



Joint Action on Networks of Expertise

Deliverable number. 4.1

Policy recommendations on sustainability

Funded by the European Union. Views and opinions expressed are, however, those of the author(s) only and do not necessarily reflect those of the European Union or HaDEA. Neither the European Union nor the granting authority can be held responsible for them



DOCUMENT INFORMATION

Author(s)	Sarah Berrocoso, Yhasmine Hamu, Dolores Verdoy, Ane Fullaondo
Deliverable lead partner	Biosistemak Institute for Health System Research (formerly Kronikgune)
Contributing partner(s)	All project partners – in particular (CNAO, INT-NAH, CIPH, INCA, UNICANCER, BMG, DKFZ, OOI, SAM-LT, NCI-LT, OIL, ICO, IDIVAL, CIBER, HSJD, SAS, MFH, MSCI and IOCN)
Work Package	WP4 Sustainability
Deliverable type	R – Document Report
Due delivery date	M24 – 30/09/2024
Actual delivery date	20/09/2024
Dissemination level	Public

The WP4 is part of the Joint Action "JANE", GA 101075328, which has received co-funding from the European Union under the EU4Health programme



DISTRIBUTION LIST

Institution	Name of recipient(s)
1 - Coord INT	Paolo G. Casali, Annalisa Trama, Joanne Fleming, Salvatore Provenzano
2 - Biosistemak	Sarah Berrocoso, Yhasmine Hamu, Dolores Verdoy, Ane Fullaondo
3 - JANE Partners	All JANE partners

REVISION HISTORY

Version	Date of Issue	Author(s)	Brief description of changes
0.1	16/09/2024	Sarah Berrocoso (BS)	Development of the document
0.2	19/09/2024	Ane Fullaondo (BS)	Revision of the document
0.3	19/09/2024	Yhasmine Hamu (BS)	Revision of the document
0.4	20/09/2024	Sarah Berrocoso (BS)	Final draft



LIST OF ABBREVIATIONS

AE	Affiliated Entity
BIOSISTEMAK	Instituto de Investigación en Sistemas de Salud (formerly Kronikgune)
CA	Competent Authority
CCC	Comprehensive Cancer Center
CCI Europe	European Childhood Cancer International
CCN	Comprehensive Cancer Networks
CraNE	JA CraNE - Network of Comprehensive Cancer Centres
DG SANTE	Directorate-General for Health and Food Safety
EAPC	European Association for Palliative Care
e-CAN	Joint Action on strengthening eHealth including telemedicine and remote monitoring for health care systems for cancer prevention and care
ECO	European Cancer Organization
EHDS	European Health Data Space
ENTYAC	European Network for TYA with Cancer
BoMS	ERN Board of Member States
EORTC	European Organization for Research and Treatment of Cancer
ERN	European Reference Network
ESMO	European Society for Medical Oncology
ESSO	European Society of Surgical Oncology
ESTRO	European Society for Radiotherapy and Oncology
EU	European Union
EU-CAYAS-NET	EU Network of Youth Cancer Survivors
EURACAN	European Reference Network on Rare Adult Cancers (solid tumors)
GDPR	General Data Protection Regulation
GENTURIS	European Reference Network on GENetic TUmour Risk Syndromes
HaDEA	European Health and Digital Executive Agency
INT	Intituto Nazionale dei Tumori
JA	Joint Action
JANE	EU JOINT ACTION NETWORKS OF EXPERTISE ON CANCER
KG	Kronikgune
MEP	Member of the European Parliament



MoH	Ministry of Health
MS	Member States
NoEs	Networks of Expertise
OECI	Organization of European Cancer Institutes
PAEDCAN	European Reference Network for Paediatric Oncology
PANCARE	Pan-European Network for Cancer of Survivors after Childhood and Adolescent Cancer
PCE	Pancreatic Cancer Europe
SIOPE	European Society for Paediatric Oncology
STRONG-AYA	Improving the Future of Adolescents and Young Adults With Cancer
TRANSLACORE	Translational control in Cancer European Network
TTF	Transversal Task Force
UNCAN.eu	European Initiative to UNDERstand CANcer
WHO	World Health Organization
WP	Work Package



RECIPIENTS OF THIS DOCUMENT

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

PROJECT INFORMATION

Project Full Title	Joint Action on Networks of Expertise
Project Acronym:	JANE
Project N:	101075328
Call:	EU4H-2021-JA-IBA
Topic:	EU4H-2021-JA-04
Starting Date:	01 October 2022
Duration:	24 months
Coordinator:	FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI (INT)



TABLE OF CONTENT

1 EXECUTIVE SUMMARY.....	9
2 INTRODUCTION.....	11
2.1 JANE project summary.....	11
2.2 Purpose of this document.....	13
2.3 Intended audience	14
3 METHODOLOGY.....	15
3.1 Identifying key aspects of the sustainability.....	15
3.2 Supporting deliberative conversations with key partners	18
3.2.1 Policy Board and Policy Dialogues.....	18
3.2.2 Stakeholder Forum.....	20
3.2.3 Engagement of additional stakeholders.....	21
4 LESSONS LEARNT FOR THE SUSTAINABILITY OF HEALTH NETWORKING.....	22
4.1 Initial key findings	22
4.2 Policy Dialogues.....	24
4.3 Stakeholder forum, international, national and regional events.....	29
5 POLICY RECOMMENDATIONS.....	33
5.1 Key areas for action.....	33
5.2 Added value of the recommendations.....	35
5.3 Next steps	38
6 CONCLUSION	41
6.1 Call-to-action for the European Commission	41
ANNEXES	42
ANNEX I JANE Policy Dialogues methodology and results report	42
ANNEX II JANE Stakeholder Forum methodology and results report.....	92



List of figures

Figure 1.	JANE Work package distribution.....	12
Figure 2.	Conceptualization and relationship of the tasks, activities and deliverables of WP4	15
Figure 3.	Reference framework for the analysis of European networks, organizations and networking projects.....	16
Figure 4.	Methodology for the <i>Mapping and analysis of existing networks</i> "	17
Figure 5.	Questions included in the survey (part of the T4.2 ' <i>Sustainability strategy of NoEs</i> ').....	18
Figure 6.	Definition of the Stakeholder Matrix of JANE.....	20
Figure 7.	Main findings of the Informal Coffee Meetings and Policy Dialogues towards NoEs sustainability.....	25
Figure 8.	Key issues and recommended strategies discussed during JANE Stakeholder Forum.....	30

List of tables

Table 1.	Key findings and initial recommendations towards the sustainability of NoEs.....	22
Table 2.	Objectives of NoEs versus main expected barriers (coming from the open consultation)	28
Table 3.	Policy recommendations on sustainability	34



1 EXECUTIVE SUMMARY

The overall objective of the JANE Joint Action was to establish seven Networks of Expertise (NoEs) in the cancer field by preparing everything necessary to launch them and by 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.

Among the JANE work packages (WPs) is WP4 related to sustainability. This WP supported the NoEs by focusing on the development of strategies to guarantee their sustainability and aligning them with European and national policies. It also generated policy recommendations and guidance to facilitate the sustainability of the networks, which could be applicable to other health care networks in the EU.

The purpose of this document is to present the results of the work done within WP4 as policy recommendations that summarise the learnings from the NoEs' internal discussions, policy dialogues, stakeholder forum and reflections of other key partners of JANE that will support their sustainability in the long-term. This document constitutes Deliverable 4.1 of JANE.

Sustainability development has been defined as “*the development that meets the needs of the present without compromising the ability of future generations to meet their own needs*”¹. Some authors have described it also as the “*complex intersection between science and politics where boundary work takes place*”². In the context of this document, policy recommendations for improving sustainability are those aimed at supporting and reinforcing the capacity of the NoEs to reach their expected impact and provide a roadmap to facilitate their sustainability.

The approach followed in JANE for the elaboration of the policy recommendations is the result of two activities: (1) the identification of key leverage points for sustainability based on lessons learned from previous health networking experiences; and (2) the collection of information obtained from consultative discussions with key partners through the Policy Dialogues and Stakeholder Forum.

¹ World Commission on Environment and Development (1987) *Our Common Future: Report of the World Commission on Environment and Development*, Oxford : Oxford University Press .

² Scoones, I. (2007). Sustainability. *Development in Practice*, 17(4–5), 589–596. <https://doi.org/10.1080/09614520701469609>



STRUCTURE OF THE DOCUMENT

The content of this document is presented as follows. **Section 1** contains the executive summary. **Section 2** provides the introductory aspects of the work presented in this deliverable, introducing the JANE Joint Action, the purpose of the document and its intended audience. **Section 3** briefly describes the methodology employed to formulate the final policy recommendations, through the three activities designed for this purpose. **Section 4** presents the lessons learnt about the sustainability of health networking. **Section 5** lists the main policy recommendations derived from the various activities and deliverables produced within JANE, as well as possible next steps. **Section 6** presents the conclusions of the work of WP4. The report also includes **two annexes** that provide more detail on the methodology and results. External documents that have also supported these final policy recommendations are also referenced in the deliverable as **Supplementary materials 1 and 2**.



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 (JA) which aim to foster cooperation, coordination, and knowledge-sharing among Member States in various areas of health policy and practice.

This JA particularly is the answer to the initiatives included in the Flagship 5 of Europe's Beating Cancer Plan³, which has envisioned the creation of a new type of Reference Networks to be established in Europe with the main objective of ensuring high standards of cancer care. The aim of these networks is to look at specific challenging cancer conditions that will benefit from cross-border cooperation and EU expertise; and that *'will connect experts, share expertise across the EU and provide answers, certainty and hope to patients where before there was none'*. Specifically, JANE conceptualized seven NoEs in the areas of complex & poor prognosis cancers, palliative care, survivorship, personalised primary prevention, omics, high-tech medical resources, and adolescents & young adults with cancer.

JANE project was coordinated by the Istituto Nazionale dei Tumori (INT), started in October 2022 and involved the participation of 16 Competent Authorities, 20 Affiliated Entities and 2 Patient Associations from 16 countries all around Europe.

The general goals of JANE were:

- To prepare everything necessary to launch the new NoEs; from defining their mission 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 centres, as well as technologically relevant aspects for optimal functioning of networking in general, in order to properly shape the new NoEs.

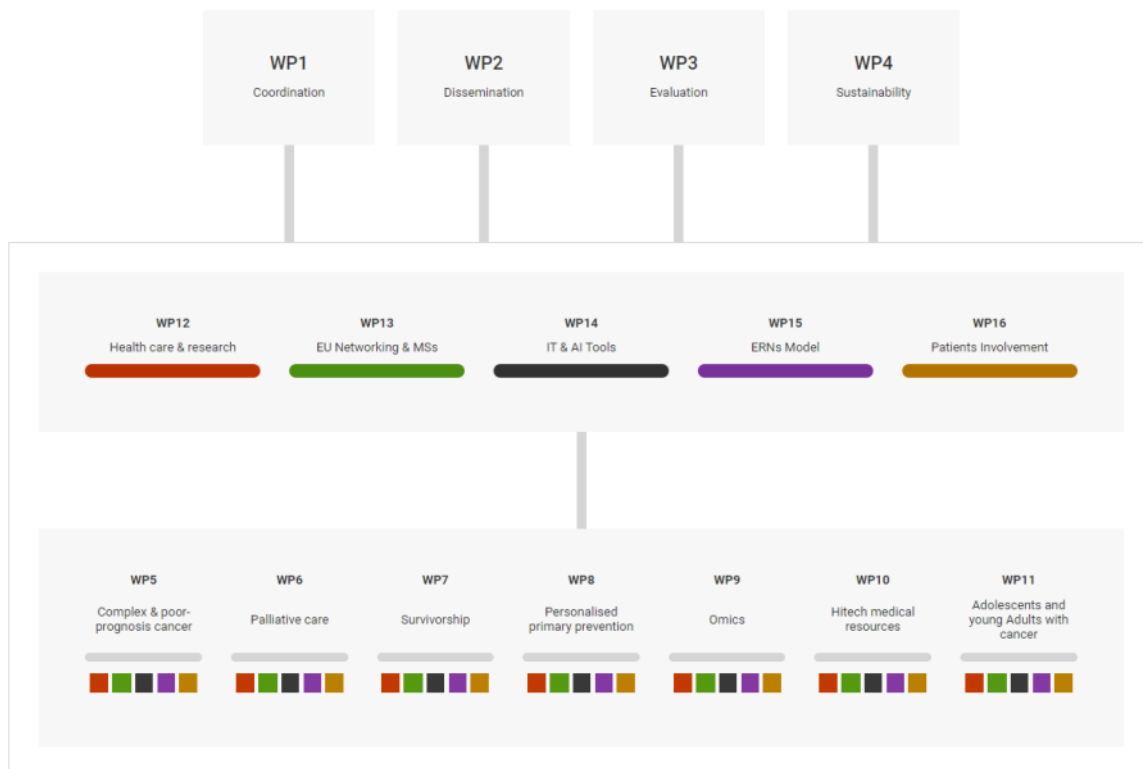
JANE has outlined and prepared these NoEs to cover these crucial areas of cancer care, bringing together the best resources available in Europe in each specific field, to support National Networks and Comprehensive Cancer Centres (CCCs). The results of the work done during JANE will serve as a basis for the follow-up Joint Action (JANE 2), which will also be coordinated by INT in Milan, and is expected

³ COMMUNICATION FROM THE COMMISSION TO THE EUROPEAN PARLIAMENT AND THE COUNCIL Europe's Beating Cancer Plan. Available in: https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf

to start in the last quarter of 2024. JANE 2 will allow the launch of the seven NoEs and will provide services aiming to contribute to the development of guidelines and best practices and to facilitate research and innovation, enhance education and training, and strengthen health policies at regional, national and European levels, supporting the concept of “network of networks” between the different Member States (MSs).

Within JANE, there is a specific work package on sustainability (WP4). This work package aims to ensure the long-term sustainability of Networks of Expertise by aligning them with European and national policies, offering policy recommendations, and providing them with guidance on this aspect.

Figure 1. JANE Work package distribution



The first task of WP4 led to the development of a milestone, which set the initial roots in conceptualising the sustainability of the NoEs. It provided information to support future leaders and members of the NoEs in defining the sustainability strategy of the networks and their infrastructure in Europe. This milestone also included the development of a *Reference framework for the analysis of European networks, organizations and networking projects*, which could also be used for the development of networks in addition to the seven to be shaped within the scope of JANE 2. The full report on the methodology and results of this milestone can be found in Supplementary material 1.

The conceptualisation and future functioning of health networks requires the involvement and engagement of multi-stakeholders and therefore, two specific tasks were designed related to the



connection and participation of external actors at two levels. First, the **Policy Board** of JANE had two main objectives (1) to align the NoEs' ecosystem to regional, national and EU policies, programs and plans; and (2) to identify and build up the potential EU added value of the NoEs. The Policy Dialogues were the means through which the Policy Board members engaged in deliberative conversations with all the JANE consortium once per year, to discuss topics of mutual interest, providing their expertise and suggestions. The full report on the methodology and results of this activity can be found in Annex I.

Second, the Stakeholder Matrix of JANE was conceived. WP4 sought to involve stakeholders from a variety of backgrounds, from national and regional governing bodies to patient organizations. In this sense, the members of the Stakeholder matrix of JANE had two main objectives (1) to initiate or contribute to legislative changes, intended to improve cancer care, to give input to support that the established NoEs assemble the best knowledge, skills and facilities available in Europe, and (2) to build synergies and partnerships that support JANE and the current and future needs of the NoEs, thus contributing to guarantee their sustainability. Events such as the Stakeholder Forum brought stakeholders together to learn from each other, share experiences and discuss solutions to the various challenges faced by the networks. In addition, dissemination activities organised within the duration of JANE by different partners, including both international and national events, workshops and scientific conferences, involved stakeholders with different expertise and decision-making levels in the Member States. The full report on the methodology and results of the JANE Stakeholder Forum can be found in Annex II.

It should be emphasised that all JANE consortium members have been involved in numerous activities to foster the future long-term sustainability of the NoEs, apart from those led or organised by the WP4 team. Among these, we highlight synergies established with leaders of other health networks at European level, promoted by the Coordination team of JANE, by the leaders of the NoEs work packages and the JANE Task Forces (TFF), which address the current problems of EU health networks; the participation in scientific and political events to present the JA and its results; the establishment of an External Advisory Board by the evaluation WP (WP3) and all dissemination activities carried out by the dissemination and communication WP (WP2) team.

2.2 Purpose of this document

The purpose of this document is to present the learnings obtained from the internal discussions held within the NoEs, Policy Dialogues, stakeholder forum and reflections of the key partners. The synthesis of these contributions has been translated into a set of policy recommendations that is presented later in this document and is intended to support and strengthen the capacity of the NoEs to achieve their expected impact and provide a roadmap to facilitate their long-term sustainability.



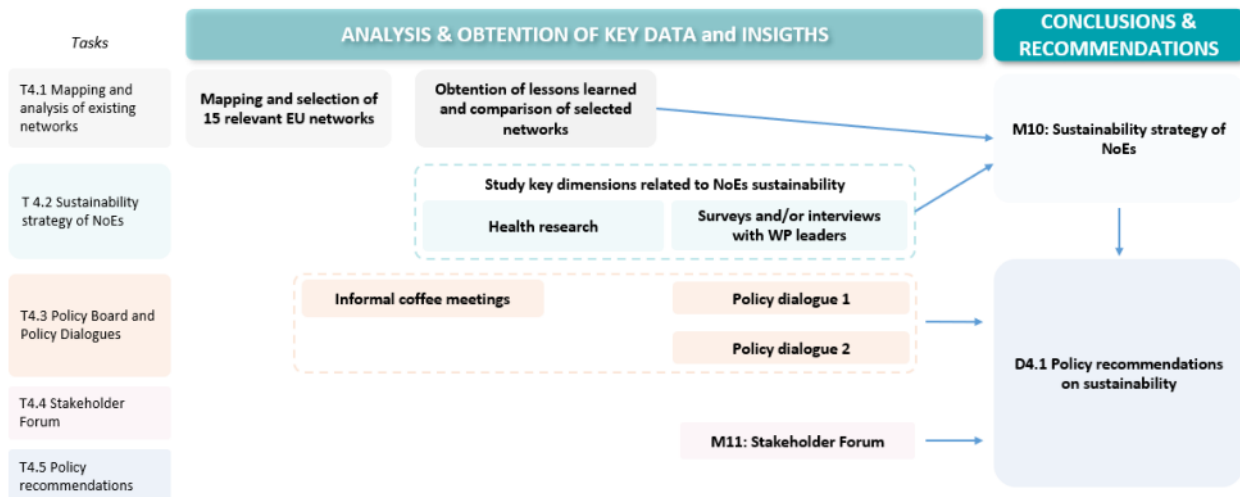
2.3 Intended audience

The intended audience of this document is people involved in the NoEs or working in the field of health networks, EU institutions, decision-makers and policymakers, and other stakeholders of these networks in the future.

3 METHODOLOGY

This section will provide a brief overview of the methodology employed to formulate the final policy recommendations presented later in this document. These recommendations are the result of the different outputs of the WP4 activities that took place throughout the project, as shown in Figure 2.

Figure 2. Conceptualization and relationship of the tasks, activities and deliverables of WP4



Following the structure of the tasks included in Figure 2, the first two tasks were related to the identification of key aspects of sustainability, while tasks 4.3 and 4.4 were related to supporting deliberative conversations with key partners. The last task included in the scheme is related to the preparation of this Deliverable.

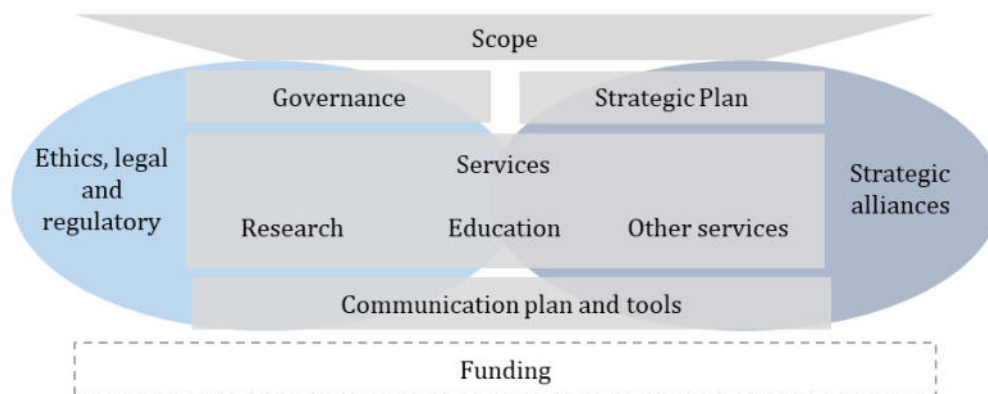
Although the work carried out by this sustainability WP has been key for the elaboration of these recommendations, the activity performed in the different WPs related to the NoEs and other core WPs, has played an influential role in shaping this document. In this sense, some of the discussions held throughout the project on the needs or challenges of health networks and their deployment and functioning in Europe, have been fundamental to some of the dialogues held with JANE policymakers and stakeholders, as well as to some of the dilemmas that have led to the elaboration of certain recommendations.

3.1 Identifying key aspects of the sustainability

The first task of WP4, Task 4.1 “*Mapping and analysis of existing networks*” aimed to gather information on key aspects of European networks, organizations and networking projects to support the first steps towards the sustainability of the NoEs over time. This analysis was based on the lessons learned from these organizations, which resulted in a set of strategies that were later discussed with experts in the field.

In order to structure this analysis, the ‘**Reference framework for the analysis of European networks, organizations and networking projects**’ was developed (Figure 3). This framework included eight dimensions (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, designed to serve as basic pillars in the definition of key aspects to ensure the sustainability of both existing or new organizations or networks over time.

Figure 3. Reference framework for the analysis of European networks, organizations and networking projects.



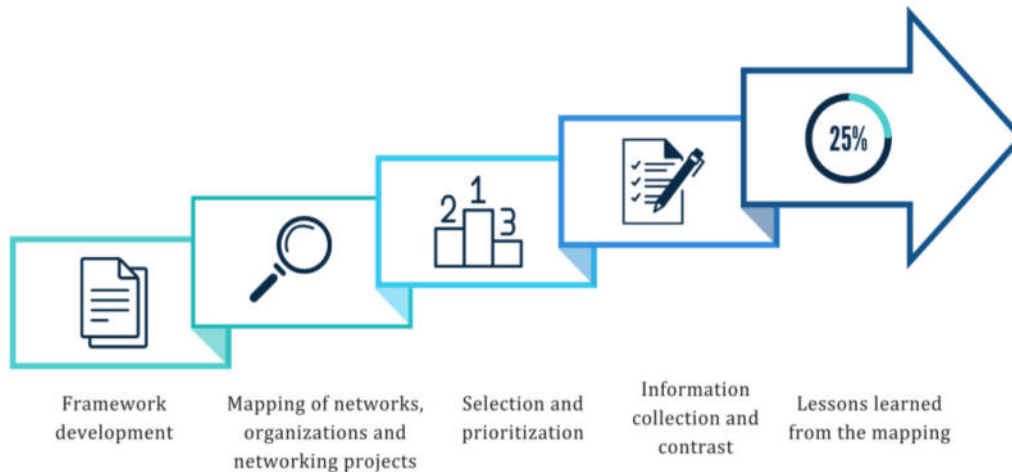
The reference framework guided the identification, selection and prioritization of 15 European networks, organizations and networking projects in the cancer field (Figure 4). Whether they are associations, professional or scientific societies, projects or other types of structures, all have in common some form of collaborative networking. These organizations were selected by members of the NoEs participating in JANE along with the NoE WP leaders. They were identified as inspiring models for the work to be developed in the 7 NoEs. In addition, given the thematic heterogeneity of the NoEs (survivorship, omics, palliative care, etc.), organizations of various fields were selected to address this diversity. Moreover, considering that the Network of Expertise model is new in Europe, it can therefore be built having different approaches in mind.

After this selection process, complete information on each organization was collected, following the dimensions of the Reference framework. This was later reviewed by WP4 members, and by 7 representatives of the analyzed organizations.

The last step of this mapping activity was the global analysis of the information gathered that helped to identify key elements to build recommendations for the sustainability of the NoEs. This global analysis comprised a comparison of the organizations based on the eight dimensions of the framework, drawing the main conclusions for the sustainability of the future NoEs. The main conclusions are briefly presented in this document, while the full report on the methodology and results of this activity is part

of the milestone ‘M10. Sustainability strategy of NoEs,’ which can be found in Supplementary material 1. Supplementary material 2 provides the complete information of each organization included in the mapping exercise.

Figure 4. Methodology for the *Mapping and analysis of existing networks*”



Note. Entities included in the mapping: EURACAN, ESMO, EORTC, OECI, GENTURIS, UNCAN.eu, PCE, EAPC, PANCARE, EU-CAYAS-NET, TRANSLACORE, ESTRO, CCI Europe, PAEDCAN and SIOPE.

Once the main conclusions of this task were drafted, Biosistemak (BS) – formerly Kronikune (KG) - prepared a workshop and also sent a survey to validate the findings to finally produce a set of recommendations that will be fundamental for JANE 2.

First, a workshop was held on 6 June 2024 with the participation of representatives from UNCAN.eu, PCE, PAEDCAN and SIOPE and the Coordination team of the JA. The workshop began with a presentation on JANE and the Sustainability Work Package (WP), followed by a brief overview of the various dimensions included in the framework. This was then complemented by a presentation of the resulting strategies that could support the sustainability of the NoEs, developed through the mapping process. The session concluded with a discussion involving organization representatives, where targeted questions were posed to gather feedback on their experiences within their organizations that could reinforce these findings.

Second, a survey was sent to the entities participating in the workshop and to others who took part in the mapping but could not attend on the day of the event. The questions included in the survey for this purpose are listed in Figure 5.



Figure 5. Questions included in the survey (part of the T4.2 ‘Sustainability strategy of NoEs’)

- What are the **main facilitators and barriers** that you encountered in relation to **funding** of the organization that you represent?
- What would you highlight as the **strengths** of the organization you represent?
- What would help to **promote the awareness** and ‘use’ of collaborative networks at the national level?
- What are the main benefits of having an external **advisory board**?
- What can support the **promotion of alliances** with other networks?
- How might being a legal or non-legal entity affect sustainability? *Bearing in mind that becoming a legal entity involves registering with 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.*

3.2 Supporting deliberative conversations with key partners

Building strategic partnerships with organisations and stakeholders is crucial to creating synergies and increasing the value of the NoEs. For those reasons the tasks 4.3 ‘Policy Board and policy dialogues’ and 4.4 ‘Stakeholder Forum’ were envisioned to create spaces that could initiate or contribute to legislative change intended to help improve cancer care, establish governance mechanisms for institutional cross-sectoral collaboration, and reach consensus on tangible actions that will address or give support to the challenges related to NoEs sustainability.

3.2.1 Policy Board and Policy Dialogues

The development of JANE Policy Board was coordinated by BS, leader of JANE WP4, with the support of INT as JANE Coordinators. The activities related to the establishment and operation of this specific board include the following: (1) Development of Policy Board and Policy Dialogues main concept and operating procedures; (2) Identification of Policy Board members; (3) Organization of informal coffee meetings with individual representatives of the Policy Board; (4) Organization of the Policy Dialogues; and (5) Preparation of the minutes and results of each event. Some of these relevant steps within the task are described below.

Identification of Policy Board members

Members of the JANE Policy Board were representatives of Member State (MS) health authorities, ideally from Ministries of Health (MoH), but also from other policy-level health institutions or relevant stakeholders. This means that they did not necessarily have to be official representatives of their



country, so no letters of nomination were required. The first membership list was available from month 6 (March 2023), and was kept open, both in terms of whether there was a change in membership during JANE, and whether members identified important policy level stakeholders to invite during the development of the project. All Competent Authorities (CA) involved in JANE were invited to nominate representatives from their countries for the Policy Board.

