OECI Magazine

Organisation of European Cancer Institutes

European Economic Interest Grouping

Number 2 - Year 2
November 2018

Editors:
Thierry Philip
and Claudio Lombardo

Editorial Office:
Giorgia Pesce, Roxana Plesoianu,
Patrizia Sommella and Anna Fackeure

OECI-EEIG Central Office
c/o Fondation Universitaire
11, Rue d'Egmont
B-1000 Brussels, Belgium
Phone: +32 2 512 0146

www.oeci.eu
oeci@oeci.eu

Graphic Designer:
Studio Sichel, Piacenza, Italy

Cover image by *Carlo Accerboni*,
courtesy of the artist

This newsletter has been realised in collaboration with: SOS europe

Index

OECI MAGAZINE n. 2-2018

The OECI vision and evolution

Thierry Philip[1,2]
1. Institut Curie
2. Organisation of the European Cancer Institutes

The OECI is an Organisation of institutions whose main objective is improving the management of a cancer centre.

For this purpose, the core of our mission is to promote quality along with the transversal and multidisciplinary model of integrated cancer centres (the so-called Comprehensive Cancer Centre).

This model is well-developed by historical centres such as the Institut Curie, the Institut Jules Bordet, the Karolinska or the Fondazione National Cancer Institute in Milan, whilst also shaping integrated systems such as the Cambridge, Oslo, or Heidelberg universities.

Each Comprehensive Cancer Centre encompasses a well-defined internal organisation, a budget, minimum requirement in number of patients, publications and research groups.

After more than twenty years of voluntary work, the OECI quality system approach, which is certified by the International Society for Quality in Health Care "ISQua", after an elaborated data-collection procedure & a peer review "in situ", offers a quality improvement plan specifically tailored for each centre, independent from the level of quality of the centre itself.

As I suggested, **quality shall continue to be our main goal** and therefore, we are working on three "position papers" on this topic to be published in 2019. I also suggested to source the financial means to carry out and publish benchmarking studies and to support centres to achieve their quality improvement plans.

Our **second priority** is **to remodel the "Cancer economics" and "Outcome research"** Working Groups so that they can evolve into the second OECI core activity. For this purpose, it is crucial not to replicate the national groups' activities but to complement their experiences with our international expertise.

I suggested reorganising the currently networks of certified "Comprehensive Cancer Centres" and "Clinical Cancer Centres" by country and appointing a National OECI Ambassador to grant the necessary link amongst national groups so as to succeed producing high-level results on Outcome Research.

The **third priority is putting the relationship with patients at the core of each OECI Member**. The "Collaboration for Good Practices with Patients" Working Group must become an engine of proposals and decisions, also with reference to our budget allocation.

I completely trust my predecessor, Dr. Dominique de Valeriola, will achieve this crucial goal for the future of the European oncology.

The other "Working Groups" are equally important and we are currently working with our chairpersons to better gear their objectives towards quality, patient relationship and outcome research. Each group shall help the Board find the budget needed to finance its activities after a two-year support guaranteed by the OECI general budget.

Finally, we would like to be part of a strategic alliance among the main actors of the European cancer community in order to define a vision during Horizon Europe regarding cancer fight in Europe. We will not do it alone but together with patient associations (EPCC), volunteers (ECL), Prevention specialists (Cancer Prevention Europe and IARC), basic research scientists (EU-LIFE), translational research organisations (EORTC, BIG, CANCER CORE EUROPE ....) and National networks having the access to real life cancer data to perform outcome research studies (UNICANCER, Alleanza Contro il Cancro…).

We hope that in the coming months the conditions for a collective, democratic achievement of the above-mentioned goals will be made possible.

With its 93 Members (soon soaring to 100), the OECI is one of the main actors of the cancer care family. The OECI does not claim the leadership of a group to define a new cancer vision but it clearly is a key Organisation that must participate to this landmark adventure.

1st OECI mission working party meeting report

Thierry Philip[1,2], ***Dominique de Valeriola***[2,3], ***Roxana Plesoianu***[2] *and* ***Claudio Lombardo***[2,4]
1. Institut Curie
2. Organisation of the European Cancer Institutes
3. Institut Jules Bordet
4. SOS Europe Srl

In the wake of the OECI Board proposal to launch a European Cancer Mission within the upcoming FP9 Framework Programme of the European Commission, the OECI WG chairpersons, together with putative partners such as ECCO, EORTC, ECPC, ESO, UNICANCER, Alleanza Contro il Cancro, EULIFE, IARC and ECL joined a democratic working party to discuss and define the interest of the European cancer community to launch a specific Mission initiative.

After an introduction of the President Thierry Philip and a brief analysis of the participating organisations, the floor gathered in a two-hour brainstorming session to answer to the following questions:

1) Why a Mission?

2) How a Mission?

3) What in a Mission?

The following productive, bottom-up debate resulted into working out different solutions for a title, a goal, as well as the means & tools for a Mission.

1. Title: Towards cancer control for all

The afternoon session opened with a discussion around a title for the Mission. The floor elaborated on a concise and effective description, as the one for the Apollo Mission, whose goal was "landing a man on the Moon and returning him safely to the Earth". Several ideas (listed below) were proposed and the winning solution was "Towards cancer control for all".

- Defeating the Cancer Tsunami
- Avoiding and controlling the European tsunami of cancer
- Defeating the tsunami of cancer in Europe using networking
- Move innovation to cancer patients
- Bring comprehensive cancer care to all patients
- Improve the competitiveness of European industry in the field of cancer
- The OECI 3B challenge (Big Idea, Big Challenge, Big Plan)
- Towards cancer control for all
- Hope on cancer
- Less life loss

2. The Challenge: Unity, Equity & Patient-Centeredness

The Mission, in compliance with Mariana Mazzuccato's definition, proposed in the article "Mission-oriented Research and Innovation in the European Union: A problem-solving approach to fuel innovation-led growth", should galvanize investment & innovation across multiple sectors and actors, whilst adopting bottom-up experimentation and cross-sectorial innovation.

Bearing this framework in mind, the participants settled on the necessity of unifying the cancer family around three main pillars holding at core the cancer patient:

- ***Prevention***
- ***Treatment***
- ***Survivorship***

An expected increase of 4.3 million cancer cases for 2035, compared to 3,6 million cancer cases in 2015, indicate a 20% increase in incidence and a 40% increase in mortality, respectively. This forecast obliges the cancer community to find new approaches to cancer control and pursue an improvement in quality of life & rehabilitation. Specific educational actions for public and professionals, along with an effective exploitation of research results are essential. Output cancer research studies on big data and a better use of IT applications are also paramount to better understand the patient responses to targeted therapies.

