

41st Steering Committee Meeting
IARC, Lyon – 6-7 April 2009**MINUTES****Final of 28 May 2009***Recorded by ESF***Present:**

F. Bray (FB), CR of Norway, outgoing Chairman of Steering Committee
E. Crocetti (EC), GRELL
A. Gavin (AG), CR of Northern Ireland
J.-M. Lutz (JML), CR of Zurich
D. M. Parkin (DMP), IACR, new Chairman (present on 7 April)
S. Rosso (SR), Piedmont CR
R. Sankila (RS), Association of Nordic Cancer Registries (ANCR)
S. Siesling (SS), CR Twente
E. Steliarova-Foucher (ESF), ENCR Scientific Coordinator

IARC:

P. Autier (PA), for ECO website only
J. Ferlay (JF), for ECO website only
O. Kelm (OK), for EUROCOURSE only
L. Voti (LV), for EUROCIM only

Apologies:

M.P. Curado (MPC), IARC

**6th April****1. Introduction**

FB opened the meeting at 13:30, after the majority of the participants arrived (FB, EC, AG, SR, SS, ESF). This was the first meeting of the renewed ENCR Steering Committee (SC) after the elections held last year.

JML joined the meeting.

ESF presented apologies behalf of the IARC director, who was not able to open the meeting in person due to unfortunate conflict of dates. She extended the Director's support to cancer registration and the ENCR. (Written statement included in meeting documents.) ENCR SC members acknowledged with grace the financial contribution of the IARC director to this meeting.

FB then presented the meeting Agenda and the available documentation. The Agenda was adopted with small modifications.

RS joined the meeting.

2. ENCR background

For the information of the new committee members, FB described briefly the history of ENCR since its inception in 1989 until the most recent years. He evoked the difficult times of ENCR as a consequence of the lack of dedicated funds for the Network since 2004.

3. Minutes of the 40th SC

The minutes of the 40th SC Meeting were skimmed through by the committee and the following points were further discussed:

- FB updated the committee on point 4c (Meeting of the Epidemiological Society of Germany (DGEpi) on 17-19 September 2009). Following informal discussion with Alexander Katalinic it was thought premature to merge this meeting with a formal ENCR general meeting. FB was invited by DGEpi to give a talk during the meeting to increase contact between the Network and DGEpi.
- In reference to point 7a (Summer course), RS raised the fact that the book by Isabel dos Santos "Cancer epidemiology" is out of print. He suggested that ENCR sends a strong message to WHO publication office to reprint the publication and fosters its availability through the web in pdf format. **Action: ESF**
- FB also updated the SC on the status of the publication Cancer Registration Principles and Methods (point 7b): Max Parkin is the leading Editor of the monograph, the content of which was drafted at the first meeting of the Editors in October 2008, with the publication planned for 2010.

4. Election of new ENCR SC Chair

FB, the Chairman of the ENCR informed the SC members of the reasons for his stepping down. He would like to avoid cumulating this office with the one of General Secretary of the IACR, into which he was nominated in 2008. He also suggested that the new ENCR chairman should be Max Parkin, due to his long-standing experience with ENCR and his current engagement with IARC as an Advisor to the Director during 2009. The ENCR SC members agreed that Max Parkin becomes the chairman for an initial period of 1 year. FB also offered to take on the role of vice-chair, and this was accepted.

5. Terms of reference of the ENCR Steering Committee and of ENCR Secretariat

The Terms of Reference of the Steering Committee (attached as Annex to the minutes of the 40th ENCR SC meeting) were endorsed as appropriate for the current period and resource availability.

There were no specific requirements formulated about the role of ENCR Secretariat before funding of ENCR is secured.

6. Candidates for the co-opted members

SR suggested that a mechanism for co-opting active SC member(s) from Central and Eastern European countries to join the ENCR Steering Committee. SC agreed with this suggestion, although no nominations were put forward. This topic is to be discussed again at the next meeting, when the role of ENCR in EURO COURSE and availability of funds becomes more clear.

It was proposed that ENCR should establish itself as a legal entity, to facilitate fundraising, notably with the European Commission. ESF will look into the procedure of registration of ENCR as an "Association loi 1901" in France (**action**) and the SC will then decide whether this is the way to proceed. On 7th April (see below), a formal status like that of IACR was suggested as an

option to be investigated. IACR is an international NGO formally recognised by WHO, a status permitting independent financial management, and receipt of membership fees and direct grants (eg, from the US NIH). The possibility of recognition as such by the European Regional office of WHO (rather than WHO HQ) requires investigation (**action – secretariat**).

