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Research and Innovation

ECancer Working Group Recommendations

Implementing the UNCAN.eu Network and the European Cancer Patient Digital Centre

ECancer Working Group recommendations

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Directorate-General for Research and Innovation
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Contents

Executive Summary

This report presents the recommendations of the eCancer Working Group, convened under the Cancer Subgroup of the Public Health Expert Group, to guide the European Commission in implementing two digital platforms: UNCAN.eu and the European Cancer Patient Digital Centre (ECPDC). These initiatives are flagships of Europe's Beating Cancer Plan and the EU Cancer Mission under Horizon Europe. The implementation timeline outlines a comprehensive plan that commenced with a preparatory phase from 2021 to 2024. This phase was succeeded by regulatory alignment and strategic planning throughout 2024 and 2025, with this report serving as a key milestone. The build-up phase is set to extend from 2025 to 2030, paving the way for full operation and scaling from 2030 onward.

The UNCAN.eu Platform

The UNCAN.eu platform is designed to facilitate and enhance data driven research on the initiation and progression of cancer. Its objectives include establishing a sustainable European network of National Cancer Data Nodes (NCDNs) that operate in alignment with the European Health Data Space (EHDS), improving the usability and quality of cancer digital assets, and fostering collaboration and knowledge sharing among cancer research institutions.

The central coordination platform will play a key role in harmonising governance and technical standards across Member States. It will host a public website offering structured information and guidance to researchers and data holders, maintain repositories for tools and research data not covered by EHDS, and support capacity-building efforts. Legally, the platform may seek designation as an Authorised Participant within the EHDS infrastructure, provided it meets the necessary regulatory requirements.

National Cancer Data Nodes are essential components of this ecosystem. These nodes should be established as national entities that serve as interfaces between cancer data holders and the broader UNCAN.eu network. Their responsibilities include improving data quality at the source, ensuring compliance with EU standards, facilitating the creation of metadata to enhance dataset discoverability, supporting secure data analysis through EHDS-compliant environments, and enabling national-level capacity building and collaboration.

Policymakers have several options for legally aligning NCDNs with the EHDS framework. These nodes may be designated as independent bodies, Health Data Intermediation Entities, Thematic Health Data Access Bodies, or Trusted Health Data Holders. National designation and sustained funding will be critical to ensure national readiness and effective integration with EU research infrastructures.

The European Cancer Patient Digital Centre (ECPDC)

The ECPDC aims to empower cancer patients and survivors to manage their own health and healthcare decisions by providing trustworthy information, community support, and guidance on data sharing. Its core objectives include delivering a reliable information portal tailored to patient needs, offering guidance on Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), and creating a secure platform for peer-to-peer exchange.

Three design models are under consideration for the ECPDC: a central EU platform; a central platform with national mirror sites; and an integrated network with national data nodes aligned with EHDS. Policymakers should assess the level of national involvement and investment

required for each model, considering legal compliance, sustainability, and the potential for enhancing patient empowerment.

Implementation Considerations

Governance of both platforms should align with EHDS principles while respecting national contexts. Financing should transition from project-based support to structural funding, leveraging EU programmes such as Horizon Europe and EU4Health, alongside national contributions. Success will depend on political commitment, stakeholder engagement, and integration with existing infrastructures.

However, several risks must be addressed. These include the potential lack of national commitment and funding, fragmented healthcare landscapes, functional overlap with EHDS and research infrastructures, delays in establishing national nodes, and unclear governance responsibilities.

Policymakers play a pivotal role in enabling these platforms to transform cancer research and patient empowerment across Europe through data-driven innovation and collaboration.

1. Introduction

This Discussion Paper presents the documented outputs of the eCancer Working Group, operating within the Cancer Subgroup of the Public Health Expert Group. The eCancer Working Group was established to provide expert advice and consolidate Member State perspectives on the policy development and implementation of two flagship initiatives under the Cancer Mission:

- UNCAN.eu a platform to enhance and facilitate the use of high-quality data in cancer research.
- European Cancer Patient Digital Centre (ECPDC) a platform aimed at improving the quality of life for cancer patients and survivors.

The nominated experts in the eCancer Working Group were tasked with providing technical advice and Member State perspectives on:

- The implementation of the two digital platforms at national level.
- The definition of essential platform functionalities, ensuring complementarity and interoperability with infrastructures established under the European Health Data Space (EHDS) Regulation.
- Identification of potential barriers to implementation, including governance and financing, and proposing strategic solutions to address these challenges.

Meetings of the eCancer Working Group were held in virtual and hybrid formats between 2024 and 2025([1]). The secretariat was jointly chaired by DG RTD and DG SANTE, with support from an external contractor responsible for conducting surveys, analysing inputs and results, and assisting in the drafting of this Discussion Paper.

While the scope of this paper is specific to cancer, its findings are also relevant to other health domains, particularly those involving data sharing and infrastructure development.

The content of this paper is based on expert inputs collected during meetings and through ad hoc surveys. A glossary of key terms is provided in Annex A.

[1] https://ec.europa.eu/transparency/expert-groups-register/screen/expert-groups/consult?lang=en&groupID=103613

2. UNCAN.eu

2.1. Objectives

UNCAN.eu is a flagship initiative of the Cancer Mission and Europe's Beating Cancer Plan. UNCAN.eu was initially foreseen ([2]) as a federated digital platform where researchers could access, share and analyse data from different sources and data domains. In this initial concept, the platform could rely on existing computing facilities of EU or national research infrastructures, by expanding and/or complementing their functions as appropriate.

Since 2022, the Cancer Mission has supported three key preparatory actions under Horizon Europe to lay the foundation for UNCAN.eu. The research project EOSC4Cancer ([3]) developed tools and services for a digital infrastructure within the European Open Science Cloud (EOSC) framework. The project CanSERV ([4]) facilitated access to services provided by various European research infrastructures to support both preclinical and clinical cancer research. Meanwhile, the Coordination and Support Action 4.UNCAN.eu ([5]) delivered the technical and strategic specifications necessary for building the infrastructure that will sustain the future UNCAN.eu platform.

