



D4.1 Blueprint of the development and Integration of comprehensive cancer care scenarios into cancer care and control

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Project Information

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Abbreviations and Acronyms

AC	Associated Country
BBMRI-ERIC	Biobank and bio-molecular resources infrastructure (https://www.bbmri-eric.eu/)
BeNELux	Belgium, Netherlands, Luxembourg
CAN.HEAL	Building the EU cancer and public health genomics platform
L	https://canheal.eu/
CCCNs	Comprehensive Cancer Care Networks
CCCs	Comprehensive Cancer Centres
CCI	Comprehensive Cancer Infrastructure
CCI4EU	Comprehensive Cancer Infrastructure For Europe
CCPIS	Cancer Control Policy Interview Survey
DKG	Deutsche Krebsgesellschaft (German Cancer Society)
EBCP	Europe's Beating Cancer Plan
EC	European Commission
ECHoS	Establishing of Cancer Mission Hubs: Networks and Synergies
ECRIN	European Clinical Research Infrastructure Network
ERN	European Reference Network
EU MSs	European Union Member State
EU network of CCCs	European Network of Comprehensive Cancer Centers
iPAAC	Innovative Partnership for Action Against Cancer
JA	Joint Action
JANE	Joint Action on European Networks of Expertise
MDT	Multidisciplinary team



CraNE____European_Network_of_Comprehensive_Cancer_Centres

MTB	Molecular Tumour Boards
NMCH	National Mission Cancer Hub
NoE	Network of Expertise
OECI	Organisation of European Cancer Institutes
TTO	Technology Transfer Office
UnCan.eu	European Initiative to UNderstand CANcer





Executive Summary

The CraNE Joint Action has been proposed for funding in response to the flagship number 5 of the Europe's Beating Cancer Plan (EBCP), which defines that the European Commission will establish by 2025 **an EU Network linking up recognised National Comprehensive Cancer Centres (CCCs) in every Member State.**

CraNE prepared the organisational framework and functional profile of this network to facilitate both the integration of existing CCCs as well as to support the Member States who still need to develop and certify such centres. The work done in Crane aims at ensuring and supporting access to 'eligible patients'¹ to high quality cancer care in the EU.

CraNE also connects the development of the future EU Network of CCCs and EUCCCs to the development of national and regional Comprehensive Cancer Care Networks (CCCNs, WP6). In addition, existing organisational models of cancer care have been investigated, including the variations of their relationships with CCCs (WP8).

The proposal further discussed in this report consists of criteria and standards for the centres to be certified as EUCCCs (WP7) and the joining process for these centres to the EU network of CCCs (WP5); the governance and activities of the EU network of CCCs (WP5); the link with the CCCNs (WP6) and the accessibility and inclusion of real-life settings organizing cancer care through hub and spoke formats (WP8).

Given the significant heterogeneity in Europe regarding the organization of cancer care, there might be concerns that the proposed model could be exclusive or fail to meet the needs of member states. Therefore, the WP4 organized governmental boards, where representatives of EU Member States were given the chance to report their concerns or needs. Hence, it has been agreed that already certified centres by OECl or DKH would benefit from a facilitated membership.

In another task, the WP4 developed a maturity model with the ambition to offer a self-assessment tool for centres and member states. This should allow to illustrate the extent to which the organization and functionalities of their models deviate from the proposed criteria and standards, and consequently, their ability to become a member of the EU network of CCCs.

The objective of the CraNE sustainability report is to bring these different outputs together (WPs 4-8) and to discuss the sustainability and feasibility of the proposed frameworks. The potential difficulties that could be encountered by (EU)CCCs or the EU network of CCCs during their development, implementation or process to become a

¹ Eligible patients can be understood as those in need of comprehensive treatment, requiring an integrated approach including a wide range of highly specialized therapies and services. However, as stated in deliverable D8.2, there is no clear definition of the term "eligible patients".



member have been identified by the WP4 and extensively discussed with CraNE steering committee and the CraNE governmental board. The results of the discussions are presented at the end of each thematic chapter of this report (from 2.1 to 2.6).

The main WP4 recommendation is that these challenges could be the focus of activities conducted by the network and involving the centres and Member States, but also, the quest of synergies with other cancer control, care or research initiatives at the EU level.

I Introduction

The CraNE Joint Action (JA) has been proposed for funding in response to the flagship number 5 of the Europe's Beating Cancer Plan (EBCP), in order to establish an EU Network linking recognised National Comprehensive Cancer Centres (CCCs) in every Member State by 2025².

The two main objectives for the CraNE JA were (a) to achieve high-quality cancer care in the EU and reduce inequalities and (b) to ensure that 90% of eligible patients have access to such centres by 2030. Therefore, this preparatory JA defines the necessary preconditions (administrative, organizational and professional), and those related to high-quality performance aiming at the integration of the existing CCCs as well as to support the Member States who still need to develop and certify such centres.

Flagship 5: The Commission will establish, by 2025, an EU Network linking recognised National Comprehensive Cancer Centres in every Member State. It will facilitate the uptake of quality-assured diagnosis and treatment, including training, research and clinical trials across the EU. This cross-border collaboration will improve patients' access to high-quality diagnostics and care and the latest innovative treatments. It can also help with patient mobility to ensure adequate treatment for patients with complex conditions. (...) This action will help deliver higher-quality care and reduce inequalities across the EU, while enabling patients to benefit from diagnosis and treatment

The JA CraNE defined the scope of its activity according to the definition of this flagship:

- ❖ Composition, governance, joining process and functioning of the EU network of CCCs, including possible activities in 'Care, treatment and diagnostics', 'Research and innovation', 'Governance and policy'(WP5)
- ❖ Organisation of high-quality cancer care in CCCNs (WP6)
- ❖ Criteria and standards for the centres to be certified as EUCCCs on governance, research, prevention and education & training (WP7)
- ❖ Equitable access to high-quality care and research (WP8)

² Official website of the Joint Action on the European Network of Comprehensive Cancer Centres: <https://crane4health.eu/>





CraNE__European_Network_of_Comprehensive_Cancer_Centres

The work of these work packages looked at different levels of activity. While the work package 6 is focusing on the provision of care and the interfaces between CCCNs and CCCs, work package 7 is focusing on setting up the criteria and standards to become an EUCCC including the following dimensions: research, innovation, prevention, integration of research and care, education and training, governance and care. The WPs 5 and 8 rather investigate how institutions are currently collaborating (WP8) and how they could be part of a transnational initiative (WP5). These differences in the level of action led to the necessity for this report which aims at bringing together the WPs 5-8 results, to carefully address the potential challenges at each level separately but also concerns related to their gathering (Figure 1).

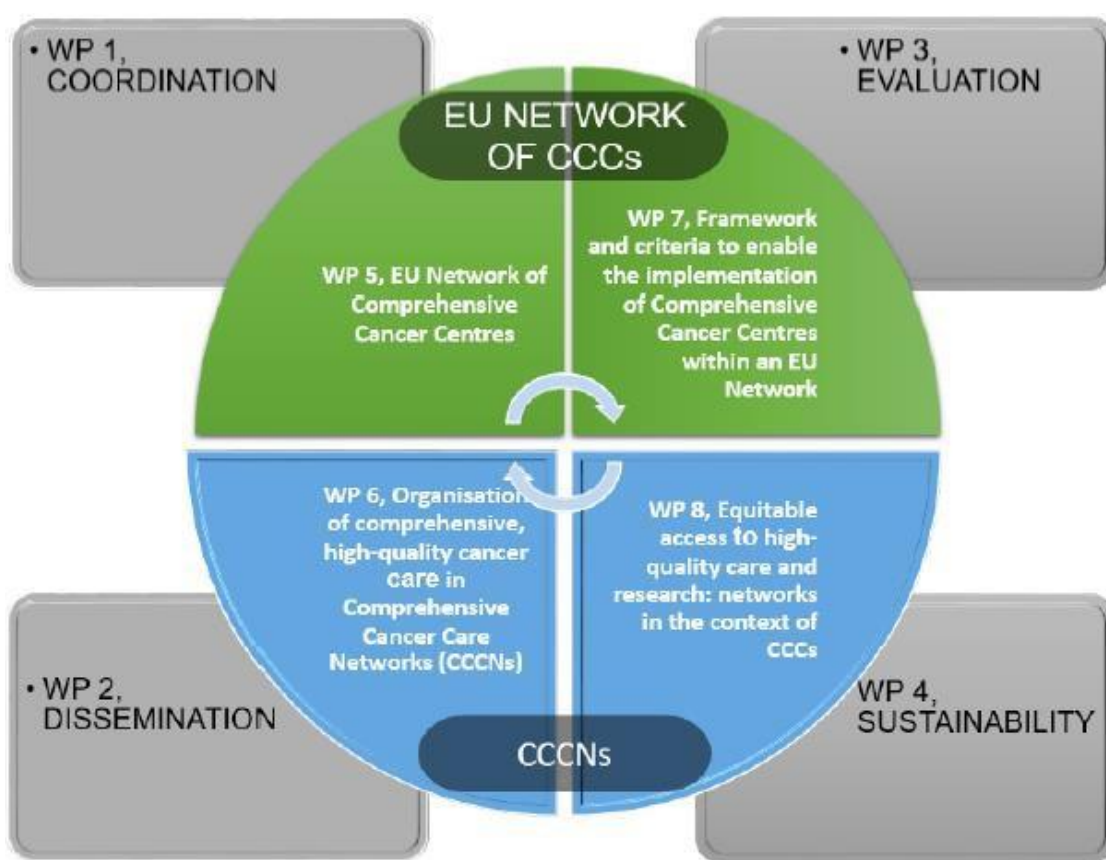


Figure 1. Organization and scope of activities of the Joint Action CraNE.

Comprehensiveness

Comprehensiveness is key for the centres to be involved in the EU network of CCCs. The requirements related to the comprehensiveness of EUCCCs, as proposed by the CraNE WP7, include four dimensions:

- (a) activities need to be organized for the **seven themes** of quality standards: research,



- innovation, prevention, integration of research and care, education and training, governance and care
- (b) the EUCCC has to provide or manage access to specialized health care services along the **entire patient pathway**
 - (c) the EUCCC should provide or manage access to diagnostics and treatment to patients in a **broad range of tumour groups**
 - (d) EUCCCs should be connected to **research from bench to bedside** and vice versa (including also fundamental, epidemiological, socio-economic, implementation, etc.).

The comprehensiveness applied to cancer care is explained in the D7.2 which states that “it is involving the question of managing access to all types of standard treatment (...) on one side and cases in need for highly specialized treatment on the other”. For the concept of research comprehensiveness, it encompasses multiple facets which can be managed within the EUCCC or through collaborations with external institutions.

EU Comprehensive Cancer Centres (EUCCCs)

As a result of the work accomplished during the CraNE Joint Action, an agreement has been reached regarding a working definition for the future EUCCCs.

A European Comprehensive Cancer Centre (EUCCC) serves as a major source of clinical care, innovation and discovery into the understanding of cancer, and for the development of more effective approach to prevention, diagnosis and therapy. It shows a direct provision of an extensive range of high-quality cancer diagnostics and care covering at least all the major cancers and ensures through its networks' access also to advance treatment for remaining diagnoses. The EUCCC demonstrates a reasonable depth and breadth of activities in basic laboratory, clinical as well as in prevention, cancer control and population-based research and it integrates research systematically with clinical practice. It serves as a focal point of a local/regional or national network and acts as a driving force promoting high quality of care & research, implementing guidelines and good practices, and engaging the populations within its catchment area. An EUCCC is committed to embody the cooperation between institutions, networks (including among others: Comprehensive Cancer Care Networks (CCCNs) and stakeholders in prevention, care and research). It takes into account the contribution of each of the stakeholders in its field of activity and competence to build a partnership that maximises the impact in its catchment area. It is also committed to cooperate with other EUCCCs and networks for the development of shared resources in the field of research, care, innovation, education and training.

A Comprehensive Cancer Centre is an organisational entity with a clear central governance and high level of infrastructure and expertise including:

- Organisational Capabilities: Physical Space, Director, administrative / managerial /



scientific governance, consortium.

- Partnership: description of the organisation of the partnership, relationship between partnership institutions, community engagement within a catchment area.
- Transdisciplinary Collaboration and Coordination: Multi-disciplinarity, transfer of scientific findings, dissemination activities (towards professionals, patients and general public)
- Institutional Commitment: EBCP and EUCCC network, Team Science, Education and training.

Objectives and methods of the Sustainability Report

This report is built around five themes transversally addressed in the JA CraNE: governance, (comprehensive) cancer care, (comprehensive) research, education & training and prevention. Each of the five core WPs (5-8) has worked to propose solutions for a framework that leads to the creation of a new ecosystem where high quality and accessible cancer care, networking and research would be at heart.

