



# iPAAC – an overview

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Budapest, 20 May 2019

Tit Albreht with the collaboration of Tina Lipušček and Karmen Hribar



Co-funded by  
the Health Programme  
of the European Union

# iPAAC Kick-off meeting a year ago...



# 1st GOVERNMENTAL BOARD MEETING

27  
June

2018

Brussels

**35**  
participants &  
**20** countries  
represented!



## PARTICIPANTS:

- Representatives of Member States
- WP Leaders

# 1st STAKEHOLDER FORUM

**20  
September**

**2018**

**Brussels**

**Nearly 60  
participants!**

## **PARTICIPANTS:**

- Work Packages Leaders
- iPAAC's Collaborating Partners

Attendace of a **large range of stakeholders** who had an opportunity to provide input that can support the iPAAC Joint Action!

**2** thematic main sessions





# 2st GOVERNMENTAL BOARD MEETING

**24**  
**January**

**2019**

**Brussels**



**40**  
participants &  
**19** countries  
represented!

## PARTICIPANTS:

- Representatives of Member States
- WP Leaders

# The iPAAC Roadmap – key deliverable

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## **Key deliverable of the iPAAC Joint Action:**

**Roadmap on Implementation and Sustainability of Cancer Control Actions, which will support Member States in implementation of iPAAC and CANCON recommendations.**

## **Information for the iPAAC ROADMAP will be gathered from 3 sources:**

- 1. WP 4 Country visits**
- 2. WP 5 - 10 work**
- 3. Other Joint Actions**

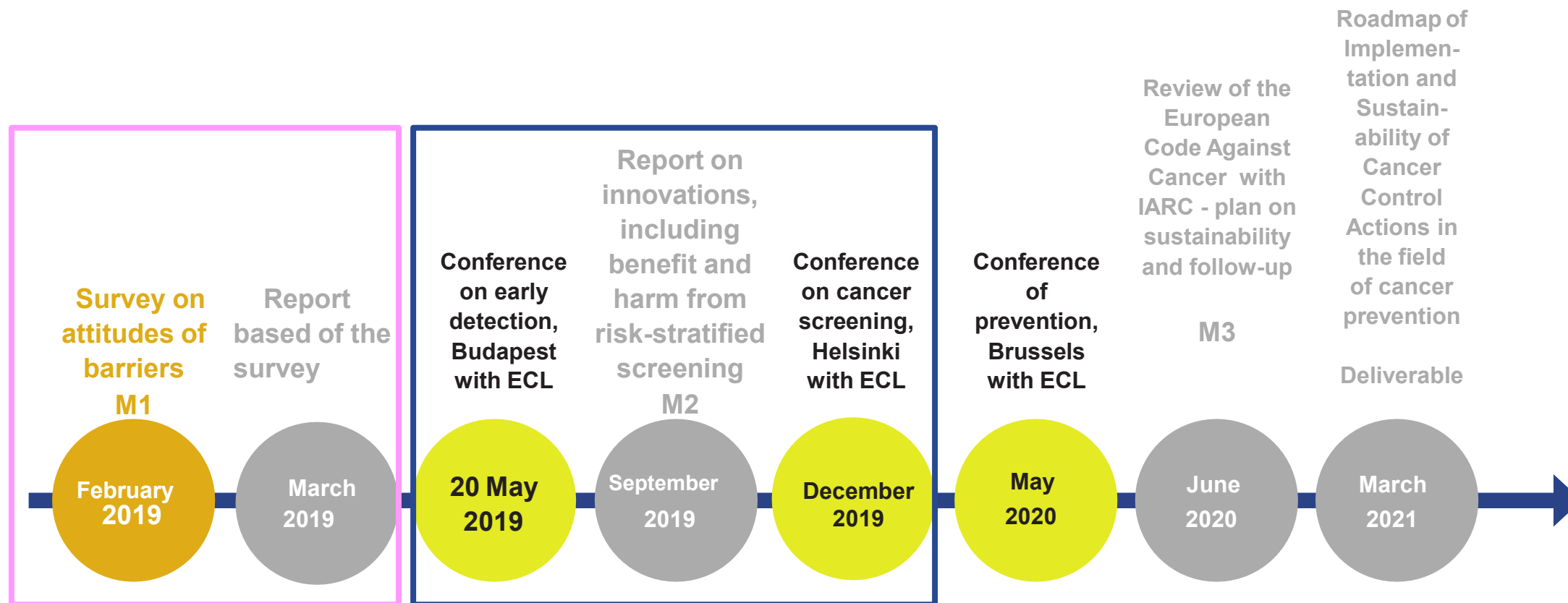
# The Roadmap – key deliverable

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It is important to remember that:

- ✓ Actions need to be implemented throughout the Joint Action and not only at its end;
- ✓ There is a need for close collaboration between the JA and the Member States;
- ✓ Priority in planning in the first 18 months needs to be given to the actions and recommendations from the previous JAs;
- ✓ The new actions and recommendations proposed by the current JA need to be defined and proposed timely with the view of the finalisation of the project.

# IPAAC WP5 Timeline of key activities





# WP6 Genomics and Cancer

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Scope: Develop practical guidance for Member States on:

- 1) organizing the **societal debate** on ethical, legal and privacy issues on the use of genome information in healthcare
- 2) installing stratified screening by **genetic testing** of high-risk cancer patients
- 3) implementing **precision genomics** in medical care
- 4) how to deal with '**Direct to Consumer**' testing
- 5) **education and training** on genomics of health professionals, policy makers and the citizens

- Task 6.1: Applying genome information in health care: a paradigm shift in healthcare
- Task 6.2: Concept for the implementation of risk-adjusted prevention: the breast cancer case
- Task 6.3: Requirements and prerequisites for implementation of 'omics' in routine molecular diagnosis in oncology
- Task 6.4: 'Direct to Consumer' genetic testing
- Task 6.5: Education and training on genomics for healthcare professionals

## Topics

1. Citizen participation methodologies
  - Citizen forum Belgium (case study)
  - French approach on genomics acceptance (case study)
  - Sienna project results (research)*
  - Wellcome Trust initiative (research)*
1. Roadbook genomics in HCS (Be, F, It) (case studies)
2. WGS in HCS (UK, F, 1M Genomes project) (case study)
3. DTC policy
4. Tool for education & training on genomics

# WP 7 – Cancer information and registries

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Task 7.1: Mapping data sources and state-of-art of integrated cancer information systems

Task 7.2: Piloting the integration of data on care pathways

Task 7.3: Piloting the integration of data on cancer costs

Task 7.4: Piloting the integration of data on long-term follow up of cancer survivors

Task 7.5: Piloting longitudinal integration of administrative health care records and centralised coding systems at national level

Task 7.6: Delivering informative epidemiological indicators on cancer prevalence and survivorship

Task 7.7: Support to the Road Map – cancer information and registries



# WP 8 – Challenges in Cancer Care



## **Task 8.1: Definition of neglected cancers: the case for pancreatic cancer**

- Preliminary list of core clinical variables for cancer registries in pancreatic cancer circulated (*March 2019*)

*Report expected before June 2019*

## **Task 8.2: Neglected cancers: proposal of criteria for reorganisation of treatment delivery**

Task Leader: ICO, Participating Partners: SAM (VUHSK), WIV-ISP, IPHS

- Literature review carried out (March / April 2019) with a focus on policy measures to reorganize treatment delivery of pancreatic cancer.
- Workshop planned for discussion in September 2019, Bratislava; with scientific societies, patients representatives, experts and national cancer plans.
- Final report expected November 2019
- ECCO (subcontract): Essential requirements for pancreatic cancer. December 2019

## **Task 8.3: MDTs and potential impact of new technologies and systems. Assessment of the opportunities for improving integration of cancer care**

Task Leader: ICO, Participating Partners: IPHS, BcSAS, NIJZ, SAM (VUHSK)

- Selection of care studies: ongoing with the support of ECCO.
- Site – visits: expected for *May to June 2019*. Methodology approach: multiple-case study.
- *Report delivered in November 2019*





# WP 8 – Challenges in Cancer Care



## Task 8.4: Economics of cancer care

Task Leader: ISS, Participating Partners: ICO, SAM (VUHSK), NIJZ, NIPH (IPMN), ISS (MoH)

4.1: To review international experiences in promoting allocative efficiency and identifying low-value or inappropriate cancer care and to map the desirable characteristics of interventions targeted to health care providers for improving the level of appropriateness in clinical care.

- Survey prepared and circulating.
- *Meeting in September 2019*

4.2. To review the recent developments in reimbursement models and experiences in introducing innovative treatments in European health systems, with special focus on radiation oncology and complex cancer surgery as case studies

- Literature review for reimbursement in radiotherapy oncology (*expected May 2019*)
- Literature review for reimbursement in surgical oncology (*expected September 2019*)
- Workshop to review the pros and cons of each reimbursement model with scientific societies, patients representatives and experts (*January 2020*)
- *Report expected April 2020.*



# WP 8 – Challenges in Cancer Care



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## Task 8.5: Pain management in the context of cancer care

Task Leader: ISS, Participating Partners: ICO, ISS, THL

- Literature review on pain prevalence, barriers to adequate pain management with focus survivors.
- *Report expected September 2020*

## Task 8.6: Palliative care

Task Leader: ISS, Participating Partners: ICO, THL

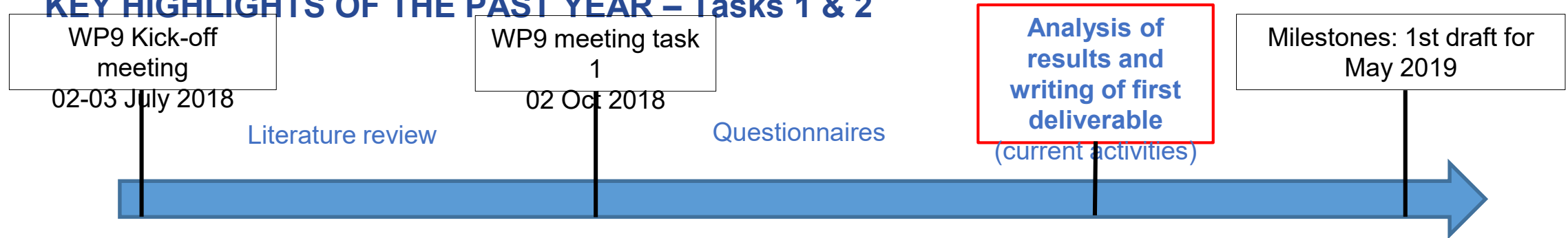
- *Report expected September 2020*



# WP 9 – Innovative Therapies in Cancer

## French National Cancer Institute (INCa)

### KEY HIGHLIGHTS OF THE PAST YEAR – Tasks 1 & 2



#### Main results from lit. review:

- 120 CPG placing innovative immunotherapies (ITS)
- Off-label recommendations identified mainly for small target groups, rare cancers
- Place of innovative immunotherapies could differ between guidelines, especially when comparison data are missing
- Hard to keep updated GPC in this fast evolving field



Completion of 1st  
questionnaire by iPAAC  
partners

#### Main results from questionnaire:

- Only half of the EU countries have included innovative ITS in at least one CPG
- Comparison between countries and between therapeutic indications regarding access in terms of reimbursement and restrictions of uses
- Existing early access programs

# WP 9 – Innovative Therapies in Cancer

## French National Cancer Institute (INCa)

### KEY HIGHLIGHTS OF THE PAST YEAR – Task 2 & 3 - Horizon scanning systems & Biomarkers

WP9 Kick-off meeting 02-03 July 2018

WP9 meeting task 2 & 3  
06 March 2019 - Bruxelles

WP9 Horizon scanning  
meeting  
November 2019 - INCa

Preparation of the task

- Literature review
- Meetings with Euroscan, IHSI

Presentation of methodology for retrospective analysis to evaluate the efficiency of HS in oncology

Review of existing  
Horizon scanning systems  
and organizations



Identification of key figures and  
issues associated with  
innovative cancer therapies



- Highlight methodological specificities needed in HS systems in the field of oncology, especially for
  - cell and gene therapies
  - Biomarkers
- Assessment of inequalities between European Countries

# WP 9 – Innovative Therapies in Cancer



French National Cancer Institute (INCa)

## PLANS FOR THE NEXT YEAR – Task 1 & 2

- Consolidation of the deliverable linked to task 1 to present results from literature review and questionnaires
- Review and validation of the deliverable by WP9 partners. Finalized version expected for September 2019
- Consolidate main fields of interests for the roadmap:
  - List of clinical practice guidelines providers in Europe in the field of oncology
  - Examples of fruitful collaborations for the production of CPG; and of endorsement methods
  - Examples of reimbursement models enabling fast access
  - Examples of frameworks enabling early access to innovative immunotherapies for an unauthorized indication
  - Innovative cancer therapies in clinical practice guidelines: remaining challenges (acceptability of off-label recommendations, how to improve production and update of CPG, visibility?, need to create a public financing system to implement studies comparing several innovative therapies between them when no comparison data are available)
  - Remaining challenges: Link with ECL – European Fair Pricing Network (increase transparency of innovative therapies prices – joint negotiations in EU)?
  - Remaining challenges for access to innovative therapies across Europe (including inequities)





# WP 9 – Innovative Therapies in Cancer

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French National Cancer Institute (INCa)

## PLANS FOR THE NEXT YEAR – Task 2 & 3 – Horizon Scanning systems

- Conduction of the retrospective analysis with the help of the questionnaire
- Additional meeting will be organized in November 2019 to validate task 3 deliverables
- For the roadmap, the following points could be included:
  - Generalities on Horizon scanning systems: definition, purposes, main methodological steps to follow to implement an HSS
  - Present some existing European HSS in place
  - Present the main ongoing collaboration initiatives existing in Europe
  - Present specificities to be considered in the HS methodology for the oncology field with a focus on innovative immunotherapies, gene and cell therapies (with the example of CAR-T cells) and biomarkers
  - Highlight challenges related to the assessment of impact of innovative therapies in the field of oncology

## PLANS FOR THE NEXT YEAR – Task 4 – Real-life monitoring of innovative immunotherapies

- Meeting dedicated to task 4 to be organized in February 2020

# WP 10 – Governance of Integrated and Comprehensive Cancer Care



German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

## KEY HIGHLIGHTS OF THE PAST YEAR 2018/19

**Goal:** “....develop practical instruments (...) (to ensure) a standardized (...) comprehensive oncological care in all Member States that is tumour-specific and delivers (...) high-quality care to all patients. These instruments should be used by NCCPs for the governance of oncological care”.

**Task 1:** Assess and review NCCPs; develop recommendations on how the results of tasks 10.2-10.5 could be included in updated NCCPs

- 1.1. Survey on National Cancer Control Programmes/Cancer Documents in EU (M12) ✓
- 1.3. Preliminary literature research on the conceptual model of governance and stewardship of cancer care (M12) ✓

**Task 2:** Review and assess existing models of oncological patient pathways; develop a generic patient pathway for CCCNs

- 2.1. Literature Review of existing models of oncological patient pathways (M12) ✓
- 2.1. Agreement of definition of patient pathways (M12)

**Task 3:** Review and assess implemented QI; develop standardized methodology; develop set of general and tumour specific QI for CCCNs *delayed ready in M14*

- 3.1. Literature Review of already implemented Qis and their respective methodology which was used (M12) –



# WP 10 – Governance of Integrated and Comprehensive Cancer Care



German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

## KEY HIGHLIGHTS OF THE PAST YEAR 2018/19 (cont.)

**Task 4:** Review and assess existing PROMs; develop a framework for the implementation and ✓ pilot the framework in CCCNs

- 4.1. Preliminary results of literature review of existing models of collecting PROMs (M18)

**Task 5:** Develop a set of generic and tumour-specific requirements (including PP, QI and PROMS) for the setup of CCCNs; develop framework to monitor the successful implementation of the set of requirements ✓

- 5.3. Establishment of CCCN pilot sites: Charité Hospital, Berlin/Germany & Lower Silesian Oncology ✓ Centre, Wrocław/Poland (M3)
- 5.1. Generic and tumour-specific requirements for the set-up of CCCN developed and agreed (M12)

**Overall:** Synergies between work packages identified

- Task 3 QI and WP 7.2 (= Piloting the integration of data on care pathways)
- Task 4 PROMs and WP8.1 (= Definition of neglected cancers: the case for pancreatic cancer)
- Task 5 CCCN and WP 8.2 + WP 7.2 (8.2 =Neglected cancers: proposal for criteria for reorganization of treatment delivery [of pancreatic cancer] ; 7.2 = with the goal to use the same key figures/quality indicators)



# WP 10 – Governance of Integrated and Comprehensive Cancer Care

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German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

## PLANS FOR NEXT YEAR 2020

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**Task 5:** Develop a set of generic and tumour-specific requirements (including PP, QI and PROMS) for the setup of CCCNs; develop framework to monitor the successful implementation of the set of requirements



# PREVENTION AND EARLY DETECTION OF ORAL CANCERS IN HUNGARY, CHALLENGES AND FUTURE PLANS

Éva Remenár MD. PhD.

National Institute of Oncology, Budapest

First WP5 iPAAC Conference

20th May 2019, Budapest



# HEAD AND NECK CANCER

✓ **„Common” head and neck cancers:** squamous cell cancer arising from the mucosa of the upper aerodigestive tract (>90% of all head and neck cancers)

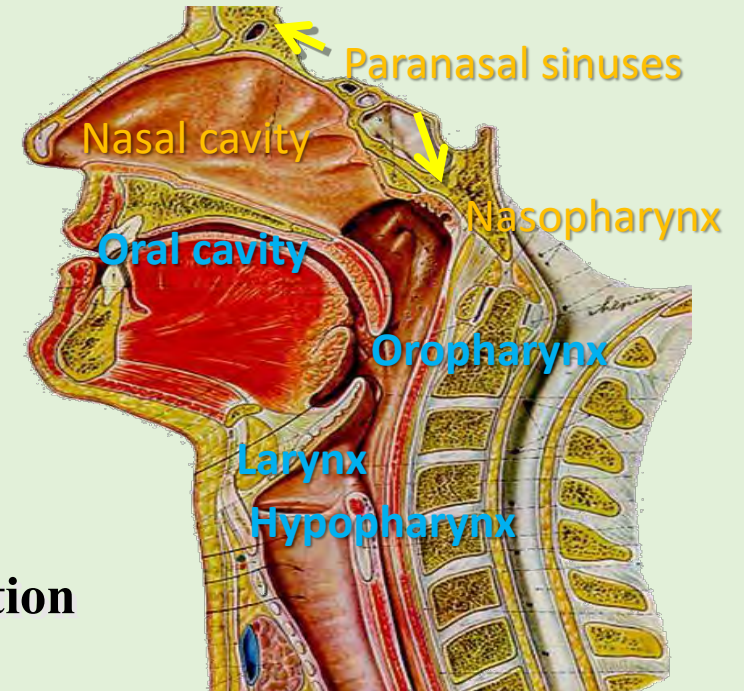
- ✓ Oral cavity (C00-C06)
- ✓ Oropharynx (C01, C05, C09, C10)
- ✓ Hypopharynx (C12, C13)
- ✓ Larynx (C32)

✓ **Rare head and neck cancers:**

- ✓ Nasopharynx (C11)
- ✓ Nose and paranasal sinuses (C30, C31)
- ✓ Salivary glands (C07, C08)

✓ **Cancers of other organ systems with head and neck localisation**

- ✓ Skin (C43, C44)
- ✓ Soft tissue and bone tumors (C49, C41)
- ✓ Thyroid and parathyroid gland cancers (C73)





# CHARACTERISTICS OF THE „COMMON” HEAD AND NECK CANCERS

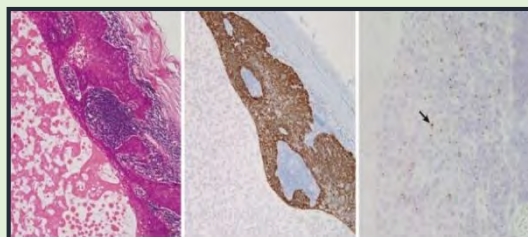
~75-80 %

Blot WJ, et al. Cancer Res  
1988;48:3282-3287

Negri E, et al. Cancer Epidemiol  
Biomarkers Prev 1993;2:189-193



Kansy K et al: Oral maxillofac Surg 2014;18: 165-172



All HN cancers: ~25% HPV+;  
Oropharynx: ~35-60% HPV+

Kreimer AR, et al. Cancer Epidemiol Biomarkers Prev 2005;14:467-475

Pannone G, et al. Infect Agent Cancer 2012;7:4

Kumar B, et al. J Clin Oncol 2008; 26: 3128-3137

- Etiology: alcohol, smoking<sup>1</sup>
- Poor oral hygiene: chronic infection and irritation of the mucosa
- HPV: most oral cavity cancers are HPV-negative, with poor prognosis and increased resistance to therapy<sup>2</sup>
- Verified squamous cell cancers are sometimes preceded by precancerous lesions, most commonly by leukoplakia, or erythroplakia<sup>3</sup>;
- However in the majority of the cases cancer develops without any alarming abnormalities of the mucosa - following around 3-month symptoms.
- At this point only 30 % of the patients have early stage diseases, characterized by good prognosis and can be treated with monotherapy (surgery or radiotherapy only)<sup>4</sup>.
- Advanced tumor-stage at diagnosis requires combined modality treatments, both local and/or regional: poor prognosis<sup>4</sup>
  - Frequent tumor recurrence within 3 years
  - Occurrence of second primary cancers (3-5 % yearly)
  - Progression of the disease negatively influences quality of life

1.Lubin JH et al: Am J Epidemiol 2009; 17: 937-47

2. Dillon MT, Harrington KJ: J Clin Oncol 2015; 33: 3251-61

3.Warnakulasuriya S, Ariyawardana A: J Oral Pathol Med 2016; 45: 155-166

4.NCCN Guidelines v.2 2018. Head and Neck Cancers

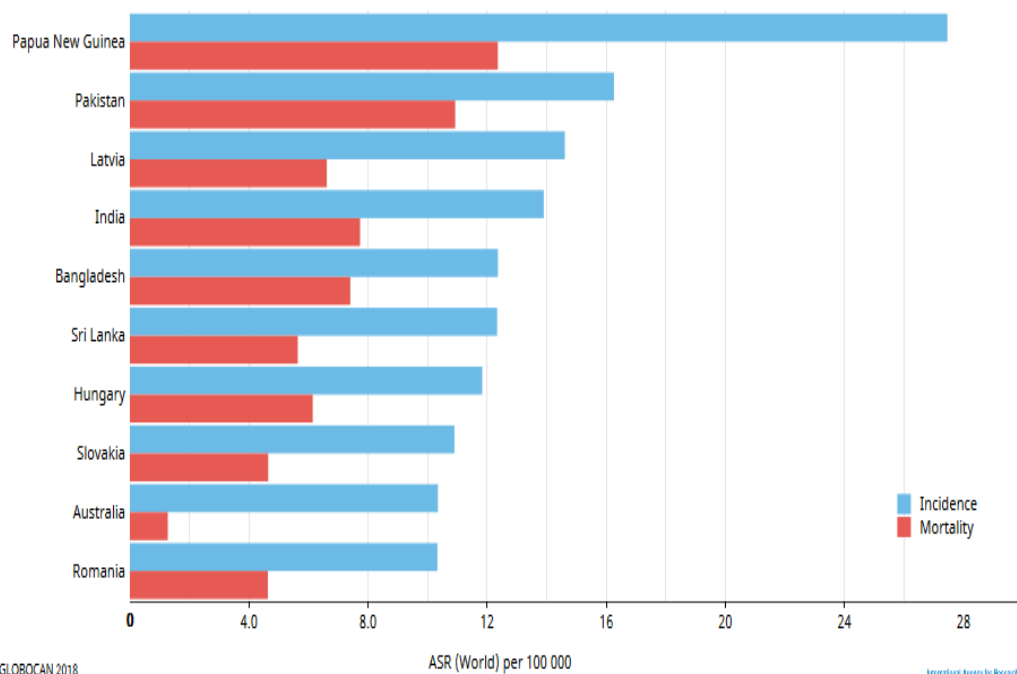
# IMPORTANCE OF CANCERS OF THE LIPS, ORAL CAVITY AND PHARYNX

- The increasing incidence of oral cavity cancer is an **important healthcare problem worldwide, mainly in the low- and medium-income countries.**
- Although the oral cavity has an easy access for examination, **less than 30% of its cancers are diagnosed at an early stage with promising survival outlook.**
- The **prognosis of advanced stage oral cavity cancers is poor**, 5-year survival is **<50%** despite their rather expensive multimodality treatment.
- In the last two decades the exponentially growing incidence and mortality figures of lip, oral cavity and pharynx cancers in Hungary attracted international attention for being **not only the highest in Europe but are among the Top10 countries with the highest incidence and mortality in the world.**

# LIP AND ORAL CAVITY CANCERS

Hungary is among the Top 10 countries with the highest incidence and mortality rates in both sexes

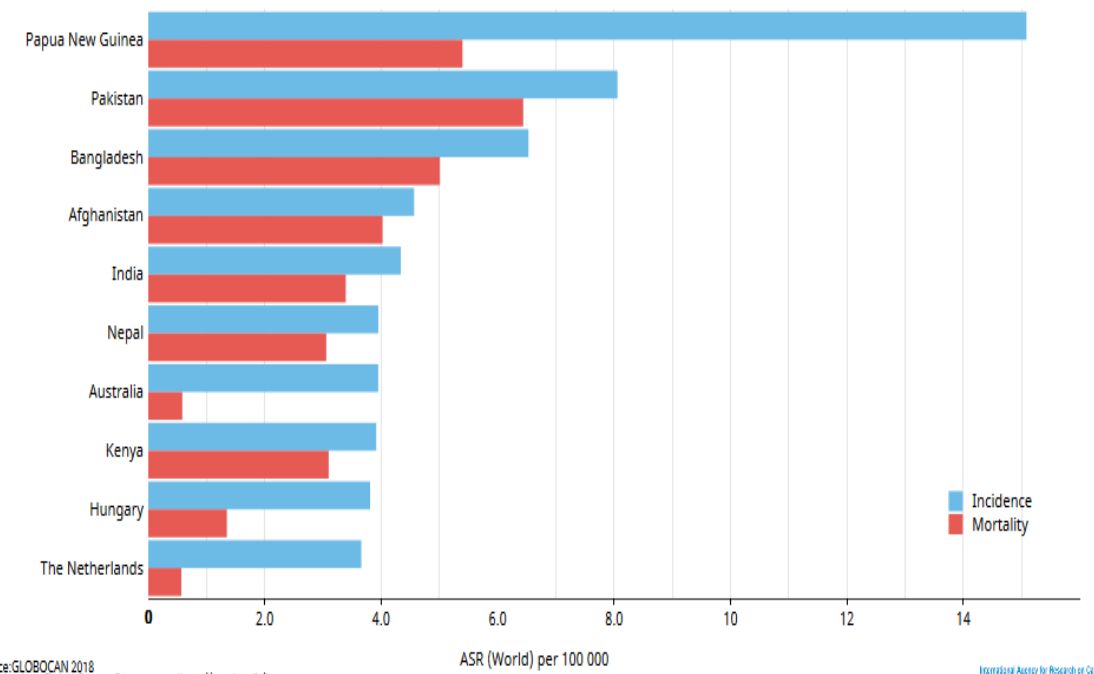
Estimated age-standardized incidence and mortality rates (World) in 2018, lip, oral cavity, males, all ages



Data source: GLOBOCAN 2018  
Graph production: Global Cancer Observatory (<http://gco.iarc.fr/>)  
© International Agency for Research on Cancer 2019

International Agency for Research on Cancer  
World Health Organization

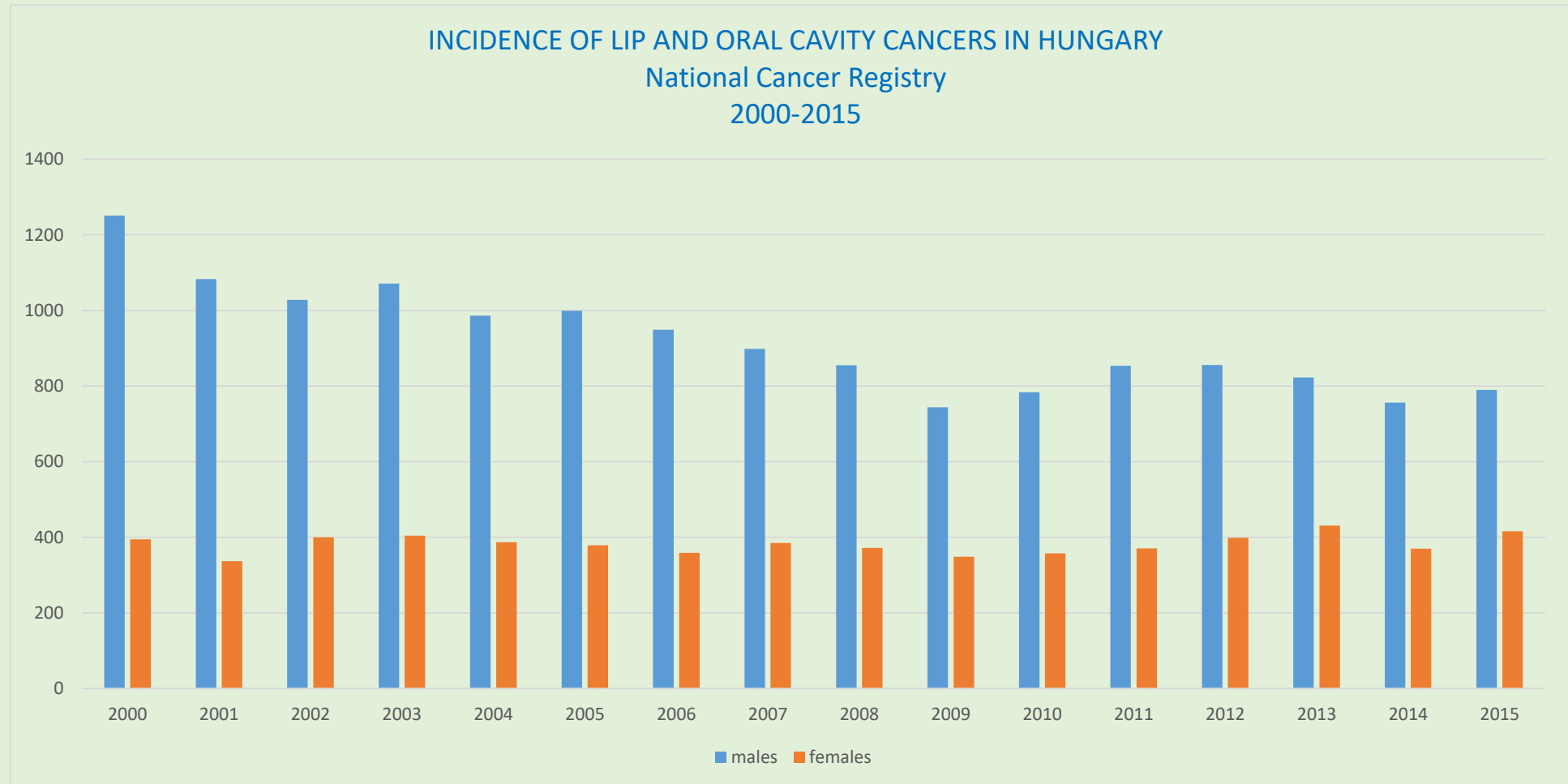
Estimated age-standardized incidence and mortality rates (World) in 2018, lip, oral cavity, females, all ages



Data source: GLOBOCAN 2018  
Graph production: Global Cancer Observatory (<http://gco.iarc.fr/>)  
© International Agency for Research on Cancer 2019

International Agency for Research on Cancer  
World Health Organization

# INCIDENCE OF ORAL CAVITY CANCERS



**Changes in the incidence over 15 years:**

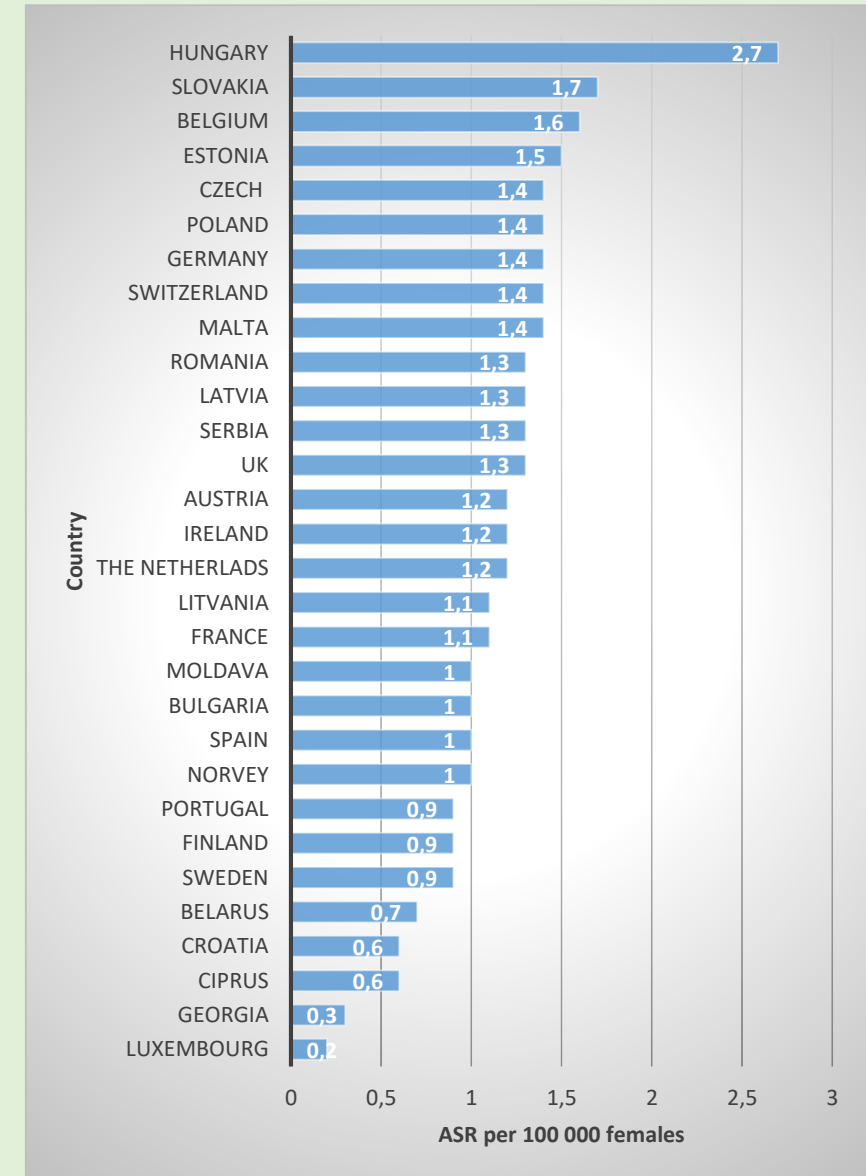
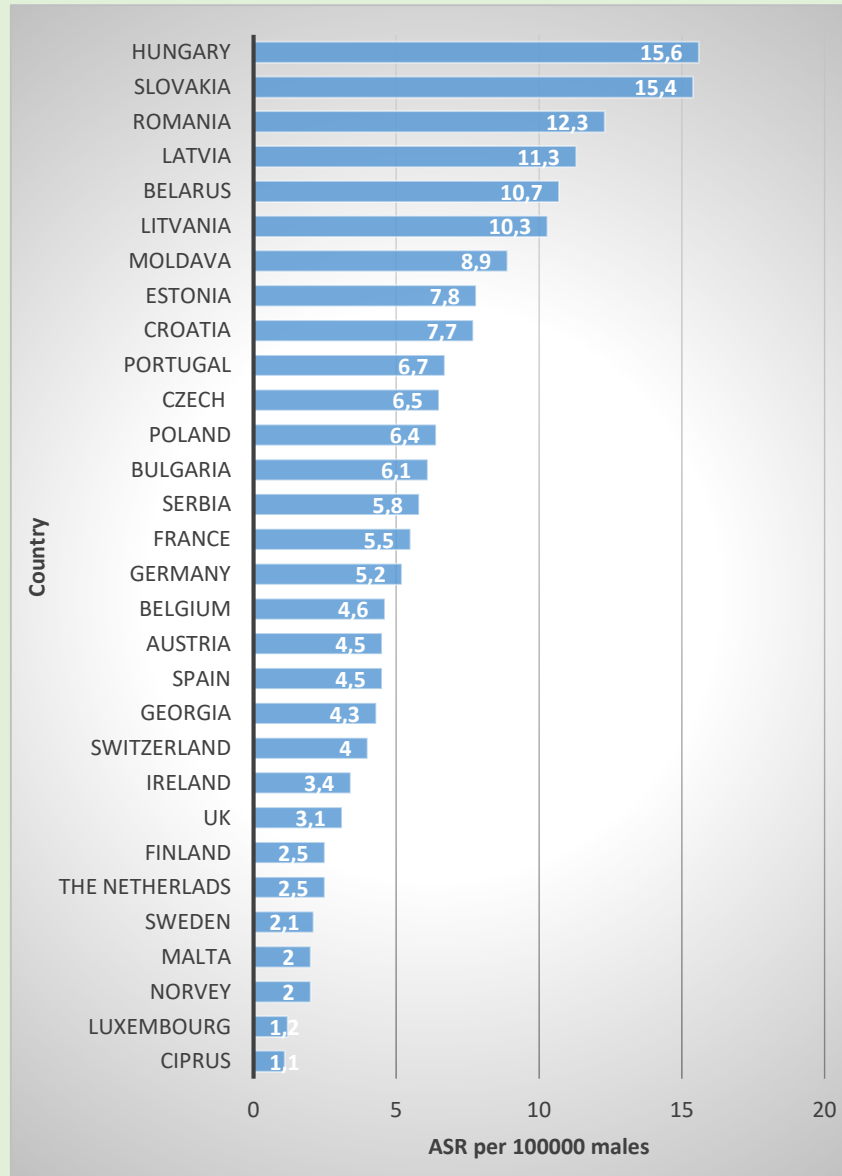
**Males: -34%**

**Females: +9%**



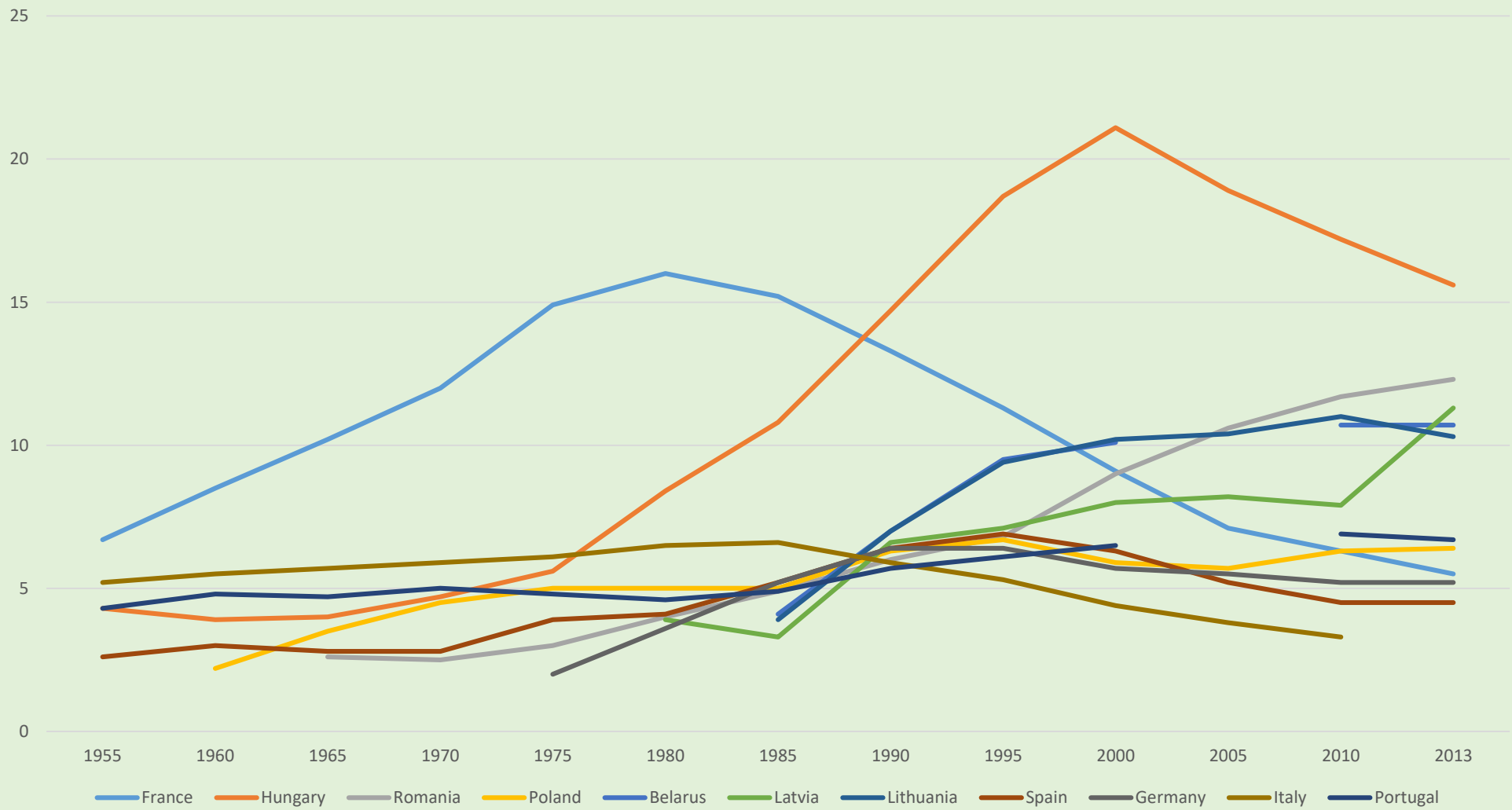
# LIP, ORAL CAVITY, AND PHARYNX CANCER MORTALITY IN EUROPE

IARC –WHO Data  
2013



# ORAL CAVITY AND PHARYNX CANCER MORTALITY IN EUROPE

Age-standardized death rates /100000 males  
WHO-IACR 1955-2013



# TOBACCO EPIDEMIC

- Manufactured cigarettes were introduced early in the 20th century
- Free distribution to soldiers and mass advertising promoted cigarette sales until the 1950s in the UK, and until the 1960s in the US
- When the hazards of smoking have been recognized, effective tobacco control policies have been introduced
  - tax on cigarettes,
  - smoke-free laws
- The decline of cigarette sales did not immediately resulted in decreasing number of deaths, on the contrary it continued to increase for several decades due to the aging of non-quitters with the longest lifetime exposition to actively inhaled smoke

# SURVIVAL TRENDS OF HEAD AND NECK CANCERS IN EUROPE

The EURO CARE-5 population-based study<sup>1</sup>

- Based on the data of **250000 HN cancer patients** from **86 registries** between **1999-2007**
- The 5-year RS improved by 3-5% for oral cavity, oropharynx and hypopharynx cancers, and remained stable for larynx cancers;
- **Five-year age-standardized RS:**

	<u>All Europe</u>	<u>Eastern Europe</u>	<u>Northern Europe, UK, Ireland</u>
• <b>Hypopharynx:</b>	<b>25%</b>		
• <b>Oropharynx:</b>	<b>39%</b>	<b>28%</b>	<b>46%</b>
• <b>Oral tongue:</b>	<b>43%</b>		
• <b>Oral cavity:</b>	<b>45%</b>		
• <b>Larynx:</b>	<b>59%</b>	<b>47%</b>	<b>62 %</b>

**Five-year RS was poor for: males, elderly persons, Eastern–Europeans**

**>50% of patients had local or distant metastasis at diagnosis**

**Early detection and timely start of treatment is necessary**

# IN-EQUALITIES IN THE EARLY DETECTION AND SURVIVAL RESULTS OF ORAL CAVITY AND PHARYNX CANCERS IN HUNGARY

- > 80% of head and neck (including oral) cancer deaths could be prevented, that develop due to tobacco use, unhealthy diets, alcohol consumption, inactive lifestyles and infection
- People at risk have:
  - History of smoking and alcohol consumption
  - Poor general and oral hygiene
  - Significant co-morbidities
  - Low educational level
  - Low socio-economic status
- Low-income groups are generally more exposed to these risk factors and have less access to the health services and health education that would empower them to make right decisions

# DIAGNOSIS AND TREATMENT DELAYS

- As the stage at diagnosis is the most important prognostic factor for survival, early detection and treatment of cancer may result in cure and long-term survival, with good quality of life.
- These patients do not reach proper healthcare in time<sup>1</sup>
- Higher rate of delayed discovery of the disease
- Patient delay: the most significant period of time between the first symptoms of cancer and the first consultation with a healthcare professional concerning the symptoms<sup>2</sup>
- The mean delay is ~3,5 months (0-730 days)<sup>2</sup>

1. Takes RP et al: Head Neck 2010

2. J Gigliotti et al: Int J Oral Maxillofac Surg 2019 (in press)

# REASONS FOR PATIENT DELAY

- <45 years old patients: majority heard of cancer, but did not think, that his/her symptoms were consistent with it
- ~40% used remedies before seeing a doctor
- Results of a psychosocial questionnaire revealed that cognitive and psychosocial factors influenced more the delay than sociodemographic or health-related ones<sup>1</sup>
- The role of the dentists:
  - Annual dental check-up patients have significantly shorter delays
  - Dentists are more likely to diagnose cancer at an early stage than primary care physicians.



