ECL
Association of European Cancer Leagues

EVALUATION

OF THE IMPACT OF THE

EUROPEAN CODE AGAINST CANCER

ON AWARENESS & ATTITUDES TOWARDS

CANCER PREVENTION

12
European Code Against Cancer
12
WAYS TO REDUCE YOUR CANCER RISK

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EVALUATION OF THE IMPACT OF THE EUROPEAN CODE AGAINST CANCER ON AWARENESS AND ATTITUDES TOWARDS CANCER PREVENTION

- Summary -

BACKGROUND

Cancer is the second leading cause of mortality in Europe. A new case of cancer is diagnosed in the EU every 9 seconds. Almost half of all deaths due to cancer in Europe could be avoided if everyone followed the **European Code Against Cancer (ECAC).**

12 European Code Against Cancer 12 WAYS TO REDUCE YOUR CANCER RISK

The ECAC is a set of **12 recommendations** that the public can follow to reduce personal cancer risk and participate in organised, population-based vaccination and screening programmes. In addition, the ECAC serves as a framework for European National Cancer Plans.

Although the ECAC has been in active use for over three decades, **no systematic evaluation** of its impact has yet been carried out. Therefore, it is largely unknown to what extent the ECAC can provoke changes in knowledge and attitudes towards cancer prevention at the individual level.

In 2017, the **Association of European Cancer Leagues (ECL)** and the **International Agency for Research on Cancer (IARC)** run an online survey among the general public to assess the level of awareness towards cancer prevention and the ECAC. This research addresses the functional level of the ECAC. It emerged that **familiarity** with the ECAC **was low,** which called for further investigation on the use of the ECAC in cancer prevention efforts.

PUBLIC AWARENESS SURVEY (2017)

WEB-BASED SURVEY to measure awareness of the ECAC among adults aged >18 from 8 EU Member States in Northern, Western, Central-Eastern and Southern Europe.

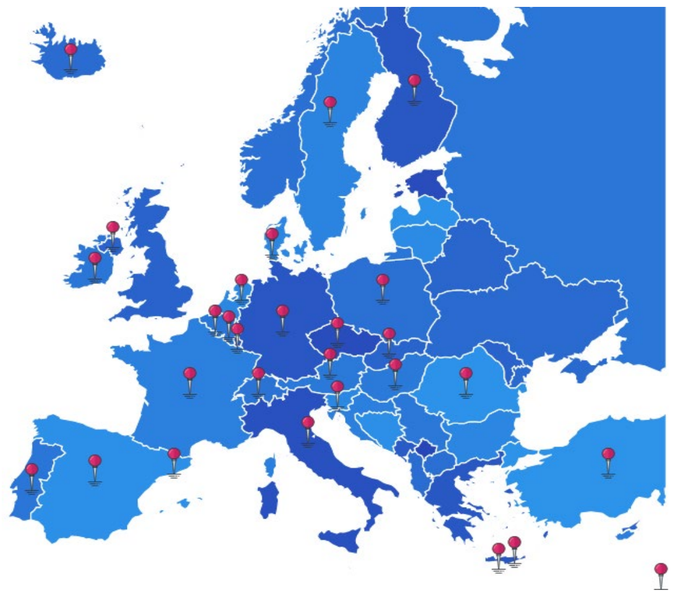
More than **70%** of the **8,171 respondents** were aware that certain cancers are preventable through lifestyle modifications. Familiarity with the ECAC among the general population was low, indicating that cancer prevention literacy does not come directly from the ECAC.

EVALUATION OF THE ECAC BY PROMOTERS (CANCER LEAGUES)

SEMI-STRUCTURED INTERVIEWS to investigate the uptake and perceived impact of the ECAC from the prespective of professionals from national and regional cancer leagues in Europe (promoters of ECAC).

