

# **ECI Magazine**

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Interest Grouping

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Oncology Days

17-19 June 2026 Warsaw, Poland

GENERAL ASSEMBLY  
SCIENTIFIC CONFERENCES  
AND RELATED EVENTS

In collaboration with  
Maria Skłodowska-Curie  
**National Research  
Institute of Oncology**



  
Organisation  
of European  
Cancer Institutes  
European Economic  
Interest Grouping



DEVELOPING  
THE FUTURE IN  
COMPREHENSIVE  
CANCER CARE



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Giovanni Apolone  
and Claudio Lombardo

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**OECI**  
**The largest Network  
of Oncology Centres  
in Europe and beyond**

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Brazil  
Bulgaria  
Chile  
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Croatia  
Cyprus  
Czech Republic  
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The Netherlands  
Turkey  
Ukraine  
United Kingdom  
Viet Nam

**Welcome of the OECI  
President: Middle-term  
Outcomes of the OECI  
Strategy 2024-2026**



**Giovanni Apolone**  
OECI President

At the General Assembly in Athens on the 13th of June, the last year of my mandate as President will begin. It is an honour and a great commitment to lead the largest organisation of cancer institutes in the world, which under my presidency has further expanded its membership not only in Europe, but also across all continents. In Paris, in 2023, I received the presidency from Professor Thierry Philip and announced that I would work to give OECI a strategy that could contribute to further strengthening our organisation's position in the European landscape. After a year of careful and demanding reflection and preparation, in Helsinki in 2024 I announced the strategy, which is based on five fundamental pillars on which we have begun to build opportunities that can create well-defined links with our Members:

- Continuous education on topics that prepare younger professionals to participate in the development of the European oncology research area.
- Involvement of new generations to prepare future managers and to gain from them the necessary contribution to the innovation process.
- Expansion of OECI's presence in other continents in order to demonstrate that the approach adopted by OECI is applicable in cultures and social situations that differ from the European one.
- Relaunch of OECI's contribution to the involvement of patients in a continuous relationship with oncology centres, ensuring their direct participation in the preparatory phases of the research activities that will involve them.
- Participation of OECI in major European research and public health projects with the involvement of our members.

One year after the announcement in Helsinki, all five pillars have been activated with initiatives that exceed our expectations and are well demonstrated by the articles included in this edition of the Magazine.

An important issue raised at the last plenary session in Helsinki remains to be defined: the need to think about a way to return to the Members, more than has been done so far, part of the scientific, educational and possibly also economic benefits generated by the OECI. There are, of course, several possibilities: from support for centres in economic or political crisis to support for accreditation and improvement programmes. This will make the 'added value' of being part of our community more objective.

I would also like to point out that communication activities have been strengthened horizontally across all five pillars, although I believe a more structured approach is necessary to better equip us to face future challenges and the ambitious goals that we have set, in which communication plays a crucial role.

The Oncology Days in Athens mark a new starting point, both to achieve the goals we have set and to address new issues such as artificial intelligence in diagnostics and treatments - sectors that remains underexplored and certainly deserves greater attention from OECI. Furthermore, there is a need to build strategic alliances with entities that do not always belong to the oncology community.

I hope that the new paths forged during my presidency will continue to evolve, enriched by additional ideas linked to the pillars we have firmly anchored to a foundation of knowledge and organisational expertise. However, these still require continuous contributions from all members to demonstrate that a bottom-up approach is fundamental to the development of a research and care system that cannot be top-down imposed.

OECI operates independently of political or industrial influences. This autonomy allows us to act with the sole purpose of providing our patients with the best available care and ensuring that, over time, the majority of patients receive treatment in highly specialised centres, certified through a quality assessment process based on qualitative and quantitative criteria, established by widely accepted standards within the oncology community, involving cancer centres, oncology organisations and patients.

I wish everyone an enjoyable read of this edition of the Magazine.

# OECI World Network: A New Working Party within OECI

**Thierry Philip<sup>1</sup>, Claudio Lombardo<sup>1</sup>, Karim Fizazi<sup>2,3</sup>, Cristian Ayala<sup>4</sup>, Victor Piana de Andrade<sup>5</sup>**

1. Organisation of European Cancer Institutes, OECIWORLD Programme. Chairperson

1. Organisation of European Cancer Institutes, General Manager

2. Organisation of European Cancer Institutes, OECIWORLD Programme, Co-Chairperson

3. Gustave Roussy, Paris, France

4. Instituto Oncológico Fundación Arturo López Pérez (FALP), Santiago, Chile, General Manager

5. A.C. Camargo Cancer Center, São Paulo, Brazil, Chief Executive Officer

## Background

As of early 2025, the Organisation of European Cancer Institutes (OECI) counts 12 Associate Members Type B, representing cancer centers outside the European Union. These centers are located in Algeria, Brazil, China, Jordan, Lebanon, Moldova, Tanzania, Turkey, Ukraine, Vietnam, Chile, and Bolivia. Recognizing their importance, the OECI Board tasked the former president of the OECI General Interest Group (GIE) with strengthening ties between these centers and European counterparts.

## The Birth of the OECI World Network

In mid-2024, initial meetings with the Associate Members were conducted both in person (Ukraine, Brazil, Tanzania, China, and Chile) and via videoconference (Lebanon, Jordan, Colombia, Vietnam, Moldova, Turkey, and Algeria). These discussions culminated in a formal gathering held in Milan, Italy, from September 10–12, 2024, at Villa Veronesi.

All centers, except Vietnam and Colombia (who later signed the agreement), participated and signed a Memorandum of Understanding, officially establishing the OECI World Network.

## Objectives of OECI World

The following objectives were defined for the newly formed network:

### Objective 1: Quality Standards and Accreditation

- A diagnostic assessment of each center’s readiness for OECI accreditation was conducted.
- Accreditation Status Updates:
- FALP in Santiago, Chile, is already OECI-accredited.
- Centers in Brazil (AC Camargo), Jordan (King Hussein Cancer Center), and Moldova (Chisinau Cancer Institute) are preparing to apply in 2025–2026.
- Guangzhou Cancer Center (China) aims for accreditation in 2027.
- Ukraine’s Kiev Cancer Center plans to apply after the war ends.
- Lebanon will first complete JACIE accreditation.
- Other centers are expected to define application timelines by the end of 2025.

### Objective 2: Support for a South American Sister Organization

In November 2024, a meeting in Santiago de Chile led to the establishment of OLACI (Organización Latinoamericana de Institutos del Cáncer). Founding members include:

- FALP (Chile)
- AC Camargo (Brazil)
- National Cancer Institute of Bogotá (Colombia)
- AUNA (Peru)
- SOLCA (Ecuador)
- Goias Cancer Center (Brazil)

The Alexander Fleming Cancer Institute (Argentina) will join as a founding member.

### Objective 3: Fostering Relationships

The network aims to strengthen collaboration both among OECI World members and between OECI World members and European centers.

Preliminary partnerships include:

- Algeria: Linked to Gustave Roussy and Jules Bordet Institutes.
- Lebanon: Linked to Institut Curie and Jules Bordet.
- China: Linked to Unicancer and Hanoi K Hospital.
- Jordan: Linked to DKFZ, Curie, and AC Camargo Institutes.
- Moldova: Linked to Cluj Cancer Institute and Curie.
- Tanzania: Linked to Institut Curie.
- FALP (Chile): Linked to AC Camargo and OLACI members.

Further structuring of these partnerships is ongoing.

### Objective 4: Collaborations with IARC and WHO

Representatives from IARC and WHO participated in the Milan meeting, initiating discussions on collaborative efforts in the 12 countries represented by OECI World.

## New Objectives for 2025

1. Site Visits: Visits to Algeria, Tanzania, Moldova, and Brazil will be conducted to assess local challenges and accreditation readiness.
2. European Visits:
  - FALP will visit European centers to explore fundraising strategies.
  - Tanzania will visit to focus on quality improvement practices.
3. Accreditation Applications:
  - King Hussein Cancer Center (Jordan) and AC Camargo Cancer Center (Brazil) will apply for OECI accreditation in 2025.
4. Preparation for Accreditation: Centers in China (Jinshazhou Hospital), Vietnam (Hanoi K Hospital), Tanzania (Aga Khan Hospital), and Moldova (Chisinau Cancer Institute) are working to meet accreditation standards.
5. Strengthening Relationships: Collaborative efforts between OECI World members and European centers will be prioritized in 2025.
6. OLACI Development: The South American network will continue to expand its membership and refine its objectives.
7. IARC and WHO Collaboration: Enhanced engagement with IARC and WHO will ensure alignment with global cancer initiatives.

## Conclusion

The creation of OECI World represents a significant step in addressing global disparities in cancer care. The network delivers a strong message of inclusion and support to Associate Members, fostering international collaboration and quality improvement in cancer care. By connecting centers from diverse regions with European expertise, OECI World aims to advance cancer care globally through shared goals, mutual support, and an unwavering commitment to excellence.

“We care.”



# OECI Academy – Empowering the Next Generation of Cancer Researchers

Launched in January 2025, the OECI Academy is a strategic initiative aimed at supporting the professional development of early-career scientists and oncologists across Europe. By offering structured educational opportunities within the framework of EU research and health programmes, the Academy strives to equip emerging professionals with the scientific, technical, and soft skills essential for impactful cancer research and improved patient care.

Following a successful kick-off webinar in January with participants from 15 European countries, the Academy introduced a four-part online training series focused on grantsmanship.

## The Academy Leadership



Claudio Lombardo



Chiara Gabbi



Per Anders Sandström



Carla Finocchiaro

The Academy's flagship initiative in 2025 is its first in-person residential training, taking place from 8–10 October at the Fondation Universitaire in Brussels. The course, How to Develop and Write a Successful Grant Application, offers a comprehensive, hands-on learning experience. Through expert-led lectures, collaborative group work, and individual assignments, participants will gain the tools to design compelling, fundable research proposals.

Applications are open until 15 July 2025. OECI will award 25 full and 25 partial bursaries.

Learn more at <https://www.oeci.eu/OeciAcademy.aspx>



# The New OECI Young Board: who we are and goals for the future

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2. Mater Private Network, Dublin, Ireland

3. Helsinki University Hospital, Helsinki, Finland

4. KU Leuven, Belgium

5. AUSL IRCCS Reggio Emilia, Italy

The **Organisation of European Cancer Institutes (OECI) Young Board** is a newly established entity, aimed at engaging early-career professionals to contribute to the development of the future of cancer research and care across Europe. By empowering young scientists and health care professionals, the Young Board will ensure that the perspectives and needs of younger professionals are represented in OECI's efforts to advance oncology.

The aim of this group is to strengthen collaboration, innovation, and professional development within the OECI network. In June 2025, a representative of the new Board will present to the OECI Board on the establishment, purpose, and goals of the Young Board during the OECI Oncology Days in Athens. This will mark a significant moment for the next generation of potential oncology leaders.

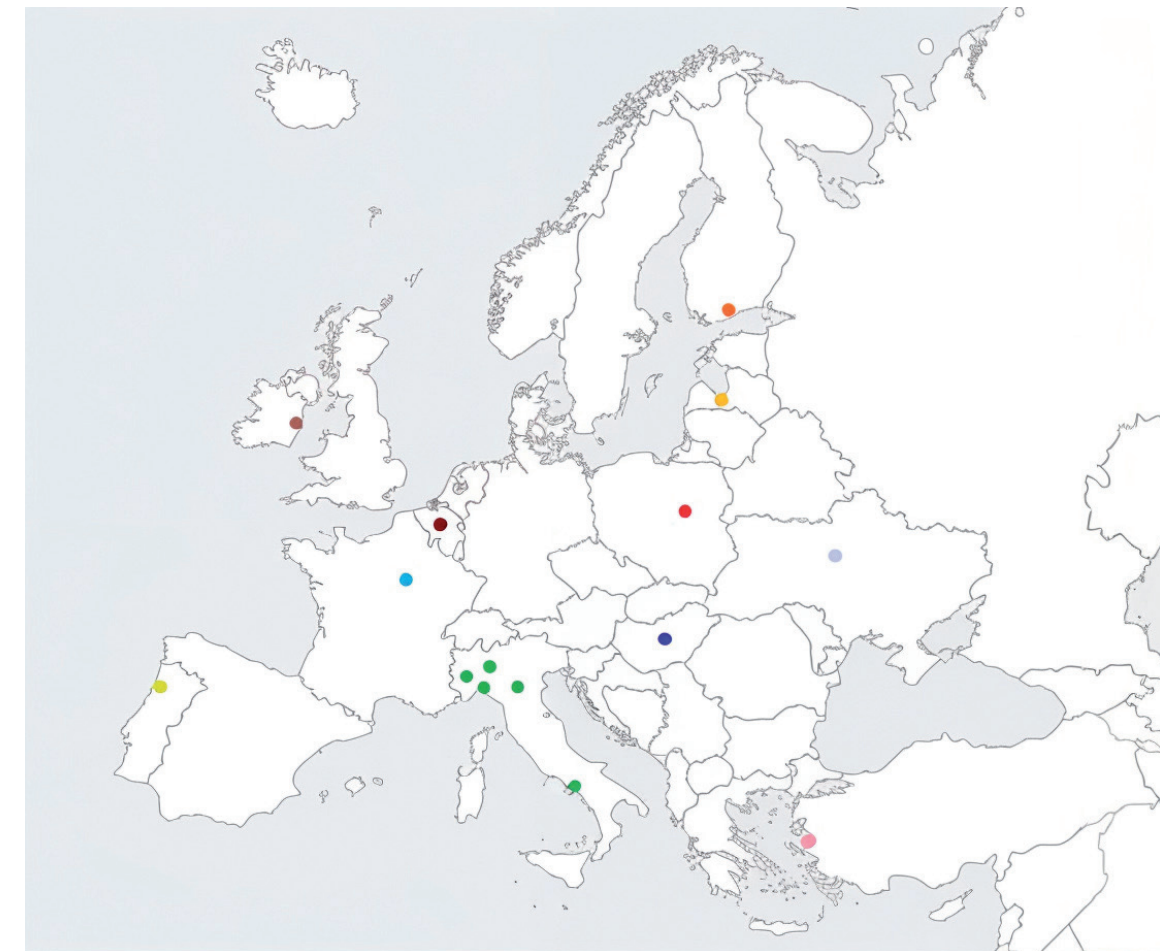


Figure 1. Countries and Institutions represented in the OECI Young Board

Creation of the OECI Young Board

The **OECI Young Board** has been created to address the growing need for early-career professionals to have a more prominent role in decision-making and future planning within the OECI community. The Board consists of young professionals from several European countries including Belgium, Finland, France, Hungary, Ireland, Italy, Latvia, Poland, Portugal, Turkey, Ukraine (Figure 1).

