

72nd ENCR Steering Committee (SC) Meeting Minutes

Date and place: 4 March 2020, Videoconference

Attendees: ENCR SC, European Commission Joint Research Centre (JRC)

2020 data call

- The <u>2020 data call protocol</u> was presented, which will serve the European Cancer Information System (ECIS) and Cancer Incidence in Five Continents (CI5-XII) Projects. It will include malignant tumours, with some exception such as CNS benign or urothelial tumours. Basal cell skin carcinoma cases will be excluded.
- The data call questionnaire depends on the protocol and is currently being drafted.
- <u>Data Protection (DP) record</u>: The work for the submission of the DP notification by the JRC is ongoing. The legal service
 of the European Commission is currently investigating the legislative basis to host and process individual health
 records (i.e. sensitive data). In parallel, the JRC is engaging the WHO-IARC lawyers to address the
 international data transfer.

2020 estimates

JRC presented the work on the 2020 national incidence and mortality estimates, done in collaboration with IARC, that should be completed in a few months. Several actions are being planned for the launch of the 2020 estimates in order to enhance dissemination.

Simultaneously, the ECIS web application will be complemented with additional features in the (2020) estimates section: new analyses by age group (with the restriction of 15-year age groups), and new summary with "big numbers" (demo not yet finalised).

ENCR Scientific meeting 2020

JRC presented details on the organisation of the event. Around 100 posters' slots are expected based on the past conferences. Abstract submission will be tentatively open in the period April - May.

ENCR SC members will lead the trainings and workshops with the following topics: Training on Urological cancers; Training on Modern diagnostic technologies and treatments; Workshop on Updates in ICD-O-3.2; Workshop on How to communicate CR data.

ENCR elections

The timeline for the 2020 elections was proposed. All SC members can be re-elected. The handover between the "old" and the newly elected 2020 ENCR SC will take place on the occasion of the 2020 scientific meeting.

ENCR-JRC trainings

- Training in Slovenia: participating registries in the "Workshop on planning and developing cancer registries" identified problems they are facing such as governance, independence, infrastructure, IT system, training,



- privacy, legislation and, most of all lack, of human resources. The training on coding topography and morphology was very well accepted by the participants.
- Training in Cluj, 24-26 June 2020: 30 local participants and 20 people from outside Romania will be accepted. Financial support may be available by the JRC. A special session/ workshop on data protection was requested by the local organisation, which the JRC will try to organise.

ENCR recommendations

- <u>date of incidence:</u> the official endorsement by IARC/IACR is still pending following concerns that the recommendation may differ too much from the American and Canadian definition. More work is necessary to solve this issue.
- <u>multiple primaries</u>: the JRC is working on the impact assessment of the new multiple primary malignant rules in the incidence estimation.
- <u>urothelial tumours</u>: the current ENCR recommendations are being reviewed by the working group in order to improve the comparability among the European cancer registries on these tumours. A minimum set of recommendations for recording and reporting urothelial tumours is being drafted.
- basis of diagnosis: a new working group will be set up to address the coding of the basis of diagnosis.

News from networking opportunities

- Prostate Cancer Europe Roundtable 2020, 01/04, European Parliament, Brussels;
- TAIEX Workshop on population based registries in SEEHN countries, 5-6 May, Montenegro.