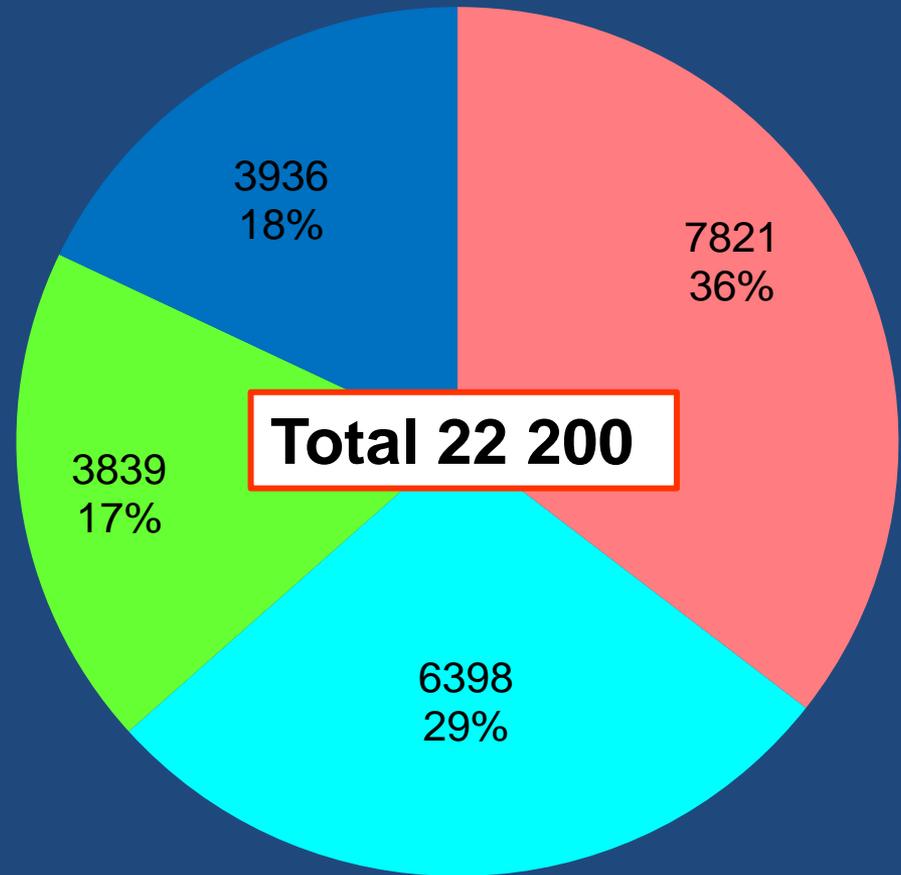
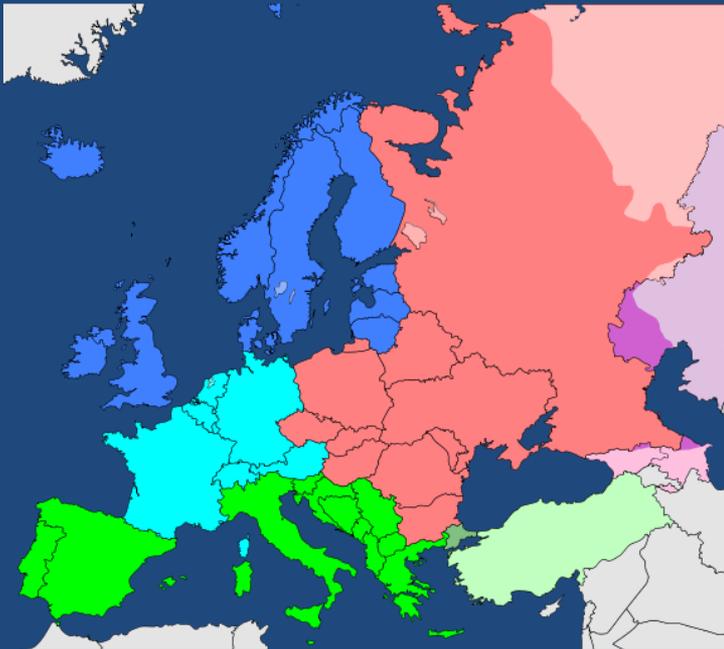


# THE NEED FOR EVIDENCE: CANCER REGISTRATION

Ana-Maria Forsea, MD, PhD  
*Melanoma Patient Network Europe,*  
Carol Davila University of Medicine and Pharmacy, Bucharest

# Estimated number of annual melanoma deaths in Europe

- Central and Eastern Europe
- Western Europe
- Southern Europe
- Northern Europe



Source: EUCAN 2012 (IARC)

