

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

This report presents the results of the external evaluation of ECL 2019

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.

ECL is “Making a difference in Cancer Control in Europe since 1980”
ECL Leaflet

The **vision** of ECL is a Europe free of cancers. The **mission** is:

- improving cancer control in Europe through supporting active collaboration amongst its members in the fight against cancer,
- being a leader in cancer control by influencing EU policies for better health outcomes and
- reducing inequalities through work in patient support.

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**.

The **13 key operational objectives** for the ECL Specific Grant Agreement (SGA) are related to the **five specific objectives** defined in the SGA. These specific and key operational objectives are also linked to the strategic goals as presented in ECL’s Strategic Plan 2019-2021².

Table 1: Specific objectives 2019, key operational objectives 2019 and strategic goals 2019-2021

Specific objectives SGA 2019	Key operational objectives SGA 2019	ECL’s Strategic Plan 2019-2021
Influence policy at EU level.	Perform survey of national contact points for the triennial Tobacco Control Scale Report.	Influence cancer control policies.
	Publish European Elections 2019 Manifesto.	
	Re-establish the MEPs against Cancer Group, following the elections 2019.	
	Organise a breakfast policy dialogue during the 2019 European Week against Cancer (May).	
Promote the European Code against Cancer.	Publish online the European Code against Cancer (ECAC) policy framework.	Promote cancer prevention.
	Launch pilot activity to evaluate the ECAC.	

¹ Based on consultation of ECL website on 23.11.2019 (<https://www.european-cancer-leagues.org/members/>)

² The strategic goal 'grow membership and increase impact of ECL in Europe' is not linked to objectives of the SGA 2019.

	Promote online the collective actions of the ECL Youth Ambassadors for ECAC on World Cancer Day 2019 (February).	
Support implementation of organised cancer screening programmes.	Publish cancer screening web portal on the ECL website.	Enhance support to cancer screening and early diagnosis.
	Deliver cancer screening training workshop for cancer leagues.	
Advocate for equitable access to treatment and care for cancer patients.	Publish cancer leagues volunteering guide.	Ensure equal access to high value cancer treatments for all cancer patients in Europe.
	Publish guide on improved communication between patients and healthcare professionals.	
	Publish position paper elaborating on issue and solution listed in the White Paper on Access to Medicines.	Develop actions supporting cancer patients, survivors and caregivers.
Implement the 'Cancon Guide' at the national level.	Collect best practices from at least 5 cancer leagues related to the implementation of the 'Cancon Guide' and disseminate to policy makers.	

2. Objectives and approach of the external evaluation

2.1. Objectives of the evaluation

The objectives of the evaluation are the following:

Objective 1: To assess the added value for member organisations being part of ECL

- What is the added value for organisations of being a member of ECL?
- To what extent are ECL's outputs used? By whom? How are the outputs used? Do outputs lead to outcomes, i.e. to the outputs lead to actions/changes?
- What are the paths, mechanisms (e.g. working groups), partnerships and other means that have contributed to impact? What has been ECL's role in this?
- What factors have impeded or hindered impact?
- What are strengths/weaknesses of ECL and its work according to members?

Objective 2: Making concrete recommendations on how to improve added value of ECL for its members

2.2. Approach and methodology of the evaluation

A variety of data-gathering instruments will be 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 strategic plan, annual work plan, and other relevant documents like e.g. agenda and minutes of meetings, lists of participants and outputs.

Table 2: References used for document analysis

	References
1	ECL Work Programme 2019 for the Specific Grant Agreement for an Operating Grant – 3 rd EU Health Programme
2	ECL Framework Partnership Agreement 2018-2021
3	ECL By-laws (2009)
4	ECL Access to Medicines (A2M) Task Force Action Plan 2019 -2020
5	ECL A2M Task Force, Berlin 14.02.2018 Meeting Minutes
6	ECL A2M Task Force, Bern, 19.03.2018 Meeting Minutes
7	ECL A2M Task Force, Prague, 25.03.2019 Meeting Minutes
8	ECL A2M EP event, Brussels, 10.10.2018, Agenda
9	Advisory group meeting on the evaluation of the impact of the European Code Against Cancer, Brussels, 27.02.2018, Meeting Minutes and list of participants
10	ECAC Workshop, Dublin and Belfast, 22-24.05.2019, List of participants and Agenda
11	ECAC Update meeting, 04.12.2019, List of participants + report
12	ECL Press Release, 10.10.2018
13	ECL GA 2018, Berlin 16.11.2018, Agenda and Minutes
14	ECL GA 2017, Minutes
15	MEPs Against Cancer (MAC) meeting EP, Agenda, 17.10.2018
16	MAC meeting EP, 16.05.2018, Agenda
17	MAC meeting EP, 23.01.2018, Agenda + report
18	MAC Elections Manifesto, List of participants, 08.01.2019
19	MAC meeting EP, 20.06.2018, Agenda + report
20	MAC meeting EP, 25.09.2018, Agenda
21	MAC internal meeting, 08.01.2019, list of participants
22	Patient Support Working Group (PDWG) Action Plan 2019-2020
23	PSWG Berlin Meeting, 2018, Minutes
24	PSWG Bucharest Meeting, 2018, Minutes
25	PSWG Helsinki meeting, 2019, Agenda + Minutes
26	ECAC Communication Toolkit, 2018
27	Youth Ambassadors Toolkit, 2018
28	ECL Youth Ambassadors Presentation Booklet, updated 2 nd edition, 2019
29	ECL Youth Ambassadors for the European Code against Cancer Advisory Group Terms of Reference, 2019
30	ECL submission to a public consultation on EMA Regulatory Science 2025, 2019
31	ECL Position Paper on the outcomes of WHO resolution on 'Improving the transparency of markets for medicines, vaccines and other health products, 2019
32	ECL comments within the EU Ombudsman's inquiry OI/7/2017/KR – Public consultation, 2018
33	LET'S TALK ACCESS! ECL White Paper on Tackling Challenges in Access to Medicine, 2018
34	ECL analysis on CAR T-Cell Therapies pricing, 2018
35	ECL position paper on European Cooperation on Health Technology Assessment (HTA), 2018
36	ECL MEPs 2019 Elections Manifesto
37	It's Your Consultation – ECL Guide for patients and healthcare professionals, 2019

38	The Priceless Help – ECL Guide on how to manage volunteers in cancer organisations, 2019
39	ECL Caregiver Support Guideline, 2018
40	ECL Return to Work: Presentation for Employers, 2018
41	ECL press releases 2019

- **15 Skype/telephone/face-to-face interviews** with a selection of ECL members, incl. Board members, and other target audiences. The emphasis of the interviews was on gathering narratives and evidence.