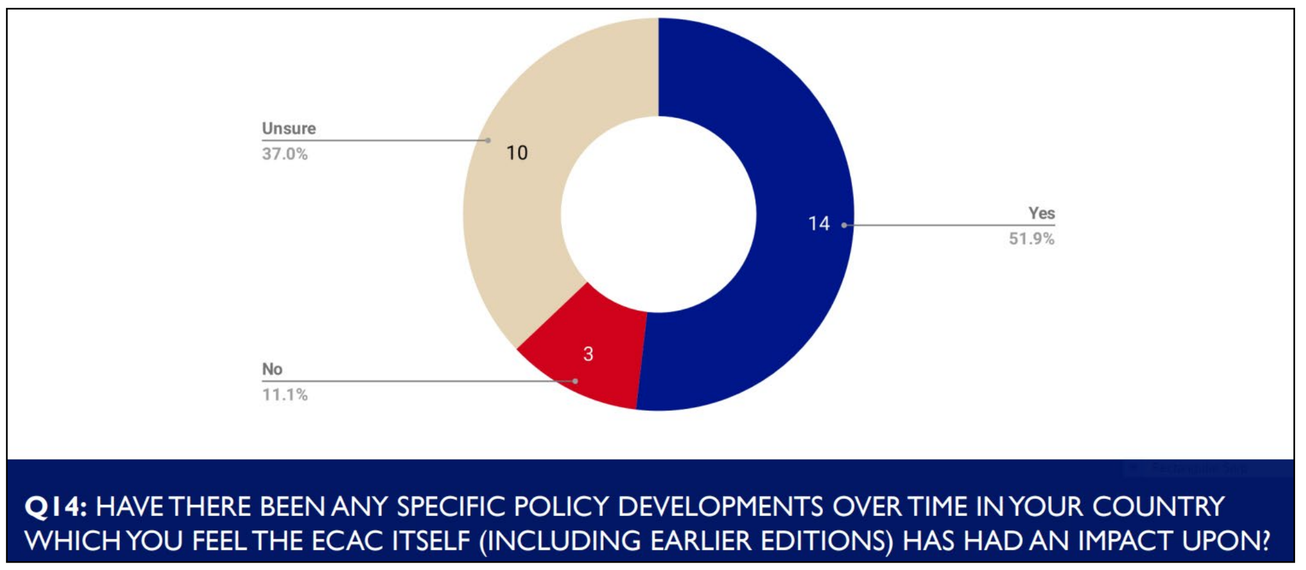
To address the impact of the ECAC at the structural level, **28** online **semi-structured interviews** were conducted from November 2018 to February 2019 covering 25 countries, including 21 EU member states.

Most promoters (n = 25) disseminated the ECAC as part of their cancer prevention actions. The majority (n = 12) disseminated the ECAC in its entirety, as a complete set of 12 recommendations. Overall, the use of the ECAC **varies significantly** by country and by region.



28 INTERVIEWS
26 ECL MEMBERS
2 ECL NON-MEMBERS
NOVEMBER 2018 – FEBRUARY 2019

Promoters confirmed that the ECAC has value beyond direct dissemination to the general population, as it is used as an **advocacy tool** to inform cancer prevention and health promotion policies and programmes.



Q14: HAVE THERE BEEN ANY SPECIFIC POLICY DEVELOPMENTS OVER TIME IN YOUR COUNTRY WHICH YOU FEEL THE ECAC ITSELF (INCLUDING EARLIER EDITIONS) HAS HAD AN IMPACT UPON?

Consequently, the impact of the ECAC cannot 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.

CONCLUSIONS

- The use of the ECAC **varies significantly** by country and according to region of Europe.
- The ECAC is being used as a **tool** to improve cancer prevention **literacy** as well as a tool for health **policy development**.
- Considerations of the impact of the ECAC cannot be limited to measuring the awareness and attitudes of the general public alone, but must **consider its real-world application** as a basis for informing public health actions.

RECOMMENDATIONS

This evaluation has considered the impact of the ECAC at two levels:
1) **Functional** – awareness and attitudes in the population;
2) **Structural** – understanding context, barriers and facilitating factors from promoters of ECAC.

The interviews carried out with ECAC promoters should be replicated with national decision-makers to further inform issues at the structural level.

In order to address the impact at the proximal/individual level (addressing behaviour change), a **full and systematic evaluation** of the ECAC is required to evaluate the combined impact of multi-risk factor recommendations.

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BACKGROUND

Cancer is the second leading cause of premature death in most countries worldwide. In 2018, the estimated number of new cancer cases in the United Nations-defined area of Europe was 4.2 million and almost 2 million deaths, accounting for around 20% of all cancer deaths globally. The projected burden is estimated to increase to at least 5.2 million new cases and 2.6 million deaths per year by 2040, translating into at least 100 million new cancer cases in the next 25 years.

