



ECCO2019

EUROPEAN CANCER SUMMIT

EUROPEAN CANCER CARE: ACROSS BORDERS

REPORT

Reaching the 70:35 Vision for cancer* requires breaking down the borders of cancer care: between countries, professions, sectors and stakeholders.

*70% average long-term survival for patients with cancer by 2035

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Foreword

Led by the European CanCer Organisation (ECCO), the ECCO 2019 European Cancer Summit convened on 12-14 September 2019 in Brussels, bringing together 350 leaders and stakeholders in cancer care, research, patient advocacy and the public-private sectors, in a unique forum.

The Summit developed the theme 'European Cancer Care: Across Borders' – that looks to the 70:35 Vision for cancer, aiming to achieve 70% average long-term survival for patients with cancer by 2035. Delivering on this ambitious goal requires that we break down the borders of cancer care to encourage broad cooperation: across countries, professions, sectors and stakeholders. The Summit was a comprehensive platform for debate and engagement on these issues.

Informative sessions explored border-busting themes such as the impacts of Artificial Intelligence on various areas of cancer care, how to better provide cancer treatment across borders, the current status in respect to cancer patients being able to participate in clinical trials in other countries and issues of professional specialisation and cross-border mobility of cancer experts.

The Summit also passed a powerful resolution on eliminating cancers caused by HPV as a public health problem in Europe and a motion on creating a truly successful and all-encompassing EU Cancer Mission.

Looking to the future, new paradigms for achieving treatment optimisation in cancer were debated, alongside new models to create sustainability for the cost of cancer medicines and the potentially revolutionary possibilities for cancer care from greater use of molecular testing.

We thank our member societies, partners, delegates, and the ECCO Board of Directors, ECCO Patient Advisory Committee, ECCO Oncopolicy Committee and the ECCO team of staff and consultants for their contributions to this year's edition. With your input, the Summit produced powerful pointers for organisational improvement in all European health systems – policy recommendations that can raise standards, outcomes and quality of care for all cancer patients.

We are pleased to present to you this report on the ECCO 2019 European Cancer Summit and welcome you to next year's edition in Brussels on 18-19 November 2020.



Prof Philip Poortmans
*ECCO 2019 European Cancer Summit Co-Chair
President of the European CanCer Organisation
(2018-2019)*



Dr Ian Banks
*ECCO 2019 European Cancer Summit Co-Chair
Chair of the ECCO Patient Advisory Committee
(2011-2019)*

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Since we met last time...

REVIEW OF PROGRESS, ACHIEVEMENTS AND CHALLENGES

The ECCO 2018 European Cancer Summit Resolutions called for better measurement of quality cancer care, reduced financial discrimination for cancer survivors and improved roles for primary care in cancer care delivery. Kicking off Summit 2019, the opening panel reviewed progress against these targets.

Primary care to improve cancer patient outcomes

Prof Mehmet Ungan said that the first steps toward the achievement of the 2018 Summit resolution on integrated cancer care has been taken with the publication of *ECCO Essential Requirements for Quality Cancer Care: Primary Care*, a peer-reviewed paper by 19 authors from a wide spectrum of countries and medical professions. He commented that this is probably the most important paper to date on the topic; and new evidence to inform health policy makers' thinking.

The paper is a consensus between 14 European professional societies and patient representatives, and presents a clear roadmap for improving primary care in cancer – with checklists and actions needed to bring patients high-quality cancer care. “Where others are talking about making this change, this group is doing it,” commented Prof Ungan.

ECCO Essential Requirements for Quality Cancer Care: Primary Care has been published in *Critical Reviews in Oncology/Hematology*. <http://bit.ly/30ToFtB>

Progressing cancer quality standards across Europe

Simon Oberst briefed the Summit on progress toward the realisation of the 2018 Summit resolution for achieving greater commonality in approach across Europe in respect to measurement and evaluation of quality cancer care. He explained that standards are critical to delivering high-quality cancer care and that oncology teams benefit greatly from the guidance and structure in approach that clear standards provide.

He outlined a series of relevant and interesting quality cancer care focused activities and initiatives underway at the European level designed to raise standards. These include: the ECCO Essential Requirements for Quality Cancer Care series, the OECI Accreditation and Designation Programme for cancer centres, activities by the German Cancer Society and partners within the EU Joint Action IPAAC (The Innovative Partnership for Action Against Cancer), and ongoing work by the European Commission's Joint Research Centre, including the European Commission Initiative on Breast Cancer.

A series of case studies demonstrated how standards support a multi-disciplinary approach to the quality of cancer treatment. Standards and accreditation are not a rubber stamp or certificate, Mr Oberst explained, but a process of learning and improvement across medical teams, based on demonstrated practices. “Who can improve? Clinicians, researchers, managers, and medical teams.” Mr Oberst said that a realistic target is to focus on 60-80 core standards that can be cascaded to non-specialist medical teams across the EU.

The right to be forgotten – each survivor's right

With increasing numbers of cancer survivors across Europe, too many are now sadly stigmatised and negatively impacted after completion of treatment by discrimination in respect to accessing certain financial services. The 2018 European Cancer Summit passed a Resolution aiming to improve this situation by pushing for national laws for ‘the right to be forgotten’.

Such legislation, as first introduced in France, enables citizens who have lived cancer free for a number of years, to not declare their past cancer diagnosis and treatment when making applications for such services as bank loans, mortgages and travel insurance. Without this legislation, in too many countries, former cancer patients find themselves discriminated against unfairly with serious negative impacts in respect to the conduct of their daily lives and attempts to secure a return to normality after cancer.

Reporting on the progress of her campaigning activity since the 2018 Summit, Prof Françoise Meunier said that France's landmark 2015 legislation is a model for countries to follow. It inspired Belgian lawmakers, who

passed their 'right to be forgotten' legislation earlier this year. "Working with ECCO, our members and partners, we won't rest until we achieve our ambition for a universal right to be forgotten across Europe," she said.

Patients voice their views and needs

Discussing personal experiences with cancer care, Kathy Oliver summarised the findings of the 2019 All.Can pan-European survey – *Patient insights on cancer care: opportunities for improving efficiency*, which polled people affected by different cancers across ten countries. <http://bit.ly/2MWiRut>

Four action areas are summarised from the survey data:

» **Ensure swift, accurate and appropriately delivered diagnosis**

When asked to select one area of cancer care where they experienced the most inefficiency, 26% of respondents chose diagnosis – more than any other area of cancer care. 32% said their cancer was diagnosed as something different, once or multiple times.

» **Improve information sharing, support and shared decision making**

Respondents said they received too much information at once. They would prefer to see relevant details at appropriate points in their journey. 41% said they received no details at the hospital on peer support groups.

» **Make integrated multidisciplinary care a reality for all patients**

Specialised cancer nurses play a critical role as 'navigators,' helping patients adapt to their situations. 69% voiced a need for psychological support; 34% said none was available.

» **Address the financial implications of cancer**

Some 51% of respondents paid part of their care personally or through private insurance. Some said that diagnosis created life-long financial insecurity.

Understanding and assessing value in healthcare and oncology

Reporting on the results of an ECCO project completed in February 2019, Prof Yolande Lievens addressed approaches to increase understanding of 'value in oncology treatment'. She led this process with international experts in patient advocacy, oncology research and treatment and statistical analysis. This led to an ECCO-led project investigating the application of value assessment methods in non-systemic oncology treatment. She stressed that patients' ability to benefit must be the starting point for measuring the value of any innovation.

