

Cancer registries' data collection in the framework of the European Cancer Information System (ECIS)

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European Commission's Joint Research Centre

eArchiving Initiative training webinar

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ECIS rationale



PROVISION OF TIMELY AND COMPARABLE DATA ON CANCER BURDEN ACROSS EUROPE

Cancer burden indicators

How many new cases?	INCIDENCE
How many deaths?	MORTALITY
How many survive and for how long?	SURVIVAL

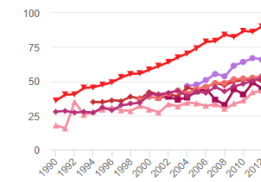
- Cancer registries of the European Network of Cancer Registries as data source
- EC contribution: harmonisation of data and registration processes, collection, analysis and dissemination of cancer burden indicators



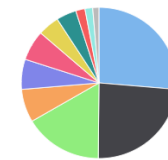
The ECIS infrastructure

- ENCR secretariat
- Secure portal for data submission
- Databases to store and manage data
- European-wide agreed procedures for cancer data quality checks and related software
- Computational routines
- Dissemination tools

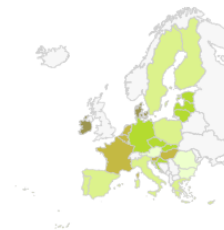
<https://ecis.jrc.ec.europa.eu/>



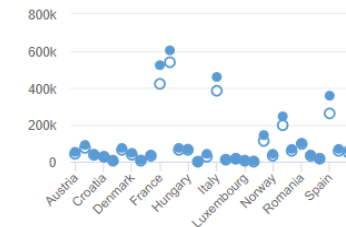
**Historical
incidence and
mortality**



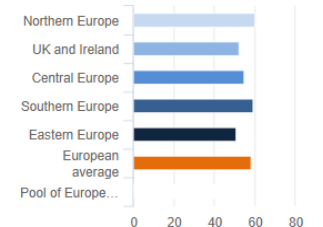
**Childhood
historical
incidence**



**Incidence and
mortality
estimates**



**Long-term incidence
and mortality estimates
up to 2040**



**Survival
estimates**




ECIS database – previous 2015 data call

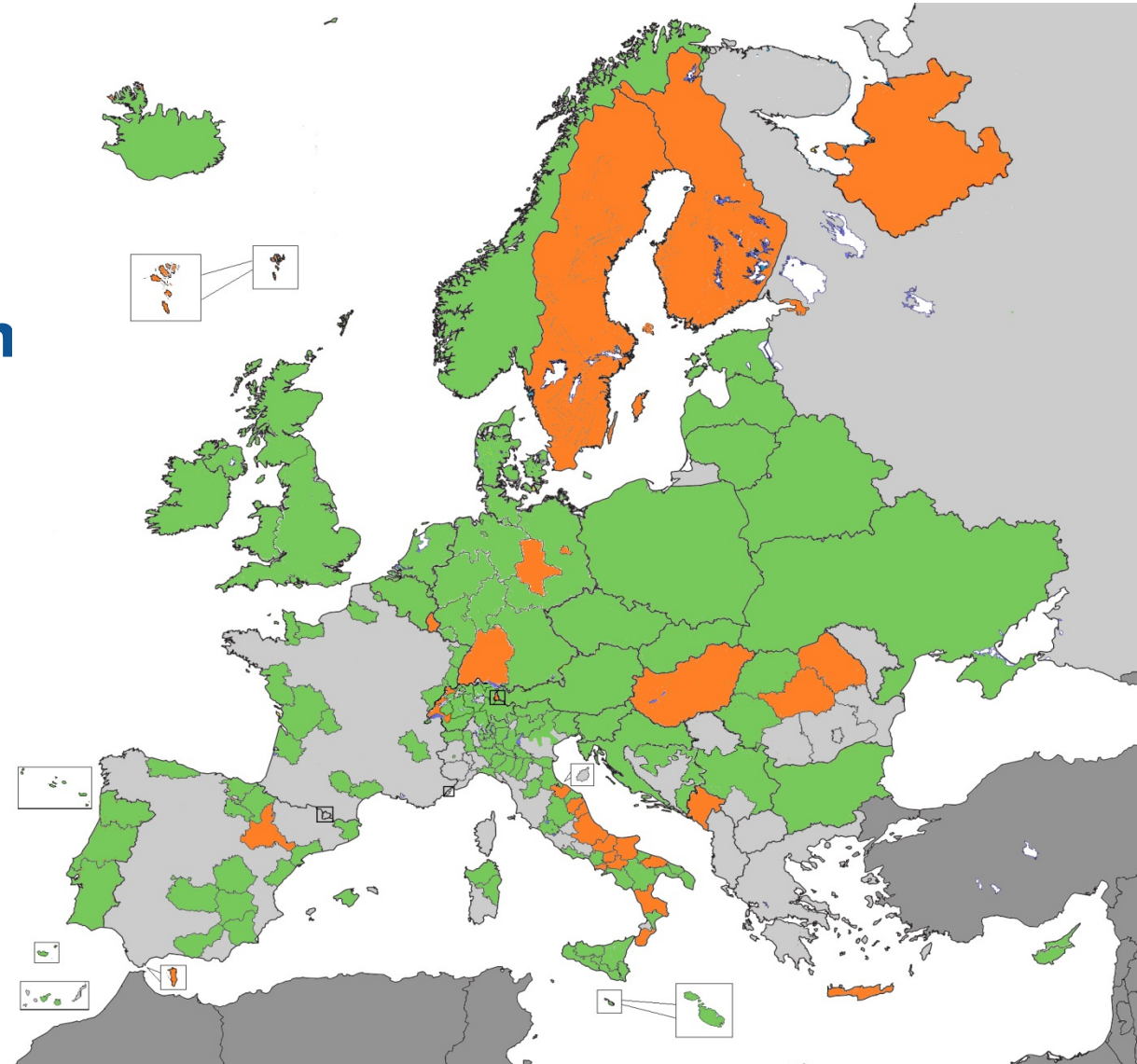
149 CRs from **34** European countries

more than **34,500,000** records in the database



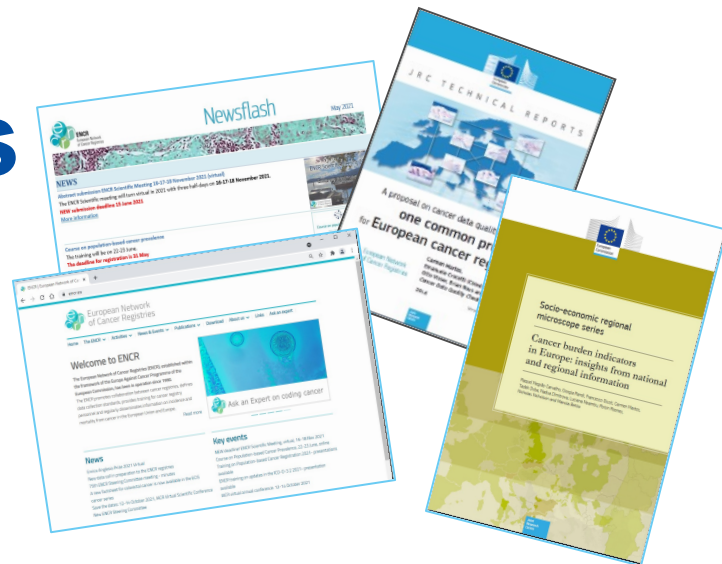
Covering about 60%
of the
EU/(CH/NO/IS)
population

