

70th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 4 June 2019, Ispra, Italy

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

Survey on GDPR

A summary from the outcome of the workshop on the new GDPR in Copenhagen 2018 was reported as well as the results from the survey to cancer registries that followed. Results from the survey show that there is a need for education about what anonymised data are and how to prepare proper documentation to comply with GDPR requirements. CRs would benefit in having guidelines (an ENCR manual) and a checklist with all the actions to be performed to ensure compliance with GDPR requirements.

Preparatory work for a 2020 data call, state-of-the-art

Work is ongoing in view of the planned new data call for 2020, particularly on the following issues:

- Data Protection notification - The work for the submission of the DP notification by the JRC is ongoing. The role of the JRC has been clarified as joint data controller. Regarding the possibility of the JRC transferring CR data to third parties (i.e. other projects like CONCORD, CI5, EUROCARE), it was decided that the JRC should carry out the data validation, and release only fully-anonymised validated records.
- Collaboration with other organisations – The JRC will make available fully-anonymised validated records to external project/institutions working with cancer registry data.
- Data Call Protocol – A draft protocol was presented and agreed by the ENCR SC. The relevance of newly proposed variables was discussed, particularly childhood staging and the introduction of a geographical variable for residence according to the NUTS3 classification.

Data in the ECIS web application

Work is ongoing to update the ECIS web application in order to disseminate childhood data according to pre-defined aggregation, i.e. 5 years' period and 5-year age group, and summing up boys and girls. Statistics will be reported by the detailed categories of ICC3-3. Aggregations will be uploaded in a private space of the ECIS web application, developed *ad hoc*, for each CR to revise them.

ENCR-JRC trainings

- WG on trainings – Following the agreement of the working group on training, cancer specific e-training materials are under preparation and will become publicly available in some specific space of the ENCR website. This material shall include information by cancer site such as epidemiology, risk factors, types of treatment, in addition to coding topography, morphology and stage. A quiz at the end of the training materials may be included, and be used for evaluation and possibly for professional recognition or accreditation of the CRs. The procedure to address the issue of including the profession of the cancer registrar in the recognised list of EU professions, along with the certification of the ENCR-JRC training materials, is under investigation.

- 2019 training courses – Two ENCR-JRC trainings for cancer registrars are being organised, 1) 5-6 June in Ispra, Italy and 2) 21-22 November in Ljubljana, Slovenia. The latter will be organised by the Slovenian cancer registry in collaboration with ENCR, JRC and IARC.

ENCR recommendations

Work ongoing for the ENCR recommendations on **Quality checks, Date of incidence, Multiple primaries** and **Urothelial tumours**.

Registry review

Montenegro, April 2019 – The reviewers who performed the site visit presented the report, which after approval, will be sent to the MoH and Public Health institute in Montenegro.