The figure below represents the idea of Mission as outlined by the Working Party. In the coming months the OECI will work to implement this strategy and translate it into a practical and sustainable approach, leading to better cancer control. This will result in a reduction of the cancer incidence, whilst giving national health systems the possibility to support the increasing costs of personalised medicine.

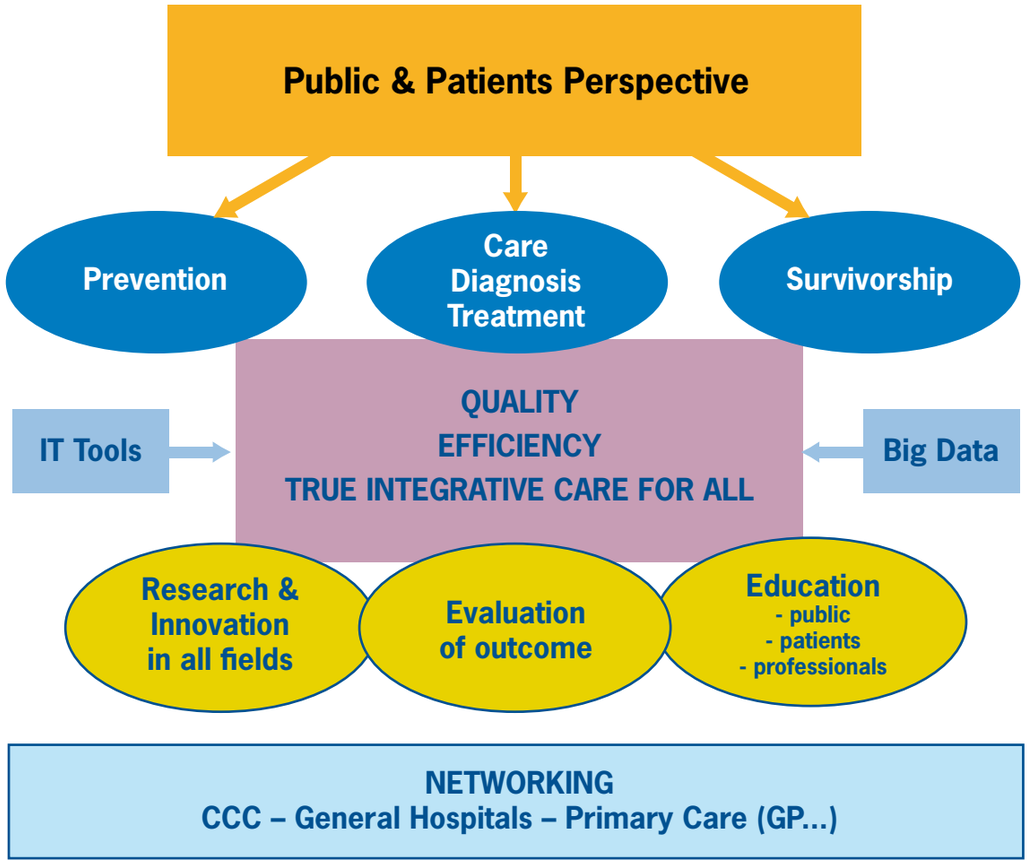


Fig. A Proposal of a Mission Framework

3. Conclusion

The OECI Mission Working Party concluded successfully, with the participants' firm belief that the key for a successful cancer Mission lies in cooperation, compromise and unity. Bringing the cancer patients on board is essential, taking into account not only the diagnosed and treated patients, but also the problems arising from survivors. At the same time, it is noteworthy that healthy individuals must be better targeted through the means of primary and secondary prevention.

ECCO 2018 European Cancer Summit took ground-breaking decisions on Measurement of Quality Cancer Care, Integration of Cancer Care and Survivorship

Philip Poortmans[1,2]
1. Institut Curie
2. , ECCO - European Cancer Organisation

Over 350 experts and leaders from across the cancer care stakeholder communities, met at the ECCO 2018 European Cancer Summit during the Austrian EU Presidency in Vienna on 7th -9th September. They decided on how Europe can improve the way in which quality of cancer care is measured, integration of cancer care is made reality, and how financial discrimination experienced by survivors of cancer can be alleviated.

The three high level, time-based goals, passed as resolutions by the Summit were:

1. By 2023 an agreed set of core standards and evidence-based indicators (based on processes and patient outcomes) to measure the quality of all cancer services in European countries should be in place.
2. By 2025, all national cancer plans in Europe should contain ambitious and measurable goals and actions to improve the integration of primary care professionals and informal carers within the multidisciplinary care given to patients.
3. By 2025, in respect to accessing financial services*, the right of cancer survivors not to declare their cancer 10 years after the end of the active treatment** and 5 years if they had cancer under 18, should be codified across European countries.

*For the purposes of this resolution, "financial services" are understood to refer to services and products provided to consumers and businesses by financial institutions such as banks, insurance companies, brokerage firms, consumer finance companies, and investment companies (Source: investorwords.com)

**For the purpose of this resolution, "active treatment" does not include maintenance treatment with hormonotherapy, immunotherapy, targeted therapy or other such therapies based on sound and increasing evidence.

The resolutions are carried forward by a set of defined actions to put them down to practice towards their achievement. The complete list of resolutions and supporting actions are available on ***www.eccosummit.eu/Resolutions***

Virtual working groups will assist in developing and implementing the action plans, supported by, reporting to, and guided by, the ECCO Oncopolicy Committee (OPC) and ECCO Patient Advisory Committee (ECCO PAC). The progress will be reported during the ECCO 2019 European Cancer Summit on 12th -14th September in Brussels, Belgium.

