

Renaissance Brussels Hotel, Brussels, 27 May 2022

# The Cancer Policy & Research Landscape in the meta-COVID Era

#### **Background**

Despite efforts to address cancer care and research in recent years, cancer remains one of the **leading medical and societal challenges of our time**. This is why the European Commission has selected cancer as one of its five new Research and Innovation Missions of the EU. The goal of the **Cancer Mission** is to **achieve 75% survival rate by 2030**, from 47% today, by focusing on cancer prevention, treatment, survivorship care, social innovation, and ensuring the reduction of existing inequities in all abovementioned areas.



Published in February 2021, **Europe's Beating Cancer Plan** represents a turning point in European cancer policy. The Plan was based on extensive stakeholder consultation, in which ECPC has participated and is very comprehensive as a result. It sets out lofty ambitions to **improve access to the latest innovations** in cancer prevention, early detection, diagnosis, and treatment while also seeking to improve the quality of life of patients, survivors, and carers. The Plan also sets out how the EU will support the Member States and where the €4 billion earmarked for actions addressing cancer will be drawn from. Personalised medicine is at the heart of the Beating Cancer Plan. The Plan clearly recognises the value of personalised medicine, also a key policy area of ECPC, a theme that cuts across many of the new initiatives it proposes to introduce, such as:



Cancer Diagnostics and Treatment for All, which aims to support greater sharing of tumour profile data with the aim of optimising cancer diagnosis and treatment and reducing inequalities in access to personalised medicine.



**Partnership on Personalised Medicine**, which will set out priorities for research and education, support research projects and make recommendations for the greater integration of personalised medicine in clinical practice.



New collaborative projects in high performance computing and artificial intelligence to support treatment decisions and advance personalised medicine, such as the European Health Data Space, the Cancer Survivor Smart-Card, the Electronic Health Records and the European Cancer Patient Digital Centre.



A Cancer Inequalities Registry which will identify disparities and inequalities in cancer care between Member States and regions. This could include exploring inequalities in access to personalised medicine.



Improving the quality of life for cancer patients, survivors and carers with the creation of code of conduct to address fair access for cancer survivors to financial services and ensuring the full implementation of the Directive on work-life balance for parents and carers.

Presently in Europe are estimated at least **20 million cancer survivors** and **5 million cured people**. Cancer survivors are a vulnerable population that requires medical and non-medical interventions. They are particularly at risk not only of having a **low quality of life** due to the **long-term side effects of treatment** with consequences for patients' physical, mental and social health. Moreover, 15% of them are at risk of developing another primary cancer. It is key that healthcare systems integrate survivorship cancer care plans in the follow-up to their cancer care plans.













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Cross-border healthcare can be a better option, particularly for rare cancer patients in situations where the most appropriate treatment or the nearest hospital is in another EU country. The **Directive on patient rights** in cross-border healthcare, currently under revision, aims to facilitate access to safe and high-quality healthcare in another EU country. This offers patients more possibilities to seek planned healthcare abroad. For the **European Reference Networks (ERNs)** to function at their full potential and for patients to be able to claim reimbursement from their national health system or their health insurance provider, there is the need for the full implementation of the EU cross-border healthcare.

Efficiency must be continuously measured according to the achievement of defined health outcomes that matter to patients and society in relation to resources spent. To this end, policymakers must urgently invest and implement policy frameworks that harness the full potential of digital data for the benefit of all people with cancer.

Low quality and unreliable data often limit the ability to impact decision-making across cancer care and damage the trust of stakeholders. Applying various **tools and techniques to improve data quality** and strengthening quality control mechanisms can help generate and maintain high-quality datasets. Data collected in our healthcare systems are often not patient-centred or aligned with patient values and preferences Patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) data should be systematically collected and analysed to guide quality improvement efforts.

On 1st July 2020, ECPC launched the **Challenge Cancer Intergroup**, the first EU parliamentary intergroup on cancer. This informal group of cross-party Members of the European Parliament (MEPs) is chaired by MEP **Cristian Buşoi** (EPP) and co-chaired by MEPs **Alessandra Moretti** (S&D), **Aldo Patriciello** (EPP), **Frédérique Ries** (Renew), with the **European Cancer Patient Coalition** (ECPC) providing the Secretariat.



Currently consisting of 37 members, the Intergroup on cancer serves as a **forum for MEPs from all political parties** to **engage in dialogue** with patients, cancer survivors and carers, scientific and medical societies, research institutions, think tanks, medical practitioners and researchers, policymakers and leaders of the health industry, civil society at large, national governments and institutions.

This year, ECPC aims to offer to our members a conference programme highlighting some of the key areas of the emblematic initiatives of the European Commission, the EU Cancer Plan and the Cancer Mission. Our members will have the opportunity to hear about the latest developments in cancer policy and research and bring back home information on how the European cancer landscape is changing while offering several opportunities to EU Member States to improve their National Cancer Plans.



