

# Europe of Disparities: The unequal nature of cancer in Europe



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# Burden of cancer in Europe

- Estimated **3.45 million** new cases and **1.75 million** cancer **deaths** (2012) <sup>1, 2</sup>
- Cancer leading cause of premature death in **28** of **53** European Countries <sup>3</sup>
- **Aging population** will underpin significant increases over the next 30 years <sup>4</sup>

<sup>1</sup> Ferlay et al, E J Cancer (2013); <sup>2</sup> Malvezzi et al Ann Oncol (2013)

<sup>3</sup> WHO Europe Health Report 2012 (2013); <sup>4</sup> Rechel et al, Lancet (2013)



- **EUROCARE -5:** Population based analysis (>10 million patients in 29 European countries)<sup>1</sup>
- Survival in **Eastern Europe** low
- **Significant disparities** between different European countries
- Survival for **lung cancer** lower in UK and Ireland
- Reflects **delayed diagnosis/access** to treatment.

<sup>1</sup> De Angelis et al Lancet Oncology 2014



- 12 health regions in Australia, Canada, Denmark, Norway, Sweden, and UK <sup>1</sup>
- Breast, colorectal, lung and ovarian
- Higher survival: Australia, Canada, Sweden
- Poorer survival: Denmark , UK
- **Reflects delayed diagnosis/access to treatment.**

<sup>1</sup> Coleman et al Lancet (2011)

# European Cancer Concord

- **Equal Partnership** between **Patient Advocates** and **Healthcare Professionals**
- **Citizen focussed** initiative
- **Key goal** is to **identify inequalities** AND **do something about it!**
- **Engagement** at **European** and **National** levels

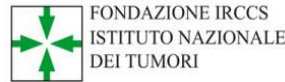




EUROPEAN  
CANCER  
PATIENT  
COALITION



Erasmus MC  
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# Building the Evidence Base for Cancer Disparities

- Access
- Age
- Gender
- Information
- Socio-economic status

# ***The European Cancer Patient's Bill of Rights***

- A **charter** to **challenge** the current **inequalities** that cancer patients in Europe are **experiencing** on a **daily** basis<sup>1, 2</sup>
- A **catalyst for change** and an **empowerment tool** for cancer patients



<sup>1</sup> Lawler et al *Lancet Oncology* 2014;

<sup>2</sup> Lawler et al *The Oncologist* 2014





**4<sup>th</sup> February 2014**

## The European Cancer Patient's Bill of Rights

Lawler M, Le Chevalier T, Murphy MJ, Banks I, Conte PF, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Armand JP, Barbacid M, Barzach M, Bergh J, Bode G, Cameron D, de Braud F, de Gramont A, Diehl V, Diler S, Erdem S, Fitzpatrick JM, Geissler J, Hollywood D, Højgaard L, Horgan D, Jassem J, Johnson PW, Kapitein P, Kelly J, Kloezen S, La Vecchia C, Löwenberg B, Oliver K, Sullivan R, Tabernero J, Van de Velde CJ, Wilking N, Wilson R, Zielinski C, zur Hausen H, Johnston PG.



**4<sup>th</sup> February 2014**

## A CATALYST FOR CHANGE: THE EUROPEAN CANCER PATIENT'S BILL OF RIGHTS

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# ***The European Cancer Patient's Bill of Rights***

**Article 1: The right of every European Citizen to receive the most accurate information and to be proactively involved in his/her care**

<sup>1</sup>Lawler et al *Lancet Oncology* 2014

<sup>2</sup>Lawler et al *The Oncologist* 2014

# Tonio Borg

## European Commissioner for Health



*"I praise the very first right that the Bill defends, the **right for the patient to receive accurate information and to be actively associated in their care**. Information is key to **enable the patient to play an active role** in his or her treatment **rather than just being a passive recipient.**"*

# ***The European Cancer Patient's Bill of Rights***

**Article 2: The right of every European citizen to equal and timely access to appropriate specialised care, underpinned by research and innovation.**

<sup>1</sup>Lawler et al *Lancet Oncology* 2014

<sup>2</sup>Lawler et al *The Oncologist* 2014

# Joan Kelly President Association of European Cancer Leagues



*“Both **national and regional inequalities** in disease prevalence and impact are holding the development of Europe back in every country in the Union. This **Bill of Rights** is a **bold step** forward to **empowering** cancer patients and citizens everywhere.”*