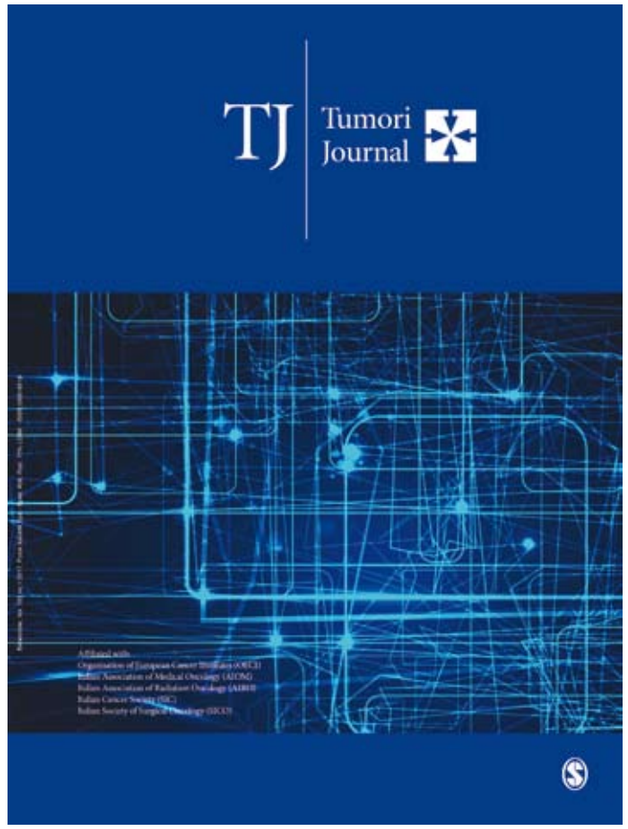
ECCO President Philip Poortmans stated: "These resolutions represent the essential intention of the ECCO European Cancer Summit: to form and drive consensus on the actions necessary to ameliorate delivery of cancer care in Europe and to improve outcomes and experience for all cancer patients. It is time for the entire European cancer community to join forces to bring these aspirations of improvement into reality."

Presentations from the ECCO 2018 Summit are available on ***www.eccosummit.eu/Programme***

With the death of Umberto Veronesi the world has lost a true visionary. He will be sorely missed by everyone who had the privilege to know and work with him, and millions of cancer patients around the world will continue to benefit from his life's work for many years to come.

Cancer precision medicine today: towards omics information in healthcare systems

Claudio Lombardo[1,2], ***Mauro Giacomini***[3] *and* ***Carmelina Ruggiero***[3,4]
1. Organisation of the European Cancer institutes
2. SOS Europe Srl
3. Dept. of Informatics, Bio-engineering, Robotics and System Engineering - University of Genoa
4. University College London



A paper on Cancer precision medicine has recently first been published on Tumori Journal. This paper focuses on the integration of omics data in electronic health records and on interoperability aspects relating to big data analysis for precision medicine.

Starting from a historical overview on "personalised medicine" and "precision medicine" the paper focuses on Next Generation Sequencing (NGS) techniques and on the use and integration of the great amount of NGS data into electronic health records.

Omics data integration methods for electronic health record and for system interoperability are considered, with special reference to the high number of specific software tools used to manage different aspects of patient treatment, which is a significant barrier against the use of this integrated approach in daily clinical routine.

Interoperability is critical for precision medicine, especially for big data analysis. The correct use of all three levels of interoperability (technical, semantic, and process interoperability) that is made possible through the implementation of standards, plays a key role in order to achieve an easy access to a significant amount of data, all with correct contextualization, which is the only way to obtain a real value from data for precision medicine.

Even though no standards for the integration of genomic data into the EHR have been established to date, Health Level Seven International (HL7), a non-profit standards developing organisation, which provides a widespread framework for exchange, integration, sharing, and retrieval of electronic health integration, has proposed many different frameworks to support format interoperability.

An architecture that could improve the potential use of data routinely collected in many health information systems is proposed, in order to achieve a real patient-centred information environment.

Full article at: ***http://www.oeci.eu/Attachments/CancerPrecisionMedicineToday.pdf***

Improving policy to support cancer survivors

Francesco De Lorenzo
European Cancer Patient Coalition President

Due to increasing investment in health, earlier diagnosis, timely treatment, and new therapies, more people are surviving a diagnosis of cancer. In 2007, it was estimated that there were approximately 8.7 million cancer survivors in Europe; in Italy today, 3,300,000 are people living with a cancer diagnosis - 1 in every 19 people in the population - while 825,000 people are cured. People with acute cancer, those with chronic cancer and those cured of cancer have different needs and preferences. Often, cancer survivors are left unchecked and not followed up properly after the end of the acute treatment phase and cancer survivors' needs remain neglected by healthcare systems. At least one quarter of cancer survivors report long-term poor health and disability and many carry a life-long fear of cancer recurrence. Returning to work is also difficult for many cancer survivors, with one recent global survey reporting that more than one-third of employers described concerns about workplace discrimination against cancer survivors. In Italy the number of requests approved for disabilities and inabilities for cancer have triplicated the ones for cardiovascular diseases. This increases the already unacceptable impact of inequalities in cancer care.

The inherently cross-disciplinary nature of survivorship care calls for the commitment and action not only of healthcare systems, but also of other socio-economic actors, like employers, insurance and bank product providers.

The "European Guide on Quality Improvement in Comprehensive Cancer Control" (CanCon) was a common effort between representatives of Ministries of Public Health from 17 EU Member States, co-funded by the European Commission. It includes a specific chapter on survivorship which provides a set of recommendations for the development of quality national survivorship care plans. The European Cancer Patient Coalition (ECPC) was a key partner of CanCon and contributed to the drafting of the guide and of the policy papers.

The European Guide presents key recommendations to improve EU countries' capacity to fight cancer. The Guide explains in detail which measures EU governments should implement to make National Cancer Control Plans more resilient and effective, focusing on key aspects of cancer care: integrated cancer control, community-level cancer control, survivorship and rehabilitation, screening.

Member States have a great responsibility in implementing the recommendations of CanCon. ECPC asks, with a strong voice and full confidence, that all 17 Member States involved in CanCon will apply the CanCon recommendations to their national cancer plans. The Italian Government is one of the first Member States that updated the Italian Cancer Plan (still in definition) with CanCon Recommendations on survivorship care.

The main messages are:

1. Cancer is not a death sentence anymore. A cultural shift is needed to fight the stigma associated with cancer.

2. Cancer survivors' follow-up, late effect management, and tertiary prevention needs to be anticipated, personalised, and implemented into care pathways, with active participation of survivors and relatives.

3. Improvement of the early detection of patients' needs and their access to rehabilitation, psychosocial and palliative care services is required.

4. An integrated and multi-professional care approach, with a coordination of community care providers and services, is needed to implement a survivorship care plan that enhances the patient's self-management and quality of life.

5. More research in the area of survivorship is needed to provide data on late effects, as well as the impact and cost-effectiveness of supportive care, rehabilitation, palliative and psychosocial care interventions.

