

Accelerating Momentum: A manifesto to 2030

European Cancer Summit Report



15–16 November 2023 Brussels and Online

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Foreword

In November 2023, the European Cancer Organisation (ECO) convened experts, policymakers, and advocates who all came together at the European Cancer Summit in Brussels to address critical issues in cancer care in the midst of a world in 'perma-crisis'.

A focal point of this year's Summit was the launch of the European Cancer <u>Manifesto</u> 2024, titled 'Time to Accelerate – Europe Together Against Cancer.' The Manifesto outlines priority areas for EU cancer policy, emphasising a collaborative approach that candidates in the upcoming European Parliament elections can endorse. The Manifesto was officially launched during the European Cancer Summit session joined by the EU Commissioner for Health and Food Safety Stella Kyriakides.

'Accelerating Momentum' highlights the cancer community's determination to go further, faster, together by addressing challenges in cancer care policy and thus significantly improving outcomes for patients. Europe's Beating Cancer Plan is the opportunity of a lifetime. It has already produced a variety of new cross border projects to better care for cancer patients and survivors. But, together, we need to do much more – and much more quickly. A new European Parliament will be elected in June 2024, and the Manifesto reflects the specific proposals received from the European Cancer Organisation's member societies and patient groups. We need to set clear deadlines for tangible progress. Cancer won't wait. So why should we?



Andreas Charalambous European Cancer Organisation President 2022–2023



Kathy Oliver Summit Programme Co-Chair European Cancer Summit 2023



Winette van der Graaf Summit Programme Co-Chair

European Cancer Summit 2023

Read the full report to discover the rich and diverse discussions from the 12 sessions of this year's Summit, attended by over 450 delegates in-person and even more participating online.



Save the Date: The next European Cancer Summit takes place on 20 & 21 November 2024

Cancer Services in Crisis Situations

Mirjam Crul and Mark Lawler, Co-Chairs of the Special Network: Impact of Covid-19 on Cancer

The session description with the full speaker list is available here.

Today, we find ourselves in a state of perpetual crisis, encompassing pandemics, wars, conflicts, environmental catastrophes, and strained public resources. Each of these factors has the potential to disrupt cancer care. However, we have also witnessed remarkable resilience and collaboration among countries, groups, and individuals, as demonstrated during the Covid-19 pandemic and Russia's invasion of Ukraine.

This opening Summit session identified key lessons learned and how to better ensure continuity in cancer care and cancer research during times of crisis. Emphasising the need for collaborative efforts across Europe, it is important to turn difficult challenges into tangible opportunities.

At times like this, it is essential to be solutionfocused, ensuring a rapid and flexible response to any crisis. Our mission is also to inform politicians about the realities 'on the ground' so that they can deliver optimal care for their constituents. Two critical aspects of the Manifesto were highlighted in this session: learning from the cross-border impacts of the Covid-19 pandemic and addressing the ongoing situation in Ukraine. The focus is on working with EU agencies and fast-tracking support for Ukraine, including the rebuilding of cancer care services and infrastructure.

Navigating an unhinged world

We are currently witnessing the most rapid expansion of conflicts globally since World War II. We are facing humanitarian challenges unprecedented in recent history. Last year alone, saw a staggering 45% increase in conflict-related mortality across sub-Saharan Africa. Half of the countries in the region are currently embroiled in some form of armed conflict. Notable conflict zones include Sudan, Mozambique, the Sahel region, Ethiopia, and Mali.



From left to right: session Co-Chairs Mirjam Crul, Mark Lawler and panelists Richard Sullivan, Nelya Melnitchouk and Ulrika Årehed Kågström



On screen: Nataly Hrad, Ukrainian Cancer Patient

In this 'unhinged world', regions are facing both permanent crises and poly-crises. 'Permanent crisis,' such as those in Libya and Syria that have persisted for years, result in continuous violence and conflict-related morbidity and mortality. Adding to the complexity is the emergence of 'poly-crises', with new intrastate conflicts, causing the destruction of health infrastructure and the displacement of healthcare professionals.

Maintaining cancer care in conflict zones proves challenging, as the traditional UN system lacks a standard operating model for such a situation. The complexities of delivering hospital-based care in expensive and difficult circumstances underscore the need for innovative, on-the-fly solutions.

Mark Lawler

Session Co-Chair and Professor of Digital Health Queen's University Belfast

'It is critical that we collect appropriate data intelligence to determine what the situation is 'on the ground' in crises situations. We need to act decisively based on reality, not opinion.'

The aftermath of conflicts raises questions about reconstructing cancer care systems. Drawing lessons from past conflicts such as the Balkans wars, the crucial role of healthcare professionals was highlighted. Professionals are often forced to leave conflict-torn regions, and addressing this issue becomes integral to rebuilding effective healthcare systems. A critical concern is the lack of a standardised approach for delivering cancer care to the approximately 104 million conflict-displaced populations. This challenge extends not only to those displaced across borders, but also to those displaced within countries.

International solidarity and collaboration are crucial in this context. Learning from emergency responses within the European Union is desperately needed. The EU and UN's creation of necessary operating models for cancer care amid conflict and overall humanitarian relief efforts, as well as plans for the reconstruction of healthcare systems in post-conflict scenarios is essential.

While the current scenario may seem daunting, solidarity within the cancer community (healthcare professionals, patients, policy makers, NGO's, EU, and UN agencies, etc.) is crucial for learning and preparing for the challenges that lie ahead. The Summit serves as a platform to unite our strengths in the face of an unhinged world and collectively shape a more hopeful future.

Resilience beyond borders: navigating both war and cancer

In a poignant presentation, a former linguistic professor, now a refugee and cancer survivor, shared her extraordinary journey from Ukraine to Poland amid the dual challenges of war and stage 4 Hodgkin lymphoma. Just weeks before the conflict erupted, Nataly Hrad received the lifealtering diagnosis.

The Russian invasion of Ukraine added another layer of complexity, disrupting her fertility preservation plans and forcing a move to western Ukraine, where overwhelmed cancer centres struggled to meet the growing demand from displaced patients.

Faced with a critical shortage of treatment options, Nataly turned to international organisations for help. Through Youth Cancer Europe, she found a lifeline to treatment in Poland. Despite the formidable hurdles of undergoing chemotherapy in a foreign country - with language barriers and difficulties retrieving medical records she expressed gratitude for the support she received from patient organisations and cancer communities that played a pivotal role in her recovery. Nataly's story underscored the strength found in collaboration, leaving the audience with a powerful reminder that collective resilience is the key to overcoming seemingly insurmountable challenges. The room erupted in a heartfelt standing ovation, recognising her courage and the profound impact of solidarity in the face of adversitv.

Survey sheds light on cancer care in Ukraine

The much-anticipated results of a recent survey on cancer care in Ukraine were unveiled at the Summit by Nelya Melnitchouk, Founder and CEO, Global Medical Knowledge Alliance. Conducted in October 2023, the survey examined the challenges faced by Ukrainian cancer patients in accessing diagnosis and treatment during the war.

Richard Sullivan

Co-Director, Conflict & Health Research Group, Institute of Cancer Policy & Kings College, London

We must reflect on the education of our healthcare professionals, to prepare them to address the humanitarian needs of our world. Many young individuals entering the medical field are passionate about contributing to global well-being yet lack essential training in humanitarian medicine. Medical training should involve global health studies, encourage practical experiences in different countries, and instil a deep understanding of humanitarian medicine. It should encompass ethical considerations and international humanitarian law, as well as medical techniques, to provide a comprehensive skill set.'



On screen: Arman Kacharian, Head of the Innovations Expert Group, Ministry of Health of Ukraine

The survey, encompassing 552 patients from four cancer centres in Ukraine, highlighted significant issues, including long waiting times (reported by 60% of patients) and out-of-pocket payments for essential imaging modalities (reported by 61% of patients). 30% of patients reported they are covering the cost of instruments, supplies and medications. Despite these challenges, 60% of patients began treatment within one month. However, the survey underscored the impact of the war, with 5% of patients reporting delays in treatment initiation, and higher percentages in regions closer to the front lines.

The statistics served as a stark reminder of the ongoing challenges of cancer care in Ukraine and prompted a call for collective efforts to: ensure the availability of systemic chemotherapy drugs; prevent interruptions in treatment; and support comprehensive cancer control plans, in line with the Manifesto, focusing on screening and quality control within Ukraine.

Ukrainian resilience: providing cancer services amidst war

In a virtual address, Arman Kacharian, Head of the Innovations Expert Group at Ukraine's Ministry of Health, explained the many obstacles faced by the country's healthcare system, particularly in maintaining cancer services during the war.

The presenter outlined three major challenges: safety concerns due to attacks on healthcare facilities; difficulties in securing and distributing medical supplies; and the 'identification crisis'; many patients lost their medical records when they moved. Despite these challenges, he highlighted three crucial factors that contributed to the survival of Ukraine's healthcare system: the protection of the Ukrainian army; support from reliable international partners offering humanitarian aid; and the resilience of Ukraine's healthcare system, driven by its commitment to universal health coverage. The presentation underscored the critical role of external support in sustaining the healthcare system through these tumultuous times.

Kacharian expressed gratitude for the aid received and emphasised the importance of ongoing support from European and US partners. The message conveyed the indispensable nature of international assistance in ensuring the survival of Ukraine's healthcare infrastructure, affirming that cancer services must not become casualties of war.

Redefining emergency healthcare to include cancer care

During crises, healthcare is endangered, and medical staff is put under huge pressure. Infrastructure is destroyed or damaged by war and healthcare professionals are killed or leave the country. Those who remain have difficulty responding to the increased needs within the collapsed systems. In this context, cancer care is not considered emergency healthcare. But it should be.

Displaced patients, both within countries and across borders, face specific hurdles including discrimination and fewer rights than they enjoyed Ulrika Årehed Kågström President-Elect, Union for International Cancer Control (UICC)

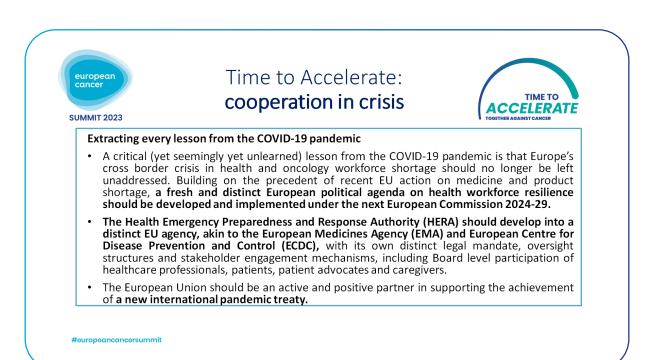


'We need to redefine emergency healthcare to encompass vital cancer treatment.'

at home. The need to redefine emergency healthcare to encompass vital cancer care emerged as a focal point, challenging the current paradigm that primarily addresses immediate necessities such as water, food, and shelter. Legal impediments preventing the swift import of crucial medicines and medical equipment constitute critical barriers that demand legislative amendments.

Other challenges include managing 'donor fatigue' and matching donor supplies to real needs on the ground.

Despite the challenges, the collective commitment of the cancer community that rallied to support Ukraine after the Russian invasion is a positive example of how cancer organisations can make a difference. As well as ensuring that cancer care continues throughout the conflict, the cancer community should look at how it can help rebuild infrastructure and support healthcare workers once the war ends.



Conclusions

In navigating the current era of 'poly-crisis', where pandemics, conflicts, and strained resources pose significant threats to cancer research and care, this session underscored the need to learn from recent crises. Disruptions witnessed during the Covid-19 pandemic and Russia's invasion of Ukraine, among other conflicts, highlight the vulnerabilities of our healthcare systems. However, the silver lining lies in the technical means available for countries, groups, and individuals to offer mutual support. Now, more than ever, it is essential to identify and highlight these lessons and enhance our readiness to deliver effective cancer research and care during crisis situations by creating standard operating procedures and training staff on humanitarian medicine. By fortifying collaborative efforts, we can ensure the continuity of vital cancer services in times of unprecedented challenges.

KEY POINTS FROM THE SESSION

- There is an urgent need for standard operating models for handling cancer care amid conflict and humanitarian relief efforts, as well as plans for the reconstruction of healthcare systems in post-conflict scenarios.
- Emergency healthcare must be redefined to encompass vital cancer treatment and care.
- Legal impediments affecting the swift import of crucial medicines and medical equipment constitute critical barriers that demand legislative amendments to facilitate faster responses to urgent healthcare needs.
- Training of healthcare professionals should involve preparation in humanitarian medicine.

FIND OUT MORE

- European Cancer Manifesto for 2024
- ECO-ASCO Special Network: Impact of the War in Ukraine on Cancer
- European Cancer Pulse

Turning Up the Dial: Advancing the Elimination of HPV and Hep B Cancers

Daniel Kelly and Margaret Stanley, session Co-Chairs of the <u>HPV Action Network</u>

The session description with the full speaker list is available here.

Europe's Beating Cancer Plan has spurred efforts to achieve the ambitious goal of eliminating HPV cancers. Collective action, reinforced by political, societal, and funding support, are still needed to realise this goal. The European Centre for Disease Prevention and Control (ECDC) could play a crucial role in helping track vaccine uptake and providing wider indicators of success and progress. Success stories and opportunities for cooperation emphasise the crucial role of implementing gender-neutral HPV vaccination systems and robust screening and treatment policies. The session featured updates from the HPV Action Network, testimonials and calls for tracking progress, wider indicators of success, and aligning HPV cancer elimination with broader health goals.

Laura's legacy: A mother's crusade for HPV vaccination

In a poignant presentation, Bernie Brennan, the mother of the late Laura Brennan, an advocate for HPV vaccination, shared the heart-breaking yet inspiring journey of her daughter. Diagnosed with terminal cervical cancer at a young age, Laura transformed her personal battle into a fierce advocacy for the HPV vaccine.

Through media campaigns, Laura's relatable voice significantly increased vaccine uptake in Ireland from 51% to over 80%. A <u>video</u> featuring Laura herself, underscored the human side of the argument and the importance of preventing such tragedies through vaccination.

Bernie Brennan Mother of Laura Brennan, HPV Vaccination Campaigner





'HPV vaccine saves lives. If Laura had received it, she would still be alive today.'



On screen: Margaret Stanley. Panelists from left to right: Joakim Dillner, Bernie Brennan, Neil Datta, Daniel Kelly (session Chair), Emilie Karafillakis, George Zaki

Laura's testimony highlights the crucial role of collaboration among governments, healthcare professionals, educators, and community stakeholders in promoting vaccine awareness to combat HPV-related cancers.

Mapping HPV across Europe

The <u>HPV Prevention Policy Atlas</u> is a research project led by the <u>European Parliamentary Forum</u> for <u>Sexual and Reproductive Rights</u> (EPF) and the European Cancer Organisation. It assesses how European countries perform across three key areas: primary prevention of HPV (vaccination), secondary prevention (screening); and reliable, accessible online information about HPV, cervical cancer, and vaccination.

The tool provides up-to-date, publicly available information across all countries of the WHO European region, in line with the <u>WHO Cervical</u>. <u>Cancer Elimination Strategy</u> and <u>Europe's Beating</u>. <u>Cancer Plan</u>.

HPV-related cervical cancer is a preventable and curable disease. Yet every year, more than 25,000 women die from it in Europe. The HPV Prevention Policy Atlas scores 46 countries throughout Europe on cervical cancer screening, HPV vaccination programmes, and online information, which reflect political will in the fight against cervical cancer.

A main goal of the EPF is to make sexual and reproductive issues (including contraception, reducing maternal mortality, abortion, and fertility) understandable to politicians. They in turn should make the voices of citizens heard and can lead the development of policies and legislation. EPF currently works with 556 members of parliament across Europe.



Neil Datta, Executive Director, European Parliamentary Forum for Sexual and Reproductive Rights



On screen: <u>Video of Laura Brennan</u>

Benchmarking countries on government policies leads to improved policies. That is why the HPV Prevention Policy Atlas was developed. The Atlas looks at a range of criteria, scoring each country from zero to 100 and then attributing a colour to each, using the traffic light system. It goes from dark green (very good) to dark red (not doing well).

