



European Cancer
Patient Coalition



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Annual Congress Report 2023



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1. Executive summary

“Nothing about us, without us” – within the last 20 years, the European Cancer Patient Coalition (ECPC) has raised this motto to the rank of a mission, becoming the voice of the cancer patient community that the Coalition has proudly served.

The Annual Congress 2023 was aimed at celebrating the twentieth anniversary of the organization (2003-2023). On this occasion, representatives of the ECPC member organisations at the national level, policymakers, academia, health organisations and pharmaceutical industry, together with the ECPC Board, Scientific Committee and staff members reunited in Brussels between 23-24 June to rejoice the achievements of the organisation, honour those who lost their battle with cancer while actively contributing to the work of ECPC and discuss the future of the organisation. Participants were filled with joy and emotion while sharing memories of the beautiful and rewarding years of collaboration with ECPC and of the common efforts to build a united patient community that continues to bring added value to the lives of those affected by cancer.

2. Introduction

In 2003 the European Cancer Patient Coalition (ECPC) has been established to become the voice of the European cancer patient community. Twenty years later, the Annual Congress 2023 has been a momentum for celebrating the hard work and accomplishments of the organisation in serving the cancer patient community and, at the same time, for acknowledging the challenges and struggles in building and rebuilding a trustful and sustainable organisation.


Indeed, within the last two decades, ECPC went through many changes: in terms of its member organisations, in terms of defining the community it represents, in terms of shaping its mission and vision, in terms of strategy and priorities, and in terms of those who serve and support cancer patients. Some of those who put their effort into building what ECPC is today are no longer with us and this Congress was timely to ensure that their memory stays alive.

During its first two decades, the European Cancer Patient Coalition focused on strengthening the involvement of cancer patients, survivors and caregivers in all initiatives in the fields of policy and research that have been developed for patients and could impact their lives. In line with this, the Annual Congress 2023 was structured in six sessions with the aim to introduce the participants to the history of the organisation and its achievements, but also to the current policy and research project work and priorities and its strategy in the long term.

The first session was dedicated to celebrating the 20 years of ECPC with high level stakeholders expressing their appreciation of what the organisation has accomplished so far and commitment to continue the collaboration for the benefit of patients.

The second session reflected on two key milestones at the EU level – the Horizon Europe’s Mission on Cancer and the Europe’s Beating Cancer Plan, where EU Institutions and the Member States committed to work together to ensure that cancer patients and survivors have access to the best care possible.

The third session brought into attention two important relevant dossiers at the EU level – the Pharmaceutical Package and the Health Technology Assessment Regulation, it pointed out the importance of patients having access to personalised medicine and biomarker testing and concluded with the role of patient advocates in shaping the EU policy landscape.



The fourth session focused on the cancer delivery landscape, talking about the need for the EU health systems to adapt to the proposed model of Comprehensive Cancer Centres and the importance of the networks of expertise, such the joint action JANE.

The fifth session was dedicated to policies to tackle inequalities in cancer care and introduced the results of the ECPC White Paper on Socio-economic Disparities in Cancer in Europe, talked about the Right to be Forgotten Law and policies in place for job retention and return to work for cancer patients and survivors and concluded with the case of Romania for addressing socio-economic disparities.

The last session focused on cancer research and pointed out the role of biomarkers in cancer research, how patients can advocate for biomarker testing at the national level and introduced the TIGER EU project where ECPC is partner.

During each session, participants asked questions and expressed their views about relevant ongoing EU projects and policy files that impact the lives of cancer patients, and about new best practices in cancer care delivery and patient advocacy.

1st Session: 20 Years of Cancer Policy Advocacy

Moderators: Francesco de Lorenzo - Kathi Apostolidis - Mary Bussell

Speakers: Francesco de Lorenzo – ECPC President

Stella Kyriakides – EU Commissioner on Health and Food Safety

Kathi Apostolidis – ECPC Past President and Chair of the Scientific Committee

Mary BUSSELL - Founding partner of TriMar Strategies

Alberto COSTA - Director of the European School of Oncology, Member of the European Commission's Europe Against Cancer Programme

Jens HABERMANN - Director General of BBMRI-ERIC, Project coordinator at CanSERV

Manuela PAUŞAN - Scientific stakeholder specialist for BBMRI-ERIC, Member of the PMT, CanSERV


Elisabetta IANNELLI - Lawyer, Vice President Aimac, General Secretary FAVO

The first session reflected on the last 20 years of the Coalition's comprehensive efforts to serve the cancer patient community which includes activities related to EU policy and advocacy and patient involvement in cancer research and the participatory approach, with the aim to improve the quality of life of cancer patients and survivors. An important part of this session focused on the vision of the organization for the next decade to serve better the cancer patient community.

