EUROPEAN
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PATIENT
COALITION

ECPC 2016 Annual Report

Francesco De Lorenzo
Brussels, 18th June 2017

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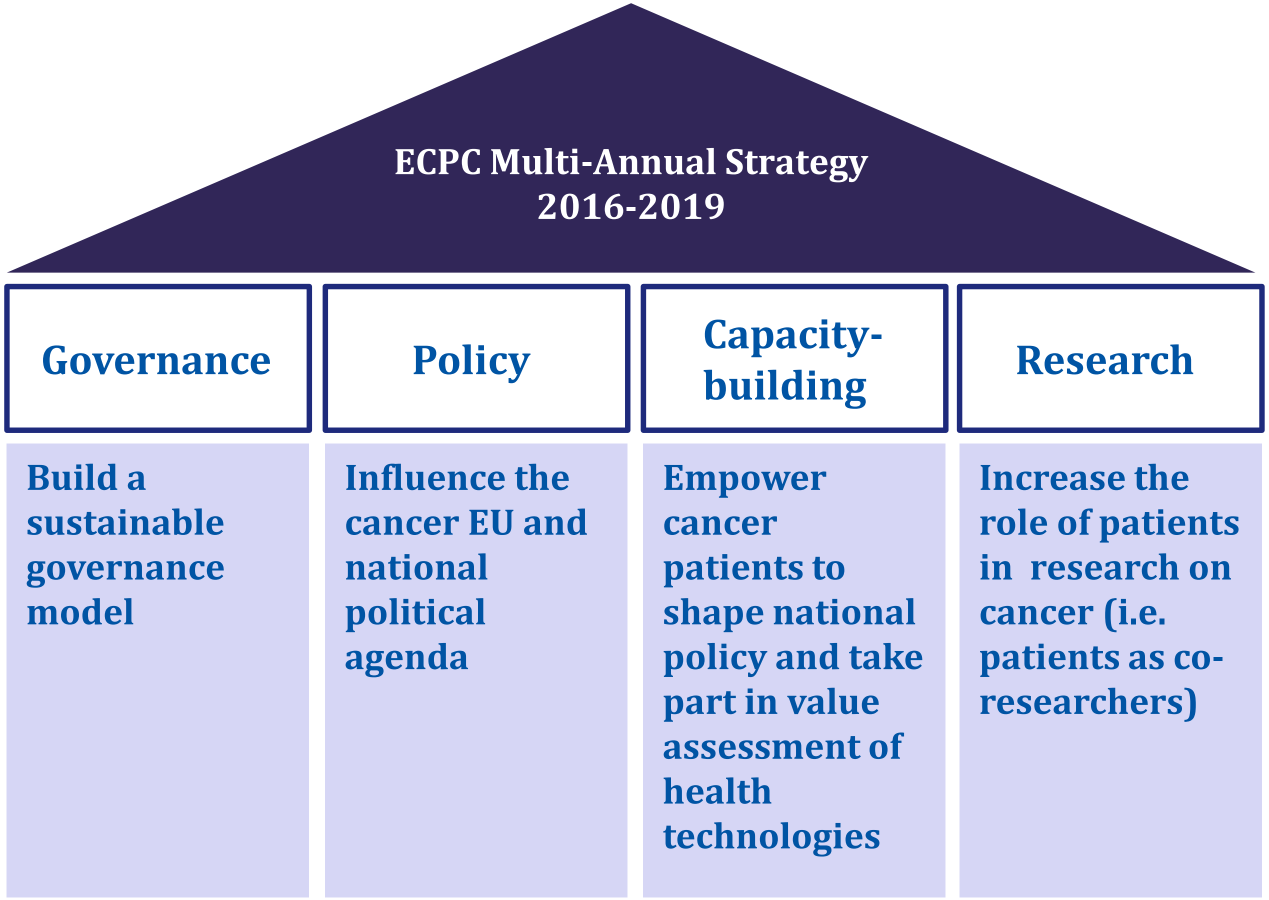
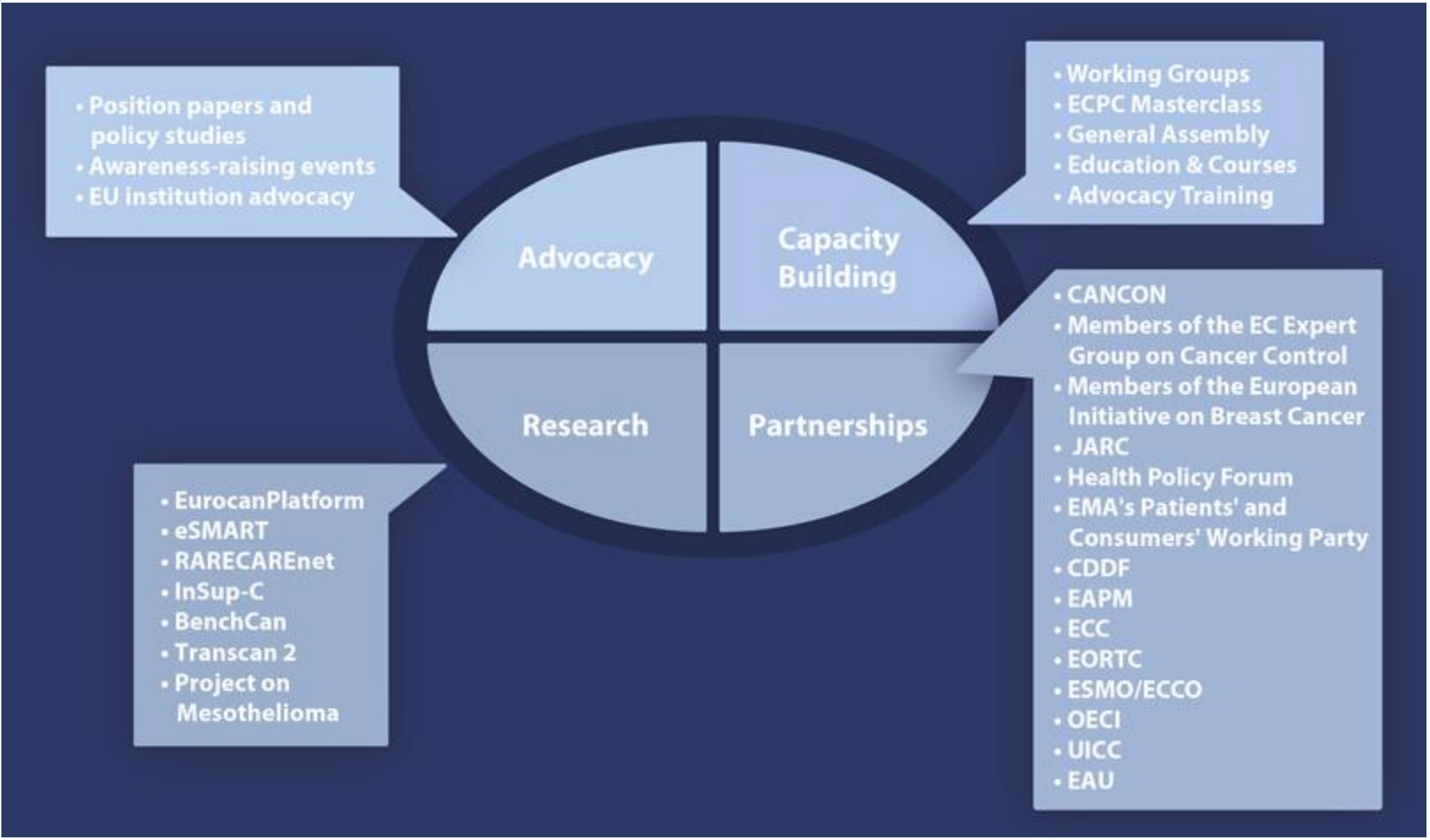
ECPC Strategy 2016 - 2019



