Health Information on Cancer and Rare Diseases

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Why JRC?

- Independence of national, private and commercial interests

- Can ensure continuity and sustainability

- Proven track record in harmonisation and standardisation of EU data systems

- Networking and consensus building of stakeholders/experts

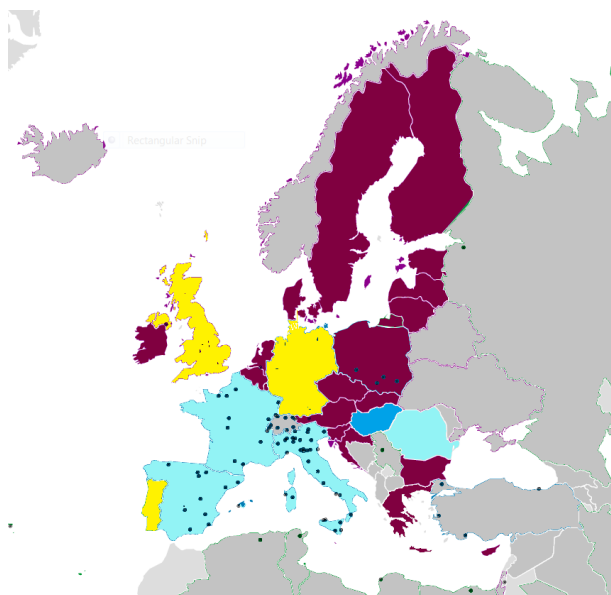- Close proximity to the EU decision makers

(1) Cancer

To fulfil the EC's Commitment to successfully reduce the burden of cancer in Europe

we need **ACCURATE and COMPARABLE** population-based European cancer data

(incidence-prevalence-survival-mortality)

Population-based cancer registries in the EU

Measuring all cases of cancer in the population in a <u>well-defined</u> geographic area

National CRs **Regional CRs covering whole country**

Regional CRs **No CR**

20 National CRs

82 Regional CRs

⬇

**covering
81% of the EU population**

JRC involvement since 2012

- **Coordinating the ENCR secretariat**

    - Coordination of ENCR activities and priority-mapping

    - Organisation and steering of ENCR working groups, workshops, general assemblies