The President of ECPC, Francesco the Lorenzo, opened the event welcoming all participants to the anniversary Congress. He summarized the key activities of ECPC in the field of policy and cancer research within the last 20 years and expressed his gratitude towards all members and collaborators. He stated that insuring patients' access to innovative medicines has been among the primary goals of the organization and that the Annual Report 2022 is the best proof of ECPC's efforts representing the voice of the cancer patients.

Following De Lorenzo's opening remarks, all participants kept a moment of silence in memoriam of Jacob Landsmann Hansen, ECPC Board Member, who passed away in May 2023.

Kathi Apostolidis explained that ECPC delivered patients advocates able to support the cancer patients across Europe. The role of ECPC is to drive the change on cancer policy where members cannot reach.



ECPC contributed to the publication of the EU Beating Cancer Plan and to the vision of the setting up of the Comprehensive Cancer Centres. ECPCs involvement CanCon and JARC joint actions represent the proof of the excellent work and achievements of the organisation. It is now time for ECPC to move ahead and design the new vision for 2023 – 2033.

In her video message, Stella Kyriakides stated that for two decades ECPC has represented the voice of all cancer patients in the EU and, in this sense, took the opportunity to congratulate all participants at the Congress. She then explained that the title of the congress “Collaboration. Connection. Listening to the Needs of Cancer Patients: The essence of EU’s Beating Cancer Plan and Cancer Mission” resonates well with the principles used to design the EU Beating Cancer Plan, that delivered many flagship initiatives, the Inequalities Registry being a key one. Investing in prevention and early detection is crucial in cancer care. Screening programmes in the EU have been extended to lung, breast and gastric cancer. The plan also calls for an EU network of Comprehensive Cancer Infrastructures (CCIs), aimed at 90% coverage among citizens by 2030. The plan is a holistic and well-founded strategy, but its success depends on the contribution of all stakeholders involved. ECPC is therefore a key partner as patients must be at the core of its implementation.

Mary Bussell emphasized the need to double the efforts and address the current challenges. WHO predicted that 1 million cancer diagnoses would be missed due to the delays caused by the Covid-19 pandemic. One month delay in cancer diagnostic will decrease a patient’s survival by 10%. There is a need to find ways to meet the demands of our next crisis – the pandemic posed by cancer. The main principles in this sense are ensuring patient centricity, eliminate obstacles to cancer care, make use and integrate technological advancements, eliminate cancer stigma, prioritize cancer to build up a more resilient and sustainable future, eliminate barriers and achieve health equity. ECPC has actively contributed to promoting patient engagement in research. New screening programmes are available, promising significant steps forward. Making use of modern research processes is vital. However, there is a need to strengthen cooperation at international and global levels. Member States know their individual situation and can learn from each other.

In his recorded message, Alberto Costa pointed out that ECPC was launched with the idea that nothing can be achieved without the patients’ participation. The organisation needs to continue its efforts to find solutions, promote innovation and avoid conflicts.

Jens Habermann wholeheartedly congratulated ECPC on its twentieth anniversary, appraising its achievements and the long-standing collaboration with BBMRI. While expressing his regrets for not being able to attend the Congress in Brussels, he pointed out ECPC involvement in cancer research throughout the whole cancer pathway and mentioned the collaboration on the CanServ EU project.

Manuela Pauşan expressed her gratitude to the ECPC members for being part of the European biobanking BBMRI-ERIC and to ECPC for being a reliable partner. The BBMRI-ERIC Stakeholder Forum is a mean to ensure that patients’ voices are heard and that patients’ representatives are involved in all relevant aspects of research. Patients can enhance clinical research by providing biobanking samples.

Elisabetta Ianneli remembered the pioneering times, AIMaC, the organization she represents, has been an ECPC member since 2003, and also the wonderful personality of former President and Founder Lynn Faults-Wood.

Evgenia Dimitrova Aleksandrova who is currently an ECPC Board Member, said that she also misses Lynn Faults-Wood, and expressed her gratitude to be part of ECPC. The organization has achieved a lot, it started as a family and it should follow this pathway in driving the policy change.

