

NEWSFLASH

November 2010

EDITORIAL

This year has seen a significant improvement in the technical capacities available for cooperation within the ENCR. A new web-based portal was developed in the IARC in collaboration with the National Cancer Registry of Ireland using joint funds of the EU (FP7 and Public Health) and IARC. All cancer registries have had a chance to submit data to the 'ENCR call for data 2010' and complete the ENCR questionnaire 'Overview of cancer registration practices'. Although this is only the beginning of a new era of modern communication within the ENCR, there is already at least one benefit to the ENCR members: a single dataset submission to two international studies. The launch was successful with 69 registries submitting data to both the EUROCIM and EUROCARE projects. The process will become more versatile with future calls. In the meantime, all registries that have not as yet used this facility are encouraged to submit their data, complete the questionnaire and, last but not least, supply their contact details.

Content

43rd Steering Committee meeting
Current prospects for ENCR
Legal status
Funding
European Partnership for Action Against Cancer
EUROCOURSE
ENCR questionnaire
Data collection
Cancer Control Summit
Training and education
Ethics guide

AGENDA

Structured review of the registries
Albania
Munster
Terms of reference
General meeting of ENCR membership
Members update

FOCUS: IARC

Reminder

Current prospects for ENCR**Legal status**

At its last meeting, SC had all necessary information at hand to examine in detail the options for the ENCR to become a legal entity. Gaining a legal independence was seen as premature in the current situation, given the difficulty, cost and the outcome of the process. This decision was also supported by the current possibility for ENCR core activities being funded from the non-competitive direct contract mechanism available to the IARC from the EU. The SC also recommended that a document 'Terms of reference for the ENCR Secretariat' should formalise the relationship between the ENCR and IARC.

Funding

There is a good chance that some ENCR core functions will be funded through a direct agreement between the EU and the IARC within the Work Plan 2010. An application is under negotiation, with the following proposed content for the ENCR work package:

1. Provision of the European cancer indicators:
 - Production and dissemination of up-to-date incidence and mortality data
 - Dissemination of survival and prevalence data
2. Support and expansion of the capacity of ENCR to provide comparable cancer data
 - ENCR Secretariat and SC meetings
 - Data quality control activities
 - Working Group on coding of haematological malignancies
 - Estimation of the cost of cancer registration

43rd Steering Committee meeting

The Steering Committee (SC) met on 17 and 18 March 2010 in Amsterdam, The Netherlands. The Agenda was made available to the membership prior to the meeting through the ENCR web-site. As in the Newsflash of January, the approved conclusions and recommendations of the meeting are reported throughout this Newsflash¹.

¹ The full minutes of the Steering Committee meeting are available to members on request

- Preparation of evidence for the importance of a cancer registration

If awarded, the direct contract will start in 2011.

The SC recommended inclusion of the following topics in future applications:

1. European data standards
 - Definition of various data items
 - Multiple primaries (e.g. with respect to survival analysis)
2. Communication with the registries
 - General meeting every two years
3. Courses
 - Linkage of multiple databases

ENCR members might also be able to apply individually for certain competitive grants to support meetings, courses or other specific activities falling within the core ENCR functions.

European Partnership for Action Against Cancer (EPAAC)

A 'joint action' of the matching name is being prepared by the DG Sanco with Slovenian coordination. The ENCR (represented by IARC) is a 'collaborating partner' within this action and will be involved in Work package 9 (WP9, Health information). The contribution of ENCR/IARC to the EPAAC will be funded through the above-mentioned direct contract. WP9 is lead by Italy (Dr Milena Sant, Milan, Italy) and is supported by the Italian Ministry of Health. Extra funds should be raised within the participating member states to support this joint action through a provision of personnel, financial or other resources.

The ENCR SC reviewed the brief work description available for WP9 and concluded that this work might facilitate collaboration between IARC and EUROCORE.

ENCR involvement in EPAAC should also be seen as an opportunity to influence the political stakeholders in proposing the future orientation of Public Health work programme (2014-2020) and to continue supporting cancer registration in Europe.

