OECI Magazine

Organisation of European Cancer Institutes

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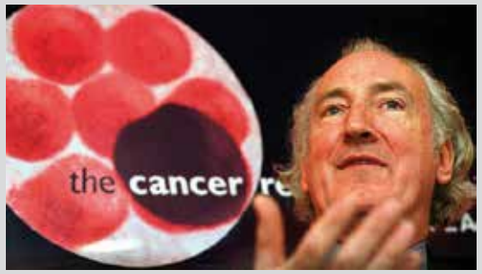
In memory of Gordon McVie

It is with great sadness that the Organisation of European Cancer Institutes remembers the premature loss of **Professor J. Gordon McVie**, a symbolic figure of the fight against cancer and an international authority in cancer research and care.



A pioneering oncologist, Professor Mc Vie passed away aged 76, leaving behind a life full of achievements with more than 40 years of clinical research, over 350 peer-reviewed papers and prominent positions in some of the world's leading cancer organisations.

After serving for many years as Clinical Director first of the Cancer Research Campaign and then of The Netherland Cancer Institute, Gordon joined the European Institute of Oncology as adviser to Umberto Veronesi. Alongside Prof. Veronesi, he also set up Ecancermedicalscience, an open cancer journal.

He brought substantial contributions to the field of cancer care including establishing localized administration of chemotherapy, and encouraging the use of chemotherapy for the treatment of lung cancer throughout the EU.

Gordon supported OECI as co-opted Member to the Board, introducing the Grouping to Ecancermedicalscience, which soon became the OECI Official Journal.

With an incredible talent in pin-pointing cutting-edge clinical research and in promoting the dissemination of science, Gordon was also a real gentlemen and a sincere OECI friend.

Our joint collaboration truly benefitted OECI, and its participation to several editions of the OECI Oncology Days was for us a real honour.

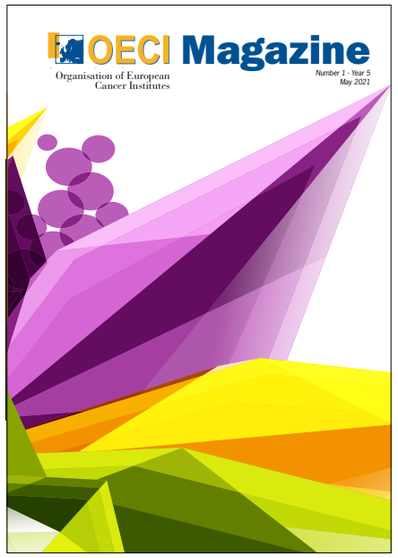
His brilliant vision and huge energy will be dearly missed, but his scientific achievements shall live on, and his initiatives will continue to benefit future generations of scientists and clinicians.

We will never forget a friend, a mentor and a real European example for everybody.

On behalf of all the OECI Cancer Centres/Institutes

*Professor **Thierry Philip***

OECI President



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Message from OECI President

Welcome to this First Edition 2021 of the OECI Magazine!

In this Issue, we have tried to capture the essence of the latest news and actions on the cancer front and walk our readers through the most outstanding initiatives promoted by OECI over the past year.

Looking back to this period marked by hardship, limitations and fear, we realise that the COVID-19 emergency has challenged our health care systems like never before, putting our resilience to test every day.

However, positivity must be sought even in the darkest of times and we are proud to say that this has also been a time when all the health care workers across the wide OECI network cooperated tirelessly. The emergency found our professionals treating and comforting patients away from their families; hospital managers struggling to find an innovative "antidote" to the overall chaos and various shortages; scientists, clinicians and administrators learning to work remotely and implementing telemedicine, launching remote training programmes, interacting virtually in view of the future challenges of the European Cancer Mission and the European Beating Cancer Plan; all our staff supporting and looking out for one another. These are all things we will remember.

In the same positive spirit, in 2021 the European Commission has many exciting initiatives in the pipeline. In particular, in this Issue, Stella Kyriakides, European Commissioner for Health and Food Safety, will provide our readers with an overview on Europe's Beating Cancer Plan - a starting point for a joint commitment between the Commission, the European Parliament, the Member States and the stakeholders.

Last year, when the EC had announced its launching, the cancer community had high expectations and acknowledged that the Plan meets many of them. In fact, structured around 10 flagship initiatives, the Plan earmarks some €4 billion for actions addressing prevention; early detection, diagnosis and treatment, and quality of life.

The Plan posits creating European Infrastructure of national cancer centres whose features are yet to be identified. Such features will likely align with the criteria OECI has already identified within the framework of the A&D Programme, which constitutes the only pan-European certification body to accredit a cancer centre in terms of prevention, research, assistance, rehabilitation and consolidated relationships with patient organisations.

In addition, OECI, a European Economic Interest Grouping constituted upon the principles of a European Regulation, is formally recognized by the European Union as a European Organisation. If, similarly to the European Reference Networks, the national government shall be tasked to identify the entities to be included in the constitution of a European Cancer Centres Infrastructure, the risk to create a heterogeneous network, based on criteria that could not be aligned with the bold objectives of the Plan must be taken into account. OECI - a strong network reuniting 108 of the most prominent European Cancer Centres – operates on principles of transparency, meritocracy, and is ran exclusively on its Members' contribution. The OECI Community comes together to embody a joint ambition: implementing access to cutting-edge solutions directly to our patients' ward thus granting our patients access to the best available treatment solutions.

Perhaps most significantly, the Cancer Plan is linked to another Commission initiative for a strong European Health Union - Horizon Europe, EU's key funding Programme for R&D. With a budget of €95.5 billion, this objective-driven Research Framework Programme grants support for innovation, a new approach to partnerships, an open science policy and five main Missions to achieve within a set timeframe. Cancer is one of them.

In this Issue you will also learn how, in a truly European spirit, OECI supports creating and better dispersing excellent knowledge and technologies. It follows that the European cancer Community moved forwards with devising a number of strategic actions shaped to galvanise innovation, including the creation of the "DIGital Institute for Cancer Outcomes REsearch" ("DIGICORE"), an European Economic Interest Grouping constituted in Brussels on April 1st, 2021. You may read more about DIGICORE in this Issue.

OECI is efficiently moving on a variety of fronts to help our patients and provide them with a single standard of care and a streamlined and seamless health care system all across Europe. This Edition of the Magazine describes several OECI actions, which include:

1) *three bold projects promoted by the A&D Programme, and the Cancer Economics & Cancer Outcome Research WGs;*
2) *an EACR-OECI Joint conference on molecular pathology of cancer;*
3) *a summary of the paper on the hallmarks and data of OECI's first 40 accredited cancer centres, recently published on Molecular Oncology.*

Looking ahead, I am also pleased to report that this year is going to be yet another year of sustainable growth for OECI. As a network, we continue to broaden our presence and through our Members we are providing services to a growing number of patients all across Europe and beyond. This year OECI is welcoming 8 new members (six Full Members and two Associate Members), thus reaching an impressive membership of 108 – a threshold we are very proud of.

The roadmap ahead is complex and I encourage you to take some time and read this OECI Magazine Edition and learn more about our Organisation and the initiatives it endorses in the years to come. Your comments and suggestions will help us better achieve our goals and to address new challenges that may improve the services to be rendered to our patients.

To conclude, I would like to warmly thank all our authors for contributing to this Edition. OECI's doors are open to all our community; if you would like to submit an article to this Magazine and make your voice heard by using our platform, you are invited to send your proposals to oeci@oeci.eu.

Thierry Philip
OECI President

Europe's Beating Cancer Plan: time to act

Stella Kyriakides
European Commissioner, DG Health and Food Safety

A cancer diagnosis is life changing news for any patient. It not only affects the patient, it also profoundly affects families and friends. Everyone near the patient is caught up in a tsunami of emotions.

A new cancer case is diagnosed in the EU every 9 seconds. Unless we take decisive action soon, cancer cases are set to increase by over 20% by 2035, making it the leading cause of death in the EU. We refuse to be bystanders when it comes to people's health.

For Europe, the time has come to act against cancer.

The pandemic has significantly affected cancer diagnosis and care. COVID-19 has interrupted vaccination and screening programmes, and made it harder to access treatment and medicines. The result is a decrease in cancer diagnoses, which reflects a situation that should give us all cause for concern. Cancer will not wait for the pandemic to be over, and we cannot fail patients. Cancer is now more than ever a key priority for the Commission. For myself, it has been a lifetime commitment.

This year, we are taking a major step towards a new era in cancer prevention, diagnosis, treatment and care. As of this year, we have a Cancer Plan for Europe.

Europe's Beating Cancer Plan is a plan that cares for patients every step of the way, from the moment they are given that life-changing diagnosis and through every phase of the pathway of the disease .With unprecedented financial support of €4 billion, the Cancer Plan will make real, significant differences in the areas of prevention, early diagnosis, detection and treatment, and survivorship.

A fundamental principle of the Cancer Plan is to prevent cancer in the first place. We will never be able to eliminate all cancers, but we do have a margin to reduce cancer with at least 40% if we tackle cancers linked to attributable causes. There is so much more we can do on prevention, so much more we can do to inform about and accompany Europeans towards healthier lifestyles.

If we take cancers caused by human papillomaviruses for example - there is definitely hope. This is why we have set an ambitious target to vaccinate at least 90% of girls and to significantly increase the vaccination of boys by 2030. Smoking and tobacco use, the leading cause of preventable cancers, is another example where we have a large scope for change. We are setting out to create, by 2041, a 'Tobacco free generation', with less than 5% of the population using tobacco.

For those who, like myself and countless others, receive a cancer diagnosis, the Cancer Plan will ensure that this happens as soon as possible, that no time is lost. We will be working towards ensuring that 90% of the target population have access to high-quality breast, cervical and colorectal cancer screening no matter where they live in the EU. Cancer does not discriminate and this Plan aims to even out inequalities in care that currently exists between and within Member States.

As science and knowledge progresses, so too do the numbers of cancer survivors. Currently over 12 million people in Europe have overcome this disease - this is great source of hope. But the life of cancer survivors can still be fraught with distress and insecurity. That is why we have as a key priority under the Plan to ensure that they can also return to society without facing discrimination or unfair obstacles, whether during or after treatment. With this goal in mind, we will be looking at survivorship issues, such as rehabilitation, emotional distress, potential tumour recurrence, and metastatic disease, as well as fair access to financial services.

I am particularly pleased that under the Plan, we will launch the 'Better Life for Cancer Patients Initiative' to focus on follow-up care and assist patients to rediscover their independence, including when returning to work and reintegrating into their communities. Other patient-driven initiatives include the virtual 'European Cancer Patient Digital Centre' which will exchange patients' data and monitor survivors' health conditions, while the 'Helping Children with Cancer Initiative' will support the most vulnerable of cancer patients.

At the core of Europe's Beating Cancer Plan is the patient, offering tangible measures to bring him or her through one of the most challenging times they will experience. The launch of the Cancer Plan is only the beginning of a journey, the start of our work, and we will now work, hand in hand with patient groups and Member States to make sure our ambitious targets become reality.

For myself, and for so many cancer patients and survivors out there, this is the chance of a lifetime: mobilising all the tools and resources we have in Europe to improve the lives of cancer patients and their families across the EU, and to make sure that no cancer patient is left behind.

Horizon Europe Cancer Mission: where OECI and DIGICORE can support and contribute

Simon Oberst[1] *and* ***Piers Mahon***[2]
1. *Chair OECI A&D Programme*
2. *DIGICORE Commercial Research Manager*

The OECI Quality approach to build a European Comprehensive Cancer Infrastructure

The European cancer Mission is a proposed major investment by the European Commission into cancer prevention and care across Europe during the next budget cycle. The recommendations of the cancer Mission planning Board were published in (May 2020) and confirmed in (September 2020). They can be found in detail at the link below[1].

Here we summarised some of the key recommendations in the context first of the OECI Accreditation and Designation Programme, and secondly DIGICORE – the new public private partnership in cancer real world evidence announced elsewhere in this edition.

Figure 1 summarises in our own words the 13 recommendations. However, two health warnings. Firstly, the language and meaning of some of the policy recommendations is open to interpretation. Secondly, the budgeting process for the Mission has not been finalised, and so what funds may be allocated to which recommendation in what way is not known at this time.

