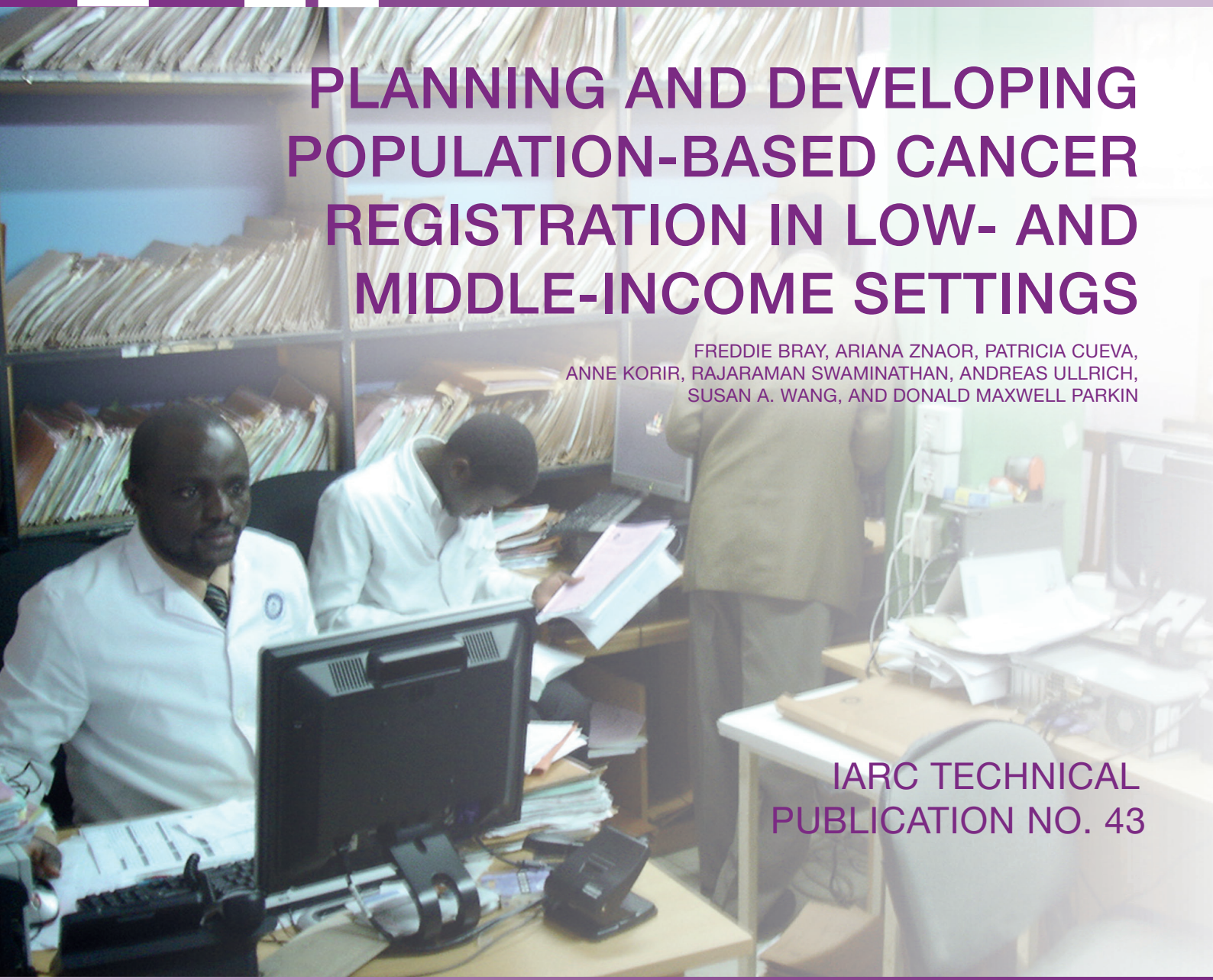
IARC TECHNICAL PUBLICATIONS



PLANNING AND DEVELOPING POPULATION-BASED CANCER REGISTRATION IN LOW- AND MIDDLE-INCOME SETTINGS

FREDDIE BRAY, ARIANA ZNAOR, PATRICIA CUEVA, ANNE KORIR, RAJARAMAN SWAMINATHAN, ANDREAS ULLRICH, SUSAN A. WANG, AND DONALD MAXWELL PARKIN

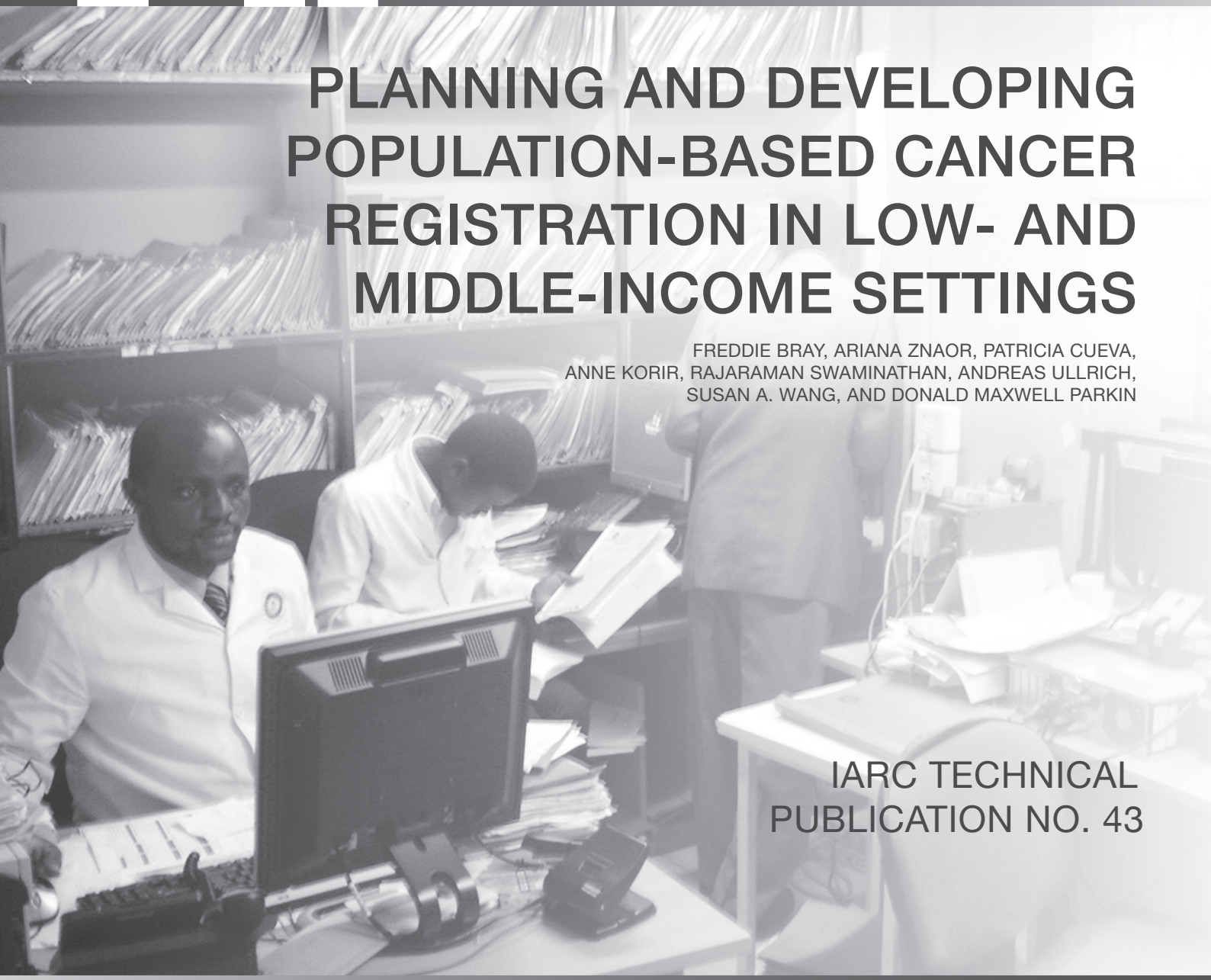
IARC TECHNICAL PUBLICATION NO. 43

World Health Organization

IACR International Association of Cancer Registries

International Agency for Research on Cancer
World Health Organization

IARC TECHNICAL PUBLICATIONS



PLANNING AND DEVELOPING POPULATION-BASED CANCER REGISTRATION IN LOW- AND MIDDLE-INCOME SETTINGS

FREDDIE BRAY, ARIANA ZNAOR, PATRICIA CUEVA, ANNE KORIR, RAJARAMAN SWAMINATHAN, ANDREAS ULLRICH, SUSAN A. WANG, AND DONALD MAXWELL PARKIN

IARC TECHNICAL PUBLICATION NO. 43

World Health Organization

IACR International Association of Cancer Registries

International Agency for Research on Cancer

World Health Organization

Published by the International Agency for Research on Cancer,
150 cours Albert Thomas, 69372 Lyon Cedex 08, France

Distributed by
WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland
(tel: +41 22 791 3264; fax: +41 22 791 4857; email: bookorders@who.int).

Cover image: Photo taken by Max Parkin at the Nairobi Hospital, Kenya, in June 2010. The photo shows the Medical Records Department of the hospital and the supervisor, Mr Desmond Ogwang (left, seated at computer).

This book is available in electronic format from
http://www.iarc.fr/en/publications/pdfs-online/treport-pub/treport-pub43/index.php.

IARC Library Cataloguing in Publication Data

Planning and developing population-based cancer registration in low- and middle-income settings / Freddie Bray, Ariana Znaor, Patricia Cueva … [*et al.*]

(IARC Technical Publications; 43)

1. Registries – standards 2. Neoplasms – epidemiology 3. Neoplasms – prevention & control 4. Data Collection – methods 4. Quality Indicators, Health Care 5. Developing Countries
I. Bray, Freddie II. Series

ISBN 978-92-832-0436-7 (NLM Classification: W1)
ISSN 1012-7348

Table of contents

Contributors

Authors

Dr Freddie Bray
Section of Cancer Information
International Agency for Research on Cancer (IARC)
150 cours Albert Thomas
69372 Lyon Cedex 08
France

Dr Patricia Cueva
Sociedad de Lucha Contra el Cáncer
SOLCA, Núcleo de Quito
Av. Eloy Alfaro 53-94 y Los Pinos
Casilla 1711 4965 CCI
Quito
Ecuador

Dr Anne Korir
Nairobi Cancer Registry
Kenya Medical Research Institute
Centre for Clinical Research
P.O. Box 20778, 00202
Nairobi
Kenya

Dr Donald Maxwell Parkin
The African Cancer Registry Network (AFCRN)
Prama House
267 Banbury Road, Oxford
OX2 7HT
United Kingdom

Dr Rajaraman Swaminathan
Head, Department of Biostatistics and Cancer Registry
Cancer Institute (WIA)
38 Sardar Patel Road
Chennai 600036
India

Dr Andreas Ullrich
Focal point cancer control/Liaison IARC
Management of Noncommunicable Diseases Department
World Health Organization
20 Avenue Appia
1211 Geneva 27
Switzerland

Dr Susan A. Wang
Department of Immunization, Vaccines and Biologicals
World Health Organization
20 Avenue Appia
1211 Geneva 27
Switzerland

Dr Ariana Znaor
Section of Cancer Information
International Agency for Research on Cancer (IARC)
150 cours Albert Thomas
69372 Lyon Cedex 08
France

Production Team

Karen Müller
English Editor

Sylvia Lesage
Publishing Assistant

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 coverage 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 studies. 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	*Cancer Incidence in Five Continents*
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

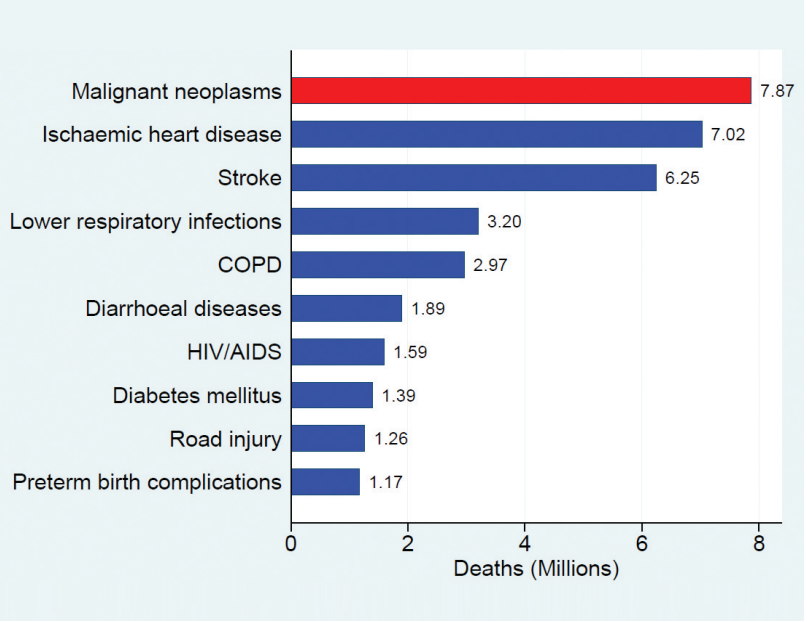
CHAPTER 1.

Introduction

Changing fertility rates, increasing longevity, and changing lifestyles have led to an increasing burden from noncommunicable diseases (NCDs) worldwide: of the estimated 55 million deaths occurring globally in 2011, almost two thirds were deaths from NCDs (WHO, 2011). The morbidity and mortality from NCDs are set to further increase over the next few decades, and for cancer, more than 20 million new cases are anticipated worldwide in 2025, with four fifths of the burden falling on low- and middle-income countries (LMICs) (Bray, 2014). According to World Health Organization (WHO) estimates in 2011, cancer is now the leading cause of death worldwide (Fig. 1.1).

In recognition of the rising burden, WHO Member States during the 65th World Health Assembly agreed to adopt a global target of a 25% reduction in premature mortality from

Fig. 1.1. The 10 leading causes of death worldwide in 2011, for all ages and both sexes. COPD, chronic obstructive pulmonary disease. Source: Data compiled from the Global Health Observatory Data Repository (http://apps.who.int/gho/data/).



cancer and the other major NCDs (cardiovascular diseases, respiratory diseases, and diabetes) by 2025. An action plan and its monitoring framework have subsequently been adopted to achieve the target (WHO, 2013).

NCD surveillance is critical to providing the information needed for policy and programme development, and to support the monitoring and evaluation of the progress made in implementing NCD policies and programmes. Cancer registries are the only disease-specific registries that are in use for NCDs and are therefore of pivotal importance not only in assessing the cancer burden but also in measuring the impact of interventions in cancer prevention and control. Population-based cancer registries (PBCRs) are thus a unique source of information for research and public health programme monitoring. In implementing the NCD action plan, WHO is mandated to report back on progress towards achieving the nine global targets in 2015, 2020, and 2025. The monitoring of indicators in the WHO Medium-Term Strategic Plan is linked directly to the indicators and targets agreed by Member States at the 66th World Health Assembly (http://apps.who.int/gb/ebwha/pdf_files/EB132/B132_27-en.pdf).