# WHICH METHOD TO USE FOR ORAL CANCER SCREENING?

- **Population-based screening:**

only one evidence-based randomized controlled trial in Kerala, India has proven that oral cavity screening performed by visual examination and palpation can result in decrease mortality during a 12-year long period:

138 oral cancer death happened in the screened group of 87655 healthy people  $\geq 35$  years old vs.

154 in the control group of 95356 healthy people  $\geq 35$  years old . This difference was not enough for the method to be accepted as basis for a population-based screening program.

# WHICH METHOD TO USE FOR ORAL CANCER SCREENING?

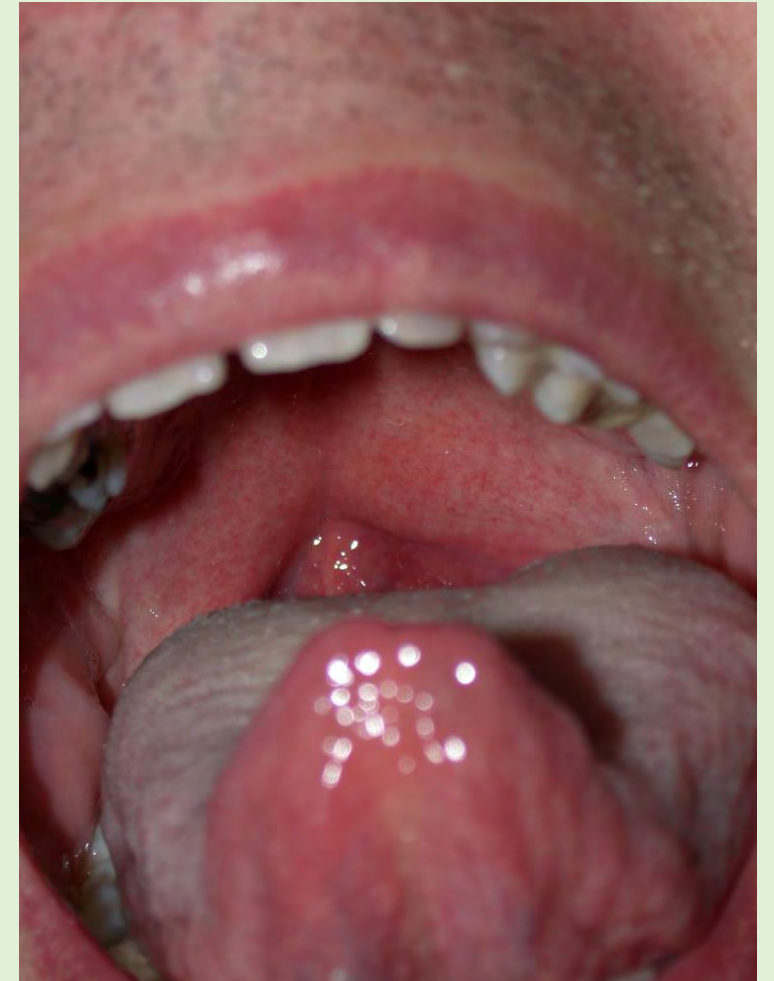
- **Opportunistic screening**: non-planned examination of the oral cavity and the neck during any patient-physician meetings for any reasons. Dental visits serve as screening opportunities ordered by the law in Hungary.
- Family physicians are also advised to perform oral cavity screening examinations.
- Unfortunately some **dentists, and GPs** do not take seriously the importance of oral cavity examinations by visual assessment and palpation.
- **Targeted screening of risk groups**: selective screening of a targeted group of the population who are at special risk to develop oral cavity cancer. This type of oral cancer screening seems to be cost-effective.

# EARLY CANCER CASES: LIP





## EARLY CANCER CASES: ORAL CAVITY



# Treatment options for early stage oral cavity cancer

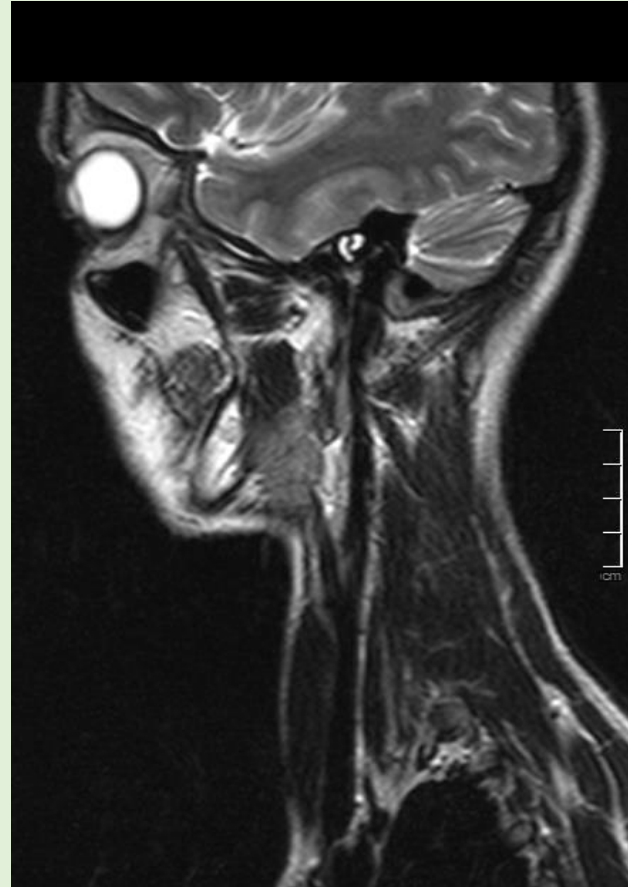
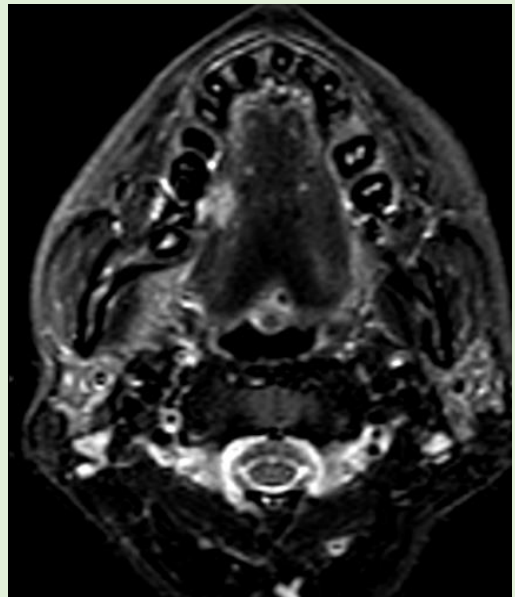
- Early, TNM I-II stage:      5-year survival < 80%

**Monotherapy:** surgery or radiotherapy





# cT1N0M0 CANCER OF THE MOBILE TONGUE



## Clinical history:

28-year old female, non-smoker, non-drinker, good oral hygiene, 21-week pregnant.

She visited her dentist for some soreness in the right side of her tongue.

The dentist discovered an ulcer of 1 cm in longest diameter and found it suspicious for being cancer. This was verified by biopsy: histology:

Gr2 squamous cell carcinoma, p16 positive.

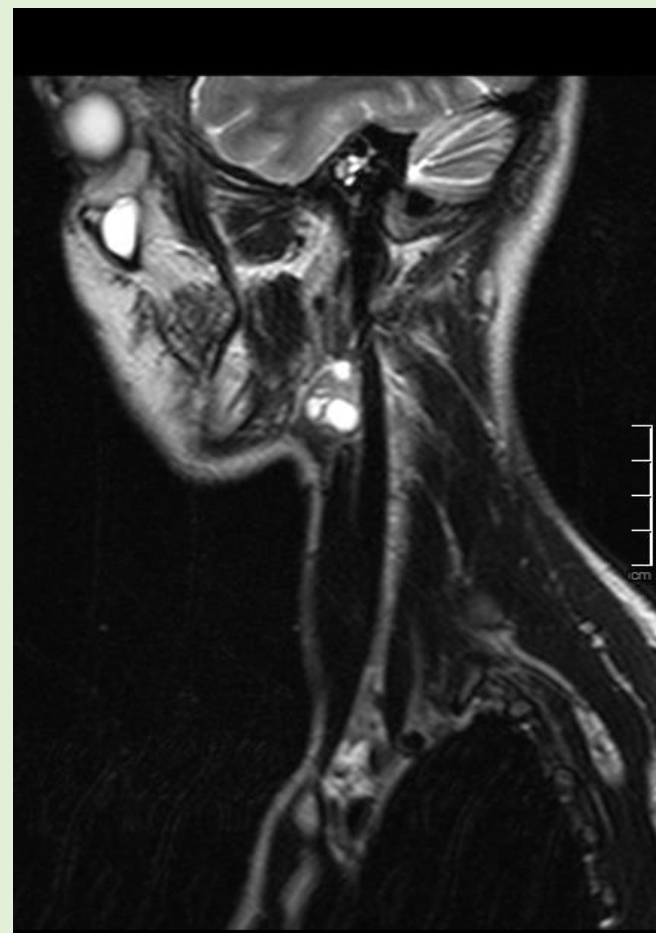
TNM stage: cT1 N0 M0

Therapy: excision of the primary cancer

# PROGRESSION OF THE CANCER



Before surgery



3 months after surgery



# THE CAREFUL DENTIST IN COLLABORATION WITH OUR MULTIDISCIPLINARY ONCOLOGIC TEAM SAVED TWO LIVES



**The mother:** following the delivery of his son by cesarean section in July 2007, a right radical neck dissection was performed and postoperative concomitant radio-chemotherapy administered.

She is a 11-year survivor with complete remission of cancer.

# CHALLENGES OF EARLY DETECTION OF LIP AND ORAL CAVITY CANCERS

- There is little knowledge of the public about etiology, signs and symptoms of oral cavity cancers
- People at risk (regular smokers, drinkers, who do not clean their teeth properly) are difficult to reach for any kinds of examination programs
- Preclinical phase of the disease is relatively short, validated methods for preclinical diagnosis are missing:
  - dyeing of the mucosa with toluidin-blue dye or fluorescein
  - brush – cytology examination or
  - salivary biomarkers
- There is not sufficient evidence to support their capacity for the early dg of subclinical stages of the pathogenic period before cancer phenotypes are manifested.

# FUTURE PLANS

Selective screening of high-risk populations for premalignant and malignant oral cavity lesions

- Based on the files of family physicians, who voluntarily join to the project the recorded smokers and drinkers who skipped the regular dental visits for more than one year should be called by a written invitation to an oral cavity screening by visual assessment and palpation.
- At the same time raising awareness can happen regarding the dangers of unhealthy lifestyles, and about the characteristic symptoms of head and neck cancer, should it occur later in the persons life.
- This short and simple examination can be taught to the primary care physicians easily, the only equipment they need is a head lamp and some spatula.



**Monday, 13th May, 2019**

**American Nicole Gibbs, 26, has withdrawn from this month's French Open after being diagnosed with a rare form of cancer that was found by her dentist.**

The world number 117 will have surgery on Friday.

"Unfortunately I will be withdrawing from the remainder of the clay season and will not be competing at this year's Roland Garros," Gibbs said on Monday.

"Fortunately this form of cancer has a great prognosis and my surgeon is confident that surgery alone will be sufficient treatment."

<https://www.bbc.com/sport/tennis/48259956>

CLOSING REMARK

Let us wish her all the best,

and let us hope time is coming and near when all the dentists will be on guard when they look into the mouth of their patients.

THANK YOU FOR THE  
ATTENTION!



# TOBACCO EPIDEMIC/2

Sequence of four stages that apply worldwide

- Stage 1: beginning of the epidemic, <20% smoking prevalence
- Stage 2: >20 % prevalence with a peak of 40%-80%. No of the tobacco attributable deaths begins to rise as a fraction of all deaths.
- Stage 3: flattening or downturn of smoking prevalence coinciding with a continuing steep increasing with the smoking-attributable deaths.
- Stage 4: Decline in both the prevalence and the smoking attributable deaths.
- WHO Framework Convention on Tobacco Control is at the centre of international efforts to reduce tobacco-related harms.





**iPAAC**  
INNOVATIVE PARTNERSHIP  
FOR ACTION AGAINST CANCER



GENERALITAT  
VALENCIANA



Fundació per al Foment de la  
Investigació Sanitària i Biomèdica  
de la Comunitat Valenciana

# Social inequalities and Early Diagnosis of Cancer

Ana Molina-Barceló

## First WP5 iPAAC Conference

Monday, 20 May 2019

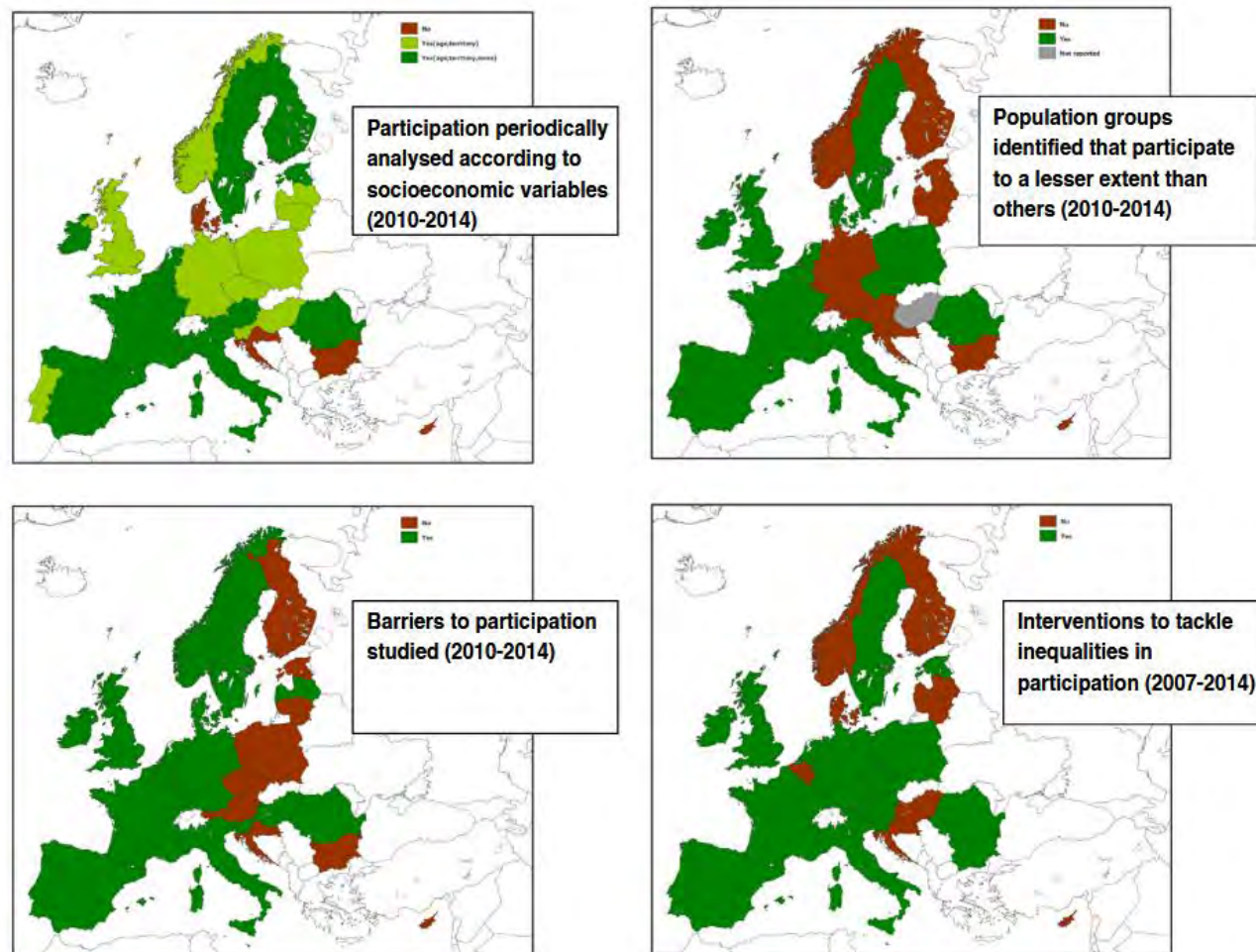
National Institute of Oncology, Budapest, Hungary

## FISABIO-Public Health



## Cancer and Public Health Unit





**Presence, characteristics and equity of access to breast cancer screening programmes in 27 European countries in 2010 and 2014. Results from an international survey.** Deandrea S, Molina-Barceló A, et al. *Prev Med.* 2016 Oct;91:250-263



## **European Guide on Quality Improvement in Comprehensive Cancer Control**

Tit Albreht, Régine Kiasuwa and Marc Van den Bulcke

## **Policy Paper on Tackling Social Inequalities in Cancer Prevention and Control for the European Population**


R. Peiró Pérez, A. Molina Barceló, F. De Lorenzo, T. Spadea, S. Missinne, F. Florindi,  
N. Zengarini, K. Apostolidis, M. P. Coleman, C. Allemani, M. Lawler



- 1** Strategies for early detection of cancer
- 2** Effective solutions for population-based screening programmes
- 3** Cancer prevention & health promotion: implementation of the European Code Against Cancer



## WP5 main tasks



■ Inequality a **cross-cutting** theme integrated in above mentioned tasks

## CONTEST OF BEST PRACTICES TACKLING SOCIAL INEQUALITIES IN CANCER PREVENTION

13. 05. 2019

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FISABIO launches the Contest of Best Practices tackling social inequalities in cancer prevention.

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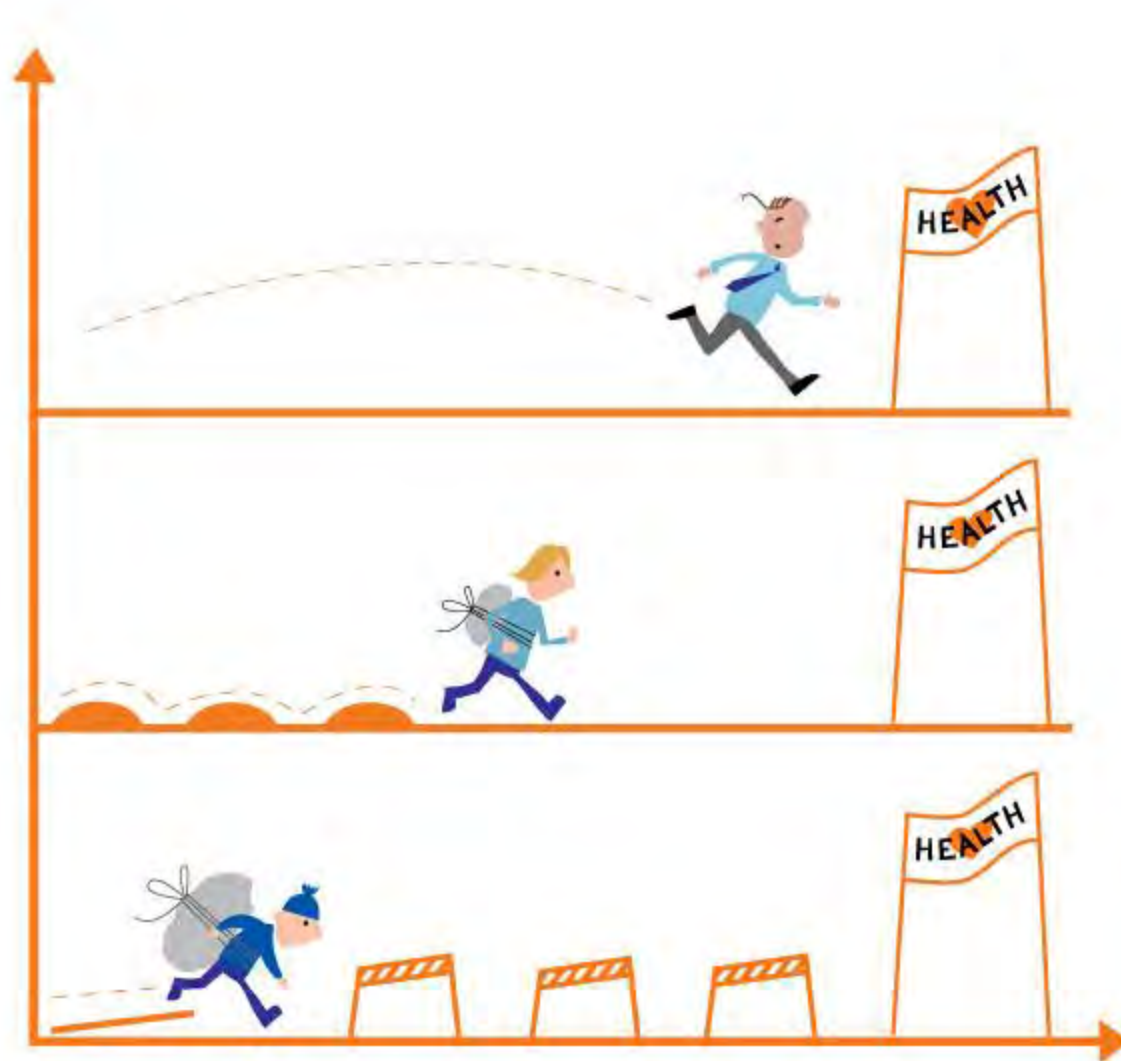
**Deadline for submission is 10th August 2019**

<https://www.ipaac.eu/news-detail/en/23-contest-of-best-practices-tackling-social-inequalities-in-cancer-prevention/>

# SOCIAL INEQUALITIES IN HEALTH

**Systematic and  
socially produced**

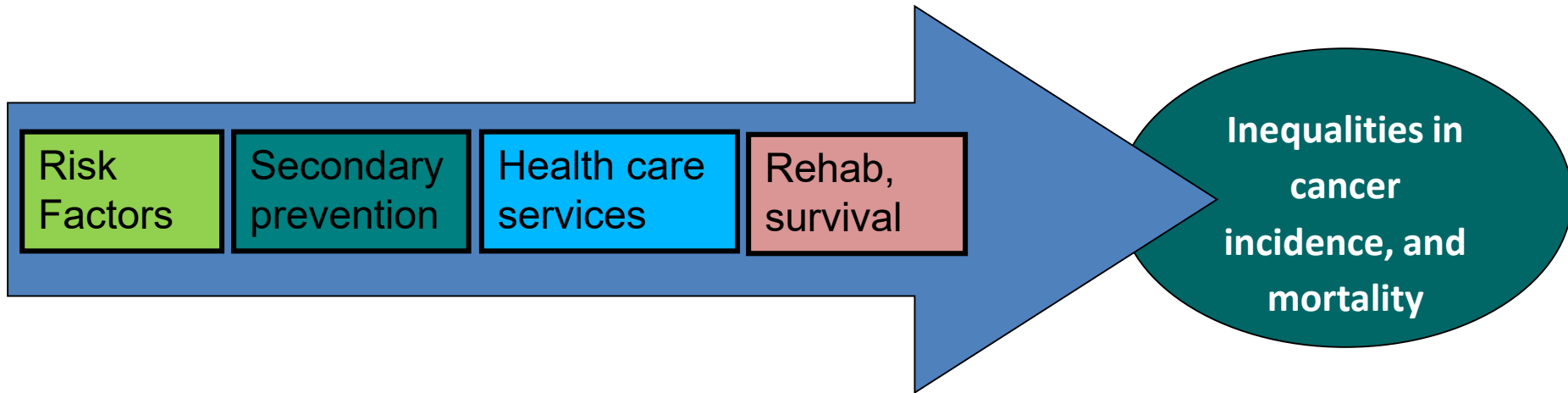
**Unfair and  
avoidable**



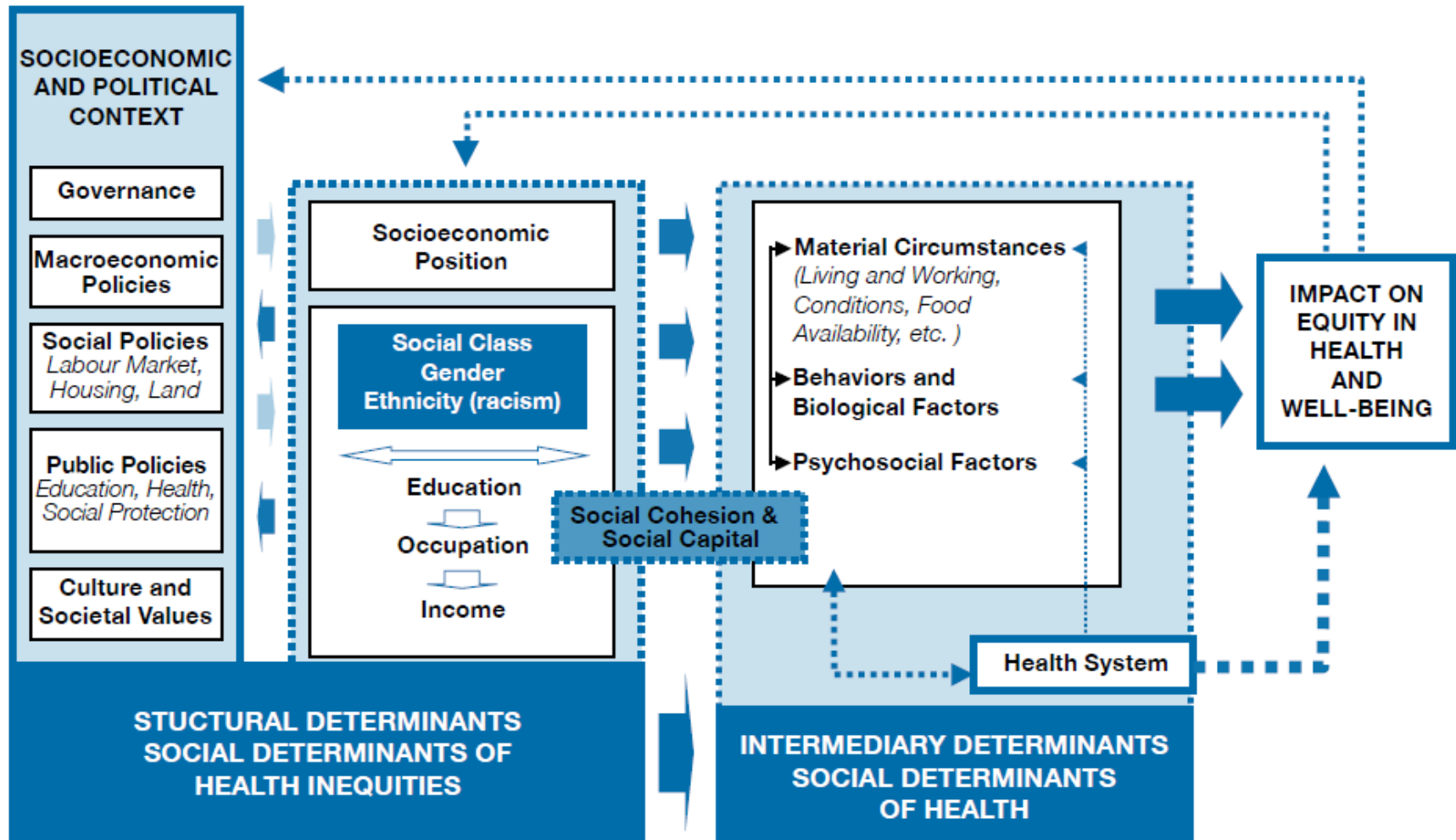
From: Norwegian Ministry of health and care services. National strategy to reduce social inequalities in health. Report No. 20 (2006–2007).



**Social inequalities in cancer** refer to health inequalities spanning the full cancer continuum across the life course (Krieger, 2005).



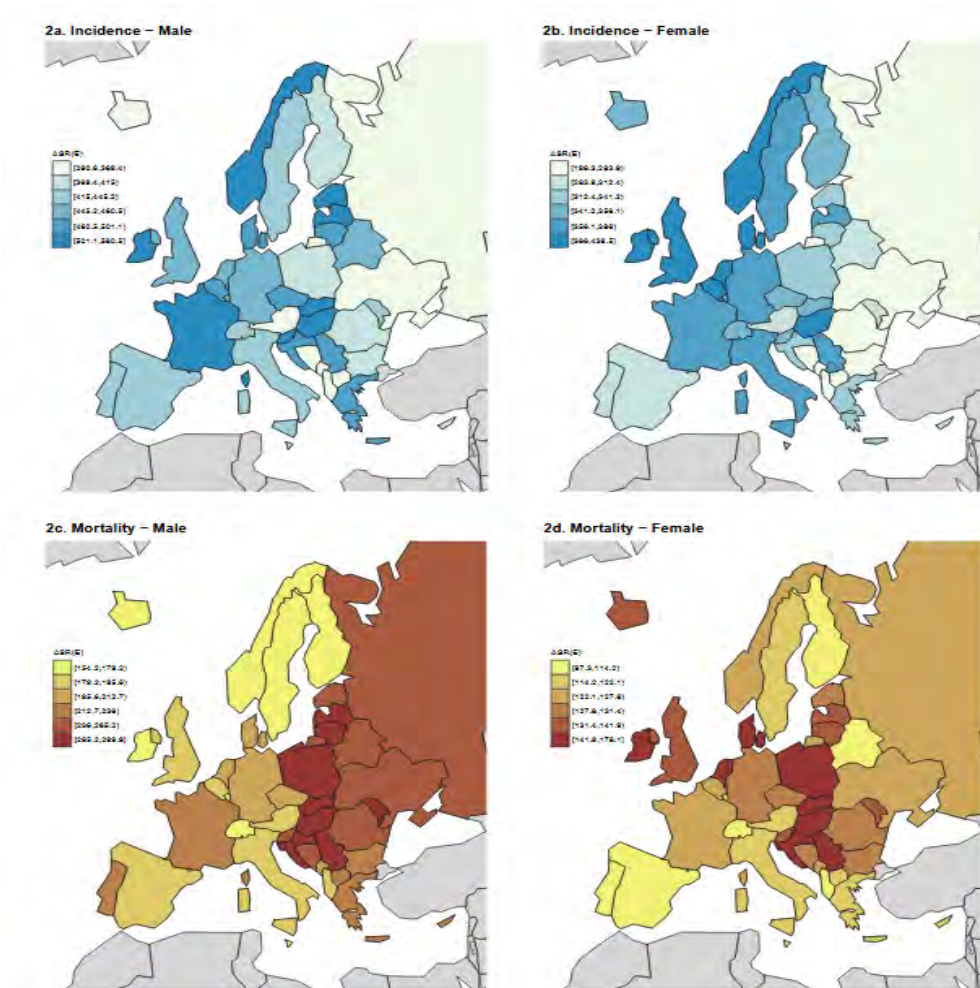
# SOCIAL DETERMINANTS OF HEALTH MODEL (WHO, 2010)



# Inequalities between countries

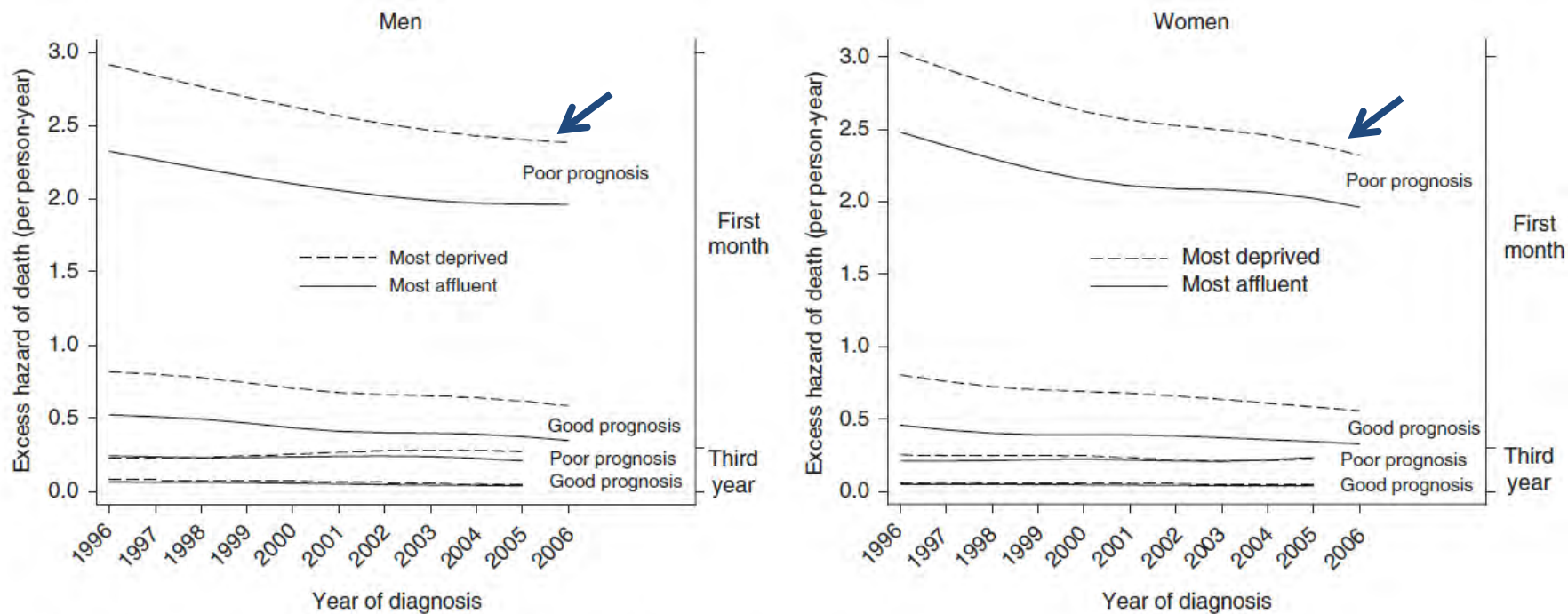
Cancer **incidence** higher is in Northern and Western European countries

Cancer **mortality** higher is in Eastern and Southern ones.



**Cancer incidence and mortality patterns in Europe: Estimates for 40 countries and 25 major cancers in 2018.**

Ferlay J, et al. Eur J Cancer. 2018;103:356-387



**Figure 3** Excess hazard of death for the most deprived and most affluent groups, by cancer prognosis, England 1996–2006.

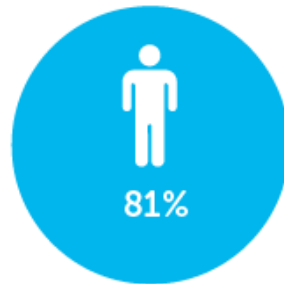
**Socioeconomic inequalities in cancer survival in  
England after the NHS cancer plan.**

Rachet B, et al. Br J Cancer. 2010 Aug 10;103(4):446-

# SURVIVAL AND STAGE OF DIAGNOSIS

TEN-YEAR SURVIVAL FOR EIGHT TYPES OF CANCER COMBINED

DIAGNOSED EARLY  
(STAGE I + STAGE II)

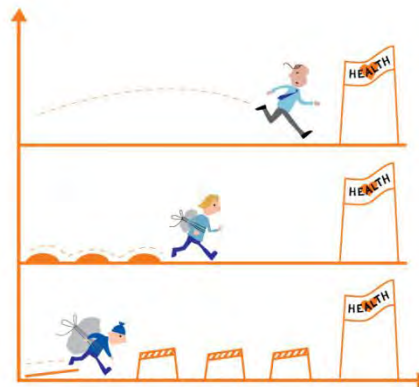


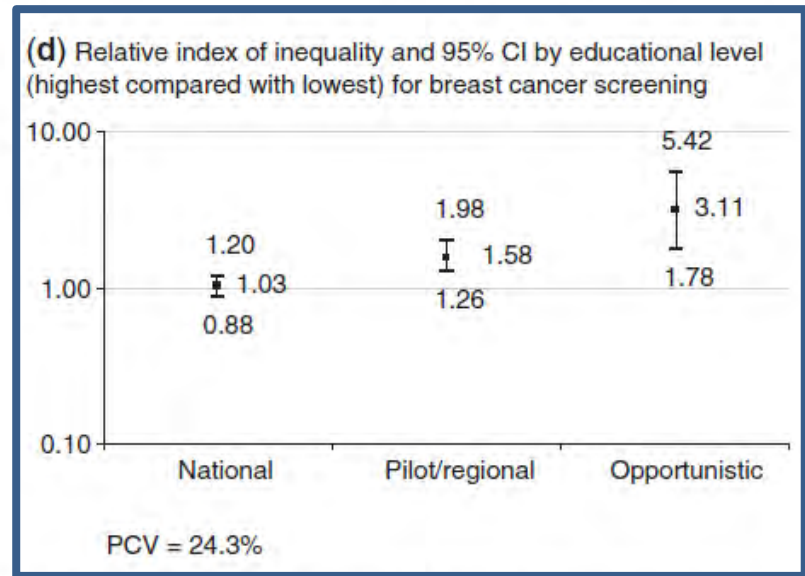
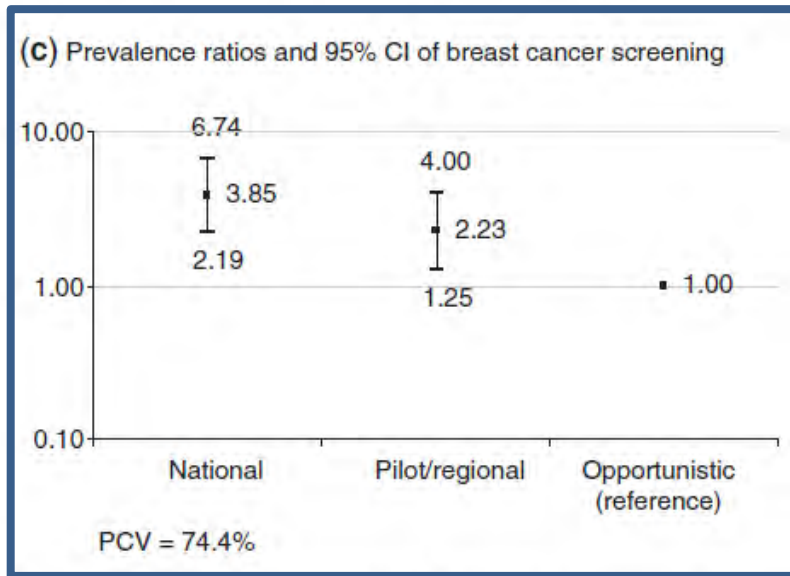
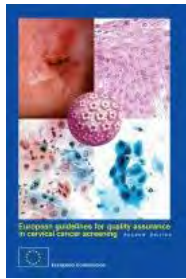
SURVIVAL IS  
MORE THAN  
THREE TIMES  
HIGHER WHEN  
CANCER IS  
DIAGNOSED  
EARLY

DIAGNOSED LATE  
(STAGE III + STAGE IV)



## EQUITY IN EARLY DIAGNOSIS





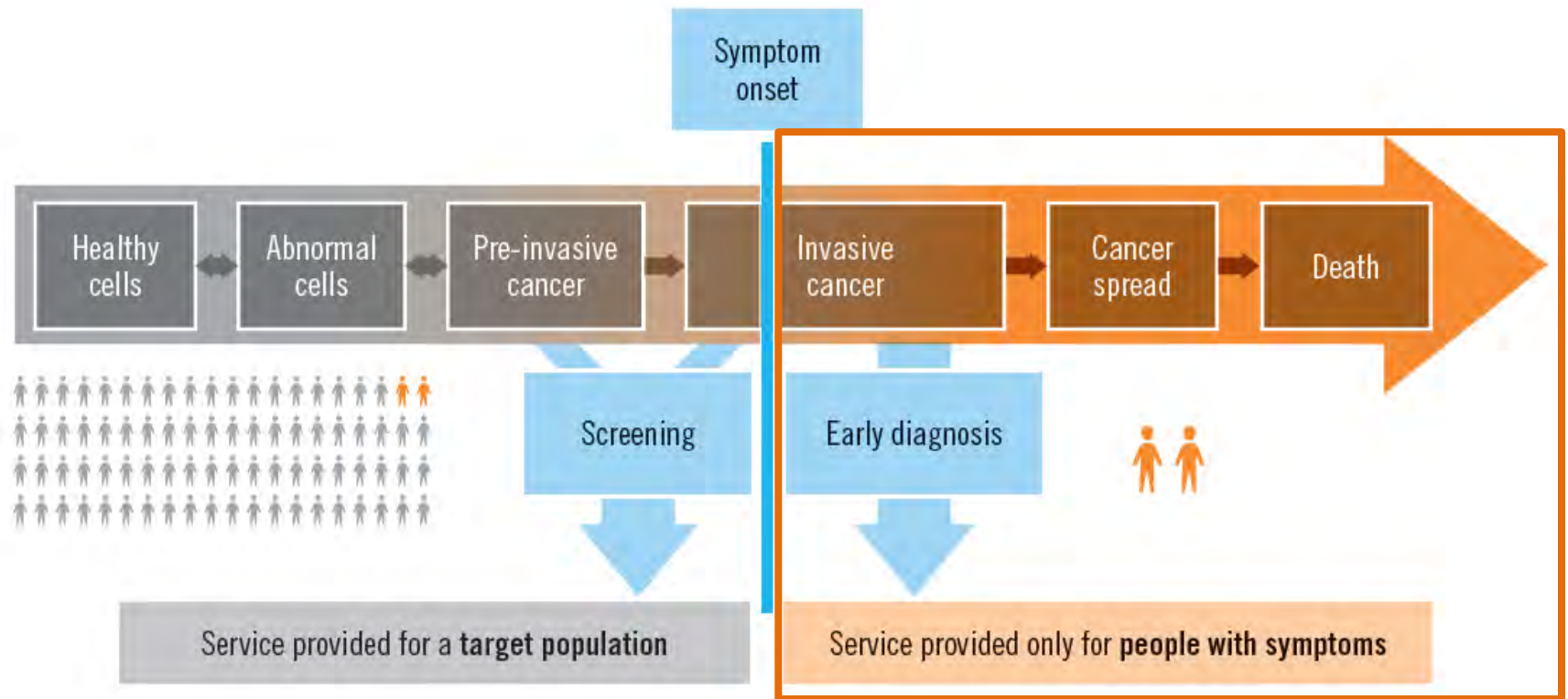
**Figure 1** Multilevel association between screening prevalence and type of screening program (prevalence ratio) and between educational level and cancer screening (RII) by type of screening program taking individual variables into account. PCV after taking into account the type of screening program.

**Socio-economic inequalities in breast and cervical cancer screening practices in Europe: influence of the type of screening program.**

Palencia et al. [Int J Epidemiol](#). 2010 Jun;39(3):757-65.