The document includes late effect management and tertiary prevention and recognises people with cancer as active partners in care. An integrated care approach is recommended in order to ensure an efficient, effective, and multi-disciplinary care pathway is implemented.

Patient organisations, through ECPC, have demonstrated the ability to link the policy environment to the reality of cancer care, producing in collaboration with the European Society for Medical Oncology the "Patient Guide on Survivorship", the first practical implementation of the Joint Action on Cancer Control survivorship recommendations. The Guide provides actionable information on follow-up care, setting the foundation for a personalised survivorship care plan.

Patient organisations can serve as catalysts to amplify the voices of people with cancer when developing policy.

A checklist of key interventions completes the document. This guide is a practical tool to empower people with cancer to engage with their healthcare team. The return to an active and normal life, for all cancer survivors who can reasonably achieve this goal, must be a priority of all healthcare systems.

Genomics and Immunotherapy Main Topics of First iPAAC Stakeholder Forum in Brussels

Tit Albreht, Marjetka Jelenc, Tina Lipušček, Nataša Voje, Karmen Hribar
National Institute of Public Health, Slovenia

Co-funded by the Health Programme of the European Union

The first Stakeholder Forum of the iPAAC Joint Action was held at the Belgian Ministry of Employment on 20th September 2018 in Brussels. The Forum gathered iPAAC Collaborating Partners from across the cancer community to reflect on the objectives of the iPAAC Joint Action and objectives of the Forum. The purpose of the Stakeholder Forum meeting was also to inform stakeholders with first-hand information and to exchange views and contributions on various elements of the Joint Action.

The meeting was organised by the Slovenian Institute of Public Health (NIJZ), which coordinates the iPAAC Joint Action. More than 60 participants from major European cancer organisations took part in this one-day meeting. The programme consisted of three main sessions. Tit Albreht, the iPAAC Scientific Coordinator, presented the main objectives of the Joint Action and its Work Packages in the introductory session. This was followed by a presentation of two thematic main sessions.

Marc Van den Bulcke (Work Package 6 Leader) from the Belgian Cancer centre of Sciensano and his colleagues introduced the first session with a presentation on genomics and cancer. At the Forum, the presentation concentrated mainly on the importance to organise the societal debate on ethical, legal and privacy issues on the use of genome information in healthcare. Several initiatives across the USA, UK and Europe that focus on educating and informing the public about the role that genomics might play in healthcare were overviewed. Whilst organising a societal debate is a promising approach to the application of genome information in a healthcare system, many questions remain unanswered.

In the second session, Muriel Dahan (Work Package 9 Leader) from the French Institut National du Cancer made a presentation on innovative therapies in cancer. The presentation outlined the main types of innovative immunotherapies in cancer as well as the possibility to investigate potential other types of innovative therapies. The focus within the Work Package 9 will be on checkpoint inhibitors and CAR-T cells. The presentation outlined the types of cancers for which checkpoint inhibitors have at least one approved therapeutic indication in the European Union. Further on, it was pointed out that CAR-T cells have been approved by the EMA in 2018 and they should be available on the market very soon for hematologic tumours.

In his concluding remarks, Stefan Schreck from the European Commission emphasised that the Commission focuses on making a measurable difference within each Member State and further introduced the forthcoming mission-oriented policy approach, which will aim to maximise the impact of the European research and innovation.

Overall, participants engaged in active discussion and exchange regarding the presented topics and will annually meet in Brussels to discuss the progress of the Joint Action. The next Stakeholder Forum is scheduled to take place in autumn 2019 in Brussels.

More information about the first iPAAC Stakeholder Forum can be obtained by visiting the official iPAAC website ***https://www.ipaac.eu/news-detail/en/11-the-first-ipaac-stakeholder-forum-20-september-2018-brussels***

For more information on how your organisation can participate in the iPAAC Joint Action, please contact ***ipaac@nijz.si***

The iPAAC Joint Action has received funding from the European Union in the framework of the Health Programme.

News on the EU Joint Action on Rare Cancers

Simon Oberst[1,2]
1. Cambridge Cancer Centre
2. Organisation of the European Cancer Institutes

The EU Joint Action on Rare Cancers ***http://jointactionrarecancers.eu*** kicked off in October 2016 with a complex remit around rare cancers which ranges from policy influencing, to registration for rare cancers, clinical guidelines, epidemiology, education, childhood cancers, and patient centeredness. Quality Assurance of Rare Cancer Networks is where OECI comes in, as leaders of Work Package 5.

Rare cancers form around 24% of cancer diagnoses in Europe, ranging from the largest group of sarcomas through to extremely rare cancers which may only constitute a handful of diagnoses per year in Europe. The public health challenges are obvious: limited professional expertise in the field, challenges for clinical research and drug development, timely and accurate diagnoses, and optimal treatment for the patient. Therefore proper referral of patients and effective clinical networking are crucial for rare cancer patients. To this end, the European Commission, through its European Reference Networks call, set up three Cancer Reference Networks in 2017, namely EURACAN, Eurobloodnet and PaedCan. These are essentially high level networks of nationally-recognised Centres of Reference for Rare Cancers.

The current Joint Action aims at optimising the work of the cancer ERNs and evaluating them. It will also encourage Member States to have clear and resourced strategies for tackling rare cancers in their Cancer Control Plans, and to create formal networks of care and research for Rare Cancers where these do not already exist.

OECI's first task, working with our partners in the Netherlands Cancer Institute (IKNL), has been to map the existing Networks for Rare Cancers in Europe. These results have yet to be published, but the interim findings indicate (rather predictably) that there is immense variation of provision in Member States, ranging from mature networks of care to an absence of co-ordinated provision for rare cancer patients. One of the drivers for the Joint Action is equality of access to care for patients with rare cancers, and so addressing the deficits in network provision will be a key recommendation.

The second task of our work is to construct a set of Quality Standards and Indicators for Networks of Rare Cancers. This is aimed firstly to help the three Cancer ERNs, but secondly as a voluntary good practice framework for Member States to set up and then evaluate the effectiveness of National Rare Cancer Networks. After an extensive process of consultation involving patients, the cancer ERNs, and our partners in the work package, we have drawn up a set of quality standards for ERNs and National Networks, covering most of the same areas, but assuming that the Centres of Reference of the ERNs are in fact the putative hubs within national networks, where most patients with rare cancers are diagnosed and treated. These standards will be approved in a plenary session of the work package in March 2019.

