The European Commission’s science and knowledge service

Joint Research Centre
Measuring the cancer burden: the European Cancer Information System

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European Commission, Joint Research Centre (JRC)
ECIS: European Cancer Information System

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

Towards a European Cancer Information System

11th European Public Health Conference, pre-conference Workshop, Ljubljana, 28 November 2018
Navigating the international health information databases: unravelling the processes behind the numbers
State of the art of cancer registration in Europe

- 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

INCIIDENCE
MORTALITY
SURVIVAL

statistics over time across Europe

https://ecis.jrc.ec.europa.eu
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
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
- EUROCASE 6
- CONCORD

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

These variables should be separated by a semi-colon.

<table>
<thead>
<tr>
<th>Variable name</th>
<th>Variable description</th>
<th>Format</th>
<th>Maximum length</th>
<th>Core</th>
<th>Missing/Unknown values</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>1_Flag</td>
<td>Check flag</td>
<td>F</td>
<td>1</td>
<td>Y</td>
<td>Not allowed</td>
<td>0→ Not checked</td>
</tr>
<tr>
<td>2_Patient_ID</td>
<td>Patient identification code</td>
<td>A</td>
<td>50</td>
<td>Y</td>
<td>Not allowed</td>
<td>According to registry coding</td>
</tr>
<tr>
<td>3_Tumour_ID</td>
<td>Tumour identification</td>
<td>A</td>
<td>50</td>
<td>Y</td>
<td>Not allowed</td>
<td>According to registry coding</td>
</tr>
<tr>
<td>4_Day_Death</td>
<td>Day of birth</td>
<td>F</td>
<td>2</td>
<td>Y</td>
<td>99</td>
<td>Range of allowed values: From 1 to 91</td>
</tr>
<tr>
<td>5_Month_Death</td>
<td>Month of birth</td>
<td>F</td>
<td>2</td>
<td>Y</td>
<td>99</td>
<td>Range of allowed values: From 1 to 12</td>
</tr>
<tr>
<td>6_Year_Death</td>
<td>Year of birth</td>
<td>F</td>
<td>4</td>
<td>Y</td>
<td>9999</td>
<td>Range of allowed values: &gt; 1942 and 0 to the current year</td>
</tr>
<tr>
<td>7_Sex</td>
<td>Sex</td>
<td>F</td>
<td>1</td>
<td>Y</td>
<td>9</td>
<td>1→ Male</td>
</tr>
<tr>
<td>8_Day_Diag</td>
<td>Day of diagnosis (incidence)</td>
<td>F</td>
<td>2</td>
<td>Y</td>
<td>99</td>
<td>Range of allowed values: From 1 to 91</td>
</tr>
<tr>
<td>9_Month_Diag</td>
<td>Month of diagnosis</td>
<td>F</td>
<td>2</td>
<td>Y</td>
<td>99</td>
<td>Range of allowed values: From 1 to 12</td>
</tr>
<tr>
<td>10_Year_Diag</td>
<td>Year of diagnosis</td>
<td>F</td>
<td>4</td>
<td>Y</td>
<td>Not allowed</td>
<td>Range of allowed values: &gt; 1942 and 0 to the current year</td>
</tr>
<tr>
<td>11_Age</td>
<td>Age at diagnosis (incidence date) in years</td>
<td>F</td>
<td>3</td>
<td>Y</td>
<td>9999</td>
<td>Range of allowed values: ≥ 0 and &lt; 111</td>
</tr>
<tr>
<td>12_Risk</td>
<td>Risk of diagnosis</td>
<td>F</td>
<td>1</td>
<td>Y</td>
<td>9</td>
<td>0→ Death certificate only (DCD). 1→Clinical. 2→Clinical investigation. 3→Specific tumour markers. 4→Cytology. 5→Histology of a metastasis. 6→Histology of a primary tumour</td>
</tr>
</tbody>
</table>
The portal for data submission

Navigating the international health information databases: unravelling the processes behind the numbers

![Screenshot of the portal for data submission](https://portal-encr.jrc.ec.europa.eu/submissions/details)

### Data Usage and Restrictions

<table>
<thead>
<tr>
<th>PROJECT/Studies Name</th>
<th>Protocol</th>
<th>Particip</th>
<th>Specific Data Restrictions</th>
<th>ENCODE Pat.</th>
</tr>
</thead>
<tbody>
<tr>
<td>EUROCAR, EUROCAR</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incidence and Mortality in Europe, ...</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Towards harmonization of cancer registry quality checks