## CANCER SCREENING vs EARLY DIAGNOSIS

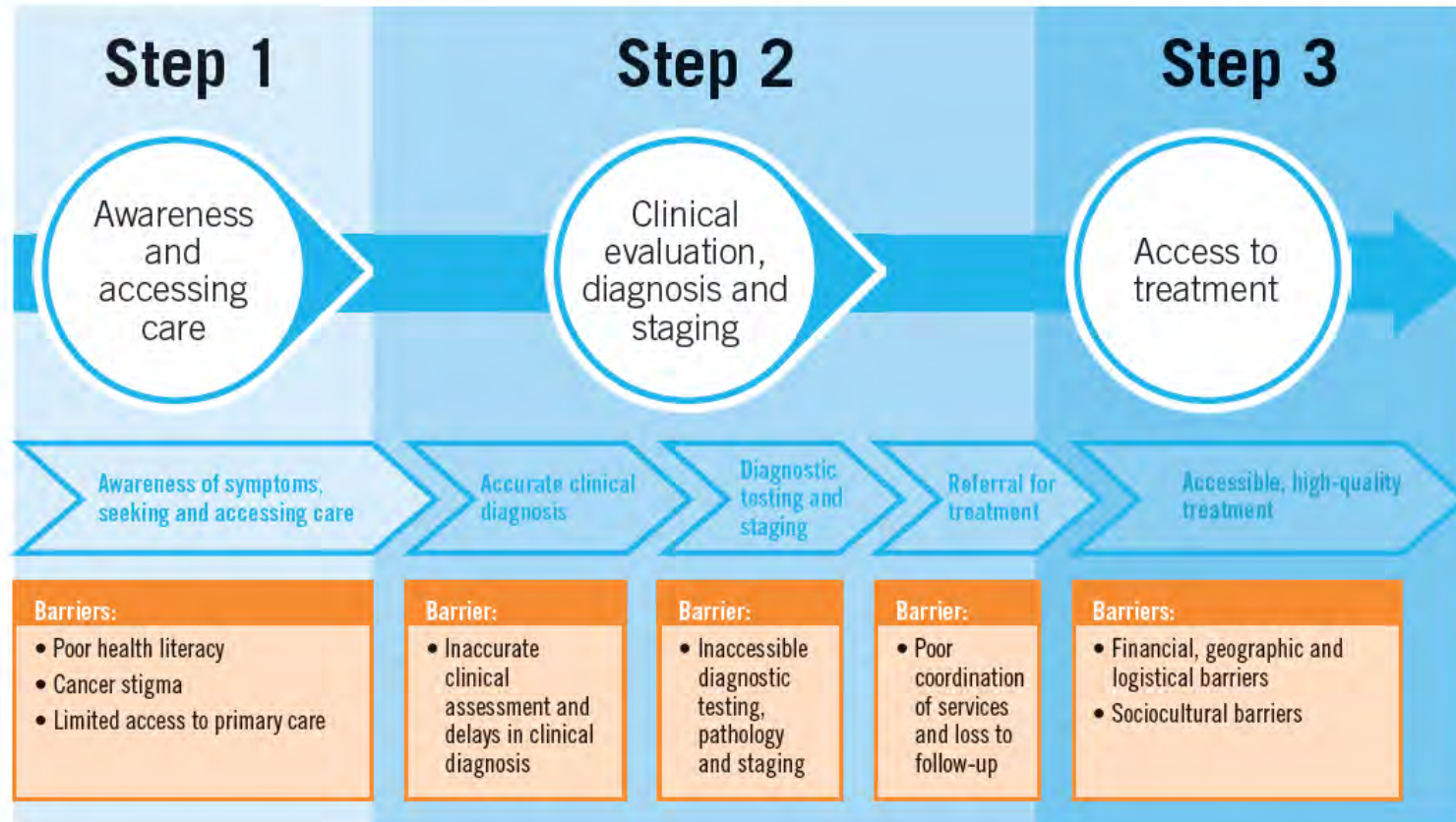


**Guide to cancer early diagnosis.**

World Health Organization (WHO); 2017. ISBN 978-92-4-151194-0



## COMMON BARRIERS TO EARLY DIAGNOSIS



**Guide to cancer early diagnosis.**

World Health Organization (WHO); 2017. ISBN 978-92-4-151194-0

# Step 1

Awareness  
and  
accessing  
care

Awareness of symptoms,  
seeking and accessing care

## Barriers:

- Poor health literacy
- Cancer stigma
- Limited access to primary care

**Table 3** Barriers to seeking medical help by ethnic group

	All (n = 1515) <sup>a</sup> (%)	White (n = 806) (%) OR (reference group)	South Asian (n = 333) (%) OR (95% CI) <sup>b</sup>	Black (n = 265) (%) OR (95% CI) <sup>b</sup>
<i>Emotional barriers</i>				
Worried about what the doctor might find	665/1462 (47.1)	313/784 (44.3) 1.00	188/313 (58.2) 2.04 (1.46 to 2.87)	120/257 (45.5) 1.22 (0.87 to 1.72)
Too embarrassed to go and see the doctor	543/1449 (37.7)	222/784 (31.3) 1.00	189/305 (61.2) 4.24 (3.00 to 6.00)	89/254 (29.9) 1.07 (0.74 to 1.54)
Lacks confidence talking about symptoms	432/1450 (29.0)	138/777 (18.8) 1.00	180/313 (54.9) 5.40 (3.77 to 7.74)	65/253 (23.9) 1.40 (0.94 to 2.08)
Too scared to go and see the doctor	406/1456 (26.9)	205/780 (28.5) 1.00	110/310 (29.3) 1.22 (0.84 to 1.77)	57/259 (20.0) 0.75 (0.50 to 1.13)
<i>Practical barriers</i>				
Too many other things to worry about	470/1468 (33.3)	257/788 (36.5) 1.00	101/315 (29.6) 0.80 (0.55 to 1.16)	80/255 (31.5) 0.87 (0.61 to 1.24)
Too busy to make time to go to the doctor	512/1482 (33.0)	275/794 (34.8) 1.00	109/316 (27.9) 0.69 (0.48 to 0.98)	88/261 (34.0) 0.98 (0.69 to 1.39)
Finds it difficult to arrange transport	211/1461 (14.7)	97/789 (15.6) 1.00	60/311 (14.1) 1.40 (0.86 to 2.28)	41/253 (13.9) 1.32 (0.80 to 2.15)
<i>Service barriers</i>				
Finds the doctor difficult to talk to	347/1455 (22.2)	180/780 (23.1) 1.00	84/315 (21.1) 0.97 (0.65 to 1.43)	61/253 (22.7) 1.08 (0.72 to 1.63)
Worried about wasting the doctor's time	519/1466 (36.5)	368/786 (52.7) 1.00	68/313 (16.7) 0.20 (0.13 to 0.32)	60/257 (20.9) 0.27 (0.18 to 0.40)
Finds it difficult to make an appointment	523/1457 (35.3)	276/782 (36.0) 1.00	133/316 (41.0) 1.21 (0.87 to 1.70)	82/254 (29.6) 0.74 (0.52 to 1.05)

Abbreviations: OR = odds ratio; CI = confidence interval. All percentages are weighted for the inverse of the probability of being selected. <sup>a</sup>111 participants were of other ethnic groups or unknown ethnic group. <sup>b</sup>Odds ratio adjusted for age group and quintile of index of multiple deprivation.

**Breast cancer awareness and barriers to symptomatic presentation  
among women from different ethnic groups in East London.**

Forbes LJ, et al. Br J Cancer. 2011 Nov 8;105(10):1474-9

## Step 2

Clinical  
evaluation,  
diagnosis and  
staging

Accurate clinical  
diagnosis

Diagnostic  
testing and  
staging

Referral for  
treatment

### Barrier:

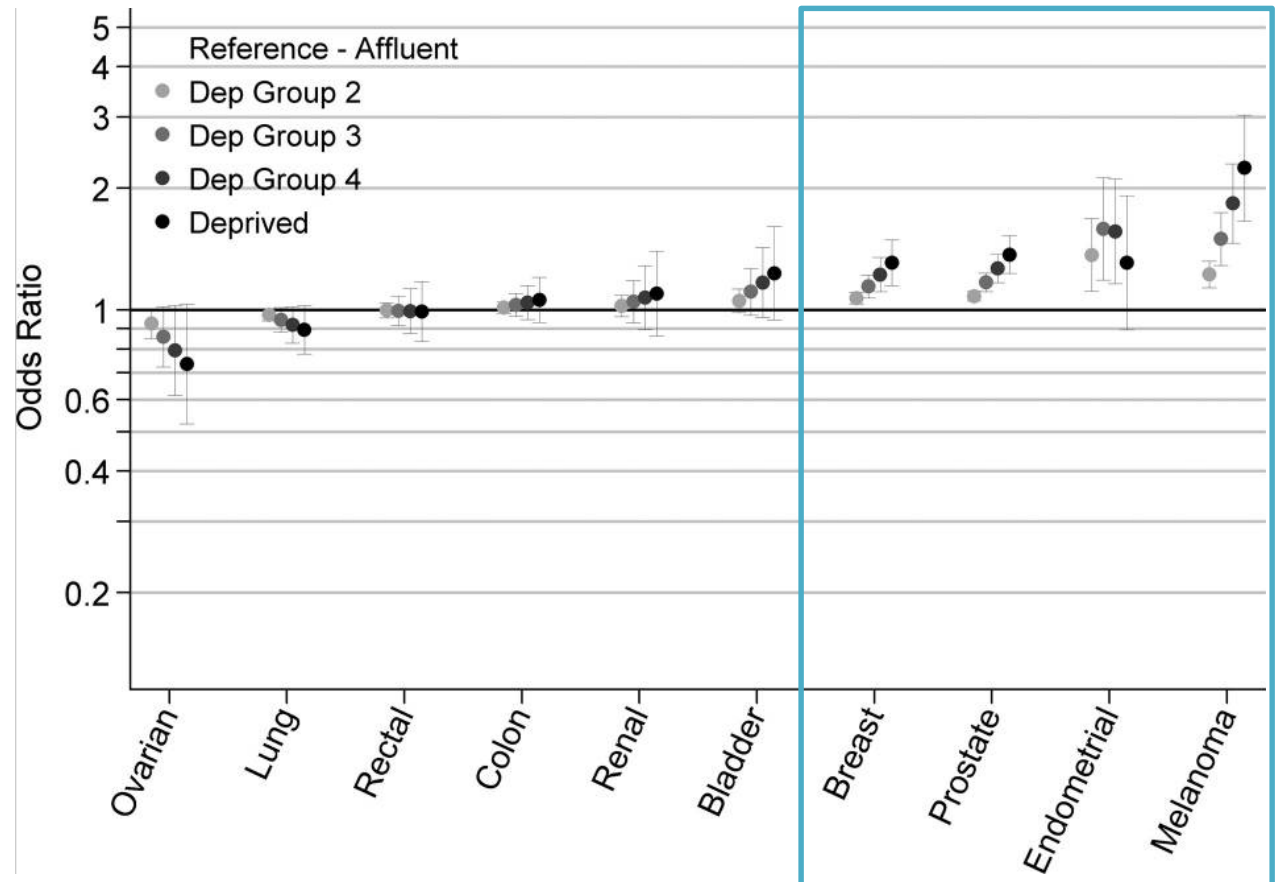
- Inaccurate clinical assessment and delays in clinical diagnosis

### Barrier:

- Inaccessible diagnostic testing, pathology and staging

### Barrier:

- Poor coordination of services and loss to follow-up



**Socio-demographic inequalities in stage of cancer diagnosis: evidence from patients with female breast, lung, colon, rectal, prostate, renal, bladder, melanoma, ovarian and endometrial cancer.**

Lyratzopoulos G, et al. Ann Oncol. 2013 Mar;24(3):843-50.

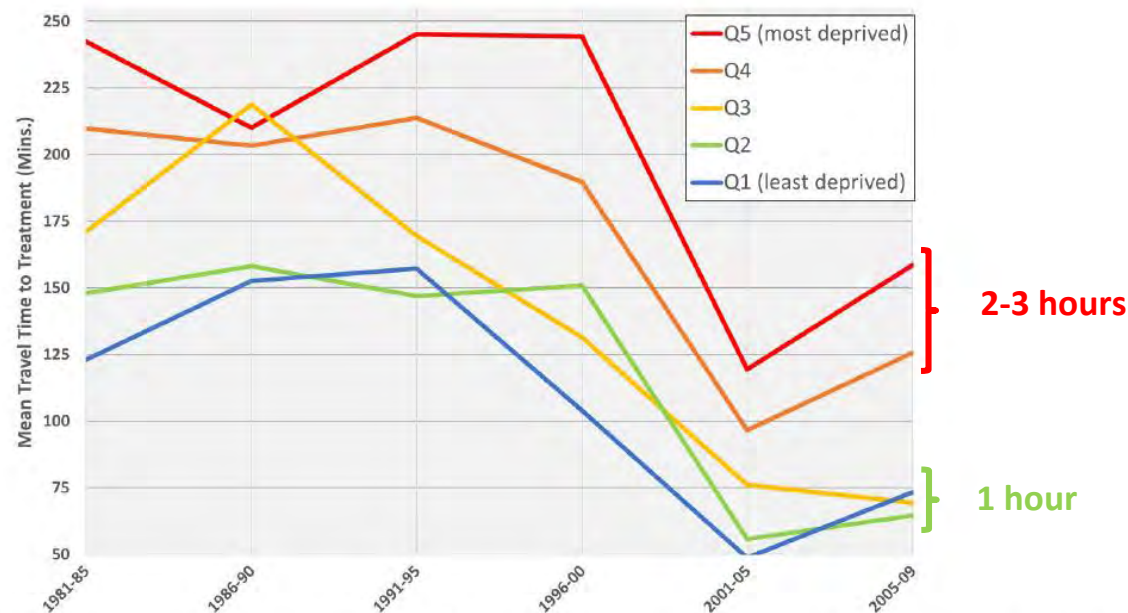


Figure 5: Mean travel time to nearest treatment center for each socioeconomic deprivation quintile by 5-year

**Socioeconomic disparities in head and neck cancer patients' access to cancer treatment centers.**

Walker BB, et al. Rural Remote Health. 2017 Jul-Sep;17(3):4210



## WHAT CAN WE DO TO REDUCE INEQUALITIES?

Population



Whole population

Targeted



Socially vulnerable people

Proportional  
Universalism



Proportionate efforts to the  
level of disadvantage

**Fair Society, Healthy Lives: The Marmot Review.**  
Marmot M. London: Strategic Review of Health  
Inequalities in England post-2010; 2010.

## Population



# Population



mela...ma

protegete del sol  
protege tu piel

GENERALITAT VALENCIANA  
2015  
A més  
+7%

Al hacer buen tiempo, adentrado en verano, los momentos de ocio de aprovechamiento generalmente para estar al aire libre, disfrutando del sol en la playa o en la montaña.

También la práctica de determinadas deportes (fútbol, natación...) y el desempeño de algunas actividades laborales o aficiones (agricultura, jardinería...) te decantan al aire libre.

Los rayos solares ultravioleta (UV) entran en la piel, te no está protegido por ropa o cremas con filtro solar, pueden causar, entre que son dañinos para la piel. Como irritaciones y quemaduras, o daños que pueden aparecer al cabo de los años: envejecimiento prematuro (arrugas), manchas y aumento del riesgo de padecer cáncer de piel.

Es muy importante proteger la piel cuando se está al sol evitando quemaduras solares, especialmente en los niños y las niñas. Hay que tener en cuenta que los rayos solares son más intensos en verano, en las montañas altas y al reflejarse en el agua, arena o nieve.

¿ cómo protejo mi piel ?

12h 17h

FACTOR SOLAR ≥ 30

Aplica siempre crema con factor de protección solar 30 o más alto. Extiéndela 20 minutos antes de estar al sol. Vuelve a aplicar cada 2-3 horas y después de sudar mucho o bañarte.

En verano, de 12 de la mañana a 3 de la tarde procura estar a la sombra; si no es muy intenso. El sol se lleva poco a poco, si estás muchas horas es riesgo de quemarte en muy pronto.

Protege tu cabeza con gorra. Tu cuerpo con camiseta, aunque mejor haciendo deporte o jugando. Tus ojos también necesitan protección, usa gafas solares.

El bronceado con rayos UV también puede aumentar tu piel.

ACÓSTUMBRATE A MIRAR TU PIEL..

Con la ayuda de un espejo podrás conocer la piel de todo tu cuerpo. Si notas que te ha salido una mancha o un nuevo lunar, o alguno de tus lunares ha cambiado de color o forma acude a tu médico. Es muy importante detectar el CÁNCER DE PIEL a tiempo: se curará totalmente.

F.A.S. DIFUSIÓN

mela...ma

protección

POCV  
Plan Oncológico Comunitat Valenciana

Guía de Prevención y Tratamiento del Melanoma

GENERALITAT VALENCIANA  
CONSELLERIA DE SANITAT

VIGILE LAS SEÑALES DE PELIGRO EN LESIONES PIGMENTADAS DE LA PIEL. HAY QUE CONSULTAR INMEDIATAMENTE AL DERMATÓLOGO SI ALGUN LUNAR O MANCHA PIGMENTADA MUESTRA:

**A** simetría  
Una mitad es distinta de la otra.

**B** ordes irregulares  
Bordes festoneados o poco delimitados.

**C** olor variado  
Cambios cromáticos de una a otra área; sombreado de moreno y marrón; negro; a veces blanco, rojo o azul.

**D** iámetro  
Más grande de 6 mm. como norma (el diámetro de una goma de borrar de un lápiz).

**E** volución  
Si aparece otro signo cutáneo anormal: inflamación, picor, sangrado, endurecimiento...

**Recuerde este A B C D E**  
PUEDEN SER SEÑALES DE MELANOMA



## Targeted



**Table 1** Health check intervention content

Intervention components	Description of component	Purpose of component	Summary of intervention functions	Behaviour change techniques [22]	Example of application within the intervention
Touchscreen questionnaire: "About you" (7 questions)	Background information about the participant including personal and family history of cancer, body mass index and cancer screening attendance <sup>a</sup> .	Contextual information about potential risk factors for cancer.	Education, persuasion, environmental restructuring	Information about health consequences <sup>b</sup> , prompts/cues <sup>c</sup>	Information about the benefits of early diagnosis. Information about factors that may increase the risk of developing cancer (e.g. being overweight). Questions about previous engagement with cancer screening.
Touchscreen questionnaire: "Your lifestyle" (5 questions)	Diet, smoking, alcohol consumption and physical activity.	Contextual information about potential risk factors for cancer.	Education, persuasion, enablement	Information about health consequences, credible source <sup>d</sup> , social support <sup>e</sup>	Signposting to local services, such as Stop Smoking Wales. Encouragement to pass the information on to friends or family.
Touchscreen questionnaire: "Your health" (14 questions)	Cancer warning signs and symptoms (see Additional file 2)	Contextual information about potential symptoms of cancer.	Education, persuasion, environmental restructuring	Information about health consequences, prompts/cues, credible source	Signposting to General Practitioner. Information about cancer warning signs and symptoms to encourage early presentation within three weeks of noticing a potential symptom (now and in the future).
Personalised results	Displays a printable summary of the individual's results and action (for example, to present to their General Practitioner with potential cancer symptoms).	Provides participants with an overview of their health check results, to act as a prompt for change (e.g. discussion at their GP appointment).	Education, enablement	Information about health consequences, action planning <sup>f</sup> , goal setting <sup>g</sup>	Participants complete the following statement: "If I notice a symptom, I will go and see my _____ within _____ of noticing the symptom". Remind participants about the benefits of early diagnosis.

## Feasibility and acceptability of a cancer symptom awareness intervention for adults living in socioeconomically deprived communities.

Smith P, et al. BMC Public Health. 2018 Jun 5;18(1):695

## CONCLUSIONS

- Social inequalities in early diagnosis of cancer exist between countries and within countries by social groups.
- It's important to identify not only the barriers to early diagnosis of cancer, but also the impact of such barriers on inequalities
- It is recommended to include an equity perspective in the early diagnosis strategies, based on a proportional universalism approach in order to reduce social inequalities in cancer.

**Thank you very much for your attention**



**Ana Molina-Barceló**  
**[molina\\_anabar@gva.es](mailto:molina_anabar@gva.es)**

# Barriers in early diagnosis

Survey results



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# Introduction

- A main objective of the whole WP5 is to identify barriers to early detection and its management
- Specifically, task 5.1 addresses early detection
- In order to examine early detection strategies from several perspectives, WP5 produced a Survey on perceptions of attitudes of barriers to early detection (Milestone 5.1)
  - The survey schedule was postponed from M5 to M11, February 2019 for accurate and well devised content
- Initially, the survey was planned to include 4-6 countries but was enlarged to the whole European level



# Background

- As background material, we used the [WHO Guide to cancer early diagnosis](#)
- The WHO guide uses the definition for early diagnosis related to **the recognition of symptomatic cancer** in patients
  - Thus the second dimension of early detection, covering cancer screening, was not in a focus in the survey
- According to WHO, the focus of cancer early diagnosis is in people who have symptoms and signs consistent with cancer. The objective is to identify the disease at the earliest possible opportunity and the link to diagnosis and treatment without delay. When done promptly, cancer may be detected at a potentially curable stage, improving survival and quality of life.
- Also, scientific literature on barriers, benefits and harms of early diagnosis was searched and benefited as background material (see References)





# Methods

**info  
support  
hope**



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20.5.2019

# Cancer types

- Based on the above-mentioned background materials CSF compiled a working paper on early diagnosis of cancer in cancer control strategies
- It included examples of programmatic services of interest which were discussed in an online-meeting of WP5 task 5.1 (early diagnosis) working group
- As a result, the cancer types chosen for the survey were:
  1. Oral cancers and precancers by dentists looking for early signs
  2. Identifying skin cancers by checking and surveillance for moles
  3. Possible early prostate cancer: symptoms as a sign for action to improve early diagnosis
  4. Diverse breast cancer symptoms: better awareness and recognition to improve early diagnosis
  5. Other, freely chosen according to interest



# Barriers

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- Initially, 11 barriers were drafted but after expert discussions, these were decreased to six (6):
  1. Lack of evidence base on benefits and harms; evidence-based guidelines can't be formed due to lack of knowledge. This barrier relates also to health policy planning: is there enough research resource for necessary knowledge production.
  2. Limited access to primary care due to long distances, lack of transportation, i.e., non-availability of services in the local setting.
  3. Lack of awareness: Poor health literacy leading to shortcomings in the knowledge of cancer symptoms and on diagnosis and treatment pathways, thus delaying seeking for care.



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# Barriers

4. Cancer stigma as sense of devaluation by individuals or communities related to cancer patients. Beliefs and values associated e.g. to gender, social class or religion, leading to reluctant attitude or fear to seek or comply to care.
5. Patient-level financial constraints in certain population groups (ethnic, social class) to access primary health services and treatment.
6. Poor organization of patient pathway: Poor coordination of services and loss to follow-up, lack of referral pathways, too many facilities for patients leading possibly to duplicate services or overuse of services, poor communication between providers, absence of patient identifiers and reliable health information system.



# Compiling survey

- When a draft version of the survey was compiled, an advisory group tested and commented it
  - The advisory group members were: Patricia Fitzpatrick (UCD), Marta Hernandez Garcia (Fisabio), Ana Molina Barcelo (Fisabio), Jennifer Priaulx (EU-topia), David Ritchie (ECL), Wendy Yared (ECL)
- The survey was executed by the Finnish company ZEF and its survey tool
- Answers were collected and handled anonymously and according to GDPR



# Survey methodology

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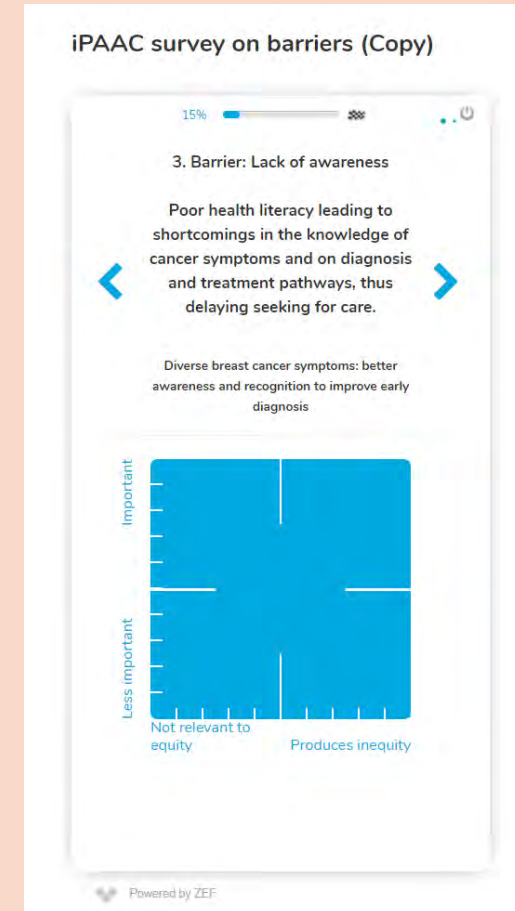
- Respondents chose first the cancer type wanted to be evaluated
- Next, they placed each barrier in a four-fold table with the response dimensions:
  1. Not relevant to equity – Produces inequity (X-axis)
  2. Important – Less important (Y-axis)



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# Materials

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# Invitations

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- The survey was sent by CSF and ECL to approx. 175 respondents including both persons and organisations
- The invited actors consisted of among others the iPAAC consortium, cancer patient and advocacy groups, WHO and its suborganisations, cancer societies, ECL members and collaborative partners, cancer industry, cancer prevention organisations, health care professional organisations
- The survey was also requested to be shared and disseminated by invited contacts
- The first invitations were sent 31 January and 1-2 reminders in Mid and/or late February
- The survey was open from answers from 31 January to 10 March
  - The initial closing date was 28 February but was extended in order to achieve a higher response rate



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# Respondents

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	N	%
Visited survey	981	100
Did not participate	641	65.3
Started answering	340	34.7
Interrupted	187	19.1
<b>Completed answering</b>	<b>153</b>	<b>15.6</b>



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# Connection of respondent to survey (N=147)

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Organization	N
iPAAC	77
Other	37
ECPC and Europa Donna	17
EU Institution	7
ECL	6

Other respondents:

- Cancer societies and leagues
- WHO
- Other patient organisations and networks
- Industry
- Universities and academia
- Health care system



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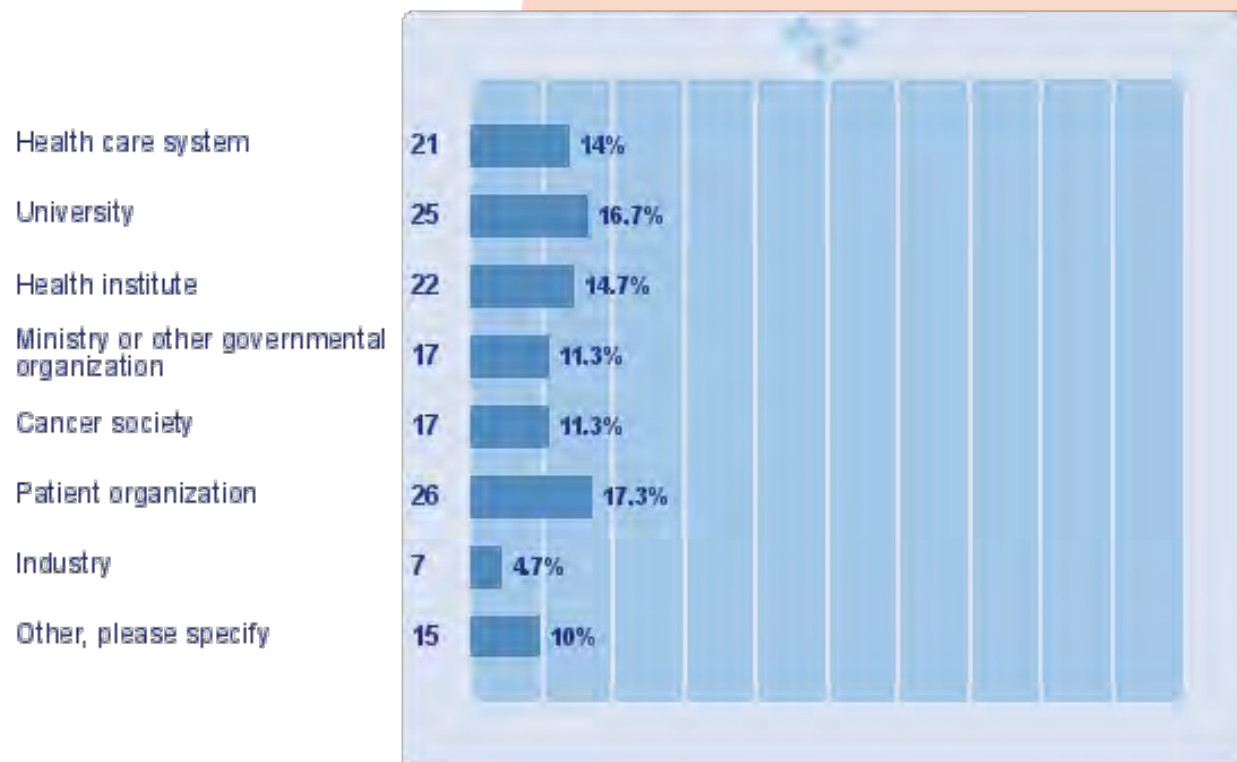
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# Professional affiliations

info  
support  
hope

2. Professional Affiliation of respondent



Other affiliations:

- Research
- Cancer registries
- Private health care professionals



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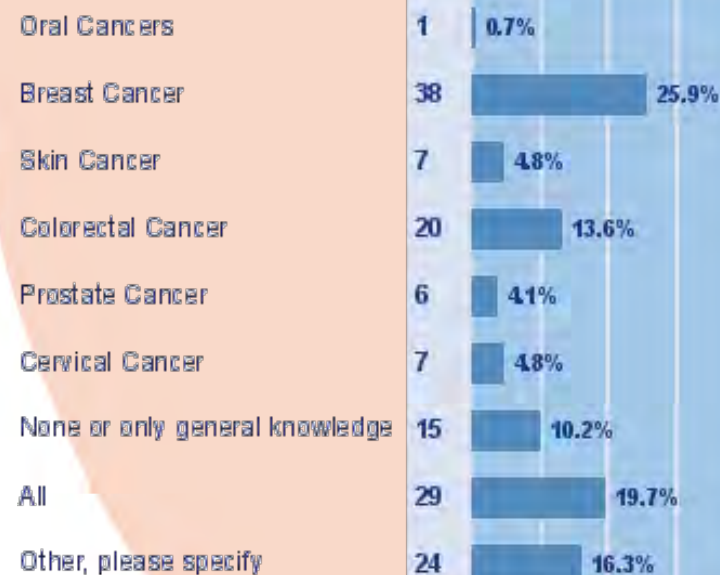
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# Expert knowledge

info  
support  
hope

3. Expert knowledge mostly in



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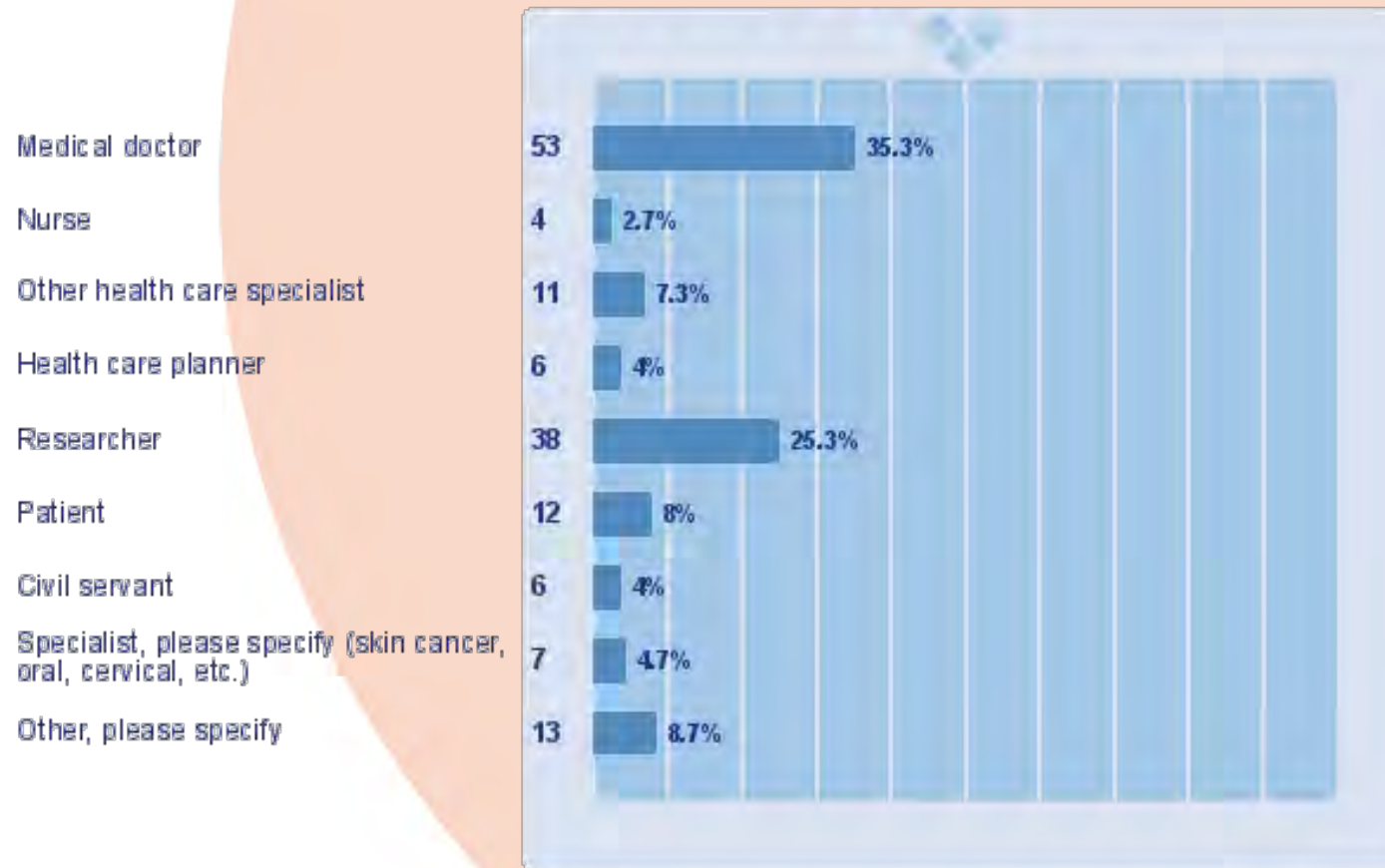
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# Professional background

4. Professional Background



# Respondents by country (N=140)

info  
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hope

Country	N
Italy	15
Spain	15
Norway	12
Belgium	10
Germany	8
Netherlands	7
Serbia	7
Denmark, Greece, Lithuania, Malta, Great Britain	5
Albania, Armenia, Austria, Bulgaria, Croatia, Cyprus, Czech Republic, Finland France, Latvia, Luxemburg, Poland, Portugal, Romania, Russia, Slovakia, Slovenia, Sweden, Switzerland, Turkey	<5



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# Results

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# Presentation of results

- Results of the survey were presented as such (original results)
- ZEF also uses a method called Z-scored Electronic Feedback referring to relative, i.e. normalized results
  - This method is utilized with the aim of removing attitude distortion
  - In this method, relative answers are calculated by moving the average to the centre of the response area and distributing all answers to the whole response area giving thus normalized answers



# Cancer type (n=329)

2. Choose the cancer type you want to evaluate.

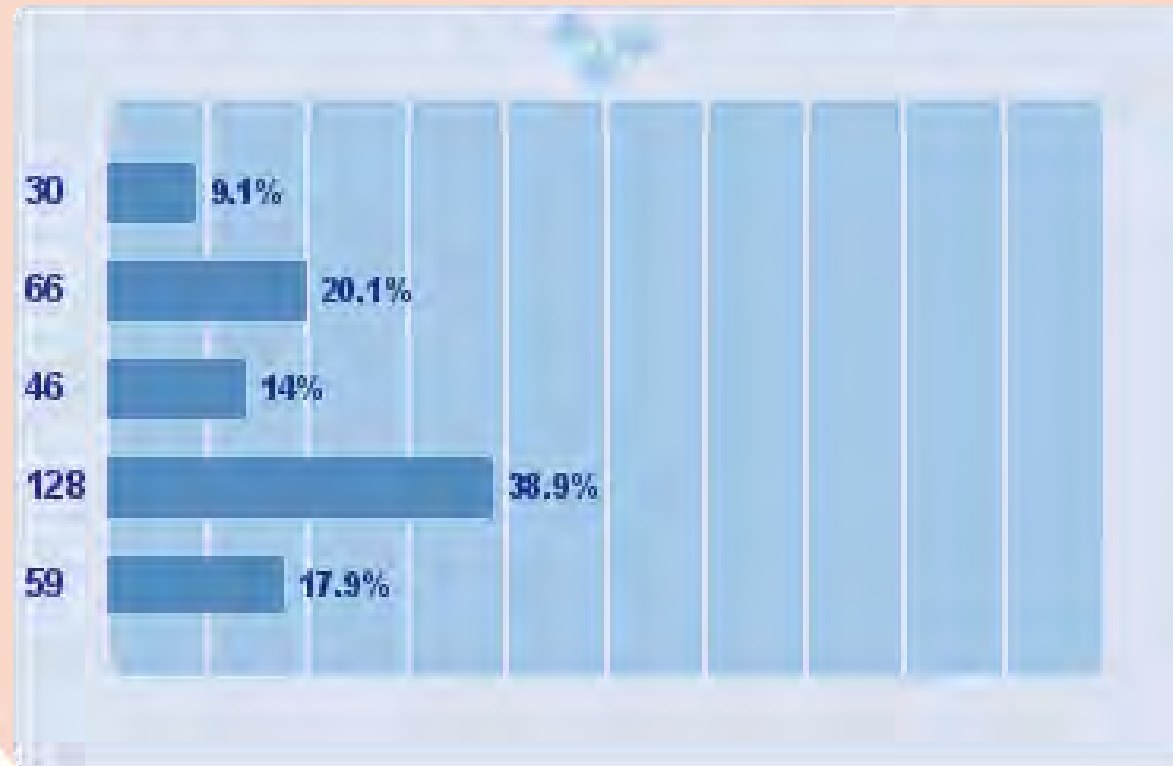
Oral cancers and precancers by dentists looking for early signs

Identifying skin cancers by checking and surveillance for moles

Possible early prostate cancer: symptoms as a sign for action to improve early...

Diverse breast cancer symptoms: better awareness and recognition to improve e...

Other cancer, please specify



# Other cancers:

- Appendix cancer (postmenopausal)
- Bladder cancer
- Blood/hematologic cancer
- Cervical cancer
- Chronic myelogenous leukemia
- Colorectal cancer (also from age 40)
- Gastric cancer
- Digestive/GI cancers
- Gastrointestinal Stromal Tumor (GIST)
- Gynaecological cancer
- Head and neck cancer
- Laryngeal cancer (early signs)
- Lung cancer
- Lymphoma
- Multiple myeloma
- Oesophagus cancer
- Ovarian cancer
- Pediatric cancers
- Rare cancers
- Sarcoma
- Uveal Melanoma





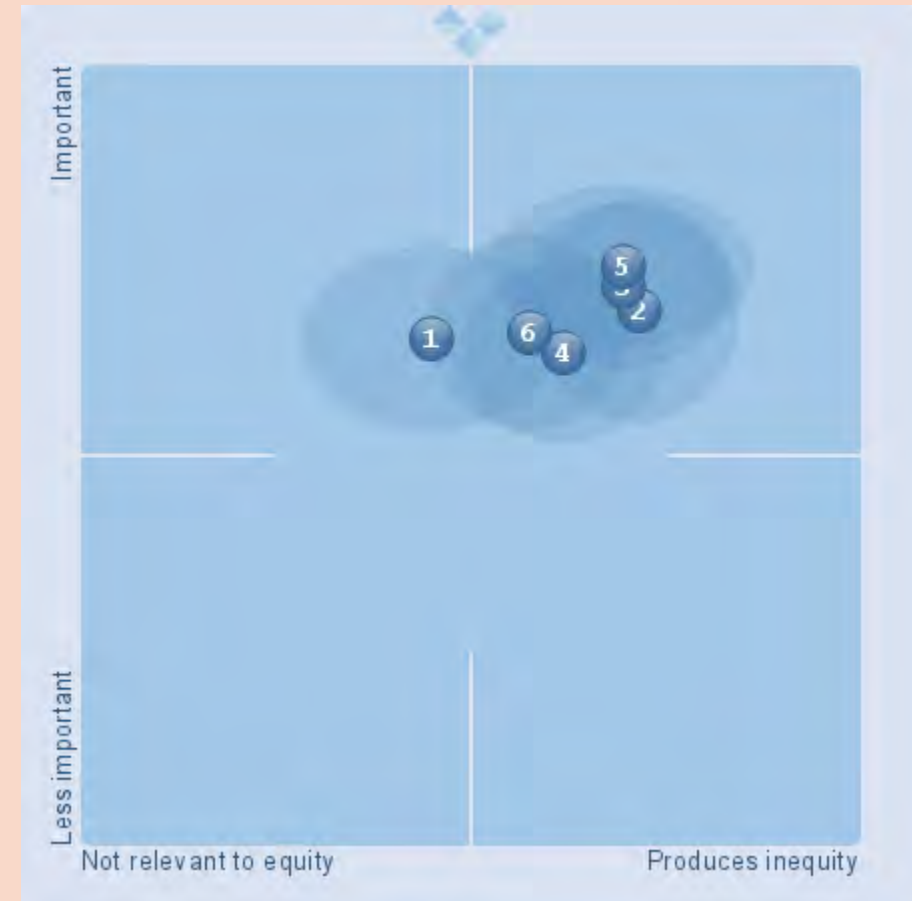
# Oral cancers

info  
support  
hope

- 1. Barrier: Lack of evidence (N=21) (X: 45,13 Y: 64,98)
- 2. Barrier: Limited access to primary care (N=15) (X: 71,69 Y: 68,36)
- 3. Barrier: Lack of awareness (N= 15) (X: 69,67 Y: 71,64)
- 4. Barrier: Cancer stigma (N=14)(X: 61,87 Y: 63,16)
- 5. Barrier: Patient-level financial constraints (N=12) (X: 69,58 Y: 74,20)
- 6. Barrier: Poor organization of patient pathway (N=13) (X: 57,66 Y: 65,77)



Cancer Society of Finland



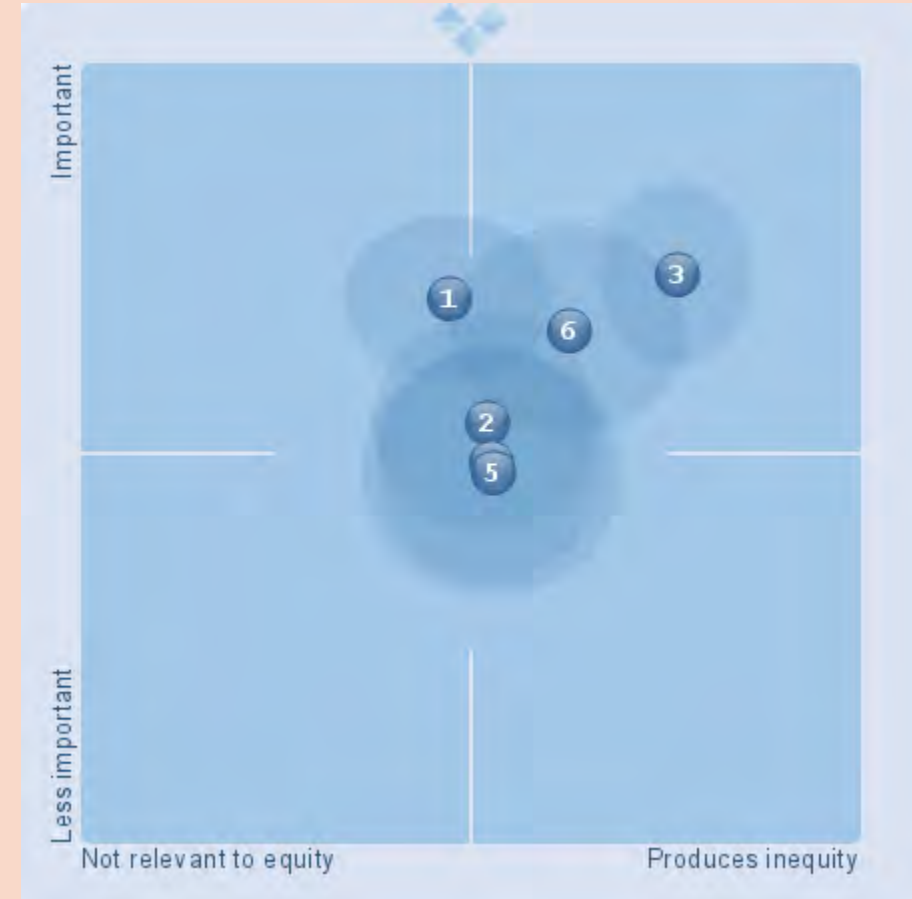
# Skin cancers

info  
support  
hope

- 1. Barrier: Lack of evidence (N=32) (X: 47,40 Y: 69,82)
- 2. Barrier: Limited access to primary care (N=31) (X: 52,12 Y: 53,93)
- 3. Barrier: Lack of awareness (N=27) (X: 76,60 Y: 72,82)
- 4. Barrier: Cancer stigma (N=27) (X: 52,71 Y: 48,75)
- 5. Barrier: Patient-level financial constraints (N=26) (X: 53,02 Y: 47,56)
- 6. Barrier: Poor organization of patient pathway (N=27) (X: 62,68 Y: 65,58)



