



Joint Action on Networks of Expertise

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18-month report

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LIST OF PARTICIPANTS

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1. OVERVIEW OF THE PROGRESS

1.1 Summary of work performed and achievements, results and impacts

Project summary

JANE is a Joint Action to shape seven new Networks of Expertise (NoEs) in the cancer field in the following domains: complex & poor-prognosis cancer(s); palliative care; survivorship; personalized primary prevention; omic technologies; hi-tech medical resources; adolescents and young adults (15-39 years at cancer diagnosis) with cancer.

The Joint Action has two goals:

- 1) to make all the necessary preparations to launch the new NoEs;
- 2) to critically evaluate existing models of current and future EU networking with a view to optimizing the functioning of the new NoEs.

The project's management goal is to shape the creation of 7 NoEs, with the final deliverable for each being a call for expressions of interest. One Work Package has been assigned to each NoE. Five Transversal Task Forces will be established, together with one additional work package, which operate transversally to all the Work Packages. The subject of the Transversal Task Forces and the additional Work Package are:

- Integration between EU networking and MS;
- Integration between information-technology infrastructures, including the use of artificial intelligence tools;
- Integration between health care and research;
- The ERN model;
- Patient involvement;
- Sustainability.

The ambition of this Joint Action is to pave the way to new NoEs able to function effectively, building on previous and ongoing EU networking experiences, and finding solutions rooted in the European oncology community.

In this regard, the outputs of the discussions and the consensus made within the Task Forces about current problems of EU health networks will be shared with the European oncology community and MS, through a Green Paper and a European conference. Health care networking can become a privileged hallmark of the EU, having the potential to target the health of its citizens in a highly coordinated fashion.

1.2 Project teams, staff and experts

Project teams and staff

Report and explain deviations from Annex 1 of the Grant Agreement regarding the organisation of staff or project teams. Provide CVs of key actors that had to be replaced (if required).

The bulk of minor changes in the organisation of staff effort were included in Amendment 1 signed in September 2023.

1.3 Consortium management and decision-making

Consortium management and decision-making

Report on important changes in the management or decision-making mechanisms

Fondazione IRCCS Istituto Nazionale dei Tumori (INT) is coordinator of JANE, ensuring coordination among the JANE partners. The Scientific Coordinator, Paolo G. Casali, is supported by:

- a project management team (PMT), whose aim is to fulfil administrative tasks and ensure correct project monitoring. It is established at INT and includes the coordinator, an experienced project manager and a financial officer;
- the Steering Committee (SC), formed by the WP and TTF leaders, with a mandate to discuss and make strategic decisions;
- an Advisory Board, with the aim to directly involve patient groups.

Communications have been facilitated by the setting up of a central coordination email address: (jane_coordination@istitutotumori.mi.it).

Compliance with schedules and administrative requirements are ensured by regular SC and project meetings involving the WP and TTF leaders. The PMT is tasked with day-to-day monitoring. Regular meetings with WP and TTF leaders help to assess that timetables are complied with, and to make any necessary adjustments and corrections.

To support activities in each WP, the JA has implemented a series of Transversal Task Forces (TTF), with objectives which cut across all the WPs. The transversal objectives have been established to bring the WPs together more efficiently, facilitate their interplay, and help foster collaboration for the adequate conduction of the different planned activities.

Internal activity reports are requested on a six-monthly basis from WPs and TTFs, and reviewed by the Scientific Coordinator, the SC, with input from the Advisory Board.

No major management changes were made in the course of the first 18 months.

1.4 Project management, quality assurance and monitoring and evaluation strategy

Project management, quality assurance and monitoring and evaluation strategy

Report on changes to the overall project management concept, quality assurance and monitoring and evaluation strategy (if any)

The Coordination Team has been established at INT and includes the Coordinator, a project manager and a financial officer. The PMT is tasked with day-to-day operational management. The PMT supports the coordinator, SC, WP and TTF leaders, and all partners. The work of the PMT includes the following tasks:

- development of tools for project management (Document Management System – Google Drive);
- preparation of SC meetings in close collaboration with the hosting organization and preparation of minutes of meetings;
- editorial, economic and administrative support to the WP and TTF Leaders, Beneficiaries and Affiliated Entities;
- financial and administrative management of the project, including the transfer of funds to the partners, collection of cost statements, monitoring of the correctness and accuracy of partners' financial reports, submission of financial reports to HaDEA;
- preparation of financial and technical reporting templates, progress reports and monitoring of deliverable and milestone achievement (the PMT has asked each WP and TTF leader to complete a WP/TTF report every 6 months; the WP/TTF report contains, for each task, the following elements: objectives (as a memorandum); work done and problems encountered, indicating possible causes; documents produced (to be attached); next steps and proposals with possible problems/risks);
- preparation and management of the risk plan.

The SC consists of the PMT together with the WP and TTF leaders and is the decision-making body of the project. The first SC meeting was chaired by the Coordinator, who has also chaired all SC meetings thus far. All WP and TTF leaders have equal voting rights. Where possible, any decisions are reached on a consensus basis. Should any conflicts arise, the Coordinator will analyse the reasons for the conflict and seek a consensus after hearing the conflicting parties. Only if no consensus is reached shall the simple majority principle apply. The SC is responsible for all strategic planning, ensuring that the timetable is maintained, the milestones are met, and corrective actions are taken as required. It receives all reports and other outputs for quality control. It agrees on agendas and programmes for workshops and conferences and decides on other future actions, which are taken cooperatively. The PMT reports to the SC which oversees the work. The SC meets every 6 months (October 2022, November 2022, May 2023, November 2023, January 2024. Further meetings are planned for July 2024 and September 2024). During the first online meeting in October 2022 and during the in-person kick-off meeting in Milan in November 2023, activities, responsibilities, and management of the project were discussed. The proposal for the follow-up Joint Action JANE-2 and thus the future of the NoEs was preliminarily discussed at the meeting in November 2023 in Barcelona. The sustainability of the NoEs was the focus of discussion at the meeting held in Milan in January 2024. The other meetings served to monitor the work and exchange information.

A General Assembly (GA), including all partners is convened annually, back to back with SC meetings. The aim of the Kick-off meeting was to discuss the JANE Joint Action and partners' roles and collaborations. Subsequent GA meetings have served to share progress and decide on future actions to be taken cooperatively.

Internal communications are ensured by the development of a mailing list including all partners (beneficiaries and affiliated entities), which is continuously updated and used to share relevant communications to all partners. Each WP and TTF leader is responsible for communicating with WP/TTF-specific partners. A mailing list dedicated to WP and TTF leaders only has also been developed and monthly WP/TTF leader teleconferences are organised to exchange WP/TTF information efficiently.

No major changes have been made to the overall project management concept, quality assurance and monitoring and evaluation strategy

1.5 Cost effectiveness and financial management

Cost effectiveness and financial management

Inform about significant budget overruns or important changes in the financial management (if any)

The overall budget for the Joint Action was conceived to provide WP leaders with sufficient funding to conduct their activities, while being inclusive for all partners, proportionately to their level of activity and involvement in the various WPs and TTFs. Considering the main objectives of the JA, emphasis has been laid on the allocation of costs for travel, seminars, participation of Advisory Board members and key external experts, and for dissemination activities, which is especially important considering that the core of the collaboration is the setup of new NoEs in Europe.

Since the project is highly qualitative in scope, cost-effectiveness is reflected by the fact that the assignment of funding is designed to help create a dynamic group, which is crucial for this JA, and constant, close collaboration among cancer centres – focusing on building an effective partnership with the strong potential to continue shared activities even after the conclusion of the funding period.

Funds for travel, accommodation and the organization of project meetings were decided on the basis of the number of meetings envisioned by the Coordination and in each WP, while each WP or TTF leader is also provided with the funds required to employ dedicated personnel tasked with project monitoring, management and the coordination of participating national consortia. Allocated funds reflect the various national personnel and service costs.

In its capacity as Coordinator, INT is responsible for financial monitoring, through both regular financial reports and internal controls.

1.6 Risk management

Critical risks and risk management strategy

Report on the state of play concerning the risks and risk mitigation measures (if any)

None of the envisaged risks has occurred to date.

1.7 Impact

Impact

Report on changes in your impact analysis/strategy (if any) and the effects on the project/need for adaptations

The impact of this JA will stem from the impact of NoEs it is shaping.

That said, the effectiveness of the NoEs will be mostly dictated by the extent to which this new kind of EU health care networking can overcome some of the challenges currently being experienced. This is why this project is equipped to assess such problems and work out possible solutions. The ambition here is to root these solutions in the European oncology community as deeply as possible. Indeed, the idea behind the concept of JAs is exactly to involve communities of stakeholders, together with MS and EU bodies, as widely as possible. The partners understand that if the launching of new NoEs was not envisaged merely as an administrative endeavour and a dedicated JA was conceived, the reason is exactly to tackle some problems of EU healthcare networking by addressing them through a wide involvement of the European oncology community. Thus, the ambition of this JA is actually to be able to involve the whole European oncology community pragmatically, i.e. in an attempt to lead to the creation of a new kind of network, as anticipated by the Commission, capable of being effective, appropriate, sustainable.

The ambition of the new NoEs, as far as their mandates are concerned, is obviously to bring the added value of EU networking to some crucial oncology areas. Healthcare networking can be exceedingly important in Europe, since it gives the EU the potential to target half a million citizens in a coordinated fashion. In a sense, Europe is privileged by being able to exploit health care networking to an extent which is not accessible to most other areas of the world. In fact, the EU has the unique opportunity to drive healthcare providers in so many countries to collaborate with each other on a networking basis, in as much as they operate in an environment which, although different from country to country, is reasonably homogenous, with special regard to the universal access to health care which it allows. Thus, healthcare networking is a somewhat functioning modality proper to Europe, in which the EU can really exert a specific added value. All the more, just because the expected outcome may be tremendous, it is vital to address all problems and obstacles. By launching JAs on healthcare networking, complementing the current networking in the rare cancer area through existing ERNs, the EU is sending a clear signal to its citizens and to the health systems of its MS. This JA has taken on the challenge, within the limited scope of the NoEs it is shaping.

In this regard, this Joint Action aims to publish a green paper for wide discussion in the European community on challenges experienced by European networks (such as the ERNs on rare cancers) and to organizing an event open to all major stakeholders, with the aim of helping European cancer networks improve and fully fulfil their mission. Issues about sustainability will be specifically addressed. At M12 there has been no major change in the impact analysis/strategy.

1.8 Communication, dissemination and visibility

Communication, dissemination and visibility of funding

Report on communication and dissemination activities undertaken (to whom, which format, how many, etc).

Describe how the visibility of EU funding was ensured

If you describe your project on your website(s) and/or social media accounts, please provide the links

The main aim of this JA's communication strategy is to make the whole European oncology community fully aware of the project to create new NoEs. This is essential in reaching out to all crucial players, in order for them to be involved in future NoEs, as well as to ensure that the current problems faced by EU health care networking is properly addressed, taking into account all past and ongoing experiences. While patient advocacy groups are seen as part of the European oncology community as far as the construction of new

NoEs is concerned, a second communication strategy will target EU patients as long as future NoEs take shape. Its aim is to make sure that information about the potential of NoEs can be reasonably disseminated as soon as they come into existence..

A JA-dedicated website has been developed. Main documents, policy papers and recommendations produced by JANE WPs and TTFs are communicated via topic-oriented sections of the JANE website and related communication tools. A stakeholder analysis has been performed, and is continuously updated, analyzing the target groups by WPs and developing key messages and communication channels for each target group. The analysis has helped to map key messages, distinguishing the information granularity needed for at least three different communication pathways in terms of content and style, i.e.: (1) health care professionals, including professional providers and related societies; (2) patients and their relatives, support groups and the general public; (3) policy makers and local/regional political authorities and institutions.

The dissemination strategy includes:

- mapping and analysis of content and targets of all other JANE WPs and the setting up of a road map to communicate the principal themes and topics;
- network surveys refreshing former maps and optimizing communication channels and content according to the intended audiences, with a view to attracting the attention of the most relevant European networks, associations and other groups);
- focus on sustainability and transfer of knowledge derived from key outcomes and recommendations of the JA. This is managed through an intrinsic communication map covering all key deliverables and outcomes of the JANE WPs/TTFs. The map interconnects reporting from WP leaders with on-line reports on the JANE portal. Clustering of multiple interactions and reports around thematic “seeds” has initiated further interactions, facilitated by networking contacts. This makes the transfer of knowledge among stakeholders and other target groups seamless and continuous.

A Green Paper on the challenges of European cancer networking is currently being drawn up by the Coordination team with the support of the WP and TTF leaders. A final stakeholder conference is currently being organized in Brussels on 24-25th September, 2024.

A list of dissemination and communication activities carried out in the first 18 months of the Joint Action can be found in a Table at the end of the report. See also WP2 – Dissemination for further details.

1.9 Sustainability and continuation

Sustainability, long-term impact and continuation

Report on changes in your sustainability analysis/strategy (if any).

WP4 of this JA is dedicated to sustainability, insofar as the sustainability of health care networking is seen as a major problem for the new NoEs.

Existing networks focused on cancer care have been mapped and their scope, structure, governance, operational aspects and functioning, resources, results, and sustainability strategies analysed. Lessons learned generated by these networks will be compiled and serve as a cornerstone for NoE creation. A Policy Board and Policy Dialogue (i.e. deliberative dialogues that gather policy makers from across disciplines to discuss a topic of mutual interest) have been organised. The Policy Dialogues in JANE aim to initiate, or contribute to, legislative change intended to help improve cancer care, establish governance mechanisms for institutional/cross-sectoral collaboration, reach consensus on tangible actions that will address obstacles related to NoE sustainability and increase political will and engagement towards new or adapted policies.

The first Stakeholder Forum (i.e. a space for discussion that facilitates the exchange of expertise, experience, and opinions of the participants) was held in persons in Barcelona in November, back-to-back with the plenary meeting. The Second Stakeholder Forum will be held online in September 2024. has been defined. The main aim of the JANE stakeholder Forum is to create a common understanding and build synergies and partnerships that support JANE and the actual and future need of the NoEs.

(See WP4 – Sustainability - for more details).

1.10 Follow-up to EU recommendations

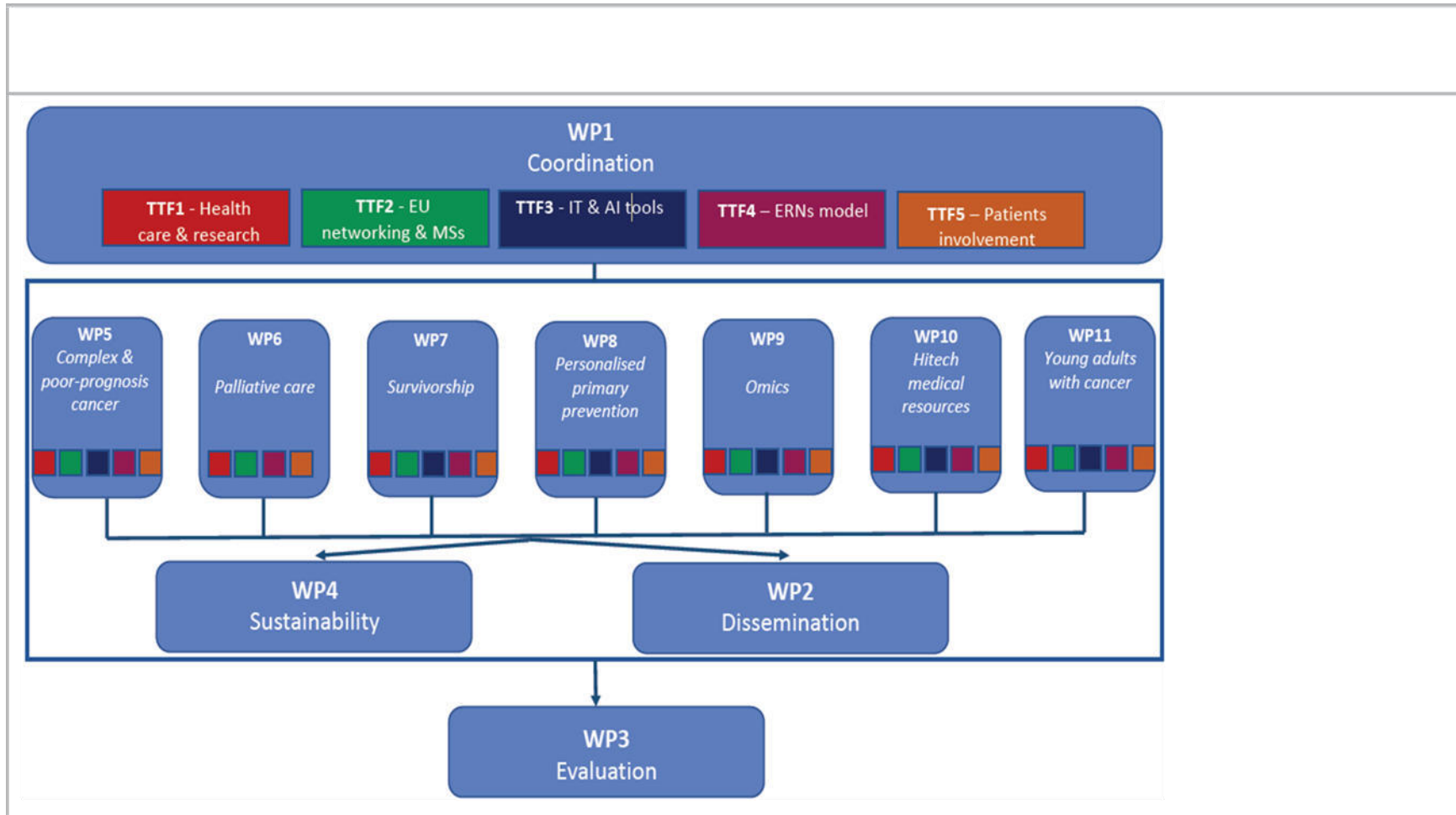
Follow-up to EU recommendations

Highlight corrective actions taken as a result of EU monitoring activities (including follow-up to EU project reviews, if any). List each recommendation/comment and explain how they have been followed up.

The EU has not to date provide any recommendations.