With the adoption of the Regulation (EU) 2025/327 on the European Health Data Space (EHDS) ([6]) regulation, it has become necessary to realign UNCAN.eu objectives and functions to ensure coherence and complementarity with the EHDS framework.

Chapter IV of the EHDS regulation provides the common legal and operational framework governing the secondary use of electronic health data across the Union.

The EHDS is a sector-specific data space for health, applicable to all types of health data regardless of disease area or data source. It ensures that the reuse of such data takes place under harmonised conditions and on a clear legal basis, complementing other lawful access mechanisms such as consent-based research or specific national schemes.

Within this framework, the future UNCAN.eu infrastructure should operate in full alignment with the EHDS, drawing on it as the primary legal basis for the secondary use of cancer-related data, and avoid duplicating functions that the EHDS already provides such as dataset cataloguing, access authorisation and secure data processing. Notably, the EHDS infrastructure for the secondary use of health data (HealthData@EU) is set to play a pivotal role in ensuring the discoverability and accessibility of health data across Europe. As this infrastructure becomes the cornerstone for secondary data use, such functions will become less central to the future role of the UNCAN.eu platform.

Instead, UNCAN.eu could evolve into a dedicated support interface helping researchers and data holders navigate and use the EHDS infrastructure effectively. It should also facilitate the utilisation of services offered by EU Research Infrastructures and related European initiatives ([7]), while promoting the reuse of cancer-related digital assets, including software, code, datasets, documents, and other digital tools, developed through EU-funded data-driven cancer research projects.

In the context of UNCAN.eu, cancer data refers to all digital assets associated with cancer that can be leveraged for research, innovation, and clinical advancement, regardless of the original purpose for which they were collected. This includes but is not limited to tools and solutions to

[2] https://research-and-innovation.ec.europa.eu/system/files/2021-09/cancer_implementation_plan_for_publication_final_v2.pdf
[3] https://cordis.europa.eu/project/id/101058427
[4] https://cordis.europa.eu/project/id/101058620
[5] See https://cordis.europa.eu/project/id/101069496/results(Blueprint for a European Federated Cancer Research Data Platform)
[6] Regulation - EU - 2025/327 - EN - EUR-Lex
[7] ERICs, EDICs, EOSC, European 1M+ Genomes and the European Cancer Imaging initiatives and similar EU wide initiatives.

work with: clinical data ([8]), molecular and genomic data ([9]), experimental and preclinical data ([10]), real-world and patient-reported data ([11]) and metadata and data standards ([12]).

The revisited objectives of UNCAN.eu are:

- To have a sustainable European network of national cancer data nodes operating within and interoperating with the EHDS infrastructure for secondary use HealthData@EU, compliant with its legal framework and supported by an administrative coordination platform.
- To improve the usability and quality of cancer digital assets from multiple sources by offering information and tools to researchers and national cancer data holders that complement EHDS infrastructure capabilities at national level and that leverage on the services offered by European Research Infrastructures and initiatives ([13]).
- To foster collaboration, capacity building and knowledge sharing in the field of cancer data among European cancer research institutions, national cancer research networks, data holders, and data nodes, with the goal of accelerating innovation and improving patient outcomes.

The operations of the coordination platform and of national cancer data nodes will rely on decisions taken by Member States and must remain aligned with the EHDS and with other relevant European infrastructures and initiatives and their respective nodes. As a guiding principle, overlapping functions should be avoided.

In the remaining part of the chapter, we differentiate between functions of the central EU-level coordination platform and the functions of the national cancer data nodes. Functions are used to break down the objectives of UNCAN.eu into a set of high-level tasks.

2.2. UNCAN.eu central platform

2.2.1. Functions

UNCAN.eu is conceived as a European network of national cancer data nodes with a central coordination platform.

Within this network, the national representatives of cancer data nodes should discuss and agree on common approaches and guidelines to streamline the work on improving cancer data quality at source or aligning on the use of common data standards.

Representatives of relevant European research infrastructures and initiatives should contribute to this network by providing expertise on services, identifying gaps, co-designing, and/or developing new or improved solutions as needed.

The coordination platform should serve as a guiding compass to navigate available resources of the EU research infrastructures and other European initiatives within the cancer data research ecosystem and the EHDS.

The platform should provide structured information on relevant data driven cancer research and innovation projects and appropriate links to available data, tools, and solutions. The platform could also offer training and guiding materials or inform on relevant training activities provided by others.

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[8] E.g. patient records, imaging, laboratory test results, Electronic Health Records.
[9] DNA/RNA sequencing, proteomics and metabolomics, biomarker profiles etc.
[10] Data from cancer models such as cell lines, organoids, animal models, drug screening and toxicology studies, preclinical and early-phase clinical trial data.
[11] Data from wearables and mobile health apps, patient-reported outcomes and quality of life measures.
[12] Descriptions of datasets, ontologies and controlled vocabularies, data provenance and quality indicators, etc.
[13] ERICs, EDICs, EOSC, European 1M+ Genomes and the European Cancer Imaging initiatives and similar EU wide initiatives.

Figure 1 below illustrates the positioning of UNCAN.eu coordination platform in the data journey through the EHDS landscape. The scenario depicted in the figure implies that cancer data nodes act as intermediaries between cancer data holders and Health Data Access Bodies (HDABs). Different options are possible (see par. 2.3.2). By establishing the links between EU research projects, infrastructures and initiatives to national cancer data nodes, UNCAN.eu helps in advancing data driven research. Notably, research infrastructures and similar entities (defined in par. 2.1) may apply to become Authorised Participants of the HealthData@EU infrastructure if eligible under the EHDS Regulation.

