

NEWSFLASH

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EDITORIAL

Over the past five years, ENCR has had to withstand some harsh times: the end of the 'Europe against Cancer' programme of DG Sanco, funding difficulties, changes to the Secretariat, etc. The network is emerging from this epoch all the more stronger, however, and increasingly recognised as a privileged partner in multidisciplinary collaborations involving cancer registration in Europe. The good news story that emerged was the successful application and launch of the EURO COURSE project which provides a strong foundation for European Registry collaborations that will help the ENCR to get back on its feet. Thanks to Freddie Bray, Henrik Moller, Hans Storm (as the lead writers on behalf of the ENCR), Lydia Voti and Olaf Kelm (the Secretariat at IARC), Jan Willem Coebergh (the Coordinator) and the numerous collaborators working on the project to ensure that it will thrive in the years to follow.

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42nd Steering Committee meeting

The Steering Committee (SC) met on 6 November in Turin to discuss the key issues of the funding of core activities, establishing an independent legal status for the ENCR, the promotion of cancer registration in Europe and involvement of ENCR in collaborative projects. The approved conclusions and recommendations of the meeting are reported throughout this Newsflash¹.

EURO COURSE

ENCR activities are currently developed mainly within the EURO COURSE project, funded from the EU Seventh Framework Programme (FP7) of European Research Area (ERA). EURO COURSE is a

partnership of "programme owners", the institutions supporting cancer registries within the member states. Involvement of the funders in EURO COURSE has a potential to create a positive political environment for further development of cancer registration. All ENCR members with good ideas and a little bit of spare time are welcome within the working groups of EURO COURSE. Those interested in specific areas should contact either the ENCR secretariat or the leader of the relevant work package directly. The Executive Board of EURO COURSE conducts a teleconference every first Monday of the month and input from ENCR members is always welcome. Further information on EURO COURSE can be found on the dedicated website <http://www.eurocourse.org>. A first Newsletter has just been released and distributed to the members.

Within work package 1, led by Jan Willem Coebergh, a large-scale consultation of the ENCR members is being prepared on registration practices, administrative and legal conditions, data collection and standardisation, etc. A series of surveys will be administered through a web-based questionnaire. The collected data will be available to the registries or to the public, according to the choice of each participant and would provide a useful tool for information and advocacy on cancer registration in Europe. The questionnaires will be developed in such a way that they address the objectives of both EURO COURSE and EUROCHIP projects.

Within work package 4, led by Harry Comber, the common Gateway for data collation and management is being developed at IARC. The Gateway will allow a high degree of automation and flexibility, reflecting the preferences of individual contributors. The gateway will collect data for all European studies, before they are

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

distributed for further processing and analysis; always according to protocols and the specified wishes of the data providers. It is of great value that the EUROCARE study group have agreed to join the process.

Data will be disseminated through a system developed for the NORDCAN project (<http://www-dep.iarc.fr/nordcan.htm>). The issues of access to data and data confidentiality will be worked out by dedicated working groups constituted within work package 4. While IARC will remain data custodian, the EU directive of 1995 and the wish of each individual contributor will be respected.

Data quality issues are being dealt with in work package 3, lead by Roberto Zanetti.

EUROCOURSE will also develop a training programme within work package 8 (Jan Willem Coebergh). The ENCR SC suggests the following topics for future courses:

- cancer registration
- statistical methods:
 - geographical analysis
 - time trends
 - predictions
 - survival
- data quality and comparability
- IT in cancer registration

Legal status of the ENCR

Becoming a legal entity would mean that ENCR could apply for funds and be legally responsible and independent. However, the only available option currently identified is to register ENCR in one of the EU member states.

Legal entity status requires conformity with relevant national laws and would mean an extra administrative burden to the Secretariat. The situation whereby IARC represents and provides for ENCR is satisfactory, although it has recently become apparent that it prohibits the ENCR from a coordinating role in the DG Sanco-supported activities, because of the exclusion of IARC from competitive fundraising. This is a major concern given the fact that for over 10 years ENCR was predominantly funded through DG Sanco. The mechanism of 'direct contract' (see below) however may provide a relatively stable funding of the ENCR core activities in near future.

The ENCR secretariat will continue exploring the options for establishing ENCR as a legal entity.

Funding the core ENCR activities

In the meantime, the new IARC Director, Chris Wild, is promoting the use of the 'direct contract' that IARC will enter into with the EU to sponsor the core ENCR activities. The 'direct contract' was specifically developed as a way of collaboration between the DG Sanco and international organisations. Although the annual budget allocated for all international organisations is limited (around 2 million euro in the last few years), it might be considered stable, as long as the ENCR/IARC activities respond to the overall Work Plan of the EU in the field of Public Health. Since the availability of data on cancer incidence, stage at diagnosis, and survival are ensured only by the cancer registries, it is likely that support of cancer registration will be of interest to the EU for some time.

The future proposal, which might receive funding in the second half of 2010, will have the following objectives:

1. To coordinate networking of European cancer registries
2. To develop high quality data standards
3. To provide measures of cancer burden in Europe
4. To facilitate continuity of knowledge by creating opportunities for training
5. To address specifically cancer in childhood and adolescence
6. To ensure wide dissemination of information generated by cancer registries

The IARC Secretariat will prepare the proposal in consultation with the ENCR Steering Committee.

Promotion of cancer registration in Europe

The Steering Committee received worrying news from several countries, where national cancer registries face serious difficulties. In Croatia, the national cancer registry is losing access to mortality data, in Slovakia data collection and availability is failing due to the changes in the registry administration and the Latvian national cancer registry was shut in May 2009.