Comments even if expressed by only one member have been used in some cases or examples in this report, as they can provide useful information, feedback or contribute to illustrate the diversity of the network. This evaluation is qualitative and not quantitative.

- **Observation of one key ECL event** (PSWG – Luxembourg, 26-27 November 2019). The selection of the event has been agreed with ECL staff. This opportunity was used to ask complementary information on the spot. At the same time, it allows the evaluator to get a sense of the ‘culture’ of the network, important background information for the interpretation of data.
- **One kick-off meeting** with the ECL staff and **one meeting to present the evaluation findings**.

Table 3: Evaluation objectives and related activities

Evaluation activities	Objective 1	Objective 2
Document analysis	X	
Telephone/Skype/face-to-face interviews	X	X
Observation of key ECL event	X	X

2.3. Outputs of the evaluation

- A short **final external evaluation report** (in EN), including an executive summary, an analysis of the data, presentation of the findings, conclusions and recommendations.
- An **infographic** to visualise the main findings and conclusions.
- A **ppt presentation** to the EPHA staff/Board on request.

3. Findings

3.1. Main results for member organisations of their involvement in ECL in 2018-2019 - relevance and added value

3.1.1 Background

The objectives, outcomes, outputs, activities and targeted audiences of ECL for the 2019 Work Programme are summarised in the following table 4.

Table 4: Objectives, outcomes, outputs, activities and targeted audiences of ECL based on the 2019 Work Programme Operating Grant 3rd Health Programme

Objectives	Outcomes/impact	Outputs	Activities/methods/tools	Audiences
Objective 1: Influence policy at European level.	<ul style="list-style-type: none"> Renewal of the MAC group in the next EP mandate (2019-2024) Press release drafted and disseminated to coincide with EWAC breakfast policy dialogue 	<ul style="list-style-type: none"> Tobacco control scale report Elections manifesto and plan for the 2019-2024 legislature of the MEPs Against Cancer group (MAC) Report of EWAC policy dialogue produced and disseminated 	<ul style="list-style-type: none"> Perform the survey of national contact points for the triennial Tobacco Control Scale report. Publish European Elections 2019 Manifesto, based on a survey ran among MAC MEPs in 2018. Re-establish the MEPs against Cancer group, following the European elections in 2019, for the European Parliament mandate 2019-2024. Organise a breakfast policy dialogue breakfast during the 2019 EWAC (European Week against Cancer 25-31 May). 	<ul style="list-style-type: none"> Cancer Leagues Policy makers at EU and national levels MAC contact list

<p>Objective 2: Promote the European Code against Cancer.</p>	<ul style="list-style-type: none"> • ECAC policy framework dissemination • Evaluation of ECAC workshop and site visits 	<ul style="list-style-type: none"> • Publication of ECAC policy framework online • Youth Ambassadors' collective action to promote ECAC online • Annual report of ECAC workshop and study visit 	<ul style="list-style-type: none"> • Publish online the European Code against Cancer policy framework outlining the supportive governmental actions needed for implementation of ECAC at national level and disseminate this via the EU Health Policy Platform by the European Week against Cancer. • Launch pilot activity to evaluate the ECAC. • Promote online the collective actions of the ECL Youth Ambassadors for ECAC on World Cancer Day 2019. 	<ul style="list-style-type: none"> • Cancer Leagues • Policy makers at EU and national levels • Scientific community • Stakeholders • General public, esp. youth < 30 years •
<p>Objective 3: Support implementation of organised cancer screening programmes.</p>	<ul style="list-style-type: none"> • Impact of cancer screening web portal • Evaluation of cancer screening workshop 	<ul style="list-style-type: none"> • Publish cancer screening portal on www.cancer.eu • Summary report of cancer leagues screening training meeting produced for public consumption 	<ul style="list-style-type: none"> • Publish cancer screening web portal on the ECL website. • Deliver cancer screening training workshop for cancer leagues. 	<ul style="list-style-type: none"> • Cancer leagues • Policy makers • Stakeholders • Scientific and technical community
<p>Objective 4: Advocate for equitable access to treatment and care for cancer patients.</p>	<ul style="list-style-type: none"> • Advocacy activities and letters based on ECL toolkits related to access to medicines developed on the national level • Number of cancer leagues publishing guidelines on their relevant websites 	<ul style="list-style-type: none"> • Publish PSWG guidelines on volunteering • Develop advocacy toolkit for cancer leagues 	<ul style="list-style-type: none"> • Publish cancer leagues volunteering guide to help cancer leagues recruit, train, use and reward volunteers used for patient support services provided by their organisation. • Publish guide on improved communication between patients and healthcare professionals to help patients get the most information possible without 	<ul style="list-style-type: none"> • Cancer leagues • Policy makers at EU and national levels, health attachés, governments (primarily health ministries), national medicines and HTA agencies • Patient representatives • Key stakeholders (industry, patients, healthcare professionals, health NGOs)

			<p>over-burdening the hospital workforce.</p> <ul style="list-style-type: none"> • Publish position paper elaborating on issue and solution listed in the White Paper on Access to Medicines. 	
<p>Objective 5: Implement the 'CanCon Guide' at the national level.</p>	<ul style="list-style-type: none"> • Cancer leagues agreement for national monitoring of CanCon guide implementation 	<ul style="list-style-type: none"> • Best practice examples of implementation of CanCon guide gathered and disseminated. 	<ul style="list-style-type: none"> • Collect best practices from at least 5 cancer leagues related to the implementation of the "CanCon guide" and disseminate to policymakers. 	<ul style="list-style-type: none"> • Cancer leagues (including non-members of ECL) • Policy makers at EU and national levels

A large majority of the activities of the ambitious 2019 work programme have been realised in 2019; some outputs are planned for the beginning of 2020.

