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The European Cancer Observatory: A new data resource

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Abstract Population-based cancer registries provide indispensable information on cancer incidence and survival, which cannot be obtained by any other means. It is clear that complete and effective use of these data is essential for cancer control, but sharing this information in a uniform, timely and user-friendly manner has been somewhat limited up to now. The European Cancer Observatory (ECO, <http://eco.iarc.fr>) has been developed in the framework of the EURO COURSE project (EUROpe against Cancer: Optimisation of Use of Registries for Scientific Excellence in Research) as a comprehensive resource combining all the information currently available in Europe on cancer incidence, mortality, survival and prevalence. The website provides analytical and presentation tools to examine national estimates for 2012 in 40 European countries (EUCAN), data for 130 national or sub-national areas covered by cancer registries for up to 60 years, until 2011 (EUREG) and a planned mechanism for data download (European Cancer Incidence and Mortality (EUROCIM)). The generated statistics outline the considerable variability across Europe in the rates of all major cancer types and help identify key concerns that need to be addressed by public health policies e.g. the unprecedented rise of lung cancer incidence in women with its full impact expected within a decade or so. The support, maintenance and further development of the ECO website should be a high priority for European cancer policymakers, to continue providing this unique information to health professionals, researchers and the general public in Europe and beyond.

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1. Introduction

The World Health Organisation has stated that ‘in any effective cancer control plan, cancer control priorities and programmes are driven by available data on the cancer needs in the general population’ and that ‘the optimal resources for determining the cancer burden are well organised population-based cancer registries that provide data on incidence and survival; and good quality mortality statistics’ [1]. Collaborations and comparisons between European registries have provided countries and regions with benchmarks for cancer control and have been essential in developing the quality of registration. The European Network of Cancer Registries (ENCR, <http://www.enrcr.com.fr/>) was established in 1990 and was jointly funded by the European Union, under the Europe Against Cancer Programme, and the International Agency for Research on Cancer (IARC). The objectives of ENCR (Box 1) have been achieved through collaborative activities—the development of data and coding standards, database development, training, mentorship tools for registries, communication forums and estimates of cancer burden in Europe [2–9].

As part of the EURO COURSE project [10] the European Cancer Observatory (ECO, <http://eco.iarc.fr>) has been developed in collaboration between IARC and 130 ENCR member registries. The Observatory builds on multiple data sources and consists of three websites—EUCAN, EUREG and European Cancer Incidence and Mortality (EUROCIM). ECO provides an innovative and comprehensive window on cancer incidence, mortality, prevalence and survival for Europe as a whole and for individual countries and registries.

2. Methods

2.1. Data sources

A dedicated working group developed the ENCR Call for data, which was released in May 2010 to all European cancer registries (available at http://www.enrcr.com.fr/DownloadFiles/ENCR_Call.pdf). The ENCR Call remains active as a standing request to the ENCR member registries to submit their data on a

Box 1

The objectives of the European Network of Cancer Registries (ENCR).

- To improve the quality, comparability and availability of cancer incidence data
- To create a basis for monitoring cancer incidence and mortality in the European Union
- To provide regular information on the burden of cancer in Europe
- To promote the use of cancer registries in cancer control, health-care planning and research

regular basis, preferably once a year. The requirements of the Call address also the needs of other international studies, including EUROCARE (<http://www.eurocare.it/>), Cancer Incidence in Five Continents (<http://ci5.iarc.fr/>), International Incidence of Childhood Cancer (<http://iicc.iarc.fr/>), ACCIS (<http://accis.iarc.fr/>) and could potentially address others.

The Call describes the required files, their layout and content. The cancer cases file contains 45 variables coded according to a defined scheme, and includes variables on patients (age, sex, date of birth, country/region of residence), their cancer (date of incidence, topography, morphology, behaviour, grade, stage at diagnosis), treatment and the outcome (date of end of follow-up, vital status and survival time). The registries are asked to provide the required information for as long a time period as possible. The submitted datasets contain anonymous records and comply with the data confidentiality requirements of the data providers.

Other required files are population data, official cancer mortality statistics and a description of the data sources. Mortality data are mainly extracted by registries from their national or regional official statistics publications or databases; a few registries produced their own mortality data. As the revision of the International Classification of Disease used to classify causes of death varied by country and period, all causes of death were converted to International Classification of Disease (ICD)-10 [11] for presentation in EUREG. Such conversion might have caused distortion of past rates for particular cancer sites, namely colorectal, liver and lung, where these were originally coded to one of the previous ICD revisions. The conversion of certain sites from ICD-9 to ICD-10 in France and Switzerland might have also affected the rates’ comparability over time [12,13]. The sources of mortality and population data are listed on the website, with a link to the relevant data source where available.

2.2. Data flow and processing

As part of the EURO COURSE project, the IARC, in collaboration with the National Cancer Registry Ireland, has developed the Registries Portal (<https://cinportal.iarc.fr/>), which includes a mechanism of automatic management of data flow between the cancer registries and the coordinating centre.

As a general rule, the Call for data is opened to all ENCR member registries. At the date of the Call release, 191 cancer registries were invited to contribute. To automate data processing, each cancer registry was requested to submit their data through the Registries Portal using a registry-specific identification code and password. The submitted data are processed and checked at IARC using in-house automatic routines based on standard data quality measures [14]. Inconsistencies in the data

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