2. WORKPLAN, WORK PACKAGES, ACTIVITIES, RESOURCES AND TIMING

2.1 Work plan



2.2 Work packages, activities, resources and timing

Work Package 1 Project management and coordination

Work Package 1: Project management and coordination				
Duration:	M1- M24	Lead Beneficiary:	INT	
Objectives				
<ul style="list-style-type: none"> ▪ To manage the action and make sure that it is implemented according to plan.. ▪ To ensure coordination with other relevant Joint Actions (e.g. CraNE, Joint Action on Telemedicine) 				
Activities (what, how, where) and division of work				
<p><i>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</i></p>				
Task No	Task Name	Implemented	Justification	Partners involved
1.1	Project management	Yes	<p>Financial and administrative management</p> <p>INT received 70% prefinancing from the EC and proceeded to distribute it to the Beneficiaries (BEN) and Italian Affiliated Entities (AE), in accordance with the Grant Agreement. Each BEN transferred the due amounts to its respective AE.</p> <p>Project management</p> <p>A Project Management Team (PMT) has been set up to oversee day to day monitoring of project execution and coherent and timely production of interim results. It is formed by:</p> <ul style="list-style-type: none"> - Paolo Casali (Coordinator) - Annalisa Trama (Co-Coordinator) - Salvatore Provenzano (Coordination Team) - Giovanni Scoazec (Financial manager) - Joanne Fleming (Project Manager) - Lucia Buratti (Project Manager). 	INT, NHRF, CIPH, Biosistemak (formerly Kronikgune), MSCl, OUS, IOCN, Sciensano, Unicancer, INCA

		<p>JA governance also involves the active participation of a Steering Committee (SC) composed of all WP and TTF leaders. Monthly conference calls are being held with the SC, formed by the WP and TTF leaders, to monitor progress and discuss key check points besides milestones, cross-cutting activities, and synergies. In the first 18 months, SC meetings have been held on the following dates:</p> <ul style="list-style-type: none"> - 10 October, 2022 - 16 January, 2023 - 13 February, 2023 - 13 March, 2023 - 17 April, 2023 - 12 June, 2023 - 10 July, 2023 - 21 August, 2023 - 11 September, 2023 - 9 October, 2023 - 6 November, 2023 - 17 November, 2023 (in person) - 22 January, 2024 (in person) - 19 March, 2024 - 15 April, 2024 <p>Additional online meetings are programmed for 20th May and 10th June.</p> <p>The JA envisages just one Reporting Period and thus a single formal technical & financial report, to be accompanied by a request for payment, is to be submitted to the EC, sixty days after the project's end (30/11/2024). The JA is being additionally monitored through 6-month periodic internal reporting. The present Deliverable 1.2 (18-month report - without a request for payment), will constitute the third six-month report.</p> <p>It was planned to hold three General Assembly meetings during the two years' duration of JANE. The first of these was the Kick-Off meeting held in Milan on 14-15 November, 2022. All BENs and AEs were invited to participate in this meeting, which was attended by 56 partners in person and approximately 35 persons online. The second Plenary meeting was held online on 9 May, 2023.</p> <p>The third GA in-person meeting was held on 16-17 November, 2023 in Barcelona, attended by 85 people in person and approximately 50 online.</p>	
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			<p>A JA JANE Consortium Agreement was drawn up, circulated for comments and modifications, and signed by all the BEN and AE.</p> <p>The Coordination Team set up a JANE account in Google Drive to store and share project material.</p>	
1.2	Scientific coordination	Yes	<p>During the early months of the JA (December 2022-January 2023), the Coordination team organized individual meetings with each of the WP and TTF leaders and their respective teams. The purpose was to discuss in more detail the planned direction each was planning to take to shape their NoE or manage their transversal task force.</p> <p>The Coordination Team also set up individual meetings with various Scientific Societies with a view to seeking their collaboration in shaping the NoEs to which they are most interested in contributing. These societies include ECO (European Cancer Organisation), ESTRO (European Society for Radiotherapy & Oncology), and ESSO (European Society of Surgical Oncology).</p>	INT
1.3	Collaborative coordination with the Joint Action, CraNE	Yes	<p>Collaborative coordination was established with Joint Action CraNE at the start of the project, with an online meeting prior to the start of the two JA, held on 22 September, 2022. The purpose of the partnership is to align the work of the two JAs and create synergies wherever possible. The Coordinator of JANE, Paolo Casali, participated at the CraNE Joint Action Kick off meeting on 3-4 November, 2022 with a presentation of JA JANE. Tit Albrecht, Coordinator of CraNE, participated at the JANE Kick Off and online Plenary meetings, with presentations of JA CraNE at both. An additional Coordinator meeting between the two was held on 11 April, 2023. Tit also took part at the GA Assembly meeting in Barcelona in November 2023.</p> <p>JANE also initiated collaboration with JA eCAN to determine and capitalise on potential synergies in terms of teleconsultation and telemonitoring. Paolo Casali participated at the respective Kick-Off meeting on 20-21 September, contributing a presentation of JANE.</p> <p>Collaboration with the project CCI4EU has also started, after its Kick-off in May 2023.</p> <p>Online meeting was organised between DG SANTE/DG RTD/HaDEA and the coordinators of JANE, CrANE, and CCI4EU on 22 June, 2023 to discuss alignment and synergies between the four projects. The ECHoS project on cancer mission hubs was subsequently added as relevant. It was agreed to perform a joint exercise to evaluate and assess the four major projects related to cancer research, with the aim to optimize the performance and impact of the four major cancer-related projects by assessing their current status, addressing any gaps or issues, and promoting collaboration among stakeholders involved in these initiatives. The primary goals were as follows:</p>	INT

			<ul style="list-style-type: none"> - Alignment and synergies: by fostering alignment and synergies among the four projects, the joint exercise can maximize its impact, improve the efficiency of resource utilization, and ultimately contribute more effectively to cancer research and treatment efforts. - Identify gaps: to identify any gaps or shortcomings in the existing projects. - Enhance impact: which may involve proposing and implementing improvements, allocating joint resources, or developing strategies to ensure that the projects are making a meaningful and positive difference in the fight against cancer in line with the Beating Cancer Mission. - Regular collaboration: to foster collaboration and networking among the participating organizations or stakeholders is likely an important objective. Collaborative efforts can lead to more comprehensive and effective solutions for tackling cancer-related challenges. <p>The Coordinator, Paolo G. Casali, representing Joint Action JANE, took part in the CraNE Stakeholder Forum organised in Oslo on 7th December, 2023, specifically in the Panel discussion on expectations from Stakeholders.</p>	
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Next Steps (1 April, 2024 – 30 September, 2024)

- Since the European Commission Call for the follow-up Joint Action to JANE was issued in October 2023, the focus of the work has partly been on coordinating the proposal and reviewing the work performed to date. The focus will also be on coordinating the work of the TTFs and the final descriptions of the NoEs.

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
M1	Kick Off meeting	1	INT	The Kick off meeting was held in Milan on 14-15 November, 2023, attended by 56 people in person and approximately 35 persons online.	1	Meeting report and minutes
M2	Establishment of collaboration between JANE and CRANE Joint Actions	1	INT	This collaboration was established before the start of the JAs, with an online meeting on 22 September, 2022. The Coordinator of JANE, Paolo Casali, participated at the CraNE Joint Action Kick Off meeting on 3-4 November, with a presentation of JANE. Tit Albreht, Coordinator of CraNE, participated at the JANE kick off meeting with a presentation of the CraNE Joint Action.	3	Minutes of the first bilateral alignment meetings

Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
1.1	Mid-term Report	1	INT	Report	Sensitive	M14	Technical and financial internal report on the progress of the Joint Action; Paper, English
1.2	18-month Report	1	INT	Report	Sensitive	M20	Technical and financial internal report on the progress of the Joint Action; Paper, English

Work Package 2 Dissemination

Work Package 2: Dissemination				
Duration:	M1- M24	Lead Beneficiary:	NHRF	
Objectives				
<ul style="list-style-type: none"> ▪ To disseminate JANE activities through multiple channels and strategies ▪ To raise awareness within the medical community and patient advocacy groups on NoEs that will be developed through JANE ▪ To contribute to the launch of calls for expressions of interest of potential participants in NoEs 				
Activities (what, how, where) and division of work				
<i>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</i>				
Task No	Task Name	Implemented	Justification	Partners involved

T2.1	Plan, build and maintain the JANE website	Yes	<p>Design, construction and maintenance of the website https://jane-project.eu/.</p> <p>The first designs for the JANE logo and the main concept of the JANE website were presented by NHRF at the Kick-off Meeting and all partners were asked to give their input. The JANE logos as well as the architecture of the website were delivered in December 2022 (D2.1).</p> <p>Due to the size and complexity of the consortium, there were difficulties in receiving partners' input and reaching a consensus on the website design during the monthly JANE WP leader meetings. This affected the website's construction and delivery schedule. This issue was solved, with the assistance of the coordination team, by organising a dedicated website meeting on March 3rd at which final decisions were made, and the JANE website was launched in full capacity at the end of April 2023.</p> <p>In the JANE website the goals, ambitions, work packages and JANE partners are fully presented in a user-friendly way. News about significant meetings and events are uploaded on News page. The first e-newsletter about the progress of the project was duly issued and uploaded, while stakeholders are able to express their interest to get involved in JANE activities (Get involved page) and register to receive the newsletters through the Mailchimp platform. The second e-newsletter of the project was uploaded in December 2023 and sent through the Mailchimp platform to 110 recipients. The audience had increased to 124 subscribers at March 2024. Moreover, a press release with the progress of ongoing activities was uploaded on the News page of the JANE website in March 2024.</p>	NHRF, INT
T2.2	Prepare the JANE Dissemination Strategy and Communication Plan	YES	<p>A detailed dissemination and communication plan was developed both for internal and external mode, addressing all target groups and audiences (D2.2).</p> <p>A document including stakeholders' analysis and internal and external dissemination tools and channels was also delivered to INT. The first draft by NHRF was submitted for input/comments to the partners involved in WP2 (INT, BIOSYSTEMAK (formerly KRONIKGUNE) in March 2023. Following their input, the document was finalized and delivered at the end of April 2023</p> <p>The first draft by NHRF was submitted for input/comments to the partners involved in WP2 (INT, BIOSYSTEMAK/former KRONIKGUNE) in March 2023. Following their input, the document was finalized and delivered at the end of April 2023</p>	NHRF, INT, BiosistemaK
T2.3	Organize the JANE final conference	No	The final conference has been scheduled to be held in Brussels on 24 th -25 th September, 2024	

Next Steps (1 April 2024 – 30 September, 2024)

- Release of the 3rd e-Newsletter focusing on the Plenary meeting (Nov.2023) and the annual progress in NoEs.
- Enlargement of the stakeholders list.
- Enhancement of the cooperation with the CraNE Dissemination and Communication team and oncology communities.
- Further enhancement of communication tools/intensity by utilizing media experts.

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
MS 3	Network Mapping	2	NHRF	Mapping & analysing contents and targets of all JANE WPs Setting up a roadmap for the communication of main items and topics	M4	Network analyses performed
MS 4	Target-specific communication platform	2	NHRF	Get involved platform on the website https://jane-project.eu/ where specific target groups (health professionals, patient groups and policy makers) can declare their interest in the activities of the project. Target group analysis was performed, and stakeholders were grouped by country in four categories: Patient advocacy groups, Patient support associations, Scientific societies and Research groups. Initially, the communication with all stakeholders was performed via e-mail. They were all informed about the project's main goals/ambitions, current activities (a promotional flyer was also sent to all of them) and invited to express their interest through the Get involved platform.	M9	Target-specific communication platform available on the website

Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
D2.1	Project website	2	NHRF	DEC, Website	PU-Public	M3	Website; English
D2.2	Dissemination strategy plan	2	NHRF	R-Document report	PU-Public	M6	Document report describing ways, tools and channels for effective dissemination & communication of JANE achievements in shaping the NoEs; English
D2.3	Report on the Final JANE conference	2	NHRF	R-Document report	PU-Public	M24	Document report on the Final JANE conference; English (to be delivered)

Work Package 3 Evaluation

Work Package 3: Evaluation				
Duration:	M1- M24	Lead Beneficiary:	CIPH	
Objectives				
<ul style="list-style-type: none"> To verify if the project is being implemented as planned and reaches its objectives. 				
Activities (what, how, where) and division of work				
<p><i>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</i></p>				
Task No	Task Name	Implemented	Justification	Partners involved

3.1	Process evaluation	Yes	<p>Internal evaluation on the basis of the WP progress information collected from partners and meeting evaluation surveys.</p> <p>Surveys of four meetings have been done:</p> <ul style="list-style-type: none"> - JANE Kick-off Meeting; - JANE 1st Policy Dialogue Satisfaction; - JANE WP & TTF leader meeting; - JANE Plenary meeting <p>Low survey response rates:</p> <p>To encourage participation in the survey, we included a QR code with a link to the survey at the end of the presentation.</p> <p>Additional measures to address low response rates have included:</p> <ol style="list-style-type: none"> 1) Sending surveys immediately after the meeting. 2) Reminding participants to complete surveys at the meeting 3) Consider sending reminders a week after the meeting 	CIPH, INT, all partners
3.2	Product Evaluation	Partially	<p>Interim evaluation report (MS8) showcasing the progress of product delivery was produced, delivered to the coordinators and accepted by them.</p> <p>External evaluation by Advisory Board in progress, they are acquainted with the processes within the project and the first AB meeting was held in September 2023</p> <p>The 2nd Independent Advisory Board meeting (MS 7) is scheduled for the first week of July 2024 in accordance with the Grant Agreement.</p>	CIPH, Advisory Board, INT, IOV, INCA, Unicancer, FHF, BMG, DKFZ, OOI, SAM LT, OIL, BS
3.3	Awareness and impact of the proposed Network of Expertise	No	A survey directed at all those attending the policy board, stakeholder forum and plenary JA meeting are being undertaken to collect major stakeholders' opinions on the impact of proposed Network of Expertise	CIPH
Description of work performed and overview of progress, including any issues				

Several milestones have been successfully completed in the project's timeline. The Advisory Board setup (MS5) was completed by the M3 deadline, establishing a foundation oversight of project objectives. The 1st Independent Advisory Board meeting (MS 6) convened by M12, and comprehensive minutes of the meeting were promptly made available, documenting important discussions and decisions.

In terms of deliverables, the Evaluation Strategy (D3.1) was successfully completed, submitted (with a minor delay) and adopted. This document serves as a key strategic guide for evaluating the JANE JA. It outlines all the basic elements of process evaluation, including key evaluation objectives and key process evaluation activities

Next Steps (1 April 2024 – 30 September, 2024)

- The 2nd Independent Advisory Board meeting (MS 7) is scheduled in July (M22), and comprehensive minutes from the meeting will be made available.
The meeting will focus on the following agenda items:
 - *Review key points from core WPs and TTFs.*
 - *Gather feedback for the final Evaluation report from external AB members and other participants.*
 - *Discuss the Interim Evaluation Report and Final Evaluation Questionnaire.*
 - *Investigate how insights from JANE1 can assist in the initiation and execution of JANE2.*
- By M20, the final evaluation questionnaire (MS 9) will be developed and published on the website, facilitating an assessment of the project's results and NoEs.
- Furthermore, the Final Evaluation Report (D3.2) is expected at the end of the Project, summarizing the outcomes derived from evaluation indicators and survey results.

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
MS5	Advisory Board setup	3	CIPH	The Advisory Board was established. The WP3 leader suggested two external experts for the AB, who are evaluating if project actions align with objectives and are executed as planned.	3	List of Advisory Board members available

MS6	1st Independent Advisory Board meeting	3	CIPH	The meeting was organised and provided valuable insight and discussion of several aspects of the JANE project. These included the structure and progress of WP1, evaluation activities in WP3, sustainability efforts in WP4 and insights from the previous JA, Joint Action on Rare Cancers (JARC).	12	Minutes of the meeting made available.	
MS7	2nd Independent Advisory Board meeting	3	CIPH	The 2nd Independent AB meeting (MS 7) is scheduled for M22, and comprehensive minutes from the meeting will be made available.	22	Minutes of 2nd AB meeting will be made available.	
MS8	Interim report	3	CIPH	Interim report of the JANE evaluation including survey results was delivered to project coordinators (paper version in English).	14	Internal report on technical advancement will be shared.	
MS9	Final evaluation questionnaire developed	3	CIPH	Questionnaire to collect vision of major stakeholders on the impact of the proposed Networks of Expertise	20	Questionnaire has been made available on the website - assessment of the project's results and the NoE structure in particular.	
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 3.1	Evaluation strategy	WP3	CIPH	R — Document, report	SEN - Sensitive	8	Definition of evaluation strategy i.e. specific indicators per each JA objective. Paper version in English.
Del 3.2	Final evaluation report	WP3	CIPH	R — Document, report	SEN - Sensitive	24	Report of the JANE evaluation including survey results. Paper version in English.

Work Package 4 Sustainability

Work Package 4: Sustainability				
Duration:	M1- M24	Lead Beneficiary:	BiosistemaK (formerly Kronikgune)	
Objectives				
<ul style="list-style-type: none"> - Ensure that the established NoEs assemble the best knowledge, skills and facilities available in Europe. - Support NoEs' creation by focusing on strategies to guarantee their sustainability and aligning them with European and national policies. - Contribute to the improvement of EU health care cancer networks ensuring a long-term sustainable model for NoEs. - Generate policy recommendations and guidance to facilitate the sustainability of NoEs, possibly extending also to other health care networks in the EU. 				
Activities (what, how, where) and division of work				
<p>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</p>				
Task No	Task Name	Implemented	Justification	Partners involved
4.1	Mapping and analysis of existing networks	Partially	<p>Biosistemak (BS) has built a reference framework for the definition, analysis and validation of European networks, organizations and societies in the cancer field. WP4 members validated this framework entitled 'Reference framework for the analysis of European networks, organizations and networking projects'</p> <p>After the development of the reference framework, WP4 partners and the leaders of the 7 NoEs of JANE provided examples of networks, organizations and networking projects that could potentially serve as a reference in the development of a sustainability model for the NoEs. As a result, 62 entities were mapped. The same JANE partners were asked to prioritize these mapped organizations according to their relevance for the future NoEs through the completion of an online questionnaire developed by BS. As a result of this selection and prioritization exercise, a total of 15 entities were selected for study. BS was responsible for completing the information for each organization according to the dimensions and sub-dimensions included in</p>	<p>BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL DKFZ, OOI, INT, NCI, LT UNICANCER, ICO, IDIVAL, CIBER, HSJD,, IRST, OUS, MSCI</p>

			<p>the reference framework. Once the analysis was completed, the information for each organization was reviewed and, where necessary, supplemented by two WP4 partners.</p> <p>The results of this work include the global analysis and comparison of the main characteristics of the 15 mapped organizations and lessons learned. The results are part of the M10. 'Sustainability strategy of NoEs'. The lessons learned from the mapping activity led to the identification of the key aspects to be considered for establishing the sustainability strategy of the NoEs. These findings will be later validated in Task 4.2 with experts in the field, to build a final set of recommendations which will be included in the final deliverable.</p> <p>This task was finalized in Month 18 of the Joint Action.</p>	
4.2	Sustainability strategy of Networks of Expertise	Partially	<p>BS will complete and extend the results obtained from the analysis conducted in the above Task 4.1 through a workshop with representatives of the mapped organizations, to be held on 6th June, 2024. This workshop will help to compare and validate the available information from the analysed organizations. The workshop will discuss aspects of these systems which are working or could be changed in order to help the sustainability development of NoEs. It also will validate the proposed strategies in the M10. 'Sustainability strategy of NoEs' to build a final set of recommendations.</p> <p>The work in this task started in January 2024 with the definition of the contents for the workshop and its structure. The results of this activity will serve as input for the Del.4.1 'Policy recommendations on sustainability'.</p>	BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL, DKFZ, OOI, INT UNICANCER, ICO, IDIVAL, CIBER, HSJD, IRST, OUS, MSCl
4.3	Policy Board and Policy Dialogues	Partially	<p>BS has developed the 'Policy Board and Policy Dialogues mission, constituency and proceedings' document which has been validated by WP4 partners. The Policy Board, formed by representatives of all countries participating in JANE and the leader of CraNE JA, was set up, with a total of 16 members.</p> <p>As a first round of contact, BS organized virtual informal coffee meetings with all Policy Board members to introduce them to the Joint Action and to also gather their initial thoughts about the NoEs. Finally, 13 meetings were held and three other members contacted by email.</p> <p>The first Policy Dialogue took place on 3 October 2023 in an online format. The two main topics of discussion were entitled, "How to build potential alliances & synergies in the European ecosystem" & "How to ensure NoEs' alignment with European and National policies". The minutes with the results of this first Policy Dialogue were distributed to the JANE Policy Board and to all JANE partners.</p> <p>A second Policy Dialogue will be organised in an online format on 27 June 2024. The main discussion topics have been defined, namely legislation and financing.</p>	BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL, DKFZ, OOI, INT UNICANCER, ICO, IDIVAL, CIBER, HSJD, SAM LT, NCI-LT, MFH, OUS, MSCl, IOCN, Sciensano