Ireland – supported by Laura's legacy – is among the best scoring countries in Europe, together with Denmark, Sweden, Finland, and the UK. These countries have primary prevention, recommendations, funding for HPV vaccination, gender-neutral vaccination, HPV vaccine registries, and a high vaccine coverage rate (VCR) for both boys and girls. On secondary prevention they offer free population-based screening, self-sampling, PAP, and HPV tests. Finally, good online public information is available. This is crucial to combat disinformation and vaccine hesitancy.

Sweden's successful journey in preventing cervical cancer

Sweden's remarkable progress in the prevention of cervical cancer, as highlighted in the HPV Prevention Policy Atlas, is an example for others in implementing comprehensive policies. The country has set an ambitious goal to eliminate cervical cancer by 2027, demonstrating a proactive approach to combating the disease.

Sweden's success is attributed to a strategic vaccination programme with high population coverage. The programme began with extensive information campaigns, as well as promoting and subsidising vaccination which resulted in 25% greater coverage. A second campaign – featuring personalised invitations with a time and venue for vaccination – reached 55% coverage. Personalised school-based invitations for HPV vaccination have resulted in a remarkable 90% coverage.

Notably, Sweden's commitment to genderneutral vaccination for both boys and girls, along with an extensive catch-up vaccination (up to 29 years), showcases a comprehensive and inclusive approach. The country's success is substantiated by data linking the nationwide vaccination registry to a cancer registry, revealing an 88% protection against invasive cancer and a significant reduction in major oncogenic HPV types, indicating a promising trajectory towards the goal of eliminating cervical cancer by 2027.

Navigating vaccine hesitancy

HPV vaccine acceptance is crucial to cervical cancer elimination. While vaccination campaigns often revolve around the safety and efficacy of vaccines, the current prevalence of vaccine hesitancy, particularly in the form of emotional decision making, is a hurdle on the road to eliminate cervical cancer.

Understanding the subjective nature of how information is interpreted and influenced by cultural, religious, and social factors, is vital to communication campaigns. Drawing on historical examples from Japan, Ireland, and Denmark, where misinformation challenged vaccine programmes, a nuanced approach to address the root causes of hesitancy is recommended.

Three key strategies are identified to effectively address vaccine hesitancy. Firstly, acknowledging the evolving online information environment and the limitations of simply debunking myths or restricting online misinformation. Social media algorithms bring up information that confirms biases. The emphasis shifts towards empowering young people with the skills to critically assess online information, fostering a sustainable solution to misinformation. Secondly, the importance of creating a space for dialogue and listening to the concerns of vaccine-hesitant individuals is highlighted. Instead of blaming, the approach advocates empathy and understanding. Finally, the creation of an environment that promotes informed decision making through proactive communication and community engagement is necessary. Sustained efforts, beyond crises or drops in vaccine coverage, are critical.

Optimising data systems for vaccination

There are three critical questions when assessing a country's vaccination landscape: government commitment to the elimination of HPV-related cancers; the ease of accessing vaccines and screening; and the availability of data to track progress. While acknowledging positive shifts in government attitudes and efforts to improve vaccination rates, it is important to ensure that these improvements translate into tangible advancements in the collection and dissemination of relevant data.

Joakim Dillner Director of Research & Development, Medical Diagnostics Karolinska



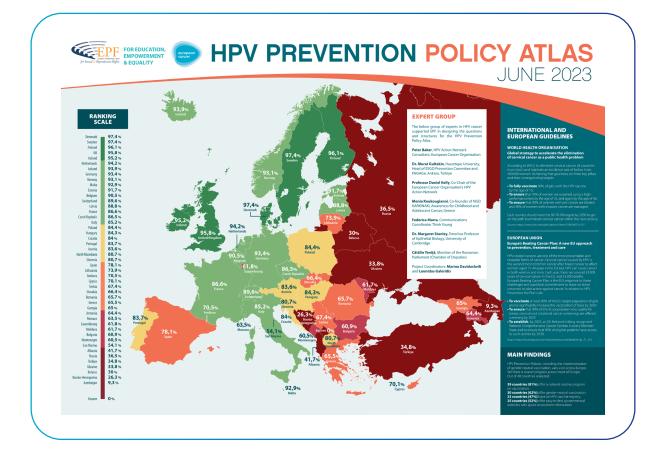
With gender-neutral HPV vaccination it is much easier to achieve population immunity and it is also more stable, with a lower risk of backlash.

France's bold reforms, introducing school vaccination programmes and allowing pharmacists to administer HPV vaccines, are strategies improving vaccination rates there. In Eastern Europe, some countries are looking for innovative solutions of their own, such as Croatia's transition from paper to e-consent, resulting in a substantial increase in vaccination coverage rate. Nevertheless, the data speaks of big vaccination coverage disparities between cities in Croatia. This underlines the crucial role of transparent data in showing the gaps and driving change. We must advocate for collection and transparency of public data to address inequalities within countries.

Learning from – and applying – successful, simple solutions, fostering dialogue among stakeholders, constant advocacy, and promoting partnerships will help increase HPV vaccination in 'red zone' regions. Retrieving data and sharing it transparently is an integral part of the process. It contributes to ongoing efforts to enhance global data systems for vaccination.

Conclusions

Many successful strategies have been tested in the global effort to combat cervical cancer through HPV vaccination. From advocacy and data transparency, to overcoming hesitancy and simplifying vaccination systems, diverse approaches taken by countries worldwide provide examples for other nations. The key takeaway is the need for a comprehensive, collaborative, and adaptive approach, leveraging successful strategies and learning from one another to eliminate HPV-related cancers in the next decade. The success of hepatitis B vaccination in reducing associated cancers, was also highlighted, with a call to reach marginalised groups such as migrants and drug users to ensure broader public health impact. High coverage and participation in both vaccination and screening are necessary to eradicate hepatitis B.



Time to Accelerate: the elimination of vaccine preventable cancers



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Annual reporting on progress towards eliminating HPV and HBV cancers elimination

Tools should be enacted to improve monitoring and reporting towards HPV and HBV cancer elimination, including:

- Mandating the European Centre for Disease Prevention and Control to put in place a monitoring system for HPV and HBV vaccine uptake across the EU, similar to systems created during the COVID-19 pandemic for real time vaccine uptake information.
- Helping EU Member States to achieve greater commonality in national immunisation registry systems to support timely monitoring and tracking, ensuring data-driven decision-making.
- Reporting on other indicators of success and progress, including:
 - vaccination rates according to indicators such as primary, catch-up cohorts, and adult and at-risk groups;
 - accessibility to vaccination programmes, including locations from which vaccination can be obtained (e.g. schools, pharmacies, etc);

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KEY POINTS FROM THE SESSION

- Remember the patient stories behind the data.
- Gender-neutral HPV vaccination is critical.
- Address vaccine hesitancy with empathy, considering emotional, social, and religious aspects.
- Educate young people to detect and manage online misinformation.
- Use real world data to identify opportunities to increase HPV vaccination.

FIND OUT MORE

- European Cancer Manifesto for 2024
- HPV Action Network
- HPV Prevention Policy Atlas 2023
- Laura's Legacy
- Europe's Beating Cancer Plan

No Letting Up: The Next EU Agenda for Prevention, Early Detection and Screening

Torsten Blum and Isabel Rubio, Co-Chairs of the <u>Prevention, Early Detection and Screening Network</u>

The session description with the full speaker list is available here.



While progress has been made updating cancer screening recommendations and multi-cancer early detection, more needs to be done on comprehensive strategies, from food and alcohol labelling to asbestos regulation and monitoring environment pollution.

The European Cancer Organisation's Manifesto states that it is time to accelerate cancer prevention. This includes encouraging national legislation to raise the European minimum age for tobacco to 21; mandatory health warnings on alcoholic beverages and nutritional labelling; regulation on sunbeds as medical devices and awareness campaigns on the risks of UV exposure, among other necessary measures. Projects are needed to support countries in achieving these goals. Ensuring access to counselling and supporting the development of an EU Atlas for early cancer warning signs are other highlighted priorities.





From left to right: Session Co-Chairs Torsten Blum, Isabel Rubio and panelists Marcis Leja, Zorana Jovanovic Andersen, Mariano Suppa, Ivana Dragojević, Michael Oberreiter, and Alessandra Moretti MEP

Advancing cancer screening in Europe

Much has been accomplished in the implementation of breast, cervical, and colorectal cancer screening programmes in Europe since 2003. The 2022 update of the European Council's recommendation on cancer screening is also a major new stimulus. However, it is imperative that these programmes adhere to quality assurance and professional guidelines, acknowledging that not all criteria are uniformly implemented today.



Newly recommended screening programmes include lung, prostate, and stomach cancer. Ongoing screening projects like <u>SOLACE</u> for lung cancer, <u>PRAISE-U</u> for prostate cancer, and <u>TOGAS</u> for stomach cancer will help overcome identified bottlenecks and address health inequalities in different European countries. They will also help provide individualised screening approaches at national or regional levels.

To achieve equality in cancer screening across Europe, addressing sustainability, leadership training, quality assurance, and comprehensive data collection are imperative. The European cancer information system, set to collect data from across European countries, highlights the need for new strategies and technologies. The Joint Action on screening implementation, currently under evaluation (with extensive EU and non-EU participation) will not be a panacea. While it will generate additional data, there is an urgent need to implement the findings to make a tangible impact.

Updated European Cancer Pulse: tracking inequalities in cancer

The updated <u>European Cancer Pulse</u> is a pivotal tool to inform policy action based on data. The tool sheds light on inequalities throughout the cancer pathway, emphasising gender, socioeconomic status, and other determinants. This comprehensive view informs researchers and policymakers, guiding effective actions to address disparities in prevention, research, diagnosis, and access to treatment.

The European Cancer Pulse achieves several key objectives:

- It provides easy public access to a wide range of currently fragmented intelligence on cancer Inequalities
- It amplifies data and initiatives from across the cancer community, collaborating with the EU Cancer Inequalities Registry and other European partners
- It pinpoints stark differences in progress across and within European countries in areas such as cancer prevention, screening, and tobacco control policies, underscoring the Pulse's crucial role in guiding policy actions that can mitigate inequalities in care, quality of life, and survival



The tool demonstrates the implementation of screening programmes across Europe and highlights the need for more comprehensive data to drive positive change. Efforts are underway to develop a Cancer Screening Implementation Policy Index, to provide a single measurement of country progress toward implementing recommended screening programmes. Ongoing pilot studies, including those in prostate cancer through the PRAISE-U project, are integral to this initiative, with plans for expert review and data gathering to further enhance the index's effectiveness.

Clearing the air: urgent call for stricter standards on air pollution

Air pollution is a significant risk factor for cancer and other serious illnesses, including diabetes, Covid-19, neurological conditions, and cardiovascular diseases. The International Agency for Research on Cancer (IARC) has classified air pollution, particularly particulate matter (PM), as carcinogenic to humans, with strong evidence supporting its association with cancer.



Zorana Jovanovic Andersen Chair of the Environment and Health Committee, European Respiratory Society & Professor,



Section of Environmental Health, University of Copenhagen 'Implementing stricter air pollution standards has a strong potential for substantial prevention

of all types of cancer in Europe, as well for improving quality of life for cancer survivors.

Emerging research indicates potential links between air pollution and breast cancer, gastrointestinal cancers, liver, colorectal, kidney, urinary tract cancers, blood cancers in adults, and tumours in both children and adults. The European Environmental Agency (EEA) calls air pollution a major environmental risk factor, estimating it could cause up to 10% of all cancers in Europe. Moreover, 19% of lung cancer deaths globally are attributed to air pollution, ranking it as a substantial risk factor after tobacco smoking.

It is urgent to address air pollution, especially with initiatives such as the EU Green Deal with its zeroemission plan. The revision of air quality standards and directives is underway and requiring alignment with WHO guidelines. Phasing out air pollution is a crucial step in reducing cancer rates and improving the quality of life for cancer survivors. Societal and economic costs associated with tackling air pollution should be considered an investment towards lowering the many diseases it causes.

A revolution in dermato-oncology

The global challenge of skin cancer has spurred the development of innovative screening techniques. Skin cancer is broadly categorised into deadly melanoma and the more common but less lethal non-melanoma skin cancers.

Traditional diagnosis relies on skilled dermatologists, but challenging cases often necessitate additional tools for early detection. Dermoscopy, a pocket-sized microscope, is a widely used tool, yet complex cases require more advanced approaches.

Two prominent non-invasive imaging techniques include: confocal microscopy, known for precision but limited tissue penetration, and conventional optical coherence tomography, which offers deep penetration but lacks precision.

A recent breakthrough - Line-field confocal optical coherence tomography (LCOCT) - combines the precision of confocal microscopy with the deep penetration of optical coherence tomography, providing instantaneous and high-resolution 3D reconstructions of skin lesions. LCOCT significantly enhances diagnostic accuracy, particularly demonstrated in tests for basal cell carcinoma (BCC), achieving a remarkable 97% accuracy. Moreover, LCOCT offers a revolutionary approach to managing skin cancer, using artificial intelligence algorithms to identify tumour margins before surgical removal, potentially reducing the need for repeated procedures. LCOCT emerges as a revolution in dermato-oncology, offering new dimensions in detecting and managing skin cancer.

Prioritising public health in the next legislative agenda

Alessandra Moretti MEP, member of the SANT Committee and founding member of the <u>National &</u> <u>European Parliamentarians for Cancer Action</u>, said that health should be the topmost priority in postpandemic Europe. She argued that the societal impact of illness extends beyond individuals, underscoring the critical role public health plays in the overall functioning of modern societies. As legislators, politicians hold great responsibility, and Moretti called for a collective understanding that health must not be just one priority among many but the overarching priority for the EU.

Moretti outlined key challenges and advocated a future where legislative decisions consider health implications comprehensively. She proposed four concrete actions for politicians and decision makers: a commitment to letting science guide health policies; an insistence on transparent communication with citizens about health risks of alcohol and other substances; an emphasis on ensuring equal access to screening and prevention across the EU, and a dedication to fighting health injustices, particularly those stemming from economic disparities. A well-funded, accessible public healthcare system is not only a necessity for societal well-being but a strategic investment for businesses. A healthy population is the best resource for any business or society.

In collaboration with the European Cancer Organisation and other societies, Moretti called for a collective effort to put health at the forefront of EU policies in the next legislative term.

Putting prevention and early detection of liver cancer on the EU agenda

Europe has the largest burden of liver cancer in the world. To address this, prevention and early detection are critical, as well as promoting healthy lifestyles from a young age, advocating for increased immunisation against hepatitis B and C; and control of disease transmission.

Alessandra Moretti MEP Member, SANT Committee



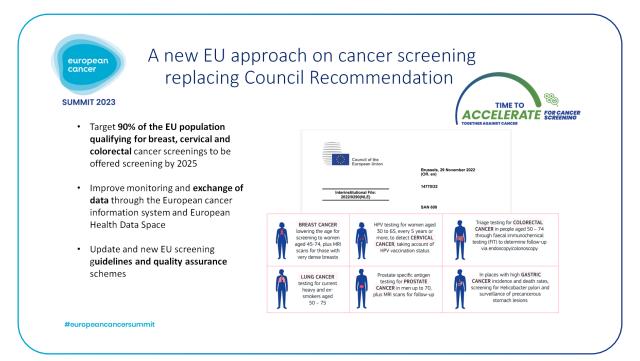
'It's not just a matter of having the most advanced screening techniques or the best prevention schemes, but to make sure they are available to everybody.'

Screening for early detection of liver cancer should be elevated on the healthcare agenda to identify at-risk populations. These include individuals with substance use disorders, those who consume alcohol, individuals with obesity, and others such as clients of beauty parlours with inadequate sterilisation processes who may face an increased risk of liver cancer.

Advocacy is needed for equality in healthcare access, treatment, research funding, and the harmonisation of guidelines.