ECL has a range of **working structures** through which activities are implemented:

- **The ECL Youth Ambassadors** on cancer prevention were founded in 2012 within the EU Joint Action European Partnership Action Against Cancer (EPAAC). The ECL Youth Ambassadors for the European Code against Cancer (ECAC) brings together young people from more than 30 different countries across Europe. Youth Ambassadors are students and young professionals drawn from many disciplines including medicine, public health, law, and political sciences. Through different events and initiatives, Youth Ambassadors undertake actions to promote the 12 messages of the ECAC. The Youth Ambassadors group meets every year for an annual Summer School to share experiences and develop common actions. The Youth Ambassadors receive secretarial support from the ECL Secretariat. Since 2017 the ECL Youth Ambassadors Advisory Group is operational. The Advisory Group has provided input into various governance and organisational matters for the programme, assisting with the strategic planning of the group's work, and contributing to the development of the agenda for the Youth Ambassadors Summer School.

ECL provides **micro-grants** (small-scale resources) to Youth Ambassadors to help with their activities, e.g. translation of ECAC, printing materials, but also for training and conference presentations. The average amount of a micro-grant is 250-300 €. An application process is installed with a standard template for application and a budget proposal. The Secretariat decides by ranking the proposals.

- **The ECL Access to Medicines Task Force (A2M TF)**, established in 2016, aims to make cancer medicines available for all cancer patients in Europe by insisting on accessibility, sustainability of the healthcare system and transparency of drug prices. 26 national/regional cancer leagues, representing over 450 million Europeans, have signed the Task Force's [Declaration of Intent](#). Two Working Groups are linked to this Task Force:
 - **Working Group Affordability.**
 - **Working Groups Advocacy.**

The Task Force has a bi-annual Action Plan.

- **The ECL Patient Support Working Group (PSWG)** was formed in 2007 to act as an information source for member organisations and to provide an international platform to share knowledge and advocate on patient support issues at national and EU level. The group meets twice a year, in the Spring and just before the Autumn General Assembly, usually hosted by one of the PSWG member leagues. This Working Group has a bi-annual Action Plan.
- The **MEPs Against Cancer (MAC) Interest Group** was founded in 2005 by a group of MEPs and is the only dedicated group for cancer policy at the European Parliament. In the 2014-19 parliamentary legislature, MAC had 40 members coming from different political groups and EU Member States. A multi-annual strategic roadmap (2014-2019) is developed for the MAC. This document is designed to provide clarity and direction to the structure of the MEPs Against Cancer (MAC) interest group at the European Parliament.
- For the work on **Tobacco control** there is not yet a formal working structure in place, but discussions on this have been on the agenda this year.

Furthermore, ECL is engaged in a number of **projects**, i.e.

- **MyPeBS** (My Personal Breast Screening) (2018-2025) is an EU-funded project that aims to assess the value of personalised breast cancer screening for women aged 40 to 70 in Europe. This project has received funding from the European Union's Horizon 2020 research and innovation programme. In this project, 26 partners are involved from 5 countries.
- **WASABY** is a 3-year pilot programme funded through the EU Health Programme, beginning in January 2018. The action focuses on the geographical analysis of population-based cancer incidence data in connection with environmental factors, using breast cancer and water/soil

contamination as an example. This project receives funding from the 3rd European Union Health Programme 2014-2020. 5 project partners are involved in the project from 5 countries.

Member-based networks

Organisations are part of a network for various reasons. Wilson-Grau, et al, (2007)³ a scholar who has worked extensively on international networks for social change summarises the functions of (membership based) networks as follows:

- Filtering, processing and managing knowledge for the members.
- Promoting dialogue, exchange and learning amongst members.
- Shaping the agenda by amplifying little known or understood ideas (for the public).
- Convening organisations or people.
- Facilitating action by members. Addressing global problems through knowledge of their local, national and regional contexts.
- Building community by promoting and sustaining the values and standards of the group of individuals or organisations within it.
- Mobilising and rationalising the use of resources for members to carry out their activities.
- Strengthening international consciousness, commitment and solidarity.

This is also the case for ECL members, as the results in the next paragraph reveal.

3.1.2. Results: added value for member organisations and strengths of ECL

Interviewees identify various aspects in the functioning of ECL that have an **added value** for them/their organisation:

- **“Filtering, processing and managing knowledge for the members”.**

Information provision. This was in particular mentioned by smaller and newer member organisations, but also member organisations that are part of ECL for a longer period embrace this part of the work. Interviewees mention that especially when their organisation is at the beginning of its life-cycle, information and material is useful (like all material on ECAC). For information provision on new applications and treatments like CAR-T Cell Therapy or on EU developments, ECL is considered to be crucial. Interviewees argue that *“developments go so fast these days; I believe that you need to be a member of an EU-level network in order to stay up-to-date”*.

- **“Mobilising and rationalising the use of resources for members to carry out their activities”.**

Provision of material to be used at national level and guidance to use material: In some countries cancer prevention is not yet well developed and the material produced by ECL is used to raise awareness. Yet, the issue of language is mentioned here as a factor hindering the use of ECL material (see also paragraph 3.3.). Material of ECL is in some cases used as it is (depending on the availability of material in national language), as a source of inspiration for developing the own material or as an accompanying resource to the own material. While the ECAC gives an agenda for active promotion of prevent, ECL provides guidance to use the ECAC and provides information about what others are doing in this area. A number of countries have translated the ECAC into their national language making it available in several EU languages.

