ENCR-JRC PROJECT 2015

UPDATING POPULATION-BASED CANCER INCIDENCE AND MORTALITY IN EUROPE

CALL

June 2015

INTRODUCTION

The European Network of Cancer Registries (ENCR) began in 1989, within the framework of the Europe Against Cancer Programme of the European Commission, on the initiative of the International Agency for Research on Cancer (IARC), the Association of Nordic Cancer Registries (ANCR), the International Association of Cancer Registries (IACR) and the Latin Language Registry Group (GRELL).

The ENCR is a professional, non-profit society dedicated to promoting collaboration between cancer registries (CRs), defining data collection standards and providing training for CR personnel.

It also aims to strengthen the basis for monitoring the cancer burden (incidence, mortality, prevalence and survival) in the European Union (EU), and Europe in a wider sense, through the provision of regular and timely information from European CRs.

IARC has provided the secretariat for ENCR since its inception in 1989 until the late 2012. Since December 2012, the ENCR secretariat is hosted by the Joint Research Centre (JRC). The JRC is part of the European Commission. It consists of seven scientific Institutes located at five sites in five different Member States, with an administrative headquarters in Brussels. The JRC is the European Commission's in-house science service, which employs scientists to carry out research, and its mission is to provide independent scientific advice and support EU policy.

The Institute for Health and Consumer Protection (JRC-IHCP) is one of JRC's seven institutes and is based in Ispra (VA), Italy.

The ENCR secretariat is located in the JRC-IHCP as one of the tasks of the Public Health and Policy Support Unit.

Towards a single data-call process

It is the wish of the ENCR to reduce the number of data calls and corresponding workload for CRs for submitting data to various European studies. As a result it was agreed by the ENCR to work towards a single ENCR-JRC call for data, serving all European projects, the public and policy makers.

JRC has, as a consequence, established a data Portal (https://portal-encr.jrc.ec.europa.eu/) on behalf of the ENCR, through which registries can submit their data. The Portal provides the functionality for registries to submit their data to several International projects via a single data submission.

In this respect, the 2015 call already serves the needs of some of the data users, starting with the collaboration of the EUROCARE-6 study and it can potentially serve the needs of other projects presently or in the future, as agreed with them.

In general, submitted data, as individual records, will be available for specific projects. Use of record-level data for research projects requires the permission of the CRs, which has to be requested from each CR for each study. All corresponding research protocols will be posted on the ENCR-JRC Portal and CRs will be asked to give their consent for using their data, by selecting a specific project box in the Portal.

AIM OF THE ENCR-JRC PROJECT

This project was planned by the ENCR Steering Committee and JRC to create a standardized and comparable database for monitoring cancer incidence and mortality in the European Union and to provide regular information on the burden of cancer in Europe. These results will be included into a European Cancer Information System (ECIS), being developed in the next years.

OUTPUT

The output from the European cancer incidence and mortality database will include epidemiological statistics on cancer incidence and mortality, considering specific analysis by cancer site, sex, age group, calendar period, geographic area, and morphology groups.

Data will be presented as aggregated data (tables and figures), including absolute numbers and rates (crude and age-specific and age-standardized) on incidence and mortality, also stratified where possible by cancer site, sex, age group, calendar period, geographic area, and morphology groups.

Outputs will be included in:

a) A dedicated section on the ENCR website

b) Factsheets

c) ENCR-JRC technical reports describing the burden of cancer in Europe

d) European Cancer atlases

e) Peer-reviewed papers that will be written taking into account suggestions from the CRs, the ENCR SC and the JRC. CRs are motivated to promote, participate in the preparation of the papers or lead them.

PERMISSION TO THE USE OF DATA

CRs willing to contribute data to the ENCR-JRC call need to provide permission for this protocol when submitting data, by selecting the specific project box in the Portal. CRs which also wish to contribute data to the EUROCARE 6 protocol must also select the EUROCARE project box.

REQUIRED DATA FILES

CRs are required to submit their data files through the ENCR-JRC Portal (https://portal-encr.jrc.ec.europa.eu/).

The following information should be submitted:

- Incidence data as a list of individual cancer cases
- Population data from the official estimates
- Mortality data from official vital statistics

The description, format and type of data files and the corresponding variables are detailed in the 'ENCR-JRC call for data, 2015' protocol, available on the ENCR-JRC Portal and on the ENCR website (http://www.encr.eu/).

After submission of the data, a request will be sent to the CR to complete a questionnaire about the rules, codes, and procedures followed by the CR.

The answers to this questionnaire will provide valuable support to researchers in interpreting and best utilizing best the CR data.

DEADLINE FOR DATA SUBMISSION

Although the ENCR-JRC Portal will be continuously open for uploading and updating data, the deadline for submitting data for this call is **1st November 2015.**

RESOURCES

Since 2012 the JRC has hosted the ENCR Secretariat and is active in supporting all ENCR activities. Dedicated resources (personnel, IT) have been provided by the JRC for the data management, secure data storage, quality checks, web-Portal maintenance and development, further development of the quality check software, data analysis and back-office procedures.

SECURITY AND CONFIDENTIALITY

The fully anonymous individual records will be stored in a secure server sitting behind a firewall at the JRC, which follows the European Commission's rules in terms of data security.

CR data and documents can be uploaded to the Portal only by the Contact person identified by the CR's Director, via username (e-mail address) and password. Only the Contact person with his/her credentials can download files/documents from the CR area in the Portal. All access to the Portal is tracked, and a feed-back on data submission will be sent to the CR's Director and Contact person.

The ENCR Secretariat will act as data manager for this call for data: all personnel involved in this project have signed data confidentiality agreements with the JRC.

The JRC has filled a data protection notification (DPO-3787.1), with the local Data Protection Officers, on 29/5/2015. The DPO requested JRC to withdraw the notification "Database of the European Cancer Information System (ECIS)" with reference DPO-3787.1 since 'JRC only processes anonymised data received from national authorities, and then the regulation does not apply'.

The JRC staff will act upon all special requirements that the contributing CRs have. If requested by the CR, an additional pseudonymisation of the provided patient ID or tumour ID will be performed. Patient ID or tumour ID will only be used for quality queries on single records to the CR. Before starting any analysis for the ENCR-JRC project patient ID and tumour ID will undergo additional pseudonymisation, providing a de facto anonymized analysis dataset. Furthermore, ENCR-JRC will also apply data restriction whenever requested by the CR in the submission form.

DATA QUALITY CHECKS

In preparation of the call for data, the ENCR and the JRC have developed a protocol for cancer data quality checks, entitled: 'One common procedure for European cancer registries'. This protocol was unanimously approved by the ENCR Steering Committee and other European stakeholders including all major European projects using CR data (EUROCARE, CONCORD, RARECARE).

It is available at:

http://www.encr.eu/images/docs/recommendations/workshops/Cancer%20Data%20Quality%20Checks%20Procedure%20Report%20online.pdf

The checks proposed in this report will be applied for checking the quality of data sent by the CRs.

For any further information please contact:

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