

ECIS

European Cancer Information System

*measuring the cancer
burden in EU and Europe*



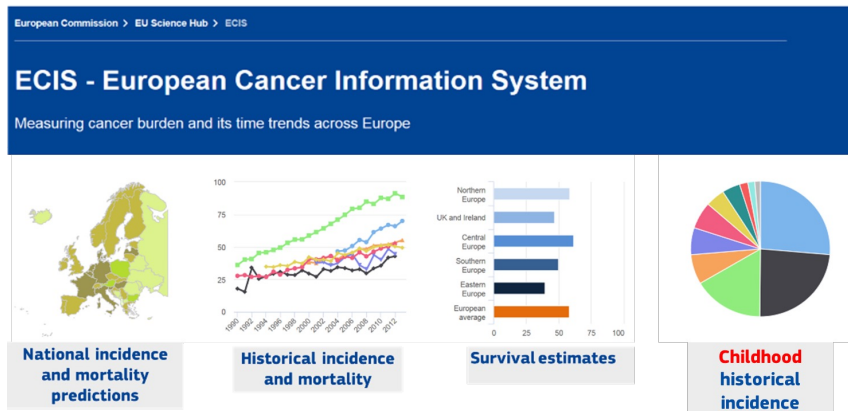
*Manola Bettio
Joint Research Centre, European Commission*

ECIS – European Cancer Information System

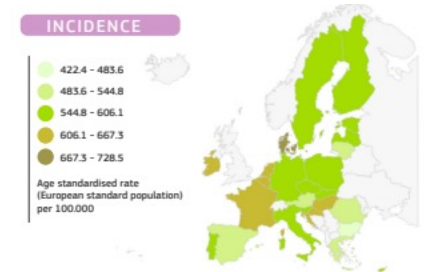
The European reference for cancer burden monitoring



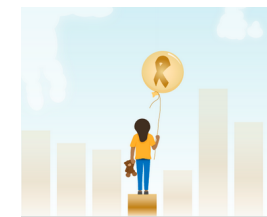
Timely and comparable data on cancer burden across Europe



All-ages indicators from general cancer registries



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



Childhood cancers from childhood cancer registries prioritised when areas overlapping with general registries

**In 2022, there were an estimated
16,000 new childhood cancer cases
(age 0-19 years)
diagnosed in the EU**

**and 2,100 childhood
cancer deaths**

*Source: ECIS - European Cancer
Information System*

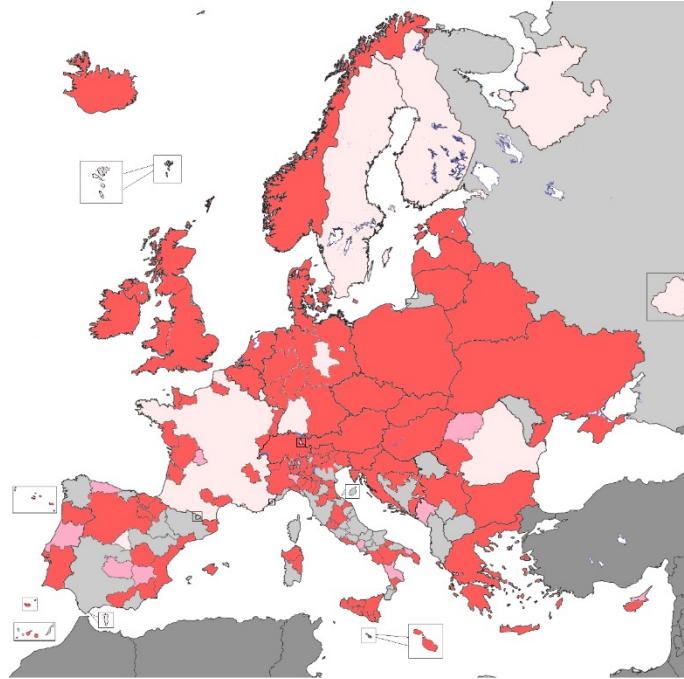
Childhood are rare tumours

- Need to pool data from across countries and regions to analyse, compare and share good practices
- The **European Cancer Information System** brings data together from across Europe, to allow policy makes and stakeholders to better monitor trends and outcomes for different diagnostic groups of childhood cancer

- *Knowledge Centre on Cancer*
- *European Cancer Inequalities Registry*
- *Europe's Beating Cancer Plan*
- *Horizon Europe Mission on Cancer*
- *EU Strategy on the Rights of the Child*



Challenges in childhood cancer data processing



ECIS incidence childhood data

- *111 European Cancer Registries*
- *in 32 European countries*

- Ad hoc processing and classification (ICCC-3)
- Childhood are rare tumours, grouped dissemination
 - data protection issues
 - statistical instability
- High quality data needed for measuring childhood cancer burden
 - ✓ *Ad hoc* data validation software and multiple primary tumour selection routines

ECIS as a JRC-ENCR collaboration



- Europe-wide standardised protocols for data collection and validation
- Aligned to and serving multiple projects
- Moving towards a rolling process with annual updates/submissions

- Collaboration agreement between the JRC and 150+ ENCR registries to structure roles in contribution to ECIS
- ECIS record in EC DPO register for accountability and transparency

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Home > About the European Commission > Service standards and principles > Transparency > Data processing register > Search

Register of the Data Protection Officer (DPO)

In a spirit of transparency, the Commission has put the register online and made it accessible to any interested person.

PAGE CONTENT

Back to list | Print

1. General information

Title: European Cancer Information System (ECIS) database

Reference: DPR-EC-00417.2

2. Purpose and description of the processing

3. Data subjects and data categories

4. Retention period

5. Recipients

6. International data transfers

7. Information to data subjects on their rights

8. Security measures

1. General information

Data protection record

Record reference

DPR-EC-00417.2

Timeline of cancer registration in Europe

1990 - - - 2012 - - - - - 2015 - - - - - 2018 - - - - - 2021 - - - - -

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OF CANCER REGISTRIES
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<http://www.encr.com.fr/>



International Agency for Research on Cancer



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



- European dataset of cancer data
- streamlining data submission and usage processes
- Building of the ECIS infrastructure

