

71th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 7 November 2019, Ispra, Italy

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

JRC-IARC meeting on 2020 Call for data and Estimates, 27 June 2019, Ispra

JRC and IARC agreed on having a joint data call for the European registries, where the JRC would collect, clean and validate the registries' data, and transfer validated records to IARC. Regarding the estimates, at the June meeting it was confirmed that after the JRC will produce European estimates of cancer incidence and mortality for 2020, IARC will use these figures for the Globocan update and embed them into the worldwide 2020 estimates.

ENCR Scientific meeting 2020 – title/topics, satellite events

The ENCR 2020 conference will take place between 11 and 13 November 2020, at the Andalusian School of Public Health in Granada, Spain. The proposed theme of the next scientific meeting is "Cancer registration saves lives". As satellite events, the following training/workshop sessions were agreed:

- Training on modern diagnostic technologies and new treatments, ½ day;
- Training on urological cancers: ½ day;
- Workshop on updates in ICD-O-3.2: 1+½ hours;
- Workshop on how to communicate cancer registries data: 1+½ hours.

Cancer staging tool

Cancer Staging is the tool under development by the N. Ireland Cancer Registry in collaboration with IARC and UICC (Union for International Cancer Control) that calculates TNM, Stage Group and other simplified and/or site-specific cancer staging classifications from the basic features of the patient's disease (e.g. tumour size or number of lymph nodes involved). The tool is currently in the development stage.

2020 data call

- Data Protection (DP) record: The work for the submission of the DP notification by the JRC is ongoing. To enable the processing of individual records, each single registry submitting the data will need to have a signed agreement with the JRC. The template for such agreement is currently under preparation by the JRC.
- List of variables: the variables for the 2020 protocol were discussed and reviewed.

Decentralised project

The JRC and IKNL in The Netherlands are setting up a joint project to check the feasibility of a decentralised processing of the cancer registry data. The project objective is to apply a proof-of-concept for a decentralised architecture, already developed by IKNL, to the infrastructure and workflow for the cancer data processing developed by the JRC, with the ultimate aim of enabling registries to deliver aggregated statistics instead of releasing individual patient data.

Survey on GDPR

The JRC run a survey conducted among the EU countries plus Norway and Iceland about the impact of the General Data Protection Regulation (GDPR) in the cancer registries' daily activities. Registries from 26 EU countries replied to the survey; results show that there are different interpretations of GDPR rules between EU countries and within the same country as well. The results suggest the need to develop a common vision, and common European guidelines for all cancer registries, specifying, in particular, how to provide data for scientific studies.

Cancer factsheets

The new template for new cancer factsheets, proposed by the JRC, was presented and reviewed by the ENCR SC.

"Ask an expert" service in the ENCR website

The service is operational and functional. Once a consistent number of questions/answers are collected, a FAQ page in the ENCR website might be developed.

ENCR-JRC trainings

- 2019 course - (20) 21-22 Nov, Ljubljana: The aim of the training is to present the classifications for coding topography, morphology and stage of cancer cases and their principles for implementation in general and for specific cancer sites.
- e-learning platform: The JRC reported on its investigations aimed at developing an e-learning platform for the ENCR.
- 2020 courses: A request for training in Cluj (Romania) was received, for a course to be organised in spring 2020. A second training opportunity will consist in the satellite events of the 2020 ENCR Scientific Meeting in Granada, which could include also a training on prevalence methods and software organised in the context of the iPAAC joint action.

ENCR recommendations

- date of incidence: The consultation to the cancer registries took place through a survey run by the JRC. Next step is the official endorsement by IARC/IACR.
- multiple primaries: The JRC is evaluating the expected impact following the implementation of the new proposed rules.
- urothelial tumours: The working group met on 12 July 2019 to review the current ENCR recommendations on bladder tumours and to draft a minimum of recommendations for recording and reporting urothelial tumours in order to improve the comparability among the European Cancer Registries on these tumours. A follow-up meeting will take place on the 8th November to finalise the recommendations.
- basis of diagnosis: a new working group will be set up to address the coding of the basis of diagnosis.

Participation to the Kidney Cancer Europe Roundtable 2019, 17 Oct 2019, European Parliament – Brussels

Focus of the event was to bring together EU policymakers, medical and clinical professionals, academic experts, healthcare players and patient groups to examine ongoing challenges in managing kidney cancer and to explore practical solutions to build a framework for policy action across the EU. An ENCR representative attended and reported on the ENCR and ECIS.

2nd Consensus meeting on Childhood Cancer Staging, 21 October 2019, Lyon

The first consensus meeting regarding childhood staging was held in 2014. The purpose of the 2nd Consensus Meeting, hosted at IARC, was to review the current staging system for childhood cancer (e.g. updates, clarifications or new classifications needed?), to update the current situation of the use of the staging system (in LMIC and HIC) and to discuss non-anatomical stage prognosticators. The 2nd Consensus meeting should result in recommendations and a peer-reviewed article.