

64th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 20 October 2017, from 9.00am to 12.00 pm, Utrecht, Netherlands.

Attendees Present: Old (2014-1017) and New (2017- 2020) ENCR SC, European Commission Joint Research Centre (JRC)

Introduction of new SC members.

AK summarised the results of the ENCR election and the Committee were informed that Liesbeth van Eycken, from the Cancer Registry of Belgium will represent IACR on the SC.

Election of Chair and vice Chair

AG was elected Chair and OV as co-Chair; it was agreed that the Chair and Co-Chair would rotate after 18 months. The possibility of co-opting a representative from Eastern Europe in the SC was discussed. It was agreed that such representatives could be invited to participate in working groups, if needed.

Challenges for 2018.

Challenges for 2018 were outlined and listed, including the organisation of the 2018 ENCR Scientific Meeting and General Assembly, the launch of a new call for data, the reopening of the WG on data quality checks, the finalisation of the new recommendations on 'date of incidence' and 'multiple primaries', further development of the ECIS website, publication strategy and authorship. Regarding the 2018 ENCR plenary event, it was suggested that the Danish Cancer Society host the meeting in Copenhagen. Another possibility is the Andalusian School of Public Health.

Overview of achievements and outstanding matters

AK summarised achievements over the past three years, including the development of the first version of the ECIS, the 2015 call for data and the related validation procedure that was set up. Pending issues handed over to the new SC are as follows: completion of feedback to the CRs on the quality of data, finalisation of the updated recommendations and related SOP for the issuing of new/updated ones, clarification of the relationship between the ENCR, IARC and IACR to possibly ensure consistency of guidelines. Moreover, an additional open issue is the need to coordinate a unique European dataset for cancer data, that once collected from the ENCR registries should be transferred to other studies/projects (e.g. CONCORD, CI5) to avoid unnecessary burden on CRs due to repeated calls. Lastly, AK encouraged the SC to increase communication/collaboration with patient groups, especially in relation to survival data, and reminded colleagues to address and enhance the role of site visits and training to registries.

Handover to new SC

AK reminded participants that CRs' priorities were raised at the groups' discussion at the symposium the previous day, and it would be worthwhile if the new SC review them in order to prioritise the SC activities for the next three year period. In particular, he underlined that some guidance from the Network could be useful to CRs in national implementation of the new Data Protection regulation.

AOB and date for next meeting

The next SC meeting will take place December 2017 or January 2018. A doodle poll will be sent out to agree on the date.