

***Standards and Guidelines for
Cancer Registration in Europe***

INTERNATIONAL AGENCY FOR RESEARCH ON CANCER

The International Agency for Research on Cancer (IARC) was established in 1965 by the World Health Assembly, as an independently financed organization within the framework of the World Health Organization. The headquarters of the Agency are at Lyon, France.

The Agency conducts a programme of research concentrating particularly on the epidemiology of cancer and the study of potential carcinogens in the human environment. Its field studies are supplemented by biological and chemical research carried out in the Agency's laboratories in Lyon, and, through collaborative research agreements, in national research institutions in many countries. The Agency also conducts a programme for the education and training of personnel for cancer research.

The publications of the Agency are intended to contribute to the dissemination of authoritative information on different aspects of cancer research. Information about IARC publications and how to order them is available via the Internet at: <http://www.iarc.fr/>

EUROPEAN NETWORK OF CANCER REGISTRIES (ENCR)

The European Network of Cancer Registries (ENCR) project, established within the framework of the Europe Against Cancer Programme of the European Commission in 1989, has been in operation since 1990.

The main goal of the Network is to improve the quality, comparability and availability of information on occurrence and outcome of cancer in Europe.

The specific objectives of the Network are:

- ◆ 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.

The Network promotes collaboration between cancer registries, defines data-collection standards, provides training for cancer registry personnel and regularly disseminates information on incidence and mortality from cancer in the European Union and elsewhere in Europe.

The main fields of ENCR activity are:

- 1) Standardization of registry procedures on:
 - (a) data definitions
 - (b) data collection procedures
 - (c) analysis and reporting methods
- 2) Central collection and validation of data
- 3) Dissemination of information
- 4) Training

Specific activities of the ENCR include surveys of the registries, Working Groups on definitions and coding, fellowships for registry personnel, consultancies, courses (on cancer registration, statistical methods, and coding), workshops, development and maintenance of cancer databases and software (i.e. EUROCIM, EUCAN, ACCISpass), and publications on cancer occurrence in Europe.

All activities of the ENCR are available to its 185 member registries and are announced at its Internet site: www.enrcr.com.fr.



WORLD HEALTH
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EUROPEAN NETWORK OF
CANCER REGISTRIES



EUROPEAN
COMMISSION

Standards and Guidelines for Cancer Registration in Europe

THE ENCR RECOMMENDATIONS

Volume I

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Foreword

When the European Commission established the “Europe against Cancer” programme more than a decade ago, one of the priorities was to promote high quality cancer registration within Europe. The aim was to achieve comparable information on cancer burden, which could be used for setting up and evaluating cancer control activities at the European level. To achieve this aim, the European Network of Cancer Registries (ENCR) was established, and has now been active for 13 years with the financial support of the Cancer Programme of the European Union.

Since cancer registries play an important role in planning and managing cancer control activities, one of the major tasks of the ENCR has been to provide support for the creation and development of cancer registries in Europe. Planning and monitoring of such activities as prevention, early detection, treatment, rehabilitation and palliative care require knowledge about national and local cancer patterns and trends. Priority setting for cancer care implies knowledge of how many patients develop cancer, and what are the most frequent sites. Assessment of the efficacy of programmes of prevention, early detection (screening) and the effectiveness of treatment procedures can all be achieved through the use of cancer registry data (e.g., by analysing trends in incidence, stage of disease, and survival).

All these activities depend on the quality of the data in the registry – that they are comparable, complete and of good quality. To achieve this, the ENCR has established Working Groups aimed at developing standards and recommendations in relation to different aspects of cancer registry practice. Some of these guidelines and recommendations deal with technical aspects of data collection, others with problems of confidentiality and privacy protection within the process of cancer registration. All the topics considered by ENCR Working Groups, and published in this monograph, are of fundamental importance to cancer registration, and, hence, to cancer control activities within the European Union and in Europe as a whole.

This monograph provides a set of the most up-to-date guidelines and recommendations prepared by ENCR Working Groups and approved by the ENCR Steering Committee and will be a useful tool for people involved in collection and registration of cancer data in Europe.

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Introduction

The European Network of Cancer Registries (ENCR) project was established in 1989 and is supported by the Cancer Programme of the European Commission (Health and Consumer Protection Directorate-General, DG SANCO).

The original objectives of the ENCR were:

- 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.

The Network:

- promotes continuous collaboration between cancer registries,
- defines data collection standards,
- provides training for cancer registry personnel,
- disseminates information on incidence and mortality from cancer in the European Union and elsewhere in Europe.

Recently, the Health Monitoring Programme of the Public Health Directorate has established projects (i.e. CaMon and EUROCHIP) which are aimed at monitoring the cancer burden in the European Union. The ENCR member registries are key data providers for such activities.

Comparability of the data between registries is therefore an important issue, and harmonizing the registries' procedures is one of the main goals of the Network. The number of cancer registries in Europe is continuously growing and creates new

challenges to maintain and improve data quality among European registries allowing their use in comparative studies within Europe, and with the rest of the world.

ENCR has established several Working Groups, which recommended standard procedures to be implemented by the registries.

The year 2002 was the last year for which a programme specifically devoted to the control of cancer was part of the Public Health Programme. This publication summarizes the ENCR achievements in harmonization of registry activities.

It brings together all recommendations and guidelines that have been prepared so far by the ENCR Working Groups, as well as recommendations prepared by the International Association of Cancer Registries (IACR) and adapted by the Network.

Several other topics, not included in this volume, are currently being studied by Working Groups, or are planned for the future. New guidelines and recommendations will be included in updates to these ENCR Recommendations.

The editors have noted that information on on-going ENCR projects could be useful for the registries. Several appendices have been added to the volume containing information about the EUROCIM software and databases, the ACCIS project on childhood cancers, automated registration, and structured registry reviews (audits). The complete address list of the member registries and a list of selected ENCR publications are also included.

We hope that this publication will be a useful tool for all the ENCR member registries. The ENCR Secretariat will welcome comments, which could help in preparing subsequent volumes.

The Editors