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

2013-2014

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

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

2018 incidence and mortality estimates
- 40 European countries
- 34 cancer sites
- Collaboration IARC/IACR/JRC/ENC

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

Incidence and mortality statistics, by registry and cancer site

- Geographic area
- Sex
- Cancer site
- Age
- Time of incidence/mortality

INDICATOR

Country/Registry: IT Varese
Sex: Both sexes
Cancer: All sites...
Age: All ages
Year: 2004 to 2010
Indicator: Incidence
### ESTIMATES 2018 – all countries

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

#### Estimated incidence by country

#### Estimated incidence by country - comparison with Europe

#### Estimated incidence by country - summary

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of cases</th>
<th>Crude rate</th>
<th>ASR (European new)</th>
<th>ASR (European old)</th>
<th>ASR (world)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albania</td>
<td>8020</td>
<td>273.3</td>
<td>334.1</td>
<td>236.3</td>
<td>169.1</td>
</tr>
<tr>
<td>Austria</td>
<td>42318</td>
<td>483.5</td>
<td>469.6</td>
<td>329.6</td>
<td>235.1</td>
</tr>
<tr>
<td>Belarus</td>
<td>41048</td>
<td>434.3</td>
<td>476.7</td>
<td>351.4</td>
<td>254.9</td>
</tr>
<tr>
<td>Belgium</td>
<td>72088</td>
<td>626.9</td>
<td>638.0</td>
<td>451.0</td>
<td>322.5</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>13987</td>
<td>399.2</td>
<td>415.8</td>
<td>300.3</td>
<td>215.3</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>33778</td>
<td>480.0</td>
<td>447.6</td>
<td>325.7</td>
<td>234.8</td>
</tr>
</tbody>
</table>

*Both sexes, All sites but non-melanoma skin.*
### Incidence and Mortality Statistics for All Registries

#### Incidence and Mortality by Registry

<table>
<thead>
<tr>
<th>Registry</th>
<th>Years</th>
<th>Number</th>
<th>Crude rate</th>
<th>ASR (W)</th>
<th>ASR (E Old)</th>
<th>ASR (E New)</th>
<th>Cumulative Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT Austria</td>
<td>2004-2010</td>
<td>271414</td>
<td>408.1</td>
<td>205.29</td>
<td>301.22</td>
<td>517.22</td>
<td>38.25</td>
</tr>
<tr>
<td>BA Republic of Serbia</td>
<td>2004-2010</td>
<td>12899</td>
<td>299.56</td>
<td>107.75</td>
<td>210.7</td>
<td>296</td>
<td>24.36</td>
</tr>
<tr>
<td>BE Belgium</td>
<td>2004-2010</td>
<td>43246</td>
<td>522.83</td>
<td>319.3</td>
<td>448.51</td>
<td>636.01</td>
<td>45.07</td>
</tr>
<tr>
<td>BO Bulgaria</td>
<td>2004-2010</td>
<td>210551</td>
<td>362.67</td>
<td>217.67</td>
<td>300.72</td>
<td>403.42</td>
<td>31.48</td>
</tr>
<tr>
<td>BY Bulgaria</td>
<td>2004-2010</td>
<td>4061</td>
<td>122.41</td>
<td>92.68</td>
<td>154.23</td>
<td>209.62</td>
<td>19.93</td>
</tr>
</tbody>
</table>

#### Incidence by Registry - Summary

**Note:** The image contains a table with data on incidence and mortality statistics for various registries. The table details the years, number of cases, crude rates, and adjusted standardized rates (ASR) for different registries. The cumulative risk is also provided for each registry.
HISTORICAL DATA – selecting the registry/ies
HISTORICAL DATA – by registry and cancer site

In this section, you will find historical data on cancer incidence and mortality statistics, categorized by registry and cancer site. The data is presented by age and period trends, allowing for a detailed analysis of cancer trends over time. Users can explore the data by selecting specific registries, countries, sexes, cancer sites, ages, and years of diagnosis or death. The charts and tables provide visual representations of the data, facilitating a better understanding of the epidemiological patterns of cancer.
SURVIVAL – all countries
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

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Thank you

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