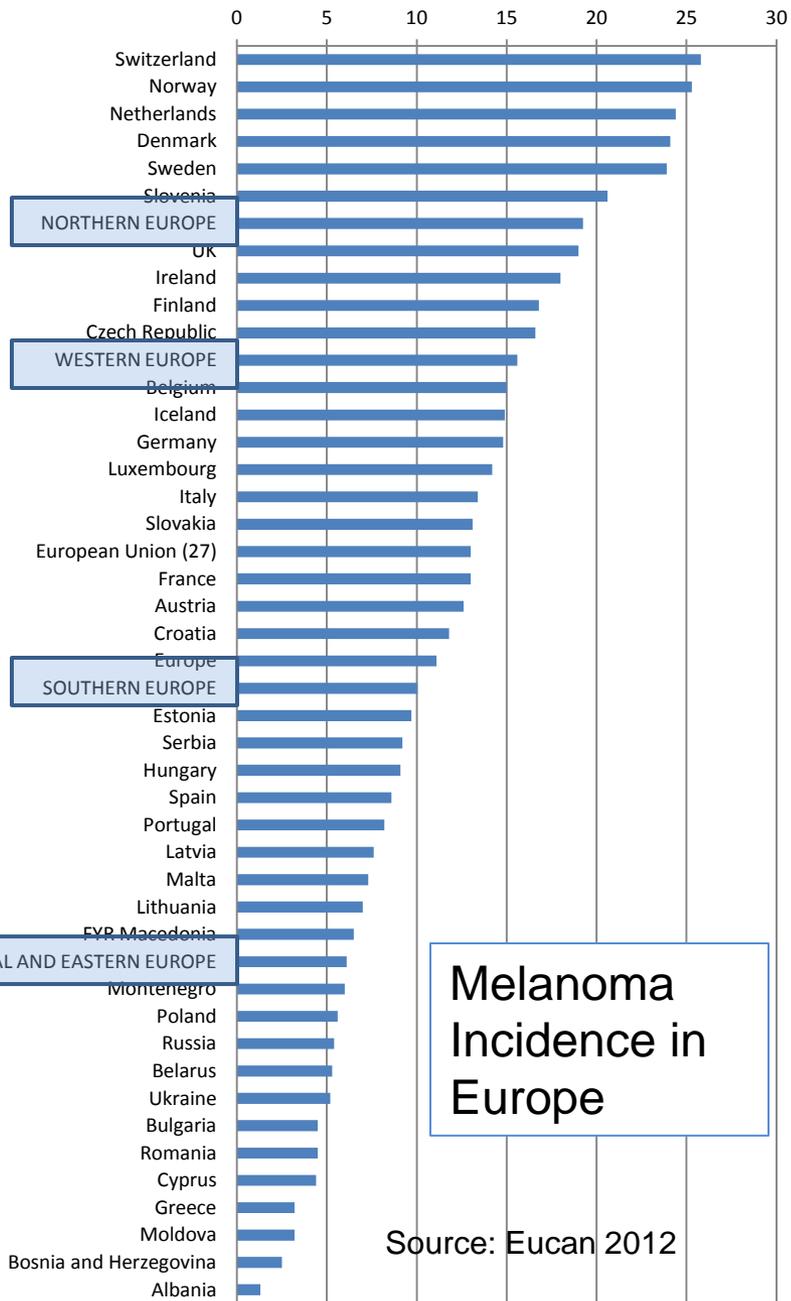
# Melanoma

## Melanoma in Romania

- No official national statistics
- Advanced stages ( 25% III/IV)
- 30% of cases > 4mm at diagnosis
- No new drugs reimbursed
- No clinical trial ongoing

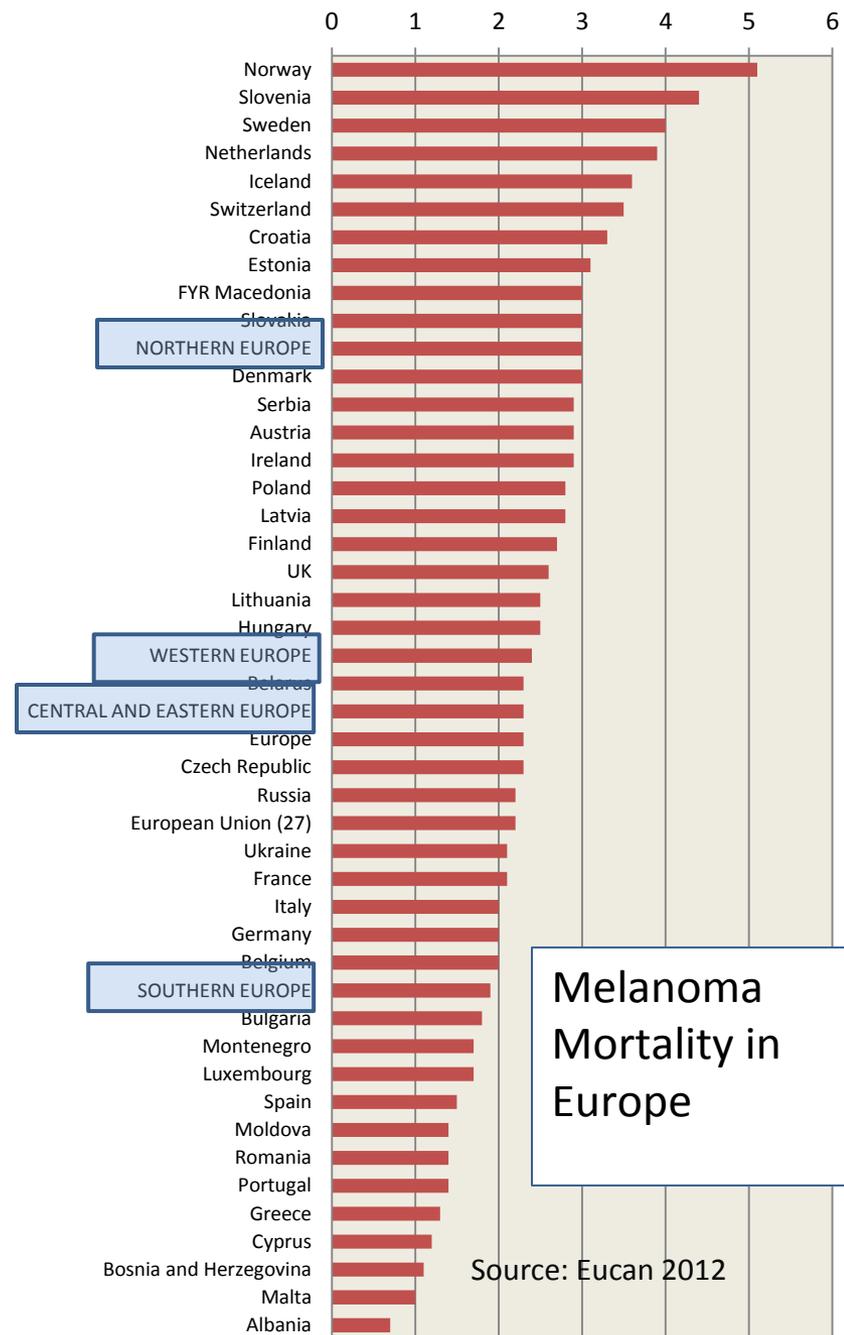


new cases/100 000 inhabitants/year (EAR)



Source: Eucan 2012

deaths/100 000 inhabitants/year (EAR)