OECI Accreditation and Designation Programme

Through the Cancer Mission Board and Assembly, OECI has been regularly consulted about the challenges of (a) providing an equal degree of high quality cancer care across all Member States (MSs) and (b) stimulating research (translational, clinical and outcomes research) in Comprehensive Cancer Centres (CCCs) throughout Europe.

One of the proposed solutions to these twin challenges is in Recommendation 10 of the Cancer Mission Board's interim Report (see Figure 1). This recommendation proposes to "set up a Network of Comprehensive Cancer Infrastructures[2] within and across all EU member states to improve the quality of research and care". Reference is also made to quality standards for care and research, and accreditation processes.

OECI is in the advantageous position of having nearly 60 large cancer centres in Europe within the Accreditation and Designation Programme (results of the first 40 of those centres are summarised elsewhere in this issue). These accredited centres constitute an almost complete coverage of cancer centres in Italy, France, Portugal and Finland, and a considerable coverage in the Netherlands, Sweden, and smaller MSs. The experience of the Programme is that a high performing cancer centre, operating to high standards of care, education and research (as set in the OECI standards, summarised in the 100 Core Standards[3] improves patient outcomes and experience, and that the research-rich CCCs take the lead in high quality investigator-led clinical trials and basic and translational research.

But there are challenges. The first challenge is that CCCs treat between 10% and 60% of cancer patients in the EU (the precise level depends on the degree of hospital specialisation and centralisation in the MS). How then is it possible to guarantee an equity of care across all parts of the EU? The answer is: effective cancer networks. We address this issue in a later article: "OECI's Vision and Standards for Comprehensive Cancer Networks".

The second challenge is that high quality research – often based in CCCs - is also variably distributed in the EU. How then is it possible to enable the growth and development of CCCs? The answer here seems to lie in a series of initiatives including research networks of CCCs for particular purposes within translational, clinical and outcomes research, or with twinning smaller centres with larger ones and finding complementarities.

The solution to both these challenges lies in creating and accrediting Comprehensive Cancer Infrastructures, a term deliberately coined to be flexible as to the shape of centres and networks, according to the health systems, degree of maturity, and geographies of particular MSs. The key question is: how to implement this recommendation? Here OECI has the natural advantage of having advised many centres re-forming themselves to become CCCs or large cancer centres, bringing together hospitals, universities and research institutes to become high-performing environments. We have provided consultancy and pre-visits to many centres in order to prepare them for accreditation.

It is evident from the Accreditation Programme's previous pre-visit and advisory work that several MSs will need consultancy work to be provided to hospitals treating cancer to form high performing cancer centres where these are not already organised. OECI has models of governance which we know work well in a University/General hospital setting, how to integrate research in Universities and institutes, and how to overcome the silos caused by different funding streams for health and research. But we find that centres are sometimes unaware of how to form good governance and organisational structures. There are also the important human elements around change and re-structuring, which will also benefit from external independent support.

So OECI plans to build up our consultancy function and combine our expertise in this area, so that we are positioned to support the creation of Comprehensive Cancer Infrastructures. We believe also that the bulk of EU investment behind this recommendation should go to the centres themselves, to build capacity in quality, data, and co-ordination of care and research.

DIGital Institute for Cancer Outcomes REsearch "DIGICORE"

Based on our best interpretation of the recommendations, we carried out a prioritisation against an assumed future real world research network with these features:

– An international contracted network with 30 to 50 large academic hospitals with strong Electronic Medical Record systems.
– Digitally mature EMRs in a common research model, with routine large panel testing data incorporated as structured data into local research data repositories
– Federated IT solutions, with local clinical data under local clinical control
– Core research communities in pathology and medical oncology (i.e. precision interested)
– A strategic emphasis on late phase / practice changing evidence, not discovery research

We then asked which of the cancer mission recommendations that network would be best placed to support. That does not mean that DIGICORE or participating hospitals could not support other recommendations (for instance, discovery research within UNCAN.eu needs samples and data that could come from a DIGICORE hospital). Just that we need to prioritise our efforts, and there are clearly other strong networks in discovery (e.g. Cancer Core Europe) and academic trials (e.g. EORTC). The priorities were set at "High" (crudely DIGICORE will lead and invest in strong bids with industry support), "Medium" (DIGICORE will help bids by connecting interested researchers early) and "Lower" priority (let the academic bid development process happen without extra help)

Clearly, the top priority for a late stage focused network is recommendation #5: personalised medicine. This recommendation is all about developing the evidence base for the broad use of large panel tests and so whole pathways of precision oncology. It will need significant outcome research – similar to the whole pathway pilots run by Intermountain Health – to show that a "precision oncology first" approach gives better outcomes on the same or lower total cost to traditional care[4]. We are working with technology vendors to get the digital tools for that evidence already. We will also need the clinical communities in many cancers – not just the obvious NSCLC/precision haem front runners – to engage in those research programmes and bring the right testing and treatment options to their patients so that we can develop the evidence for large panel introduction and complex precision pathways downstream of those panels. Cancers that are rich in homologous recombination deficiency[5] mutations might make good targets given the treatment options becoming available, such as ovarian, breast, pancreatic and prostate cancer.

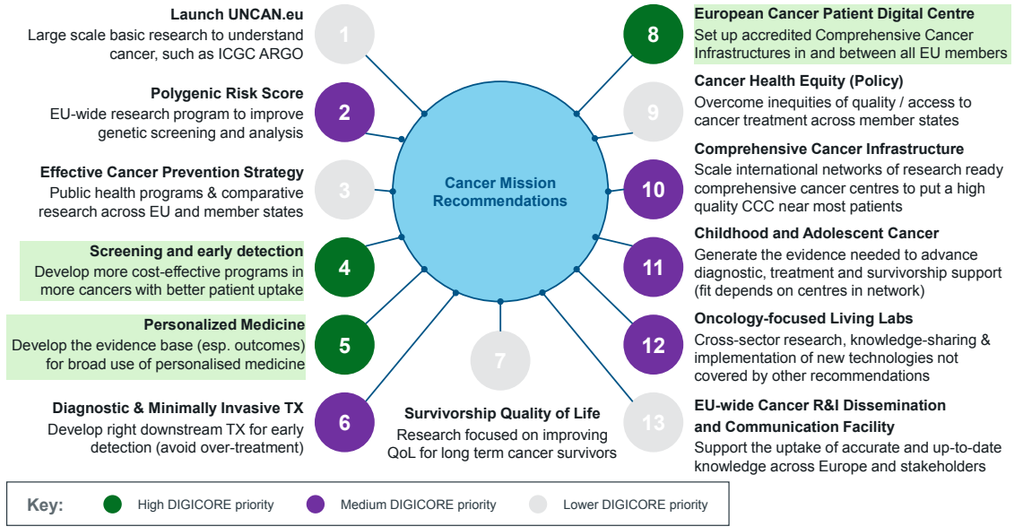


Figure 1: The Cancer Mission recommendations and proposed DIGICORE priorities

The second priority is screening and early detection, with an emphasis on blood based molecular tests for early detection (be they auto-antibody based like Oncimmune, or liquid biopsy based like Grail or Guardant). But establishing specificity and sensitivity on those tests for early detection is not enough. We need to establish that the down stream treatments that will result from early diagnosis will do more good than harm (i.e. solve the overtreatment issues that has bedevilled many screening programmes). Given those cancers will be at an earlier stage than normal, that may require different treatment interventions. We know that in theory the early detection tests can also provide information to guide treatment choice and intensity. For instance, early detection by auto-antibody may find tumours when they are immunologically hot (and so potentially better treated with immune oncology drugs rather than surgery). But that is not proven. We need to develop new pathways and evidence downstream of those tests to maximise the benefits of early detection.

The third priority is in empowering patients to take control of their data and work with the medical profession to get better care. In the US, Health Insurance Portability and Accountability Act (HIPAA) provides for full data portability to patients – they can take their complete history (and care) to any provider or researcher. The budgets to do this US -style ($27B) are unlikely to be available. However, a pragmatic solution would be to mobilise enough patient history to allow a second opinion, perhaps via virtual molecular tumour boards. Pilots of these in the US have shown that the patient summary needed for a good second opinion is relatively brief. As a result, we envision a world in which a hospital in Poland can ask for a second opinion on an off-label drug or trial options for a patient from a deeply expert hospital in France by sharing a pseudonymised clinical summary with high quality molecular test data. Institut Curie already has pilots of such services underway, which we could digitise. In addition, if we were to capture the actual treatment chosen and subsequent outcomes from those patients we have developed a learning health care solution for precision oncology.

1. *https://ec.europa.eu/info/publications/conquering-cancer-mission-possible_en*
2. *Definition in the Mission Report: "National or regional infrastructures that provide resources and services to support, improve and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/ carers. Different formats of Comprehensive Cancer Infrastructures are possible, including existing Comprehensive Cancer Centres or Care Networks".*
3. *100 European core quality standards for cancer care and research centres Lancet Oncology 21 (8) pp2009-1011, DOI: https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(20)30318-1/fulltext*
4. *Haslem DS, Chakravarty I, Fulde G, et al: Precision oncology in advanced cancer patients improves overall survival with lower weekly healthcare costs. Oncotarget 9:12316-12322, 2018*
5. *Nature Communications volume 11, 5584 (2020)*

European Research Infrastructures for cancer research and innovation: new opportunities under Horizon Europe

Roberta Zobbi
European Commission – DG RTD – Directorate ERA and Innovation
Deputy Head of the "ERA Governance and Implementation" Unit

"The fight of those battling cancer is our fight as well, in Europe."
Ursula von der Leyen, President of the European Commission

Research Infrastructures (RIs) are facilities that provide resources and services for the research communities to conduct research and foster innovation in their fields. This definition includes the associated human resources, and it covers major equipment or sets of instruments; knowledge-related facilities such as collections, archives or scientific data infrastructures; computing systems, communication networks, and any other infrastructure, of a unique nature and open to external users, essential to achieve excellence in research and innovation. Where relevant, they may be used beyond research, for example for education or public services and they may be 'single sited', 'virtual' or 'distributed'. They are essential tools for the development of leading-edge research in scientific and technological fields as well as for knowledge creation, transmission and exchanges, and knowledge preservation.

Specific activities implemented throughout the successive R&I Framework Programmes (FPs) have led to an efficient, open and effective use of national research infrastructures and to a coherent and strategy-led approach for pan-European research infrastructures, developed with the European Strategy Forum on Research Infrastructures (ESFRI) and in close cooperation with the Member States. This cooperation with ESFRI triggered, so far, the development of 55 European research infrastructures across all fields of science, of which 37 are already implemented, mobilising close to €20 billion in investments[1].

RIs, in conjunction with the European Open Science Cloud, are a crucial asset for the European scientific community and industrial researchers. To exploit their potential, EU Framework Programmes have also extensively supported trans-national and virtual access to RIs, providing researchers across Europe with state-of-the-art services and resources for carrying out their scientific activities.

As a result of their ability to assemble a 'critical mass' of people, unique instrumentation and investment, RIs contribute to the development of multidisciplinary approaches to solve increasingly complex problems: European RIs (such as BBMRI, EATRIS, ECRIN and ELIXIR, EuBioimaging, Instruct, Erinha, Infrafrontier - just to mention a few of them), are uniquely placed to help addressing cancer research challenges along the whole R&I cycle. They are acknowledged as key contributors to address the ambitious goal proposed by the Board for the Mission on Cancer[2], i.e.: to achieve, *"by 2030, more than 3 million lives saved, living longer and better"* as well as to support the EU approach to prevention, treatment and care in the context of the Europe's Beating Cancer Plan[3].

The provision of RIs services funded at EU level has been so far mainly organised per type of infrastructures or disciplines. The complexity and urgency of fighting cancer requires a well-integrated interdisciplinary RIs ecosystem and a new challenge-driven provision of customised services and access to data, able to accelerate the pace of the research cycle and the delivery of solutions.

Two new targeted and mutually supporting topics under the Horizon Europe Research Infrastructures programme have been designed to help in enhancing cancer research and innovation in Europe. These topics are expected to be published already in June, once Horizon Europe and its implementing work programme 2021-2022 are adopted.

The first topic will specifically focus on *"Research infrastructures services to support research addressing cancer"*: an indicative budget of EUR 15 mio for the provision of RIs transnational and virtual access to a wide and inclusive portfolio of complementary services and customised workflows supporting R&I activities along the development pipeline, from discovery research to personalised cancer treatments. RIs services to address the socio-economic dimension of cancer, the development of evidence-based public health measures and patient-centred approaches and regulatory aspects of novel biomedical products or relevant biomarkers are also expected to be tackled.

