

## **Cancer Registry and Its Different Aspects**

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### **Abstract**

*At both the national and community level, cancer registration schemes are central to research into the nature and causation of cancer, to the planning of health service resources and cancer control programmes, and to the assessment of their efficacy. Cancer registration is thus a part of the modern health information system. There are two major types of cancer registries – hospital-based registries and population-based registries. It is of paramount importance that the issue of development of cancer registry in developing countries should be taken into account. Although, the cancer registry system in Bangladesh is in infantile stage, it should be the aim of the health planner of our country to develop population-based cancer registry as early as possible. The extra difficulties and expenses involved are certainly outweighed by the enhanced validity and usefulness of the data generated.*

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### **Brief History**

The idea of using a written, catalogued registry of man's afflictions in order to understand them better dates to at least the late 16th century.<sup>1</sup> A first, unsuccessful, cancer census took place in London in 1728 and up to the beginning of this century, attempts at establishing reliable and comparable mortality or morbidity statistics were abortive and little factual knowledge was gained.<sup>2</sup> Although what constitutes a true population-based cancer registry (PBCR) could be debated, it is clear that the earliest registries that attempted to cover defined populations using multiple-source reporting were in Hamburg (established in 1927), New York (established in 1940), Connecticut (established in 1941) and Denmark (established in 1942).<sup>3</sup> Efforts to register patients with cancer began in the 18<sup>th</sup> century.<sup>2</sup> In 1930, it was suggested that all cancer cases be subject to compulsory notification.<sup>4</sup> The first well-functioning population-based cancer registries were established in Germany.<sup>5</sup> Reporting of individuals by name

allowed their follow-up and assessment of outcome. In the USA, three population-based cancer surveys were done in 1937-38, 1947-48, and 1969-71, which provided morbidity, mortality, and prevalence data. However, the fate of patients was unknown and a systematic continuous registration was preferred for studies of cancer burden ever since.<sup>6</sup> G Wagner published further facts on the history of cancer registration,<sup>7,8</sup> and the more recent evolution of the role of cancer registries is reviewed by Maxwell Parkin.<sup>3</sup> The Connecticut Tumor Registry and the Danish Cancer Registry began operation in 1935 and 1942, respectively, with the voluntary notification of cancer patients from hospitals and their attending physicians. The Danish Cancer Registry, founded in 1942, is the oldest functioning population-based cancer registry with a national coverage.<sup>9</sup> At the initiative of its founder, Johannes Clemmesen, worldwide coordination of cancer registration was recommended in 1946.<sup>10</sup> Four principles were

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established: to obtain data from patients with cancer in as many different countries as possible; to follow an agreed standard for the records for international comparability; to establish a central record of patients for every nation; and to correlate data and statistics from every country through an international body. The international coordination of these efforts was initially ensured by WHO,<sup>11</sup> the International Union Against Cancer (UICC),<sup>12</sup> and, since its establishment in 1965, the International Agency for Research on Cancer (IARC). In 1966, the International Association of Cancer Registries (IACR) was formed in Tokyo, Japan, as a professional society dedicated to fostering the aims and activities of cancer registries worldwide,<sup>13</sup> convening every year to boost international collaboration.

## Introduction

Cancer registry may be defined as an organization for the collection, storage, analysis and interpretation of data on persons with cancer. Cancer registration is the process of continuing, systemic collection of data on the characteristics of all cancers and of the persons diagnosed with cancer, and is the basic activity of a cancer registry. Cancer registration is the fundamental method in the United States by which information is systematically collected about the incidence and types of cancer, the anatomic location, the extent of disease at the time of diagnosis, the kinds of treatment received by cancer patients, and the outcomes of treatment and clinical management.<sup>14</sup> Cancer registries provide data on the occurrence of cancer in the population, and are a considerable resource for clinical and epidemiological research. The data collected is available for use by the medical staff, hospital administration and other health care providers for statistical analyses, special studies, reporting requirements and program evaluations. Cancer registration is thus part of a modern health information system. The cancer registry represents an effective and relatively economic method of providing information for the planning of cancer control measures. Cancer registration has expanded considerably: there are now more than 250 population-based cancer registries in operation in over 60 countries. As these registries mature, they are increasingly being used for a wide variety of clinical and epidemiological research.<sup>15,16</sup>

## Types of Registries

There are two major types of cancer registries: a) Hospital-based registries and b) Population-based registries.

