



Joint Action on Networks of Expertise

Deliverable number. 1.1

Mid-term report

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

| DOCUMENT INFORMATION | |
|---------------------------------|--|
| Author(s) | INT |
| Deliverable lead partner | INT |
| Contributing partner(s) | INT, NHRF, CIPH, BS, MSCI, OUS, IOCN, Sciensano, Unicancer, INCa |
| Work Package | WP1 |
| Task | T1.1 |
| Deliverable type | Document, report |
| Due delivery date | 14 |
| Actual delivery date | 17 |
| Dissemination level | SEN - Sensitive |
| Annex version | 19 September, 2023 |

This document contains information which is proprietary to the JANE consortium. Neither this document nor the information contained herein shall be used, duplicated or communicated by any means to any third party, in whole or parts, except with the prior written consent of the JANE Consortium.

| PROJECT | |
|-----------------------|---------------------------------------|
| Project number | 101075328 |
| Project acronym | JANE |
| Project name | Joint Action on Networks of Expertise |
| Call | EU4H-2021-JA-IBA |
| Topic | EU4H-2021-JA-04 |
| Type of action | EU4H-PJG |
| Service | HADEA/A/01 |
| Project starting date | 1 October, 2022 |
| Project duration | 24 months |

| REPORTING PERIOD | |
|----------------------------------|--------------------------------------|
| Period covered | 1 October, 2022 – 30 September, 2023 |
| Reporting period number | 1 |
| Periodic report date and version | 30 November, 2023; Version 1 |

Revision History

| Version no. | Date of Issue | Author(s) | Brief description of change |
|-------------|---------------|--|-----------------------------|
| 1 | M17 | INT, NHRF, CIPH, BS, MSCI, OUS, IOCN, Sciensano, Unicancer, INCa | |

TABLE OF CONTENTS

| | |
|--|-----------|
| LIST OF PARTICIPANTS | 5 |
| 1. OVERVIEW OF THE PROGRESS | 7 |
| 1.1 Summary of work performed and achievements, results and impacts | 7 |
| 1.2 Project teams, staff and experts | 7 |
| 1.3 Consortium management and decision-making | 8 |
| 1.4 Project management, quality assurance and monitoring and evaluation strategy | 8 |
| 1.5 Cost effectiveness and financial management | 9 |
| 1.6 Risk management | 9 |
| 1.7 Impact | 9 |
| 1.8 Communication, dissemination and visibility | 10 |
| 1.9 Sustainability and continuation | 11 |
| 1.10 Follow-up to EU recommendations | 11 |
| 2. WORKPLAN, WORK PACKAGES, ACTIVITIES, RESOURCES AND TIMING | 12 |
| 2.1 Work plan | 12 |
| 2.2 Work packages, activities, resources and timing | 14 |
| <i>Work Package 1 Project management and coordination</i> | <i>14</i> |
| <i>Work Package 2 Dissemination</i> | <i>17</i> |
| <i>Work Package 3 Evaluation</i> | <i>20</i> |
| <i>Work Package 4 Sustainability</i> | <i>23</i> |
| <i>Work Package 5 Complex and poor prognosis cancers</i> | <i>29</i> |
| <i>Work Package 6 Palliative care</i> | <i>33</i> |
| <i>Work Package 7 Survivorship</i> | <i>38</i> |
| <i>Work Package 8 Personalised primary prevention</i> | <i>41</i> |
| <i>Work Package 9 Omics Network of Expertise for Cancer</i> | <i>46</i> |
| <i>Work Package 10 Hi-tech medical resources</i> | <i>50</i> |
| <i>Work Package 11 Adolescents and Young Adults with Cancer</i> | <i>54</i> |
| <i>Work Package 12 Integration between health care and research</i> | <i>58</i> |
| <i>Work Package 13 Integration between EU monitoring and Member States</i> | <i>61</i> |
| <i>Work Package 14 Integration between IT infrastructures and AI tools</i> | <i>63</i> |
| <i>Work Package 15 The ERN model</i> | <i>65</i> |
| <i>Work Package 16 Patient involvement</i> | <i>67</i> |
| DISSEMINATION AND COMMUNICATION ACTIVITIES | 70 |
| <i>Dissemination activities</i> | <i>70</i> |
| <i>Communication activities</i> | <i>75</i> |
| <i>Events and training</i> | <i>80</i> |
| 3. SUBCONTRACTING | 81 |
| 4. TIMETABLE | 83 |
| 5. ANNEX: SUMMARY OF THE SEVEN NETWORKS OF EXPERTISE BEING SHAPED BY JANE | 88 |

LIST OF PARTICIPANTS

| PARTICIPANTS | | | | | | | |
|--------------|------|------------|---|---------|-----------|------------|------------|
| Partner No. | Role | Short name | Legal name | Country | PIC | Entry date | Exit date |
| 1 | COO | INT | Fondazione IRCCS Istituto Nazionale dei Tumori | IT | 998538759 | 01/10/2022 | 30/09/2024 |
| 1.1 | AE | IRST | Istituto Romagnolo per lo Studio dei Tumori Dino Amadori – IRST SRL | IT | 998400534 | 01/10/2022 | 30/09/2024 |
| 1.2 | AE | CNAO | Fondazione Centro Nazionale di Adroterapia Oncologica | IT | 998528089 | 01/10/2022 | 30/09/2024 |
| 1.3 | AE | INT-NA | Istituto Nazionale Tumori – Fondazione Pascale | IT | 997819892 | 01/10/2022 | 30/09/2024 |
| 1.4 | AE | IOV | Istituto Oncologico Veneto | IT | 968344405 | 01/10/2022 | 30/09/2024 |
| 1.5 | AE | GASLINI | Istituto Giannina Gaslini | IT | 999448037 | 01/10/2022 | 30/09/2024 |
| 1.6 | AE | ACC | Alleanza Contro il Cancro | IT | 999563661 | 01/10/2022 | 30/09/2024 |
| 2 | BEN | Sciensano | Sciensano | BE | 906160809 | 01/10/2022 | 30/09/2024 |
| 2.1 | AE | IJB | Institut Jules Bordet ASBL | BE | 991172094 | 01/10/2022 | 30/09/2024 |
| 2.2 | AE | UGent | Universiteit Gent | BE | 999986096 | 01/10/2022 | 30/09/2024 |
| 3 | BEN | CIPH | Hrvatski Zavod Za Javno Zdravstvo | HR | 998128255 | 01/10/2022 | 30/09/2024 |
| 4 | BEN | INCA | Institut National du Cancer GIP | FR | 999953892 | 01/10/2022 | 30/09/2024 |
| 4.1 | AE | Unicancer | Unicancer | FR | 952728375 | 01/10/2022 | 30/09/2024 |
| 4.2 | AE | FHF | Federation Hospitaliere de France | FR | 999562109 | 01/10/2022 | 30/09/2024 |
| 5 | BEN | BMG | Bundesministerium Fuer | DE | 998954889 | 01/10/2022 | 30/09/2024 |
| 5.1 | AE | DKFZ | Deutsches Krebsforschungszentrum Heidelberg | DE | 999990073 | 01/10/2022 | 30/09/2024 |
| 6 | BEN | NHRF | Ethniko Idryma Erevnon | EL | 999479853 | 01/10/2022 | 30/09/2024 |
| 6.1 | AE | NKUA | Ethniko Kai Kapodistriako | EL | 999643007 | 01/10/2022 | 30/09/2024 |

| | | | | | | | |
|------|-----|------------|---|----|-----------|------------|------------|
| | | | Panepistimio Athinon | | | | |
| 7 | BEN | OOI | Orszagos Onkologiai Intezet | HU | 991549909 | 01/10/2022 | 30/09/2024 |
| 8 | BEN | SAM LT | Lietuvos Respublikos Sveikatos Apsaugos Ministerija | LT | 933839468 | 01/10/2022 | 30/09/2024 |
| 8.1 | AE | VULSK | Viesoji Istaiga Vilniaus Universiteto Ligonine Santaros Klinikos | LT | 991636530 | 01/10/2022 | 30/09/2024 |
| 8.2 | AE | LSMUL KK | Lietuvos Sveikatos Mokslu Universiteto Ligonine Kauno Klinikos | LT | 923616832 | 01/10/2022 | 30/09/2024 |
| 8.3 | AR | NCI LT | Nacionalinis Vezio Institutas | LT | 912763114 | 01/10/2022 | 30/09/2024 |
| 9 | BEN | MFH | Ministry for Health – Government of Malta | MT | 974144423 | 01/10/2022 | 30/09/2024 |
| 10 | BEN | OUS | Oslo Universitetssykehus HF | NO | 991104000 | 01/10/2022 | 30/09/2024 |
| 11 | BEN | MSCI | Narodowy Instytut Onkologii Im. Marii Sklodoswskiej-Curie-Panstwowy Instytut Badawczy | PL | 999533203 | 01/10/2022 | 30/09/2024 |
| 12 | BEN | DGS | Ministerio da Saude – Republica Portuguesa | PT | 986364095 | 01/10/2022 | 30/09/2024 |
| 13 | BEN | IOCN | Institutul Oncologic Prof Dr Ion Chiricuta Cluj-Napoca | RO | 989404075 | 01/10/2022 | 30/09/2024 |
| 14 | BEN | OIL | Onkoloski Institut Ljubljana | SI | 986222475 | 01/10/2022 | 30/09/2024 |
| 15 | BEN | Kronikgune | Asociacion Instituto de Investigacion en Servicios de Salud - Kronikgune | ES | 955006420 | 01/10/2022 | 30/09/2024 |
| 15.1 | AE | ICO | Institut Catala d'Oncologia | ES | 998420031 | 01/10/2022 | 30/09/2024 |
| 15.2 | AE | IDIVAL | Fundacion Instituto de Investigacion Marques de Valdecilla | ES | 946556944 | 01/10/2022 | 30/09/2024 |
| 15.3 | AE | CIBER | Consorticio Centro de Investigacion | ES | 997154957 | 01/10/2022 | 30/09/2024 |

| | | | | | | | |
|------|-----|----------|-----------------------------|----|-----------|------------|------------|
| | | | Biomedica en Red M.P. | | | | |
| 15.4 | AE | HSJD | Hospital Sant Joan de Deu | ES | 997929890 | 01/10/2022 | 30/09/2024 |
| 15.5 | AE | SAS | Servicio Andaluz de Salud | ES | 998853621 | 01/10/2022 | 30/09/2024 |
| 16 | BEN | UH MOTOL | Fakultni Nemocnice v Motole | CZ | 964458391 | 01/10/2022 | 30/09/2024 |

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 prepare everything necessary 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 the correct monitoring of the project. It is established at INT and includes the coordinator, an expert 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 changes have been made to management in the course of the first 12 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). During the first meeting in October 2022, activities, responsibilities, and management of the project were discussed. The other meetings have 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 how far the 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 networks, 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 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.

It is planned to produce a green paper on European cancer networking together with a dedicated wide public event.

A list of dissemination and communication activities carried out in the first year 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.

A Stakeholder Forum (i.e. a space for discussion that facilitates the exchange of expertise, experience, and opinions of the participants) 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

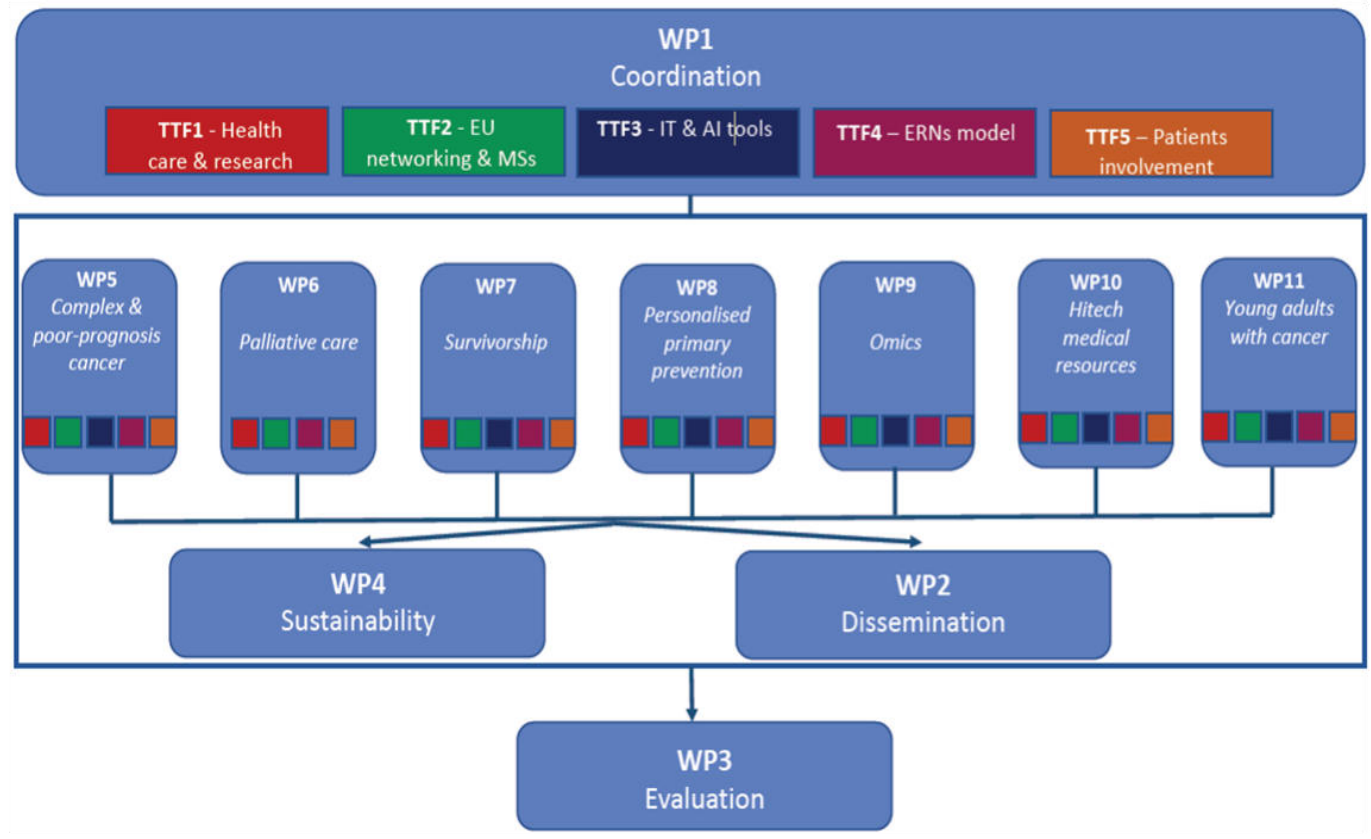
Highlight corrective actions taken as a result of EU monitoring activities (including follow-up to EU project reviews, if any). List each recommendation/comment and explain how they have been followed up.

