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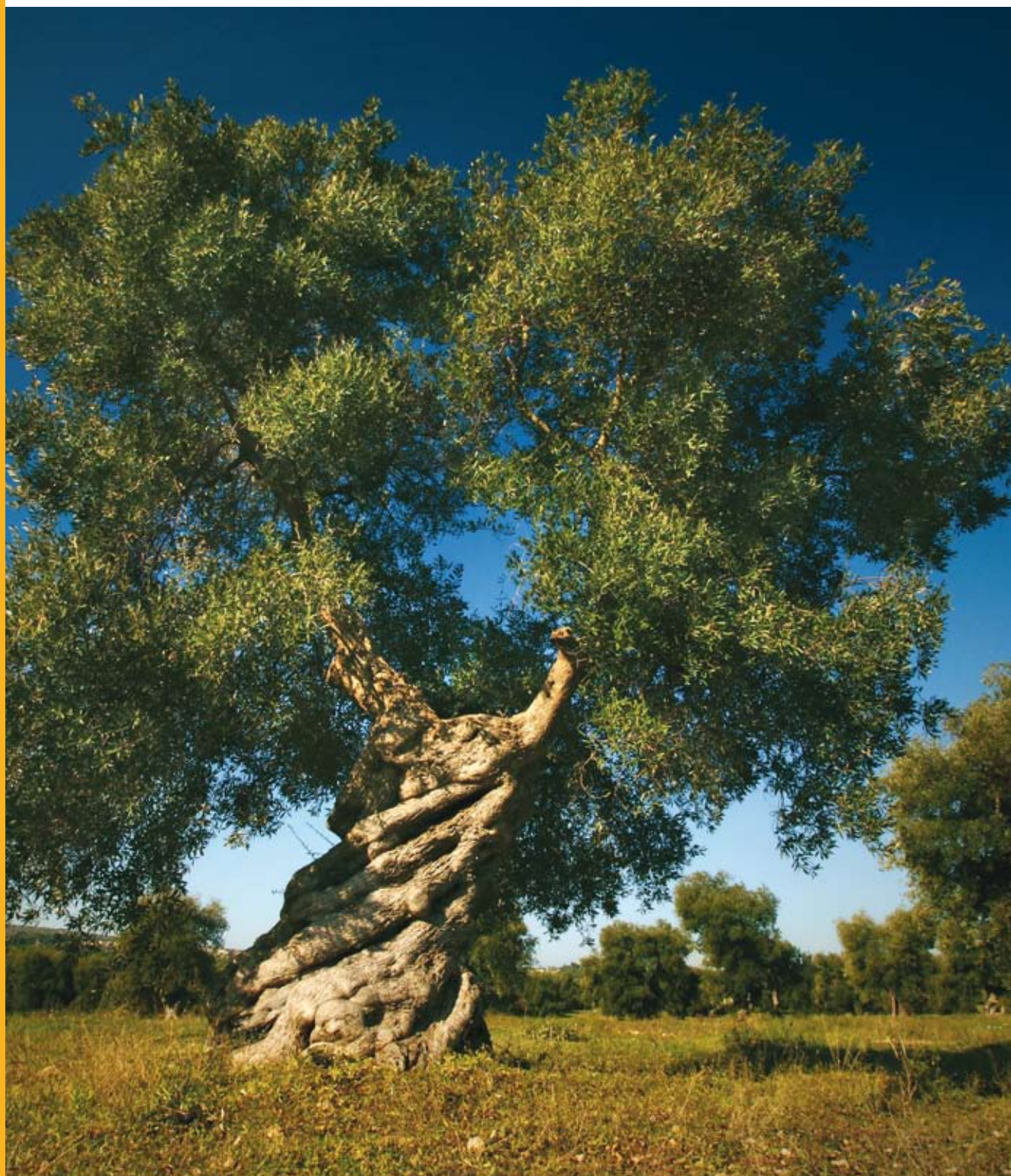

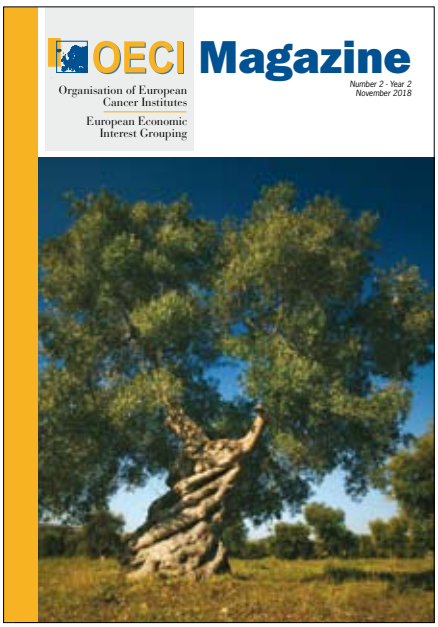

Editors:
Thierry Philip
and Claudio Lombardo

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

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Index

OECI MAGAZINE n. 1-2019

Welcome of the OECI President

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

Dear OECI Members,

Dear Readers,

In occasion of the third year of publication of the OECI Magazine, the Editorial Board has decided to dedicate the first issue of 2019 to the presentation of the activities that OECI carries out on its own, thanks to direct self-financing, or the availability of the researchers of our Members to bear the participation costs.