Simona Ene representing the Association of Cancer Patients in Brasov (Romania) said she started her volunteer work as patient advocate twenty years ago, soon after she was diagnosed with cancer. She first attended the ECPC congress in Warsaw in 2005. Between 2007-2012, she was ECPC Board member, honored to be part of organisation and contribute to its development.

Piero Rivizzigno representing Codice Viola (Italy) shared the need for the organization to look to the future. We are in a revolutionary moment due to digital technology, and we have to adjust accordingly. Patients must contribute and not remain passive. He expressed the hope that ECPC would take the leadership in this sense.

In his final remarks, President De Lorenzo said that within the last 20 years, ECPC has played an essential role in Europe by successfully acting as the voice of cancer patients. ECPC has successfully shaped the EU healthcare policy landscape by working closely with the European Commission, Parliament and Council. In this sense, he point out the most important achievements so far:

- in 2008, under the leadership of the President and Founder Lynn Faults-Wood, ECPC was one of the promoters of the establishment of the EPAAC-European Partnership for Action Against Cancer, under the Slovenian Presidency of the Council of Europe. At that time, Slovenia was the first country to put cancer high on their Presidency agenda;
- In 2015, at the initiative of ECPC, and in collaboration with MEP Gardini, a Call to Action (Signed by 250 MEPs) was put forward to harmonize the HTA Evaluation at European level. The initiative was welcomed by the Health Commissioner Vytenis Andriukaitis. Soon after, The EU Commission proposed the HTA Regulation (EU) 2021/2282EN.
- ECPC also brought a valuable contribution to the Joint Action on Rare Cancers - JARC, that further evolved to become to the Rare Cancer Agenda 2030.
- after the European elections of 2019, ECPC has set up the first and only Parliamentary “Challenge Cancer Intergroup” that gathers 37 MEPs from different political groups

ECPC also faced crisis situations, namely, in 2009, when founder and President Lynn Faults Wood was obliged to resign, and in 2020, when President Kathi Apostolidis was removed by an ad hoc Board majority.

Due to its strong roots in all EU Member States, its direct involvement at all institutional levels – ECPC represents a hub of expertise, knowledge and recognition that must be valued. The EU’s Beating Cancer Plan recognized the importance of active patient involvement in cancer care. At the beginning of 2023, ECPC signed a Memorandum of Understanding with OEI - to actively collaborate on new policy areas, with an important focus on survivorship care.

“As President of ECPC in this critical mandate, to bridge the past and the future, I will work closely with all ECPC members to develop transparency, democracy, mindfulness, evidence, truthfulness. This can only be achieved with the support, experience, knowledge, commitment, and voluntary involvement of all members, partners, sponsors, and friends. We can advance into the new decade only if we remain united and continue to speak with one voice, the ECPC voice, about cancer. “

2nd Session: EU Beating Cancer Plan and the Mission on Cancer: How far have we come?

Moderators: Denis Horgan

Speakers: Sandra Gallina - Director General for Health and Food Safety (DG SANTE), European Commission

Walter Ricciardi – President of the Mission Board for Cancer of European Commission

Marc Van den Bulcke - Head of service at the Cancer Centre of Sciensano, Project Coordinator at Can.Heal

Eric Solary - Full-Professor in Hematology at Université Paris-Saclay and a physician scientist in Gustave Roussy Cancer Center (Villejuif, France) Project Coordinator, UNCAN.eu

Giovanni Apolone - Scientific Director, Fondazione IRCCS Istituto Nazionale Tumori
President and Chairperson EU Affairs – OECL, Project Coordinator, CCI4EU

The second session reflected on the EU's commitment to defeat cancer, particularly in relation to patients. The focus of the discussions was on the two key milestones at the EU level – the Horizon Europe's Mission on Cancer and the Europe's Beating Cancer Plan. Joint Actions were identified as the policy arms of the EU Beating Cancer Plan.

Sandra Gallina stated that ECPC has shown the importance of equity in access to the highest quality cancer care. The long-term efforts to empower cancer patients are recognized in the Europe's Beating Cancer Plan. This is why the plan tackles inequalities in cancer care and addresses the need for patients to be at the core of all initiatives that impacts them. The plan is closely connected with the Horizon Europe Mission on Cancer, and seeks to tackle cancer throughout the disease pathway, from prevention, early detection, treatment, to ensuring that people affected by cancer have an optimal quality of life. In both initiatives, prevention and early detection play a very important role. The new Council Recommendation on Cancer Screening adopted last December marked the most recent prevention milestone. Joint success depends on close cooperation across all levels of society. By working together, we can make even greater strides in the next 20 years.