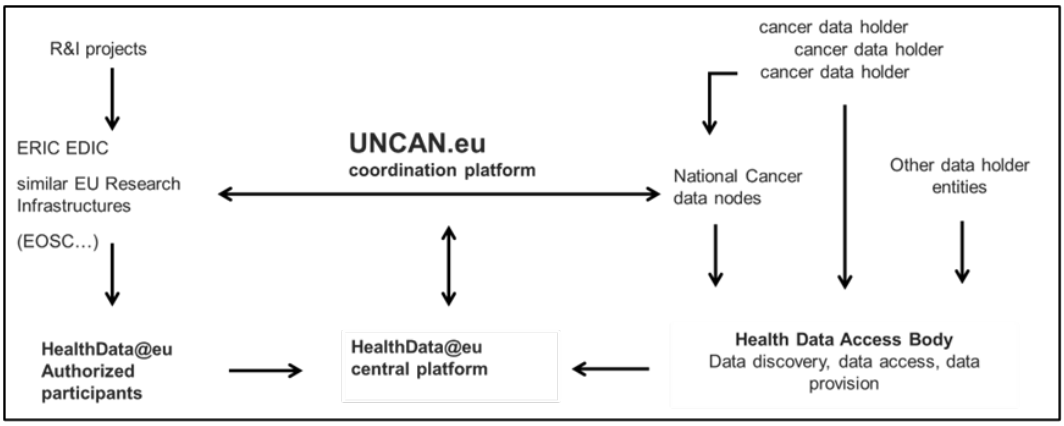

Figure 1. Positioning of UNCAN.eu in the data journey through the landscape of EU research infrastructures and the EHDS

The below table presents a condensed version of the functions identified by the Working Group for the UNCAN.eu central coordination platform and provides a detailed description.

Functions	Description
Coordination and governance	The coordination platform should facilitate discussion and knowledge sharing among national cancer data nodes and provide administrative and logistical support. High-priority topics should be data normalisation (e.g., harmonising datasets at the national level), data standardisation (e.g. common data models), data quality criteria, interoperability of datasets, dataset building methodologies and others as appropriate. It should define and agree on common objectives and a roadmap. It should provide support, coordination, and documentation before, during, and after network meetings. It should assist in drafting relevant technical and policy documents.
Provide a public website	The coordination platform should host a public website designed to support transparency, knowledge sharing, and reusability of resources across the cancer research community.

Functions	Description
	The UNCAN.eu website must display structured summaries of ongoing and completed data-driven EU cancer projects, with a focus on their data-related components without duplicating the information provided in other European websites. The UNCAN.eu website must provide clear, accessible guidance on which data standards to use based on specific data types (e.g., clinical, genomic, imaging and others) and point to best practices for data curation, management, and analysis. It should highlight methodologies to work with cancer data and should provide links to repositories of data, tools and workflows (e.g. in research infrastructures and initiatives) facilitating the reuse of those digital assets by others.
Provide a repository for tools and solutions to work with cancer data	To support cancer researchers and data holders, the central coordination platform should include a repository of tools and solutions for working with data of different formats and domains. Examples of those tools include software for data curation at source, specialised secure processing environment focusing on cancer and other relevant IT tools. It must include direct links to data complementing national catalogues provided by HDABs. It must include direct links to tools, platforms, and services relevant for cancer research and cancer data holders that are hosted by European research infrastructures and similar initiatives (defined in par. 2.1), promoting their reuse and interoperability. The UNCAN.eu repository could initially be populated with digital assets produced in Cancer Mission projects and EU Research Infrastructures and initiatives and gradually extended to include cancer-related data assets from other EU, national, and regional projects.
Provide a repository for research data not covered under Article 51 of the EHDS regulation	The UNCAN.eu platform could make findable cancer research data that are not included in Article 51 of the EHDS regulation. Examples are laboratory experimental models (in vitro models, in vivo models), in silico models (e.g. computer-based simulations used to model cancer initiation and progression, drug response, or genetic interactions) and ex-vivo models. The UNCAN.eu platform will not duplicate datasets already covered by Article 51 of the EHDS Regulation. Instead, it will reference cancer-related datasets described in EHDS catalogues and complement them with other research data not falling within the EHDS legal scope or not collected under the EHDS remit.

Functions	Description
	A catalogue of those data with structured summaries of the projects that generated them, and related digital assets could also be included, as appropriate.
Provide capacity building to cancer researchers	The UNCAN.eu coordination platform could provide training opportunities for researchers and professionals, organize and coordinate events within the digital health ecosystem (including data holders), and collaborate with existing EU initiatives and institutions offering similar resources ([14]). The platform could cross reference to those learning and training resources (like e-courses, workshops, summer and winter schools and events) related to cancer data. Topics relevant for cancer researchers include but are not limited to data maturity analysis, HealthDCAT-AP, data models, documentation of metadata, the use of AI with health data, FAIRification of data, navigation of data catalogues and data request journeys.

2.2.2. Legal alignment of the central coordination platform UNCAN.eu with EHDS

Should the UNCAN.eu coordination platform be established as a legal entity under Union law (see below), it could apply to become an Authorised Participant (AP) to the HealthData@EU infrastructure subject to the criteria defined in the implementing act. under Article 75 of the EHDS Regulation.

An AP to HealthData@EU is an entity established under Union law that may connect to the EU central platform of HealthData@EU and perform specific functions in accordance with the EHDS Regulation, provided it meets the technical and organisational requirements laid down in the implementing act. APs must ensure interoperability with the EHDS infrastructure and maintain compliance with data protection, security and governance obligations. In the context of UNCAN.eu, key functions as AP ([15]) are:

- to make its metadata records interoperable and hence discoverable through the common EU datasets catalogue (metadata catalogue) of the EHDS;
- to be able to receive and handle data access applications. The AP could receive data access applications directly from the EU central platform;
- To decide on data access applications, authorise and grant access to electronic health data falling within their remit and in accordance with their legal basis and Chapter IV of the EHDS regulation, whenever APs are mentioned. For example, where an AP makes data available based on contractual agreements with data holders or the consent from subjects to reuse their health data, those requirements remain.

