

Europe's Beating Cancer Plan

AmCham Romania's response to the European Commission's Proposal

Executive summary

AmCham Romania welcomes the European Commission's proposal for a European Cancer Plan as well as the commitment to elevate cancer as a top priority on the healthcare agenda at the European and national levels.

Despite great progresses made with the approval of innovative medical technologies and treatments in the last years, high inequalities in terms of access continue to exist between the member states of the European Union. **Gaps in access to treatment and cancer care are a regrettable reality and it is imperative that any EU plan considers to address this weakness in the EU healthcare ecosystem, in order to be successful.** There is a clear pattern of wealthier countries to record higher survival rates than poorer countries.¹ The European Commission should command an in-depth **analysis of access to care and financing in oncology** in order to have a comprehensive understanding of the gaps between member countries and citizens when it comes to **prevention, diagnosis, treatment and life after cancer care**. At the same time, this analysis should be made public, for all European citizens to understand the real needs of cancer patients across regions.

It is our strong belief that **healthcare is not a cost, but an investment**. The outcome of this investment will be reflected in discernible improvements in the lives of European citizens. **A main indicator of a successful EU Cancer Plan should be the reduction in the incidence, prevalence and mortality caused by cancer.** Convergence in terms of treatment and care should mean that EU citizens have equal and timely access to early diagnosis, screening, innovation in cancer treatment, therapies and care, regardless of the country they live in. Member states should commit to implementing **National Cancer Plans** monitored & evaluated by KPIs (clinical, financial, patients' measurements) and the EU should track progress at both national and European levels. If it succeeds in this bold endeavor, the EU has a potential to become a leader on cancer data, innovation and R&D investments and a model of best practices worldwide.

Prevention

- Since the death rates from preventable and treatable causes are among the highest, the implementation of policies oriented towards preventing cancer such as the **development of health literacy**, the encouragement of citizens to participate and engage in active **screening**, the **promotion of healthy habits** (consumption of healthy food, physical activity, reduction of bad vices) and the **improvement of vaccination rates** (i.e. HPV and hepatitis) is highly necessary in order to achieve a turnaround in cancer incidence;

¹ According to IHE Cancer Comparator Report, cancer mortality rates have decreased in all countries between 1995 – 2018, except in Romania, Bulgaria and Greece. Moreover, the 5-year survival rates for the most common cancer ranged from 50% in Romania to 68% in Belgium and Iceland (the 72% estimate in Cyprus has a low reliability). For lung cancer, prostate cancer, malignant melanoma, lymphoid cancers - Romania, Romania, Poland, Croatia, and Slovakia tend to have the lowest survival rates. Complete statistics are available here: https://ihe.se/wp-content/uploads/2020/01/IHE-Report-2019_7_.pdf

- Information about **risk factors** is essential as risk factors continue to be a leading cause of deaths across Europe. The level of health literacy must be improved in order to increase disease prevention and health promotion. To this end, **the European Commission should recommend member states to include a dedicated chapter on Health Literacy in their National Health Strategies and public policies;**
- **Reducing stress and burnout syndromes** particularly at work-places in order to aim for work-life balance and safeguard the **mental health** of citizens is vital – it is important for employers and businesses to revamp metrics and cultures that reward long hours and presence, focusing instead on deliverables, performance, diversity, equity, inclusion and work-life balance;
- Environmental policies aimed at **reducing air pollution** should be an essential part of prevention.

Screening and early diagnosis

- **EU funding for screening programs at national level should be extended for the most common cancer types – lung and prostate, in addition to breast, cervical and colorectal.** In 2018, the most frequently diagnosed cancer was of the lung (11.6% of all cases), followed by female breast (11.6%) and colorectal cancer (10.2%). The 10 most common cancers are responsible for 60-70% of cancer incidence and mortality.² **Lung cancer shall be mandatorily included in screening programs** since it is the cause of 1 out of 5 of all cancer deaths in EU and it kills almost as many citizens as breast, colon and prostate cancer combined. Moreover, lung cancer is usually discovered at late stages and earlier detection may be life-saving, as it is the case for prostate cancer that is highly treatable in early stages;
- Extension of screening should further be considered for **top 5 hematologic cancers**, namely non-Hodgkin lymphoma, chronic lymphocytic leukemia, acute myeloid leukemia, acute lymphoblastic leukemia, and multiple myeloma;
- **People must be encouraged to participate in screening programs** – in this respect, health literacy is crucial for building a **screening culture** for citizens. Screening programs shall be positioned as necessary for a healthy life(style) in order to avoid that the word “cancer” might induce fear among citizens and indirectly discourage them from taking part in such programs. Proximity is very important especially for employed people, along safety and quality of medical equipments. Another important aspect is the **trust in the healthcare institutions**, as people need to be confident that they will get the best available treatment & care once/if diagnosed with cancer;
- The European Commission should formulate **a mandatory provision for member states to implement extended screening programs at national level** and provide **financial support** to ensure adequate funding for quality and efficacy of cancer services. The **European Social Fund+** could be considered for the improvement of medical infrastructure and capabilities for early detection and diagnosis. Chances to get cured are higher for some of the types of cancer where with appropriate diagnostic and treatment many patients can be back to society and economy.

