

55th ENCR Steering Committee (SC) Meeting

Date: 12 November 2014, Ispra, Italy

The meeting was called to order at 08:45 at the JRC site in Ispra, Italy. Quorum was established.

Agenda item 1 Adoption of the Agenda

The newly elected SC members were welcomed by the chairman and modifications in the agenda were proposed.

Agenda item 2 Review of the minutes of the 54th SC meeting

The 54th SC meeting minutes were adopted without any changes.

Agenda item 3 Handover to the new SC

a. JRC/IARC negotiations

The status of the JRC-IARC negotiations was presented to the new SC members. It was mentioned that differences in the data and in the incidence rates produced by different parties are worrisome for the registries. The registries prefer processing and sending the data to one data repository and then have them included in other studies –upon permission first from the individual registries. It was decided to propose a joint *Call for Data* with EUROCARE and make the announcement during the General Assembly (GA). The SC gave the mandate to the JRC to hold a joint JRC-ENCR *Call for Data*, designed in a suitable way for accommodating the needs of various international studies that use European data. A data portal and quality checks software will be developed at the JRC for the data call. The coordination of working groups (WGs) to provide guidance on the relevant tasks, as advised by the SC, will be the responsibility of the JRC.

b. Working groups and recommendations

The QC working group encountered obstacles due to the lack of recommendations for the collection of specific data items. The group compiled the following list of issues that require the development or revision of related recommendations:

- Multiple primaries' rules (coded in ICD-O3)
- Definition of C-factor
- Time of diagnosis, considering the new diagnostic technologies used
- CNS for children
- Lack of coding standards for treatment data
- EOD for paediatric cancers
- ICD-O-3 and WHO Blue book discrepancies that impact coding standards
- Guidelines related to privacy
- Portal of data calls

WG need to be formed to discuss, agree upon standards and provide recommendations to the registries. The ENCR SC will propose the WGs to be formed and procedures to be followed for the recruiting of members.

c. Training

Training courses are needed. Duplication should be avoided and capitalising on existing training tools is necessary. Holding regional training and using e-learning tools would be ideal. The JRC will collect information from CRs regarding their training needs.

d. ENCR Membership criteria

With the merger of registries in some countries, ENCR membership criteria may have to be reconsidered, especially for (ENCR SC) voting purposes. With new types of registries that are being formed, cancer may fall under the (general) category of 'disease registration' and the effect that this will have on cancer registration professionals has to be taken into account in terms of the membership criteria. It was agreed that the issue of voting rights will be raised at the GA, for ENCR member consultation, and will be included in the next SC agenda.

Agenda item 4 Fine-tuning of the GA interventions

Topics to be brought up for discussion at the GA were set.

Agenda item 5 Election of the new SC chairperson

Alexander Katalinic will serve as the chairman and Harry Comber as the co-chairman of the new ENCR SC, taking duties from November 2014 onwards.

Agenda item 6 AoB and date for the new SC meeting

A date for the next SC meeting, which will be held in February or the beginning of March 2015, will be fixed soon. Monthly conference calls will be held in addition to quarterly SC meetings. A new WG to provide guidance on the data portal will be established as soon as possible, in order to start its functions. The first conference call is envisaged for January 2015.