EUROPEAN
CANCER
PATIENT
COALITION

The added value of ECPC policy work

Francesco De Lorenzo

ECPC Annual General Meeting

Brussels, 19th June 2015

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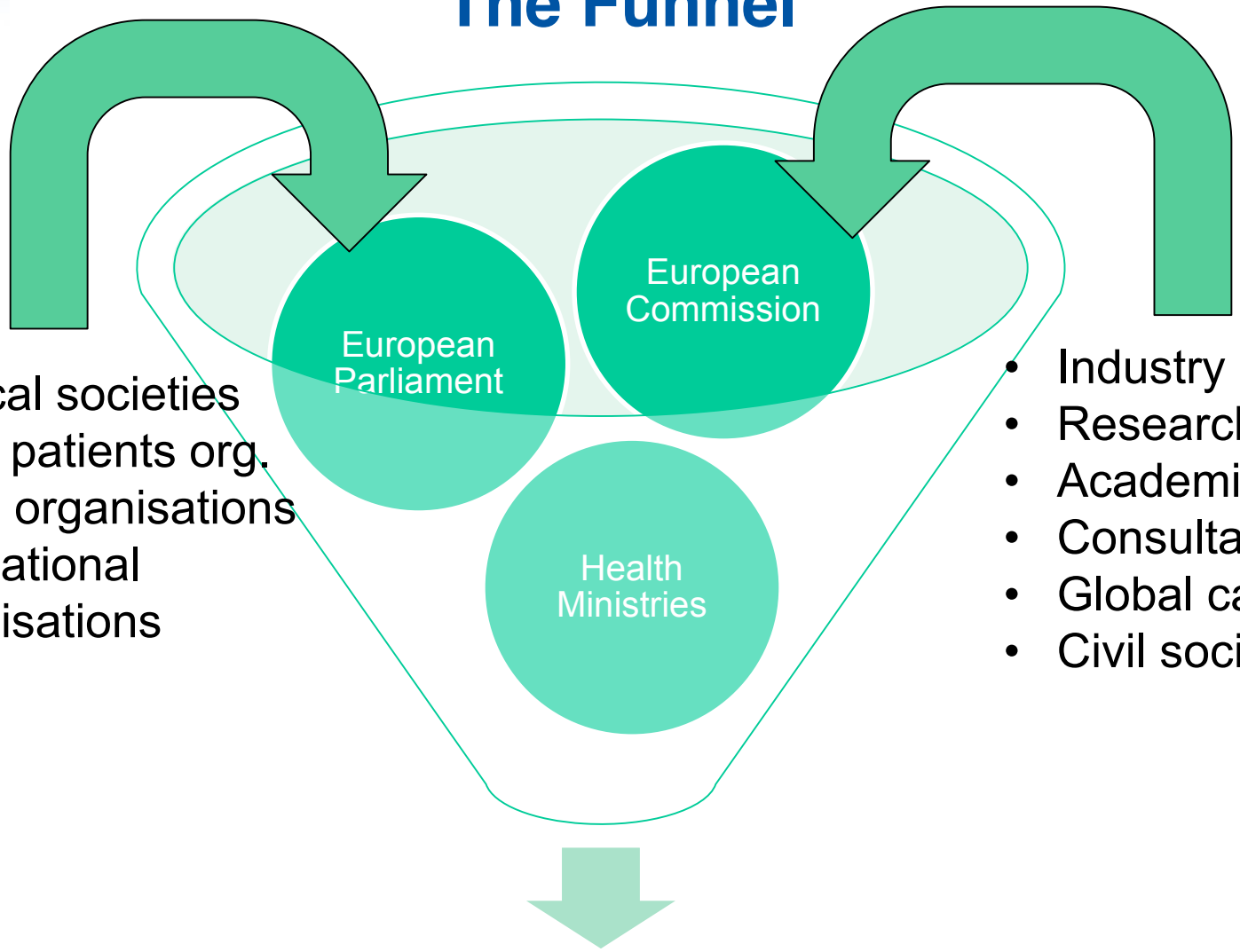
The Funnel



- Medical societies
- Other patients org.
- Trade organisations
- International organisations

- Industry
- Researchers
- Academia
- Consultancies
- Global campaigns
- Civil society

EU Policies

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How can cancer patients influence European policy making?