Open and FAIR[4] data are the new norm for research: researchers, healthcare professionals, cancer patients and survivors contributing to cancer research regularly interact with EOSC to store, share, access, analyse and process research data and other research digital objects from their own discipline, across disciplines and national borders. The topic on "FAIR and open data sharing in support of cancer research" aims at enhancing access, management, interoperability and reuse of digital information by using and integrating EOSC resources, ranging from EOSC federated infrastructures, services and data to guidelines, best practices, tools and metrics for the management of FAIR and open data. This should be achieved through cross-domain, strategic use cases of direct relevance to the cancer Mission areas and European Partnerships and should contribute to the consolidation of a European Health Data Space. An indicative budget of the order of EUR 8 mio is foreseen for activities under this topic.

Besides these two specific RIs topics targeting cancer research, the RIs programme under Horizon Europe will support the development of the next generation of scientific instrumentation, notably ground-breaking RI technologies, (including scientific instruments, tools, methods and advanced digital solutions) to enable new discoveries and keep Europe's RIs at the highest level of excellence in science, while paving the way to innovative solutions to societal challenges and new industrial applications, products and services.

Finally, Horizon Europe will continue supporting the development, consolidation and optimisation of the European Research Infrastructures landscape, thus maintaining its global leadership. Support will be provided for the development of new concepts for the next generation of research infrastructures of European interest[5], single/multi sited, distributed or virtual, that none or few countries might individually be able to afford, in all fields of research as well as for the preparatory phases of new infrastructures included in the ESFRI roadmap.

Training for RI users, as well as enhancements of scientific, technical and managerial competencies of RIs staff, will underpin all the activities implemented under the Research Infrastructures work programme, thus offering education and employment opportunities to new generations of researchers, technologists and high level science managers.

Disclaimer: The information and views set out in this article are those of the author and do not necessarily reflect the official opinion of the European Commission.

1 *See* ***http://roadmap2018.esfri.eu***
2 ***https://ec.europa.eu/info/horizon-europe/missions-horizon-europe/cancer_en***
3 ***https://ec.europa.eu/info/strategy/priorities-2019-2024/promoting-our-european-way-life/european-health-union/cancer-plan-europe_en***
4 *Findable, Accessible, Interoperable, Reusable,* ***https://www.go-fair.org/fair-principles***
5. *A research infrastructure is of European interest when is able to attract users from EU or associated countries other than the country where the infrastructure is located.*

Introducing the DIGital Institute for Cancer Outcomes REsearch "DIGICORE"

Digicore Board of Directors and Commercial Research Manager

After almost two years incubation time, early in April 2021 a new Organisation focused on producing cancer real world evidence, came into legal being – the DIGital Institute for Cancer Outcomes REsearch (DIGICORE). Like the Organisation of European Cancer Institutes, DIGICORE is set-up as a European Economic Interest Grouping with 18 prominent cancer centres and 2 cancer networks (UNICANCER and Alleanza Contro Il Cancro) as Members. A strategic partnership with the OECI is part of DIGICORE agenda. DIGICORE's objectives are to help prepare members for the digital revolution that will transform research through the routine use of electronic health records (EHR) and molecular diagnostic information (MDX) for trial automation, outcomes research, digital diagnostics and care quality management.

Two commercial partners have joined this ambitious endeavour: IQVIA, the leading contract research organisation and Illumina, the global leader in DNA sequencing and bioinformatics. These commercial parties have been chosen to ensure medical hypothesis neutrality. We believe this is an important principle and differentiator for DIGICORE when compared to pharma sponsored networks. IQVIA and Illumina also have the size, technology solutions and research experience to help set-up DIGICORE and support cancer centre members across Europe on their journey towards digital outcomes research.

This article lays out the scientific rationale and constitution for DIGICORE, the protections set-up for cancer centres that join and the benefits to cancer centres from becoming members or associate members. It will also provide some history and context to the new Organisation. Those themes and benefits to stakeholders are summarised below in Figure 1.

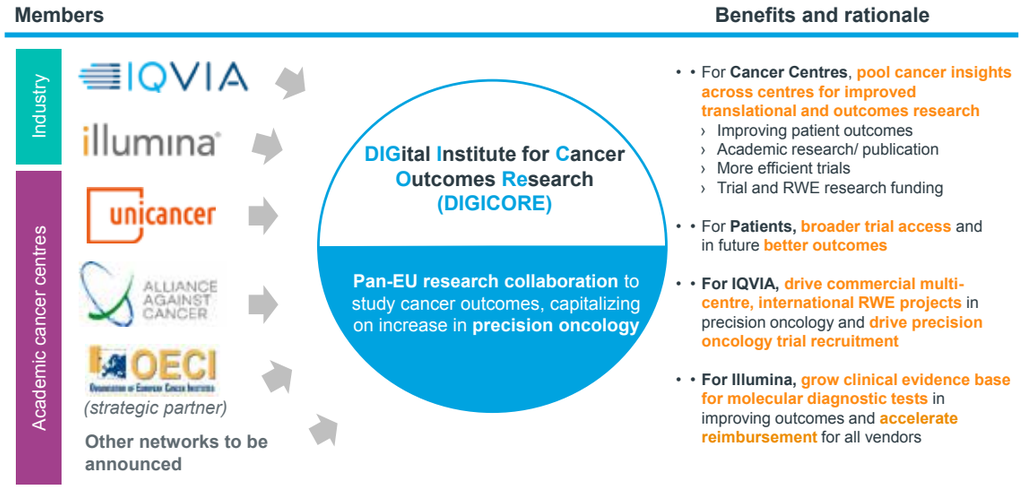


Figure 1: DIGICORE summarised

1. The scientific need for scale in cancer outcomes research

Cancer has seen an explosion of sub-types over the last decades as our increasing knowledge of disease aetiology leads to increasing specificity of classification. Initially this was by organ of origin, then by cell type, stage and grade and now by molecular subtype (especially somatic mutation subtype). This makes every cancer a rare cancer and places an emphasis on large scale collaboration.

Figure 2 illustrates this, using information from the Boston Tumour – Normal whole genome sequencing programme. It shows the rarity of most driver mutation events, and then asks a thought experiment to illustrate the rarity challenge - how big a country is needed to recruit a 250 patient cohort within 1 year with a given biomarker, for various cancers and biomarker frequencies, assuming all newly diagnosed patients can be recruited.

The results are challenging for existing research approaches, given most mutations occur in around 1% of patients or less. For a common cancer like lung, we would need all the patients in a large European country like the UK or France to recruit such a cohort. For a cancer like pancreatic (#10 ranked by incidence) we would need half of Europe, and for Liver (#20) almost every patient.

There are many challenges to achieving this scale, but a key one is cost. Traditional precision oncology cohort research is eCRF based and relies on costly re-type of clinical information and the research funding of molecular tests. We estimate costs for 10 cancers to get clinically relevant 100 patient cohorts on the 1% somatic mutations in each cancer at €0.5B to €1B using these methods[1]. This is clearly unaffordable.

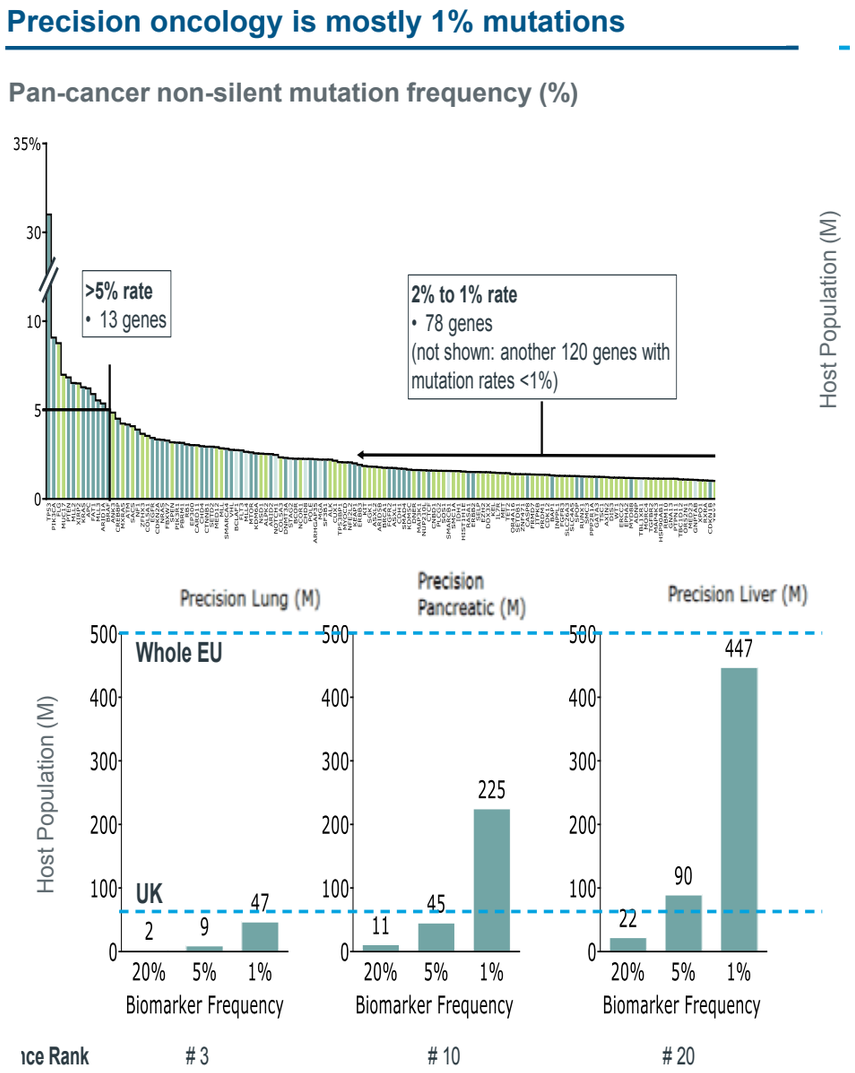


Figure 2: a thought experiment on precision oncology reproduced from Mahon & Tenenbaum 2015

However, if we can access similar information from routine care electronic health record, and avoid laborious re-type, we can transform those costs. We will also democratise research and trial access and allow more patients in need to access innovation. Clinical informatic[2] and bioinformatic[3] solutions are now coming of age and lie at the heart of the "digital" within DIGICORE.

By focusing on building an at-scale network, we will collectively get other benefits. Firstly, clinical variation in practice provides natural experimentation that can identify future best practice care. By having a larger network in academic comprehensive cancer centres like the OECI membership, we will see more of this clinically led innovation. In turn that can be validated in the DIGICORE network and cost-effectively rolled out to support national cancer plans. Secondly, we can develop and deploy digital care quality management tools – such as management analytics – that can help centres better drive guideline-based care into their practice. Thirdly, at-scale digital networks are highly desirable partners for both academic and commercial research in the precision era. We have interest from industrial partners in new forms of research, such as off-label observatories and using Mendelian randomisation to understand the impact of biomarkers in large panels on treatments that are not traditionally biomarker selected such as chemotherapy or radiotherapy. DIGICORE will provide its member centres the opportunity – but not the requirement – to participate in such exciting programmes of collaborative research.

2. Origins to DIGICORE

We can trace back the discussions that eventually led to the constitution of DIGICORE to the OECI Board meeting in Brussels, 2018. As this time, the OECI had already established its own working groups for outcomes research; IQVIA was exploring ways of partnering with European cancer centres to undertake real-world cancer research. A constructive dialogue ensued. This led to the recommendation to form a real-world research focussed new European Economic Interest Grouping (EEIG), where the main founding members would be cancer centres from across Europe. The new EEIG would be the legal vehicle for a public-private partnership to tackle outcome research.