The EU has not to date provide any recommendations.

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

2.1 Work plan

Work plan
Provide a brief description of the overall structure of the work plan (list of work packages or graphical presentation (Pert chart or similar)).



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 as planned. ▪ 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, 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 12 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 <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 will be additionally monitored through 6-month periodic internal reporting. The present Deliverable 1.1 (12-month report - without a request for payment), will constitute the second 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 is planned for 16-17 November, 2023 in Barcelona, with an expected attendance of 85 people in person and 50 online.</p> <p>The Consortium Agreement has been drawn up, circulated for comments and modifications, and signed by all the BEN and AE.</p> <p>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> | INT |

| | | | 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). | | | | |
|---|---|-----------------|---|--|----------------------------|----------------------------|-----|
| 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 has also been invited to take part at the GA Assembly meeting in Barcelona in November.</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> | | | | INT |
| Next Steps (1 October 2023 – 31 March, 2024) | | | | | | | |
| <ul style="list-style-type: none"> Since the European Commission Call for the follow-up Joint Action to JANE will be issued in October 2023, the focus of the work will partly be on coordinating the proposal and reviewing the work performed to date. The focus will also be on the work of the TTFs. | | | | | | | |
| 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

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 |
|---------|--|-------------|---|------------------------|
| T2.1 | Plan, build and maintain the JANE website | Yes | Design, construction and maintenance of the website https://jane-project.eu/ . | NHRF, INT |
| T2.2 | Prepare the JANE Dissemination Strategy and Communication Plan | YES | A detailed dissemination and communication plan has been developed both for internal and external mode, addressing all target groups and audiences (D2.2). A document including stakeholders' analysis and internal and external dissemination tools and channels has also been delivered to INT. 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 | NHRF, INT, BiosistemaK |
| T2.3 | Organize the JANE final conference | No | | |

Description of work performed and overview of progress, including any issues

Task 2.1

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). Due to the size and complexity of the consortium, there were difficulties in receiving partners' input and reaching a consensus on the design of the website during the monthly JANE WP leaders' meetings. This affected the website's construction and delivery schedule. To resolve this issue, with the assistance of the coordination team, a dedicated website meeting was organized on March 3rd, final decisions were made, and the JANE website was launched in full capacity at the end of April 2023.

In Jane website the goals, the ambitions, the work packages and the Jane partners are completely presented in a user-friendly way. News about significant meetings and events are being uploaded on News page. The first e-newsletter about the progress of the JA has been issued and uploaded, while stakeholders are able to express their interest in getting involved in JANE activities (Get involved page) and registering to receive newsletters through the Mailchimp platform.

Task 2.2

A detailed dissemination and communication plan was developed both for internal and external mode, addressing all target groups and audiences (D2.2).
 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/former KRONIKGUNE) in March 2023. Following their input, the document was finalized and delivered at the end of M7

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

- Release of the 2nd 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 | 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) |
|---|-------------------------------------|-----------------|------------------|--|---------------------|----------------------------|---|
| | | | | also sent to all of them) and invited to express their interest through the Get involved platform. | | | |
| 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 | | | |

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 |
|---------|---|-------------|---|---|
| 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 three meetings were done:</p> <ul style="list-style-type: none"> - JANE Kick-off Meeting; - JANE 1st Policy Dialogue Satisfaction; - JANE WP & TTF leader meeting. <p>Low survey response rates:</p> <p>Should be addressed by:</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>Internal evaluation is being performed by the WP3 team, the progress of product delivery is being monitored and will be described in the interim evaluation report.</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> | 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 will be 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 October 2023 – 31 March, 2024)

- The interim report (MS 8), due by M14, is anticipated to be submitted on time, or with a delay of less than a month. Brief surveys have been dispatched to WP/TTF leaders to collect valuable insights.
- The 2nd Independent Advisory Board meeting (MS 7) is scheduled for M22, and comprehensive minutes from the meeting will be made available.
- 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 by M24, 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 WP3 leader suggested two external experts for the AB, which 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 provided valuable insight and discussion of several aspects of the JANE project, including the structure and progress of WP1, evaluation activities in WP3, sustainability efforts in WP4 and insights from the previous 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. 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 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

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 |
|---------|--|-------------|--|--|
| 4.1 | Mapping and analysis of existing networks | Partially | <p>Biosistemak (BS) has built a 'Comparative Framework for European networks' for the definition, analysis and validation of European networks, organizations, and societies in the cancer field. WP4 members validated this framework. Based on this framework BS reviewed and analysed a total of 15 networks, organizations, and societies. Moreover, this analysis has been peer reviewed and completed by WP4 members, and is available on request.</p> <p>BS is currently conducting a global comparative analysis of the 15 networks. The results of this comparative analysis will set the base for the study of the key dimensions related to the sustainability of the NoEs and will be complemented with the work done in Task 4.2 'Sustainability strategy of the Networks of Expertise' (see below) serving as input for the MS10 'Sustainability strategy of NoEs', planned by Month 18.</p> | BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL DKFZ, OOI, INT UNICANCER, ICO, IDIVAL, CIBER, HSJD |
| 4.2 | Sustainability strategy of Networks of Expertise | Partially | <p>BS will complete and extend the results obtained from the analysis conducted in the previous Task 4.1 with more relevant information obtained from health research and surveys and/or interviews conducted with WP5-10 leaders under this Task 4.2.</p> <p>The work in this task will start in January 2024 and the results will also serve as input for the MS10 'Sustainability strategy of NoEs'.</p> | BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL DKFZ, OOI, INT UNICANCER, ICO, IDIVAL, CIBER, HSJD |
| 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 composed 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 the Joint Action and also gather their initial thoughts about the NoEs. Finally, 13 meetings were held and three other members were contacted by email.</p> | BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL DKFZ, OOI, INT UNICANCER, ICO, IDIVAL, |

| | | | | |
|---|------------------------|-----------|---|--|
| | | | <p>After that, the date for the first Policy Dialogue was set at 3 October, 2023 and the main discussion topics have been defined: “How to build potential alliances & synergies in the European ecosystem” & “How to ensure NoEs’ alignment with European and National policies”. A second Policy Dialogue will be organised in 2024.</p> <p>The main conclusions gathered in these meetings will be included in the official Deliverable, D4.1 ‘Policy recommendations on sustainability’ scheduled for month 24 of the project.</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. Proposed solutions: extending the final nomination of Policy Board members throughout the project (representative from Norway is still missing) and open up the members’ profiles also leaving open the possibility to change the representatives for each country at a later stage.</p> | CIBER, HSJD, SAM LT |
| 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 will be held on 16 November in a hybrid format and the second Stakeholder Forum will follow in 2024.</p> <p>There were difficulties in nominating representatives of all MS participating in JANE. Proposed solution: leaving open the possibility to include more members to the Stakeholder matrix during the life of the project.</p> | BS, CNAO, INT-NA, IOV, CIPH, INCA, BMG, OIL DKFZ, OOI, INT UNICANCER, ICO, IDIVAL, CIBER, HSJD |
| 4.5 | Policy recommendations | Partially | <p>This task is related with 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, INT-NA, IOV, CIPH, INCA, BMG, OIL DKFZ, OOI, INT UNICANCER, ICO, IDIVAL, CIBER, HSJD |
| Description of work and overview of progress, including any issues | | | | |
| <p>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</p> | | | | |

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 12 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.

Task 4.2 Sustainability strategy of Networks of Expertise

The results obtained from the analysis conducted in Task 4.1 will set the base for the study of the key dimensions related to the sustainability of the NoEs. Moreover, relevant information will be obtained from health research and surveys and/or interviews conducted with WP5-10 leaders. This task has not started yet but will accompany and extend the work done in Task 4.1.

Task 4.3 Policy Board and Policy Dialogues

During the first 12 months of the JANE project, 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. The date has been set at: 3 October 2023 and the main discussion topics have been defined: "How to build potential alliances & synergies in the European ecosystem" & "How to ensure NoEs alignment with European and National policies".

Task 4.4 Stakeholder Forum

During the first 12 months of the JANE project, 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. The date has been set on 16 November, 2023 in Barcelona, back to back with the annual JA JANE meeting.

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 October 2023 – 31 March, 2024)

Task 4.1 Mapping and analysis of existing networks

- Complete the global analysis of the mapping task. The global analysis will include a comparison of the 8 dimensions included in the framework, key features and weaknesses of the organizations analysed. Obtaining of main conclusions
- Summarise the lessons learnt from the analysis of key aspects to ensure the sustainability of JANE NoEs

Task 4.2 Sustainability strategy of Networks of Expertise

- Define key sustainability dimensions derived from the analysis conducted in Task 4.1
- Conduct interviews with representatives of the examined organizations or other interested groups (e.g., CRANE JA) to gather additional input
- Analyse documentation from health research to obtain additional insights
- Prepare a strategic document detailing the next steps and long-term activities of the NoEs

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
- Organize the first Stakeholder Forum (16 November, 2023)
- Make an intermediate update to the Stakeholder Matrix members
- Organize the second Stakeholder Forum (2024)

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 will include the results of Task 4.1 'Mapping and analysis of existing networks' complemented with key insights obtained in a workshop with representatives of the analyzed networks and also the leaders of JANE's NoEs as part of Task 4.2 'Sustainability strategy of the Networks of Expertise'. This milestone will include information about the key dimensions to ensure the NoEs' future mechanisms for sustainability, the next steps and long-term activities of the NoEs. | | 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 be a place for discussion that facilitates 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 JA 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. |

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 rates (>20 per 100,000/year) and low survival (relative survival ≤40% at 1 year, ≤30% at 3 or 5 years after diagnosis). 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 by WP5 leader – Prof. Iwona Lugowska and accepted by 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 Institute de Cancer (INCa)</p> <p>The list of experts was prepared and sent to the Coordinator.</p> | MSCI, NIPH, EURACAN, BS, 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 relating to pilot pancreatic cancer NoE and its scaling up to other poor prognosis cancers was organised</p> | MSCI, INCA, EURACAN, BS, IDIVAL, NHRF, INT |
| 5.3 | NoE Governance development | Yes | <p>PPC governance model was developed based on the EURACAN governance model and agreed on at working group meetings – discussion about aims, partners' roles, future activities and their impact on poor prognosis cancer care and pancreatic cancer care in particular</p> | MSCI, EURACAN, BS, IDIVAL, NHRF, INT |
| Description of work and overview of progress, including any issues | | | | |
| <p>During the kick-off meeting, the WP Leader – Prof. Iwona Lugowska - presented the concept for PPC NoE to be governed as the domain model developed by EURACAN.</p> <p>Online meetings were held where NoE PCC experts in collaboration with INCa developed the final definition of poor prognosis cancers, which is considered to be a defined cancer population with 5-year overall survival below 33%. The mission of the NoE on PPC was established: to increase the survival rate of patients with PPC at least above 33%. The group decided to run a pilot NoE PPC dedicated to pancreatic cancer since the 5 year overall survival in this group is around 10%. There is a need to increase the quality of care, as well as better understand the tumour biology enabling introduction of innovative therapies, personalised prevention and early detection. The Pancreatic cancer group was formed.</p> <p>Existing models of pancreatic cancer were evaluated for current and future networking and existing initiatives dedicated to pancreatic cancers were mapped.</p> | | | | |

There was consensus about building a multidisciplinary group gathering expertise, professionals from different specialisations, PAGs and societies or institutions representing the healthcare systems across Europe. The list of experts involved in model WP5 Poor Prognosis Cancers was prepared.

The Pancreatic cancer working group revised the deliverables and the set of standards on early diagnosis, guidelines and education produced by IPAAC (e.g. the patient pathway; <https://www.ipaac.eu/res/file/outputs/wp10/patient-pathway-template-pancreas.pdf>). Four domains for pancreatic cancer NoE were defined: research and innovation (led by Prof. Marta Mańczuk), clinical care (Prof. Michel Ducreaux), policy and patient engagement (Prof. Joseph Borrás), education & training (led by Prof. Nuria Malats) and Piero Rivizzigno as patient representative.