# ***The European Cancer Patient's Bill of Rights***

**Article 3: The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable health care**

<sup>1</sup>Lawler et al *Lancet Oncology* 2014

<sup>2</sup>Lawler et al *The Oncologist* 2014

# Daciana Sârbu – Romania

## Member, European Parliament



*“Launching the Bill of Rights in the European Parliament on **World Cancer Day** underlines the commitment of the Parliament to abolish disparities in cancer care for the European citizen. In Southern, Eastern and Central Europe, where the **public health systems are under constant pressure from austerity** measures, cancer patients and their families are the **first to feel the impact** on their health, finances and quality of life”*

- Nice words
- **BUT**
- Have we backed them up with **ACTIONS?**

# Cancer Disparities

- **Access**
- Age
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# Inequality in Access to Cancer Drugs

- Cancer Drugs Fund initiated in England in 2010
- **Access to innovative cancer drugs**
- **Scotland** and **Wales** have also moved towards (better) variations of the English model



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# 'Postcode lottery keeps cancer drugs from Ulster patients'

*SDLP man says life-extending medicines only offered in Britain*

BY VICTORIA McMAHON

# Inequality in Access to Cancer Drugs

- Cancer Drugs Fund initiated in England in 2010
- **Access to innovative cancer drugs**
- **Scotland** and **Wales** have also moved towards (better) variations of the English model
- **Why not Northern Ireland?**

# This is an Inequality Issue

- **Lack of Access** to optimal care
- Knock on effect on **future clinical trials**

# Influencing the political agenda

- Cancer Charity **Cancer Focus Northern Ireland** adopt the Bill of Rights
- Establish Forum to **inform** health care **spokespeople** from **each political party**
- **Debate** in the NI **Parliament**

# iCampaigner: Bringing the campaign to the people

- Partnership
- **Fighting for Equal Access**
- Online and Postcard Campaign





# Harnessing People Power

- Nearly **30,000 Signatories**
- Presented to (the then) New Minister for Health on **Tuesday 7<sup>th</sup> October 2014**



# People power works!

- **17<sup>th</sup> February 2015**
- Minister Wells announces consultation and the establishment of **Specialist Medicines Fund<sup>1</sup>**



<sup>1</sup>Lawler et al *The Conversation* 2015

# From Belfast to Bucharest





# From Belfast to Bucharest



## Încă o victorie a pacienților în justiție

19 bolnavi cronici care s-au tratat cu medicamente ce nu se află pe actuala listă de compensate își vor primi banii înapoi de la statul român. Pacienții au acționat statul în justiție în urmă cu trei săptămâni și au obținut ieri decizia favorabilă, printr-o procedură de urgență (ordonanță președințială).

Este vorba de pacienți pentru care actualele terapii compensate nu funcționează și cărora medicii le-au recomandat tratamente din lista de 140 evaluate în 2013, dar niciodată promulgate.

"Este o victorie cu gust amar, pentru că pacienții sunt obligați să acționeze statul în justiție pentru a avea dreptul la viață. Din păcate, autoritățile responsabile, deși au elaborat mai multe acte normative în vederea transpunerii Directivei Europene nr.89/1988, în fapt n-au făcut altceva decât o tergiversare a procedurii de includere a medicamentelor pe lista de compensate", spune Dan Cimpoeșu, avocatul pacienților.

