Joint Action on Networks of Expertise on Cancer

Milestone 4.1

Analysis of needs assessment

30/04/2026

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Deliverable lead partner	Biosistemak
Contributing partner(s)	
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CONTENIDO

1 EXECUTIVE SUMMARY

JANE-2 is the second European Joint Action on Networks of Expertise on Cancer, building on the outcomes of Joint Action JANE (2022–2024) and implemented within the EU4Health Programme. Its objective is to establish and operationalise seven Networks of Expertise addressing key transversal domains in cancer care, strengthening collaboration, knowledge sharing and alignment across EU Member States.

Within JANE-2, Work Package 4 (WP4) focuses on ensuring the long-term sustainability of the Networks of Expertise through a structured, stakeholder-driven and needs-based approach. WP4 aims to translate ecosystem demand into concrete service portfolios, engagement strategies and business models capable of supporting NoE activities beyond the project lifetime.

This document constitutes the first milestone of WP4 and presents the results of Task 4.1, which combined a structured stakeholder mapping exercise with a comprehensive needs assessment survey. The milestone captures stakeholders' needs, expectations and perceptions of value in relation to NoE-specific services, and explores acceptable forms of engagement and contribution.

Survey results show consistently high levels of interest across the proposed service categories, with particular emphasis on networking and collaboration, research promotion, and knowledge and skills development. In parallel, the analysis of stakeholder roles, levels of engagement and willingness to contribute highlights a strong preference for collaborative partnership-based interaction models, alongside differentiated contribution patterns.

Overall, the findings presented provide a robust evidence base to inform the development and prioritisation of initial NoE service portfolios and to guide subsequent WP4 activities on engagement models and long-term sustainability.

2 INTRODUCTION

2.1 JANE-2 project summary

EU Joint Action JANE (2022-2024) was implemented within the framework of the European Union's EU4Health Program, specifically under the Joint Actions strand designed to foster cooperation, coordination and knowledge-sharing among Member States in priority areas of health policy and practice. JANE involved 16 Competent Authorities, 20 Affiliated Entities and 2 patient associations from 16 European countries.

Joint Action (JA) JANE laid the groundwork for the creation of Networks of Expertise (NoEs) in oncology, with the primary objective of preparing the conditions necessary to launch seven new Networks of Expertise in the following domains:

- complex and poor-prognosis cancer(s) (PPC)
- palliative cancer care (PC)
- survivorship
- personalized primary and secondary prevention (PPP)
- omic technologies
- hi-tech medical resources
- adolescents and young adults with tumours (AYA)

These domains represent some of the most critical and complex challenges in contemporary oncology. Addressing them effectively requires greater harmonisation across the European Union, strengthened cooperation between healthcare and research institutions, and an enhanced level of scientific and technological exchange. Functioning transnational health networks are key enablers to meet these challenges.

Building on the outcomes and achievements of Joint Action JANE, **the second European Joint Action on Networks of Expertise on Cancer (JANE-2)** was launched in November 2024. Coordinated by the Istituto Nazionale dei Tumori (INT), JANE-2 brings together 121 organisations from 29 European countries. Over the next four years, JANE-2 aims to establish and operationalise seven new Networks of Expertise focusing on transversal aspects of cancer care, with the overarching goal of ensuring the highest possible standard of oncology care for EU citizens and residents.

The Networks of Expertise developed under JANE-2 are designed to provide services to the wider European oncology community, including the development of clinical practice guidelines and recommendations, quality-of-care criteria, healthcare and economic models, educational support,

research promotion, support to patient advocacy and political advocacy activities. All network activities are firmly grounded in a patient-centred approach.

The creation of these Networks of Expertise directly contributes to the implementation of Europe's Beating Cancer Plan, launched in 2021. By the end of 2028, JANE-2 aims to support the establishment of active and permanent Networks of Expertise in oncology across the European Union, representing a highly ambitious and strategic objective for strengthening cancer care at EU level.

2.2 Purpose of this document

Among the work packages in the JANE-2 Joint Action (Figure 1), WP4 is a cross-cutting work package specifically dedicated to supporting the long-term sustainability of the Networks of Expertise (NoEs). WP4 adopts a structured approach to sustainability, encompassing the identification of target stakeholders, the development of value propositions, the definition of service portfolios, the establishment of engagement and partnership models, and the elaboration of tailored business models to support the continued delivery of NoE services beyond the project lifetime.

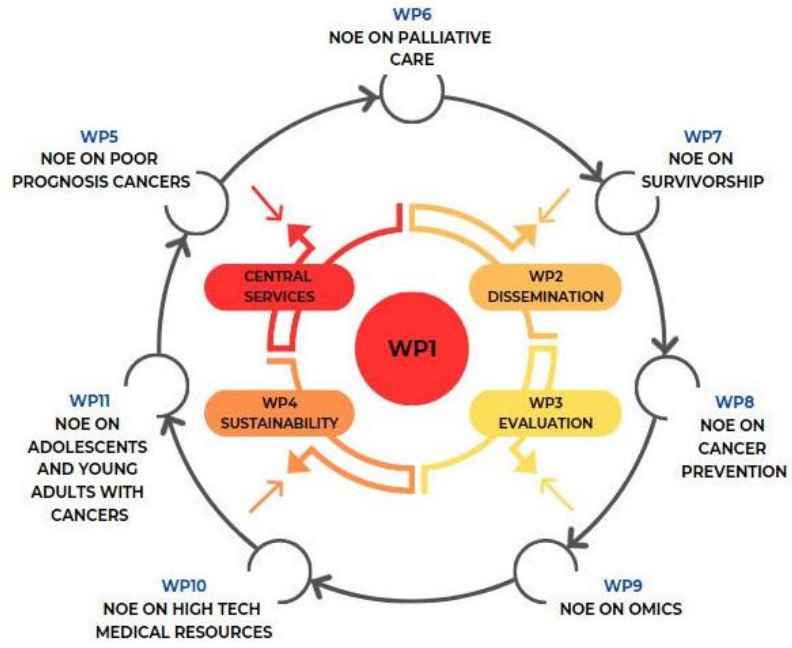


Figure 1. JANE-2 Work package structure

Within this overall framework, the activities of WP4 are organised into a sequential and interconnected process, starting with stakeholder identification and needs assessment, and progressively advancing towards service portfolio definition, validation, and business model development. This logic, illustrated in the WP4 reference framework (Figure 2), positions stakeholder input as the foundational building block for all subsequent WP4 activities.

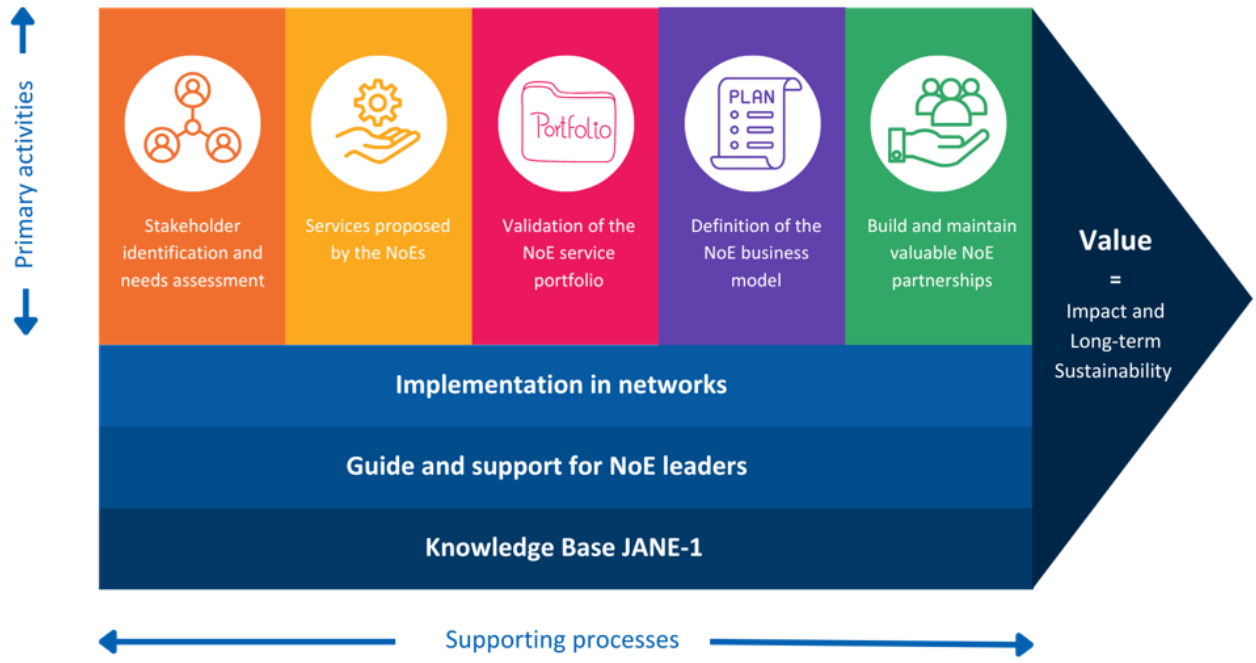


Figure 2. WP4 - Transforming knowledge into sustainable actions

The aim of this document, which constitutes the first milestone of WP4 and is associated with *Task 4.1 - Stakeholder identification and needs assessment*, is to present the results of the analysis conducted with key stakeholders of the JANE-2 NoEs. Its primary objective is to capture stakeholders' needs, expectations and perceptions of value in relation to NoE-specific services, as well as to explore the types of contribution and engagement models that stakeholders consider acceptable in relation to potential NoE services.

This assessment seeks to ensure that future NoE service portfolios are grounded in an evidence-based understanding of stakeholder demand, perceived needs and expectations. In doing so, it informs the development of an initial NoE service portfolio and supports the exploration of acceptable forms of stakeholder contribution, thereby providing a solid foundation for subsequent WP4 activities on service design, partnership building and long-term sustainability.

The contents of this document are presented as follows. **Section 1** contains the executive summary of this document. **Section 2** introduces the context and scope of the work presented in this milestone. **Section 3** describes the methodology applied to develop and implement the stakeholder mapping and needs assessment survey. **Section 4** presents the results of both activities and constitutes the core of this milestone. **Section 5** outlines the preliminary conclusions drawn from the work conducted, while the final section contains a set of appendices with additional supporting documentation.

3 METHODOLOGY

3.1 Stakeholder mapping

Within Task 4.1, an initial desk-based research activity was conducted to identify and characterise potential key stakeholders of the Networks of Expertise and to map their positioning within the cancer care ecosystem. This work aimed to achieve a preliminary understanding of stakeholder roles, motivations and potential modes of engagement in relation to NoE services. The exercise built on existing work already performed by the Networks of Expertise during Joint Action JANE-1, as well as on several coordination-led activities promoted at Joint Action level.

In this context, all Networks of Expertise were invited to carry out a structured self-analysis designed to articulate the strategic foundations of their future activities. Each network was asked to define its core objectives and to identify the main activities required to achieve those objectives. In parallel, networks were requested to specify the types of final users, target groups, partners and collaborators that could be involved in or benefit from these activities, considering different geographical scopes (national and EU level) and forms of collaboration (Figure 3). This exercise enabled a first, systematic linkage between NoE objectives, planned activities and the stakeholders potentially involved in service delivery or uptake.

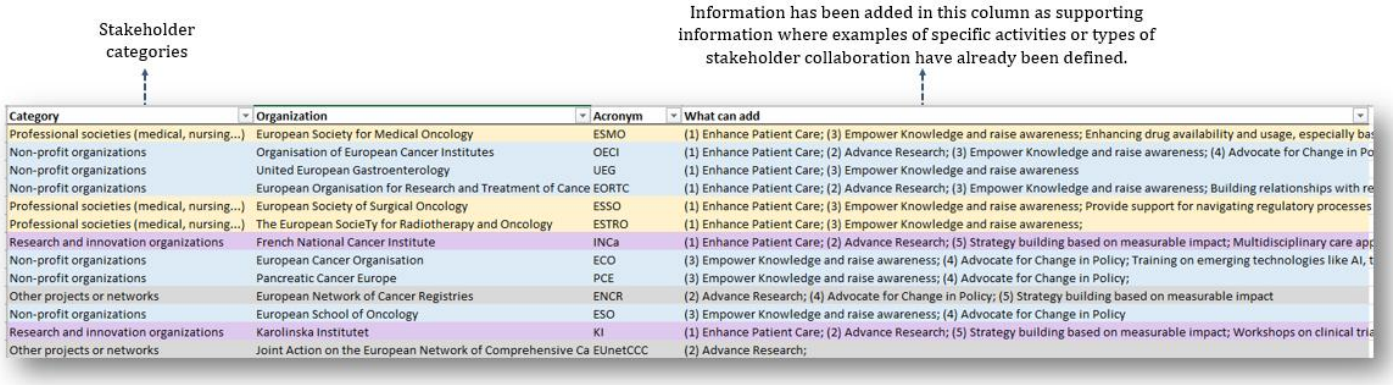
Activities	Final user	Final target (general)	Final target (specific)	Full partners			No. per country	Criteria	Collaborators
				Type of Full	EU scope	National scope			
1. **Enhance Patient Care:** Provide comprehensive, patient-centred care that addresses the physical, and psychological needs of patients and their families throughout their journey	HCP/CCC medical professionals and researchers, PAGs, Medical Societies/ Organisation, and policymakers/ stakeholders	Achieve increase in overall survival rates and quality of life in complex and poor prognosis cancers at equal level in each MS (done by focus groups per cancer type eg pancreatic cancer NoE)	improvement of the quality of care and treatment outcomes for patients diagnosed with PPC	1.Representative experts on PPC from accredited CCI who meet endorsement criteria and are involved in interdisciplinary	Representatives from CCI with expertise in care of PPC (national influence and international experience), preferably involved additionally in Medical Societies/Organisations (eg ESMO, UEG, ESSO, ESTRO, OECI)		at least 1 per country; based on geographical spread, diversity in the provision of care, research, policy, education and strategy building (up to 50 participants in focus group dedicated to defined poor prognosis population)	General criteria: alignment with network goals, objectives and values; involvement in guidelines development, changing practice research and involvement in policy-making processes, leadership skills; capability and resources for actively participating in NoE activities, representing national and international groups. Experts: leadership position, top qualifications (board certification, advanced degrees, track record of excellence of clinical and research fields), endorsement from CCI/international organisations, ability to impact on the decisions making process, the organization of cancer care, research and education at the MS level Healthcare providers: track record of clinical excellence with high-quality patient care outcomes, strong reputation within its speciality areas, clinical resources (state-of-the-art equipment, specialized facilities, skilled healthcare workforce), relevant specializations align with the	Other NoE and JA representatives, patient advocates, governmental bodies (eg. MoH, MoS), and non-governmental organizations, industry, medical societies, HTA, epidemiology and pub-lic health organizations, academic/Research Institutions, educational institutions. Representatives other research project on PPC (eg UNCAN)
2. **Advance Research:** Drive innovative research to uncover breakthroughs in the early detection, treatment, and prevention of poor prognosis cancers.			to accelerate a deeper understanding of cancer biology, the development of more effective anti-cancer therapies and diagnostics	2. Researchers from accredited CCI, who meet endorsment criteria , societies, and institutions involved in changing practice	Representatives from CCI with expertise in research of PPC (national influence and international experience), preferably involved additionally in Medical Societies/Organisations (eg EORTC, OECI), Medical Research Agencies, Reaserch Institutes or international research project dedicated to PPC				
3. **Empower Knowledge and Raise Awareness:** Foster collaboration among healthcare professionals, researchers, stakeholders and patient advocates to share knowledge and best practices and raise public awareness about poor prognosis cancers			raise awareness of the disease among the public to improve early detection	3.Charities and Non-Profits Organizations, PAGs, CCCs, Health Educators, Social Media and Health Bloggers/Vlogers	Representatives from CCI with expertise in education/dissemination/PR of PPC (national influence and international experience), preferably involved additionally in educational Medical Societies/Organisations (eg ESO, PAGs)				
4. **Advocate for Change in Policy:** Advocate for policy changes, increased funding, and improved access to cutting-edge therapies and treatments to reduce the burden of poor prognosis cancers on individuals and society. Offer a network of support services, including counselling, financial assistance, and emotional support, to patients and families facing the			improvement of timely access to treatment as well as reduce inequalities in access to cancer treatments and healthcare services across EU member states	4. Cancer Networks, Healthcare Management Professionals, Governments and Public Health Organisations, PAGs and Industry (including Pharmaceutical Companies	Representatives from CCI with expertise in policy/stakeholder engagement of PPC (national influence and international experience), preferably involved in influential organisation on	Ministry of Health, National Cancer Institution, National cancer registry, National Health Fund			