- **“Promoting dialogue, exchange and learning amongst members”.**

³ Wilson-Grau, R., and M., Nuñez, (2007), *Evaluating international social-change networks: a conceptual framework for a participatory approach*, in: *Development in Practice*, Volume 17, number 2, April 2007, Routledge

Mutual learning is considered to be an important reason for organisations to be member of ECL:

- Getting to know other professionals to share ideas (professional development).
- To learn what is going on elsewhere, to be kept up-to-date with what is happening in other countries and how similar organisations solve similar problems. For example, a visit was recently paid by other ECL members to the Danish Cancer Society to learn amongst others about how they operate their research unit.
- To learn from ‘good practices’ of other organisations. An example was given of the different initiatives in various countries about access to medicines and how inspiring practices in this field influence the approach in the own country.
- To bring lessons learned to other member organisations, e.g. on how to integrate the ECAC into national cancer prevention/control plans through liaising with those actors who can influence decision-making in this area, or to bring expertise on communication between patients and medical professionals in the network.

Interviewees explain that **mutual learning processes in ECL go beyond the exchange of ideas**, it is also about identifying parts of policies and practices that could be used in the own context. During the interviews, members argue that ECL provides the platform, but it is up to the member organisations to take it a step further (transfer, take-up), often on a bilateral basis.

- **“Building community by promoting and sustaining the values and standards of the group of individuals or organisations within it”.**

Building partnerships: ECL provides the opportunity to build a network and community of experts to exchange with, as well as to build partnerships with other member organisations and to develop and implement projects together.

- **“Facilitating action by members. Addressing global problems through knowledge of their local, national and regional contexts”.**

Increasing the own visibility and position at national/transnational level: Some interviewees explain that because they are member of ECL, their arguments are more valued at national level, since ECL represents a much wider community. Using the work of ECL gives them credibility to defend their position. *“Through participation in ECL, the leagues’ own profile can be raised at national level and beyond”.* One of the examples is that through organising an event in a specific country together with the member organisations, there is the possibility to involve other national-level organisations. *“ECL provides us knowledge, material and a platform to further develop our own organisation”.* Involvement in ECL opens doors to fora where cancer policies are discussed.

- **“Shaping the agenda by amplifying little known or understood ideas (for the public)”.**

Advocacy: ECL gives a voice to its members and brings this voice to the EU level. ECL provides a platform and a diving board for advocacy purposes. This is amongst others operationalised through the MAC group. ECL is for interviewees the way to raise their voice at EU-level and to contribute to changes in relation to prevention and patient support. *“ECL is the eyes and ears in Brussels”.* ECL can rely on a network of member organisations, and therefore has a stronger voice than each of the members individually. *“There is a difference when an argument is shared by many organizations, then when it is an argument from a single organisation”.* The advocacy function of ECL is strengthened by its (financial) independence from pharmaceutical groups.

Influencing the EU-level policy development is for members (mainly) possible through ECL. The example was given in relation to health technology assessment; for individual member organisations it would be difficult to make a meaningful contribution.

Through the Manifesto, some Members have contacted directly their MEPs to send their message at both National and European level. Members are also invited to MAC meetings organised by ECL and can in this way be directly involved in advocacy.

- **“Strengthening international consciousness, commitment and solidarity”.**

Providing a platform to tackle issues at European level: To tackle particular issues, a European approach is necessary, like e.g. accessibility of medicines. A European network like ECL can play a crucial role in this through information provision, knowledge sharing, capacity building of members and advocacy. ECL is filling in a gap that individual members could not do on their own.

- **“Convening organisations or people”.**

The **Young Ambassadors (YA) group** is considered to be an added value of ECL. It is an interdisciplinary group, which is seen by interviewees to be important to get a broader perspective on cancer prevention. The group expanded to about 70 persons. According to interviewees, part of this group young people, this exchange is important to learn how to advocate, but also to clarify some aspects of the code. YA who took part in the evaluation interviews express that the Summer School improves every year. Yet, other interviewees explain that a closer link with the work of ECL at national level.

Also the **CEO meetings** that takes place connected to the GA are assessed by interviewees as useful to discuss organisational and managerial issues related to running an association, setting priorities, how to manage volunteers, etc.

3.2. Strengths and weaknesses of the functioning and work of ECL in 2018-2019

3.2.1. Strengths of ECL according to the members

The strengths of ECL according to interviewees can be summarised as following:

- It is a unique network as its members are (mainly) cancer leagues, providing a unique fora for them to exchange and influence policies in such field.
- **Embracing the membership:** Interviewees explain that ECL takes good care of its members. There is a great willingness and openness to share information and skills. Interviewees argue that all members are being heard, regardless size or the number of years they are member of ECL. Furthermore, ECL produces strong statements and represent common interests of their members.
- **Effective relation management:** ECL is by interviewees considered to be good in relation management, not only within the own network (*“through ECL we share the information of what we are doing and what is working, close point of contact and be able to share ideas”*), but also with external stakeholders; *“they know the right people at EU-level to liaise with”*.
- **Diversity** as a strength: ECL unites various member organisations (very large and small organisations, public health organisations and organisations representing patients, etc.) and represents a wide community. This strength is useful for advocacy purposes since ECL provides a united voice of this diverse community to the EU-level institutions.
- The **Youth Ambassadors** is a very good initiative to involve young people in advocacy activities of an issue of general interest.
- **Open to new ideas and approaches:** Interviewees explain that ECL is very open to new ideas and out-of-the-box thinking.
- **Support in advocacy at national level:** material that is developed by ECL can be used by the members. For the YA a toolkit to be used at national level is developed, while national leagues can make use of the policy and position papers developed by ECL.
- **Capacity building of members** through development of material for practitioners and patients.

- **Advocacy approach with structural contacts with MEPs** through the MAC group. This is considered to be very important to pass on messages on daily challenges and practice of member organisations to the EU level.
- **Coverage of various levels of work:** ECL develops and implements relevant for the three main levels: policy making, community level and the level of health professionals.
- **The professionalism of the Secretariat staff:** The team in the Secretariat is professional, motivated and enthusiastic.
- **Level of engagement of Board members:** most interviewees consider the level of engagement of Board members quite high in the network. Yet, at the same time other interviewees also explain that they as a member do not have much contacts with Board members and that for them it is not clear what the role is of Board members in e.g. the further development of the network.
- **The independence of ECL and its member which gives ECL credibility in comparison for example with network receiving support from medical firm.** The example of the European Patient Forum was mentioned in an interview.

