

91st ENCR Steering Committee (SC) Meeting and Meeting of the JRC-ENCR Management Committee minutes

Date and place: 05 December 2024, Videoconference

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

Welcome and adoption of the minutes of the 90th ENCR SC meeting

A new colleague was welcomed as newcomer in the Cancer Information group at the JRC. The minutes of the previous meeting were approved with a minor modification.

Feedback on the record-level data validation and aggregated data submission (JRC)

- 93 record-level data submissions were received so far via the JRC-ENCR Portal.
- Based on the feedback received during the pilot phase with ENCR SC members registries, the JRC finalised the workflow for the preparation of internal consistency reports of the submitted incidence data.
- The JRC sent the internal consistency reports to 82 registries, representing almost all general registries having submitted record-level data. In addition, the incidence indicators calculated based on the data cleaned by the JRC were uploaded and shared with cancer registries using ECIS private spaces.
- Cancer registries are expected to provide response to the feedback sent by the JRC. They can either transmit the excel files with corrections or decisions on records with inconsistencies, or approve to publish the data according to the data cleaning procedures suggested by the JRC.
- The beta version of the aggregation tool CRATE was finalised and distributed to the registries that expressed interest. It was accompanied by the manual of CRATE and the instructions to prepare the data for ECIS before the aggregation. Interested registries have been asked to test the tool, provide feedback and submit aggregated data via the JRC-ENCR portal.

Timeline for the data publication in ECIS and workplan 2025 (JRC)

- Cancer registries were given three weeks to provide the response on the internal consistency reports. The JRC will implement the corrections sent by the registries and prepare the data for publication in the ECIS web application in Q1 2025.
- ECIS2 web application: the JRC reported on the new ECIS2 web application development, including a new database, operational and already hosting the new ECIS data, and a new interface.
- Other ECIS projects planned for 2025 include addressing childhood registries' data, publishing data quality indicators, computing 2024 estimates, analysing stage and treatment information and updating/revamping of ECIS factsheets.

ECIS Quality indicators

ENCR SC members were consulted on data quality indicators to be published in ECIS.

Preliminary results on stage analysis

ENCR SC members were consulted on the completeness and distribution of cancer stage variables, as resulting from preliminary analysis of ECIS 2022 data.

ENCR conference 2025

A joint ENCR-GRELL meeting will take place in Porto, Portugal, 27-30 May 2025. The ENCR SC discussed the logistics of preparations, proposals for the conference workshops and keynote speakers.

ENCR recommendations and working groups (WGs)

- Treatment: Last comments have been processed and the recommendation should be published by the end of the year.
- CNS: Remarks were received from cancer registries and ENCR SC members. The revised final draft was shared with the JRC for publication.
- Recurrences: New comments received from the ENCR SC will be considered before the publication of the final text.
- Multiple primary tumours: Work is in progress.
- Survival: Work is in progress, specific tasks are divided between four technical subgroups. Subgroups 1 and 2, focusing on methodological aspects and quality checks respectively, has already prepared documents which will form basis of the WG deliverables. They will also provide input for the work of subgroup 3 and 4, dealing with data sharing to third parties and aggregated data submission respectively.
- Non-melanoma skin cancers: A chair for this WG has been appointed. The call for experts remains open, the group will start working in early 2025.
- New working group on AI and IT tools for cancer registration: A new multidisciplinary WG was proposed. Its aim would be to define the guidelines and best practices on how to work on cancer registry data using AI tools, including legal aspects of such work. A call for experts will be opened.

AoB:

Progress on International Childhood Cancer Data Partnership

The ENCR SC members will be updated on the progress of this initiative.