

The EU Network of Comprehensive Cancer Centres –

Sketches of possible activity areas

A report from WP5, task 5.3.1 working group

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2 Project Information

Project Full Title:	Network of Comprehensive Cancer Centres: Preparatory activities on creation of National Comprehensive Cancer Centres and EU Networking
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3 Abbreviations and Acronyms

- CCC Comprehensive Cancer Centre
- EBCP European Beating Cancer Plan
- EC European Commission
- EU European Union
- WP Work Package



4 Executive Summary

The main ambition of the CraNE project is to prepare the implementation of an EU Network of CCC which able to deliver added value for the cancer centers, member states and for the entire cancer community in EU and associated countries covering both care, research and education. This added value is supposed to emerge from organized collaboration and interaction between the members in this network. The CraNE project is thus an essential measure to follow up the ambitions in Flagship no 5 in EU Beating Cancer Plan (EBCP). CraNE work package 5 had the objective to describe the governance structure of the network and the design of collaborating activities. The latter task was defined as subtask 5.3.1. This report is the result from the process conducted in this subtask. WP5 has been led by Alleanza Contro il Cancro (ACC) and the subtask 5.3.1 has been led by Oslo University Hospital (OUS).

The process leading to this report has been managed through the following principles: Involvement of experts from potential members of the EU Network, searching for activities that are experienced as relevant for the potential member, and encouraging broad spect rum of ideas as well as creativity in identifying ideas. We also kept in mind the key role that this task would have in connecting CraNE to the follow up implementation project that we knew would be launched as a call during our work. Essential for the accomplishment of the task has been the working group established in the early autumn of 2023 with the mission to deliver the description of possible activity areas. The work process following the Open Forum concept has moved from brainstorming to systematic analysis of ideas and conceptualizing of activities. The report describes 13 so-called thematic possible activity areas and 5 generic activities.

During the work with this, we have recognized that the process of providing added values created by the activities in the EU Network should be precisely understood through several distinctions. Initially in the report we therefore describe these, like: collaboration through different types of networking, different types of possible added value, categorizing activities and types of measures, collaboration involving external partners, and the need of taking into account the time required to mature towards a managerial level being able to fully to exploit the potential in these networking activities. We also underline that in the construction of governance model of the EU Net CCC, the crucial role it will have in managing the network activities should be considered. Finally, we are pointing at the mutual interaction that should be actively encouraged between the joint network activities and the certification processes.



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5 Introduction

5.1 Background

This document describes the possible joint activities organized by an EU Network of Comprehensive Cancer Centres (CCCs). This is the mission of subtask 5.3.1 in WP5 "The EU Network of CCCs: Composition, Governance, Joining Process and Functioning" in CraNE. This subtask might also be considered as delivering a core output expected from CraNE and creating a link between CraNE and the follow up project supposed to be implementing this EU network. The mission and role of our work are expressed clearly through this citation taken from the project description of CraNE:

Impact and ambition — Progress beyond the state-of-the-art

This work will connect to objective 2 of CraNE:

The **main ambition** of CraNE is to fulfil the main objective of delivering the organisational framework and functional profile for the Network of CCCs. As this is one of the flagships of Europe's Beating Cancer Plan (EBCP), the complete setup of the Network will have an important impact on the future organisational models in cancer care in Europe. CraNE will prepare the design and functionalities of the EU Network of CCCs and define how the development and quality evaluation of CCCNs will enable the quality of care of CCCs to reach 90% of eligible patients by 2030. The focus will be on the added value of the EU Network, which will provide collaborations, interactions as well as research and training opportunities. The **short-term effect** will be in establishing closer collaboration among CCCs in the EU. This collaboration will provide the framework for broader exchanges of best practices, improvements of cancer care as well as for research. The **medium-term effect** will be in establishing different types of networking, cross-border collaborations and implementation projects based on the endorsement of best and good care practices within the Network.

The following sources are also relevant to have in mind when we are working on this task: The grant agreement's comment on quality (page 7):

Available resources within the Network (e.g. expertise, research, education, samples, data, trials, and core facilities) will be leveraged by devising activities to foster collaboration within the Network and with regional and local networks, and to formalize the role of patients and other key stakeholders in the co-creation of CCCs and of the Network.

The grant agreement's comment Risk Management (page 17):

13: Risk that the benefits from forming a new Network of CCCs in the EU are not clearly articulated in such a way as to secure 'buy in' and motivation of CCCs as well as MS. The entire JA should define the benefits for research and care as a part of an early milestone of the JA. 14: Risk that criteria for CCCs are set too high to include centres in certain Member States, or so low that some centres have less motivation to improve. WPs need to define development processes, which allow for inclusivity and well as requiring continuous improvement in all CCCs, whatever their baseline.





The grant agreement's comment Impact and ambition (page 18):

The focus will be on the added value of the EU Network, which will provide collaborations, interactions as well as research and training opportunities. The short-term effect will be in establishing closer collaboration among CCCs in the EU. This collaboration will provide the framework for broader exchanges of best practices, improvements of cancer care as well as for research. The medium-term effect will be in establishing different types of networking, cross-border collaborations and implementation projects based on the endorsement of best and good care practices within the Network.

Linking these citations with the specific mission and the expected output, WP5 subtask 5.3.1 illustrates the role of this deliverable to the overall aims of the CraNE project:

Design of collaboration activities of	Definition of activities to foster collaborations		
national CCCs within the European	aimed at improving care, education and		
context	research		

Our work process to deliver the sketches of activities

To accomplish this task, we have been appling these principles:

- a) To foster CraNE integration actively: Actively involving core representatives from different parts of CraNE
- b) Showing broad relevance: Making the sketches of activities relevant for all Member States
- c) To encourage diversity and creativity: ensuring that both obvious and not-so-obvious sources of activities come to the surface and are assessed
- d) Building commitment to support the transition from CraNE1 to CraNE2 both through engaged individuals and through building team of ambassadors for the joint proposal delivered

These principles were applied when selecting experts, establishing the working group, and in choosing appropriate working methods. We selected a working group that included 18 persons from 10 Member States and with a background from several WPs and tasks in CraNE. As an entrance to our work, we chose a concept labelled Open Forum combining the facilitation of creativity, equal opportunities to contribute for all and leading us from the free brainstorming via the structured editing and assessing of the ideas to an integral description of the possible network activities based on a unified template. This approach depends on a first step consisting of a workshop requiring physical presence. (This phase could not be accomplished efficiently without). Face-to-face interactions are necessary to release creativity and build mutual trust and engagement in the group – not least when it is a group that is to be created through this process. The coordination team (Elena Preziosa, Ingrid Jenny Guldvik and Per Magnus Mæhle) processed the output from the first workshop held on 5 September 2023 in Paris (a bunch of flipcharts with ideas more or less systematically described). The document resulting from this process was distributed to the working group and discussed at a new video-based workshop which contributed to further improve the document. This step was repeated, with interactions in between meetings involving the coordinating group and



the members. In general, this approach provided us with a structure appropriate for the purpose of our work, but it also allowed a necessary flexibility to adjust and detail the process and the results based on the experiences we made during the process.

Based on a mixture of the general templates for Open Forum and on the specific purpose of its application, we designed a structure to systematically describe the ideas to be included in this sketch of activities. This structure was as follows:

- Proposing a proper title for the activity
- Identification of possible specific areas and types of activities
- Describing the benefit for the cancer centres and the MSs
- Describing the joint benefit for the EU on improving cancer care and research
- Determining the success criteria of this activity
- What is the requirement of contributions from the network and from the CCCs if the network shall succeed?
- Connection to other EU projects
- Connection to other activity areas in this document

In this work of defining possible activities of the Network of CCCs, we have excluded the role and activities that are directly related to the certification of CCCs. We have considered this as a separate process that should be the focus of other tasks in CraNE. However, we recognize two important connections between our work and the certification of CCCs: first, certification is not the core activity of the EU network of CCCs; it is a tool and a process of linking CCCs to the Network and to its core activities as envisaged in the proposals in this document. Second, the potential benefit of CCC certification expands considerably when linked to the Network activities, promoting mutual learning and creating spaces for joint actions delivering quality improvement and knowledge contributions. Thus, numerous activities of our proposal, directly and indirectly, stimulate the CCC certification process.