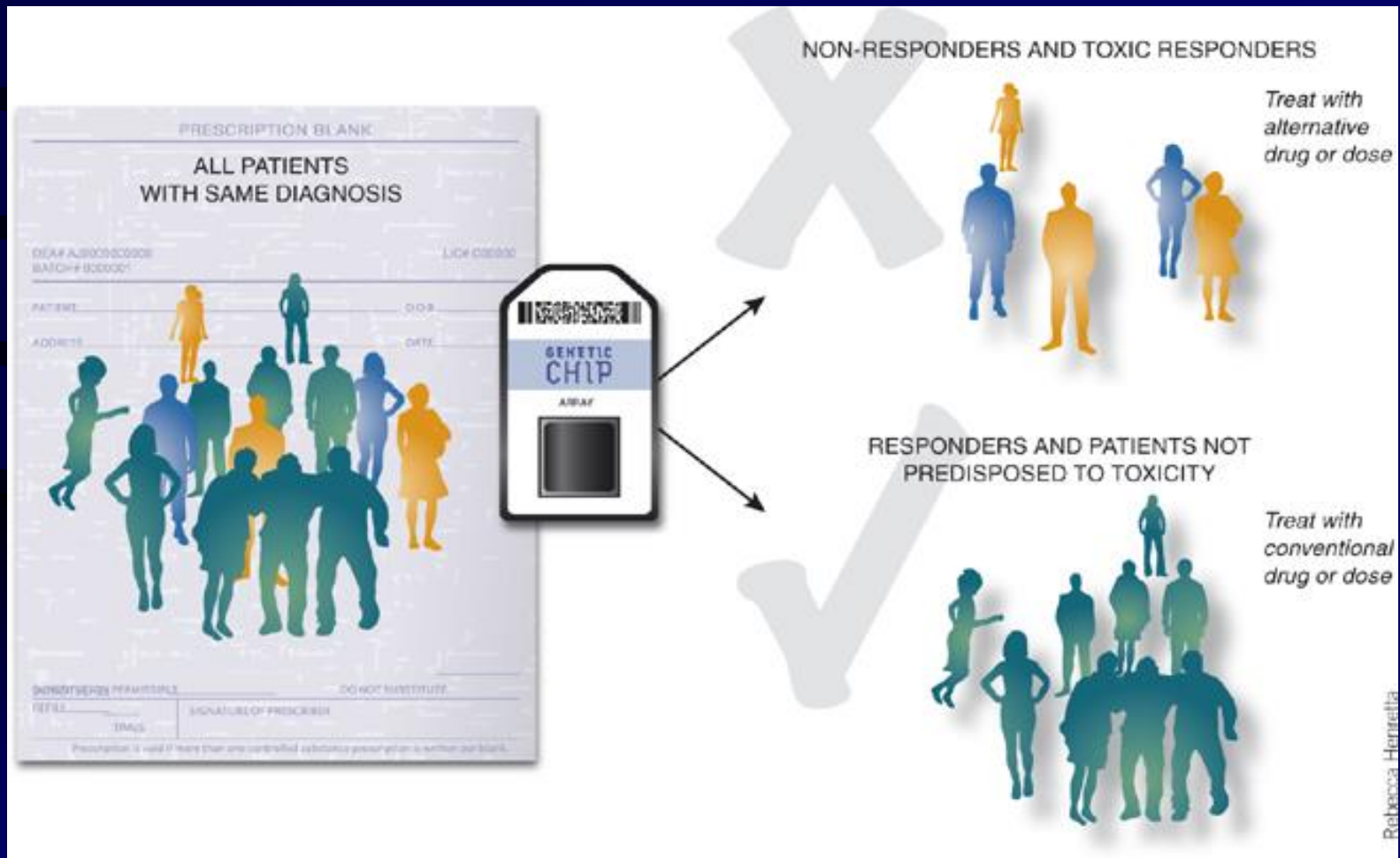
Este a doua reușită a Alianței Pacienților Cronici, după demersul similar făcut în iunie pentru alți 7 pacienți. "Am câștigat pentru cei 19 pacienți un drept firesc, dreptul la sănătate. Avem informații că cel puțin 1.000 de pacienți în toată țara, pe diferite patologii cronice, sunt



