Cancer in Switzerland: Current situation and development

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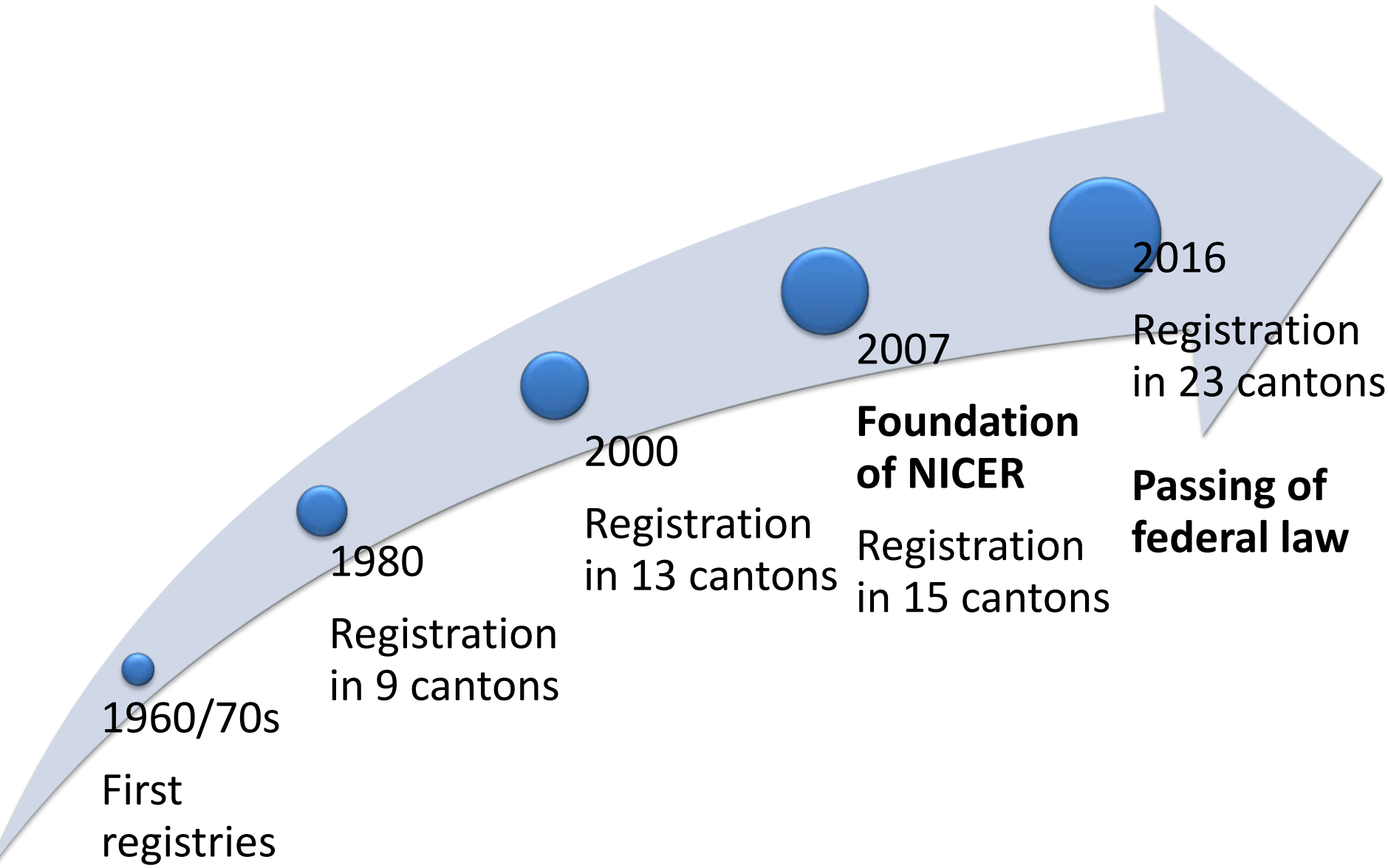
c/o University Zurich

EBPI Lunch seminar 23.11.2016

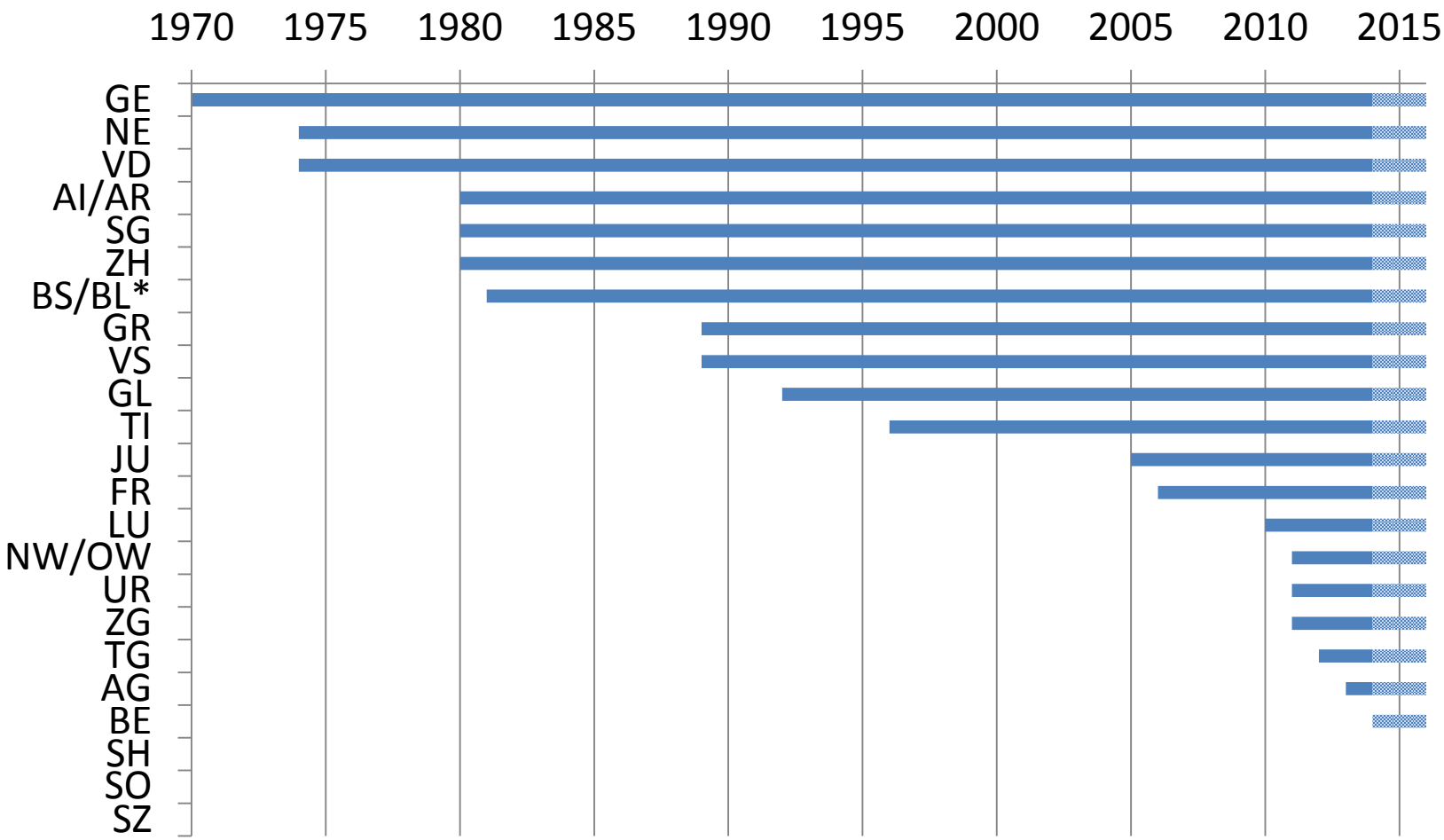
Outline

- Cancer Registration in Switzerland
- NICER Core Data Set
- Swiss Cancer Report
  - Methods
  - Selected results
- Data requests and current research activities
- Outlook: The new law

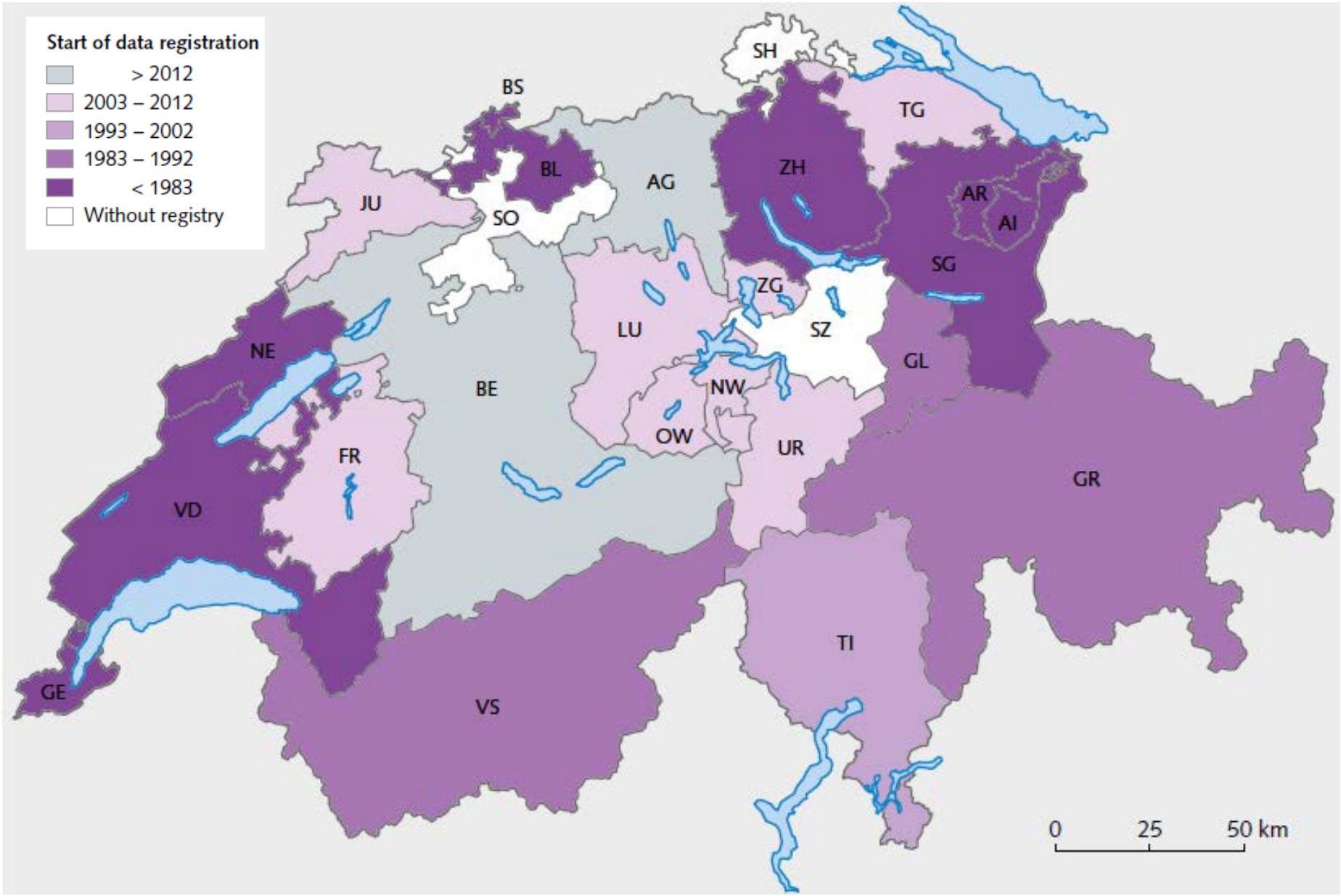
Development of cancer registration in CH



…cancer registration by canton



Current status of cancer registration (2016)



National Institute for Cancer Epidemiology & Registration

- Independent foundation
- Established in 2007 by **Oncosuisse** and the **Swiss Association of Cancer Registries**
- Associated with the University of Zurich
- Funding:
  - Swiss Federal Office of Public Health (BAG)
  - Swiss Cancer Research (KFS)

nicer
Foundation
National Institute
for Cancer Epidemiology
and Registration

Mission

- Act as national coordination centre
- Harmonize the work of the cantonal cancer registries
- Aggregate cancer data
- Provide quality assurance
- Analyse the data on a national level
- Promote epidemiological cancer research

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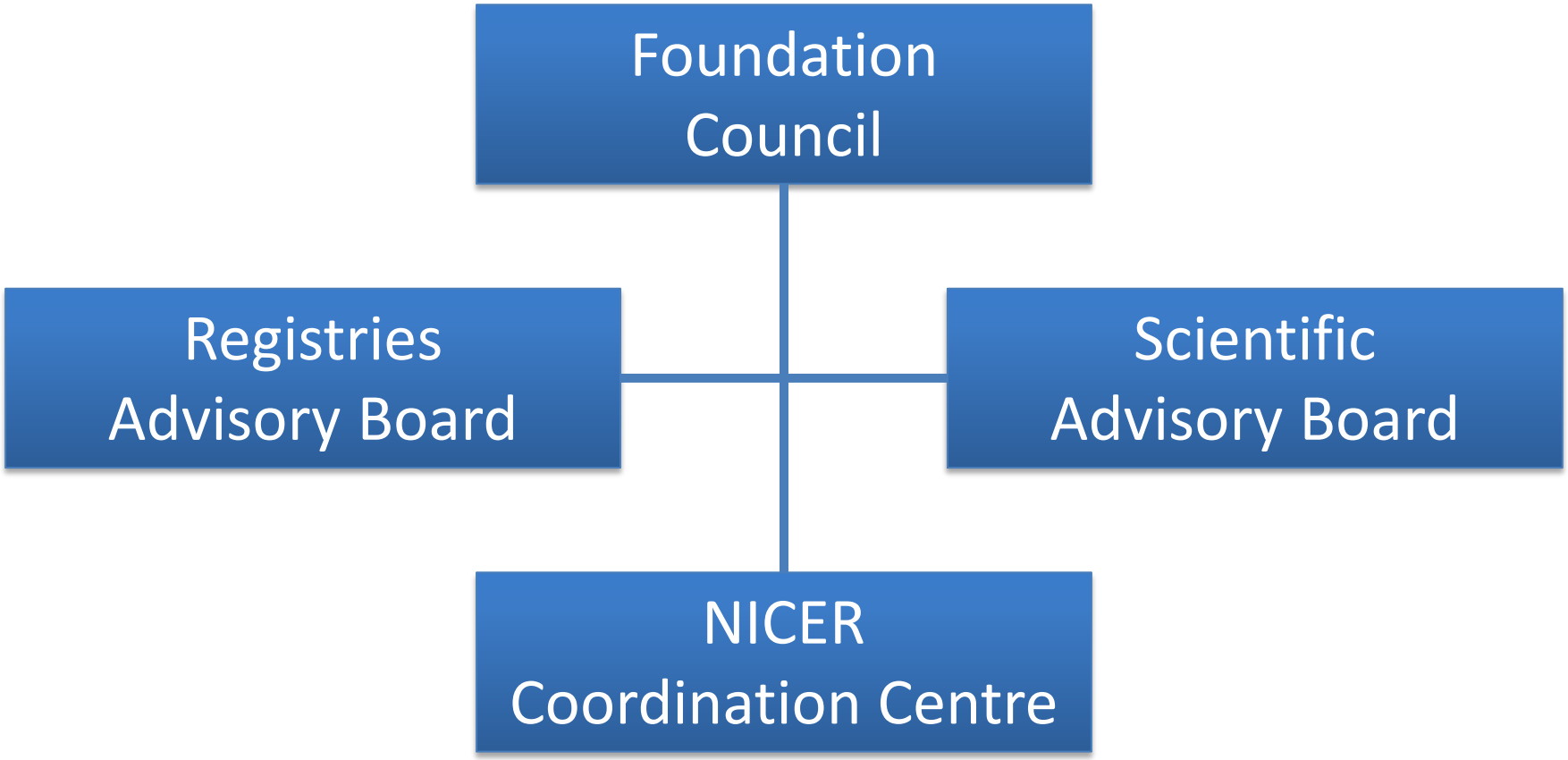
and Registration