Figure 3. JANE-1 coordination exercise carried out by the PPC NoE

This exercise enabled a first, systematic linkage between NoE objectives, planned activities and the stakeholders potentially involved in service delivery or uptake.

Following the review of existing documentation and background information related to the Networks of Expertise, a common stakeholder mapping template was developed and shared with all NoEs to support a harmonised and structured mapping exercise. This template was pre-populated with

information derived from documentation produced by each NoE during Joint Action JANE-1 and complemented with additional materials generated at the start of JANE-2, including an initial list of stakeholders previously identified as potentially benefiting from NoE services (Figure 4).



Category	Organization	Acronym	What can add
Professional societies (medical, nursing...)	European Society for Medical Oncology	ESMO	(1) Enhance Patient Care; (3) Empower Knowledge and raise awareness; Enhancing drug availability and usage, especially ba
Non-profit organizations	Organisation of European Cancer Institutes	OECI	(1) Enhance Patient Care; (2) Advance Research; (3) Empower Knowledge and raise awareness; (4) Advocate for Change in Po
Non-profit organizations	United European Gastroenterology	UEG	(1) Enhance Patient Care; (3) Empower Knowledge and raise awareness
Non-profit organizations	European Organisation for Research and Treatment of Cance	EORTC	(1) Enhance Patient Care; (2) Advance Research; (3) Empower Knowledge and raise awareness; Building relationships with re
Professional societies (medical, nursing...)	European Society of Surgical Oncology	ESSO	(1) Enhance Patient Care; (3) Empower Knowledge and raise awareness; Provide support for navigating regulatory processes
Professional societies (medical, nursing...)	The European SocieTy for Radiotherapy and Oncology	ESTRO	(1) Enhance Patient Care; (3) Empower Knowledge and raise awareness;
Research and innovation organizations	French National Cancer Institute	INCa	(1) Enhance Patient Care; (2) Advance Research; (5) Strategy building based on measurable impact; Multidisciplinary care ap
Non-profit organizations	European Cancer Organisation	ECO	(3) Empower Knowledge and raise awareness; (4) Advocate for Change in Policy; Training on emerging technologies like AI, t
Non-profit organizations	Pancreatic Cancer Europe	PCE	(3) Empower Knowledge and raise awareness; (4) Advocate for Change in Policy;
Other projects or networks	European Network of Cancer Registries	ENCR	(2) Advance Research; (4) Advocate for Change in Policy; (5) Strategy building based on measurable impact
Non-profit organizations	European School of Oncology	ESO	(3) Empower Knowledge and raise awareness; (4) Advocate for Change in Policy
Research and innovation organizations	Karolinska Institutet	KI	(1) Enhance Patient Care; (2) Advance Research; (5) Strategy building based on measurable impact; Workshops on clinical tri
Other projects or networks	Joint Action on the European Network of Comprehensive Ca	EUnetCCC	(2) Advance Research;

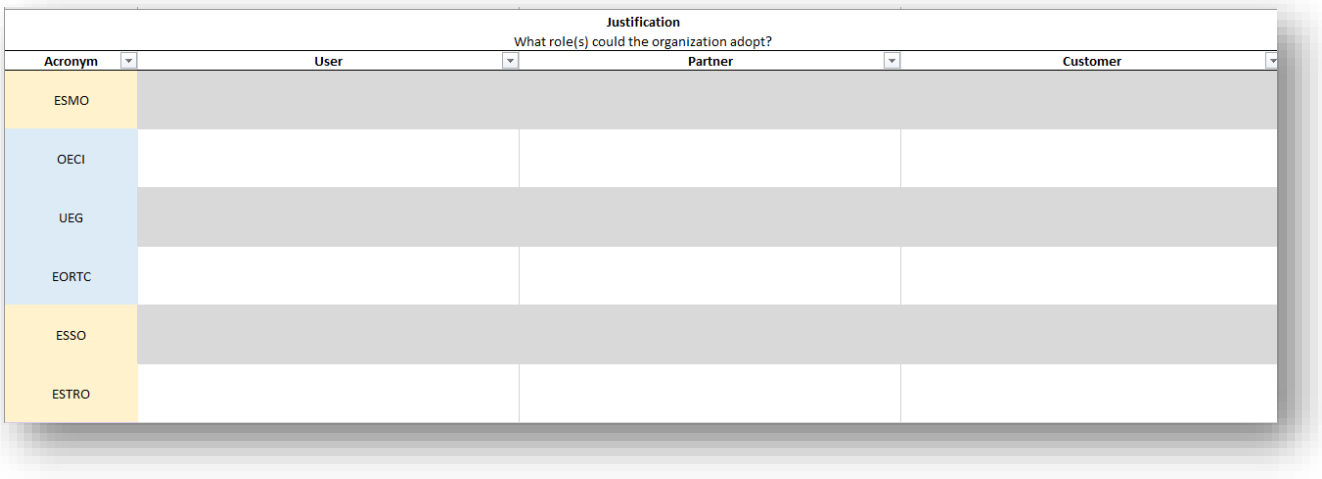
Figure 4. Pre-filled information for PPC NoE

The template, implemented as a structured Excel workbook, was designed to be self-explanatory and to guide NoEs through a step-by-step validation and enrichment process. NoE leaders were asked to review, validate, delete or expand the pre-filled list of stakeholders, and to confirm or refine their categorisation according to stakeholder typology (e.g. professional societies, non-profit organisations, healthcare providers, research networks). To facilitate consistency across networks, stakeholder categories were standardised and visually coded within the template (Figure 5).

Patients and the public
Health and care provider organisations
Professional societies (medical, nursing...)
Health and care payers
Public health agencies
Policymakers
Research and innovation organizations
Industry (pharma)
Industry (medtech)
Non-profit organizations
Academia
NoEs
Other projects or networks
Others

Figure 5. Stakeholder typology categorization

A dedicated 'role explanation' section within the template further supported NoEs in assigning one or more potential roles (e.g. user, partner, customer) to each identified stakeholder and in describing the expected form of contribution associated with these roles.



	Justification What role(s) could the organization adopt?		
Acronym	User	Partner	Customer
ESMO			
OECI			
UEG			
EORTC			
ESSO			
ESTRO			

Figure 6. Role explanation sheet.

Note. Networks of Expertise were invited to assign one or more potential roles (user, partner, customer) to each mapped stakeholder and to describe the corresponding types of contribution. Not all roles needed to be assigned to every stakeholder.

Examples and guidance were provided to facilitate a consistent interpretation of stakeholder roles across Networks of Expertise (Tables 1-3). To this end, an additional worksheet was included in the template, presenting illustrative examples of how different types of organisations (e.g. patient organisations, professional societies, research actors or healthcare providers) could engage with the NoEs as users, partners or customers. These examples were intended to inspire and support networks in assigning roles and describing potential contributions, while allowing flexibility to reflect the specific context of each NoE.

Professional societies (medical, nursing...)	
EXAMPLES	Professional scientific associations à *ESMO, ESSO, ESTRO, SIOPE...*
USER ROLE	To access repositories, databases, and evidence-based resources; participate in trainings; learn about successful use cases and benefits; understand best adoption practices; advance the profession; engage with patients.

PARTNER ROLE	*Prioritization*	Perceived health needs, gaps in the clinical practice. Clinical guidelines/protocols used in different countries, validity of the clinical content, quality and patient safety considerations, impact in the clinical practice
	Advisement	Acceptability of developed guidelines/technologies/procedures
	Implementation	Feasibility of new guidelines/technologies/procedures
	Evaluation	Use of new guidelines/technologies
	Dissemination	Of new guidelines/technologies/procedures to their members, and to decision makers about funding priorities and clinical practice
CUSTOMER ROLE	*Sponsor*	Charitable sponsorship of knowledge content relevant to the professional organisation
	Funder	Could provide funding base for the NoE (association to the NoE)

Patients, patient advocacy groups and the public.		
EXAMPLES	Patients, caregivers, patient organisations, wellbeing and prevention organisations à *e.g.: CCI-E, ONKONET, ECPC, European Patients' Forum…*	
USER ROLE	Benefits derived from publishing CPGs, the participation in forums and/or trainings for patients and the public and patient care enhancement.	
PARTNER ROLE*	*Co-thinker*	Is asked to give opinion and/or feedback
	Advisor (people with lived experience)	Give insight on patients' needs/requirements, experiences and perspectives
	Partner	Works as an equal partner in all the phases of the project/activity/development. E.g.: • In the *preparation phase: developing ideas, formulating questions, ethical approvals…* • *In the execution phase: choosing instruments, data collection, data analysis…* • *In the implementation phase: report writing, dissemination processes, translation to practice…*
	Decision-maker	Takes initiative (final) decision
CUSTOMER ROLE	*Sponsor*	Sponsorship of relevant content to improve the quality of cancer care, such as care model implementation processes, GPG development and capacity building. This support could extend to initiatives that raise

		awareness, improve health outcomes and/or promote patient empowerment.

*JANE patient involvement toolkit, original source: Involvement Matrix https://www.kcrutrecht.nl/involvement-matrix/ Center of Excellence for Rehabilitation Medicine Utrecht

Other projects or networks		
EXAMPLES	Other ongoing European projects, Joint Actions or networks à e.g.: ECRIN, STRONG AYA, EUnetCCC, CCI4EU, ERNs, EMQN, JA PreventNCD, NCCN, EUCan, CanWON…	
USER ROLE	Access to repositories/trainings/databases	
PARTNER ROLE	*Prioritization*	Collaboration/synergies within networks and projects
	Advisement	Expertise, databases, repositories; exchange of experts
	Implementation	Implementation of care models; participation in study/pilot cases
	Evaluation	Share analysis on common topics
	Dissemination	*Foster research*: collaborate to promote high quality research by sharing methodologies, procedures and knowledge; twinnings; *event synergies*
CUSTOMER ROLE	Sponsor	Occasional collaborations, contributions to other initiatives

Tables 1-3. Illustrative examples of stakeholder roles and interaction modes with the NoEs

Although the template was designed to be self-explanatory, its completion was supported through regular discussions during WP4 monthly meetings, where methodological aspects were clarified and common challenges addressed. Bilateral support was also provided where needed to assist individual NoEs during the validation process. Together, this approach ensured a harmonised yet flexible stakeholder mapping process. Toward the end of 2025, Network of Expertise leaders were given the opportunity to revisit and update their stakeholder mapping, in order to reflect any adjustments considered necessary after the first year of the Joint Action or to incorporate newly identified organisations. This revision process was designed to actively involve both NoE leaders and co-leaders,

as well as the leaders of sustainability-related tasks within each Network of Expertise where such task were defined.

It should be noted, before concluding this section, that for the purpose of this mapping exercise, stakeholders were defined broadly to include not only formal organisations, but also relevant Networks of Expertise from other NoEs, relevant European projects and collaborative initiatives active in related domains. This decision reflects the recognition that, within the oncology ecosystem, networks and projects often act as collective knowledge holders, service users and multipliers, playing a relevant role in shaping demand, alignment and uptake of NoE services.

3.2 Need assessment survey

3.3 Survey development

The needs assessment survey was designed to support each Network of Expertise in gaining a structured understanding of the specific needs, interests and expectations of key stakeholders in relation to the seven cancer domains addressed within JANE-2. The overarching aim of the survey is to ensure that future NoE services respond to real demand from the ecosystem and are aligned with stakeholders' perceived value.

Specifically, the survey sought to capture meaningful and accurate stakeholder input on needs, expectations and perceptions of value in relation to NoE-specific services, as well as to explore acceptable forms of engagement and contribution, including different participation and support models. The insights gathered through this process are intended to inform the design, prioritisation and sequencing of future services across the Networks of Expertise.

To address these objectives in a structured manner, the survey was organised into three main sections, each targeting a complementary dimension of stakeholder input. These sections are described in detail below, while the full survey can be consulted in **Annex 1**.

