

European Cancer Patient Coalition Multi-annual Strategy 2017 – 2019

NOTHING ABOUT US, WITHOUT US!



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1 STRATEGIC CONSIDERATIONS

1.1 WHAT IS ECPC?

The European Cancer Patient Coalition (ECPC) is the voice of cancer patients in Europe. With over 400 members, ECPC is Europe's largest umbrella cancer patients' association, covering all 28 EU member states and many other European and non-European countries. ECPC represents patients affected by all types of cancers, from the rarest to the most common.

1.2 THE OBJECTIVES OF THE MULTI-ANNUAL STRATEGY 2016 – 2019

The ECPC Multi-annual Strategy 2016 – 2019 aims at increasing the impact of the organisation in the cancer field throughout Europe by developing long-term aspirations. The Coalition is interested in streamlining its activities by developing and implementing together with its Members a coherent multi-annual strategy. It intends to consolidate and focus its activities, following a sustained period of growth over the past three years.

The Multi-annual Strategy covers the period 2016 – 2019, which coincides with the mandate of the current ECPC Board of Directors, elected in June 2016 for the duration of 3 years.

1.3 THE MOTTO, VISION AND MISSION OF ECPC

The vision and mission of ECPC are established by the ECPC statute, voted and adopted by the ECPC General Assembly in June 2015.

1.3.1 MOTTO

Nothing about us, without us!

1.3.2 VISION

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. ECPC believes that cancer patients are the most important partners in the fight against cancer and against all the cancer-related issues affecting our society. Policy makers, researchers, doctors and industry should recognise cancer patients as co-creators of their own health.

1.3.3 MISSION

- Empower European cancer patients through the dissemination of information;
- Foster co-operation among cancer patients' organisations through joint activities;
- Ensure that state-of-the-art cancer care practices are shared across the EU;
- Make cancer a priority for action on the European health policy agenda;
- Have an active role in shaping European and national healthcare policies;
- Contribute to change or create EU and national laws to satisfy cancer patients' needs;
- Call for the role of patients to be increased in cancer research;

2 DEVELOPMENT OF THE STRATEGIC PLAN

In June 2016, European Cancer Patient Coalition requested the support of Hanover Communications for the development of its multi-annual strategy. ECPC conducted an internal consultation with the Board Members, while Hanover conducted an audit of the Secretariat. Hanover reviewed other patient advocacy groups strategies and best practices, and presented the first draft to the ECPC Board. The final strategy is a result of ECPC Secretariat and Board collaboration.

2.1 STRATEGIC FRAMEWORK

The strategy is composed of two parts:

OBJECTIVES

define an over-arching breakthrough vision, and are linked to the organisation vision. They are long-term, and answer the questions *“Where do we want to be in 2019?”* and *“What do we want to achieve?”*.

TACTICS

are stepping stones to achieving the higher-level objectives that are specific, measurable, and inter-compatible. The tactics mentioned in this Multi-annual Strategy are indicative and can be adapted to the necessities. Each year, ECPC develops an annual Action Plan 2017 which re-defines and updates the tactics and specific actions to be implemented each year. Tactics are short-term, and they answer the question *“How do we achieve our objectives?”*

2.2 FOCUS ON KEY POLICY ISSUES FOR CANCER PATIENTS

Objectives and tactics are divided in four main areas of action that ECPC identified. The four areas of actions have been identified by the ECPC Board in line with the vision and mission of ECPC. For each main area of action, the Multi-annual Strategy identifies a general objective (Figure 1).