There are various approaches to understand value in healthcare. But what are the optimal pathways; and is a common approach across different domains possible – for example pharmaceutical and non-systemic treatments? This project clarifies potential answers to some of these questions by reporting on the application of value-based healthcare across the cancer care spectrum. <http://bit.ly/2J7WGjM>

Since we met last time

Prof Mehmet Ungan, President, WONCA Europe: Greater integration of primary care to improve cancer patient outcomes

Simon Oberst, Chair, Organisation of European Cancer Institutes (OECI) Accreditation & Designation Programme: Reviewing OEI and ECCO activities to progress quality of cancer care across Europe

Prof Françoise Meunier, Vice President, Federation of European Academies of Medicine (FEAM): Legislative achievements in 2019 on protecting cancer survivors from financial discrimination

Kathy Oliver, Co-Director, International Brain Tumour Alliance (IBTA), Vice-Chair ECCO Patient Advisory Committee: All.Can initiative's survey of 4,000 people affected by different cancers across 10 countries

Prof Yolande Lievens, Past President, European Society for Radiotherapy and Oncology (ESTRO): Update – Value-based healthcare to achieve greater application to non-systemic treatment areas

Moderators:

Prof Philip Poortmans, President of the European CanCer Organisation (ECCO)

Dr Ian Banks, ECCO Board Member, Chair of the ECCO Patient Advisory Committee



*Prof Françoise Meunier,
Vice President, Federation
of European Academies of
Medicine (FEAM)*

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The European Cancer Mission: Reaching the moon with our feet on the ground

TOWARD EUROPE'S NEXT GENERATION OF CANCER CONTROL AND RESEARCH

Research and innovation are the keys to continually rolling back the harm that cancer causes to society. But these are only part of the well-functioning ecosystem that is needed to control and reduce the disease to bring better health outcomes to Europe's patients.

Other ecosystem elements include prevention and diagnosis, improved health literacy and education, the vigorous exchange of best practices between the research and public health sectors, well-functioning health systems and more strategic use of data – all driven by patients' needs and expectations.

This session was led by a panel of policy makers in health and in research, together with a patient representative. They engaged participants to explore how to build the ecosystem that will deliver the cancer groundshot.

What's needed, they say, is an 'integrated approach' that drives multi-sectoral and multi-disciplinary action for cancer control. The EU's new Cancer Mission – part of the upcoming EU Horizon Europe research agenda – promises a moonshot approach to bring together all players in society to find new cures and reduce cancer's impact on the population.

Session panelists discussed a less technocratic, more patient-focused approach than they see in the US cancer moonshot model. They called for a 'groundshot' to deliver 'improved, equitable, sustainable and affordable cancer outcomes, in data-enabled health systems, bringing better outcomes to 738 million EU citizens.'

The progress of this effort is guided by the Lancet Oncology Groundshot Commission, a group of leaders and experts working to identify cost-effective and proven measures that exist today, that can be shared to improve cancer prevention and treatment. The initiative is a call to action for all of Europe, with an emphasis on Eastern Europe.

The groundshot also calls for a more networked exchange of practice, research and learning on what is working in cancer control, by creating and linking cancer centres in every European country.

Increasing health literacy and bridging Europe's East-West divide in access to the best treatments

KEY MESSAGE

If we don't focus on people as the priority over technology and really put the patient first, we won't be able to solve Europe's cancer problem. This is what 'Groundshot' thinking is all about – focusing the best science and innovation on the real needs of our society.

and cancer care are two priority areas for action. One participant commented that all European citizens are entitled to the same levels of access and care, saying that it is not acceptable that a country's economic level should determine the level of health of its citizens. So the issue that many citizens in lower income locations face today is less of a cancer problem than a problem of inequality in health.

Panelists stressed the importance of cooperation, sharing of know-how and practices and training of healthcare professionals.

Investment is required in data collection and sharing to better understand what is working well, and where improvements are needed so that health and research systems deliver better outcomes to their citizens. Early diagnosis was highlighted as another practical strategy that will make a difference, and an important research area that requires adequate funding.

Delegates welcomed the innovative and forward-looking concept of the EU Cancer Mission and its potential to harness science to deliver real outcomes to Europe's citizens. But if this is to be truly effective as a



tool for society, the Mission's Board composition needs to be revised. If cancer research is about people not technology, the patients and their representatives need to have a political voice, in positions of influence to shape the Mission's policies and programmes.

A look at pan-European cancer figures makes a compelling case for thinking out of the box and rolling out new, aggressive approaches to the fight against cancer:

- » Across Europe one person dies every three minutes from some form of cancer, a situation approaching epidemic levels.
- » The International Agency for Research on Cancer predicts that by 2030, the number of new cancer cases occurring every year will double, reaching some 22 million.
- » The cancer survival rate in Western Europe is up to 40% higher than for its Eastern counterparts. Poland registers lung cancer mortality at 83% compared to the EU average of 56%; Romania's cervical cancer mortality is 14%, compared with the EU average of 3.7%.
- » Factors causing higher cancer mortality in Europe's lower income economies include late diagnosis, a lack of multidisciplinary teams and community engagement efforts, less priority given to oncology and health systems, poor infrastructure, low investment in financial and human resources, lack of access to innovative treatments and information, and lower coverage, quality, and frequency of primary prevention.

The Lancet Oncology article – Cancer groundshot – going global before going to the moon. <http://bit.ly/31WvThu>

Beating Cancer is 'Mission Possible' – statement of MEP Against Cancer group. <https://bit.ly/2GpHoqV>



Prof Mark Lawler, Queen's University Belfast and the European Cancer Concord

'Putting a person on the moon': How to deliver mission orientated cancer activity

What have we learned so far; what are the secrets of mission success?

Dr Jan-Willem van de Loo, Scientific and Policy Officer, European Commission Directorate-General for Research and Innovation: Update on the background and current status of the EU Cancer Mission

Prof Thierry Philip, President, Organisation of European Cancer Institutes (OECI), convenor of stakeholders for consensus positioning on cancer mission matters (see special issue, *Tumori Journal*, June 2019): The need for a mission to fight inequalities in cancer across Europe

Prof Mark Lawler, Queen's University Belfast and the European Cancer Concord: Work of the *Lancet Oncology*

Cancer Groundshot – cost-effective, practical and proven measures for improving outcomes to fight cancer that are yet to be fully taken up across Europe

Panel perspectives:

Prof Gilles Vassal, Past President of the European Society of Paediatric Oncology (SIOP Europe)

Prof Véronique Trillet-Lenoir, MEP, Liste Renaissance, France

Moderators:

Prof Mark Lawler, Queen's University Belfast & Vice President of the European Cancer Concord

Gilliosa Spurrier-Bernard, ECCO Patient Advisory Committee and Melanoma Patient Network Europe



Eliminating cancers caused by HPV as a public health problem

THE SCIENCE AND EVIDENCE ARE CLEAR. NATIONAL AND EU DECISION MAKERS NOW NEED EFFECTIVE PROGRAMMES TO VACCINATE, SCREEN, TREAT AND INFORM THEIR POPULATIONS.

The goal of eliminating cancers related to the Human Papilloma Virus (HPV) with universal vaccination is within reach. A solid foundation of evidence is emerging, but as in many public health efforts, the last mile is the biggest hurdle. Jumping this one requires a broad multi-stakeholder and multidisciplinary effort – supported by public health education and literacy to promote the benefits of this solution to every family and to society.

This session saw animated exchanges on how close we are to reaching the goal of HPV eradication, and what is standing in the way. The example was presented of the successful gender-neutral vaccination campaign for girls and boys in the UK – a potential model for a Europe-wide effort. The case of Turkey’s effective national DNA-HPV screening initiative – that reaches urban and more remote village populations – shows that high-tech approaches can also work in lower income settings.

There was a lively discussion on the issue of ‘fake news’ on public perception of vaccination. The discussion highlighted a critical need for countries to be better at practically communicating research evidence and the reality of HPV to families, in simple and practical messages.

