

VIEWPOINT OF CANCER LEAGUES ON THE FUTURE UPDATE OF THE EUROPEAN CODE AGAINST CANCER

Email: ecl@europeancancerleagues.org

Website: <https://www.europeancancerleagues.org/pedwg-activities/>

Disclaimer

Co-funded by the Health Programme of the European Union. ECL has received funding under an operating grant (SGA: 101015525) from the Third Health Programme (2014-2020). The content of this paper does not reflect the views of the European Commission, the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains.

Viewpoint of Cancer Leagues on the update of the European Code against Cancer

Introduction

The European Code against Cancer (ECAC) informs the public about the easy-to-understand messages they can take to reduce their cancer risk or the cancer risk of their family members.

First launched in 1987, the ECAC is currently in its 4th edition having been comprehensively reviewed and updated by the International Agency for Research on Cancer (IARC) in 2014.

The present edition is comprised of 12 messages and is supported by an extensive questions and answers section on the official website, hosted by IARC. In addition, the scientific review of the evidence coordinated by IARC, which included dozens of leading cancer control experts drawn from all corners of Europe, resulted in 14 publications detailing the rationale for inclusion of each message into the 4th edition of the ECAC, and explained the overall methodology for the update.

The Association of European Cancer Leagues (ECL) has consistently based all our cancer prevention work on the sound and reliable evidence provided by each edition of the ECAC. Since 2014, the ECL has built on the existing work performed over many years prior to increasingly invested considerable time and resources into supporting member leagues to use the ECAC and apply the evidence behind it to promote cancer prevention at the national and local levels.

With the adoption of Europe's Beating Cancer Plan in February 2021, the European Commission signalled its intention to update the European Code against Cancer as part of the extensive cancer prevention activities detailed in the Cancer Plan. The update shall take into account the latest scientific developments and add new evidence-based recommendations to improve health literacy. The Cancer Plan sets a target of aiming to make at least 80% of the population aware of the ECAC by 2025.

Aim

The purpose of this paper is to describe clearly the views, opinions and preferences of Cancer Leagues regarding the processes to consult, draft and communicate the ECAC before, during and after the forthcoming update. The views of the Cancer Leagues will also consider the ambitious target of increasing awareness in the public of the ECAC and/or its messages by 2025.

The paper will build on the findings of ECL's recent work to evaluate the impact of the ECAC and the recommendations from the Innovative Partnership for Action Against Cancer (iPAAC) Joint Action. However, it will not focus on the specific content of the messages of the

ECAC in its forthcoming update as the content shall be determined as part of the systematic review of the evidence.

Importance of Cancer Leagues

From the launch of the first edition of the ECAC in the late 1980s, it has been the Cancer Leagues who have been the early adopters and primary promoters of the ECAC. Cancer Leagues have not only directly communicated the ECAC to the general public but have used the ECAC in a number of important ways to inform targeted communication to specific groups, provide the evidence to develop health promotion interventions, and support specific population-wide policy recommendations at the governmental level.

Considering the leading and essential role played by Cancer Leagues from the length and breadth of Europe (including countries and regions outside of the European Union), it is critical that the perspective of Cancer Leagues is brought to the forefront during each major step and decision taken in the process to update the ECAC. In the absence of this, the ECAC would risk losing support and relevance to Cancer Leagues, who will be greatly needed to promote the next edition and reach the bold awareness target in the Cancer Plan.

ECAC impact evaluation (2021)

In 2019, ECL collaborated with IARC to perform a limited impact evaluation of the ECAC, which involved interviewing representatives from 28 Cancer Leagues. This process aimed to investigate awareness and attitudes towards cancer prevention and the ECAC in the European general population, and subsequently assess internal and external factors affecting its promotion and dissemination.

When exploring with representatives from Cancer Leagues factors affecting the promotion and dissemination of the ECAC, few reported that public awareness of the ECAC itself was either a major supporting or limiting factor from their perspective. This is reflecting the view that the ECAC is not a tool simply for disseminating directly to the general public but can also be addressed to a range of key stakeholders including policymakers, civil society and advocacy groups, and health professionals.