- LEUVEN CANCER INSTITUTE – KU LEUVEN, Leuven, Belgium
- HUS, Helsinki, Finland
- INSTITUT CURIE, Paris, France
- NATIONAL INSTITUTE OF ONCOLOGY, Budapest, Hungary
- TRINITY ST JAMES CANCER INSTITUTE, Dublin, Ireland
- MATER PRIVATE NETWORK, Dublin, Ireland
- IRCCS OSPEDALE POLICLINICO SAN MARTINO, Genoa, Italy
- OSPEDALE SAN RAFFAELE, Milan, Italy
- FONDAZIONE INT, Milan, Italy
- IRCCS POLICLINICO SAN MATTEO, Pavia, Italy
- ISTITUTO NAZIONALE TUMORI- IRCCS G. PASCALE, Naples, Italy
- AUSL IRCCS REGGIO EMILIA, Reggio Emilia, Italy
- CANDIOLO CANCER CENTRE, Turin, Italy
- P. STRADINS CLINICAL UN. HOSPITAL, Riga, Latvia
- INSTITUT CURIE WARSAW, Warsaw, Poland
- IPO PORTO, Porto, Portugal
- DOKUZ EYLUL UN. INSTITUTE OF ONCOLOGY, Izmir, Turkey
- RE KAVETSKY IEPOR, Kyiv, Ukraine

These members bring together a wide range of expertise from different fields of cancer research, clinical care, and policy, creating a dynamic and multidisciplinary team.

The creation of this board represents a key step towards a more inclusive, collaborative, and innovative environment within OECI, where young professionals can play an active role and bring their vision of the future of cancer care across Europe.

Purposes

The OECI Young Board is currently in the process of defining the agenda, setting detailed goals, and outlining the strategic direction for the coming years. This includes the formulation of terms and conditions that will guide our activities and initiatives moving forward. The following main topics have already been identified as key focus areas for the work of the board (Figure 2).

What’s Next

The creation of the **OECI Young Board** represents a significant step for the active inclusion of early-career professionals in shaping the future of cancer research and treatment. Through collaboration, education, and commitment, it aims to contribute to and shape the oncology community.

Working alongside the OECI Board, the Young Board will be committed to the overall mission of OECI, particularly by increasing collaboration, providing professional development opportunities, and advocating for the needs of young scientists. The group will work by meeting regularly to ensure further development of its goals, and the smooth progress and follow-up of the goals set.

The Oncology Days 2025 in Athens will be a key moment to present the creation of this new academic group, to listen to your ideas and engage with the broader OECI community. We look forward to playing our role and making our contribution.



Figure 2. Key focus areas of the OECI Young Board



# CCI4EU: the Deep Dive capacity building experience

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4. Organisation of European Cancer Institutes, President  
5. Istituto Nazionale Tumori di Milano, Italy, Scientific Director

In a previous article (include reference to previous OEI Magazine) we have given an introduction to CCI4EU (Comprehensive Cancer Infrastructures for the EU) and explained the background to the definition of Comprehensive Cancer Infrastructures, the development of the Maturity Model, and an outline of the different capacity building interventions the Action has designed.

One the principal capacity building interventions, and certainly the one which is most labour-intensive, has been dubbed “Deep Dives”. This article seeks to explain the process of this kind of intervention and how it is working.

The intention of the Deep Dives is to provide ‘target’ prospective CCIs with a one year programme of in depth consultancy by experts in the chosen fields of intervention. These experts are drawn from Cancer Centres, mainly belonging to the beneficiary organisations in the consortium. Each Deep Dive consists of 3 site visits or approximately 3 days each, interspersed with videoconferences and exchanges of information.

The first process was to select consultant experts from the beneficiary organisations. These experts needed to have skills and experience which crossed the 8 Themes of the Actions, being:

- 1. Comprehensive Cancer Infrastructure
- 2. Comprehensive Cancer Centre
- 3. Interfaces between research and care
- 4. Discovery and translational research
- 5. Clinical research
- 6. Outcomes research
- 7. Screening and early detection
- 8. Patient Pathways

A call went out to the beneficiary organisations, with suggestions for expertises required. Candidates were required to submit a CV, and to signify that they would be available for up to 22 days work allotted to a particular Deep Dive site. The candidates/ CVs were scrutinised by a subcommittee of the relevant workpackage of CCI4EU, and 95 experts were chosen covering a multiplicity of fields:

Domain	Number of experts
Clinical Trials	29
Specifically, Early Phase trials	12
Translational research	32
Outcomes and Implementation Research	24
Data science and IT	16
Innovation processes and technology transfer	16
Education and Training (research)	24
Education and Training (clinical)	30

Medical Oncology	19
Radiation Oncology	11
Surgical Oncology	4
Pathology including molecular pathology	4
Radiology including nuclear medicine	5
Precision cancer medicine	18
Haemato-Oncology	7
Paediatric Oncology	2
Governance and management	29
Quality management	17
Cancer screening	14
Public health and primary prevention	8
Population Cancer Registries	9
Technical patient pathway design	8
Patient involvement and empowerment	23
Oncology Nursing	10
Survivorship and rehabilitation	7
Patient pathway coordination	14
Palliative and supportive care	11
Psycho-oncology	12
Benchmarking	7
Health Economics	7
National Cancer Strategies	21
Consultancy and/or mentoring in change management	16

The next step was to select the CCI sites to receive the Deep Dives. This was a complex process which began with the population of the Maturity Model by prospective CCIs. 39 CCIs answered the questionnaire in whole or in part by 31 May 2024. Immediately thereafter a selection committee drawn from the workpackage leading institutions clustered the replies according to degree of maturity and drew up a shortlist for intervention. The committee was guided by a number of principles. The most important of these was to give priority to less mature CCIs within central and eastern Europe. The second principle was that the CCI had completed most of the modules of the maturity model. Thirdly was a principle to provide variety of context and of requested themes of intervention.

The selection committee came up with a shortlist of 12 CCIs. These were then interviewed by another subcommittee of the action to assess their readiness to receive a Deep Dive. The theory here was that there is no point in mobilising up to 10 experts for 3 site visits and an investment of around €350,000 each if the target site is not ready or able to make effective use of the intervention. The interviews were structured and lasted 90 minutes each. At the end of this process, 10 Deep Dives were chosen and one ‘mini dive’ (the latter a paediatric network in France).

These CCI were as follows:

	Estonia	Croatia	Slovakia	Spain (Basque)	Romania Moldova	Czech	Italy (Piedmonte)	North Portugal	Ireland	Bulgaria
Structure of CCI										
CCC										
Interfaces										
Discovery & translational research										
Clinic research										
Outcomes research										
Screening & early detection										
Patient pathways										

The table shows not only the choice of the Deep Dive sites (Member States or regions or Member States) but also the theme of intervention chosen for intervention. It will be seen that some Deep Dive sites cover a whole Member State (for instance, Estonia) and in other cases a province of a larger country (such as Piedmonte and Val D'Aosta, in Italy).

The successful CCI sites were informed, and asked to form project teams to receive the intervention. A small budget was allocated by the Action to each CCI in order to fund a project coordinator at their end, with a specific job description. Similarly, each Deep Dive was allocated a Project Manager from within the beneficiaries of the Action. These individuals were especially chosen for their project management expertise. Then the experts were allocated to each Deep Dive CCI by matching their skills and experience per the CVs with the requested intervention by that site. Finally, chairs of the expert teams were chosen by the leaders of the relevant workpackage. Each chair (5 male; 5 female) was chosen as having substantial experience in leading multiprofessional teams in cancer.

The Deep Dive sites were all asked to sign a contract for the Deep Dive setting out expectations and requirements, and the experts all signed confidentiality agreements and conflict of interest documents.

The next stage of the planning was to orientate and coach the expert teams. This was done by means of an initial videoconference in May 2024, and then a 2-day face to face Conference in Milan on 3-4 September 2024. In that conference, not only were the aims and objectives of CCI4EU explained to all, but the themes were unpacked, and there were initial meetings of each expert team and their project manager. Finally, coaching was provided by an independent consultancy firm specialising in change management, introducing experts to common change management techniques which they would require.

The first Deep Dive visits (or approximately 3 days each) took place in November-December 2024, and interim reports were written by the expert teams (with input from the CCIs).

The feedback was that these visits were very intensive, but that they largely achieved the stated aims for a first visit. Those initial aims were:

- 1) That a SWOT analysis was mutually completed by the expert team working with the local experts, for each theme of intervention, and:
- 2) SMART objectives were set for each theme of intervention, for implementation during the 12 months of the intervention, linking each objective to the target level of the criteria of the maturity model for that CCI.

Some of the recipient Deep Dive CCIs were able to report back their responses directly to external reviewers of the project. These feedbacks confirmed that progress towards the agreed objectives was being made. The main scientific themes arising from the first visits are given in the tables below:

Theme	Main issues
CCI structure	1. Formalizing the collaboration (existing template) 2. Neutralising the fear of small centres to collaborate 3. IT systems across CCI 4. Budget for the CCI 5. Quality assurance
CCCs	1. Quality assurance 2. Continuity of case outside CCC 3. Patient involvement
Interfaces and data	1. Collabotation agreements 2. Data flux between and within instructions 3. Primary structured data in EMR 4. Regulations and synchronisation of data 5. Common research admin platform in CCI
Discovery and traslational research	1. Forming a DTR unit 2. Data sets ( connection to clinical databases - primary data structure) 3. Budget
Clinical Research	1. Clinical Trials Units 2. Acces to entire CCI 3. Regulation burden, contracts etc 4. Data protection issues 5. Patient involvement
Outcomes research	1. Standard set of questionnaires 2. Routine practice 3. Integration into IT System
Screening and Early Detection	1. Staff and Budgeting 2. Standardization of recommendation across CCI 3. Competition public vs private re screening 4. Communication with public
Patient Pathways	1. Creation of patient pathways 2. Key performance indicators 3. Quality assurance and indicators 4. Extention from CC/CCC to CCI (out of hospital care) 5. IT support for real time dashboards

At the time of writing, the second wave of site visits is underway (March-April 2025). The objectives of these second visits are to make progress on the SMART objectives agreed in the first site visit, working together with the local teams. In many Deep Dives this second visit is involving more travel within the locality of the CCI – visiting hospitals and Universities away from the Member State/Provincial capital, sometimes travelling more than 300 kms encompass the whole of that CCI.

The next steps are that the third site visits will take place in September/October 2025, and after that final reports will be written on the impact of the capacity building interventions. At the same time, the CCIs will be asked to re-score their maturity model, and to signify what improvements have been made to the levels of maturity in the chosen domains of intervention. These scores will then be correlated to the effort required in making the intervention, as part of the Global Efficacy Score of the project. A summary of the 10 Deep Dives' final reports is a deliverable of the CCI4EU project, in early 2026.

Altogether, the Deep Dives are probably one of the largest mobilisations of cancer experts to deliver onsite consultancy ever achieved within Europe.



