ENCR - the European Network of Cancer Registries

Collecting, monitoring and improving cancer data

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EMA, 29-11-2019

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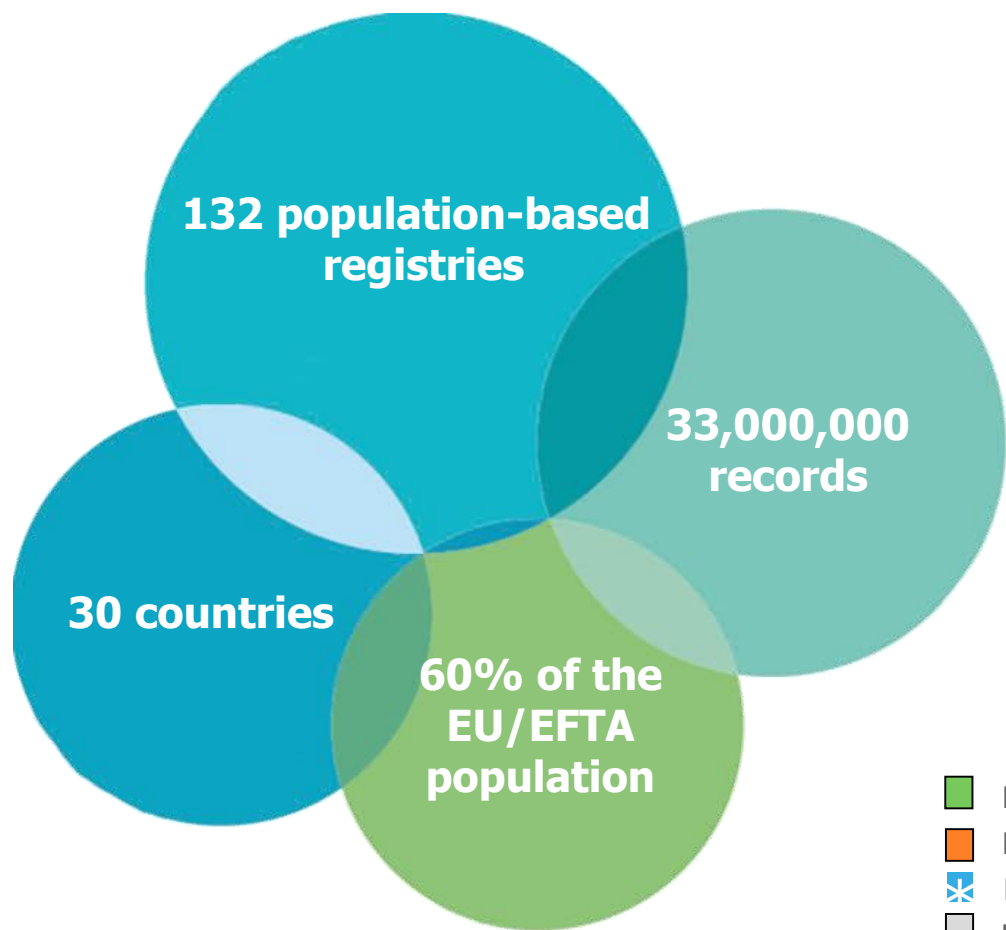
The Network and its structure

- Active since 1990

- Established within the framework of the "*Europe Against Cancer* "*programme of the* **European Commission** on the initiative of IARC, ANCR, IACR and GRELL

- Governed by a **Steering Committee** (currently 11 people) with 3-years term

- **Secretariat** hosted at the EC **Joint Research Centre** since 2012 (previously at IARC)

- The JRC also supporting the ENCR in its activities aimed at harmonisation and improvement of cancer registration in Europe