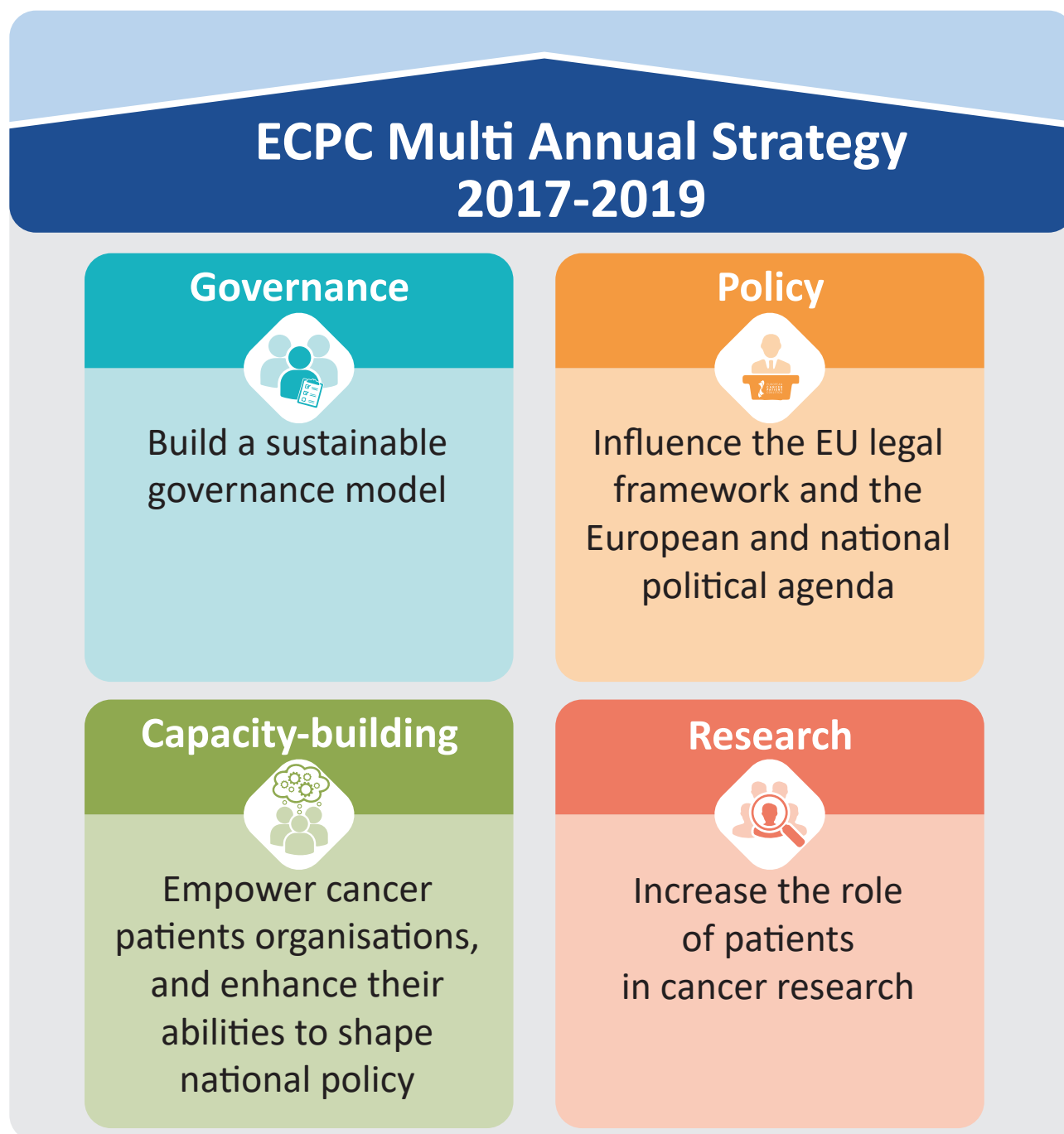


Figure 1. The Multi-annual strategy of the European Cancer Patient Coalition

2.3 EVALUATION

In 2019, the ECPC Board will produce a report on the implementation of the Multi-annual Strategy, to be presented and adopted by the ECPC General Assembly.

3 GOVERNANCE

Good governance is vital to ensure that the European Cancer Patient Coalition does good work. Governance is important because the organisation needs to be run well in order to last, as well as to retain and attract new Members and supporters. Without good governance, the organisation will cease to exist.

3.1 STRATEGIC OBJECTIVES

- Build a sustainable governance model;
- Improve the inclusion of the European Cancer Patient Coalition membership in the decision-making processes of the organisation;
- Implement an internal decision-making process that is transparent, accountable, democratic and collegial;
- Produce clear, short and medium term objectives for the ECPC Board that will be reached through the implementation of specific activities defined in the annual Action Plans.

3.2 TACTICS

- ✓ Write the European Cancer Patient Coalition Regulation;
- ✓ Develop a job description for Board Members, employees and volunteers in order to better assign responsibilities;
- ✓ Ensure regular communication between membership, Board members and Secretariat, by:
 - Creating centralised calendar for meetings and teleconferences;
 - Creating template for Board members to report when attending external events;
 - Implementing more frequent and robust newsletters to the European Cancer Patient Coalition members;
 - Creating a “Members’ Area” on the European Cancer Patient Coalition website;
- ✓ Benchmark efforts against other patient organisations.

4 POLICY

4.1 STRATEGIC OBJECTIVES

Despite progress in the policies to support people with cancer and their families, there is still a lot of unfairness, exclusion, and misunderstandings. The European Cancer Patient Coalition works with its Members to produce policy recommendations and advocate for better access to treatment and care, and more patient participation in processes and decision-making.