			<p>The main conclusions gathered in these meetings will be included in the official deliverable, D4.1 'Policy recommendations on sustainability,' scheduled for submission on month 24 of the Joint Action.</p> <p>Some difficulties were encountered in finding representatives from all MS participating in JANE and also to have political decision-makers in all cases. Moreover, after the 1st Policy Dialogue, some policy board representatives ceased to be part of JANE. Proposed solutions: extending the final nomination of Policy Board members throughout the project (a representative from Norway is still missing) and open up the members' profiles leaving also open the possibility to change the representatives for each country at a later stage.</p>	
4.4	Stakeholder Forum	Partially	<p>BS has developed the 'Stakeholder Forum main concept and operating procedures', which has been validated by WP4 partners.</p> <p>Guided by the methodology proposed by BS, WP4 partners and JANE CAs have nominated experts to build the Stakeholder Matrix.</p> <p>The first JANE Stakeholder forum took place on 16 November, 2023 in a hybrid format, which included a face-to-face meeting in Barcelona and the opportunity to connect online. Some of the topics discussed among the experts were the added value NoEs bring to the European cancer health ecosystem, and how organisations external to the project can contribute to the creation and functioning of these networks. Exploring patient involvement in NoEs was also discussed. The minutes with the results of this first Stakeholder Forum were distributed to the JANE Stakeholder Matrix and to all JANE partners.</p> <p>A second Stakeholder Forum will be organized in September 2024.</p> <p>There were difficulties in nominating representatives of all MS participating in JANE. Proposed solution: leaving it open the possibility to include more members in the Stakeholder matrix during the life of the project.</p>	BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL DKFZ, OOI, INT, OUS UNICANCER, ICO, IDIVAL, CIBER, HSJD, MSCl
4.5	Policy recommendations	Partially	<p>This task is related to the preparation of the official Deliverable D4.1, which will include the results of the previous four tasks: Task 4.1 'Mapping and analysis of existing networks', Task 4.2 'Sustainability Strategy of Networks of Expertise', Task 4.3 'Policy Board and Policy Dialogues' and Task 4.4 'Stakeholder Forum'. The deliverable is expected to be finalized between June and September 2024.</p>	BS, CNAO, IOV PASCALE, OIL, CIPH, INCA, BMG, DKFZ, OOI, INT, OUS, UNICANCER, ICO, IDIVAL, CIBER, HSJD, IRST, MSCl
Description of work and overview of progress, including any issues				

WP4 Monthly follow-up meetings have been set every third Tuesday of the month (14:00 to 15:30 CET). Invitations for all meetings until the end of the project have already been sent including the connection links. The agenda for the session is sent out in advance of the Monthly meeting with the main points to be covered. In addition, within 3 working days after the meeting, BS produces written minutes which include the meeting summary, decisions taken and next steps or ToDo items with deadlines and responsibilities for each task. WP4 members can send their input or feedback within 7 days. Finally, the minutes are sent together with the links to the recording and PowerPoint of the session, which are uploaded in the JANE WP4 meetings Drive folder.

Task 4.1 Mapping and analysis of existing networks

During the first 18 months of the project, the following activities have been achieved:

- Selection and prioritisation of existing networks and associations in Europe in the cancer field: BS listed a total of 62 existing EU cancer networks, societies and associations. WP4 partners were invited to rank and prioritize them according to their relevance through an online survey, where relevance was defined as: "significant, valued or important in the area ". As a result, a total of 15 networks were selected to be further analysed in depth.
- Definition and validation of a comparative framework of the key characteristics of the networks, societies and associations. The framework is composed of 8 dimensions: (1) scope, (2) governance, (3) strategic plan, (4) research, education and services, (5) strategic alliances, (6) communication strategy and tools, (7) ethics legal & regulatory and (8) funding.
- Gather information on the 8 key dimensions for the 15 networks and associations and validation by WP4 partners.
- Global analysis and comparison of the main characteristics of the 15 mapped organizations and lessons learned. The results of this analysis are included in the M10. 'Sustainable strategy of NoEs'.

Task 4.2 Sustainability strategy of Networks of Expertise

The results obtained from the analysis conducted in Task 4.1 will set the base to build a set of recommendations for the NoEs sustainability after its validation in a workshop with experts from the mapped organizations.

The work is still in progress

Task 4.3 Policy Board and Policy Dialogues

The following activities have been achieved:

- Development and validation of the 'Main Concept and Operating procedures of the Policy Board and Policy Dialogues of JANE'. This document contains relevant information regarding the objectives, kind of membership, secretariat, communication procedures and specific activities that will be organized in the context of Task 4.3. The expected contributions of the Policy Board are to give recommendations and orientation on the key aspects to be considered for establishing sustainable added value of NoEs and will serve as input for Deliverable 4.1. These outputs will be obtained from the informal bilateral coffee meetings and two Policy Dialogues (annual) organized by BS.
- Nomination of representatives of each MS for the Policy Board belonging to: Ministries of health, regional policy level and institutes of research/cancer.
- Individual Informal Coffee Meetings with Policy Board representatives. A total of 13 interviews were held between May-July 2023. The main conclusions obtained from these conversations were classified in four categories: (1) Management & Infrastructure, (2) Networking & Communication, (3) Resources & Capacities and (4) Inspired and/or supported by other European models, such as ERNs. The results of these interviews inspired the topics of discussions for the first Policy Dialogue and will also be included in the D4.1.
- Organization of the first Policy Dialogue on 3 October 2023 in an online format and preparation of the minutes for the event.
- Organization of the second Policy Dialogue. The date has been set: 20 June 2024 and the main discussion topics have been defined: "Legislation" and "Financing".

Task 4.4 Stakeholder Forum

The following activities have been achieved:

- Development and validation of the 'Stakeholder Matrix and Stakeholder Forum: main concept and operating procedures'. This document contains two main sections, firstly the relevant information about the Stakeholder Matrix is introduced, including aspects such as the objectives, kind of membership, secretariat and communication procedures. Secondly, the Stakeholder Forum is presented together with its objectives and operating procedure.
- WP4 partners and JANE CAs have nominated representatives for the Stakeholder Matrix who have been invited to join as stakeholders of the project.
- Organization of the first Stakeholder Forum held on 16 November, 2023 in Barcelona, back to back with the annual JA JANE meeting and preparation of the minutes..

Other issues:

Some WP4 partners with assigned contribution (as defined in the Grant Agreement) have not actively participated in the WP4 meetings or activities. BS has been in close contact with the Coordination team to manage the situation. As mitigation actions, some CAs assumed the work of their AEs and BS took on part of the work

Next Steps (1 April 2024 – 30 September, 2024)

Task 4.1 Mapping and analysis of existing networks

- This activity has been completed.

Task 4.2 Sustainability strategy of Networks of Expertise

- Organization of a workshop with the 15 organization representatives of the mapping analysis.
- The strategies included in M10 will be validated during the workshop to build a set of recommendations for NoEs sustainability

Task 4.3 Policy Board and Policy Dialogues

- Analyse the insights obtained in the Informal coffee meetings
- Organize the first Policy Dialogue (3 October, 2023)
- Make an intermediate update to the Policy Board members
- Organize the second Policy Dialogue (2024)

Task 4.4 Stakeholder Forum

- Nomination of more experts to build the Stakeholder Matrix
- Make an intermediate update to the Stakeholder Matrix members (April 2024)
- Organize the second Stakeholder Forum (2024)
- Prepare the minutes with the results of the second Policy Dialogue

Task 4.5 Policy recommendations

- Develop the official Deliverable 4.1 Policy Recommendations on Sustainability

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description		Due Date (month number)	Means of Verification
MS10	Sustainability strategy	WP4	BS	This milestone includes the results of Task 4.1 'Mapping and analysis of existing networks'. This work, which has been submitted to the coordination team includes the global analysis and comparison of the main characteristics of the 15 mapped organizations and lessons learned. The results of this milestone will be later validated as part of the Task 4.2 'Sustainability strategy of the Networks of Expertise' with the representatives of the mapped organizations to build the final set of recommendations for NoEs sustainability.		18	Publication of a strategy paper detailing the next steps and long-term activities of the NoEs
MS11	Holding of a Stakeholder Forum	WP4	BS	<p>The main goal of the Stakeholder Forum is to serve as a place for discussion facilitating the exchange of expertise, experience and opinions and networking of the Stakeholder Matrix members and organizations participating in JANE.</p> <p>It is also aimed at facilitating dialogue and collaboration among key agents in the cancer ecosystem, including the NoEs, civil society, academia, private sector, and other relevant stakeholders.</p> <p>Finally, it expects to foster collaboration, share progress, and explore opportunities to strengthen the impact and sustainability of JANE and the future NoEs</p>		24	Event minutes, summaries, dissemination material
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 4.1	Policy recommendations on sustainability	WP4	BS	R- Document, report	PU - Public	24	Report including political recommendations. Paper version in English.

Use of resources

Budget implementation —Use of resources (deviations)

Explain deviations from the budget planning (i.e. differences between actual and planned use of resources, especially for personnel).

Include explanations on transfers of cost categories in the estimated budget (if applicable)

Don't forget to attach the detailed cost reporting table (if any).

Since Biosistemak is the Competent Authority for Spain, deviations for their Affiliated Entities will be reported in this section.

CIBER: Given the adjustment of PMs included in Amendment 1 and considering the actual PMs cost and the actual personnel effort, CIBER would like to adjust the budget and PMs distribution. Besides, since they will no longer be able to travel during the project due to internal issues, they would like to transfer the €2,000 allocated to travel costs to the personnel budget, dividing it between contributions in WP4 and WP12. Taking into account these two deviations, the budget distribution for CIBER would be:

WPs	PMs	Personnel costs	Other direct costs (travel)	Indirect costs (7%)	Total costs
WP4	3,3	14.000,00		980	14.980,00
WP12	1,8	7.500,00		525	8.025,00
WP14	0	0		0	0
WP15	0,3	1.625,00		113,75	1.738,75
WP16	0,3	1.625,00		113,75	1.738,75
CIBER	5,7	24.750,00	0	1.732,50	26.482,50

Work Package 5 Complex and poor prognosis cancers

Work Package 5: Complex and poor prognosis cancers				
Duration:	M1- M24	Lead Beneficiary:	MSCI	
Objectives				
<p>Some cancers, such as pancreatic cancer, gastric cancer and head and neck cancers, are considered as poor-prognosis cancers due to their high mortality (>20 per 100,000/year) and low survival (relative survival ≤40% at 1 year, ≤30% at 3 or 5 years after diagnosis) rates. The goal of WP5 will be to establish at least one NoE dedicated to one complex/poor prognosis cancer to increase the efficacy of treatments and quality of care, reduce inequality across the EU, boost basic/preclinical research and the use of innovative technologies, promote education, clinical practice guidelines and multidisciplinary care development, as well as epidemiological surveillance. Since some poor-prognosis cancers fall within cancers which are already covered, at least in part, by existing ERNs (namely, EURACAN), a discussion with stakeholders will be held to decide whether some poor-prognosis cancers may be added to EURACAN's domains already in place (with regard to head & neck cancers).</p> <p>The specific objectives include the definition of:</p> <ul style="list-style-type: none"> - the scope of the NoE - the activities of the NoE - potential partners - governance - sustainability - indicators of efficacy and cost/efficacy - interplay with MSs, networks, CCCs, EU patients 				
Activities (what, how, where) and division of work				
<p>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</p>				
Task No	Task Name	Implemented	Justification	Partners involved
5.1	Establishment of a framework for the NoE on poor prognosis cancers	Yes	<p>Concept PPC NoE based on domain model developed by EURACAN was proposed and accepted by the consortium members and coordinator.</p> <p>A definition of poor prognosis cancers, considered to be a defined cancer population with a 5-year overall survival rate below 33%, was developed by NoE PCC experts in collaboration with the Institut National du Cancer (INCa). The list of experts was prepared and sent to the Coordinator.</p>	MSCI, INCa, NIPH, BS, EURACAN, IDIVAL, NHRF, INT

			Meeting minutes and presentations were sent to coordinator and working group members	
5.2	Definition of the scope of the NoE(s) on complex and poor prognosis cancers	Yes	<p>Means to achieve PPC NoE's mission were defined by the working group: improving knowledge and research, diagnosis and treatment; raising awareness in the community and among policymakers about the needs of poor prognosis cancers; educating the community; empowering patients.</p> <p>The working group decided to run a pilot NoE PPC dedicated to pancreatic cancer.</p> <p>Existing models of pancreatic cancer were evaluated by WP4 and WP5 leaders for current and future networking and existing initiatives dedicated to poor prognosis cancer were mapped.</p> <p>The working group agreed to build a multidisciplinary network gathering expertise and professionals from different specialisations, PAGs and societies or institutions representing the healthcare systems across Europe.</p> <p>The pancreatic cancer working group revised IPAAC's set of standards.</p> <p>Four domains were defined for the Pancreatic Cancer NoE: 1) clinical care; 2) research and innovation; 3) education and training; 4) policy and patient engagement.</p> <p>Follow-up meeting was organised relating to pilot pancreatic cancer NoE and its scaling up to other poor prognosis cancers.</p>	MSCI, INCA, EURACAN, BS, IDIVAL, NHRF, INT
5.3	NoE Governance development	Yes	<p>The PPC governance model, developed based on the EURACAN framework and agreed upon at working group meetings, has been subtly modified to enhance integrated cooperation among the various governance structures. The following governance structure was defined: transversal focus domains concerning specific tumour types and five working packages – clinical care, research and innovation, policy and patient engagement, education and training, and governance. These include governance, dissemination, evaluation, sustainability.</p> <p>The pilot dedicated to pancreatic cancer focus domain was established.</p>	MSCI, EURACAN, BS, IDIVAL, NHRF, INT
5.4	Identification of the endorsement criteria and application modalities for healthcare providers willing to join the NoE dedicated to poor prognosis cancers	YES	<p>Based on discussions with the coordinator and on consensus within WP5 PPC, it is considered very difficult to set a restrictive cutoff under the endorsement criteria for individuals, HCP and societies. The value is in the cooperation with all MS.</p> <p>The possible endorsement criteria for partners not included in the JANE2 proposal will consist of a two-step procedure:</p> <p>Step 1: Applicants must submit their applications in a narrative format, clearly illustrating how their skills align with the endorsement criteria defined for the role.</p>	MSCI, IDIVAL, NHRF, BS, ICO, VULSK, NKUA, UNICANCER,

			Step 2: Applicants will present potential input and commitment contributions to the network. The Executive Board of PPC will make a decision after presentation of applicant's experience and competences demonstrating its suitability for the specified role within the defined field.			
5.5	Centre selection		Considering the continuation of the project in JA JANE2, experts from approximately 69 institutions from 27 countries have been nominated and defined. Therefore, the selection process for participation in the WP5 PPC was at the country level. For new members the selection will be based on endorsement criteria developed on PPC.	CA + AE		
5.6	Identification of NoE activities	Ongoing	Under implementation.	MSCI		
Next Steps (1 April, 2024 – 30 September, 2024)						
<ul style="list-style-type: none"> • During this period, work on identifying activities, priorities and deliverables of the NoE will continue. For this purpose, a survey will be implemented among the project partners involved in the PPC. • Meetings of WP5 and the pancreas group will be held on regular basis. • It is also planned to organise online meetings with each of the countries involved in the PPC in order to better understand the needs and activities in PPC in each country. These meetings are planned to take place in May-June. 						
Milestones and deliverables (outputs/outcomes)						
Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
MS12	Expert group definition	WP5	MSCI	Finalised list of participating experts	3	List of experts sent to the coordinator
MS13	Complex Cancers NoE Scope	WP5	MSCI	The list of objectives for this NoE will be made available	6	List of objectives – provided

MS14	Complex Cancers NoE Governance	WP5	MSCI	Details on the NoE's governance structure are made available on the project's website.		12	Governance model sent to coordinator
MS5.4	Endorsement criteria	WP5	MSCI	Identification of the endorsement criteria for participant centres		M14	Endorsement criteria sent to coordinator
MS5.5	Site selection	WP5	MSCI	Expression of interest for the NoE launched		M18	List of participants for WP5 PPC of JA JANE 2 proposal
M5.6	List of NoE activities	WP5	MSCI	Description of activities, priorities and deliverables of the NoE		M22	In progress
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 5.1	NoE on complex and poor prognosis cancers	WP5	MSCI	R — Document, report	PU - Public	24	Report clarifying: - scope of the NoE - expected activities of the NoE - partners - governance - sustainability - indicators of efficacy and cost/efficacy evaluation criteria - interplay with MSs, other EU networks, CCCs, patients Paper version in English

Work Package 6 Palliative care

Work Package 6: Palliative care				
Duration:	M1- M24	Lead Beneficiary:	OUS	
Objectives				
<p>The overall objective of WP6 is to establish a sustainable, high profile NoE on palliative care, to support the integration of evidence-based palliative care into routine cancer care and to ensure equitable access to palliative care across EU MSs, according to needs.</p> <p>The specific objectives will include the definition of:</p> <ul style="list-style-type: none"> - the scope of the NoE on palliative care - breadth of its activities - its potential partners - its governance - its sustainability beyond two years. including proof of evidence - its indicators of efficacy and its cost/efficacy constraints - its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients 				
Activities (what, how, where) and division of work				
<p>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</p>				
Task No	Task Name	Implemented	Justification	Partners involved
6.1	Leading expert scoping. Scoping leading experts in the field of palliative care to reflect the diverse health care services and levels of care throughout the EU, best expertise and networking abilities.	YES	Scoping of Palliative care and cancer care networks, and organisations to ensure a broad representation throughout Europe	OUS, INT, DGS, ICO, SAS, IOCN

6.2	Leading expert selection. Active recruitment of opinion leaders, professional stakeholders and educators, multi-professional researchers and top clinicians throughout the EU.	YES	Reaching out to internationally renowned experts, clinicians, stakeholders, organisation leaders etc., multiprofessionals, with diverse geographical affiliations and representing diverse levels of health care services to assemble a group of experts to ensure a sustainable, trustworthy NoE. Submitted month 3	OUS, INT, DGS, ICO, SAS, IOCN
6.3	Definition of the scope of the NoE (INT, Task Forces). Facilitating experts' agreement on the objectives of the NoE (e.g. to define European clinical practice guidelines for palliative care and integrate existing ones, to promote the implementation of evidence-based care pathways to integrate palliative care into routine cancer care, to develop site specific educational programmes, to match cultural diversity). Overall, the NoE will ultimately ensure that all outputs are adapted to the different socio-economic and health care organisation of each EU country, to different levels of care [primary to tertiary, curative/palliative etc.] and cultural diversity	YES	<p>Mutual decision among the WP6 participants to use the Lancet Commission (2018) as the basis and Proof of Concept (POC) for the work, i.e., definition, organisation and structure, operationalisation, applicability, and sustainability of the NoE in Palliative care. The POC clearly describes the need to integrate the principles of application of care into mainstream cancer care, regardless of an individual's cancer prognosis. Patient-centred care is the underlying premise that should guide the delivery, extent, and content of palliative care.</p> <p>The framework underpinning patient-centred care is the use of patient-centred care pathways (PCCPs), which represent a way of organising care for a given patient according to needs and in accordance with consensus-based treatment and palliative care guidelines.</p> <p>These principles are orchestral at any care level. Ensuring full access to palliative care for all Europeans is not feasible, as this is as much a political and economic issue as a quality-of-care issue.</p> <p>Participants have agreed on the scope of the NoE that has been submitted (Month 5). The work has been divided into 5 working groups (WG):</p> <p>WG1: Definition of the content, WG2: List of indicators; WG3: Implementation, WG4: Development of PCCPs, WG5: Relevant competence</p> <p>Notably, OUS is currently leading one large EU-funded project MyPath (HORIZON-HLTH-2021-DISEASE-04) on implementation of digital patient-centred care pathways and is WP leader in another EUonQOL on standardisation of PROMs. There is a high degree of synergies that undoubtedly will facilitate the integration of palliative care and inform the work of JANE.</p>	OUS, INT, DGS, ICO, SAS, IOCN