3.2.2. Weaknesses of ECL

The weaknesses of ECL as identified by interviewees can be summarised as following:

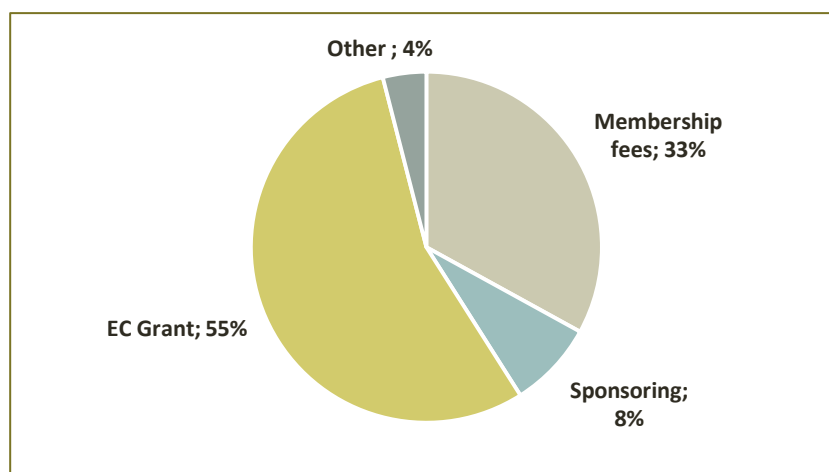
- **The vulnerability of the ECL Secretariat:** The ECL team in the Secretariat is small in numbers and in that sense quite vulnerable according to interviewees. Each of the staff members is a key player in one of the domains of work of ECL. If a staff member would take a next step in his/her career, or become ill, this would jeopardize policy work. Some have expressed concerns about the high workload on staff and extended working hours. Also, some activities such as YA are driven by trainees which by definition don't stay long at ECL, meaning a loss of capacities but also for the YA to readapt each time to another person with different ways/views on how to conduct the work.
- **The diversity of the network:** While the diversity of the network is considered as a strength, it is at the same time identified as a weakness. The membership is very diverse (large/very small organisations – old/new organisations – organisations with a well-developed research department, etc.) and situated at different stages of the life cycle of the development of the association. There are members that are well established organisations and members that are newer organisations with specific needs, e.g. in relation to capacity building. When ECL is organising activities, issues are looked for that are relevant for all, yet it is explained by some interviewees, that there is “[...] the risk of ending up with activities that are not relevant to anyone”.
- **The scope of the work covered by ECL:** Especially because the Secretariat has a limited size, some interviewees recommend focussing on fewer topics and to prioritise instead of “*wanting to do everything and being everywhere*”. “*There is a difference between capacity and ability*”. This entails the risk of diluting and the need to prioritise at the same time. Yet, considering the diversity within the network, there is a multitude of needs of members to cater for.
- **The lack of clarity about the role of ECL in relation to research:** One interviewee expresses the necessity to be visible in scientific papers while another hopes that ECL will stay focused on its preliminary role which is prevention and not deviate to be part of research projects. Also other interviewees have questions about the position of research in the network, taking into account the nature of some member organisations (e.g. cancer research organisations) and the reference of research in the Strategic Plan 2019-2021 and in the ECL by-laws.
- **The balance between input in some activities and outputs and results:** The example of the 2019 Manifesto (available in 11 languages) was mentioned. It took time to develop this Manifesto and the results of the use of it are questioned by some members.
- **The composition and level of activity of members in the network:** One of the weaknesses identified by interviewees is related to the composition of the network, i.e. that a few important leagues are not member of ECL and to the level of participation of some members. When some

members are less active, it is argued that this is 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 the participants’ lists of seven events in 2018-2019⁴ reveals that about 1/3rd of the membership is very active (representatives of these leagues participated in at 5/7 of these meetings), 1/3rd active at a moderate level (participating in between 2-4/7 of these meetings) and 1/3rd of members participating in less than 2/7 meetings, of which 9 members in none of these meetings at all.

Challenges identified by interviewees are related to:

- **Keeping the network alive in between annual conferences/general assembly meetings.** For members who only participate in the General Assembly meetings and/or Annual Conference and not in Task Force or Working Group meetings, it is sometimes difficult to follow what is happening. These members, with sometimes very limited capacity, should not be forgotten according to some interviewees.
- **The (financial) sustainability of ECL.** The EC Operating Grant is a main financial resource and has allowed the development of the network. Furthermore, membership fees are also generating 1/3rd of the resources (2018). Complementary financial resources need to be generated, e.g. through projects. Yet, ECL does not want to compete with its own members when applying for projects.

Figure 1: Financial structure of ECL 2018 – Annual Report



The ‘other’ category refers to EU projects. Yet, further complementary resources are explored for financial diversification purposes. However, the possibilities are limited:

- National foundations are not a real option, as ECL could become a competitor of its own members. Yet, national funding could be used for cooperation between ECL Secretariat and one of more members.
- The independence of the organisation needs to be guaranteed, meaning that sponsoring by Industry is bound by strict conditions, as explained in the [Transparency Statement](#), i.e. industry funding is accepted only in the form of unrestricted educational grants for specific projects and activities at the discretion of the ECL Board. Any support from the tobacco industry, or any other companies who produce products that are deemed harmful to health, is not accepted. For interviewees it is important that ECL remains a “clean” organisation.

⁴ A2MTF Berlin, 2018; A2MTF Bern, 2019; A2MTF Prague, 2019; PSWG Budapest, 2018; PSWL Berlin 2018; PSWG Helsinki, 2019; ECAC Dublin/Belfast, 2019.

- Funding through projects is a possibility (like e.g. Horizon2020 and Joint Actions in the past), though not all interviewees are in favour of projects in which not all members are involved or could be involved.

Yet, it is argued during the interviews that the funding should not steer the strategy; **strategy comes first**.

