



EUROPEAN CANCER PATIENT COALITION

The reality of multidisciplinary care: HIT as enablers for more equitable cancer care

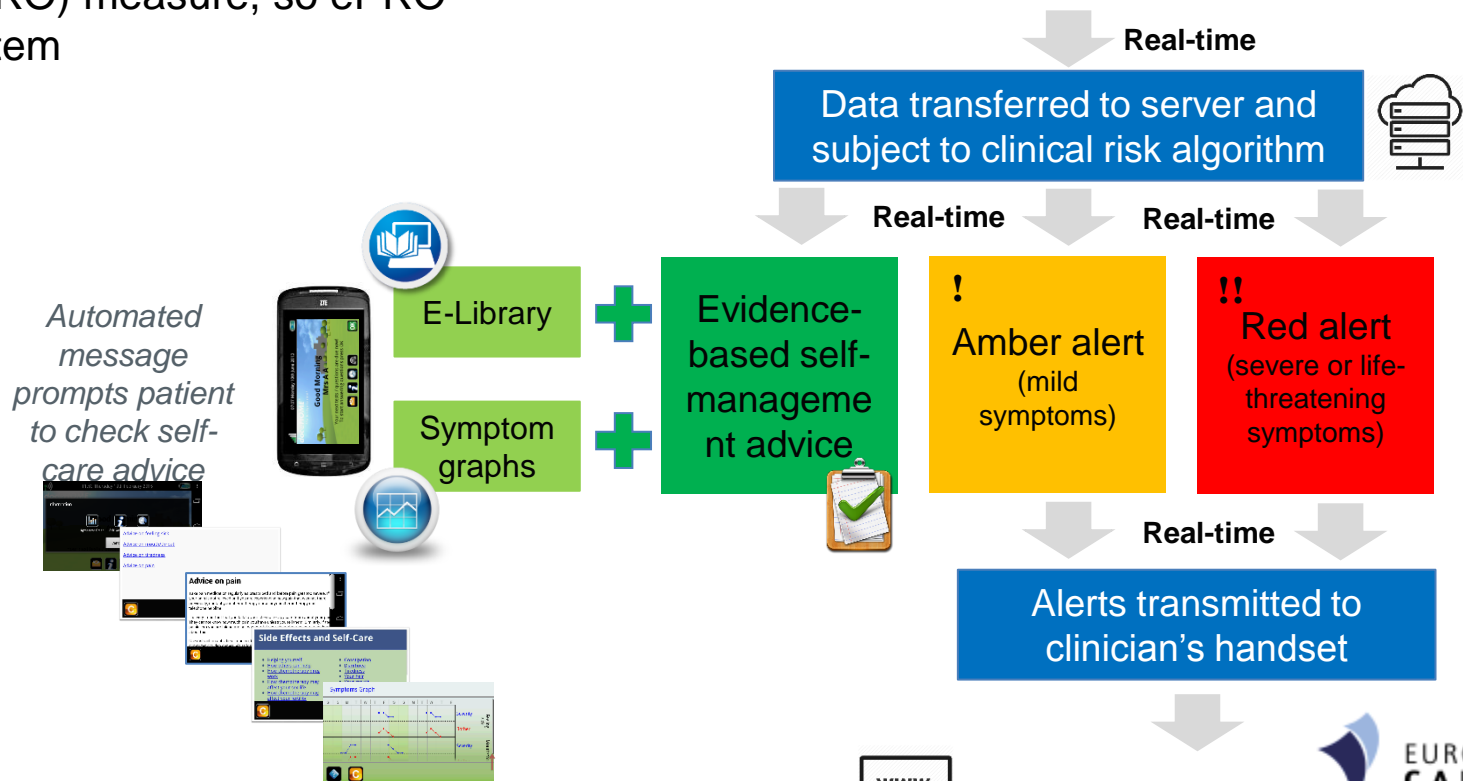
Brussels, 25th April 2017

ECPC: "Nothing about us, without us" @cancereu – www.ecpc.org

- **Representing 408 cancer patient groups in 44 countries**
- **All cancer types** – common and rare
- **Run and governed by patients**
- **Reducing disparity and inequity** across the EU
- Promoting **equitable and timely access** to appropriate prevention, screening, early diagnosis, treatment and care for all cancer patients
- Encouraging the **advance in cancer research & innovation**
- Increasing **cancer patients' influence** over **European health and research policy**