Our Conference will be also a great time to **meet** and **reconnect** with all of you after two years and a half. We invite you to join the live event to expand your network, **present your work and ideas** to others and **share your experience** with the pandemic and how it has affected you and your organisations, to combine our efforts in the fight against cancer. We regret that not all our members might be able to come to Brussels to attend the conference and the AGM but we hope that in 2023, we will have the possibility to travel freely without the fear of Covid-19.















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14:00 - 15:30 Registations / Coffee & light lunch

Welcome address 15:30 15:40

Kathi Apostolidis - ECPC President Online

15:40 15:55

Address of the Health and Food Safety Commissioner 

Video Message

Stella Kyriakides - Commissioner for Health and Food Safety

Chairs: Kathi Apostolidis, ECPC President & David Ritchie, ECL Cancer Prevention Manager

16:00 16:15

What does the Cancer Mission mean for patients?

Denis Horgan - Executive Director of the European Alliance for Personalised Medicine (EAPM)

16:15 16:30

Living Beyond Cancer - 20 Million Reasons why we need to get it right

Mark Lawler - Professor of Digital Health, Queen's University Belfast Co-Chair of the European Cancer Organisation's Special Network on the Impact of COVID-19 on Cancer Member Scientific Committee

16:30 16:45

Cancer Patient organisation involvement in cancer policy and EU cancer Plan priorities

Charis Girvalaki - ECPC Director

16.45 17:05

Q&A

17:05 - 17:40 Coffee Break

Chairs: Mark Lawler, ECPC Scientific Committee member & Matti Jarvinen, ECPC Board Secretary

17:45 18:00

Sharing Data, Knowledge and Expertise across borders Online

Challenge Cancer Intergroup: Collaboration of MEPs with Members of National

18:00 18:15

Parliaments in the fight against cancer Video Message

Cristian-Silviu Buşoi - Member of the European Parliament, Chair of the EU Parliamentary Challenge Cancer Intergroup

18:15 18:30

Patient mobility and cancer / JAs Online

Jean Yves Blay - Network Director of ERN-EURACAN, ESMO

Tit Albreht - Coordinator of the third Joint Action on cancer control, entitled innovative Partnership for

Action Against Cancer (iPAAC)

18:30 18:55

Q&A / Open discussion

18:55 19:00

19:00

19:30

Conclusions / Next day programme

Parallel session: Stakeholders Engagement in the European Oncology Living Labs

Panos Bamidis - LifeChamps Project Coordinator, Director of Lab of Medical Physics & Digital Innovation, Aristotle University of Thessaloniki

Antonis Billis - LifeChamps Scientific Coordinator, Research Associate at Lab of Medical Physics & Digital Innoation, Aristotle University of Thessalonik

Despina Mantziari - PhD Candidate, Research Assistant at Lab of Medical Physics & Digital, Aristotle University of Thessaloniki



19:30 - 20:00 Networking Reception



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# The Cancer Policy & Research Landscape in the meta-COVID Era

Join us in this interesting discussion shedding light upon the cancer policy and research landscape and therole of the patients and informal carers.

# **Opening remarks**



#### Kathi Apostolidis **ECPC President**

Kathi is the President of the European Cancer Patient Coalition. She has previously served from 2013 to 2019 as ECPC Vice President. On the national level, Kathi is a founding member and elected President of the Hellenic Cancer Foundation - ELLOK and a Board Member of the Greek National Cancer Institute, which is currently under establishment. Kathi is a Public Affairs Consultant with diversified experience in the private and public sectors and a breast cancer survivor with a long and active involvement in breast cancer and patient rights advocacy.

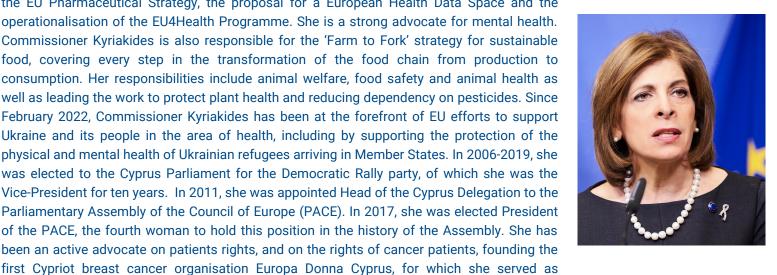
#### Stella Kyriakides

**European Commissioner for Health and Food Safety** 

Commission's work on the public health response to COVID-19. Commissioner Kyriakides is responsible for a number of initiatives in the area of health aiming to establish a strong European Health Union. These include Europe's Beating Cancer Plan, the implementation of the EU Pharmaceutical Strategy, the proposal for a European Health Data Space and the operationalisation of the EU4Health Programme. She is a strong advocate for mental health. Commissioner Kyriakides is also responsible for the 'Farm to Fork' strategy for sustainable food, covering every step in the transformation of the food chain from production to consumption. Her responsibilities include animal welfare, food safety and animal health as well as leading the work to protect plant health and reducing dependency on pesticides. Since February 2022, Commissioner Kyriakides has been at the forefront of EU efforts to support Ukraine and its people in the area of health, including by supporting the protection of the physical and mental health of Ukrainian refugees arriving in Member States. In 2006-2019, she was elected to the Cyprus Parliament for the Democratic Rally party, of which she was the Vice-President for ten years. In 2011, she was appointed Head of the Cyprus Delegation to the Parliamentary Assembly of the Council of Europe (PACE). In 2017, she was elected President of the PACE, the fourth woman to hold this position in the history of the Assembly. She has