A general understanding of the application of networks in this context

In the EBCP and Cancer Mission, the introduction of networks is prevalent. Unfortunately, however, the application of this expression is not always made clear and unambiguous. As an introduction to the presentation of ideas on activities of the EU Network of CCCs, we therefore consider it useful to provide some clarifications on three areas.

1) <u>Networks on several levels</u>

There are already many networks focused on cancer care and research in Europe. However, they act mainly on specialized topics connected to professions, tumour groups (including rare cancers), diagnostics and treatment modalities and so on. Within the CraNE framework, we are dealing with networking on the institutional, i.e. cancer centre level. These might already exist on several organizational and geographical levels. A comprehensive cancer centre might itself be a network by building an alliance or a consortium to be comprehensive in care and research. Then there are wider institutional networks as stated in the above-referred CraNE



mission – which are necessary to provide equal access to specialised care and research for the vast majority of inhabitants. These networks have previously been labelled as CCCNs. Then there are examples of regional and cross-country networks of centres partially connected to the collaboration to or between CCCs. Finally, the ambition of building a European network of CCCs is raised. This is what our sketches of activities are focusing on. However, all these levels of networks of cancer centres will depend on each other to succeed in line with the EBCP. Even the further implementation of the EU network must recognize this.

2) <u>Different roles and purposes of Networks</u>

When elaborating the activities in the Network and releasing the potential that might lie in a Network, four types of Network potential have to be recognized:

- a. Facilitating mutual learning and support
- b. Building joint initiatives in areas where synergies between centres exist
- c. Deliver common standards for cancer on the institutional level
- d. Coordinating joint external initiatives based on common interests of the CCCs in the Network
- e. Coordinating the clinical pathway of the patient through levels of care

In the proposed activities of an EU Network of CCC described in this document, there are examples of all five of these purposes. Many of them contain even a mixture of two or more. A reason why it is important to make the distinction between these five categories is that the type of purpose will influence the way activities should be organized.

3) Different ways of categorizing network activities

Already in the brainstorming part of this process, we recognized that we could group the ideas that emerged in two:

- a) The activities might be covering specific thematic areas that we currently agree to be important to build a network around (related to at least one of the types of networking mentioned above)
- b) The activities might be more generic networking activities that depend on developing a kind of more general infrastructure capacity for networking initiatives

We allowed both types of activities to be developed and described during our work simply because we think the EU Network of CCCs should contain both. In practice, there should be an interaction between them. The more generic activity will hopefully release more focused initiatives of activities and vice versa.

4) The crucial interaction between action areas for the EU network

There will be connections between different action areas. This might be the result of having different action areas contributing to un-tap the potential of the Network or solving more or less similar challenges, engaging overlapping communities, interacting with overlapping decision processes, applying similar methodologies. In addition, there is certainly the important possibility to exchange lessons from other activities in the network based on their practical experiences. The supportive infrastructure of what is called the generic activities should be supplied jointly to the thematic activities and crossover learning and synergies should be facilitated by the leaders of the activities. We have assumed that all activities should



describe possible overlapping fields and processes of potential synergies. We have tried to indicate such interfaces at each activity in this catalogue.

5) <u>The crucial connection to other projects and institutions</u>

At several activity areas of an EU Network of CCC there will be parallel initiatives on related topics and with related targets. This might be other EU projects, organized professional communities and societies, and NGOs at European, regional or national level or multi-center initiated programs. It must be an ambition for the EU Network of CCCs to analyse these regularly and try to connect to and build on them if possible. The advantage of the EU Network is that it is connected to presumably strong institutional structures (Cancer Centres / University hospitals /General hospitals) and dissemination and implementation of models, systems, practice and projects can benefit substantially from this. In this catalogue, examples of current relevant exciting collaborative partners are indicated.

6) <u>The process of developing network activities</u>

The process for developing network activities may be organized and carefully aligned with the specific challenges, tasks to be accomplished, and the targeted outcome. There will not be one process that is proper for all cases. Tools and approaches should be made available through what we have called generic types of activities. However, very generally speaking, we assume that models of organizing networking may include models of initial analysis of potential and challenges, start-up activities, capacity building interventions, sharing of expertise, mobility between centres and countries, patient involvement, dissemination of information and knowledge, information on existing examples and projects, possible extra funding, facilitating synergies with other programs and so on.

7) <u>Some remarks on the maturity level of the network and consequences regarding</u> <u>dynamics and types of activities</u>

The EU Network will have a formal governance structure proposed by WP5 (connecting this to the network activities – see next point). The formal organization will not be one monolithic structure. It will have to be a kind of collegial body and be very much dependent on the support and trust from the members, the EU CCCs, and also from the MSs. This will then also affect the dynamic connected to initiating and accomplishing the activities of the network. There will always be an interaction between initiatives and needs of activities emerging from the members and the facilitation and support from network management and boards. Developing a sound pattern for this interaction depends on skilful and careful leadership both at the level of entrepreneurial CCCs and at the network level. When this pattern develops, it would ideally constitute a culture with collectively internalized routines and processes that could be labelled as the network culture. However, this will not be present from day one. It cannot be declared and decided. It is a question of carefully building collective experiences and together developing it along a kind of track toward network maturity.

A consequence from recognizing this will be that the activities of the centre should be built step by step, preferably through launching some pilots that could pave the tracks and function as references. These should represent different types of activities so that different relevant



roadmaps for organizing activities could be established. We assume that the first activities might need more support than later activities. We should also emphasize that the first groups of activities should foster facilitators and leaders that will be a core resource for later activities. An important approach to reduce the time needed to reach a mature network structure and culture regarding managing activities should be to collaborate with other existing EU projects that have already gained valuable experience in running cross institutional and cross-national development projects related to cancer. Some of these projects might acknowledge the EU Network of CCCs as a possible harbour for a more permanent and long-term institutional networking.

8) <u>Some remarks on the formal role of the network organization and the</u> <u>consequence for the organization of network activities</u>

The formal organizational structure of the EU Network of CCCs will be the governance structure that makes the decisions regarding engagement in initiatives, type and degree of involvement and the deployment of resources connected to the possible activities. The necessary balance of the bottom-up and top-down dynamics in these processes mentioned in the previous point has to be taken into consideration when designing the governance structure. It must be emphasized that the elected leaders and supporting management have the responsibility to encourage and facilitate cross-border activities initiated by members or group of members. However, often these ideas often need some processing from the immediate version to a performable network activity. Then the formal structure of the network should provide arenas suitable for this. The structures and processes of the governing bodies of the network should favour the application of accumulated insights from excellent practice and overview of similar challenges as a source to initiate collective network initiatives. These recognitions should influence the design of governance structures of the network, the processes through which it works and the required characteristics of persons that should be recruited for governing managerial positions.

The role of these ideas of activities in the establishment of the EU network of CCCs

The glue binding together the EU network of CCCs will consist of two elements; first, the certification based on a common framing of criteria, standards and requirements for the conduction of certification process and secondly, the collaborative activities directly (and indirectly) organized by the network. This means that, when establishing the network, organizing the first joint activities should have high priority. However, since the establishment of the formal organization of the network and the connecting, generally accepted, system for membership admission (through a certification accepted by MSs) will take some time, the initial development of joint activities should be initiated and managed by the implementation project. This will then also provide valuable experiences for final structuring of the network and its governance and management.

The relation between network activities and certification of CCCs

The collaborative network activities of the EU network of CCCs could be anticipated as the second leg of the EU network, while the first leg is the certification process. There should be



obvious synergies between these. First, the experiences gained through the certification process and its attached preparatory and improvement activities should provide the network with crucial information on possible areas and ideas of joint collaborative action by the network. Secondly, commonly identified preparatory and improvement activities connected to certification could be supported through joint activities by the network and thus directly engaging the network in creating equal access and equity to services and research of CCCs.

