

74th ENCR Steering Committee (SC) Meeting Minutes – Videoconference

Date and place: 11 November 2020, Videoconference

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

Data call

- Data Protection (DP) record: the JRC reported on the work for the submission of the DP notification particularly on a proposal by the legal service to disseminate adult's data in ECIS by suppressing tables with counts less than 5 and displaying only rates for these situations. The ENCR SC opposed this general proposal because the determination of threshold for visualisation should consider the population size as denominator rather than just the number of cases. The ENCR SC requested a final attempt in the DP notification to describe the low probability of disclosing the identity of any patient from aggregated statistics from cancer registry data.
- IT tools: the JRC presented the IT tools under development/update to serve the new data call including i) the QCS Protocol Data Adapter - a variables' layout converter that helps mapping the variables defined in the protocol with those found in the cancer registry data archive, ii) the QCS 2.0, an updated version of the JRC-ENCR Quality Check Software adapted to the protocol of the new data call, and including new checks related to TNM and stage and iii) a tool for the in-house selection of MPMTs that discriminates among the duplicates when preparing the files for analysis.
- Data call protocol: JRC presented the revisions of the data call protocol following the comments received from EURO CARE.

Revision of the cancer entities

JRC presented the ongoing revision of cancer entities definitions for data visualization and data comparability and proposed to create a small working group to update the definitions. The SC will support the JRC in this task.

ENCR SC elections

JRC presented the eight candidatures received, which covered the four European regions, among which three from the current SC. The handover of the SC will happen at the next SC meeting.

Rescheduling of ENCR events/activities

- The ENCR scientific meeting will be converted into a virtual event, tentatively planned for the fall 2021 and spanning over 2-3 half-days, with digital posters.
- ENCR trainings in 2021 will be virtual events, spread over several months from March to September.

Impact of COVID-19 on cancer registration

The JRC presented the results from the survey to assess the impact of COVID-19 pandemic on cancer registration among the SC members. The ENCR SC suggested several issues to be highlighted in a manuscript: the impact on cancer care and the role of the CRs in its monitoring, delays and changes in treatment, stage shifts, as well as challenges in ensuring

compliance to data protection rules from registrars when working remotely. IARC reported on the findings of a similar survey done at global level.

The different members of the ENCR SC exchanged information on data available from Cancer registries monitoring COVID-19.

2020 estimates

The JRC reported on the release of the 2020 estimates in the ECIS web application in July 2020. Statistics about website visits showed an increase of visits that correlated well with the timing of several promotion activities by the JRC, ENCR and at national levels.

Cancer staging tool

A cancer staging tool was presented, to be distributed freely to population cancer registries. The ENCR decided to endorse the use of TNM for staging, and acknowledged that the software provides a valuable tool to support stage registration. Once finalised the tool will be shared for testing.

ENCR recommendations

The work related to the update of the recommendations was presented.

Cancer factsheets

The JRC presented the new breast cancer factsheet recently released and will propose a calendar for the release of subsequent cancer site factsheets, preferably in alignment with known cancer awareness dates.