    - Communication – newsflashes, factsheets, website

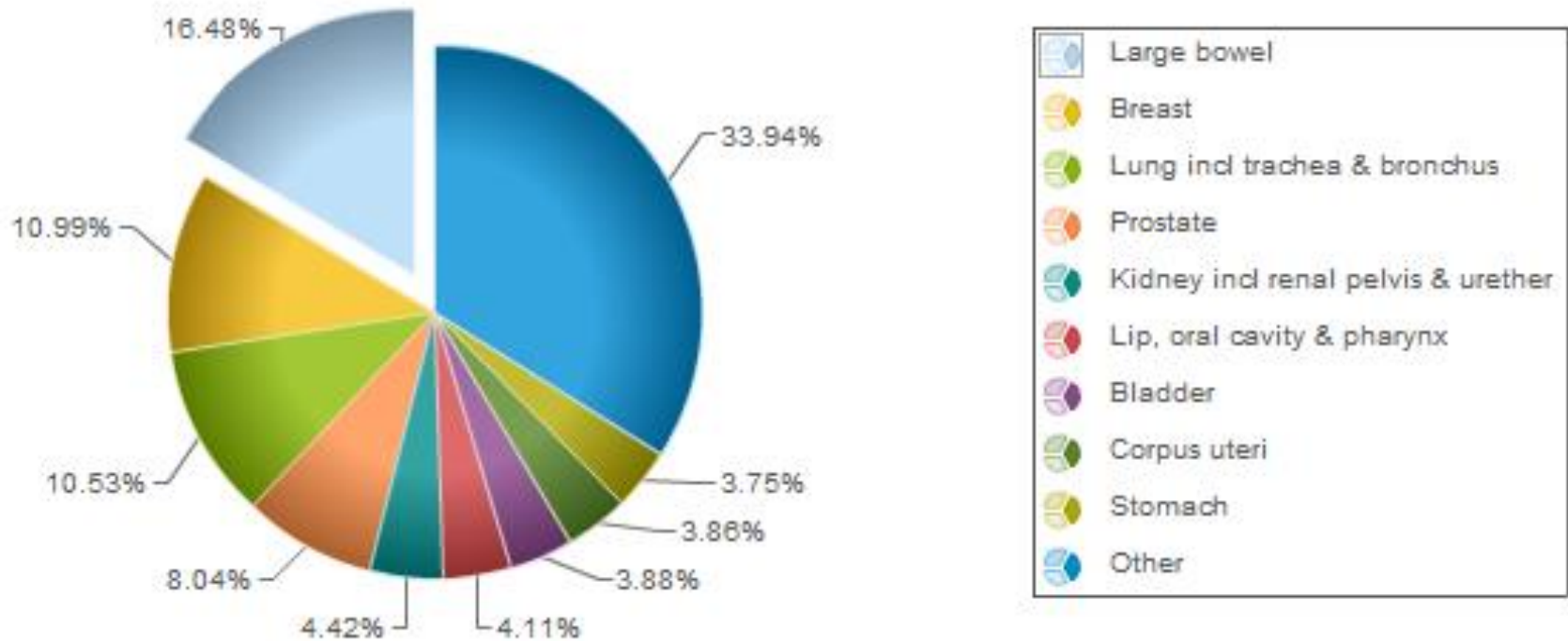- **Developing the Knowledge Service**

    - Establishment of data submission portal

    - Open-source harmonised data cleaning publication and software

    - Data-visualisation tools and atlases

    - Organisation of 2015 data-call - data collection and processing
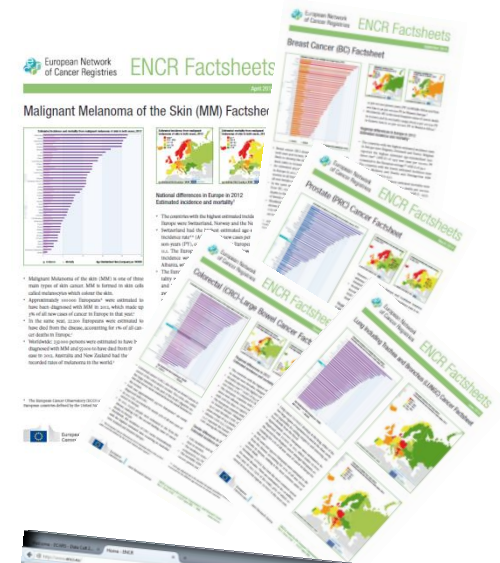
Country Factsheets