The aim of this report is to highlight the potential hindering factors, but also levers, opportunities and challenges that could be encountered, at different levels (CCC, CCCNs, MS or network), in relation to the functionalities of the future EUCCCs or EU network of CCCs, and to propose, when possible and relevant, solutions for overcoming the challenges.

Given that the EUCCCs and the EU network of CCCs have not yet been implemented, the extent to which these barriers will actually arise remains to be seen, as well as unforeseen issues and scenarios.

The material used for drafting this report comes from the work done in the core CraNE WPs (4-8), including literature reviews and analysis, consultation processes among a broad range of stakeholders, surveys, experts' consultation and brainstorming and workshops with thematic working. Extensive presentation of the methods used in each WP and their results can be found in their deliverables to which this report will systematically refer.

The following content focusses on their main results, presents, integrates and discusses them. In order to identify the potential hindering factors:

- ❖ a literature review has been performed in order to identify the (contextual) features³ that could impede or facilitate the development and implementation of transnational healthcare networks and,

³ Contextual features need to be understood as external factors to the CCCs, CCCNs or to the EU network of CCCs which can directly or indirectly impact their development, implementation and functioning. For Example, national laws, regulations, socio-economic characteristics, level of institutions competition, values etc.



- ❖ challenges reported in the Innovative Partnership for Action Against Cancer (iPAAC)^{4,5,6} were (re)examined with the aim to assess whether the EU network of CCCs would support or propose solutions for these challenges.

A numerous number of hindering factors were identified. In order to prioritize these factors and asses their relevance, two half-day workshops with CraNE WP leaders (WPLs) were organized to select and discuss the factors which have the potential to interfere with the development or membership of the EUCCCs, the CCCNs and the EU network of CCCs (see section 2).

Moreover, Joint Actions are designed to encourage national authorities, academic and non-profit organisations to join forces with the EC to address major public health issues where the added value of EU-level involvement is high. Therefore, an important instrument to achieve these goals is the involvement of Member States to ensure the development of useful outputs, helping them to address the major issues related to cancer control. In the framework of this JA, four governmental board meetings have been organized, presenting the main results of the core WPs but also discussing the potential concerns that the implementation of the results could raise in the EU MSs⁷.

II Towards a European network of Comprehensive Cancer Centres

The overall aim of the future EU network of CCCs is to establish an integrated and cohesive consortium of CCCs across Europe to improve access to high-quality services and research and ultimately guarantee better care for patients. This could be achieved through two main pillars, namely the establishment of a certification process for CCCs to facilitate the improvement and establishment of EUCCCs in Europe and the development of an EU collaborative community of (comprehensive) cancer centres by establishing a platform where EUCCCs will collaborate and mutually strengthen their capacities and enhancing collaboration with other key EU initiatives on cancer.

In the following, we provide a thematic description of the main results of CraNE (governance, research, education and training, care and prevention), discuss the related potential hindering factors identified and propose responses.

⁴ iPAAC Official website : <https://www.ipaac.eu/>

⁵ These challenges are described in details in the iPAAC Sustainability report: <https://www.ipaac.eu/res/file/outputs/wp4/sustainability-report.pdf>

⁶ iPAAC Implementation challenges : <https://www.ipaac.eu/res/file/outputs/wp4/ccpis-reported-challenges.pdf>

⁷ Minutes of the first GB meeting (20th April 2023). Available at (28th August 2024): https://crane4health.eu/wp-content/uploads/2024/07/CraNE_WP4_GB_20042023_Minutes_Final_Version.pdf

Minutes of the second GB meeting (1st December 2023). Available at (28th August 2024): https://crane4health.eu/wp-content/uploads/2024/07/CraNE_WP4_GB_20231201_Minutes_official.pdf

Minutes of the third GB meeting (20th June 2024). Available at (28th August 2024): https://crane4health.eu/wp-content/uploads/2024/06/CraNE_WP4_GB_20240717_Minutes_FINAL.pdf



2.1 Governance

While national cancer control programs and strategies are set by policy-makers, the implementation of cancer care and research networks remains mainly the prerogative of hospitals together with relevant research institutions and academic faculties.

In order to ensure integrated cancer care and research services (core task of EUCCCs), multi-level governance processes are required in response to the strengths and limitations of the contexts which can influence (as supporting or hindering factors) the network-based working⁸.

Therefore, a clear and operational governance model is necessary at both institutional and network levels. Within the CraNE Joint Action, four work packages worked on the understanding and the development of frameworks for governance, at both levels.

The WP7 investigated and proposed criteria and standards for the governance of EUCCCs⁹ including the requirements to be part of the wider networks and interfaces with CCCNs (D7.2 and D6.1). They based their work on existing schemes for the certification of CCCs (e.g., the US National Cancer Institute program, NCI¹⁰; Organisation of European Cancer Institutes, OEI¹¹ and the German Cancer Aid, DKH¹²), but also on the results from a survey performed among existing CCCs and potential future EUCCCs (D7.1). The main contribution in constructing standards related to governance came, however, from an extensive involvement of experts and experienced representatives from European (comprehensive) cancer centres participating in workshops, writing groups; focus groups etc.

In the meantime, task 4.2 developed a maturity model based on an intermediate version of standards. They conducted a survey to assess the understanding of the requirements and standards used for each of the maturity levels, and to collect examples of evidence to enrich the model. While informative, the results obtained need to be read in light of the limited number of volunteer testing institutions, ranging from 6 to 13 CCCs, which limit the extrapolation of the results to the whole group of CCCs. Moreover, the testing of an intermediate version of the standards led to potential misunderstanding due to the missing definitions (D4.3, p 20). However, we must be aware that errors in the responses may have occurred due to the limited knowledge of the respondents and the silo effect; and measurement error might have occurred due to respondents' answers who might have had answered questions affirmatively in order to present themselves or the organisation they

⁸ Tremblay D. et al. 2016. Understanding cancer networks better to implement them more effectively: a mixed methods multi-case study. Implementation Science, 11:39.

⁹ CraNE WP7 webpage: <https://crane4health.eu/wp7-framework-and-criteria-to-enable-the-implementation-of-comprehensive-cancer-centres-within-an-eu-network/>

¹⁰ NCI-designated centres: <https://www.cancer.gov/research/infrastructure/cancer-centers>

¹¹ OEI Accreditation and designation system: <https://accreditation.oeci.eu/>

¹² German cancer aid certification program: <https://www.krebsgesellschaft.de/gcs/german-cancer-society/certification.html>





represent in the best possible way. This type of error can also be related to routine answering of questions without needed reflection or fact-checking (D4.3, p 21).

These exercises resulted in the definition of ten core governance standards for the future certified EUCCCs (D 7.2):

The EUCCC has a **governing body**¹³ responsible for the centres' strategy, including care, research, and education.

According to the results of the maturity model testing, 13 of the responding centres reported having a governing body established¹⁴.

The EUCCC has **multidisciplinary teams** (MDT/tumour boards) for every tumour type¹⁵ treated by the EUCCC or by collaborating institutions

The EUCCC integrates patient perspectives, through **involvement of patient representatives and patient q advisory council** in assessing outcome and quality of care and relevant change and improvement initiatives.

The governing body of the EUCCC has sufficient resources¹⁶ to deliver the **regular provision of both cancer data- based reporting and analysis** and *ad hoc* need of cancer related analysis.

The EUCCC has **formal agreements and a coordinating committee with other hospitals and external clinical units collaborating** with the EUCCC on cancer patient pathways.

Six responding centres reported collecting agreements from all stakeholders while developing the overall strategy.

Importantly, results from WP8 showed that some regions/countries/centres have patient pathways while others do not. In general, patient pathways have not been formulated as a way to promote inter-hospital cooperation. It is essential that pathways also reflect the trajectory of patients that are (regularly) referred from other institutions in order to avoid inequities of care (delays, etc.)¹⁷.

The EUCCC has developed and approved a **comprehensive cancer strategy** covering all aspects of oncology.

Five of the responding centres to the 'governance' module of the maturity model testing (n=13) reported having a strategy that covers all aspects of oncology including implementation of personalised cancer care and integration of research and care.

The EUCCC has internal **rules of procedure to guide the management of cross-organisational matters**.

¹³ Cancer Centre Board (CCB) or Executive Committee

¹⁴ D 4.2 page 22

¹⁵ % ICD coverage

¹⁶ Competent personnel with capacity and responsibility

¹⁷ D8.2





Seven centres reported having set out internal rules of procedure to manage inter-organisational affairs¹⁸.

The EUCCC actively **uses a data monitoring system** (dashboard) to follow up essential¹⁹ metrics in care and research, available at both the centre and pathway/tumour group levels and accessible to all employees.

Eight of the responding centres (n=13) stated that their centre actively uses metrics collected by the data monitoring system to improve its management²⁰.

The EUCCC has **processes on collaboration on MDT/tumour boards** in a geographical area with shared patient pathways regarding participation²¹.

Results from the WP8 emphasize that widespread use of multi-centric MTM in the context of inter-hospital collaboration makes it a quality standard. Minutes of the multi-centric MTMs may become Evidence for the EU network of CCCs certification scheme²².

The EUCCC **participates in at least one cross-border network** organising collaborative institutional activities between EUCCCs.

Ten of the respondents reported to be engaged in at least one cross-border network organising collaborative institutional activities²³.

The CraNE WP5²⁴ developed a model for **the governance of the EU network of CCCs**, based on literature search on existing models for the governance of (transnational) care networks and Delphi rounds with a large range of different stakeholders (D5.1). The process to identify a governance model followed a collaborative approach involving partners from various WPs and other stakeholders to incorporate diverse perspectives on organizational structure, functions, composition and decision-making processes. This process resulted in the identification of three possible governance models of the EU network of CCCs (D5.3): clinical and research centred, mixed approach, or policy centred.

Of these three models, the mixed approach has been assessed as responding the best to the governance need of the network (Figure 2). In this model, decision-making power is distributed between the MS Board and the General Assembly. The MS Board, representing both MSs and ACs, advises the General Assembly on the alignment between national policies and those of EUNetCCC. It approves the admission of newly certified CCCs and CCC evaluation outcomes as proposed by the General Assembly and assesses funding opportunities for the Network. The General Assembly, which includes representatives from all Network members, approves the

¹⁸ D 4.2, page 29

¹⁹ E.g.: patient outcomes, publications, and third-party funding

²⁰ D 4.2, page 30

²¹ participation of external physicians, also EUCCC physicians joining external tumour boards

²² D 8.2

²³ D 4.2, page 41

²⁴ CraNE WP5 webpage: <https://crane4health.eu/wp5-the-eu-network-of-comprehensive-cancer-centres-composition-governance-joining->





Network's strategy, policies, and activities, endorses the working methods of the Network Board, and sets policy priorities for the MS Board. The Network Board, composed of a selected group of Network member representatives, holds executive power and is responsible for implementing the strategies, policies and activities of the Network as proposed by the General Assembly. Additionally, a Stakeholder Forum plays a consultative role, providing a platform for the exchange of ideas and best practices together with relevant stakeholders. Finally, a Secretariat supports the operations of all these bodies, ensuring their effective functioning (Fig. X).

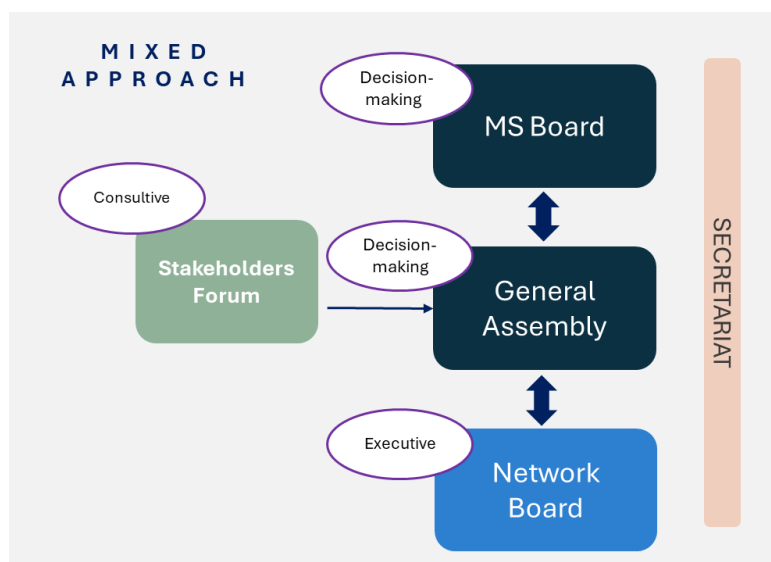


Figure 2. The mixed approach model chosen for building the governance model of the EU network of CCCs.

