

## **Cancer Leagues' recommendations for the implementation of Europe's Beating Cancer Plan**

### **Introduction**

The [Association of European Cancer Leagues \(ECL\)](#) is a non-profit, pan-European network of 30 national and regional cancer societies. **ECL members operate across the whole cancer continuum and patient pathway. Cancer leagues are the main resource for the public for cancer control information and services.** ECL provides a unique platform for members to collaborate with their international peers, primarily in the areas of cancer prevention and early detection, access to medicines, and patient support, creating opportunities to advocate for these issues at the EU level.

Our members warmly welcome the bold and ambitious strategy, and we are delighted to see so many of the issues and activities that ECL proposed as part of [our contribution](#) to the fruitful consultation process conducted in 2020.

With this summary, ECL and its member leagues aim to provide the European Parliament with an **overview of our reflections on the Europe's Beating Cancer Plan (EBCP) and our recommendations to accelerate the implementation of the Plan** along each of the following areas:

- [Prevention](#)
- [Early Detection](#)
- [Treatment & Care](#)
- [Psychosocial support & Survivorship](#)
- [Cross-cutting issues](#)

### **Prevention**

**Cancer leagues are delighted with the high priority given to primary prevention and health promotion within the EBCP.** We agree and take note of the importance that action on cancer prevention can have towards reducing the burden of other major non-communicable diseases (NCDs).

Considering that at least 40% of cancer deaths are preventable through action on modifiable risk factors, as outlined by the [European Code Against Cancer \(ECAC\)](#), investing in prevention is essential for getting cancer under control. This will require commitment to the actions planned in the EBCP extending well into the next decade and beyond. Therefore, **we**

view the EBCP as the beginning of a renewed long-term commitment to reducing the burden of cancer, which in the case of cancer prevention, often takes a significant amount of time to demonstrate full impact.

Tobacco consumption remains the largest avoidable health risk in the European Union and is responsible for [700,000 deaths each year](#). Concerning the cancer burden, tobacco consumption is the leading cause of preventable cancer, with [27% of all cancers attributed to tobacco use](#). Consequently, **the EBCP must be a major accelerator in the battle against tobacco.**

**We make special praise for the population-level, policy-focused actions foreseen in the EBCP**, which is the most effective way to address not simply the major risk factors for cancer but also the wider, social and commercial determinants of health, which are beyond the scope of influence of an individual's personal action. In particular, we praise the commitment to:

- **Entering the endgame for tobacco** with the ambitious goal for a tobacco-free generation, and delivering a thorough, evidence-based review of EU legislation in tobacco control;
- Taking meaningful action to **reduce the harmful effects of alcohol consumption** to reach the specific target for alcohol consumption ([target 3.5](#)) within the [Sustainable Development Goals \(SDGs\)](#);
- Promoting healthy diets, nutrition and physical activity to **address the obesogenic environment in Europe** by reviewing fiscal measures on, for example, sugary-sweetened beverages and ensuring that the EBCP and the [Farm to Fork Strategy](#) complement each other;
- Promoting and monitoring the **equitable access to vaccination** against **Hepatitis B** and the Human papillomavirus (HPV) across Europe;
- Taking concrete measures to **reduce exposure to occupational carcinogens and mutagens**, plus action on the harmful effects on **ultraviolet radiation (UV)** and use of cosmetic **tanning devices** (sunbeds).

### *Recommendations for implementing the EBCP*

- The goal for a tobacco-free generation could be broadened to also encompass the ambition for a 'smoke-free' generation. **Cancer leagues call on the European Commission to establish a subgroup on the tobacco endgame within the [Expert Group on Tobacco Control](#)**. All discussions in tobacco control should be protected from influence by tobacco industry and their front groups consistent with the FCTC Article 5.3.
- **We note with some concern the language used to communicate the proposed actions on alcohol consumption** (i.e. "reducing harmful alcohol consumption"). This implies that there is a healthy level of alcohol use even though it is known that **no level of alcohol consumption can be considered safe and may lead to some confusion in**

regards to the ongoing communication of the recommendation on alcohol consumption in the [European Code against Cancer \(ECAC\)](#), which reinforces the public health message of no safe level of consumption. We have concerns that the present language, during implementation, may lead to focus specifically on excessive consumption, which would overlook the considerable impact (on a population basis) on cancer of moderate intake.