- Influence EU legal framework related to cancer and EU and national political agenda, to:
 - Fight against inequalities in cancer care;
 - Promote patient-centric survivorship and rehabilitation policies;
 - Promote patient-centric innovation;
 - Continue to defend the rights and needs of rare cancer patients;
- Position the European Cancer Patient Coalition as a 'legal watchdog' for the implementation of EU legislation.

4.2 TACTICS

4.2.1 HORIZONTAL

- ✓ Continue to build two-way alliances and collaborate with medical societies, scientific organisations, patients' associations willing and able to contribute to the ECPC's objectives.
- ✓ Promote the dissemination and implementation of Cancer Control Joint Action guidelines at the national and European level.

4.2.2 INEQUALITIES

- ✓ Monitor implementation of key EU legislations, e.g.:
 - Cross Border Healthcare Directive;
 - Transparency Directive;
 - Clinical Trials Regulation;
- ✓ Raise awareness of patients' perspective on key topics, e.g.:
 - Shortages of medicines;
 - Sustainability of health care;

4.2.3 SURVIVORSHIP

- ✓ Promote concept, uptake and implementation of survivorship cancer plans at EU & national level;
- ✓ Implement campaigns to defend patients' right after the acute treatment, e.g.:
 - Right to return to work;
 - Right to be forgotten;
 - Right to receive correct and timely information about follow up.
- ✓ Increase health professional's awareness on need to provide guidance to cancer survivors.

4.2.4 INNOVATION

- ✓ Call for more patient involvement and harmonisation of Health Technology Assessment;
- ✓ Monitor pricing and reimbursement policies and processes at national level;
- ✓ Monitor and analyse adaptive pathways and other fast-track approval schemes;
- ✓ Promote adoption of novel organisation of care's models to increase patient outcomes and quality of life, e.g.:
 - Promote multidisciplinary patient pathways;
 - Promote the development and implementation of solid eHealth infrastructures at EU and national level;
 - Promote the development of patient-centric mHealth applications in cancer.

4.2.5 RARE CANCERS

- ✓ Contribute to Joint Action on Rare Cancers and ensure transfer into national cancer plans;
- ✓ Support implementation of European Reference Networks for rare cancer.

5 CAPACITY BUILDING

The European Cancer Patient Coalition exists to serve its Members. Building the capacity of our Members improves the capability of patient organisations to develop, implement, and advocate for patient empowerment at the national, regional, and global level.

5.1 STRATEGIC OBJECTIVES

- Increase the European Cancer Patient Coalition members' capacity to exploit European Cancer Patient Coalition (policy and research) achievements at national level;
 - European Cancer Patient Coalition deliverables used by members to create internal knowledge and build capacity to engage nationally;
- Increase European Cancer Patient Coalition members' capacity to get autonomously involved in national healthcare decision making;
 - Members build on European Cancer Patient Coalition work to improve cancer policies and cancer education nationally.

5.2 TACTICS

- ✓ Facilitate the exploiting by Members of the ECPC's achievements:
 - Thorough dissemination of relevant policy information to all ECPC Members;
 - Dedicated trainings to increase ECPC Members' functional understanding of the EU;
 - Increase ECPC members' understanding of clinical research, in particular ECPC's research projects, functioning and importance of HTA processes (national level and EU cooperation).
- ✓ Increase involvement at national level:
 - Provide clear and comprehensive information / trainings on HTA to cancer patients in order to increase participation in HTA processes at national and EU level;
 - Create a network of legal experts to provide legal assistance on an ad hoc and pro bono basis;
 - Continue supporting European Cancer Patient Coalition members in producing their national policy strategies.

6 RESEARCH

Research projects allow the European Cancer Patient Coalition to be on the forefront of scientific developments. The European Cancer Patient Coalition works to ensure that the patient perspective is heard and respected, while improving scientific knowledge about cancer.

6.1 STRATEGIC OBJECTIVES

- ✓ Promote the concept of patients as co-researchers and the need for research projects to focus on patients' priorities;
- ✓ Influence EU research priorities to match cancer patients' needs;
- ✓ Foster the inclusion of appropriate Quality of Life indicators for the evaluation

6.2 TACTICS

- ✓ Patients as co-researchers:
 - Increase ECPC's participation in patient-oriented research projects (H2020, IMI, 3rd Health programme, etc.);
 - Kick off ECPC own research projects, including increasing translational research from bench to bedside;
 - Enable patients to shape priorities of research community;
- ✓ Research priorities:
 - Identify key research priorities to meet cancer patients' unmet needs;
 - Promote the priorities identified to EU decision makers (DG RTD and DG SANTE);
- ✓ Quality of life:
 - Call the international research community to better include appropriate quality of life in the design of clinical trials.



EUROPEAN **CANCER** **PATIENT** COALITION

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