** for the effective functioning of the NoEs. Clarity in defining the **roles and functions of different members**, along with **eligibility criteria and responsibilities**, is essential.
- Special attention should be given **to how to coordinate and transfer the knowledge of these networks at the national level**.
- It is recommendable for NoEs to have **well-defined strategic plans and sustainability measures**, indicating their **validity and mechanisms for evaluation**.
- **Transparency** can be enhanced through the **inclusion of general performance indicators** aligned with the strategic vision in annual reports.
- The strategic vision of NoEs in research is crucial, **facilitating the creation of specialized groups and mechanisms for collaborative research**.
- Efforts should be made to support processes emphasizing the **dissemination of research outcomes** or other types of content such as **clinical practice guidelines and valuable resources for the field**.
- **Education is one of the basic pillars for networking**, to encourage the exchange of best practices and specialization in different techniques or working models. NoEs could offer **diverse educational content** ranging from written materials like guidelines to specialized courses and continuous medical education.
- The knowledge translation could be supported by giving access to **electronic platforms**.



- Conducting **needs assessments** is vital to ensure that NoEs provide **services aligned with user needs**.
- Establishing strategic alliances with existing organizations and stakeholders is vital for **generating synergies** and **enhancing the value proposition** of the network.
- **Key partnerships will be crucial for NoEs**, also to ensure the interplay with MSs, and other EU cancer networks and structures such as CCC (such as CraNE), CCN and ERNs. **Formal integration of other entities** such as scientific societies, patient advocacy groups, and research institutes is encouraged.
- It would be important for the NoEs to develop a **communication strategy**. **Tailoring communication plans** to the **needs** and **preferences** of target audiences is crucial.
- **Tailoring ethical considerations to the specific needs of each NoE is essential**, ensuring compliance with regulations like GDPR, harmonization proposals in EU regulations impacting standard of care or addressing data sharing platforms' security and access guarantees.
- **The development of a sustainable business model** is critical to the longevity of NoEs and requires the identification of target stakeholders and the creation of value propositions tailored to their needs.



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**Annex 1.** List of the networks, organizations or networking projects included in the analysis



# Task 4.1 Mapping and analysis of existing networks, organizations and networking projects: general scope

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## JANE WP4 - Task 4.1

### General scope of preselected European networks

**JANE, the Joint Action on Networks of Expertise on Cancer**, aims to establish seven Networks of Expertise in the cancer field by preparing everything necessary to launch them and critically evaluating existing models of current and future EU networking.

In this regard, Works Package 4 (Sustainability) is now working in the mapping and analysis of existing health care networks in the EU.

In order to complement the survey for ranking the networks shared with the partners, this document contains the complete description of the general scope of the list of European networks, organizations and networking projects of cancer identified according to their relevance in the field. Firstly, there is a list of 25 networks on generic areas, and later six lists of specialization areas are presented: (1) Advocacy groups; (2) Pediatric, Adolescents & Young Adults (PAYA); (3) Survivorship; (4) OMICS; (5) Complex and poor prognosis; and (6) Hi-Tech medical resources.



## Common block

### Networks on generic areas of cancer

1. [EURACAN](#) is the European Reference Network (ERN) for all rare adult solid cancers; it is composed by 10 workgroups (e.g. sarcomas, genitals and placenta, neuroendocrine system, digestive tract, endocrine organs, head and neck, thorax, skin and eye melanoma & brain and spinal cord).
2. [EUROBLOODNET](#) is the ERN of oncological and non-oncological rare hematological diseases including rare anemias, rare coagulation disorders, polycythemia, and myeloid, lymphoid tumors and rare hereditary hemochromatosis.
3. [GENTURIS](#) is the ERN for all patients with one of the rare genetic tumor risk syndromes.
4. [ECRIN](#) is the European Clinical Research Infrastructure Network. It facilitates networks of clinical trial units across Europe, through its scientific partners to fulfil its vision of generating scientific evidence to optimize medical practice.
5. [ESMO](#) is the leading professional organization for medical oncology. Its core mission is to improve the quality of cancer care; to educate on the best practices and latest advances; and to promote equal access to optimal care.
6. [EORTC](#) aims to coordinate and conduct international translational and clinical research to improve the standard of cancer treatment for patients. It also aims to increase people's survival and Quality of Life by testing new therapeutic strategies based on existing drugs, surgery, and radiotherapy.
7. [TRANSPLANT-CHILD](#) aims to have a significant impact on children's quality of life in the long term. It encompasses both solid organ transplantation (SOT), included multiorgan and complex procedures, and hematopoietic stem cells transplantation (HSCT).
8. [ECICC](#) provides essential levels of quality care that are equally accessible across Europe and seeks to offer to healthcare providers and women clear and independent guidance on screening and care.
9. [ETOP](#) is the leading European organization performing international clinical and translational research in thoracic malignancies. Is a joint entity formed by the European Thoracic Oncology Platform and the International Breast Cancer Study Group.
10. [IRCI](#) supports the development of international clinical trials for patients with rare cancers in order to boost the progress of new treatments for these patients.
11. [FOSTER](#) wants to bring patients, researchers, clinicians and sarcoma charities together from across the globe to share ideas, advance research and to improve outcomes for those diagnosed with osteosarcoma.



12. [IG17104](#) aims to be a program for the continuous education of scientists working on multidrug resistant tumors (MDR), to develop promising interventions, prototypes and products ready for the market and to improve the standard of care of MDR tumors.
13. [EURO-CHOLANGIO-NET](#) aims to increase the understanding of cholangiocarcinoma (CCA) to translate basic research and preclinical findings into clinical practice, through the collaboration in different groups as Molecular Profiling, Epidemiology, Trials and Early Diagnostic Biomarkers among others.
14. [ERICA](#) aims are to create a platform that integrates all ERNs research and innovation capacity and seeks to improve better patient involvement, enhanced quality and impact of clinical trials, among others.
15. [TCA](#) is an international network of national thyroid cancer support organizations and/or thyroid support groups, dedicated to working together towards providing support, information and encouragement to those affected by the disease throughout the world.
16. [EANO](#) is the Europe's multidisciplinary Neuro-Oncology organization representing all medical and scientific disciplines involved in the prevention, diagnosis and treatment of tumors of the central nervous system (CNS).
17. [EHNS](#) wants to promote exchange of knowledge in all aspects of head and neck neoplastic diseases and to promote the highest standards of research, education and training, disease prevention and patient care.
18. [ENETS](#) aims to increase the knowledge and awareness of Neuroendocrine Tumor (NEN) in all healthcare systems, to improve early diagnosis of NEN, and to enable patients to be referred to NEN specialist centers, and monitor and audit the standards of care in NEN centers.
19. [ESGO](#) strives to improve the health and well-being of women with gynecological cancers through prevention, research, excellence in care and education.
20. [ESSO](#) aims to advance the science and practice of cancer surgery for the benefit of patients through education, research and innovation and multidisciplinary care, in Europe and beyond.
21. [ECO](#) aims to create and develop relationships between European institutions and the European cancer care community, and with Member Societies and networks, to facilitate collaboration and consensus on focused topics towards tangible and impactful policy improvement.
22. [OECI](#) aims to accelerate the application of multidisciplinary personalized care approaches to reduce mortality and to guarantee an equitable access. It has been working groups as cancer economics and biobanks and molecular pathobiology, among others.



23. [UNCAN.eu](https://uncan.eu) aims to understand cancer and its mechanisms better in order to improve cancer prevention, early diagnosis and treatment; to set up a European Federated Cancer Research data hub and to generate a series of use cases, addressing major challenges in cancer research.

24. [HARMONISATION](#) wants to constitute a multidisciplinary network to harmonize clinical care and research on adrenal tumors throughout Europe. It is organized in five Working Groups (clinical practice; research and omics practice; Information Technology (IT)/Artificial Intelligence (AI) tools; ethical and legal framework and communication, dissemination and inclusiveness).

