



European Cancer
Patient Coalition

Action Plan 2024

06, Avenue des Arts
1210 Brussels
Belgium
info@ecpc.org
www.ecpc.org

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Correspondance

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Avenue des Arts 6

1210 Brussels

Belgium

info@ecpc.org

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Introduction

The European Cancer Patient Coalition has been serving the cancer community for 20 years (2003 – 2023): “Nothing about us, without us”.

As a coalition of patient organizations ECPC went through many changes: in terms of its member organizations, in terms of the people affected by cancer, who are its members, in terms of those who braved through their treatments and learned to live as cured patients, and in terms of those who serve and support cancer patients, their carers, in terms of those who are no longer with us.

The first two decades of the European Cancer Patient Coalition focused on cementing the fact that patients, and specifically all people affected by cancer, including their caregivers and survivors, need to be a part of all initiatives that are developed for patients. With health being a national competence, this has proven to be a challenging task. But, with the support of ECPC’s strong and diverse membership, this became possible.

During the 2019- 2024 legislature of the European Parliament and the European Commission, an agreement on prioritizing cancer at the supranational level was reached: 1) First, via Horizon Europe’s Mission on Cancer; 2) the launch of Europe’s Beating Cancer Plan. These milestones reflect the thirty year-long commitment of the European Union and its Member States to work together to provide people with cancer with the best possible care.

Throughout the current five-year term, dossiers such as the Cross-Border Healthcare Directive, Medical Devices Regulation, In-Vitro Diagnostics Regulation, Personalized Medicine, Rare Cancers, Digital Health, Biosimilars, Car-T Cell Treatments, among others were assessed and implemented. New files such as the Health Technology Assessment Regulation and Proposals for a European Health Data Space, Pharmaceutical Directive and Regulation, Artificial Intelligence Act, among others were launched. Additionally, there were numerous Joint Actions, such as the Joint Action on European Networks of Expertise, the Innovative Partnership for Action Against Cancer (iPAAC) and many others.

The European Parliament created a Special Committee on Beating Cancer, which was then transformed into a sub-committee on Public Health, SANT. And last, but not least, the funding for projects regarding cancer research increased drastically – due to Europe’s Beating Cancer Plan and its implementation, and the corresponding funding associated with the Mission on Cancer (Horizon Europe).

All these points indicate that a case for health at EU-level, catalysed by COVID-19 which made the world lose more than two years, and thousands of lives (including those affected by cancer), is being tested in spite of health being a national competence. And cancer, is the chosen pilot.

However, despite the prioritization at EU level, much remains to be done for health systems and especially for people affected by cancer – including 1) ensuring that every single Member State has a national cancer plan; 2) ensuring that people affected by cancer are included in the process of developing national policies, and research projects that aim to ameliorate their lives.

Every five-years, the EU community is given a chance to reflect on how the past

5 years have passed, what changes have been made (positive or negative), and what still needs to be done. The year 2024 will be crucial as it marks the end of a 5-year cycle, and the beginning of the next term of the institutions. It will be a transition year where the EU will be looking forward to welcoming a new European Commission and European Parliament. Thus, with the changes at the helm of the European Union, and health still being a national competence, it is up to the health community, and especially the oncology community, to ensure that the areas that are vital to protect the needs of patients are kept high on the political agendas.

Vision 2023 – 2033: Patient-centricity in all policies

Over the past 20 years, the European Cancer Patient Coalition (ECPC), the largest umbrella organization¹ representing patients with cancer has dedicated itself to protecting the needs of patients in EU policies, and beyond. The outcome of its dedication is reflected in various EU policies, with patients being increasingly seen at the centre of all EU policies.

The third decade of the European Cancer Patient Coalition will focus on ensuring that people with cancer will be at the centre of all EU policies and research projects, not only in name, but in practice.