Cancer Society of Finland



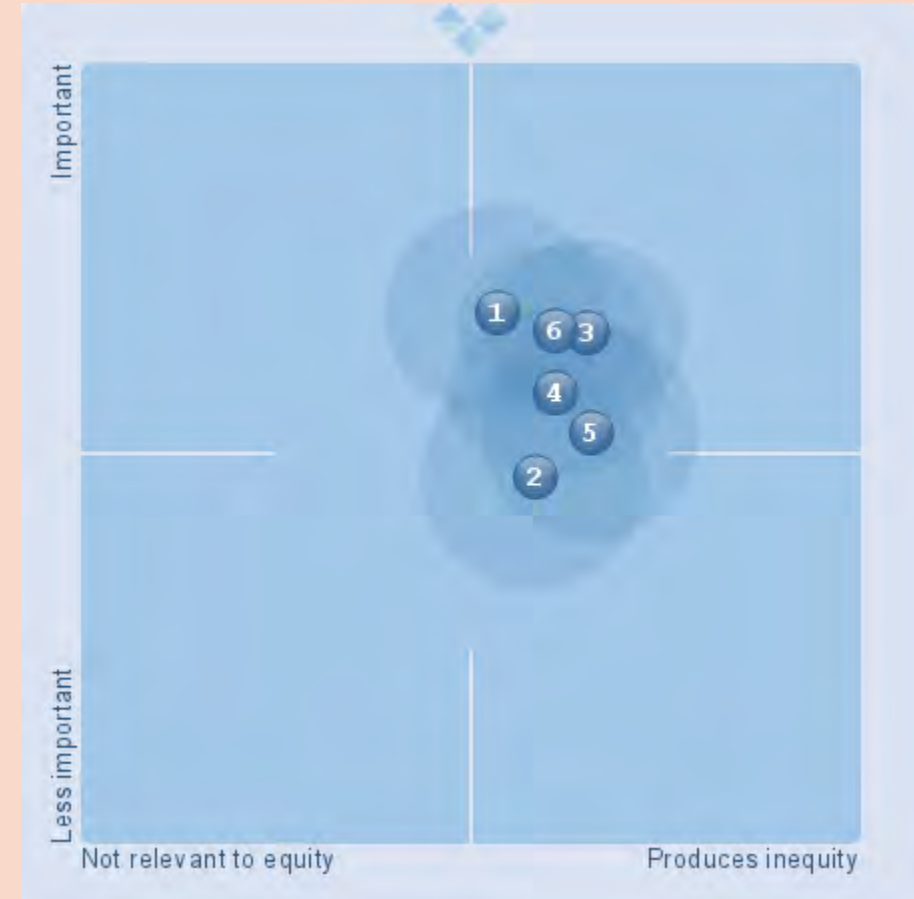
# Prostate cancer

info  
support  
hope

- 1. Barrier: Lack of evidence (N=32) (X: 53,35 Y: 67,91)
- 2. Barrier: Limited access to primary care (N= 29) (X: 58,45 Y: 46,82)
- 3. Barrier: Lack of awareness (N=26) (X: 64,97 Y: 65,33)
- 4. Barrier: Cancer stigma (N=26) (X: 60,93 Y: 57,68)
- 5. Barrier: Patient-level financial constraints (N=25) (X: 65,43 Y: 52,45)
- 6. Barrier: Poor organization of patient pathway (N= 24) (X: 60,77 Y: 65,58)



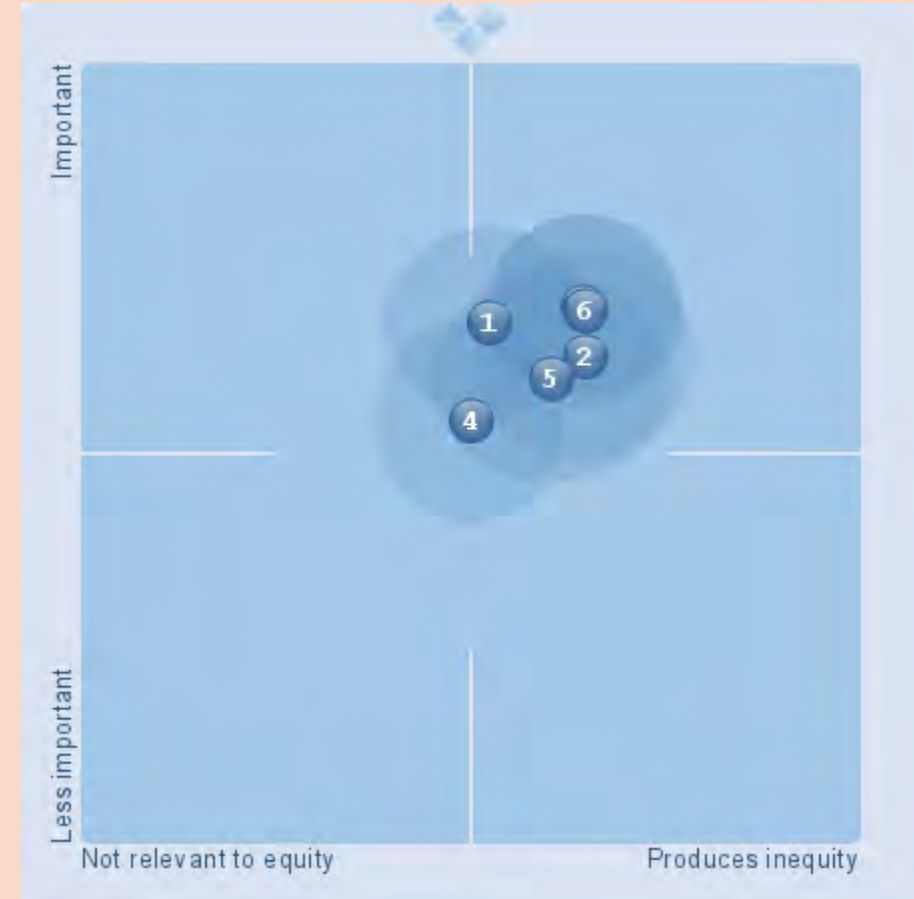
Cancer Society of Finland



# Breast cancer

info  
support  
hope

- 1. Barrier: Lack of evidence (N=82) (X: 52,31 Y: 66,55)
- 2. Barrier: Limited access to primary care (N=75) (X: 64,71 Y: 62,30)
- 3. Barrier: Lack of awareness (N= 72) (X: 64,44 Y: 68,68)
- 4. Barrier: Cancer stigma (N=71) (X: 50,19 Y: 54,02)
- 5. Barrier: Patient-level financial constraints (N=67) (X: 60,32 Y: 59,39)
- 6. Barrier: Poor organization of patient pathway (N= 65) (X: 64,81 Y: 68,22)



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# Other cancers

info  
support  
hope

- 1. Barrier: Lack of evidence (N= 40) (X: 53,68 Y: 74,38)
- 2. Barrier: Limited access to primary care (N= 37) (X: 54,00 Y: 54,29)
- 3. Barrier: Lack of awareness (N=38) (X: 56,65 Y: 68,76)
- 4. Barrier: Cancer stigma (N=34) (X: 46,96 Y: 54,56)
- 5. Barrier: Patient-level financial constraints (N=32) (X: 56,60 Y: 61,48)
- 6. Barrier: Poor organization of patient pathway (N=31) (X: 53,52 Y: 62,03)



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# Summary & Discussion

**info  
support  
hope**



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Clarissa Bingham

20.5.2019



# Barriers according to importance

Importance	Oral cancers	Skin cancers	Prostate cancer	Breast cancer	Other cancers
Most important	5	3	1	3	1
2. important	3	1	6	6	3
3. important	2	6	3	1	6
4. important	6	2	4	2	5
5. important	1	4	5	5	2
Least important	4	5	2	4	4

Barriers: 1. Lack of evidence 2. Limited access to primary care 3. Lack of awareness 4. Cancer stigma 5. Patient-level financial constraints 6. Poor organization of patient pathway



# Barriers according to (in)equity

Equity	Oral cancers	Skin cancers	Prostate cancer	Breast cancer	Other cancers
Produces most inequity	2	3	5	6	3
2. most inequity	3	6	3	2	5
3. most inequity	5	5	6	3	2
4. most inequity	4	4	4	5	1
5. most inequity	6	2	2	1	6
Not relevant to inequity	1	1	1	4	4

Barriers: 1. Lack of evidence 2. Limited access to primary care 3. Lack of awareness 4. Cancer stigma 5. Patient-level financial constraints 6. Poor organization of patient pathway



# Discussion

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hope

- In general, the three most important barriers of early detection were 1. Lack of evidence, 3. Lack of awareness and 6. Poor organization on patient pathway
  - The least important was 4. Cancer stigma
- Respectively, 2. Limited access to primary care, 3. Lack of awareness, 5. Patient-level financial constraint and 6. Poor organization of patient pathway way perceived to produce inequity
  - 1. Lack of evidence and 4. Cancer stigma were not as relevant to equity
- Variation between cancer type was found



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# Discussion

- The number of respondents decreased significantly between those who addressed the survey, started answering and completed answering
- Explanations for this include the new and unfamiliar survey method, possible irrelevance of the scope of the survey in relation to respondents' expertise, lack of knowledge of the specific questions; and unfamiliarity of the iPAAC
  - Most responses (77) finalised among those with a connection to iPAAC
  - We think that the results represent rather well the perceptions within the iPAAC partners
- In summary, this survey reveals a large amount of information of barriers of early detection of cancer in Europe
- The results are to be examined further in order to achieve more detailed information according to cancer types, barriers and background factors (countries, professions etc.) Also scoring needs further attention.



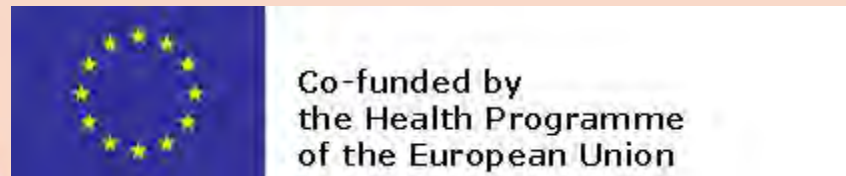
# References

- 1. World Health Organization (WHO). Guide to cancer early diagnosis. World Health Organization, 2017 (ISBN 978-92-4-151194-0)
- 2. European Committee for standardization (CEN). Health care services - Quality criteria for health checks. Collaborative Workshop Agreement (CWA) 16642:2013 (E).
- 3. International Agency for Research on Cancer (IARC). Breast cancer screening. IARC Handbooks of cancer prevention, vol. 15. IARC, Lyon 2016.
- 4. Zanetti R, Sacchetto L, Coebergh JW, Rosso S. To accelerate cancer prevention in Europe: Challenges for cancer registries. Eur J Cancer 2018;104:151-159.
- 5. Roland M, Neal D, Buckley R. What should doctors say to men asking for a PSA test? BMJ 2018;362:k3702 doi: 10.1136/bmj.k3702 (an editorial).



# THANK YOU!

info  
support  
hope



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Clarissa Bingham

20.5.2019





# Burden and trend of Cancer in Europe: First step towards Earlier Detection

International Agency for Research on Cancer  
Lyon, France

Isabelle Soerjomataram

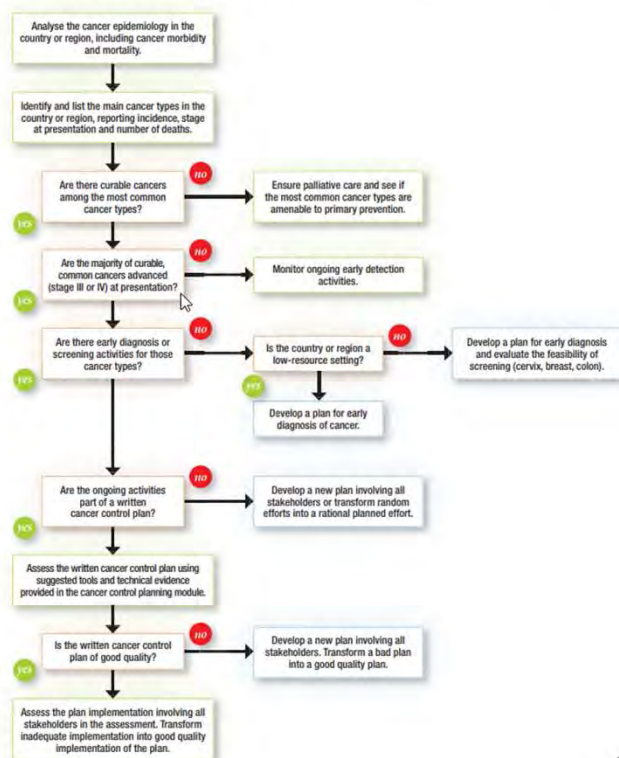
International Agency for Research on Cancer



Budapest – 20 May 2019

# Early Detection: Recommendation

**Figure 1.** How to decide if an early detection component is needed within a cancer control plan



7

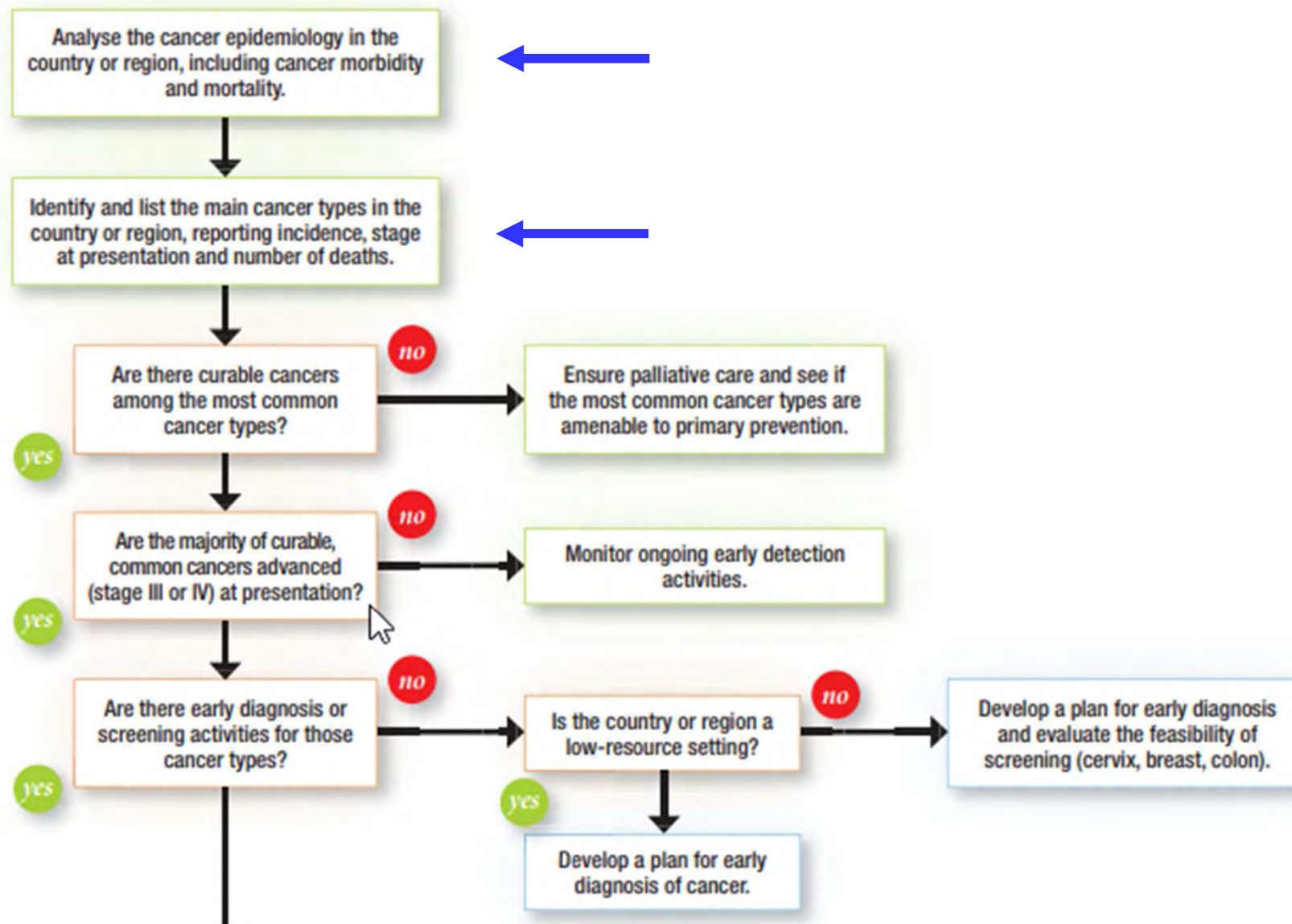
**Table 1.** Recommended activities for early detection of selected cancers

Site of cancer	Activities for	
	Early diagnosis	Screening
Breast	Yes	Yes <sup>a</sup>
Cervix	Yes	Yes
Colon and rectum	Yes	Yes <sup>b</sup>
Oral cavity	Yes	Yes
Naso-pharynx	Yes	No
Larynx	Yes	No
Lung	No	No
Oesophagus	No	No
Stomach	Yes	No
Skin melanoma	Yes	No
Other skin cancers	Yes	No
Ovary	No	No
Urinary bladder	Yes	No
Prostate	Yes	No
Retinoblastoma	Yes	No
Testis	Yes	No

<sup>a</sup> Screening for breast cancer using mammography is recommended in high-resource settings only.

<sup>b</sup> In high-resource settings only.

# Early Detection: Recommendation



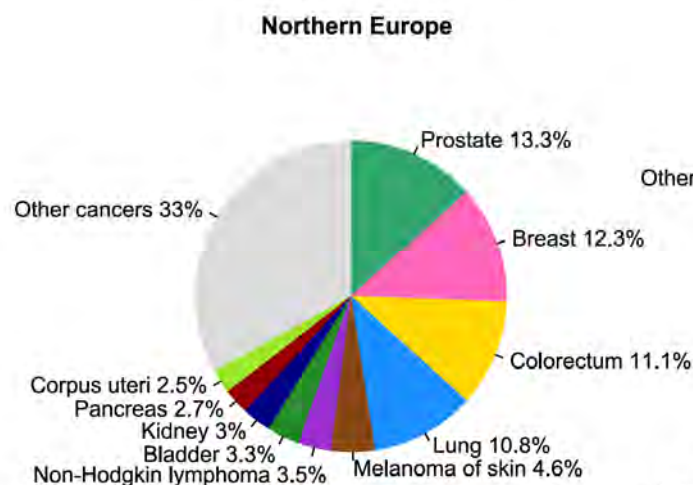
# Burden of Cancer in Europe

International Agency for Research on Cancer

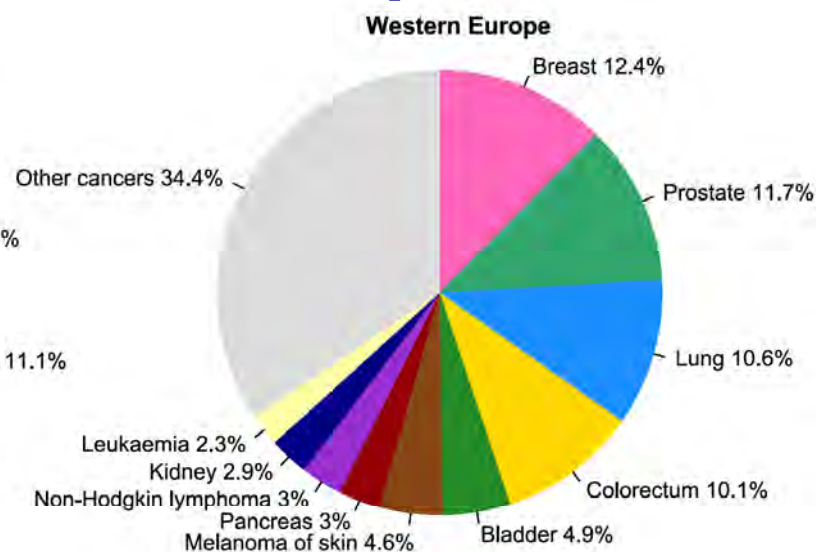




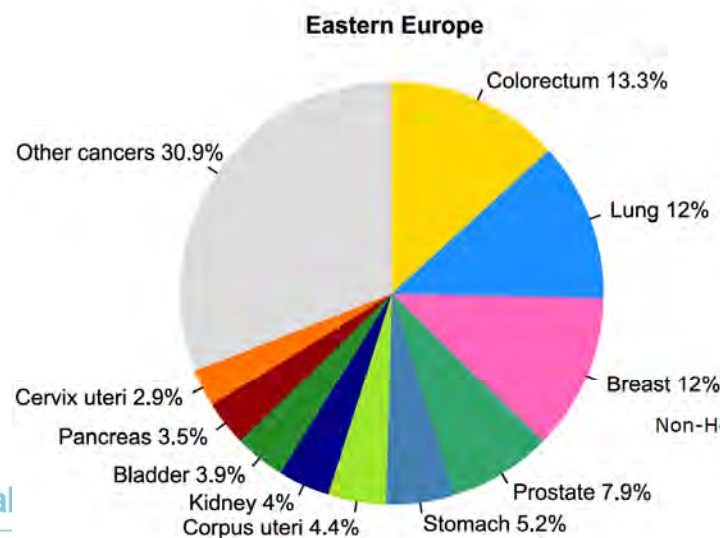
# Cancer incidence: European Regions



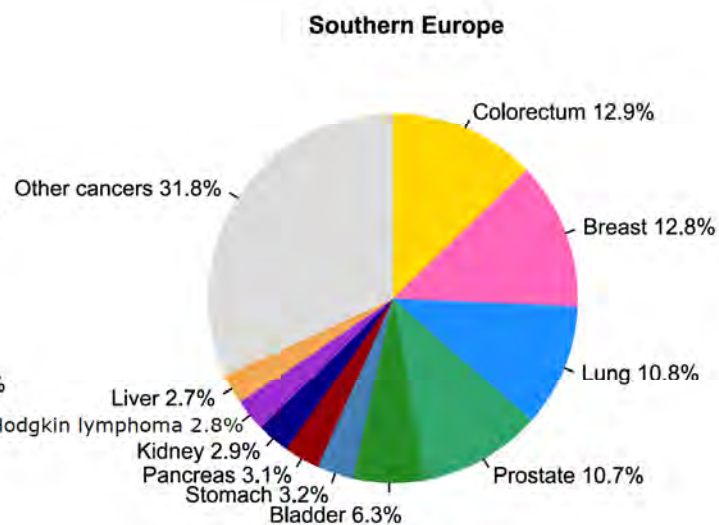
686,000 new cases



1,370,000 new cases



1,240,000 new cases

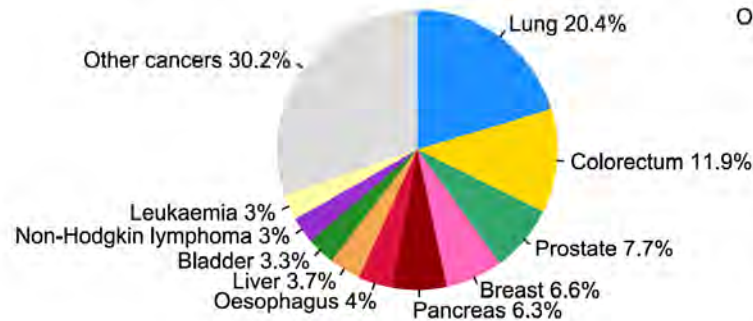


933,000 new cases

Source: GLOBOCAN 2018

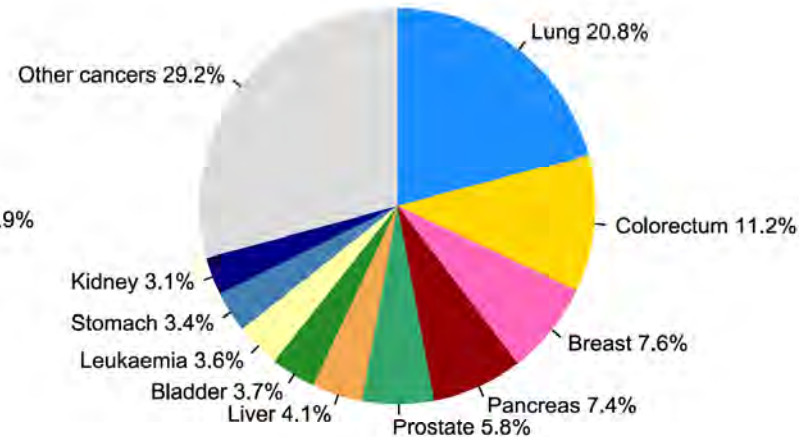
# Cancer mortality: European Regions

**Northern Europe**



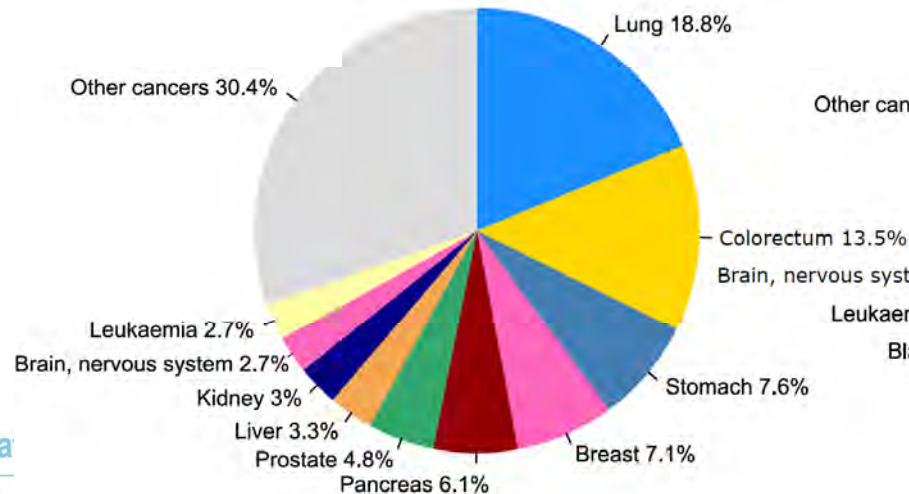
274,000 new cases

**Western Europe**



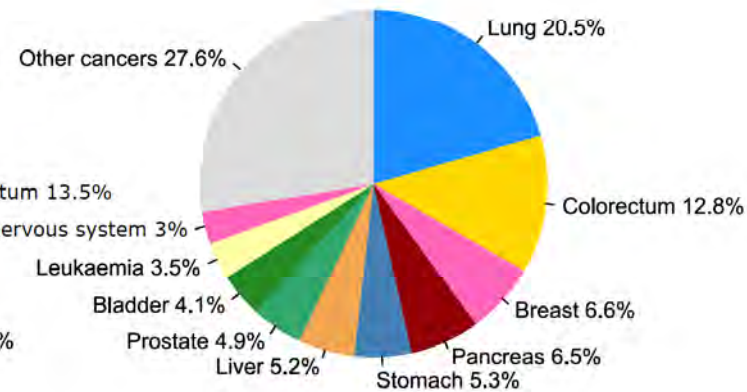
548,000 new cases

**Eastern Europe**



699,000 new cases

**Southern Europe**



422,000 new cases

Source: GLOBOCAN 2018



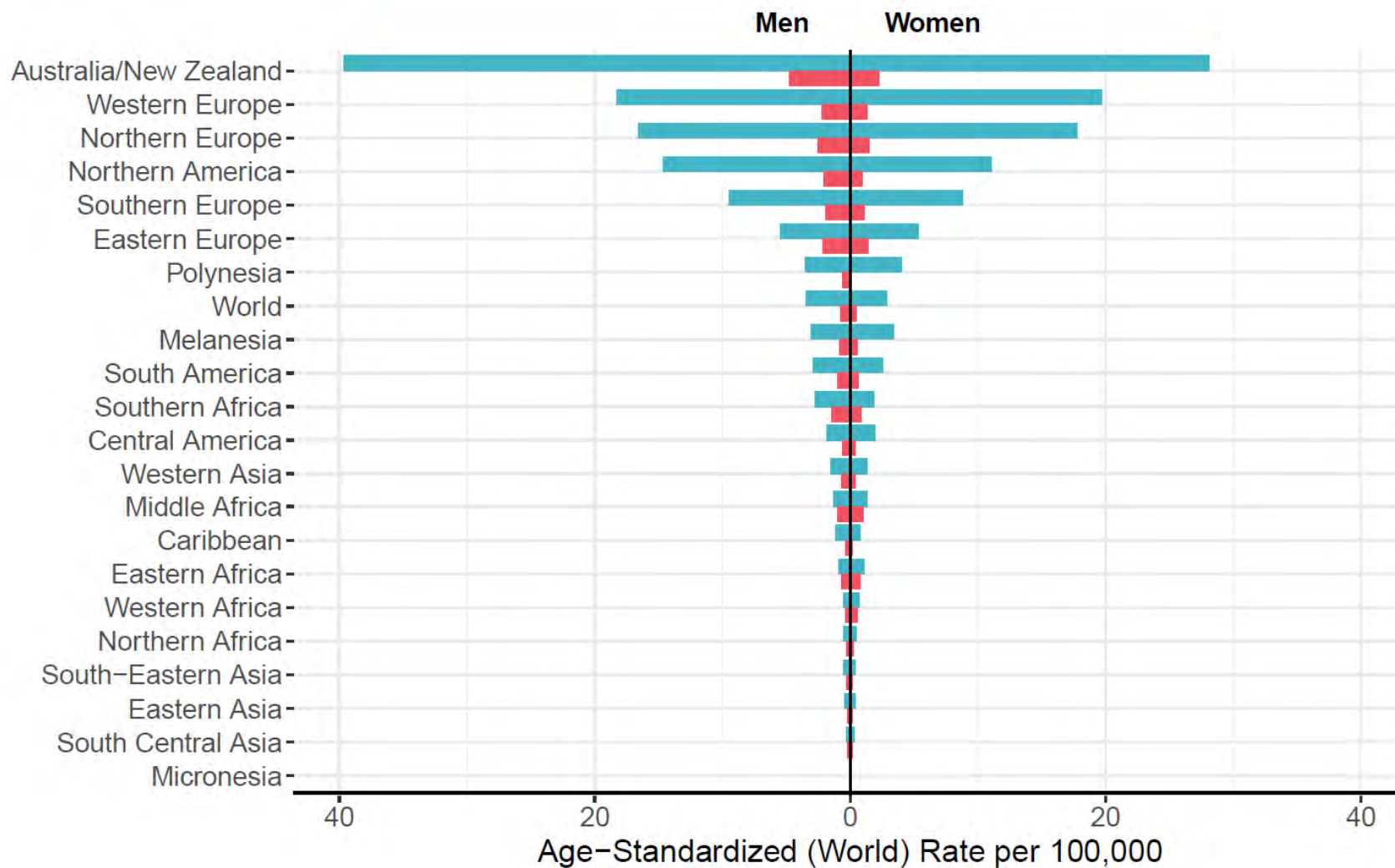
# Melanoma of the Skin

International Agency for Research on Cancer



World Health  
Organization

# Incidence & Mortality Melanoma



Internat

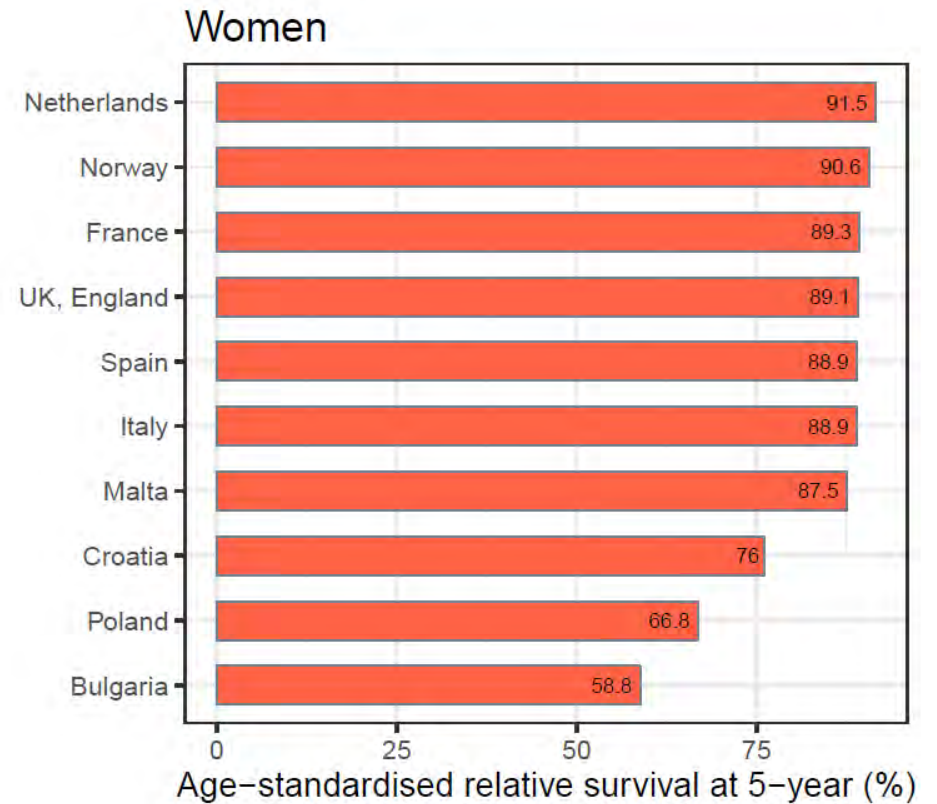
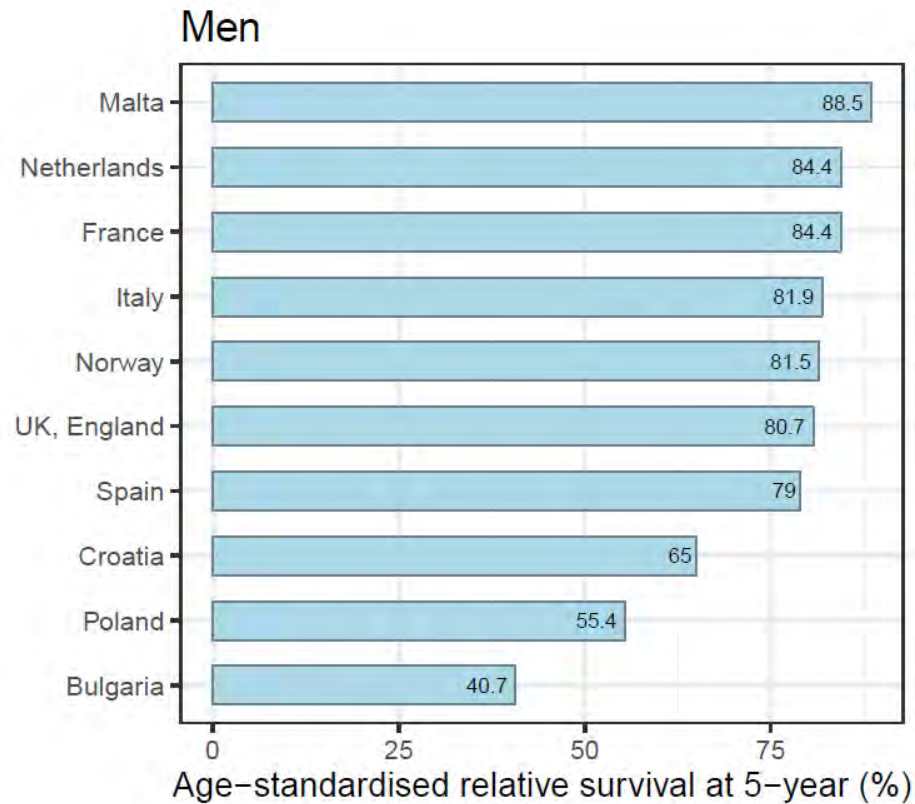