-  Data submitted
-  Data not submitted
-  Data not available



Documents and software tools

- ENCR recommendations
*How to **code and report** cancer cases*
- Call for Data Protocol for European Population-Based Cancer Registries (2022)
*How to **prepare files for submission** to the ECIS 2022 data call*
- JRC report “A common data quality check procedure for European cancer registries”, [Data Structure Converter and Quality Check Software](#)
- *How to **perform data quality checks***



Call for Data Protocol 2022

Required files

Cancer incidence	Cancer mortality	Population	Life tables	Questionnaire
<p>Record-level data 39 variables in 5 variable groups:</p> <ul style="list-style-type: none"> ■ Patient ■ Tumour ■ Follow up ■ Stage ■ Treatment 	<p>5–6 variables, data aggregated by:</p> <ul style="list-style-type: none"> ■ Sex ■ Age ■ Geographical area (where applicable) 			<p>Qualitative information</p> <ul style="list-style-type: none"> ■ Grouped by file type ■ Context for the quantitative data

ECIS data validation workflow 2022

Data workflow	Processes and tools used
Data submission	<ul style="list-style-type: none">▪ Data files submission via secure submission portal▪ Questionnaire submission via EU survey
1st phase validation 1 st feedback report	<ul style="list-style-type: none">▪ Checks: completeness, consistency with the questionnaire and between the files, formatting▪ New version of the files may be generated▪ Resubmission of files may be asked
2nd phase validation 2 nd feedback report	<ul style="list-style-type: none">▪ Quality Check Software: detailed univariate and multivariate checks, checks for multiple primary tumours▪ Resubmission of files may be asked

