



# OECCI Magazine

Organisation of European  
Cancer Institutes

European Economic  
Interest Grouping

Number 1 - Year 7  
June 2023

A window  
on the past,  
a door to the  
OECCI future



**OECI**  
 Organisation  
 of European  
 Cancer Institutes  
 European Economic  
 Interest Grouping



*Oncology Days*

11<sup>th</sup>-14<sup>th</sup> June 2024 Helsinki, Finland

GENERAL ASSEMBLY  
 SCIENTIFIC CONFERENCES  
 AND RELATED EVENTS



DEVELOPING  
 THE FUTURE IN  
 COMPREHENSIVE  
 CANCER CARE

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OECI MAGAZINE n. 1-2023

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# The OECI Presidency 2018-2023: 5 years later

**Thierry Philip**<sup>1,2</sup>

- 1. OECI President
- 2. Curie Executive Board Chairman

My presidency started in June 2018 at the General Assembly of Brno. At that time, OECI was comprising 73 full members and 21 associate centres. I am proud to announce that in 2023 we have 104 full members (+31) and 28 associate members (+7), totalling 132 members of this European Economic Interest Grouping, which remains very special because we are an association of centres and not an association of individuals. We are the only European organisation of cancer institutes and the largest worldwide organisation of cancer centres. [Table 1](#) shows our organisation's substantial growth of over the last five years.

I have obviously not done anything on my own but with a highly involved Board ([Table 2](#)) - 9 members of which 2 women (including the past President, Professor Dominique de Valeriola) at the start in 2018. As of 2023, 3 women are part of the Board of 9 and we still have some work to do to progress towards the necessary balance.

The 2018 Board was composed of one Belgian, one Portuguese, one English, one Hungarian, one Norwegian, one Italian and one Dutch, i.e. a good European representation with only one member from an Eastern European country. Today, there is one French, one Italian, one German, one Spanish, one Polish, one Norwegian, one Dutch woman and one Slovenian member, thus resulting in a better representation between the West and the smaller countries.

The successive Boards shown in [Table 2](#) have increased the OECI budget from € 650.000 to almost € 10 Million ([Table 3](#)), and we have gone from a minor deficit of about € 8.000,00, to a surplus of over 2 million. This result is also thanks to the considerable support offered by the OECI General Manager, Claudio Lombardo and his teams in Genoa and Brussels.

It is important to underline the role of the Board members as ambassadors of OECI in their countries. The French example is quite significant: as the number of French members increased during this presidency from 13 to 22 with 2 associate members ([Table 4](#)), the number of French centres in the accreditation programme has been multiplied by 4.

It follows that the importance of the presence of our German and Spanish colleagues, two major countries where we need to progress in terms of membership, and of course in Poland and Hungary, seeing as the East/West inequalities are at the heart of the Board's and the General Assembly's concerns.

The good financial results are the result of our involvement on two major levels:

- the transformation of the Accreditation & Designation working group into an OECI core programme
- our strong involvement in major European projects under the leadership of Giovanni Apolone and Simon Oberst.

**Table 1 - OECI Membership modification from 2018 to 2023**

Full Members and Associate Members (Type A and Type B) from 2018 to 2023

	2018	2019	2020	2021	2022	2023
ASSOCIATE A	13	11	11	16	15	15
ASSOCIATE B	8	12	13	12	13	13
TOTAL ASSOCIATE	21	23	24	28	28	28
FULL MEMBER	73	79	80	82	95	104

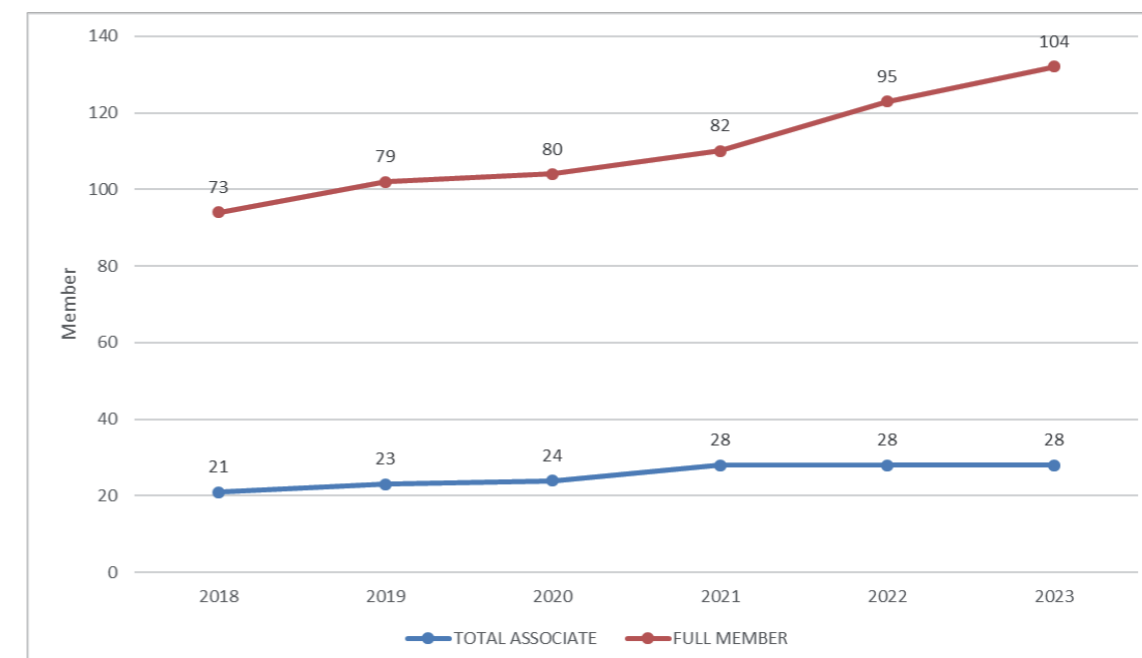


Table 2 - Board composition modification from 2018 to 2022

OECI BOARD Composition 2018		
<b>President</b>	Professor Thierry PHILIP	(for the period 2018-2021) whose mandate, as Member of the Executive Board, is to be renewed at the 2019 General Assembly
<b>Outgoing President</b>	Dr. Dominique de VALERIOLA	(whose mandate expires at the 2020 General Assembly)
<b>Executive Secretary</b>	Dr. José Maria LARANJA PONTES	(for the period 2018-2021) (whose term of office expires at the 2020 General Assembly)
<b>Elected member and Treasurer</b>	Professor Manuel LLOMBART FUERTES	(for the period 2018-2021) (whose term of office expires at the 2021 General Assembly)
<b>Elected member</b>	Professor Carlos Manuel SIMAO DA SILVA CALDAS	(whose term of office expires in principle at the 2019 General Assembly)
<b>Elected member</b>	Dr. Jozsef LÖVEY	(whose term of office expires at the 2021 General Assembly)
<b>Elected member</b>	Professor Gunnar SAETER	(whose term of office expires at the 2020 General Assembly)
<b>Elected member</b>	Dr. Giovanni APOLONE	(whose term of office expires at the 2021 General Assembly)
<b>Elected member</b>	Mrs. Marien VAN DER MEER	(whose term of office expires at the 2021 General Assembly)
OECI BOARD Composition 2019		
<b>President</b>	Professor Thierry PHILIP	(for the period 2018-2021)
<b>Outgoing President</b>	Dr. Dominique de VALERIOLA	(whose mandate expires at the 2020 General Assembly)
<b>Secretary General</b>	Dr. José Maria LARANJA PONTES	(for the period 2018-2021)
<b>Elected member and Treasurer</b>	Professor Manuel LLOMBART FUERTES	(for the period 2018-2021)
<b>Elected member</b>	Mr. Simon OBERST	(whose mandate expires in principle at the General Assembly of 2022)
<b>Elected member</b>	Dr. Jozsef LÖVEY	(whose term of office expires at the 2021 General Assembly)
<b>Elected member</b>	Professor Gunnar SAETER	(whose term of office expires at the 2020 General Assembly)
<b>Elected member</b>	Dr. Giovanni APOLONE	(whose term of office expires at the 2021 General Assembly)
<b>Elected member</b>	Mrs. Marien VAN DER MEER	(whose term of office expires at the 2021 General Assembly)
OECI BOARD Composition 2020		
<b>President</b>	Professor Thierry PHILIP	(until the General Assembly of 2022)
<b>Secretary General and Vice president</b>	Dr. Giovanni APOLONE	(for the period 2020-2023)
<b>Elected member and Treasurer</b>	Professor Manuel LLOMBART FUERTES	(for the period 2018-2021)
<b>Elected member</b>	Mr. Simon OBERST	(whose mandate will in principle expire at the General Assembly of 2022)
<b>Elected member</b>	Dr. Jozsef LÖVEY	(whose term of office will expire at the 2021 General Assembly)
<b>Elected member</b>	Professor Gunnar SAETER	(whose term of office will expire at the General Assembly of 2023)
<b>Elected member</b>	Professor Cristian BRANDTS	(whose mandate will expire at the General Assembly of 2023)
<b>Elected member</b>	Mrs. Marieneke Emilie VAN DER MEER	(whose mandate will expire at the General Assembly of 2021)

Table 2 - Board composition modification from 2018 to 2022

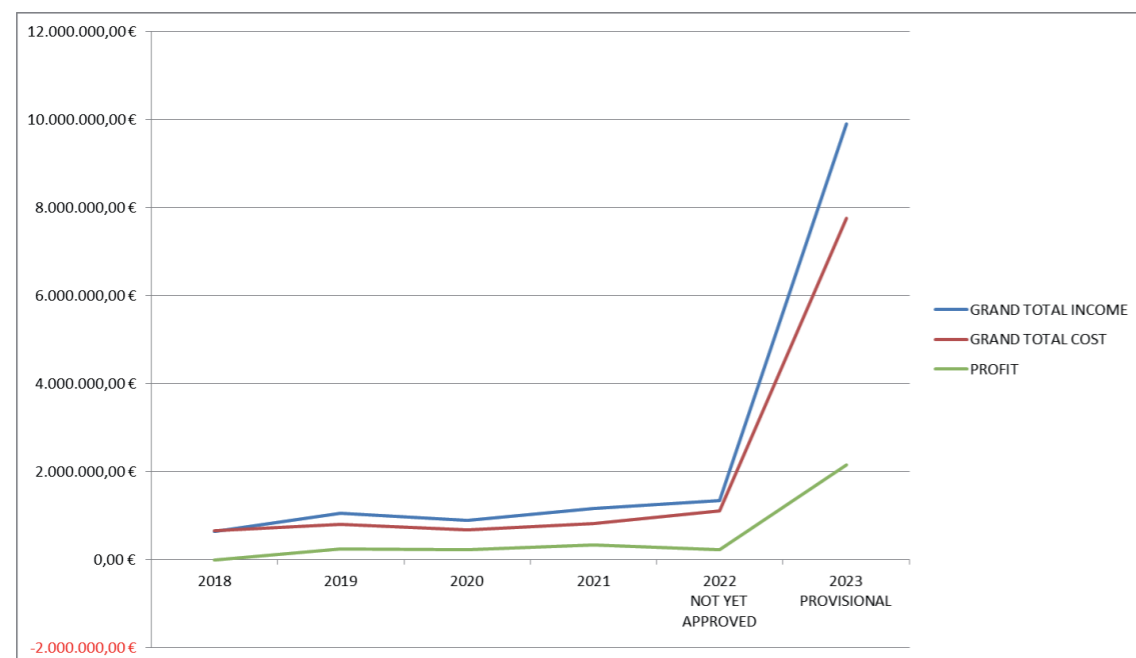
OECI BOARD Composition 2021		
<b>President</b>	Professor Thierry PHILIP	(until the 2022 General Assembly)
<b>Secretary General and Vice-President</b>	Dr. Giovanni APOLONE	(whose term of office will expire at the 2024 General Assembly)
<b>Elected member and Treasurer</b>	Professor Manuel LLOMBART FUERTES	(whose term of office will expire at the General Assembly of 2024)
<b>Elected member</b>	Mr. Simon OBERST	(whose mandate will in principle expire at the General Assembly of 2022)
<b>Elected member</b>	Dr. Jozsef LÖVEY	(whose term of office expires at the 2024 General Assembly)
<b>Elected member</b>	Professor Gunnar SAETER	(whose term of office will expire at the General Assembly of 2023)
<b>Elected member</b>	Professor Cristian BRANDTS	(whose term of office will expire at the General Assembly of 2023)
OECI BOARD Composition 2022		
<b>President</b>	Professor Thierry PHILIP	(whose term of office as a member of the Executive Board will expire at the 2025 General Assembly and whose term of office as President will expire at the 2023 General Assembly)
<b>Secretary General and Vice-President</b>	Dr. Giovanni APOLONE	(whose term of office will expire at the 2024 General Assembly)
<b>Elected member and Treasurer</b>	Professor Manuel LLOMBART FUERTES	(whose term of office will expire at the General Assembly of 2024)
<b>Elected member</b>	Professor Christian BRANDTS	(whose term of office will in principle expire at the General Assembly of 2023)
<b>Elected member</b>	Professor Maja CEMAZAR	(whose term of office will in principle at the General Assembly of 2025)
<b>Elected member</b>	Dr. Jozsef LÖVEY	(whose term of office will expire at the 2024 General Assembly)
<b>Elected member</b>	Professor Iwona LUGOWSKA	(whose term of office will expire at the General Assembly of 2025)
<b>Elected member</b>	Professor Gunnar SAETER	(whose term of office will expire at the General Assembly of 2023)
<b>Elected member</b>	Professor Jacqueline STOUTHARD	(whose term of office will expire at the General Assembly of 2025)

Since 2018, we participated to several EC actions. Below the list of Projects, Joint Actions and Coordination and Support Actions where we have been or we are still involved:

- The Joint-action JARC on rare cancer, 2016-2019
- IPAC JA 2018-2021: Innovative partnership for action against cancer control in Europe
- Interact Europe: Innovative collaboration for inter speciality cancer training in Europe
- Integrated and standardized NGS workflows for Personalised therapy - Instand-NGS4P, 2020-2024
- Improving cancer care coordination and screening in Latvia and Slovakia – ICCCS (LATVIA DG REFORM), 2022-2024
- Network of Comprehensive Cancer Centres: Preparatory activities on creation of National CCCs and EU Networking, 2022-2024
- Joint Action on European Networks of Expertise – JANE, 2022-2024
- A Coordination and Support Action to prepare UNCAN.eu platform, 2022-2024
- European Commission Initiative on Breast Cancer to improve quality of care and to reduce inequality in Europe – ECIBC, 2023-2023
- Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe- EUonQoL, 2022-2023
- Comprehensive Cancer infrastructures 4 Europe – CCIAEU, 2023-2025

