

## **ECL recommendations to inform the next steps of the 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.

With this summary, ECL and its member leagues aim to provide the European Economic and Social Committee with our views and recommendations to successfully achieve the objectives the Europe's Beating Cancer Plan ([EBCP](#)) along each of the following areas:

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

### **Recommendations for implementing the EBCP**

#### Prevention

- **Cancer leagues call on the EU Institution to establish a Task Force on the tobacco end game** composed of experts from the Member States who have already taken steps in this direction, and for all discussions in tobacco control to be protected from influence by the tobacco industry and their front groups.
- **We note with some concerns 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 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.
- 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 should be carefully considered in consultation with actors and stakeholders at the member state level to ensure the relevance and eventual uptake. **Cancer leagues remind 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 complement actions within the [Chemicals Strategy for Sustainability](#) and be linked to other chemical policy frameworks to rationalise the EU's chemical and pesticide regulations for substances causing cancer.

## Early Detection

**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.

- **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 WHO has produced [guidance on enhancing early diagnosis capacities](#), which can support the EBCP.
- **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.** Firstly, any action to recommend the extension of programmatic screening to new cancer types shall **be performed together with WHO and International Agency for Research on Cancer (IARC) to ensure coherence..** Secondly, consultation on this matter with stakeholders should be done **with full**

**transparency regarding potential professional and commercial conflicts of interest**, which present a serious cause of concern concerning professional societies and patient groups. The conclusions of the [Innovative Partnership for Action on Cancer \(IPAAC\) Joint Action](#) present a relevant evidence-based with which to begin this process.

- 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

**To fulfil the flagships and actions outlined in the EBCP**, the development of a strong [European Health Union](#), the implementation of a high-quality [Pharmaceutical Strategy for Europe](#), the revision of the Orphan and Paediatric Regulations, and the revision of the general pharmaceutical legislation, will be crucial. **The successful implementation of these initiatives will depend to a large extent on their effective synergies.**

In the EBCP framework, and looking at the entire medicine pathway, from basic research to access to health technologies, cancer leagues recommend:

- Where needed, **to consider in the dedicated fora changes to the Treaty on the Functioning of the European Union (TFEU).**
- To support the **repurposing of medicinal products**. 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.
- While the EBCP recognises that shortages of cancer medicines have increased in the last years, the 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 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.
- To carefully assess 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.

- **Real-World Data (RWD) and Real-World Evidence (RWE)** can play a major role when it comes to clinical trials with a limited number of patients (e.g., rare cancers). Hence, the interplay between the upcoming European Health Data Space and the EBCP should be carefully considered for the **impact on research & development and post-marketing phase** to ultimately assess the value of innovative medicines in the long-term and consider the adequacy of value-based pricing models.
- 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 leagues call for **adolescents and young adult cancer patients and survivors** 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 services and networks.
- High-quality, multidisciplinary research is needed to understand the long-term side effects of cancer treatments and the biological mechanisms behind adverse effects that occur during and after the treatment. To improve the quality of life of cancer patients, more attention should be dedicated to **palliative care**, which is currently under-considered in the EBCP.

### Psychosocial support & Survivorship

Cancer leagues welcome the Plan's comprehensive approach to patients' physical, social, and psychological rehabilitation recognising the importance of patients' centrality in follow up care.

- 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 the 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 as well.

- The EBCP outlines the intention to look into the **Occupational Safety and Health Strategic Framework** to identify psychosocial risks of cancer survivors. Cancer leagues look forward to gaining additional insights on the tools and strategies that would be used for this purpose.

## 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 should monitor behaviour change and behaviour change outcomes; clinical outcomes; 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 tailored metrics.

In general, to ensure the EBCP addresses the needs and expectations of its end-users, the stakeholder consultation 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. **Cancer leagues stand ready to support.**

### Health literacy

The description of health literacy should be expanded during the 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.

### Tackling inequality across the entire spectrum of cancer

Cancer leagues welcome the strong emphasis on **fighting inequalities between nations and within countries**. 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.

### **Engagement with non-EU countries to deliver mutual benefit**

Whilst the EBCP understandably prioritises actions 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 in relation to research collaboration.