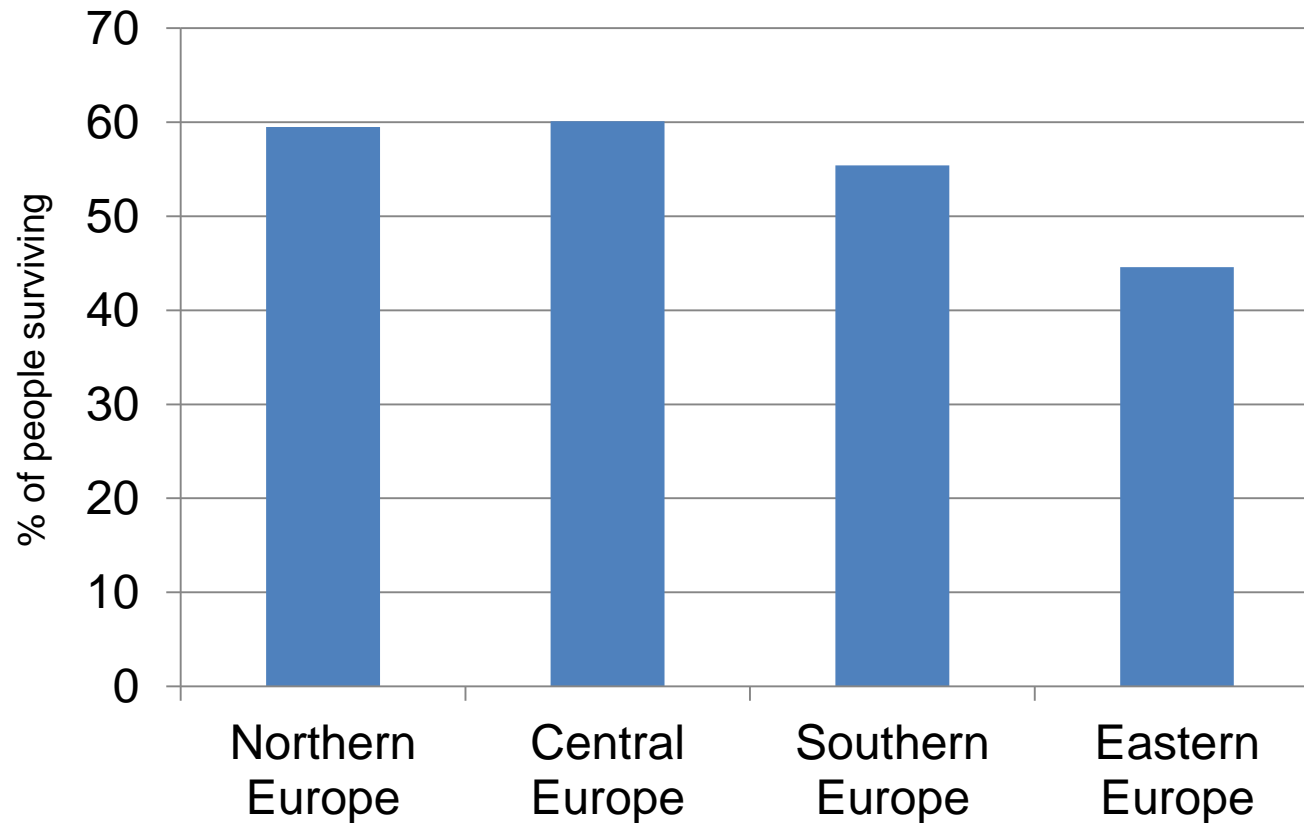
Our eHealth/mHealth expertise: Electronic Symptom Management System Remote Technology (eSMART) study

