



Consultation event to identify specific Cancer Mission actions where early multistakeholder cooperation is a critical success factor

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Abbreviations

Abbreviation	Full Name	
AC	Associated Countries	
ECHoS	Establishing of National Cancer Mission Hubs: Networks and synergies	
MS	Member States	
MS#	Milestone	
NCMH	National Cancer Mission Hub	
QoL	Quality of Life	
R&I	Research and Innovation	
WP	Work Package	





Abstract

The current report documents the completion of Milestone 8 (MS8) under Work Package 3, Task 3.3. It outlines the preliminary activities and key findings in our effort to enhance the capacity of ECHoS collaborators for establishing complex partnerships with multiple stakeholders. The activities have focused so far on identifying needs and gaps that must be considered when developing models for stakeholder engagement and cooperation. The present report also explores the opportunities to address areas in cancer care where dominant designs are missing, leveraging the comprehensive multistakeholder approach of the Mission on Cancer. These may act as baseline use cases in Work Package 3, guiding the development of activities centred on multistakeholder engagement. The various insights will also inform future National Cancer Mission Hubs in building successful partnerships, ensuring an impactful contribution from all relevant actors to the Cancer Mission.





Background

Context

Multistakeholder cooperation is at the core of the mission design, aiming at establishing comprehensive approaches to bring tangible solutions to complex societal challenges. Under the Mission on Cancer, ECHoS supports the implementation of National Cancer Mission Hubs (NCMHs) in all Member States and Associated Countries (MS/AC). These hubs will serve as pivotal platforms for mobilising and fostering operational and strategic cooperation between relevant stakeholders from national to local levels, beyond research and innovation (R&I), and beyond health.

Focus & objectives

Work Package 3 (WP3) is committed to empower ECHoS consortium partners and future NCMHs to identify, engage and connect stakeholders, ensuring their active and impactful contributions to the Cancer Mission. It aims to create versatile training materials, toolkits, and models that are adaptable at the level of local communities, regions, and MS/AC. The present report documents activities of WP3-Task 3.3 of ECHoS' proposal which aim at (i) exploring needs, gaps, and possible barriers in mobilising multiple stakeholders across the penta-helix (ii) identifying baseline use cases for WP3 activities, endorsed by ECHoS partners, where multistakeholder cooperation is a critical success factor.





Activities

As part of WP3-Task 3.3, various activities were implemented to seek input from ECHoS partners. While some activities followed predetermined structures, others embraced a more spontaneous and open-ended formats.

Educational seminar

Key activities included an educational seminar facilitated early September 2023 by Oslo Cancer Cluster, Task 3.3 leaders. The seminar meant to give some background on the role of culture and values in shaping successful collaborative projects, prior to the consultation event. Tone Ringstad, the speaker, guided WP3 partners through fundamental concepts and shared insights from her own experience in working with multistakeholder initiatives within the health sector, particularly at the Cancer Clinic at Oslo University Hospital and at the Institute for Cancer Research. A relevant example she highlighted was the impact of culture in the CONNECT consortium - a nationwide public-private partnership to advance the implementation of precision cancer medicine. The seminar took place online and was followed by n=25 partners of WP3. Post-event, the seminar recording, and presentation slides were made accessible to all ECHoS partners for internal reference and use.

Consultation event

In a consultation event on September 20th, 2023, leaders from Task 3.3 invited ECHoS partners to consider how multistakeholder cooperation, as proposed in the Mission approach, could provide opportunities within cancer care where dominant designs are missing. The objective was to foster bottom-up thinking and tap into the experience of participants within their own ecosystems. Discussions also addressed possible challenges in building capacity among NCMHs in facilitating multistakeholder engagement and collaboration. A total of n=33 partners joined the online workshop and were split into three working groups according to their primary area of interest collected beforehand through a survey: prevention and early detection, diagnosis and treatment or quality of life. Each group was assigned a moderator, a note-taker, and a rapporteur - sharing the main insights in the plenary session following the group work. See Figure 1 for an example on how working groups conducted their discussions.







Figure 1 – Brainstorming conducted by the 'Quality of Life' working group during the consultation event.

Open-ended dialogue

Alongside learnings from organised events, the report incorporates relevant inputs gathered from open-ended conversations during ECHoS and WP3 meetings,





exchanges between NCMH entities - such as the visit of the Swedish partner to the Norwegian NCMH, or dialogues at different forums - including the Nordic Precision Cancer Medicine conference in Oslo, the Economist World Cancer Series Europe in Brussels (both events took place in September 2023), and ESMO in Madrid (October 2023).