Organization of informal coffee meetings with individual representatives of the Policy Board

Informal online coffee meetings were held from May through July 2023 with the different representatives of the Policy Board, with the main aim of introducing and contextualizing JANE, gathering initial reactions to the JA approach, and discussing the potential impact that NoEs can have on the cancer care ecosystem in Europe. These informal coffee meetings were the first contact after the nomination and acceptance of representatives from each MS to be part of the Policy Board of JANE. The outcomes of these initial meetings helped introduce some of the topics that would be discussed in JANE's Policy Dialogues. Specifically, questions were drawn from the conclusions of these meetings.

Organization of the Policy Dialogues

The main events for the Policy Board representatives were the annual Policy Dialogues. Together with the other partners in WP4 and with the approval of the Coordination Team, a series of topics were pre-identified to be addressed in these Policy Dialogues. The themes for the first event were “How to build potential alliances & synergies in the European Ecosystem” and “How to ensure NoEs alignment with European and National Policies,” while the second Policy Dialogue focused on the legal and funding dimensions. Both aspects were considered crucial for developing strategies to support the long-term sustainability of the NoEs and to gain MS support for the development of services that NoEs will provide within the European ecosystem.

The events were organized by BS with the support of INT as coordinator. They also helped to invite representatives from the Directorate-General for Health and Food Safety (DG SANTE) and/or the European Health and Digital Executive Agency (HaDEA) to attend the event as observers or to participate in specific sessions as keynote speakers.

For each event, a concept note and agenda were prepared in advance to inform Policy Dialogue participants on the topics and specific questions to be addressed. After the Policy Dialogues, minutes and outcomes were compiled (see Annex I) and disseminated among the Policy Board members and the whole JANE consortium. The dissemination team (WP2) also disseminated the results of these events. Satisfaction surveys were developed in collaboration with the evaluation team (WP3) to gather feedback

on organizational aspects to identify gaps and improve the organization of future events (see Annex I). The results of the surveys are presented in D3.2.

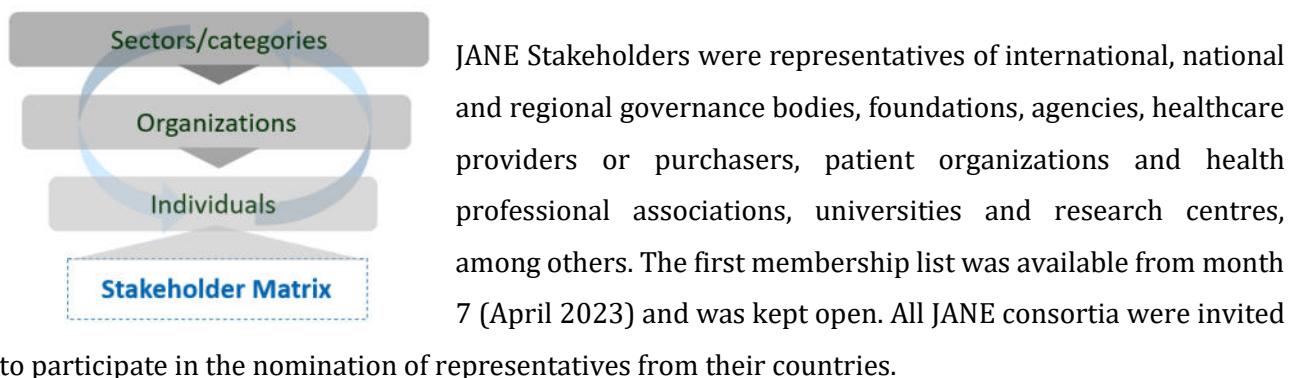
3.2.2 Stakeholder Forum

The constitution of the JANE stakeholder matrix was also coordinated by BS, with the support of INT. Their activities followed a similar structure to that of the Policy Board, including the following: (1) Development of Stakeholder matrix and Stakeholder Forum main concept and operating procedures; (2) Identification of stakeholders; (3) Organization of the Stakeholder Forum; and (4) Preparation of the minutes and results of the event. Some of these steps are described below.

Identification of stakeholders

This is a group of stakeholders that have an interest or a stake in, are affected by, or may be able to influence NoEs. This stakeholder matrix has been developed through an iterative process in three steps, with feedback from the JANE partners (Figure 6). First, relevant non-exclusive sectors/categories were identified, then key organisations within these sectors/categories were listed and finally individuals were approached as proposed by JANE Stakeholder Matrix members.

Figure 6. Definition of the Stakeholder Matrix of JANE



The Stakeholder Forum was the space for discussion and collaboration between key actors in the cancer ecosystem that took place in November 2023. The topics selected for the JANE Stakeholder Forum were designed to foster meaningful discussions and collaborations. The first topic focused on presenting the status and achievements of JANE, while also addressing the main concerns of NoEs leaders in establishing strong alliances with key stakeholders. The second topic aimed to explore the needs and expectations of stakeholders regarding the NoEs and how they can contribute to addressing the current challenges in the cancer ecosystem. Lastly, the forum sought to discuss what NoEs can expect from civil society, academia, the private sector, and other key players in terms of support and collaboration.

The event was organized by BS with the support of NoE leaders and specially from the Coordination team, as the event was held simultaneously with a Plenary Meeting of the consortium (Barcelona). As



in the case of the Policy Dialogue, an agenda and a concept note for the event were prepared, satisfaction with the event was analyzed and the results were disseminated (see Annex II).

3.2.3 Engagement of additional stakeholders

During JANE, several other activities involving stakeholders from governments, academia, cancer networks, scientific, professional and civil societies, among others, helped to explain the goals of JANE, build a common understanding and create synergies and partnerships to support JANE and future NoEs. In addition, the involvement of these stakeholders has made it possible in other cases to advance specific project tasks, as well as the preparation of the upcoming JANE 2 Joint Action.

Nevertheless, this series of events and contacts of different types did not follow a common methodology agreed by the consortium, but data were collected on those that took place or will take place soon after the end of JANE. However, we can classify the role of these stakeholders involved in JANE according to a typology in relation to their level of involvement in the activities that took place in the JA.

In this sense, three types of involvement can therefore be distinguished:

- **Informative - knowledge diffusion:** Stakeholder target audience for communication and dissemination purposes (WP2 - Dissemination)
- **Consultative:** Representatives who are involved in the Policy Board, Stakeholder matrix (WP4 - Sustainability) or as members of the JANE Advisory Board (WP3 – Evaluation)
- **Collaborative participation.** Stakeholders being contacted by the Coordination team or different NoE leaders to be part of the networks in the future or to establish potential synergies (all NoEs)

4 LESSONS LEARNT FOR THE SUSTAINABILITY OF HEALTH NETWORKING

4.1 Initial key findings

The initial recommendations for the future sustainability of NoEs have been designed according to the dimensions of the framework described in Task 4.1. This preliminary study was based on an extensive process of analysis of health networks already operating in Europe. This was done in the knowledge that lessons learned from models that could serve as inspiration for NoEs could help ground their design and implementation, thus ensuring their long-term sustainable development.

This first approach has considered management and infrastructure aspects related to the building ground of the NoEs, while other sustainability activities, such as the Policy Dialogues or Stakeholder Forum, have focused on dimensions related to strategic alliances, services and legal aspects that could benefit from knowledge sharing with stakeholders, in order to try to be aligned with the expected needs and interests of these networks from their beginnings.

A summary with the key findings and initial recommendations are presented in Table 1. The description of each of the dimensions included in the framework for this first set of recommendations are included in **Supplementary material 1**.

Table 1. Key findings and initial recommendations towards the sustainability of NoEs

Scope		<ul style="list-style-type: none">• The definition of the objectives, mission, vision and values could support the definition of action plans and future activities of the NoEs.
Governance		<ul style="list-style-type: none">• 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.

Strategic plan



- It is advisable 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.

Services



- 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.
- Knowledge translation could be supported by giving access to **electronic platforms or open repositories**.
- Conducting **needs assessments** is vital to ensure that NoEs provide **services aligned with user needs**.

Strategic alliances



- 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 JA CraNE - Network of Comprehensive Cancer Centres), Comprehensive Cancer Networks (CCNs) and ERNs. **Formal integration** of other entities such as scientific societies, patient advocacy groups, and research institutes is encouraged.

Communication strategy and tools



- 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.



Ethics, legal and regulatory



- Tailoring **ethical considerations to the specific needs** of each NoE is essential, ensuring compliance with regulations like the General Data Protection Regulation (GDPR), harmonization proposals in EU regulations impacting standard of care or addressing data sharing platforms' security and access guarantees.

Funding



- The development of a **sustainable business model** is critical to the maintenance of NoEs and requires the identification of target stakeholders and the creation of value propositions tailored to their needs.

4.2 Policy Dialogues

The Policy Board of JANE was created as an external advisory body to provide strategic guidance on policy matters related to the Joint Action. It was specifically established to gather insights from policymakers at various levels of decision-making across Europe.

The Policy Board was composed of policymakers at different decision levels and other key representatives from National Cancer Research Centres and Public Health organizations, that were nominated and invited to participate by the Competent Authority of each Member State.

The primary role of the Policy Board is to offer guidance and recommendations regarding European Networks of Expertise (NoEs) in cancer care. The Policy Board had two main roles:

1. To align the NoEs' ecosystem to regional, national and EU policies, programs and plans
2. To identify and build up the potential EU added value of NoEs.

Throughout the development of JANE, the board included 22 representatives from the consortium's participating MSs (Belgium, Czechia, Croatia, France, Germany, Greece, Hungary, Italy, Lithuania, Malta, Norway, Poland, Portugal, Romania, Slovenia, and Spain), along with an additional representative relevant for the work on sustainability from Joint Action CrANE. In addition, DG SANTE and DG EAC members were also involved as observers or key speakers at Policy Board events. Additionally, in the second Policy Dialogue, the European Observatory on Health Systems and Policies actively participated as a facilitator and the coordinator of the Joint Action Towards the European Health Data Space.

The Board has been actively involved in multiple online events during the Joint Action, beginning with informal meetings aimed at introducing the objectives of JANE, gathering feedback, and discussing the potential impact of NoEs on cancer care in Europe.



One of the key mechanisms through which the Policy Board works is the Policy Dialogues, which are deliberative discussions that bring together policymakers to address topics of shared interest. These dialogues help the Policy Board to achieve its main objectives, which include:

- Initiating or contributing to legislative changes aimed at improving cancer care.
- Establishing governance mechanisms for collaboration across institutions and sectors.
- Reaching consensus on concrete actions to overcome obstacles related to the sustainability of NoEs.
- Increasing political will and engagement in support of new or adapted policies.

Policy Board members participated in two Policy Dialogues during the project (2023 and 2024), organized by BS with the support of INT as coordinator. The themes selected for the first event were "How to build potential alliances & synergies in the European Ecosystem" and "How to ensure NoEs alignment with European and National Policies," while the second Policy Dialogue concentrated on the legal and funding dimensions. These topics were deliberately chosen as they are considered key factors for ensuring the long-term sustainability of the NoEs. The involvement and support of the MSs prior to the launch of the NoEs is considered essential to ensure the integration of the services these networks will provide within the European ecosystem, aligning these resources with the existing needs and political priorities surrounding cancer care.

The main conclusions of the informal coffee meetings and Policy Dialogues are presented in Figure 7 and Table 2. More detailed information on the Policy Board can be found in Annex I to this report.

Figure 7. Main findings of the Informal Coffee Meetings and Policy Dialogues towards NoEs sustainability

MANAGEMENT AND INFRASTRUCTURE

- **Learning from other models:** NoEs should actively learn from existing frameworks, such as the membership model of the ERNs. Analyzing successful models provides valuable insights and helps to refine the approach of NoEs, ensuring that they adopt effective strategies and avoid common pitfalls.
- **National leadership and governance:** The appointment of national leaders is essential for effective coordination and alignment with national policies. Clear governance mechanisms are crucial for decision-making, accountability and smooth operation in all participating countries.
- **Network sustainability and connectivity:** A sustainable network requires elements such as shared interests, recognition of members, effective integration of new members and ongoing motivation. Effective curation through regular contact and meetings strengthens network identity and belonging, ensuring long-term commitment and success.



- **Linking expertise and infrastructure:** The integration of expertise with the necessary infrastructure is essential for the delivery of high quality, cross-border cancer care. Strong integration of these elements will enhance the capacity of networks to deliver advanced solutions.
- **Strategic planning and commitment:** A robust strategic plan is necessary to ensure sustainability, address challenges and implement evaluation and monitoring processes. Ensuring continuity and commitment from lead organizations is essential to maintain progress and support future opportunities.

FUNDING

- **Knowledge sharing:** Current funding instruments, such as Horizon Europe, offer significant opportunities for collaborative grants, which are essential for sharing knowledge and advancing cancer care. Joint Actions allow Member States (MS) to share best practices and learn from each other, despite differences in health systems and populations. This collaborative approach strengthens best practice and contributes to improving cancer care in all countries.
- **Strategic planning and commitment:** A robust strategic plan is necessary to ensure sustainability, address challenges and implement evaluation and monitoring processes. Ensuring continuity and commitment from lead organizations is essential to maintain progress and support future opportunities. Sustainability through relevant services: For networks and ecosystems to secure sustainable funding, they must provide services that are relevant to the needs of each MS. As health responsibilities are managed at national level, it is crucial for networks to demonstrate clear value to their national systems in order to maintain financial support. Projects funded under the EU's Next Generation Plan highlight the need for clear guidance from the European Commission to ensure that products and services are harmonized across MS, facilitating their integration into national systems.
- **Synergies with EU cancer priorities:** Alignment with European Commission priorities, including the Beating Cancer Plan and EU4Health, is essential to promote synergies between Joint Actions (JA) and Action Grants.

LEGAL ASPECTS: INTEROPERABILITY, DATA MANAGEMENT AND INTEGRATION

- **Interoperability and Alignment with National Policies:** Ensuring interoperability between national and EU networks is crucial for both the European Reference Networks and emerging NoEs. MS are responsible for creating national networks, and their alignment with national policies, such as those outlined by the European Health Data Space (EHDS), is key. The EHDS's focus on health data usage aligns with initiatives in several countries, raising strategic questions about whether a single national node or multiple regional nodes are best for data management.



- **Leveraging Data and AI:** Harnessing real-time data and advancements in artificial intelligence is essential for developing key indicators for benchmarking, policy evaluation, and clinical practice improvement. Effective integration of healthcare and research can be achieved by promoting interoperability and adopting AI-driven solutions, with NoEs playing a pivotal role in addressing gaps and fostering better integration.
- **Paradigm Shift for Healthcare Professionals:** To fully realize the potential of EHDS and NoEs, a shift in healthcare professionals' daily practices is necessary. This paradigm change involves adapting infrastructure and altering how healthcare is delivered and data is managed to support successful integration of these systems.

RESOURCES AND CAPACITIES

- **Support for implementation and research:** It is essential to support the implementation of strategic plans and recommendations, promote research and facilitate policy support. This includes disseminating evaluations, updating strategies and supporting monitoring processes. Encouraging research and facilitating aspects such as the exchange of personal data are also important.
- **Information and dissemination:** NoEs should focus on providing information and advice to stakeholders, policy makers and patients. Broad dissemination through journals and other platforms helps to raise awareness and support for cancer initiatives.
- **Use of existing platforms:** The use of existing European platforms, as the EU Health Policy Platform, can enhance collaboration and support for cancer-related initiatives.

FOSTERING ALLIANCES AND NETWORKING

- **Working with stakeholders and patients:** Effective collaboration with stakeholders, including patient organizations, is from the outset crucial to creating patient-centered networks. Involving experts, policy makers and EU representatives in joint meetings helps to build relationships and ensure comprehensive support and input. This collaboration extends to alliances between cancer projects and networks, such as ERNs and CraNE, which enrich results and facilitate knowledge exchange, especially in areas that are not mainstream in cancer such as high-tech oncology.
- **Multi-level coordination and challenges:** One of the main challenges is to coordinate efforts between the European and national levels. While professionals can innovate, a structured coordination table between MS and EU institutions is needed. In addition, the involvement of patient advocacy groups at the same level is essential for successful outcomes. Despite common objectives, different national contexts require tailored approaches to address specific challenges.
- **Learning and policy transfer:** NoEs should focus on informing policy and transferring good practice in patient care. Learning from different projects and coordinating efforts between them can create opportunities for research collaboration and improve overall effectiveness.



- **Increase visibility:** Increasing the visibility of NoEs through events, congresses and journals is important to raise awareness and encourage further collaboration.

PATIENT ENGAGEMENT

- **Support for Patient Collaboration:** Collaborating with cancer patients, particularly through patient organizations, is crucial. While some countries use toolkits to involve patients in developing clinical guidelines, more structured support at both European and national levels is necessary to ensure productive collaboration.
- **Co-Designing in Participating Projects:** Effective co-design requires true inclusivity by recognizing and valuing patients' unique expertise. Despite some efforts toward inclusion, patients often feel undervalued due to perceived technical knowledge gaps. Addressing this involves acknowledging patients as experts and coordinating their inputs effectively, which enhances the co-design process and leads to more impactful outcomes.

Table 2. Objectives of NoEs versus main expected barriers (coming from the open consultation)

Objectives of NoEs	Main Barriers Identified
<p>1. Launch and prepare the new Networks of Expertise: Define their missions, objectives, design and selection criteria for participants.</p>	<p>1. Financial support and legal implementation: Lack of long-term financial planning and clarity on legal frameworks.</p>
<p>2. Facilitate cross-border cooperation: Enable expertise sharing across the EU to address challenging cancer conditions.</p>	<p>2. Maintaining interest and engagement of professionals: Difficulty in keeping sustained involvement from healthcare professionals over time.</p>
<p>3. Build a strong operational foundation: Set up calls for expressions of interest and define selection criteria for participants.</p>	<p>3. Involvement of key actors from the start: Delays in securing early involvement of critical stakeholders.</p>
<p>4. Critically evaluate EU networking models: Review existing research infrastructures, comprehensive cancer centres, and aspects to shape NoEs.</p>	<p>4. Instability in the political agenda: Changing priorities in political landscapes affecting continuity and support for NoEs.</p>
<p>5. Promote cutting-edge medical and technological resources: Encourage the use of omics, high-tech medical tools, and personalized care related to some NoEs.</p>	<p>5. Personal data sharing challenges: Legal and privacy concerns around cross-border exchange of patient data.</p>
<p>6. Focus on specific cancer areas: Target complex cancers, survivorship, palliative</p>	<p>6. Demonstrating patient benefits: Challenges in clearly proving the advantage</p>



care, and cancer in adolescents and young adults.	of NoEs for patients across different Member States.
---	--

4.3 Stakeholder forum, international, national and regional events

The Stakeholder Forum was created as a space for discussion and collaboration among key actors in the cancer ecosystem, including NoEs, civil society, academia, the private sector, and other relevant stakeholders. Its primary purpose was to facilitate the exchange of expertise, experience, and perspectives, fostering networking opportunities between stakeholders and participating organizations in JANE. Building such synergies at an early stage could lead to the development of partnerships that support both JANE and the evolving needs of future NoEs, while addressing issues of mutual interest.

The JANE Stakeholder Matrix was an external body composed of stakeholders with a vested interest in the establishment of NoEs. These stakeholders are both impacted by the NoEs and have the capacity to influence the Joint Action. The role of the representatives of the Stakeholder Matrix is twofold:

1. To offer input to ensure that the established NoEs bring together the best knowledge, skills, and resources available in Europe.
2. To build synergies and partnerships that support JANE and address the current and future needs of the NoEs, thereby contributing to their long-term sustainability.

The matrix included a total of 88 members from 54 organizations, that was informed about JANE and its objectives in the long-term. The JANE Stakeholder Forum, which took place in 2023, aimed to present the status and achievements of JANE, share key concerns of NoE leaders to build strong alliances, explore stakeholders' needs and expectations for NoEs, and discuss how civil society, academia, the private sector and other key stakeholders can contribute to addressing challenges in the cancer care ecosystem. The main highlights of this event are presented in Figure 8, while the full report can be found in Annex 2.



Figure 8. Key issues and recommended strategies discussed during JANE Stakeholder Forum

- **Lessons Learned from Other European Networks:** Participants underscored the importance of learning from challenges faced by other European networks, particularly the ERNs. Strengthening the connection and communication between networks at national and regional levels is critical. Enhancing interconnectivity would facilitate the seamless transfer of knowledge across these levels, contributing to the long-term sustainability of the networks.
- **Strengthening the Network within the EU Cancer Health Ecosystem:** While the European Commission's commitment to these initiatives is acknowledged, the central challenge remains in reinforcing the networks within the EU cancer health ecosystem. Demonstrating their tangible added value at the European level will be crucial to ensuring their impact and sustainability.
- **Diversity Across Member States:** The significant legislative and therapeutic differences between European countries were highlighted. These disparities need to be addressed when establishing connections within the networks, as varied national contexts present unique challenges that must be considered.
- **Inequities in ERNs and Potential for NoEs:** The discussion emphasized existing inequalities in ERNs, particularly in access to resources across different countries. However, NoEs hold the potential to address these geographical disparities by sharing knowledge and raising awareness of optimal treatment options and resource availability in each country.
- **Key Role of Patients:** A shift in the patient communication model was highlighted, with patients now seen as experts and valuable contributors to the process. The need for continuous dialogue and co-creation was stressed, advocating for the inclusion of patient organizations in the network from its inception to ensure integration of their perspectives.
- **Patient Involvement:** Concerns were raised about the phenomenon of "cherry-picking" patient voices. It was emphasized that judgements should not be based solely on professional opinions or vested interests but should reflect the diverse and legitimate experiences of patients.
- **Importance of Member State Support:** It was underscored that securing support from MS is critical to the success of the networks. Direct involvement of legal representatives in discussions is necessary to gather feedback and ensure alignment with national healthcare policies.
- **Interconnection Between Stakeholders:** Learning from existing European models is vital to ensuring effective interconnection between key actors within future networks. This would enhance the collaborative capacity of these networks, making them more resilient and adaptable.



- **Mechanisms to Engage Key Stakeholders:** Identifying mechanisms to engage all relevant stakeholders, including CCCs and European infrastructures, was a priority. Sharing foundational principles drawn from the ERN experience will be essential in guiding future collaboration.
- **Addressing Operational Challenges:** The need to confront operational challenges within the networks was emphasized. Strengthening ties within the EU cancer ecosystem and promoting inclusive participation are pivotal to ensuring the sustainability and effectiveness of these expert networks.

Throughout the duration of the Joint Action, in addition to the established relationships with the members of the JANE Stakeholder Matrix, the different JANE members actively engaged with a wide range of experts, policy makers and organizations. These interactions involved different types of activities, including outreach efforts to **disseminate project information** through key stakeholder mailing lists (e.g. JANE newsletters or public platforms such as the [EU Health Policy Platform](#)), bilateral meetings, participation in international scientific and policy events, invited communications from other projects or programs, and knowledge exchange events.

For example, JANE members, including the coordination team, have participated in more than 30 events aimed at **presenting the JANE objectives to various interested stakeholders**, such as European Society of Surgical Oncology (ESSO), European Cancer Organization (ECO), Organization of European Cancer Institutes (OECI), the European Network for TYA with Cancer (ENTYAC), STRONG-AYA-Improving the Future of Adolescents and Young Adults With Cancer, among others. Not only do these activities foster the creation of synergies that will prove valuable in achieving JANE's goals, but they also lay the groundwork for future cooperation and the work to be undertaken in the forthcoming Joint Action, JANE 2.

In addition, over 23 activities were undertaken **to identify synergies with other cancer-related projects**. In particular, **several initiatives focused on establishing collaborative links with the CraNE JA** and exploring ways to work together effectively. One such activity involved assessing areas for collaboration and familiarizing participants with the first drafts of the CCCs standards to align them with the JANE endorsement criteria. Another key event was organized by the "[LIVERATION](#) – Unravelling the impact of radiofrequency in liver surgery" project, which hosted an **online workshop entitled, "Innovative Practices for Stakeholder Engagement in Cancer-Related EU Projects"** on 29 April 2024. This workshop, that was organized together with [SHINE 2Europe](#), presented the JANE JA and the different strategies implemented in WP4 to promote stakeholder engagement. It brought together representatives from eleven EU projects related to cancer research ([LIVERATION](#), [EUonQoL](#), [4P-CAN](#), [RadioVal](#), [INCISIVE](#), [CCI4EU](#), [JANE](#), [ECHOS](#), [Smartcare](#), [SALVOVAR](#) and [CINDERELLA](#)). During



the event, common challenges and issues faced by these initiatives in relation to stakeholder engagement in cancer research projects were addressed. Following this synergy workshop, a lay publication will be prepared by all initiatives participating in the workshop, which will focus on innovative practices used by these initiatives for stakeholder engagement, and will also open discussion on challenges, limitations, lessons learned and future work on these strategies.

Other **events targeting the national level have also been identified**, which will be crucial for JANE 2 to operate as a "network of networks" in the future, supporting the concept of European networks being translated into national levels in the different MS. A total of 10 such events have been documented and are expected to contribute to this goal. However, not all the meetings held by the Competent Authorities (CAs) in each MS with their Affiliated Entities (AEs) or national representatives are included. Furthermore, other events are planned in the coming months, such as the **national event organized by the Ministry of Health to be held in Spain on 12 November 2024**. This event will include several roundtable discussions with participants from the three Joint Actions on Cancer - JANE, CraNE and eCAN (Joint Action on strengthening eHealth including telemedicine and remote monitoring for health care systems for cancer prevention and care) - with the aim of disseminating the results of each Joint Action and highlighting the role of Spain through its participation in these initiatives. This event will bring together national representatives from the three Joint Actions to participate in roundtable discussions on topics such as networking, the future impact of the Joint Actions on our national health system, and barriers and facilitators for the future implementation of the Joint Actions.

These national events have also contributed to the results of the current Joint Action, such as the one held in Belgium with participants from patient organizations, which has helped to create **toolboxes** for each NoE and for the patient community. In this sense, these guidelines will help NoEs to involve the patient community, including specific tools for this purpose. The patient toolboxes will explain the role of NoEs, why it is important to get involved and how to get involved in the work of NoEs. Information on this action can be found in the TTF5 deliverable on Patient Involvement.

The final meeting of JANE will be held in Brussels, Belgium, on 24-25 September 2024, with the participation of all JANE partners. Discussions will focus on the development of the NoEs currently being shaped, as well as on the challenges of networking in healthcare, in particular in cancer care, as outlined in the JANE Green Paper. In addition, a **special event entitled "Networks of Expertise: An Ambitious Vision for Tackling Healthcare at EU Level"** will be held at the European Parliament, with the participation of Members of the European Parliament (MEPs) and representatives of the European Commission's DG SANTE.

A list of some of the additional activities targeted at stakeholders by different members of JANE is provided in Annex II.



5 POLICY RECOMMENDATIONS

This section lists the main policy recommendations derived from the various JA activities, their rationale and possible next steps for the sustainability of the networks of expertise once they are up and running.

5.1 Key areas for action

As mentioned earlier in this document, policy recommendations in the context of NoEs should aim at supporting and strengthening the capacity of NoEs to achieve their expected impact and added value in Europe, and at providing a roadmap to facilitate their sustainability.