It is important to note that ECPC is the only patient organization representing the needs of patients in most of the EU projects, including UNCAN.eu (a flagship of Europe's Beating Cancer Plan and one of the recommendations of the Mission on Cancer), CCI4EU (Comprehensive Cancer Infrastructures for Europe), CAN.HEAL (building the EU Cancer and Public Health Genomics platform), INSTAND (Integrated and standardized NGS workflows for Personalised Therapy), canSERV (providing cutting edge cancer research services across Europe), among others. It is also one of the few patient organizations represented in Joint Actions, such as JANE, iPAAC, among others. And lastly, it is also one of the few representing the needs of patients in EU policies, for example the Cross-Border Healthcare Directive, Health Technology Assessment Regulation, General Data Protection Regulation, among others.

ECPC's unique position allows the Coalition to inform its national member organizations as well as raise awareness about key points about EU policies, research projects and joint actions at national level. To keep patients, caregivers and survivors at the centre, they need to be informed, educated, and included in advocacy efforts to improve the care for patients with cancer. And this is one of the most important aspects of ECPC's vision for the next ten years.

Another issue that will be addressed during this term is the sustainability of patient organizations. ECPC's work has been recognized by all stakeholders as being pivotal to shaping policies and including the cancer patient perspective. However, for an organization to be sustainable, the foundational structure needs to be strong. ECPC will be working towards defining new, innovative mechanisms to safeguard its future, and the future of people affected by cancer.

Healthcare systems have been created to take care of those who will be experiencing the care. Thus, with cancer high on the political agenda, it is crucial to ensure that patients are involved in the creation of all policies from a foundational level. This can only be achieved if the community works together, collaboratively. As there is "nothing about us, without us".

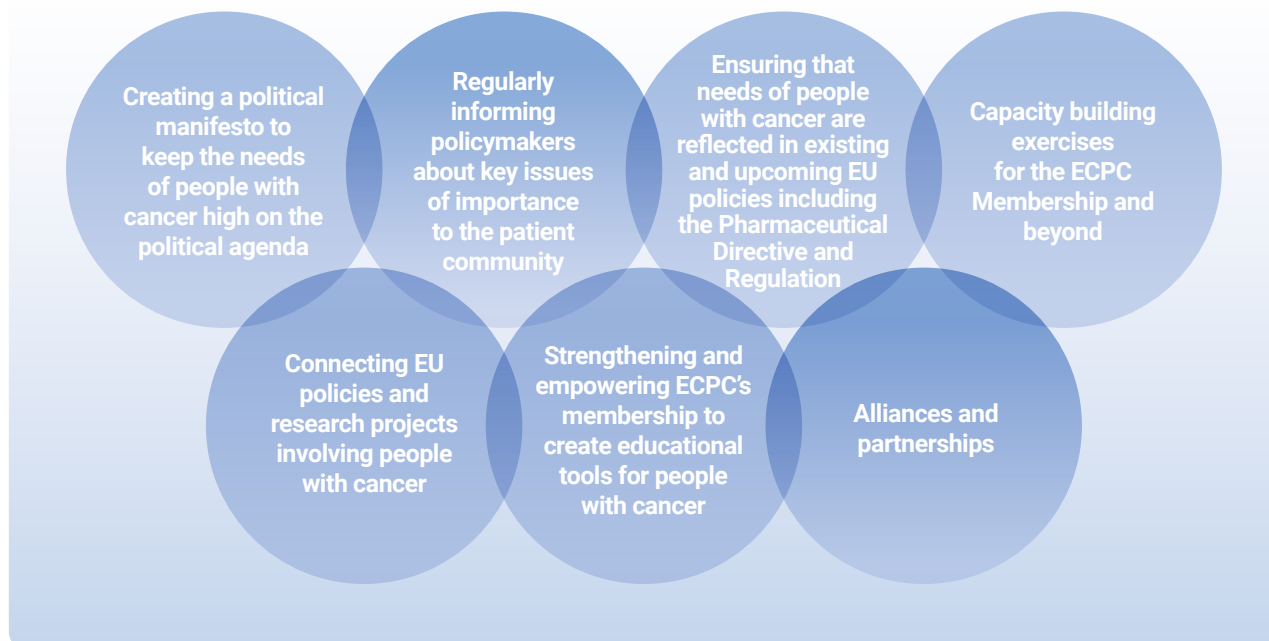
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ECPC Members: 473