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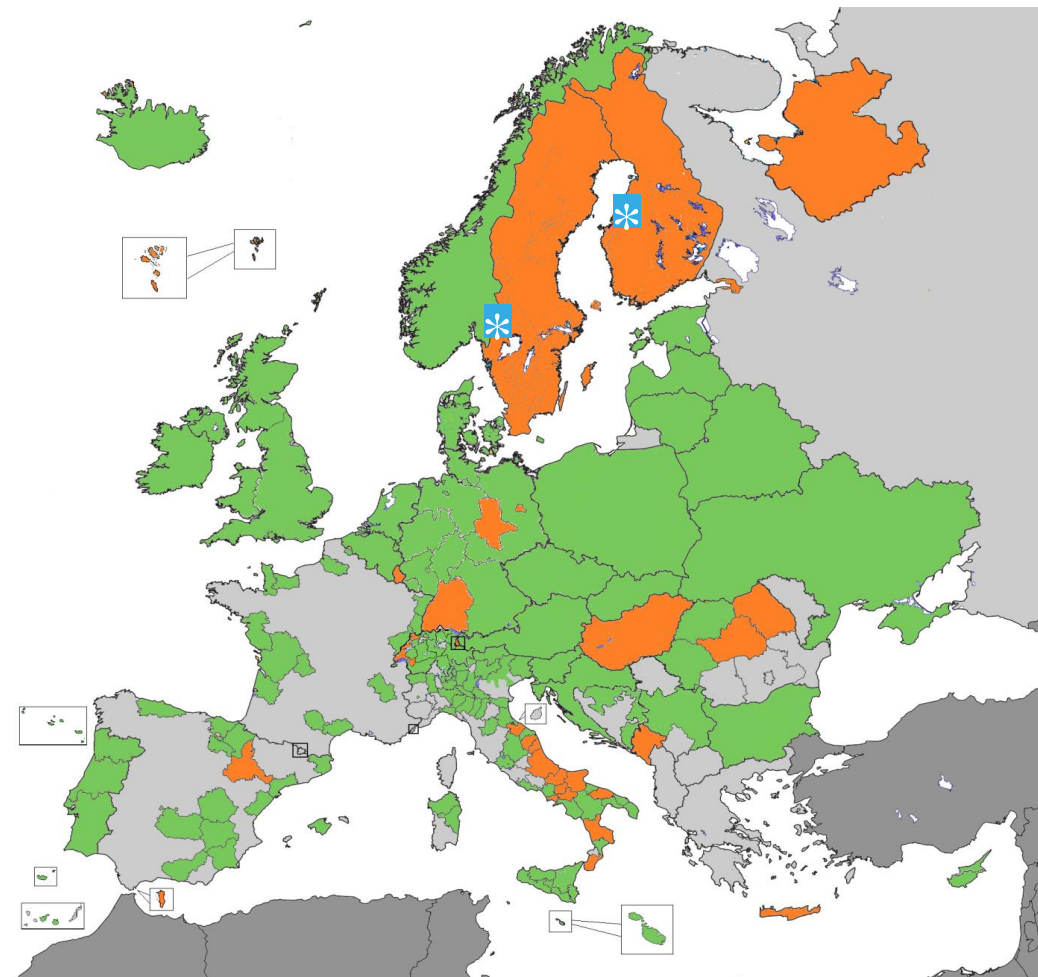
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ENCR objectives

- Provide **information** on the burden of cancer (incidence, mortality and survival)
- **Monitor** trends
- Increase the **quality**, **comparability** and **availability** of cancer data
- Promote the **use** of data from cancer registries

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Active members / Participation in latest call for data (2015)

132 population-based registries

33,000,000 records

30 countries

60% of the EU/EFTA population

Legend:
- Data submitted
- Data not submitted
- Data with privacy issues
- Data not available