6 Thematic activities - building collaboration and coordination on specific topics of joint interest

6.1 Care, Treatment and Diagnostics

We have grouped the proposed thematic activities into three groups. The first five activities are to a large degree related to the field of cancer care, treatment and diagnostics. What connects these is their contribution to identify and disseminate best practice through standards, tools for continuous improvement and creating space for mutual learning – either in general or on specific parts of the patient pathways. Several of these areas will also be linked to the two other activity groups; research and innovation, and governance.

6.1.1 Clinical guidelines

Title: Advancing Cancer Care: Defining Unmet Needs and Promoting Best Practices

Specific possible areas and types of activities:

- Dissemination of existing clinical guidelines:
 - Partner with existing expertise and actors in clinical guideline development (organisations/developers, e.g., ESMO).
 - Establish a database of existing evidence-based guidelines, including different aspects of cancer care (prevention, diagnostics, treatment, follow-up, etc.), with regular updates.
 - \circ $\;$ Disseminate information on established guidelines and updates.
 - Sharing strategies for implementation (experience, successful and less successful; recognised barriers and how to overcome these).
- Promote implementation and adherence to guidelines in alignment with managing CCC standards and certification processes.
- Establish a platform to:
 - Monitor and evaluate:
 - Adherence to guidelines.
 - Strategies for implementation.
 - Mutual learning: how to help CCCs monitor its adherence to guidelines and share practices on effective (and less effective) strategies for implementation and improvement.



- Patient involvement: designing and disseminate possible models for patient involvement in guideline development.
- Defining Unmet Needs:
 - Establishing channels for healthcare professionals and stakeholders to provide feedback on needs, report challenges, successes and lessons learnt in implementing existing guidelines and suggest areas for improvement.
 - Conduct a thorough assessment to identify gaps or areas where clinical guidelines are needed. This may involve reviewing existing guidelines, analysing healthcare data, and consulting with key stakeholders—for example, social support, psycho-oncology, survivorship, lifestyle, etc.
 - Stakeholder Engagement: Involve relevant stakeholders, such as patient advocacy groups, healthcare organisations, and policymakers, to provide input and feedback.
- Create communication channels to connect with established organisations (disciplinespecific or general that develop guidelines) and express the need for guidelines in the specific areas identified in connection with the patient pathway (within the scope of responsibilities of the CCC or outside). Stay involved in updating clinical guidelines (share experiences from the CCC).

Benefits for CCCs and MSs:

CCCs:

- Short term:
 - Easy access to a reference database of essential guidelines.
 - Facilitated standardised and evidence-based care practices through the application and management of guidelines.
 - \circ Updated guidelines based on the latest scientific evidence and expert consensus.
 - Improved patient safety: Reducing the likelihood of errors, complications, and adverse events.
 - Guidance on implementation strategies (reducing the need for trial-and-error approaches).
 - \circ Identified gaps in knowledge and areas where further research is needed.
 - Simplified processes for expressing needs, ensuring patient and public involvement, dissemination and implementation.

MSs:

- Short term:
 - A guided process of building excellence reduces unwarranted practice variations and ensures that patients receive consistent care regardless of where they receive treatment.
 - o Benchmarking: ensuring that providers meet established quality benchmarks.
 - Optimised resource allocation: assisting healthcare systems in allocating resources efficiently by recommending the most efficient and cost-effective interventions.



- Enhanced patient-centred care: Involving patients in gap analysis ensures that recommendations align with patient preferences, values, and needs.
- Informed policy and regulations: use clinical guidelines to impact the development of healthcare policies, quality standards, and reimbursement strategies.

Joint benefit for EU:

- Short term:
 - Streamlined care processes.
 - Shared knowledge and harmonisation of care practices across borders.
 - Evidence-based recommendations supporting clinical decision-making (especially for complex or rare medical cancers).
 - Guidance on priorities in policy on research and care.
- Long-term:
 - Improved healthcare equity and outcomes.
 - Optimised resource allocation and efficient healthcare delivery (reducing patient waiting times).
 - Patient involvement and empowerment: Clinical guidelines implemented in alignment with patient preferences, values, and needs.

Indicators of success:

- Comprehensiveness of the database of clinical guidelines; number of areas covered and used
- Broad dissemination: number of visitors (unique or based on CCC) of database
- Higher adherence to guidelines; number of centres following guidelines
- Number of new guidelines in areas with unmet needs
- Uptake of new guidelines by other actors

Contributions required from the Network and CCCs:

Network:

- Establishing a common database for clinical guidelines and ICT.
- Facilitating establishment and coordination of expert panels for guideline collection and gap analysis.
- Developing strategies for (and executing) dissemination of tools (e.g. database, newsletters and webinars).
- Share and collect experiences on advocacy and implementation strategies for CCCs.

CCCs:

- Sharing expertise/guidelines on relevant areas.
- Incorporating new practices.
- Facilitating channels for patients and professionals to express needs.
- Sharing data on the implementation of clinical guidelines and adherence to guidelines.



• Performing internal benchmarking and evaluating new practices (based on standardised procedures delivered by the network).

Connections to other EU projects:

Development and dissemination of new guidelines will be aligned with the development of European Clinical Practice Guidelines within the European Reference Networks (ERN) focused on rare cancers like paediatric cancers (ERN PaedCan <u>https://paedcan.ern-net.eu/the-escpproject/</u>), rare adult Cancers (ERN EURCAN doi: 10.1093/annonc/mdy310 doi: 10.1016/j.annonc.2021.08.1995) and rare blood diseases (ERN EuroBloodNet. <u>https://eurobloodnet.eu/best-practices/guidelines-and-recommendations/</u>)

Clinical guidelines developers: ESMO, discipline specific, nursing associations.

Connection to other activity areas: The development of guidelines might be connected to research through dissemination of research results and processes of implementing new knowledge into practice. The process of managing guidelines also links to the governance of a CCC. In addition, it will be directly an output from cross diagnosis activities on areas such as survivorship, prevention, and precision diagnostics.

6.1.2 Clinical data for research and quality monitoring

Title: "Harmonisation of Data Collection and Sharing Practices in CCCs: Advancing Quality Development and Research Collaboration"

Specific possible areas and types of activities:

- Mapping existing initiatives on clinical data for research: identify existing tools, potential gaps in current EU and national initiatives and creating a joint discussion based on the results.
- Needs assessment: identifying the needs of MSs and CCCs so that the Network could pool resources, harmonise practices and develop one unique tool in connection to the European Health Data Space (EHDS).
- Promote existing platforms and/or create new ones (if gaps are identified) to share knowledge: provide an arena to exchange ideas and identify areas where data cooperation/sharing would be more beneficial and to implement pilot initiatives based on previous projects.
- Tracking the involvement of the Network in key EU initiatives and its results.
- Developing a quality monitoring system through standardised data collected from Network members (EHDS, OPTIMA).
- Promote and share practice on data collection related to patients' quality of life, outcome (PROMS) and experiences (PREMS) and their translation into clinical routine.

Benefit for CCCs and MSs:



- CCCs:
 - Learning from each other regarding the process of designing a data architecture for internal and external access.
 - Easier access to aggregated clinical data for research across multiple CCCs.
 - Enabling joint research projects based on clinical data across borders.
 - Knowledge of opportunities to join established EU initiatives and consortiums fostering development and quality assurance in clinical data for research and care.
- MSs:
 - Defining areas for improvement and setting priorities based on similarities and experiences by other healthcare systems and countries.
 - Support the development of evidence-based policies and national cancer strategies.

Joint benefit for EU on improving cancer care and research:

- Evaluate performance and allocate resources more efficiently.
- Harness and develop strategic capacity in policy development and launching initiatives aligned to the need.
- Become more attractive to the industry and improve overall cancer outcomes.

Indicators of success:

- Creation of a platform, including a definition of the core variables to be included.
- An increasing number of CCCs and MSs are participating and collecting clinical data in accordance with agreed procedures and harmonised format.
- A comprehensive breath in data points is collected and shared.

Contributions required from the Network and CCCs:

- Network: designation of certain CCCs to organize the process.
- CCCs: identifying key personnel by area of expertise (clinical, IT, legal, research).

Connections to other EU projects

UNCAN.eu, EU4Health Dataspace, EHDEN, OPTIMA, ELIXIR, EDIC, ERIC, EU Open Data Space, Galaxy, GA4GH, ISO, Derivated EGA, 1M+ Genome project, JANE.

