



European Cancer
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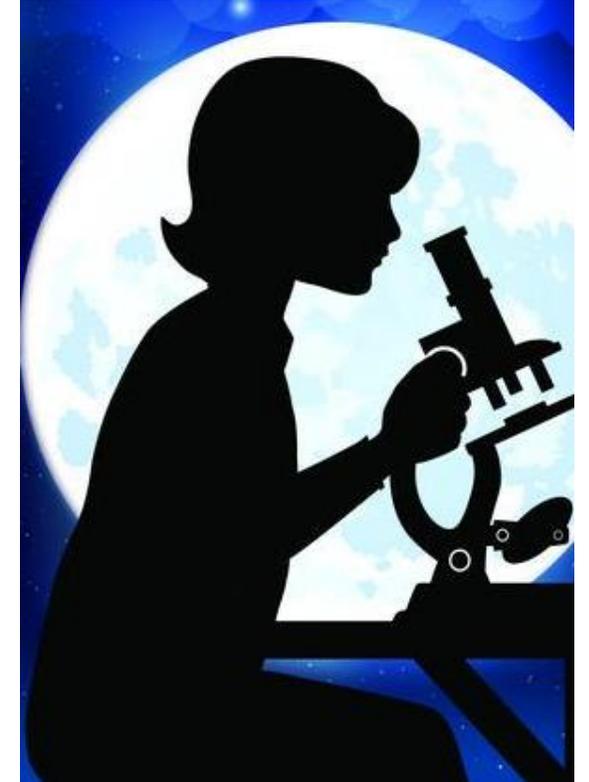
How cancer patient organizations can contribute to the Cancer Mission

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The 'Mission' approach

- Horizon Europe will consist of the following missions:
 1. Adaptation to climate change including societal transformation
 2. Cancer
 3. Climate-neutral and smart cities
 4. Healthy oceans, seas, coastal and inland waters
 5. Soil health and food
- Inspired by the Apollo Program, research missions are meant to be bolder, to inspire cross-sectorial and multidisciplinary innovation and enable bottom-up solutions to deal with the largest societal issues.
- Prof. Mariana Mazzucato provided detailed recommendations for the implementation of EU's new missions:
 - They must engage diverse national and regional stakeholders to guide innovation across multiple sectors and spur further political action through broad public engagement
 - They must have concrete targets and objectives in order to measure their societal impact and evaluate their successfulness
 - Contain diverse funding instruments, where the solutions are not predefined but rather open to bottom-up solutions
 - They should be flexible, and accommodating of change in methods if there is a possibility that the objective will not be reached. This can include increasing budgets and building in-house capabilities as compared to outsourcing.





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To have impact on society at large, the **Cancer Mission** aims at uniting countries to substantially reduce the massive EU cancer burden and improve the quality of life of patients by promoting cost-effective, evidence-based best practices in cancer prevention, treatment, and care. The goal is to achieve 10-year cancer survival for 75% patients by the year 2030.



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There is an urgent need for solutions to the economic and social inequalities in cancer care that still exist in many European countries.

Patient preferences, 'big data', mobile digital technology and molecular and genomic profiling are among the innovative research topics that connect cancer patients to comprehensive cancer centres, and link translational research to cancer diagnosis, treatment and care.

- Can Europe deliver the complex infrastructure needed for universal coverage and equitable access to cancer care?

ECPC has a central role in bringing the unmet needs of patients with cancer to the forefront of cancer policy, care and research.

ECPC believes that innovation cannot emerge and grow without patient involvement and is fully committed to increasing patient education and contribution in cancer research through its active participation in various European cancer research programmes and educational resources. ECPC has a major role in the mission on cancer, given its previous achievements in policy and research to help overcome the inequalities in cancer prevention, treatment, rehabilitation and survivorship care. The mission on cancer will be facilitated by active collaboration between patient organisations and scientists, clinicians, politicians and industry, with the aim of identifying important research questions regarding quality of life and social issues for cancer patients of all ages.



