ECPC Strategy 2016 - 2019

<table>
<thead>
<tr>
<th>Governance</th>
<th>Policy</th>
<th>Capacity-building</th>
<th>Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Build a sustainable governance model</td>
<td>Influence the cancer EU and national political agenda</td>
<td>Empower cancer patients to shape national policy and take part in value assessment of health technologies</td>
<td>Increase the role of patients in research on cancer (i.e. patients as co-researchers)</td>
</tr>
</tbody>
</table>
ECPC Policy work
Advocacy and finding new allies

Advocacy
- Position papers and policy studies
- Awareness-raising events
- EU institution advocacy

Capacity Building
- Working Groups
- ECPC Masterclass
- General Assembly
- Education & Courses
- Advocacy Training

Research
- CANCON
- Members of the EC Expert Group on Cancer Control
- Members of the European Initiative on Breast Cancer
- JARC
- Health Policy Forum
- EMA's Patients' and Consumers' Working Party
- CDDF
- EAPM
- ECC
- EORTC
- ESMO/ECCO
- OECI
- UICC
- EAU

Partnerships
- EurocanPlatform
- eSMART
- RARECAREnet
- InSup-C
- BenchCan
- Transcan 2
- Project on Mesothelioma
The PARTNERSHIPS pillar

- Formal collaboration in progress
- Formal collaboration signed
The POLICY Pillar

STRATEGIC OBJECTIVE

✓ Influence the cancer 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

TACTICS

Inequalities

✓ Monitor the implementation of the Cross Border Healthcare Directive
✓ Raise awareness on patients’ perspective on key topics, e.g.:
  ▪ Shortages of medicines’ causes (in particular parallel trade)
  ▪ Health in the European Semester
  ▪ Update the EU legal framework for the authorisation and pricing of new medicines (Transparency Directive)

Survivorship

✓ Promote the concept of survivorship cancer plans at EU and national level
✓ Implement campaigns to defend patients’ right to return to work
✓ Increase HCP’s awareness on the need to provide guidance to cancer survivors

Rare cancers

✓ Contribute to the Joint Action on Rare Cancers
✓ Support the implementation of the European Reference Networks for rare cancer

Innovation

✓ Call for more harmonisation of Health Technology Assessment
✓ Pricing and reimbursement of drugs
✓ Adaptive pathways and other fast-track schemes
✓ Promote the adoption of novel organisation of care’s models to increase patients’ outcomes and quality of life, e.g.:
  ▪ Multidisciplinary patients’ pathways
  ▪ eHealth-mHealth
ECPC: the voice of cancer patients in Brussels

• **European Commission**
  - Joint Action on Cancer Control (CanCon)
  - European Partnership for Action Against Cancer (EPAAC)
  - Next Joint Action on Cancer (IPAAC)
  - Joint Action on Rare Cancers (JARC) and ERN
  - European Commission’s Expert Group on Cancer Control
  - European Network of Cancer Registries
  - ECBIC – Initiative on Breast Cancer

• **European Medicines Agency**
  - Patients’ and Consumers’ Working Party

• **Strong relationship with the European Parliament**
  - EU Regulation 726/2004 AMENDED
  - Access to medicines report AMENDED 2017
Survivorship

<table>
<thead>
<tr>
<th>Objectives</th>
<th>ECPC Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Fight the stigma</td>
<td>• CanCon recommendations on survivorship</td>
</tr>
<tr>
<td>• Promote Survivorship Care Plans</td>
<td>• ECPC-ESMO Guide on Survivorship</td>
</tr>
<tr>
<td>• Cancer is a public health emergency AND a socio-economic one</td>
<td></td>
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</tbody>
</table>
## Inequalities and innovation