Connection to other activity areas: This activity area will have close connection to the activity areas of Research and Clinical Trials.

6.1.3 Cancer in children, adolescent and young adults and survivorship

Title: "Widening Horizons: addressing specific needs of children, adolescents and young adults with cancer and beyond"



Specific possible areas and types of activities:

- Establishment of CCCs with specific expertise or infrastructure (e.g. proton therapy, cellular therapy, etc.) suitable for children and young adults with cancer (CAYA).
- Defining national and cross-border referral pathways to ensure rapid access to optimal detection, diagnosis, treatment, and care for CAYA.
- Providing facilities for innovative therapies within academia and industry-driven clinical trials applicable in CAYA.
- Supports late-follow-up clinics for survivors and issues of long-term follow-up recommendations, including SurPass.
- Facilitation of preventive initiatives aiming at early detection of second cancer in survivors.
- Spreading knowledge on specific medical, educational and societal needs of survivors to all relevant stakeholders.
- Conduct observational research on late effects.
- Evaluation of national childhood cancer survivor cohorts in collaboration with epidemiologic cancer registries.
- Collaboration with parents, survivors, patient advocacy groups and NGOs.

Benefits for CCCs and MSs:

- CCCs:
 - Establishment of strong links within the Network of CCCs and facilitation of access to specific diagnostics and/or therapies.
 - Scaling-up and improvement of survivorship care.
 - Accumulation of knowledge of national, regional and European activities on survivorship care and research and gaining expertise in the field.
 - $\circ~$ Establishment of a common approach in second cancer prevention.
- MSs:
 - Empowering society in the decision-making of the best care for CAYA.
 - Facilitation of cross-border referral pathways necessary to access to specific expertise.

Joint benefit for EU on improving cancer care and research:

- Reducing inequalities in access to innovative therapies and survivorship care across EU member states.
- Scaling-up survivorship care, research and quality of life.
- Knowledge sharing and best practices (standardised, evidence-based approaches to survivorship care).
- Improved quality of life of European citizens who overcame cancer in the past.

Indicators of success:

- Increasing number of children included in early-phase clinical trials
- An increasing number of survivors were provided with individual follow-up recommendations and followed





• Number of specialized late-effect clinics

Contributions required from the Network and CCCs:

- CCCs:
 - Share practices and data on cancer prevention (including research) and support policy implementation at regional and national levels.
- Network:
 - Provide arenas and infrastructure to share knowledge.

Connections to other EU projects

ERN PaedCan, PanCareSurPass project, SurPass, PanCare, IHGH (https://www.ighg.org/), Jane – Network of Expertise

Connection to other activity areas: This activity will be closely linked to both research by possibly providing data to research projects- not least in the perspective of so-called real-world data/evidence- and governance by releasing data-platforms for more data-driven governance and leadership regarding management of quality and logistics in cancer care.

6.1.4 Precision cancer diagnostics

Title: Precision diagnostics in cancer – sharing knowledge on technology, analyses, logistics, education and organisation to strengthen cross-centre and cross-national collaboration on standardisation and implementation of methodology from research to clinical impact.

Specific possible areas and types of activities:

- Creating infrastructures for personalised medicine with a focus on cancer care and research:
 - Strategies for implementation: national, regional and local challenges and sharing of best practices and experiences.
 - Access procedures to new technologies, diagnostics, and medicinal products.
 - Strategies for dealing with organisational challenges and adaptation of existing organisational structures to accommodate for clinical care/research interphase.
 - Standardisation and (In Vitro Diagnostic Medical Device Regulation) IVDR collaborations.
- Management structures and procedures for stakeholders engagement; patient organisations, pharma industry, health authorities, policy makers etc.
- Unmet needs relating to research:
 - Broad access to patient data, biobanks etc.
 - ICT infrastructure, data integration and storage.
 - Technology assessment and testing.
- Development of evidence-based guidelines, detailed decision trees, potential for collaboration to create necessary evidence base for individualised treatment options.



- Collaborative experimenting regarding the organization of patient involvement in the design of communication connected to the output from precision diagnostics
- Possible products from these activities:
 - Guideline developments.
 - Educational programs.
 - Mentoring programs.

Benefits for CCCs and MSs:

CCCs:

- Facilitated access and procedures to implement precision cancer diagnostics and/or perform research within precision cancer diagnostics.
- Establishing infrastructures needed to provide precision medicine directly or as partners in clinical trials.

Member States:

• Providing equal access to precision cancer diagnostics and precision cancer medicine.

Joint benefit for EU:

- Short term: Knowledge transfer between CCC centres. Shorten time and resources used when implementing methodology, shared expertise making local efforts in developing precision medicine.
- Long-term: Harmonised access to precision diagnostics and thus to treatment programs and clinical trials.

Indicators of success:

- Number of sites/CCCs providing access to platforms in precision diagnostics.
- Number of patient pathways including precision diagnostics.
- Number of research projects within precision diagnostics.
- Number of clinical trials within precision medicine.
- Number of programs developed to develop and ensure precision diagnostics.
- Cumulative funding generated for initiatives connected to precision cancer diagnostics and precision medicine.

Contributions required from the Network and CCCs:

- Providing platforms for mutual learning:
 - \circ $\;$ Sharing best practices of precision cancer diagnostics (database).
 - $\circ \quad \text{Sharing strategies for implementation.}$
 - Sharing experiences on building required infrastructures, educational programs, and strategies for implementation (including organisational adaption).
 - \circ Guidance for IVDR and GDPR (legal support).





- Develop/provide access to educational and mentoring programs covering aspects related to precision cancer diagnostics and precision medicine across all disciplines (including management).
- Contact point for stakeholders: patient organisations, pharma industry, health authorities, policy makers etc.

Connections to other EU projects:

Education and training, data management, PCM4EU, PRIME-ROSE, CCI4EU, CAN.HEAL, B1MG, DIGICORE, EUCAIM, ICPerMed.

Connection to other activity areas: The development of precision diagnostics will provide cancer research in general and clinical trials specifically with new opportunities of recruiting patients, designing trials and cross-center collaboration (e.g. connected to molecular tumour boards).

6.1.5 Primary and secondary prevention and early detection

Title: "Harmonizing Horizons: Advancing Cancer Prevention through European Comprehensive Cancer Centres" OR "Harmonizing Horizons: CCCs for Advances in Cancer Prevention"

Specific possible areas and types of activities:

- Facilitate interaction and synergies between public and specialised health care in cancer.
- Mapping cancer stage at diagnosis across Europe by linking National Cancer Registries and other clinical cancer databases for cancer entities where prevention and early detection strategies are in place.
- Providing support to institutions and other actors on primary and secondary prevention and contributing to their prevention strategies by providing data, experiences and results.
- Development of joint guidelines and activities on cancer prevention to ensure consistency and quality across the network.
- Strengthening capacity within the Network in terms of prevention and standards for prevention.
- Possible collaboration with JANE's Network of Expertise on Primary Prevention and other initiatives on cancer.
- Research on misinformation to support public authorities in primary prevention.
- Establishing a space for patient participation in defining the development of efficient prevention.

Benefit for CCCs and MSs:

• CCCs:



- Increased awareness of national, regional and European activities related to prevention in the CCC.
- Fostered interconnectivity and promotion of activities within prevention for improved patient outcomes.
- Build strategic partnerships to do research on prevention and citizen and patient-centred unmet needs.
- MSs:
 - Reduced silo-thinking on cancer care, develop and harvest synergies. On a national level this will support the activities to lower incident and mortality rates.

Joint benefit for EU on improving cancer care and research:

- Enhanced public health (earlier cancer detection, more effective treatments, and reduced cancer-related mortality rates).
- Economic prosperity: improved cancer care and prevention research can alleviate the economic burden associated with cancer.
- Knowledge sharing and best practices (standardised, evidence-based approaches to cancer prevention).

Indicators of success:

- More effective preventive measures including vaccination programs, early detection campaigns, and lifestyle interventions.
- Periodic monitoring of cancer stage at diagnosis where prevention and early detection strategies are in place.

