



*Legal notice*

## ENCR Activities

### 2016 ENCR Scientific Meeting and General Assembly

The ENCR Scientific Meeting and General Assembly took place in Baveno, Italy, 5-7 October 2016. With over 160 participants, 36 oral presentations and 50 posters, the scientific conference was a great success. During the six Scientific Sessions experts from cancer registries presented their work. Presentations covered quantification of the cancer burden in Europe, use of cancer registries for the evaluation of cancer care, methods and measures for assessing cancer data quality and statistical and other software tools currently used for data collection and quality control.

Three keynote speakers presented talks on the future of cancer registration; patients' attitudes about using their data for cancer research; and childhood cancer outcomes research.

The General Assembly took place on Thursday 6 October 2016 and was an opportunity for the JRC and the ENCR to update participants on ENCR- JRC activities between 2014 and 2016. These include the following:

- the 2015 ENCR-JRC Call for Data and related development of the data submission portal;
- the release of the Quality Check software and continuous planned improvements;
- new ideas for the development of data visualisation tools;
- the initiatives around the revision of specific ENCR recommendations;
- the updating of ENCR Membership rules;
- new and planned publications, including factsheets;
- training events and registry reviews.

A tentative timetable for the ENCR-JRC project was presented. The last deadline to submit data to the current call is 31 October 2016. A new Call for Data will be launched at the end of 2017.

A talk was presented on the new Data Protection Regulation, highlighting the fact that cancer registries will have to work very hard to ensure data sharing restrictions do not impact public health and clinical research.

The results of the survey of cancer registries were summarized. The main concerns for cancer registries include sustainable funding, quality control processes and implementation of the new Data Protection Regulation. The benefit of exchanging information on best practices, including on how to effectively and efficiently run a cancer registry, were discussed especially since some cancer registries have limited resources. It was also acknowledged that translation of ENCR documents, including training materials, is very important for cancer registries with staff that do not speak English.

The need for a formal certificate for tumour registration officers was discussed. Some registries are investigating the possibility of designing and implementing a formal accreditation and will keep the ENCR updated.

More information, including copies of presentations, is available at <http://encr.eu>.

A Training Workshop on Quality of Cancer Registry Data took place before the Scientific Meeting and General Assembly, on Wednesday 5 October from 9.00-13.00 am. Almost 50 participants attended the workshop which covered the process of data quality evaluation, methods for assessing the completeness of data, use of the JRC-ENCR Quality Check software and reading outputs. The JRC provided feedback on the ENCR-JRC project and the further processing and feedback that will be sent to the registries.

### 2015 ENCR-JRC Call for Data and Project – update

The 2015 ENCR-JRC Call for Data, intended for all European population-based Cancer Registries, aimed to build a unique anonymised database of cancer information and to accommodate multiple studies (JRC-ENCR project, EUROCARE, and CIS-XI). So far, 113 cancer registries, from 29 different European countries, have submitted data through the ENCR-JRC portal. More information on the Call is available at <http://encr.eu/index.php/activities/2015-call-for-data>.

For the ENCR-JRC project 107 CRs for 29 European countries are participating. The last opportunity for registries to submit data is 31 October 2016. In the coming months each cancer registry will receive a summary feedback report on the quality of data submitted. Preliminary results will be shared with the cancer registries before publication. A second Call for Data will be launched at the end of 2017.

### New JRC- ENCR Software for Quality Checks

The JRC- ENCR software includes format checks for incidence, population, mortality, and life table files. Multivariate consistency edits of incidence data are also included. A new version of the software was launched in July 2016. This was presented at the training workshop held prior to the ENCR Scientific Meeting and General Assembly. Your feedback is very welcome and of great value to improve and further develop the software. For the moment, the software is intended for limited distribution to ENCR-affiliated registries only and can be downloaded from the following address: <https://portal-encr.jrc.ec.europa.eu/download>.

### The 61<sup>st</sup> ENCR Steering Committee meeting

The summary of the minutes of the 61<sup>st</sup> ENCR Steering Committee on 4 October 2016 will be posted on the ENCR website: [http://encr.eu/images/docs/sc/61st\\_SCmeeting-Summary-minutes.pdf](http://encr.eu/images/docs/sc/61st_SCmeeting-Summary-minutes.pdf).

### 38<sup>th</sup> IACR Annual Meeting

19-21 October 2016, Marrakech, Morocco

This Annual Conference of the International Association of Cancer Registries was hosted by the Casablanca Cancer Registry and the Princess Lalla Salma Foundation. Professor Alexander Katalinic, Chair of the ENCR, presented a keynote speech, "One the way to a sustainable structure – Recent activities of the European Network of Cancer Registries". The JRC Cancer Information Group contributed with one oral and four poster presentations. More information is available at <http://www.iacr.com.fr/>.

## Upcoming events

### 9<sup>th</sup> European Public Health Conference: All for Health – Health for All

9-12 November 2016, Vienna, Austria

The European Public Health Conference Foundation, the European Public Health Association (EUPHA) and the Österreichische Gesellschaft für Public Health are organising the 9<sup>th</sup> European Public Health Conference. This Conference aims to contribute to the improvement of public health in Europe by offering a means for exchanging information and a platform for debate to researchers, policy makers, and practitioners in the field of public health and health services research as well as public health training and education in Europe.

The JRC will participate and organise a workshop, at the conference, dedicated to the ENCR- JRC activities. Updates on the ENCR- JRC project and data quality assessment of related collected data will be presented.

The Conference will be held in Austria Center Vienna (ACV). More information is available on the conference website: <https://ephconference.eu/>.

### European Commission Initiative on Breast Cancer (ECIBC) Plenary meeting

24-25 November 2016, Lake Maggiore District, Italy

This meeting will take place in Italy on 24-25 November 2016 in the surroundings of Lake Maggiore. This year's plenary theme is ECIBC: when Science and Policy collaborate for Health. The first day will focus on Science for Policy Development and the second day on Policy for Science Implementation.

More information is available at: <http://ecibc.jrc.ec.europa.eu/-/ecibc-plenary-2016>.

### 28<sup>th</sup> EORTC-NCI-AACR symposium on "Molecular targets and cancer therapeutics"

29 November – 2 December 2016, Munich, Germany

This symposium will be hosted by the European Organisation for Research and Treatment of Cancer (EORTC), the National Cancer Institute (NCI) and the American Association for Cancer Research (AACR). The event will bring together around 2000 academics, scientists and pharmaceutical industry representatives from across the globe to discuss innovation in drug development, target selection and the impact of new discoveries in molecular biology. More information is available from the European Cancer Organisation: <http://www.ecco-org.eu/ENA2016>.

## Recent publications

Recent publications using European Cancer registry data, from 1 August 2016- 31 October 2016, can be found on the ENCR website: <http://encr.eu/index.php/publications/recent-articles>.

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