To provide information on progress in the implementation of the action plan, Member States agreed to the collection of 25 indicators, including "cancer incidence". More specifically, the request is for governments to collect data on "cancer incidence, by type of cancer, per 100 000 population", and thus commit to developing and sustaining PBCRs. The PBCR is unique in that it systematically collects and classifies information on all reportable cancers occurring in a geographically defined population from multiple sources, including hospitals, diagnostic laboratories, and vital statistics departments. As well as collating the data, PBCRs are responsible for analysing and reporting. The routine calculation of rates "per 100 000" by PBCRs provides information on how the cancer patterns are affecting their communities and how the trends in different cancers are evolving. PBCRs provide the solid basis for the planning, establishment, monitoring, and evaluation of cancer control programmes and the dimension of cancer care services required.

This guidance document consists of six chapters that provide technical advice to planners and health specialists in LMICs wishing to implement and develop PBCRs as information systems that inform cancer control policy. This first chapter has placed the need for cancer registration in the context of the rapidly increasing burden from the disease seen worldwide. Chapter 2 describes the characteristics of the different types of cancer registry and the unique functions of PBCRs and their present status worldwide. Chapters 3 and 4 outline the critical steps in planning and developing a PBCR in lower-resource settings, including discussion of the key sources of information required and the minimal standard set of data items that the PBCR should collect. Aspects in the set-up that will help ensure the sustainability of the registry are emphasized, including comments on infrastructure and resource requirements as well as the commitment of stakeholders. Chapter 5 describes the main techniques to evaluate and further enhance the data quality at the PBCR. Chapter 6 provides some advice on reporting the results to the community at large in support of cancer control and thus promoting the increasing utility of the registry.

Key points

- Along with an increasing NCD burden, more than 20 million new cases of cancer are predicted worldwide in 2025, with four fifths of the burden falling on LMICs.
- As a response, WHO Member States have agreed to adopt a global NCD target of a 25% reduction in premature mortality from the four major NCDs by 2025 and to collect data on cancer incidence by type to provide information on progress.
- PBCRs are critical for collecting and collating such incidence data so as to assess how cancer patterns are affecting their populations and how trends in different cancers are evolving. They provide the solid basis for the establishment, monitoring, and evaluation of cancer control programmes.

CHAPTER 2.

The role and status of population-based cancer registration

Population-based cancer registration represents the gold standard for the provision of information on cancer incidence in a defined population; PBCRs can serve to identify possible causes of cancer in the community and to assess the impact of cancer control activities. A functioning health care system is, however, of critical importance to achieve full case ascertainment and an unbiased picture of the true cancer burden.

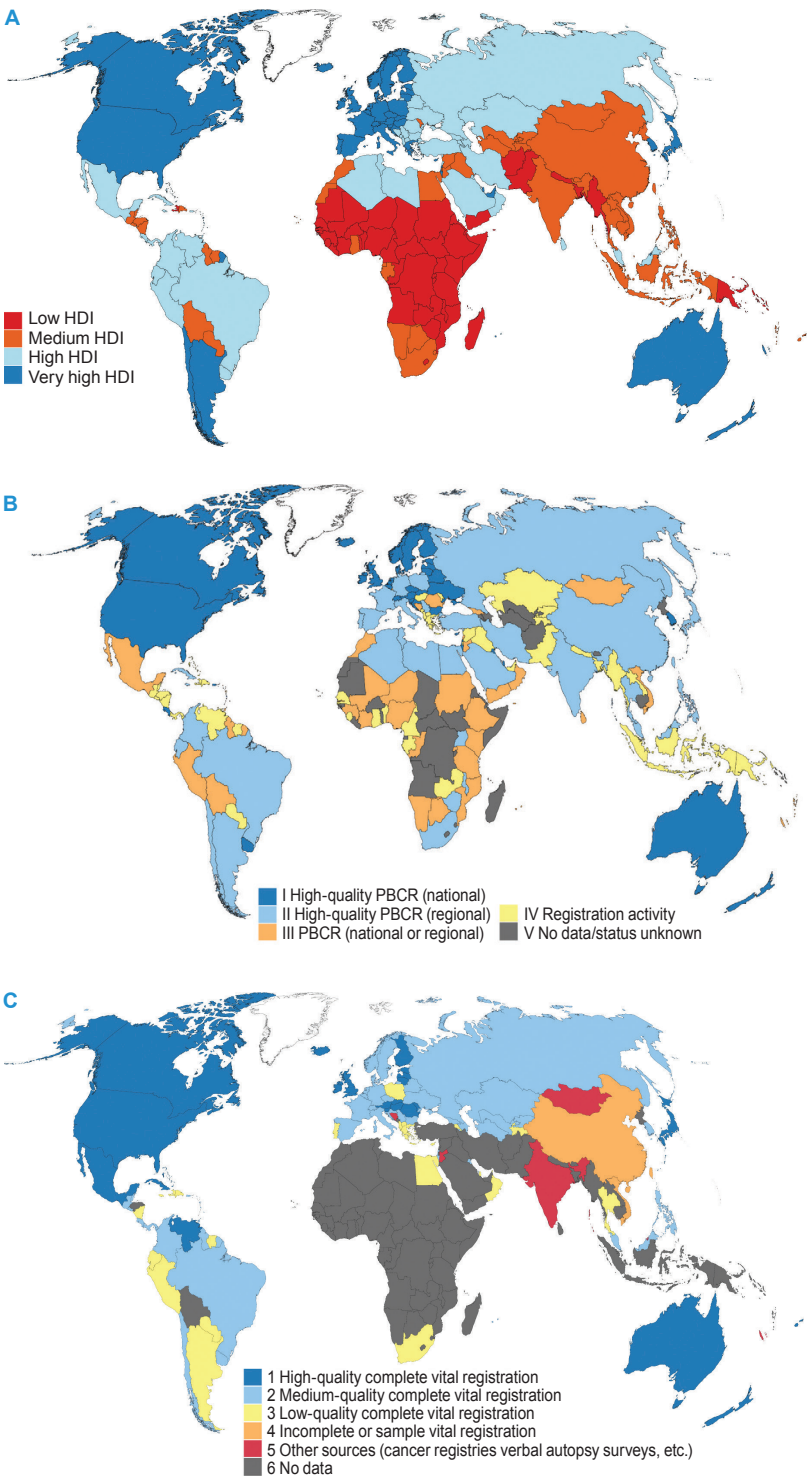
Fig. 2.1 compares present levels of the national Human Development Index (HDI) (Fig. 2.1A) versus available sources of cancer incidence (Fig. 2.1B) and mortality (Fig. 2.1C) data. Cancer incidence and mortality data are more commonly available in countries that have attained high or very high levels of HDI; such countries have a longer history of reasonably complete national mortality statistics, and many have developed either a national PBCR or one or more regional PBCRs over the past decades, notably during the 1970s and 1980s. In such settings, the activities of PBCRs have developed far beyond the basic role of estimating rates and comparing cancer profiles in different populations (Parkin, 2006). Registries expand their range of activities as they develop, undertaking studies of cancer causes and prevention, and providing the information required in planning and evaluating cancer control programmes (see Box 2.1).

The situation is different for countries presently categorized as having low or medium HDI. In many of these areas of the world, most notably in sub-Saharan Africa and South Asia, both vital registration and PBCR systems of reasonable quality have been slower to emerge.

1. What is the status of population-based cancer registration worldwide?

The concept of population-based cancer registration has been in existence for well over half a century, with the first PBCR founded in the 1930s. Currently, there are more than 700 PBCRs worldwide, although their pace of development has been much slower in LMICs than in high-income countries. This reflects a shortage of human and financial resources in LMICs, rather than a lack of awareness of need. The *Cancer Incidence in Five Continents* (CI5) series (http://ci5.iarc.fr) published by IARC and the International Association of Cancer Registries (IACR) is regarded as the definitive source of high-quality cancer incidence data, and in Volume X published incidence data for the period circa 2003–2007.

Fig. 2.1. Global maps depicting (A) the development level of individual countries, according to the four-level Human Development Index (HDI), based on quartiles, for 2012; (B) status of population-based cancer registries (PBCRs), as of mid-2013; (C) status of vital registration systems, as of mid-2013. Source for A, B: Data compiled from the United Nations Development Programme.



Although there is a substantial disparity between high-HDI countries and low- or middle-HDI countries in coverage in CI5 (e.g. almost complete coverage in North America compared with < 10% in South America, Asia, and Africa), the circumstances are less bleak when it is considered whether cancer information is available and can be built upon in a given country in these regions.

A series of IARC Regional Hubs for Cancer Registration in Africa, Asia, and Latin America have been established and will be the first point of call for countries within the respective regions. The Hubs in liaison with IARC develop specific tools in support of registries to:

- assess cancer registry quality, publication, and presentation of data
- assess capacity for registry development and evaluate the quality of existing registries
- monitor overall progress in expanding coverage of cancer registration
- coordinate the development, follow-up, and evaluation of formal agreements between individual cancer registries and IARC, covering specific activities consistent with the needs and recommendations and a time-limited plan
- coordinate research projects, including the development of monographs in collaboration with IARC, including continental reports based on all available registry data in the Hub region.

Currently, the registration status of the 138 countries within the six Hubs can be placed into one of five categories, as indicated in Fig. 2.1B:

Grade I. High-quality PBCRs (included in CI5 Volume X) and nationally representative (registries with coverage of ≥ 50% of the country's population)

Grade II. High-quality PBCRs (included in CI5 Volume X) and regionally representative (< 50% coverage)

Grade III. National or regional registries that are, or are close to becoming, population-based (rates can be calculated)

Grade IV. Registration activity: hospital- and/or pathology-based systems (rates cannot be calculated), or documented evidence of efforts to establish a PBCR

Grade V. No data available, or status of registration unknown.

1.1 Countries graded as I or II

Countries with high-quality PBCRs (graded as I or II) may appear to need less support from IARC and the Hubs, yet empirically, several flagship registries in LMICs deemed of high quality (e.g. included in a CI5 volume) have subsequently languished, and sustainability of high-quality data from well-functioning registries is an obvious concern. There is a need to develop within-country and regional networks in support of the development of standards of quality and comparability, and to foster collaborations between registries. Staff from PBCRs graded as I or II in LMICs have unique experience and expertise to offer in support of the Hub activities, having successfully developed PBCRs under similarly challenging circumstances. Such experts are crucial in developing a roster of regional experts who collaborate with IARC and the Hubs as mentors and trainers, taking part in site visits to registries in targeted countries, and joining the teaching faculty of regional courses.

1.2 Countries graded as III or IV

A particular aim of the Hubs is to raise registration quality standards in those countries where registration systems are in place, or where there are local actions under way to develop these. The target for direct support is then those countries graded as III (national or regional PBCRs, including those close to becoming population-based) or IV (countries where hospital- and/or pathology-based systems are in place, or local efforts are under way to establish a PBCR). The focus is on building upon, enhancing, and extending existing registry activities and resources to invoke a significant change in the status of such cancer registries towards high-quality registration. Actions include:

- developing clearly defined operational procedures for registration
- ensuring that a suitably trained and appropriately skilled workforce is in place

Box 2.1. Examples of the use of population-based cancer registries in cancer control. Source: Adapted from Parkin (2006), by permission from MacMillan Publishers Ltd, copyright 2006.

The World Health Organization (WHO) notes that population-based cancer registries (PBCRs) are a core component of cancer control strategy (WHO, 2011). There are important roles for PBCRs in estimating the current cancer burden, examining recent trends, and predicting their probable future evolution. The scale and profile of cancer can be evaluated in terms of incidence and mortality, but other dimensions are often considered, including prevalence, person-years of life lost, and quality- or disability-adjusted life years. An appraisal of the current situation provides a framework for action, and cancer control planning should include the setting of explicit targets, which permits the success (or otherwise) of interventions to be monitored.

Primary prevention

The effectiveness of preventive interventions against cancer has rarely been evaluated by randomized controlled trials; more usually, success has to be inferred from observations after the introduction of programmes. This can involve comparing observed versus expected incidence rates (allowing for a time lag for the effects to emerge), with the expected rates based on a prediction model of some kind. This approach can be used, for example, to evaluate the success of interventions against tobacco smoking, and to assess the observed and expected impact of national implementation of the hepatitis B and human papillomavirus (HPV) vaccines.

Early detection and screening

Cancer registry data have been used widely in the evaluation and monitoring of screening programmes. Where there is no information on the screening status of individuals, time trends can be examined, in terms of incidence, for cancers for which screening should prevent invasive disease (e.g. cervical cancer), or mortality, for programmes that are designed to detect early invasive cancers (e.g. breast, colon, and prostate cancer). No reduction in incidence should occur in programmes detecting early invasive cancers; indeed, the introduction of screening should bring about a rise in incidence (as prevalent, asymptomatic cases are detected), followed by a fall, with cumulative incidence unchanged over what it would have been without screening.

Evaluating cancer care

Although essential as a measure of the success of cancer control activities in different populations, trends in mortality rates are not ideal, as they are influenced by both incidence and survival. The objective of measuring population-level survival is to give an indication of the possible role of the process of diagnosis and care, and not simply the effectiveness of a specific treatment, as a determinant of survival differences.

- establishing robust links with all the clinical services where cancer patients are diagnosed and treated
- ensuring that relevant ministries and other officials commit to a sustained support of registry activities and build population-based cancer registration into their cancer control strategies.

1.3 Countries graded as V

In large countries with ambitious plans but no cancer registration systems in place at present (graded as V), there may be opportunities for high-level negotiations to enable an international task force of surveillance experts to participate in a timetabled set of initial and follow-up visits, as a means of accelerating the development of a registry programme.

2. Essential differences between population-based cancer registries and other types of cancer registry

PBCRs systematically collect information on all reportable neoplasms occurring in a geographically defined population from multiple sources. There are two other important types of cancer registry with different functions than PBCRs: hospital-based cancer registries (HBCRs) compile data on cancer cases diagnosed and/or treated in a defined institution or institutions, and pathology-based cancer registries record cancer cases diagnosed in pathology laboratories, mostly based on histopathology or cytology reports. Depending on how the care system is organized, data on a more or less biased subgroup of cancer patients are thus collected.

HBCRs have been developed in many LMICs, particularly in Asia and Latin America, often at the initiative of dedicated clinicians. They serve a range of purposes, providing, for example, information about the diagnosis and treatment of patients in relation to specific tumour characteristics and their clinical outcome. The data from HBCRs and pathology-based systems are an integral part of hospital and laboratory management, respectively, by serving administrative purposes and aiding the review of performance.