The statements to be presented in Table 3 will include key policy recommendations based on the following domains:

- **Management and infrastructure:** it includes aspects related to the NoEs' foundation ground, such as, scope and governance, strategic plans, inspiration in other health networks/models, among others.
- **Networking and Communication:** it encompasses all activities aimed at promoting cooperation between stakeholders and NoEs, as well as those within the network.
- **Interoperability and data sharing:** it includes aspects related to access and management of health data, including their use for knowledge or research, and those related to interoperability between EU and national networks.
- **Resources and capacities:** it comprises aspects related to the services that NoEs will provide, such as those concerning research, education and training, as well as those related to the sources of economic input for NoEs.

These domains encompass the results of the different discussions held with multi stakeholders, and therefore the specific topics on which possible aspects of network sustainability were explored.

**Table 3.** Policy recommendations on sustainability

Key Domains	Key Policy Recommendations
Management and Infrastructure	1. <i>Actively learn from existing frameworks like the ERN model to refine NoEs' approaches and avoid pitfalls.</i>
	2. <i>Develop a robust strategic plan for sustainability, including evaluation and monitoring, and ensure continuity and commitment from lead organizations.</i>
	3. <i>Integrate expertise with infrastructure to enhance cross-border cancer care delivery.</i>
	4. <i>Appoint national leaders to ensure effective coordination and alignment with national policies.</i>
Networking and Communication	1. <i>Establish robust collaboration mechanisms with stakeholders and patients from the outset to build patient-centered networks and relationships with experts, policymakers, and EU representatives. Ensure the interplay with MSs, and other cancer networks and structures such as CCCs, CCNs, and ERNs as well.</i>
	2. <i>Increase the visibility of NoEs through events, congresses, and journals to raise awareness and encourage collaboration.</i>
	3. <i>Utilize existing European platforms like the EU Health Policy Platform to enhance collaboration and support.</i>
	4. <i>Emphasize continuous dialogue and co-creation with patient organizations to integrate their perspectives effectively.</i>
Interoperability and Data Sharing	1. <i>Prioritize the development and implementation of interoperability standards across EU, national, and regional levels for seamless health data exchange.</i>
	2. <i>Foster governance mechanisms and data sharing agreements to ensure responsible and secure health data sharing, while protecting patient privacy.</i>
	3. <i>Promote the adoption of open standards for transparent and accountable data exchange among stakeholders.</i>
	4. <i>Address technical and organizational barriers to interoperability and data sharing to foster collaboration and innovation in EU digital health.</i>



Key Domains	Key Policy Recommendations
<p>Resources and Capacities</p>	<p>1. <i>Translate EU Cancer priorities into practices in the cancer care continuum.</i></p>
	<p>2. <i>Focus on providing information and advice to stakeholders, policymakers, and patients.</i></p>
	<p>3. <i>Explore diverse financing mechanisms like Horizon Europe, for collaborative grants to advance cancer care and knowledge sharing, and ensure networks provide relevant services to each Member State to secure sustainable funding, also from national levels.</i></p>
	<p>4. <i>Address disparities in the cancer care continuum across underserved populations and regions in EU policy implementation.</i></p>
	<p>5. <i>Encourage collaboration between academic institutions, health care providers and other sectors such as industry to develop practical education and training programs at all policy levels, and also the promotion of collaborative research opportunities.</i></p>
	<p>6. <i>Leverage data and AI to develop key indicators for benchmarking and policy evaluation, and promote a paradigm shift in healthcare professionals' practices for effective EHDS and NoEs integration.</i></p>

5.2 Added value of the recommendations

The presented policy recommendations are based on the work developed in JANE JA. In this sub-section these recommendations are compared to the existing literature in relation to health networking and key aspects related to sustainability.

The policy recommendations begin underlying principles of the NoE such as **scope and governance**. There is a certain agreement in the literature in establishing that governance represents the efforts and processes by which the priorities of an action are achieved⁴⁵, and it is therefore one of the main reasons why this aspect has been and should be taken into account throughout the life of the networks, including health networks. This is the case of a current study on Italian health networks, which provided three **factors that can affect the effectiveness of networks** and are matched with our findings⁶. These

⁴ Barbazza E, Tello JE. A review of health governance: definitions, dimensions and tools to govern. *Health Policy*. 2014;116(1):1-11

⁵ Hanleybrown F, Kania J, Kramer M. Channeling change: making collective impact work. *Stanf Soc Innov Rev* 2012

⁶ Romiti, A., Del Vecchio, M., & Sartor, G. (2020). Network governance forms in healthcare: empirical evidence from two Italian cancer networks. *BMC Health Services Research*, 20, 1-16.



factors are: a) the importance of looking at network governance modes not in isolation, but in relationship to the governance of regional systems; b) the influence of a specific network's governance structure on the network's ability to respond to tensions and to achieve its goals; and c) the need to take into account the role of professionals in network governance. In line with basic aspects for NoEs, the recommendations also highlighted the importance of developing a **strategic plan**. By taking the time to develop and maintain the strategic plan, it can encourage the thinking, action and learning that leads to improvement⁷. Always bearing in mind possible adjustments over time in order to ensure the sustainability of the network⁸.

In addition, the various communications with stakeholders have underlined **the importance of maintaining the involvement of professionals and organizations in the networks**. As indicated by Siraneh et al. (2018)⁹, we found that different studies indicate that factors that influence organizational commitment can be personal background, organizational support and commitment, job satisfaction, salary levels, degree of autonomy over work, levels of stress in the workplace, gender, educational achievement, seniority, diversity of roles occupied, values and attitudes towards the job. In some conversations at the JANE events, it was highlighted that this commitment can be compromised when professionals are encouraged by their organizations and systems to participate in such opportunities, but on the other hand no time, space or recognition is given for participation, often leading to a sense of overload for the professional. In this context, some authors suggest that practices related to clear job design, and in this case organizational support, can eliminate sources of ambiguity and stress, and promote commitment in the long-term¹⁰.

On the other hand, the **ERN model** was stressed as a reference model on numerous occasions and for various aspects, given that this type of infrastructure has been in operation in Europe for some time, which makes it possible to learn from its trajectory. Moreover, as noted in the JANE Green Paper, such

⁷ 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

⁸ 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].

⁹ Siraneh, Y., Ololo, S., Tsega, G., Yitbarek, K., Adamu, A., Erchafo, B., Hailu, M., & Woldie, M. (2018). Level and Factors Associated with Professional Commitment of Health Professionals Providing Institutional Delivery Services in Public Health Facilities, Southwest Ethiopia. *Ethiopian journal of health sciences*, 28(4), 495-504. <https://doi.org/10.4314/ejhs.v28i4.15>

¹⁰ Rodríguez-Fernández, M., Herrera, J., & de Las Heras-Rosas, C. (2021). Model of Organizational Commitment Applied to Health Management Systems. *International journal of environmental research and public health*, 18(9), 4496. <https://doi.org/10.3390/ijerph18094496>



health networks in Europe face common challenges, and these common concerns can facilitate the joint search for solutions.

These challenges identified by ERNs¹¹ relate to the issues of governance and regulation, and in particular to who should take the main responsibility for the governance of ERNs: the EU or the MSs. The **principle of subsidiarity** was also discussed, with the claim that tasks should be carried out at the smallest possible level. ERNs have also opened the discussion to other issues such as the **lack of legal status, insufficient and unsustainable funding**, insufficient exploitation of ERN potential in research, and non-existence of ERN integration into national systems. On this last point, **the ERN Board of Member States (BoMS) has recently proposed a general framework for ERN integration into national systems** along with a non-exhaustive list of proposed measures, which could serve as an inspiration to the NoEs. Importantly, this model has already advanced that adaptations will have to be taken into account in each of the MSs, due the diversity of contexts and needs.

Regarding **specific needs at the national level**, it has been said that the benefits brought by open access to evidence-based practice and expertise with networks must go hand in hand with infrastructure. Recent articles on barriers to optimal cancer care in resource-limited countries have suggested that possible solutions to these barriers would include coordinated efforts on prevention strategies, increased screening uptake, training programs, equitable distribution of facilities, and policy directives in line with global commitments.¹²

The latter underlines the need for the forthcoming Joint Action to **maintain continuous communication at the political level, at both national and European level**, translating scientific knowledge and evidence-based interventions into policies, guiding legislative efforts and enlisting the support of these actors to continue the work of the networks. While there is little evidence of the use of research results in policy, this capacity could be facilitated by schemes such as Joint Actions, where national representation at policy level has been present from the outset. Furthermore, this translation could be also supported by new frameworks working on that specific topic¹³.

¹¹ Tumiene, B., Graessner, H., Mathijssen, I. M., Pereira, A. M., Schaefer, F., Scarpa, M., Blay, J. Y., Dollfus, H., & Hoogerbrugge, N. (2021). European Reference Networks: challenges and opportunities. *Journal of community genetics*, 12(2), 217–229. <https://doi.org/10.1007/s12687-021-00521-8>

¹² Mansour, R., Abdel-Razeq, H., Al-Hussaini, M., Shamieh, O., Al-Ibraheem, A., Al-Omari, A., & Mansour, A. H. (2024). Systemic Barriers to Optimal Cancer Care in Resource-Limited Countries: Jordanian Healthcare as an Example. *Cancers*, 16(6), 1117. <https://doi.org/10.3390/cancers16061117>

¹³ Crowley, M., Scott, J. T. B., & Fishbein, D. (2018). Translating Prevention Research for Evidence-Based Policymaking: Results from the Research-to-Policy Collaboration Pilot. *Prevention science : the official journal of the Society for Prevention Research*, 19(2), 260–270. <https://doi.org/10.1007/s11121-017-0833-x>



Effective collaboration with other types of stakeholders, including patient organizations, from the outset is crucial to creating patient-centered networks. This collaboration also extends to alliances between cancer projects and networks, such as ERNs and CraNE, which enrich results and facilitate knowledge exchange. Furthermore, learning from different projects and coordinating efforts between them can create opportunities for research collaboration and improve overall effectiveness of the NoEs. **Special attention should be given to the patient populations**, as they are essential for these initiatives. Moreover, patient involvement has already been shown to improve research, enhancing their quality and relevance¹⁴ also in co-creation processes in health care^{15,16}.

It is also important to **keep these groups and other interested public informed about the progress of the NoEs**. Increasing its visibility through events, congresses, and journals could raise awareness and encourage collaboration. In the case of health research, such efforts have been shown to **push toward knowledge translation and practice change**¹⁷. Among the recommendations was the use of the [EU Health Policy Platform](#) as it is the main forum for communication and cooperation between health interest groups and organizations, and the European Commission. The platform also aims to provide a framework for dialogue, facilitate targeted discussions, make health policy dialogue transparent, build knowledge of public health issues and relevant expertise, spread information about DG Health and Food Safety's projects (e.g. co-funded Health Programme projects) and gather and circulate research outcomes¹⁸.

Finally, other aspects remain open, such as **interoperability and the search for other funding mechanisms for NoEs**. These two issues are two of those common to the ERNs mentioned above and have been discussed in various forums and scientific publications. The fact that they are included as recommendations only serves to underline that the focus on them should remain in the spotlight, although they remain open to discussion.

5.3 Next steps

This document is intended to support the sustainability strategy of NoEs prior to their establishment in the European ecosystem. All these recommendations have been elaborated and elevated to

¹⁴ Sand, A. S., Grimsgaard, S., & Pettersen, I. (2020). Patient and public involvement in health research: A Nordic perspective. *Scandinavian journal of public health*, 48(1), 119–121. <https://doi.org/10.1177/1403494819863522>

¹⁵ Manafo, E., Petermann, L., Mason-Lai, P., & Vandall-Walker, V. (2018). Patient engagement in Canada: a scoping review of the 'how' and 'what' of patient engagement in health research. *Health research policy and systems*, 16, 1-

¹⁶ Hardyman, W., Daunt, K. L., & Kitchener, M. (2015). Value co-creation through patient engagement in health care: a micro-level approach and research agenda. *Public Management Review*, 17(1), 90-107.

¹⁷ Edwards D. J. (2015). Dissemination of Research Results: On the Path to Practice Change. *The Canadian journal of hospital pharmacy*, 68(6), 465–469. <https://doi.org/10.4212/cjhp.v68i6.1503>

¹⁸ https://health.ec.europa.eu/eu-health-policy/interest-groups/eu-health-policy-platform_en



recommendations at the policy level. These recommendations were represented taking into consideration different domains of action that would cover aspects that can support and reinforce the capacity of the NoEs to reach their expected impact and facilitate their sustainability in the long term.

In this sense, all the recommendations have been given as a general overview of the operation of these health networks, without taking into account the specificities that each of the 7 NoEs may have. On one hand, there are aspects that can be applied to all of them transversally, in terms of the design of the governance model of these networks, or aspects related to communication with external actors at international and national levels (e.g. how to articulate representation at national level within European networks). On the other hand, there are aspects, such as funding models or type of services, that depend closely on the specific objectives and scope of each NoE.

For this reason, **a number of future steps have been envisaged**. This approach will be designed to ensure that the services provided by the NoEs are aligned with stakeholder needs, while at the same time ensuring a robust business model that can support their long-term financial and operational sustainability.

The first step in this process involves a **desk research** aimed at identifying key stakeholders to better understand their motivations and roles in relation to the services that NoEs will provide. This work will take advantage of the work done in JANE and will be based on the expectations of the NoE leaders. As part of this activity, a needs assessment will be conducted to verify if there is demand for the services proposed by each NoE and to prioritize their rollout according to user needs.

Two primary sources of information could be used for this **needs assessment**: (1) recommendations resulting from the Policy Dialogues and Stakeholder forum organized in JANE, and (2) results from a survey targeting representatives of the key stakeholder groups. This data will allow for the creation of a preliminary **service portfolio** that aligns with both the expectations of NoE leaders and the real needs of the cancer community. By tailoring services to stakeholder needs, NoEs could offer more targeted solutions, thereby increasing their perceived relevance to the public, and thus, are more likely to attract support and funding.

As a second step, **the prioritization of the services** that each NoE will offer would be advisable. This exercise will link the demand-driven and stakeholder-oriented services identified with the strengths and capacities of NoE members to provide these services. Thus, the feasibility and affordability of the real provision of the services can be guaranteed.

The next logical step would be to develop **a business model to ensure service continuity and pave the way for sustainability beyond JANE 2 JA**. This could be done through strategies such as the one



proposed by the Business Model Canvas methodology¹⁹, which is a strategic management and lean startup template for developing new or documenting existing business models. It is a visual diagram with elements that describe a company or product's value proposition, infrastructure, customers, and finances. The model consists of nine building blocks: customer segments, value proposition, channels, customer relationships, revenue streams (in-kind or cash), key resources, key activities, key partnerships and cost structure.

This model could offer several benefits to NoEs, tailoring strategies to the unique needs and capabilities of each network. The visual layout of the methodology makes it easier for members to understand and communicate their own model and also to identify different financial and operational models, such as membership fees, pay-for-access services, sponsorship or in-kind contributions, to find the most sustainable combination for each network. In addition, new applications of this methodology have shown that it can be used to support conversations about particular changes in organizations, which could facilitate change to meet the changing needs of society²⁰.

Finally, it will remain essential **to involve experts, policy makers and EU representatives in joint meetings**. Such collaboration will strengthen relationships and ensure comprehensive support for the NoEs, allowing them to remain relevant and well-integrated into the broader European health framework. Furthermore, alliances with other cancer-related networks and projects, such as the ERNs and CraNE, should be maintained to foster synergies and collaborative work.

This holistic approach could lead the operational sustainability of each NoE and also help to build a resilient and adaptable framework for these new networks in Europe. By aligning strategic goals with practical tools such as the Business Model Canvas and fostering collaboration at multiple levels, NoEs could achieve long-term sustainability and continue to provide valuable services to the cancer care community.

¹⁹ Osterwalder, A. and Pigneur, Y. (2010) Business Model Generation: A Handbook for Visionaries, Game Changers, and Challengers. Wiley, New Jersey.

²⁰ Joyce, A., & Paquin, R. L. (2016). The triple layered business model canvas: A tool to design more sustainable business models. Journal of cleaner production, 135, 1474-1486.



6 CONCLUSION

6.1 Call-to-action for the European Commission

The Networks of Expertise have been envisioned to ensure high standards of cancer care across Europe, focusing on addressing challenging cancer areas with unmet needs that can benefit from cross-border cooperation and expertise at the EU level. With the forthcoming Joint Action JANE 2, these networks will connect experts across Member States, creating a new infrastructure that will facilitate knowledge sharing and generation, creating new opportunities to improve cancer care in Europe.

However, considering the work that has been developed in Joint Action JANE and the policy recommendations provided in this document, some aspects remain unclear and there is uncertainty about how they will be addressed. For this reason, we would like to ask the European Commission to keep the discussions open, as the future Networks of Expertise and other infrastructures already in place or in the process of being launched, such as the ERNs or CCCs, will need its guidance.

The JANE 2 consortium will need support and cooperation to identify possible solutions for the legal basis and possible regulations to be considered for NoEs. Since there are no known answers to these questions, other related issues, such as future sources of funding for the networks, will be of great relevance, as the networks' lack of legal status can present many challenges, including limited competitiveness in calls, less funding opportunities, and complicated management of applications, grants and funds.

Such actions show that representation and cooperation between all MS is possible. That stakeholder involvement is channeled at different levels of decision-making, and we will continue to push for this. Together, it would be possible to keep going and address the current and future challenges of cancer and to offer the best care to the whole community without gaps while guaranteeing equal access.



ANNEXES

ANNEX I JANE Policy Dialogues methodology and results report



TASK 4.3 POLICY BOARD AND POLICY DIALOGUES

MAIN CONCEPT AND OPERATING PROCEDURES

Date: 15/02/2023

Doc. Version: 4.0





TABLE OF CONTENT

1	Introduction	45
2	Policy Board	45
2.1	Objectives	45
2.2	Membership	45
2.3	Secretariat.....	Errore. Il segnalibro non è definito.
2.4	Communication.....	46
3	Policy Dialogues.....	47
3.1	Objectives	Errore. Il segnalibro non è definito.
3.2	Operating procedures	Errore. Il segnalibro non è definito.



1. INTRODUCTION

JANE, the Joint Action on Networks of Expertise (NoEs) 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.

Work Package 4 works for ensuring a long-term sustainable model for the NoEs aligned with European and national policies. To this end a Policy Board and a Policy Dialogue will be set up.

This document contains the description of the main concept and operating procedures of the Policy Board and the Policy Dialogues.

2. POLICY BOARD

2.1 Objectives

The Policy Board of JANE is an external board composed of policy-makers at different decision levels. The role of the Policy Board will be to give input on policy recommendations and guidance to ensure that the established NoEs assemble the best knowledge, skills and facilities available in Europe and are aligned with European and national policies, thus, contributing to guarantee their sustainability.

The Policy Board has two main objectives:

- To align the NoEs' ecosystem to regional, national and EU policies, programs and plans
- To identify and build up the potential EU added value of NoEs

2.2 Membership

The Policy Board will be represented by health authorities of the Member States, ideally from Ministries of Health (MoH), but also other policy level health institutions or relevant stakeholders. Representatives of the countries participating in Joint Action JANE may be proposed by Competent Authorities (in agreement with their Affiliated Entities). Representatives from Member States within EU/EEA that do not participate in JANE are invited directly by the Secretariat through national focal points for Health Programme at EC (or other representatives of MSs identified by them).

Policy Board members are not official representatives of their respective countries, so no Letters of nomination are required on their behalf. First membership list will be available since month 6 (March 2023), and is kept open, since partners may identify important policy-level stakeholders to be invited during development of the project.



The final list of members will be confirmed with all JANE partners. It will be composed by one or two members per each of the 16 countries participating in JANE. Additional members relevant for the work on Sustainability may be designated. In this regard, the following may be considered: JANE coordinators, CRANE coordinators, representatives of Member States not participating in JANE, etc.).

2.3 Secretariat

As proposed in the Grant Agreement of the Joint Action JANE, the Policy Board is led by Kronikgune, who also provides the secretariat and elaborates a proposal for the main aim and operating procedures.

The contact persons are:

- Yhasmine Hamu, Institute for Health Services Research Kronikgune, leader of JANE work package on sustainability

Email: yhamu@kronikgune.org

- Sarah Berrocoso, PhD, Institute for Health Services Research Kronikgune, leader of JANE work package on sustainability

Email: sberrocoso@kronikgune.org

2.4 Communication

Secretariat will communicate to the Policy Board members timely in relation to the proposed activities. The Policy Board members, in turn, are encouraged to communicate with the Secretariat and to ask for clarification whenever necessary. Regular contacts are performed via e-mail.

Policy Board members will be initially contacted to confirm their participation in the Policy Board of JANE. After confirmation, WP4 will organize informal virtual coffee meetings bilaterally with Policy Board members to present them the Joint Action and the expectations for their participation in the Policy Board. Furthermore, input on relevant areas for the Joint Action will be gathered from the conversations and will be appropriately used to enrich WP4 work.

Other bilateral meetings may be organised optionally by telephone, videoconference or other means of communication, if required.

Secretariat will distribute relevant documents to the Policy Board members and they will provide comments when necessary at the agreed timeline. The results, recommendations and/or decisions that will arise from the meetings and other work of the Policy Board will be presented to members of the Policy Board for their final approval.



3. POLICY DIALOGUES

The Policy Dialogues will be the means through which the Policy Board will reach its main objectives. Policy Dialogues are deliberative conversations that gather policy makers to discuss a topic of mutual interest.

3.1 Objectives

The Policy Dialogues within JANE will be aimed at:

- Initiating or contributing to legislative change intended to help improve cancer care
- Establishing governance mechanisms for institutional/cross-sectoral collaboration
- Reaching consensus on tangible actions that will address obstacles related to NoEs' sustainability
- Increasing political will and engagement towards new or adapted policies

3.2 Operating procedures

The Policy Board members will meet once a year in the Policy Dialogues, for a total to two meetings throughout the project. The 1st meeting will be conveyed in a virtual format and the format for the 2nd meeting will be decided in accordance with the Coordination of the Joint Action. Meetings are organised, moderated and supported by the Secretariat.

Before the Policy Dialogue

Save-the-date for the meeting will be sent out to Policy Board members and other applicable attendees at the earliest convenience when defined.

The Secretariat will draft the agenda in alignment with the Coordinator IRCCS INT, DG SANTE and HADEA and distribute it together with relevant documents at least one month before each Policy Dialogue.

Members of the Policy Board can provide feedback with suggestions for changes to the agenda up to three weeks before the Policy Dialogue, that will be appropriately considered as deemed necessary by the Secretariat.



After the Policy Dialogue

Minutes of the Policy Dialogues will be produced by the Secretariat summarising the main conclusions extracted from the session and shared with Policy Board members and other attendees no later than three weeks after the meeting.

Policy Board members and other attendees will be given two weeks after the reception of the minutes to provide feedback with suggestions for changes that will be appropriately considered by the Secretariat.



JANE Policy Board members

The Policy Board brought together representatives of different National health authorities at different decision levels and other key representatives from National Cancer Research Centres and Public Health organizations, that were nominated and invited to participate by the Competent Authority of each Member State.

Throughout the development of JANE, the board included 22 representatives from the consortium's participating MSs (Italy, Belgium, Croatia, France, Germany, Greece, Hungary, Lithuania, Malta, Norway, Poland, Portugal, Romania, Slovenia, Spain and Czechia), along with an additional representative relevant for the work on sustainability from CraNE JA. Some countries had more than one representative on the Policy Board, both because of changes in its composition and because of the participation of additional representatives, given their expertise in the different policy dialogues. In addition, DG SANTE and DG EAC members were also involved as observers or key speakers at Policy Board events. See Table 1 for more information.

Table 1. List of JANE Policy Board members

EU MS	Organization	Policy Board member/s
Italy	Ministry of Health	Giampaolo Latella (Functionary)
Belgium	Sciensano	Marc Van Den Bulcke (Head of Service)
Croatia	Croatian Institute of Public Health (CIPH)	Mario Šekerija (Head of Croatian National Cancer Registry)
France	The French National Cancer Institute (INCA)	Thomas Dubois (Head of European and International Affairs)
Germany	Federal Ministry of Health (BMG)	Karen Budewig (Division 324 "Cancer")
Germany	Federal Ministry of Health (BMG)	Verena Kurz (Senior Policy Advisor Division 511 – New technologies and data use)
Greece	Ministry of Health	Vasiliki Karaouli (General Director)
Hungary	National Institute of Oncology (OOI)	József Lövey (Clinical Director)
Hungary	National Institute of Oncology (OOI)	András Masszi (Head of Department)



Lithuania	Ministry of Health of the Republic of Lithuania	Inga Cechanovičienė (Head of Specialized Health care Division)
Malta	Ministry of Health of Malta (MFH)	Miriam Dalma (MD MSc MBA PhD Consultant Public Health)
Norway	Norwegian Directorate of Health	Irene Olaussen (Program Manager for EU4Health at the Norwegian Directorate of Health)
Poland	Lublin Oncology Center of St. John of Dukla, Department of Clinical Oncology	Tomasz Kubiowski (Clinical Oncologist)
Portugal	Directorate-General of Health (DGH)	Nuno Sousa (Deputy of the National Oncological Diseases Programme)
Romania	The Oncology Institute (IOCN)	Delia Nicoara (Public Health Specialist at The Oncology Institute)
Slovenia	Ministry of Health	Mojca Gobec (Head of the Sector for Disease and Injury Prevention at the Public. Health Directorate)
Slovenia	National Institute of Public Health of the Republic of Slovenia (NIJZ)	Tit Albreht (CraNE Scientific Coordinator)
Slovenia	National Institute of Public Health of the Republic of Slovenia (NIJZ)	Marjetka Jelenc (CraNE Coordination team)
Spain	Ministry of Health	Rocío Fernández González (Subdirección General de Calidad Asistencial, D. G de Salud Pública, Ministerio de Sanidad),
Spain	Ministry of Health	Yolanda Agra Varela (Subdirector of General de Calidad Asistencial Ministerio de Sanidad. Ministerio de Sanidad)
Spain	Ministry of Health	Alicia M ^a Fernández Montero (Subdirección General de Calidad Asistencial)
Spain	Ministry of Health	Pilar AparicioAzcárraga (Subdirección General de Calidad Asistencial)



Summary report of JANE Informal Coffee Meetings

The purpose of this document is to summarize the main highlights of the Informal Coffee Meetings (ICMs) held from May to July 2023 with the various representatives of the JANE Policy Board. These meetings were created with the main objective of introducing and contextualizing JANE, gathering initial reactions to the JA approach and discussing the potential impact that NoEs can have on the cancer care ecosystem in Europe. These informal coffee meetings were the first contact after the nomination and acceptance of representatives from each Member State to be part of the JANE Policy Board. The outcomes of these initial meetings helped to introduce some of the topics that would be discussed in the JANE Policy Dialogues. In particular, questions were drawn from the conclusions of these meetings.