ECPC Multi-Annual Strategy 2016-2019

Governance	Policy	Capacity-building	Research
Build a sustainable governance model	Influence the cancer EU and national political agenda	Empower cancer patients to shape national policy and take part in value assessment of health technologies	Increase the role of patients in research on cancer (i.e. patients as co-researchers)

ECPC Policy work
Advocacy and finding new allies



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

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

- EurocanPlatform
- eSMART
- RARECAREnet
- InSup-C
- BenchCan
- Transcan 2
- Project on Mesothelioma

- 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

The PARTNERSHIPS pillar

OECI
Organisation of European Cancer Institutes
European Economic Interest Grouping

uicc
global cancer control
A MEMBERSHIP ORGANISATION
FIGHTING CANCER TOGETHER

EORTC
The future of cancer therapy

ESTRO
European Society for
RADIOTHERAPY
& ONCOLOGY

BBMRI-ERIC®
Biobanking and
BioMolecular resources
Research Infrastructure

ECCO

European Alliance for
Personalised Medicine

CDDF
Cancer Drug Development Forum

eau
European
Association
of Urology

- Formal collaboration in progress
- Formal collaboration signed

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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

EUROPEAN CANCER PATIENT COALITION

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**
  - European Cancer Patients Bill of Rights (2015): launch at the EP with previous Health Commissioner
  - EU Regulation 726/2004 AMENDED
  - Access to medicines report AMENDED 2017

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Survivorship

Objectives	ECPC Actions
• Fight the stigma • Promote Survivorship Care Plans • Cancer is a public health emergency AND a socio-economic one	• CanCon recommendations on survivorship • ECPC-ESMO Guide on Survivorship

Inequalities and innovation

Objectives	ECPC Actions
• Fight the ***unacceptable inequalities*** in access to quality care • Fight the ***delays in access to meaningful innovative drugs*** • Make ***cancer care sustainable***	• CanCon recommendations on inequalities and disinvestment • ECPC Value of Innovation White Paper • ECPC work on Health Technology Assessment • ECPC contribution to the INI report on access to medicines • ECPC contribution to the WHA resolution

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

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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

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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

BD4BO	BenchCan	Cancer A. Academy
ERN-EURACAN	eSMART	EurocanPlatform
H2020MM04	IMMUNOSABR	InSup-C
JARC	PREFER	RARECARENet
TRANSCAN 2		

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www.imi-prefer.eu

prefer.

PATIENT PREFERENCES

This work has received support from the EU/EFPIA Innovative Medicines Initiative [2] Joint Undertaking PREFER grant n˚ 115966.

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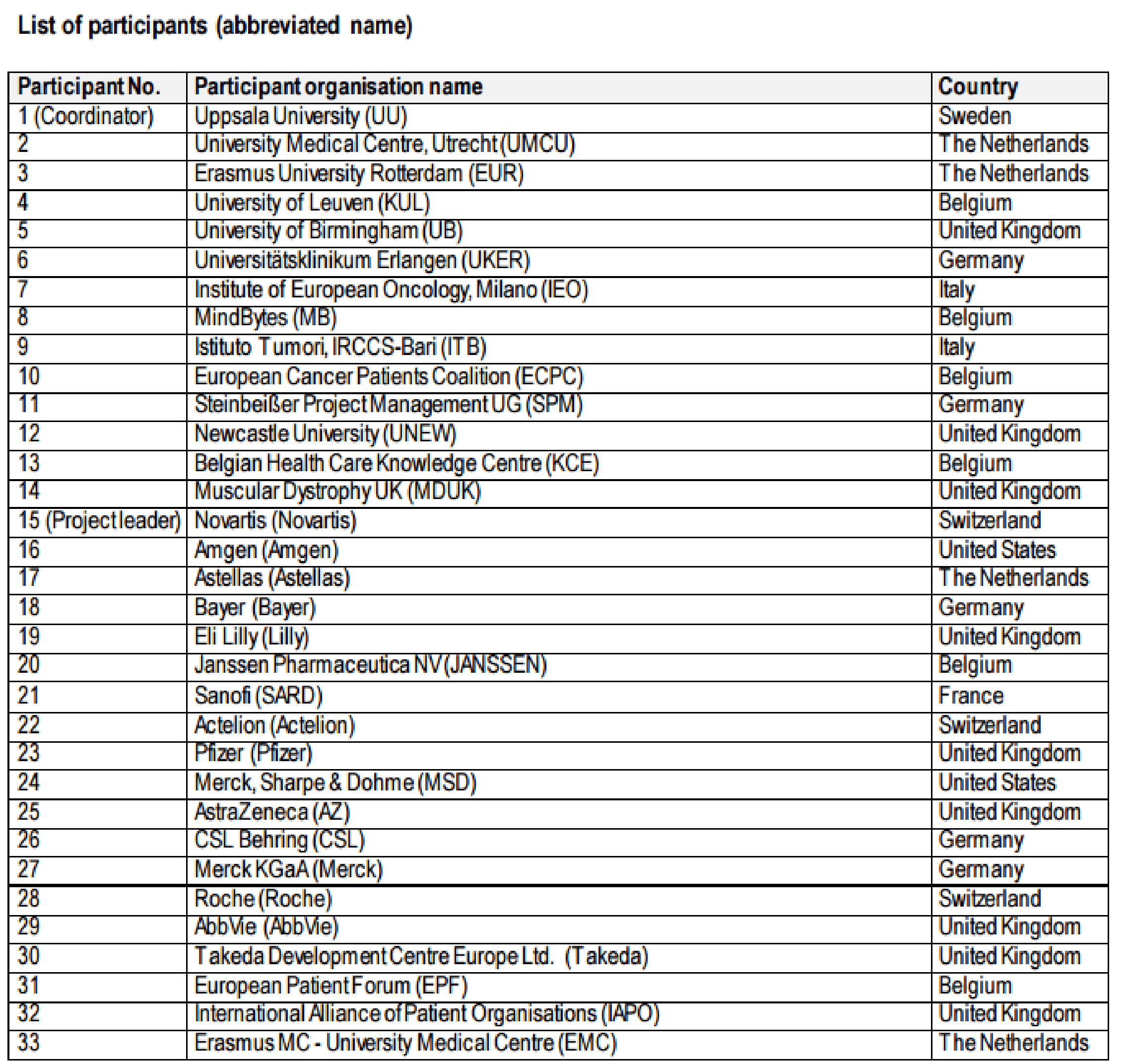
PREFER

