

Acknowledgements

The authors would like to express their gratitude to Professor David Roder, Cancer Epidemiology and Population Health, School of Population Health, University of South Australia and Senior Principal Research Scientist, South Australian Health and Medical Research Institute, and to Professor Rajesh Dikshit, Tata Memorial Hospital and the Principal Investigator of the IARC Regional Hub for Cancer Registration, Mumbai, for their insightful comments and suggestions on an earlier draft of this document.

IARC and WHO thank the GAVI Alliance, whose unrestricted financial support has made the production of this document possible.

Foreword

Cancer control planning without reliable data from cancer registries is prone to misplaced emphasis and wasted investment. This is exactly the position many countries still find themselves in at the beginning of the 21st century. Particularly in low- and middle-income countries, this situation reflects a lack of advocacy for the value of registries, a lack of trained staff and other resources, and a lack of prioritization for “counting cancers” in among the many demands on limited health care services.

Nevertheless, there are positive signs that the position may be changing. First, the emphasis on noncommunicable diseases (NCDs) at the highest political level and recognition of their role in hampering human development are changing priorities within countries and among donors. Second, the World Health Organization Member States agreed that among the indicators of progress in the fight against NCDs is the need to record “cancer incidence, by type of cancer, per 100 000 population”, thus placing an onus on countries to establish population-based cancer registries and to report on progress. At the same time, several technical and funding organizations are working in a cooperative and coordinated manner to improve the quality and cov-

erage of cancer registration under the auspices of the Global Initiative for Cancer Registry Development (GICR). This is leading to noticeable improvements in training, advocacy, and data collection and analysis. This dual approach – top-down and bottom-up – will translate into a step change in the availability of reliable data on cancer occurrence globally. This, in turn, would be a cornerstone of cancer control in the coming decades.

Accepting the value of cancer registration, what should be measured? Certainly in addition to incidence, there is enormous value in estimating cancer survival by following up cancer patients with respect to their vital status so as to obtain information on the quality of cancer services at the population level. As cancer information systems develop, there are further opportunities to link cancer registry databases with other data sets on, for example, cancer screening, treatment, co-morbidities, and so on. Registry data can also catalyse research into causes of the disease and the effectiveness of national or regional intervention strategies.

Knowing what to measure is fundamental, but how should it be done? This is where the current publication fulfils an important

function, providing practical guidance on gathering, processing, and checking the quality of information collected, within the context of a population-based cancer registry situated within a low- or middle-income country.

As Director of the International Agency for Research on Cancer, this book has particular resonance for me. Upon its inception 50 years ago, the Agency had a prime goal of studying the geographical variations in cancer occurrence to learn about the causes and prevention of the disease. This led to five decades of work alongside an uncountable number of impressively dedicated colleagues, determined to develop cancer registries under the most demanding of circumstances; theirs has frequently been a labour of love. It is my firm conviction that the contents of this book, developed within an enduring partnership with the International Association of Cancer Registries, represent another important step in supporting cancer registrars as they seek to provide the figures needed to ensure that the best possible cancer control measures are available for all populations worldwide.

Dr Christopher P. Wild
*Director, International Agency
for Research on Cancer*

Preface

Population-based cancer registries have provided decisive contributions to cancer epidemiology and cancer control, spanning three quarters of a century. Cancer registration began in earnest in the 1930s and 1940s, at the same time that modern epidemiology began to seek the causes of chronic diseases. Cancer registration progressively expanded during the subsequent decades, and cancer registries have now become definitive and unique resources for measuring the cancer burden in the community (still today, no comparable data system is available for other major diseases). Registries have contributed in a number of important ways across the spectrum of cancer control, from determining the burden and geographical variation in cancer, and thereby aiding understanding of its causes, through to population-based survival analyses and assessments of the quality of diagnosis and care received by cancer patients.

The accumulation and expansion of registry data have enabled geographical and time trends of incidence, mortality, survival, and prevalence to flourish. The individual data sets collected have also fed into a very large number of analytical epidemiological stud-

ies. More recent developments include research based on registry linkages with clinical databanks and biological sample repositories. Although these achievements are becoming standard practice in registries in industrialized countries, much work still remains to ensure a similar development in low- and middle-income countries (LMICs). Registry coverage with high-quality data remains well below 10% in Africa, Asia, and Latin America, and there is an urgent need to support the initiation, expansion, and development of registries in many LMICs. The approach relies upon the synergy between local resources and willingness on the one hand, and international cooperation on the other. It is in this context that the International Association of Cancer Registries, an organization with member registries across all continents, will be pleased to link activities and future plans with the ongoing development of the IARC Regional Hubs for Cancer Registration, as part of the Global Initiative for Cancer Registry Development (GICR).