KEY MESSAGE

By taking the right policy actions on HPV vaccination, screening, treatment and research, the possibility of eliminating HPV caused cancers as a public health problem in Europe is a goal that can be achieved.

A range of evidence and practices were exchanged, including the recently published updated systematic review of the population-level impact of vaccinating girls and women against HPV, on HPV infections and related conditions. This includes data from 60 million people and up to eight years of post-vaccination follow-up. <http://bit.ly/338h6Rg>

At the session, participants overwhelmingly supported a resolution calling on European and national decision makers to increase their efforts on HPV cancer elimination. The European Cancer Summit Resolution on HPV Cancer Elimination states: “By 2030, effective strategies to eliminate cancers caused by HPV as a public health problem should be implemented in all European countries.” <http://bit.ly/2LUmIZK>

Alongside the resolution ECCO, ESGO and other partners have started developing an action plan setting out how countries and public health partners can make HPV eradication a reality. Key points include: by 2025, all European country cancer plans should include actions toward gender-neutral vaccination and they should be in place by 2030; by 2030 the target vaccination rate for adolescents of both genders will be 90%. Accompanying targets are being developed for early diagnosis and treatment. <http://bit.ly/3OUVrDU>

Resolution Session: Eliminating HPV-related cancers

Co-led by the European CanCer Organisation (ECCO) and the European Society of Gynaecological Oncology (ESGO)

The Global Picture: the opportunities for HPV elimination

Dr Maria Kyrgiou, Imperial College London, UK: Epidemiology of HPV infection and impact of HPV vaccination

Dr Murat Gultekin, Chair, European Society of Gynaecological Oncology (ESGO) Prevention & Diagnostics Task Force, European Network of Gynaecological Cancer Advocacy Groups (ENGAGE): Opportunities for improving HPV screening, international ESGO-led collaborations

Eliminating HPV in Europe: toward a Summit resolution

Peter Baker, Campaign Director, HPV Action UK: The campaign for gender neutral HPV vaccination in the UK – progress towards a similar European-level campaign

Prof Daniel Kelly, ECCO Board Member, Past President of European Oncology Nursing Society (EONS)

Moderator: Prof Daniel Kelly



Dr Maria Kyrgiou, Imperial College London, UK



Cross-border access to clinical trials is a puzzle that Europe needs to solve

The current EU directive on patients' rights for cross-border healthcare guides how patients can travel for care in another country. But it does not account for the needs of cancer patients seeking access to clinical trials abroad. Today's challenges and opportunities for cross-border trials are summarised in a new study that was discussed at the ECCO 2019 European Cancer Summit.

Patients benefit from access to innovative medicines through clinical trials, and the EU single market should facilitate patient participation in trials in other countries. Results emerging from a recent study on cross-border clinical trials indicate that ease-of-access for clinic trials in another country is not there yet.

The study highlights that there is a current lack of EU legislation or guidelines to facilitate patients' participating in trials in other locations. But cross-border trials are happening, and the trend is growing in some regions. This lack of a European legal framework means that patients travelling to another country for trials face issues such as: a lack of clarity on protocols for follow-up when they return home, and how national insurance covers costs; and practical issues such as who is responsible for covering the cost travel, lodging and related logistics.

These obstacles to participating in trials in other countries suggest improvements to the legislative, administrative and regulatory frameworks around cross-border trial participation in Europe are still possible. Developing the new legislation will take time, and it is a puzzle that needs to be solved, said

KEY MESSAGE

Greater facilitation for cross-border clinical trials is possible through further legal and administrative clarification.

discussants. But despite the lack of a legal basis, there are bright spots that can guide practice in the meantime. A range of practical examples that show what is working today can serve as guidance until an EU directive or regulation is finalised.

The Nordics – Denmark, Finland, Norway, Sweden – have a network for sharing new trial results and information on access to new therapies. Slovakia's legislation specifies that their citizens participating in trials in other countries will be covered by national insurance at home, provided they inform medical authorities. In the Netherlands-Germany border regions, university hospitals cooperate on research, they exchange data and, for trials, work together to facilitate and simplify patients' access.

These issues are complex. But participants agreed that sharing these and other practical examples will help harmonise the situation for patients today. It was emphasised that the purpose of cross-border trials is not to encourage mass movements of patients between countries. Discussants said this is unlikely to happen in any case, as patients prefer treatment near home in a familiar environment. Cross-border trials add value to treatment in specific cases, such as rare diseases, where there are no local options left. At this point, the possibility to easily access new therapies in another country brings life-changing potential.

The study's research partners are now building on the results to prepare a call to action with guidelines for cross-border trials, hopefully moving toward EU legislation.

Spotlight session: Clinical trials across borders

Teodora Lalova, European Organisation for Research and Treatment of Cancer (EORTC): Overview of the study on issues and gaps related to cross-border access to clinical trials in Europe, by the European Forum for Good Clinical Practice (EFGCP), EORTC, KU Leuven and Patvocates, with support of the European Federation of Pharmaceutical Industries and Associations (EFPIA)

Panelist: Dr Ingrid Klingmann, European Forum for Good Clinical Practice (EFGCP)

Moderator: Jan Geissler, ECCO Patient Advisory Committee and CML Advocates Network



Teodora Lalova, European Organisation for Research and Treatment of Cancer (EORTC)



Artificial Intelligence for oncology

REVIEWING PRACTICE AND EVIDENCE OF ARTIFICIAL INTELLIGENCE, MACHINE LEARNING AND DEEP LEARNING IN ONCOLOGY.

Artificial Intelligence (AI) in cancer care has arrived and will transform healthcare roles and skills. Evidence and emerging practice are demonstrating that AI tools are a powerful assistant to oncologists, helping them improve the speed of diagnosis and data analysis – and ultimately the quality of care.

A competition between man and machine was organised in China two years ago, in an image analysis challenge pitting 15 radiologists against an artificial intelligence computer. The medical team had 30 minutes to interpret MRI data; the computer had 15 minutes. The computer won the contest.

Against this background, participants in the Artificial Intelligence session engaged in lively discussions on the future of medical professions in today's 'AI' age. One fact was confirmed: Artificial Intelligence already impacts every aspect of our lives. But concerns that machine learning and AI could threaten the value of interactions between healthcare professionals and patients were suggested as over-stated during the session. Indeed, time may well be freed for doctors and other healthcare professionals to spend more time with patients.

This session looked at the implications and benefits that learning algorithms have on the quality of care in respect to radiology and cancer screening. Looking to a near future where hospital radiology teams – already submerged with data to interpret – will be

KEY MESSAGE

The ability of Artificial Intelligence to analyse massive volumes of data and images will almost instantly free oncologists to focus on problem solving and to spend more time with patients. To unleash AI's full potential to improve discovery, research, cancer care and prevention, some key issues need to be addressed – including the ethics of storing patient data, and ensuring data quality and access.

faced with an increasing flood of information, AI tools can be a godsend, it was suggested.

So, rather than having a turf battle with the computer, discussants saw that radiology departments can benefit by harnessing these new tools to process massive volumes of information more efficiently. This frees radiologists to focus their knowledge on high-complexity interpretation. It also allows them to spend more time interacting directly with patients and other healthcare professionals, adding value and helping to personalise care to a greater degree than might otherwise be possible.

The panel's bottom line for AI and improved patient care: if a computer application can process and interpret millions of data points in seconds, it is an excellent right-hand assistant for oncologists. This also improves the quality of diagnostics, treatment decisions and targeted therapies, they said. The challenge is now to learn how to best harness this potential.

As Artificial Intelligence and its related techniques of machine learning and deep learning bring benefits, they will also require a rethinking of medical processes and practices. AI's disruptive effects on existing models of care were therefore discussed. Ethical concerns of processing and sharing large amounts of medical records and data were also raised. The use of AI needs to find a balance between protecting patients' data and unlocking the potential of these tools for learning and innovation – tapping their ability to process and compare vast amounts of data, almost instantly.