How the private sector can support cancer screening advocacy

The global cost of cancer is projected to reach a staggering 25 trillion US dollars by 2050. Despite the approval of updated cancer screening recommendations by EU member states, inequalities remain in access to screening programmes. Once barriers are identified, the challenges should be addressed collaboratively, leveraging the expertise of the private sector, including scientists and economists who can provide data and evidence to support advocacy efforts.



To enhance cancer screening, social and economic determinants of health must be considered. The private sector can provide policymakers with arguments for investing in health as well as insights from behavioural science to understand the backgrounds of individuals that influence the success of screening programmes.

Reliable data are crucial to instil confidence in the implementation of screening programmes. Roundtables that bring together public, private, and patient organisations to collectively address the challenges in screening advocacy are a valuable tool to combat current inequalities in the uptake of recommendations.

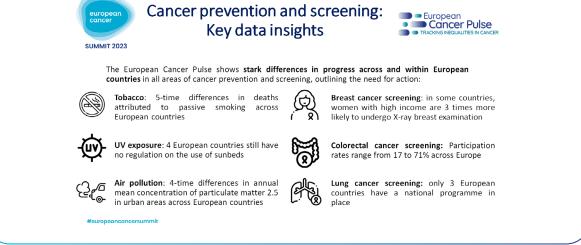
Conclusions

Prevention, screening and early detection, and screening for cancer should be a priority for the next EU legislative agenda. Despite advances such as the 2022 EU screening recommendations, there is still need for much greater accessible and equal screening programmes in Europe.

European Cancer Pulse data intelligence points to many inequalities in early detection across Europe, while the European Cancer Manifesto identifies opportunities to improve early cancer detection and recommends priority areas for legislative action.

The importance of collaboration between patients, healthcare professionals, scientists, policy makers and the private sector is essential to address health inequalities and to shape the framework for effective cancer prevention and early detection strategies in the next EU legislative agenda.







support countries in achieving the EU Council Recommendations' expanded advice on cancer screening programmes.

#europeancancersummit

europear cancer

KEY POINTS FROM THE SESSION

- Health must be the overarching priority for the new EU legislative agenda. •
- Accelerating the prevention of cancer requires (among other measures) national legislation to raise the minimum age for tobacco to 21; mandatory health warnings on alcoholic beverages and nutritional labelling; regulation on sunbeds as medical devices; and awareness campaigns on the risks of UV exposure.
- New strategies and technologies are needed for cancer screening. •
- Screening programmes must adhere to quality assurance and professional quidelines, and • criteria should be uniformly implemented.
- Air quality directives in the EU must evolve to align with WHO guidelines, establishing stricter standards.
- Screening for early detection of liver cancer should be elevated on the healthcare agenda to identify at-risk populations.
- Barriers to cancer screening should be addressed collaboratively, including patients, healthcare professionals, scientists and the private sector.

FIND OUT MORE

- European Cancer Manifesto for 2024
- **European Cancer Pulse**
- EU new cancer screening recommendations (2022)
- European Liver Patients' Association (ELPA)

All Cancer Patients Equal: Achieving That Vision

Nicolò Battisti and Sarah Collen, Co-Chairs of the Inequalities Network

The session description with the full speaker list is available here.

Pursuing the vision: 'All cancer patients equal', members of the European Cancer Organisation Inequalities Network collaborate to draw on the experiences of diverse communities. They have crafted recommendations to bridge gaps and raise standards and outcomes in cancer care for all.

As we approach a significant milestone with the European Parliament elections next year, the ECO's Manifesto provides proposals to address inequalities, encompassing dimensions such as geographical, socioeconomic, age, gender, LGBTQI+, and urban disparities. Valuable insights are provided by the European Cancer Inequalities Registry and the European Cancer Pulse. Based on this data, the Manifesto calls for the implementation of strategies that foster equality in cancer care.

Accessible and personalised healthcare for everyone

Drawing from a wealth of medical and political experience, Belgian Deputy Prime Minister Petra de Sutter highlighted persistent barriers to proper healthcare, especially socio-economic, cultural, and gender-related issues.

For example, socio-economic vulnerabilities can impact breast cancer mortality rates, emphasising the need for improved access to screening and preventive measures. Cultural differences, especially in the perception of pain, contribute to unequal access to specialists and care. Additionally, gender-specific issues such as historical biases in clinical trials must be addressed to ensure proper representation of women in medical research. On the other hand, gender-specific vaccination against HPV (offered in many countries



Speaking: Petra de Sutter. On screen: Sybil Green. From left to right: session Co-Chairs Nicolò Battisti, Sarah Collen and panelists Shereen Nabhani-Gebara, Tanimola Martins, Robert Greene, Sandra Caldeira, Manan Shah

only to women) reveal how policy decisions can inadvertently contribute to healthcare inequalities. Blind spots also exist in healthcare systems around LGBTQI+ people indicating that sexual orientation can lead to unequal access to healthcare.

To reduce inequalities, there is an urgent need for: increased awareness among healthcare professionals about cultural and other significant biases; further research into the causes of healthcare inequalities; the inclusion of diversity training in healthcare education and the integration of targeted care policies. Community health workers are crucial agents in bridging gaps between individuals, communities, and healthcare professionals, ensuring that policies address the specific needs of target groups.

De Sutter's overarching prescription was a comprehensive, inclusive, and transversal approach at the core of healthcare policies. She urged policymakers to champion general awareness and cater to the specific needs of target groups, ensuring optimal care irrespective of individual backgrounds or vulnerabilities.



Tanimola Martins Research Fellow, University of Exeter

'You cannot really know what you don't qualify, so we really need the data.'

Championing equity, diversity, and inclusion

The British Oncology Pharmacy Association (BOPA) shared the organisation's proactive steps to champion equity, diversity, and inclusion in cancer care. Starting with the establishment of an <u>Equity, Diversity, and Inclusion Subcommittee</u> in January 2022, BOPA engaged with its members to identify their concerns, focusing efforts on their experience with workplace discrimination and microaggressions.

A significant aspect of the inclusive workstream involves collaborative research with the UK-based charity <u>Outpatients</u> to understand the cancer journey experiences of minority groups, including ethnic minorities, neurodiverse individuals, and the LGBTQI+ community. The collaboration resulted in a comprehensive guide addressing safe and effective prescribing practices for transgender and non-binary individuals diagnosed with cancer. This live document encompasses definitions,

Petra de Sutter Deputy Prime Minister, Belgium







'Understanding the causes of inequality in healthcare and the underlying patterns is essential to rolling out target specific policies. We need health policies that value people as individuals and target special needs or risks.'

inclusive consultation recommendations, and considerations about the potential interactions of cancer and gender-affirming hormone treatments, to bridge knowledge gaps among healthcare professionals.

The evidence base is limited today, underscoring the need for ongoing research, inclusive project development, and comprehensive data collection to tackle healthcare inequalities affecting LGBTQI+ individuals.

Recognising the multifaceted nature of disparities, concerted efforts are necessary to train healthcare workers in inclusivity and secure funding to generate robust data for more informed decision making.

Advocating for inclusive healthcare: the imperative of local data collection in cancer care for ethnic minorities

Progress has been made in highlighting disparities in cancer care over the past decade, but discussions must be translated into informed actions. To address ethnic inequalities in cancer care, the role of comprehensive data collection is critical. In the UK, the availability of ethnicity data enables tracking patients throughout their healthcare journey, offering a comprehensive view from GP visits to diagnosis and treatment. This is in contrast with some European countries where legal constraints limit the collection of ethnic data in healthcare.

Two examples from the UK illustrate the necessity of local data for targeted interventions instead of relying on evidence from other countries, particularly the United States. In the UK, ethnic minorities, especially Asians and Black patients, experience longer delays in diagnosis, prompting an exploration of systemic inefficiencies. A study reveals that a minority patient's symptoms are often not recorded, raising questions about GP considerations and potential biases. It is vital to collect local data to improve diagnostic pathways, care, and advocacy so that every patient has accessible care.

Advancing patient representation

While it is important to acknowledge positive strides in patient representation, more must be done to ensure equitable cancer care irrespective of geographical location, skin colour, gender, or age. The aim of the global cancer community is to guarantee the best possible care for every patient, leaving no group marginalised or underserved. Vigilant representation in decision making is crucial. Talking about challenges is not enough. The people who voice those hurdles must be the ones experiencing them.

Three key areas to develop include: cultural competence training for healthcare professionals and patient organisations (among others); proactive community outreach programmes to address challenges faced by minorities; and a broader interpretation of patient advocacy extending to preventive measures.

Reducing the data gap in Europe

Europe's Beating Cancer Plan has made important strides to bridge the data gap. With a focus on cancer screening and vaccination targets, the European Commission is working to implement initiatives addressing inequalities based on country, education, income and age, as highlighted in the European Cancer Inequalities Registry.

However, there is insufficient data for certain communities, including migrants, the homeless, and the Roma community. Increased efforts and greater collaboration are needed to fill these gaps to improve cancer care, emphasising the importance of the European Cancer Pulse.

Inequalities in cancer care: the US perspective

Cancer care today is a result of actions taken - or not taken - in the past decade. It is time to accelerate to ensure progress in reducing inequalities in cancer care globally.

The American Society of Clinical Oncology (ASCO) has been actively involved in reducing health inequities, covering aspects such as Medicaid reform, insurance coverage for low-income individuals, and addressing healthcare disparities in race, ethnicity, sexual orientation, gender identity,

Enea Venegoni

Policy Research & EU Projects Officer, European Cancer Organisation



'Inequalities start when you don't get a screening invitation because you have body parts that do not conform to the gender that society puts on your ID.'

and age. The overarching goal is equitable access for all, reducing the burden of cancer, and improving outcomes.

Unique challenges in the US include the absence of universal healthcare, adding to the burden faced by marginalised communities. Policy priorities include expanding insurance coverage, addressing under-insurance issues, and implementing caps on out-of-pocket expenses. Drug pricing reforms, access to clinical trials for marginalised communities, increased funding for public health programmes, and support to navigate the complex US healthcare system (to find insurance and financial aid and reduce debt) are critical areas where ASCO works to make cancer care more affordable and accessible in the US.

Collaboration and commitment from industry partners

A multifaceted approach is needed to address inequalities in cancer care, including education, collecting local data, and collaboration between stakeholders. In the US, the National Minority Quality Forum provides valuable local evidence. The private sector contributes to reduce inequalities by sponsoring tangible actions (such as the <u>City</u> Cancer Challenge, and the Global Breast Cancer Initiative) and partnerships with organisations such as the European Cancer Organisation, EFPIA, All.Can and UICC. The focus on partnership, dialogue, and involving every stakeholder, is crucial to achieve meaningful progress. Businesses can also focus on diversity within their own organisations, which will result in more inclusive and effective outcomes in different diseases.

Conclusions

There is an urgent need to address inequalities in cancer care from diverse perspectives and with data-driven initiatives.

Local data, inclusive training for healthcare professionals, guideline creation, and the formation of partnerships and collaborative platforms, are all recognised as essential components in the mission to improve equitable cancer care. Progress requires coordinated efforts from diverse stakeholders. The emphasis must be on prioritising concrete actions inspired by diverse voices, notably those of patients from underrepresented communities.

Robert Greene

Founder, HungerNdThirst Foundation



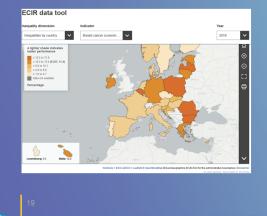


'Care and treatment should not depend on where we live, on the colour of our skin, gender, or age.

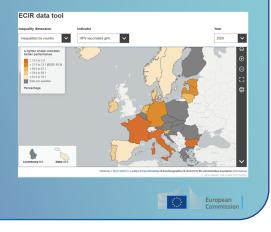
Everyone should get the best care possible that's out there now. That's it. No group at all should be left behind.

Cancer-related inequalities in the EU

EBCP: To ensure that 90 percent of the EU population who qualify for breast, cervical, and colorectal cancer screenings are offered screening by 2025.



EBCP: To vaccinate at least 90 percent of the EU target population of girls, and to significantly increase the vaccination of boys by 2030.







SUMMIT 2023

european cancer

Addressing data gaps in our cancer inequalities understanding

The establishment of the European Cancer Inequalities Registry is applauded as a ground-breaking policy tracking tool for cancer at the EU level. For next stages of development, the cancer community recommends:

- Concerted efforts with relevant agencies such as EUROSTAT and others, including civil society, to ensure better coverage to important areas of cancer inequalities such as patient access to key services and professions, especially in view of a current health workforce shortage crisis.
- Recognition that indicators should be included to better understand inequalities in cancer related to specific segments of society. This includes, but is not limited to: older persons, adolescents and young adults, racialised communities, Roma, undocumented migrants, refugees from areas of conflict, individuals from the LGBTQI+ community, persons in institutionalised settings, neuro-divergent individuals, and persons with physical disabilities.

#europeancancersummit

KEY POINTS FROM THE SESSION

- Secure funding for further research into the causes of healthcare inequalities to generate robust data for informed decision making.
- Need for local evidence (relying on data from other countries may lead to inappropriate interventions).
- Establish comprehensive data collection mechanisms. Implement initiatives to collect and analyse data from various communities, particularly those lacking representation such as migrants, the homeless, and the Roma community, to address disparities in cancer care access. The European Cancer Pulse can be very informative in this regard.
- Remember that mentally disabled patients and people with learning disabilities need information delivered in adequate ways (using visual tools for example).
- Representation is vital. No voice should be missing. Make sure those who speak are the ones experiencing the challenges.
- Include diversity training in a healthcare professional's education.
- Integrate targeted care policies to overcome systemic inefficiencies in the healthcare system.
- Train healthcare workers in inclusivity.
- Create guidelines to address safe and effective prescribing practices for transgender and non-binary individuals diagnosed with cancer, addressing pharmacokinetic and pharmacodynamic issues.
- Foster collaboration and knowledge sharing: Encourage partnerships between research institutions, policymakers, and advocacy groups to pool resources, share insights, and collectively work towards reducing both the data gap and inequalities in cancer care.

PATIENT VIEWS

Patients are navigating not only the healthcare system but their own pathway. We strive for shared decision making, but most information today is designed for the elite. It is great to have apps, but 40% of people don't use them. How do we deliver information? How do we give people with learning disabilities a choice?

FIND OUT MORE

- European Cancer Inequalities Registry
- European Cancer Manifesto for 2024
- <u>European Cancer Pulse</u>
- Outpatients
- National Minority Quality Forum
- <u>UICC</u>
- All.Can

Time to Accelerate: Europe's Beating Cancer Plan & 2024 European Parliament Manifesto Launch

Andreas Charalambous, European Cancer Organisation President 2022–2023

The session description with the full speaker list is available here.

The European Cancer Organisation launched the European Cancer Manifesto for 2024 at the European Cancer Summit. The Manifesto spurs momentum in implementing Europe's Beating Cancer Plan, recognising it as a significant opportunity for change. The Manifesto, a culmination of extensive consultations with more than 50 organisations, outlines a collective vision for the future of cancer care in Europe. This comprehensive document reflects the progress made in the Beating Cancer Plan's implementation across Europe, showcasing new projects, screening campaigns, and the formation



of collaborative networks. It marked the start of a widespread rollout across Europe, engaging diverse stakeholders and seeking endorsements



Speaking: Stella Kyriakides. From left to right: panelists Sara Cerdas MEP, Kathy Oliver, Winette van der Graaf, Gilly Spurrier-Bernard, Isabel Rubio, Anna Kirby ahead of the upcoming European Parliament elections in June 2024. The focus remains on building a better future for cancer patients, their caregivers, their families, and the cancer workforce.

Europe's Beating Cancer Plan

EU Commissioner for Health and Food Safety, Stella Kyriakides, hailed Europe's Beating Cancer Plan, initiated over four years ago, as a ground-breaking collaboration involving EU institutions, governments, and stakeholders with a shared commitment to improving the future for cancer patients and their families. Noteworthy achievements include the establishment of 28 EU-supported cancer projects addressing prevention, early detection, cancer care, and quality of life across member states.

