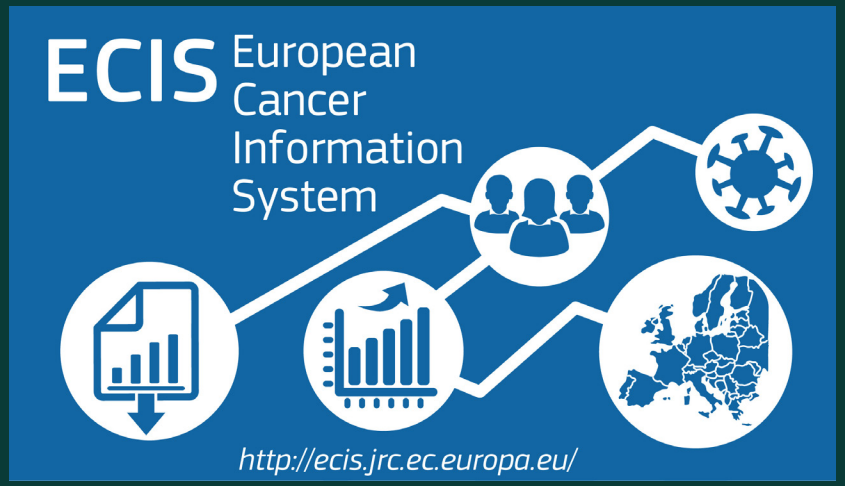
The European Commission's science and knowledge service

Joint Research Centre

European Commission

Measuring the cancer burden:
the European Cancer Information System



ENCR
European Network
of Cancer Registries

Manola Bettio

European Commission, Joint Research Centre (JRC)

11th European Public Health Conference, pre-conference Workshop, Ljubljana, 28 November 2018
Navigating the international health information databases: unravelling the processes behind the numbers

European Commission

ECIS: European Cancer Information System

EC Initiative requested by Council of the EU, endorsed by EP and coordinated by EC's Joint Research Centre

TO PROVIDE TIMELY COMPARABLE DATA ON CANCER BURDEN

- evidence for development and monitoring of policies to prevent and treat cancer
- resource for epidemiological research
- promotion of citizens empowerment

OUR QUESTION

What is the burden of cancer in Europe?

- Cancer registries are the data source
- EC contribution: harmonisation of data and registration processes, collection, analysis and dissemination of cancer burden indicators

ENCR
European Network of Cancer Registries

European Commission

Towards a European Cancer Information System

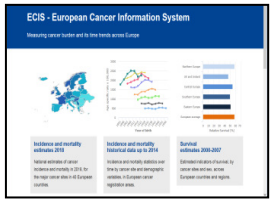
State of the art of cancer registration in Europe

1990 – – – – – – · 2012 – – – – – – – – – – – – – – – – 2015 – – – – – – – – – – – · 2018 – – – – –

ENCR
European Network of Cancer Registries

- mapping of European CRs, registration processes, needs
- guidelines, recommendations, trainings aimed at harmonisation

- set up of a European dataset for several studies/projects
- streamlining data submission and data-usage processes
- development of tool to disseminate statistics on cancer burden



INCIDENCE
MORTALITY
SURVIVAL

statistics over time across Europe

https://ecis.jrc.ec.europa.eu

ENCR
EUROPEAN NETWORK OF CANCER REGISTRIES
ENCR Secretariat
International Agency for Research on Cancer
World Health Organization

European Commission

Components of the ECIS

- ✓ 2015 data call
- ✓ Ad-hoc portal for data submission
- ✓ Databases to store and manage data
- ✓ Common procedures for cancer data quality
- ✓ Harmonised data validation tools
- ✓ ECIS web-application

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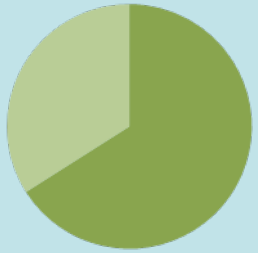
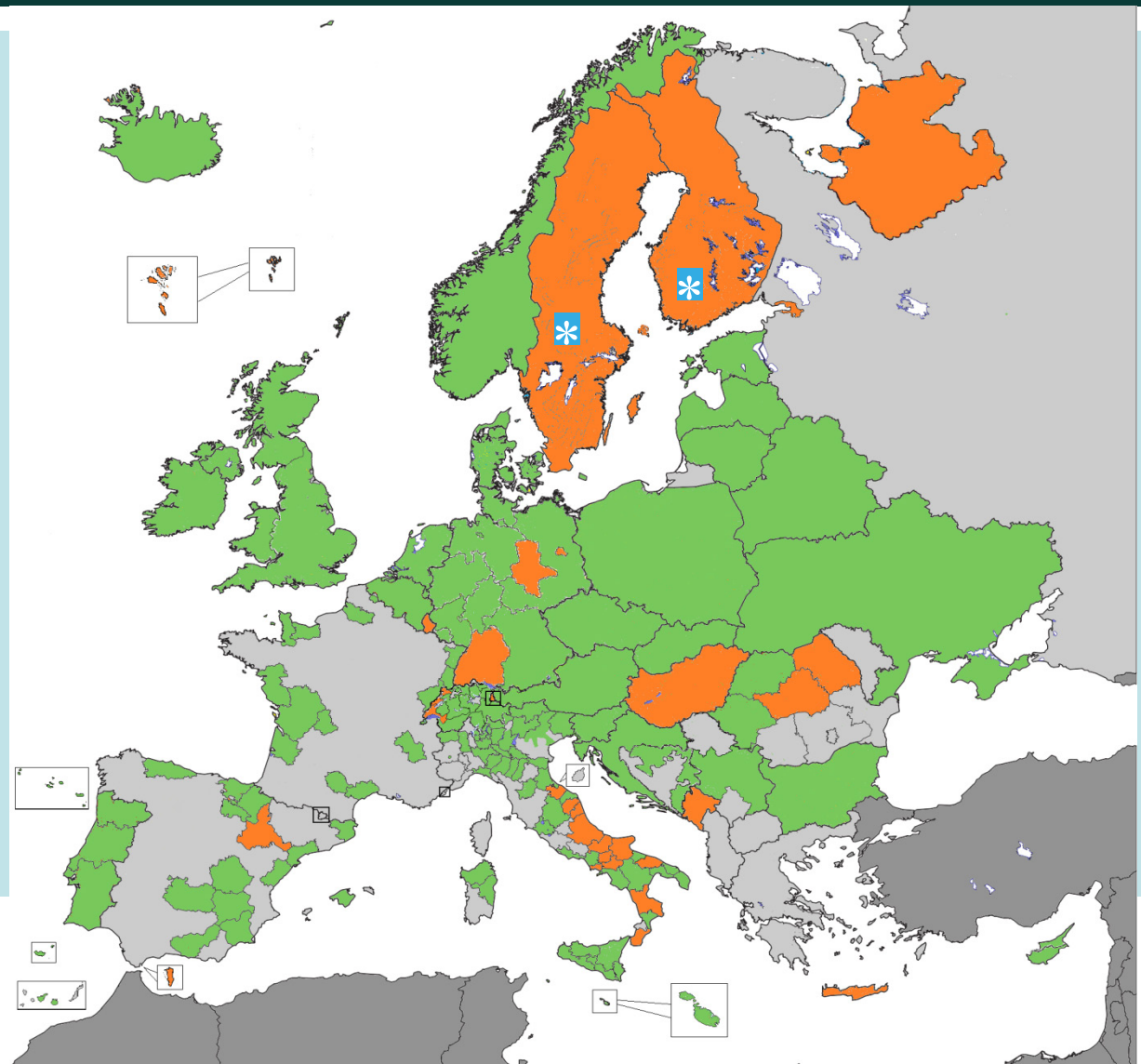
Where do the data come from?
2015 data call, ENCR-JRC project