As a result, the evaluation concluded that the ECAC has value beyond the direct dissemination to the general population, as the ECAC has been regularly used as an advocacy tool to inform cancer prevention and health promotion policies and programmes. Consequently, the impact should not be limited to measuring the awareness and attitudes of the general population alone but must consider its real-world application as a basis for informing population-level actions.

The full results and findings of this work have been published in the journal 'Cancer Epidemiology' and can be accessed at: <https://doi.org/10.1016/j.canep.2021.101898>.

Recommendations from the iPAAC Joint Action

As part of the iPAAC Joint Action, ECL collaborated with the Cancer Society of Finland, IARC, and other partners to draft a number of recommendations for the sustainability and monitoring of the ECAC.

A co-creational methodology was used to gather and refine the inputs from a variety of stakeholders focusing particularly on the scope of a future 5th edition of the ECAC, including updating and maintaining the scientific evidence, and on strategies to further expand the dissemination of the ECAC across the European Union (EU). The emerging findings were discussed at a virtual workshop attended by over 100 experts in cancer prevention and health promotion.

In total, eight specific recommendations for the next edition of the ECAC were reached as a result of this work:

- 1) *The ECAC should include cost-effective evidence-based cancer prevention measures at the individual and population levels;*
- 2) *A framework should be established, including the formal process to assess the evidence, to translate it into action, and to evaluate the impact; a governance structure and implementation and dissemination plan;*
- 3) *The ECAC should follow a multidisciplinary approach to develop evidence-based cancer-specific recommendations in synergy with preventive measures for NCDs with special attention to social inequalities;*
- 4) *Enhance the visibility of the ECAC as the unifying tool in cancer prevention, while allowing adaptation to the national context at the implementation and dissemination level;*
- 5) *The ECAC should be developed to address messages to different target groups (especially health professionals and policymakers);*
- 6) *The ECAC should be updated periodically, maintaining its high-quality process with a centralised governance of a permanent inter-institutional infrastructure;*
- 7) *Develop a Dissemination Action Plan including a description of the recommended strategies to tailor messages to the different target audiences; and the implementation of novel, attractive, and modern distribution formats, channels and methods to reach the general public;*
- 8) *Engage in intersectoral partnerships to promote the ECAC.*

The full results of this work have been published in 'Cancer Epidemiology' and can be accessed at: <https://doi.org/10.1016/j.canep.2021.101933>.

Cancer Leagues input towards the next edition of ECAC

Scope of update (ECAC 5th edition)

The general aim and objectives of the ECAC should continue to be to inform individuals about evidence-based measures they can take to reduce their cancer risk. This should be focused on primary and secondary prevention measures, at individual and population-level, supported by the latest evidence to ensure continuity with previous editions. Consideration of psychological, social and emotional wellbeing could be addressed in the scope of the next edition. The precise content itself shall be decided during the review of the evidence by independent experts.

ECL supports the recommendations from the iPAAC Joint Action to explore tailoring ECAC's messages to different audiences, such as health professionals and policymakers. Cancer Leagues recognise that whilst the ECAC recommendations aim to inform people about what can be done to reduce their cancer risk, however, the current edition does not describe **how** this can be done. The update of the ECAC should, therefore, include an implementation package linked to World Health Organization (WHO) developed materials in NCD control, addressed to specified target groups.

The materials can address cross-cutting themes, including:

- Communicating ECAC to cancer survivors;
- Cost-effectiveness data to support investment in cancer prevention;
- ECAC in the context of low health literacy;
- ECAC and the role social inequalities;
- Effective communication & dissemination methods for different settings: healthcare / workplace / schools / digital / mass media, etc;
- Evaluation of the ECAC impact;
- Exploring the synergy with NCD prevention and achieving targets of the SDGs;
- Implementing the ECAC through the Health in All Policies principle (HiAP);
- Implementing the ECAC through National Cancer Control Plans;
- Understanding the scientific evidence behind the ECAC messages.