**Table 3 - OECl Balance from 2018 to 2023**

RESULTS	2018	2019	2020	2021	2022 NOT YET APPROVED	2023 PROVISIONAL
GRAND TOTAL INCOME	637.022,88	1.041.130,13	882.876,96	1.161.500,00	1.332.238,20	9.898.934,52
GRAND TOTAL COSTE	645.572,92	804.021,44	665.449,43	824.545,84	1.103.162,46	7.754.366,00
<b>PROFIT</b>	<b>-8.550,84</b>	<b>237.108,69</b>	<b>217.427,53</b>	<b>336.954,16</b>	<b>229.075,74</b>	<b>2.144.568,52</b>



**Table 4**



**French Members certified from 2018 to 2023**

	2018	2019	2020	2021	2022	2023
ACCREDITATED	2	3	4	6	8	8
IN ACCREDITATION	1	3	4	4	5	5

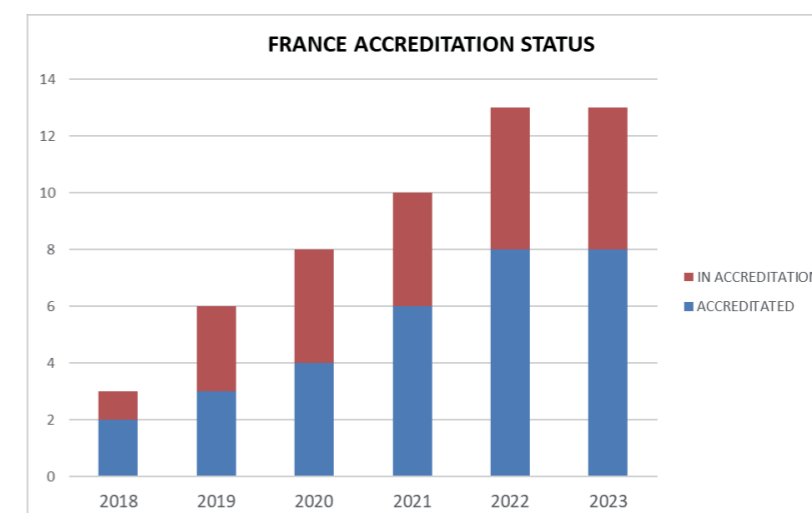
The adventure is only beginning and we are aware that great revolutions entail fundamental changes and significant responsibilities. As we cooperate to achieve the impactful results required by the EC, we bear in mind that OECl is not embarking in this venture to unexplored lands, but to use available resources and collaborate effectively to find the right balance in the complexity of today's cancer landscape and deliver our patients the answers they expect.

From 2021, in anticipation of the next presidency, Professor Giovanni Apolone has been asked to cover the role of executive president elect for European affairs. This choice and the considerable help offered by the other members of the Board and the team around Simon Oberst allow this European issues to be in continuity and will be part of the 2023-2026 objectives outlined in this same issue by Giovanni Apolone.

The patient work of the "Biobanks and Molecular Pathobiology" working party led by Giorgio Stanta and the considerable work that is reaching maturity and therefore the publication stage of our "Cancer Economics" working party must also be highlighted.

The «Cancer Outcomes Research» working party has resulted in the creation of DIGICORE, which is part of your Board's balance sheet and will be reported on in detail.

Lastly, the «Collaboration for Good Practices with Patients» group has produced a lot of work in each of our centres and has enabled this topic to be often at the heart of the post-accreditation Improvement Plan. An important agreement with the European Cancer Patients Coalition has been signed in 2022 and we are in the process of restructuring this working party which should become as important a programme as the Accreditation and Designation Programme in the future of OECl.



**Table 5 - OECI Full Members certified or in the A&D Programme from 2018 to 2023**

	2018	2019	2020	2021	2022	2023
ACCREDITED	32	35	35	40	49	50
IN ACCREDITATION	6	7	13	15	15	16

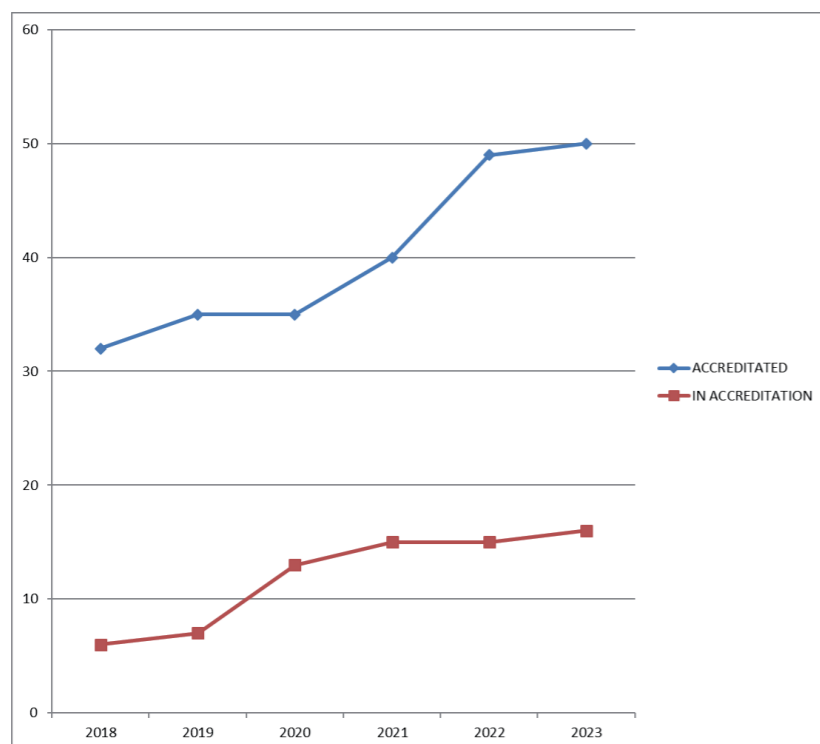


Table 5 shows the considerable increase in members who have joined our flagship accreditation programme. In 2018, 32 of our 73 members were accredited (48%), compared to 2023, when 50 of our 104 members are accredited (still 48%). If we add those who are in the programme we arrive at 63% of our accredited members, which is considerable. During this period the number of auditors doubled (43 to 83), with 5 auditor training courses being organised. I will not comment further on this OECI flagship programme.

This 2018-2023 period was also marked by the launch of the Cancer Mission (two of us, including your President, were members of the General Assembly) and that of the Parliament and the Commission leading to Europe's Cancer Beating Plan. The OECI Board was thoroughly involved in these initiatives, particularly (but not only) on the question of Comprehensive Cancer Centres, Comprehensive Cancer Centre Networks and Infrastructures.

OECI has been a key player in the Cancer Mission and the Cancer Beating Plan. We have contributed extensively, in particular through significant publications in peer-reviewed journals (Table 6) and in our OECI magazine

**Table 6 - OECI Scientific Papers 2018-2023**

**Cancer precision medicine today: Towards omic information in healthcare systems**

Norbert Maggi, Roberta Gazzarata, Carmelina Ruggiero, **Claudio Lombardo** and Mauro Giacomini  
*Tumori Journal* 1– 9 - 2018

**Vision 2030 for the optimal approach to cancer research and care in Europe: A mission or a network of networks?**

Thierry Philip, Geneviève Almouzni and Philip Poortmans  
*Tumori Journal* - 1–6 - 2018

**What could be a cancer mission objective if we join our forces in the fight against cancer?**

Thierry Philip, Sakari Karjalainen, Francesco De Lorenzo, Kathi Apostolidis, **Claudio Lombardo**, Mef Nilbert, Denis Lacombe, Philip Poortmans, Tit Albrecht, Pamela Kearns and Gilles Vassal  
*Tumori Journal* - 2019, Vol. 105(6) 447– 455

**100 European core quality standards for cancer care and research centres**

**Simon Oberst**, Wim van Harten, Gunnar Saeter, Peter Nagy, Jean Benoit Burrion, Jozsef Lovey, **Thierry Philip**  
*Lancet Oncology* – Volume 21, Issue 8 – 1009-1011 August 2020

**Towards a cancer mission in Horizon Europe: recommendations**

Anton Berns, Ulrik Ringborg, Julio E. Celis, Manuel Heitor, Neil K. Aaronson, Nancy Abou-Zeid, Hans-Olov Adami, Kathi Apostolidis, Michael Baumann, Alberto Bardelli, Rene Bernards, Yvonne Brandberg, Carlos Caldas, Fabien Calvo, Caroline Dive, Angelika Eggert, Alexander Eggermont, Carolina Espina, Frederik Falkenburg, Jerome Foucaud, Douglas Hanahan, Ulrike Helbig, Bengt Jonsson, Mette Kalager, Sakari Karjalainen, Miklos Kasler, Pamela Kearns, Klasarre, Denis Lacombe, Francesco de Lorenzo, Françoise Meunier, Gerd Nettekoven, **Simon Oberst**, Peter Nagy, **Thierry Philip**, Richard Price, Joachim Schulz, Eric Solary, Peter Strang, Josep Taberner and Emile Voest  
*Molecular Oncology* 14 (2020) 1589–1615 - 2020

**Analysing the attributes of Comprehensive Cancer Centres and Cancer Centres across Europe to identify key hallmarks**

Sebastian Kehroesser, **Simon Oberst**, Willien Westerhuis, Astrid Wendler, Anke Wind, Harriët Blaauwgeers, Jean-Benoit Burrion, Péter Nagy, Gunnar Saeter, Eva Gustafsson, Paolo De Paoli, József Lovey, **Claudio Lombardo**, **Thierry Philip**, Dominique de Valeriola, Marjet Docter, Femke Boomsma, Mahasti Saghatchian, Marek Svoboda, Irene Philip, Francesco Monetti, Henk Hummel, Gordon McVie, Renée Otter, Wim van Harten  
*Mol Oncol.* 2021;15(5):1277—1288.

**Conquer cancer for everyone?**

Augusto Caraceni, **Giovanni Apolone**  
*The Lancet Oncology* 2021; 22(5):583–4

**A focused ethnography in the context of a European cancer research hospital accreditation program**

Elisa Mazzini, Francesco Soncini, Loredana Cerullo, Lucia Genovese, **Giovanni Apolone**, Luca Ghirotto, Massimo Costantini  
*BMC Health Services Research* (2021) 21:446

**Use of information and communication technologies (ICTs) in cancer multidisciplinary team meetings: an explorative study based on EU healthcare professionals**

Joan Prades, Cristina Coll-Ortega, Lissandra Dal Lago, Karolien Goffin, Eugen Javor, **Claudio Lombardo**, Johan de Munter, Jordi Ponce, Daniele Regge, Ramón Salazar, Vincenzo Valentini, Josep M Borrás  
*BMJ Open* 2022; Oct 6; 12(10)

**European Groundshot – addressing Europe's cancer research challenges: a Lancet Oncology Commission**

Mark Lawler, Lynne Davies, Simon Oberst, Kathy Oliver, Prof Alexander Eggermont, et al  
*The Lancet Oncology Commission* | Vol. 24, Issue 1, 11-56, January 2023

**Evaluating comprehensive cancer networks; a review of standards and evaluation methods for care networks to inform a comparison with the OECI comprehensive cancer network standards**

Anke Wind, **Simon Oberst**, Willien Westerhuis, Harriet Blaauwgeers, Gunnar Sæter, Paolo de Paoli, Peter Nagy, Jean-Benoit Burrion, Eva Jolly, Jozsef Lovey and Wim van Harten  
*ACTA ONCOLOGICA* 2023, Vol. 62, No. 1, 15–24

**Quality of Life in Oncology: Measuring What Matters for Cancer Patients and Survivors in Europe: The EUonQol Project.**

**Apolone G, Brunelli C.**  
*Journal of Ambulatory Care Management* 2023;46(2):139–42

**Table 7 - List of Oncology Days with titles of Scientific Conferences from 2019 to 2023**

• **2019 – BARI**

Scientific Conference:

**Tackling tumor heterogeneity:**

**Biological, Laboratory, Clinical and Regulatory Implications**

Plenary Lecture

TUMOR CLINICAL HETEROGENEITY: STATE OF THE ART

**Christian Rolfo** (video-conference)

1<sup>st</sup> Session - BIOLOGICAL HETEROGENEITY

2<sup>nd</sup> Session - PHASE I CLINICAL, MASTER PROTOCOLS AND REGULATORY APPROACHES

3<sup>rd</sup> Session - ROLE OF NATIONAL AND EUROPEAN NETWORK

• **2021 – MILAN**

Scientific conference:

**Cancer Quality Session - Evaluating Quality Improvement in European Cancer Services**

Plenary Lecture

EVALUATING QUALITY IN CANCER CARE AND RESEARCH IN EUROPE

**Simon Oberst**

1<sup>st</sup> Workshop - DEVELOPMENTS IN THE OECI QUALITY PROGRAMME

2<sup>nd</sup> Workshop - MEASURING QUALITY OUTCOMES

3<sup>rd</sup> Workshop - QUALITY IN THE CONTEXT OF THE AIMS OF THE EU CANCER MISSION AND EUROPE'S BEATING CANCER PLAN

• **2022 – VALENCIA**

Scientific Conference:

**ARTIFICIAL INTELLIGENCE: a tool in modern and future oncology**

Opening lecture

COMPREHENSIVE CANCER CENTERS IN EUROPE: OECI AND EUROPEAN ALIGNMENT

**Thierry Philip**

1<sup>st</sup> Session - AI IN DIAGNOSTIC PROCEDURES

2<sup>nd</sup> Session - AI IN CLINICAL OUTCOME PREDICTION

Key Lecture: BIG DATA & AI - **Alfonso Valencia**

3<sup>rd</sup> Session - AI FUTURE DIRECTIONS

4<sup>th</sup> Session - APPLICATIONS OF AI IN ONCOLOGY

Key Lecture: THE CHALLENGE OF AI FOR OECI MEMBERS - **Giovanni Apolone**

I would like to remind you that the Board is only the emanation of your General Assembly and that the "Oncology Days" are at the heart of the feedback that the Board owes to the OECI Members, in particular the General Assembly and the activity and financial reports.

If Covid did not allow us to meet in 2020, we were able to do so (Table 7) in Bari in 2019, in Milan in virtual format in 2021, in Valencia in 2022 and in Paris in 2023.