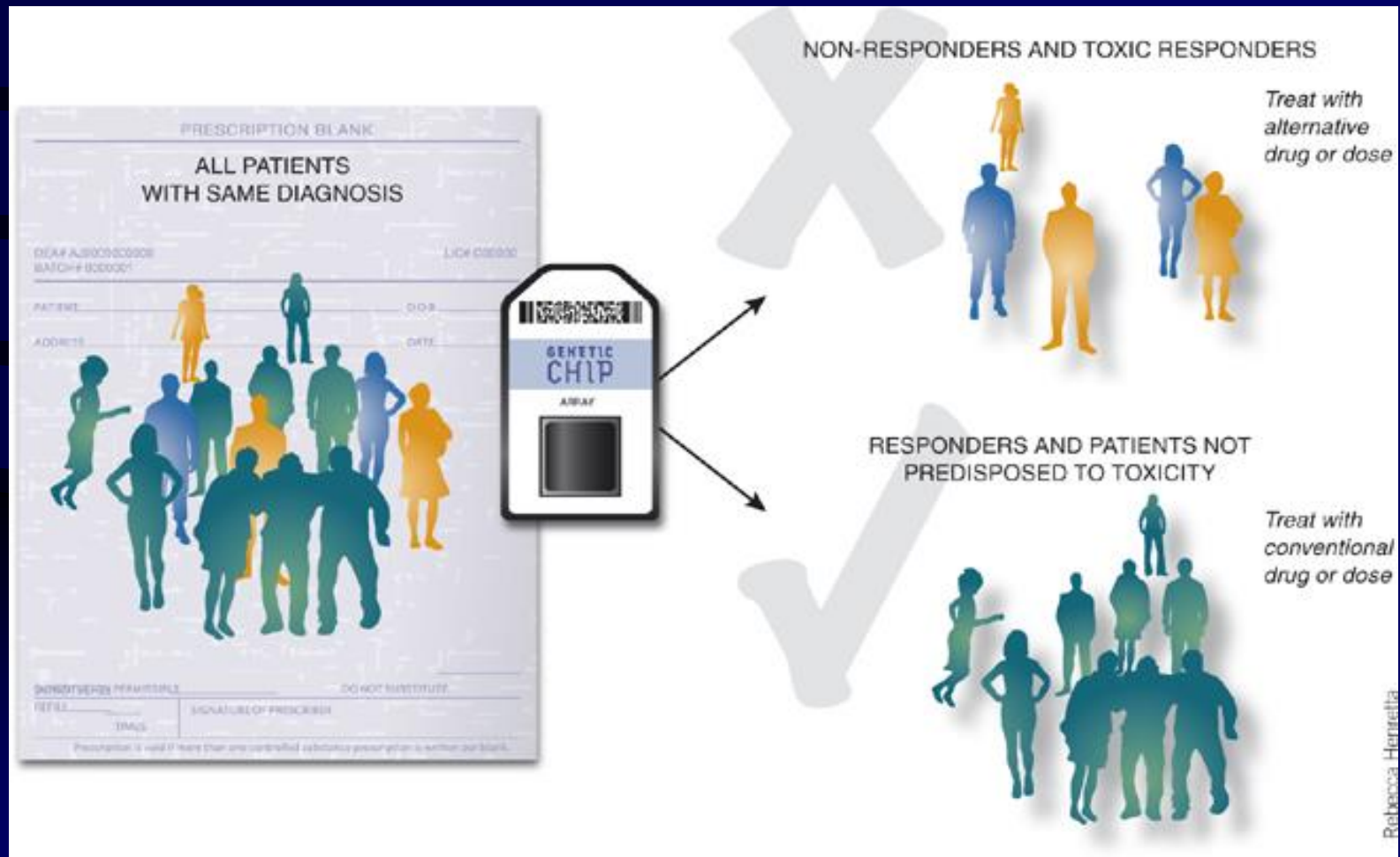
# **Taking the fight to the courts**

- **18<sup>th</sup> June, 2014:** 7 cancer patients won a case in the Romanian Court of Appeal to **receive new, innovative cancer medicines for free**
- **July, 2014:** all 7 patients receive their treatment
- **November 20<sup>th</sup> 2014:** A further 19 patients win their right to access to innovative drugs
- **Currently 50 cancer patients successful**
- **Romanian Alliance of Chronic Patients – breach of Directive 89/105 (The 180 day rule)**

# Getting the right intervention to the right patient(at the right time)



# Getting the right intervention to the right patient (the first time!)



# The Future of Personalised Medicine is NOW! <sup>1, 2</sup>

- 14<sup>th</sup> May 2013 <sup>3</sup>
- The day personalised cancer medicine and genomic technologies came of age for our society



<sup>1</sup> Johnston P, Lawler M, The Oncologist (2012)

<sup>2</sup> Lawler M, Selby P, The Oncologist (2013)

<sup>3</sup> Jolie A. New York Times (2013)



