

60th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 31 May 2016, from 9.00am to 5.30pm, JRC-Ispra.

Attendees Present: ENCR SC, European Commission Joint Research Centre (JRC)

Update on the 2015 Call for Data and the ENCR JRC Project

At the end of May 2016, 106 data submissions were initiated, 99 finalised, 7 to be finalised. Out of these, 94 CRs applied for the ENCR-JRC project.

The next steps for the ENCR-JRC project will include finalising the data collection from cancer registries (CRs) not yet participating; checking data; data quality assessment and feedback on this to CRs; data analysis and production of results to be shared with CRs before publication. Outputs of the analyses will be posted on the ENCR website and will include factsheets, ENCR-JRC technical reports, European cancer atlases and peer-reviewed papers.

The New DP Regulation and its implications for CR data handling

Whereas the pseudonymised data currently collected is considered as "anonymous data" by the European Commission's Data Protection Office, different interpretations between data-protection entities exist in some countries, preventing them sharing information. Given that IARC is experiencing similar difficulties, this matter will be discussed in greater depth trilaterally with ENCR, IARC, and JRC.

Alternative plans to visualise CR data

A prototype of a new cancer data dashboard/explorer, aimed at displaying statistical indicators computed from cancer registry data, is currently under development by the JRC. This web-based tool is intended to display extensive information on one page with an almost instantaneous data refresh following user selections.

Data Sharing

For dissemination purposes and sharing information with researchers aggregated data will continue to be available for download, since data protection issues do not apply at this level.

Regarding the aggregation parameters, the standard variables - age, sex, ICD-O/ICD-10 - will be used for grouping. For more detailed queries the ENCR secretariat should be contacted.

Quality check software v.1.5

A second and complete version of the JRC-ENCR Data Quality Check software is foreseen to be released to registries by mid-July. Future versions of this software will have editable checks so that registries will be able to check their own additional variables besides the official ones.

Proposed feedback to CRs on quality of submitted datasets

A proposal for feedback to CRs on the quality of submitted datasets was discussed. This proposal consists of a technical report for each single CR including the evaluation of all quality dimensions.

Feedback on the collaboration with EUROCARE

Collaboration between ENCR-JRC and EUROCARE group has so far been very positive. Given that JRC is currently developing a data visualization tool for indicators computed from CR data, there is mutual interest from both groups to include survival statistics on the new website to be developed. The output of the JRC-ENCR Quality Checks software will be checked against EUROCARE's routines for cross-validation.

CONCORD-3 Call for Data

Data collected for the 2015 ENCR-JRC could be offered for the CONCORD-3 study (upon expression of a single registry's agreement in the JRC Portal).

ENCR Scientific Meeting and General Assembly, October 5-7 2016

The conference programme and the General Assembly agenda were discussed. The conference will be preceded by a short training on the quality of cancer registry data, for a selected number of applicants in the morning of the 5th prior to the starting of the main event.

ENCR Recommendations

Two working groups will address the updating of ENCR recommendations on multiple primaries (reference person: Harry Comber) and on date of incidence (reference people: Alexander Katalinic and Maria Dolores Chirlaque).

Updates on other projects

PANCREOS: The data collection protocol is being developed by the PancreOs team and ENCR-JRC.

EORTC-ENCR collaboration: EORTC submitted a proposal for an Horizon2020 project. If successful, ENCR will be involved in a Work Package on the analysis of data on survival, prevalence and other epidemiological indicators for adult cancer survivors.

EPICOST: this Italian project examines information provided by population-based cancer registries and information on treatment and corresponding costs provided by other administrative sources, with the aim to estimate the distribution of cancer patients and associated health care expenditures.

Date for next meeting

The ENCR SC next meeting will be held on the afternoon of October 4th 2016.