Based on the established evidence that around 40% of cancer cases can be prevented and further mortality can be reduced through practices and actions targeted at the individual and population levels, the European Code against Cancer (ECAC) has stood out as a clear and integrated instrument for primary and secondary prevention of cancer. The ECAC informs the public about how to avoid or reduce exposures to established causes of cancers, to adopt behaviours to reduce cancer risk, and to participate in vaccination and screening programmes under the appropriate national guidelines; in addition, it serves as a framework for European National Cancer Plans.

Although the ECAC has been in active use for over three decades, no systematic evaluation of its impact has been carried out yet. Therefore, it is largely unknown to what extent the ECAC can produce changes in awareness and attitudes towards cancer prevention.

Following discussions with experts from the scientific committee of the 4th edition of the ECAC on how to evaluate its impact, three levels of enquiry were identified: functional, structural, and behavioural. The present evaluation builds on previous research to describe the functional level (the 2017 public awareness survey outlined below) and focuses on the structural elements influencing the impact of the ECAC by investigating the opinions and experiences of the organisations promoting the ECAC. The level of assessing the impact at the behavioural level is beyond the scope of the evaluation due to limitations in resources.

PUBLIC AWARENESS SURVEY

A web-based survey was used to measure awareness of the ECAC through a six-item questionnaire. The sample population for respondents to the survey was adults, aged >18 years old, registered within the YouGov international online panel database. Respondents were contacted by email following a simple random selection from the online panel database.

Eight European Union (EU) member states countries were selected to provide a representative geographic scope: Finland (Northern Europe); France, Republic of Ireland and the United Kingdom (Western Europe); Hungary and Poland (from Central and Eastern Europe); and Portugal and Spain (Southern Europe).

The survey was conducted between the 18th and 24th October 2017 by the Association of European Cancer Leagues (ECL) and the International Agency for Research on Cancer (IARC).

National divergences in cancer prevention awareness in general, and of the ECAC in particular, were observed. Although more than 70% of responders are aware that cancers could be prevented by making lifestyle changes and more than 63% would make some of those changes to reduce their cancer risk, less than 50% responded correctly that around 40% of all cancers could be prevented.

More importantly, knowledge on prevention does not appear to come from the ECAC in the countries investigated, as only a maximum of 21% of responders (in Hungary and Poland) have heard of the ECAC before this study.

Gender did not seem to play a strong role on cancer prevention and ECAC literacy. However, women were significantly more likely to make lifestyle changes to reduce their risk of cancer, independently of the ECAC or as a result of reading the ECAC. Women were also significantly more likely to have learnt something new after reading the ECAC recommendations.

Familiarity with the ECAC is higher amongst younger age groups, perhaps suggesting stronger promotion efforts towards the general population in recent editions of the ECAC. Overall, familiarity with the ECAC was low, which calls for further investigation on the use of the ECAC in cancer prevention efforts.

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METHODOLOGY

Semi-structured interviews were performed to investigate the uptake and perceived impact of the ECAC by examining internal and external factors affecting its promotion and dissemination. The target group were professionals from national and regional not-for-profit cancer societies in Europe working in cancer prevention and health promotion. They were selected, as their organisations are the main promoters of the ECAC in their respective countries.

A topic guide for the interviews was developed according to the theoretical framework of the Health Belief Model. Informed consent was obtained from all interviewees prior to interview, which were all conducted via Skype. A summary report of all interviews was transcribed and shared with interviewees for approval.

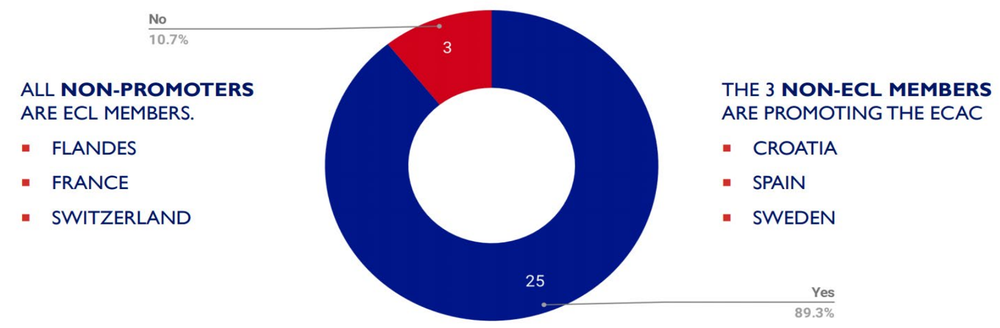
Twenty-six cancer prevention contact points from ECL member leagues and two from non-members were interviewed between November 2018 and February 2019.