149 CRs from 34 European countries

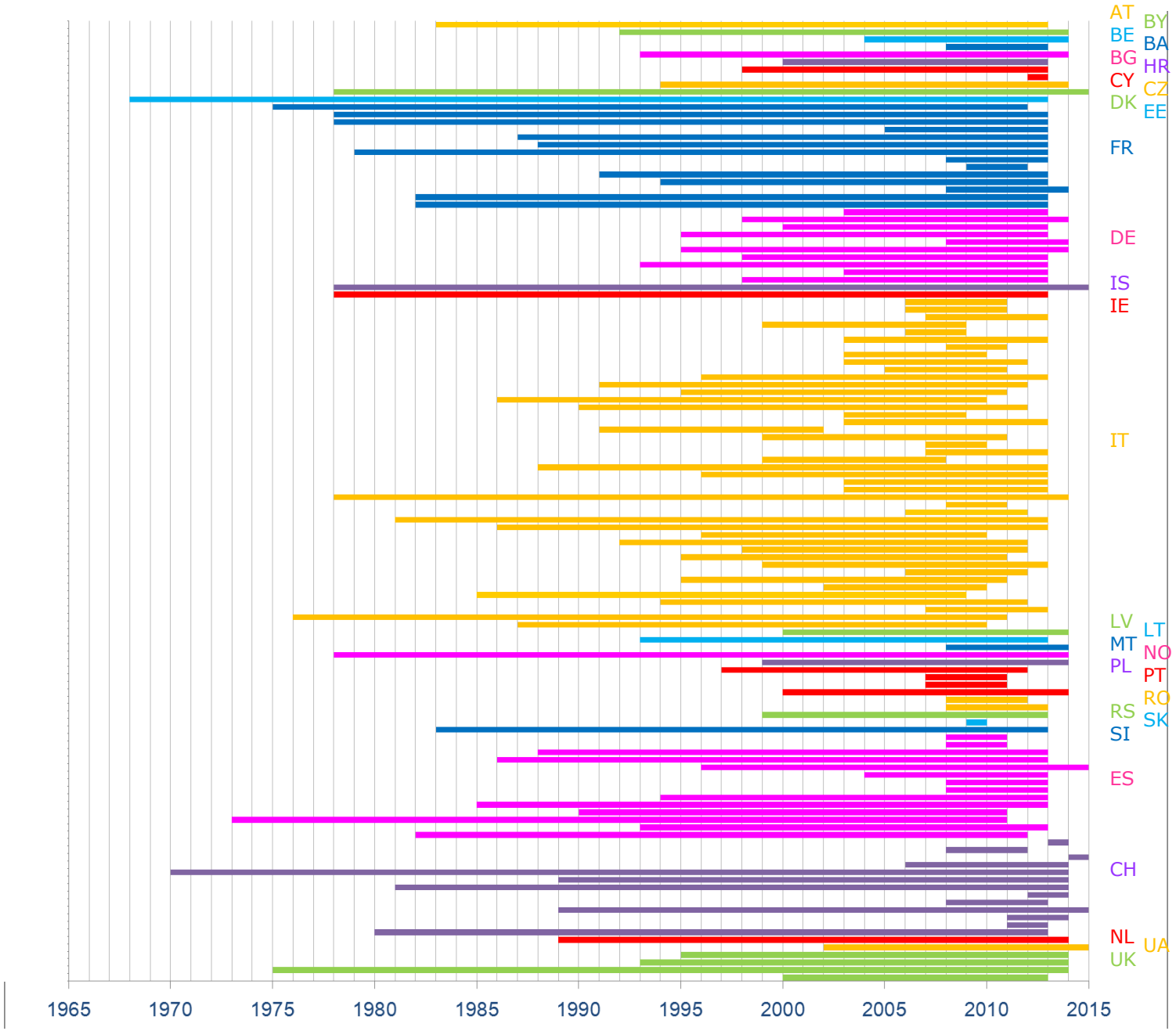
more than 34,500,000 records in the database

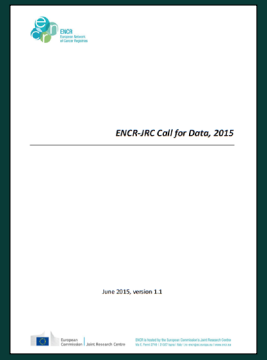


Covering about 60% of the EU/EFTA population



Submitted time periods





The data call protocol

- **Cancer case file**
  - *56 variables - 21 core*
- Population file
- Mortality file
- Life table
- Questionnaire

INCIDENCE

- ENCR-JRC project
- *Cancer Incidence in Five Continents (IARC)*

MORTALITY

- ENCR-JRC project

SURVIVAL

- EUROCARE 6
- *CONCORD*

Table 1.Variable number, name, description, format, core/additional, missing/unknown values and coding schema

These variables should be separated by a semi-colon.