DIGICORE FOUNDERS
1. ALLEANZA CONTRO IL CANCRO (Italy)
2. FONDAZIONE POLICLINICO UNIVERSITARIO A. GEMELLI IRCCS (Italy)
3. ISTITUTO EUROPEO DI ONCOLOGIA (Italy)
4. INSTITUT CURIE (France)
5. INSTITUT DE CANCEROLOGIE DE L'OUEST (France)
6. IQVIA (Belgium)
ASSOCIATE MEMBERS
1. UNICANCER (France)
2. CENTRE DE LUTTE CONTRE LE CANCER LEON BERARD (France)
3. AZIENDA UNITÀ SANITARIA LOCALE DI REGGIO EMILIA IRCCS (Italy)
4. FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI (Italy)
5. FONDAZIONE IRCCS POLICLINICO SAN MATTEO (Italy)
6. HUMANITAS MIRASOLE SPA (Italy)
7. IRCCS ISTITUTO ROMAGNOLO PER LO STUDIO DEI TUMORI "DINO AMADORI" – IRST s.r.l. (Italy)
8. IFOM - THE FIRC INSTITUTE OF MOLECULAR ONCOLOGY (Italy)
9. ISTITUTI FISIOTERAPICI OSPEDALIERI (Italy)
10. OSPEDALE SAN RAFFAELE (Italy)
11. INSTITUTE OF ONCOLOGY LJUBLJANA (Slovenia)
12. MARIE SKLODOWSKA-CURIE MEMORIAL CANCER CENTRE (Poland)
13. MASARYK MEMORIAL CANCER INSTITUTE (Czech Republic)
14. INSTITUTO PORTUGUES DE ONCOLOGIA DO PORTO (Portugal)
15. UNIVERSITY CANCER CENTER FRANKFURT (Germany)
16. ILLUMINA NETHERLANDS BV (The Netherlands)

Table 1: DIGICORE Membership

The very purpose of establishing a dedicated "European research infrastructure" was to allow the joint-design of governance, technology and research operations by representatives of the cancer centres. Through a series of working sessions, the major strategic choices were agreed unanimously. These principles (see Section 3) covered topics such as the importance of each centre retaining absolute control over their data (achieved in part by data never being transmitted 'off site') and research/study participation. Over the course of several months, there was enthusiastic participation in these working sessions, which allowed the nature of DIGICORE to be shaped and clarified. Despite the emergence of the pandemic and its consequences (of which we are all aware) the momentum behind the project continued. In the 2nd half of 2020, the draft agreements were prepared to allow centres to review and formally decide on their preferred participation: Founding Member or Associate Member. Given the complexity of the project and the backdrop of COVID-19, it is a tremendous achievement to have reached agreement and officially formed DIGICORE on the 1st of April 2021! The membership of DIGICORE (See Table 1) remains open, similar to the OECI. DIGICORE is therefore open to any cancer centre interested in participating to the Grouping and endowed with data collection & management expertise.

The grouping is represented by its President (Prof Gennaro Ciliberto) and the Board of Directors (currently composed of Prof Mario Campone as Vice-President, Dr Sergio Maria Liberatore as Executive Secretary, Dr Xosé Fernández as Treasurer, and Prof Roberto Orecchia). Finally, a General Manager (Claudio Lombardo) ensures the day-to-day activities and manages the operating secretariat, reporting to the Board. Two research managers entrusted with academic and commercial programmes are in place. Dr Piers Mahon, from IQVIA, has been already appointed to cover the position of Commercial Manager. Finally, a General Assembly of all Members may be convened by the President. The DIGICORE General Assembly holds ultimate power to change the DIGICORE Board composition; the Grouping's by-laws; to approve the Balance and the Provisional Budget; to vote on new Member candidacies; and to take formal decisions when the finances of the grouping may be at risk.

3. Principle and protections for Cancer Centres

The guiding principles for the establishment of DIGICORE, its information governance and research operations have been unanimously agreed. An extremely important feature is the unambiguous centre-ownership and control over their local data. This is in part achieved by data remaining "on-site" and reinforced through DIGICORE's governance. As a consequence, research will be conducted via a federated analytic approach – the cutting edge of real-world data science. Given Illumina's role in DIGICORE, it is also appropriate to confirm that DIGICORE and its members are under no obligation to use central lab facilities or modify any aspect of their pathology labs and sequencing capabilities; neither is there any obligation to make use of software, terms or infrastructure that may be made available to DIGICORE.

Below is a set of principles agreed upon ahead of starting any legal drafting, which served as the 'blueprint' for the eventual formal contracts. In sum, they provide a powerful set of agreements as to how DIGICORE will operate as a collaborative partnership:

1. **Control**: Cancer centres are the only data custodians and controllers of their local data
2. **Study and Research Governance**: Each cancer centre decides independently if they wish to participate in any given study
3. **Economic Model**: DIGICORE's finances are regulated by the EEIG's statutes and 'fair market value' considerations on commercial studies (and funder rules for academic research)
4. **Common Operating Model for Research Execution**: for DIGICORE studies, centres will converge toward a common data model and common research practices over time; incoming funding will be used to build centres' local capabilities for research execution – there is no requirement on centres to reach a minimum standard on their own budgets. However, the technical standard of a centre will influence the research it can participate in

5. **Technical Infrastructure**: DIGICORE also expects to compete for EU funding with a view to reinforcing infrastructure locally, in line with an agreed DIGICORE technical architecture and common data model that is under development
6. **Information Governance**: centres will not incur additional costs for new systems or adaptations, however rigorous pseudonymisation is expected to be in place, and the information governance procedures and basis for research processing under GDPR of a centre may influence the types of research a centre can participate towards
7. **Inter-operability and pragmatic target datasets**: the evolution of research infrastructure needs to consider existing systems and software; existing electronic medical records systems have to be "research proficient", including with respect to GDPR and pseudonymisation. We will be pragmatic in how we approach this, prioritising data item sourcing and standardisation that are of the most importance to outcomes research. The work done in France to define the OSIRIS target data set provides an example[4]
8. **Funding the Establishment of the Entity**: members will contribute an annual membership fee to cover administration of DIGICORE; set-up costs were supported by IQVIA and over time we will expand funding by participation in collaborative bids
9. **Research Governance for unfunded research** (member proposed studies, no sponsor): this is an expected activity of DIGICORE, decision-making remains with individual members. Example projects pilot include multi-centre natural history studies in Ovarian Cancer and Multiple Myeloma, and the board is reviewing research priorities for other cancers[5]
10. **Governance of the Entity**: all EEIG members are equal, each having 1 vote[6]; collectively cancer centres have majority control; formal positions within DIGICORE academic research governance are to be held only by representatives from cancer centres.

	Bronze Centres	Silver Centres	Gold Centres
1. Precision oncology research maturity	**MDX testing below NCCN guidelines** • Testing almost all "IHC + some Sanger" • Very limited local precision expertise • Don't recruit to a Biomarker driven trials	**Testing at / above NCCN guidelines** • Small panel the norm only in NSCLC • Some but limited precision expertise • Recruit rarely for SoC biomarker trials.	**Large Panel MDX standard for all cancers** • Molecular tumour board pilots • Lots of precision trials underway, especially in "new biomarkers"
2. Routine clinical data digital research maturity	**No Data Warehouse, but core EMR exists** • Siloed Clinical Systems, very partial data • Unstructured Data often paper based • No Data Standardisation • Traditional eCRF studies only	**Basic clinically focused Data Warehouse** • Core Clinical Systems integrated • Identifiable Data, some standardisation • Unstructured Data is digital, un-mapped • Taking first steps in Database Research	**A research ready local Data Warehouse** • All cancer data in (chemo, radio, path), with strong master data management • Strong privacy norms (pseudo etc) • Do multi-site database research routinely
3. Pragmatic outcomes maturity	**Minimal routine outcomes in EMR** (death in hospital, ER admissions only) • Manual research processes established for date of death, but frequency of routine scans confounds rwPFS measures	**Outcomes interested but gaps remain** • Some communities of care track key outcomes, often outside of EMR • Progression only well tracked where easy to measure (e.g. CA125 in ovarian)	**Preparing for outcomes research at scale** • EMR captures progression and death • Experimenting with routine digital outcomes – PROs tools, AI on scans etc • Maybe pilots in liquid biopsy for relapse
4. Information Governance Maturity	**Not systematic on GDPR research reuse** • Very basic patient notifications on data, often limited to clinical use • eCRF processes use traditional pathways of study specific consent or national consent waivers	**GDPR foundations based on notification** • High Quality patient Notification and Opt-out process cover research • Database Studies have robust internal processes for release of aggregated data • Patient level data release requires consent or death	**Strong secondary use consents the norm** • Secondary consents routine, and provide a broad basis for research processing • Strong operational processes for privacy risk assessment and anonymisation, allowing appropriate anonymised patient level data release for research use

Figure 3 – Framework for the assessment of digital research maturity

Immediate focus – helping members prepare for digital research

The immediate focus for DIGICORE is to help its members to get ready for the era of digital research. We are a broad community and recognise that the digital maturity of cancer centres is highly variable. Given our belief in the need for scale, we anticipate programmes of work to help members prepare, as well as execute research. At the heart of this will be an honest assessment of our digital maturity so that we can better plan our collective research. Figure 3 provides a framework we are developing for that assessment. It has four main dimensions. Firstly, the availability of high quality, routine molecular diagnostic data. Secondly, the availability of high quality, integrated clinical information in common, pragmatic data models to both make data available for protocolised research and allow inter-centre digital interoperability. Thirdly, the availability of strong outcome data to turn activity data into science. Finally – and critically – strong information governance to allow the appropriate use of that patient information for research under GDPR and local information privacy laws.

There are centres on the Gold spectrum of this framework within DIGICORE. However, unlike other networks we will be extending a helping hand to less mature centres. This reflects our belief that the precision era requires scale, and to get scale we must work together to help everyone achieve a common standard. DIGICORE is as interested in helping the Bronze work towards Silver, and the Silver work toward Gold as it is in driving research between Gold centres. The only minimum standard is that a centre must have electronic health records and be interested in getting those records ready for research, funds permitting. We will be working with members to secure such funding. We are developing assessment tools to help centres understand their maturity and prioritise investment.

While funding will help develop the network, it is not essential to start doing research together. IQVIA's existing real world evidence networks have already shown that international real world evidence can be semi-automated without major IT investments. Instead, during protocol development a common data model can be pragmatically agreed between participants, and as records are extracted and curated, they can be converted to that model. This allows the development of common analytical R-scripts that can be shared between centres to automate cohort analysis. An example of this way of working is a recent 7 centre natural history study in ovarian cancer led by Prof. Geoff Hall at Leeds Teaching Hospital that is starting to read out and generate publications, without external funding. We will be looking to extend these expert collaborations to other cancers within DIGICORE after a board discussion on priority areas.

DIGICORE has started to map collaborative funding opportunities. Various members made their first joint submission in April, towards the CRUK – NCI Cachexia Grand Challenge.

Ultimately, DIGICORE wishes to play a strong role in the European Cancer Mission in the supply of large digital research cohorts and the digitisation of trial screening. We also wish to support the national cancer control plans with the supply of outcome and health systems research insights.

DIGICORE is open to establish formal collaboration with other sister cancer Organisations to build a common collaborative approach to these themes. We invite every cancer centre to join us on our mission to make "every willing patient a research patient and so transform cancer care".

1. *In each cancer we will need 10,000 patients to get 100 patients on key 1% mutations. For 10 cancers we need 100,000 patients. Costs per patient will be around €1000 to €2000 for a high quality panel test, and around €4000 to €8000 per patient for high quality clinical records, or a total of €5000 to €10,000 per patient.*
2. *The digital analysis of electronic health records*
3. *The digital analysis of molecular test results*
4. ***https://en.e-cancer.fr/OSIRIS-a-national-data-sharing-project***
5. *Protocols and more details are available on request from any OECI centre that is interested*
6. *The EEIG has two tiers of membership, which a cancer centre can select from. Members, with a vote and joint and several liability or associate members with no vote and no liability. For research activity, there is no difference in rights between the membership tiers.*

Analysing the hallmarks and data of OECI's first 40 accredited centres

Simon Oberst
OECI Accreditation and Designation

There is a persistent variation in cancer outcomes among and within European countries suggesting (among other causes) inequalities in access to or delivery of high-quality cancer care. European policy (EU Cancer Mission and Europe's Beating Cancer Plan) is currently moving towards a mission-oriented approach addressing these inequalities (see elsewhere in this Issue). One of the main reasons for OECI to start the Accreditation & Designation Programme was to provide cancer patients equal access to high quality cancer care, and overcome the current differences in access to diagnostics, treatment and therapeutic options that patients experience in different parts of Europe. After 12 years, OECI has built up a wealth of information from more than 40 large European cancer centres.

