

EUROCHIP-II
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ANNEX 01

**RECOMMENDATIONS TO THE
NETWORK OF COMPETENT AUTHORITIES
TO SUPPORT CANCER REGISTRIES**

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INTRODUCTION

This paper would like to underline the important role of the *population-based cancer registries* for the European Public Health system.

On 23 September 2002, the European Parliament and the Council adopted a new Community action programme for Public Health. This programme runs for a 6 year period (2003-2008).

This programme is based on three general objectives: health information, rapid reaction to health threats and health promotion through addressing health determinants.

About the first objective, the purpose of the European Union Health Information System is to provide quality, relevant and timely data, information and knowledge in order to support public health decision-making at European, national, sub-national and local level. Within each geographical area, the Health Information System is a tool necessary to make decisions at strategic, control and operational level, to set directions, to monitor their implementation and to evaluate their impact. The Community Public Health Programme aims to produce comparable indicators on health and health-related behaviour of the population (e.g. data on life styles and other health determinants); on diseases (e.g. incidence and ways to monitor chronic, major and rare diseases); and on health systems (e.g. indicators on access to care for everyone, on quality of care provided, on health human resources, and on financial viability of health care systems).

One of the European Commission Public Health Structures is the Network of Competent Authorities. Its main task is to provide advice on an implementation strategy in regard to the health information and knowledge strand of the Public Health Programme.

About cancer, the EUROCHIP project identified a list of indicators describing cancer in terms of burden, prevention activity, standards of care and cure rates. Various indicators on cancer burden (incidence, survival and prevalence) are collected by *population-based cancer registries*, that is bodies organised at local or at national level in the majority of the European countries. These bodies allow to have comparable cancer data across Europe. Comparisons of cancer registry data across Europe were already performed by IARC (International Agency of Research on Cancer), EUROCARE (for cancer survival), EUROPREVAL (for cancer prevalence), ecc.

Population-based cancer registries are necessary to reach the objectives of the European Union Health Information System. Each European country has to facilitate the activity of cancer registries both in terms of funding and in terms of availability of cancer patient data (privacy law restrictions sometimes did not allow a cancer registry to work).

This document, produced by EUROCHIP, aims to underline to the Network of Competent Authorities the importance of *population-based cancer registries* for the European Union Health Information System and the main problems highlighted by them in Eastern European countries.

WHAT IS EUROCHIP?

EUROCHIP-2 is a Europe-wide multidisciplinary three-annual (2004-2007) project to define an organisational and logical model that will effectively fight inequalities in cancer in Europe. It aims to improve access to and organisation of information and knowledge on cancer in all European countries. In doing so, it will add value to each individual country by allowing comparison with Europe as a whole and forming a basis for political action on health. The starting point of the project is the network established by EUROCHIP-1.

The EUROCHIP-1 project under the large-scale Health Monitoring Program (HMP), funded by the European Commission, has provided an important boost to the Europe-wide surveillance system on cancer. EUROCHIP-1 identified a list of indicators describing cancer in terms of burden, prevention activity, standards of care and cure rates. Indicators were selected according to the criteria of ease of collection and comparability. Standardised methods of validating and collecting data were also been proposed. The final list was one of maximum consensus between all interested parties.

More than 130 experts in various fields pertinent to cancer (physicians, economists, sociologists, epidemiologists, planners, etc.) from all European Union (EU) member countries (15 countries) participated in drawing up the list and a final report containing the proposed list of indicators and appending detailed information regarding them was produced.

To reduce inequalities across Europe, some countries have to prioritise action on prevention, others on care, others on surveillance, etc. Other countries for basic epidemiological information need to establish or to maintain population-based cancer registries. However, it is vital for each countries' success in the fight against cancer, that the trans-national European nature of the study is maintained at all levels of data collection, data analysis, problem evaluation, and action. Cancer control must develop where different tasks are evaluated and implemented as part of the whole process.

