



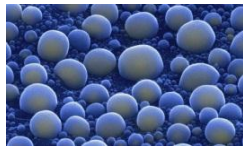
Towards a **comprehensive and harmonised**
cancer information system:
the role of the **European**
Commission's Joint Research
Centre

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

JRC – Institute for Health and Consumer Protection (IHCP)



Molecular Biology and Genomics



Nanobiosciences



Public Health Policy Support



Systems Toxicology



Chemical Assessment and Testing



Public Health Policy Support
Ciaran Nicholl
(Head of Unit)

Unit Work Programme Coordinator
Nicholas Nicholson

Competence Groups

Nutrition and Health
Sandra Louro Caldeira

Cancer and Rare Diseases
Ciaran Nicholl f.f.

Behavioural Research
Benedikt Herrmann

Health Information on Cancer

European Cancer Information System

1. Cancer is the second most common cause of death in the EU

3.45 million new cases of cancer and 1.75 million deaths from cancer in Europe estimated in 2012*

2. European Institutions active in this area since 1987

3. EC Commitment → to reduce the burden of cancer in Europe

Measures to implement this goal depend on accurate and comparable European cancer data (incidence-prevalence-survival-mortality).

*Ferlay et al. Cancer incidence and mortality patterns in Europe: estimates for 40 countries in 2012. EJC. 2013; 49: 1374-1403.

Main Achievements so far

- Hosting of ENCR Steering Committee Meetings at JRC-Ispra (Italy) – starting from December 2012 (2 in 2013 and 3 in 2014).
- Official transfer of the ENCR Secretariat to JRC – August 2013.
- Development and adoption for the ENCR of a new corporate image (including logo, updated website and newsflash) and provision of a common “look and feel” for all ENCR products – August 2013.



European Network of Cancer Registries (ENCR)

- **The ENCR was established (1990) within the framework of the Europe Against Cancer Programme of the European Commission.**
- **Objectives:**
 - To promote collaboration between cancer registries.
 - To define data collection standards.
 - To provide training for cancer registry staff.
 - To disseminate information (incidence, mortality and survival) from cancer in the European Union and Europe.



The screenshot shows the ENCR website homepage. At the top is the ENCR logo and the text "European Network of Cancer Registries". Below this is a navigation menu with links for Home, Who we are, News, Activities, Publications, Downloads, and Links. The main content area features a banner with images of a flagpole, a building, a woman working at a computer, and a map of Europe. Below the banner, there is a "Last news" section with several news items, including "ENCR Scientific Meeting and General Assembly 2014" and "Towards a harmonised cancer information system in Europe". The European Commission logo is also visible.

<http://www.encl.eu/>

- ✓ The ENCR is governed by the Steering Committee.
- ✓ The ENCR is hosted by the European Commission's Joint Research Centre.
- ✓ The ENCR is affiliated to the International Association of Cancer Registries (IACR).

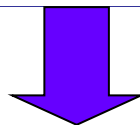
European Network of Cancer Registries (ENCR)

ENCR membership

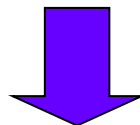


Population-based cancer registries

1. They operate in Europe.
2. They completed the ENCR questionnaire 'Overview of the registration practices' launched on May 2010 and on May 2014.



159 members (37 countries and 66% of population)



←----- 21 countries (1 registry)Spain (16), France (20) and Italy (37) -----→

The ENCR Newsflash



Last news

- Call for applications at IARC
- New Breast Cancer Factsheet
- 55th ENCR Steering Committee Meeting
- 54th ENCR Steering Committee Meeting
- Preliminary results on quality checks for analysing cancer registry data

ENCR Upcoming and Current Activities

Congratulations to the Newly Elected Members of the ENCR Steering Committee!