[14] Examples are the future EU network of Comprehensive Cancer Centers and the Networks of Expertise on Cancer.
[15] Please refer to EHDS regulation for full description of authorised participants to HealthData@eu (https://eur-lex.europa.eu/eli/reg/2025/327/oj/eng).

2.3. National cancer data nodes

2.3.1. Functions

National Cancer Data Nodes serve as foundational components of the UNCAN.eu network, designed to support both cancer researchers and data holders. These nodes will function as the main interface between the UNCAN.eu coordinating platform and national data providers and end users, effectively bridging national stakeholders with the broader UNCAN.eu, EHDS and research infrastructure ecosystems.

National Cancer Data Nodes could be formally established under Member States responsability, either as newly created entities or by leveraging existing national infrastructures with relevant expertise and capacity. A list of suggested national cancer structures is provided in par. 2.3.3.

Figure 2 below illustrates the high-level interplay between UNCAN.eu national cancer data nodes and the EHDS bodies. The primary interactions are foreseen between the national cancer data node(s) in each member state and cancer data holders.

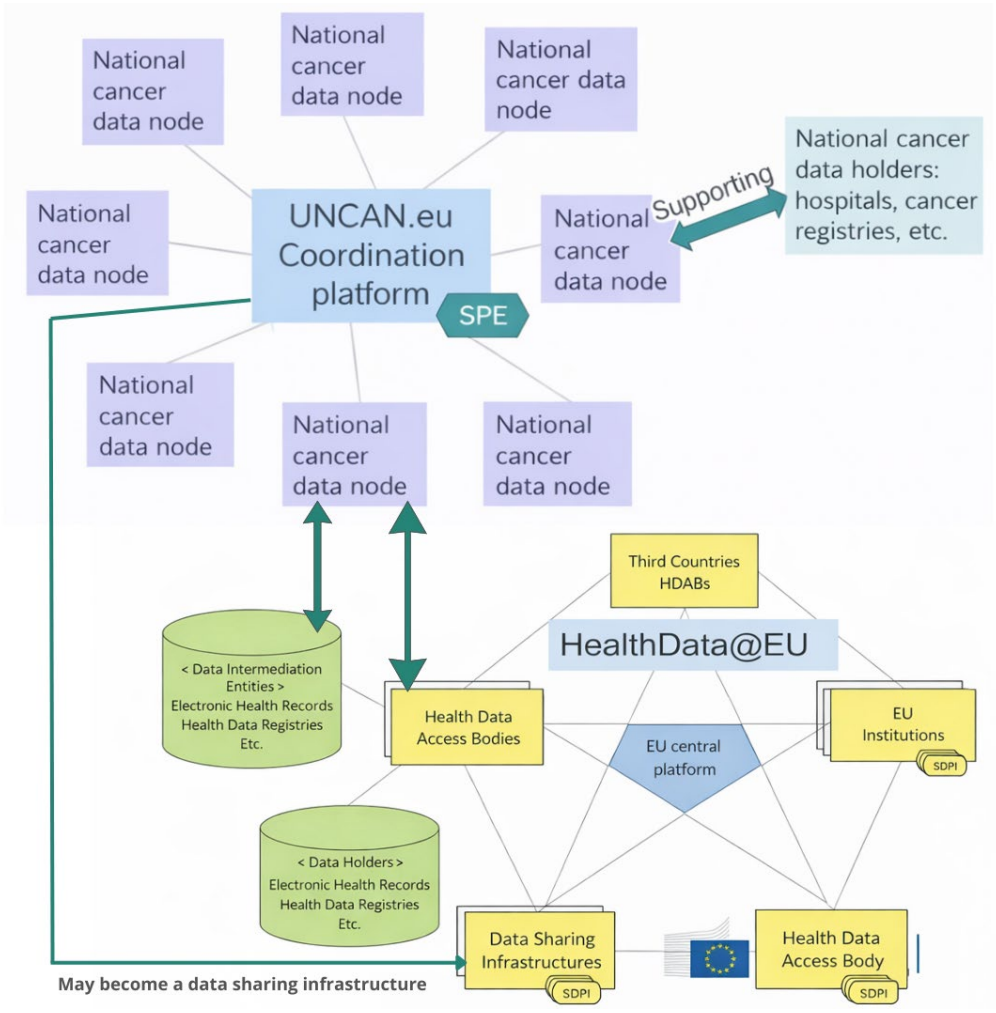

Figure 2. Envisaged interplay between UNCAN.eu and the EHDS

The functions for national cancer data nodes proposed by the eCancer Working Group are further detailed in the following table based on the experts' feedback.