1. **General information**

   The first section of the needs assessment survey focused on general organisational information and was mandatory for all respondents. Its objective was to contextualise subsequent responses by capturing key characteristics of the participating organisations and the profile of the individual completing the survey.

   This section included questions on the organisation's full name and acronym, the position or role of the respondent within the organisation, and the organisational typology best describing the respondent's institution. In addition, respondents were asked to indicate the nature of their

organisation (non-profit or for-profit) and its primary operational scope, covering local, regional, national and international contexts.

Finally, this section included a classificatory question allowing respondents to indicate the cancer domain(s) relevant to their organisation among the seven Networks of Expertise developed within JANE-2. This information supported the subsequent analysis of responses by Network of Expertise and stakeholder profile, enabling domain-specific interpretation of stakeholder input.

2. Needs assessment

The second section of the needs assessment survey constituted the core analytical component of the questionnaire and focused on the assessment of service relevance and unmet needs for each Network of Expertise. This section was designed to capture stakeholders' perspectives on the added value, applicability and completeness of the service categories envisaged within the current conceptual scope of the NoEs.

The needs assessment is structured around two complementary questions, designed to capture both quantitative and qualitative stakeholder input. This section was completed once for each Network of Expertise selected by the respondent in the general information section, allowing stakeholders active across multiple cancer domains to provide domain-specific input. This design ensured that feedback reflected the specific context, priorities and gaps associated with each NoE, rather than generic or non-differentiated responses.

The first question invited respondents to assess the relevance of a predefined set of broad service categories that each Network of Expertise could potentially offer. Stakeholders were asked to rate each category using a 0–10 scale, based on their organisation's perceived gaps, priorities and strategic goals.

During the survey design phase, it was observed that some initially proposed services by the JANE-2 JA were formulated at the level of specific activities (e.g. organising training events or webinars), rather than at the level of the underlying service dimension (e.g. knowledge and skills development). To address this heterogeneity and ensure conceptual consistency, an abstraction exercise was carried out to consolidate individual activities into broader service categories capable of encompassing the full portfolio of activities envisaged by the NoEs.

These broader categories were intentionally defined to capture the diversity of planned activities, enable consistent data collection across all Networks of Expertise, and support comparative analysis and aggregation of results. As a result of this consolidation process, a total

of **twelve service categories** were defined and used as the basis for the quantitative component of the needs assessment survey.

	1	2	3	4	5	6	7	8	9	10
Knowledge and skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○
Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○
Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Figure 7. Needs assessment service categories

The second question complemented this rating exercise through an open-text format. Recognising that predefined service categories cannot fully capture the diversity and specificity of stakeholder needs, respondents were explicitly invited to identify additional requirements or expectations that they considered insufficiently addressed by the listed categories. This question was designed to capture emerging themes, context-specific needs and innovative ideas, providing qualitative depth and supporting the refinement of future NoE service portfolios.

3. Potential collaboration

The third section of the needs assessment survey explored potential collaboration models between stakeholders and the Networks of Expertise. In contrast to the domain-specific needs assessment section, this part of the questionnaire was general in nature and was completed once per respondent, regardless of the Network(s) of Expertise previously selected. Its objective was

to capture stakeholders' envisaged modes of interaction, levels of engagement and willingness to contribute to the Networks of Expertise as a whole, thereby informing future governance, engagement and sustainability strategies.

Envisaged stakeholder roles: The first question in this section invited respondents to reflect on the role their organisation could potentially assume when interacting with the Networks of Expertise. This role-based approach was developed to differentiate between distinct modes of interaction and contribution, and to support the definition of governance and engagement models aligned with stakeholders' expectations and capacities.

Respondents were asked to select the role that best described their organisation's envisaged relationship with the Networks of Expertise in general. The roles were defined as follows:

- **Partner**: a stakeholder actively engaged in the day-to-day life of the Network of Expertise, participating in working groups or committees and contributing expertise, strategic guidance and, where relevant, decision-making input, as well as logistical or scientific support. Partners are full members of the Networks of Expertise and are expected to contribute through a membership fee.
- **User**: a stakeholder benefiting from the services provided by the Network of Expertise without being deeply involved in core activities. Users may participate as occasional collaborators or event participants, primarily receiving information, updates and shared resources. Users are considered members of the Network of Expertise and are expected to contribute through a membership fee.
- **Customer**: a stakeholder making occasional use of Network of Expertise services without being a network member. Interaction is limited and sporadic, focused on accessing specific services when needed. A fee-for-service model is envisaged for this role.
- **Sponsor**: a stakeholder supporting the Network of Expertise through financial contributions or in-kind resources without being directly involved in day-to-day activities or membership structures. Sponsors often provide logistical or financial support that enables the implementation of Network initiatives.

By distinguishing between these roles, the survey aimed to capture stakeholders' preferred relationship with the Networks of Expertise and to provide an initial framework for differentiating participation, governance and contribution models.

Expected level of involvement: Recognising that the same stakeholder role can be associated with varying degrees of engagement, the second question explored the expected level of activity

organisations foresee in relation to the Networks of Expertise. This question aimed to assess not only the type of role envisaged, but also the anticipated intensity and continuity of participation.

Respondents were asked to select one level of involvement, ranging from very active involvement (leading or highly engaged participation), active involvement (regular participation and meaningful contribution), occasional involvement (periodic engagement depending on relevance and capacity), minimal involvement (limited or peripheral interaction), to no involvement.

This dimension provides additional nuance to the role-based analysis, supporting a more realistic understanding of potential engagement patterns and informing the design of flexible participation models capable of accommodating different levels of stakeholder commitment within the Networks of Expertise.

Willingness to contribute: The final question in this section addressed stakeholders' willingness to contribute to the Networks of Expertise through different forms of support. Beyond conceptual engagement, this question aimed to explore the practical and financial dimensions of collaboration, which are critical for the long-term sustainability of the Networks of Expertise.

Respondents were asked to rate, on a 0–10 scale, their organisation's openness to different forms of contribution, including annual membership fees, payment of fees for specific services, provision of in-kind contributions, and logistical support (e.g. spaces, tools or infrastructure).

This approach was chosen to capture a graduated view of contribution readiness rather than binary yes/no responses, allowing the identification of relative openness across different contribution modalities. The results provide valuable insight into how the ecosystem perceives its capacity and willingness to support the Networks of Expertise, and constitute a key input for the development of differentiated engagement and sustainability models within WP4.

Once the survey structure and content had been defined, a structured validation process was carried out to ensure clarity, relevance and alignment with the objectives of WP4. In this context, the WP4 monthly meetings were used as a key forum to present progress in the conceptualisation and development of the survey, with WP4 partners and all Network of Expertise leaders and co-leaders invited to participate. These discussions provided an opportunity to collectively review the approach, clarify outstanding issues and ensure consistency across Networks of Expertise.

In addition, targeted exchanges were held with selected NoE leaders, particularly within the survivorship domain, to gather more detailed feedback on how best to approach specific stakeholder groups once the survey was launched. Following this iterative process, a draft version of the survey was

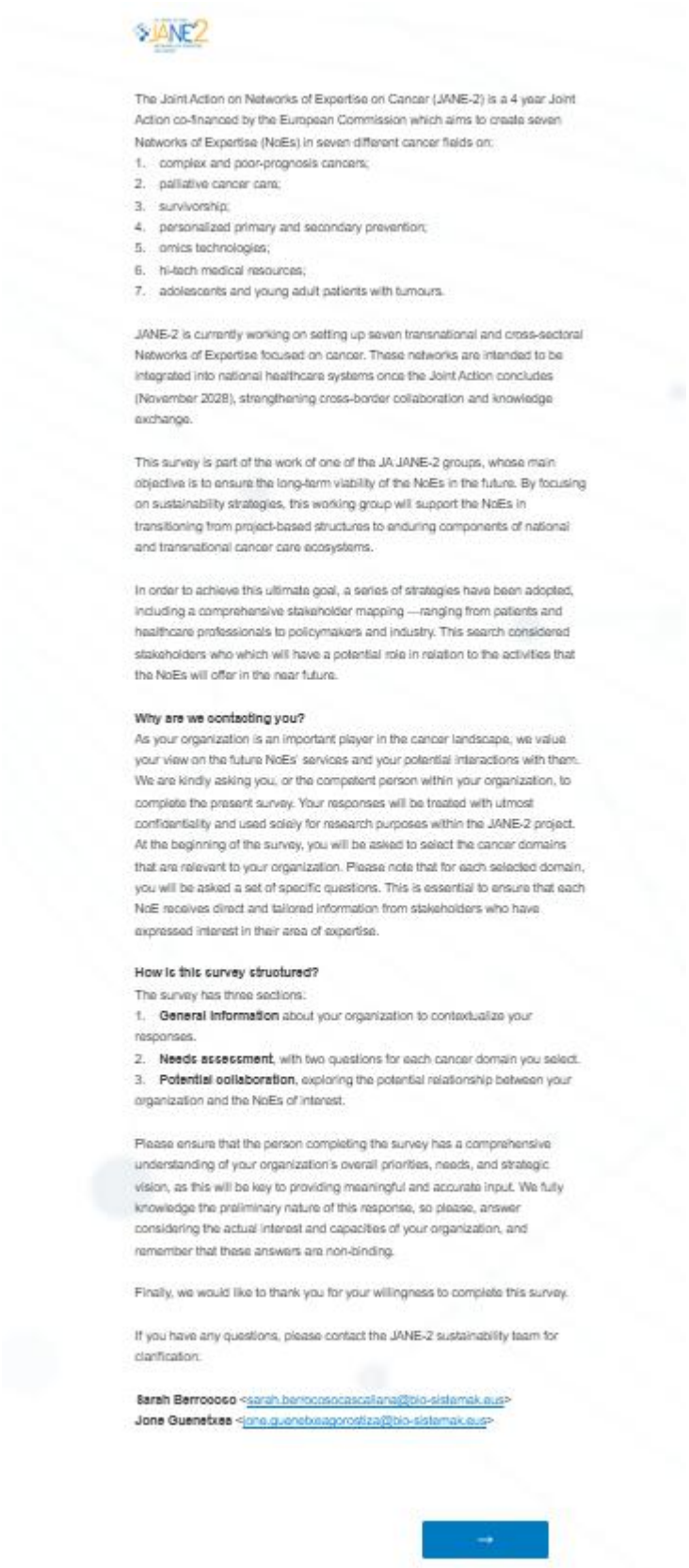
circulated among all WP4 partners and NoE leaders for final review and feedback. Detailed and constructive input was received from several organisations, including DGS, DKG, HSJD, ICO, IDIVAL, INT, NIJZ, OIL, OUS, SAS, SCIENSANO, UKW, ULSSM and UZA. This validation process contributed to refining the survey instrument and strengthening its robustness prior to dissemination.

3.4 Data collection and dissemination

The dissemination and data collection strategy for the needs assessment survey was designed to ensure both broad reach across the oncology ecosystem and the collection of meaningful, high-quality input. Special emphasis was placed on reaching the most appropriate representatives within organisations, namely individuals with a comprehensive understanding of their organisation's structure, strategic priorities and operational goals, in order to obtain accurate and relevant responses.

To support this objective, WP4 partners were actively consulted during the preparation phase and invited to share ideas on how best to reach relevant organisations beyond generic contact points. Based on this input, a tailored invitation letter was prepared, explicitly encouraging recipients to forward the survey internally to the most suitable individual within their organisation if needed. As an alternative, organisations were also given the option to consolidate the required information internally and submit a single response on behalf of the appropriate individuals.

Data collection took place between March and April 2026. Stakeholders identified through the mapping exercise were contacted and invited to complete an online questionnaire developed using the Qualtrics platform (see Annex 1). While the online version was the primary data collection tool, an offline version of the survey was made available upon request, and responses via email were accepted if needed. Although several contacts requested the offline version, no completed questionnaires were ultimately returned through this channel.



The Joint Action on Networks of Expertise on Cancer (JANE-2) is a 4 year Joint Action co-financed by the European Commission which aims to create seven Networks of Expertise (NoEs) in seven different cancer fields on:

1. complex and poor-prognosis cancers;
2. palliative cancer care;
3. survivorship;
4. personalized primary and secondary prevention;
5. omics technologies;
6. hi-tech medical resources;
7. adolescents and young adult patients with tumours.

JANE-2 is currently working on setting up seven transnational and cross-sectoral Networks of Expertise focused on cancer. These networks are intended to be integrated into national healthcare systems once the Joint Action concludes (November 2028), strengthening cross-border collaboration and knowledge exchange.

This survey is part of the work of one of the JA JANE-2 groups, whose main objective is to ensure the long-term viability of the NoEs in the future. By focusing on sustainability strategies, this working group will support the NoEs in transitioning from project-based structures to enduring components of national and transnational cancer care ecosystems.

In order to achieve this ultimate goal, a series of strategies have been adopted, including a comprehensive stakeholder mapping —ranging from patients and healthcare professionals to policymakers and industry. This search considered stakeholders who which will have a potential role in relation to the activities that the NoEs will offer in the near future.

Why are we contacting you?

As your organization is an important player in the cancer landscape, we value your view on the future NoEs' services and your potential interactions with them. We are kindly asking you, or the competent person within your organization, to complete the present survey. Your responses will be treated with utmost confidentiality and used solely for research purposes within the JANE-2 project. At the beginning of the survey, you will be asked to select the cancer domains that are relevant to your organization. Please note that for each selected domain, you will be asked a set of specific questions. This is essential to ensure that each NoE receives direct and tailored information from stakeholders who have expressed interest in their area of expertise.

How is this survey structured?

The survey has three sections:

1. **General information** about your organization to contextualize your responses.
2. **Needs assessment**, with two questions for each cancer domain you select.
3. **Potential collaboration**, exploring the potential relationship between your organization and the NoEs of interest.

Please ensure that the person completing the survey has a comprehensive understanding of your organization's overall priorities, needs, and strategic vision, as this will be key to providing meaningful and accurate input. We fully knowledge the preliminary nature of this response, so please, answer considering the actual interest and capacities of your organization, and remember that these answers are non-binding.

Finally, we would like to thank you for your willingness to complete this survey.