All our activities are aimed at preparing the ground for future applications that could refer to specific calls supported by the Framework Research Program of the European Union or other funding entities.

This is also a special issue because it is published in conjunction with the 11th Edition of the OECI Oncology Days, an event that has become a classic appointment for the Directors of the European Cancer Centres and the other non-European Institutes we are honored to include amongst our Members.

Even if the OECI "Family" is ever increasing and the 100 Members goal has now been reached, we must look at facts and respect the expectations of those who believe that a network of cancer institutions can do something that does not refer to the mandate of other professional cancer organisations/ associations.

Information is the best tool to regularly report on our activities and to give the cancer community the opportunity to participate to our initiatives and/or to propose new ones.

As you know, the OECI considers quality certification to be the Organisation's core business. As a result, the Board decided to upgrade Accreditation and Designation into a "Programme", so as to distinguish it from the activities carried out by the Working Groups that may not have the same continuity our European Quality Certification System has.

I would also like to reiterate that the Working Groups do not play a less important role as their commitments are paramount and they must also support the Accreditation and Designation Programme, backing the definition of new standards.

In order to empower the Working Group Chairpersons, we decided to define specific rules of engagement (see the Director's article) which list the rights they enjoy and the duties to be respected. These rules unequivocally clarify that the mandate, or the Working Group itself, can be dismissed in case the conditions to continue or renew it are not met.

As requested by many Members, I hope these rules comply with a principle of transparency binding Organisations such as the OECI, that carry out their activities solely thanks to the contribution of their own Members.

For the above reasons, I asked all the Working Groups and the A&D Programme Chairs to contribute to this issue with an article on their present and future initiatives so as to grant access to information on our activities also to those who cannot participate to the annual General Assembly.

I conclude by reiterating that the OECI has been engaged for some time to aggregate those in the European cancer community who are convinced that only thanks to an open collaboration it will be possible to define a credible and sustainable Project to launch a "European Cancer Mission", as requested by the Research Council and the European Parliament. In fact, the two European Bodies consider that the theme of Cancer should be the subject of a particular action in the framework of the Research Programme "Horizon Europe", which will be accompanying us from 2021 to 2027. The European Cancer Mission may be the most important action to fight cancer in the history of cancer research worldwide: we cannot allow Cancer Centres to be excluded from such an adventure!

I hope that thanks to the contribution of our Institutes, we can reach the ambitious goals in terms of prevention and treatment, and that the interests of individuals will not prevail over the expectations of our patients who must always be at the centre of all our efforts.

Rules of Engagement for the OECI Working Groups

Claudio Lombardo
Organisation of European Cancer Institutes

Since its foundation in 1979, the OECI network has been steadily growing and it is likely to reach 100 Members in the next future. An ever-increasing network evidently poses serious challenges to the effective -though inclusive- functioning of the OECI Working Groups.

In this perspective, and in agreement with a kind suggestion coming from the Italian Cancer Network, the Board discussed a practical proposal concerning organisational changes so as to maximize WG efficiency, sustainability and inclusivity, with a particular attention to the involvement of young people.

After a long discussion, the Board and Extended Board members agreed upon a final document "The Rules of Engagement for OECI WG" bound to be a practical answer to the request of transparency coming from our Members and the need to involve young generations in the main OECI activities, in order to guarantee continuity to our Organisation. A mechanism of change of the chairs has been also decided upon to grant dynamism and renewal. A yearly activity report should be delivered to the OECI Board for evaluation, and subsequently shared with all the OECI Members. The report should include information related to resource allocation in compliance with the sustainability plan, and verifiable results of the planned WG activities.

Below the full text of the RoE, already published on the OECI website at
https://www.oeci.eu/WorkingGroupsMW.aspx

Rules of Engagement (RoE) to be adopted by the OECI Working Groups (WGs)

Part 1: Constitution

1. The proposal for the constitution of a new WG may come from a Member or a Board Member.
2. A WG (and the designation of its Chairperson) is established upon a proposal of the OECI Board, to be submitted to the approval of the majority of the OECI Full Members (absolute majority).
3. Each WG may be renewed by the Board every 3 years only after a positive evaluation of the WG by external reviewers chosen by the Board. Similarly, each Chairperson of a WG holds the charge for three years and may be renewed only after the positive evaluation of the external review.
4. Each WG shall identify a WG Board composed by 3 to 10 members of the WG engaged to support the preparation phase of the initiatives of the WG.
5. Each WG Chair shall nominate a Secretary, preferably a young scientist/doctor, charged with the daily management of the WG activities.
6. Chair, Secretary and Board members should be renewed every three years, each in a different year to ensure continuity (nomination rules to be defined).
7. The WG may be dismissed even before the three-year term following a Board decision if its activities are not sufficient to justify its existence.

Part 2: Resources

8. Unless otherwise agreed after the external evaluation, each WG shall reach its financial autonomy within three years from the date of approval of the RoE. During said three-year period, the OECI may assign it a financial support amounting up to, and not exceeding, € 20.000/year in expenses.