EUROCHIP-2 (www.tumori.net/eurochip) is:

- producing results at two levels: for European Union as a whole and for individual countries
- focusing on the problems and inadequacies of individual countries in order to suggest policy changes at the country level
- organising activity as a continuous process, i.e. taking a global view of the information system, involving on one hand the promotion of data collection, on the other analysis of already available data, on the other evaluation promoting political action on established inequalities; all as a continuously re-evaluated process
- organising actions to reduce cancer health information problems.

WHY A CANCER REGISTRY?

Cancer is a major burden in each European country. Reducing the nation's cancer burden is a great cause that involves many people, including physicians, researchers, epidemiologists, public health planners, legislators, medical students, and others. All of these people appreciate and rely on cancer data in their effort to win the "War against Cancer". To do this population based cancer registries (CR) are fundamental.

Unlike the system for certain communicable diseases, the registration process for cancer is not usually based on notifications from individual clinicians. Instead, cancer registries receive routine (when possible electronic) notifications from a variety of sources. These sources include district general hospitals, cancer centres, hospices, private hospitals, cancer screening programmes, other cancer registers, primary care, nursing homes and death certificates. Data are frequently received from several sources within an individual institution (e.g. pathology departments, medical records and radiotherapy databases) and refer to entire population covered by the CR.

Cancer registry data are necessary for those interested in the aetiology, diffusion of various diagnosis and treatment procedures. Cancer patient data at population level collected by cancer registries are becoming useful for several reasons.

There are five main reasons why it is necessary to collect information that identifies patients.

- Patients often attend more than one hospital. It is important to know that a cancer reported from a number of different hospitals relates, in fact, to the same person, otherwise registrations would be duplicated and cancer incidence rates would appear to be misleadingly high.
- An important indicator of the effectiveness of cancer services is the percentage of patients who survive their cancer. It would not be possible to link a patient's date of death to their cancer records without identifying information.
- People are often concerned that there might be a high risk of cancer in their locality. These risks cannot be investigated properly without knowing where patients with cancer live (based on postcode of residence).
- People are often worried that their family history may put them at high risk of cancer. An accurate family history is crucial if these individuals are to be offered appropriate advice. The CR is often asked by clinical geneticists to confirm the details of a cancer diagnosis in a relative of someone attending their clinic. In the case of living relatives, this information is only released with the written informed consent of the relative concerned. Often, especially when medical records have been destroyed, the CR is the only available source of such information.
- Occasionally, a previously unforeseen, significant late effect of therapy comes to light many years or even decades after that treatment was in widespread use. In these circumstances, it will be necessary, using all available information sources including the cancer registry, to try and trace all patients who might be at risk, so that they can be informed and counselled about possible interventions to reduce their risk.

WHAT IS A CANCER REGISTRY USEFUL FOR?

Cancer registries undertake a range of public health surveillance and health protection functions.

The main functions of cancer registries are:

- monitoring trends in cancer incidence, prevalence and survival (and mortality) over time and between different areas and social groups
- evaluating the impact of environmental and social factors on cancer risk
- supporting investigations into the causes of cancer
- evaluating the effectiveness of cancer prevention and screening programmes. For example, population based data are required to monitor the effectiveness of the existing national screening programmes for breast and cervical cancer and to inform the design of new programmes, e.g. screening for colorectal and ovarian cancer
- evaluating the quality and outcomes of cancer care by providing comparative data about treatment patterns and outcomes
- investigating differences in cancer incidence, survival and access to treatment between social classes and thus contributing to programmes aimed at reducing health inequalities
- providing information in support of cancer genetic counselling services for individuals and families at higher risk of developing cancer.

For example, what we know as a result of information obtained from cancer registration:

- mesothelioma is caused by exposure to asbestos
- skin melanoma rates have been increasing year on year
- lymphoma and oral cancer rates are higher in ethnic minorities
- there is wide variation in how cancer is treated around the country and across countries
- cancer survival for patients living in poor areas is lower than for those living in rich areas
- cancer survival in children has improved dramatically over the last 30 years.