The WP5 proposed a set of activities for the EU network of CCCs related to 'Governance and Policy', in five specific areas (D5.3): (1) organization of the governance of the network; (2) continuous update of criteria and standards; (3) influencing policy and politics on delivering High-Quality Care and Research across Europe; (4) ensuring patient participation at all levels and (5) fostering dialogue and collaboration with the industry to create opportunities for growth and development.

These activities are directly linked to the role of EUCCCs, aiming at exchanging experiences, models and application of standards for their governance and of 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, at the EU level.

In order to assess the implementation process and to understand the related challenges faced by the entities setting up CCCNs, interviews were conducted by the WP6 team and resulted in the identification of the following challenges. One can acknowledge that these challenges could be relevant also for (EU)CCCs:

- **Change management:** the multi-stage certification process can be conflict-prone, time-



consuming, and costly, involving potential changes to processes, IT solutions, and the creation of new positions or responsibilities.

- **Additional workload:** at the beginning; certification often means more work for everybody involved (e.g., more documentation, different workflow, more meetings, ...).
- **Digitalization:** for documenting data sheets; a functional IT-System as a foundation must be created, which can be challenging for some MS.
- **Staff resources and staff availability:** due to the lack of uniformity in documentation systems and the high time expenditure required for implementation, it is essential to have a digital officer/data manager who can provide significant assistance. CCCN coordinators need to be able to dedicate significant time to certification project.
- **Financing:** the biggest challenge for hospitals regarding certification is funding (i.e., costs, IT system, additional human resources(re-)certification)

The testing of the Maturity model in WP4 raised the following challenges related to the formulation of requirements/standards in the governance dimension (D4.3, p 34):

- A definition of “real decision power” should be provided
- The requirements for stakeholder participation need to be clarified
- The composition of the Governance Board does not always correspond to the formulated requirements in terms of representation of organisational areas/dimensions
- sometimes the CCCs surveyed define/understand the functional scope represented on the board differently
- Often, survey participants confused project support for research and innovation project with support for change management/continuous improvement
- Wording “quality of relationship with stakeholders” sometimes considered as unclear
- Additionally, participants pointed out frequent coordination problems with CCC like structure.

The WP8 investigated real-life examples of cancer care organizational models and looked at how the governance is organized and ensured (D8.1).

In this exercise, the focus on cancer networks was addressed specifically under the conceptual label of “networks built around CCC”, an expression used to cover any situation by which cancer care and/or research areas are formally coordinated between the CCCs and other providers. However, the configuration of networks built around CCCs involved different types and degrees of collaboration. For instance, as it can be observed in Figure 4, the CCCs itself may result from the aggregation of different institutions, a situation that is not unusual in EU health systems. (Figure 4).



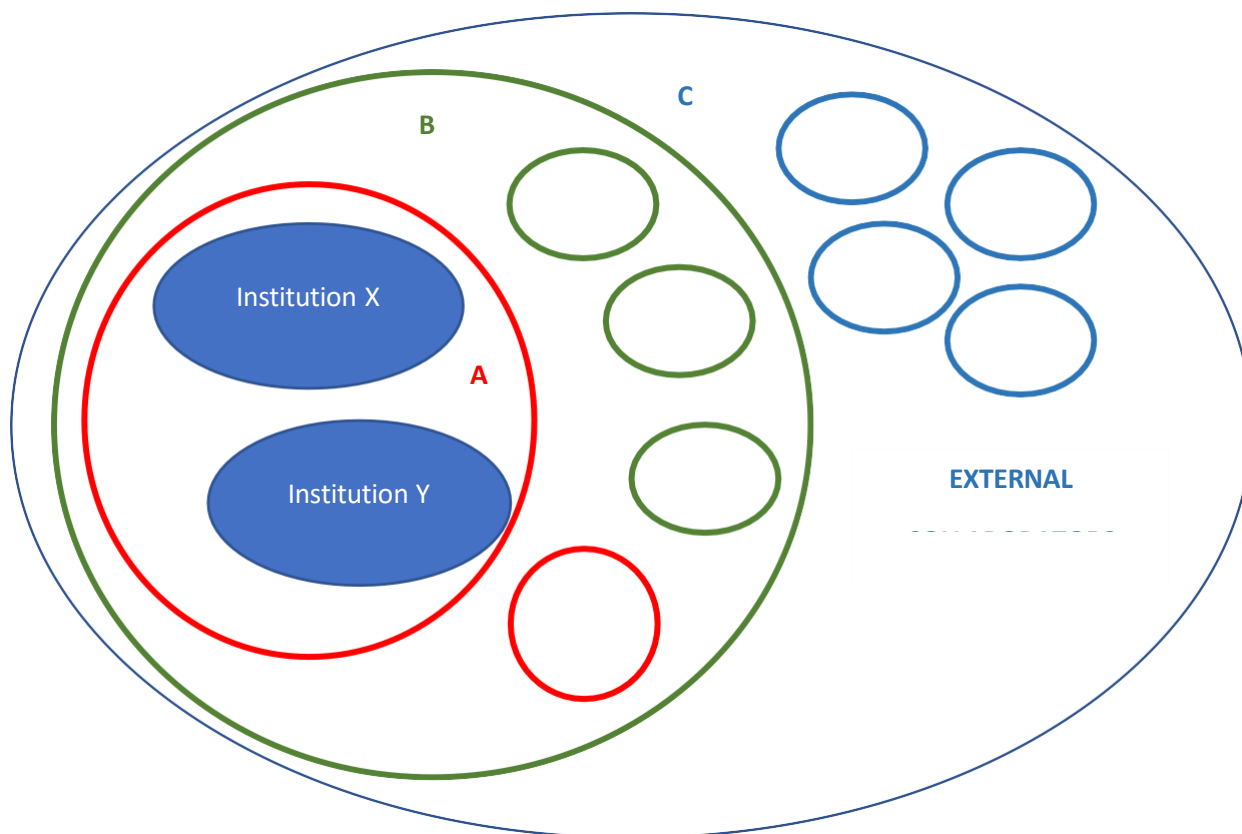


FIGURE 4. Three types of collaborating providers involved in the cancer care provision

LEGEND

(A) Partners making up the CCC

(B) Providers with which the CCC collaborates regularly through formal agreements (regional/national decree or interhospital agreement) and/or typical mechanisms used to radiate expertise and increase quality of care (e.g., pathways, multidisciplinary team meetings, common clinical protocols, common tracks to ensure patient access to RCT).

(C) External healthcare providers that refer patients (even regularly) to the CCC in the absence of formal integration of cancer services and/or agreements

The networks built around CCCs show similarities and differences, and grouping the experiences into clear-cut models was not straightforward. Context matters, and none of the networks analysed were the result of a mere rational choice between one model or another. However, four models (a-d) considered as “ideal types” can be envisaged concerning the critical element that determines the networks’ dynamics and ways of integration:

- a) CCC-driven network model. The CCC is the main driver for change at a network level and brokers the interests of all stakeholders. The scope of the network tends to be limited to diagnosis and treatment planning, and patients’ enrolment to clinical trials is actively pursued. In this network model, structured dialogue (e.g., through multicentre MTMs) is more important than common rules. Examples are Catalonia, Toulouse, Cantabria, and Cluj-Napoca.
- b) Evidence-driven network model: The use of care pathways (plus sometimes a



regulated healthcare framework) greatly contributes to defining partners' cooperation, distribution of competences, and clinical interventions. Since evidence is used for internal negotiations, the CCCs' ability to assume a prominent position is critical to centralising critical interventions. The scope of the network also encompasses the area of supportive care. Examples are Piemonte, Linz, Skåne, and Campania.

- c) Highly regulated network model. A context of active national policies, combined with the use of both care pathways and a hub-and-spokes shaped network, leads to a clear stratification of clinical roles among network stakeholders. In this model, shared norms are more important than formal settings for multidisciplinary decision-making (e.g., multicentre MTMs). Examples are found in Oslo, Frankfurt, and Slovenia.
- d) Cross-border network model. Cooperation between professionals and/or institutions from different countries or regions is driven by geographical and political criteria such as small populations within a MSs or insular territories. The geography and political context of this type of networks implies – almost by default – specific requirements for the model of cooperation between network partners and the relationship with the policy environment. Examples are found in Malta and Luxembourg.

All the experiences and models analysed fell into the so-called 'hub and spoke' model, in which clinical expertise radiates from cancer centres (tertiary hospitals – the hub) towards cancer units (local or district hospitals – the spokes) across large geographical areas with always a CCC playing the role of a central stakeholder.

Given the list of criteria and standards developed in the WP7 and the proposal made in WP5 for the governance of the EU network of CCCs, all members will have representation in the network's governance. Each EUCCC must select one or more representatives to participate in governance bodies. When confronting the proposed criteria, standards and governance model to the WPs 4 and 8 results, some issues have been raised during the WP leader workshops:

- ❖ *Could this **representation of CCCs at the EU network level** have an impact on the internal governance of the CCCs, especially when acting as a network of several entities?*

Results from discussions: It is up to each (EU)CCC to decide how they want to be represented at the level of the network. This should not necessarily imply new governance at the level of the CCCs or network to become a member and participate in the activities of the EU network of CCCs. The participation or interaction of CCCs with the EU network will not undermine their independence.

In case of scenario B and C (Figure 4), which actor(s) need to be part of the certification process? Should all entities be assessed together or independently?



Results from discussions: The level and type of formal agreements among the entities will probably lead to the decisions of who should be certified so that the network can become a member (case by case logical).

One should notice that nine out of the thirteen centres having participated in the Maturity model testing reported having a governing body which could lead to the assumption that they will not have to create a new one. However, still a third will need to do so and experience from implementation of CCCNs showed that the certification process requiring changes in the structure of the governance at the centre/CCCN level was considered as an important burden or challenge.

- ❖ Regarding the core criteria: “The EUCCC has **processes on collaboration on MDT/tumour boards** in a geographical area with shared patient pathways regarding participation”²⁵ and given that scenario A is the most common (Figure 4), it would be appropriate to not take for granted that the **cooperation between the partners** of the (EU)CCC is aligned in all essential dimensions (e.g., indicators used to evaluate performance, patient access to clinical trials). This leads to the following question: *Do the Criteria and Standards’ formulation “take for granted” that the partners making up the (EU)CCC do collaborate and are aligned to enter the process of certification as a single entity?*²⁶
- ❖ **Formal agreements**²⁷: Concerns could be raised regarding the extent to which agreements of collaboration among partners forming a CCC or a CCCN²⁸ need to be formally established. *What would this mean in practice? Are formal agreements necessarily binding?*

Results from discussions: In the future, piloting the development and implementation of (new) EUCCCs should investigate the need to define what a formal agreement is or provide examples.

A proper monitoring of practical challenges should be organized by the governing structure of the EU network of CCCs to ensure jurisprudence.

Importantly, during the testing of the maturity model, 12 of the 13 participating centres reported having formal agreements that set out the terms and conditions of cooperation between legal entities constituting the EUCCC while only 6 recognized that their governance model ensure clinical coordination, ensuring quality care across tumour groups,

²⁵ participation of external physicians, also EUCCC physicians joining external tumour boards

²⁶ OEI certification of “Comprehensive Cancer Network” is a special label that allowed a case of two centers to be certified as one. These two centers do not consider themselves a network, but this certification path was the only way to proceed in order to certify them.

²⁷ (CORE) standard for EUCCCs: for EUCCCs composed of multiple legal entities, there are formal agreements in place that define the collaboration terms among these entities.

²⁸ Notably, in the framework of CCCNs, requirements regarding formal agreement(s) on certain topics can also be found (e.g., TMB, care pathways, audits, etc.) which mainly relate to mutual understanding of rules and responsibilities.



organisational boundaries, and the entire patient pathway (D4.2).

- ❖ **The role and involvement of stakeholders in governance (and overall):** the main challenge is the number of (profiles of) stakeholders and the difficulty to be exhaustive (e.g., authorities, interest groups, industry, patients and families, scientific societies, etc.).

Results from discussion:

- (1) Practical considerations raised: this issue should be cross-checked with other EU initiatives having stakeholder forums (SHF) to discuss possible solutions to avoid that these stakeholders will have to participate in many different SHFs.
- (2) Proposed solution: in the future, some tasks of the network need to address the targeted communications to members, relevant stakeholders, and specific citizen groups.