Treatment & care

- The European Commission must aim for **addressing the delays and gaps in patients’ access to cancer treatment** in member states, since accelerating the time it takes to get new treatments to

² Complete statistics available on the page of the Global Cancer Observatory – WHO: <https://gco.iarc.fr/>

patients is critical from the perspective of improving patients' outcomes. Statistics prove that there is significant variation in delays in patient access to treatment with patients in Romania waiting 50% longer than in Bulgaria or Czech Republic until a new treatment reaches them mainly due to lack of appropriate funding and bureaucracy, and out of the selected 62 innovative drugs only 24 are reimbursed in Romania, significantly behind Western European standards³; To this end, **EU standards for access to care** should be put in place and adopted by member states in parallel with a **monitoring and evaluation system** to ensure that every country delivers and that access of patients across Europe to the best available treatment options is guaranteed;

- **Timely access to innovation** requires a holistic approach that considers broadly also other policies related to life-sciences. In this regard, the European Commission should encourage a **solid R&D ecosystem at EU level that fosters and incentivizes innovation**, in order to equally stimulate competitiveness and growth. A strong and predictable IP framework and maintaining OMP incentives stimulates innovation to bring new medicines to the market and continue investments. Moreover, once with the new innovative personalized treatments development, **new managed entry agreements** should be put in place at country level to allow fast access;
- The European Commission should recommend **fast healthcare technology assessment (HTA)** and reimbursement as well as to recognize the need for decreasing the time to treatment enrolment following diagnosis by decreasing the bureaucracy;
- The EU shall work with EMA to refine **definitions & agree on standards for cancer patients related outcomes (PROs) and to consider novel surrogate endpoints for clinical trials in oncology**. Data access, ownership, consent and governance are **all legal barriers to health data**, which should be addressed as current treatment regimens involve multiple lines and combinations of treatment, which cannot be reproduced in a controlled setting. Highly-innovative therapies are increasingly approved through accelerated/adaptive pathways, with limited time to run clinical trials, while the latter are conducted for certain indications, but not all potential uses. Some rare forms of cancers can only be studied in one-arm trials for ethical reasons, to ensure patients receive treatment and support continued anonymity;
- **Information about available cancer treatment services available at both national and EU level** must be improved. National databases should be created and patients should benefit from access to such data and complete information regarding their disease and treatment/care options and improved diagnosis tests to streamline the time to diagnosis and ensure timely access to treatment. In this regard, national and EU level portals dedicated to cancer treatment with comprehensive information care should be made available for healthcare professionals, patients and general public – such platforms could be developed in partnership with patient associations and public authorities. National patients' journeys shall aim to be as close as possible to European guidelines but there are **gaps to be covered as time is crucial for patients struggling with cancer – early diagnostic including precision diagnostics, available investigations, availability of radiotherapy, availability of medicines and reimbursement of novel therapies**.
- **The European Commission should monitor and work with member states to facilitate and accelerate the development and enrolment in clinical trials programs, and secure equal opportunities for European patients.**

³ IQVIA Study on Access to innovative medicines in Romania, commissioned by ARPIM, 2018

Quality of life with and after cancer

- **As cancer is a major burden for the patient but also for the family and carers, different support measures by authorities, employers, NGOs should be devised for social integration and quality of life** – including work flexibility with possibility to take time off without the risk of job loss (financial and fiscal incentives for employers could be mobilized); development and provision of systematic psychological services for patients and their families and creation of special care/ support centers and services to stimulate interaction and social initiatives; for unemployed people, caring shall be reimbursed (salary paid) and counted as a job; allow online appointments and honor them, along making available home delivery and administration for stabilized treatments to relief hospitals and ambulatories and patients, families and friends;
- The experience and quality of life that patients have through and beyond diagnosis and treatment is equally as important as clinical effectiveness. Many of the cancer patients suffer from co-morbidities. **Quality of life measures should be developed in order to support people to live well outside hospital and to return to their lives as far as possible after treatment has ended;**