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



Inequalities in cancer care: European reality

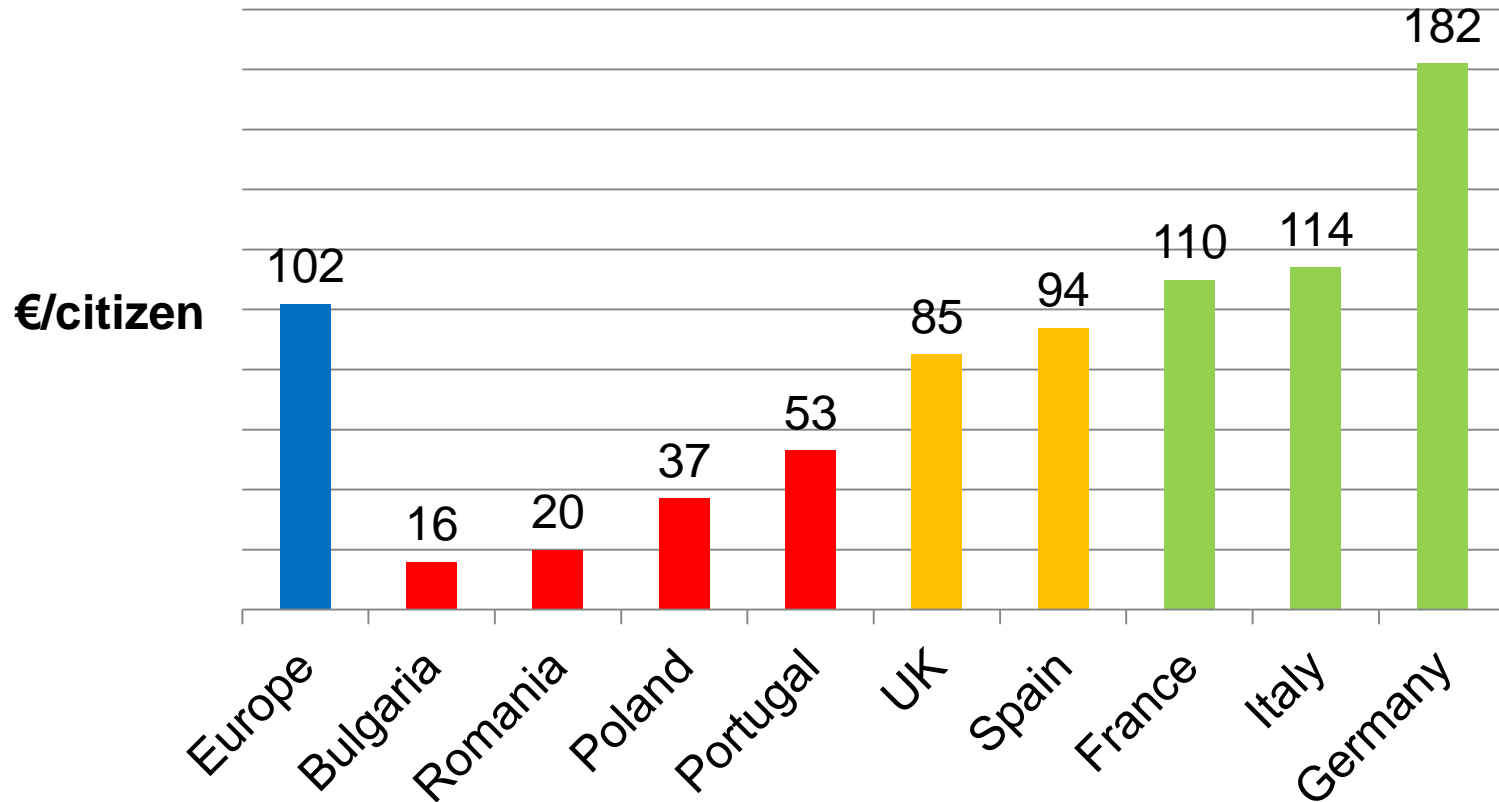
The example of colorectal cancer



Cancer survival in Europe 1999–2007 by country and age:
results of EUROCare-5—a population-based study, 2013

Inequalities in cancer care: an economic problem?