Walter Ricciardi explained that in the report "Conquering cancer: mission possible", the joint efforts are not as successful as desired, but they are on the right track. The mission approach allows Europeans to tackle the most important challenges of our time: climate change, water, food and agriculture, and cancer. The reason for including cancer among these incredible challenges is the fact that the pandemic of this disease is hitting Europe in a serious way. With less than 10% of the global population, the EU experiences 30% of the world's disease burden. Without a prompt and appropriate response at different levels, this the global burden of disease will reach 50% by 2030. The mission-oriented approach is inspired to create a common narrative to make people understand multidisciplinary teams like the missions to the moon.

In summarizing what has been done in the field of the mission has provided concrete solutions created together (by researchers, professionals, patients, the most citizen, managers, stakeholders). The importance of compiling the report with all stakeholders has been identified as a key to success (including cancer patients and citizens, industry, media). The Board Mission came up with 13 bold recommendations in the areas of prevention and early diagnosis, in diagnosis and treatment, in quality of life and cross cutting areas. The most iconic is essentially – the European Cancer Patient Digital Centre. Among the obstacles to the implementation of this recommendation into practice are considered limits of privacy law and the GDPR. Citizens should have access and afford the best existing care and medical expertise, no matter where they live.

Marc Van den Bulcke's speech focused on the EU Joint Actions. The Joint Actions are designed to encourage national authorities, academic and non-profit organisations to join forces with the European Commission (EC) to tackle major public health issues. Their added value is the high level of EU involvement. A significant amount of funding has been made available through Joint Actions and supports the objectives of the Health Programme by stimulating European and national investment in the health sector in Europe. Joint Actions aim to develop the best solutions to common European public health problems.

The implementation of the EU Beating Cancer Plan in Belgium consists of the development of a structure that facilitates:

1. the exchange of knowledge and information about needs and opportunities
2. obtaining financial support from the EC program(s)

3. align with the EU Beating Cancer Plan Implementation Roadmap¹

There are overlaps in the initiatives launched through different programs, there is a lack of a helicopter tool that allows overseeing the many activities, and a need for a clear vision and ownership of the initiative, and for lean and agile processes. The main issue remains if the current format of Joint Actions really matches the ambitions.

Eric Solary stated that cancer remains the leading cause of premature death and one of the greatest challenges facing Europe. Modern oncology started 170 years ago and the joint focus is on taking advantage of data sciences to generate the next breakthrough in cancer prevention, diagnostic, and care. There was a therapeutic breakthrough every 50 years (1850 – Microscopy, 1900 – Radiations, 1950 – Chemotherapy, 2000 – Targeted / Immunotherapies, 2030 – target for another break point). In order to achieve this goal, the ‘UNCAN.eu’ platform has been established. This is a unique digital platform where researchers from all over the world share and have access to high-quality cancer research data. A Coordination and Support Action (CSA) will develop a blueprint in order to prepare a fully-fledged and sustainable platform managed by Member States, associated countries & stakeholders. Twenty-nine core and advisory partners from 20 countries joined their effort for this initiative.

Giovanni Apolone said that CCI4EU project is as a capacity building program with the objective to strengthen the research capacities of the Comprehensive Cancer Infrastructures on three levels – individual, institutional, and Systematic. The program aims to involve various stakeholders: citizens, patients and their caregivers, healthcare professionals and GPs, cancer organizations, social media, researchers, health care authorities, policy makers and industry. The main goal is to upgrade the Comprehensive Cancer Infrastructure in each member state. It is important to distinguish between CCCs (Comprehensive Cancer Centres) and CCIs (Comprehensive Cancer Infrastructures). CCIs are the *“national or regional infrastructures that provide resources and services to support, improve, and integrate cancer care, research, training of care professionals and education for cancer patients, survivors and families/carers.* EU Cancer Actions Group brings together coordinators of key associated EU projects – UNCAN, CRANE, JANE, ECHOS and common cooperation and coordination are vital.

In his closing remark, Denis Horgan summarized the 13 practical recommendations of the Cancer Mission and pointed out that the key issue is finding solutions on how patient organisations can support their implementation.