Our efforts and results have been recognised by the cancer community, and we hope that in a near future OECI may receive a formal recognition by the EU. This is a task I entrust to my successor, Giovanni Apolone – who is presently chairing OECI's EU Projects and Affairs tasks- to enhance the Grouping's role in the EU Research Space.

It is therefore safe to say that OECI has a clear vision of its roadmap. We are fully aware that no other organisation could better galvanise participation in the main European initiatives geared towards driving research and organising national health systems to better fit the ambitious European challenges, namely Europe's the Beating Cancer Plan and the Cancer Mission.

In the coming years, we will be turning our eye toward younger generations: it is time to invest in providing them with the needed instruments to participate in the daily changing world where innovation of technologies, methodologies, and treatments are creating a difficult journey for everyone. This is where we call our Members to participate with their best tools and support a global growth.

To implement this ambitious agenda, OECI will develop young talent by organising a series of training courses on designing and managing EC applications and projects. This initiative aims to develop a new class of experts needed by the global oncology community to tackle future challenges and reduce the burden of cancer.

In addition, it is imperative that we actively engage and listen to our patients. OECI will cooperate with ECPC to develop a European model for survivorship based on the close collaboration of Cancer centres/networks and patient organisations.

Finally, I would like to spend a few words on the current geopolitical scenario, which has seen Russia's attack on Ukraine bring disastrous economic and social consequences. Amongst them, it has forced a break in communication with our Russian Colleagues. We look forward to re-establishing a dialogue with them soon, as we do not hold them responsible for this drama and are aware of the important role they played in the creation of OECI, an Organisation aiming to heal and unite. Science is the best way to overcome differences and obstacles.

However, at this point, all our efforts are geared towards helping our friends from Ukraine and Professor Vasyl Chekhun will be our honored guest speaker in the next Paris Meeting.

To conclude, I would like to thank the Board Members, Claudio Lombardo's team, as well as all the Members of the General Assembly for your trust during these five years.

I believe that OECI has made great progress thanks to the Accreditation & Designation Programme and to its major investment in European projects. As a result, the membership and budget have also grown considerably during this period.

The Board is proud of it, you can be proud of it and I am honoured to have had the opportunity to contribute to this growth as President of OECI.

A generation leap will occur in our organisation during Giovanni Apolone's term of office.

I have confidence in him! I have confidence in you!

# The OECI Presidency 2023-2026: connecting the dots

Giovanni Apolone<sup>1,2</sup>

1. President Elect OECI

2. Scientific Director Fondazione IRCCS Istituto Nazionale dei Tumori - Milan

OECI is the largest European network of cancer centres/institutes with more than one hundred members in Europe and beyond its borders. We are still suffering from the long effects resulting from the recent pandemic, which are affecting the economic, social and health care sectors. Despite the difficulties caused by COVID-19, during Professor Thierry Philip's presidency of, the OECI mission pushed ahead, with the practical objective of contributing to the EU cancer plan to reduce mortality, increase survival and improve quality of life. OECI efforts were mostly geared towards improving the quality of care and granting access to the best available and affordable treatments for all cancer patients.

Over the past 4 years, the OECI membership increased to more than 130 members, covering 26 EU Member States. Of these, some 50% of our Members are currently participating in the Accreditation & Designation Programme. Thanks to the support of the Board and of the General Management, the President gave a practical voice to OECI's mission by expanding its activities and contributing to the creation of a new independent Grouping aiming to make the best use of real world data through a common and federated digital platform (DIGICORE). Furthermore, he engaged OECI in a more active involvement in European actions, moving from the participation to projects coordinated by other entities to become a major player and even Coordinator of key cancer initiatives related to the Cancer Mission.

In the incoming three years of my Presidency, the keywords will be: continuity, trying to consolidate what is underway, sustainability, paying particular attention to the economic and financial aspects, and inclusion, trying to involve our members to a greater extent in OECI activities.

In this context, I would especially like to further expand on the third aspect. At the moment, OECI has three focuses: the A&D Programme, its four Working Groups and the participation in EU activities. OECI also has three main sources of funding, including the membership fees, the revenues from the A&D Programme and the financial support coming from our participation to EC activities. For the first time, in 2023, the latter constitutes OECI's main financial income. Strategies and applications are discussed and implemented through a solid and efficient governance based on several independent bodies including the President office, the Board of Directors and the General Assembly. This process - however democratic, with a final decisional power assigned to the General Assembly - only involves our members' health care personnel and researchers in strategic decisions to a limited extent, thus reducing their practical participation.

It follows that one of the objectives of my Presidency, in addition to ensuring continuity and sustainability, will be to broaden our Members' participation base, with particular attention to young generations and to countries that need to improve quality more than others.

How can this be achieved? We have to work together and develop focused initiatives geared towards specific actions to solve important issues I will closely examine as follows. First of all, including in the OECI Board other elected members representing the new European scenario and its emerging needs; secondly, giving a practical answer to the new needs by redirecting the Working Groups toward more relevant topics, with special attention to the one that regards patients participation and involvement; eventually, by increasing the participation of member institutions in projects coordinated by OECI; finally, opening up OECI to young generations through their inclusion and active participation in the decision-making and consultative bodies. To achieve the latter objective, it is mandatory to think and develop ad hoc initiatives, two of them the most useful and feasible: creating an Advisory Board of young colleagues to assist the President, and establishing continuing educational activities on OECI relevant topics, such as quality, developing and management of research projects, emerging research topics, data protection and patient's involvement in research.

In essence, transforming the points that now identify the OECI institutions on the map of Europe into a new living and participating entity, a more interactive network, a living community connected by a common objective and shared activities. It is essentially a matter of connecting the dots and keeping alive the system. A real network is something more than a list of members but a large number of people and institutions that have a connection with each other and work together as a system. To achieve the above goals, it is not sufficient to have a well-oiled "management machine" and a Programme, we need the active participation of all the members, we need to hear their voices, to be able to give answer, to support the less developed countries because patients is the focus of our mandate and we are called to give practical answer to their expectations. Only as above briefly described, OECI will expand its critical mass of active participation, increase its visibility and assume a more relevant role in the European scenario, and may be beyond its borders, not only reactive to opportunities but proactive towards the various stakeholders and policy makers. Regarding this last point, OECI must succeed in becoming a priority partner of the European bodies dealing with quality and health, continuing the efforts initiated during the presidency of Prof. Thierry Philip, using the strength of a more connected and stronger community.

## List of possible initiatives during the 2023-2026 Presidency\*

- Enlargement of the OECI Board to include new Directors of Institutes
- Creation of an Advisory Board of young people
- Redirection and creation of new Working Groups on emerging topics
- Activation of courses on topics related to European projects
- Selection and co-financing of projects proposed by young researchers
- Reduction of fees for institutes in countries with economic and political problems
- Strengthening of OECI offices to increase the efficiency of coordination activities

\* Proposed by the President and discussed by the OECI Board

## OECI Participation to EC Activities

 <p><b>EUonQoL</b> Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe</p>	 <p><b>INTERACT-EUROPE</b> Innovative collaboration for Inter-specialty cancer training across Europe</p>	 <p><b>JANE</b> Joint Action on European Networks of Expertise</p>
 <p><b>4.UNCAN.eu</b> A Coordination and Support Action to prepare UNCAN.eu platform</p>	 <p><b>CraNE JA</b> Network of Comprehensive Cancer Centres: Preparatory activities on creation of National CCCs and EU Networking</p>	 <p><b>ICCCS (LATVIA DG REFORM)</b> Improving cancer care coordination and screening in Latvia and Slovakia</p>
 <p><b>ECIBC</b> European Commission Initiative on Breast Cancer</p>	 <p><b>Instand-NGS4P</b> Integrated and standardized NGS workflows for Personalised therapy</p>	 <p><b>CCI4EU</b> Comprehensive Cancer Infrastructures for Europe</p>



# The OECI witness: diving into the past and sustaining its future

**Claudio Lombardo<sup>1</sup>**  
1. OECI General Manager

At the end of a presidency as long as Thierry Philip's, it was natural for me to propose an issue of our Magazine that could emphasise the contributions of an enlightened presidency and, at the same time, plan for continuity with a future vision of a new presidency.

The largest worldwide network of cancer centres must have ambitious projects and programmes to prepare new generations for the incoming challenges. Future managers face the challenge of ensuring the continuity of a network born in 1979 when, on 14 May, in Dubrovnik, under the UICC chairmanship of Umberto Veronesi, some of the most prominent oncologists decided to establish the Organisation of European Cancer Institutes. The inspiring principles were few and simple, but we can still consider them as the foundation that should guide our actions today:

- to create greater cooperation among cancer centres and institutes in the field of cancer control, data collection and dissemination, and finally in collaborative research;
- to make sure that the membership of the new organisation would be open only to the Cancer Institutes working solely in the field of cancer;
- to develop an interdisciplinary approach within the Institute, which would be a prerequisite for membership;
- to improve the West-East collaboration to overcome political obstacles unrelated to cancer treatment and the physician's right to offer patients the best available treatment;
- to implement a cancer network to interact with the Association of American Cancer Institutes, founded in 1959;
- to establish links with other regional networks in the starting phase, such as Latin America, Asia, and the Middle East.

In 1986, as a young biochemist at the lysosomal diseases laboratory of the Giannina Gaslini Pediatric Institute in Genoa, I had been invited as a visiting professor at UCLA. After this experience, I applied for the position of deputy director of the Clinical Pathology laboratory at the National Cancer Institute of Genoa. A few months later, Professor Leonardo Santi, scientific director of the Institute, invited me to cover the position of head of the scientific secretariat, a fundamental department for the development of the young Institute. I immediately realised the importance of investing in international relations because the fledgling European collaborative research would become a real challenge for the years to come. In fact, in 1986, the II EU RTD Framework Programme was under preparation, to be officially launched with the signing of the Single European Act. It was with this Programme that "Research" became for the first time a policy and a Community responsibility.

Prof. Paolo Fasella, an internationally renowned scientist, and General Director of DG Research (at the time DG XII) for 14 years, was a fundamental engine in the birth of European RST Programmes. Professor Fasella collaborated with research Commissioners Etienne Davignon, Karl-Heinz Narjes, Filippo Pandolfi, Antonio Ruberti and Edith Cresson: a strong Italy-France contribution to building the European RST. In the same year, as representative of the Genoa Cancer Centre, I participated in Heidelberg at the OECI General Assembly under the chair of Professor Claude Lagarde, Director of the University Cancer Institute of Bordeaux "Bergonié". This meeting led me to discover the large potential of OECI.

At that time, meetings consisted of presentations of administrative matters by the UICC Executive Secretary, followed by a discussion of issues of possible joint interest. The following year in Bratislava, in the Slovak Republic, still part of the USSR, I suggested to the directors (about 30 participants) to establish a working group for the exchange of clinical data. Nobody knew who I was but everyone

immediately understood my spirit of initiative, in particular Prof. Natale Cascinelli, deputy director of the National Cancer Institute in Milan, who promoted my formal presence in the OECI Board in the years to come.

Since that day, my life and the history of OECI have followed a parallel but converging path towards a common goal: to create a cancer organisation enabling all patients to receive the best available treatments. Over the years, under the presidencies of Sir Walter Bodmer, Professor Harold zur Hausen, Nobel Prize for Medicine 2008, and Professor Andrzej Kulakowsky, my presence in OECI increasingly assumed an active role.

In 1998, when I started my diplomatic assignment as First Counsellor at the Italian Embassy in Brussels and at NATO, I had the chance to meet Professor Guy Storme, OECI President and director of the UZ-VUB cancer centre, who invited me to the OECI Programme Committee. During the OECI presidency of Professor Thomas Tursz, I realised that the translational process could only be achieved with a more flexible legal entity, and, above all, with a formal recognition of the EU as European body. Therefore, I proposed the establishment of a new Cancer Organisation that would allow collaboration among the most prominent and innovative OECI cancer institutes. At that time, OECI was still under the coordination of UICC, whose Executive Secretary, Isabelle Mortara, also covered the role of Executive Secretary of OECI. Therefore, in practice, OECI was a Swiss organisation.

In 2000, following the conference Towards a European Space for Oncology, supported by the Italian Embassy in Brussels, the European Economic Interest Grouping LINC Liaison Network for Cancer, chaired by Guy Storme, was established and headquartered in Brussels at the Fondation Universitaire. LINC comprised 23 prominent cancer centres/institutes and immediately acquired the coordination of the European project TRANSFOG under the leadership of Professor Enzo Medico of the Cancer Institute of Candiolo (Turin). At the same time, the OECI President, Professor Tursz, developed the idea of establishing a Programme for quality assessment in oncology. I did not hesitate to support the idea by organising, under the leadership of Thomas, a meeting of a few OECI representatives: that must be considered the starting point of the OECI Quality Programme. The crucial role in the birth of what is now known as the OECI Accreditation and Designation Programme, should be recognised to a young oncologist of the Institut Gustav Roussy, Mahasti Saghatchian. OECI and LINC shared the same Board except for the President, but in 2004, in agreement with the presidents of OECI (Tursz) and of LINC (Storme), it was decided to interrupt the activities of OECI and, at the same time, LINC agreed to change its name becoming the "New OECI", which is today's legal structure.

Nearly 20 years forward, the OECI membership has grown to over 130 Members, making OECI the world's largest network of cancer centres/institutes. I hereby remember the presidencies of Ulrik Ringborg, Marco Pierotti, Wim van Harten, Dominique de Valeriola and Thierry Philip, which have contributed in different ways to the growth of our Organisation with their knowledge and experience. We do not have to forget the support of Antonio Lombart Bosch, who never covered the position of President but received the recognition of *Honorary President*.

In offering my loyalty, honesty and competence, I believe I have contributed to the innovation process of the Organisation with my ideas, among which I mention the OECI Oncology Days, whose first edition took place in Genoa in 2008 and has now become a classic appointment of the European cancer community. The event every year, for three days, brings together our Members to discuss scientific topics of great relevance and global interest.

During its Presidency, Thierry Philip reinforced the concept of a Europe where there are no political or geographical borders and where the right of all patients to receive the best care is affirmed. Unfortunately, our founders' dream of bringing the West closer to the East was interrupted by a senseless tragedy, which also distanced us from our Russian colleagues who had begun an essential path of interaction, which I hope will soon be re-established.