- **The visibility of advocacy work of ECL in some areas:** The example is given of ECL being part of the anti-smoking lobby (Smoke Free Partnership), which is concretely visible for member organisations.
- **The difference in membership fees** mean for some interviewees that you should ensure that biggest contributors are also “benefiting” and not just supporting other members through exchanges of practices and visits.
- The position of ‘**research**’ in the network and the role ECL plays in relation to research, needs some clarification, according to some interviewees. Some current members are cancer research organisations (e.g. UK and Turkey), while other members have an important research department and fund cancer research (e.g. Denmark, the Netherlands). In the Strategic Plan 2019-2021 and in the ECL by-laws reference is made to research:

In ECL’s Strategic Plan 2019-2021:

- “ECL provides an exclusive platform for members to collaborate with their international peers, primarily in the areas of cancer prevention, tobacco control, cancer research, access to medicines and patient support, and creates opportunities to advocate for these issues at the EU and national level” (p2).
- “The Secretariat brings together members working in specific fields (e.g., cancer prevention, access to medicines, cancer research and patient support) and works proactively to influence key EU decision-makers and cancer control policies to achieve the ECL strategy”. (p2)
- “Promote activities to monitor funding of research and advocate for more EU resources for cancer research”. (p6)

In by-laws: “The ECL’s major fields of activity are, among others: (a) cancer prevention, (b) public education and information, (c) professional education and information, (d) assistance, services and rehabilitation for patients and their families and relatives, (e) fundraising, (f) tobacco control, g) patients ‘rights, (h) participation in, and support for, scientific research”. Membership is open to “a cancer league which has objectives and carries out activities in common with the purpose and activities of ECL as set out in article 3”. (p14)

According to the specifications in the Strategic Plan and by-laws, ECL promotes scientific cancer research, supports it, and can also participate in this research.

3.3. Quality and usefulness of outputs of ECL in 2018-2019

Various outputs have been produced by ECL in the period 2018-2019:

- Dissemination of the European Code against cancer at National level.
- White paper “Let’s talk access”.
- ECL Patient Guide 2019.
- ECL Position paper on Health Technology Assessment.
- Best practice on how to manage volunteers.
- European Election Manifesto.
- Thematic info, e.g on CAR T-cell technology.
- Newsletter.

Overall, the interviewees express that the various outputs of ECL are of good quality and are used by members. Interviewees state that the work of ECL is well grounded and based on research. Outputs are used in various ways:

- In their original format, i.e. in English or translated version, to be used in the own work of the member or for dissemination.
- Parts of the outputs are used by the member, in their original language or translated to be used in the own work or for dissemination.
- Outputs are used as source of inspiration.
- Outputs of ECL are accompanied by own material of the member.

For dissemination purposes, ECL materials are shared with main actors/institutes in the members' country, which opened doors for members in some cases: *"It allowed us to have access to other institutions and to provide them with material, that on our own we would never have been in a position to develop this because of a lack of resources"*. The use and uptake of ECL outputs depends also 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.

Many interviewees also explain that they have been involved in the development of the outputs in various ways (input, translation, etc.) and that this also facilitates the motivation to use and disseminate the material.

The use and dissemination of the various outputs was commented on during the interviews. Some examples:

- **Dissemination of the ECAC at national level:** many members have disseminated the ECAC at national level, which led in some cases to uptake in the national Cancer Programme (e.g. Romania and Poland). Micro-grants have been granted in the past for local dissemination of the ECAC. Other interviewees explain that they did not use the ECAC as such, since in their country the prevention approach is a bit different (i.e. informing the public about the pros and cons of screening and not promoting only screening as such). The main driver for dissemination is to address the young generation through contests in schools and the YA actions.
- **White paper "Let's talk access"?** This output is used as a source of information by members and as input for drafting policy proposals at national level.
- **ECL Position paper on Health Technology Assessment:** this output is used as a source of information and as input for drafting policy proposals at national level.
- **Newsletter.** The Newsletter is considered to be useful; It permits to transmit information to members of the member organisations. For some interviewees, the previous format of the Newsletter which was sent as an annex by email was, for them, easier in use.
- **The website.** Interviewees explain that the quality of the website has improved; it has become more user-friendly and easier to find information.

An issue mentioned during the interviews in relation to the outputs is the **language**:

- For native English speakers, some 'translation' is sometimes necessary since 'EU jargon' is used, which makes it not always easily accessible for those not familiar with this language.
- Some members explain that they translate some parts of the material for dissemination purposes. This is especially useful for the guides that are produced e.g. by the PSWG on how to communicate effectively with healthcare professionals or the guide on how to manage volunteers in cancer organisations.

3.4. Working structures of ECL

The working structures of ECL are mainly composed by a Task Force, Working Groups, Youth Ambassadors and the MAC group (see paragraph 3.1.1.). In relation to the working structures and working methods, the following issues were expressed by the interviewees:

- **Face-to-face meetings are considered to be very important** for interviewees: *“This is where the things are happening”*. They express that it is mainly the combination of the different working structures/methods used, which is useful; the working methods reinforce each other, e.g. While the Task Force has a specific purpose (making cancer medicines available for all cancer patients in Europe by insisting on accessibility, sustainability of the healthcare system and transparency of drug prices), the PSWG has a broader mission, i.e. connecting cancer care experts and therefore acting as an information source for member leagues and to provide an international platform to share knowledge and advocate on patient support issues at national and EU level).
- **Working Groups and the sub-groups** are considered to be relevant since not all members are interested in all subjects and through the Working Groups members can focus on one or more issues that are of particular interest to them. Working Groups are gathering experts on the topics involved. These working structures ensure a better share of knowledge (positive factor in view of turnover in ECL Secretariat staff).
- The **Annual Conference** is developing in a positive way according to interviewees: the content is more interesting and more high-level speakers have been attracted. It is explained that the Annual Conference is interesting for ALL members.
- The **MAC group** is considered to be very useful, bringing speakers from different countries together with MEPs to interact on topics of cancer prevention and care. It is argued by interviewees that this would not exist without ECL. While members are invited to all MAC meetings, in general members usually not participate. These are short meetings and for members, of which majority is not based in Brussels, it is not an efficient investment.
- The **Youth Ambassadors** are considered by interviewees as an important working structure in the network. Young people are an important target group of health promotion and prevention: instilling health-supporting behaviour will have benefits that last across the life-course. The number of Youth Ambassadors has grown and therefore not all can participate anymore in the Summer School. Youth Ambassadors are recruited through an open call whereby members are encouraged to help to promote and to recruit. Though Youth Ambassadors are not restricted to people already working with the member leagues. The Youth Ambassadors initiative is further developing. The first step was to identify, train and engage them 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. So, also at this level there is some vulnerability.
At least one Youth Ambassador is invited to every prevention event and the group meets at a side meeting to the Annual Conference.