We will consult with the leaders of DG-Health and Consumer Protection and the ERN Monitoring Group to ensure that the standards can and will be implemented in practice, and that the mechanisms can be created for evaluation and monitoring. There may be a case for phasing in the implementation of the standards, depending on the level of resource and the e-tools which can be designed at EU level. The expected outcome is that the evaluation system will comprise regular gathering of evidence-based quality indicators, and then a 5-year evaluation of the ERNs and their Healthcare Providers which will include both a self-assessment component and an external assessment by an independent body. This would also be the suggested process of evaluation for existing and future national networks for rare cancers.

Our prize is to improve the consistent level of research-informed care given to rare cancer patients and their families throughout Europe.

12 New Members approved by the OECI 2018 General Assembly

Giorgia Pesce *and* ***Patrizia Sommella***
SOS Europe Srl

During the last OECI General Assembly held on June 22nd in Poznań, 12 Cancer Centres joined the membership.

The OECI warmly welcomes the 9 New Full Members and the 3 Associate Members and hopes that their active collaboration will provide a significant support in implementing and promoting the OECI Programme of activities.

The Participants to the OECI Oncology Days in Poznan - June 2018

The New OECI Full Members

Cancer Center of Kuopio University Hospital
www.psshp.fi
Finland

Oulu University Hospital
www.ppshp.fi
Finland

Institut du Cancer de Montpellier (ICM)
www.icm.unicancer.fr
France

Institut Universitaire du Cancer de Toulouse-Oncopole
www.iuct-oncopole.fr
France

Institut Jean-Godinot
https://institutjeangodinot.fr
France

Institut de cancérologie des Hospices Civils de Lyon
www.chu-lyon.fr
France

Assistance Publique – Hôpitaux de Paris APHP-CARPEM
Cancer Research for PErsonalized Medicine
http://carpem.fr
France

Assistance Publique – Hôpitaux de Paris APHP – IUC
Institut Universitaire de Cancérologie APHP 6 – Sorbonne Université
www.iuc.upmc.fr
France

Centre François Baclesse
www.baclesse.fr
France

Fondazione Istituto Oncologico del Mediterraneo IOM
www.fondazioneiom.it
Italy

The New OECI Associate Members

Comprehensive Cancer Centre Zürich
www.cancercenter.usz.ch
Switzerland

Instituto Oncológico Fundación Arturo López Pérez – FALP
www.falp.cl
Chile

Instituto Nacional de Cancerologia – ESE Bogotà
www.cancer.gov.co
Colombia

The OECI membership increases to 93 members. More information on the New OECI Members are available via ***www.oeci.eu/Membership.aspx***

Modification of the OECI Statute: 2 different categories for Associate Members

José Laranja Pontes[1,2] *and* ***Manuel Llombart Fuertes***[1,3]
1. Organisation of the European Cancer Institutes
2. Instituto Português de Oncologia do Porto, Francisco Gentil – EPE
3. Fundación Instituto Valenciano de Oncologia, IVO

Organisation of European Cancer Institutes
European Economic Interest Grouping

At the Oncology Days 2018 held in Poznań from 19th -22nd June, the OECI welcomed 12 new Institutes to its 82 Member network.

As a result, the OECI will be counting among its Members both European Institutes and two new South American Members, which adhered to our network attracted by the dynamic activities of our Working Groups and in particular by the Accreditation and Designation Programme – the only existing European instrument, ISQua certified, to measure the quality standards and the internal organisation of a cancer centre.

The increasing request of collaboration coming from non-European Cancer Centres from Central America and the Middle East called for a necessity to revise and change the OECI Statute. Hence, at the 22nd June OECI General Assembly, the Members voted and approved the Board proposal to modify the Article 6.2 of the OECI Statute, subsequently dividing the Associate Member Institutions into Category A and Category B.

Namely, the Associate Members which fulfil the conditions provided for in Article 4 of EEC Regulation n° 2137/85 of 25th July, 1985 on the creation of a European Economic Interest Grouping and those coming from Switzerland, will fall under category A of the "Associate Members". Conversely, those Members which do not comply with the conditions of the above-mentioned article will be listed under the Category B Associate Members.

Starting from 2019, this modification will also entail a distinction of the yearly membership fees: for Category A it will be raised from € 2.000 to € 4.000; the fee for Category B Associate Members, instead, will not be subjected to any changes and shall be maintained at € 2.000.

With regard to the Full Members of the European Union, the countries participating to the Internal Market and Switzerland, starting from 2019, the membership fees will figure to € 6.500, as opposed to the current € 5.000 fee.

For the new Members that will be admitted from 2019 on, the admission fee is € 6.500, the same for all the membership categories.

The increase of the Membership fee is justified by the Euro depreciation over the past 15 years, as well as the need to fully support the provisional budget for the coming years. We are trying to avoid dipping into the OECI bank reserves that, for a general decision, must be sufficient to cover our budget for a two-year period.

The 41st anniversary: welcome to Bari

OECI41

Giovanni Apolone[1,2], ***Gennaro Ciliberto***[3], ***Ruggero De Maria***[4], ***Paolo De Paoli***[4], ***Claudio Lombardo***[2,5], ***Thierry Philip***[2,6], ***Nicola Silvestris***[7]
1 Fondazione Istituto Nazionale dei Tumori di Milano, IRCCS
2. Organisation of the European Cancer Institutes
3. Istituto Nazionale Tumori Regina Elena, IRCCS
4. Alleanza Contro il Cancro
5. SOS Europe Srl
6. Institut Curie
7. Istituto Tumori Giovanni Paolo II .IRCCS

In collaboraiton with
Giovanni Paolo II Cancer Centre

The year 2019 marks the 41st Anniversary of the OECI foundation. After 11 years, Italy has been designated as the host country for OECI Oncology Days 41 and Bari awarded the privilege of welcoming the prestigious event. The event will be organised thanks to the collaboration and support of all the scientific directors of Italian cancer centres and of the Italian cancer network "Alleanza Contro il Cancro".

The OECI 41st Anniversary will be held in Bari, Italy, from June 19th to June 21st in collaboration with the Cancer Institute "Giovanni Paolo II".
The "2019 OECI Oncology Days" cover a range of topical issues in oncology. In particular, the Scientific Conference will be devoted to "Tackling tumor heterogeneity: Biological, Laboratory, Clinical and Regulatory Implications".