Example: avg. cancer expenditures per citizen in the EU



“Economic burden of cancer across the European Union: a population-based cost analysis.” Luengo-Fernandez R1, Leal J, Gray A, Sullivan R., 2013.

It's not just about pouring money in cancer care

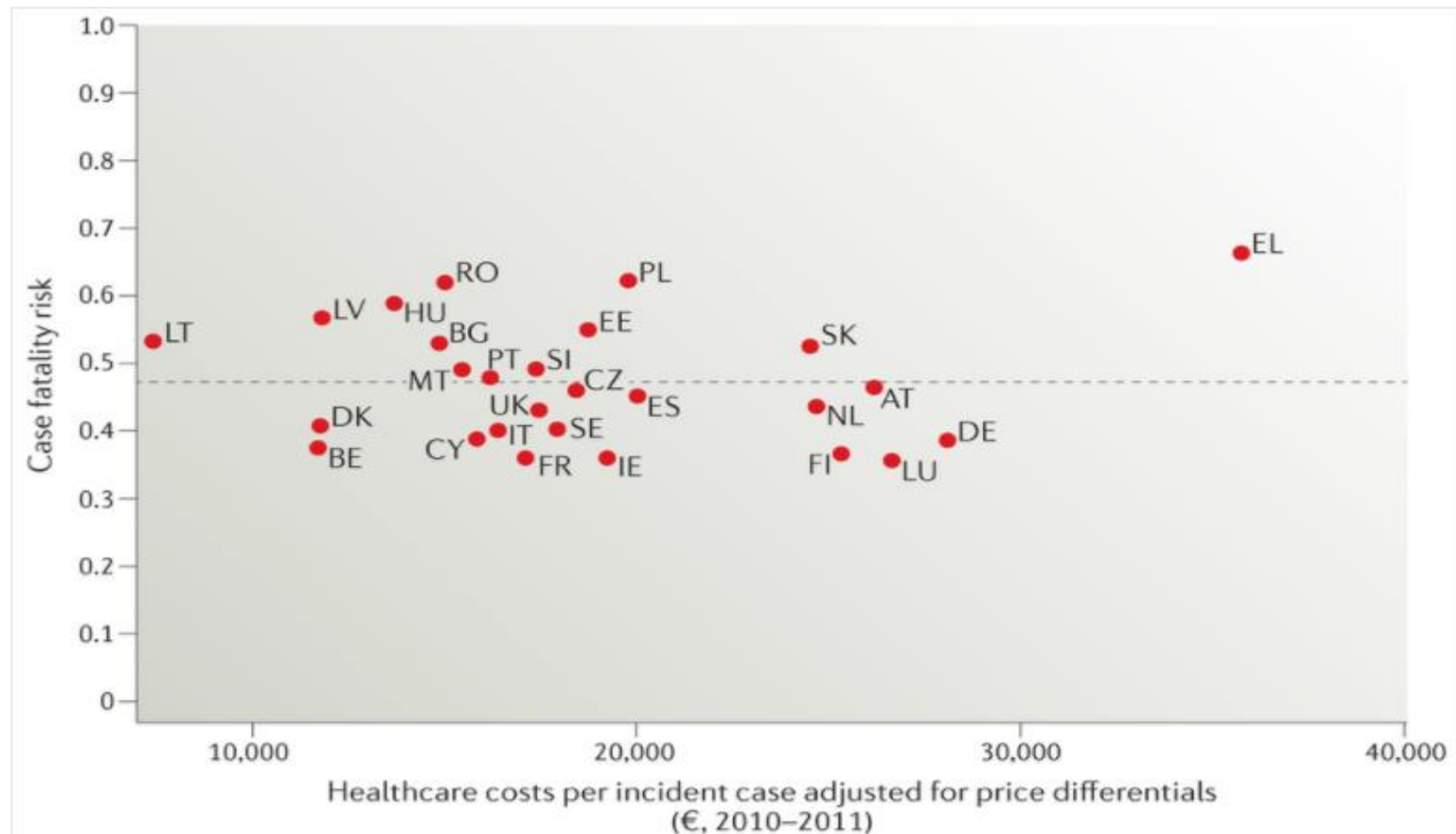
Figure 1: Relationship between cancer case fatality risk by country and health-care costs.

