



Map existing or newly created hub-like structures

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1. Introduction

National Cancer Mission Hubs (NCMH) structures are envisaged as new conceptual initiatives aiming to create bridges within and beyond research and innovation and health systems to cover all relevant areas in cancer control (from EU Mission: Cancer). By raising awareness of the Mission on Cancer, these hubs aim to foster a coordinated approach to its implementation at national, regional, and local levels. At the same time, synergies with actions under Europe's Beating Cancer Plan are expected to be generated.

ECHoS project aims to promote the establishment and implementation of NCMHs in all Member States and Associated Countries (MS/ACs). A critical step in ensuring a structured, harmonised, and efficient rollout of NCMHs is to define their conceptual models. These models should then be tailored to the specific context of individual MS/ACs. The generated concept models will also outline a minimum set of features and deliverables, such as:

- 1. Types of communication channels with healthcare providers, researchers, policymakers, and citizens.
- 2. Level of autonomy.
- 3. Degree of integration/collaboration with national healthcare providers, research organisations and patient advocacy groups working in the cancer field.
- 4. Extent of communication and collaboration with non-traditional stakeholders.
- 5. Other relevant aspects to guide MS/ACs in setting functional benchmarks for individual NCMHs.

To achieve the above-mentioned goal ECHoS undertook an internal mapping exercise to gain a comprehensive understanding of the specific characteristics of existing NCMH-like structures, strength and challenges of the countries who do not have a NCMH-like structure as well as to gather information on the perspectives of each country for the components and priorities of the future NCMH. This initiative lays the groundwork for informed discussions and the subsequent development of future NCMH concept models.

This report presents a summary of countries' responses, encompassing a comprehensive analysis of organisational characteristics, governance frameworks,



stakeholder engagement, funding sources, and activities undertaken by the existing NCMH-like structures and the perspectives for the future NCMH.

2. Methodology

To facilitate the mapping exercise, a comprehensive questionnaire (Annex I) was developed and distributed among consortium members. The questionnaire has a total of 36 questions and is structured in two parts:

- **Part 1** Existence and characteristics of a National Cancer Mission Hub or a NCMH-like structure in MS/AC.
- Part 2 Opinion about the scope and structure of the future ideal NCMH.

Questionnaire design

The following steps were implemented:

Definition of the objective

The survey objectives were clearly delineated, outlining the specific information essential for collection. This strategic approach not only ensured precision in data gathering but also underscored the direct benefits anticipated for both WP2 and consortium members.

Questionnaire design team

A proficient team, consisting of experts from WP2 members and relevant third parties' contributors, was strategically assembled. This collaborative effort proved instrumental in crafting an adept and thoughtfully designed questionnaire.

Design of the Questionnaire (see Annex I)

The survey commenced with introductory inquiries, primarily focusing on demographic information. This initial section aimed to establish a welcoming atmosphere for participants, employing language that was both clear and unbiased. Special attention was given to formulating questions that were specific and devoid of any potential for misinterpretation. A deliberate strategy involved incorporating various question formats, such as multiple-choice, open-ended, and ranking questions, ensuring a diversified approach.



The questionnaire investigates three main possible scenarios:

- i. Countries that have organisation/structure that could take the role of a National Cancer Mission Hub as described in ECHoS;
- ii. Countries with no organisation/structure able to take the role of a National Cancer Mission Hub;
- iii. Countries that have potential eligible organisation that could take the role of a National Cancer Mission Hub.

The questionnaire, included in Annex I, is structured in two sections:

The first part was meant to collect informative data on existing NCMH-like structure (an existing structure that does not match the definition and function of a NCMH but that can be upgraded) in MS/AC. If these organisations exist, the respondent is asked questions regarding their structure, governance, and mode of operation. If, on the contrary, they do not exist, after question number five the respondent is directed to other questions regarding the current situation in their country.

The second part of the questionnaire sought to gather input and insights regarding the respondent's opinion about the scope and structure of the future NCMH. The responses were provided considering what consortium members deemed as the ideal NCMH.

Pre-test

The questionnaire was pre-tested among the Fondazione IRCSS Istituto Nazionale dei Tumori and its third parties (Fondazione Don Carlo Gnocchi, Fondazione Regionale Ricerca Biomedica, Fondazione The Bridge) with Università Cattolica del Sacro Cuore and its Affiliated Entity Alleanza Contro il Cancro to identify any issues with clarity or ambiguity.

Afterwards, the questionnaire was pre-tested among WP2 members to identify any issues, such as confusing questions and gather their general feedback.



Answers collection

Microsoft Forms was used to collect the questionnaire replies, this tool simplifies the data collection and the data analysis. The finalised questionnaire was transferred in the online form using branching logic to redirect the respondent to a different set of questions when relevant.

The 57 beneficiaries, encompassing affiliated entities and associated partners spanning 28 MS/AC, were solicited to coordinate with ECHoS partners within their respective nations to formulate a unified response per country. The survey concluded in the autumn of 2023.

Feedback was gathered from 28 MS/AC, comprising 57 beneficiaries, affiliated entities, and associated partners. Stringent measures were implemented to guarantee data integrity and quality, with a steadfast deadline set for September 15, 2023. Recognizing the complexity of the task, a degree of flexibility was granted to ensure the comprehensive collection of responses from all partners.

Data analysis

The gathered and consolidated data underwent a comprehensive analysis utilizing statistical tools and software, including Microsoft Forms and Excel. This rigorous analysis aimed to discern trends and patterns, bringing forth valuable insights. Subsequently, a comprehensive report encompassing key findings and insights was meticulously crafted for presentation to WP2 and consortium members. This report served as a catalyst for an in-depth discussion, exploring the implications of the results for the overarching project (see Annex II).



3. Results & Discussion

This chapter delves into the findings of the mapping exercise, providing valuable insights into the current landscape of National Cancer Mission Hub-like structures and the perspectives of participating countries regarding the ideal NCMH.

