

## 53<sup>rd</sup> ENCR Steering Committee Meeting Summary

**Date: 3 February 2014**

The meeting was called to order at 09:00 at the JRC site in Ispra, Italy. Quorum was established.

### Review of the of the 52<sup>nd</sup> ENCR SC meeting minutes

Resolved: A correction to the name of the director of the UK national cancer registry was requested and with this change, the 52<sup>nd</sup> SC meeting minutes were approved.

### Update on the JRC organisational chart

The two newly hired members of the *Cancer Information Team* of the *Public Health Policy Support Unit* at the JRC were presented to the SC; a new *Grantholder Cat 40* position is envisaged to be advertised soon.

### EC invited guest

A presentation entitled *Health system outcomes, patient engagement and international benchmarking – ENCR & University Hospital Birmingham routes to collaboration*, focussed on the information system set up at UHB, integrating data from various hospitals, and its uses. Potential collaboration with the ENCR was discussed.

### Report on ENCR activities:

- **Update from Working Group on Quality Checks**
  - Action: Circulate a draft final document to the WG experts, by 15/03, for comments/remarks (JRC)
  - Action: Circulate a revised final document to all cancer registries for comments (JRC)
- **ENCR membership list and filled questionnaires**
  - Action: Obtain the most current membership list and filled questionnaires to carry out the upcoming ENCR elections (JRC/IARC)
- **Factsheets**
  - Action: Finalise prostate cancer factsheet for publication, and continue drafting factsheets on lung, breast, melanoma and cervical cancers (JRC)
- **ENCR website and Newsflash**
  - Action: The *ENCR Newsflash* to be produced approximately every 3 months
- **Update on JRC/IARC collaboration:** the JRC and IARC will try to finalise the contractual agreement for the transfer of the ECO system to the JRC before summer.
  - Action: Report to the SC on the service requirements, tasks and deliverables negotiated with IARC (JRC)
- **Report on site visits:** Briefing on the visit to Moldova and potential future visit to Macedonia
  - Action: Produce an updated version of the document with the items to be addressed during site visits (SC member)
  - Action: SC to reply to the request for support from Macedonia (SC member)
- **Recommendations document on haematological malignancies**
  - Action: Circulate report and tables to the SC for approval from the ENCR (SC member)
- **Workshops/conferences planned**

- Action: A workshop on *Quality Checks* will be held 4 June 2014 at the JRC (JRC/SC member)
- **ENCR general assembly:** The *ENCR General Assembly* will be held 12-14 November 2014 in Ispra. The theme and agenda of the meeting are currently being determined. A call for abstracts (presentations and posters) will be organised by March 2014. The abstract submission deadline will be 1 June 2014.
  - Action: Provide themes for the *General Assembly* (SC)
  - Action: Produce a concept document for the *General Assembly* (JRC)
  - Action: Set up process for receipt and evaluation of abstracts and organise the meeting (JRC)
- **ENCR new data call:** The new call for data will be coordinated by the ENCR secretariat. The call document was reviewed but further revisions are needed. Data use rules need to be explicitly mentioned in the call document.
  - Action: Draft call for data documents and send to the SC for approval (JRC)
- **Horizon 2020 proposals:** Emphasis should be given to projects that can have continuity and sustainability.
  - Action: The SC will evaluate incoming proposals for collaboration; deadlines for applications are 11 March and 14 October 2014 (SC)
- **Accessibility to ECO and the CI5 databases:** The mechanism of getting approval for using the registries' data for different study protocols needs to be updated, taking into account privacy rules and respecting authorship.
- **Planning of the ENCR 2014 elections:** Three voted members are finishing their terms in this year, and elections will be organised in the fall of 2014.
  - Action: Develop a time table and organise elections (JRC)

#### Interaction with other European and international consortia

- ENCR SC members and the JRC members were invited as speakers at the European Parliament workshop *Towards a European Cancer Information System*, Brussels, 12 Feb 2014.
- An abstract on quality checks was submitted for the IACR conference (Ottawa, 25-29 June 2014), on behalf of the JRC and the ENCR.
- The JRC drafted a study protocol: *Impact of data quality on estimating cancer survival*, aiming at evaluating the effects of various data quality indicators on survival data from cancer registries.

**AoB and date of next meeting:** The 54<sup>th</sup> SC meeting will be held 3 June, 2014 in Ispra, Italy.