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While cancer research has revolutionised cancer care, it has also created problems, particularly with regards to affordability as many patients in the EU still cannot access innovative life-saving treatments and diagnostic tests. The oncology community is somewhat fragmented

The mission-oriented approach to cancer has provided a novel strategy to overcome the burden.

The cancer mission:

- combining innovative prevention and treatment strategies,
- Rehabilitation and multidisciplinary follow-up
- a sustainable, contemporary, virtual European cancer infrastructure.

The social and economic implications of this should not be underestimated.



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Member States and the general public should be involved in the mission on cancer in a coherent and systemic way, encompassing quality assurance and accreditation.

The ECPC strongly supports the deployment of quality assurance schemes and the accreditation of cancer centres and to this purpose closely collaborates with the OECI.

Dissemination of information to the general public on the genomics revolution in cancer diagnosis and treatment by comprehensive cancer centres and patient organisations will facilitate this process.

Patient organisations will collaborate with scientists, clinicians, politicians and industry to overcome the unacceptable disparities in cancer treatment and care, and the associated stigma by identifying important research questions concerning QOL and social issues for all cancer patients, regardless of age.

ECPC facilitates these collaborations and has central role in the mission on cancer.



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The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer

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Keywords

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There is an urgent need for solutions to the economic and social inequalities in cancer care that still exist in many European countries. Patient preferences, 'big data', mobile digital technology and molecular and genomic profiling are among the innovative research topics that connect cancer patients to comprehensive cancer centres, and link translational research to cancer diagnosis, treatment and care. The question is whether Europe can deliver the complex infrastructure needed for universal coverage and equitable access to cancer care. The European Cancer Patient Coalition (ECPC), the leading 'umbrella' cancer patient organisation in Europe, has a central role in bringing the unmet needs of patients with cancer to the forefront of cancer policy, care and research. The ECPC is a respected and reliable partner in the oncology community and has effectively collaborated with institutional stakeholders and organisations, as well as with the European Commission, on cancer research projects and in the development of tools to advance health care and cancer policies at the European and national level. The ECPC believes that innovation cannot emerge and grow without patient involvement and is fully committed to increasing patient education and contribution in cancer research through its active participation in various European cancer research programmes and educational resources. The ECPC is expected to play a major role in the mission on cancer, given its previous achievements in policy and research to help overcome the inequalities in cancer prevention, treatment, rehabilitation and survivorship care. The mission on cancer will be facilitated by active collaboration between patient organisations and scientists, clinicians,

Abbreviations

AGM, Annual General Meeting; ASyMS, Advanced Symptom Management System; BBMRI-ERIC, Biobanking and BioMolecular resources Research Infrastructure; CanCon, Cancer Control; CDDF, Cancer Drug Development Forum; DIA@C, Dyadic Psychosocial Interventions for people with Advanced cancer and their Informal Caregivers; EACS, European Academy of Cancer Sciences; EAPM, European Alliance for Personalised Medicine; EAU, European Association of Urology; ECCO, European Cancer Conference; ECIBC, European Commission Initiative on Breast Cancer; ECPC, European Cancer Patient Coalition; eHealth, electronic processes supporting healthcare processes; ELBA, European Liquid Biopsy Academy; EMA, European Medicines Agency; ENCePP, European Network of Centres for Pharmacoepidemiology and Pharmacovigilance; ENVI, European Parliament's Committee on Environment, Public Health and Food Safety; EORTC, European Organisation for Research and Treatment of Cancer; EP, European Parliament; EPAAC, European Partnership for Action Against Cancer; ERN, European Reference Network; eSMART, electronic Symptom Management using the Advanced Symptom Management System (ASyMS) Remote Technology; ESMO, European Society for Medical Oncology; ESSO, European Society of Surgical Oncology; EU, European Union; EURACAN, European Network for Rare Adult Solid Cancers; HTA, health technology assessment; IMI, Innovative Medicines Initiative; iPAAC, Innovative Partnership for Action Against Cancer; JARC, Joint Action on Rare Cancers; MEP, Member of European Parliament; mHealth, mobile digital technologies supporting healthcare processes; OECC, Organisation of European Cancer Institutes; PREFER, Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle; PRO, patient-reported outcome; QOL, quality of life; SABR, stereotactic ablative radiotherapy; UICC, Union for International Cancer Control; WIN, Worldwide Innovative Networking.