The power of credibility

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First things first: the power of credibility

- **European**
  - ECPC has a **specific geographical scope**: covers the need of the more than 10 million cancer patients across Europe
  - **Interacts directly with the European Institutions**
- **Cancer**
  - It is the **first killer in 17 out of 28 Member States**
  - The **incidence is on the rise**, due to ageing population
- **Patient**
  - **Half of the ECPC Board** must be a cancer **patient** or a **survivor**
  - Same rule applies for ECPC Members
- **Coalition**
  - ECPC brings together **364 cancer patients organisations**: **we are Europe largest cancer patients association**

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Credibility = TRUST
ECPC as a partner of EU institutions

European Commission's Expert Group on Cancer Control

- Created to advise the Commission on cancer-related policies
- Kathi Apostolidis and I represent ECPC
- Representatives from all member states Health authorities
  - Industry
  - Other civil society organisations
  - Medical societies
- Topics of discussion:
  - Joint Action on Rare Cancers
  - Palliative Care
  - European Code Against Cancer

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Credibility = TRUST
ECPC as a partner of EU institutions

CanCon
Cancer Control Joint Action

Joint Action on Cancer Control – CanCon

- Follow up of EPAAC Joint Action
- Co-funded by Commission and 17 EU Member States
- Objective: create guidelines for harmonisation of NCPs
- Started in February 2013 – Duration: 3 years
- 6 Operational Work Packages
  - WP4: Guide coordination
  - WP5: Member State Platform
  - WP6: Integrated Cancer Control
  - WP7: Community-Level Cancer Care
  - WP8: Survivorship and Rehabilitation
  - WP9: Screening

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Credibility = TRUST
ECPC as a partner of EU institutions

ECPC is the only Collaborative Partner involved in all Work Packages

- WP 4 -Guide coordination: De Lorenzo
- WP 5 -Member State Platform: De Lorenzo
  - ECPC promoted the creation of a position paper on inequalities in cancer care: APPROVED (to be finalised in 2016)
- WP 6 -Integrated Cancer Control: De Lorenzo - Apostolidis
- WP 7 - Community-Level Cancer Care: Apostolidis
- WP 8 – Survivorship and Rehabilitation: De Lorenzo
  - ECPC provides key contribution to recommendations
- WP9: Screening: Presti
- WP2 Dissemination (Florindi)

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Credibility = TRUST
ECPC as a partner of EU institutions

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

European Medicines Agency
Patients' and Consumers' Working Party

- ECPC fully meets very strict criteria to be included in PCWP
- ECPC represented by Kathi Apostolidis and Rafal Swierzewski
- PCWP has important consultative role

European Commission's Joint Research Centre
Project on breast cancer
ECPC Representative: Kathi Apostolidis

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Other partnerships
Creating and nurturing a network of stakeholders

- **European Society for Medical Oncology - ESMO**
  - ECPC works within ESMO Patients Working Group
  - ECPC partners with ESMO on several policy topics
    - Data protection
    - Survivorship

- **Organisation of European Cancer Institutes - OECI**
  - Memorandum of Understanding to be finalised soon
  - Strong collaboration on various topics
    - Comprehensive Cancer Centres
    - Joint events
    - BenchCan project (Pietro Presti involved)

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Other parntership

Creating and nurturing a network of stakeholders

- **Cancer Drug Development Fund - CDDF**
  - Participation to CDDF events
  - CDDF will collaborate in ECPC initiatives on immuno-oncology
- **European Cancer Concord - ECC**
  - Bringing forward the mission of the European Cancer Patient Bill of Rights
  - Collaboration on « **Europe of Disparities** »
- **European CanCer Organisation**
  - Jana Pelouchova contributes to the ECCO Patient Advisory Committee
- **European Society for RadioTherapy and Oncology - ESTRO**
  - Support multidisciplinarity in cancer treatment (paper)
  - ECPC represented in ESTRO Patients Group (Voiculescu)
- **European Federation of Pharmaceutical Industries and Associations**
- **European Association of Hospital Pharmacists**

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Creating new partnerships
ECPC participating to international events

- ECPC Board and Staff participated to **more than 30 international events**, including:
  - ESMO congress
  - ASCO congress
  - Cancer Drugs Development Forum Alpine Meeting
  - European Heath Forum Gastein
  - EU Council Health Events in Greece, Latvia
- **Next events:**
  - OECI Oncology Days, 22-23 June 2015
  - « The Economist » War on Cancer, 20th October
  - European Commission's Celebrations for 30th anniversary opf European Health policies

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Monitoring relevant EU policies