Importantly, the proposal of WP5 for the governance of the EU network of CCCs foresees the definition of a strategy to ensure the active engagement of relevant stakeholders, such as patients' organizations, healthcare professionals etc., including the use of a series of indicators to monitor and evaluate such activities, e.g., number of stakeholders involved, types or categories of stakeholders, etc. (D5.1, p 12).

- ❖ **MS representatives:** the challenge will be to ensure having the relevant representatives participating (or at least correctly informed)

Results from the discussions:

- (1) those participants to the MS Board meetings and activities need to have regular contact, as part of their role, with ministries and centres managers;
 - (2) the EU network could foresee the development of a framework that ensures the translation or transmission of results of discussions or open issues to the right audience in the countries;
 - (3) the interaction with the EC steering (sub-)group on cancer could be investigated as a vehicle for some stakeholders.
- ❖ **Patient's involvement:** both EUCCCs and the EU network of CCCs should involve patients in the definition of strategy but also as a part of their quality improvement.

Given the numerous initiatives at the EU level (esp. within the EBCP and the Cancer Mission), patients representatives and associations could be overwhelmed with requests for their involvement and collection of perspectives²⁹.

²⁹ Cancer control Policy Interview Survey. Main challenges reports by EU Member States: <https://www.ipaac.eu/res/file/outputs/wp4/ccpis-reported-challenges.pdf>



- (1) One should think to also (or rather) involve relatives.
- (2) One could learn from experience of centres where patients are already active in the decision-making process and see how to translate.
- (3) the practical implementation of patient involvement should be addressed, at both (EU)CCCs and EU network of CCCs levels, by e.g. developing support for a Patient's Council with up to 10 members, covering meeting participation, material preparation, and event involvement, alongside the development of an IT platform to connect EUCCC institutions for enhanced collaboration.

2.2 Comprehensive cancer Research

According to the results of the CraNE WP5, research and innovation represent the group of activities aiming 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” (D5.3).

The research activities of the EU network of CCCs should aim at improving the access of members to expertise, leveraging the specialised skills and experiences of other (EU?) CCCs, accelerating their research and clinical capabilities. It will also enhance collaboration, fostering a culture of teamwork and interdisciplinary cooperation. It could also avoid duplication and competitive research projects, rather encouraging and enabling synergies (D5.3).

Regarding the scope of activities of the future EUCCCs, emphasis has been placed on research and the capacity to conduct research activities from bench to bedside.

Thirty core standards were drafted in relation to research, integration of research and care and innovation³⁰ for the centres to be certified as EUCCC (D7.2, p 27-52).

Those presented and discussed hereafter are those that have been used for the testing of the maturity model or which have raised specific concerns among the Crane steering committee.

- ❖ At least one organizational entity that makes up an EUCCC has **in-house activity in translational research** or is integrated in a network conducting translational research.
- ❖ The EUCCC is involved in **research on at least two additional cancers**, which may include Rare cancers, Paediatric cancers, Hematologic cancers.

Seven of the nine respondents to the ‘research’ module of the maturity model testing exercise reported to have in-house activity in translational research but four are involved in research in

³⁰ See deliverable 7.2 (pages 27-52).



at least 2 rare cancers.

- ❖ The EUCCC provides training in **research integrity**.
- ❖ The EUCCC provides **guidelines for safe collection, storage, retention and deletion of informed consent and the connected research data**.

Seven of the centres reported that guidelines for the secure collection, storage, retention and disposal of data related to research have been developed (level2).

Eight reported offering legal advice regarding the sharing and transfer of research data (level 2).

- ❖ The EUCCC offers **mentoring programs to researchers** (including evaluation).

Five of the respondents (out of the nine testing centres) reported providing mentoring programmes to researchers.

- ❖ The EUCCC **provides administrative/legal support** to perform (design, coordinate, run and monitor) research and specifically clinical trials.

According to the results of the MM testing, eight of the 9 respondents to the “research” module, reported that their centre offers legal advice regarding the sharing and transfer of research data.

- ❖ The EUCCC **participates in international research projects** in translational and clinical medicine.

The results of the testing of the maturity model revealed that 6 of the 9 respondents reported participation in European/international research projects in basic, translational and clinical medicine.

- ❖ The EUCCC **provides access to shared ICT platforms** for research activities.

Seven respondents (n=9) reported having adequate infrastructures for data management in the centre (level 1) while five reported having ICT in order to link biobank samples to clinical data (level 3).

- ❖ The EUCCC participates in regular, **external evaluation of Research groups**.

Four centres reported having regular, external evaluation of research groups

Although not identified as a core standard by the WP7³¹, the maturity model included questions on the involvement of patients in research activities. Between 4 and 5 participants (n=9) reported to have identified stakeholders and patients’ representatives to collaborate but only 17-28% actually engage them and have formal agreements of collaboration. None of them

³¹ See page 35 of the D 7.2



reported to have mandatory educational programs to prepare them for being involved in research activities (D 4.2).

According to results from interviews conducted in the framework of the testing of the maturity model, the standards in this dimension did not usually cause problems in terms of understanding, but some respondents pointed out in a few cases the difficulty of interpreting certain wording/terms:

- ❖ the phrase 'supportive disciplines' may be understood differently in different units,
- ❖ the term 'technological research core facilities' needs to be defined precisely,
- ❖ the term high-quality research may be interpreted differently.

Furthermore, as confirmed by individual interviews with respondents, the content of questions related to competency-based models and systems was often misinterpreted. Also, respondents highlighted problems with the formal participation of patient groups in the future research planning.

The WP8 evaluated the experience of eight molecular tumour boards (MTBs)³² in order to understand their internal operation, the potential of integration in a multi-provider context and to explore how they coordinate to facilitate access of patient from different hospitals (D 8.3)³³. MTBs were identified as a case study for evaluating the different models to translate research progress into clinical practice. During the testing of the maturity model, 63% of the respondents (n=8) acknowledge having a molecular tumour board (MTB) with competent staff in place for interpreting results, which are then documented in medical records³⁴.

One of the main results concerns the differences in knowledge in the field of precision medicine, which could be solved by connecting MTBs to CCCs where usually most professionals are well trained and knowledgeable about precision medicine.

Regarding the activities of the EU network of CCCs in research, innovation and integration of research and care, the WP5 proposed three main groups of activities (D5.3): (1) unlocking cancer research synergies; (2) advancing cancer research together (i.e. support knowledge transfer, strengthen capacities, etc.) and (3) building the European clinical trials engine.

Many challenges regarding the development and uptake of innovation in routine practice were identified. They are presented below with the proposed activities that could be held in the framework of the future EU network of CCCs that will address them and may help to overcome these challenges.

³² Molecular tumour boards (MTBs) are multidisciplinary groups that combine molecular and clinical data from cancer patients in order to formulate treatment recommendations for precision medicine. (from Irelli et al. 2023)

³³ Crane4health WP8 official web page: <https://crane4health.eu/wp8-equitable-access-to-high-quality-care-and-research-networks-in-the-context-of-cccs/>

³⁴ D 4.2, page 107.





- ❖ **Ethical, legal and social issues (ELSIs)** restrictions and differences (especially related to the differences in the GDPR interpretations) among collaborating centres and countries may impact the conduct of inter-institutional and transnational research activities. Data sharing remains a key challenge for many researchers at the local level but even more at European/international level.

Results from discussions: possible solutions could be found in the results from other initiatives and projects having specifically worked on that aspect as for example:

(a) The Joint Actions TEHDAS³⁵, PHIRI (ref) and Can.Heal³⁶

(b) Data-related concerns and activities are crucial to have successful research activities and could benefit from the development of KPIs for assessment and (continuous) improvement.

- ❖ **Integration of research and care:** one could easily notice that there are often many opportunities for conducting fundamental research but relatively less for integration of research results into practices, at both national and EU levels.

Results from discussions: the management board of the EU network of CCCs could foresee activities in order to raise awareness among funders, but also to stimulate activities in the centres.

From the Joint Action iPAAC, challenges regarding implementation of innovations into practice were identified by respondents from EU MSs³⁷, such as affordability of new drugs and new tests; contradiction of rapid innovations and slowness and heaviness of new drug introduction in healthcare systems; need of an increased EU collaboration on: HTA, cost-effectiveness studies, horizon scanning, price negotiation and informed consent; role of healthcare professionals in facilitating the introduction or opposing. Some of these challenges have been addressed through the iPAAC WP9 deliverable entitled “Innovative cancer therapies in clinical practice guidelines”³⁸.

Given these very practical concerns and challenges, the EU network of CCCs could foresee a monitoring of these issues and translate them into activities of the network, supporting the development of capacity of the members of the network. As already proposed in the iPAAC sustainability report³⁹, twining activities, capacity-building and mutual learning programs could present great opportunities to learn from each other’s^{40,41}.

³⁵ TEHDAS JA WP5 official webpage: <https://tehdas.eu/tehdas1/packages/package-5-sharing-data-for-health/>

³⁶ Can.Heal JA WP12 official webpage: <https://canheal.eu/wp12-law-ethics-and-citizen-engagement/>

³⁷ iPAAC JA WP4 List of challenges: <https://www.ipaac.eu/res/file/outputs/wp4/ccpis-reported-challenges.pdf>

³⁸ Innovative cancer therapies in clinical practice guidelines (Deliverable9.1). Available at: <https://www.ipaac.eu/res/file/outputs/wp9/innovative-cancer-therapies-clinical-practice-guidelines.pdf>

³⁹ Sustainability & Implementation of Cancer Control Actions in EU MSs: <https://www.ipaac.eu/res/file/outputs/wp4/sustainability-report.pdf>

⁴⁰ Example from Austrian One Pager: <https://www.ipaac.eu/roadmap/detail/31>

⁴¹ iPAAC One pager, promoting a framework to improve early access to immunotherapies: <https://www.ipaac.eu/roadmap/detail/58>





2.3 Education and Training

An important objective of EU network of CCCs will be to strengthen capacity of its members to ensure high-quality of care, research and education. Rapid advancements in cancer diagnosis and treatment strategies underscore the importance of keeping health professionals updated, ensuring that patients benefit from the latest innovations.

The WP7 survey emphasised the role of CCCs being active in education and training. Respondents reported high adherence to aspects of education and training, with close to all participants partaking in educational programs along the routes of care and research, both under- and post-graduate (D7.1).

A central mission of EUCCCs would therefore be continuous educational opportunities for professionals and knowledge dissemination to patients, their families, and the broader community. Establishing such programs demands significant resources. EUCCCs often collaborate with educational entities and patient groups to craft comprehensive educational curricula (D7.2).

Seven core criteria were proposed by the WP7:

- ❖ The EUCCC **collaborates with training centres**, universities, research institutions, and community partners, including patient representatives, to create and offer cancer-related training and education programs.
- ❖ The EUCCC **collaborates with patient associations or advocacy groups to co-create education and training** programs, ensuring they are aligned with patients' needs and perspectives.

In the maturity model, these two core standards have been integrated in the level 2 of the criterion: “stakeholder involvement and participation in the preparation and improvement of education and training programmes”. If 82% of the centres participating in the test (n=11) reported collaborating with universities and training institutions, only 45% do so with civil society (i.e., patient associations or advocacy groups)⁴².

- ❖ The EUCCCs offers its employees **access to comprehensive list of formal education programs**.

Only 3 respondents (n=11) reported to offer their employees a comprehensive list of formal education programs with specific objectives, serving as an annual checklist to ensure alignment with strategic goals⁴³.

- ❖ The EUCCC **fosters interdisciplinary and multidisciplinary collaboration** by providing educational programs to unite healthcare professionals in a cohesive working relationship.

⁴² D 4.2, page 59

⁴³ D 4.2, page 60





Less than half (five) of responding centres to the maturity model testing reported fostering interdisciplinary and multidisciplinary collaboration by providing educational programs to unite healthcare professionals in a cohesive working relationship⁴⁴.

- ❖ The EUCCC **offers a comprehensive range of educational activities** to meet the diverse learning needs of healthcare professionals and cover all stages of the cancer patient pathway.

This core standard has been integrated in the maturity model as part of the level 2 of the maturity levels for the criterion describing the approach to the issue of training and development planning and the range of training and educational activities offered. From the 11 centres having participated in the testing of the maturity model for the module on 'education & training', 8 centres report to evaluate specific educational needs and competencies required for different professional roles in cancer care and designing training programs; 7 centres providing access to trainings for healthcare professionals covering all stages of the cancer patient pathway; and 7 providing access to trainings aimed at improvement of communication skills with patients⁴⁵.

- ❖ The EUCCC **provides access to support groups**, survivorship programs, and community resources that can **offer additional support and information**.