Contributions required from the Network and CCCs:

- CCCs: Share practices and data on cancer prevention (including research), support policy implementation on institution regional and national level.
- Network: provide arenas and infrastructure to share knowledge.

Connections to other EU projects

CONCORD, EUROCARE-5 and 6 studies, European Network of Cancer Registries (https://encr.eu/) and the European Cancer Information System (https://ecis.jrc.ec.europa.eu/) of the Joint Research Centre of the European Commission. EUCanScreen, European Cancer Inequality Registry (https://cancerinequalities.jrc.ec.europa.eu/data-tool-by-country) for data on prevention and early detection.

Connection to other activity areas: These activity areas might have connections to the ones on research and precision diagnostics, based on the recognition that more precise, targeted primary and secondary prevention will benefit from improving the current knowledge base in these areas.



6.2 Research and Innovation

Research and innovation represent the second group of thematic activities. Such group aims at fostering continuous improvement by creating collaborative synergies (sharing volume and expertise), mutually catalysing the performance of research, trials, and innovations, and facilitating equal participation and access to the dissemination of research outcomes and to innovative solutions.

6.2.1 Research

Title: Unlocking Cancer Research Synergies through the European Network of CCCs

Specific possible areas and types of activities:

- On a general level:
 - Develop a resource-sharing strategy (protocols, data, equipment, education on research methodology including clinical trials).
 - Foster mobility through shared projects or mobility programs on individual level or team.
 - Establish platforms to enable data sharing (in alignment and through collaboration with other EU initiatives).
 - Share practices on data management (platforms and pipeline for analysis).
 - Promote and facilitate comprehensive research projects (platform to disseminate calls and promote collaborative proposals) + can be paired with securing mobility.
 - Promote sharing negative findings.
- Related to basic research:
 - Develop a database for available cell lines and/or animal models within the network (or connect to existing databases or initiatives with similar activities).
- Related to translational:
 - Develop a database for available in vivo/on-chip models within the network (or connect to existing databases or initiatives with similar activities).
 - Share best practices on tissue collection and data handling.
 - Establish a database for ongoing translational projects within the network (open for new collaborations).
- Related to clinical research (in addition to clinical trials):
 - Collect bottom-up information on the 90% outreach objective at the local level and drivers of inequalities.
 - \circ Support updating/development of guidelines related to prevention.
 - Foresee a mechanism supporting RT research in terms of funding, given the restricted participation of the medical devices industry.





- Related to patient involvement:
 - Sharing experiences of patient involvement in different phases of research and from this building a database of experiences.

Benefit for CCCs and MSs:

- CCCs:
 - Access to expertise: leverage the specialised skills and experiences of other CCCs, accelerating their research and clinical capabilities.
 - Enhanced collaboration: foster a culture of teamwork and interdisciplinary cooperation among CCCs. Identify similar/complementary research objectives – collaborations.
 - Avoiding duplication and competitive research projects enabling synergies and increased impact.
 - Elevated reputation: attractive partners for national and international research projects and collaborations, research funding and potential industry partnerships.
- MSs:
 - Improved competitiveness.
 - Faster development in research and innovation.
 - Economic benefits (job creation, investment in healthcare infrastructure, and the potential for spin-off companies and start-ups in the biotech and pharmaceutical sectors).

Joint benefit for EU on improving cancer care and research:

- Improve competitiveness.
- Faster development in research and innovation.
- For CCCs and EU: easy transfer and development of translational research to industry (not reasonable for a single centre).
- Economic benefits.

Indicators of success:

- Increased number of publications in basic, translation and clinical research.
- Increased impact on publications.
- More multi-disciplinary research.
- Achieve scientific goals and improve public health across Europe.

Contributions required from the Network and CCCs:

- Network:
 - Build platforms with databases to share experience and overview of ongoing research projects in the network.



- Facilitate open forums and meeting points to discuss research, open calls, set research agendas and coordinate shared applications.
- CCCs:
 - Devotion and commitment.
 - Motivation to improve.
 - \circ $\;$ Willingness to share knowledge and resources.
 - Propose different models for research evaluation/ papers with international authors.

Connections to other EU projects:

The existing Horizon Europe Widening programme supports a raise in research and innovation in Widening European countries that underperform in research and innovation indicators https://research-and-innovation.ec.europa.eu/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe/widening-participation-and-spreading-excellence_en.

Connection to other activity areas: The research activity area will be linked to all the others under Research and innovation and to the activity area on clinical data.

6.2.2 Innovation

Title: Innovations in Comprehensive Cancer Centres: Advancing Together

Specific possible areas and types of activities:

- Strengthening the capacity of CCCs' standards on innovation:
 - Networking:
 - Organising forums to share innovative ideas.
 - Match-making activities to connect companies to CCCs.
 - \circ $\:$ Identifying some areas where to organise connection events.
 - Training opportunities exchange programmes specifically on innovation.
 - Knowledge-transfer:
 - Developing experience-based joint models for the cancer related innovation infrastructure.
 - Sharing experiences on how to facilitate the building of regional or national innovation clusters.
 - Helping with technology transfer, IP protection and commercialisation.
 - Sharing experiences, practices and pooling resources.
 - Providing resources to support innovation in CCCs.
 - Developing and experimenting with models for patient driven innovations
- Ensuring that innovation includes all areas of cancer care and research.

Benefit for CCCs and MSs:

• CCCs:



- Increased capacity to meet standards on innovation and facilitate internal activities in innovation (including promoting an innovative culture).
- $\circ\quad$ Strengthen its brand and reputation.
- Foster extramural financing gain.
- Become an attractive partner for industry.
- Attract and train talents with multidisciplinary background (including experience and knowledge in health tech).
- MSs:
 - Strengthened innovative culture.
 - \circ Provided arenas for economic development in health technology.
 - \circ Capacity building in knowledge and internationalisation of innovation in health care.
 - Foster development of spin-off companies (jobs etc.).

Joint benefit for EU on improving cancer care and research:

- In the long term, the EU could be at the forefront of innovation on cancer.
- Increased competitiveness towards industries (e.g. innovation clusters).

Indicators of success:

- The formation of innovation clusters or membership in innovation clusters.
- CCCs fulfilling standards on innovation.
- Spin-off developed associated with CCCs.
- Number of initiatives the Network took (ideas exchange opportunities, training).

Contributions required from the Network and CCCs:

- Network:
 - Involving innovation centres in activities.
- CCCs:
 - Providing those who are more successful with incentives, start-up toolkit and know-how.

Connections to other activity EU projects

IMI- Flagship on EU innovation Cancer Mission projects within Horizon Europe.

Connection to other activity areas: This activity area should be linked to the activity areas of research, industry relations, policy and policy makers and regarding service innovation to prevention and survivorship care.

6.2.3 Clinical trials

Title: Advancing Clinical Research: Building the European Clinical Trials Engine





Specific possible areas and types of activities:

- Establish a platform to foster clinical trial activity:
 - Database of ongoing clinical trials:
 - Within the Network
 - Connected to EudracT and euclinicaltrials.eu and other existing databases
 - Facilitated for patient recruitment from CCCs in the network (but avoid exclusivity)
 - Develop complementary databases for disseminating information on available trials, resources and eligibility, SOPs and trial results to avoid duplication.
 - Assess needs and develop strategies in areas with unmet needs.
 - Analyse the need for adjusted outcome measures (harmonisation in connection to clinical data collection).
 - Establish a pipeline to set up CCCs within the network to be study sites for clinical trials and facilitate local treatment for eligible patients.
 - Establish a clinical database for research (acc. GDPR and so on).
 - Build evidence to support policy-making and promotion of clinical trials.
- Standards and development:
 - Promote transparency in clinical trial results: possible early results, especially negative.
 - Promote low threshold for patient participation¹; rare tumour and connect to ERNs.
 - Guidance for proposing new clinical trials (initiation, protocol writing, funding and competitiveness).
 - Propose new evaluation methods for clinical trials (ask a proper research question, build enough expertise).
 - Facilitate translational research to be embedded in clinical trials:
 - Promote and facilitate biobanking as an integral part of clinical trial activities to foster translational research and cross- and multidisciplinary research activities.
 - Facilitate collection of clinical data to share with biobanked material and for translational/clinical research.
- Partnership building:
 - Foster partnership for funding: academic and sponsored.
 - Promote public-private partnerships.
 - Develop a search tool for finding collaboration partners.