# Making the EUonQoL project a reality through applied implementation

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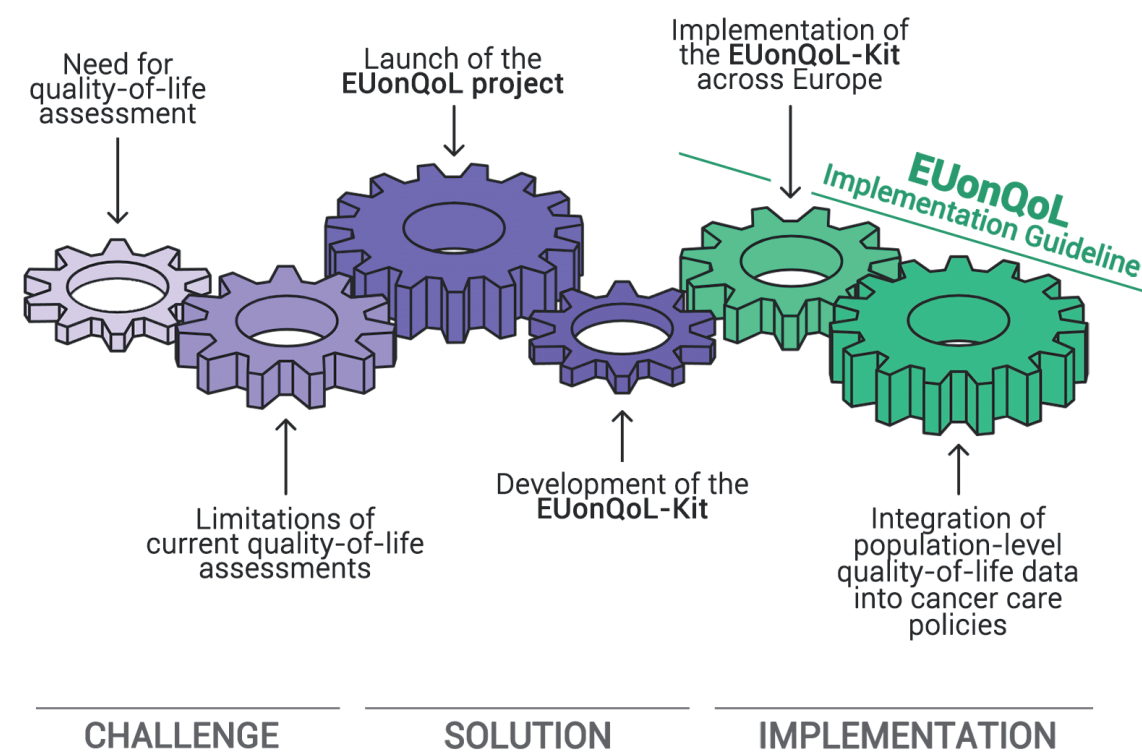


Figure 1. From challenge to solution, from solution to implementation

## From challenge to solution

Although cancer is increasingly managed as a chronic condition, where those affected benefit from follow-up care addressing biological, psychological, and social needs, health policy decisions continue to emphasize biomedical indicators (e.g., survival, treatment, and cure rates) to determine effectiveness. This emphasis persists despite extensive research demonstrating what it means to live well with chronic conditions and the benefit of incorporating biopsychosocial or patient-centred models into clinical practice across the cancer care trajectory [1-5]. While quality of life is the overarching quantifiable indicator within these models, it remains underrepresented in policy evaluation with no apparent justification for its omission.

Indeed, the existing cancer-related policies have substantially improved survival and added years to life for many. However, merely prolonging life is no longer a sustainable healthcare strategy; we must also adopt policies that ensure (quality of) life is added to years by reducing health-related burdens [6]. Such cancer care policies not only benefit patients and caregivers but can also mitigate the long-term need for healthcare resources, indirectly contributing to healthcare sustainability.

Collecting standardized quality-of-life data and aggregating it at the population level (regional or national) is essential; on one side, to identify what truly matters to patients and survivors and, on the other, to evaluate the progress and effectiveness of national and global health initiatives. Global initiatives include but are not limited to the World Health Organization's Health System Performance Assessment Framework [7] and Universal Health Coverage [8], the United Nations' Sustainable Development Goals [9], and the European Commission's Mission on Cancer [10] and Europe's Beating Cancer Plan [11]. Altogether, this underscores the pressing need for a robust methodology capable of systematically and accurately capturing quality-of-life data.

Currently, there is no European-wide adopted "gold standard" quality-of-life assessment tool. While well-established assessments such as EQ-5D-5L [12] and EORTC QLQ-C30 [13] exist, these instruments were developed several decades ago. Consequently, they often either insufficiently capture cancer-specific lived experiences or lack the cultural and linguistic adaptability necessary for reliable pan-European comparisons [14].

The EUonQoL project (January 2023 – December 2026) [15], funded under Horizon Europe and aligned with the Mission on Cancer and Europe's Beating Cancer Plan, is developing the EUonQoL-Kit, a novel benchmarking tool designed to become Europe's standardized measure for collecting population-level quality-of-life data. Coordinated by the Fondazione IRCCS Istituto Nazionale Tumori di Milano (Italy), the project is a consortium of 27 partners across 32 countries. The EUonQoL-Kit will assess quality of life across the entire cancer care continuum, i.e., active treatment, survivorship, and advanced disease, and is developed using a co-design methodology that integrates insights from individuals with lived cancer experience, clinicians, scientific experts, and other key stakeholders. This collaborative approach ensures that the questions within the EUonQoL-Kit directly reflect the experiences and priorities of those most affected by cancer. Additionally, the questionnaires are carefully adapted and translated to ensure cultural relevance and linguistic appropriateness across Europe.

In order to ensure widespread adoption of the EUonQoL-Kit and facilitate the use of population-level quality-of-life data for European-wide health policy decision-making, the EUonQoL project is developing a web-based implementation guideline, the EUonQoL Implementation Guideline (EUonQoL IG). This guideline is country-specific and designed to accommodate Europe's diverse healthcare systems, cultural contexts, digital infrastructures, data governance, and demographic characteristics. In addition to providing practical guidance for implementing the EUonQoL-Kit and effectively utilizing its collected data at the national level, the EUonQoL IG also aims to support European-level policymakers in integrating population-level quality-of-life data into overarching cancer care policies. While the EUonQoL IG is still under development, we aim here to describe its methodology and outline the upcoming steps.

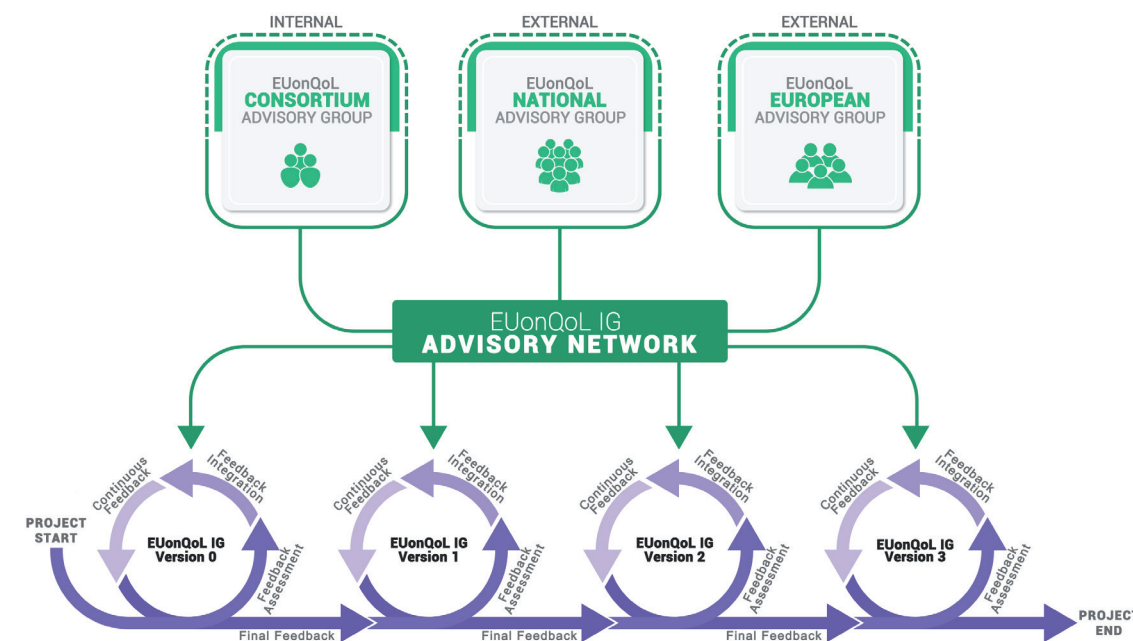


Figure 2. Overview of the iterative development of the EUonQoL Implementation Guideline (EUonQoL IG) and the feedback collection through the EUonQoL IG Advisory Network

## From solution to implementation

The EUonQoL IG is being developed iteratively through multiple versions. This iterative approach involves continuously gathering and integrating feedback from internal consortium members and external stakeholders representing diverse professions and countries. External stakeholders (e.g., policymakers, clinicians, researchers, and individuals with lived experience of cancer) are organized into two advisory groups: the EUonQoL National Advisory Group and the EUonQoL European Advisory Group. The national group provides country-specific insights into implementing the EUonQoL-Kit within individual countries, whereas the European group advises on matters concerning European-level policies and frameworks. Together with the internal EUonQoL Consortium Advisory Group, these groups form the EUonQoL IG Advisory Network, which serves as the primary source of iterative feedback for refining the EUonQoL IG (Figure 1).

The feedback collected from the EUonQoL IG Advisory Network addresses both the usability (e.g., structure, navigation, user-friendliness) and content (i.e., general and country-specific implementation guidance) of the EUonQoL IG. It also ensures that supplementary materials, such as descriptions of the EUonQoL-Kit's development and validation processes, remain clear and accessible. This iterative methodology follows a cyclical feedback loop in which insights drive refinements, prompting additional feedback from the advisory groups – an approach drawing on agile methodologies and evidence-based implementation strategies [16–21] (Figure 2). More detailed information about this process can be found in the EUonQoL report “D8.2 – Iterative scoping rounds and Implementation guidelines” [22].

The EUonQoL IG content offers practical guidance within two key dimensions: (1) a technical dimension, which provides step-by-step instructions for nationwide integration of the EUonQoL-Kit, and (2) a system-level dimension, focusing on proactively identifying and overcoming barriers to effectively incorporate population-level quality-of-life data into cancer care policies. The consequences of not adequately identifying and addressing system-level barriers were illustrated during the COVID-19 vaccine rollout, where inadequate infrastructure and administrative capacity resulted in resource wastage of up to 30% [23]. These lessons motivated the development of an implementation readiness assessment designed to identify and overcome the barriers hindering successful systematic implementation. Failure to determine readiness and adapt strategies accordingly may result in substantial resource expenditure with minimal or no tangible outcomes.

Similarly, we believe such an implementation readiness assessment methodology (i.e., a structured approach for identifying and mitigating potential barriers) is essential to support the successful national and European-wide rollout of the EUonQoL-Kit (or any other population-level quality-of-life assessment tool). While comprehensive research on various implementation barriers linked to population-level quality-of-life assessment tools is needed, we have already identified several. These include, but are not limited to, governance and healthcare structures, digital infrastructure, data governance and privacy, representative participation, effective communication strategies, and public trust in healthcare and governmental institutions.

Additionally, based on the advisory groups' feedback, four interrelated dimensions of willingness emerged as critical for implementation readiness: (1) national-level willingness among policymakers and healthcare authorities to adopt the EUonQoL-Kit, (2) individual willingness among citizens to complete the EUonQoL-Kit questionnaires, (3) institutional willingness among healthcare providers and researchers to collect, analyse, and interpret population-level quality-of-life data, and (4) policy-level willingness among European, national, and regional policymakers to integrate this insight into cancer care policies.

Considering that European countries face healthcare workforce shortages and resource constraints, we believe a proactive implementation readiness strategy is paramount. Establishing an implementation readiness assessment based on the identified barriers and dimensions of willingness can enable countries to adopt the EUonQoL-Kit end-to-end while effectively mitigating potential resource wastage. As this implementation readiness assessment is currently at a conceptual stage, further research is necessary to validate and refine the selected criteria to ensure accuracy and comprehensiveness, as well as studies to demonstrate its practical usability in a real-world setting.

## Conclusion

In summary, systematically measuring the population-level quality of life among individuals with lived experience of cancer is essential for the implementation of tailored national, European, and global cancer care policies. The EUonQoL project not only aims to deliver a standardized, reliable tool (the EUonQoL-Kit) for capturing these data but also seeks to provide countries with a structured, adaptable, and practical approach to its implementation. By proactively addressing technical, systemic, and strategic barriers, the EUonQoL Implementation Guideline can facilitate the true implementation of quality-of-life insights into cancer care policies across Europe's diverse healthcare contexts and sociodemographic landscapes.