3.1 Mapping of NCMH-like structures

By analysing the responses from the 28 countries that participated in the questionnaire, 12 indicated to have a well-established organisation or structure capable of assuming the role of a NCMH. Another 10 countries acknowledged the absence of a NCHM-like structure but mentioned a potential candidate. Six countries confirmed to lack both, an existing organisation/structure, and a potential candidate structure. Specific details, such as the organisation/structure name, website, and main contact person, are not included in this analysis, but can be referenced in the country-specific reports.

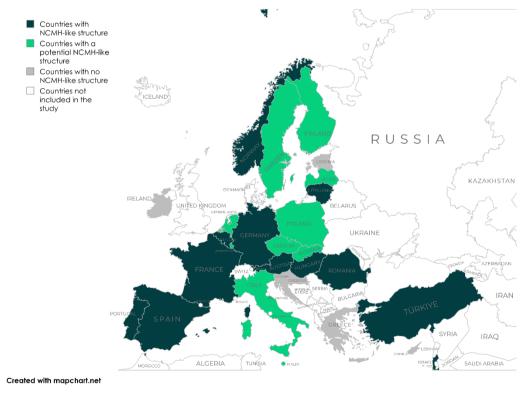


Figure 1 Mapping of the existent NCMH-like structures in ECHoS participating countries https://www.mapchart.net/europe.html



Examining the types of organisations operating as NCMH-like structures, insights from ECHoS MS/AC reveal a diverse landscape. Most operate as Legal organisations or consortiums, nevertheless some claim to be joint ventures or to be organised as coordinated national actions, informal groups, or entities without legal status. Furthermore, some are still in the process of defining their organisational type.

Notably, governmental bodies, research institutes, and healthcare institutions are prevalent coordinating/hosting organisations for these structures across the majority of ECHoS participating countries. In fact, most countries with NCMH-like structures have them formally endorsed by governmental bodies, with some operating at both national and cross-national levels.

Regarding the governance framework of the NCMH-like structures, the questionnaire sought to identify envisaged governance bodies. Respondents commonly indicated the presence of a Governing Board, an Executive Board, and/or a Thematic Working Group.

In terms of stakeholders' integral to the governance framework, findings across the 22 countries highlighted the involvement of Governmental bodies, Research institutions, and Healthcare institutions. Notably, 17 respondents reported having Governmental Bodies involved in their NCMH-like structures operating at national level.

When exploring funding sources for these structures, across the 22 countries, Governmental Funding emerges as the predominant support. However, some countries also rely on Competitive Funding, with European grants cited as an additional source, or no funding at all. Activities undertaken by NCMH-like structures vary, including organising events, direct participation in initiatives, awareness-raising activities, and coordinating the development of EU policy and funding. In assessing performance, countries commonly utilise Key Performance Indicators and other mechanisms, often reporting to the General Assembly or their national Ministry of Health.

For the six countries without an existing NCMH-like structure (Croatia, Cyprus, Estonia, Greece, Ireland, Slovenia), opinions on the current situation and potential implementation barriers were sought. Informal conversations with stakeholders were noted in most cases, with one country indicating partial role fulfilment by different actors and another reporting the creation of a separate organisation as an ongoing process. Identified constraints to future NCMH



implementation in these countries primarily revolved around financial limitations, insufficient infrastructure, and resources.

Responding to an open question about potential candidates and their roles in NCMH development, notable contributions were outlined. Slovenia reported no potential candidates, while Croatia highlighted the Tumour Clinic in the University Hospital Center. Cyprus emphasised the Cyprus Cancer Research Institute, and Estonia mentioned proposals from the Ministry of Social Affairs, two universities, and two cancer centres. Greece outlined the Cancer Guidance Center and the Integrated Center for Research on Cancer in Athens, and Ireland detailed collaboration between the HSE National Cancer Control Programme and the All-Island Cancer Research Institute.



3.2 Ideation of the future NCMH

To establish a foundation for shaping the structure and function of future NCMHs, ECHoS engaged its partner countries to gather their perspectives. A summary of the responses is provided below.

3.2.1 NCMH priorities

In evaluating the core priorities and focal points of a National Cancer Mission Hub, the results reveal a trend regarding the priorities of the future NCMH (Figure 2). The overarching focus should be on Cancer Mission related actions, with Other International Policies being the least important consideration. Partners across the surveyed 28 countries emphasised the necessity for the future NCMH to secure formal endorsement from government bodies and advocate for its optimal operation at the national level.

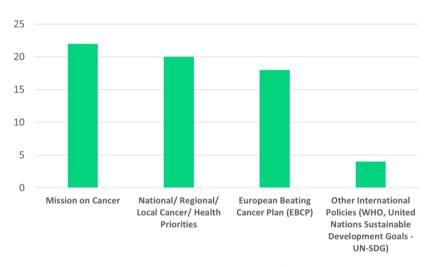


Figure 2 Priorities of NCMHs



3.2.2 NCMH Level of autonomy and Organisational structure

Delving into the autonomy aspect of the prospective NCMH, analysis showed that most respondents assigned a substantial score of 7.22 on average (Figure 3). This indicates that most partners believe that the NCMH should possess a high degree of decision-making autonomy (both financial and operational), while not advocating for complete independence.

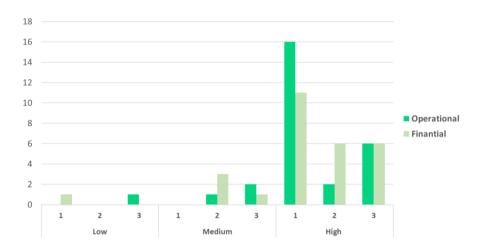


Figure 3 Autonomy level of NCMHs

When envisioning the organisational structure of a NCMH, most countries express a preference for it to be constituted as a Legal Organisation, Consortium, or a Coordinated National Action, while few believe that it should be organised as a joint venture (Figure 4).

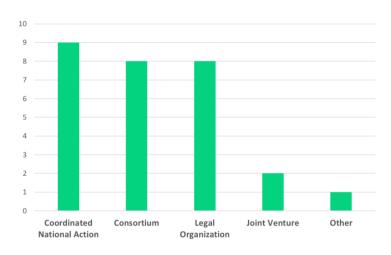


Figure 4 Organisational Structure of NCMHs



3.2.3 NCMH governance

The responding countries show a tendency towards the incorporation of Advisory Boards, Executive Boards, and/or Governing Boards within the NCMH structure (figure 5). Governmental Bodies, Research and Healthcare Institutions, and Patient Associations should play pivotal roles in the governing bodies of a NCMH. Furthermore, most partners agreed that Governmental Bodies should be involved in the governance of a NCMH and that NCMH should operate at a national level.