3rd Session: The EU Health Policy Landscape

Moderators: Denis Horgan – George Kapetanakis

Speakers: Elena Petelos – Vice-President at HTA EUPHA


Dimitra Lingri – Lawyer and Managing Director at EHFCN

Denis Horgan – Executive Director at the European Alliance for Personalised Medicine

Adela Maghear – Senior EU Affairs Manager at ECPC

The session was aimed at exploring the EU cancer health policy landscape, including the present challenges of the legislative framework and the future opportunities for patient engagement. The

¹ https://ec.europa.eu/health/sites/default/files/non_communicable_diseases/docs/2021-2025_cancer-roadmap_en.pdf




invited experts in this session shared their insights on the new EU Pharmaceutical legislation, the Health Technology Assessment Regulation (HTAR), and also about means to offer access to personalized medicine and biomarker testing to all and the role of patient advocates in driving the change on the EU health policy landscape.

Elena Petelos explained that the Pharmaceutical Strategy is based on four main pillars: ensuring access to affordable medicines and addressing unmet medical needs; supporting competitiveness, innovation and sustainability of the EU's pharmaceutical industry and the development of high quality, safe, effective and greener medicines; enhancing crisis preparedness and response mechanisms via diversified and secured supply chains, and addressing medicines shortages; ensuring a strong EU voice in the world by promoting a high level of quality, efficacy, and safety standards. At present, access to certain innovative medicines varies considerably among Member States and there is no obligation to market a medicine in all EU countries. This affects patients in small and less wealthy countries. The Health Technology Assessment process is highly fragmented, with heterogeneous reimbursement systems, limiting EUs' negotiation power. An important objective of the new Pharmaceutical Package is to move away from 'one size fits all' system of incentives for pharmaceutical companies to a modulated system of incentives that rewards companies that fulfil important public health goals, such as giving access to medicines in all EU Member States, developing medicines that fulfill unmet medical needs, conducting comparative clinical trials and developing medicines that can treat other diseases as well. The new legislation comes with new demands in terms of data protection and market exclusivity, but also with changes in the EMA operational structure where the CHMP will include patient representatives. However, more clarity is needed regarding the governance of the regulatory framework and the process of patients' involvement.

Dimitra Lingri stated that at the EU level, we have a new HTAR that entered into force in January 2022 and will be applied starting with January 2025. The EU HTA is limited only to clinical assessments, both for medicines and medical devices, while the non-clinical assessment (social, economic and ethical aspects) remains in the remit of the Member States. The HTAR is aimed at promoting innovation which offers the best outcomes for patients and society as a whole and is an important tool for ensuring proper application and use of health technologies. At the same time, the HTAR will improve scientific evidence that is used to inform clinical decision-making and patients access to health technologies, stimulate innovation and achieve a high level of protection of health for patients. Patients can take part in the assessment process both individually and via patient organisations and are actively involved in the stakeholder network that supports the work of the HTAR Coordination Group. However, only patients with a certain level of health literacy, that understand the HTA process, can provide their feedback.

Denis Horgan pointed out that, in spite of the many legislative tools at the EU level and policies in place at the national level, EU is very slow in bringing innovation into the healthcare sector. The generation and diffusion of precision medicine consists of 3 main steps: scientific research, translational research and the implementation phase. However, relevant questions and challenges need to be addressed regarding how to translate scientific research into the healthcare systems, the lack of skilled healthcare force, or how to reorganize the healthcare systems. Patient organisations have a key role in ensuring that the existing EU regulations and the health policies and guidelines at the national level include all relevant aspects that matter to them and are properly implemented. The governance at the regional level should be involved in promoting and speeding up the training for new healthcare professional profiles, defining new reimbursement schemes for personalized medicine and a new framework for the HTA implementation. Other important aspects to be addressed at this level include the design of a new performance evaluation system in order to monitor public and private providers, the design of



a new information system and a big data analytics system linked to the EU Health Data Space, and planning a new investment agenda based on a rational allocation of resources.

Access to biomarker testing is very important for cancer patients as it guides clinical decision by monitoring disease progression. Key actions need to be taken to improve access and diagnostics for all in oncology, namely, to educate the population on the benefit that a Liquid Biopsy can deliver as a complement to tissue testing, upskill laboratories via training to allow more facilities to perform Liquid Biopsy based testing, and support equitable reimbursement and policy coverage for Liquid Biopsy based biomarker testing.