6.4	Identification of participants' endorsement criteria (Task Forces). Facilitating experts' agreement on the endorsement criteria for participants' selection	YES	The endorsement criteria have been agreed upon by the participants, and have been uploaded on the JANE website (Month 10)	OUS, INT, DGS, ICO, SAS, IOCN
6.5	Scoping of sites (OUH, NoE) : Scoping the potential centres whose participation in the palliative care NoE may be beneficial	YES	<p>This task was described as partially completed in the previous 12-month report. In the DoA the content of this task concerns scoping and approaching sites that would serve as major contributors to an NoE in PC given their expertise, experience from clinical PC and research as well as sites that would benefit from participating in the NoE in a national context to improve PC access throughout Europe. The duration of this work was presented in the JANE1 DoA (Gantt Chart) as a continuous process that would go on from Month 14 through Month 16</p> <p>One deviation applies. Initially, we had planned to organise this as surveys distributed in the different countries. However, the call and application for JANE2 changed the perspectives of this work. Recruiting sites and engaging these to participate in JANE2 became a joint effort in most JANE1 WPs, supported by the JANE coordination team. The scoping of the PC organisation, content and access was therefore confined to the sites directly involved in WP6.</p>	OUS, INT, DGS, ICO, SAS, IOCN
6.6.	Site selection (Task Forces): Launching an expression of interest call	YES	Sites have been selected, and work tasks assigned as part of the Working groups. Synergies with other WPs and TTFs within JANE have been defined and are work in progress	OUS, INT, DGS, ICO, SAS, IOCN
6.7	Planning palliative care NoE deliverables (OUH, all partners) Developing the core deliverables of the NoE: clinical practice guidelines or initiatives to integrate existing ones, educational programs, pathway optimisation and testing across EU MSs, development of indicators of efficacy and	YES, partially	The planning on how to move forward and how to conduct the necessary work in a timely manner to deliver the WP6 deliverable is according to schedule. All 5 working groups (WG) in WP6 have separate responsibilities in that they focus on smaller parts related to the organisation of and access to PC: Each WG will describe essential parts of the description on why and how to define and describe the content of an NoE in palliative care, in relation to the following 5 areas; content, indicators, implementation, pathways, and competence. Further, emphasis is placed on how to extend the influence of the NoE and ensure sustainability for further consolidation in JANE2. Presented to go on from Month 16 through Month 24 in the JANE1 DoA (Gantt Chart)	OUS, INT, DGS, ICO, SAS, IOCN

	actions to evaluate cost/efficacy			
6.8	NoE governance development	Partially	This work builds on the work in the working groups and will summarize the written material produced there. The concrete output is Deliverable 1, due by Month 24. Presented to go from Month 16 through Month 24 in the JANE1 DoA (Gantt Chart).	OUS, INT, DGS, ICO, SAS, IOCN

Description of work and overview of progress, including any issues

All activities that have been performed or are ongoing, i.e., are in progress, have been described above. No unforeseen issues/deviations have occurred at this stage.

Several stakeholders were involved in the discussions:

- The Royal Marsden, UK
- Fondazione IRCCS Istituto Nazionale dei Tumori, Italy
- Siunsoite Oncology and Palliative Care Center, Finland
- Programa Nacional para as Doenças Oncológicas - Direção-Geral da Saúde, Portugal
- North Estonia Medical Center, Estonia
- Instituto Català d'Oncologia, Spain
- University Medical Centre Groningen , the Netherlands
- Närvårdskliniken Linköping / Linköping Universitet, Sweden
- Palliativa kliniken Västerås, Närsjukvård Öst
- Cancer Research UK Edinburgh Centre, UK
- Sistema Andaluz de Salud, Spain
- Charité Centrum (CC) für Tumormedizin, Germany
- Oncohelp, Romania
- Aarhus Universitetshospital og Syddansk Universitet, Denmark

Next Steps (1 April, 2024 – 30 September, 2024)

- The main activities in the coming months are to discuss, elaborate and finalize the summaries from each of the 5 WGs. The main responsibility of producing these summaries lies with the WG leads, but the WP lead (OUS) has had to take the major lead in 3 of these WGs, as some of the participants have not been able to comply with the agreed-upon work, due to different circumstances.
- To ensure that the final report, i.e., WP6 deliverable D1, is finalized in due phases, a scheduled series of meetings has been organised. These are mutual meetings for all WP6 participants, and smaller meetings among the WG leads and the leads of WP6. Each group will provide 1-2 pages (500-600 words) of recommendations related to their assigned subjects in the form of short reports. These will be discussed, revised, aligned, and put into a wider context to serve as the WP6 deliverable reports due in Month 22.

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description		Due Date (month number)	Means of Verification
MS18	Selection of list of leading experts	6	OUS	The participants constituting the list of experts of WP6 has been defined		M3	List submitted to the JANE steering group
MS19	Definition of the scope of the Palliative Care NoE	6	OUS	The objectives have been defined and explicitly conceptualized in the endorsement criteria		M5	List of NOE objectives submitted to the JANE steering group
MS20	Endorsement criteria/	6	OUS	Endorsement criteria: A specified description and list of endorsement criteria published on the JANE website		M10	Published, approved by coordination steering group
MS21	Expression of interest	14	OUS	Documentation of the expression of interest (launch event minutes, if held, expression spread, etc.).		M14	
MS22	Palliative care NoE deliverables	18	OUS	List of NoE-specific deliverables available		M18	
MS23	Pilot POCs	21	OUS	Documentation of means of verification (feasibility, logistics, patient satisfaction and PROMs)		M21	
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 6.1	Palliative Care - NoE	6	OUS	Document, report	Public	M24	Report clarifying: <ul style="list-style-type: none"> - scope of NoE - expected activities - partner governance sustainability - capacity of participating centres to perform as required

							<ul style="list-style-type: none"> - indicators of efficacy/ cost/efficacy evaluation criteria - interplay with MSs, other EU networks, CCCs, patients Paper version in English
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Work Package 7 Survivorship

Work Package 7: Survivorship				
Duration:	M1- M24	Lead Beneficiary:	MSCI	
Objectives				
<p>The overall objective of WP7 is to establish a sustainable, high-profile NoE on survivorship and cured patients to support the integration of evidence-based approaches to cancer survivorship into routine care and to ensure equitable access across EU MSs, also driving the identification of all relevant issues pertaining to the increased survival of cancer patients and possible solutions.</p> <p>The specific objectives will include the definition of:</p> <ul style="list-style-type: none"> - the scope of the NoE on survivorship - its activities - its potential partners - its governance - its sustainability - the indicators of efficacy and its cost/efficacy constraints - its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients. 				
Activities (what, how, where) and division of work				
<p><i>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</i></p>				
Task No	Task Name	Implemented	Justification	Partners involved

7.1	Leading expert scoping	Yes	The WP leader invited potential members to join from among the EU countries. The list of collaborators has been created	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO, Gaslini, CIPH, NKUA, ICO, HSJD, FAVO
7.2	Leading Expert Selection	Yes	Identification of the leading experts on 4 different aspects of survivorship (connected with cancers, adverse events, psychological distress, and social aspects)	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO, Gaslini, CIPH, NKUA, ICO, HSJD, FAVO
7.3	Definition of the scope of the survivorship NoE	Yes	The survivorship definition provided by ESMO was approved by members of WP7	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO, Gaslini, CIPH, NKUA, ICO, HSJD, FAVO
7.4	Identification of the endorsement criteria for survivorship NoE sites and / or services	Yes	Identification of endorsement criteria regarding health providers (1 st set) and other sites/ services/entities (2 nd set), brainstorming with the group members.	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO, Gaslini, CIPH, NKUA, ICO, HSJD, FAVO
7.5	Scoping of sites and or services	Yes	Based on the questionnaire prepared by the WP leader, potential partners (CCC, networks, and societies) were identified whose participation in the project may be beneficial.	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO, Gaslini, CIPH, NKUA, ICO, HSJD, FAVO
7.6	Site and relevant stakeholder selection	Yes	Contact with larger organisations for closer collaboration ex ESMO, SIOPE, OECl, PanCare, ECO	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO, Gaslini, CIPH, NKUA, ICO, HSJD, FAVO
7.7	Planning survivorship NoE deliverables	Yes	The list of deliverables (sites and services that NoE will provide) has been identified. The desired deliverable of NoE Survivorship is achieving comprehensive and coordinated management and care for cancer survivors. Implementation of the plan	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO,

			requires coordination and organization across health systems. Cooperation with JANE 2 is helpful to achieve the objectives and put the deliverables into practice.	Gaslini, CIPH, NKUA, ICO, HSJD, FAVO		
7.8	NoE governance development	In progress	Still working on developing the NoE governance	MSCI, INT, Sciansano, INCA, ACC, BS, Unicancer, SAS, CNAO, Gaslini, CIPH, NKUA, ICO, HSJD, FAVO		
Description of work and overview of progress, including any issues						
<p>The Survivorship team's approach is based on brainstorming during the meetings. They initiate contacts with potential partners, organisations, societies, and advocacy groups. They seek to collaborate with CCCs in EU countries. They are working on implementation of the Survivorship Passport based on the experience and knowledge of PanCare members.</p> <p>Several stakeholders were involved in the discussions:</p> <ul style="list-style-type: none"> - European Cancer Organisation - the Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer - Polish National Oncological Strategy and Survivorship Plan, Polish Oncological Society 						
Next Steps (31 March, 2024 – 30 September, 2024)						
<ul style="list-style-type: none"> • Developing the NoE governance, including specific strategies to ensure the interplay with MSs, other EU networks, CCCs, patients – this is the shared step with JANE 2. We are planning the separate meeting dedicated to this task to determine the next steps. • The activities of the Polish National Oncological Strategy and Survivorship Plan are being expanded. The WP7 team is in the process of implementing the Survivorship Passport in Poland and improving the organisation of health care for survivorship. 						
Milestones and deliverables (outputs/outcomes)						
Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
MS7.1	Leading experts	WP7	MSCI	Leading experts identified	3	List of experts available
MS7.2	Definition of the scope	WP7	MSCI	Objectives of the NoE established	5	List of the NoE objectives available

MS7.3	Identification of the endorsement criteria for survivorship NoE	WP7	MSCI	Definition of endorsement criteria for NoE participants developed	10	List of endorsement criteria published on the JANE website	
MS7.4	Site and relevant stakeholder selection	WP7	MSCI	Expression of interest for the NoE launched	12	Documentations of expression of interest (launching event, minutes, expression spread)	
MS7.5	Planning survivorship NoE deliverables	WP7	MSCI	Description of expected outputs of the NoE	16	List o NoE deliverables available	
MS7.6	NoE governance development	WP7	MSCI Sciensano	Description of the organization and management structure of NoE – in progress	22		
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 7.1	The NoE dedicated to survivorship	WP7	MSCI	Document, report	Public	24	The strategic document will contain all the specificities of the NoE. Paper version in English

Work Package 8 Personalised primary prevention

Work Package 8: Personalised primary prevention			
Duration:	M1- M24	Lead Beneficiary:	IOCN
Objectives			
The overall objective of WP8 is to establish an NoE to promote the implementation of personalised primary prevention at the community level.			
The specific objectives will include the definition of:			

- the scope of the NoE on personalized primary prevention
- its activities
- its potential partners
- its governance
- its sustainability
- its indicators of efficacy and its cost/efficacy constraints
- its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients

Activities (what, how, where) and division of work

Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.

Task No	Task Name	Implemented	Justification	Partners involved
8.1	Define the scope of the Network of Expertise on Personalised Primary Prevention	Yes	The NoE on Personalised Primary Prevention aims to create a collaborative platform for professionals, researchers, and organisations focused on advancing personalised approaches to primary prevention in the field of health and well-being. The scope encompasses the identification and implementation of tailored strategies to prevent health issues at their earliest stages, considering individual variations and risk factors.	IOCN, INCA, Sciensano, BS, Unicancer, MSCl, INT
8.2	Identify the agenda and main activities for this NoE	Yes	Considering that family physicians are stakeholders responsible for delivering prevention interventions in the community, the WP8 team believes it appropriate to investigate their perspective in more detail in terms of these services. A qualitative study was conducted using a data collection method based on semi-structured interviews. Key milestones will be wrapped up and progress reports drawn up with achievements, challenges, and lessons learned, as well as recommendations for improvement and refinement of activities. Upcoming Actions include a roadmap for the next 12 months, detailing upcoming projects and priorities, as well as input on future directions and initiatives.	IOCN, INCA, Sciensano, BS, Unicancer, MSCl, INT
8.3	Define the criteria for participation and identify participants in the network	Yes	The purpose of this deliverable is to define and outline the criteria for participation in the future network dedicated to Personalized Primary Prevention. This network will bring together various stakeholders, including healthcare centres, experts, and healthcare providers, to collaborate in advancing personalized primary prevention strategies. This document will provide a comprehensive framework for the selection and inclusion of relevant parties into this network. The criteria for participation and identification of participants in the network (Milestone 33) has been revised and updates have been made to illustrate the necessary adjustments.	IOCN, INCA, Sciensano, BS, Unicancer, MSCl, INT

8.4	Conduct meetings and liaise with the stakeholders involved in this NoE	Yes	Meetings and Stakeholder Liaison include regular meetings and stakeholder engagement meetings. Monthly virtual meetings are conducted to discuss progress, challenges, and upcoming activities. Communication channels have been established with key stakeholders, including government agencies, industry partners, and advocacy groups. Feedback and input have been sought from stakeholders to enhance the impact of the NoE.	IOCN, INCA, Sciensano, BS, Unicancer, MSCI, INT
8.6	Wrap up of key deliverables for the first 12-months and define upcoming actions	Yes	Key milestones are being wrapped up and progress reports drawn up with achievements, challenges, and lessons learned, as well as recommendations for improvement and refinement of activities. Upcoming Actions include a roadmap for the next 12 months, detailing upcoming projects and priorities, as well as input on future directions and initiatives.	IOCN, INCA, Sciensano, BS, Unicancer, MSCI, INT
Description of work and overview of progress, including any issues				
<p>In the first twelve months, the dedicated team for the NoE on Personalised Primary Prevention made significant strides in advancing its mission. The team successfully conducted a comprehensive needs assessment and gap analysis, laying the groundwork for the development of a robust conceptual framework for personalised primary prevention. Collaboration efforts among diverse participants have been fruitful, leading to the initiation of joint research projects and the establishment of effective communication channels. Unexpectedly, we faced challenges in coordinating meetings across different time zones, impacting the timely progress of certain initiatives. In response, the team implemented a rotational meeting schedule to accommodate participants globally. Additionally, it encountered delays in onboarding due to unforeseen administrative hurdles, leading to a temporary resource strain. Nevertheless, the restructuring at IOCN has attracted new talents, offsetting these challenges. These unexpected events prompted the team to refine its planning and timing strategies, ensuring a more resilient and adaptive approach in the coming months. Despite these obstacles, its commitment to the project remains unwavering, and is confident in its ability to navigate future challenges while maintaining momentum towards its objectives.</p> <p>Several stakeholders were involved in the discussions:</p> <ul style="list-style-type: none"> - European Cancer Patient Coalition (ECPC) - The Babeş-Bolyai University <p>In the following six months, the criteria for the participation and identification of participants in the network (Milestone 33) were revised and updated.</p> <p>Considering that family physicians are stakeholders responsible for delivering prevention interventions in the community, the WP8 team believed it was opportune to investigate their perspective in more detail regarding these services. They conducted a qualitative study, using a data collection method based on semi-structured interviews.</p> <p>Meetings and Stakeholder Liaison include regular meetings and stakeholder engagement meetings. Monthly virtual meetings are held to discuss progress, challenges, and upcoming activities. Communication channels have been established with key stakeholders, including government agencies, industry partners, and advocacy groups. Feedback and input from stakeholders are sought to enhance the impact of the NoE.</p>				
Next Steps (1 October 2023 – 31 March, 2024)				
<ul style="list-style-type: none"> • Establish the initial stage of governance and prepare the first draft. 				

• Complete the final report and deliverable						
Milestones and deliverables (outputs/outcomes)						
Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
MS31	WP8 Expert Group definition	WP8	IOCN	The list encapsulates the following: Representatives on Health from each MS and Keynote speakers on Cancer Prevention.	2	List of leading experts available
MS32	Personalised Prevention NoE objectives	WP8	IOCN	This milestone involved finalizing the conceptual framework for personalised primary prevention. It included defining key components, methodologies, and guidelines for implementing individualised interventions.	4	List of NoE objectives available
MS33	Endorsement criteria	WP8	IOCN	Criteria Setting for Participation in the Future Network for Centres, Experts, and Healthcare Providers in the Context of Personalised Primary Prevention Purpose of this milestone is to define and outline the criteria for participation in the future network dedicated to Personalised Primary Prevention. This network will bring various stakeholders, including healthcare centers, experts, and healthcare providers, to collaborate in advancing personalised primary prevention strategies. This document will provide a comprehensive framework for the selection and inclusion of relevant parties into this network.	10	List of endorsement criteria published on the JANE website
MS34	Expression of interest	WP8	IOCN	Preparatory work was conducted and the first draft of the documentation of expression of interest	12	Documentation of the expression of interest (launch, event minutes, if held, expression spread, etc.).

MS35	Deliverables	WP8	IOCN	Preparatory work was conducted		16	List of NoE specific deliverables available
MS36	Governance	WP8	IOCN	The first draft on the NoE's governance structure was prepared		22	Details on the NoE's governance structure are made available and included in the final report, D8.1
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 8.1	Personalised Primary Prevention NoE	WP8	IOCN	Document, report	Public	24	Key strategic document describing the NoE for Personalised Primary Prevention. Paper version in English.

Work Package 9 Omics Network of Expertise for Cancer

Work Package 9: Omics Network of Expertise for Cancer			
Duration:	M1- M24	Lead Beneficiary:	Sciensano
Objectives			
<p>This WP will focus on the development of an NoE fostering the integration of omic technologies into the EU healthcare systems (HCSs) to ameliorate prevention, diagnosis, and treatment of cancer. Cancer is to be considered a disease that should be prevented, diagnosed early in a timely manner and treated appropriately within a continuum (the PDT cycle).</p> <p>The specific objectives will include the definition of:</p> <ul style="list-style-type: none"> - the scope of the omics technologies "as is" and "to be" - the scope of NoE on omics resources "as is" and "to be" - the tasks and roles of an NoE 'omics' 			

- the integration of omics NoE in the European/global omics ecosystem
- the omics NoE governance structure
- its sustainability
- its indicators of efficacy and its cost/efficacy constraints
- its relationship with MSs, other EU and national networks, patients and citizens.

WP9 will ensure the launch of a NoE on genomics and omic technologies in the cancer area, to improve optimal PDT throughout the EU. Genomics covers a broad-range of novel technologies based on mass-parallel sequencing of DNA/RNA obtained from various sources (tissue, blood, other body fluids). Transcriptomics, proteomics, and metabolomics are to be added to genomics, while a wide range of other omics grow up, including epigenomics, lipidomics, and interactomics, up to radiomics in a separate field. Omic technologies are gradually becoming increasingly important in supporting clinical decisions, especially in regard to biotherapies and advanced therapies, while of course they underlie clinical and translational research, including the most cutting-edge. Overall, this NoE will ensure a link with relevant cancer infrastructures throughout the EU in an effort to promote equitable access to these advanced technologies in all MS.