Europe's Beating Cancer Plan put cancer at the forefront of the EU political agenda and facilitated unprecedented collaboration among member states. Future endeavours include the creation of the first EU network of comprehensive cancer centres, the introduction of ambitious screening recommendations, and a forthcoming prevention package addressing smoke-free environments and vaccine recommendations. Focus is also placed on improving the quality of life for cancer survivors, with plans for a code of conduct on fair access to financial services (implementing 'the Right to Be Forgotten').

The plan's holistic approach is a role model for health initiatives in other countries and for other diseases. It calls for continued collaborative efforts to ensure its success in delivering tangible benefits



From left to right: Andreas Charalambous President (2022-2023), European Cancer Organisation and Stella Kyriakides, EU Commissioner for Health & Food Safety



Manifesto –Time to Accelerate: for Europe

for cancer patients and citizens across Europe. Europe's Beating Cancer Plan is a pillar of a strong European Health Union.

Patient Advocate Perspective on the European Cancer Manifesto

In the patient's perspective of the Manifesto, emphasis is placed on prevention: the best cancer is the one that you don't get. While acknowledging the importance of preventing cancers, strategies are also needed for those facing non-preventable cancers. Early diagnosis emerges as a critical factor. Hurdles must be addressed in many European countries related to workforce shortages, and systemic and budget issues, all of which pose a threat to early diagnosis efforts. Metastatic cancers also need better strategies.

Regarding the European Health Data space, the Manifesto calls for easy access to health records and patient engagement in data-use decisions, while acknowledging the evolving nature of this field.

Patient engagement is vital for health systems. Researchers, healthcare professionals, and other stakeholders must learn to work with engaged patients. This will lead to more relevant research and joint decision making. Educated input from advocates on topics that directly impact patients is vital. Partnership will help us rise to the challenges facing the cancer community: workforce issues, capacity shortages, the challenge of ageing populations, the impact of climate change, pandemics, and wars. Professionals and patients alike must remain engaged.

Urgent needs of the surgical oncology community

Prevention, early detection of cancer, screening and eliminating risk factors are all crucial to outcomes. Once a patient is diagnosed with cancer, 80% will require a surgical intervention along the course of the disease. Nevertheless, surgery is undervalued today, even though cancer surgery is still the most cost-effective modality for treating solid tumours.

European data reveals disparities in cancer surgery across EU member states, with a lack of surgical oncologists, lack of specialised training for surgical oncologists, no recognition for the specialty and limited funding for cancer surgery in many countries. An estimated 82% of countries have an inadequate number of cancer surgeons and current trends show that we won't meet projected needs. Surgeons are part of multidisciplinary care, but each part of the chain must be strengthened to deliver high quality cancer care across Europe. The Lancet Oncology Commission on Global Cancer. Surgery suggested pragmatic solutions to improve cancer surgery outcomes worldwide.



Gilly Spurrier-Bernard

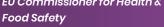
Patient Advocate, Melanoma Patients Network Europe, Co-Chair, Patient Advisory Committee, European Cancer Organisation

'The best cancer is the one you don't get, so prevention is vital. We know that only 40% of cancers are preventable right now, so we need strategies for patients with cancers that are not preventable, we must avoid the artificial divide.'

Challenges of poor-prognosis cancers

Poor-prognosis cancers (those with high mortality rates and low survival), including pancreatic, mesothelioma, oesophageal, and brain tumours, face many unmet needs such as the lack of effective treatments and psychosocial support, rapid reduction in quality of life, and late-stage diagnoses. Despite new treatments, many cancers remain highly aggressive and resistant to treatment.

Stella Kyriakides EU Commissioner for Health &







'Cancer concerns us all in one way or another, that is why collaboration and partnership form the backbone Europe's Beating Cancer Plan It's the first of its kind and it has brought together EU institutions, governments, and stakeholders around a common goal. We are all engaged to make it work for Europe's citizens, and it is delivering already.'

The European Cancer Manifesto calls for efforts to improve outcomes for people diagnosed with poor prognosis cancers, and a doubling of survival rates by 2035 (as well as a 70% ten-year survival for other European cancer patients by 2035: the 2035 vision).

Initiatives, including the <u>Lancet Oncology</u> <u>Commission's European Groundshot</u> and recommendations from the French National

Cancer Institute, highlight the urgency to shift research focus, enhance data sharing, improve the quality and speed of care delivery, and greater access to innovative therapies. Cross-border research and information exchange, supported by European Reference Networks and European Cancer Centres, is crucial to these patients, along with the need for political will to achieve meaningful progress.

An oncology workforce in crisis

The oncology workforce shortage in Europe is not a time-bomb, it is already here. The shortage, estimated at over 4 million healthcare workers by 2030, threatens the implementation of the <u>European Code of Cancer Practice</u>, which calls for specialised multidisciplinary care for every cancer patient.

The Time to Accelerate Manifesto details the harmful impact of these shortages and makes the case for an EU Action Plan to address this crisis. It also recommends actions such as precise data collection on workforce shortages and on workforce wellbeing; reducing bureaucracy; encouraging task sharing, cultivating an agile healthcare system; ensuring funding for innovations that drive quality; better use of digital technology; adopting efficiencies of scale and speed through the implementation of international guidelines and learning networks. Both the engine (workforce) and the vehicle (healthcare system) need optimising to deliver high-quality cancer care to all European cancer patients.

Promoting clinical trials that are more translatable to practice and meaningful to patients

There is need to bridge the gap between clinical trials and clinical practice in Europe. The Manifesto calls for research that addresses questions relevant and meaningful for patients, such as pragmatic trials designed to assess the effectiveness of an intervention or treatment in real-world, everyday clinical practice conditions. More optimisation trials are also needed immediately after therapy approval. These require a dialogue between regulatory bodies like the European Medicines Agency and organisations such as European Organisation for Research and Treatment of Cancer. Pragmatic trials are needed not only for drugs but for medical procedures such as radiotherapy and surgery, and for combinations of treatment strategies. Patients with rare cancers could particularly benefit from pragmatic clinical trials to improve their prognosis.

The Manifesto urges the EU to allocate funds towards optimisation needs, to infrastructural needs (to support optimisation), as well as the translation of clinical evidence into the health system. The Manifesto also addresses health system issues, including drug prices and interventions across Europe, to expedite reimbursement processes.



Kathy Oliver



Chair and Co-Director, International Brain Tumour Alliance (IBTA), Co-Chair, Patient Advisory Committee, European Cancer Organisation

'There is a great deal of unmet need in poorprognosis cancers. For example, there's a lack of effective treatments, absence of psychosocial support for patients and their caregivers, rapid reduction in quality of life, limited knowledge of risk factors for prevention, limited knowledge of diagnostic biomarkers, and lack of screening, leading to late-stage diagnosis.'

Prevention: a legislative battleground in the EU

Statistics in Europe are alarming: cancer is the second leading cause of death. Although only 10% of the world's population is in Europe, it has 25% of the cancer cases worldwide. If no action is taken, by 2035 cancer will be the leading cause of death.

Sara Cerdas MEP

Rapporteur of Mental Health Report





'We have the power to shape a healthier and more resilient European Health Union if we tackle exposure to known risk factors.'

The EU is committed to the implementation of Europe's Beating Cancer Plan, backed with significant funding. Four pillars are basic to the Plan: prevention, early detection, access to quality treatment, and quality of life, not only for survivors but also their caregivers and their families. Preventing cancer is vital to individuals but also to Europe's socioeconomic health.

Legislation plays a prominent role in cancer prevention. Unfortunately, political battles in the European Parliament have watered down proposed preventive measures such as recommendations on alcohol and tobacco use, among others. Focus is needed on empowering consumers with accurate health information to enable them to make the best choices for their health and on providing the best available evidence to legislators. As elections approach, EU citizens are encouraged to engage with parliamentarians and candidates to ensure accountability and support for preventive measures.

Conclusions

The session on Europe's Beating Cancer Plan and the European Manifesto highlighted the critical challenges and opportunities in the fight against cancer. Speakers emphasised the urgent need for a comprehensive approach that addresses prevention, early detection, accessible and quality treatment, and the overall well-being of cancer patients and their caregivers. The European Manifesto, with its focus on pragmatic and relevant clinical trials, workforce crisis, and cancer prevention, serves as a roadmap for policymakers and stakeholders.

Discussions underscored the significance of political commitment and financial support. However, concerns were raised about the need for more focused legislation, particularly in prevention, and the importance of aligning policies with the latest scientific evidence.

The session concluded with a call for continued collaboration, engagement with policymakers, and a commitment to addressing the challenges

outlined in the Manifesto. The overarching goal is to shape a healthier and more resilient European Health Union, highlighting the importance of prevention and ensuring that the entire cancer care continuum, as well as research, are optimised for the benefit of patients across Europe.

Stella Kyriakides

EU Commissioner for Health & Food Safety





'I believe in a strong European Health Union that should be there to better protect the health of citizens, and to fight inequality. To address future threats, we need to work together to make sure that Europe's Beating Cancer Plan really does deliver.'











Delegates signing the Manifesto board





The European Cancer Charter 2024

SUMMIT 2023

Deliver in full, the promise and potential of Europe's Beating Cancer Plan and the EU Research Mission on Cancer, through 2024 and to 2030 and beyond

• Expand the pan-European goal-orientated approach to cancer control

Setting clear goals in any field of activity gives clarity, certainty, accountability and unites diverse stakeholders via a common aim. In the context of European cancer policy it can also serve as a vital mechanism for addressing inequalities in cancer care that exist between and within countries.

Make Europe a global leader in the fight against cancer

There is now opportunity for the EU to give leadership at world level. Chances to synergise global efforts, such as the WHO goal of cervical cancer elimination and connecting EU cancer efforts with US Cancer Moonshot endeavours, should be actively pursued.

Address Europe's oncology workforce crisis

The new European Commission 2024-29 should set shared goals and conduct initiative to combat the persistent and growing crisis of shortage in the oncology and health professions experienced by all EU countries.

#europeancancersummit

KEY POINTS FROM THE SESSION

- Create EU Action Plan to address workforce shortages.
- Advocate for recognition of surgical oncology as a speciality in Europe, and incentivise specialised training for the profession.
- Double survival rates for poor prognosis cancers by 2035 as outlined in Time to Accelerate: Together Against Cancer by:
 - Improving the quality and speed of care delivery, including time to diagnosis and treatment;
 - O Allowing early access to novel therapies;
 - O Embracing emerging technologies such as big data and artificial intelligence for better understanding of these cancers;
 - Supporting international collaboration through initiatives like European Reference Networks and Cancer Centres;
- Prioritise clinical trials that are relevant to practice.
- Establish research programmes promoting data sharing and collaboration across borders.
- Invest in innovative approaches, personalised medicine, and immunotherapy for improved outcomes.
- Prioritise cancer prevention in EU legislative action to address risk factors for diseases, focusing on empowering consumers with accurate health information and promoting healthier choices.
- Combat industry misinformation particularly in the context of cancer prevention, to ensure that public health policies align with the best available evidence.
- Support the development of a European mental health strategy and corresponding national strategies, ensuring integrated mental health care and support for cancer patients and survivors.

FIND OUT MORE

- Europe's Beating Cancer Plan
- European Cancer Manifesto for 2024
- <u>European Cancer Charter</u>
- INTERACT-EUROPE
- The Lancet Oncology Commission on Global Cancer Surgery
- <u>European Groundshot-addressing Europe's cancer research challenges: a Lancet Oncology</u>
 <u>Commission</u>
- European Code of Cancer Practice



Richard Price, Head of Policy, European Cancer Organisation (left) and Mike Morrissey, CEO, European Cancer Organisation (right)

The Next Generation of Cancer Leaders

Ajay Aggarwal and Andreas Charalambous

The session description with the full speaker list is available here.

Commitment to the European Cancer Manifesto implies the need to invest in people – nurturing expertise, fostering opportunities, and honing networking skills to drive impactful change, with a particular focus on the next generation of oncology leaders.

The ECO <u>Young Cancer Professionals Group</u> was designed for individuals aged 40 or younger. The collaborative platform seeks to provide young professionals with a space to address concerns related to leadership, capacity building, and participation in decision making, among other topics. By investing in talent, ECO hopes to contribute to a fairer healthcare system and a robust workforce.

ECO also reserved a space for young professionals at the Summit via a call for abstracts. The resulting <u>selection of 15 abstracts</u>, linked to priority areas within ECO's focused networks, Europe's Beating Cancer Plan and the EU Cancer Mission recommendations, showcases the motivation and creativity of young cancer professionals. Some of those abstracts were presented in this session.

EU Cancer Mission: a comprehensive approach for a healthier Europe

Against the backdrop of a stark reality, where approximately 2.7 million individuals in the EU receive a cancer diagnosis each year, with 1.3 million succumbing to the disease annually, including over 2,000 young people, urgent and decisive action is imperative. Projections indicate a concerning 24% increase in cancer cases by 2035, making it the leading cause of death in the EU.



Speaking: Iliana Ivanova. From left to right: panelists Irfan Lone, Sophie Schellack, Dimitris Protogiros, Joanna Dodkins, Alex Filicevas



Iliana Ivanova

EU Commissioner for Innovation, Research, Culture, Education and Youth



'When thinking about the next generation of cancer leaders, the importance of training and career development of researchers cannot be underestimated. EU programmes are essential to shape the next generation of leaders nurturing their expertise and passion and guaranteeing a brighter tomorrow in the fight against cancer.'

The EU Cancer Mission seeks to address this challenge through coordinated research, innovation, and governmental collaboration. The Mission has facilitated dialogue with member states, shaping policies, and influencing revisions, such as the 2022 updated recommendations that extend screening to gastric, prostate, and lung cancers by 2025. The Cancer Mission's commitment, including funding of nearly €135 million for projects spanning 2021 to 2023, underscores its dedication to prevention and early detection of cancer.

Iliana Ivanova, the EU Commissioner for Innovation. Research, Culture, Education, and Youth said efforts extend beyond conventional approaches, embracing social innovation by engaging citizens, advocacy groups, and cancer charities. More than €378 million in funding between 2021 and 2023 have supported 40 projects aligning with the Mission's objectives. Recognising the vital role of training and career development for researchers, the EU has funded 553 cancer research projects since 2014, fostering over 2,230 researchers. Embracing the future, the integration of artificial intelligence and big data analytics holds immense promise, aiding in deciphering cancer complexities, predicting outcomes, and advancing drug discovery. The EC Data Platform, a flagship project, combines patient health data with existing initiatives, contributing to breakthroughs in cancer prevention and personalised care.

Looking ahead, the Cancer Mission plans to launch new initiatives, including a pilot bus roadshow in 2024, bringing cancer prevention and screening closer to communities. The Mission emphasises the importance of understanding and addressing the real experiences of cancer patients, survivors, families, and caregivers. Notably, the EU CAYAS net has provided a safe space for young cancer survivors to share challenges and ideas. This initiative has yielded excellent proposals (including a platform for mental health), influencing the research and innovation topics for the next Cancer Mission work programme in 2024.

The Cancerless Project: cancer prevention for the homeless

Cancer poses formidable challenges, particularly when compounded by the complex circumstances of homelessness. There is an urgent need to address the disproportionately high incidence of cancer among the homeless population. The <u>Cancerless project</u> (funded by the EU's Horizon 2020 programme) seeks to do this, with insights from people experiencing homelessness incorporated through focus group discussions. The <u>Health Navigator Model</u> emerges as a unique approach to cancer prevention, promoting equity, inclusion, and integrated care pathways. The Health Navigator Model is an evidence-based patient-centred intervention that develops patient empowerment through health education and social support, promoting timely access to primary and secondary prevention services. By employing health navigators who work closely with the homeless, this bottom-up strategy facilitates access to existing healthcare facilities, fostering inclusion, health literacy and delivering equity. The role of initiatives such as Cancerless are crucial in the face of rising challenges, advocating for a collective commitment to ensuring health and quality of life for all, especially the most vulnerable among us.