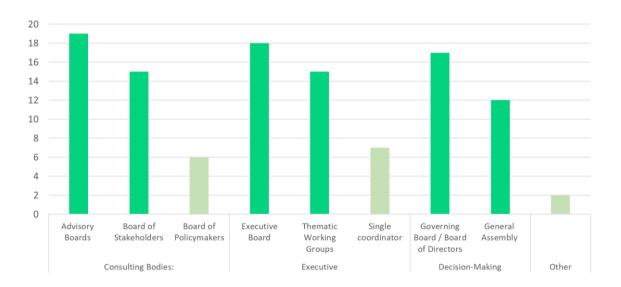


Figure 5 NCMHs Structure Bodies



3.2.4 NCMH Funding Sources & Human Resources

In terms of funding, all 28 countries stated that the future NCMH should count with Governmental Funding, although a significant portion of respondents also acknowledge the viability of Private and/or Competitive Funding (Figure 6).

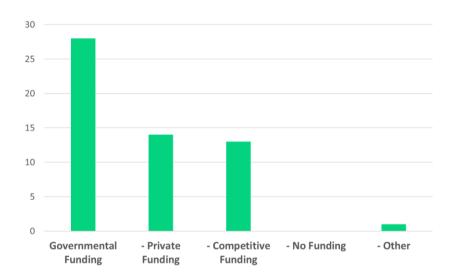


Figure 6 Funding Sources of NCMHs

Addressing the ideal staff composition, most countries are in favour of a NCMH having dedicated staff exclusively (Figure 7). However, some countries advocate for shared staff with other initiatives across different organisations. While few other countries agree that a NCMH should count with staff shared with other initiatives in the same organisation.

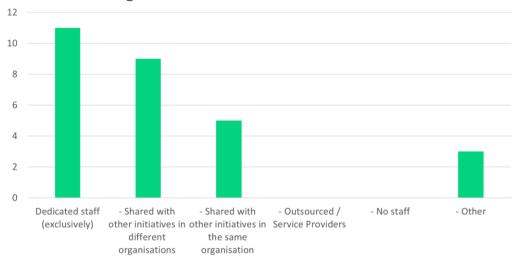


Figure 7 NCMHs Human Resources



3.2.5 Activities

Regarding operational priorities, most countries emphasised the importance of organising events, participating in, and promoting research and development (R&D) and policy projects, as well as publishing policy reports. Oversight of the implementation of research and health policies is also deemed critical, while the funding of external R&D and/or policy projects is not accorded the same level of priority.

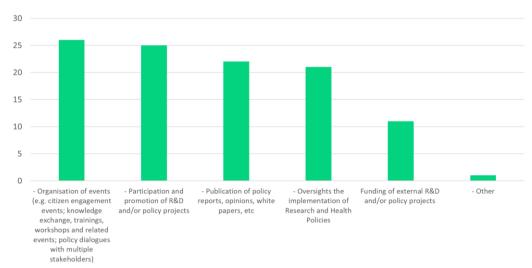


Figure 8 Activities

3.2.6 Communication tools

In the realm of communication tools, there is a trend on the prioritisation of social media; news, and other website tools; in-person/hybrid events. Some partners also consider traditional media as a priority for raising public awareness, communicating results, disseminating activities, creating awareness, and attracting supporters for NCMHs. On the other hand, direct emails, reports, peer-reviewed publications, and group dynamics are perceived by some as being less critical in this context (Figure 8).



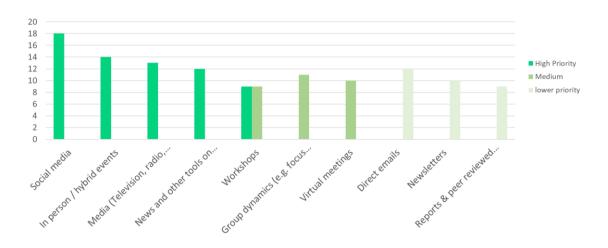


Figure 9 Communication Tools

3.2.7 Type of organisations (stakeholders) in governing bodies

As imprinted in the <u>Mission on Cancer Implementation Plan</u> and in the <u>Cancer Mission assessment report</u>, NCMHs should aim to grow towards a Penta helix model for the involvement of 5 stakeholders namely from, Industry/Commercial sector (e.g. Pharmaceutical Industry, Philanthropic organisations), Government/Authorities (e.g. Regulators), Patients/Citizens (e.g. Patient organizations and Civil Society), the Academia (e.g. Universities and Research Institutes) and Healthcare.

In this survey, the high priority organisations to involve in NCMH are representative of 4 of 5 types of stakeholders from the Penta helix model suggesting a clear trend towards the model.



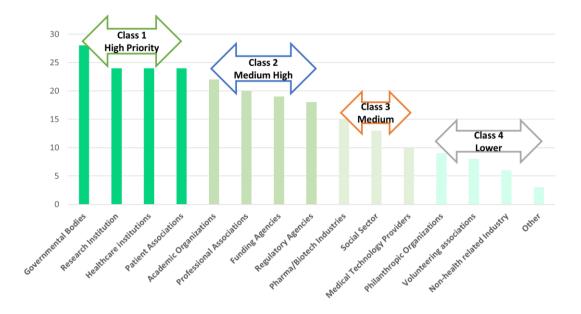


Figure 10 Type of Organisations in Governing Bodies



4. Conclusions and next steps

The comprehensive mapping exercise provides the foundation for identifying four potential organisational structures for the future NCMH: **Consortium**, **Coordinated National Action**, **Legal Organisation** (meaning an organisation endorsed by the Government), and **Joint venture**. Although the Joint Venture gathered only 7 % of the votes this may potentially be a useful model in highly specific national contexts.