Mission

- To empower people with cancer through the dissemination of information
- To foster collaboration and co-operation among cancer patient organisations through joint activities
- To ensure that state-of-the-art cancer care practices are shared across the European Union
- To make cancer a priority for action in the European health policy agenda
- To have an active role in shaping European and national healthcare policies
- To contribute to change or create European and national laws to meet the needs of people with cancer
- To call for the people with cancer to be included in cancer research

ECPC Action Plan 2024



Activities foreseen in the ECPC Action Plan 2024

1. Creating a political manifesto to keep the needs of people with cancer high on the political agenda

Context: With 2024 being a transition year, there is a need to ensure that the policy priorities that are relevant for the oncology community, remain high on the political agenda and are understood by all concerned. Thus, it will be important to conduct an awareness campaign prior to the European Parliament elections.

How: ECPC will work with its members and partners to create a political manifesto highlighting existing and new topics that are crucial for the oncology community, especially people with cancer.

Output:

- **Survey:** Create a survey for the membership to gather information regarding the state of play for people with cancer
- **Gap analysis:** Analyze the results and prepare a gap analysis
- **Political Manifesto:** Draft the political manifesto incorporating the priorities of ECPC members and the cancer patient community
- **Raise awareness:** Use vehicles such as the European Parliament's Challenge Cancer Intergroup – to conduct 2 meetings prior to the European Parliament elections.

- **Disseminate manifesto:** Disseminate the manifesto to ECPC members, to be adapted to national circumstances.
- **Communication activities:** Create a communication strategy to disseminate information amongst the policymakers, as well as the oncology community and use social media and other tools including publications, as vehicles
- **Toolkit for National Manifestos:** Develop a set of tools in several European languages for ECPC members to use on the national level, to advocate among the national candidates for EU elections the importance of adding cancer and health care in their political agenda.
- **National Workshops:** Organize national workshops to brief our members about political advocacy for cancer and offer guidance and support to their campaigns.

Duration: 12 months

2. Regularly informing policymakers about key issues of importance to the patient community

Context: The second half of 2024 will focus on informing the new European Parliament and the incoming European Commission on the priorities for cancer community, specifically people with cancer. With the information gathered from the gap analysis survey, it will be important to reinforce the key areas that need to be reflected over 2024 – 2029.

How: ECPC holds the secretariat of the Challenge Cancer Intergroup (2019 – 2024). Thus, with the new legislature, ECPC will focus on re-creating the Challenge Cancer Intergroup and once re-established, having regular meetings on key topics for the cancer patient community. In order to do that, ECPC will be using the results gathered from the gap analysis survey conducted amongst its members to create a list of topics that need to be addressed at EU level.

Deliverables:

- **Develop a guide for new MEPs:** Create a brief guide for the new MEPs for ensuring continuity in cancer policy.
- **Challenge Cancer Intergroup:** Advocate MEPs to re-create the Challenge Cancer Intergroup, with a new Chair and co-Chair.
- **European Parliament meetings:** With a new, re-created Challenge Cancer Intergroup, ECPC will hosting regular bi-monthly (every 2 months) meetings of the Challenge Cancer Intergroup, on important topics for the cancer patient community.
- **Communication activities:** Create a communication strategy to disseminate information amongst the policymakers, as well as the oncology community and use social media and other tools, including publications, as vehicles.
- **ECPC Members:** Disseminate information as well as work together with the membership to advocate for the needs of people affected by cancer at EU level and at national level to their elected national MEPs.