If you have any questions, please contact the JANE-2 sustainability team for clarification:

Sarah Berrocoso <sarah.berrocosocascallana@bio-sistemak.eus>
Jone Guenetxea <jone.guenetxeagorostiza@bio-sistemak.eus>

Figure 8. Welcome message of the online questionnaire previewed in Qualtrics

All responses collected were consolidated into a single dataset covering all Networks of Expertise. The dataset was subsequently cleaned to remove duplicate and incomplete entries, with detailed information on data cleaning and final sample composition presented in the results section. To maximise response rates, two reminder rounds were conducted during the data collection period. A dedicated tracking spreadsheet was used to monitor contacted organisations, incoming responses and follow-up actions in a systematic manner.

In addition to direct outreach to mapped stakeholders, a broader dissemination strategy was implemented to extend the reach of the survey. WP4 partners were invited to share the survey within their relevant professional and institutional networks. As part of this effort, HSJD, IDIVAL, OUS and SCIENSANO reported additional dissemination activities within their respective networks. Further dissemination was also supported through collaboration with Joint Action partners and related European initiatives, including the Joint Action on Personalised Cancer Medicine (JA PMC) and the European Clinical Research Infrastructure Network (ECRIN), which helped circulate the survey among their member organisations. These entities had already been identified as relevant stakeholders within the mapping exercise.

Finally, the survey was promoted through social media channels, primarily via LinkedIn, to further increase visibility and encourage participation from relevant actors within the European oncology ecosystem.

It should be noted that access to the survey has not been formally closed at this stage. In order to further strengthen the evidence base informing the development of the NoE service portfolios, additional outreach rounds may be considered, particularly for Networks of Expertise with lower response rates, with the aim of gathering further targeted input from relevant stakeholders.

4 RESULTS

This section presents the results of all activities carried out under Task 4.1, aimed at identifying, characterising and engaging relevant stakeholders across the different Networks of Expertise.

First, a general overview of the stakeholder mapping exercise conducted for each Network of Expertise is provided, including the typology of stakeholders identified and the roles initially envisaged for their engagement within the networks. This initial mapping served as a foundational input to inform subsequent project activities. A more detailed analysis of stakeholder positioning, expected contributions and interaction models will be further developed within Task 4.2 (Validation of NoE service portfolio), dedicated to the design of the service portfolio for each NoE, and Task 4.4, focused on the establishment of NoE partnerships.

Second, the section presents the results of the needs assessment survey addressed to external stakeholders. The analysis begins with descriptive information on survey participation and the profiles of responding stakeholders. This is followed by a domain-specific review of the relevance attributed to the predefined service categories for each Network of Expertise, aimed at identifying overall patterns of interest and areas of relative emphasis. Finally, results related to expected roles, levels of involvement and willingness to contribute to the Networks of Expertise are presented, providing a first indication of potential engagement models.

4.1 Overview of the stakeholder mapping across NoEs

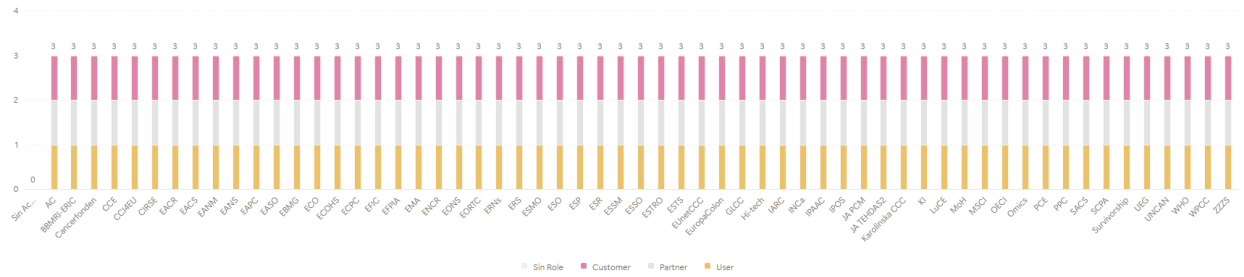
As an initial output of Task 4.1, a descriptive overview of the stakeholder mapping conducted across the Networks of Expertise was compiled. This mapping aimed to provide a high-level picture of the breadth and diversity of relevant stakeholders identified for each NoE, without entering into a detailed analysis at this stage. Across the seven Networks of Expertise, the mapping identified a heterogeneous set of stakeholders spanning multiple segments of the cancer care ecosystem, including professional societies, research and innovation organisations, non-profit organisations, public health agencies, policymakers, patient and public representatives, industry actors, as well as other European projects and networks.

The following paragraphs provide a brief descriptive snapshot of the stakeholder mapping results for each Network of Expertise, including the total number of stakeholders identified and their distribution across stakeholder typologies. A visual overview of the mapped stakeholders and their envisaged roles (partner, user or customer) for each NoE is included after the corresponding description.

Complex and poor-prognosis cancers

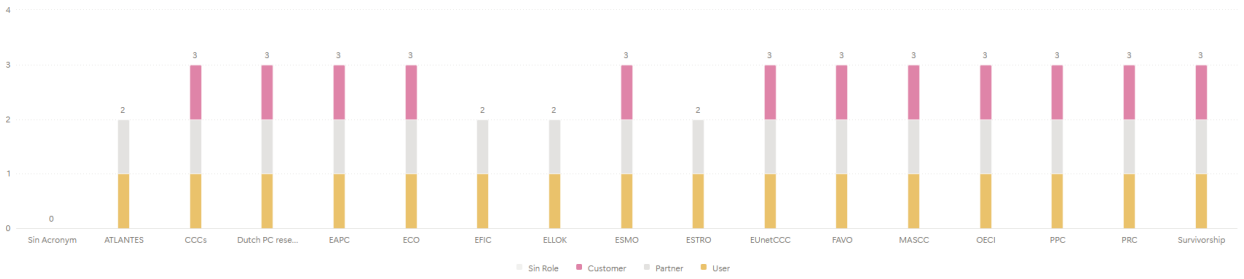
For the Complex and Poor-Prognosis Cancers Network of Expertise, a total of 59 stakeholders were mapped. The stakeholder landscape is dominated by professional societies and research and innovation

organisations, complemented by non-profit organisations, public health agencies, policymakers, industry representatives and other European projects and networks. The graphic illustrates the distribution of mapped stakeholders and their envisaged roles within the network.



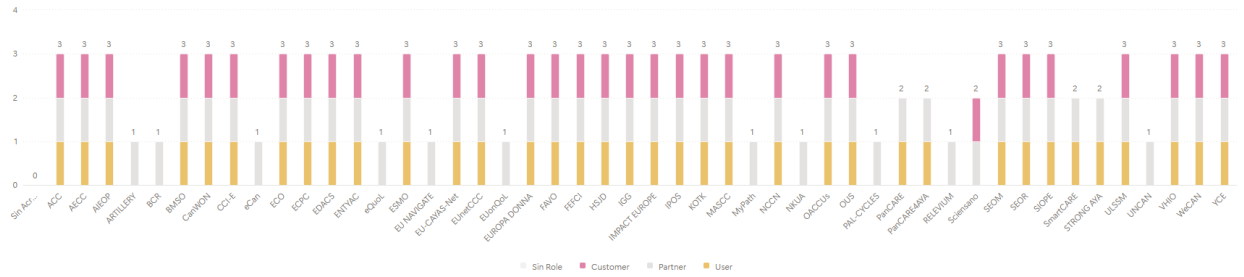
Palliative Cancer Care

The Palliative Cancer Care Network of Expertise identified a total of 23 stakeholders. These include a balanced mix of non-profit organisations, professional societies, research and innovation actors, patient and public representatives, healthcare providers, policymakers and other collaborative initiatives. A graphical overview of stakeholder roles is presented in the graphic below.



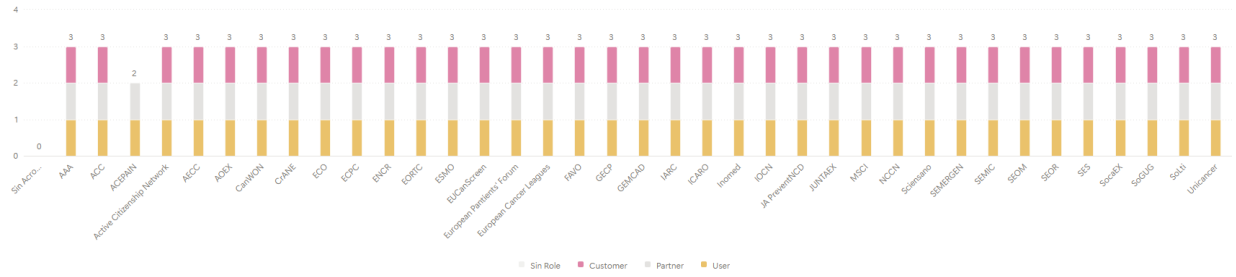
Survivorship

For the Survivorship Network of Expertise, 47 stakeholders were mapped, with a strong presence of other European projects and networks, patient and public representatives, professional societies and healthcare provider organisations. This reflects the broad and cross-sectoral nature of the survivorship domain. The corresponding role distribution is shown in the graphic.



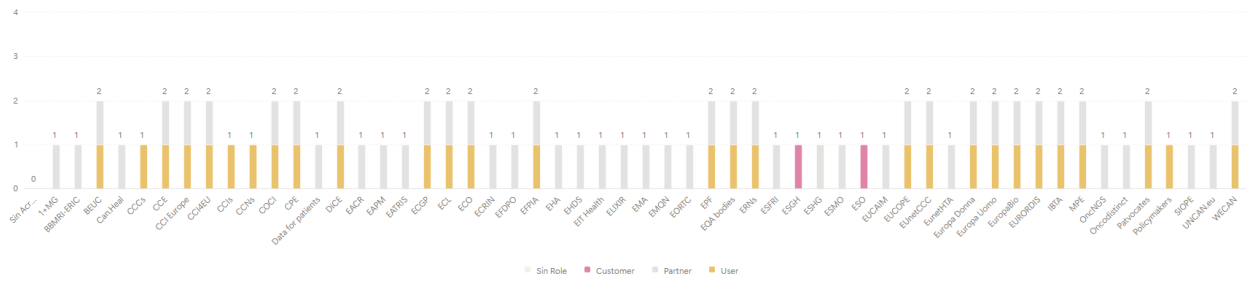
Personalised Primary and Secondary Prevention

The Personalised Primary and Secondary Prevention Network of Expertise mapped 33 stakeholders spanning professional societies, research and innovation organisations, patient and public representatives, other projects and networks, as well as selected industry and policy actors. The graphic provides an overview of the envisaged stakeholder roles.



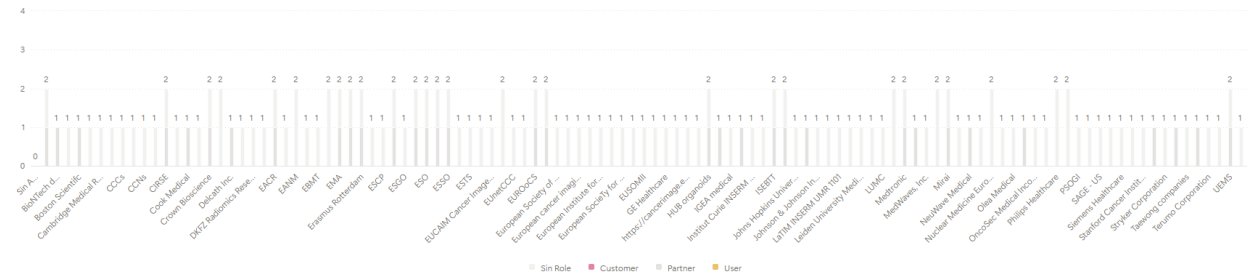
Omic technologies

The Omic Technologies Network of Expertise identified 58 stakeholders, characterised by a diverse ecosystem including industry actors (both pharmaceutical and medtech), patient and public organisations, research and innovation entities, professional societies and collaborative European initiatives. The variety of envisaged interaction roles is displayed in graphics.



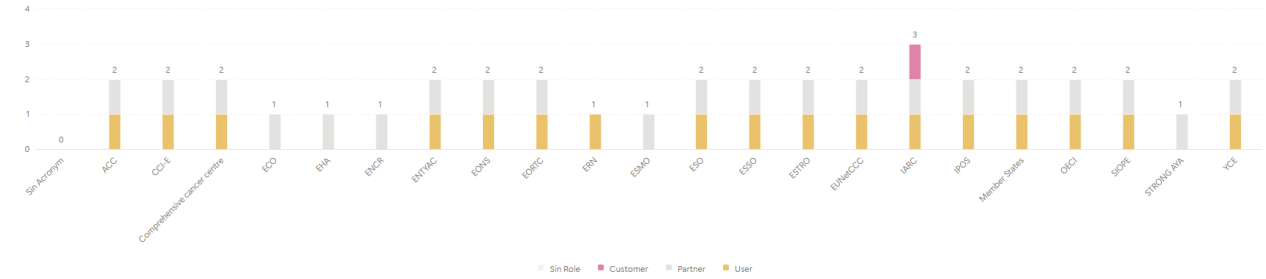
Hi-Tech Medical resources

The High-Tech Medical Resources Network of Expertise mapped a total of 75 stakeholders. This network displays a particularly strong representation of industry actors, professional societies, research and innovation organisations and academic institutions. Given the transversal and infrastructure-driven nature of this domain, the stakeholder analysis was further refined through individual sub-domain mappings carried out within the network. The aggregated overview of stakeholder roles is presented in the graphic.



Adolescents and Young Adults

For the Adolescents and Young Adults Network of Expertise, 23 stakeholders were identified, including healthcare professionals, non-profit organisations, professional societies, patient and public representatives, policymakers and other collaborative initiatives. The graphic summarises the distribution of stakeholder roles within this network.



4.2 Needs assessment survey results

The analysis of responses collected through the needs assessment survey is primarily based on descriptive statistics, including absolute numbers (N), mean scores and relative percentages. This approach was chosen to provide a clear and transparent overview of stakeholder input across different dimensions of interest. Where relevant, selected open-text responses were systematically reviewed, synthesised and recoded into analytical categories, allowing qualitative insights to be integrated alongside quantitative findings. Together, this mixed-methods approach supports a consistent and robust interpretation of stakeholder perspectives.

