JRC registries project and potential interaction with ERNs

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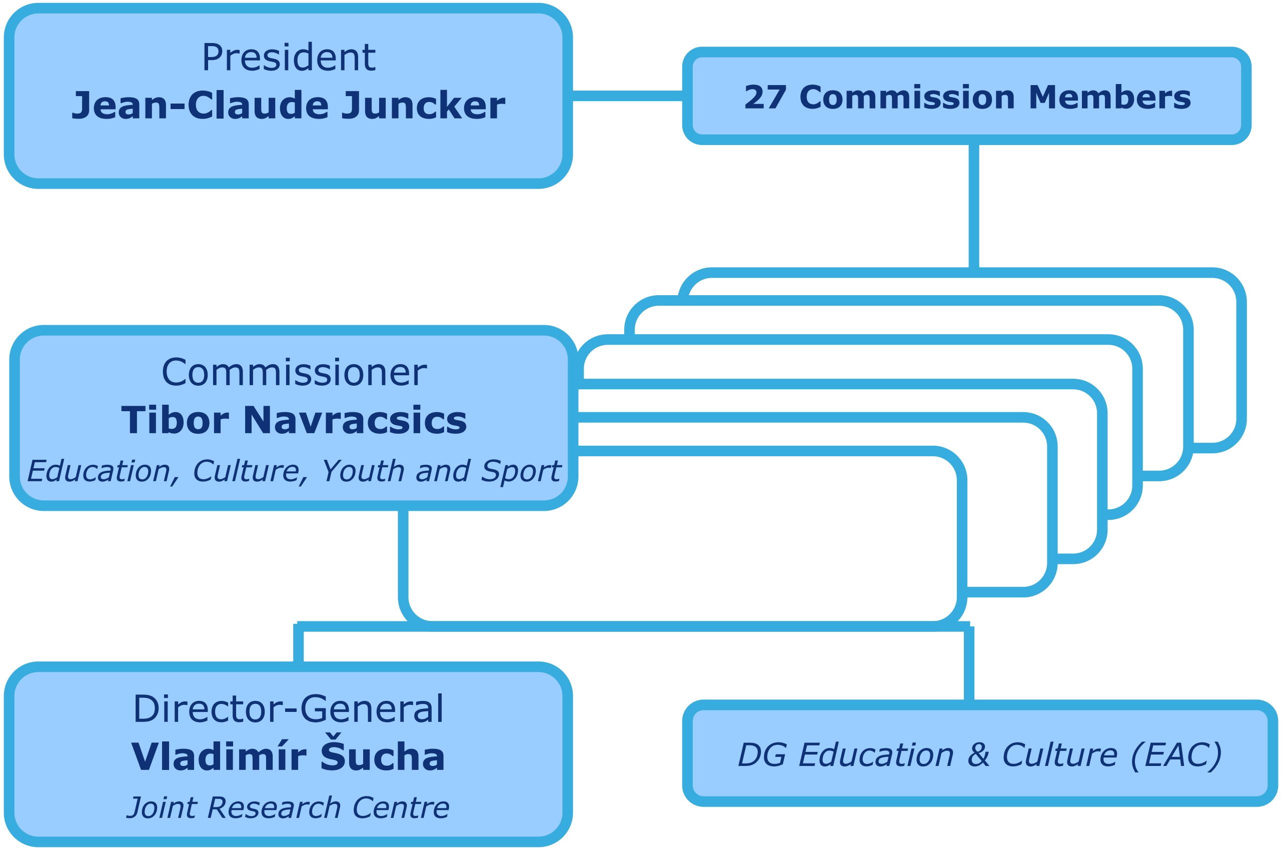
Joint Research Centre
The European Commission's
in-house science service