Recent evidence on AI, machine learning and deep learning in cancer care was presented in several case studies.

- » In medical imaging analysis a study assessed neural networking's ability to do complex analysis of MRI data to assess traumatic brain injuries. It concludes that the method has potential for use in a variety of research and clinical settings. The source code to this application is publicly available. <http://bit.ly/2ntwMiU>
- » A breast cancer study compared the ability of deep learning algorithms to detect metastases in images of lymph nodes of women with breast cancer, with pathologists' diagnoses. It found that the algorithms outpaced the analysis of 11 pathologists. This potential of improve diagnostic accuracy now needs assessment in a clinical setting. <http://bit.ly/2Op3E7k>
- » For skin cancer detection, a study compared the ability of neural networks to analyse more than 100,000 clinical images against some 2,000 diseases with the accuracy of 21 dermatologists. The algorithm classified skin cancer conditions at the same level of accuracy as the specialists. There then exists the exciting potential to link deep neural networks to mobile phones to benefit detection activities by patients outside the clinic. Looking at the estimated 6.3 billion smartphone users projected for 2021, this kind of innovation opens a wealth of options for low-cost universal access to diagnostic care. <http://bit.ly/2VldCbg>

Artificial Intelligence: Breaking down borders in cancer care in ways not yet known?

Led by the European Society of Radiology (ESR)

How is AI impacting cancer care today and what can we expect for future impacts?

Prof Ivana Isgum, Image Sciences Institute, UMC Utrecht: Artificial Intelligence in cancer care

Panel perspectives:

Saila Rinne, Programme Officer – EU Policies, European Commission DG CONNECT

Laura McDonald, Associate Director, Real-World Research, CORDS, Bristol-Myers Squibb

Dr William Allum, Consultant Upper GI surgeon, Royal Marsden NHS Foundation Trust, UK

Prof Vincenzo Valentini, Past President European Society for Radiotherapy and Oncology (ESTRO)

Dr Adrian Brady, Chair of the ESR Quality, Safety and Standards Committee

Moderators:

Prof Regina Beets-Tan, ECCO Board Member, EU Cancer Mission Board Member and 2nd Vice-President, European Society of Radiology (ESR)

Sema Erdem, ECCO Patient Advisory Committee and Europa Donna

“

I think AI will give us better focus, with better imagery of anatomy, as we will have better accuracy of where we need to operate. We could use also AI, to learn from the data of previous operations.

– Dr William Allum, consultant surgeon at the Royal Marsden Hospital

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From left: Prof Regina Beets-Tan, ESR; Prof Ivana Isgum, UMC Utrecht; Saila Rinne, European Commission DG CONNECT; Dr Adrian Brady, ESR; Laura McDonald, CORDS, Bristol-Myers Squibb; Dr William Allum, Royal Marsden NHS Foundation Trust; Prof Vincenzo Valentini, ESTRO; Sema Erdem, ECCO Patient Advisory Committee and Europa Donna





In conversation with Commissioner Vytenis Andriukaitis

PROGRESS AND ACHIEVEMENTS 2014-2019: UPDATE FROM THE EU COMMISSIONER FOR HEALTH AND FOOD SAFETY.

Dr Vytenis Andriukaitis, the outgoing EU Commissioner for Health and Food Safety shared his reflections on the achievements of the EU Health Programme in progressing the European health agenda for the 2014-2019 European Commission, and how he sees the future of cancer care and prevention.

Getting on top of cancer requires investment in research and innovation. Cancer is relentless. Nobody knows this better than the patients and survivors here today. But science is also relentless. And so is our collective determination to fight this disease. Europe has a massive amount of expertise, experience and data, and it is up to us to collaborate and make the most of the available tools.

When I took up my position as Commissioner for Health and Food Safety, I announced that cancer, promotion of health, protection and prevention would be one of my main priorities. Today, five years later, I am fully convinced of the need to tackle non-communicable diseases like cancer at their source.

KEY MESSAGE

Cancer is relentless. Nobody knows this better than the patients and survivors. But science is also relentless. And so is our collective determination to fight this disease.

Here is a summary of what we have achieved together in cancer prevention and treatment over the past five years.

EU Health Programme in action

The EU Health Programme has funded actions to reinforce cancer plans, address rare cancers, improve vaccination campaigns and promoted healthy lifestyles. We spend 3% of our resources on prevention. That is a drop in the ocean and we urgently need to increase this amount. But we can make sure that we spend our available funds most effectively, agreeing best practices that can be proposed to Member States with EU financial support.

The EU's Steering Group on Health Promotion, Disease Prevention and Management of Non-communicable Diseases is central to this effort. It identifies Member State priorities and highlights best practices that can be transferred, scaled up, and implemented with EU support. The Commission's Best Practice Portal is a powerful tool to share top quality practices across Europe; and the EU Health Policy Platform helps civil society and health professionals engage on public health concerns.

Promoting healthy lifestyles

The fourth edition of the European Code Against Cancer is a strong foundation for promoting healthy life choices as a cancer prevention strategy. I am delighted with current efforts of the European cancer leagues:

- » The Hungarian League Against Cancer ran a national roadshow explaining the European Code Against Cancer, reaching 23 million people.
- » In Ireland, the X-HALE programme supports youth organisations working for a tobacco-free generation.
- » Spain targets exercise and healthy diets messages on radio, television, public transport, and social media.
- » In Cyprus, teachers are participating in prevention efforts.

Tobacco control and reduction

Tobacco consumption has fallen. This is essential – it is the leading preventable cause of cancer and cancer deaths. Vital components of our effort to reduce tobacco consumption even further are the Tobacco Products Directive, the new European system for tobacco traceability, and the Framework Convention on Tobacco Control. This Directive is also the first comprehensive legislation regulating e-cigarettes. I encourage all stakeholders to participate in maintaining this momentum and to remain vigilant to new tobacco products entering the market.

Screening

Screening for cancer types such as breast, cervical and colorectal cancers is saving lives every day. Over the past decade we have seen continuous improvement in national screening; 25 EU Member States have screening programmes for breast cancer, 22 for cervical cancer and 20 for colorectal cancer.

Science and innovation networks

Cooperation on cancer research and innovation is growing. We have four European Reference Networks

for rare cancers, set up under the Cross-Border Healthcare Directive, that connect medical specialists across the EU. They hold vast potential for cancer treatment and today are bringing answers to patients with aggressive lymphoma, rare malignant sarcomas and rare heart tumours.

Clinical trials

Clinical trials are key drivers of medical innovation in oncology. During my mandate, we have taken important steps towards implementing the new Clinical Trial Regulation, adopted in April 2014. This Regulation aims to make Europe more attractive for all types of clinical trials, including cancer trials, while ensuring patients' safety and the reliability of the data, and safeguarding patients' rights. This opens the door to early patient access to innovative treatments.

As I come to the end of my mandate, I assure you that cancer will remain a priority for the next Commission. Our President-Elect Ursula von der Leyen has already asked my successor, Commissioner-candidate Stella Kyriakides, to put forward a European plan to beat cancer. Given Stella Kyriakides' extensive experience as policy maker and advocate in the area of cancer, you are in excellent hands.

In conversation with Dr Vytenis Andriukaitis, EU Commissioner for Health and Food Safety 2014-2019

Reflections on the achievements of the 2014-2019 European Commission mandate in helping countries combat cancer and assisting patients to receive optimal care and treatment



Commissioner Andriukaitis in conversation with ECCO's President, Philip Poortmans (left), and President-Elect, Matti Aapro (right)



Don't stop us now! The benefits of cross- border cancer care, where patients and knowledge travel easily

PHYSICIANS, RESEARCHERS AND PATIENT ADVOCATES MAKE THE CASE FOR LONG-TERM INVESTMENT IN CROSS-BORDER CANCER TREATMENT AND KNOWLEDGE EXCHANGE.