The purposes of and fundamental differences between hospital-based, pathology-based, and population-based cancer registries are summarized in Table 2.1. Perhaps owing to their relative ease of establishment, a misconception has been perpetuated that HBCRs and pathology-based

Table 2.1. Characteristics, purposes, and uses of different types of cancer registries

Registry type	Characteristics	Purpose	Can this type of registry be used in formulating cancer plans?
Hospital-based cancer registry	Collects information on all cases of cancer treated in one or more hospitals	Useful for administrative purposes and for reviewing clinical performance	NO. An incomplete and biased sample of the population. Data set is based on patient attendance at given hospital or hospitals. Cancer profile is determined by referrals, in part based on the facilities and expertise within key institutions.
Pathology-based cancer registry	Collects information from one or more laboratories on histologically diagnosed cancers	Supports the need for laboratory-based services and serves as a quick "snapshot" of the cancer profile	NO. An incomplete and biased sample of the population. Data set is constructed from laboratory-based surveillance only. Cancer profile determined by cancers for which tumour tissue investigations were undertaken.
Population-based cancer registry	Systematically collects information on all reportable neoplasms occurring in a geographically defined population from multiple sources	The comparison and interpretation of population-based cancer incidence data support population-based actions aimed at reducing the cancer burden in the community.	**YES.** The systematic ascertainment of cancer incidence from multiple sources can provide an unbiased profile of the cancer burden in the population and how it is changing over time. These registries have a unique role in planning and evaluating cancer control programmes.

registries can function beyond their clinical, managerial, and administrative roles. Both types of system are of great value in providing a quality assessment of the services rendered, but they can deliver no clear picture as to the underlying local, regional, or national epidemiology of cancer. As the collected data derive from either patient attendance at a given hospital (HBCRs) or the number of cancers that have been biopsied (pathology-based systems), inclusion as a case is determined by the extent of facilities and expertise available within the respective institutions. The aggregated cases recorded therefore comprise a subset of the total case load, and thus such systems have little utility in planning, monitoring, or evaluating cancer programmes.

Key points

- The roles of hospital-based, pathology-based, and population-based cancer registries are different and complementary. The first two types of registry serve important administrative and clinical functions, but only PBCRs provide an unbiased profile of the present cancer burden and how it changes over time. PBCRs have a unique role in planning and evaluating population-based cancer control actions aimed at reducing the cancer burden in the community.

- Although there is a lack of high-quality data in LMICs, as witnessed by the present lack of coverage in *Cancer Incidence in Five Continents*, the circumstances are more positive when one considers the cancer information available in many LMICs. Many countries have national or regional registries that aim to become population-based, and serve as a starting point from which the registration systems can be further developed.

- 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 local activities in a given country are provided to increase the data quality, coverage, and utility of PBCRs in serving cancer control purposes.

CHAPTER 3.

Planning and developing a population-based cancer registry

Establishing a new cancer registry requires collective agreement on the need for, or at the least the desirability of, the enterprise. As the cancer registry responds to the requirements of a community and its health system, the key players in cancer control should be involved in backing the progress and ensuring the sustainability of the registry. The success of the operation depends on the collaboration of clinicians, pathologists, and staff in administration in ensuring access to their data. There are many things to consider when planning a registry, as discussed in this chapter. But some components are absolutely essential (👍) or highly desirable (✔) in ensuring the success of the venture.

- In the institutional/professional domain:
  - 👍 a director: the individual who will take professional responsibility for the registry, working together with other stakeholders and supervising the staff
  - 👍 the medical specialists concerned with the diagnosis and treatment of cancer: pathologists and oncologists (radiation, medical, and surgical)
  - ✔ the directors of the major hospitals in the area served by the registry
  - ✔ departments dealing with registration of deaths in the area served by the registry.
- As part of the political/administrative framework:
  - ✔ the health department of national or local government concerned with planning and managing services for cancer treatment and prevention
  - ✔ inclusion of the cancer registry as part of the health information system of these departments.

At the outset, it is very important that all of the key stakeholders, who will be concerned with the registry as data providers or users, are aware of, and agree with, the concept of a PBCR, as it has been described in Chapters 1 and 2. Briefly:

- The cancer registry must collect information on *every* case of cancer identified within an agreed population (of a defined geographical area).
- Within the defined geographical area, the registry will be able to distinguish between residents of the area and those who have come from outside the area.
- The registry will register cases of cancer in residents treated outside the area.
- The registry must have sufficient information on each case to avoid registering the same case twice (which implies including personal information, including names).

• The registry must have access to all sources within the area where cancer patients are diagnosed and cared for.

The precise requirements for a cancer registry depend to a large extent on the local circumstances with respect to the level of development of medical services (diagnostic, therapeutic, and palliative) for cancer patients, the size and geographical dispersion of the population, and the resources – material and financial – available. Some basic principles were summarized in *Cancer Registration: Principles and Methods* (Jensen and Whelan, 1991; see Box 3.1).

1. The population

1.1 The population covered ("target population")

The most basic decision to be made is to define the population covered by the registry: the "target" population in which cancer cases are occurring that the registry will enumerate. The issue of choosing a local or regional population, rather than the entire national population, for countries with a population of more than 4 or 5 million is an important issue to decide upon at the outset. The population covered by the registry may be the entire population of the country (or province), but more often it is just *part* of it – a "sample", or one or more "sentinel sites" from which inferences (estimates) of what is going on in the whole population can be made.

The ideal solution to cancer surveillance might seem to be to develop a national PBCR with a catchment population comprising the entire country, yet in practice this is usually an unrealistic prospect. Either it is technically unfeasible, or the cost involved greatly outweighs the benefits additional to those obtained from registration of a sample of the population.

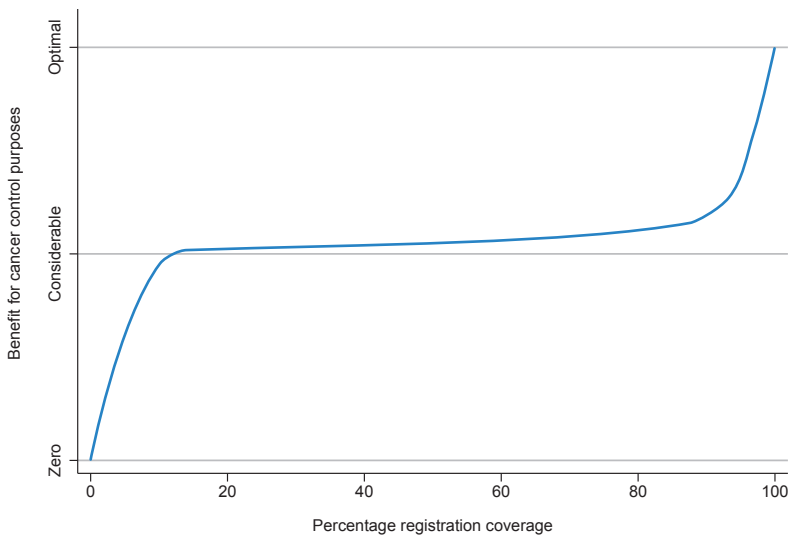
In Fig. 3.1, the benefits of registration (and associated representativeness of the national profile) in support of cancer control and cancer research activities increase as registration coverage (and associated cost) increase. The benefits are immediate after the introduction of a regional PBCR, and ideally the registry area will be selected to ensure that statistics generated can be extrapolated beyond the confines of the catchment population. With further increments in coverage, the benefits increase only minimally. However, at the point of national coverage and heavy financial investment the benefits of registration are maximized, enabling, as an example, an assessment of health service performance by local geographical area.

In summary, given the prohibitive costs involved, most of the requirements for planning and monitoring can be achieved through registration of a subset (sample) of the national population, using one or more regional PBCRs. The rolling out of a series of PBCRs is becoming increasingly common in LMICs, as a means to have representative cancer data that account for the underlying inter-regional and urban–rural demographic and epidemiological differences.

Box 3.1. Requirements for a cancer registry.

Conditions necessary to develop a cancer registry include generally available medical care and ready access to medical facilities, so that the great majority of cancer cases will come into contact with the health care system at some point in their illness. There must also be a system for reporting clinical and pathological data, and reliable population data should be available. The cooperation of the medical community is vital to the successful functioning of a registry. Planning must allow for an adequate budget, since expenses tend to increase as time goes by, as well as the necessary personnel and equipment.

Fig. 3.1. Benefits of increasing population coverage by cancer registration.



The choice of which local or regional population to register is dictated by practical considerations, rather than the ideal of an area (or areas) likely to be "representative" of the whole country. Thus, the area covered should have well-developed (by local standards) diagnostic and treatment services for cancer. Thus, it will attract cancer patients from outside the area (for diagnosis or care), and only few of its residents are likely to go outside the area for such services. For the cancer registry, it is very much easier to identify (and exclude from some calculations) non-residents diagnosed and treated in local hospitals than it is to try to find residents who have gone outside the area for their cancer care. Normally, then, the registry will be in an area where there are teaching hospitals, specialist oncology services, and pathology laboratories – that is, a major urban centre (usually including the capital city).

This major practical constraint on the choice of registration area will dictate the size of the population to be registered, as well as any theory as to what size is "ideal". Thus, some cancer registries must cover much bigger populations than might be thought reasonable (the Mumbai Cancer Registry covers a population of about 13 million), while others might be very small, and so record rather few cases each year (the Seychelles National Registry covers a population of only 86 000; http://afcrn.org/membership/members/96-seychelles).

How much of the rural hinterland of the urban area to include depends upon the nature of the administrative divisions in the country, and on practical considerations, such as the size of the population and the distances involved. In any case, the registry area should conform to an administrative unit (city, district, province, etc.) for which information on the size and composition of the population is available – the denominator for calculation of incidence rates.

1.2 Population denominators

"Population at risk" figures are used as denominators in the formulae for the calculation of incidence rates. The registry must have available estimates of the size of the population covered, by sex and 5-year age group, and, where there are important subgroups within the population (e.g. by race/ethnicity), for these strata also. Such data come from censuses, which are held at infrequent intervals (usually no more often than every 10 years). Between censuses, the population is estimated (intercensal estimates), as it is for the years following the most recent census (postcensal estimates). The latter are likely to be more speculative. Some of the issues involved in preparing such estimates have been described elsewhere (Pottier, 1992). However, the registry may find it preferable to rely on estimates prepared by official bodies, presumably staffed by appropriate experts, such as national or local government statistics offices.

It is important to remember that the accuracy of the incidence rates reported by the registry depends not only on the completeness and validity of the data it collects on cancer cases (see Chapter 5) but also on the accuracy of the "population at risk" data. Also, population estimates are likely to change over time; in particular, estimates that were based on postcensal projections often undergo quite drastic revisions when new census counts become available. This means that that some published incidence rates will have to be revised in later publications.

2. Personnel

2.1 Director

In establishing the cancer registry, the most important element is the leadership of a motivated and respected director. A director will commonly (but not always) be medically trained, and will need to provide specialist advice on, for example, pathology, clinical oncology, epidemiology, and statistics (either personally or through colleagues).

2.2 Technical staff

Adequate staffing of the registry must be ensured from the outset and is dependent on the number of new cases expected annually, the data sources, and data collection procedures. In a large registry covering a population of several million, staff can be allocated to perform specific tasks, such as case finding and abstracting, coding and data entry, data analysis, software maintenance, and presentation of the results, whereas in a small registry the staff (sometimes only one person) will perform multiple functions. Staff skills are not limited to the technical aspects of registration but involve considerable personal and communication skills in liaising with staff and colleagues from medical institutions and other sources.

2.3 Training of staff

In particular in LMICs, the quality of the cancer registry data will be highly dependent on the qualifications of the registry staff and their technical competence. Cancer registration demands specific training, mostly on the job. Formal training courses and use of standard manuals for cancer registrars are recommended to avoid the establishment of individualized practices by single staff members,

as well as individualized practices by single registries deviating from standard procedures (see links below).

There are a few training resources for staff of registries in LMICs:

- The IARC–IACR *Manual for Cancer Registry Personnel* (Esteban *et al*., 1995) is available from the IARC website (http://www.iarc.fr/en/publications/pdfs-online/treport-pub/treport-pub10/index.php).
- A useful training manual, *Pathology of Tumours for Cancer Registry Personnel* (Buemi, 2008), is available from the IACR website (http://www.iacr.com.fr/PathologyManualApr08.pdf). It explains in simple terms the genesis of tumours and the techniques used for pathological diagnosis, and contributes to the understanding of the terminology used. The first edition of this manual is available in French (http://www.iarc.fr/fr/publications/pdfs-online/epi/sp95/index.php).
- The Surveillance, Epidemiology, and End Results (SEER) Program of the USA provides many training materials, including some interactive training opportunities via the Internet (http://seer.cancer.gov/); however, these are not always well adapted to the circumstances of smaller registries in LMICs.

3. Physical location of the registry

The physical location of the cancer registry will generally be determined by its administrative dependency. The precise location, whether in a hospital department, university or research institute, government department, or the offices of a nongovernmental organization, is less important than its functional linkage with government health services and professional groups. In any case, the registry (generally through the director) should have the authority – administrative or professional – to be able to request and obtain detailed clinical information on cancer cases from medical services in the region. It is therefore advisable that the registry be linked in some way with government health services (which may also facilitate access to official statistics databases, such as mortality and population data) and with professional groups. A location in a hospital (or pathology laboratory) might allow better access to clinical data and input from health professionals. Regardless of the location of the registry, it should maintain sufficient autonomy to facilitate cooperation with other health agencies and collaboration at both the national and international levels.

4. Equipment and office space

The office space required is obviously related to the size of the registry, in terms of number of staff and the need for storage of paper documents (registration forms, pathology reports, etc.). All registries now require computer equipment. Even the smallest registry needs a good-quality desktop computer, with an Internet connection, for running the registry management system (e.g. CanReg5; see Annex 1), as well as other standard software. The number of machines required is dependent on the size of the registry and the number of operators for data entry and analysis. Other essential equipment includes at least one printer/scanner/photocopier, as well as, depending on local electricity supplies, a voltage stabilizer or emergency power source.

5. Finance

The costs of cancer registration depend on the size and population of the registration area, the number and type of different data sources, the number of data items collected, and the data collection methods. These will determine the number of staff required and the costs incurred in data collection, which will be major budget items.

The United States Centers for Disease Control and Prevention (CDC) has collected cost data and conducted economic analysis and an evaluation of the National Cancer Registry Program (NCRP) in the USA (Tangka *et al*., 2010). The true cost of operating cancer registries is unknown in LMICs, although the CDC has been validating a registry costing tool based on collaborations with several registries in Kenya, India, and Colombia. The aim is to aggregate cost for each registry activity based on staff salaries, consultancies, computers, travel, and training. The cost per case can then be calculated for core and advanced activities, and factors that affect cost can be further explored.

The elements that need to be to be considered when planning the budget for a cancer registry are shown in Box 3.2.

When planning a longer-term budget, it should be considered that the costs of the cancer registration process may increase over time as the registry expands its range of activities (e.g. to include follow-up of registered cases).

6. Legal aspects and confidentiality

It is advisable to ensure the legal basis for the operation of cancer registration in a given jurisdiction. Data confidentiality laws vary from country to country and should be taken into account when planning the cancer registry. In the setting of medical research, storage of medical data on identifiable individuals usually requires their informed consent. It is not possible for cancer registration to function under such a constraint. Cancer registries do not collect information from patients but rely on secondary sources, and thus asking for informed consent

Box 3.2. Elements for planning the cancer registry budget.

1. Capital costs (one-off)
- Office space and equipment/furnishings
- IT equipment (computers, printers, Internet link, etc.)

2. Recurring costs
- Salaries
  - Direct: registry staff (full-time or part-time)
  - Indirect: allowances for part-time/contract work
- Running costs
  - Travel expenses (in particular for active data collection)
  - Rental/maintenance (including costs of water, electricity, etc.)
  - IT equipment maintenance/replacement
  - Consumables (office material)
  - Publishing reports and/or establishing and maintaining the registry website

3. Training/workshops

Funding can be sought on an ad hoc basis once the registry is established.

is impossible. Individual patients must be identifiable, at the very least to permit notifications of the same cancer from different sources, or different time periods, to be linked in a single record. The value of a cancer registry in medical research is enormously enhanced if it can be used to identify cancers occurring in defined groups of subjects (cohorts), a procedure that also requires individual identification.

