

58th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 29th September 2015 from 9.00am to 5.30pm, JRC-Ispra.

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

Review of the of the 57th ENCR SC meeting minutes

Resolved: With some small changes, the 57th SC meeting minutes were approved.

Update on JRC team

New members of the team were introduced and profiles will be posted on the ENCR website.

Update on call for data, transfer of data, use of quality software

An update on the Call for Data was presented including the number of data submissions in the ENCR-JRC portal, detailing those already transferred to EURO CARE and those still on-going. As data protection restrictions differ from one country to another, it was suggested that JRC adopt a case-by-case approach to understand any constraints (technical or legal) to submission.

It was agreed that JRC and IARC should meet to discuss and plan a data transfer protocol for data submitted through the ENCR-JRC portal with permission to forward to IARC's CI5 study.

An update on the quality check software was presented. The software has been written with checks hard-coded in the scripts, since the aim was to have a working tool in a very short time. Therefore, it's not easily customizable by users. A more flexible tool is envisaged for the future. The SC recommended that the software be designed to enable CRs to submit files without basic mistakes (or missing data), to reduce the workload on JRC.

ENCR- JRC standard data sharing agreement

JRC has a data-management policy on the website and all studies have a data-use protocol. It remains to be seen whether these documents are sufficient for individual CR needs.

ENCR database – data extraction, analysis, and data visualisation. Identification of basic requirements.

There is a need to decide how data can both be best accessed and presented. The first priority is to display aggregated data; access to record-level data can be handled via the current process in the portal (via submission of a data-use protocol to which individual registries can sign up).

ECO data are out of date but the tool could be used for the current call as an interim measure until a new data visualization tool is developed. JRC will liaise with IARC for a possible solution. In any temporary absence of data visualisation tool, factsheets are extremely valuable.

The development of the system towards a more comprehensive European cancer information system requires the input of all the various stakeholders and it was suggested that a working group could capture the requirements and understand if the development could proceed as a collaborative venture with different entities developing the various modules of the system.

Report back from the teleconference with WHO Europe and Cancer training in St Petersburg

During the third week of September cancer registry training was organised in St Petersburg, Russian Federation. This was a four-day course organised by IARC and supported by WHO EURO. Overall participants were pleased with the course and would like to attend more training courses and receive information from the ENCR.

Definition of Europe in connection with eNCR membership

It was decided to introduce two types of ENCR membership:

- the FULL membership, having voting rights and Registry data collected and displayed, for population-based Registries in countries within the UN geographical definition of Europe plus Cyprus. The UN definition covers 42 countries and most of the EU (except Cyprus).
- the ASSOCIATE membership, for countries outside the UN definition (such as Azerbaijan in the Caucuses and Central Asian countries). This is a new category of membership. Support, including training, provision of information etc., can be provided to these countries bilaterally; however, Associate Members would submit data to IARC and not to ENCR-JRC. Associations of Cancer Registries can also apply for Associate Membership.

The Steering Committee agreed for collaboration in organizing training between ENCR-JRC, WHO EURO and IARC. WHO EURO previously expressed their interest in collaborating with ENCR- JRC on training at country level.

Collaboration between ENCR –JRC and IARC

The two institutions could work together on the following:

- training courses: IARC could host training events. It was suggested that training courses for trainers be organised to help ensure a wide a distribution of the training as possible. Ideas from NAACR, which has an extensive training programme, will be examined.
- cancer burden estimates: the latest released are the ones reported in the EUCAN section of the ECO's website, referred to 2012. IARC and JRC should work together to revise the methodology and update European figures.

Particular attention will be given to web-based tools and on support to new registries.

Some recommendations need to be updated to ensure compatibility between Europe and the rest of the world.

A Memorandum of Understanding (MoU) between JRC and IARC would be beneficial.

ENCR Working Groups and meetings

A Workshop on Recommendations and Training Needs will be organized by JRC in Ispra on 24th November.

It was agreed that the 2016 ENCR Scientific Meeting and General Assembly Conference would take place during 5-7 October 2016.

Collaboration with SANTE

A talk was presented on the planned Joint Action on Rare Cancers. This Joint Action will be funded under the Health Programme and the co-funding from DG SANTE. If organisations are interested in participating in this Joint Action they need to contact their Permanent Representative.

An important objective of DG SANTE is the compilation of health profiles. A number of projects and initiatives are underway to start addressing the requirements (BRIDGE, a proposed ERIC for health indicators, etc., with which it would be important to collaborate. A number of pilot phases will start soon)

The SC agreed that these profiles would be important outputs and highlight the work carried out by ENCR and JRC.

Other studies

The aim of the Pancreos study is to link clinical cases with cases registered in population-based cancer registries. It was agreed that ENCR need to consider how data can be collected on follow-up of cases including quality of life indicators. These should be compatible between studies.

The SC agrees to host, on the ENCR website, information provided by the EORTC and potentially, the ENCR- JRC to provide epidemiologic support.

The World Medical Association has drafted a declaration on data-protection issues.

ENCR – JRC Promotion including Slide Set

A promotional slide set including long term aims and general aims was presented. The SC suggested that some patient-centred objectives be included.

Date for next meeting.

It was proposed that the 59th SC meeting be held during the last 10 days of January 2016 or first week of February 2016.