EUCAN
national estimates

Estimated incidence for both sexes in Slovakia, 2012

- Large bowel
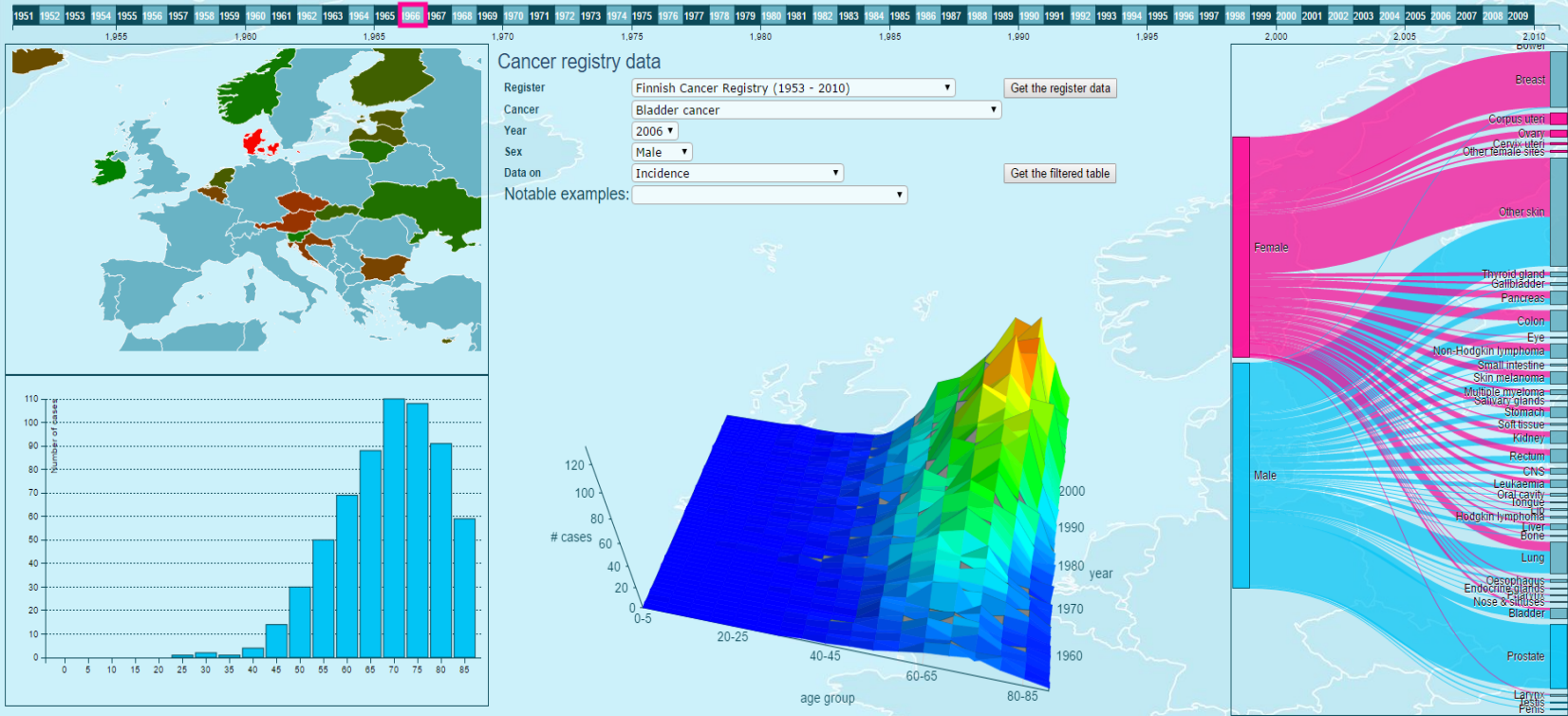- Breast
- Lung incl trachea & bronchus
- Prostate
- Kidney incl renal pelvis & urether
- Lip, oral cavity & pharynx
- Bladder
- Corpus uteri
- Stomach
- Other

16.48%
33.94%
10.99%
10.53%
8.04%
4.42%
4.11%
3.88%
3.86%
3.75%

New user-friendly ECO – coming soon!

(2) Rare Diseases

- ❑ Low prevalence: less than 5 per 10,000 persons (EU)

- ❑ 6,000-8,000 distinct rare diseases

- ❑ 6%-8% of the EU population affected

>30 million people affected in the EU

❑ Limited number of patients per MS

❑ Scattered knowledge and expertise (diagnosis, treatment)

❑ Fragmentation of data sources (>600 registries) across all EU Member States

EURORDIS

Clear EU Added Value

Joint Research Centre

EU Platform on Rare Diseases Registration

Knowledge generation centre for Rare Diseases

- **Registries**
  - national
  - regional
  - local
  - hospital
  - patients'

  …

- **European surveillance networks**

European-level solutions supporting interoperability of data sources:

- **tools (IT tools) guidelines**
- **methods, harmonisation, standardisation**
- **training**

For information providers …… For information users

Data Sharing leads to Knowledge

- patients: - healthcare, social planning
  - good clinical practices, care protocols
  - therapy development

- healthcare   - knowledge development
  providers: - good clinical practices
  - therapy development

- policy makers: - healthcare, social planning
  - evidence for therapy decision making
  - reference for Member States