Key Learnings

Key learnings are split into: (1) Transversal insights - primarily focusing on first-hand experience from ECHoS partners in fostering mobilisation and collaboration among stakeholders of the penta-helix and (2) Thematic insights identifying gaps in cancer care that could leverage the comprehensive multistakeholder approach of the Mission on Cancer and be used as baseline use cases (see Figure 2).

Transversal insights

Trust and culture in cross-sectorial partnerships

A central theme in our activities so far has been the importance of trust, especially when navigating a landscape of multiple actors, across sectors, with diverse perspectives, interests, and goals. A possible barrier we have identified in establishing cross-sectorial partnerships under the Cancer Mission, is the hesitation within the academic community to engage with industry partners. This was observed in some extent within the consortium but also in the broader ecosystems of our partners. This calls for exploring innovative collaborative models acknowledging and integrating the various cultural influences present in Cancer Mission partnerships, ranging from the sectorial and organisational subcultures to individual perspectives (see Figure 3, extracted from educational seminar). The path ahead involves promoting the development of a shared culture in Cancer Mission projects, as a common set of values that guide collaboration and decision-making.





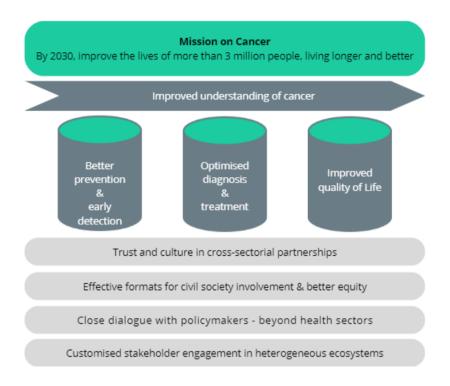


Figure 2 - Effective stakeholder engagement across the Cancer Mission pillars: transversal and thematic needs.

Engaging the civil society for better health equity

ECHoS partners shared their challenge in identifying effective formats and forums to mobilise citizens and the wider society in the Cancer Mission, extending beyond awareness and fund-raising campaigns. While patients show a higher inclination to engage in activities, e.g. in decision-making processes, advisory boards or in cocreation of research and healthcare solutions, a gap remains in integrating the perspectives of the general civil society in relation to cancer care services, R&I, and policy development. Luckily, citizen engagement is gathering momentum in different fields to ensure the development of policies that are more effective, transparent, and accountable. It is increasingly recognised as a valuable tool in addressing health inequalities. ECHoS will be able to rely on previous work to develop recommendations for future NCMHs. Among others, the Dialogue Forum tool in the CO-CREATE project (funded under the Horizon 2020 research and innovation programme, grant agreement No 774210) stands out as a successful example, effectively connecting youth with decision-makers from various sectors and stakeholder groups.





Enhancing dialogue between scientists and policymakers, beyond the health sector

The need to reconnect scientists and technologists with those who have the authority to shape cancer policies - from national strategies to healthcare services, and further transforming their role in the cancer mission, was voiced by some ecosystems. Overall, there is a wish to support and facilitate a more systemic approach to policy development that would allow better integration in practice between different EU policy areas, e.g. including health, climate change, pollution of soil and oceans, etc – in line with the 'health in all' thinking.



Figure 3 - Designing a shared culture in multistakeholder partnerships: acknowledging and integrating individual values and various subcultures. Source:

Tone Ringstad, Culture Intelligence





Addressing heterogenous needs in multistakeholder engagement strategies

Tackling inequities in healthcare and research is a strong priority for the EU, resulting in the implementation of an array of policies, initiatives, and instruments. Discussions around disparities in healthcare resources and capacities across various European regions have also been central in all working groups, underscoring the difficulty to address it in practice. Within ECHoS, such disparities could also limit the capacity of NCMHs for extensive stakeholder engagement initiatives in some regions. The heterogeneous political frameworks in different European countries, together with lower prioritisation of patient engagement and cancer care policies, might present additional challenges. This highlights the need to support NCMHs in developing targeted approaches and identify successful strategies in these ecosystems.

Thematic insights

Prevention and early detection

The discussion within this working group revolved around advancing and refining strategies for primary cancer prevention, particularly considering the disparities that exist across various European regions. Romanian partners contributed with insights from a project in Eastern Europe, drawing attention on disparities in vaccination coverage and smoking rates between the Balkans and Western countries as an example. The group underscored the importance of enhancing communication around primary prevention to be more inclusive and effective, emphasising the need to address misinformation and disinformation. The conversation also touched upon the necessity of translating project findings into actionable policies. Several takeaways around secondary cancer prevention are inspired from panel discussions in the World Cancer Series Europe.

Key takeaways on priority areas

- 1. Improving communication and information flow on primary prevention
 - Funding research and implementation projects to improve the understanding and management of information flow for instance





through network analysis, with a focus on **combating misinformation** and disinformation related to cancer prevention.