Prof. Matthias Lohr, in collaboration with Dr. Ana Dugic, will oversee the actions of all four domains.

The Pancreatic working group developed PPC governance model based on the EURACAN governance model.

Results achieved during the period of 01/10/22 to 30/09/23:

- Definition of scope of the network
- Definition of expertise needed
- Establishment of the pilot dedicated to pancreatic cancer
- Development of PPC Governance model

Other issues:

It was difficult to reach a final consensus on the definition of poor prognosis cancers and selection of the best model of cooperation. With the most pragmatic approach developed in collaboration with INCa these problems were overcome.

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

- Identification of the endorsement criteria for healthcare providers, organisations and experts willing to join poor prognosis cancer NoE. The expert working group will agree on required endorsement criteria for centre selection. The application criteria for joining the NoE will be defined at working group meetings and final document produced, critically evaluating the ERN experience.
- Launch of an expression of interest call and selection of applicant sites based on endorsement criteria.
- Commencement of discussions about future activities of the PPC NoE and pilot pancreatic cancer NoE.

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 |
| 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: <ul style="list-style-type: none"> - 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.</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 - its activities - its potential partners - its governance - its sustainability beyond 2 years. incl. 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), that represent a way of organising the 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) | |
| 6.5 | Scoping of sites (OUH, NoE) : Scoping the potential centres whose participation in the palliative care NoE may be beneficial | Partially | Direct scoping of the sites in terms of a survey / interviews has been reconsidered. Two important aspects apply: 1: A NoE should not get directly involved in clinical care, but serve as a source of expertise for managers, administrative personnel and multiprofessional clinicians regarding the implementation of the principles of palliative care into cancer care at different health care levels 2. We have decided to use the consortium/WP participants to provide the necessary information about the state of palliative care integration at the different sites in JANE1. This information may be supplemented by more detailed scoping/statistics in the potentially forthcoming JANE2 | |
| 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 | |
| 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 actions to evaluate cost/efficacy | In progress | Work in progress, will among other sources make use of the work conducted in the working groups. | |

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 October 2023 – 31 March, 2024)

- The main activities relate to the work performed in the different WGs. Group meetings will be held on a regular basis and have already started. Mutual meetings for all WP6 participants, and smaller meetings between the WG leads and the leads of WP6 will be held to ensure progress and active engagement. Each group will provide 1-2 pages 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 due in Month 24.

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 |
|---|---|-----------------|------------------|--|---------------------|-----------------------------|--|
| MS6.1 | List of leading experts | 6 | OUS | The participants constituting the list of experts of WP6 has been defined | | M3 | Submitted to the JANE steering group |
| MS6.2 | List of NOE objectives | 6 | OUS | The objectives have been defined and explicitly conceptualized in the endorsement criteria | | M5 | Submitted to the JANE steering group |
| MS6.3 | Endorsement criteria/ Definition of the scope of NoE | 6 | OUS | Endorsement criteria: A specified description and list of endorsement criteria published on the JANE website | | M10 | Published, approved by coordination steering group |
| 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 - indicators of efficacy/ cost/efficacy evaluation criteria interplay with MSs, other EU networks, CCCs, patients Paper version in English |

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>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 |
| 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, Sciensano, INCA, ACC |
| 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) | |

| | | | | |
|-----|---|---------------|---|--|
| 7.3 | Definition of the scope of the survivorship NoE | Yes | The survivorship definition provided by ESMO was approved by members of WP7 | |
| 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. | |
| 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. | |
| 7.6 | Site and relevant stakeholder selection | Yes | Contact with bigger organisations for closer collaboration ex ESMO, SIOPE, OECI, PanCare, ECO | |
| 7.7 | Planning survivorship NoE deliverables | In progress | Still working on developing the core outputs of NoE: clinical practice guidelines or initiatives to integrate existing ones, on survivorship-specific issues (including the cross-border use of Cancer Smart Card), educational programs for health professionals and patient advocates, including patient empowerment strategies pathway optimisation and testing across EU. | |
| 7.8 | NoE governance development | To be started | | |

Description of work and overview of progress, including any issues

The Survivorship team's approach is based on brainstorming during the meetings. They initiate contacts with potential partners, organisations, societies, and advocacy groups. They are 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.

Several stakeholders were involved in the discussions:

- 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 (1 October 2023 – 31 March, 2024)

As indicated above, the team is currently also working on the Deliverables. In the near future the Governance structure of the NoE on Survivorship will be created.

| 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) |
| 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 | 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 | | | | |
| <p>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:</p> <ul style="list-style-type: none"> - 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 | | | | |
| <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 |
| 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 | <p>Agenda and main Activities:</p> <ol style="list-style-type: none"> 1. Needs Assessment and Gap Analysis: <ul style="list-style-type: none"> - Evaluate existing personalised primary prevention strategies globally. - Identify gaps and areas for improvement in current approaches. 2. Framework Development: | IOCN, INCA, Sciensano, BS, Unicancer, MSCl, INT |

| | | | | |
|-----|---|-----|--|---|
| | | | <ul style="list-style-type: none"> - Establish a conceptual framework for personalised primary prevention. - Define key components and methodologies for individualised interventions. <p>3. International Collaboration:</p> <ul style="list-style-type: none"> - Foster collaboration among consortiums, organisations, and research centres. - Facilitate knowledge exchange through conferences, webinars, and collaborative projects. <p>4. Data Sharing and Analysis:</p> <ul style="list-style-type: none"> - Develop protocols for secure data sharing among participants. - Analyse collective data to derive insights for personalised prevention strategies. <p>5. Policy Advocacy:</p> <ul style="list-style-type: none"> - Advocate for policies that support the integration of personalised prevention approaches. - Engage with policymakers to promote awareness and implementation. | |
| 8.3 | Define the criteria for participation and identify participants in the network | Yes | <p>Criteria for Participation and Identified Participants:</p> <p>1. Expertise:</p> <ul style="list-style-type: none"> - Individuals and organisations with expertise in health, medicine, genetics, and preventive care. - Researchers with a focus on personalised medicine and primary prevention. <p>2. Diversity:</p> <ul style="list-style-type: none"> - Inclusion of participants from various geographical regions and cultural backgrounds. - Representation from academia, healthcare institutions, and non-profit organizations. <p>3. Commitment:</p> <ul style="list-style-type: none"> - Participants committed to actively contribute to the NoE's activities. - Willingness to collaborate on projects and share relevant resources. | IOCN, INCA, Sciensano, BS, Unicancer, MSCl, INT |
| 8.4 | Conduct meetings and liaise the stakeholders involved in this NoE | Yes | <p>Meetings and Stakeholder Liaison:</p> <p>1. Regular Meetings:</p> <ul style="list-style-type: none"> - Conduct monthly virtual meetings to discuss progress, challenges, and upcoming activities. - Rotate meeting times to accommodate participants from different time zones. <p>2. Stakeholder Engagement:</p> <ul style="list-style-type: none"> - Establish communication channels with key stakeholders, including government agencies, industry partners, and advocacy groups. - Seek feedback and input from stakeholders to enhance the impact of the NoE. | IOCN, INCA, Sciensano, BS, Unicancer, MSCl, INT |
| 8.5 | Propose actions, initiatives and consolidate materials relevant for the project | Yes | <p>Proposed Actions and Initiatives:</p> <p>1. Project Collaborations:</p> <ul style="list-style-type: none"> - Initiate collaborative research projects among NoE participants. - Seek funding opportunities for joint initiatives. <p>2. Public Awareness Campaigns:</p> <ul style="list-style-type: none"> - Develop and implement public awareness campaigns on personalised primary prevention. - Utilise social media, webinars, and other channels to disseminate information. | IOCN, INCA, Sciensano, BS, Unicancer, MSCl, INT |

| | | | | |
|---|---|-----|---|---|
| | | | 3. Resource Consolidation: <ul style="list-style-type: none"> - Create a centralised repository for research materials, best practices, and tools. - Foster a culture of resource-sharing among participants. | |
| 8.6 | Wrap up of key deliverables for the first 12-months and define upcoming actions | Yes | Wrap-Up of Key Deliverables for the first 12 months: <ol style="list-style-type: none"> 1. Progress Report: <ul style="list-style-type: none"> - Summarises achievements, challenges, and lessons learned during the initial 12 months. - Provides recommendations for improvement and refinement of activities. 2. Documentation: <ul style="list-style-type: none"> - Compile a comprehensive report consolidating research findings, collaborative projects, and policy advocacy efforts. 3. Upcoming Actions: <ul style="list-style-type: none"> - Outline a roadmap for the next 12 months, detailing upcoming projects and priorities. - Seek participant input on future directions and initiatives. | IOCN, INCA, Sciensano, BS, Unicancer, MSCI, INT |
| Description of work and overview of progress, including any issues | | | | |
| <p>Over the past months, the dedicated team for the NoE on Personalised Primary Prevention has 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 | | | | |
| Next Steps (1 October 2023 – 31 March, 2024) | | | | |
| <ol style="list-style-type: none"> 1. Refinement of Research Initiatives: <ul style="list-style-type: none"> - Building on the established conceptual framework, the next step involves refining and prioritising specific research initiatives within the Network of Expertise on Personalised Primary Prevention. This includes identifying key focus areas, setting research objectives, and allocating resources effectively to address gaps in knowledge and practice. 2. Implementation of Collaborative Projects: | | | | |

- Actively implement the collaborative research projects that have been initiated, ensuring seamless coordination among participants. Monitor progress, share findings, and encourage continuous engagement to foster a culture of knowledge exchange and collective problem-solving.

3. Expansion of Stakeholder Engagement:

- Broaden the network's reach by expanding stakeholder engagement. This includes reaching out to additional organisations, government agencies, and industry partners who can contribute valuable insights or support the network's goals. Develop strategic partnerships to enhance the impact and influence of the personalised primary prevention initiatives.

4. Continuous Improvement of Communication Channels:

- Evaluate the effectiveness of communication channels established within the network. Identify areas for improvement and implement enhancements to facilitate smoother information flow, collaboration, and engagement among participants. Ensure that all stakeholders remain informed about ongoing activities, achievements, and upcoming milestones.

5. Preparation for Upcoming Events and Initiatives:

- Anticipate and plan for upcoming events, conferences, and initiatives that align with the network's goals. Develop a roadmap for the next 12 months, outlining specific actions, timelines, and responsibilities. Ensure that all participants are well-prepared and engaged in the successful execution of planned activities.

By focusing on these next steps, the Network of Expertise on Personalised Primary Prevention can continue its journey towards advancing tailored approaches to primary prevention and making a meaningful impact on global health and well-being.

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 involves finalizing the conceptual framework for personalised primary prevention. It includes defining key components, methodologies, and guidelines for implementing individualised interventions. The completion of this milestone signifies a critical step toward providing a structured, comprehensive approach to personalised prevention strategies. | 4 | List of NoE objectives available |

| MS33 | WP8 Endorsement criteria | WP8 | IOCN | <p>Criteria Setting for Participation in the Future Network for Centres, Experts, and Healthcare Providers in the Context of Personalised Primary Prevention</p> <p>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.</p> | 10 | List of endorsement criteria published on the JANE website | |
|---|-------------------------------------|-----------------|------------------|--|---------------------|--|--|
| MS34 | WP8 Expression of interest | WP8 | IOCN | | 12 | Documentation of the expression of interest (launch, event minutes, if held, expression spread, etc.). | |
| 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 as a disease that should be prevented, early/timely diagnosed 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 <p>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 more and more important to support clinical decisions, especially in regard to biotherapies and advanced therapies, while of course 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.</p> <p>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.</p> <p>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),</p> | | |

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 | At the WP9 Kick-off-meeting in Paris on 11 th January 2023, 6 use cases were selected and discussed that helped to define the scope of the NoE on Omics. Participants also included ECRIN | Sciensano, INCA, IJB, INT DKFZ/NCT, UZ Gent, ICB, ICO, MDH, IOCN, IRST, OECl, IDIVAL FAVO/ ECPC, NHFR, Unicancer |
| 9.2 | Identification of participants' endorsement criteria | Yes | WP9 organised a 1st meeting on 4 th 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 19 th September 2023 and the final results will be presented at the mid-term meeting in Barcelona on 16 th and 17 th November. 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. | Sciensano, INCA, IJB, INT DKFZ/NCT, UZ Gent, ICB, ICO, MDH, IOCN, IRST, OECl, IDIVAL FAVO/ ECPC, NHFR, Unicancer |
| 9.3 | Scoping of service providers and/or centres | Partly | Discussion of the partners of the future NoE on OmiCs during the online meeting on 11 th January 2023. | Sciensano, INCA, IJB, INT DKFZ/NCT, UZ Gent, ICB, ICO, MDH, IOCN, IRST, OECl, IDIVAL FAVO/ |

| | | | | |
|---|--|--------|--|--|
| | | | | ECPC, NHFR, Unicancer |
| 9.4 | Service provider and/or centre selection | No | Next steps | |
| 9.5 | Identification of NoE deliverables | Partly | Discussion of the mission and vision of the future NoE on OmiCs during the online meeting on 24 th March 2023.March. | Sciensano, INCA, IJB, INT DKFZ/NCT, UZ Gent, ICB, ICO, MDH, IOCN, IRST, OECl, IDIVAL FAVO/ ECPC, NHFR, Unicancer |
| 9.6 | Governance development | No | Next step: this will be elaborated at the next joint meeting with WP10 on 20th February 2024. Online meeting between leaders of WP0 and WP10 on 15 th September 2023: decision of co-lead of WP9 and WP10 by Sciensano and Unicancer | |
| Description of work and overview of progress, including any issues | | | | |
| <p>13/12/22: (online)</p> <ul style="list-style-type: none"> - methodology - members of WP9 <p>11/01/23: 1-day F2F kick-off (Paris)</p> <ul style="list-style-type: none"> - scope definition - selection of 6 use cases - partners of the future NoE <p>24/03/23: (online)</p> <ul style="list-style-type: none"> - Technology Readiness Assessment of the different omics (survey) - Mission and Vision <p>04/07/23: (online)</p> <ul style="list-style-type: none"> - methodology for endorsement criteria <p>15/09/23: (online between WP leaders of WP9 and WP10)</p> <ul style="list-style-type: none"> - methodology for endorsement criteria <p>04/07/23: 1-day F2F joint meeting with WP10 (Paris)</p> <ul style="list-style-type: none"> - endorsement criteria and maturity levels - Synergies of the NoEs Omics and High Tech Medical Resources in the Cancer Ecosystem <p>15-16/11/23: F2F mid-term meeting (Barcelona)</p> | | | | |