The EU Cross-Border Healthcare Directive was adopted eight years ago. Where are we today? This session's panelists and the audience reviewed progress, shared examples of what is working, and the challenges that lie ahead to make quality cross-border treatments a reality for all the patients that need them.

Update on Directive on patient rights in Cross-Border Healthcare

The European Commission's Directorate-General for Health and Food Safety gave an update in respect to the Cross-Border Healthcare Directive, originally passed in 2011. The current state of European Reference Networks and the challenges these groups face was reviewed. Naturally, most patients prefer treatment close to home. So the purpose of the EU's Cross-Border Healthcare Directive is not to spark mass movement of patients between countries but rather to address the reality that a significant number of patients face because of where they live, or for specific treatments available to them.

Today, seven million European citizens live in another EU country. Some 30% of the Union's population live

KEY MESSAGE

The EU Cross-Border Healthcare Directive is making cancer care across countries a reality. But major obstacles remain to achieving its full potential, including administrative barriers, low awareness of cross-border treatment options by patients and healthcare professionals, and GDPR issues that restrict sharing of patient data.

near a border area, where it is natural to seek services in the neighbouring country – including healthcare. A further 2 million people benefit from planned or unplanned healthcare in another country. Some seek treatment abroad; others may need help while on holiday or business travel.

The Cross-Border Healthcare Directive was intended to create a smooth experience for citizens seeking treatment in another country by improving arrangements in respect to recognition of medical insurance, and reimbursement and access to treatments in other countries. A growing number of citizens are making use of its provisions.

But there are challenges to giving patients a fully seamless treatment experience in another country. For example, many European citizens who are patients abroad are not aware of their rights provided by the Directive. Clearer information needs to be provided, said the discussants. Agreements are in place, but administrative obstacles remain in some countries, such as easy access to medical records.

It was highlighted that rare disease patients gain particular value from the Cross-Border Healthcare Directive's provisions. This gives such patients access to specialised skills and care that may not be locally



available. But some said that this potential remains untapped as not enough people know of these possibilities and how to access them. Some of the responsibility for improving transparency falls on national systems, who need to make cross-border rights better known to their citizens. Better access to information will open access to care for these patient populations.

See the European Commission's manual for patients' right to access healthcare in any EU country. <http://bit.ly/2VjpQkk>

As healthcare becomes more digital and data-driven, medical knowledge and services have new ways of being shared and travelling to where they are needed. This includes increasing opportunities for patients, including cancer patients, to receive more of their care and treatment at home and in the community setting.

Facilitating greater sharing of knowledge and expertise between countries and centres is among the core goals of the European Reference Networks established by the Cross-Border Healthcare Directive. Launched as an EU initiative in 2017, these are virtual networks that link healthcare providers across Europe. Amongst their aims are to boost the level of professional exchange and facilitate collaborative problem-solving opportunities in respect to complex cases for patients with rare diseases and cancers.

The focus of the European Reference Networks on rare diseases and cancers allows a concentration of knowledge and resources into specialised scientific and clinical areas that simply may not be possible otherwise, especially for smaller countries in the EU. 'Rare' or low-prevalence, complex diseases may have a small patient community per country, but from a European perspective they affect the daily lives of some 30 million EU citizens.

“

One participant commented:
*In ten years we will look back and ask,
how could we have done without this?*

”

Update on the first wave of European Reference Networks 2017-2019

The first wave of 24 ERNs now links 900 highly-specialised healthcare units in over 300 hospitals in 26 EU countries. They address thematic issues such as rare cancers, bone and blood disorders, childhood cancer and immunodeficiency. ERNs are currently in their start-up phase. The effort is now to embed them into national health systems.

ERN panelists in this session shared their experience of running first-wave ERNs, highlighting achievements and the challenges they see for further developing the Networks.

Challenges include the need to better embed the concept and value of cross-border healthcare within national systems. Long-term, secure and appropriate levels of funding are also required to truly realise the potential of the ERNs.

Many panelists highlighted and agreed on this need for standards and other underpinnings to support clinical data exchange between country health systems. Yet, conversely, they reported that GDPR data privacy regulation appears to be erecting new barriers to medical and patient data exchange. What is needed, they suggested, is a much better system of 'one-time consent' from each patient to make their data available. This will help cross-border digital health work better.

Further developments to focus on in respect to improving cross-border cancer care in Europe included: integrating cross-border healthcare concepts in national health systems and in national cancer plans; appropriate national cancer registration; cancer pathways linked to tumour boards in the country of origin; European S2 Cooperation for planned treatment in EEA countries; and customised information flows for the Clinical Patient Management System for digital records exchange, for example in cross-country case registration.

Colleagues from three pilot ERNs presented their activities:

- » **EURACAN** convenes the largest network of active EU centres managing patients with adult rare solid cancers such as sarcoma, rare brain and spinal cord conditions, rare neuro endocrine, skin, eye, thoracic cancers and others. <http://euracan.ern-net.eu>
- » The **EuroBloodNet** ERN shared its first experiences from its pilot phase. It links 66 multidisciplinary healthcare teams in 15 countries, including access to advanced specialised medical equipment and infrastructure. Together the EuroBloodNet centres address oncological and non-oncological rare hematological diseases including rare anemias, rare coagulation disorders, polycythemia, and myeloid and lymphoid tumours and rare hereditary hemochromatosis. Its members include the European Hematology Association, European Network on Rare and Congenital Anaemias, and several European Patient Advocacy Groups. <http://eurobloodnet.eu>
- » **PaedCAN** is the ERN for paediatric oncology. The network works to increase access to specialised know-how and paediatric oncology treatments. An example of its activity includes its cross-border virtual paediatric oncology tumour board network for sharing expertise and advice. <http://paedcan.ern-net.eu>

Accessing treatment across borders: Don't stop us now!

Hélène le Borgne, Caroline Hager, European Commission Directorate-General for Health and Food Safety

The way forward:

Prof Béatrice Gulbis, ERN EuroBloodNet

Dr Annalisa Trama, ERN EURACAN

Lejla Kamerić, Childhood Cancer International (CCI)

Moderators:

Prof Ruth Ladenstein, Project Coordinator, European Reference Network on Paediatric Cancer (ERN PaedCan), EU Cancer Mission Board Member

Anita Kienesberger, ECCO Patient Advisory Committee and Childhood Cancer International (CCI)

Hélène le Borgne, European Commission DG for Health and Food Safety





From left: Teodora Kolarova, INCA; Maria Krini, Cyprus Association of Cancer Patients and Friends; Dr Kim Linton, University of Manchester; Dr Detlev Parow, DAK-Gesundheit; and Dr Alexandre Lourenço, Portuguese Association of Hospital Managers

Reshaping our health systems around new technologies and patient needs

WHAT'S THE KEY TO A SUSTAINABLE HEALTH SYSTEM?

This session's wide-ranging discussion started with the question of the challenge for health systems to adapt to the new world of revolutionary treatments such as gene therapy and CAR-T cell therapy.

In its work on CAR-T cell treatment in the UK, a research team at Manchester University has been working with the national health system to understand what systems and processes are needed to deliver CAR-T therapies most optimally to patients. Looking at the workflow for CAR-T technology, it became clear to the development team that the ecosystem needed to deliver CAR-T and similar innovations to patients requires an entirely new approach, that health systems need to understand and adapt to.

It provides hope too. Some 50% of people suffering from Diffuse Large B-Cell Lymphoma are cured with chemotherapy and a further 10% with second-line treatments. But the remaining 40% face a bleak future. The CAR-T breakthrough treatment brings them new hope.