Duration: 12 months

3. Ensuring that needs of people with cancer are reflected in existing and upcoming EU policies including the Pharmaceutical Directive and Regulation

Context: The year 2024 will be a critical year for the oncology community, to ensure that the momentum that was created in the 2019 – 2024 term of the European institutions does not lose traction. The Pharmaceutical Directive and Regulation are examples of policies that will be carried forward to the next term of the European institutions. Thus, it will be important for ECPC to continue working on these dossiers, and representing the needs of people affected by cancer, along with reducing social disparities to allow all patients across the EU 27 to receive care in a timely manner.

How: ECPC will be working with its members and its partners to understand the needs with respect to the specific dossiers and will reflect them accordingly.

Deliverables:

- **Survey:** To understand the status quo regarding access to treatment, including aspect of shortages.
- **Paper:** To update ECPC's paper on social disparities and the earlier ECPC Policy Paper on "Challenging The Europe of Disparities in Cancer - A Framework for Improved Survival and Better Quality of Life for European Cancer Patients."
- **Report:** To develop a report based on the information gathered and highlight key points that need to be addressed in the dossiers.
- **Meetings:**
 - Conduct 1 meeting with the new European Parliament to inform the community of the findings of the report.
 - Conduct meetings with members, partners and stakeholders as necessary.
- **Communication activities:** Raise awareness of the issues with the EU institutions and ECPC members via social media and other communication tools.
- **Monthly newsletter:** regularly inform ECPC members on key developments affecting the oncology community at EU level, via newsletters.
- **ECPC Members:** disseminate information as well as work together with the membership to advocate for the needs of people affected by cancer at EU level.

Duration: 12 months

4. Capacity building exercises for the ECPC Membership and beyond

Context: The European Cancer Patient Coalition is there to serve its members. Being the largest umbrella organization representing members from the EU 27, it is ECPC's responsibility to understand their needs and provide them with the tools to assist people affected with cancer living in their country.

How: As a Coalition ECPC works at the supranational level, reflecting the needs of patients in all relevant initiatives, and at the national level – ECPC works

with its members to empower them where needed. This will be done by first gathering the data regarding the needs of our membership, and then using that data to create tailored initiatives at the national level.

Deliverables:

- **Survey:** Understand the key topics that need to be addressed/tackled at national level.
- **Trainings:** Conduct 2 capacity building trainings at national level – based on the results of the survey.
- **Toolkit:** Create a capacity-building toolkit.
- **ECPC Members:** Disseminate information as well as work together with the membership to advocate for the needs of people affected by cancer at EU level, for example: with respect to developing national cancer plans (in line with Europe's Beating Cancer Plan).

Duration: 12 months

5. Connecting EU policies and research projects involving people with cancer

Context: ECPC is the only umbrella organization representing the needs of patients in EU funded health and research projects. In 2023 – 2024, ECPC will participate in 31 Health and Research Projects (25 ongoing in 2023 and 6 starting in 2023). These projects are the result of the focus on cancer at the EU level, via Europe's Beating Cancer Plan as well as the Mission on Cancer. ECPC is actively involved in all projects and is in a unique position to understand the needs of people affected by cancer, as well as recognize the gaps.

How: In order to understand the vast number of projects happening at the EU-level, focusing on cancer, it is crucial to have an understanding of all the projects, the categories they represent, and their interconnected nature to EU policies. As 2024 will be a transition year, it will be important to underscore where more funding is needed based on the existing distribution of projects.

Deliverables:

Mapping: Create an overview of the existing projects with ECPC involvement and connecting the projects.

Raising awareness and connecting projects: ensuring that the projects that ECPC is taking the lead on reach policymakers and patient organizations, and other relevant stakeholders.

Monthly newsletter: regularly inform ECPC members on key developments affecting the oncology community at EU level, via newsletters.

ECPC Members: disseminate information as well as work together with the membership to advocate for the needs of people affected by cancer at EU level.

Develop educational tools: Create educational tools connecting the projects, such as brochures, to inform ECPC members and beyond.

Duration: 12 months

Annex: More information regarding projects and ECPC involvement.