Giovanni Apolone, President of the OECI since 16 June 2023, receives a rich and heavy heritage which

I am sure he will honour with a programme that will inspire greater intensity in the participation of the OECI in EU actions and in training future leaders. I will be supporting his presidency with the same loyalty and enthusiasm that have characterized my work at OECI so far.

I thank the dozens of collaborators who have allowed me to achieve successful results since the beginning of my work in the Organisation. In particular, I would like to mention Lutgarde d'Hauwers, former head of the GEIE-LINC and OECI secretariat in Brussels. I am also grateful to my collaborators at the OECI Liaison Office in Genoa and in the Brussels Office who have over the years acquired the needed skills to ensure the management of all the OECI activities. I wish them a bright future at OECI.

I wish also dedicate a few words to **Professor Leonardo Santi**, who believed in me by entrusting me with tasks that perhaps I was not prepared to tackle but which I have carried out with loyalty and diligence. During about 40 years, I referred to him as "professor", and only in a recent meeting, at 96 years old, he asked me, "Dr. Lombardo, why don't you call me Leonardo?". This is the right opportunity to say: **"Thanks Leonardo, I'm sure that Genoa, your adopted city, will also remember you with the same gratitude and respect that I have for you"**.

I hope that this article, written for those who do not yet know the origins and history of OECI, will help not to forget those who, with their perseverance and dedication, have allowed OECI to become the reality it is today.



Above  
OECI and LINC Board Meeting –  
Advanced Biotechnology Centre  
Genoa – April 2001  
Standing from left: Leonardo  
Santi, Guy Storme, Thomas Tursz,  
Adriana Albini  
Bottom from left: Claudio  
Lombardo and the Italian  
cosmonaut Franco Malerba



Left  
Genoa 2008  
OECI Oncology Days 1st Edition  
Handover of the OECI Presidency  
from Ulrich Ringborg to Marco  
Pierotti



Genoa 2008 – OECI Oncology Days 1st Edition and OECI 30th Anniversary  
From the left Claudio Lombardo, The Captain of the Palinuro Italian Navy School,  
Riccardo Rosso, Ulrich Ringborg, Marco Pierotti and Mr. Guano, the Pastry Chef

# Policy on diversity, equity and inclusion at the Netherlands Cancer Institute: an example of how gender equality should be applied

Jaqueline Stouthard<sup>1,2,3</sup> and Joana Silva<sup>1,4</sup>

1. The Netherlands Cancer Institute

2. Elected member OECI Board

3. Chairperson OECI Gender Equality Committee

4. Co-founder of the Diversity, Equity and Inclusion Committee and the Green Labs at the NKI

## Introduction

On September 2021, the EC Directorate General for Research and Innovation adopted the **“Horizon Europe Guidance on Gender Equality Plans (GEPs)”**

The Organisation of European Cancer Institutes “OECI”, in its capacity of European Economic Interest Grouping is not bound to devise and implement a Gender Equality Plan “GEP”. In fact OECI activities are mainly based on the voluntary participation of OECI Member representatives to the Grouping’s Working Groups, A&D Programme and EC Projects.

OECI considers it essential to ensure that our efforts are geared towards finding ways of engaging equally qualified women and men in all aspects of the Organisation. We want to ensure equality of treatment based on merit, and an inclusive culture that considers gender diversity as an asset to the strength and performance of teams. As an organisation, we are convinced that our success crucially hinges on the diversity, commitment and engagement of the entire OECI team.

All the above stated, OECI believes adopting a GEP is a moral duty of the Organisation. The OECI GEP will mainly be geared towards fostering the adoption and implementation of GEPs throughout the OECI Membership and the OECI service providers. The Plan, published at <https://www.oeci.eu/GenderEqualityStrategy.aspx> is the outcome of a self-assessment exercise on the gender equality status within the OECI. It covers a period of 3 years (2022 – 2025), and it was approved unanimously by the OECI Board of June 14, 2022 when I was appointed as Chairperson of the OECI Gender Equality Committee, the body to which is assigned the control of the respect of the GEP inside OECI and by its Members.

With this first article of my new position inside the OECI GEP, I want to introduce an example on how diversity has been adopted by the Netherlands Cancer Institute, one of the top European Comprehensive Cancer Centre.

In order to promote the participation of women to cancer research, a paper authored by two prominent women scientists follows this article.

## The NKI

The Netherlands Cancer Institute (NKI) in Amsterdam, the Netherlands, is an OECI accredited Comprehensive Cancer Centre consisting of both a research institute and a hospital focusing on cancer, with one board of directors. The hospital provides treatment and care for cancer patients facing the full range of tumor types, rehabilitation for patients and their relatives through our Center for Quality of Life, and early cancer detection through the Center for Early Diagnostics. The hospital also provides training for specialized oncology doctors, nurses and paramedics. The research at the NKI covers the whole spectrum of cancer research from discovery (fundamental) research through translational research to clinical research and research into (cost) benefits of new treatments. The organization has in total 3,314 employees 77% of whom are women and 23% are men.

## What we believe in

The NKI is a nationally and internationally recognized institute of excellence, regarding both our research and our patient care and education and training. As such, the Strategy 2030 paper rightly affords considerable attention to further developing our strategic priorities. The four core values underlying all of the NKI’s care and research (*committed, excellent, groundbreaking, together*) serve as our compass in developing our strategy. The NKI aims to offer every cancer patient the best possible personalized care, and to stop cancer from being a terminal illness. Implementing this mission and vision means that we will need to ensure diversity and inclusion at all levels of our organization, harnessing the unique perspective of each and every staff member to stay at the forefront of optimal patient care, both now and in the future.

We believe that we can only safeguard the effective care for our patients by implementing diversity and inclusion into our daily practice. It is key that we work together to create an inclusive environment at all levels of our organization. We at the NKI believe that a diverse employee population with differing perspectives, backgrounds and insights serves to enhance its creativity and powers of innovation<sup>1</sup>. What’s more: it helps us to improve the quality of care to better help our patients.

The NKI started structurally developing and implementing gender equality policies and measures in 2015. The NKI was one of the members of the EC-funded LIBRA consortium [www.eu-libra.eu/](http://www.eu-libra.eu/)

As a member of this consortium the NKI performed an initial assessment, developed a Gender Equality Plan (GEP), implemented actions, and was assessed for its improvements on gender equality at the end of the project in 2019. Using this experience and the tools that were provided and developed during the LIBRA project, our GEP was developed. During the preparation we benefitted from the vast experience and know-how available within the EU-LIFE consortium with its dedicated working group on gender equality <https://eu-life.eu> in which the NKI actively participates, and within the ACT Life Science Community of Practice <https://lifescicop.act-on-gender.eu> of which the NKI is an active associate member. Our GEP is based on the guidelines provided by the EC (Horizon Europe Guidance on Gender Equality Plans) and the national action plan of the Dutch Ministry of Education, Culture and Science <https://www.rijksoverheid.nl/actueel/nieuws/2020/09/01/nieuw-nationaal-actieplan-voor-diversiteit-en-inclusie>.

Our policy on diversity, equity and inclusion (DEI) is primarily focused on staff. Some aims and initiatives may affect patients because they are key to the way our employees carry out their work. Examples include trainings or workshops in culturally sensitive care: such training will affect both staff and patients. All mentions of the NKI in this document refer to the entire institute, patient care, education and research.

## What constitutes an inclusive organization?

An inclusive organization is an integrated community of people who relate to one another and identify with one another. Inclusion means that people relate to one another and recognize each other’s needs. An inclusive organization is also an environment in which the different talents and capacities of various staff members are optimized. In such an environment all employees, regardless of background, are able to reach their full potential.

## What we say, aim for, and do

The NKI has a prominent societal role. That’s why we aim for a diverse workforce and an inclusive organization. Our diversity policy can be defined as a policy that is targeted towards recognizing and valuing the differences between people. Among other things, it aims to reflect the diversity found within our society in its own employee base as well as in the culture of our organization. In addition, our policy focuses on combatting negative perceptions, cultural stereotypes, and exclusion. The NKI sees equality as the key to making room for differences (equal treatment and opportunities). But it also relates to the way we, as an organization, handle differences and become aware of the ways in which people are or can feel excluded.

1. (SER) Diversiteit in Bedrijf, information paper ‘Divers werven en selecteren’ (diversity in recruitment and selection), February 2021, p.6

**Anchoring DE&I in the organization**

Excellent care and research is inclusive, and that's why it's also strategically important to link diversity and inclusion targets to patient care, research, education and training, and to staff recruitment and promotion. As such, each department and the people working there have a professional duty to ensure diversity and inclusion. To support this process, we have to work towards creating awareness and avoiding prejudice, empowering staff and cooperating in various teams. Working on diversity, equity and inclusion is a shared responsibility. Individual leadership, with an eye for these values and with personal responsibility, is essential. The outcome of our efforts to achieve the goals on diversity, equity and inclusion will be documented each year in the NKI's annual report.

**Diverse leadership**

The NKI aims to be a reflection of the care sector when it comes to the share of women in leadership roles, women with a migratory background in leadership positions, and traditionally marginalized groups. To achieve this, we are aiming for a 50% growth in the number of women in leadership roles and a 10% growth in the number of women with a migratory background in leadership positions leading up to 2030. Our ultimate aim is to see as many staff members from differing backgrounds in leadership roles as possible. In 2023 we will have a plan of action in place, setting out how the NKI will achieve this goal. With this goal and deadline we fulfill the requirements of the Socio-economic Council (SER) charter that we committed to.

**Addressing hiring biases**

When we look at the overall staff that serves both our hospital and research institute, we currently consist of 77% female employees and 23% male employees. However, when we focus on research groups, we can see the number of female employees decrease significantly as you look at the higher positions (Fig. 1). Amongst the many factors that contribute to this scenario, a crucial one lies at the postdoctoral level. 42% of postdocs at the NKI are female, which may not be ideal, but does not seem very concerning. However, when we take a closer look at the distribution of postdocs per research group, we find that female group leaders hire 61% female postdocs vs 39% male postdocs, while male group leaders hire 32% female postdocs vs 68% male postdocs (Fig. 2). We should acknowledge the implicit bias in hiring and the consequences this has. As scientists, we believe in the importance of collecting and analyzing data in the most comprehensive way. With women representing only 36% of group leaders, it becomes clear how important it is to strive for a more balanced representation at top positions.

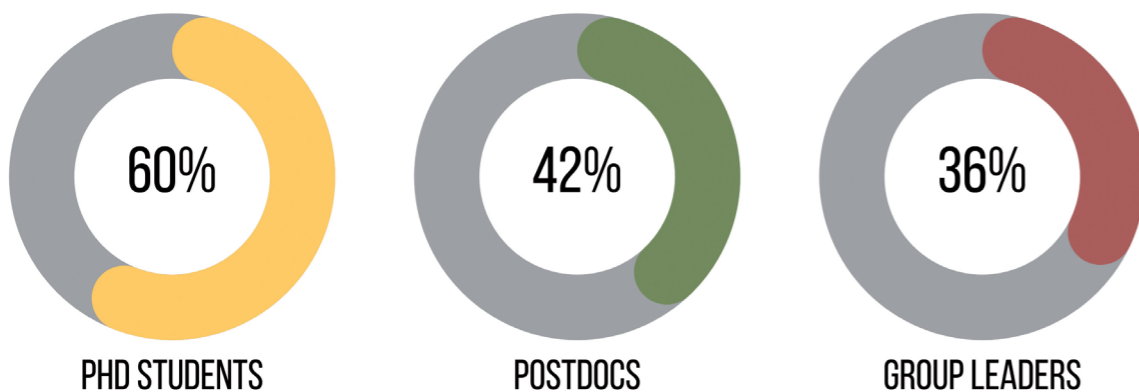


Figure 1 - Percentage of female employees at the NKI, distributed based on the different levels of seniority.

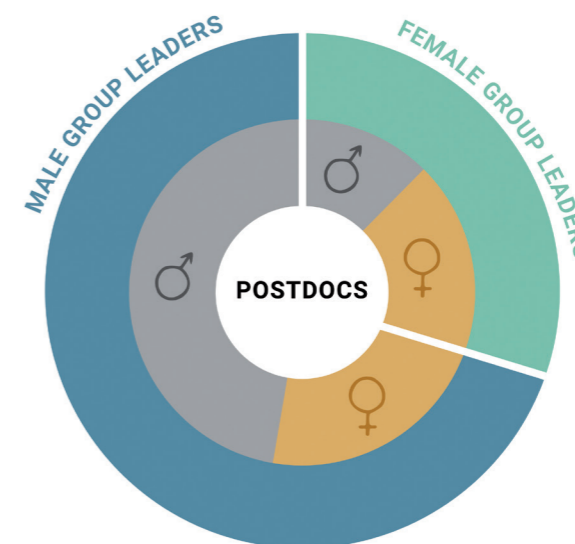


Figure 2 - Gender distribution of postdocs based on the gender of the hiring group.

**The NKI DEI committee**

The NKI DEI committee was founded in 2018 and is the result of a “bottom-up” approach, highlighting the active concerns and willingness to improve workplace culture coming from the staff. Currently, it consists of more than 20 volunteers, including group leaders, postdoctoral fellows and PhD students, who come together every few weeks to discuss which subjects should be tackled in order to achieve equitable work conditions. Some of the successful initiatives organized by the DEI committee include the implementation of gender-neutral bathrooms, the organization of several educational seminars on topics such as feminism and sex and gender disparities in biomedical research, and the celebration of important dates such as International Day of Women and Girls in Science.

**Training and courses**

For an inclusive work environment, it is important that everyone feels safe. To that end, all employees at the NKI have been invited to participate in the Active Bystander Training [www.activebystander.co.uk](http://www.activebystander.co.uk) and many teams did participate in 2022. An e-learning for care workers on culturally sensitive care also forms part of the orientation program for all newcomers.

**Our goals**

With our vision on diversity and inclusion we are taking the next steps towards fostering a culture where everyone feels welcome and valued, enjoys their work, and is granted equal opportunities. “The NKI gives you the space to be who you want to be, to make yourself heard and to want to join the conversation, because we see diversity and inclusion as major contributors to creativity and innovation. To realize these ambitions we have set a number of goals to work towards as an organization.”