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Towards a Cancer Mission in Horizon Europe

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Ever since former Commissioner for Research Philippe Busquin established the European Cancer Research Area (ECRA) in 2002 (http://europa.eu/rapid/press-release_SPEECH-02-408_en.htm) to address the fragmentation of cancer research in Europe, the cancer community and policymakers have been trying to develop strategies to bridge the gaps between basic/preclinical and clinical research and research and healthcare (Celis and Pavalkis, 2017). These efforts culminated in 2014 with the creation of Cancer Core Europe (Eggermont *et al.*, 2019), a patient-centred legal structure on therapeutics that currently consists of seven large cancer centres (mainly Comprehensive Cancer Centres (CCCs), institutions that link research with the healthcare system; Saghatelyan *et al.*, 2008) across Europe. Inspired by the Cancer Core Europe

initiative, a consortium of 10 cancer prevention centres was recently established – Cancer Prevention Europe – to reinforce the complete cancer prevention research continuum (Wild *et al.*, 2019). At present, Cancer Core Europe and Cancer Prevention Europe are in the process of integrating their strategies to create a coherent plan for prevention, early detection and treatment, and efforts are underway to engage the outcomes research geometry and to network with other infrastructures, CCCs, and research and clinical centres across Europe (<https://febs.onlinelibrary.wiley.com/doi/10.1002/1878-0261.12585>).

To date, several prominent scientific cancer organisations and cancer centres are collaborating to develop a unified insight towards a mission-oriented approach to cancer. These include Cancer Core Europe, Cancer



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European **Cancer Plan** is instrumental for the planning by the **Mission Board** to direct the work of the Cancer Mission to be able to provide input to Member States on aspects of legislation, economic and social problems as well as basic and translational research including health technology assessments to guarantee equal access for all EU citizens to optimal treatment.

ECPC is, therefore, gratified to collaborate with the European Academy of Cancer Sciences (EACS) that has shared our position on cancer patients as shown in the special issue of *Molecular Oncology* regarding the Mission on cancer. The EACS platform is working on its recommendations, some of which have already been sent to the Cancer Mission Board. The platform has also established a committee on survivorship in which ECPC will take part.



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Major role of patient organisations is to increase quality of life!

Quality of life during and after treatment includes reducing the burden faced by long-term cancer survivors such as return to work, access to education, and financial services).

Upcoming Cancer Plan should tackle social inequalities, namely ensuring the return to work of cancer survivors, providing the appropriate follow-up care and the reintegration of survivors into ordinary societal roles and activities without discrimination.

Moreover, the European Cancer Plan should take steps to promote the transposition of the Right to Be Forgotten legislation (which currently is established in FR, BE, LU and soon others) into Union-level legislation to prevent unfair discrimination in cancer patients' access to financial services and employment. This will ensure that they are able to overcome the existing barriers they face in access to life insurance and mortgages.

The impact of cancer on society and its members should be addressed in a number of areas, in order to improve the lives not only of cancer patients and survivors, but also of their carers and those around them.



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ECPC first proposed action at EU-level in 2013 and has been doing so since then.

First steps taken to address this was the EPAAC and CanCon joint actions.



A joint action is a type of funding instrument encouraging and supporting cooperation between Member States to improve the health policies that benefit their citizens

The Commission provides money, voluntary participation of Member States, action taken together.

Reminder! the Commission has only shared competence in the area health.



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Member States should be encouraged and supported to use the policy recommendations of both CanCon and iPAAC for the update and implementation of their national cancer control plans.

ECPC will participate in the work packages relating to genomics, cancer information and registries, and challenges in cancer care. In particular, the aim of the genomics work package is to develop practical guidance for EU Member States on important aspects of successful integration of genomics in the healthcare system.

Moving forward, the European Commission should continue and increase its engagement in the fight against cancer and to collaborate with the Member States for the recognition and adoption of the recommendations.