Functions	Description
Provide tools to improve data quality of cancer data at source	National cancer data nodes should play a coordination, supportive and advisory role toward national cancer data holders. They should help in facilitating data standardisation and quality assurance, support compliance with EHDS and GDPR regulations, guide data holders in making their datasets FAIR and interoperable. National cancer data nodes should initiate or participate in discussions and decision-making on topics like e.g. European common data standards, data quality and interoperability. National cancer data nodes should support researchers and data holders in improving the quality of cancer data collected at source and facilitating the dialogue among them. For example, they could develop or adapt cancer-focused applications (like the use of common data models) or other tools for ensuring data quality, standard formats, FAIR principles, annotation with metadata and other tasks as appropriate.
Provide tools for cancer data analysis to be used in secure processing environments (SPEs)	Cancer data nodes could participate in developing and provide information and guidance to end users on new and existing tools and software for federated analysis of cancer datasets that can be installed in EHDS compliant SPEs (Art. 2(1)(c) and Art. 73 of EHDS regulation).
Ensure all cancer datasets have a metadata record in the EU dataset catalogue	National cancer data nodes could support researchers and data holders in creating metadata records describing their datasets, compliant with the metadata standard used in the EU dataset catalogue, namely Health DCAT-AP. In this way most cancer datasets across Europe will be well described and findable through the national metadata catalogues and the EU dataset catalogue, held by the EU central platform of the HealthData@EU infrastructure.
Provide advice on common variables for cancer datasets	Since national nodes maintain direct contact with data holders, they could contribute in identifying and defining the key characteristics of common variables for cancer-related datasets. Drawing on this input, the central platform could develop harmonised guidance to support the implementation of any guidance developed, in alignment with any existing ongoing standardisation initiatives. The European Health Data Space may be leveraged for the implementation of such guidance on common variables for cancer datasets. According to Article 80 of the EHDS regulation the Commission may, by means of implementing act, set out minimum specifications for datasets of high impact. Such datasets of high impact can be cancer-related datasets.
Capacity building at national level	National Cancer Data Nodes could facilitate dialogue at national level, exchange of ideas and project results and networking among researchers, data holders and other data users.

2.3.2. Legal alignment of National Cancer Data Nodes with EHDS

Integration with the HealthData@EU infrastructure could be pursued, where appropriate, through national decisions designating cancer data nodes to perform functions equivalent to those of Health Data Intermediation Entities, or Thematic Health Data Access Bodies or Trusted Health Data Holders, in accordance with the EHDS Regulation.

The establishment and operation of national cancer data nodes remain under the responsibility of Member States, in line with the EHDS framework and national governance arrangements. It is therefore responsibility of each Member State to determine which option best fits its national landscape and its level of commitment to investing in the UNCAN.eu infrastructure. Such designations remain voluntary and depend on how each Member State implements the EHDS at national level.

The table below presents the legal and technical alignment options for national cancer data nodes with the HealthData@EU infrastructure and governance, along with a description of their core functions. These functions generally complement those outlined in section 2.3.1, although potential conflicts of interest should be assessed on a case-by-case basis.

Functions	Description
Option A: No mandate to integrate with HealthData@EU	Under this scenario, cancer data nodes do not operate as entities connected to the HealthData@EU infrastructure. As a result, their functions are not embedded within the data flow governed by the EHDS regulation. This option would allow flexibility but would not benefit from the shared legal and technical infrastructure of HealthData@EU.
Option B: Mandate national cancer data nodes to act as health data intermediation entities	Under Articles 50 and 59 of the EHDS Regulation, authorised HDIEs may support health data holders by preparing, curating, and securely transferring data to approved users following a decision by the competent HDAB. In the context of UNCAN.eu, Member States could choose to extend the mandate of their national cancer data nodes to act as intermediaries between cancer data holders and HDABs. This implies that cancer data nodes should not decide on data access permits but would provide metadata records and curated datasets to the HDAB once a permit for this data has been administered to a data applicant, transfer data securely to the Secure Processing Environment (SPE) of the HDAB and support data preparation and delivery, relieving the burden on individual data holders. In the context of UNCAN.eu ([16]), key functions of HDIEs shall be: - act as intermediaries between cancer data holders and HDABs; - ensure technical and computational readiness to handle, prepare, and securely transmit data; - support metadata generation to ensure datasets are discoverable in the EHDS health dataset catalogue;

[16] Refer to EHDS regulation for full description of health data intermediation entities (https://eur-lex.europa.eu/eli/reg/2025/327/oj/eng)

Functions	Description
	operate under strict legal and ethical compliance, without making decisions on data access.
Option C: Mandate national cancer data nodes to act as (thematic) HDABs	Under EHDS regulation Member States could decide, under national law, to entrust cancer data nodes with the functions of a thematic HDAB for cancer. In this context, a national cancer data node could be mandated to act as a thematic HDAB for cancer, provided national legislation supports this role. Key functions of a thematic HDAB in the context of UNCAN.eu ([17]) shall be: - evaluate applications for secondary use of cancer data (e.g., for research, innovation, policymaking); - ensure requests meet legal, ethical, and scientific criteria; - grant or deny access to datasets based on compliance with EHDS regulation; - coordinate with data holders and health data intermediation entities to facilitate access; - provide Secure Processing Environments (SPEs) where approved users can analyse data without extracting it; - charge fees for making electronic health data available for secondary use; Articles 55, 57, 58, 59, 63 and 64 of the EHDS Regulation further apply to thematic HDABs.
Option D: Mandate national cancer data nodes to act as Trusted Health Data Holder	The EHDS regulation allows Member States to designate Trusted Health Data Holders (THDH; Art. 72): a designated entity that holds and manages specific types of health data, such as cancer data, and is trusted by national authorities to provide secure, high-quality data access for secondary use. This means that a THDH must be officially recognised by the Member State and demonstrate both the technical and organisational capacity to handle data access requests. Specifically, it should be able to evaluate applications within the required timeframe and provide a well-founded recommendation to the national Health Data Access Body, which is responsible for making the final decision on the permit. Key functions of a THDH in the context of UNCAN.eu ([18]) must be: - to maintain high-quality, well-documented cancer datasets; - to ensure its datasets are discoverable via the EHDS health dataset catalogue; - to provide an EHDS compliant SPE to data users once a permit has been granted by the relevant national HDAB; - to operate under strict legal, ethical, and technical standards.

[17] A thematic HDAB refers to a national HDAB designated with a specialised remit (e.g. cancer), performing all or selected tasks under Article 57 of the EHDS Regulation (https://eur-lex.europa.eu/eli/reg/2025/327/oj/eng)

[18] Refer to EHDS regulation for full description of single trusted health data holder: https://eur-lex.europa.eu/eli/reg/2025/327/oj/eng

2.3.3. National cancer data node establishment

Input received from the Working Group suggests that establishing national cancer data nodes within an existing organisation could be the most viable solution. Knowledge on the landscape will be crucial for establishing national cancer data nodes and for a successful execution of their tasks.