CAR-T is very different from standard cancers therapies. Each patient's T-cells are harvested by the

KEY MESSAGE

Treat the patient, not the cancer.
Let's have more focus on quality of life in this discussion.

research team and manufactured and returned to them for them in a personalised medication where their T-cells are modified and administered to bind to cancer cells and kill them.

This entirely new type of treatment has fundamental implications for the health system and services that are needed to support it. New skills, knowledge of the technology and an entirely new workflow and value chain need to be developed. In the UK, the drug currently treats a small patient population, with promising results. Its process of producing one individual therapy per patient is currently manageable. But to be delivered at scale to a national patient population, a rethink of the health system approach is needed.

But health system renewal is deeper than the need to adapt to the latest technologies, said the group. Looking beyond the revolutionary therapies, audience members and panelists discussed the payer, patient and hospital perspectives on what a next generation health system will look like. It was said that different approaches are possible. But all agreed that the system architecture and services need to be designed around the patient, which is not necessarily the case today.

The comments in summary:

The patient needs to be at the centre of any new approach. There's nothing new here. But discussants stressed the fundamental difference between 'considering' the patient's perspective – which can be brought by outsiders – and involving the patient and their needs in the design and decision-making process. One participant remarked that we can factor patient perspectives in our designs but we will never see the situation the way they do. For example, in addition to drug performance, they have practical questions such as: 'can I avoid queueing; why can't we have clean bathrooms...'

Innovation is about more than high-tech and cutting-edge science. It is about how we deliver sustainable increases in population health. Health services should include building health literacy to improve long term health in society. One participant asked: 'why aren't we doing one hour per week of health literacy in schools...alongside music and dance?, or educating the next generation about vaccines, diet etc.' These preventive strategies, at scale, will greatly improve population health and reduce pressure on the health system.

Other comments included: 'If we focus only on science and innovation, we miss the picture of what is needed to redesign healthcare. Patients see innovation as practical aspects of their treatment experience that go beyond technology solutions.'

Likewise, a hospital manager's example of new thinking is: 'how can we design a system that delivers healthcare services – not drugs or hospital care?'

The group concluded that new therapies and technologies are of great value to patients and society. But they go hand-in-hand with long-term strategies for prevention that improve population health and reduce the need for treatment and care. Like treatment, prevention should be a core health systems issue.

Concluding health systems considerations:

- » **Researchers** need to be driven by patient needs – from drug development to follow-up and data collection.
- » **Payers** need to understand what a fair price for a product is; or it will be difficult for them to make an informed decision.
- » **Hospitals and healthcare professionals** will strive to develop a common agenda with pharma, payers and patients.
- » **Patients** need to continually send messages to create fundamental system change that revolves around the patient. System change will come from more health literacy, education and prevention.

How does access to innovative cancer medicines fit in high-quality cancer care and a well-functioning health system?

Led by the European Cancer Leagues (ECL)

This session built on research of the ECL Access to Medicines Taskforce, on disparity in availability of cancer treatments in Europe, causes and areas for improvement.

Dr Kim Linton, Clinical Senior Lecturer, Division of Molecular & Clinical Cancer Sciences, University of Manchester: Delivering innovative cancer medicine in the modern health care system

Panel perspectives:

Dr Detlev Parow, Head of Patient Care Management, DAK-Gesundheit, Germany

Usman Khan, Executive Director, European Patients' Forum

Dr Alexandre Lourenço, President, Portuguese Association of Hospital Managers, Portugal

Moderators:

Teodora Kolarova, ECCO Patient Advisory Committee and International Neuroendocrine Cancer Alliance (INCA); **Maria Krini**, Research & Development Manager, Cyprus Association of Cancer Patients and Friends

Dr Kim Linton, Division of Molecular & Clinical Cancer Sciences, University of Manchester





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Clinical cancer research across Europe: Do we need to change tracks?

What does a better future for European clinical cancer research look like? For a clearer picture of what is needed, Europe's cancer research community needs to work together to define patient-relevant outcomes that are agreed by payers and regulators – then push for the best research to deliver them.

Exchanges in this session built on the report of the European Organisation for Research and Treatment of Cancer (EORTC): Manifesto for a new approach for better medicine in Europe. The widely endorsed manifesto presents key recommendations for reforming the treatment research paradigm in Europe, including a much-needed refocusing of attention to post-market approval research, including via use of real world evidence.

Panel members discussed the key role that access to data has in driving change in research and looked at obstacles to the open exchange of results for cancer research initiatives. They also considered how Europe's clinical cancer research models can better integrate the expertise of stakeholder groups such as patients and healthcare professionals.

The EORTC Treatment Optimisation manifesto was developed in consultation with cancer stakeholder group and is actively supported by a number of MEPs. It calls for reform of the current system to use a true patient-centred approach. Research design and execution need to respond directly to patients' real-world situations – for example: by comparing and sharing data on the effectiveness of treatment options and setting processes for long-term drug safety monitoring.

KEY MESSAGE

Treatment optimisation is a key research topic that the Manifesto's authors say should be included in the upcoming Horizon Europe Research Mission.

This thinking places treatment optimisation at the core of the drug development process, and the Manifesto's authors recommend that the treatment optimisation agenda form a part of the EU's Cancer Mission.

Along with the technical and scientific complexity of cancer research, programmes also need to respond to an ever-changing epidemiological situation. For example, lessons from the tuberculosis (TB) research community's response to drug resistance hold useful lessons for their cancer colleagues.

TB's public-private-partnerships deliver combined therapies to respond rapidly to resistance. A 'PPP' approach for cancer research can look beyond one-drug and condition to bring a 360 view of the problem – speeding innovation, as data is shared by clinicians, drug developers, diagnostics specialists, patients and healthcare professionals.

Developers' future research approaches, presented by the European Federation of Pharmaceutical Industries & Associations (EFPIA), are considering four strategies:

- » Data strategy to understand and support decisions across the healthcare value chain.
- » Digital strategy to increase speed of interaction, learning and communication across stakeholder groups.
- » Deeper patient engagement, to ensure that science and development questions are seen through the patients' eyes from the outset.
- » Increased collaborative research on common topics, where developers find ways to cooperate in a non-conflictual space.

Clinical cancer research across Europe: Do we need to change tracks?

Dr Denis Lacombe, Director General, European Organisation for Research and Treatment of Cancer (EORTC): Potential approaches for bringing new therapeutic strategies into being; proposed reforms to existing processes in Europe's regulatory environment

Dr Magda Chlebus, Executive Director of Science Policy, European Federation of Pharmaceutical Industries and Associations (EFPIA): What is required to make treatment optimisation a reality

Dr Ralf Herold, Scientific Officer, European Medicines Agency (EMA): EMA's response to evolving debates on new endpoints, continuing controversies and potential misunderstandings in this area

Panel perspectives:

Marcus Guardian, Chief Operating Officer, European Network for Health Technology Assessment (EUnetHTA)

Jo de Cock, Chief Executive Officer, National Institute of Health and Disability Insurance, Belgium

Moderators:

Dr Denis Lacombe

Roger Wilson, sarcoma survivor and patient advocate

*Dr Denis Lacombe,
Director General, European
Organisation for Research and
Treatment of Cancer (EORTC)*



The European Medicines Agency (EMA) presentation emphasised some of the possibilities that come from sharing of trial results and data. Overall, the Agency seeks to be supportive of treatment optimisation through activities it conducts in respect to post-market authorisation requirements. This means building learning processes into trial design, and encouraging research teams to rapidly capture and share their data to the benefit of all. For this sharing to work at scale, across dozens of concurrent trials in Europe, an integrated research data infrastructure is needed. However, many participants cautioned that sadly such an infrastructure remains quite lacking and that this should be addressed.