Interviewees argue that all forms of working methods used within ECL are useful and relevant; the most important issue related to these working formats is ‘learning from each other’. The choice for involvement in specific working structures, is based on personal preferences and sometimes organisational considerations of member organisations.

3.5. Key areas of results of ECL in 2018-2019

3.5.1. Key results at level of member organisations

The key results of ECL for member organisations as identified by the interviewees coincide very much with the strengths listed (see paragraph 3.2.1):

- Through the use of information and knowledge that is provided by ECL and through the dissemination of material of ECL, some members explain that they have improved/strengthened their position at national level. Some examples were given:
 - The material produced around the ECAC made it easier to contact a national Ministry of Education to disseminate the code in schools and to raise awareness in this way. Teachers are trained once a year to support this dissemination process.
 - The work on innovative medicines is considered as important and was mentioned as an example of allowing good exchanges with the Ministry of Health and the Presidency of the country.
 - Following the presentation of the Manifesto (press conference, Nicosia, 12 March 2019), new MEPs are interested in work of the member organisation and in the MAC group.
 - ECL material is used to provide evidence of what is needed and why it is important when lobbying and applying for projects.
- ECL actions have contributed to capacity building of members. An example cited is the introduction of the function of ‘volunteer coordinator’ in one of the member organisations, as a result of discussing with another member organisation, having such a function already in place. Participation in ECL activities strengthens the work of members: *“ECL is like a bonus”*.
- ECL provides a platform for networking with other member organisations and beyond, and this platform is used by member organisations to further the achievement of their goals related to influencing the EU-level and to open doors at EU level (like e.g. access to the European Fair Pricing Network).
- ECL helped members connecting with their MEPs enabling them to contribute to impact at EU level. More MEPs are becoming interested in the MAC group, which can be considered as evidence that ECL is making a difference.
- ECL helped members with their advocacy actions at national level. Two examples were reported on the integration of cancer screening into the national agenda/health programme. Furthermore, during the meetings of the working structures, e.g. the A2M TF participants (member leagues) exchange information on approaches and results of advocacy actions at their national level.
- ECL has been very active in relation to patients’ rights. Since there are large differences between EU countries in this domain, work of ECL is considered to be of particular importance.
- Added value is not only provided at the level of member organisations, but also at the level of the respective countries. An example was given of the contribution of ECL activities to the development and implementation of a full screening programme in one country.

3.5.2. Key results at EU level according to members interviewed

- Not all members have a complete view on the advocacy work of ECL at EU level, nor on its results. The MAC group plays a major role in policy influencing at EU level, whereby various examples were given of results, e.g. in the area of prices of cancer medication, vaccination, tobacco control, plain packaging of cigarettes and the [Tobacco Products Directive](#). This Directive aims to improve the functioning of the internal market for tobacco and related products, while ensuring a high level of health protection for European citizens. The Directive, which is based on the proposal of the

European Commission, entered into force on 19 May 2014 and became applicable in the EU Member States on 20 May 2016.

- The fact that President Juncker, in partnership with the WHO during the Global Vaccination Summit in Brussels on 12 September 2019 defended the importance of vaccination, is considered by interviewees as a victory for ECL.
- ECL has played a major role in making the ECAC accessible, i.e. taking a complex body of research to 10 essential points

3.5.3. Factors contributing to or hindering achievement of results

Factors contributing to the results

- The fact that **ECL takes all its members seriously**, regardless the phase in their life-cycle or size. Interviewees state that as a result of this, members are also likely to be more engaged. It is considered as a genuine collaboration. The responsiveness of the ECL Secretariat to its members is much appreciated and is considered to contribute to the results.
- ECL uses a **distributive representation model**, i.e. not only the president and/or Secretariat play a role as representatives of the organisation, but all Board members as well as ECL members. ECL representation depends on the context and representation requested by the external meetings. Technical and theme-based meetings are attended by staff leading those areas, e.g., tobacco control meetings are attended by our TC officer, etc. Meetings involving establishing or maintaining external relations are usually attended by a Board member or Director (again, it depends on the context). ECL members can also represent ECL as the Chair of a working group (e.g., Access to Medicines Task Force), or to present on a topic where national expertise is required (e.g., regulation on sunbeds or on nutrition).
- ECL knows **where to be at the right time**: *“They know the right people and they lobby in a very considered way”*.
- The **professionalism and engagement of the ECL Secretariat team** is surely considered as a factor contributing to the achievement of results and is stressed by a large majority of interviewees. Staff members are recognised as experts in their field.
- The **working structures are key in the implementation of the workplan and the Strategic Plan** of ECL. The different working methods complement and reinforce each other: while the Task Force is focusing on a specific purpose, the Working Groups have the broader goal to connect expertise and acting as a source of information. Both the Task Force and the Working Groups stimulate exchange and mutual learning between the member organisations. The MAC group is the vehicle to voice the concern and needs of the members and to influence EU-level policy making.
- The **relation management of the ECL Secretariat is positively assessed**, not only in interaction with their members, but also with various other stakeholders at EU-level and international level of which the most important are:
 - EPHA (European Public Health Alliance): membership and collaboration on areas like Access to Medicines
 - ECCO (European CanCer Organisation): general membership, contribute to policy committee and expert working groups.
 - Smoke Free Partnership: Memorandum of Understanding for TC
 - OECI (Organisation of European Cancer Institutes): informal collaboration so far
 - ECPC (European Cancer Patient Coalition): information collaboration on patient-related issues
 - HEAL (Health and Environment Alliance): membership and collaboration on environment and cancer issues