9. It is up to the Chairperson to decide how to use the allocated budget. Normally the participation in the WG is on a voluntary basis and each OECI Member should support his/her delegate for all the expenses incurred.
10. The contribution is assigned to the WG Chair's Member Centre/Institute on the basis of a Programme of activities approved by the OECI Board.

Part 3: Programme of activities and reports

11. The WG shall deliver a three-year activity rolling plan, to subsequently be shared with all the OECI members. The plan should include:
    a. Strategic aims, highlighting possible impacts e.g. on cancer centre operational efficiency, research progress, patient care and health system, at the national and European level
    b. Operational objectives and tasks
    c. Expected verifiable results
12. The WG shall deliver a yearly sustainability plan to the OECI Board for evaluation, to be subsequently shared with all the OECI Members. The plan should clearly state how resources for the WG activities are going to be obtained, e.g. from:
    a. Voluntary contribution by members or other parties
    b. Fee for services
    c. Grant applications
    d. Organisation of meetings
    e. Pharma-funded clinical studies
13. The WG shall deliver a yearly activity report, to be subsequently shared with all the OECI Members. The report should include information related to resource allocation in compliance with the sustainability plan, as well as verifiable results of the planned WG activities. Plans and reports should be concise and to the point, to facilitate review and consultation. Further details, if appropriate, should be provided through additional documents/web resources.
14. The WG must have a regular and transparent connection with the Members in order to give everybody the possibility to participate in the WG activities. The Regular meetings of the WG Board should be organised using a teleconferencing system (like e.g. GoToMeeting) to be provided by the Institute/Centre of the Chair, with credentials transmitted to the Secretary. WG face-to-face meetings should be organised at least once a year, possibly during the Annual OECI Oncology Days.
15. The WG must publish at least one scientific paper every 3 years in an International peer reviewed Journal. The authors must report their affiliations to their Institutes and to the OECI. The article must report that the activities were carried out also thanks to the OECI support.
16. Upon request of the OECI Director, the Chairperson or his/her Secretary, must send the specific contribution to be used to update the website, the leaflet or other OECI dissemination material.
17. Upon a WG's decision to submit an externally funded research proposal, the OECI must be involved as a partner.
18. In case of a European large competitive project, an OECI Member may play the role of Coordinator.

*Please note that the OECI Accreditation and Designation is a Programme of OECI and not a WG subject to the RoE.

The promises of patient involvement for European Cancer Centres

Dominque de Valeriola[1] *and* ***Patrick Miqueu***[2]
1. Institut Jules Bordet, Université Libre de Bruxelles, Brussels, Belgium
2. Organisation of European Cancer Institutes (OECI), Collaboration for Good Practices with Patients (CGPP) working group, Brussels, Belgium

Patient involvement offers new opportunities for European cancer centres, and especially when it comes to increase the quality of care, research and education, the main goal of OECI. Indeed, it is now recognized that patients are bringing a different and valuable perspective to the quality improvement process by expressing their special needs and priorities.

The OECI Collaboration for Good Practices with Patients (CGPP) working group has been launched in June 2017 during the 39th Oncology Days in Brno. The working group acts as a reflector and as an intermediary passing on the feedbacks of practices designed with patients into OECI cancer centres in the aim of improving the quality of their organization and activities. Since its creation, the OECI CGPP working group is building a roadmap by collecting experiences of patient involvement, making an inventory of patient involvement-related projects launched in and by OECI centres and sharing experiences. Recent results of a survey achieved by the working group in 2018 have demonstrated that patient involvement and collaboration with patient organisations are widely adopted in OECI cancer centres, in very diverse areas of care and research. But cancer centres are missing guidelines and guidance on the implementation of patient involvement actions; for example and especially, when defining methodologies of patient involvement or when assessing the impact of it with indicators of performance. From the survey, recurrent concerns and topics were identified when implementing patient involvement for improving the quality related to care, research and survivorship. These topics have been selected as main issues for the OECI CGPP working group : 1) the selection of patient involvement projects and their management; 2) the selection and training of both patients and professionals involved in patient involvement projects; 3) the sustainability of projects with a major activity on patient involvement; 4) the promotion of patient involvement as a core dimension for quality improvement and 5) the assessment of the value of patient involvement in projects.

As these major topics are of interest for many OECI centres, the CGPP working group, supported by the OECI board, proposed to organize the first OECI Patient Day during the Oncology Days in Bari. This one-day conference will give the opportunity to share practices of patient involvement and will focus on 3 priority fields - Quality of care, Research and Survivorship -, in order for the presenters and chairs to detail their experiences of patient involvement and collaborations with patient organisations. Indeed, the vision of the CGPP working group stands in solving recurrent issues in cancer care and research by promoting the collaborations between cancer centres and patient organisations through patient involvement; in accordance to the framework of collaboration that has been produced conjointly by the OECI and the European Cancer Patient Coalition (ECPC).

A robust and fruitful with patient organisations is crucial for cancer centres and the OECI since patient organisations perceive, by various ways, what are the main patients' needs and concerns across the cancer journey.

THE WARRIOR

(By courtesy of National Cancer Institute "Giovanni Pascale" Foundation - Naples)

I am a warrior
and I fight with all my strength.

I am a warrior
enlisted in a battle
I have never wanted to fight.