- Presentation of the progress of the WP on Omics in tandem with WP10 on High Tech Medical Resources

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

- Governance structure and sustainability of the NoE: joint effort with WP10 (F2F meeting on 20th February 2023)
- Prioritisation of the deliverables of the NoE, by domains (4)
- Scoping and selection of service providers and/or centres
- Documentations of the expression of interest

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 | | |
| MS40 | Omics NoE Deliverables | WP9 | Sciensano | List of NoE deliverables available. | 22 | | |
| 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 | | |
| Deliverable No (continuous numbering linked to WP) | Deliverable Name | Work Package No | Lead Beneficiary | Type | Dissemination Level | Due Date | Description (including format and language) |

| | | | | | | | |
|---------|-----------|-----|-----------|------------------|--------|----------------|--|
| | | | | | | (month number) | |
| 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.</p> <p>The specific objectives will include the definition of:</p> <ul style="list-style-type: none"> - 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>The team will have to include flexibility and prospection into its governance and sustainability strategy in order to remain at the forefront of innovation.</p> | 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>The team intends to work closely with national competent authorities while developing the JANE 2 proposal in order to identify the most relevant partners of the future NoE on hi-tech medical resources able to cover the 5 sub-groups of resources.</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) | No | Scoping (prioritising advanced technologies and current needs) the potential centres and service providers whose participation in the NoE may be beneficial | |
| 10.4 | Service providers / centers selection (INCA, UNICANCER, FHF, task forces) | No | Launching an expression of interest call. | |

| | | | | |
|---|--|----|---|--|
| 10.5 | Identification of NoE Deliverables (INCA, UNICANCER, FHF, task forces) | No | Developing the NoE deliverables: continuous mapping of existing high-profile technologies in health care across EU MS; determining standards for each thematic/advanced technology; developing strategies for progressive coverage of needs and integrating the use of cross-border research; providing medical and patient education; road mapping to scale up the use of advanced technologies. | |
| 10.6 | Governance development (Task forces, INCA, UNICANCER, FHF) | 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 | | | | |
| <p>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.</p> <p>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).</p> <p>Several stakeholders were involved in the discussions:</p> <ul style="list-style-type: none"> - 'Aghia Sophia' Children's Hospital -Region Zealand - University Hospital Roskilde/Næstved | | | | |
| Next Steps (1 October 2023 – 31 March, 2024) | | | | |
| <p>T10.3 - Scoping of service providers / centres</p> <p>T10.4 - Service providers / centre selection</p> <p>T10.5 - Identification of NoE Deliverables</p> <p>T10.6 - Governance development</p> <p>MS44 - WP10 Expression of interest (Documentations of the expression of interest) – M14</p> <p>MS45 - Hi-tech NoE Deliverables (List of NoE-specific deliverables available) – M18</p> <p>MS46 - Hi-tech NoE Governance (Governance strategy available) – M24</p> <p>D10.1 - Hi-tech NoE – M24</p> | | | | |

| 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 | Documentation of expression of interest | | 14 | |
| 45 | WP10 Hi-tech NoE Deliverables | WP10 | Unicancer/ INCa | List of NoE-specific deliverables available | | 18 | |
| 46 | Hi-tech NoE Governance | WP10 | Unicancer/ INCa | Governance strategy available | | 24 | |
| 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 | | | | |
| <p>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.</p> | | | | |
| 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 |
| 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 Unicancer, BS, MFH, INCa, ICO NKUA, IOCN, Sciansano, CIBER, UH Motol, SIOPE |
| 11.2 | Identification of participants | Yes | Identify participants for the NoE including MS, scientific societies, patient associations and definition of the endorsement criteria for participants' selection. | INT, HSJD, OIL Unicancer, BS, MFH, INCa, ICO NKUA, IOCN, Sciansano, CIBER, UH Motol, SIOPE |

| | | | | |
|--|------------------------------------|--|---|--|
| 11.3 | Sites identification | | An expression of interest call will be launched. | |
| 11.4 | Definition of the NoE deliverables | | 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 | | 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 | | | | |
| <p>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.</p> <p>Several stakeholders were involved in the discussions:</p> <ul style="list-style-type: none"> - E.Saloustros (Larissa, Greece) - ESMO-SIOPE AYA Working Group - I. Bozovic (Belgrade, Serbia) - ESMO-SIOPE AYA Working Group - F. Peccatori (Milan, Italy) - ESMO-SIOPE AYA Working Group - Dan.Stark (Leeds, UK) - ENTYAC chair - Owen.Smith (Dublin, Ireland) - SIOPE AYA committee - P.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 | | | | |
| Next Steps (1 October 2023 – 31 March, 2024) | | | | |
| To discuss Expression of interest (Milestone 49) and 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>We defined the list of the objectives of the NoE and the related actions.</p> <p>Objectives:</p> <ol style="list-style-type: none"> 1. Support development of AYA dedicated programme (starting with defining what is a local, a national and an international AYA dedicated programme) 2. Support collaboration between paediatric and adult oncologists 3. Define the referral pathway 4. Develop specific clinical recommendations/ guidelines on AYA specific topics (e.g. age-specific psychosocial support, fertility & sexuality, transition, etc) and different type of cancer across age groups 5. Become the Network where existing health care professional societies, national AYA professional groups, NGOs (patients, advocates and their families) can co-operate 6. Raise awareness of cancer in AYAs 7. Monitor AYA cancer epidemiology, leveraging what is available or underway 8. Define and promote dedicated training on cancer in AYA 9. Support Patient and Public Involvement and Engagement | 4 | List of the NoE objectives |
| M48 | Endorsement criteria | 11 | 1-INT | <p>The team defined the endorsement criteria for:</p> <ol style="list-style-type: none"> a) Health care providers, b) Scientific and professional societies/ networks/ research groups, c) Patient advocacy groups. | 8 | List of endorsement criteria |

| | | | | The main criteria will be European scope. For national health care providers, national representativeness/ mandate and expertise on AYA are two additional essential criteria. To keep the future NoE manageable and ensure inclusiveness, the idea is to have a limited number of HCP from each country and to have each EU MS in the NoE. | | | |
|---|---|-----------------|------------------|---|---------------------|---|--|
| M49 | Expression of interest | 11 | 1-INT | To be completed as a next step | 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 | 1-INT | To be completed as a next step | 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 | Key strategic document describing composition and activities and next steps of NoE regarding expertise on AYA with cancer. It will clarify: - 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 Paper version, English. |

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. Widene participation in research and improve the efficiency of research. | | | | |
| 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 |
| 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 that has been reviewed by all WP12 partners. The activities of this task are still ongoing and all WP12 partners are actively involved. Preliminary results are expected to be produced by January 2024. 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> <p>Part of work done for the desktop search coincided with the summer months and several partners had problems to comply with the deadlines. It is expected that all necessary resources will be collected and additional input will be sought from partners to have available results by January 2024.</p> | BS, OIL, ICO, IDIVAL, CIBER, HSJD, SAS, INT, Unicancer, FHF, MFH, OUS, MSCl, IOCN |
| 12.2 | Establishing clinical research networks (CRN) | No | Global aim of this task is to define effective mechanisms and clarify legal and regulatory requirements to establish clinical research networks between NoEs, CCC, and ERNs; and to promote partnerships and participation mechanisms improving EU-level funding mechanisms, including the Mission on Cancer. | BS, OIL, ICO, IDIVAL, CIBER, HSJD, SAS, INT, Unicancer, FHF, MFH, |

| | | | | |
|------|--|-----------|--|---|
| | | | The methodology to conduct this task has been defined but the activities have not yet started. The estimated date to finalize this task is April 2024 and the conclusions will be included in Deliverable 12.1. | OUS, MSCI, IOCN |
| 12.3 | Proposing guidelines for effective and efficient organization and management of research efforts facilitated by NoEs | Partially | This task consists of the elaboration 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 |

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 of the session, which are uploaded in the JANE WP12 meetings Drive folder.

Regarding the WP12 tasks, during the first 12 months of the project, the efforts of WP12 partners have been focused on the first task of the WP 'Assessing current challenges in research portfolios and integration between health care and research'. In the first WP12 regular meeting partners were asked for input on areas of research needed to cover the daily clinical practice. The information gathered, together with a preliminary literature review, served as input to build a 'Framework of challenges and facilitators of the integration of research and health care'. This framework is based in the Innovative Care for Chronic Conditions (ICCC) which serves as a roadmap for policy development and the redesign of health care systems and facilitates comparative analysis and the identification of best practices.

Following this preliminary review, 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.

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 to assess current challenges in integration between health care and research
- Discussion, selection and definition of the methodology for the literature review (systematic review) and desktop search "Search Strategy document"
- Identification of resources for the desktop search (identify/select/review)
- Identification of the search strategy (terms) for the systematic review

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 October 2023 – 31 March, 2024)Task 1. Assess current challenges in research portfolios and integration between healthcare and research

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

Task 2. Establish clinical research networks (CRN)

- Define the methodology for the establishment of the CRNs
- Define the state of the art of the CRNs in Europe
- Organize thematic group for discussion

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

- Develop the 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 |
|---|------------------|-----------------|------------------|-------------|---------------------|----------------------------|--|
| N/A | | | | | | | |
| Deliverable No (continuous numbering linked to WP) | Deliverable Name | Work Package No | Lead Beneficiary | Type | Dissemination Level | Due Date | Description (including format and language) |

| | | | | | | | |
|----------|---|----|--------------|---------------------|-------------|----------------|--|
| | | | | | | (month number) | |
| Del 12.1 | Recommendations for effective and efficient organization and management of research efforts | 12 | BIOSISTE MAK | 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 monitoring 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 | Yes | The team has successfully identified commonalities and differences between 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, MSCl, 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 |
|---|--|-----------------|---|-------------------|---------------------|----------------------------|--|
| 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 October 2023 – 31 March, 2024) | | | | | | | |
| WP13 – TTF2 has made substantial progress in understanding the intricacies of MS health systems, identifying commonalities and differences, and leveraging existing solutions within the JANE project. The results achieved provide a solid foundation for the development of tailored integration solutions that consider the unique contexts of each MS within the broader EU networking framework. | | | | | | | |
| 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 | | | | |
| This TTF will focus on the objective 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 | Ongoing | Recruiting expertise on: <ul style="list-style-type: none"> - secondary use of data for cancer care (also covering how to allow some primary use of data without a specific consent). - how to achieve institutional governance of data for AI in cancer for trustworthy AI - how to align national strategies | OUS, INCa, VULSK, IDIVAL, SAS, INT |
| 14.2 | Mapping partners' infrastructures to interact within European space | Ongoing | It is essential to identify relevant infrastructures and plans for use in the cancer context, including ELIXIR, ECRIN and BBMRI, in order to realize data aggregation and computations as required. Currently, the cancer field has established many biomedical research resources, but less in the context of cancer care in Europe. | OUS, INCa, VULSK, IDIVAL, SAS, INT |
| 14.3 | Mapping available options for computation | Ongoing | Where to compute: European Health Data Space and others. Relationship between central and distributed systems: ELIXIR, European Open Science Cloud, 1+MG and others. How to compute: Develop cancer network competence within: GPU-based computing in context of deep neural nets. Heavy parallel computing. Algorithmic: deep learning technology (DELT) | OUS, INCa, VULSK, IDIVAL, SAS, INT |

| 14.4 | Mapping of interoperability expertise | Ongoing | Interoperability is essential for any machine-based approach to cancer research and care. This includes standards for such aspects as file formats, APIs, portability (container technology). Some of these elements are developed by community efforts, such as the GA4GH and similar initiatives. Standardised digital EHR collecting minimum clinical data (exchange format) which will be used for AI algorithms, e.g. for trajectory analyses. Quality control aspects and development of curated data sets. Recently, DOME recommendations were published, being a set of community-wide recommendations for reporting supervised machine learning-based analyses applied to biological studies. Broad adoption of these recommendations will help improve machine learning assessment and reproducibility. | | | | OUS, INCa, VULSK, IDIVAL, SAS, INT |
|--|---------------------------------------|-----------------|---|-------------|-----------------------------|-----------------------|------------------------------------|
| Description of work and overview of progress, including any issues | | | | | | | |
| Task 14.1: Meetings were held with relevant ESFRI infrastructures, meetings in TTF | | | | | | | |
| Task 14.2: Survey of infrastructure ongoing, lectures and meetings in TTF, meetings with other WPs, particularly WP9/10, evaluating gaps in IT/AI capabilities in coordination with their technology assessment. | | | | | | | |
| Task 14.3: Survey of infrastructure ongoing. TTF is currently addressing AI aspects. | | | | | | | |
| Task 14.4: Planning of activities initiated | | | | | | | |
| Any issues | | | | | | | |
| Limited scientific community. This has led to the survey, in order to both engage the TTF and the partners to develop a better understanding. | | | | | | | |
| Next Steps (1 October 2023 – 31 March, 2024) | | | | | | | |
| Move forward with the set tasks. | | | | | | | |
| 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 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. |