Table 1. List of organisations

Country	League
Belgium	Belgian Foundation Against Cancer
Catalonia (Spain)	Catalan Federation of Entities against Cancer (FECEC)
Cyprus	Cyprus Association of Cancer Patients &Friends
Cyprus	The Cyprus Anti-Cancer Society
Czech Republic	League Against Cancer Prague
Denmark	Danish Cancer Society
Finland	Cancer Society of Finland
Flandes (Belgium)	Stand Up to Cancer
Hungary	Hungarian League Against Cancer
Iceland	Icelandic Cancer Society
Ireland	Irish Cancer Society
Israel	Israel Cancer Association
Luxembourg	Luxemburgish Foundation Cancer
Netherlands	Dutch Cancer Society
Northern Ireland	Cancer Focus Northern Ireland
Poland	Polish League Against Cancer
Portugal	Portuguese Cancer League
Romania	Romanian Cancer Society
Slovakia	League Against Cancer Slovakia
Slovenia	Association of Slovenian Cancer Societies
Switzerland	Swiss Cancer League
Turkey	Turkish Association for Cancer Research and Control
Italy	Rete per la prevenzione
France	French Cancer League
Germany	German Cancer League
Croatia	Croatian League Against Cancer
Spain	AECC
Sweden	Cancer Fonden

28 online semi-structured interviews were conducted from November 2018 to February 2019 covering 25 countries, including 21 EU member states at the time of the interview. 4 non-EU member states (Iceland, Israel, Switzerland, and Turkey) were included as the ECAC has been promoted widely in those countries.

Fig. 1 Summary of survey respondents



A qualitative thematic analysis was performed for each interview. Two investigators reviewed the content of each interview summary report and systematically coded items into conceptually related categories. Following review by the third investigator, the coded categories were added to the interview summary report and returned to interviewees for final approval. Discrepancies were agreed upon by a verbal consensus amongst investigators.

Interview Guide

Respondents were required to provide answers to questions 1-5 prior the interview. Questions 6 to 16 were addressed during individual skype or phone interviews with the respondents.

Table 2. Interview guide questions

Interview questions
1. Does your cancer league currently promote the European Code against Cancer (ECAC)?
2. Does your cancer league currently promote the ECAC as a single entity (i.e. all 12 messages concurrently)?
3. How does your cancer league promote the ECAC? Please check the methods that apply and describe below, stating the target groups.
4. Has your cancer league adapted, removed or added some of the messages of the ECAC at a national level?
5. Are you aware of the ECL Youth Ambassadors for the ECAC?
6. Thinking in terms of the content of the ECAC, what do you think are the general advantages of the ECAC as a whole?
7. Thinking in terms of the content of the ECAC, what do you think are the general disadvantages of the ECAC as a whole?
8. Thinking about the context in your country, what are the factors that may support the promotion & use of ECAC?
9. Thinking about the context in your country, what are the factors that may make it difficult to promote & use the ECAC?
10. In your opinion, are any of the following key stakeholders in your country especially supportive (approve) of the ECAC?
11. In your opinion, are any of the following key stakeholders in your country NOT supportive (disapprove) of the ECAC?
12. Do you feel that you have the materials and services needed to promote ECAC?
13. Are there any current policies in place that make the promotion & use of the ECAC easier? e.g. a national cancer control plan, health promotion strategy etc.
14. Have there been any specific policy developments over time in your country which you feel the ECAC itself (including earlier editions) has had an impact upon? e.g. development and implementation of cancer screening programme, etc.
15. Are the any recent developments in public health that may have an impact (either positive or negative) upon how the ECAC is received by different target groups in your country? e.g. roll-out of Hepatitis B vaccination, HPV vaccination, tobacco packaging legislation etc.
16. During your work in cancer prevention for your organisation, how difficult is it to remember to refer to the ECAC?