I am a warrior
I win and I lose,
I fall and I rise again.

I am a warrior
and when I win
I see everything more colorful
things, people
and my face.

I am a warrior
and I can feel the smell of life
like no one else.

I am a warrior
and I still hear
the steps of my enemy.

I am a warrior.
In such a difficult life,
I see the one who was supposed to protect me
turning away as if I were not here.

I am a warrior
and sometimes I lose and cry within,
wearing a smile on my face.

I am a warrior.
Everyone tells me about it,
looking at me
and giving me more courage.

I am a warrior
in the army of ordinary people.
Someone gets discouraged,
someone smiles and advances,
armed with courage.

I am a warrior
and I fight every day
with a quiet enemy
which is so strong.

I am a warrior
but watch out:
do not be so proud of yourself
and do not look at me boldly.
You are my enemy,
always with me.
And do know:
sooner or later,
I will defeat you.

A cancer patient

42nd ANNIVERSARY OECI

OECI

Organisation of European Cancer Institutes

European Economic Interest Grouping

OECI42

Oncology Days

10th-12th June 2020 Helsinki, Finland

DEVELOPING THE FUTURE IN COMPREHENSIVE CANCER CARE

GENERAL ASSEMBLY
SCIENTIFIC CONFERENCES
AND RELATED EVENTS

In collaboration with:

HUS

Helsinki University Hospital
Comprehensive Cancer Center (UHS)

Biobanks and Molecular Pathobiology

Molecular diagnostics and clinical research in clinical tissues

Giorgio Stanta[1,2]
1. Comprehensive Cancer Centre CRO Aviano
2. Organisation of European Cancer Institutes

The rapid development of molecular pathology is producing a gap between new knowledge and clinical application, so we need a faster application. To reach this goal we have today a major problem, related to the reproducibility of clinical research and diagnostic molecular analysis. (*The Economist*, October 2013; *Nature*, October 2018). This problem can have a heavy clinical impact because even molecular results cannot be exchanged among different clinical institutions. This issue is related especially to three main technical questions, the first one to pre-analytical conditions of the biological material (garbage in, garbage out), the second one to a missing standardization of analytical methods and well-defined standard operations procedures (SOPs) and the necessity of internal controls (but also external quality assurance). The third one is the intra-tumour heterogeneity, which we know is related in many cases to tumour progression and treatment failures.

The pre-analytical conditions are studied in Europe by the SPIDIA4P project, in which academic and industry experts are producing new technical specifications in collaboration with CEN and the BBMRI-ERIC Quality working group. The CEN technical specifications are already official European documents, which are then translated into ISO international standards. The application of these technical specifications for a correct treatment of tissue and biologic liquids improve the reproducibility of the analyses.

Standardization of methods is the second major cause of irreproducibility. We use to study many different biomarkers at DNA and RNA level by the Next Sequencing Generation technique (NGS). In this method there are at least two levels of possible irreproducibility. The first one is related to technical issues and the second one to a correct interpretation of the results. OECI Biobanking and Molecular Pathobiology WG is proposing together with a large group of academic and scientific institutions a new European project about NGS applications in clinics.

Heterogeneity is one of the major characteristics of tumours and especially the intra-tumour one can take to misleading molecular analysis results. At the moment there is not a clinical standardized sampling to cover the clonal and functional aspects of primary tumours and metastatic spreading. OECI B&MP WG is testing together with the homologous WG of the European Society of Pathology (ESP) a new standardized sampling of primary tumours, taking into consideration the different tumour areas (G. Stanta and S. Bonin, Front Med 2018). At the molecular level this can give a better idea of tumour heterogeneity in a specific patient with a better indication for treatments.

Reproducibility is not the only problem in the clinical application of molecular diagnostics and clinical research. In many tumour cases it is necessary to analyse deeper the molecular alterations at DNA, RNA and protein level. Recently in the European Commission Initiative on Breast Cancer it has been considered the importance of clinical research performed directly in the clinical institutions, at least in some specific specialized centres. We could consider that this type of activity should be developed in OECI Comprehensive Cancer Centres, especially where artificial intelligence facilities (AI) and specific tumour boards are present. A wide molecular analysis interpretation, in fact, can be performed only with the use of AI. The issues related to clinical research and big data were analyzed by the European Commission conference on Integrating Genomics into personalized healthcare: a science-for-policy prospective, that was held in Brussels on 12th and 13th February 2019. The importance of pre-analytical conditions of clinical material was presented at European level on 5th March in Brussels in the European Parliament, with the initiative of SPIDIA4P.

The over reported considerations show how molecular pathology today is intrinsically connected with clinics and that the related knowledge is continuously developing, with the necessity of a wide flexibility in the clinical frame.

OECI Outcomes WG about to launch Pilot Study in Summer

Milena Sant[1,2]
1. Fondazione IRCCS – Istituto Nazionale dei Tumori di Milano
2. Organisation of European Cancer Institutes

The interest in real world observational studies on cancer outcomes among OECI centers became evident in 2017 and 2018, confirming the input from the questionnaire circulated in OECI in 2016. At the 1st OUTCOMES WG Meeting, during the 2018 Oncology Days in Poznań, we decided to start a pilot study on cancer outcomes on breast and colorectal cancers, and the OECI Board gave it the green light in December 2018.