To contextualise survey responses, selected variables derived from open or semi-structured questions were re-classified into broader analytical groupings. In particular, the professional role of the respondent within their organisation was recoded into four profile categories reflecting different levels of decision-making authority and organisational responsibility: strategic leadership or governance roles (e.g. Presidents, CEOs, Executive Directors), senior management or department leadership roles (e.g. Directors, Heads of Unit or Institute Managers), operational or project management roles (e.g. Project Managers, EU affairs or coordination functions), and technical or academic profiles. This reclassification enabled a more meaningful interpretation of responses beyond individual job titles.

Survey results are presented across three main analytical sections. **First**, descriptive information on survey participation and respondent profiles is provided, offering context on the organisations and individuals contributing to the assessment. **Second**, the relevance attributed by stakeholders to the predefined service categories is examined, both across and within Networks of Expertise, to identify overall patterns of interest and areas of relative emphasis. **Finally**, results related to envisaged stakeholder roles, expected levels of engagement and willingness to contribute are presented, providing an initial evidence base to inform future engagement models and sustainability considerations for the Networks of Expertise.

4.2.1 Participation and respondent profiles

A total of 81 responses were initially collected through the needs assessment survey. Following data cleaning, four records were excluded due to duplication or incompleteness, and nine additional responses were excluded as the survey was started but not completed, resulting in a final dataset of 68 valid responses. Of these, 21 responses correspond to stakeholders previously identified and mapped within the NoEs. Of the the total of respondents, only 45 participated in the last part of the survey about stakeholder roles, level of engagement and willingness to contribute.

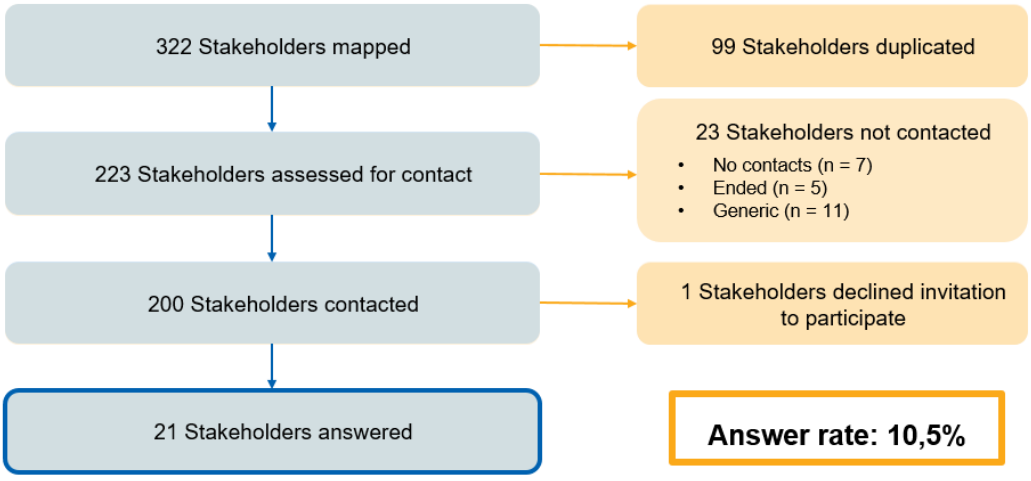


Figure 9. Contact and response overview

Organization typology

Organization typology	Number of stakeholders	%
Academia	7	10,29%

Health and care payers	1	1,47%
Health and care providers (belonging to Comprehensive Cancer Centres)	18	26,47%
Health and care providers (not belonging to Comprehensive cancer centres)	8	11,76%
Health Authorities	2	2,94%
Network	4	5,88%
Other	10	14,71%
Patient Organizations	7	10,29%
Public health agencies	3	4,41%
Research and innovation organizations	8	11,76%
Total	**68**	**100,00%**

Operational context

Operational context	N	%
International: your organization works in more than one country.	21	30,88%
Local: your organization works in a small part of a region, such as a city or a municipality.	7	10,29%
National: your organizations activities are scattered all around a country in more than one region.	25	36,76%
Regional: your organization works in more than a city or municipality of a country, but those are encompassed within the same administrative entity, which name can vary attending to the geopolitical management of the country.	15	22,06%
Total	**68**	**100,00%**

To contextualise the responses, the role of the respondent within the organisation was reclassified into broad categories reflecting strategic, managerial, operational and technical profiles.

- **Strategic leadership / governance**: This category includes roles with high decision making capacity and an institution wide or strategic vision, such as President or Chairman, CEO or General Manager, Executive Director, Secretary General, and Founder.
- **Senior management / department leadership**: This category covers senior functional, clinical or scientific leadership roles with transversal organisational oversight, including Directors, Heads of Unit or Department or Institute Managers.

- **Operational / project management**: This category comprises roles primarily involved in the operationalisation of organisational strategies and day-to-day coordination activities, such as Project Managers or EU affairs.

Most survey responses were provided by individuals in strategic leadership or senior management positions (45.59% and 14.71%, respectively), indicating that the needs assessment largely reflects organisational-level priorities and institutional perspectives rather than individual viewpoints. A substantial proportion of responses also came from operational and project management profiles (23.53%), suggesting a meaningful contribution from stakeholders involved in the practical implementation of activities. Technical or academic profiles accounted for a more limited share of responses (10.29%), while a small proportion of respondents could not be clearly categorised based on the information provided (5.88%).

4.2.2 Relevance of service categories across NoEs

Stakeholders assessed the relevance of each predefined service category using a 1–10 rating scale (1 = very low relevance; 10 = very high relevance). Mean scores derived from this scale are used throughout the analysis to describe overall levels of interest and relative emphasis across Networks of Expertise. To support a consistent interpretation of results, mean values were categorised using a descriptive framework, with scores between 1.0 and 3.9 indicating low interest, scores between 4.0 and 6.9 indicating moderate interest, and scores from 7.0 to 10.0 indicating high interest.

To ensure a structured yet comprehensive interpretation, results are presented separately for each Network of Expertise. For each NoE, the analysis follows a sequential approach, starting with the number of responding stakeholders, followed by an overall assessment of service relevance based on mean scores, a disaggregation by stakeholder typology, and finally a qualitative synthesis of open-text responses addressing needs beyond the predefined service categories.

This approach allows for both within-NoE interpretation and cross-NoE comparison, highlighting convergent patterns of interest across domains while also capturing context-specific differences

4.2.2.1 Complex and poor-prognosis cancers

For the PPC NoE, responses were received from 49 stakeholders, whose assessments are summarised below.

Overall, stakeholders expressed a high level of interest across all service categories, with mean scores ranging from 6.92 for legal and ethical support to 7.78 for advocacy, and an overall average score of 7.52. Within this overall positive assessment, slightly higher scores were observed for services related to **networking and collaboration** (8.67), **research promotion** (8.20), and **knowledge and skills**

development (7.80), indicating areas of relatively stronger emphasis rather than exclusive prioritisation.

When results are disaggregated by stakeholder typology reveals broadly consistent patterns of high interest across all service categories, with only expected variations in emphasis according to organisational roles (e.g. advocacy-related services for patient organisations and benchmarking or infrastructure-related services for research-oriented stakeholders). A detailed breakdown of these results is presented in Annex 2.

To complete these quantitative findings, stakeholders were also invited to **identify additional needs that they considered insufficiently addressed by the predefined service categories**. The following section summarises and categorises these open-text responses, providing qualitative insight into perceived gaps and additional areas of relevance within the PPC NoE.

Stakeholders highlighted key unmet needs related to data interoperability and quality benchmarking across Europe (e.g. robust interoperable data platforms, comparative quality data and alignment of national registries), alongside improved access to novel therapies and support for the uptake of innovation in real world clinical settings. Strong emphasis was also placed on strengthening independent clinical research and multinational academic studies, harmonising care pathways and clinical guidelines, and improving integrated care models, including earlier and more coordinated integration of palliative care.

While most identified needs align well with the predefined service categories, several stakeholders also highlighted structural and system-level challenges — such as infrastructure capacity, sustainable research funding and workforce constraints — which fall beyond direct service provision but provide important context for the implementation and long-term impact of the NoEs.

Below is a breakdown of the responses provided by the stakeholders, along with specific examples they have given.

1. Care Pathways, Models of Care & Transition

Focus on organisation of care, continuity, and patient-centred models:

- Transition care from pediatrics to adult
- Specific patient care models
- Integration of palliative care services to support earlier and more patient-centred symptom management
- Accessibility of network partners and co-care-providing institutions
- Data registration of quality of clinical management

2. Access to Innovation and Novel Therapies

Focus on availability and uptake of new treatments and diagnostics:

- Access to novel therapies
- Knowledge about new treatments
- Equity in access to innovative treatments, biomarker testing and comprehensive cancer care
- Support to implement and scale innovation in precision oncology, genomics and digital health

3. Clinical Research Development & Independent Research

- Focus on trials, academic research, and research capacity:
- Clinical research development
- Advice in clinical trials improvement (number of patients recruited; phase I trials)
- Financial support for independent research
- Sustainability and funding models for multinational academic clinical studies
- Acquire financial support for the area
- Protected time and resources for clinicians to engage in research

4. Data, Registries & Interoperability

Focus on data quality, sharing, and EU-level alignment:

- Comparative quality data across Europe
- Robust, interoperable data platforms supporting standardized collection, validation and benchmarking
- Strengthening data interoperability and secure cross-border data exchanges
- Alignment of national registries with EU standards
- Data registration of quality of clinical management

5. Guidelines, Standards & Benchmarking

Focus on harmonisation and quality standards:

- Support in the development of clinical guidelines
- Use of screening tools
- Harmonization of cancer care pathways across Europe

- Benchmarking and quality standards across countries

6. Infrastructure, Equipment & Technical Capacity

Focus on physical and organisational capacity:

- Infrastructure and staff
- Technical updated equipment sharing, minimizing costs
- Research infrastructures providing services to research, policy makers and patient organisations
- Medical Physics expert recognition across Europe

7. Research Infrastructures & Network Integration

Focus on connecting infrastructures, networks, and care systems:

- Alignment between Research Infrastructures and cancer care networks
- Integration of Research Infrastructures into oncology pathways
- Sharing existing tools and expertise and avoiding duplication
- Accessibility of network partners

8. Industry Collaboration & Drug Development

Focus on interaction with pharma and innovation pipelines:

- Collaboration with pharma to develop drugs for unmet needs

9. Legal, Ethical & Regulatory Support

Focus on GDPR, ethics and compliance:

- Support in implementing GDPR-compliant data processing solutions
- Legal and ethical support (e.g. GDPR)

10. Funding, Sustainability & Participation in EU Initiatives

Focus on long-term viability and engagement:

- Sustainable funding mechanisms for national societies
- Support for long-term participation in EU initiatives
- Financial support for network activities
- Funding models enabling engagement beyond voluntary contribution

11. Governance, Coordination & Knowledge Exchange

Focus on coordination at EU and network level:

- Enhance coordination and knowledge exchange across cancer domains
- Strategic alignment between national cancer priorities and EU initiatives
- Governance and coordination support

12. Patient Involvement, Advocacy & Co-creation

Focus on patient voice and policy influence:

- Enhanced patient involvement and co-creation in cancer policies
- Structured methodologies to incorporate patient perspectives
- Advocacy and policy engagement

4.2.2.2 Palliative cancer care

For the PC NoE, responses were received from 40 stakeholders, whose assessments are summarised below.

Overall, stakeholders expressed a high level of interest across all service categories, with mean scores ranging from 8.50 to 7.48, and an overall average score of 8.10. Within this overall positive assessment, slightly higher scores were observed for services related to research promotion (8.50), Development of health or care organizational models (8.40), and networking and collaboration (8.40), highlighting domains where interest is relatively more pronounced, rather than indicating clear-cut priority areas.

In the palliative care domain, disaggregation by stakeholder typology reveals consistently high levels of interest across all service categories, with limited variation in overall intensity. As expected, differences in emphasis reflect organisational roles: research-oriented stakeholders show stronger interest in research promotion, data sharing, benchmarking and public awareness, while care providers and payers prioritise organisational models, clinical guidelines and capacity-building services. Patient organisations place comparatively greater emphasis on advocacy-related activities, public awareness and networking, whereas authorities and public agencies highlight benchmarking and system-level organisational support. Legal and ethical services, while still positively rated, receive slightly lower scores across most stakeholder groups. A detailed breakdown of results is provided in Annex 2.

In the open-ended questions stakeholders most frequently highlighted unmet needs related to the availability and interoperability of data on palliative care across Europe (e.g. comprehensive and accessible cross-country data and quality registries), alongside the need for harmonised and comprehensive clinical guidelines on critical areas such as pain management, access to palliative care

and care transitions. Strong emphasis was also placed on strengthening clinical research and innovation in palliative care, including support for clinical trials and novel therapeutic approaches, improving integrated care models for specific populations such as adolescents and young adults, and enhancing public awareness and understanding of palliative care beyond end-of-life settings.

While most of these needs align with the predefined service categories, several respondents also pointed to broader structural and system-level challenges — including infrastructure capacity, workforce constraints and sustainable funding mechanisms — which fall beyond direct service provision but provide important context for the effective implementation and long-term impact of the NoEs.

1. Data, Registries & Cross-country Comparability

Focus on availability, interoperability and quality of data:

- Detailed, accessible and comprehensive data about all European countries
- Data registration of quality of clinical management
- Strengthening data interoperability and alignment of datasets with EU standards

2. Clinical Guidelines, Standards & Care Pathways

Focus on harmonisation and evidence-based practice:

- Comprehensive guidelines on critical areas such as pain management
- Guidelines on access to palliative care and transition pathways
- Harmonisation of care pathways across Europe

3. Integrated Care Models & Continuity of Care

Focus on coordination, transitions and population-specific needs:

- Integration of palliative care into broader oncology pathways
- Transition from paediatric to adult care
- Adolescents and Young Adults (AYA) care needs

4. Clinical Research, Trials & Innovation in Palliative Care

Focus on research capacity and novel approaches:

- Clinical trials in palliative care
- Improving clinical trial numbers and outcomes
- Novel approaches for palliative care (e.g. use of psychedelics)

- Biobank development

5. Infrastructure, Equipment & Technical Capacity

Focus on physical and organisational resources:

- Modern infrastructure and updated equipment sharing to minimise costs
- Infrastructure supporting high-quality palliative care delivery

6. Access to Innovation and Emerging Technologies

Beyond traditional palliative interventions:

- Access to advanced diagnostics and new therapies
- Implementation of emerging technologies (e.g. digital tools, AI) in real-world settings

7. Public Awareness, Education & Reframing of Palliative Care

Focus on societal understanding and visibility:

- 'Re-branding' palliative care for the general public
- Palliative care is not end-of-life care
- Educating the public

8. Funding, Sustainability & Workforce Capacity

System-level enabling conditions:

- Protected time and resources for clinicians to engage in research
- Sustainable support for participation in EU initiatives
- Long-term funding for national scientific societies

9. Patient Involvement, Advocacy & Co-creation

Focus on patient voice and policy influence:

- Structured patient involvement in care design and policies
- Co-creation methodologies
- Advocacy and patient-centred policy engagement

4.2.2.3 Survivorship

For the survivorship NoE, responses were received from 34 stakeholders, whose assessments are summarised below.