6. Strengthening and empowering ECPC's membership to create educational tools for people with cancer

Context: ECPC works with patients, survivors, and their caregivers on a regular basis. By involving them in EU-funded projects, by informing them of the latest developments via its network and communication tools, and by creating long-lasting relationships with those who need it most. During this process, the gaps regarding the needs at the national level also become evident. Health literacy is one of the most important areas for patients, survivors, and their caregivers. It empowers them to understand what they and their loved ones are going through. Thus, it is extremely important to focus on the needs and develop tools to empower patients, survivors, and their caregivers.

How: ECPC will gather evidence regarding the needs of its members, the focus areas and then develop tools based on the information received. Specifically, tools for patients, survivors, and their caregivers on areas most relevant for the members will be created.

Deliverables:

Survey: Conduct a survey amongst ECPC members to understand the areas they would like to understand better.

Health literacy campaign: Develop a health literacy campaign based on the results of the survey, e.g., health literacy regarding guidelines, digital health etc.,

Monthly newsletter: Regularly inform ECPC members on key developments affecting the oncology community at EU level, via newsletters.

Duration: 12 months

7. Alliances and partnerships

Context: Collaboration with patient organizations, scientific societies, healthcare professionals including nurses, stakeholders, industry – is crucial to tackle cancer. ECPC's members represent numerous patients, caregivers, and survivors, and thus it is paramount that the needs are discussed with all stakeholders involved in the oncology community to co-create campaigns tackling the challenges faced by those who need it most.

How: ECPC will be conducting meetings with all relevant stakeholders, to bring them together to build partnerships and work together to improve the needs of patients with cancer.

Deliverables:

Meetings: Conduct 1-2 meetings with stakeholders to reflect the needs of patients as well as co-create campaigns to tackle these needs.

Campaign: Develop a stakeholder campaign based on 1 common area stemming from these discussions.

Report: Develop a short report based on the discussions, reflecting the campaign.

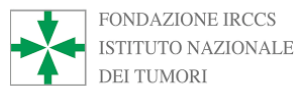
Communication: communicating the efforts via social media and other vehicles.

Duration: 12 months

Annex

#	Category	Project	Start	End
1	AI, Big data and personalized medicine	CAN.HEAL	2022	2024
2	AI, Big data and personalized medicine	INSTAND	2020	2024
3	AI, Big data and personalized medicine	QUALITOP	2020	2024
4	AI, Big data and personalized medicine	TIGER	2021	2025
5	AI, Big data and personalized medicine	INTERVENE	2021	2025
6	AI, Big data and personalized medicine	AIDAVA	2022	2026
7	AI, Big data and personalized medicine	OPTIMA	2021	2026
8	AI, Big data and personalized medicine	CGI-Clinics	2022	2027
9	AI, Big data and personalized medicine	COMFORT	2023	2027
10	Prevention	ONCODIR	2023	2026
11	Digital health	TRANSITION	2023	2025
12	Digital health	XpandDH	2020	2024
13	European policy initiatives	Uncan.eu	2022	2023
14	European policy initiatives	SMART CARE	2023	2024
15	European policy initiatives	EOSC4CANCER	2022	2025
16	European policy initiatives	CAN.SERV	2022	2025
17	European policy initiatives	CCI4EU	2023	2026
18	Imaging	IMAGIO	2023	2027
19	Imaging	IDERHA	2023	2028
20	Palliative care	PALLIATIVE SEDATION	2019	2023
21	Palliative care	INSPIRE	2022	2026
22	Palliative care	PAINLESS	2022	2027
23	Palliative care	PALCYCLES	2022	2027
24	Patients and caregivers	LIFECHAMPS	2020	2023
25	Patients and caregivers	DIADIC	2019	2024

26	Patients and caregivers	RELEVIUM	2022	2026
27	Patients and caregivers	MY PATH	2022	2027
28	Patients and caregivers	PREFERABLE II	2022	2027
29	Treatment and care	IMMUNOIMAGE	2019	2024
30	Treatment and care	IMMUNOSABR	2017	2024
31	Treatment and care	SALVOVAR	2023	2028





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