The general aim of the pilot study is to test the feasibility to share a set of standardized data among OECI centres in order to study cancer outcomes on colorectal and breast cancers using properly anonymized patient identification codes. This exercise should help to identify a common system for data integration (molecular, clinical and health care administrative sources) and data sharing among OECI Centers. The pilot promotes a voluntary collection of data from OECI centres, and it is intended to function as a *proof of concept* for a larger EU collaborative project.

The proposal draws on numerous past and ongoing initiatives within OECI centres over the years, and also on well-established EU-wide cancer outcomes experiences using population data such as the EUROCARE (www.eurocare.it) and the European High Resolution studies (www.hrstudies.eu).

It is known that data repositories exist in all the Comprehensive Cancer Centers, with various levels of organization and, over the years, many OECI Centres implemented platforms for the centralization and analysis of clinical-health data on cancer (e.g. big data on health).

In France, 20 CCCs collaborate in the UNICANCER R&D EPIDEMIOLOGICAL STRATEGY and MEDICAL ECONOMICS (ESME), describing the care evolution through real world data. In Italy, ACC is moving towards this type of studies. Similarly, in Belgium, thanks to the connection between the hospital registries and the national population-based cancer registry (CR), records of hospitalized patients can be updated with clinical events or death occurring during the course of the disease. The study protocol was discussed at the 2nd OUTCOMES WG meeting in Milan, on 19th March 2019.

Every participating centre will contribute with a minimum 200 primary invasive female breast and/or a minimum 100 primary invasive colorectal cases. These will be new consecutive tumour diagnosed in 2016/2017 and followed up till the end of December 2019, for all stages, and all morphologies. Indicators of standard care, as well as items from OECI A&D will be investigated:

For both colorectal and breast cancers

- % of patients with metastatic disease (at diagnosis and at the entry of the study) treated with targeted therapy, by disease subgroup (e.g. molecular or morphological), and, if feasible, by inclusion in clinical trials
- % of adhesion to multidisciplinary team (MDT) indications to include new targeted drugs
- description of treatment of the metastasis (e.g. stereotactic radiotherapy)

- description of waiting time between diagnostic procedure and cancer confirmation by pathological report
- description of waiting time between the cancer confirmation and the first treatment

For colorectal cancers

- 30 - and 90- day post-surgery mortality
- % of stage III (and II) resected colon cancer patients treated with adjuvant chemotherapy
- % of stage III resected rectal cancer patients treated with pre- vs. post-operative radiotherapy
- % of rectal cancers not operated (exclusive radiotherapy)

For breast cancers

- % of pre- and post- surgery chemotherapy in locally advanced breast cancer
- % of breast-conserving surgery in stage I and II disease
- % of radiotherapy in breast-conserving surgery
- % of re-intervention (y/n; dates) and description of reasons (e.g. suboptimal oncological surgery, complications, plastic surgery)
- % of post-operative radiotherapy after mastectomy
- % of partial breast irradiation, % brachytherapy
- % of sentinel lymph node dissection in cN0 breast cancer

Today, 17 Centres from 9 EU Member States are members of the Pilot Study WG, from Belgium, France, Finland, Estonia, Poland, Portugal, Italy, and Slovenia.

The final Study Protocol will be available online at the end of April 2019, and it will be presented to all OECI centres at the OECI Oncology Days 2019, in Bari.

Provided all data access agreements are in place, data collection will start in Autumn 2019 and the first analyses will be available by the end of the year. All interested centres are warmly encouraged to get in contact!

OECI Cancer Economics/Health Economics and Technology Assessment


Wim H. van Harten[1,3,4] *and* ***Valesca P. Retèl***[2,4]
1. Rijnstate
2. Netherlands Cancer Institute
3. Organisation of European Cancer Institutes
4. University of Twente

The objective of this working group is to raise awareness on health economic and technology assessment related issues and methods in cancer research and services. An important driver is the relatively limited awareness that seems to exist within research and clinical environments of the translational cancer research community on the increasing importance of Health Technology Assessment (HTA) and health economics. HTA in early phases of R&D can assist in creating optimal conditions for coverage of innovative treatments and adequate implementation in practice.[1]

The participation of the WG so far, has been with a strong involvement from Karolinska Cancer Research Institutet, Porto Comprehensive Cancer Center (IPO Porto), National Institute of Oncology (NIO Budapest), University Hospital Brussels and the Netherlands Cancer Institute (NKI-AVL); others have joined/participated on an ad hoc basis.

Actual monitoring of Cancer Drug costs

As a follow up to the earlier survey on actual drug costs and their consequences with heavy involvement from OECI member institutions[2], we received many positive reactions on the initiative. We propose to cooperate in a more continuous form of monitoring, as this can be of use to stimulate the discussion on this important issue and to contribute in forcing pharmaceutical companies in reconsidering their business model of pricing cancer drugs. This has also been discussed with the European Cancer League committee on Cancer drugs, the European Cancer Patient Coalition (ECPC) and the European Society for Medical Oncology (ESMO) committee on Cancer medicines. The European Cancer League (ECL) - in their meeting of 26th March in Prague has taken the position to support and create a platform, involving the mentioned organizations to start periodic monitoring of actual drug prices, assemble best practices in purchasing and monitor accessibility issues throughout Europe. The OECI has expressed its commitment to this to activity, through this WG. So far a modest seeding grant has been committed by the Open Society Foundation and Cancer Leagues will gather forces to raise additional funds by end of 2019.

