

66th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 7 March 2018, Ispra, Italy

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

ECIS release and future developments

The ECIS web-application was discussed and revised. It was agreed to address as future implementations the development of an harmonised methodology to facilitate presentation of national estimates where only recorded data from regional registries are available (countries not fully covered by cancer registration). Future developments include also addressing the site specific CRs data (also ensuring the consistency of site definitions in the different ECIS tables), the paediatric CRs data, country level summary analysis, cancer and country factsheets.

Regarding the organisation and periodicity of future data calls, to update the data in ECIS, it was proposed to give the opportunity for the CRs to send their data annually, with a binding deadline to have the data included in the annual update of the overall database.

ENCR Scientific Meeting, 26-28 September 2018, Copenhagen

It was decided that the ENCR Scientific Meeting and General Assembly would have the over-arching topic "Data linkage and cancer registries". A poster session will be organised with maximum 100 posters. Financial support for a limited number of participants will be provided by JRC. Review of abstracts will be organised in June with the ENCR SC support.

Workshop on data protection legislation (agenda, speakers), morning of 26 September 2018, Copenhagen

The implementation of the new regulation on data protection should be the focus of the workshop. A representative of the EC (data protection officer) will give the overall perspective on the new General Data Protection Regulation. A questionnaire to the CRs and their organisations will be prepared and distributed in June to collect information on how the directive was transposed into national law and related issues, in preparation for the workshop.

ENCR-JRC Trainings 2018

The training of June 2018 will be focused on topics related to cancer incidence, mortality and time trends, and including as well an introduction to survival analysis. A second training will be organised in September 2018 in Copenhagen, on the 25th September, on coding of topography, morphology and stage with an emphasis on difficult cases, such as haematological and rare malignancies.

ENCR rules and procedures

It was proposed that a 'Terms of reference' for the Secretariat role should to be developed, describing the role of JRC and acknowledging the EC contribution.

Composition of the ENCR SC

A new proposal for the ENCR SC composition was introduced, with the overall aim to ensure a balanced representation of different areas and prevent overrepresentation of selected regions, taking into account the population size and the number of CRs and the representation of all European regions. The goal is that the new rules should be presented and agreed at the General assembly in Copenhagen.

ENCR-JRC Publication plan

A proposal for authorship rules and publication policy was presented for discussion. It was decided to monitor publications between the JRC and the ENCR SC through a Publication Plan with details on the planned papers. For external publications, it was agreed that it's not possible to monitor them.

Rules for access to ECIS data

Different types of access, aiming to allow for a wider use of collected data, were presented for discussion. The statistics published in the ECIS web-application can be used without limitation, with proper reference.

ENCR Recommendations

The on-going work for the update of the "Date of Incidence" and "Multiple Primaries" recommendations were revised and discussed.

AoB

ENCR/JRC participation in external events:

- training course in St. Petersburg , 31.05 – 01.06: the JRC will participate as a faculty in a training for CRs from North-Western Russia;
- one representative from the ENCR SC will participate to the N. Ireland Cancer Registry review in June 2018;
- one representative from the ENCR SC participated to the Prostate Cancer Round Table, European Parliament, in January 2018;
- one representative from the ENCR SC will participate to the EMA meeting in Amsterdam, dedicated to rare cancers;
- the JRC was invited to present ECIS at the AIRTUM 2018 meeting.