69th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 17 January 2019, Ispra, Italy

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

Preparatory work for a new 2020 new data call

A new data call that is aimed at for the beginning of 2020. It was agreed for the future to keep the submission constantly opened, but set a deadline for inclusion in the yearly update of statistics. The timeline for dissemination should take into account the time needed for validation of data before. It was agreed to seek a report of all years data, not just focusing on recent years. For the 2020 data call, the following issues are to be addressed:

- <u>Data Call Protocol</u> – According to the data minimisation principle in the GDPR, the need of each single variable should be justified, as well as the need for individual data (even if pseudoanonymised). So far, individual data is needed for the validation, and at a later stage it can be envisaged that a new model in which validation is carried out at CR level may become available.

- <u>Data Transfer Agreements (DTAs)</u> – to be established with each single CRs. Transfer of data (individual or aggregated) to other external entities should also be addressed into the DTA.

- <u>Data Protection notification</u> - is a requirement for receiving, hosting and processing CR data; the JRC is currently addressing this.

Collaboration for a single call and a single European dataset

The steps for a unique European data call serving different projects were revised. Establishing a unique European dataset of cancer cases would avoid duplication and decrease the burden on the CRs. Once data are validated according to commonly agreed rules, different projects should then refer to the ECIS database, where the validated data are stored. The first step towards alignment consists in the ENCR to prepare the protocol for the next data collection and then sharing it with the other interested projects for comments, in view of a unique data call.

A decentralized model for cancer registry data

A proposal on an alternative model for cancer registry data was discussed. The decentralized approach would keep the data at source, thereby removing problems with maintaining data integrity across multiple copies of data sets and difficulties in handling sensitive data due to the increased rigour of the general data-protection directive (GDPR). This architecture would require registries to run algorithms (defined for any given study) at the local level on the local data and pass the aggregated results back to the study coordinator. The approach is currently being tested at IKNL (The Netherlands), that put forward a proposal to JRC and ENCR on a feasibility study on cancer registry data. In this process a critical step to be properly considered is the data validation, to ensure harmonized and comparable output.

ENCR-JRC trainings

The Working Group on trainings will meet in March 2019, to discuss and propose an ENCR training agenda. For the 2019 courses, a first training on coding will be organised for 5-6 June. A second training will occur in November.

National estimates for historical data in ECIS

The results of the preliminary analysis comparing two different methods for estimating national incidence for the countries without full coverage were presented. These results were also introduced to the concerned countries in a workshop held at the JRC on 25 October 2018, and following this a discussion with FRANCIM took place at the beginning of December. In order to finalise the exercise, the collaboration with the involved countries is crucial, not only for technical reasons (alignment of definitions, alignment between incidence and mortality data collected in the ENCR-JRC data base and those available at the country level) but also to avoid the JRC-ENCR releasing different figures from the one computed locally for the countries in which a similar exercise is already in place.

Request for support from Montenegro

One representative from the ENCR SC and one from the JRC agreed to perform the requested site visit in Montenegro, planned for April 2019.

ENCR website, "Ask a registrar" section webpage

A "questions & answers" on coding issues is to be added to the ENCR website as a service for the cancer registries. The JRC will set up this functionality.

New ENCR election rules

No objections were collected from the CRs, therefore the new election rules are adopted. They will be published on the ENCR website and implemented from the next election onwards.

Toronto childhood staging system

The ENCR formally endorsed the Toronto childhood staging system. The guidelines will be referenced in the ENCR website, in the recommendations table.

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