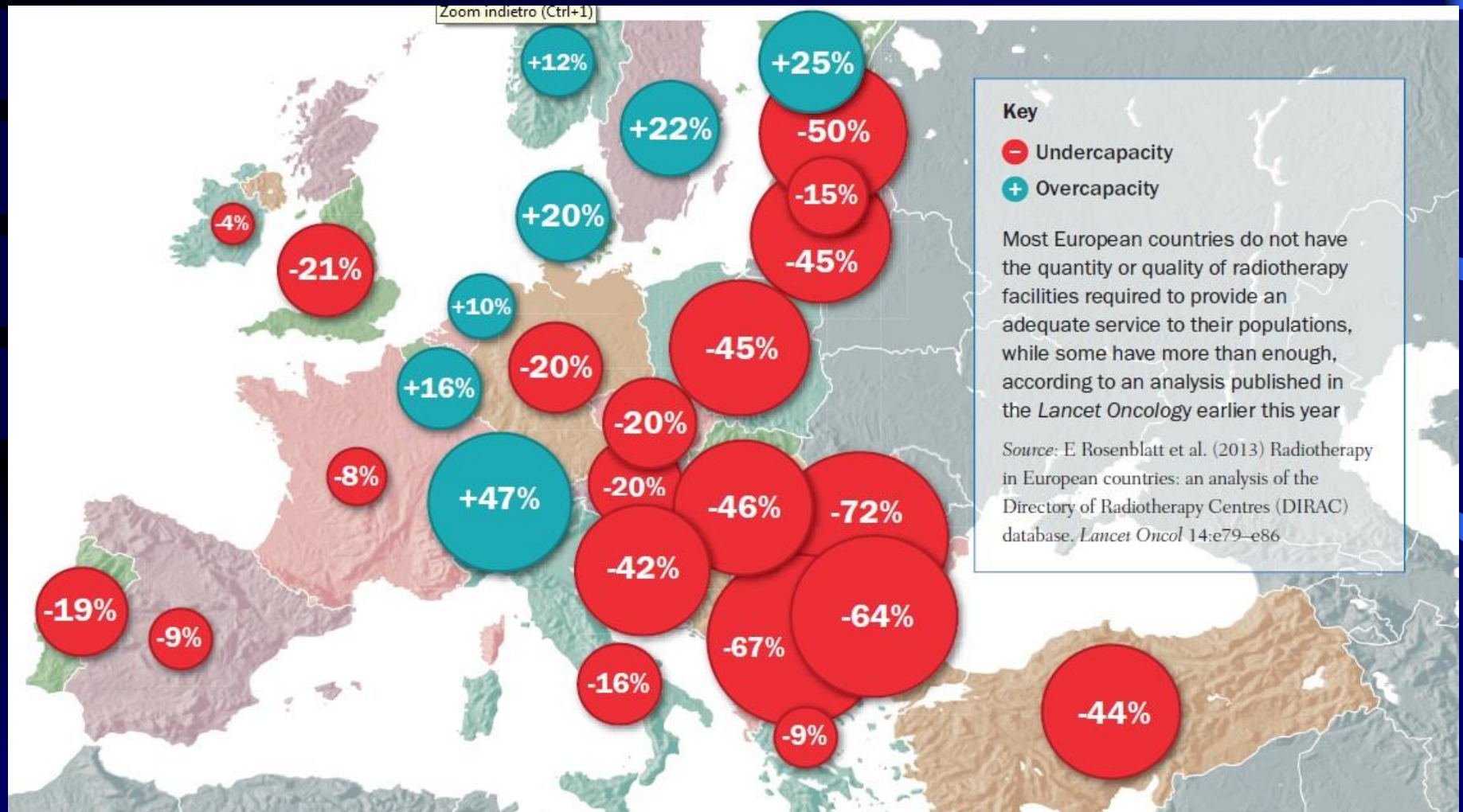
# Embedding Personalised Medicine in European Health Systems

- *Develop a patient-centred European Translational Research Platform*
- **Empower** patients as advocates for PM integration
- **Increase PM literacy** amongst **all** relevant stakeholders
- **Provide** evidence base for **clinical, health economic** and **societal** advantage of PM
- **Create** a more **agile pan European regulatory framework** to enable rapid translation of PM into clinical practice





# And its not just drugs! Disparity in radiotherapy capacity across Europe



# Cancer Disparities

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# Susan from Warwickshire<sup>1</sup>

- “I’d signed the chemotherapy consent form but when I went to see the **consultant** he threw every **negative** at me about maybe never being the same again and anyway it may not work. I came out of the appointment and burst into tears.
- “I asked him later why he’d not pushed it and was told, “You’re **60 not 30**. At **30** you’d have **more life** in front of you”. I’m still alive but I just wish I’d had proper support to make an **informed decision**.”

