

# Cancer survival trends and inequalities: what is the role for Europe?



**European Joint Action on Comprehensive Cancer Control 2014-2017**

**Brussels, Belgium, 13 May 2015**

## Measures of cancer burden – definition

- **Incidence** – new cases (number, rate)
- **Survival** – probability alive at time “ $t$ ”
- **Prevalence** – survivors (number, %)
- **Mortality** – deaths (number, rate)

## Measures of cancer burden – for me

- Incidence – what's my risk?
- Survival – what are my chances?
- Prevalence – how many of us are there?
- Mortality – those we have lost ...

# Measures of cancer burden - application

- Incidence – prevention, planning
- Survival – effectiveness of health care
- Prevalence – care, survivorship
- Mortality – priorities

# Population-based cancer registry

**Attempts to record information on all new cases of cancer in a defined population**

***Person:** habitual resident*

***Place:** defined territory*

***Time:** continuous*

# Cancer in Europe 2002-2020

Annual change in incidence rates	New cases per year	Increase from 2002
No change	3,300,000	+ 20 %
1% rise	4,000,000	+ 40 %
2% rise	4,800,000	+ 70 %

# Global surveillance of cancer survival

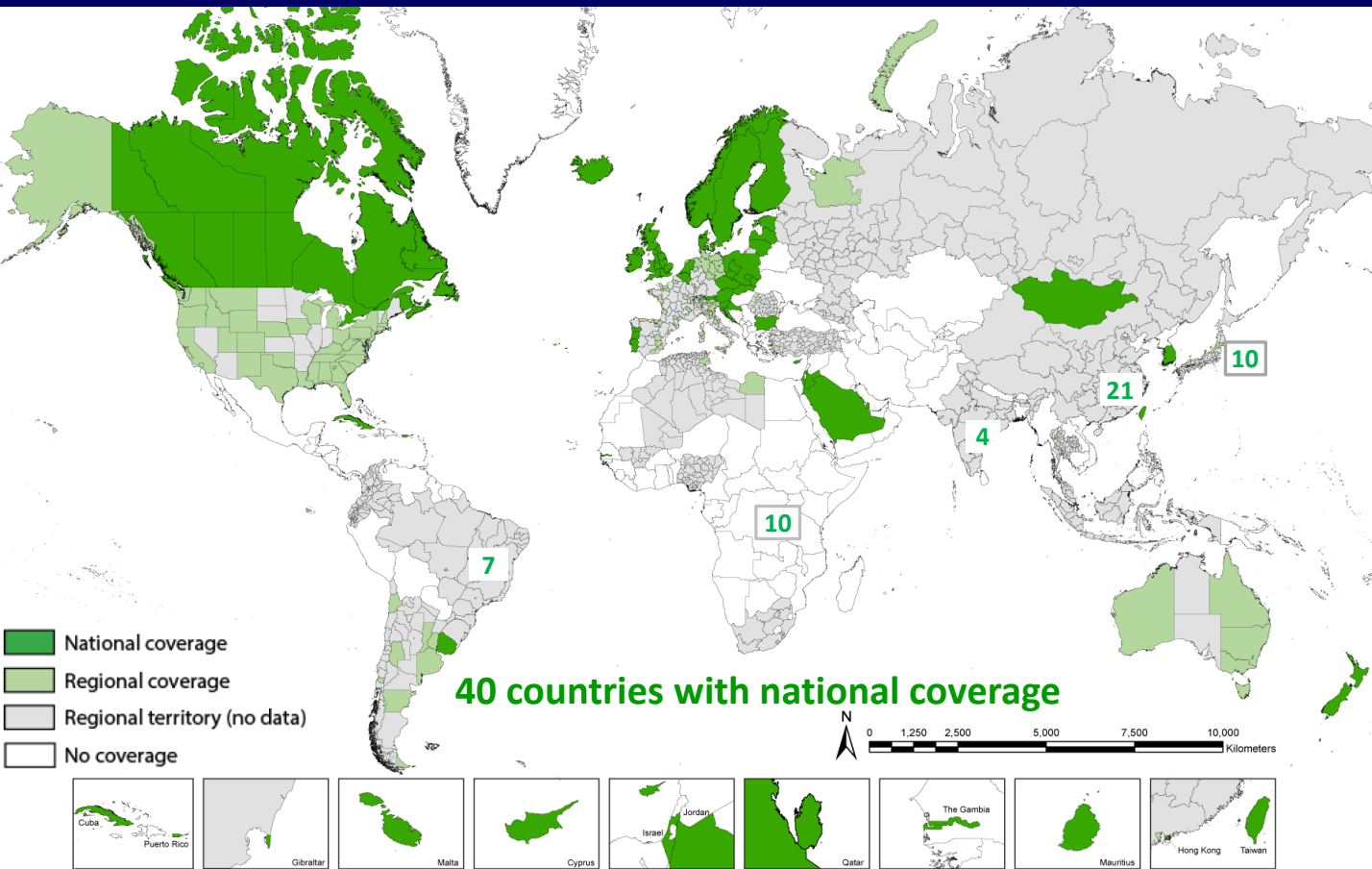
## Participants

- 279 cancer registries (128 in Europe)
- 67 countries (29 in Europe)