Following the end of term of Stefano Rosso, Anna Gavin, Sabine Slesling, and Alexander Katalinic, as well as the resignation of Ariana Znaor, ENCR-affiliated cancer registries were invited to cast their votes from 1 September 2014 to 15 October 2014 for the renewal of the elected members of the ENCR Steering Committee. Among the nine candidates, the following nominees were elected: Nadya Dimitrova, Harry Comber, Carlotta Buzzoni, Alexander Katalinic and Maria Dolores Chirinaque. More information about the newly elected members of the ENCR Steering Committee is available here. If you want to know more about the rules and composition of the ENCR Steering Committee, please visit this page.

The 55th ENCR Steering Committee Meeting

12 November 2014

The previous and newly elected ENCR representatives will meet for the first time on the morning of 12 November 2014, right before the opening session of the 2014 ENCR Scientific Meeting. The main topics of discussion will include current and future ENCR activities, particularly in view of the General Assembly on the 13 November 2014.

2014 ENCR Scientific Meeting and General Assembly

12-14 November 2014, Ispra (IT)

The final programme of the 2014 ENCR Scientific Meeting is available online. The event will open with one plenary session on the results from the ENCR working group activities on quality data checks and will continue with five scientific sessions including contributions from five invited speakers, 26 oral and 73 poster presentations. The Scientific Meeting will cover several topics, from quality checks to clinical data, including a discussion on availability of information and statistical methods. All meeting documents, including abstracts of posters and oral presentations, will be distributed at the conference and will be available on the ENCR website.

2014 ENCR Membership Survey: Preliminary Results

13 November 2014, Ispra (IT)

In May 2014, the JRC and the ENCR invited all European cancer registries to participate in the 2014 ENCR survey on cancer registration practices. To date, a total of 118 European cancer registries responded to the invitation and completed the survey. Some preliminary results of the survey will be presented at the 2014 ENCR General Assembly, on 13 November 2014. If for any reason you haven't yet received the invitation to participate in the membership survey, please contact the ENCR secretariat at JRC-ENCR@ec.europa.eu.

- July 2013
- December 2013
- May 2014
- July 2014
- October 2014

The ENCR Factsheets

The factsheets provide an overview of the cancer burden in Europe. They inform about regional differences in incidence within Europe, on gender patterns and on trends over the last decades. Complete with a summary of screening and prevention methods and an overview of causes and risk factors.

Colorectal (CRC)-Large Bowel Cancer Factsheet

Regional differences in 2012
Estimated incidence and mortality

- The countries with the highest estimated incidence rates in Europe were Slovakia, Hungary and Denmark.
- Slovakia reported the highest estimated age-standardized incidence rate** (ASR-E) of 63.5 new cases per 100,000 person-years, to be compared to the European ASR-E of 45.5.
- The European countries with the lowest estimated incidence were Albania, Greece and Bosnia and Herzegovina, with ASR-E less than or equal to 14.
- The European countries with the highest mortality belong to Eastern Europe: Hungary (ASR-E: 34.3), Croatia (ASR-E: 29.0) and Slovakia (ASR-E: 28.6), compared with an European average of 19.5 deaths per 100,000 person-years.
- Albania (ASR-E: 6.5), Cyprus (ASR-E: 10.0) and Iceland (ASR-E: 13.1) reported the lowest estimated mortality rates from CRC among the European countries for 2012.

Gender differences in 2012
Estimated incidence and mortality

- CRC incidence and mortality were notably higher in men than in women.
- The incidence ASR-E in European level was 55.7 for men compared to 34.7 for women.
- The mortality ASR-E were 39.3 compared to 19.4 cases per 100,000 person-years for men and women respectively.

** ASR-E: age-adjusted rate to the standard European population (2012, 100%); age-specific rates to account for the different age structure in various countries.

Prostate (PRC) Cancer Factsheet

Regional differences in 2012
Estimated incidence and mortality

- The countries with the highest estimated incidence rates in Europe were Norway, France and Sweden.
- Norway reported the highest estimated age-standardized incidence rate* (ASR-E) of 93.2 new cases per 100,000 person-years, to be compared to the EU-27** ASR-E of 36.4.
- The countries with the lowest estimated incidence rates in Europe were Ukraine, Moldova and Albania, with ASR-E less than 35.
- The countries with the highest estimated mortality were Lithuania (ASR-E: 36.0), Denmark (ASR-E: 35.7) and Estonia (ASR-E: 25.8), compared with the estimated EU-27 average of 19.3 deaths per 100,000 person-years.
- Albania (ASR-E: 15.4), Malta (ASR-E: 15.6) and Italy (ASR-E: 14.1) reported the lowest estimated mortality rates from PRC in Europe for 2012.
- The variability in estimated mortality rates is clearly minor compared to the variability in estimated incidence rates.