¹ Low-threshold clinical trials: clinical research studies or trials that are designed with simplified or reduced entry criteria for participants, making it easier for a broader range of individuals to enrol. The term "low threshold" implies that the eligibility criteria for participation in these trials are less stringent or demanding compared to traditional clinical trials. It would be nice to provide a source of this definition



- Collaboration in designing and conducting academic (non-industry driven) clinical trials.
- Developing and disseminating models for patient involvement in the decisions processes connected with establishment of investigator initiated clinical trials

Benefit for CCCs and MSs:

- CCC:
 - Increased research activities.
 - Financial gain and resource consolidation.
 - Access to more eligible patients for clinical trials.
 - Broadened portfolio for patients for clinical trials: Provide easy access to eligible patients to the clinical trials to be executed abroad or at the local hospital patient availability for participating in the clinical trials.
 - Knowledge exchange.
 - Avoiding duplication of trials.
 - Translational and clinical attracted collaboration to be made available if other elements are interested.
- MSs:
 - Local capacity building.
 - Fast-tracked development of evidence.
 - \circ Better access to innovative treatment and improved survival for patients.
 - Decreased cost of performing clinical trials.

Joint benefit for EU on improving cancer care and research:

- Advancing health care for cancer patients.
- Accelerated progress of cancer research.
- Global impact (attracting industry).
- Streamlined regulatory processes.
- Navigate complex regulatory processes collectively (help expedite regulatory approvals, ensuring that clinical trials can begin more quickly).

Indicators of success:

- Increased accrual rate.
- Improved survival.
- Increased funding acquisition.
- Increasing number of academic trials.
- Increased multi-institutional trials (non-pharma)
- More biobanked material available for translational research (publications).

Contributions required from the Network and CCCs:

- Network:
 - Coordination unit (maintain DB; IT support and tools).



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- Guidance (protocol etc.).
- Platform for exchange of ideas (TTO service).
- CCCs:
 - Provide data (clinical trials data, patients).
 - Biobanking activities.
 - Human resources.
 - Dissemination: recruit/enrolment.
 - Monitoring, publish and report.

Connections to other activity points and EU projects:

EudracT /(<u>Clinical Trials in the European Union - EMA (euclinicaltrials.eu)</u>), PCM4EU, PRIME-ROSE, ACTEU, EU-IN, ECRIN (<u>https://ecrin.org/clinical-trials</u>)

Connection to other activity areas: This activity area will be linked to the activity areas of clinical data and research.

6.3 Governance and Policy

The most peculiar group of activities organized by the EU Network of CCCs is probably the one connected to governance and policy. These activities are linked directly to the managerial role of Cancer Centres. These activities aim at exchanging experiences, models and application of standards for the governing of CCCs and the networks to which they are connected often as a hub. These activities also seek to facilitate joint initiatives on the development of collaborative structures involving political bodies, academic institutions, patients' organisations and relevant businesses.

6.3.1 Governance and organisation of CCCs

Title: Enabling the development, uptake and implementation of Effective Governance Structures and Processes to Improve CCCs' Performance and Operations

Specific possible areas and types of activities:

- Standards:
 - Investigating into the relations between the health care systems and the governance models of CCCs.
 - Development of Standards of governance (multidisciplinary teams).
 - Putting in place conflict management mechanisms with clear procedures and roles.
 - The governance should include processes, procedures and dedicated personnel to manage external relations (universities, institutions, GP).
 - Developing experience based models for patient involvement in the governance of CCCs
- Networking
 - Creation of a Network linking Cancer Centre Leaders.



- Implementation:
 - Support with strategy development.
 - \circ Creation of guidelines on how to implement effective governance processes.
 - Providing a platform to exchange experiences to guide governance processes.
 - Exchanging and analysing experiences of governance models related to CCCs and governance of the networks they are embedded within.
 - Access to support connected to organisational change and development according to the requirements of being and continuing to be a CCC.
 - Providing training opportunities for managers.

Benefits for CCCs and MSs:

CCCs:

- To improve their performance, capacity and cross-organizational problem-solving.
- To improve clinical management and enhance the overall management model.

MSs:

- Access to better options, management best practices, treatment, etc.
- Increase the total capability to deliver high quality governance comprehensively coordinated in and across the cancer centres in each MS.

Joint benefit for EU on improving cancer care and research:

- Better care for patients across the EU.
- Homogenisation of standards related to governance throughout the EUCCCs.
- The EU could improve its competitiveness and efficiency; the new governance structure could help reach current and new targets in cancer care.

Indicators of success:

- Number of CCCs that meet the standards and the proposition of total number of potential cancer centres.
- Number of comprehensive networks connected to the cancer centers.
- Number of new partnerships being formed.
- Number of managers trained.

Contributions required from the Network and CCCs:

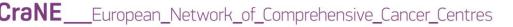
EU Network:

- The Network should provide knowledge and resources.
- The Network could build partnerships with institutes such as the EHMA (European Health Management Association) for training activities.
- The Network should be responsible for the dissemination of opportunities among its members.

CCCs:

- CCCs should provide personnel interested in these activities.
- CCCs should demonstrate their availability and commitment.





• CCCs should communicate these opportunities and their importance to all relevant personnel.

Connections to other activity points and EU projects:

Possible points: Connect to experiences made from other EU projects based on matrix processes and networks (like JANE, ERN, UNCAN, and so on).

Connection to other activity areas: This activity area should potentially be connected to all the others

6.3.2 Standards for CCCs

Title: Standards providing *state-of-the-art* high-quality comprehensive cancer care and research across Europe

Specific possible areas and types of activities:

- Governance:
 - Establishing and administering/coordinating a governance body responsible for updating common standards /definitions (separately for different areas, e.g. prevention, treatment, screening, diagnosis) in alignment with new developments in cancer care and research and patient's needs.
 - Harmonisation of criteria of different CCCs certification systems across Europe.
 - Monitor and evaluate adherence to standards.
- Establishing a platform for:
 - Continuous improvement: Assessing unmet needs and establishing multidisciplinary expert panels (healthcare professionals, researchers, methodologists, quality managers and patient representatives with relevant expertise) to perform gap analysis, recommend updates and/or development of standards.
 - Supporting and facilitating implementation: Develop and disseminate strategies for the effective implementation of new standards.
 - Collecting experience and mapping of barriers: Addressing countryspecific challenges (barriers) linked to adherence to standards for CCCs (comment: different countries may experience different challenges related to the county-population/patient volume/expertise, research infrastructure and funding, national healthcare and educational system organisation).
- Facilitating stakeholder engagement: e.g., patient advocacy groups, healthcare organisations, and policymakers in various arenas.

Benefit for CCCs and MSs:



- CCCs:
 - Short term:
 - A society with shared standards for benchmarking.
 - o A platform for knowledge exchange on implementation strategies.
 - A framework fostering continuous improvement.
- MSs:
 - Short term:
 - A common program that supports the quality of cancer care, research and education in the country.

Joint benefit for EU on improving cancer care and research:

- EU will have a tool for reducing inequality in cancer care, research and education.
- Harmonised criteria for certification.
- Realising its <u>ambition to ensure high standards in cancer care in the EU as set out in</u> <u>the EBCP-</u>

Indicators of success:

- Homogenisation of the application of the standards
- Increased number of institutions adhering to the criteria and standards.
- Indicators of effective implementation of standards and continuous improvement on both institutional and network levels.
- Indicators of high-quality care and research are improving on institutional and network levels.
- Periodic evaluations of the adherence to standards and recommendations.

Contributions required from the Network and CCCs:

Network:

- Developing and defining standards and updating them.
- Evaluation of standards and centres' adherence to standards.
- Develop a platform to enable:
 - \circ Sharing of standards and collecting feedback (experiences).
 - $\circ \quad \text{Disseminating updates on standards.}$
 - Sharing experiences in implementation.
 - o Monitoring (dashboard of quality indicators)

CCCs:

- Be active partners in implementation strategies.
- Provide data on quality indicators for care, research, related to adherence and improvements.
- Share experience on specific topics related to standards and promote updates when relevant.