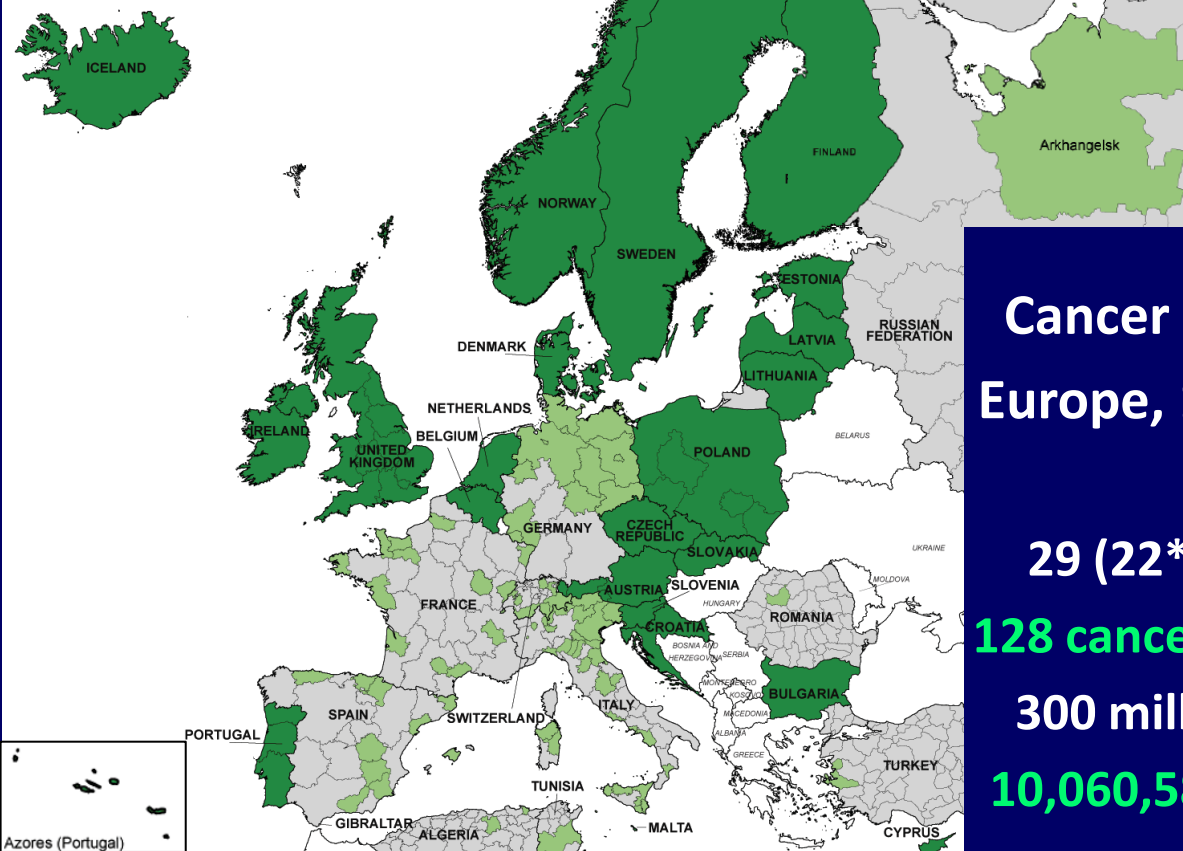
## Long-term trends, 10 common cancers

- Patients diagnosed 1995-2009
- Follow-up to 2009
- Stomach, colon, rectum, liver, lung, breast (women), cervix, ovary, prostate, leukaemia
- Acute lymphoblastic leukaemia in children