**Definitions of Diversity, Equity and Inclusion**

*Diversity is about all the ways in which people can differ from one another. Such characteristics may be visible (such as age or skin color) or they may be invisible, such as gender identity or ethnicity*

*Equity is the key to making room for difference and means that everyone is afforded equal opportunities. Everyone's contribution is valuable.*

*Inclusion is about creating a culture in which people feel at home and interconnected with one another. An inclusive organization is one in which people are given the same opportunities and where they feel able safely to voice their ideas and concerns.*

# The Role of Cancer Patient Organizations in Comprehensive Cancer Centers

**Kathi Apostolidis<sup>1</sup> and Francesco De Lorenzo<sup>2</sup>**

1. Past President – Chair Scientific Committee – European Cancer Patient Coalition – ECPC

2. President - European Cancer Patient Coalition – ECPC

The ECPC plays an essential role in Europe by effectively acting as the voice of cancer patients. The organization is committed to representing patients’ interests and proposing patient-centric solutions to cancer-related problems. As such, the ECPC has been a critical stakeholder in defining cancer policy in Europe. Supported by the ECPC capacity building strategy, its member patient organisations have the vital role of advocating for cancer policy recommendations at the national level.

The OECI – Organisation of European Cancer Institutes and the ECPC – European Cancer Patient Coalition share the same interest for patient – centered, state of the art, cancer care in comprehensive cancer centers, whose services, staff and installations are evaluated regularly for quality assurance compliance, to the accreditation standards of OECI.

OECI and ECPC are the two major complementary actors in the fight against cancer and in all the cancer and survivorship related issues in Europe. They share similar objectives about quality of care, respect of patients preferences, cancer survivorship, research, and innovation.

These common interests were reflected in the Memorandum of Understanding (MoU) that the two organizations signed in 2015, in their collaboration towards the Joint Declaration of 2016 promoting Dialogue, Mutual Comprehension, Respect and Actions, and in the new MoU entered in 2023.

The principles that govern the OECI-ECPC MoU of 2023 are based on the role that the EU Cancer Plan and the Mission on Cancer reserve to Comprehensive Cancer Centers, to Comprehensive Cancer Infrastructures, to the recognition of the role of cancer patients, as equal partners in the decisions affecting their health and care, to the quality of cancer care, and to the commitment of both organizations to the principles of the Joint Declaration of 2016.

The length, complexity, and intensity of the cancer patient journey make the relation of the cancer patients to their treatment team and to their treating hospital a unique experience. The cancer patients who arrive at a cancer center for the first time, worried about the outcome of their encounter with their doctors, have an imposing, life changing experience, where everything is new and threatening. Newly diagnosed patients and their carers have to learn a lot, from finding their way within the cancer center to learning about health system’s procedures, to understanding unknown medical terms, and most importantly, to understand their doctors’ diagnosis and suggested treatment options.

Physicians and nurses, in today’s fast paced cancer care in large cancer centers, do not dispose of as much time as they would like to devote to each patient. In France, the medical appointment is by law fixed to 20’ minutes, while in other EU member states, it is only 10 minutes. Does the physician have sufficient time to get the patient’s history, what is the problem that brings him to his practice, what does the patient expect from the medical appointment? On the other hand, the cancer patient may have heard that he should be prepared for his medical appointment, writing down all questions, he may have for his doctor. It is though common that most cancer patients are so anxious during their medical appointment, that they forget most of what they planned to ask their doctor and remember only parts of what the physician explained.

ECPC had the opportunity, and I would correct the learning opportunity, to collaborate in 2014 with OECI in the revision of its accreditation manual and contribute in sharing the patient perspective on what cancer patients would expect from an accredited cancer center. In the “OECI Accreditation and Designation Programme - European Quality Standards for Cancer Networks”:

There is a Chapter 3 - [https://www.oeci.eu/Attachments/OECI\\_AD\\_MANUAL\\_3\\_2\\_2022.pdf](https://www.oeci.eu/Attachments/OECI_AD_MANUAL_3_2_2022.pdf) Patient involvement and empowerment, extending on seven pages and which has the following parts:

- Patient involvement
- Patient pathways
- Patient information
- Information to the patient on responsible person
- Access to the network
- Holistic care
- Patient satisfaction / experience
- Website information

Is that sufficient to cover the needs of today’s cancer patients? Surely not, but this Chapter constitutes a basis for patients to ask more from cancer centers and also to invite OECI to include other areas of interest to cancer patients, as well provide for cancer carers. The latter are quasi-absent from Chapter 8. Under Chapter 9 Education and Training, there are two parts dedicated to patients, namely:

- Patient education
- Patient education strategy

What is striking is that in the OECI Accreditation Programme there is no role foreseen for cancer patients and cancer patient organizations, other than that of the “patient”. Can cancer patients, survivors and cancer patient organizations have other roles than that of “patient” in a cancer center? The answer is yes, cancer patients and survivors can collaborate with cancer centers in co-creating their care, education, understanding and participation in cancer research, and this is what are going improve within the scope of the current MoU.

In 2016, OECI and ECPC collaborated for “**Solving issues, building relationships**”, a jointly developed program aiming to propose methods for building mutually satisfactory and meaningful for cancer patients’ relations among accredited cancer centers, cancer patients and their families, and cancer patient organizations operating in the region. The purpose of the program was to bring together the cancer centers and the neighboring cancer patient organizations, where these centers operate, to foster a better understanding of the priorities, preferences, and values of patients for their care, treatments and research questions they may have. The collaboration would also lead to get information about gaps in the cancer patient pathway within the cancer center, so that such gaps could be removed.

### What does a Collaborative Relationship look like?

- Mutual respect for skills & knowledge
- Honest, timely & clear communication
- Understanding & empathy
- Mutually agreed upon goals
- Shared planning & decision making
- Open two-way sharing of information
- Accessibility & responsiveness
- Joint evaluation of progress & successes
- Absence of labelling and blaming

### Focus on Collaboration

Patient engagement is an opportunity to create a third space where the focus is on the ‘we’ and not on patients, the system or providers. Through engagement the expertise and experience of all stakeholders can be heard and acted on!

### Respecting Expertise

Making engagement a priority supports patient & family advisors by acknowledging the importance of their stories and perspectives while also recognizing that they are the “**experts on their own experience**” not the health care professionals or administrators.

## Collaborative Relationship

In fact, the program “Solving issues, building relationships” was envisioned as a framework on how patient and patient organization involvement in the daily activities of cancer centers can be implemented through collaboration.

We searched for best practices in this area, that could guide us, but it was difficult to find documents and reports coming from a cancer center or a cancer patient organization and describing how they envisaged to collaborate together. Instead, we tried to envisage and describe what “collaborative relationships” between cancer centers, patients and patient organizations could be.

In late 2017, ECPC was already collaborating with the platform of the scientific and medical societies led by the European Academy of Cancer Sciences, where a lot was debated about the importance of Comprehensive Cancer Centers (CCCs) and the role they would play in the coming years in the programs that the Commission had under preparation for cancer care. The CCC concept, as well as that of CCCs networks that would have one CCC of Excellence per network, were a preferred topic of discussion in cancer conferences and congresses. At ECPC, we worked towards a better understanding of the CCCs on the European and national levels and of the role that cancer patients and cancer patient organizations would have in the new cancer care model in development.

The EU’s Beating Cancer Plan, published in 2021, recognizes the importance of active cancer patient involvement in their care and foresees the creation of ‘National Comprehensive Cancer Centre(s)’ in all Member States and an EU CCCs network by 2025. The pertinent EU funded projects and Joint Actions (Joint Action on Networks of Excellence-JANE, CRANE, CCI4EU, uncan.eu) of the EU Cancer Plan and Mission on Cancer are already ongoing, however, no practical provision has been made on how these CCCs will relate and collaborate with patients and cancer patient organizations.

Comprehensive cancer centers (CCCs) are at the heart of the landscape of cancer research, education and care in Europe. They are vital hubs where the historic gaps in the research to clinical care continuum are bridged. ECPC has sought to improve the level of collaboration and communication of cancer patients and families with the cancer centers in which they are treated. The active collaboration of patients and families with the hospitals /cancer centers, where they are treated, and now with the forthcoming CCCs, through open 2-way communication was the objective of the earlier ECPC’s collaboration with the Organization of European Cancer Institutes (OEI), which resulted in joint initiatives of ECPC members with OEI-certified comprehensive cancer centres and is now renewed in the current context of the EU Cancer Plan.

This already existing long standing collaboration between OEI and ECPC can now be further strengthened to respond to the needs of cancer patients, cancer patient organizations, of health care professionals, who will be working in the new CCCs but also in accredited cancer hospitals. Till now, there is no structured European relationship model between cancer centers and cancer patient organizations. Cancer patients and patient organizations continue to be seen by cancer centers only as people to be treated, “patients”, and not as equal partners, who can meaningfully contribute in improving cancer care delivery and co-create better cancer care services.

Over the 20 years of its operation, the ECPC has worked with a significant number of European institutional, scientific and industry oncology and cancer care stakeholders to establish viable partnerships aiming to build a broad consensus on issues important to European cancer patients. These partnerships effectively foster a European community of like-minded cancer experts. This broad expertise shared with our members, through capacity building programs and actions, can greatly contribute in designing a new era of active patients and patient organizations involvement and participation in CCCs and other OEI accredited cancer centers.

In this respect, OEI and ECPC can collaborate to develop a methodology for active patients’ and patient organizations’ involvement in the day-to-day activities of the OEI accredited cancer centers by cancer patient organizations. From our patients’ perspective, we can recommend that the Chapter 3 - Patient Involvement and empowerment and Chapter 9 Education and Training, should also include patient education and involvement in cancer research, cancer survivorship, patient safety, quality of life, that are also the focus of EU funded projects in which ECPC is a partner.

## 1. Cancer Survivorship

Cancer survivorship is the “after” that looks uncertain and far away, when patients are still in treatment. When patients get their discharge instructions and leave the cancer center after long months of treatment, they need to readjust to everyday life.

The long-term follow-up of cancer patients and survivors should be a mandatory mission of the CCCs, where cancer care, integrated with cancer research, includes too rehabilitation, psychosocial oncological support and monitoring for late side effects. The CCCs should also provide the personalized management of cancer survivors by a specialized multidisciplinary and multi-professional team to ensure the support of cured cancer patients, beyond the phase of acute treatment and during their lives.

## 2. Cancer Research

The primary missions of the ECPC are to educate patients, raise their interest and involvement in cancer research and care, and disseminate information about cancer and cancer research results to the general public. As partners in CCI4EU, ECPC and OEI will collaborate for the empowerment of patients and cancer patient advocates, (and not of expert cancer patients who use other patient educational channels), in all fields of research and care, making use, among other, of the ESO and IARC repository platforms to develop educational materials to support the patients’ role in clinical trials development, in cancer research and in eliminating gaps in the patient pathway. Patient-centric trials are defined as investigations that prioritize the needs of the patient at all stages, including design, activation, enrollment, data collection, completion and outcome reporting. In patient-centric trials, hypotheses that are important to patients can be formulated, study designs that minimize burden to patients can be used.

This interaction with cancer patients and patient advocates can offer too valuable information to the cancer centers for improving their cancer care services towards truly patient-centered care.

Moreover, the EU funded projects, in which ECPC is a partner, offer great opportunities for cancer patient involvement from being co-researchers together with ECPC staff and other project partners, to participate in the various activities of the projects like advisory boards, patient surveys, personal testimonies, stakeholder meetings, review of project deliverables, and more, as per each project’s needs.

## 3. Patient Safety

Most hospitals have, in some countries by law, a patient safety committee whose members are physicians, nurses, laboratories staff, technologists. Patients and patient organizations representatives should be members too of these committees as they are the ones who are experiencing the results of patient safety measures.

ECPC emphasizes the importance of involving patients as co-researchers and strongly advocates for patients’ early participation in defining research priorities and patient-centric treatment decisions. This active engagement of patients is vital to improving the quality of cancer care in Europe and to understanding patient preferences about their treatment and care, that are crucial elements of patient-centered care. The collaboration of patients and patient organizations with OEI accredited cancer centers and CCCs, active in cancer research, will facilitate patient involvement in cancer research that is also supported by the EU funded projects in which ECPC and OEI are partners.

The above suggested areas of collaboration are only indicative and it is sure that cancer centers, patients and patient organizations may select also other areas, that may be more relevant to their local circumstances. Patients lived experience of cancer, their preferences about their treatment, their relations with their treating team, the gaps they had to overcome in their cancer pathway, can offer valuable information to the cancer centers for improving their cancer care services towards developing truly patient-centered care services.

# Update from DIGICORE on development of a digital outcomes research network design

Gennaro Ciliberto<sup>1,2</sup> and Piers Mahon<sup>1,3</sup>

1. Digital Institute for Cancer Outcomes Research –EEIG

2. Regina Elena Cancer Institute

3. IQVIA - UK

DIGICORE aims to help its European members prepare for the digital revolution that will transform research through the routine use of electronic health records and molecular diagnostic information for trial automation, outcomes research, digital diagnostics, and care quality management. The development of the DIGICORE alliance begun with OECI institutions and representatives 4 years ago and after almost 2 years incubation time came into legal being in April 2021. Like the Organisation of European Cancer Institutes (OECI), DIGICORE is set-up as a European Economic Interest Grouping (EEIG). The current DIGICORE network includes 36 hospitals and 2 cancer networks (UNICANCER and Alleanza Contro Il Cancro) in 16 European countries and welcomes additional institutions to join the network. The two commercial partners are IQVIA, the leading contract research organisation, and Illumina, the global leader in DNA sequencing and bioinformatics.

The intended benefits of DIGICORE participation for researchers is to share experiences, set standards in data harmonisation, and share best practices in privacy conserving research approaches without data pooling. For cancer centres the benefit will be a network of centres to increase the sample of patient data to improve translational research. Most importantly, for patients DIGICORE hopes to improve clinical outcomes through more efficient real world evidence studies including care quality monitoring.

## DIGICORE update: Progress in creating digital interoperability in cancer across Europe

One of the critical objectives for DIGICORE is to establish a basis for European digital interoperability in hospital oncology electronic health records. By defining a scalable common international minimum dataset for cancer, and piloting technology to extract this data more efficiently than traditional manual approaches, this has the potential to transform the management of cancer care and reduce the cost of precision oncology research. To address this objective, in 2022 DIGICORE opened an application process to develop a federated, interoperable, pan-European network and the resulting pilot is called the DIGital Oncology Network for Europe (DigiONE).

DIGICORE invited care quality-focused hospitals from its own membership and those from the OECI to apply for funding in a two-step process. Step 1 included the development of clinical consensus on a European minimum data standard to describe cancer. 16 cancer centres in 13 European countries participated in the clinical consensus to define the minimum data standard. DIGICORE set Minimal Essential Description of Cancer (MEDOC) as the target specification for an open innovation challenge for the participating hospitals.