Variable name	Variable description	Format	Maximum length	Core	Missing /unknown values	Coding
1_Flag	Check flag	F	1	Y	Not allowed	0 → Not checked 1 →Checked
2_Patient_ID	Patient identification code	A	50	Y	Not allowed	According to registry coding
3_Tumour_ID	Tumour identification	A	50	Y	Not allowed	According to registry coding
4_Day_DoB	Day of birth	F	2	Y	99	Range of allowed values: From 1 to 31
5_Month_DoB	Month of birth	F	2	Y	99	Range of allowed values: From 1 to 12
6_Year_DoB	Year of birth	F	4	Y	9999	Range of allowed values: > 1842 and ≤ the current year
7_Sex	Sex	F	1	Y	9	1 →Male 2 → Female 3 →Other
8_Day_DoI	Day: date of incidence	F	2	Y	99	Range of allowed values: From 1 to 31
9_Month_DoI	Month: date of incidence	F	2	Y	99	Range of allowed values: From 1 to 12
10_Year_DoI	Year: date of incidence	F	4	Y	Not allowed	Range of allowed values: > 1941 and ≤ the current year
11_Age	Age at diagnosis (incidence date) in years	F	3	Y*	999	Range of allowed values: ≥ 0 and < 121
12_BoD	Basis of diagnosis	F	1	Y	9	0→Death certificate only (DCO) 1→Clinical 2→Clinical investigation 4→Specific tumour markers 5→Cytology 6→Histology of a metastasis 7→Histology of a primary tumour

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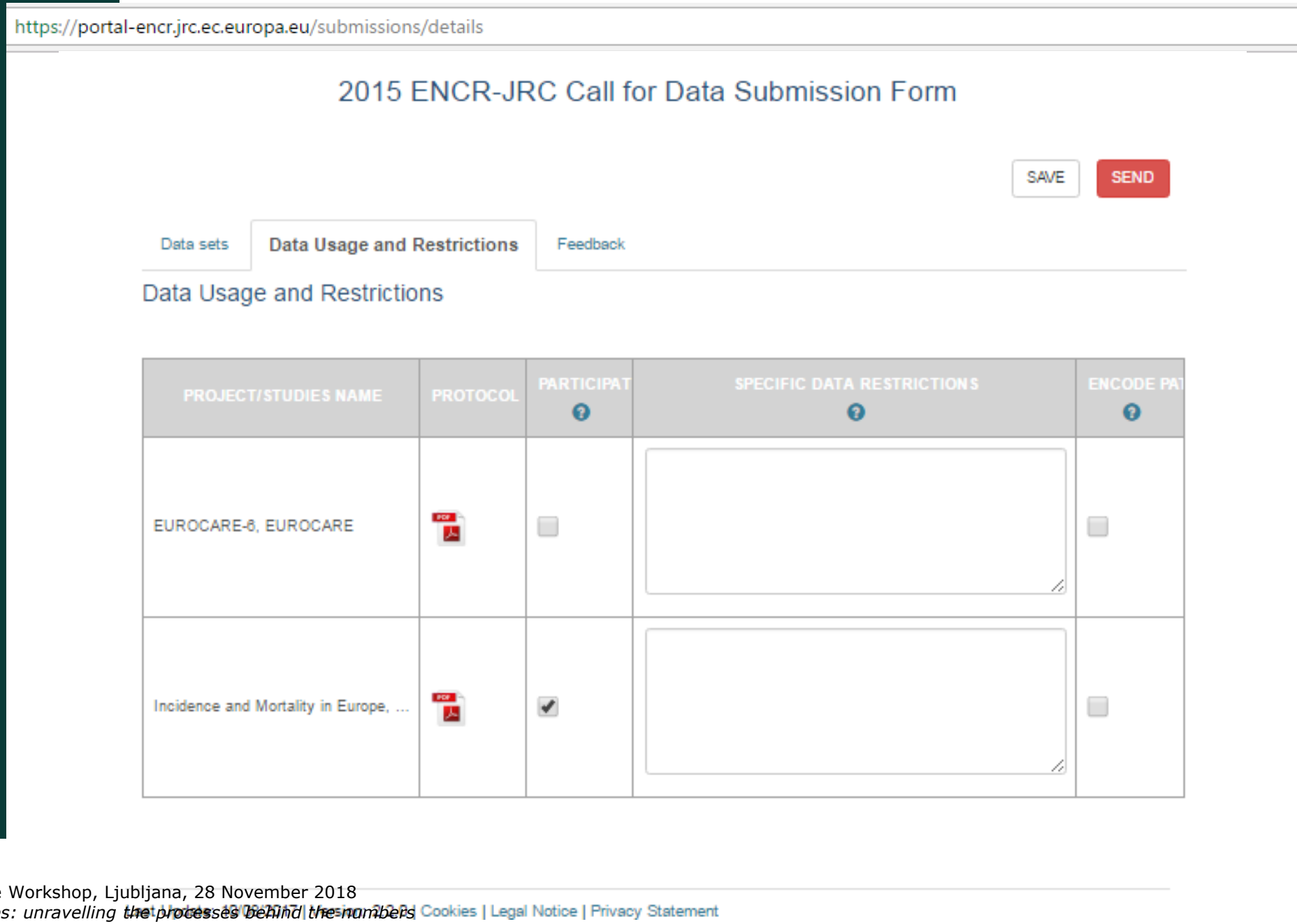
The portal for data submission



Towards harmonization of cancer registry quality checks

2013-2014

agreement on common protocols to meet standards required by European and international projects