As European Commissioner for Health and Food Safety, Stella Kyriakides has been leading the

■ Video Message





globally.



President for over 15 years. She was elected President to the European Breast Cancer Coalition Europa Donna, and served on numerous European patient advocacy and scientific boards. She is the recipient of numerous awards from her community service in Cyprus and









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# The EU Cancer Plan, the Cancer Mission and Patient Engagement

Chairs: Kathi Apostolidis, ECPC President & David Ritchie, ECL Cancer Prevention Manager



# **Denis Horgan**

#### **Executive Director of the European Alliance for Personalised Medicine (EAPM)**

Prof. Denis Horgan, is a former policy advisor in the European Parliament and worked with various international NGOs on health development projects as well as with the European Cancer Patient Coalition. He has published over fifty academic articles related to the area of personalised medicine. Today, Denis is the Editor in Chief of the journal entitled Public Health Genomics and he is the Executive Director of the European Alliance of Personalised Medicine (EAPM).

#### **Mark Lawler**

Professor of Digital Health, Queen's University Belfast; Co-Chair of the ECO's Special Network on the Impact of COVID-19 on Cancer; ECPC Member Scientific Committee

Mark is an internationally renowned scientist. He is Associate Director of Health Data Research Wales-Northern Ireland. He is the Scientific Director of DATA-CAN, the UK's National Health Data Research Hub for Cancer. He is also Chair of the International Cancer Benchmarking Partnership. Architect of the European Cancer Patient's Bill of Rights, Mark's work on addressing inequalities and access issues in relation to cancer care formed the development centrepiece of the European Code of Cancer Practice. Mark co-chairs the European Cancer Organisation's Special Focussed Network on Covid-19 and cancer.



# Charis Girvalaki ECPC Director

Dr Charis Girvalaki is the Director of the European Cancer Patient Coalition. She has a ten-year experience in European and International projects and has worked with a wide range of key players and stakeholders, including European and governmental institutions, academia, health services, local authorities. Charis graduated from Chemistry Department, University of Crete, Greece. She holds a Master's degree in Public Health and Healthcare Management specialized in Epidemiology and a PhD from Medical School, University of Crete, Greece.













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#### Cancer in the meta-COVID Era

Chairs: Mark Lawler, ECPC Scientific Committee member & Matti Jarvinen, ECPC Board Secretary



■ Online

# Jean-Yves Blay

#### Network Director of ERN-EURACAN, ESMO

Professor Jean-Yves Blay is a medical oncologist, General Director of the Centre Léon Bérard, the Comprehensive Cancer Centre of Lyon France, researcher and a Professor at the University Claude Berard, France. Since 2019, he has been the President of the French Federation of Cancer Centers, Unicancer. His work focuses on sarcoma, genomics and the targeted treatment of cancer, immuno-oncology, and the relationship between the tumour immunologic microenvironment and malignant cells, with the goal of clinical applications in the field of diagnosis, prognosis and treatment.

#### Cristian-Silviu Bușoi

# Member of the European Parliament, Chair of the EU Parliamentary Challenge Cancer Intergroup

Cristian-Silviu Buşoi is a Member of the European Parliament and Chair of the Industry, Research and Energy Committee. He is also Member of the Delegation for Southeast Asia, as well as a substitute Member of the Environment, Public Health and Food Safety, Committee on Economic and Monetary Affairs and the Delegation for the Arab Peninsula. Buşoi graduated in Medicine from Carol Davila University in Bucharest, Law from Titu Maiorescu University in Bucharest, and Diplomacy from the Romanian Diplomatic Institute in Bucharest.





Online

#### Tit Albreht

#### Coordinator, Third Joint Action on Cancer Control (iPAAC)

Dr. Tit Albreht, M.D., has is the Head of the Centre for Health Care at the National Institute of Public Health of Slovenia, Senior Researcher in the field of health services research, health policy and health systems research, Member of the Scientific Committee of EUPHA, President of the Slovenian Preventive Medicine Society. He is an Associate Professor of Public Health at the Medical Faculty of Ljubljana, Slovenia as well as at the Faculties of Medicine and Health Sciences of the University of Maribor, where he is leading on public health and epidemiology and health promotion.