The article published in March in Molecular Oncology[1] describes the compliance with quality standards of these 40 centres, identifies the hallmarks common to all centres, and shows the distinctive features of Comprehensive Cancer Centres. All Comprehensive Cancer Centres (CCCs) and Cancer Centres (CCs) accredited by OECI show generally good compliance with the quality standards related to care, multidisciplinarity and patient centredness. Both the CCC and the CC designations are regarded by OECI as "gold standards". However, perhaps not surprisingly, Comprehensive Cancer Centres on average showed significantly better scores on indicators related to the volume, quality and integration of translational research, such as high-impact publications, clinical trials activity (especially in Phase I and Phase IIa trials) and filing more patents as early indicators of innovation. However, irrespective of their size, centres showed significant variability regarding effective governance when functioning as entities within larger hospitals.

To our knowledge, no earlier studies involving so many different countries in Europe (18 countries) have been published, especially using data from both care and research domains. The data will also enable future benchmarking studies.

Just to pick out two interesting findings:

1) Governance and organisation

The comparatively lower scoring of the standards in this domain, among both CCCs and CCs, appears to demonstrate the challenges in this area for a centre to reach optimum effectiveness. A common problem for centres is establishing an authoritative Cancer Board for the centre, which is adequately balanced between research and clinical care. This is easier for standalone cancer centres; for centres within a University Hospital setting, needing to leverage the research of several institutes and University departments, this is a much greater challenge (hence the need for consultancy, as referred to in this Issue in relation to the EU Cancer Mission). These challenges may also account for the apparent weaknesses in some centres in strategic planning and resourcing, which should clearly integrate research endeavours and clinical priorities. Research on how certain CCCs have been formed in recent decades within University Hospitals is being performed by OECI, which should help inform the future growth of key centres more evenly across Europe.

2) Differences between CCCs and CCs in clinical research

Our analysis showed that the median CCC had nearly four times more prospective interventional clinical trials open to recruitment than its CC counterpart (figure 1A). As significantly, the rate of patient accrual to those trials is more than seven times the median of CCs. It would be important to understand the reasons for the difference between CCCs and CCs and how to improve on trial recruitment rates, although we fully appreciate that volume isn't the only criterion – the quality of the trial and the scientific question being addressed is perhaps a more important feature. We discuss whether this may be an indication that only CCCs can adequately finance and support investigator-led studies, and also an indication that pharma tends to concentrate their collaborations with CCCs for reasons of capability, efficiency or effectiveness. Nevertheless, the data show that when restricted to interventional therapeutic trials only, the 10% average recruitment rate is quite a high bar, even for some CCCs (figure 1C).

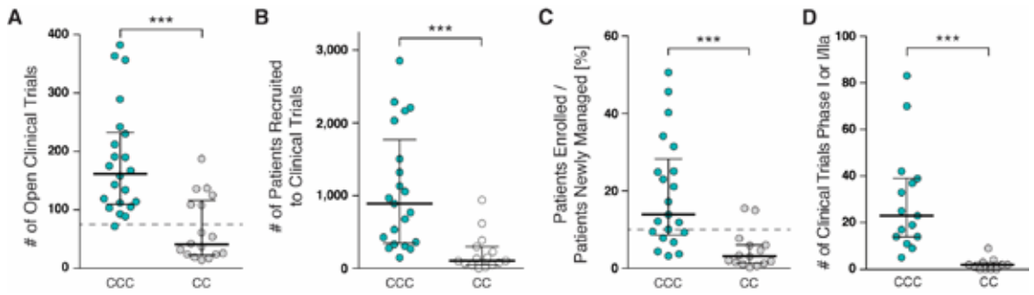


Figure 1

The differences between the cohorts are even more striking when considering Phase I and IIa trials (figure 1D). Here, the median CCC conducted 8 times more trials than the equivalent CC, indicating that the designated CCCs are the engine room of early therapeutic innovation in Europe. This is an important finding in preparation for an EU network of Cancer Centres, in order to identify the existing cohort of centres with the capacity to respond to calls for co-ordinated projects in the early phase trials space.

For the full analysis of the results and the discussion, please see the article
https://febs.onlinelibrary.wiley.com/doi/epdf/10.1002/1878-0261.12950

Regarding outcomes, the paper concludes: "Despite some seminal studies in the United States, the superiority of treatment of equivalent patient cohorts in CCCs or large cancer centres over those in general hospitals has not yet been fully established. This is related to the obvious methodological challenges in outcomes research, especially the multifactorial contributors to better outcomes when comparing centres. Establishing a completely level playing field of equivalent cohorts based on cancer, stage of diagnosis, co-morbidities, and social and economic indicators, in order to identify the specific contributions of the treating centre, is a major challenge when averaged across all cancers. So far, comparative studies have been successful only in the field of specific cancers, especially in relation to surgery and particularly related to volume differences. In the future, wider outcome studies related to the availability of molecular diagnostics and targeted treatments, and the impact of specialised and research-active multidisciplinary teams in CCCs, would be welcome."

My thanks go to the A&D Board, the co-ordination team in the Netherlands, audit teams, all authors, and the 40 OECI centres, for making this study possible.

[1] *Sebastian Kehrloesser, Simon Oberst, Willien Westerhius et al. Analysing the attributes of Comprehensive Cancer Centres and Cancer Centres across Europe to identify key hallmarks. Mol Onc, March 2021.*
https://doi.org/10.1002/1878-0261.12950

OECI's Vision and Standards for Comprehensive Cancer Networks

Simon Oberst[1] ***and Thierry Philip***[2]
1 Chair OECI Accreditation and Designation Board
2 President, OECI

Cancer Networks have been in the course of development in Europe ever since the famous Calman-Hine Report of 1995 which recommended their creation in the UK. But their implementation in Member States (MSs), whether as general cancer networks, or specific to particular cancers, is patchy. So too is the degree of effectiveness of such networks – ranging from loose associations where best practice is exchanged, to tightly-knit networks operating the same clinical guidelines, sharing extended multidisciplinary teams, having ICT interoperability, and having clear governance of the network, usually based around a Comprehensive Cancer Centre (CCC) or large Cancer Centre.

We know that most MSs do not yet have a fully networked regional infrastructure linking cancer research and care. A mapping exercise of networks performed as part of the EU Joint Action on Rare Cancers[1] in 2017 showed that only 13 Member States have Cancer Networks covering the whole MS. So there is work to be done – to enable the creation of new networks according to pre-defined principles, and standards which are both robust and flexible as to context. Due to its 12 years of experience of reviewing cancer care and research in Europe, OECI is very well placed to provide consultancy input into this process of creation, development, and accreditation of Cancer Networks.

Due to the fact that specialist cancer centres only treat a minority of cancer patients in most member states (France and Italy are exceptions to this, with large specialist cancer centres) cancer networks are vital to providing equal access for patients to high quality care and research across a local geography. This is obviously a key objective of Recommendation 10 of the EU Cancer Mission to set up a Network of Comprehensive Cancer Infrastructures[2] within and across all EU member states to improve the quality of research and care. These infrastructures will include cancer networks as part of the care and research provision to a locality.

OECI had anticipated this development by trying to tackle the challenge of evaluating the quality of cancer networks. The available literature is very thin on the subject, although we have some research in preparation. But clearly the challenge for constructing quality standards for networks is different in kind to that for cancer centres, where the latter generally have greater integration and accountability for clinical and research quality (and sometimes are a single legal entity). The second major challenge is that existing networks come in a wide variety of forms and sizes across Europe, a variety which is often driven by differing health systems.

On the basis of OECI's experience with leading a workpackage of the EU Joint Action on Rare Cancers (JARC) the Accreditation Programme began a process of consultation to develop a new set of standards which focused on the connectivity between institutions diagnosing and treating cancer in a wide geography, together with constituent or partner universities and research institutes. These standards now exist in draft form[3] and have recently been pilot tested in a network in France, and are presently being evaluated. Further pilots are being planned. The draft standards can be accessed here.

The standards are focused on topics that require co-ordination and alignment within a network, such as on governance and co-ordination of the network, multidisciplinary co-operation (extended multi-disciplinary teams (MDTs), patient pathways, referral of patients, exchange of knowledge / patient information), quality (use of guidelines, quality indicators on cancer, reporting of incidents, learning events), research (promotion of and enrolment in clinical trials, publications, biobanking) and education (oncology training, promotion of innovation, patient education). The standards build upon the CanCon requirements for Cancer Networks[4], as summarised in 2017.

So far, the evaluation OECI's European Standards for Cancer Networks shows that the standards robustly test the effectiveness of the network in driving consistency and equity throughout the healthcare provider (HCP) members, and scientific institutes.

What almost everyone is agreed about is that the process of networking, negotiating new patient pathways between HCPs (and dealing with financial issues of referral and reimbursement), ensuring consistent processes of extended MDTs and equity for patients, is hard work, and requires both resource and leadership. Solving ICT challenges is also critical to success, since all HCPs in the network must have access to electronic patient records of patients being discussed in extended MDTs, as well as the associated pathology and radiology images.

OECI's vision for Comprehensive Cancer Networks is that - in line with the Cancer Mission objective – these infrastructures become a widespread solution to levelling up quality throughout Member States, rather than by developing the centres of excellence on their own. What makes the Networks qualify as "comprehensive" is not just that they can treat all cancers (except perhaps the very rarest) but that they use instruments within the network to integrate translational and clinical research with patient care, and offer clinical trials equally to all patients in the network. As stated above, a Comprehensive Cancer Network would be expected to have at least one CCC or large Cancer Centre at its hub, co-ordinating and accelerating research into in clinical implementation. This has always been OECI's vision, to drive up consistent high quality of diagnosis and treatment to all patients.

1. ***https://jointactionrarecancers.eu/index.php/jarc-deliverables/262-list-of-the-jarc-deliverables***, *Deliverable D5.1 of the EU Joint Action on Rare Cancers, 2017-19.*
2. *Definition in the Mission Report: "National or regional infrastructures that provide resources and services to support, improve and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/carers. Different formats of Comprehensive Cancer Infrastructures are possible, including existing Comprehensive Cancer Centres or Care Networks".*
3. *OECI's draft European Standards for Cancer Networks can be found at* ***www.oeci.eu/Accreditation/ReadNews.aspx?id=53***
4. *Albreht T, Kiasuwa R, Va den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. CanCon - Cancer Control Joint Action. https://www.researchgate.net/publication/323280714_European_Guide_on_Quality_Improvement_in_Comprehensive_Cancer_Control*

OECI ACCREDITATION & DESIGNATION PROGRAMME THE WAY TO QUALITY IN ONCOLOGY

Current events in the OECI Accreditation and Designation Programme

1) Success of virtual peer review visits

The year 2020 started with a full schedule of peer review visits in the Accreditation and Designation (A&D) Programme. We started with the peer review at Centre François Baclesse in Caen in January. Unfortunately, in February, we had to decide to cancel the peer review visit at Azienda Unità Sanitaria Locale di Reggio Emilia-IRCCS. After a temporary halt to peer reviews in the first half of 2020, we started with hybrid and virtual peer reviews for centres participating in the programme in the re-accreditation process.

A hybrid visit means that two auditors – originating from the same country as the centre – are on-site and the rest of the audit team participate virtually via videoconferencing. During a 100% virtual peer review, all interviews are done via videoconferencing. The interviews for both hybrid and virtual peer reviews take place over three days instead of two (as is customary during an on-site peer review). The participating centres are asked to provide videos or live tours on the departments, to give an impression of the centre.

The first peer review in September 2020 at Centro di Riferimento Oncologico (CRO), IRCCS in Aviano was a hybrid virtual visit. The next six visits (at Azienda Unità Sanitaria Locale di Reggio Emilia-IRCCS, Istituto Oncologico Veneto (IOV) – IRCCS in Padova, Istituto Nazionale Tumori IRCCS "Fondazione G. Pascale" in Naples, Istituto Nazionale Tumori Regina Elena in Rome and Fondazione IRCCS Istituto Nazionale dei Tumori in Milan, IRCCS CROB Referral Cancer Center of Basilicata in Rionero in Vulture) were performed completely virtually. As these centres had already been visited during the previous accreditation cycle, it was not considered necessary by the A&D Board to follow up these visits with a one-day site visit.