What we may not know in future if cancer registration becomes unreliable:

- how many cancers occur each year, and which are the most common
- whether cancer rates are increasing or decreasing
- if cancer incidence rates in a country are higher or lower than in other countries
- if cancer survival rates in a country have caught up with other European countries
- if inequalities in cancer treatment or survival between rich and poor have been reduced
- if cancer screening programmes are effective
- if people living near landfill sites or power lines have an increased cancer risk
- whether some late deaths in childhood cancer survivors are related to earlier treatments
- if the risk of developing certain cancers is higher in some occupational groups.

CURRENT SITUATION IN EASTERN EUROPE

In Eastern European countries there was a transition from a centralised, government funded system of health care into one in which the funding is based mainly on a new national health insurance scheme. In these circumstances, there is a need to be vigilant in maintaining those health care information systems which provide data on the health profile of the nation, and which can be used to evaluate the effectiveness of the health care programmes. Health insurance-based statistics are very often related to the use of resources, and have proved of little value in monitoring effectiveness of cancer control activities (prevention and treatment). On the other hand, it is well recognised that cancer registries are particularly useful tool for this purpose.

Even if Slovakia, Estonia and Bulgaria are in the fortunate situation of already possessing a national cancer registry, in these three countries cancer registries have a set of problems in terms of funding and in terms of availability of cancer patient data.

For example Estonia made a huge public health error by legislation to make it impossible for the Estonian cancer registry to obtain access to death certificates. Legislation to facilitate such access in the interests of public health would be a wiser course of action.

Without access to death certificates, as an example, the registry cannot produce reliable estimates of cancer survival for the whole population. As a result:

- we will not know in future if cancer survival rates in Estonia are improving
- we will not know if national or regional investment in earlier diagnosis, screening or treatment services has improved cancer survival for all Estonians
- we will not know if cancer survival in Estonia is approaching the level in other European countries
- we will not even know the true cancer risks of the Estonian population, or how they change with time, because death certificates are crucial to ensuring complete cancer registration

The specific problem for the Bulgarian Cancer Registry is the budget and the support of cancer registration. At present, all health establishments in Bulgaria received their budget from the National Health Insurance Fund via clinical pathways. The National Cancer registry and the 13th regional registries in Bulgaria are parts of health establishments - National oncological hospital and 13th dispensaries. In that case, there is no resources provided for activities like cancer registration, and no national legislation regularizes the statute of that oncological system in Bulgaria.

Poland has the lowest cancer survival in Europe. In order to compare Polish cancer control strategies with other European countries it is necessary that Polish cancer registries participate to international projects aimed to compare cancer strategies and cancer outcomes.

CONCLUSIONS

EUROCHIP-2 is an European project to define an organisational and logical model that will effectively fight inequalities in cancer in Europe. It aims to improve access to and organisation of information and knowledge on cancer in all European countries.

At this purpose, the main providers of cancer data at population level are cancer registries.

For the European Union Health Information System, cancer registries should have to be considered as the National Institutes of Statistics as they are the only providers of cancer data necessary to estimate cancer incidence, survival and prevalence indicators at population level.

EUROCHIP-2 would like to bring the following points to the attention of the Network of Competent Authorities and the European Commission:

- cancer registries are necessary for cancer control and epidemiological research, public health program planning, and patient care improvement
- cancer registry provide standardized data comparable across Europe
- cancer registries are necessary to implement the European Union Health Information System relatively to cancer
- cancer registries are the unique providers of cancer data at population level

National health authorities should note that:

- **cancer registries need to be maintained and supported**
- **cancer registries need ad-hoc national legislations restricting privacy**

European Commission is encouraged to note that:

- **cancer registries should have to be considered with a role comparable to National Institutes of Statistics**
- **European projects connecting cancer registries are the best way to compare cancer burden across Europe**