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Introduction

The need for data on cancer

It has been estimated that in 1985 there were 7.6 million new cancer cases in the world, 52% of which occurred in the developing countries (Parkin et al., 1993). The burden of cancer will increase very rapidly in the next few years, largely due to an increasing proportion of elderly people in most countries. In the year 2000, there will be some 10.5 million new cases, and nearly six million of these will occur in the developing world. Cancer, which has long been a major problem in the more developed countries, is now a major public health problem in all countries.

In order to undertake any programme of cancer control, it is necessary to understand the burden of cancer in a community. Cancer is not a single disease, it is a term which describes many different diseases. It is not sufficient to know the total number of cancers in a population, because patterns of occurrence vary widely between geographical areas, between ethnic groups, by socio-economic categories, by occupation and by a wide variety of cultural factors. So data on cancer have to show the distribution of the different types of cancer in a population.

Once the baseline data are established it is possible to search for the aetiological or causative agents, and establish appropriate interventions to prevent the cancers from developing. Examples of activities to prevent cancer are screening programmes, notably for cancer of the cervix (this is called secondary prevention, because it prevents cancer from developing by removing it at an early stage), and education about the ill-effects of tobacco or the benefits of healthy eating (primary prevention to stop the cancer occurring at all).

The role of the population-based cancer registry is to collect the data which will give an accurate picture of cancer in a population, in order to understand and so control the impact of cancer in that population. Analysis of the data collected will show how many cancers there are, and which types are the most frequent. This will permit studies to identify the causes of cancer, and at the same time the registry data can be used to evaluate the effect of screening programmes or other activities designed to reduce cancer incidence in the population, as well as to study the effect of early diagnosis and of treatment. The cancer registry data can also be used to plan requirements for the personnel, medical facilities and equipment needed for the diagnosis and treatment of the cancer patient.

The cancer registry

A registry is simply a place where registers or records of, for example, births, marriages and deaths are kept. There are many different types of registry or register, there are registries which record information on illnesses other than cancer, and there are several types of cancer registry.

The hospital cancer registry is concerned with cancer patients from the hospital in which it operates, or the group of hospitals for which it has responsibility. It has a primarily clinical function, and the data produced are used to assess the medical care given to the cancer patient, to improve treatment regimes, and to follow the patient to ensure that check-up visits are made regularly. The data recorded will include extensive clinical information which would not normally be collected by a population-based cancer registry, for example on diagnostic procedures and courses of therapy. The hospital registry does not distinguish between residents and non-residents in an area, but collects information on all patients in the hospital irrespective of where they come from.

The pathology registry collects all pathological or histological diagnoses made in a laboratory, and data from such registries have been used to calculate minimum incidence data for areas where no other information has been available. Again, no distinction is made between residents of the area and those who come from elsewhere. This type of registry will not have complete information, because all cases diagnosed clinically or by a technique other than pathology will not come to the attention of the registry, but the quality of the data will be very good.

The population-based cancer registry (also called a tumour registry) aims to collect information on every case of cancer occurring in a defined population. In order to accomplish this task, a clearly delimited geographical area must be decided and accurate data on the population living in this area acquired. Every effort must be made to exclude patients who do not live in the designated area from the incidence data. It is essential to cover every potential source of data for residents of the area.

The manual

This manual has been prepared to help people working in population-based cancer registries. The different chapters follow the order of the tasks which have to be performed by the registry personnel, starting, in Chapter 2, with learning how to recognise the medical vocabulary used to describe the symptoms, the diagnosis and the treatment of cancer. Chapter 3 introduces the different sources from which information may be found, concentrating on the various hospital departments where it is likely that cancer patients may have been diagnosed or treated, and presents the type of data which you should be looking for and how to record it.

Once the information has been located and collected, the data have to be put into a coded format. The items which are used to produce statistics on cancer incidence are the site and the type of cancer, and Chapter 4 gives instructions on how to code the medical diagnosis. Chapter 5 follows the steps involved in the management of the

data in the cancer registry. The quality of the data, with some indicators to show how it can be monitored, is discussed in Chapter 6. Once the data have been collected, coded and put together it is important to use all this information. Chapter 7 gives a description of how data can be analysed and presented in the form of tables and graphs. Chapter 8 stresses the need for confidentiality in the cancer registry and suggests methods of ensuring that the data are kept secure.

The manual has been designed for anybody who comes to work in a registry. You may have medical training, in which case it will not be necessary to study the section at the end entitled Medical Terminology Course. We know that many of the people working in cancer registries do not have medical training, and we hope that this section will be of help. It is designed to help you understand human physiology and the terms which you will come across in the medical records.

The emphasis throughout is on active registration. This manual is primarily designed to help people operating cancer registries in developing countries, where it is not possible to rely on routine notifications and it is necessary to go out and actively search for information on cases in the hospitals.

The format is loose-leaf, so that additional material can be added by you and so that separate chapters can be replaced and updated from time to time.

The Manual is intended as a complement to the book Cancer Registration: Principles and Methods (Jensen et al., 1991), which describes the steps involved in planning and operating a population-based registry. You should be familiar with the contents of this book, and you can also use it as a resource if you wish to have additional information on how to report the results of the registry and statistical methods.

Acknowledgements