From

Health policy: Putting a price on cancer

Richard Sullivan & Ajay Aggarwal

Nature Reviews Clinical Oncology 13, 137–138 (2016) | doi:10.1038/nrclinonc.2016.12



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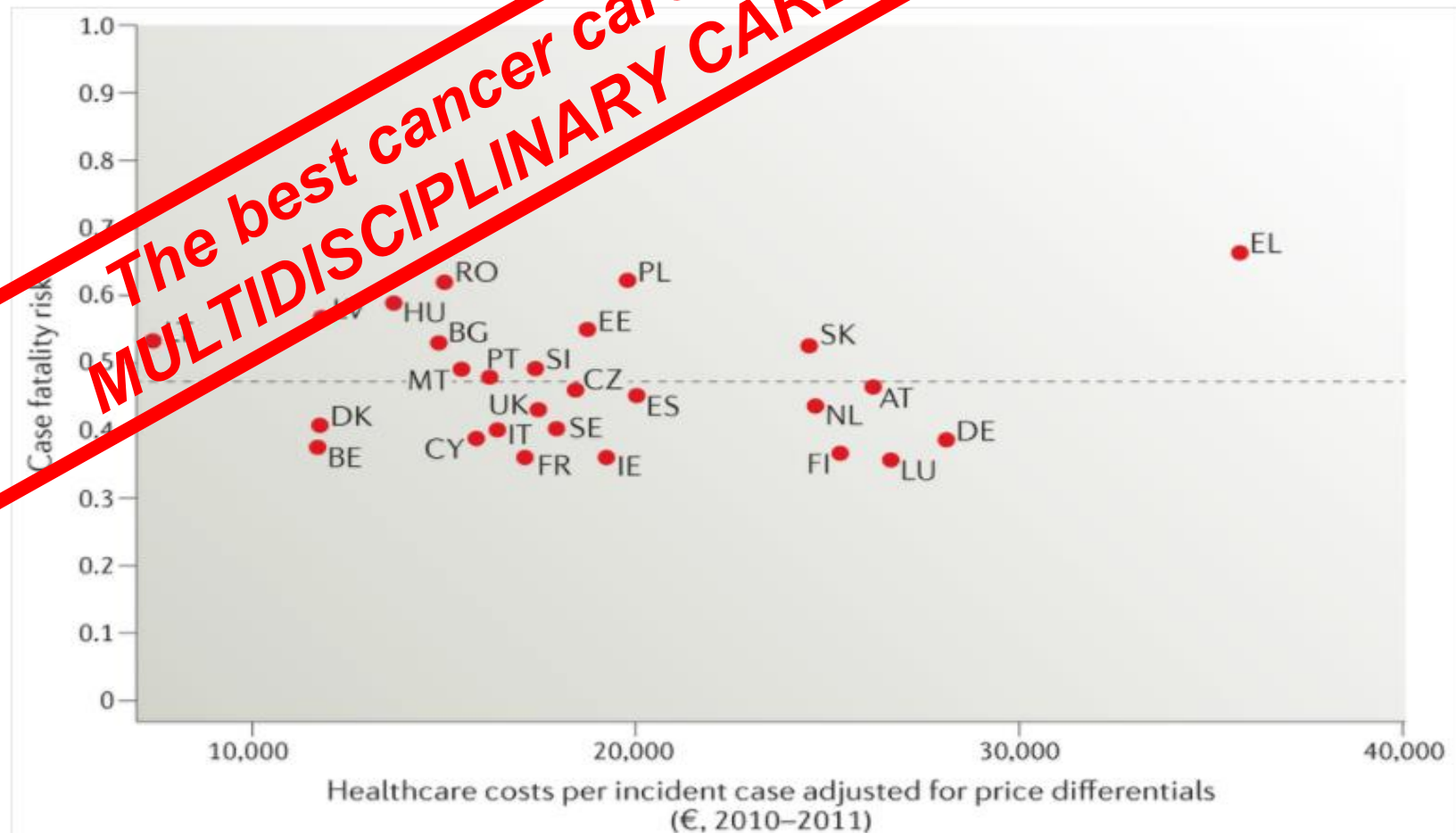
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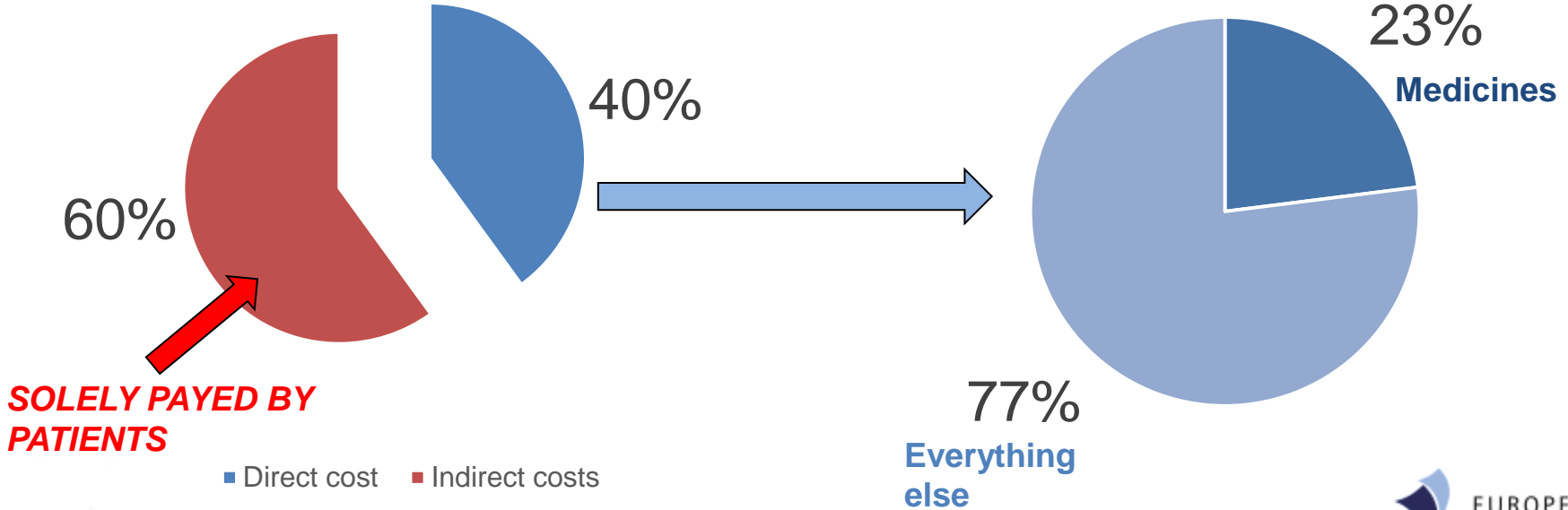
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How are we spending money on cancer?

- **Best cancer care = Multidisciplinary care**
 - Radiotherapy and surgery save cancer patients;
 - Medicines are more and more effective, but they are not the sole instrument to fight cancer
- **Cost of cancer care = 126 billion EUR/year in Europe (2013)**



Lancet, 2013

Notwithstanding inequalities more and more patients survive cancer



INCIDENCE

2,6 million

MORTALITY

1,7 million



5 YEARS PREVALENCE

9 million

Source: EUCAN

CANCER IS NOT A DEATH SENTENCE

I tumori in Italia • Rapporto AIRTUM 2014 • PREVALENZA

Schede specifiche per tumore



Pool of Italian Cancer Registries - 1 January 2010

TUTTI I TUMORI ESCLUSI I TUMORI NON MELANOMATOSI DELLA CUTE ALL TYPES BUT SKIN NON-MELANOMA

(ICD-10 C00-43, C45-96, D09.0, D30.3, D41.4)