Data sharing issues sparked a lively exchange with the audience, on how to best manage data, who owns and curates it so that it is future-safe and accessible. Some suggested a European initiative, possibly linked to the European Reference Networks. Others felt that 'society' should be responsible for product and public registries of drug development data. But how to manage this? Is there an ISO standard for medical research data? These are all-important questions for the von der Leyen Commission, which has set data infrastructure for all economic sectors as a priority.

Manifesto for a new approach for better medicine in Europe. <http://bit.ly/33fiscO>





In conversation with Dr Blase Polite, Member of the American Society of Clinical Oncology Board of Directors

CHANGING PAYMENT SYSTEMS TO MEET THE 'TRIPLE AIM' OF BETTER HEALTH, BETTER CARE, LOWER COSTS

Europe's cost pressures on cancer care are not suffered in isolation. If anything, they may be reaching a tipping point rather sooner in the US, explained Dr Blase Polite of the American Society of Clinical Oncology (ASCO) Board of Directors, during a special 'In conversation with...' segment of the ECCO 2019 European Cancer Summit.

"Health insurance costs are continually increasing and this situation now constitutes a crisis and, as we all know, cancer is constantly in the spotlight when it comes to healthcare," he commented.

In less than 15 years, health insurance premiums in the US have risen by more than three times the rate

KEY MESSAGE

Put simply, quality in oncology care is: Right care, right person, right time, good outcome ...
... and sharing data and practice experiences as widely as possible.

of the average workers' salaries. In this light, Dr Polite joked that a definition of 'chutzpah' could be for an American oncologist to travel to Europe to lecture on the costs of cancer care. But solutions emerge from dialogue, he said, and from this perspective, answers to this common problem will emerge from open debate and discussion on the best ways forward, sparking new opportunities for shared learning and new approaches.

Reflecting on other aspects of the Summit programme that he attended, Dr Polite sensed a shared desire in Europe and the US to create cancer care systems that effectively direct resources to areas where their use delivers the highest value. But achieving this requires policy action that enables systems to better identify and avoid low-value treatments, and to develop mechanisms that reduce expensive but potentially avoidable costs. This includes, for example, avoiding presentation of cases at the emergency room and managing levels of inpatient hospitalisation and readmission.

Summarising, he commented, “It’s all about getting more for doing more. That is where we all have to go.”

Injecting quality management into clinical oncology care and practice is about more than guidelines, frameworks and quality audits. Dr Blase Polite shared the US experience on how new thinking on quality cancer care encourages continuous learning and improvement.

Dr Polite also spoke to the approaches developed in the US to help ensure quality of cancer care, giving the example of the ASCO Quality Oncology Practice Initiative (QOPI®). Looking at ECCO’s activity with OEI to encourage a more common approach to cancer care quality in Europe, Dr Polite highlighted the benefits that the global cancer care community can reap from future international cooperation in this area. “No matter where you live, in the US, Europe or elsewhere, a cancer patient should have the right to the same high-quality standard of care.”



From left: Emma Woodford, European Oncology Nursing Society (EONS); Dr Andreas Charalambous, EONS; Prof Klaus Meier, European Society of Oncology Pharmacy (ESOP); Prof Sergio Sandrucci, European Society of Surgical Oncology (ESSO); Anne-Marie Baird, Lung Cancer Europe (LuCE)



Specialisation in cancer care makes a real difference to patient outcomes and quality of life

Europe's debate on specialisation in cancer care is not new. But today's increased pace of research, sophisticated cancer treatments and the trend toward personalised medicine are bringing a new urgency for healthcare professionals to gain skills that are in tune with these innovations. More specialists are being trained, but their presence across all countries is uneven. To deliver optimal care, the need to ensure healthcare professions are given the opportunity required to develop specialised knowledge and expertise in oncology must be recognised and provided for.

This session explored workforce specialisation needs in cancer care. Panelists discussed the history of professional specialisation, the benefits it brings and the factors driving the need for oncology skills in the workforce. Case studies and examples were presented from oncology nursing, clinical pharmacy and the surgical profession.

Cancer treatment experts see a need for more specialised care across Europe. This is driven by the progress of research and innovation. Today's detailed knowledge of tumour biology, the advent of precision therapies, more sophisticated or combined treatments all call for new skill sets for clinicians, nurses, technicians and support staff.

The project Recognising European Cancer Nursing (RECaN), led by the European Oncology Nursing Society (EONS) and supported by the European Cancer Organisation (ECCO), is surveying how specialised cancer nursing benefits patients along their journey.

KEY MESSAGE

All national health systems need to ensure the provision of healthcare professions with specialised knowledge to truly provide the best cancer care to patients.

The RECaN project is revealing in clear terms the uneven distribution of specialised cancer nursing care across Europe. Yet the study is also demonstrating that cancer patients who do have access to specialised cancer nursing benefit from improved outcomes and higher quality of care.

Evidence from RECaN also demonstrates that care quality is increased if cancer nurses are core members of multi-professional oncology teams. For this to happen across the EU, the project calls on cancer nursing to be recognised as a specialised profession across Europe and supported by a common curriculum.

Three studies on specialised cancer nursing found that these specialists play a pivotal role in prostate cancer care – improving long-term quality of life and positive patient experiences. These nurses also contributed to increasing patients' knowledge of their conditions and improved self-management.

In the discussions, nurses were championed as the radar of what is happening in oncology wards, as they link patients' needs and feelings to the medical team. Further examples showed that nurses are more likely to build trusted relations with patients who confide in them, to advocate for patients' issues in the medical team. In these relationships patients know they are being heard.

Looking at the surgical profession, the discussion highlighted that every patient naturally wants to be treated by the best surgeon. The challenge then is how to make education and specialisation systems such

that all oncology surgeons are close to being ‘the best’ surgeon.

The surgical oncologist combines knowledge of surgical techniques with detailed experience on tumour biology. With these special skills they handle complex and unusual presentations of cancer and coordinate multidisciplinary cancer care teams. Examples of recent studies on oncology surgery specialisation show increased quality of care for patients of gastric, breast, head and neck cancer.

The European Society of Surgical Oncology’s (ESSO) recent 24 country survey found that 15 European countries have national surgical oncology societies and nine do not. To improve access to these specialists for all European cancer patients, several hurdles need to be overcome, including: a standard European approach to surgical oncology education, increased visibility for the profession, and concentrating surgical oncology skills in a small number of centres.

Summit delegates also heard how oncology specialisation for oncology pharmacists improves levels of care. This discussion showed that university studies, in respect to the initial pharmacy qualification, do not fully prepare pharmacists for the growing complexity of pharmaceutical treatment in cancer. In oncology wards, the pharmacist’s first challenge is to understand how these medications work. To bridge this gap, the first European Certification Programme for Oncology Pharmacy – European Specialization in Oncology Pharmacy (EUSOP) – was created. EUSOP is a 100-hour programme of webinars, e-learning modules, an Excellence Course for Oncology Pharmacy and national training sessions. Graduates receive a certification and the title of European Pharmacist in Oncology Pharmacy.

European Certification Programme for Oncology Pharmacy. www.esop.li/eusop.php
RECaN cancer nursing multi-country study. www.cancernurse.eu/research/recan.html

Specialisation in cancer care: It’s a cross-border issue

Dr Andreas Charalambous, President-Elect, European Oncology Nursing Society (EONS):
Overview – history of specialisation in cancer care, drivers and challenges to overcome; overview of RECaN cancer nursing multi-country study

Panel perspectives:

Prof Klaus Meier, ECCO Board Member, President of the European Society of Oncology Pharmacy (ESOP) and Chair of the ECCO Oncopolicy Committee
Prof Sergio Sandrucci, European Society of Surgical Oncology (ESSO)

Moderators:

Emma Woodford, Chief Operating Officer of the European Oncology Nursing Society (EONS)
Anne-Marie Baird, ECCO Patient Advisory Committee and Lung Cancer Europe (LuCE)



*Dr Andreas Charalambous,
President-Elect, European
Oncology Nursing Society (EONS)*



*Emma Woodford, Chief Operating Officer,
European Oncology Nursing Society (EONS)*



From left: Prof Sir John Burn, European Hereditary Tumour Group (EHTG); Prof Crispin Hiley, Francis Crick Institute; Prof Peter Schirmacher, European Society of Pathology (ESP); Dr Matti Aapro, ECCO President-Elect

Bringing molecular tumour diagnostics into real-life daily practice

Molecular tumour diagnostics have great potential to improve oncology care performance. But embedding them in Europe's health systems presents a range of challenges that policy makers need to understand and address. These issues were at the core of the discussions in this Summit session.