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RESULTS

The majority of promoters interviewed, disseminate the ECAC in its entirety - as a complete set of 12 recommendations. Notably 6 out of 7 organisations in central eastern Europe reported to “always” promoting the ECAC as a whole, whilst none of the 4 organisations in northern Europe reported doing so. Several organisations, evenly distributed across all European regions, reported adapting the recommendations of the current edition of the ECAC (n=10).

Most organisations in Northern Europe reported having made adaptations of the recommendations withing the ECAC for promotion and dissemination purposes. Regarding existing national policies that facilitate the promotion and dissemination of the ECAC, 18 promoters reported inclusion in their countries’ national (or where applicable, regional) cancer control plans.

Table. 1 Summary of findings of promoters’ survey.

ORGANISATIONAL CHARACTERISTICS		NUMBER OF ORGANISATIONS BY GEOGRAPHICAL REGION[a]				TOTAL
		Northern Europe	Western Europe	Central & Eastern Europe	Southern Europe[b]	
European region in which the organisation is based		4	9	7	8	28
Promotes and disseminates the ECAC	Yes	4	6	7	8	25
	No	0	3	0	0	3
Promotes the ECAC as a whole (package of recommendations)	Always	0	2	6	4	12
	Sometimes	3	4	1	4	12
	Never	1	3	0	0	4
ECAC recommendations adapted by the organisation	Yes	3	3	2	2	10
	No	1	6	5	6	18
Dissemination methods used	Public dissemination materials (e.g. Leaflets, posters, etc.)	1	6	7	6	20
	Specific programmes or interventions incorporating the promotion of the ECAC	2	5	4	5	16
	Specific campaigns to promote the ECAC	1	3	5	5	14
	Dissemination events dedicated to the ECAC	0	4	3	3	10
	Other (e.g. Dedicated website, social media)	2	6	5	7	20
Current national policies that facilitate the promotion and dissemination of the ECAC	National cancer control plan	0	5	7	6	18
	Health promotion & NCD control strategy	1	5	4	6	16

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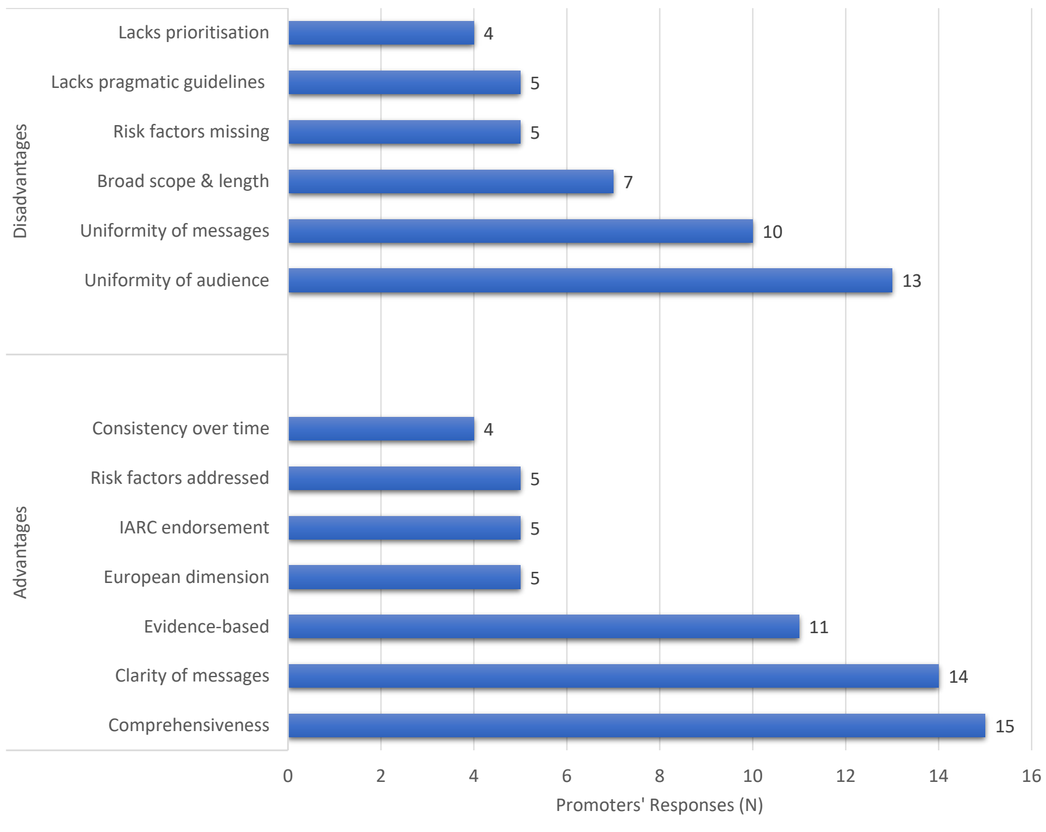
RESULTS (cont.)