Work Package 15 The ERN model

| Work Package 15: Transversal Task Force: The ERN model | | | | |
|---|--|--------------------------|---|--|
| Duration: | M1- M24 | Lead Beneficiary: | Unicancer / INCa | |
| Objectives | | | | |
| This TTF will assess current rare cancer ERNs' functioning 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. | | | | |
| 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 |
| 15.1 | Assessment of ongoing problems and challenges in regard to optimal | Partially | - An assessment will be made of ongoing problems and challenges in regard to optimal functioning of current ERNs on rare cancers will be made, in light of the work previously done by JARC and in the perception of current ERNs | Unicancer, INCa INT, OIL, BS, CIBER, HSJD, |

| | | | | |
|------|---|-----------|---|---|
| | functioning of current ERNs on rare cancers | | <ul style="list-style-type: none"> - An inventory will be made of ERNs' main open issues according to JARC's conclusions. - Main open issues will be mapped based on the perception of the four ERNs on cancer: EURACAN, EuroBloodNet, GENTURIS, PaedCAN. Dedicated meetings will be held with each of them and jointly to this end. | SAS, MSCl, OUS, IOCN |
| 15.2 | Assessment of current functioning of ERNs on rare cancers | Partially | <p>An assessment will be made with regard to:</p> <ul style="list-style-type: none"> - integration between health care and research; - integration between ERNs and MSs; - Integration between information-technology infrastructures and artificial-intelligence tools; - sustainability; - patient involvement | Unicancer, INCa INT, OIL, BS, CIBER, HSJD, SAS, MSCl, OUS, IOCN |
| 15.3 | Holding of brainstorming meeting | Partially | A brainstorming meeting will be held to work out innovative solutions to ongoing problems and challenges in collaboration with current ERNs, involving all their multidisciplinary components including patient advocacy groups. | Unicancer, INCa INT, OIL, BS, CIBER, HSJD, SAS, MSCl, OUS, IOCN |

Description of work and overview of progress, including any issues

Task 15.1 Unicancer has engaged 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.

Task 15.2 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 will make more sense to see what we can learn from the ERNs on cancer.

Task 15.3: Four online meetings have been held. Discussions will continue.

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 October 2023 – 31 March, 2024)

Another online meeting will be held to refine the interaction of each NoE with each of the 4 ERNs on cancer, in order to draft recommendations (D15.1 - Recommendations to improve EU cancer care networking in general and specifically for the new NoEs by M24 of the JA).

| 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 | 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 |
| Description of work and overview of progress, including any issues | | | | |
| <p>A literature review was performed, reading various scientific articles and existing methods on patient engagement. An interactive Miro board was established to provide an overview of existing evidence in the form of a mind map tool.</p> <p>A list of direct contacts from patient organizations was drawn up for all partnering countries. Everyone was contacted for an interview. A patient organisation workshop was held on 28 June, 2023 in Brussels.</p> <p>Meetings were held with partner organisations in Belgium, France, Italy, Greece, Hungary and at the European level. The aim was to share experiences on different ways of engaging patients and to hold at least one meeting per country.</p> <p>Discussions were held with the various NoEs to understand their objectives and needs in terms of patient involvement.</p> <p>The team created the basis for a guide that can be used by everyone. The aim is to develop specific tools for NoEs and patient organisations.</p> | | | | |
| Next Steps (1 October 2023 – 31 March, 2024) | | | | |
| <ul style="list-style-type: none"> - Hold a new round of meetings with all leaders - Pilot project: patient involvement guide for WP11 (AYA) - Modifications based on feedback - Adaptation for all NoEs - Development of a guide for patient organizations, patient representatives and patients | | | | |
| 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. |

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 Chiricuță" 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 Chiricuță" 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 Chiricuță" Cluj-Napoca, "About Breast Cancer", 3 rd Edition | | JANE, Reporter Medical, Asociatia Redescopera Fericirea Stop Cancer | <p>The primary objective of the 3rd Edition of the IOCN Magazine: Journal of the Oncology Institute "Prof. Dr. Ion Chiricuță" 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 |
| 3 rd ACCC-Athens Comprehensive Cancer Center Symposium, 3-4/11/2022 | Conference- Oral presentation | Industry, business partners EU institutions Policymakers and authorities, International | Raise awareness on JANE's ambitions and goals | Delivered |

| | | | | |
|--|---|---|---|-----------|
| | | <p>Polymakers and authorities, national Scientists Medical oncologists</p> | | |
| CraNE kick off meeting,4/11/2022 | <p>Meeting Collaboration with EU- funded projects</p> | <p>Beneficiaries of CraNE, Coordinators of related projects/ networks</p> | JANE-CraNE collaboration | Delivered |
| PRC (European Palliative Care research centre) Conference, Nov2022 | <p>Conference, oral presentation</p> | <p>Scientists, multiprofessional clinicians, national managers</p> | Follow-up and updates of JANE, EUonQOL, MyPath as part of OUS portfolio | Delivered |
| Meeting with Board of ESSO, 3/4/2023 | <p>Conference- Oral presentation</p> | <p>ESSO Board members</p> | Raise awareness on JANE's ambitions and goals | Delivered |
| CraNE-JANE Coordinator meeting, 11/4/2023 | <p>Meeting Collaboration with EU- funded projects</p> | <p>Internal Coordinator meeting</p> | JANE-CraNE collaboration | Delivered |
| Scientific Council Meeting of ESTRO, 18/4/2023 | <p>Conference- Oral presentation</p> | <p>ESTRO Scientific Council Members</p> | Raise awareness on JANE's ambitions and goals | Delivered |
| Meeting to establish collaboration with ECO | <p>Meeting</p> | <p>Members of the European Cancer Organisation (ECO)</p> | <p>Collaboration with ECO in the field of Survivorship</p> | Ongoing |
| Reducing disparities across EU (26-27/04/23) | <p>High Level Stakeholders Conference</p> | <p>EU institutions and members of EU parliament scientist, International policy makers and authorities, Oncology societies and organisations, Industry, Business partners</p> | <p>Networking in relation "Tackling the implementation gap: SWOT"</p> | Delivered |
| Poor prognosis cancer meeting related to Swedish presidency | <p>International policymakers and authorities</p> | <p>PPC - presentation in relation to PPC NoE</p> | | Delivered |
| European Week Against Cancer, 25-31/5/2023 | <p>Conference- Webinar, Factsheet</p> | <p>Industry, business partners EU institutions Policymakers and authorities, International Policymakers and authorities, national Scientists Medical oncologists</p> | Raise awareness on JANE's ambitions and goals | Delivered |

| | | | | |
|--|-------------------------------------|--|--|-----------|
| Europe's Beating Cancer Plan - First EU4Health Project Showcase, 25/5/2023 | 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 | 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 | 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) | Meeting | "Follow up" | Organization of survivorship care at the national level | Ongoing |
| We Infoday Joint Action del Programma EU4Health, 15/6/2023 | Meeting | Italian researchers/ clinicians | Raise awareness on JANE's ambitions and goals | Delivered |
| OECI Oncology Days - European Cancer Strategic Initiatives, 15/6/2023 | 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 | Conference- Oral presentation | Experts | Ongoing EU4Health and Horizon Europe projects | Delivered |
| MyPath general assembly meeting, June-23 | 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) | 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 | 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 | 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 | 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 | 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 | Conference- Oral presentation | Members of ECO | Raise awareness on JANE's ambitions and goals | Delivered |
| ENTYAC meeting, 20/09/2023 | Meeting | | | Delivered |
| STRONG-AYA Stakeholders meeting | Meeting | | | Delivered |
| Anticancer treatment at end-of-life, ESMO, October 2023 | 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?" | Webinar Green Horizon organised by National Contact Point for EU (26/10/23) | Policy makers and national authorities Mission Cancer National Societies | Raise awareness on projects in the field of Oncology in general | Delivered |
| Meeting of Italian AIOM-AIEOP Working Group on AYAs | Turin, 14th November 2023 | AIOM-AIEOP steering committee | | Delivered |
| Stakeholder Forum (16/11/2023) | Conference | JANE leaders | Summary and further plans | Delivered |
| Meeting on implementation of Survivorship Passport (21/11/2023) | Meeting | PanCare | Implementation of Survivorship Passport, future collaboration | Ongoing |
| Cooperation request | Collaboration with EU societies | ESMO | Collaboration in case of guidelines including Survivorship issues | Ongoing |
| Scientific paper (Task 4.1) | Other | Scientists [Other] | The objective is to present the 'Comparative Framework for European networks' developed by BS and the results of the mapping analysis that will | Ongoing |

| | | | | |
|-------------------------------------|-------|-------------------------|--|---------|
| | | | serve as input to define the recommendations for the sustainability of the NoEs | |
| Systematic review paper (Task 12.1) | Other | [Scientists] [Other] | The objective is to map available evidence of potential gaps that need to be addressed to improve the integration between health care and research. This systematic review will identify strategies, barriers, and facilitators to integrate research into health care practice. | Ongoing |

Communication activities

| Communication activities | | | | | |
|---------------------------------|---|-------------------------|---------------------------------|--|-----------|
| Communication activity name | Description | Who? Target audience | How? Communication channel | Outcome | Status |
| JANE Logo | Digital material | All target groups | JANE website and all activities | Visibility | Delivered |
| OECI Magazine No.2-2022 | Article | All target groups | Article | | Delivered |
| JANE-1st E-Newsletter-June 2023 | Release of the 1st e-newsletter focusing on the six-month progress of JANE. | All target groups | Website, E-mailing | 90 registrations on the Mailchimp platform to receive the newsletter | Delivered |
| JANE Flyer | A 4-page promotional flyer was created including key information on JANE project. | All target groups | Print material (brochure) | 150 copies were sent to the European Cancer Summit, ECO, November 15th-16th 2023, Brussels | Delivered |

| | | | | | |
|--|---|---------------------|-------------------------------------|---|-----------|
| | | | | 50 copies distributed at JANE Plenary meeting, November 16th -17th, 2023, Barcelona | |
| EU Health Policy Platform (EUHPP) – Agora | | All target groups | E-material to be uploaded | | Ongoing |
| Targeted meetings with oncologists in Greece | Meetings | Medical oncologists | Physically, tele-meetings regularly | Coordination and interaction at national level | Ongoing |
| Collaboration with Hellenic Ministry of Health-CraNe team | Meetings | Policymakers | Regular meetings tele-meetings | Coordination and interaction at national and European level | Ongoing |
| Collaboration with CraNE and policymakers in Norway | 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: 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 | 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 | Website post | All target groups | website | Visibility | Delivered |
| Unicancer's posts in LinkedIn (from the most recent to the less one): 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 https://www.linkedin.com/feed/update/urn:li:activity:7059104515714605056?utm_source=share&utm_medium=member_desktop https://www.linkedin.com/feed/update/urn:li:activity:7056567792329728000?utm_source=share&utm_medium=member_desktop https://www.linkedin.com/feed/update/urn:li:activity:7051494285216509952?utm_source=share&utm_medium=member_desktop https://www.linkedin.com/feed/update/urn:li:activity:7032680260521316352?utm_source=share&utm_medium=member_desktop https://www.linkedin.com/posts/muriel-santoro-b3116754_fondazioneircc-jane-eucancerplan-activity-6998270452523528192-qhYr?utm_source=share&utm_medium=member_desktop | Social media posts | All target groups | website | Visibility | Delivered |
| Website publication: 'Kronikgune attends the kick-off meeting of the European project JANE' | Publication of a new about the kick-off meeting of JANE | | Website | Website visitors | Delivered |
| Website publication: "European Week Against Cancer (EWAC)" | Publication of new about the EWAC including highlights of the activities | | Website | Website visitors | Delivered |

| | | | | | |
|--|--|---|---|---|--|
| | conducted by BS in the WP that they lead | | | | |
| 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 |
| Online team meeting (WP5) | Online meeting with Ministry of Health representative (22/08/23) | National authorities- Ministry of Health | Online team meeting | Visibility in Poland | Delivered |
| Website (WP5) | Information re JANE project | National authorities Local authorities | MSCI Website | Visibility in Poland | 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) | Finalising Program for the PRC conference in February 2024 | Scientists, Clinicians- multi-professional, & lay organisations | Meeting with workshop | Plenary lecture, parallel lecture/workshop | Ongoing |
| Meetings with Patient Organizations | 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 | 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] |
| | | WP6 Palliative Care | Online | | |
| | | WP8 Personalized Primary Prevention | Online | | |
| | | WP9 Omics NoE for cancer | In-person | | |

| | | | | | |
|--|--|----------------------|-----------|--|--|
| | | WP11 AYA with cancer | In-person | | |
|--|--|----------------------|-----------|--|--|