<sup>1</sup> “Cancer Services Coming of Age” MacMillan Report (2012)

# Tailoring therapy to the older patient

- We require a **geriagnostic-focused** approach<sup>1</sup>
- Need to **enable** the delivery of **evidence-based, tailor-made and patient-focused cancer care** to our rapidly growing elderly patient population.

<sup>1</sup> Hamaker et al. *Ann Oncol.* 2014

# Remember

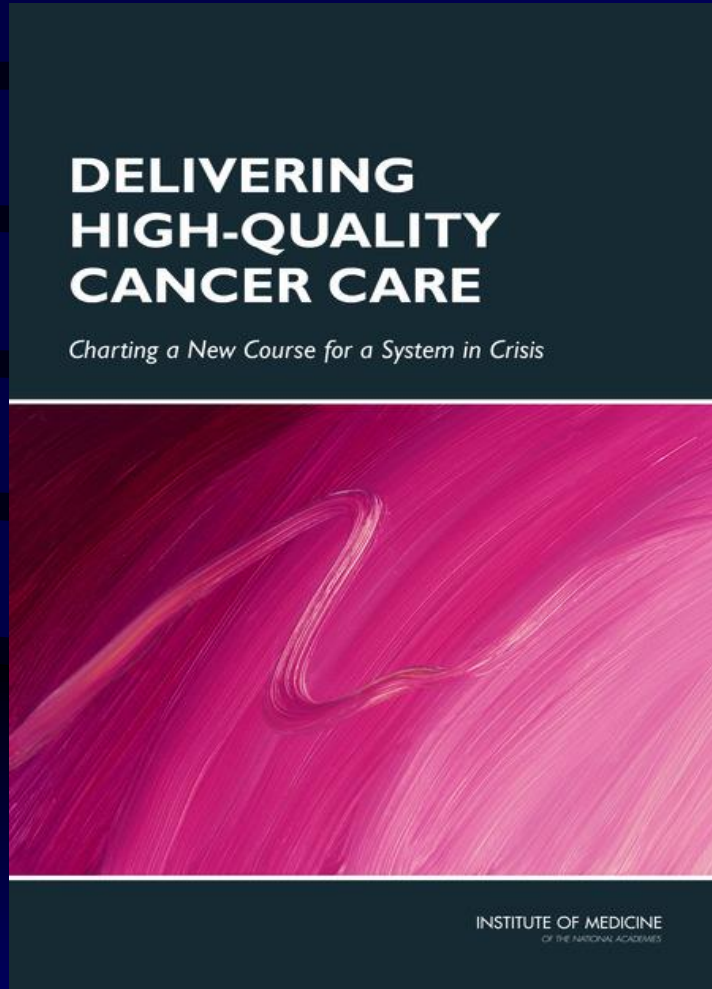
- **Age is just a number**
- **We NEED to CHANGE the MINDSET! <sup>1</sup>**

<sup>1</sup> Lawler et al, British Medical Journal 2014

# Survivorship

- Over **14 million cancer survivors** in Europe
- **Are we doing enough?**

# Are we in crisis? <sup>1</sup>



- **Urgent** need to **address** the **cost/value rubicon** in cancer care
- Must develop **optimal but viable** solutions for patients and society

<sup>1</sup> Lawler et al. America's Cancer Care crisis; is Europe any better? Lancet (2013)