# World – 279 registries, 67 countries

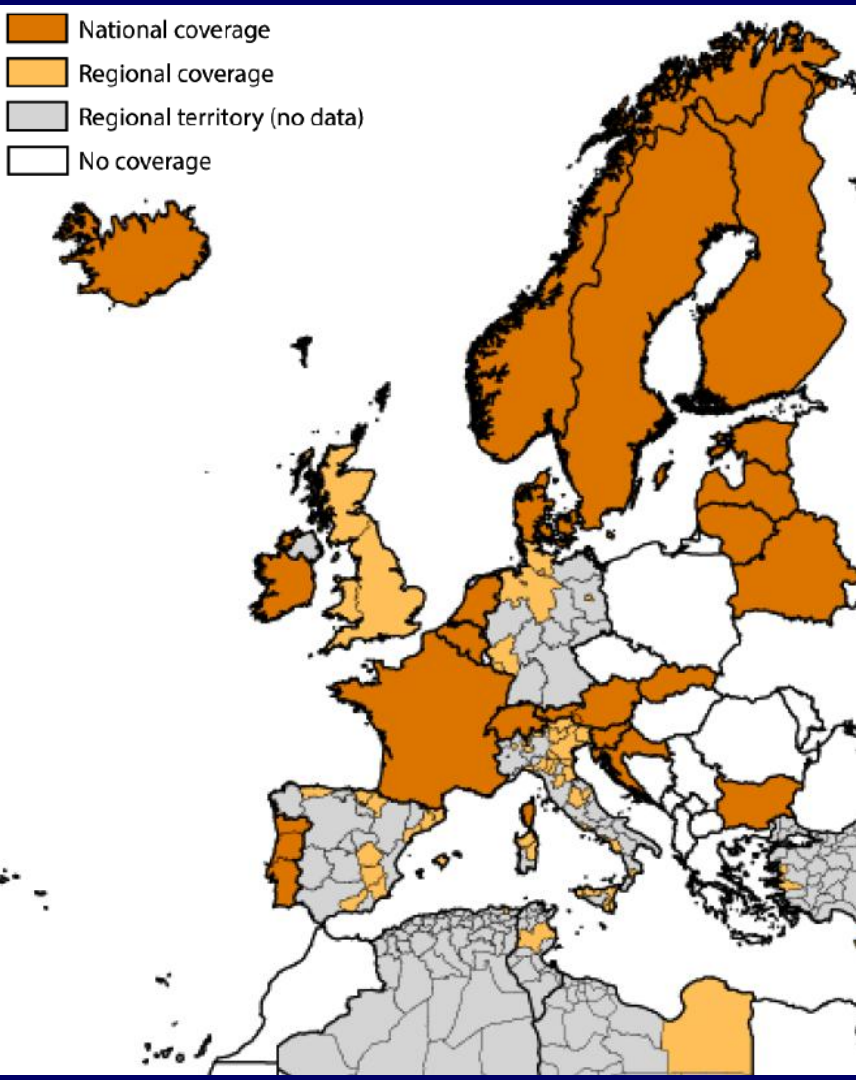


- National coverage
- Regional coverage
- Regional territory (no data)
- No coverage