This NoE must first investigate where, to date, genomics and other omics can represent an added value at all three levels of the PDT cycle. For this, the team will define the scope of the NoE and update the current evidence on genomics and other omics in the PDT cycle of cancer (task 9.1) and the degree to which omics are implemented to date in HCSs throughout the EU (Task 9.2). In Task 9.3 the team will endeavour to identify who should participate in principle in the NoE.

To foster and define the partners required to integrate omics within the PDT continuum, the WP9 team will work with three use cases: one will focus on the capacity building in less-advanced countries for providing cancer patients access to genomics tumor profiling (the AURORA trial will be used as a model study); a second study will explore all this within the context of an ERN such as EURACAN, with a focus on how to organise a pan-Europe genomic-driven trial infrastructure for rare cancers (sarcomas being used as a case model); thirdly, the team will investigate the possibility to integrate familial history and cancer predisposition information into the PDT continuum, in collaboration with GENTURIS. The team will then identify a workplan for this NoE (milestones, deliverables, etc.) (Task 9.5) and propose a governance structure (Task 9.6), which all together will be summarised in a Blueprint document containing a set of recommendations, tools and good practices for future infrastructures and networks to be developed to facilitate introduction of genomics and other omics into cancer care in an evidence-based sustainable manner (Del 9.1).

Activities (what, how, where) and division of work

Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.

Task No	Task Name	Implemented	Justification	Partners involved
9.1	Definition of the scope of the NoE	Yes	The scope and objectives of the NoE Omics have been defined with: <ul style="list-style-type: none"> - the support of 6 use cases - an assessment of the technological readiness of the different types of Omics in the different fields of applications (carried out with the WP9 partners) 	Sciensano, DKFZ/NCT, UZ Gent, FAVO/ ECPC, IJB, Unicancer, ICB, ICO, MDH, IOCN, IRST, OECl, ECRIN, IDIVAL

9.2	Identification of participants' endorsement criteria	Yes	<p>WP9 organised a 1st meeting on 4th July 2023. WP9 suggested endorsement criteria for an omic platform to participate in the NoE with three different maturity levels. Following this meeting, the presenters of the use cases from the first meeting as well as all WP members were asked for their input on the endorsement criteria. This input was discussed at a second joint meeting between WP9 and 10 on 19th September 2023 and the final results were presented at the mid-term meeting in Barcelona on 16th and 17th November.</p> <p>Because WP9 and WP10 (High Tech Medical resources) share similar characteristics and common challenges, both WPs have worked very closely together. They applied the same methodology to elaborate the endorsement criteria with common principles.</p>	Sciensano, DKFZ/NCT, NHRF, NCI, IOCN, CNAO, IOV, IGR ESTRO, LSMUL, IDIVAL, Unicancer, Elixir
9.3	Scoping of service providers and/or centres	Yes	<p>Discussion during the different meetings in 2023 (11th January, 24th March, 4th July and 19th September): distinction between</p> <ul style="list-style-type: none"> - final users: within Comprehensive Cancer Infrastructures - partners: experts linked to omics platforms - collaborators / stakeholders 	Sciensano, INCA, IJB, INT, DKFZ/NCT, UZ Gent, ICB, ICO, MDH, IOCN, IRST, OECl, IDIVAL FAVO/ ECPC, NHRF, Unicancer
9.4	Service provider and/or centre selection	Partially	<p>This has been incorporated into the participants' endorsement criteria (see 9.2).</p> <p>Replacement of the launch of the expression of interest with meetings with stakeholders, which take place during the course of the JA (still ongoing)</p>	Sciensano, IJB, DKFZ/NCT, UZ Gent, FAVO/ ECPC, ICB ICO Unicancer, MDH, IOCN, IRST, OECl, ECRIN, IDIVAL, ELIXIR
9.5	Identification of NoE deliverables	Partially	<p>The activities of the NoE on Omics were discussed at the different meetings in 2023: 11th January, 24th March, 4th July and 19th September.</p> <p>These were refined during the preparation of the proposal for JANE 2 WP9 on Omics with the corresponding task and domain leaders (final meeting 20th February 2024).</p> <p>These deliverables as well as the proposed organisation have been challenged during individual interviews with each use case as well as the WP5 NoE on poor prognosis cancers to validate and identify the priority deliverables. The results of this consultation will be presented and discussed with JANE 1 partners as well as JANE 2 task and domain leaders in June 2024.</p> <p>Organisation of a meeting with JANE 1 and JANE 2 leaders on 8th April 2024.</p> <p>Active work on a Blueprint to be given to the JANE Coordination on the progress,</p>	<p>Sciensano, NHRF, FAVO/ ECPC, ELIXIR, OUS, IDIVAL, IOV, MSCI, KI, MFH, IBMCB, DGH, INT, ACC, DKFZ/INCT</p> <p>JANE2 WP and task leaders</p>

			work and goals of the NoE Omics. Organisation of individual calls with the 6 (+1) use cases to understand what they expect from the NoEs and to include this in the deliverable.				
9.6	Governance development	Partially	<p>The governance of the NoE on Omics has been discussed during the preparation of the proposal for JANE 2 WP9 with the corresponding task and domain leaders' proposal.</p> <p>This will be refined with JANE 1 partners in collaboration with JANE 2 task and domain leaders at the next meeting in June 2024.</p>				<p>Sciensano, NHRF, FAVO/ECPC, ELIXIR, OUS, IDIVAL, IOV, MSCl, KI, MFH, IBMCB, DGH, INT, ACC, DKFZ/INCT</p> <p>JANE2 WP and task leaders</p>
Next Steps (1 April, 2024 - 30 September 2024)							
<ul style="list-style-type: none"> - Individual calls with the 6 use cases + WP5 NoE on poor prognosis cancer - Governance development with JANE 1 partners and JANE 2 task and domain leaders - Production of a blue print for JANE 1 							
Milestones and deliverables (outputs/outcomes)							
Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification	
MS37	Omics NoE Scope	WP9	Sciensano	List of objectives available.	5	Presentation at mid-term meeting in Barcelona on 16 th and 17 th November	
MS38	WP9 Endorsement criteria	WP9	Sciensano	List of endorsement criteria for the NoE centres published on the JANE website.	10	Presentation at mid-term meeting in Barcelona on 16 th and 17 th November	
MS39	WP9 Expression of interest	WP9	Sciensano	Documentations of the expression of interest.	20	Final blueprint	

MS40	Omics NoE Deliverables	WP9	Sciensano	List of NoE deliverables available.	22	Final blueprint	
MS41	Omics NoE Governance	WP9	Sciensano	Details on the NoE's governance structure are made available and included in the final report, D9.1.	22	Final blueprint	
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 9.1	Omics NoE	WP9	Sciensano	Document, report	Public	23	Report clarifying: - the scope of the NoE - the activities of the NoE - partners - governance - sustainability - indicators of efficacy and cost/efficacy - interplay with MSs, networks, CCCs, EU patients Paper version in English

Work Package 10 Hi-tech medical resources

Work Package 10: Hi-tech medical resources			
Duration:	M1- M24	Lead Beneficiary:	Unicancer, INCA
Objectives			
<p>The overall objective of WP10 is to establish an NoE on emerging/innovative and/or privileged technologies in the cancer area to ensure optimal coverage of patient needs throughout the EU. Such technologies include biotherapies and advanced therapies, innovative surgical procedures, complex radiation equipment (e.g. hadron therapy), innovative therapeutic nuclear medicine solutions, interventional radiology techniques, early phase clinical research centres dedicated to first-in-human studies and the like. Overall, this NoE will ensure a link with the network of CCCs to progressively promote equitable access to these advanced technologies in the EU and MS. The specific objectives will include the definition of:</p>			

- the scope of the NoE on hi-tech medical resources
- its activities
- its potential partners
- its governance
- its sustainability
- its indicators of efficacy and its cost/efficacy constraints
- its relationship with MSs, other EU and national networks, CCCs throughout the EU, patients.

Activities (what, how, where) and division of work

Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.

Task No	Task Name	Implemented	Justification	Partners involved
10.1	Definition of the scope of the NoE	Yes	<p>WP participants have defined the scope of the NoE. The team selected 5 sub-groups of hi-tech medical resources as priorities and identified 3 other sub-groups for the future. The team defined the NoE objectives and principles.</p> <p>As hi-tech medical resources evolve fast, the number of sub-groups of resources needed to be limited to the most urgent needs and promising resources.</p> <p>From September 2023, WP participants finally validated 7 sub-groups, or “domains” likely to become “sub-networks”:</p> <ol style="list-style-type: none"> 1. Nuclear medicine 2. Radiomics 3. Innovative radiotherapies 4. Innovative surgery 5. Physical methods of ablation 6. Cell therapies 7. Ex-vivo testing of agents 	Unicancer, INCa, IOCN, Sciensano, SAS NVI, MSCl, CNAO, IRST, LSMUL KK, NHRF, OIL, BS, NKUA, IDIVAL, DKFZ
10.2	Identification of participants' endorsement criteria	Yes	<p>Several methodologies were tried before finding a common one with Sciensano (WP9 on Omics). Unicancer's experts in each of the 5 sub-groups of hi-tech medical resources then worked on proposing endorsement criteria in their respective fields.</p> <p>The team sought to identify “reference centres” in each of the 5 sub-groups per country, but it was too soon.</p> <p>During a hybrid meeting in Paris on 19/9/23, WP participants pre-validated the endorsement criteria list for each of the 7 sub-networks of this NoE.</p>	Unicancer, INCa, IOCN, Sciensano, SAS NVI, MSCl, CNAO, IRST, LSMUL KK, NHRF, OIL, BS, NKUA, IDIVAL, DKFZ

10.3	Scoping of service providers / centers (INCA, UNICANCER, FHF, task forces)	Yes	From September 2023, especially during a hybrid meeting in Paris on 20/2/24, WP participants identified a very important number of centers and experts across Europe interested in contributing to the 7 sub-networks to be created in the JANE 2 Joint Action.	Unicancer, INCa, IOCN, Sciensano, SAS, NVI, MSCI, CNAO, IRST, LSMUL KK, NHRF, OIL, BS, NKUA, IDIVAL, DKFZ
10.4	Service providers / centers selection (INCA, UNICANCER, FHF, task forces)	Ongoing	<p>WP participants are currently checking that JANE 2 WP10 participants (about 85 organizations across Europe) meet the endorsement criteria as defined in Task 10.2.</p> <p>In parallel, WP participants have initiated the identification of other relevant stakeholders for the 7 sub-networks, such as:</p> <ul style="list-style-type: none"> • Relevant scientific societies • Existing projects/tools/networks • Relevant industrial partners • Missing relevant stakeholders, including from missing Member States • Existing training programmes 	Unicancer, INCa, IOCN, Sciensano, SAS, NVI, MSCI, CNAO, IRST, LSMUL KK, NHRF, OIL, BS, NKUA, IDIVAL, DKFZ
10.5	Identification of NoE Deliverables (INCA, UNICANCER, FHF, task forces)	Ongoing	<p>WP participants are preparing the NoE final deliverable, focusing on the NoE's mission and main tasks under JANE 2 JA:</p> <ol style="list-style-type: none"> 1. Governance of the network: organizing the governance of the network 2. Advocacy: establishing recommendations for MS regarding urgent needs and biggest gaps across Europe 3. Innovation observatory: positioning the network at the forefront of innovation 4. Infrastructural and procedural support: supporting centres to better integrate innovative therapies 5. Education and training: improving continuous education of health care professionals and enhancing patient and public literacy and involvement 6. Dissemination and sustainability: Ensuring the visibility and the sustainability of the network 	Unicancer, INCa, IOCN, Sciensano, SAS, NVI, MSCI, CNAO, IRST, LSMUL KK, NHRF, OIL, BS, NKUA, IDIVAL, DKFZ
10.6	Governance development (Task forces, INCA, UNICANCER, FHF)	Ongoing	<p>Online sub-networks brainstorming sessions are being held with WP participants, in order to make recommendations on governance development. Flexibility will be a key factor for this NoE to coordinate the 7 sub-networks, which all have a different level of maturity and specificities of their own. Sub-networks leaders and co-leaders will provide the impetus needed to implement the activities.</p> <p>(This task will work closely with WP4)</p>	

Description of work and overview of progress, including any issues

The definition of the scope and objectives of the NoE and the identification of participants' endorsement criteria were conducted by Unicancer in collaboration with INCa and several partners. The team also began to work on NoE synergies with other existing stakeholders, networks and projects at the EU and national levels.

The team is about to identify the partners to be involved in the future NoE in JANE 2 and to refine the NoE activities, as well as other stakeholders/collaborators from the European cancer ecosystem to be included (in view of JANE 2).

Several stakeholders were involved in the discussions:

- 'Aghia Sophia' Children's Hospital
- Region Zealand - University Hospital Roskilde/Næstved

Next Steps (1 April, 2024 – 30 September, 2024)

T10.4 - Service providers / centre selection

T10.5 - Identification of NoE Deliverables

T10.6 - Governance development

D10.1 - Hi-tech NoE – M24

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
42	Hi-tech NoE scope	WP10	Unicancer/ INCa	List of objectives available	5	List of objectives available
43	WP10 Endorsement criteria	WP10	Unicancer/ INCa	List of endorsement criteria for the NoE centres	10	List of endorsement criteria for the NoE centres
44	WP10 Expression of interest	WP10	Unicancer/ INCa	List of relevant stakeholders	14	List of relevant stakeholders (in progress)

45	WP10 Hi-tech NoE Deliverables	WP10	Unicancer/ INCa	List of NoE-specific deliverables available	18	List of tasks as per JANE-2	
46	Hi-tech NoE Governance	WP10	Unicancer/ INCa	Governance strategy available	24	Governance recommendations (in progress)	
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
D10.1	Hi-tech NoE	WP10	Unicancer/ INCa	Document, report	Public	24	Report clarifying: - scope of NoE - activities of NoE - partners - governance - sustainability - indicators of efficacy and cost/ efficacy - interplay with MSs, networks, CCCs, EU patients Paper version, English

Work Package 11 Adolescents and Young Adults with Cancer

Work Package 11: Adolescents and Young Adults with Cancer			
Duration:	M1- M24	Lead Beneficiary:	INT
Objectives			
The overall objective of WP11 is to establish an NoE on young adults to ensure that special challenges of this population are adequately addressed throughout the EU. Such challenges include unique epidemiology, specific tumour biology, insufficient awareness of cancer in this population, diagnostic delay, limited inclusion in clinical trials, psychosocial needs etc. Overall, this WP will ensure a link with the Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE) on adolescent and young adults with cancer.			

Activities (what, how, where) and division of work

Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.

Task No	Task Name	Implemented	Justification	Partners involved
11.1	Definition of the scope of the NoE	Yes	Discussion on the needs and specificities of adolescents vs, young adults with cancer. Identification of the type of NoE needed (to care, to support research, etc), definition how many NoE should be developed considering differences between adolescents and young adults.	INT, HSJD, OIL, BS, MFH Unicancer, INCa, ICO, NKUA, IOCN, Sciansano, CIBER, UH Motol, SIOPE
11.2	Identification of participants	Yes	Identification of participants for the NoE including MS, scientific societies, patient associations and definition of the endorsement criteria for participants' selection.	INT, HSJD, OIL, BS, MFH Unicancer, INCa, ICO, NKUA, IOCN, Sciansano, CIBER, UH Motol, SIOPE
11.3	Sites identification	Yes	An expression of interest call will be launched.	
11.4	Definition of the NoE deliverables	Yes	Developing the core deliverables of the NoE: mapping dedicated programmes on AYA with cancer across MS, monitoring young adult cancer epidemiology, development of clinical practice guidelines, support for educational programmes for patients and health care professionals, definition of referral pathway within MA and across EU MSs, development of indicators of efficacy and actions to evaluate cost/efficacy	INT, HSJD, OIL Unicancer, BS, MFH, INCa, ICO NKUA, IOCN, Sciansano, CIBER, UH Motol, SIOPE
11.5	NoE Governance development	No	Developing the NoE's governance (e.g. organisation and management structure, legal basis, operational procedures, funding sources), including specific strategies to ensure the interplay with MSs, other EU networks, CCCs, patients. (This task will work closely with WP4.)	

Description of work and overview of progress, including any issues

WP 11 was successful in creating the core group involving key people from different already existing European projects dedicated to AYAs. The team thereafter focused on the objectives of the NoE and the actions. It took longer than expected to reach a common understanding on the objective: major issues raised were related to the interplay

between the national and EU level. The team therefore decided to prioritise the discussion on the NoE Deliverable, postponing the discussion on endorsement criteria. The team then discussed possible synergies with potential stakeholders according to the different objectives, to finalise the endorsement criteria and list of participants.

Several stakeholders were involved in the discussions:

- Emmanouil Saloustros (Larissa, Greece) - ESMO-SIOPE AYA Working Group
- Ivana Bozovic (Belgrade, Serbia) - ESMO-SIOPE AYA Working Group
- Fedro Peccatori (Milan, Italy) - ESMO-SIOPE AYA Working Group
- Dan.Stark (Leeds, UK) - ENTYAC chair
- Owen.Smith (Dublin, Ireland) - SIOPE AYA committee
- Paola.Quarello – (Turin, Italy) - SIOPE AYA committee
- Anne Blondeel (Brussels, SIOPE) - SIOPE AYA committee
- Winette van der Graaf (Amsterdam, Netherlands) – PI STRONG AYA project
- Katie Rizvi - Youth Cancer Europe / EUCAYAS project
- Anita Kienesberger - CCI Europe / EUCAYAS project
- Carina Schneider – CCI Europe/ EUCAYAS project

The objectives of the NoE were revised to better fulfil the overarching scope of the NoE on AYAs, i.e. to be the network where healthcare professionals collaborate with NGOs, patient groups and relevant stakeholders about AYA with cancer and where collaboration between paediatric and adult cancer services will be strengthened to improve AYA care, from prevention to survivorship.

The specific objectives of the NoE were therefore the following:

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

To address these objectives, we identified 7 possible tasks to be included in the future NoE on AYAs (1. Governance, 2. Development of AYA dedicated programmes, 3. Development of clinical recommendations, 4. Development of training on cancer in AYA, 5. Promotion of AYA/trans-age clinical cancer research [with a specific focus on access to clinical trials], 6. Monitoring AYA cancer indicators, 7. Definition of the sustainability strategy).

The endorsement criteria were defined by type of partner categories, i.e. for health care providers, for scientific/professional societies/networks/research groups, and for patient advocacy groups. The main criteria will be the European scope. For national health care providers, national mandate and expertise on AYA are two additional essential criteria.

Thereafter, we have started the discussion on the possible synergies with potential stakeholders according to the different objectives.