Data aggregation
publication in CR-private workspace

CR verification

Publication in ECIS

Importance of file archiving: ECIS data call

- **Guidance documents:** updated versions, training materials, clarifications (e.g. via communication with the ENCR secretariat or “Ask an expert” ENCR)
- **Data files:** original datasets and updated versions
- **Feedback reports and communication** between the ENCR secretariat and Cancer Registries
- **Output of software tools:** e.g. Data Structure Converter and Quality Check Software

Facilitated workflow in the future Data Calls
Improved long-term accessibility of cancer data

Thank you



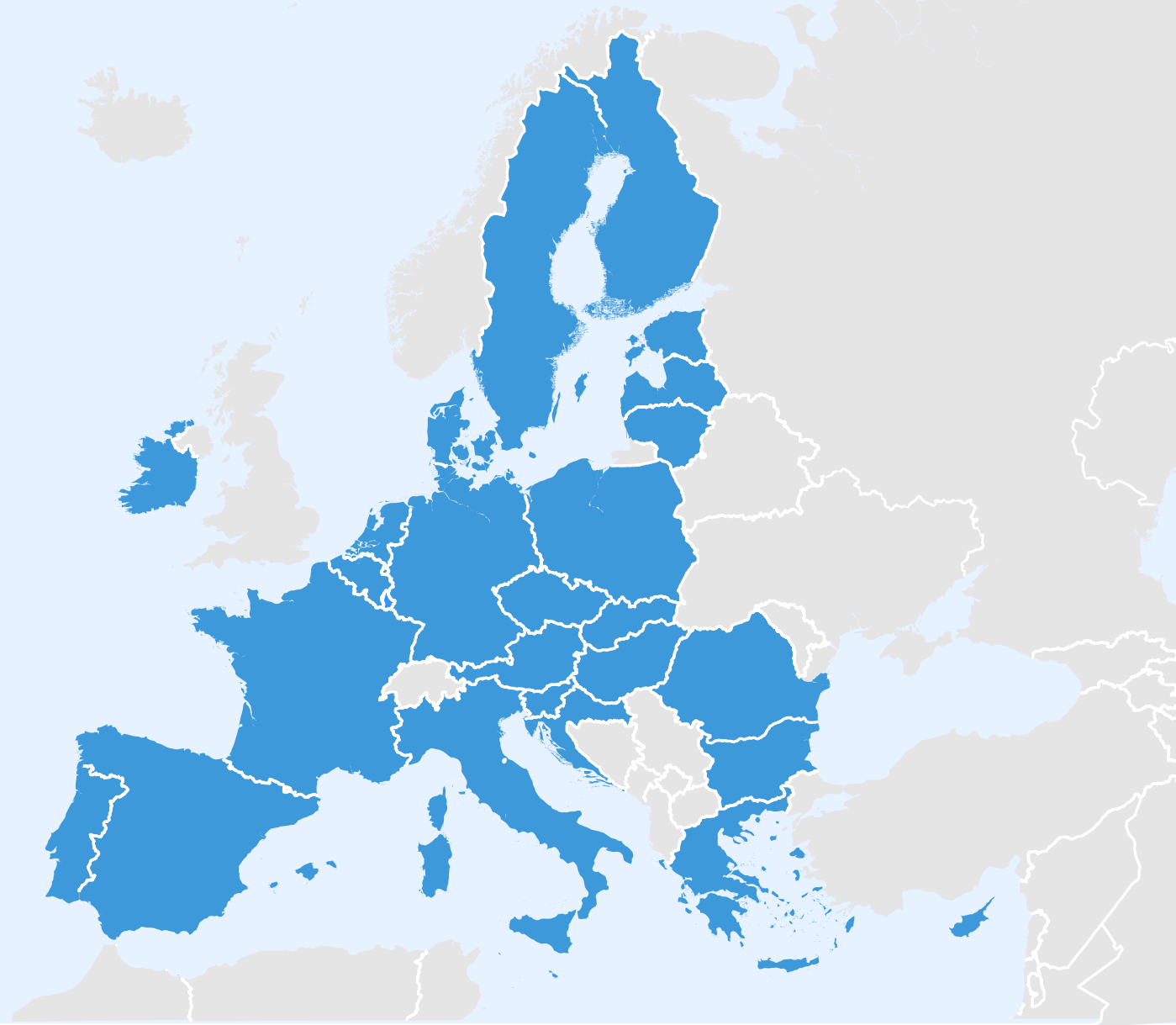
European Cancer Information System: <https://ecis.jrc.ec.europa.eu/>
European Network of Cancer Registries: <http://www.enchr.eu/>



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EU countries



0 250 500 1,000 Km

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