**Cancer in adults:  
Europe, 1995-2009**

**29 (22\*) countries**  
**128 cancer registries**  
**300 million people**  
**10,060,587 patients**



## Leukaemia in children: Europe, 1995-2009

26 (22\*) countries

86 cancer registries

25,558 children

# Central Europe





**Germany**

**13 Länder**

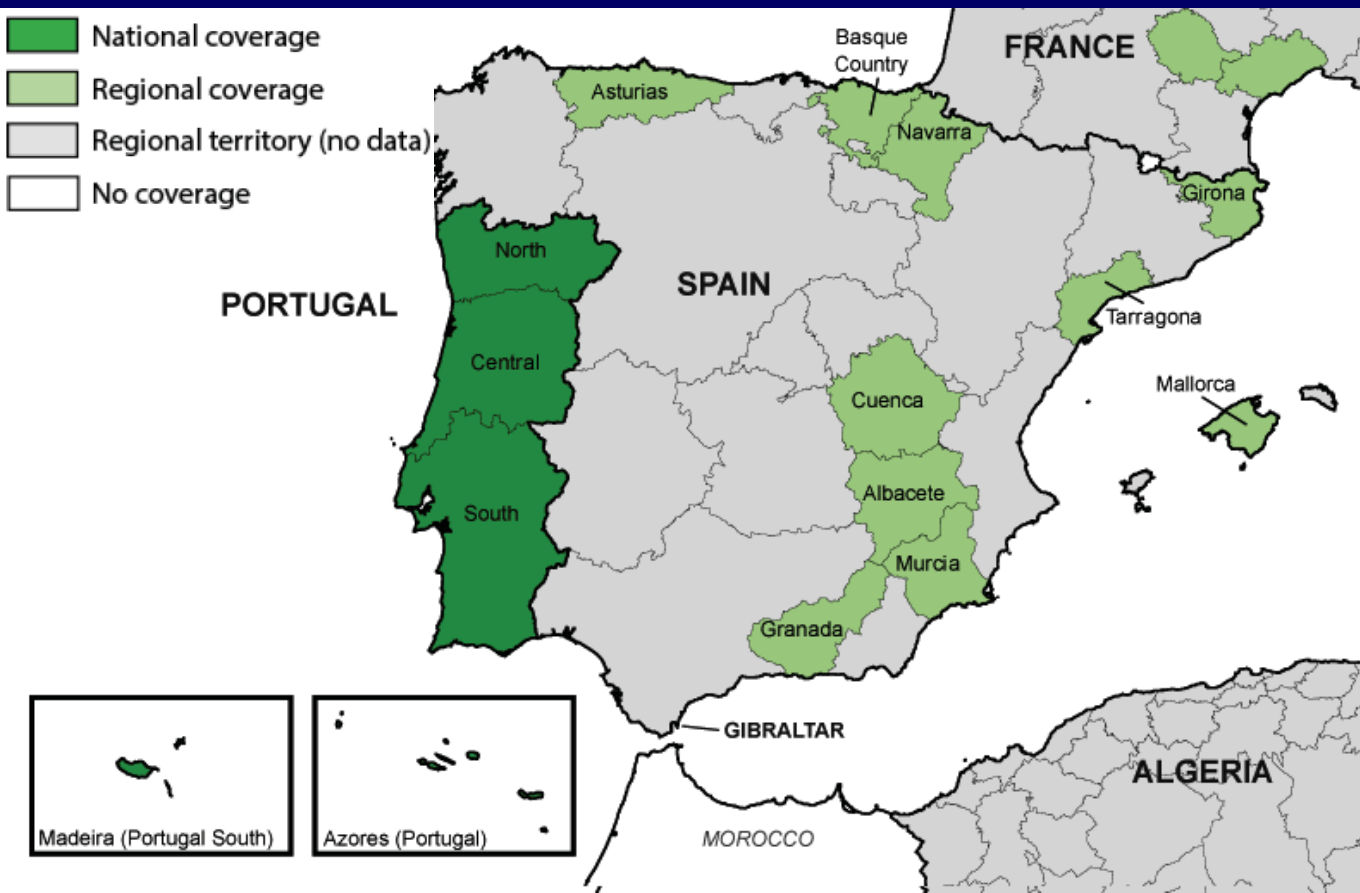
**43.9% coverage**

**1,367,345 patients**



**Portugal:** 4 registries, 100% coverage, 225,902 patients

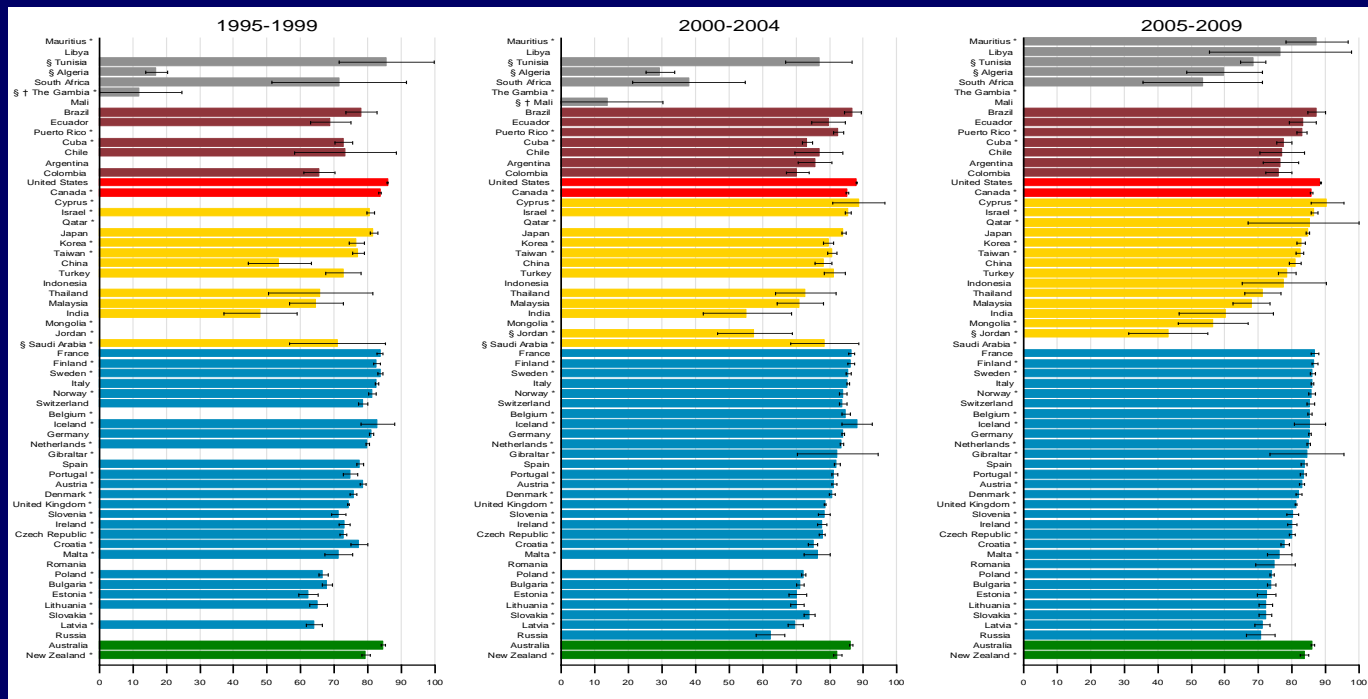
**Spain:** 10 registries, 21.9% coverage, 308,081 patients