- It is important that the EBCP takes measures to reduce the skin cancer burden by addressing UV exposure, in particular, the harm caused by the use of cosmetic tanning devices (sunbeds). Currently, sunbeds are mostly regulated at the EU level in the framework of the [Low Voltage Directive \(LVD\)](#) (2014/35/EU), which does not serve the public health impact of these devices. Cancer leagues would welcome moving the file back to DG SANTE, and for the opportunity to develop a roadmap towards the outright ban of these devices classified as a Group 1 Carcinogen. National actions would then be able to be aligned with actions that can be taken at the EU level, taking inspiration from the endgame strategy for tobacco control.
- The commitment to improve the uptake of HPV vaccination in line with the [WHO Global Strategy on the Elimination of Cervical Cancer as a Public Health Problem](#) is much appreciated, however, the strategy encompasses much more than vaccination to include screening, access to treatment and rehabilitation. Therefore, we call for a more comprehensive approach to implementing the action supporting the elimination strategy, which extends beyond primary prevention. Our Joint Statement, outlining 7 priority actions for eliminating cervical cancer in Europe can be found [here](#).
- Several activities on awareness-raising at the individual level are proposed but these must be carefully considered in consultation with actors and stakeholders at the member state level to ensure the relevance and eventual uptake. Cancer leagues remind the Commission of the importance of prioritising with the EBCP population-level actions, consistent with [WHO guidance and recommendations](#).
- Cancer leagues would welcome further explanation of how the EBCP seeks to address the environmental drivers of cancer, in particular, increasing understanding on the effect from [endocrine-disrupting chemicals \(EDCs\)](#) on human health and the cancer burden. The EBCP should be linked to other chemical policy frameworks and should complement actions within the [Chemicals Strategy for Sustainability](#) to rationalise and simplify the EU's chemical and pesticide regulations for substances causing cancer.

## Early Detection

Cancer leagues support the flagship initiative of EBCP to launch a Cancer Screening Scheme for breast, cervical and colorectal cancer to improve access, quality, and diagnostics. This proposal will help coordinate actions on cancer screening that are supported by the EU and more effectively network coordinators of cancer screening programmes across Europe.

We also support the plan to review and update the [Council Recommendation on Cancer Screening \(2003\)](#) considering developments in the field that have taken place in the past decade, and the ongoing support to develop and disseminate quality assurance guidelines for breast, cervical and colorectal cancer.

The commitment to perform the third implementation report on the Council Recommendation on Cancer Screening is very welcome as comparable data is needed to support the monitoring of the performance of cancer screening programmes in Europe. We have co-authored an [important paper](#), highlighting the key issues that need to be considered while revising the current annex of the European Council Recommendation (2003) on cancer screening.

### *Recommendations for implementing the EBCP*

- Cancer leagues note that the section on early detection focuses mostly on cancer screening and is lacking in the specific area for early diagnosis. Currently, most cancer cases are not amenable to early detection via a programmatic screening approach, which means early diagnosis strategies are essential. The World Health Organization (WHO) has produced [guidance on enhancing early diagnosis capacities](#), which can be supported by the EBCP.
- ECL is deeply involved in the development of the third implementation report on cancer screening in Europe alongside the authors of the [second 'Cancer Screening in the EU' implementation report](#). The reports must be produced more regularly, on a 3-5 year cycle that supports a continuous process of monitoring and evaluation of cancer screening data, which supports quality improvement.
- Cancer leagues call for the establishment of a permanent platform to enable the networking of cancer screening programme coordinators, facilitate the training and capacity-building for improving quality in screening programmes, act as central hub for projects and initiatives on cancer screening supported by the EU, and maintain the network of data providers to the implementation report in a long-term perspective.
- Efforts supported by the EBCP in the field of early detection should make full use of existing assets and initiatives in the field, not least those organised by the WHO and the International Agency for Research on Cancer (IARC). It will be important that guidance in the field complements that of the WHO and the handbooks on cancer prevention of IARC.