These structures should:

- 1. Have a governmental endorsement.
- 2. Operate at a national level.
- 3. Have different types of boards: decision, executive and consultive/advisory.
- 4. Include diverse organisations representing a wide range of sectors of the society (governmental, research, health, citizens, industry, etc.)
- 5. Have a high level of decisional autonomy.
- 6. Have a high level of financial autonomy.

The priorities of NCMHs should align with those of the Mission on Cancer, with the National/regional priorities, and with the European Beating Cancer Plan. Thus, these priorities should be reflected in the overall structure, activities, and outcomes of NCMHs.

To promote the sustainability of the future NCMHs, these structures should count on one or more main sources of funding such as governmental, private, and competitive.

The mapping exercise also highlighted the importance of specific activities that NCMHs should undertake to achieve their objectives. These activities include:

- **Organising events to** engage citizens, facilitate knowledge exchange, and foster collaboration among stakeholders.
- Participating in and promoting R&D and/or policy projects to drive innovation and inform policy decisions.
- Publishing policy reports, opinions, and white papers to disseminate evidence-based information and guide decision-making.



• Overseeing the implementation of research and health policies to ensure alignment with national and international goals.

To guarantee a proper dissemination of future activities, mobilize stakeholders, communicate results and information, etc, NCMHs should master communication tools and channels including, but not limited, to digital and conventional communication platforms.

The mapping exercise highlighted the importance of NCMHs as central structures for coordinating cancer research, prevention, and care across Europe. By embracing a collaborative approach and adopting a Penta helix structure, NCMHs can significantly enhance their impact on improving cancer outcomes for patients. This modern working approach emphasises co-design, co-development, and co-creation, ensuring that all stakeholders are involved in shaping initiatives and making informed decisions.

The subsequent stages will involve a comprehensive exploration and development of these frameworks, representing the next critical step in shaping the most effective structures and concepts for the NCMH.

Next steps

The approach adopted will encompass both a broad overview and an indepth examination of specific aspects. A breakdown of the proposed next steps is presented below:

Stage 1: Broad Overview

Produce elaborated country specific reports. (task 2.1)

Conduct a Workshop with all ECHoS partner organisations to further discuss and develop the preliminary findings of this survey. (task 2.1)

Further explore the existing NCMH-like structures, including their organisational models, governance frameworks, stakeholder involvement, funding sources, and activities undertaken. (task 2.2)

Identify common strengths and weaknesses across existing NCMH-like structures. (task 2.1 and task 2.2)



Taking into consideration the results of the current survey, develop a preliminary understanding of the diversity of NCMH-like structures in terms of positioning and governance, encompassing national, regional, or local hub-like frameworks, involvement from healthcare systems, research institutions, and society at large. (task 2.2)

Review the Mission on Cancer, National/regional priorities, and the European Beating Cancer Plan to identify key priorities that should be addressed by NCMHs. (task 2.1)

Explore the concept of a Penta helix structure and its potential role in fostering collaboration among stakeholders. (task 2.1 and task 2.2)

Stage 2: Focused Examination of Specific Aspects

Refine the four potential organisational structures for NCMHs – Consortium, Coordinated National Action, Legal organisation, and Joint venture – based on the findings from Stage 1 – through the organisation of a Workshop with all the ECHoS partner organisations. (task 2.1)

Develop detailed criteria for evaluating the suitability of each organisational structure for different contexts and priorities. (task 2.2)

Facilitate a series of workshops with experts and stakeholders to gather feedback on the proposed organisational structures and concept frameworks. (task 2.1 and task 2.2)

Refine the concept frameworks based on the feedback received from the workshops. (task 2.1)

Stage 3: Consolidation and Recommendations

Consolidate the findings from Stages 1 and 2 into a comprehensive report that outlines the optimal organisational structures and concept frameworks for NCMHs. (task 2.2)

Develop clear and actionable recommendations for the establishment and implementation of NCMHs in different contexts and settings - Guidelines. (task 2.2)



Disseminate the report and recommendations to relevant stakeholders, including policymakers, healthcare providers, researchers, and patient advocacy groups. (task 6.1)



Annex I - Questionnaire

ECHoS - Countries' preliminary survey on NCMH models

In the scope of the ECHoS project, which focuses on establishing Cancer Mission Hubs and promoting networks and synergies, Work Package 2 aims to design and create National Cancer Mission Hubs (NCMHs) and facilitate the exchange of knowledge.

This questionnaire serves as a method to collect data for mapping the presence and maturity of NCMH structures in participating Member States/Associated Countries (MS/AC) as well as to collect expectations over such structures.

From the call topic HORIZON-MISS-2022-CANCER-01-05: Establishing of national cancer mission hubs and creation of network to support the Mission on Cancer, a National Cancer Mission Hub (NCMH) will:

"Facilitate integration of the activities of the Mission on Cancer at national, regional, and local levels e.g., identifying synergies between European, national, regional and local policies and initiatives related to cancer;

Facilitate engagement of relevant actors and stakeholders at national, regional or local level going beyond the research and innovation and health systems to cover all relevant areas in cancer control and support policy dialogues on cancer (examples include employment, education, socio-economic aspects); Support citizen engagement activities at national, regional and local levels, including new participatory formats."

The following questionnaire is structured in two parts:

- 1. The first part is meant to collect informative data on existing NCMH (National Cancer Mission Hub) or a NCMH like structure (an existing structure that does not match the definition and function of a NCMH but that can be upgraded) in MS/AC. If these organisations exist, you will be asked to answer various questions regarding their structure, governance, and mode of operation.
- If, on the contrary, they do not exist, after question number 5 you will be directed to other questions regarding the current situation.
- 2. The second part of this questionnaire seeks to gather input and insights regarding your opinion about the scope and structure of the future NCMH. Please



provide your responses considering what you consider being the ideal NCMH.

Each question has to be answered, instructions are given for some questions.

By submitting this survey, in line with GDPR, you authorise the collection, analysis and re-use of the data provided for eventual follow-up activities developed in the scope of the ECHoS project.

Part 1

- 1. Name Enter your answer
- 2. Email Enter your answer
- 3. Country Enter your answer
- 4. Organisation Enter your answer
- 5. Does your country have an organisation/structure that could take the role of a National Cancer Mission Hub as described in ECHoS?