As part of this work a survey on issues related to monopolistic drug prices and alternative policy schemes has been initiated in the 2nd quarter of 2019.

Innovative technologies in OECI Institutions

As part of the activities on next generation sequencing, a survey on costs of whole genome sequencing (WGS) is ongoing, of which the first results will be presented during the OECI Annual pathology meeting in Bari. In addition scenario´s on development, implementation and diffusion of WGS will be discussed in a session and used for input in health economic modelling of this new technology. These activities are being carried out in the framework of the Technology Assessment of Next Generation Sequencing in Personalized Oncology (TANGO)-study[3], in which the OECI participates in the above mentioned projects.

Benchmarking

After the BenchCan project two follow up initiatives have been originated. An mid European Interreg project uses the methodology to improve the cancer services in a number of Italian regions and Hungary. An industry sponsored international benchmarking project involving The Netherlands, Portugal, Finland, France and Slowakia builds on this project by adding registry based outcome data and Value Based Health Care principles. The European Cancer Consumer Questionnaire will be further validated in this project in a number of new EU countries.

By the end of 2019 an invitational meeting among OECI Members to discuss relevant policy choices for the OECI working group on Health economics will be organized. Results from the surveys, the status of the EFPN and new initiatives for 2020 will be discussed.

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Supportive and Palliative Care

Tiina Saarto[1,2]
1. Central Hospital (HUCH) Comprehensive Cancer Center
2. Organisation of European Cancer Institutes

The recognition of palliative care has increased significantly during last decade. World Health Assembly Resolution of palliative care in 2014 called upon WHO and Member States to improve access to palliative care as a core component of a health system. Palliative care is explicitly recognized as part of the comprehensive services required for the non-communicable diseases including cancer. In a new European Councils' resolution of "Provision of palliative care in Europe" in 2018 Parliamentary Assembly recognised that palliative care is fundamental to human dignity and a component of a human right to health.

The European population is getting older and the cancer incidence is increasing. At the same time treatment options of cancer care have improved and more patients with incurable disease benefit from anticancer treatments. However, the symptom burden and psychosocial suffering of cancer patients have not diminished at the same extent. Introducing palliative care early into a main stream oncology practice has improved the quality of life of patients and their families.

A modern cancer care is a multidisciplinary teamwork with a holistic approach to better control the cancer disease and to better preserve the quality of life of the patients and their families. To be able to coordinate and develop palliative care and supportive care services, there is a need for a dedicated palliative care unit with specialised multi-professional palliative care team as an organisational entity of each cancer institute. Both inpatient and outpatient specialized palliative care services shall be available. Palliative care should be part of the cancer patients care pathway from the curative treatment to the end of life care including home care organized in collaboration with community care providers to support daily living at home. A modern multi-professional palliative care team includes physicians and nurses specialised in palliative care, the specialist of psycho-oncology, spiritual care and pain management in collaboration with different supportive care disciplines like social workers, physiotherapists and nutritionists among others.

There is a common understanding that access to specialised palliative care services should be a standard practice offered early in the course of the disease e.g. for patients with newly diagnosed incurable disease or patients with high symptom burden or unmet physical or psychosocial needs despite the disease stage or anticancer treatments. However, to have a low threshold for services, all professionals taking care of cancer patients are responsible for the systematic symptom assessment and psychosocial distress of the patients and for providing basic palliative care. Vice versa palliative care team need to have a good knowledge of cancer diseases and treatments to be able to participate in cancer patients' care in early stage of the disease. A shared decision making of future treatments and treatment goals helps patients and professionals to recognize special needs for patients and families early in the course of the illness and to make individual advance care plans including a plan for the care at the end of life.

To be able to build up a model of multidisciplinary cancer care there is a need for a shared vision of how palliative care is integrated into cancer care with defined quality indicators and standards for palliative care and supportive services in the OECI member institutes. Supportive and Palliative care Working Group is inquiring the current situation of palliative care services in OECI Cancer Institutes including the regulations and leadership of palliative care, service models, referral practices, the role of palliative care team and education and research of palliative care. The survey results help us in a future development and standardization of palliative care and supportive care services in OECI member Institutes aiming for a better quality of cancer care.

Communication and Dissemination Activity: Dr Edoardo Cazap to replace Prof Gordon McVie as Editor-in-Chief of *ecancer*

Claudio Lombardo[1,2] *and* ***Roxana Plesoianu***[2]
1. Organisation of European Cancer Institutes
2. SOS Europe Srl

April 8th 2019 – ecancer bids farewell to editor-in-chief, Prof Gordon McVie who decided to retire from his role after 12 years of activity. Dr Eduardo Cazap has been appointed to the position, effective April 1st 2019, with McVie continuing to be on the touchline and supporting the journal as a member of the Editorial Board.

