



European Cancer
Patient Coalition

2019 – 2022 Strategy
Brussels, 11 December 2019



ECPC works for a Europe of equality, where all European cancer patients have timely and affordable access to the best treatment and care available, throughout their life regardless:

- nationality/the country they were born in
- where they live
- their education
- sex
- age
- social background

ECPC works to ensure that the scope of the entire cancer care pathway effectively includes prevention, treatment, survivorship and palliative care.

Policy makers, researchers, doctors and industry should recognize cancer patients as co-creators of their own health.



Mission 2019 2022

- Empower European cancer organisations and cancer patients through:
 - trainings, dissemination of strategic and scientific information, educational tools, overall and ad hoc support;
- Foster co-operation and strengthen the network among cancer patients organisations through joint activities and shared good practices;
- Influence and shape the outputs of the Cancer Mission and play a significant role on developing and assessing the implementation of Europe's Beating Cancer Plan;
- Remain vigilant on sensitive and emerging topics related to cancer as and when they arise;
- Contribute to change or create EU and national laws to improve cancer patients' outcomes. This would range from reducing mortality to improving patient and carer quality of life throughout the cancer care continuum;
- Call for patient centricity in cancer research.



Objectives

The ECPC Multi-annual Strategy *2019 – 2022* aims:

- to increase the impact of the organisation in the cancer field by reducing treatment access disparities within Europe
- to reinforce its activities and a to continue to grow its membership base and strengthen its collaboration with current members, scientific committee, partners and stakeholders

The strategy will be implemented using the 5 pillars



Each Pillar is structured by Objectives and Tactics:

Objectives answer the questions:

- “Where do we want to be in 2022?”
- “What do we want to achieve?”

Tactics answer the question:

- “How do we achieve our objectives?”
- “What we do to achieve our objectives?”



5 pillars

Governance – Build a Sustainable Governance Model

Policy and Advocacy – Influence the European and National Political Agenda

Health and Research – Foster and Guarantee Patients Centricity in Health Research

Capacity Building – Empower Cancer Patients and Enhance Their Abilities to Shape National Policy

Communication – Support all ECPC activities towards its members, partners and stakeholders



Good governance is vital to the sustainability and credibility of ECPC. Good governance is at the basis of an open and transparent participation of ECPC members into the decision making process and to attract new members, partners, stakeholders and retain them.

STRATEGIC OBJECTIVES

- Consolidate a sustainable governance model based on the work already started
- Continue improving the inclusion of ECPC members in the decision-making process through transparent, accountable, democratic and collegial mechanisms
- Restructure the secretariat to adapt to the changes in the Belgian law and in the overall cancer patient political landscape
- Develop and implement a staff retainment strategy

TACTICS

- Make the necessary changes into the ECPC Statute and Internal Regulations to comply with the new Belgian law
- Develop policies for members, board members and staff to improve transparency and overall governance
- Differentiate funding resources so to increase the overall sustainability of ECPC
- Develop and implement mechanisms to detect and answer ECPC members needs
- Create a supportive environment for staff, establish clear lines of reporting and regular coordination meetings



Despite progress in policies that support access to diagnosis, treatments and survivorship for people with cancer, their families and their carers, there remains considerable inequalities, exclusion and disparities across Europe, among and within countries. ECPC works with its members to empower them to demand early diagnosis, best quality treatment and care and to participate in decision-making and treatment process.

STRATEGIC OBJECTIVES

- Influence and contribute to shaping the European and national political agenda on issues related to cancer diagnosis, treatment access, cancer patients and carers quality of life, cancer survivorship, including rare cancer
- Ensure that cancer remains high on the political agenda beyond the conclusion of the work on the Europe's Beating Cancer Plan and the EU Cancer Mission, as ECPC will be ensuring not only the development of the Plan and the Mission, but also their proper implementation



TACTICS

- Continue to build new and strengthen existing **alliances** with relevant partners and stakeholders, including medical societies, research and patient organisations.
- Promote the dissemination and implementation of the **Joint Action on Rare Cancers (JARC)** recommendations at both national and European levels.
- Represent the voice of cancer patients throughout the development and implementation of the European **Cancer Mission** and the **Europe's Beating Cancer Plan**, also through a new Parliamentary Intergroup on Cancer
- Promote the concept, uptake and implementation of **survivorship** through cancer plans at national and European level focusing on the right to return to work, Right To Be Forgotten, right to follow up.
- Leverage the membership base for advocacy: disseminate information and provide members with toolkits to carry the messages at national level
- Support the proper implementation of the Plan promoting and being part of a Cancer Plan Dashboard
- Monitor the implementation of key European legislations, such as
 - (1) Cross-border Healthcare Directive,
 - (2) work-life balance directive,
 - (3) upcoming legislation on HTA
 - (4) shortages of medicinesand proactively develop position papers.



Research projects allow ECPC to be at the forefront of scientific developments in cancer treatments, societal, economic and policy aspects during and after treatment

STRATEGIC OBJECTIVES

- Influence EU research priorities to match cancer patients' needs
- Promote the concept of patients as co-researchers so to focus on patients' priorities
- Promote cancer patients' centrality in the implementation of any research project
- Foster quality of life indicators in any cancer related research evaluation

TACTICS

- Increase ECPC participation and strengthen ECPC role in patient-oriented health research projects
- Start ECPC involvement in non health specific research EU funded programmes, such as Erasmus and social discrimination
- Promote research focus on cancer patients' priorities, such as quality of life during and after treatment, innovation, survivorship
- Exploit the scientific committee engagement on new research projects



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Capacity Building 2019-2022

ECPC serves its Members representing cancer patients with all types of cancer from the most common to the rarest. ECPC will increase Members' capacity in understanding EU policy and research and how they can help shape the national landscape. ECPC will shape and organise its work based on Members' priorities. Therefore, engaging a dialogue, fostering a collaboration and providing Members with tools to advocate and campaign is essential to become a strong network.

STRATEGIC OBJECTIVES

- Make our Members feel part of a strong and united community through enhancing the dialogue between members and ECPC and among members themselves and facilitating challenge and best practice exchange among members
- Increase ECPC members capacity to exploit ECPC achievements (policy and research) at national and local level through organising workshops and webinars on previously agreed national and local priorities
- Foster the development of existing and possibly new ECPC Working Groups
- Increase the membership basis and strengthen ECPC presence across all EU Member States

TACTICS

- Develop a **survey** to assess ECPC Members' needs and interests to inform a **catalogue of services and tools** that ECPC can offer
- Support the organisation of **workshops and webinars at country level** on priorities identified together with the Members
- Strengthen the collaboration on **awareness raising campaigns** through the development of ad hoc tools
- Facilitate **mentoring programmes** between strong and weak members



Strong and effective internal and external communication will boost the outreach of ECPC to its members, partners and stakeholders across all ECPC areas of work from governance to capacity-building, policy and advocacy, health and research. Positioning ECPC like an indispensable actor in the fight against cancer through all its communications will improve further its reputation and serve its final goals.

STRATEGIC OBJECTIVES

- Raise ECPC profile and increase its reputation
- Create a sense of community among its members
- Receive EU and specialised media attention for our messages towards decision makers, the scientific community cancer patients and, eventually, the general public
- Support partnership development through identifying new partners and stakeholders sharing the same values

TACTICS

- Develop an ad hoc communication strategy addressed at internal and external, direct and indirect audience, including assessing and identifying ad hoc communication tools (website, newsletter, social media, annual congress)
- Disseminate campaigns, provide members with toolkits and translations of the campaigns to carry the messages at national level
- Media train senior staff and Board Members on how to best communicate with media and the general public