NICER Coordination Centre (NCC)

- Dr. Rolf Heusser (Director)
- PD Dr. Volker Arndt (Scientific Director)
- Dr. Matthias Lorez (Senior Bio Statistican)
- Anita Feller (Research Associate)
- Regina Nanieva (Medical Documentalist)
- Francesco Galli (Research Associate)
- Aron Bauman (Communication, Law)
- Nina Pupikofer (Administration)
- Daniel Bosshard (Fiduciary, Secretary to the Boards)

NICER CORE DATASET (NCD)

NICER Core Dataset (NCD)

Population covered

- Swiss citizens and foreigners with long-term residence permits with main address in registration area

Diagnoses included

- All invasive tumours
- In-situ: bladder, breast, cervix
- All intracranial/intraspinal neoplasms (irrespective of behaviour)
- Over 800.000 cancer cases (1980-2013), yearly updated
- Completeness > 95% for most tumour sites

NICER Core Dataset (NCD)

Patient information

- ID / home canton / gender / (nationality)
- Date of birth (mm, yy),
- Age at diagnosis (days)
- *Vital status, date of last vital status (mm, yy), length of follow-up (days)*

Tumour information

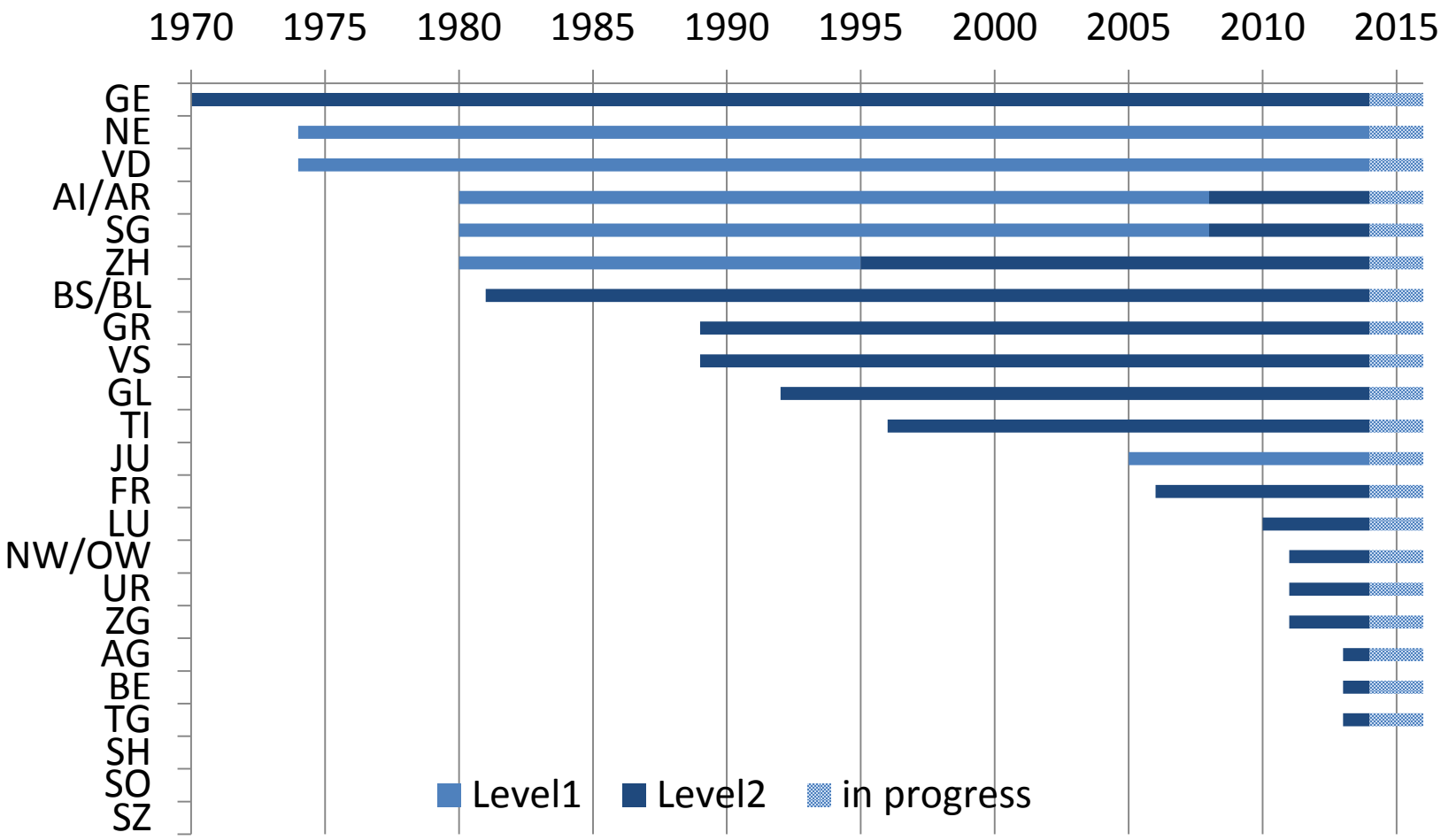
- Date of diagnosis (mm, yy)
- Topography, morphology, and behaviour (ICD, ICD-O)
- Mode of detection, basis of diagnosis
- *Stage (TNM), Grade*
- *Hormone receptor status and HER2 expression (breast cancer)*

Treatment information

- *Date and type of 1st treatment*
- *Type of 2nd up to 5th treatment (for breast and colorectal cancer)*

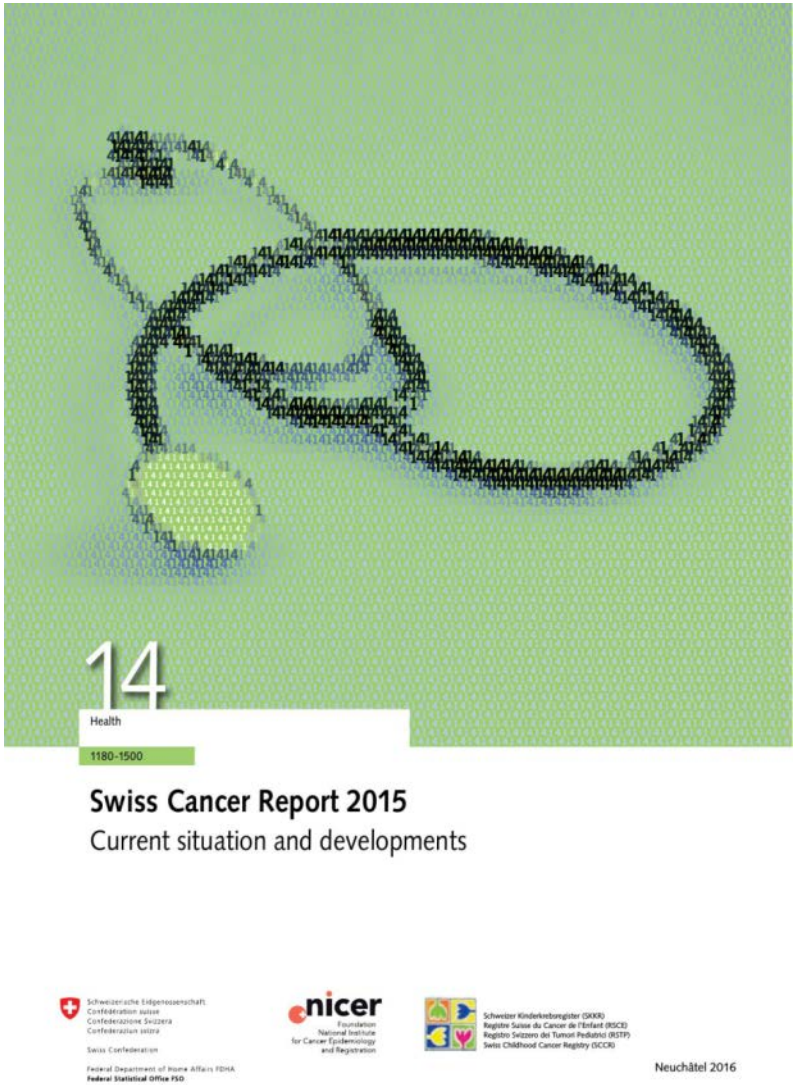
Level 1 data (incidence) ***Level 2 data (clinical, prognostic data, BC & CRC)***

Progress of cancer registration



Swiss Cancer Report 2015

- Collaboration:
  FOPH, SCCR, NICER
- Current situation
  - Incidence
  - Mortality
  - Survival
  - Prevalence
- Trends
- Regional and international comparisons (I,M,S)
- Overall and 23 specific sites



Material & Methods

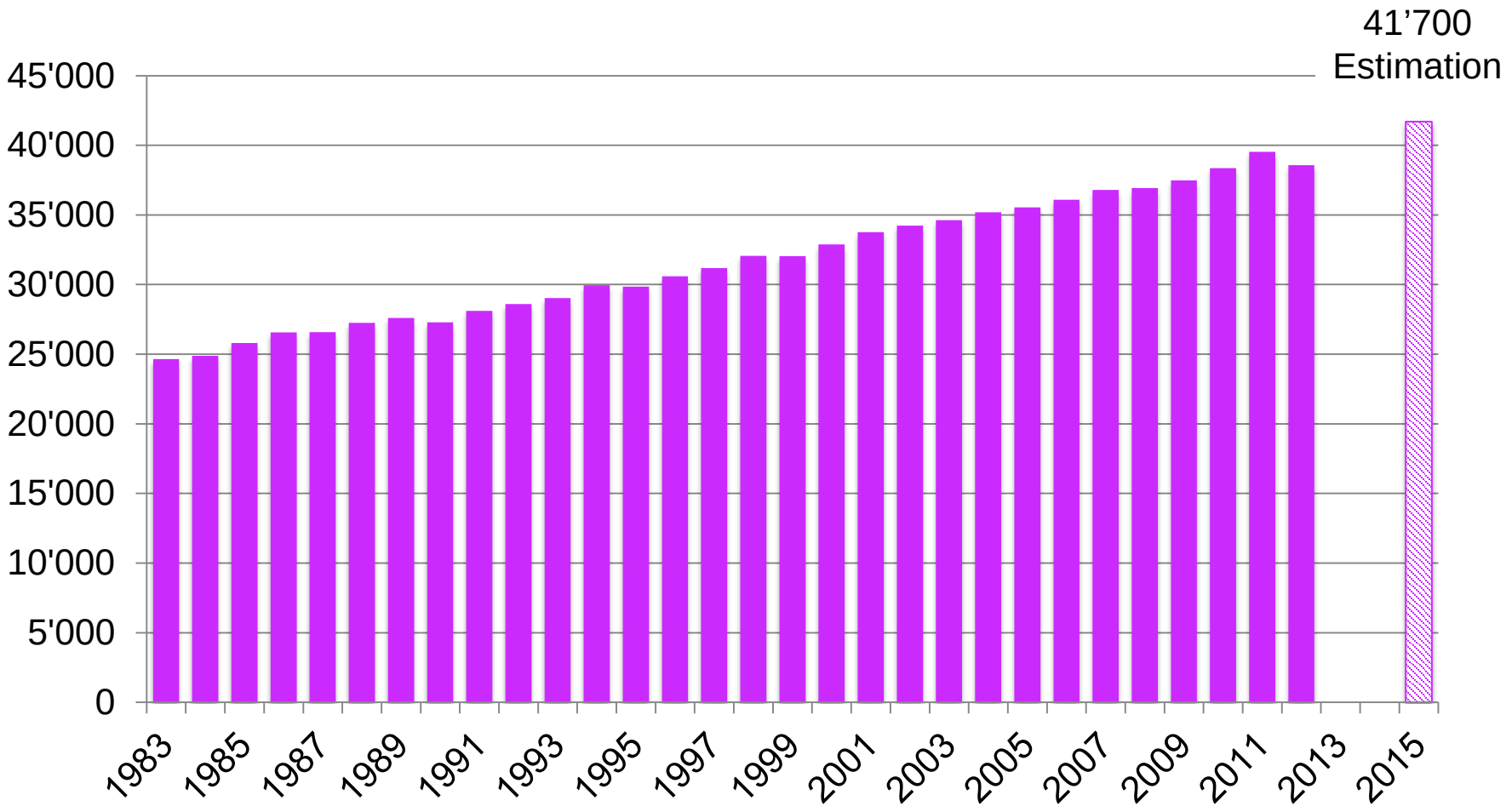
- Data base
  - NCD 1983-2012
  - National Death Statistic 1983-2012
  - International data:
    - National incidence and mortality statistics (Ferlay et al., 2013)
    - Survival: EUROCARE-5 (De Angelis et al, 2014)

- Measures
  - Age standardised incidence and mortality
  - Life time risk (cumulative risk up to age 80 (m), 85 (f))
  - Potential life years lost (before age 70)
  - Incidence and mortality estimates for 2015
  - Absolute and relative survival (1-5-10 year)
  - Prevalence (limited and complete)

Main Results

All sites combined

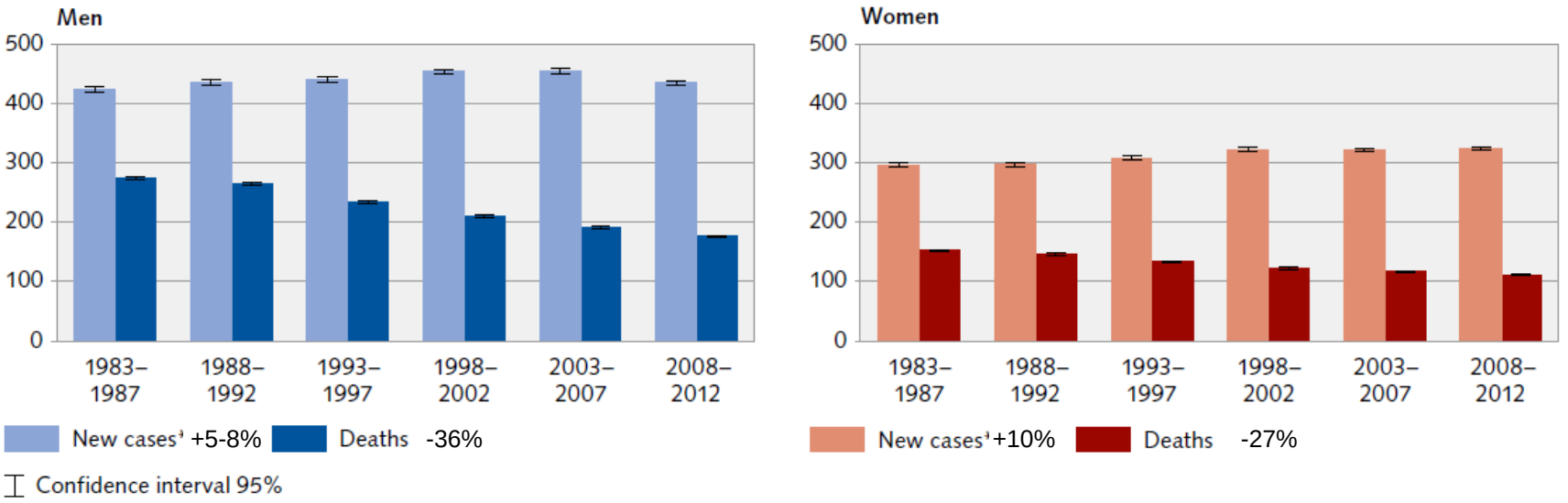
Cancer in Switzerland, 1983 – 2015
Incident cases per year