Returning to work after cancer

Recognising the pivotal role of employment in people's well-being and overall quality of life, identifying factors associated with the return to work for cancer survivors is important. Outcomes of the <u>CraNE Joint Action</u> showed that 36% of new cancer diagnoses affect individuals of working age (between the ages of 20 and 64), prompting a closer examination of return-to-work rates across Europe, which range from 39% to 77%. Along the patient pathway, key phases where the work situation may change are diagnosis, treatment planning, the treatment phase itself, and the follow-up phase, including rehabilitation.

A systematic literature review identified predictors of return to work in Europe, classifying them into six categories: socio-demographic, work-related, disease-related, psychosocial, treatmentrelated, and social system-related predictors. Heterogeneous results were noted, with variations influenced by diverse contexts, including different cancer entities, social systems, country-specific measurements, and definitions of return to work. Return to work should be considered throughout the cancer pathway, using identified predictors to align with the goals of the Europe's Beating Cancer Plan and the Manifesto. Further research is needed, particularly on when and by whom these predictors should be addressed, forming the focus of the second part of the CraNE initiative.

Developing leadership skills to enable change

The <u>ASCO Leadership Development Program</u> (LDP) plays a crucial role in advancing leadership skills among oncology professionals. ASCO offers grants to members in many areas such as research and education. The focus extends beyond grants to encompass clinical research training through symposiums and virtual mentorship programmes. Leadership development is an especially important area for ASCO. Recognising that implementing change at any level requires leadership skills (that are often not cultivated during medical training) the society has strategically invested in programmes to help medical professionals acquire these. LDP focuses on emotional intelligence, team building, communication, conflict management, negotiation, and influencing policy at various levels. International ASCO members are encouraged to apply.



Iliana Ivanova

EU Commissioner for Innovation, Research, Culture, Education and Youth



"We must recognise the key role of artificial intelligence and big data analytics. Al is everywhere. These technologies are not just processing information, they are deciphering the complexities of cancer biology to help predict patient outcomes and accelerate drug discovery. The fusion of human expertise and artificial intelligence is propelling us towards personalised, targeted therapies, minimising side effects and maximising effectiveness."

Mapping digital skills in oncology across Europe

The <u>TRANSITION</u> consortium addresses the



integration of technological innovations that have profoundly transformed healthcare, particularly in oncology. The project helps elevate digital skills among healthcare professionals, clinicians, nonclinical staff, patients, and informal carers. Eleven activities were designed to upskill and reskill the oncology workforce in digital health solutions.

Key findings from an online survey, following the Kirkpatrick evaluation model, revealed significant gaps in digital skills in 6 out of 14 European countries, indicating a pressing need for training programmes. Only 4.2% of the 57 identified training programmes were specifically targeted to the oncology workforce. A multifaceted approach involving government policies, educational institutions, industry, and individuals to address the digital skills gap is essential to ensure Europe maintains a competitive health workforce in the digital era.

Translation of research into clinical practice

Treatment landscapes are evolving rapidly, particularly in the context of metastatic hormonesensitive prostate cancer. Nevertheless, translation of research into clinical practice does not always follow. In the case of metastatic hormone-sensitive prostate cancer, overall survival has improved with treatments like docetaxel, abiraterone, enzalutamide, and apalutamide. Despite evidence of their efficacy, a study based on a systematic review of international literature, revealed significant under-utilization of these treatments in the real world. Only 9% to 38% of eligible patients received recommended treatments.

Determinants such as age, comorbidities, ethnicity, and the specialty of the treating physician impacted uptake of novel therapies, showing that clinical trial advancements alone are not enough. Three key actions were recommended: obtaining high-quality data to understand epidemiological trends; conducting qualitative research to explore reasons behind underutilization; and implementing designs to ensure equitable access to new treatments. Increased investment in implementation studies is also needed to bridge the gap between research and real-world patient access to novel therapies.

The evolving landscape of patient advocacy

Cancer patients and survivors have a vital role shaping the landscape of cancer care and policies. Their first-hand experience provides invaluable insights into the challenges and nuances of the disease. Patient advocacy has evolved beyond representing voices and providing support; it now involves building evidence bases, participating in research, shaping clinical trials, using registries, and driving policy. The changing landscape of advocacy recognises the diversity of cancer experiences, from different types and stages of cancers to unique needs of patients depending on age and other factors. A collaborative approach is crucial to effective advocacy, leveraging the expertise and experiences of a community of patients to drive research, create evidence, and actively participate in policy discussions to make a tangible difference in the lives of cancer patients.

Conclusions

The importance of fostering a new generation of leaders in the field of oncology is evident. The emphasis is not only on medical expertise but also on leadership skills, innovation, and collaboration. Initiatives and programmes aimed at supporting young professionals and researchers are crucial to drive progress in cancer care. Collaboration between different sectors, including healthcare,







Young Cancer Professionals & Poster Presentations

Joanna Dodkins

National Prostate Cancer Audit Clinical Research Fellow, The Royal College of Surgeons of England





'The budget that we spend on research and development should be equal to the spend on implementation research, to ensure that these treatments that we know to have improved efficacy are reaching the patients that need them the most.'

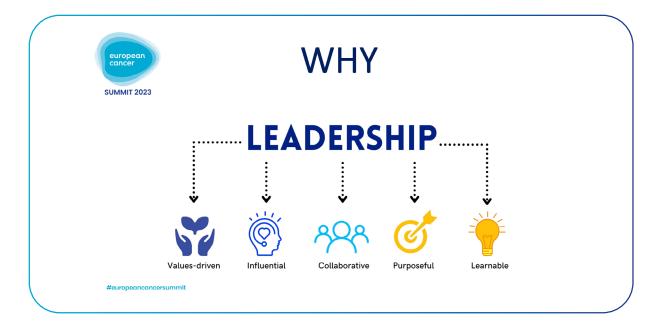
research, advocacy, and policy, is essential to accelerate the momentum to beat cancer. The session also underscored the significance of patient advocacy, recognising that the voices and experiences of cancer patients and survivors are instrumental in shaping policies and improving overall cancer care and research.







european cancer SUMMIT 2023		Return	to work	in patient	pathw	ays 🛛	
	0	(Temporary) withdrawal from work because of symptoms	Understand and discuss treatment plans as well as the consequences for work	Manage treatment and work	Organize life during follow- up and return to work		
	Start of pati pathway Figure 1: Patien	ent Diagnosis It pathway and work	Planning of treatr	nent Treatment & care	Follow-up		
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- Ensure that research informs policy choices.
- Address the unique challenges faced by marginalised populations in accessing healthcare, ensuring that cancer prevention efforts are comprehensive and consider the broader social context.
- Develop targeted interventions addressing identified predictors of return to work within the cancer survivorship process and align them with the goals outlined in the Europe's Beating Cancer Plan and Time to Accelerate: Together Against Cancer.
- Recognise the key role of artificial intelligence and the big data analytics to decipher the complexities of cancer biology, help predict patient outcomes and accelerate drug discovery.
- Encourage oncology professionals to participate in leadership development programmes to acquire essential skills and inspire change.
- Address identified gaps in digital skills, ensuring comprehensive training programmes for healthcare professionals.
- Allocate resources and funding for implementation research that focuses on understanding hurdles to translation of novel therapies into real-world clinical settings.

FIND OUT MORE

- Young Cancer Professionals Group
- Summit 2023 selected abstracts
- EU Cancer Mission
- Cancerless
- <u>ASCO Leadership Development Program</u>
- TRANSiTION Consortium

European Cancer Community Foundation Rising Star Grants

The European Cancer Community Foundation recently initiated the <u>Rising Star Grants</u>. <u>announcing a call for applications last September</u>. These grants, each amounting to \in 3,000, were established in memory of Véronique Trillet-Lenoir, an influential MEP and oncologist who recently passed away. The selection process proved challenging due to the many applications received. However, the foundation chose to award three grants.

Congratulations to the winners:

- Andrada Turcas from Romania, focusing on the impact of radiotherapy and repetitive anaesthesia on neurocognitive outcomes in paediatric cancer patients
- Amy Taylor from Ireland, working on new evidence regarding the role of palliative care in cancer survivorship



 Jemma Arakelyan from Armenia, investigating the experiences of financial toxicity on the mental health and psychosocial well-being of cancer patients.

The Foundation looks forward to sharing updates on future grants in the coming year, and interested parties can find more information on the <u>website</u>.



Andreas Charalambous, President (2022-2023), European Cancer Organisation and Rising Star Grant recipients: Amy Taylor (left), Andrada Țurcaș (right)

Cancer Survivors Matter: Championing the European Cancer Survivorship Day and Advancing the Right to Be Forgotten

Csaba Dégi and Nevenka Krčevski Škvarč, Co-Chairs of the <u>Survivorship and Quality of Life Network</u>

The session description with the full speaker list is available here.

Survivorship transcends surviving cancer; it represents an entirely new and uncharted territory. This session explored a few challenges, as well as initiatives driving effective change. Romania's successful template could be used to establish a European Cancer Survivorship Day, to create awareness and engage with politicians on the challenges facing the growing population of survivors in Europe.

Many EU projects address the unique challenges of cancer survivors: <u>smartCARE</u>, the EU carers strategy, EU network for cancer survivors, <u>STRONG-AYA</u>, EUonOoL, and



others. Nevertheless, gaps remain that could be tackled via tools such as the European Cancer Inequalities Registry and by collaboration with the European Commission's DG EMPL and DG SANTE to facilitate return to work and combat workplace discrimination for survivors. Strong foundations have been established thanks to Europe's Beating Cancer Plan, but we must envision a future where these initiatives thrive and endure, benefiting EU cancer survivors and society.



Speaking: Charles La Haye. From left to right: session Chair Csaba Dégi and panelists Carina Schneider, Penilla Gunther, Nicoleta Pauliuc, Françoise Meunier

Insights from a brain tumour patient's journey

Some patients question the label of 'survivor' as they still felt like a patient due to ongoing treatment, limited life expectancy and financial challenges, highlighting the complexities cancer survivors face. While active treatment is over, follow up and sequalae of treatment and effects of financial toxicity remain. While patients would like to focus on their treatment alone, they need to consider finances remaining employed. These issues may even impact decisions on proposed treatments. The financial burden (and ensuing relationship problems) remains a challenge in the EU, even in developed countries with universal healthcare. Supporting caregivers is also an important area for improvement. Comprehensive support from hospitals and the community are needed to ensure the caregiver's wellbeing.



Nicoleta Pauliuc Romanian Senator & Cancer Survivor



'We should understand that society's work does not end when patients leave the medical facility, there is still much to be done for the quality of life of cancer survivors.'

Challenges facing paediatric cancer survivors

Surviving a childhood cancer brings unique challenges. To begin, there is the discrepancy between the expectations of returning to a normal life after treatment, and the reality of coping with physical and psychological changes. The lack of follow-up care and psychosocial support for survivors (especially when they become adults and no longer have access to paediatric services) is a significant concern, with late effects of treatment being prevalent among survivors. Ongoing EU-funded projects addressing these challenges, including Pan Care Follow Up and the European Network of Youth Cancer Survivors, are steps in the right direction. While there has been progress in understanding and addressing the issues faced by survivors of childhood cancers, there is a need for funding the implementation and evaluation of these tools at a European and national level to improve the quality of life for survivors.

Using personal adversity to influence broader societal change

A survivor journey that led from lymphoma to meningitis, heart failure (due to side effects of cancer treatment), a heart transplant and then breast cancer, represent the rocky healthcare journey of Penilla Gunther. Throughout these ordeals, she encountered both public support and criticism as a public person. They taught her the importance of politicians listening to and learning from those with diverse experiences and led her to fight for a more inclusive and understanding environment in politics, particularly in the era of social media.

Confronted with adversity, Penilla committed to using her experience to drive positive policy changes. This included support for single parents during sickness and to alleviate the financial stress that often accompanies illness. Overall, her story highlights the interconnectedness of personal health challenges and political endeavours, emphasising the potential for using personal adversity to influence broader societal change.

Impact and management of pain in cancer patients and survivors

Pain has a significant impact in the cancer journey, affecting more than 50% of patients at all disease stages, 70% in advanced stages, and persisting in 40% of survivors. Pain encompasses physical, social, and spiritual dimensions, making its management complex. About a third of patients do not receive adequate pain relief, and special attention is needed for neuropathic pain, which is difficult to treat. The long-term effects of cancer, such as chronic pain syndromes, fatigue, and cognitive changes, deteriorate quality of life. There is a growing need for comprehensive, multiprofessional approaches to pain management in cancer survivorship. The focus should be on improving pain screening, monitoring, and treatment, including both conventional and complementary methods, and enhancing training in pain management. The overall goal is to acknowledge pain's impact and provide effective relief to cancer patients and survivors.

Access to new diagnostics and treatments

EU regulations should evolve to facilitate access to innovative diagnostics and therapeutics in cancer care. Thanks to novel treatments there is a growing number of cancer survivors in Europe, currently around 20 million, and it is important to continue to increase these rates. However, the significant challenge in Europe is the lack of access to adequate diagnostics, particularly in precision medicine, which in turn hinders access to these new treatments. Advanced diagnostics, such as liquid biopsies, are critical but remain inaccessible. A collective effort in policy and infrastructure development is needed to ensure that patients can access cutting-edge tests and treatments, ultimately improving survivorship rates in cancer.

Laws for Life: enhancing cancer care in Romania

Several 'laws for life' have been initiated in Romania to support cancer patients, survivors, and their families, offering potential models for other countries. A key law provides free psychological counselling for cancer patients and their families at the time of diagnosis, recognising the emotional turmoil and need for specialist support to cope with the disease. Caregivers, facing their own challenges and often at risk of burnout, are granted days off to manage their wellbeing. The importance of personalised medicine is highlighted, advocating for the quick adoption of new technologies and drugs, and the implementation of screening programmes for early detection of rare diseases.

Pain management is stressed, advocating for the inclusion of medical services for pain therapy covered by social health insurance. The 'Right to Be Forgotten' initiative, particularly impactful, allows cancer survivors to have their disease removed from medical records after a set period, reducing financial service discrimination. The ongoing need for quality-of-life management for survivors post-treatment, is highlighted. Finally, the establishment of a Cancer Survivors Day is proposed to celebrate life, inspire newly diagnosed patients, raise community awareness, and provide policy opportunities.



Elcin Barker Ergun CEO, Menarini Group, ECO's Community 365



'One thing is what can we do to help survivors – and there are many facets of that – but we need to continue working all of us together, to increase the number of survivors.'

Carina Schneider

Managing Director, Childhood Cancer International Europe & Cancer Survivor



(

'You get the impression that you should be so happy to be alive that you shouldn't complain about the things that are not working.'

Advancing the 'Right to Be Forgotten'

Significant progress made in cancer treatment over the last 50 year has transformed a once fatal diagnosis into a curable condition. However, this progress brings new responsibilities, particularly in addressing the long-term effects and discrimination faced by cancer survivors. The 'Right to Be Forgotten' initiative is aimed at ending financial discrimination against cancer survivors. Six countries - France, Belgium, Netherlands, Portugal, Romania, and Spain – have established legal frameworks to prevent this discrimination. The EU Commissioner for Health has prioritised ending discrimination, and a code of conduct is being developed through roundtable discussions. While this is a positive step, concerns remain about its non-binding nature and potential setbacks for countries with existing laws. Three additional European countries are considering similar legislation, indicating a growing momentum for change.

Conclusions

Cancer survivorship signifies navigating uncharted territories, as well as confronting multifaceted challenges affecting one's quality of life. The European Union must be prepared to facilitate the journeys of its 20 million survivors, for instance drawing inspiration from Romania's successful model, or from the 'Right to Be Forgotten' initiative. This session underlined the necessity to improve access to innovative diagnostics and treatments in all member states to empower cancer survivors across borders.



#europeancancersummit

- The experiences of those who have experienced cancer should inform and drive policy changes that address needs such as financial support during illness, improved access to palliative care during and after treatment, and the 'right to be forgotten'.
- Implement comprehensive pain management protocols, including regular pain assessments and multidisciplinary approaches, to ensure effective pain relief for cancer patients and survivors.
- Establish lifelong follow-up care for paediatric cancer survivors, including medical, psychosocial, and transitional support when they become adults.
- Support for caregivers of cancer patients must d be provided throughout the cancer journey of their loved one.
- Implement EU regulation to enhance access to advanced diagnostic tools, including liquid biopsies and precision medicine tests, ensuring that cancer patients can promptly benefit from innovative treatments and therapies.
- Establish a dedicated European Cancer Survivors Day to create awareness and policy opportunities.

