

**94th ENCR Steering Committee (SC) Meeting
and Meeting of the JRC-ENCR Management Committee minutes**

Date and place: 23 June 2025, 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 93rd ENCR SC meeting

The minutes of the previous meeting were approved.

ECIS release

- Childhood cancer statistics: the JRC is finalising tools for the validation, aggregation and publication of childhood cancer historical data in the new ECIS web application. According to the planned timeline, childhood data validation is scheduled for July and August. Publication in ECIS is planned for September 2025.
- 2024 estimates: JRC and IARC are working on the updated 2024 figures. In parallel, the JRC is working on a series of revamped cancer factsheets.
- New ECIS submissions: several registries updated their submission in 2025: these data are being processed and indicators published over the course of 2025. The process will continue on the rolling basis: data submitted by the 31st January each year will be considered for the annual update of ECIS.

ENCR recommendations and working groups (WGs)

- Multiple primary tumours: a draft recommendation is being finalized.
- Survival: work is underway on a position paper, to be finalized by end of July so that it can be the basis for envisaged implementation under the CancerWatch initiative. A tentative timeline for further work on survival in ECIS in 2026 was discussed.
- Non-melanoma skin cancers: The first meeting of the WG took place. The objectives of the working group will be: 1) Revise NMSC definition in ECIS 2) Revise the rules for recording and reporting NMSCs 3) Discussion on the methods to be used for the NMSC estimates.
- New working group on AI and IT tools for cancer registration: The WG defined its objectives: 1) Clarify the opportunities on how to use AI tools in the context of cancer registration, state-of-the-art 2) Technical and legal challenges.

ECIS Data requests

A draft document outlining the workflow for record-level data requests from ECIS was discussed, in line with the ECIS data protection record and the collaboration agreement signed by the registries.

UNCAN updates from Cancer Mission project

The overall goal of UNCAN is to provide an EU wide cancer research infrastructure connecting cancer centers, research data, biobanks, imaging data. In this context, National Cancer Data Nodes (NDCN) are envisaged an intermediate role between data holders and the HDABs (Health Data Access Bodies), and with a mission to promote research on cancer. As Member States need to define their national EHDS implementation in two years' time, it is important that cancer registries understand their local context and define their role in the upcoming infrastructure.

ECIS cancer entities

Updated ECIS indicators have been published in April 2025, according to revised cancer entities definition defined in order to account for the ICD-O.3.2 classification, to align with the TNM and to consider the clinical perspective. Compared to previous definitions, selected cases with behaviour 2, 1 or 0 are now considered. Cancer registries were already introduced to the new definitions when checking data in the ECIS private section ahead of public release. To further improve transparency, the new entities will be mentioned in the upcoming ENCR newsflash.

AoB

CancerWatch and ICD-O-4

Dedicated tasks within CancerWatch will work on the alignment of data quality tools ahead of the implementation of ICD-O-4. In collaboration with expert from IARC, ENCR E-learning modules should also be updated accordingly.

Albanian CR: new ENCR member

The national CR in Albania requested the ENCR membership. An introductory meeting is being organised between the ENCR chairs, the JRC and the Albanian CR representatives.

Canstaging tool

In the context of CancerWatch task 5.1.1, the cancer registries survey will also target cancer registries needs and interest in the tool. Based on the feedback received, CancerWatch should determine a sustainable way forward for the tool's use and maintainance.