Cancer: Trends over time

G 3.6

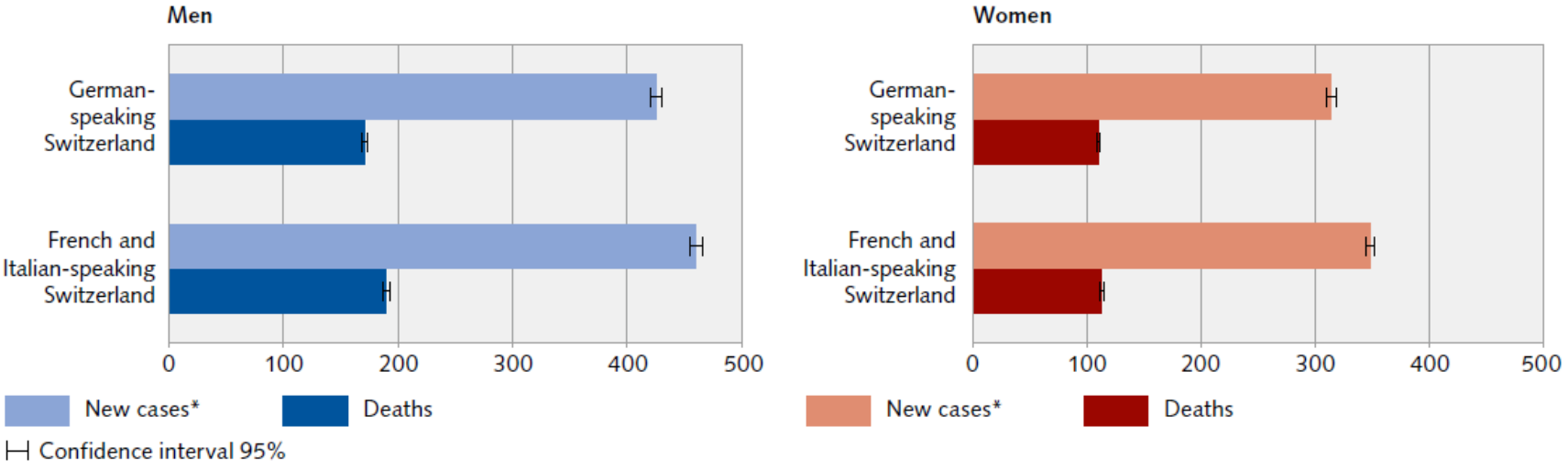
Rate per 100,000 inhabitants, European standard



Cancer in regional comparison, 2008–2012

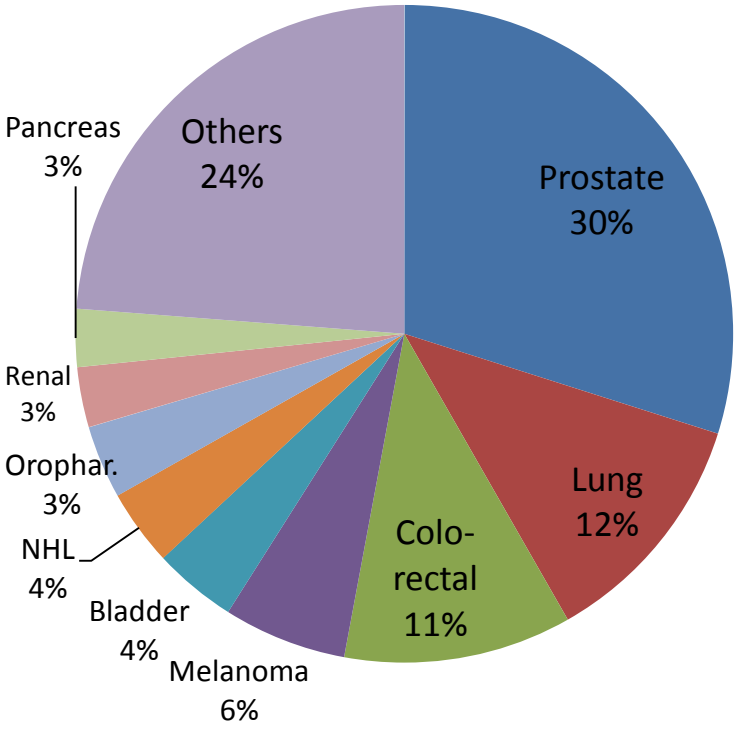
G 3.4

Rate per 100,000 inhabitants, European standard

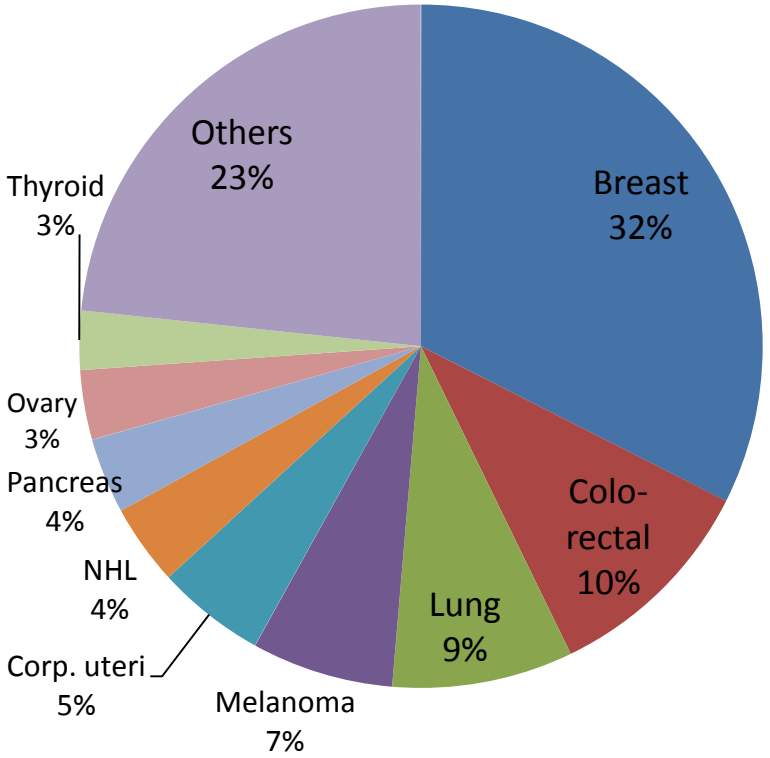


Proportion of incident cases by site (2008-2012)

Males



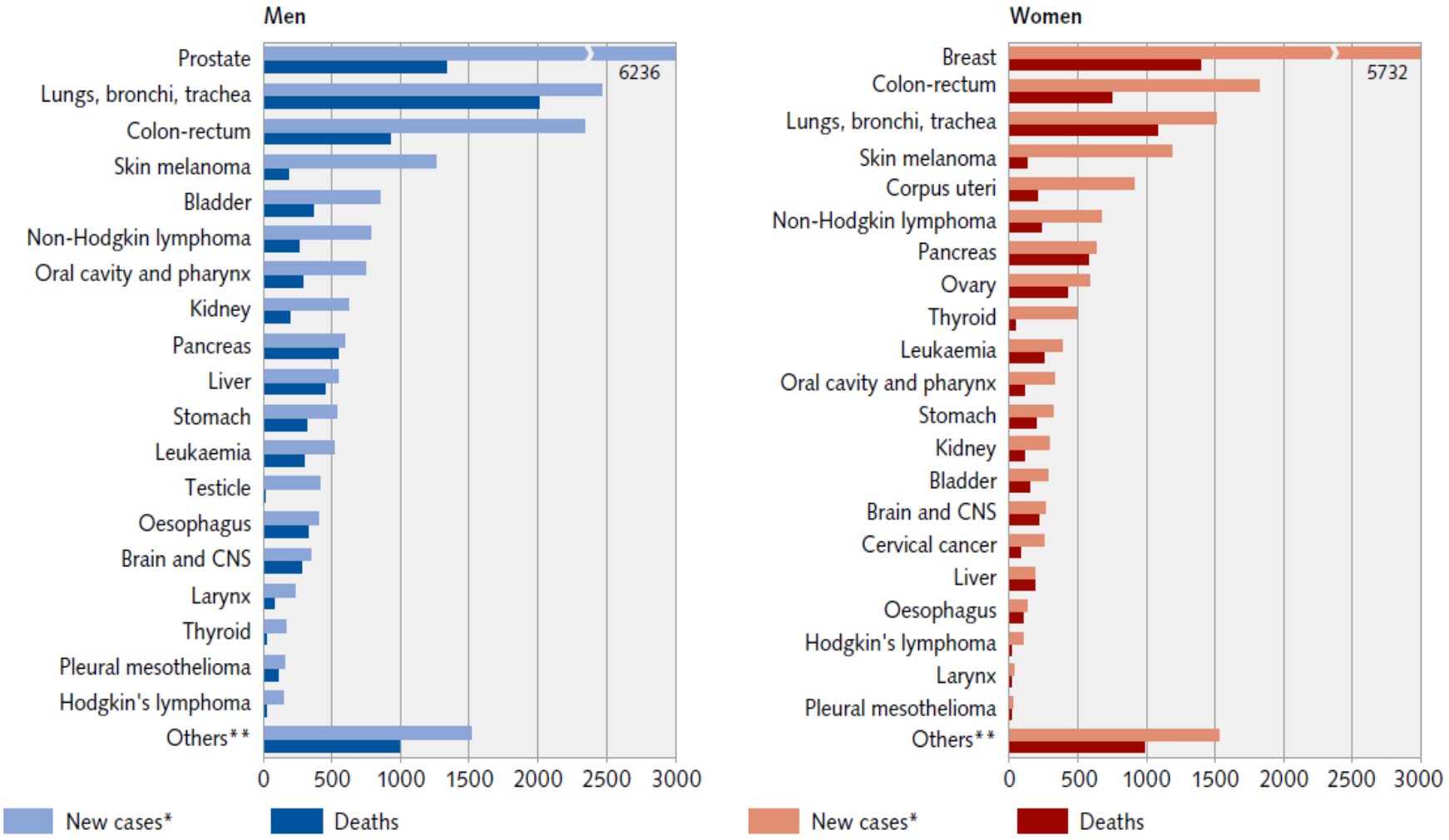
Females



New cases and deaths by cancer site, 2008–2012

G 3.1

Average number per year



* New cases estimated on the basis of cancer registry data
** New cases excl. non-melanoma skin cancer

Sources: NICER – New cases; FSO – Deaths

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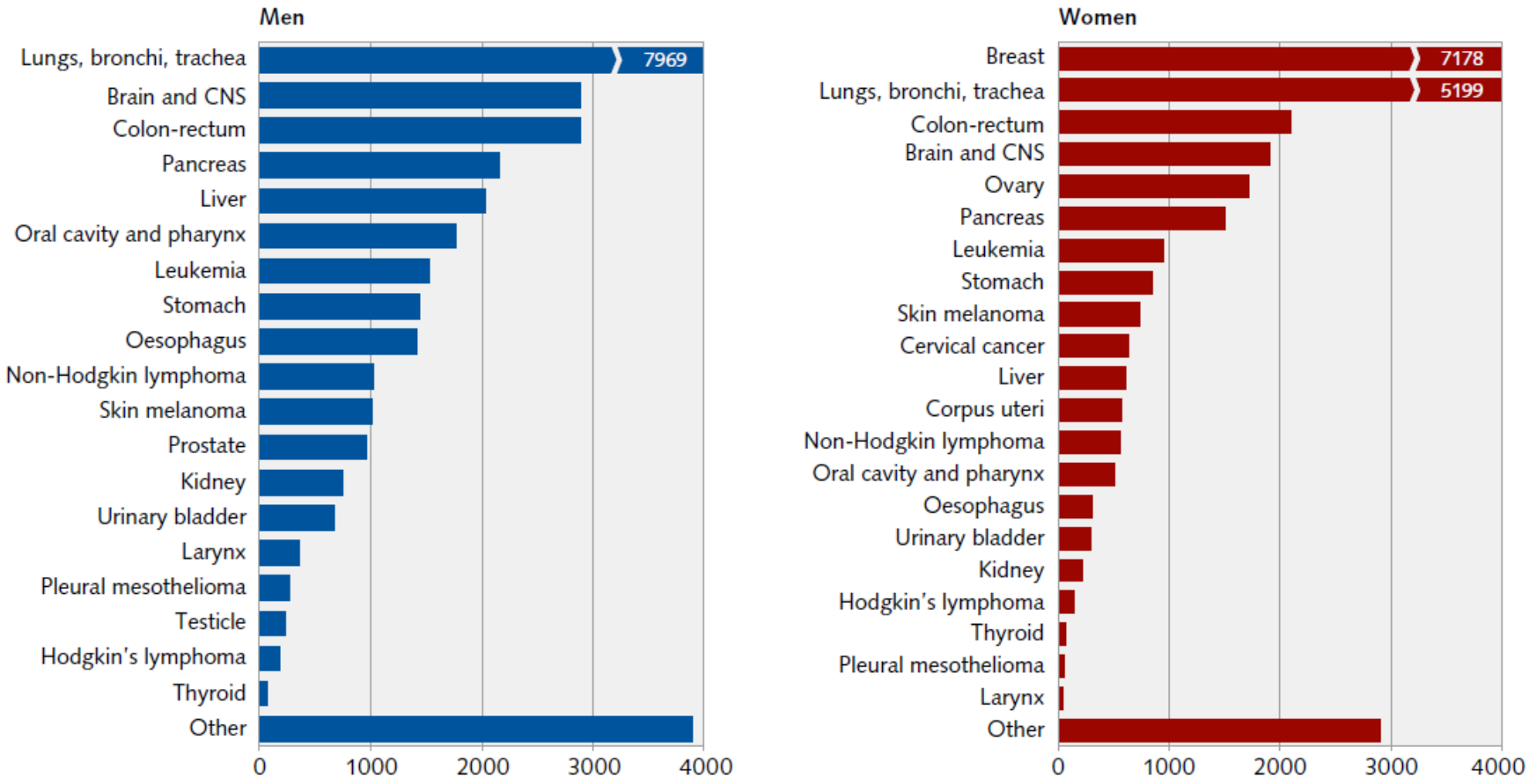
Years of potential life lost (YPLL) by cancer site, 2008–2012 G 3.3