Next Steps (1 April 2023 – 30 September, 2024)

To discuss NoE Governance (Milestone 51)

Milestones and deliverables (outputs/outcomes)						
Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
M47	Definition of the scope of the NoE	11	1-INT	<p>The overreaching scope of the NoE on AYAs is to be the network where healthcare professionals collaborate with NGOs, patient groups and relevant stakeholders about AYA with cancer and where collaboration between paediatric and adult cancer services will be strengthened to improve AYA care, from prevention to survivorship.</p> <p>Specific objectives are:</p> <ul style="list-style-type: none"> — To support the development of AYA dedicated programme — To develop specific clinical recommendations on AYA-specific topics (e.g. age-specific psychosocial support, fertility) and different types of cancer across age groups — To promote cancer research in AYAs — To raise awareness of cancer in AYAs — To monitor AYA cancer epidemiology, leveraging what is available or underway — To define and promote dedicated training on cancer in AYA — To support Patient and Public Involvement and Engagement 	4	List of the NoE objectives
M48	Endorsement criteria	11	1-INT	<p>The team has defined the endorsement criteria by type of partners categories, i.e. for health care providers, for scientific/professional societies/ networks/research groups, and for patient advocacy groups. The main criteria will be European scope. For national health care providers, national mandate and expertise on AYA are two additional essential criteria.</p>	8	List of endorsement criteria

M49	Expression of interest	11	1-INT	<p>The need to define a precise path for the expression of interest was overcome by the rapid approval and development of the JANE-2 programme.</p> <p>The different partners have been involved directly by the different national groups with a formal endorsement.</p> <p>The identification and involvement of the potential stakeholders is ongoing.</p>	12	Documentation of the expression of interest	
M50	Deliverables	11	1-INT	The different specific NoE activities have been identified for each of the objectives	16	List of the NoE specific deliverables	
M51	Governance	11	13-IOCN	Ongoing	22	Details of NoE governance	
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 11.1	Adolescent and young adults with cancer NoE	WP11	INT	Document, report	Public	24	<p>Key strategic document describing composition and activities and next steps of NoE regarding expertise on AYA with cancer.</p> <p>It will clarify:</p> <ul style="list-style-type: none"> - scope of NoE on AYA - activities of the NoE - partners - governance - sustainability - indicators of efficacy and cost/efficacy - interplay with MSs, networks, CCCs, EU patients <p>Paper version, English.</p>

Work Package 12 Integration between health care and research

Work Package 12: Transversal Task Force: Integration between health care and research				
Duration:	M1- M24	Lead Beneficiary:	BiosistemaK (BS, formerly Kronikgune)	
Objectives				
<ul style="list-style-type: none"> ▪ Map current challenges in the integration between healthcare and research in the perception of clinical researchers and physicians. ▪ Analyse existing opportunities to conduct large low-cost clinical trials and generate real-world evidence through networking. ▪ Improve the coordination of research by providing effective and efficient mechanisms by means of the new NoEs. ▪ Widen participation in research and improve the efficiency of research. 				
Activities (what, how, where) and division of work				
<p>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</p>				
Task No	Task Name	Implemented	Justification	Partners involved
12.1	Assessing current challenges in research portfolios and integration between healthcare and research	Partially	<p>BS has developed a search strategy for this task which has been reviewed by all WP12 partners. This activity includes the completion of two analyses: a desktop search and a literature review. The activities of this task are still ongoing and all WP12 partners are actively involved.</p> <p>Preliminary results of the desktop search have been analysed.</p> <p>Regarding the literature review, a protocol with the search strategy to conduct a systematic review has been prepared and published in the PROSPERO database with the following reference: 'Challenges in the Integration between Health Care and Research in the Cancer Field: A Systematic Review [CRD42024520574].</p> <p>The final conclusions of this analysis will be included in the official Deliverable 12.1 'Recommendations for effective and efficient organization and management of research efforts'.</p>	BS, OIL, ICO, IDIVAL, CIBER, HSJD, SAS, INT, Unicancer, FHF, MFH, OUS, MSCl, IOCN, IRST

			Part of work done for the desktop search in 2023 coincided with the summer months and several partners had problems complying with the deadlines. As a result, the inputs for the desktop search were finalized in early 2024.	
12.2	Establishing clinical research networks (CRN)	No	Global aim of this task is to define effective mechanisms for establishing clinical research networks to enable collaborative research through the study of clinical research platforms, funding programmes and opportunities, and tools for evaluating NoEs. The methodology to conduct this task has been defined but the activities have not yet started. The estimated date to finalize this task is May 2024 and the conclusions will be included in Deliverable 12.1.	BS, OIL, ICO, IDIVAL, CIBER, HSJD, SAS, INT, Unicancer, FHF, MFH, OUS, MSCI, IOCN, IRST
12.3	Proposing guidelines for effective and efficient organization and management of research efforts facilitated by NoEs	Partially	This task consists of the development of Deliverable 12.1, which will include a set of recommendations based on the NoEs experiences on how to better integrate research and healthcare, in both scientific and management approaches. The conclusions of Tasks 12.1 and 12.2 will serve as input for this final deliverable, which is expected to be finalized between May and September 2024.	BS, OIL, ICO, IDIVAL, CIBER, HSJD, SAS, INT, Unicancer, FHF, MFH, OUS, MSCI, IOCN, IRST

Description of work and overview of progress, including any issues

WP12 Monthly Meetings have been set every fourth Tuesday of the month (13:00 to 14:30 CET). Invitations for all the meetings have been sent including the links to the online connection. The agenda for the session is sent out in advance with the main points to be covered. In addition, within 3 working days after each meeting BS produces the minutes that include the meeting summary, decisions taken and next steps or ToDo items with deadlines and responsibilities for each task. W12 members can send their inputs or feedback within 7 days. In addition, the minutes are sent together with the links to the recording and PowerPoint presentations of the session, which are uploaded in the JANE WP12 meetings Drive folder.

Task 1. Assessing current challenges in research portfolios and integration between health care and research

The following activities have been accomplished:

- Organisation of a workshop to define a common framework to represent the current situation of translational research.
- Definition of a framework assessing the current challenges in integration between health care and research, based on the discussions of the workshop and literature review. This framework is based on the Innovative Care for Chronic Conditions (ICCC) that serves as a roadmap for policy development and the redesign of health care systems and facilitates the comparative analysis and identification of best practices.
- Preparation of a document outlining the search methodology for conducting a literature review on the integration between health care and research was developed. The review aims to identify challenges, facilitators, and gaps in the field before the implementation of JANE. The outcomes of this activity will include mapping available evidence and developing recommendations to enhance integration in the future NoEs. This methodology includes the development of a desktop search and a systematic literature review.

- Identification of resources for the desktop search (identify/select/review)
- Preparation and publication of a research protocol in PROSPERO database with the following reference: 'Challenges in the Integration between Health Care and Research in the Cancer Field: A Systematic Review [CRD42024520574].

Task 2. Establishing clinical research networks (CRN)

- The methodology to conduct this task has been defined but the work is still ongoing.

Other issues:

WP12 tasks require updating the state of the art in these areas. Thus, probably the BS team will mainly produce part of the documentation for its development. Although other WP12 partners are contributing highly to the development of some tasks such as the literature review, the expected response may not be forthcoming as these are more demanding activities.

For this reason, additional steps have been included in the methodology, such as desktop search. These activities will lead to a more active involvement of the other partners.

Next Steps (1 April, 2024 – 30 September, 2024)

Task 1. Assess current challenges in research portfolios and integration between healthcare and research

- Conduct a systematic review and analyse its results
- Prepare a report with the results of both activities (desktop search and literature review)

Task 2. Establish clinical research networks (CRN)

- Explore research networking platforms clarifying legal and regulatory requirements
- Explore funding mechanisms and opportunities for research collaboration
- Explore mechanisms for research collaboration and evaluation of results in NoEs
- Organize thematic group for discussions with WP12 partners

Task 3. Propose guidelines for effective and efficient organization and management of research efforts facilitated by NoEs

- Develop Deliverable 12.1 'Recommendations for effective and efficient organization and management of research efforts'

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
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Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
N/A							
Del 12.1	Recommendations for effective and efficient organization and management of research efforts	12	BS	R- Document, report	PU - Public	24	Set of recommendations based on the NoEs experiences on how to better integrate research and health care, in both scientific and management approaches. Report version in English.

Work Package 13 Integration between EU networking and Member States

Work Package 13: Transversal Task Force: Integration between EU networking and Member States				
Duration:	M1- M24	Lead Beneficiary:	IOCN	
Objectives				
The big challenge ahead is to establish specific solutions for each MS, sticking to general principles while taking into account all those features which are unique to MS health systems vis-a-vis the specificities of each NoE compared to others. This TTF will focus on all solutions potentially able to improve the interplay between national health systems, including their possible networking facilities, and EU networking systems, such as the new NoEs, the new network of CCCs, existing ERNs.				
Activities (what, how, where) and division of work				
<i>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</i>				
Task No	Task Name	Implemented	Justification	Partners involved

13.1	Identification of commonalities and differences across MS health systems as far as EU networking needs are concerned	Yes	The team has successfully identified commonalities and differences among MS health systems. This crucial step lays the foundation for developing solutions that consider the unique characteristics of each MS while aligning with overarching principles.	IOCN, BS, MSCI, OUS, Unicancer, Sciensano
13.2	Mapping Existing Solutions within JANE Project	Yes	Extensive efforts have been made to map existing solutions within the JANE project. This involves identifying beneficial solutions for policy implementation and fostering connections between MS. The aim is to leverage knowledge and experiences gathered within the JANE project to inform and enhance the integration process.	IOCN, BS, MSCI, OUS, Unicancer, Sciensano
13.3	Comparative documents on inequalities and similarities among MS	Yes	A research study was conducted to highlight cancer challenges, systemic and individual issues, inequities, and country-specific findings. Target countries: Italy, France, Romania, Hungary, Poland, Spain, Greece, Czechia, Slovenia, Belgium, Norway, Lithuania, Malta, Portugal, Germany, and Croatia. Comprehensive and comparative documentation for 16 countries improved knowledge and decision-making. Facilitated the project's goal of launching effective and sustainable Networks of Expertise.	IOCN
13.4	Healthcare networking in the EU and its constraints given the EU Treaties and Threats to integration between the EU and MSs	Yes	This activity examines the challenges and limitations of healthcare networking within the European Union (EU) framework, focusing on constraints imposed by EU Treaties. It also explores potential threats to integration between the EU and its MS, identifying areas where collaboration can be improved and highlighting legal and political barriers that impact effective healthcare cooperation. The goal is to foster a deeper understanding of the intricacies involved in EU healthcare policies and to propose solutions for enhanced integration and networking.	

Description of work and overview of progress, including any issues

The primary focus of WP13 – TTF2 during the specified period has been on addressing the significant challenge of establishing tailored solutions for each MS while adhering to general principles. The objective is to enhance the interaction between national health systems and EU networking systems, encompassing the newly formed NoEs, the network of CCCs, and existing ERNs. The lead beneficiary, in Romania, has diligently undertaken tasks to facilitate this integration.

Next Steps (1 April, 2024 – 30 September, 2024)

- Deliver the necessary information for the Green Paper

Milestones and deliverables (outputs/outcomes)							
Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description		Due Date (month number)	Means of Verification
N/A							
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
D13.1	Recommendation to support national healthcare systems interconnection with EU networking	WP13	IOCN	Document – report	Public	24	Recommendation on how to improve interactions and interconnections between national healthcare systems and EU networks

Work Package 14 Integration between IT infrastructures and AI tools

Work Package 14: Transversal Task Force: Integration between IT infrastructures and AI tools			
Duration:	M1- M24	Lead Beneficiary:	OUS
Objectives			
To contribute to the improvement of EU health care networking on cancer with regard to the challenges of integrating local IT infrastructures with IT tools for European cancer networking and to exploit the use of AI.			
Activities (what, how, where) and division of work			
<i>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</i>			

Task No	Task Name	Implemented	Justification	Partners involved
14.1	Recruiting expertise on AI and IT resources	Ongoing	The TTF3 team has successfully onboarded 12 active TTF3 group members who are AI, data, or IT experts. The team has worked with these members to grow a list of additional skilled academics and professionals working within the European Cancer AI community. The TTF3 team has been collaborating to discuss and map innovative solutions that would streamline AI research and applications within the JANE network. They have communicated with additional work packages including WP9 and WP10 to discuss required expertise moving forward into JANE2 efforts. They are also connected to the full ELIXIR Europe network, including their established Cancer Data Community, as well as several EOSC infrastructure projects.	JANE TTF3 group, ELIXIR Cancer Data Community, ELIXIR Europe, 1+MG/GDI, EOSC ENTRUST, EOSC4Cancer, AIDA Data Hub, BiGPicture Imaging Consortium
14.2	Mapping partners' infrastructures to interact within European space	Ongoing	<p>Progress has been made in identifying and mapping the technological capabilities of our partners across Europe. We have constructed an IT and data sharing survey to further advance these important goals. This will be sent to members at over 35 cancer care and research institutions within Europe. Information gathered from the survey will help our task force better assess the baseline of data sharing capabilities and guide downstream resource investment for JANE and JANE2.</p> <p>Additionally, we had interactive presentations from ELIXIR Cancer leaders within the TTF3 group meetings to track the state-of-the art as well as practical solutions for AI infrastructure. These efforts have set the stage for a unified and cooperative European research environment.</p>	OUS, INCa, VULSK, IDIVAL, SAS, INT, CraNE
14.3	Mapping available options for computation	Postponed	After preliminary mapping and discussions within the Task Force meetings, this activity was postponed to prioritize Task 1 and Task 2, which were deemed to be higher priority. We have, however, connected to the EOSC ENTRUST project for computation across Trusted Research Environments (TREs).	OUS, INCa, VULSK, IDIVAL, SAS, INT
14.4	Mapping cancer data and AI interoperability expertise	Ongoing	The TTF3 has made strides in evaluating IT systems for enhanced interoperability, with a particular focus on genomic and imaging data (efforts here include WP9 collaboration). A framework for the secure sharing and analysis of cancer-related datasets has been discussed including procedures and best practices for federated data networks. Our efforts have earmarked federated data solutions as of especially high interest for JANE and JANE2 moving forward. The TTF3 group sees the value of these approaches for fostering collaborative research efforts within the EU.	OUS, INCa, VULSK, IDIVAL, SAS, INT, WP9 and WP10

Next Steps (1 April, 2024 – 30 September, 2024)

- Send out IT and Data Survey to JANE contacts and partner institutions
- Analysis of Survey Data
- Complete list of AI expert mapping context
- Write white paper on the EU IT and data sharing status based on survey (pending on the gathering of useful data)
- Contribute to JANE1 Green Paper

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification	
1	List of EU AI experts	TTF3	OUS	The compiled list of AI expert and contact information gathered and reviewed by the TTF3 working group.	6		
2	Results of EU data sharing and IT survey	TTF3	OUS	The raw results of the survey (number of responders, identity of institutions, and aggregated responses) will be provided to JANE leadership and administrators. We aim to further disseminate results via a white paper (see details below).	7	Peer review through white paper	
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 14.1	Recommendations to integrate local IT infrastructures for European cancer networking	WP14	OUS	Document, report	Public	24	Set of recommendations on how to better integrate existing European IT infrastructures with each other, to better support joint research networks.

Use of resources

<p>Budget implementation —Use of resources (deviations)</p> <p><i>Explain deviations from the budget planning (i.e. differences between actual and planned use of resources, especially for personnel).</i></p> <p><i>Include explanations on transfers of cost categories in the estimated budget (if applicable)</i></p> <p><i>Don't forget to attach the detailed cost reporting table (if any).</i></p>	
No deviations	
Other issues	<p>The TTF3 team did not have full participation from the assigned members, including those with funding earmarked for work on the task force.</p> <p>Only about 12 TTF3 members were consistently engaged and active during group meetings, follow up tasks, assignments, and communications. Others did not attend, respond, or engage during this 18-month period.</p>

Work Package 15 The ERN model

<p>Work Package 15: Transversal Task Force: The ERN model</p>				
Duration:	M1- M24	Lead Beneficiary:	Unicancer / INCa	
<p>Objectives</p> <p>The main objective of TTF4 is to assess the functioning of current rare cancer ERNs to identify problems, challenges, and solutions with regard to EU networking, in order to suggest improvement strategies for EU cancer care networking in general and specifically for the new NoEs, in collaboration with the other TTFs plus the WP on Sustainability. The specific topics dealt with by each of the latter will be individually assessed.</p>				
<p>Activities (what, how, where) and division of work</p> <p><i>Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.</i></p>				
Task No	Task Name	Implemented	Justification	Partners involved

15.1	Assessment of ongoing problems and challenges in regard to optimal functioning of current ERNs on rare cancers	Yes	- Unicancer has engaged in discussions with the 4 ERNs to assess ERNs' ongoing challenges. It was initially difficult to focus at this early stage on ERNs' challenges as the team first had to defined exactly the differences between NoEs and ERNs. It was necessary for each NoE to first define their scope and objectives, in order to better understand their added value and their interactions with ERNs on cancer.	Unicancer, INCa INT, OIL, BS, CIBER, HSJD, SAS, MSCl, OUS, IOCN
15.2	Assessment of current functioning of ERNs on rare cancers	Partially	- Unicancer has engaged discussions with the 4 ERNs in order to better understand ERNs' functioning (through a list of transversal topics), in order to see how they could inspire the future NoEs. Now that the NoEs are taking shape, it is easier see what we can learn from the ERNs on cancer.	Unicancer, INCa INT, OIL, BS, OUS, CIBER, HSJD, SAS, MSCl, IOCN
15.3	Holding of brainstorming meeting	Yes	Four online meetings have been held. The main challenges of this TTF from the very beginning were to understand the differences and complementarities between both types of networks (ERNs on cancer and NoEs), in terms of scope, final targets and objectives. Lately, the discussion focused on EURACAN, as Prof. Jean-Yves Blay coordinates both the ERN and this TTF4 within the JANE JA. The main recommendations for NoEs from the EURACAN's experience will be: 1) Providing mechanisms to facilitate EURACAN/future NoEs connections 2) Make it compulsory for ERNs on cancer to participate in JAs of interest such as JANE 2 3) Simple governance for NoEs 4) Securing funding for ERN-type structures 5) Facilitating cross-border health care 6) Working with EHDS to create mandatory registers.	Unicancer, INCa INT, OIL, BS, CIBER, HSJD, SAS, MSCl, OUS, IOCN
Description of work and overview of progress, including any issues				
Any issues: The main challenges of this TTF from the very beginning were to understand the differences and the complementarities between both types of networks (ERNs on cancer and NoEs), in terms of scope, final targets and objectives.				
Next Steps (1 April, 2024 – 30 September, 2024)				

Production of D15.1 - Recommendations to improve EU cancer care networking in general & specifically for new NoEs – M24							
Milestones and deliverables (outputs/outcomes)							
Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description		Due Date (month number)	Means of Verification
N/A							
Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 15.1	Recommendations to improve EU cancer care networking in general & specifically for new NoEs	WP15	Unicancer/ INCa	Document – Report	Public	M24	Report on ERN framework leading to recommendations aimed at improving EU cancer care networking, in particular to support the new NoEs

Work Package 16 Patient involvement

Work Package 16: Transversal Task Force on Patient Involvement			
Duration:	M1- M24	Lead Beneficiary:	Sciensano
Objectives			
<p>This TTF will focus on developing strategies to improve patient empowerment and engagement through European health care cancer networking. The goal will be to develop a toolkit for different methods of patient and citizen engagement that can be tailored to specific contexts and build on existing national and European patient organization networks for the implementation of the tools.</p> <p>Three main sources will feed the toolkit:</p> <p>1) A process of co-construction during several workshops and working groups with established patient organizations.</p>			

- 2) Existing methods of deliberation and participation developed in the field of deliberative democracy.
 3) The outcomes of the JA TEHDaS e- consultation on patient and citizen engagement.

The TTF will focus on maintaining close relations with the work done in WP 4-9 to make sure that patient empowerment and engagement is part of the new NoE's by design. The toolkit will specifically be developed to maximize the potential for practical implementation in these areas.