The cancer registry is an important tool in public health; without it, strategies for cancer control would be greatly hampered. A useful analogy is the notification of infectious diseases, which is so important in their control. As for infectious diseases, provision should be made for cancer to be a reportable disease. While this provides the necessary legal framework and may help with the number of cancer cases notified to the registry by clinical staff, mandatory reporting does not guarantee data quality or completeness of reporting. It does, however, provide some legal protection for data owners (hospital administrations, records officers, directors of private hospitals) who may be otherwise concerned with the ethics, or legality, or permitting cancer registry staff access to the data they require.

Cancer registries have been concerned about the production of a code of confidentiality for the purpose of recording data on cancer. IARC–IACR have published *Guidelines on Confidentiality for Population-Based Cancer Registration* (available from the IACR website; http://www.iacr.com.fr/confidentiality2004.pdf). The basic principles of confidentiality are presented, as well as a set of measures from which a registry may select those appropriate for their local codes of practice. Although the publication is primarily adapted for European registries, it contains useful guidance for LMICs, for example on measures that the registry can use to safeguard confidential information, and on the development of guidelines and procedures for the release of registry data.

7. Advisory committee

The importance of involving all relevant stakeholders in planning a registry has already been emphasized. Their continued involvement in its operation should be ensured when establishing an advisory committee for the registry. The relevant stakeholders will vary according to local circumstances, but in any case, it is important that the advisory committee consist of members from the public health, clinical, and academic communities, as the major users of the cancer registry data. Cooperation and involvement of clinicians, as the main providers of cancer registry data, is particularly important. If other groups such as cancer societies, hospice care services, and patient associations operate within the registration area, representatives of these stakeholders should be involved as well.

The role of the advisory committee is to oversee the activities of the registry, including formulating policies for staff recruitment and training, reviewing the results of the registry and ensuring that they are available to decision-makers as well as researchers, and helping to solve operational problems. The committee members may also provide assistance and contacts in efforts to attract funding to sustain or further develop activities at the registry. The committee may wish to establish subgroups, to deal with, for example, written requests for access to registry data. Working closely with the responsible programme owners in developing the registry programme and enquiring as to their needs can also be important in gaining funding support and obtaining local “buy-in” in the use of the data for cancer control.

Key points

- Given the prohibitive costs involved, 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.

- At the outset, it is very important that all of the key stakeholders, who will be concerned with the registry as data providers or users, are aware of, and agree with, the concept of a PBCR.

- The key players in cancer control should be involved in backing the progress and ensuring the sustainability of the registry. Success depends on the collaboration of clinicians, pathologists, and staff in administration in ensuring access to their data.

- The cancer registry must collect information on every case of cancer identified within a defined geographical area and be able to distinguish between residents of the area and those who have come from outside the area.

- In planning a PBCR, there are many things to consider, including the definition of the population, the necessary personnel, the physical location of the registry, the equipment and office space required, adequate financing, ensuring that legal aspects and confidentiality are dealt with, and – last but not least – the appointment of an advisory committee to oversee the activities of the registry.

CHAPTER 4.

Sources of information for the population-based cancer registry

A key feature of the PBCR is the use of multiple sources of information on cancer cases in the target population. This facilitates the identification of as many as possible of the cases diagnosed among the residents of the registry area. It does not matter if information on the same cases is received from several sources (indeed, as described in Chapter 5, this feature of a PBCR may be used to evaluate its success in case finding). Registry procedures allow identification of the same cancer case from different sources (while avoiding duplicate registrations); this is a built-in feature of the CanReg5 software (see Annex 1).

1. Sources of information on cancer cases

The sources can be grouped into three broad categories, each of which is discussed below:

- hospitals
- laboratories
- death certificates.

1.1 Hospital sources

The registry should attempt to identify all cancer cases that are diagnosed or treated in hospitals or clinics in the registry area. The institutions concerned will vary depending on location, but it is important to identify and enumerate them all, and the likely number (and type) of cancer patients seen in each. If there are special cancer treatment facilities (medical/surgical oncology, radiotherapy), their contribution to the registry is essential. Often, such services maintain a register of cases diagnosed, treated, or under follow-up.

Most other hospital services will see cancer patients, although the proportion of cases that are malignant disease will vary depending on the specialty. If there is a hospital information system, from which patients plus their diagnoses can be abstracted, the registry will use this as the primary case-finding mechanism. Even without a computerized hospital information system, the medical records department may maintain manual indexes of hospital discharges, which can be sorted by diagnosis. When there is no central information system, the work of the registry is more laborious and may involve visits to individual clinical services.

Private hospitals or clinics tend to be smaller than the larger public hospitals, and may not have specialist treatment facilities for cancer. Nevertheless, they may be important to include among the data sources, if identification of cancer patients

among their clientele is relatively easy. Confidentiality issues (real or imagined) with respect to collaboration with the cancer registry may be raised by the owners.

Hospice and palliative care services are very important sources. The great majority of their clients are cancer patients, documentation of diagnosis is usually good, and follow-up until death is the norm (indeed, the purpose).

1.2 Laboratory services

The pathology laboratory is a key – indeed, essential – source of data. For most cancer patients, the definitive diagnosis is based on histology (although the proportion of cases for which the tumour is examined by the pathologist depends on the site/type of cancer). Pathology laboratories always keep a record of their work in the form of a register – often as a computerized database, but even paper registers are easy to scan for cancer diagnoses. However, the laboratory will often be dependent on the request form, which accompanies the specimen, for information on the cancer patient. These, in turn, may contain inadequate information or be badly completed – especially with respect to place of residence. This variable is essential to the PBCR, and special effort is needed to find the information for cases found via the laboratory.

Other laboratory services are less fruitful sources, although clinical haematologists (rather than pathologists) are generally responsible for examination of bone-marrow specimens (and hence for diagnosis of haematological malignancies). Among the medical imaging services, only magnetic resonance imaging (MRI) and computed tomography (CT) scans have a high enough yield of cancer cases to be worth considering as sources of data. Their utility depends on the ease with which cancer cases can be identified among the lists of patients examined.

1.3 Death certificates

Information on persons dying from (or with) cancer is a very important source of case data for the registry. This information may be from civil registration systems (where "cause of death" is recorded by a medical practitioner on a death certificate), even if this process is incomplete (in the sense that not all deaths are certified). The correct assignment and coding of cause of death are often a problem in civil registration systems in LMICs. In many lower-income countries, death registration is confined to deaths in hospital (with no medical certification for deaths occurring at home); even these limited data should be exploited by the registry.

Identifying individuals dying from (or with) cancer serves three purposes for the registry:

- It allows identification of cancer cases that had been "missed" by the data collection system.
- It allows the death of registered cancer cases to be recorded (used in calculation of survival).
- Knowledge of the numbers of cases first notified via a death register provides one method for estimating the completeness of cancer registration.

2. Data collection

Traditionally, a distinction is made between "passive" collection of data (relying on health workers to complete notification forms and forward them to the registry) and "active" methods, whereby staff of the cancer registry visit the various sources to identify and abstract the relevant information. Registration that relies entirely on the diligence and goodwill of others to do the work of abstraction of information on cancer cases is never successful. Nevertheless, most registries use a mixture of methods, and although active case finding remains the norm, the development of computerized health information systems provides some scope to use electronic databases for case finding.

With an increasing number of computerized data sources available, cancer registries are sometimes put under pressure to abandon their traditional modes of operation. Whereas in the long term registries should develop a strategy to move from paper to digital data sources, it is a misconception to believe that cancer registry data can be automatically derived from the health information system. Regardless of the data sources and data collection methods used, skilled cancer registry staff are required to produce high-quality incidence data. In some LMICs, the person-time available for cancer registration allows only for routine data processing and production of incidence data. Making use of data from health information systems could enable such registries to spend less person-time on data entry and allocate more time to quality control, data analysis, and possibly research.

3. Variables collected by the registry

Cancer registries set out to record data for a set of variables on each cancer case. There is a uniform tendency, when a cancer registry is planned, to aim for too many variables. It must be remembered that the data are being collected from secondary sources (clinical and pathology records, hospital discharge abstracts, death certificates) and NOT from the patients themselves. Thus, items of information that are not routinely available in these

Table 4.1. Basic information for cancer registries

Item	Comments
The person	
Personal identification[a]	
Name	According to local usage
Sex	
Date of birth or age	Estimate if not known
Demographic	
Address	Usual residence
Ethnic group[b]	When population consists of two or more groups
The tumour	
Incidence date	
Most valid basis of diagnosis	
Topography (site)	Primary tumour
Morphology (histology)	
Behaviour	
Source of information	For example, hospital record number, name of physician

[a] The minimum information collected is that which ensures that if the same individuals are reported again to the registry, they will be recognized as being the same person. This could also be a unique personal identification number.

[b] Ethnic group is included here because it is important for most registries, especially in developing countries.

Source: MacLennan (1991).

sources should be avoided. This applies especially to items of information that can be reliably recorded only by interviewing the patient (risk factors such as tobacco and alcohol use, diet, etc.), as well as those likely to be recorded in only a subset of cases (and not a random subset, at that), such as occupation or HIV status. As a general rule, unless reliable information can be collected on 80–90% of cases, the item should not be included in the registry data set. Some variables, although easy to capture, are of little relevance and are also best avoided (e.g. marital status). In *Cancer Registration: Principles and Methods*, a set of 10–11 essential variables is proposed (Table 4.1), and it is true that no cancer registry could function with less than this, so that these might be considered the ***minimum data set***.

However, a reasonable list of ***essential variables*** is more substantial than this. Table 4.2 is based on the recommendations of the European Network of Cancer Registries (http://www.encr.eu/images/docs/recommendations/recommendations.pdf).

There are many ***optional variables*** that might also be included, depending on specific local interests, bearing in mind considerations of the availability of the items of information in the data sources, as described above.

4. Coding

Several of the variables listed require coding, to facilitate analysis. For a number of the variables, standard, international coding schemes are available, 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) system.

In addition, local coding schemes will be needed for:

- place of residence
- ethnic group (if recorded)
- source of information.

4.1 Classification of cancers – International Classification of Diseases for Oncology

Now in its third edition, ICD-O has been used for more than 35 years as the standard tool for coding diagnoses of neoplasms in cancer registries.

ICD-O is a multi-axial classification of the site, morphology, behaviour, and grading of neoplasms (and, in addition, it provides standard codes for the basis of diagnosis).

The topography code describes the **site of origin** of the neoplasm (the *primary site*, not the location of any metastasis) and uses the same three-character and four-character categories as in the neoplasm section of Chapter II of the International

Table 4.2. Essential variables for cancer registries

Item	Comments
The person	
Personal identification	In some countries a unique identification number, in others full name combined with date of birth and sex
Date of birth	Given as day, month, and year (dd/mm/yyyy)
Sex	Male (M) or female (F)
Ethnic group	According to local situation
Address including postal (or zip) code (and telephone number)	Needed for identification purposes and for geographically based studies
The tumour	
Incidence date	This date should be given priority, as outlined by the ENCR recommendations.
Primary tumour site	This should as a minimum be according to ICD-O.
Laterality	This should be recorded for all paired organs, but as a minimum for breast, eye, ovary, testis, and kidney (but observe the multiple primary rules).
Primary tumour histology	This should as a minimum be according to ICD-O.
Behaviour	This should as a minimum be according to ICD-O.
Basis of diagnosis	Most valid basis is recommended. All relevant methods may be recorded. The basis codes should be according to ICD-O.
Stage – (condensed TNM)	Stage is needed for international studies and for servicing clinicians. It is recommended to use the ENCR condensed TNM.
Initial therapy (i.e. initiated within 4 months from incidence date) [A clear manual on what is included should be available from the registry for all treatment items.]	As a minimum the registries should be able to present on a yes/no basis the treatment modalities used.
Surgery	Any surgical procedure of curative or palliative nature
Radiotherapy	Any radiotherapy of curative or palliative nature
Chemotherapy	Any cancer chemotherapy of curative or palliative nature
Endocrine (hormones)	Exogenous therapy, i.e. medication
Sources of information	
Sources of information	It is important to record ALL of the sources of information (hospital/institution) for each diagnosis and treatment modality in order to be able to do quality control, or to collect additional information. The relevant date and hospital/laboratory number are recorded for each.
Follow-up	
Last follow-up date	Needed to study follow-up (dd/mm/yyyy)
Vital status (at last follow-up date)	It may be of value to indicate whether known or assumed (e.g. based on linkages to death certificates) (dd/mm/yyyy)
Date of death	Needed to study survival and follow-up (dd/mm/yyyy)

ENCR, European Network of Cancer Registries; ICD-O, International Classification of Diseases for Oncology; TNM, tumour–node–metastasis.
Source: *Recommendations for a Standard Dataset for the European Network of Cancer Registries* (http://www.encr.eu/images/docs/recommendations/recommendations.pdf).

Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) classification of malignant neoplasms (except for those categories that relate to secondary neoplasms and to specified morphological types of tumours). ICD-O thus provides greater site detail for tumours than is provided in ICD-10. In contrast to ICD-10, ICD-O includes topography for sites of haematopoietic and reticuloendothelial tumours (as well as other cancers that, in ICD-10, are defined by histology, such as Kaposi sarcoma, melanoma, and sarcomas of soft tissue and bone).

The morphology axis provides five-digit codes ranging from M-8000/0 to M-9989/3. The first four digits indicate the specific histological term. The fifth digit, after the slash (/), is the behaviour code, which indicates whether a tumour is malignant, benign, in situ, or uncertain (whether benign or malignant).

A separate one-digit code is also provided for histological grading (differentiation).

The International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3) book has five main sections. The first section provides

general instructions for using the coding systems and gives rules for their implementation in tumour registries and pathology laboratories. The second section includes the numerical list of topography codes, and the third section the numerical list of morphology codes. The combined alphabetical index provided in the fourth section gives codes for both topography and morphology and includes selected tumour-like lesions and conditions. The fifth section provides a guide to differences in morphology codes between the second and third editions of ICD-O.

To the greatest extent possible, ICD-O uses the nomenclature published in the World Health Organization Classification of Tumours series ("WHO Blue Books"). As these are revised, and new morphological terms introduced, new codes are prepared as updates/addenda to ICD-O, pending a fourth edition.

ICD-O has been published in a wide variety of languages (Chinese, Czech, English, Finnish, Flemish/Dutch, French, German, Japanese, Korean, Portuguese, Romanian, Spanish, and Turkish). It can be purchased from WHO (http://www.who.int/classifications/icd/en/) or from the International Association of Cancer Registries, for members of that organization. A CSV file can be downloaded from the WHO website (http://apps.who.int/classifications/apps/icd/ClassificationDownloadNR/login.aspx?ReturnUrl=%2fclassifications%2fapps%2ficd%2fClassificationDownload%2fDLArea%2fDownload.aspx).

The IARC–IACR Cancer Registry Tools (IARCcrgTools) package includes *batch* programs for conversion from ICD-O to ICD-10. The conversion and check programs can only process text files having a *fixed field format*, although a File Transfer option allows conversion of a text file from delimited to fixed field format. The IARCcrgTools package is available from the website of IACR or IARC (http://www.iacr.com.fr/iacr_iarccrgtools.htm).