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# ALTHEA: digital technologies for psycho-oncological assessment and support throughout the cancer journey

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## The psychological burden of cancer diagnosis

According to the World Health Organization (WHO), cancer is the second leading global cause of death<sup>1</sup>. Oncological diagnoses are increasing all over the world, with over 2.7 million new cases and 1.3 million deaths reported in 2022<sup>2</sup>. The consequences of cancer not only extend to the purely physical sphere, but also profoundly affect mental and emotional well-being and cognitive functioning. Some patients describe the cancer diagnosis as a potentially traumatic experience that drastically changes their lives. For example, personal goals can be altered due to the treatments' side effects, and daily activities can require a necessary reorganisation. Patients frequently report distress, anxiety, and depression after their diagnosis<sup>3,4</sup>, and cognitive dysfunctions (such as alteration of attention and memory or insomnia) can occur at any stage of the cancer journey, from diagnosis and treatment to survivorship and beyond<sup>5</sup>.

Despite existing evidence, many cancer patients, survivors, and their caregivers do not receive the psychological support they need. This might be due to a lack of awareness, but also to internal and external barriers. For example, some patients or caregivers avoid seeking support due to cultural and socio-demographic factors such as stigma, religion, or low education<sup>6</sup>. As a matter of fact, mental health is still burdened by significant stigma, and cancer patients may fear being judged unstable if they admit feeling emotional difficulties. They may also fear being "difficult patients" from the perspective of their healthcare providers or family members, which may compromise their care<sup>7</sup>. On the other hand, fatigue, pain, and the significant treatment's side effects can lead some cancer patients to minimize mental health problems, focusing on physical treatment, believing their emotional difficulties are justifiable given the circumstances and burdens. Therefore, it is essential to raise awareness about mental health in cancer patients, reduce the stigma associated with seeking help, and ensure easy and timely access to psychological support services.

Recognizing the multiple barriers hindering cancer patients from seeking psychological support, research and clinical practice are moving towards the development of new care tools, particularly digital ones. Recent studies have tested the effectiveness of digital technologies, such as apps and online platforms, which offer, for example, various psychoeducation programs to enhance understanding of mental health disorders and their symptoms, helping patients recognize their effective needs<sup>8</sup>. The integration of these digital technologies into cancer care can support a more comprehensive recognition encourage patients to recognize their psychological and cognitive issues, and emphasize the importance of mental well-being and psychological support in the cancer journey<sup>9</sup>.

## What ALTHEA aims for

The ALTHEA project, co-funded by the European Union under the EU4Health program, is coordinated by Prof. Gabriella Pravettoni at the European Institute of Oncology (Milan, Italy), involving a vast consortium of 29 partners from across Europe. This project aims to develop and implement a web-based platform for the psychological and cognitive screening of cancer patients/survivors and their families, while supporting healthcare providers in delivering tailored psychological support.

The ALTHEA platform will support the identification of patients at risk of experiencing psychological and cognitive impairment during their cancer journey through a specific personalized assessment. Based on these results, patients and caregivers will receive evidence-based and personalized information, including self-help resources, educational materials, and the available psycho-oncological treatment options. Furthermore, the platform will provide healthcare professionals with the necessary tools and resources to identify and address mental health issues in their cancer patients, survivors, and caregivers. In other words, the ALTHEA project aims to improve

the well-being and quality of life of people affected by cancer, survivors and their families by providing timely, personalised and accessible educational materials and psychological support.

Throughout the project, an in-depth analysis of the current landscape will be conducted, identifying the needs and challenges of patients and healthcare professionals regarding mental health screening and psychological support, laying the foundation for developing robust guidelines and standardised care procedures. Identifying possible disparities in mental health screening and support will help to ensure equitable access across diverse populations. To achieve this, the researchers map the capabilities, capacities, and patient care procedures regarding psychological/cognitive screening and support in targeted countries.

The **Organisation of European Cancer Institutes (OECI)** will help the exploration of adherence to existing psychological assessment and support guidelines in comprehensive cancer centres, identifying areas for improvement. In this regard, **a survey will soon be disseminated to OECI centres** for the purpose of mapping information regarding psycho-oncological treatments and the existing standards of care. These efforts will culminate in the development of clinical recommendations for psychological assessment and support, providing a standardised framework for high-quality standards of care.

At the heart of ALTHEA is the creation of an integrated digital platform featuring personalized psychological and cognitive assessments and access to educational resources, and communication with healthcare professionals, while offering clinicians a decision support system for managing the results of the risk stratifications. The effectiveness, adoption and sustainability of this platform will be rigorously evaluated using both quantitative and qualitative methods.

## Conclusion

According to the World Health Organization (WHO), cancer is the second leading global cause of death<sup>10</sup>, with significant consequences not only on the physical side but also on the emotional and psychological well-being. Along with the management of cancer, patients may experience negative emotions such as anxiety, depression, emotional distress, and fear of cancer recurrence. Also cognitive impairments, such as alteration in memory or attention, could be faced by patients during the cancer pathway, impacting their well-being. The profound impact of the oncological diagnosis extended far beyond patients, including also dedicated caregivers and families. Additionally, caregivers often report emotional burdens and unmet needs that significantly impact their quality of life. Despite this, not always cancer patients and their carers ask for support.

In this context, the ALTHEA project aims to fill these gaps by developing and implementing an innovative digital platform designed to facilitate systematic mental health screening, provide personalised support and improve access to educational resources for patients, caregivers, and healthcare providers. By exploiting digital technologies and adopting a user-centred approach, ALTHEA has the potential to improve the cancer care landscape, enabling patients and their families to face the care pathway with greater adherence and an overall positive impact. ALTHEA is committed to addressing not only the immediate challenges, but also the long-term sustainability of its initiatives, by assessing the scalability, durability and integration of the future results into existing health systems. This focus on sustainability aims to ensure that efforts to address gaps in psycho-oncological care remain effective and accessible for future generations.

In conclusion, ALTHEA represents a significant step forward in providing comprehensive and personalised mental health care for cancer patients and their families across Europe. Through digital innovation, collaborative synergy and user-centred implementation, ALTHEA aims to improve the paradigm of psychological care for cancer patients.



ALTHEA Kick-off Meeting

## Contact details

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# Introducing Next Generation Sequencing in daily clinical practice in Oncology

## Challenges in Technology Assessment and Coverage

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### The Instand-NGS4P Project – aims and challenges

Instand-NGS4P is an EU-funded Pre-Commercial Procurement (PCP) project for improving cancer patient's benefit from Next Generation Sequencing (NGS) by developing integrated and standardized NGS workflows for common and rare cancers in adults and children. To enable companies to join and develop products separately in different parts, the workflow was divided into four parts.

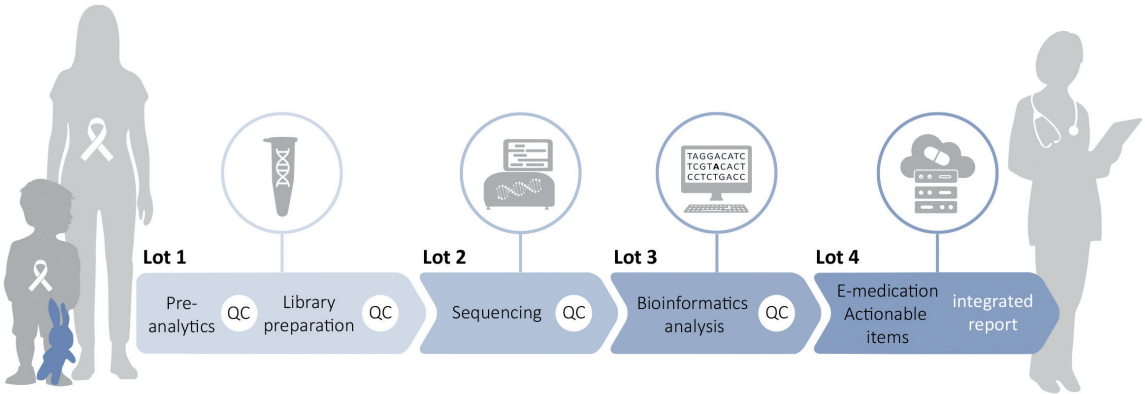


Figure 1: Instand-NGS4P workflow divided into 4 different Lots

The project is based on patients' and users' (i.e., clinical) needs) which were identified during an extensive Open Market Consultation of relevant stakeholders, and addresses certain specific challenges including that the final solution should cover a complete NGS workflow from collection of samples from patients to the support of decision making at the bedside and producing reports optimised for clinicians and patients respectively. Efforts towards improving the reliability of NGS results include contribution to 2 new CEN Technical Specifications, which are currently being developed into ISO standards:

**CENTS 17981-1:2023 In vitro diagnostic Next Generation Sequencing (NGS) workflows – Part 1: Human DNA examination**

**CENTS 17981-2:2023 In vitro diagnostic Next Generation Sequencing (NGS) workflows – Part 2: Human RNA examination**

As the workflow should be used for medical diagnosis it has to comply with requirements of the European in vitro diagnostic medical device regulation (IVDR), that came into force in 2022 with a transition period for Class C category devices until 2028.

The workflow includes the analysis of cancer-related genetic alterations as well as the analysis of pharmacogenomics variants in order to increase the patient's benefit from NGS. An additional challenge is that the solutions to be



developed should also be suitable for rare cancers, for some of which no CE marked IVD will be developed because of economic reasons. Therefore, these should on the one hand be compliant with IVDR for IVDs manufactured by industrial manufacturers, and on the other hand for IVDs manufactured by the health institutions for internal use (so called lab-developed tests). This requires that solutions are open enough that they can also be used by health institutions for lab-developed tests in case no CE-marked IVD is available. Another challenge that emerged as a result of the Open Market Consultation in this project is that, particularly for rare cancers, there is increased medical need for using whole exome or whole genome NGS platforms. Although these platforms are technically well advanced there is neither experience on how the massive data generated can comply with IVDR nor FDA requirements in case of diagnostic application.

## Solutions under development in Instand-NGS4P

In response to a Request for Tender in 2021, 24 tenders were received from a variety of Solution Providers ranging from SMEs to large companies. After an initial design phase involving 15 Contractors, 11 Contractors were selected for Phase 2 to develop prototypes in the Lots for sample preparation (“Pre-analytics and library preparation”), analysis of sequencing data (“Bioinformatics analysis”) and presentation of the results for clinicians and patients (“Integrated Reporting”).

In this final Phase of the Instand-NGS4P project, seven individual Solutions are being tested by a subgroup of the project's Consortium members in a real world diagnostic setting, to evaluate the performance as part of an innovative integrated and standardised workflow.

Lot		Lead Contractor (Click name to read the project abstracts)
<b>Lot 1</b> <b>Pre-Sequencing</b>		<b>QIAGEN GmbH</b>  <b>Twist Bioscience Corporation</b>
<b>Lot 3</b> <b>Bioinformatics Analysis</b>		<b>Congenica Ltd</b>  <b>Consorcio para la explotación tación del Centro Nacional de Análisis Geómico</b>
<b>Lot 4</b> <b>Integrated Reporting</b>		<b>BC Platforms AG</b>  <b>Congenica Ltd</b>  <b>Consorcio para la explotación tación del Centro Nacional e Análisis Geómico</b>

Figure: Phase 3 Contractors including links to the abstracts of the Solutions under development

In parallel, efforts are being made towards improving the availability of NGS for patients by advancing the health technology assessment evidence, as described below.

## Budget impact and reimbursement

The economic burden of cancer and cancer treatment in the western world is high and affordability a growing issue. To measure the expected economic impact of diagnostic- and treatment options and their cost-effectiveness, Health Technology Assessment (HTA) is used to identify, measure, value, and compare the consequences of alternative strategies. Using various scenarios reflecting different technology applications of genomic screening, be it single mutation tests, small or large sized genomic screen panels either provided in centralized or decentral laboratories, HTA can support the adoption process in guiding development and reimbursement decisions of different future pathways and settings. In Personalized Medicine (PM), several challenges exist to conduct HTAs, amongst others the availability and quality of underlying data, data governance and regulatory restrictions, to finally bring PM timely to the patient with a smooth reimbursement process. Especially the absence of RCTs and the tendency to resort to one armed- or cohort studies carries the risk of discrepancies between clinician's opinions and regulator's demands related to filing content, as long as external coverage is needed to finance the costs of testing. Apart from the specs needed to comply with the IVDR regulations to be implemented on the European market and in individual hospitals, from 2026 onwards every country has to decide on coverage. This can be a decision that NGS has to be covered from institutional budgets or from existing DRG tariffs, leaving it to institutional management to decide on the consequences of its budget impact. It can also be a separate national coverage decision with additional funding. The new EU Regulation on HTA and joint clinical assessments that came into force in January 2025, will only embark on diagnostics in later years, so diverting national procedures and unequal access throughout Europe are the likely consequence.

## Technology Assessment of NGS and WGS testing

Currently, we notice that the reimbursement discussion on wide panel genomic testing is in a vicious circle. Clinical data and HTA evidence for clinical utility is scarce but demanded by regulator agencies, whereas molecular- and medical oncologists seem convinced of the added value and often find randomization unethical.

To assess the status-of- and the further needs for HTA in the final stages of the project we will describe 1. the State-of-the-art regarding evidence of HTA in relation to NGS, 2. the type of data necessary for HTA and 3. How to generate this evidence for HTA and define study designs.