Incidence data – submitted time period by registry (2015 call for data)
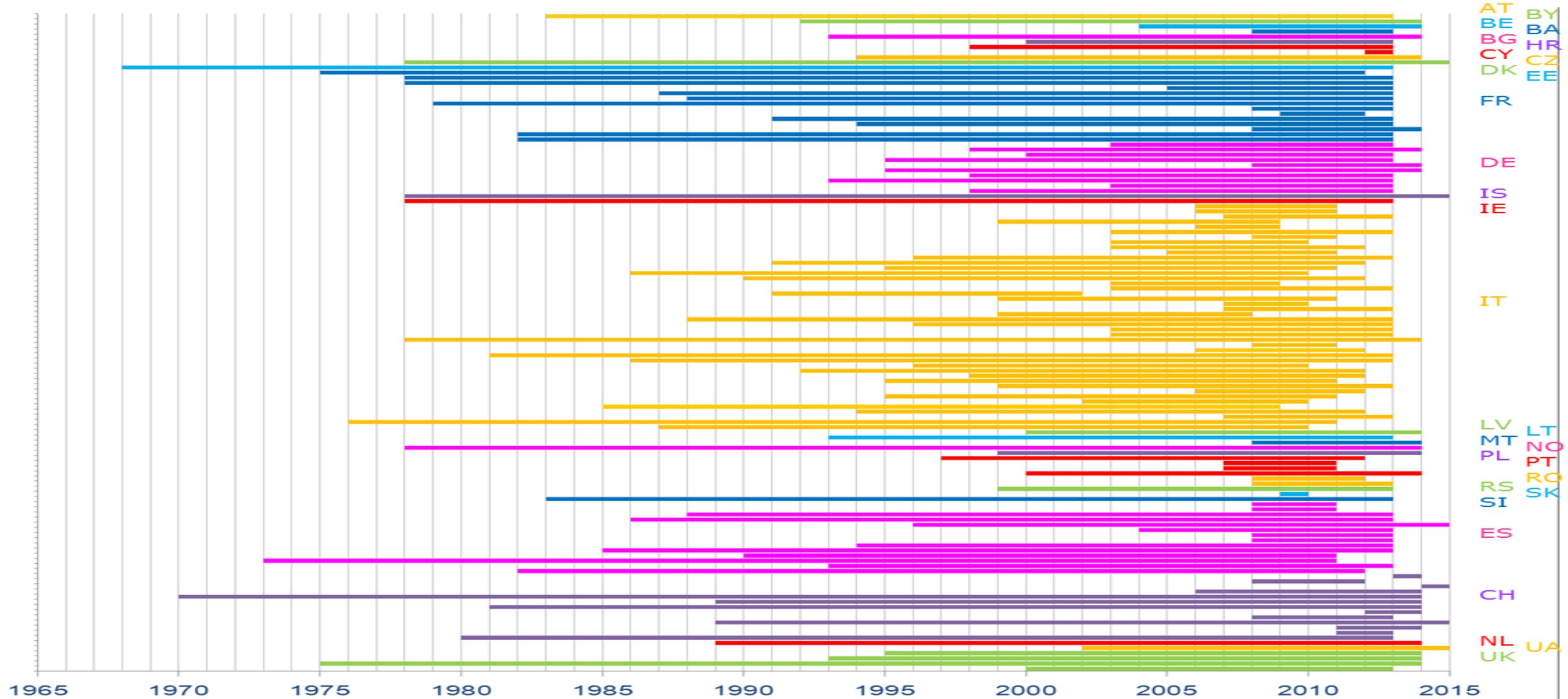
Funding and legislation

- In most European countries legislation is in place
- However, this does not guarantee proper funding nor does it guarantee completeness
- Funding mostly by regional of national health authorities
- Funding often only covers data collection with limited resources for data analysis, research and publication of the results

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How do registries work?

1. Passive
   - receive information from hospitals or other sources
   - on paper and/or electronic (lists, excel-files, etc.)
   - level of detail and the quality differs by registry
2. Active
   - collection of data in hospitals by registration clerks
3. Combination
   - receive information from hospitals, but with the possibility to check or complete the registry in the hospital

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Main sources of notification

- Pathology (80-95%)
- Hospital discharge registries (5-20%)
- Death certificates* (5-10%)
  - With trace back: DCI (death certificate <u>initiated</u>)
  - Without trace back: DCO (death certificate <u>only</u>)
  - Sweden and the Netherlands have no access to death certificates
- Other sources (claims, radiotherapy departments, etc.)

Cause of death registration is always independent from the cancer registry

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Completeness of the registry

Based on a number of indicators the completeness can be estimated:

- Mortality/incidence ratio (mortality < incidence)
- Proportion of DCO's (not higher than 5-10%)
- Comparison with neighbouring registries/countries

Completeness of the registry should be at least ~90%, but preferably higher

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What do registries collect?
Minimal data set (WHO)

- Personal identifiers (name or civil service number)
- Date of birth, age
- Sex
- Ethnicity (country of birth)
- Postal code

