

87th ENCR Steering Committee (SC) Meeting and Meeting of the JRC-ENCR Management Committee minutes

Date and place: 01 February 2024, Videoconference

Attendees: ENCR SC (2021-2023), ENCR SC (2024-2026), JRC-ENCR Management Committee,

Representatives from the European Commission Joint Research Centre (JRC)

Welcome to the new members and Tour de table

Members of the previous and newly appointed ENCR Steering Committee (SC) and the JRC team presented themselves. Key messages were shared to guide the way forward of the new SC.

Experiences/feedback from Granada ENCR-IACR meeting, November 2023

The event was attended by around 330 participants, majority of whom (230) were from Europe. These numbers are comparable to the attendance recorded at previous in-person meetings. The feedback on the event highlighted its good organisation and the value of scientific exchanged during plenary sessions, additional side meetings, poster sessions and networking breaks.

Ongoing ENCR – JRC activities 2021-2023

Ask an expert tool

Ask an expert is a service, launched in 2019 in a dedicated ENCR website <u>page</u>, which allows cancer registrars to ask questions related to cancer coding, received and answered by OV. It is possible now to submit answers in the original language.

Trainings and webinars

The new SC will propose trainings for the current year.

E-learning

Work is currently on-going on six additional E-learning modules in the ENCR website (Urothelial Tumours, Sarcomas, New diagnosis and treatment, Hepatobiliary & pancreas, Colorectal and Breast cancer). New proposals for additional e-learning modules will be put forward by the new ENCR SC

Cancer registry reviews

Two cancer registry reviews were finalised in 2022 (Romanian National Childhood Cancer Registry and Madrid Childhood and Adolescent Cancer Registry).

Focus on ENCR recommendations and Working groups

The following recommendations were finalised in the period 2021-2023:

- Urothelial tumours
- Basis of Diagnosis
- Incidence Date
- Standard item set for cancer registries
- Cancer cases in migrant populations.

Three of these recommendations were the subject of scientific articles, which increases their impact.

The work on the following recommendations is ongoing:

- Treatment (final phase)
- Recurrences Central Nervous System (CNS) tumours
- Haematological Malignancies

Upcoming working groups:

- Multiple primary tumours registration
- Survival data in ECIS

Frontiers in oncology, special issue 2022-2023

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". 12 articles were submitted and 2 additional papers are under review. A closing paper is also under preparation.

Focus on ECIS and the new data call (JRC)

Data call status: to date, 88 CR submitted data for the 2022 call, out of which 86 received the first feedback Following the release of the JRC-ENCR Quality Check Software v2.0 in November 2023, the 2nd phase validation has started, focusing on consistency checks among variables. Also feedback from this phase will be relayed to the cancer registries.

<u>Joint Action (JA) to support quality improvement of cancer registry data feeding the European Cancer</u> Information System

The JA to support the quality improvement of cancer registration data follows the initiative of the JRC, as an opportunity to provide support, also from the financial side, to the European cancer registries, including countries with low cancer registration coverage. The JA, included in the EU4Health Work Programme 2024 (page 65), has a budget of 13 million euro. Cancer registries that are interested to participate should ensure they are well connected to national official authorities as beneficiaries of the JA.

Nomination of ENCR SC chair(s)

LvE and GG will be the chairs of the ENCR SC 2024-2026.