For all new applicants to our programme the peer reviews were further delayed. In February 2021, it became clear that the COVID19 pandemic would probably remain an issue until the summer of 2021 and the A&D Board decided to also offer the option of a virtual audit to new centres in the A&D Programme. OECI strongly believes that a site visit is essential for centres being accredited for the first time, so the three-day virtual peer review will be followed by a one-day site visit before the approval of the final report and the improvement action plan by the OECI A&D Board. During this one-day visit the chair of the audit team, one additional auditor and co-ordinator will meet with the Board and Management Team of the centre, will visit one multidisciplinary team (MDT) in action, and will discuss the remaining issues with other groups of the centre. The decision on certification will depend on the outcomes of the virtual peer review and the additional one-day visit. The first virtual audit at a new centre will take place in May 2021 at the Kuopio University Cancer Centre in Kuopio (Finland), followed by the virtual visits to Gothenburg and Lund in June.

2) New accreditations

Currently there are 51 centres in the A&D Programme. 40 centres have been certified, of which 24 are OECI Comprehensive Cancer Centre and 16 are OECI Cancer Centre. 11 new centres are newly in the process and a further 10 centres are in the re-accreditation process.

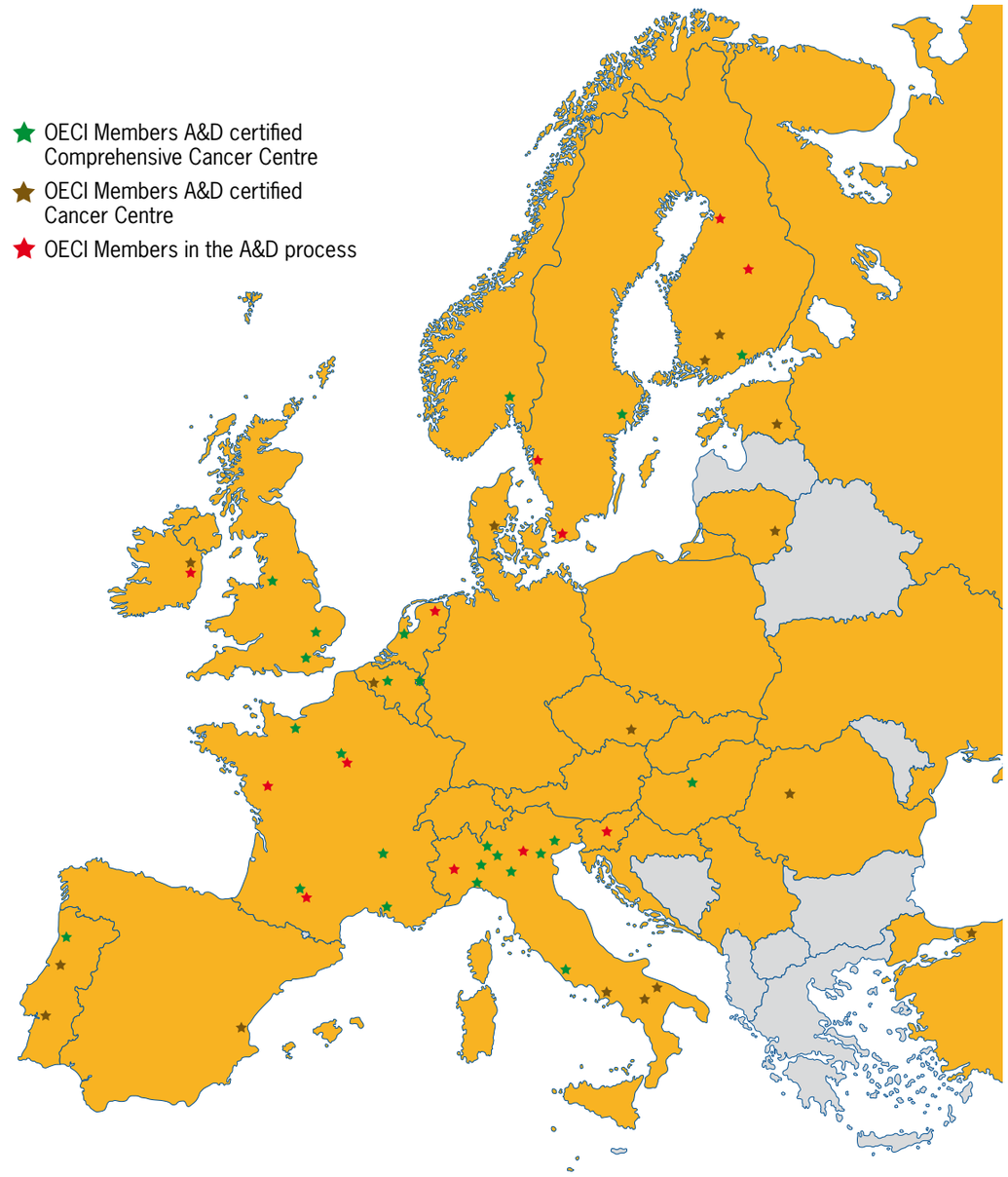
In the past year (May 2020 – April 2021) the following centres have been certified, and we offer our congratulations to these centres for their quality in care, education and research, and for their commitment through robust action plans to continuous quality improvement.

New accreditations Comprehensive Cancer Centre

Centre François Baclesse, Caen (France)
Institut Universitaire du Cancer de Toulouse-Oncopole, Toulouse (France)
Maastricht UMC+, Maastricht (the Netherlands)

Re-accreditations Comprehensive Cancer Centre

HUS Helsinki University Hospital Comprehensive Cancer Center, Helsinki (Finland)
Istituto Oncologico Veneto (IOV) – IRCCS, Padova (Italy)
Azienda Unità Sanitaria Locale di Reggio Emilia - IRCCS, Reggio Emilia (Italy)



FEEDBACK FROM OUR CENTRES:

IRCCS Centro di Riferimento Oncologico della Basilicata (CROB)

On the 16th - 19th of March 2021 the IRCCS Centro di Riferimento Oncologico della Basilicata (CROB) went through a peer-review organised within the framework of its Re-Accreditation process with the OECI A&D Programme.

The Centre had already earned a designation with the OECI A&D Programme as a Clinical Cancer Centre in 2015.

Below is a letter of Dr Alessandro Sgambato, the Scientific Director of the Centre, to the Editor-in-Chief of the OECI Magazine, Prof. Thierry Philip, who is also the President of the European Cancer Organisation.

Dr Sgambato wished to personally share his impression of the peer review process, which, as a result of the COVID-19 related restrictions, was carried out in virtual format. Below is his letter, which we would like to share with our readership in order to shed more light on our Member's experience with the A&D Process and the way our peer reviews are conducted.

We would like to extend our gratitude to Dr Sgambato for the kind words and for taking the time to share with us his precious feedback – we truly appreciate it.

Grazie, Alessandro!

Dear Editor-in-Chief,

as you certainly know, this week we have received the peer review visit of the OECI Accreditation & Designation audit team at the IRCCS Centro di Ricerche Oncologiche della Basilicata (CROB) to verify the accreditation of our Institute as a Clinical Cancer Center after the initial designation in 2015.

The visit has been completely performed in a virtual format because of the COVID-19 pandemic.

This was my first experience with OECI and I want to sincerely express my appreciation for how the entire process has been performed.

At the end of the visit, I publicly thanked the team for its competence, attention, patience, and kindness. The auditors put everyone at ease: something that was not given for granted at the beginning and that has been highly appreciated by all the personnel involved in the process.

The coordinator of the team was Marjet Docter who, after supporting us in the self-assessment process, has been really supportive in the preparation of the visit and have helped us to get to it well prepared, also from a technical point of view, in order to make the audit as smooth as possible, despite the virtual format. Moreover, with her kind and polite manner, she has been precise and rigorous in enforcing the agenda thus making the entire process much easier and well organised.

As for the interviews, the team chair was Gunnar Sæter; he and all the team auditors stood out for their competence, their knowledgeable and expert comments and advices, as well as their empathy and thoroughness.

As I told Gunnar in the final address, I was asked the questions that I expected to be asked as a scientific director. This was very rewarding and stimulating and the same is true for all those who have been involved in the interviews.

The auditors helped us to look at issues and problems from a different perspective going beyond our local one and treasuring the experience deriving from hundreds of institutes like ours.

So, whatever the final decision will be, this will remain an interesting and positive week for all of us and as an occasion to better realize the importance of what we do and the way we do it, and how to improve it in the future.

As I mentioned publicly, we all went back home happy at the end, being more aware of what we do and of our potential.

We are looking forward to the final report ready to take advantage of OECI suggestions as well as criticisms knowing that they are intended just as useful advices to improve our work for the benefit of our patients that we care most about.

With my best regards,

Alessandro

OECI One-Shot Project Socio-economic consequences of cancer: a patient perspective

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Cancer patients are often confronted with financial distress caused by a decrease in household income and a subsequent increase in (treatment related) expenditures after cancer diagnosis. The OECI decided to sponsor this research into an issue that received rather little attention in Europe so far. By distributing a survey to cancer patients across Europe, we aim to evaluate the socio-economic consequences of cancer diagnosis, such as losing work (hours) and out-of-pocket expenses. To ensure optimal patient accrual in this ongoing trial, we welcome any OECI member willing to participate as an inclusion center.

Introduction

National cancer care expenditures and pharmaceutical expenditures have been rapidly rising over the past decades and jeopardize the financial sustainability of European health systems[1,2]. The economic situation per member state, the access to health insurance, its reimbursement policies and sometimes co-payments for treatments can affect patients' access to treatment and indirect and direct patient costs[3]. Even in countries with a strong economic situation, cancer patients experience loss in income and increase of debts[4,5].

Patient expenses are affected on multiple levels: increased insurance fee, co-payments, traveling costs but also income loss due to reduced ability to work and falling into debt. Cancer care is relatively expensive, and often consists of sequential treatment lines including targeted therapy, immunotherapy, surgery, radiotherapy and combinational treatments[6]. Cancer patients with health insurance are sometimes paying higher premiums than in the past. They are also paying more for travel expenses, coinsurance, non-prescription medication and specialized equipment[7,8]. Second, various studies have found that cancer patients receiving treatment, reported reduced leisure activities, less spending on clothing and food, reduced savings, and even selling of possessions due to financial distress from their cancer treatment[9,10]. Patients might also try to increase their financial resources by using savings, investing manpower, or obtaining help from family and friends[11,12]. Third, patients with cancer may experience disruptions in employment, reduction of income, or face substantial out-of-pocket costs. Perhaps not surprisingly, cancer patients file for bankruptcy more often than the general population[13]. Several studies have also indicated that socio economic consequences and financial toxicity can significantly affect treatment compliance[7,8]. This has been reported to have a direct negative impact on the health state and treatment outcome of the patients and can be associated with poorer quality of life of patients[14,15]. Eventually patients find themselves in a vicious cycle of increasing (treatment-related) expenses and loss of household income, which results in (financial) distress and reduced quality of life (Figure 1).

Most of the research regarding patients' socio-economic consequences has been performed in the United States; the socio-economic impact of cancer in European health care systems, and inter-country variability is seldom reported upon and thus far poorly understood[8].

We aim to explore the socio-economic impact of cancer diagnosis and treatment on patients across Europe and analyze the relation of financial distress with socio-economic demographics, coping strategies and quality of life.

Method

We aim to include a minimum of 200 patients per participating country. Cancer patients who are currently or were recently treated with systemic and/or hormonal therapy and/or radiotherapy and/or surgery will be included.

A questionnaire will be distributed among cancer patients to measure the level of socio-economic impact of cancer. The Financial Index of Toxicity (FIT) questionnaire consists of nine questions, and is used to score patients' financial distress on a score ranging from 0 to 100[16]. The EQ-5D-5L questionnaire is a short measurement tool to objectify a patients' quality of life at the actual timepoint[17]. Moreover, questions regarding sociodemographic patient characteristics, diagnosis & treatment, coping behavior and treatment adherence are included in the questionnaire. Parameters affecting financial distress (FIT-score) may include, but are not limited to cancer diagnosis and treatment, reporting patients' socio-demographics, and National healthcare characteristics and healthcare expenditures. The EQ-5D-5L index score, and coping strategies will reflect the social implications of the level of financial distress.

The Organisation of European Cancer Institutes (OECI) network provides a powerful platform to conduct this trial. Through the OECI cancer centers patients will be recruited in the outpatient clinic. Patients will have the possibility to complete the survey (preferably) online but also on paper. We will also approach patient organizations, who may share a link on their website, social media or in a newsletter. Lastly there is the possibility for other cancer institutes or organizations to share a link online.