However, the role of patient advocates in shaping the EU policy framework must not be neglected, as explained by Adela Maghear. Patient advocacy is an important pillar of healthcare policymaking; patients are the primary stakeholders in healthcare, and their voices and perspectives must be considered when developing healthcare policies. The digital era has led to a paradigm shift where patients have become more and more knowledgeable about their disease and their expertise brings added value to policymaking. Advocacy can take many forms, including public awareness campaigns, lobbying efforts, and joint statements, calls to action, coalitions/clusters building, sharing best practices, analysis and research studies. ECPC has a vision for a Europe of equality, where all Europeans with cancer have timely and affordable access to the best treatment and care available. The organisation works towards this vision by influencing the European political agenda, empowering and educating its members, and increasing the role of patients in cancer research. Knowledge and skills around legislative advocacy are key factors to drive the change in the political landscape. The best patient advocates are those who can combine their knowledge and skills while being deeply committed to their cause.

4th Session: The New Cancer Care Delivery Landscape

Moderators: Anton Berns – Kathi Apostolidis

Speakers: Anton Berns - Honorary Staff member and Director Emeritus, The Netherlands Cancer Institute – Antoni van Leeuwenhoek Hospital, Amsterdam

Paolo Casali - Associate Professor of Medical Oncology Università degli Studi Milano, Italy

Francesco de Lorenzo – ECPC President

The 4th session of the ECPC 20 years Annual Congress focused on the strategy that the EU cancer plan will follow to provide cancer care in Europe after 2025. In particular, discussions were held on how European countries will collaborate in the creation of Comprehensive Cancer Centres (CCC) and the implementation of Expert Networks, as well as the role that cancer patients will play in this.

This session, which also featured Anton Berns as a speaker, highlighted the challenge that Europe is facing due to the ever-increasing incidence of cancer, the growing demand for health professionals, the rising costs of cancer drugs and the inequalities in access to cancer between and within countries. In addition, it was discussed how cancer research infrastructures, with well-defined scientific objectives and strong governance, can meet these needs. As an example of successful CCCs, Anton Berns presented Cancer Core Europe (CCE), which was created 5-6 years ago and is a network that includes leading comprehensive cancer centres with a high volume of clinical activity, highly developed research infrastructures and a shared vision: research should benefit patients. He believes that these structures and networks can be built by incentivizing cancer centres to acquire critical mass and

commit to quality. Furthermore, he emphasized that the EU Cancer Mission is in a unique position to facilitate this process.

The next presentation was given by Paolo Casali, who explained the importance of establishing Networks of Expertise (NoE). He mentioned that the Beating Cancer Plan includes a step forward in the creation of healthcare networks in the European Union: the networks of expertise on cancer. This is a new type of networks and the Joint Action is the strategy to pave the way for the creation of these NoE. Specifically, the Joint Action includes 7 NoE on the following topics (1) one or more complex and poor prognosis cancers, (2) personalized primary prevention, (3) survivorship, (4) palliative care, (5) omics technologies, (6) high-tech medical resources, and (7) cancer in adolescents and young adults. He commented that given the NoE topics, these should stay behind the centers and networks that reach patients and should provide services to them. He also mentioned the need to include professional networking, patient networking and institutional networking within these NoE and the importance of obtaining government endorsement for their creation. He then explained that the mission of a joint action is to reach out to all communities in Europe, including patients, to get their opinion and to convey a final message to the Commission on how the NoE should be shaped, what they should do, etc. He encouraged all communities to contribute to these networks and wondered how patient involvement in the structure and infrastructure of the NoE can be foreseen. Finally, he expressed concern about the challenge of advocacy in a country other than Belgium (because of its proximity to the EU bubble) and the fact that cancer patients have not been included as full members of any NoE to date.

Finally, Francesco de Lorenzo emphasized the importance of patient advocacy and how patients are being recognized and invited to participate in research. He also encouraged ECPC member organizations to share their needs with ECPC so that they can be involved in research projects. ECPC is currently participating in 26 projects related to big data and personalized medicine, knowledge sharing networks, patients and caregivers, palliative care and treatments (e.g., INSTAND, UNCAN, CCI4EU) and in the Joint Action on Expert Networks Jane. In JANE, ECPC is trying to facilitate and reach an expert agreement on different aspects of survivorship: survivorship awareness, definition of clinical practice, guidelines, etc. He stressed the need to develop a set of tools that can empower patients and citizens and be adapted to specific context. In addition, he promoted taking advantage of existing national and European networks of cancer patient organizations for the application of these tools. He also paid special attention to survivorship, because people living after cancer diagnosis can have a better quality of life, as it has not been taken into account so far, but it is our future.