** ASR-E: age-adjusted rate to the standard European population (2012, 100%); age-specific rates to account for the different age structure in various countries.

Lung Including Trachea and Bronchus (LUNGCC) Cancer Factsheet

Regional differences in 2012
Estimated incidence and mortality

- Lung cancer (LUNGCC) develops in the lung, either of the two large organs of respiration located in the chest cavity and responsible for adding oxygen to and removing carbon dioxide from the blood.
- Approximately 69,000 Europeans were estimated to be diagnosed with LUNGCC in 2012, which makes LUNGCC the second most frequent cancer among Europeans, accounting for 17% of all new cases of cancer in Europe for that year.
- In the same year 23,000 Europeans were estimated to die from the disease, accounting for 20% of all new cancer deaths in Europe, making it the most common cause of cancer death.
- Worldwide LUNGCC has been the most common cancer for several decades. There are estimated to be 18 million new cases in 2012 (15% of the total), 59% of which occurred in low income regions. LUNGCC is the most common cancer in the lung, either of the two large organs of respiration located in the chest cavity and responsible for adding oxygen to and removing carbon dioxide from the blood.
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Breast Cancer (BC) Factsheet

Regional differences in 2012
Estimated incidence and mortality

- The countries with the highest estimated incidence rates in Europe were Belgium, Denmark and France. Belgium reported the highest estimated age-standardized incidence rate* (ASR-E) of 147.5 new cases per 100,000 PP compared to the European average** ASR-E of 94.3.
- The countries with the lowest estimated incidence were Ukraine, Moldova and Bosnia and Herzegovina with ASR-E less or equal to 24.0.
- The countries with the highest estimated mortality were FYR Macedonia with ASR-E of 36.3 deaths per 100,000 PP. Serbia (ASR-E: 35.9) and Belgium (ASR-E: 35.5) compared to the estimated European average of 31.5.
- Estonia (ASR-E: 19.1), Spain (ASR-E: 18.7) and Lithuania and Hungary (ASR-E: 18.6) reported the lowest estimated mortality rates from BC in Europe for 2012.

Temporal changes in selected European countries^{1,4}

- Due to differences in country-specific screening activities, BC care services and the distribution of aetiology.

** ASR-E: age-adjusted rate to the standard European population (2012, 100%); age-specific rates to account for the different age structure in various countries.

December 2013

March 2014

June 2014

September 2014

Training courses

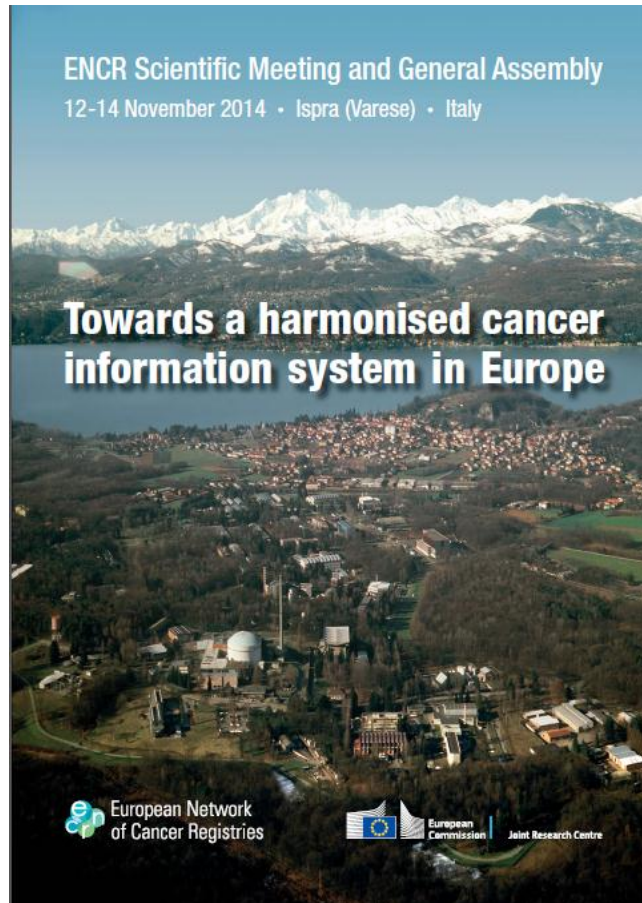
- Organisation and funding of a Cancer Registry Training Course (45 participants): Izmir, Turkey, 30 Sep - 4 Oct 2013