25. [LOBSTERPOT](#) aims to better understand, diagnose and treat patients with invasive lobular carcinoma (ILC), streamlining of the “from bench-to-bedside” principal to enable uniform diagnosis and tailored treatment for ILC patients.



## Networks on specialized fields

### Advocacy Groups networks

1. [LuCE](#) provides an European platform for lung cancer patient advocacy associations and networks and supports the establishment of national lung cancer patient groups in those European countries where such groups do not yet exist.
2. [CCI Europe's](#) mission is to unite parents, patients and survivors and advocate for their rights to: improve the medical and psychosocial care for children and adolescents; implement European Standards of Care; and improve the quality of survivorship.
3. [IBTA](#) is a worldwide community for brain tumor patient organizations and others involved in the field of neuro-oncology.
4. [DiCE's](#) mission is to contribute to early diagnosis and decreased mortality from digestive cancers and to increase overall survival and quality of life.
5. [INCA's](#) mission is to raise awareness about all types of neuroendocrine tumors (NETs); push for scientific advancements with a focus on identified unmet needs; and to provide a platform for global collaboration.
6. [WECAN's](#) mission is to strengthen patient advocacy in Europe and improve outcomes for all cancer patients. Furthermore, the network provides valuable resources for Childhood Cancer International (CCI) members to obtain knowledge (i.e. through training courses).
7. [Nothing about us without us!](#) Project aims at finding out about prevailing knowledge and opinions towards patients and public involvement and engagement (PPIE) – from both patients and health care professionals – and developing a training tool based on the findings.



## **Pediatric, Adolescent & Young Adult (PAYA) networks**

1. [PAEDCAN](#) aims to reduce inequalities in childhood cancer survival by providing high-quality, accessible and cost-effective cross-border healthcare to children and adolescents with cancer, regardless to where they live.
2. [EPSSG](#) seeks to improve the quality of care offered to children, teenagers and young adults with soft tissue sarcoma (STS). EpSSG aims to spread best clinical practice; provide expert opinion and promote and support clinical trials, among others.
3. [EXPeRT](#) aims to empower research on pediatric value radiation therapy (VRT) in rare cancers by promoting cooperation between the national groups behind its foundation, supporting the creation of other such groups elsewhere in Europe, and fostering international collaboration schemes with other networks.
4. [SIOPEN](#) is a Neuroblastoma Research Network to ultimately improve the survival in children suffering from neuroblastoma.
5. [ITCC](#) 's goal is to accelerate the introduction of new effective and safe therapies in the treatment of children and adolescents with cancer, prioritizing potentially effective drugs and better preclinical evaluation.
6. [ENTYAC](#) exists to improve and enhance inter-professional teamwork processes, to promote team-based specialist care. It also aims to improve aspects regarding key scientific, medical, nursing and psychosocial barriers facing AYA cancer patients.
7. [SIOP](#) Europe is the only pan-European organization representing all professionals working in the field of childhood cancers. SIOPE is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe.
8. [Pancare](#) is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer.
9. [CAC2](#) is a collaborative network of organizations and individuals who support and serve the childhood cancer community. Their aim is to foster and sustain greater levels of coordinated action, information exchange, learning and broad-based collaboration.
10. [STRONG-AYA](#) is a multi-stakeholder European network to improve healthcare services, research and outcomes for AYA patients. They will develop a healthcare research network with data-driven, interactive policy and visualization tools to bring novel insights into AYA healthcare.



## Survivorship networks

1. [PAEDCAN](#) ERN will reduce inequalities in childhood cancer survival by providing high-quality, accessible and cost-effective cross-border healthcare to children and adolescents with cancer, regardless to where they live.
2. [PANCARE](#) is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer.
3. [EU-CAYAS-NET EU](#) project will develop an interactive virtual platform and a network that will foster social networking, peer-support, knowledge-exchange, and aims at improving: the quality of life of survivors, the care for AYA with cancer, and Equality, Diversity and Inclusion.
4. [PanCareSurFup](#) carried out research studies into late effects of treatment for cancer, established guidelines for follow-up, and disseminated the results and provided training and workshops for stakeholders.
5. [PanCareFollowUp](#) aims to improve the quality of life for survivors of childhood cancer by bringing evidence-based, person-centered care to clinical practice in the real world.
6. [INE-CSC](#) aims to systematically support the sustained translation of evidence-based interventions into routine clinical practice as part of a cross boundary, systems level cancer survivorship pathway which ultimately enhances the health and wellbeing of cancer survivors.



## OMICS networks

1. [TRANSLACORE](#) provides a unique opportunity to understand this biological process leading to reconsider our view of gene expression control in this disease and deliver novel therapeutic opportunities.
2. [LOBSTERPOT](#) aims to better understand, diagnose and treat invasive lobular carcinoma (ILC), streamlining of the “from bench-to-bedside” principal to enable uniform diagnosis and tailored treatment for ILC patients.

## Complex and poor prognosis networks

1. [PCE](#) aims at bringing together relevant stakeholders to advocate for an improvement in the standard of care for patients with pancreatic cancer, by addressing the existing gaps related to the lack of awareness, diagnosis and data collection.
2. [SIOPEN](#) project aims to build a European Neuroblastoma Research Network to ultimately improve the survival in children suffering from neuroblastoma.

## Hi-Tech medical resources networks

1. [EDHEN's](#) mission is to reduce the time needed to provide answers in real world, health research. It will achieve this by developing the required infrastructure in a federated network at scale across Europe, collaboration on research methodologies, and education in an open science collaboration.
2. [ESTRO](#) supports all radiotherapy professionals in their needs of continuous professional development. The needs of a growing society in terms of governance and leadership will actively be addressed. The Society will also increasingly embrace its role in policy, through a broadening network of partnerships with all relevant stakeholders.
3. [ENCR](#) promotes collaboration between cancer registries, defines data collection standards, provides training for cancer registry personnel and regularly disseminates information on cancer incidence and mortality in Europe.
4. [EXPeRT](#) aims to empower research on pediatric value radiation therapy (VRT) in rare cancers by promoting cooperation between the national groups behind its foundation, supporting the creation of



other such groups elsewhere in Europe, and fostering international collaboration schemes with other networks.



## Annex 2. Questionnaire



## Presentation



Dear expert,

We are glad to invite you to collaborate with JANE, the Joint Action on Networks of Expertise on Cancer, due to your great knowledge and experience in the area. We would appreciate it if you could take the time to complete this survey that will help us with the mapping and analysis of existing European networks.

To this end, we ask you to please rank a list of European networks of cancer identified according to their relevance in the field, considering relevant as significant, valued or important in the area.

The survey is divided in 2 blocks:

- Block 1: where we ask you to please rank 25 European networks that cover generic areas of cancer. This block is mandatory for all respondents.

- Block 2: where we ask you to please rank the networks of your area of expertise. The survey will force you to rank at least once networks of expertise. Once you finish, the next block will be optional.

If you have any questions during its realisation, please contact Ms. Sarah Berrocoso:  
[sberrocoso@kronikgune.org](mailto:sberrocoso@kronikgune.org)

## Sociodemographic data

Before starting, we would thank you to complete the following information that will help us in the analysis and reporting.

### Sociodemographic data



Please select your organization:

If you select Other, please indicate the name of your organization.

Profile of your organization

- National/Regional Ministry of Health
- Health Technology Assessment Agency
- Insurance
- Healthcare provider
- Research/Academia
- Industry
- Other

If you select Other, please indicate the profile of your organization.

General European Networks

#### Block 1: Networks on generic areas of cancer

This block is mandatory for all respondents. Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance.