- 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

PREFER



List of participants (abbreviated name)

Participant No.	Participant organisation name	Country
1 (Coordinator)	Uppsala University (UU)	Sweden
2	University Medical Centre, Utrecht (UMCU)	The Netherlands
3	Erasmus University Rotterdam (EUR)	The Netherlands
4	University of Leuven (KUL)	Belgium
5	University of Birmingham (UB)	United Kingdom
6	Universitätsklinikum Erlangen (UKER)	Germany
7	Institute of European Oncology, Milano (IEO)	Italy
8	MindBytes (MB)	Belgium
9	Istituto Tumori, IRCCS-Bari (ITB)	Italy
10	European Cancer Patients Coalition (ECPC)	Belgium
11	Steinbeißer Project Management UG (SPM)	Germany
12	Newcastle University (UNEW)	United Kingdom
13	Belgian Health Care Knowledge Centre (KCE)	Belgium
14	Muscular Dystrophy UK (MDUK)	United Kingdom
15 (Project leader)	Novartis (Novartis)	Switzerland
16	Amgen (Amgen)	United States
17	Astellas (Astellas)	The Netherlands
18	Bayer (Bayer)	Germany
19	Eli Lilly (Lilly)	United Kingdom
20	Janssen Pharmaceutica NV (JANSSEN)	Belgium
21	Sanofi (SARD)	France
22	Actelion (Actelion)	Switzerland
23	Pfizer (Pfizer)	United Kingdom
24	Merck, Sharpe & Dohme (MSD)	United States
25	AstraZeneca (AZ)	United Kingdom
26	CSL Behring (CSL)	Germany
27	Merck KGaA (Merck)	Germany
28	Roche (Roche)	Switzerland
29	AbbVie (AbbVie)	United Kingdom
30	Takeda Development Centre Europe Ltd. (Takeda)	United Kingdom
31	European Patient Forum (EPF)	Belgium
32	International Alliance of Patient Organisations (IAPO)	United Kingdom
33	Erasmus MC - University Medical Centre (EMC)	The Netherlands

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

prefer.

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

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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

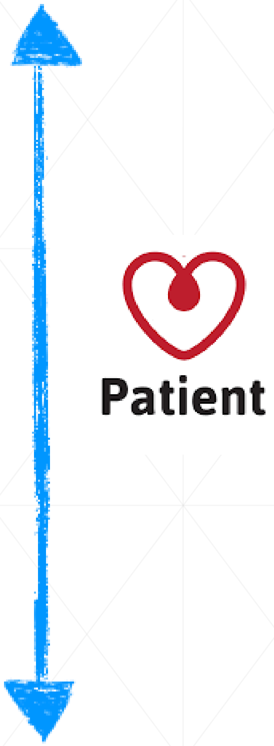
JARC' which has received funding from the European Union's Health Programme (2014-2020)

Coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan (Italy)

Dissemination by School of Medicine, National and Kapodistrian University of Athens, Greece

JARC Work packages

WP number	WP name
1	Coordination
2	Dissemination
3	Evaluation
4	Epidemiology
5	Assuring Quality of Care
6	Clinical practice guidelines
7	Innovation and access to innovation
8	Medical education
9	Childhood Cancers
10	Rare Cancer Policy



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European Reference Networks

JARC
JOINT ACTION ON RARE CANCERS

EUROPEAN CANCER PATIENT COALITION


BETTER CARE & DIAGNOSIS
NEW TREATMENTS
BETTER DATA
CAPACITY BUILDING
GENERATE EVIDENCE
EQUAL ACCESS
ECONOMY OF SCALE

EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES
Share. Care. Cure.