The JRC in the European Commission



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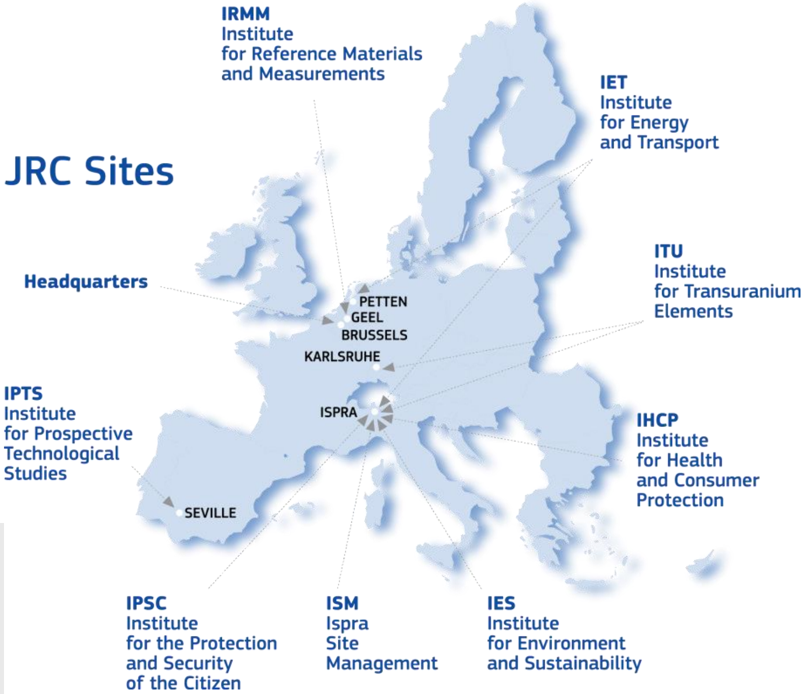

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Public Health Policy Support

