CANCER PEDIA

CORE SERVICES / INFRASTRUCTURE

HOSPITAL REGISTRY

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A. INTRODUCTION

Cancer registries are systems for collecting, storing, analyzing and interpreting data on patients who have been diagnosed with cancer.[1] Generally, registries: identify the incidence of cancer; provide information on the types of cancer and its causes in a defined group; help evaluate and inform decisions about, and funding for, cancer control programs; provide data for research; and monitor cancer rates and trends over time. Most importantly, registries provide objective data on the burden of cancer, which guides resource allocation and the prioritization of funding.

There are two main types of cancer registries:

1. ***Hospital-based registries*** include all new cancer cases seen by a particular cancer centre, hospital or group of hospitals. A cancer centre's hospital registry is an integral part of the cancer program.[2] A hospital extracts information for its registry from the health records of its cancer patients. While hospital-based cancer registries provide important information at a relatively low investment, they are influenced by several factors beyond cancer incidence trends and are, therefore, less potent than population-based cancer registries.

2. ***Population-based registries*** include all new cancer cases in a population, which is usually determined by geography (e.g., city, region, province/state, territory, country). These registries may be used to identify cancer patterns in subpopulations with certain demographic characteristics (e.g., age, gender, ethnicity, occupation, neighbourhood) or types of cancer. Population-based registries pull in information from multiple sources, including cancer centres, teaching and community hospitals, community-based specialists and pathology laboratories. Compared to hospital-based registries, population-based registries tend to be broader and may influence larger administrative, cancer research, cancer control and patient care programs. See the *Cancerpedia: Population-Based Registries and Risk Factor Surveillance* chapter for more information.

This chapter was informed by the National Institutes of Health National Cancer Institute Surveillance, Epidemiology and End Results (SEER) Training Modules Cancer Registration & Surveillance Modules.[3]

B. OVERVIEW

Hospital-based cancer registries include selected personal and medical information relating to patients who have been diagnosed with and/or treated for cancer at a cancer centre. A single hospital may collaborate with other cancer centres to establish a multi-institutional hospital-based cancer registry that includes information on patients seen at one or more of the hospitals. This type of registry enables hospitals to identify patterns of care for patients receiving services from multiple sites, track patients' course of cancer and analyze larger groups of patients.

The Commission on Cancer (2016) in the United States requires cancer centres that wish to be considered for initial accreditation to have a cancer registry database including complete data and follow-up activity. Developing a hospital-based registry requires an initial and ongoing investment of resources, which can be justified if the data collected is used effectively.[1,3]

1. BENEFITS

Patient Care and Quality Control

Hospital-based registry data can be used to plan, monitor, evaluate and improve the quality of care, management and follow-up of cancer patients. For example, clinicians can use hospital registry data to: identify the number and types of new patients and determine the volume and source of demand for services; identify the age, gender and stage at diagnosis of patients, and highlight any early detection and referral issues; identify the types of tumours and treatments required by patients and inform specialized training and procedures; examine the time intervals between diagnosis and treatment and address wait time and process-based systemic issues; evaluate the number and causes of deaths in hospital and improve clinical and palliative care; identify and compare patterns of care between centres; facilitate retrospective research studies; and identify the number of potential and actual patients in clinical trials to advance care and research.[1]

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Multi-institutional hospital registries can support consistent standards of care across care locations, improve efficiencies and promote effective care transitions. For example, hospital registry data can be used to identify the incidence of duplicate visits, medical images and laboratory and pathology tests, as well as inform follow-up care across institutions.[1]

Cancer Service Administration and Planning

Hospital-based registry data is an effective administrative and resource-planning tool for senior executives, committees, program leaders and practitioners.