World Health  
Organization

Incidence Mortality

Source: GLOBOCAN 2018

# Melanoma of skin

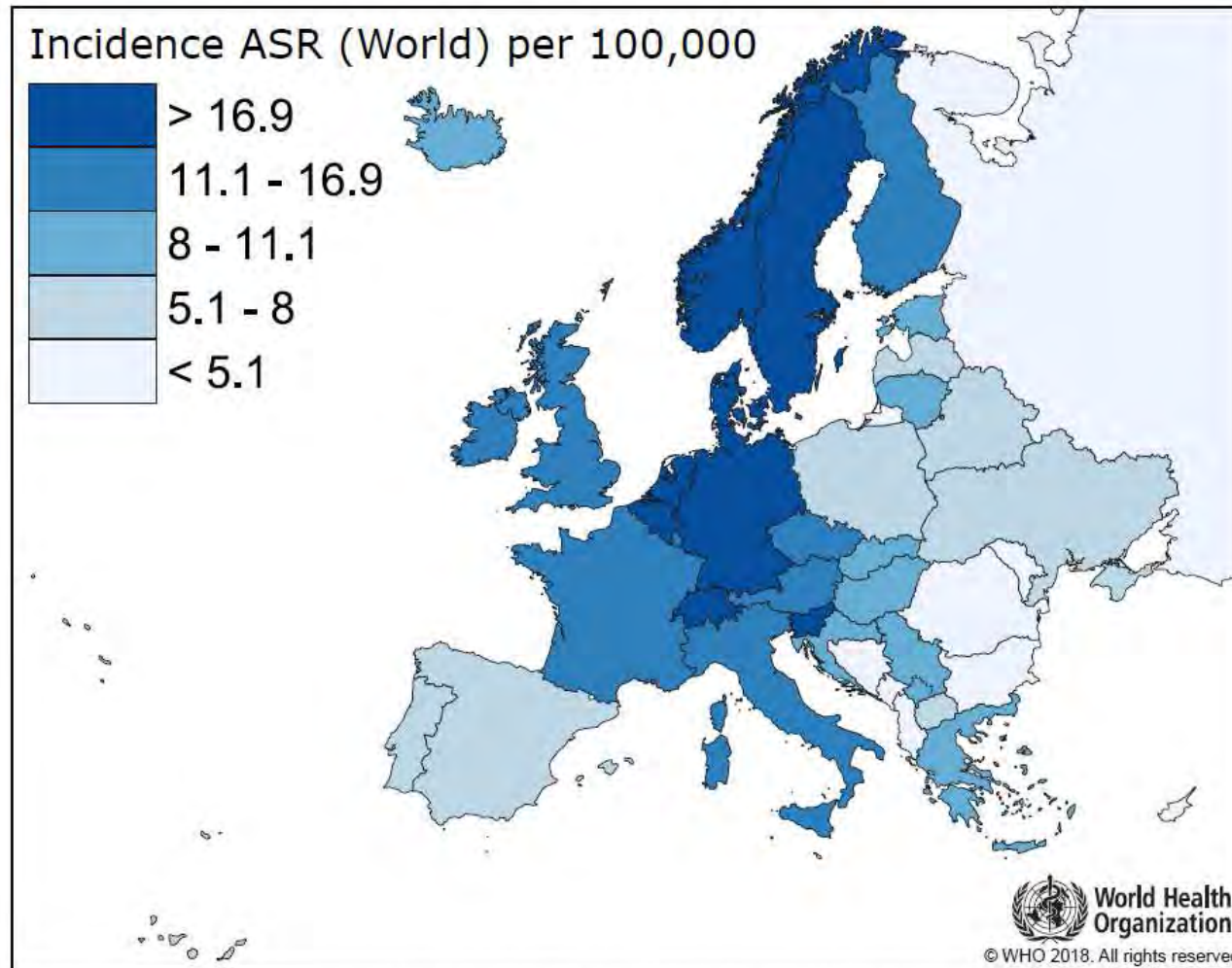


International Agency for Research on Cancer



Source: ECIS

# Incidence of Melanoma



International Agency for

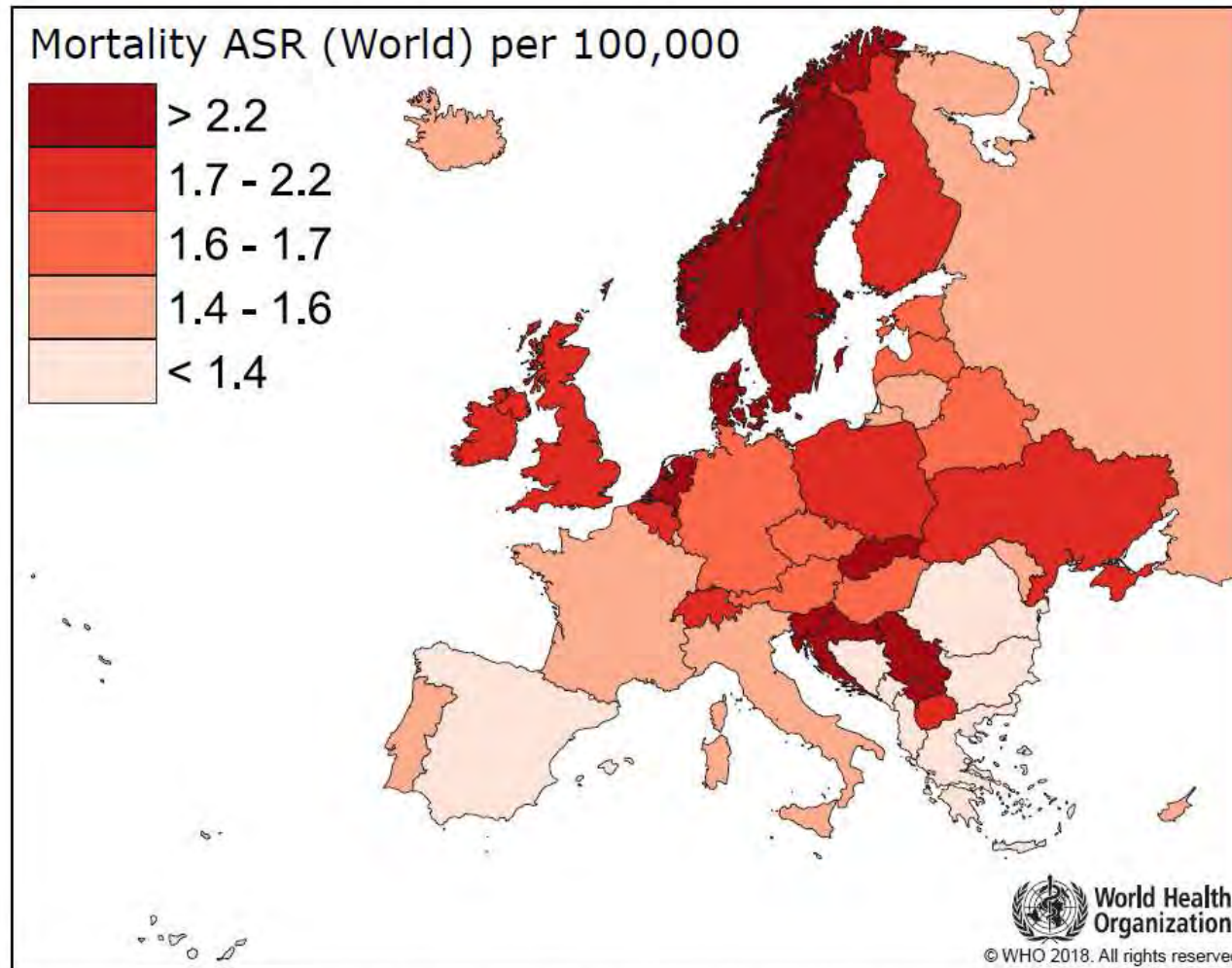


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Source: GLOBOCAN 2018



# Mortality of Melanoma



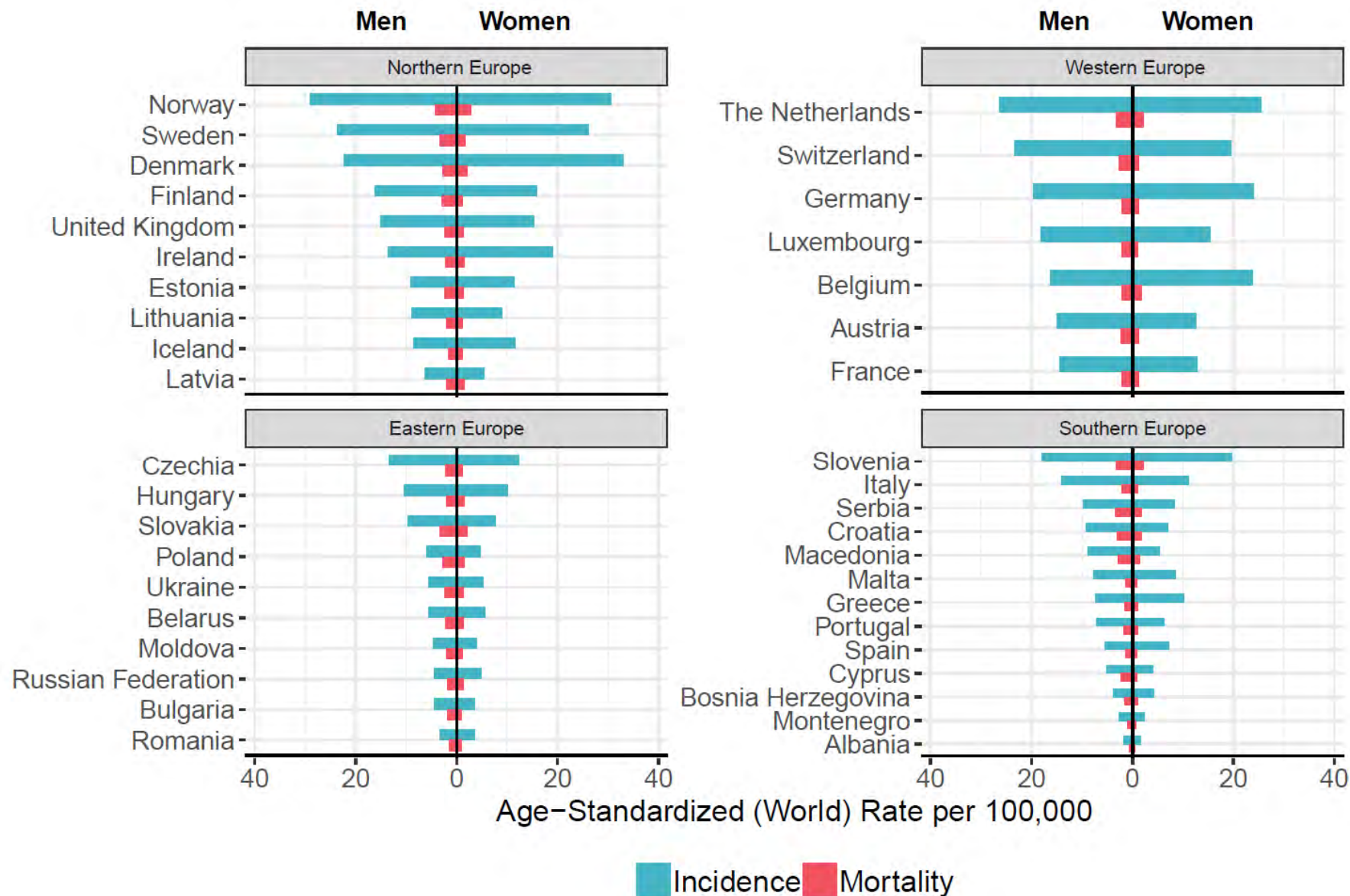
International Agency for



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Source: GLOBOCAN 2018

# Incidence & Mortality Melanoma, E

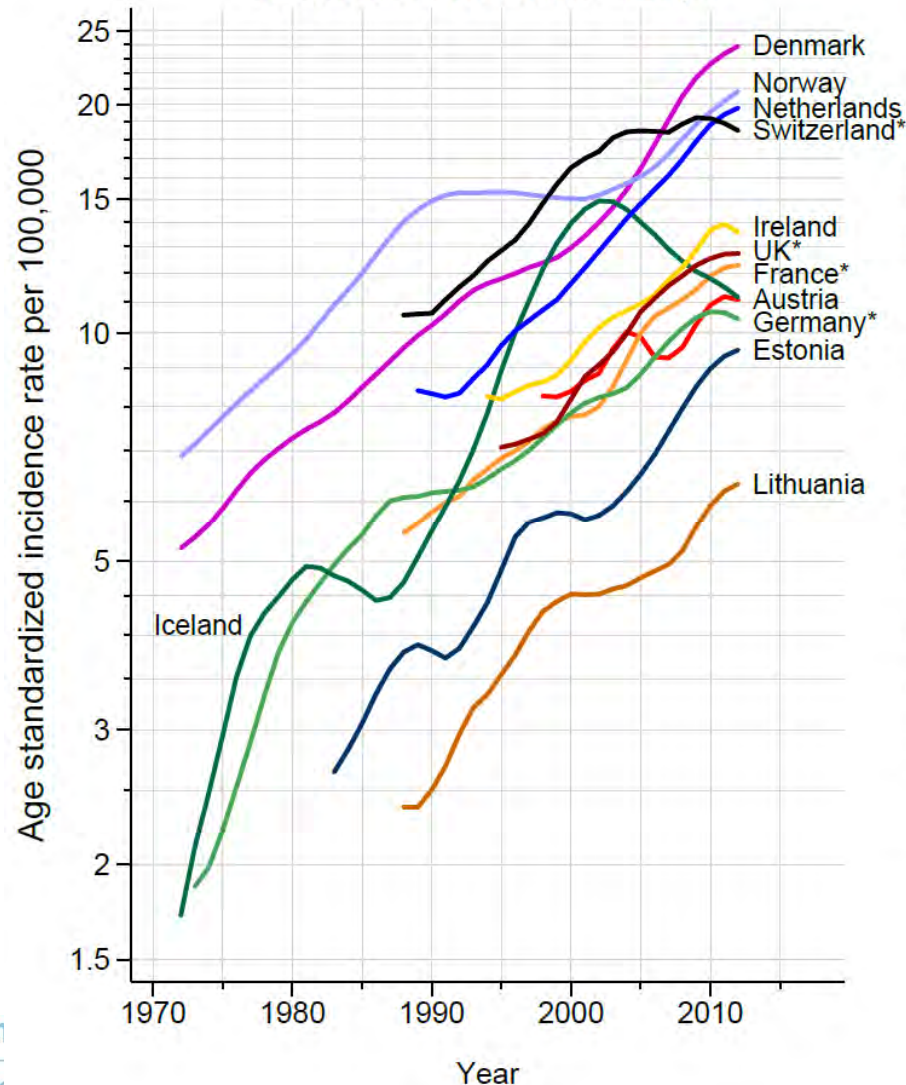


Source: GLOBOCAN 2018

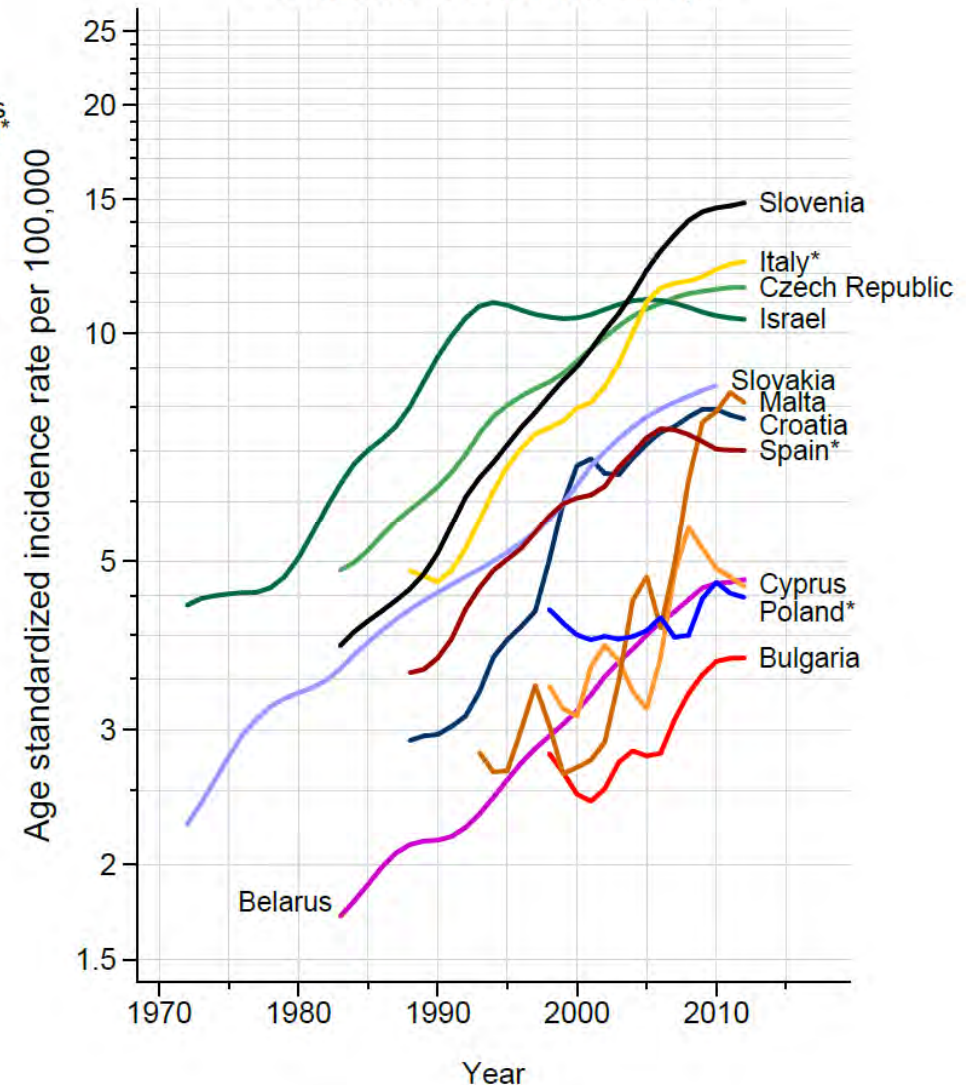


# Trend incidence of Melanoma

Northern & Western Europe



Southern & Eastern Europe

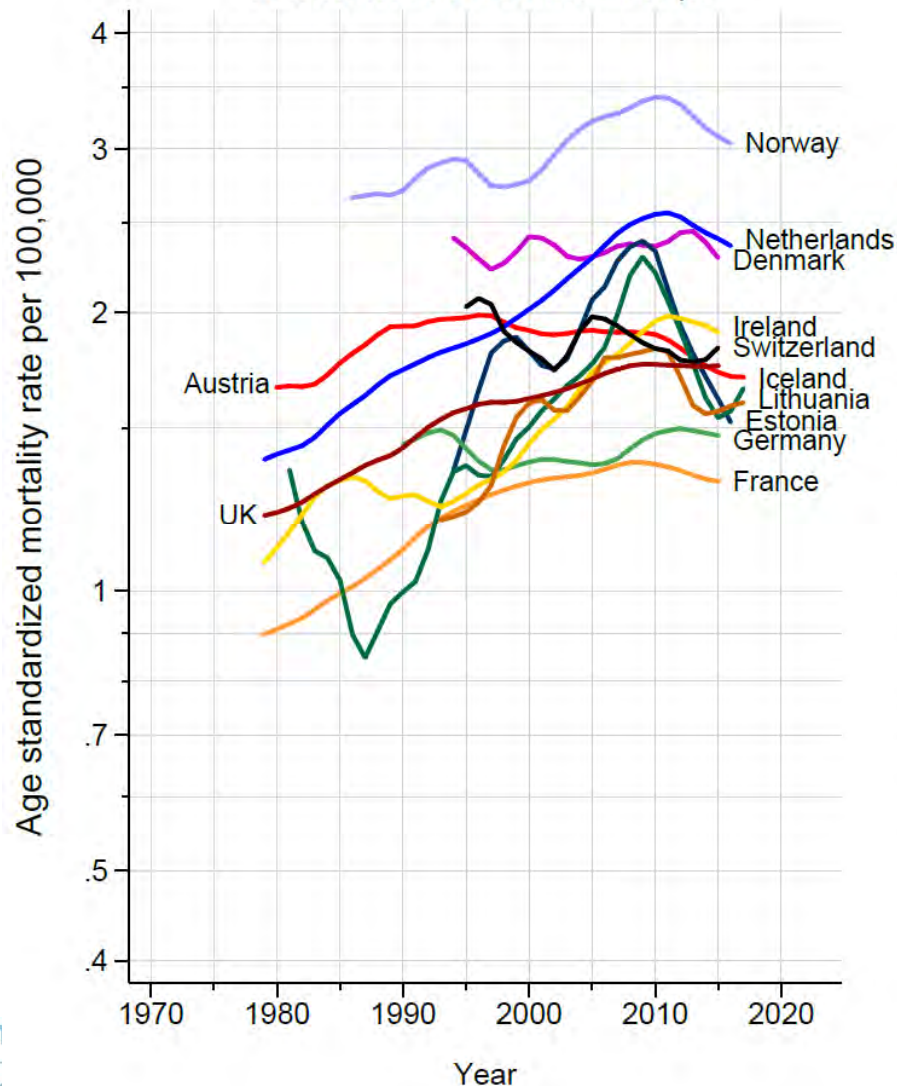


\* regional registries

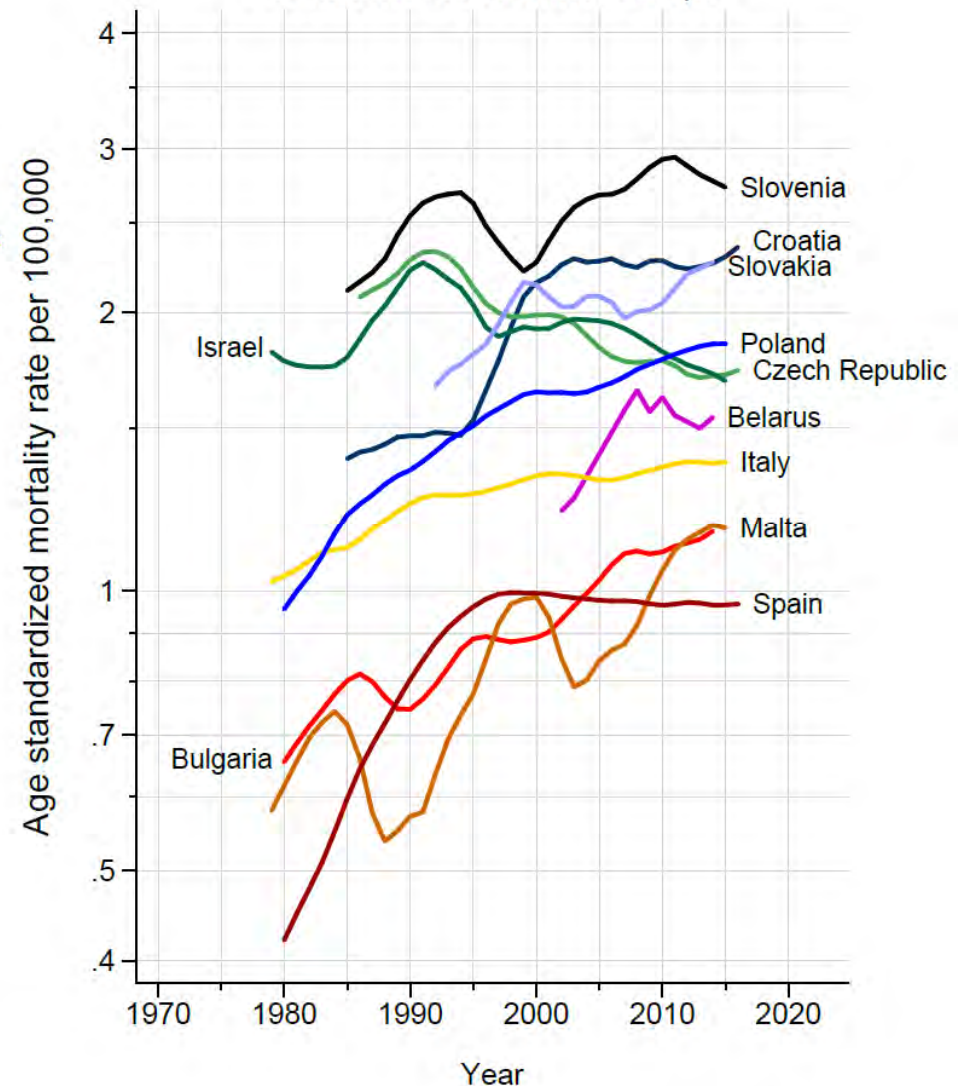
Source: CI5plus

# Trend mortality of Melanoma

Northern & Western Europe

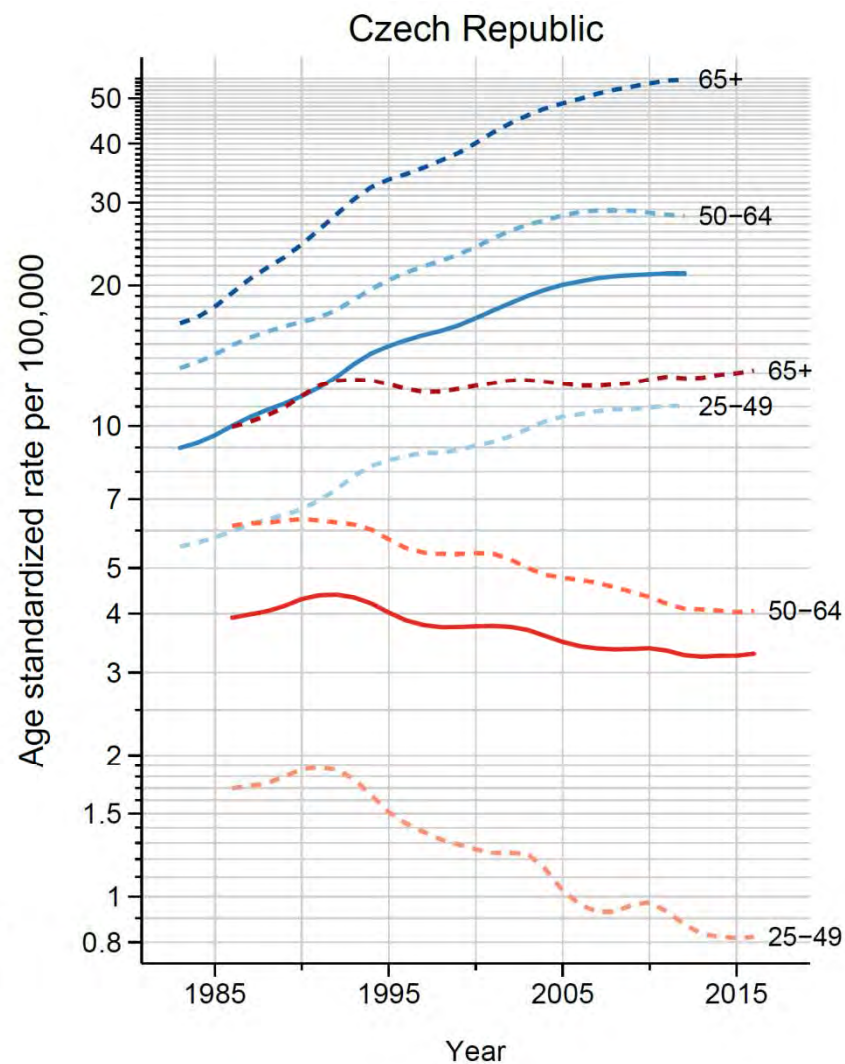
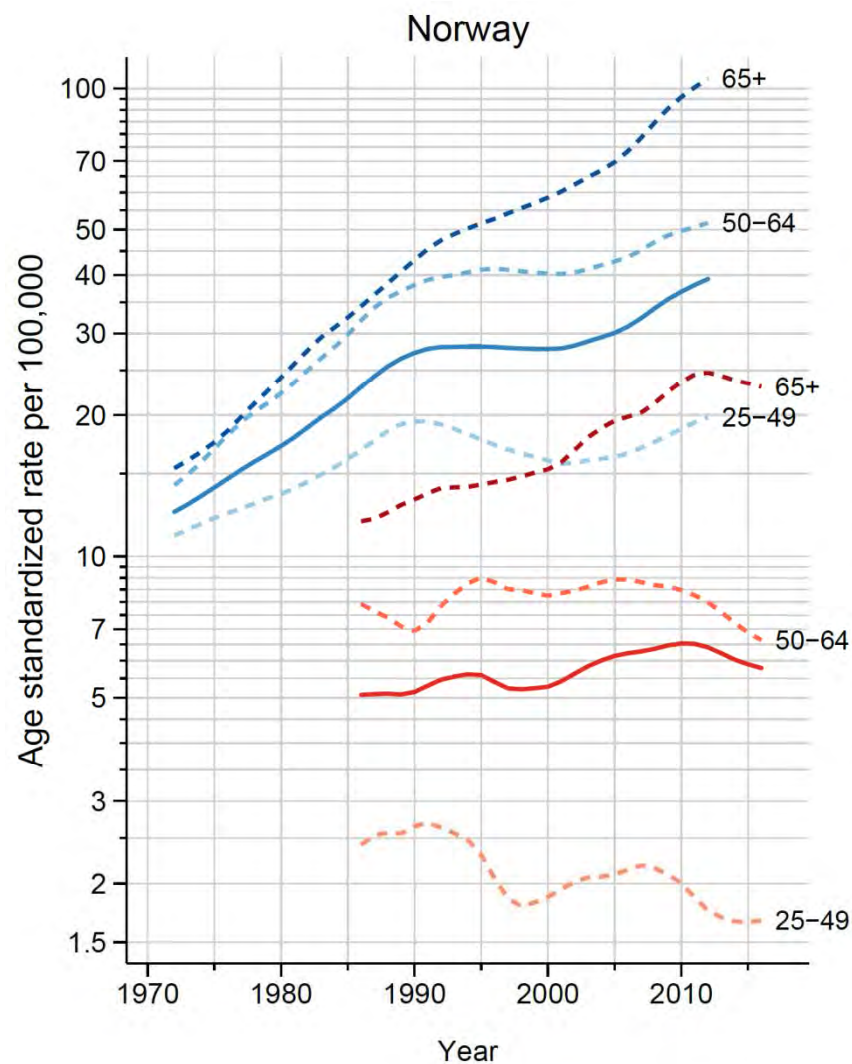


Southern & Eastern Europe





# Incidence & Mortality – by age

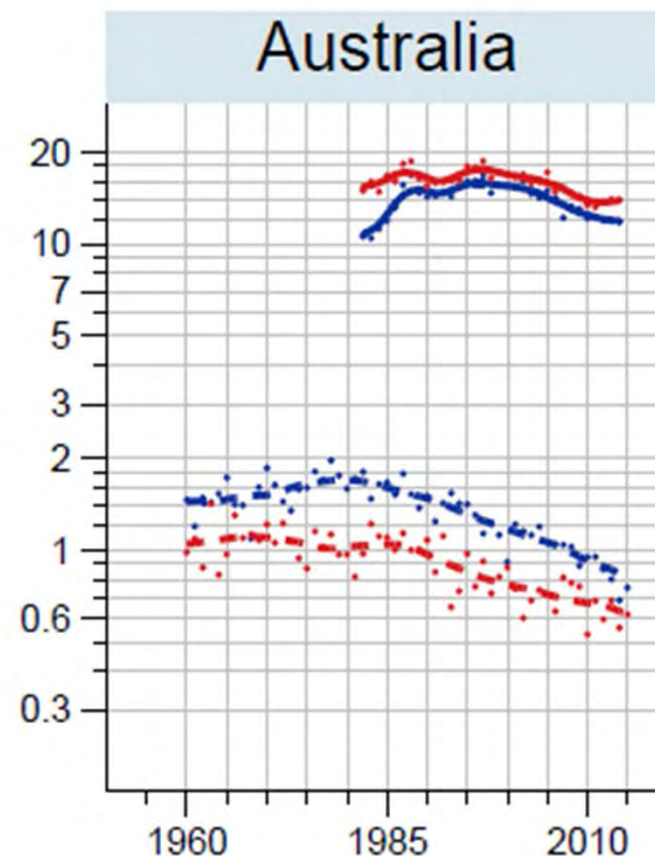


# Success in Prevention of Melanoma

- SunSmart since 1980
- Secular changes
- 'Population dilution'

Mortality reduction

- Better treatment and follow-up
- Early detection

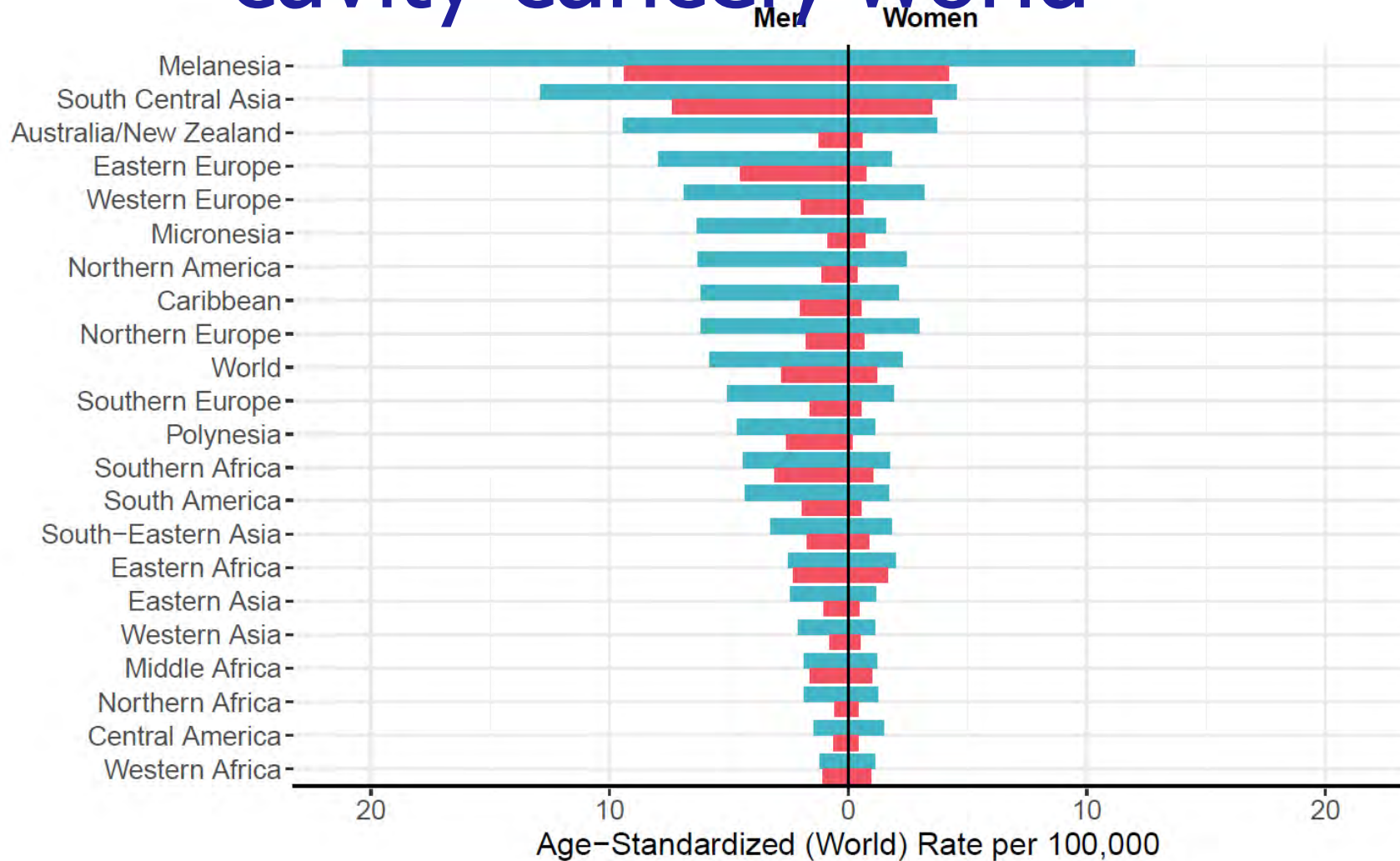


# Oral Cavity Cancer

International Agency for Research on Cancer



# Incidence & Mortality from oral cavity cancer, world



Internat



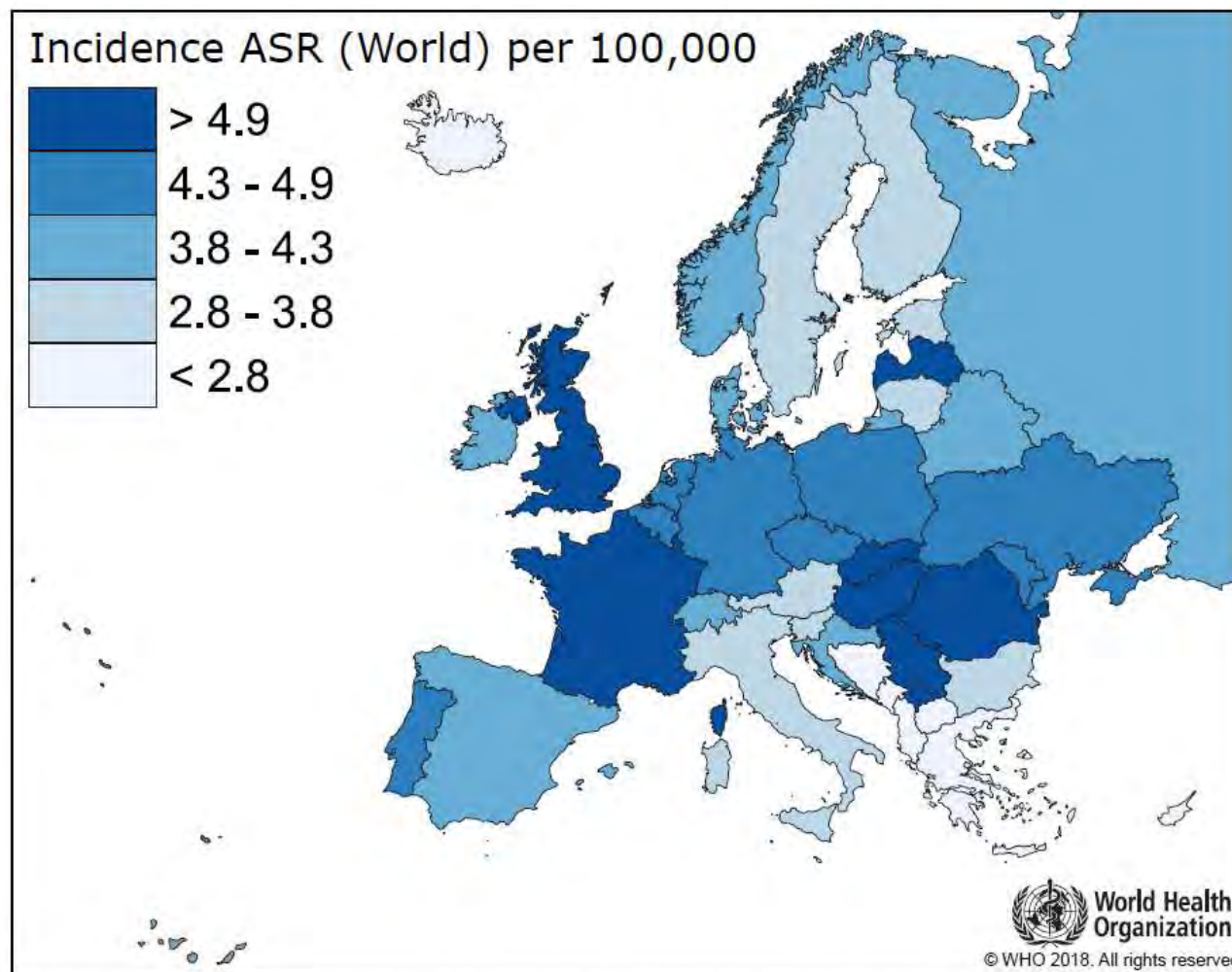
World Health Organization

Incidence Mortality

Source: GLOBOCAN 2018



# Incidence of Oral Cavity cancer



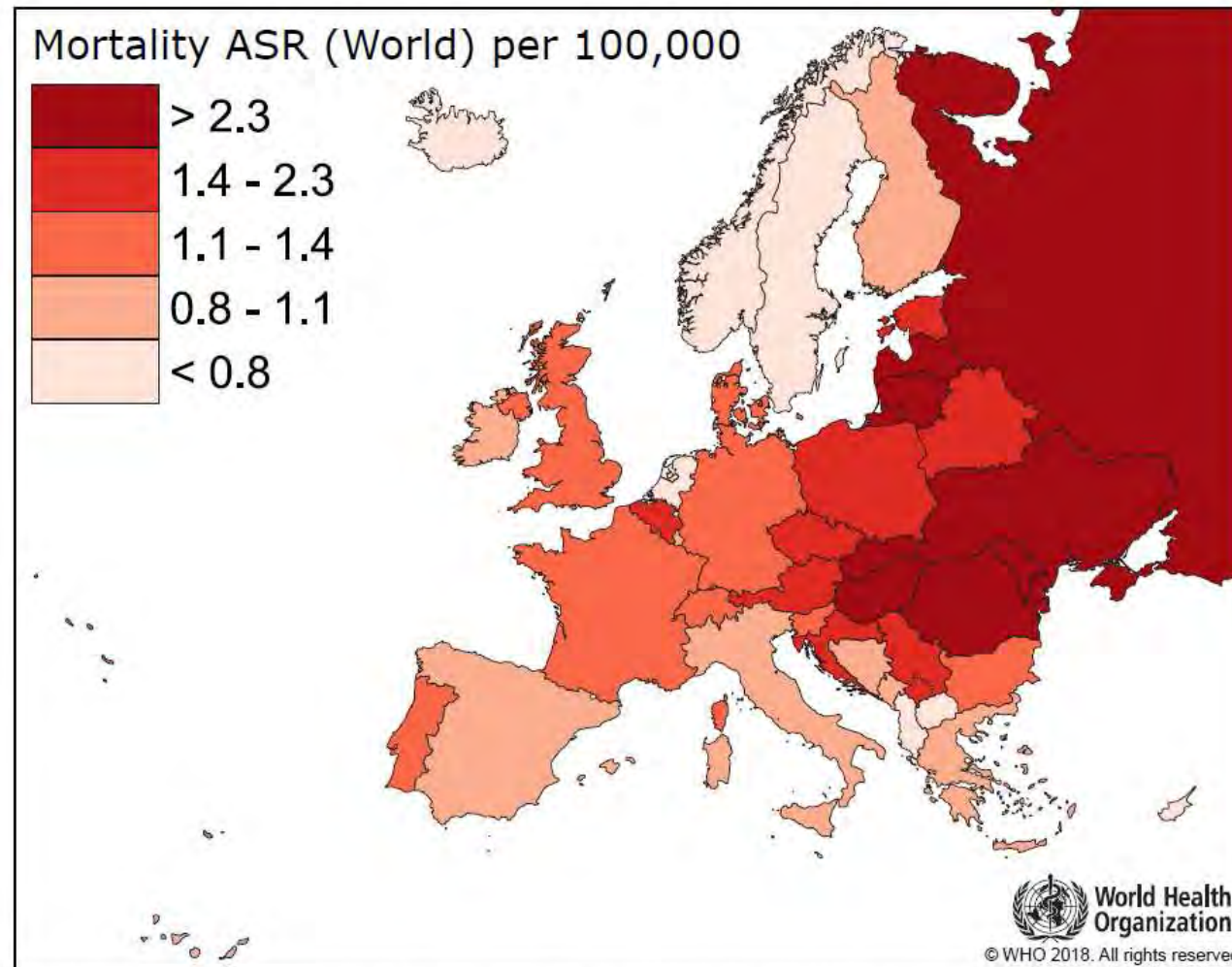
International Agency for



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Source: GLOBOCAN 2018, incl. lip

# Mortality of Oral Cavity cancer



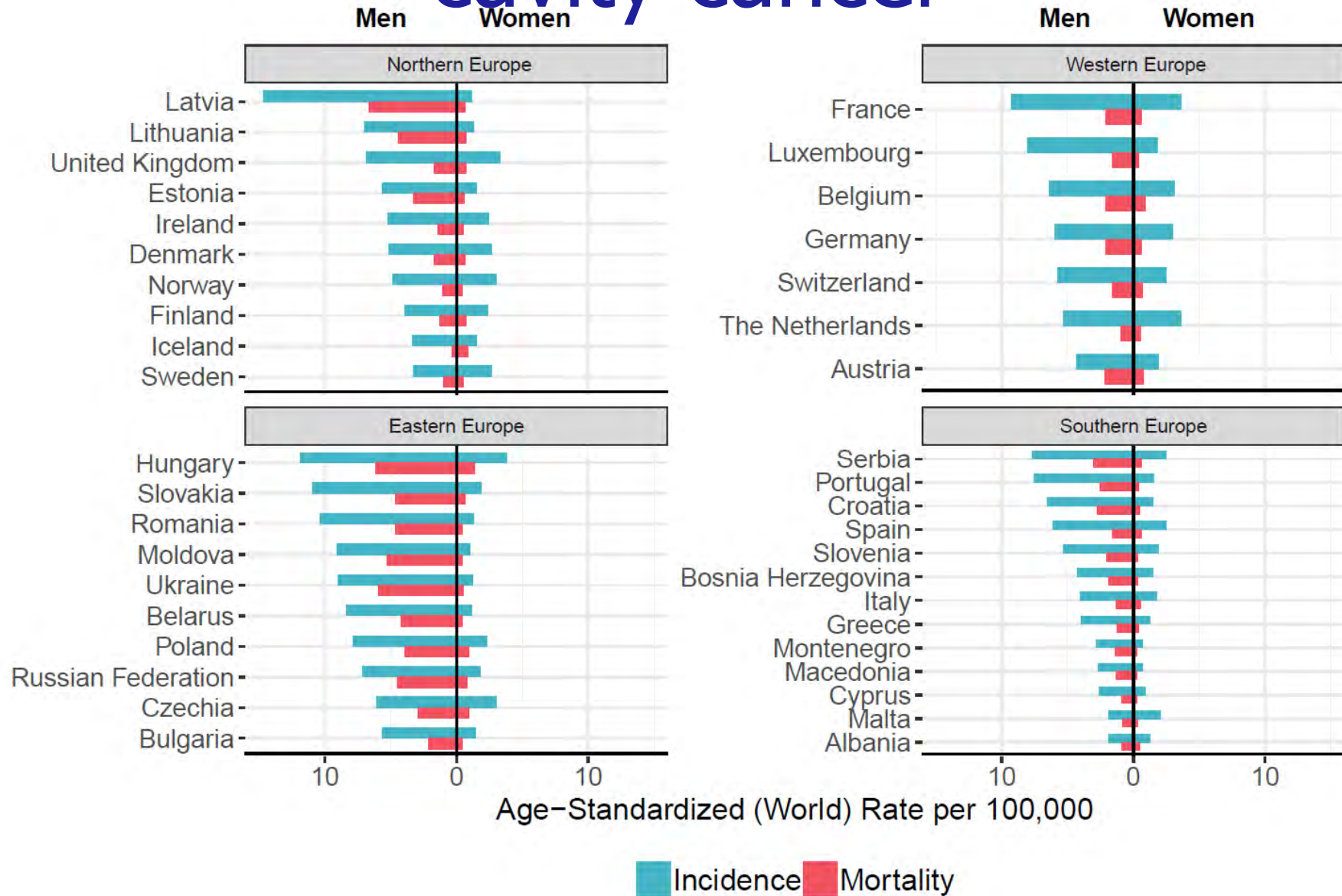
International Agency for



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Source: GLOBOCAN 2018, incl. lip

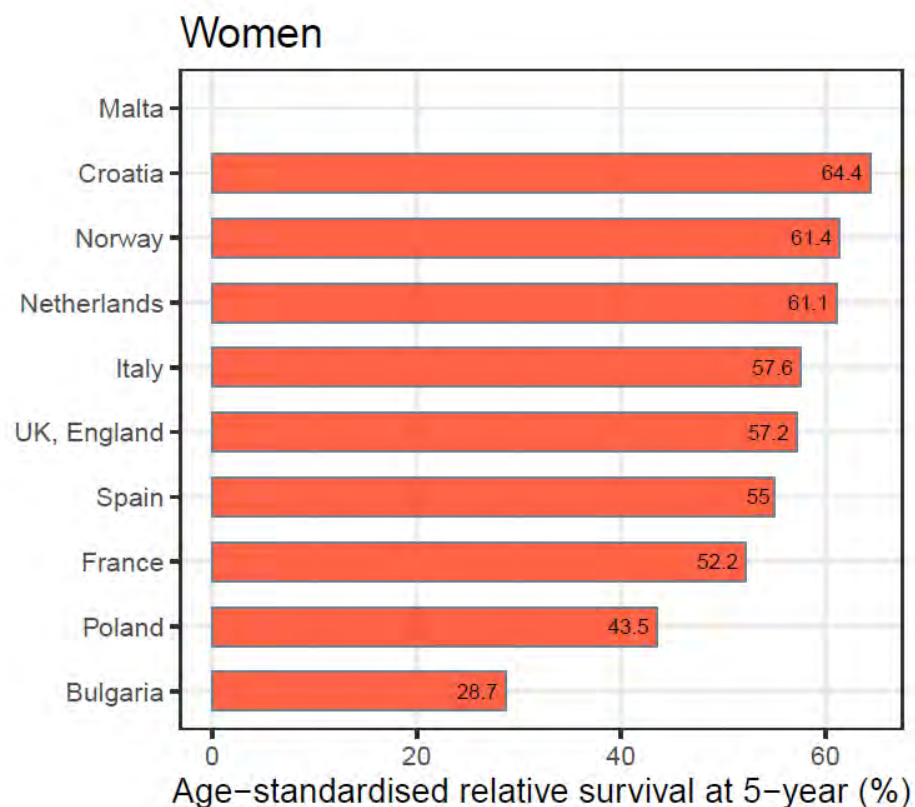
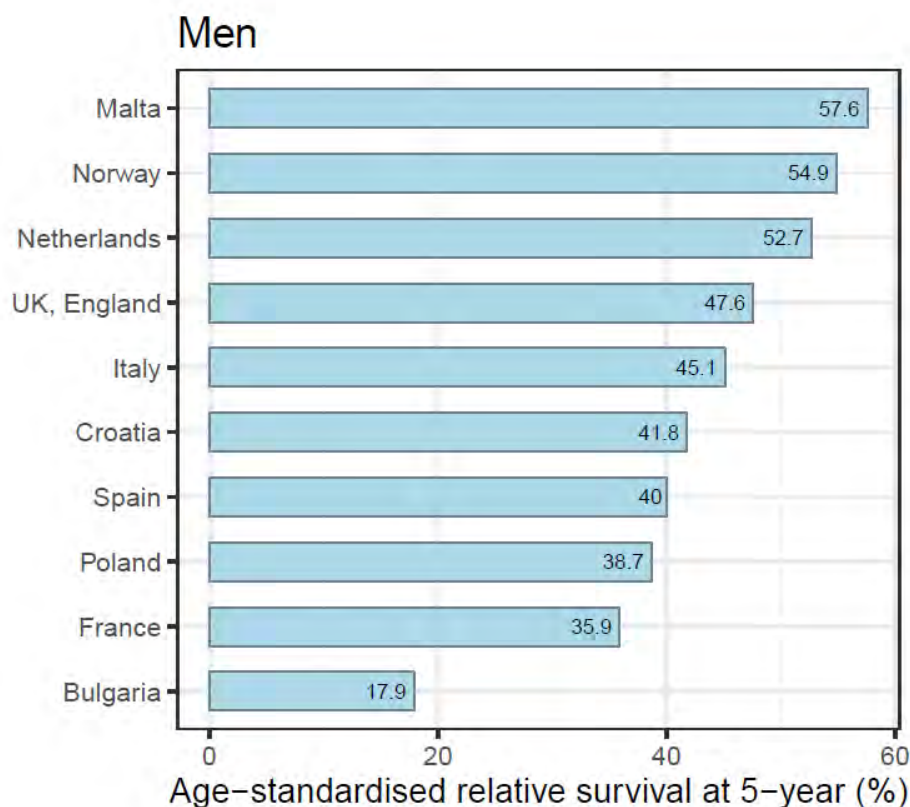
# Incidence & Mortality from oral cavity cancer