The aim of the Conference is the exchange of data and ideas regarding the difficulties and opportunities which will emerge from a thorough understanding of the impact of tumour heterogeneity in cancer treatment. We envision that this approach may provide ground to move to the next generation of cancer treatments, in which a dynamic clinical practice can provide timely adjustments of antineoplastic strategies.

Differences between tumours of the same type in different patients as well as genetic and epigenetic differences between cancer cells in a tumour establish the tumour heterogeneity. Heterogeneity provides the fuel for drug resistance, strongly impacting on the response to therapy and may be responsible for the persistence of some tumor cells even after cancer treatment. Therefore, an accurate assessment of tumour heterogeneity is mandatory for the development of effective therapies and the liquid biopsy, through serial characterization of genetic variants in plasma samples of cancer patients, providing reliable information on spatial and temporal heterogeneity. If we want to explain these spatial and temporal heterogeneity, we have to consider the dynamism of the tumour evolution in both its spatial (locally and throughout the body) and temporal organisation, throughout the course of the disease. In fact, analysis of different areas of the tumour would reveal different genetic and epigenetic alterations in cancer cells and the analysis of the same tumour in function of time might reveal distinct patterns of genetic evolution with respect to the clonal composition of the tumour entity with disease progression or regression. Another factor to consider in the field of tumor heterogeneity is that it could be intertumor (tumor by tumor) and intratumor (within a tumor) heterogeneity.

Intratumor heterogeneity is given by the presence of genomic and biological variations within a tumor lesion gained by tumor cell evolution under diverse microenvironments linked to different etiologies. It has been described in several solid tumours, including lung, breast, ovarian, pancreatic, kidney, colorectal, brain, thyroid and prostate cancers, as well as hematological malignancies. Intertumor heterogeneity identify the same kind of tumors from different patients whose altered genotype and phenotype are induced by diverse etiological and environmental factors. The most well-known inter-patient tumour heterogeneity may be related to host factors, such as tumour microenvironment, germ line mutations influencing treatment response, and the unique somatic mutations that can occur within the tumour of each individual patient. Moreover, metastatic lesions on different secondary sites can arise from different cellular populations within a primary tumour, resulting in heterogeneity among

Saint Nicolaus - ph Franco Cappellari

metastases, known as intermetastatic heterogeneity and since metastatic lesions can acquire new mutations and evolve independently with each cell division, heterogeneity within a metastasis can also exist, known as intrametastatic heterogeneity. Ultimately, the decoding of complex clonal relationships and the combinatorial approaches that pair therapies targeting both the predominant drug-sensitive cancer cells and the drug-resistant and drug-tolerant cells seem likely to induce the most-durable responses.

The three Sessions included in the Scientific Conference will be followed by a special Session on "Quality of cancer research and care", where the advancements of the OECI Quality Programme will be presented together with the State of Art of OECI already certified centres.

The Oncology Days 2019 includes the classic appointment with the OECI pathologists that will meet on June 20th to debate on "Early diagnosis in aggressive tumours". The general structure of the Day refers to tumours in which the diagnosis is usually difficult and late. New evidences of early diagnosis will be explored for the following three tumor types:

– pancreatic cancer, usually diagnosed in a very late stage;

– ovarian high-grade serous carcinoma, representing over 20% of ovarian tumours and with very poor prognosis and short survivals;

– lung cancer, where some very interesting new possibilities of early diagnosis may be discussed.

The increased interest to involve patients in our actions and the need to define practical protocols to support the request coming from survivors, triggered the OECI to launch for the first time a "Patients' Day", which will take place on June 20th in parallel with the Pathology Day. The event should be organised in collaboration with the European Cancer Patients Coalition and other interested cancer organisations.

During and after the conference, there will be time for the participants to relax and enjoy the surroundings. Bari is a charming city, with its origins going back 3500 years, before the bronze age. The City is easy to visit being divided into three different areas: the historical centre, between the two historical city gates, where the visitors may revive a centuries-old atmosphere where past domains can easily be recognized in the architecture and historical monuments; the "murattian" area, with modern buildings, interesting and elegant shops and a beautiful seashore promenade and beyond the central railway station, the sprawling residential suburban area.

The Full Social Programme, which includes a visit to Matera, the European City of Culture 2019, will be soon announced at ***oeci@oeci.eu***

OECI and the National and Local Organisers hope that the Oncology Days 2019 will be successful and look forward to welcoming you to Bari.

OECI
Organisation of European Cancer Institutes

ecancermedicalscience

Official OECI Journal
In collaboration with

Giovanni Paolo II Cancer Centre

Proceedings published on a special issue of

TJ Tumori Journal

Oncology Days

OECI 41

BARI 2019
GENERAL ASSEMBLY, SCIENTIFIC CONFERENCES AND RELATED EVENTS

Bari, Italy
June 19th-21st 2019
Hotel Nicolaus

41th ANNIVERSARY OECI

ph Carlo Elmiro Bevilacqua

June 20th - **Pathology Day**
Early diagnosis in aggressive tumours

June 20th - **Patient Day**
Patient-stakeholder engagement

June 21st - **Scientific Conference**
Tackling tumour heterogeneity: Biological, Laboratory, Clinical and Regulatory Implications

June 21st - **Accreditation and Designation Session**
Using quality systems and comprehensiveness to improve patient outcomes and experience