Connections to other activity points and EU projects:

• ERNsat EU level.

6.3.3 Influencing policy and politics regarding cancer

Title: Shaping the Future: Driving the policy on delivering High-Quality Care and Research across Europe

Specific possible areas and types of activities:

- Mapping/creatingrepresentativeness of the EU Network of CCCs on the policy level both on the European (EU Parliament) and National (Ministry of Health?).
- Mapping of existing National Cancer Plans and if they address National actions regarding CCCs/CCCN.
- Definition of the governance and strategy of the Network to engage with EU institutions and organisations.
- Communication and dissemination of current and upcoming EU programmes and initiatives on cancer within the Network.
- Establishment of a regular dialogue with EU institutions: the Network could influence EU cancer policy by providing data, evidence-based strategies, practices and experiences from CCCs.
- Reporting on the effect of policies and initiatives (regional, national, European): evaluate outcomes and areas of improvement.
- Guiding policymakers in making informed decisions: contribute to developing cancer policies by providing evidence-based recommendations on cancer prevention, screening, and treatment.
- Advocating for increased funding for cancer research, treatment, and prevention; highlighting the importance of these investments, cancer centres can influence policymakers to prioritise cancer-related issues in their policy agendas
- Building alliances with patient organizations on European and national level

Benefits:

CCCs:

• Increased influence on external factors affecting CCCs' operations and activities.

MSs

• More informed priorities on cancer policy. Justification and legitimation of launched initiatives with support from key opinion leaders (CCCs) for implementation.

Joint benefit for EU on improving cancer care and research:

• Strategic capacity to keep the EU at the forefront of stakeholder involvement. Otherwise, same as for CCCs and MSs, and the EU will be more competitive with the rest of the world.



• Increased evidence-based EU programmes, initiatives and projects on cancer.

Indicators of success:

- Established channels to influence and make recommendations with a political or governance channel.
- Governance structures to facilitate channels of dialogue regarding development and implementation of strategies and cancer related regulations.
- Increased funding for care and/or research.

Contributions required from the Network and CCCs:

Network:

- Prioritise setting up channels to MoH or equal policy and decision-makers.
- Be active to coordinating efforts to build evidence for recommendations.

CCCs:

• Active participation in the Network, with time allocation.

Connections to other activity points and EU projects:

EBCP and National Cancer Plans in each MS.

This thematic activity is connected to the ECHoS project aiming to coordinate R&I and Healthcare actions on cancer with policy-making processes.

Connection to other activity areas:

6.3.4 Patient involvement

Title: Ensuring Patient Participation and Involvement within CCCs and the EU Network

Specific possible areas and types of activities:

- Gathering and analysing patients' involvement and experiences in CCCs of different MSs.
- Establishing a platform to share what has worked from the clinical side (clinicians and professional societies) for getting patients involved and what has worked for patients to be involved. Assessing experiences of patient involvement, documenting and disseminating excellent practices among CCCs (and empowerment). The EUnetCCCs should propel best practises and integration of successful involvement.
- Mapping of patient organisations at both national and European levels.
- Organisation of patients' forums and "living labs".

Benefits for CCCs and MSs:

CCCs:

• Lowered threshold for securing patient involvement: using already tested trajectories for patient involvement in processes related to the CCC.



- Lifting patient involvement to meet the requirements from national/regional authorities.
- Organisation and governance of CCCs will become more efficient and inclusive.

MSs:

- Patients will have better access to expertise in a broad Network of CCCs.
- Quality of care adapted to patients and citizens' perceived needs.

Joint benefit for EU on improving cancer care and research:

• Decreasing inequality and improving public health.

Success criteria for this activity:

- Increased trust in science and cancer care by patients, families and citizens.
- Number of patients or patients' representatives involved

Contributions required from the Network and CCCs:

- Networks:
 - Facilitate a forum to discuss patients' involvement, routines and researchdriven engagement.
 - Share practices on patient involvement, procedures and patient representative roles.
- CCCs
 - Adherence of patient participation by CCCs; patient organisation on a national level.

Connections to other activity points and EU projects:

JANE: Transversal task force on Patient Involvement, UNCan.eu, CCI4EU.

Connection to other activity areas: This activity area is now integrated in the description of most of the other activity areas

6.3.5 Industry relations

Title: Fostering Dialogue and Collaboration with the Industry to Create Opportunities for Growth and Development

Specific possible areas and types of activities:

- Developing partnerships and collaborations with the industry (e.g. biobanks):
 - Potential collaboration and participation in the activities of the <u>Innovative</u> <u>Health Initiative</u>, a partnership between the EU and EU life science industries. https://www.ihi.europa.eu/about-ihi
- Facilitating partnerships between CCCs and the industry on clinical trials by promoting and disseminating future opportunities.
- The Network has a legal department to regulate and facilitate such partnerships.



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Benefits for CCCs and MSs:

CCCs:

- Faster, easier and cheaper access to drugs.
- Negotiation of prices.
- Lower paper pathway.
- Cheaper and faster access to technology.
- Lower inequalities, same standards of care, same equipment.

MSs:

- Increased competitiveness.
- Overall improvement in terms of public health.

Joint benefit for EU on improving cancer care and research:

- Boosting the competitiveness of both European cancer centres and EU industry.
- The EU would become more competitive and create more partnerships with the private sector.

Success criteria for this activity:

- Number of contracts and partnerships formed.
- Number of joint research projects in collaboration with industry.

Contributions required from the Network and CCCs:

- Network:
 - Act as a facilitator between CCCs and the industry.
 - Act as a representative of CCCs.
 - Develop a blueprint for the new partnerships.
 - Represent smaller centres and advocate on their behalf.

CCCs:

- CCCs should communicate their needs and share results.
- Evaluate support and activities and provide feedback and further recommendations for the Network.

Connections to other activity points and EU projects

The Innovative Health Initiative,



7 Overarching activities - targeting the design and management of connecting processes with an open outcome or a thematic focus

7.1 Network building

Title: "Facilitating Collaboration and Networking Opportunities to Deliver High-Quality Care and Research in Europe"

Specific possible areas and types of activities:

- To build a database with dedicated contact points/persons per CCC dealing with networking requests or providing support.
- Developing networks based on a CCC aimed at improving coordination and clinical pathways of cancer care in a specific region.
- Developing networking opportunities clearly outlining goals and objectives to stimulate motivation and encourage participation.
- Creating linkages with regional networks and fostering regional access to expertise.
- Creating partnerships with other networks, such as ERNs on rare cancers and Networks of Expertise (JANE).

Benefit for CCCs and MS:

- CCCs:
 - Increased access to opportunities and expertise.
 - More opportunities for growth and development.
 - Easy and efficient access to expertise.
 - Optimisation of resources within the area of expertise: contact persons and channels for collecting and disseminating info.
- MSs:
 - Having a national resource and hub for collecting state-of-the-art knowledge for cancer care and research.
 - Providing access to state-of-the-art care and clinical trials for citizens.

Joint benefit for EU on improving cancer care and research:

- Fostering collaboration among different types of Networks and initiatives in Europe.
- Improving the sustainability of EU initiatives and Networks on cancer in the long term.

Success criteria for this activity:

- Networking should be recognized by CCCs, with personnel appointed as facilitators.
- CCCN working as a hub and spoke model.
- Understanding of benefits, budget for CCC people/contacts.
- Feedback on the networking for improvement purposes.





- Indicators for measuring the outcomes.
- Conferences, meetings, sharing good examples.