- **General Data Protection Regulation**
  - In partnership with ESMO
  - Results achieved:
    - ECPC facilitated meeting between the Italian Ministry of Justice and ESMO to present amendments to the current draft
- **Cross Border Healthcare Directive**
  - Meeting with DG SANTE Healthcare systems Unit
    - Discussion on the implementation of the Directive, following meeting with the Commissioner
- **Clinical Trials Regulation**
  - Follow up: monitoring the creation of the EU CTR Directory

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Awareness campaings:
Working with Members

- **1st World Pancreatic Cancer Day – 13th Nov. 2014**
  - Event at European Parliament, hosted by Sarbu (RO), Juvin (FR), De Backer (BE) and Grossetete (FR)
  - Launch of multi-stakeholder Pancreatic platform and ECPC Working Group, with the participation with two ECPC Members:
    - Pancreatic Action UK
    - EuropaColon

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Awareness campaings:Working with Members

- **Immuno-Oncology Policy Action Framework, 19th Nov. 2014**

- Launch at the European Parliament, hosted by De Backer (BE),Busoi (RO)
- First EU cancer patients initiative on I-O
- Our Members translated and distributed the Guide!
  17 translations already available thanks to:

NFK	Estonian cancer society	Magyar Rakellenes Liga
AIMaC	BAPD	Dzivibas koks
POLA	Let's Win Health	Pulmonale
FABC	DOBS	GEPAC
Pembe Hanim	SVE za NJU	Greek patients' org.
Czech Rep. Patients' org.		

Awareness campaings:
Making the Institutions understand our position

- **Get Tested Campaign, 24th March 2015**
  - Raising awareness on RAS biomarkers for patients with metastatic colorectal cancer
  - Launch of multi-stakeholder platforms

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Awareness campaings: Approaching all institutions

World Cancer Day – 3 key activities:

- **Meeting with Commissioner Andriukaitis**
  - Discuss Commission's priorities on cancer, in particular
    - Implementation of Cross Border Healthcare Directive
    - Cancer patients' contribution to Commission's policies
- **Meeting with MEP La Via, ENVI Chair**
  - Promote discussion in ENVI Committee on better implementation of Cross Border Healthcare Directive
  - Discuss cancer care inequalities in Europe
- **Press conference & Declaration with MEP Gardini**
  - Strong political message to end inequalities in cancer care
  - **Endorsed by 160 MEPs**

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Awareness campaings: Approaching all institutions

World Cancer Day – 3 key activities:

- **Outcome: Written Declaration**
  - Official document of the European Parliament
  - To be tabled in Summer by 19 MEPs
  - To be approved by ½ European Parliament
- **Objectives**
  - Inequalities in cancer care
  - Treatments shortages
  - Harmonise HTAs' at the European level

The Written Declaration calls the Commission & Council

to ACT!

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Awareness campaigns
Creating resources for our Members

- **Nutrition**
  - Fundamental need of cancer patients and survivors
  - In practice, it is neglected by physicians and patients!
  - **What to do?**
    Understand first what patients & advocates know about nutrition!
- **Survey on medical nutrition in cancer**
  - Created in partnership with academia, communication company
  - Translated into 11 languages
  - **Result: 658 single replies!!!**

THANK YOU FOR YOUR HELP!