YPLL before age 70, average number per year



Source: OFSO – Death

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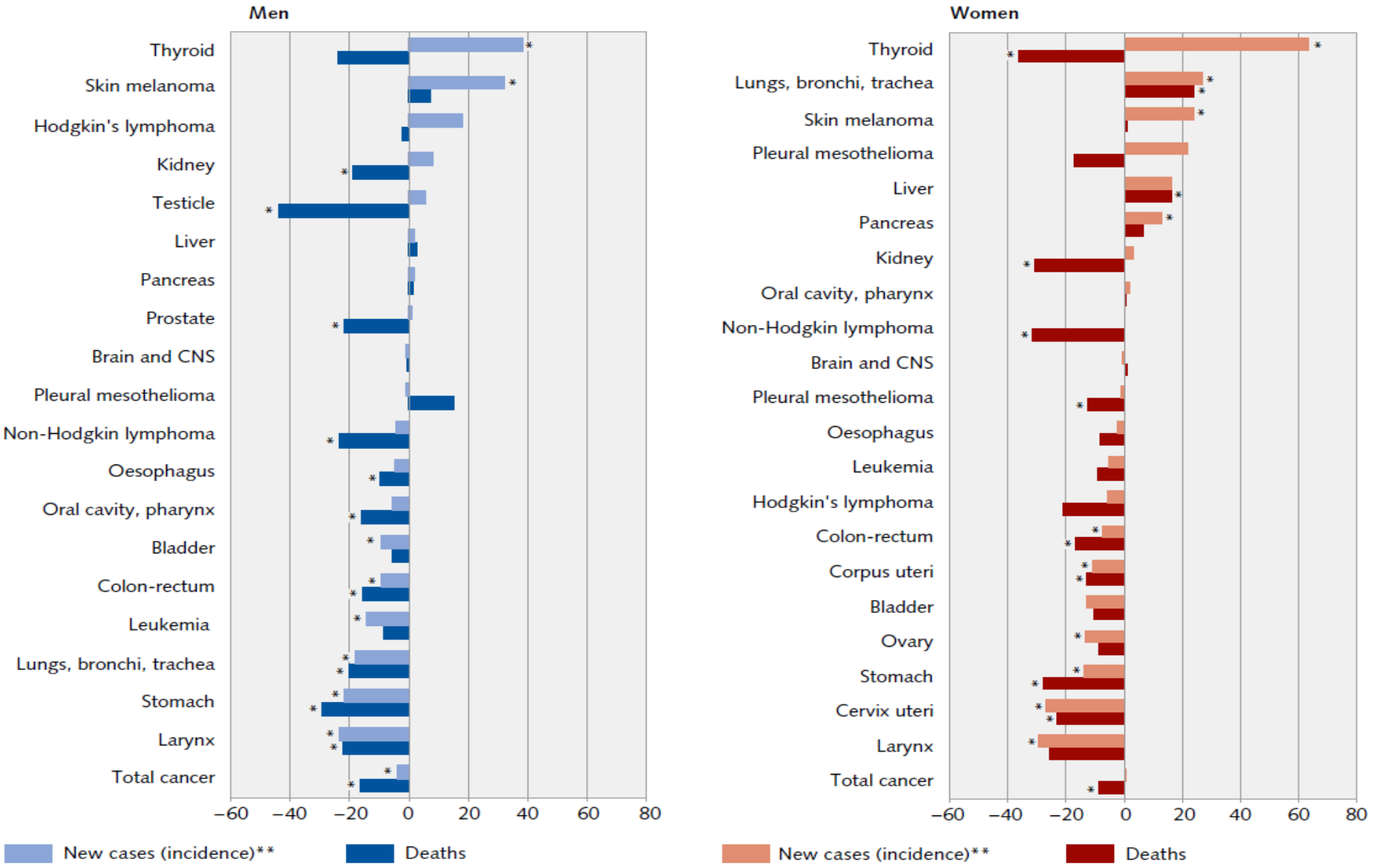
Trends in incidence and mortality rates by cancer site

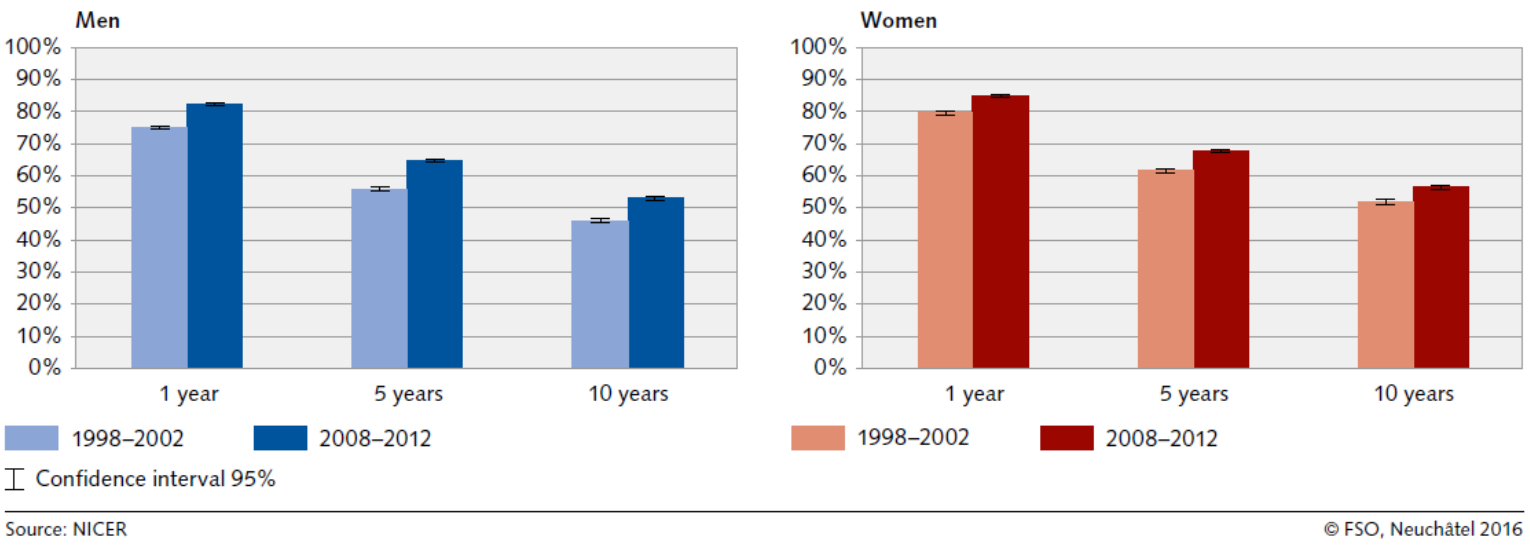
G 3.7

Percentage change in age-standardised rates, average 2008–2012 vs 1998–2002



* Statistically significant change ($p<0.05\%$)

** New cases estimated on the basis of cancer registry data; excl. non-melanoma skin cancer



Excourse to Period Methodology?

Traditional estimates of long-term relative survival rates ...

- pertain to patients diagnosed many years ago
- may be seriously outdated in case of recent improvement in prognosis
- may unduly discourage patients, their relatives and clinicians

What can we do to overcome these short comings?

Example: 10-Year Survival

	Years of Follow-up												
Diagnosis	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
2000	1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10		
2001		1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10	
2002			1	½	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10
2003				1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10
2004					1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9
2005						1	1/2	2/3	3/4	4/5	5/6	6/7	7/8
2006							1	1/2	2/3	3/4	4/5	5/6	6/7
2007								1	1/2	2/3	3/4	4/5	5/6
2008									1	1/2	2/3	3/4	4/5
2009										1	1/2	2/3	3/4
2010											1	1/2	2/3
2011												1	1/2
2012													0/1

Traditional Method (a): Cohort Analysis 2000-2002

Diagnosis	Years of Follow-up												
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
2000	1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10		
2001		1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10	
2002			1	½	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10
2003				1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10
2004					1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9
2005						1	1/2	2/3	3/4	4/5	5/6	6/7	7/8
2006							1	1/2	2/3	3/4	4/5	5/6	6/7
2007								1	1/2	2/3	3/4	4/5	5/6
2008									1	1/2	2/3	3/4	4/5
2009										1	1/2	2/3	3/4
2010											1	1/2	2/3
2011												1	1/2
2012													0/1

Traditional Method (b): Complete Analysis 2000-2012

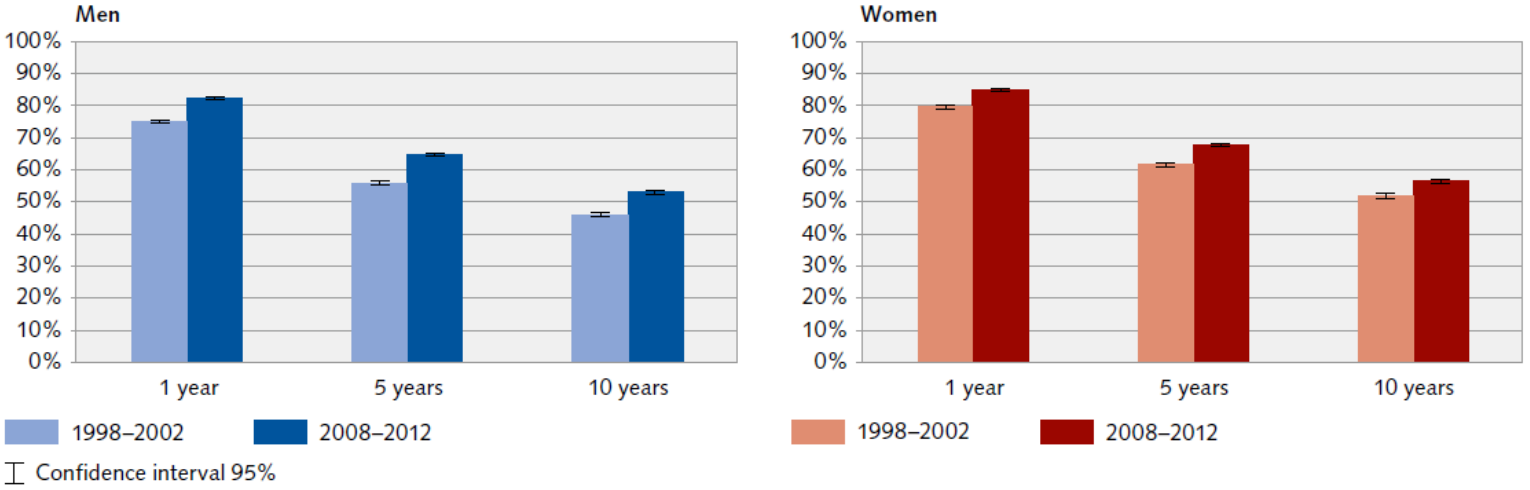
Diagnosis	Years of Follow-up												
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
2000	1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10		
2001		1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10	
2002			1	½	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10
2003				1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10
2004					1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9
2005						1	1/2	2/3	3/4	4/5	5/6	6/7	7/8
2006							1	1/2	2/3	3/4	4/5	5/6	6/7
2007								1	1/2	2/3	3/4	4/5	5/6
2008									1	1/2	2/3	3/4	4/5
2009										1	1/2	2/3	3/4
2010											1	1/2	2/3
2011												1	1/2
2012													0/1

Alternative Method: Period Analysis 2010-2012

Diagnosis	Years of Follow-up												
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
2000	1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10		
2001		1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10	
2002			1	½	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10	10
2003				1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9	9/10
2004					1	1/2	2/3	3/4	4/5	5/6	6/7	7/8	8/9
2005						1	1/2	2/3	3/4	4/5	5/6	6/7	7/8
2006							1	1/2	2/3	3/4	4/5	5/6	6/7
2007								1	1/2	2/3	3/4	4/5	5/6
2008									1	1/2	2/3	3/4	4/5
2009										1	1/2	2/3	3/4
2010											1	1/2	2/3
2011												1	1/2
2012													0/1

Cancer: Relative survival rate after 1, 5 and 10 years

G 3.8



Source: NICER

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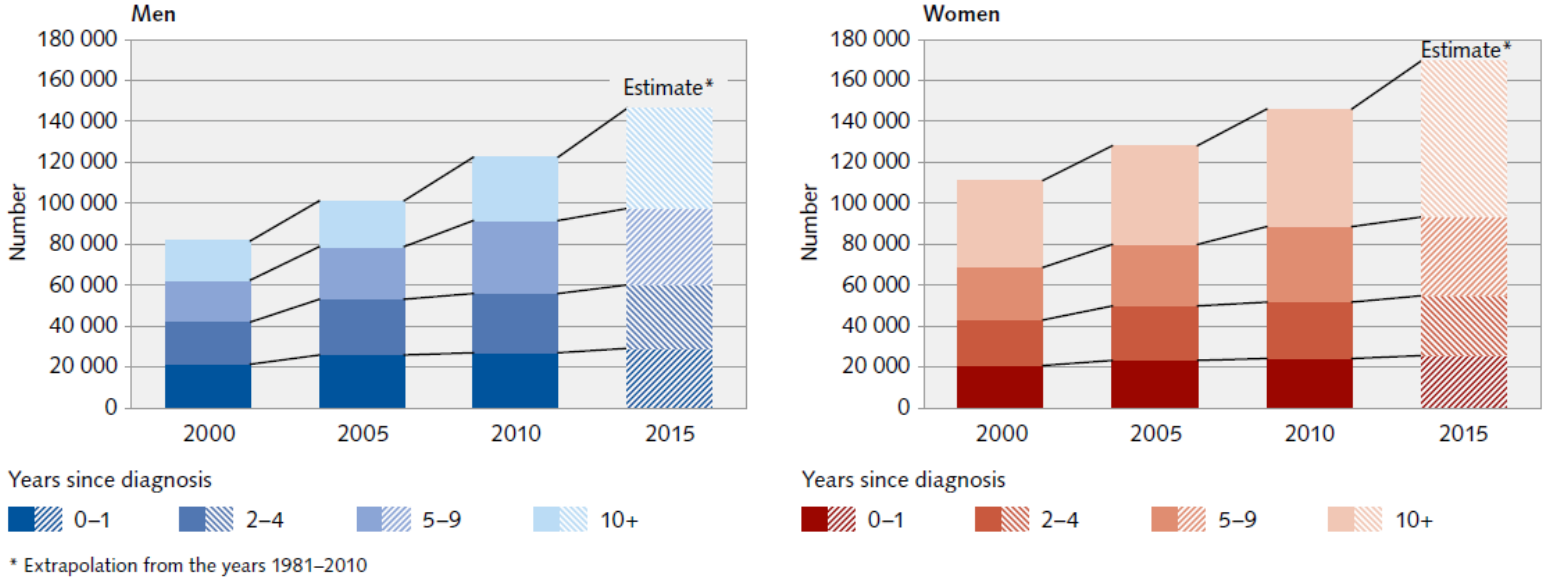
Cancer: Number of survivors (prevalence)