1. **EURACAN** is the European Reference Network (ERN) for all rare adult solid cancers, it is composed by 10 workgroups (e.g. sarcomas, genitals and placenta, neuroendocrine system, digestive tract, endocrine organs, head and neck, thorax, skin and eye melanoma & brain and spinal cord). (Official website: <https://euracan.eu/>).
2. **EUROBLOODNET** is the ERN of oncological and non-oncological rare hematological diseases including rare anemias, rare coagulation disorders, polycythemia, and myeloid, lymphoid tumors and rare hereditary hemochromatosis. (Official website: <https://eurobloodnet.eu/>).
3. **GENTURIS** is the ERN for all patients with one of the rare genetic tumor risk syndromes. (Official website: <https://www.genturis.eu/>).
4. **ECRIN** is the European Clinical Research Infrastructure Network. It facilitates



networks of clinical trial units across Europe, through its scientific partners to fulfil its vision of generating scientific evidence to optimise medical practice. (Official website: <https://ecrin.org/>).

5. ESMO is the leading professional organisation for medical oncology. Its core mission is to improve the quality of cancer care; to educate on the best practices and latest advances; and to promote equal access to optimal care. (Official website: <https://www.esmo.org/>).

6. EORTC aims to coordinate and conduct international translational and clinical research to improve the standard of cancer treatment for patients. It also aims to increase people's survival and Quality of Life by testing new therapeutic strategies based on existing drugs, surgery, and radiotherapy. (Official website: <https://www.eortc.org/>).

7. TRANSPLANT-CHILD aims to have a significant impact on children's quality of life in the long term. It encompasses both solid organ transplantation (SOT), included multiorgan and complex procedures, and hematopoietic stem cells transplantation (HSCT). (Official website: <https://www.transplantchild.eu/>).

8. ECICC provides essential levels of quality care that are equally accessible across Europe and seeks to offer to healthcare providers and women clear and independent guidance on screening and care. (Official website: <https://healthcare-quality.jrc.ec.europa.eu/ecicc>).

9. ETOP is the leading European organization performing international clinical and translational research in thoracic malignancies. Is a joint entity formed by the European Thoracic Oncology Platform and the International Breast Cancer Study Group. (Official website: <https://www.etop-eu.org/>).

10. IRCI supports the development of international clinical trials for patients with rare cancers in order to boost the progress of new treatments for these patients. (Official website: <https://project.eortc.org/irci/>).

11. FOSTER wants to bring patients, researchers, clinicians and sarcoma charities together from across the globe to share ideas, advance research and to improve outcomes for those diagnosed with osteosarcoma. (Official website: <https://osteosarcomanow.org>).

12. IG17104 aims to be a program for the continuous education of scientists working on multidrug resistant tumors (MDR), to develop promising interventions, prototypes and products ready for the market and to improve the standard of care of MDR tumours. (Official website: <https://www.cost.eu/actions/IG17104/>).

13. EURO-CHOLANGIO-NET aims to increase the understanding of cholangiocarcinoma (CCA) to translate basic research and preclinical findings into clinical practice, through the collaboration in different groups as Molecular Profiling,



Epidemiology, Trials and Early Diagnostic Biomarkers among others. (Official website: <https://www.cost.eu/actions/CA18122/>).

**14. ERICA** aims is to create a platform that integrates all ERNs research and innovation capacity and seeks to improve better patient involvement, enhanced quality and impact of clinical trials, among others. (Official website: <https://erica-rd.eu/>).

**15. TCA** is an international network of national thyroid cancer support organizations and/or thyroid support groups, dedicated to working together towards providing support, information and encouragement to those affected by the disease throughout the world. (Official website: <https://thyroidcanceralliance.org/>).

**16. EANO** is the Europe's multidisciplinary Neuro-Oncology organization representing all medical and scientific disciplines involved in the prevention, diagnosis and treatment of tumors of the central nervous system (CNS). (Official website: <https://www.eano.eu/>).

**17. EHNS** wants to promote exchange of knowledge in all aspects of head and neck neoplastic diseases and to promote the highest standards of research, education and training, disease prevention and patient care. (Official website: <https://www.ehns.org/>).

**18. ENETS** aims to increase the knowledge and awareness of Neuroendocrine Tumor (NEN) in all healthcare systems, to improve early diagnosis of NEN, and to enable patients to be referred to NEN specialist centers, and monitor and audit the standards of care in NEN centers. (Official website: <https://www.enets.org/>).

**19. ESGO** strives to improve the health and well-being of women with gynaecological cancers through prevention, research, excellence in care and education. (Official website: <https://esgo.org/>).

**20. ESSO** aims to advance the science and practice of cancer surgery for the benefit of patients through education, research and innovation and multidisciplinary care, in Europe and beyond. (Official website: <https://www.essoweb.org/>).

**21. ECO** aims to create and develop relationships between European institutions and the European cancer care community, and with Member Societies and networks, to facilitate collaboration and consensus on focused topics towards tangible and impactful policy improvement. (Official website: <https://www.europeancancer.org/>).

**22. OECI** aims to accelerate the application of multidisciplinary personalized care approaches to reduce mortality and to guarantee an equitable access. It has been working groups as cancer economics and biobanks and molecular pathobiology, among others. (Official website: <https://www.oeci.eu/>).

**23. UNCAN.eu** aims to understand cancer and its mechanisms better in order to improve cancer prevention, early diagnosis and treatment; to set up a European Federated Cancer Research data hub and to generate a series of use cases, addressing major challenges in cancer research. (Official website: <https://uncan.eu/>).

**24. HARMONISATION** wants to constitute a multidisciplinary network to harmonize



clinical care and research on adrenal tumors throughout Europe. It is organized in five Working Groups (clinical practice; research and omics practice; Information Technology (IT)/Artificial Intelligence (AI) tools; ethical and legal framework and communication, dissemination and inclusiveness). (Official website:

<https://www.cost.eu/actions/CA20122/>).

25. **LOBSTERPOT** aims to better understand, diagnose and treat patients with invasive lobular carcinoma (ILC), streamlining of the “from bench-to-bedside” principal to enable uniform diagnosis and tailored treatment for ILC patients. (Official website:

<https://www.cost.eu/actions/CA19138/>).

In order to rank networks according to order of importance and interest, you have to select (clicking) the network that you consider has to be in the first place and drag it to the first position. Secondly, you will drag the one that you think should be in that position, and thus put them in the order of priority that you consider appropriate.

**EURACAN:** European Network on Rare Adult Cancers (solid tumors)

**EUROBLOODNET:** European Network on oncological and non-oncological rare hematological diseases

**GENTURIS:** European Reference Network on GENetic TUmour Risk Syndromes

**ECRIN:** European Clinical Research Infrastructure Network

**ESMO:** European Society for Medical Oncology

**EORTC:** European Organisation For Research and Treatment of Cancer

**ECICC:** European Commission Initiative on Colorectal Cancer

**TRANSPLANT-CHILD:** European Commission Initiative on Colorectal Cancer

**ETOP:** -European Thoracic Oncology Platform

**IRCI:** International Rare Cancer Initiative

**FOSTER:** Fighting OsteoSarcoma Through Everyday Research

**IG17104:** Pan-European Educational Platform on Multidrug Resistant Tumours and Personalised Cancer Treatment

**EURO-CHOLANGIO-NET - CA18122:** European Cholangiocarcinoma Network

**ERICA:** European Rare Disease Research Coordination and Support Action

**TCA:** Thyroid Cancer Alliance



**EANO:** European Association of neuro-oncology

**EHNS:** European Head & Neck Society

**ENETS :** The European Neuroendocrine Tumor Society

**ESGO:** European Society of Gynaecological Oncology

**ESSO:** The European Society of Surgical Oncology

**ECO:** European Cancer Organisation

**OECI:** Organisation of European Cancer Institutes

**UNCAN.eu:** European Initiative to UNderstand CANcer

**HARMONISATION - CA20122:** Harmonizing clinical care and research on adrenal tumours in European countries

**LOBSTERPOT - CA19138:** Lobular Breast Cancer: Discovery Science, Translational Goals, Clinical Impact

### **Second block: Networks on specialized fields**

Now, we ask you to please rank the networks of your area of expertise. Where we ask you to please rank the networks of your area of expertise. The survey will force you to rank at least once networks on specialized fields. Once you finish, the next block will be optional.. Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance.