Expected results

This study allows us to examine the level of financial distress in all European member states, and objectify the economic effects of cancer care on a patient level. We hypothesize that financial distress after cancer diagnosis is present in many, if not all, of the European member states to a certain value and in different presentations. The level of distress might depend on healthcare policies regarding insurance, co-payments and social security. Countries that spend less on cancer care or healthcare, might have a higher degree of co-payments resulting in more financial burden for cancer patients. We would like to assess the degree of inequity between countries, that may be related to this phenomenon. We will analyze factors related to socio-economic burden and highlight effects on coping behavior and patients' quality of life.
We invite all OECI members to participate in this project and include patients in this study.

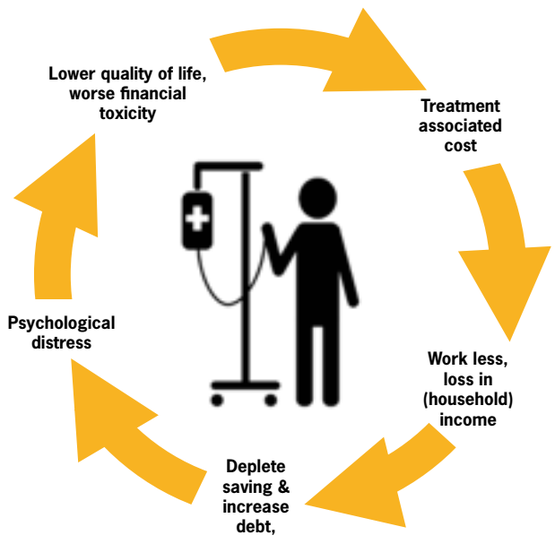

Figure 1: Vicious cycle of a cancer diagnosis and financial distress (ref)

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OECI One-Shot Project
OECI initiative on strategies of implementation of PROMs and PREMs in oncology clinical practice, research & benchmarking

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2. Organisation of European Cancer Institutes

It is now widely accepted that the point of view of patients and citizens on their own life and health is relevant and necessary to evaluate the efficacy, safety and feasibility of health care interventions, and this is mostly true in the context of Outcome Research studies that has been defined as the "... scientific discipline that describes , interprets and predicts the yield of health care interventions on final outcomes that matter for decision makers...", including patients and citizens reports and evaluations. (Figure 1)

A large body of evidence now support the validity, reliability and interpretability of information collected through patients' self reported questionnaires, today mostly known as Patient Reported Outcome Measures (PROMs), when focusing on aspects related to Heath Related Quality of Life dimensions, and Patient Reported Experience Measures (PREMs), when focusing on patients' perceptions of their experience of care.

PROMs and PREMs (PRMs) were initially developed to be applied to clinical research in assessing efficacy and effectiveness of medical interventions, but they a are also relevant in clinical practice to drive medical decisions as well as in performance evaluation of health care programs to inform quality improvement (patient-centered benchmarking). While the use of PRMs in clinical research is fairly well established, systematic assessment is not widely implemented in routine care delivery and may pose practical challenges, like the burden for healthcare providers in administering questionnaires during the medical encounter or the difficulty in interpreting results. Moreover, systematic symptom assessment in oncology practice is considered one key element of effective integration between oncology and palliative care and there is now convincing evidence that routine use of PROMs with rapid feed-back of results to health care providers, can improve symptom control, patient well-being, cost effectiveness as well as patient engagement and survival.

The European Commission Cancer Mission set the goals to reduce mortality, improve survival and quality of life of patients and citizens, and many of the actions, that are expected to be undertaken and implemented in specific calls, involve the active participation of patients and citizens. To respond to these demands, projects applying to future calls will need to adopt tools to assess and collect to PROMs and PREMs, develop expertise in their use in clinical practice and research and methods to integrate them in electronic clinical records.

For these reasons an OECI initiative was established with the following aims:

- Establish OECI priority of promoting implementation of PROMs and PREMs stepping from rhetoric to practice.
- Underline the role of PROMs and PREMs implementation as one step towards patient centred approach in clinical practice and research.
- Identify PROMs and PREMs that fit the needs of different patient populations: those undergoing treatment with curative intent, patients with advanced or metastatic disease (palliative care population) and disease free long term survivors.

- Propose implementation strategies (use of e-devices for the assessment, stakeholder engagement, organizational and reimbursement issues) in the context of the OECI Institutes.
- Scope feasibility and implementation experiences within a network of selected collaborating centers.

A panel of experts was identifies and invited to a kick off meeting was held on May 3rd 2021 (Table 1).

Participants discussed about the multiple reasons for a standardized collection of PRMs, about the real world and experimental evidence supporting its positive impact on patient outcomes, as well as barriers to implementation. A particular attention was devoted in defining how such tools can impact on the clinical decision making process. The panellists described experiences of institutional and multicenter developed programs with different targets such as flexible implementation across all clinical services (National Cancer Institute Milan), regional cancer centers network screening of outpatients and referral to palliative care (Princess Margaret Cancer Center Canada and Ontario Cancer Care Project) monitoring in research of treatment side effects in specific disease conditions (Rigshopsitalet Copenhagen) , integration of "patient units" for shared decision making and specific disease (prostate, breast , lung head and neck) pathway management (The Netherlands Cancer Institute). A specific contribution from the OECI Collaboration for Good Practices with Patients Working group focused on expanding patient involvement to help cancer centres to increase the quality of care, research and education, a perspective that is strongly needed to sustain and integrate a patient centred approach within the OECI initiative.

In following up of the current OECI initiative the panel will be expanded to a) include other centres and experts to identify a common set of valid, reliable an d robust PRM, b) develop standards guidelines and c) to scope the adoption of a common platform for routine data collection within the OECI network. The final aims are to evolve the quality of care delivered and offering a common framework and a platform database for future European research initiative in the context of the future Cancer Mission calls.

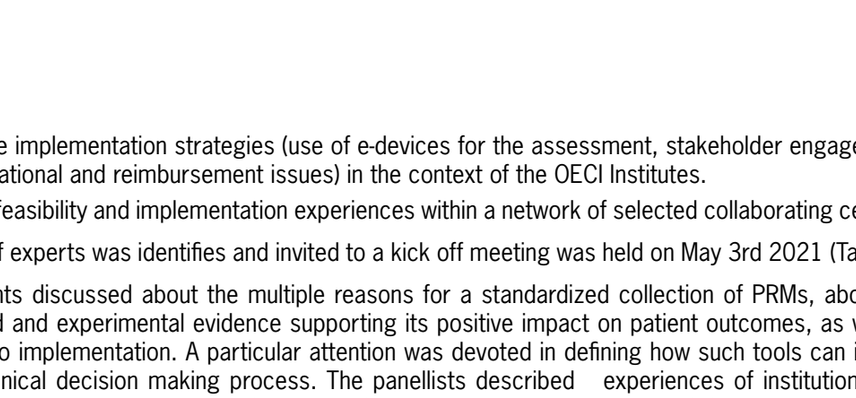

Figure 1

Making every patient's experience an added value for improving care and quality of life

Table 1: Participants at the first meeting of the OECI initiative on Patients Reported Measures

Giovanni Apolone	Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy
Augusto Caraceni	Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy
	European Association for Palliative Care Research Network
Cinzia Brunelli	Fondazione IRCCS Istituto Nazionale dei Tumori, Milan, Italy
Dominique de Valeriola	Institut Jules Bordet, Brussels, Belgium
	Chair of OECI Collaboration for Good Practices with Patients Working Group
Patrick Miqueu	Institut Jules Bordet, Brussels, Belgium Coordinator of OECI Collaboration for Good Practices with Patients Working Group
Wim H. van Harten	Rijnstate Hospital, Arnhem, The Netherlands Netherlands Cancer Institute, Amsterdam, The Netherlands
	Chair of OECI Cancer Economics and Benchmarking Working Group
Camilla Zimmermann	Princess Margaret Cancer Centre, University Health Network, Toronto, Canada
Stein Kaasa	Oslo University Hospital, Oslo, Norway
Marianne Jensen Hjermstad	Oslo University Hospital, Oslo, Norway
Helle Pappot	Oncology Centre, Rigshospitalet, Copenhagen, Denmark
Alex Gilbert	Leeds Cancer Centre, Leeds, United Kingdom
Giuseppe Recchia	daVinci Digital Therapeutics, Milan, Italy

Integrated and standardized NGS workflows for personalized therapy (INSTAND-NGS4P): Open Market Consultation concerning patient and medical needs

on behalf of the INSTAND-NGS4P consortium:
***Kurt Zatloukal**, Diagnostic and Research Center for Molecular Biomedicine; project coordinator*
***Ana Pudja**, St. Anna Children's Cancer Research Institute; leader of the open market consultation*

INSTAND-NGS4P is an EU-funded Pre-Commercial Procurement project (PCP) for improving cancer patient's benefit from Next Generation Sequencing (NGS) in routine health care by developing an integrated and standardized NGS workflow for common and rare cancers in adults and children. The integrated workflow will generate and compile information from cancer gene testing, pharmacogenomics testing and e-medication in proper presentation to medical doctors for supporting therapy decision making at bedside, widely applicable in health systems.

The solutions to be developed will focus on unmet medical and technical needs assessed in an Open Market Consultation (OMC) comprising a (virtual) meeting and widely distributed questionnaire. The results of the OMC will lay the foundation for a Call for Tenders addressing solution providers (companies and academic institutions) to develop their products to better meet the users' needs.

The current use of NGS by INSTAND-NGS4P clinical partners was analysed and the results provide an overview of the present application of NGS in routine cancer care in different countries, highlight open issues, and demonstrate the current level of evidence for including genetic alterations in decision-making. One specific aspect that was addressed referred to the type and quality of biological samples used for NGS analysis. This information will be used to specify requirements of the NGS workflow and the biological samples to be generated for performance testing and verification according to the European regulation on in vitro diagnostic medical devices (IVDs) (Regulation [EU] 2017/746). Furthermore, information has been obtained from contacting key stakeholders, such as Genomics England, EASI-Genomics and the 1+Million Genome Initiative, highlighting the increasing importance of genome-wide approaches (such as whole genome sequencing, exome and transcriptome sequencing), not only in large research programs but also in routine health care. Due to the facts that rare diseases are often not properly covered, even by extended sequencing panels, and that a large diversity of genetic alterations to be analyzed for pharmacogenomics testing exists, it was necessary to widen the specifications of the workflow to include a virtual panel based workflow (suitable for whole exome and transcriptome sequencing), in addition to the originally planned exclusively targeted panel-based approach.

Broad application of NGS in routine diagnostics and patient care requires standardization of all steps, from collection of samples from patients to decision making at the bedside, based on NGS results. Even though NGS is becoming more streamlined and simplified by the providers (panel-based), it is still a complicated workflow with several pitfalls. From a technical perspective, all involved steps outside and inside the laboratory can introduce errors, and might affect the sequencing outcome leading to erroneous and potentially harmful results for use in health care. Therefore, it is mandatory to implement appropriate quality control steps for each part of the workflow.

To meet this requirement it will be critical that the entire workflow, from patient sample collection to final diagnostic result report, is fully integrated. This is not available yet and is a major source of current NGS errors, which limits result reproducibility. Therefore, the essential and differentiating goal of this project will be to assure that NGS information, clinically relevant for the physician and patient, is correct by controlling, specifying and verifying all components and steps of the workflow and their interplay / interphases.

Currently, a series of questionnaires for the 4 different lots of the NGS workflow are published on the project website and widely distributed, to collect further information on unmet needs from patients, clinicians, industry representatives and other stakeholders, as well as to assess the innovative trends in solution development to address the unmet needs. The obtained results will feed into the specifications of the Call for Tenders, which is planned to be published in September 2021. The questionnaires are open until May 31st 2021. For further information on the project and access to the questionnaires please visit the website ***www.instandngs4p.eu***

An integrated and standardized NGS workflow from patient to patient

Joint Action iPAAC at the finish line

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Co-funded by the Health Programme of the European Union

Introduction

Innovative Partnership for Action Against Cancer (iPAAC) is a Joint Action project jointly co-funded by the European Commission's agency CHAFEA (Consumers, Health, Agriculture and Food Executive Agency) and by the governments of the participating EU Member States (MSs). In iPAAC, a total of 22 MSs as well as Moldova and Serbia as candidate countries took part with a total of 44 different partners and EU co-funding of 4.5 million EUR. It is the third in a series of projects supporting the development of evidence-informed policy in the field of cancer care and control. Previous Joint Actions – EPAAC[1-2] and CanCon[3-4] – were also dealing with several important elements of comprehensive cancer control. With the introduction of the Work Package dedicated to the sustainability of the results of the JA, the European Commission paved the way for an even more forward oriented project.