- **We take note of the ambition towards “extending targeted cancer screening beyond, breast, colorectal and cervical cancer to include additional cancers” and would like to express a note of caution about the scope and modality of this activity.** First and foremost, any action to recommend the extension of programmatic screening to new cancer types must **be performed together with WHO and IARC to ensure coherence.** Without this, the recommendations will suffer serious risk to their credibility and uptake at national level. Secondly, consultation on this matter with stakeholders must be done **with full transparency regarding potential professional and commercial conflicts of interest**, which present a serious cause of concern in respect to professional societies and patient groups. The conclusions of the [Innovative Partnership for Action on Cancer \(IPAAC\) Joint Action](#) present a relevant evidence-base with which to begin this process.
- **Cancer leagues urge that the guidelines for quality assurance in cancer screening are updated as a matter of priority, in particular the guidelines for cervical cancer screening should be fast-tracked for update** to seize the momentum of the recent adoption of the [WHO Global Strategy on the Elimination of Cervical Cancer as a Public Health Problem](#) and to reach the ambitious targets of the strategy for 2030.
- Development and implementation of new technologies can have a great impact on the success and societal uptake of cancer screening. **Cancer leagues welcome the possibilities in the EBCP for the stimulation of research and implementation towards a more individual risk-based approach for cancer screening.** ECL is a partner in the Horizon 2020 project [My Personal Breast Cancer Screening \(MyPeBs\)](#), which the EBCP should carefully monitor to be informed and seize upon the findings of this important project.

## Treatment & Care

The EBCP acknowledges the need to ensure access to high standards of care and treatment in all Member States. Among the various flagships and actions foreseen in the next few years, ECL welcomes the clear, bold target of ensuring that 90% of eligible patients have access to **National Comprehensive Cancer Centres by 2030** and the establishment of an **EU Network linking such Cancer Centres in every Member State by 2025**, as recommended by the [Horizon Europe’s Cancer Mission](#) and the [CanCon Joint Action](#). We very much hope that the Cancer Centres and the new ‘**Cancer Diagnostic and Treatment for All**’ initiative will improve out-patients care and patients’ access to the latest innovative treatments close to their homes.

The cancer leagues are pleased to see that the EBCP recognises the importance of **supporting researchers working on novel health technologies and personalised treatments** through tailored support, and the creation of **interoperable digital platforms to facilitate cross-border and interdisciplinary collaboration.**

The EU is already helping Member States improving resource allocation when it comes to cancer and the adoption of new, innovative treatments. **It is encouraging to see that the European Commission is highly motivated to push for the timely adoption of the proposal for a Regulation on Health Technology Assessment (HTA)** by the Council and the European Parliament. **Our latest statement** on the decision of Member States' Ambassadors to the EU to move forward with the **latest HTA proposal can be found [here](#).**

We look forward to the **launch of a Knowledge Centre on Cancer on 30 June 2021**, which will coordinate scientific and technical cancer-related initiatives at the EU level, and **hope that it will foster the implementation of best practices so that efforts are effective, sustainable, and coherent across the EU, associated countries and with our partners beyond the EU.**

### *Recommendations for implementing the EBCP*

- Cancer leagues note that (i) the development of a strong [European Health Union](#), (ii) the implementation of a high-quality [Pharmaceutical Strategy for Europe](#), (iii) the revision of the [Orphan and Paediatric Regulations](#), and (iv) the [revision of the general pharmaceutical legislation](#), will be crucial for the achievement of the flagship and supporting actions under the treatment and care pillar of the EBCP. **The successful implementation of these initiatives will depend to a large extent on their effective synergies.**
- Cancer leagues stress the importance of **carefully assessing the impact of the flagships of the EBCP in the area of personalised medicines** together with the legislative developments in other areas because **personalised treatments should not lead to an increased number of orphan medicinal products** and additional fragmentation of the rare disease space accompanied by an unsustainable incentive framework.
- The **repurposing of medicinal products**, for both products protected by patent and those outside intellectual property protection, should be supported. This means (i) supporting data and know-how sharing, (ii) new collaborative frameworks to make new uses of on-label medicines, (iii) introduce legal changes, and (iv) support independent clinical research.
- The Plan rightly recognises the roles of national governments and the pharmaceutical industry in funding research. **It will be important to recognise fully the vital contribution of charity-funded medical research** to health outcomes across the EU.
- Looking at the entire medicine pathway, cancer leagues recommend, **considering changes to the Treaty on the Functioning of the European Union (TFEU) in the dedicated fora.** To date, according to the [Article 5 Decision 1082/2013/EU](#), institutions of the Union and Member States may engage in a joint procurement procedure with a view to advance purchase of medical countermeasures for serious cross-border threats to health, and public procurement is regulated by [Directive 2014/24/EU](#). We can apply lessons learnt from the joint procurement of COVID-19 vaccines to purchase medicines



beyond communicable diseases. This will require changes to the current legal framework.