The JRC-ENCR quality checks software

to validate cancer registry data and improve **quality** and **comparability**

- 2016 first release
- revision and finalisation, including MPT checks 2018

European Commission

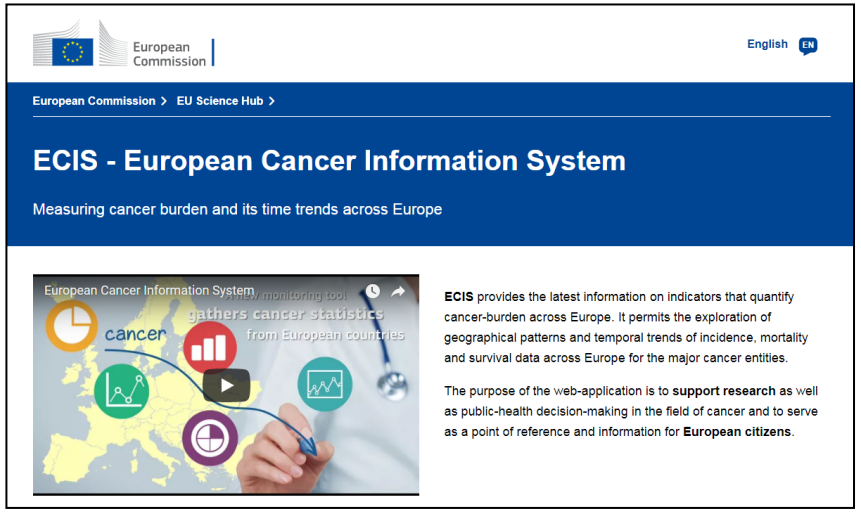
Data dissemination

- ✓ Public launch on 05 February 2018 (World Cancer Day)
- ✓ incidence and mortality historical data up to 2014
- ✓ survival for cases diagnosed 2000-2007 and followed up to 2008
- ✓ national 2018 incidence and mortality estimates

The ECIS web-application

https://ecis.jrc.ec.europa.eu

First step to a single quality-controlled information system integrating all relevant data in a systematic and continuous way

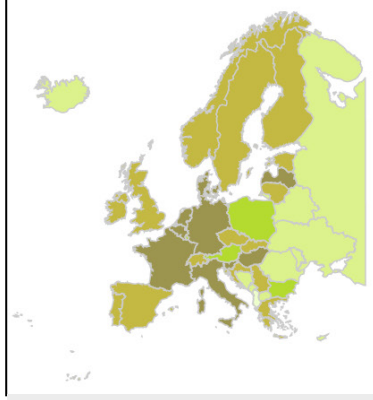


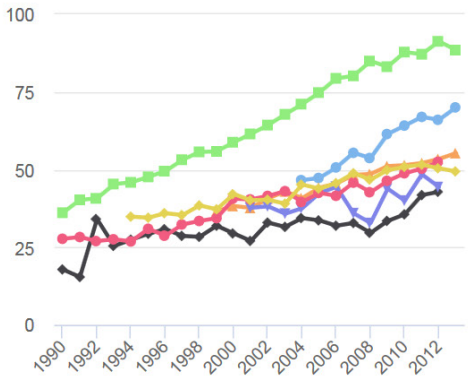
European Commission

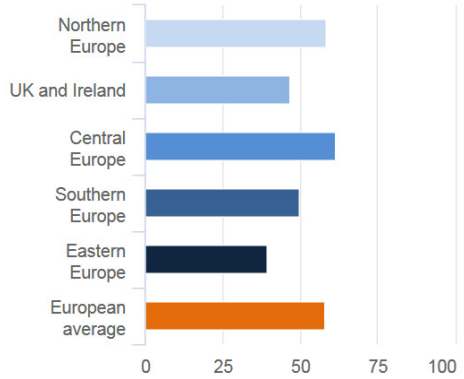
European Commission > EU Science Hub > ECIS

ECIS - European Cancer Information System

Measuring cancer burden and its time trends across Europe







2018 incidence and mortality estimates

- 40 European countries
- 34 cancer sites
- Collaboration IARC/IACR/JRC/ENCR

Historical incidence and mortality up to 2014

- 34 European countries
- 149 Cancer Registries
- 58 cancer sites
- ENCR-JRC project

Survival estimates

- 26 European countries
- 99 Cancer Registries
- 46 cancer sites
- EUROCARE-5 study

The ECIS database and the data providers

Rationale for the ECIS

The history and purpose of the European Cancer Information System.

The population-based cancer registries

The data providers, enabling the computation of cancer burden statistics.

ECIS contributing initiatives and studies

The studies and projects reporting on European cancer registry data.

ECIS database description

The contributing cancer registries, including the available periods and statistics.

Cancer sites definition

The list and description of cancer sites for each study and project in the ECIS.

Glossary

The specific terminology and/or acronyms used across the ECIS web-application.

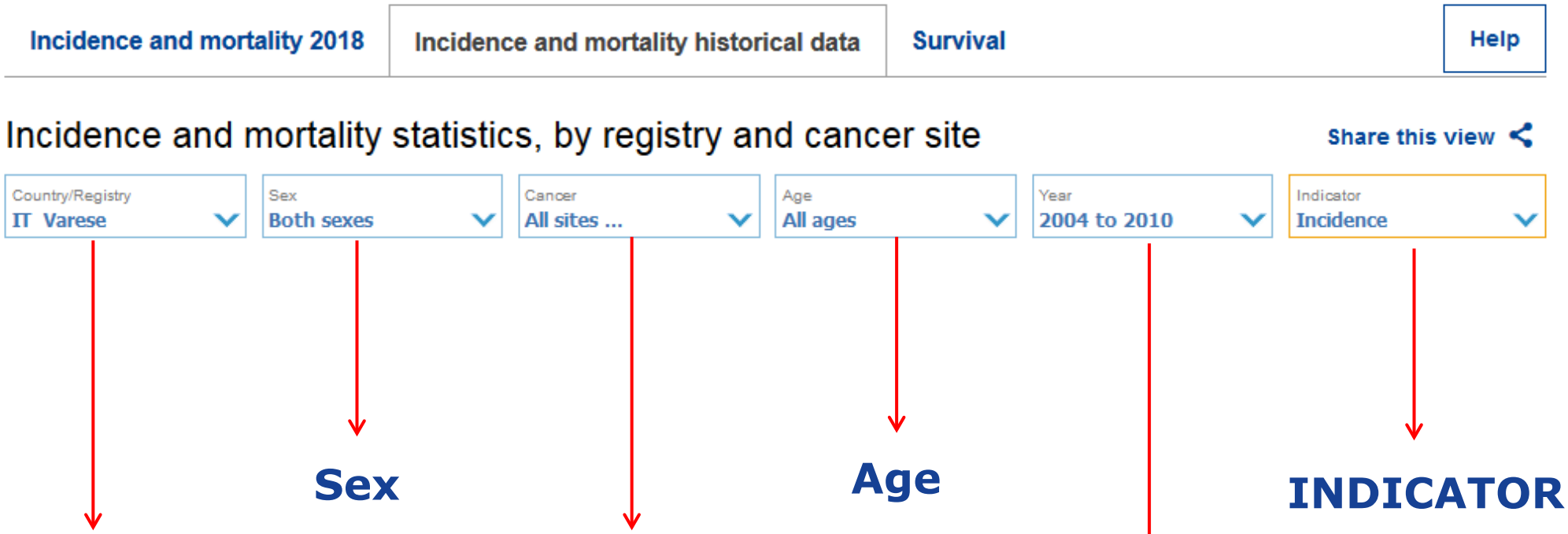
Acknowledgements

European Network of Cancer Registries

EUROCARE

International Agency for Research on Cancer

Three initiatives – same navigation structure



Geographic area

Sex

Cancer site

Age

Time of incidence/ mortality

INDICATOR

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ESTIMATES 2018 – all countries

