

NEWSFLASH

November 2005

The new Steering Committee met on 19-20 September 2005 at IARC in Lyon. H. Møller was unanimously elected Chairman. The main topics and decisions are outlined below:

1. Constitution

The following changes to the constitution were proposed and will be submitted to the ENCR members for ratification at the next general meeting:

(a) *Membership*

As ENCR is no longer funded by the European Commission, the previous distinction between full and associate members based on EU member countries, is obsolete. From now on **all general and specialised population-based cancer registries in Europe are full members.**

(b) *Composition of Steering Committee*

The Steering Committee is composed of four elected members, representatives of IACR, ANCR and GRELL, and coopted members as needed. The representative of IARC will be part of the Secretariat.

(c) *Mandates*

The mandate for elected and nominated members will remain as before, i.e. three years with possibility of renewal once. Coopted members may have a mandate of one year or three years, with possibility of renewal, depending on the reasons for the cooption.

(d) *Elections*

Due to the new memberships status, all ENCR members can stand for election, can support a candidate and can vote.

2. Funding

There are currently three sources of funding supporting different activities of ENCR for the next 2-3 years: (a) Cancéropôle Rhône-Alpes, France (**European Cancer Observatory**); (b) the EC Public Health Programme (**EUNICE**); and (c) the EC Sixth Framework Programme (**Eurocadet**).

3. Annual membership fee

As the financial situation has improved, the recent proposal to collect an annual membership fee as a source to fund some core ENCR activities has been

abandoned for the moment. The willingness of registries to contribute an annual fee to a special fund (cf Calum Muir Memorial Fellowship) will be discussed at the next meeting.

4. ENCR status

Steps will be taken to make ENCR a legal entity in the form of an association. This may facilitate future funding applications.

5. Updating cancer registry manuals

(a) *Pathology of tumours for cancer registry personnel*

Parts of this manual have been updated by A. Buemi. These parts are currently being translated into English and Spanish. The manual has also been prepared in Italian. The new versions will include the histological classification tables from the WHO Classification of Tumours series.

(b) *Cancer Registration – Principles and Methods*

This book needs updating. IARC or IACR are still discussing the composition of the Editorial Group. Pending the new version, it may be necessary to prepare a reduced technical report with the most important changes, as this manual is largely used at all IARC, IACR and ENCR courses.

6. Visibility of ENCR

To make ENCR and the ENCR activities more visible, the ENCR **website** will be completely redesigned and updated to facilitate access and use. ENCR **Newflashes** will be produced on a regular basis, and every time a meeting has been held to summarise the results. The series of **Cancer Fact Sheets** will continue on a more regular basis, and will be available on the ENCR website. The possibility of producing these in BMC Cancer will be investigated. **ENCR members are invited to contribute to Fact Sheets using data from recently published work.**

7. Data collection and processing

From the survey in 2004, it became clear that cancer registries are interested in a common quality controlled data submission facility, and ENCR has decided to offer this gateway. Data will be collected and maintained centrally at IARC, to be used for several predefined projects (e.g. CI5, EUROCIM, ACCIS, EUROCARE).

A software has been developed for checking the data, incorporating all quality checks applying to the predefined projects, as well as SEER checks. The program will be distributed to the registries with a letter inviting them to run the checks **before** submitting the data to IARC. A request for data will be sent at the end of October, stating the conditions for use of the data.

The use of this common gateway is optional and registries can decide not to use it, or to use it to submit data for a specific project only, however, the Steering Committee strongly encourages you to use this facility. It should also be stressed that **the database remains the property of the cancer registries.**

8. EUROCIM

The EUROCIM database will be updated and the EUROCIM entities re-discussed at the next meeting.

9. ENCR recommendations

(a) Basis of diagnosis

Part of these recommendations need to be updated in the light of the increasing number of molecular markers being identified for different neoplasms. This will be discussed jointly with IACR.

(b) Coding of bladder tumours

A number of registries are unable to use the recommendations of the first Working Group (1995), and a second Working Group was set up in 2002 to revise them. No progress has been made and due to the complexity of the topic, it was decided for the moment to postpone the revision. The recommendations currently on the ENCR website will be deleted.

(c) Completeness

Before setting up a Working Group to investigate the topic and propose a policy for dealing with completeness, a workshop will be held in conjunction with the next general meeting to discuss methods and compare results.

A commonly used programme to check completeness of registration to be used with STATA is available on-line and will be advertised on the ENCR website.

10. Consultancy/structured reviews

The consultancy and review services which have been frozen in the last two years will be reactivated. If you are interested in having an ENCR consultant visiting your registry, or a review team reviewing your registry, please contact the ENCR Secretariat.

11. Courses

The ENCR courses are core activities of the Network and have been very successful. The basic cancer registration courses, as well as the statistical analysis courses, will therefore continue. A first statistical course on **predictions** is planned for 2006. Other topics suggested were: mapping, EUROCIM, survival, prevalence, guesstimates. Other suggestions are welcome.

The deadline for applications to the course on automated cancer registration to be held on 12-14 December 2005 is now closed. Due to the large number of applicants, two courses may be organised, the first one in December this year at IARC, the second in UK in 2006.

12. General meeting

The feasibility of holding an ENCR meeting and workshop in conjunction with the 2006 GRELL meeting in Palma de Mallorca, Spain (24-26 May), is currently being investigated. The one-day ENCR meeting would consist of a half-day workshop on 'Completeness of cancer registration' and a half-day general meeting.

13. Biobanking

Biobanks are of increasing interest to cancer registries and the feasibility of cancer registries routinely flagging records with biological material should be investigated for exploitation in studies. The topic will be put on the agenda for the next meeting.

14. Next meeting

The next meeting of the Steering Committee will take place on 17-18 January 2006.

15. Departure of Eva Démaret

Eva Démaret retired on 30 September 2005 after over 30 years at IARC. She has been working for ENCR since 1992. The Secretariat and the Steering Committee express their gratitude for her devoted and valued work.

16. New e-mail address

For all correspondence with the ENCR Secretariat please use encr@iarc.fr.

The mailing address remains the same:

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