EPAAC has its website at http://ec.europa.eu/health/major_chronic_diseases/diseases/cancer/index_en#fragment1.htm, where the updates on activities are timely reported.

EUROCOURSE

The annual meeting of the Steering Board of the EUROCOURSE project immediately followed the meeting of the ENCR SC on 17 March 2010 in Amsterdam (with all ENCR SC members present as members of the EUROCOURSE Steering Board). The

Executive Board met on 18 March in Amsterdam and will meet again on 15 November in Amsterdam, The Netherlands. The work progress is intermittently reported and discussed also during the monthly teleconferences of the Executive Board. Two Newsletters are available on the EUROCOURSE web-site and a third should be released before the end of November. All members of the ENCR are encouraged to join any of the activities, presented at the EUROCOURSE web-site <http://www.eurocourse.org/>. The current activities include:

ENCR questionnaire

The first on-line ENCR questionnaire 'Overview of cancer registration practices' was launched on 4 May 2010. It is accessible through the new portal at <http://cinportal.iarc.fr>, using a registry-specific username and a password. For the first time ever, the questionnaire re-uses data previously provided through other questionnaires to the international studies coordinated by IARC, most notably C15-IX, so that the respondents only verify the data already stored. Likewise, information entered to this questionnaire may be re-used in future surveys.

The questions describe the context in which a registry operates registry practices, data sources, items collected, standardisation and dissemination of the results. By mid-October, 73 of the 224 invited cancer registries completed the survey. Some 90% of the respondents conform to the ENCR definitions of 'basis of diagnosis' and 'date of incidence'. More than 80% collect stage data, about a half of them for all tumour sites. Information on treatment was collected by three quarters of the registries, with the date of first treatment for all tumour sites in about 40%. Information on screening for breast and cervical cancer was collected in 25 and 15 cancer registries, respectively. These and other preliminary results were presented at the 32th IACR meeting in Yokohama, Japan by Dr Sabine Siesling (Comprehensive Cancer Centre North East, The Netherlands).

A reminder letter circulated in mid-October to all the ENCR members aims to improve the percentage of respondents. The collected data will be available to all participants (according to the level of granted permission) and will provide a strategic basis for advocacy and further development of ENCR. Therefore, all ENCR members should find it in their interest to participate.

Data collection

An 'ENCR call for data' was launched on 21 May 2010. The content of the call resulted from the work of a dedicated working group 'Data calls and submission mechanisms' chaired by Dr Henrik Møller (Thames, UK).

Currently, data are being submitted through the new portal at <http://cinportal.iarc.fr>, using a registry-specific username and a password. Until mid-October, 69 registries used the facility and confirmed their wish to participate in the EUROCIM (52) or EUROCARE (46) databases. The datasets submitted to the portal for EUROCARE were transferred from IARC to the EUROCARE server.

The datasets submitted so far to EUROCIM will be verified by the DEPEdits software, which has been updated to correspond to the ENCR call for data published in May. Further modifications of the software aim at improvement of efficiency and functionalities and ease of use. A modified version should be released to the registries in early 2011. A specific preliminary analysis of the data will inform the relevant working group of a need to modify the Call and if so, in which way.

In the meantime, the working group 'Data analysis and presentation' led by Dr Freddie Bray (IARC) has discussed and will propose the uses of the collected data, in accordance with the outline provided within the ENCR call for data.

The issues of data custody, permissions for use, details of downloaded datasets, condition of publication of the results based on the data assembled by the ENCR members will be explored in

November 2010 by a working group 'Data sharing and ownership', chaired by Dr Stefano Rosso (Piedmont, Italy).

Many ENCR members are involved in these working groups and all are welcome to interact. The outcome of these working groups will be circulated to the membership for comments and final information/approval.

Reminder

The deadline for submitting the data to the current ENCR Call for Data 2010 is now extended until **31 December 2010**. Inclusions of any datasets submitted after this deadline cannot be guaranteed. The database will be closed for analyses in March next year.