G 3.11



* Extrapolation from the years 1981–2010

Source: NICER

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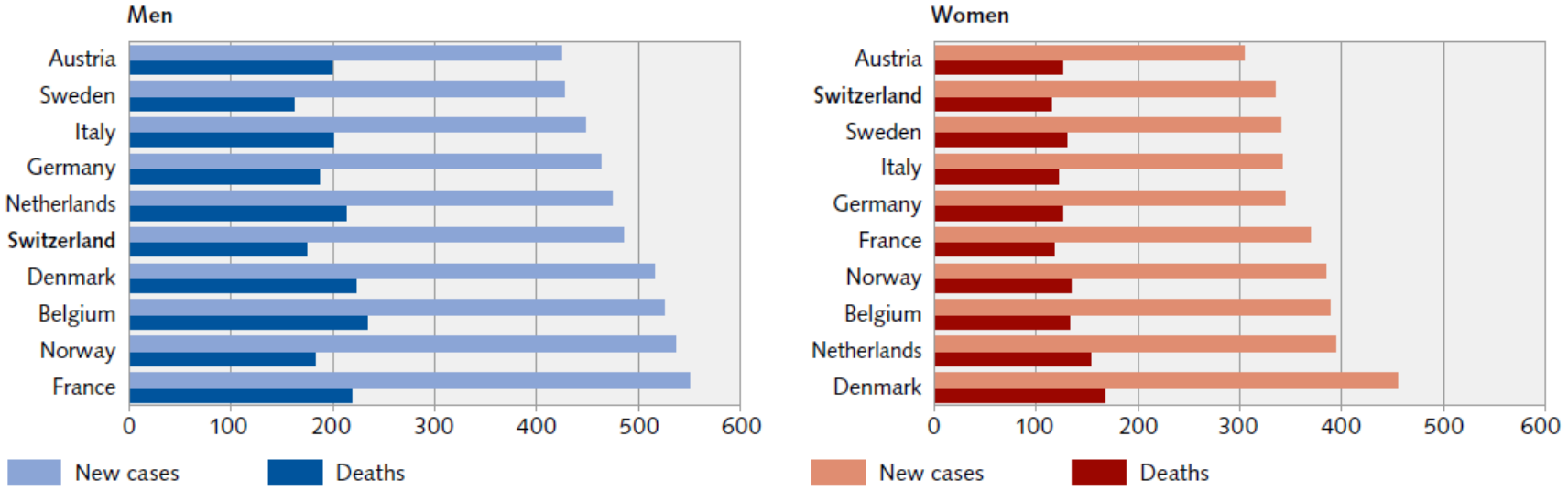
Cancer in international comparison, 2012 — G 3.5

Rate per 100,000 inhabitants, European standard



Source: Ferlay J. et al. (2013). Cancer incidence and mortality patterns in Europe: Estimates for 40 countries in 2012

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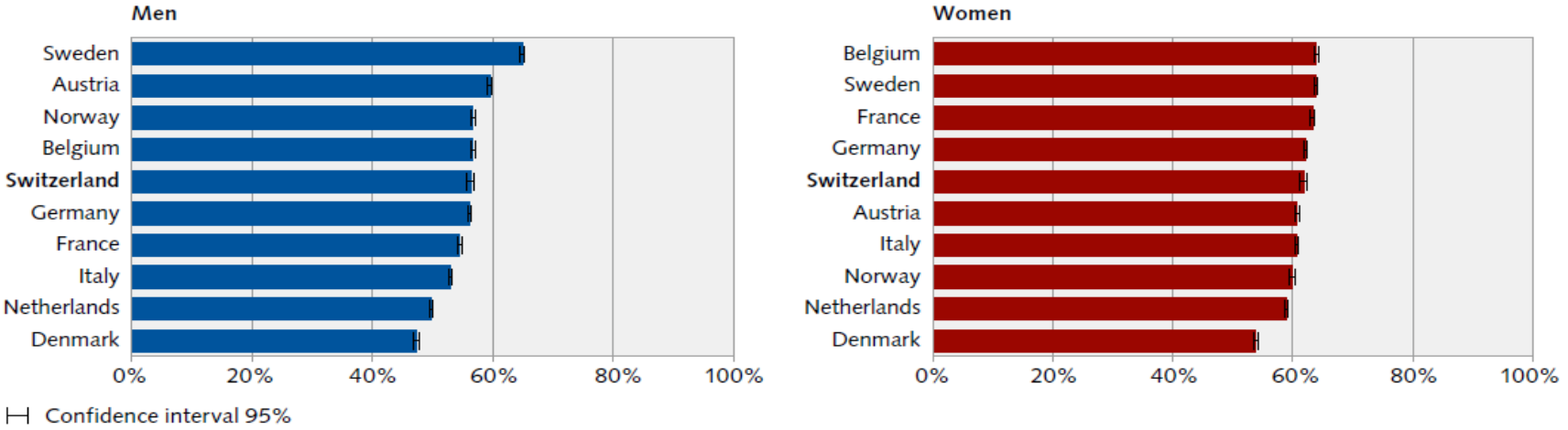
Cancer: Relative 5-year survival rates in international comparison, 2000–2007 — G 3.10



Data for Belgium, Germany, France, Italy and Switzerland are based on regional data that do not cover the whole country

Source: EUROCARE-5 Database – Survival Analysis 2000–2007

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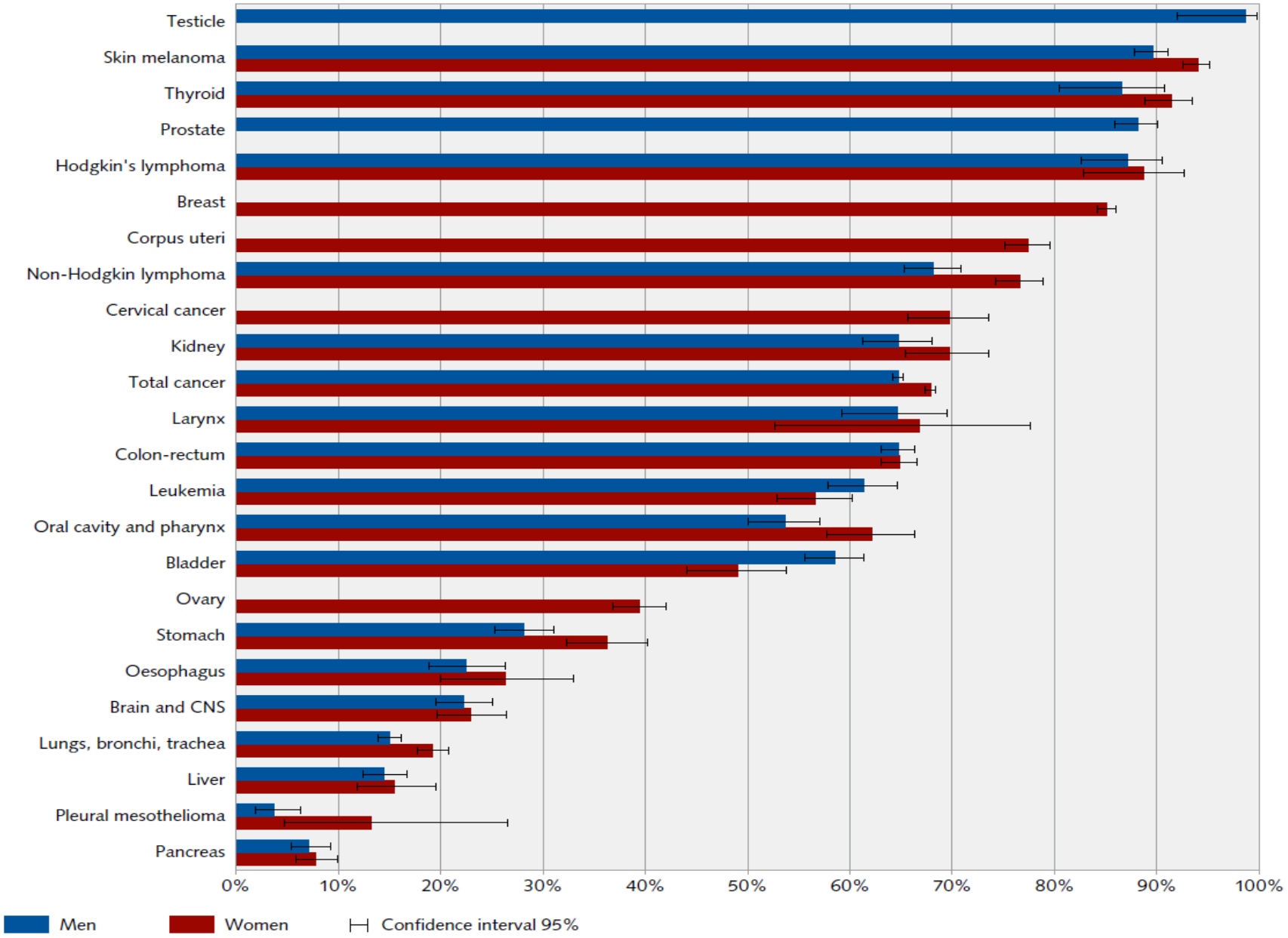
Relative 5-year survival rates, by cancer site, 2008–2012

G 3.9



Source: NICER

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Site specific results

Lung Cancer

T4.8.1 Lung cancer: Key epidemiological figures

	Men		Women	
	Incidence	Deaths	Incidence	Deaths
Number of cases per year, average 2008–2012	2463	2010	1509	1079
Number of cases 2015 (estimated)	2500	2055	1762	1322
Proportion of all cancer cases, average 2008–2012	11.8%	22.3%	8.5%	14.9%
Crude rate (per 100,000 inhabitants and year), 2008–2012	63.9	52.2	38.0	27.1
Average annual change in the crude rate, 2003–2012	–1.1%	–0.9%	2.2%	3.0%
Crude rate 2015 (estimated)	61.5	50.5	42.4	31.8
Standardised rate (per 100,000 inhabitants and year), 2008–2012	50.5	40.3	27.4	18.7
Average annual change in the standardised rate, 2003–2012	–2.4%	–2.4%	1.3%	1.9%
Median age at diagnosis and death, average 2008–2012	69.7	71.5	68.5	70.3
Lifetime risk, 2008–2012	6.5%	5.5%	3.6%	2.7%
Cumulative risk before the age of 70, 2008–2012	2.8%	2.1%	1.8%	1.1%
Years of potential life lost before the age of 70, average 2008–2012	–	7969	–	5199

	Men	Women
Number of patients (prevalence), on 31.12.2010	5274	3653
of whom diagnosed within the past 5 years	3303	2341
Observed 5-year survival rate, on 31.12.2012	13.6%	18.1%
Relative 5-year survival rate, on 31.12.2012	15.0%	19.2%

Sources: NICER – New cases; FSO – Deaths

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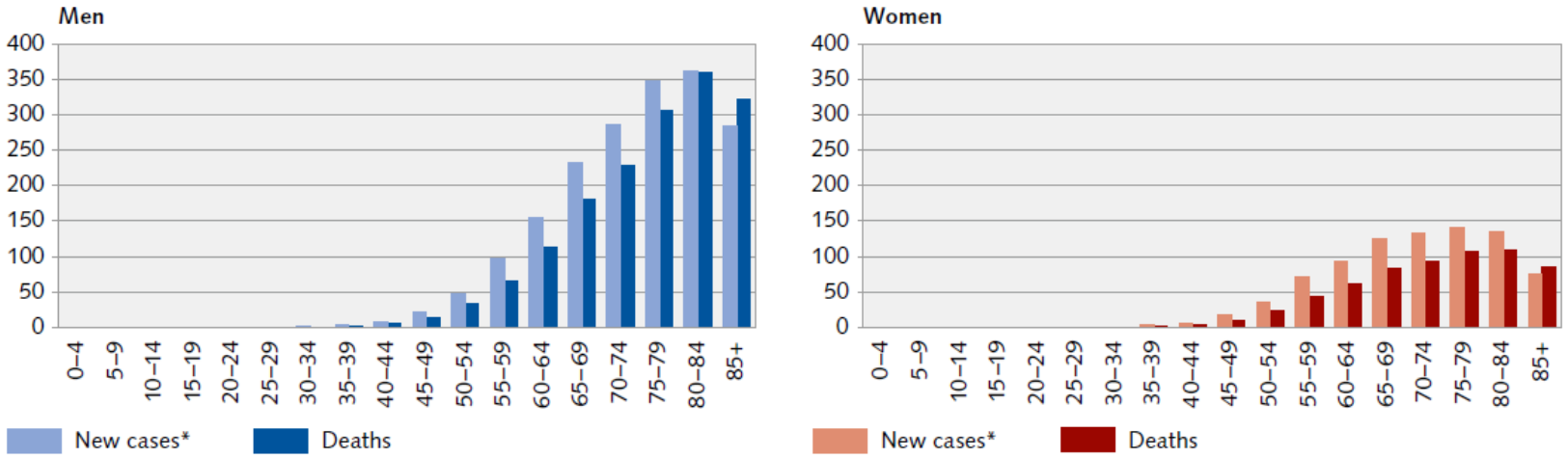
Lung cancer by age, 2008–2012

G 4.8.1

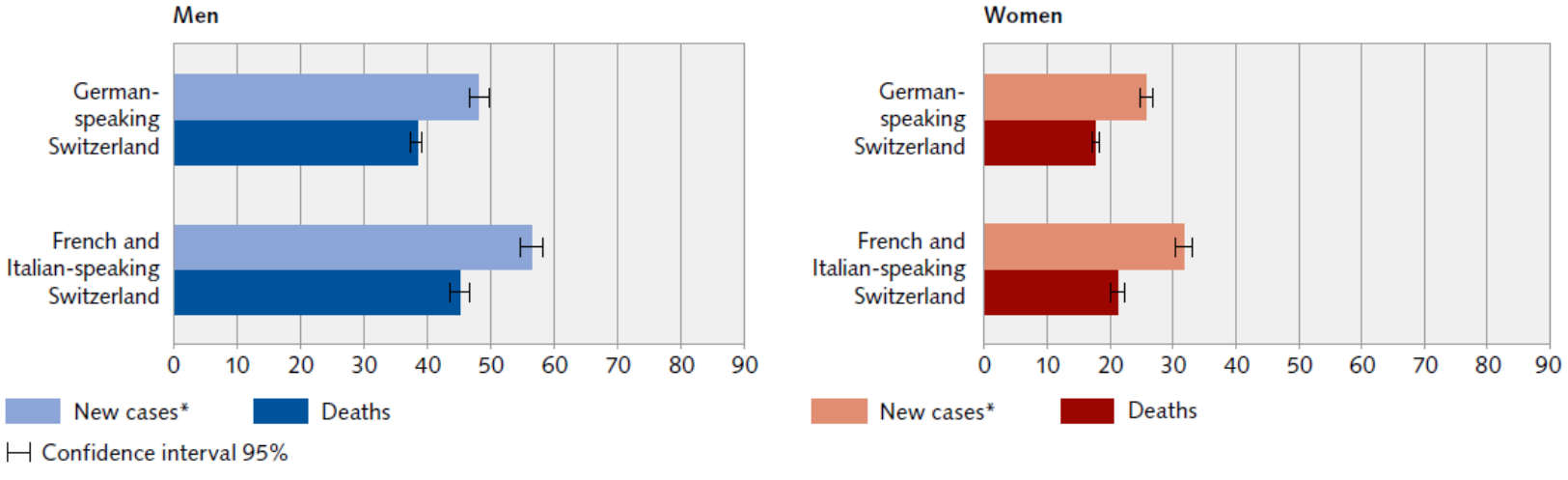
Age-specific rate per 100,000 inhabitants



