



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

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

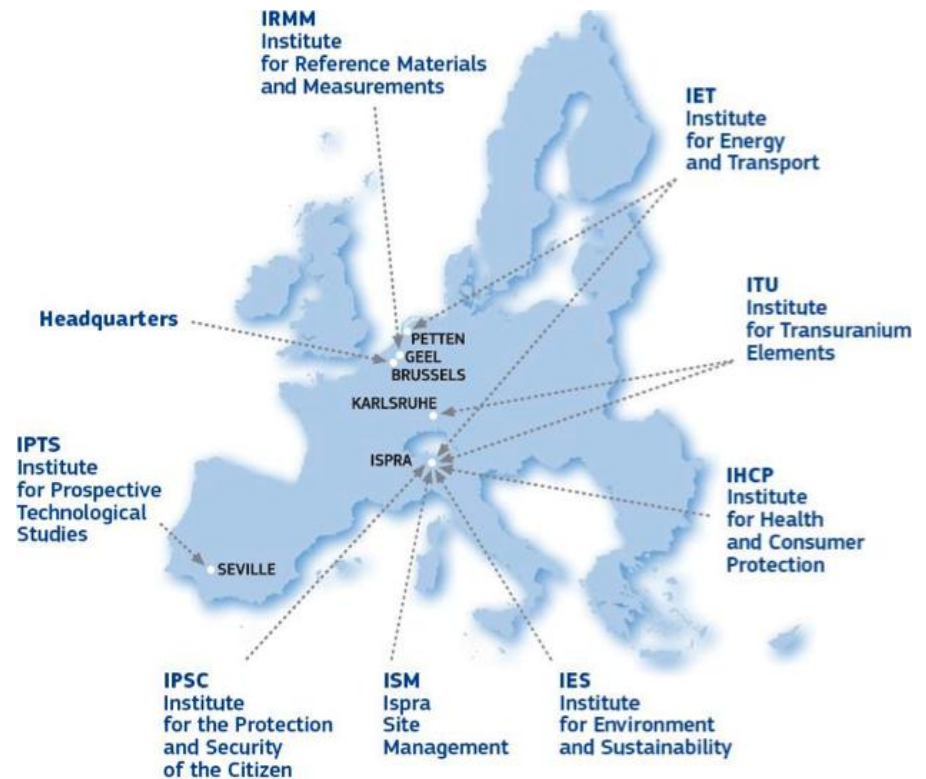
Joint  
Research  
Centre



# The Joint Research Centre within the European Commission



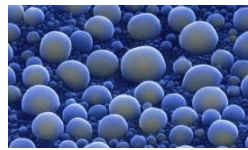
- Established 1957.
- 7 institutes in 5 countries.
- 2822 permanent and temporary staff in 2012.
- 1443 scientific publications in 2012.
- Budget: €380 million annually, plus €69 million earned income.



# 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**

# Background – 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 successfully 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". *Eur J Cancer* (2013 Apr) 49(6):1374-403.

# European Cancer Information System

## Main Achievements so far

- Hosting of ENCR Steering Committee Meetings at JRC-Ispra (Italy) – starting from December 2012.
- 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) providing 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 personnel.
  - 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 logo with three stylized figures in green and blue, followed by the text "European Network of Cancer Registries". Below this is a navigation bar with buttons for "Home", "Who we are", "News", "Activities", "Publications", "Downloads", and "Links". The main content area features a banner with four images: a row of flags, a modern building, a woman working at a computer, and a map of Europe. Below the banner, there is a "Last news" section with a list of recent events, including the "ENCR Scientific Meeting and General Assembly 2014" held in Varese, Italy, from November 12-14, 2014. A prominent headline reads "Towards a harmonised cancer information system in Europe". To the right of the text is the European Commission logo and a note stating "ENCR is hosted by the European Commission's Joint Research Centre".

<http://www.encr.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).

# Main Achievements so far

Launch of the new ENCR website  
[www.encr.eu](http://www.encr.eu) – August 2013.

The *ENCR Newsflash*:  
– August 2013  
– December 2013



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 buttons for Home, Who we are, News, Activities, Publications, Downloads, and Links. The main content area features a large image of a woman working at a computer, with a map of Europe to the right. Below the image is the text: "ENCR Scientific Meeting and General Assembly 2014 12-14 November 2014, Ispra (Varese), Italy". To the left of this text is a sidebar with "Last news" and a search box. Below the main text is the European Commission logo and the text: "ENCR is hosted by the European Commission's Joint Research Centre".