4.2 TNM coding system

The Union for International Cancer Control (UICC) TNM classification is the internationally accepted standard for cancer staging. It is an anatomically based system that records the primary and regional nodal extent of the tumour and the absence or presence of metastases.

Each individual aspect of TNM is termed a category:

- The T category describes the primary tumour site.
- The N category describes the regional lymph node involvement.
- The M category describes the presence or otherwise of distant metastatic spread.

Cancer staging is important not only for clinical practice; it also provides vital information for policy-makers developing or implementing cancer control and prevention plans, and it is therefore important to include the TNM classification as part of cancer registration.

The TNM classification is regularly updated and is now in its seventh revision.

The UICC website gives an explanation of the use of the TNM classification system and how to obtain the relevant coding manuals (http://www.uicc.org/resources/tnm).

Cancer registrars in LMICs may have difficulty in abstracting the full TNM code from clinical records, if this has not been explicitly recorded by the clinicians or pathologists. For this reason, a simplified version has been created by the European Network of Cancer Registries: the condensed TNM, available in English and French (http://www.encr.eu/images/docs/recommendations/extentofdisease.pdf).

This version allows for recording of T and/or N and/or M when they have not been explicitly recorded in the clinical or pathological records. The cancer registry then attempts to score extent of disease according to the condensed TNM scheme:

T:	**L**	**A**	**X**
N:	**0**	**+**	**X**
M:	**0**	**+**	**X**

(**A**, advanced; **L**, localized; **X**, cannot be assessed), where T and N are extracted, if possible, from the pathology report, or, in its absence, from the clinical record (endoscopy, X-ray, etc.). M is based on the best available information, whether clinical, instrumental, or pathological. For M, clinical signs and findings are enough to justify M**+** in the absence of pathological confirmation of metastatic deposits.

Both the full TNM and the condensed TNM allow tumour extent to be expressed according to the familiar numerical staging scheme:

I Tumour localized (T**L**/N**0**/M**0**)
II Tumour with local spread (T**A**/N**0**/M**0**)
III Tumour with regional spread (any T/N**+**/M**0**)
IV Advanced cancer (metastatic) (any T/any N/M**+**).

4.3 Local coding schemes

4.3.1 Place of residence

"Place of residence" codes should correspond to national subdivisions of the population as they appear in national statistical publications and for which there is information available on the size and composition of the population. It may be possible to develop a hierarchical coding scheme, where there are several levels of population subdivision (region, province, district, city ward, etc.).

4.3.2 Ethnic group

"Ethnic group" codes should correspond, if possible, to any official

categories recognized in national statistical publications, especially if there is information available on the size and composition of the population, by ethnic group.

4.3.3 Source of information

The codes for "source of information" will almost always be specific to the cancer registry, and will have to be developed by the registry itself. Careful thought should be given to developing a hierarchical coding scheme that will facilitate extraction of information (e.g. lists of cases) from the registry database, and tracing the records of lists of cases.

Thus, a coding scheme might aim to have different levels, such as:

1. Type of source (hospital, diagnostic laboratory, death certificate)
1.1. List of hospitals – public
1.2. List of hospitals – private
1.3. Hospices
1.1.1. Clinical services (medicine, surgery, radiotherapy, etc.).

It is important, when developing the coding scheme, to allow for its expansion in the future, as new sources of case data are included, while respecting the structure of the coding scheme.

As noted above (Table 4.2), the registry will record the case record number, but unless it is clear to which hospital/service or laboratory this number refers, it will be very difficult to trace the record if it is required for extracting additional information, for correcting errors in the registry database, or for research purposes.

5. Information on the population at risk

As described in Chapter 3, the registry should maintain a population file, which, for each calendar year, contains the population estimate for every combination of:

- ethnic group (if applicable)
- sex
- age (standard 5-year age groups, IF possible, separating infants [age, 0 years] from children [age, 1–4 years]) and including the numbers of persons of unknown age.

Key points

- A key feature of the PBCR is the use of multiple sources of information on cancer cases in the target population. Registry procedures allow identification of the same cancer case from different sources (while avoiding duplicate registrations). The sources can be grouped into three broad categories: hospitals, laboratories, and death certificates.
- Most registries use a mixture of active and passive methods of case finding.
- The development of computerized health information systems may provide some scope to use electronic databases for case finding.
- Cancer registries set out to record data for a set of variables on each cancer case. There is a uniform tendency, when a cancer registry is planned, to aim for too many variables.
- There are some 17–20 variables that it is essential for a registry to collect on each case registered. Additional, "optional" variables should be kept to a minimum. Several of the variables listed 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 ICD-O, and the coding of stage, using the TNM system.

CHAPTER 5.

Quality control at the population-based cancer registry

All cancer registries should be able to give some objective indication of the quality of the data that they have collected. The methods available were described in an early IARC Technical Report (Parkin *et al*., 1994) and updated in a pair of papers in 2009 (Parkin and Bray, 2009; Bray and Parkin, 2009). They describe four dimensions of quality: comparability, validity, timeliness, and completeness.

1. Comparability

Comparability of the statistics generated for populations and over time requires the standardization of practices concerning classification and coding of new cases, and consistency in definitions of incidence, such as rules for the recording and reporting of multiple primary cancers occurring in the same individual. The standard for classification and coding of cancer is ICD-O, published by WHO, which provides the standards for coding topography (location of the tumour in the body), morphology (microscopic appearance of the tumour), behaviour (whether the tumour is malignant, benign, or in situ), and grade (the extent of differentiation of the tumour). In addition to that, ICD-O-3 also provides a standard coding scheme for recording the basis of diagnosis and the IARC rules for coding multiple primary cancers. As carcinogenesis is a process that can sometimes take decades, the definition of incidence date is arbitrary, and therefore it is of particular importance to follow the agreed standards. Rules for the definition of incidence date have been given by the European Network of Cancer Registries (http://www.encr.eu/images/docs/recommendations/recommendations.pdf).

In low- and middle-income settings, some objective obstacles might impede following the international standards. For example, the lack of coverage by pathology laboratories, or difficult access to diagnosis, will reduce the percentage of morphologically verified cases, as well as result in postponement of the incidence date according to the standard European Network of Cancer Registries recommendations, prioritizing the date of the first histological or cytological confirmation of the malignancy as the date of incidence.

2. Validity

Accuracy of recorded data is greatly enhanced by consistency checks carried out at the time of data entry, such as those incorporated

into CanReg (see Annex 1). Most registries will also, formally or informally, check on the accuracy of the work of staff by carrying out some sort of re-abstraction (going back to one or more sources, to check on accuracy of recording) or recoding exercises, and acting to correct any obvious deficiencies.

Most registries will report on three statistics that have a bearing on the accuracy of the recoded data. They are:

- the proportion (or percentage) of cases with missing data
- the percentage of cases with a morphologically verified diagnosis (MV%)
- the percentage of cases for which the only information came from a death certificate (DCO%).

2.1 Proportion (or percentage) of cases with missing data

The proportion of cases with unknown values of different data items, such as age or stage, is also an indicator of data quality. An important element to assess here is the proportion of cases with primary site uncertain (PSU%). In addition to the ICD-O code for unknown primary site (C80.9), this category should also include other ill-defined sites.

Some data items can be very difficult to collect in low- and middle-income settings. This can apply, for example, to personal identification number, which then results in more demanding and less accurate linkage procedures. Many LMICs share the problem of unavailability or low quality of mortality data. This can pose numerous problems for a cancer registry, such as under-registration because of the lack of "death certificate only" (DCO) cases contributing to incidence, and inability to calculate the standard data quality indicators (apart from the percentage of cases with a morphologically verified diagnosis [MV%]). The only insight into completeness of cancer registration in the absence of mortality data can be provided by the independent case ascertainment or capture–recapture methods (described below).

2.2 Percentage of cases with a morphologically verified diagnosis (MV%)

Morphological verification refers to cases for which the diagnosis is based on histology or cytology. This is traditionally considered as a sort of "gold standard", with suspicion falling upon the accuracy of diagnosis by other means (although it is questionable whether exfoliative cytology is always more accurate than MRI or CT scan). A high MV% is taken to mean accuracy of diagnosis, whereas a low MV% casts doubt on the validity of the data.

The editorial checks of CI5 include a formal comparison of the MV% (by sex, for the major cancer sites) with a "standard", based on values observed in the same region 5 years earlier. Annex 2 provides the tables with "standard" values of selected data quality indicators, including MV% by country or region, which are used in the CI5 editorial process. Whereas a MV% significantly lower than the expected value may give rise to concern about a lack of validity, it is generally not the cancer registry that can influence the availability of, or use of, pathology services within its area. Usually, in LMICs, the opposite situation – a relatively high MV% – is cause for concern. Collecting data on cancer cases from pathology departments is much simpler than trawling through clinical services or ill-organized hospital archives. A large proportion of cases diagnosed via the pathology department may well suggest defects in case finding and, hence, incomplete registration. Worse, the incompleteness will be biased, with the database containing a deficit of cancers that are not easy to biopsy (e.g. lung, liver, brain, and pancreatic cancer).

2.3 Percentage of cases for which the only information came from a death certificate (DCO%)

DCO cases are those registered on the basis of information on a death certificate, and for which no other information could be traced. As described earlier, the nature of death certificates in LMICs varies widely, from those issued as part of a civil registration of vital events to those generated in a hospital mortuary. However, almost always the accuracy of the diagnostic information is questionable, since the person writing out the certificate may have had little contact with the patient before death and may be ill-informed about how to record cause of death. Thus, if no other clinical record for persons who apparently died of (or with) cancer can be found, there is a reasonable suspicion that the diagnosis was simply wrong. Nevertheless, registry practice demands that such cases are included, but when they comprise a large proportion of cases, the validity of the data is suspect.

Establishing objective criteria of an acceptable DCO% is difficult – it is sensitive to local circumstances, for example availability of death certificates, success in record linkage to the registry database, quality of cause-of-death statements, and facility to trace back cases.

2.4 Internal consistency

Data checks and edits should be applied to newly submitted records to check for item validity, internal

consistency, and inter-record consistency before they are linked with the central database. Such data checks and edits should also be applied to the registry database after any changes have been made.

3. Timeliness

Rapid reporting is often required from the cancer registries. However, for cancer registries (and their clients), a trade-off must be recognized between data timeliness and the extent to which the data are complete. The timeliness depends on the rapidity with which the registry can collect, process, and report sufficiently complete and accurate data. In some countries, such as in the United Kingdom, electronic data capture has expedited the registration process. Some registry networks, such as SEER and the North American Association of Central Cancer Registries, contract their member registries to report data within 22–24 months after the close of a diagnosis year. Some registries use methods such as a delay model estimating the undercount at the time of reporting, or short-term predictions to provide the estimates for the current year.

4. Completeness

Parkin and Bray (2009) distinguish between

- qualitative (or semiquantitative) methods, which give an indication of the degree of completeness relative to other registries, or over time

and

- quantitative methods, which provide a numerical evaluation of the extent to which all eligible cases have been registered.

4.1 Semiquantitative methods

Among the semiquantitative methods, the possibility that a relatively high MV% may represent incompleteness of data collection has already been noted.

A given case may be identified from different sources (hospitals, laboratories, or death certificates), and a large number of different sources per registered cancer case is generally taken to imply that zero sources (i.e. the case was not found in any of them) might be relatively uncommon. The other widely used indicators are:

- mortality-to-incidence ratio
- stability of incidence over time
- comparison of incidence rates with other (similar) populations.

4.1.1 Mortality-to-incidence ratio

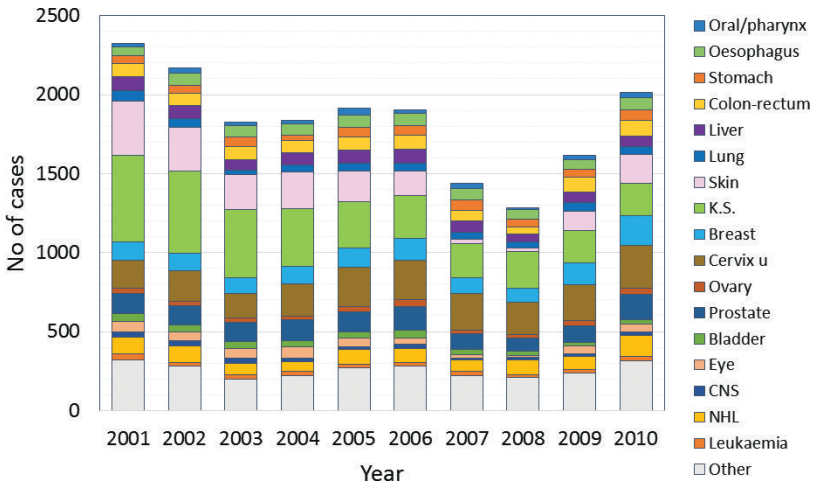
The mortality-to-incidence ratio (M:I) is an important indicator that is widely used – for example, in CI5 – to identify possible incompleteness. It is a comparison of the number of deaths, obtained from a source independent of the registry (usually, the vital statistics system), and the number of new cases of a specific cancer registered in the same time period. Application of this method does require, however, mortality data of good quality (especially with respect to accurate recording of cause of death), so that M:I is approximated by: 1 – survival probability (5 years). This permits objective standards of M:I values to be established, applicable to regions where survival is likely to be more or less similar (see Annex 2). The method cannot be used where there is no comprehensive death registration, or when the cause of death is missing or inaccurate – the situation in almost all countries in Africa, and many of those in Asia.

4.1.2 Stability of incidence over time

It is a simple task for a registry to rapidly check on the number of cases being registered each year. In the absence of marked changes in the population, this can quickly identify potential defects in case finding.

Fig. 5.1 provides an example. There is an obvious deficit of cases for the years 2007, 2008, and 2009, and although this involves most cancer sites, it is especially marked for cancers of the skin.

Fig. 5.1. Number of new cancer cases by site in a cancer registry, 2001–2010. CNS, central nervous system; K.S., Kaposi sarcoma; NHL, non-Hodgkin lymphoma.



CHAPTER 5

4.1.3 Comparison of incidence rates with other (similar) populations

Of course, not all populations will have the same pattern of incidence rates; observing differences is one of the objectives of cancer registration. Nevertheless, it is worth comparing results with those of registries serving a similar population (similar geographically, or of similar ethnic composition) – provided the data from other registries are of good quality themselves – to look for differences. Some variation is to be expected, or may be explicable on the basis of exposure to known risk factors, but a systematic difference (many rates lower than expected) may lead to a suspicion of under-registration.

This method is used by the editors of CI5, where results from each registry are compared with those from a group of registries in the same country (or geographical region) (Annex 2).

4.2 Quantitative methods

Three methods are available to obtain a quantitative evaluation of the degree of completeness of registration:

- independent case ascertainment
- capture–recapture methods
- death certificate methods.

4.2.1 Independent case ascertainment

Comparison of the registry database with sets of cancer cases that have been compiled independently of the cancer registry's case-finding procedures is a particularly useful and objective method of evaluating completeness. It requires record linkage between the cancer registry database and the independent case series, to estimate the numbers of cases in the latter "missed" by the registry. The proportion of eligible patients who are already registered is a direct and quantitative estimate of completeness.