The state of the art will be established through a Scoping Review. We will assess what evidence is available and necessary for HTAs concerning NGS - especially wide panel testing - in oncology, both focusing on “in house” as well as commercially available NGS technology. This can focus on predictive and prognostic testing especially identifying options for targeted treatment, both on- and off-label as well as for trial selection.

Guidance is needed on how to generate the right evidence for HTAs concerning the implementation of NGS in clinical oncology practice. Further building on earlier reviews, experience with DRUP like studies and building on the tool drafted in the EU funded CANHEAL project, we will write a guidance for NGS labs with methodological advice involving the HTA regulator perspective, on how to set up the right studies in order to generate evidence for reimbursement dossiers.

-> This will specially relate to identifying the appropriate set of Population, Intervention, Comparator and Outcomes characteristics and data (PICO) from projects.

-> Further we will propose appropriate decision factors for coverage as methodological challenges are known and to bridge the divide between clinicians and regulators.



**Instand**  
**NGS**  
for Personalized Therapy

# Precision Diagnostics for Precision Cancer Care

Improving patient access to innovation

## High Level Seminar

European Parliament – Brussels  
May 20<sup>th</sup>, 2025 - 14:00-18:00 CET

Hosted by MEP  
**Vlad Vasile Voiculescu**




EU Horizon Pre-commercial procurement project "Tempered and standardized NGS pipelines for Personalized Therapy" Grant no. 874716. Co-funded by the European Union

Lastly, we will produce a set of recommendations for (future) evidence generation, based on different phases of (very) early HTA, early HTA -> HTA for reimbursement purposes and translate these in trial design proposals that can be implemented in future international projects. The objective is to generate data that comply with the common principles of reimbursement (through HTA and Cost effectiveness analyses) or purchasing (through cost calculations and budget impact analysis for the payor).

The Instand-NGS4P project and the need for adequate coverage approaches were presented in a high-level meeting at the European Parliament on the 20th of May 2025, for discussions on the following topics:

There is a clear medical need for NGS and precision diagnostics in cancer care

- the challenges and opportunities for improving the access of cancer patients to recent innovations will be discussed

How can innovative technologies meet regulatory requirements for in vitro diagnostics and how European standards can help

Health economic benefits of NGS as prerequisite for reimbursement scheme

- how to overcome inequalities for patients in accessing precision diagnostics in Europe.

## Conclusion

Many institutions are implementing various forms of NGS and WGS testing. There seems to be limited awareness that the IVDR regulations will also become active in this field. Apart from achieving market- and institutional access, coverage is a challenge. In addition to the project tasks directed towards stimulating the development of innovative NGS Solutions, we will propose methods to bring technology assessment further in order to stimulate equal access to patients throughout Europe.

### Integrated and Standardized NGS Workflows for Personalised Therapy

<https://www.instandngs4p.eu/>

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# Digital Health Literacy and Patient Empowerment in the Era of Precision Oncology

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In today's rapidly evolving landscape of precision oncology, digital health literacy has emerged as a critical component of patient-centered care. As treatment options become increasingly sophisticated - involving genomics, targeted therapies, and complex clinical trial designs - the knowledge gap between specialists and patients continues to widen. This challenge directly addresses the EU Cancer Plan's **Flagship 3 on "Equitable access to cancer care"** and **Flagship 7 on "Improving access to innovative cancer diagnosis and treatments,"** which emphasize ensuring all patients can "benefit from advances in innovative technologies" regardless of geographic location, socioeconomic status, or educational background.

## Digital Literacy at the Intersection of Innovation

The convergence of cancer genetics, artificial intelligence, and innovative diagnostic technologies has created an unprecedented acceleration in oncology advancements. As Keener and Haendel (2022) observe, "The half-life of medical knowledge in oncology has decreased from 7 years to less than 2 years, creating significant challenges for patients attempting to navigate treatment decisions." This rapid evolution makes digital health literacy not merely beneficial but essential for informed patient participation.

Studies by Timmermans et al. (2023) demonstrate that patients with limited understanding of genomic concepts are 68% less likely to enroll in precision medicine trials and 47% more likely to discontinue targeted therapies prematurely. Similarly, Forbes et al. (2024) found that while AI-powered diagnostic tools are becoming standard in many cancer centers, 76% of patients report uncertainty about how these algorithms influence their care pathways. As Ahmed and Petrov (2023) note, "The democratization of genetic information and AI-driven healthcare requires a parallel investment in digital literacy infrastructure; otherwise, innovation may inadvertently widen rather than close health disparities."

## The Digital Divide in Cancer Care

Research indicates that while 70% of cancer patients seek information online, only 30% feel confident evaluating its reliability (Johnson et al., 2023). This digital divide is particularly pronounced among older patients, those from lower socioeconomic backgrounds, and residents of rural areas—precisely the populations identified in the EU Cancer Mission's intervention areas for reducing inequalities. Digital health literacy encompasses not merely access to technology but the ability to find, understand, appraise, and apply digital health information to make informed decisions. For the OECl cancer centers committed to patient empowerment, addressing this divide must become a strategic priority.

## Practical Implementation Models for OECl Centers

OECl centers can establish structured collaborations with patient organizations to systematically improve digital health literacy through several evidence-based approaches:

### 1. Digital Navigation Programs

A 'Digital Patient Navigator' model could pair trained volunteers from patient organizations with newly diagnosed patients. In this approach, navigators would help patients access and interpret online resources, patient portals, and telehealth platforms, with centers providing the technical infrastructure while patient organizations contribute authentic peer perspectives. Cancer patient associations in Greece, France, have already structured training programs for volunteers, who assist patients in cancer hospitals. This model has demonstrated a 45% increase in patient portal utilization and a 38% improvement in treatment understanding (Becker et al., 2024).



## 2. Co-Developed Educational Resources

Langer Research Collaborative (2023) found that simplified genomic education materials co-designed with patients improved comprehension of mutation-driven therapies by 59% compared to standard materials. Following this evidence, the OEI for Patients Working Group can collaborate with the OEI cancer centers for establishing “Content Co-Creation Committees”, where clinicians and patient advocates jointly develop resources. This process begins with needs assessments conducted by patient organizations to identify specific knowledge gaps. Materials undergo user testing with diverse patient groups before deployment, ensuring they address varying literacy levels and cultural contexts—directly supporting the EU Cancer Plan’s goal to **“improve health literacy on cancer risks and determinants.”**

## 3. Virtual Communities of Practice

Secure online platforms where patients, clinicians, and researchers interact create vital information ecosystems. These communities - moderated jointly by center staff and patient advocates - allow real-time clarification of complex concepts while enabling peer-to-peer knowledge exchange. The Netherlands Cancer Institute’s “Knowledge Exchange Portal” exemplifies this approach, connecting over 3,000 patients with specialists through structured discussion forums and monthly webinars focused on emerging treatment approaches. Zhang et al. (2024) documented that participants in such communities demonstrated 52% higher comprehension of AI-driven diagnostic procedures and 47% greater likelihood of participating in molecular profiling studies.

## 4. Digital Decision Aid Integration

In response to the EU Cancer Plan’s emphasis that **“patients need to understand and control data concerning their health,”** OEI cancer centers can integrate in collaboration with the OEI for Patients Working Group digital decision aids into standard care pathways. Assistance in planning, designing, implementing decision aids could be sought at the ISDM – the International Shared Decision Making Society. These tools—co-designed by SDM experts and patient organizations—visualize treatment options, potential outcomes, and quality of life considerations. When supplemented with trained decision coaches from patient advocacy groups, these aids have increased decision satisfaction by 56% and reduced decisional conflict by 42% (Martinez et al., 2023). Particularly promising are interactive tools that visualize complex NGS testing reports, genomic data and predict treatment responses based on molecular profiles, making abstract concepts tangible for patients with varying levels of scientific literacy.

## Measuring Impact and Ensuring Inclusivity

For digital health literacy initiatives to avoid exacerbating inequalities, rigorous evaluation frameworks must be established. The German Cancer Research Center’s “Digital Inclusion Scorecard” provides a template, measuring initiatives against key metrics including:

- Accessibility across devices and assistive technologies
- Multilingual availability reflecting regional demographics
- Usage patterns across different socioeconomic groups
- Impact on treatment adherence and patient-reported outcomes
- Representation of diverse patient voices in development processes

Patient organizations play a crucial role in this evaluation, conducting regular digital literacy assessments among their communities and providing feedback loops for continuous improvement. As Cavanagh et al. (2022) argue, “The speed of innovation in cancer care must be matched by equally innovative approaches to ensuring patient understanding.”

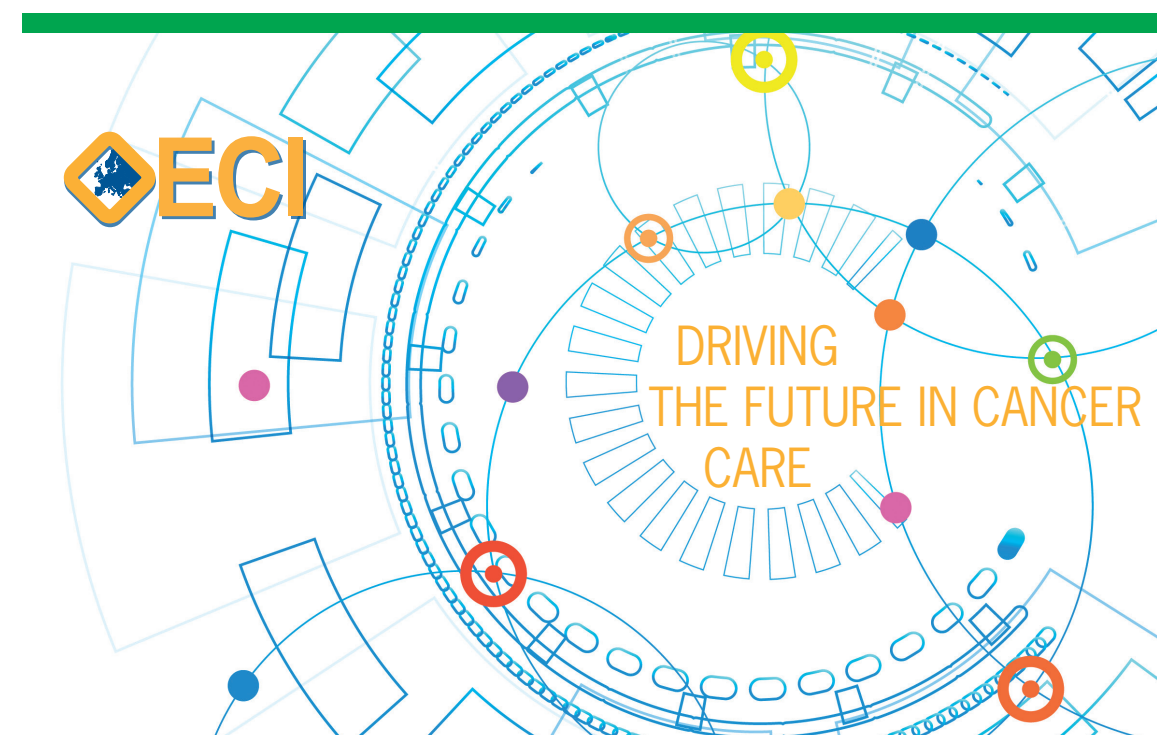
## Future Directions: The EU Cancer Plan in Action

As the EU Cancer Plan aims to **“launch a Knowledge Centre on Cancer to facilitate the uptake of digital innovations,”** the OEI for Patients Working Group and patient associations in collaboration with OEI cancer centers are uniquely positioned to serve as implementation laboratories. By documenting successful digital literacy interventions and sharing these models across the OEI network, they directly contribute to the Plan’s vision of democratizing cancer knowledge.

The future of patient empowerment in precision oncology depends not on technology alone but on the thoughtful integration of digital tools within human support systems. When cancer centers and patient organizations collaborate to prioritize digital health literacy, they fulfill the EU Cancer Mission’s promise of **“improving the lives of more than 3 million people by 2030”** through more informed decision-making, enhanced patient autonomy, and truly personalized care that addresses both the biomedical and human dimensions of the cancer experience.

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# Revising the OECI Accreditation and Designation Standards to remain leading in the world

## The A&D Board

Every five years the OECI Accreditation and Designation (A&D) Standards and Manual go through a full and exhaustive revision and improvement process. In this article we explain the process, through which we believe OECI continues to be at the leading edge of cancer centre standards in the world.

This time around, the process began in October 2023. The first step was for our coordination team based in the Netherlands Comprehensive Cancer Centre (IKNL) to compare the present manual 3.2 standards with all the other possible cancer standards throughout the world. There are nine other sets of standards which should seriously be considered, excluding very generic health-based standards. The OECI A&D standards are unique in spanning translational and clinical research as well as care, and we filter from different sources what we judge to be evidence-based standards. The A&D Board had made a prior decision that in Manual 4.0 we would not have a greater number of standards than at present, meaning that if there was an argument in favour of new standards on AI (which there is) then certain other standards, which have become so rudimentary to cancer care and are fulfilled by every centre, should be dropped.