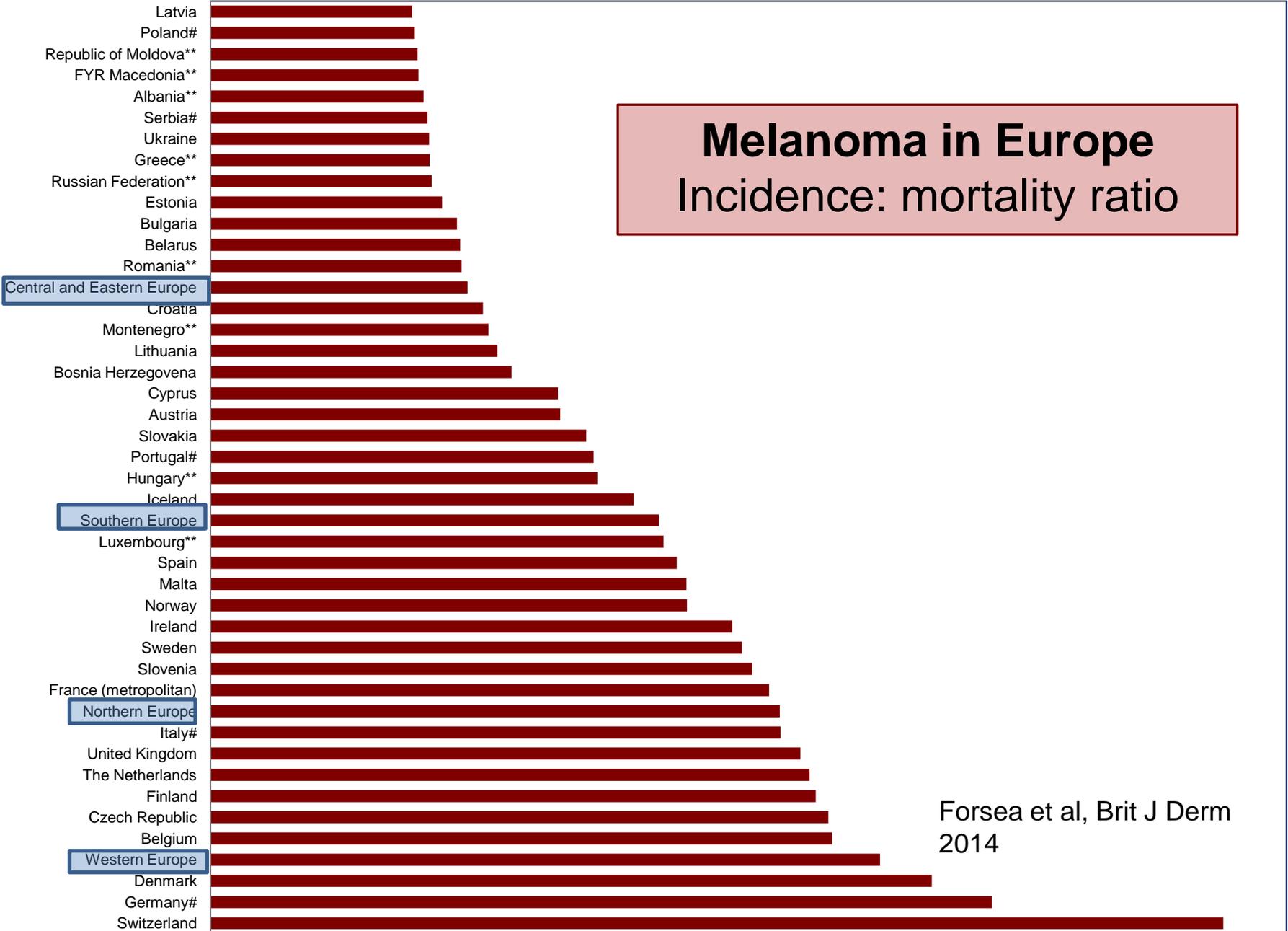


Source: Eucan 2012

0,0 2,0 4,0 6,0 8,0 10,0 12,0

# Melanoma in Europe

## Incidence: mortality ratio



Forsea et al, Brit J Derm  
2014

# Cancer registry data are indispensable to:

- Evaluate the cancer burden and estimate future trends
  - ▣ Number of new cases (incidence), existing cases (prevalence), deaths (mortality)
  - ▣ Estimate survival
- Decide on allocation of resources and capacity investments for different types of interventions of cancer therapy/prevention
- Follow & evaluate the quality of oncological treatment
  - ▣ Evaluate and justify the cost-effectiveness of cancer care including new expensive drugs
  - ▣ Utilization according to evidence-based guidelines
  - ▣ Late side effects
  - ▣ Risk & management of recurrences
- Monitor the impact of preventive/therapeutic initiatives
- Monitor mass screening
- Provide comparable data for cross-border health care and trans-national research

# Epidemiologic information for cancer in Europe

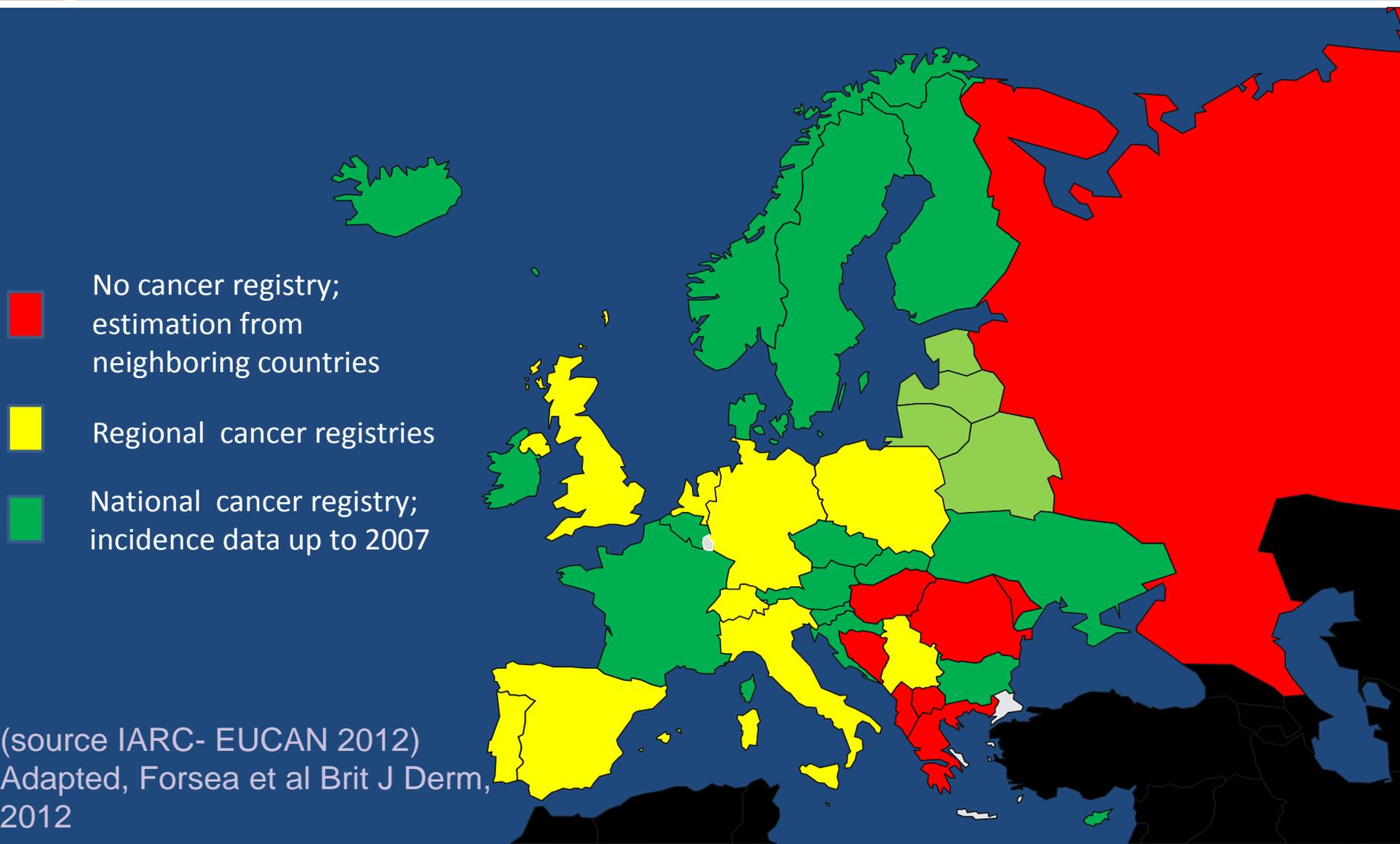
- IARC Cancer in Five Continents (vol X, 2013)
  - ▣ **Recorded** data from cancer registries, up to 2007
- IARC Globocan Project 2012
  - ▣ **Estimated** data for all countries, based on input data from cancer registries (projected to 2012)
- European Cancer Observatory
  - ▣ IARC data for Europe
- European consortia studies (EUROPREVAL, EURO CARE...)
  - ▣ Data from cancer registries in selected countries
- Individual reports from national/regional cancer registries