 Single choice
 - Yes
 - No, but there is a potential candidate (eligible organisation entity)
 - No

If NO, go to Q. 20

- 6. Please write the name of the NCMH or NCMH-like structure in your country. Enter your answer
- 7. Please write the website of the NCMH or NCMH-like structure in your country.

Enter your answer

8. Please write the main contact person details of the NCMH or NCMH-like structure in your country.

Enter your answer



9. Please select the type of organisation operating as NCMH or NCMH-like structure.

Single choice

- Legal Organisation Consortium
- Joint venture
- Other
- 10. Please select who is the coordinating/hosting organisation of the NCMH or NCMH-like structure.

Select all that apply

- Governmental Bodies
- Research Institutes
- Funding Agencies
- Academic Organizations
- Healthcare institutions
- Patient Associations
- Professional Associations
- Industry
- Other
- 11. Is the NCMH or NCMH-like structure in your country formally endorsed by governmental bodies?

Single choice

- Yes
- No
- Don't know
- 12. At what level does the mentioned NCMH or NCMH-like structure operate? Single choice
 - National
 - Regional
 - Local
- 13. Does the mentioned NCMH or NCMH-like structure operate also at cross-national level?

- Yes
- No
- Don't know



14. Which governance body(ies) is envisaged by your NCMH or NCMH-like structure?

Select all that apply

- Single coordinator
- Executive Board
- Governing Board
- Advisory Boards
- General Assembly
- Thematic Working Group
- Board of Stakeholders
- Board of Policymakers
- Other
- 15. Who are the stakeholders involved in the governance of the NCMH or NCMH-like structure?

Select all that apply

- Governmental Bodies
- Regulatory Agencies
- Funding Agencies
- Philanthropic Organizations
- Research Institution
- Academic Organizations
- Healthcare institutions
- Patient Associations
- Professional Associations
- Non-health related Industry
- Pharmaceutical and Biotechnological Industries
- Medical Technology Providers
- Organizations from the Social Sector
- Volunteering associations
- Other
- 16. If Governmental Bodies are involved in the governance of the NCMH or NCMH-like structure, please specify at what level do they operate?

- National
- Regional
- Local
- 17. What is the source of funding for the NCMH or NCMH-like structure?



Select all that apply

- Governmental Funding
- Private Funding
- Competitive Funding
- No Funding
- Other
- 18. What type of activities are developed by the NCMH or NCMH-like structure? Select all that apply
 - Funding of internal initiatives or projects that are relevant for cancer research and/or policy making
 - Funding of external initiatives or projects that are relevant for cancer research and/or policy making
 - Direct participation initiatives or projects that are relevant for cancer research and/or policy-making
 - Activities of awareness raising and mobilising for projects that are relevant for cancer research and/or policy-making
 - Organisation of events (citizen engagement events; knowledge exchange, trainings, workshops, and related events; policy dialogues with multiple stakeholders)
 - Aligning national, regional and local policy levels, initiatives, and/or R&I funding, with Europe's Beating Cancer Plan and Mission on Cancer
 - Coordinating and providing feedback to the development of EU policy and funding based on evidence gathered from multiple stakeholders, at national, regional and local level
 - Publication of policy reports, opinions, white papers, etc.
 - Other
- 19. Regarding monitoring and assessment of performance of the NCMH or NCMH-like structure, what type of mechanisms are established?

 Select all that apply
 - None
 - Based on Key Performance Indicators
 - Based on the analysis by external experts
 - Don't know
 - Other
- 20. In your opinion, which of the following options best describe the current situation regarding the implementation of a NCMH in your country?

- No actions initiated yet
- Informal conversations with different stakeholders



- Formal nomination of the responsible organisation/consortium for the implementation of the future NCMH
- Other
- 21. In your opinion, what are the main constraints/critical issues to the implementation of the future NCMH in your country?

Select all that apply

- No or reduced Political support
- Reduced framing in national priorities for research and health
- Financial constraints
- Infrastructure and resources
- Regulatory and ethical challenges
- Socioeconomic and geographical disparities
- Poor recognition of the EU Cancer Mission relevance at the national level
- Other
- 22. Describe potential candidate and describe their actual role.

Enter your answer

Part 2

- 23. In your opinion, what should be the main priorities/focus of a NCMH? Please, rate each of the following priorities from 1 to 4, where 1 is the lowest and 4 is the highest.
- Mission on Cancer
- National/Regional/Local Cancer/Health Priorities
 - European Beating Cancer Plan (EBCP)
 - Other International Policies (WHO, United Nations Sustainable Development Goals - UNSDG)
- 24. In your opinion, is it important for the successful implementation of a NCMH to have formal endorsement by government bodies?

Single choice

- Yes
- No
- Don't know
- 25. In your opinion, what is the ideal operational level of a NCMH?

- National
- Regional
- Local



- 26. In your opinion, what is the ideal level of decisions autonomy of a NCMH? Rate from 1 to 9, where 1 is no autonomy and 9 is fully autonomous.
- 27. In your opinion, what is the ideal level of financial autonomy of a NCMH? Rate from 1 to 9, where 1 is no autonomy and 9 is fully autonomous.
- 28. In your opinion, what is the ideal type of organisation acting to enable a successful implementation of a NCMH and its goals?

Single choice

- Legal organisation
- Consortium
- Joint Venture
- Coordinated National Action
- Other
- 29. In your opinion, which of the following bodies should integrate a NCMH? Select all that apply
 - Single coordinator
 - Executive Board
 - Governing Board
 - Advisory Boards
 - General Assembly
 - Thematic Working Group
 - Board of Stakeholders
 - Board of Policymakers
- Other
- 30. In your opinion, what type of entities should integrate a NCMH's governing bodies?

Select all that apply

- Governmental Bodies
- Regulatory Agencies
- Funding Agencies
- Philanthropic Organizations
- Research Institution
- Academic Organizations
- Healthcare institutions
- Patient Associations
- Professional Associations
- Non-health related Industry



- Pharmaceutical and Biotechnological Industries
- Medical Technology Providers
- Organizations from the Social Sector
- Volunteering associations
- Other
- 31. If Governmental Bodies are involved in the governance of the NCMH structure, please specify at what level do they operate.