The screenshot shows the ENCR Newsflash newsletter for December 2013. The header includes the ENCR logo and the text "European Network of Cancer Registries" followed by "NEWSFLASH" in large letters. Below the header is a decorative image of a microscopic view of tissue. The main content is organized into sections: "Last news" with a list of recent events, "In Brief" with a summary of the ENCR's move towards harmonisation of quality checks, "IARC and JRC Participates in the International Association of Cancer Registries 35th Annual Conference", "Highlights from Cancer Registries Training Course", and "Recent Events" with details about a paediatric oncology training course. The footer includes the European Commission logo and the text "European Commission".



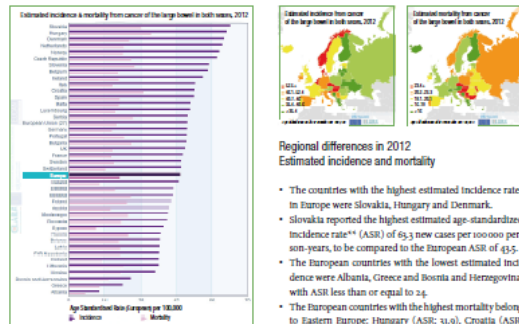
# Main Achievements so far

## ENCR Cancer Factsheets December 2013

European Network of Cancer Registries **ENCR Factsheets**

December 2013

### 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) of 63.3 new cases per 100,000 person-years, to be compared to the European ASR of 43.5.
- The European countries with the lowest estimated incidence were Albania, Greece and Bosnia and Herzegovina, with ASR less than or equal to 24.
- The European countries with the highest mortality belong to Eastern Europe: Hungary (ASR: 31.9), Croatia (ASR: 29.0) and Slovakia (ASR: 28.6), compared with an European average of 19.5 deaths per 100,000 person-years.
- Albania (ASR: 6.5), Cyprus (ASR: 10.8) and Iceland (ASR: 12.2) 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 ASRs at European level were 55.7 for men compared to 31.7 for women.
- The mortality ASRs were 25.2 compared to 15.4 cases per 100,000 person-years for men and women respectively.

- 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 447,000 Europeans\* are newly diagnosed with CRC.
- In 2012 CRC accounted for nearly 13% of all new cases of cancer in Europe.
- In 2012, 214,673 people were estimated to die from the disease, making CRC the second leading cause of cancer deaths in Europe.
- Worldwide, the incidence of CRC varies tremendously, with the highest estimated rates occurring in Australia/New Zealand and Western Europe.

\* The European Cancer Observatory (ECO) estimates refers to the 39 European countries defined by the United Nations plus Cyprus.

\*\* ASR: age-adjusted rate to the standard European population (Doll, 1996), to account for the different age structure in various countries.

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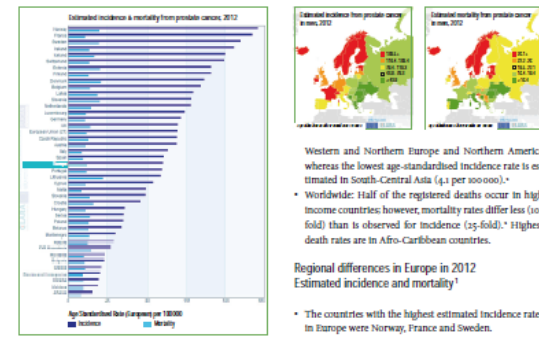
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## ENCR Cancer Factsheets March 2014

European Network of Cancer Registries **ENCR Factsheets**

March 2014

### Prostate (PRC) Cancer Factsheet



- Western and Northern Europe and Northern America whereas the lowest age-standardized incidence rate is estimated in South-Central Asia (4.1 per 100,000).
- Worldwide: Half of the registered deaths occur in high income countries however, mortality rates differ less (10-fold) than is observed for incidence (35-fold). 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\* (ASR-E) of 193.2 new cases per 100,000 person-years, to be compared to the EU-39\*\* ASR-E of 96.0.
- The countries with the lowest estimated incidence were Ukraine, Moldova and Albania, with ASR-E less than 32.
- The countries with the highest estimated mortality were Lithuania (ASR-E: 36.0), Denmark (ASR-E: 33.7) and Estonia (ASR-E: 32.8), compared with the estimated EU-39 average of 19.5 deaths per 100,000 person-years.
- Albania (ASR-E: 13.4), Malta (ASR-E: 13.6) 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 more compared to the variability in estimated incidence rates.