Step 2 asked hospitals to design a local implementation of that consensus in near-real-time routine data. Hospitals designed and costed a local working prototype for one of many nodes in a federated network with appropriate privacy management under the general data protection regulation (GDPR). In keeping with DIGICORE's open innovation approach, they could use any IT solution of their choice, be it open source or commercial. Training will be provided on modern technology options such as optical character recognition (OCR) and natural language processing (NLP) to help hospitals integrate state-of-the-art technologies. Combined with improvements in primary data capture, these solutions promise to deliver high-quality, complete data essential for modern research and care quality monitoring.

Entries were judged by an independent expert committee, including patient representation, in October

2022. The hospitals selected to take part in the DigiONE pilot and awarded funding are:

- **Frankfurt University Hospital** in Germany, led by Prof Dr Christian Brandts, Prof Dr Janne Vehreschild, and Prof. Holger Storf
- **Leeds Teaching Hospitals NHS Trust** in England, led by Prof Geoff Hall
- **Maastricht Comprehensive Cancer Centre** in the Netherlands, led by Prof Andre Dekker and Dr Alberto Traverso
- **Oslo University Hospital** in Norway, led by Prof Åslaug Helland and Sissel Jor
- **Cliniques Universitaires Saint-Luc** in Belgium, led by Prof Cedric Van Marcke
- **Ospedale San Raffaele University and Research Hospital** in Italy, led by Prof Giovanni Tonon

Following a few months of required contracting, work on the DigiONE initiative began in March 2023 with the first meeting of representatives from all 6 selected hospitals (plus collaborators from 4 other hospitals). The DigiONE pilot is expected to be complete end Q1 2024 with dissemination of research outputs.

## The first DigiONE meeting in Frankfurt

The first meeting, including participants from all 6 DigiONE hospitals, took place in Frankfurt in March 2023. The meeting had 3 key objectives: 1) to catalyse a European digital care quality improvement community, 2) to co-develop a portfolio of exciting research concepts, and 3) to start the detailed data normalisation planning.

## Objective 1: Catalyse a European digital care quality improvement community

There were 55 attendees in total including representatives from 10 hospitals. These 10 hospitals include the 6 DigiONE hospitals listed above plus the Regina Elena National Cancer Institute in Italy, Tartu University Hospital in Estonia, Tays/Tampere University Hospital in Finland, and Trinity St James Cancer Institute in Ireland. The meeting was attended by individuals belonging to various disciplines, including those with clinical, scientific, IT, and project management roles. This is rather unusual and a strength of DigiONE to have IT, data managers, and clinicians in the same meetings working together towards a scientific research interest.



DigiONE and IDEAL4RWE meeting - Frankfurt, March 2023

### Objective 2: Co-develop a portfolio of exciting research concepts

The goal of the DigiONE network is to fill evidence gaps in multimodal cancer care with transformative real-world evidence. It is up to the research teams at the 6 hospitals to decide which research questions they want to address in the next 12 months. To develop a list of research ideas, there were sessions on subjects such as ‘comparative health systems research’, ‘research opportunities using routine blood data’, ‘impact of Covid-19 on cancer care’, ‘predictive biomarkers’, and ‘comparative effectiveness’.

Members of the network presented real-world data studies they had been a part of, including the rationale for key design considerations and complexities with data normalisation. This included the Ovarian Real World International Consortium’s (ORWIC) study<sup>1</sup> discussed by Prof Geoff Hall from Leeds Teaching Hospital which is an example of the type of natural history study that DigiONE may conduct in other indications. The attendees also heard from four research teams that have ongoing studies as part of the IDEAL4RWE Leadership Training Programme, which is an initiative within DIGICORE to provide training and funding for researchers <45 years old to build the skills necessary to lead multi-site real-world data studies.

Out of the sessions there was a long list of research ideas ranging from simple studies with few data items which can be conducted pan-cancer to test our data quality to more complicated studies which require extensive information per patient on narrower cohorts such as natural history and comparative effectiveness studies. Such analyses will also provide international benchmarking on care quality. The research ideas will be prioritised by individuals from the 6 DigiONE hospitals to be developed into protocols. IQVIA will provide support by making available the services of a medical writing team to develop protocols, and plan to develop 5 to 10 real-world research protocols in 2023. The protocols the DigiONE network proceed with will be based on feasibility in terms of clinical interest, approval by hospital ethics committees, availability of data, and sufficient number of patients for informative outputs.

### Objective 3: Start the detailed data normalisation planning

Retrospective research typically involves a substantial amount of manual retype from medical notes at the hospital to an eCRF, given that many key baseline clinical characterisation data items (such as history of comorbidities and other cancer diagnoses, disease stage at diagnosis, performance status) and outcomes data items (such as response to treatment) are not in a structured format that can be automatically extracted. One of the key objectives of DigiONE is to test the use of NLP with the aim of increasing data completeness and reducing the manual effort for hospital staff conducting research. Given the hospitals do not want to have to wait for multi-site data harmonisation and testing of technology such as NLP to be complete to begin research, there may be studies conducted earlier during the 12-month pilot that can run using manual curation for data not in a structured format.

Sessions such as ‘Cancer OMOP Normalisation’ were carried out by the Observational Medical Outcomes Partnership (OMOP) team from IQVIA, including discussing how to convert local data into a common data format so that the ‘data means the same thing’ across the network. The DigiONE network intend to conduct analysis using the privacy conserving federated analysis approach, which allows reporting of outputs from multiple hospitals without pooling patient-level data and only needing to share aggregate outputs outside the hospital.

### Network building over beer

The molecular biologist James Watson once said: “At lunch Francis [Crick] winged into the Eagle [pub] to tell everyone within hearing distance that we had found the secret of life [DNA]”. Watson and Crick joked that most of their innovation was done at the Eagle pub near their laboratory in Cambridge.

1. Cheeseman S, Levick B, Sopwith W, Fenton H, Nam EJ, Kim D, Lim S, Martin E, Frenel JS, Bocquet F, Kubelac P. Ovarian Real-World International Consortium (ORWIC): A multicentre, real-world analysis of epithelial ovarian cancer treatment and outcomes.

At the DigiONE meeting in Frankfurt, ample time was given in the agenda to catalyse international collaboration outside of formal sessions. On the first night, most attendees sat with colleagues from their hospitals, however by the second night most tables had individuals from three or more hospitals (and it was a lot noisier!). The group enjoyed German beer and a cruise on the river Main with the backdrop of the Frankfurt skyline (known as ‘Main-hattan’).



DigiONE and IDEAL4RWE meeting - Frankfurt, March 2023

### How to get involved with DigiONE research

Clinicians from the 6 DigiONE hospitals will soon be selecting which study ideas to prioritise for this 12-month pilot and IQVIA’s medical writing team will be developing protocols which will be ready in June. The DigiONE network welcome additional OECl hospitals to join a research protocol and for those contributors to be authors in the publications, provided they can fund their teams to create the required dataset without support. Piers Mahon, from IQVIA’s European Data and Evidence Networks group and Commercial Research Manager for DIGICORE, will be at the OECl meeting in June in Paris and would be delighted to speak to attendees about DIGICORE and DigiONE.



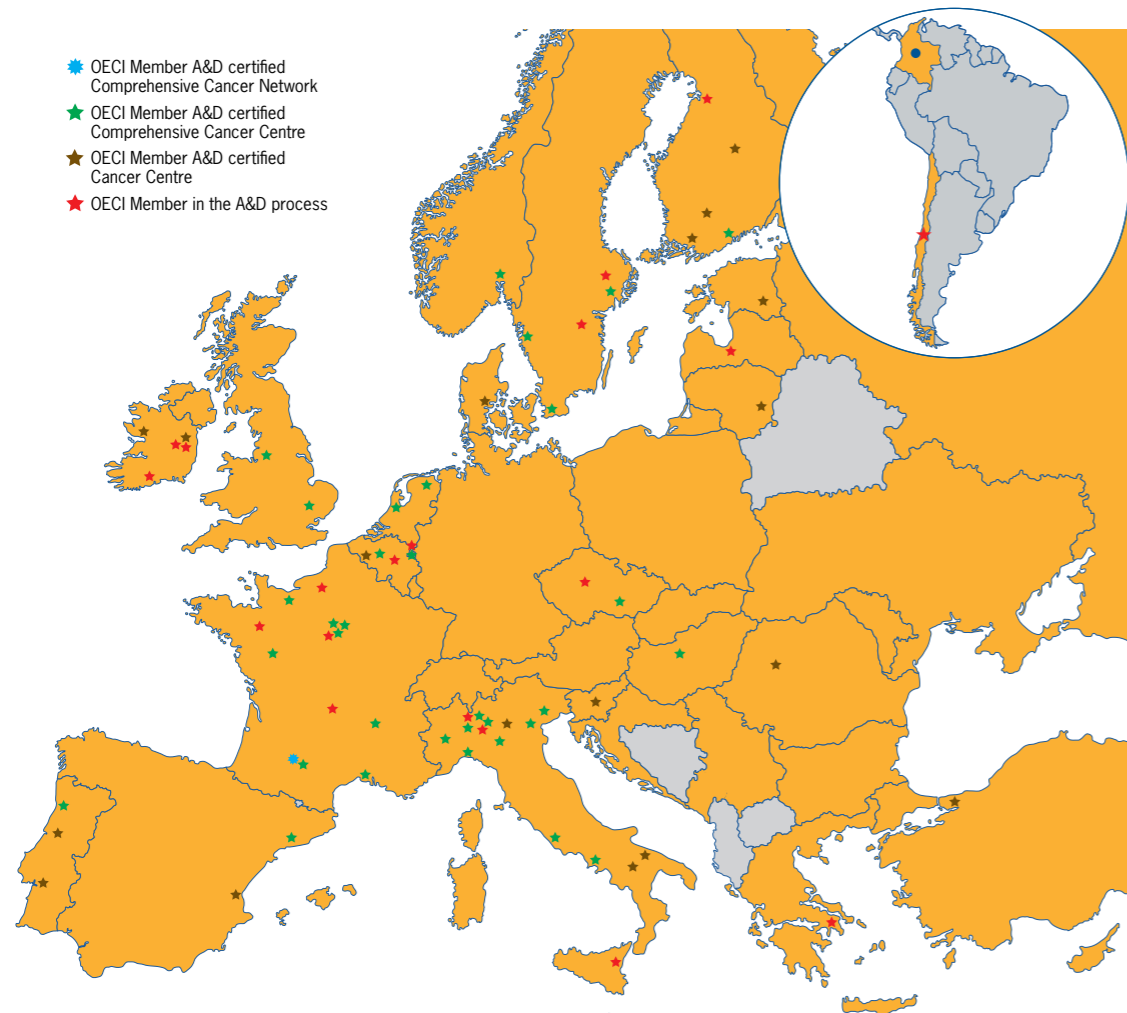
# The OECI Accreditation and Designation Programme – catalysing quality improvements in our centres now and into the future

Simon Oberst<sup>1,2</sup>, Jean-Benoît Burrion<sup>2,3</sup>

1. Improvingcancerservices
2. Organisation of European Cancer Institutes
3. Brussels University Hospital

The OECI Accreditation and Designation (A&D) Programme has always been about improving quality for cancer patients. The standards, indicators and peer review programme are a comprehensive toolbox to achieve this.

Over the last few years, the A&D Programme has grown from strength to strength – with 35 accredited centres accredited as OECI Comprehensive Cancer Centres and 18 as OECI Cancer Centres, which have high quality care, but a smaller scope of cancer research. The accredited centres cover 19 Member States of the EU, plus the UK, Norway and Turkey, and there are 18 more centres in the self-assessment stage. A peer review visit has also been completed in Santiago, Chile.



Key to the growth has been our wonderful group of trained auditors, now numbering 96, who are specialists in their own field in OECI member centres, and who provide that vital multidisciplinary approach at the onsite review. As the auditor group has grown larger, we are working harder to provide online refreshment courses, and events at the annual OECI Oncology Days.

The excellent coordination team that OECI has in the Netherlands, at the Netherlands Comprehensive Cancer Institute and associated staff is also expanding to meet our growth, now numbering six coordinators.

## Patient empowerment

The A&D programme has a big emphasis on patient empowerment – with a whole chapter of the standards devoted to this subject. This is probably the most developed set of standards in any cancer accreditation programme. In line with this vision, much of the Quality Session on 14<sup>th</sup> June at the Paris Oncology Days is devoted to examples of patient involvement and empowerment around the OECI centres. This is where we learn of each other's excellent practices. The A&D Programme has also appointed a Patient Expert onto the A&D Board – Dr Kristel de Gauquier. Kristel is a MD with an extended experience in Public Health and Health Services Research, both in public and private sectors, and has been involved in training patient experts for several years.

## Networks and Networking

The word “network” has become overused in recent years, and yet of course networks are key to comprehensive cancer care, and are axiomatic to the ambition in Europe's Beating Cancer Plan to reach 90% of eligible patients by 2030. We want to mention three aspects of networks and networking.

First, OECI has recently published a paper in *Acta Oncologica - Evaluating Comprehensive Cancer Networks; a new tool to drive up quality in the European Union* – Wind A, Oberst S, Westerhuis W et al<sup>1</sup>. This paper is unique in combining a meta-analysis of methods of evaluating the effectiveness of health networks (not just cancer) and then presenting the new OECI Cancer Network standards which are being piloted.

Secondly, another Network pilot of the new OECI Cancer Network Standards will take place later in 2023 in the Oncozon, the Cancer Network centred around Maastricht in the Netherlands. From this we should be able to judge how effective these standards are, and roll out the accreditation programme to more cancer networks.

Thirdly, we find it very heartening to see that accredited Centres are building their own informal networks in regions of Europe, partly with the enabling of OECI. Whereas the larger EU countries already have formal organisations of cancer centres, such as Unicancer (France), Alleanza contra il cancro (Italy), and FICAN (Finland), it is good to see a very active Nordic/Baltic consultative network of cancer centres developing its programme with meetings twice a year, including at the OECI Oncology Days. We would encourage this model of working in other European regions.