COMPLETE PREVALENCE BY YEARS SINCE DIAGNOSIS

YEARS →	≤2	(2-5]	(5-10]	(10-15]	(15-20]	>20
No. →	493 439	550 376	625 093	370 198	218 987	329 254
% →	19%	21%	24%	14%	8%	13%
PROPORTION PER 100 000 →	866	969	1 102	653	385	583

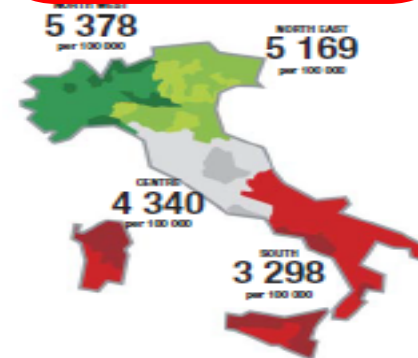
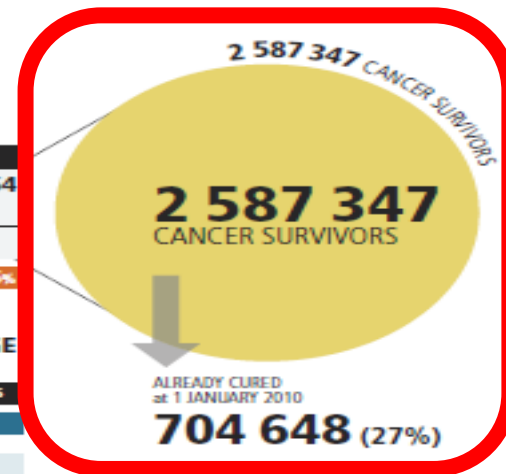
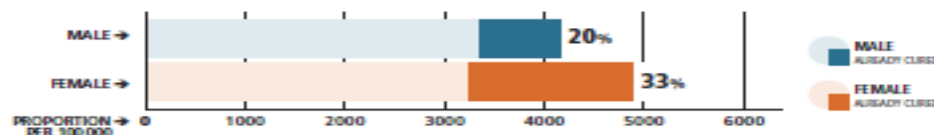
MALE 44%

FEMALE 56%

COMPLETE PREVALENCE BY SEX, MACRO-AREA, AND AGE (PROPORTION PER 100 000)

AGE CLASS →	0-44	45-59	60-74	75+	ALL AGES
MALE					
NORTH WEST	603	2 856	12 024	22 395	4 988
NORTH EAST	582	2 872	11 873	22 820	4 758
CENTRE	556	2 537	9 392	19 125	4 021
SOUTH	525	2 239	8 244	15 198	3 013
POOL	566	2 643	10 683	20 222	4 197
FEMALE					
NORTH WEST	797	5 178	11 520	15 029	5 734
NORTH EAST	811	5 309	11 747	15 029	5 558
CENTRE	802	4 809	9 774	15 323	4 639
SOUTH	721	4 237	8 455	12 649	3 566
POOL	775	4 891	10 589	13 645	4 896
BOTH SEXES					
NORTH WEST	699	4 042	11 752	17 665	5 378
NORTH EAST	694	4 097	11 807	17 665	5 169
CENTRE	678	3 703	9 592	18 066	4 340
SOUTH	623	3 267	8 357	15 167	3 298
POOL	669	3 788	10 634	16 092	4 558

COMPLETE PREVALENCE AND PROPORTION OF ALREADY CURED SURVIVORS BY SEX



COMPLETE PREVALENCE
Overall number (or proportion)
of cancer survivors.

EUROPEAN
CANCER
PATIENT
COALITION

ECPC – ESMO Survivorship Guide

- Full partnership between patients/doctors
- Filling a gap in patients' knowledge
- In line with science –and policy recommendations



- What is it?

- Info on
 - Physical rehabilitation
 - Psychological rehabilitation
 - Financial issues
 - Return to work
 - Nutritional / sexual rehabilitation



GOOD SCIENCE
BETTER MEDICINE
BEST PRACTICE

- Checklist for patient & oncologist (what to do when, follow up)
- Translated in several languages
- ***To be published in October 2017***



What is the Value of Innovation in Oncology?