1. **Health Information**
    a) **Cancer**
    b) **Rare Diseases**

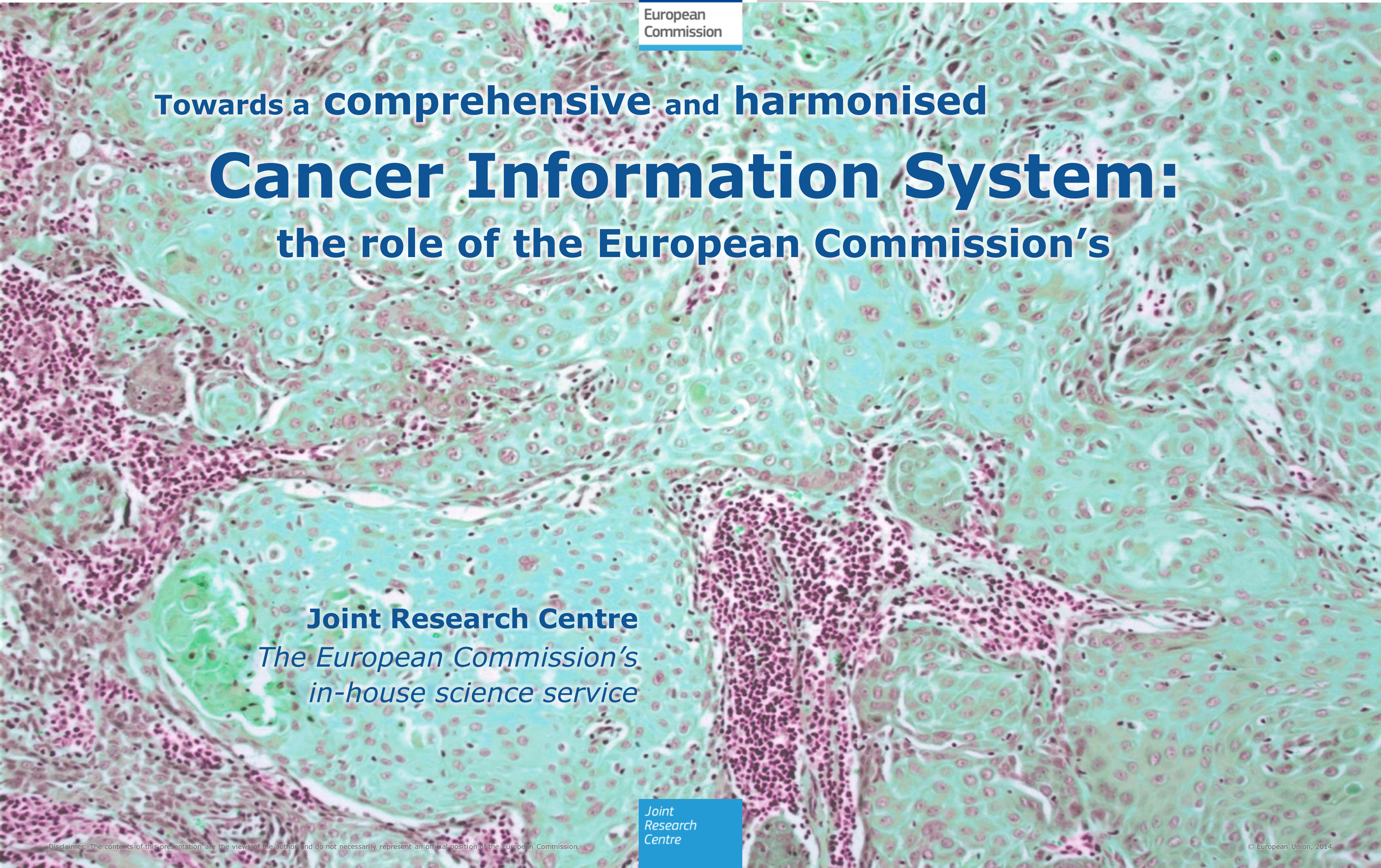
2. **Healthcare Quality**

3. Nutrition & Lifestyle

4. Behavioural Sciences

JRC engagement in Public Health – strategic elements

- Close proximity to the EU decision makers
- Proven track record in harmonisation and standardisation (science base) and consensus building of scientific networks, models and data systems
- Independence of all national/private/commercial interests
- A structure that provides continuity and sustainability
- Networking, engaging stakeholders/experts, organising events
- Flexibility to adapt/grow according to future (political) needs
- Facilitator, coordinator, and scientific-policy partner



Towards a comprehensive and harmonised Cancer Information System: the role of the European Commission's

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Aim and strategy

- To build a comprehensive European Cancer Information System (ECIS)
- Establishing the framework for interoperability of all national/regional registries
- Eventual interoperability with other registries (rare diseases in particular) Coordination with: Eurostat, Joint Actions, WHO
- Collaboration with the INSPIRE framework – integration of health data

European Commission Target

An integrated, comprehensive European cancer information system, to serve:

Science

- ✓ Epidemiological research

Policy making

- ✓ Basis for decision making
- ✓ Basis for health-policy evaluation

Building blocks: the cancer registries

- Support the European Network of Cancer Registries (ENCR)
- Bring together of all stakeholders (countries), agencies (IARC) and projects (EUROCARE, CONCORD, CANCON, etc.)

European Network of Cancer Registries (ENCR)

ENCR was established (1990) within the framework of Europe Against Cancer, a Program of the European Commission

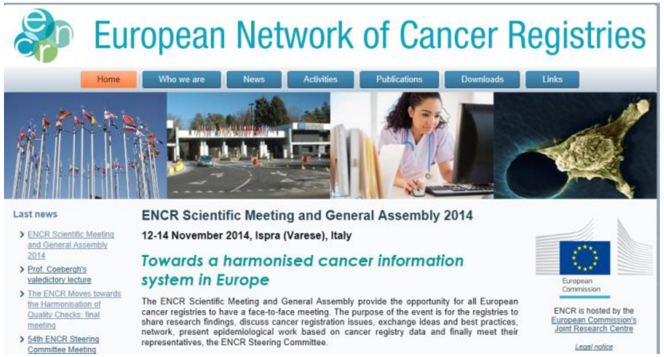
Objectives

To promote collaboration between cancer registries.

To define data collection standards.

To provide training for cancer registry personnel.

To disseminate information (incidence, mortality and survival) from cancer in the European Union and Europe.