- Incidence date
- Basis of the diagnosis (imaging, pathology)
- Topography (primary site)
- Morphology, including the behaviour code (pathological classification)
- Vital status
- Date of follow-up/date of death
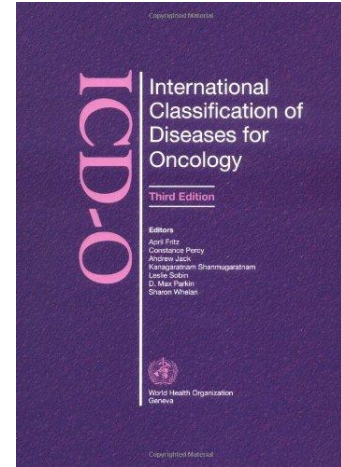
Collected by all registries (except ethnicity)
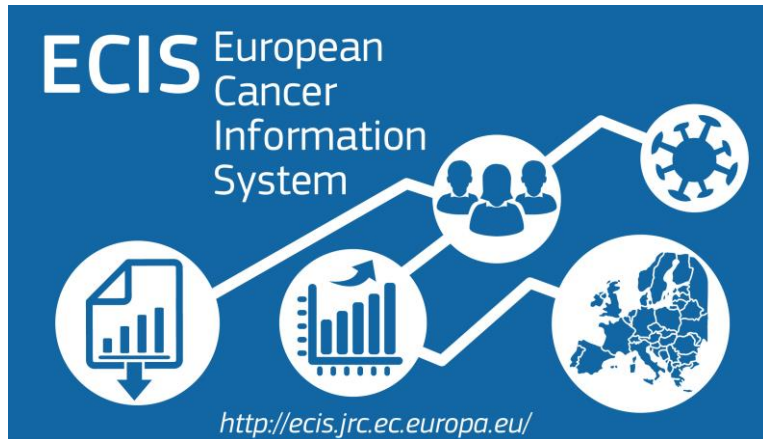
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Main indicators from cancer registries

Cancer incidence

Cancer survival
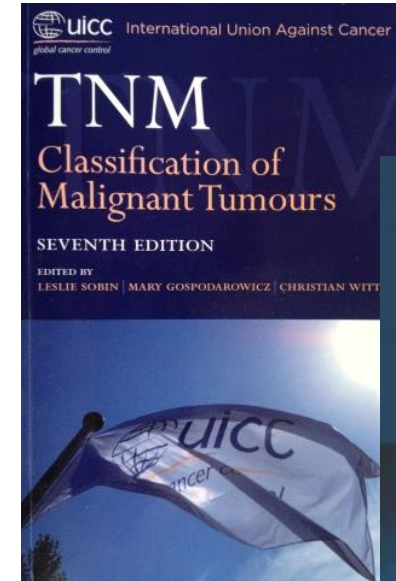
Cancer prevalence

(Cancer mortality)

- By cancer site
- By morphology (including rare cancers)
- By age group
- By sex
- By ethnicity/country of birth
- By geographical area
- Trends

What do registries collect?

Other data

- Stage (TNM, extent of disease)
- Primary treatment
  - Surgery
  - Radiotherapy
  - Chemotherapy
  - Hormonal therapy
  - Other therapy

Stage is collected by most registries but with large variations in data quality which severely hampers the comparability

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What do registries collect?

Other data

- Cytogenetics, molecular diagnostics (sometimes included in ICD-O)
- Investigations (type of imaging, etc.)
- Detailed treatment data
  - Date of start/stop of the treatment
  - Type of surgery (amputation vs conserving operation); type of chemotherapy, scheme/drug; radiotherapy fields or dose
- Co-morbidity; adverse events
- Recurrence/progression

Collected by a minority of registries and mostly for small patient cohorts

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Combining data

Many registries have the possibility to link to other sources
- Clinical registries (UK, Nordic countries, the Netherlands)
- Insurance companies (claims)
- Screening organizations
- Hospitals discharge registries (co-morbidity)
- Pharmaceutical databases
- Pathology databases

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Data quality

Data quality depends on

1. The quality of the available sources
2. The ability of the registry to abstract the available information correctly
3. Following international or European guidelines/recommendations, for example for the incidence date or multiple tumours.

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Challenges of cancer registration in Europe

- **Timeliness** in data provision (typically 3-4 years lag)
- **Data availability**, **harmonisation** of data processing and reporting
- Long-term **sustainability**
- **Coverage**
- **Variety** of organisation, funding, health systems and infrastructures
- **Multilingualism**
- Lack of a formal data-collection **mandate** at EU level
- **Confidentiality** and sensitive data
- … **reluctance** to share the data!

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What are JRC/ENCR working on?

- Data call 2020
- Data handling agreements with between JRC and the registries
- Formal mandate from the EU
- Data quality checks software
- New or updated recommendations
- Organize trainings (2-3 per year) on coding (topography, morphology, stage) and statistical methods and set up an e-learning platform
- Inform registries how to deal with the GDPR (what is allowed, what not)

Funding and the availability of proper sources for the registry remains the responsibility of the registry

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www.encr.eu