Single choice

- National
- Regional
- Local
- 32. In your opinion, what sources of funding should be ensured to facilitate the implementation and sustainability of a NCMH and its goals?

Select all that apply

- Governmental Funding
- Private Funding
- Competitive Funding
- No Funding
- Don't know
 - Other
- 33. In your opinion, NCMH staff should consist of:

Single choice

- Dedicated staff (exclusively)
- Shared with other initiatives in the same organisation
- Shared with other initiatives in different organisations
- Outsourced / Service Providers
- No staff
- Other
- 34. In your opinion, what type of communication tools should be prioritised by the NCMH for public awareness and outreach?

Please, rate the following communication tools from 0 to 5, where 0 is the lowest priority and 5 is the highest.

- Social media
- Direct emails
- Newsletters
- News and other tools on websites



- Virtual meetings
- In person / hybrid events
- Workshops
- Media (Television, radio, newspaper, magazines)
- Reports & peer reviewed publications
- Group dynamics (e.g. focus groups)
- 35. In your opinion, what type of activities should a NCMH prioritise? Select all that apply
 - Funding of external R&D and/or policy projects
 - Participation and promotion of R&D and/or policy projects
 - Organisation of events (e.g. citizen engagement events; knowledge exchange, trainings, workshops and related events; policy dialogues with multiple stakeholders)
 - Publication of policy reports, opinions, white papers, etc
 - Oversights the implementation of Research and Health Policies
 - Other
- 36. What are your expectations regarding the role and impact of the upcoming NCMH in your country? Please frame your answers in the implementation of the EU Cancer Mission.

Enter your answer



Annex II - Analysis of the aggregated data

This analysis was carried out before receiving Israel's and Austria's final feedback. Therefore the data from question 9 till the end of the analysis is not updated yet.

Part 1 - Existence of a NCMH-like structure

The replies to questions 1, 2, 3, 4, are not incorporated in the analysis because they include personal data of the respondent.

5. Does your country have an organisation/ structure that could take the role of a National Cancer Mission Hub as described in ECHoS?

- Yes 12 countries
- No, but there is a potential candidate (eligible organisation entity) 10
 countries
- o No 6 countries

22 out of 28 countries have replied that there is a **NCMH** or a **NCMH-like structure** in their country.

From question n° 6, only countries with a NCMH or NCMS-like structure are replying (20 countries).

Yes	No, but there is a potential candidate (eligible organisation entity)	No
Austria	Czech Republic	Croatia
Belgium	Finland	Cyprus
France	Italy	Estonia
Germany	Latvia	Greece
Hungary	Luxembourg	Ireland
Israel	Malta	Slovenia
Lithuania	Poland	
Norway	Slovakia	
Portugal	Sweden	
Romania	The Netherlands	
Spain		
Türkiye		

The data from <u>questions 6-7-8 [Name, website and main contact person of the NCMH or NCMH-like structure]</u> are not included in this analysis but can be found in the country specific reports.

9. Please select the type of organisation operating as NCMH or NCMH-like structure.



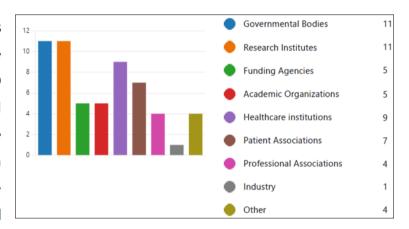
Out of 20 countries, 8 have replied that their NCMH or NCMH-like structure is a **Legal Organisation**, 6 of them replied that they have a **Consortium**, 2 countries replied



that their NCMH or NCMH-like structure is a **Joint venture**, and 4 countries are still defining the type of organization that is operating in their NCMH or NCMH-like structure.

10. Who is the coordinating/hosting organisation of the NCMH or NCMH-like structure?

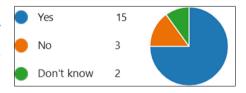
In this question, respondents could select more than one reply. Most of the 20 countries (that replied positively regarding the existence of a NCMH or a NCMH-like structure) have indicated **Governmental**



Bodies and/or **Research Institutes** and/or **Healthcare institutions** as the coordinating/hosting organisation.

11. Is the NCMH or NCMH-like structure in your country formally endorsed by governmental bodies?

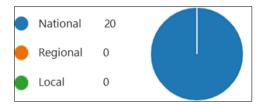
Governmental bodies are predominantly **participating** in the NCMH or NCMH-like structure.





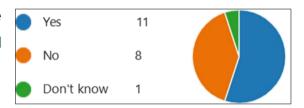
12. At what level does the NCMH or NCMH-like structure operate?

All the 20 countries have a NCMH or NCMH-like structure that operates at **national level**.



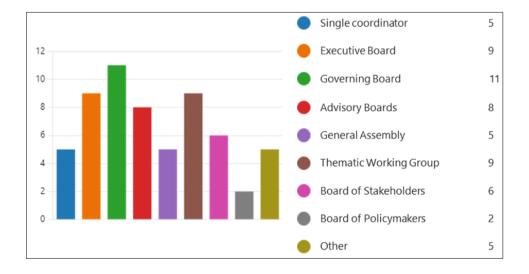
13. Does the NCMH or NCMH-like structure operate also at cross-national level?

In most countries, the NCMH or NCMH-like structure operates also at **cross-national** level.



14. Which governance body(ies) is envisaged by your NCMH or NCMH-like structure?

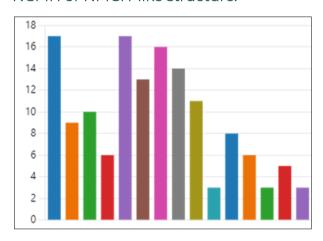
When replying to this question, respondents could select more than one governance body. Most of them have indicated **Governing Board** and/or **Executive Board** and/or **Thematic Working Group** as the governance bodies in their NCMH or NMCH-like structure.