7. ECO web-site

PA presented the new ECO web-site (<http://eu-cancer.iarc.fr>) to the Steering Committee members. The web-site was developed by external company Clininfo in collaboration with JF. Its development was sponsored by CLARA (*Cancéropôle Lyon Auvergne Rhône-Alpes*) in the framework of the European Cancer Observatory project (2004-2007). PA had asked for permission to attach the logo of ENCR on this web-site.

The SC members acknowledged the attractive presentation of cancer data. However, the SC did not approve the display of the ENCR logo on the ECO web-site for the reasons listed below. This decision was made following a vote of SC Members.

- The website does not show information from all the European registries (Italy, Austria, Switzerland)
- The incidence data are the estimates for 2006, while more recent data are available publicly (eg in Nordcan and other national web-sites)
- The difference between recorded data and estimates is not made clear
- The website is hosted and managed outside IARC and no mechanism is available for maintenance and updates of the web-site at IARC
- The regular updates of the website are costly (due to the external subcontractor)
- The ownership of the website is unclear (*Cancéropôle*, IARC, other?)
- The web-site was not developed in collaboration with ENCR and its place in relation to other projects is unclear

In summary, SC believes that a web-site of a superior quality and sustainability could be developed by ENCR. The NORDCAN website was named as a possible model for such a development.

8. EURO COURSE project

8.1. ERA-NET philosophy

OK presented the topic. ERA-NET is a competitive funding mechanisms opened to European “Programme owners” or “Funders”, which excluded many cancer registries, as well as IARC, to be the partners in this project. The philosophy is to allow a more effective use of available resources to reduce fragmentation and support collaboration in research across Europe. EURO COURSE is funded within the 7th Framework Programme of the Directory General (DG) Research of the European Commission. The project started officially on 1st April 2009 and the contract has been signed for three years.

8.2. Overview of the EURO COURSE project

A short summary of the objectives and structure of the EURO COURSE project was distributed with meeting documents. All registries received the “Description of Work” by mass mailing on 19 January 2009.

FB informed the SC of the history of the EURO COURSE application. In addition to fulfilment of the objectives of the funder, this project is to provide funding for some core activities of ENCR and increase the awareness and political importance of the Network. The coordinator of EURO COURSE is Jan Willem Coebergh (Eindhoven CR). Three boards steer the project.

8.3. Intersection between ENCR and EUROCOURSE

ENCR is a perennial network, which gave rise to a 3-year EUROCOURSE project. EUROCOURSE received money to support and promote the ENCR. Therefore, ENCR SC is present in the management bodies of EUROCOURSE. All SC members are also the members of the Steering Board of EUROCOURSE project, comprising also all 15 contractual partners. Two elected members (FB and SS) represent ENCR on the Executive Board of EUROCOURSE, which includes also the 5 leaders of 10 workpackages. The members of the Advisory Board will be identified in response to topics addressed by the project.

IARC (ensuring ENCR Secretariat) is an important subcontractor of the project and as such, it is also represented on Steering and Executive Boards of EUROCOURSE (1 member in each).

RS stressed that EUROCOURSE should ensure sustainability of ENCR activities by strengthening cooperation with the funders and decision-makers.

8.4. Kick-off meetings

Two meetings landmark the start of EUROCOURSE, the Steering Board meeting on 7th April 2009 and the Executive Board meeting on 8th April 2009. The mission of the ENCR delegates is to make sure that the interests of ENCR and its membership are met in conduct of and output from EUROCOURSE. The minutes of the two meetings will be available on a temporary ftp site hosted by IARC (<http://pftp.iarc.fr/>) before a dedicated EUROCOURSE website is developed.

The meeting closed for the day at 18:30.



The meeting resumed at 8:30 with DMP joining in. He was briefed on the discussions and decisions made so far, after which he took over the chair of the meeting. In respect to the issue of legalisation of ENCR, DMP contributed the experience of IACR of which he is Immediate Past President (point 6. above). However, there are disadvantages to an independent status, notably additional accounting, reporting and related paper work. The question of physical location will also have to be resolved.

9. Funding opportunity: DG Sanco (deadline 20 May 2009)

A new call for proposals was published on 23 February 2009 by the European Commission, within the DG Sanco (Directorate of Public Health and Consumers). Within the "Call for projects", a topic "Development of indicators or indexes specifically concerning cancer to better support action on cancer across the EU" seemed particularly well suited the ENCR objectives and activities.