Participants from: Albania, Algeria, Armenia, Azerbaijan, Bahrain, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Egypt, Faroe Island, the Former Yugoslav Republic of Macedonia, Georgia, Iceland, Israel, Iraq, Jordan, Kosovo, Lebanon, Libya, Liechtenstein, Kuwait, Moldova, Montenegro, Morocco, Norway, Occupied Palestinian Territory, Oman, Qatar, Romania, Russia, Saudi Arabia, Serbia, South Sudan, Sudan, Switzerland, Syria, Tunisia, Turkey, Ukraine, United Arab Emirates, Yemen, Western Sahara.

- Paediatric Oncology for Cancer Registries Training course: IARC, Lyon (France), 25 to 29 November 2013

ENCR Scientific Meeting and General Assembly

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



165 participants and
99 abstracts
26 oral presentations
73 posters

2014 ENCR survey: Cancer registration practices

Aim

- Build the JRC database of European registries
- Update information on registration practices
- Disseminate info to the ENCR members and SC

118 registries in 35 countries

Contact info

Registry description (geography, coverage, type, year established)

Conditions of cancer registration (legislation, personal identifiers, restrictions)

Funding sources

Data sources

Registration criteria and procedures (sites, data collected and coding, etc.)

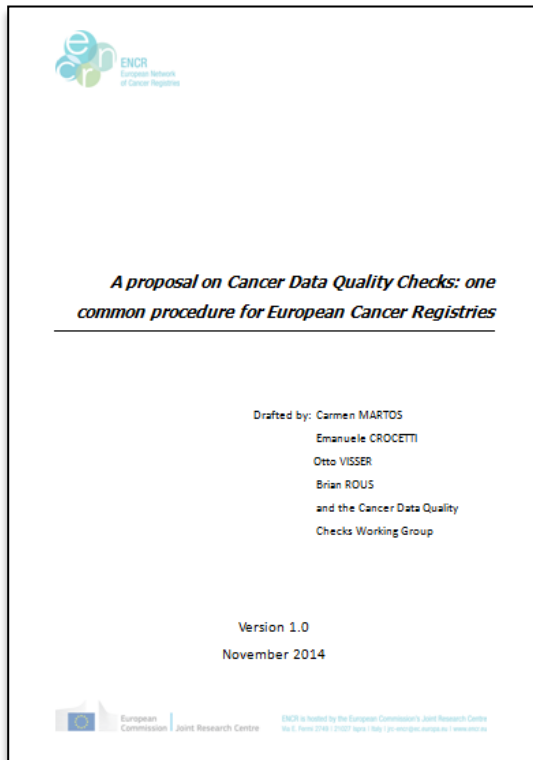
A proposal on Cancer Data Quality Checks

Objectives

- ❑ To establish a comprehensive, standardised, and common list of quality checks for harmonising CR data for international studies
- ❑ To stimulate collaborations between CRs and the main stakeholders in cancer information in Europe

Focuses on

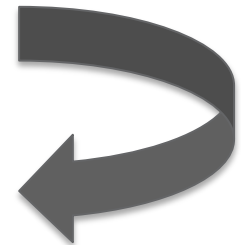
- ❑ Case definition
- ❑ Variables and their formats
- ❑ Internal consistency checks