5th Session: The Inequalities in Cancer Care


Moderators: Françoise Meunier, Francesco de Lorenzo, Delia Nicoară

Speakers: Roberto de Miro - Lawyer, Italian Association of Cancer Patients (AIMaC)

Regine Kiasuwa - Head of the supportive care and care organisation unit at Belgian Cancer Center of the National Institute of Public Health (Sciensano)

Françoise Meunier - Member of the Belgian Royal Academy of Medicine and Member of the ECPC Scientific Committee

Delia Nicoară - Public Health and Management Specialist, The Oncology Institute Cluj-Napoca




The 5th session discussed different aspects of inequalities in cancer care across Europe. From maintaining employment and returning to work for cancer patients and survivors to cancer-specific socioeconomic disparities in Romania, with a particular focus on the right to be forgotten.


Roberto De Miro spoke about the results included in the ECPC white paper on socioeconomic disparities in cancer in Europe. The fact that much is known and followed about discrimination in access to therapies and/or healthcare services, but very little about the socioeconomic issues faced by families of cancer patients motivated the initiation of the project in 2018. A 32-question questionnaire was distributed to ECPC members in 2019 and full responses were collected from 15 countries: Belgium, Bulgaria, Czech Republic, Cyprus, Denmark, Hungary, France, Ireland, Italy, Latvia, Lithuania, Slovenia, Spain, Switzerland and the United Kingdom.

It was concluded that, despite the EU's commitment to equality and human rights at work, the employment rights of people with cancer appeared to differ significantly at the national level. The self-employed were more vulnerable when diagnosed with cancer and cancer survivors needed specialist support to return to work or find new employment. Roberto mentioned that ECPC will continue its battle for a cultural shift towards the rights and social rehabilitation of cancer patients and their family caregivers. Both cultural and legislative changes are still needed to realize the right of a cancer survivor or caregiver to maintain their active role as a citizen and to overturn the stigma and negative attitude that relegates these people to care and social exclusion.

Régine Kiasuwa Mbengi spoke of the challenge of researching and generating evidence on return to work, as this is a new, complex and multidisciplinary field of research, and one in which it is difficult to compare EU countries. Their studies show that when patients enter long-term disability, they are much less likely to ever return to the labour market. On the other hand, five years after cancer diagnosis, the rate of return to work for survivors is quite similar to that of the general population. However, their quality of life may be different. She noted that to further research in this field, there is a need to implement a harmonized epidemiological exercise in the EU, to organize the collection of patient-reported experiences and outcomes, and to organize return-on-investment (ROI) studies. Her studies pointed to the requirement for effective measures to support and facilitate the return-to-work process that should be integrated into the usual cancer care pathway. In addition, better collaboration and communication between health professionals, social workers and employers needs to be organized in order to adequately support cancer survivors in their professional reintegration. More research efforts must be made, at local and EU level, and a change of mindset is needed to achieve a new balance between productivity and equity, inclusion and social justice.

Françoise Meunier, an oncologist who has been working for almost 50 years to increase the survival and quality of life of cancer patients, realized a few years ago that more and more patients were being cured but were instead coming back with the problem of being discriminated against when they wanted to return to a normal life. Motivated by this unfair situation, in 2014 she organized the first survivorship summit to discuss the right to be forgotten and survivorship. She emphasized that this right is about ending financial discrimination in cancer survivorship and that it is an EU competence, not a national one, for which it is important to have a harmonized legal framework in the EU. In 2016, France was the first EU country to establish the right to be forgotten. Since then, it has served as a model for the rest of Europe. It is currently implemented in 6 EU countries (Belgium, Netherlands, Luxembourg, Portugal, Romania), although there are differences between them, but it is based on similar fundamental principles. Another 4 countries are in the process. Françoise opted to use the French case as a model for the rest of the European Union countries, which has proven to be successful to date.





Finally, Delia Nicoară drew the audience's attention to the socioeconomic disparities in cancer in Romania. For example, they have the lowest public spending in the EU on cancer care, lack sufficient oncologists to adequately care for cancer patients or the fact that more is paid for cancer drugs in Romania than in high-income countries. She also explained how the first Romanian National Cancer Plan implemented in 2022 intends to address these challenges. The country is now focused on finding solutions to the challenges they have faced so far: creating a national cancer registry, ensuring standards in cancer care, extending national screening. In addition, from a financial point of view, the plan includes the creation of a health innovation fund, cost coverage for treatment, testing, genetic testing, and prevention for all types of cancer that can be prevented. It will also address the problem of alcohol consumption in Romania. The plan aims to improve prevention by investing in communication. Delia also mentioned the strategies that will be followed to improve the mental health and quality of life of patients. Finally, she stressed the positive impact of cancer patients' associations in policy making, bridging the gap between theories and real needs based on the experiences of cancer patients.