To summarise, Member States have several options for participating in the UNCAN.eu network through the designation of national cancer data nodes. These nodes may be established as one of the following:

- a specific body not included within HealthData@EU;
- a Health Data Intermediation Entity;
- a (thematic) Health Data Access Body;
- a Single Trusted Health Data Holder.

Among the potential group of candidate organisation are cancer registries, national or regional cancer institutes, national nodes of EU research infrastructures, and cancer research hospitals. Specific organisations are favoured in some countries as listed below:

- Austria: BBMRI.at or ELIXIR-AT or Austrian Comprehensive Cancer Network
- Croatia: Research Institute Ruđer Bošković or UHC Zagreb
- Czechia: ELIXIR-CZ or BMMRI-CZ node
- Cyprus: National cancer registry under the Ministry of Health
- Estonia: University of Tartu
- Finland: Finnish Cancer Centre FICAN
- France: Institut national du Cancer (INCa)
- Germany: German Cancer Research Center (DKFZ) or Cancer registries (DKR e.V.) or German Centre for Cancer Registry Data (RKI)
- Hungary: National Institute of Oncology
- Ireland: ELIXIR-IE node
- Latvia: National Cancer Centre
- Lithuania: National Cancer registry or University Hospitals
- Luxembourg: National Cancer Institute (Luxembourg Institute of Health)
- Netherlands: Health-RI node in close collaboration with The Netherlands Comprehensive Cancer Centre (IKNL)

- Norway: Cancer Registry of Norway
- Poland: Maria Sklodowska-Curie National Research Institute of Oncology
- Portugal: Serviços Partilhados do Ministério da Saúde (SPMS)
- Romania: Oncology Institute Cluj Napoca
- Slovakia: National Health Information Centre (NCZI) or Slovak Centre of Scientific and Technical Information
- Slovenia: National Institute for Cancer

The eCancer group noted that the decision on which organisation would be suitable further depends on the chosen configuration of national cancer data nodes and therefore needs to be decided on an individual basis in consultation with the country concerned.

3. European Cancer Patient Digital Centre

3.1. Objectives

The European Cancer Patient Digital Centre (ECPDC) is a flagship initiative of the Cancer Mission and Europe's Beating Cancer Plan. The ECPDC was initially foreseen ([19]) as a digital platform providing services to support cancer patients and survivors to facilitate their access to reliable and trustworthy information, covering the entire spectrum of the cancer journey. In the original plan, patients could also deposit their health data (both clinical data and patient-reported data) for personal use and for consent-based sharing with healthcare and research professionals and institutions.

The Cancer Mission supported a preparatory study for the ECPDC that resulted in specifications for the creation of the infrastructure sustaining the platform and a suggestion of possible functions ([20]).

Following the adoption of Regulation (EU) 2025/327 establishing the European Health Data Space (EHDS), the objectives and functions of the ECPDC must be realigned to ensure coherence and complementarity with the EHDS framework.

The EHDS establishes individuals' rights to access and portability of their electronic health data and provides for national health data access services, interoperable via the European Electronic Health Record Exchange Format (EEHRxF). These services may be delivered through national or regional patient portals, mobile applications or directly by healthcare providers.

Accordingly, the ECPDC will no longer focus on providing access or portability of personal health data, as these functions are now addressed within the EHDS, but will concentrate on complementary objectives that empower patients, improve data literacy, and strengthen the patient voice in cancer data ecosystems.

The revisited objectives of ECPDC are:

- Establish a European Cancer Patient Digital Centre – a digital platform dedicated to empowering patients and survivors with resources that enhance their quality of life.
- Support information needs of patients, survivors and caregivers and healthcare professionals through a reliable information portal.
- Provide reliable guidance for reporting, depositing, and sharing of data on Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) for personal uses and research (improving research and innovation).
- Provide to patients and survivors a safe place to exchange with peers and experts (e.g., community forum) and provide access to tools and other resources to improve patients' quality of life during and after treatment.

The remainder of this chapter outlines the key functions required to achieve the stated objectives. It is important to note that the specific roles assigned to the EU-level coordination platform and to any potential national ECPDC nodes will ultimately depend on the final design of the ECPDC.

[19] https://research-and-innovation.ec.europa.eu/system/files/2021-09/cancer_implementation_plan_for_publication_final_v2.pdf
[20] An operational concept for a European Cancer Patient Digital Centre https://data.europa.eu/doi/10.2777/78242

3.2. ECPDC functions and design

3.2.1. Functions

In the table below the core functions of the ECPDC are outlined.

Functions	Description
Information portal for cancer patients	The aim of the information portal of the ECPDC is to support the information needs of patients, survivors, caregivers, and health professionals covering the cancer patient journey from diagnosis to life after cancer. The information provided must be based on a knowledge centre that efficiently accesses and selects scientific evidence and can return this evidence in lay terms tailored to the user needs and background, in full compliance with EU ethical and data protection standards. Other information such as national solutions to ensure data access and sharing for primary use under the EHDS regulation (without providing or mediating such services directly), options for cross-border care, psychosocial and legal support, ongoing research studies etc. could be provided. National level information could be made available through the ECPDC information portal by cross-linking relevant pages of cancer information portals of national ministries, when available. The knowledge centre behind the information portal and the associated IT services (including eTranslation services) could be hosted by an existing EU research Infrastructure or other European initiatives. The possibility and technical feasibility of integrating ECPDC information portal in the existing JRC Knowledge Centre on Cancer could be explored. An ECPDC editorial committee could be responsible for the contents.
Platform for safe exchange with peers and experts (e.g. community forum)	The goal of providing to patients and survivors a safe space for peer-to-peer exchange is to help alleviate the psychological stress and social isolation that cancer patients may experience. The ECPDC should offer a secure online community where patients can share experiences and support with one another. Depending on the ambition and scope of the central ECPDC platform, this community space could be moderated by a dedicated team to ensure a safe and supportive environment.
Guidance for PROMs and PREMs data reporting and sharing for research	The central ECPDC platform should contribute to develop European guidance and best practices for collecting Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs). This will enhance interoperability and facilitate the reuse of data for research purposes, contributing indirectly to the objectives of UNCAN.eu. Existing EU-funded initiatives focused on 'quality of life' should be leveraged to inform the development of scalable solutions

Functions	Description
	for the collection, storage, and sharing of PROMs and PREMs at the EU level.