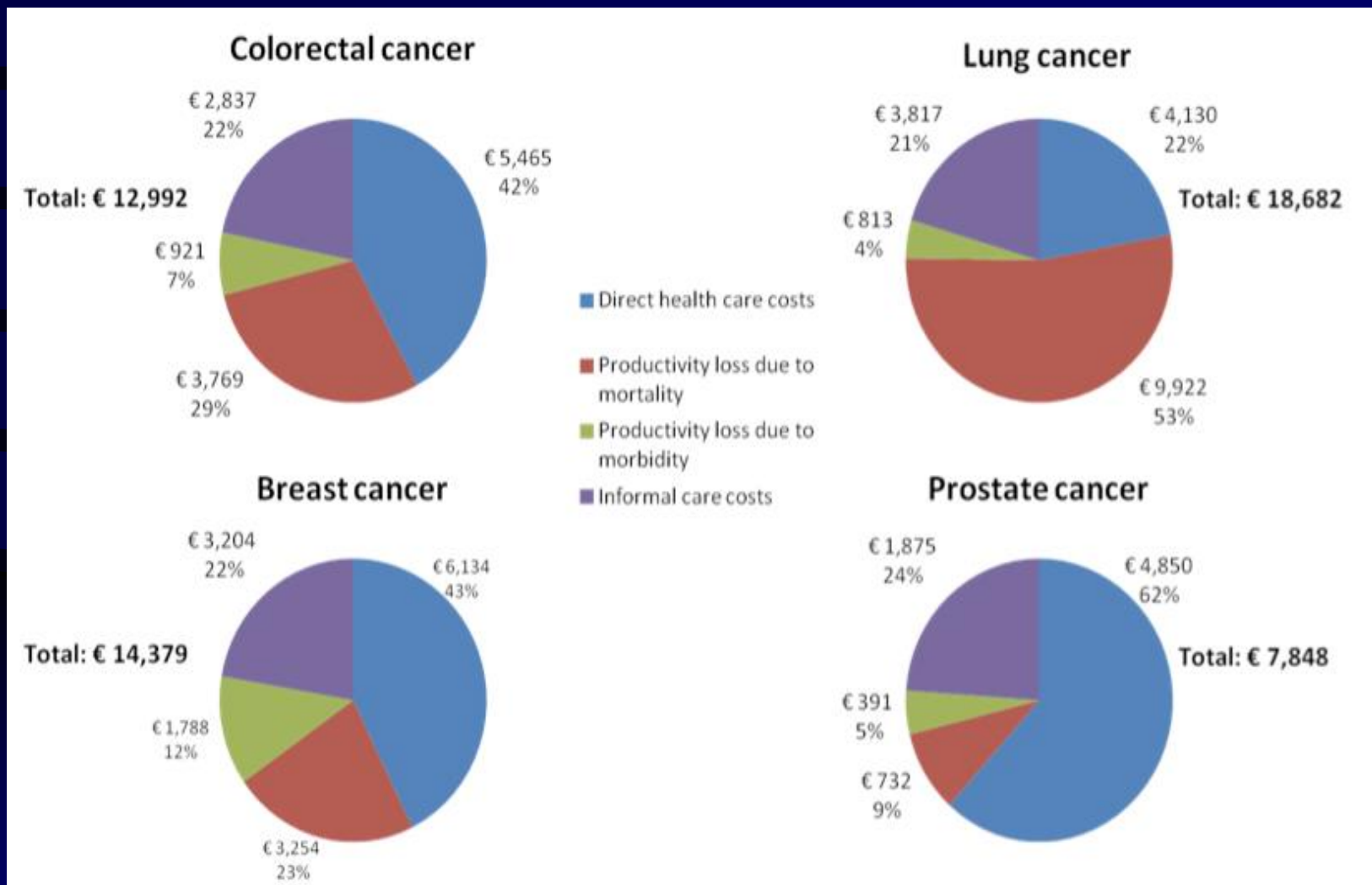
# The Economic Burden of Cancer

- **Global economic burden** of cancer, due to premature death and disability, was **\$1.16 Trillion** (2010) <sup>1</sup> (>2% of worldwide GDP)
- **Europe: €124 billion** (2009) <sup>2</sup>
  - Direct Healthcare Costs (39%)
  - Loss of Productive Life Years (61%)

<sup>1</sup> American Cancer Society (2010)