15. Who are the stakeholders involved in the governance of the NCMH or NCMH-like structure?

The respondents were asked to select all the answers that apply to the governance of their NCMH or NCMH-like structure. Most of the 20 countries have indicated **Governmental bodies** and/or **Research institutions** and/or **Healthcare institutions** as the stakeholders involved in the governance in their NCMH or NMCH-like structure.





16. If Governmental Bodies are involved in the governance of the NCMH or NCMH-like structure, please specify at what level do they operate?

The respondents that selected "Governmental Bodies" in the previous question, were asked to specify at what level they operate

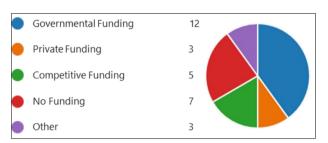


in their NCMH or NCMH-like structure and all the 17 respondents replied that the Governmental Bodies in their NCMH operate at **national level**.



17. What is the source of funding for the NCMH or NCMH-like structure?

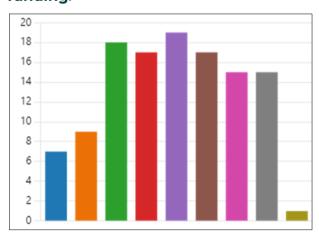
The source of funding for the NCMH or NCMH-like structure of the 20 countries is mostly **Governmental**Funding and/or No Funding and/or Competitive Funding, some have



added European grants as "other" source of funding.

18. What type of activities are developed by the NCMH or NCMH-like structure?

When replying to this question, respondents could select more than one type of activity. The 20 countries replied that, in their NCMH or NCMH-like structures, the principal activities developed are **Organisation of events** and/or **Direct participation initiatives** and/or **Awareness raising activities** and/or **Coordinating development of EU policy and funding**.

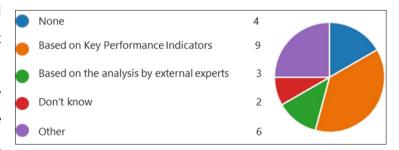


	Funding of internal initiatives or projects that are relevant for cancer research and/or policy making	7
•	Funding of <u>external</u> initiatives or projects that are relevant for cancer research and/or policy making	9
•	Direct participation initiatives or projects that are relevant for cancer research and/or policy-making	18
•	Activities of awareness raising and mobilising for projects that are relevant for cancer research and/or policy-making	17
•	Organisation of events (citizen engagement events; knowledge exchange, trainings, workshops, and related events; policy dialogues with multiple stakeholders)	19
•	Aligning national, regional and local policy levels, initiatives, and/or R&I funding, with Europe's Beating Cancer Plan and Mission on Cancer	17
	Coordinating and providing feedback to the development of EU policy and funding based on evidence gathered from multiple stakeholders, at national, regional and local level	15
	Publication of policy reports, opinions, white papers, etc.	15
	Other	1



19. Regarding monitoring and assessment of performance of the NCMH or NCMH-like structure, what type of mechanisms are established?

The respondents were asked to select all the answers that applied to the monitoring and assessment of performance of their NCMH or NCMH-like structure. In most countries.



the monitoring of performance of the NCMH or a NCMH-like structure is done with **Key Performance Indicators** and/or **other** mechanisms as **reports to the General Assembly / Ministry of Health** and/or are **still being defined**.

Questions 20 - 21 - 22 were asked only to the respondents that stated they don't have a NCMH or a NCMH-like structure in their country (7 countries: Austria, Croatia, Cyprus, Estonia, Greece, Ireland, Slovenia).

20. In your opinion, which of the following options best describe the current situation regarding the implementation of a NCMH in your country?

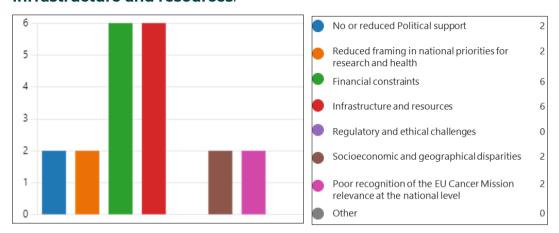
In the seven countries that stated the non-existence of a NCMH or NCMH-like structure, there are mostly Informal conversations with different stakeholders while in one country "Different actors partially fulfil the different roles of a NCMH" and in another country "The hub as a separate organisation is under creation".





21. In your opinion, what are the main constraints and critical issues to the implementation of the future NCMH in your country?

This question allowed the respondents to select more than one reply. The main issues on the implementation of a NCMH are **Financial constraints** and/or **Infrastructure and resources**.



22. Describe potential candidate and describe their actual role.

This was an open question and respondents wrote the replies that we have summarized below:

Austria: No potential candidate.

Croatia: Tumor Clinic in the University Hospital Center "Sisters of Mercy" (UHCSM), prevention and treatment of cancer patients, education of students and health personnel.

Cyprus: Cyprus Cancer Research Institute has a Research and Innovation hub dedicated to cancer research, it partners with University of Cyprus and BoC Oncology clinical center.

Estonia: NCMH development underway with proposals from the ministry of social affairs, two universities, and two cancer centers.

Greece: Cancer Guidance Center (Kapa3) for patients, their families and caregivers; Integrated Center for Research on Cancer in Athens (ACCC) for research and clinics. **Ireland**: HSE National Cancer Control Programme (NCCP) implements the

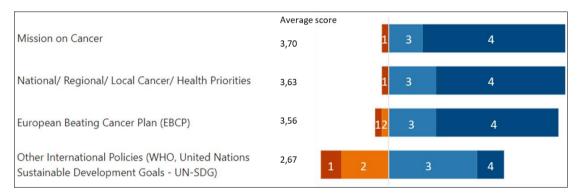


recommendations of the Cancer Strategy 2006; the All-Island Cancer Research Institute (AICRI) is a virtual institute. Both collaborate on establishing a NCMH. **Slovenia**: No potential candidate.

Part 2 - Opinion about the scope and structure of the future ideal NCMH

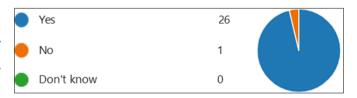
23. In your opinion, what should be the main priorities/focus of a NCMH?