Overall, stakeholders expressed a high level of interest across all service categories, with mean scores ranging from 6,50 to 8,79, and an overall average score of 7,60. Within this overall positive assessment, slightly higher scores were observed for services related to , revealing a marked concentration of interest in engagement-oriented activities that clearly stand out from the remaining service categories.

When results were analysed by stakeholder typology reveals differentiated patterns of emphasis across service categories, alongside generally positive assessments overall. Patient organisations and networking entities consistently report higher levels of interest in services related to networking and collaboration, advocacy or policy influence, and public awareness, underscoring the centrality of engagement- and visibility-oriented activities for these groups. Research-oriented stakeholders (academia and research and innovation actors) show stronger interest in research promotion, data access and sharing, and benchmarking-related services, while health and care providers and health authorities display comparatively higher scores for organisational models, clinical guidelines and quality-related support. By contrast, infrastructure improvement and legal and ethical services receive lower, though still positive, ratings across most stakeholder categories. A detailed breakdown of results is presented in Annex 2.

In the open-ended questions stakeholders most frequently highlighted unmet needs related to survivorship-specific data generation and cross-country comparability of outcomes (e.g. data sharing enabling international collaboration and benchmarking), alongside improved access to research and innovation relevant to long-term follow-up, including precision medicine and digital monitoring tools. Particular emphasis was placed on transition pathways and the specific needs of populations such as adolescents and young adults, as well as on survivorship-related rights and social reintegration issues, including the Right to Be Forgotten, return-to-work policies and protection against financial discrimination.

While many of these needs align with the predefined service categories, several stakeholders also pointed to broader legal, policy and system-level challenges — such as EU-level harmonisation of survivorship rights, cross-sector engagement beyond health systems, and sustainable capacity for professional and advocacy involvement — which extend beyond direct service provision but are critical for achieving meaningful and equitable survivorship outcomes across Europe.

1. Care Pathways, Transitions & Population-specific Needs

Focus on continuity of care and specific survivor populations:

- Transition from active treatment to survivorship and follow-up
- Transition pathways across life stages
- Specificities of Adolescents and Young Adults (AYA)

2. Access to Innovation and Precision Medicine in Survivorship

Focus on long-term follow-up, monitoring and tailored approaches:

- Better knowledge about the development of precision medicines
- Access to innovation, including advanced diagnostics and new therapies
- Implementation of emerging technologies (precision oncology, digital tools, AI) in routine clinical practice

3. Research, Data Sharing & Outcome Comparability

Focus on survivorship-specific evidence generation:

- Access to research in survivorship
- International collaboration and data sharing across countries
- Comparisons of survivorship outcomes across Europe
- Strengthening data interoperability and alignment with EU standards

4. Survivor Rights, Legal Protection & Social Reintegration

Focus on rights-based and socio-economic dimensions of survivorship:

- Right to Be Forgotten (RTBF)
- Addressing financial discrimination in access to insurance, mortgages and loans
- Return-to-work policies and social reintegration of cancer survivors
- Legal harmonisation and implementation mechanisms at EU level

5. Policy Alignment, Advocacy & Cross-sector Engagement

Focus on multi-actor coordination beyond health systems:

- Policy and legal harmonisation at EU level
- Cross-sector engagement between advocates, clinicians, policymakers, regulators, insurers and financial institutions
- Monitoring and evidence generation on real-world discrimination and survivor impact

6. Digital Tools, Monitoring & Empowerment of Survivors

Focus on self-management and long-term monitoring:

- Digital tools for health monitoring
- Awareness-raising and survivor empowerment
- Practical guidance to help survivors understand and exercise their rights

7. Clinical Research Capacity & Professional Engagement

System-level enabling conditions:

- Clinical research development

- Protected time and resources for clinicians to engage in research and EU initiatives
- Support for national scientific societies to participate sustainably in European networks

8. Governance, Coordination & Implementation Capacity

Horizontal coordination across networks and countries:

- Support for coordinated EU-level action on survivorship
- Ensuring implementation, not only policy declarations
- Translating EU-level advances into meaningful national and patient-level impact

4.2.2.4 Personalised primary and secondary prevention

For the PPP NoE, responses were received from 25 stakeholders, whose assessments are summarised below.

Overall, stakeholders expressed a high level of interest across all service categories, with mean scores ranging from 8.50 to 7.48, and an overall average score of 8.10. Within this overall positive assessment, slightly higher scores were observed for services related to research promotion (8.50), Development of health or care organizational models (8.40), and networking and collaboration (8.40), highlighting domains where interest is relatively more pronounced, rather than indicating clear-cut priority areas.

In the PPP domain, analysis by stakeholder typology reveals generally high and consistent levels of interest across service categories, alongside differentiated patterns of emphasis reflecting organisational roles. Research-oriented stakeholders (academia and research and innovation actors) report particularly high interest in services related to knowledge and skills development, research promotion, data access and benchmarking, highlighting the central role of evidence generation and data-driven prevention approaches. Health and care providers show comparatively stronger scores for networking and collaboration as well as for organisational and implementation-oriented services, underscoring the importance of coordination and feasibility in preventive actions. Patient organisations and public health agencies place greater emphasis on advocacy, public awareness and patient-oriented support, reflecting the relevance of population engagement and behavioural change in prevention strategies. While infrastructure improvement and legal and ethical support receive slightly lower scores across several stakeholder groups, overall ratings remain positive, indicating broad alignment on the relevance of the proposed service portfolio. A detailed breakdown of results is provided in Annex 2.

In the open-ended questions stakeholders most frequently highlighted the need for stronger support in the implementation of screening and prevention programmes, underpinned by improved analysis of cancer risk factors across countries and regions (e.g. population-level risk stratification and heatmaps to inform local, regional and national policies). Particular emphasis was placed on advancing research on genetic predisposition and clinically relevant mutations, strengthening data registration and impact

assessment of prevention initiatives, and enabling personalised prevention advice that is feasible and ensures adherence in real-world settings. Lifestyle-related prevention priorities, especially smoking prevention and cessation, were also repeatedly identified as critical areas for action.

Overall, while these needs are largely aligned with the predefined service categories, stakeholders pointed to the importance of effectively translating data, research outputs and policy frameworks into practical, implementable prevention strategies that can be adapted to diverse population contexts.

1. Implementation of Screening and Prevention Programmes

Focus on deployment, feasibility and uptake:

- Help in the implementation of screening programmes
- Feasibility and compliance of prevention strategies in real-world settings

2. Risk Stratification, Epidemiology & Population Analysis

Focus on data-driven prevention and regional tailoring:

- Analysis of cancer risk factors for countries and regions
- Heatmaps at local, regional and national level
- Identification of good practices supporting prevention policies

3. Genetic Risk, Biomarkers & Precision Prevention Research

Focus on biologically informed prevention:

- Research on genetic predisposition and clinically relevant mutations
- Incorporation of genetic and molecular risk into clinical trials

4. Clinical Research & Trial Promotion in Prevention

Focus on research participation and evidence generation:

- Promotion of clinical trials within organisations
- Access to research opportunities in primary prevention

5. Data Registration, Monitoring & Impact Assessment

Focus on evaluation of prevention strategies:

- Data registration regarding the impact of prevention campaigns
- Monitoring outcomes of personalised prevention advice in clinical consultations

6. Personalised Advice, Behavioural Change & Compliance

Focus on individual-level prevention:

- Personalised prevention advice delivered in consultations
- Assessment of compliance and behavioural adherence

7. Public Health Priorities & Lifestyle Prevention

Focus on modifiable risk factors:

- Strong focus on smoking prevention and smoking cessation

8. Knowledge Transfer & Multi-stakeholder Support

Focus on services across the prevention ecosystem:

- Provision of services and knowledge to the research community, industry, patient organisations and policymakers

4.2.2.5 Omics technologies

For the Omics technologies NoE, responses were received from 22 stakeholders, whose assessments are summarised below.

Overall, stakeholders expressed a high level of interest across all service categories, with mean scores ranging from 8.86 to 7.05, and an overall average score of 7.64. Within this overall positive assessment, slightly higher scores were observed for services related to knowledge and skills development (8.86), networking and collaboration (8.68), and research promotion (8.55).

In the omics domain, evaluation by stakeholder typology reveals distinct and differentiated patterns of interest across service categories, reflecting the diverse roles and expectations of the involved actors. Academic and research-oriented stakeholders report particularly high levels of interest in knowledge and skills development, research promotion and networking and collaboration, underscoring the importance of capacity-building and collaborative frameworks in this field. Health authorities and public agencies place comparatively greater emphasis on organisational models, benchmarking and quality-related services, consistent with their system-level responsibilities. Patient organisations and networking entities show stronger interest in advocacy-related activities and public awareness, highlighting the relevance of engagement and visibility-focused services within the omics ecosystem. Infrastructure-related as well as legal and ethical support services present more variable and, on average, lower scores across stakeholder groups, though they remain positively evaluated overall. A detailed breakdown of results is provided in Annex 2.

In the open-ended questions stakeholders most frequently highlighted unmet needs related to equitable access to precision diagnostics and targeted therapies, particularly ensuring that molecular testing and

subsequent treatment options are available when actionable findings are identified. Strong emphasis was also placed on prioritising clinically relevant and translational research, improving clinical trial efficiency for molecularly defined populations, and strengthening infrastructure and resource-sharing mechanisms to support high-quality omics testing. In addition, stakeholders underscored the importance of practical guidance for the real-world implementation of emerging technologies — including precision oncology, digital tools and AI — as well as improved data interoperability and alignment of molecular datasets with EU standards.

While many of these needs align well with the predefined service categories, respondents also pointed to broader system-level challenges — such as workforce capacity, protected research time and sustainable engagement of scientific societies — which extend beyond direct service provision but are critical for the effective integration of omics into routine cancer care and for maximising patient benefit.

1. Equitable Access to Precision Diagnostics and Targeted Therapies

Focus on access, equity and clinical translation:

- Fair patient access to innovative precision medicine devices and tools
- Availability of tests and targeted drugs when a positive finding is identified through NGS or other molecular platforms
- Reducing inequalities in access to innovative diagnostics and treatments across regions

2. Clinically Relevant and Translational Research

Focus on research priorities aligned with patient impact:

- Prioritising clinically relevant research
- Support for translational research bridging molecular findings and clinical decision-making

3. Clinical Trials and Research Participation

Focus on trial efficiency and patient inclusion:

- Clinical trials improvement
- Increasing participation of patients with actionable molecular findings in trials

4. Infrastructure, Testing Capacity & Resource Sharing

Focus on operational capacity and efficiency:

- Sharing of infrastructure resources within and across units
- Support for organising access to specialised molecular diagnostic infrastructure

5. Implementation of Emerging Technologies in Real-world Practice

Focus on uptake beyond research settings:

- Practical guidance for real-world implementation of precision oncology, digital tools and AI
- Efficient integration of molecular technologies into routine clinical workflows

6. Data Interoperability and Alignment with EU Standards

Focus on data integration and usability:

- Improving data interoperability across institutions and countries
- Alignment of oncology and molecular datasets with EU standards

7. Care Pathways, Coordination & Integration

Focus on system-level organisation of care:

- Harmonisation of cancer care pathways associated with molecular diagnostics
- Better integration of omics-based decision-making into care pathways

8. Research Capacity, Workforce & Professional Engagement

System-level enabling conditions:

- Protected time and resources for clinicians to participate in research and EU initiatives
- Sustainable mechanisms enabling scientific societies to engage in EU networks

4.2.2.6 Hi-tech medical resources

For the Hi-tech NoE, responses were received from 22 stakeholders, whose assessments are summarised below.

Overall, stakeholders expressed a high level of interest across all service categories, with mean scores ranging from 7.82 to 6.09, and an overall average score of 7.14. Within this assessment, higher scores were observed for services related to networking and collaboration (7.82), knowledge and skills development (7.77), and research promotion (7.64).

In the high-tech domain, analysis by stakeholder typology reveals markedly differentiated patterns of interest across service categories, reflecting the diverse functional roles within this ecosystem. Academic and research- and innovation-oriented stakeholders consistently report high levels of interest in knowledge and skills development, research promotion, and networking and collaboration, highlighting the importance of capacity-building and collaborative frameworks in high-tech settings. Health and care providers show comparatively stronger preferences for organisational models,

technical and clinical guidelines, and benchmarking-related services, while health authorities and public agencies place more moderate but focused emphasis on quality- and system-level support functions. Networking entities display particularly high interest in networking and collaboration services, whereas patient organisations prioritise advocacy-related activities and public awareness, albeit with greater variability across categories. Infrastructure improvement and legal and ethical support services tend to receive lower, though still positive, ratings across most stakeholder groups. A detailed breakdown of results is presented in Annex 2.

In the open-ended questions stakeholders most frequently highlighted unmet needs related to equitable access to high-tech medical resources and sustainable pricing models, alongside improved coordination between research infrastructures and cancer care networks to enable more efficient sharing of advanced technologies. Additional emphasis was placed on optimising infrastructure and equipment sharing across units, strengthening identification and mobilisation of specialised expertise, and improving clinical trial performance — particularly early-phase trials that depend on access to high-tech platforms.

While these needs are broadly aligned with the predefined service categories, respondents also underlined structural and system-level challenges — including funding sustainability and long-term integration of high-tech resources into clinical pathways — which extend beyond direct service provision but are critical to maximising the impact of high-tech infrastructures for patients and health systems.

