

56th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 9 March 2015, from 9.00am to 5.30pm, JRC-ISPRRA.

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

Agenda item 1. Adoption of the Agenda

It was accepted that a standing item on training be included in future agendas.

Agenda item 2. Review of the of the 55th ENCR SC meeting minutes

The 55th SC meeting minutes were adopted without any changes.

Agenda item 3. Briefing on the EUROCORE SC Meeting

A bilateral EUROCORE and ENCR- JRC teleconference took place on 12 December 2014 before the EUROCORE Steering Committee (SC) meeting on 29 January 2015. There was agreement, in principle, that there would be one ENCR-JRC/ EUROCORE call. EUROCORE will carry out work on survival and prevalence and ENCR-JRC on mortality and incidence. All communication will be via the ENCR-JRC Portal and completely anonymised data are to be submitted and shared by the cancer registries (CRs). Explicit permission from the CRs will be necessary for any data use. Investigators requesting data should submit a detailed protocol, which explicitly states how the data will be used.

Agenda item 4. Briefing from the EUROCORE SC Meeting

The EUROCORE Steering Committee accepted the data flow plan proposed by ENCR-JRC and requested that the final opening for the data call, for EUROCORE-4, be 30 April 2015

Agenda item 5 Briefing on the communication with CONCORD

A meeting took place on 14 January 2015. The planned date for the launch of CONCORD III is the end of 2015. An update will be provided under agenda item 10.

Agenda item 6. Report on the ENCR WG Call for data - status of portal, data flow process, status of protocol and status of call

A talk was presented on the ENCR- JRC portal. The portal can be used for updating contact details, uploading data, communicating consent to European stakeholders, on data usage, and for filling in the data questionnaire. Files can be submitted by the CRs and checked using quality control software. Data files will be rejected if they do not comply with file format. The portal is designed to allow ENCR-JRC to receive files from the CRs and then to send the files to the stakeholders (e.g. CONCORD, EUROCORE, IARC) and receive feedback regarding data quality, errors etc. from both the stakeholders and the CRs. The portal will be further developed and will have other functions to fulfil additional ENCR and JRC (administrative) needs.

Discussions took place on two issues: i) Data collection and ii) data usage.

i) Data collection. It was suggested to include new variables, e.g. rural/ urban, in the questionnaire and to ask the CRs if they would be willing to share this information in future calls.

ii) Data usage. It is important to make it clear that the CRs own the data. Each study will provide a detailed protocol which includes the purpose of the study, the data usage, the variables that will be used for the study, the statistics that will be produced, the methodologies that will be followed and the study's research plan. CRs, on the basis of this protocol, will be free to allow the inclusion of their data in the study.

A consent mechanism will be needed for CRs requiring a further scrambling of the patient identification and further restrictions related to patient confidentiality, before data can be used by the various stakeholders. Pseudonimisation of the received ID was agreed.

It was agreed that ENCR SC produce a statement to be sent to the CRs on the 2015 ENCR-JRC call for data, by the end of March 2015. The plan is to test the system, on the portal, by mid- April 2015 and launch the call by the end of April 2015.

The protocol for the call for data and the questionnaire were reviewed by the ENCR SC, taking into account comments made by EUROCARE. It was agreed that if EUROCARE plan to include life tables, information for these tables will be included in the protocol.

It was agreed that information is needed in the questionnaire indicating which multiple primary rules the CR follow (IACR or other).

As regards TNM, there will be one field for clinical and one for pathological: when CRs do not know if TNM is pathological or clinical they need to specify this in the questionnaire. The need to stick with the core items of TNM was stressed. Other classifications for stage e.g. Ann Arbor, Breslow (for melanoma) and Gleason, are to be included in the call for data protocol and questionnaire in line with the proposal made by EUROCARE.

It was agreed that the call for data protocol and questionnaire to be updated by the end of March 2015.

Agenda item 7. Report on the ENCR WG Call for data – Software demonstration

The first version of the software, to be used for data quality checking, was demonstrated. The current software can detect every error according to file format and allowed variable values. Other types of errors to be detected (such as between variable consistency) will be developed in a second phase. Output files will include summary and detailed reports on errors and warnings. This is an interim solution and the final aim is to develop a more interactive and flexible software. The data quality revision, in the 2015 ENCR-JRC call for data, will be performed directly by EUROCARE. Feedback from EUROCARE on the QC checks will be used by JRC to verify and improve this software.

It was agreed that JRC improve and test the ENCR-JRC data quality check software and compare the results of the QC checks with those produced by the EUROCARE QC checks.

Agenda item 8. ENCR recommendations: needed revisions

Recommendations that need revision were outlined. These include:

The definition of multiple primaries (coded in ICD-O3) rules

-Date of incidence

-How to convert to ICD 2011

-Recommendations for DCOs

-Using the new "standard population"

-Evaluation of data quality indicators

-New diagnostic methods and their impact on pertinent fields collected by CRs

-CNS tumours

-Basic and additional variable list for CR

It was suggested that a WG be set up to examine each issue, in collaboration with IACR. There is a need for consistency at European level. Communicating via email or through TCs could be considered as options for getting agreement on some of the proposed recommendations.

It was agreed that a "WG on coding issues" be set up. This working group would be tasked with 1) getting opinions from the ENCR SC on the priorities for updating/additions to the guidelines; 2) drawing up a list of required new/ updated guidelines; 3) working with JRC on organising a workshop to agree a plan to recruit people to work on different areas on the list

This group should include representatives from IARC and IACR. A small Working Group should be set up first before a workshop of coding experts is organised.

It was agreed that a WG on Coding to be set up.

Agenda item 9. Queries to ENCR from SC

The SC discussed an upcoming training programme in Russia organised by IARC. It is not easy for JRC to co-fund courses with other organisations due to EC financial rules and constraints. JRC can organise courses but these need to be planned within JRC's annual cycle of work programming.

Agenda item 10. Update from the CONCORD study and discussion

A talk was presented on the CONCORD-2 study. This study included 279 cancer registries from 67 countries and covered the years 1995- 2009. More than 300 CRs took part and 2527 datasets were analysed. The main findings have shown worldwide differences in cancer survival, increases in survival for breast, colorectal and prostate cancers and higher survival rates for stomach cancer in Japan and Korea. However, the study also showed a wide range in survival and inequity in diagnosis and treatment across the globe. Many lessons can be learnt. A key message is that world-wide surveillance is crucial for cancer control policies and cancer registries need political and financial stability.

The publication is " Allemani et al, Lancet, 2014 and includes an Appendix on-line (book of 175 pages). Additional outputs will include site specific articles, data quality, Life tables, and survival by macroeconomic indicators, avoidable deaths, and cure.

The CONCORD study also estimated life tables for each CR, included in the study, and this will be a topic to be published in a future paper.

The major differences between the CONCORD study and the EURO CARE study are: 1) different definitions for certain sites; 2) different methods for building life tables and for estimating survival (EURO CARE is using Seerstat vs Poham Perme method used by CONCORD), 3) different exclusion criteria,

Agenda item 11. Training courses on Cancer Registration in SE European Commission

To assist WHO Euro and help set up the new Cancer Registry in Moldova, JRC will send a member of JRC staff, who has expertise in cancer registration and who can also speak Romanian, along with a member of the ENCR SC.

Agenda item 12. AoB and date for next meeting.

It was proposed that the 57th SC meeting be held during the first two weeks of June in Ispra, Italy.

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