Knowledge & digital health

- **Digitalization** creates benefits and opportunities ranging from developing patients' navigators, guidelines and applications to interoperable databases and electronic patients' registries that would facilitate communication within multidisciplinary tumor boards (MTBs). All necessary electronic systems should be in place to ensure a real evidence-based decision making as well as transparency towards the patients, healthcare professionals, caregivers and society in general;
- **Electronic registries – are one key point that might improve the outcome of the patients by helping the healthcare professionals in a better management of the disease.** Also, the registries could be part of a better access to innovative medicines. The electronic monitoring and control registries, together with the diversification of Managed Entry Agreements represent sustainable solutions already verified in other European countries. The use of electronic registries brings multiple benefits for the healthcare systems. In our vision, countries should establish structures dedicated to health information and the EU should ask countries to develop and implement national e-Health strategies which should include the development of electronic registers, interoperable with the other IT systems to allow comprehensive data analysis and evidence based policy decision making.
- The European Commission has a strong reputation as an advocate of digitalization in healthcare and has been stimulating member states to transform their national healthcare systems taking advance of technological breakthrough. The newly proposed EC – Digital Europe programme shall consider specific **support for building healthcare digital strategic capacities and interoperability of existing data systems in all EU member states.** EU shall secure the access and exchange of health data, create frameworks for voluntary collaborations and data exchanges to accelerate targeted and faster research, diagnosis and treatment, facilitate supply of innovative digital-based solutions for health- including efficient public funding, promote and mobilize member states to implement the European electronic health record exchange format

Financing

- In the context of the need to decrease the inequalities between member states regarding patients' outcomes, the European Commission should take into consideration clear provisions and **allocation of adequate and sustainable funds for the implementation of National Cancer**

Control Plans in order to improve **prevention, early detection and diagnosis, treatment and care**. Moreover, specific recommendations regarding efforts to reduce waste and improve the efficiency of cancer care should be taken into consideration. It is essential to ensure funding on all segments – medical infrastructure, human resources and development of competences, innovative medical equipment, diagnostics, consumables and treatment.

- Healthcare systems across Europe should ensure adequate **funding for cancer care**, matching the genuine systemic and patients' needs, complemented by a **strong strategy to fight cancer**, supported by a **monitoring and evaluation mechanism**.
- **Financing should be available for both public and private actors** in the field, considering that the private sector is an emerging segment in the healthcare system, with the potential to complement and shorten the waiting time to facilities and treatments provided by the public segment.
- **Increase countries capacities to implement the pay for performance principle and deliver value-based healthcare services.**

Fighting cancer requires a multi-stakeholder approach – we need to join forces as citizens, patients, businesses, healthcare professionals, national governments and the EU as a whole. **Citizens have an important role to play.** They need to be correctly informed, take preventive measures to reduce exposure to major risk factors and embrace a culture of healthy habits. Risk groups should follow recommendations for regular screening, while diagnosed patients must follow precisely doctors' recommendations, take the prescribed treatment and do the required tests. Other citizens can join support groups and offer psychological comfort to patients and play an active role by involving in NGOs or advocacy initiatives for a better healthcare ecosystem to reduce cancer burden in Europe. **Healthcare professionals are the direct interface between patients and the healthcare system. As they are on the first-line of defense against cancer,** healthcare professionals should act as patients' ambassadors and advocate in front of authorities for fast access to innovation, know and use state-of-the-art scientific and clinical information to improve early diagnosis, treatment, cancer care delivery and related services. Doctors should offer patient-centered communication, correct and complete information concerning all available therapies and treatment options and deliver high-quality, innovation-driven care for patients. **National governments should develop targeted policies in all areas of cancer care** (prevention, extended screening, diagnosis, treatment, care process) and make sure that all access barriers are removed and patients have access to proper information and cancer care in a timely and efficient manner. The regulatory framework should be adapted and proper funding should be allocated to match the needs of cancer patients and care professionals. Authorities should adopt and incentivize innovation in cancer treatment and care (ensure fast access to state-of-the-art medicines and information technology solutions), invest in innovation and ensure patients' access to treatment based on **value-based healthcare**.

AmCham Romania recommends that **any EU Cancer Plan should include a standardized approach for EU member states national plans** together with a solid monitoring system to track outcomes at both national and EU levels. Complementary to this, developing and agreeing on **Key Performance Indicators (KPIs)** such as clinical measurements, financial measurements, and most importantly patient feedback (measurements that make sense to patients) will help that every citizen and cancer patient benefits in the same way from cancer control and care across Europe. **Agreeing on the need and working together towards a solution for the benefit of the many cancer patients is already a first step.**