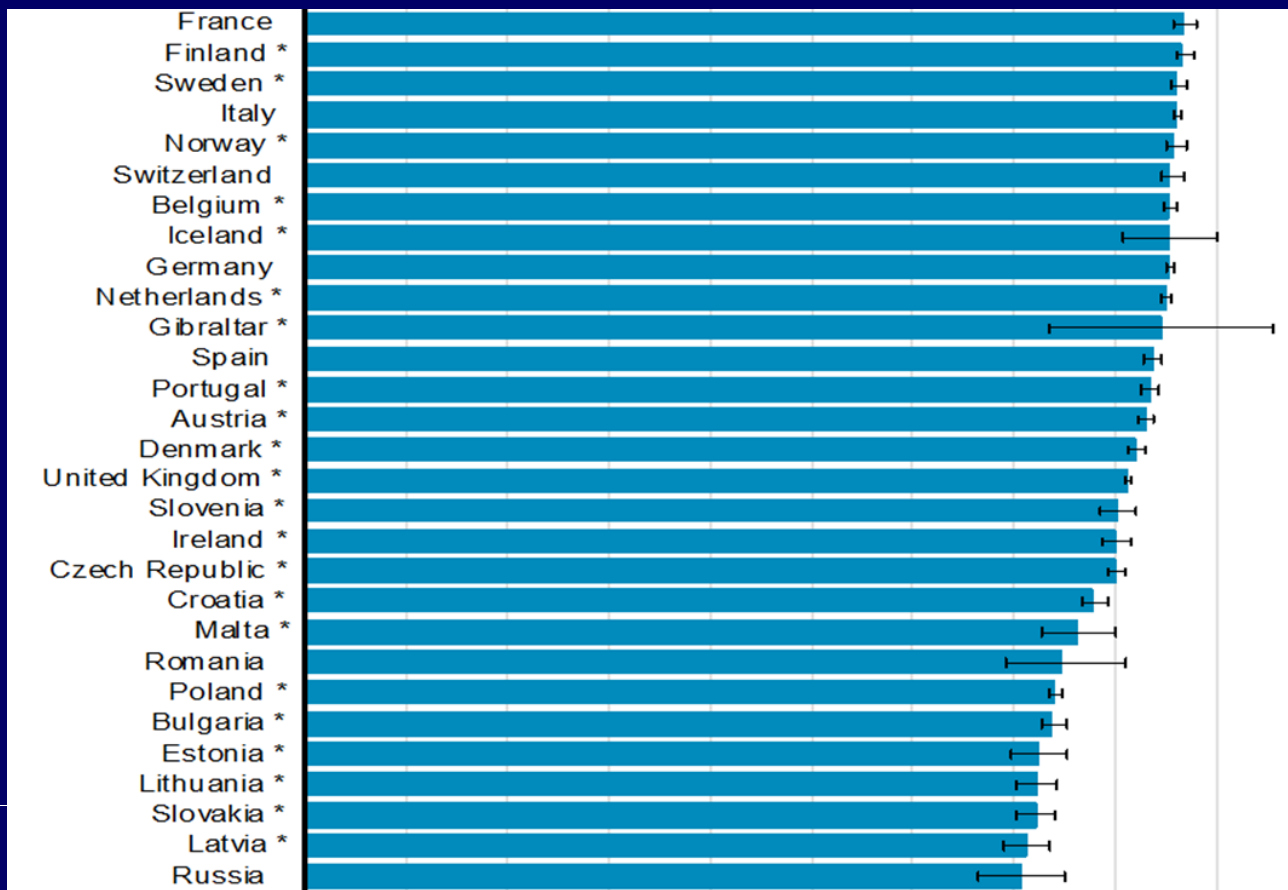
# Cancer patients in survival analyses

<b>Africa</b>	<b>12,509</b>
<b>America C+S</b>	<b>349,052</b>
<b>America N</b>	<b>11,282,731</b>
<b>Asia</b>	<b>3,274,733</b>
<b>Europe</b>	<b>10,086,145</b>
<b>Oceania</b>	<b>837,995</b>
	<b>25,676,887</b>

