

59th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 5th February 2016, from 9.00 am to 5.30pm, JRC-Ispra.

Attendees Present: ENCR SC, European Commission Joint Research Centre (JRC), Invited Guest from Istituto Tumori, Milan, Italy

Update on the JRC Cancer Information team

Francesco Giusti, a new member of the team, having joined since January 2016, was introduced.

JRC-SANTE- IARC meeting on 19th January 2016

Positive and constructive meeting with agreement that IARC, JRC and ENCR work together 'with and for' the cancer registries. Main conclusions of the meeting: a) JRC and IARC will co-develop a "one stop portal" for cancer registries data submissions b) JRC will support the transfer of data to IARC submitted by the cancer registries to JRC in response to the CI5-XI call c) IARC agreed to transfer the ECO website and related IPR to JRC.

Update on the 2015 Call for Data

As of beginning of February 2016, 89 CRs participating and 84 having finalised the submission on the ENCR-JRC portal. A status report on submissions will be posted on the ENCR website and updated monthly.

More specifically, the ENCR- JRC project currently covers 36.6% of the EU28 population, but there is potential to cover 81%.

A quality report will be sent as feedback to the CRs that submitted data.

Quality check software v.1.4

Feedback from CRs on the software received so far will be incorporated into the new version of the software, to be issued soon.

Proposals on how to update rules for ENCR Membership

A proposal on updated rules for ENCR membership was discussed, and once finalized, will be posted on the ENCR website.

Addressing ENCR recommendations and training following the outcome of the WG on 24 November 2015.

The report from this workshop will be available soon. CRs expressed their need to have clear rules and, in addition, guidelines on implementing these rules. Training will be needed every time a new recommendation is released.

A workshop/training session will be organised on the morning of October the 5th (4 hrs), prior to the ENCR conference. This workshop will be focused on data quality and include the presentation of the JRC quality check software.

ENCR FACTSHEETS

Future factsheets will address pancreatic, thyroid, kidney and liver cancers.

ENCR 2016 Scientific meeting and General Assembly, 5-7 October 2016

Organisational details of the conference were revised and discussed. Abstract revision will be organised by the JRC and carried out by the SC members. The *European Journal of Cancer Prevention* will release a special issue on Cancer Registration linked to the ENCR Scientific Meeting and General Assembly 2016.

Other Projects

EU Joint Action on Rare Cancers (Invited Guest): deliverables will include a list of rare cancers and recommendations on how to exploit CR data for research.

PancreOs: new research groups were identified in France and the UK. Another meeting will be held in Madrid in March 2016. A draft data collection protocol will be prepared with the participation of the JRC.

AoB and date for next meeting.

It was proposed that the 60th SC meeting be held during the month of May.