# Cancer registries

- Coverage: national/regional with cumulative national coverage/ regional
- Sources of data
- Collection of data: passive/active
- Cancer reportable disease: no/ recommendation/ regulation/ legislation
- Minimum data: age, sex, tumor site, stage
- Quality indicators:
  - ▣ percentage of cases microscopically verified (MV%),
  - ▣ percentage of cases registered from a death certificate only (DCO%),
  - ▣ ratio (as percentage) of the number of deaths from a particular cancer to the number of cases registered in the same period (MI%)

# Cancer registration in Europe



(source IARC- EUCAN 2012)  
Adapted, Forsea et al Brit J Derm,  
2012



# Data Sources- German States Cancer Registries

(\*IARC Cancer in 5 Continents, X, 2013)

	Hamburg	Munich	N. R. Westphalia	Bremen	Schleswig- Holstein	Branden- -burg	Mecklenburg- Vorpommern	Saxony	Saarland
<b>Radiotherapy</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Public hospital in-patient</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Private hospital in-patient</b>	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Public hospital out-patient</b>	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Private hospital out-patient</b>	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
<b>Public hospital discharge</b>	No	No	No	Yes	No	Yes	Yes	Yes	No
<b>Private hospital discharge</b>	No	No	No	Yes	No	Yes	Yes	Yes	No
<b>Oncology dept.</b>	Yes	No	No	Yes	No	Yes	Yes	Yes	Yes
<b>Other hospital</b>	No	No	No	No	No	No	No	No	No
<b>Imaging center</b>	No	No	No	No	Yes	No	No	No	No
<b>Pathology laboratories</b>	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes
<b>Autopsy services</b>	Yes	No	No	No	Yes	No	No	No	Yes
<b>Hematology laboratories</b>	No	Yes	Yes	Yes	Yes	No	No	No	Yes
<b>Death certificates</b>	Yes	No	No	Yes	Yes	No	No	No	Yes
<b>General practitioner</b>	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes
<b>Health insurance</b>	No	No	No	No	No	No	No	No	No
<b>Hospice /palliative care</b>	No	Yes	No	Yes	No	No	No	No	No

# Melanoma registration issues

- ❑ Cancer registries of quality absent in 9 European countries
- ❑ Incomplete population coverage by existing cancer registries
- ❑ Mostly passive cancer registration in Central and Eastern Europe countries
- ❑ Ambulatory and private dermatological care/pathology labs not well covered
- ❑ The majority of cancer registries do not systematically record melanoma thickness
- ❑ Stage, but not thickness reported
- ❑ Estimation of time trends from existing serial estimations is not recommended by IARC

# Level of confidence in melanoma registration in Europe

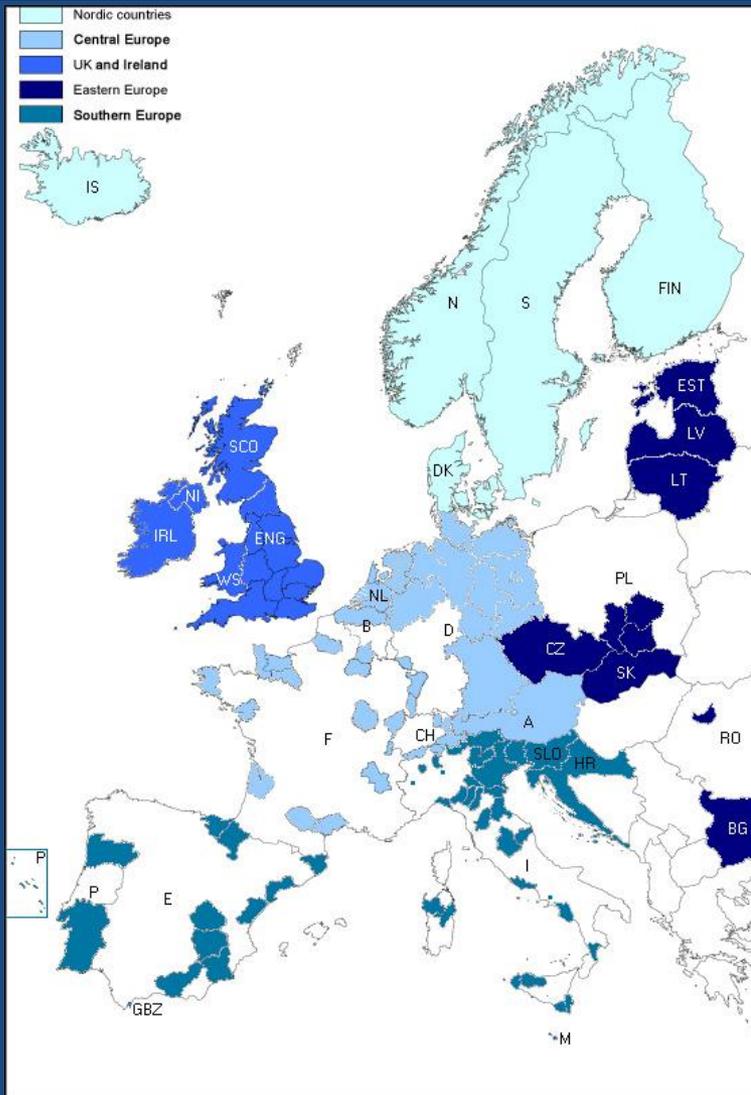
Q7 No. of respondents confident that the national/regional registry of cancer in own country provides correct evaluation of melanoma	Number of respondents			
	Western Europe		Eastern Europe	
	N=26	(%)	N=26	(%)
Incidence	17	65	17	65
Mortality	18	69	18	69
Tumor thickness	14	54	11	42
Tumor stage	13	50	11	42

