Chapter 1. Introduction

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The cancer registry has a pivotal role in cancer control. Its primary function is the maintenance of a file or register of all cancer cases occurring in a defined population in which the personal particulars of cancer patients and the clinical and pathological characteristics of the cancers, collected continuously and systematically from various data sources, are documented. The registry analyses and interprets such data periodically and provides information on the incidence and characteristics of specific cancers in various segments of the resident population and on temporal variations in incidence. Such information is the primary resource not only for epidemiological research on cancer determinants but also for planning and evaluating health services for the prevention, diagnosis and treatment of the disease.

Cancer registries can also be used for monitoring occupational groups and cohorts of individuals exposed to various carcinogens and as a convenient source of subjects for clinical and epidemiological studies. Those based in hospitals have an important supportive role in the care of cancer patients by assisting clinicians in the follow-up of their cases and by providing statistical data on the results of therapy.

The value of a cancer registry depends on the quality of its data and the extent to which they are used in research and health services planning. It is obviously important that the registration of cancer cases should be as complete as possible. The operation of some registries has been seriously curtailed by laws or regulations, designed to ensure secrecy of information, that prevent cross-linkage of different data files, including access to the personal identity of deceased persons in death records. In view of the enormous and rapidly increasing burden of cancer on the community, it is hoped that cancer registries, working under codes of secrecy acceptable to local circumstances, will have access to such information. Epidemiological research, based on comprehensive cancer registration, remains the most valid and efficient way to plan and evaluate all aspects of cancer control.

Most of the cancer registries now in operation, and whose data are published in the IARC series *Cancer Incidence in Five Continents*, are in Europe and North America. There is an urgent need for more registries in the developing countries in Asia, Africa and South America, where cancer is already recognized as a major health problem and is likely to increase in importance with the control of infectious diseases and an increased expectancy of life. The data collected by individual registries may vary according to local needs and availability of information but the nomenclature and definition of each item should be the same in all registries to facilitate international comparability of cancer data. There should also be an internationally accepted core of data items which all registries may endeavour to collect. It is one of the objectives of this book to promote such uniformity.

This book is the outcome of collaboration between the International Agency for Research on Cancer and the International Association of Cancer Registries and aims to provide guidelines on all aspects of cancer registration. It replaces the earlier publication *Cancer Registration and its Techniques* (IARC Scientific Publications No. 21), from which it differs in several respects. A multi-author format is used here, and there is an overall assumption that cancer registries will be computer-based. The uses of cancer registration are more fully described (Chapter 3). The importance of cancer registration in planning and evaluating cancer-related health services is dealt with in greater detail in the IARC monograph *The Role of the Registry in Cancer Control* (IARC Scientific Publications No. 66). There is a major emphasis on population-based registration which is primarily concerned with the epidemiological and public health aspects of cancer control. The items of data recommended for registration have been kept to a minimum, with emphasis on the quality rather than the volume of information; these may be expanded, if necessary, to suit local needs. The operation of hospital-based cancer registries, which are more concerned with the care of patients, clinical research and hospital administration, is described in Chapter 13. Such registries may serve as the nucleus for the later development of population-based registration in countries where the latter is not immediately feasible.

It is hoped that the operational methods described in this volume will encourage the establishment of more cancer registries, especially in countries where the incidence and characteristics of the disease are as yet poorly described, and will help to maximize the usefulness of the data collected through the adoption of uniform methods in all aspects of cancer registration.