

Towards a European Cancer Information System

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Background

Cancer is the second most common cause of death in the European Union. In 2009, the European Commission adopted the *Communication on Action Against Cancer: European Partnership* which defines several objectives for reducing the burden of cancer in Europe. Evaluation of measures to implement this goal is critically dependent on accurate and comparable European cancer data available for derivation of incidence, prevalence, survival and mortality statistics. For this purpose, the Joint Research Centre (JRC), in its role as a scientific service to the European Commission, and in close collaboration with the Directorate-General for Health and Food Safety (DG SANTE), is supporting the creation of a cancer-information system for Europe to be built upon existing experience, competence and cooperation of national and regional cancer registries.

In 2012, two Directorate-Generals of the European Commission (DG SANTE and the DG JRC) entered a formal collaboration to address actions in support of the European Network of Cancer Registries (ENCR), consisting of over 160 individual registries. The actions primarily address standardization of quality evalu-

ation procedures and processing of data across the European cancer registries, which will enable the publication and accurate comparison at EU level of the collected data. Not only has this support ensured the continuity of the ENCR secretariat, allowing the administrative functioning and networking of the ENCR, but has also resulted in the on-going coordination and development of some of the specific infrastructural elements of a cancer-information system. These include the establishment of a common procedure on cancer data-quality checks, a new data portal providing a central gateway that has rationalised the process of European cancer-data collection and onward data transfer, the development of open-source data-quality check software on the basis of the agreed common procedure, and the development of data-visualisation tools.

Present: what did the JRC achieve since 2012?

Administrative

- Organised and hosted four ENCR steering committee meetings every year as well as the biannual ENCR Scientific Meeting and General Assembly for scientific and epidemiological networking.

- Updated the ENCR member list and revised rules for membership.
- Organised training workshops and competence exchange initiatives for cancer registries.
- Developed and launched a new ENCR web-site <http://www.encr.eu/>.
- Started issuing a new series of ENCR Factsheets providing a quick overview of key facts on specific cancers, including summary figures showing the unacceptable disparities of cancer burden in Europe <http://www.encr.eu/index.php/publications/factsheets>.
- Started issuing regular Newsflashes to the cancer registries <http://www.encr.eu/index.php/publications/newsflash> reporting latest news on ENCR activities and ENCR members, providing general cancer-related information as well as hints on the most recent scientific research.

Scientific

- During 2013/2014, the JRC set up an inter-stakeholder Working Group, which issued an ENCR-endorsed recommendation document addressing the quality standards required by major European and international projects, finalized at harmonization of cancer registry quality checks.
- Following the rules described in the above-mentioned report, the JRC released in June 2016 the 'JRC-ENCR Data Quality Checks' software, publicly distributed, as a free tool to validate cancer registry data to facilitate and ensure high quality encoding of the collected variables.
- In preparation for the 2015 call for data, the JRC developed a dedicated (new) portal for uploading the data, as a unique gateway for data submission and communication with European cancer registries and meant to serve all European and international calls. Organised the call for European cancer-registry data in summer 2015, in order to build a unique anonymised database of cancer cases serving also the EUROcare 6 study on cancer survival and IARC's study on cancer incidence in five continents. Unlike other calls for data in the past, this 2015 call

streamlined the data-submission procedure into a one-step process serving the majority of data-user stakeholder needs. This has significantly eased the demands on registries, which were previously required to upload data in different formats to different portals at different times.

- Launched the ENCR-JRC project on 'Incidence and Mortality in Europe', aimed at creating a standardised and comparable database for assessing and monitoring cancer burden all over Europe. The JRC is currently processing and validating data collected from around 110 population-based registries, and will then move forward to detailed analysis of cancer incidence and mortality in Europe and related dissemination.
- In preparation of the public release of aggregated data from the 2015 call, the JRC is currently developing a suite of interactive data-visualisation tools that will not only serve research/epidemiology fields but also policy needs and the broader information requirements of the general public.

Future

The JRC intends to:

- continue harmonising cancer data and increasing the coverage throughout Europe
- upscale dissemination activities (factsheets, publications, etc.) based on the 2015 data call
- merge existing data sources to create knowledge, *i.e.* further develop and extend the overlay of cancer data with environmental and socio-economic data as well as data sets provided by EUROSTAT
- support population-based cancer registries and give visibility to their importance for EU policy and epidemiological research
- keep the operational data collection and encoding processes at the country level (which is also strategic for data-protection purposes) and use the aggregated datasets for policy and research of EU-added value
- investigate the means of ensuing sustainable models in the process of collecting population-based registry data.