Objectives of the project

The main objective of iPAAC is the production of a solution, which would embrace the richness of the different deliverables and outputs from the three JAs and ensure their sustainability for the foreseeable future. At the same time, this solution should enable updating of some of the important elements in the recommendations, which should be live documents and tools.

Main deliverables

iPAAC has two levels of deliverables. The first one is the overarching one with the deliverables pertaining to the 'Roadmap'. This will be a tool integrating the experiences from the three JAs and the results from the extensive work with the MSs.

1. The Cancer Control Policy Interview Survey.
   In the first year of the project, the project team visited almost all MSs and met with key informants and stakeholders involved in national cancer control. This resulted in a report[5], which summarises the rich inputs provided by the direct communication with national partners. Stakeholder thus actually formed national focus groups and provided richness of data, which would not be easily obtained by the means of a classical survey. The results represent an important amendment to the work of the previous two JAs, especially in the field of national cancer policy but also in several specific topics presented.
2. One-pagers
   In order to underline the importance of specific topics from the three JAs and also some issues specifically raised from the survey mentioned above, it was decided that a series of one-pagers would be produced with the aim of providing policymakers with succinct and focused information. The production is underway and will be completed until autumn 2021 with several hundred well-elaborated one-pagers.
3. Sustainability report
   iPAAC will prepare, based on the above documents and based on the assessment of the previous outputs from the first two JAs, a report which will comprehensively present all the issues with references that should be maintained and updated for the future. Provisional and advance discussions are underway with the JRC, which will host the Cancer Knowledge Centre of the European Union.

We are looking forward to the solution, which will support the continued availability of all the recommendations, findings, tools and documents of the three JAs on cancer policy.

In consensus with iPAAC partners, it has been decided that this Roadmap will be a tool to encourage and facilitate mutual learning among EU MSs regarding the implementation of innovative cancer control policy. As most EU MSs already deal with cancer control since, at least, one decade (often much longer) and that they focus or priorities have been found to be slightly different, one could reasonably assume that the sharing of their experience can be beneficial. The Roadmap will be on online repository, providing information regarding innovative cancer control approaches, identified from the iPAAC WP5-WP10 and from implementation experiences in 28 EU countries (CCPIS). This information is provided in the format of a "one-pager", describing key implementation steps, barriers and lessons learned.

Each of the Work Packages (WPs) has its own specific tasks, which are - in most cases – also related to the deliverables. This JA has been the first one in which we had a special Work Package dedicated to governance and it was tackling several important elements of comprehensive cancer management in Europe. Worth mentioning are in particular activities related to the catalogue of standards for the Comprehensive Cancer Control Networks (CCCNs) as well as patient pathways[6-7]. The former are a result of close collaboration between iPAAC and OECI. Patient pathways present in an innovative approach to the development of two pathways, one for pancreatic cancer and the other for colorectal cancer. Other tasks on governance include the work on PREMs and PROMs and recommendations on improving the National Cancer Control Programmes (NCCPs) in terms of the findings of the same WP.

iPAAC in the context of the Europe's Beating Cancer Plan (EBCP)

Although iPAAC was developed as a project with its defined contents, objectives and deliverables prior to the idea of the EBCP had materialised, it prioritised some of the topics, which will definitely present a clear link and interaction between the two. This is certainly true of all the activities that iPAAC as well as previous JAs carried out in primary and secondary prevention, development of concepts of survivorship and Comprehensive Cancer Control Networks (CCCNs). In Table 1. there is a presentation of all the interactions and close links between iPAAC and the EBCP.

Table 1. Topics of close interaction between iPAAC and EBCP

Topic	iPAAC	EBCP
Health promotion and screening	Implementation of European Code against Cancer Reviewing additional evidence on screening	Strong focus on health determinants, interventions and strengthening of screening as well as early detection
Genomics and cancer	Continuation of work done in the previous JA, building on the Policy Paper developed there	Included in the first three pilars
Cancer registries	Expansion of the datasets in order to include data on staging, survival as well as socioeconomic data	European Registry of inequalities in cancer
Current issues in cancer care	Special focuses: ‚neglected' cancers (ex. pancreatic), in particular on early detection, economics of cancer, MDTs, palliative care	Third pillar is all about cancer care
Immunotherapy in cancer	Reimbursement models for immunotherapy	Therapy as a part of the third pillar and survivorship
Governance	NCCPs, standards, PREMs and PROMs, patient pathways, CCCNs	Governance and organisational models

We would like to commend excellent collaboration with all key European cancer organisations, both those, which represent the scientific and professional societies as well as all the patient and advocacy organisations. Their contribution has been precious and has by far exceeded the anticipated framework and work effort nominally declared.

Working together towards better cancer care in Europe
iPAAC will finish its work with the end of 2021. One of the final steps will be the project's final conference, which will be an opportunity to meet stakeholders in cancer care and control with the aim of discussing the outcomes of the project in the light of the EBCP implementation and the forthcoming activities. The conference is scheduled for 13 and 14 December 2021 in Ljubljana, but as a hybrid event adapted to the international events in times of the COVID-10 pandemic. It will be an opportunity to discuss the outcomes of the JA in the context of the EBCP as well as of the future of cancer control and overall cancer management in Europe.

We believe that the legacy of iPAAC (but also of the previous two JAs) is a very important one. This is true because of the different tools, concepts, definitions and guidances that we have developed. But also, in terms of the close links we have developed with the partners in the EU Member States (MSs) for the practical implementation of all the ambitious ideas and results from iPAAC, as well as those from the EBCP, lie with the MSs. Continued collaboration between the partners working on the different topics in the JAs as well as with the different European organisations in the field of cancer working hand in hand with the European Commission and with the MSs can ensure stability for the diverse activities that we all need to take part in with the overarching aim of improving cancer care and control in Europe, contributing to even bigger advancement in quality of cancer care as well as in reducing the unacceptable inequalities in cancer both across the EU as well as within the different MSs.

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OECI Oncology Days 2021-2025

The OECI ONCOLOGY DAYS, the annual meeting of our European and extra-European Member Institutes are celebrating this year their 43rd Edition.

The preparatory work of the Oncology Days is complex and requires a long-term planning of the venues hosting the event. Should your Institute be interested in hosting an Oncology Days event, please contact us at ***oeci@oeci.eu***

This year's the OECI ONCOLOGY DAY shall be organised in virtual format, on June 16th 2021, thanks to the kind support of the Fondazione IRCCS- Istituto Nazionale dei Tumori di Milano.
More details at ***https://www.oeci.eu/NewsDetail.aspx?id=166***

The next editions, which we all hope will be held in person, will take place as follows:

- **2022: Spain, Valencia**
  thanks to the kind support of the Fundacion Instituto Valenciano de Oncologia
- **2023: France, Paris**
  planned in collaboration with the Institut Curie
- **2024: Finland, Helsinki**
  held by the Helsinki University Hospital Comprehensive Cancer Center
- **2025: Norway, Oslo**
  hosted by the Oslo University Hospital (OUH)

OECI appoints new Chair of the Accreditation Committee

Simon Oberst *– Chair of the OECI Accreditation and Designation (A&D)Programme*

After 7 years of dedicated service, the chair of the OECI Accreditation and Designation Committee, Professor Gunnar Saeter, is stepping down and passing the torch to Dr Jozsef Lovey.

OECI and the A&D Programme are truly grateful to Gunnar, who during his tenure has provided us consistent and thoughtful guidance and been committed to expanding our Programme all across Europe and beyond with his insight, ideas, dedication and advocacy.

Gunnar helped guide the A&D Programme through several transitions, including the publication of two A&D Manuals – Manual 2.0 and Manual 3.0 – and a revision of the latter. He also proactively supported the Programme in obtaining the ISQua certification.

By all measures, we have improved our services on his watch at the Accreditation Committee, and we are grateful to Gunnar for his time and energy. Gunnar will continue to collaborate with us as Member of the OECI and of the A&D Board.

At the same time, we would like to warmly welcome the new Chair of the Accreditation Committee, Dr Jozsef Lovey. Jozsef, who has an extensive experience in coordinating international and European initiatives, is Medical Director of the National Institute of Oncology of Budapest and is also an Elected Member of the OECI Board since 2015. We are grateful and excited to have him bring his unique drive, expertise and tenacity to the work of the A&D Programme.

The A&D Board, Coordinators and Staff, along with the entire OECI family would like to recognize and appreciate the enormous contributions these both individuals have given to our Organisation as a whole and in particular to the A&D Programme.

OECI new members 2021

OECI Liaison Office
SOS Europe Srl - Genoa

OECI is pleased to welcome to its network 7 new applications for Full Membership and 2 applications for Associate Membership.
The arrival and the involvement of these Institutes in the OECI community will surely endorse the activities promoted over the years in order to achieve the common goals in the field of the cancer research and treatment.
OECI wishes its new Members a fruitful and productive collaboration!

Full Membership

Istituto Oncologico del Mediterraneo s.p.a. (IOM)
www.grupposamed.com/it/istituto-oncologico-del-mediterraneo
Italy

Maria Sklodowska-Curie
National Research Institute of Oncology
www.pib-nio.pl
Poland

Fondazione Policlinico Universitario Agostino Gemelli IRCCS
www.policlinicogemelli.it
Italy

East Tallinn Central Hospital
www.itk.ee
Estonia

Centre de lutte contre le cancer Eugène Marquis
www.centre-eugene-marquis.fr
France

Saolta University Health Care Group
www.saolta.ie
Ireland

Vall d'Hebron Barcelona Hospital Campus
www.vallhebron.com/es
Spain

Associate Membership

Fondazione I.R.C.C.S. Policlinico San Matteo
www.sanmatteo.org/site/home.html
Italy

University Hospital of Umeå
www.regionvasterbotten.se
Sweden

Report from the 8th EACR-OECI Joint Virtual Conference: Molecular Pathology Approach to Cancer

Jane Smith[1] *and* ***Claudio Lombardo***[2]
1. Director European Association for Cancer Research
2. Director Organisation of European Cancer Institutes

The EACR is pleased to partner with the OECI on projects that enable communication and collaboration among researchers and clinicians, including on a number of valuable and successful joint conferences. The 8th EACR-OECI Joint Virtual Conference: Molecular Pathology Approach to Cancer was held virtually on 23-24 March 2021. 134 participants enjoyed 2 days of high-quality talks and discussions, including a Virtual Poster Discussion Session on the platform 'Gather'.
The Scientific Chairs for the event were Leonor David (Portugal), Eli Pikarsky (Israel), Ragnhild A. Lothe (Norway), Luigi M. Terracciano (Switzerland) and Giorgio Stanta (Italy).

Feedback from participants
Molecular Pathology Approach to Cancer has always been a popular conference with participants, and this trend continued in 2021 despite the transition to a virtual platform. 96% of respondents to our post-conference survey said that they would recommend EACR virtual conferences to a colleague based on their experience at this event. The scientific content was also considered to be very high with over 93% of participants rating the overall quality of the scientific content of the conference either 'excellent' or 'very good'.
Some of the other feedback we received included:
"It was different from other kinds of medical conferences in the way that it gives a global approach to cancer by combining molecular biology, pathology, AI as well as oncologic research. In addition, it brings researchers from all around the world together giving the opportunity to exchange experience and knowledge."
"I think it was a great opportunity to increase our network, collaborations and to keep us up-to-date. Virtual conferences from EACR allows us the closest experience to [in-person] conferences."
"EACR conference on Molecular Pathology Approach to Cancer was very interesting and informative. It was organized on a high level and speakers discussed hot topics in their field of research. Although totally virtual, the meeting became a place to bring together researchers with a common interest in pathology and it was really great!"
"I thought that the hosts for each session were very open and inclusive about inviting questions and allowing others the opportunities to ask questions."

Feedback from exhibitors
We also received very positive feedback from our virtual exhibitors, many of whom echoed the sentiments expressed by the participants.
"The 'Gather' session in particularly was very well-received an compared to be as close to a the real thing as possible in a virtual world."
"The talks were great and informative, really good combination and well presented."

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