Table 1. List of Informal Coffee Meetings

EU MS	Organization	Policy Board member/s	Date of the Informal Coffee meeting
Belgium	Sciensano	Marc Van Den Bulcke (Head of Service)	Written answer
Croatia	Croatian Institute of Public Health (CIPH)	Mario Šekerija (Head of Croatian National Cancer Registry)	14/07/2023
France	The French National Cancer Institute (INCA)	Thomas Dubois (Head of European and International Affairs)	20/06/2023
Germany	Federal Ministry of Health (BMG)	Karen Budewig (Division 324 "Cancer")	22/06/2023
Greece	Ministry of Health	Vasiliki Karaouli (General Director)	20/06/2023
Hungary	National Institute of Oncology (OOI)	József Lövey (Clinical Director)	31/05/2023
Lithuania	Ministry of Health of the Republic of Lithuania	Inga Cechanovičienė (Head of Specialized Health care Division)	13/07/2023



Malta	Ministry of Health of Malta (MFH)	Miriam Dalma (MD MSc MBA PhD Consultant Public Health)	29/05/2023
Poland	Lublin Oncology Center of St. John of Dukla, Department of Clinical Oncology	Tomasz Kubiowski (Clinical Oncologist)	23/06/2023
Portugal	Directorate-General of Health (DGH)	Nuno Sousa (Deputy of the National Oncological Diseases Programme)	27/06/2023
Romania	The Oncology Institute (IOCN)	Delia Nicoara (Public Health Specialist at The Oncology Institute)	11/07/2023
Slovenia	Ministry of Health	Mojca Gobec (Head of the Sector for Disease and Injury Prevention at the Public Health Directorate)	16/06/2023
Spain	Ministry of Health	Rocío Fernández González (Subdirección General de Calidad Asistencial, D. G de Salud Pública, Ministerio de Sanidad) and Yolanda Agra Varela (Subdirectora General de Calidad Asistencial Ministerio de Sanidad. Ministerio de Sanidad)	21/06/2023



The responses of the policy makers who participated in these bilateral meetings were classified into four categories to facilitate the analysis of aspects related to the sustainability of the networks. The following categories were distinguished (1) Management & Infrastructure; (2) Networking & Communication; (3) Resources and Capacities; and (4) Inspired and/or supported by other European models (e.g. ERNs). The results on the answers to the questions posed in the ICMs are summarized below.

1. What could you expect from the NoEs?

The table below summarize (by clustering) the **answers**.

Management & Infrastructure

- **Necessary infrastructure:** A key takeaway is that infrastructure is essential for expertise development; you cannot become an expert without the proper technological support. The success of the networks depends on securing advanced infrastructure and resources to support their activities.
- **Inevitable conceptualization:** The conceptualization of the networks must inevitably consider both the combination of expertise and the necessary infrastructure. Without harmonizing these two components, the networks will struggle to function effectively across borders.
- **Defining expected outcomes and objectives:** It is crucial to clearly define the expected outcomes, scope, and specific objectives for each network. This includes identifying a common objective that unites all networks of expertise to ensure aligned efforts and cohesive goals within JANE.
- **Developing a well-defined scope:** The scope of each network needs to be thoroughly developed, addressing specific issues relevant to their focus areas. A well-crafted scope will help avoid overlaps and ensure that each network tackles the most pressing challenges within its domain.
- **Planning, coordination, and implementation of European cancer programmes:** The planning, coordination, and execution of European cancer programmes should be closely integrated into the networks of expertise. This will help ensure that NoEs align with broader EU initiatives and capitalize on existing resources and strategies.
- **Identifying and sharing good practices:** Identifying and sharing best practices across the networks will be essential for addressing organizational challenges. This process will allow the networks to learn from one another and improve their operational efficiency and effectiveness.



- **Facilitating technical support:** There is a need to facilitate technical support for cancer care and control institutions, tailored to each of the specific areas of expertise within the networks. Providing this support will enhance the networks' ability to meet the needs of the cancer care ecosystem across Europe.

Networking & Communication

- **Removing inequalities and enhancing expert capacity through networking:** The Networks of Expertise (NoEs) have the potential to reduce healthcare inequalities and enhance the capacity of experts through effective networking. By fostering strong connections, the NoEs can contribute to improving the quality of care provided across Europe, ensuring that patients receive better and more equitable attention.
- **Support from Cancer Centres, Networks, and policymakers:** It is essential to secure the support of Cancer Centres and Cancer Networks, alongside the active involvement of policymakers. Their backing will be crucial in driving the success of the NoEs and ensuring that the necessary resources, expertise, and political will are in place to support their objectives.
- **Relationship with ERNs:** Building a strong relationship with the ERNs is necessary to align efforts, share expertise, and ensure that the NoEs contribute to a broader framework of cross-border healthcare in Europe. This connection will be key in addressing rare and complex cancers and enhancing the overall impact of the networks.
- **Learning through networking:** Networking provides an opportunity for continuous learning, where experts can share experiences, knowledge, and best practices. This collaborative learning environment will help improve the capabilities of professionals involved in the NoEs and foster innovation in cancer care.
- **Engaging stakeholders from the outset:** It is important to engage stakeholders early on and build strong relationships from the start. Early involvement will ensure that stakeholders feel invested in the success of the NoEs and contribute meaningfully to their development and sustainability.
- **Building capacity through international collaboration:** International collaboration is a key component of the NoEs, as it helps build capacity by leveraging expertise and resources from across Europe. This collaboration will ensure that the networks are equipped to address the most challenging aspects of cancer care.
- **Collaboration among EU stakeholders:** Fostering collaboration among EU stakeholders, including healthcare providers, researchers, and policymakers, will be essential for the



long-term success of the NoEs. By working together, these stakeholders can create synergies that enhance the effectiveness of the networks.

- **Facilitating knowledge exchange between bodies:** Facilitating the exchange of knowledge between different bodies involved in cancer care and control is crucial for the continuous improvement of the NoEs. This exchange will ensure that best practices, innovations, and advancements are shared across borders, contributing to the overall success of the networks.

Resources & capacities

- **Fighting inequalities and facilitating access to knowledge:** The NoEs play a crucial role in reducing inequalities by facilitating access to knowledge for countries that face challenges in both experience and opportunities. By pooling expertise and resources, the NoEs will ensure that all countries have the tools they need to provide high-quality cancer care, regardless of their starting point.
- **Defining policies, best practices, and resources:** The NoEs will contribute to the definition of policies and best practices, identifying transferable models and resources that can be used to treat individual patients. This will help standardize care and ensure that all patients have access to the best possible treatments and support, regardless of their location.
- **Knowledge sharing and capacity building:** Sharing knowledge, expertise, capacity, and best practices across the networks is essential. The NoEs will act as a platform for continuous learning, allowing professionals to improve their skills and knowledge in line with European guidelines, including the Beating Cancer Plan.
- **Centralized cancer data registry and expertise pooling:** Establishing a single point of contact, such as a registry or repository for cancer data, will streamline access to crucial information. This central platform will pool clinical, diagnostic, and treatment expertise, making it easier for healthcare professionals across Europe to access the latest data and improve patient outcomes.
- **Defining outcome criteria and implementation processes:** The NoEs will focus on defining clear reporting and outcome criteria, as well as implementation processes. This will ensure that all members of the network are aligned in terms of goals and strategies, enhancing the overall impact of the NoEs.
- **Strengthening capacity at national and European levels:** The NoEs aim to strengthen capacity at the European level, while also helping to build national-level capacity. This dual



approach will ensure that all Member States are equipped to improve cancer care and develop sustainable healthcare systems.

- **Addressing reimbursement, data registries, and access to care:** Key issues such as reimbursement, data registries, and access to high-quality cancer care must be addressed to ensure that patients receive the support they need. The NoEs will work to remove barriers to access, ensuring that high-quality care is available to all.
- **Up-to-date knowledge for healthcare professionals:** It is essential for physicians and other healthcare professionals to have access to up-to-date knowledge based on established standards. The NoEs will provide a platform where professionals can seek advice and stay informed on the latest developments in cancer care.
- **Focal point for European collaboration:** Acting as a focal point at the EC level, the NoEs will facilitate collaboration between Member States, providing a platform to share experiences, knowledge, and best practices in alignment with the Beating Cancer Plan's guidelines.

Inspired and/or supported by other European models (e.g. ERNs)

- **Interest in the ERN membership model:** There is significant interest in adopting or adapting the membership model used by European Reference Networks (ERNs). This model provides a framework for collaboration and membership that could be beneficial for the NoEs, offering insights into how to structure membership and engagement effectively.
- **Implementation strategies:** The implementation of the NoEs should build on existing structures to facilitate evaluation and operational work. Using the ERN model as a reference, the NoEs can leverage established frameworks to streamline their processes and ensure that their implementation is both effective and efficient.

2. How do you think that JANE can contribute to establish added value NoEs?

The table below summarize (by clustering) the **answers**.

Management & Infrastructure

- **Necessary infrastructure:** The infrastructure, particularly in terms of technology, is essential for the success of the networks of expertise. Expertise alone is insufficient without the right infrastructure in place to support the activities and initiatives. This combination is critical for establishing long-term sustainability and impact.
- **Union of expertise and infrastructure:** The networks must ensure a strong integration of expertise with the necessary infrastructure. Without this union, the ability to deliver high-



quality, cross-border cancer care and support will be limited. Combining these two elements will strengthen the networks' capacity to provide cutting-edge solutions.

- **Planning, coordination, and implementation of European programmes in cancer care:** The success of the networks will also depend on their alignment with the planning, coordination, and implementation of European cancer care programmes. This connection will ensure that the networks are not working in isolation but are contributing to and benefiting from wider European efforts in cancer care.
- **Identification of good practices:** Identifying good practices within the networks is essential for learning about both cancer care and the broader organizational and administrative aspects of health systems. These practices will not only improve cancer care delivery but also enhance the management and operational structures of health systems across Europe.
- **Facilitate technical support:** There is a clear need to facilitate technical support for cancer care and control institutions in relation to each of the topics covered by the networks. Providing this support will be critical in enabling institutions to adopt best practices and strengthen their capacity to respond to the challenges in cancer care.

Networking & Communication

- **Support from Cancer Centres, Networks, and policymakers:** Securing the support of Cancer Centres and Cancer Networks, along with the active involvement of policymakers, is essential for the success of the NoEs. Their backing will provide the necessary resources, strategic direction, and political commitment to help the networks achieve their goals.
- **Relationship with ERNs (European Reference Networks):** Developing a strong and necessary relationship with the ERNs will enable the NoEs to benefit from established cross-border healthcare networks. This collaboration will help address rare and complex cancers more effectively, leveraging the expertise and infrastructure of ERNs.
- **Strengthening capacities through international collaboration:** International collaboration is crucial for strengthening the capacities of the NoEs. By pooling expertise and resources from across Europe, the networks can enhance their ability to tackle complex challenges and improve cancer care on a larger scale.

Resources & capacities

- **Fighting inequality and facilitating access to knowledge:** The NoEs are crucial in addressing healthcare inequalities by facilitating access to knowledge for countries facing challenges in both experience and opportunity. By serving as a knowledge hub, the NoEs will ensure that all countries can benefit from shared expertise and resources.



- **Defining policies and sharing best practices:** The NoEs will play a key role in defining policies, good practices, and transferable models. They could provide resources and guidance on treating individual patients, thereby setting standards that can be adopted across different regions.
- **Centralized data and expertise hub:** Establishing a central connecting point, such as a repository or register for cancer data, will enhance data accessibility and utility. Pooling clinical, diagnostic, and treatment expertise at a European level will enable more effective health planning and management.
- **Capacity building at European and national levels:** The NoEs aim to improve capacity at both the European and national levels. Strengthening capacity development within countries will help ensure that local health systems are equipped to provide high-quality cancer care.
- **Improving real-world data quality:** Enhancing the quality of real-world data will generate comparable and transferable evidence-based information. This will support better decision-making and ensure that cancer care practices are based on robust evidence.
- **Reimbursement and data management:** Addressing issues related to reimbursement, registries, and data management is crucial for ensuring access to high-quality cancer care. The NoEs could work to streamline these processes and improve the overall efficiency of cancer care systems.
- **Focal point at the European Commission level:** Acting as a focal point for cancer-related issues at the European Commission level, the NoEs could facilitate coordination and collaboration across Member States, ensuring that efforts are aligned and effective.

Inspired and/or supported by other European models (e.g. ERNs)

- **Interest in the ERN membership model:** There is considerable interest in adopting the membership model used by European Reference Networks (ERNs) for the NoEs.
- **Building on existing models:** To develop a valid membership model for the NoEs, it is crucial to consider and learn from existing models like those used by ERNs. Evaluating these established frameworks will provide a strong foundation for creating a membership system that is both practical and effective.
- **Implementation strategy:** The NoEs should aim to build on existing structures to streamline implementation and facilitate evaluation. Leveraging established models, such as those from ERNs, can help simplify processes and enhance the effectiveness of the NoEs' operational strategies.



3. How do you think that JANE can ensure that the established NoE's are aligned with European and national policies?

The table below summarize (by clustering) the **answers**.

Management & Infrastructure
<ul style="list-style-type: none"> • Nomination of leaders at the national level: The nomination of leaders at the national level is essential to ensure the effective coordination and management of the networks. National leaders will play a critical role in aligning the NoEs with national policies and ensuring that their objectives are achieved at both national and European levels. • Establishment of governance mechanisms: The establishment of clear governance mechanisms is crucial for the successful operation of the networks. These governance structures will provide a framework for decision-making, accountability, and coordination across all participating countries, ensuring that the NoEs function smoothly and effectively. • Alignment with objectives from the start: It is important to align the networks from the beginning with their specific objectives, whether in prevention, screening, or research. This alignment will ensure that each NoE focuses on its key areas of expertise while contributing to the broader goals of cancer care in Europe. • Extension of the Joint Action to ensure sustainability: Extending the “project” beyond its initial phase, either as a platform or in another form, is vital for ensuring the long-term sustainability of the networks. This extension will help maintain momentum, foster ongoing collaboration, and ensure that the NoEs continue to deliver value to the cancer care ecosystem. • Creation of an ad hoc body for knowledge exchange: Installing an ad hoc body dedicated to supporting the exchange of knowledge and advancements within each of the initiatives is essential. This body will facilitate continuous learning and sharing of progress, helping the networks evolve and adapt to emerging challenges and opportunities.
Networking & Communication
<ul style="list-style-type: none"> • Alignment with policymakers' goals: The initiatives must be closely aligned with the goals of policymakers to ensure that the Networks of Expertise (NoEs) contribute to national and European cancer care strategies. Providing a framework that ensures NoEs are relevant to EU policies and act as policy drivers and informants is key for their success. • Addressing differing national contexts and inequalities: While Member States may share common objectives, their national contexts differ significantly, presenting important challenges. Collaboration with patient associations is vital to address these differences and



ensure that the initiatives are adaptable and responsive to each country's specific needs. The main objective should be to tackle inequalities and promote the sharing of knowledge across borders.

- **Involvement and collaboration with stakeholders and patients:** Close collaboration with stakeholders, including patients' associations, is essential for these initiatives. Engaging patients from the outset helps ensure that the networks remain patient-centered, while working closely with stakeholders such as experts, policymakers, and EU representatives ensures comprehensive support and input.
- **Cancer prevention coalition and policy link:** There is a need to create a cancer prevention coalition that connects EU evidence with policy initiatives, such as tobacco control measures. This coalition would play a key role in addressing cancer prevention at the EU level, providing a unified approach to pressing health concerns. Providing a framework and ensuring that NoEs are informative of EU policies: relevant, policy drivers and informants.
- **Collaboration across Member States and EC initiatives:** JANE brings together representatives from numerous Member States, many of whom are involved in other EC initiatives. This broad involvement facilitates cross-initiative collaboration, ensuring that NoEs are informed by and contribute to a wider European health landscape.

Resources & capacities

- **Addressing inequity through expert-driven models:** By developing and implementing models based on expert recommendations, we can apply the necessary pressure to ensure equitable coverage and access. These models could help address disparities by setting standards that guarantee the provision of comprehensive care.
- **Bottom-up models for strategy development:** Utilizing bottom-up models allows for a deeper understanding of how to effectively develop and implement strategies. These models provide insights into expectations and practical approaches for achieving desired outcomes.
- **Supporting implementation processes:** The NoEs will support implementation processes not only through strategic planning but also by assisting with the practical application of recommendations. This includes providing guidance on how to operationalize strategies and monitor their effectiveness.
- **Supporting research and policy development:** The NoEs will support research initiatives and policy development by disseminating evaluations, updating recommendations, and promoting necessary changes. This will help ground strategies in evidence and assist in ongoing monitoring and improvement.



- **Providing information for policy development:** Effective implementation requires providing policymakers with relevant information and insights. The NoEs could contribute by offering data and perspectives that inform the development of policies and strategies.
- **JANE's perspective on NoE topics:** JANE can offer valuable insights from its experience with the NoEs, providing a perspective on the specific topics and issues they address. This input will be crucial for refining strategies and ensuring that the NoEs effectively meet their goals.

Inspired and/or supported by other European models (e.g. ERNs)

- **Collaboration with CraNE:** Close collaboration with CraNE is essential for success. While we can lay the groundwork for effective models and strategies, the full impact can only be realized with robust infrastructure and the active uptake or implementation of these initiatives. CraNE's involvement is crucial to ensure that these models are effectively integrated and their benefits fully realized.
- **Linking strategies with existing organizations:** It is important to align strategies with existing organizations and networks. By connecting with established entities, we can leverage existing resources and expertise, ensuring that new strategies are practical, well-supported, and seamlessly integrated into ongoing efforts.
- **Benchmark certification schemes:** Implementing benchmark certification schemes is key to maintaining high standards and quality assurance. These schemes will help evaluate and certify the effectiveness of models and practices, ensuring that they meet established benchmarks and deliver consistent, high-quality outcomes.

4. How do you see the future of these networks from 2025 onwards?

The table below summarize (by clustering) the **answers**.

Management & Infrastructure

- **Strategic plan for sustainability and long-term success:** A strategic plan is essential to ensure the sustainability of the NoEs, addressing new challenges as they arise and implementing robust evaluation and monitoring processes. This will help the networks remain adaptable and effective over time, ensuring long-term success.
- **Creation of quality indicators:** Developing quality indicators is critical to assess the impact of the NoEs. These indicators may need to be segregated by country, and while they may not seem immediately relevant, their importance will grow over the course of 2-3 years. They will serve as key benchmarks for tracking progress and improvements in cancer care.



- **Securing funding and external support:** Obtaining reliable sources of funding is crucial for the sustainability of the networks. External funding, including membership or fellowship programs, will provide financial stability. The search for funding should begin early, ensuring that the necessary resources are in place to support the long-term operation of the NoEs.
- **Structures for sustainability, efficiency, and feasibility:** Establishing well-defined structures is essential to ensure the sustainability, efficiency, and feasibility of the NoEs. These structures will support the smooth functioning of the networks, helping them to achieve their objectives and operate efficiently over time.
- **Ensuring continuity and commitment from leading organizations:** The outcomes of JANE will further materialize in the upcoming Joint Action NoEs, making it crucial to guarantee continuity. Leading organizations must commit to supporting these networks from the outset, ensuring that the groundwork laid by JANE is carried forward into future projects.

Networking & Communication

- **Benchmarking for care improvement:** The NoEs should help establish benchmarking processes that focus on indicator-based improvements in cancer care. These benchmarks will allow for the measurement of progress, setting a standard for care quality across Member States and facilitating continuous improvement.
- **Opportunities for research collaboration:** NoEs will generate valuable opportunities for research collaboration at the European level. By working together across borders, experts can pool resources and knowledge, advancing research initiatives that lead to innovations in cancer care and treatment.
- **Policy-informative objectives and knowledge transfer:** The NoEs must set clear, policy-informative objectives, learning from best practices and models to effectively inform healthcare policies. Their role is not only to improve care but also to serve as a bridge between research, clinical practice, and policy, transferring successful models to patient care across Europe.
- **Cross-border collaboration and knowledge sharing:** Sharing expertise and knowledge at a European level is key for the success of the NoEs. Cross-border collaboration will ensure that all Member States benefit from advancements in cancer care, creating a unified approach to addressing the most pressing healthcare challenges.

Resources & capacities



- **Providing information and advice:** The NoEs should play a key role in offering information and expert advice. This support will be essential for guiding healthcare professionals and policymakers in the effective management and treatment of cancer, ensuring that decisions are informed by the latest knowledge and best practices.
- **Benchmarking in pancreatic cancer:** Establishing benchmarks for pancreatic cancer is critical. By setting standards for diagnosis, treatment, and care, the NoEs can help improve outcomes and ensure consistency in the quality of care provided. Benchmarking will also facilitate comparisons and identify areas for improvement in pancreatic cancer management.

Inspired and/or supported by other European models (e.g. ERNs)

- **Collaboration with Comprehensive Cancer Centres (CCCs):** The NoEs should work closely with Comprehensive Cancer Centres (CCCs) to support the dissemination of knowledge and assist in the implementation of best practices. This collaboration will help ensure that the NoEs' strategies and recommendations are effectively integrated into existing cancer care frameworks.
- **Supporting European Reference Networks (ERNs):** The NoEs should also support European Reference Networks (ERNs) by aligning their efforts with these established networks. This support will enhance the overall effectiveness of cancer care initiatives and foster greater coordination across different cancer care platforms.
- **Building on existing models:** It is crucial to build on established models rather than reinventing the wheel. By drawing from existing successful frameworks and practices, the NoEs can develop effective strategies more efficiently and avoid duplicating efforts.
- **Learning from other models:** The NoEs should actively learn from and draw inspiration from other models. Analyzing lessons learned from existing frameworks will provide valuable insights and help refine the NoEs' approaches, ensuring that they incorporate proven strategies and avoid common pitfalls.

In addition, Policy Board members were asked how they thought their country would support the NoEs and what the barriers might be.

- Financial support and legal implementation
- Maintain interest and engagement of professionals
- Involve key agents since the early beginning
- Instability in the political agenda



- Exchange of personal data
- Clearly demonstrate the advantage of such network for the patients

The following table summarizes the main NoEs and the barriers detected following the open consultation with policymakers and key experts:



Main objectives VS main barriers (coming from the open consultation)

Main Objectives of NoEs	Main Barriers Identified
<p>1. Launch and prepare the new Networks of Expertise: Define their missions, objectives, design and selection criteria for participants.</p>	<p>1. Financial support and legal implementation: Lack of long-term financial planning and clarity on legal frameworks.</p>
<p>2. Facilitate cross-border cooperation: Enable expertise sharing across the EU to address challenging cancer conditions.</p>	<p>2. Maintaining interest and engagement of professionals: Difficulty in keeping sustained involvement from healthcare professionals over time.</p>
<p>3. Build a strong operational foundation: Set up calls for expressions of interest and define selection criteria for participants.</p>	<p>3. Involvement of key agents from the start: Delays in securing early involvement of critical stakeholders.</p>
<p>4. Critically evaluate EU networking models: Review existing research infrastructures, comprehensive cancer centers, and aspects to shape NoEs.</p>	<p>4. Instability in the political agenda: Changing priorities in political landscapes affecting continuity and support for NoEs.</p>
<p>5. Promote cutting-edge medical and technological resources: Encourage the use of omics, high-tech medical tools, and personalized care related to some NoEs.</p>	<p>5. Personal data sharing challenges: Legal and privacy concerns around cross-border exchange of patient data.</p>
<p>6. Focus on specific cancer areas: Target complex cancers, survivorship, palliative care, and cancer in adolescents and young adults.</p>	<p>6. Demonstrating patient benefits: Challenges in clearly proving the advantage of NoEs for patients across different Member States.</p>

This table aligns the primary objectives of launching and operating the NoEs with the critical barriers that need to be addressed to ensure their long-term sustainability.



1st JANE POLICY DIALOGUE

Concept note with Agenda for JANE Policy board members

Date and time: 3rd October, 2023 at 11AM (CET)

Setting: the event will be held online. Policy Dialogue Zoom connection link: <https://us02web.zoom.us/j/86334879557?pwd=dG10NmppVEJsdnh2T2ZSL1dDcXpiQT09>

Organizer contact: policyboardjane@kronikgune.org

CONCEPT NOTE

The 1st Policy Dialogue will be held on **October 3** and will be approximately 3 hours long.

The Policy Dialogue will have two thematic modules:

1. How to build potential alliances & synergies in the European ecosystem
2. How to ensure NoEs alignment with European and National policies

During the first part of the meeting the leaders of the WP4 team on Sustainability will present the rationale of this event. In second place, the JANE Coordinator team will present a brief update of the status of the project during its first year of activity. It also will outline the key aspects of the close collaboration between the Policy board representatives and JANE members.

Following this introduction, the event will continue with the two thematic modules, both of them will be opened with a presentation of a key speaker. Then, the dialogue on the specific module will start with the representatives of the policy board on two questions drawn from the conclusions of the informal coffee meetings held from May through July 2023.

In this event, EU-level policy makers will meet and discussed with the Member States involved in the Joint Action JANE, aiming at establishing contact before the implementation of these expertise networks and work together in the search for solutions, ensuring the sustainability of the JA JANE results. To this end, each of the modules will feature a Q&A session with JANE participants.

The first thematic module '**How to build potential alliances & synergies in the European ecosystem**' will be opened by the Coordinator of the European Reference Network on Rare Adult Cancers. This communication will present key aspects to promote the strengthening of collaboration between different organizations (CCCs, ERNs, societies, patient advocacy).

The second thematic module '**How to ensure NoEs alignment with European and National policies**' will be opened by a representative of DG SANTE (HaDEA). EC expected impact from the NoEs and the alignment of this project with European and National policies will be discussed. The knowledge of the expected impact of these networks will help the leaders of the NoEs to shape the work during the duration of the joint action. In the second part of this module, policy board members will be invited to discuss possible solutions to ensure NoEs alignment with European and National policies.

The event will be concluded with a summary of key lessons learnt and an outline of next steps for the sustainability work package.

Outcome: Policy board members will identify solutions about two main pillars with an aim to achieve the sustainability of the future NoEs.



Upon conclusion, Policy board meeting minutes and Policy dialogue results will be prepared and shared with the Policy board members. A follow-up satisfaction survey will be conducted within two weeks after the event. Based on the results, next steps for preparation of Sustainability strategy of NoEs and Policy Recommendations on sustainability will be achieved.

Agenda for the Policy dialogue

Time	October 3 at 11AM (CET)	Participation: Policy Board members, WP1, WP4, DG SANTE/HaDEA and JANE partners
11:00-11:10	Welcome to the JANE 1st Policy Dialogue: Purpose of the Policy Dialogue.	WP4 Leader – KRONIKGUNE
11:10-11:25	Opening session: Update of the status of JANE during its first year of activity.	WP1 – Coordination team – INT (Paolo Casali)
How to build potential alliances & synergies in the European ecosystem		
11:25-11:40	<p>Key aspects related to the strengthening of collaboration mechanisms in Europe – How could networking between different organizations (CCCs, ERNs, societies, patient advocacy) be promoted?:</p> <p>The key aspects related to the strengthening of collaboration mechanisms in Europe will be summarized.</p>	ERN EURACAN Coordinator (Jean-Yves Blay)
11:40-12:30	<p>Policy dialogue among Policy board members: In this thematic module, policy board members will be invited to discuss possible solutions to improve alliances and synergies in the European ecosystem. Two main questions will be addressed:</p> <ul style="list-style-type: none"> • How could networking between different organizations (CCCs, ERNs, ERNs, societies, patient advocacy) be promoted? • How to improve the positioning of clinicians and researchers, communication with stakeholders and policy-makers or the communication mechanisms of the networks? <p>Q&A Session with JANE Participants:</p> <p>I. Which do you think would be the main challenges and opportunities at EU level?</p>	Policy board members Facilitator: KRONIKGUNE
Break		
How to ensure NoEs alignment with European and National policies		
12:40-12:55	<p>EC expected impact from the NoEs: alignment with European and National policies</p> <p>What the EC does expect from the NoEs? Could these networks help in the political decision-making, as well as in ensuring the</p>	DG SANTE (Matthias Schuppe, Deputy Head of Unit in DG SANTE B.1: Cancer, Health in all policies)



	effectiveness of the implementation processes of the initiatives proposed by European and national strategies?	
12:55-13:45	<p>Policy dialogue among Policy board members: In this thematic module, policy board members will be invited to discuss possible solutions to ensure NoEs alignment with European and National policies. Two main questions will be addressed:</p> <ul style="list-style-type: none"> • What kind of resources would be appropriate to promote collaboration and exchange mechanisms between cancer experts, policy-makers and EC representatives? • Do you believe that the current national ecosystem has what it takes, or does it facilitate the existence of these networks? If not, what do you think is missing? <p>Q&A Session with JANE Participants:</p> <p>I. Which do you think would be the main challenges and opportunities at national level?</p>	Policy board members Facilitator: KRONIKGUNE
Conclusion		
13:45-14:00	Conference summary and discussion about WP4 further steps	KRONIKGUNE (Ane Fullaondo)



1st JANE Policy Dialogue

Minutes of the Meeting

Meeting Title:	1 st JANE Policy Dialogue	Meeting Date/Time:	03/10/2023, 11:00-14:00 CET
Meeting Type:	Online Meeting	Meeting Location:	ZOOM platform
Meeting Coordinator:	Institute for Health Systems Research BIOSISTEMAK (Formerly Kronikgune)		

JANE, the Joint Action on Networks of Expertise (NoEs) 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.