This core standard corresponds to the level 3 of the maturity model proposed and 8 of responding centres (n=11) recognized providing access to support groups, survivorship programs, and community resources that can offer additional support and information; while 6 reported to regularly held events for patients and their careers⁴⁶.

An important concern raised about the future EU network of CCCs is the extent to which patient and professionals could navigate within the network. Regarding professional mobility, it has been recognized that the mobility of researchers, especially young doctors leads to an important brain drain. Results of discussions: the EU network could support centres and MSs to hold their human resources (not only researchers) by fostering synergies and improvements opportunities at local level.

⁴⁴ D 4.2, page 60

⁴⁵ D 4.2, page 62

⁴⁶ D 4.2, page 63





INTERNATIONAL COOPERATION IN EDUCATION, TRAINING AND DEVELOPMENT [In need for validation]		Avg. (n=11)
Level 1		82%
Level 1-req1: training and development activities and knowledge exchange through international cooperation (occasionally or incidentally)		82%
Level 2		55%
Level 2-req1: involvement in numerous forms of international cooperation in the knowledge sharing		55%
Level 3		73%
Level 3-req1: improvement of staff competence by supporting international mobility (participation in student exchange programs, fellowships, and staff mobility)		73%
Level 4		55%
Level 4-req1: improvement of training and development of exchange knowledge based on experiences and information gathered through international cooperation		55%

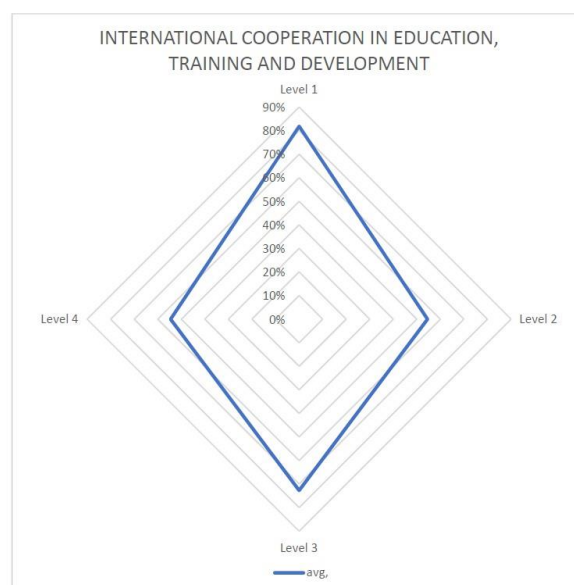


Figure 5. Results from questions to participating centres to the Maturity model testing to the questions related to international cooperation in education, training and development.
(Page 66). Available at (date):

2.4 Comprehensive cancer care

The WP7 defined more than hundred and thirty standards for the care dimension for EUCCCs among which the sixteen core ones are listed here below. Six centres participated in the testing of the maturity model for the module “care” and their reported level of maturity is provided alongside the description of the core standards.

- ❖ The EUCCC has a **physical and/or virtual information and support centre that is available** for staff, patients, family members and care givers.

This core standard was part of the level 2 in the maturity model and all the six respondents acknowledge having this support, of which 5 reported to use it for informing and supporting patients about the potential late effects⁴⁷.

- ❖ The EUCCC **documents relevant information**⁴⁸ communicated to the patient in the patient’s record.

This core standard was part of the level 1 in the maturity model and all the six respondents acknowledge documenting all information communicated to the patient in the patient’s record.

⁴⁷ D4.2, page 91.

⁴⁸ Most relevant for the patient: patient rights, diagnosis, treatment options, shared decision making, treatment plan, prognosis, supportive care, rehabilitation, psycho-oncology, survivorship care.



- ❖ The EUCCC performs **regular reviews and updates on the documented patient pathway** based on new evidence-based knowledge and assessment of practice experiences.

This core standard was part of the level 4 in the maturity model and four respondents acknowledged regularly performing review and updates on the documented patient pathway⁴⁹.

- ❖ The EUCCC has **established procedures for identifying eligible patients⁵⁰ for MDT consultation** as part of their patient pathway and before any treatment decisions.

All responding centres reported established procedures for identifying eligible patients for MDT consultation as part of their patient pathway and before any treatment decisions⁵¹.

- ❖ The EUCCC **ensures that recommendations made by MDT-meetings (when available) are followed, and if relevant, reason for why these are not followed are documented** in the medical record and communicated to the patient and the MDT.

4 of the 6 responding centres reported ensuring that recommendations from MDTs are followed and deviation documented⁵².

- ❖ The EUCCC follows **formally agreed clinical guidelines⁵³** for treatment and follow-up and provides easy access to the guidelines in written or digital form.
- ❖ In EUCCC, the **staffing levels of key disciplines contributing to cancer surgery are planned** to ensure safety, accuracy, and high-quality care.

These core standards were part of the level 1 in the maturity model and all respondents (n=6) reported having planned the staffing levels for cancer surgery⁵⁴.

- ❖ In EUCCCs **minimum surgical requirements of quality of personnel and equipment are documented** and followed up in each tumour type.

This core standard was part of the level 3 in the maturity model and half of the respondents (3 out of 6) reported documented minimum surgical requirements of quality of personnel and equipment.

- ❖ In EUCCC **the staffing levels of key disciplines contributing to cancer radiotherapy are**

⁴⁹ D 4.2, page 84.

⁵⁰ Eligible patients as defined by national tumour specific guidelines

⁵¹ D 4.2, page 84.

⁵² D 4.2, page 84.

⁵³ institutional/local/regional/national/international

⁵⁴ D4.2, page 87. Available at (date):



This core standard was part of the level 2 in the maturity model and four of the respondents (out of 6) answered positively.

- ❖ In EUCCC, the staffing levels of key disciplines contributing to cancer systemic therapies are planned to ensure safety, accuracy and high-quality care.

This core standard was part of the level 2 in the maturity model and five of the respondents (out of 6) answered positively.

- ❖ In EUCCC, there is a quality assured digital system for the prescription, preparation, and administration of anti-cancer drugs.

This core standard was part of the level 2 in the maturity model and five of the respondents (out of 6) answered positively.

- ❖ In EUCCC there are SOPs for the administration of anti-cancer drugs.
- ❖ In EUCCC anti-cancer drugs are administered by nurses who have completed a specific training programme for chemotherapy administration (Core)

These two core standards were part of the level 3 in the maturity model and five of the respondents (out of 6) answered positively.

- ❖ In EUCCC each patient has a medical consultation prior to the commencement of systemic therapy.

This core standard was part of the level 1 in the maturity model and five of the respondents (out of 6) answered positively.

- ❖ The EUCCC has SOPs for screening to identify patients with needs of specific follow-up of needs connected to medical or psycho-social consequences of cancer disease or cancer treatment.
- ❖ The EUCCC gives advice and support to patients and caregivers on how to detect early signs and symptoms of recurrence.

These core standards were part of the level 1 in the maturity model and five of the respondents (out of 6) answered positively.

On the other hand, the WP6 continued the work on CCCNs which was already initiated in the predecessor Joint Actions CanCon⁵⁵ and IPAAC⁵⁶ with the goal to further develop the

⁵⁵ <https://cancercontrol.eu/archived/guide-landing-page/guide-integrated-cancer-control.html>

⁵⁶ <https://www.ipaac.eu/en/work-packages/wp10/>



access and availability of the comprehensive high quality of care in CCCNs with a focus on the interfaces between care and research (CCCN and CCC).

In the light of the emergence of the important role CCCs, the initial CCCN definition developed in CanCon (reference) was jointly further developed to define and acknowledge the interfaces between CCCNs and research (D6.1):

- (a) *A CCCN consists of multiple units belonging to different institutions dedicated to early detection, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation for the benefit of cancer patients and cancer survivors. They encourage the enrolment of their patients in clinical trials conducted within the CCCN or in the co-operating CCC.*
- (b) *A CCCN is a collaborative organizational structure united by having joint tumour-specific patient pathways, covering one or more joint patient pathways.*
- (c) *A CCCN must have a formal collaboration with a Comprehensive Cancer Centre (CCC), e.g. for complex disease situations, diagnostics and/or study activities. The CCCN can be an extension of the care network of a CCC and/or cooperating with a CCC.*
- (d) *In a CCCN an inter-professional and multidisciplinary team work together along a tumour-specific, guideline-based patient pathway or along several pathways for the benefit of patients with each particular type of tumour.*
- (e) *In a CCCN the inter-professional and multidisciplinary team also works together on topics depending on and benefiting from pan-pathway collaboration – like precision cancer medicine, exploiting of diagnostic and treatment capacities, prevention, survivorship, palliation and cancer related education and training.*
- (f) *The units interact and have a formal agreement to work together in a programmatic and structured way with common governance structure, in order to pursue their goals more effectively and efficiently through collective synergies.*
- (g) *The CCCN promotes a uniform system of quality assurance. It provides both tumor-specific Quality Indicators as well as pan-cancer related indicators. They are used through the governmental processes of the CCCN to make the quality of care in the CCCN transparent and to continuously improve it.*
- (h) *The objective of a CCCN is to provide comprehensive cancer care to all the people living in a certain geographic area and specifically securing access to the advanced services of CCCs to all eligible patients, thus pursuing equality and the improvement of outcomes and quality.*



Care of oncological patients always needs cooperation of many disciplines and professional groups. CCCN tumour-specific Set of Standards (SoS) compile standards for the partners of these networks. These include, among other things, requirements for qualitative and quantitative expertise and for guideline-based processes and results. In addition, there are specifications for the governance and structure of the network as well as for the personnel and technical resources that must be provided (D.6.2).

In addition, a Set of Quality Indicators (QIs) for Lung Cancer and a Set of Standard (SoS) for Lung Cancer CCCNs were developed (=D6.2); a training concept with instruments to enable and empower member states to set up quality assured CCCNs was developed (D6.3); and an updated methodology to create a patient pathway⁵⁷ that can be used by lung cancer patients and clinicians was prepared as well as.

interoperability guidelines for digitalization of patient pathways in CCCNs and CCC are prepared (=D.6.4).

The WP5 identified five areas where the EU network of CCCs would be active in terms of care, treatment and diagnostics: clinical guidelines, clinical data for research and quality monitoring, cancer in children, adolescents and young adults and survivorship, precision cancer diagnostics, primary and secondary prevention and early detection⁵⁸.

In the iPAAC Joint Action, a long list of challenges faced in the field of cancer care, treatment and diagnostics have been identified, such as the management of comorbidities (prior or post cancer treatment) or the organization of the concentration care as for example for complex surgeries⁵⁹.

2.5 Prevention

In terms of primary and secondary prevention and early detection, the EU network of CCCs should aim at advancing cancer prevention through European Comprehensive Cancer Centres⁶⁰. Proposed activities could therefore e.g. facilitate interaction and synergies between public and specialized health care in cancer providing data and experience to others actors involved in the design and implementation of prevention strategies. These activities could reduce the silo-thinking on cancer care, develop and harvest synergies. On a national level this will support the activities to lower incident and mortality rates.

Although comprehensive prevention encompasses primary prevention to mitigate cancer risk, secondary prevention and early detection to thwart carcinogenesis and tertiary prevention targeting specific individual interventions, the EUCCCs will champion tertiary prevention as an integrated part of its follow-up procedures and survivorship program, while also synergizing

⁵⁷ A patient pathway is an evidence-based tool that supports the planning and management of the care process of individual patients within a group of similar patients with complex, long-term conditions. It details the phases of care, guiding the whole journey a patient takes by defining goals and milestones, and supports mutual decision-making by the patient and his/her multidisciplinary care team collaborating in a comprehensive network of care providers." (Richter, Hickmann, Schlieter 2021).

⁵⁸ D 5.3.

⁵⁹ iPAAC Implementation challenges: <https://www.ipaac.eu/res/file/outputs/wp4/ccpis-reported-challenges.pdf>

⁶⁰ D 5.3, page 20





By leveraging their advanced expertise and technical platforms, EUCCCs can offer risk stratification services and screening for high-risk groups. These activities should complement national policies and local infrastructure, and EUCCCs should also endorse recommended population-based screening programs. One core standard has been proposed for the EUCCCs (D7.2):

- ❖ the EUCCC **contributes to national or local population-based screening programs**, serving as a screening unit, a referral centre, or both.

Eleven respondents participated to the testing of the maturity model for the module on 'prevention'. This core standard was part of the requirements for the level 1 and ten respondents reported to contribute to national or local population-based screening programs and nine of them as screening unit or referral centre⁶².

Although not being core standards, the results regarding the criterion "Prevention through information programmes and cooperation with public institutions" revealed that all centres (n=11) have formal collaboration with relevant governmental entities, while only five centres take initiatives to improve the existing health-related preventive programs suggest new educational cancer preventive programs⁶³.

