

## 73rd ENCR Steering Committee (SC) Meeting Minutes – Videoconference

**Date and place:** 4 March 2020, Videoconference

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

### New EC Knowledge Centre on Cancer, new opportunities for the ENCR & ECIS

JRC reported on the activities related to the setting up of the new EC Knowledge Centre on Cancer (KCC), as connected to other EC cancer-related initiatives such as RTD's Mission on Cancer and the Europe's Beating Cancer Plan. As for the EC health strategy, the next EU for Health Programme will increase dramatically in budget, allowing for important funding opportunities. As regards opportunities for ENCR registries, possible topics and issues needing support have been identified and proposed, including dissemination according to cancer staging, increased geographical detail, linkage of cancer data with external datasets (socio-economic, environmental, etc.) and focus on selected populations such as childhood. The ENCR SC highlighted further issues meriting support such as training, data collection on comorbidities and data analysis as well as support on overcoming the limitations on data sharing imposed by the GDPR within the context of the European Health Database.

### Data call

- Data Protection (DP) record: The work for the submission of the DP notification by the JRC is ongoing particularly focusing on the legal basis for JRC's processing of individual records. An annex is under preparation to describe in detail the activities carried out for the cancer data processing, including the transfer of individual records to third entities such as IARC. A data transfer agreement with each single CR as data provider will be needed.
- Data call protocol: some pending issues regarding the definition of reporting cases were discussed. It was decided the following: i) for urothelial tumours, behaviours 1 and 2, in addition to behaviour 3 will be considered, ii) only in situ for breast cancer will be included, iii) cervical and colorectal in situ tumours will not be included and iv) GIST cases with behaviour 0 and 1 will be included.
- Mortality data: only the missing data periods will be asked of the non-national registries. Whenever available, the JRC will use EUROSTAT mortality data at NUTS2 level, without asking the registries.
- Life tables: only data not available from the previous data call will be asked.
- Harmonisation of the "Stage" variable: the analysis was carried out by the JRC and the ENCR SC and will affect the development of the Quality checks software.

### The geographical detail in the 2020 data call

JRC presented two additional geographical variables introduced in the data call protocol – "geo-code" and "geo-label". These geospatial variables, identifying the residence of the patients at time of diagnosis, aim to support EU health-policy processes by allowing linkage of different health datasets at regional level. The coding of these two variables should follow the EUROSTAT's NUTS 2 classification (and when possible NUTS3). The ENCR SC observed that socio-economic comparisons (for example) analyses are more useful at SES (socio-economic status) level than at NUTS level. The ENCR SC suggested displaying data in ECIS by geographical area (at NUTS2 detail) rather than by registry, even though registry-level data are also needed for the computation of quality indicators.

## 2020 estimates

The JRC is computing the estimates (currently national estimates for EU27+UK are completed) that are validated afterwards by IARC for alignment and consistency with GLOBOCAN. The JRC and ENCR SC raised concerns about the impact of COVID-19 on the estimates. Even though at the current stage it is not possible to account for such impact, the issue will be highlighted and commented in the corresponding publication.

## Rescheduling of ENCR activities due to COVID-19

- The elections for the ENCR SC will suffer a delay of a few months – the submission of the candidatures will be opened in September-October and elections should take place in January 2021.
- The ENCR scientific meeting and side events, planned for the fall 2020 in Granada, will be postponed.
- The training in Cluj, Romania, will be postponed.

## ENCR recommendations

- Urothelial tumours: the WG prepared the recommendation and some final comments are pending from the SC. Some CRs may volunteer to test the implementation of the recommendation.
- Multiple primaries: JRC reported on the impact of the new rules on incidence.
- Date of incidence: IACR's endorsement is still pending.
- Basis of diagnosis: work has started with reference to the coding of the basis of diagnosis for liver cancer.

## COVID-19 questionnaire

The JRC presented a draft questionnaire to assess the impact of COVID-19 pandemic on cancer registration among the SC members. After finalisation, the questionnaire will be submitted to the ENCR CRs.