

External evaluation of ECL 2019



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Abbreviations

EC	European Commission
ECAC	European Code against Cancer
ECL	Association of European Cancer League
EP	European Parliament
EU	European Union
EWAC	European Week Against Cancer
GA	General Assembly
MAC	MEPs Against Cancer
MEP	Members of the European Parliament
PSWG	Patient Support Working Group
YA	Youth Ambassadors

1. Introduction: objectives and approach of the external evaluation

ECL (the Association of European Cancer Leagues) is a Brussels-based non-profit, non-governmental organisation uniting national and regional cancer leagues in Europe. ECL was established in 1980 and consists (currently) of **29 member leagues in 24 European countries of which 20 EU Member States**¹. These members represent more than 450 million citizens and employ a workforce of over 3.000 people and more than 200.000 volunteers. ECL is the only organisation on a European scale providing a dedicated platform for cancer leagues, from all over Europe, to network and exchange best practices.

The overall **purpose** of ECL is to play a leading role in the prevention and reduction of cancer through engaging in **advocacy, networking, capacity building** and **patient support**.

In 2019, SAGO Research was contracted to implement the external evaluation of the functioning of ECL. The objectives of the evaluation were defined as follows:

- **Objective 1: To assess the added value for member organisations being part of ECL**, including an assessment of the factors contributing to results and factors hindering impact, as well as strengths and weaknesses of ECL according to its members.
- **Objective 2: Making concrete recommendations on how to improve added value of ECL for its members**

A range of data-gathering instruments was used, allowing triangulation (the use of a variety of methods and instruments in a single piece of evaluation research to check the robustness of the findings), i.e.: **document analysis** (including the strategic plan, annual work plan and other relevant documents), **15 Skype/telephone/face-to-face interviews** with a selection of ECL members, and **observation of one key ECL event** (PSWG – Luxembourg, 26-27 November 2019). The data gathering took place in the period September and December 2019.

2. Evaluation findings

Overall, the external evaluation of ECL covering the past two years with a focus on 2019, provides a **positive picture**. Besides the external evaluation conducted in 2019, evidence can be found in documents that also internal evaluation is taking place in the framework of the working structures, e.g. online evaluation sent by the Secretariat in the framework of the A2MTF in the beginning of 2019 or the reflections shared on the functioning of the working structures during the various meetings.

The **added value** for organisations of being a member of ECL ranges from information provision, to mutual learning, providing a platform for building partnerships, but also to tackle issues at EU level, increasing their own visibility and position at national/transnational level to ECL voicing the concerns and stakes of its members at EU level. The fact that the network is gathering national Cancer Leagues gives credibility to the network and the members.

Various **outputs** have been produced by ECL the past years and overall the interviewees assess these as being of good quality. ECAC was one of the outputs the most mentioned as useful by interviewees which is not surprising as it is part of the core business of members (prevention against cancer). The **use and uptake of ECL outputs** depends amongst others on the capacity of the member organisation: larger member organisations have their own research department, producing outputs to be used for information dissemination and campaigning and on where the member is situated in its life-cycle. Especially for newer organisations that are member of ECL, the information and material produced is useful for own use. Various examples are given on how the outputs are used by member organisations,

¹ Based on consultation of ECL website on 23.11.2019 (<https://www.europeancancerleagues.org/members/>)

e.g. in the original format for own use or translated for dissemination, as a source of inspiration of for dissemination accompanied by own material of the member. Interesting to notice is that many interviewees report that they have been involved in the development of the outputs and that this also facilitates uptake and dissemination. Language is an issue in outputs, i.e. the jargon used and the fact that some practical tools and guidelines have the most use when they are in the native language of the user (e.g. patient guides).

There are **two levels of outcomes of the work of ECL** in the past period:

- **The level of member organisations.** Key results identified by interviewees are related to an improved/strengthened position at national level, strengthened capacity of the member organisation, further the achievement of the goals of members related to influencing both the national and EU level. Members report the importance of ECL in helping them to connect with decision makers in order to contribute to impact at EU level e.g. in relation to access to medicines, tobacco regulation etc.
- **The EU-level.** The role of the MAC group is considered to be vital in this. This unique working structure of ECL² is important to influence policies but also to pass on messages on daily challenges and practices of member organisations to the EU level. In the 2019-24 parliamentary legislature, MAC has 136 members coming from different political groups and EU Member States. This working structure creates a huge potential for policy influencing and advocacy.

The fact that the different working structures complement and reinforce each other, are a key ingredient in the **success of ECL**. Other success factors are the effective relation management by the Secretariat in interaction with the members, but also with relevant stakeholders at EU level and international level, the quality of the outputs as well as the professionalism of the ECL staff.