Lung cancer in regional comparison, 2008–2012

G 4.8.2

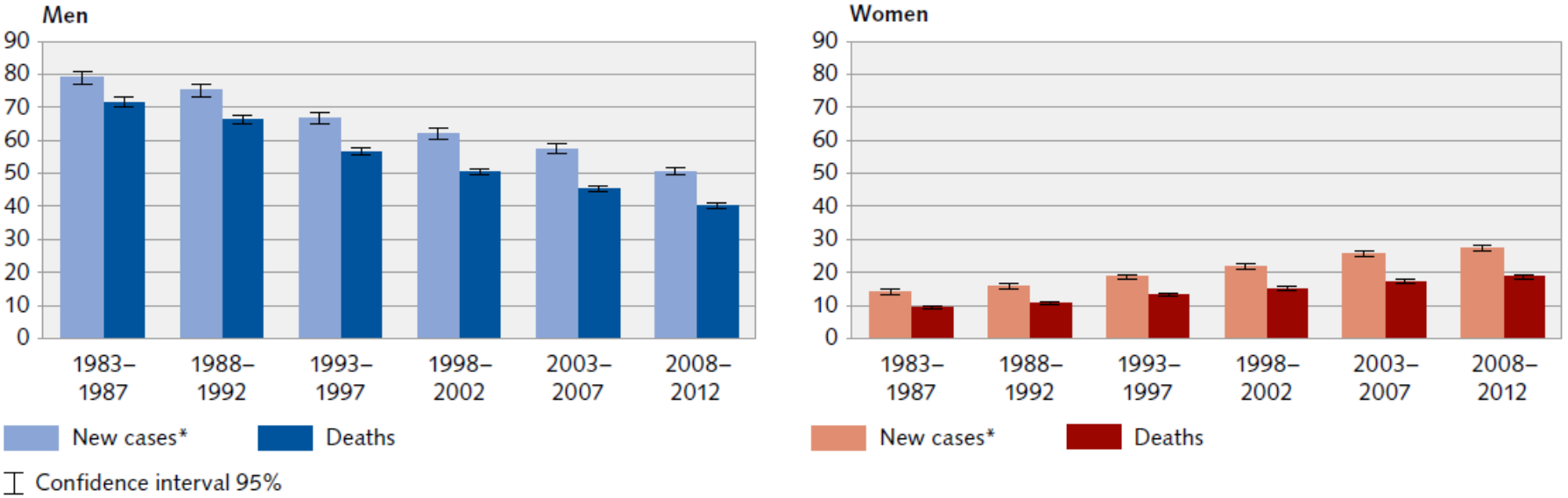
Rate per 100,000 inhabitants, European standard



Lung cancer: Trends over time

G 4.8.4

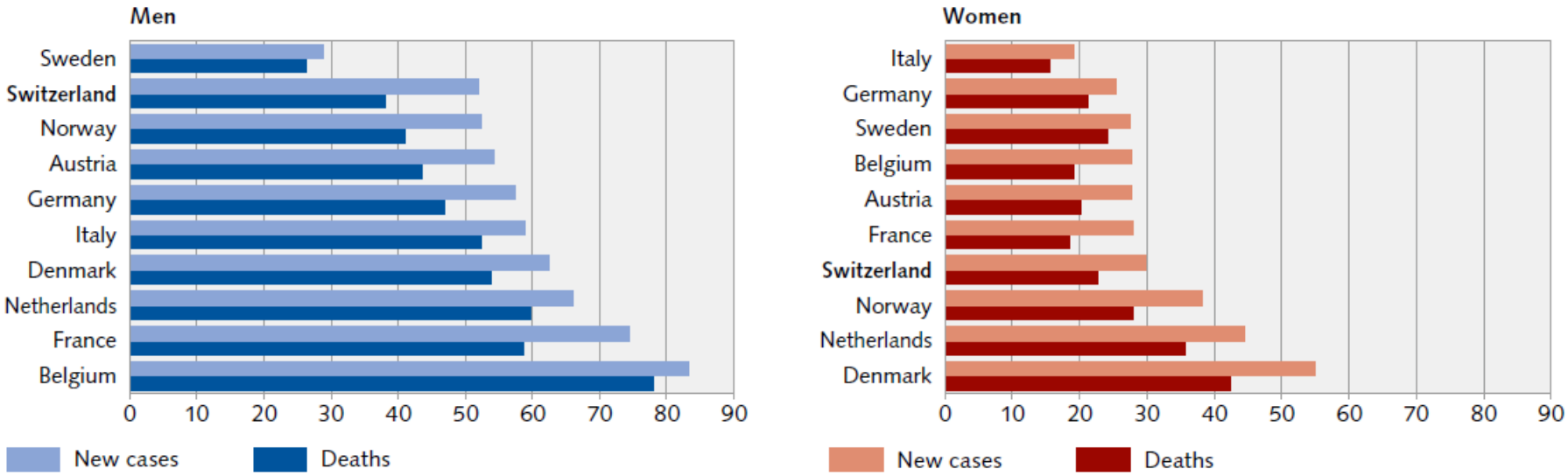
Rate per 100,000 inhabitants, European standard



Lung cancer in international comparison, 2012

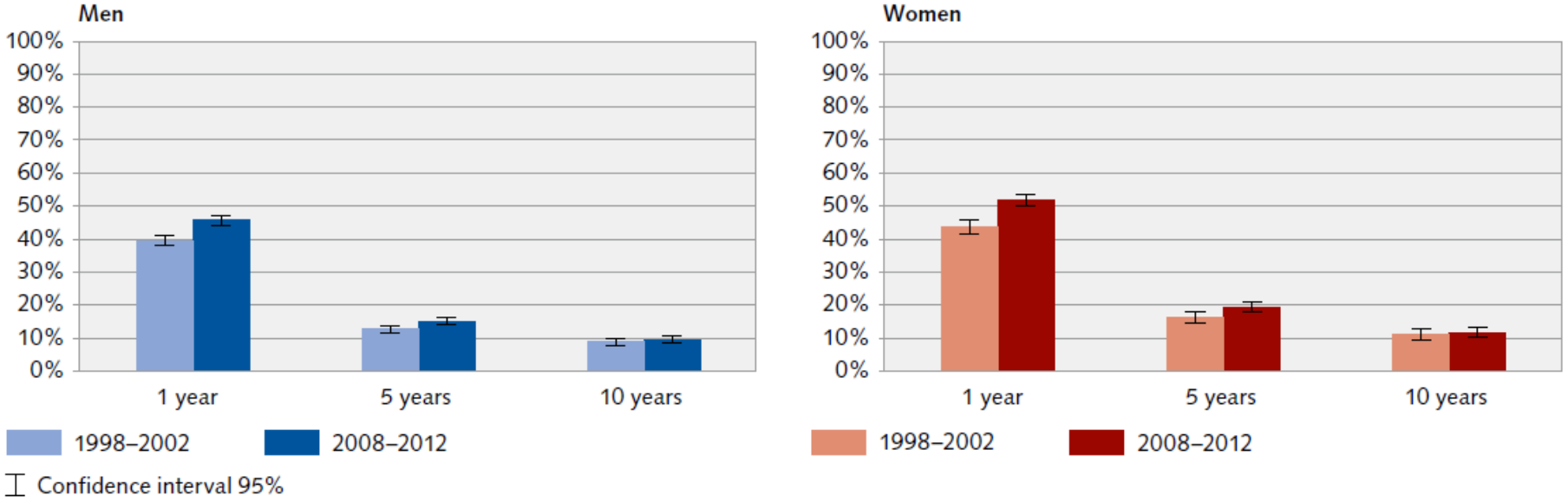
G 4.8.3

Rate per 100,000 inhabitants, European standard



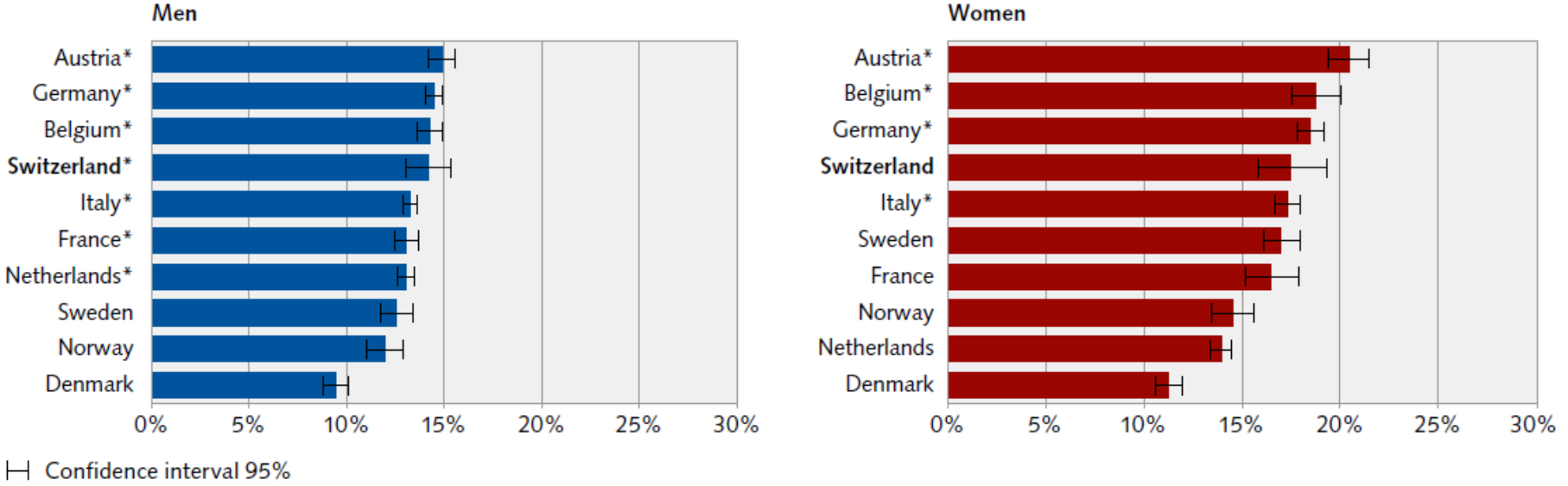
Lung cancer: Relative survival rate after 1, 5 and 10 years

G 4.8.5



Lung cancer: Relative 5-year survival rates in international comparison, 2000–2007

G 4.8.6



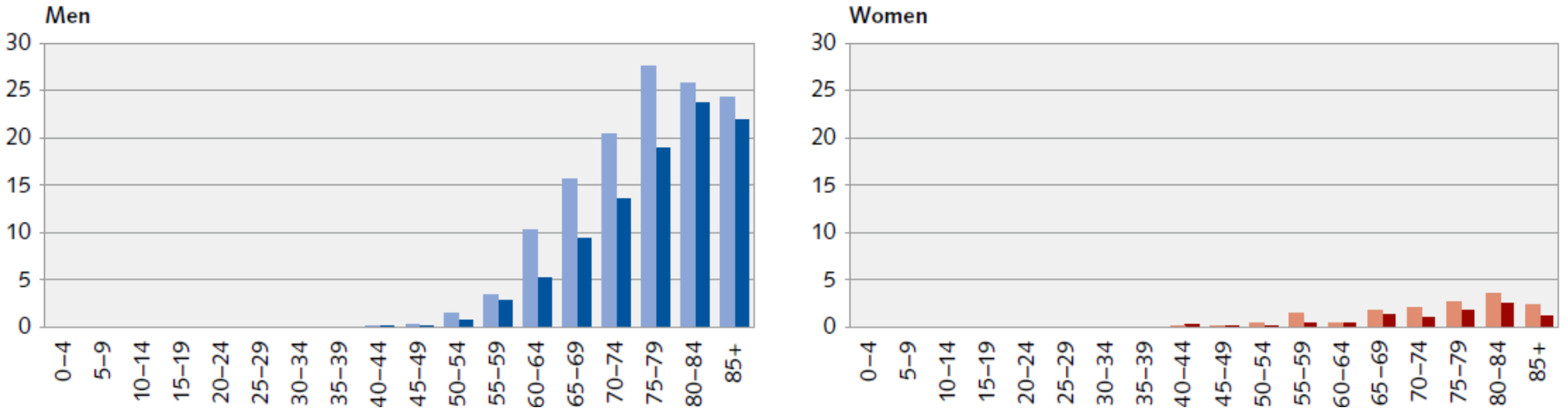
Mesothelioma

180 cases /year

Pleural mesothelioma by age, 2008–2012

G 4.9.1

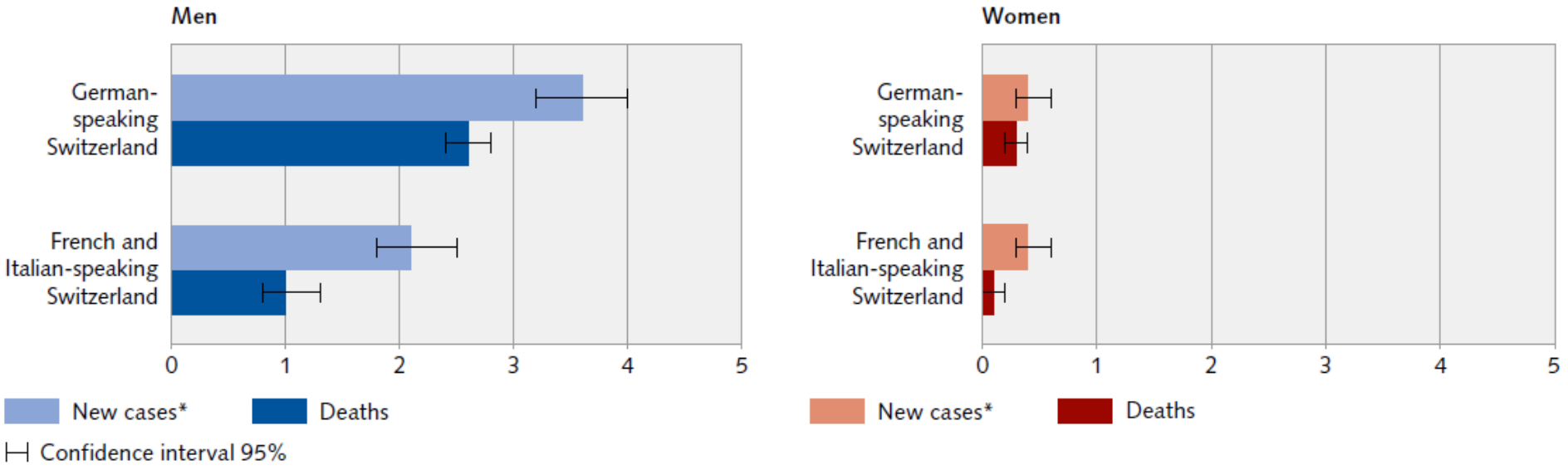
Age-specific rate per 100,000 inhabitants