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 Stake-holder Conference: Reducing Disparities Across EU | F2F Meeting | Project debrief and activities follow-up | Rome, Italy | 26/04/2023 – 27/04/2023 | | X | | |
| 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 | |

3. 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 | COO: INT | 40,000 | Expertise and advice of patient associations and expert groups. | Activity monitoring, regular internal reports |

| | | | | | | |
|----------|-------|--|--|-----------------------------------|--|--|
| | | Cancer Associations | | | Best value for activities proposed with their central national role – only able service provider with this capacity. | |
| 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 Design Solutions Web Creations Threadcase | BEN: NHRF Website setup, running, maintenance | 1,240.00* 21,700.00 620,00* | Technology and expertise support for construction and set up of dissemination tools | Open tender |
| WP8 | S8.1 | TBD | BEN: IOCN All tasks pertaining to local IT support | 18,000 | Technology & expertise support for construction + set up of dissem. 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”

4. 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 | | | | | | | | | | | | | | | | | | | | |

| | | | | | | | | | | | | | | | | | | | | | | | | | | | |
|---|---|---|-----|-----|---|---|---|---|-----|-----|---|-----|---|---|---|-----|-----|--|--|--|-----|-----|--|--|--|-----|----|
| T6.6 Centres' selection | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| T6.7 Defining NoE deliverables | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| T6.8 NoE governance development | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | MS1 | MS2 | | | | | MS3 | | | MS4 | | | | | MS5 | | | | MS6 | MS7 | | | | | D1 |
| T7.1 leading expert scoping | ■ | ■ | | | | | | | | | | | | | | | | | | | | | | | | | |
| T7.2 Leading expert selection | | ■ | ■ | | | | | | | | | | | | | | | | | | | | | | | | |
| T7.3 Definition of the Scope of the NoE | | | ■ | ■ | ■ | | | | | | | | | | | | | | | | | | | | | | |
| T7.4 Identification of the endorsement criteria | | | | | ■ | ■ | ■ | ■ | ■ | ■ | | | | | | | | | | | | | | | | | |
| T7.5 Scoping centres | | | | | | | | | ■ | ■ | ■ | | | | | | | | | | | | | | | | |
| T7.6 Centres' selection | | | | | | | | | | | | ■ | ■ | ■ | ■ | | | | | | | | | | | | |
| T7.7 Defining NoE deliverables | | | | | | | | | | | | | ■ | ■ | ■ | ■ | | | | | | | | | | | |
| T7.8 NoE Governance development | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| | | | MS1 | MS2 | | | | | MS3 | MS4 | | | | | | MS5 | | | | | | | | | | MS6 | D1 |
| T8.1 Establishment of a network of key partners | ■ | ■ | | | | | | | | | | | | | | | | | | | | | | | | | |
| T8.2 Definition of the scope of the NoE | | ■ | ■ | ■ | | | | | | | | | | | | | | | | | | | | | | | |
| T8.3 Identification of the endorsement criteria for NoE centres | | | | ■ | ■ | ■ | ■ | ■ | ■ | ■ | | | | | | | | | | | | | | | | | |

| | | | | | | | | | | | | | | | | | | | | | |
|---|---|-----|---|-----|---|---|---|---|-----|-----|-----|---|---|---|-----|---|-----|---|-----|-----|----|
| T8.4 Centre identification | | | | | | | | | | ■ | ■ | ■ | | | | | | | | | |
| T8.5 Definition of the NoE deliverables | | | | | | | | | | | ■ | ■ | ■ | ■ | | | | | | | |
| T8.6 NoE Governance development | | | | | | | | | | | | | | | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| | | MS1 | | MS2 | | | | | | MS3 | MS4 | | | | MS5 | | | | | MS6 | D1 |
| 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 | | | | | | | | | | | | | | | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| | | | | MS1 | | | | | MS2 | | | | | | | | MS3 | | MS4 | MS5 | D1 |
| 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 | |

5. ANNEX: SUMMARY OF THE SEVEN NETWORKS OF EXPERTISE BEING SHAPED BY JANE

Summary of NoE on Complex and Poor Prognosis Cancer(s)

| Objectives | Activities | Final user | Final target (general) | Final target (specific) | Full partners | | No per country | Criteria | Collaborators | |
|---|--|--|--|---|--|---|---|---|---|---|
| | | | | | Type of Full partners | EU scope | | | | National scope |
| Increase survival, Improve the quality of care and reduce inequalities across the EU in complex and poor prognosis cancers | 1. Enhance Patient Care: Provide comprehensive, patient-centred care that addresses the physical, and psychological needs of patients and their families throughout their journey | HCP/CCC medical professionals and researchers, PAGs, Medical Societies/ Organisation, and policymakers/ stakeholders | Achieve increase in overall survival rates and quality of life in complex and poor prognosis cancers at equal level in each MS (done by focus groups per cancer type eg pancreatic cancer NoE) | improvement of the quality of care and treatment outcomes for patients diagnosed with PPC | 1. Representative experts on PPC from accredited CCI who meet endorsement criteria and are involved in interdisciplinary clinical practice guidelines | Representatives from CCI with expertise in care of PPC (national influence and international experience), preferably involved additionally in Medical Societies/Organisations (eg ESMO, UEG, ESSO, ESTRO, OECI) | at least 1 per country; based on geographical spread, diversity in the provision of care, research, policy, education and strategy building (up to 50 participants in focus group dedicated to defined poor prognosis population) | General criteria: alignment with network goals, objectives and values; involvement in guidelines development, changing practice research and involvement in policy-making processes, leadership skills; capability and resources for actively participating in NoE activities, representing national and international groups. Experts: leadership position, top qualifications (board certification, advanced degrees, track record of excellence of clinical and research fields), endorsement from CCI/international organisations, ability to impact on the decisions making process, the organization of cancer care, research and education at the MS level Healthcare providers: track record of clinical excellence with high-quality patient care outcomes, strong reputation within its speciality areas, clinical resources (state-of-the-art equipment, specialized facilities, skilled healthcare workforce), relevant specializations align with the expertise of the NoE, history of research and innovation, accreditations and certifications, ethical conduct, diversity in workforce and patient population, commitment to quality improvement, patient data protection, and clinical training and education programmes. Organisations: interest in collaboration, knowledge sharing and research initiatives, access to valuable data, resources or tools that can enhance the NoE aims, Quality of Network/Organisation governance and decision making that supports society's voice and interests, Ethical and Legal compliance and long-term viability. | Other NoE and JA representatives, patient advocates, governmental bodies (eg. MoH, MoS), and non-governmental organizations, industry, medical societies, HTA, epidemiology and public health organizations, academic/Research Institutions, educational institutions. Representatives other research project on PPC (eg UNCAN) | |
| | 2. Advance Research: Drive innovative research to uncover breakthroughs in the early detection, treatment, and prevention of poor prognosis cancers. | | | to accelerate a deeper understanding of cancer biology, the development of more effective anti-cancer therapies and diagnostics | 2. Researchers from accredited CCI, who meet endorsement criteria, societies, and institutions involved in changing practice research | Representatives from CCI with expertise in research of PPC (national influence and international experience), preferably involved additionally in Medical Societies/Organisations (eg EORTC, OECI), Medical Research Agencies, Research Institutes or international research project dedicated to PPC | | | | |
| | 3. Empower Knowledge and Raise Awareness: Foster collaboration among healthcare professionals, researchers, stakeholders and patient advocates to share knowledge and best practices and raise public awareness about poor prognosis cancers | | | raise awareness of the disease among the public to improve early detection | 3. Charities and Non-Profits Organizations, PAGs, CCCs, Health Educators, Social Media and Health Bloggers/Vloggers | Representatives from CCI with expertise in education/dissemination/PR of PPC (national influence and international experience), preferably involved additionally in educational Medical Societies/Organisations (eg ESO, PAGs) | | | | |
| | 4. Advocate for Change in Policy: Advocate for policy changes, increased funding, and improved access to cutting-edge therapies and treatments to reduce the burden of poor prognosis cancers on individuals and society. Offer a network of support services, including counselling, financial assistance, and emotional support, to patients and families facing the challenges of poor prognosis cancer. | | | improvement of timely access to treatment as well as reduce inequalities in access to cancer treatments and healthcare services across EU member states | 4. Cancer Networks, Healthcare Management Professionals, Governments and Public Health Organisations, PAGs and Industry (including Pharmaceutical Companies) | Representatives from CCI with expertise in policy/stakeholder engagement of PPC (national influence and international experience), preferably involved in influential organisation on policy making (eg ECO, OECI, PAGs) | | | | Ministry of Health, National Cancer Institution, National cancer registry, National Health Fund |
| | 5. Strategy building based on measurable impact: Continuously assess and measure our impact on improving the outcomes and quality of life for those affected by poor prognosis cancers and establishment of the future strategy through collaborative efforts guided by Real-World Evidence (RWE). (Other domains) | | | development of KPI to measure the impact | 5. Representatives from International organizations and associations focused on cancer care and research | Representatives from CCI with expertise in strategy building of PPC (national influence and international experience) | | | | National Cancer Registries representatives, National Public Health Institutes |

Summary of NoE on Palliative Care

| Activities | Final user | Final target | Full partners | EU scope | National scope | No per country | Criteria | Collaborators | | |
|---|--|--|--|---|--|---|--|---|--|--|
| <p>1) Integration of the principles of palliative care (PC) into routine cancer care, regardless of the health care level at which the anti-cancer treatment/care/ follow-up is provided.</p> <p>2) Define key criteria to facilitate this integration; define the basic content of PC, develop indicators on how to monitor integration, use patient-centered care pathways (PCCP) as the framework for integration, ensure adequate PC competence in routine CC and PC</p> <p>2) Access to PC (training and implementation of PC also in remote areas), e.g., online resources</p> <p>3) Connect and liaise: 1) to increase visibility, collaboration and work of common identified gaps; 2) to become a platform for PC experts for the discussion of excellence of care. i.e., to create an expertise forum/international board where PC specialists can discuss difficult cases and symptoms</p> | <p>Hospitals at primary, secondary, tertiary levels, hospices/ homocare, health care managers, politicians, educational entities, European cancer networks (professional and lay) through a high degree of networking /liaison</p> | <p>Integration of PC principles and patient-centered care in routine cancer care in Europe</p> | 1) Accredited experts on PC | Representatives from cancer centers with expertise in PC (national influence and international experience) | | at least 1 per country; >1 based on geographical spread, diversity in provision of care. Pt.: All parts of Europe are represented, Northern, Middle, Southern and former eastern European countries. All do not have a formal national anchoring, nor are they certified as CCCs. This will be ensured in the forthcoming JANE2 | <p>Clinical, leadership and management experience in PC and its integration in cancer care. Specialist training in PC, supplemented with persons with long-standing experience in general PC, inside or outside the hospital setting. Centres with PC accreditation or with proven experience, links to national and international PC organisations, link to health care system, link to patients associations</p> | <p>MoH at national level (JANE policy board), One representative of the EU Commission with expertise in PC acknowledged in PC Implementation science experts e.g. researchers/lecturers in from specialised sections at the wellknown universities University representatives to address and advise on GAPS in education and training Liaison /collaboration with other NOEs, e.g., survivorship care, EoNs and CCCs + other initiatives, e.g., CRANE</p> | | |
| | | | 2) 1 representative from CCC | | | | | | One representative from the future NoE on CCCs. One representative from the future EON | |
| | | | 3) Stakeholders who can influence their organization and care provision of CCCs | | Hospital administrators and managers. Policy makers and government representatives. | | | | Representatives from CCC with influence or contact with stakeholders that can impact the organization of cancer care of their institution such as management representatives with clinical background and experience | |
| | | | 4) Scientific societies, ESMO, ECO 5) Patients and caregivers + relevant organisations | Existing patient representatives' organisations and advocacy groups at the national and international level (i.e.: FAVO, ELLOK, ECPC, EAPC etc.). | | | | | | |
| | | | 6) Representatives from National PC organisations. | | national scope | | | | 1 representative from each of the national PC organisations of the different EU countries | |
| | | | 7) Representatives from centres and institutions that provide care and support the delivery of PC (Charities, Hospices, primary healthcare professionals). | | National influence, international experience | | | | | 1) prove capability or resources for forming and representing national groups 2) international experience and future presence in the international agenda 3) Involvement in national guidelines development. |
| | | | 8) Representatives from International organizations and associations focused on cancer care and research | ESTRO, EAPC, ESMO, MASCC, OECI, ECO, PRC; European palliative care research centre, ATLANTES global observatory of palliative care, Palzon, Dutch PC research group, European Pain Federation, European Oncology Nursing Society, International PsychoOncology Society (IPOS) | | | | | | Institution and/or organisation focusing on research |