### Hospital-based registries

There are two sub-categories under hospital-based registries: single hospital registry and collective registry. Hospital-based cancer registries maintain data on all patients diagnosed and/or treated for cancer at a particular facility. The focus of the hospital-based cancer registry is on clinical care and hospital administration. The goals of hospital-based registries include:

- i) Improvement of patient care
- ii) Professional education
- iii) Administrative information
- iv) Clinical research

### Population-based registries

Population-based registries record all new cases in a defined population (most frequently a geographical area such as a state) with an emphasis on epidemiology and public health. Population-based registries may be general (recording all tumors) or specialized (restricted to a given site-group or age-group). The goals of population-based registries are:

- i) Cancer prevention
- ii) Early detection
- iii) Determination of cancer rates and trends
- iv) Patterns of care and outcomes
- v) Research
- vi) Evaluation of control efforts

In contrast to hospital-based registries, population-based registries are designed to determine cancer patterns among various populations or sub-populations, to monitor cancer trends over time, to guide planning and evaluation of cancer control efforts, to help prioritize health resource allocations, and to advance clinical, epidemiological and health services research. In comparison to the hospital-based cancer registry, the data collected by the population-based registry serves a wider range of purposes. Advantages of a population-based cancer registry

include cancer control programmes, patient care programmes, administrative programmes and cancer research programmes. Data from population-based registries can be used for monitoring the distribution of late-diagnosed cases of cancer of the types for which early diagnosis is the strategy for control, especially, communities, ethnicities, age and other demographic groups.

### ***Planning a population-based cancer registry***

It is essential that the purposes of cancer registration be clearly defined before a registry is established: priorities for individual registries have to be decided in the context of the medical facilities already existing and of particular local needs. The population-based cancer registry must collect information on every case of cancer identified within a specified population over a given period of time. This implies that the registry will operate within a defined geographical area, be able to distinguish between residents of the area and those who have come from outside, register cases of cancer in residents treated outside the area, have sufficient information on each case to avoid registering the same case twice, and have access to an adequate number of sources within the area. The way in which a registry operates depends, inevitably, on local conditions and on the material resources available. 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 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.<sup>15</sup>

### **Sources of information for cancer registry**

Notifications of cancer may be derived from many sources, such as the treating physician, surgeon, radiologist or radiotherapist; hospital admissions and records departments, the hospital discharge report, or laboratories of pathology, cytology, haematology or biochemistry; medical records of social security systems; and coroners and vital statistics offices (death certificates). Notifications may be submitted on paper records or, increasingly, on magnetic media. In some areas, registry employees may visit the source of information to obtain notifications (**active registration**), while in others the sources of information may submit these

directly to the registry (**passive registration**). Many registries use both active and passive methods of registration.<sup>17</sup>

### **Use of cancer registry data**

The purposes for which data collected by the cancer registry are used should be clearly defined. Cancer registries are important sources of data, both for clinical purposes and for research intended to advance understanding of the causes, occurrence and outcome of cancer, and adequate evaluation of a population-based cancer screening program. Information provided by the cancer registry on the numbers of cancer patients can also help the health authorities in various ways, including long-term planning for the provision of medical facilities and the training of health care professionals, establishment of priorities and programs for cancer control, evaluation of the effects of intervention and estimation of the numbers of cancer patients in the future (projections).<sup>17</sup>

### **Confidentiality of cancer registry**

Cancer data are highly confidential. Improper disclosure of these data could result in emotional, psychological, and financial harm to patients and their families. Therefore, one of the most important responsibilities of cancer registry professionals is to protect the confidentiality of cancer patient information. A cancer registry must maintain the same standards of confidentiality in handling identifiable data as customarily apply to the doctor-patient relationship; this obligation extends indefinitely, even after the death of the patient registration.<sup>17</sup>

### **Function of cancer registry**

The cancer registry plays a central role in the systematic collection, recording and analysis of data relating to individuals with cancer. For each such person it is the function of the registry to record, as fully and as accurately as may be possible, both a clinical description of the extent of the disease and also information which will identify the patient,

the tumor, the hospital and the clinicians involved with the case. When these data are combined with additional information describing treatment and subsequent progress (routine follow-up), in which recurrences, metastases and further treatment are included, terminating with the date and cause of death (whether from cancer or not), a very full and invaluable data bank can be created.<sup>18</sup> It must be borne in mind that a cancer registry is a long-term operation: the first valid results cannot necessarily be anticipated for several years after beginning operations. By its nature, the registry will expand and require increasing material support as time goes by.