1. Equitable Access, Pricing & Sustainability Models

Focus on affordability and patient access:

- Fair pricing and patient access models
- Sustainable funding models for academic multinational clinical studies

2. Integration of High-Tech Resources into Care Pathways

Focus on coordination between infrastructures and care delivery:

- Alignment between Research Infrastructures and Cancer Care Networks
- Integration of RIs into oncology pathways to enable sharing of tools and resources
- Avoiding duplication of high-tech resources

3. Infrastructure, Equipment & Resource Sharing

Focus on efficiency and optimisation of existing capacities:

- Sharing modern technology among units

- Sharing infrastructure resources to minimise costs
- High-tech resources including infrastructures, tools and equipment

4. Clinical Trials and Research Enabled by High-Tech Resources

Focus on early-phase and technology-dependent trials:

- Improvement of clinical trials, including phase I trials
- Support to clinical research relying on advanced technologies

5. Expertise Mapping & Technical Capacity Building

Focus on identifying and mobilising know-how:

- Identification of expertise related to innovative omics and high-tech resources
- Mapping of human resources, infrastructures and tools

6. Collaboration with Specialised Organisations

Focus on ecosystem interaction:

- Collaboration with organisations specifically dedicated to high-tech medical resources

4.2.2.7 Adolescents and young adult patients with tumours

For the AYA NoE, responses were received from 22 stakeholders, whose assessments are summarised below.

Overall, stakeholders expressed a high level of interest across all service categories, with mean scores ranging from 8.18 to 6.41, and an overall average score of 7.30. Within this assessment, higher scores were observed for services related to knowledge and skills (8.18), networking and collaboration (8.14), and research promotion (7.68).

In the AYA domain, disaggregation by stakeholder typology points to differentiated patterns of interest across service categories, reflecting the specific clinical, psychosocial and advocacy-related needs associated with this population group. Patient organisations and networking entities place particularly strong emphasis on networking and collaboration, advocacy or policy influence, and public awareness, highlighting the importance of visibility, representation and cross-stakeholder coordination in the AYA context. Health and care providers show higher interest in organisational models, clinical guidelines and capacity-building services, reflecting the need for age-appropriate and integrated care pathways. Research-oriented stakeholders display sustained interest in research promotion and data-related services, while public authorities and agencies prioritise benchmarking and system-level organisational

support. Legal and ethical services tend to receive comparatively lower, though still positive, scores across most stakeholder groups. A detailed breakdown of results is provided in Annex X.

In the open-text responses, stakeholders highlighted unmet needs related to patient rights and age-appropriate psycho-oncological support, alongside the need to strengthen integrated support models for adolescents and young adults through closer collaboration with psychosocial, social and insurance-related services. Particular emphasis was also placed on improving access to research, clinical trials and new therapies for AYA populations, as well as addressing structural gaps in screening and early detection, given that existing programmes often do not meet eligibility criteria for younger patients. Digital tools tailored to AYA needs were further identified as important enablers of engagement and long-term follow-up.

While many of these needs align with the predefined service categories, respondents also pointed to broader system-level challenges — including policy support for research access, sustainable funding models and better integration of research infrastructures into care pathways — which extend beyond direct service provision but are critical to ensuring equitable and comprehensive AYA cancer care across Europe.

1. Patient Rights, Psychosocial Support & Well-being

Focus on holistic and age-appropriate care:

- Patient rights
- Psycho-oncological support
- Addressing psychosocial needs specific to adolescents and young adults

2. Integrated Support Services & Cross-sector Collaboration

Focus on coordination beyond clinical care:

- Fostering collaboration with support services
- Involvement of psychologists, social workers, insurance companies and other non-clinical actors

3. Access to Innovation, Research & New Therapies

Focus on research participation and innovation uptake:

- Policy support to promote research and access to new drugs
- Access to clinical trials and innovative treatments for AYA patients

4. Screening, Early Detection & Eligibility Gaps

Focus on structural barriers for young populations:

- Screening programmes not available for young patients due to eligibility criteria

- Need to develop alternative methods to reach AYA populations

5. Digital Tools & Age-appropriate Solutions

Focus on engagement and monitoring tools:

- New digital tools tailored to AYA needs
- Use of digital solutions to support follow-up, communication and empowerment

6. Research Infrastructures, Networks & Resource Sharing

Focus on system-level support and efficiency:

- Alignment between Research Infrastructures and Cancer Care Networks
- Sharing of existing tools and resources to avoid duplication
- Integration of Research Infraestructures into oncology pathways relevant for AYA

7. Funding, Sustainability & Capacity Building

System-level enabling conditions:

- Sustainability and funding models for multinational academic clinical studies
- Long-term support to sustain research and services relevant to AYA populations

4.2.3 Stakeholder roles, level of engagement and willingness to contribute

Out of the 68 stakeholders who participated in the needs assessment survey, 48 provided responses to the section addressing expected roles, levels of engagement and willingness to contribute to the Networks of Expertise. The following results are therefore based on this responding subset and should be interpreted accordingly.

A key dimension of the needs assessment is the explicit consideration of **different stakeholder roles in relation to the NoEs**. Stakeholders were not approached as a homogeneous group, but rather as potential users, partners, or customers, depending on their expected mode of interaction and contribution to future services. This role-based perspective supports a more nuanced understanding of how services may be accessed, co-developed or financially supported, and provides an early framework for differentiating engagement strategies across stakeholder types.

When asked to identify their envisaged role in relation to the Networks of Expertise, a clear preference emerged for active and sustained forms of engagement. A majority of respondents selected the partner role (60.42%), indicating a strong inclination towards active participation in the life of the NoEs, including involvement in working groups, events, decision-making processes and the co-development of activities.

Other roles were selected less frequently. Approximately 22.9% of respondents identified themselves as customers, reflecting an interest in occasional, service-based interaction with the NoEs without

recurring involvement or membership obligations. A smaller share of stakeholders identified as users (10.42%), indicating participation as network members primarily benefiting from shared information, resources and selected activities. Only a limited proportion of respondents selected the sponsor role (4.7%), and a small fraction of responses could not be clearly classified (2.08%).

Overall, the predominance of the partner role suggests that many stakeholders envisage a collaborative and contributory relationship with the Networks of Expertise, going beyond purely transactional service use. This finding provides an important foundation for the design of engagement strategies and sustainability mechanisms explored in subsequent tasks, particularly with regard to membership-based interaction models and long-term involvement.

Beyond the type of role envisaged, the needs assessment also explored the **expected level of activity with which stakeholders anticipate engaging** in the NoEs. This variable provides an indication of the intensity and continuity of participation foreseen by stakeholders, complementing the role-based perspective by distinguishing between more sustained and more occasional forms of involvement.

Among the 48 respondents who completed this section, the majority envisaged an active or recurrent form of participation in the Networks of Expertise. Most stakeholders indicated either occasional involvement (41.67%), reflecting engagement on a needs-driven or capacity-dependent basis, or active involvement (35.42%), signalling regular participation and meaningful contribution to network activities. A smaller proportion of respondents anticipated a very active involvement (14.58%), suggesting a leading or highly engaged role in the networks' activities.

Only a limited share of stakeholders foresaw minimal (4.17%) or no involvement (4.17%) in the Networks of Expertise. Overall, these results point to a generally positive outlook regarding stakeholder engagement, characterised by a predominance of active and intermittent participation models rather than purely marginal involvement. This engagement profile reinforces the relevance of flexible participation mechanisms within the Networks of Expertise, capable of accommodating varying levels of activity while sustaining a committed core of stakeholders.

When examining **willingness to contribute by envisaged stakeholder role** (See Annex 2) clearly differentiated contribution patterns emerge between customers and partners. Stakeholders identifying as customers primarily associate their engagement with service-based financial contributions, showing a stronger openness to paying fees for specific services, while displaying very limited willingness to engage through annual membership fees. This pattern reflects a more transactional and needs-driven relationship with the Networks of Expertise, characterised by occasional use of services rather than recurring involvement or long-term commitment. In-kind or logistical contributions among this group remain secondary and are generally envisaged on a case-by-case basis.

By contrast, stakeholders identifying as partners demonstrate a markedly different contribution profile. This group shows a high level of openness both to annual membership fees and to service-based payments, alongside a strong willingness to provide in-kind and logistical support. Such a balanced contribution pattern aligns with the active and sustained role envisaged by partners, who anticipate contributing not only financially but also through expertise, resources and operational support as full members of the Networks of Expertise.

Overall, the contrast between customer- and partner-oriented contribution models highlights the relevance of differentiated financial and engagement mechanisms within the Networks of Expertise, combining transactional service-based models with membership-based and contributory arrangements to support long-term sustainability.

In addition to the **role-based analysis, willingness to contribute** was also examined according to the level of activity stakeholders envisage within the Networks of Expertise. Results show that stakeholders anticipating active or occasional involvement account for the largest share of willingness to contribute across all contribution modalities, including membership fees, service-based payments, in-kind contributions and logistical support. By contrast, stakeholders foreseeing minimal or no involvement display consistently lower levels of openness to contribute. This pattern reinforces the strong link between anticipated engagement intensity and contribution readiness, and further supports the relevance of differentiated participation and sustainability models within the Networks of Expertise. A detailed breakdown of results by level of involvement is provided in Annex 2.

5 CONCLUSIONS

This milestone provides the first consolidated synthesis of stakeholder needs, expectations and engagement preferences across all Networks of Expertise developed under JANE-2. Building on both quantitative ratings and qualitative inputs, the conclusions presented below distil the main cross-cutting messages emerging from the needs assessment and outline how these findings will inform subsequent WP4 activities related to service design, governance, partnerships and long-term sustainability.

Across all Networks of Expertise, stakeholders consistently reported high levels of interest across the full set of proposed service categories, with overall average scores remaining well within the high-interest range in all domains. Despite differences in clinical focus and target populations, a remarkably convergent pattern emerges: services related to networking and collaboration, research promotion, and knowledge and skills development systematically rank among the highest-scoring categories across almost all Networks of Expertise.

This convergence suggests that stakeholders primarily value the Networks of Expertise as platforms for connection and collaboration, mechanisms for capacity-building and knowledge exchange, and catalysts for integration rather than as providers of isolated or highly specialised services. Variations observed across individual Networks of Expertise reflect differences in context and emphasis — for example, stronger engagement- and advocacy-oriented priorities in survivorship, or more implementation-focused interests in palliative and preventive domains — but do not indicate divergent or competing needs. Overall, these findings point to a shared underlying mission centred on collaboration, alignment and equity across the European oncology ecosystem.

Analysis of the open-ended survey responses, in which stakeholders were invited to identify needs not fully addressed by the predefined service categories, further reinforces the presence of shared challenges and expectations that transcend specific cancer domains. Stakeholders repeatedly highlighted the need for stronger coordination, enhanced knowledge exchange, improved data interoperability and better translation of innovation into real-world clinical practice, alongside more harmonised care pathways across Europe.

Beyond domain-specific services, there is a clear and consistent demand for structured collaboration mechanisms that connect clinical care, research infrastructures, policy frameworks and patient engagement. These findings reinforce the role of the Networks of Expertise as unifying European frameworks — not only delivering specialised services, but acting as enablers of systemic integration, capacity-building and long-term alignment across countries and regions.

Taken together, these cross-cutting results underline the importance of approaching the development of the Networks of Expertise through a coordinated and flexible governance model. The strong convergence observed across service priorities suggests that certain foundational services and collaboration mechanisms can be developed in a harmonised manner across NoEs, while preserving sufficient flexibility to address domain-specific needs.

These cross-NoE insights will be further explored through bilateral discussions with individual Networks of Expertise and in close collaboration with the coordination team, particularly for aspects extending beyond service design and touching upon governance models, inter-NoE synergies and shared operational structures.

Next steps

The results of the needs assessment will directly inform the development of service portfolios for each of the seven Networks of Expertise. By analysing expressed needs, expectations and preferred interaction models, WP4 will support the prioritisation of services that respond to clearly identified demands, are perceived as valuable by stakeholders, and can be realistically delivered given the available expertise and infrastructure.

This needs-based approach ensures that service portfolios are evidence-informed and stakeholder-validated, rather than being defined exclusively through internal perspectives. As a result, it enables a phased and adaptive roll-out of NoE services, aligned with stakeholders' readiness to engage and capacity to contribute, and increasing the likelihood of adoption, iterative refinement and long-term embedding within existing workflows and networks.

Beyond service design, the needs assessment also plays a critical role in preparing the ground for long-term sustainability and viable business models. Insights into stakeholders' willingness to engage as recurring users, strategic partners or paying members provide essential input for the definition of future value propositions and interaction models. These sustainability-related dimensions will be further examined in Task 4.3 through the development of tailored business models for each Network of Expertise, using a structured business model canvas approach exploring key partners, activities, channels, revenue streams and cost structures, including internal resources such as infrastructures and human capacity. In this way, the needs assessment closes the loop between stakeholder expectations, service design and long-term operational sustainability.

ACKNOWLEDGEMENTS

The WP4 leadership team would like to sincerely acknowledge and thank all organisations that contributed to the needs assessment survey for their time, engagement and valuable insights. The feedback provided by stakeholders representing different parts of the cancer ecosystem was essential to better understand ecosystem interests, perceived needs and expectations towards the Networks of Expertise. This input constitutes a key evidence base to inform service design, engagement models and sustainability considerations, and will play an important role in shaping subsequent WP4 activities. A complete list of organisations that participated in the needs assessment is provided in Annex 3.

ANNEXES

ANNEX 1. JANE-2 Needs Assessment Survey

The Joint Action on Networks of Expertise on Cancer (JANE-2) is a 4 year Joint Action co-financed by the European Commission which aims to create seven Networks of Expertise (NoEs) in seven different cancer fields on: 1. complex and poor-prognosis cancers; 2. palliative cancer care; 3. survivorship; 4. personalized primary and secondary prevention; 5. omics technologies; 6. hi-tech medical resources; 7. adolescents and young adult patients with tumours.

JANE-2 is currently working on setting up seven transnational and cross-sectoral Networks of Expertise focused on cancer. These networks are intended to be integrated into national healthcare systems once the Joint Action concludes (November 2028), strengthening cross-border collaboration and knowledge exchange. This survey is part of the work of one of the JA JANE-2 groups, whose main objective is to ensure the long-term viability of the NoEs in the future. By focusing on sustainability strategies, this working group will support the NoEs in transitioning from project-based structures to enduring components of national and transnational cancer care ecosystems. In order to achieve this ultimate goal, a series of strategies have been adopted, including a comprehensive stakeholder mapping — ranging from patients and healthcare professionals to policymakers and industry. This search considered stakeholders who which will have a potential role in relation to the activities that the NoEs will offer in the near future.