Summary of Survivorship NoE

| Objectives | Activities | Final user | Final target | Full partners | | | Criteria | Collaborators | |
|--|---|--|--------------|---|----------|----------------|----------------|---|--|
| | | | | Type | EU scope | National scope | | | No per country |
| Support the development of survivorship plan including all the specific needs that should be addressed: health (cancer and not cancers related), psychological, social, legal etc. | 1) Organize the multidisciplinary (MDT) approach to anticipate, personalize, and implement cancer survivors' follow up. 2) Mapping available experience. 3) Identify and share best practices also organising workshops or seminars, 4) Advocate about the importance of survivorship (plan, organisational model, principles against discrimination of survivors) 5) identification of indicators for monitoring the appropriateness of a survivorship plan and its implementation | CCC, experts, healthcare providers (HCP), patient support organisations, professional societies, and policy makers | | 1) HCP of the NoE experts in survivorship | X | X | | general and specific survivorship expertise, leadership, engagement with national organisation and planning, with available survivorship plan and several specific/dedicated services for survivors | collaborative projects dedicated to survivorship (PANCARE; STRONG AYA) SIOPE-MASCC-ESMO PanCare Follow-up Care CCI Europe |
| Support the definition of survivorship care model tailored to country specificities (population, geographical spread, health care organisation etc) including definition of role of oncologists, GPs and other relevant experts (eg, cardiologists, psychologists, endocrinologists, pneumologists, neurologists, urologists, etc....) | | | | 2) Scientific societies: ESMO, SIOPE, NCCN... 3) patients organisation | X | | | Scientific societies already working on survivorship | National initiatives: ACC... Government representatives: as National Oncological Council in Poland (Krajowa Rada Onkologiczna) CraNE2, ONKONET Slovenia (patient organisations) AIEOP (Associazione Italiana di Ematologia e Oncologia MASCC, ESMO, PanCare, CCI Europe |
| Promote training on survivorship issues | Development of training and relevant materials on survivorship specific issues such as psycho-oncology, pain management, comorbidity, sexual medicine, social counseling, vocational counseling, etc. | | | 1) HCP experts of the NoE; 2) scientific societies: ESMO, SIOPE, European Society of Cardiology, IPOS 3) Patient's organisation | X | | 1 per country? | | |
| Contribute to reduce discrimination | Define needs and activities to reduce the impact of cancer on employment, education, insurance (eg. promotion of the right to be forgotten) | | | 1) Patient's organisation 2) IPOS | X | | | | Legal, social and economy experts (kindly provide an example) Françoise Meunier (Right to be forgotten) Previous COST Action CanWON (Angela de Boer) |
| Promote research on survivorship/develop the research agenda of survivorship across different age groups (children, AYA, adults) | Map ongoing project on survivorship (across age group), identify needs, advocate for survivorship research priority in national and EU calls for proposal. | | | 1) HCP experts of the NoE; 2) scientific societies (SIOPE, ECO) | X | | | | Research projects dedicated to survivorship ESMO, MASCC, SIOPE, UnCan, PanCare |
| Support the definition of the burden of long-term cancers adverse events | Identify indicators and data sources, develop reports | | | 1) HCP experts of the NoE; 2) scientific societies: ESMO, SIOPE, European Society of Cardiology, IPOS 3) Patient's organisation | X | | | | ESMO, MASCC, AFSOS, PanCare |
| Promote patients engagement | | | | 1) Patient's organisation; 2) HCP experts of the NoE; | | | | | Sciensano, SIOPE, CCI Europe |
| Development of guidelines on specific items related to survivors follow-up | Map and continuously review available guidelines; identify topics for guideline developments (eg. pain management, lifestyle changes, screening for second cancers, fertility preservation, rehabilitation, genetic counseling, nutrition professionals) | | | 1) HCP experts of the NoE; 2) scientific societies: ESMO, SIOPE, European Society of Cardiology, IPOS.... 3) Patient's organisation | | | | | ESMO, MASCC, AFSOS, PanCare |
| Digitalization of healthcare for data collection for quality indicators | Collaborate with national cancer registries to establish a standardised approach to data collection and reporting for cancer survivorship issues. PanEU database - virtual European Cancer Patient Digital Centre for monitoring survivors' health conditions | | | | | | | | |

Summary of Personalised Prevention NoE

| Objectives | Activities | Final user | Final target | Type | EU scope | National scope | Full partners | | Collaborators |
|---|---|---|--------------|---|---|---|----------------|---|--|
| | | | | | | | No per country | Criteria | |
| 1) Support the development of Personalised Primary Prevention dedicated programme 2) Provide guidance to everyone who plans to create projects or programmes focused on personalised prevention | Define standards and tools to develop a personalized cancer prevention plan. Provide support to four government, schools, NGO's, different groups or stakeholders on PPP. | National Consortium, governments, CCCs, professionals societies | | Comprehensive Cancer Centers (CCC) Health care centres Genetic centres Nutrition centres Patient Advocates General Practitioners | to create a comprehensive prevention strategy at EU level | to develop an uniform strategy at national level for prevention | 1 partner / MS | <ul style="list-style-type: none"> 1) experienced personnel in primary prevention and personalised medicine; 2) documented evidence of research on PPP and PPP activities; 3) institutional arrangements that nurture research talent and career development; 4) proven collaboration with GPs; 5) availability of technological tools relevant for PPP (e.g., genetic testing platforms, innovative healthcare technologies). | <ul style="list-style-type: none"> Health care centres Genetic centres Nutrition centres Patient Advocates General Practitioners Collaborators in personalized medicine research and implementation |
| | Identify and assess effectiveness of personalized prevention strategies Collaborate with academic research institutions to conduct comprehensive studies on the effectiveness of personalized prevention strategies. | | | Public health institute Nutrition centres Patient Advocates Health Economics and Policy Centers | | <ul style="list-style-type: none"> Public Health Institute: <ul style="list-style-type: none"> -Expertise in public health issues. -Strong infrastructure, research engagement, and academic achievements. -Accreditation by relevant national and international bodies. Nutrition Centers: <ul style="list-style-type: none"> -Broad nutrition expertise. -State-of-the-art infrastructure and collaboration with health professionals. -Involvement in community outreach and research. -Accreditation by relevant nutritional organizations. Patient Advocates: <ul style="list-style-type: none"> -Expertise in patient advocacy. -Effective infrastructure, research involvement, and patient education programs. -Recognition by patient advocacy networks. Health Economics and Policy Centers: <ul style="list-style-type: none"> -Expertise in health economics and policy analysis. -Robust infrastructure, contribution to policy development, and academic achievements. -Accreditation by national and international health economics and policy organizations. | | <ul style="list-style-type: none"> Government health departments Educational institutions Non-Governmental Organizations Public health organizations Academic Research Institutions Public health research organizations Data analysis experts | |
| | Map and define best practices about support services to individuals and families Conduct regular surveys and interviews to identify evolving needs and preferences for support services. | | | Patient Advocates Support Centers | | <ul style="list-style-type: none"> Patient Advocates: <ul style="list-style-type: none"> -Expertise in patient advocacy. -Effective infrastructure for communication and support. -Active involvement in research, patient education, and empowerment. -Recognition by patient advocacy networks or organizations. Support Centers: <ul style="list-style-type: none"> -Robust infrastructure for providing support services. -Demonstrated effectiveness in addressing evolving needs and preferences. -Continuous improvement through feedback mechanisms. -Collaboration with patient advocacy groups, social workers, and psychologists. | | <ul style="list-style-type: none"> Patient Advocacy Groups Support Centers Social workers Psychologists | |
| | Define the minimal essential requirement establish, the essential structural and functional characteristics for a center (age-appropriate psychosocial support, genetic counselling etc). Ensure a patient-centered approach in the development and implementation of these standards. | | | <ul style="list-style-type: none"> Research and Innovation Hubs CCC Academic Medical Centers Rehabilitation Centers Mental Health Clinics Health Information Technology Companies Pharmaceutical Research Organizations Maternal and Child Health Centers | | | | <ul style="list-style-type: none"> Demonstrated expertise in the respective field (e.g., cancer research, mental health, rehabilitation). Presence of experienced personnel specializing in the specific focus area. Evidence of active research initiatives and contributions in the area of focus (e.g., clinical trials, translational research). Effective institutional arrangements fostering the development of research talent and supporting career advancement. Collaboration with General Practitioners and other relevant healthcare professionals. Technological infrastructure for the specific focus area (e.g., genetic testing platforms, innovative healthcare technologies). | <ul style="list-style-type: none"> Patient Advocacy Groups Healthcare Professionals Accreditation bodies |
| 3) Promote research on PPP | Identify research priority and innovative tools for PPP and PPP implementation. Establish a collaborative research agenda to identify emerging trends and technologies for personalized prevention. Facilitate partnerships with pharmaceutical and biotechnology companies to explore innovative approaches. | | | <ul style="list-style-type: none"> Research and Innovation Hubs Academic Medical Centers | to identify the polygenic risk factors, to create the questionnaires | map the different risk factors in different MS (country profiles) | | <ul style="list-style-type: none"> Demonstrated excellence in conducting and contributing to cutting-edge research initiatives. Proven track record in fostering innovation and integrating advanced technologies into healthcare practices. Active engagement with academic institutions and collaborative research efforts. Involvement in clinical, translational, and basic research, contributing to advancements in healthcare. | <ul style="list-style-type: none"> Pharmaceutical and Biotechnology Research Centers Research and Innovation Hubs Pharmaceutical and Biotechnology Research Centers Comprehensive Cancer Centers (CCC) Academic Medical Centers |
| | recommendations | | | Cancer research organizations | | | | <ul style="list-style-type: none"> Demonstrated expertise in cancer research. Proven record of active cancer research initiatives. Supportive institutional arrangements for talent development in cancer research. Established collaboration with healthcare professionals, including general practitioners. Access to advanced technologies for cancer research. | <ul style="list-style-type: none"> International Cancer Research Organizations Multidisciplinary teams of healthcare professionals Epidemiologists and statisticians |
| 5) Raise awareness regarding cancer prevention in all age groups: support educational programmes for general population and health care professionals | Promote community outreach and education on the importance of cancer prevention and PPP. Collaborate with educational institutions, NGOs, and healthcare providers to develop and implement educational programs. Utilize diverse communication channels, including social media and community events, to reach all age groups. | | | <ul style="list-style-type: none"> Public health institute Nutrition centres Patient Advocates General Practitioners Educational institutions NGOs Healthcare providers | to create training programmes for physicians on importance of prevention (including oncologists from hospitals, to help families of cancer survivors) | to distribute preventive messages in the entire hospital - for caregivers | | <ul style="list-style-type: none"> Demonstrated expertise in their respective domains. Proven positive impact on public health, nutrition, patient advocacy, & general healthcare. Active collaboration with healthcare professionals, NGOs, & educational institutions. Effective engagement with communities for health promotion and education. | <ul style="list-style-type: none"> Educational Institutions Non-Governmental Organizations (NGOs) Healthcare Providers Social Media and Communication Experts |
| 6) Promote training on PPP | Support training on PPP for GPs. Develop comprehensive training modules in collaboration with medical associations. Organize workshops and webinars to disseminate knowledge and build expertise among general practitioners and other relevant healthcare professionals. | | | <ul style="list-style-type: none"> Research and Innovation Hubs CCC Academic Medical Centers | | | | <ul style="list-style-type: none"> Emphasis on a multidisciplinary approach, fostering collaboration across various medical disciplines. Accreditation by relevant bodies and recognition for academic and research achievements. Active collaboration with academia, industry and healthcare institutions. Involvement in clinical trials and translational research, translating research findings into practical applications. Active participation in education and training programs for healthcare professionals and researchers. Integration of advanced technologies into research and clinical practices. | <ul style="list-style-type: none"> Medical Associations Healthcare Training Institutions Workshops and Webinar Facilitators Continuing Medical Education Providers |

Summary of Omics Technologies NoE

| Scope | Final target | Final user | Full partners | Objectives - principles | Activities | Fields (Domains) | EU scope | National scope | No per country | Criteria | Participation levels | Collaborators |
|---|-----------------------|--|--|---|---|--|----------|----------------|---|---|---|---|
| Development of a NoE fostering the integration of omics technologies into all EU healthcare systems to improve clinical decisions in precision medicine in oncology and onco-hematologie (genetic susceptibility, diagnosis, treatment, follow-up, palliative care) | MTBs in CCI/CCCs/CCNs | health care providers: medical oncologists, hematologists, geneticists and other clinicians experts: Pathologists, clinical biologists, bio-IT... | Omics technological platforms, within CCI/CCCs/CCNs at the national, regional or local level | Fast integration of innovation into care Equal access to excellence and high quality services Flexibility given the Member States' specificities | - Support the integration of existing guidelines (elaborated by (inter)national scientific societies) and/or contribute to the elaboration of missing guidelinesEstablish recommendations on how to integrate omics technologies in the healthcare system | Established Omics in Standard of Care in at least one cancer type (eg Genomics, transcriptomics, ...) | X | X | 1 to 2 Omics platforms | A- Type and volume of activity: 1) Available omics technologies 2) Fields of application 3) Activity volume 4) Cancer types B- Infrastructure, resources, capability: 5) Available infrastructure and core facilities 6) Human resources and expertise 7) Quality management 8) Track record C- Workflow, accessibility, collaboration: 9) Integration into care 10) Accessibility 11) Connection with clinical cooperative groups, clinical trials, ERNs and other EU platforms 12) Clinical practice guidelines, training and education 13) Cost and NHDl reimbursement (only level 3 has to facilitate and engage discussion for NHDl) reimbursement according to national regulations | CATEGORY 1: Participants with resources (not all), interested in increasing their resources (care, research, training) and in participating to clinical trials involved as a mentee in twinning program with a category 3 platform. <i>Inclusive criteria (human resources, platforms, etc.)</i> CATEGORY 2: Participants intermediate between categories 1 & 3. CATEGORY 3: Participants are leader in the field, with mature and autonomous platforms, able to combine care, research and education, involved in enhancing reimbursement, involved in twinning program with a Category 1 platform as a mentor. Objective criteria (track records). | - Innovative clinical trial units (regional, national, EORTC, with ECRIN) - Life science infrastructures, biobanks (regional, national, BMMRI-ERIC), ELIXR, ESFRI - 4 ERNs on cancers - International & National scientific societies (ESMO, EHA, ESTRO, ESO, ESH, SIOPE...) - National & regional decision-making bodies - EU official bodies (EMA, EunethTA, ...) - Patient advocacy groups - Private sector |
| | | | | | - Make recommendations to value research and innovation in collaboration with CCIs (capacity building) | Omics Technologies Undergoing Validation for Standard of Care (Phase 2 or 3 Clinical Trials) in at least one cancer type (eg methylomics, proteomics, ...) | X | X | Category 3 >2 >1 with twinning programs | | | |
| | | | | | - Identify inequalities between the Member States (resources, reimbursement, accessibility...) and establish recommendations regarding urgent needs, biggest gaps and inequalities across Europe | Omics Technologies Ready for Clinical Testing and Validation (Phase 1-2 Clinical Trials) in at least one cancer type (eg metabolomics, lipidomics, ...) | X | X | | | | |
| | | | | | - Define the needs for the training and continuous education of health care professionals | Emerging Omics technologies (eg spatial omics, single-cell omics, exposomics, AI tools, ...) | | | | | | |
| - Enhance patient and public literacy and involvement | | X | X | | | | | | | | | |