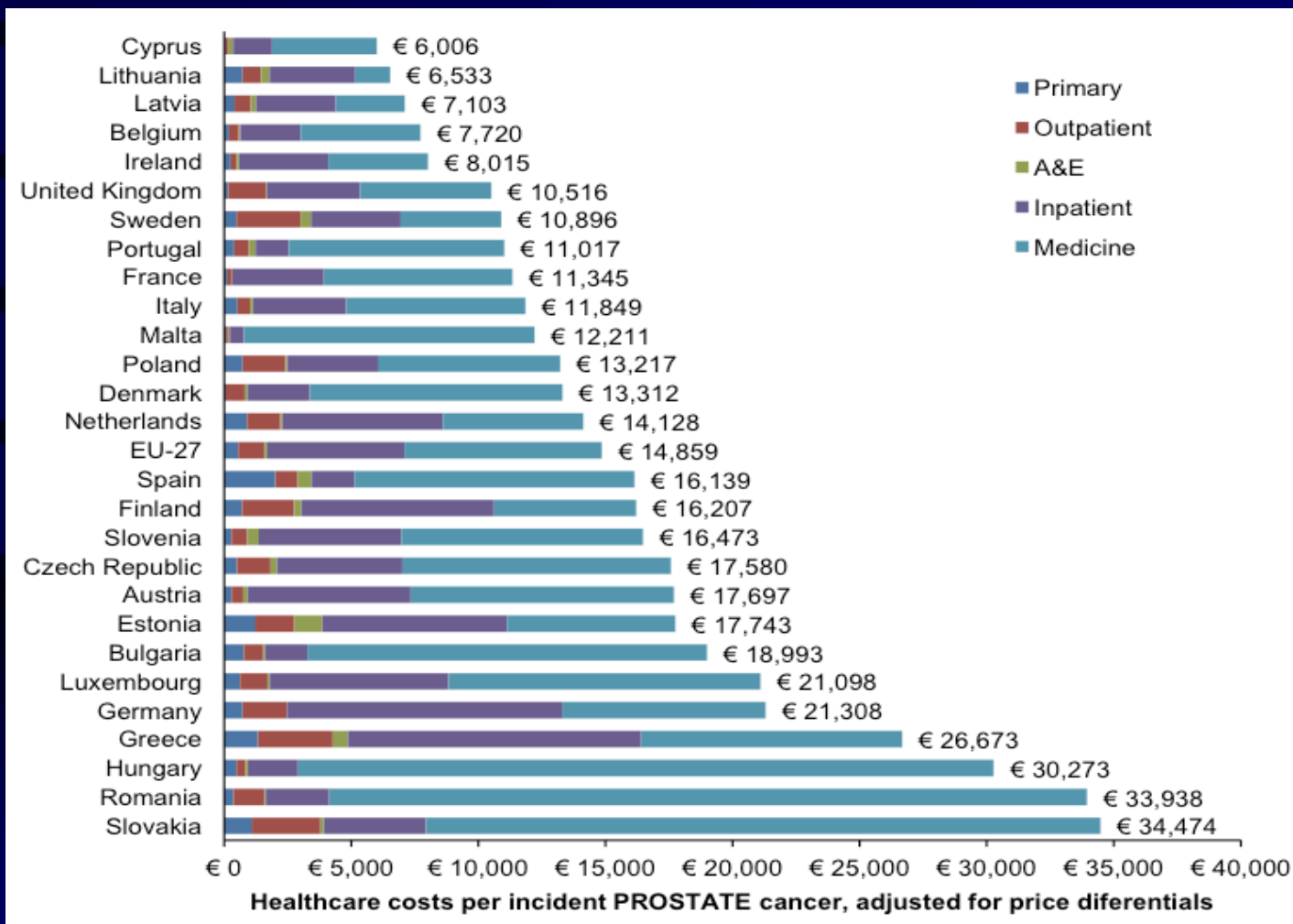
<sup>2</sup> Luengo Fernandez R et al Lancet Oncology (2013)

# The Real Cost of Cancer





# Is expenditure linked to outcome?



- **Its not what you spend its  
the way that you spend it!**

# Wealth is Health 2008

- **Tallinn** Charter
- Pledge to **invest** in improvement of **European Health Care Systems**
- Now a distant memory
- **BUT!**

# Justification should not be forgotten

- **Appropriate investment** brings not only **better health** but
  - Drives **economic growth**
  - Increases **innovation**
  - Improves **productivity**
  - **Reduces pressure** on future **health** and **social welfare** systems

# Rekindling “Greatest Wealth is Health” Agenda

- **Earlier access** to high quality diagnosis **underpins** more **successful therapeutic intervention**
- **Optimal cancer care** contributes to the **health and socio-economic benefit** of **European citizens**

# Key messages

- The **right** to the most up-to-date information (**and not what Susan from Warwickshire got!**)
- Equitable and transparent access to optimal cancer care is the **right of every European Citizen – young or old and whether you live in Belfast or Bucharest**
- Clear pathways to clinical innovation, (prevention, diagnostics, surgery, radiotherapy, medicines) informed by research and innovation (**getting the right intervention to the right patient**)
- Active re-integration and participation in society (**no matter what age you are or where you live!**)
- **Cost effective** cancer plan (**and spending it appropriately!**)