- researchers: - source of quality data

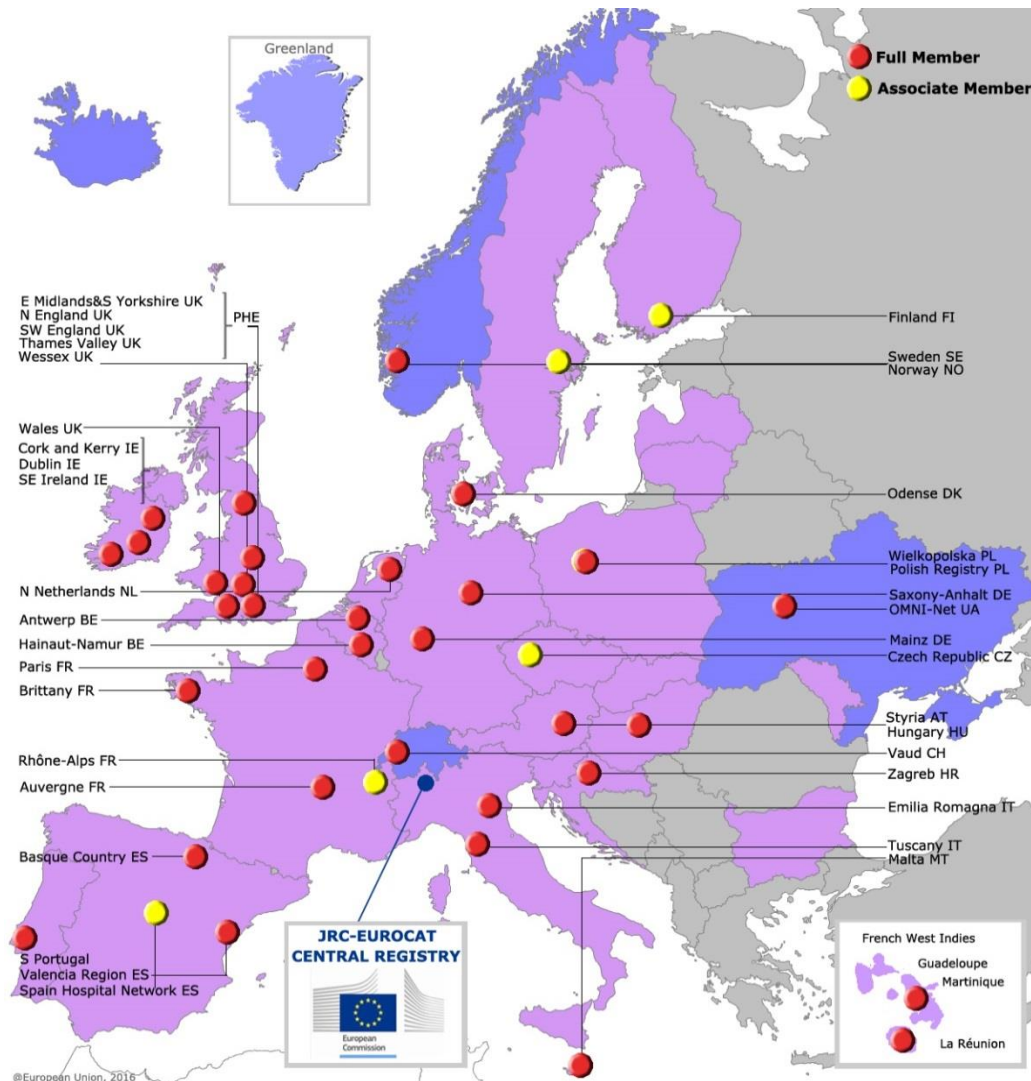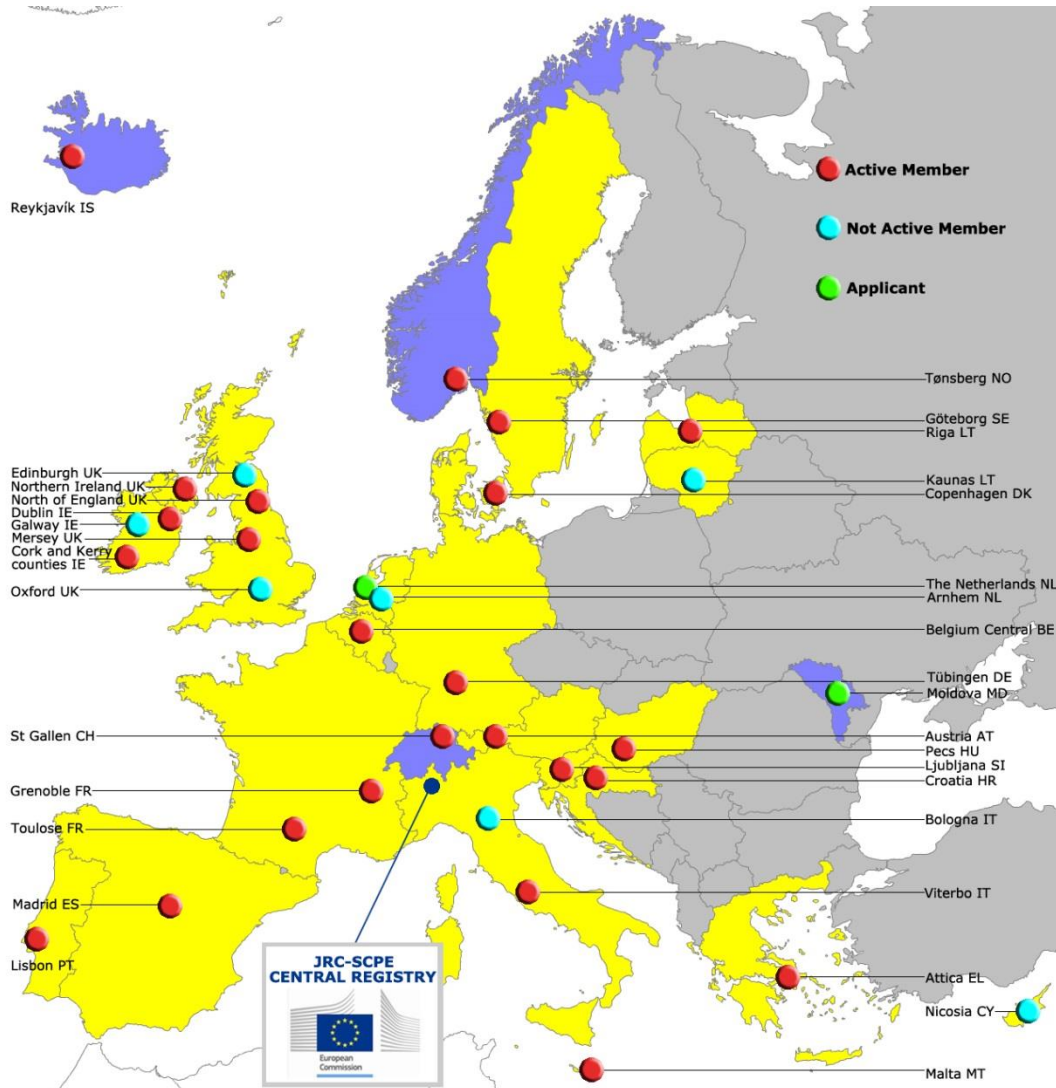- industry: - source of quality data