The main challenges include conflicts between different patient organizations and a lack of communication and coordination with WP4-9. To manage potential conflicts in the development of the toolkit, the team will use its experience from previous participatory projects and develop at length the concept paper (M 9) and final presentation of the toolkit (M 21). This time will be used to build trust, to thoroughly engage with any issues at hand and for co-construction. To ensure good communication and maximize toolkit implementation (even as it is developing up to M21), someone from Sciensano will meet with representatives from WP4-9 separately at regular intervals (at least every two months, with higher frequency around major milestones).

Activities (what, how, where) and division of work

Report on the implementation status of the activities that were to be implemented during the reporting period and explain deviations from Annex 1 of the Grant Agreement. In case an activity was not implemented, or a deliverable not produced, please explain why.

Task No	Task Name	Implemented	Justification	Partners involved
16.1	Establishing a working group and literature review	Yes	Establishing a working group consisting of a variety of national and European cancer patient organisations to support the activities of the TTF and guarantee transversality	Sciensano, IDIVAL, INT, IRST, BS, FAVO LSMUL KK, NCI LT, CIBER, HSJD, ELLOK
16.2	Applying methods	Yes	Applying methods from the field of deliberative democracy and recommendations generated in the JA TEHDaS citizens' consultation to the specific needs of NoEs.	Sciensano, IDIVAL, INT, IRST, BS, FAVO LSMUL KK, NCI LT, CIBER, HSJD, ELLOK
16.3	Developing toolkit for patient empowerment	Partially	Developing a toolkit for patient empowerment and engagement in different contexts and for different subjects The guide has been created at high level and will be completed with concrete examples and tailored to the needs of the networks.	Sciensano, IDIVAL, INT, IRST, BS, FAVO, LSMUL KK, NCI LT, CIBER, HSJD, ELLOK
16.4	Facilitating implementation of relevant tools	Partially	Facilitating the implementation of relevant tools for patient empowerment and engagement in WP 4- 9	Sciensano, IDIVAL, INT, IRST, BS, FAVO LSMUL KK, NCI LT, CIBER, HSJD, ELLOK

16.5	Hold a new round of meetings with all leaders	Partially	Meetings with WP experts have been postponed, particularly in view of the implementation of JANE 2	
16.6	Pilot project: patient involvement guide for WP11 (AYA)	Partially	Priority was given to the development of the general guide because of the uncertainty created by the development of JANE2	
16.7	Modifications based on feedback	Partially	Meetings were held with patient organizations to discuss the general guide, and comments/ feedback were added	
16.8	Adaptation for all NoEs	Partially	Specific literature has been studied with regard to expertise networks, and still needs to be adapted to their concrete needs	
16.9	Development of a guide for patient organizations, patient representatives and patients	No	No longer considered a priority for the time being, meetings with patient organizations have served to feed the guide for experts and will potentially serve as a basis for collaboration between them and expertise networks	

Next Steps (1 October 2023 – 31 March, 2024)

- General guide finished
- Meetings planning with WP leaders to adapt the guide to their specific needs
- Meetings planning with Patient organizations
- General guide tailored to each network
- Clean-up of guides (“clickable mindmap”)
- Background report for the toolkit

Milestones and deliverables (outputs/outcomes)

Milestone No (continuous numbering not linked to WP)	Milestone Name	Work Package No	Lead Beneficiary	Description	Due Date (month number)	Means of Verification
N/A						

Deliverable No (continuous numbering linked to WP)	Deliverable Name	Work Package No	Lead Beneficiary	Type	Dissemination Level	Due Date (month number)	Description (including format and language)
Del 16.1	Toolkit for patient empowerment and engagement in different contexts and for different subjects	WP16	Sciensano	Demonstrator, pilot prototype	Public	M24	Development & implementation of tools facilitating participation of patients in research, their engagement and empowerment.

4. DISSEMINATION AND COMMUNICATION ACTIVITIES

Dissemination activities

Dissemination activities				
Dissemination activity name	What?	Who?	Why?	Status
CraNE-JANE Coordinator meeting, 22/9/2022 – INT (WP1)	Meeting Collaboration with EU-funded projects	Internal Coordinator meeting	JANE-CraNE collaboration	Delivered
Collaboration possibilities with CRANE - MSCI (WP5)	Online meeting	German Cancer Society + MSCI + CraNE	Synergy - JANE and CraNE networking	Delivered
Collaboration possibilities with CRANE - MSCI (WP13)	Online meeting	IOCN, CraNE	Synergy - JANE and CraNE networking	Delivered
MyPath and other EU funded projects	Conference – oral presentation	ESMO, September 2022	Part of invited lecture on MyPath, one of other EU funded projects in which OUS is involved (HORIZON-HLTH-2021-DISEASE-04)	Delivered
MATRIX, 1 st General assembly, Sept 2022	Oral presentation	Scientists, multiprofessional clinicians, national managers	Inauguration meeting in MATRIX, an overlapping large scale Norwegian project that facilitates the implementation of the palliative care concepts in JANE	Delivered
MATRIX semi-annual meetings	Oral presentation	Scientists, multiprofessional clinicians, national managers	Follow-up and updates of JANE as part of OUS portfolio	Delivered
IOCN Magazine: Journal of the Oncology Institute "Prof. Dr. Ion Chiricuța" Cluj-Napoca, "About Pediatric Cancer", 2 nd Edition		JANE, Reporter Medical, Asociatia Redescopera Fericirea Stop Cancer	<p>The primary objective of the 2nd Edition of IOCN Magazine: Journal of Oncology Institute "Prof. Dr. Ion Chiricuța" Cluj-Napoca, entitled "About Paediatric Cancer," is to provide comprehensive insights into various aspects of paediatric cancer. The magazine aims to serve as an authoritative source of information on the different types of paediatric cancers, their prevalence, risk factors, and the latest advancements in diagnosis and treatment. By offering a holistic view, the publication strives to enhance understanding and awareness of paediatric cancers among healthcare professionals, caregivers, and the general public.</p> <p>A key objective is to empower families and caregivers of paediatric cancer patients with knowledge and resources. The magazine seeks to include articles and features that address the emotional, psychological, and practical challenges faced by families dealing with paediatric cancer. By providing supportive information on coping strategies, available resources, and stories of resilience, the publication aims to create a sense of community and offer guidance to those navigating the complexities of paediatric cancer care.</p>	Delivered

IOCN Magazine: Journal of the Oncology Institute "Prof. Dr. Ion Chiricuța" Cluj-Napoca, "About Breast Cancer", 3 rd Edition (WP8)		JANE, ReporterMedical, Asociația Redescopera Fericirea Stop Cancer	<p>The primary objective of the 3rd Edition of the IOCN Magazine: Journal of the Oncology Institute "Prof. Dr. Ion Chiricuța" Cluj-Napoca, titled "About Breast Cancer," is to serve as a comprehensive educational resource. This involves providing up-to-date and evidence-based information on various aspects of breast cancer, including prevention, early detection, treatment options, and supportive care. The magazine aims to empower readers with knowledge, fostering a deeper understanding of breast cancer and its management.</p> <p>Another key objective is to showcase cutting-edge research and innovative developments in the field of breast cancer. The magazine seeks to feature articles, studies, and insights from prominent researchers, clinicians, and healthcare professionals. By highlighting advancements in breast cancer research, treatment modalities, and supportive technologies, the publication aims to contribute to the dissemination of knowledge and inspire further progress in the fight against breast cancer.</p>	Delivered
Social media posts and online Cancer Prevention Campaign (WP8)	Clustering activities	Public	This campaign aims to disseminate crucial information about cancer prevention through a series of online activities, including webinars, social media posts, and collaboration with international health organizations. The goal is to reach a broad audience, raise awareness, and promote healthy lifestyle choices that can reduce cancer risk.	
3 rd ACCC-Athens Comprehensive Cancer Center Symposium, 3-4/11/2022 (WP2)	Conference- Oral presentation	Industry, business partners EU institutions Policymakers and authorities, International Policymakers and authorities, national Scientists Medical oncologists	Raise awareness on JANE's ambitions and goals	Delivered
CraNE kick off meeting, 4/11/2022 (WP1)	Meeting Collaboration with EU-funded projects	Beneficiaries of CraNE, Coordinators of related projects/ networks	JANE-CraNE collaboration	Delivered
PRC (European Palliative Care research centre) Conference, Nov2022	Conference, oral presentation	Scientists, multiprofessional clinicians, national managers	Follow-up and updates of JANE, EUonQOL, MyPath as part of OUS portfolio	Delivered
Meeting with Board of ESSO, 3/4/2023 (WP1)	Conference- Oral presentation	ESSO Board members	Raise awareness on JANE's ambitions and goals	Delivered
CraNE-JANE Coordinator meeting, 11/4/2023 (WP1)	Meeting Collaboration with EU-funded projects	Internal Coordinator meeting	JANE-CraNE collaboration	Delivered

Scientific Council Meeting of ESTRO, 18/4/2023 (WP1)	Conference- Oral presentation	ESTRO Scientific Council Members	Raise awareness on JANE's ambitions and goals	Delivered
Meeting to establish collaboration with ECO (WP1)	Meeting	Members of the European Cancer Organisation (ECO)	Collaboration with ECO in the field of Survivorship	Ongoing
Reducing disparities across EU (26-27/04/23) (WP5)	High Level Stakeholders Conference	EU institutions and members of EU parliament scientist, International policy makers and authorities, Oncology societies and organisations, Industry, Business partners	Networking in relation "Tackling the implementation gap: SWOT"	Delivered
Poor prognosis cancer meeting related to Swedish presidency (WP5)	Meeting	International policymakers and authorities	PPC - presentation in relation to PPC NoE	Delivered
	EURACAN Board meeting (16-18/05/23)	EU Institutions, International policy makers and authorities	Presentation on, "How to succeed in Horizon Europe oncology projects in practice?"	
European Week Against Cancer, 25-31/5/2023 (WP1)	Conference- Webinar, Factsheet	Industry, business partners EU institutions Policymakers and authorities, International Policymakers and authorities, national Scientists Medical oncologists	Raise awareness on JANE's ambitions and goals	Delivered
Europe's Beating Cancer Plan - First EU4Health Project Showcase, 25/5/2023 (WP1)	Webinar- Oral presentation	Industry, business partners EU institutions Policymakers and authorities, International Policymakers and authorities, national Scientists Medical oncologists	Raise awareness on JANE's ambitions and goals	Delivered
Quality Cancer Care Network Meeting, 26/5/2023 (WP1)	Conference- Oral presentation	Members of ECO	Raise awareness on JANE's ambitions and goals	Delivered
GRELL Group for Cancer Epidemiology & Registration in Latin Language Countries, 31/05-02/06/2023 (WP1)	Conference	Population-based cancer registries meeting	To engage cancer registries in the future NoE on survivorship and adolescents and young adults	Delivered

Creating an NoE on Survivorship at national (Polish) level (13/06/2023) (WP7)	Meeting	"Follow up"	Organization of survivorship care at the national level	Ongoing
We Infoday Joint Action del Programma EU4Health,15/6/2023 (WP2)	Meeting	Italian researchers/ clinicians	Raise awareness on JANE's ambitions and goals	Delivered
OECI Oncology Days - European Cancer Strategic Initiatives, 15/6/2023 (WP1, WP5)	Conference- Oral presentation	OECI members	Raise awareness on JANE's ambitions and goals	Delivered
Subgroup on Cancer Meeting under the Public Health Expert Group, 28/6/2023 (WP1)	Conference- Oral presentation	Experts	Ongoing EU4Health and Horizon Europe projects	Delivered
MyPath general assembly meeting, June-23 (WP6)	General Assembly, oral presentation	International, Scientists, Clinicians, managers- multiprofessional	Part of invited lecture on liaison activities on national / international research projects on patient-centred care and Palliative care integrations	Delivered
In-house meetings, Nov 22-June 23 (OUS) (WP6)	Oral presentations	In-house staff	General in-house meetings and teaching activities covering all three EU-funded projects (MyPath, JANE, EUonQOL) in which OUS is involved	Delivered
Summer School – ProMIS, 5/7/2023 (WP2)	Meeting	Italian entities interested in participating in Joint Actions	Raise awareness on JANE's ambitions and goals	Delivered
13 Informal Coffee meetings with Policy Board, May-July 2023 (WP4)	Meetings	Policymakers and public health specialists	Introducing and contextualizing JANE project to the Policy Board members- Gathering their initial reactions to the project's approach- Discussing about the potential impact that the NoEs can have on the cancer ecosystem in Europe.	Delivered
High Level Meeting - Challenges in Cancer Care, 31/8/2023 (WP2)	Conference- Oral presentation	Spanish Government, European Commission, experts in the field of cancer	Raise awareness on JANE's ambitions and goals	Delivered
Subgroup on Cancer Meeting under the Public Health Expert Group, 18/9/2023 (WP2)	Conference- Oral presentation	Experts	EU4Health Work Programme 2023 - upcoming Joint Action on new Networks of Expertise	Delivered
Quality Care Cancer Network Meeting, 18/9/2023 (WP2)	Conference- Oral presentation	Members of ECO	Raise awareness on JANE's ambitions and goals	Delivered
ENTYAC meeting, 20/09/2023 (WP11)	Meeting			Delivered

STRONG-AYA Stakeholders meeting (WP11)	Meeting			Delivered
Anticancer treatment at end-of-life, ESMO, October 2023 (WP6)	Conference – Oral presentation	Scientists, Clinicians-multiprofessional, patient/professional organisations, international International, Scientists, Clinicians, managers-multiprofessional EU institutions, Policymakers and authorities, international, Scientists, Clinicians-multiprofessional, professional and lay organisations	Part of invited lecture on anticancer treatment at end-of-life AND Parallel session, Education/training organization/learners	Delivered
“How to succeed in Horizon Europe oncology projects in practice?” (26/10/23) (WP2)	Webinar Green Horizon organised by National Contact Point for EU	Policy makers and national authorities Mission Cancer National Societies	Raise awareness on projects in the field of Oncology in general	Delivered
Collaboration with Patient Representatives (WP5) 10/11/2023, Milan	Meeting	Patients and patient advocacy groups	Meeting with a patient advocacy group representative to set up a strategy for further activities of PPC addressing patients' needs	Delivered
Meeting of Italian AIOM-AIEOP Working Group on AYAs, Turin, 14/11/2023 (WP11)	Working group meeting	AIOM-AIEOP steering committee		Delivered
Stakeholder Forum (16/11/2023) (WP4)	Conference	JANE leaders, policy makers and national authorities	Summary and further plans	Delivered
Meeting on implementation of Survivorship Passport (21/11/2023) (WP7)	Meeting	PanCare	Implementation of Survivorship Passport, future collaboration	Ongoing
Cooperation request (WP7)	Collaboration with EU societies	ESMO, SIOPE, OECl, PanCare	Collaboration in case of guidelines including Survivorship issues	Ongoing
Scientific paper (Task 4.1) (WP4)	Other	JANE Consortium led	Present 'Comparative Framework for European networks' developed by BS and results of mapping analysis that will serve as input to define recommendations for sustainability of NoEs	Ongoing
Systematic review paper (Task 12.1) (WP12)	Other	[Scientists] [Other]	Map available evidence of potential gaps to be addressed to improve integration between health care and research. This systematic review will identify strategies, barriers, and facilitators to integrate research into health care practice.	Ongoing

Challenges in the Integration between Health Care and Research in the Cancer Field: A Systematic Review [CRD42024520574]	Other	[Scientists] [Other]	Published PROSPERO research protocol related with the T12.1. The study aims to perform a systematic review to explore the available evidence to answer the following research questions: 1. What are the barriers of implementing cancer research evidence in the health care? 2. What are the facilitators of implementing cancer research evidence in the health care?	Delivered
Meeting on the future and sustainability of JANE	Consortium meeting	Members of the JANE Consortium	Discussing future engagement of CAs and AEs in future activities of PPC	Delivered
'Innovative practices for stakeholder engagement in cancer-related EU projects' organized by LIVERATION project, 29 April, 2024	Online synergy Workshop	Partners of cancer-related projects	Stakeholder engagement	Delivered
National Cancer Awareness Conference	Conference	Policy-makers and authorities, national	The objective of this conference is to bring together leading cancer researchers, healthcare professionals, and policymakers to discuss the latest advancements in cancer prevention, early detection, and treatment. It aims to foster collaboration, share knowledge, and develop strategies to reduce the incidence and mortality of cancer at the national level.	

Communication activities

Communication activities					
Communication activity name	Description	Who? Target audience	How? Communication channel	Outcome	Status
JANE Logo (WP2)	Digital material	All target groups	JANE website and all activities	Visibility	Delivered
OEI Magazine No.2-2022 (WP2)	Article	All target groups	Article		Delivered
<ul style="list-style-type: none"> 2 posts Twitter: 2 Tweets (thread) on 14th November 2022 : https://twitter.com/BE_CancerCentre/status/1592234125658058754 1 Tweet on 15th May 2023: https://twitter.com/BE_CancerCentre/status/1658173102767976450 	A tweet for the Kick Off and for the European Week Against Cancer.	EU institutions, National authorities, Regional authorities, Local authorities, Civil society, Citizens, Research	Twitter	Visibility	Delivered

		communities, specific user communities			
JANE-1st E-Newsletter-June 2023 (WP2)	Release of the 1st e-newsletter focusing on the six-month progress of JANE.	All target groups	Website, E-mailing	90 registrations on Mailchimp platform to receive newsletter	Delivered
JANE Flyer (WP2)	A 4-page promotional flyer was created including key information on JANE project.	All target groups	Print material (brochure)	150 copies were sent to European Cancer Summit, ECO, November 15th-16th 2023, Brussels 50 copies distributed at JANE Plenary meeting, November 16th -17th, 2023, Barcelona	Delivered
EU Health Policy Platform (EUHPP) – Agora (WP2)		All target groups	E-material to be uploaded		Ongoing
Targeted meetings with oncologists in Greece (WP2)	Meetings	Medical oncologists	Physically, tele-meetings regularly	Coordination & interaction at national level	Ongoing
Collaboration with Hellenic Ministry of Health-CraNe team (WP2)	Meetings	Policymakers	Regular tele-meetings	Coordination and interaction at national and	Ongoing

				European level	
Collaboration with CraNE and policymakers in Norway (WP2)	2-3 Coordinating meetings with CraNE and competent authorities in Norway at the health political level.	Policymakers	Meetings	Coordination and interaction at national level	Delivered
2 posts: (WP2) JANE Project "EU Joint Action on Networks of Expertise" 1st Newsletter of JANE Project "EU Joint Action on Networks of Expertise on News page of National Hellenic Research Foundation website www.eie.gr	Website posts	All target groups	website	Visibility	Delivered
Post called "Kronikgune attends the kick-off meeting of the European project JANE" on News page of BIOSISTEMAK (former KRONIKGUNE) website www.kronikgune.org (WP2)	Website post	All target groups	website	Visibility	Delivered
Dedicated section on CraNE and JANE called "CraNE and JANE: building a better Europe against cancer" on page with international activities of Unicancer website www.unicancer.fr/en (WP2)	Website post	All target groups	website	Visibility	Delivered
Unicancer's posts in LinkedIn (from the most recent to the less one): (WP2, WP10) https://www.linkedin.com/posts/unicancer_cancaezrologie-eu4health-healthunion-activity-7131278748544331776-_akw?utm_source=share&utm_medium=member_desktop https://www.linkedin.com/posts/unicancer_jane-eu4health-eucancerplan-ugcPost-7109907614213230593-MQNe?utm_source=share&utm_medium=member_desktop https://www.linkedin.com/feed/update/urn:li:activity:7061732258574921729?utm_source=share&utm_medium=member_desktop	Social media posts	All target groups	website	Visibility	Delivered