- Prostate cancer (PRC) develops in the prostate, a gland in the male reproductive system located directly beneath the bladder, which adds secretions to the sperm during the ejaculation of semen.
- Approximately 417,000 Europeans were estimated to be diagnosed with PRC in 2012, which makes PRC the most frequent cancer amongst European men accounting for 12% of all new cases of cancer in Europe for this year.
- In the same year 90,200 European men were estimated to die from the disease accounting for 5% of all new cancer deaths in Europe.
- 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 (104.2 per 100,000),

\* ASR-E: age-adjusted rate to the standard European population (Doll, 1996) to account for the different age structure in various countries.

\*\* The European Cancer Observatory (ECO) estimates refers to the 39 European countries defined by the United Nations plus Cyprus.

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Via E. Fermi 2749 | 21027 Ispra (VA) | Italy [www.enccr.eu](http://www.enccr.eu)



## Main Achievements so far

- Organisation and funding of a Cancer Registry Training Course, in collaboration with ENCR, IARC, MECC and the US National Cancer Institute, E&I countries, Izmir, Turkey, 30 Sep - 4 Oct 2013:
  - to provide CR staff with understanding of good practices and procedures to establish/improve their registries and harmonise their processes for data collection;
  - to facilitate inter-comparative studies on specific cancer types;
  - to provide participants basic principles of cancer epidemiology and use of statistical tools;
  - to develop closer links with the ENCR, JRC, IARC.

*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.

# Main Achievements so far

3 Workshops on "Quality checks for analysing cancer registry data: development for one common procedure"

- **2 July 2013**

Overview of data quality checks in the EU and open discussions on a range of quality control.

- **15 October 2013**

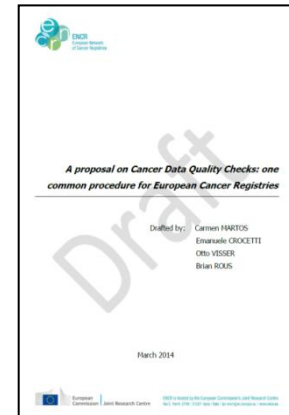
Agreements were reached for the mandatory and basic variable list and their format. A working group for revision and proposal of internal consistency checks was created.

- **4 June 2014**

Final revision, discussion and agreements



*Summary of Cancer Data Quality Checks*



# On-going and Future Priorities

## 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.

The scientific sessions will cover topics such as:

- *Availability, completeness and reliability of information collected by registries*
- *Clinical data: Integration and use of clinical datasets in population-based registries*
- *Privacy and data confidentiality issues: current national and EU regulations*
- *Coding issues such as extent of disease, haematological malignancies coding rules date of diagnosis and multiple cancers*
- *Statistical methods and software for use of cancer registries*
- *Collaboration with public health, patients and non-governmental organizations*
- *Cancer burden in Europe: incidence, mortality, survival and prevalence*
- *Electronic data collection: new tools or old threats.*



Meeting venue: the JRC-Ispra site, the third biggest Commission site after Brussels and Luxembourg, covers an area of 167 hectares and is located in Ispra (VA), a small town on the shore of Lake Maggiore in the province of Varese of the Lombardy region, Italy. After more than 50 years of development, Ispra is firmly established as one of Europe's leading research campuses. Nested in the beautiful setting of the Italian lakes, Ispra provides a fascinating, multicultural working environment for people from all over Europe and beyond. For more information on the Ispra site, please visit the JRC web page.

## On-going and Future Priorities

- Providing an up-to-date **mapping of the European cancer registries**, their individual registration processes and needs.
- Becoming a reliable and sustainable **data hub for epidemiological research** in the cancer data domain.
- Start gradually the **transfer of ENCR data and tools to the JRC**, to stabilise the management of cancer data by the European Commission on a permanent basis in the future.
- Bring all **stakeholders and expert groups together** to tackle priority issues through training programmes, conferences, workshops.
- Ensure alignment with other EU-wide initiatives and other EC DGs (SANCO, EUROSTAT, RTD).



# For More Information

## Websites

[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