June 22nd - **OECI General Assembly 2019**

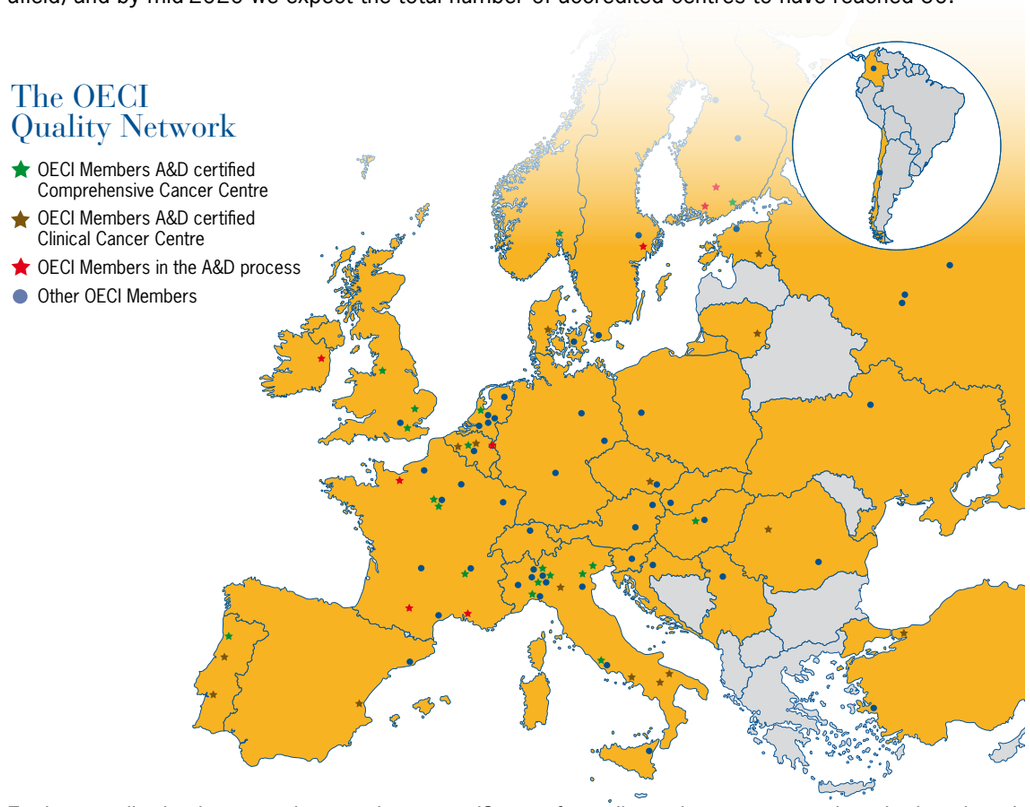
ESO European School of Oncology learning to care

ESO Recommended

The OECI Accreditation and Designation Programme: 10 years of evidence-based Quality Assurance

Simon Oberst[1,2] & the ***Accreditation and Designation Board***[2]
1. Cambridge Cancer Centre
2. Organisation of the European Cancer Institutes

The Accreditation and Designation (A&D) Programme of the OECI is now celebrating its 10 year anniversary of existence. In that time OECI has accredited 15 large Clinical Cancer Centres and 19 Comprehensive Cancer Centres all over Europe, with a further 7 Centres newly in the self-assessment phase. We have a pipeline of interested Centres from Scandinavia to Israel (and some from further afield) and by mid-2020 we expect the total number of accredited centres to have reached 50.



Each accreditation is so much more than a certificate of excellence in care, research and education. It is the culmination of a long processes of self-assessment and external validation of all the operations and governance of the Cancer Centre across all modalities of treatment, and all parts of the patient pathway from referral to survivorship or end of life care. The important product of this process is the Improvement Plan generated by the Centre as a result of the Opportunity Points raised by the audit team in the Peer Review. It is this agreed document, with accountabilities and milestones, which drives the continuous improvement of the centre for the benefit of patients.

The A&D Programme is both tumour-specific and institution-wide, and OECI regards it as vital that these two elements are retained in step. Right from the start we have affirmed the key evidence-based principles that cancer diagnosis and treatment need to be delivered by Tumour Boards (often known as Multidisciplinary Teams). These Boards need to work to consistent Procedures, with pre-determined disciplines being present. They should have discussions of the case of each patient at key points in the patient pathway, reaching conclusions based on agreed Clinical Guidelines and recorded consistently for discussion with the patient. The OECI Peer Review teams find the process of attending these Tumour Boards in real time and observing the discussions and conclusions one of the most instructive and revealing aspects of the Review.

The workings of all the Tumour Boards need to be underpinned by consistent Standard Operating Procedures, a consistent use of the Electronic Patient Record, data gathering and exchange, which flows into an integrated Quality Management System. Whilst OECI recognises that quality is driven by the clinicians of all disciplines working in the Tumour Boards, it is also shaped and often accelerated by a centralised reporting system to management. Quality, Improvement and Patient Safety should be absolutely and personally accountable at Board/Director level of the Health Care Provider. The data flowing to this level, best encapsulated in a dashboard of indicators, will inform investment decisions, areas of concern, or workforce, to improve patient-centred care, research and education.

This comprehensive approach to quality assurance, combining tumour-specific and institution-wide domains, is what has enabled the A&D Programme have its standards successfully accredited by the International Society for Quality in Healthcare (ISQua). It is the only cancer-related Accreditation System in Europe to have this imprimatur. [check about JACIE]

Development of New Accreditation Standards

Notwithstanding the accolade of the ISQua certification of the OECI A&D Standards, there is a need for regular revision of the standards to be at the forefront of best practice and take into account advances in cancer research and care. OECI performs a major consultation and update of the standards every five years, and the current process of revision began in July 2018 and will continue until implementation on 1 January 2020.

The process involves consulting multiple stakeholders including the reviewed cancer centres, the audit teams, the Accreditation and Designation Board, patients, professional societies and experts, and other health accreditation programmes. Every single standard will be reviewed for efficacy.

The A&D Board - Cambridge 9th - 10th October 2018

This round of revision is going to be more radical than 5 years ago. It will identify Core Standards for the first time, the significance of which will be that these are so key to quality for cancer patients that centres in re-accreditation will be required to show selected evidence of compliance with these, whereas non-core standards at re-accreditation will simply require scoring and narrative description of compliance.

Network Standards

The revision will also identify standards which are applicable to cancer networks. This is an important development which will enable the growth and recognition of Comprehensive Cancer Networks in Europe, a hot topic at the present time. Readers will be aware of the moves in many EU Member States to establish these networks in response to the need to establish equality of access to high quality care across a region or nation. In certain Member States only 10 per cent of new cancer patients are diagnosed and treated in Comprehensive Cancer Centres and University Medical Centres combined. Thus the majority of diagnoses and treatments are performed in general hospitals, and highly performing networks with clear pathways of care and ensuring equitable access to clinical trials are required. The new OECI programme will set the standards for these new networks. This will also be applicable to the development in Work Package 10 of the IPAAC Joint Action.

New standards around prevention and molecular diagnostics

A new area of emphasis will be around prevention. The OECI experience over ten years is that Cancer Centres have often downplayed their role in prevention or screening, as if this were the sole responsibility of public health or regional/national governments. And yet increasingly it is recognised that Cancer Centres have rôles in education of the public around prevention factors in lifestyle, awareness of signs and symptoms, working with other agencies in developing novel screening and biomarkers, and working with academic partners and public health in identifying high risk groups in the population. New standards will target these requirements.

