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 57 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/).
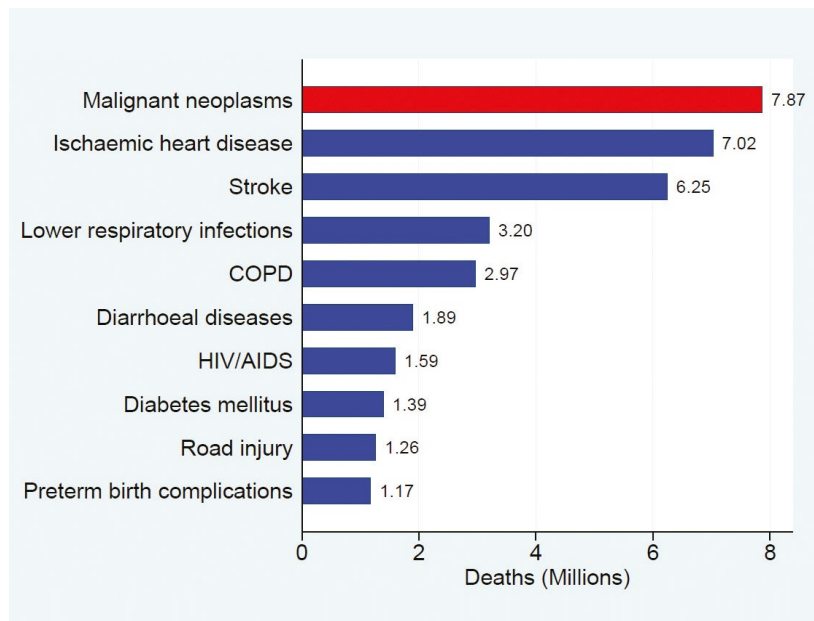
cancer and the other major NCDs (cardiovascular diseases, respiratory diseases, and diabetes) by 2025. An action plan and its monitoring framework have subsequently been adopted to achieve the target (WHO, 2013).

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/WHA66/A66_9-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.