FIND OUT MORE

- European Cancer Manifesto for 2024
- <u>smartCARE</u>
- <u>STRONG-AYA</u>
- <u>EUonQoL</u>
- Pan Care Follow Up
- European Network of Youth Cancer Survivors
- <u>EU care strategy</u>
- European Cancer Inequalities Registry
- <u>DG EMPL</u>
- <u>DG SANTE</u>

Digital Health: A Powerful Ally in the Fight against Cancer

Wim Oyen and Carlo Catalano, Co-Chairs of the Digital Health Network

The session description with the full speaker list is available here.

The transformative potential of digital tools in cancer care also presents challenges. These include regulatory roadblocks, integrating diverse digital systems both within and across countries, and the need for ongoing professional education to keep pace with rapidly evolving technology. Key focus areas include the European Health Data Space (EHDS) and Artificial Intelligence (AI) regulation, highlighting the importance of scrutiny to protect data, avoid overregulation, and the necessity of building trust through high standards and stakeholder governance. The promise and complexities of AI in healthcare were explored, emphasising the need for high quality data, competent implementation, and the potential for advancements in drug research, diagnostics,

medication systems, registry interoperability, and data collection on cancer recurrence and comorbidities.

Enhancing healthcare through connected digital systems

There is a crucial need for interconnected digital systems in healthcare. The Netherlands, for example, faced significant challenges after rejecting a national electronic health report in 2011, leading to a fragmented system where healthcare professionals repeatedly enter and re-enter data, sometimes over 100 times for complex cases. This lack of connectivity not only consumes time but also increases the risk of errors. By comparison, a unified language, and standards, as exemplified by the current ONCONEXT project in



From left to right: session Chair Wim Oyen, and panelists Carla Meeuwis, Saila Rinne, Teodora Kolarova, Ben Newton and Tomislav Sokol MEP

the Netherlands, bridges gaps between radiology, pathology, and electronic health records for certain cancer types. This project demonstrates the feasibility and benefits of data sharing, including efficiency in research and enhanced patient safety. The Dutch initiative aligns with the European Health Data Space concept, aiming for a more integrated, EU-wide approach. The urgent need for IT companies to collaborate and support this transition is underscored, proposing either legal mandates or starting anew with a European electronic health record system. This



Carla Meeuwis Radiologist, Rijnstate Hospital



'We all work with different systems, and none of the different systems relate to each other, so we must read, highlight, and copy and paste the information over and over, sometimes over 100 times.'

initiative is vital, considering the rising healthcare costs and increasing cancer rates, coupled with administrative burdens that consume significant resources. The goal is to ensure high-quality data leads to better healthcare outcomes.

Advancing healthcare through EU digital health initiatives

The European Union's digital health initiatives, particularly the European Health Data Space (EHDS), are pivotal in transforming healthcare efficiency and safety. The EHDS, a key component of the European Health Union, is designed to empower individuals with greater control and access to their personal health data both nationally and across the EU. It supports the primary use of data for healthcare delivery, research, and policy making, while ensuring a secure exchange of health information. This initiative is part of a broader EU strategy to create a fair and transparent data economy across various sectors, with special attention to the sensitive nature of health data.

The EU's approach includes a legislative and regulatory framework to ensure interoperability of electronic health records and the ethical use of health data. This encompasses initiatives like the European Cancer Imaging Initiative, the Genome of Europe, and the 1+Million Genomes (1+MG) project, which enhances cancer treatment and genomic research. The emphasis on computational modelling and creating virtual human twins further illustrates forward-looking approaches to healthcare. There is active collaboration among EU member states to standardise and improve the quality of health data. These initiatives underscore the EU's commitment to leveraging digital technologies for improved healthcare outcomes.

European Health Data Space: perspectives from the EU Parliament

The European Parliament is actively debating the implementation of the EHDS, focusing on the balance between patient privacy and efficient data use. Negotiations have been delayed due to technical complexities.

Primary use of data and electronic health-record certification have been broadly accepted, with third-party certification agreed upon for better safety control. However, the secondary use of data presents more controversies. Concerns revolve around patient consent, especially for sensitive data, and the potential misuse of data by private companies. A consensus is emerging towards a general opt-out system for data use, with an opt-in requirement for particularly sensitive or genomic data. The interpretation of the General Data Protection Regulation (GDPR) in this context also raises issues of potential fragmentation across member states.

The Parliament is also advocating for increased EU funding for EHDS, beyond national recovery plans, recognising that current proposals are insufficient. Member states may request more time for implementation due to varying levels of digitalisation. Ultimately, the objective is to harmonise data use across the EU while respecting patient privacy and ensuring that data is used for public interest, particularly in healthcare and research.

Patient needs in EU digital health initiatives

From the patient's perspective, the EHDS represents a significant opportunity for enhancing healthcare, particularly in the fields of digitalisation and Al. Patients seek timely diagnoses, prompt care, and the best possible treatment. They see the potential of digital health initiatives to address these needs, provided these initiatives are structured to protect patient interests and ensure proper use of information. The EHDS, which aims to improve the sharing and use of health data for both primary and secondary health purposes, is still facing challenges related to implementation, especially due to varying levels of digitalisation across Europe. Patients, principally those with rare cancers, would greatly benefit from the EHDS, as it enables access to expertise across Europe without the need for physical travel.

Furthermore, patients advocate the use of AI as a tool to support, not replace, the expertise of healthcare professionals. It should empower patients to make informed decisions while being integrated into a patient-centred care approach. This approach should be responsive and respectful to individual patient needs and values. Patients must be active partners in their care, with shared decision-making processes normalised. Additionally, there is a pressing need for full digitisation of medication management systems and the development of an interoperable European cancer registry. These improvements would reduce the bureaucratic burden on healthcare professionals and enhance patient care. Patients also stress the importance of controlling their own data, ensuring it is used responsibly and for their benefit across borders.

Enabling better cancer care through open data ecosystems

The health workforce is expected to deliver improved outcomes with limited resources and must be supported with new tools aimed at managing their workload to reduce stress and burnout. A holistic approach to patient care is necessary as well, considering the entire patient journey from detection through treatment. Critical factors for implementing digital solutions include system interoperability and creating an open ecosystem for data exchange. However, the lack of necessary standards and the reluctance of some medical technology vendors to support open data ecosystems hinder this process. The cancer community must advocate to incentivise the development of AI and software tools within an open and accessible environment. By addressing these issues and promoting integration and interoperability, we can achieve better patient outcomes through enhanced data use and patient-centric care.

Teodora Kolarova

Executive Director, International Neuroendocrine Cancer Alliance, Member of the Patient Advisory Committee, European Cancer Organisation

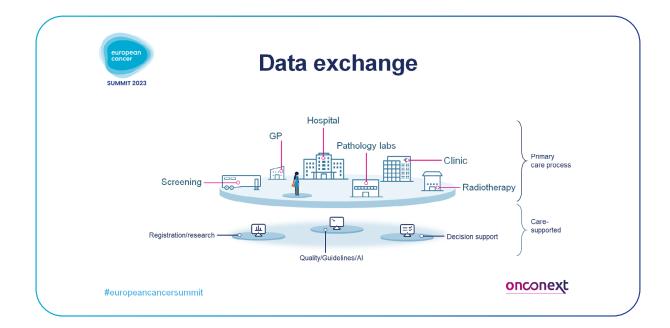


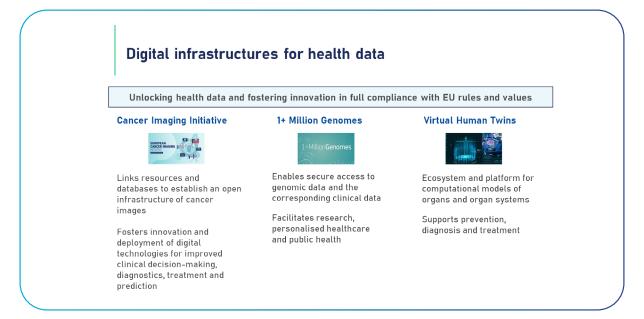


Patients demand timely diagnosis and the best care they can get, in a timely manner. If digitalisation and artificial intelligence can facilitate that then we want to have this change happen as soon as possible, but also in a very structured way that makes sure that patients' interests are safeguarded, and that information is be used in a proper, constructive way.'

Conclusions

The collective insights from patients, policymakers, healthcare professionals, and industry representatives underscore the critical role of digital health in revolutionising cancer care in Europe. Patients emphasise their need for timely, patient-centred care and the use of digital tools to empower informed decisionmaking. Policymakers highlight the importance of robust data infrastructure and harmonised legislative frameworks to ensure the success of initiatives like the European Health Data Space (EHDS). Industry voices call for open ecosystems and interoperability standards to facilitate seamless data exchange, crucial for advancing cancer treatment and research. Healthcare professionals stress the need for integrated digital tools to enhance patient care and alleviate workforce challenges. The unified vision is to leverage digital health as a transformative force in the fight against cancer, ensuring that technological advancements are aligned with patient needs, supported by adequate policy frameworks, and implemented effectively across the healthcare spectrum. The journey ahead requires collaboration, innovation, and a steadfast commitment to making cancer care more efficient, accessible, and patient-focused across Europe.







- Develop a unified, interconnected digital health system to improve patient safety, efficiency, and research capabilities. This initiative requires collaboration among healthcare providers, IT companies, and policymakers, emphasising the standardisation of language and data formats to ensure seamless data exchange and integration across different systems and countries.
- Build a strong legislative and regulatory framework to support the interoperability of electronic health records across the EU. This is essential for the seamless exchange and ethical use of health data.
- Find a balance between patient privacy and the efficient use of health data. This includes establishing clear guidelines for patient consent and data usage, particularly for highly sensitive information.
- Increase EU funding to support the successful implementation and development of EHDS.
- Digital health initiatives should be patient-centred, with patients playing a leading role in decision-making processes.
- Advocate for open ecosystems and interoperability in medical technology and data systems to ensure seamless, secure data exchange and integration.

FIND OUT MORE

- European Cancer Manifesto for 2024
- <u>EU Health Data Space</u>
- <u>European Cancer Imaging Initiative</u>
- European '1+ Million Genomes' Initiative
- <u>Digital Europe Programme</u>
- <u>The Genome of Europe</u>
- <u>The Minimal Dataset for Cancer of the 1+Million Genomes Initiative</u>
- Europe's Digital Decade 2030
- <u>DG Connect</u>

Comprehensive Quality Cancer Care for All

Fedro Peccatori and Simon Oberst, Co-Chairs of the <u>Quality Cancer Care Network</u>

The session description with the full speaker list is available here.

The EU Network of Comprehensive Cancer Centres, a key aspect of Europe's Beating Cancer Plan, aims to improve equal access to quality cancer care and harmonise standards across Europe. The ambitious goal is to provide 90% of eligible patients with comprehensive care, which is defined as integrating research, care, and education within cancer centres or networks.

Comprehensive cancer centres already exist in Europe and have undergone strict certification processes. However, only 20% to 40% of patients in certain countries receive treatment in these centres of excellence. A critical issue is the disparity in quality and resources for cancer treatment between northern/western Europe and central/eastern Europe. The European Union must allocate resources to build comprehensive cancer

Patrycja Rzadkowska

Vice-Chair, Patient Advisory Committee, European Cancer Organisation, Pancreatic Cancer Europe





'I knew something was not OK with me, even when my GP didn't believe me and simply wanted to get rid of me. I found my way around and, with unconditional support from my family, I finally got the correct diagnosis.'

centres in underserved areas. The 'twinning' of cancer centres across borders could help raise standards and share expertise.



From left to right: session Co-Chairs Simon Oberst, Fedro Peccatori and panelists Patrick Michl, Patrycja Rzadkowska, Michail Okoliyski, Mef Nilbert, Christof Kastner, Martin Fensch

As networks grow, their value and productivity increase, making them attractive outside the EU. This expansion could lead to new paradigms of cancer care, particularly in post-conflict scenarios like Ukraine.

Addressing inequalities in pancreatic cancer diagnosis and treatment

On Pancreatic Cancer Day, data is presented to shed light on the increasing prevalence of pancreatic cancer in the Western world, where it is projected to become the second leading cause of cancer-related deaths by 2030. This rise is attributed to factors like lifestyle, obesity, smoking, and alcohol consumption. The disease's challenging nature, characterised by late diagnosis, resistance to systemic therapy, limited surgical options, and disparate access to advanced cancer care, exacerbates the situation.

There is a noticeable disparity in pancreatic cancer incidence and mortality across European countries, as illustrated by data comparisons between countries like Ireland and Hungary. Annually, Europe sees over 150,000 new cases of pancreatic cancer and a similar number of deaths. Addressing this requires a multifaceted approach: enhancing understanding of the disease, improving primary prevention, identifying at-risk individuals, establishing effective early diagnosis methods, and ensuring rapid access to care. Research and investment are crucial to develop new strategies to overcome therapy resistance. Importantly, access to comprehensive cancer centres must be expanded across Europe to improve patient outcomes, which currently vary significantly and unacceptably across different regions.

Navigating pancreatic cancer as a patient

A significant obstacle in pancreatic cancer treatment is the lengthy and complex diagnostic process. Early diagnosis is crucial for successful treatment, yet the average time from initial symptoms to diagnosis is about 100 days. Pancreatic cancer survival rate is low, with only 8% of patients living more than five years post-diagnosis. This is largely attributed to late diagnosis, stemming from a range of non-specific symptoms like nausea, loss of appetite, weight loss, jaundice, and even depression. The current diagnostic pathway for pancreatic cancer is protracted, often starting with GP visits, and progressing through various tests before reaching definitive imaging techniques like CT scans or MRI. Better diagnostic tools are urgently needed. This process can be even longer for younger patients, where pancreatic cancer is less suspected despite clear symptoms. Increased awareness about pancreatic cancer in needed, as well as educating patients and healthcare professionals on symptoms and risk factors.

Martin Fensch

Vice-President, Government Affairs and Strategic Partnerships, Europe and Canada, Daiichi Sankyo





'We need universal healthcare coverage in all European countries, and an even stronger network of cancer centres and cancer research. We see inequalities by gender, socioeconomic status, education, and different regions, and these are not acceptable.'

How to build a comprehensive cancer centre

Building a comprehensive cancer centre involves a meticulous and collaborative process. It starts by identifying existing resources within hospitals, including radiotherapy, systemic therapies, and surgery. These are often dispersed across multiple divisions within the hospital's organisational structure. Universities and other institutes play a crucial role, housing departments including genetics, pathology, and oncology, as well as other relevant fields like physics and chemistry.

The next step involves breaking down silos between these entities and integrating clinical components with research and education. This requires identifying and engaging researchers from universities and other institutes, as well as those involved in cancer education. Building a high performing team with effective governance and data management is crucial. A central budget to facilitate programmatic links is also beneficial. The goal is to establish multidisciplinary teams within the cancer hospital that are closely linked to research and clinical trials. The process takes three to five years even in developed, well-funded countries. It can present a significant challenge, particularly in central and eastern Europe. However, successful implementation and networking can

significantly improve survival and quality of life for patients. European projects such as <u>JANE</u> and <u>CRANE</u> build upon previous efforts such as the OECI and the German Cancer Society, to further advance comprehensive cancer care.

Transforming Bulgaria's cancer care

Bulgaria is actively working to reform its health system, particularly in the field of oncology, in alignment with the recommendations of the European Union. The country has developed the National Beating Cancer Plan 2027, focusing on prevention, screening, diagnostics, and the development of human resources in oncology. Access to oncological treatment in Bulgaria is relatively straightforward and comprehensive.