- Pediatric, Adolescent & Young Adult (PAYA)
- Survivorship
- Hi-Tech medical resources
- Complex and poor prognosis
- Advocacy groups
- Omics

### **Omics**

#### **OMICS networks**

Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance.

**1. TRANSLACORE** provides a unique opportunity to understand this biological process



leading to reconsider our view of gene expression control in this disease and deliver novel therapeutic opportunities. (Official website: <http://ww.cost.eu/actions/CA21154>).

2. **LOBSTERPOT** aims to better understand, diagnose and treat invasive lobular carcinoma (ILC), streamlining of the “from bench-to-bedside” principal to enable uniform diagnosis and tailored treatment for ILC patients. (Official website: <https://www.cost.eu/actions/CA19138/>).

In order to rank networks according to order of importance and interest, you have to select (clicking) the network that you consider has to be in the first place and drag it to the first position. Secondly, you will drag the one that you think should be in that position, and thus put them in the order of priority that you consider appropriate.

**TRANSLACORE - CA21154:** Translational control in Cancer European Network

**LOBSTERPOT - CA19138:** Lobular Breast Cancer: Discovery Science, Translational Goals, Clinical Impact

Thank you!

If you want to collaborate ranking more networks, please select (is optative).

- Pediatric, Adolescent & Young Adult (PAYA)
- Survivorship
- Hi-Tech medical resources
- Complex and poor prognosis
- Advocacy groups
- No, I'm done here :)

## Advocacy groups

### Advocacy Groups networks

Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance.

1. **LuCE** provides an European platform for lung cancer patient advocacy associations and networks and supports the establishment of national lung cancer patient groups in those European countries where such groups do not yet exist. (Official website: <https://www.lungcancereurope.eu/overview/>).

2. **CCI Europe's** mission is to unite parents, patients and survivors and advocate for



their rights to: improve the medical and psychosocial care for children and adolescents; implement European Standards of Care; and improve the quality of survivorship. (Official website: <https://ccieurope.eu/>).

3. **IBTA** is a worldwide community for brain tumor patient organizations and others involved in the field of neuro-oncology. (Official website: <https://theibta.org/>).

4. **DiCE**'s mission is to contribute to early diagnosis and decreased mortality from digestive cancers and to increase overall survival and quality of life. (Official website: <https://digestivecancers.eu/>).

5. **INCA**'s mission is to raise awareness about all types of neuroendocrine tumors (NETs); push for scientific advancements with a focus on identified unmet needs; and to provide a platform for global collaboration. (Official website: <https://incalliance.org/>).

6. **WECAN**'s mission is to strengthen patient advocacy in Europe and improve outcomes for all cancer patients. Furthermore, the network provides valuable resources for Childhood Cancer International (CCI) members to obtain knowledge (i.e. through training courses). (Official website: <https://wecanadvocate.eu/>).

7. **Nothing about us without us!** Project aims at finding out about prevailing knowledge and opinions towards patients and public involvement and engagement (PPIE) – from both patients and health care professionals – and developing a training tool based on the findings. (Official website: <https://www.cost.eu/actions/CA19138/>).

In order to rank networks according to order of importance and interest, you have to select (clicking) the network that you consider has to be in the first place and drag it to the first position. Secondly, you will drag the one that you think should be in that position, and thus put them in the order of priority that you consider appropriate.

**LuCE:** Lung Cancer Europe

**CCI Europe:** European branch of Childhood Cancer International (CCI) & Parents and survivors

**IBTA:** International Brain Tumour Alliance

**DiCE:** Digestive Cancers EUROPE

**INCA:** International Neuroendocrine Cancer Alliance

**WECAN:** Workgroup of European Cancer Patient Advocacy Networks

**Nothing about us without us!**



Thank you!

If you want to collaborate ranking more networks, please select (is optative).

- Pediatric, Adolescent & Young Adult (PAYA)
- Survivorship
- Hi-Tech medical resources
- Complex and poor prognosis
- Omics
- No, I'm done here :)

**Before you leave**

**Before you leave...**

If after reading the European networks included in the analysis you think we should take into account any that do not appear here, please let us know.

**Complex and poor prognosis**

**Complex and poor prognosis networks**

Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance:

1. PCE aims at bringing together relevant stakeholders to advocate for an improvement in the standard of care for patients with pancreatic cancer, by addressing the existing gaps related to the lack of awareness, diagnosis and data collection. (Official website: <https://pancreaticcancereurope.eu>).
2. SIOPEN project aims to build a European Neuroblastoma Research Network to ultimately improve the survival in children suffering from neuroblastoma. (Official website: <https://www.siopen.net/>).

In order to rank networks according to order of importance and interest, you have to select (clicking) the network that you consider has to be in the first place and drag it to the first position. Secondly, you will drag the one that you think should be in that position, and thus put them in the order of priority that you consider appropriate.

PCE: Pancreatic Cancer Europe





SIOPEN: International society of pediatric oncology European neuroblastoma network

Thank you!

If you want to collaborate ranking more networks, please select (is optative).

- Pediatric, Adolescent & Young Adult (PAYA)
- Survivorship
- Hi-Tech medical resources
- Advocacy groups
- Omics
- No, I'm done here :)

### Hi-Tech medical resources

#### Hi-Tech medical resources networks

Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance.

1. **EDHEN's** mission is to reduce the time needed to provide answers in real world, health research. It will achieve this by developing the required infrastructure in a federated network at scale across Europe, collaboration on research methodologies, and education in an open science collaboration. (Official website: <https://www.ehden.eu/>).
2. **ESTRO** supports all radiotherapy professionals in their needs of continuous professional development. The needs of a growing society in terms of governance and leadership will actively be addressed. The Society will also increasingly embrace its role in policy, through a broadening network of partnerships with all relevant stakeholders. (Official website: <https://www.estro.org/>).
3. **ENCR** promotes collaboration between cancer registries, defines data collection standards, provides training for cancer registry personnel and regularly disseminates information on cancer incidence and mortality in Europe. (Official website: <https://www.encl.eu/>).
4. **EXPeRT** aims to empower research on pediatric value radiation therapy (VRT) in rare cancers by promoting cooperation between the national groups behind its foundation, supporting the creation of other such groups elsewhere in Europe, and fostering international collaboration schemes with other networks. (Official website: <https://www.raretumors-children.eu/>).



In order to rank networks according to order of importance and interest, you have to select (clicking) the network that you consider has to be in the first place and drag it to the first position. Secondly, you will drag the one that you think should be in that position, and thus put them in the order of priority that you consider appropriate.

**EDHEN:** European Health Data & Evidence Network

**ESTRO:** The European Society for Radiotherapy and Oncology

**ENCR:** The European Network of Cancer Registries

**EXPeRT:** European Cooperative study group for pediatric rare tumors

Thank you!

If you want to collaborate ranking more networks, please select (is optative).

- Pediatric, Adolescent & Young Adult (PAYA)
- Survivorship
- Complex and poor prognosis
- Advocacy groups
- Omics
- No, I'm done here :)

## Survivorship

### Survivorship networks

Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance.

1. **PAEDCAN ERN** will reduce inequalities in childhood cancer survival by providing high-quality, accessible and cost-effective cross-border healthcare to children and adolescents with cancer, regardless to where they live. (Official website: <https://paedcan.ern-net.eu/>).
2. **PANCARE** is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer. (Official website: <https://www.pancare.eu/>).
3. **EU-CAYAS-NET** EU project will develop an interactive virtual platform and a network



that will foster social networking, peer-support, knowledge-exchange, and aims at improving: the quality of life of survivors, the care for AYA with cancer, and Equality, Diversity and Inclusion. (Official website: <https://beatcancer.eu/>).