The existence of such files of cancer patients from the registration area – for example, from research studies or surveys – provides an opportunity to evaluate registry completeness that should not be missed.

4.2.2 Capture–recapture methods

Like the numbers of sources per case, this method exploits the fact that cancer registries receive notifications of the same cancer cases from multiple sources. Usually, for this method, sources are grouped into hospital, laboratory (pathology), and death certificate, which are, more or less, independent of each other. The basic idea is that if we know how many cases are notified by one source, a pair of sources, or all three sources, we can estimate how many are notified by none (i.e. were missed). Practically, capture–recapture analysis of completeness requires that record linkage is successfully carried out (so that cases identified by each of the multiple sources are correctly classified). This is no problem for users of CanReg, where the sources of information for each cancer case are brought together. Because of the linked-file structure of CanReg5, this sort of analysis should be particularly straightforward.

4.2.3 Death certificate methods

The death certificate methods depend on the availability of relatively high-quality (complete and accurate) certification of cause of death in the area covered by the cancer registry, and will not be readily applicable in many settings in LMICs. The other two methods can, however, readily be applied.

5. Data quality indices for population-based cancer survival

Unlike incidence data, estimating cancer survival requires a high quality of follow-up information. This is optimally achieved if all-cause mortality data are available as a data source for the registry, and efficient linkage procedures (optimally based on unique identification number) are in place. As in LMICs vital registration systems are often absent, unreliable, or unavailable to the registries, many registries in LMICs have resorted to active follow-up methods. The indices for cancer survival data quality due to exclusion from analysis are frequency of DCO cases and frequency of cases excluded from the study due to lack of any follow-up (Swaminathan *et al.*, 2011). Loss to follow-up is a cause of bias even in registries in high-income countries, as even a small underestimation of deaths can result in overestimation of long-term survival (Brenner and Hakulinen, 2009). In LMICs, with poorly functioning routine health statistics data systems and unavailable mortality data, cancer survival estimates from PBCRs can sometimes provide the only insight into the status of cancer care in the country.

As Skeet noted in *Cancer Registration: Principles and Methods* (Skeet, 1991), "all registries should be able to quote some objective measure of (ascertainment) rather than relying on received wisdom and pious hope." This is sound advice, which is not always heeded. Reporting of registry results demands some evaluation of their quality, especially as the purpose is almost always to allow a valid comparison of cancer rates and risks, between populations and subgroups and over time, that are not the results of artefacts of the registration process.

Key points

- All PBCRs should be able to provide some objective indication of the quality of the data that they have collected.
- The methods available have been described and updated, and cover four dimensions of quality: comparability, validity, timeliness, and completeness.

CHAPTER 6.

Making the population-based cancer registry heard – reporting the results

A key objective of a cancer registry is to produce statistics on the occurrence of cancer in a defined population. This information can be disseminated by different means, such as cancer incidence reports, cancer registry websites, research articles, and press releases, as well as through direct communication with clinicians, health authorities, the media, and other data users.

The cancer incidence report is the routine and baseline means of presenting registry data. These 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. Even though cancer incidence does not vary markedly on an annual basis, most cancer registries are required by their stakeholders to publish new data annually. However, the registries with smaller populations and low yearly counts of rare cancers might choose to publish more detailed reports at longer intervals (e.g. 2 years or 5 years).

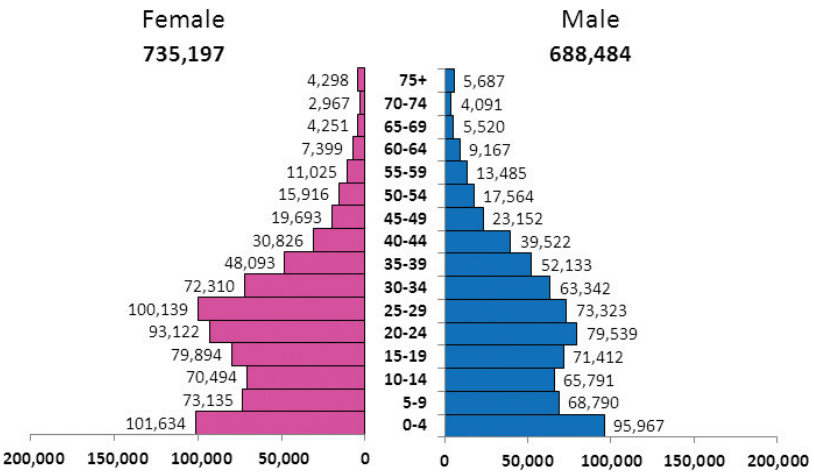
1. Basic contents of the report

Even though more and more cancer registries publish their data online, printed reports are still widely used. Therefore, the appearance (cover page) and size of the report should be considered. The initial pages of the report typically contain: name and address of the cancer registry (contact numbers, website, logo, etc.), names and designations of registry staff and members of the advisory committee, funding agency, date of the report, and table of contents. Stakeholders, for example the ministry of health, might be asked to contribute a foreword to the cancer registry report. Thereafter, a short executive summary of the report should be provided. The main components of the report are background information, evaluation and presentation of the results, and the tabular section.

1.1 Background information

This section should contain a brief description of the registry and registration procedures, in particular concerning classifications, rules, and definitions applied. The area and population covered should be described, and population counts should be presented in tabular or graphical format (e.g. Fig. 6.1). Sources of population estimates or data should be listed, and important demographic characteristics, such as ethnicity or religion, described. This section should also contain a description of data sources and a list of reportable diseases. Statistical

Fig. 6.1. Estimated average annual population of Harare City for the period 2010–2012. Source: Harare Cancer Registry Triennial Report, 2010–2012.



methods used for calculation of rates should be described and referenced.

1.2 Presentation of the results

Cancer registry tables are usually included as an annex to the report. The basic table is a frequency distribution of the number of cases during a specified time period according to the cancer site, age, and sex. The distribution should be given by 5-year age groups and by three-digit ICD level. This table should be accompanied by a similar table providing the age-, sex-, and site-specific annual rates. In addition to the age-specific information, this table should also contain crude, cumulative, and age-standardized rates. The guidelines for tabular presentation of the data (Hill, 1971) are summarized below:

- The contents of the table as a whole and the items in each separate column should be clearly and fully defined.
- If the table includes rates, the denominator on which they are based should be clearly stated.
- The frequency distributions should be given in full.
- Rates or proportions should not be given alone without any information as to the number of observations upon which they are based.
- Full particulars of any deliberate exclusions of registered cases must be given, with the reasons for and the criteria of exclusion being clearly defined.

As well as a tabular presentation, the reports should contain well-drawn and clear graphical depictions of selected results. Commonly these include the frequencies of different cancers or the ranking of age-standardized rates of the most common cancer sites (as bar graphs or pie charts) and the rates by age of different cancers or the trends of a given cancer over a calendar period (as line graphs). Commonly used graphs

Fig. 6.2. Ten most frequent cancers in males (percentages) in Malaysia in 2007. Source: Malaysia Cancer Registry Report, 2007.

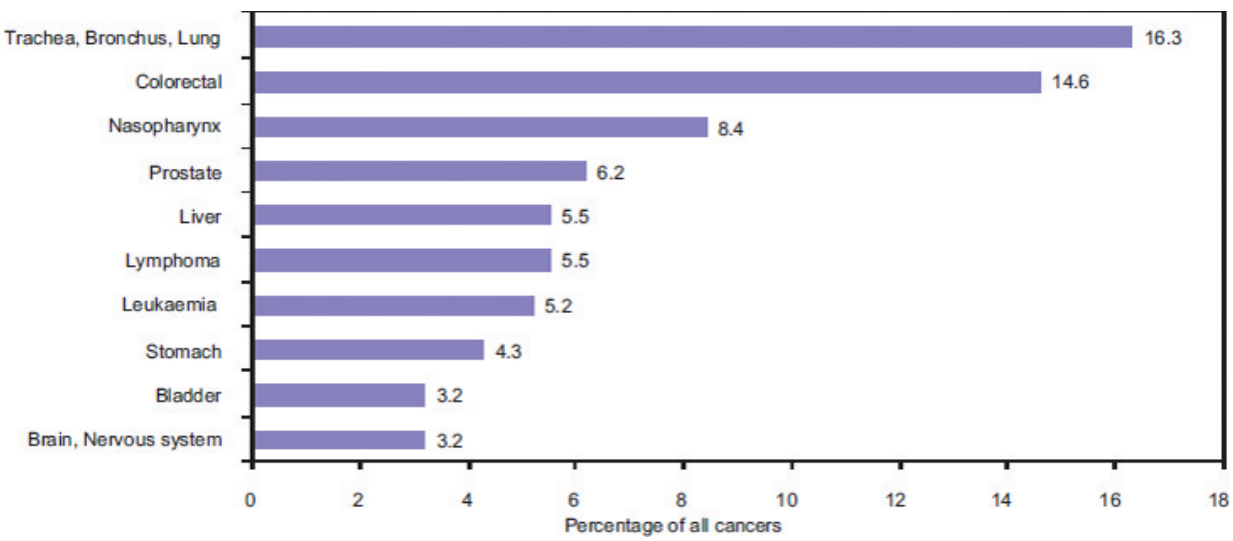
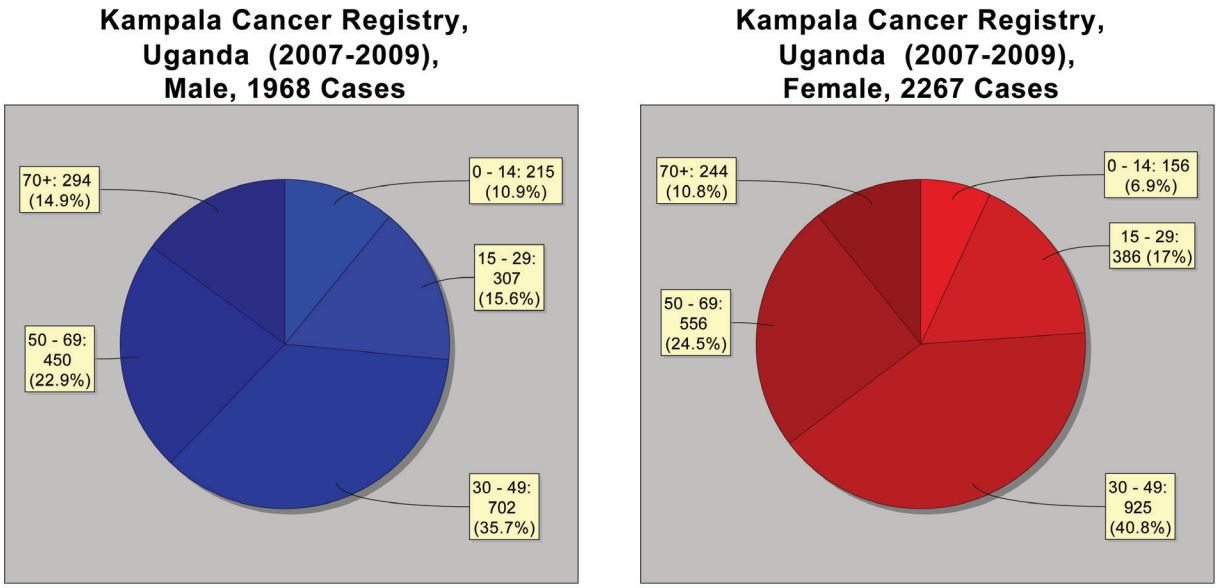


Fig. 6.3. Number of cases in 3-year period by age group and sex. Source: Kampala Cancer Registry Triennial Report, 2007–2009.



in presentation of cancer registry data include the following:

- *Bar graph or histogram*: commonly used for illustrations of frequencies, proportions, and percentages (e.g. Fig. 6.2).
- *Component band graph*: illustrates the size of components of the whole, using different colours, for example for different histologies (see Fig. 5.1).
- *Pie chart*: presents the contribution that different components make to the whole, commonly used to present the distribution of the most common cancer sites or age at incidence (e.g. Fig. 6.3).
- *Line graph*: commonly used to plot age-specific incidence rates or time trends (e.g. Fig. 6.4).

Examples of the recommended presentation of tables and graphs in cancer registry reports are also available in the African Cancer Registry Network model report at http://afcrn.org/resources/publications/115-model-registry-report.

2. Evaluation of the results

The aim of this section is to assist the reader in interpreting the results and to facilitate comparison with other registries. It should provide information on any changes in registration procedures compared with the preceding period. The important elements in evaluating the results are consistency of the number of cases in each calendar year, site distribution, and indices of quality of diagnosis. The indices generally used are

Fig. 6.4. Age-specific incidence rates (black males). N.H.L., non-Hodgkin lymphoma. Source: Harare Cancer Registry Triennial Report, 2010–2012.

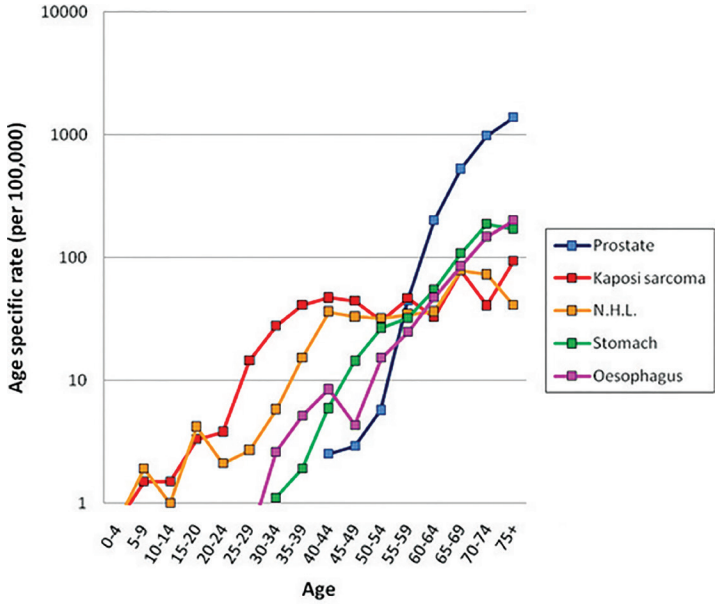


Table 6.1. Report checklist

Number	Recommended component
1	Executive summary of the report
Background information	
2	Outline of the organization of the cancer registry
3	List of the professional staff
4	Description of the reporting procedures
5	Description of the sources of cases
6	List of reportable diseases
7	Description of coding procedures
8	Clear statement of definitions used in reporting
9	Population covered by registration
10	Reference for the population denominator data
11	Description of statistical terms and methods
Evaluation of findings	
12	Consistency of the number of cases in each calendar year
13	Site distribution
14	Indices of validity of diagnosis
15	Demographic data
16	Differences compared with similar areas
Tabular presentation	
17	Clearly defined contents of the table and the items
18	Denominator for rates
19	Frequency distribution in full
20	Rate or proportion, with the number of observations
21	Particulars and criteria of exclusions
22	Number of cases by site, age, and sex
23	Annual incidence rates by site, age, and sex
24	Age-standardized rates
25	Cumulative incidence rates
26	Tables for subsets of the population
27	Tables for indices of the validity of diagnoses
Graphical presentation	
28	Limited amount of data per graph
29	Tabular information for the graphs must be presented
30	Appropriate choice of scale
31	Graphs should form self-contained units
32	Appropriate use of bar graphs, pie charts, and line graphs

the percentage of cases with morphological confirmation (MV%), the percentage of cases registered based on death certificate only (DCO%), and, if data on mortality are available, mortality-to-incidence ratio (M:I) (see Chapter 5 for definitions). These indices should also be presented by sex and site in the tabular section. Comparisons with other similar or neighbouring areas are also useful, as differences, such as lower incidence rates of major cancers, might point to under-reporting. A checklist of recommended components to be included in a cancer registry report is given in Table 6.1 (compiled from Jensen and Storm, 1991).

