EUROPEAN
CANCER
PATIENT
COALITION

European Cancer Mission – **Patients' Involvement**

October 3, 2018

Prof. Francesco de Lorenzo, ECPC President

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Who are we?

- **ECPC is the largest European cancer patients' umbrella organisation.**
- Representing more than 400 organisations in 46 EU and non-EU countries.
- **Our 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.

Advocacy

Position papers
Policy
Awareness

Capacity-Building

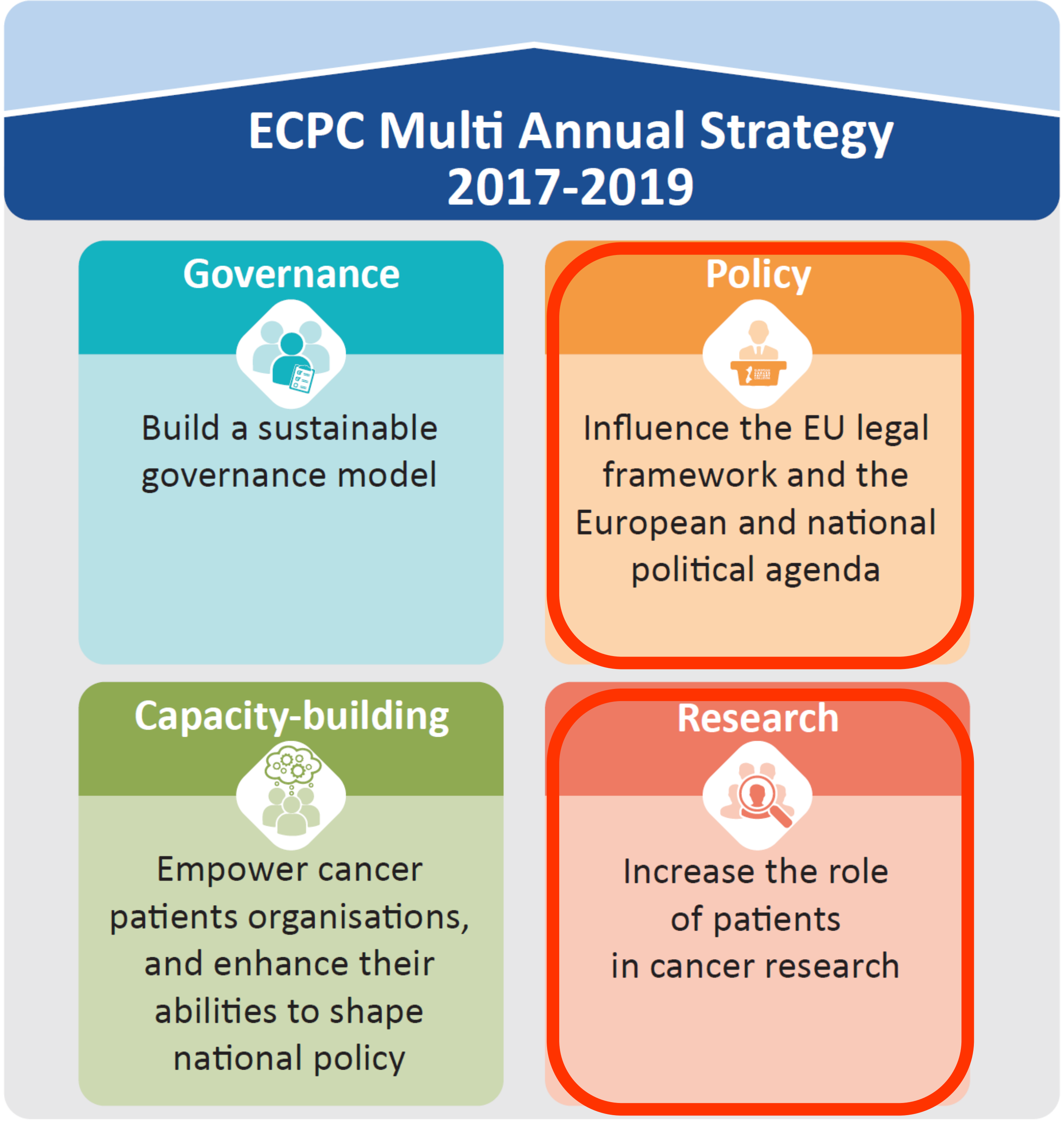
Working groups
Education
Annual Congress

Research

IMI PREFER
FP7 eSMART

Partnerships

iPAAC
EMA
ESMO



ECPC Multi Annual Strategy
2017-2019

Governance

Build a sustainable governance model

Policy

Influence the EU legal framework and the European and national political agenda

Capacity-building

Empower cancer patients organisations, and enhance their abilities to shape national policy

Research

Increase the role of patients in cancer research

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

The Voice of Cancer Patients in Europe

Trusted partner in Policy and Research

European Cancer Patient Coalition’s Activities

CAPACITY BUILDING

POLICY

PARTNERSHIPS

RESEARCH

BenchCan
BD4BO > Do-IT
ELBA
eSMART
EuroCan Platform
H2020MM04
Insup-C
IMMUNASIA
IMMUNOSABR
Nutrition
PIONEER
PREFER
RareCAREnet

Members of the EC Expert Group on Cancer Control
Members of the European Initiative on Breast Cancer
Health policy Forum
EMA’s Patients’ and Consumers’ Working Party

BBMRI-ERIC
CANCON
Cancer Core Europe
CDDF
ECC
EORTC
ESMO
UICC
EAPM
ECCO
ESSO
OECI
WIN Consortium

EURACAN
JARC

ECPC's key partnerships

ESMO

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

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ECPC - a strong partner in science

EACS
EUROPEAN ACADEMY
OF CANCER SCIENCES

Science Policy Committee Member
Independent advisory body of eminent oncologists and cancer researchers, placing science at the core of policies to sustainably reduce the burden of cancer in Europe. The Science Policy Committee identifies issues that are of importance to the cancer community and provides evidence-based advice to implement policies and responds to consultations from high-level advisory bodies.

Cancer Core
Europe

Board Member
European cancer association of leading cancer centres carrying out innovative research propelling cancer medicine into a new era. Cancer Core Europe's efforts pave the way for a multi-site cancer institute, which will drive the development of new treatments and earlier diagnoses for patients and more effective cancer prevention for Europe's citizens.

CDDF
Cancer Drug Development Forum

Board Member
International non-profit organisation providing a platform for all stakeholders involved in the development of oncology drugs, which works to accelerate the delivery of effective oncology therapies to patients.

WIN

General Assembly Member
The Worldwide Innovative Networking (WIN) Consortium in personalized cancer medicine represents a global collaboration of cancer centers, life science and biotech organizations, pharmaceutical and technology companies, health plans, and not-for-profit organizations. It is focused on delivering promise of effective, personalized cancer medicine to patients worldwide.

ECPC: the voice of cancer patients in Brussels and a partner of EU institutions

European Medicines Agency

- Patients' and Consumers' Working Party

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 Parliament

- 4th February 2015 Declaration: 160 signatures
- 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)
- WHA resolution AMENDED (2017)

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EU Research and Innovation Action

- The European Commission states in January 2017 for the published IMI 2 Call 10: ‘There is a **growing body of evidence showing that patient-stakeholder engagement** at key decision points throughout the medicines life cycle **can drive better innovation and process efficiency and quality**. Processes and outcomes become more relevant to individual patients, patient groups, healthcare consumers in general and society at large when they are based on a mutual understanding between patients, other healthcare stakeholders and manufacturers about their respective needs.’

- Many initiatives have recently started to focus on **bringing the patient closer to the centre of medicines development, authorization and reimbursement processes** in the EU.

- This presents **an opportunity to advance patient engagement** and make it more meaningful, systematic and effective.

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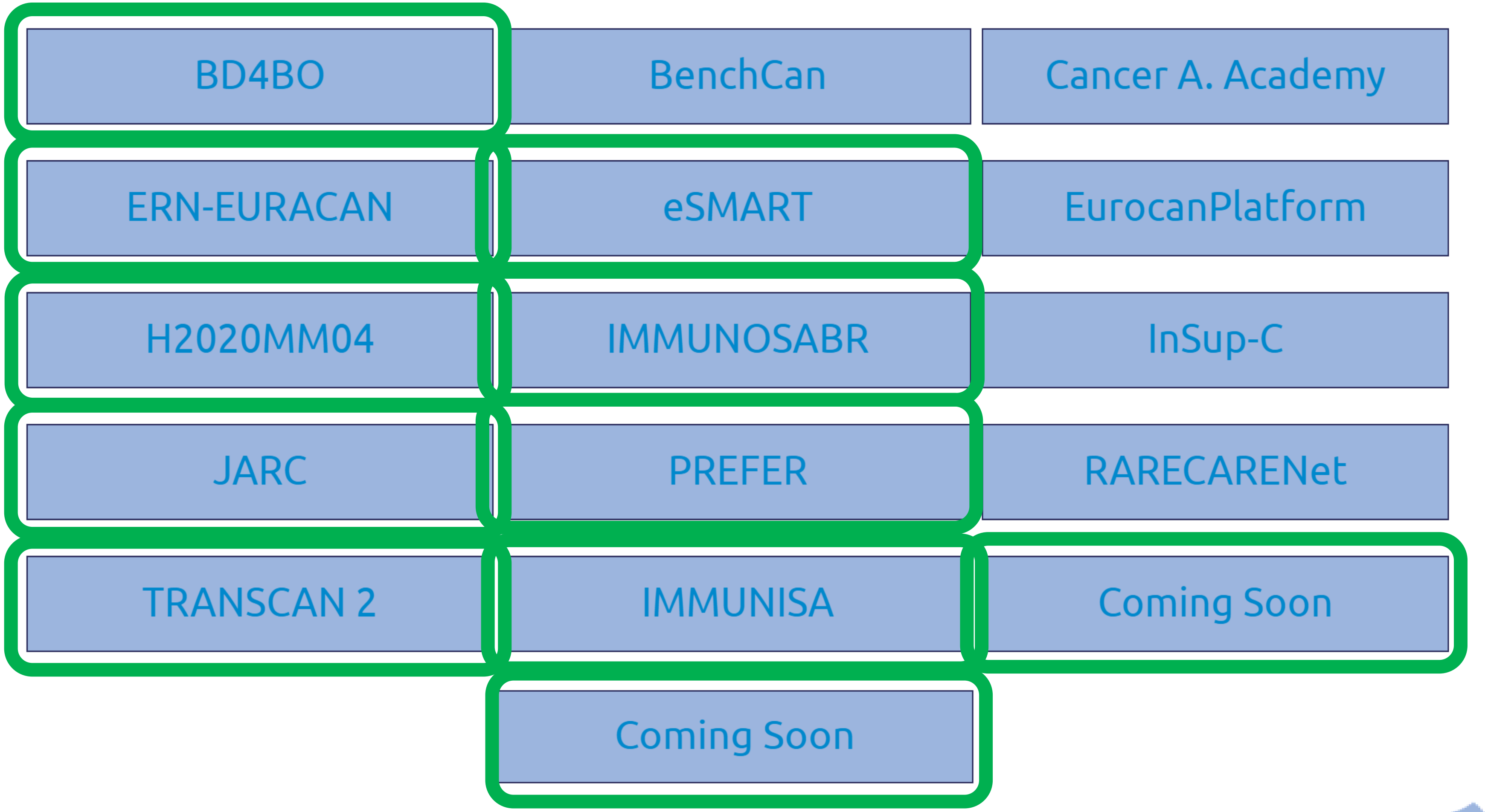
European Cancer Patient Coalition work in RESEARCH

ECPC is **one of the few cancer patient organisation actively involved in the design and implementation of EU funded research projects**, among other ongoing activities.

The European Cancer Patient Coalition participates in several European Union's Research and Innovation framework programmes: this includes **IMI 1** projects, the **Seventh Framework Programme (FP7)** and **IMI 2** projects under the current **Horizon 2020 (H2020)**.

ECPC emphasises the importance of **involving patients as co-researchers, involved in defining research priorities and patient preferences regarding their treatment** and strongly a**dvocates for the best partnership model** between both researchers and patients, allowing patients to contribute their unique experience working towards a more patient-centric study while participating in crucial project decisions. ECPC through its programs offers capacity building to its membership for understanding the patient experience role in clinical trials and research programs

ECPC RESEARCH Projects



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

- **Ongoing Projects**

Patient

This research is supported by the EU/EFPIA Innovative Medicines Initiative [2] Joint Undertaking PREFER grant n° 115966.

imi innovative medicines initiative

efpia

PREFER is funded by the Innovative Medicines Initiative (IMI): a part of the EU Horizon 2020 Programmme, Grant Agreement N° 115966.

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prefer.
PATIENT PREFERENCES

- **Patient Preferences in Benefit-Risk Assessments during the Drug Life Cycle** (PREFER is a five-year project funded by the **European Commission's Innovative Medicines Initiative (IMI) 2 programme** to **evaluate different ways of assessing clinical patient preferences**.

- The project will **establish recommendations to support development of guidelines for industry, Regulatory Authorities and HTA bodies** on **how and when to include patient perspectives** on benefits and risks of medicinal products.

- The project has been structured with **equal leadership and participation** between patients, academia, and industry in all areas of the project, underlining the collaborative and inclusive approach that guides our work.

- **The research project will run from October 2016 to September 2021.**

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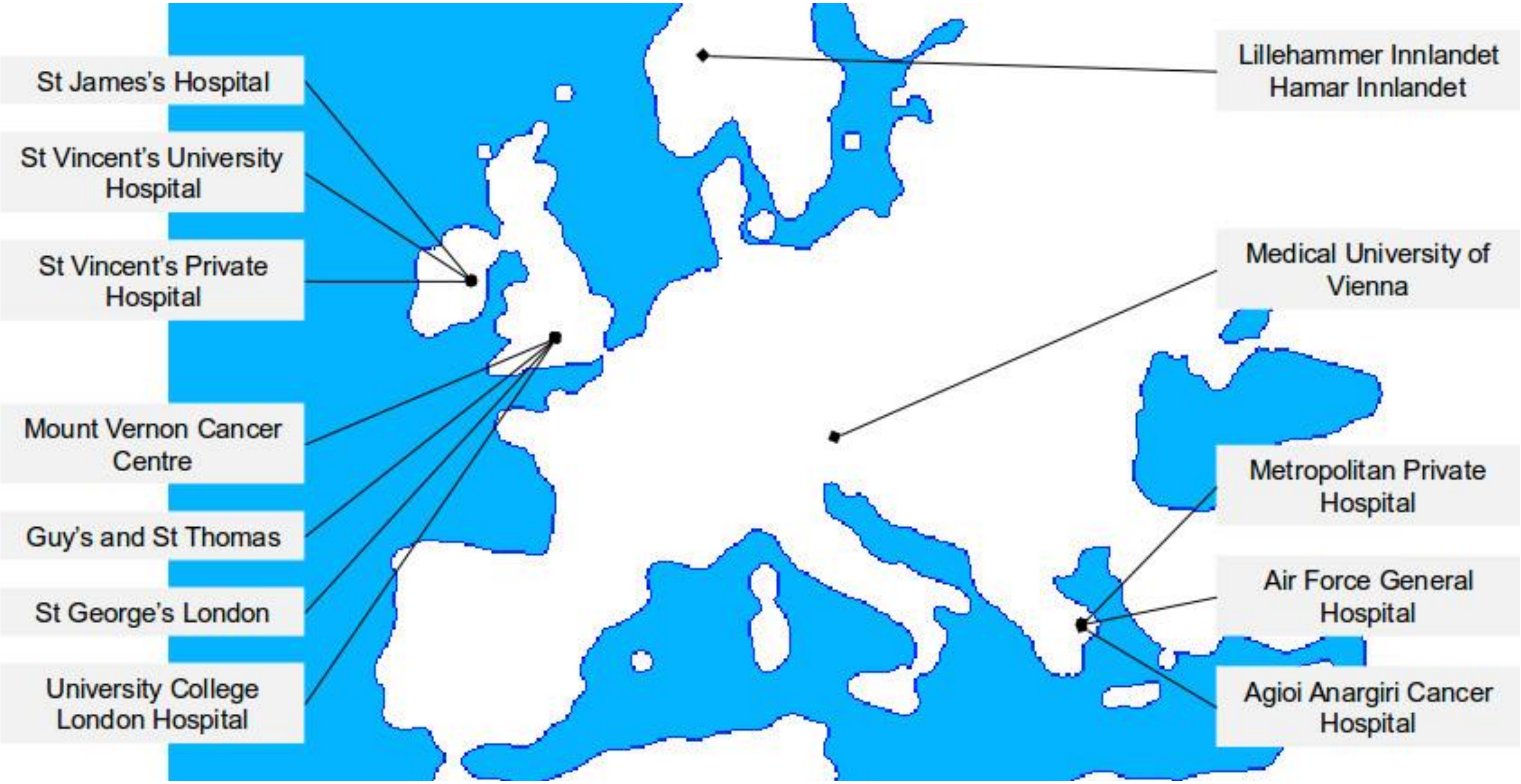
- The e-Symptom Management using Advanced Symptom Management System Remote Technology (**eSMART**) is funded by the European Commission's **Seventh Framework Programme.**

- The clinical trial aims to **evaluate the impact of a mobile phone-based**, **remote monitoring**, **symptom management intervention** (Advanced Symptom Management System, ASyMS) **on the delivery of care to people diagnosed with non-metastatic breast, colorectal or hematological cancer** **during chemotherapy and for one year after treatment**.

- **Patients have a prominent co-researcher role in eSMART** and participate in all project activities from project concept to implementation. ECPC, in its patient representative role**, participates equally with other researchers within the eSMART** Project Technical Management Board, the Publications Committee, and the Exploitation Committee**, offering advice and feedback to** ensure that the trial is designed and conducted in line with patients' needs and preferences.

- **The research project will run from February 2014 to January 2019.**

eSMART is being conducted across **12 sites in Europe**: Greece, UK, Ireland, Austria, Norway recruiting 1108 cancer patients.



Patient

eSMART

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JOINT ACTION ON RARE CANCERS

on Rare cancers (JARC)

- The **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 European Reference Networks (ERNs).**

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

European
Reference
Networks

European Commission | Health

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Working Group on Rare Cancers (WGRC)

- **ECPC counts on the expertise and collaboration of rare cancer patient organisations all over Europe to continuously represent the rare cancer patient community.**
- ECPC **has established** the WGRC **operating in parallel** with the JARC, in order to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, are contributing to the activities of the Joint Action: currently the WGRC hosts **65 member organisations**.
- ECPC is **building on experience** gained during its 3 years collaboration in **RARECAREnet** project.

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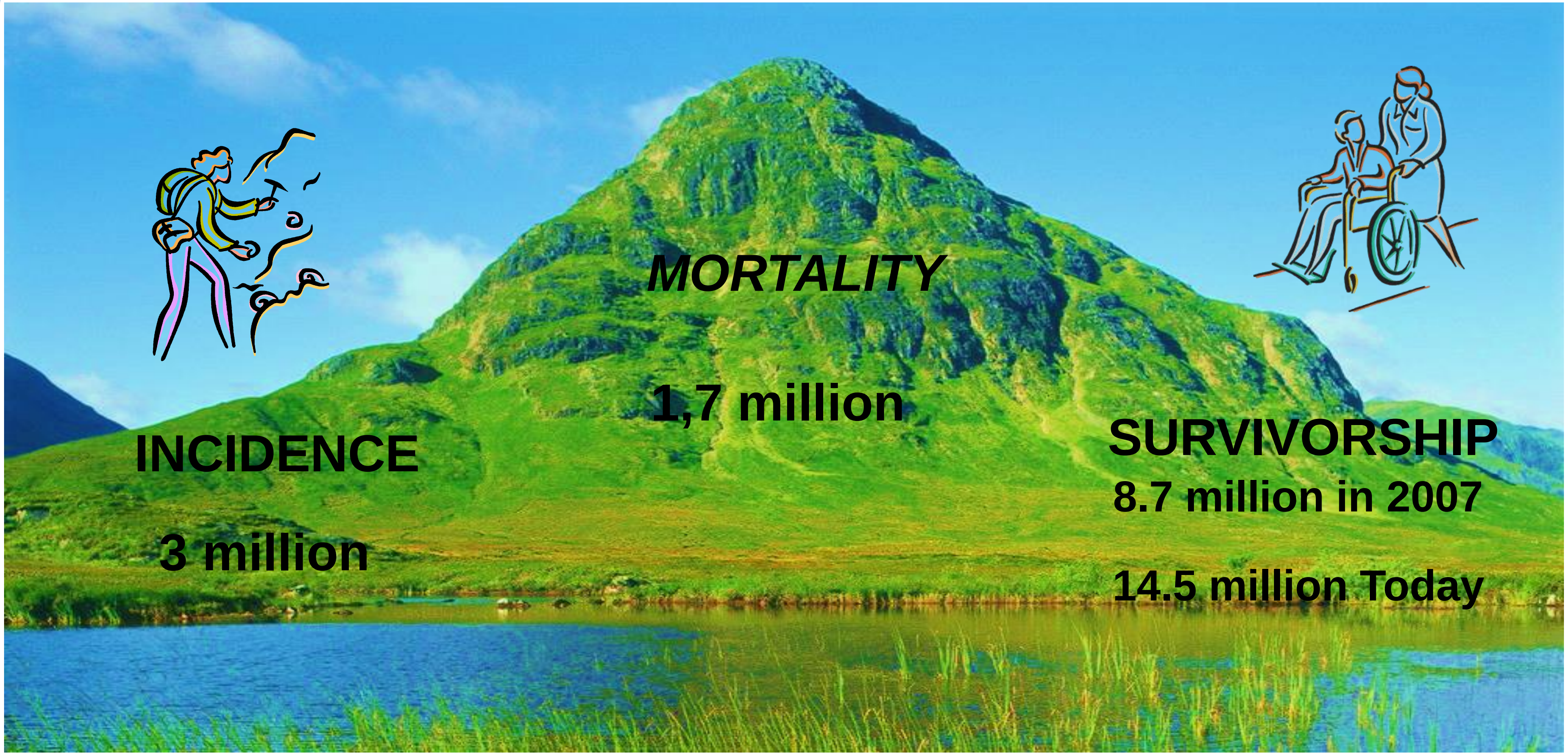
The Numbers of Cancer



INCIDENCE

3 million

MORTALITY

1,7 million

SURVIVORSHIP

8.7 million in 2007

14.5 million Today

Sources:
EURACAN 2015
Ferlay J, Steliarova-Foucher E, Lortet-Tieulent J, et al: Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. Eur J Cancer 49:1374-403, 2013
S. Rossi, P. Baili, R. Capocaccia, M. Caldora, E. Carrani, P. Minicozzi, D. Pierannunzio, M. Santaquilani, A. Trama, C. Allemani, A. Belot, C. Buzzoni, M. Lorez, R. De Angelis, EUROCARE-5 Working Group, The EUROCARE-5 study on cancer survival in Europe 1999-2007: database, quality checks and statistical analysis methods, Eur. J. Cancer Oxf. Engl. 1990. (2015). doi:10.1016/j.ejca.2015.08.001.
Parry C, Kent EE, Mariotto AB, et al: Cancer survivors: a booming population. Cancer Epidemiol Biomarkers Prev 20:1996-2005, 2011
Ferlay J, Shin HR, Bray F, et al: Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. Int J Cancer 127:2893-917, 2010

CanCon WP8: Placing survivorship cancer plans on EU policy agenda

European Commission’s Joint Action on Cancer Control

- Developed recommendations for high-quality survivorship care and rehabilitation:
  - ✓ a **European framework for high-quality cancer survivorship care and rehabilitation** that could be promoted at EU level
  - ✓ tools, **a European "distress barometer", and personalised rehabilitation and survivorship care plan**.
- The recommendations address the following:
  - ✓ deals with all fields across the cancer control continuum from clinical guidance to psychological and social rehabilitation
  - ✓ takes into account patients' status (patient’s reported outcomes-PROs)
  - ✓ includes subsequent policy recommendations, which take care of the feasibility and acceptability of recommendations by all MS and associated countries, and have a **special focus on employment issues.**
- **CanCon is a milestone for all European cancer patients** because of the arguments that the European Cancer Patient Coalition brought forward . Many of the in the final Guide and policy papers contents come directly from the people fighting against cancer every day, and we can proudly say that CanCon achievements are also the achievements of the European cancer patient community

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CanCon: perspectives in survivorship and rehabilitation cancer research

- The literature shows that more data are needed concerning the different components of survivorship care.
- A number of studies published in the decade have discussed the need to categorise patients and have also introduced the “cured” category, in which there is no measurable difference in terms of survival compared to the general population.

- **The main unanswered issues are:**
  - ✓the impact of clinical follow-up on medical outcomes in a wide-range of cancers
  - ✓the clinical, biological and cellular mechanisms of late-effects
  - ✓the impact of supportive care and psychological support on quality of life (short and long term) survival, return-to-work
  - ✓the long-term impact of education programmes
  - ✓the long-term follow-up of adults surviving a childhood cancer,2 even 10, 20 and 30 years after end of treatment.
  - ✓the determinants of cancer inequalities linked to survivorship and
  - ✓the impact and management of comorbidities and other health care disparities.
  - ✓Furthermore, there is need for research networks and collaboration to initiate innovative clinical trials, such as intervention trials or RCTs.

Survivorship Plans and ESMO-ECPC Patient Guidelines

- In 2017, the CanCon Joint Action published policy **recommendations for survivorship care** plans in the European Guide The European Guide on Quality Improvement in Comprehensive Cancer Control.

- The first practical implementation of these recommendations was the **"Patient Guide on Survivorship",** produced by the European Society for Medical Oncology in collaboration with the European Cancer Patient Coalition.

- This was the first time that the **European Society for Medical Oncology** recognised the need for a cancer survivorship guide. The guide is a bridge between the oncologist and the general practitioner, and **empowers the cancer patient** and their carers to ask the right questions when planning follow-up care.

- It includes a section on **cancer rehabilitation** and timely detection, management and treatment of tumour-related symptoms, as well as use of a **survivorship care** plan that people with cancer can use in collaboration with their healthcare team in order to facilitate continuous care and the return to a normal life.

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- Increasing interest in cancer survivorship during recent years: Journal of Cancer Survivorship, survivorship conferences organised in recent years, the CanCon survivorship and rehabilitation policy recommendations, the iPAAC work package on cancer information and registries, and collaborative research initiatives such as that of the EORTC for the development of new survivorship measures

- Cancer survivorship research needs greater attention and acknowledgement in the scientific literature.

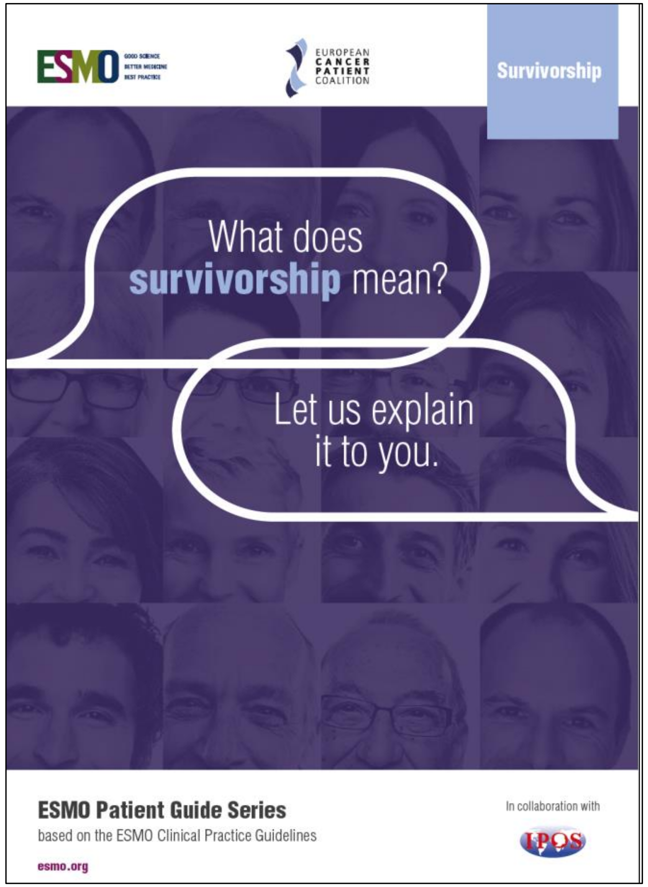
- Compared to all other areas of cancer research, the publication of high quality research on cancer survivorship is still lacking.

- This lack of high quality publications is associated with the scarce resources allocated by national or international bodies for observational studies on cancer survivorship.

- In fact, much less funding and fewer calls are dedicated to observational clinical studies, compared to experimental studies or basic research.

- A dedicated framework for these issues will contribute to fulfil the needs of a vastly growing population of cancer survivors.
-

Patient Guide on Survivorship – transferring policy recommendations into concrete action



ESMO
GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

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Survivorship

What does survivorship mean?

Let us explain it to you.

ESMO Patient Guide Series
based on the ESMO Clinical Practice Guidelines
esmo.org

In collaboration with
IPOS

- **Aimed at:** (1) post treatment cancer survivors having no disease after treatment, or (2) continue to receive treatment to reduce the risk of relapse, and (3) people with well controlled disease and few symptoms, who receive treatment to manage cancer as a chronic disease.
- **Why?:** To regain (1) the important aspects of a patients' life before cancer, and (2) to find new pathways to a satisfactory life going forward.

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Survivorship

- Survivorship is a ticking bomb: more than 7 million Europeans survive the disease for more than 5 years since diagnosis, but almost all EU countries do not have sufficient policies in place to ensure that these citizens receive appropriate physical, psychological, sexual, nutritional rehabilitation, or can return to work, or access loans, mortgages and health insurances.

- Returning to work is also difficult for many cancer survivors, with one recent global survey reporting that more than one-third of employers described concerns about workplace discrimination against cancer survivors.

- Cancer patients often face workplace discrimination and even loss of employment, leading to financial and social burdens

Conclusions

- Innovative cancer research was instrumental to better cancer care and survivorship
- Patients have an undeniable role in scientific research
- There is a long way to go to achieve patient centricity and the role of the patient in decision-making
- It is essential that the vital role that patients and patient organizations play in the decision-making process is acknowledged by formalizing the participation of patients
- Patient organisations help to enlarge and formalise the patient voice into cancer policy recommendations
- The existing alliances that ECPC has with scientific societies means that all stakeholders can work together in a patient-centric manner, using CanCon as a roadmap to implement national cancer care plans and translating policy into practice.

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