



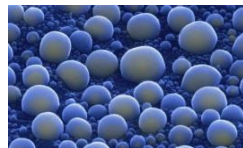
Towards a **comprehensive and harmonised**  
**cancer information system:**  
the role of the **European**  
**Commission's Joint Research**  
**Centre**

Jerica Zupan, MSC Pharm, MBA  
**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)*

**Competence Groups**

**Nutrition and Health**

*Sandra Louro Caldeira*

**Cancer and Rare Diseases**

*Nicholas Nicholson*

**Behavioural Research**

*Benedikt Hermann*

**Cancer Information**



European  
Commission

# 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, there is a navigation menu with links for Home, Who we are, News, Activities, Publications, Downloads, and Links. Below the menu is a banner image featuring a map of Europe, a person working at a computer, and a building. The main content area is titled "ENCR Scientific Meeting and General Assembly 2014" and "Towards a harmonised cancer information system in Europe". It includes a list of "Last news" items and a logo for the European Commission's Joint Research Centre.

<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).

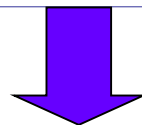
# European Network of Cancer Registries (ENCR)

ENCR membership

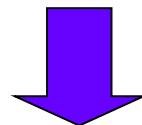


**Population-based cancer registries**

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 Zhaor, 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 Chiriac. 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](mailto:JRC-ENCR@ec.europa.eu).

- July 2013
- December 2013
- May 2014
- July 2014
- October 2014
- January 2015 – in preparation

# 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. New Factsheet in preparation (Melanoma)

## Colorectal Cancer (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\*\* (ASIR) of 63.5 new cases per 100,000 person-years, to be compared to the European ASIR of 45.5.
- The European countries with the lowest estimated incidence were Albania, Greece and Bosnia and Herzegovina, with ASIR less than or equal to 24.
- The European countries with the highest mortality belong to Eastern Europe: Hungary (ASIR: 39.3), Croatia (ASIR: 39.0) and Slovakia (ASIR: 38.0), compared with an European average of 19.3 deaths per 100,000 person-years.
- Albania (ASIR: 6.5), Cyprus (ASIR: 10.8) and Iceland (ASIR: 13.1) reported the lowest estimated mortality rates from CRC among the European countries for 2012.

### Gender differences in 2012 Estimated incidence and mortality

- Colorectal cancer (CRC), also known as Bowel Cancer, is cancer of the colon and/or rectum. The colon, also called the large intestine, is the part of the body's digestive system that moves waste material from the small intestine to the rectum.
- Each year approximately 497,000 Europeans\* are newly diagnosed with CRC.
- In 2012 CRC accounted for nearly 15% of all new cases of cancer in Europe.
- In 2012, 144,975 people were estimated to die from the disease, making CRC the second leading cause of cancer death in Europe.
- Worldwide, the incidence of CRC varies tremendously, with the highest estimated rates occurring in Australia and New Zealand and Western Europe\*.

\*\* ASIR: age-adjusted rate to the standard European population (2012, 100,000) to account for the different age structure in various countries.

December 2013

## Prostate Cancer (PRC) Cancer Factsheet



Western and Northern Europe and North America whereas the lowest age-standardized incidence rate is estimated in South-Central Asia (4 per 100,000)\*\*.

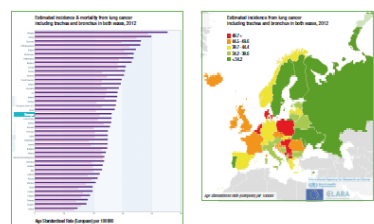
- Worldwide: Half of the registered deaths occur in high income countries however, mortality rates differ less (50-fold) than is observed for incidence (35-fold).<sup>1</sup> Highest death rates are in Afro-Caribbean countries.

