

67th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 7 June 2018, Ispra, Italy

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

ENCR-JRC events, 24-28 September 2018, Copenhagen

The logistic issues for the organisation of the Copenhagen events were revised. Agenda and faculty for the Training on data coding on the 25 Sept were discussed. Aims of the Workshop on data protection (26 Sept, morning) were defined, and it was agreed to run a survey addressed to the cancer registries to assess their status in relation to their compliance and the impact the General Data Protection Regulation (GDPR) has on their organisation and activities. The revision of the abstracts submitted for the ENCR Scientific Meeting (26-28 Sept) was organised.

Further developments of ECIS – definition of priorities

The ongoing work related to ECIS and considered to be priority addresses the following aspects:

- Graphical enhancements, to improve the user-friendliness of the web-application;
- Initiative on national estimates computation: with the aim to define a common methodology to complement the registry data in ECIS with national estimates for the countries without full population coverage;
- Rare tumours and childhood cancers will be also addressed specifically inside ECIS, and the ongoing work on this was commented.

New rules for the composition of the ENCR SC

It was agreed to discontinue representation in the ENCR Steering Committee from GRELL and ANCR, but to keep representations from IACR and IARC. On the basis of the discussion, new rules will be drafted and presented during the general assembly in Copenhagen in September.

Terms of Reference (ToR) for the JRC-ENCR collaboration

A first draft for the ToR of the JRC-ENCR collaboration was introduced. Once a final version is agreed, it will be published in the ENCR website and will serve as a reference to understand the role, involvement and expectations of the JRC vis-à-vis the ENCR and its members as cancer data providers.

Updates on the work on recommendations on incidence data and multiple primaries

A revised proposal for the "Date of incidence rules" was discussed, in which date of imaging is introduced to take into account the latest diagnostic techniques. For the Multiple primaries recommendation, an evaluation of the possible consequences of change of the rules using the data from selected registries will be done.

Requests for access to data

Two situations requesting access to data from the ENCR-JRC project received by the ENCR Secretariat were reviewed. Once the data are validated, a proper workflow to address this type of requests needs to be implemented.

Cancer factsheets

A new template for the cancer factsheet was presented and discussed. The new factsheets will report the data from the ECIS web application.

Requests received

- A request was received for involvement in a workshop on recurrences. It was decided that the ENCR is not interested to invest or to lead activity on this topic for the time being.
- Training on stage for childhood cancer according to Toronto guidelines: the topic will be integrated in the September training agenda.
- Working group to address urothelial tumours: a Working Group should be set up to address the topic.

Briefing on the JRC-ENCR Training on Statistical Methods for Analysis of Cancer Registry Data, Ispra 5-6 June 2018

The training was attended by 31 participants from 16 countries. The feedback collected from participants was reviewed and discussed.. A roadmap to address future training and prioritize among possible topics will be drafted.

Briefing from the Training for Russian cancer registries, 31.05/01.06 St. Petersburg, Russia

A training for the Russian cancer registries took place in St. Petersburg, with around 80-100 people attending. Following the successful event, the request to the ENCR for support from Russia was discussed.

Briefing on the iPACC WP7 Cancer Information Registries Kick-Off Meeting on May 31st in Milan

An involvement of the ENCR was advocated in many different tasks of this new Joint Action, in support of several registries that are directly involved in piloting the different activities.