In this first analytical step, the accumulated comments of auditors, the Accreditation Committee (AC) and the A&D Board, about which standards were confusing, hard to interpret, redundant or missing, were considered. The A&D Board then considered general issues such as the form of standards. Our principle from the beginning in 2006 has been an indicative statement in one sentence which can be scored for compliance: Yes; Mostly; Partially; and No, according to the classic Deming cycle. The Board also considered core standards and the use of these, and examined new trends in evaluating research.

In the next step, working groups comprising members of the Board, the AC, and auditors, were formed, to have videoconferences to go through all of the chapters of the standards, one by one, to analyse for missing, redundant, or unclear standards. New standards were then commissioned on subjects such as AI, molecular pathology, cancer networks, adolescents and young adults, and aspects of diagnosis and treatment. The recommendations from those working groups were then examined exhaustively by the A&D Board in a number of meetings, and decisions made.

## Scientific evaluations

One of the interesting developments to be considered was the whole question of trends in how to evaluate cancer research in our OECI centres. Accordingly, in October 2024 a conference of directors of science of OECI centres was arranged, which was attended by more than 70 scientists, and co-chaired by Prof Mef Nilbert and Dr Josep Tabernero. This conference considered the requirement of open access, the fields of cancer science which reach differing levels of impact factor, the advantages and disadvantages of using a Q1 measure for each scientific field within cancer, and the current trends in clinical trials in Europe and what can reasonably be expected of our Comprehensive Cancer Centres.

Key recommendations from this conference were:

- To maintain the measurement of overall number of peer reviewed international papers.
- To keep using Impact Factor >10 publications for now, but also to gather data on Q1 papers through the quantitative questionnaire, and review this over time as centres get better in collecting and presenting such data
- To introduce an input measure on staffing of research, to measure full-time equivalent scientists (including PhD students) of 50 or more.
- To maintain the current measure of €8 million for the research budgets

- To be more clear and more flexible about measuring clinical trials: prospective interventional trials should include all interventions, not just new therapies, and should include trials with no phase.

The next phase of the process was for the revised set of standards, the quantitative questionnaire, and other standards to be circulated to all members of OECI with a request for comments on what was missing, unclear, or redundant. 39 replies were received in greater or lesser detail, and then the A&D Board scrutinised and made a judgement on all these suggestions. At this stage three new elements were introduced/improved. First, a column of “recommended evidence” was included within the standards, to guide centres about what evidence to produce. Secondly, the glossary was extensively improved and added to, to explain the requirements and definitions within many standards. Thirdly, the concept of Core-Essential Standards was introduced. The idea of these (less than 20) essential standards was that compliance or non-compliance with these would guide the A&D Board in assessing Go/No-Go decision for peer reviews, or determining whether a particular centre's accreditation should be postponed until these essential standards were addressed and complied with. Examples include:

- Whether a cancer centre is an identifiable entity with clear governance and organisation
- Whether Multidisciplinary Teams are present for every cancer managed in the centre
- Whether documented patient pathways exist for every cancer managed in the centre

## Standards Revision Conference, Brussels

The next major element of the process was the convening of a Standards Revision Conference on 12-13 February 2025 in Brussels. This was a conference in hybrid form, but mainly onsite, and convened 110 participants from 23 countries -

<https://accreditation.oeci.eu/event/experts-consensus-meeting-on-oeci-accreditation-and-designation-standards>

Key speeches were made by Presidents/Board Members of key professional societies in Cancer – ESMO; ESTRO; and ESSO. These spoke about the requirements for quality standards within their professional fields of medical oncology; radiation oncology, and surgical oncology. Recurring themes came out of these speeches: the need for interdisciplinarity and the importance of cancer centres; the importance of accelerating innovation but also keeping in mind the cost/benefit analysis; the positive effect of setting and monitoring quality standards across centres to improve patient outcomes. The conference also had representation from radiologists, pathologists, supportive and palliative care, patient groups, and nursing. It was evident that societies representing these professions are keen to continue to work with OECI to set appropriate, relevant and binding standards. In addition to the plenary sessions and discussions, working groups were convened to examine certain subjects in more detail:

- Artificial intelligence and data sharing
- Molecular pathology and molecular tumour boards
- Patient involvement and empowerment
- Nursing, Supportive and palliative care
- Prevention and Early Detection
- Governance, strategy and integration of research and care
- Basic and translational research
- Standards on clinical research

These workshops came back with new suggestions in each of those areas, and new comments were received from the floor, including whether certain standards should be core standards, or core-essential.

Two significant strategic issues were also raised and discussed:

- 1) The importance of cancer networks around the (comprehensive) cancer centres. Many European countries are working hard to make such networks more formally organised, often with a cancer centre or comprehensive cancer centre at the hub of the network. The Nordic countries are developing these networks strongly, and the Netherlands has almost completed its formal coverage with 8 networks covering the whole nation. OECI estimates that on average, 45% of cancer patients are now managed by health providers which are either a centre, or part of a cancer network. This begins to work towards the 90% ambition in the EU Mission on Cancer.
- 2) The question of excellence in research and innovation. It is evident from OECI analyses (for instance, the publication in Molecular Oncology<sup>1</sup>) that there is a high degree of variability within OECI cancer centres when it comes to the depth and breadth of research. The question has been raised as to whether the A&D programme

should add more value to these centres, especially in a re-accreditation, by developing “modules of excellence” in, say, clinical research, or translational research, to which some of the larger centres could aspire, and which would require a deeper scientific view. OECI could work together with other scientific societies on these questions, if there is an appetite from our Comprehensive Cancer Centres to develop these.

As a result of this extensive conference, the A&D Board again convened to make decisions on the key recommendations made. A new version of the main questionnaires was then drawn up, and this forms the version to be submitted to the OECI Board for final approval. Manual 4.0 will be launched at the Athens Oncology Days and go live for centres whose application is approved after 1 July 2025. The e-tool will be updated and upgraded at the same time, to include clearer references to the definitions in the glossary, and the evidence required.

We are immensely grateful to all those who have contributed over nearly 2 years to the improvement and refinement of OECI Standards and the new Manual. We believe that as a result of all this hard work and extensive input from many quarters, the OECI Standards for cancer centres and comprehensive cancer centres are among the best in the world, clear, practical, relevant, evidence-based, and ambitious. OECI remains committed to our principles that our programme is:

- Voluntary and not regulatory
- A true peer review and not a technical audit
- Supportive of continuous quality improvement
- Spanning discovery and translational research through to all modes of diagnosis and care

As a result, we hope that patients of all our constituent cancer centres, and the networks around them, will continue to benefit from the ever-increasing quality of innovative cancer care, and that their outcomes and quality of life will be transformed.

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# The OECI for Patients WG: Putting Patients at the core of Cancer Care and Research

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3. The Organisation of European Cancer Institutes, Operations Manager

The relaunch of the OECI4Patients Working Group under a revitalised identity marks a major step forward in embedding patient perspectives into cancer care and research across the Organisation of European Cancer Institutes.

Now supported by a newly elected Steering Committee, the group draws on the expertise of international leaders in patient advocacy, education, healthcare quality improvement, patient partnerships and cancer care coordination. Together, they are committed to fostering meaningful collaboration between OECI Member centres, patients, and cancer patient organisations.

This renewed vision was officially introduced at OECI Oncology Days 2024, a hallmark gathering of the world's leading oncology experts. The event offered an ideal platform to underscore OECI for Patients' alignment with OECI key goals: **to integrate research and innovation into patient pathways and place patients firmly at the heart of cancer care.**

OECI, a network of over 160 members across Europe and beyond, promotes personalised, multidisciplinary, high-quality cancer care. Through its comprehensive approach, OECI ensures that scientific progress is translated into real-world patient benefit, driving excellence in care, research, and education.

Central to this ambition is the Accreditation & Designation (A&D) Programme - the world's only cancer accreditation programme that evaluates comprehensive cancer care and research in a seamless process. Now in their most comprehensive form following three major revisions, the A&D Standards feature a dedicated chapter on Patient Involvement and Empowerment. The establishment of the OECI for Patients WG, represents a natural evolution of this commitment, reinforcing the central role of patient-centred care in institutional quality frameworks.

## Strategic priorities of the WG ongoing activities

OECI for Patients has initiated an in-depth mapping exercise to analyse existing patient involvement models.

This thorough assessment aims to identify both exemplary practices and critical gaps, laying a robust foundation for **a universally adaptable, yet locally sensitive patient involvement model.**

Following the mapping phase, the Working Group will launch a wide-reaching patient survey across all OECI member institutions. Designed to maximise engagement and inclusivity, the survey will inform a detailed gap analysis and help address overlooked patient needs and experiences of engagement. Ultimately, this innovative patient involvement model will become an essential practical guideline for member centres—one that supports the delivery of care that is not only evidence-based, but genuinely patient-centred.

The influence of OECI for Patients already extends strategically within OECI's activities. WG members played an active role in the A&D Expert Consensus Meeting on OECI Standards held in Brussels on 12–13 February 2025. They contributed significantly to refining the standards

## The WG Steering Committee

**Delia Nicoară**

Chair of the WG, IOCN Cluj-Napoca, Romania

**Paulina Bravo**

Director of Patient Education and Involvement, Fundación Arturo López Pérez, Santiago, Chile

**Alexandre Brutti**

Board Member, LuCE Lung Cancer Europe, Paris, France

**Francesco De Lorenzo**

President, Federazione Italiana delle Associazioni di Volontariato in Oncologia (FAVO), Italy

**Caitriona Higgins**

Cancer Patient Partnership Lead, Beaumont RCSI Cancer Centre, Dublin, Ireland



on patient involvement and empowerment that will appear in the upcoming A&D User Manual V.4, to be published on 1 July 2025. In addition, WG Member Paulina Bravo is now an Elected Member of the A&D Board.

Beyond internal OECI initiatives, the group is also making its mark in Europe's cancer research landscape. Through the CCI4EU Coordination and Support Action, WG Member Alexandre Brutti provided expert input in the deep-dive intervention to enhance Ireland's comprehensive cancer infrastructure.

Alongside Chair Delia Nicora, he co-organised the fifth CCI4EU online course - an insightful webinar on patient empowerment and patient-centred care.

Involvement in ALTHEA, another prominent European initiative aimed at providing high-quality, remote, psychological support through digital platforms, further emphasizes the working group's strategic importance within OECI's broader agenda.

Key milestones on the horizon include the finalisation of the comprehensive patient involvement model, its widespread implementation across OECI centres, and continued contribution to European cancer initiatives. Together, these efforts are reshaping the future of oncology, ensuring that cancer care becomes more inclusive, responsive, and truly attuned to the voices and needs of patients.

### The role of support groups in patient empowerment

In the changing medical landscape, the role of patients has evolved dramatically. They are no longer passive recipients of care; they have become active participants, collaborators and advocates for their own causes and for the communities they represent. Patient engagement is not just a trendy concept; it is actually a fundamental change that can improve health outcomes, ensure quality of healthcare and facilitate communication. Work in this area focuses on connecting the individual actions of patients with the collective efforts of cancer patient associations, creating a living ecosystem where every voice matters.

The mission behind this approach is clear and firm: **to empower patients by integrating them into the decision-making processes of the healthcare system.** This means informing them about their treatment plans and medical rights, encouraging their active participation in the decisions that affect their lives, and promoting more effective communication with healthcare professionals. The result is not only greater adherence to treatment, but also the creation of an environment where shared decision-making becomes common practice. Efforts do not stop at the individual level. The aim is to tackle the power of communities and patient associations to advocate for systemic change so that health systems become transparent, responsive and equitable. By institutionally including patients' perspectives at all levels, from day-to-day interactions in hospitals to institutional strategies, a model of care that truly responds to people's needs can be built.

The long-term vision looks to a future where patients are not just participants, but active partners in the design and improvement of healthcare. It is a world in which their involvement goes beyond self-advocacy and becomes a broad collaborative effort in which healthcare providers, patients and patient advocates work together to innovate and improve care. In this vision, cancer patient associations play a key role in amplifying patient voices, advocating for policies that eliminate inequities and using technology to make health more accessible. Hospitals become centres of partnership, where transparency and a patient-centred approach are everyday realities. Achieving this vision requires commitment, creativity, and, above all, a willingness to listen, which are principles that underpin all initiatives in this field.



### Activities that connect patient and the role of cancer patient organisations

Activities reflect this dual approach, combining individual and collective involvement. At the individual level, patients are encouraged to become key actors in their care. This involves understanding treatment plans and their rights, participating in decision-making processes with health professionals and giving feedback that contributes to service improvement. Patient education programmes play a key role in giving patients the tools to confidently manage their health. Beyond the individual, connecting with communities is achieved through peer-led initiatives such as support groups for patients and their families, health literacy programs that clarify medical information, and mental health support initiatives that address the emotional impact of illness.