To investigate the divergences between countries in the awareness and attitudes toward the ECAC by the general public, promoters were asked to describe factors which may support or limit the promotion and dissemination of the ECAC.

Figure 2 shows the responses provided by promoters regarding the advantages and disadvantages affecting ECAC promotion at the national level. Promoters most frequently cited the comprehensiveness of the 4th edition of ECAC regarding the cancer prevention topics addressed (n = 15), the clarity of phrasing for each recommendation (n = 14), and the robust evidence base underpinning ECAC (n = 11) as the key positive internal factors (or advantages). Promoters also noted that the coordination and endorsement of the International Agency for Research on Cancer (IARC) (n = 5) and the European Commission (n = 5) provides credibility to promotion of the ECAC. Additionally, the prominence given to the main modifiable risk factors (n = 5), which have been emphasised consistently in each edition of ECAC (n = 4) were reported as additional positive factors.

Fig. 2 Advantages and disadvantages of the ECAC influencing its promotion and dissemination. *Factors represent the most frequent coded categories derived from a thematic analysis of the interviews performed with 28 promoters of ECAC.*

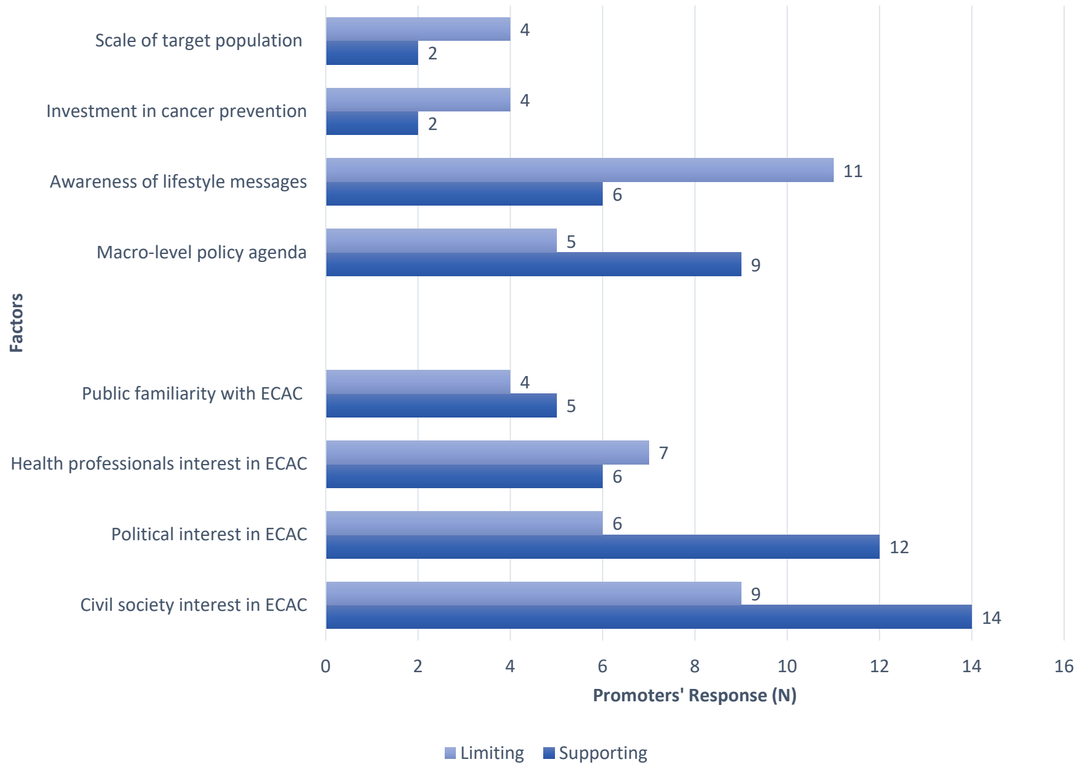


Regarding the negative internal factors (or disadvantages), promoters most frequently noted the one-size-fits-all approach towards the general population as the target audience of the ECAC (n = 13). This was identified as a disadvantage as promoters preferred to have the ability to tailor ECAC to meet the needs of different groups. Likewise, the standardisation of the 12 messages of ECAC was identified as a disadvantage (n = 10) as several messages were not considered appropriate to communicate in the respective national context. For example, promoters in countries without systematic screening as recommended by ECAC reported that this message should not be communicated as it appears in the ECAC. Several promoters also felt that the presentation of ECAC suggests all 12 messages are equivalent in their importance to the cancer burden, which is a factor that was viewed as a disadvantage (n = 4).

Additional factors reported include the word length of the 4th edition of the ECAC (n = 7), omission of certain environmental risk factors (n = 5) and the lack of guidance for operationalising the ECAC (n = 5), which has led to asymmetric promotion of ECAC across Europe.

Figure 3 shows the contextual factors that affect the promotion and dissemination of the ECAC. Several promoters reported that macro-level policy trends, such as the sustainable development goals, presented a favourable context for the ECAC promotion (n = 9). These organisations see the ECAC as an evidence-based tool to advocate towards enactment of local and national health-promoting policies and actions, rather than as an instrument to communicate directly to the general public. On the other hand, five promoters noted that the cancer-specific approach of the ECAC conflicts with their preference of addressing the modifiable risk under a common framework to tackle the major non-communicable diseases and the broader social determinants of health. The main limiting contextual factors reported by promoters refers to the variety of competing lifestyle-focused messages directed at the general population (n = 11).