Cancer Control Summit

EUROCOURSE will culminate during a conference with a participation of some 150 European multidisciplinary stakeholders. The preliminary date is mid-November 2011. The programme of the Summit will be discussed in detail at the forthcoming Executive Board of the EUROCOURSE, opened to all ideas from the membership until then.

AGENDA



23 September 2010: EUROCOURSE working group on Data calls(IARC, Lyon)

2-3 November 2010: EUROCOURSE working group on Data analysis and presentation (IARC, Lyon)

15 November 2010: EUROCOURSE meeting of the Executive Board (Amsterdam, the Netherlands)

23 November 2010: EUROCOURSE working group on Data ownership and sharing (IARC, Lyon)

24-25 November 2010: ENCR Steering Committee meeting (IARC, Lyon): see the Agenda on-line

22-23 March 2011: EUROCOURSE meetings of the Steering Board and the Executive Board (IARC, Lyon)

September 2011: UKACR meeting (London, UK)

October 2011: IACR annual meeting (Mauritius)

November 2011: EUROCOURSE European Cancer Control Summit; possibly including a course or a workshop

October 2012: IACR annual meeting (Cork, Ireland)

Training and education

Training courses have always been a part of the ENCR activities, until the dedicated funds were cut in 2004. The last ENCR course on Automated Cancer Registration was held in Lyon on 7-10 July 2003. EUROCOURSE now provides an opportunity to revive this tradition: it is planned to conduct a pilot course with a revisited curriculum in the EUROCOURSE framework.

Simultaneously, the recurring issue of a certification process of cancer registry personnel was reopened at the meeting of the ENCR SC in March.

Establishing a standard procedure internationally would require a considerable investment due to variability across Europe. On the other hand, should certification be established, it would bring benefit to the registries and recognise skills of the staff. It would also mean a development and support to on-going quality training, including examination.

It was therefore proposed that as a first step, a European curriculum for a course that was accredited by the ENCR would be developed for use in national setting, in the framework of EUROCOURSE.

Ethics guide

The Draft Guide for Research Ethics Committee Members proposed by the Group of Specialists on Biomedical Research (CDBI-CO-GT2) working under the authority of the Steering Committee on Bioethics (CDBI) of the Council of Europe was brought to the attention of the ENCR SC by Dr Timo Hakulinen (Finland).

One of the principles of the Guide was free and informed consent of the research subjects, participants in all biomedical research, including stored biological samples, as well as collected data (page 4 of the Guide).

At their meeting, the ENCR SC concluded that the Guide was not appropriate for epidemiologic research and especially cancer registration. The latter being governed by national laws, the Guide would interfere with their remit. Epidemiology was mentioned merely as a 'useful discipline' to be represented in Research Ethical Committees. Some biological samples have been collected many years earlier for specific projects or clinical purposes (e.g., pap smears). It should be possible to link these with other data without a need of the informed consent. Biobanks are extremely useful resources, which should be preserved for future.

ENCR SC has sent a letter to the Guide originators on behalf of ENCR and the individual ENCR members were encouraged to also raise a request for further improvement of the Guide. No response as to the content of the letter has been received so far.

Structured review of the registries

Albania

A consultation visit from IARC to the National cancer registry of Albania was commissioned and sponsored by the Albanian WHO office and conducted in November 2009 by Dr Maria Paula Curado (then IARC). The registry has existed for the past 20 years, but no data were ever submitted to IARC or published internationally. The data processing was mostly manual, with yearly registrations recorded in Excel. The registry had suboptimal material working conditions and the issues of data ownership and supervision of the registry seemed to be unresolved. The mortality statistics office was reportedly working fine.

ENCR SC concluded that as a first step the registry should first try to define its structure and relationships. A twinning partnership with another (European) registry might be useful. Help may also be thought from other international partners, notably WHO, UICC and Middle-East Cancer

Consortium. Assistance may also be possible through the new IARC programme of support to cancer registries in low and medium income countries.

Munster

The review, conducted in January 2010 was summarised in a report prepared by the Review Committee composed of Dr Chris Carrigan (National Cancer Intelligence Network, UK), Dr Sabine Siesling (Comprehensive Cancer Centre North East, The Netherlands) and Dr Alexander Katalinic (Cancer Registry of Schleswig-Holstein, Germany).