Q6 Sources from which the national/regional cancer registry in your country gathers data on melanoma		Western Europe (% of responses)	Eastern Europe (% of responses)
<b>From dermatologists in oncology centers</b>	Yes	50	69
	No	12	8
	Do not know	23	23
<b>From dermatologists in public hospitals</b>	Yes	50	62
	No	19	15
	Do not know	23	23
<b>From dermatologists in private practice</b>	Yes	46	27
	No	15	35
	Do not know	27	38
<b>From oncology centers</b>	Yes	54	73
	No	19	0
	Do not know	23	23
<b>From public health authority records</b>	Yes	38	31
	No	0	8
	Do not know	35	58
<b>Melanoma reporting compulsory for physicians</b>	Yes	38	46
	No	50	15
	Do not know	8	35

# Causes of cancer registries pitfalls in South-East Europe

- Lack of experienced staff
  - Low salaries, frequent personal cuts, frequent administrative changes
- Inconstant and insufficient financing
- Lack of understanding and knowledge from the health authorities and decision-makers
- Bureaucracy, lack of political support, lack of coordination and cooperation between managing entities
- Incomplete coverage of data
  - Passive collection, reporting not compulsive and not reinforced, physicians and hospitals insufficient motivated to report
- Challenging transition to electronic data

# Pan-European studies and consortia



## EUROCARE

- Available recorded data on cancer survival in Europe (EUROCARE 1-5)
- Melanoma 5 years survival:
  - Europe Mean 83.2%
  - Northern Europe: 87.7%
  - Central/Western Europe: 87.6%
  - Eastern Europe: 73.7%
  - Bulgaria 49.6%
  - Poland 61.5%
  - Slovakia 74.7%
  - Czech 83.4%
  - Baltic states: 65.1-71.3%

# National registries

- European Network of Cancer Registries (<http://encr.eu/>)
- Eurocourse Project (<http://www.eurocourse.org/>)
- Obstacles:
  - national language, delayed publication, variable quality, incomplete coverage, insufficient coverage of non-oncological, ambulatory and private health care facilities, passive registration

# Romania Cancer Registration

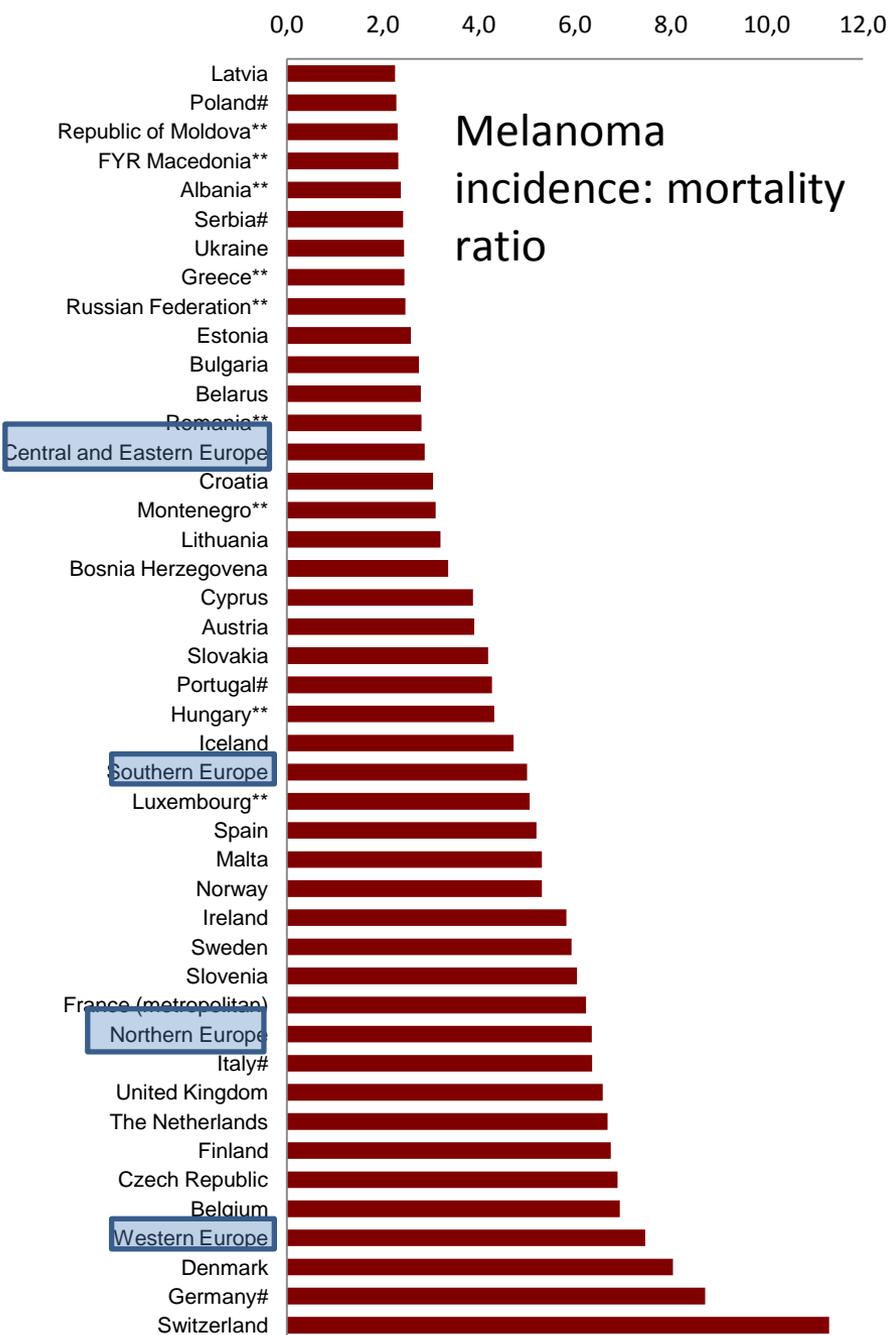


- National Cancer registry established by law in 2008
- 8 regional registries
- 1 registry ( West) is accepted as sufficient quality by IARC
- Underreporting, covering oncology only, passive registration mainly
- Underfinanced, understaffed

What to do when no data is available?

