Europe’s course for better cancer control and research

Cancer is one of the primary causes of disease and death worldwide, and cancer control (including research into its causes) is a global public health priority. Given sufficient resources, cancer registries (especially in Europe) have seized the opportunity to move beyond their traditional role of data collection and descriptions of patterns of cancer incidence, cancer care, and outcome. This expanded role is fundamental to alleviating the disease burden in Europe.

The EUROCOURSE (Europe Against Cancer: Optimisation of the Use of Registries for Scientific Excellence in Research) action recognises that harmonising cancer registration and promoting collaboration among registries in Europe will lead to more reliable and comparable data, and better use of registry data for more effective research.

Cancer registration has been recognised as an important tool for cancer control and research since the 1940s. National and regional governments, as well as research and charity organisations, are responsible for the collection and registration of cancer in their catchment areas and its use as an instrument for aiding cancer control policies.

It is vital for the work of cancer registries to be continued in collaboration with the public health and clinical communities, to enable a common strategy for further improving the quality and availability of cancer incidence and outcome data throughout Europe. EUROCOURSE seeks to promote the use of cancer registries in cancer control and health-care planning, in providing regular and timely information on the burden of cancer, in providing examples of best practice in the evaluation of screening effectiveness, in genetic studies using biobanks, and in the evaluation of clinical care at the population level.

A European repository with reliable and timely data

Unfortunately, at the European level the information collected by cancer registries is heterogeneous, under-used and inaccessible to all stakeholders. There is an urgent need for a European system to produce key statistics on incidence, mortality, prevalence and survival that are comparable and reliable. Such a European information repository would be capable, for example, of producing comparisons between European populations within regions, and to help shape cancer control strategies from translational cancer research customised to specific subpopulations to a broader, pan-European level.

The EUROCOURSE action represents a commitment to fostering a greater exchange of information (e.g. technical know-how, best practices, and recommendations) between cancer registries in Europe to achieve two overarching objectives. The participants involved span the European cancer registry and the cancer control and cancer research landscape, and the consortium is expected to expand as new parties are introduced during the action’s lifetime.

Firstly, the consortium will explore ways to link and integrate European funding programmes aimed at supporting cancer registries. Programme owners and managers of funding bodies will work together to harmonise the way registries are funded and organised in Europe, and consolidate the role they play in combating cancer. Participants will compare strategies and practices, and exchange experiences in the funding and management of cancer registries, with the overall intention of creating a starting block for recommendations on best practice. The approach is expected to tackle the issue of fragmentation in funding, and enhance the capacity of cancer registries across Europe.

Secondly, the EUROCOURSE action intends to develop the necessary standards and
infrastructure to streamline the data collected by European cancer registries in order to provide quality statistics at European level. Best practices will be documented and recommendations will be drafted on the issues of ethics, the effectiveness of screening programmes using cancer registries, and the design of population-based genetic studies using biobanks. Importantly, this knowledge is also expected to highlight opportunities for future research.

The work of the ERA-NET will be guided, on the one hand, by a network of owners (including funding bodies) of cancer registries, clinical databases and biobanks. And on the other hand, registries across Europe will be responsible for collecting, storing, using and disseminating the data, in collaboration with the European Network of Cancer Registries (ENCR).

**First ever European Cancer Control Summit**

The ERA-NET will employ practical steps to build on the aims of ENCR and the Europe Against Cancer programme. In the same spirit, EUROCOURSE will seek to collaborate (and hence avoid duplication of efforts) with partners on several current European activities, such as the EUROCHIP project, which aims to establish cancer indicators and assess variability in cancer control practices, and the EUROCADET project, which aims to identify effective primary preventive strategies and their subsequent effects.

A landmark summit will be held at the conclusion of the ERA-NET in 2010 to provide an opportunity for some 200 stakeholders to offer their expertise and experience and propose sustainable funding solutions for cancer registration. The meeting will be used to gauge and share the advances made since the ERA-NETs began, and realign priorities for long-term collaboration. In fact, the main aim of the summit will be to discuss and outline a common strategy for the future of European cancer registration guidelines.

Striving for scientific excellence in European research means achieving the highest possible scientific standards and results for the benefit of Europe and its citizens. When combined, EUROCOURSE’s many activities are expected to generate mechanisms for consensual planning and decision-making to enhance the services provided by cancer registries and the quality of the data that are available in Europe.