Source: GLOBOCAN 2018, incl lip



# Survival from Oral cavity Cancer



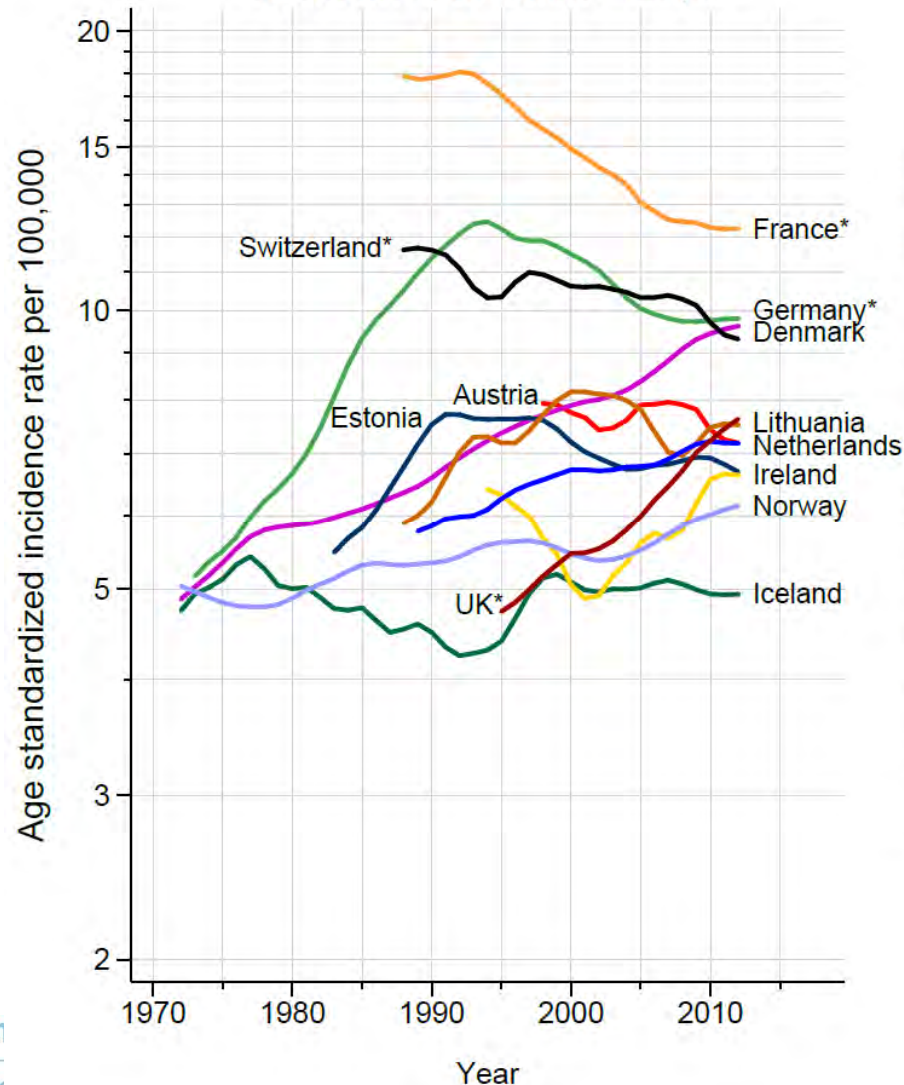
International Agency for Research on Cancer



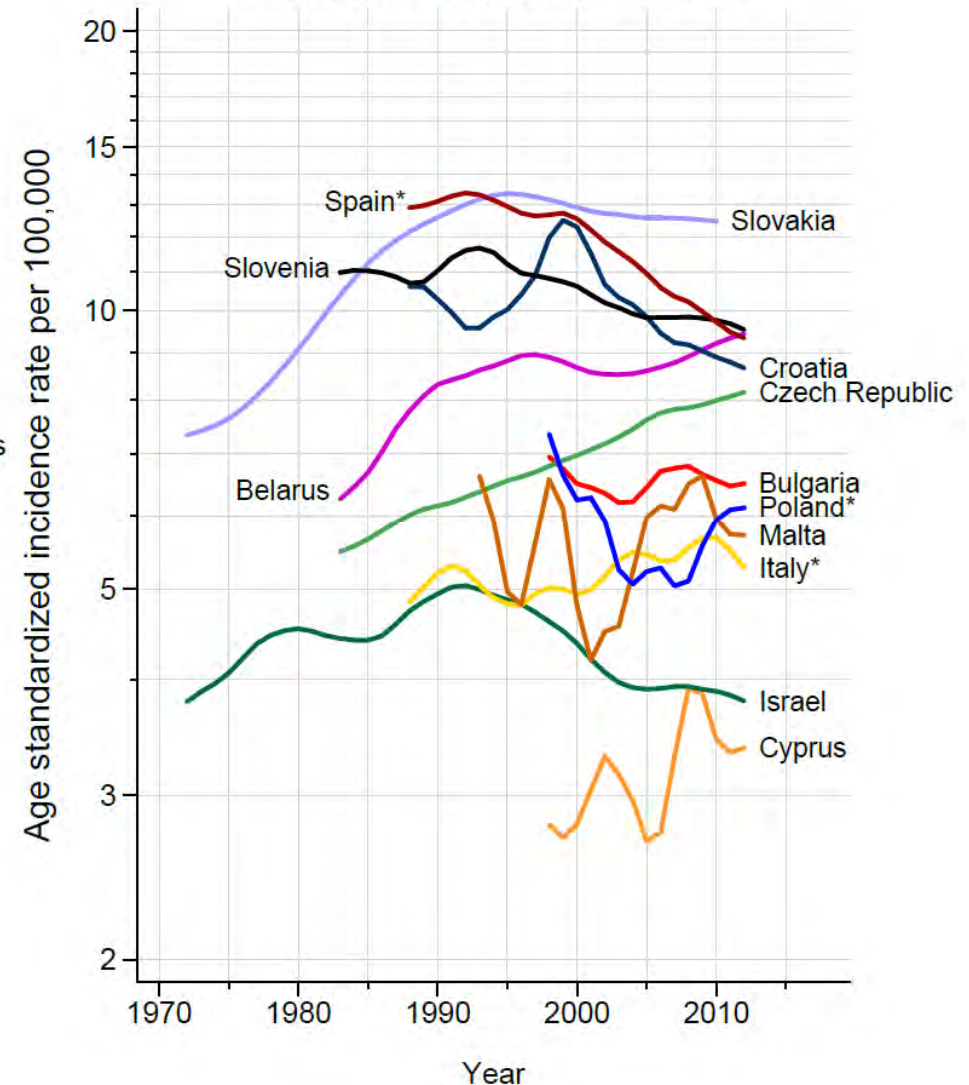
Source: ECIS

# Lip, oral cavity and pharynx

Northern & Western Europe



Southern & Eastern Europe

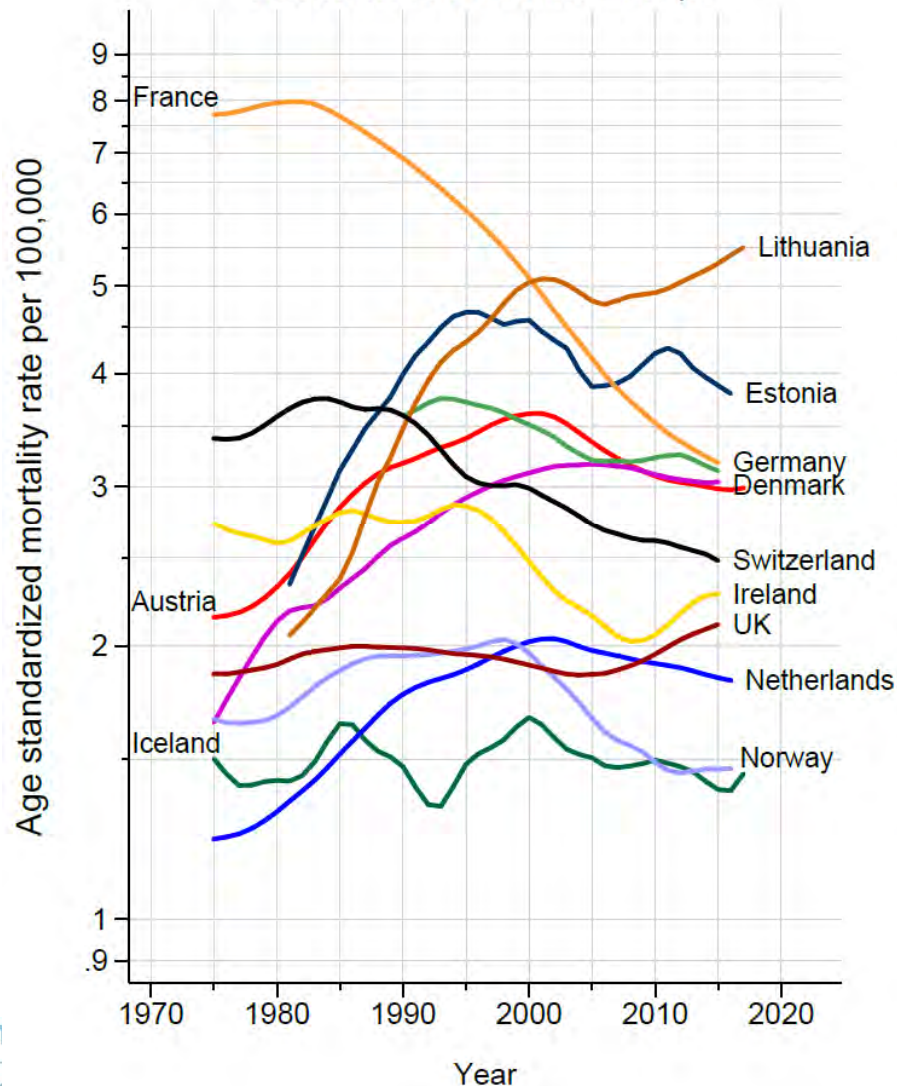


\* regional registries

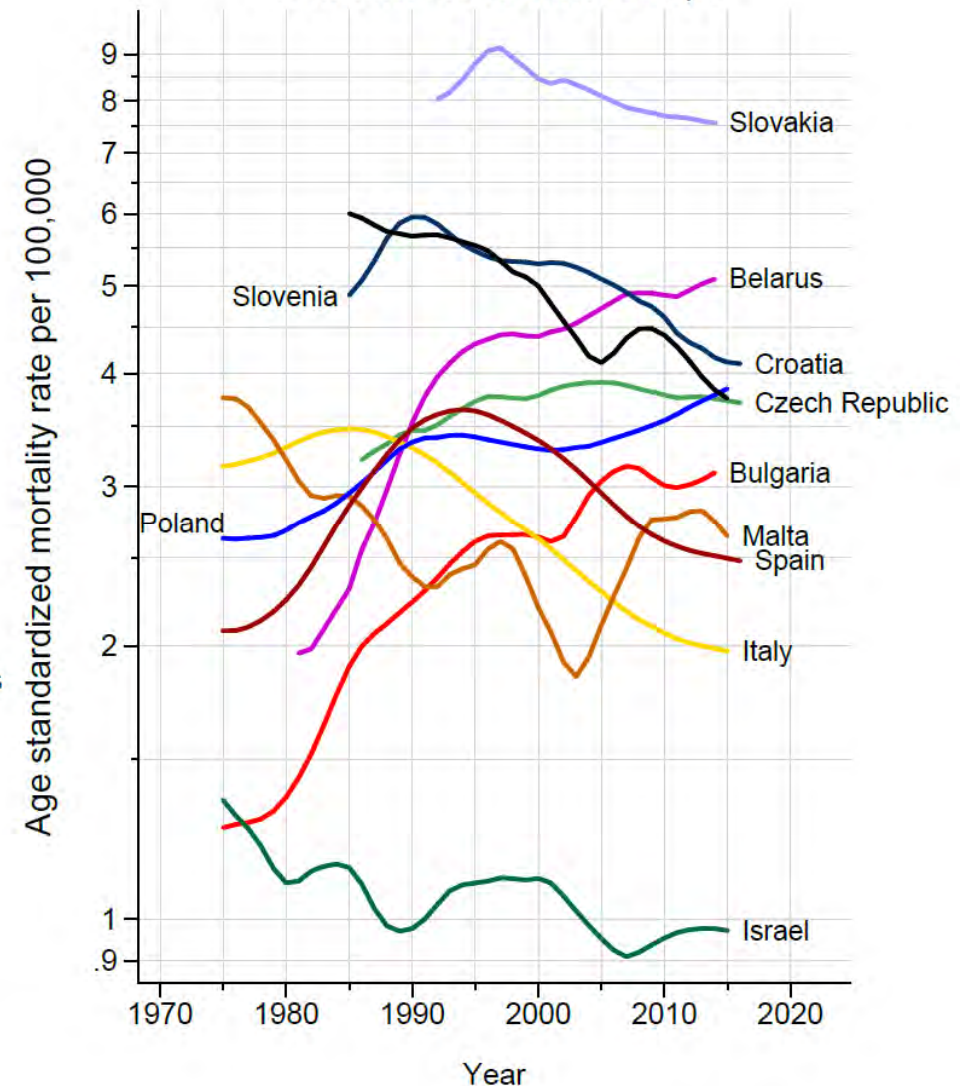
Source: CI5plus

# Lip, oral cavity

Northern & Western Europe



Southern & Eastern Europe





# Prevention - Oral Cavity

- Separate w Lip Cancer!
- Primary prevention
- Screening – visual & physical examination for Oral Potential Malignant disorders
- Early detection – GP and dentists
  - Smokers & alcohol drinkers

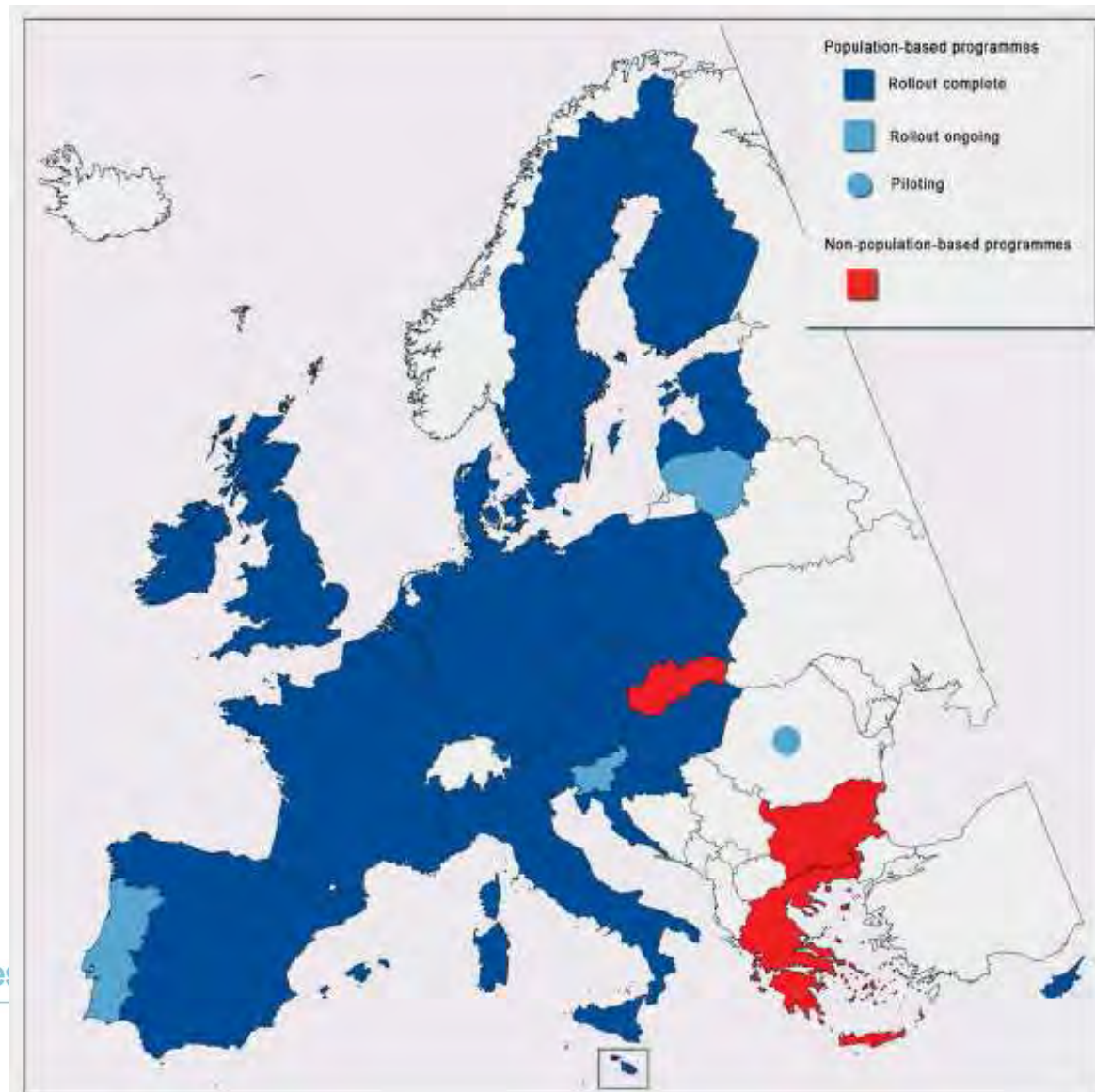
# Breast Cancer

International Agency for Research on Cancer

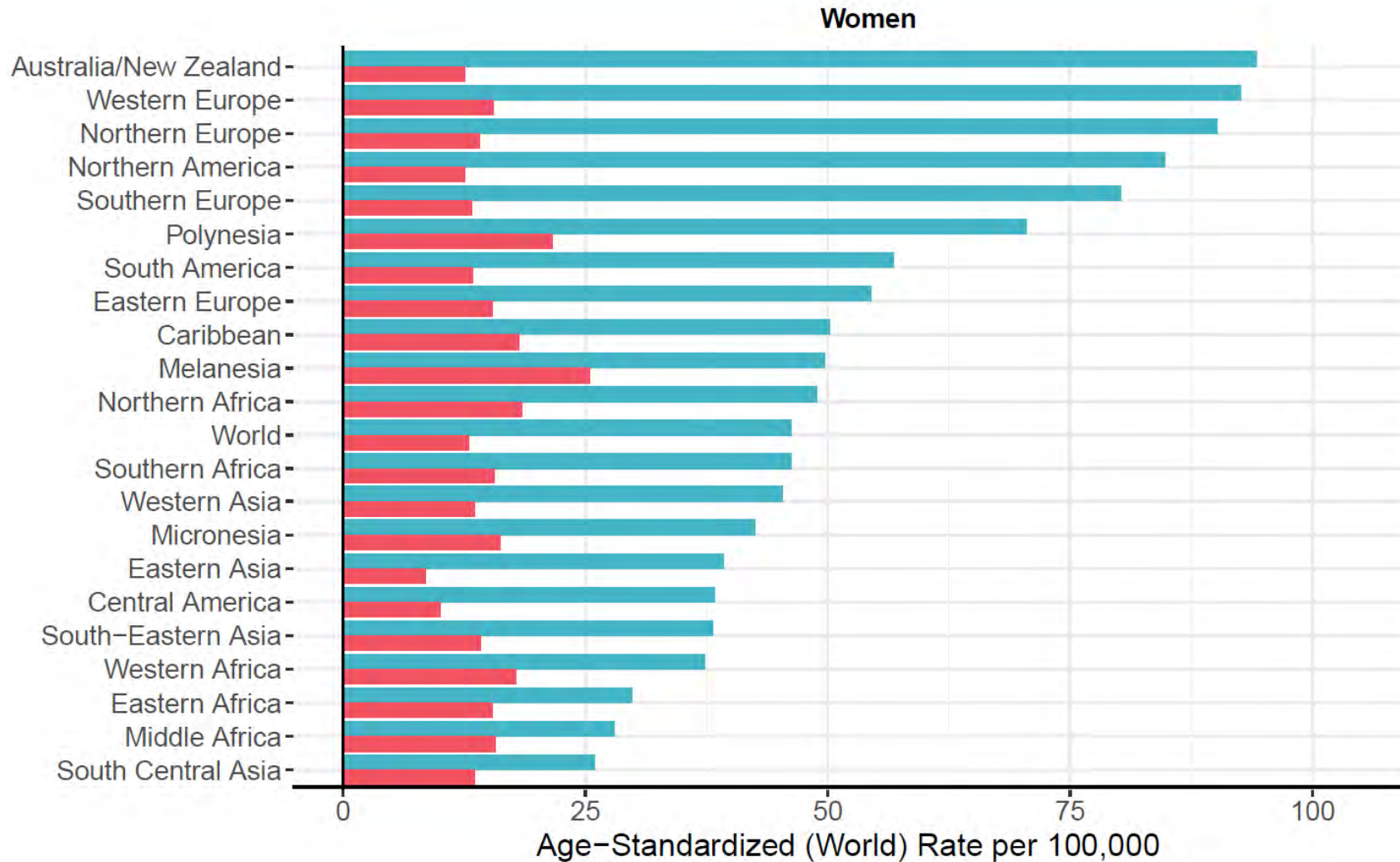
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# Breast cancer screening: status



# Incidence, Mortality of Breast cancer



Internat

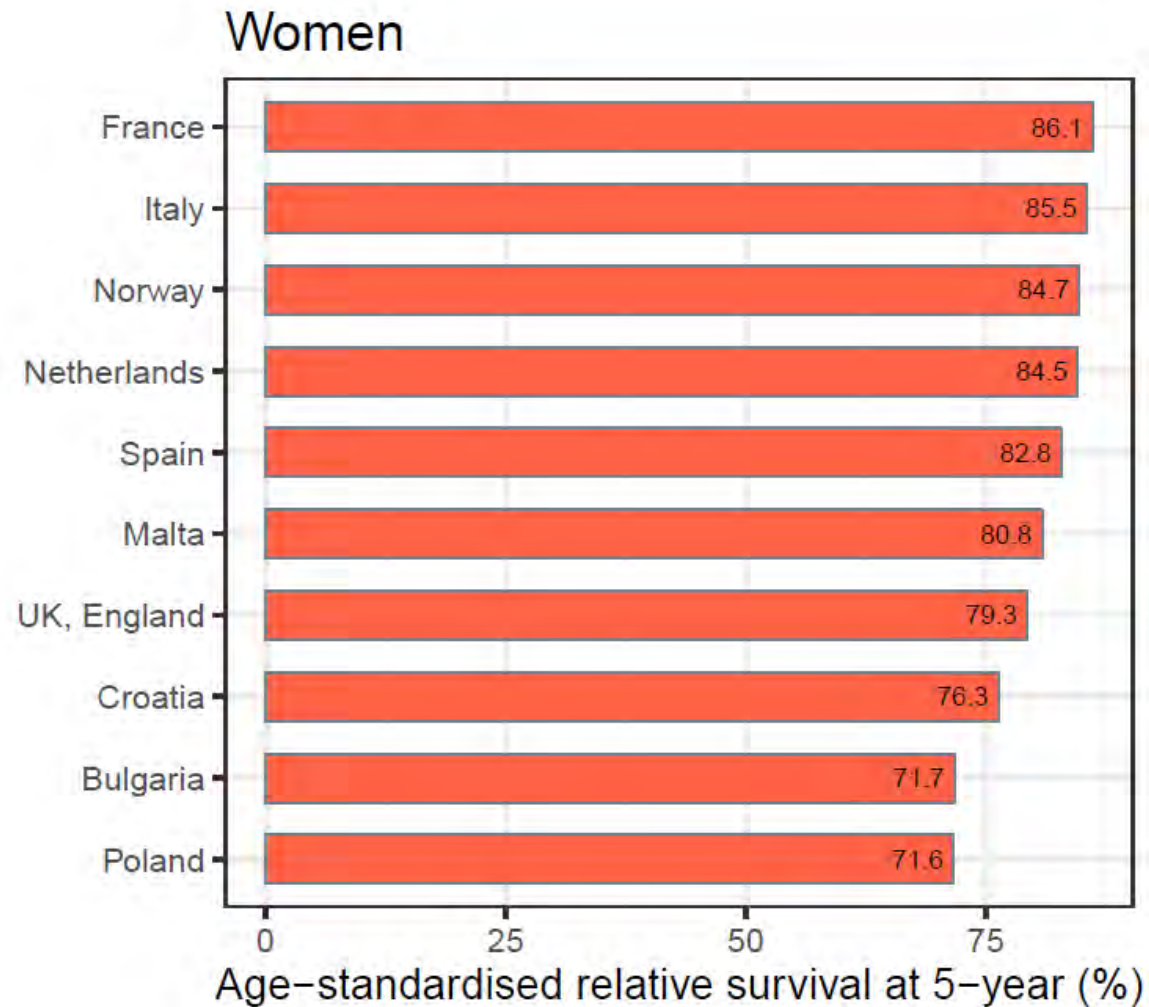


World Health  
Organization

Incidence Mortality

Source: GLOBOCAN 2018

# Survival from Breast cancer



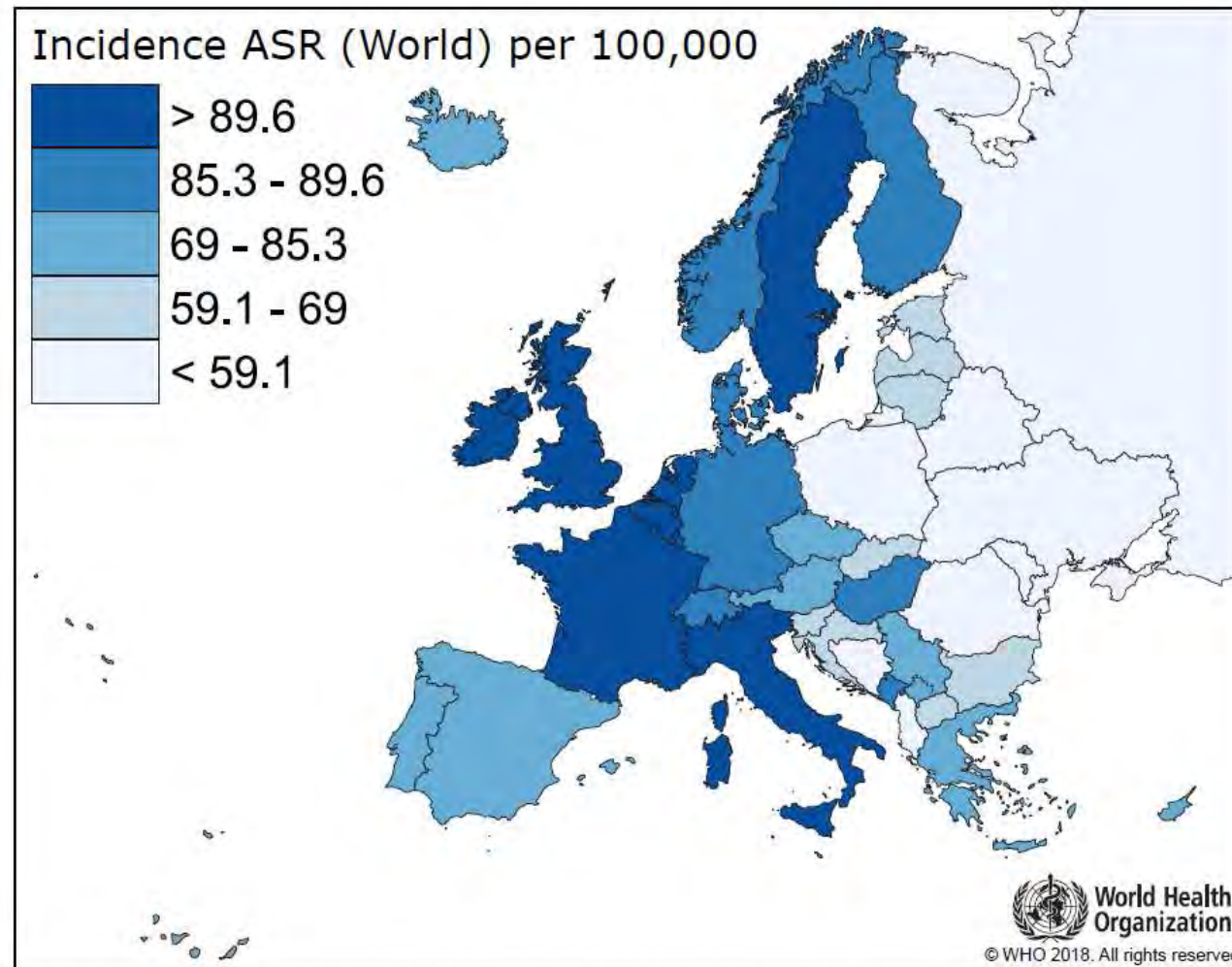
International Agency for Research on Cancer



Source: ECIS



# Incidence of Breast cancer



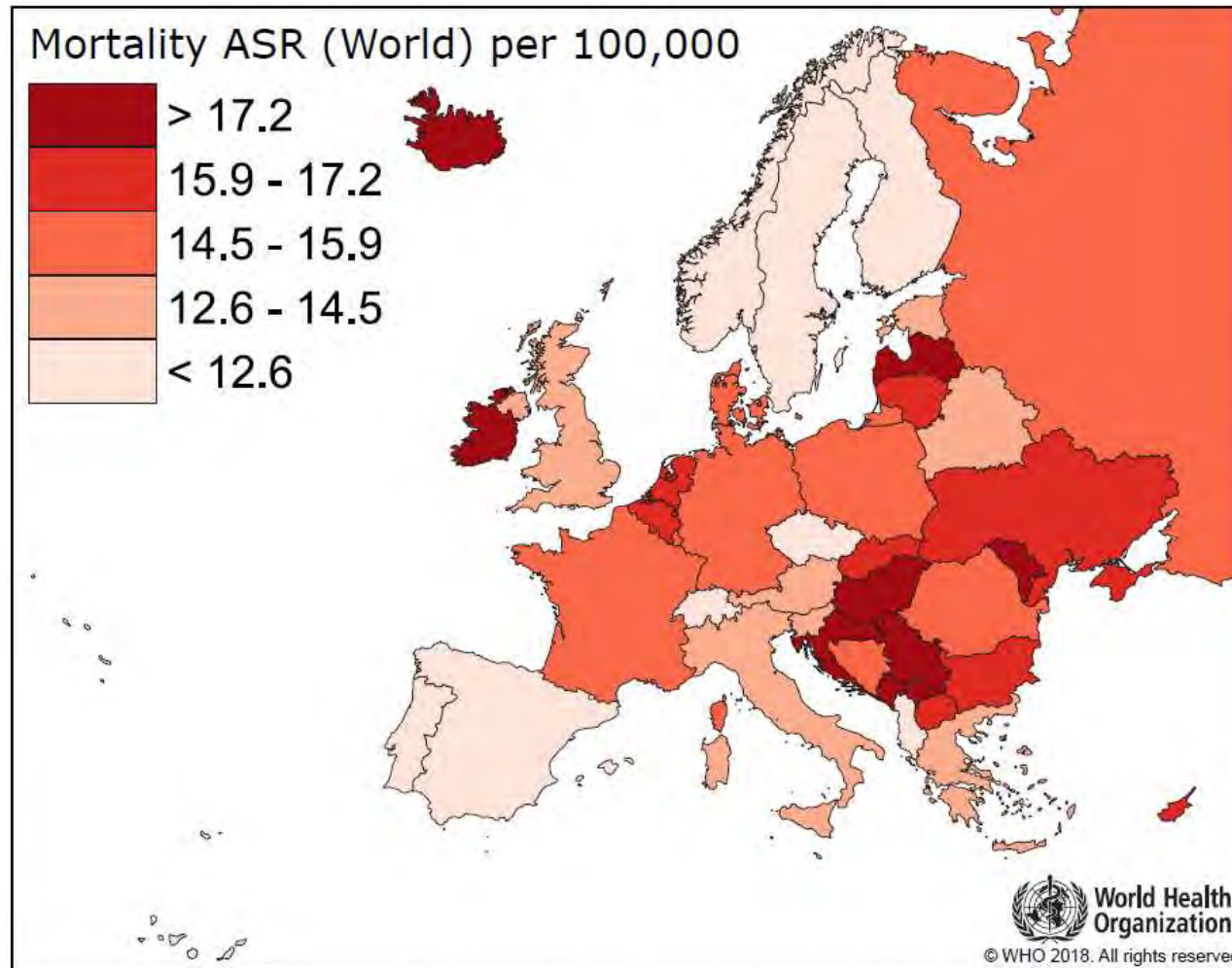
International Agency for



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Source: GLOBOCAN 2018

# Mortality of Breast cancer



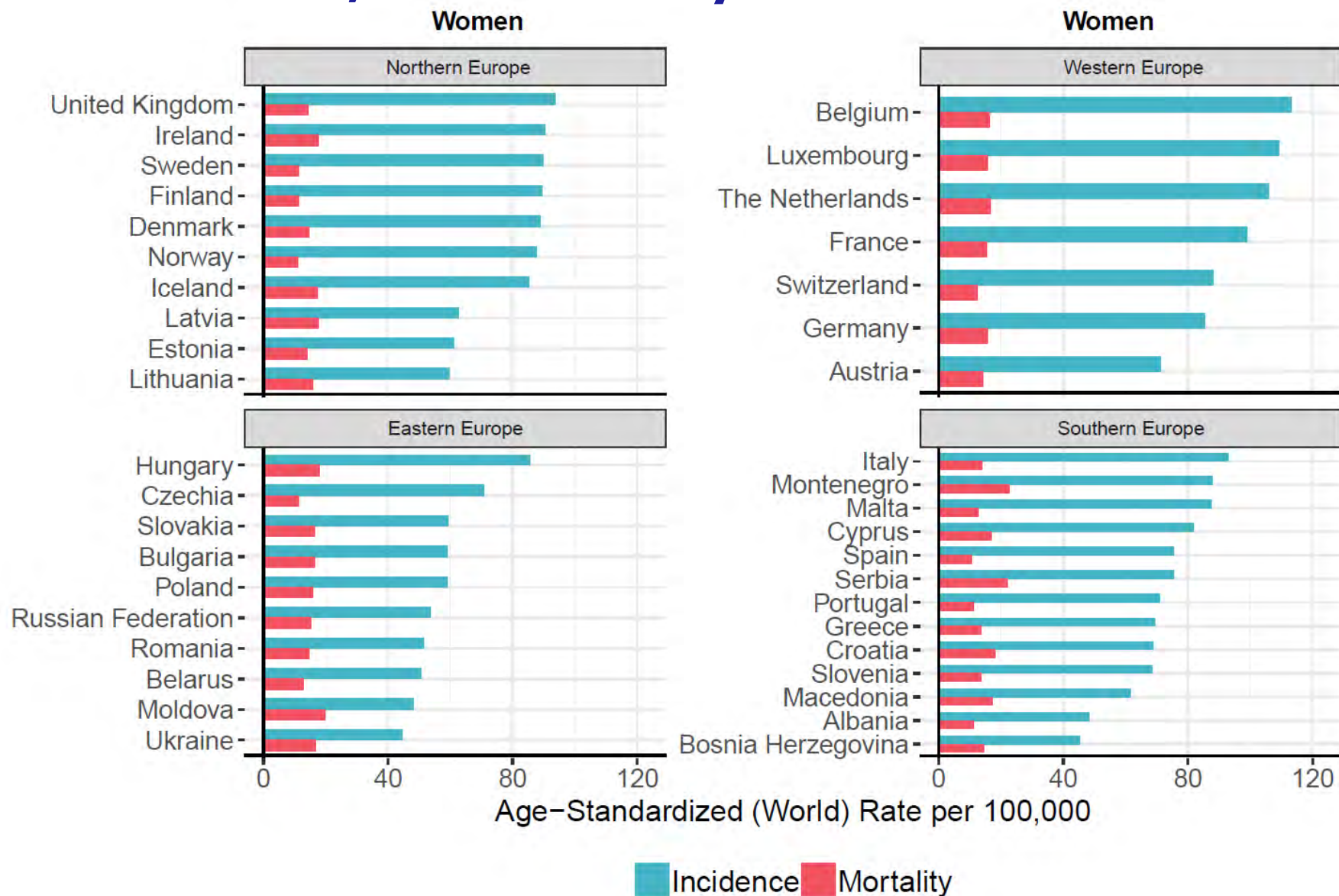
International Agency for



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Source: GLOBOCAN 2018

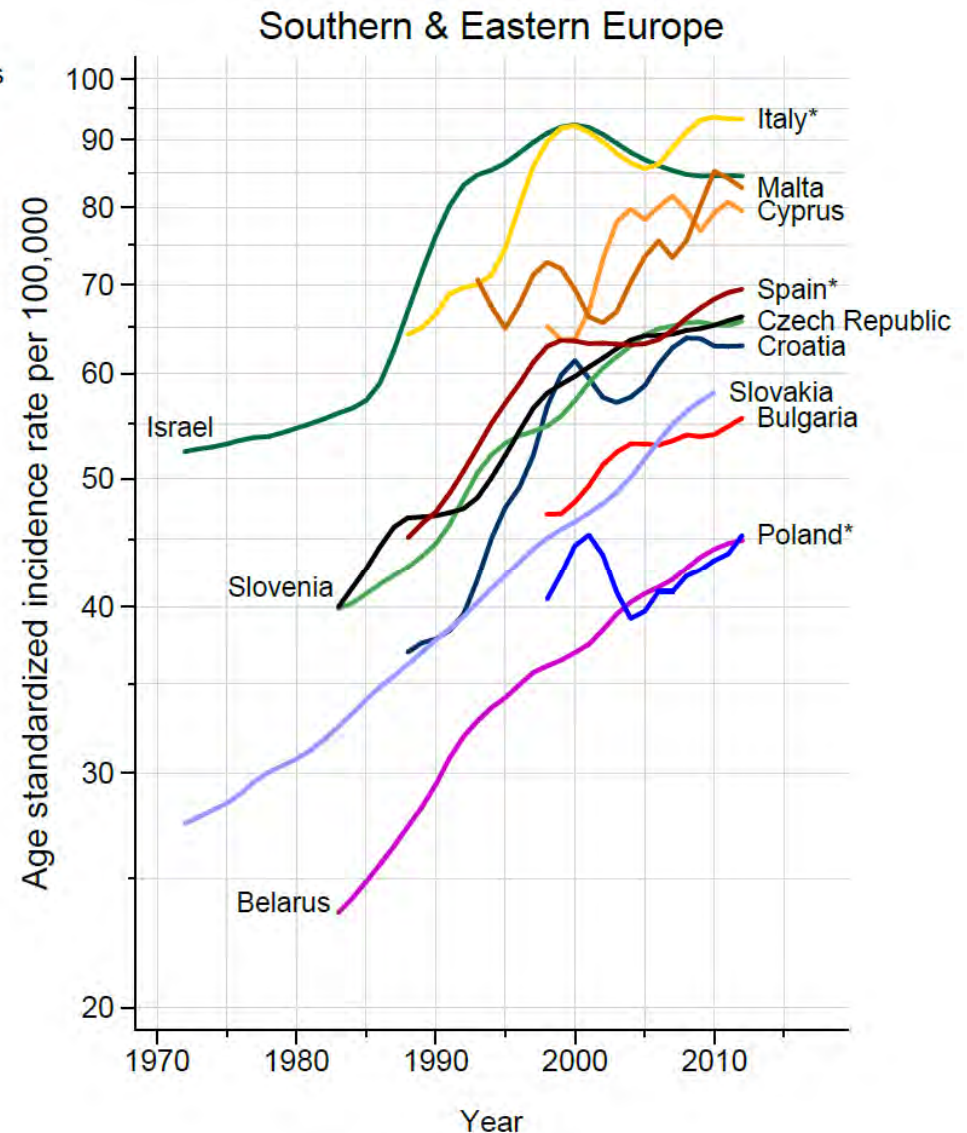
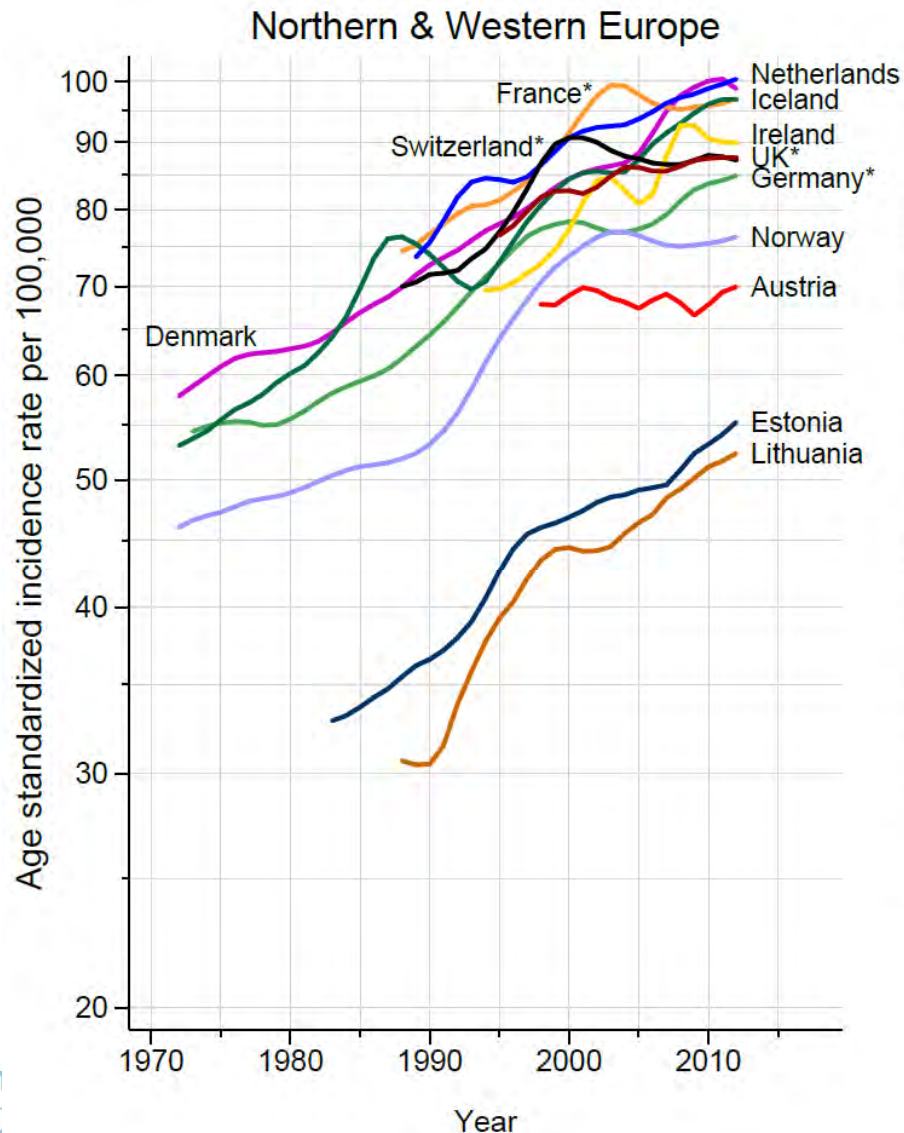
# Incidence, mortality of Breast cancer