# Leveraging information

- Search scientific literature ( e.g. PubMed) for individual reports
- Health reports: WHO, OECD, Eurostat
- Ask national public health authorities
- Ask national health professionals societies
- Research:
  - ▣ Expert opinion survey
  - ▣ Physicians surveys ( e.g. Eurodermoscopy)
  - ▣ Hospital/pathology laboratory databases



## Germany:

Median tumor thickness at diagnosis 0.53mm in 2000 (down from 1.8mm in 24 years);

Survival in 2009: 87%-91%

Garbe et al, Clin Derm, 2009; Baumert et al, Mel Res, 2009; Eisemann et al, Br J Derm 2012

## Romania:

Melanoma thickness on presentation (reference center): <1mm (10%); 1-2mm (35%); 2-4 mm (30%); >4mm (25%)

Forsea D et al, 2000

## Serbia

Military Medical Academy database 2005 - 2010

Ulceration in 40% of primary tumors; mean Breslow: 3.95 mm; primary tumors > 4 mm in 32% of patients

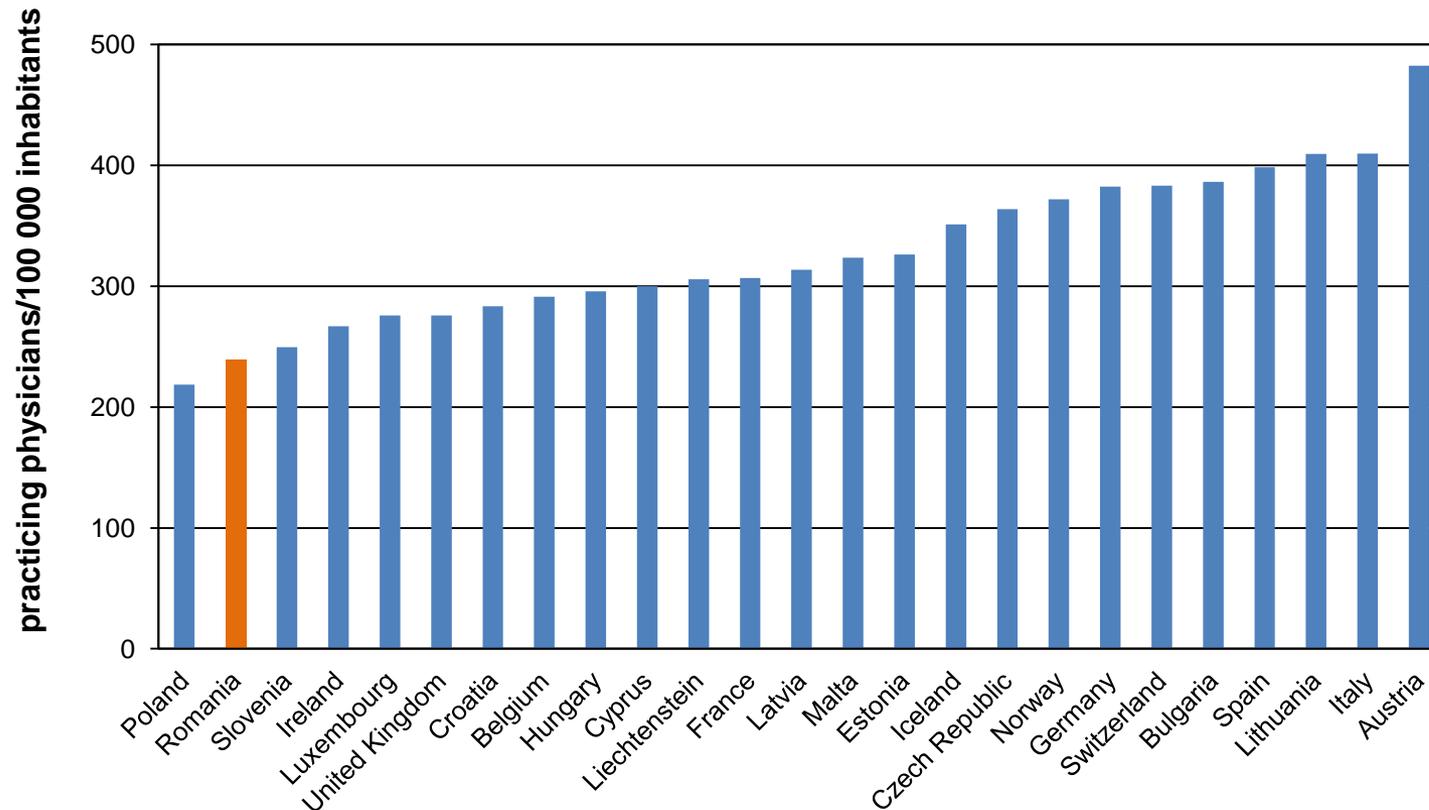
Kandolf-Sekulovic et al, Mel Research 2011

# Leveraging information

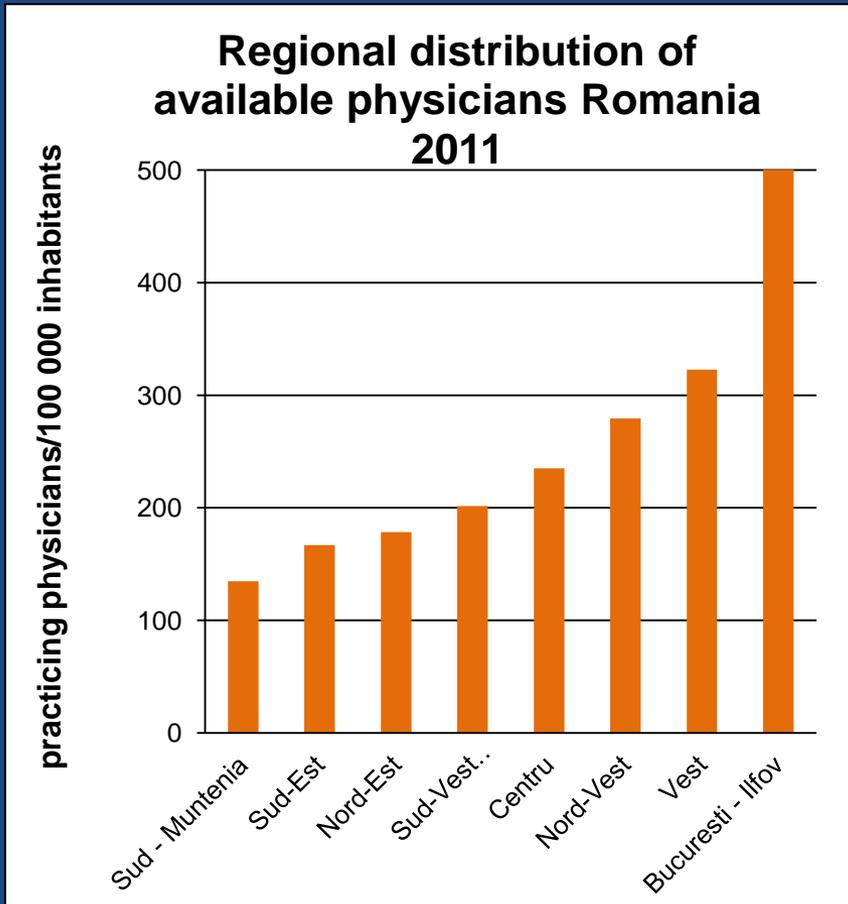
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# Physicians availability in Europe