4. **PanCareSurFup** carried out research studies into late effects of treatment for cancer, established guidelines for follow-up, and disseminated the results and provided training and workshops for stakeholders. (Official website: <http://www.pancaresurfup.eu/>).

5. **PanCareFollowUp** aims to improve the quality of life for survivors of childhood cancer by bringing evidence-based, person-centered care to clinical practice in the real world. (Official website: <https://pancarefollowup.eu/>).

6. **INE-CSC** aims to systematically support the sustained translation of evidence-based interventions into routine clinical practice as part of a cross boundary, systems level cancer survivorship pathway which ultimately enhances the health and wellbeing of cancer survivors. (Official website: <https://www.cost.eu/actions/CA21152/>).

In order to rank networks according to order of importance and interest, you have to select (clicking) the network that you consider has to be in the first place and drag it to the first position. Secondly, you will drag the one that you think should be in that position, and thus put them in the order of priority that you consider appropriate.

**PAEDCAN:** The European Reference Network on Paediatric Cancer

**Pancare:** Pan-european Network for care of survivors after cancer treatment

**EU-CAYAS-NET:** European Youth Cancer Survivors Network

**PanCareSurFup:** PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies

**PanCareFollowUp:** Novel, patient-centred survivorship care to improve care quality, effectiveness, cost-effectiveness and accessibility for survivors and caregivers

**INE-CSC - CA21152:** Implementation Network Europe for Cancer Survivorship Care

Thank you!

If you want to collaborate ranking more networks, please select (is optative).

- Pediatric, Adolescent & Young Adult (PAYA)
- Hi-Tech medical resources
- Complex and poor prognosis
- Advocacy groups
- Omics



No, I'm done here :)

## PAYA

### Pediatric, Adolescent & Young Adult (PAYA) networks

Firstly, please find a short description of the general scope of the networks. After that, you could rank them according to their relevance.

1. **PAEDCAN** aims to reduce inequalities in childhood cancer survival by providing high-quality, accessible and cost-effective cross-border healthcare to children and adolescents with cancer, regardless to where they live. (Official website: <https://paedcan.ern-net.eu/>).
2. **EpSSG** seeks to improve the quality of care offered to children, teenagers and young adults with soft tissue sarcoma (STS). EpSSG aims to spread best clinical practice; provide expert opinion and promote and support clinical trials, among others. (Official website: <https://www.epssgassociation.it/en>).
3. **EXPeRT** aims to empower research on pediatric value radiation therapy (VRT) in rare cancers by promoting cooperation between the national groups behind its foundation, supporting the creation of other such groups elsewhere in Europe, and fostering international collaboration schemes with other networks. (Official website: <https://www.raretumors-children.eu/>).
4. **SIOPEN** is a Neuroblastoma Research Network to ultimately improve the survival in children suffering from neuroblastoma. <https://www.siopen.net/>
5. **ITCC's** goal is to accelerate the introduction of new effective and safe therapies in the treatment of children and adolescents with cancer, prioritizing potentially effective drugs and better preclinical evaluation. (Official website: <https://www.itcc-consortium.org/>).
6. **ENTYAC** exists to improve and enhance inter-professional teamwork processes, to promote team-based specialist care. It also aims to improve aspects regarding key scientific, medical, nursing and psychosocial barriers facing AYA cancer patients. (Official website: <https://siope.eu/news/discover-ENTYAC-Oct22/>).
7. **e-SIOP - SIOP Europe** is the only pan-European organization representing all professionals working in the field of childhood cancers. SIOPE is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe. (Official website: <https://siopeurope.eu/>).
8. **PanCare** is a multidisciplinary pan-European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer. (Official website:



<https://www.pancare.eu/>).

9. CAC2 is a collaborative network of organizations and individuals who support and serve the childhood cancer community. Their aim is to foster and sustain greater levels of coordinated action, information exchange, learning and broad-based collaboration. (Official website: <https://cac2.org/>).

10. **STRONG-AYA** is a multi-stakeholder European network to improve healthcare services, research and outcomes for AYA patients. They will to develop a healthcare research network with data-driven, interactive policy and visualization tools to bring novel insights into AYA healthcare. (Official website: <https://cordis.europa.eu/project/id/101057482>).

In order to rank networks according to order of importance and interest, you have to select (clicking) the network that you consider has to be in the first place and drag it to the first position. Secondly, you will drag the one that you think should be in that position, and thus put them in the order of priority that you consider appropriate.

ERN PAEDCAN: The European Reference Network on Paediatric Cancer

EPSSG: European pediatric Soft tissue sarcoma Group

EXPeRT: European Cooperative study group for pediatric rare tumors

SIOPEN - : International society of pediatric oncology European neuroblastoma network

ITCC : Innovative therapies for children with cancer

ENTYAC: European Network for TYA with Cancer

e-SIOP - SIOP EUROPE: The European Society for Paediatric Oncology

Pancare: Pan-european Network for care of survivors after cancer treatment

CAC2: Coalition Against Childhood Cancer

**STRONG-AYA**: European network to improve healthcare services, research and outcomes for Adolescents and Young Adults (AYA) with cancer

Thank you!

If you want to collaborate ranking more networks, please select (is optative).

- Survivorship
- Hi-Tech medical resources
- Complex and poor prognosis

- Advocacy groups
- Omics
- No, I'm done here :)

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**Annex 3.** Dimensions results summary table



	EURACAN	ESMO	EORTC	OECI	GENTURIS	UNCAN.eu	PCE	EAPC	PANCARE	EU-CAYAS-NET	TRANSLACORE	ESTRO	CCI Europe	PAEDCAN	SIOPE
3.1.1.	Yes. The values are distinguishable but they are not included in an explicit way in the website description	Yes.	Yes.	Yes.	Yes.	Yes.	Yes	Yes	Yes	Yes, although there is no specific references to their vision	No. Only its objectives.	Yes. There is no reference for the values.	Yes. There is no reference for the values.	Yes.	Yes.
3.1.2.a	Yes. General Assembly, Steering Committee, Scientific Advisory Group, Domains of clinical action and Transversal Task forces. EURACAN distinguishes between thematic and sub-thematic areas of rare adult solid cancer	Yes. General Assembly, Executive Board, ESMO Council and several Committees and task forces	Yes. General Assembly, Board Committees, EORTC Board, Chief Executive Officer, Operational Committees, Scientific Chairs Council, EORTC Headquarters, Groups and Taskforces.	Yes. General Assembly, Board, Accreditation and Designation Programme and Working Groups.	Yes. ): General Board, Advisory Board, Executive Committee, Research Board, National Coordinators Board, Coordinator, ePAG Patient Council, Task Force teams and Project Bureau	No, Coordinator, Executive Committee, core partners and advisory partners. They are working to develop a governance structure.	Yes. Work Streams, Administration board, Secretariat and Communication Office.	Yes. EAPC Board of Directors, Head Office Team, Task forces and Reference Groups	Yes. General Assembly, Executive Committee, Committees, Groups and Taskforces	No. Coordinator, Beneficiaries and Associated Partners	Yes. Action Chair, Action Vice Chair, Grant Holder Scientific Representative, Science Communication Coordinator, Grant Awarding Coordinator, Working Group leaders (WG1-WG5) and WG Co-leaders	Yes. General Assembly, Board, Committees, Councils and Focus Groups.	Yes. CCI Europe Committee and Core Team.	Yes. General Assembly, Oversight Committee, The Network Management Team, SIOPE Office and Ethics Advisory Committee.	Yes. General Assembly, Team and SIOPE Board.
3.1.2b	Non-for-Profit Organization, ERN – non legal entity, under the European Union's Directive on patient's rights in cross-border healthcare	Non-for-Profit Organization under Swiss law. Legal entity.	Non-governmental organizations, platforms and networks and similar under Belgian law. Legal entity.	European Economic Interest Grouping (EEIG) under the Belgian law.	Non-for-Profit network, ERN – non legal entity, under the European Union's Directive on patient's rights in cross-border healthcare	Non legal entity, is not a formal organization but rather an initiative that fosters collaboration	Non-profit network (ASBL), registered in Brussels – Belgium	Non-profit organization, legal entity, under Belgian law	Non-governmental organizations, platforms and networks and similar. Legal entity under the Dutch law	Non legal entity, is a collaborative network funded by the EU4Health Programme	Non legal entity, is a collaborative network funded by the COST Programme	Non-profit organization constituted in accordance with the provisions of Title III of the Belgian Statute	a 'Non-governmental organizations, platforms and networks and similar – Legal branch (under the Austrian law)'	Non-for-Profit Organization, ERN – non legal entity, under the European Union's Directive on patient's rights in cross-border healthcare	Non-governmental organizations, platforms and networks and similar. Legal entity under the Belgian law.
3.1.2c	There are 4 types of affiliation to EURACAN: full member, affiliated partner, associated	Yes, Full membership (free) and Student membership (free)	Yes, individual and institution memberships.	Yes.	Yes: full member or affiliated partner. The process to become a full member of GENTURIS	No	Yes	Yes	Yes.	No	Yes	Yes, Individual and collective memberships.	Yes. Full and associate membership	Yes: full member or affiliated partner. The process to become a full member of PaedCan	Yes.