3.2.2. Design

To fulfil the functions described above, the ECPDC is anticipated as a network of national ECPDC nodes. However, if the ambition of the ECPDC is lowered to the informative component, there is no need of specific functions dealing with personal data. In this scenario, the central platform and associated website could be hosted by a single EU level initiative, optionally mirrored at national level. Three potential design models are under consideration: (1) a central EU platform; (2) a central EU platform with national 'mirror' sites; and (3) a central EU platform integrated with a network of national data nodes subject to legal alignment with the EHDS as described in par 2.3.2. These options reflect varying levels of Member State involvement and investment and are described in the table below.

Functions	Description
ECPDC as EU platform	In this scenario, the central platform and associated website could be hosted by an EU level initiative. All the resources (information centre, community forum and PREMs and PROMs guidance), including eTranslation, should be provided by the central platform. An editorial committee could be responsible for the information content and the moderation of the community forum.
ECPDC as EU platform with national mirror sites	In this scenario, the central platform and its associated website could be hosted by an EU-level initiative. All core resources (the information centre, community forum, and PROMs/PREMs guidance) should be provided centrally. This platform could be mirrored in national languages through country-specific mirror sites, forming a coordinated network under the central ECPDC platform. Each national mirror site could be responsible for delivering country-specific content and could also offer editorial services tailored to national contexts.
ECPDC as EU platform integrated with a network of national data nodes	In this more complex and resource demanding scenario, the central platform could be hosted by an EU-level initiative and operates as part of a broader network of cancer data nodes integrated within the UNCAN.eu network. Key ECPDC resources (information centre, community forum, and PROMs and PREMs guidance) could be shared across nodes, depending on national capabilities and expertise. Beyond their informational role, cancer data nodes could optionally provide services that enable patients to submit PROMs and PREMs to appropriate European research infrastructures and initiatives, which in turn should ensure their availability for secondary use in compliance with current EU regulations.

4. Key factors for the establishment of the platforms

4.1. Governance

The EHDS Regulation defines the governance principles for the use and reuse of health data. Accordingly, the governance of the UNCAN.eu network and ECPDC must align with these principles. Where required, Member States should apply these principles to fit their national contexts, respecting the principle of subsidiarity.

4.2. Financing

Ensuring long-term sustainability requires dedicated funding for the establishment and operation of UNCAN.eu and ECPDC. The financial needs will vary depending on the selected implementation scenario, the number of national data holders involved, and the extent to which existing infrastructures can be leveraged upon. Competency requirements for each scenario are derived from the functions outlined throughout this document.

Potential sources of funding include EU programmes such as EU4Health, Horizon Europe, Digital Europe, as well as national or regional contributions. For long-term sustainability, financing models should gradually transition from project-based support to structural funding mechanisms (e.g. integration in ERIC/EDIC governance or dedicated EU support measures).

4.3. Enablers & risks

Key enablers for the success of UNCAN.eu network and ECPDC platform include a clear governance and coordination mechanism, the engagement of the necessary pool of stakeholders, the integration with existing EU health and research infrastructure capabilities and the strong alignment with EU priorities.

At the national level, the successful establishment of national cancer data nodes hinges on strong political commitment from Member States. This includes the following enablers:

- Clear governance and coordination mechanisms aligned with EHDS structures, including the possibility to designate one or more appropriate organisations to serve as national cancer data node(s). In cases where the node is expected to function as a dedicated Health Data Access Body, Health Data Intermediation Entity, or Single Health Data Holder, the designation should be formalised through an official legal act.
- Political commitment from Member States to designate and support national cancer data nodes or national ECPDC mirrors, as appropriate.
- Coordination with relevant national stakeholders to identify the most suitable implementation model, based on the options outlined in Chapters 2 and 3.
- Creating synergies with health and digital literacy projects, joint actions, and other European initiatives relevant for the objectives of UNCAN.eu and ECPDC.
- Provide guidelines to stakeholders in the digital health ecosystem and technical support (e.g., via capacity-building programme) to ensure that national level organisations are up to their tasks.

- Improve the capacity of individuals and their representative organisations to actively demand the realisation of health data related rights (Health Data Activism) ([21]).
- Include the needs of patients and their empowerment in national cancer control strategies could further increase the ambitions of the ECPDC.

The following risks to the effective implementation of UNCAN.eu were identified:

- Lack of political commitment from Member States to designate and support national cancer data nodes.
- Fragmented national landscapes, with varying healthcare system structures and readiness levels when it comes to supporting the secondary use of data.
- Unclear governance responsibilities, especially in aligning national nodes with EHDS bodies.
- Risk of duplication with EHDS and research infrastructures functions if UNCAN.eu functions are not clearly differentiated and complementary.
- Lack of secured long-term funding for both the central coordination platform and national nodes and dependence on EU project-based funding, which do not ensure continuity.
- Delays in establishing national nodes, especially where no clear candidate organisations exist.
- Challenges in coordinating across multiple stakeholders, including ministries, research infrastructures, and research organisations.
- Responsibility ambiguity for ensuring content accuracy and on data governance.