In the WP8 exercise, prevention has not been identified as subject to networking. The networking of cancer services (including CCCs) encompass many areas (care, research, etc.) but never prevention.

Although not presented as core, the WP7 identified three standards for the EUCCCs to contribute to research on prevention. One important associated challenge relates to:

- ❖ **the availability of reliable data and (structural) funding for monitoring and assessment of preventive activities.** The impact of (health)preventive actions requires long periods of observation accompanied by regular systematically registered measures, at the level of the population. This implies long-term vision, policies and funding.

Results from the discussions: the ambition of the EU network of CCCs could be to offer the opportunity to collect the essential personal data, supporting evidence-based decision-making and research for personalized prevention and early detection.

Although not directly challenging the activities of the EUCCCs or the EU network of CCCs, the following challenges importantly hinder preventive interventions and could be contemplated at the level of the EU network of CCC.

⁶¹ D7.2, pages 53-57.

⁶² D 4.2, page 74.

⁶³ D4.2, page 72.



- ❖ **Role and communication with first line & share of prerogatives:** the role of the first line is key for effective prevention. Certainly, for tertiary prevention, an effective communication with the

first line is crucial, ensuring adherence to behavioural changes, monitoring and managing side effects and screening of (symptoms of) recurrence.

Results from discussions: activities of the EU network of CCCs and the centres could help in designing protocols for such communication and collaboration.

- ❖ **Cultural barriers and habits:** several regions and communities struggle with (strong) cultural habits related to risk behaviours (tobacco smoking, overweight, sugar consumption, physical inactivity, alcohol consumption, etc.).

Results from discussions: The development by the Members of the EU network of CCCs of joint guidelines and activities on cancer prevention could help ensuring consistency (and mutual learning) and quality across the network.

- ❖ **Level of implementation of screening programs:** several regions report difficulties regarding the implementation and uptake of cancer screening programs. It relates to the lack of practitioners but also the unpopularity of certain screening.

Results from the discussions: the EUCCCs will have an important role in performing screening and early detection but also developing, testing and implementing innovation for screening and early detection, as important tool for increasing the uptake.

III Sustainability

3.1 The case of Smaller Member States: delivering high-quality comprehensive cancer care in the context of cross-border models

These cases relate to Member States and their CCCs that provide some of the cancer care services for patients in cross-border facilities (particularly those that require a level of expertise/high-level specialisation which will not be feasible to have in-house because for a number of reasons including the small number of patients within its catchment population).

The need of some CCCs to engage in cross-border care delivery is not only an issue (and a solution) for small MSs but also a consideration for peripheral regions of bigger MSs whereby cross-border may make more sense with facilities across a border than with facilities in other regions of the same MS.

In September 2023, a Small Member States' Workshop took place to identify similar issues and concerns Although not organized in the framework of the CraNE Joint Action, nor with the



presence of CraNE representatives, some of the results of the workshop related to the organisation of cancer care and cancer research are presented hereafter.

Access to highly specialised expertise

Most small MSs face a shortage of human resources on technical, clinical and administrative levels (e.g., project management). The relative clinical burden may be higher, which may be prohibitive towards engagement in extra-clinical activities such as research and collaborations. Consequently, the comparative representation of MSs by size in the open calls and in other programmes such as Joint Actions is lower the smaller the population size of the MS.

Access to innovation (clinical trials)

The pharma industry is generally not as keen to recruit from smaller populations. Therefore, the access of small MS to these trials can only be possible if patients are to be recruited by multi-country consortia.

Economies of scale & availability of resources

Concerns especially relate to highly specialised human resources and technologies, due to the effect of the economies of scale and supply limitations caused by *inter alia* smaller number of patients at the national level. This results in (1) higher costs per unit at the procurement stage (e.g., medicines) and

(2) additional costs are incurred by transport to and from island countries/peripheral regions.

Implementation of CCCs & Organisational structures

The proposed concept of CCCs is based on models from larger MS and two pre-existing certification systems, the working definition of CCCs may lead to challenges in identifying the suitable national centres eligible for classification or certification as EUCCCs. Potential EUCCCs in small MSs are also more likely to network with specialised centres in other countries, and these may be outside the EU (e.g., Malta networks with several reference centres in the UK for highly specialised care and expertise for cancer and rare diseases, including rare cancers).

3.2 Synergies with other EU initiatives

The WP5 conducted an analysis of the synergies between the forthcoming EU Network of CCCs and other initiatives⁶⁴. In total, eleven initiatives have been categorised into three groups.

First, the already existing or newly created EU Networks on cancer, including the European Reference Network (ERN) EURACAN⁶⁵ and related projects, such as the JA JARDIN⁶⁶, the

⁶⁴ D5.2.

⁶⁵ Official website: <https://euracan.eu/>

⁶⁶ Official website: <https://ern-ithaca.eu/jardin-project-the-joint-action-on-integration-of-erns-into-national-healthcare-systems/>



upcoming Networks of Expertise (NoEs) developed in the JA JANE⁶⁷, and other emerging structures like National Mission Cancer Hubs (NMCHs) and the EU Network of NMCHs developed by the CSA ECHoS⁶⁸.

Synergy between this first group of initiatives and the EU network of CCCs could facilitate, support, encourage or improve the access and leveraging of the resources and expertise of these interconnected networks, thereby amplifying collective impact and ensuring their sustainability.

The second group includes the established infrastructures operating in various domains such as research, clinical trials, and data sharing, such as ECRIN⁶⁹ and BBMRI-ERIC⁷⁰. The integration of the members of the EU Network of CCCs into these infrastructures may facilitate access to specialised services and resources essential for driving innovation and excellence in cancer treatment and research.

The third and last group concern ongoing or recently concluded EU projects, such as CCI4EU, Can.Heal, CanServ, UnCan.eu and HealthData@EU Pilot project. Specific activities aligned with the objectives and scope of each project, envisioning a collaborative landscape where project teams proactively identify synergies and opportunities for cooperation, thereby magnifying the effectiveness and endurance of these initiatives.

⁶⁷ Official website: <https://jane-project.eu/>

⁶⁸ Official website: <https://cancermissionhubs.eu/>

⁶⁹ <https://ecrin.org/projects/eosc4cancer>

⁷⁰ <https://www.bbmri-eric.eu/>





CraNE

European Network of Comprehensive Cancer Centres

WP4 Sustainability – The CraNE Blueprint

BE Cancer Centre, Sciensano

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BACKGROUND

From October 2022 to October 2024, CraNE partners have worked together to prepare the framework for the implementation of the EU Network of Comprehensive Cancer Centres (CCCs), through 5 core work packages:

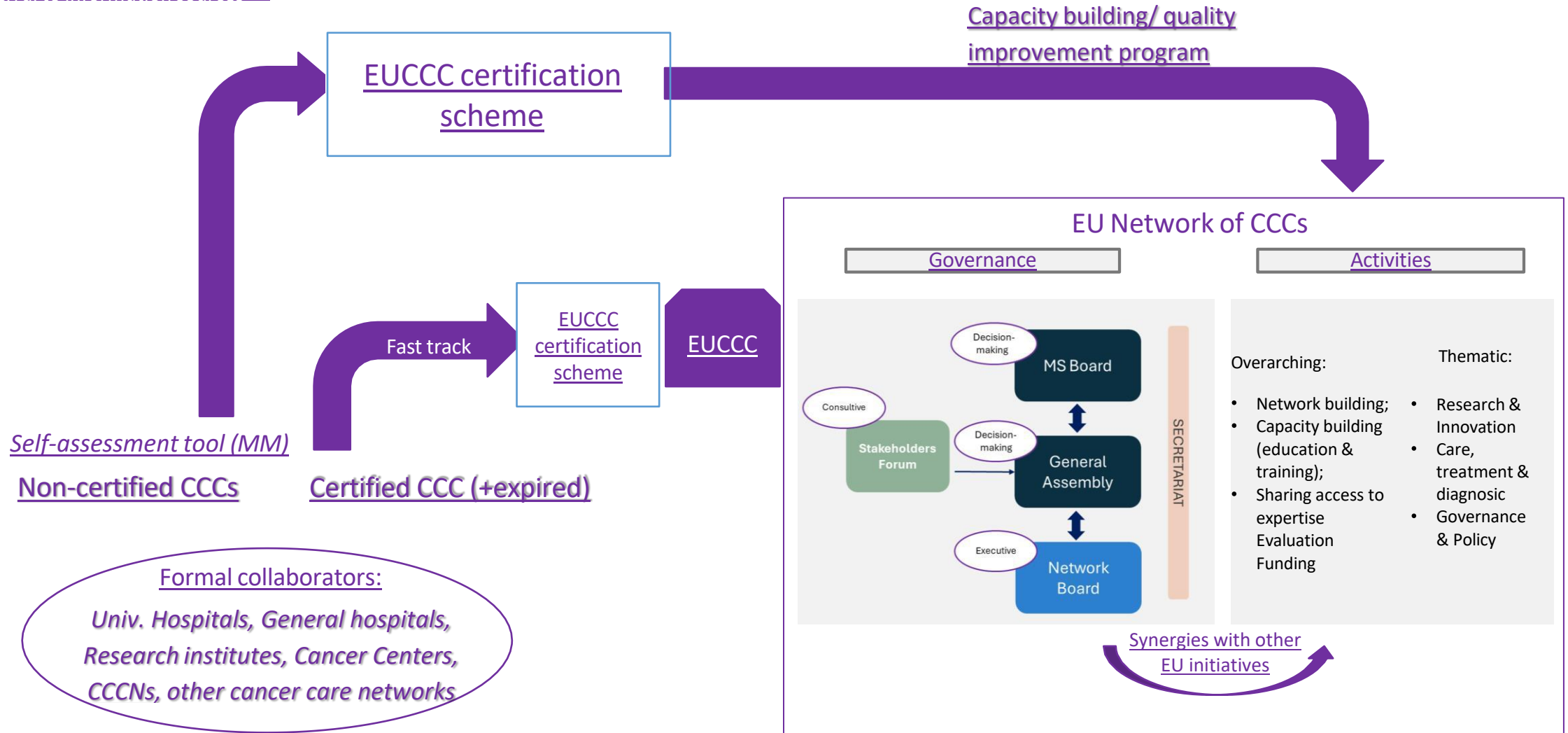
- ❖ **The WP4** worked on (1) the development of a maturity model to be used as self-assessment tool for future EUCCCs and to (2) the identification of hindering and risk factors for the sustainability of the network
- ❖ **The WP5** carefully thought and made a detailed and coherent proposal for the Composition, governance, joining process and functioning of the EU network of CCCs, including possible activities in 'Care, treatment and diagnostics', 'Research and innovation', 'Governance and policy'
- ❖ **The WP6** continued the work started in CanCon and iPAAC regarding the development of supporting documentation for the development, implementation and functioning of Comprehensive Cancer Care Networks
- ❖ **The WP7** proposal consists of a set of criteria and standards for the centres to be certified as EUCCCs and a detailed certification scheme
- ❖ **The WP8** investigated the accessibility and inclusion of real-life settings organizing cancer care through hub and spoke formats and their relationship with CCCs

What's the CraNE Blueprint?

- ❖ The output developed through the CraNE JA are interconnected. The aim of the Blueprint is to depict their interaction with one another and to shed light in a layman language on the path towards their introduction into national cancer plans or strategies and ultimately, the certification of national/regional infrastructures as CCCs and the membership to the EU Network of CCCs.
- ❖ The Blueprint has been thought as an interactive tool, gathering and summarizing the main outputs of the Crane preparatory Joint Action.
- ❖ For each element included in the Blueprint, a brief summary is provided but also, referrals (hyperlinks) are made to the documents where more extensive explanation can be found.
- ❖ In addition of practicalities (definitions, functionalities, etc.), some challenges for the EUCCCs and the EU Network of CCCs were identified and added the elements of the Blueprint, where they would most probably be relevant
- ❖ Importantly, the content of the blueprint remains a proposal that needs to be further developed, tested and improved.