As our understanding of cancer increases, molecular diagnostics are becoming an increasing feature of the clinical pathway, as well as large scale molecular profiling for research purposes. Many cancer centres now have a formal Molecular Tumour Board which interacts with the tumour specific MDTs to determine molecular diagnoses with specifically actionable therapies. The new standards will ensure that these developments are built into the patient pathway and appropriately managed in centres and networks. Associated with this and traditional histopathology, OECI needs to strengthen our standards for biobanking and sample handling, specifically ensuring that biobanks are achieving technical accreditations by such bodies such as BBMRI.

Strengthening tumour-specific indicators and increasing patient participation

OECI recognises that we need to strengthen our focus on the performance of individual Tumour Boards, sometimes known as Integrated Practice Units. Whilst already we monitor Quality Indicators for Tumour Boards and visibly observe the practice of selected individual MDTs, it is felt that the A&D Programme could operate more specifically at Tumour Board level and benchmark outcome and evidence-based process indicators against comparable teams.

At the same time, the many activities of diagnosis, treatment and aftercare of patients are so diverse that OECI should selectively rely on other specific certifications which regulate certain areas, for instance, ISO certifications, and general hospital assessments by national bodies, where appropriate. This is so as to avoid unnecessary duplication of assessment and accreditation processes.

We also want to make our own Accreditation processes more responsive to patients' needs. To that end, we will be seeking to involve patients and patient organisations more in our accreditation processes and policy. In this respect we believe that OECI will setting a new norm for cancer organisations in Europe.

36 new auditors in training for the OECI A&D Programme

Willien Westerhuis[1,2] *and* ***Roxana Plesoianu***[2]
1. Integraal Kankercentrum Nederland
2. Organisation of the European Cancer Institutes

The participants to the 2018 Inveruno training course for A&D auditors and the OECI coordination staff.

The OECI Accreditation & Designation Programme aims to help European cancer institutes to implement a quality system for oncology care and provide cancer patients within Europe an equal access to high quality of cancer care, backed up by excellent training and translational research.

A multidisciplinary team of professionals in oncology (quality, nursing, medical, research) visits Cancer Centres (either Clinical Centres or Comprehensive) as part of the A&D programme. This two-day peer review visit is to assess the quality of cancer care, education and research within the centre, give feedback of the results of the visit and work together with the centre to formulate recommendations for improvement. The OECI auditors are all highly skilled in their own fields, and in addition are trained in how to perform a peer review audit for OECI so as to ensure complete consistency within the programme.

The A&D Programme is expanding all the time, and already accredited centres are also going for their 5-year re-accreditation. As a result, it is necessary for OECI to expand the team of experts. On 19 – 21 November 18 new auditors were trained during a two-day training course in Villa Verganti Veronesi in Inveruno, Italy.

The new auditors come from cancer institutes all over Europe (Croatia, Denmark, Estonia, France, Ireland, Italy, Portugal, Sweden, The Netherlands, Turkey, the UK). A second cohort of auditors will receive the same training in Spring 2019. The training courses are provided by Patrick Corstiaans from KERTEZA (kerteza.com), an independent Belgian company performing training for quality programmes.

During the two training days the auditors were informed about the content of the standards, how to prepare for an audit using the web-based e-tool, how to perform interviews and how to report the findings in the e-tool. During the second day the trainees performed interactive mock interview exercises.

"The training was very useful both from a theoretical and a practical point of view, the objectives were clearly explained and achieved, and all aspects were clearly illustrated and in context" stated the 18 audit trainees. The trainers were very experienced and able to answer all of our queries and everybody gained a good knowledge on the subject matter.

Whilst emphasizing the undeniable elevated quality of the training, some trainees also underlined the importance of putting down to practice all the theoretical knowledge gained throughout the course.

The new auditors will therefore gradually be deployed in experienced audit teams. During their first peer review the new auditors will be guided and evaluated by the chair of the audit team so that the programme retains its maximum effectiveness.

9 OECI Members certified in Poznań

Harriet Blaauwgeers[1,2] *and* ***Willien Westerhuis***[1,2]
1. Integraal Kankercentrum Nederland
2. Organisation of the European Cancer Institutes

Every year during the OECI General Assembly, Accreditation & Designation certificates are handed out to members who have successfully completed the Accreditation & Designation process. On 22 June 2018 nine members received their Accreditation & Designation Certificate at the General Assembly in Poznan. Certificates were presented to Directors of Cancer Centres by the President of OECI, Professor Thierry Philip, and the Chair of the Accreditation and Designation Board, Simon Oberst. In their speeches it was emphasized that achievement of a certification – whether designated as Clinical or Comprehensive – is a considerable achievement for any Centre. The difference between the designations does not relate to the quality of patient care, but rather the volume of research and clinical trials conducted.

Designated as Clinical Cancer Centre

- **Institut of Oncology**
  Cluj Napoca (Romania)
- **Anadolu Medical Centre**
  Kocaeli (Turkey)
- **Fundacion Instituto Valenciano de Oncologia (IVO)**
  Valencia (Spain) – Re-accreditation
- **Kortijk Cancer Centre – AZ Groeninge**
  Kortrijk (Belgium)
- **National Cancer Institute**
  Vilnius (Lithuania) – Re-accreditation

Designated as Comprehensive Cancer Centre

- **Netherlands Cancer Institute (NKI)**
  Amsterdam (the Netherlands) – Re-accreditation
- **Institut Jules Bordet**
  Brussels (Belgium) – Re-accreditation
- **National Institut of Oncology**
  Budapest (Hungary) – Re-accreditation
- **Institut Curie**
  Paris (France)

The certificates are valid fore 5 years.

Delivery A&D certificates Poznań - 2018

Institut Curie, Paris - France

Netherlands Cancer Institute, Amsterdam The Netherlands

Országos Onkologiai Intézet, Budapest Hungary

National Cancer Institute, Vilnius - Lithuania

Anadolu Saglik Merkezi, Kocaeli - Turkey

AZ Groeninge, Kortrijk - Belgium

Institut Jules Bordet, Brussels - Belgium

The "Prof. Dr. Ion Chiricuta" Institute of Oncology, Cluj-Napoca - Romania

Fundación Instituto Valenciano de Oncologia, Valencia - Spain

OECI-EEIG
c/o Fondation Universitaire
11, Rue d'Egmont
B-1000, Brussels, Belgium
Phone: +32 2 512 0146

www.oeci.eu
For membership contact:
oeci@oeci.eu