

57th ENCR Steering Committee (SC) Meeting Minutes

Date and place: 11 June 2015, from 9.00am to 5.30pm, JRC-ISPRA.

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

Agenda item 1. Adoption of the Agenda

An item on EORTC was included under agenda item 7.

Agenda item 2 Review of the of the 56th ENCR SC meeting minutes

The 56th SC meeting minutes were adopted without any changes. The minutes of the Working Group meeting on the Portal and Call for Data, held on 10 March, were also adopted without any changes.

It was agreed that all SC members be cc'd in letters to be sent to the CRs and receive the Newsflash in future

Agenda item 3 Call for data:

a. Portal – current status and further development

It was agreed to keep the final correct file as a "locked" file and to ensure that a control system is in place to deal with previous (incorrect) versions i.e. a clear description of data flow. A "time-limited" rule for submission, and rules consistent with Data Protection legislation for dealing with deletion of files sent by the CRs (as required by their policies), was discussed. It was agreed to label all the subsequent versions of the files with the date of uploading and to keep, after all checks and corrections are carried out, only the last ('locked') one, deleting all the others. Each CR will be able to download the last version, i.e. the locked version, of each file from the Portal..

It was also agreed that a SOP would be developed for data flow with CRs and EURO CARE. It was also agreed that the JRC be cc'd in any communication that takes place between EURO CARE and the CRs regarding errors or changes in the datasets.

b. ENCR-JRC Call for Data Protocol

It was agreed that the JRC should ask the CRs, via the Portal, if data should be submitted to IARC for Cancer Incidence in Five Continents. As this is the first time that JRC is launching a call for data, the IARC view was to test the whole system during the ENCR Call 2015 and agree on technical details before it can be used for data transfer from JRC to IARC in the future. In the meantime, IARC is counting on using the existing Registries Portal hosted by IARC (which the registries have used since 2010), for the CI5-XI data call. The CI5 was originally announced for May but should come out soon.

It was agreed, for the moment, to delete the CONCORD 3 project, as an option on the Portal, as no protocol is available and it is not decided if, or when, the study will be carried out.

It was agreed that it should be possible to easily update information on the call for data questionnaire in case mistakes are made. This is possible using the "EU survey", through the option of 'open survey' which allows the participants to change the answers to the submitted questionnaires and provide clear information about these answers.

Agenda item 4 Data quality, criteria and process

a. QC software current status

it was agreed that ENCR-JRC will ensure a distinction is made between "unlikely" events (warnings) and errors (Warnings and errors)

b. Decision mechanism for acceptance of data and associated quality criteria

It was agreed that it would be useful for the CRs to receive a quality evaluation/ competent technical support from the JRC.. It was agreed that ENCR- JRC should support CRs i.e. guide CRs on how to improve the quality of data submitted. The mechanism will be one of "intensive feedback" as opposed to "accepting or rejecting data sets".

It was also agreed, by the SC members, that ENCR- JRC should reach the same level of sophistication as the North American Central Cancer Registries (NAACCR) in the USA and Canada and show that ENCR-JRC have competence to do this. It was agreed that ENCR-JRC review procedures in NAACCR and IARC for benchmarking. It was also decided that ENCR-JRC carry out a survey of CRs to assess how they are staffed and funded (combined with Survey on training needs).

It was agreed that ENCR- JRC cannot rely on internal consistency checks but also need to have preliminary assessments on comparability, completeness and validity. An editorial group or committee could examine the quality of the data for a specific project. . If something is incongruent ENCR-JRC should contact with the CRs for clarification. Pass/ fail criteria could be used regarding the protocol criteria, especially for missing values or if data are not usable.

c. Approval mechanism for affiliates of EUROCARE and other stakeholders

A discussion took place on the meaning of "data sets" as various data sets are available at different levels (aggregation and variable suppression). It was agreed that aggregated data be downloadable and be made available on the website while individual data would not be posted on the website. However, permission to process the data will have to be agreed with the national and regional cancer registries providing the data and, therefore, retain the ownership of it. It was agreed to include a clear message on the Portal as to the availability of all aggregated data sets and to include data use terms in the JRC protocol.

There was a discussion about the role of the ENCR-SC in evaluating data requests. The JRC could carry out a first basic review of the protocol and keep the SC informed. Once the proposal has passed the filter, the proposal and the protocol would be placed on the portal and CRs would be alerted. CRs would need to agree to the use of their data. The website could list ongoing and completed projects.