### Regional differences in Europe 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\* (ASIR-E) of 39.3 new cases per 100,000 person-years, to be compared to the EU-28\*\* ASIR-E of 36.0.
- The countries with the lowest estimated incidence were Ukraine, Moldova and Albania, with ASIR-E less than 20.
- The countries with the highest estimated mortality were Lithuania (ASIR-E: 36.0), Denmark (ASIR-E: 35.7) and Estonia (ASIR-E: 24.8), compared with the estimated EU-28 average of 19.3 deaths per 100,000 person-years.
- Albania (ASIR-E: 13.4), Malta (ASIR-E: 13.6) and Italy (ASIR-E: 14.3) reported the lowest estimated mortality rates from PRC in Europe for 2012.
- Worldwide: three quarters of the registered cases of PRC occurred in high income countries in 2008. Incidence rates of PRC vary tremendously (35-fold); the highest rates are in Australia/New Zealand (69.5 per 100,000).
- ASIR-E: age-adjusted rate to the standard European population (2012, 100,000) to account for the different age structure in various countries.
- \*\* The European Cancer Observatory (ECO) estimates incidence in the European countries defined by the United Nations plus Cyprus.

March 2014

## Lung Including Trachea and Bronchus (LUNG) Cancer Factsheet



- Lung cancer (LUNG) 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 690,000 Europeans were estimated to be diagnosed with LUNG in 2012, which makes LUNG the second most frequent cancer amongst Europeans, accounting for 21% of all new cases of cancer in Europe for that year.
- In the same year 350,000 Europeans were estimated to die from the disease, accounting for 30% of all new cancer deaths in Europe, making it the most common cause of cancer death.
- Worldwide: LUNG has been the most common cancer for several decades. There are estimated to be 1.4 million new cases in 2012 (15% of the total), 95% of which occurred in low income regions. LUNG is the most com-

June 2014

## Breast Cancer (BC) Factsheet



### Regional differences in Europe in 2012 Estimated incidence and mortality<sup>1</sup>

- The countries with the highest estimated incidence rates in Europe were Belgium, Denmark and France. Belgium reported the highest estimated age-standardized incidence rate\* (ASIR-E) of 47.5 new cases per 100,000 PY compared to the European average\*\* ASIR-E of 36.2.
- The countries with the lowest estimated incidence were Ukraine, Moldova and Bosnia and Herzegovina with ASIR-E less or equal to 14.0.
- The countries with the highest estimated mortality were FYR Macedonia with ASIR-E of 36.4 deaths per 100,000 person-years, compared to the estimated European average of 13.1.
- Estonia (ASIR-E: 24.3), Spain (ASIR-E: 16.7) and Bosnia and Herzegovina (ASIR-E: 16.3) reported the lowest estimated mortality rates from BC in Europe for 2012.

### Temporal changes in selected European countries<sup>1,3</sup>

- Due to differences in country-specific screening activities, BC care services and the distribution of aetiology.
- ASIR-E: age-adjusted rate to the standard European population (2012, 100,000) to account for the different age structure in various countries.
- \*\* The European Cancer Observatory (ECO) estimates incidence in the 39 European countries defined by the United Nations plus Cyprus.

September 2014





# Training courses

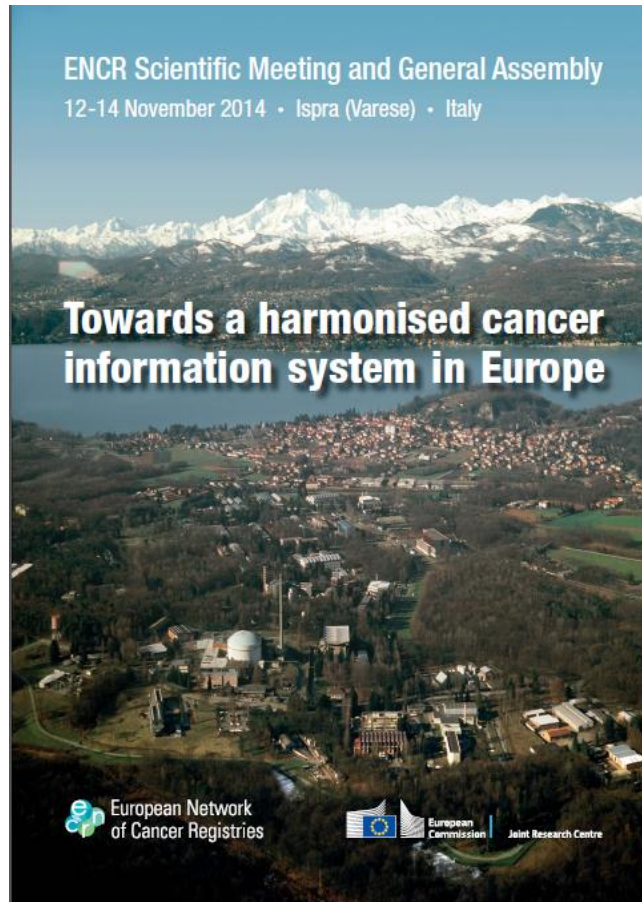
- Organisation and funding of a Cancer Registries (Training Course) (45 participants): Izmir, Turkey, 30 Sep - 4 Oct 2013

