

80th ENCR Steering Committee (SC) Meeting Minutes - Videoconference

Date and place: 8 June 2022, Videoconference

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

The new data call

Collaboration Agreement (CA) between the JRC and the ENCR registries

To date 42 registries signed the agreement. On top of the data protection, the CA regulates several additional aspects regarding the governance of the network, addressing IPR, publications, etc. Signing the Agreement is a guarantee at the registry level, as following the GDPR principle of accountability, the CA reports and describes on purposes and means of sensitive data processing and ensure proper data safeguards along the process.

Some registries referred they will not sign the agreement, but will send aggregated data. The JRC is working on a software to enable data aggregations at local level.

The newly established JRC-ENCR the Management Committee

Its role and responsibilities are detailed under article 6 of the CA as the governance body to be established to coordinate the activities under the ECIS collaboration. A page in the ENCR webpage describing its functions has been added. From now on, joint meetings will be held for the ENCR SC as well as for the JRC-ENCR Management Committee.

ENCR recommendations and Working groups

- The recommendation on **Urological Tumours** is now finalised and can be published on the ENCR website.
- Work is ongoing for the Working groups dealing with **Basis of Diagnosis, ENCR standard dataset, Tumour Recurrences, Cancer Entities Revision, Treatment Data Harmonisation**.
- Given in many European countries the number of migrants (including refugees) is increasing, cancer registries need guidelines on if and how to register these cancer cases.

Cancer incidence and mortality estimates 2022

The JRC and IARC are working together to update the cancer burden projections to the current year 2022, in collaboration with the ENCR and the International Association of Cancer Registries.

ENCR Training and events

Material for the training on Urological Tumours is under preparation, following the newly adopted recommendation. Additional e-learning modules are envisaged, work is ongoing.

Next ENCR conference

Given the positive experience for the 2021 online event, the next ENCR conference is envisaged for the second half of 2023 and could still take place in a virtual setting.

ENCR site visits

Review of the Madrid childhood CR

Two out of the planned virtual review meetings were organised. After the third and last meeting, a report will be drafted.