As part of the implementation package, support should be provided to EU member states to contextualise the ECAC to their specific circumstances in terms of the cancer burden and corresponding risk factors.

ECL's evaluation of the impact of the ECAC reported that the presentation of ECAC messages in the current edition can give the impression of equivalence of all the messages in terms of the contribution to reducing cancer risk. The scope of the next edition could consider the potential to weight messages in accordance with their importance to cancer risk and prioritise their order subsequently. This could be presented, for illustration, as a dynamic interface on the website hosting the ECAC similar to the visualisation used for the [Global Burden of Disease](#), and [Global Cancer Observatory](#).

Evidence-base for the update

The 4th edition of the ECAC was largely dependent upon the IARC Monographs and Handbooks for Cancer Prevention, World Cancer Research Fund (WCRF)/ American Institute for Cancer

Research (AICR) reports, and topic specific systematic reviews to analyse and appraise the evidence to support the development and decision-making of each message. Cancer leagues recommend the update follows the same approach taken for the 4th edition in order to maintain integrity of process and acceptability of messages. It is important that recommendations of the ECAC have their foundation in the most reliable and comprehensive evidence available.

Cancer Leagues endorse the recommendations from the iPAAC Joint Action to ensure that the approach for the update for the ECAC is to develop evidence-based cancer-specific recommendations in synergy with NCDs preventive messages, with special attention to social inequalities.

As mentioned in regards to the scope of the next edition, Cancer Leagues suggest including existing data on evidence about effective measures to help people adopt the recommendations of the ECAC, and about the impact of health determinants on each risk factor. This would help to guide the implementation.

Languages of ECAC

For the 4th edition, the ECAC and the accompanying questions and answers were translated into all official EU languages. Cancer leagues recommend continuing with this approach, as it allows for widespread dissemination of the ECAC at the community level across Europe.

The translations of the 4th edition were launched one year following the official launch of the 4th edition in 2014, which led some leagues to translate the ECAC on their own volition ahead of the publication of the formal translations by the European Commission. This should be avoided with the next update by having a multilingual launch of the ECAC from the outset.

Cancer Leagues stand ready to support the translations of the next edition of the ECAC by working to support the active translation process and validate the translations performed by the European Commission services or another professional translation service. This will ensure the subject and context specific knowledge of Cancer Leagues feeds into the translated texts.

Coordination of the update

The 4th edition was coordinated by IARC who have since developed the [Cancer Prevention Europe](#) (CPE) initiative bringing together a number of leading European research institutions, who are committed to prioritising cancer prevention. In the view of ECL and Cancer Leagues, IARC is the most suitable organisation to continue with the coordination of the ECAC, and CPE could provide an ideal platform to engage the appropriate experts in the review of the evidence.

IARC is independent, has the expertise and experience in view of the coordination of the 4th edition. ECL has worked closely with IARC on the monitoring and dissemination of the ECAC since the launch of the 4th edition, which provides us with an excellent base to work towards the 5th edition. IARC has also invested significantly in the concept of the ECAC, developing a strategy for replicating the approach to other global regions and will begin soon an adaptation of the ECAC for Latin America.

During the update process, Cancer Leagues recommend the coordination to follow two 'tracks': the first is the work to update the scientific evidence and crafting messages for

individuals and communities; the second, is the work of Cancer Leagues to prepare for the promotion and dissemination of the Code. The methodology for the update could therefore consider this process and adapt accordingly to ensure the engagement of the promoters of ECAC from the outset.

Engagement of Cancer Leagues

Given the role of Cancer Leagues as the primary promoters of the ECAC at the national, regional and local levels, and that the adoption of the update by Cancer Leagues will be essential to its successful promotion and use in practice, Leagues must be provided prominent roles throughout each step of the process. Indicative roles that could be played by Cancer leagues may include:

- Participation in the overall steering group / committee for the update;
- Lead role in the working group on communication and dissemination strategy;
- Supporting role on gathering evidence from practice to support implementation package;
- Role in validation of translation of the original text of next edition;
- Engaging citizens from the outset in the update process.