Policy Dialogues are deliberative conversations that gather policy makers to discuss a topic of mutual interest. The Policy Dialogues will be the means through which the Policy Board will reach its main objectives:

- Initiating or contributing to legislative change intended to help improve cancer care
- Establishing governance mechanisms for institutional/cross-sectoral collaboration
- Reaching consensus on tangible actions that will address obstacles related to NoEs' sustainability
- Increasing political will and engagement towards new or adapted policies

The Policy Board members will meet once a year in the Policy Dialogues, for two meetings throughout the project.

In the 1st JANE Policy Dialogue, EU-level policy makers met and discussed with the Member States involved in the Joint Action JANE, aiming at establishing contact before the implementation of these expertise networks and work together in the search for solutions, ensuring the sustainability of the JA JANE results.

The results of this first meeting are presented below.

<p>Attendees (PB members, PB coordination team, JANE coordinator, DG SANTE/HaDEA and JANE partners)</p> <p><u>Policy board members:</u> Marie Delnord and Linda Abboud (Belgium), Mario Šekerija (Croatia), Thomas Dubois (France), Vasiliki Karaouli (Greece), József Lövely (Hungary), Giampaolo Latella (Italy), Vilija Kondrotienė (Lithuania), Miriam Dalmás (Malta), Delia Nicoara (Romania), Rocío Fernandez and Alicia Fernández (Spain)</p> <p><u>Policy board secretariat and coordination:</u> Sarah Berrocoso, Yhasmine Hamu, Dolores Verdoy (BIOSISTEMAK)</p> <p><u>JANE coordinators:</u> Paolo Casali, Annalisa Trama and Joanne Fleming (INT)</p> <p><u>DG SANTE:</u> Matthias Schuppe (speaker) and Radostina Getova</p>
--



Observers: Irene Olaussen (Norwegian Directorate of Health), Olga Martinez Julve (Project Officer – DG EAC)
With apologies: (Policy Board members)
Karen Budewig (Germany), Tit Albreht (CraNE JA), Marc Van den Bulcke (Belgium)

Time	October 3 at 11AM (CET)	Participation: Policy Board members, WP1, WP4, DG SANTE/HaDEA and JANE partners
11:00-11:10	Welcome to the JANE 1st Policy Dialogue: Purpose of the Policy Dialogue.	WP4 Leader – BIOSISTEMAK (Dolores Verdoy on behalf of Ane Fullaondo)
11:10-11:25	Opening session: Update of the status of JANE during its first year of activity.	WP1 – Coordination team – INT (Paolo Casali)
How to build potential alliances & synergies in the European ecosystem		
11:25-11:40	Key aspects related to the strengthening of collaboration mechanisms in Europe – How could networking between different organizations (CCCs, ERNs, societies, patient advocacy) be promoted?: The key aspects related to the strengthening of collaboration mechanisms in Europe will be summarized.	ERN EURACAN Coordinator (Jean-Yves Blay)
11:40-12:30	Policy dialogue among Policy board members: In this thematic module, policy board members will be invited to discuss possible solutions to improve alliances and synergies in the European ecosystem. Two main questions will be addressed: <ul style="list-style-type: none"> • How could networking between different organizations (CCCs, ERNs, ERNs, societies, patient advocacy) be promoted? • How to improve the positioning of clinicians and researchers, communication with stakeholders and policy-makers or the communication mechanisms of the networks? Q&A Session with JANE Participants: I. Which do you think would be the main challenges and opportunities at EU level?	Policy board members Facilitator: BIOSISTEMAK
Break		
How to ensure NoEs alignment with European and National policies		
12:40-12:55	EC expected impact from the NoEs: alignment with European and National policies What the EC does expect from the NoEs? Could these networks help in the political decision-making, as well as in ensuring the effectiveness of the implementation processes of the initiatives proposed by European and national strategies?	DG SANTE (Matthias Schuppe, Deputy Head of Unit in DG SANTE B.1: Cancer, Health in all policies)



12:55-13:45	<p>Policy dialogue among Policy board members: In this thematic module, policy board members will be invited to discuss possible solutions to ensure NoEs alignment with European and National policies. Two main questions will be addressed:</p> <ul style="list-style-type: none"> • What kind of resources would be appropriate to promote collaboration and exchange mechanisms between cancer experts, policy-makers and EC representatives? • Do you believe that the current national ecosystem has what it takes, or does it facilitate the existence of these networks? If not, what do you think is missing? <p>Q&A Session with JANE Participants:</p> <p>I. Which do you think would be the main challenges and opportunities at national level?</p>	<p>Policy board members Facilitator: BIOSISTEMAK</p>
Conclusion		
13:45-14:00	Conference summary and discussion about WP4 further steps	BIOSISTEMAK (Ane Fullaondo)

Meeting Summary

Main aims of the meeting were to present an update of the project status during its first year of activity and to establish opportunities to strengthen close collaborations between Policy board representatives and JANE members. The event was focused in two topics of discussion: (1) How to build potential alliances & synergies in the European ecosystem; and (2) How to ensure NoEs alignment with European and National policies.

The meeting started with the **introductory presentation** from BIOSISTEMAK, leaders of the WP4 team on Sustainability, and INT, Coordinators of JANE, welcoming the participants and presenting the rationale of the event and the status of JANE. Paolo Casali presented the project's goals and objectives, highlighting the need for collaboration and to convert overlaps into synergies among the networks given the complexity of the European cancer ecosystem.

After this introduction, **the two thematic modules were presented following a common structure.** Both of them were introduced by the presentation of a key speaker, then, the dialogue on the specific module with the representatives of the Policy Board were based on two questions drawn from the conclusions of the informal coffee meetings held from May through July 2023.

The opening session on the 'How to build potential alliances & synergies in the European ecosystem' module it was a pre-recorded session by the ERN EURACAN Coordinator, Jean-Yves Blay. The presentation was based on key aspects related to the strengthening of collaboration mechanisms in Europe, in the first place, the work model of the ERNs is presented, and in particular EURACAN itself as a reference. In this sense, the governance structure of this network and the activities in which it is involved is presented. Among them stands out the STARTER registry (STarting an Adult Rare Tumour Europe Registry) as an example of initiative that manages to gather forces from different countries under the same objective. Similarly, at the national level, the National Network of Sarcoma in cancer (NETSARC+) was provided as an example.



The intervention ends by adding key aspects to promote networking between different organisations, including the following: (1) connecting to national networks for rare cancers; (2) supporting multinational registries; (3) guiding patients; (4) cross-border health care; (5) dedicated research calls (Mission cancer, BECA...); and (6) Strengthen funding.

Finally, with reference to the ERN model and its Clinical Patient Management System (CPMS), it highlights the need to simplify information in order to function more operationally.

Afterwards, questions to guide the discussion were presented to the Policy Board members: (1) How could networking between different organizations (CCCs, ERNs, ERNs, societies, patient advocacy) be promoted?; (2) How to improve the positioning of clinicians and researchers, communication with stakeholders and policy-makers or the communication mechanisms of the networks?

Statements of the panellist experts:

Mario Šekerija (CIPH, Croatia): It is important to create a follow up and also to take advantage and create alliances with CraNE Joint Action. Be part of these network is especially useful for small countries, and have the opportunity to learn thanks to the collaboration with experts and medical professionals.

Vasiliki Karaouli (Ministry of Health, Greece): Sometimes is difficult to find an expert or Coordinator in a country to promote new initiatives. In that sense, the future networks of expertise could promote the establishment of a reference centre on cancer in Greece. This would make the things and coordination of activities easier.

József Lövely (OOI, Hungary): We count with different kind of organizations, networks and Joint Action in the European ecosystem, the implementation of the NoEs will contribute to further improve the synergies and actually to build it out. That would especially be important in those areas that are not in the mainstream in the cancer field, but will support the better understanding of the oncology care, such as High Tech area.

Miriam Dalmás (Ministry of Health, Malta): JANE 2 will help in the process of how implement recommendations and challenges in different Member States. This would be especially useful for small countries.

Rocío Fernandez and Alicia Fernández (Ministry of Health, Spain): A good measure to promote the collaboration between networks would be establishing the governance of JANE because identifying clearly the coordinators of all the actions would help to collaborate. Strengthening the communication could help to coordinate and identify the future coordinators.

Delia Nicoara and Nina Nicoara (IOCN, Romania): When it comes to the collaboration, one suggestion is to have a platform where all the Member States could share their challenges, their legislations, their success stories, their strategies. That would help not reinventing the wheel and do not duplicate the efforts. But at the same time to learn from each other because maybe there are some best practices in one of the country that could be applied to another country and take advantage of this. Furthermore, the governance structure could facilitate to impose these kind of actions that influence all the Members States and all the organizations from all the countries.



Vilija Kondrotienė (Ministry of Health, Lithuania): Promoting research and exchange opportunities and facilitating bureaucracy aspects such as the exchange of personal data.

Marie Delnord and Linda Abboud on behalf of Marc Van Den Bulcke (Sciensano, Belgium): To establish cancer research centres or HUBs with key agents of different fields. In Belgium there is a national stakeholder platform whose objective is to coordinate European funding opportunities and the needs at the national level, analysing gaps and strengthening the opportunities in European cancer calls. Furthermore, in research it is important to highlight the impact on the Health Systems. One HUB developed in Belgium, has benefited from a good mapping process, establishing the stakeholder matrix, making it easy to know who does what, which is conducive to reaching out to different organisations. They have also benefited from the existence of thematic working groups (e.g: survivorship, transversal issues such as quality of life) that are chaired by cancer experts and in which experts and different care centres can register. Keeping the network informed, through newsletters and project updates, helps to generate opportunities for the HUB to function. The first steps to promote this HUB has included the diffusion of this opportunity to the research and care centres contacts.

Thomas Dubois (INCA, France): At the national level, they have different activities of networking, in both in research and clinical aspects. One of the latest was the creation of national networks on cancer for poor prognosis (pretty aligned with JANE's work). There could be two main challenges for the JANE project, in first place the different level of participation, having comprehensive cancer centres, experts and clinicians on different national networks. The added value of JANE could be to link these different profiles and organizations. The second challenge is comprehensiveness, how we can manage to address challenges on both clinical care organizations and research aspects. It could be very valuable to start thinking in objectives for the future in an operational way. Develop this kind of approaches and working with other joint actions, in some point, all those projects should connect and coordinate between them.

The final remarks about this question, includes the insights of Alicia Fernández suggesting that a call for good practice could be a good way to demonstrate the work being done in the field, generate expectations and be helpful in connecting experts. On the other hand, the Coordination team remarks that the NoEs are now working trying to define opportunities to explain to future experts their networks. In last place, Miriam Dalmas from Malta, perhaps having greater visibility at congresses, events and journals of different specialties could be attractive and generate opportunities.

The opening session on 'How to ensure NoEs alignment with European and National policies' was held by Matthias Schuppe, Deputy Head of Unit in DG SANTE.B.1: Cancer, Health in all policies. The presentation was based on the EC expected impact from the NoEs: alignment with European and National policies. On the previous topic of networking, note that at the level of the European Commission and DG-Sante Y HaDEA have started discussions with projects that are working in this area, to first have conversations between the coordinators of these projects and also to align them. A mapping exercise has been done, analysing deliverables and outcomes and how they could feed each others, including their predecessors, in the case of JANE, JANE 2. Both Crane and JANE have seen that there are transversal tasks between the projects and even between the work packages and their coordinated work could enrich their results. Once again brings to light the issue of the platform that has been brought out by some of the policy board representatives. And he invites that if anyone has any ideas about this, they will be happy to work on it.



On the subject of this module, and first of all, what is expected of the NoEs, at least in rare cancers we have a reference model on which we can build, the ERNs. Analyse the lessons learnt as well as the challenges they have had, as well as their own work, exchanging good practices.

In discussions with the Member States, it is considered to be an initial step (in these 7 areas there are people who ask for new ones, in order to achieve that, we will need a model or protocol of inspiration in how to proceed for the creation of new networks. Working on framework areas and criteria of who should be involved. It will be in the JA where a proposal of advantages and disadvantages is made.

As for expectations, and how to link with other networks, the work that is already being done in some JANE meetings with presentations from ERNs are beneficial and what is expected. It would also be the question of how to link it with the new CCCs, and for this, we will benefit from the project that is working on it, including also other types of cancer structures.

Regarding the question ‘Could these networks help in the political decision-making, as well as in ensuring the effectiveness of the implementation processes of the initiatives proposed by European and national strategies?’ Matthias highlighted that at this stage HaDEA has a “feedback for policy” section to ensure lessons learnt and project outcomes come to the attention of policymakers to work on them. This is rather a basic level, but in many cases, they arrive when the projects have finished. But in the current landscape of cancer at the project level and politically, they have started this process much earlier, they have regular feedback from the different cancer projects such as JANE and CraNE with feedback to the cancer subgroups, since some of the actors of these workforces are not part of these projects and want to have feedback on their development when the new steps take place.

Regarding the effectiveness of the implementation processes of European and national policies, if there is integration with health systems, and taking into account sustainability at the national level, it could be helpful for the participating entities to be integrated and not only dependent on funding. There has to be a commitment at the national level beyond the existence of funding for business continuity for sustainability.

Spreading the word, informing stakeholders and policymakers in the cancer community, and also to patients. Dissemination in a wider sense could be helpful, including journals or other options. At the national level, we could draw inspiration from the examples of Belgium, the mirror groups of the cancer mission (there are several countries that have these groups), and think about how integration could be facilitated at the national level.

After the intervention of Matthias Schuppe, an open question arises, right now the cancer centers are developing, how could be combined so that the new CCCs can incorporate this expertise that JANE promotes in the centers and can benefit, and that JANE and CraNE can collaborate and enrich each other.

Afterwards, questions to guide the discussion were presented to the Policy Board members: (1) What kind of resources would be appropriate to promote collaboration and exchange mechanisms between cancer experts, policy-makers and EC representatives?; (2) Do you believe that the current national ecosystem has what it takes, or does it facilitate the existence of these networks? If not, what do you think is missing?

**Statements of the panellist experts:**

Delia Nicoara and Nina Nicoara (IOCN, Romania): We have a transversal work package at JANE that works in EU networking perhaps that could be a realistic first mechanism. Another way to promote this communication would be through the platform that has been discussed throughout the policy dialogue.

Rocío Fernandez and Alicia Fernández (Ministry of Health, Spain): In relation to the collaboration, Spain has the collaboration with patient advocacy, scientific societies and policymakers when they have to prepare national strategies or cancer policies. If we have to think at European level, for example EU4Health, they are examples of collaboration mechanisms between organizations, policymakers and experts. If the projects are through these calls, they could help. It is important to simplify the information, prioritizing it could favor the transmission of information to policymakers, so that they do not get lost between all the information.

Vilija Kondrotienė (Ministry of Health, Lithuania): As policymakers is very helpful to have a platform to learn about legal regulation of other countries, legal circumstances and best practices to ensuring the provisional services. The creation of uniform protocols and tools for the sharing of data would help to prepare data systems for exchanging of data. The challenge now is to prepare digital systems for exchanging.

József Lövely (OOI, Hungary): Sometimes the relationships with policymakers are very difficult, it takes a lot of work and meetings to make good influence and not always, what we seek to convey is among the list of priorities. Actually, if there is could be this kind of platform to share practices and to influence the policymakers about useful things could be very enrichful. An example would be palliative care, not always understood to what extent it applies, there is a lot of confusion with this and other terms. This could be a challenge, but collaboration between different countries could be a good influence, a flow of information. It is important to share concise and short messages.

Thomas Dubois (INCA, France): Having national strategic plans can help, with very specific and concrete objectives. Having that common platform, sharing data, this is how you have progress although at the technical and legal level right now there are problems, making such comparisons is what helps to make progress.

Mario Šekerija (CIPH, Croatia): It would be useful to reuse resources at the national level, for example, the good practice portal that is already available. What would be useful would be to have a forum of education in how to communicate resources and needs to stakeholders or policymakers. It is very important that no efforts be replicated.

In relation to the last question, the following points are highlighted:

Mario Šekerija (CIPH, Croatia): It could be very helpful to have a common platform to seek this information or focal points in particular countries. The fact that JANE's is covering different areas, have that people who do not belong to the same scientific/medical communities may be participating, this is an opportunity but also a great job of making more stakeholders aware of this opportunity and how to communicate and engage more people.



Thomas Dubois (INCA, France): If we got a significant number of experts in different areas linked to different NoEs, and most of them able to get involved and implement activities, it would be a way to prove it.

Delia Nicoara and Nina Nicoara (IOCN, Romania): While Romania have a well database of documentation and position papers, culture of collaboration is needed.

Rocío Fernandez and Alicia Fernández (Ministry of Health, Spain): Spain has a decentralized system; they always need to find the consensus between the different communities. In the end, they are used to work in a collaborative way.

The WP4 Sustainability team closed the First JANE Policy Board meeting.



Contact

For any questions or queries, please contact with JANE's Policy Board Secretariat:

Sarah Berrocoso, PhD, Institute for Health Systems Research Biosistemak, leader of JANE work package on sustainability

sberrocoso@kronikgune.org

Yhasmine Hamu, Institute for Health Systems Research Biosistemak, leader of JANE work package on sustainability

yhamu@kronikgune.org



2nd JANE POLICY DIALOGUE

Concept note with Agenda for JANE Policy board members

Date and time: 27th June 2024 at 9AM (CEST)

Setting: the event will be hold online. Policy Dialogue Zoom connection link: <https://us02web.zoom.us/j/81545904835?pwd=8nMBGtVEdba72s8zwcw8gQvKdqubFAu.1>

Organizer contact: policyboardjane@kronikgune.org

CONCEPT NOTE

The 2nd Policy Dialogue will be held on **June 27** and will be approximately 3 hours long.

During the first part of the event the leaders of the WP4 Sustainability team will explain the motivation for this second Policy Dialogue that will be focused on **legal and funding dimensions**. Following this, the Coordination team will provide an update on the status of the JANE Joint Action (JA) and the rationale for the follow-up JA JANE 2, which is expected to start in the last quarter of 2024.

After the introduction, the second part of the event will bring together EU policy makers and Member States participating in the JA JANE to maintain contacts before the implementation of these networks of expertise (NoEs) and to work together to find solutions and ensure the sustainability of the JANE results.

To this end, the **dialogue with the representatives of the policy board** will be raised through **specific questions about the two thematic modules on funding and legal dimensions**. Furthermore, each module will also include a question-and-answer session with JANE participants.

The forthcoming JANE 2 will allow for the launch of the seven NoEs in the field of cancer, enabling them to start fulfilling their mission. That's why it would be important to promote these bilateral discussions with the different Member States to ensure that the impact of these future networks is also transferred to the national and regional contexts.

The thematic module on legal dimension will be opened by the Coordinator of TEHDAS2 introducing the issue of interoperability in the healthcare networking. The participation in networks favours the generation of research opportunities, in fact, the NoEs could be considered as research boosters. As such efforts often rely on the need to share data across borders, NoEs will need to follow-up and be regularly updated and aligned with the efforts on the European Health Data Space (EHDS), which will be a key pillar. Policy board members will also be invited to discuss around this topic and to share how their country is dealing with these changes.

The thematic module on funding will open the dialogue on the costs of healthcare networking. Policy Board members will be invited to share their thoughts on how to financially support the promotion of synergies and collaboration between different networks and other types of organisations in the cancer ecosystem, as well as external and internal funding mechanisms to support long-term surveillance of the NoEs.



After the dialogue with the Policy Board members, representatives of the European Observatory on Health Systems and Policies will present an experiential session. The European Observatory on Health Systems and Policies runs a much smaller and less complex set of networks that JANE will but its experience does suggest some ideas on how to engage and sustain interest. The session will give the briefest outlines of ‘things that have helped’ and be a chance for JANE members and policy partners to reflect on what would help them sustain their role in the JANE networks of expertise.

The event will be concluded with a summary of key lessons learnt, with a special focus on sustainability planning for JANE 2.

Outcome: Policy board members will identify solutions about two main pillars with an aim to achieve the sustainability of the future NoEs.

At the end of the event, minutes of the Policy Board meeting and the outcomes of the Policy Dialogue are prepared and shared with Policy Board members. A follow-up satisfaction survey will be done within two weeks after the event. Based on the results, the next steps for the preparation of the NoEs' sustainability strategy and policy recommendations on sustainability will be achieved.

Agenda for the Policy dialogue

Time	June 27 at 9 AM (CEST)	Participation: Policy Board members, WP1, WP4, TEHDAS Coordinator, OBS and JANE partners
9:00-9:10	Welcome to the JANE 2nd Policy Dialogue: Purpose of the Policy Dialogue.	WP4 Leader – BIOSISTEMAK
9:10-9:30	Opening session: Update at the end of JANE1 and follow-up of JANE 2.	WP1 – Coordination team – INT (Paolo Casali)
Legal		
9:30-9:50	Interoperability: work towards JANE 2	Coordinator in the EU's Joint Action Towards the European Health Data Space -TEHDAS- (Markus Kalliola)
9:50-10:30	<p>Policy dialogue among Policy board members: In this thematic module, policy board members will be invited to discuss about:</p> <ul style="list-style-type: none"> How your countries are dealing around the common standards promoted by the EDHS? <p>Q&A Session with JANE Participants.</p>	Policy board members Facilitator: BIOSISTEMAK
Break		
Funding		



10:40-11:20	<p>Policy dialogue among Policy board members: In this thematic module, policy board members will be invited to discuss about:</p> <ul style="list-style-type: none"> • How can funding instruments promote synergies and collaboration between different networks and organisations in the cancer ecosystem? • How to ensure the survival of NoEs? (Research efforts, portfolio services, membership fees...) <p><i>Q&A Session with JANE Participants.</i></p>	<p>Policy board members Facilitator: BIOSISTEMAK</p>
Conclusion		
11:20-11:50	<p>Building sustainable networks: some reflections: The session will give the briefest outlines of ‘things that have helped’ the OBS and be a chance for JANE members and policy partners to sustain their role in the JANE networks of expertise.</p>	<p>European Observatory on Health Systems and Policies – OBS. Observatory Brussels hub and Observatory Technical University of Berlin hub (Suszy Lessof and Yulia Litvinova)</p>
11:50-12:00	<p>Conference summary and discussion about WP4 further steps</p>	<p>BIOSISTEMAK (Dolores Verdoy)</p>



2nd JANE Policy Dialogue

Minutes of the Meeting

Meeting Title:	2 nd JANE Policy Dialogue	Meeting Date/Time:	27/06/2024, 09:00-12:00 CEST
Meeting Type:	Online Meeting	Meeting Location:	ZOOM platform
Meeting Coordinator:	Institute for Health Systems Research BIOSISTEMAK (Formerly Kronikgune)		

JANE, the Joint Action on Networks of Expertise (NoEs) on Cancer, aims 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.

The JANE Policy Dialogues were created to provide a space to discuss with the Policy Board representatives important aspects for the sustainability of the networks of expertise. The first JANE Policy Dialogue was held on October 2023 and dealt with issues related to how to build potential alliances and synergies in the European ecosystem, and how to ensure the NoEs alignment with national and European policies.

JANE's second Policy Dialogue covered two themes of relevance in other European networks, that are related with financing and legal aspects. In particular, the issue of interoperability in healthcare networking and an open dialogue on the costs of healthcare networking.

The results of this first meeting are presented below.

Attendees (PB members, PB coordination team, JANE coordinator, TEHDAS coordinator, European Observatory of Health Systems and Policies and JANE partners)

Policy board members: Mario Šekerija (Croatia), Thomas Dubois (France), Karen Budewig and Verena Kurtz (Germany), Vilija Kondrotienė (Lithuania), Irene Olaussen (Norway), Nuno Sousa (Portugal), Pilar Aparicio (Spain) and András Masszi (Hungary).

Policy board secretariat and coordination: Sarah Berrocoso, Yhasmine Hamu, Dolores Verdoy (BIOSISTEMAK)

JANE coordinators: Paolo Casali, Annalisa Trama and Joanne Fleming (INT)

Key speakers: Markus Kalliola (TEHDAS), Suszy Lessof and Yulia Litvinova (OBS)

*Detailed list of the 63 participants (including JANE partners) that provided their personal data is available as a separate document: [JANE Second Policy Board meeting participants' list](#) (excel sheet)

With apologies: (Policy Board members)

Vasiliki Karaouli (Greece), András Masszi (Hungary), Miriam Dalmás (Malta) and Delia Nicoara (Romania).



Time	June 27 at 9AM (CEST)	Participation: Policy Board members, WP1, WP4, TEHDAS Coordinator, OBS and JANE partners
9:00-9:10	Welcome to the JANE 2nd Policy Dialogue: Purpose of the Policy Dialogue.	WP4 Leader – BIOSISTEMAK (Dolores Verdoy on behalf of Ane Fullaondo)
9:10-9:30	Opening session: Update at the end of JANE1 and follow-up of JANE 2.	WP1 – Coordination team – INT (Paolo Casali)
Legal		
9:30-9:50	Interoperability: work towards JANE 2	Coordinator in the EU's Joint Action Towards the European Health Data Space -TEHDAS- (Markus Kalliola)
9:50-10:30	Policy dialogue among Policy board members. In this thematic module, policy board members will be invited to discuss about: <ul style="list-style-type: none"> How your countries are dealing around the common standards promoted by the EDHS? Q&A Session with JANE Participants.	Policy board members Facilitator: BIOSISTEMAK (Dolores Verdoy)
Break		
Funding		
10:40-11:20	Policy dialogue among Policy board members. In this thematic module, policy board members will be invited to discuss about: <ul style="list-style-type: none"> How can funding instruments promote synergies and collaboration between different networks and organisations in the cancer ecosystem? How to ensure the survival of NoEs? (Research efforts, portfolio services, membership fees...) Q&A Session with JANE Participants.	Policy board members Facilitator: BIOSISTEMAK (Sarah Berrocoso)
Conclusion		
11:20-11:50	Building sustainable networks: some reflections: The session will give the briefest outlines of 'things that have helped' the OBS and be a chance for JANE members and policy partners to sustain their role in the JANE networks of expertise.	European Observatory on Health Systems and Policies – OBS. Observatory Brussels hub and Observatory Technical University of Berlin hub (Suszy Lessof and Yulia Litvinova)
11:50-12:00	Conference summary and discussion about WP4 further steps	BIOSISTEMAK (Dolores Verdoy)



Meeting Summary

Main aims of the meeting were to discuss the implementation of the European Health Data Space (EHDS) across Member States (MSs) and to explore strategies for ensuring the sustainability of the Networks of Expertise (NoEs) beyond the initial funding period. The last part of the meeting moderated by the European Observatory on Health Systems and Policies (OBS), aimed to open the discussion on aspects that could make the participation of members and policymakers in NoEs sustainable, based on the experience of the OBS with this type of interactions.

The meeting started with the **introductory presentation** from BIOSISTEMAK, leaders of the WP4 team on Sustainability, and INT, Coordinators of JANE, welcoming the participants and presenting the rationale of the event and the status of JANE. Paolo provided an update on the transition from JANE1 to JANE 2, emphasizing that JANE is grounded in the European Beating Cancer Plan. He highlighted that the aim is to establish seven Networks of Expertise (NoEs) focusing on various cancer-related challenges.