The Bulgarian government is also addressing early diagnostic challenges by increasing the budget for outpatient care and investing in prophylactic examinations for the early detection of various diseases, including cancer. Efforts to improve participation in preventive health checks are underway. Currently, only 38% of Bulgarian citizens undergo these checks despite a legal obligation. An information campaign is being launched to encourage people to use available health resources. The National Health Insurance Fund covers examinations for tumour markers, and medical institutions are required to provide complex treatments for cancer patients. More than 800 million Bulgarian Lev have been allocated in the 2024 budget for the treatment of malignant diseases. Lastly, the Ministry of Health is calling for health education for children, recognising that early health education can lead to healthier adults and a more health-conscious society.

Advancing comprehensive cancer care in Sweden

Sweden, known for its strong welfare system and public healthcare, faces significant inequalities in cancer care due to geographical and socioeconomic disparities. With a decentralised healthcare system across 21 regions, each having its own taxation and healthcare policies, the challenge is accentuated by the country's diverse population, including significant immigrant communities from various countries. Prior to 2009, Swedish cancer care lacked connectivity among regions and hospitals. The introduction of the first cancer strategy in 2009 was a turning point, leading to the establishment of regional cancer centres. These centres, responsible for cancer registration,



Michail Okoliyski, Deputy Minister of Health, Bulgaria

quality control, and development of joint guidelines, brought about greater coordination among the 21 regions and 70 hospitals.

The Cancer Centre Certification Process in Sweden using the OECI programme, aims to standardise cancer registration, care pathways, and basic treatment principles at a national level. Sweden also centralised the treatment of rare cancers, such as pancreatic cancer, referring all locally advanced cases to expert centres for collaborative decisionmaking. However, challenges remain, particularly in coordinating clinical trials at a national level and adapting to precision medicine. There's also a need for more impactful national-level research and improvements in primary and palliative care. The solution lies in cancer centres taking a broader responsibility, integrating local and regional hospitals into their research networks. This approach not only fosters coordination but also aligns with the missions of the Europe's Cancer Plan, promoting equity and effectiveness in cancer care.

Value-based care in prostate cancer treatment: The Cambridge experience

The implementation of value-based care relies on the use of data to measure outcomes and improve service quality. This approach is rooted in integrated practice units that cross various specialties, moving from traditional hierarchical structures to horizontal ones for better transparency and outcome measurement. An example from Cambridge demonstrates the success of this model, where early adoption of MRI for prostate cancer assessment led to significant improvements. Thanks to this initiative, 40% of patients avoided biopsies, with a high detection rate for the remaining 60%, resulting in both patient benefits and health economic savings.

However, challenges remain in maintaining quality management. Automated analysis and contemporaneous reporting of data are crucial, yet difficult to sustain. Financial incentives help drive quality management. Additionally, the role of data sharing and utilisation is highlighted. In Cambridge, an electronic medical record system integrates various hospital functions, providing a comprehensive data pool. Expanding this pool to include data from other cancer centres could help standardise and benchmark care, ensuring that patients receive equal and high-quality treatment regardless of location.



Christof Kastner Consultant Urologist & Clinical Director for Outpatients, Cambridge University Hospitals



'Value based care will benefit our patients directly but also their finances.'

The evolving landscape of cancer care

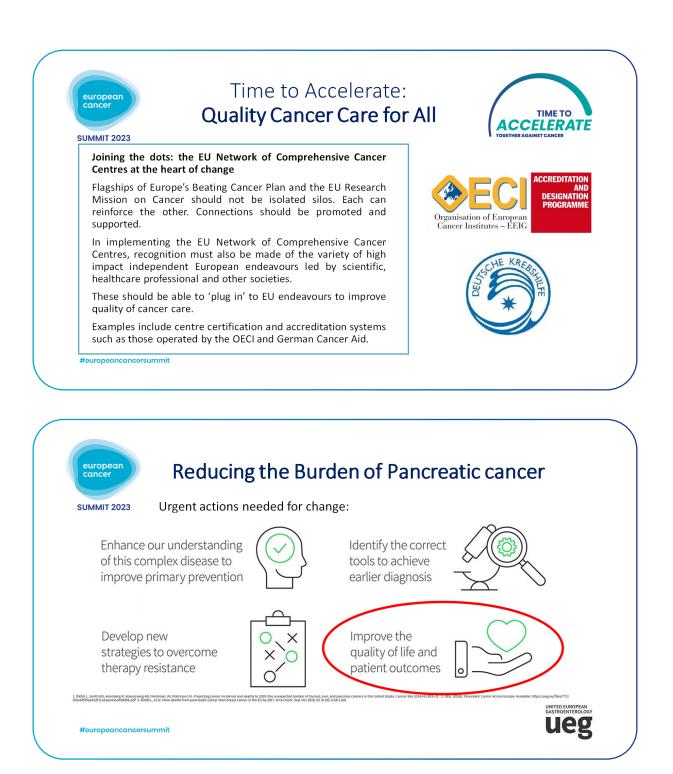
Cancer care has seen remarkable advancements in the last two decades, transitioning from merely extending life by a few months to focusing increasingly on chronic management and potential cures for various tumour types. This progress is attributable to new surgical techniques, diagnostics, radiotherapy, drug therapies, and the collective efforts of oncologists, nurses, healthcare organisations, and policymakers. The pharmaceutical industry has played a pivotal role, not only in medication development but also in areas like biomarker testing and data analysis for side effect management. Despite these achievements, there are still critical areas needing improvement. Prevention is key, with a focus on enhancing screening services and health literacy to detect cancer at earlier stages where treatment is significantly more effective. Access to new treatments varies greatly across the EU, highlighting the need for universal healthcare coverage and a robust network of cancer centres and research networks. Lastly, the challenge of assimilating the vast and ever-growing body of medical knowledge through digitalisation presents an opportunity to transform this information into improved cancer treatments and outcomes.

Conclusions

Achieving equal cancer care requires a multifaceted approach involving healthcare professionals, researchers, patients, the pharmaceutical industry, policymakers, and other professions such as data scientists. Improved prevention strategies, enhanced screening programmes, and the promotion of health literacy for early detection of cancer are also needed. Universal healthcare coverage and the expansion of cancer care networks are also vital to ensure equitable access to treatments. An integrated approach to cancer care, driven by evidence and the right incentives underscored the need for systemic changes, investment in infrastructure and training, increased research, and better resource allocation, to achieve equality in cancer care.



Panelists from left to right: Patrick Michl, Patrycja Rzadkowska, Michail Okoliyski, Mef Nilbert



- Pancreatic cancer is becoming a growing cause of cancer-related deaths in Europe, with disparities in incidence, mortality, and access to care highlighting an urgent need for enhanced understanding, early diagnosis, and equitable treatment.
- Increase investment in preventive health measures, health literacy and early detection for cancers.
- Implement comprehensive health education programmes starting from childhood to foster a proactive health-conscious society.
- Financially incentivise quality management in healthcare and ensure data accessibility for standardised, high quality care across different regions.
- Implement value-driven culture, learning from data.
- Strengthen coordination across regions and hospitals, focusing on centralisation in specific areas like rare cancers and clinical trials.
- Enhance involvement of local hospitals in national cancer networks for more equitable care.
- Establish universal healthcare coverage across Europe.
- Improve cancer infrastructure.

FIND OUT MORE

- European Cancer Manifesto for 2024
- EU Networks of Expertise on cancer
- Organisation of European Cancer Institutes
- CraNE Joint Action

Pragmatic Clinical Trials: A crucial building block for health systems and treatment?

Denis Lacombe and Yolande Lievens, Co-Chairs, Health Systems and Treatment Optimisation Network

The session description with the full speaker list is available here.

The Health Systems and Treatment Optimisation Network started its work in April 2020, working with over 45 representatives from European Cancer Organisation Member Societies, Patient Advisory Committee and Community 365 participating in the Network, as well as with invited experts.

The guiding mission of the Health Systems and Treatment Optimisation Network is to bring about a reorientation of health systems and research approaches in cancer to achieve the twin aims of:

- treatment optimisation (i.e. optimising cancer treatment for the benefit of the patient); and
- health systems optimisation (i.e. optimising cancer care delivery for the benefit of the healthcare system).

Pragmatic clinical trials are instrumental to this mission, offering a more realistic and applicable understanding of how treatments perform in realworld conditions. Unlike traditional clinical trials, which often occur in controlled environments with strict participant criteria, pragmatic trials are designed to reflect the complexities and variability of everyday clinical practice. They typically involve a broader patient population and more flexible protocols, mirroring actual clinical settings and patient behaviours. This approach allows for a more comprehensive evaluation of the effectiveness, efficiency, and applicability of treatments in diverse and routine healthcare scenarios.



On screen: Christopher Booth. From left to right: session Co-Chairs Yolande Lievens, Denis Lacombe and panelists Ajay Aggarwal, Francesco Pignatti, María Jesús Lamas Díaz, Ana Amariutei

An alternative perspective on treatment optimisation

Pragmatic clinical trials in cancer care have a critical role, particularly in addressing treatment optimisation and understanding the real-world impact of cancer therapies. Highlighting the use of Folfox's in bowel cancer as an example, significant variations were noted in patient outcomes and side-effect profiles across different hospitals. This variation calls for pragmatic clinical trials to better understand the impact of drugs and treatment regimens in diverse settings. Discussions also revealed disparities in care, such as the variation in the use of radiotherapy versus surgery for certain cancers, influenced by factors like age, comorbidity, and socioeconomic status. These disparities underscore the need for more inclusive trials and data-driven approaches to treatment optimisation.



Francesco Pignatti

Head of the Office of Oncology and Haematology in the Human Medicines Division, European Medicines Agency



'So, clearly there is no scepticism from the regulators about pragmatic trials used in different contexts.'

Regarding the potential of artificial intelligence (AI) in cancer care, a cautious approach was advocated, since the effectiveness of AI applications in cancer care remains under evaluated, with few prospective studies conducted. The Archery study, focusing on AI in radiotherapy planning across different global health settings, was cited as an example of how to rigorously test Al applications. More value-based healthcare strategies are needed, including research that considers patient-relevant endpoints such as quality of life and functional outcomes. This approach could guide clinicians and policymakers in making informed decisions about reimbursement and the integration of new technologies, ultimately optimising cancer care.

Pragmatic clinical trials: perspectives from a regulator

Pragmatic clinical trials, in contrast with traditional trials, are designed to reflect real-world scenarios more closely. This approach acknowledges that in real life, not everyone receives treatment according to intended protocols due to various factors, such as protocol errors and intercurrent events. The focus is on outcomes that matter to patients, like disease progression, rather than strictly adhering to traditional endpoints. Regulators do not inherently oppose these trials; instead, they encourage efficiency and relevance in data collection, moving away from bureaucratic approaches that often gather insignificant data. Importantly, trials must be 'fit for purpose', answering specific questions effectively.

However, the application of pragmatic trials is approached cautiously by regulators. Their place in the drug development process isn't fully defined, needing more research. A systematic approach is needed to determine where and when these trials are most appropriate. This includes defining models and using value frameworks to balance uncertainties and patient values at different disease stages. The discussion also touches on the need for more effective communication of trial limitations and assumptions, not just at the time of drug approval but throughout the drug development process.

The recent Health Technology Assessment regulation in Europe is seen as a positive step towards coordinating evidence generation and supporting treatment optimisation efforts.

Improved methodologies needed for real-world evidence

The national regulatory perspective on pragmatic clinical trials underscores the need for a more unified and efficient approach across Europe. The <u>EU clinical trial regulation</u>, which came into application recently, aims to centralise and harmonise the assessment process for clinical trials. This change is expected to facilitate greater European involvement in research.

The ACT EU initiative seeks to address the low participation of European patients in clinical trials, which is seen as a missed opportunity for both patients and health systems. One of the initiative's priorities is to enhance academic research, recognising the gap in knowledge post-authorisation of medicines. Real-world evidence (RWE) and pragmatic clinical trials are crucial in understanding how medicines perform in diverse populations and conditions, not typically included in initial clinical trials. This approach supports regulatory needs throughout the entire lifecycle of medicines, ensuring quality, safety, and efficacy even after authorisation. The use of large databases like **DARWIN EU** and Spain's **BIFAP** for real-world data analysis is highlighted as a promising development for post authorisation research.



María Jesús Lamas Díaz Director, Spanish Agency for Medicines and Health Products



Pragmatic information about how to get the best of medicines is mainly done by academia, mostly in national trials. So, representativeness is not always as good to inform health policy or regulatory checks. That is why we need to improve the way academia research is done in Europe.'

Nevertheless, there is a need to improve methodologies for analysing and using real-world evidence and data from pragmatic clinical trials. This effort is crucial for filling knowledge gaps post-authorisation and ensuring that regulatory decisions throughout the medicine lifecycle are informed by robust and comprehensive data.

A call for inclusivity and real-world relevance

From a patient's viewpoint, traditional cancer treatments, though beneficial, are not fully meeting their needs. This gap is partly due to limitations such as restrictive inclusion criteria, which often exclude patients who ultimately receive the treatment. The endpoints of these trials may not align with what is meaningful for patients, and the trials can be costly and slow, making them impractical for urgent needs of cancer patients. Pragmatic clinical trials, conducted in real-world settings like local hospitals, are seen as a beneficial alternative. They are potentially quicker to approve, have broader inclusion criteria, and can better inform clinical and policy decisions. Patients appreciate the opportunity for early engagement in these trials and the simplicity of consent processes.

However, pragmatic trials face challenges such as lack of strict controls, variability in data quality, and comparability issues. Incorporating data from electronic health records is another hurdle. Despite their potential to optimise care by addressing effectiveness, toxicity, adherence, and cost in real-world settings, pragmatic clinical trials are rare. Patients advocate for trials that not only prolong life, but also enhance its quality. These trials need to focus on what patients value, need, and experience, ensuring that endpoints are meaningful and defined in collaboration with patients.

Common sense oncology

Pragmatic clinical trials are needed to address the 'value crisis' in oncology. While acknowledging advancements in cancer treatments, focus should shift towards outcomes meaningful to patients, namely overall survival, and quality of life. Christopher Booth describes what he classifies as a paradox cancer care: the overutilisation of marginal and expensive treatments, contrasted with the lack of access to effective treatments and palliative care for most patients worldwide. This crisis is attributed to factors like the staggering costs of cancer care, issues in clinical trial design, the overemphasis on progression-free survival, small effect sizes of new treatments, and communication breakdowns within the field.

A new initiative: Common Sense Oncology seeks to recalibrate the field towards patient-centred outcomes, focusing on access, affordability, and health justice. This global movement, involving various stakeholders, promotes evidence generation, interpretation, and communication that prioritise patient needs. Its guiding principles include the right to quality cancer care, the necessity of treatments that improve life quality and duration, informed decision making, equitable access to care, and a holistic approach to cancer treatment beyond just medication. The initiative emphasises the importance of effective evidence generation in clinical trials, critical thinking in treatment selection, and clear communication with patients and policymakers, striving to reduce global disparities in cancer care access and quality.

Ana Amariutei Research Manager, European Patient Advocacy Institute



'We must try to remember that health-related but also non-health related values are important for the patients.'

Conclusions

Pragmatic clinical trials should be randomised and have the benefit to bring robust methodology to evaluate real-world effectiveness. Inclusivity helps ensuring that treatments are not only clinically effective but also aligned with patient needs and experiences. Patients benefit from trials that prioritise outcomes meaningful to them, such as quality of life and overall survival. Regulators and national agencies emphasise the importance of harmonising trial methodologies and using real-world evidence to make informed decisions throughout the lifecycle of medicines. This approach helps bridge the gap between clinical trial data and actual patient outcomes post-authorisation. Healthcare professionals advocate for a reorientation of clinical research towards tangible patient benefits, moving away from surrogate endpoints to focus on genuinely impactful outcomes. Initiatives like '<u>Common Sense Oncology</u>' highlight the necessity of generating evidence that truly reflects patient priorities, critically evaluating treatment efficacy, and maintaining clear communication with all stakeholders.

Overall, pragmatic clinical trials have the potential to create a more responsive, effective, and patient-centred healthcare system. However, they must address challenges such as ensuring consistent data quality, managing variability across different settings, and integrating diverse data sources effectively to optimise their impact on health systems and treatments.