Molecular tumour diagnostics are bringing unprecedented levels of precision to cancer identification and care, and with this, fundamental changes to the oncology profession. These technologies analyse a person's genetic code, allowing healthcare professionals to deliver personalised therapies that work best for the individual patient – that are specific to their tumour type and condition.

For patients molecular diagnostics bring clear answers to questions such as: “Do I have cancer or am I at increased risk? What type of cancer do I have?” For oncologists and other medical professionals, these tools inform choice of the most effective medication per patient, and help determine how a cancer is likely to respond to it. They also help to indicate dosage levels and measure if a cancer is under control, or has returned.

Should molecular technologies be an essential requirement of cancer care? Presenters and panellists said yes. But they cautioned that many of today's health systems are not yet prepared to integrate

KEY MESSAGE

There is a lot of talk that the latest technologies can revolutionise cancer care. But this is not a revolution if most of the patient population is not reached – which is currently the case for molecular diagnostics. How can we create a situation where more people have access?

them. To make this a reality, countries need to better inform and educate their medical professionals on molecular approaches, embed new skill sets, and encourage a new data management and sharing culture in healthcare organisations.

Then there is the issue of cost: where patient advocates in this session cautioned against molecular diagnostics becoming a ‘supermodel’ option – that ‘... is lovely to look at, very costly, accessible only to a few, and with no real value to many.’

HIGHLIGHTS OF THE SESSION'S EXCHANGES:

How molecular diagnostics will change the health systems landscape

The power of next-generation sequencing needs molecular genetics to harness these technologies. It is clear, said some discussants, that the dialogue on next-generation sequencing needs to move out of academic forums and into the medical service world. Medical practitioners need to be better informed of these technologies, of what is available today and how medical professionals need to organise to tap their potential.

The presentations highlighted that some oncologists have not embraced molecular diagnostics simply because they do not know about these technologies. One participant commented that some oncologists are not necessarily thinking of molecular biology as they are unaware of the benefits it provides. Likewise, many of today's medical professionals are unaware of how fundamentally molecular diagnostics will change the way they work and improve diagnosis and treatment. So more effort is needed to inform them of the technologies available and the changing landscape.

These technologies will generate a flood of new data, which will only be useful if the skills and infrastructure are in place to manage and interpret it. It is likely that for health services, the value of molecular diagnostics will be defined by how rapidly and accurately they can interpret the data they generate.

The data challenge goes beyond skills and infrastructure. A cultural shift is needed in health systems to make data sharing standard practice. The example was given of a multi-country group that organised the sharing of 45,000 data sets on different cancer types. In addition to the complexity of managing and interpreting it, the partners took 18 months to reach a data sharing agreement. Cases like this illustrate that innovation in diagnostics relies on innovation in process simplification at different levels in the health system.

Just as the medical professional needs to adapt, regulators also need to be brought up to speed with the changing landscape that molecular diagnostics and personalised medicine are bringing. Here, key questions are: what are the implications of these changes for the health system, and how does it need to evolve to handle them?

For regulators, the question is how to make guidelines integrate these new diagnostics into the health system most effectively. For the European Union, the European Medicines Agency (EMA) has developed a new focus on companion diagnostics. It specifies how diagnostics are used in tandem with a drug to determine how it applies to a specific person, their type and condition. Where the US FDA licences specific tests required for this process, the EU framework does not regulate diagnostics or systems. Its 'guideline' approach describes the results to be achieved and requires that the tests used are described in the reporting.

An EMA concept paper was the starting point for a consultation on the development and lifecycle of personalised medicines and companion diagnostics, to assess the most likely response to a specific treatment. <http://bit.ly/2DAKxk7>

Hereditary cancer diagnosis

Participants also heard perspectives on hereditary cancer and how molecular diagnostics can improve the situation for patients at risk of inherited oncological conditions. GENTURIS is the European Reference Network on hereditary cancers. It serves all patients affected by one of the rare genetic tumour risk syndromes, needing specific treatment and follow-up. <http://bit.ly/2DCraaE>

Given the hereditary nature of these conditions, ERN-GENTURIS takes a family-based approach. It focuses on the patient and their relatives who may also be at risk. Its services focus on improved identification of people living with a genetic tumour risk syndrome; developing evidence-based clinical guidelines; and providing access to a range of resources and information.

Dr Matti Aapro, ECCO President-Elect and Board Member of the European School of Oncology (ESO)





Patients: opening equitable access to molecular diagnostics

The patient perspective was a recurring theme in these discussions. Patient advocates commented that there is much talk about new technologies that are revolutionising cancer care and patient experience. But this cannot be called a revolution if the technology does not reach most of the patient population. Which is currently the case for molecular diagnostics.

How to make molecular tumour diagnostics a reality for all patients? Panellists see that the European situation for progressing access to molecular tumour diagnostics is on a good path – thinking and practice are moving toward recognition of high-performance personalised medicine. It also helps that molecular testing is well-established in other cancer areas such as Chronic Myeloid Leukemia (CML) – which has 20 years of experience to share.

CML can be a model for other areas of cancer diagnostics. It has a broad patient population that has equitable access to these technologies. Today CML patients benefit from frequent testing, that allows detailed tracking of their illness. This means that 25% of CML patients are identified as in remission and can be off treatment and be closely monitored with molecular diagnostics for changes in their condition.

As these technologies become more integrated in oncology practice, the good news is that their cost is expected to plummet. One delegate put this in a practical context, commenting that, even as costs fall, one aspect will continue to remain prohibitively expensive – misdiagnosis. This is an area where molecular approaches are likely to bring improvements to health systems.

Molecular tumour diagnostics in cancer care: should they be an essential requirement?

Co-led by the European CanCER Organisation (ECCO) and the European Society of Pathology (ESP)

Prof Peter Schirmacher, European Society of Pathology (ESP): Molecular tumour diagnostics potential, needs and challenges

Jan Geissler, CML Advocates Network and ECCO Patient Advisory Committee: Molecular tumour diagnostics in cancer care: should it be an essential requirement? A patients' perspective

Prof Koen Norga, European Medicines Agency (EMA): Regulatory framework for companion diagnostics and medical devices

Panel discussion perspectives:

Prof Sir John Burn, European Hereditary Tumour Group (EHTG)

Prof Crispin Hiley, Radiation Oncology Consultant & Associate, Francis Crick Institute, UK

Prof Fatima Carneiro, University of Porto

Moderators:

Prof Peter Schirmacher

Dr Matti Aapro, ECCO President-Elect and Board Member of the European School of Oncology (ESO)

Anne-Marie Baird, ECCO Patient Advisory Committee and Lung Cancer Europe (LuCE)



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Acknowledgements

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We would like to thank the following organisations and companies for their support and fruitful cooperation which made the ECCO 2019 European Cancer Summit a success and look forward to continuing these partnerships to achieve our shared goals.

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From left: Prof Philip Poortmans, ECCO President; Mike Morrissey, ECCO Chief Executive; Dr Matti Apro, ECCO President-Elect

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