<table>
<thead>
<tr>
<th>Objectives</th>
<th>ECPC Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Fight the <em>unacceptable</em> inequalities in access to quality care</td>
<td>• CanCon recommendations on inequalities and disinvestment</td>
</tr>
<tr>
<td>• Fight the <em>delays in access to meaningful innovative drugs</em></td>
<td>• ECPC Value of Innovation White Paper</td>
</tr>
<tr>
<td>• Make <em>cancer care sustainable</em></td>
<td>• ECPC work on Health Technology Assessment</td>
</tr>
<tr>
<td></td>
<td>• ECPC contribution to the INI report on access to medicines</td>
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<tr>
<td></td>
<td>• ECPC contribution to the WHA resolution</td>
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</tbody>
</table>
ECPC position on Health Technology Assessment

- Centralised – 1 for whole of EU
- Relative EFFECTIVENESS assessment
- Done by new Agency, funded by EC/MS
- HTA valid, binding and directly implemented in all EU MS
  - Considers patients-reported outcomes
- Patients’ involvement in HTA must become the norm: need to identify precise methodologies

HTA shall be an instrument to evaluate ALL medical tech, including medical devices, pathways
ECPC policy achievements
A great partnership with the European Parliament

• **World Cancer Day 2015 declaration:** 160 MEPs supported ECPC to fight inequalities in cancer care

• **Written declaration 30/2015:** ECPC & 19 MEPs ask the European Parliament to take a position on sustainability of healthcare, requesting the Commission to do more to harmonise HTA process at EU level

• **Amendments to the EMA regulation 726/2004:** ECPC supported the amendments to the regulation to pave the way for the EMA to centralise the HTA assessment at the EU level and increase harmonisation

• **Own initiative report on access to medicines:** ECPC produced a position paper and 20 amendments, all included in final version
European Parliament must work towards implementation of INI report

• Promote universal access to affordable, effective, safe and timely cancer care;

• Push for increased collaboration on pricing and reimbursement, including joint procurement;

• Request the Commission to propose a new Transparency Directive
ECPC is not alone
A global movement calling for action

• World Health Assembly resolution on NCDs:
  • Approved in May 2017
  • Main recommendations
    • Reaffirms the importance of national cancer care plans
    • Promotes cancer research
    • Reaffirms need to access to innovative quality medicines
    • Reaffirms key role of patients organisations and calls for increased interaction between health decision makers and patients

• European Public Health reaction to the Future of Europe
  • Health must remain a key priority for action for the EU
  • Promote more and better evidence-based legislation on health
  • Coordinate action of all EU countries vs health threats, promoting cross border collaboration
  • Solid and well funded Health Programme
  • Particular attention on NCDs and inequalities
The RESEARCH pillar

<table>
<thead>
<tr>
<th>BD4BO</th>
<th>BenchCan</th>
<th>Cancer A. Academy</th>
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<tbody>
<tr>
<td>ERN-EURACAN</td>
<td>eSMART</td>
<td>EurocanPlatform</td>
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<tr>
<td>H2020MM04</td>
<td>IMMUNOSABR</td>
<td>InSup-C</td>
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<tr>
<td>JARC</td>
<td>PREFER</td>
<td>RARECARENet</td>
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<tr>
<td>TRANSCAN 2</td>
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</table>
This work has received support from the EU/EFPIA Innovative Medicines Initiative [2] Joint Undertaking PREFER grant n° 115966.
PREFER

• Development of guidelines for
  – Industry
  – Regulatory Authorities
  – HTA bodies
  on how and when to include patient perspectives on benefits and risks of medicinal products.

• Duration: 5 years

• 3 case studies, one on cancer
List of participants (abbreviated name)