Christopher Booth

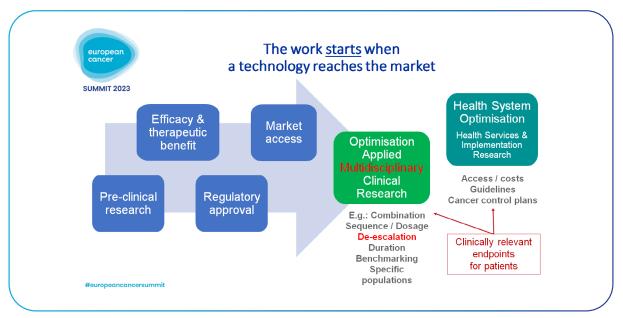
Director, Division of Cancer Care and Epidemiology, Cancer Research Institute, Queen's University





'Common Sense Oncology will promote interventions that measurably improve the lives of patients. We will celebrate well conducted trials and promote effective treatments, but we will also speak up about, and challenge, interventions that might cause more harm than good.'





- Expand the use of pragmatic clinical trials to understand real-world effectiveness and sideeffect profiles of cancer treatments.
- Invest in technology and AI applications, ensuring their effectiveness through robust, prospective studies.
- Develop a more systematic and evidence-based approach to determine the appropriate use and timing of pragmatic trials in the drug development process. This approach should consider the generalisability of results and the specific contexts where these trials are most effective.
- Improve communication about the limitations and assumptions of different types of trials, including pragmatic trials. Regulators, along with academic and healthcare institutions, should collaborate to effectively communicate these aspects, extending beyond drug approval to encompass the broader context of drug development and treatment optimisation.
- Strengthen the centralised and harmonised assessment of clinical trials across Europe to encourage broader participation and ensure that trials are more representative of diverse populations and healthcare needs.
- Improve methodologies for analysing and use of real-world evidence and data from pragmatic clinical trials. This effort is crucial to fill post-authorisation knowledge gaps and ensuring that regulatory decisions throughout the medicine lifecycle are informed by robust and comprehensive data.
- Finding and supporting a place for academic research in the new regulatory environment.
- Pragmatic clinical trials should routinely include patient-reported outcomes and preferences.
- Ensure that clinical trials in oncology focus on outcomes that truly matter to patients, such as overall survival and quality of life. This involves re-evaluating current trial designs and endpoints to align with the real-world needs and experiences of cancer patients.
- There is a critical need to increase the number and scope of pragmatic clinical trials to ensure broader inclusivity.
- Pragmatic trials should be designed to reflect real-world scenarios more accurately, thereby providing treatments that improve patients' lives in practical, tangible ways.
- Collaboration among various stakeholders, including patients, healthcare providers, and researchers, is essential to address these issues effectively and optimise treatment and healthcare systems.
- Address the global disparities in access to effective cancer treatments and palliative care.
- Foster a collaborative approach to ensure fair pricing and availability of cancer therapies, along with the necessary supportive services, to patients regardless of their geographic location or financial status.

FIND OUT MORE

- European Cancer Manifesto for 2024
- Data Analysis and Real-World Interrogation Network (DARWIN EU)
- Accelerating Clinical Trials in the EU (ACT EU)
- <u>EMA on clinical trials</u>
- <u>BIFAP</u>
- <u>EU Clinical Trial Regulation</u>
- <u>Common Sense Oncology</u>



From left to right: Ajay Aggarwal, Clinical Director for the National Cancer Audit Collaborating Centre & Board Member, European Cancer Organisation; Francesco Pignatti, Head of the Office of Oncology and Haematology in the Human Medicines Division, European Medicines Agency and María Jesús Lamas Díaz, Director, Spanish Agency for Medicines and Health Products

An Oncology Workforce in Crisis: They care for us. Do we care for them?

Wendy Oldenmenger, Mirjam Crul and Beate Rau, Co-Chairs of the <u>Workforce Network</u>

The session description with the full speaker list is available here.



Europe is currently facing a significant crisis in its oncology workforce. Healthcare professionals, including doctors, nurses, pharmacists, and pathologists, are under unprecedented strain due to the severe shortages. The immense pressure of increased responsibilities, growing caseloads, and administrative burdens is leading to burnout, with many professionals leaving their careers in healthcare. As a result, the burden on those left behind increases and the quality of cancer care is being compromised. This session delved into the multiple challenges facing the oncology workforce in Europe, examining the underlying causes, the impact on healthcare delivery, and potential strategies to address this growing concern. It underscores the urgent need for data and a comprehensive response to support those who dedicate their lives to caring for cancer patients.

Oncology nurses struggling to cope

The nursing profession, crucial in cancer care, has not recovered from the pandemic's impact. Nurses report feeling isolated and unsupported, exacerbating the challenges in providing quality care. <u>Testimonials from various oncology nurses</u> across Europe paint a grim picture: severe understaffing, with nurses overwhelmed by patient loads, insufficient time for patient education, and inadequate training in chemotherapy protocols. Junior nurses and temporary staff, lacking in experience and competency, are thrust into demanding roles, while experienced staff are leaving the profession due to burnout and untenable working conditions. The shift



From left to right: session Co-Chairs Mirjam Crul, Beate Rau and panelists Heather Moses, Wendy Oldenmenger, Marta Cohen, Heather Moses, Antanas Montvila, Rachel Giles, Cris Scotter

from personalised care to managing increased patient ratios – sometimes as high as 12 patients per nurse – has led to more medical errors, pressure ulcers, and delays in providing essential treatments like chemotherapy. This crisis is not limited to nursing but is a widespread issue affecting all healthcare professionals. To better understand the scale and impact of this crisis, healthcare professionals are encouraged to share their experiences, contributing to a broader awareness of the workforce challenges in cancer care across Europe. <u>Tell us your story</u>.

Increased pressure on the pathology workforce

The pathology workforce, essential in cancer diagnosis and treatment, is facing severe challenges globally. These challenges include burnout, a trend towards early retirement and part-time work for better work-life balance, and migration of professionals to countries offering better working conditions. The situation is compounded by difficulties in recruiting and training new pathologists, particularly with the varying standards of training across regions. In the UK, a significant portion of the workforce is nearing retirement age, with no clear plan to replace them. This shortage is resulting in delays in cancer diagnoses, impacting patient outcomes. Studies have shown that delays in pathology testing can lead to significant delays in treatment that in turn increase the mortality risk for cancer patients.

The field of pathology is also bracing for the challenges posed by advancements in genomics and molecular genetics. These technological strides are increasing both the complexity and volume of tests required for early and accurate cancer diagnosis. Pathologists must adapt to

\bigcirc

Registered oncology nurse

'I've never seen staffing as bad as it is right now. Before the average ratio was one nurse for every four to six cancer patients; today the ratio is closer to one nurse for every eight to twelve patients, and sometimes even worse. Covid created issues for us. A lot of staff burnt out and this partly resulted in the crisis we're in right now. It's not unusual to see an increase in errors, increase in pressure ulcers, patients not receiving medication in a timely manner, or even having nutrition needs covered. These all have great implications for the outcomes of cancer care.'

Antanas Montvila Vice-President, European Junior Doctors Association (EJD)





'We identified that there is a great shift in specialty and career choices. The young generation tends to choose 'sexier' professions that offer better quality of life, more flexibility, and options to work in private practice. Sadly, for oncology, this profession is no longer so 'sexy.' They don't want to choose these kinds of high-demand professions.'

these evolving demands, which require a further increase in workforce and expertise to meet the growing need in these areas.

Using digital technology to alleviate the work burden

The pharmaceutical industry can play a supporting role to alleviate the cancer workforce crisis, particularly by providing digital innovation and help to implement efficient practices. Advanced digital tools, such as computational pathology driven by artificial intelligence, can significantly reduce the workload for healthcare professionals. These technologies not only streamline diagnostic processes but also enhance precision in patient care, potentially reducing diagnostic errors and increasing job satisfaction. Automation in healthcare systems, exemplified by advancements in diagnostic tests and patient triaging, contributes to the efficient allocation of resources and improves access to care.

Optimising multidisciplinary teams (MDTs), which are central to cancer care decision-making is also important. Tools and programmes for selfassessment and best practice sharing in MDTs are being developed to improve organisation and reduce variability in quality. Streamlining workflows within these teams can alleviate bureaucratic hurdles, thus enhancing collaboration and decision-making efficiency. Additionally, quality improvement processes, such as streamlined diagnostic and treatment pathways, are vital. By simplifying these pathways, the industry can help ensure timely and appropriate care, freeing up resources for early detection and prevention efforts. These multifaceted approaches aim not only to improve workforce efficiency but also to reduce healthcare costs and enhance patient care.

Redefining priorities: the new generation of cancer care workers

The healthcare system, as highlighted in a recent OECD report, is described as 'underprepared. understaffed, and chronically underfunded,' reflecting the enduring issues in the medical workforce. Junior doctors, aware of the expectation of working extra hours and personal life sacrifices, perceive this crisis as an ongoing challenge. A study involving interviews with members of a junior doctor society across 27 countries, led to the report From Tradition to Transition: Navigating through Healthcare Workforce Crisis. This qualitative research reveals widespread job dissatisfaction and disappointment among junior doctors in Europe, irrespective of the country. A notable finding is the heavy workload crushing junior medical professionals, stemming from a healthcare model focused on service provision rather than quality outcomes. Additionally, the report identifies a 'generational shift' in the medical profession, where newer generations seek a better work-life balance and resist sacrificing personal life for hospital duties. This shift is accompanied by a redefined professional calling, leading to a silent protest characterised by resignations from medical professionals unwilling to support a failing system.

Patients struggle in the healthcare workforce crisis

The current healthcare workforce crisis significantly affects patient care, leading to deteriorating quality of service and exacerbating existing healthcare disparities. Patients increasingly find themselves in situations where errors occur due to overburdened healthcare systems. This decline in care quality is reflected in patient surveys, with notable drops in satisfaction rates. A major concern is the communication breakdown between healthcare providers and patients. Time constraints in healthcare interactions lead to misunderstandings, confusion about treatment plans, and a sense of neglect among patients, who turn to patient organisations for clarity and support.

Patient stress levels have significantly risen, partly due to limited time for patient interaction. This has resulted in patients feeling intimidated to discuss their concerns with healthcare professionals, further compromising the treatment experience. Empathy and understanding from healthcare professionals, despite high pressures, are crucial to improve patient outcomes, especially during the vulnerable period between diagnosis and treatment. Patient organisations advocate for enhanced training for doctors in empathetic communication. Patient organisations, which also generate evidence through randomised control trials, emphasise their role as part of the solution, advocating for substantial recognition and integration into the healthcare system.

Cris Scotter

Human Resources for Health Policy Advisor, World Health Organization





'We need to encourage investment, we need to build supply, we need to think about planning the service. We need to consider the three Rs: recruitment, retention, and return. The loss to the system of people leaving or retiring early is powerful; it costs so much to retrain someone to gain all that experience. We should not just allow them to walk out the door.'

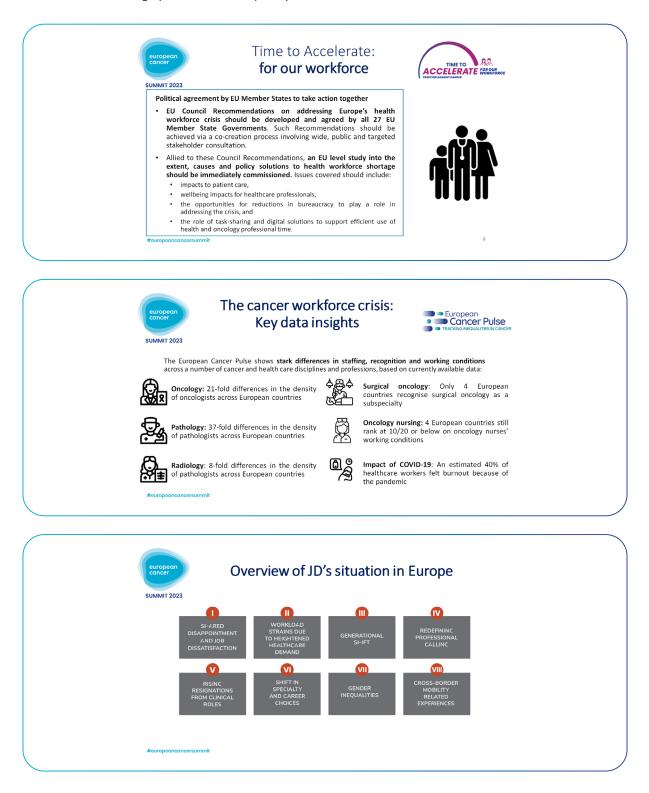
Addressing the healthcare workforce crisis

The healthcare workforce crisis in Europe, a longstanding issue exacerbated by Covid-19, has revealed significant shortcomings in workforce investment and planning. Historically viewed as a cost rather than as an investment, the healthcare workforce has faced neglect from governments, leading to shortages and poor supply governance. These shortages directly impact patient care, with a clear correlation between workforce availability and positive health outcomes. The crisis is further intensified by an ageing workforce, increased feminisation, and changing work profiles, with a growing preference for family-friendly hours among all genders. The competition for talented young professionals and the retention of existing staff, compounded by migration trends, present ongoing challenges. Sustainable solutions require workforce policies that are integral to service delivery planning.

Addressing this crisis requires a multifaceted approach: investing in the workforce, building supply, and thoughtful service planning. This includes considering finance, equipment usage, and focusing on team capabilities rather than individual competencies. The focus should be on the 'three Rs': recruitment, retention, and return, encouraging professionals who have left the workforce to re-join. Optimising team performance, using technology, and integrated planning are crucial.

Conclusions

The workforce crisis in healthcare, particularly severe in oncology, is a multifaceted issue that requires urgent and comprehensive action. The crisis stems from chronic underinvestment, lack of strategic planning, and a failure to view the healthcare workforce as a vital asset. This has led to staff shortages, burnout, and a decline in quality patient care. In oncology, where the complexity of care demands a highly skilled and adequately supported workforce, the challenges are particularly acute. To address these challenges, a collaborative approach involving governments, healthcare organisations, and educational institutions is crucial. Key strategies include investing in workforce development, enhancing recruitment and retention, adopting new technologies to streamline processes, and rethinking service delivery models. By prioritising these actions, the healthcare sector can build a more resilient and effective oncology care system for the future.



- Invest in the workforce and comprehensive service planning.
- Adopt a multifaceted approach to workforce management with focus on recruitment, retention, return, and optimisation of team performance.
- Improve communication between healthcare professionals and patients.
- Encourage training for healthcare providers in empathetic communication.
- Embrace technological advancements as tools to enhance productivity and support the workforce.
- Increase the number of training posts for pathologists and enhance the visibility of pathology as a career option in medical schools.
- Invest in digital pathology and the development of non-medical practitioner roles to help alleviate the burden on pathologists.
- Integrate digital innovation and automation into healthcare workflows to streamline processes, reduce manual workloads, and enhance the efficiency and accuracy of cancer diagnosis and treatment.
- Strengthen the organisation of multidisciplinary teams through tools for self-assessment, best practice sharing, and streamlined workflows.
- Implement a pan-European approach to prepare medical professionals, acknowledging the long-term nature of this process.
- Prepare healthcare systems to operate effectively with the current or even reduced numbers of healthcare professionals.
- Unified training of healthcare professionals across Europe to maintain high standards.
- Leverage patient organisations as partners in generating valuable data and evidence.

FIND OUT MORE

- European Cancer Manifesto for 2024
- Tell us your story
- Take the ECO survey for cancer workforce
- From Tradition to Transition: Navigating through Healthcare Workforce Crisis
- Repository of Best Practices and Innovations
- <u>WHO on health workforce</u>

Acknowledgements

We would like to thank the following organisations for their support and cooperation which made the European Cancer Summit 2023 such a success. We look forward to continuing these partnerships to achieve our common goals.



Save the Date: The next European Cancer Summit takes place on 20 & 21 November 2024



As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.

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