Working with cancer patient associations is at the forefront of this approach. Organisations advocate for patients' rights, establish their own biobanks and collaborate with national ones, raise awareness of key health issues, and work with hospitals to design services that better meet real needs. They advocate for increased research funding, establish their own biobanks and collaborate with national ones, organise workshops, conferences, surveys, publish in journals and collaborate with hospitals' administration to establish patient advisory boards that bring diversity to hospital governance. Through these activities and partnerships, they increase transparency in decision-making and ensure that patients' voices shape institutional policies and practices. Engagement strategies include formalising patient roles in hospital governance, developing joint educational initiatives, and expanding regional patient networks. All these efforts create a complex web of engagement that connects the individual, community and institutional levels coherently and dynamically.



Patient involvement models provide a clear framework for transforming healthcare, aligning with the 13th Recommendation of the Mission on Cancer "Transform cancer culture, communication and capacity building". Shared decision-making, where practised, may empower patients by actively involving them in treatment choices, leading to superior outcomes. An international example is Macmillan Cancer Support in the UK, which promotes patient involvement by providing personalised support for those diagnosed with cancer. This organisation works closely with hospitals to facilitate access to quality care, addressing not only the physical aspects of the disease, but also the emotional, social and financial needs, which exemplifies this model perfectly.

Another illustrative example comes from France, where more than half of the Comprehensive Cancer Centres (CCCs) within the Unicancer federation (which includes 20 centres) have integrated peer support into various care pathways, particularly in breast, prostate, and ENT cancers. These peer programmes address a wide range of topics, from physical and psychological aspects of the disease to challenges related to daily life and employment. Additionally, several Unicancer CCCs actively involve patients in diverse institutional activities, including training healthcare professionals, contributing to hospital infrastructure projects, co-developing communication tools and care pathways, and participating in research initiatives. This multidimensional involvement reflects a growing recognition of patients as essential partners in the continuous improvement of cancer care.

Participatory health service design integrates patient feedback into service design, and the Research Centre for Patient Involvement (ResCenPI) in Denmark provides a concrete example. This centre works with hospitals to assess the impact of involvement interventions on patient and family experiences, clinical health indicators and professional practices, contributing to more patient-centred care. The Danish Society for Patient Safety facilitates training programs, conferences and projects that promote patient safety and engagement, supporting hospitals in implementing new methods and technologies. Healthwatch England represents the voice of patients in the UK healthcare system, collecting their views and experiences to influence healthcare policy and practice.

### Improving quality of life through patient involvement

Cancer patients and survivors increasingly seek care models that not only address their medical conditions but also respond to their social needs, Quality of Life (QoL) during and after care, and work with hospitals to design



services that better meet real needs. Moreover, over the last ten years, there has been increased social debate and research on the unmet social needs of cancer patients, survivors and families and how unmet needs and cancer affect their quality of life.

Research consistently shows that unmet social needs significantly impact cancer outcomes and quality of care. According to Zebrack et al. (2020), over 60% of cancer patients report unaddressed social challenges including financial toxicity, transportation barriers, and inadequate social support. Myloneros T. et al. (2023) mention that, in a survey of its members completed in 2019, the ECPC-European Cancer Patient Coalition members believe, supported by the scientific findings on financial toxicity, that socio-economical rehabilitation is not only a necessary part of the treatment and a fundamental right of the persons affected by cancer, but also a prerequisite of social cohesion and healthy and sustainable development.

Basch et al. (2017) demonstrated that routine QoL monitoring of patient-reported symptoms was associated with improved survival compared to usual care. This evidence-based approach aligns with the EU Cancer Mission's Action Area 4, which promotes “developing tools to improve quality of life,” including standardized assessment instruments. The EU Cancer Plan specifically calls for a “**Cancer Survivor Smart Card**” that connects patients to QoL monitoring and acknowledges that “Europe’s beating cancer plan aims to mitigate the impact of cancer on the lives of patients and their families,” recognizing QoL as a primary outcome. The EORTC QLQ-C30 and other validated instruments provide structured frameworks for measuring physical, emotional, and functional well-being throughout the cancer journey. Research by Fitzmaurice et al. (2019) shows that early integration of palliative care services—focused explicitly on QoL enhancement—significantly improves symptom management and reduces psychological distress.

Quality of life (QoL) has emerged as a critical element in comprehensive cancer care, directly supporting the EU Cancer Plan’s **Flagship 9: “Better quality of life for cancer patients, survivors, and carers.”**

The OECI for Patients Working Group’s emphasis on QoL assessment directly contributes to the EU Cancer Plan’s initiative to “launch a new project to map inequalities in quality of life among cancer survivors” and addresses the Plan’s recognition that “quality of survivorship” is an essential measure of successful cancer care.

When identifying barriers, cancer patients reported a greater number of institutional barriers than barriers related to individual provider or patient characteristics. This aligns directly with the **EU Cancer Plan’s Flagship 5: “Reducing cancer inequalities across the EU,”** which emphasizes addressing socioeconomic determinants of cancer outcomes.

The EU Cancer Plan specifically calls for Member States to “**improve access to cancer services and reduce social disparities**,” recognizing that social needs create barriers to optimal care. The European Cancer Mission further supports this through Action Area 3, which aims to “**optimize support systems around individuals**” by establishing integrated, patient-centred care pathways. The IOM report “Cancer Care for the Whole Patient” reinforces that comprehensive cancer care must address these social determinants to be truly effective. As noted by Boyce and Suls (2018), patients with strong social networks demonstrate better treatment adherence, lower psychological distress, and improved survival rates.

By systematically screening for social needs and implementing coordinated interventions OECI centres in collaboration with the OECI4Patients WG can directly contribute to the EU Cancer Plan’s goal of reducing the cancer burden and addressing the “**unacceptable disparities in cancer prevention and care**” highlighted as a key challenge in the Plan.

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# Biobanks and Personalised Cancer Care: a timely opportunity for OECI

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In recent years, biobanks have become a crucial element of modern hospital infrastructure. By collecting, processing, storing and delivering biological material from consented individuals, they support fundamental, translational, and clinical research. They also provide material for enterprises developing novel diagnostics and innovative treatments. Biobanks bridge the gap and facilitate the transfer of new research findings to clinical care. The integration of AI tools into clinical care and personalised cancer treatment requires the biological samples and phenotypic information offered only by large-scale biobanking. While the need is unmistakable, we lack multicentric initiatives that generate sufficiently large cohorts to answer targeted research questions, and in particular, fulfil the big data analysis and AI algorithm development requirements.

Information that was collected as part of OECI’s Accreditation and Designation programme indicates that over 90 OECI certified centres host biobanks operating at various activity levels. Thus, the OECI network has an excellent opportunity to play a significant role in advancing coordinated biobanking efforts to rapidly collect samples and data in a harmonised manner. Deeper understanding of the OECI biobanks’ activities, and establishing joint biobanking practises and goals, would enhance cancer research, thereby improving clinical care. While interests and resources between different OECI biobanks and hospital are likely different, common goals are easy to find. Joint activities would be especially crucial in rare cancer research, from fundamental studies to improved diagnostics and clinical trials.

Examples of research areas that could be piloted within the OECI centres are numerous. For personalized disease prevention, biobank samples can be screened for genetic alterations that increase a person’s cancer risk, and these individuals can be offered targeted preventative care. Similar opportunistic screening studies are already being piloted in several biobanks, with encouraging results. Development and optimisation of new diagnostic tests for cancer detection, response evaluation or follow-up is an area of opportunity, but it requires substantial sample numbers, preferably from multiple sites. For example, AI tools for digital pathology are rapidly entering diagnostic laboratories, but more advanced algorithms providing truly meaningful information for pathologists are still needed, and can only be achieved by the means of large, well-curated, sample collections. Similarly, longitudinal blood sample collections from cancer patients are essential for cell-free DNA and biomarker studies. Prospective cancer tissue collection provides the foundation for multiomic profiling studies, which aim to identify novel therapy targets and understand mechanisms of treatment resistance and cancer evolution. Clinical trials, including those using molecular profiling as a basis for investigating off-label use and efficacy of targeted anti-cancer drugs, certainly benefit from the biobank infrastructures that provide professional, standardised, sample collection and handling.

While the opportunities are clear, preparatory work must be done before joint OECI activities can be forwarded. As a first step, we need to identify a group of enthusiastic biobanks/biobankers to draft and define concrete aims and a working plan, as part of the OECI’s Biobanking and Molecular Pathobiology Working Group (BMP-WG) agenda. A survey on the activities and resources of OECI biobanks is being planned, to help focus the future activities of BMP-WG, with the goal of closer collaboration and joint projects. It is essential that we collect biobank samples in a harmonised fashion, using established quality standards. Similarly, harmonisation of metadata, including not only sample-related information, but also phenotypic (clinical) information, is essential for optimal utility. Legal issues and varying practises between countries and institutes need to be considered, including the impact of European Health Data Space (EHDS) and the EU AI Act. These activities require coordination and collaboration with existing European infrastructures, such as BBMRI-ERIC and EU-funded projects. Of special interest are new European AI initiatives, such as the AI factories that will foster innovation, collaboration, and development of AI models.

In conclusion, establishment of common goals and activities by the OECI biobanks provides a golden opportunity for the entire OECI network to facilitate research and bring new discoveries to clinical care. I sincerely hope the visions and future of biobanking is actively discussed during the OECI Oncology Days in Athens. Now is the prime time to act, for the benefit of cancer patients.

# Breast Cancer Care: Achievements and Perspectives

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## Introduction

Breast cancer is the most diagnosed cancer among women worldwide, representing nearly 25% of all cancer cases and affecting approximately 2.2 million individuals annually. While significant progress has been made in early detection and treatment, the burden of the disease varies across regions. In developed countries, early-stage breast cancer has a five-year survival rate exceeding 90%, largely due to advancements in screening programs, molecular diagnostics, and targeted therapies. However, disparities in healthcare access contribute to higher mortality rates in low- and middle-income countries.<sup>1</sup>

Despite these advances, breast cancer continues to present clinical challenges. One in three patients diagnosed with early-stage disease eventually develops recurrence or metastasis. Moreover, approximately 10% of cases in Western Europe are diagnosed at an advanced stage, a percentage that rises significantly in resource-limited countries.<sup>2</sup>

Breast cancer is a heterogeneous disease, encompassing multiple subtypes with distinct genetic and molecular characteristics. This complexity necessitates increasingly individualized approaches to treatment and management.

## The Evolution of Precision Medicine in Breast Cancer

Traditional approaches to breast cancer treatment followed a “one-size-fits-all” model, which has now been replaced by a new era based on precision medicine.

Main advances in breast cancer care in the recent years have included:

### 1. Genetic Testing and Risk Assessment

Genetic testing plays a pivotal role in breast cancer care, particularly in assessing hereditary risks associated with mutations in BRCA1 and BRCA2 genes. Carriers of these mutations face a significantly higher lifetime risk of developing breast and other types of cancer, such as ovarian, as compared to the general population. The identification of these mutations has transformed preventive strategies and treatment approaches.

For individuals with germline BRCA mutations, clinical management may include:

- **Enhanced surveillance**, including specific and more frequent breast imaging
- **Risk-reducing surgery**, such as prophylactic mastectomy or salpingo-oophorectomy.
- **Targeted therapies with PARP inhibitors**: the OlympiA Phase III trial demonstrated that adjuvant olaparib, a PARP inhibitor, significantly improves outcomes in patients with high-risk, HER2-negative early breast cancer with germline BRCA mutations. After 6.1 years of follow-up, olaparib reduced the risk of invasive disease recurrence by 35% and distant recurrence by 35%, while also improving overall survival.<sup>3</sup>

### 2. Genomic Tests and Chemotherapy Decision-Making

Molecular profiling has revolutionized breast cancer diagnosis and treatment. Biomarker analysis allows for the classification of tumors based on their genetic and molecular characteristics, enabling more effective therapeutic strategies.

The development of genomic assays, such as Oncotype DX, has transformed decision-making in early-stage breast cancer, particularly for hormone receptor-positive (HR+), HER2-negative patients.

- The TAILORx trial confirmed that chemotherapy can safely be spared for patients with a Recurrence Score (RS) of 0-10, favoring endocrine therapy alone.
- Patients with a RS of 11-25 do not derive significant benefit from chemotherapy, except for premenopausal women under 50, where adjuvant chemotherapy showed an advantage, particularly with RS values above 21.<sup>4</sup>
- The RxPONDER trial extended this concept to node-positive patients (1-3 positive axillary nodes), demonstrating that postmenopausal women with RS 0-25 do not benefit from chemotherapy, whereas premenopausal women with similar scores may still derive significant benefit.<sup>5</sup>

These findings have led to a shift in clinical practice, sparing many patients from unnecessary chemotherapy while ensuring appropriate treatment for those at higher risk of recurrence.