# Breast cancer in 5,486,928 women (15-99 years): age-standardised 5-year net survival (%)

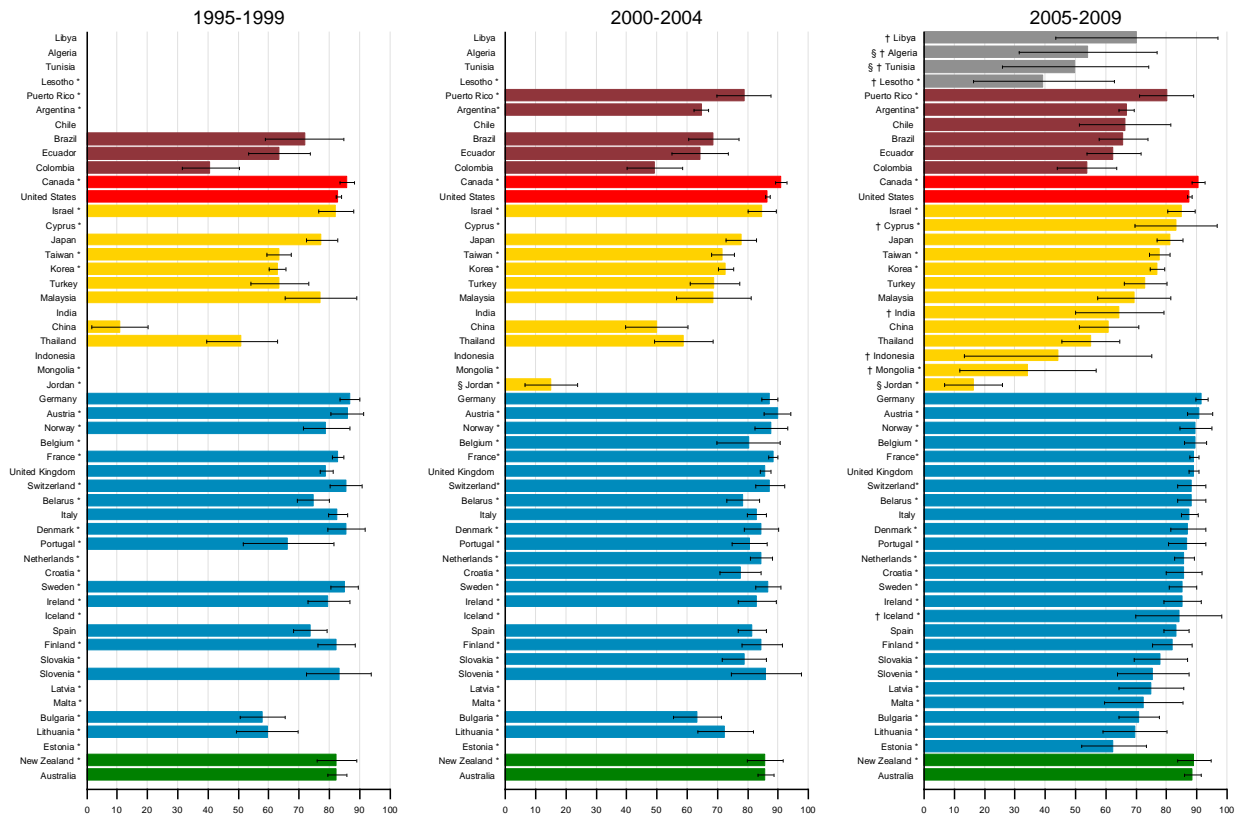


# Breast cancer in 5,486,928 women (15-99 years): age-standardised 5-year net survival (%)



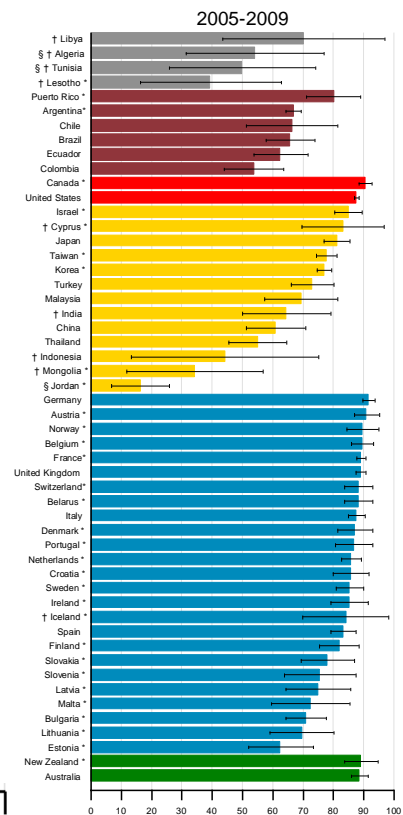
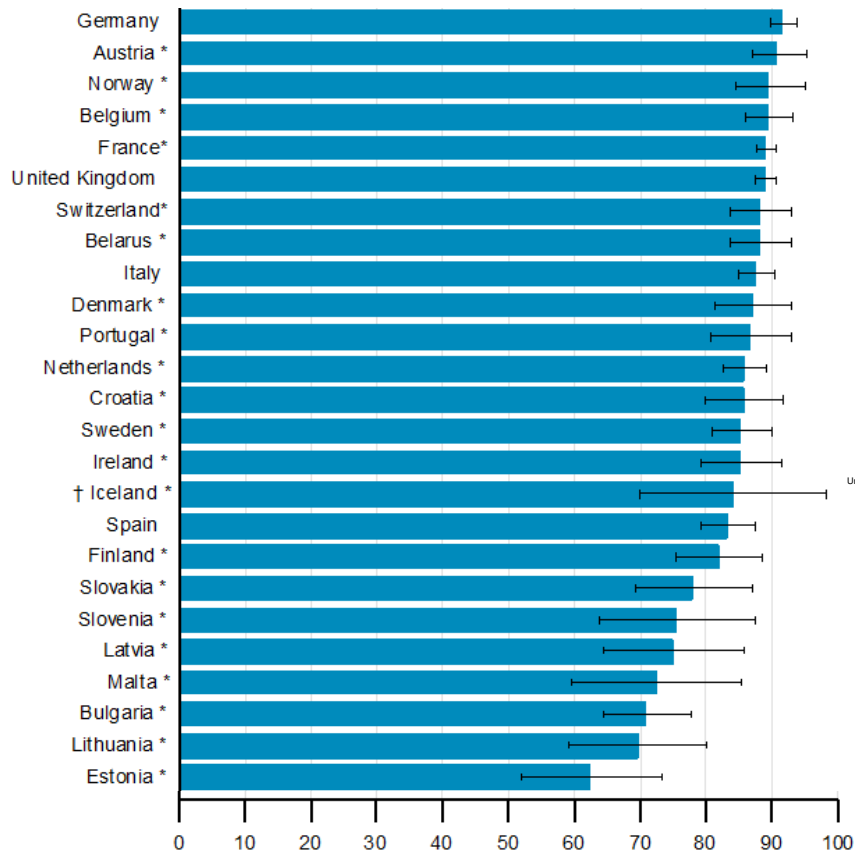
# Acute leukaemia in 74,343 children (0-14 years): age-standardised 5-year net survival (%)

## Acute lymphoblastic leukaemia in children



# Acute leukaemia in 74,343 children (0-14 years): age-standardised 5-year net survival (%)

Acute lymphoblastic leukaemia in children



# Some key messages

- 🏠 Cancer survival for 67 countries, home to 2/3 of world population
- 🏠 Fits overarching goal of UICC World Cancer Declaration 2013  
“There will be major reductions in premature deaths from cancer, and improvements in quality of life and cancer survival”
- 🏠 Wide range in survival – inequity in diagnosis and treatment
- 🏠 Differences in survival suggest lessons can be learnt
- 🏠 Raises questions for further research
- 🏠 World-wide surveillance is crucial for cancer control policy
- 🏠 Cancer registries need political, legislative and financial stability

# WHO European Region

## Global surveillance of cancer survival (CONCORD)

- **Evidence base for health care effectiveness**
- High-quality evidence for surveillance of public health threats
- **Is coherent with WHO strategic objectives**
- Enables comparison between low-income countries with innovative programmes
- **Fills a huge gap in the knowledge of cancer survival world-wide**

# Organisation of Economic Co-operation and Development

## Global surveillance of cancer survival (CONCORD)

- “ ... proving to be hugely valuable in our own work in documenting the quality of health care across countries.”
- “ ... has contributed to a sea-change in how national policymakers are using international comparisons to improve their health systems.”