Last news

- ENCR Scientific Meeting and General Assembly 2014
- Prof. Coebergh's valedictory lecture
- The ENCR Moves towards the Harmonisation of Quality Checks: final meeting
- 54th ENCR Steering Committee Meeting

ENCR Scientific Meeting and General Assembly 2014

12-14 November 2014, Ispra (Varese), Italy

Towards a harmonised cancer information system in Europe

The ENCR Scientific Meeting and General Assembly provide the opportunity for all European cancer registries to have a face-to-face meeting. The purpose of the event is for the registries to share research findings, discuss cancer registration issues, exchange ideas and best practices, network, present epidemiological work based on cancer registry data and finally meet their representatives, the ENCR Steering Committee.

ENCR is hosted by the European Commission's Joint Research Centre

Legal notice

http://www.encr.eu/

- ✓ ENCR is governed by an elected Steering Committee.
- ✓ The ENCR secretariat is hosted at the European Commission's Joint Research Centre since 2012.
- ✓ The ENCR is affiliated with the International Association of Cancer Registries (IACR).

Rare Diseases

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Rare Diseases

European Commission's strategy

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1. To improve recognition and visibility on rare diseases
2. To support policies on rare diseases in the Member States
3. To develop European cooperation, coordination and regulation for rare diseases

Legal framework

- **Regulation (EC) No 141/2000 on orphan medicinal products** – provides incentives for bringing new drugs for rare diseases to the market

- **Communication from the Commission** to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions **on "Rare Diseases: Europe's challenges"** (2008)

- **Council Recommendation on an action in the field of rare diseases** (2009)

- **Directive** 2011/24/EU **of the European Parliament and**
- **Directive of the Council** (2011) **on the application of patients' rights in cross-border healthcare** covering several aspects of the treatment and care for rare diseases patients

Development of the

EU Platform on Rare Diseases Registration

at the Joint Research Centre (JRC) in collaboration with DG SANTE

Main functions:

- **INTEROPERABILITY**

  600+ existing patient registries across Europe

- **SUSTAINABILITY**

  European surveillance networks

INTEROPERABILITY

- To create the premises for developing interoperability between registries
- To facilitate networking activities
- To support the creation of new registries
- To prepare the conditions for connecting the Platform with other health- or health-related data systems

SUSTAINABILITY

- Transfer to the JRC-Platform of the central registry and European-level coordinating activities of **EUROCAT** (network for surveillance of congenital anomalies in Europe)
- Transfer to the JRC-Platform of the central database and European-level coordinating activities of **SCPE** (network for the surveillance of cerebral palsy in Europe)

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The European Commission Initiative on Breast Cancer (ECIBC)

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A European dimension for quality in healthcare

Inequalities in outcomes occur across Europe.

HOW TO IMPROVE? Quality of care should be defined, measured, and monitored by common *essential* requirements based on evidence.

- **(The what)**
  *In collaboration with Member States, the **EC proposes***
  to develop a set of ESSENTIAL and EVIDENCE-BASED requirements for healthcare services which will be monitored and audited.

- **(The how)**
  Countries can implement them ***in total autonomy***
  according to **Art. 168 of the treaties** (decide on which model to apply in order to attain those requirements).

NO QUALITY WITHOUT MEASUREMENT

NO IMPACT WITHOUT IMPLEMENTATION

Healthcare Quality Team activity

- **Aim**

  To design a tool for balancing efficiency and quality
  for an **increased confidence** of **citizens**
  in quality of healthcare

- **Deliverables**

  European quality assurance schemes
  underpinned by **evidence**-based guidelines
  and accreditation legal frame

- **Method**

  Working groups (individuals)
  Open consultations (stakeholders)
  National contacts

  Transparency & Consensus →Implementation & impact

Potential interactions between ERN and the ECIBC QA scheme

- **The ECIBC *European QA scheme***

  Will set organisational and clinical (evidence-based) requirements for breast cancer services associated to indicators. It will cover all breast cancer care processes. Inclusion of analogue rarer BCs is under discussion

European
Reference
Networks

- **The ERN**

  Concerns in particular rare diseases and cancers. As well requirements need to be set for launching a 'disease-specific' network and for pertaining / leading it. In case rare BCs should be covered, ECIBC can refer to them instead of re-inventing the wheel

Healthcare Quality Team email jrc-cancer-policy-support@ec.europa.eu

European Commission

Thank you for your attention

ec.europa.eu/jrc/

Joint Research Centre