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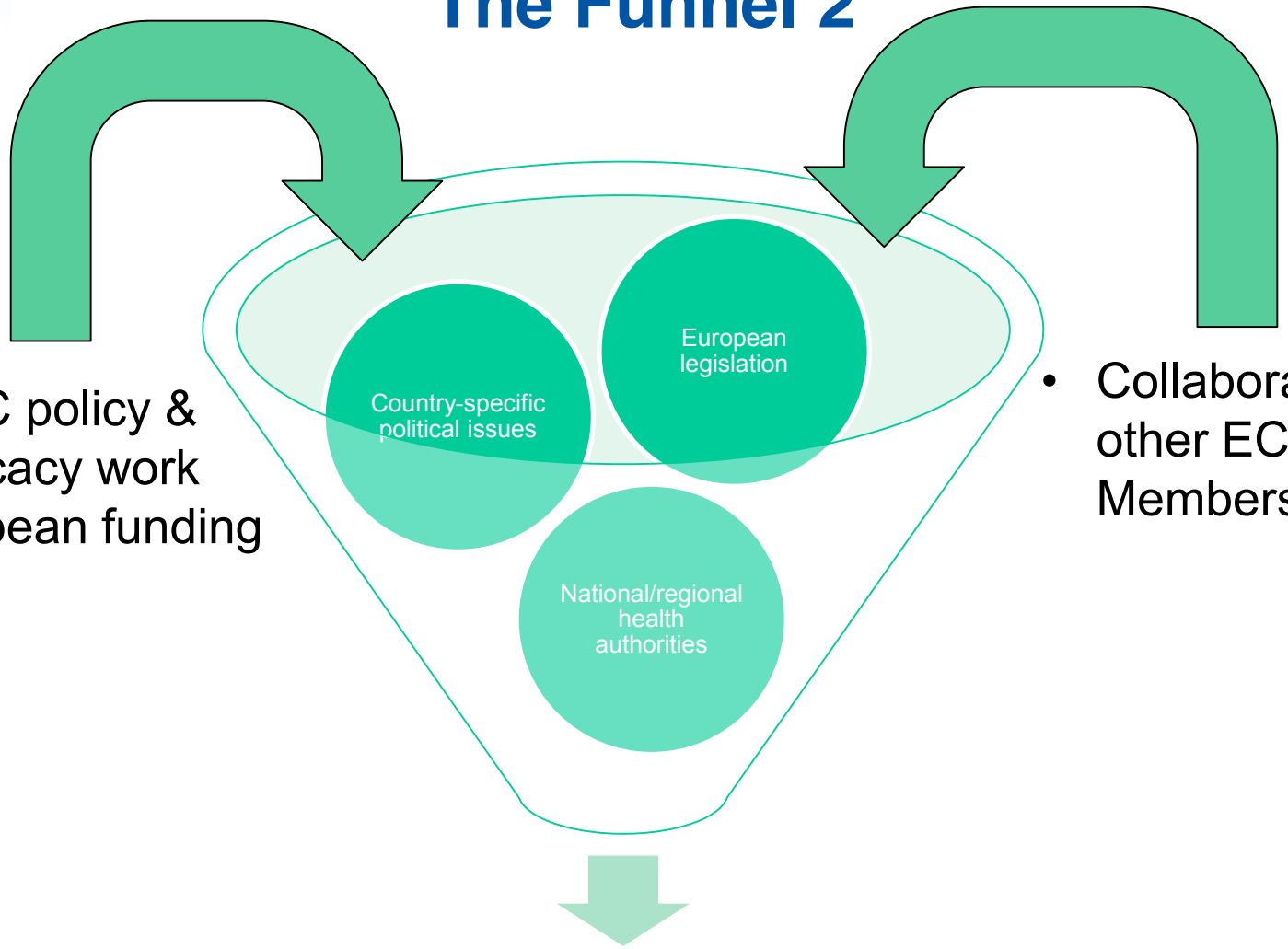
The Funnel 2

- ECPC policy & advocacy work
- European funding



- Collaboration with other ECPC Members

How can ECPC Members use ECPC work at national level?

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Awareness campaigns

Working in partnership with our Members

ECPC policy and advocacy work

becomes even more precious, if translated in initiatives

WITH our members and at national level!

- **Immuno-Oncology**
  - Members translated and disseminated the leaflet
  - I-O event planned in Greece in October 2015
- **LuCE**
  - Event at the European Parliament on Immuno-Oncology treatment for lung cancer in November 2015
- **Fight Bladder Cancer UK & Action Bladder Cancer UK**
  - Launch of the White Paper « Bladder: the forgotten cancer »
- **KEFI/Greece**
  - Awareness activities on pancreatic cancer

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Awareness campaings
Working in partnership with our Members

Head and neck cancers: the model to follow

- **Make Sense Campaign**
  - Launched at EU level, in partnership with several ECPC Members
  - Implemented for 2 years in a row

Next step: ACT LOCAL

- **Italy** – AILAR & ECPC H&N Awareness Campaign
  - Bus touring Italy to promote screening
  - Advertisements on major Italian media
  - Funding requested – to be confirmed
- **Spain** – GEPAC & ECPC Testimonial
  - Awareness campaign vs H&N
  - A H&N Soprano will record a testimonial
  - Funding raised through **sports events**

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Help ECPC helping you: Europe of Disparities

ECPC attempt to solve inequalities in cancer care

- **3 objectives:**
  - Identify nature of inequalities in cancer care in Europe
  - Identify the causes of inequalities
  - Suggest policy recommendations to solve inequalities
- **Multidisciplinary and participative**
  - Based on **YOUR** input
  - Contribution from various experts (health economists, oncologists, epidemiologists, geneticists, patients & carers, industry, pharmacists, radiologists, etc…)
- **Next step: use EoD at national level**
  - **Leverage vs national/regional health authorities**
  - **Include country-specific issues to be targeted**

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Thank for your attention

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European Cancer Patient Coalition

ECPCtv

Nothing About Us Without Us

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