The following key risks to the effective implementation of the ECPDC have been identified:

- Responsibility for information accuracy. The ECPDC central platform is intended to serve as a trusted source of comprehensive information across the cancer care continuum for patients, survivors, and caregivers. Content must be grounded in the latest research and official EU guidelines (e.g., ESMO Clinical Practice Guidelines). However, this information could be complemented by national guidelines, standards, and procedures (e.g., those covered by health insurance schemes). An editorial board could be established to oversee content management and ensure quality and consistency.
- National funding commitments. Member States must allocate funding to support EHDS-related bodies and could formally designate the ECPDC – within the UNCAN.eu framework – as an official EHDS entity. This could include recognising a health data intermediation organisation as the national ECPDC node.
- Capacity of entities designated as national nodes to develop and operate the ECPDC platforms.

[21] With strong advocacy and awareness of the possibilities of data altruism (i.e. with prepared patients, survivors, and health professionals), the ECPDC could reach its full potential.

4.4. Implementation timeline

The timeline reported below is tentative.

Phase	Period	Description
Preparatory phase	2021–2024	Preparatory actions supported; strategic and technical blueprints of the platforms produced.
Regulatory alignment and strategic planning	2024-2025	Finalisation of the eCancer discussion paper; feedback collected from relevant EC working groups and services
Built-up phase	2025-2030	Engagement with national authorities and designation of cancer data nodes. Member States select legal alignment options and identify candidate organisations. Member State experts provide feedback on implementing project workplans and aid in engaging national ministries. Development of the prototype of the UNCAN.eu coordination platform. Development of ECPDC modules covering core functions and finalisation of its design.
Strengthen & scale up	2030 – 2035	Network expansion and integration of new functionalities as needed. UNCAN.eu and ECPDC platforms become fully operational.

Annex A - Glossary

4.UNCAN.eu: A Coordination and Support Action (CSA) with a time frame 2022-2023 that developed the strategic and technical blueprint for the UNCAN.eu platform.

Authorised Participant (AP): An entity connected to the HealthData@EU infrastructure, capable of handling data access applications and issuing permits.

Cancer Project Tool: project visualisation tool included in Knowledge4Policy (K4P) - the EU Commission's platform for evidence-based policymaking

CANDLE: A project under the Cancer Mission with a time frame 2025-2028 that aims at facilitating the dialogue in establishing National Cancer Data Nodes.

CanSERV: An EU-funded project with a time frame 2022-2025 providing access to services from European research infrastructures to support cancer research.

Comprehensive Cancer Centers (CCCs): integrated infrastructures that combine cancer care, research, education, and training.

Data Altruism: The voluntary sharing of personal data for the common good, particularly for research and innovation.

Data Maturity Analysis: The process of assessing the readiness and quality of data for reuse, including its structure, documentation, and compliance with standards.

Digital Asset: any structured digital resource that supports cancer research including datasets, metadata, analytical tools, software services, and knowledge outputs.

ECPDC: European Cancer Patient Digital Centre – a digital platform to empower cancer patients and survivors with information, tools, and community support.

EDIC: European Digital Infrastructure Consortium – a legal instrument for implementing multi-country digital projects.

EEHRxF: European Electronic Health Record Exchange Format – a standard for cross-border exchange of electronic health records.

EHDS: European Health Data Space – an EU regulatory framework for secure and standardised access to health data for primary and secondary use.

EOSC: European Open Science Cloud – an EU initiative providing a federated environment for sharing and processing research data.

EOSC4Cancer: A project under the EOSC initiative with a time frame 2022-2025 that developed tools and services for cancer data sharing and analysis.

ERIC: European Research Infrastructure Consortium – a legal framework to support pan-European research infrastructures.

EUCAIM: is a flagship initiative under Europe’s Beating Cancer Plan, aimed at establishing a secure, federated European infrastructure for cancer imaging data.

EU-CIP: A project under the Cancer Mission with a time frame 2025-2029 that aims at implementing the ECPDC information portal.

FAIR: A set of principles to make data Findable, Accessible, Interoperable, and Reusable.

HDAB: Health Data Access Body – a national authority designated to evaluate and authorise access to health data for secondary use.

HDIE: Health Data Intermediation Entity – an entity that facilitates the technical and legal processes of data sharing between data holders and HDABs.

Health DCAT-AP: A metadata standard used to describe datasets in the EHDS dataset catalogue.

HealthData@EU: The central infrastructure under EHDS that enables discoverability and access to health data for secondary use across the EU.

Metadata Catalogue: A structured registry of metadata records that describe datasets, enabling their discoverability and reuse.

National Cancer Data Node: A designated national entity responsible for coordinating cancer data holders, ensuring data quality, and interfacing with the UNCAN.eu and EHDS ecosystems.

PREMs: Patient-Reported Experience Measures – data reflecting patients' experiences with healthcare services.

PROMs: Patient-Reported Outcome Measures – data reported directly by patients about their health condition and treatment outcomes.

SPE: Secure Processing Environment – a controlled digital space where authorised users can analyse sensitive health data without extracting it.

THDH: Trusted Health Data Holder – a designated organisation responsible for securely managing and providing access to specific types of health data.

UNCAN.eu platform: Understanding Cancer Platform – platform designed to enhance and facilitate the use of data in cancer research.

UNCAN-CONNECT: A project under the Cancer Mission with a time frame 2025-2030 that aims at implementing UNCAN.eu platform leveraging over several use cases.

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This report presents the recommendations of the eCancer Working Group, convened under the Cancer Subgroup of the Public Health Expert Group, to guide the European Commission in implementing two digital platforms: UNCAN.eu and the European Cancer Patient Digital Centre (ECPDC). These initiatives are flagships of Europe's Beating Cancer Plan and the Cancer Mission under Horizon Europe.

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