One of his major concerns was how to sustain the Networks of Expertise beyond the initial four-year funding period provided by the Joint Actions. Once the EU funding concludes, it remains unclear how these networks will be financially supported and maintained in the long run. Paolo Casali emphasized that member states need to take a proactive role in ensuring these networks have the necessary resources to continue operating effectively. This includes financial support at the national level, as well as potential contributions from other sources, such as research grants, public-private partnerships, or healthcare organizations. He raised the critical question of what role both the EU and MSs will play in ensuring these networks remain functional after JANE 2. He suggested that there needs to be a clearer governance model, with responsibilities and financial commitments clearly defined.

On other hand, Paolo Casali warned about the risk of redundancy and overlap between different NoEs. For instance, several networks might develop their own clinical guidelines or conduct similar research, potentially leading to inefficiencies and a duplication of efforts. With multiple networks working on various oncology topics, there is a high risk of duplication if each network works independently without coordinating with others. This could lead to wasted resources and confusion among stakeholders about which guidelines or recommendations to follow. He advocated for synergy instead of overlap, where networks can collaborate, share knowledge, and build on each other's work. This would involve developing a system of communication and coordination between networks, ensuring that their work complements rather than competes with one another.

Regarding this last point, legal issues related to cross-border data sharing, particularly in the context of clinical practice guidelines and research, were another key concern. The complexity of the legal frameworks and how they differ across MSs (e.g. varying legal interpretations of the General Data Protection Regulation (GDPR) across EU countries), could create barriers to effective collaboration (e.g. inconsistencies in how patient data is shared and used for research). Paolo Casali called for the development of **clearer legal frameworks** at the EU level that address these challenges. This includes creating uniform regulations for data sharing and clarifying the legal responsibilities when applying EU-level clinical guidelines in national contexts.

Another proposed challenge was the integration of EU and national networks. Paolo Casali highlighted the disconnection between the European networks being established and the national networks already in place. He stressed that for the EU Networks of Expertise to function effectively, they need to be



integrated into national healthcare systems. The sustainability of the EU networks largely depends on how well they can be embedded within national cancer networks and systems. If MSs do not create national networks that align with the European ones, there is a risk that these EU networks will remain isolated and not fully utilized. The **principle of subsidiarity** was raised, this requires strong collaboration between EU and national institutions to ensure that these networks are networks of networks—not standalone entities, but ones deeply connected to the national frameworks and healthcare ecosystems of member states.

The last point was about the complexity of multiple networks working at the same time, Paolo Casali used the metaphor of the Tower of Babel to describe the potential confusion and inefficiency that could arise if too many networks are created without proper coordination and governance. Each network may end up speaking a different "language" in terms of standards, processes, and goals. This lack of coordination could prevent the full potential of these networks from being realized, as efforts are scattered and disconnected. He stressed the need for a **unified governance structure** that ensures these networks are not just silos, but part of a cohesive European system. This would involve clear rules about how networks should collaborate, share resources, and avoid duplicating efforts.

After this introduction, **the first module on the legal dimension was opened by the Coordinator of TEHDAS2, Markus Kalliola**, provided a comprehensive overview of the EHDS framework and its implications for health data interoperability across Europe. Markus Kalliola highlighted the critical role of the EHDS in facilitating cross-border healthcare by standardizing data exchange formats and ensuring that electronic health records (EHRs) are interoperable across member states. He also discussed the challenges related to the legal and technical aspects of data sharing, emphasizing the need for a harmonized approach to overcome the fragmented landscape currently seen across different countries. His presentation set the stage for further discussions on how MSs can align their national systems with EHDS requirements to enhance research, policy-making, and patient care in the European cancer ecosystem. This effort aims to enable efficient data sharing and research, which is critical for the success of cancer networks.

Key points included:

- The need for harmonized data standards across European countries.
- The importance of compliance with EHDS regulations for both primary and secondary use of health data.
- Challenges member states are facing in preparing for the full implementation of EHDS by 2030.

Afterwards, a question to guide the discussion was presented to the Policy Board members: How your countries are dealing around the common standards promoted by the EDHS?

Statements of the panellist experts:

Mario Šekerija (Croatian Institute of Public Health - CIPH, Croatia): Croatia is making progress in preparing for the EHDS, benefiting from having a single public health insurance system, which simplifies data collection. Mario emphasized the importance of timely and accessible data, particularly for modern and precision oncology, and noted the role cancer registries will play in this transformation.

Thomas Dubois (The French National Cancer Institute - INCA, France): France has initiated the implementation of the EHDS with a consortium of 20 national partners led by the *Health Data Hub*.



Although still in its early stages, this consortium is working to coordinate efforts and structure actions related to EHDS standards and procedures.

Verena Kurz (Federal Ministry of Health - BMG, Germany): Germany is actively involved in European projects such as TEHDAS and Quantum, working toward standardization and data interoperability. However, there is no top-down approach from the ministry to implement these standards yet, but they are working towards a common specifications of the data sets in the different 16 state cancer registries. She explained that the body in charge of this standarization work in the Federal Institute for Durges and Medicine. They are also building up the health data access bodies in Germany, while the Ministry is supporting and coordinating this work.

Vilija Kondrotienė (Ministry of Health, Lithuania): Lithuania has recently established a national cancer network consisting of six regional cancer centers. This network is aligned with EU standards and is working to improve data interoperability and collaboration for research, particularly in oncology.

Irene Olaussen (Norwegian Directorate of Health, Norway): As a European Economic Area (EEA) country, Norway has not yet taken an official position on the EHDS until its publication in the EU's Official Journal. However, Norway is actively participating in different EU projects when it comes to EHDS and has already established a national node for health data management, which will be crucial for future EDHS implementation. She raised a strategic quetion about the data architecture, wheter to establish a single node for all data or multiple regional nodes specific to areas like cancer, alongside a national node. This architectural decision is deemed critical for effective data handling. She mentioned a working group under the Public Health Expert Group (PEG) that is currently addressing e-health in the context of cancer, suggesting that coordination with this group would be beneficial.

Nuno Sousa (Directorate-General of Health – DGH, Portugal): Portugal has a well-advanced national system that enables electronic prescriptions and transparent access to medical records across the national healthcare system. Despite some gaps in standardizing clinical data, Portugal is on track to adopt EHDS regulations and align its system with European standards, as each hospital has its own regulatory framework and coding system by the moment.

Pilar Aparicio (Ministry of Health – MoH, Spain): Spain, with its decentralized healthcare system, has made significant progress in interoperability between regions. Spain has a Commission for Digital Health, and the possibility to interchange data for the pharmacy, drugs, medications for the health digital stories. Spain is actively working on EHDS implementation, and also establishing collaboration with other european neighhbor countries such as Portugal.

András Masszi (National Institute of Oncology – NIO, Hungary): NoEs face difficulties of data sharing aggregate data for research purposes, sharing individual data is nearly impossible. With EHDS paving the road for data sharing, NoEs may have better access to research data under its secondary use for their research questions. Countries must comply not only to the GDPR, though, but also to heterogeneous national data protection rules. NoEs may contribute to that legal harmonisation work, too. Data transfer is challenging also for IT infrastructure and capacities (e.g. large files, server capacities and protocols, bandwidth, interoperability). EHDS shall mean a great step for building IT capacity and standardization, with the support of NoEs.



Following this question, Policy Board members were encouraged to discuss **the main challenges their countries face in implementing the EHDS by 2030.**

Mario Šekerija (CIPH, Croatia): Croatia's challenge is ensuring that cancer registries are integrated with the national healthcare system and aligned with EU data standards to facilitate data sharing and interoperability.

Thomas Dubois (INCA, France): The main challenge for France is coordinating the many partners within the consortium and ensuring that all organizations work together effectively to implement EHDS standards across the country.

Verena Kurz (BMG, Germany): One of Germany's key challenges is coordinating its 16 regional cancer registries and aligning them with European data standards without a centralized national strategy.

Vilija Kondrotiene (MoH, Lithuania): Lithuania's main challenge lies in integrating its national cancer network's data infrastructure with EU standards and ensuring seamless collaboration for research and data sharing.

Annalisa Trama (INT, Italy): Annalisa Trama stressed the importance of aligning primary and secondary data use to facilitate data reuse for research. She called for closer collaboration with electronic health record (EHR) vendors to ensure that critical data for cancer research is collected and structured appropriately.

Irene Olaussen (NDH, Norway): there is a strategic challenge in whether to establish a single national data node or several regional nodes specialized by health area, such as cancer. This decision will shape Norway's approach to EHDS implementation and data management. She also discussed that would be important to get some proof of concept to mobilize and motivate the further implementation. So both JANE and CraNE should be aware of the new joint action starting in 2025 on EHD as readiness in concert clinics to make sure that their expertise is part of developing, testing, piloting new digital solutions based on EHDS.

Nuno Sousa (DGH, Portugal): Despite having strong infrastructure, Portugal faces the challenge of harmonizing the coding systems used in medical records and ensuring that European standards are adopted across the country.

Pilar Aparicio (MoH, Spain): Spain's biggest challenge is managing the vast amounts of data generated across different levels of healthcare. Pilar Aparicio also emphasized the need to change how healthcare professionals record and use data, to enhance real-time decision-making and policy evaluation with AI-driven insights.

After a short break, the second part of the session was opened on the aspects of funding. **Questions to guide the discussion about this topic were presented to the Policy Board members:** (1) How can funding instruments promote synergies and collaboration between different networks and organisations in the cancer ecosystem? (2) How to ensure the survival of NoEs? (Research efforts, portfolio services, membership fees...).



Statements of the panellist experts:

Mario Šekerija (CIPH, Croatia): Highlighted the need for better alignment between different cancer registries and national cancer control programs. Funding should focus on integrating existing national initiatives into broader European networks. He emphasized that smaller countries, like Croatia, could particularly benefit from EU funding to foster collaboration with larger countries and tap into expert networks.

Vilija Kondrotiene (MoH, Lithuania): Noted that national funding instruments played a crucial role in promoting synergies and collaborations between different countries and organizations. However, the main challenge was data integration. In Lithuania, several projects were implemented to align the national system with EU data standards. These projects were financed by the funds from the New Generation Lithuania Plan for Economic Revitalization and Resilience, and involved the Ministry of Health, along with partners such as state-registered centers and cancer centers, in developing a platform for the exchange and monitoring of medical data. Despite these efforts, there was a clear need for guidance and support from the European Commission to ensure these initiatives could align effectively with those of other countries.

Karen Budewig (BMG, Germany): Emphasised the importance of cancer plans remaining a priority, with efforts focused on advocating and aligning the Cancer Mission with the EU4Health programme. The main objective could be to identify synergies and ensure that they are aligned in terms of timing and content. This could lead to more synergies for joint actions and other action grants.

Thomas Dubois (INCA, France): Suggested that funding should be directed toward creating more flexible structures to allow for better coordination between national cancer institutions and European networks. He also mentioned the importance of targeting funds for joint projects that bring research and healthcare providers together to bridge gaps between national and European systems. He stated that CraNE and JANE will be in the position to strengthen synergies between initiatives about cancer.

Irene Olaussen (NDH, Norway): Raised a critical point about the relationship between CraNE and JANE. She suggested that if CraNE is responsible for building structures and institutionalizing collaboration within the EU, while JANE provides the experts and expertise, then CraNE and the Comprehensive Cancer Centers (CCCs) should be seen as the driving forces behind the Europe's Beating Cancer Plan. The speaker questioned whether JANE should be more closely integrated with CraNE to leverage its structures and connections with national authorities, which are essential for securing funding and ensuring sustainability. She agreed with the importance of openness but also stressed the need for strategic alignment with policymaking to solidify the involvement of experts in JANE, potentially through institutional bases and nominations by policymakers.

Nuno Sousa (DGH, Portugal): Suggested that funding for a cancer ecosystem will be challenging to secure unless the ecosystem can clearly demonstrate the value it provides to individual member states. Given that healthcare responsibilities lie primarily with member states rather than the EU, any network or ecosystem must show tangible benefits to these states to justify and obtain the necessary funding. The success of procuring and sustaining funding will depend on the ecosystem's ability to deliver specific services that meet the needs of each member state. Without proving this value, it will be difficult to secure the funding required for sustainability.



Pilar Aparicio (MoH, Spain): Emphasized the importance of EU funding to complement national efforts, especially in countries with decentralized healthcare systems like Spain. She pointed out that funding should aim to harmonize the efforts of different regions within countries and across Europe, supporting the interoperability of data and the integration of networks. Such as for example in the case of Joint Actions, where countries learn about best practices of different countries. Additionally, she mentioned the need for funding to support training and capacity-building to strengthen the collaboration between healthcare providers and research institutions.

András Masszi (National Institute of Oncology – NIO, Hungary): emphasized that to secure funding for networks, several strategies can be employed. Consistent funding models can enhance commitment to participation in NoEs, while in-person meetings can further strengthen member engagement, suggesting a mix of regular online meetings and an annual in-person gathering. NoEs can also play a role in defining goals for infrastructural development beyond just research. Implementing a membership fee might increase active participation, and offering group subscriptions to certain databases can also encourage involvement. Additionally, NoEs provide a greater lobbying and representation potential when negotiating with decision-makers for funding. They can help standardize training and accreditation, which may positively influence funding opportunities. Finally, reflecting on the lessons learned during the COVID pandemic regarding the importance of NoEs and remote networking could support funding requests.

Paolo Casali (INT, Italy): emphasized that creating synergies among European networks is crucial for their collaboration and success, particularly within projects like CraNE and JANE. He noted that while professionals can find innovative ways to work together, the real challenge lies in aligning European and national levels to effectively fund and promote these synergies. He highlighted the need for greater involvement from MSs and suggested the establishment of a coordination table between the EU and national levels. Additionally, he stressed the importance of involving patients, as their advocacy can drive coordination. However, Paolo Casali questioned the extent to which MSs are willing to coordinate in healthcare areas that fall outside of EU regulations.

Francesco de Lorenzo (ECPC, Italy): Raised concerns about the uncertainty of support at the European level, particularly for patient initiatives and projects. He questioned whether the EU Commission will continue to provide support and what resources will be made available. Another key issue is how Member States will facilitate new projects and improve collaboration with cancer patients and advocacy groups. While involvement of patients in several networks would be beneficial, there is a lack of productive knowledge on critical aspects like survivorship plans. The speaker pointed out that while some countries have toolkits for collaboration and patients are involved in developing clinical guidelines and patient pathways, this is not consistent across Europe.

Finally, Mario Škerija acknowledged that there is no specific answer to ensuring the survival of Networks of Expertise (NoEs) across different levels (European/national) in the cancer area. They suggested that sustainability might be achieved through various approaches, such as membership fees or providing services. They emphasized the importance of exploring opportunities across the cancer continuum of care and ideally developing an overarching strategy to maintain sustainability at the European level.



After the dialogue with the Policy Board members, Suszy Lessof and Yulia Livinova, representatives of the European Observatory on Health Systems and Policies presented an experiential session. The European Observatory on Health Systems and Policies runs a much smaller and less complex set of networks that JANE will but its experience does suggest some ideas on how to engage and sustain interest. The session gave briefest outlines of ‘things that have helped’ and be a chance for JANE members and policy partners to reflect on what would help them sustain their role in the JANE networks of expertise.

Suszy Lessof introduced the Health Systems and Policy Monitor, a key formal network that assists in evaluating country performance for the European Commission. The Monitor produces various outputs, including health system reviews and country profiles, which are vital for understanding national health contexts. The emphasis on informal collaboration within these networks was reiterated, suggesting that while the Observatory’s approach may seem simpler compared to other initiatives, it is still deeply rooted in meaningful partnerships and shared objectives.

Key themes emerged regarding network sustainability. A strong sense of belonging and identity among members was identified as essential for maintaining engagement. The size of the network can significantly influence its effectiveness; smaller networks often foster closer connections, while larger ones may struggle with coherence. The importance of regular updates and communication was highlighted, as these practices help members stay motivated and engaged, further reinforcing the network's identity and purpose.

A summary of these aspects can be found below:

- **Saliency:** Network members share common interests and align with the network’s objectives. Being part of the network fits with their day-to-day responsibilities.
- **Identity:** Members feel recognized for their participation, and their contributions are valued. They publish on matters important to them, reinforcing their identity within the network.
- **Recognition:** Adequate recognition of members and their contributions is provided. Consistency in participation is evident, and there is an effective integration of new members.
- **Motivation:** Members are motivated by the smooth integration of new participants and the non-exclusive nature of the network. It avoids feeling like a "closed group" and supports ongoing participation.
- **Curation:** The network maintains ongoing contact among members, organizes annual meetings, and provides opportunities for interaction at conferences, contributing to effective curation of the network.

These elements could ensure that the network remains cohesive, relevant, and motivating, supporting its long-term sustainability. After this presentation, **the participants of the Policy Dialogue were invited to participate in brainstorming sessions, where participants were encouraged to reflect on the insights shared and how they could apply them to their own contexts, particularly regarding cancer policy and network sustainability.**

This session was attended by Policy Board members, JANE partners and other JA stakeholders. Some of the participants who took part in the talks were: Marie Delnord (Sciensano), Mario Škerija (CIPH), Nuno Sousa (DGH), Thomas Dubois (INCA), Paolo Casali (INT), Sonja Tomši (OIL), Chiara Pilotti (FAVO), Katerina Nikitara (ELLOK), Vilija Kondrotiene (MoH) and Pilar Aparicio (MoH).



Below are some of the highlights of the conversation.

The initial reflections focused on the advantages of participating in networks. In smaller countries, for instance, it was noted that the development of guides often stems from insights gained from larger centers that may not be accessible locally. Additionally, active participation in these networks can enhance opportunities for training. However, it was emphasized that networks like the NoEs should offer mentoring to their members and help raise their visibility within the network. To foster engagement, it's crucial for members to recognize the benefits of their membership, which include access to training and research opportunities.

In the discussion about how NoEs can sustain member interest over time, several key points emerged. Members perceive their involvement in NoEs as valuable, as it grants access to extensive resources, including methodologies, infrastructures, knowledge sharing, and collaborations. Looking ahead, NoEs present opportunities for joint research, clinical trials, and training programs, though engaging experts remains a challenge. Each NoE is unique, requiring tailored approaches, and it's essential for each to have specific aims that resonate with professionals. To maintain solid and sustainable commitment, it's important not to overwhelm members with too many meetings (e.g. regular online meetings + in-person once a year). Conducting brief annual surveys can help identify key areas of interest and ensure the NoE aligns with members' needs.

Additionally, cross-exchange of expertise is considered valuable, as it can enhance the network's benefits. Participation in EU networks can bring significant advantages, especially for small countries, where translating research on cancer presents challenges. Recognizing shared solutions and challenges across countries can be beneficial, allowing members to learn from each other's experiences.

Opportunities for interaction among professionals and patients were noted as an important aspect of engagement. During the conversation about co-design and encouraging patient involvement, participants were directly asked what would motivate them to engage in these processes. A key theme was the importance of patients feeling like they truly belong. The group was also questioned about their previous experiences with such activities or networks and whether they believed they could find time in their lives to contribute. Participants emphasized the need for true inclusivity, noting that while some efforts are made, they often fall short. If patients feel genuinely included, they are more likely to participate. It was acknowledged that patients may not always see themselves as having technical expertise, even though they are experts in their own experiences. Recognizing this perspective could help coordinate their input more effectively and enhance their engagement in these discussions.

Regarding how this approach would work for policymakers, the significant added value of these initiatives was highlighted, particularly in reaching a standard of care and enhancing national cancer sites, expressing commitment to this goal. It was also discussed that even though participation in these networks can be time-consuming, engaging in these networks is important for collaboration, despite the dual challenge of organizing time and effort to participate. It was emphasized that these networks help build Europe by including various stakeholders—professionals, citizens, and different health sectors—promoting mutual understanding and respect for differences.

It was noted that investment in these processes yields valuable results, but maintaining motivation requires effort. It was recognized that participants often expect more work than initially anticipated.



emphasizing the need for clear expectations and understanding of deadlines. Balancing personal life with commitments to these networks is crucial for sustained engagement.

These conversations concluded with an emphasis on the importance of fostering more dialogue among stakeholders, which is essential for advancing the sustainability of NoEs.

The WP4 Sustainability team closed the Second JANE Policy Board meeting.

Contact

For any questions or queries, please contact with JANE's Policy Board Secretariat:

Sarah Berrocoso, PhD, Institute for Health Systems Research Biosistemak, leader of JANE work package on sustainability

Yhasmine Hamu, Institute for Health Systems Research Biosistemak, leader of JANE work package on sustainability

yhamu@kronikgune.org



ANNEX II JANE Stakeholder Forum methodology and results report



TASK 4.3 STAKEHOLDER MATRIX AND STAKEHOLDER FORUM

MAIN CONCEPT AND OPERATING PROCEDURES

Date: 21/03/2023

Doc. Version: 1.0



Co-funded by the
Health Programme of
the European Union



TABLE OF CONTENT

1	Introduction	95
2	Stakeholder Matrix.....	95
2.1	Objectives	95
2.2	Membership	95
2.3	Secretariat.....	96
2.4	Communication.....	96
3	Stakeholder Forum.....	97
3.1	Objectives	97
3.2	Operating procedures	97



1. INTRODUCTION

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

Work Package 4 works for ensuring a long-term sustainable model for the NoEs. To this means a Stakeholder Matrix will be conformed and Stakeholder Forums will be organized to raise awareness of the work in JANE and foster networking between all relevant agents.

This document contains the description of the main concept and operating procedures of the Stakeholder Matrix and Stakeholder Forum.

2. STAKEHOLDER MATRIX

2.1 Objectives

The Stakeholder Matrix of JANE is an external board composed by key agents with interest or concern in the establishment of the NoEs, who are both impacted by it and can have impact on the JA themselves.

The role of the Stakeholder Matrix will be:

- to give input to support that the established NoEs assemble the best knowledge, skills and facilities available in Europe, and
- to build synergies and partnerships that support JANE and the current and future needs of the NoEs, thus, contributing to guarantee their sustainability.

2.2 Membership

Key external partners who bring value to the Joint Action and with whom collaboration can enable NoEs sustainability will be identified.

The Stakeholder Matrix members will be identified by means of a three step iterative process, as feedback provided by JANE partners may adapt the conclusions of each step at any moment of the process. In the first step, relevant non-exclusive sectors/categories will be identified. Secondly, determinant organizations of those sectors/categories will be listed. Finally, specific individuals will be addressed as proposed members for the Stakeholder Matrix of JANE.

In the first phase, the relevant non-exclusive sectors/categories identified include:



- Public sector
- Private sector
- Civil society: e.g.: patient organizations and health professionals associations
- Health care industry/developers: e.g.: pharmaceutical industry, medical products and technology suppliers
- Research and academia

JANE partners are encouraged to give their input along the whole identification process, starting from the identification of key sectors/categories.

First Stakeholder Matrix membership list will be available since month 7 (April 2023), and is kept open, since partners may identify important stakeholders to be invited during development of the project.

The final list of members will be confirmed with all JANE WP4 partners and Coordinators.

2.3 Secretariat

As proposed in the Grant Agreement of the Joint Action JANE, the Stakeholder Forum is led by Kronikgune, who also provides the secretariat and elaborates a proposal for the main aim and operating procedures.

The contact persons are:

- Yhasmine Hamu, Institute for Health Services Research Kronikgune, leader of JANE work package on sustainability
Email: yhamu@kronikgune.org
- Sarah Berrocoso, PhD, Institute for Health Services Research Kronikgune, leader of JANE work package on sustainability
Email: sberrocoso@kronikgune.org

2.4 Communication

Secretariat will communicate to the Stakeholder Matrix' members timely in relation to the proposed activities. The Stakeholder Matrix' members, in turn, are encouraged to communicate with the Secretariat and to ask for clarification whenever necessary. Regular contacts are performed via e-mail.



Stakeholder Matrix' members will be initially contacted to confirm their participation in the Stakeholder Matrix of JANE. Bilateral meetings may be organised optionally by telephone, videoconference or other means of communication, if required.

Secretariat will distribute relevant documents to the Stakeholder Matrix' members and they will provide comments when necessary at the agreed timeline. The results, recommendations and/or decisions that will arise from the Stakeholder Forums and other work will be presented to members of the Stakeholder Matrix for their final approval.

3. STAKEHOLDER FORUM

The Stakeholder Forum is a space for discussion that facilitates the exchange of expertise, experience and opinions and the networking of the Stakeholder Matrix' members and the organizations participating in JANE.

3.1 Objectives

The main aim of the JANE stakeholder Forum will be to create a common understanding and build synergies and partnerships that support JANE and the actual and future needs of the NoEs.

The Stakeholder Forum will be deliberative conversations that gather relevant stakeholders from across disciplines to discuss a topic of mutual interest.

3.2 Operating procedures

A Stakeholder Forum will be organized led by Kronikgune Institute. The meeting will be conveyed in a hybrid format (face-to-face and virtual). The meeting is organised, moderated and supported by the Secretariat. The main tasks related to the planning and organization of the Stakeholder Forum will be: providing a location and catering; inviting participants; defining the agenda and contents together with the JANE coordinating team; supporting the knowledge transfer and exchange during the event.

Before the Stakeholder Forum

Save-the-date for the meeting will be sent out to the invitee at the earliest convenience when defined.

The Secretariat will draft the agenda in alignment with the Coordinator IRCCS INT, DG SANTE and HADEA and distribute it together with relevant documents at least one month before each Stakeholder Forum.



Members of the Stakeholder Matrix can provide feedback with suggestions for changes to the agenda up to three weeks before the Stakeholder Forum, that will be appropriately considered as deemed necessary by the Secretariat.

After the Stakeholder Forum

Minutes of the Stakeholder Forum will be produced by the Secretariat summarising the main conclusions extracted from the session and shared with attendees no later than three weeks after the meeting.

Stakeholder Matrix' members will be given two weeks after the reception of the minutes to provide feedback with suggestions for changes, that will be appropriately considered by the Secretariat.



JANE Stakeholder Matrix

The JANE Stakeholder Matrix brought together key actors in the cancer ecosystem including civil society, academia, the private sector and other relevant stakeholders.

Throughout the development of JANE, the board included 88 members from 54 organizations. Eleven of this organizations took part in the JANE Stakeholder Forum which took place in 2023, aimed to present the status and achievements of JANE, share key concerns of NoEs leaders to build strong alliances, explore stakeholders' needs and expectations for NoEs, and discuss how civil society, academia, the private sector and other key stakeholders can contribute to addressing challenges in the cancer care ecosystem. See Table 1 for more information.