Contributions required from the Network and CCCs:

- Network:
 - Facilitate meeting points
 - Potentially contribute with funding for strategic network activities
 - \circ ~ Influencing the release of dedicated funding from the EU
 - o Disseminating opportunities
 - o Organization and coordination of networking initiatives
- CCCs:
 - Active participation in networking activities
 - Share contacts
 - Promote the Network and its activities

Connections to other activity points and EU projects:

JANE, ERNs (ERN EURACAN, EuroBloodNet, ERN PaedCan, ERN GENTURIS)

7.2 Capacity building

Title: Strengthening Capacity of CCCs to Ensure High-Quality Care, Research and Education

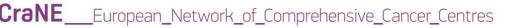
Specific possible areas and types of activities:

- Mapping needs in terms of education and training and identifying gaps and barriers.
- Mapping opportunities development, increased capacity, cooperation, expertise and knowledge sharing: mentorship programmes; teaming and twinning (institutional level, professional level); exchange programs; working groups; dissemination.
- Organisation of forums, workshops or meetings that bring together a wide variety of actors (e.g. CCCs, institutions, authorities at national and EU levels), as well as facilitators to discuss specific topics.
- Creation of IT tools/ platforms available to all within the Network.
- Close connection and potential synergies with CCI4EU on CCIs: utilising tools developed in CCI4EU.
- Identifying models for capacity building in alliance with patients and their organizations

Benefit for CCCs and MSs:

- CCCs:
- Improving processes on care, research and education and training.
- Increased visibility (institutional, EU, international levels).
- $\circ\,$ Increased productivity: scientific production, innovation, patients' outcomes.





- MSs:
 - o Decrease in low-quality care, better patient outcomes, quality of life and survival.

Joint benefit for EU on improving cancer care and research:

- Improving care, research, education and training in the EU.
- Increasing efficiency of operations.
- Reducing inequality between regions within the EU.

Indicators of success:

- Number of meetings/events organised.
- Turnout for capacity building activities.
- Perceived usefulness of these activities.

Contributions required from the Network and CCCs:

Network:

- Provide know-how, organize and facilitate events and meetings.
- Share effective communication strategies to sponsor events and initiatives.

CCCs:

- Willing and open to participate and actively contribute.
- Share their needs and experiences.
- Promote participation to these initiatives among its employees.
- Identify lecturers.

Connections to other activity points and EU projects

Twinning project TREL <u>https://cordis.europa.eu/project/id/952438</u> <u>European Cancer Inequality Registry (https://cancer-inequalities.jrc.ec.europa.eu/)</u> <u>CCI4EU.</u>

7.2.1 Education and training

Title: Strengthening relevance and quality of cancer specific Education and Training to Deliver Higher-Quality Care and Research in Europe

Specific possible areas and types of activities:

- Medical: creation of research; oncology (radiation, etc.), guidelines.
- Non-medical: offering digital; communication training, technical trainings etc.
- Patients and caregivers: Training on topics such as prevention, survivorship, side effects, psychological and nutritional support.
- Institutional authorities: collaboration with NGOs and national and regional authorities.
- Private partners: collaboration with insurance companies and small businesses.



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• Education and training providers: collaboration with providers of continuing medical education, health management training etc. to deliver specific training to healthcare professionals.

Benefit for CCCs and MSs:

CCCs:

- Increased continuous improvement of professionals.
- Better quality of life for patients, early diagnosis.

MSs:

• Lower incidence of cancer and lower mortality in the long term.

MSs and CCCs:

• Base for collaborative and innovative ideas.

Joint benefit for EU on improving cancer care and research:

- Financial resources could be better allocated, resulting into more efficient programs and less overlap).
- More exchange programs and knowledge sharing within the EU; close the gap in inequalities between MSs; contributing to the de-stigmatisation of cancer.

Indicators of success:

- Number of programs implemented in MSs, CCCs.
- Number of joint programs/initiatives.
- Presence of a core team for education.
- Dissemination, impact, team, sustainability.
- Number of participants/trainees.
- Quality assurance.
- Number of publications/books/articles.

Contributions required from the Network and CCCs:

Network:

- Creation of a team dedicated to education and training.
- Provision of general and specific training, as well as linking CCCs to existing programs and opportunities.
- Facilitating access to financial resources.
- Encouraging the exchange of knowledge and best practices.

CCCs:

• CCCs should provide information about their status to identify gaps and needs across the various departments and roles (e.g. medical and non-medical professionals, patients etc.).

Connections to other activity points and EU projects:

ESMO, SIOPE educational courses, ERNs provide webinars, ESO, EHMA





7.3 Sharing access to expertise

Title: Increasing cross-border Access to Expertise to Strengthen Cancer Care and Research in Europe

Specific possible areas and types of activities:

- Opportunities to increase access to second opinions and consultation services (multidisciplinary teams with experts).
- Providing and facilitating training opportunities on highly specialised procedures.
- Linkages with JA Network of Expertise (JANE): Identifying gaps and areas that JANE is not currently covering and creating opportunities to fill those gaps.
- Facilitating access to expertise (especially for junior profiles) on funding (e.g. research quality assessment and grant evaluation), methods, research, quality management, and governance.
- Organization of forums with Q/A sessions to match requests to expertise (the Network could go over requests and match them to the expertise needed).
- Connecting and collaborating with ERNs.

Benefit for CCCs and MSs:

CCCs:

• Quick access to experts and better care.

MSs:

• Improved public health.

Joint benefit for EU on improving cancer care and research:

- Building capacity to implement new policies and harmonise standards across multiple levels.
- Strengthening cross-border collaboration in Europe.
- Integration: Creating a European expert community.
- Fill gaps in expertise in EU MSs and regions and increase overall healthcare quality and outcomes.

Success criteria for this activity: number of matches with experts

• Collaboration with ERNs.

Contributions required from the Network and CCCs:

- Network: infrastructure, development of a database/website.
- CCC: list of available experts with their area of expertise.

Connections to other activity points and EU projects JANE, ERN, ELIXIR



7.4 Evaluation

Title: "Advancing High-Quality Care and Research in the Network through the Creation of Effective Monitoring and Evaluation Mechanisms"

Specific possible areas and types of activities:

- Development of indicators, both quantitative and qualitative, to ensure continuous development of CCCs within the Network, such as: game-changing publications, adherence to new guidelines/recommendations, better outcome of cancer care results/outcomes, cross-disciplinary research –team science, demonstration of collaboration, the success of young researchers through the Network; publication of evaluation results.
- Periodic surveys sent to all Network members to gather data (both quantitative and qualitative).
- Collect bottom-up information on the 90% outreach objective at local level as well as drivers of inequalities.

Benefit for CCCs and MSs:

CCCs:

• Indicators can lead to more global improvements and address real complex issues.

MSs:

- Improved outcomes in all areas (prevention, care, education, research)
- Higher survival rate, public health, quality of life.

Joint benefit for EU on improving cancer care and research:

• Increased competitiveness for the EU (economy, intellectual capacity etc.)

Indicators of success:

- Develop indicators and adherence to the standards for CCCs
- Acceptance of indicators and of the evaluation process
- Participation from every CCC and the willingness to improve according to the evaluation results

Contributions required from the Network and CCCs:

CCCs: participation, providing data within the requested timeline

Connections to other activity points and EU projects

All ERNs were evaluated in 2023 - how the Networks performed in 2017-2022. Clinical data monitoring – other initiatives?





7.5 Funding

Title: Increasing Access to Funding Opportunities to Ensure Development of EUCCCs and EU Network of CCCs

Specific possible areas and types of activities:

Centralised funding to ensure the network sustainability:

- Promotion of funding opportunities.
- Funding regulations should be harmonised across EU countries.
- Facilitation of co-funding for leverage effect.
- Pooling national, regional, and private funding opportunities for research.

Benefit for CCCs and MSs:

- CCCs:
 - Joint applications for research funding.
 - Better resource management
 - Increased opportunities for education and training activities.
- MSs:
 - Better performance and competitiveness at the national level
 - Stimulating innovation and growth
 - Attract and retain talent (preventing and reversing brain drain)
 - o Increased public health

Joint benefit for EU on improving cancer care and research:

- Better allocation of total available resources
- Alleviate disparities in terms of resources and performance among MSs and different regions in the EU (e.g. research)
- Overall improvement in care and research in the EU

Indicators of success:

• Amount of funding secured, either for single CCCs or joint projects

Contributions required from the Network and CCCs:

- Network:
 - Disseminating opportunities.
 - Support in proposal writing.
 - Mapping gaps to shape more competitive applications.
- CCCs:
 - (Avoiding submission of competitive proposals from members of the same Network, join forces).
 - o Active collaboration with other members to work on joint applications
 - O Sharing projects in need of funding