## Busy with EU Actions

As demonstrated in the last issue of the OECI Magazine, OECI is heavily involved in a plethora of EU actions in connection with the EU Cancer Mission and Europe's Beating Cancer Plan. The A&D Programme is deeply involved in a subset of these. An example to highlight has been a DG REFORM project to advise on the setting up of a Comprehensive cancer Infrastructure in Latvia. This project was as a subcontractor to the International Agency for Research on Cancer (IARC) and lasted for 12 months, involving four site visits of a team of 3 consultants and meeting with many different hospitals, Universities, research institutes and Ministries in Latvia. This project provided good experience to

1. <https://www.tandfonline.com/doi/full/10.1080/0284186X.2023.2170275>

OECI, in that it required the same approach that is likely to be followed when capacity building within the 'deep dives' which are going to be a key part of the CCI4EU project which OECI is coordinating over the next 3 years.

But the OECI A&D Programme is much wider than the European Union. We are not only European (and let's continue to collaborate with our partners in the UK), we are international in scope.

So what are the unique features of the OECI A&D Programme as we move forward in an increasingly complex field?

- It is a voluntary programme. This is precious to us, because we never want to get regarded as being a regulatory organisation. Our culture is that of helping each other to continuously improve quality in cancer care, research and education.
- We believe in peer review, not technical audits. Our auditors are more than technicians; they are experienced experts in their own field of cancer care or research, and bring their own collective experience, as well as that of the A&D programme corporate resources.
- We are democratic. As part of the membership organisation of OECI, we are not subject to national or EU governance, and we can order our affairs and programme as our member experts and scientific findings demonstrate are best standards and practices.
- We want to galvanise and spread the excellent practices of OECI member centres around the world. We want to be an effective community of practice where we enable each centre to improve, develop and learn from each other.

So the future of the OECI A&D Programme, along with OECI itself, has an international vision. Our discussions with North American similar organisations, and our development into South America, are small demonstrations of what the future can bring, to enable many more centres and networks to beat cancer together.



Site visit at Vilnius



Auditor training 2022



Above  
Beaumont RCSI OECI Peer Review Visit

Left  
Auditor training 2023



Karolinska Audit Team

# The OECI Working Group on Cancer Economics: work in progress and future program

**Wim van Harten<sup>1</sup>**

1. Chairperson OECI Cancer Economics WG

With a growing incidence of new cancer cases, a promising -but also debated- pipeline of innovative treatments and increasing numbers of cancer survivors requiring follow up services and survivorship care health systems are under stress. Human resources are scarce, finances are strained while equitable access to comprehensive cancer infrastructures and to promising innovative treatments are demanded.

Health Economics (HE) and Health Technology Assessment (HTA) are fields that are increasingly important in view of these challenges. As with other industrial domains, the earlier the guidance with HE and HTA are involved, the better the chances of a technology to become cost effective and actually become reimbursed and available for patients.

Apart from the role of biotech- and pharmacological industries and (governmental) agencies, having this expertise close to the primary process of care and research in Comprehensive Cancer Centers (CCC) ensures a closer connection between the values of patients and professionals and that of policy makers.

The OECI Working Group on Cancer Economics consists of around 30 representatives from- or connected to OECI member organisations that meet 3 to 4 times a year to exchange knowledge on HE and HTA, to discuss developments and project (proposals) and actually takes part in project consortia and European projects.

*In recent years main projects in which OECI provided major input were:*

A European Survey on Socio Economic Consequences of cancer. This survey in which over 3,000 patients from 14 EU countries participated, will lead to papers in 2023 and 2024 on e.g. cross-country comparisons, and SEC of specific subgroups like breast cancer patients and Young Adult Cancer patients (AYA's) over Europe and finally the validation of SEC-measurement instruments.

Further and parallel to this project a broad Task Force with heavy involvement of OECI members (and lead by Prof. Michael Schlander (DKFZ) and prof. Wim van Harten (NKI)) is active on methodological issues, like a uniform Taxonomy, selection of measurement instruments and preparation of further EU-wide surveys. This will lead to a number of methodological and consensus papers bringing the state of the art in Europe to a next stage.

Surveys on the access to innovative cancer medicines and Targeted Combinations Treatments (TCTs) were distributed throughout the EU, and showed impressive differences in EU member states. Inequities within and between countries are impressive. This leads to suggestions on research into effectiveness of TCTs, on transparency of research & development data, and to suggestions for policy makers in decisions on reimbursement.

## Working program of the WG Cancer Economics

In the coming years and during the new presidency we foresee continuation of the WG activities in knowledge exchange, project initiation and- involvement and especially in EU project involvement in view of the OECI's position in Cancer Mission projects.

Continuation of 3 to 4 annual meetings will be planned, partly be face-to-face and partly digital.

The involvement in- and support of the task Force on Socio Economic Consequences (SEC) will lead to a numbers of papers on SEC-taxonomy, SEC-measurement instruments and surveys on SEC related issues through OECI hospitals and patient related societies.

Currently ongoing is the establishment of a research group on access to expensive innovative cancer drugs, in close cooperation with the European Fair Pricing Network (EFPN). The EFPN is an initiative sponsored by (so far) 11 EU cancer Charities that aims to generate data to enable discussions on equitable access to cancer treatment in EU countries, to stimulate regulation changes that lead to reduced prices and to generate data supporting these aims. The OECI WG on Cancer Economics is closely cooperating with this important initiative. A first important project is a consortium involving WG members to stimulate transparency on rebates and actual prices through data sharing and benchmarking.

A project to work towards standardized- and uniform costing for HE related research projects, is lead by Prof Lionel Perrier (Centre Léon Bérard, Lyon) and Prof Valesca Retel (NKI, Amsterdam).

Lastly, the OECI Working Group on CE increasingly serves as the platform to channel HE and HTA input for OECI related Cancer Mission and Horizon projects. We can name a few:

- **Intercept COST Action**, addresses the challenge of unmet oral cancer prevention and bring new paradigm to disease management of oral potentially malignant disorders. The WG provides input and meets in knowledge exchange sessions with external stakeholders. Interested OECI-members can become a COST-action member to participate via **e-COST**.

Website: **Action CA21140 - COST**

**CAN.HEAL**, meant to contribute to building a EU wide platform on genomics for cancer treatment and Public Health values. The OECI WG acts as a channel to involve OECI members and to disseminate knowledge. Website: **Can.Heal | Building the EU genomics platform <https://canheal.eu/>**

- **ONCOVALUE**, a Horizon EU project focusing on the use of integrated data lakes from Comprehensive Cancer Centers to generate Real World Data that can be used to (re-)evaluate (cost-) effectiveness of medical technologies or drugs and provide innovative input for HE and HTA procedures. The WG will serve as a channel to involve OECI members and to disseminate knowledge.

Website: Home - Oncovalue

- **CCI4EU**, the large OECI lead project to stimulate the establishment of Comprehensive Cancer Infrastructures in Europe. Through the WG, methods establishing the budget impact and knowledge dissemination on how to involve HE and HTA related expertise in CCI building will be contributed.

## Future outlook

The financial sustainability of health systems will almost certainly an issue of further increasing relevance for the coming years, in view of postpandemic, the economic consequences of the Ukraine war and energy crisis and the transformation of economy in view of climate challenges.

Nevertheless patient demands will understandably increase while new treatments continue to be introduced to the market. This leads to challenges in equitable access, disputes on treatments (not) being reimbursed and on budget impact or cost effectiveness of costly infrastructures. These issues are so important that closer involvement from CCCs is not only justified but necessary to ensure balanced decision making on policy levels. The OECI Working group on Cancer Economics welcomes all initiatives within the OECI that contribute to that aim.

The board of the OECI WG on Cancer Economics is composed by:

- Prof. Wim van Harten (Chair, NKI & Rijnstate hospital, NL)
- Prof. Michael Schlander (DKFZ, GE),
- Prof. Davide Gallegati (IRST/IRCCS, IT),
- Dr. Lionel Perrier (Centre Léon Bérard, FR),
- Dr. Edit Pornczy (NIO/HU),
- Prof. Valesca Retel, Coordinator Working Group Cancer Economics (NKI, NL)

# Monitoring Quality of Life in Oncology: a challenge we can meet

Luana Caselli<sup>1</sup> and Cinzia Brunelli<sup>1</sup>

1. Fondazione IRCCS Istituto Nazionale Tumori, Milano

The widespread interest in Patient-Reported Measures (PRMs), questionnaire-based instruments that empower patients to be heard and enable their health-related outcomes (PROMs) and care experiences (PREMs) to be quantified, reflects a recent fundamental shift from conventional to patient-centered healthcare models in oncology.

Engaging patients in “measuring what matters to them” is now seen as critical to improving the quality of care and PRMs are strongly encouraged as effective tools for directly capturing patients’ perspective on their health condition and care pathway, with potential positive return at many levels of the healthcare journey. It is widely accepted that the use of PRMs in clinical research can provide valuable evidence on the cost-effectiveness of interventions and that the routine implementation of PRM data along with standard clinical assessment can tailor real-time patient care to individual needs and symptoms, improving disease and treatment outcomes, as well as quality of life and, in some cases, survival. PRMs can also be valuable to benchmark service performance with the aim of identifying gaps and scopes for improvement, and to support healthcare systems in evaluating cancer programs and policies to benefit whole populations.



Despite the many potential advantages of integrating PRMs into healthcare and the opportunities provided by digital technology to enhance the use and uptake of patient data collection, current applications of PRMs still remain sparse and inconsistent. While their systematic use in clinical research is well established, their full implementation in routine oncology practice and in healthcare policymaking and evaluation is still far to be reached. Employing such practices can be challenging and their development requires overcoming several issues. Indeed, barriers can exist at the patient, health professional and service levels. They range from burden and acceptability for patient, to perceived irrelevance and lack of value of self-reported information by clinicians, cultural validity issues, time limitations, increased clinical workload, difficult integration into existing clinical workflows, inadequate IT infrastructure and unclear shared goals.

Implementation issues also concern PRMs for health policy purposes and are mainly related to:

- the definition of a standard set of scientifically sound metrics to be used;
- the standardization of the data collection process;
- the translation of results into improvement actions.

PREMs and PROMs are now becoming valuable tools for regional and national healthcare performance assessment and improvement. However, further research is needed to ensure that these measures can support valid comparisons across healthcare systems and countries and reliable public reporting. Recent OECI initiatives carried out through the Cancer Outcome Research Working Group have been established with the goal of fostering a patient-centered approach to cancer care, by promoting a

standardized adoption of PRMs (<https://www.oeci.eu/WG.aspx?id=13&group=1>). To this purpose, they have been working on building and coordinating a network of clinical cancer centers that share common procedures for the routine collection of PRM data. Many strategies are being explored to improve PRM implementation, including stakeholder involvement with particular attention to patients, setting qualitative standards for data collection and sharing, training healthcare personnel, and integrating PRMs with medical records.

These efforts have recently found application in the European project “EUonQoL Quality of life in Oncology: measuring what matters for cancer patients and survivors in Europe”, whose overall goal is to contribute to the progress of the EC Mission on Cancer, aimed at reducing mortality and improving survival and quality of life of cancer patients, from diagnosis across treatment, survivorship, and advanced stages, through the active participation of patients and citizens.

The project, already introduced in a recent issue of this journal (OEI Magazine 2/2022, p. 16-17) has started in January 2023 and is aimed to develop the Oncology Quality of Life Toolkit (EUonQoL-Kit), an innovative PROM for the assessment of quality of life (QoL) among cancer patients and survivors, to be mostly used to support the development and evaluation of cancer programs and policies. The ambition of EUonQoL consists in designing, validating, and implementing a unified and comprehensive toolkit of questionnaires for QoL assessment, which incorporates the perspective of patients at different stages of their disease trajectory.

First, EUonQoL is based on participatory co-design, which implies the involvement of a representative group of stakeholders, including patients, who act as co-researchers at different stages of the project. Patients will provide important insights into their preferences and priorities to inform the list of items that are most relevant for QoL assessment, will contribute to planning, organizing and carrying out the studies in EUonQoL, and will help develop the guidelines for future implementation of the EUonQoL-kit. This participatory approach will raise awareness about PROMs and will create opportunities for promoting data collection and disseminating project findings.

Second, the toolkit will be designed to meet all metrological requirements for scientific soundness. Existing QoL questionnaires, metrics, item banks and databases are now under review with the purpose to identify QoL dimensions not adequately covered by the tools available in the literature. The EUonQoL-kit will provide standardized valid QoL measures, easy to implement, digitally administered, tailored to patients’ health condition, available in both static and dynamic versions, culturally adapted and translated in many European languages. These qualities will support wide application across Europe and will ensure reliable evaluation and comparison of different policies and programs addressing cancer at the European level.

Finally, the EUonQoL-kit will be validated through its first large-scale application in a wide European pilot survey of cancer patients and survivors. The patients will be enrolled from many clinical sites, mostly selected among members of OEI and through the network of contacts of OEI Management. The role of OEI will be central in coordinating data collection.



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# Cancer Molecular Pathology: Evolution and Future

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The so defined precision medicine was first announced by the United States National Research Council in 2011 and suggests an overlapping of the clinical, morphological and molecular information for each patient case to produce a precise picture of the clinics to better define a target therapy <sup>(1)</sup>. The landscape of genomic alterations in cancer gives us the substrate to try new types of treatment <sup>(2-6)</sup>, but it also revealed the high level of heterogeneity among tumours, but also within every single cancer. This landscape should be studied with new sophisticated methods to better understand how can we efficiently treat cancer.

Molecular pathology analyses results are strictly related to diagnosis and treatment especially in oncology but also in other medical fields. At the moment molecular pathology is not normalized at the European level and its evolution is very rapid. There is a continuous development of new biomarkers to better characterize the tumour and to define the best treatment. For this reason we need very plastic instruments to standardize molecular pathology, allowing us to produce constantly updated documents to be rapidly diffused. We need to define the methods, the controls, the biomarkers with their specific clinical meaning.

The Biobanking and Molecular Pathobiology Working Group (BBMP WG) of OECI is working in this direction. The BBMP WG is collaborating at the development of a European Master in Molecular Pathology (EMMP), together with other initiatives. These are other projects in which the WG is involved directly or indirectly: HERCULES European project about tumour heterogeneity, the European SPIDIA4P project for pre-analytics standardization of the clinical material, Instand-NGS4P, that is a project on the evaluation of NGS products that are present on the market. OECI is officially participating in the European project JANE - a European Action on Networks of Expertise and it acts as a network of European Comprehensive Cancer Centres. Giorgio Stanta as chairman of the BBMP WG was involved in "The European Commission Initiative on Breast Cancer" for which a final document to help to obtain high level uniformity is in preparation and it will be disseminated. He is also involved in the European Commission Initiative on Colorectal Cancer (ECICC)" aiming to provide essential levels of quality care equally accessible across Europe. The WG is also organizing meetings to help a continuous updating in molecular pathology of cancer. All these initiatives are developed to help the evolution of knowledge on molecular pathology of cancer and to offer to people working in the oncology field a continuous updating. The BBMP WG is collaborating with several European societies and organizations: with European Association for Cancer Research (EACR) for courses, with European Cancer Patients Coalition (ECPC), with the Molecular Pathology WG of the European Society of Pathology (ESP), with the Quality Expert WG of the Biobanking and Biomolecular Resources Research Infrastructure (BBMRI-ERIC), with the European Committee of Standardization (CEN), with the European Union of Medical Specialities (UEMS) for the master, with the IMPACTS Group for the molecular analyses in fixed and embedded tissues. There is the necessity to understand how molecular pathology is evolving at clinical level.