Fig. 3 Contextual factors influencing the promotion and dissemination of the ECAC. *Factors represent the most frequent coded categories derived from a thematic analysis of the interviews performed with 28 promoters of ECAC.*



Regarding the general awareness of the ECAC by the general public, similar numbers of promoters reported that local familiarity of it was a either supporting factor (n = 5) or, conversely, lack of familiarity was a limiting factor in the promotion and dissemination of the ECAC (n = 4). In addition, promoters were asked to report their perceptions of the positive or negative interest that various stakeholders (such as civil society and advocacy groups, governmental actors, the media, health professionals) may have in the ECAC. Promoters reported that civil society (n = 14) and political decision-makers (n = 12) are broadly more supportive of the ECAC than resistant to its promotion nationally. On the contrary, several promoters (n = 5) identified that health professionals' support for the ECAC is perceived to be limited.

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DISCUSSION

Interviews with promoters reported that 25 of the 28 organisations represented by promoters actively promote the ECAC. Regional differences were found in the use of the ECAC as an integrated instrument for cancer prevention and health promotion. While most of the promoters' organisations in central and eastern Europe promote the ECAC as a single instrument for cancer prevention and health promotion, as recommended by the scientific coordinators of the current edition, only two of the nine organisations in western Europe and none of the four in northern Europe do so.

These results may help to explain the divergences between countries in awareness of the ECAC, as countries from central and eastern Europe, such as Poland and Hungary, have documented extensive national promotion and dissemination of the ECAC in its entirety. In addition, promoters from organisations based in central and eastern Europe reported a national cancer control plan as an example of a national policy that facilitate the promotion and dissemination of the ECAC. Furthermore, although not explored in depth, some promoters reported that the ECAC has had impact on public health policies and programmes over time, in particular on the development of organised cancer screening programmes, which themselves could be suitable places to promote and disseminate the ECAC to a large number of people.

One informant noted that:

[in their country] there has be a lot of effort to implement screening programmes to our health system and ECAC could be one of the things that helped.

When exploring factors conditioning the promotion and dissemination of ECAC, few promoters reported that public familiarity with the ECAC was either a major supporting or limiting factor from their perspective. This result is initially surprising considering the roles promoters and their organisations play in communicating to the general public. However, the interviews revealed that, from a promoters' perspective, the ECAC is typically not disseminated solely to the general public but is also addressed to a range of key stakeholders including policymakers, civil society and advocacy groups, and health professionals. Thus, the general public represents one of a range of target audiences from the promoters' perspective.

One informant noted that

Even if awareness of stakeholders is good, more could be done, for example by the media.