Challenges in relation to outcomes and impact of ECL are the balance between the number of staff members and the volume and scope of the work. Some members expressed concerns about the workload of staff and potential effect on staff turnover. While some interviewees propose to narrow down the scope of the work and to find a niche in which ECL can be most influential, the diversity of the membership also drives this broad scope of the work of ECL. Financial diversification for sustainability is certainly an issue on the ECL agenda but is at the same time also a real challenge for many EU-level networks. ECL has a Transparency Statement, which is a useful guidance in this process.

Some more **coordination and clear linkages between the different parts of the work** is considered by members to be beneficial. An area where improvements could lead to great benefits are the Youth Ambassadors. This group founded in 2012 plays an important role in cancer prevention within ECL. A first step was to identify, train and engage them. The following step is to link them more closely to the member organisations at national level. The group is growing in numbers, and according to interviewees they need more support in implementing their tasks at national level.

Keeping ECL interesting for both smaller/newer organisations and larger/older ones is something to stay vigilant about. The diverse membership of ECL (size, nature, different stage in the life-cycle of development) is according to some interviewees a weakness (*“trying to cater for all and having the risk of ending up with activities that are not relevant for nobody”*) while for others it is a strength since it represents a broad voice of a wide community.

The level of engagement of some members is considered by some interviewees as a weakness, as it is according to them hindering the process of *“constructing something together”*. The **active participation of all members is considered to be important**, given the limited size of the Secretariat team. Analysis of participants' lists of a limited number of (7) events in the period 2018-2019 reveals that about 1/3rd of the membership is not very active (participated in less than 2/7 meetings). Based

² Based on work of the external evaluator with about 15 other EU-level networks.

on comparative work of the evaluators (with other EU-level networks), this is an average participation pattern.

Interest increased in the last meeting of the Patient Support Working group. One element put forwarded by few participants interviewed during the meeting is that before the support to patient was diffuse, not enough delineated while now the focus for the coming two years is on two specific topics (work and sexuality).

3. Recommendations

1. Clarification of the role of research in the network

The position of research in the network and the role ECL plays in relation to research needs some further explanation, based on the content of the Strategic Plan 2019-2021 as well as the by-laws. Clarification is needed for members, who can be member of ECL (cancer league involved in research or also a cancer research organisation) and the position of research within ECL (e.g. also space for scientific publications?).

2. Active engagement of members in ECL activities

Participation levels change over time and member organisations and individuals may move through different levels of participation on a regular basis, influenced by various factors (e.g. available resources, interests, priorities, etc.). It is acknowledged that member leagues have valuable human resources that could be drawn upon by the secretariat to add to their substantial expertise. Since the task is big and the ECL team is small (a concern expressed by various interviewees and also discussed during the 2018 GA meeting) an active engagement of members is needed to accomplish the goals.

2. Clarifying and strengthening the role of Board in organisational processes

Some interviewees express the need to have more clarity about the role of Board members in organisational process, like e.g. the further development of the network, liaising with members on specific issues or linking the different components of the work of ECL. It is further recommended to reflect on strengthening the role of Board members in network development and relation management with member organisations.

4. Youth Ambassadors further support

Further development of the Youth Ambassadors initiative is recommended during the interviews. The first step was to identify, train and engage Youth Ambassadors in the ECL work. The second step is to link them more closely to the member organisations at national level. Furthermore, they need support, as in some cases these are individuals that have to deal with a large population at national level.

5. Financial diversification

The EC Operational Grant and the membership fees are currently the main financial sources of ECL. Further investigation is necessary on possible complementary financial sources (e.g. foundations, projects).

6. Gathering evidence in a structured way

It is clear that there is sufficient evidence that ECL makes a difference at the level of member organisations and at EU-level. Still, to better monitor progress towards the strategic objectives to be achieved, it is recommended to gather evidence of changes to which ECL has contributed at the level of member organisations, national and/or EU level in a structured way.

7. Strengthening links between different components of the work of ECL

Based on the evaluation, it is recommended to strengthen the links between the different components of the work of ECL, e.g. between the existing working structures (with the focus on the Working Groups and Task Force), as well as between the Youth Ambassadors and the related national member leagues and this to strengthen effectiveness and efficiency.

8. Outputs: language and target groups

The type of output and language used, needs to be clearly attuned to the target audience. Based on the interviews and the evaluator's analysis this could be further reviewed. For example, the publication 'It's your consultation!' is both addressing patients and health professionals, which are two distinct target groups who might need a different approach and language.