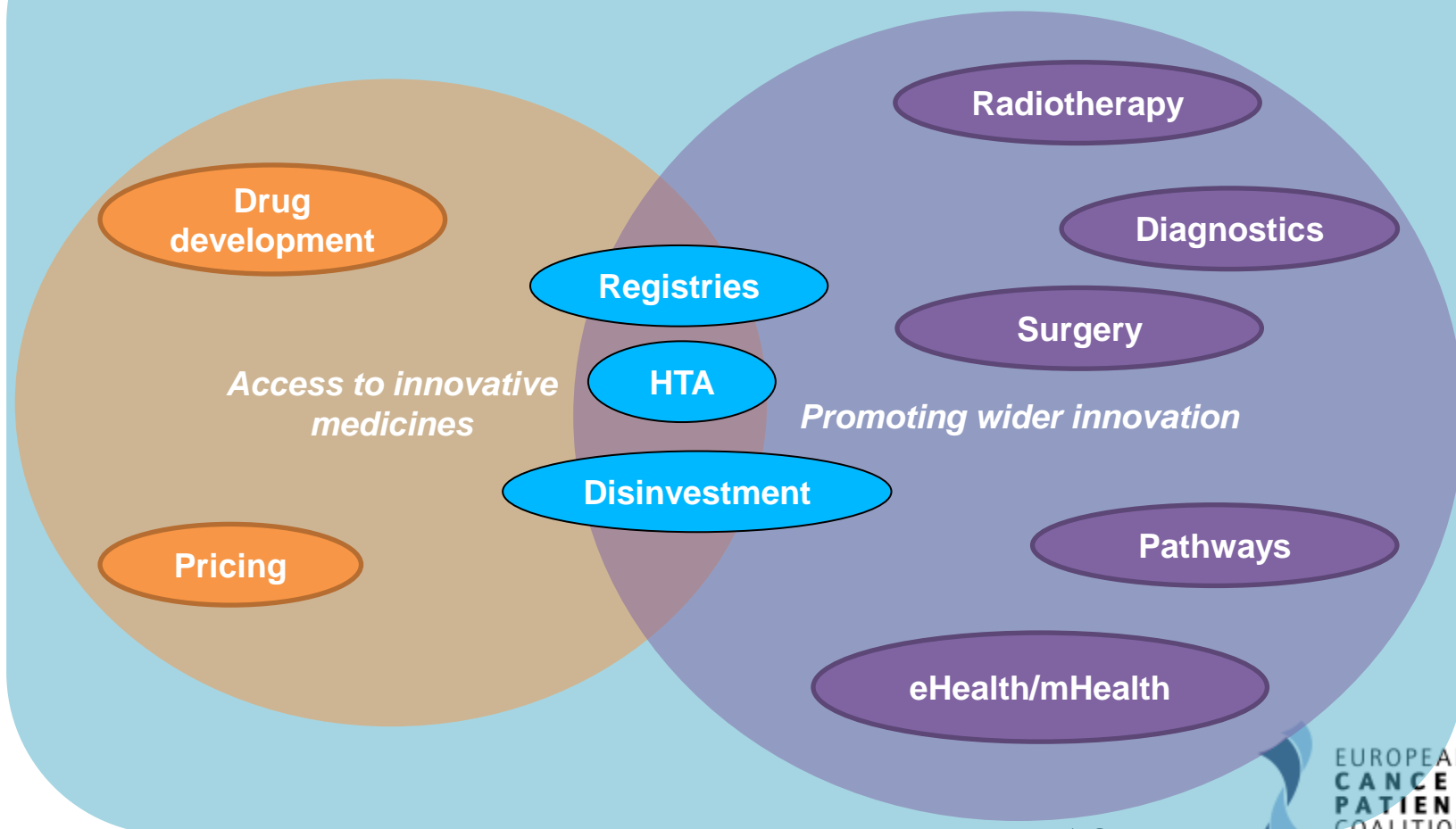
WWW.ECPC.ORG/INNOVATION

- ***ECPC vision for the future of cancer care***
- It answers to the questions:
 - ***Why cannot cancer patients access the innovation they need?***
 - How can patients help decision-makers identify innovation that is meaningful to patients?
 - What can the Commission and Member States do in practice?
- It aims to:
 - Provide recommendations for decision makers
 - Guide our Members' advocacy work at national level
- ***Based on evidence – in line with CanCon recommendations***