Promoters frequently reported that the perceived interest in the ECAC of policymakers and civil society were a key factor conditioning its promotion and dissemination. Therefore, whilst the awareness of the ECAC in the general population may be low in certain countries, supportive attitudes of these specific stakeholders towards it, from the perspective of promoters, indicates a good awareness of the ECAC amongst stakeholders engaged in public health policy development. This result shows that the ECAC is used as an advocacy tool towards cancer prevention and health promotion policies and programmes in several countries, some of whom support the promotion of the ECAC in their national cancer plans.

The factors most frequently identified by promoters as limiting the promotion and dissemination were the recommendation of the ECAC to communicate the public as the primary target group, and the abundance of competing cancer prevention and health promotion messages that are already being communicated to the public. These factors were especially a hindrance for promoters whose organisations who adopt an integrated Non-Communicable Diseases (NCDs) perspective to their cancer prevention and health promotion activities, rather than a disease-specific approach.

Promoters from organisations privileging an NCD perspective also noted that the general public in their respective countries are subject to a wide variety of comparable, and sometimes conflicting, lifestyle-focused disease prevention messages. Therefore, from their perspective, the strength of the ECAC is to act as the reference point for entities who are engaged in the mediation between evidence generation and communication to the general public.

Informants also noted that the explicit "endorsement" of IARC and the European Commission in the development of ECAC

Adds weight as they are not just national recommendations.

On the other hand, for promoters (mostly those based in central and eastern Europe) who reported that their organisation always disseminates the ECAC in its entirety, the ECAC was reported as being a valued and necessary tool to communicate directly to the general population. The diverging views of promoters on this issue reflects the importance of national context towards the promotion and dissemination of the ECAC and could be explained by the potential lower intensity of competing and conflicting lifestyle-focused messages in the central and eastern regions. If so, this may increase the value of promoting the ECAC directly to the general public thereby partly accounting for the geographic variation in its awareness across countries.

One informant stated that the ECAC had helped draw attention to the link between alcohol and cancer:

Alcohol and cancer link was not well known and [the ECAC] helped to bring forward the argument on this issue.

The strength of this study is that it provides new evidence on awareness and attitudes towards cancer prevention and the ECAC and unpacks the internal and external contextual factors contributing to its promotion and dissemination. The results can, therefore, help improve activities to use the current edition of the ECAC and inform the development of future editions. However, there are several limitations. Firstly, due to the use of the online omnibus survey, it is not possible to report the completion rate nor response rate as data on the number of invitations sent and surveys started but not completed was not reported. Secondly, selection bias should be acknowledged regarding the individuals interviewed as promoters of the ECAC. Whilst the geographical scope and coverage is broad enough to be representative, individuals with potentially unfavourable views about ECAC may have been less likely to respond to the invitation to be interviewed. Finally, both the online survey and interviews with promoters were conducted in a limited number of European countries, therefore, caution should be exercised when generalising the results widely.

CONCLUSION

Interviews with promoters identified several internal and external contextual factors conditioning the promotion and dissemination of ECAC, which provided insights to explain variation in the awareness of the ECAC across countries. Promoters confirmed that the ECAC has value beyond the direct dissemination to the general population, as it is used as an advocacy tool to inform cancer prevention and health promotion policies and programmes. Consequently, its impact cannot 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 results of this study partially address a gap in knowledge about the impact of the ECAC, yet, in view of the consensus that public resources should be prioritised towards supporting evidence-based practice, a full and systematic evaluation of the ECAC is warranted. Therefore, the next and future editions of the ECAC should be accompanied by such an evaluation studies to further elaborate the impact for society.

1. The use of the ECAC varies significantly by country and according to region of Europe.

2. As well as being a tool for improving cancer prevention literacy, the ECAC is used as a tool for health policy development.

3. The impact of the ECAC should not be limited to measuring the awareness but must consider its real-world application as a basis for informing population-level actions.

RECOMMENDATIONS

This evaluation has considered the impact of ECAC at two levels:

1) Functional – awareness and attitudes in the population;
2) Structural – understanding barriers and facilitating factors from promoters of ECAC.

The interviews performed with ECAC promoters should be replicated with national decision-makers to further inform issues at the structural level.

In order to address the impact on the level of behavioural change, a **full and systematic evaluation** of the ECAC is required to evaluate the combined impact of a multi-risk factor recommendations.

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