Engagement and wider input of stakeholders

There are many organisations working on cancer prevention and NCD prevention (e.g., [WCRE](#), [Cochrane](#), '[Global burden of diseases](#)') who should be involved in the next edition or whose data should be analysed. Cancer Leagues support the engagement of key stakeholders who will be necessary to promote and adopt the end product. An initial stakeholder mapping can help identify those stakeholders to inform and involve, which is advisable to do at the earliest opportunity available. When engaging with stakeholders, it is vital all declarations and potential conflicts of interest are declared, and full transparency is maintained throughout the process in order to ensure the integrity and credibility of the final product.

Considering the potential to tailor the ECAC messages to a variety of audiences, it would be necessary to have representation of these respective audience engaged from the beginning in the update, for example, with representatives of health professionals and citizens. Cancer Leagues can facilitate the engagement of citizens, for instance via methodologies such as "citizens juries", to provide end user feedback on the next edition as the update progresses.

Communications strategy

As the main promoters of the ECAC, Cancer Leagues will be essential partners to communicate the ECAC. The 4th edition involved a dedicated working group of experts on behavioural change and communication of health information to help ensure the suitability of the language of the messages included in the 4th edition. Despite this, the ECAC lacked a concrete communication plan following the launch, which led to different approaches at the national level.

Consequently, a robust multi-national communication plan is required ahead of the launch of the next edition of ECAC. This plan should incorporate guidance for regular systematic communication following the launch phase. Cancer Leagues are an ideal partner to lead on this process given their extensive experience in communication to the public about all issues in cancer control.

Communications should be synchronised from the outset with comparable resources available in all EU member states. This will require the development and adoption of a consistent brand identity for the next edition and promotional materials ready for the launch phase. Cancer Leagues stress the importance of seizing the small window of opportunity provided by the launch of the next edition as the unique occasion on which the ECAC is highly newsworthy to the mass media. Sufficient resources should be allocated to ensure that Leagues of all sizes can participate and provide their expertise, and to ensure the professionalism of the communication methods and tools.

The regular systematic communication of the ECAC over time following the launch of the next edition should be supported by strategic guidance to communicate about the ECAC towards different audiences and subgroups of public e.g., health professionals, civil society, educators, students, vulnerable groups, etc.

Format of the ECAC and supporting materials

The ECAC, its official translations and the supporting materials, documents, tools, and instruments to be developed during the update should all be hosted on a central website. Cancer Leagues value the “questions and answers” developed for the current edition of the ECAC. This very useful repository of information can be updated in line with emerging evidence and the updated messages of the next edition.

Cancer Leagues support the findings of the iPAAC Joint Action to the implementation of novel, attractive, and modern distribution formats, channels and methods to reach the general public and tailored towards different audiences. Ideally, templates will be developed for widespread use by promoters from the launch of the next edition onwards, outlined in the ‘scope of the update’ section.

As part of the implementation package, outlined in the ‘scope of the update’ section, guidelines for the national implementation of the ECAC should be developed as supporting materials for the next edition.

Evaluation strategy

Cancer Leagues support the recommendation from the iPAAC Joint Action to evaluate the impact of the ECAC, taking account of its continuous use across Europe since the publication of the first edition in 1987. This should also feed into a process that ensures the sustainability of the ECAC in a long-term perspective.

The evaluation should be built on that conducted by ECL and IARC. In our study, Cancer Leagues reported that behaviour changes and public health gains as a result of promoting the ECAC are more important than knowledge of the ‘ECAC’ identity itself.

Cancer Leagues take note of the awareness targets referenced in Europe’s Beating Cancer Plan: to achieve 80% awareness of the ECAC by 2025. This should be clarified to understand if the target refers to the ECAC itself or to the respective messages.