### **Importance of cancer registries<sup>19, 20</sup>**

1. Cancer registries enable public health professionals to understand and address the cancer burden and determine cancer patterns in various populations.
2. Cancer registries provide information for a national database of cancer incidence.
3. Cancer registries monitor cancer trends over time.
4. Registry data are critical for targeting programs focused on risk-related behaviors (eg, tobacco use and exposure to the sun) or on environmental risk factors (eg, radiation and chemical exposures) and set priorities for allocating health resources.
5. Such information is also essential for identifying when and where cancer screening efforts should be enhanced and for monitoring the treatment provided to cancer patients.
6. Reliable registry data are fundamental to a variety of research efforts (eg, advanced clinical, epidemiologic, and health services research), including those aimed at evaluating the effectiveness of cancer prevention, control or treatment programs.

### **Cancer registration in developing countries**

The role of the cancer registry in developing countries must not be underestimated. At first sight, it may seem that cancer registration is a luxury that ought to occupy the bottom in the priorities of the health services of a developing country, given the many competing demands upon usually slender financial resources. Yet this would be a mistaken

belief, firstly because cancer is already a significant health problem in the developing countries of the world, and one that is likely to increase in future, and secondly because the presence of an adequate information system is an essential part of any cancer control strategy. At present, half of the new cancer cases in the world occur in the developing countries.<sup>21</sup> The problems involved in collecting and analyzing cancer registry data in developing countries have been summarized by Olweny<sup>22</sup> and by WHO.<sup>23</sup>

1. Lack of basic health services
2. Lack of stability of the population
3. Identity of individuals
4. Lack of trained personnel
5. Lack of follow-up
6. Non-availability of census data
7. Lack of data-processing facilities
8. Confidentiality

### **Status of cancer registry in Bangladesh**

The National Institute of Cancer Research & Hospital (NICRH), Dhaka started cancer registry in the year 2005 for the first time in Bangladesh with technical assistance from the World Health Organization.<sup>24</sup> The process of cancer registration in Bangladesh is a very slow process and is not rich in all sorts of reliable information necessary for clinical, epidemiologic, and health services research. Cancer registries are urgently needed in developing countries like Bangladesh because the cancer burden is usually poorly known. In the past few decades, developing countries have had an increase in chronic-disease burden, including cancer. To fight this burden, the extent of the cancer must be known so that programmes for cancer control can be planned efficiently, not only to implement standards of care but also to define strategies for prevention of cancer in Bangladesh.

### **Conclusion**

Reliable registry data are fundamental to a variety of research efforts, including those aimed at evaluating the effectiveness of cancer prevention, control, or treatment programmes. Cancer registries are rich sources of population-based information on cancer incidence, management, treatment and outcomes. Population-based cancer registries (PBCRs) are a key



element and essential part for any rational cancer control program. Cancer registries are a vital source of information on cancer epidemiology and cancer services. Hence, cancer registries are a considerable resource for clinical and epidemiological research. The potential of cancer registration needs to be realized by clinicians and health authorities. By its nature, the registry will expand and require increasing material support as time goes by. 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. Cancer registration is an arduous task in developing countries like Bangladesh, owing to shortages of medical facilities and personnel. It is wise to start simply with an objective of developing a comprehensive cancer registry system in the country within a reasonable period of time. In developing countries, cancer registries have an important role to play in tackling the emerging importance of cancer burden. The importance of registration in a comprehensive cancer control programme should be stressed when putting the case for starting a registry. The setting up and management of good cancer registries in developing countries like Bangladesh is important and possible.

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