Source: GLOBOCAN 2018



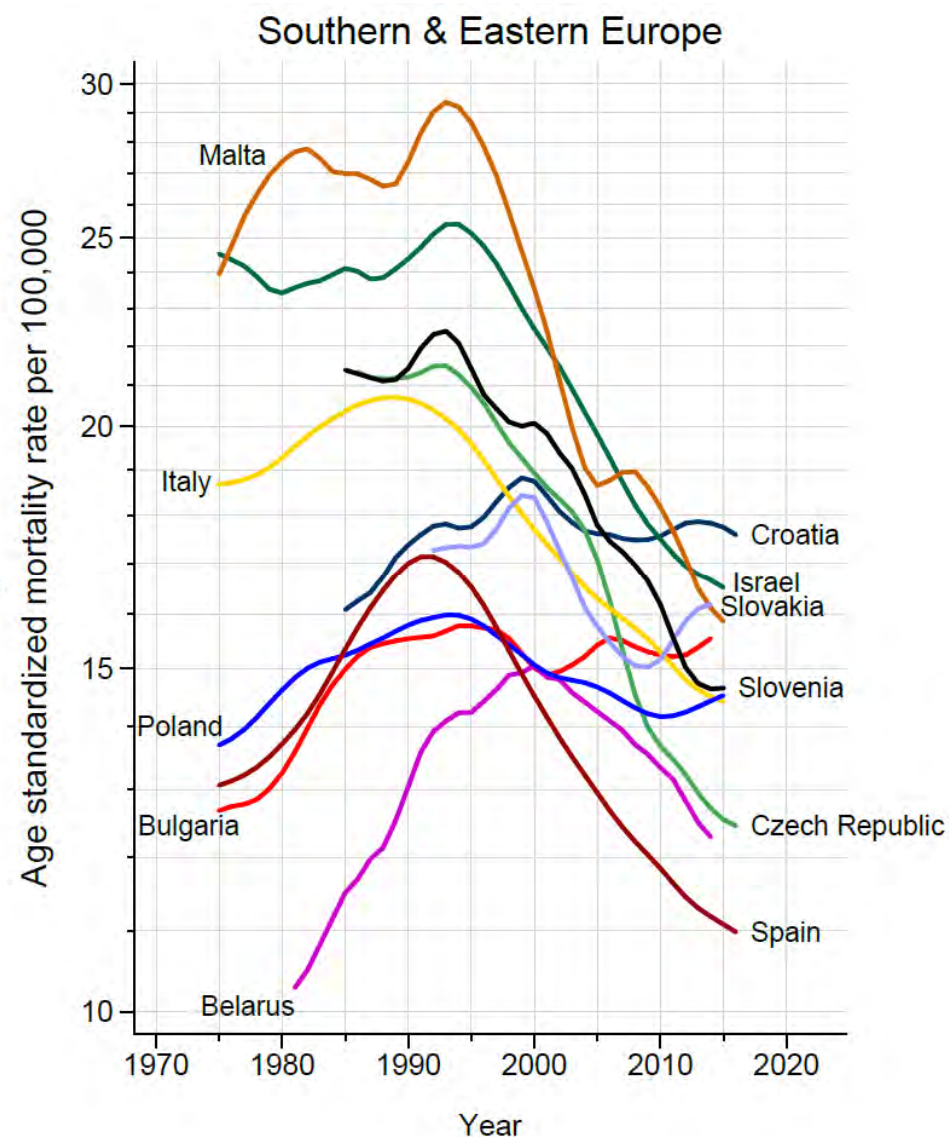
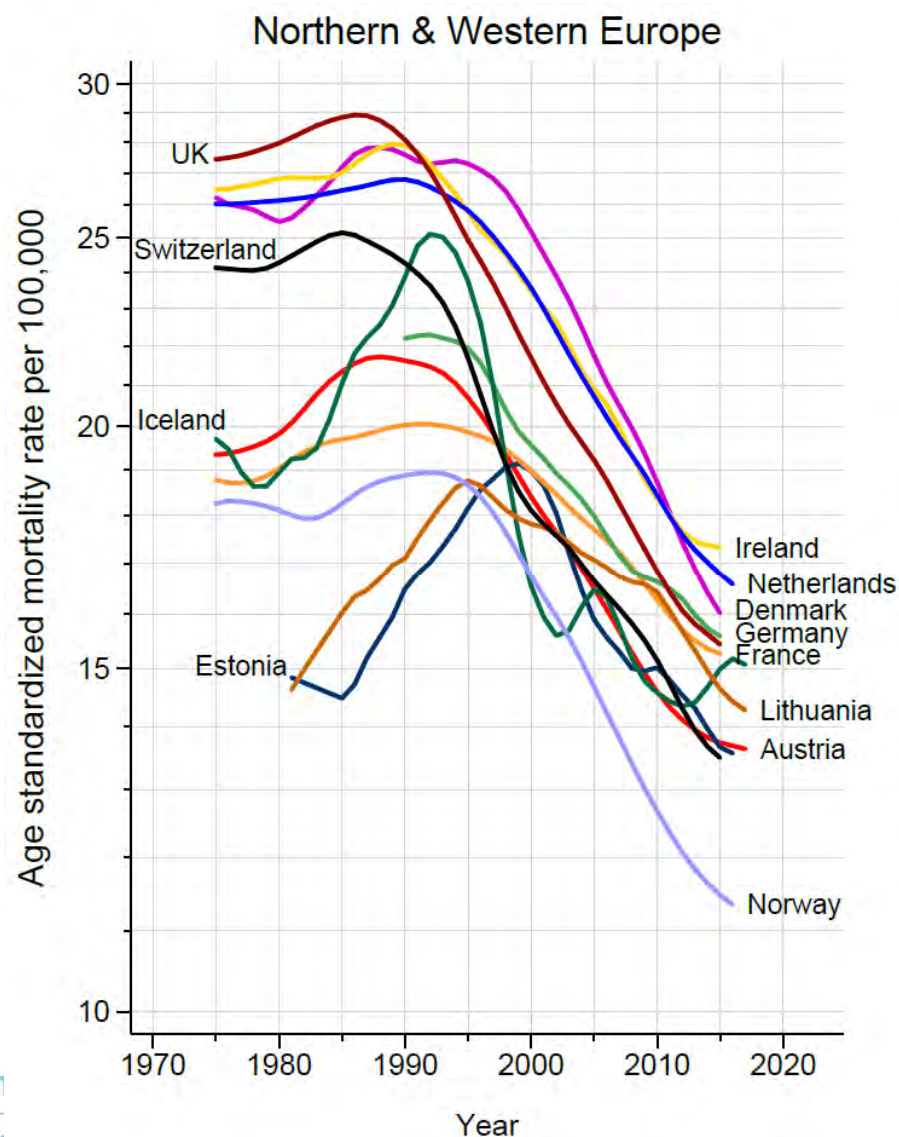
# Trend incidence of Breast cancer



\* regional registries

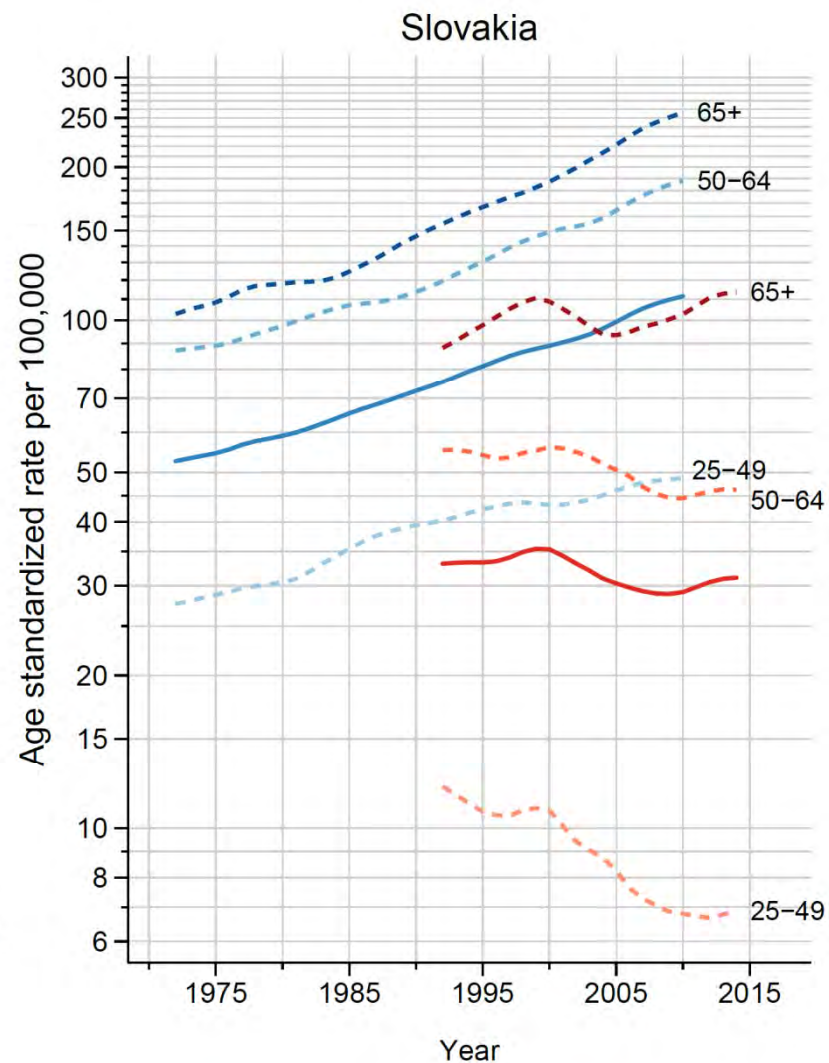
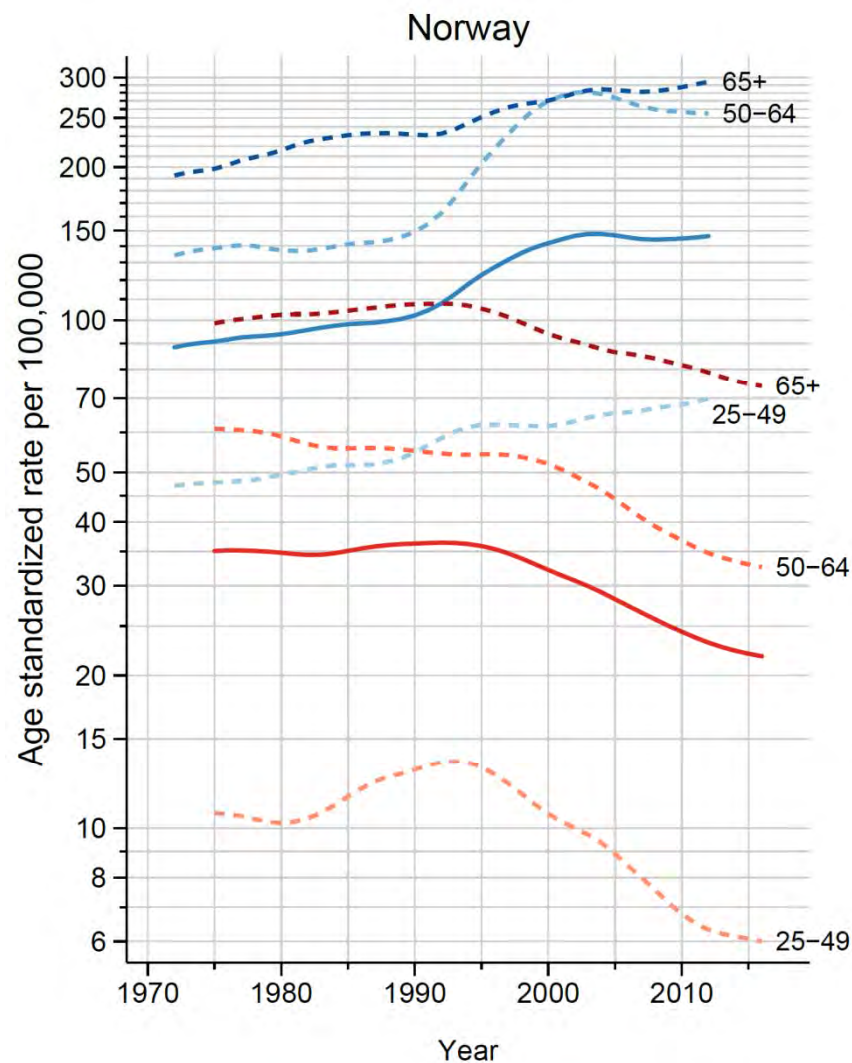
Source: CI5plus

# Trend mortality of Breast cancer





# Trend incidence – by age



# Breast Cancer Prevention

- Primary prevention
- Screening
- Early detection
  - Clinical Breast Examination – sufficient evidence for stage shift but not mortality reduction
  - Self Breast Examination – inadequate evidence to reduce mortality even if done correctly

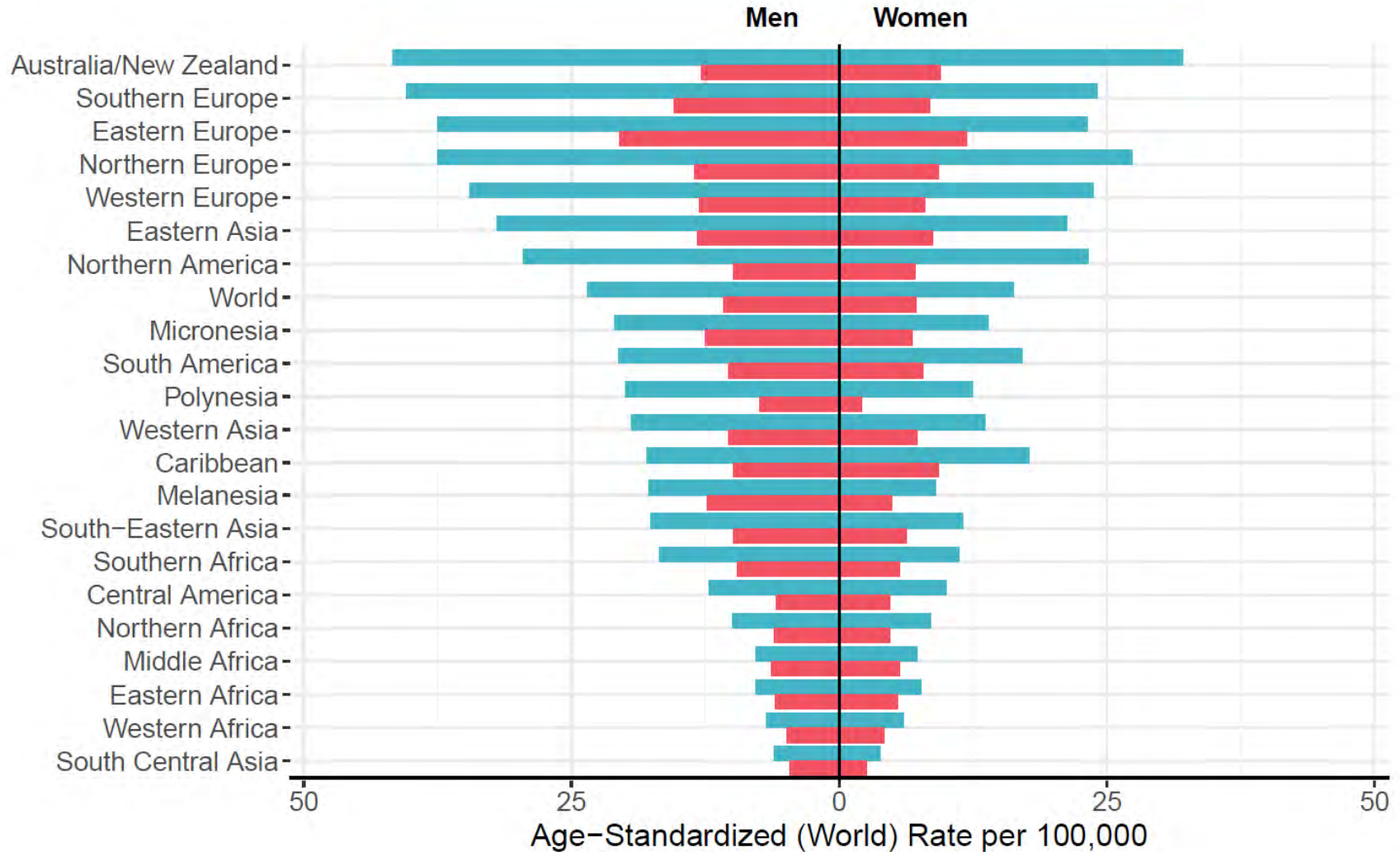
# Colorectal cancer

International Agency for Research on Cancer

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# Incidence, mortality of CRC

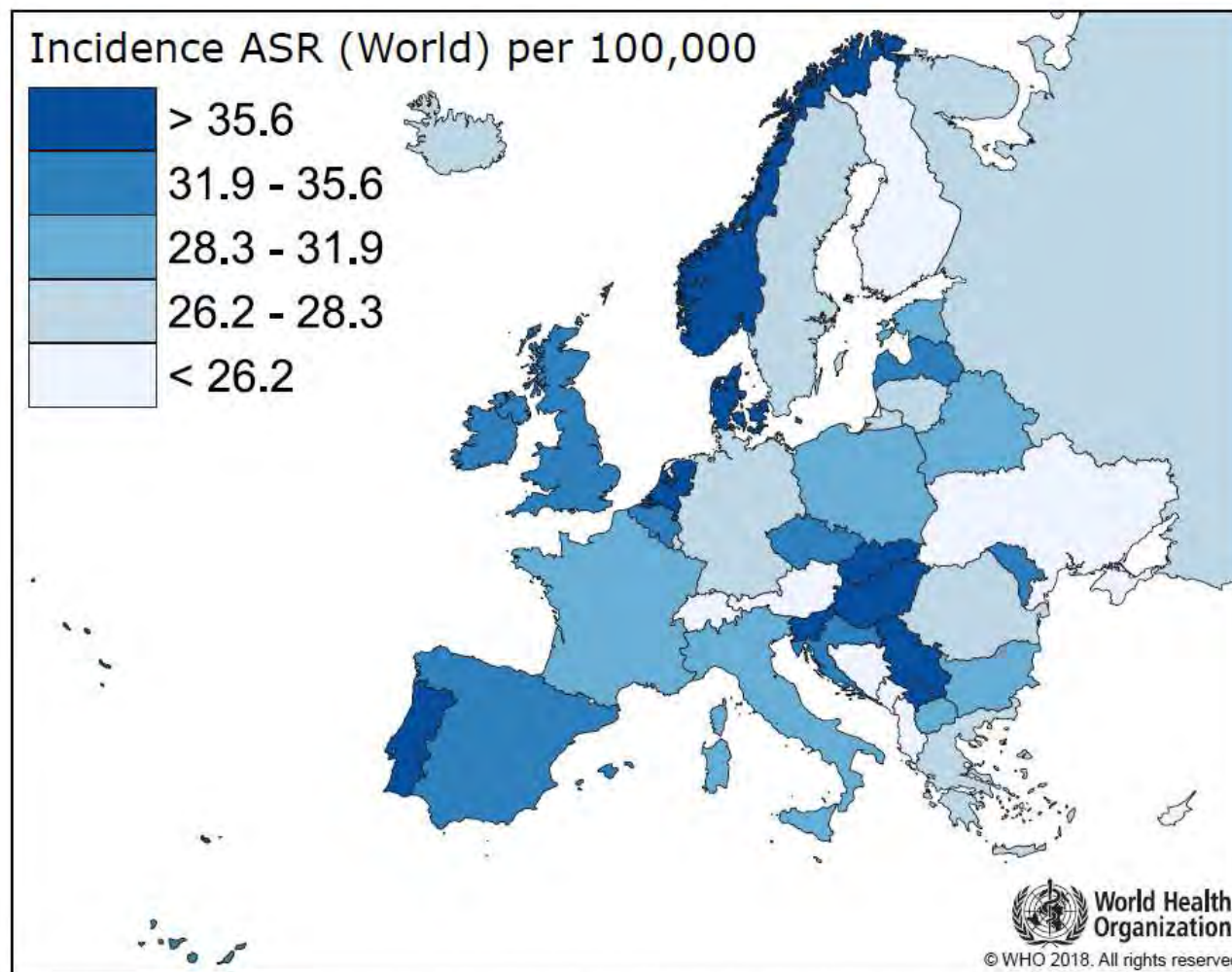


Internat



Source: GLOBOCAN 2018

# Incidence of Colorectum cancer



International Agency for

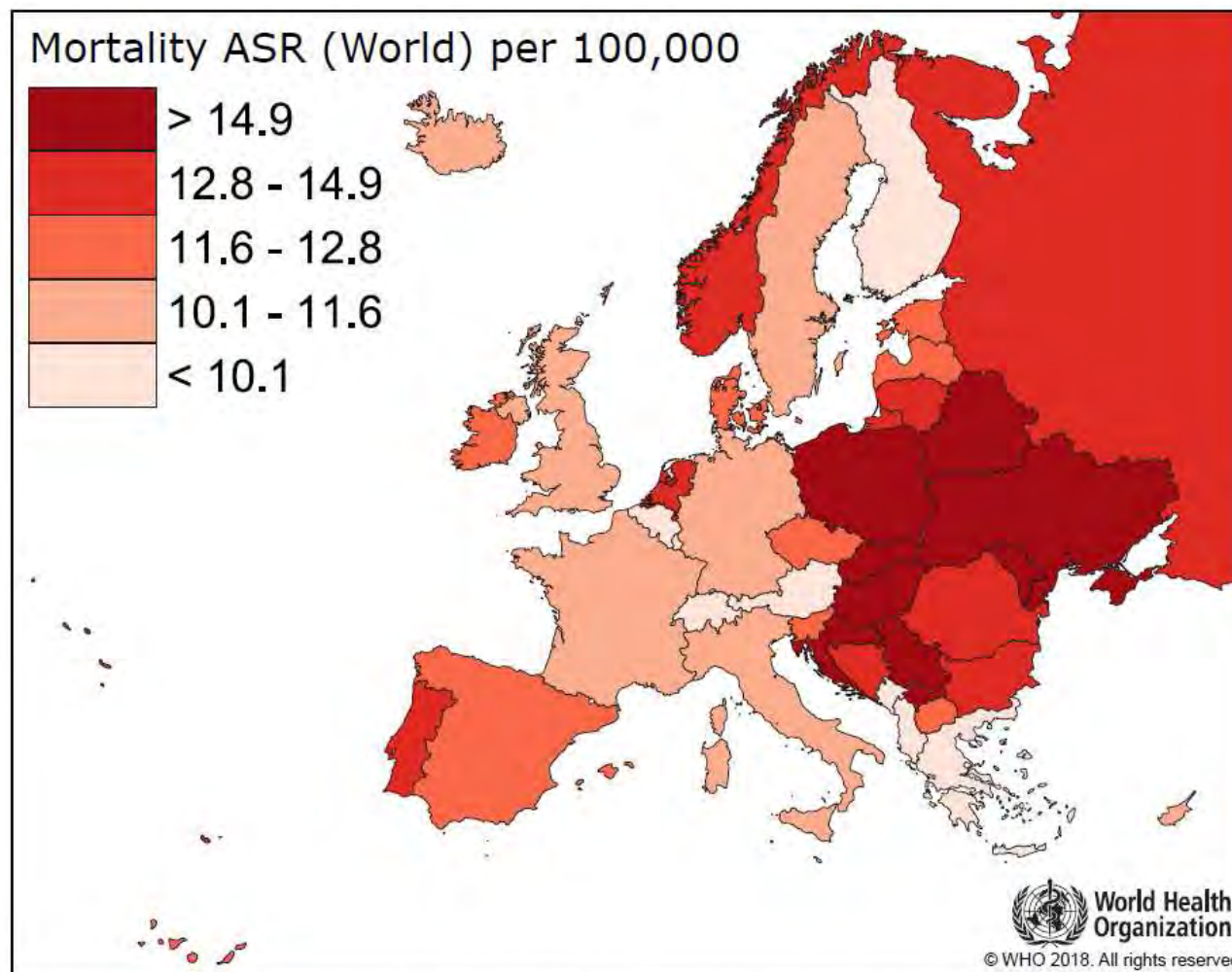


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Source: GLOBOCAN 2018



# Mortality of Colorectum cancer



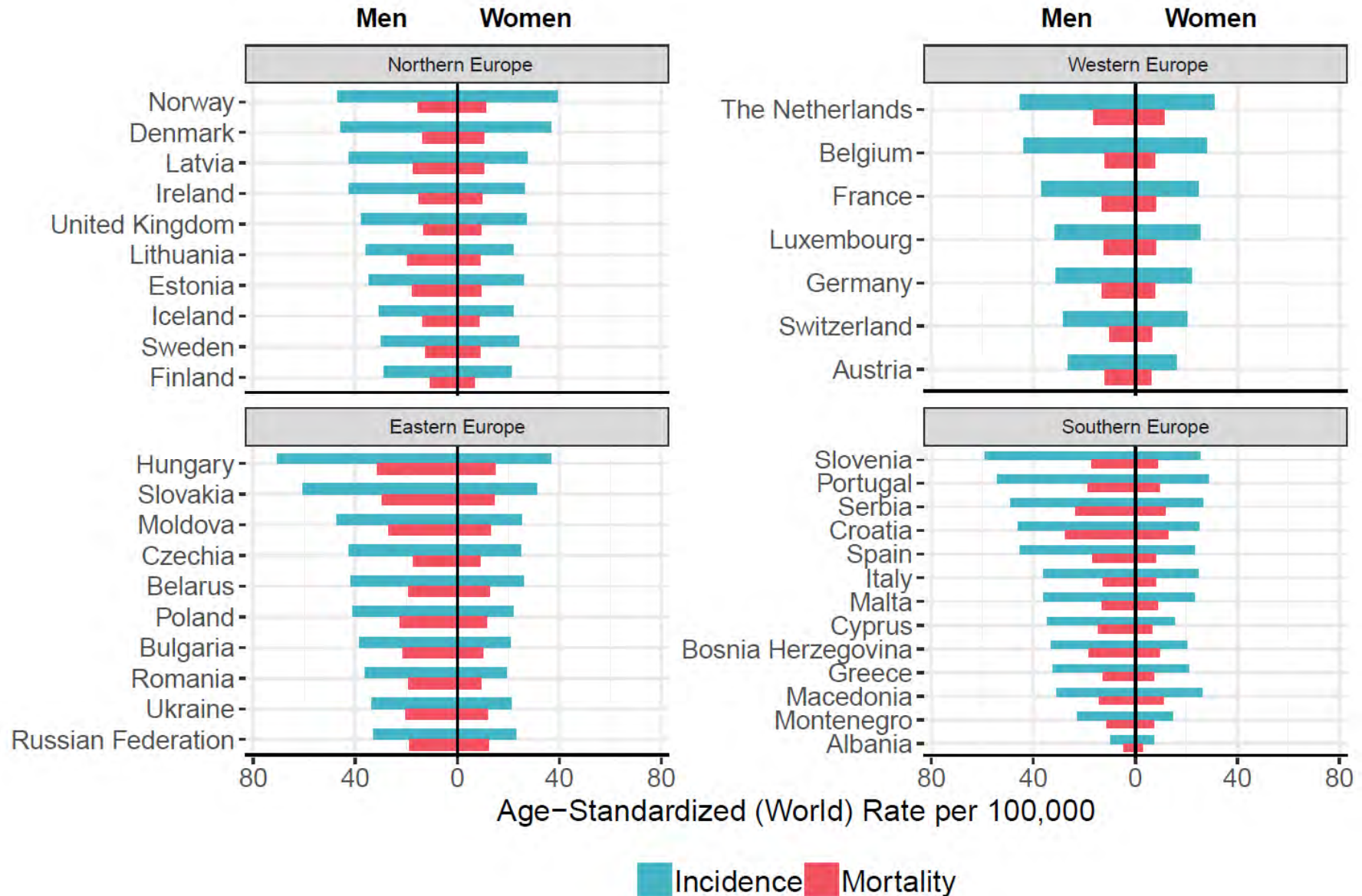
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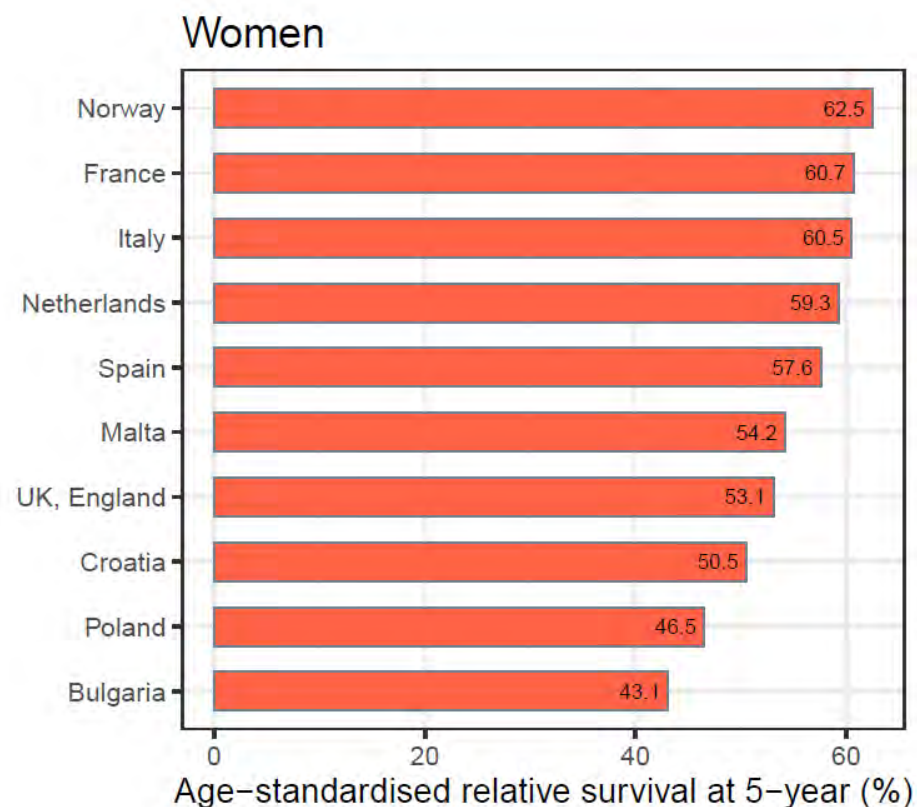
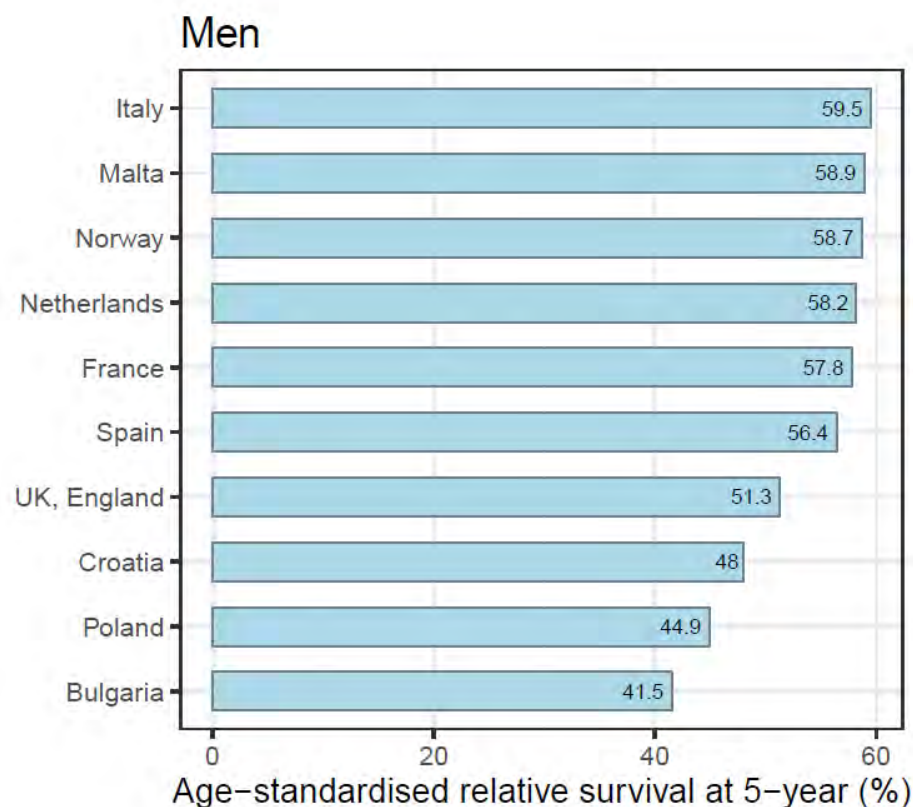
Source: GLOBOCAN 2018

# I & M of Colorectum cancer



Source: GLOBOCAN 2018

# Survival from Colorectum Cancer



International Agency for Research on Cancer

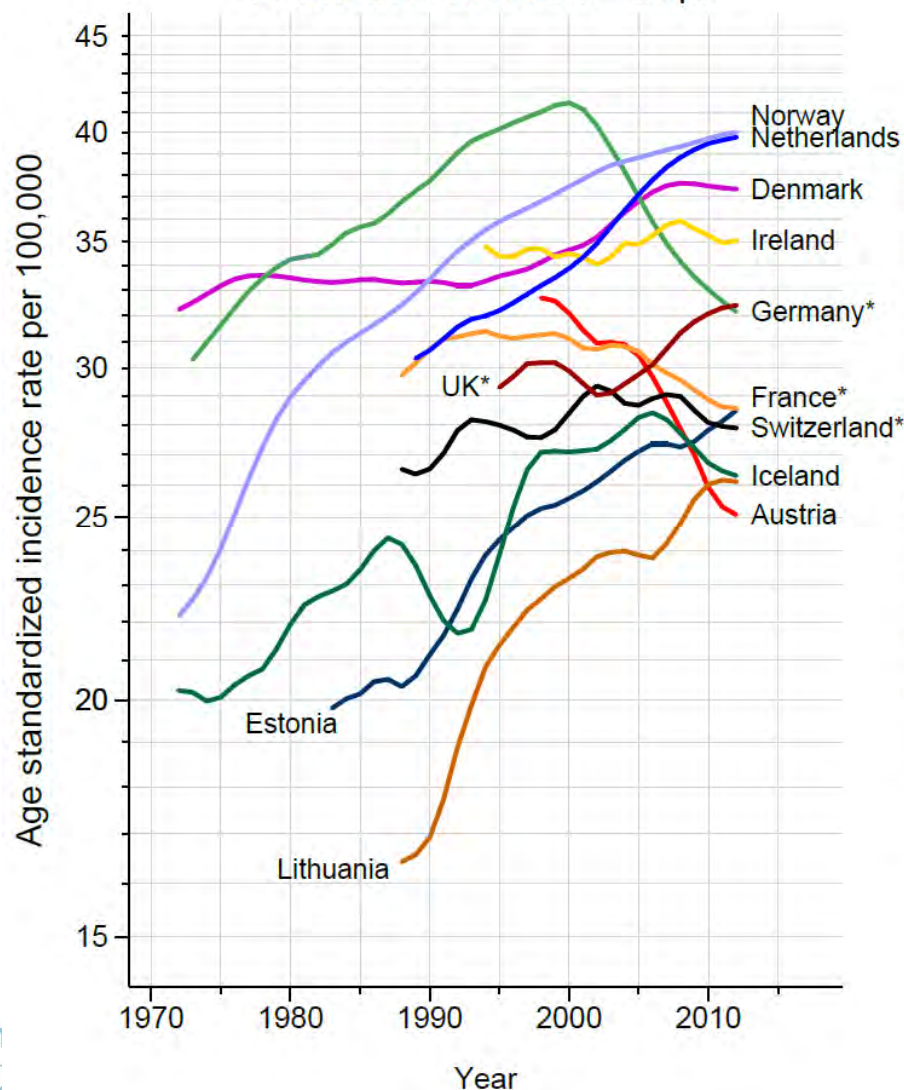


Source: ECIS

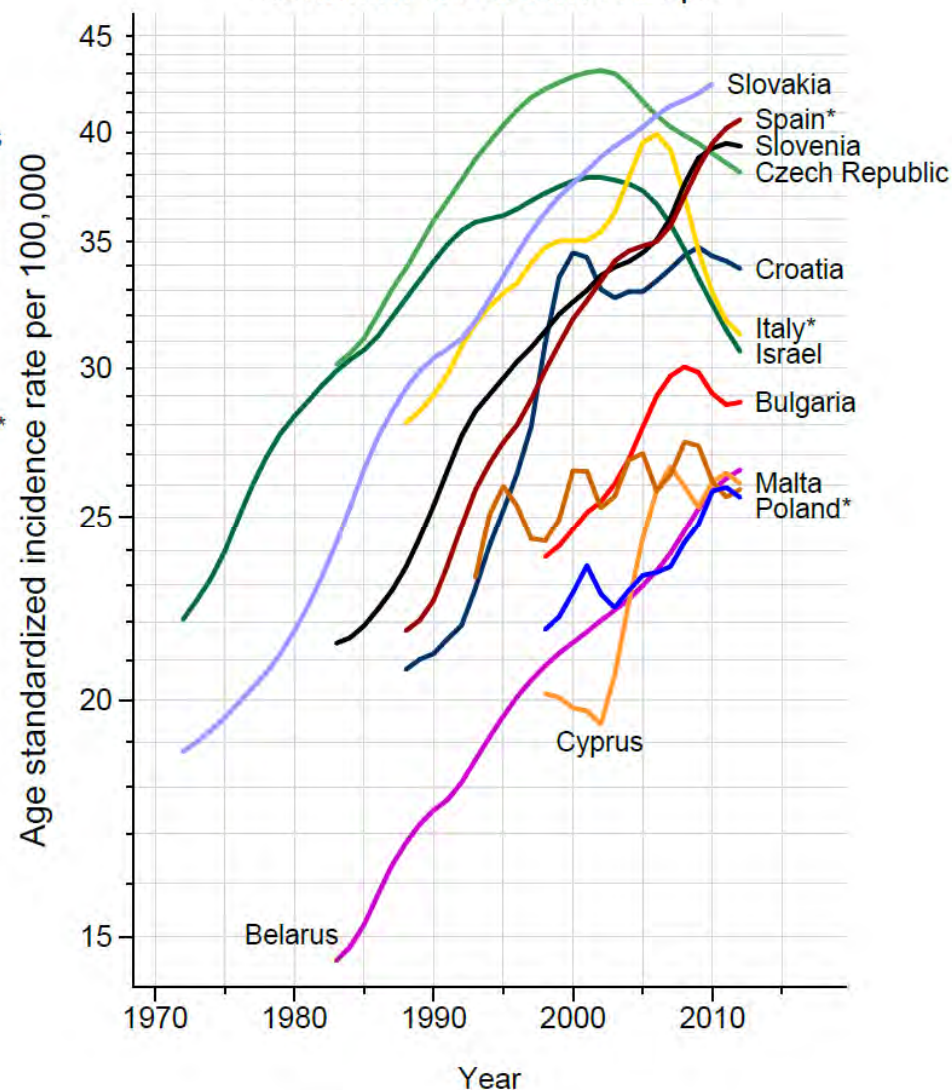


# Trend incidence of Colorectum cancer

Northern & Western Europe



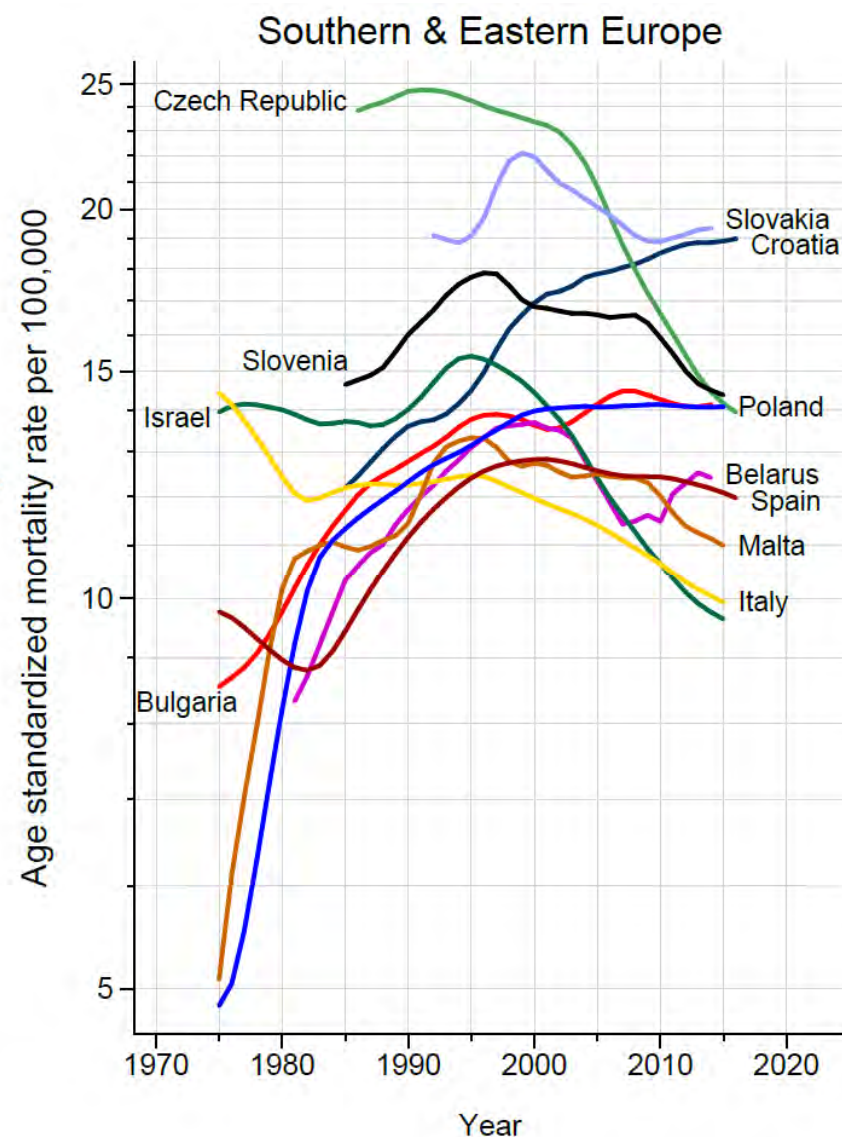
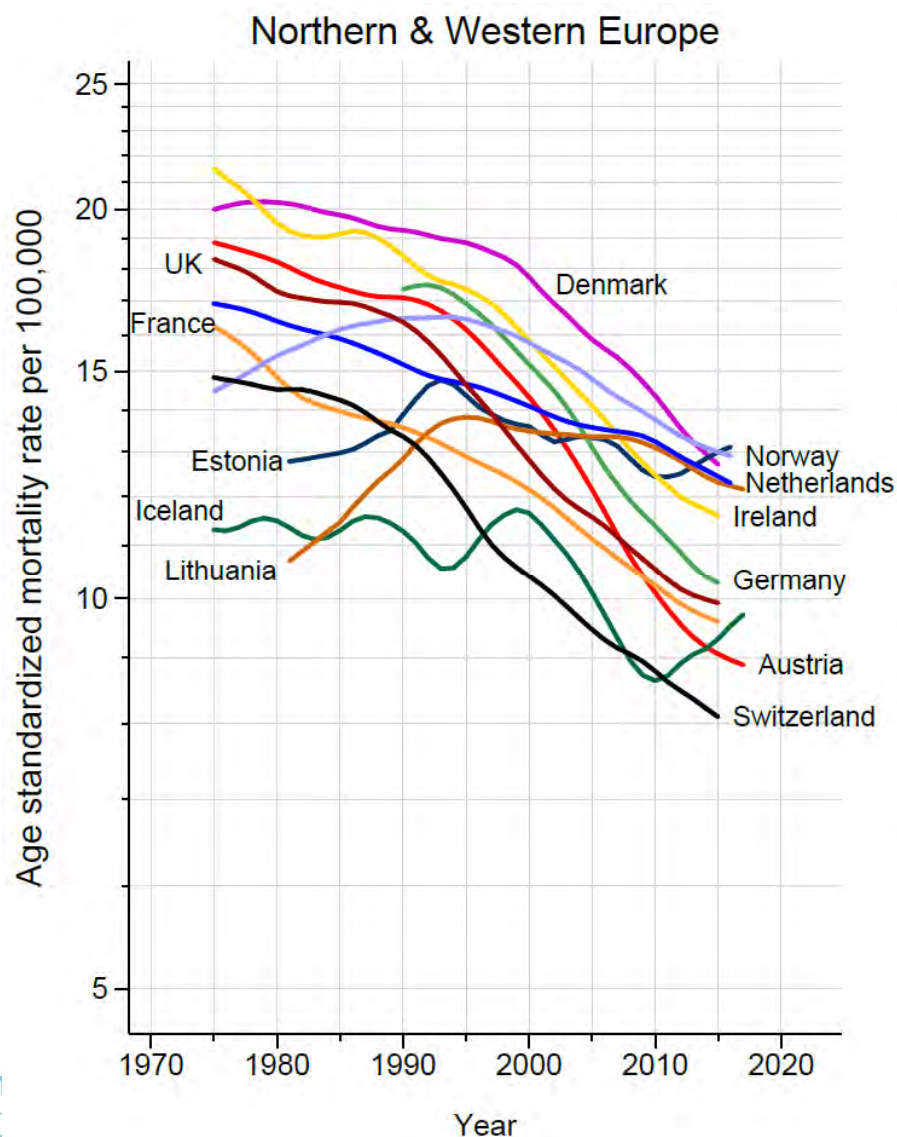
Southern & Eastern Europe



\* regional registries

Source: CI5plus

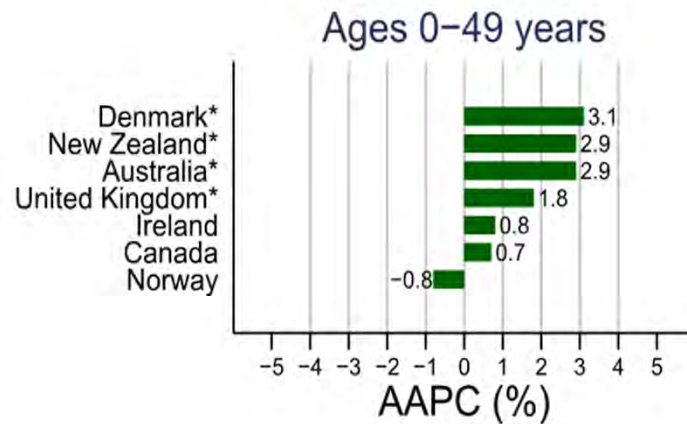
# Trend mortality of Colorectum cancer



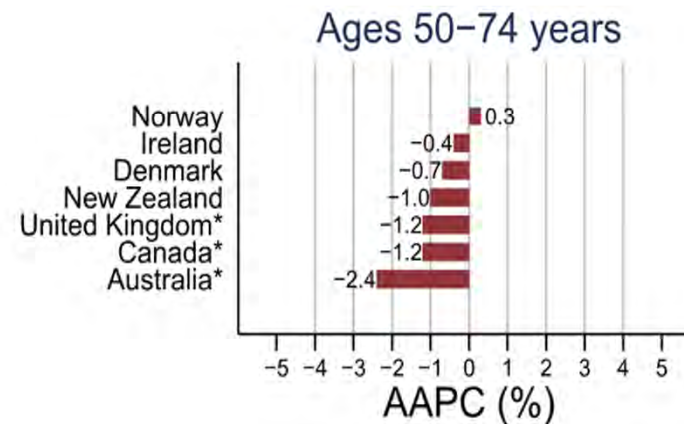
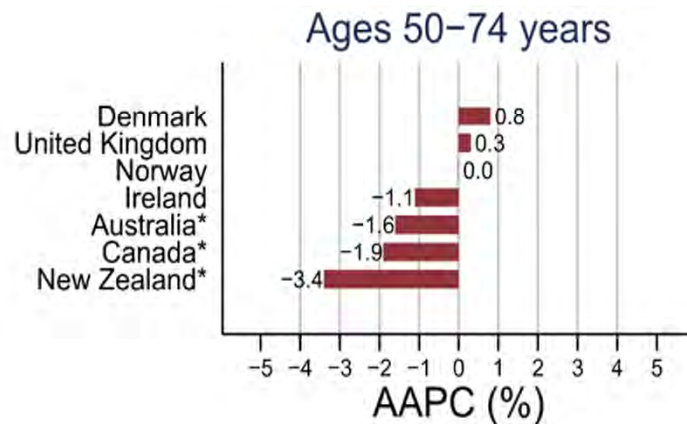
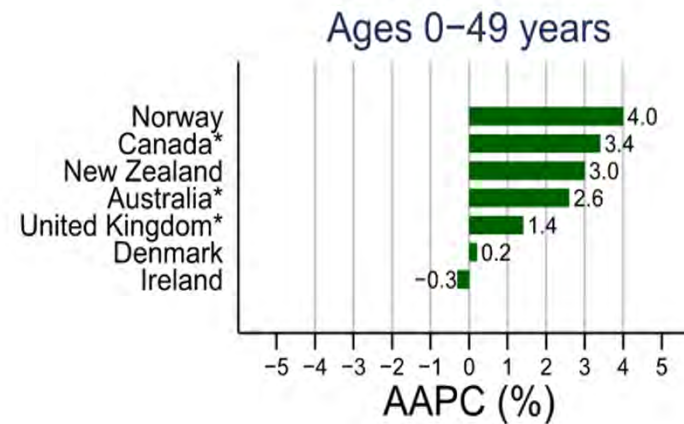


# Increasing rates in young adults

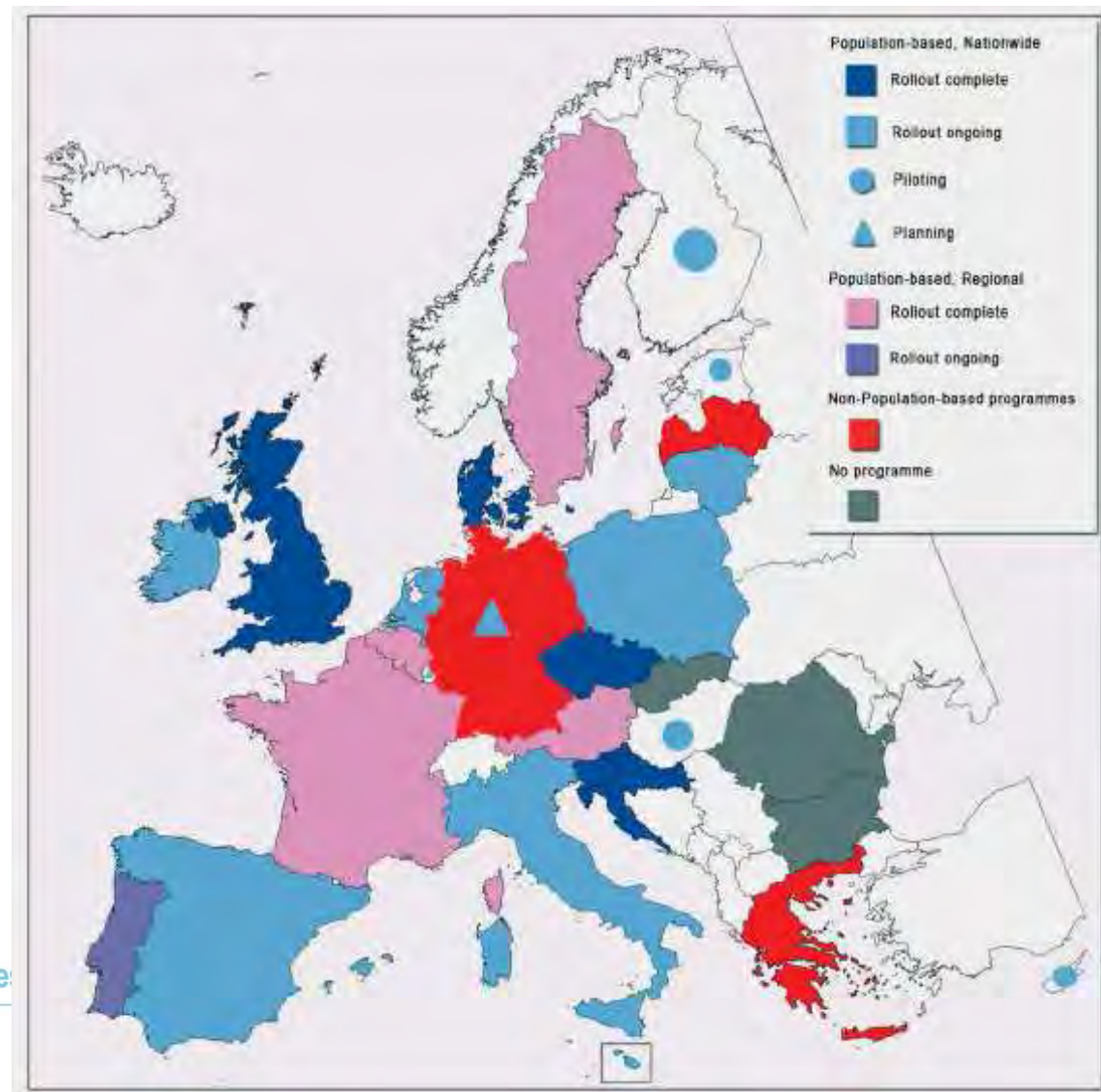
## Colon Cancer



## Rectal Cancer



# Colorectal cancer screening: status



# Colorectal Cancer Prevention

- Primary prevention
- Better screening (implementation & quality control)
- Early detection?