Estimates of cancer incidence and mortality in 2018, for all countries

Share this view

Country/Region	Sex	Cancer	Age	Year	Indicator
By country	Both sexes	All sites but non-mela	All ages	2018	Incidence

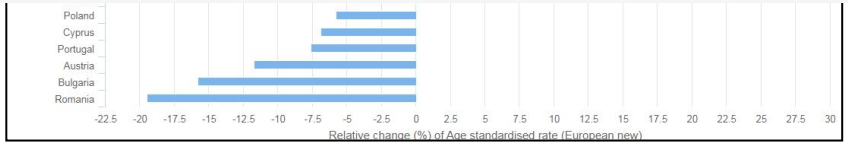
Estimated incidence by country

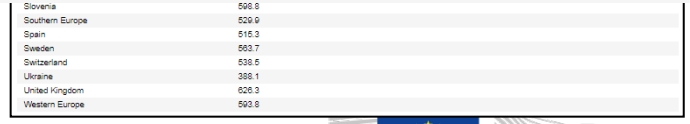
Estimated incidence by country - comparison with Europe

Estimated incidence by country - summ

Both sexes, All sites but non-melanoma skin

Country	Number of cases	Crude rate	ASR (European new)	ASR (European old)	ASR (world)
Albania	8020	273.3	334.1	236.3	169.1
Austria	42318	483.5	469.6	329.6	235.1
Belarus	41048	434.3	476.7	351.4	254.9
Belgium	72088	626.9	638.0	451.0	322.5
Bosnia and Herzegovina	13987	399.2	416.8	300.3	215.3
Bulgaria	33778	480.0	447.6	325.7	234.8





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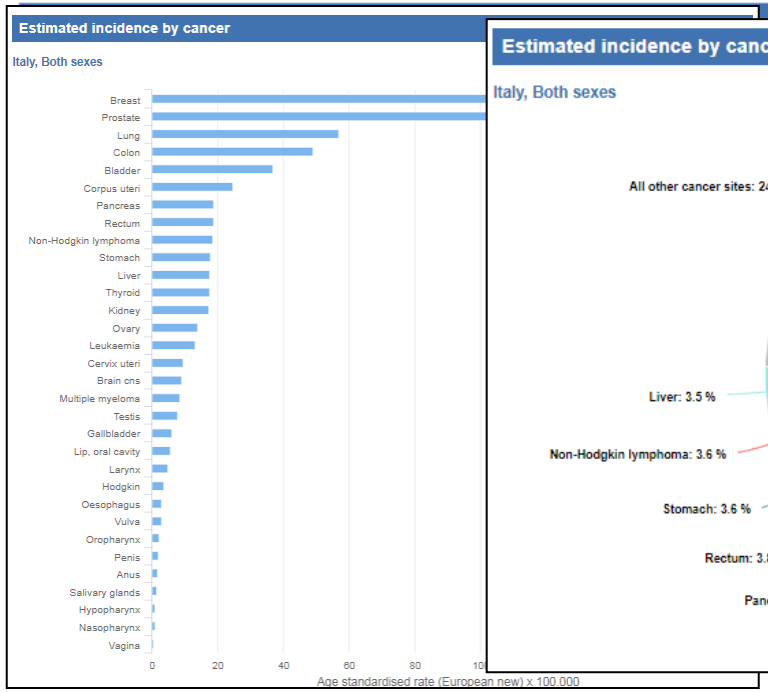
ESTIMATES 2018 – all cancers, ITALY

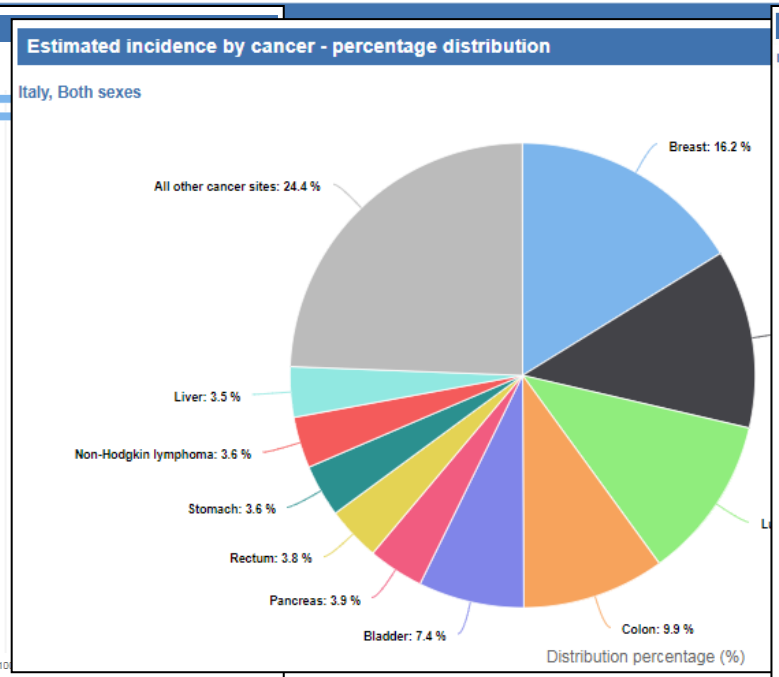
Incidence and mortality 2018 | Incidence and mortality historical data | Survival | Help