- While the EBCP recognises that shortages of cancer medicines have increased in recent years, cancer leagues note a disconnect between this objective and the ongoing legislative developments aimed at extending the mandate of the European Medicines Agency (EMA) and its role in managing pharmaceutical shortages. It is important to clarify the role that the new [European Health Emergency Preparedness and Response Authority \(HERA\)](#) will play in overseeing the provision of medicines and medical devices in Europe. It is important to manage pharmaceutical shortages beyond the current COVID-19 crisis. Obligations and sanctions for marketing authorisation holders (MAHs) should be considered to strengthen the pharmaceutical supply chain.
- The [General Data Protection Regulation 2016/67 \(GDPR\)](#) has become a matter of great concern for the cancer research community. Despite Member States' attempts to ensure a consistent application of the law, major discrepancies at national level remain, ultimately contradicting the harmonisation aim of the Regulation. Cancer leagues echoes the [European Society for Medical Oncology's](#) concern that the ambiguous guidance provided by the European Data Protection Board, specifically on aspects related to consent and health research, is resulting in a fragmented implementation of the GDPR which, in turn, makes the research environment increasingly unattractive and collaboration arduous. Clearer guidance is crucial for the future of health research.
- Patient-centredness and participatory decision-making must be at the heart of treatment and care development processes. "Data altruism" for non-commercial usage only, as reported by the European Commission in the [Regulation on data governance – Questions and Answers](#), will be essential for achieving the flagship initiatives within the treatment and care pillar. Lessons learnt from the experience in Denmark, Germany, and the UK can be valuable. Patients should be included from the very start in any actions related to the use, storage, and re-use of patients' health data for policy-making, research purposes, and in data governance. They should be free to consent, if willing, to donate their data for health-research purposes with strict safeguards in place.
- As highlighted in the [report of the Horizon Europe's Mission Board on Cancer](#) (under recommendation 7), cancer leagues would like to underline the importance of high-quality, multidisciplinary research 'to limit the (late) side effects of cancer treatments, to relieve pain and improve palliative care' to complement the commitment to create new guidelines and quality assurance schemes on palliative care for colorectal and cervical cancer. Adequate EU funding should be allocated to the development of multidisciplinary research into palliative care and digital health solutions involving the patient perspective.

## Psychosocial support & Survivorship

Cancer leagues welcome the EBCP's recognition of the importance of ensuring that cancer patients have the highest possible quality of life throughout the disease pathway and beyond. In particular, we appreciate the Plan's comprehensive approach to patients' physical, social, and psychological rehabilitation recognising the importance of patients' centrality in follow-up care.

The EBCP mentions examining practices in financial and insurance services from the point of view of fairness towards cancer survivors in long-term remission. **We welcome the recognition of the serious financial discrimination issues faced by cancer survivors and the urgent need for fair access for cancer survivors to financial services and products.**

We are also pleased to see that EBCP acknowledges the essential role played by informal carers and the toll exerted on their own physical and mental wellbeing, and on their income due to reduced working hours.

### *Recommendations for implementing the EBCP*

- Cancer leagues reiterate the importance of developing and implementing actions in collaboration with patient advocates and groups representing cancer patients, survivors and caregivers. It is essential that all actions are co-designed, co-implemented and co-evaluated with those for whom they are targeted.
- To put an end to financial discrimination and strengthen social rights for cancer survivors, the European Commission should adopt a Regulation to ensure a common legal framework among Member States on the Right to be Forgotten building on existing legislative initiatives in force in France, Belgium, Luxembourg and the Netherlands. The subgroup on cancer within the [Steering Group on Health Promotion, Disease Prevention and Management of NCDs](#) should monitor progress in countries where the Right to be Forgotten has already been implemented. Nonetheless, cancer leagues note that the Right to be Forgotten is just one aspect of financial protection. The importance of strong social security systems and the full implementation of [Anti-discrimination Directives](#), could be addressed in the implementation of the EBCP.
- Efforts to address fair access for cancer survivors to financial services, via a Code of Conduct and a reflection on long-term solutions, should make full use of existing assets, such as the [European Agency for Health and Safety at Work \(OSHA\)](#). It will be important that the study related to the return to work of cancer survivors would also quantify the economic impact and financial toxicity experienced by survivors and their families.



