88th ENCR Steering Committee (SC) Meeting and Meeting of the JRC-ENCR Management Committee minutes

Date and place: 08 April 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 87th ENCR SC meeting

Minutes were approved without any modifications.

ECIS and the new data call

The JRC updated ENCR SC members on the status of the submissions to the ECIS 2022 data call. 91 submissions were received so far, while 73 registries still have not transmitted the data (including 11 registries that declared readiness to transmit aggregated data). The ENCR SC members offered to reach out to the remaining cancer registries that still have not submitted data.

The work is ongoing on the development of the aggregated data delivery tool, which will be distributed to the cancer registries unable to transmit record-level data. All of the registries that already submitted record-level data received the first round of feedback, while the 2nd phase data validation (based on the Quality Check Software output) is in progress.

Direct Grant to Member States: Support to quality improvement of cancer registry data feeding the ECIS

Several ENCR SC members took initiative to advertise among the ENCR registries the call for the direct grant to Member States for ECIS (Joint Action). A summary of the call was prepared and published on the ENCR website. The structure and timeline of the Joint Action was outlined, highlighting the upcoming deadline for the national health authorities to nominate competent authorities and affiliated entities that would take part in the Joint Action. The ENCR SC members were invited for further proactivity in ensuring that the national health authorities are aware of this deadline and would take the necessary actions.

Data requests

Following the previous discussions on this topic with the ENCR SC 2021-2024, the JRC proposed to establish a documented workflow for the future assessment and fulfilment of requests for aggregated ECIS data, in cases where the required data aggregations are not available through the publicly disseminated indicators. This workflow would

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enter into action following the publication of data from the 2022 ECIS data call. A document was drafted, outlining the workflow and conditions for data access and a template data requests form.

ENCR training agenda 2024

The ENCR SC members proposed potential workshops for 2024 ENCR training agenda, including workshops on: Media Engagement and Communication, Software, applications and IT tools for data collection and quality assurance, AI supported solutions for cancer registries.

ENCR recommendations and working groups

ENCR working groups currently ongoing:

- Treatment
- Tumour recurrences
- Central nervous system tumours

Upcoming ENCR working groups – working group leaders nominated:

- Survival data in ECIS
- Multiple primary tumours registration

The working group on haematological malignancies has paused its activities until release of the ICD-O-4 classification.

CanScreen-ECIS project

The CanScreen-ECIS project (Sept 2022–Feb 2024) developed and piloted a new cancer screening data management system, with the aim of its eventual inclusion into ECIS. A leaflet on project outcomes was published on the project website. Further activities will follow to ensure a sustainable process of future collection and inclusion of cancer screening indicators in ECIS.