- EUROCARE (collaborative research project on cancer survival in Europe): collaboration on alcohol and cancer issues
 - EUROSKIN, EADV, EUROMELANOMA: collaboration on skin cancer issues, and with all three when possible.
 - EONS (European Oncology Nursing Society): for issues related to nurses or health care professionals in general.
 - ESR (European Society of Radiology): for radiology, and exploring AI for screening and diagnosis.
 - Atomium / AI4People: Artificial intelligence and cancer
 - COCIR (European Trade Association representing the medical imaging, radiotherapy, health ICT and electromedical industries): collaboration by providing speakers to this medical devices trade association.
 - EFPIA (European Federation of Pharmaceutical Industries and Associations): informal collaboration for this association of pharma companies.
 - WHO (World Health Organisation): cooperation and currently discussing more formal relationship
 - IARC/WHO (International Agency For Research on Cancer): regular cooperation linked to our work disseminating their Code Against Cancer, as fellow subcontractors in the Joint Action on Innovative Partnership Action Against Cancer, and working together on advancing screening.
 - UICC (Union for International Cancer Control): assisting them with World Cancer Day actions
- The **quality and usability of the outputs** is considered as an important ingredient of the success of ECL.
 - Furthermore, often **short and catchy messages** are used in communication, which makes them easily accessible for a larger public.

Factors hindering results and challenges

- The **team in the Secretariat is small and the scope of their task is large**. The vulnerability of a small team is also related to the concentration of expertise in a limited number of staff members. Each of the staff members is an expert in his/her domain and that would mean that expertise in a specific domain will be lost, if a staff member would leave. Some concerns were expressed about the workload and extended working hours of staff.
- Some interviewees make a plea for **more focussing the work**; not going too broad and keeping the strategic objectives in mind. *“Brussels is easy to be dragged on”*. Related to this, some interviewees explain that it is important for ECL to find the ‘niche’ in which ECL can be most influential.

In the PSWG, the last election of the chair of the group gave the opportunity to candidates to present their future plans. The elected chair presented a focus for the coming years on two issues: cancer and work and cancer and sexuality. Previously, the work was more scattered around different subjects. According to feedback during the observation of the last meeting of this group in Luxembourg, the number of members present was exceptionally high, with a very high diversity of country leagues represented (North, South, East and West, small and bigger leagues). Concentration of the work on a limited number of topics seems to be adequate to attract participation of members.

- The **financial situation of ECL** is considered to be not very sustainable and the financial resources are limited. Both financial and operational sustainability is needed and both should be further investigated. The Operating Grant of the EC allowed a level of work that would not have been possible otherwise.
- While the quality of the outputs is well appreciated, interviewees also state that these outputs are not always written in **a language accessible** for the specific target groups.
- Some **more clear linkages between parts of the work** could be beneficial. An example given is of the Youth Ambassadors; their work needs to be more linked with the other parts of the work of ECL and with the work of the national members. The growing number of Youth Ambassadors is questioned by some, since this has implications for the allocation of micro-grants and for the competition between Youth Ambassadors in receiving such a grant.
- The **role of 'research' needs clarification**. Is ECL a driver to communicate on (new) research or should ECL also finance research or undertake/subcontract research? Related to this, a small minority of interviewees propose more space for 'science' in ECL, like e.g. scientific publications.
- One of the main challenges according to interviewees is **to keep ECL interesting** for both smaller/newer organisations and larger/older organisations. All members should be able to see the added value that ECL could bring to them. *"There should be a return on the investments in ECL in terms of membership fee, time and expertise"*.

4. Conclusions and recommendations

4.1. Conclusions

ECL is a Brussels-based non-profit, non-governmental organisation gathering national and regional cancer leagues in Europe. Established almost 40 years ago, it currently consists of 28 member organisations in 24 European countries. The Secretariat consists of 7 people and interviewees describe it as a “*small team and the scope of their task is big*”. The professionalism and engagement of the ECL Secretariat team is surely considered as an important factor contributing to the achievement of results and is stressed by a large majority of interviewees. Staff members are recognised as experts in their field.

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, e.g. in the original format for own use or translated for dissemination, as a source of inspiration or 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).

Examples were provided by interviewees on **how the use of outputs has led to changes** in their context, e.g. to open doors at national governmental level to take further action, or to capacity building of member organisations.

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 ECL⁵ 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 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).

⁵ Based on work of the external evaluator with about 15 other EU-level networks.

4.2. 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. According to the Strategic Plan 2019-2021 as well as the by-laws ECL promotes scientific cancer research, supports it and can also participate in research and promotes activities to monitor funding of research. The by-laws further explain that membership is open to “a *cancer league* which has objectives and carries out activities in common with the purpose and activities of ECL as set out in article 3”. 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.).

As was already mentioned in GA meeting (e.g. 2018) member leagues have valuable human resources that could be drawn upon by the secretariat to add 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. Activation of members is recommended to make the network function in an optimal way. This could be done by liaising with members that are currently not that active in the network, to better understand their needs and possible contributions to ECL.

Also cooperation with organisations working in the same field could be part of using resources in the most effective and efficient way. An environmental scan might be necessary to analyse the situation at EU level of organisations working in the same field to identify where further collaboration might be possible. That means that utility of some actions can be assessed such as a specific week campaign on cancer.

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

Some interviewees express the wish 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.

The active role of Board members in representing ECL in ‘external’ meetings is already positively assessed, while it is recommended to reflect on further strengthening the role of Board members in network development and relation management with member organisations.

4. Youth Ambassadors further support

Some 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. Furthermore, financial diversification contributes to the sustainability of the organisation, though further investigation is necessary on possible complementary financial sources (e.g. foundations, projects). In the development of a financial plan, it is recommended to make a distinction between restricted and unrestricted income. Restricted funds can only be used for specific purposes that have been agreed with the donor (like EC funding or projects). Unrestricted funding can be used for any purpose that will help ECL to achieve its mission. Unrestricted funds are membership fees and sponsorship.

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. It is important for ECL to inform members on what they deliver (strategic goals), success but also difficulties.

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.