The Journal came to life in 2007, when two pioneering visionaries - Prof Umberto Veronesi and Prof Gordon McVie - created ecancermedicalscience, an online knowledge bank incorporating free educational resources so as to reduce fragmentation and raise the standards of cancer care across the globe.

Starting from 2009 ecancer has also been the official Journal of the OECI, enabling the organisation to effectively promote its activity thanks to the wide dissemination of the online platform.

"Knowledge must be free" was Prof Veronesi's "motto" and Prof McVie fiercely stood by it, doggedly helming the cause of making information and education accessible to everyone. His driving force has left visible marks and OECI, alongside the whole cancer family acknowledges its profound gratitude for his instrumental contribution and leadership.

Prof McVie will be succeeded by Dr Eduardo Cazap MD, PhD, FASCO.

ecancermedicalscience may well rely on Dr Cazap's forty years of experience. Founder and the first President of the Latin American & Caribbean Society of Medical Oncology (SLACOM), as well as a Board Member of the American Society of Clinical Oncology (ASCO) are just a few of the prestigious roles the Argentinian oncologist covered.

"Cancer is a global challenge, but the solutions must be provided at a local level", he explains. Every 8 minutes an Indian woman dies from cancer of the cervix. Figures are staggering in Africa, where breast, prostate, lung and colorectal malignancies are soaring. Under these circumstances, in the next decade the journal's activity will be focusing on cancer research in middle and low income regions, namely India, Africa & Latin America.

"Education is the key" and with its impressive 60,000 monthly views, 3,000 authors and 23,000 users, ecancer will produce future publications on primary&secondary prevention, timely diagnosis, palliative care, end of life and morphine access, continuing to be an excellent tool for better control of cancer around the world.

Furthermore, this charity-supported peer-reviewed platform will also include presentations coming from prominent international experts in order to have insight into the newest developments of research and to outline the efforts that are currently being undertaken worldwide in cancer treatment.

More on Prof McVie and Dr Cazap's statements at
https://ecancer.org/journal/news/15795-new-editor-in-chief-for-ecancer.php

New auditors for the OECI Accreditation and Designation Programme

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

The OECI Accreditation & Designation (A&D) Programme aims to help European cancer centres implement a quality system for oncology, and provide cancer patients in Europe with equal access to high quality cancer care, backed up by excellent training and translational research.

As part of the A&D programme a multidisciplinary team of professionals in oncology (nursing, medical, quality, research) visits cancer centres for a peer review. This two-day visit is to assess the quality of cancer care, education and research within the centre, produce a report and work together with the centre to formulate recommendations for improvement. The OECI auditors are highly skilled in their own fields, and in addition are trained in how to perform a peer review audit for OECI in such a way as ensures complete consistency within the programme.

As many new centres are entering the A&D Programme from all parts of Europe, OECI has been looking to expand the team of expert auditors. On 4th and 5th March 2019 a group of 14 new auditors was trained during a two-day training course in Villa Verganti Veronesi in Inveruno, Italy. A earlier group of 18 new auditors was trained on 19th and 20th November 2018. The new auditors come from cancer institutes all over Europe (Denmark, Lithuania, Estonia, France, Ireland, Italy, Portugal, United Kingdom, Sweden, the Netherlands, Croatia and Slovenia).

The training course was provided by Patrick Corstiaans from KERTEZA (kerteza.com), an independent training company for auditors. 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 interviews.

This now means that we have around 60 trained auditors in the field for OECI. We are confident that our programme has a solid team of qualified auditors with whom we can meet the growing demand for participation in the A&D Programme.

OECI leadership of the quality workpackage of the Joint Action on Rare Cancers

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

OECI is leading workpackage 5 (WP5) of the EU Joint Action on Rare Cancers (JARC) on Quality Assurance. One of the central pillars of the JARC is the support for the three cancer European Reference Networks (ERNs), EURACAN for adult solid cancers, Eurobloodnet for rare haematological malignancies, and PaedCan for childhood cancers. A related objective is to spur the creation or consolidation by Member States of new national networks of centres diagnosing and treating rare cancers. WP5 is an essential workpackage to assure the quality of the diagnosis and holistic care of rare cancer patients. It is complementary to the work of WP6 on the use of highquality Clinical Guidelines.

This work builds on OECI's 11 years' experience in cancer quality systems in Europe. Most of OECI's assessment and evaluation work to date has been based on cancer centres. Networks pose significantly different challenges, and the quality standards which WP5 has crafted are a mix of standards which relate to the treatment and care given in individual centres, and quality standards which relate to the way the network connects together, and should offer a seamless continuity of care along the patient pathway.

JARC is now in its third and final year of work. In the first year of WP5 we reviewed all the existing forms of quality standards for networks globally in operation. The last year has been a process of honing the proposed standards down to those which are objective and essential measures of quality, ambitious but realistic.

On 26-27 March the WP5 and all associated parties met in the lovely Sicilian town of Catania for a consensus meeting on the Quality Standards and Indicators, hosted by the Istituto Oncologico del Mediterraneo. We held rounds of intensive interactive sessions looking in detail at the proposed Quality Standards and Indicators. One set of these is intended for recommendation and feeding into the proposed ERN system to be called AMEQUIS – Assessment, Monitoring, Evaluation and Quality Improvement System. The second set of Standards and Indicators is intended for recommendation to national policy-makers for use by emergent or future rare cancer networks. This second set would no doubt be adapted for national circumstances, although the standards have been crafted to be applicable to a wide variety of health systems and forms of network.