**Table 1.** List of JANE Stakeholder Matrix members

Country	Name	Surname	Affiliation
Czechia	Tomas	Buchler	Charles University and University Hospital Motol
Czechia	Marek	Svoboda	Masaryk Memorial Cancer Institute (MMCI)
France	Guilles	Vassal	SIOPE
Germany	-	-	Berufsverband der Niedergelassenen Ärztinnen und Ärzte für Hämatologie und Medizinische Onkologie in Deutschland e.V. - Professional Association of Registered Physicians for Hematology and Medical Oncology in Germany e.V.
Germany	Verena	Blum	Ministerium für Arbeit, Gesundheit und Soziales des Landes Nordrhein-Westfalen - Ministry of Labor, Health and Social Affairs of the State of North Rhine-Westphalia
Germany	Verena	Blum	Ministerium für Arbeit, Gesundheit und Soziales des Landes Nordrhein-Westfalen
Germany	Carsten	Bokemeyer	Deutsche Gesellschaft Für Hamatologie Medizinische Onkologie (DGHO)
Germany	H.	Brenner	Nationales Centrum für Tumorerkrankungen Heidelberg
Germany	Beate	Brenner	Technische Universität Dresden
Germany	-	-	Bundesärztekammer - Federal Medical Association
Germany	Bernd	Crusius	Haus der Krebs-Selbsthilfe – Bundesverband e.V. - House of Cancer support group federal association
Germany	-	-	Deutsche Krankenhausgesellschaft - German Hospital Association
Germany	Stefan	Froling	Nationales Centrum für Tumorerkrankungen Heidelberg
Germany	Gemeinsamer Bundesausschuss - The Federal Joint Committee	Gemeinsamer Bundesausschuss - The Federal Joint Committee	Gemeinsamer Bundesausschuss - The Federal Joint Committee



Country	Name	Surname	Affiliation
Germany	Gesetzliche Krankenversicherung Spitzenverband - National Association of Statutory Health Insurance Funds	Gesetzliche Krankenversicherung Spitzenverband - National Association of Statutory Health Insurance Funds	Gesetzliche Krankenversicherung Spitzenverband - National Association of Statutory Health Insurance Funds
Germany	Ellen	Grieshammer	Deutsche Krebsgesellschaft - German Cancer Society
Germany	-	-	Kassenärztliche Bundesvereinigung - National Association of Statutory Health Insurance Physicians
Germany	Markus	Kessel	Frauenselbsthilfe Krebs - Women's cancer support group
Germany	Franz	Kohlhuber	Stiftung Deutsche Krebshilfe - German Cancer Aid Foundation
Germany	Simone	Kungl	Universitätsmedizin Mannheim -Medizinische Fakultät Mannheim
Germany	S.	Loges	Deutsches Krebsforschungszentrum - German Cancer Research Center
Germany	Giorgia	Manuzi	SIOPE
Germany	Claudia	Mayer	Deutsches Krebsforschungszentrum - German Cancer Research Center
Germany	Gerd	Nettekoven	Stiftung Deutsche Krebshilfe - German Cancer Aid Foundation
Germany	Michael	Oldenburg	Deutsche Gesellschaft für Hämatologie und Medizinische Onkologie - German Society for Hematology and Medical Oncology
Germany	Peggy	Richterr	Technische Universität Dresden - Dresden University of Technology
Germany	Hannes	Schlieter	Technische Universität Dresden - Dresden University of Technology



Country	Name	Surname	Affiliation
Germany	TIEDE		Stiftung Deutsche Krebshilfe - German Cancer Aid Foundation
Germany	Simone	Wesselman	Deutsche Krebsgesellschaft - German Cancer Society
Greece	Aristotelis	Bamias	ΙΑΤΡΙΚΗ ΣΧΟΛΗ ΤΟΥ ΕΘΝΙΚΟΥ ΚΑΙ ΚΑΠΟΔΙΣΤΡΙΑΚΟΥ ΠΑΝΕΠΙΣΤΗΜΙΟΥ ΑΘΗΝΩΝ
Greece	Aristotelis	Bamias	ΙΑΤΡΙΚΗ ΣΧΟΛΗ ΤΟΥ ΕΘΝΙΚΟΥ ΚΑΙ ΚΑΠΟΔΙΣΤΡΙΑΚΟΥ ΠΑΝΕΠΙΣΤΗΜΙΟΥ ΑΘΗΝΩΝ
Greece	Martina	Fenech	Puttinu Cares
Greece	Konstantina	Kakogianni	ΙΑΤΡΙΚΗ ΣΧΟΛΗ ΤΟΥ ΕΘΝΙΚΟΥ ΚΑΙ ΚΑΠΟΔΙΣΤΡΙΑΚΟΥ ΠΑΝΕΠΙΣΤΗΜΙΟΥ ΑΘΗΝΩΝ
Greece	Karl Vella Foundation	Karl Vella Foundation	Karl Vella Foundation
Greece	Roubini	Zakopoulou	-
Italy	Luca	Battistelli	IRCCS Istituto Romagnolo per lo Studio dei Tumori "Dino Amadori" - IRST SRL
Italy	Paolo	De Paoli	Alleanza Contro il Cancro
Italy	Riccardo	Haupt	Istituto Giannina Gaslini
Italy	Silva	Mitro	Istituto Oncologico Veneto
Italy	Ester	Orlandi	Fondazione Centro Nazionale di Adroterapia Oncologica
Italy	Maria Carmela	Piccirillo	Istituto Nazionale Tumori Fondazione Pascale
Lithuania	Audrius	Dulskas	NACIONALINIS VEZIO INSTITUTAS (NCILT)
Malta	Reginald	Aquilina	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Guillermo Luis	Chantada	SIOP
Malta	Lara-Suzanne	Farrugia	Hospice Malta
Malta	Nathalie	Galea	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Alexander	Gatt	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Godfrey	Grech	L-Università ta' Malta
Malta	Hospice Malta	Hospice Malta	Hospice Malta



Country	Name	Surname	Affiliation
Malta	Danika	Marmara	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Claire	Micallef Pule	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Doreeen	Pace	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Nick	Refalo	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Sascha	Reiff	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Janabel	Said	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Malta	Jeanesse	Scerri	MINISTRY FOR HEALTH – GOVERNMENT OF MALTA
Portugal	Miguel	Abreu	Portuguese Society of Oncology
Portugal	Margarida	Brito	Sociedade Portuguesa de Oncologia
Portugal	Andreia	Capela	Associação de Investigação de Cuidados de Suporte em Oncologia (AICSO)
Portugal	José	Capelo Martinez	NOVA School of Science & Technology - Department of Chemistry
Portugal	Luis	Costa	Centro hospitalario universitário Lisboa, norte
Portugal	Carina	Dantas	SHINE 2Europe
Portugal	João Maria	de Lencastre de Bragança	ACREDITAR - Associação de pais e amigos de crianças con cancro
Portugal	Jose	Machado	i3S - Instituto de Investigação e Inovação em Saúde da Universidade do Porto
Portugal	Joana	Marinho	Associação de Investigação de Cuidados de Suporte em Oncologia (AICSO)
Portugal	Cristina	Potier	Fundação Rui Osório de Castro
Portugal	Gabriela	Sousa	Ministerio Da Saude
Portugal	Rui	Sousa Silva	Administração central do sistema de saúde, IP
Portugal	Alexandra	Teixera	Sociedade Portuguesa de Oncologia
Portugal	Elena	Torou	SIOPE
Portugal	Brina	Zagar	Slovensko Zdruzenje Bolnikov Z Limfomom in Levkemijo
Spain	Lucia	Aboud	Asociación Española Contra el Cáncer (AECC)



Country	Name	Surname	Affiliation
Spain	Pedro	Carrascal Rueda	Plataforma de Organizaciones de Pacientes (POP)
Spain	Svoboda	Castellano	Hospital Universitario 12 de Octubre & member of GenitoUrinary Alliance for R&D GUARD
Spain	Ana	Fernandez Marcos	Asociación Española Contra el Cáncer (AECC)
Spain	Belén	Fernández Sánchez	Asociación Española Contra el Cáncer (AECC)
Spain	José Pablo	Maroto Rey	Hospital Santa i Creu i Sant Pau & member of GenitoUrinary Alliance for R&D GUARD
Spain	Nuria	Masana Nagarro	Asociación Española Contra el Cáncer (AECC)
Spain	Andrés	Morales	Hospital SantJoan de Deu
UK	Andy	Powrie-Smith	European Federation of Pharmaceutical Industries and Associations (efpia)
	Samira	Essiaf	SIOPE
	Giorgia	Manuzi	SIOPE
	Stejsi	Shehi	SIOPE
	Elena	Torou	SIOPE



1st JANE STAKEHOLDER FORUM

Date and time: 16th November 2023 -10:00-13:00 (CET)

Setting: the event will be in a hybrid format, at the [Hotel Abba Garden in Barcelona-Spain](#), and also online.

Stakeholder Forum connection link:

<https://us02web.zoom.us/j/89045223000?pwd=L0ZTaklWNmFxd0FUbzh2OTVVO1ZkZz09>

Organizer contact: sberrocoso@kronikgune.org

CONCEPT NOTE

The EU Joint Action JANE on Networks of Expertise is pleased to invite you to its first Stakeholder Forum. This forum aims to facilitate dialogue and collaboration among key actors in the cancer ecosystem, including Networks of Expertise (NoEs), civil society, academia, the private sector, and other relevant stakeholders. The objective is to aims to foster collaboration, share progress, and explore opportunities to strengthen the impact and sustainability of the JANE Joint Actions and the future NoEs.

The 1st Stakeholder Forum will be held **on November 16** and will be approximately 3 hours long. This event will be focused on the following specific objectives:

1. **Present the current status and achievements of JANE and share the main concerns of the NoEs leaders** to establish solid alliances with different key agents.
2. **Explore Stakeholders' needs and expectations about NoEs** and how they can contribute to addressing current challenges in the cancer ecosystem.
3. **Discuss what NoEs can expect from civil society, academia, the private sector, and other key agents** in terms of support and collaboration.

During the first part of the meeting, the leaders of the WP4 Sustainability team will present the rationale for this event. Secondly, the JANE coordinating team will present a brief update on the status of the project during its first year of activity. Following these two interventions, the leaders of the NoEs on omics and high-tech resources will jointly present the work of their network. Following this, the team of Palliative Care NoE will also present their activities. These two presentations will serve as an example of the models to be developed by future JANE networks in this Joint Action.

Following this first introduction, the event will have three panel discussions, which will explore Stakeholder's expectations about NoEs and how this key agents could contribute with the creation and long-term sustainability of these networks. Furthermore, it will include a bilateral discussion about the patient involvement in the NoEs.

The event will be concluded with a summary and an outline of next steps for the sustainability work package. It should be noted that additional topics could be tailored to suit the needs and goals of the event.

Upon conclusion, Stakeholder Forum meeting minutes and results will be prepared and shared with the JANE stakeholders and members. In addition, a follow-up satisfaction survey will be carried out. Based on the results, next steps for preparation of Sustainability strategy of NoEs and Policy Recommendations on sustainability will be achieved.



Agenda for the Stakeholder Forum

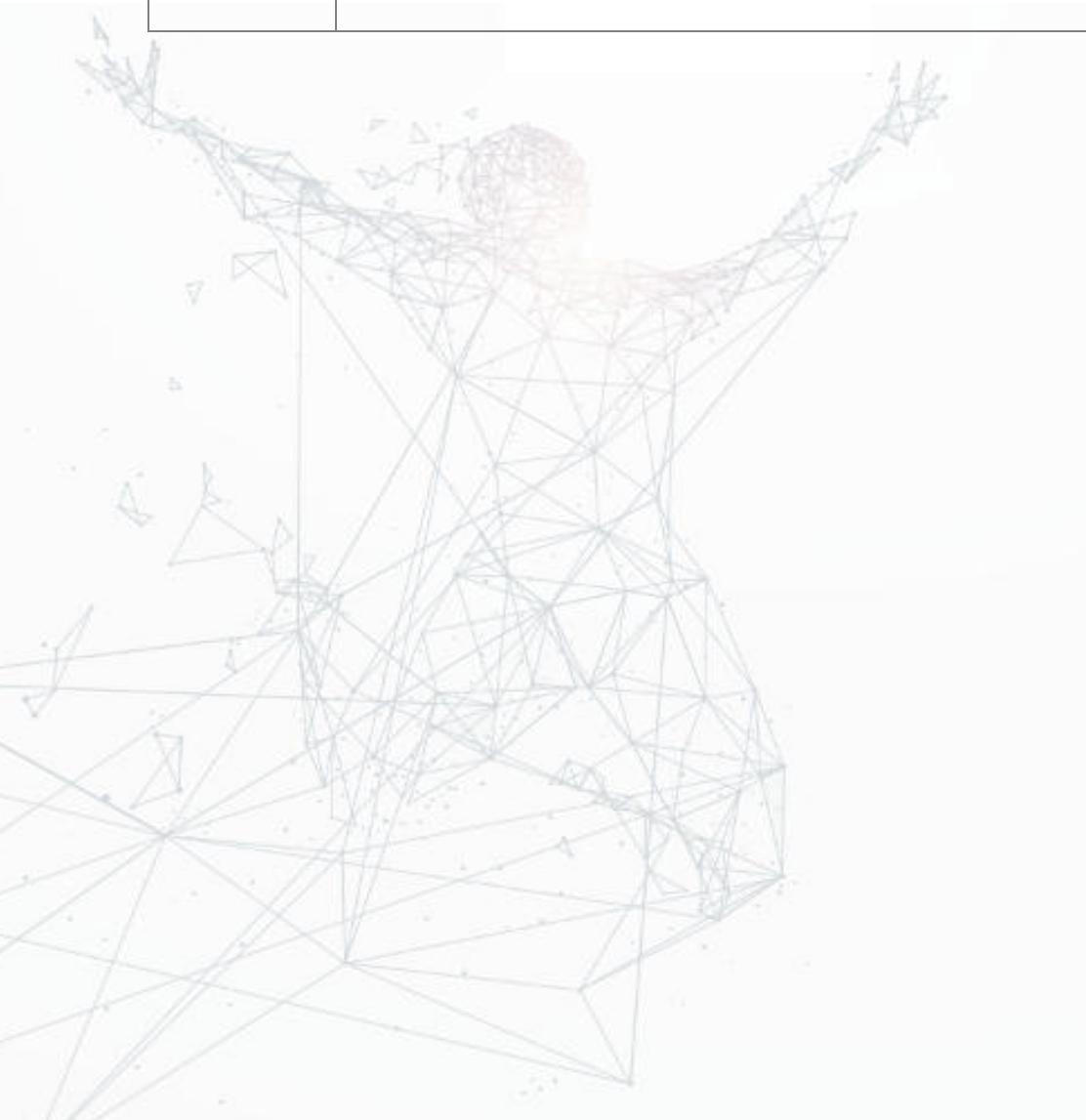
Time	November 16 at 10AM (CET)	Participation: Stakeholders of JANE, WP1, WP4 and JANE partners
Presentation of JANE		
10:00-10:15	Welcome to the JANE 1st Stakeholder Forum: Purpose of the Stakeholder Forum + Sustainability methodology	WP4 Leader – BIOSISTEMAK (Ane Fullaondo & Sarah Berrocoso)
10:15-10:30	Opening session: Update of the status of JANE during its first year of activity.	WP1 – Coordination team – INT (Paolo Casali)
10:30-10:40	Presentation of a NoE on Omics Technologies and Hi-Tech resources: <ul style="list-style-type: none"> • Main aim and needs to fulfil • Organization model • Endorsement criteria • Synergies with other NoEs • Cooperation with other organization in the cancer ecosystem Additional requirements	WP9 & WP10 – (Hélène Antoine-Poirel & Muriel Santoro)
10:40-10:50	Presentation of a NoE on Palliative Care: <ul style="list-style-type: none"> • Main aim and needs to fulfil • Organization model • Endorsement criteria • Synergies with other NoEs • Cooperation with other organization in the cancer ecosystem Additional requirements	WP6 – (Stein Kaasa)
10:50-11:10	Coffee break	All
Panel discussions		
11:10-12:10	Which are your needs and expectations about the NoEs? Main objectives <ul style="list-style-type: none"> • Can you think of any current challenge in the cancer ecosystem that the NoEs could address? • How do you envision the added value of the NoEs compared to the current cancer ecosystem? Endorsement criteria <ul style="list-style-type: none"> • Who do you think should be part of the NoEs? Relationship with cancer ecosystem	Facilitator: BIOSISTEMAK (Sarah Berrocoso & Yasmine Hamu) Stakeholders: <ul style="list-style-type: none"> • AECC (Ana Fernández, Nuria Masana, Belén Fernández & Lucia Aboud) • AICSO (Joana Marinho) • Dresden University of Technology (Peggy Richter)



	<ul style="list-style-type: none"> How do you think the NoEs could interact with other organizations in the cancer ecosystem? (civil society, academia, private sector) 	<ul style="list-style-type: none"> German Cancer Research Centre (Claudia Mayer) German Cancer Society (Ellen Griesshammer) Hospital Santa I Creu i Sant Pau (José Pablo Maroto Rey) Ιατρική σχολή του εθνικού και καποδιστριακού πανεπιστημίου αθηνών (Aristotelis Bamias) Ministry for Health – Government of Malta (Janabel Said & Reginald Aquilina) The European Society for Paediatric Oncology – SIOPE (Samira Essiaf) SHINE 2Europe (Carina Dantas) Slovensko Zdruzenje Bolnikov Z Limfomom in Levkemijo (Brina Zagar) Technische Universität Dresden - Dresden University of Technology (Hannes Schlieter)
12:10-12:30	Conversation about patient involvement in the NoEs	<p>Facilitator: BIOSISTEMAK (Dolores Verdoy)</p> <p>Data for Patients (Kristof Vanfraechem) & JANE Patient involvement leader – (Wannes Van Hoof)</p>
12:30-12:55	<p>How could the civil society, academia, the private sector and other key agents contribute to...</p> <ul style="list-style-type: none"> the creation of the NoEs? the sustainable establishment of the NoEs? 	<p>Facilitator: BIOSISTEMAK (Sarah Berrocoso & Yhasmine Hamu)</p> <p>Stakeholders from Civil society, Academia and the Private sector:</p> <ul style="list-style-type: none"> AECC (Ana Fernández, Nuria Masana, Belén Fernández & Lucia Aboud) AICSO (Joana Marinho) Dresden University of Technology (Peggy Richter) German Cancer Research Centre (Claudia Mayer) German Cancer Society (Ellen Griesshammer) Hospital Santa I Creu i Sant Pau (José Pablo Maroto Rey) Ιατρική σχολή του εθνικού και καποδιστριακού



		<p>πανεπιστημιου αθηνων (Aristotelis Bamias)</p> <ul style="list-style-type: none"> • Ministry for Health – Government of Malta (Janabel Said & Reginald Aquilina) • The European Society for Paediatric Oncology – SIOPE (Samira Essiaf) • SHINE 2Europe (Carina Dantas) • Slovensko Zdruzenje Bolnikov Z Limfomom in Levkemijo (Brina Zagar) • Technische Universität Dresden - Dresden University of Technology (Hannes Schlieter)
Conclusion		
12:55-13:00	Conference summary and discussion about WP4 further steps	WP4 Leader BIOSISTEMAK (Ane Fullaondo)





1st JANE Stakeholder Forum

Minutes of the Meeting

Meeting Title:	1 st JANE Stakeholder Forum (SHF)	Meeting Date/Time:	16/11/2023, 10:00-13:00 CET
Meeting Type:	Hybrid	Meeting Location:	Hotel Abba Garden in Barcelona-Spain
Meeting Coordinator:	Institute for Health Systems Research Biosistemak (Formerly Kronikgune)		

JANE, the Joint Action on Networks of Expertise (NoEs) 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.

The Stakeholder Matrix of JANE is an external board composed of 21 key actors from eight different countries with an interest or concern in the establishment of the NoEs. The stakeholders can have an impact on the future NoEs bringing them an added value, and also they could also benefit from being involved in these networks. The role of the Stakeholder Matrix (representatives) is:

- Initiating or contributing to legislative change intended to help improve cancer care to give input to support that the established NoEs assemble the best knowledge, skills and facilities available in Europe, and
- to build synergies and partnerships that support JANE and the current and future needs of the NoEs, thus, contributing to guarantee their sustainability.

The stakeholders of JANE will meet once a year in the Stakeholder Forum, for two meetings throughout the project.

1st JANE Stakeholder Forum was aimed at improving the dialogue and collaboration among key actors in the cancer ecosystem, including Networks of Expertise (NoEs), civil society, academia, the private sector, and other relevant stakeholders. These links could help to foster collaboration, share progress, and explore opportunities to strengthen the impact and sustainability of the future JANE Joint Action NoEs. A total of 11 stakeholders participated in this event, 66 onsite and 66 in the online format.

The results of this first meeting are presented below.

<p>Attendees (SHF members, SHF secretariat and coordination team, JANE coordinator, DG SANTE and JANE partners)</p> <p><u>JANE Stakeholder matrix members:</u> Lucia Aboud (Asociación Española Contra el Cáncer – AECC, Spain), Reginald Aquilina and Janabel Said (Ministry for Health – Government of Malta, Malta), Samira Essiaf (SIOPE), Carina Dantas (SHINE 2Europe), Joana Marinho (Associação de Investigação de Cuidados de Suporte em Oncologia – AICSO, Portugal), José Pablo Maroto Rey (Hospital Santa i Creu i Sant Pau, Spain), Claudia Mayer (Deutsches Krebsforschungszentrum, Germany), Peggy Ritcher (Technische Universität Dresden, Germany) and Brina Zagar (Slovensko Zdruzenje Bolnikov Z Limfomom in Levkemijo, Slovenia)</p> <p><u>Stakeholder Forum secretariat and coordination:</u> Sarah Berrocso, Yhasmine Hamu, Dolores Verdoy and Ane Fullaondo (Biosistemak)</p>



<p><u>JANE coordinators</u>: Paolo Casali and Joanne Fleming (INT)</p> <p><u>DG SANTE</u>: Radostina Getova</p>
<p>With apologies: (SHF members)</p>
<p>Ana Fernandez Marcos, Nuria Masana Nagarro and Belén Fernández Sánchez (Asociación Española Contra el Cáncer - AECC, Spain)</p>

Time	November 16 at 10AM (CET)	Participation: Stakeholders of JANE, WP1, WP4 and JANE partners
10:00-10:15	Welcome to the JANE 1st Stakeholder Forum: Purpose of the Stakeholder Forum + Sustainability methodology	WP4 Leader – Biosistemak (Ane Fullaondo & Sarah Berrocoso)
10:15-10:30	Opening session: Update of the status of JANE during its first year of activity.	WP1 – Coordination team – INT (Paolo Casali)
10:30-10:40	<p>Presentation of a NoE on Omics Technologies and Hi-Tech resources:</p> <ul style="list-style-type: none"> • Main aim and needs to fulfil • Organization model • Endorsement criteria • Synergies with other NoEs • Cooperation with other organization in the cancer ecosystem <p>Additional requirements</p>	WP9 & WP10 – (Hélène Antoine-Poirel & Muriel Santoro)
10:40-10:50	<p>Presentation of a NoE on Palliative Care:</p> <ul style="list-style-type: none"> • Main aim and needs to fulfil • Organization model • Endorsement criteria • Synergies with other NoEs • Cooperation with other organization in the cancer ecosystem <p>Additional requirements</p>	WP6 – (Stein Kaasa)
Coffee break		
Panel discussions		
11:10-12:10	<p>Which are your needs and expectations about the NoEs?</p> <p>Main objectives</p> <ul style="list-style-type: none"> • Can you think of any current challenge in the cancer ecosystem that the NoEs could address? • How do you envision the added value of the NoEs compared to the current cancer ecosystem? <p>Endorsement criteria</p>	<p>Facilitator: Biosistemak (Sarah Berrocoso)</p> <p>Stakeholders</p>



	<ul style="list-style-type: none"> Who do you think should be part of the NoEs? <p>Relationship with cancer ecosystem</p> <ul style="list-style-type: none"> How do you think the NoEs could interact with other organizations in the cancer ecosystem? (civil society, academia, private sector) 	
12:10-12:30	Conversation about patient involvement in the NoEs	<p>Facilitator: Biosistemak (Dolores Verdoy)</p> <p>Data for Patients (Kristof Vanfraechem) & JANE Patient involvement leader - (Wannes Van Hoof)</p>
12:30-12:55	<p>How could the civil society, academia, the private sector and other key agents contribute to...</p> <ul style="list-style-type: none"> the creation of the NoEs?the sustainable establishment of the NoEs? 	<p>Facilitator: Biosistemak (Yhasmine Hamu)</p> <p>Stakeholders from Civil society, Academia and the Private sector</p>
Conclusion		
12:55-13:00	Conference summary and discussion about WP4 further steps	Biosistemak (Ane Fullaondo)

Meeting Summary

Main aims of the meeting were to update the status of the project after its first year of activity and to establish opportunities to strengthen close collaborations between JANE Stakeholder Matrix representatives and JANE members. Furthermore, the core conceptualisation aspects of three NoEs were presented as an example of the models to be developed by future JANE networks.

The event had three panel discussions, which explored Stakeholder's expectations about the NoEs and how JANE Stakeholders could contribute to the creation and long-term sustainability of the networks. It also included a bilateral discussion with two invited experts about the patient involvement in the NoEs.

The meeting started with the **introductory presentation** from Biosistemak, leaders of the WP4 team on Sustainability, and INT, Coordinators of JANE, welcoming the participants and presenting the rationale of the event and the status of the project.

Paolo Casali (INT) stressed the need to further explore the problems of other European networks (e.g. ERNs), such as operational problems in connecting and/or communicating between the European networks and the national and regional levels. This iteration will serve both to facilitate the representativeness of organisations at European level and to ensure the transfer of knowledge from these networks to national and regional levels. Working on such aspects would help to ensure the sustainability of these networks over time.

He talked about two hot topics that JANE partners will need to address in 2024. One is the typology of services that NoEs should provide to health professionals or networks of professionals. Some examples



were given, such as the development of guidelines or health organization/education models, the promotion of research, the definition of quality criteria, patient and public involvement, and advocacy/policy/awareness. At this point, he said, work needs to focus on specifying which of these services will contribute to each NoE. For example, in the palliative care network of expertise, a specific service could be how to organise palliative care in a country.

On the other hand, during this first year, the possible overlap of these networks with other European networks has been discussed in project meetings and other events at European level. According to Paolo Casali, this should no longer be a cause for concern, because although there will be overlap in terms of themes, it is possible to work on the same theme but on different things, which could be called synergies. This will happen not only with the European Reference Networks (ERNs), Comprehensive Cancer Centres (CCCs), but also with the rest of the cancer community.

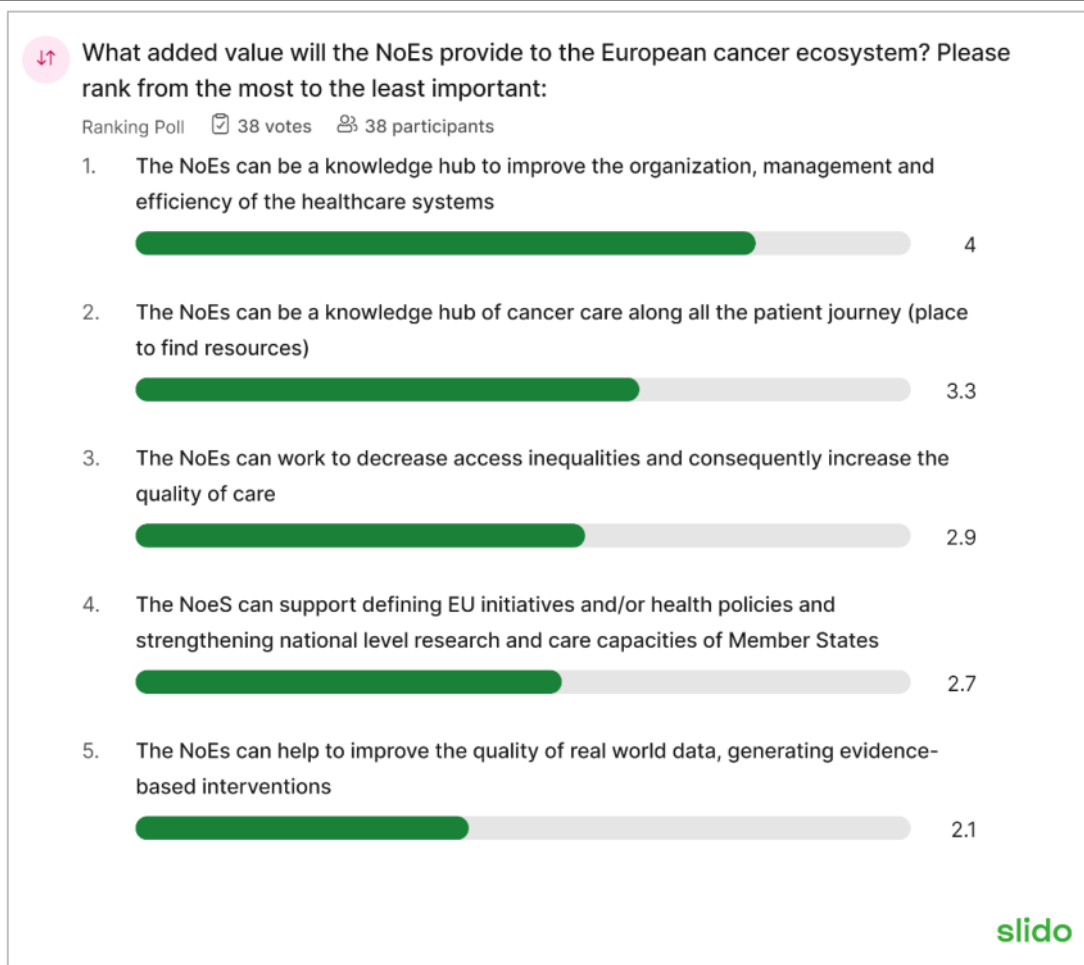
In addition, Paolo highlighted the still unfulfilled need to define the organisational nature of NoEs, as it has been confirmed that they should not be legal entities. According to him, it is important to define this aspect as some typologies could be a limiting factor in the functioning of NoEs.