Pleural mesothelioma in regional comparison, 2008–2012

G 4.9.2

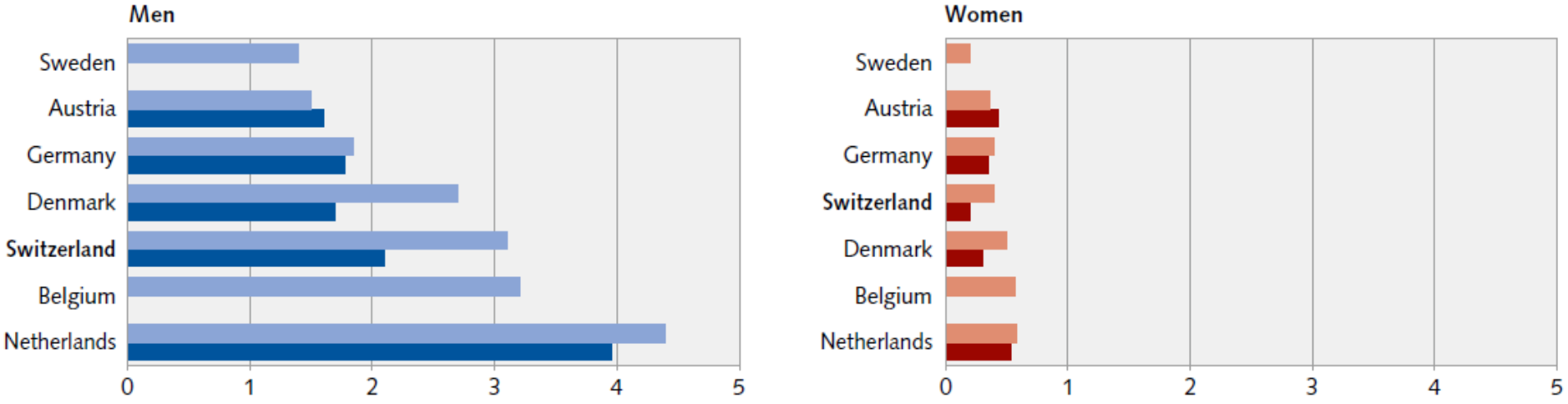
Rate per 100,000 inhabitants, European standard



* New cases estimated on the basis of cancer registry data

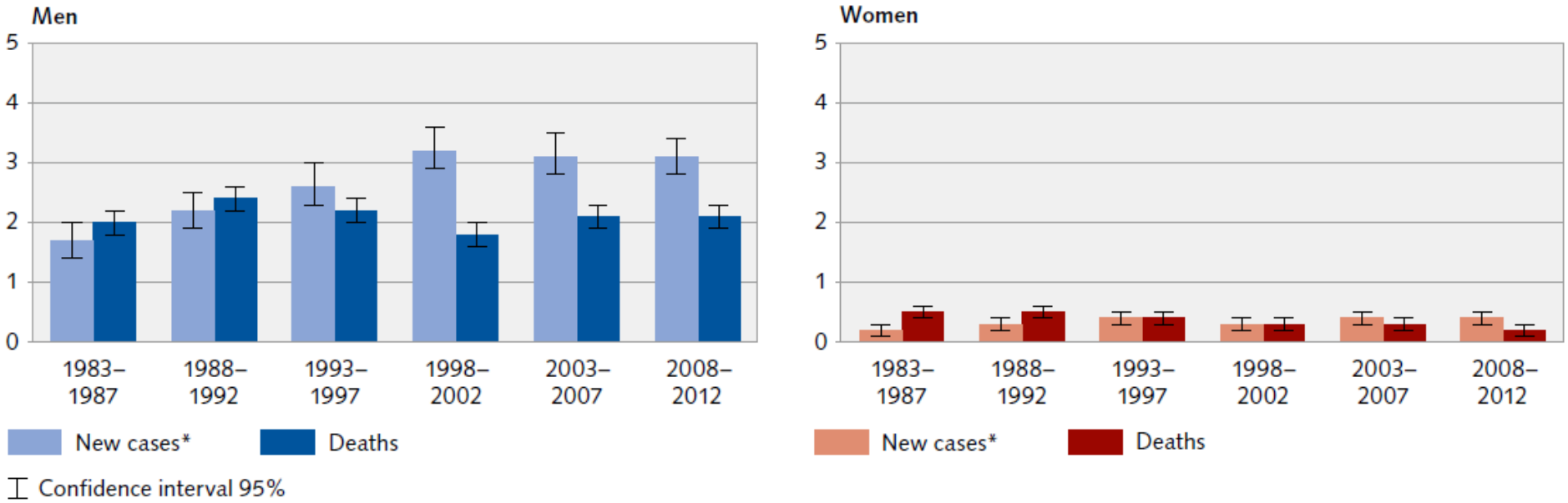
Mesothelioma in international comparison, 2011–2012* G 4.9.3

Rate per 100,000 inhabitants, European standard



Pleural mesothelioma: Trends over time G 4.9.4

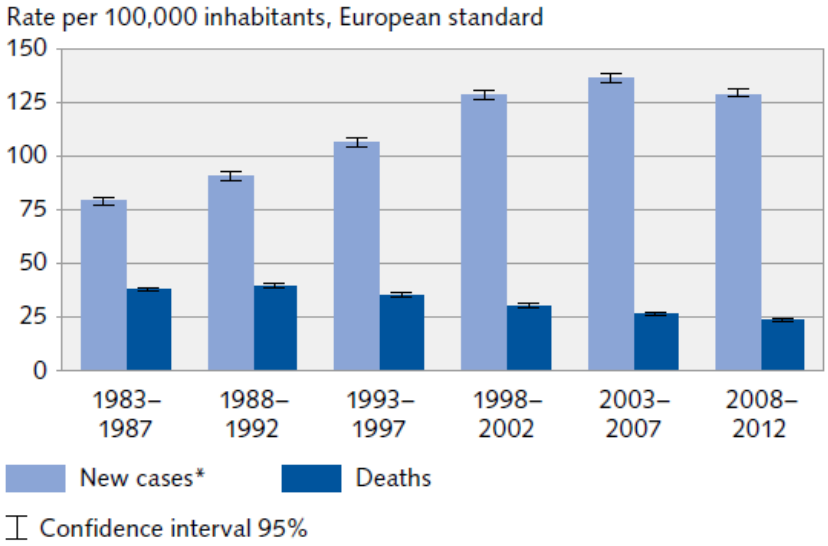
Rate per 100,000 inhabitants, European standard



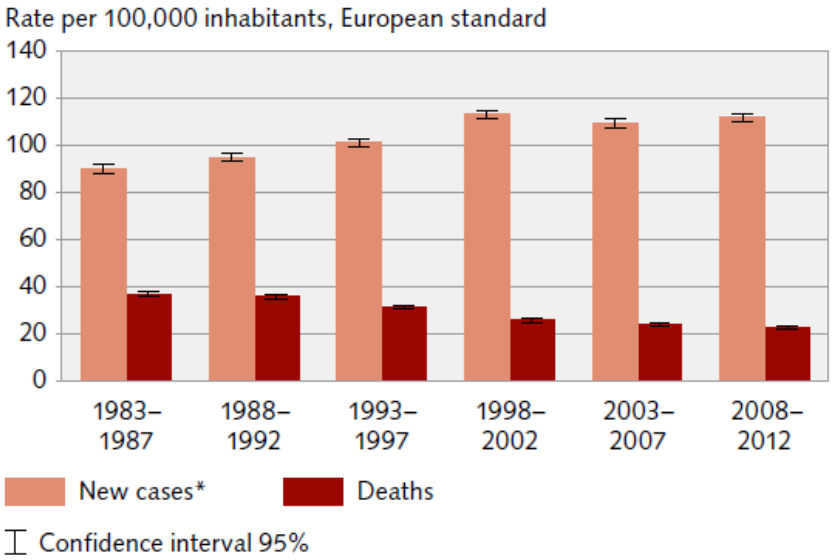
Trends over time and regional comparisons

Selected results

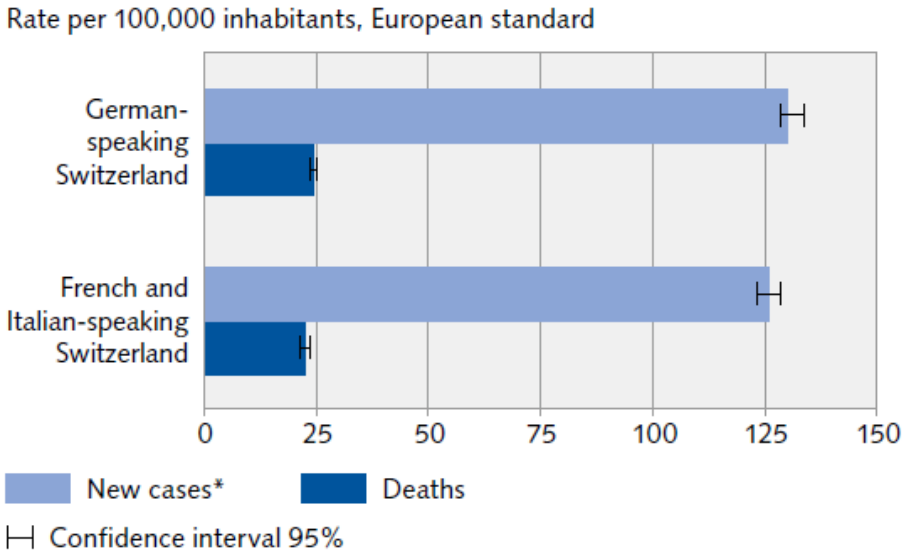
Prostate cancer: Trends over time G 4.14.4



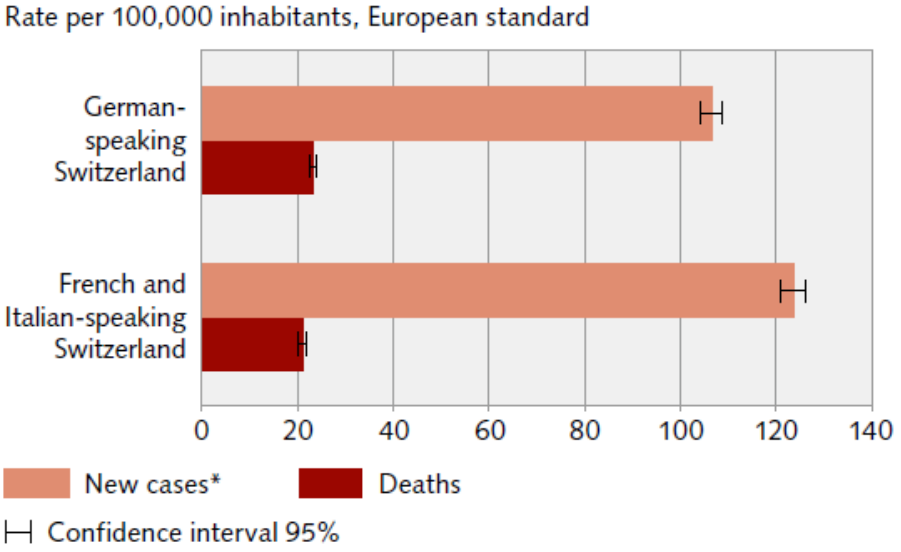
Breast cancer: Trends over time G 4.11.4



Prostate cancer in regional comparison, 2008–2012 G 4.14.2



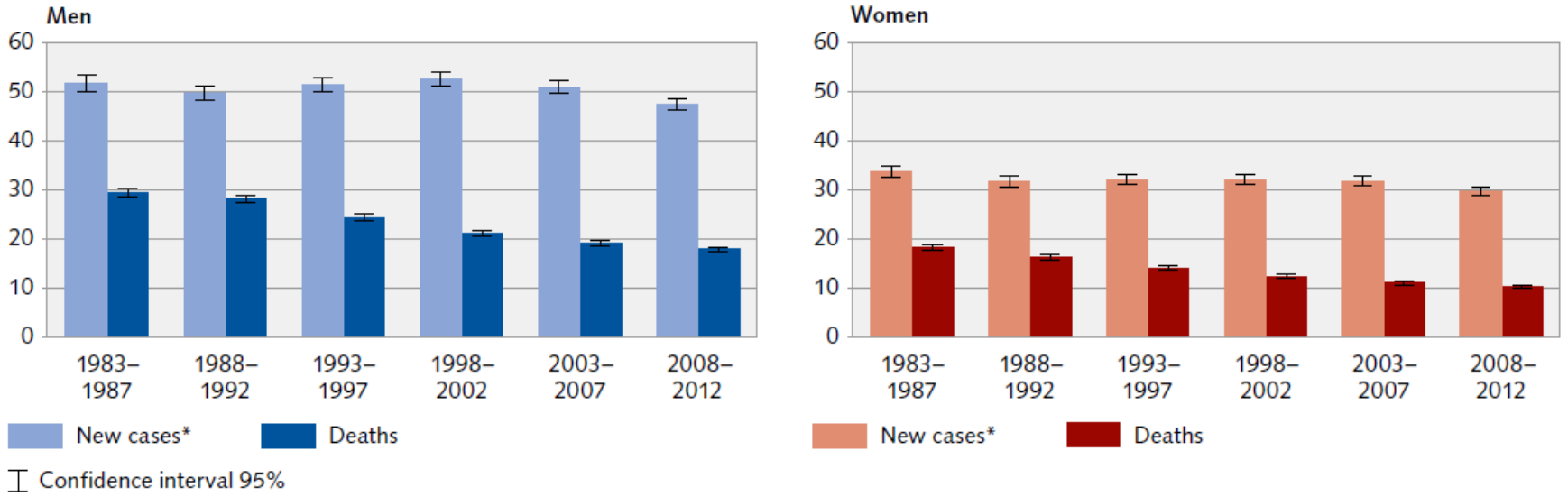
Breast cancer in regional comparison, 2008–2012 G 4.11.2



Colorectal cancer: Trends over time

G 4.4.4

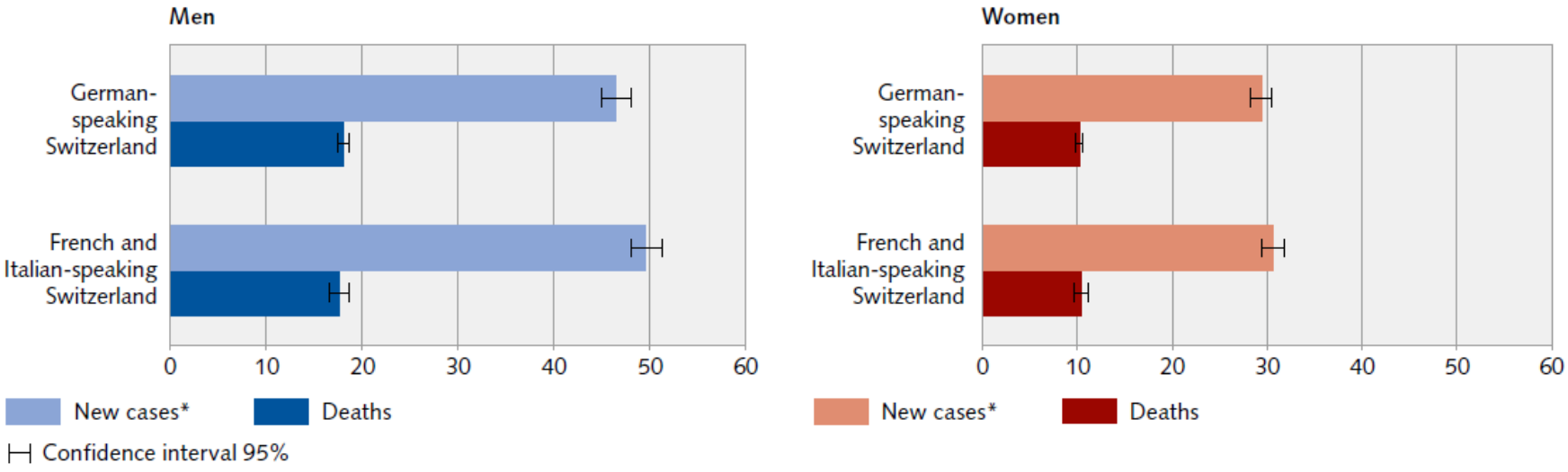
Rate per 100,000 inhabitants, European standard