*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



# 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



J R C T E C H N I C A L R E P O R T S



A proposal on cancer data quality checks:

**one common procedure**  
for **European cancer registries**



Carmen Martos,  
Emanuele Crocetti (Coordinator),  
Otto Visser, Brian Rous and the  
*Cancer Data Quality Checks Working Group*

2014

Version 1.0 - November 2014



Report EUR 27 028 EN

## 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

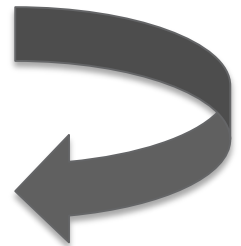
## Focuses on

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

**Impossible codes or combinations → Error**

**Very unlikely codes or combinations → Warning**

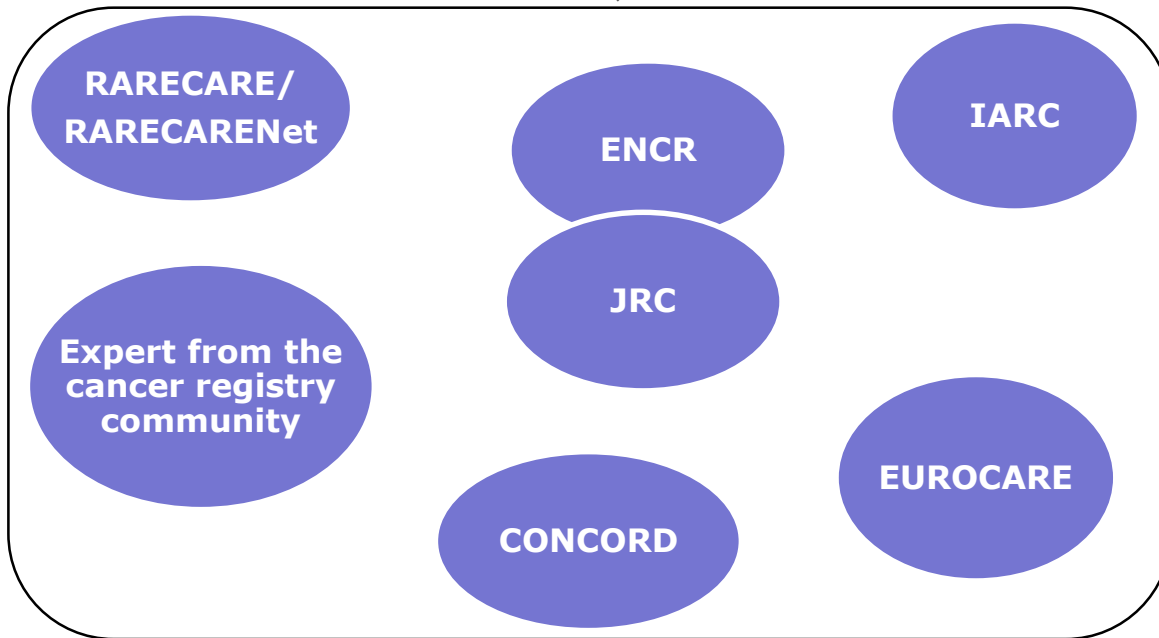
**Possible, but very rare code or combinations → Warning**



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# 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**.
- Ensure alignment with other EU-wide initiatives (ex.INSPIRE) and other EC DGs (SANTE, EUROSTAT, RTD,...).

### For More Information:

[http://ihcp.jrc.ec.europa.eu/our\\_activities/public-health/cancer\\_policy\\_support](http://ihcp.jrc.ec.europa.eu/our_activities/public-health/cancer_policy_support)

<http://www.encr.eu>

# Thank You for Your Attention

[JRC-ENCR@ec.europa.eu](mailto:JRC-ENCR@ec.europa.eu)



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