

85th ENCR Steering Committee (SC) Meeting and Meeting of the JRC-ENCR Management Committee minutes

Date and place: 12 October 2023, Videoconference

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

Data Call 2022: update on the Collaboration Agreements, data submissions and data validation workflow

To date, 87 cancer registries have signed the collaboration agreement, 85 registries submitted the data, 59 expected submissions are still missing (including 7 countries awaiting aggregation tool). The ENCR SC members offered help in following up on cancer registries that still did not submit data.

The JRC presented the data submission processes, following two different streams: via aggregated data delivery or via secure submission of individual record-level data in the dedicated JRC portal.

JRC is developing a tool to address the need expressed by several cancer registries that due to data protection reasons cannot submit data as individual records. When ready, this aggregation tool will be distributed to cancer registries to produce locally aggregated statistics based on predefined cancer entities to be submitted for contribution to ECIS. Cancer registries will be first required to perform data validation and cleaning using the Quality Check Software.

In the case of record-level data submission via the JRC portal, JRC is performing data validation in two steps. In the 1st phase, the following aspects are checked: submission completeness, consistency between files and the questionnaire, file formatting, missing or out-of-range values for core variables. Corrections/modifications to the received files by the JRC and request for corrections to the registry are detailed in the 1st phase validation report.

The 2nd phase validation is to be carried out using the QCS, currently under finalisation in its update to version 2.1. Errors and warnings identified through the QCS will be notified back to Cancer Registries for corrections. The validated dataset will be aggregated using the new 2022 cancer entities.

ENCR Cancer Registries practices survey

The aim of the survey, currently ongoing, is to get an updated overview of cancer registration in the Member States, and report about cancer registries practices. For now, 110 cancer registries responded. Completion of this survey is also a criterion for the ENCR membership.

2024 EU4Health Joint Action to support quality improvement of cancer registry data feeding ECIS

Joint Actions (direct grants to Member States) are funding instruments designed and co-financed by the EU with the participating countries to address specific priorities under the EU4Health Programme. Currently, following an earlier

initiative of the JRC and ENCR SC members, a proposal for a Joint Action in support of cancer registries is being prepared.

ENCR recommendations and Working Groups (WG)

Tumour recurrences

An ENCR recommendation is being finalised, to provide guidance on definitions and related coding of recurrences, disease progression and/or transformation.

Treatment data harmonisation

The current draft is open to the comments of the cancer registries.

Recommendation on multiple primaries, possible re-scoping

The need for a recommendation addressing recording of multiple primary tumours was discussed. A dedicated Working Group on this topic will be set up at the beginning of the term of the 2024-2026 Steering Committee.

Haematological malignancies

The work is ongoing.

CNS tumours

The work is ongoing.

ENCR-IACR conference 2023: 14-16 Nov, Granada

The status of the registrations and details regarding conference programme were discussed.

ENCR elections

Elections for the ENCR SC 2024-2026 are currently open and first candidatures are being received.

Agenda item 9. Follow-up on the special issue in Frontiers in Oncology (LvE)

The research topic “Joining Efforts to Improve Data Quality and Harmonization Among European Population-Based Cancer Registries”, was proposed in the journal “Frontiers in Oncology”. At the moment, there are 12 accepted or published articles.

Update on the Canscreen-ECIS project

The updates from [CanScreen ECIS](#) project (timeline Sep 2022 – Feb 2024) were discussed. As one of the project deliverables, a survey is launched to collect feedback on current ECIS functionalities with the aim of improving user experience, as well to understand the expectations about the future inclusion of cancer screening data into ECIS.

2022 estimates released

2022 European estimates were released by the JRC in the beginning of October, as an outcome of the collaboration between JRC and IARC. Method description for computing the estimates is available on the ECIS website in the section on the ECIS contributing initiatives and studies. The JRC is also currently working on the related 2022 paper, where the methods will be described in more detail.