	partners and scientific societies. The process to become a full member of EURACAN is done by an application in a call for interest launched by the EC				is done by an application in a call for interest									is done by an application in a call for interest	
3.1.2d	Both	Individuals	Both.	Organizations.	Organizations (the application could be done by an individual representing HCP organizations)	Organizations (at the moment)	Both	Individuals and Organizations	Individuals.	Individuals and organizations	Individuals and organizations	Individuals and organizations	Individuals and organizations	Organizations (the application could be done by an individual)	Both
3.1.3a	Yes	Yes	Yes.	Yes.	Yes	No	Yes	Yes	No	Not reported	Yes	Yes	Yes	Not reported, but as an ERN must have it.	Yes.
3.1.3b	No	Yes	Yes.	Yes.	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	No	Yes.
3.1.3c	3-5 years	4 years	3-5 years.	3 years.	Should be every 3-5 years	No	Each year	4 years	No	No	4 years	Not clearly defined, 8-10 years.	1 year	Should be every 3-5 years	5 years.
3.1.3d	After the first 5 years	Not mentioned	Not mentioned.	Annual.	Should be after the first 5 years and performed by the EC	No	Not reported	No	No	No	Each year	Not clearly defined, 8-10 years.	Not mentioned	Should be after the first 5 years	5 years.
3.1.3e	Yes	Not mentioned	Yes.	Yes.	Yes	No	Yes	No	No	No	Yes	Yes, in the annual reports	Not mentioned	Yes	Yes.
3.1.3f	Yes	Not mentioned as such	Yes.	Yes.	Not reported	No	Not reported	No	No	No	No	Yes	Yes	No	Yes.
3.1.4.1a	Yes, all three.	Scientific Advisory Board (only editorial); Strategic Plan (yes);	Yes.	It has working groups.	GENTURIS have a Research Strategic Plan and Research	No	It has a Work Stream in Research	No mentioned, but they has a Research Networks which	No	No	No	Scientific Advisory Board (yes); Strategic Plan (yes); Research	Scientific Advisory Board (no, they have a strategic pillar on	No	Yes.



		Research Working Groups (Yes)			Working Groups.			provides an established structure for collaborative research				Working Groups (yes)	research); Strategic Plan (not reported); Research Working Groups (Yes)		
3.1.4.1b	Yes, 15.	Yes, 500.	Yes, more than 500.	12	Yes, 15.	Yes, 4.	2	Yes	Yes, 39	No	Not reported	Yes	Yes, 2	Yes, 15.	Yes, 101.
3.1.4.1c	One Board meeting per year (last one in May 2023) the previous one took place in February 2022	More than 515 (data on meetings are reported)	In 2022 more than 6.000 delegates participated in EORTC-led events.	Yes.	Yes	Yes, 2.	Yes	Yes	Yes	6	Yes, 5	Yes, 30 in 2022	8 on 2023	Yes, 17	Yes, 125.
3.1.4.1d	Not found data	Data not found	Yes, more than 200.	No data found.	Yes	No	No data found	No	No	No	No	No	Not found data	No	Yes.
3.1.4.1e	Yes. ARCAGEN and SELNET.	Data not found	Yes.	Yes.	Yes (as partners and leaders)	Is an European project.	Yes	Yes	Yes	Is an European project	Is an European project	Yes	Yes	Yes. ESCP Project	Yes.
3.1.4.1f	Yes. EURACAN's e-tool.	Yes. oncologyPRO	Yes, clinical trials database, guidelines, public policy.	Yes. OECI standards for high qualitative cancer.	Yes. Clinical Patient Management System (only for members), clinical practical guidelines, care pathways and patient journeys	No	Yes. Leaflets, registries, white paper	Yes, guidelines, white papers, reports...	Yes	Yes. Articles, guidelines, infographics, publications and reports	Yes. Articles, Application notes and Standard operating procedures	Yes	Yes	Yes. Clinical Patient Management System (only for members) and ESCP surveys	Yes. Development of European Standards.
3.1.4.2	Yes. Fellowship and ERN-Exchange programme; online courses	Yes. ESMO Congress, conferences, continuing medical education, patient seminars, and other additional courses.	Yes. Courses, research workshops, webinars, symposiums, conferences.	Yes. Self-training courses.	Yes, GENTURIS collaborates with ESMO and ESHG/Bertinoro courses	Not yet	Yes. Short scientific stays and multistakeholder meetings	Yes, webinars, workshops, congresses	Yes. Courses.	Yes. Thematic webinars, trainings for youth cancer ambassadors, peer visit trainings	Yes. Training schools, short-term scientific missions (STSM).	Yes. Courses (multidisciplinary and specific interdisciplinary), workshops, e-learning, ESTRO school teaching programme	Yes, conferences, webinars, e-learning opportunities	Yes. Interactive webinar series.	Yes. Courses, webinars, fellowships, collaborative activities, documents, annual meetings
3.1.4.3a	No	Yes	Yes.	No	No	No	No	No	No	No	Yes	No	No	No	Yes.