The JRC will develop and post on the website its policies: required reference for all publications using the data, copyright and reuse policy and a disclaimer for endorsement and liability.

It was suggested to evaluate the possibility and the usefulness of a space on the portal for communication among CRs for these types of requests. It was agreed that a tool would be developed, on the website, for closed dialogue, including a "one click" broadcast email function.

e. Use and publication of data by ENCR-JRC

Statistics that could be calculated include crude and standardised incidence rates, age specific incidence rates by CR, sex and year, time trend analysis, childhood cancer, age-period cohort (APC) analysis and second primary tumour analysis. Other epidemiological studies could explore cancer incidence inequality, ecological studies including environment data (at least at the geo-spatial resolution of registry catchment area). Factsheets, technical reports, monographs and scientific peer/reviewed papers could be produced.

There is a need focus on analysis for the ECIS i.e. data for the public on incidence by sex, time, age, and tumour groups. The ECO webpage is a good starting point (with maps, figures and tables). Information on the quality of the

data should also be provided. The presentation of data should also be harmonized with IARC. Some CRs may be able to provide more detailed information on morphology or other variables which could be used to elaborate the ENCR Factsheets.

It was suggested that data at the NUTS III or NUTS IV level be combined with environmental data for correlation studies, if the CR registries submit geospatial information at that level (i.e. residence of patient administrative code at the NUT III, or IV level or treatment/diagnostic facility etc.). There is a need to root the research in policy as politicians have an interest in the ECIS, which, in turn, may leverage financial support for cancer research. However, there is a need to ensure such studies are not "over interpreted". Maps can make correlation studies seem causal. It is best that specific stand-alone studies are carried out on environmental risk factors.

It was pointed out that any criticism of ecological studies will come back to the CRs providing the data. Such studies are best carried out at a local level, with additional data and carefully thought out epidemiological designs.

Agenda item 5. ENCR Working Groups

a. WG on Coding

A WG could be set up to decide what the priorities are and a specialist group could look at specific areas. A WG on Coding (recommendations) was proposed addressing, firstly, 'the quality standards'. Considering the expertise of the prior WG on Data Quality, some people could be invited to participate in this WG with additional experts.

b. Training

The SC agreed that more information is needed on training needs. The WG on Coding could examine the issue of training. Suggested topics for training include coding, survival analysis, basic analysis, translation of manuals. E-Learning could be an option. Collaboration with the WHO Regional Office for Europe to promote cancer registration in SE Europe could be beneficial. TA certain amount of funds could be budgeted for in 2016.

It was agreed that a Basic Cancer Registration course be organised in 2016. It would be beneficial to map what CRs are doing. Moreover, it would be useful to map which resources are already available on the web (CDC, IARC, etc. including e-learning) and put a list on the ENCR Web-site. It was agreed that ENCR-JRC carry out survey of training tools

Agenda item 6. ENCR Newsflash and website

It was agreed that the SC review the draft before it is sent to the CRs. A short deadline of two weeks will be given, as agreed with other documents (Factsheets etc). The SC will be contacted by email for suggestions on what to include in

Agenda item 7 a. Pathways to deal with patient and clinicians' groups

b. Process for dealing with adhoc requests for collaboration and prioritisation of requests

- PICORET

A presentation on the PICORET project, a project proposal coordinated by the Institute for Child Health, and which has passed the first stage of the Horizon 2020 evaluation process, was made. The co-ordinator was PICORET proposed organising a workshop dedicated to research of cancer in childhood in collaboration with ENCR-JRC. The idea of workshop was discussed informally in autumn 2014 with the JRC and ENCR SC representatives. However, the SC need more precise information the workshop before any commitment is made.

- Platform on pancreatic cancer

A briefing on the Platform on Pancreatic Cancer was presented. The Pancreos project will include data from hospitalised patients, not population/based data and, therefore, the benefit of collaboration is limited. It was suggested that Pancreos work with the CRs, at the national level, and not through ENCR. The SC are in favour of collaboration

and assistance but not to include the group in the Network of ENCR. Scientific exchange of information could be beneficial. ENCR-JRC could assist in contacting the CRs and facilitate exchange of information.

- EORTC

JRC/ENCR was approached by the EORTC and a TC was organized. It was agreed that there would be collaboration between ENCR- JRC and EORTC.

Agenda item 9. AoB and date for next meeting.

It was proposed that the 58th SC meeting be held during the last week of September or first week in October in Ispra, Italy.

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