6th Session: Role of Biomarkers in Personalised Medicine

Moderators: Nicola Normanno, Christina Olsen

Speakers: Nicola Normanno - President Elect of the Italian Society of Cancerology (SIC), Member of the ECPC Scientific Committee

Ritchie Head - Managing Director at Ceratium, Project Coordinator at TIGER EU Project


Wim Vos - CEO at Radomics

Kathi Apostolidis – ECPC Past President and Chair of the Scientific Committee

The 6th Session included presentations on state of the art of cancer biomarkers, the TIGER project and on biomarker developments and challenges.

Nicola Normanno's group has been one of the first to use next-generation sequencing (NGS)-based techniques in clinical trials. He emphasized the importance of cancer biomarkers. There are characteristics of the tumour that can be measured, usually in the tissue or in the blood, and biomarkers will provide relevant information for the diagnosis of that tumour. Thanks to biomarkers, at present, we can understand whether a tumour is aggressive, predict its toxicity and whether it will respond to specific drugs. Dr Normanno's group has expertise in liquid biopsy and is also involved in clinical diagnostics and in the organisation of national and international external quality assessment (EQA) schemes in molecular pathology. It is expected that in the next few years genomics will be crucial for the management of cancer patients. More research efforts must be made in many countries, the risk is that many European cancer patients will not be able to access all the innovation in the fields of diagnostics and therapeutics.

Following this presentation, the session expanded the discussions beyond TIGER to explain the range of biomarker uses and the importance of improving patient access to key biomarkers across Europe. The format included presentations from TIGER partners and leading cancer biomarker researchers followed by a panel discussion to identify the knowledge gaps and opportunities in cancer biomarker research and develop a strategy to address the challenges in cancer biomarkers. TIGER project aims at advancing exciting and innovative biomedical diagnostics to provide new tools to support later stage clinical studies, future oncology therapy development and patient stratification. Since, the IV mRNA cancer vaccine platform can use virtually any antigen, this means that any type of cancer can be



targeted with the right antigens. This project will enable further application of the technology in a wide range of cancers using other tumour antigens.

Radiomics is pleased to bring their advanced imaging biomarker technology and expertise to the TIGER consortium. TIGER is a great opportunity to further develop and validate unmet clinical needs for HPV+ cancers, increasing the understanding of the patients' tumours and offering actionable insight via routine standard medical imaging. Radiomics can support the development of next generation immunotherapies for cancer, such as the first-in-class therapeutic mRNA vaccine. Their final goal is to support insight-based decision making for optimizing pharmaceutical and biotech companies' clinical trials and drug development studies and for providing clinicians with a patient-centred approach based on personalized medicine.

Finally, Kathi Apostolidis highlighted how ECPC had identified the need to raise awareness of biomarkers to patients, issues around equal access, and the challenges to biomarker testing in Europe. All patients in Europe should have access to the biomarkers that are indicated for their tumour. And all cancer patients eligible for biomarker linked therapy should undergo testing for all clinically relevant biomarkers that are indicated for precision medicine therapy with the use of extended panels where appropriate.

The session concluded that expanding the existing research to identify knowledge gaps and new opportunities for biomarker testing in the next few years, will be key for the management of cancer patients.

3. Conclusions

The ECPC Annual Congress 2023 has been both intense and rewarding.

The event looked back at the last 20 years, giving the opportunity to member organisations and external collaborators to share memories and express views on how ECPC has uniquely represented the interests of all cancer patient groups, from the most common to the rarest forms of cancer.

When discussing the future of the organisation, participants shared their vision of how ECPC should continue to embody the views of people affected by cancer in the European healthcare landscape and enable and empower them to become patient advocates, actively involved in cancer research and policy at both EU and national level.

The ECPC of the next decade will continue to be the voice of a strong and united patient community by providing a forum for Europeans with cancer to exchange information, best practice, and share concerns on their national cancer care policies, and education modules on topics that align with the changing needs of the cancer patients. At the same time, the organisation will strengthen its collaboration with the EU Institutions to ensure that patients will be at the core of the next EU legislative mandate.



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