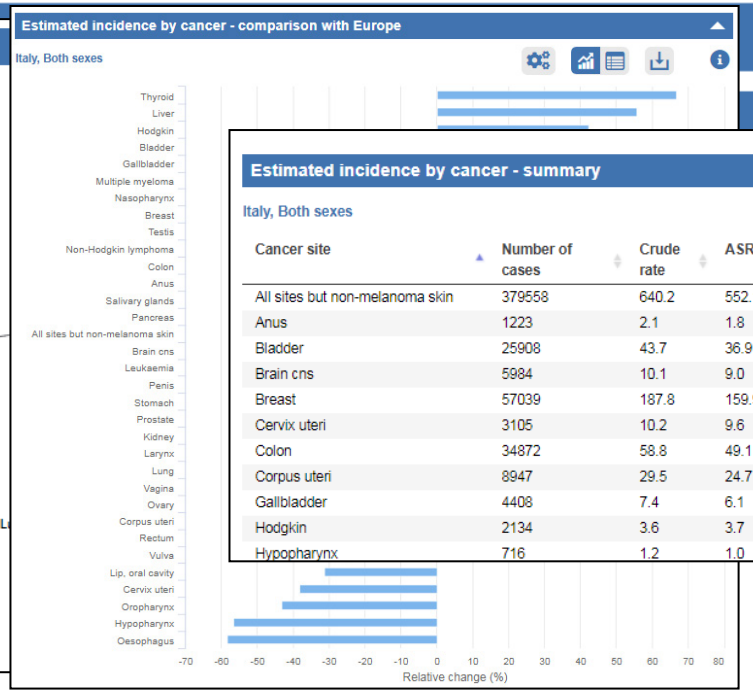
Estimates of cancer incidence and mortality in 2018, for all cancer sites

Share this view

Country/Region: Italy | Sex: Both sexes | Cancer: By cancer | Age: All ages | Year: 2018 | Indicator: Incidence







Estimated incidence by cancer - summary

Italy, Both sexes

Cancer site	Number of cases	Crude rate	ASR (European new)	ASR (European old)	ASR (world)
All sites but non-melanoma skin	379558	640.2	552.1	387.0	277.0
Anus	1223	2.1	1.8	1.2	0.8
Bladder	25908	43.7	36.9	23.6	15.9
Brain cns	5984	10.1	9.0	7.1	5.7
Breast	57039	187.8	159.9	125.4	92.8
Cervix uteri	3105	10.2	9.6	8.7	7.1
Colon	34872	58.8	49.1	31.0	20.6
Corpus uteri	8947	29.5	24.7	18.5	13.2
Gallbladder	4408	7.4	6.1	3.6	2.3
Hodgkin	2134	3.6	3.7	3.6	3.5
Hypopharynx	716	1.2	1.0	0.7	0.5

HISTORICAL DATA – all registries

Incidence and mortality 2018 | Incidence and mortality historical data | Survival | Help

Incidence and mortality statistics, for all registries

Share this view

Country/Registry	Sex	Cancer	Age	Year	Indicator
By registry	Both sexes	All sites ...	All ages	2004 to 2010	Incidence And Mortality

Incidence And Mortality by registry

All sites (excl. other skin), Both sexes, All ages, 2004 to 2010

Incidence by registry - summary

All sites (excl. other skin), Both sexes, All ages, 2004 to 2010

Registry	Years	Number	Crude rate	ASR (W)	ASR (E Old)	ASR (E New)	Cumulative Risk
AT Austria	2004-2010	271414	468.1	256.29	361.22	517.22	38.25
BA Republic of Srpska	2008-2010	12898	299.56	157.78	218.7	299	24.36
BE Belgium	2004-2010	432446	582.83	319.3	448.51	635.01	45.07
BG Bulgaria	2004-2010	210561	392.67	217.87	300.72	408.42	31.46
BY Belarus	2008-2010	105012	368.14	232.49	320.1	433.85	33.14

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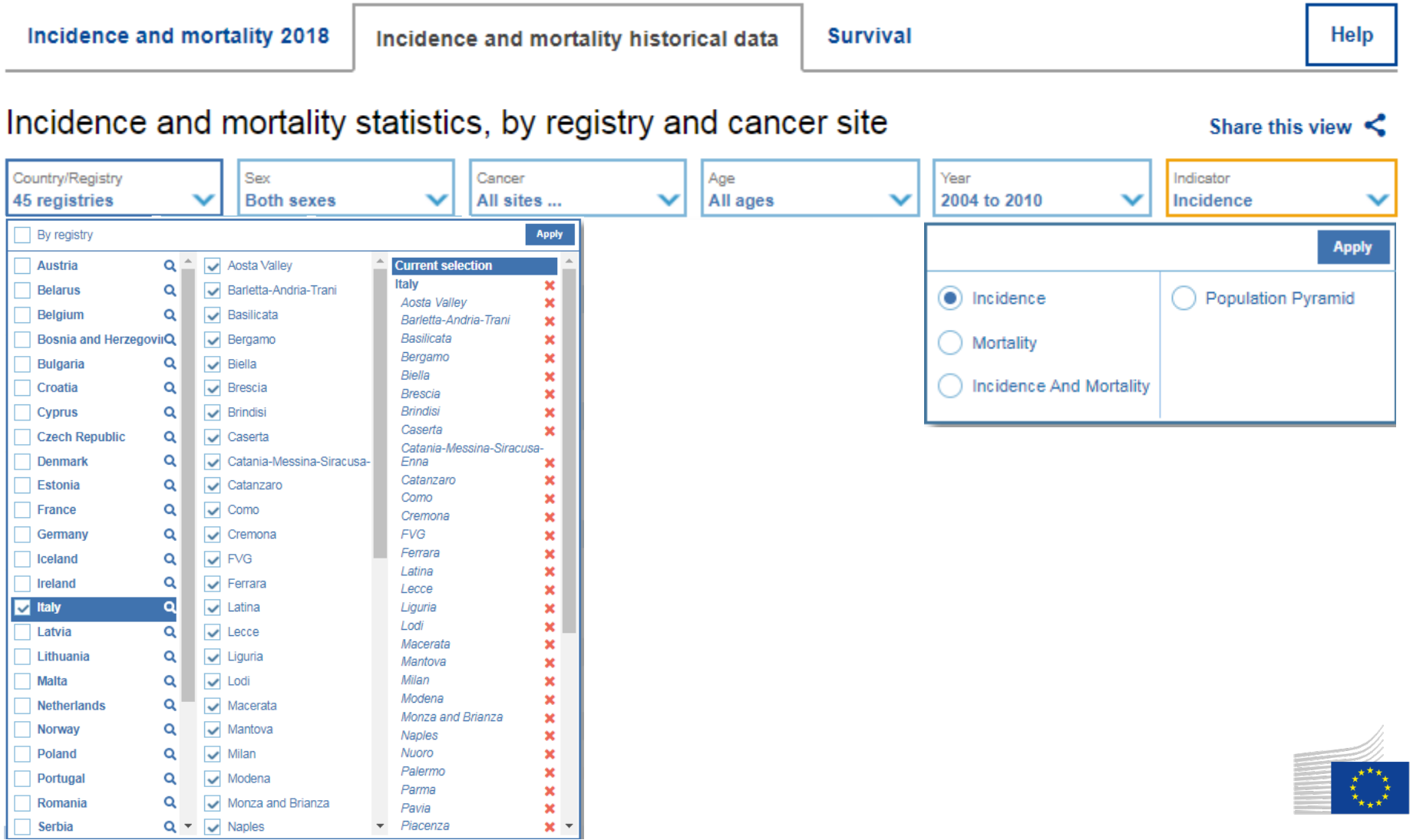
HISTORICAL DATA – selecting the registry/ies