3.1.4.3b	Yes	Yes	Yes.	Yes	Yes	Not yet	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes.
3.1.4.3c	No	No	Yes.	No	Yes, in the CPMS – consultancy for patients	No	No	No	No	No	No	No	No	Yes	No.
3.1.4.3d	No	No	Yes. Infrastructure projects, expert consultations, royalties, study tools,	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	No	No	Yes.
3.1.5	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders	Visible list; Initiatives; Connect with relevant stakeholders
3.1.6	Yes provided to the EC	Apparently, yes.	Not found.	Not found.	Yes	No	Yes	No	No	No	Yes	Yes	Apparently, yes.	Yes	Apparently, yes.
3.1.6a	Yes	Yes	Yes.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes.
3.1.6b	Yes	Yes	Yes.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes.
3.1.6c	Yes	Yes (in a form of newsroom webpage)	Yes.	Yes	Yes	Yes	Yes	Yes	Yes	Yes, prior subscription required	No	Yes	Yes	Yes	Yes.
4.6.4d	Twitter, Facebook and LinkedIn	Twitter, Facebook, LinkedIn, Youtube and Instagram	Twitter, Facebook, LinkedIn, Youtube and Instagram.	Yes: Facebook, LinkedIn and Twitter.	Linkedin	Twitter and LinkedIn	Yes: Facebook, Instagram, LinkedIn, Twitter and YouTube	Twitter, LinkedIn, Instagram, Facebook, YouTube	Twitter, Facebook, LinkedIn, Youtube and Instagram	Twitter, Facebook, LinkedIn, Instagram and YouTube	Twitter, Facebook and LinkedIn	Twitter, Facebook, LinkedIn and Instagram	Twitter, Facebook, LinkedIn, Youtube and Instagram	Twitter, Facebook and LinkedIn (not available)	Twitter, Facebook, LinkedIn, Youtube and Instagram.
3.1.7	Yes, about the legal framework of the ERNs	Yes, about clinical trials and data protection	Yes, about clinical trials, data protection, and other regulation issues.	Yes, about GDPR	Yes (legal framework of the ERNs, ethical standards, protection of human in research and the appropriate uses of biomedical technologies )	No	Yes, about GDPR	Yes, about Medicine regulation and Human Rights; and frameworks for euthanasia and physician assisted suicide	Not found	No	Yes, about GDRP and IPR	Yes, ESTRO Radiation Therapist cod of Ethics and Conduct	Yes, about Ethics in fundraising and in Pediatric Clinical Trials	Yes (legal framework of the ERNs, ethical standards, protection of human in research and the appropriate uses of biomedical technologies )	Yes, about clinical trials, data protection and pediatric & orphan.
3.1.8	Not mentioned.	Yes	Yes.	Yes	Not reported	No.	Yes	Yes	Yes	Not reported	No	Yes	Yes	No	Yes.



3.1.8a	Yes. Support for the fellow and exchange programmes	Yes	Yes.	Yes, both.	Yes	No	Yes, in-kind	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes.
3.1.8b	Yes. Funded by the EC, support of the EJP Rare Diseases and close collaboration with EIT Health Rare Cancer. Participation in competitive funding calls.	Yes (donors, industry, associations ...)	Yes (donors, industry, grants, royalties, subsidies, events...).	Yes, membership fees, grants and donors.	Co-funded by the EC; Participation in European Projects	No	Sponsored	Yes, EU funding and membership system	Yes (members contributions, EU funding and donations)	Co-funded by the EU4Health Programme	Co-funded by the COST Programme	Yes, donations, EU funding and grants	Yes, membership system	Co-funded by the EC; Participation in the ESCP project	Yes (members contributions, grants, EU funding and donations).

*Note.* 3.1.1. SCOPE: Does the organization defined their objectives, mission, vision and values?; 3.1.2. GOVERNANCE: a) Does the organization defined a governing entity, their organizational and functional structure and their capability?; b) Network organizational model; c) Membership; d) Kind of members (organizations, individuals or both); 3.1.3. STRATEGIC PLAN: a)description; b) Bodies or professionals involved explained; c) Strategic Plan time validity; d) Time for progress or performance review; e) Impact evaluation and/or performance assessment; f) Sustainability Strategy; 3.1.4.1 RESEARCH: a) Does the organization have Scientific Advisory Board, Strategic Plan and Research Working Groups?; b) Peer reviewed publications; c) Participation and/or organization in scientific congress/events; d) Participation in Clinical Trials; e) Participation in European projects; f) Others; 3.1.4.2 EDUCATIONAL ACTIVITIES ORGANIZATION; 3.1.4.3 SERVICES: a) Matchmaking; b) Knowledge exchange activities; c) Consultancy; d) Others; 3.1.5. STRATEGIC ALLIANCES; 3.1.6. COMMUNICATION STRATEGY; a) Website; b) News section; c) Newsletter; d) Social Media accounts; 3.1.7. ETHICS, LEGAL & REGULATORY; 3.1.8 FUNDING: Process or model for financial sustainability; a) Members' own investments (in-kind and/ or financial); b) Potential external funding.



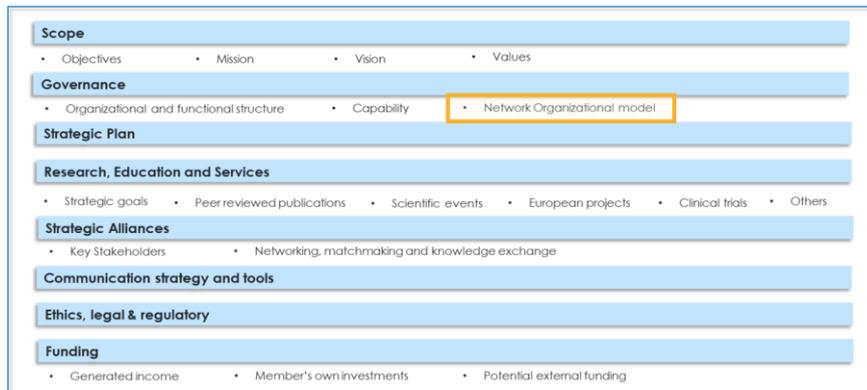
## Annex 4. Sustainable governance of NoEs, what direction?

### Sustainable governance of NoEs, what direction?



- Part of the task 4.1 “Mapping and analysis of existing networks”
- We are using a Comparative framework which includes a total of 8 dimensions

Figure 4. Dimensions and sub-dimensions of the Comparative Framework for European networks.



### Sustainable governance of NoEs, what direction?



There are several types of organizational models, these are a few examples, and there may be variations or combinations depending on the specific organization and its goals.

- For-profit organizations
- Non-profit organizations
- Cooperatives
- Government agencies
- International organizations
- Professional associations
- Worker cooperatives
- Foundations
- European Economic Interest Grouping (EEIG)
- Hybrid organizations





## Sustainable governance of NoEs, what direction?



Today we will explore the pros and cons between some of the types that could better address the nature of the NoEs:

- **For-profit organizations**
- **Non-profit organizations**
- Cooperatives
- Government agencies
- International organizations
- Professional associations
- Worker cooperatives
- Foundations
- European Economic Interest Grouping (EEIG)
- Hybrid organizations



## Sustainable governance of NoEs, what direction?



### For-profit organizations

These are businesses that operate with the goal of making a profit (corporations, partnerships...).

E.G: *Genetech & AstraZeneca*.

- The primary goal is to generate profits for the owners or shareholders
- The owners have a great deal of control over the business
- Focus on profits = expense of other goals such as social
- There may be pressure to prioritize short-term profits over long-term growth





## Sustainable governance of NoEs, what direction?



### Non-profit organizations

Operates with the goal of serving a specific mission or purpose, rather than making a profit (Charities, Foundations...).

E.G: *are International Cancer Advocacy Network (ICAN) & Center for Advancement in Cancer Education and Young Survival Coalition.*

- The organization may be eligible for tax-exempt status
- It can receive donors
- The organization's board of directors has a legal obligation to act in the best interests of the organization
- **May rely heavily on grants or donations**
- **The board of directors may be subject to strict legal requirements and fiduciary duties**



A non-profit organization typically needs to register with the relevant government authority or regulatory body in the country where it operates. This registration process grants the organization legal recognition and establishes its status as a separate legal entity.



## Sustainable governance of NoEs, what direction?



### Government agencies

Created and funded by governments to provide public services and enforce laws and regulations.

E.G: *World Health Organization (WHO) & European Medicines Agency (EMA).*

- Has the resources and authority of the government behind it
- Can provide important public services and regulate industries
- **May be subject to political influence or pressure**
- **The decision-making process can be slow and bureaucratic**
- **May have limited flexibility to adapt to changing circumstances**





## Sustainable governance of NoEs, what direction?



### European Economic Interest Grouping (EEIG)

Designed to facilitate economic activity between its members, who can be businesses or other organizations.