Summary of NoE on Hi-Tech Resources

| Scope | Final target | Final user | Full partners | Principles | Fields (sub-groups) | Ending objective | EU scope | National scope | No per country | Criteria | Collaborators |
|--|-------------------------------|--|--|---|--------------------------------|---|----------|----------------|---|--|---|
| <p>Emerging and innovative resources Privileged and very expensive resources Rare technologies in the cancer area</p> <p>Prioritization criteria: - Excellence (quality) - High impact in terms of survival (quality, efficiency) - Uneven presence in Member States (equity of access) - Promising / innovative resources (exploration, sustainability)</p> | <p>MTBs in CCI/CCCs/CCCNs</p> | <p>Health care providers: medical oncologists, hematologists, geneticists and other clinicians Experts: Radiation oncologists, nuclear physicians, radiologists,....</p> | <p>Hi-tech Medical Resources platforms, within CCI/CCCs/CCCNs at the national, regional or local level</p> | <p>Fast integration of innovation into care Equal access to excellence and high quality services Flexibility given the Member States' specificities</p> | 1 - INNOVATIVE RADIOTHERAPY | Establish recommendations on how to integrate the Innovative Radiotherapy in the healthcare system and proposing organization system to ensure the access of all EU candidate patients to the facilities. | x | x | 1 tper 10 Mhab High-Tech platforms >1 with twinning programs | <p>CATEGORY 1: Participants with resources (not all), interested in increasing their resources (care, research, training) and in participating to clinical trials involved as a mentee in twinning program with a category 3 platform. Inclusive criteria (human resources, platforms, etc.)</p> <p>CATEGORY 2: Participants intermediate between categories 1 & 3.</p> <p>CATEGORY 3: Participants are leader in the field, with mature and autonomous platforms, able to combine care, research and education, involved in enhancing reimbursement, involved in twinning program with a Category 1 platform as a mentor. Objective criteria (track records).</p> | <ul style="list-style-type: none"> - Innovative clinical trial units (regional, national, EORTC, with ECRN) - Life science infrastructures, biobanks (regional, national, BBMRI-ERIC), ELIXIR, ESFRI - 4 ERNs on cancers - International & National scientific societies (ESMO, EHA, ESTRO, ESO, ESH, SIOPE...) - National & regional decision-making bodies - EU official bodies (EMA, EunetHTA, ...) - Patient advocacy groups - Private sector |
| | | | | | 2. INTERVENTIONAL RADIOLOGY | Establish recommendations on how to integrate the Interventional Radiology in the healthcare system and proposing organization system to ensure the access of all EU candidate patients to the facilities. | x | x | Category 1 : About 1 tper 5Mhab Tech platforms Category 3 : 1/10 Mhab >1 with twinning programs | | |
| | | | | | 3. INNOVATIVE NUCLEAR MEDICINE | Establish recommendations on how to integrate the Innovative Nuclear Medicine in the healthcare system and proposing organization system to ensure the access of all EU candidate patients to the facilities. | x | x | Category 1 : About 1 per 5Mhab Tech platforms Category 3 : 1/10 Mhab >1 with twinning programs | | |
| | | | | | 4. CELLULAR THERAPIES | Establish recommendations on how to implement academic or mixed PP cellular therapy manufacturing platforms, to evaluate the performance of the cell products, to integrate these therapies in the healthcare system, to propose organization system to ensure the access of all EU candidate patients to the facilities. | x | x | TBD Category 3 : 1/10 Mhab >1 with twinning programs | | |
| | | | | | 5. EX-VIVO AGENT TESTING | Developing preclinical test to identify novel candidate agents for the treatment of cancer. | x | TBD | TBD, 1 at least | | |
| | | | | | 6. INNOVATIVE SURGERY | | | | | | |
| | | | | | 7. RADIOMICS | | | | | | |

Summary of NoE on Adolescents and Young Adults with Cancer

| Objective 1 | Activities | Partners | Synergies |
|---|--|--|---|
| To support the development of AYA dedicated program | Mapping existence experience to share best practice on: <ul style="list-style-type: none"> - model of AYA dedicated programme - model for bringing organisation together | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC....) | |
| | Support the identification of the best model according to country specificities (needs assessment, context analyses, discussion with stakeholders, recommendations) | AYA experts/national HCP of the NoE SIOPE Patient advocates | Research projects dedicated to AYA (STRONG AYA...) |
| | Identification of sustainable national funding models | Health economy institute Local HCP mandate by the government | CCI/CCCN |
| | Advocacy activities to promote the importance of an AYA dedicated program | AYA experts/national HCP of the NoE SIOPE, ESMO, ECO | |
| Objective 2 | Activities | Partners | Synergies |
| To support collaboration between paediatric and adult cancer services, right from cancer prevention, through diagnosis, treatment, to survivorship or the end of life | Mapping trans-age organisations and identify core activities dedicated to AYA (vs those for young children or adult) | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) Patient advocates | |
| | Establish collaborations, with trans age organisations or with different specific age organisations, to define AYA dedicated actions to improve AYA care from prevention to survivorship | ESMO, SIOPE, EHA OECI AYA dedicated collaborative groups (eg, ENTYAC....) | ERNs National societies, national AYA programmes/network |
| Objective 3 | Activities | Partners | Synergies |
| To define referral pathway | Mapping existence experience to share best practice on referral pathways in different health care organisation context (centralised, decentralised, geographical spread etc) | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) Patient advocates | National societies, national AYA programmes/network |
| | Promote studies to understand causes of diagnostic delays. Define indicators of timely diagnosis and a system for monitoring them. | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) Patient advocates | National societies, national AYA programmes/network |

| | | | |
|--|--|---|---|
| | Support the definition of the optimal referral pathway at country level collaborating with national oncology networks. | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) Patient advocates | National societies, national AYA programmes/network CCC/CCCI |
| | Define roadmap/workplan to implement the referral pathway including training of GP, awareness raising, etc. | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) Patient advocates ECO, ESO | National societies, national AYA programmes/network CCC/CCCI |
| Objective 4 | Activities | Partners | Synergies |
| To develop specific clinical recommendations/guidelines on AYA-specific topics (e.g. age-specific psychosocial support, fertility and sexuality, transition, and so on) and different type of cancer across age groups | Mapping existing guidelines | AYA experts/national HCP of the NoE SIOPE ESMO EHA | National societies, national AYA programmes/network CCC/CCCI |
| | Develop recommendations on AYA specific topic and AYA-cancers in collaboration with existing expert groups and advocacy groups and youth organizations | <u>Guidelines on AYA cancers</u> AYA experts/national HCP of the NoE SIOPE, ESMO, EHA <u>Guidelines on AYA specific topics</u> AYA experts/national HCP of the NoE International Psycho-Oncology Society Patients advocates AYA dedicated collaborative groups (eg, ENTYAC...) | CCC/CCCI/ERN |
| | Define methodological approaches for defining recommendations | AYA dedicated collaborative groups (eg, ENTYAC...) AYA experts/national HCP of the NoE | SIOPE, ESMO EHA |
| | Support the dissemination of the recommendations developed | Patients advocates AYA dedicated collaborative groups (eg, ENTYAC...) | SIOPE, ESMO, EHA |
| | Explore innovative approaches for guideline implementation, such as digital tools, decision support systems | AYA dedicated collaborative groups (eg, ENTYAC...) | Research projects |
| | Monitoring guidelines implementation and impact | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) | ENCR OEI, ERNs |
| Objective 5 | Activities | Partners | Synergies |
| To promote cancer research in AYAs (epidemiology, genetic, biologic, clinical research, | Support the development of new collaboration cross scientific societies to promote AYA/Trans-age research | AYA dedicated collaborative groups (eg, ENTYAC...) AYA experts/national HCP of the NoE ESMO, SIOPE, EHA | |

| | | | |
|---|---|--|--|
| including recruitment in clinical trials) by identifying barriers and advocating for actions to overcome them | Promote research for AYA (genetic/biologic, clinical, epidemiological, late effects, palliative care) | AYA dedicated collaborative groups (eg, ENTYAC...) AYA experts/national HCP of the NoE EORTC, ENCR | NoE palliative care CCI/CC/CCCN NoE survivorship |
| | Promote clinical trials , access to clinical trials and ensure early access to anticancer drug (ensure patients engagement) | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) EORTC, SIOPE Patient advocates | ACCELERATE |
| | Increase awareness on importance of clinical trials including dissemination of information on open trail | AYA experts/national HCP of the NoE EORTC, SIOPE, Patient advocates | ERN, CCI, CCC ACCELERATE |
| | Define research priorities | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) | |

| Objective 6 | Activites | Partners | Synergies |
|---|--|---|--|
| To be the Network where committed healthcare professionals' interface and cooperate with Non-Governmental Organizations (NGOs) and patient groups about AYA with cancer | work with the leadership of existing international professional organisations, to develop AYA-focused initiatives | ESMO, SIOPE, EHA, EONS, ECO, ESTRO, ESSO, IPOS, <i>OECI</i> | ERNs |
| | map existing national and EU AYA-focused professional organisations, understand structures and capacity; bring together those existing organisations, to define a specific core of joint actions. | ENTYAC | National societies, national AYA groups. |
| | provide more detail to existing maps of national Eu AYA-focused NGOs; understand specific skills and structures, bring together those existing organisations and define joint actions (e.g. joint fundraising initiatives/project grants). | PPI (YCE, CCI-E, ECPC) | National NGOs |
| Objective 7 | Activites | Partners | Synergies |
| To raise awareness of cancer in AYAs | map and share information campaigns focusing on AYA (directed to general population, patients and their families) (e.g. on early diagnosis, on prevention) | ESMO, SIOPE PPI (YCE, CCI-E, ECPC) | National groups/societies ERNs |

| | | | |
|--|--|--|---|
| | map ongoing awareness programmes/activities within the public health care systems (i.e. university courses and training programs for general practitioners) | AYA experts/national HCP of the NoE | |
| | define a dissemination strategy and identify the specific objectives, communications channels, targets | ESMO, SIOPE PPI | ERNs |
| Objective 8 | Activites | Partners | Synergies |
| To monitor AYA cancer epidemiology, leveraging what is available or underway | Define all AYA relevant cancers to monitor and relevant indicators | AYA experts/national HCP of the NoE European Network of Cancer Registries | National cancer registries Research projects (STRONG AYA....) |
| | Collaborate with the Joint Research Centre, the European Network of Cancer Registry Agency and the International Agency on Research on Cancer (IARC) to develop reports on AYA with cancers (e.g. incidence, survival, trends, differences between countries) and propose collaborative studies also to interpret survival differences | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) European Network of Cancer Registries/ JRC | IARC Research projects (STRONG AYA....) |
| | discuss the possibility to establishing AYA-dedicated (clinical) registries versus trans-age registries along with harmonization of data collection and reporting | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) | Research projects (STRONG AYA....) |
| | define a road map to identify data sources and initiatives potentially relevant to monitor AYA cancer outcomes to establish collaboration | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) | |
| Objective 9 | Activites | Partners | Synergies |
| To define and promote dedicated training on cancer in AYA | Develop an European Blueprint (i.e. a written comprehensive document describing the specific elements and complexities of AYAs with cancer, the challenges that need to be addressed, the possible solutions and interventions) | AYA experts/national HCP of the NoE AYA dedicated collaborative groups (eg, ENTYAC...) ESMO, SIOPE EHA, EONS, ECO, ESTRO, ESSO, IPOS, OECI | ESO International disease-specific/discipline groups/societies; |

| | | | |
|--|---|----------------------|---|
| | create a curriculum dedicated to AYA with cancer, develop training courses | | National groups/societies ("local" training) ERNs |
| Objective 10 | Activities | Partners | Synergies |
| To support Patient and Public Involvement and Engagement | map PPI groups in EU | YCE CCI-E ECPC | SIOPE ERN ENTYAC |
| | advocate PPI in national AYA programs; investigate existing barriers | YCE CCI-E ECPC | ENTYAC National groups/societies |
| | support educational programs for AYA patients/survivors | YCE CCI-E ECPC | SIOPE NoE survivorship |