In response to these pieces of bad news, the ENCR will act with the IACR and engage in a vigorous advocacy of cancer registration through national authorities, with the support from the IARC, WHO and the EU. In addition, visibility of the ENCR will be intensified at the policy-making level. Support through topical publications will also be tested. Volunteers and ideas are welcome.

AGENDA



- 17 March 2010:** ENCR Steering Committee meeting, Amsterdam, Netherlands
- 18 March 2010:** EUROCOURSE Steering Board meeting, Amsterdam, Netherlands
- 19 March 2010:** EUROCOURSE Executive Board meeting, Amsterdam, Netherlands
- 12-14 October 2010:** IACR 32nd annual meeting, Yokohama, Japan
- March 2011:** European Cancer Control Summit; a course or a workshop

Collaborative studies

The output produced by the ENCR membership is of increasing interest and potential use to other researchers in related fields. While the Network's aim is to make data as widely available as possible, agreed rules would reinforce collaboration and data potential. Therefore, the ENCR SC will recommend relevant, feasible and interesting proposals to the membership. If access to the common database is required, each registry will be consulted directly to establish whether they wish to participate in a given project. In the case of approval, the submitted data will be provided directly from the Gateway under mutually-agreed conditions. The extended use of data generated from these initiatives will undoubtedly increase the usefulness of the Network and each participating registry.

Haemacare

A manual of coding and reporting of haematological malignancies was prepared by the Haemacare working group, who requested ENCR to recommend the manual for use in cancer registries. While a need for standardisation of coding haematological neoplasms is acknowledged by the Steering Committee, a number of shortcomings in the manual did not allow ENCR to endorse the publication for general use in cancer registries. However, new ENCR recommendations on this topic will be mandated by the Steering Committee and Haemacare representatives would certainly be invited to join a future working group.

EUROCADET

This project (www.eurocadet.org), funded by FP6, is being finalised. One of the key aspects of the project is the utilisation of the Prevent software, which many ENCR members were able to learn more about in four courses organised in different countries. The software models the future incidence and mortality of cancer, depending on the assumed risk factors, such as smoking, alcohol consumption, obesity, physical activity, fruit and vegetable consumption and socio-economic status. The final report and a number of publications are being prepared.

ACCIS and IICC-3

Continuation of the ACCIS project is supported by ENCR. The project will restart by an update of the database, which will be built together with the database of the International Incidence of Childhood Cancer monograph. The first priority will be the analysis of cancer incidence trends.

PanCare

PanCare is a European network aiming at an improvement of the conditions of survivors of cancer in childhood or adolescence (www.pancare.eu). PanCare has sought the contribution of ENCR in building a database of long-term survivors of cancer in childhood and adolescence. ENCR supports this collaboration and recommends collection and provision of data through the common Gateway. Only the data of the registries wishing to participate will be concerned. The project is currently submitted for funding in FP7.

SIOP Europe

The European branch of SIOP (Société internationale d'oncologie pédiatrique, www.siope.eu), is also seeking collaboration with ENCR as part of a study group entitled the 'European network for cancer research in children and adolescents'. Coordinated by IARC, collection and evaluation of selected clinical data at the population level for children and adolescents with cancer will be piloted. It is also planned to develop a training module addressing issues specific to childhood cancer, which could be incorporated in a more general course on cancer registration. The ENCR supports this collaboration.

Book on migrants health

The network MEHO (www.meho.eu.com) monitors the health status of migrants in Europe. ENCR agreed to participate in the preparation of a chapter dedicated to cancer registration in Europe. A survey of cancer registries in selected countries has been organised directly by the project's collaborators. This work is expected to be completed during 2010.

FOCUS: Germany

A stream of activities around cancer registration is reported from Germany. A meeting of the German Epidemiological Society (DGEpi) held on 17-19 September 2009 had confirmed the efforts expended by the Federal German Government in the field of cancer registration. An establishment or reinforcement of cancer registration will be supported in each state. National coverage by cancer registration is laid down by German law in 2009.

Of the 16 German states, 11 are currently covered by regional population-based cancer registries. Together with the national childhood cancer registry they cover a population of 82 million inhabitants. According to the latest estimates, at least nine states provide complete cancer data for 2006. National estimates of cancer incidence are published biannually, most recently for 2004.

The cancer registry community in Germany has established an association GEKID in 2004 (www.gekid.de). GEKID counts more than 100 members from cancer registries and the epidemiology field. The activities comprise of an annual conference, workshops on coding, survival, record linkage etc. GEKID published recently a German Cancer Registration Manual and a national incidence and mortality atlas is at work.

New ENCR SC member



Represented by their Chairman, Alexander Katalinic, GEKID expressed a need to create a stronger links with international associations of cancer registries, starting with the ENCR. To strengthen the exchange between GEKID and other European cancer

registries, ENCR SC is pleased to announce the 1-year cooption of Alexander Katalinic in its Steering Committee.

ENCR Structured Review in Münster

In the meantime, the North Rhine-Westphalia Epidemiological Cancer Registry, located in Munster, requested an ENCR Structured Review. The review will be led by Chris Carrigan (National Cancer Intelligence Network, UK). The other two members will be Sabine Siesling (Comprehensive Cancer Centre North East, The Netherlands) and Alexander Katalinic (Cancer Registry of Schleswig-Holstein, Germany). Hans-Werner Hense, Ulrich Batzler and other staff of the Munster registry are expecting the review team in January 2010. The Review is funded by the North Rhine-Westphalia Epidemiological Cancer Registry.