# Global surveillance of cancer survival 1995–2009: analysis of individual data for 25 676 887 patients from 279 population-based registries in 67 countries (CONCORD-2)



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## Summary

**Background** Worldwide data for cancer survival are scarce. We aimed to initiate worldwide surveillance of cancer survival by central analysis of population-based registry data, as a metric of the effectiveness of health systems, and to inform global policy on cancer control.

**Methods** Individual tumour records were submitted by 279 population-based cancer registries in 67 countries for 25.7 million adults (age 15–99 years) and 75 000 children (age 0–14 years) diagnosed with cancer during 1995–2009 and followed up to Dec 31, 2009, or later. We looked at cancers of the stomach, colon, rectum, liver, lung, breast (women), cervix, ovary, and prostate in adults, and adult and childhood leukaemia. Standardised quality control procedures were applied; errors were corrected by the registry concerned. We estimated 5-year net survival, adjusted for background mortality in every country or region by age (single year), sex, and calendar year, and by race or ethnic origin in some countries. Estimates were age-standardised with the International Cancer Survival Standard weights.

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Allemani et al., *The Lancet* 2015

<http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2814%2962038-9/fulltext>

# Private autonomy **vs.** public interest

**How do we balance the individual's right to privacy with society's right to understand the health risks we all face, and how effectively those risks are being controlled?**

# Use of identifiable data: public interest

Potential risk to individuals

**Some loss of autonomy**

**Very low risk of breach of confidentiality**

Proven benefit to individuals and society

**Information on cause of diseases – prevention**

**Public health surveillance – protection**

**Survival – effectiveness of health system**

**Survivorship – quality of life, rehabilitation, care**

# European Directive on the protection of individuals' personal data, 1995

**Article 8(3) *exempts* data collection from the requirement for the patient's consent if it is:**

“... required for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of healthcare services, *and* where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy.”

# European Regulation on Data Protection, 2015

“Processing of personal data concerning health which is necessary for historical, statistical or scientific research purposes shall be permitted **only** with the consent of the data subject, and shall be subject to the conditions and safeguards referred to in **Article 83.**”

*European Parliament legislative resolution on the proposal for a regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation) (COM(2012)0011 – C7-0025/2012-2012/0011(COD) Amendment 191 (12 March 2014)*

# Medical research - threatened by insistence on patient consent

*“I don’t expect patients just to tolerate the kind of work that cancer registries and epidemiologists do: I believe they would be astonished if it weren’t done.”*

# European Regulation on Data Protection

**Threatens retrospective clinical research, biobanks and population-based cancer registries**

**Would require patient's informed consent to record their disease in a cancer registry**

**Would require researchers to ask for a patient's 'specific' consent *every single time* new research is carried out on available data**

# Informed consent will stop disease registries

- **West Germany – informed consent, 1990-**
  - Hamburg and Saarland registries closed for 2 years
- **East Germany – informed consent, 1990-**
  - Closure of largest European cancer registry (1953-)
- **Hungary – Personal Data Protection Act 1992**
  - Cancer registration stopped until 1999
- **UK – General Medical Council guidance 2000**
  - Emergency legislation required to protect registries
- **Nordic countries – statutory, no consent**
  - Efficient, complete, productive cancer registries

# **Members of the European Parliament**

**... could explain to the public why, despite the underlying principle of consent for data collection, identifiable data must for some purposes be collected without consent, for public health research that harms no-one and benefits everyone.**

# European Commission could...

- Survey **public attitudes to cancer registration**
- Promote **cancer to become a reportable disease**
- Endorse **registries as key instrument in cancer control**
- Develop **a European Cancer Information System**

# **European Union institutions ...**

**Balance personal autonomy and societal benefit –  
as with communicable diseases**

**One-time consent for retrospective, observational  
research**

**Derogation from consent for disease registries and  
public health research**

**Disease registries to remain public agencies with  
strict rules and public oversight**

# **Is it now time to create a new European Centre for Cancer Control ?**

**Astonishing disparity in EU public health commitment between communicable and non-communicable diseases:**

**Communicable diseases – about 1% of all deaths**

**European Centre for Disease Prevention and Control (ECDC)  
(Solna, Sweden, 2004-)**

- **300 staff**
- **€ 58.3 million budget (2014)\***

**Cancer – 3,400,000 cases, 1,800,000 deaths (20-28% of all deaths)**

**Cancer team, Joint Research Centre (Ispra, Italy, 2013-)**

- **5 staff**