

76th ENCR Steering Committee (SC) Meeting Minutes – Videoconference

Date and place: 19 April 2021, Videoconference

Attendees: ENCR SC (2021-2023), Representatives from the European Commission Joint Research Centre (JRC)

The new data call

Data protection (DP) notification: a data protection (DP) record was approved and published in the EC Register of the Data Protection Officer at the following link: <https://ec.europa.eu/dpo-register/detail/DPR-EC-00417>, regulating data collection and processing, and related data protection safeguards.

Following the publication of the DP record, the new data call to the European cancer registries can be organised. The preparation of the necessary contracts with the cancer registries and IARC is ongoing and will be detailed in a dedicated meeting with the cancer registries, to explain the legal part and to initiate the administrative procedures necessary for the data collection. The possibility to submit data will be open as soon as contracts with each registry have been signed. These contracts give the framework for the data transfer between the registries and the JRC, and it won't be necessary to renew them for each new submission.

Despite the DP rules were not made explicit in the 2015 data call, data currently at JRC are subject to the same safeguards as described in the published record.

The data call protocol and questionnaire: the protocol, shared with IARC and EURO CARE is being finalised.

IT tools, finalisation and testing (JRC-ENCR DTA & QCS v2): an overview of the tools updated/developed by the JRC in preparation to the new data call was presented and SC members were invited to join the beta testing phase.

ENCR events calendar 2021

The updated calendar for the online training activities in 2021 include:

- Training on updates in the ICD-O-3.2, 21 April;
- Training on Cancer Registration Cluj, 25-28 May;
- iPAAC Course on cancer prevalence, 22-23 June;
- ENCR Scientific conference 2021, 16-18 November.

For the ENCR Scientific conference, oral presentations will be pre-recorded. Short poster presentations can be pre-recorded as well. The ENCR general assembly, which in the past was associated to the Scientific Meeting as a side event, will not be included in the virtual programme.

Discussion paper on the JRC-ENCR collaboration

Motivated by the momentum of the several EC initiatives on cancer, the JRC prepared and distributed a document identifying areas where further work is needed to strengthen the role of ENCR and ECIS in supporting data requests coming from the policy side. The paper outlines topics to be addressed and how to involve the network in this prioritisation.

Initiative on treatment variables' harmonisation: the establishment of a working group was proposed to harmonise treatment data and ensure its comparability at European level.

Concept for a second COVID-19 survey

The results of the first survey were presented and the concept for a second survey was introduced.

Special issue on data quality

The JRC presented a proposal for a special issue on data quality from the results of the 2015 data call, envisaging contributions from the current and previous SC members.

ENCR recommendations

- Work is ongoing for the recommendations on Urothelial tumours, Date of incidence and Multiple primaries.
- Two new ENCR Working Groups are proposed to address the topics of Basis of diagnosis and Stage.