Impossible codes or combinations → Error

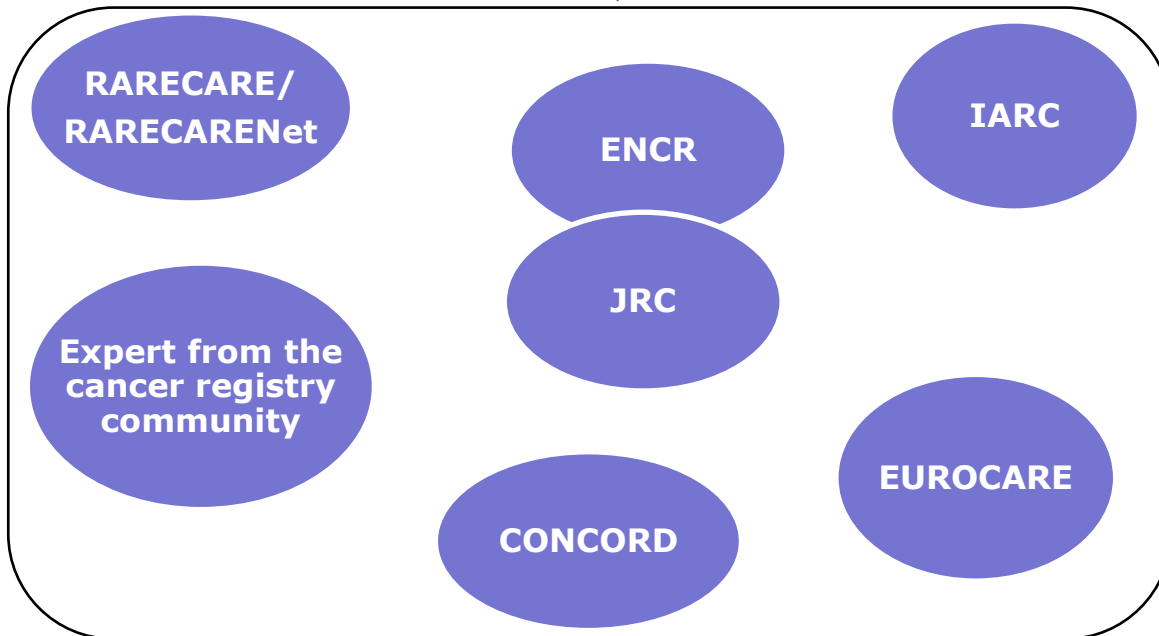
Very unlikely codes or combinations → Warning

Possible, but very rare code or combinations → Warning



A proposal on Cancer Data Quality Checks

Working Group



3 Workshops at JRC - Ispra (Italy)



2 July 2013

Overview of data quality checks used by major EU studies and open discussions on quality control methods.

15 October 2013

Agreement was reached on the mandatory and basic variables list and their formats.

4 June 2014

Discussion and agreement for "One common procedure for European Cancer Registries"

On-going and Future Priorities

- Providing an up-to-date **mapping of the European cancer registries**, their individual registration processes and needs.



Analysis of the 2014 ENCR survey

- Becoming a reliable and sustainable **data hub for epidemiological research** in cancer.



Development of a free software for quality checks

Call for data in 2015

- Bring all **stakeholders and expert groups together** to tackle priority issues



ENCR-JRC working groups

On-going and Future Priorities

- Organising **training courses** and **workshops**.
- Collaborating in projects like **HIRESELD** – European High Resolution Study on ELDERly patients (co-morbidity), childhood cancer, etc
- Ensure alignment with other EU-wide initiatives (ex.INSPIRE) and other EC DGs (SANCO, EUROSTAT, RTD,...).

For More Information:

http://ihcp.jrc.ec.europa.eu/our_activities/public-health/cancer_policy_support

<http://www.encre.eu>

Thank You for Your Attention

JRC-ENCR@ec.europa.eu



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