The backbone of a well-functioning National Cancer Control Plan should be the Comprehensive Cancer Care Networks (CCCNs), which should be distributed across the EU with at least one in each Member State, and with each serving between 5 and 10 million citizens. Since CCCNs are the backbone of national cancer plans, it stands that they can also serve as the backbone of the EU's Cancer Plan. European Reference Networks (ERNs) could also serve as a complementary backbone of the Plan.



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The European Cancer Research Area was established to address the fragmentation of cancer research in Europe.

Since then, the cancer community and policymakers have been trying to develop strategies to bridge the gaps between basic, translational, preclinical and clinical research and research and healthcare. **Cancer Core Europe** was created in 2014 as a patient-centred legal structure on therapeutics that currently consists of seven large cancer centres.

The cancer prevention research continuum reinforced by recently established **Cancer Prevention Europe**.

At present, Cancer Core Europe and Cancer Prevention Europe are in the process of integrating their strategies to create a coherent plan for prevention, early detection and treatment, and efforts are underway to engage the outcomes research geometry and to network with other infrastructures, CCCs, and research and clinical centres across Europe.



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Parliamentary Intergroup on Cancer recently established and **ECPC will act as the secretariat.**

ECPC will therefore play a crucial role in the dissemination of information in both directions between the Commission and the Member States, interested stakeholders, civil society and European citizens. This allows policy areas are enriched with contributions by all interested stakeholders and European citizens.



European Parliament

ECPC believes that the collaboration of the newly established Intergroup on Cancer with both organs of the Cancer Mission and the European Commission will be beneficial for the successful implementation of both policies.



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ECPC's important role as part of EACS

ECPC will help shape the Cancer mission based on the principle of “Science with and for society” with the contribution of evidence-based, patient-centred solutions.

- Past President and Chair of the ECPC Scientific Committee Francesco de Lorenzo will continue to represent patients views in the European Academy of Cancer Sciences (EACS) Board of Directors and Science and Policy Committee where ECPC has contributed to the following recommendations:
- The mission should achieve long-term survival of 75% of patients with cancer by 2030 through the uptake of innovative and multidisciplinary treatments that are multidisciplinary an follow-up patients through the entire cancer treatment pathway from primary through tertiary prevention.

To achieve this the following is needed:

- Integrated, networked and distributed infrastructures are needed to reach the critical mass of resources, multidisciplinary expertise , technologies, data, patients and coordinated collaborative projects that are essential to promote science-driven and social innovations in the era of personalised precision cancer medicine
- Effective collaboration between all stakeholders (basic, translational and clinical researchers, healthcare professionals, pathologists, radiation oncologists, surgeons, prevention researchers, epidemiologists, patient organisations, universities, industries, regulatory bodies and funders.
- Establishment of Coordinated Networks of Comprehensive Cancer Centres (CCCs) that link research with the healthcare system (translational research) with a sufficiently large portfolio of clinical trials and multidisciplinary cancer services covering the entire care pathway that can stimulate best practices to treat patients.
- The use of cohesion funds to ensure the successful participation of central and eastern European Member States
- Involvement of cancer research, prevention/health care and cancer patient communities at all stages of policymakers.



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On Tuesday, the Commission officially opens the consultation period of its new initiative at the EU level – the **EU Cancer Plan**. Since the plan will be ambitious and will cover not only health aspects but also other non-health areas, close cooperation with the Member States will be required.

The Commission's is comprehensive and focuses on **prevention, cure, care and quality of life**. The Plan aims to have a strong impact for citizens.

The next steps at the EU level are built around:

1. Horizon Europe Strategic Planning
2. Horizon Europe Mission for Cancer
3. EU Action Plan against Cancer.

Missions aim to achieve a bold, inspirational and measurable goal within a set timeframe. More importantly, missions have to have a strong impact for citizens by finding solutions to some of the major challenges faced by European citizens. It was stressed that missions are not research oriented but are rather an entirely new approach based on portfolios of actions working towards broadly defined goals and should therefore not be confused with existing methods and instruments. Among others, Mission Boards will advise the Commission on identification of one or more missions in the respective mission area and on the content of work programmes, with input from stakeholders and citizens.



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Thank you!

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