Upon publishing a report, it is advisable to assemble a stakeholders' committee to provide feedback to stakeholders, specific policy and research recommendations based on the results, and further plans and budgetary requirements. A response should also be provided to the data contributors, with the aim of improving quality and reporting. The pertinent media outlets should be briefed about the main findings.

Key points

- A key objective of a cancer registry is to produce statistics on the occurrence of cancer in a defined population.
- This information can be disseminated via cancer incidence reports, cancer registry websites, research articles, and press releases, and through direct communication with clinicians, health authorities, the media, or other data users.
- Even though cancer incidence does not vary markedly on an annual basis, most cancer registries are required by their stakeholders to publish new data annually. The cancer incidence report is the routine and baseline means of presenting registry data. These 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.
- The important elements in evaluating the results are consistency of the number of cases in each calendar year, site distribution, and indices of quality of diagnosis.

References

Bray F (2014). Transitions in human development and the global cancer burden. In: Stewart BW, Wild CP, editors. *World Cancer Report 2014*. Lyon: International Agency for Research on Cancer; pp. 54–68.

Bray F, Parkin DM (2009). Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. *Eur J Cancer.* 45(5):747–55. http://dx.doi.org/10.1016/j.ejca.2008.11.032 PMID:19117750

Brenner H, Hakulinen T (2009). Implications of incomplete registration of deaths on long-term survival estimates from population-based cancer registries. *Int J Cancer.* 125(2):432–7. http://dx.doi.org/10.1002/ijc.24344 PMID:19422045

Buemi A (2008). *Pathology of Tumours for Cancer Registry Personnel*. Lyon: International Agency for Research on Cancer and International Association of Cancer Registries. Available from http://www.iacr.com.fr/PathologyManualApr08.pdf.

Esteban D, Whelan S, Laudico A, Parkin DM, editors (1995). *Manual for Cancer Registry Personnel*. Lyon: International Agency for Research on Cancer and International Association of Cancer Registries (IARC Technical Reports, No. 10). Available from http://www.iarc.fr/en/publications/pdfs-online/treport-pub/treport-pub10/index.php.

Hill AB (1971). *Principles of Medical Statistics*. London: Lancet.

Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, editors (1991). *Cancer Registration: Principles and Methods*. Lyon: International Agency for Research on Cancer (IARC Scientific Publications, No. 95). Available from http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/index.php.

Jensen OM, Storm HH (1991). Reporting of results. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, editors. *Cancer Registration: Principles and Methods*. Lyon: International Agency for Research on Cancer (IARC Scientific Publications, No. 95); pp. 108–125. Available from http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/index.php.

Jensen OM, Whelan S (1991). Planning a cancer registry. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, editors. *Cancer Registration*: *Principles and Methods*. Lyon: International Agency for Research on Cancer (IARC Scientific Publications, No. 95); pp. 22–28. Available from http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/index.php.

MacLennan R (1991). Items of patient information which may be collected by registries. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, editors. *Cancer Registration*: *Principles and Methods*. Lyon: International Agency for Research on Cancer (IARC Scientific Publications, No. 95); pp. 43–63. Available from http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/index.php.

Parkin DM (2006). The evolution of the population-based cancer registry. *Nat Rev Cancer.* 6(8):603–12. http://dx.doi.org/10.1038/nrc1948 PMID:16862191

Parkin DM, Bray F (2009). Evaluation of data quality in the cancer registry: principles and methods. Part II: completeness. *Eur J Cancer.* 45(5):756–64. http://dx.doi.org/10.1016/j.ejca.2008.11.033 PMID:19128954

Parkin DM, Chen V, Ferlay J, Galceran J, Storm HH, Whelan SL (1994). *Comparability and Quality Control in Cancer Registration*. Lyon: International Agency for Research on Cancer (IARC Technical Reports, No. 19).

Pottier D (1992). Population at risk. In: Parkin DM, Muir CS, Whelan SL, Gao YT, Ferlay J, Powell J, editors. *Cancer Incidence in Five Continents*, Volume VI. Lyon: International Agency for Research on Cancer (IARC Scientific Publications, No. 120); pp. 174–177.

Skeet RG (1991). Quality and quality control. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, editors. *Cancer Registration: Principles and Methods*. Lyon: International Agency for Research on Cancer (IARC Scientific Publications, No. 95); pp. 101–107. Available from http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/index.php.

Swaminathan R, Lucas E, Sankaranarayanan R (2011). Cancer survival in Africa, Asia, the Caribbean and Central America: database and attributes. In: Sankaranarayanan R, Swaminathan R, editors. *Cancer Survival in Africa, Asia, the Caribbean and Central America*. Lyon: International Agency for Research on Cancer (IARC Scientific Publications, No. 162); pp. 23–31. Available from http://survcan.iarc.fr/survivalchap4.php.

Tangka F, Subramanian S, Beebe MC, Trebino D, Michaud F (2010). Economic assessment of central cancer registry operations, part III: results from 5 programs. *J Registry Manag.* 37(4):152–5. PMID:21688745

WHO (2011). *Global Status Report on Noncommunicable Diseases 2010*. Geneva: World Health Organization. Available from http:/www.who.int/chp/ncd_global_status_report/en/.

WHO (2013). *Global Action Plan for the Prevention and Control of NCDs 2013–2020*. Geneva: World Health Organization. Available from http://www.who.int/nmh/en/.

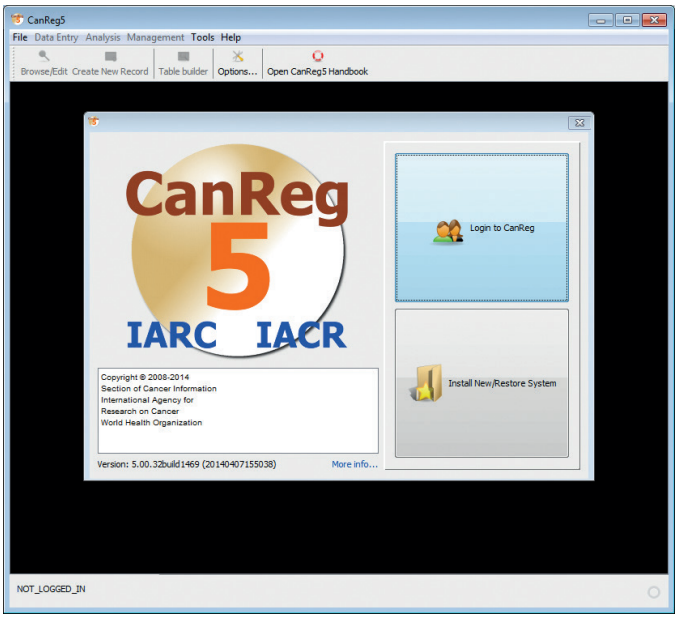
ANNEX 1.

CanReg5

CanReg is an open-source tool developed by the International Agency for Research on Cancer (IARC) specially designed to input, store, check, and analyse population-based cancer registry data. CanReg software is updated with consistency checks according to the international guidelines: Age/Incidence and birth dates; Age/Site/Histology (International Classification of Diseases for Oncology, 3rd Edition [ICD-O-3]); Site/Histology (ICD-O-3); Behaviour/Site (ICD-O-3); Behaviour/Histology (ICD-O-3); Basis of diagnosis/Histology (ICD-O-3). The latest version of the software, CanReg5 (Fig. A1), has improved multiuser capacities and enables adding new variables, recording multiple data sources, tailoring the data entry forms, and so on. CanReg5 is available in Chinese, English, French, Portuguese, Russian, and Spanish, and can be downloaded free of charge from IARC or the International Association of Cancer Registries (IACR) (http://www.iacr.com.fr/canreg5.htm).

As mentioned above, CanReg5 incorporates consistency checks. For population-based cancer registries using other software, the IARC–IACR Cancer Registry Tools (IARCcrgTools) program for conversion between ICD editions, consistency checks between variables, and multiple primary checks can be downloaded from the IACR website (http://www.iacr.com.fr/iarccrgtools.htm). The program runs in batch mode, using text files with a fixed-length record, and includes online help in English.

Fig. A1. The CanReg5 welcome window.



ANNEX 2.

Selected data quality indicators by country or region

Table A1. Mean values of data quality indicators for cancer registries in Brazil[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	86.9	36.4	19.6	81.2	22.9	4.9
C15	Oesophagus	79.5	66.1	10.5	77.3	55.6	2.6
C16	Stomach	81.2	55.2	24.3	79.8	50.3	11.1
C18–21	Large bowel	83.3	38.1	22.5	82.5	36.9	20.2
C22	Liver	89.6	181.6	4.2	84.3	205.7	2.5
C25	Pancreas	40.1	95.6	4.7	42.0	95.1	3.7
C32	Larynx	83.0	46.7	9.4	76.1	27.3	1.4
C33–34	Trachea, bronchus, and lung	68.8	75.6	25.6	68.5	68.0	9.9
C43	Melanoma of skin	99.2	20.5	4.8	99.5	16.7	4.4
C50	Breast	84.7	12.0	0.6	83.6	22.9	61.7
C53	Cervix uteri	0.0	0.0	0.0	87.8	23.4	29.3
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	77.9	39.0	10.5
C56	Ovary	0.0	0.0	0.0	76.3	39.3	7.7
C61	Prostate	85.3	20.8	79.6	0.0	0.0	0.0
C62	Testis	78.7	13.7	1.6	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	76.1	34.5	5.3	77.3	32.5	2.8
C67	Bladder	87.3	26.6	12.9	80.8	28.4	3.6
C70–72	Brain, central nervous system	61.4	64.6	6.8	56.4	62.9	5.2
C73	Thyroid	87.0	8.8	2.4	87.4	4.0	8.8
C81–88, C90	Lymphomas	97.9	35.6	13.6	98.0	36.7	9.5
C91–95	Leukaemia	95.8	51.2	7.0	95.6	53.1	5.0
C76–80	Unspecified	47.8	46.1	12.9	48.0	43.7	10.1
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	80.5	42.6	285.7	80.1	34.9	232.3

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.

[a] Campinas (1991–1995), Brasilia (1998–2001), Cuiaba (2000–2002), Goiania (1999–2002), São Paulo (1998–2002).

Table A2. Mean values of data quality indicators for cancer registries in China[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	91.4	44.3	10.7	89.9	35.1	4.5
C15	Oesophagus	68.4	78.6	21.4	61.1	80.8	10.4
C16	Stomach	73.1	64.6	32.9	70.6	67.0	15.4
C18–21	Large bowel	85.0	46.6	18.8	83.9	46.1	15.2
C22	Liver	33.4	83.7	33.4	28.1	85.0	10.5
C25	Pancreas	35.0	81.7	5.0	32.9	81.1	3.6
C32	Larynx	86.8	46.4	3.0	75.7	54.3	0.5
C33–34	Trachea, bronchus, and lung	56.3	80.4	47.6	51.2	78.8	20.7
C43	Melanoma of skin	90.9	38.8	0.3	90.8	45.1	0.3
C50	Breast	90.2	23.8	0.2	92.7	23.2	22.4
C53	Cervix uteri	0.0	0.0	0.0	91.5	38.4	3.6
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	90.5	25.7	4.8
C56	Ovary	0.0	0.0	0.0	83.1	52.8	3.9
C61	Prostate	80.7	32.5	3.9	0.0	0.0	0.0
C62	Testis	92.7	14.4	0.5	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	75.7	36.8	2.9	74.6	40.0	1.5
C67	Bladder	83.8	36.5	6.2	81.9	43.3	1.5
C70–72	Brain, central nervous system	61.2	61.8	4.3	61.7	53.7	3.7
C73	Thyroid	90.5	19.7	0.9	93.6	9.8	2.7
C81–88, C90	Lymphomas	93.1	52.8	5.3	92.7	52.3	3.3
C91–95	Leukaemia	90.8	64.0	5.1	89.1	63.5	3.7
C76–80	Unspecified	53.3	59.3	3.4	54.1	60.1	2.4
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	65.8	64.2	215.1	72.7	50.9	142.3

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] Beijing (1993–1997), Linzhou (1993–1997), Qidong County (1993–1997), Tianjin (1993–1997), Wuhan (1993–1997), Guangzhou (2000–2002), Hong Kong Special Administrative Region (1998–2002), Jiashan (1998–2002), Nangang District, Harbin City (1998–2002), Shanghai (1998–2002), Zhongshan (1998–2002).

Table A3. Mean values of data quality indicators for cancer registries in India[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	87.3	32.0	19.9	86.6	27.9	8.5
C15	Oesophagus	76.0	48.8	7.2	77.4	45.8	4.3
C16	Stomach	72.1	47.8	5.6	68.9	48.7	2.7
C18–21	Large bowel	81.1	31.9	5.3	79.4	34.6	4.1
C22	Liver	76.0	53.7	2.9	69.8	56.9	1.1
C25	Pancreas	59.9	51.3	1.7	52.1	49.7	1.0
C32	Larynx	81.0	38.6	6.0	76.0	43.1	0.7
C33–34	Trachea, bronchus, and lung	71.3	49.5	10.8	71.4	52.0	2.5
C43	Melanoma of skin	99.5	14.6	0.3	99.4	13.0	0.2
C50	Breast	82.8	31.9	0.6	85.7	24.5	24.1
C53	Cervix uteri	0.0	0.0	0.0	87.5	24.9	17.3
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	86.4	31.6	2.8
C56	Ovary	0.0	0.0	0.0	79.0	32.8	6.0
C61	Prostate	78.7	38.1	5.1	0.0	0.0	0.0
C62	Testis	88.2	17.1	0.7	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	91.1	26.3	1.6	89.3	31.1	0.7
C67	Bladder	78.6	30.6	3.3	76.7	37.0	0.8
C70–72	Brain, central nervous system	87.7	32.1	3.3	86.3	33.2	2.1
C73	Thyroid	83.0	24.0	1.0	84.8	14.6	2.4
C81–88, C90	Lymphomas	98.1	34.2	6.0	97.8	35.9	3.7
C91–95	Leukaemia	93.3	48.7	4.1	92.5	48.2	2.9
C76–80	Unspecified	53.1	70.5	9.6	47.6	76.2	6.2
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	80.3	40.2	101.6	82.0	32.8	100.3

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] Ahmedabad (1993–1997), Bangalore (1993–1997), Mumbai (1998–2002), Chennai (1998–2002), Nagpur (1998–2002), Poona (1998–2002),Trivandrum (1998–2002), Karunagappally (1998–2002), New Delhi (1998–2002).