European Reference Networks

European Commission | Health


FACTS

FOCUS ON

Associated Partners

Collaborating Partners

PUTTING PATIENT CARE FIRST

EU Joint Action on Rare Cancers (JARC)

"The final goal of the Action will be to contribute to improve health outcomes for patients with rare cancers and to decrease health inequalities for rare cancer patients across Europe".
- Commissioner Vytenis Andriukaitis

www.jointactiononrarecancers.eu

- 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**.

JARC' which has received funding from the European Union's Health Programme (2014-2020)

Coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan (Italy)

Fondazione IRCCS Istituto Nazionale dei Tumori
Sistema Socio Sanitario Regione Lombardia

Dissemination by School of Medicine, National and Kapodistrian University of Athens, Greece

JARC

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.

24 European Reference Networks

- 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

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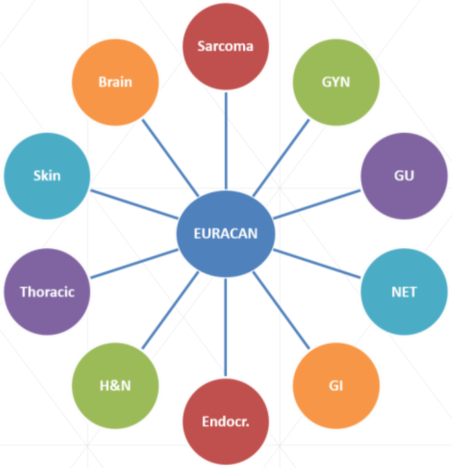
ERN-EURACAN

- 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.

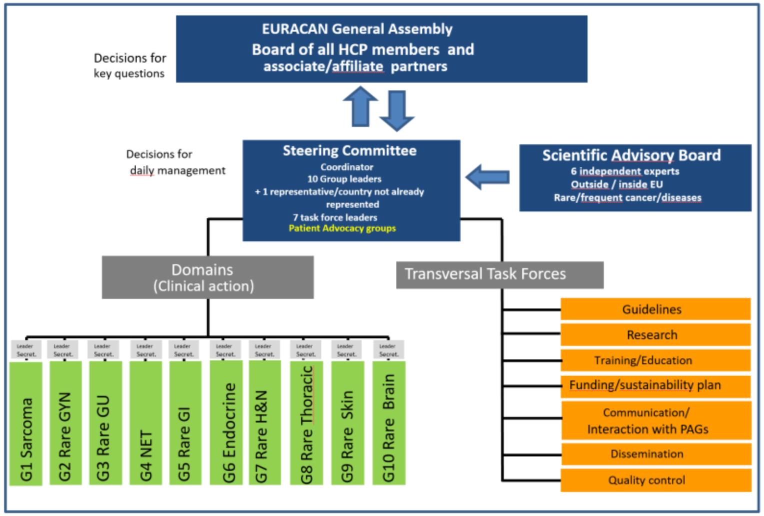
European Reference Networks



EURACAN

European network for Rare adult solid Cancer

Patient



Decisions for key questions

EURACAN General Assembly
Board of all HCP members and associate/affiliate partners

Decisions for daily management

Steering Committee
Coordinator
10 Group leaders
+ 1 representative/country not already represented
7 task force leaders
Patient Advocacy groups

Scientific Advisory Board
6 independent experts
Outside / inside EU
Rare/frequent cancer/diseases

Domains
(Clinical action)

- G1 Sarcoma
- G2 Rare GYN
- G3 Rare GU
- G4 NET
- G5 Rare GI
- G6 Endocrine
- G7 Rare H&N
- G8 Rare Thoracic
- G9 Rare Skin
- G10 Rare Brain

Transversal Task Forces

- Guidelines
- Research
- Training/Education
- Funding/sustainability plan
- Communication/ Interaction with PAGs
- Dissemination
- Quality control