Sustainability of ECAC

Updating the ECAC is a complex, lengthy process which would benefit from becoming a more continuous process of analysis of the rapidly evolving EU and global literature. The ECAC has been updated on four occasions previously since the publication of the first edition. Cancer Leagues recommended that a mechanism, with a strong governance model, is established to ensure the routine monitoring and regular updating of the ECAC from this edition onwards. This would allow for the experts and stakeholders involved in the update to be maintained and avoid re-starting the process afresh for each edition. A permanent mechanism could also be nimble and react in a timely fashion to the latest evidence and developments in cancer prevention as they arise.

Regular monitoring of the promotion, dissemination and implementation of the ECAC in practice will help reach defined targets set in the evaluation of the ECAC which could consider the general awareness of the messages, the ECAC itself, and its application by promoters and stakeholders at national level.

From recommendations to policies

There are thousands of interventions linked to the messages of the ECAC, some of which are not effective at all and should therefore not be recommended. As recommended by the iPAAC Joint Action, establishing a framework to translate evidence-based recommendations into actions and to evaluate their impact may be needed to inform strategies aimed to expand the dissemination of the ECAC.

Cancer Leagues, therefore, highlight the need to increase the impact of the ECAC by describing the cost-effective interventions at the population level for each of the messages. This would require adopting a standardised methodology to orient decisions about the adoption of preventive policies at the population level, based on explicit and transparent prioritisation criteria.

Implementing such a process would require combining context specific information about the burden of disease, as well as about the preventable fraction attributable to the main risk factors, with evidence about the health impact and cost-effectiveness of preventive interventions aimed to contrast those risk factors. The Prevention Lab approach (see annex) developed to support the design of the Italian National Prevention Plan, may support this process, providing at the same time additional valuable information about the estimated size and time horizon of the expected benefits of different policy scenarios (in terms of avoided DALYs and costs savings).

This evidence, together with the assessment of the health equity impact of the scenarios considered, may be crucial to favour the adoption of explicit and transparent prioritisation criteria to contextualise the communication, to inform decisions about the adoption of preventive policies at the population level, and to develop priority criteria for updating and developing new ECAC recommendations.

Conclusion

Cancer Leagues remain committed to promoting the ECAC and will continue to use the ECAC as the basis for their cancer prevention work. The 5th edition of the ECAC represents a golden opportunity to build on the successes of the current and 4th edition by expanding the scope to incorporate tools and materials to aid implementation and dissemination. These materials should be oriented towards various target groups according to their needs, interests, and preferences.

The opportunity window of the launch of the next edition should not be wasted, thus, a comprehensive communication strategy is needed and will require the active engagement of Cancer Leagues to develop and deliver. Lessons learnt from the experience of developing and launching the 4th edition must be applied to ensure that all translations are ready from the outset.

Across the entire process, Cancer Leagues should be involved and engaged in key elements of the update. In particular Cancer Leagues call for the establishment of, and their active engagement in, a robust governance model supported by a permanent mechanism whose objective is to provide long-term sustainability to the ECAC beyond the development of the next update.

ANNEX: Prevention Lab approach

A multidisciplinary group identifies prevention priorities based on data at national level of burden of disease, preventable fraction, effectiveness of interventions, and cost-benefit ratio. Effective interventions were identified and combined in different scenarios to estimate, with forecasting analysis, their impact in terms of DALYs avoided and saved costs .

Steps of the Prevention Lab:

- **Health profile** of the target population (preventable burden of disease)
- **Selecting evidence based preventive interventions**, based on a literature review and evaluation, considering effectiveness, feasibility and sustainability
- **Economic evaluation and cost-effectiveness analysis** for selected interventions
- **Assessing opportunity cost and estimating the ROI (*Return of Investment*)** of different policy scenarios, using a predictive model
- **Stakeholder** engagement

The Prevention Lab approach can convey relevant information about the health impact and cost of preventive interventions to inform decisions about the adoption of preventive policies.