Information on the number and types of cancer patients, their residence and referral sources, and clinical needs is critical to guiding important cancer centre decisions. Hospital registry information influences internal cancer centre operations, such as the size and type of cancer programs, treatments and requirements for skilled healthcare professionals, as well as hospital infrastructure requirements, such as physical facilities and treatment space. Hospital registry information may also influence operations beyond the walls of the cancer centre by informing effective and appropriate referrals and information flow to and from partner organizations and community providers, the consolidation of highly-specialized treatments into one centre (i.e., the centralization of care), and the need for additional services and resources in the community. These latter decisions should be made in collaboration with the involved organizations and potential funders.

Cancer Research

Hospital-based registries are important sources of information for cancer research into the causes, prevention, early detection, diagnosis, treatment, outcomes, and short and long-term follow-up of cancer and cancer patients. Registry data can also be used for research studies of clinical care, epidemiology, health services and health systems. Depending on the breadth of the data collected, hospital-based registries may contribute significantly to implementation science and health services research.

Healthcare Provider Education

Hospital registry information can be used to educate healthcare providers on the types of cancer patients who are seen at the cancer centre, and issues that need to be addressed. For more information, see the *Cancerpedia: Education* chapter.

Contribution to Population-Based Registries

Hospital-based cancer registries are probably the most important sources of information for population-based cancer registries. Generally, hospital-based registries collect more detailed information than population-based registries.[1] Cancer centres may be required by legislation or encouraged by government bodies to use consistent, standard definitions and incorporate population-based data for alignment between registries. In this way, the hospital-based registry may include data items that are needed by the population-based registry, but may not have direct utility for the hospital registry.[2]

2. LIMITATIONS

Hospital-based cancer registries are excellent sources of information relating to patients who have been diagnosed and/or treated at the cancer centre. Generally, hospital registry data does not reflect the complete cancer experience of patients who are also receiving care elsewhere (e.g., other clinics or hospitals, community-based physicians, hospices).

In addition, since hospital-based registries reflect the experience of one or a few facilities, the data cannot be extrapolated to identify the incidence or prevalence of cancer in the population.[1] Similarly, the data cannot be used alone to develop system-level cancer plans. Most importantly, hospital-based cancer registries are subject to inconsistent referral patterns and changes in access to cancer care facilities; for example, the introduction of additional cancer treatment facilities invariably causes major changes in the distribution of patients accessing care at individual centres.

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3. INCLUSIONS

A cancer centre abstracts information for its hospital registry from the health records of its cancer patients; therefore, the quality of hospital registry data depends on the quality of health records.[1] See the *Cancerpedia: Health Records* chapter for more information. To be of value, the data recorded in a hospital registry must be accurate, reliable, timely and as complete as possible.[4]

Each hospital registry needs a start or reference date, which is the first day that the registry collects patient information. The first step in building a hospital registry is to define what constitutes an eligible patient case. Eligibility for inclusion in a hospital-based cancer registry requires the patient to have interaction with the cancer centre, through diagnosis and/or treatment.

Generally, hospital-based cancer registries include detailed data in the following categories:

- Patient demographics, including personal information such as the patient's name, unique identification (i.e., social security number or other national identifier), age, gender, ethnicity, birthplace, residence at the time of diagnosis and current residence.
- Cancer information, including the patient's diagnostic procedures and dates, diagnostic findings, primary site of the malignancy, cell type, and extent of disease (i.e., TNM staging). Cancer information may also include the tumour size, number of nodes examined, and other information about the spread of the disease.
- Treatment information, including the details and dates of each treatment the patient receives (e.g., surgery, radiotherapy, chemotherapy, hormone therapy, immunotherapy, etc.).
- Treatment outcomes, including response to treatment, recurrence and follow-up. The patient's status must be regularly updated to ensure registry accuracy. Registries that include lifetime patient follow-up are an important record contributing to patient survival data.