The CraNE Blueprint

The 9 hyperlinks of this figure lead to more information on each element, including referral to information sources



Comprehensive Cancer Care Networks_CCCNs

- A CCCN consists of multiple units belonging to different institutions dedicated to early detection, diagnosis, treatment, follow-up, supportive and palliative care and rehabilitation for the benefit of cancer patients and cancer survivors. CCCNs encourage the enrolment of their patients in clinical trials conducted within the CCCN or in the co-operating CCC to ensure the integration of research and care.
- A CCCN is a collaborative organizational structure united by having joint tumour-specific patient pathways, covering one or more patient pathways.
- A CCCN must have a formal collaboration with a Comprehensive Cancer Centre (CCC), e.g. for complex disease situations, diagnostics and/or research activities. The CCCN can be an extension of the care network of a CCC and/or cooperating with a CCC.
- In a CCCN an inter-professional and multidisciplinary team work together along a tumour-specific, guideline-based patient pathway or along several pathways for the benefit of patients with each particular type of tumour.
- In a CCCN the inter-professional and multidisciplinary team also works together on topics depending on and benefiting from pan-pathway collaboration – like precision cancer medicine, exploiting of diagnostic and treatment capacities, prevention, survivorship, palliation and cancer related education and training.
- The units interact and have a formal agreement to work together in a programmatic and structured way with common governance structure, in order to pursue their goals more effectively and efficiently through collective synergies.
- The CCCN promotes a uniform system of quality assurance and a unified informatics system for optimal exchange of information. It provides both tumor-specific Quality Indicators as well as pan-cancer related indicators. The indicators are used by the governmental processes of the CCCN to make the quality of care in the CCCN transparent and to continuously improve it.
- The objective of a CCCN is to provide comprehensive cancer care to all the people living in a specific geographic area and specifically securing access to the advanced services of CCCs to all eligible patients, thus pursuing equality and the improvement of outcomes and quality.

❖ Crane results fro CCCNs:

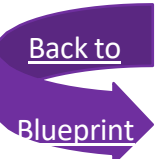
<https://crane4health.eu/wp6-organization-of-comprehensive-high-quality-cancer-care-in-comprehensive-cancer-care-networks-cccn/>

❖ CanCon Result_Background information on/ for the set-up CCCNs

https://cancercontrol.eu/archived/uploads/images/Guide/042017/CanCon_Guide_5_Control_LR.pdf

❖ iPAAC results

<https://www.ipaac.eu/en/work-packages/wp10/>



COMPREHENSIVENESS (1/2)

Other stakeholders involved in cancer care, research, education & training

The organizational considerations, addressing the issue on whether all types of diagnostics and treatment options and patient pathway alternatives are managed within the EUCCC or through collaborations with external institutions

- ❖ Formal collaboration with institutions representing cancer **prevention** and screening
- ❖ Formal collaboration and coordination with **palliative care institutions and hospices**
- ❖ Formal collaborations with home care organizations, **general practitioners** and **nursing homes**

WP7 requirements for the certification process D7.2



Activities also seek to facilitate joint initiatives on the development of collaborative structures involving political bodies, academic institutions, patients' organisations and relevant businesses

WP5 Sketches of possible activity areas D5.3

- ❖ The EUCCC governance structure ensures that all patients, regardless of tumour group or whether they have a common or rare cancer diagnosis, have access to the necessary diagnostic and treatment options as specified by their patient pathways. These services are provided either directly by the EUCCC or through collaboration with other specialized units, coordinated by appropriate governance structures. (CORE)

WP7 criteria and standards D7.2

COMPREHENSIVENESS (2/2)

Other stakeholders involved in cancer care, research, education & training

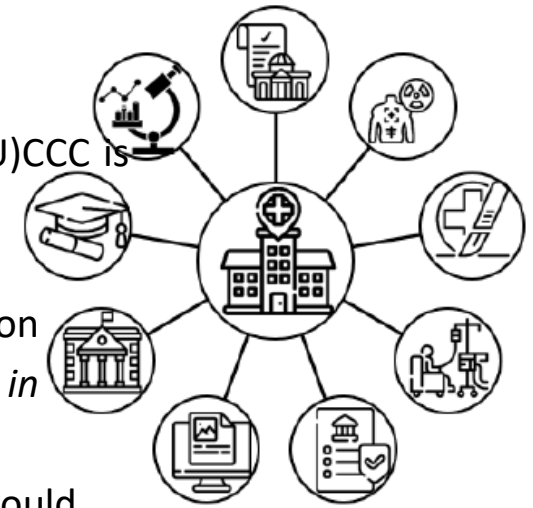
Some challenges were identified regarding the collaborations of CCCs to be certified as EUCCCs:

- ❖ Regarding the core criteria *“The EUCCC has processes on collaboration on MDT/tumour boards in a geographical area with shared patient pathways regarding participation »*

-> would be appropriate to not take for granted that the cooperation between the partners of the (EU)CCC is good enough. This leads to the following question

- ❖ **Formal agreements:** Concerns could be raised regarding the extent to which agreements of collaboration among partners forming a CCC or a CCCN need to be formally established. *What would this mean in practice? Are formal agreements necessarily binding?*

Results from discussions: In the future, piloting the development and implementation of (new) EUCCCs should investigate the need to define what a formal agreement is or provide examples.



Comprehensiveness

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[Blueprint](#)

EUCCC

As a result of the work accomplished during the Crane Joint action, an agreement has been reached regarding a working definition for the future EUCCCs.

A European Comprehensive Cancer Centre (EUCCC) serves as a major source of clinical care, innovation and discovery into the understanding of cancer, and for the development of more effective approach to prevention, diagnosis and therapy. It shows a direct provision of an extensive range of high-quality cancer diagnostics and care covering at least all the major cancers and ensures through its networks access also to advanced treatment for remaining diagnoses. The EUCCC demonstrates a reasonable depth and breadth of activities in basic laboratory, clinical as well as in prevention, cancer control and population-based research and they are integrating research systematically with clinical practice. It serves as a focal point of a local/regional or national network and acts as a driving force promoting high quality of care & research, implementing guidelines and good practices, and engaging the populations within its catchment area. An EUCCC is committed to embody the cooperation between institutions, networks (including among others: Comprehensive Cancer Care Networks (CCCNs) and stakeholders in prevention, care and research). It takes into account the contribution of each of the stakeholders in its field of activity and competence to build a partnership that maximises the impact in its catchment area. It is also committed to cooperate with other EUCCCs and networks for the development of shared resources in the field of research, care, innovation, education and training.

A comprehensive cancer centre is an organisational entity with a clear central governance and high level of infrastructure and expertise including:

- Organizational Capabilities: Physical Space, Director, administrative/managerial/scientific governance, consortium.
- Partnership: description of the organisation of the partnership, relationship between partnership institutions, community engagement within a catchment area.
- Transdisciplinary Collaboration and Coordination: Multi-disciplinarity, transfer of scientific findings, dissemination activities (towards professionals, patients and general public)
- Institutional Commitment: EBCP and EUCCC network, Team Science, Education and training.

Certified CCCs

In the implementation phase, an initial call of interest will be launched for Comprehensive Cancer Centre that are already certified through DKH and OECl schemes, to express their interest in becoming member of the network. The supporting documentation required will be further defined as well as the content of the call. Yet they will become the first members of the network (D5.1, p8).

Considering that certification have a duration limited in time, centres with expired certification should be free to re-enter the network by either existing schemes (e.g. OECl, DKH) or through the future EU- certification scheme, when ready (D5.1, p8).

Non-certified CCCs

Comprehensive Cancer Centres that do not hold a certification from one of the existing scheme are invited to become a member of the European network of CCCs by following the process of admission from an existing scheme or thru the future European scheme (D5.1, p9).

Self-assessment tool (maturity model)

An eTool will be at the disposal of centres willing to start a certification process, containing all the criteria and standards foreseen for the EUCCCs. The audit team and certification board will have access to the results of this self-assessment.

[WP7 The Certification Application Process \(D7.2, pages 195-196\)](#)



Example question from the tool:

* 33. Does the CCC evaluate the quality of its relationships with stakeholders and improve relationships by responding to stakeholders' needs?

☒ Yes
☐ No
☐ I do not know

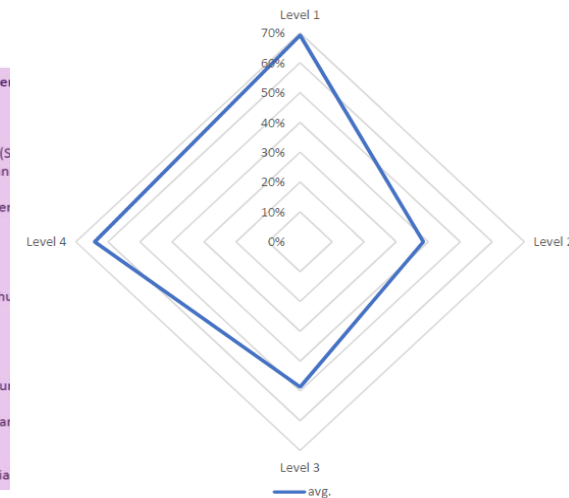
If yes, please provide evidence.

Buttons: Prev, Next

Instruction: If marked „Yes“, do not forget to provide evidence

Examples of evidence for ALL dimensions:

- Meeting minutes
- Meeting agendas
- Internal reports
- Standard operating procedures (SOPs)
- Documentation confirming organization of training, workshop sessions
- Initiatives/programmes implemented in consultation with stakeholders
- Legal agreements
- Internal agreements
- Organogram
- Materials on clinical trials (brochures, websites, public events)
- KPIs
- Strategic plans
- Operational plans
- Patient Pathway written procedures
- List of members for different initiatives/research groups/programmes
- List of events
- List of patents filled
- Catalogue of educational materials



[WP4 Road to the EUCCC capacity The role of maturity model D4.2](#)

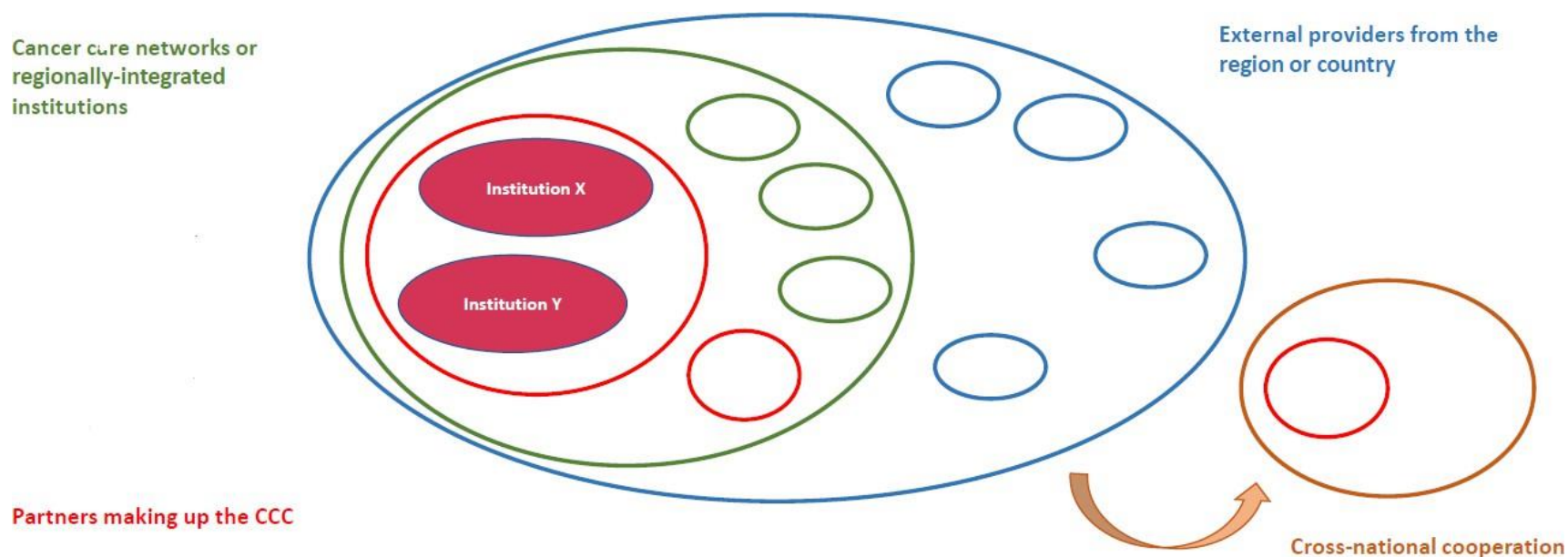
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EUCCC_Capacity building

Following the examination of the self-assessment results, a centre can be referred to capacity-building

[WP7 Examination of the self-assessment page \(D7.2, page 200\)](#) [WP4 Maturity model D4.2](#)

Experience and results from WP8 (about of clustering the CCCs models) will allow to correctly understand the context in which the CCC has to develop, and subsequently, select the most adequate capacity-building interventions



[WP8 Mapping organisational models of networks built around CCCs](#)

EUCCC_Capacity building

Examples of capacity-building that could be offered in the framework of the EU Network of CCC' 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

WP5 Sketches of possible activities D5.3

Many concerns were raised, at several occasions, regarding the equity among MSs/CCCs, within and across Member States, in terms of capacity to meet the criteria and standards and subsequently to become member of the EU network of CCCs, have a voice in the governance and participate to the activities. Through this process of capacity building and quality improvement no one would be excluded.