### 3. Systemic Therapy Optimization

The optimization of systemic therapy has led to significant advancements in both neoadjuvant and post-neoadjuvant settings:

- **Neoadjuvant therapy**, initially used for inoperable disease, is now a standard approach for many early-stage cancers, allowing for treatment response assessment and potential escalation or de-escalation strategies.
- **Post-neoadjuvant therapy** has become crucial in high-risk patients with residual disease, based on trials such as CREATE-X (capecitabine for triple-negative breast cancer) and KATHERINE (T-DM1 for HER2-positive residual disease).<sup>6,7</sup>

### 4. Antibody-Drug Conjugates (ADCs)

ADCs are designed to deliver chemotherapy directly to cancer cells by combining a monoclonal antibody that targets specific cancer cell antigens with a cytotoxic agent. This allows the drug to be concentrated at the tumor site, reducing the systemic side effects typically associated with traditional chemotherapy. ADCs are at the forefront of precision medicine: by targeting specific biomarkers, ADCs provide a more personalized treatment approach that improves efficacy while reducing side effects.

Sacituzumab govitecan is an ADC that combines an anti-Trop-2 monoclonal antibody with SN-38, a potent chemotherapy agent. Trop-2 is overexpressed on the surface of many cancers, including TNBC, making it an ideal target for this therapy. In clinical trials, sacituzumab govitecan reduced the risk of progression and death compared to traditional chemotherapy in patients with metastatic breast cancer who had previously received multiple lines of therapy.<sup>8,9</sup>

T-DXd (Trastuzumab deruxtecan) is an ADC designed for the treatment of HER2-positive breast cancer, a subtype in which the HER2 protein is overexpressed on the surface of cancer cells. HER2-positive breast cancer is aggressive and usually requires targeted therapies. T-DXd combines trastuzumab, a monoclonal antibody that targets HER2, with deruxtecan, a chemotherapy agent. This combination allows T-DXd to deliver the chemotherapy directly to HER2-positive tumor cells, significantly improving the treatment effectiveness.

In clinical trials, T-DXd has demonstrated impressive results in patients with HER2-positive metastatic breast cancer who had previously failed other HER2-targeted therapies, including trastuzumab and pertuzumab. The long-term analysis of the pivotal Destiny-Breast03 trial reported the longest median OS (52.6 months) in this disease setting with more than two-thirds of patients still alive at 3 years, reinforcing the role of T-DXd as a new standard of care for patients HER2-positive metastatic breast cancer.<sup>10</sup>

Moreover, T-DXd has also shown encouraging efficacy in patients with HER2-low breast cancer, a subset of tumors with low but detectable HER2 expression. Recent studies have highlighted that T-DXd can be effective in this population, offering a treatment option for patients previously considered ineligible for traditional HER2-targeted therapies. The DESTINY-Breast04 and 06 trials demonstrated that T-DXd significantly improved progression-free survival in patients with HER2-low breast cancer, marking a pivotal moment in the treatment of this tumor subtype. These findings broaden the potential use of T-DXd, offering new hope for patients with tumors that do not have high HER2 expression but still benefit from targeted therapy.<sup>11,12</sup>

Ongoing clinical trials are also exploring the use of ADCs in different subtypes of breast cancer, expanding their applicability and improving outcomes for a broader group of patients.

### 5. Liquid Biopsy

Liquid biopsies represent a groundbreaking, non-invasive technique in cancer diagnosis and surveillance, providing real-time insights into tumor genetics and behavior. This approach involves analyzing circulating tumor DNA (ctDNA) or specific biomarkers present in blood samples, offering a promising avenue for monitoring treatment response, detecting potential resistance mechanisms, and guiding timely therapy adjustment.<sup>13</sup>

Liquid biopsy has emerged as a valuable tool for detecting ESR1 mutations, which represent a significant mechanism of acquired resistance to endocrine therapy in hormone receptor-positive metastatic breast cancer. The detection of ESR1 mutations through ctDNA analysis provides a minimally invasive method to monitor treatment resistance in real-time, without the need for repeated tissue biopsies. Studies have shown that ESR1 mutations can be detected in the plasma of patients who have progressed on aromatase inhibitors, often before clinical or radiological evidence of progression. Liquid biopsy not only allows for early detection of these resistance-conferring mutations but also enables tracking their evolution and heterogeneity throughout treatment. This information has significant clinical implications, as patients with ESR1 mutations benefit to selective estrogen receptor degraders (SERDs) like elacestrant compared to aromatase inhibitors, potentially guiding treatment decisions and sequencing strategies.<sup>14</sup> Emerging evidence also suggests that monitoring the clearance of ESR1 mutations in ctDNA during



treatment may serve as an early predictor of response, offering an opportunity for timely intervention and therapy adjustment. 15

### Challenges and Future Perspectives

Despite significant advances, several challenges remain in the widespread adoption of precision medicine:

- **Healthcare disparities:** Access to diagnostic resources for early detection, genetic testing and targeted therapies is limited in many low-resource settings, leading to disparities in outcomes. 2
- **Tumor complexity:** Breast cancer is highly heterogeneous, and resistance to targeted therapies remains a significant hurdle.

Precision medicine is transforming breast cancer care. While significant progress has been made, continued research, equitable healthcare access, and interdisciplinary collaboration are essential to fully realize the potential of personalized treatment, ensuring the optimal outcome for each patient.

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# 5th Annual Marie Skłodowska-Curie Symposium on Cancer Research and Care

OECI invites its Members to Join the 5th Annual Marie Skłodowska-Curie Symposium on Cancer Research and Care, taking place September 3–5, 2025, in Warsaw, Poland.

This international event brings together leading minds in oncology research, clinical care, biotechnology, and health policy from across Europe, North America, and beyond.



5th Annual  
Marie Skłodowska-Curie  
Symposium on Cancer  
Research and Care



### Invitation

5th Annual Marie Skłodowska-Curie Symposium on Cancer Research and Care

Shared knowledge, shared goals: Advancing Cancer Research Together

Date: **3-5 September, 2025**

Location: **Warsaw, Poland**

The Marie Skłodowska-Curie Symposium on Cancer Research and Care (MSCS-CRC) fosters collaboration among cancer researchers and care providers from the U.S., Canada, and Central and Eastern European Countries (CECs). After four successful editions at Roswell Park Comprehensive Cancer Center in Buffalo (NY), this year will be held in Europe to enhance international dialogue in cancer research. This initiative focuses on accelerating new therapies, improving early detection, and raising awareness to enhance cancer care and quality of life for patients and families.

**If You are:**

- A cancer researcher or clinician interested in advancing treatment options
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★ **Key Areas of focus:**

- **Enhancing Cancer Prevention:** Developing innovative public health policies and raising awareness about cancer risks and preventive strategies.
- **Advancing Research Collaboration:** Creating a collaborative projects database to support early-phase clinical trials and preclinical developments.
- **Promoting Personalized Medicine:** Leveraging advancements in AI and immunotherapy to improve treatment strategies and patient outcomes.

**Agenda overview:**

<b>Day 1 – September 3, 2025:</b> <b>Public Health &amp; AI Innovations in Oncology</b> <ul style="list-style-type: none"><li>• <b>Innovative Public Health Policies:</b> Developing policies to enhance cancer prevention and screening.</li><li>• <b>Global Health Initiatives:</b> Addressing disparities in cancer care across the globe.</li><li>• <b>AI in Oncology:</b> Exploring the RCMC Project and advancements in personalized medicine.</li></ul>	<b>Day 2 – September 4, 2025:</b> <b>Breakthroughs in Oncology</b> <ul style="list-style-type: none"><li>• <b>Advancements in Immunotherapy:</b> Challenges and innovations in clinical settings.</li><li>• <b>Precision Medicine in Action:</b> Translating molecular science into tangible treatments.</li><li>• <b>Healthcare-Biotech Collaboration:</b> Strategies to accelerate innovation in cancer research.</li></ul>	<b>Day 3 – September 5, 2025:</b> <b>Emerging Innovations in Cancer Research</b> <ul style="list-style-type: none"><li>• <b>Innovative Public Health Policies:</b> Developing policies to enhance cancer prevention and screening.</li><li>• <b>Global Health Initiatives:</b> Addressing disparities in cancer care across the globe.</li><li>• <b>AI in Oncology:</b> Exploring the RCMC Project and advancements in personalized medicine.</li></ul>
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**Important dates:**

- Abstract Submission Opens: **April 15, 2025**
- Submission Deadline: **May 30, 2025**
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- **Naef K Basile Cancer Institute at the American University of Beirut Medical Center**, Beirut

### Lithuania

- ★ **National Cancer Institute**, Vilnius
- ★ **Vilnius University Hospital Santaros Klinikos**, Vilnius

### Luxembourg

- **Institut National du Cancer (INC)**, Strassen

### Moldova

- **Public Health Institution Oncological Institute**, Chisinau

### Norway

- ★ **Oslo Universitetssykehus (OUS)**, Oslo
- ★ **Helse Bergen HF (Haukeland University Hospital)**, Bergen
- ★ **Akershus University Hospital Trust**, Lørenskog

### Poland

- **Narodowy Instytut Onkologii im. Marii Skłodowskiej-Curie Państwowy Instytut Badawczy**, Warsaw
- **Wielkopolskie Centrum Onkologii**, Poznań

### Portugal

- ★ **Instituto Português de Oncologia do Porto Francisco Gentil, E.P.E. (IPO-Porto)**, Porto
- ★ **Instituto Português de Oncologia de Lisboa Francisco Gentil, E.P.E. (IPO-Lisboa)**, Lisbon
- ★ **Instituto Português de Oncologia de Coimbra Francisco Gentil, E.P.E. (IPO-Coimbra)**, Coimbra

### Romania

- **The “Prof. Dr. Ion Chiricuta” Institute of Oncology (IOCN)**, Cluj-Napoca
- **Institutul Oncologic “Prof. Dr Alexandru Trestioreanu” Bucuresti**, Bucharest

### Serbia

- **Oncology Institute of Vojvodina**, Sremska Kamenica

### Slovakia

- **Biomedicínske centrum Slovenskej akadémie vied**, Bratislava

### Slovenia

- ★ **Onkološki Inštitut Ljubljana**, Ljubljana

### Spain

- ★ **Vall d’Hebron Barcelona Campus Hospitalari**, Barcelona
- ★ **Cancer Center Clinica Universidad de Navarra**, Pamplona
- ★ **Fundación Instituto Valenciano de Oncología IVO**, Valencia
- ★ **Institut Català d’Oncologia ICO**, L’Hospitalet de Llobregat (Barcelona)
- ★ **Fundación Jiménez Díaz University Hospital**, Madrid
- ★ **Institut d’Oncologia de la Catalunya Sud Hospital Universitari Sant Joan de Reus**, Reus
- ★ **Hospital Universitario 12 de Octubre**, Madrid
- ★ **Clinic Barcelona Comprehensive Cancer Centre**, Barcelona
- ★ **Hospital Universitario Clínico San Carlos**, Madrid
- ★ **Hospital Universitario Puerta de Hierro Majadahonda**, Majadahonda
- **Centro Integral Oncológico Clara Campal**, Madrid
- **Hospital Universitario La Paz**, Valencia
- **Hospital Universitario Ramon Y Cajal**, Madrid
- **Hospital Clínico Universitario de Valencia (Departamento de Salud Clínico-Malvarrosa)**, Valencia
- **Hospital General Universitario Gregorio Marañón**, Madrid

### Sweden

- ★ **Karolinska Institute and University Hospital**, Stockholm
- ★ **Skånes Universitetssjukhus**, Lund
- ★ **Uppsala University Hospital**, Uppsala
- ★ **Sahlgrenska University Hospital**, Göteborg
- ★ **Linköping Comprehensive Cancer Center**, Linköping
- ★ **Norrlands Universitetssjukhus**, Umeå

### Switzerland

- **Comprehensive Cancer Center Zürich (CC CZ)**, Zurich

### Tanzania

- **The Aga Khan Hospital, Dar es Salaam**, Dar es Salaam

### The Netherlands

- **OncoZON Cancer Network**, Maastricht
- ★ **Netherlands Cancer Institute**, Amsterdam
- ★ **Erasmus MC Cancer Institute**, Rotterdam
- ★ **Maastricht University Medical Centre+**, Maastricht
- ★ **University Medical Center Groningen Comprehensive Cancer Center (UMCG-CCC)**, Groningen
- ★ **Rijnstate**, Arnhem
- **IKNL Integraal Kankercentrum Nederland**, Utrecht
- **Radboudumc Centrum voor Oncologie**, Nijmegen

### Turkey

- ★ **Anadolu Sağlık Merkezi**, Kocaeli
- **Dokuz Eylül Üniversitesi Onkoloji Enstitüsü**, Izmir
- **Türkiye Cancer Institute-TKE**, Instambul

### Ukraine

- **RE Kavetsky Institute of Experimental Pathology, Oncology and Radiobiology of National Academy of Sciences of Ukraine (IEPOR)**, Kyiv
- **National Cancer Institute of Ukraine**, Kyiv

### United Kingdom

- ★ **The Christie NHS Foundation Trust**, Manchester
- ★ **Cancer Research UK Cambridge Centre**, Cambridge
- **Viet Nam**
- **Bệnh viện K**, Hanoi

- **OECI Member A&D certified Comprehensive Cancer Network**
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- ★ **OECI Member in the A&D process**
- **OECI Member**



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