

The contribution of Cancer Leagues towards 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.

We thank the European Commission for the opportunity to [discuss](#) Europe's Beating Cancer Plan ([EBCP](#)) with Public Health Director John F. Ryan on 17 February 2021. 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 Commission with an overview of our reflections on the 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.

How we can help implement EBCP

- **Cancer leagues have the means and credibility to boost evidence-based messages tailored to community needs and behaviours.** Many are seen as trusted institutions and **should be engaged as such to help boost messages of benefit to public health** and specifically cancer prevention. Long-standing national observances and celebrations, such as the [Catalan Cancer Prevention Week \(SECAPC\)](#), [Christodoula March](#), the [Czech Day Against Cancer](#), [Mimosa Day](#), the [Slovak Cancer League Week](#), and the [Slovenian Week for the Fight Against Cancer](#), are known to be effective in communicating prevention messages and reaching the general public at the national, regional and local level.
- **Cancer leagues are the main promoters of the [European Code against Cancer \(ECAC\)](#) at the national and local level**, having not only promoted the ECAC but also applied in practice the messages of the ECAC using it as the basis for prevention and health promotion activities. **ECL has published the [first ever impact evaluation](#) of the ECAC, which gives food for thought for future editions.** Additionally, ECL along with the Cancer Society of Finland and IARC in the framework of the iPAAC Joint Action, **has produced [12 concrete recommendations](#) and research needs for the next edition.** **Cancer leagues, therefore, stand ready to work closely on the update on the ECAC and welcome the opportunity to devise realistic plans for achieving the ambitious target for increasing awareness of the specific messages of the ECAC and make at least 80% of the population aware of the ECAC by 2025.**
- ECL, as a partner of the preparatory action [WASABY](#), has **developed an [educational mobile app](#)** which lets users **discover the messages within the ECAC using spaced-based repetition with gamification to enhance learning.** The app, [launched on World Cancer Day 2021](#) and developed with the support of cancer leagues and [Salumedia](#), **targets young people** aged 14 to 19 to inform them about the importance of healthy lifestyle choices for cancer prevention in a fun and interactive way. **The lessons learnt from developing this app should be considered for the 'EU Mobile App for Cancer Prevention' as mentioned in the EBCP.**
- **[ECL's Prevention and Early Detection Working Group](#)** gathers the expertise of European cancer leagues through the participation of **more than 80 focal points covering all 30 member leagues.** The working group has two specific **subgroups on tobacco control and obesity**, which stand ready to help implement the actions of EBCP.

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.

How we can help implement EBCP

- [ECL's Prevention and Early Detection Working Group](#) gathers cancer leagues expertise in screening and early diagnosis with a focus on effective strategies to communicate cancer screening and promote the uptake of screening among the population. The group is mapping and analysing current and past tools used in all EU countries to inform and promote screening to the public for each of the 3 recommended screening programmes.
- ECL members would welcome a discussion about bigger ambitions for diagnosing cancer earlier. To develop further the early diagnosis strand of the EBCP, inspiration can be taken from the [Early Detection and Diagnosis of Cancer Roadmap](#) developed by Cancer Research UK, which contains recommendations. In addition, together

with the **IPAAC Joint Action**, ECL has come forward with [possible ways to advance early diagnosis of cancer](#), which can be used to boost support for early diagnosis EBCP.

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 out-patients care and improve 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 in 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 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 for and where appropriate.**
- Cancer leagues reiterate that **patient-centredness and participatory decision-making must be at the heart of treatment and care development processes.** 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.
- **"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. The possibility of individual opt-out **should remain possible.**

How we can help implement EBCP

- [ECL Access to Medicines Task Force](#) gathers cancer leagues' expertise in access to treatment issues with a focus on (i) fair prices and fair pricing, (ii) medicine shortages, (iii) cross-border collaborative and joint procurement initiatives and (iv) orphan and paediatric medicines. **The Task Force aims to make safe and effective medicines available to all cancer patients in Europe, by insisting on accessibility, availability, affordability, and increased transparency related to medicine prices,** ultimately leading to sustainability of healthcare systems. The Task Force stands ready to support the implementation of the EBCP and push for alignment with the Pharmaceutical Strategy.
- ECL is a partner of the [European Fair Pricing Network \(EFPN\)](#), which will soon have robust data and evidence available about the availability of medicines to patients, the net prices of several medicines and the current amount of public investment in pharmaceutical R&D. ECL has also recently published a **paper titled "[What is a Fair Price?](#)"**, offering a new definition of 'fair price' for cancer medicines and calling for the establishment of a High-Level Working Group on fair pricing coordinated by the European Commission.
- In view of the EBCP's recognition of the **significance of medicines shortages**, the **French Leagues Against Cancer can provide [valuable data](#)** on how this issue has affected patients and addressed at the national level.

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.

- 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.
- The EBPC 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.

How we can help implement EBPC

- **Cancer leagues in most countries are providing essential grassroots services which are not supported by national health systems**, such as the ['Afetiria' Post-Therapy Support Center](#), the [Reprèn Job Counselling Service](#), the [Rehabilitation Course](#), the ['Cancer and Work' services](#), and the ['Cancer & Work' conferences and workshops for companies](#). Some **cancer leagues** act as mediators between citizens and governments and between employees and employers and **should be engaged** as such **in helping cancer survivors facing obstacles to return to work, as well as helping businesses with their codes of conduct and policies**.
- [ECL Patient Support Working Group](#) gathers the expertise of European cancer leagues through the participation of more than 50 focal points covering all 30 member leagues. The working group has two specific subgroups on **return to work** and **sexuality issues**, which stand ready to help implement the actions of the EBPC. In particular, the Working Group has carried out extensive work on the reintegration of patients and survivors in the workplace. In 2020, it developed [guidelines for employers and human resources professionals on how to handle cancer at the workplace](#) and how to best support employees affected by cancer. The Working Group has also been exploring the [impact of cancer on sexuality and intimacy](#).

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.

Data and digitalisation

Cancer leagues can share their experiences and concerns on how data and digitalisation should be addressed in cancer research, and in the sharing of data across borders, (e.g. on their experiences with the GDPR, and their support for the need for interoperability and the enforcement of data protection rules). ECL sits in the Advisory Group of the [Joint Action Towards the European Health Data Space \(TEHDAS\)](#), which will develop European principles for the secondary use of health data.

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.**