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Participant organisation name</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (Coordinator)</td>
<td>Uppsala University (UU)</td>
<td>Sweden</td>
</tr>
<tr>
<td>2</td>
<td>University Medical Centre, Utrecht (UMCU)</td>
<td>The Netherlands</td>
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<tr>
<td>3</td>
<td>Erasmus University Rotterdam (EUR)</td>
<td>The Netherlands</td>
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<tr>
<td>4</td>
<td>University of Leuven (KUL)</td>
<td>Belgium</td>
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<tr>
<td>5</td>
<td>University of Birmingham (UB)</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>6</td>
<td>Universitätsklinikum Erlangen (UKER)</td>
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<tr>
<td>7</td>
<td>Institute of European Oncology, Milan (IEO)</td>
<td>Italy</td>
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<td>8</td>
<td>MindBytes (MB)</td>
<td>Belgium</td>
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<td>9</td>
<td>Istituto Tumor, IRCCS-Bari (ITB)</td>
<td>Italy</td>
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<td>10</td>
<td>European Cancer Patients Coalition (ECPC)</td>
<td>Belgium</td>
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<td>11</td>
<td>Steinbeisser Project Management UG (SPM)</td>
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<td>12</td>
<td>Newcastle University (UNEW)</td>
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<td>Belgian Health Care Knowledge Centre (KCE)</td>
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<td>14</td>
<td>Muscular Dystrophy UK (MDUK)</td>
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<tr>
<td>15 (Project leader)</td>
<td>Novartis (Novartis)</td>
<td>Switzerland</td>
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<td>16</td>
<td>Amgen (Amgen)</td>
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<td>Eli Lilly (Lilly)</td>
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<td>Janssen Pharmaceutica NV (JANSSEN)</td>
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<td>Sanofi (SARD)</td>
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<td>Merck, Sharpe &amp; Dohme (VSH)</td>
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<td>AstraZeneca (AZ)</td>
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<td>Takeda Development Centre Europe Ltd. (Takeda)</td>
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<td>31</td>
<td>European Patient Forum (EPF)</td>
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<td>32</td>
<td>International Alliance of Patient Organisations (IAPO)</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>33</td>
<td>Erasmus MC - University Medical Centre (EMC)</td>
<td>The Netherlands</td>
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</tbody>
</table>
Patient Advisory Group

Coordinator: European Cancer Patients Coalition (ECPC)

Consortium Members

- European Cancer Patients Coalition (ECPC)
- Muscular Dystrophy UK (MDUK)
- European Patient Forum (EPF)
- International Alliance of Patients’ organizations (IAPO)

Stakeholder Advisory Board Members

- European Cancer Patients Coalition (ECPC) – PAG Lead
Patient Advisory Group

PAG Lead: Isabelle Manneh (ECPC)

Consortium Members

ECPC: Francesco De Lorenzo, Kathi Apostolidis, Lydia Makaroff, Francesco Florindi
  - MDUK: Jenny Sharpe
  - EPF: Valentina Strammiello
  - IAPO: Antonio Ciaglia

Stakeholder Advisory Board Members

- European Cancer Patients Coalition (ECPC) – PAG Lead:
  - Isabelle Manneh

Name underlined: attends the IMI PREFER kick-off meeting
Big Data for Better Outcomes
BD4BO-DO>IT

• Innovative Medicines Initiative (IMI)
• Coordination and Support Action
• 2 years (2017 – 2019)
• Objectives:
  harnessing the opportunities of big data to promote patient-centred outcomes-focused healthcare in Europe and to develop innovative methods for integrating, analysing, and using big data.
• ECPC’s role:
  • Patient input in developing informed consent form
  • Patient input in developing communication plan
  • Dissemination
Joint Action on Rare cancers (JARC)

is aimed to **integrate** and **maximize** efforts of the European Commission and EU Member States to **advance quality of care** and **research** on rare cancers.

- The public health challenge posed by rare cancers combines both the **typical problems of rare diseases** and **cancers** where the need of timely diagnosis and access to quality treatment is vital.
- JARC is shaping its efforts around the ERNS
## JARC Work packages

<table>
<thead>
<tr>
<th>WP number</th>
<th>WP name</th>
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<tbody>
<tr>
<td>1</td>
<td>Coordination</td>
</tr>
<tr>
<td>2</td>
<td>Dissemination</td>
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<tr>
<td>3</td>
<td>Evaluation</td>
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<td>4</td>
<td>Epidemiology</td>
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<td>5</td>
<td>Assuring Quality of Care</td>
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<td>6</td>
<td>Clinical practice guidelines</td>
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<td>7</td>
<td>Innovation and access to innovation</td>
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<td>8</td>
<td>Medical education</td>
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<td>9</td>
<td>Childhood Cancers</td>
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<tr>
<td>10</td>
<td>Rare Cancer Policy</td>
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</tbody>
</table>
- The Joint Action on Rare Cancers and the European Reference Networks are crucial game changers for rare cancer patients in Europe bringing together scarce knowledge and fragmented resources to maximise synergies and results.