Despite this, he stated that the real challenge is to reinforce the networking in the EU cancer ecosystem, and also to show the added value of networks at the European level. In this respect, the European Commission has been supporting such initiatives in recent years, which is a clear advantage compared to other parts of the world. In his words, defining how European networks can interact at national and regional level, will determine the success of the NoEs.

After this introduction, the key characteristics of **three NoEs were presented**. Firstly, representatives of the Omics and Hi-Tech resources' NoEs, H  l  ne Antoine-Poirel and Muriel Santoro presented the common objectives, endorsement and methodology criteria of both NoEs. The close collaboration between these two networks will derive in future shared governance (co-lead), although they will maintain each their specific dimensions or areas of work.

Later on, Stein Kaasa, leader of the Palliative Care NoE shared one of the main concerns of palliative care. Despite the proven efficacy of palliative care in high-impact journals, and having been shown for decades to improve the survival rates and quality of life of patients and family members. At present, it is still not integrated into routine cancer care. He highlighted the need collaboration and support of all stakeholders, highlighting policymakers, to introduce it to mainstream oncology. According to his words, events and discussion such as the stakeholder forum could help to achieve this kind of goal. It could also be supported by economic incentives, knowledge sharing and synergies between the various European initiatives already working in this field.

The first panel discussion, moderated by Sarah Berrocoso, started presenting the responses of all attendees to the question **'What added value will the NoEs provide to the European cancer ecosystem?'** that was launched before at the beginning of the meeting. The attendees were asked to rank various options from the most to the least important:



Later, JANE Stakeholder Matrix representatives were guided to discuss about: Which are your needs and expectations about the NoEs?

Contributions of JANE Stakeholder Matrix members:

Nikolai Goncharenko (INC-LU) Director at Institut National du Cancer (INC) Luxembourg stated that it would be important to establish cross boarding collaborations and explore ways to establish these collaborations, also with neighbouring countries. Finally, he also asked to the consortium what platforms could be used to achieve this.

The coordinator of JANE, Paolo Casali replied that the NoEs could organise ways in which small countries can find resources from larger neighbouring countries. However, it stated that it visualises NoEs as providers of organizational model solutions. These could provide solutions for Member States (MSs) with measures to be taken, based on the expertise gathered in the NoEs.

Claudia Mayer (Germany) added that a great challenge is the access to cancer research. JANE is in a very good place to reduce these difficulties. For example, by enabling Eastern European countries to access more information and other resources that can help reduce inequities in Europe.



Carina Dantas (SHINE 2Europe) following the line of previous comments, explained that it would be easier to involve patients if there is a follow-up or continuity, and of course if there is a network where advances in treatment, in research can be shared... All this could help fight against inequities.

Jose Pablo Maroto (Spain) agreed with previous comments about inequities. He also explained that it is important to bring patients to these networks, something that is missing in Spain for example.

Brina Zagar (Slovenia) »There are many differences between countries even in Europe, such as legislation and access to therapies. It is very important to keep these differences and situations in countries in mind and to take them into consideration when making connections.«

The moderator of the discussion, Sarah Berrocoso (Biosistemak) then addressed the common view of all stakeholders on the existing inequalities in Europe in cancer therapies and services and asked them for their opinion on how to tackle them. Could the NoEs provide this kind of service (raising awareness of the existing disparities) to the rest of Europe taking advantage of the knowledge they gather?

Carina Dantas (SHINE 2Europe) argued that there are some public authorities and also agencies that are fighting against inequalities. But since there are financial dependencies in this area, commitment and good representation in the public system should be achieved.

Lucia Abboud (Spain) added that it is important to improve joint forces to battle inequities, for example by creating indicators and also centralising information. In Spain, the Association Against Cancer (AECC) works closely with patients and in sharing information with them.

Paolo Cassali (Italy) stated that there is a lot of criticism about inequalities in ERNs, as it is not real that rare cancer patients could move from one country to another to access specific resources. ERNs cannot overcome this inequality. However, while geographical limitations on access to resources could be an obstacle for ERNs, this is something that NoEs can overcome, as knowledge can transcend geographical barriers and be freely shared. As a specific example, the NoE of hi-tech resources could not ensure that all Member States pay for a particular technology in their countries, but could raise awareness of the best treatment options and the information available about them and/or the availability of hi-tech resources in each country.

Joana Marinho (Portugal) gave a concrete example on accessibility talking about some countries that do not reimburse genetic testing costs. This is a very important aspect for patients, as well as it is having access to certain therapies. In relation to OMICS, the NoEs should have principles that can be shared with policymakers and patients' organisations about this type of resource, such as, guides about genetic tests for targeted cancer therapies, or about other initiatives, therapies or technologies.

Secondly, a bilateral discussion on patient involvement took place, between Wannes Van Hoof (Cancer Centre of Sciensano, Belgium) and Kristof Vanfraechem (Data for Patients, Spain) and moderated by Dolores Verdoy (Biosistemak Institute, Spain).

The main topic of the discussion was the role of patients as key agents in the creation and sustainability of the NoEs. This dialogue aimed to obtain insights about the challenge of incorporating patients into the NoEs so that their participation is successful and meaningful for both parties.



The panelists' answers to the first question 'Why is it important to involve patients in knowledge generation?' were as follows.

Wannes Van Hoof pointed to the change in the patient's communication/teaching model, in which the patient is now an expert and a valuable source of knowledge. For example, in matters related to privacy, end-of-life and well-being, they can provide knowledge adapted to the life situation. While these perceptions may already be very different between different people, as far as the professional is concerned, the professional may have assumptions that are not shared by the patient. These situations make it necessary to dialogue and the possibility of establishing co-creation situations, where patient organisations have to be part of the network, not only in the theoretical part of conceptualisation. To do this we need to get into an early stage dialogue, and that's what they're doing in their JANE work package. For this they are contacting through interviews and also workshops to large patient associations to see how to transfer these good practices or difficulties encountered in a guide.

Kristof Vanfraechem pointed out that it is necessary to define partnerships with patients. For example, both palliatives and NoE related to preventive medicine, should not be worked without taking into account the patient.

Dolores Verdoy addresses Wannes Van Hoof and asks him about the main challenges of his workshops, as well as the involvement of patients in them. He responds that in any dialogue always predominates the need to try to understand the other person. However, they are finding that in some situations, if you are a policy maker or professional, there is a phenomenon of Cherry picking, that is, sometimes patients find that attending to the needs or interests of the professional/policy maker, their ideas are or not taken into account.

In this sense, it was stressed that we cannot judge the legitimacy or validity of a person's judgment based on the personal opinions or interests of professionals. He pointed out that it would be important to solve these types of problems, because it is something that they have also found in their meetings, confronting the associations themselves judging who had the greatest capacity to speak on certain topics.

On the other hand, he explained that in his work package they plan to make several guidelines, some to explain to patients what each NoE is. And then others for the NoEs of how to involve patients.

After this, the following question was discussed: "Taking into account that there are more initiatives that seek patient involvement, what could be the solution to ensure their involvement in a project like JANE?"

Kristof Vanfraechem argued that if you have a diverse group it would be difficult to reach common agreements. In a project it is necessary to build from the beginning and with the input of the patients, but based on a previous design and work. The NoEs should be formed on a top-down perspective, and for this you need to design a panel of experts that works in this same direction, what would be one of the challenges to face.

Iwona Ługowska asked if the language can be a sweep in these collaborative processes. Wannes added that while the best thing to generate engagement would be to share the same language, it is not a barrier that we cannot overcome. Kristof, meanwhile, added that it is important for patients to understand medical and thematic language that makes sense to them.

(FAVO, Italy) She asked panelists if they could give an example of confrontational situations with patients. Wannes replied that this is something that happens continuously, sometimes out of mere ignorance, patients or relatives could detect symptoms and come early to receive care. Something as simple as health literacy could save lives in some cases.

Francesco De Lorenzo (FAVO, Italy) added that JANE should currently adapt to the needs of patients. But firstly, organisations such OECI and CCCs should be involved, as their experience in this field should be taken into account. The need to formally involve OECI was highlighted.

Before concluding this panel, the Coordinator Paolo Casalli added that it would be necessary that the leaders of the NoEs work in the analysis of what the NoEs can provide and where may patients be involved, adding as an example the creation of good practice guides.

The second and last panel discussion, moderated by Yhasmine Hamu, aimed at exploring 'How could the civil society, academia, the private sector and other key agents contribute to... the creation of the NoEs? And the sustainable establishment of the NoEs?'

Related to this topic, at the beginning of the meeting the attendees were asked about their opinion on the contribution of stakeholders to the sustainability of the NoEs and their responses all together came up with the following cloud of words:



Contributions of JANE Stakeholder Matrix members:

Brina Zagar (Slovenia) explained that as part of the civil society patient organisations can contribute a lot to the generation of knowledge in a bottom-up perspective. It would be necessary for all networks to have an established mechanism to engage patients, carers or other actors interested in this area.



Claudia Mayer (Germany) added it would be vital for the networks to maintain continuous dialogues organising events such as the Stakeholder Forum or meetings where invited experts from the same field could give their input. Moreover, she added that thematic discussions would also be beneficial.

Jose Pablo Maroto (Spain): in the same line as the previous participants, he stressed that participating in this type of meetings and sharing ideas, and if possible in person, would be even more beneficial.

After these first interventions by the stakeholders, other JANE partners went on to present their ideas.

First, Hélène Antoine-Poire (leader of the Omics NoE), explained that in the NoE that she leads there is a need to interact with the private sector, since innovation does not come only from academia. In this sense, the new ideas should be gathered from these two worlds in conjunction, as they have synergies.

For her part, Iwona Ługowska (leader of the Complex and Poor Prognosis NoE) stressed the importance of the implementation processes and that collaboration in these networks should also be aimed at this objective.

The last part of the discussion of this forum was opened by Miriam Dalmas. She raised the question of how the different networks will collaborate, since at the present time this point did not seem to be clear. She argued that before disseminating information there is a need to structure how NoEs will interact between them and consolidate it.

The Coordinator, Paolo Casali commented that it will be crucial to find out how Member States will support these networks. He underlined that it is crucial to look for ways to involve legal representatives directly in these kinds of discussions in order to get their feedback.

As an example, the MS board of the ERNs, he suggested that JANE partners should work on the search for similar mechanisms for the NoEs. It is stressed that sustainability may not be a problem as long as without the direct involvement and support of Member States these networks will not be able to function.

Miriam made her last speech highlighting that while this model of the ERNs differentiates between two types of boards, which led to the simple one would represent the closest to the government and the other to the clinical world. The importance is that both boards are interconnected and meet frequently. There are models already at European level that are working in this way, thus, it would be interesting to learn from them and apply it in these future networks.

Paolo closed the discussion claiming that it is necessary to look for mechanisms to involve all key players, as well as to incorporate other agents such as CCCs or European infrastructures. We should envisage mechanisms to involve all these players effectively building on the experience of the ERNs. The mechanisms will be different from these, but the principle should be shared.

The WP4 Sustainability team closed the First Stakeholder Forum of JANE.



Contact

For any questions or queries, please contact with JANE's Stakeholder Forum secretariat:

Sarah Berrocoso, PhD, Biosistemak Institute for Health Systems Research, leader of JANE work package on sustainability

sberrocoso@kronikgune.org

Yhasmine Hamu, Biosistemak Institute for Health Systems Research, leader of JANE work package on sustainability

yhamu@kronikgune.org



Engagement of additional stakeholders

The following list includes other activities involving stakeholders from governments, academia, cancer networks, scientific, professional and civil societies, among others, that have helped to explain the goals of JANE, build a common understanding and create synergies and partnerships to support JANE and future NoEs.

Table 2. List of JANE events

Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2022	CraNE-JANE Coordinator meeting	Invitation from other projects, programs, etc,	JANE-CraNE collaboration	Internal Coordinator meeting
2022	Collaboration possibilities with CRANE - MSCI	Invitation from other projects, programs, etc,	Synergy - JANE and CraNE networking	German Cancer Society + MSCI + CraNE
2022	Collaboration possibilities with CRANE - MSCI (WP13)	Invitation from other projects, programs, etc,	Synergy - JANE and CraNE networking	IOCN, CraNE
2022	MyPath and other EU funded projects	Invitation from other projects, programs, etc,	Part of invited lecture on MyPath, one of other EU funded projects in which OUS is involved (HORIZON-HLTH-2021-DISEASE-04)	29.300 participants from more than 150 countries



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2022	MATRIX, 1st General assembly	Invitation from other projects, programs, etc,	Inauguration meeting in MATRIX, an overlapping large scale Norwegian project that facilitates the implementation of the palliative care concepts in JANE	Scientists, multiprofessional clinicians, national managers
2022	MATRIX semi-annual meetings	Invitation from other projects, programs, etc,	Follow-up and updates of JANE as part of OUS portfolio	Scientists, multiprofessional clinicians, national managers
2022	3rd ACCC-Athens Comprehensive Cancer Center Symposium	Scientific and policy international events	Raise awareness on JANE's ambitions and goals	Industry, business partners EU institutions Policymakers and authorities, International Policymakers and authorities, national Scientists Medical oncologists
2022	CraNE kick off meeting	Invitation from other projects, programs, etc,	JANE-CraNE collaboration	Beneficiaries of CraNE, Coordinators of related projects/ networks



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2022	PRC (European Palliative Care research centre) Conference	Invitation from other projects, programs, etc,	Follow-up and updates of JANE, EUonQOL, MyPath as part of OUS portfolio	Scientists, multiprofessional clinicians, national managers
2023	CraNE-JANE Coordinator meeting	Invitation from other projects, programs, etc,	Internal Coordinator meeting	Internal Coordinator meeting
2023	Meeting with Board of ESSO	Invitation from other projects, programs, etc,	Raise awareness on JANE's ambitions and goals	ESSO Board members
2023	Scientific Council Meeting of ESTRO	Invitation from other projects, programs, etc,	Raise awareness on JANE's ambitions and goals	ESTRO Scientific Council Members
2023	Meeting to establish collaboration with ECO	Invitation from other projects, programs, etc,	Collaboration with ECO in the field of Survivorship	Members of the European Cancer Organisation (ECO)
2023	Reducing disparities across EU	Policy dialogues, Stakeholder Forum or other stakeholder events	High Level Stakeholders Conference. Networking in relation "Tackling the implementation gap: SWOT"	EU institutions and members of EU parliament scientist, International policy makers and authorities, Oncology societies and organisations, Industry, Business partners



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2023	Poor prognosis cancer meeting related to Swedish presidency	Scientific and policy international events	International policymakers and authorities. PPC - presentation in relation to PPC NoE	International policymakers and authorities
2023	EURACAN Board meeting	Scientific and policy international events	Presentation on, "How to succeed in Horizon Europe oncology projects in practice?"	EU Institutions, International policy makers and authorities
2023	European Week Against Cancer	Scientific and policy international events	Raise awareness on JANE's ambitions and goals	Industry, business partners EU institutions Policymakers and authorities, International Policymakers and authorities, national Scientists Medical oncologists
2023	Europe's Beating Cancer Plan - First EU4Health Project Showcase	Scientific and policy international events	Raise awareness on JANE's ambitions and goals	Industry, business partners EU institutions Policymakers and authorities, International



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
				Policymakers and authorities, national Scientists Medical oncologists
2023	Quality Cancer Care Network Meeting	Invitation from other projects, programs, etc,	Raise awareness on JANE's ambitions and goals	Members of ECO
2023	GRELL Group for Cancer Epidemiology & Registration in Latin Language Countries	Scientific and policy international events	To engage cancer registries in the future NoE on survivorship and adolescents and young adults	Population-based cancer registries meeting
2023	Creating an NoE on Survivorship at national (Polish) level	Knowledge-sharing events	Organization of survivorship care at the national level	Experts
2023	We Infoday Joint Action del Programma EU4Health	Knowledge-sharing events	Raise awareness on JANE's ambitions and goals	Italian researchers/ clinicians



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2023	OECI Oncology Days - European Cancer Strategic Initiatives	Knowledge-sharing events	Raise awareness on JANE's ambitions and goals	OECI members
15/07/1905	Subgroup on Cancer Meeting under the Public Health Expert Group	Knowledge-sharing events	Ongoing EU4Health and Horizon Europe projects	Experts
2023	MyPath general assembly meeting	Knowledge-sharing events	General Assembly, oral presentation. Part of invited lecture on liaison activities on national / international research projects on patient-centred care and Palliative care integrations	International, Scientists, Clinicians, managers-multiprofessional
2022	In-house meetings (OUS)	Knowledge-sharing events	General in-house meetings and teaching activities covering all three EU-funded projects (MyPath, JANE, EUonQOL) in which OUS is involved	Internal experts
2023	In-house meetings (OUS)	Knowledge-sharing events	General in-house meetings and teaching activities covering all three EU-funded	Internal experts



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
			projects (MyPath, JANE, EUonQOL) in which OUS is involved	
2023	Summer School – ProMIS	Scientific and policy international events	Raise awareness on JANE’s ambitions and goals	Italian entities interested in participating in Joint Actions
2023	Informal Coffee meetings with Policy Board	Policy dialogues, Stakeholder Forum or other stakeholder events	13 Bilateral meetings between Biosistemak and JANE Policy Board members introducing and contextualizing JANE project to the Policy Board members- Gathering their initial reactions to the project's approach- Discussing about the potential impact that the NoEs can have on the cancer ecosystem in Europe.	Policymakers and public health specialists
2023	High Level Meeting - Challenges in Cancer Care	Scientific and policy international events	Raise awareness on JANE’s ambitions and goals	Spanish Government, European Commission, experts in the field of cancer



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2023	Subgroup on Cancer Meeting under the Public Health Expert Group	Scientific and policy international events	EU4Health Work Programme 2023 - upcoming Joint Action on new Networks of Expertise	Experts
2023	Quality Care Cancer Network Meeting	Invitation from other projects, programs, etc,	Raise awareness on JANE's ambitions and goals	Members of ECO
2023	ENTYAC meeting	Invitation from other projects, programs, etc,	Raise awareness on JANE's ambitions and goals	Members of ENTYAC
2023	STRONG-AYA Stakeholders meeting	Policy dialogues, Stakeholder Forum or other stakeholder events	Raise awareness on JANE's ambitions and goals	Stakeholders of STRONG-AYA
2023	Anticancer treatment at end-of-life, ESMO	Scientific and policy international events	Part of invited lecture on anticancer treatment at end-of-life AND Parallel session, Education/training organization/learners	Scientists, Clinicians- multiprofessional, patient/professional organisations, international International, Scientists, Clinicians, managers-



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
				<p>multiprofessional</p> <p>EU institutions, Policymakers and authorities, international, Scientists, Clinicians- multiprofessional, professional and lay organisations</p>
2023	“How to succeed in Horizon Europe oncology projects in practice?”	Scientific and policy international events	Webinar Green Horizon organised by National Contact Point for EU . Raise awareness on projects in the field of Oncology in general	<p>Policy makers and national authorities</p> <p>Mission Cancer National Societies</p>
2023	Collaboration with Patient Representatives	Knowledge-sharing events	Meeting with a patient advocacy group representative to set up a strategy for further activities of PPC addressing patients’ needs	Patients and patient advocacy groups
2023	Meeting of Italian AIOM-AIEOP Working Group on AYAs	Knowledge-sharing events	Working national group on AYAs	AIOM-AIEOP steering committee



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2023	Stakeholder Forum	Policy dialogues, Stakeholder Forum or other stakeholder events	To improve the dialogue and collaboration among key actors in the cancer ecosystem, including Networks of Expertise (NoEs), civil society, academia, the private sector, and other relevant stakeholders.	66 onsite participants, 67 online participants, 11 stakeholders
2023	Meeting on implementation of Survivorship Passport	Knowledge-sharing events	Implementation of Survivorship Passport, future collaboration	PanCare
2024	Innovative practices for stakeholder engagement in cancer-related EU projects	Knowledge-sharing events	Stakeholder engagement	Partners of cancer-related projects
2023	National Cancer Awareness Conference	Scientific and policy international events	The objective of this conference is to bring together leading cancer researchers, healthcare professionals, and policymakers to discuss the latest advancements in cancer prevention,	Policymakers and authorities, national



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
			early detection, and treatment. It aims to foster collaboration, share knowledge, and develop strategies to reduce the incidence and mortality of cancer at the national level.	
2023	Targeted meetings with oncologists in Greece	Knowledge-sharing events	Physically, tele-meetings regularly	Medical Oncologists
2023	Collaboration with Hellenic Ministry of Health-CraNe team	Scientific and policy international events	Coordination and interaction at national and European level	Policymakers
2023	Collaboration with CraNE and policymakers in Norway	Scientific and policy international events	Coordination and interaction at national and European level	Policymakers
2023	Online team meeting	Scientific and policy international events	Online meeting with Ministry of Health representative. Visibility in Poland. Visibility in Poland(22/08/23)	National authorities- Ministry of Health



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2023	1st JANE Policy Dialogue	Policy dialogues, Stakeholder Forum or other stakeholder events	Deliberative conversations between Policy Board members, moderated by Biosistemak on the following key discussion main areas: policy strategies and relationships, alliances & synergies	Attendees: 10 members of Policy Board & 75 participants. [EU institutions] [National authorities] [Regional authorities] [Local authorities] [Civil society] [Research communities]
2023	Meetings with Patient Organizations	Knowledge-sharing events	Meetings organized with patient organizations in all project partner countries (+ Bulgaria) to share experiences on how to involve patients in their organizations, projects, etc. Get input from patient organizations on good and less good engagement practices	Sciensano & 35 reps from EU patient organizations including ECPC, ELLOK Kom Op, Kickcancer, PEC, FAPA, Think Pink, ...)
2023	Meeting Swiss Oncology Hematology Society	Knowledge-sharing events	Communicate the activity of JANE	Meeting Swiss Oncology Hematology Society



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2023	Course on Adolescentology	Knowledge-sharing events	Residential course on Adolescentology. Communicate the activity of JANE	Residential course
2023	SIOPE AYA course	Knowledge-sharing events	Masterclass. Communicate the activity of JANE	Fellows in paediatric or adult haematology and oncology; junior faculty at academic medical centres in Europe; people training for other disciplines caring for AYA cancer patients and survivors
2024	AIEOP Congress	Scientific and policy international events	Communicate the activity of JANE	AIEOP Congress
2024	Patient workshop	Knowledge-sharing events	Presentation of the toolkit	EU and national patient organizations General public
2024	CraNE workshop	Scientific and policy international events	Presentation of the toolkit. Collaboration with EU-funded projects	EU institutions Policy-makers and nation and international authorities, Scientists



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
2023	CRANE JA7 workshop	Invitation from other projects, programs, etc,	Synergies with CRANE. Assessing areas for collaboration Familiarise with first sketches of CCC standards to find link with JANE endorsement criteria	CraNE members
2023	OECI	Invitation from other projects, programs, etc,	Discussion of JANE and CRANE JA projects	OECI members
2023	Conference: Reducing Disparities Across EU	Knowledge-sharing events	Project debrief and activities follow-up	Italian National Institute of Health, Rome. High-level Stakeholder Conference: Reducing Disparities Across EU
2023	JANE-TTF2 Meeting	Invitation from other projects, programs, etc,	Dr. Delia Nicoara, Project Manager – Introduction + progress TTF2 Dr. Adela Maghear, Senior EU Affairs Manager, Brussels –Beyond JANE1 - Strategies for stakeholder engagement at EU and MS level Dr. Per Magnus Mæhle, General manager	



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
			Cancer Center Board, Oslo, Norway – Case Study & CraNE Synergy: the Nordic and Baltic CCCs Consortium Model	
2023	CraNE Stakeholder Forum	Policy dialogues, Stakeholder Forum or other stakeholder events	Synergies with CraNE. Assessing areas for collaboration	
2023	1st JA JANE Advisory Board	Scientific and policy international events	The meeting provided valuable insight and discussion of several aspects of the JANE project, including the structure and progress of WP1, evaluation activities in WP3, sustainability efforts in WP4 and insights from the previous Joint Action, Joint Action on Rare Cancers (JARC	1. Kathy Oliver (IBTA); 2. Sakari Karjalainen; 3. Mario Šekerija (CIPH); 4. Petra Čukelj (CIPH); 5. Ivana Andrijašević (CIPH); 6. Joanne Fleming (INT); 7. Paolo G Casali (INT); 8. Lola Verdoy (KRONIKGUNE Institute); 9. Yhasmine Hamu (KRONIKGUNE Institute) <ul style="list-style-type: none"> • Sakari Karjalainen, retired a year ago from the Cancer Society of Finland where he was



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
				<p>a secretary general for ten years. He served as European Cancer Leagues (ECL) president for five years. Sakari was involved in CANCON and JARC. He was also a Director General of the Department of Education and Science Policy of the Ministry of Education and Culture in Finland.</p> <ul style="list-style-type: none"> • Kathy Oliver (IBTA), formal training as a journalist, helped to establish an International Brain Tumor Alliance, which started with work in 2005. Kathy was active in a number of different projects and initiatives around Europe and internationally – EURACAN,



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
				JARC, European commission Group on Cancer Control and WECAN.
2024	2nd JA JANE Advisory Board	Scientific and policy international events	2nd Advisory Board of JANE	1. Annalisa Trama (INT); 2. Sakari Karjalainen (Advisory Board); 3. Mario Šekerija (CIPH); 4. Ante Malinar (CIPH); 5. Ivana Andrijašević (CIPH); 6. Karmen Korda (CIPH); 7. Joanne Fleming (INT); 8. Paolo G Casali (INT); 9. Sarah Berrocoso Cascallana (Biosistemak); 10. Yhasmine Hamu (Biosistemak); 11. Iva Kirac (Sestre milosrdnice University Hospital Center, Zagreb, Croatia)
2024	Spanish Ministry of Health Conference: eCan, CraNE and JANE	Scientific and policy international events	To disseminate the final results of each Joint Action, and to make visible the role	Policymakers at national level



Year	Title of the dissemination opportunity	Category of the dissemination	Main objectives to be covered within the content	Target/Audience
			played by Spain through the participation in these three initiatives.	
2024	OECI	Invitation from other projects, programs, etc,	Alignment and synergies among the most relevant European Joint Actions CraNE2 and JANE 2	OECI members