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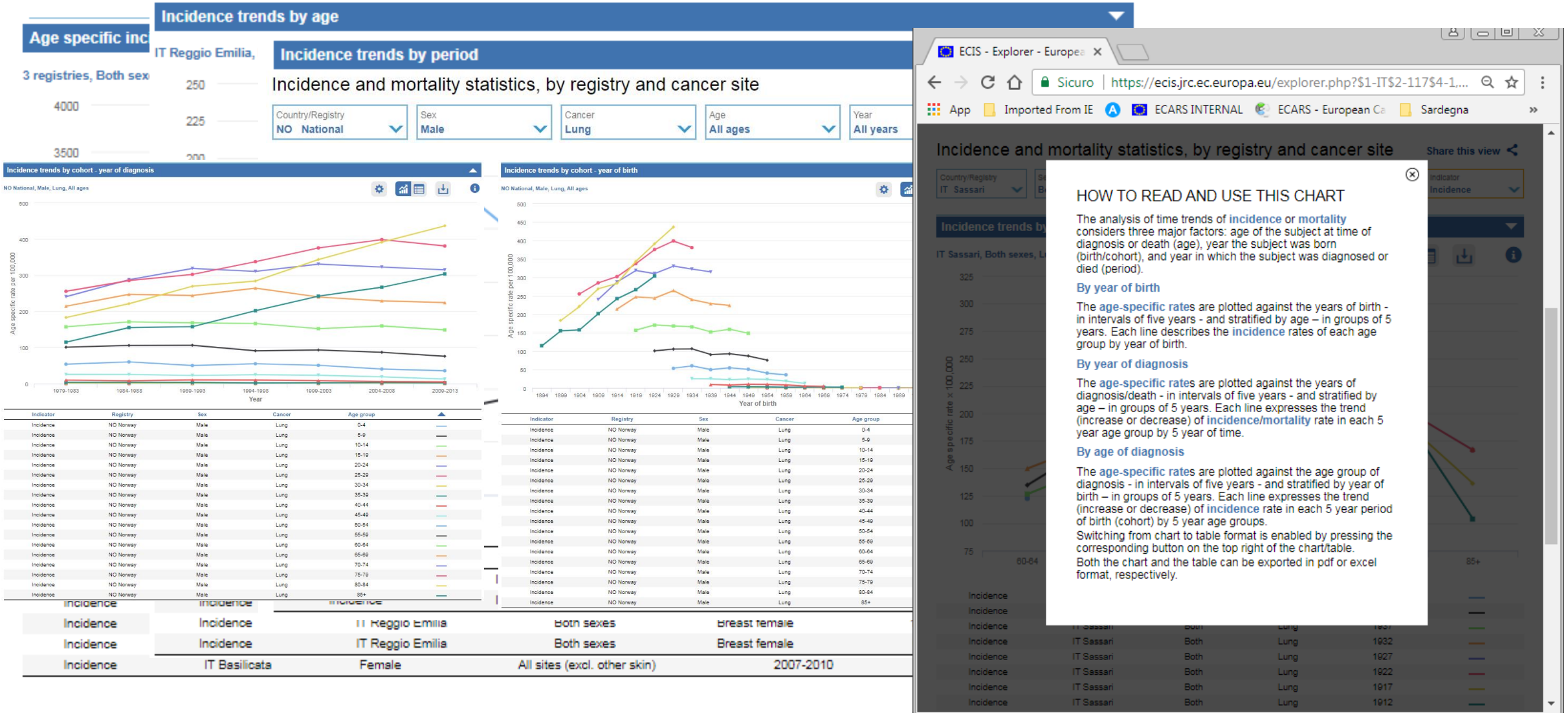
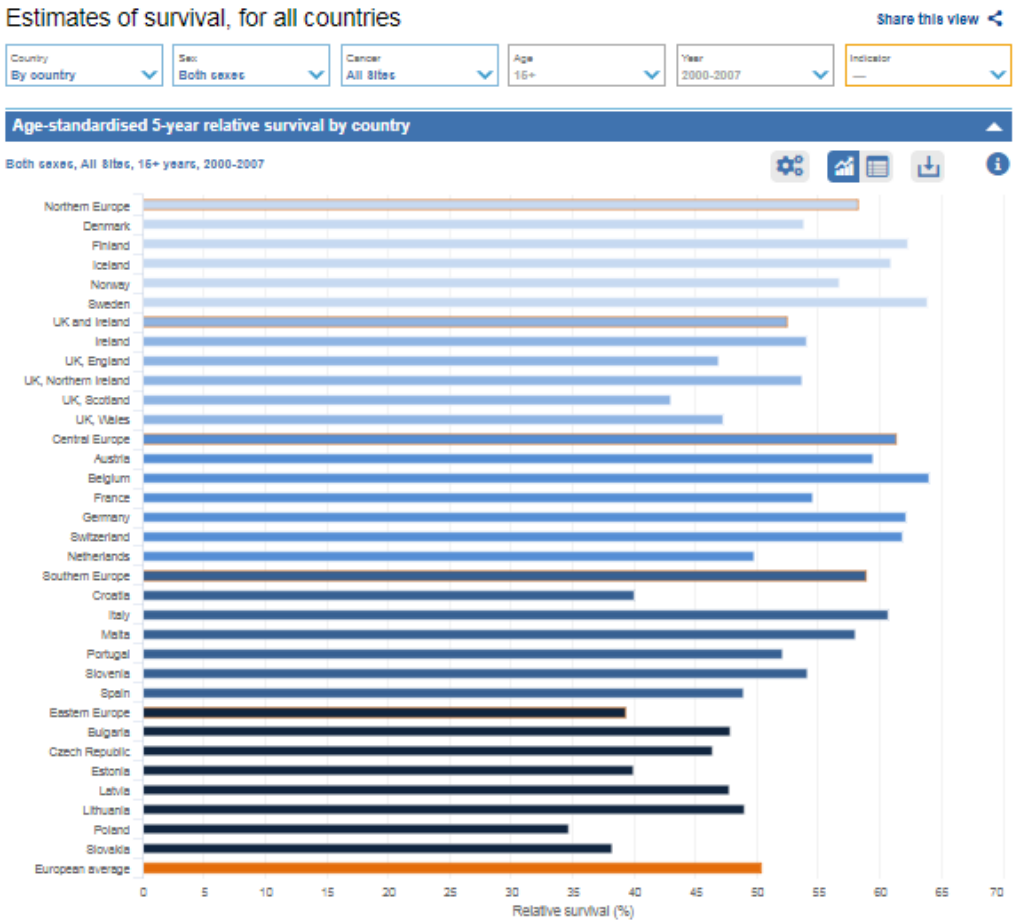
HISTORICAL DATA – by registry and cancer site