A key requirement for the development of population-based cancer registries is resources to support the delivery of training. Needs vary,

from detailed how-to guides for cancer registrars to instruction in statistical methodologies for the analysis of registry data sets. This guidance document provides an overview of the key concepts in cancer registration, covering the steps involved in planning a registry, the sources of information a registry will need to access, methods for ensuring data quality, and how registry results should be reported. As such, it will be of value to those who are seeking to establish a registry or are in the early stages of developing a registry. It covers the major components that need to be thought about when setting up a registry and ensuring that it provides the necessary information for its main stakeholders – especially those involved in cancer control planning.

Roberto Zanetti, MD, PhD
President, International Association of Cancer Registries

David Forman, PhD
Head, Section of Cancer Information, International Agency for Research on Cancer Executive Secretary, International Association of Cancer Registries

Executive summary

More than 20 million new cases of cancer are predicted worldwide in 2025, with four fifths of the burden falling on low- and middle-income countries (LMICs). To understand the local cancer situation and tackle the increasing incidence, there is a pressing need for planners to have relevant and unbiased data on the cancer burden in their communities. Population-based cancer registries (PBCRs) provide such information and are a standard requirement for cancer control planning and evaluation in every country of the world. They are especially valuable in LMICs, where few other population-based data on cancer occurrence and outcome are available.

In planning a PBCR, there are many elements to consider, including the definition of the population, the personnel required, the physical location of the registry, the necessary equipment and office space, adequate financing, ensuring that legal aspects and confidentiality are appropriately addressed, and – last but not least – the appointment of an advisory committee to oversee the activities of the registry. Most of the requirements for planning and monitoring can be achieved through registration of a subset (sample) of

the national population, using one regional PBCR or a series of regional PBCRs. The political will and support of the key stakeholders are very important at the outset to ensure the sustainability of the PBCR. Success also depends on the collaboration of clinicians, pathologists, and staff in administration in ensuring access to their data.

PBCRs rely on the use of multiple sources of information on cancer cases in the target population. These sources can be grouped into three broad categories: hospitals, laboratories, and death certificates. Registry procedures allow identification of the same cancer case from different sources (while avoiding duplicate registrations). The minimum data set is the list of variables for a given case that is essential for any cancer registry to collect. Several of the variables require coding, to facilitate analysis. Standard, international coding schemes are available for some variables, and cancer registries should use them so that comparison of results between registries is possible. The most important are the coding of the tumour (site, histology, behaviour, basis of diagnosis), using the International Classification of Diseases for Oncology (ICD-O), and the coding of stage, using the

tumour–node–metastasis (TNM) staging system.

As well as collating the data, PBCRs are responsible for analysing and reporting. Cancer incidence reports contain information on all reportable cancers and represent the main deliverable of a cancer registry, providing feedback to the stakeholders and the data providers. The main components of the report are background information, evaluation and presentation of the results, and the tabular section. All PBCRs should be able to provide some objective indication of the quality of the reported data. The methods available are described in the context of lower-income settings and cover the four dimensions of data quality: comparability, validity, timeliness, and completeness.

To support the local planning and development of PBCRs in countries within defined regions, a series of IARC Regional Hubs for Cancer Registration in Africa, Asia, and Latin America have been established. A tailored set of recommended local activities involving training, technical guidance, research capacity-building, and advocacy are provided to increase the data quality, coverage, and utility of PBCRs in serving cancer control purposes.

Abbreviations

ASR	age-standardized rate (World Standard) per 100 000
CDC	Centers for Disease Control and Prevention
CI5	<i>Cancer Incidence in Five Continents</i>
CT	computed tomography
DCO	death certificate only
DCO%	percentage of cases for which the only information came from a death certificate
ENCR	European Network of Cancer Registries
GICR	Global Initiative for Cancer Registry Development
HBCRs	hospital-based cancer registries
HDI	Human Development Index
HPV	human papillomavirus
IACR	International Association of Cancer Registries
IARC	International Agency for Research on Cancer
IARCcrgTools	IARC–IACR Cancer Registry Tools
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th Revision
ICD-O	International Classification of Diseases for Oncology
ICD-O-3	International Classification of Diseases for Oncology, 3rd Edition
LMICs	low- and middle-income countries
M:I	mortality-to-incidence ratio
M:I%	percentage mortality-to-incidence ratio
MRI	magnetic resonance imaging
MV%	percentage of cases with a morphologically verified diagnosis
NCDs	noncommunicable diseases
NCRP	National Cancer Registry Program
PBCRs	population-based cancer registries
SEER	Surveillance, Epidemiology, and End Results
TNM	tumour–node–metastasis
UICC	Union for International Cancer Control
WHO	World Health Organization