ESF informed the SC of the draft proposal of collaboration sent by Riccardo Capocaccia to the IARC director on 16 March and 6 April 2009 in response to the above call.

SC committee decided that an application should be prepared on behalf of ENCR, in accordance with the following guidelines:

- IARC should be the leader of the project
- The project should be developed in collaboration with EUROCARE groups
- EUROCHIP group should also be involved
- Care should be taken to avoid overlap with the existing projects

[Status on 5th May: IARC was disqualified from this competitive call due to a specific mechanism newly developed by the EC for direct funding of public health projects conducted by international organisations. The ineligibility of international organisations to apply for

competitive grants was not explicit in the official texts and was clarified only by 23 April. In the meantime, an advanced draft proposal was prepared, but was not circulated due to the turn of events. It is planned to use the new mechanism of “direct grants” for funding those core activities of ENCR that fulfil the objectives of the new programme “Action against cancer: European Partnership” of DG Sanco. An explanatory letter was sent to the ENCR SC on 8 May.]

10. Consultancies

ESF informed the SC of two requests for consultancies ENCR (specified below). Since no funds are available for these activities at present, the modalities of satisfying these requests should be investigated.

10.1. Albania

The request was submitted by Renee Otter in her capacity of the WHO consultant for cancer in Europe. DMP pointed out that Albania is already receiving help on cancer registration in the framework of Programme of Action for Cancer Therapy (PACT) project of the International Atomic Energy Agency (IAEA) and it might be premature to do a consultancy in this situation. However, the progress of PACT in this country should be investigated and recommendations should be subsequently revised by ENCR SC (*action: ESF*).

The identified members of the potential mission are: RS, and Roberto Zanetti (as the leader of Workpackage 3 on data quality issues in EUROCOURSE).

10.2. Germany, North Rhine-Westphalia

The request for consultation was submitted by Ulrich Batzler, who is affiliated to this registry. First, it should be investigated if the inviting CR would be able to sponsor financially the consultancy.

If the funds are identified, the possible members of the mission could be Chris Carrigan, Hans Storm (to address data protection issues within his EUROCOURSE Workpackage 2 on data confidentiality), or Sabine Siesling (proximity).

11. Collaborative studies

ESF introduced the subject with a description of the current procedure of application for collaborative studies. This is fairly informal, consisting in a submission of a project description to the ENCR Steering Committee. The study proposals are published on the ENCR web-site.

SR suggested that a more formal rules and follow-up should be developed. It was noted that at present the EUROCIM rules are prevailing in these circumstances. FB suggested that for each such project a collaborator(s) or a referee be nominated by the ENCR SC.

11.1. Haemacare

JML informed the SC of this 2-3 year programme with the objective to revise groupings and develop recommendations for coding of haematopoietic malignancies. The final report is being finalised, after which it will be passed on to the ENCR Secretariat for approval by the ENCR SC and, if approved, for a dissemination to cancer registries.

11.2. Non-melanoma skin cancer

Esther de Vries submitted a project proposal “The practice of registering BCC incidence in Europe in 2009” (enclosed with the meeting documents). The study was approved by the ENCR SC.

12. EUROCIM-2

LV presented the results of data collection for EUROCIM-2. Data from 61 cancer registries were submitted so far. The statistics on data quality showed 20% median proportion of erroneous records. Further fine-tuning of the DEP-Edits software is under way. The data are received and processed in Descriptive Epidemiology Production Group at IARC.

It is envisaged in the near future to collect data for EUROCIM-2 and EUROCOURSE through a common gateway.

The rules and procedure for access to data should be reviewed. SR offered to prepare a proposal, based on the rules used in other networks of cancer registries in Europe.

13. Other issues

13.1. Courses

During the past few years, no courses were organised specifically by ENCR. Annually, cancer registration courses are organised at IARC (IARC Summer School), targeted at cancer registrars in developing countries. Within EUROCOURSE, Workpackage 8 is devoted to a development of a course syllabus; however no funding is available for actually holding the course. It might be possible to apply for additional resources to hold a course (or courses) according to the guidelines developed in EUROCOURSE.

13.2. Certification

AG raised the issue of certification of cancer registries and/or accreditation of cancer registrars. Accreditation already exists in some European countries on national level and outside Europe (e.g., North American Association of Cancer Registries, NAACR). However, it might be more difficult to put in place such a system on European level, due to linguistic and administrative barriers. The needs and justification for setting up such a system should be investigated first and this could possibly be done through the EUROCOURSE project.

DMP closed the meeting at 11:00 a.m.