E.G: *Trans-European Research and Education Networking Association" (TERENA).*

- Facilitate cross-border economic activity between its members
- Can provide its members with access to funding and other resources
- Can apply for grants and other forms of financing from EU institutions and other funding bodies
- It is important to carefully consider the legal and regulatory requirements for establishing and maintaining an EEIG



## Sustainable governance of NoEs, what direction?



### Pros and cons sum up

Organizational Model	Pros	Cons
<b>For-profit organization</b>	Potential for high profits and growth	Profit motive may conflict with social or environmental goals; pressure to prioritize shareholder interests over other stakeholders
<b>Non-profit organization</b>	Mission-driven focus; tax-exempt status and ability to receive grants and donations	Dependence on donors and grants for funding
<b>Government agency</b>	Public accountability and transparency; access to public funding and resources	Bureaucratic and slow decision-making; susceptibility to political influence and budget constraints
<b>European Economic Interest Grouping</b>	Cross-economic activity; improves economic sustainability	Legal and regulatory requirements; maintenance

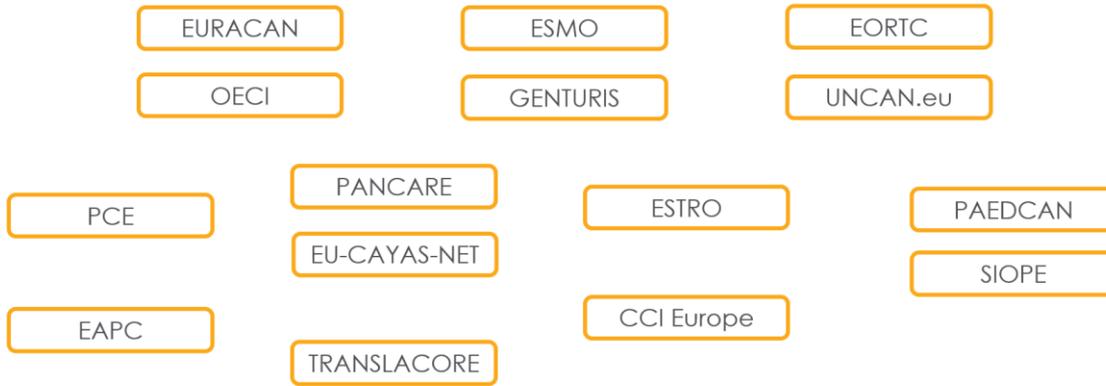




### Sustainable governance of NoEs, what direction?



**Examples:** Kronikgune has analysed the organizational model of the following organizations as part of the Task 4.1 - *Mapping and analysis of existing networks*:



### Sustainable governance of NoEs, what direction?



Organization	Organizational Model
EURACAN	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
<a href="#">ESMO</a>	Non-profit organization, trade unions and professional associations, legal entity, non-political under Swiss law
<a href="#">EORTC</a>	Non-profit organization (AISBL), legal entity, under Belgian law
OECI	European Interest Grouping, non-governmental Organisation under the Belgian law
GENTURIS	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
UNCAN.eu	Non legal entity, is not a formal organization but rather a initiative that fosters collaboration
<a href="#">PCE</a>	Non-profit network (ASBL), under Belgian law
<a href="#">EAPC</a>	Non-profit organization, legal entity, under Belgian law
<a href="#">PANCARE</a>	Non-profit network
EU-CAYAS-NET	Non legal entity, is a collaborative network funded by the EU4Health Programme
TRANSLACORE	Non legal entity, is a collaborative network funded by the COST Programme
ESTRO	Non-profit organization, legal entity, under Belgian law
<a href="#">CCI Europe</a>	Non-governmental organisations, platforms and networks and similar/ legal branch
PAEDCAN	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
<a href="#">SIOPE</a>	Non-profit association (ASBL), legal entity, under Belgian law

Under review!



Note that in some cases, such as EURACAN and PCE, the organizations are structured as networks of institutions rather than as single entities.





## Sustainable governance of NoEs, what direction?



Under review!

Organization	Organizational Model
EURACAN	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
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SIOPE	Non-profit association (ASBL), legal entity, under Belgian law

 ERN

 Non-profit

 European Interest Grouping

 Non-legal entity (project)


Note that in some cases, such as EURACAN and PCE, the organizations are structured as networks of institutions rather than as single entities.

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## Sustainable governance of NoEs, what direction?



Organization	Organizational Model
EURACAN	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
GENTURIS	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare
PAEDCAN	ERN – non legal entity, under the Europeans Union’s Directive on patient’s rights in cross-border healthcare

### Please note:

- [European Reference Networks \(ERNs\)](#) are virtual networks of healthcare professionals and centers of expertise across Europe.
- ERNs are not legal entities, it functions as a collaborative network which operates within the framework of the ERN initiative and is supported by the European Commission.
- The structure and governance of ERNs is a unique model that has been developed in Europe supported by EC funding.
- Activities focused on improving patient care and outcomes rather than generating a profit.
- Some ERNs such as EURACAN are studying the liability to become established legal entities supported by the EC.

Actually, ERNs work as a Non-profit networks



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## Sustainable governance of NoEs, what direction?



Organization	Organizational Model
ESMO	Non-profit organization, legal entity, non-political under Swiss law
PCE	Non-profit <u>network (ASBL)</u> , under Belgian law

### Differences between non-profit organizations and non-profit networks

Operate on a non-profit basis, meaning their primary goal is not to generate profit but rather to pursue a mission or serve a particular cause.

#### Non profit organization:

- Legal entity formed to carry out specific activities or objectives for the benefit of the public or a specific group of people
- Typically has its own governance structure
- Can range from small local community groups to large international organization

#### Non profit network:

- Association or collaboration of multiple organizations that come together to address a shared interest or goal
- Each member organization retains its own legal and operational independence (*CCI Europe*)
- They joint to share resources, expertise, and best practices



## Sustainable governance of NoEs, what direction?



- **The choice of organizational model will depend on the specific goals, resources, and requirements** of the research network or consortium.
- It is important to **consult with legal and financial experts** to determine the most appropriate structure for the organization, and to **ensure compliance with laws and regulations**.

### NoEs objectives (some examples):

- **(WP5)** To initiate and promote novel translational research programmes
- **(WP6)** To promote the access of health care providers to existing educational and training programs and resources regarding PC
- **(WP8)** To offer support to patients organisations or other interested stakeholders in organising health prevention dedicated campaigns
- **(WP10)** Map where we stand for each high-tech medical resources
- **(WP11)** To support trans-age academic societies and collaboration between pediatric and adult oncologists on the AYAs' theme





## Sustainable governance of NoEs, what direction?



- **The choice** of organizational model **will depend on the specific goals, resources, and requirements** of the research network or consortium.
- It is important to **consult with legal and financial experts** to determine the most appropriate structure for the organization, and to **ensure compliance with laws and regulations**.

### NoEs objectives (some examples):

#### Common point?

- To gather knowledge from different experts across Europe
- To exchange knowledge
- To participate in collaborative activities

Subject to further conversations with experts on the field, NoEs leaders & Coordination team



## Sustainable governance of NoEs, what direction?



### Network or consortium model:

#### Potential benefits

- Access to a wider pool of expertise
- Shared resources – cost savings
- Increased visibility and credibility
- Opportunities for collaboration

#### Potential challenges...

- Coordination & communication
- Decision-making and governance
- Managing conflicts and competing interests
- Maintaining engagement and commitment - sustainability

- Revenue comes from grants from institutional, corporate and private donors and fees charged for studies conducted with partners or services, membership fees, **grants...**
- A non-profit organization (legal entity) could receive funds from its participation in funded projects, such as those funded by Horizon Europe. However, it is important to note that **the purpose of such funding would be to support the activities and objectives of the project, not to generate a profit\***

\*This could include funding research activities, supporting oncology education and training programs, and promoting patient advocacy initiatives (E.g., ESMO).

Subject to further conversations with experts on the field, NoEs leaders & Coordination team





Thank you!

WP4