EU Certification scheme for EUCCCs (1/2)

A process focussing on development and ownership



Process	Allowance to apply					Certification application					On-site audit, reporting & improvement plan		Certification attribution		Follow-up and improvement plan implementation			
Steps	Initiation	Preparation and filling of the application form	Initial review	Application examination	Contractualization & Payment	Core team set-up and Planning	Detailed self-assessment	Quality assurance review	Final Go/No go decision	Payment	On-site audit	Reporting & improvement plan definition	Final review validation	Certification	Feedback follow up	Progress report on the improvement plan	Certification board review of the progress report	Yearly updates and events
Time	1 to 4 weeks	1 to 4 weeks	2 weeks	2 to 4 weeks	6 to 10 weeks	2 to 3 weeks	1 to 2 months	7 weeks to 4 months	2 weeks	2 to 4 weeks	1 to 2 weeks	4 to 6 weeks	1 month	2 to 4 months	1 to 4 weeks	1 year maximum	1 month	To the centre's discretion
Parallel steps						Composing and preparing the audit team	Composing the on-site audit agenda	Preparation of the on-site audit										
Applicant centre	■	■		■	■	■	■	■	■	■	■	■		■	■	■	■	■
EUCCC Coordinator		■	■	■		■	■	■	■			■	■	■	■	■	■	■
Certification board					■				■					■			■	
Audit team							■	■	■		■	■	■					
Liaison office					■					■								

EU Certification scheme for EUCCCs (2/2)

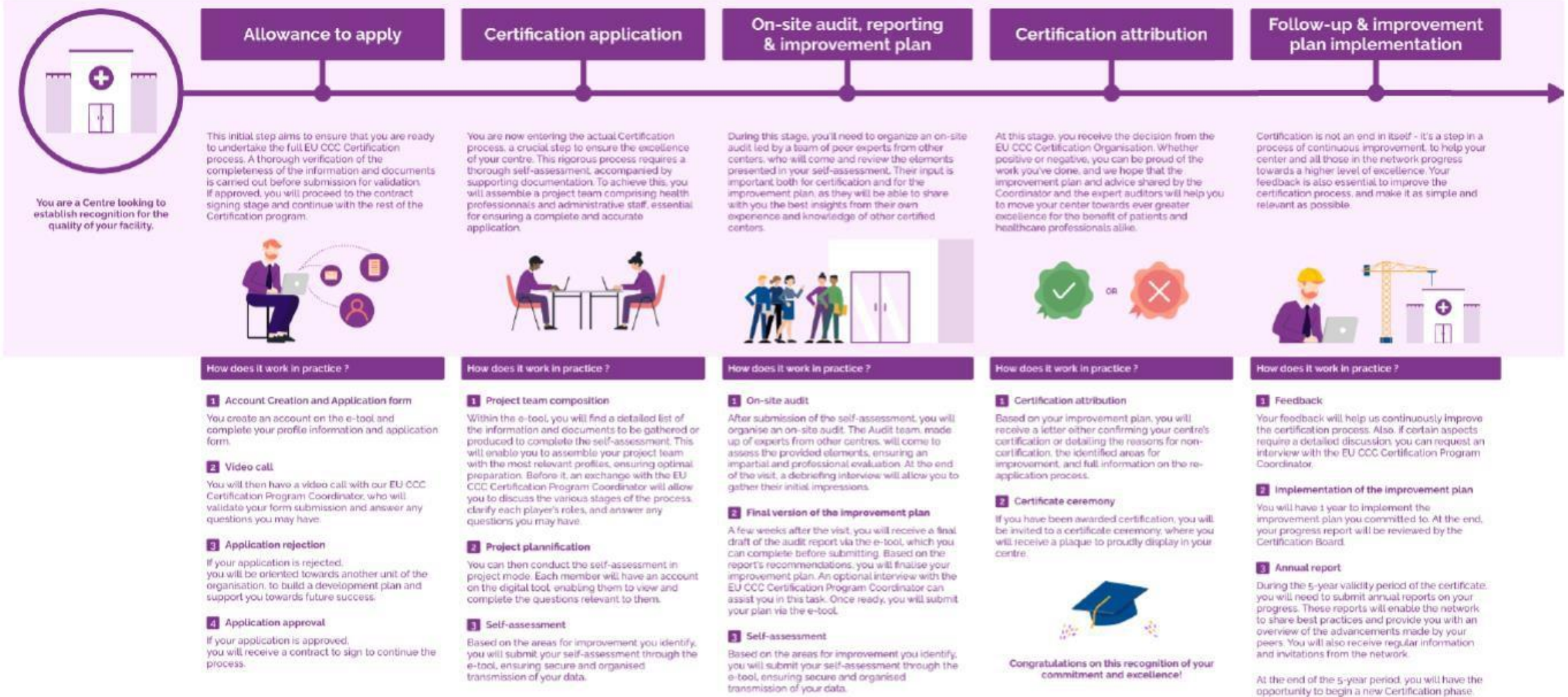
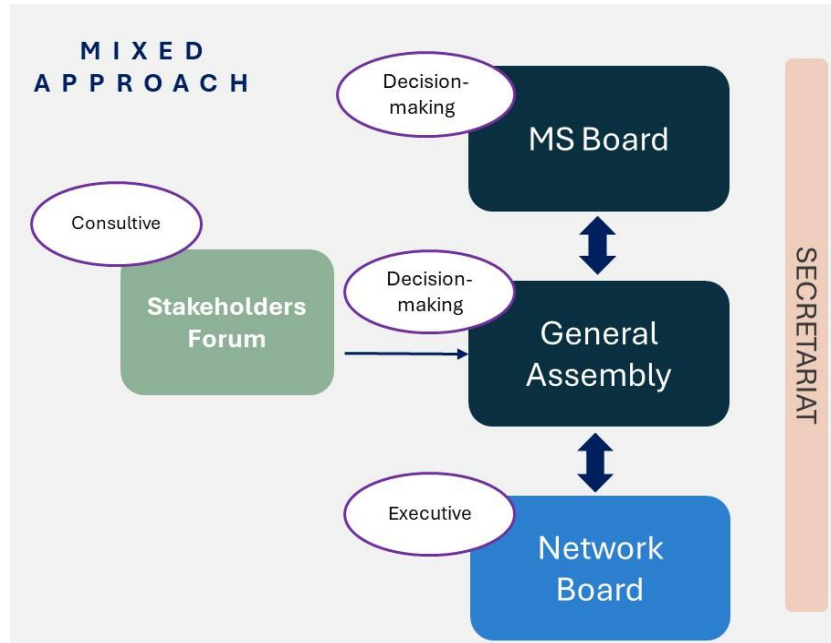


Figure 1. An illustration of the overall proposal on the certification process for members of the EU network of CCCs.

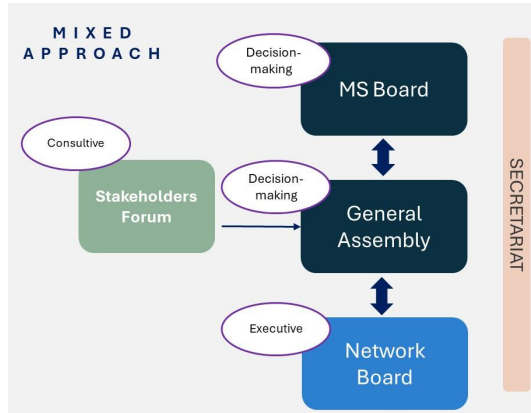
EU Network of CCCs_Governance model and functions (1/2)



A mixed approach has been selected as responding the best to the governance need of the network. In this model, decision- making power is distributed between the Member State Board (MS, composed of the European Commission and two appointed representatives for each MS and ACs with voting right) and the General Assembly.

	Composition	Functions
MS Board	EC and MS representatives	- evaluates the funding opportunities - advises the GA on integration between network and member states policies - approves entry of new CCCs
GA	CCC representatives	- approves the strategy, policies and activities - selects and appoints members of the Board - approves the working methods - approves the process, methodologies and criteria - approves the budget and advises the MS Board on funding opportunities - transfers the policy priorities to the MS Board
Network Board	Director Deputy Director 7/8 CCC representatives Network coordinator	- implements strategy, policies and activities - identifies and periodically reviews KPIs - drafts the Annual Review - defines the working methods of the Network Board and the budget - collects and analyses data provided by member - Manages communication with members

EU Network of CCCs_Governance model and functions (2/2)



❖ Challenge(s) regarding the role and involvement of stakeholders in the governance:

the main challenge is the number of (profile of) stakeholders and the difficulty to be exhaustive (e.g. authorities, interest groups, industry, patients and families, scientific societies, etc.).

Results from discussion:

- (1) Practical considerations raised: this issue should be cross-checked with other EU initiatives having stakeholder forums (SHF) to discuss possible solutions to avoid that these stakeholders will have to participate in many different SHFs.
- (2) Proposed solution: in the future, some tasks of the network need to address the targeted communications to members, relevant stakeholders, and specific citizen groups.

[Sustainability Report, pages 17-18](#)

Some challenges identified regarding the active participation of Member States' representatives:

- ❖ During the final meeting, 8 participants shared that it is difficult in their country to identify representatives;
- ❖ Meetings need to have strict agenda, discuss proposals to tackle practical issue, with a calendar planned well in advance;
- ❖ Assigning clear roles with a roadmap to engage them and holding them accountable;
- ❖ Incentives for active participation could be taking the form of fundings, such as research grants, monetary incentives for quality, funding of audits abroad or other type of support for projects

The EU network of CCCs' activities (1/2)

Activities contributing to the development of infrastructural capacities for networking between EU CCCs

1. Network building
2. Capacity building
3. Sharing access to expertise
4. Evaluation
5. Funding

Overarching activities target the design and management of connecting process with an open outcome or thematic focus. They could take the form of network building, capacity building (including education and training), sharing access to expertise, evaluation and funding (D5.3 p 2).

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.

Thematic-focused activity areas relevant to build a network around

1. Clinical Guidelines
2. Clinical Data for research and quality monitoring
3. Cancer in children, adolescents, young adults and survivorship
4. Precision cancer diagnostics
5. Primary and secondary prevention and early detection
6. Research
7. Innovation
8. Clinical Trials
9. Governance and Organization of CCCs
10. Standards for CCCs
11. Influencing politics and policy regarding cancer
12. Patient involvement
13. Industry relations

The EU network of CCCs' activities (2/2)

Some challenges identified and reported regarding the activities:

- ❖ **Ethical, legal and social issues (ELSI)** restrictions and differences (especially related to the differences in the GDPR interpretations) among collaborating centres and countries may impact the conduct of inter-institutional and transnational research activities. Data sharing remains a key challenge for many researchers at the local level but even more at European/international level.
Results from discussions: possible solutions could be found in the results from other initiatives and projects having specifically worked on that aspect as for example:
 - (a) The Joint Actions TEHDAS, PHIRI and CanHeal
 - (b) Data-related concerns and activities are crucial to have successful research activities and could benefit from the development of KPIs for assessment and (continuous) improvement.
- ❖ **Integration of research and care**: one could easily notice that there are often many opportunities for conducting fundamental research but relatively less for integration of research's results into practices, at both national and EU levels. Results from discussions: the management board of the EU network of CCCs could foresee activities in order to raise awareness among funders, but also to stimulate activities in the centres.
- ❖ **Expectations and concerns were raised during the Crane final conference regarding the EU Network of CCCs**:
 - (a) its (long-term) financing;
 - (b) the risk of increased inequalities among centers within and across EU MSs;
 - (c) the lack of political support; the time required for implementation of the network and the risk of slow processes and bureaucracy it entails.

EU Network of CCCs – Synergies

The WP5 identified three categories of EU initiatives with which synergies could be sought:

- (1) EU Networks on cancer (e.g. ERNs; JANE NoEs; ECHoS) ;
- (2) Established infrastructures operating in specific domains (e.g. ECRIN; BBMRI-ERIC) ;
- (3) recent and ongoing EU funded projects (e.g. CCI4EU, CanHeal).

Areas of collaborations have been listed with a defined implementation timeline to serve as a framework supporting implementation for the EU network of CCCs (D5.2) . Yet further establishment of the network will regularly scrutinize collaborative opportunities with other pivotal EU projects to build strong partnership benefiting the Network in the short and long term (D5.2, p35).

WP5 Integration with EU initiatives D5.2

Process proposed for the integration with other EU initiatives:

