



# EUROPEAN CANCER PATIENT COALITION

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Director of ECPC

***ECPC position on pain and cancer***

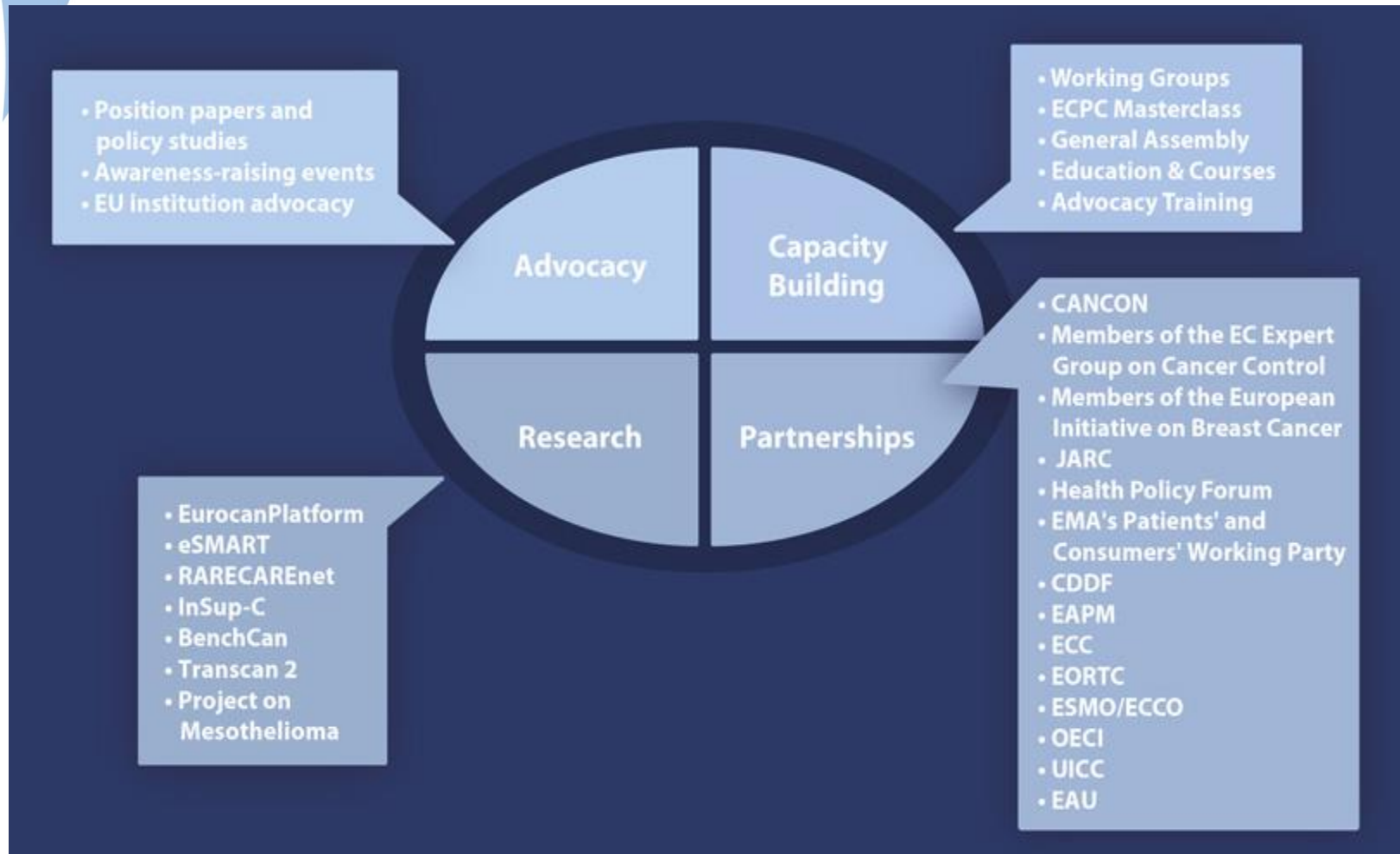
European Parliament, 23 May 2016



# ECPC: "Nothing about us, without us!"

- **Representing 402 cancer patient organisations in 46 countries**
- **All cancers** are represented - common and rare
- **Run and governed by patients**
- Providing decision makers with first hand patient experience
- Raising awareness about initiatives affecting cancer patients

# European Cancer Patient Coalition's Activities



# Introduction

Cancer supportive care in most countries is not included in standard cancer care and is often delivered by patient organisations.


Almost all ECPC members offer psycho-social support services to patients and families.

ECPC believes that every citizen must have access to pain relief and palliative care to ensure that each day is lived as fully as possible until the very end.

# Integrate palliative care and oncology

- Palliative care is an essential pillar of cancer care that should be introduced early after diagnosis.
- Early integration of palliative care improves quality of life and ensures longer survival (*Temel, Metastatic non-small-cell lung cancer patients*)
- **Opportunity:**
- **The Cancer Control Joint Action (CanCon), WP 6 Integrated Cancer Control.**

# Heterogeneous care models with a shared objective

Healthcare providers need to adapt as patients move through their illness  to foster autonomy

A role for different players to promote palliative care:



For Member States to decide on the best way to deliver palliative care



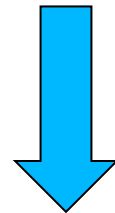
For the EU to ensure a consistent and high quality palliative care within the Union



For stakeholders to monitor the implementation Cross Border Directive. Palliative care an example to assess the quality of care in different countries, identify gaps and make concrete proposals for improvement.

# Monitoring the implementation of the Cross-Border Healthcare Directive

**Article 8 paragraph 5** of the Cross-Border Healthcare Directive foresees that **an objective assessment of ‘the degree of the patient’s pain’ must be used to assess the right to cross-border healthcare.** Indicators are therefore needed in member states to set criteria for granting access to cross-border healthcare and to compare the quality of health care services available to citizens, consumers and patients.



**A working group to help the European Commission with data?**

# Research Funding

**Significant lack of funding – only about 1% of overall NIH research funding**

- **OPCARE9:** EU's 7<sup>th</sup> Framework funded Project meant to optimise research for care of cancer patients in the last days of life.
- Further research to look at care models to integrate palliative care and oncology earlier to the benefit of patients.

**Opportunity: palliative care and pain control to be a priority in Horizon 2020.**



# More research in palliative care needed

**In-Supp:** best methods to deliver care to patients with advanced cancer, heart failure or lung disease as they come **towards the end of their lives.**



**eSMART:** how **mhealth technology** can be instrumental in the delivery of patient focused, **anticipatory care** that improves the outcomes & quality of life of cancer patients during chemotherapy.

# A well trained workforce

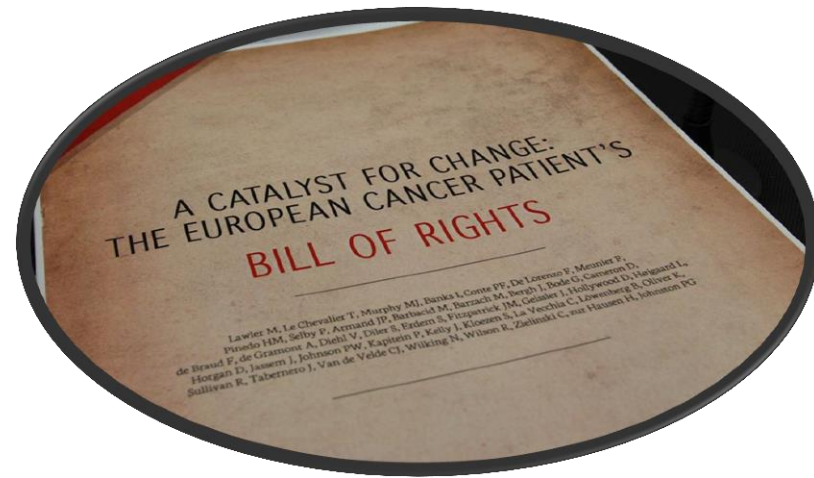


- EU MS should follow [WHO recommendation](#) (2004) to include palliative care in training curricula for health workers at all levels.
- Support [EAPC approach](#) to palliative care training: **general** and **specialist level**.

# Access to opioids

- Access to opioids is not uniform in all EU countries.
- Objective: Access to opioids, together with accompanying care should be granted to all patients in need.
- **Action: ECPC is setting up a Working Group among its member associations to understand barriers to access opioids and suggest solutions.**

# A patient right



ECPC recognises the right of every European citizen to access palliative care and pain management through the continuum of care – **Article 3** of the **European Cancer Patients' Bill of Rights**.

# A labour right

- ECPC has joined the campaign “Dying to Work” promoted by MEP Glenis Willmott.
- Calls for terminal illness to be recognised as a ‘protected characteristic’.
- An employee with a terminal illness could not be dismissed as a result of their condition.



***Thank you for your attention***

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**European Cancer Patient Coalition**



**ECPCtv**

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