Respondents were asked to rate each priorities/focus of a NCMH giving a score from 1 to 4, where 1 is the lowest and 4 is the highest. For most countries, the main priorities/focus of a NCMH is **Mission on Cancer** while the least important is **Other International Policies**.



24. In your opinion, is it important for the successful implementation of a NCMH to have formal endorsement by government bodies?

For most countries, it is important to have **formal endorsement by government bodies** to successfully implement a NCMH.





25. In your opinion, what is the ideal operational level of a NCMH?

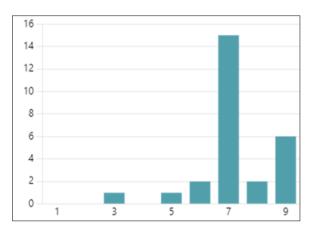
For all the 27 respondents, the ideal operational level of a NCMH is **National level**.



26. In your opinion, what is the ideal level of decisions autonomy of a NCMH?

The respondents were asked to rate from 1 to 9 the ideal level of decisions autonomy of a NCMH, 1 is no autonomy and 9 is fully autonomous.

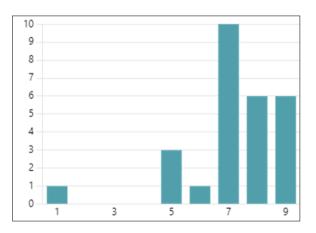
On average, the 27 countries gave a score of 7,22 stating that the ideal **level of decisions autonomy** of a NCMH should be high but NCMHs should not be completely autonomous.



27. In your opinion, what is the ideal level of financial autonomy of a NCMH?

The respondents were asked to rate from 1 to 9 the ideal level of financial autonomy of a NCMH, 1 is no autonomy and 9 is fully autonomous.

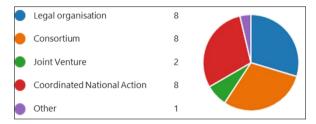
On average, the 27 countries gave a score of 7,19 stating that the ideal **level of financial autonomy** of a NCMH should be high but NCMHs should not be completely autonomous.





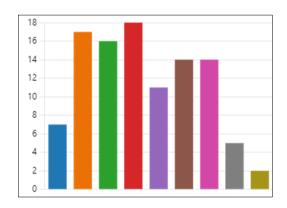
28. In your opinion, what is the ideal type of organisation acting to enable a successful implementation of a NCMH and its goals?

Most countries think that ideally a NCMH should either be a **Legal Organisation**, a **Consortium** or a **Coordinated National Action**.



29. In your opinion, which of the following bodies should integrate a NCMH

This question allowed the respondents to select more than one reply. Most countries think that **Advisory Boards** and/or an **Executive Board** and/or a **Governing Board**, should integrate a NCMH.



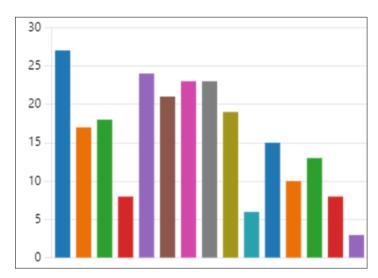




30. In your opinion, what type of entities should integrate a NCMH governing bodies?

Answering this question, respondents could select more than one type of entity that should integrate a NCMH governing body.

All countries think that **Governmental Bodies** and/or and many others think that **Research Institutions** and/or **Healthcare Institutions** and/or **Patient Associations** should be the entities that integrate a NCMH's governing





bodies.

31. If Governmental Bodies are involved in the governance of the NCMH structure, please specify at what level do they operate

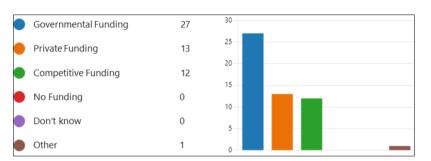
All the countries think that when Governmental Bodies are involved in the governance of a NCMH, they should operate at **National Level**.





32. In your opinion, what sources of funding should be ensured to facilitate the implementation and sustainability of a NCMH and its goals?

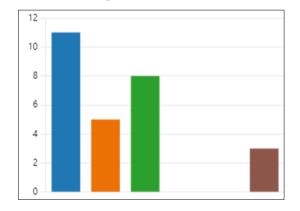
This question allowed the respondents to select more than one reply. All the 27 countries agree that the ideal source of funding of a NCMH

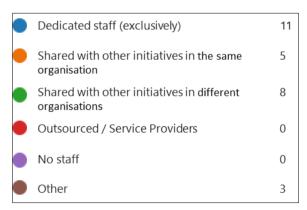


should be **Governmental Funding** however, almost half of the respondents selected **Private** or **Competitive Funding** as well.

33. In your opinion, NCMH staff should consist of:

The respondents were asked to choose the ideal staff composition for the NCMHs. Most countries think that a NCMH should have **Dedicated staff (exclusively)** but some countries think that the staff should be **Shared with other initiatives in different organisations**.



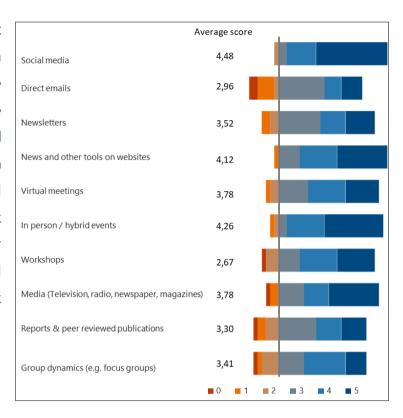


34. In your opinion, what type of communication tools should be prioritised by the NCMH for public awareness and outreach?

Respondents were asked to rate each type of communication tool giving a score from 0 to 5, where 0 is the lowest priority and 5 is the highest priority. For the



respondents, the most important communication tools that a NCMH should use to raise public awareness are social media, news, and other tools on websites, in person/hybrid events, and traditional media. Direct emails. Reports peer reviewed publications, and Group dynamics, should not be prioritised.



35. In your opinion, what type of activities should a NCMH prioritise?

This question allowed the respondents to select more than one reply. Almost all the countries think that NCMHs should prioritise **organisation of events** and/or **participation and promotion of R&D / policy projects**. The funding of external R&D and/or policy projects should not be as prioritised.