The Review Committee and the staff of the Munster Cancer Registry led by Dr Hans-Werner Hense agreed that the review was a success.

The SC endorsed the Executive Summary of the review, which is available on the ENCR web-site.

Terms of reference

The Structured Reviews are most often conducted in response to a need expressed by an individual cancer registry. The registries should be careful not to ask for a review too early after the start of the registry. In future, the registry's access to the mortality records and the possibility of linkage with the registry database should affect the evaluation of data quality and a coordinated pressure on national bodies to allow availability of these data for cancer registration would be beneficial. The results of the reviews will be published on the ENCR web-site, unless the registry disagrees.

General meeting of ENCR membership

The election of Cork, Ireland as the site of the IACR annual meeting 2012 will stimulate organization of a general meeting of the ENCR membership in a satellite meeting. Funds allowing, an earlier general ENCR meeting could be held before then, before or in conjunction with the EURO COURSE summit planned for autumn 2011.

Members update

In response to the alarming news about (possible) closure of cancer registries in some European countries, it was suggested that more support should be given during registries' life. This could be done in terms of bilateral exchanges. Hopefully, more resources for this kind of support should become available soon. Cancer registries should be informed promptly and regularly about the issues affecting ENCR and vice versa, they are encouraged to contact the ENCR secretariat with burning issues that can be alleviated through ENCR-coordinated action.



FOCUS: International Agency for Research on Cancer

The arrival of Dr Christopher Wild as the IARC director in January 2009 brought about a renewal of IARC activities in support of cancer registration worldwide and in Europe. A new Section of Cancer Information (CIN) has been created from the former structures and a new leadership team was recruited. A component of a specific funding mechanism that the European Union accords to the IARC is designated to support some of the core functions of the ENCR.



Dr David Forman became Head of CIN in April 2010, and he has emphasised the importance to IARC in supporting future progress of ENCR: "Rooting the ENCR within the Agency provides the European network with a solid support base and a

wide international perspective. One of the founding missions of the Agency is to collect and disseminate cancer data. Therefore, there will always be a strong impetus for the IARC to cooperate with cancer registries worldwide. The location of the Agency naturally creates strong links with the European cancer registries. The collaboration between the EU and the UN/WHO (of which IARC is an integral part) was confirmed in 2003 by a special agreement which resulted in provision of direct support to selected IARC projects by the EU Directorate of Public Health and Consumers (DG-Sanco). We are currently negotiating renewed funding of ENCR for, hopefully, many years to come. IARC occupies a unique situation and has long-standing experience in coordinating European collaboration and CIN is working towards expanding this tradition." Dr Forman was previously Professor of Cancer Epidemiology at the University of Leeds and Director of the Northern & Yorkshire Cancer Registry in the UK from 1994-2010. He also played a central role in the creation of a National Cancer Intelligence Network in the UK.



Dr Freddie Bray is an elected member of the ENCR Steering Committee since 2005. He returned to IARC in April 2010, after five fruitful years at the Cancer Registry on Norway. He has been delegated as the IARC representative on the ENCR Steering Committee as of

October 2010. His previous work at IARC included the analysis, interpretation and dissemination of European data based on the EUROCIM, EUCAN and CaMon projects. He has subsequently contributed to the EUROOURSE project. Dr Bray is positive about the enormous potential for the ENCR-IARC collaboration: "The ENCR has been going strong for two decades and continues to provide a platform for European Cancer Registries via the collaboration of its Members, their appointed Steering Committee and the Secretariat in Lyon. The number of Registries and their data quality has increased since the Network's inception, and the datasets of many have now accrued sufficiently to enable the study of the temporal developments of cancer rates. Using newly-established tools for data processing, novel approaches to data sharing, analysis, presentation and ownership are under development as part of the EUROOURSE activities that will feed in the future of the ENCR. A set of online resources in each of these domains will ensure optimal use is made of Registry data at the European level, and should provide the ENCR and its Members with a much greater visibility of their collective work."