Why are we contacting you? As your organization is an important player in the cancer landscape, we value your view on the future NoEs' services and your potential interactions with them. We are kindly asking you, or the competent person within your organization, to complete the present survey. Your responses will be treated with utmost confidentiality and used solely for research purposes within the JANE-2 project. At the beginning of the survey, you will be asked to select the cancer domains that are relevant to your organization. Please note that for each selected domain, you will be asked a set of specific questions. This is essential to ensure that each NoE receives direct and tailored information from stakeholders who have expressed interest in their area of expertise.

How is this survey structured?

The survey has three sections:

1. **General information** about your organization to contextualize your responses.
2. **Needs assessment**, with two questions for each cancer domain you select.
3. **Potential collaboration**, exploring the potential relationship between your organization and the NoEs of interest.

Please ensure that the person completing the survey has a comprehensive understanding of your organization's overall priorities, needs, and strategic vision, as this will be key to providing meaningful and accurate input. We fully knowledge the preliminary nature of this response, so please, answer

considering the actual interest and capacities of your organization, and remember that these answers are non-binding.

Finally, we would like to thank you for your willingness to complete this survey. If you have any questions, please contact the JANE-2 sustainability team for clarification:

Sarah Berrocoso <sarah.berrocosocascallana@bio-sistemak.eus>

Jone Guenetxea <jone.guenetxeagorostiza@bio-sistemak.eus>

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1. General information

This part of the survey is required for all participants.

Q1 Please, provide the full name and acronym of your organization.

- ○ Organizations full name _____
- ○ Organizations acronym _____

Q2 Your position/role in your organization:

_____

_____

_____

_____

_____

Q3 Please, check the organization typology that best describes your organization:

- ○ Patient Organizations
- ○ Health and care providers (belonging to Comprehensive Cancer Centres)
- ○ Health and care providers (not belonging to Comprehensive cancer centres)
- ○ Health and care payers
- ○ Public health agencies
- ○ Health Authorities
- ○ Research and innovation organizations
- ○ Industry (pharma)
- ○ Industry (medtech)
- ○ Academia
- ○ Network
- ○ Other

Q4 Attending to their nature, organizations can be non-profit or for-profit. Please, select the option that applies to you:

- ○ Non-Profit Organization
- ○ For-Profit Organization

Q5 Organizations operate across various geographical levels. To better understand your organization's operational context, please identify the scope at which it conducts its core activities:

○ **Local**: your organization works in a small part of a region, such as a city or a municipality.

○ **Regional**: your organization works in more than a city or municipality of a country, but those are encompassed within the same administrative entity, which name can vary attending to the geopolitical management of the country.

○ **National**: your organizations activities are scattered all around a country in more than one region.

○ **International**: your organization works in more than one country.

Q6 The following is a list of cancer-related domains. Your organization may be actively engaged in or interested in one or more of these areas. Please select all domains that are of interest to your organization's current activities or future priorities:

You will be asked to complete additional sections of the survey for each of the domains you select.

☐ Complex and Poor Prognosis Cancers

☐ Palliative Care

☐ Survivorship

☐ Personalised Primary Prevention

☐ Omics

☐ High-Tech Medical Resources

☐ Adolescents and Young Adults

Needs Assessment (Complex and Poor Prognosis Cancers)

Please answer only if you selected 'Complex and poor-prognosis cancers' in Q6

Q7_WP5 Needs Assesment (Complex and Poor Prognosis Cancers) Which types of services would be most valuable in addressing your organization´s needs?

Below you will find a list of broad service categories that the Complex and Poor Prognosis Cancers network of expertise could potentially offer in the future.

These categories represent areas where different types of resources, methodologies, or systems could be made available.

We would like to understand which of these services your organization would find most useful or relevant, based on its current gaps, priorities, or strategic goals. Please rate each category from 0 to 10, where **0 means no relevance** or need, and **10 means the highest level of relevance** or need.

	1	2	3	4	5	6	7	8	9	10
Knowledge and skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○
Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○

Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Q8_WP5 In the previous section, you were asked to rate a set of service categories that align with the current scope and capabilities of the Complex and Poor Prognosis cancer network. These categories reflect activities that the network is conceptually prepared to deliver.

Now, we would like to hear directly from you: **What specific needs does your organization have in the area of cancer that may not have been addressed by the categories listed above?**

_____

_____

_____

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Needs Assessment (Palliative Care)

Please answer only if you selected 'Palliative Care' in Q6

Q7_WP6 Needs Assessment (Palliative Care) Which types of services would be most valuable in addressing your organization´s needs?

Below you will find a list of broad service categories that the Palliative Care network of expertise could potentially offer in the future.

These categories represent areas where different types of resources, methodologies, or systems could be made available.

We would like to understand which of these services your organization would find most useful or relevant, based on its current gaps, priorities, or strategic goals. Please rate each category from 0 to 10, where **0 means no relevance** or need, and **10 means the highest level of relevance** or need.

	1	2	3	4	5	6	7	8	9	10
Knowledge and skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○
Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○

Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Q8_WP6 In the previous section, you were asked to rate a set of service categories that align with the current scope and capabilities of the Palliative Care. These categories reflect activities that the network is conceptually prepared to deliver.

Now, we would like to hear directly from you: **What specific needs does your organization have in the area of cancer that may not have been addressed by the categories listed above?**

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Needs Assessment (Survivorship)

Please answer only if you selected 'Survivorship' in Q6

Q7_WP7 Needs Assessment (Survivorship) Which types of services would be most valuable in addressing your organization´s needs?

Below you will find a list of broad service categories that the Survivorship network of expertise could potentially offer in the future.

These categories represent areas where different types of resources, methodologies, or systems could be made available.

We would like to understand which of these services your organization would find most useful or relevant, based on its current gaps, priorities, or strategic goals. Please rate each category from 0 to 10, where **0 means no relevance** or need, and **10 means the highest level of relevance** or need.

	1	2	3	4	5	6	7	8	9	10
Knowledge and skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○
Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○

Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Q8_WP7 In the previous section, you were asked to rate a set of service categories that align with the current scope and capabilities of the survivorship network. These categories reflect activities that the network is conceptually prepared to deliver.

Now, we would like to hear directly from you: **What specific needs does your organization have in the area of cancer that may not have been addressed by the categories listed above?**

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Needs Assessment (Personalised Primary Prevention)

Please answer only if you selected 'Personalised Primary Prevention' in Q6

Q7_WP8 Needs Assessment (Personalised Primary Prevention) Which types of services would be most valuable in addressing your organization´s needs?

Below you will find a list of broad service categories that the Personalised Primary Prevention network of expertise could potentially offer in the future.

These categories represent areas where different types of resources, methodologies, or systems could be made available.

We would like to understand which of these services your organization would find most useful or relevant, based on its current gaps, priorities, or strategic goals. Please rate each category from 0 to 10, where **0 means no relevance** or need, and **10 means the highest level of relevance** or need.

	1	2	3	4	5	6	7	8	9	10
Knowledge and skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○
Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○

Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Q8_WP8 In the previous section, you were asked to rate a set of service categories that align with the current scope and capabilities of the Personalised Primary Prevention network. These categories reflect activities that the network is conceptually prepared to deliver.

Now, we would like to hear directly from you: **What specific needs does your organization have in the area of cancer that may not have been addressed by the categories listed above?**

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Needs Assessment (Omics)

Please answer only if you selected 'Omics' in Q6

Q7_WP9 Needs Assessment (Omics) Which types of services would be most valuable in addressing your organization´s needs?

Below you will find a list of broad service categories that the Omics network of expertise could potentially offer in the future.

These categories represent areas where different types of resources, methodologies, or systems could be made available.

We would like to understand which of these services your organization would find most useful or relevant, based on its current gaps, priorities, or strategic goals. Please rate each category from 0 to 10, where **0 means no relevance** or need, and **10 means the highest level of relevance** or need.

	1	2	3	4	5	6	7	8	9	10
Knowledge skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○
Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○

Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Q8_WP9 In the previous section, you were asked to rate a set of service categories that align with the current scope and capabilities of the Omics network. These categories reflect activities that the network is conceptually prepared to deliver.

Now, we would like to hear directly from you: **What specific needs does your organization have in the area of cancer that may not have been addressed by the categories listed above?**

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Needs Assessment (High-Tech Medical Resources)

Please answer only if you selected 'High-Tech Medical Resources' in Q6

Q7_WP10 Needs Assessment (High-Tech Medical Resources) Which types of services would be most valuable in addressing your organization´s needs?

Below you will find a list of broad service categories that the High-Tech Medical Resources network of expertise could potentially offer in the future.

These categories represent areas where different types of resources, methodologies, or systems could be made available.

We would like to understand which of these services your organization would find most useful or relevant, based on its current gaps, priorities, or strategic goals. Please rate each category from 0 to 10, where **0 means no relevance** or need, and **10 means the highest level of relevance** or need.

	1	2	3	4	5	6	7	8	9	10
Knowledge and skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○
Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○

Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Q8_WP10 In the previous section, you were asked to rate a set of service categories that align with the current scope and capabilities of the High-Tech Medical Resources network. These categories reflect activities that the network is conceptually prepared to deliver.

Now, we would like to hear directly from you: **What specific needs does your organization have in the area of cancer that may not have been addressed by the categories listed above?**

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Needs Assessment (Adolescents and Young Adults)

Please answer only if you selected 'Adolescents and Young Adults' in Q6

Q7_WP11 Needs Assessment (Adolescents and Young Adults) Which types of services would be most valuable in addressing your organization´s needs?

Below you will find a list of broad service categories that the Adolescents and Young Adults network of expertise could potentially offer in the future.

These categories represent areas where different types of resources, methodologies, or systems could be made available.

We would like to understand which of these services your organization would find most useful or relevant, based on its current gaps, priorities, or strategic goals. Please rate each category from 0 to 10, where **0 means no relevance** or need, and **10 means the highest level of relevance** or need.

	1	2	3	4	5	6	7	8	9	10
Knowledge and skiKnowledge and skills development	○	○	○	○	○	○	○	○	○	○
Research promotion	○	○	○	○	○	○	○	○	○	○
Development of health or care organizational models	○	○	○	○	○	○	○	○	○	○
Networking and collaboration	○	○	○	○	○	○	○	○	○	○
Patient support tools and resources	○	○	○	○	○	○	○	○	○	○
Advocacy or policy influence	○	○	○	○	○	○	○	○	○	○
Advice in data access and sharing	○	○	○	○	○	○	○	○	○	○
Public awareness	○	○	○	○	○	○	○	○	○	○
Benchmarking, Quality Standards and Accreditation Criteria	○	○	○	○	○	○	○	○	○	○

Technical and clinical guidelines development	○	○	○	○	○	○	○	○	○	○
Infrastructure improvement	○	○	○	○	○	○	○	○	○	○
Legal and ethical support (e.g., GDPR, IVDR, AI Act, EHDS)	○	○	○	○	○	○	○	○	○	○

Q8_WP11 In the previous section, you were asked to rate a set of service categories that align with the current scope and capabilities of the Adolescents and Young Adults. These categories reflect activities that the network is conceptually prepared to deliver.

Now, we would like to hear directly from you: **What specific needs does your organization have in the area of cancer that may not have been addressed by the categories listed above?**

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3. Potential collaborators

This part of the survey is required for all participants.

Q9 Organizations may have different roles in their relationship with NoEs. Please, read the different roles envisioned to engage with the NoEs and select the one that best suits the relationship your organization may have.

In this section, we ask you to reflect on the role your organization could have when interacting with NoEs. These questions refer to your organization's potential engagement with NoEs in general, not to the specific NoE area you selected earlier. Please select the role that best describes the relationship your organization may have with these networks

○ Partner: This type of participant is actively engaged in the daily life of the NoE, taking part in working groups or committees. Partners are involved in events and activities as full NoE members, offering their expertise and strategic guidance. Their participation may also be related with decision making processes in the NoE, as well as providing logistical and scientific support. Membership fee needs to be covered by partners.

○ User: Users benefit from NoE services but are not deeply involved in core activities. They may take part as occasional collaborators or event participants and are considered NoE members. Users primarily receive updates, information, and resources shared by the network. Membership fee needs to be covered by users.

○ Customer: A customer occasionally makes use of NoE services but is not a network member. Their interaction is limited and sporadic, focusing on taking advantage of resources when needed without recurring involvement. Fee for service is envisioned.

○ Sponsor: Sponsors support the NoE through financial contributions or in-kind resources, yet are not network members. Often, they offer logistical assistance and play a crucial role in sustaining and enabling NoE initiatives, without being involved in the day-to-day work.

Q10 Within each role provided above, organizations can have different levels of activity. Please, choose from the options below the level of activity you envision your organization will have in the network's activities.

○ Very active involvement – Your organization would play a leading or highly engaged role in the network's activities.

○ Active involvement – Your organization would participate regularly and contribute meaningfully to the network.

○ Occasional involvement – Your organization would engage with the network from time to time, depending on relevance and capacity.

○ Minimal involvement – Your organization would have limited interaction with the network, mostly observational or peripheral.

○ No involvement – Your organization does not foresee participating in the network's activities.

Q11 Organizations may engage with the NoE through various forms of support, including financial contributions and in-kind resources.

To assess your organization's willingness to contribute, please rate the following statements on a scale from 0 to 10—where **0 indicates no willingness to provide** the specified resource, and **10 indicates a strong commitment** to doing so. My organization is…

	1	2	3	4	5	6	7	8	9	10
Open to annual membership fees.	○	○	○	○	○	○	○	○	○	○
Open to pay fees for services.	○	○	○	○	○	○	○	○	○	○
Open to provide in-kind contributions.	○	○	○	○	○	○	○	○	○	○
Open to provide logistical support (spaces, tools…).	○	○	○	○	○	○	○	○	○	○

End of the survey.

Thanks for your participation!

ANNEX 2. Summary tables of results

This annex is not part of the public version of the milestone due to the inclusion of sensitive internal information.

ANNEX 3. Stakeholders involved in the Needs Assessment

This annex is not part of the public version of the milestone due to the inclusion of sensitive internal information.