<p>https://www.linkedin.com/feed/update/urn:li:activity:7059104515714605056?utm_source=share&utm_medium=member_desktop</p> <p>https://www.linkedin.com/feed/update/urn:li:activity:7056567792329728000?utm_source=share&utm_medium=member_desktop</p> <p>https://www.linkedin.com/feed/update/urn:li:activity:7051494285216509952?utm_source=share&utm_medium=member_desktop</p> <p>https://www.linkedin.com/feed/update/urn:li:activity:7032680260521316352?utm_source=share&utm_medium=member_desktop</p> <p>https://www.linkedin.com/posts/muriel-santoro-b3116754_fondazioneircc-jane-eucancerplan-activity-6998270452523528192-qhYr?utm_source=share&utm_medium=member_desktop</p>					
Website publication: 'Kronikune attends the kick-off meeting of the European project JANE' (WP2)	Publication of a new about the kick-off meeting of JANE		Website	Website visitors	Delivered
Website publication: "European Week Against Cancer (EWAC)" (WP2)	Publication of new about the EWAC including highlights of the activities conducted by BS in the WP that they lead		Website	Website visitors	Delivered
Informal Coffee Meetings (WP4)	13 individual Informal Coffee Meetings with the Policy Board representatives to gather their thoughts about NoEs: expectations, added value and alignment with other European and national policies.		Event (conference, meeting, workshop, internet debate, round table, group discussion etc)	Main conclusions of the meetings	Meetings delivered Main conclusions ongoing
JANE-2nd E-Newsletter-June 2023 (WP2)	Release of the 2nd e-newsletter focusing on the 12-month progress of JANE.	All target groups	Website, Mailchimp platform	110 subscribers received the 2nd newsletter through the Mailchimp platform	Delivered
Online team meeting (WP5)	Online meeting with Ministry of Health representative (22/08/23)	National authorities- Ministry of Health	Online meeting team	Visibility in Poland	Delivered

Website (WP5)	Information re JANE project	National authorities Local authorities	MSCI Website	Visibility in Poland	Delivered
Website publication: 'JANE project organizes the first Policy Dialogue meeting'	Publication of news item on the first Policy Dialogue meeting of JANE	[EU institutions] [National authorities] [Regional authorities] [Local authorities] [Research communities]	Website	Website visitors	Delivered
1st JANE Policy Dialogue	1st JANE Policy Dialogue event (3rd October 2023, online event)	[EU institutions] [National authorities] [Regional authorities] [Local authorities] [Civil society] [Research communities]	Event	Attendees: 10 members of Policy Board & 75 participants	Delivered
1st JANE Policy Dialogue. Minutes of the meeting	Report with the results of the first Policy Dialogue of JANE.	[EU institutions] [National authorities] [Regional authorities] [Local authorities] [Civil society] [Research communities]	Other	Report	Delivered
Website publication 'The JANE project holds its third plenary meeting'	Publication of news item on the third Plenary Meeting of JANE	[EU institutions] [National authorities] [Regional authorities] [Local authorities] [Research communities]	Website	Website visitors	Delivered
Meeting with NIPH representative (WP5)	One-to-one meeting with NIPH representative	Local authorities (NIPH)	One-to-one meeting	Visibility in Poland	Delivered
Activities in progress (OUS) (WP6)	Finalising Program for the PRC conference in February 2024	Scientists, Clinicians- multi-	Meeting with workshop	Plenary lecture, parallel	Ongoing

		professional, & lay organisations		lecture/work shop	
JANE-Press release-March 2024 (WP2)	Publish of the press release in national websites in Greece	All target groups	Websites	Publication of the press release in 36 websites	Delivered
Meetings with Patient Organizations (WP16)	Meetings organized with patient organizations in all project partner countries (+ Bulgaria) to share experiences on how to involve patients in their organizations, projects, etc.		Online/in-person interview	Get input from patient organizations on good and less good engagement practices	Delivered
		LUSS (Belgium)	Online		
		Kickcancer (Belgium)	Online		
		FAPA (Belgium)	Online		
		France Assos Santé (France)	In-person meeting		
		Ligue Nationale contre le Cancer (France)	Online		
		ELLOK (Greece)	Online		
		FAVO (Italy)	Online		
		AIMaC (Italy)	Online		
		Lélek-Zet (Hungary)	Online		
		APOZ (Bulgary)	Online		
		ECPC (European level)	In-person interview		

Meetings with NoE leaders (WP1)	Meetings organized with the leaders of certain NoEs to get an overview of their work and what they would need in terms of patient engagement.		Online-in-person interview	Clearer NoE direction to better target patient engagement needs	[Delivered]
1st JANE Stakeholder Forum (WP4)	1st JANE Stakeholder Forum event (17th November 2023, hybrid event)	EU institutions, National authorities, Regional authorities, Civil society, Research communities,	Event	Attendees: 66 onsite participants, 67 online participants, 11 stakeholders	Delivered
Website publication 'JANE project holds its first Stakeholder Forum' (WP4)	Publication of news item on the first Stakeholder Forum of JANE	[EU institutions] [National authorities] [Regional authorities] [Local authorities] [Research communities]	Website	Website visitors	Delivered
1st JANE Stakeholder Forum Meeting – Minutes of the event (WP4)	Report with the results of the 1st Stakeholder Forum	EU institutions, National authorities, Regional authorities, Civil society, Research communities,	Other	Report	Delivered
EU Health Policy Platform (EUHPP) – Agora Network (WP2)	Upload of 2 posts: JANE-EU Joint Action on Networks of Expertise on Cancer (30/11/2023) JANE :EU Joint Cancer to fight cancer (06/03/2024)	All target groups	E-material	Visibility	Delivered

Online synergy Workshop 'Innovative practices for stakeholder engagement in cancer-related EU projects' organized by the LIVERATION project, 29 April, 2024	Digital communication	Lay audience	E-material	Visibility	Delivered
Synergies with CraNE	Activities to establish synergies	IOCN and partners	Onsite/online	Establish similarities between JAs	Ongoing
Synergies with EUNetCCC	Activities to establish synergies	IOCN and partners	Onsite/online	Establish similarities between JA	Ongoing
Synergies with JANE2	Activities to establish synergies Online and onsite meetings with future partners in JANE2 and current partners in JANE1	IOCN and partners	Onsite/online	Establish similarities between JA	Ongoing
Social Media Posts on Prevention Topics	A series of social media posts focusing on various cancer prevention topics, including healthy lifestyle choices, regular screenings, and vaccinations.	General public Social media users	IOCN Facebook page IOCN LinkedIn page	Increased engagement on social media Improved public knowledge on cancer prevention methods	Ongoing
Website publication on the Sciensano website: https://www.sciensano.be/fr/projets/action-conjointe-sur-les-reseaux-europeens-dexpertise	Description of the project, structure, Work Packages, associated projects and implicated scientists.	Innovators, EU institutions, National authorities, Regional authorities, Local authorities, Civil society, Citizens, Research communities	Website	Website visitors	Delivered
Website publication on the Europe's Beating Cancer website: https://www.beatingcancer.be/project/jane-joint-action-european-networks-expertise-cancer/	Description of the project (in the framework of Europe's Beating Cancer Plan).	Innovators, EU institutions, National authorities, Regional	Website	Website visitors	Delivered

		authorities, Local authorities, Civil society, Citizens, Research communities, specific user communities			
<p>Reference to the project in the EBCP mirror group newsletter:</p> <ul style="list-style-type: none"> November 2022 : https://www.beatingcancer.be/wp-content/uploads/2023/09/Newsletter-BE-EBCP-mirror-group-November-2022.pdf January 2023 : https://www.beatingcancer.be/wp-content/uploads/2023/09/Newsletter-BE-EBCP-mirror-group-January-2023.pdf April 2023 : https://www.beatingcancer.be/wp-content/uploads/2023/09/Newsletter-BE-EBCP-mirror-group-April-2023.pdf May 2023 : https://www.beatingcancer.be/wp-content/uploads/2023/09/Newsletter-BE-EBCP-mirror-group-May-2023.pdf October 2023 : https://www.beatingcancer.be/wp-content/uploads/2023/11/Newsletter-BE-EBCP-mirror-group-October-2023.pdf <p>November 2023: https://www.beatingcancer.be/wp-content/uploads/2023/11/Newsletter-Belgian-EBCP-Mirror-Group-November-2023.pdf</p>	Description of the project, main areas and timeline.	Civil society, Citizens, Research communities, specific user communities	Newsletter/Web site	Visibility/Information	Delivered
Meeting of the Italian AIOM-AIEOP Working Group on AYAs (WP11)	Turin, 14th November 2023	AIOM-AIEOP steering committee		Meeting of Italian AIOM-AIEOP Working Group on AYAs	Turin, 14th November 2023
Meeting Swiss Oncology Hematology Society, Basle, 23rd November 2023 (WP11)	Conference	Sarcoma IN AYA	Communicate the activity of JANE	Meeting Swiss Oncology Hematology Society, Basle, 23rd November 2023	Conference

Course on Adolescentology (WP11) Milan, 16th December 2023	Residential course		Communicate the activity of JANE	Course on Adolescentology Milan, 16th December 2023	Residential course
SIOPE AYA course (WP11) Varese, 29-30 September 2023	Masterclass	Fellows in paediatric or adult haematology and oncology; junior faculty at academic medical centres in Europe; people training for other disciplines caring for AYA cancer patients and survivors	Communicate the activity of JANE	SIOPE AYA course Varese, 29-30 Sept	Masterclass
AIEOP Congress (WP11) Bologna, 23 April 2024	Congress		Communicate the activity of JANE	AIEOP Congress Bologna, Bologna, 23 April, 2024	Congress
White paper EU IT and cancer data sharing (TTF3)	A paper describing the results of the EU IT and Cancer Data Sharing survey. The paper will discuss ongoing opportunities and challenges related to sharing clinical data, imaging, and biomarker data to enable cancer research in the EU	Institution IT administrators, EU funding bodies, and AI Cancer Researchers in EU			Paper

Patient workshop Sciansano March 2024	Workshop	EU and national patient organizations General public	Presentation of the toolkit	Delivered	Delivered
CRANE workshop April 2024	Collaboration with EU-funded projects	EU institutions Policy-makers and nation and international authorities, Scientists	Presentation of the toolkit	Delivered	Delivered

Events and training

Events and trainings (including workshops, conferences, etc)										
Event no. (continuous numbering linked to WP)	Participant	Description					Attendees			
		Name	Type	Area	Location	Duration	Male	Female	Non-binary	Total
WP5) 1.	Prof. Iwona Lugowska Anna Ciemuchowska	CRANE JA7 workshop	Workshop	Synergies with CRANE. Assessing areas for collaboration Familiarise with first sketches of CCC standards to find link with JANE endorsement criteria	Paris	21.04.2023		X		
WP5) 2	Anna Ciemuchowska	OECI	Conference	Discussion of JANE and CRANE JA projects	Paris	14-15.06.2023		X		
WP8) 1	Delia Nicoara	Italian National Institute of Health, Rome. High-level	F2F Meeting	Project debrief and activities follow-up	Rome, Italy	26/04/2023 – 27/04/2023		X		

		Stake-holder Conference: Reducing Disparities Across EU								
WP8) 2	Delia Nicoara	High Level Meeting: Challenges in Cancer Care	F2F Meeting	Spanish Presidency announcement	Barcelona, Spain	31/08/2023				
WP8) 1	Delia Nicoara	JANE - WP 10 & WP 9 meeting: onsite meeting	F2F Meeting	WP 10 on Hitech medical resources, jointly with WP 9 on Omics: governance, functioning, sustainability of the NoEs	Zoom	19/09/2023				
TTF2) 1.	Delia Nicoara	JANE-TTF2 Meeting	Online Meeting	Dr. Delia Nicoara, Project Manager – Introduction + progress TTF2 Dr. Adela Maghear, Senior EU Affairs Manager, Brussels –Beyond JANE1 - Strategies for stakeholder engagement at EU and MS level Dr. Per Magnus Mæhle, General manager Cancer Center Board, Oslo, Norway – Case Study & CraNE Synergy: the Nordic and Baltic CCCs Consortium Model	Online (Zoom)	03/10/2023				
TTF5) 1	Sciensano & 35 reps from EU patient organizations including ECPC, ELLOK Kom Op, Kickcancer, PEC, FAPA, Think Pink, ...)	Patient workshop	Workshop	Patient engagement	Brussels	3h	19	16	0	35
WP5	Iwona Lugowska (MSCI)	CraNE Stakeholder Forum	Event	Synergies with CraNE. Assessing areas for collaboration	Oslo	07/12/2023		X		
WP7	Delia Nicoara	High-Level Conference on Ending Financial Discrimination	High-level Conference	Ending Financial Discrimination against Cancer Survivors	Palace of the Academie	15 February 2024		Female		1

		Against Cancer Survivors		<p>The Right to be Forgotten as a Human Right</p> <p>European NGOs Advocating for Cancer Survivors</p> <p>Progress from the European Cancer Mission</p> <p>The European Parliament Advocating for Cancer Survivors</p> <p>Protecting Cancer Survivors through a Comprehensive European Legislation</p>	s, Brussels					
WP8	Delia Nicoara	Onsite meeting with Danish partners	Forum	A flagship initiative aimed at establishing a European network of Comprehensive Cancer Centers (CCC)	Denmark	11 th - 13 th April 2024		Female		1
WP8	Delia Nicoara	<p>The Joint Euro-American Forum on Cancer, Dublin, Ireland</p> <p>“Cancer has no borders – together stronger”</p>	Conference	<p>Launch of Policy Document and Recommendations “Time To Accelerate –empowering transatlantic co-operation”</p> <p>Recognising Euro-US-Ireland leadership in cancer control.</p> <p>Transatlantic Cooperation for Cancer: Prime Time for Action</p>	Mansion House, Dublin	24th-26th April 2024		Female		1
WP8	Delia Nicoara	BEACON: Mobilising Collaboration among Stakeholders to Optimise the Growing Potential of Data for Tackling Cancer	High-level Conference	<p>One of the core outcomes of the event is to develop a roadmap to scale current capacity and capabilities of cancer centers in order to address existing cancer disparities for access and diagnostics for ALL as well as public health Genomics.</p> <p>Objective: The conference provides a chance to re-align priorities to evaluate the needs of patients, healthcare professionals and health systems to facilitate improved and safer therapies.</p>	Warsaw, Poland Maria Sklodowska-Curie National Research Institute of Oncology	May 16th/17th, 2024		Female		1

TTF3	TTF3 Working Group	Joel Hedlund, LIU	Scientific talk and training	Federated data sharing expertise	Zoom	1 hour				
TTF3	TTF 3 Working Group	Macha Nikolski, Université de Bordeaux	Scientific talk and training	AI data sharing for imaging and genomics	Zoom	1 hour				

5. SUBCONTRACTING

Subcontracting						
Work Package No	Subcontract No (continuous numbering linked to WP)	Subcontract Name (subcontracted action tasks)	Description (including task number and BEN/AE to which it is linked)	Estimated Costs (EUR)	Justification (why is subcontracting necessary?)	Best-Value-for-Money (how do you intend to ensure it?)
WP2	S1.1	FAVO-Italian Federation of Cancer Associations	COO: INT	40,000	Expertise and advice of patient associations and expert groups. Best value for activities proposed with their central national role – only able service provider with this capacity.	Activity monitoring, regular internal reports
WP2	S1.2	OECI	COO: INT	47,080	OECI is a European GEIE with capacity and out-reach to implement training/networking/ dissemination activities across all EU MS, its participation is necessary for good implementation of WP2 tasks	Activity monitoring, regular internal reports
WP2	S2.1	KOUKOUGIANNI MENIA MON IKE	BEN: NHRF	1,240.00* 21,700.00	Technology and expertise support for construction and set up of dissemination tools	Open tender

		Design Solutions Web Creations Threadcase	Website setup, running, maintenance	620.00*		
WP8	S8.1	TBD	BEN: IOCN All tasks pertaining to local IT support	18,000	Technology & expertise support for construction + set up of dissemination tools	Open tender
WP1 1	S11.1	SIOPE- European Society of Paediatric Oncology	COO: INT (coordinator)	36,000	Subcontract with scientific manager of SIOPE Committee on AYA. Her very specific experience and expertise on AYA is necessary for the good implementation of WP11	Activity monitoring and regular internal reports
WP1 6	S16.1	ELLOK	BEN: Sciensano Local patient expert groups for identification and support to patients involved in patient engagement activities	25,000	Patient association with close-knit collaborations with European patient groups network – tasks: support WP leader in identifying & involving patient engagement target stakeholders	Regular monitoring

*These items can probably be accounted for under “Services”

6. TIMETABLE

ACTIVITY	MONTHS																							
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Timetable																								
Task 1.1 - Project management																								
Task 1.2 - Scientific coordination																								
Task 1.3 - Collaborative coordination																								
	M S 1		MS2											D1										D2
Task 2.1 - Plan, build and maintain the JANE website			D1	MS1																				
Task 2.2 - JANE Dissemination Strategy						D2			MS2															
Task 2.3 Organize the JANE final conference																								D3
Task 3.1 - Process evaluation																								
Task 3.2 - Product Evaluation																								
Task 3.3 - Awareness and impact of the NoE																								
			MS1					D1			MS2		MS3						MS4		MS2		D2	

Task 4.1 Analysis of the existing networks	■	■	■	■	■																		
Task 4.2 Sustainability strategy of NoE				■	■	■	■	■	■	■	■	■	■	■	■								
Task 4.3 Policy Board and Policy Dialogues	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Task 4.4 Stakeholder forum	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
Task 4.5 Policy recommendations	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■
																		MS 1					MS2 -D1
T 5.1 Establishment of a framework for the NoE	■	■	■																				
T5.2 Definition of the scope of the NoE			■	■	■	■																	
T5.3 NoE Governance					■	■	■	■	■	■	■	■											
T5.4 Identification of the endorsement criteria									■	■	■												
T5.5 Site selection											■	■	■	■	■								
T5.6 Identification of activities, deliverable																		■	■	■	■	■	■
			MS1			MS2				MS3	MS4				MS 5					MS6			D1
T6.1 Leading expert scoping	■	■																					
T6.2 Leading expert selection		■	■																				
T6.3 Definition of the Scope of the NoE			■	■	■																		
T6.4 Identification of the endorsement criteria				■	■	■	■	■	■														
T6.5 Scoping centres								■	■	■	■	■											

T8.4 Centre identification																												
T8.5 Definition of the NoE deliverables																												
T8.6 NoE Governance development																												
		MS1		MS2																								
Task 9.1 - Definition of the scope of the NoE																												
Task 9.2 - Identification of endorsement criteria																												
Task 9.3 - Scoping service providers and/or centres																												
Task 9.4 Service provider and/or centre selection																												
Task 9.5 Identification of NoE deliverables																												
Task 9.6 Governance development																												
Task 10.1 - Definition of the scope of the NoE																												
Task 10.2 - Identification of endorsement criteria																												
Task 10.3 - Scoping service providers, centres																												

Task 10.4 Service provider and/or centre selection																								
Task 10.5 Identification of NoE deliverables																								
Task 10.6 Governance development																								
				MS1			MS2			MS3			MS4										MS5 D1	
Task 11.1 Definition of the scope of the NoE																								
Task 11.2 Identification of participants																								
Task 11.3 Sites identification																								
Task 11.4 Definition of the NoE deliverables																								
Task 11.5 NoE Governance development																								
				MS1			M S2			MS3			MS4										MS5	D1