In the Catania session we were very pleased to rationalise the sets of standards, and reduce their number to 36 for the Cancer ERNs and 51 for National Networks. They follow the headings of the ERN Operational Criteria, being:

- Highly Specialised Healthcare
- Governance and Co-ordination
- Patient centredness and care
- Multi-disciplinary approach
- Good practice, outcome measures and quality control
- Research
- Education, training and development
- Networking and collaboration
- Infrastructure and Data

On quantitative indicators, the consensus group has honed the list down to 19 indicators of Structure, Process and Outcome (according to the Donabedian Model) and 4 extra cancer-specific indicators for the ERNs to add to the 18 indicators already agreed by the ERN monitoring group. The Catania meeting was pleased to involve Michell Battye from that ERN monitoring group to enable us to make the key recommendations. All these proposals will now be taken forward to the final recommendations of the JARC.

Accreditation and Designation Programme Standards Revision experts meeting in Brussels

The OECI Accreditation and Designation Board

As an essential part of the long process of the 5-year major revision of the OECI Quality Standards, OECI held an experts meeting in Brussels on 10th April 2019. About 40 people were present, representing the OECI Board and Accreditation and Designation (A&D) Board and Accreditation Committee, our OECI Working Group Chairs, a selection of 8 OECI auditors, the 4 IKNL co-ordinators, and representatives from other significant European Cancer Societies. These were the patient groups ECPC and ECL, ESMO, Cancer Core Europe, EACS, ESTRO, EORTC, Cancer Prevention Europe, EONS, and ECCO.

The meeting was chaired by Simon Oberst, the Chair of the A&D Programme, and at the outset it was explained that this meeting was being held partway through a long process initiated by the A&D Board, which had already revised the chapter headings of the Standards, and introduced new and important Standards on: Molecular Diagnostics; Surgical Oncology; Radiotherapy; Pathology; Survivorship and Prevention. At the meeting, parallel sessions were held on Patient-centredness; Multidisciplinarity; Palliative and Supportive Care; Molecular Diagnostics; Research and Education. In each of these sessions the input of the experts was received to clarify the standard, delete, or add standards, and to confirm whether the standards should be a Core Standard. The significance of designating a standard as 'Core' is that compliance with the core standards will be regarded as more vital than other standards, and that evidence of compliance will always be required in a re-Accreditation of the centre.

Valuable input of the experts was received, and many of the standards were improved and re-crafted. In the afternoon sessions more general subjects were covered: the proposed streamlined re-Accreditation process (which will be explained in more detail at the Bari A&D session at the OECI Oncology Days 2019); the Designation Criteria for Clinical and Comprehensive Cancer Centres; and the relationship between organ-centred approaches to quality or accreditation and institution- or centre-wide quality accreditation programmes such as OECI. There was lively discussion on all these three topics. The re-Accreditation proposals were widely welcomed, which will reduce the burden on centres re-accrediting by not requiring a full upload of audit evidence on every single standard. All standards will still need to be scored, but only new Standards, Core Standards, and those previously scored other than 'Yes' by the Centre would require audit evidence to be uploaded. The Audit visit would remain 1.5 days with a team of 4 auditors, and the A&D fees would be the same as for a first Accreditation (the A&D work being of the same magnitude).

The Designation criteria were broadly confirmed as unchanged in terms of clinical minimum numbers, but the research criteria for Comprehensive Cancer Centres (CCCs) were clarified. A decision was made to re-name "Clinical Cancer Centres" as "OECI Cancer Centres", on the grounds that many of these do have a research (although not the volume of CCCs) and the designation as "Clinical" might be misleading. Commensurate with that decision, minimum research criteria will be set for OECI Cancer Centres.

The discussion on the relationship between the OECI Centres approach to accreditation and organ-based approaches was wide-ranging. It was agreed that these approaches are complementary to one another, and that the landscape in Europe – especially around organ-centred approaches – is becoming more crowded, with various different sets of requirements including ECCO Essential Requirements for

Quality in Cancer Care (ERQCC), the German Cancer Society Requirements, the European Commission Initiative in Breast Cancer, and the European Urology Association requirements for Prostate Cancer. Not all of the latter organ-based requirements have a fully-fledged Peer Review system around them, as OECI does. A strong point was made that patients and patient associations such as ECPC and ECL should, along with OECI, be making patients aware of detailed organ-based requirements such as the ECCO ERQCC series, as a means of ensuring that individual tumour teams comply and continuously improve, not just in large cancer centres, but where cancer is treated in general hospitals too.

This was a hard-working and successful event which will help the A&D Board shape the revised Standards for Manual 3.0 which will come into effect for applications after 1st January 2020. At the Bari OECI Oncology Days the draft Standards will be explained, and OECI Members will have had a prior opportunity to see them and feed back on them. We feel sure that the resulting set of standards will be at the leading edge of cancer standards worldwide, assessing not only clinical care, but research and education as well.

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