EUROCAT

FULL MEMBERS

- 32 registries in 18 countries

- population-based registries transmitting case data on all congenital anomaly (CA) cases in their region.

ASSOCIATE MEMBERS

- 6 registries in 6 countries

- transmit an aggregate file containing the total number of cases in each congenital anomaly subgroup by type of birth.

SCPE

31 registries in 23 countries

- A network of population-based registries specialised in epidemiologic surveillance of cerebral palsies (CP)

- Active since 1998

- Active registries: 24

- Non-active registries: 7

Legend:
- Active Member
- Not Active Member
- Applicant

Map labels:
- Reykjavík IS
- Tønsberg NO
- Göteborg SE
- Riga LT
- Edinburgh UK
- Northern Ireland UK
- North of England UK
- Dublin IE
- Galway IE
- Mersey UK
- Cork and Kerry counties IE
- Oxford UK
- Kaunas LT
- Copenhagen DK
- The Netherlands NL
- Arnhem NL
- Belgium Central BE
- Tübingen DE
- Moldova MD
- St Gallen CH
- Austria AT
- Pecs HU
- Ljubljana SI
- Croatia HR
- Grenoble FR
- Toulose FR
- Bologna IT
- Madrid ES
- Viterbo IT
- Lisbon PT
- Attica EL
- Nicosia CY
- Malta MT

JRC-SCPE CENTRAL REGISTRY

Joint Research Centre

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