- The EBCP outlines the intention to adopt a **new Occupational Safety and Health Strategic Framework to identify psycho-social risks of cancer survivors**. Cancer leagues look forward to gain additional insights into the tools and strategy the Commission wishes to use to identify such risks.

## Cross-cutting issues

### Monitoring and evaluation of the EBCP

Cancer leagues welcome the proposal to establish a governance structure that will monitor the implementation of the EBCP. **We look forward to the concrete outcome measures being elaborated in the Implementation Roadmap. We propose that the roadmap includes a capacity building framework with indicators and intended outcomes linked to proposed activities and investments.**

These **indicators should be focused on outcomes and targets outlined in the EBCP and focus in a meaningful way on individual and systemic outcomes**, including, but not limited to (i) behaviour change and behaviour change outcomes, (ii) clinical outcomes and (iii) research and innovation developments.

Given the fragmentation of the national healthcare systems and the diversities across the Member States, **national authorities should be encouraged to develop additional metrics or bespoke realistic but ambitious targets by which they can measure the success of the EBCP within their national programmes.**

### Stakeholder relations during the implementation

We support the decision to develop a triumvirate of consultation groups focusing on a) the internal communication of the European Commission and other EU institutions; b) consultation with Member States; and c) guidance and discussion with external stakeholders. **The suggestion to split the Stakeholder Contact Group into the main thematic areas of EBCP is supported and should be complemented by a horizontal group** who can address complex and overlapping concerns, such as action to reduce inequalities.

In general, to ensure the EBCP addresses the needs and expectations of its end-users, the Stakeholder Contact Groups should **make all reasonable efforts to reach representatives of organisations who have a direct impact on the ground**, bringing the ambitions of EBCP into reality. **This will require extra effort, which cancer leagues stand ready to support.**

## Health literacy

The description of health literacy should be expanded during implementation to go beyond knowledge acquisition in the field of health promotion and be promoted as a priority concept in areas relating to treatment, rehabilitation and survivorship. **Health literacy could also be systematically and routinely measured across the EU** to monitor the progress of EBCP implementation. **Greater consideration could also be given to demonstration or pilot projects** with the aim of motivating and maintaining behavioural change. Greater focus on social policy and funding in this area should be considered, as an integrated or complementary element to the EBCP.

## Tackling inequality across the entire spectrum of cancer

Cancer leagues welcome the strong emphasis on fighting inequalities between nations and within countries. **It will be important** to communicate a commonly understood definition of the issue, **delineating between inequality and inequity**, and **emphasise the need to guarantee access to clinical research as well as health services**. The EBCP should consider specific needs of vulnerable populations and minorities. The proposal for a **Cancer Inequalities Registry** is a welcome initiative, which **could make use of the [European Deprivation Index](#) methodology** as has been explored in the [WASABY](#) pilot preparatory action.

## Needs of Adolescents and Young Adult Cancer Patients and Survivors (AYA)

The focus on the specific needs of paediatric cancers is greatly appreciated, considering the extensive experience and added value that EU supported action can bring in this area. **This includes access to international clinical trials, given the limited options for treating rare and childhood cancers.**

Cancer league call for **AYA cancer patients be recognised at the EU level as a particular patient group** with specific medical characteristics and psychosocial needs that differ from those of children and the great majority of (older) cancer patients. **Cancer leagues fully support the recommendations of [ESMO and SIOPE](#)**, stressing the need for a centralisation of care into dedicated and financially well-supported specialist AYA services and networks.

## Engagement of non-EU countries to deliver mutual benefit

Whilst the EBCP understandably prioritises action within the Member States of the European Union, during the implementation phase, **greater consideration could be made of the involvement of associated countries and regions outside of the EU, particularly on research collaboration.**