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

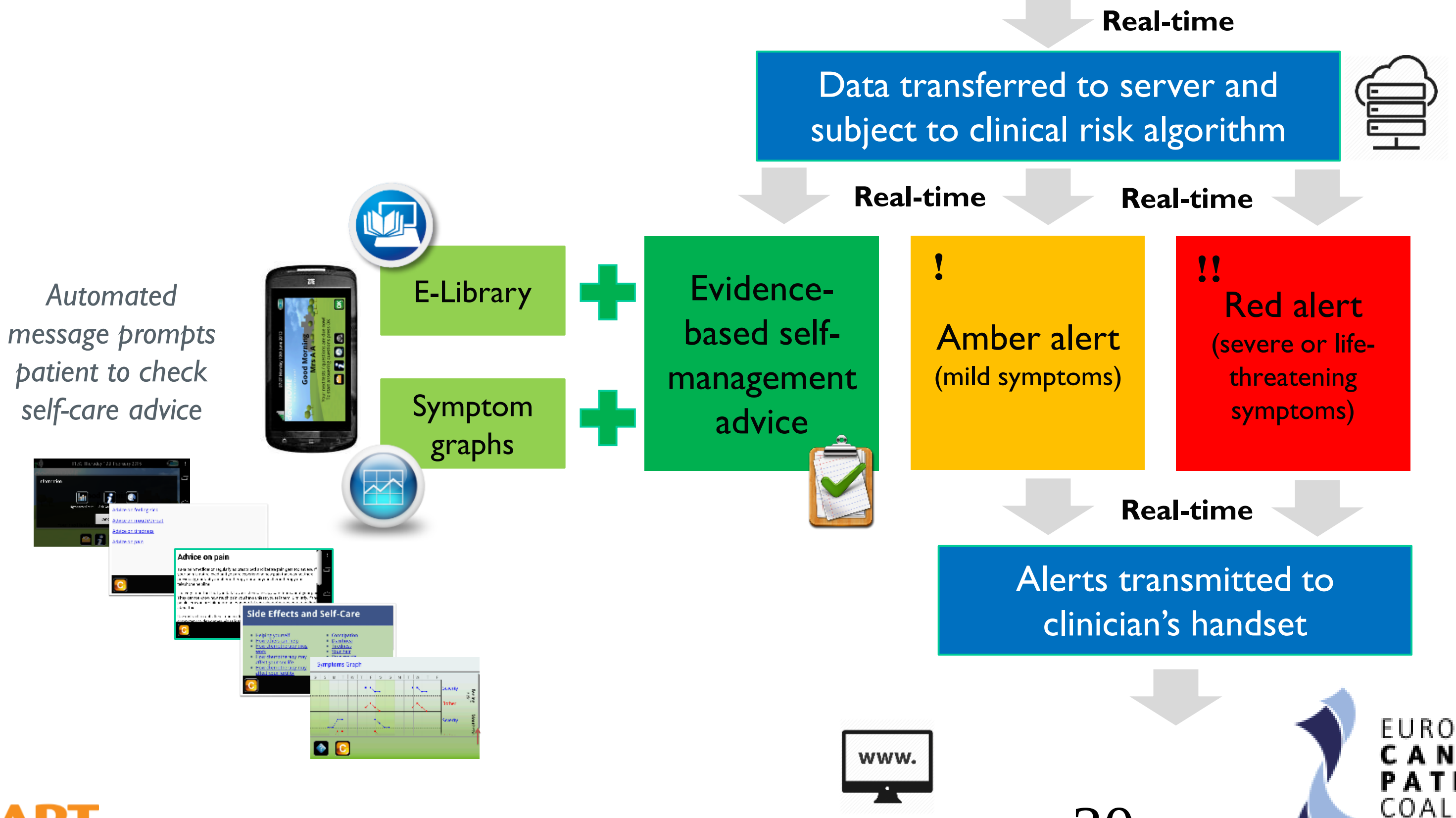
IMMUNOSABR

a combination of immunotherapy and stereotactic ablative radiotherapy

- 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 immuno-oncology 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



Automated message prompts patient to check self-care advice

Real-time

Data transferred to server and subject to clinical risk algorithm

Real-time

Real-time

E-Library

Symptom graphs

Evidence-based self-management advice

! Amber alert (mild symptoms)

!! Red alert (severe or life-threatening symptoms)

Real-time

Alerts transmitted to clinician's handset

eSMART

EUROPEAN CANCER PATIENT COALITION

Thank for your attention

Francesco De Lorenzo
President

European Cancer Patient Coalition

@cancereu

European Cancer Patient Coalition

ECPCtv

Nothing About Us Without Us

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