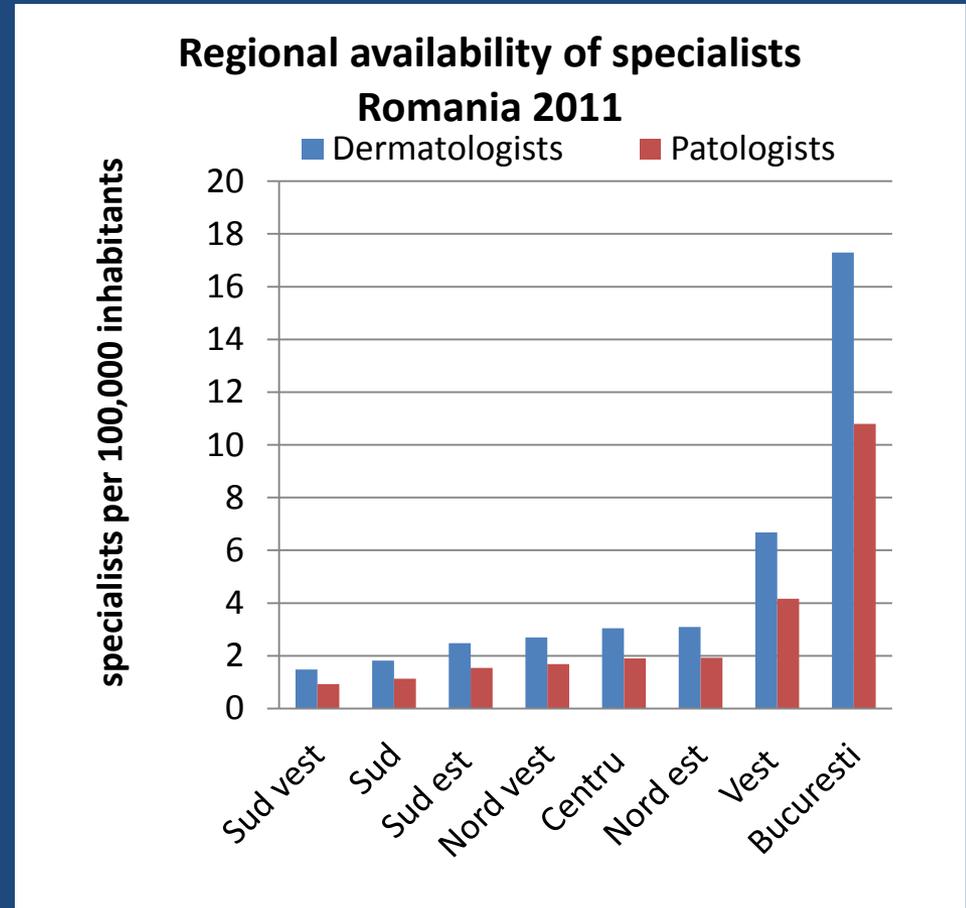
**Practicing physicians Europe 2011**  
(OECD Health Indicators)