Table A4. Mean values of data quality indicators for cancer registries in Thailand[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	90.7	36.9	10.9	89.6	60.1	5.5
C15	Oesophagus	79.0	49.7	3.5	70.4	128.1	0.9
C16	Stomach	79.1	40.5	4.4	79.0	39.4	2.9
C18–21	Large bowel	79.3	38.3	11.2	78.8	36.8	8.4
C22	Liver	21.5	44.0	32.4	19.6	66.9	12.6
C25	Pancreas	39.7	53.7	1.6	43.8	65.5	1.1
C32	Larynx	87.4	34.2	2.8	83.8	84.9	0.4
C33–34	Trachea, bronchus, and lung	62.3	45.8	28.8	66.5	44.6	14.1
C43	Melanoma of skin	100.0	20.7	0.6	100.0	11.1	0.3
C50	Breast	75.9	677.3	0.2	89.6	15.7	19.6
C53	Cervix uteri	0.0	0.0	0.0	89.8	17.4	21.4
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	90.0	21.8	3.4
C56	Ovary	0.0	0.0	0.0	83.0	20.3	5.7
C61	Prostate	86.0	23.2	4.8	0.0	0.0	0.0
C62	Testis	80.5	8.8	0.5	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	82.1	33.1	1.6	78.5	30.1	0.8
C67	Bladder	88.0	29.2	5.0	82.8	45.6	1.4
C70–72	Brain, central nervous system	46.8	54.1	1.8	55.0	44.4	1.9
C73	Thyroid	88.8	45.1	1.2	90.5	12.5	4.3
C81–88, C90	Lymphomas	98.7	43.0	6.6	98.5	46.3	4.7
C91–95	Leukaemia	90.3	28.0	4.3	87.1	19.8	3.8
C76–80	Unspecified	24.2	52.4	14.6	29.0	57.5	9.4
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	59.8	47.3	145.6	74.3	35.8	130.0

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] Chiang Mai (1998–2002), Songkhla (1998–2002), Lampang (1998–2002), Bangkok (1995–1997), Khon Kaen (1993–1997).

Table A5. Mean values of data quality indicators for cancer registries in sub-Saharan Africa[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	68.6	0	3.3	71.4	0	2.3
C15	Oesophagus	46.7	0	8.6	45.9	0	4.4
C16	Stomach	53.1	0	9.0	53.4	0	9.9
C18–21	Large bowel	62.1	0	5.5	61.3	0	5.6
C22	Liver	11.7	0	27.0	12.6	0	13.2
C25	Pancreas	16.8	0	2.5	22.2	0	1.9
C32	Larynx	66.2	0	1.7	73.3	0	0.4
C33–34	Trachea, bronchus, and lung	44.7	0	5.6	64.1	0	2.4
C43	Melanoma of skin	76.9	0	0.6	90.0	0	1.3
C50	Breast	66.7	0	0.7	66.1	0	18.3
C53	Cervix uteri	0.0	0	0.0	62.4	0	41.0
C54–55	Corpus uteri, uterus unspecified	0.0	0	0.0	64.6	0	5.1
C56	Ovary	0.0	0	0.0	51.3	0	5.0
C61	Prostate	59.8	0	22.7	0.0	0	0.0
C62	Testis	48.3	0	0.5	0.0	0	0.0
C64–66	Kidney, renal pelvis, and ureter	68.8	0	1.0	67.1	0	1.3
C67	Bladder	39.7	0	5.6	45.0	0	3.1
C70–72	Brain, central nervous system	51.5	0	0.6	41.8	0	1.0
C73	Thyroid	65.4	0	0.4	73.8	0	1.9
C81–88, C90	Lymphomas	84.5	0	6.9	82.0	0	5.9
C91–95	Leukaemia	87.2	0	1.4	88.4	0	1.6
C76–80	Unspecified	48.4	0	5.2	39.8	0	5.3
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	57.4	0	142.2	61.1	0	151.3

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] The Gambia (1997–1998), Mali, Bamako (1994–1996), Uganda, Kyadondo County (1993–1997), Zimbabwe, Harare: African (1993–1997).

Table A6. Mean values of data quality indicators for cancer registries in Central America and the Caribbean[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	94.2	44.0	12.2	92.8	42.0	3.4
C15	Oesophagus	81.3	99.8	5.3	73.5	89.3	1.1
C16	Stomach	77.4	75.9	18.3	73.5	76.8	8.9
C18–21	Large bowel	85.3	49.9	17.5	82.7	49.5	17.3
C22	Liver	39.7	74.5	4.6	31.5	84.8	2.8
C25	Pancreas	39.9	75.3	4.3	34.0	79.1	3.3
C32	Larynx	91.9	57.2	6.4	87.4	58.3	0.9
C33–34	Trachea, bronchus, and lung	60.0	95.7	21.1	57.3	101.2	8.3
C43	Melanoma of skin	98.6	35.7	1.6	100.0	30.2	1.2
C50	Breast	92.8	27.9	0.5	95.0	31.6	42.9
C53	Cervix uteri	0.0	0.0	0.0	90.5	35.5	13.3
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	89.1	33.4	8.3
C56	Ovary	0.0	0.0	0.0	80.9	37.8	5.6
C61	Prostate	89.0	32.9	79.9	0.0	0.0	0.0
C62	Testis	90.9	11.7	1.6	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	78.3	32.3	3.6	79.1	30.4	2.3
C67	Bladder	88.7	30.0	8.1	83.9	37.1	2.3
C70–72	Brain, central nervous system	72.8	53.5	4.3	68.1	55.3	2.9
C73	Thyroid	95.9	9.1	1.3	95.2	5.9	6.7
C81–88, C90	Lymphomas	95.0	53.6	12.2	94.9	53.2	8.9
C91–95	Leukaemia	85.5	77.7	7.1	81.4	71.3	4.9
C76–80	Unspecified	47.7	54.4	6.5	48.5	52.2	5.2
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	81.1	51.9	226.7	82.3	46.8	159.3

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] Costa Rica (1998–2002), Cuba, Villa Clara (1995–1997), France, Martinique (1998–2002), Puerto Rico (1992–1993).

Table A7. Mean values of data quality indicators for cancer registries in South America (excluding Brazil)[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	86.4	37.4	12.5	82.8	24.9	3.6
C15	Oesophagus	78.5	68.7	8.5	76.1	62.3	2.4
C16	Stomach	79.2	60.3	24.4	76.3	57.2	11.7
C18–21	Large bowel	81.9	42.2	20.8	80.8	41.9	17.5
C22	Liver	78.6	169.2	3.7	69.2	182.6	2.4
C25	Pancreas	38.4	97.0	5.1	39.0	96.0	4.0
C32	Larynx	82.9	48.8	7.4	76.2	32.2	1.0
C33–34	Trachea, bronchus, and lung	67.0	78.3	28.2	67.0	72.2	8.3
C43	Melanoma of skin	98.7	22.0	3.7	99.2	17.7	3.9
C50	Breast	83.0	20.5	0.6	82.3	24.8	58.7
C53	Cervix uteri	0.0	0.0	0.0	88.8	24.6	27.2
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	78.3	42.3	9.5
C56	Ovary	0.0	0.0	0.0	76.3	43.2	7.9
C61	Prostate	84.4	25.0	58.5	0.0	0.0	0.0
C62	Testis	84.9	14.2	3.4	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	76.8	38.9	6.2	77.1	37.1	3.1
C67	Bladder	86.6	29.3	11.5	80.5	31.4	3.0
C70–72	Brain, central nervous system	64.9	65.1	5.6	60.3	63.1	4.3
C73	Thyroid	87.5	11.7	1.9	88.5	5.4	6.9
C81–88, C90	Lymphomas	97.1	37.5	13.2	97.3	38.7	9.4
C91–95	Leukaemia	95.1	58.2	7.9	95.1	59.9	5.6
C76–80	Unspecified	46.6	55.4	12.7	47.9	53.6	9.5
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	79.4	46.6	252.2	79.3	38.6	217.9

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] Argentina, Concordia (1993–1997), Argentina, Bahia Blanca (1998–2002), Brazil, Campinas (1991–1995), Brazil, Brasilia (1998–2001), Brazil, Cuiaba (2000–2002), Brazil, Goiania (1999–2002), Brazil, São Paulo (1998–2002), Chile, Valdivia (1998–2002), Colombia, Cali (1998–2002), Ecuador, Quito (1998–2002), Peru, Trujillo (1998–2002), Uruguay, Montevideo (1993–1995).

Table A8. Mean values of data quality indicators for cancer registries in Oceania (excluding Australia/New Zealand)[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	91.9	0	15.5	91.5	0	3.8
C15	Oesophagus	91.1	0	6.5	81.8	0	0.9
C16	Stomach	81.0	0	6.8	81.5	0	4.5
C18–21	Large bowel	88.7	0	20.6	87.9	0	14.7
C22	Liver	62.4	0	9.3	53.8	0	3.5
C25	Pancreas	68.2	0	3.6	65.6	0	2.7
C32	Larynx	93.5	0	3.7	80.0	0	0.4
C33–34	Trachea, bronchus, and lung	82.5	0	51.0	82.6	0	20.2
C43	Melanoma of skin	95.7	0	4.8	98.1	0	3.6
C50	Breast	90.0	0	0.8	92.9	0	58.7
C53	Cervix uteri	0.0	0	0.0	96.4	0	13.8
C54–55	Corpus uteri, uterus unspecified	0.0	0	0.0	91.3	0	13.6
C56	Ovary	0.0	0	0.0	91.4	0	7.4
C61	Prostate	93.2	0	46.9	0.0	0	0.0
C62	Testis	93.3	0	1.8	0.0	0	0.0
C64–66	Kidney, renal pelvis, and ureter	88.7	0	5.0	75.9	0	2.5
C67	Bladder	93.2	0	7.2	90.5	0	1.8
C70–72	Brain, central nervous system	57.1	0	2.4	68.8	0	2.3
C73	Thyroid	100.0	0	4.9	99.1	0	30.9
C81–88, C90	Lymphomas	93.9	0	10.0	88.9	0	8.4
C91–95	Leukaemia	87.1	0	7.2	91.9	0	4.8
C76–80	Unspecified	70.9	0	6.7	69.0	0	5.7
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	86.7	0	225.9	90.1	0	215.4

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] French Polynesia (1998–2002), Guam (1998–2002), New Caledonia (1998–2002).

Table A9. Mean values of data quality indicators for cancer registries in North Africa and West Asia[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	87.3	32.0	19.9	86.6	27.9	8.5
C15	Oesophagus	76.0	48.8	7.2	77.4	45.8	4.3
C16	Stomach	72.1	47.8	5.6	68.9	48.7	2.7
C18–21	Large bowel	81.1	31.9	5.3	79.4	34.6	4.1
C22	Liver	76.0	53.7	2.9	69.8	56.9	1.1
C25	Pancreas	59.9	51.3	1.7	52.1	49.7	1.0
C32	Larynx	81.0	38.6	6.0	76.0	43.1	0.7
C33–34	Trachea, bronchus, and lung	71.3	49.5	10.8	71.4	52.0	2.5
C43	Melanoma of skin	99.5	14.6	0.3	99.4	13.0	0.2
C50	Breast	82.8	31.9	0.6	85.7	24.5	24.1
C53	Cervix uteri	0.0	0.0	0.0	87.5	24.9	17.3
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	86.4	31.6	2.8
C56	Ovary	0.0	0.0	0.0	79.0	32.8	6.0
C61	Prostate	78.7	38.1	5.1	0.0	0.0	0.0
C62	Testis	88.2	17.1	0.7	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	91.1	26.3	1.6	89.3	31.1	0.7
C67	Bladder	78.6	30.6	3.3	76.7	37.0	0.8
C70–72	Brain, central nervous system	87.7	32.1	3.3	86.3	33.2	2.1
C73	Thyroid	83.0	24.0	1.0	84.8	14.6	2.4
C81–88, C90	Lymphomas	98.1	34.2	6.0	97.8	35.9	3.7
C91–95	Leukaemia	93.3	48.7	4.1	92.5	48.2	2.9
C76–80	Unspecified	53.1	70.5	9.6	47.6	76.2	6.2
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	80.3	40.2	101.6	82.0	32.8	100.3

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.
[a] Algeria, Algiers (1993–1997), Algeria, Setif (1998–2002), Bahrain: Bahraini (1998–2002), Egypt, Gharbiah (1999–2002), Israel: non-Jews (1998–2002), Kuwait: Kuwaitis (1998–2002), Oman: Omani (1998–2001), Tunisia, Central (1998–2002), Turkey, Izmir (1998–2002), Turkey, Antalya (1998–2002).

Table A10. Mean values of data quality indicators for cancer registries in Central, East, and South Asia[a]

ICD-10 code	Cancer site	Male			Female		
		MV%	M:I%	ASR	MV%	M:I%	ASR
C00–14	Oral cavity and pharynx	88.9	37.0	17.0	86.0	29.4	9.3
C15	Oesophagus	78.5	86.6	3.6	77.3	66.2	2.0
C16	Stomach	74.1	60.3	13.9	73.1	57.6	7.4
C18–21	Large bowel	86.4	42.9	18.8	86.4	44.2	14.0
C22	Liver	29.2	86.7	16.5	28.5	95.1	5.0
C25	Pancreas	44.7	85.2	2.9	45.6	82.8	2.2
C32	Larynx	90.5	43.1	4.8	83.9	40.7	0.7
C33–34	Trachea, bronchus, and lung	68.2	81.0	36.4	69.1	78.5	10.3
C43	Melanoma of skin	92.8	28.0	0.6	93.3	36.7	0.3
C50	Breast	76.8	44.4	0.6	91.0	23.4	40.2
C53	Cervix uteri	0.0	0.0	0.0	89.5	30.0	15.7
C54–55	Corpus uteri, uterus unspecified	0.0	0.0	0.0	85.2	17.1	6.6
C56	Ovary	0.0	0.0	0.0	82.5	37.1	8.0
C61	Prostate	83.1	27.6	11.5	0.0	0.0	0.0
C62	Testis	84.8	8.8	0.9	0.0	0.0	0.0
C64–66	Kidney, renal pelvis, and ureter	78.3	35.0	3.0	73.8	37.5	1.5
C67	Bladder	89.9	32.0	5.4	86.2	34.0	1.3
C70–72	Brain, central nervous system	70.7	62.0	2.4	66.6	64.0	1.8
C73	Thyroid	88.9	11.2	1.6	92.4	8.6	5.1
C81–88, C90	Lymphomas	90.4	38.7	8.3	89.2	41.3	5.3
C91–95	Leukaemia	91.0	45.1	5.6	89.6	54.1	4.4
C76–80	Unspecified	62.6	58.5	9.0	60.8	55.0	6.4
C00–96 (excluding C44)	All sites (excluding non-melanoma skin)	73.4	56.5	171.7	82.0	42.1	156.0

ASR, age-standardized rate (World Standard) per 100 000; ICD-10, International Statistical Classification of Diseases and Related Health Problems, 10th Revision; M:I%, percentage mortality-to-incidence ratio; MV%, percentage of cases with a morphologically verified diagnosis.

[a] Malaysia, Sarawak (1998–2002), Malaysia, Penang (1998–2002), Pakistan, South Karachi (1998–2002), Philippines, Manila (1998–2002), Philippines, Rizal (1993–1997), Singapore (1998–2002), Viet Nam, Hanoi (1993–1997), Viet Nam, Ho Chi Minh City (1995–1998).