- Developing **inclusive and effective communication strategies** to ensure that cancer prevention messages and recommendations reach all population groups, including communities with different languages and lower inclusion.
- **Enhance citizen empowerment**, drawing from experience of the covid-19 pandemic, where limited citizen involvement negatively impacted compliance with vaccination efforts and social restrictions.

2. Leveraging technology and multimodal data for cancer prevention

- Further exploring and implementing the **use of technology**, social media, and digital tools to optimize cancer prevention strategies for different population groups.
- Integrating multimodal data in cancer prevention and bringing synergies with other missions into a reality. E.g. by combining genetic/epigenetic aberrations with environmental exposure data (chemicals, pollution, etc) to give more accurate representation of atrisk individuals.

3. Defining an economic model for cancer screening

 Developing incentives for private investment to expand access to screening or use of innovative technologies, and ultimately to contribute to reducing cancer mortality rates through earlier detection. These incentives could take various forms, such as funding through private-public partnerships, subsidies or fast-tracked regulatory approvals for companies investing in innovative screening technologies.

Diagnosis and treatment

This working group kicked off the discussions by focusing on the implementation of precision medicine, with specific examples from Norway, Luxembourg, and Czech Republic. The group highlighted the variations in healthcare systems and economy among European countries, emphasising the potential challenges these differences could create in accessing diagnostics and treatments in certain areas. The dialogue also underscored the importance of fostering public-private





partnerships to deliver innovative solutions to patients, as well as encouraging greater collaboration across countries to guarantee a more uniform access to cancer treatments. This point was illustrated by referencing the collaborative efforts observed during the COVID-19 pandemic. The potential of AI and advanced tools and the need for high-quality data were also stressed by several participants. Discussions continued in the plenary session to identify topics, beyond precision medicine, that could benefit from the Cancer Mission framework.

Key takeaways on priority areas

1. Enhancing accessibility and participation in cancer clinical trials

- Streamlining patient access and raising awareness about the value and availability of clinical trials, especially for underrepresented populations and regions with limited clinical trial infrastructure.
- Supporting decentralised clinical trials and leveraging telemedicine and remote monitoring technologies to allow broader participation.

2. Bridging the gap in applying novel technologies in clinical practice

- Despite the availability of highly effective digital pathology solutions for instance, there is a lag in transitioning from traditional to digital pathology laboratories. Discussions underscore the necessity of creating financial frameworks that can facilitate this transition.
- Promoting research on **transparent and understandable AI systems** within **Oncology**, as the current "black box" nature of these technologies hinders their integration into regular clinical workflows.

Quality of Life of Cancer Patients, Survivors, and their families

The working group on Quality of Life (QoL) highlighted the growing relevance of QoL in cancer care as the number of cancer survivors continues to grow. Discussions emphasised the crucial role of psycho-oncology care, including in patient-related outcomes, and the need to empower patients in making informed decisions about their cancer care journey. Participants discussed the necessity of addressing often overlooked non-medical needs and highlighted disparities between countries in this regard. The group stressed the importance of implementing the "right to be forgotten" universally, outlining its economic advantages and its contribution to the financial independence of survivors. Finally,





the discussion highlighted the Cancer Mission framework's potential to facilitate a holistic approach to QoL, emphasising the importance of involving government departments and in incorporating QoL considerations into national cancer strategies throughout all EU countries.

Key takeaways on priority areas

- 1. Integrating psycho-oncology services into standard oncology care
 - Ensuring that findings from multidisciplinary psycho-oncology research are translated into clinical practice. Interventions should assess psychological health of patients and provide accessible support at all stages of the disease, including the long-term psychological and social challenges faced by cancer survivors.
 - Providing educational resources to patients and their families about the psychological aspects of cancer and reduce stigma associated with seeking mental health support.
- 2. Developing tools and resources for patients, survivors, and their families, beyond medical needs
 - Evaluating the full impact of cancer on various aspects of a person's life.
 This includes challenges related to employment, social welfare, and financial stability.
 - Implementing holistic support to cancer patients and their families, addressing their needs for career/financial counselling, legal resources, etc.





Limitations

One of the challenges we met over the course of the first months of the project, is the diversity in levels of understanding and familiarity with the EU Cancer Mission among the partners. To succeed in our collaborative efforts, it is crucial to establish common foundations and equip partners of ECHoS with necessary background knowledge on the mission's thinking, enabling us all to contribute effectively to our ambitions. Together with WP2 and WP3 partners, we are exploring ways to further build capacity among ECHoS collaborators in the EU mission methodology and its integration with conventional R&I. This resource could also be included in training packs delivered to future NCMHs.