In this review we do not treat specifically the immune-reaction to cancer or the well known clinical entities related to specific genetic alterations because this aspects are widely developed in a huge literature.

## European Master in Molecular Pathology

We have an urgent need for standardization of the molecular analyses to obtain reproducibility and exchangeability among European institutions for a safety and efficient treatment of patients.

At the last meeting of the EACR/OECI "Molecular Pathology Approach to Cancer" that took place in Bergamo in June 2022 our WG presented the issue "Next Generation Molecular Pathology: European Master in Molecular Pathology as an Instrument of Molecular Pathology Normalization at European Level". The Master will start in October 2023 with its organization site in the university of Nice. The EMMP is officially a UEMS initiative. The UEMS is a non-governmental organization representing national associations of medical specialists at the European Level. It is "committed to promote the free movement of medical specialists across Europe (while) ensuring the highest level of training which will pave the way to the improvement of quality of care for the benefit of all European citizens" <sup>(7)</sup>.

The master was chosen as a plastic modality to standardize diagnostic molecular pathology in Europe. The steering committee of the master (people in charge of the different country molecular pathology initiatives) can modify the program continuously allowing the diagnostic molecular pathology to be always updated. This Master course is established in response to the extremely urgent need to perform reproducible and exchangeable molecular diagnostic analysis at the European level. This is even more pressing because of the continuously increased use of diagnostic, prognostic and predictive biomarkers, directly related to treatment choices. Other types of more sophisticated techniques are now used at the molecular level with a continuous rapid development. The interpretation of results of diagnostics and clinical research molecular analysis are increasingly complex.

Recent decisions that have been taken within the European Commission Committees (European Commission Initiative on Breast Cancer - ECIBC) pointed out the importance of clinical research performed directly on today patients for today patients and the collection of big data. This means the necessity of reproducible and exchangeable molecular diagnostic analysis and the preparation of new professionals.

The objectives of EMMP will guarantee practical training in the field of molecular pathology diagnostics and clinical research especially in the fields of oncology but also in infectious diseases with a common European language. In the future other issues can be developed.

Theoretical and technical aspects will be covered and diagnostic interpretation will be included for all the main diagnostic areas of pathology together with bioinformatics and artificial intelligence aspects. Quality assurance will be one of the main issues to guarantee reproducibility and exchangeability of the results. Bioethical aspects will be considered also with evaluation of the different country rules in Europe. The modules of the first and second year of courses are reported in table 1. The official location of the master and technical management will be at the University Cote d'Azur, Nice. UEMS will give the final Diploma, with the full accreditation for applicants who successfully passed the CESMA (Council of European Specialist Medical Assessment - <https://www.uems.eu/areas-of-expertise/postgraduate-training/cesma>) exam. The maximum number of students per promotion is 20-30.

The dedicated website for inscriptions is

<https://ecandidat-uca1.univ-cotedazur.fr/#!accueilView> or e-mail [msc-emmp@univ-cotedazur.fr](mailto:msc-emmp@univ-cotedazur.fr)

## The problem of tumor heterogeneity

In tumors multiple alterations are present at same time. Only some of them are detectable in the entire tumor, many are present only in some tissue areas, defining the so called intra-tumor heterogeneity (ITH) <sup>(8-14)</sup>. Heterogeneity is evident at morphological and molecular level. This complexity makes useful to adopt sensible methods of analysis and specific type of sampling and these will increase in the future with the development of knowledge about causes of ITH and its detrimental influence in treatment efficacy.

The causes of ITH in tumors is not only related to genomic instability, such as copy number alterations (CNA), as basic mechanism of mutations but epigenetic alterations are also clonal <sup>(8,9)</sup>.

There is another heterogeneity that is not clonal connected with microenvironment interactions such as autocrine and paracrine mechanisms <sup>(10,13,14,17)</sup>. Epithelial-mesenchymal transition (EMT) and the mesenchymal-epithelial transition (MET) can be often recognized at histological level in cancer tissues.

Clonal and not clonal heterogeneity are both defining the phenotype of the cancer cells at the primary site and at metastatic level (TAB. 2).

The mechanisms related to heterogeneity in cancer are complex. DNA heterogeneity is increasing while E or D polymerases are altered<sup>(18)</sup>, or microsatellite instability (MSI) is present<sup>(19)</sup>, or there is chromosomal copy number alteration (CNA) related to chromosomal instability<sup>(20-22)</sup>. There are several well known clinical entities in which these types of alterations are recognized, we leave these to specific literature.

Also non-coding gene alterations<sup>(23,24)</sup> and DNA hypo-methylation<sup>(25-27)</sup> can increase genomic instability. The tumor stroma can also be heterogeneous<sup>(28-32)</sup>. There is the so called functional phenotypic plasticity. At the phenotypic level it can be recognized as epithelial-mesenchymal transition (EMT). There is also a stochastic plasticity<sup>(8-10)</sup>, in which every cell can be functionally different from the others<sup>(33)</sup>. This means that the same clonal and non-clonal alterations can be differently expressed in different cells. ITH can be detected also at metabolic and immuno-editing level<sup>(34)</sup>.

Tumor heterogeneity is one of the major causes of cancer therapy failure. To improve efficient treatment it is absolutely necessary to deeply analyze, evaluate and consider in the treatment choices ITH. At the moment ITH is not sufficiently recognized at clinical level such as one of the major problem in molecular pathology. There are European projects studying ITH and OECl is partially involved in them through BBMP WG. The HERCULES project on "Tumour Heterogeneity via Single Cell Analysis in High Grade Serous Ovary Carcinoma" might provide a guideline to the analysis and interpretation of heterogeneity in cancer at clinical level.

#### Other aspects of the future evolution of molecular pathology

Some European projects are trying to develop standardization or at least some criteria of normalization to improve molecular pathology at European level. This is, of course, very important especially in oncology. OECl is involved in these projects with the activities of the BBMP WG.

The SPIDIA4P project is developed in collaboration with the European Standardization Committee (CEN) of Berlin and has already developed technical specifications for the pre-analytical conditions of the biological material used for diagnosis. These technical specifications, that are already official documents in Europe, should be applied from all the European institutions. This should improve the quality of diagnosis with a higher level of standardization and a higher exchangeability among European hospitals. They will be then translated to "ISO international standards". Many technical specifications are already available such as DNA, RNA and protein analysis in fixed, frozen tissues and blood.

NGS is one of the most used techniques today in molecular diagnosis, the Instand-NGS4P project is developing an evaluation of the NGS products that are present on the market. At the moment there are no other types of evaluation and normalization of the NGS kits used in diagnostics. The results of the project will be spread among the European hospitals and especially in OECl institutions. The modules of the project to be analysed are involving the pre-analytical conditions of the biological materials, library preparation, sequencing, bioinformatics analysis, actionable items and integrated report.

OECl is officially participating in the European project JANE - a European Action on Networks of Expertise and it acts as a network of European Comprehensive Cancer Centres. OECl is collaborating for integration of omics technologies into the EU healthcare systems (HCSs) to ameliorate prevention, diagnosis and treatment of cancer. OECl is assuring a link with the European infrastructures especially in order to find the best-standardized approach for molecular analysis to be spread among all the European hospitals.

OECl is also involved in the Commission Initiatives about breast and colon cancer. "The European Commission Initiative on Breast Cancer" has concluded the official activities and is preparing a final document to be disseminated in Europe. The goal of the initiative is to assure a diffused high level of treatment of breast cancer among the European countries. The same - "The European Commission Initiative on Colorectal Cancer (ECICC)" started in 2022 aims at providing essential levels of quality care equally accessible across Europe.

All these activities are developed to gain a comprehensive understanding of future directions, and challenges in molecular pathology, with a particular focus on clinical development.

Tab. 1 – European Master Molecular Pathology - Modules

1 <sup>st</sup> YEAR	2 <sup>nd</sup> YEAR
Basic Molecular Biology	Immunopathology
Methods in Molecular Biology	Quality controls and regulation
Pre-analytical and analytical methodology	Digital Pathology, Bioinformatics and AI
Applied Molecular Pathology in Oncology	Accreditation and Biobanking
Infectious diseases	Research Methods
Laboratory Project – Final Report	

Tab. 2 – Heterogeneity Classification

CLONAL HETEROGENEITY	NON-CLONAL TRANS. HETEROGENEITY
GENOMIC INSTABILITY > mutations and CNA, related also to treatment	FUNCTIONAL PLASTICITY > autocrine, paracrine, related to microenvironment
EPIGENOMICS > genes and histones, related also to treatment	STOCHASTIC PLASTICITY > related to single cell efficacy and to microenvironment

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# STRONG-AYA: Building a value-based healthcare research ecosystem for Adolescents and Young Adults with Cancer

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Cancer at Adolescent and Young Adult (AYA) age (defined as 15-39 years at diagnosis) is rare, although 6 times more frequent than paediatric cancer and together AYA cancer patients encompass 5% of all adult cancer diagnoses. Cancer at this young age has a significant impact on patients; with a decreased productivity and health-related quality of life due to the impact of the disease and treatment during formative years and long-term complications or disabilities it not only leads to personal, but also to societal costs. [1]. Unlike dedicated healthcare and trials for paediatric cancer patients, AYA-specific healthcare services are scarce and vary across Europe. AYAs who are at the core of society and economy need access to age-adjusted and high-quality healthcare.

The AYA Working Group (WG) of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOP Europe) concluded in 2021 that finding rapid solutions to 'speak the same language' among healthcare professionals (HCPs) is essential to further improve health outcomes for AYAs [2]. The WG reported that standard clinical trial endpoints, such as five-year overall survival, progression-free survival, and cancer-specific survival, often do not address the specific needs of the AYA population. The WG found a widespread geographic variation, nationally and internationally, in AYA care programs with an unstructured, often merely philanthropic, funding [2]. When ESMO and SIOPE members were asked if their patients had access to specialized services for AYA with cancer, or if such services were in development, only 33% confirmed that they had, namely: 13% in Eastern and South-Eastern Europe, 45% in Western Europe and 60% in Northern Europe [3]. In addition, substantial inequalities in support by specialised HCPs, such as psychologists, social workers, physiotherapists, dieticians and AYA-dedicated nurses were found between AYA care programs [3]. The WG also reported an absence of outcome measures for monitoring and evaluating AYA cancer care programs and control [2]. Similar observations were described in the United States' National Cancer Institute (NCI) report "Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer" in 2006 [4]. Since then, research on AYA cancer has increased and the discipline of AYA oncology has made progress with the development of more AYA care programs [5]. In 2016, the NCI updated the AYA cancer progress review group report and examined scientific gaps and opportunities for future AYA oncology [6]. It was concluded that one of the most important contributions to AYA research would be to pool data (e.g. patient-reported outcomes, clinical and treatment data) across institutions and countries and create large cohorts for researchers to address the burden of cancer in AYA [6].

The recommendations by the ESMO-SIOPE WG and NCI clearly indicate a need to comprehensively assess patients' age-specific needs, screen for physical and psychosocial problems and provide multidisciplinary, holistic, age-specific hospital and community support among others fertility counselling, appropriate psychological support (e.g. body image, sexuality and relationships), and occupational and financial support services (e.g. education and career development). By evaluating AYA cancer patients' healthcare experiences and outcomes we believe their care and outcomes can be improved and unjustified variations in quality of care reduced. We believe that this can be done by maximizing the potential of multi-stakeholders data (e.g. number of AYA patients who have been offered specialised AYA care such as dedicated AYA nurse/psychologist/rehabilitation etc., timely discussions on fertility preservation, education and work, who were informed about potential late effects of treatment; hospital and national evaluations of treatment and survival outcomes). Although an ever increasing amount of data is available, the collection, access, processing, and use of these data are still very fragmented within and especially across national health systems. There is a lack of

data standardization, data interoperability and (prospective) collection of outcomes of relevance for AYAs with cancer. The development and implementation of a Core Outcome Set (COS), a consensus-based agreed minimum set of outcomes that should be measured and reported, with patient-centred outcomes of value for AYAs with cancer, represents an opportunity to enable data-driven healthcare innovation and serve as a basis to address clinically relevant questions for this vulnerable patient group [7].

For this reason STRONG-AYA was launched on October 1 2022. STRONG-AYA is a new, interdisciplinary, multi-stakeholder European network to improve healthcare services, research and outcomes for AYA with cancer. Within STRONG-AYA we will set up a value-based healthcare research ecosystem to develop data-driven, interactive policy and visualization tools that bring, in co-creation with all stakeholders including patients, novel insights into AYA healthcare. The project objectives, include:

- (1) Development of a COS for AYAs with cancer;
- 2) Implementation of the COS in five national healthcare systems across Europe, with participating centres in the Netherlands, France, Italy, Poland and the United Kingdom, and the establishment of national infrastructures for outcome data management and clinical decision-making and a pan-European ecosystem that also welcomes future European countries.
- 3) Dissemination of outcomes and facilitation of interactions between national and pan-European stakeholders to develop data-driven analysis tools to process and present relevant outcomes, establish feedback loops for AYA cancer patients and the healthcare systems, and improve the reporting and assessment of outputs towards policy-makers.

At its core, STRONG-AYA will:

- Equip AYAs with cancer with the data to better optimise their healthcare, support them and personalise decision-making between AYA and health care providers.
- Enable AYA healthcare quality monitoring by monitoring access to AYA nurse specialists, fertility consultants, and social workers for discussion about work etc.
- Establish benchmarking between the different countries on these key performance indicators.
- Enhance data sharing of AYA research.
- Provide real-world evidence on best care practices to all important AYA oncology decision-makers.
- Share insights with policy-makers to address and reduce inequalities across the entire disease pathway of patients with different cancer diagnoses in AYAs in different regions in Europe.

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