# Specialist physicians availability

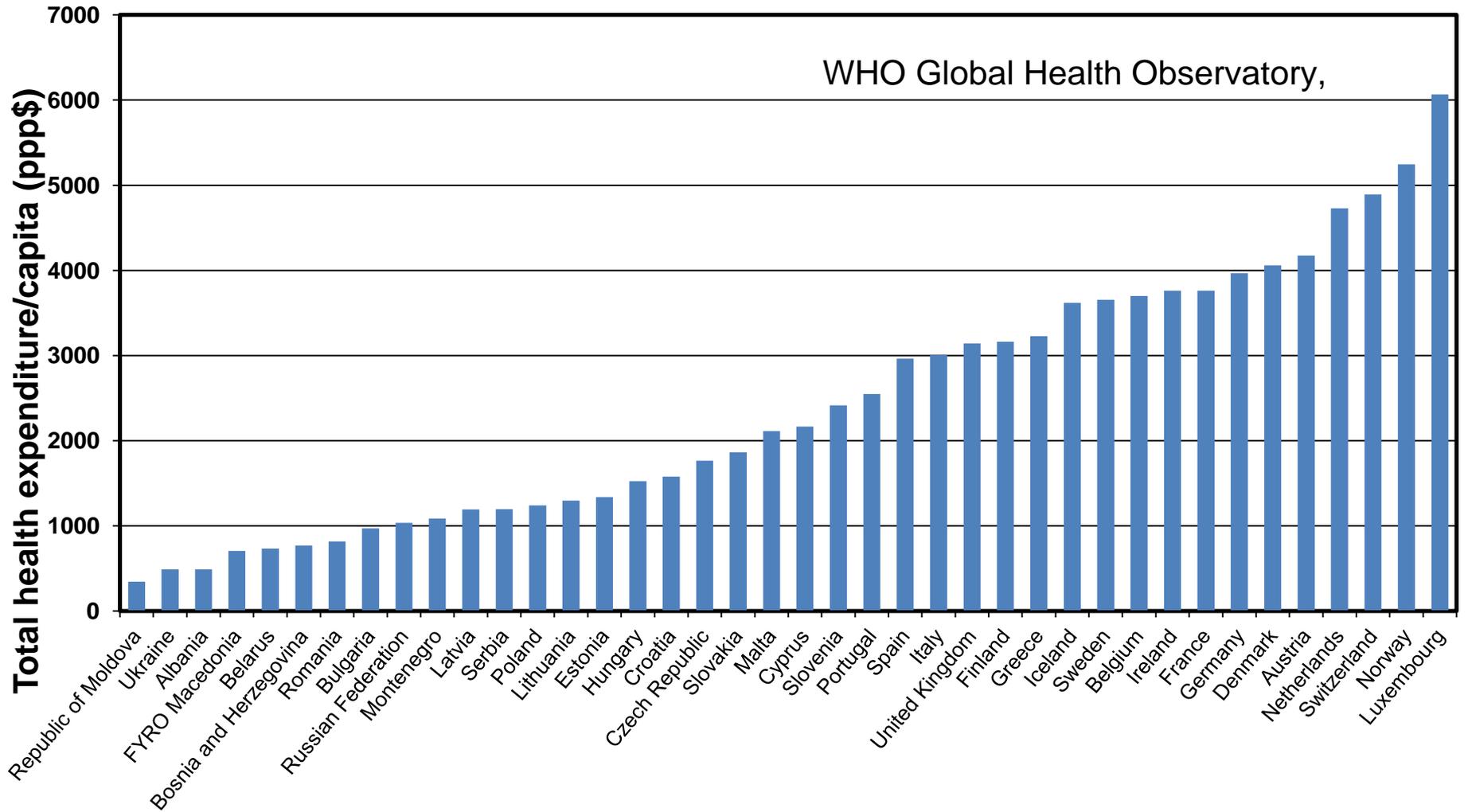


Source: Eurostat



Source: Eurostat, National Physicians College Romania

# Total health expenditure/country



# Leveraging information

- Search literature (“Pubmed”) for individual reports
- Health reports: WHO, OECD
- Ask national public health authority
- Ask national dermatological/professional society
- **Research:**
  - ▣ Expert opinion survey
  - ▣ Physicians surveys (e.g. Eurodermoscopy)
  - ▣ Hospital/ pathology laboratories databases

# Europe: Melanoma thickness at diagnosis

- The majority of cancer registries do not systematically record melanoma thickness

Q12. Estimated proportion of melanomas diagnosed in each thickness category	Western Europe Average percentage of the region	Eastern Europe Average percentage of the region
<1mm	60%	28%
1-2mm	21%	24%
2-4mm	12%	22%
>4mm	7%	24%

# Eurodermoscopy

International Dermoscopy Society

## EURODERMOSCOPY PAN-EUROPEAN STUDY OF DERMOSCOPY USE

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## Welcome to EURODERMOSCOPY!

*Last Updated on Wednesday, 12 March 2014 17:57 | *

**Eurodermoscopy is the first Pan- European study that aims to enhance the use of dermoscopy for the diagnosis of skin diseases and for the early detection of skin cancers in European countries**

[Background](#)

Newsflash

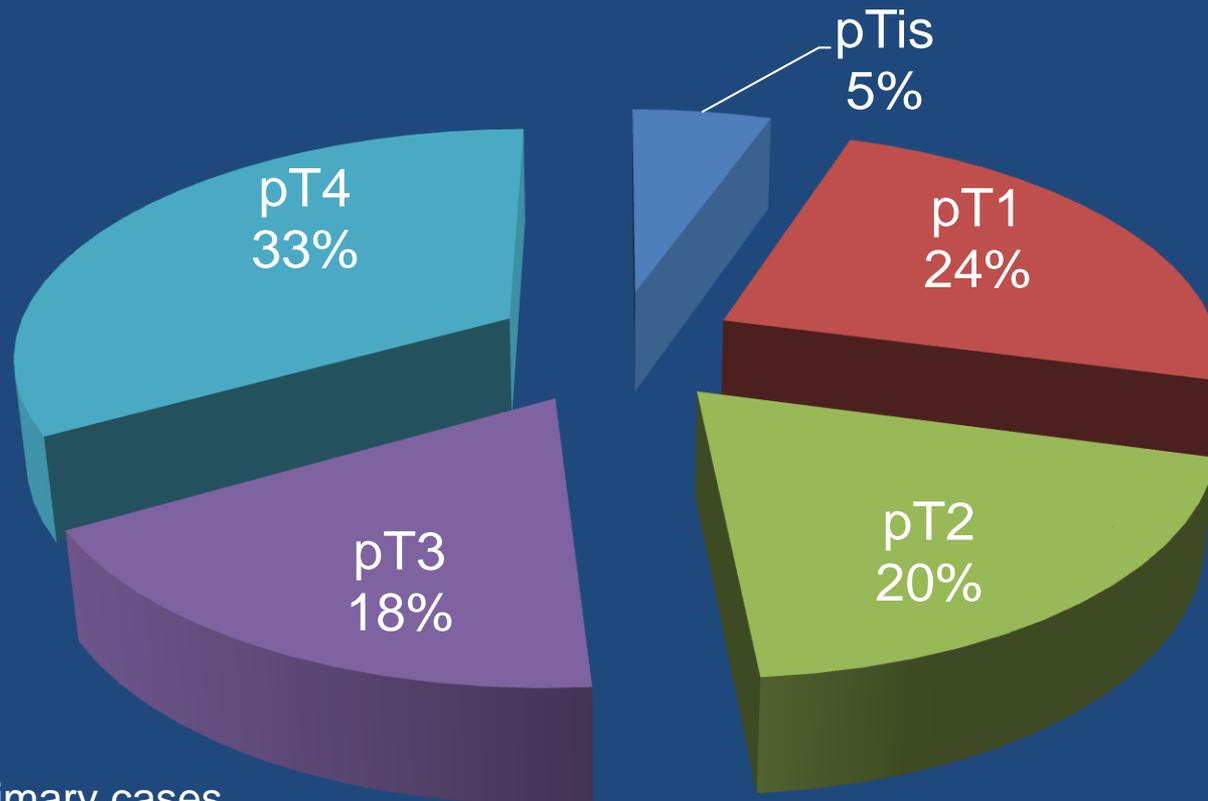
**Study online survey is preparing to be launched**

Data will be collected by an online survey, using the IDS platform. Additionally, in each participating country, other methods may be used (post mail, e-mail, fax, phone interview etc.), at the choice of the

# Melanoma thickness estimation Romania

Melanoma thickness distribution

Reference University Center for Dermato-oncology, Bucharest 2002-2011



318 new primary cases

Zurac S et al, in press, 2014

# Leveraging information

- Search literature( Pub med) for individual reports
- Health reports: WHO, OECD
- Ask national public health authority
- Ask national dermatological/professional society
- Research:
  - ▣ Expert opinion survey
  - ▣ Physicians surveys ( Eurodermoscopy)
  - ▣ Hospital/ pathology lab databases
- LOBBY: for cancer registration
- SUPPORT: research on epidemiological data/ NGO-registries

# Annual melanoma deaths in Europe



Source: EUCAN 2012 (IARC)

# Annual melanoma deaths in Europe



**22 200**

**= 1 Jumbo Boeing crashing every week, one year long**



Thank you for attention!