Colorectal cancer in regional comparison, 2008–2012

G 4.4.2

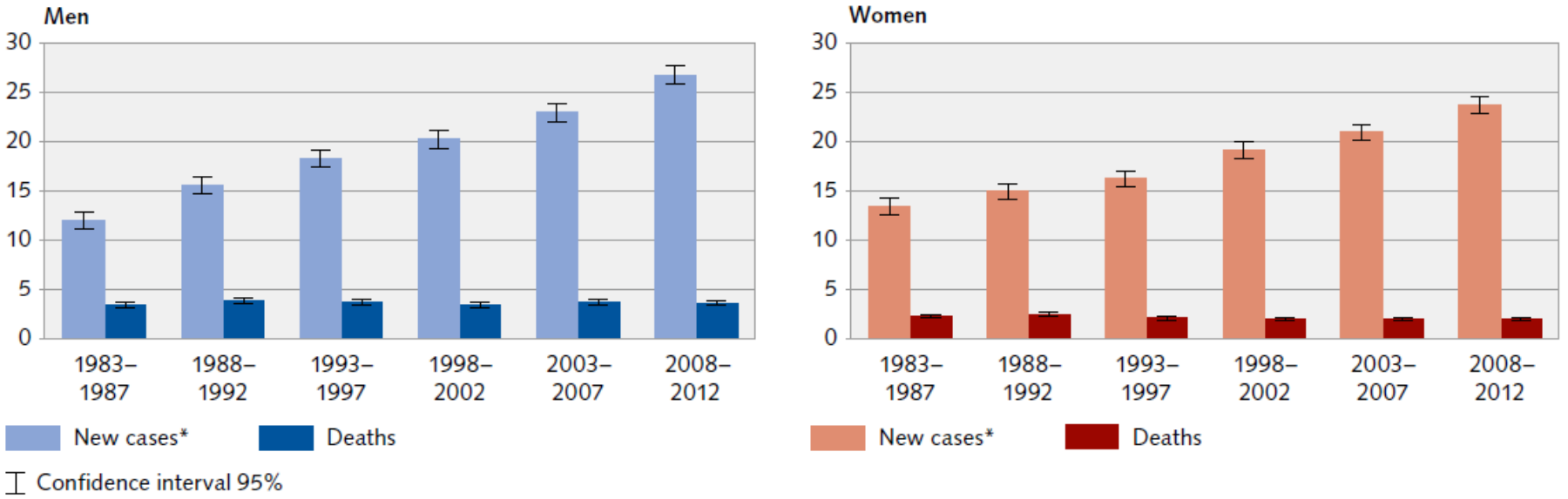
Rate per 100,000 inhabitants, European standard



Skin melanoma: Trends over time

G 4.10.4

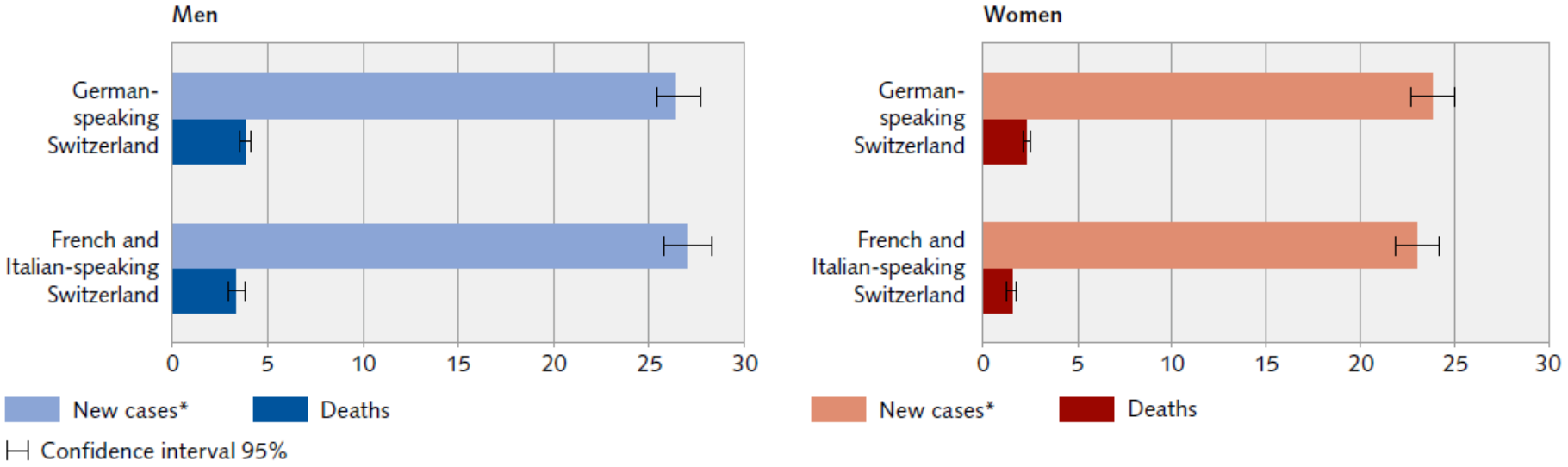
Rate per 100,000 inhabitants, European standard



Skin melanoma in regional comparison, 2008–2012

G 4.10.2

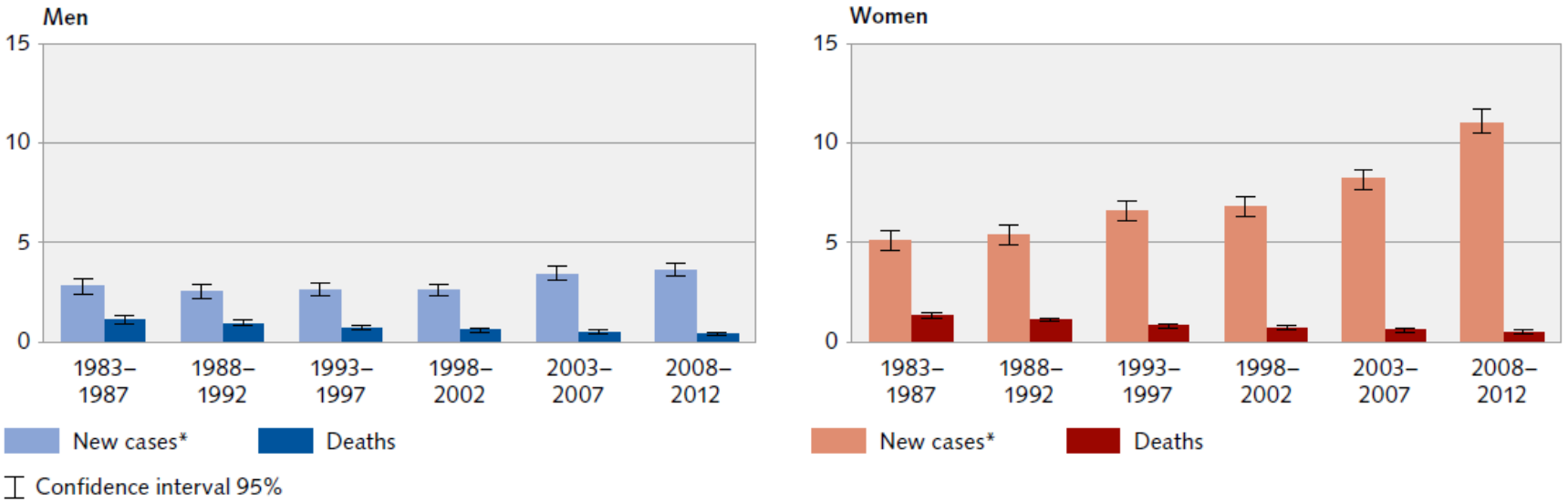
Rate per 100,000 inhabitants, European standard



Thyroid cancer: Trends over time

G 4.19.4

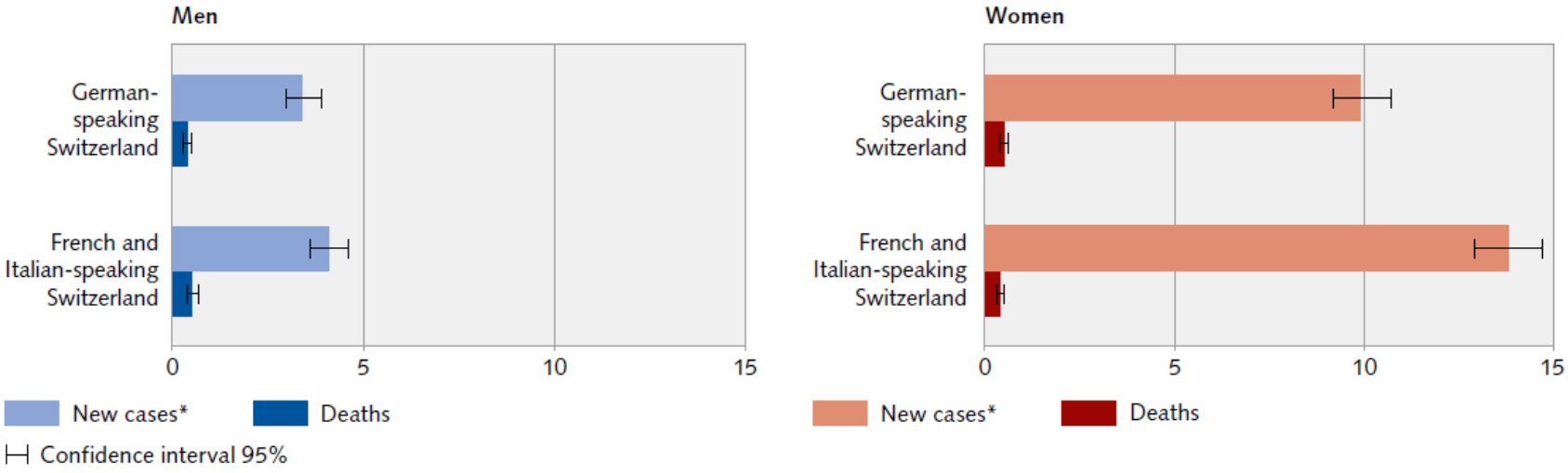
Rate per 100,000 inhabitants, European standard



Thyroid cancer in regional comparison, 2008–2012

G 4.19.2

Rate per 100,000 inhabitants, European standard



Swiss Cancer Report 2015 - Summary

- Over 40’000 new cases and 17’000 deaths per year
- Numbers will increase due to demograohic ageing
- Mortality rates had been declining
- Cancer risk is comparable to other European states
- Regional variation exist which deserve further attention

Research activities & Data request

Ongoing Research Projects
(Initiated by NICER or in collaboration)

- Trends in survival series (age, gender, stage)
- Trends in incidence (by age, gender, stage, region)
- Mammography screening and breast cancer incidence
- Thyreoid cancer incidence
- Epidemiology of myelodysplastic syndrome (MDS)
- Pattern of care studies
  - Prostate Cancer
  - Elderly patients with gastrointestinal cancer
- Prostate cancer survivorship
- SNC Linkage study
- Risk of multiple primaries

nicer
Foundation
National Institute
for Cancer Epidemiology
and Registration

Cancer incidence
Cancer mortality
Cancer prevalence
Cancer survival

How to request simple statistics
Previous Requests

How to request simple statistics

The NCC wants to share the anonymized data in the central cancer database with eligible partners. If you wish to get simple statistics from the NICER database, please complete the respective form with some defined user-specified criteria:

REQUEST FOR SIMPLE CANCER STATISTICS

Requestor information

Name *

Phone *

Institution *

Email *

Project information

Project Title *

Are any follow-up requests anticipated? *

Yes
No

Date information is needed by *

Please state intended use(s) of the statistics Will data from this request be used for public or private purposes? (please see fee structure below) *

If yes, please specify

30-40 requests per year: Examples from 2016

- Support CONCORD-3 data submission (all-cause mortality and population counts)
- Prognosis Stage IV renal cell cancer in Switzerland
- Gebärmutterhalskrebs ist in der Schweiz bei Frauen zwischen 20 und 49 Jahren
- Stage specific breast cancer incidence among Swiss population
- Gliomainzidenz-Trend 1989-2013 in der Schweiz
- Mortality calculations Haemacare groups based on updated icd-codes
- Inzidenz Vulva- und Vaginaltumore
- Completeness civil status, pathological tumour size, lymph node information for RNJT
- Anzahl Neuerkranken und Todesfälle pro Geschlecht und Krebsart für 2009-2013
- Leukämien und Lymphome
- Calculation of rates for cancer screening evaluation
- Survival haemacare groups
- Incidence, Mortality and Survival of haematological cancers
- Angiosarcoma of the breast, code thorax (C49.3)
- CLL Incidence and Prevalence
- Zunahme Inzidenz Uterine Sarkome
- Global Time Trends in Incidence of Esophageal Squamous Cell Carcinoma
- Entwicklung der Mortalität und Überlebensrate bei Brust- bzw. Hodenkrebs
- Häufigkeit der Strahlentherapie von Lungenkrebs in der Schweiz

The „new“ cancer registration act

Cancer Registration in CH
The current status

- Federal structure of system
- Legal basis for systematic CR is lacking
- Right to deliver data, but no obligation
- Incomplete coverage
- Cantonal heterogeneities
- Difficult access to population control data
- Only few data collected concerning treatment and disease progression

The „new“ federal cancer registration act (March 2016)

- Mandatory reporting
- Mandatory core data set
- Harmonization (top down)
- Linkage with vital status and death statistics
- Clincal data (linkage, e-dossiers?)
- Identification of duplicate records
- Withdrawals

Cancer registration act - Purpose

- Monitoring of cancer in Switzerland
- Planning, implementation and evaluation of prevention/public health programmes
- Evaluation of Quality of care/diagnosis
- Support for health care planning

Research and the new law?

- Linkage with external data, e.g. cohorts, surveys, other existing data bases?
- Reidentification for supplementary data and case control studies?
- Catalog of core variables (e.g. risk factors, treatment, additional outcome variables (PROs)?

Schedule

- Consultation process by-laws: early 2017
- Adaptations of cantonal laws 2017/18
- New law entering into force: 1.1.2019

Conclusions

- Harmonized data base
- Monitoring will improve
- Basic data set without profession/risk factors
- Not permissive for research