- The European Cancer Patient Coalition (ECPC) is one of the partner patient organizations representing the needs, rights and hopes of rare cancer patients within: JARC and ERN-EURCAN.
European Reference Networks (ERNs)

- European Reference Networks (ERNs) are networks connecting health care providers and centers of expertise of highly specialised healthcare.

- With the purpose of improving access to diagnosis, treatment and the provision of high-quality healthcare for patients with conditions requiring a particular concentration of resources or expertise in Europe.

- The first ERNs were launched in March 2017, involving more than 900 highly specialised healthcare units from over 300 hospitals in 26 Member States.

- 24 ERNs are working on a range of thematic issues including bone disorders, childhood cancer and immunodeficiency.
These are **not directly accessible to individual patients**. However, with the patients’ consent and in accordance with the **rules of their national health system**, the patient’s case **can be referred to the relevant ERN member** in their country by their healthcare provider.

The **European Reference Networks (ERNs)** must generally comply with the following:

- apply EU criteria to **tackle rare diseases** requiring specialised care
- serve as **research and knowledge centers** treating patients from other EU countries
- ensure the **availability of treatment facilities** where necessary
ERNs for rare cancer

EURACAN  →  Solid tumours – adults
Clinical lead: Prof Jean-Yves Blay

EuroBloodNet  →  Sub-group rare haematological malignancies: Myeloid and Lymphoid malignancies
Clinical lead: Prof Pierre Fenaux

PaedCan  →  All paediatric cancers
Clinical lead: Prof Ruth Ladenstein
ERN-EURACAN

- The **ERN for adult rare solid cancers: EURACAN** is coordinated by the **Centre Léon Bérard** with the objective to **improve the quality of care** for all European citizens affected by rare cancers, while ensuring an optimized and homogenous care and access to innovation, is provided throughout the EU member states.

- EURACAN is a **multi-domain ERN** that gathers the largest network of active EU centers involved in the management of patients with **adult rare solid cancer**: the network distinguishes rare cancers into **10 domains** corresponding to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD10) and RARECARE.
European Reference Networks

EURACAN
European network for Rare adult solid Cancer
H2020MM04
Mesothelioma

- Horizon 2020
- Four years (2016 – 2019)
- Led by Erasmus University, Netherlands
- Objectives
  - use dendritic cell-based immunotherapy to treat Malignant Mesothelioma derived from chronic exposure to asbestos
- ECPC’s role:
  - Dissemination and communication
  - Provide patient’s perspective
IMMUNOSABR

• Horizon 2020
• Six years (2017 – 2022)
• Led by Maastricht University, the Netherlands

Objectives
• randomised open label phase II clinical trial, stereotactic ablative radiotherapy (SABR) will be combined with L19-IL2 immunoncology therapy in people with limited metastatic non small cell lung cancer
• Find new biomarkers

ECPC’s role:
• Dissemination and communication
• Provide patient’s perspective
Our eHealth/mHealth expertise:
Electronic Symptom Management System
Remote Technology (eSMART) study

- Mobile phone-based
- Utilises an electronic Patient-Reported Outcomes (ePRO) measure, so ePRO system

- Evidence-based self-management advice
- Automated message prompts patient to check self-care advice
- E-Library
- Symptom graphs
- Data transferred to server and subject to clinical risk algorithm
  - Real-time
  - Data transferred to clinician's handset
- ! Amber alert (mild symptoms)
- !! Red alert (severe or life-threatening symptoms)
- Alerts transmitted to clinician’s handset
Thank for your attention

Francesco De Lorenzo
President
European Cancer Patient Coalition

@cancereu

European Cancer Patient Coalition

ECPCtv

Nothing About Us Without Us