SURVIVAL – all countries



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SURVIVAL – ITALY

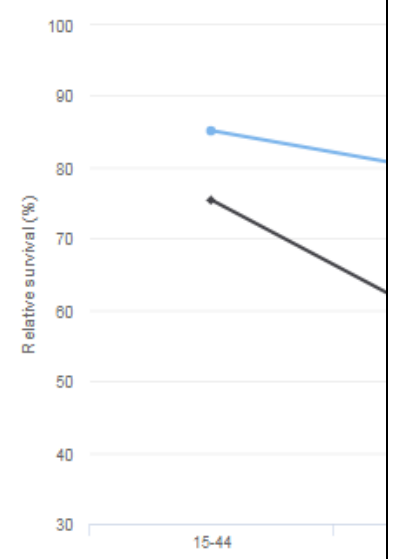
Estimates of survival, by country and cancer site

Share this view

Country	Sex	Cancer	Age	Year	Indicator
Italy	Both sexes	All Sites	15+	2000-2007	Survival

Age specific 5-year relative survival

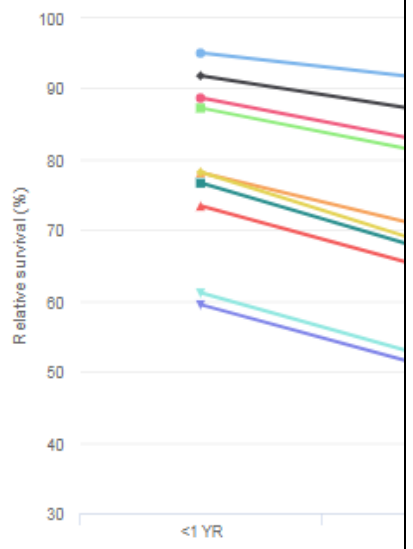
Italy, Both sexes, All Sites, 15+ years, 2000-2007



Country
Italy
Italy

Age specific and age standardised relative survival by follow-up interval

Italy, Both sexes, All Sites, 15+ years, 2000-2007



Country	Sex		
Italy	Female		
Italy	Female		
Italy	Female	All Sites	55-64
Italy	Female	All Sites	65-74
Italy	Female	All Sites	75+

Age specific and age standardised observed (obs) and relative (rel) survival

Italy, All Sites, 15+ years, 2000-2007

Male

Age group	Number of cases		One year	Three years	Five years
ICSS-Std	386340	obs	70.12	53.19	45.69
		rel	72.25	58.02	52.90
15+	383999	obs	68.79	51.57	43.75
		rel	71.40	57.27	52.19
15-44	18974	obs	88.56	78.68	74.95
		rel	88.67	78.96	75.41
45-54	28538	obs	77.91	61.81	56.15
		rel	78.19	62.52	57.33
55-64	78385	obs	75.94	59.92	53.58
		rel	76.66	61.75	56.57
65-74	133625	obs	71.65	54.93	47.03
		rel	73.42	59.41	54.20
75+	126818	obs	56.30	36.41	26.71
		rel	61.14	46.75	41.43

JRC Intranet

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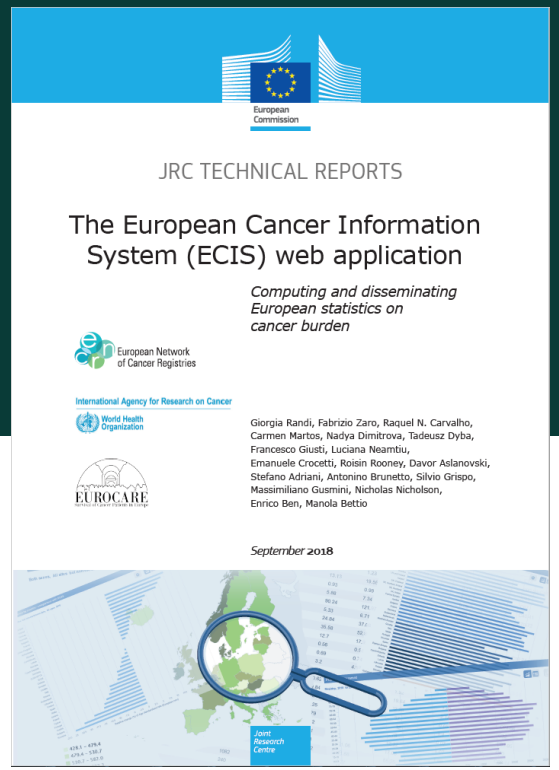
ECIS - COMING NEXT

2018

- Focus on Paediatric Registry Data
  - childhood specific + general registries
- From registry to country level: national estimates for countries without national coverage
  - On-going methodological investigation
- Customised cancer and country factsheets
- Routine data collection to keep ECIS statistics constantly updated

European Commission



Thank you

European Cancer Information System

https://ecis.jrc.ec.europa.eu/

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