Summary and the way forward

The main findings of MS8 are summarised in Table 1 and the material produced during WP3 activities have been made available in the shared folders and will be used as a resource for ECHoS partners. **Relevant insights will be integrated to WP3 work**, including in the development of impact models, stakeholder identification and training packs. Knowledge that has the potential to shape the design of NCMHs and its knowledge exchange program in WP2, along with WP6's work on citizen engagement, will be **shared with the respective WPs**. Building on our learnings, we propose the following actions to bridge knowledge gaps, and ensure the project's objectives are met effectively:

- 1. **Create a Digital Collaboration Platform**: In collaboration with WP6, explore the possibility of establishing a digital platform for easy access to shared resources, to host webinars and educational seminars, and to provide a space for open-ended dialogues across EU. The platform would be used at first by ECHoS partners and could be open to NCMHs at a later stage, as part of the training packs. Objective: To foster continuous collaboration, knowledge sharing, and problem-solving among ECHoS partners and between NCMHs.
- 2. **Build on Successful Case Studies**: Document and publish case studies highlighting successful multistakeholder cooperation from various ecosystems across EU, like the Precision Oncology milieu. These case studies can serve as a reference for stakeholders' engagement and collaboration, showcasing best practices and lessons learned. Special focus will be given to exemplary cases in certain Eastern European regions, where the limited resources, gaps in infrastructure and disparities in access to cancer care make the implementation of the Cancer Mission more challenging. Case studies could for instance be documented in Harvard Business case review style. Objective: To provide real-world examples of successful cooperation, helping to understand potential challenges and solutions.
- 3. Facilitate Stakeholder Engagement Meetings: Promote interactive learning across the penta-helix through meetings/workshops specifically designed to bridge the knowledge gap on the EU Cancer Mission. These workshops can be tailored to different stakeholder groups, including national politicians, ensuring that each group gains a comprehensive understanding of the mission's objectives and methodologies. Objective: To ensure all stakeholders have a uniform understanding of the project's goals and can contribute effectively.





4. **Establish an EU Cancer Mission Day:** In collaboration with WP6, launch a Cancer Mission Day campaign to educate the community about the importance of the Cancer Mission and the role of multistakeholder cooperation. This campaign could for instance be part of The Economist cancer series 2024 and utilize various mediums such as social media, blogs, podcasts, and community events. Objective: To increase understanding and support for Cancer mission, ensuring its long-term success and impact.



Table 1 - Summary of main findings of Task 3.3 activities

	Needs		Challenges	Opportunities
Transversal insights	Trust in multistakeholder partnerships		Hesitation of some sectors to engage with other partners	Develop common set of values that guide collaboration and decision-making Create culture-intelligent working groups orchestrated by NCMHs, as neutral platforms
	Effective mobilisation of the civil society & equitable access		Low mobilisation of the general civil society beyond awareness and fund-raising campaigns Persistent disparities in health within the EU	Improve knowledge and capacity of citizens to engage in policy processes by building on momentum in other fields Tackling disempowerment of the civil society
	Fac	:ilitate (re)-connection of scientists/technologists to policymakers	Roles of stakeholders not evolving Limited integration of different EU policy areas and 'Health in all policies'	Use NCMHs as forum for national stakeholders to have a closer dialogue with their policymakers Facilitate national collaborations across missions and support health in all approach in MS/AC
		Customized strategies for stakeholder engagement	Disparities in healthcare resources & capacities across EU could limit the capacity of NCMHs for extensive stakeholder engagement initiatives in some regions.	Identify successful strategies from heterogeneous ecosystems and develop a set of targeted/customizable approaches adapted to MS/AC needs
Thematic insights	g of cancer	Prevent what is preventable	Misinformation and disinformation related to cancer prevention Data silos within health & beyond, leading to lack of multimodal integration Low engagement of the industry in cancer prevention	Improve understanding and management of information flow, alongside developing inclusive communication strategies Promote multidisciplinary collaborations and synergies between missions Creating incentives for private investment to expand access to screening or use of innovative technologies
	mprove understanding	Optimise diagnostics and treatments	Inequal access and participation to cancer clinical trials Gap in applying novel Al-driven technologies in clinical practice	Supporting decentralize clinical trials and leveraging digital solutions for monitoring Facilitate the creation of financial frameworks for transitioning from traditional to digital labs Promoting research on transparent & understandable AI to gain trust among healthcare professionals
	_	Support the quality of life of people living with and after cancer	Non-systematic psycho-oncology support Lack of availability of resources for patients, survivors and their families, beyond medical needs	Ensuring that findings from multidisciplinary psycho- oncology research are translated into clinical practice Learn from best practices for holistic support to cancer patients and their families across MS/AC

