

68th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 24 September 2018, Copenhagen, Denmark

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

ENCR-JRC events, 24-28 September 2018, Copenhagen

The material and the agenda for the training on 25th September on Data Coding and for the Workshop on data protection legislation (morning of Wednesday 26th) were reviewed and discussed. Depending on the outcome of the workshop, more structured actions can be envisaged in support of the CRs. The agenda of the General Assembly on the Thursday afternoon and the overall organisation of the conference were reviewed.

ENCR SC election rules

The GRELL and the association of Nordic registries agree with the proposed change in the election rules of the ENCR Steering Committee - namely the representatives of GRELL and Nordic registries will not have a reserved place at the ENCR SC, but can be candidates for elections as any other candidates. There will be a formal election for all the seats at the ENCR SC, besides two positions for IARC and IACR representatives, which are expected to ensure the efficient communication between the corresponding organisations. The voting rules are to be presented at the ENCR General Assembly on 27th September, to be posted on the ENCR website for one month and if no objections received, they will come into force for the next ENCR elections.

ECIS

The JRC issued a technical report describing the functionalities of the ECIS web application, to be distributed at the conference. The ongoing work related to ECIS was reviewed:

- Data from paediatric cancer registries will be uploaded in a specific restricted area to be checked by each concerned registry before public release;
- A workshop on the national estimates initiative will take place on 25 October in Ispra, to discuss results and methods with the concerned 10 countries having regional registries not covering the whole country population.

Updates on the work on recommendations on incidence data and multiple primaries

The revised proposal of the "Date of incidence" recommendation will be tested with some CRs. Data validation rules and data quality checks for the registry datasets are under revision.

ENCR Training

A working group to revise the available training materials and to prepare the concept for trainings will be established.

Requests for access to data

The finalisation of the procedure for access to individual records from the ECIS database is postponed at least until data validation is completed.