# Conclusion

- Great variation in Europe
- Examples based on best practice
- Early detection
  - Determine burden
  - Scope for early detection
  - Implementation
  - Quality assurance

# Acknowledgement

- Cancer registries – Cancer incidence
- Jerome Vignat
- Organisers

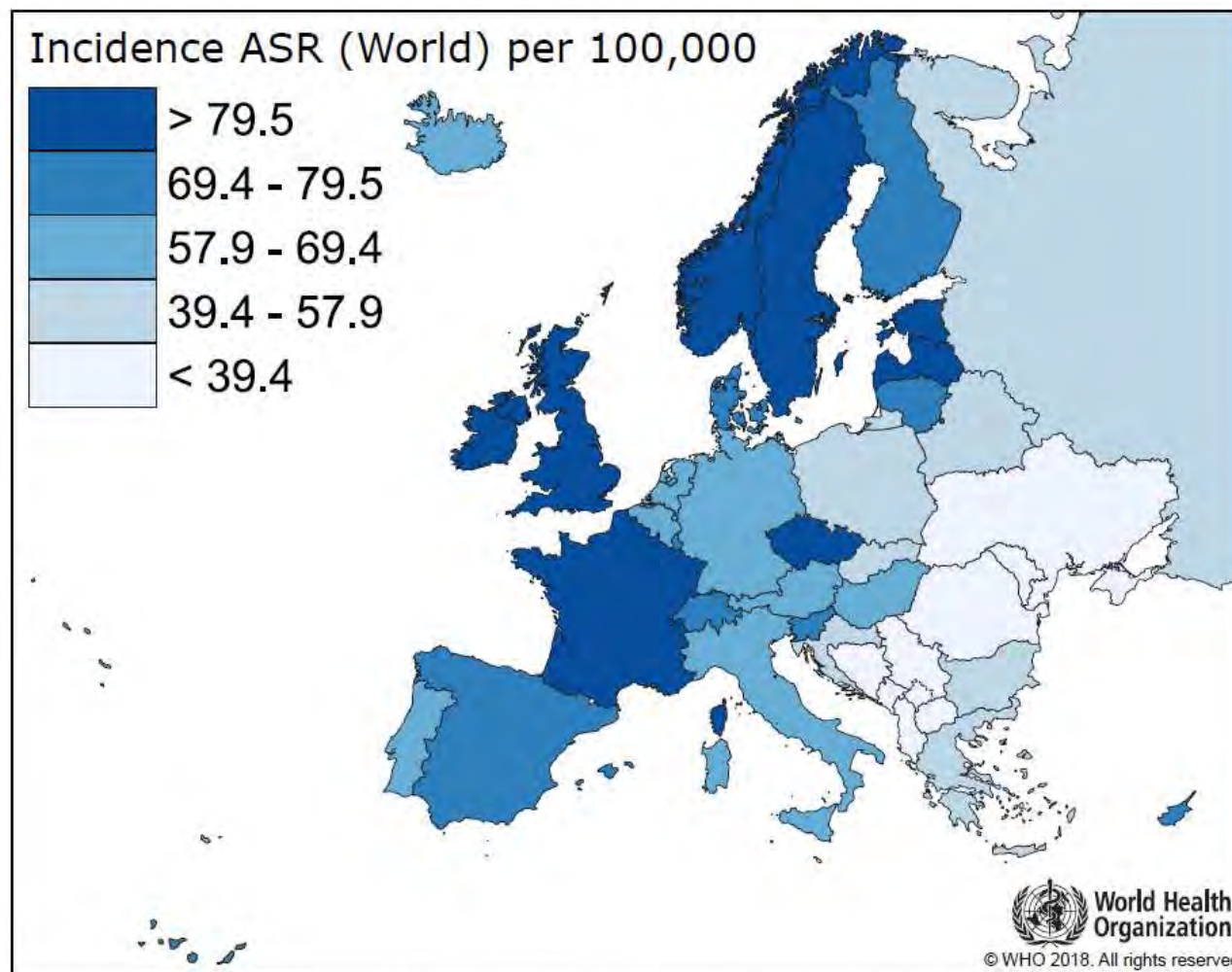


# Prostate cancer

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# Prostate Cancer Incidence



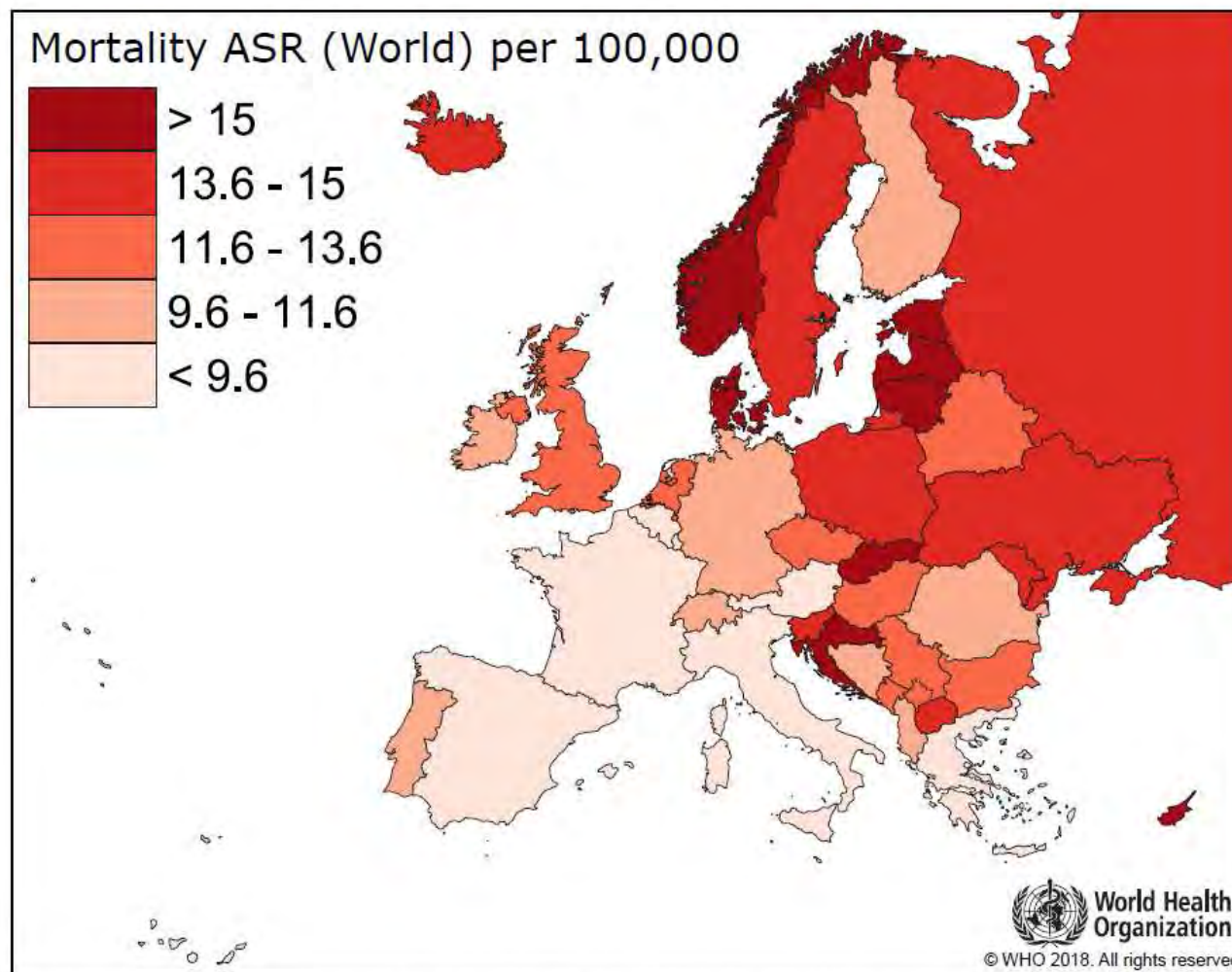
International Agency for



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Source: GLOBOCAN 2018

# Prostate cancer mortality



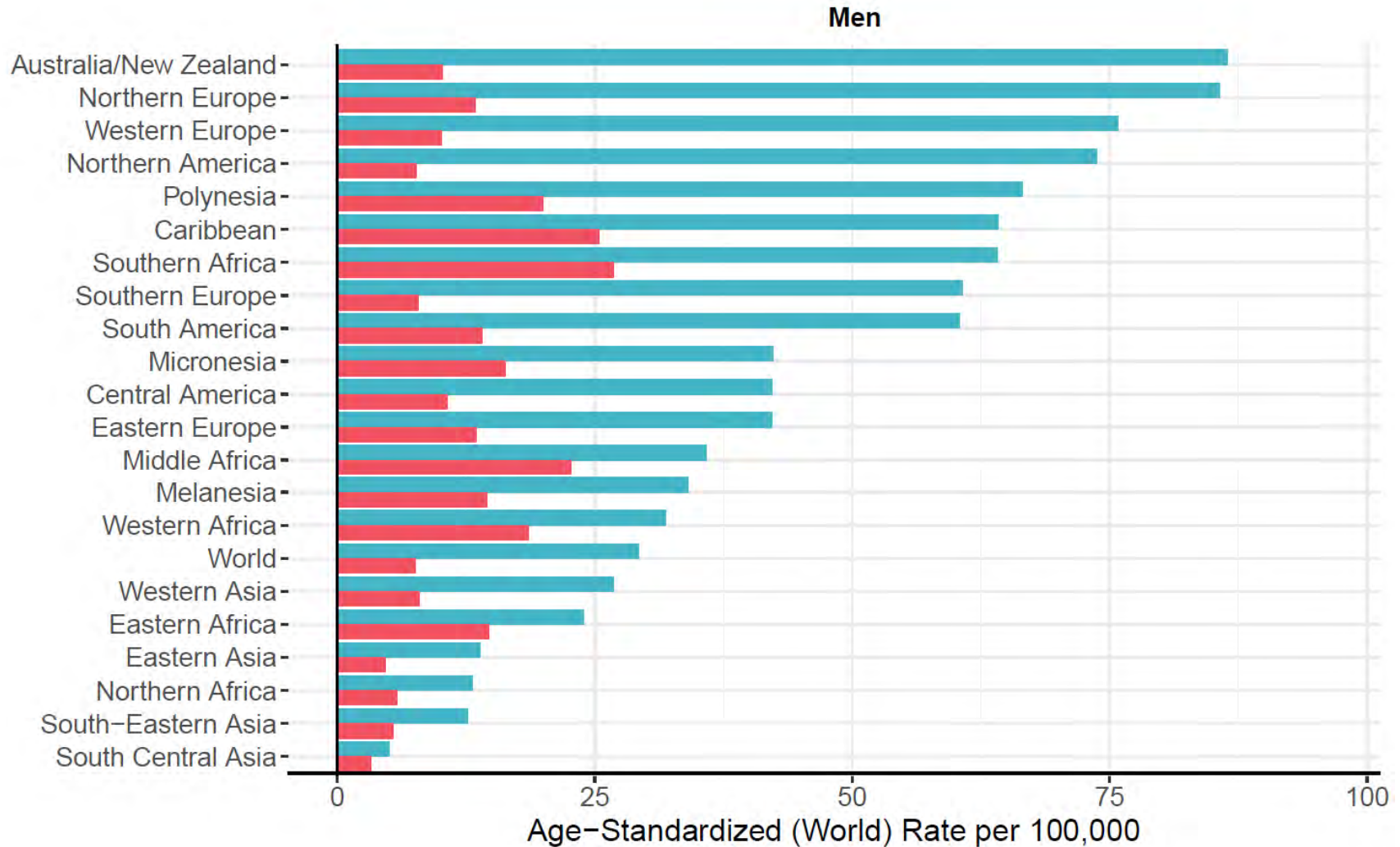
International Agency for



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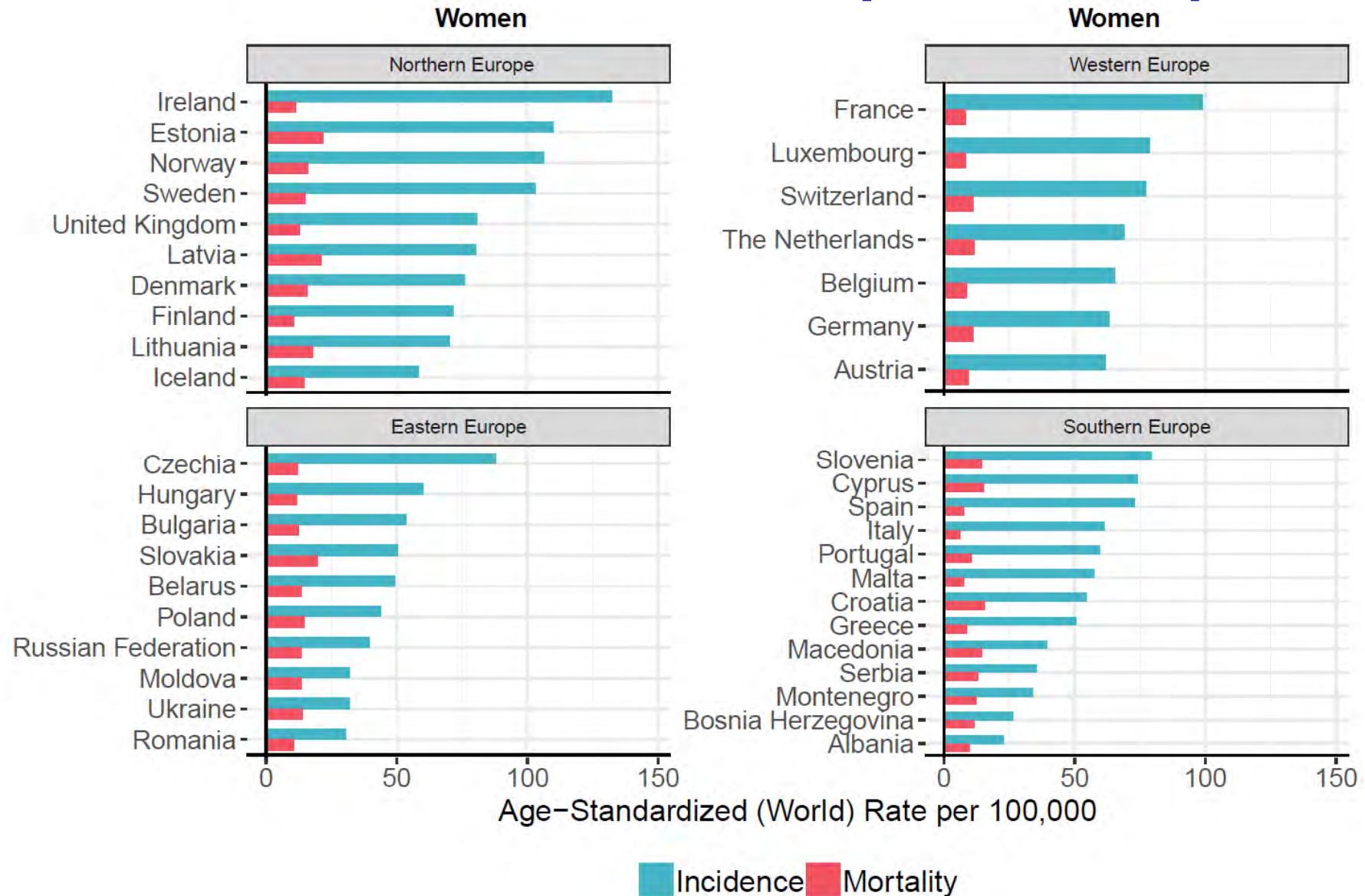
Source: GLOBOCAN 2018

# Incidence, mortality - global





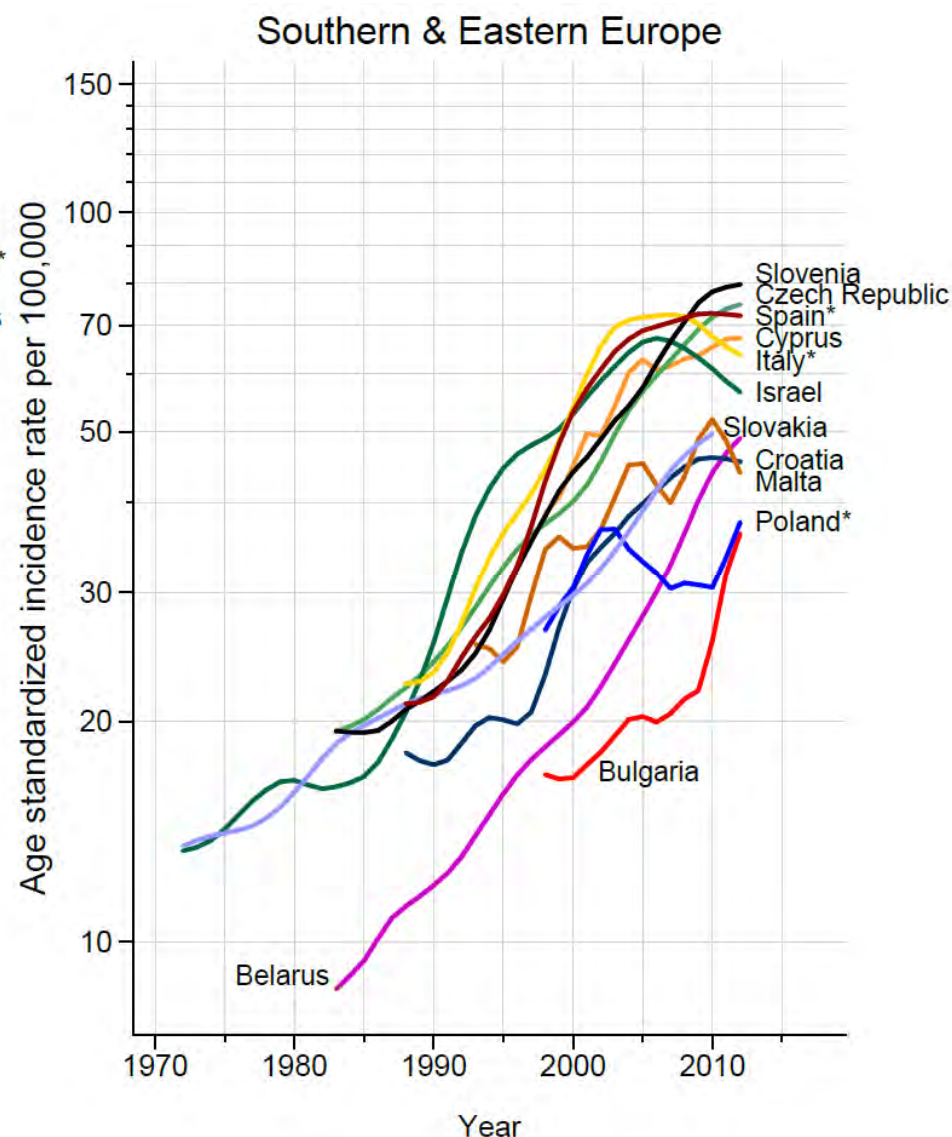
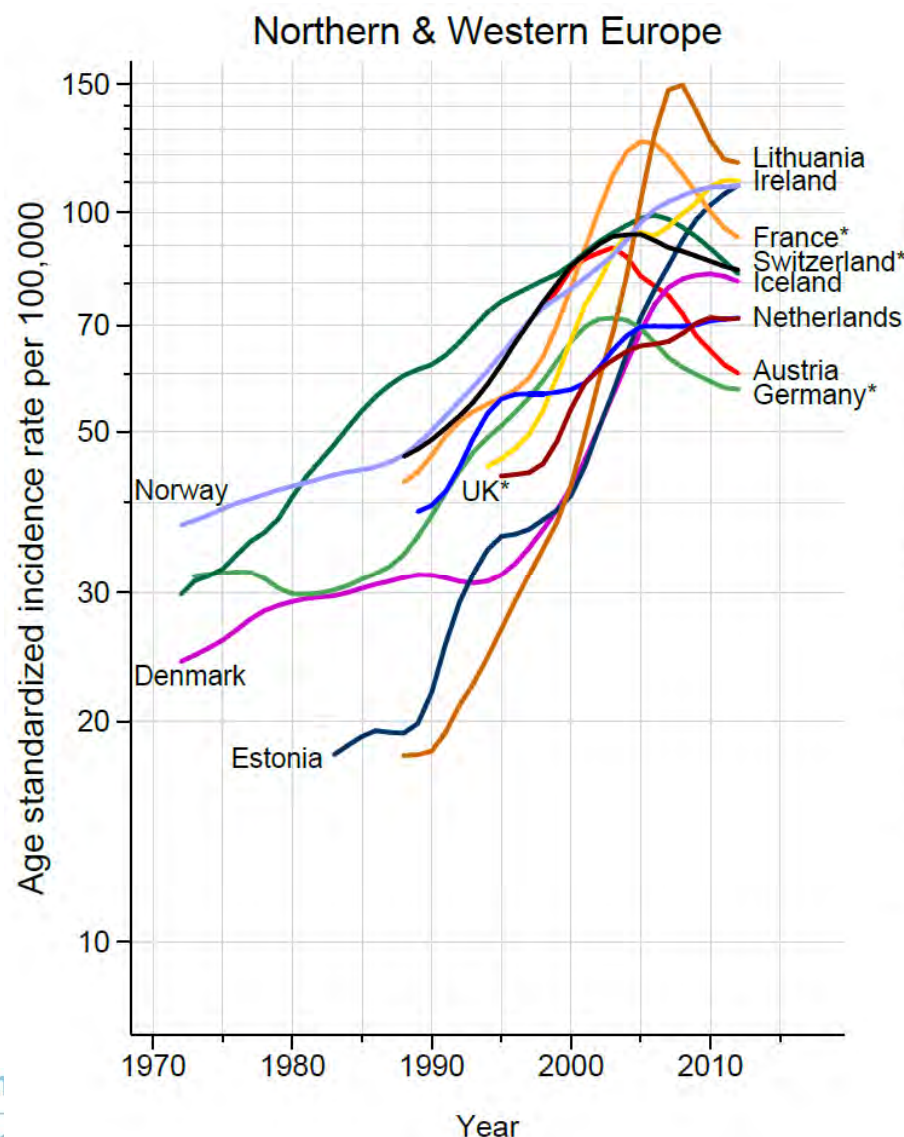
# Incidence, mortality – Europe



Source: GLOBOCAN 2018

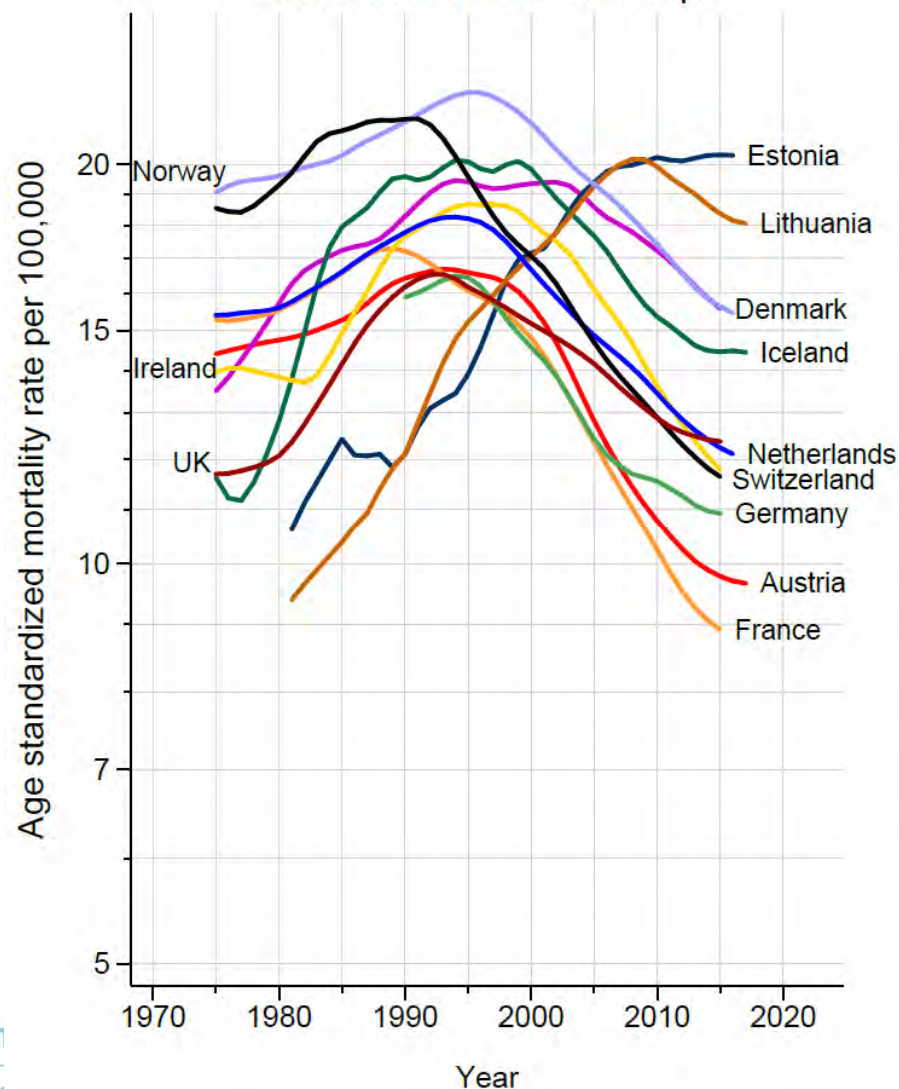


# Trend incidence: Prostate cancer

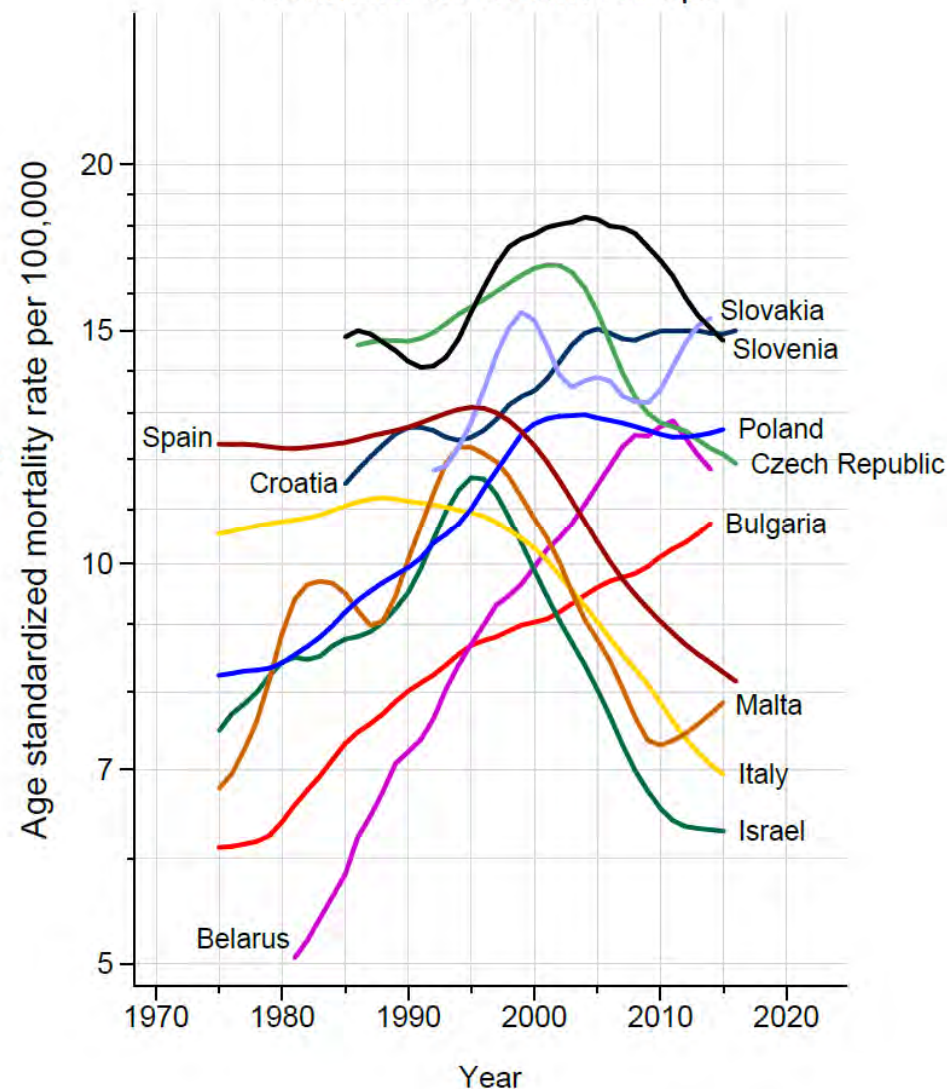


# Trend Mortality: Prostate cancer

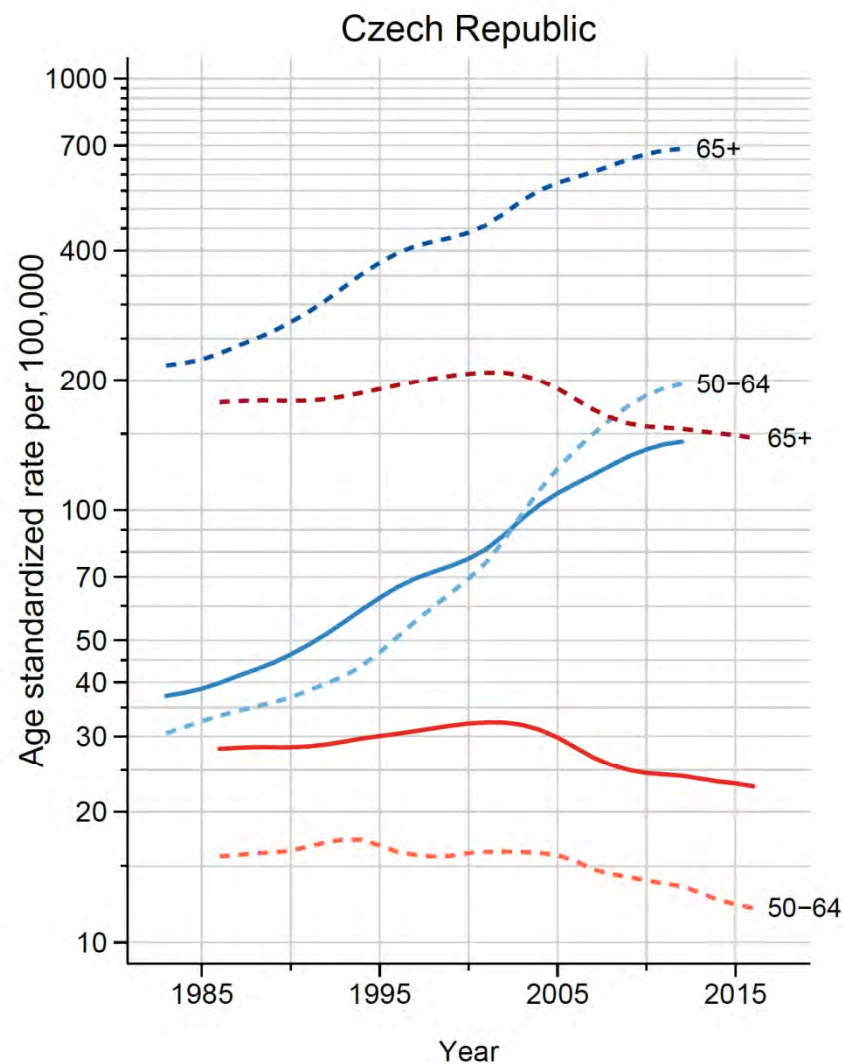
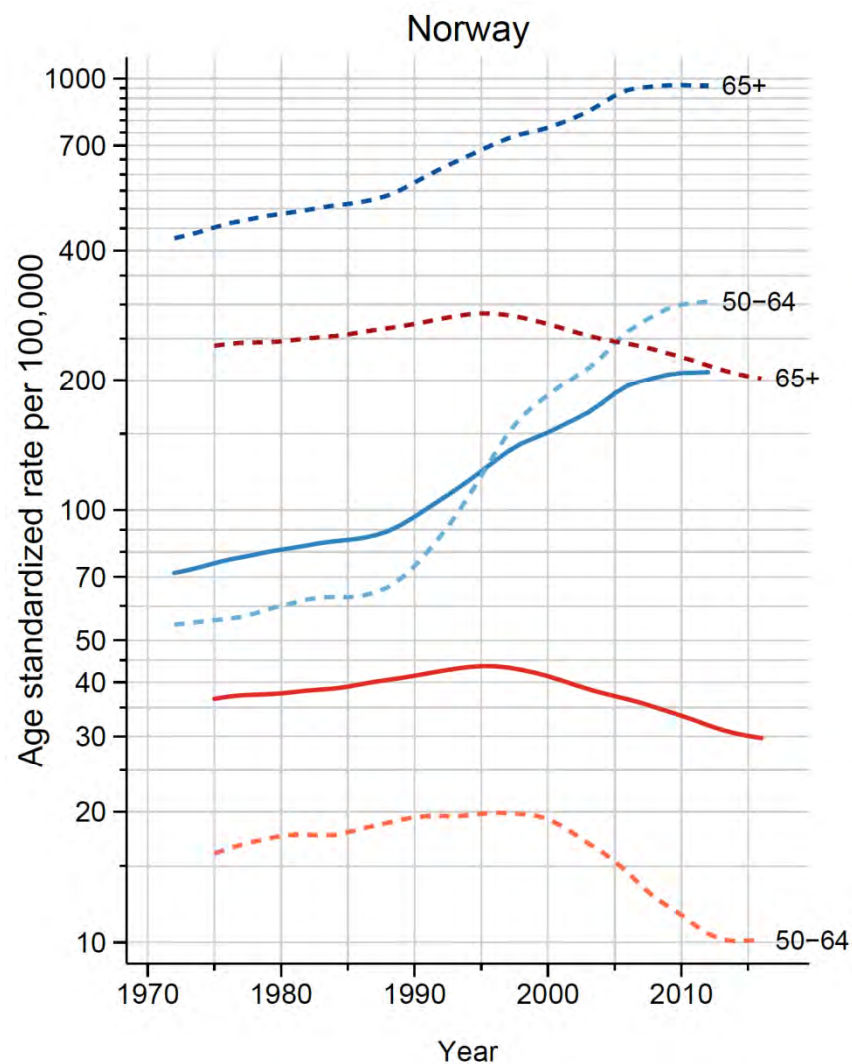
Northern & Western Europe



Southern & Eastern Europe

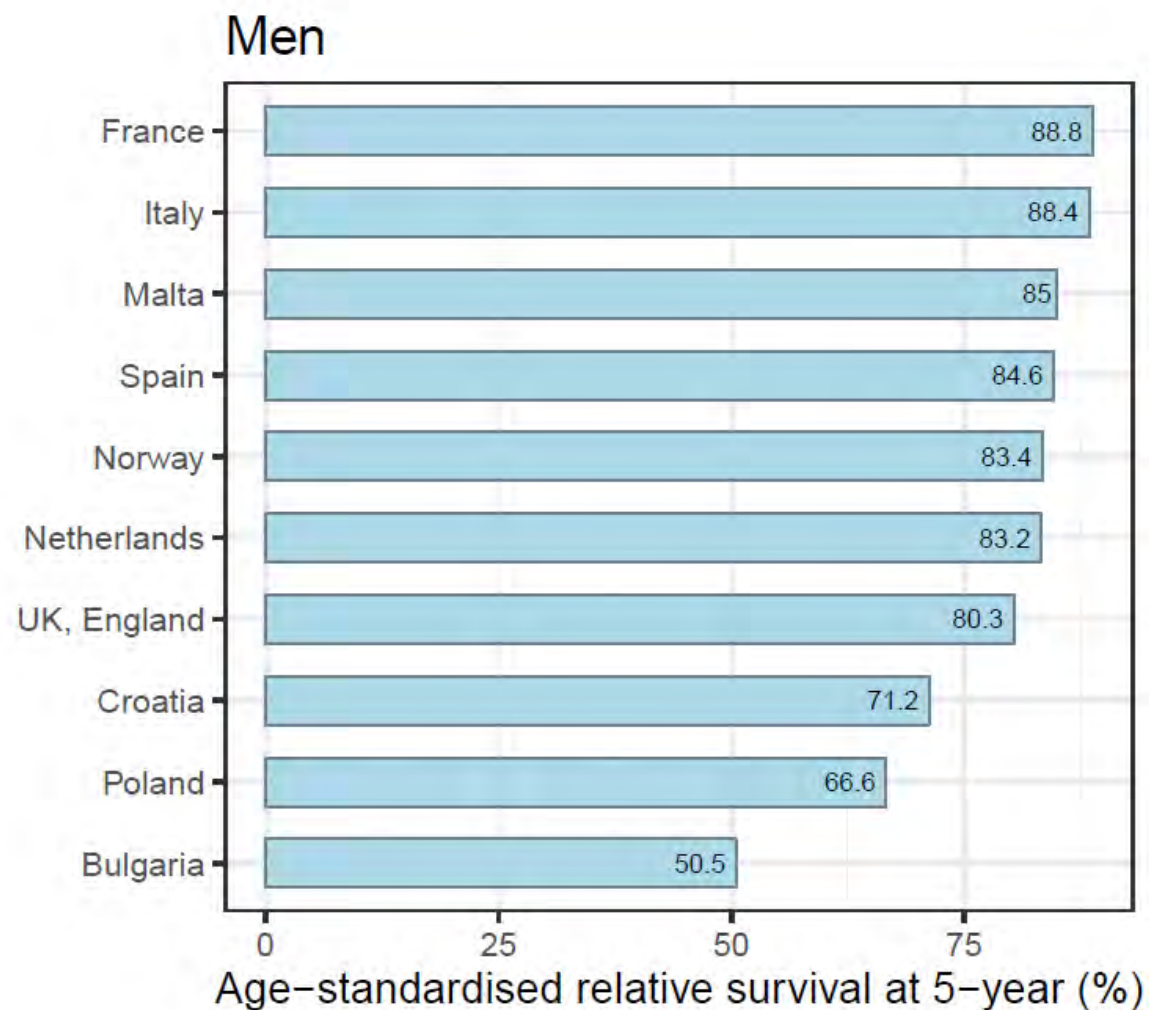


# Prostate cancer trend – by age





# Survival from Prostate cancer



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Source: ECIS