White Paper's structure

WWW.ECPC.ORG/INNOVATION

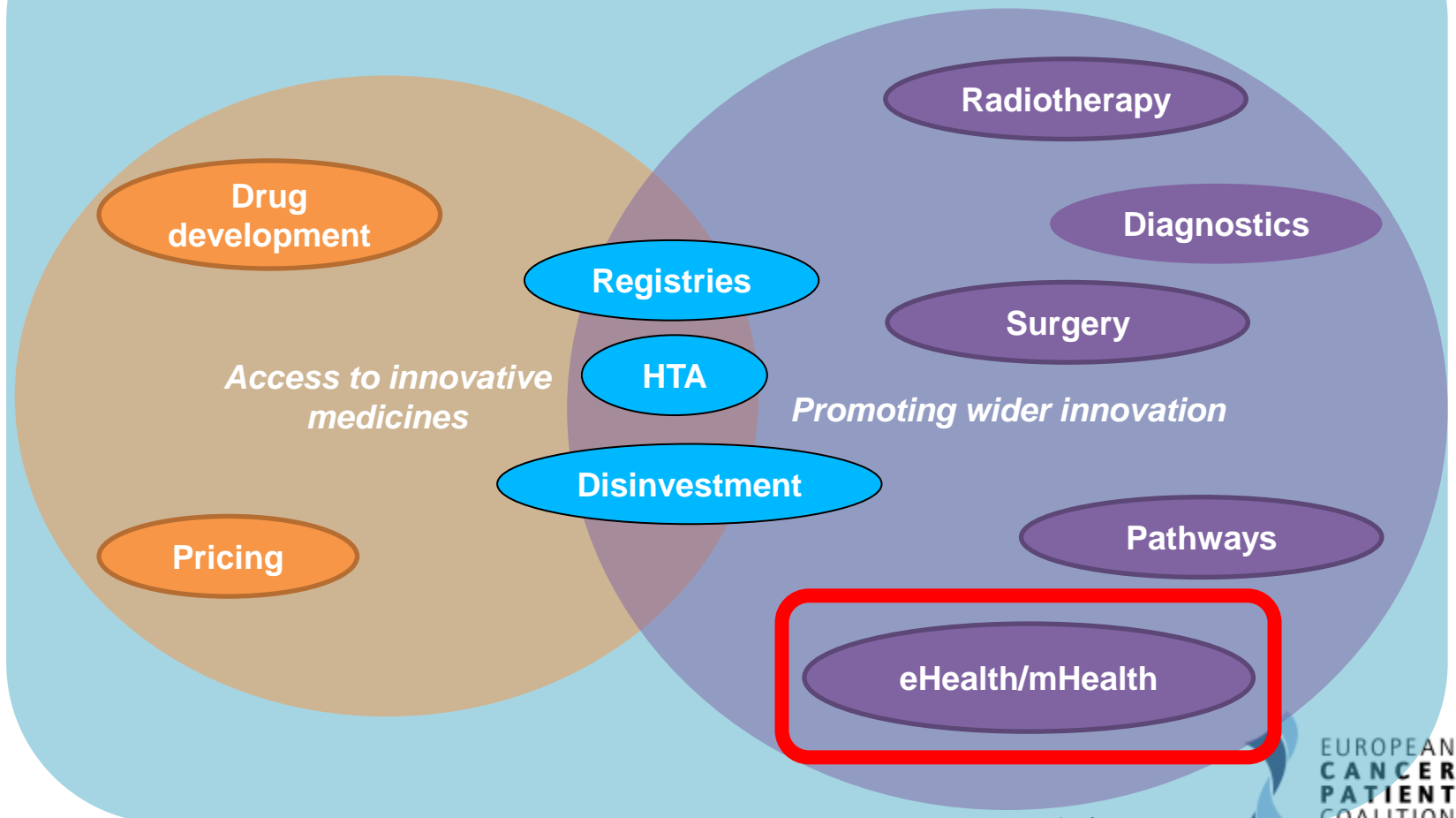
Main systemic barriers to access to innovation in oncology



White Paper's structure

WWW.ECPC.ORG/INNOVATION

Main systemic barriers to access to innovation in oncology



Our general recommendations on eHealth - mHealth

- **Interoperability**

- **Implementation of eHealth standards** to harmonise deployment of solutions
- eHealth cost-effectiveness: **use HTA to evaluate eHealth tools**
- EU MS and EC should expand innovative payment models implementing eHealth solutions (**pay per outcome**) – **BUT WE NEED TO LINK REGISTRIES!**

- **mHealth**

- **Informed consent** should be gained using a short simple statement, no legal jargon
- ***Patient-centeredness by design and by default***
- App should provide reliable information
- OK to collect anonymised data for research purposes
- OK to reimbursement of mHealth tools **that provide value**

Integration in clinical practice

- Will **patients** use mHealth apps?
 - YES! Patients are ALREADY using them.
 - Patient advocate push for:
 - Apps designed in partnership with patients
 - User-friendly apps
 - Scientifically accurate contents
 - *mHealth assessment guidelines?*
- Will / can **health professionals** use mHealth apps?
We don't know!
- **2 issues**
 - **To have meaningful clinical value, mHealth should be embedded into care process activities** = collaboration with medical societies, inclusion into care guidelines and pathways
 - **Digital skills of healthcare professionals**

EUROPEAN
HEALTH PARLIAMENT

Improving access to innovative medicines

Pricing & reimbursement

- EU MS should cooperate more on information sharing, transparency, horizon scanning and joint procurement;
- EU MS need to consider future different financing models for cancer medicines
- Increase patients' associations' involvement
- Pricing and reimbursement must be aligned with health outcomes (**pay-per-outcome models**)

This won't happen without proper IT infrastructure!

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

Thank for your attention

**Francesco Florindi
Head of EU Affairs
European Cancer Patient Coalition**



@cancereu; @francescoflo



European Cancer Patient Coalition



ECPCtv

Nothing About Us Without Us