As noted previously, the hospital-based registry may be asked to include data items that are useful to population-based registries, but have limited utility for the hospital registry.[2]

The cancer centre must use standard operating procedures (SOPs) to develop and maintain its registry along with a standard dataset and definitions. The suite of data and definitions may be influenced by a number of factors:

- The strategic needs of the cancer centre, and the purpose and value of the registry to the organization.
- Requirements to contribute data to population-based registries in the same jurisdiction.
- Standards set by global, national and subnational bodies. For further details and examples, refer to the *Use of Standards* section included in this chapter.

C. BEST PRACTICES

4. REGISTRY INFRASTRUCTURE

The hospital-based cancer registry service must be professionally managed by a head registrar, with both leadership and specialized cancer data management education. The head registrar is accountable for all activities related to developing and maintaining a high-quality hospital-based registry, including standards, staffing, space and equipment. In addition, the head registrar must work with the cancer centre's senior leadership, clinicians, researchers and planners to support the development of the cancer program, ensure all registry standards are met, respond to requests and provide cancer information.

The hospital-based cancer registry service also requires oversight by a steering or advisory committee, which can advise on operational issues related to data collection and requests for data. The committee should be co-chaired by clinical leadership and the head registrar of the hospital-based cancer registry. Committee members may include professional representatives from pathology, medical imaging, surgical oncology, radiotherapy, medical oncology, biostatistics, pharmacy, information technology and others, as appropriate.

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Various professionals are needed to support registry work, which includes: collecting, abstracting, coding and entering data; ensuring data quality; conducting follow-up; analyzing data; assessing data requests; developing reports; and collecting and storing data. Staffing requirements depend on the needs and size of the registry. Depending on their responsibilities, staff may need to be certified cancer or tumour registrars. Certification requirements usually include a formal accredited education program, in-house training and/or experience. Once certified, staff must meet continuing education requirements. For more information, see the National Cancer Registrars Association, and in particular the Certified Tumour Registrar.[5]

5. USE OF STANDARDS

Hospital-based registries must meet data standards as well as standards to support effective and efficient registry operations.

Various global, national and subnational bodies set standards for datasets and data definitions, collection and reporting relating to hospital-based registries. These standards address the data to include and exclude, consistent coding, updating data and rules for grouping procedures. Standardization allows cancer-related data to be compared across organizations, and pooled for research and service planning.

Standards for registry operations include policies and procedures for: collecting, abstracting, coding and entering data within standard timelines, preferably using electronic linkages; ensuring data quality and compliance with standards; conducting follow-up; addressing backlogs; meeting productivity standards; meeting technical requirements for collecting and storing data; and analyzing and reporting data.

Selected examples of standard setting organizations include the following.

- The World Health Organization and its International Classification of Diseases for Oncology[6]
- The North American Association of Central Cancer Registries[7]
- The Commission on Cancer [8,9]
- The National Cancer Institute and its Surveillance, Epidemiology, and End Results (SEER) Program[10]
- The American College of Surgeons and its Registry Manuals and Coding Guidelines[11]
- International Association of Cancer Registries (IACR), a professional society created to foster the aims and activities of cancer registries globally, promote the exchange of information between registries, and help improve data quality and comparability between registries.[12] Although the IACR is primarily for population-based registries, its members also include hospital-based registries.

6. CONFIDENTIALITY OF HEALTH INFORMATION

At all times a patient's personal health information is confidential and must be treated as such. Most jurisdictions have national and/or subnational legislation and regulations that balance the patient's right to keep their personal health information private with the need of healthcare providers and researchers to use and share this information.

Legislation or regulations identify agents that have the legal right to collect personal health information. These agents usually include organizations and professionals who deliver healthcare services. Agents must obtain direct consent before they collect, use or disclose a patient's personal health information. Consent includes explaining the information to be collected and how it will be used. Patients must consent for their data to be included in the hospital registry.

Hospital registries draw the majority, if not all, of their information from patient health records. Registries must meet the same confidentiality requirements as health records. Although the agents of hospital-based registries do not collect personal health information, they are data custodians and are also accountable for ensuring privacy for patients and the confidentiality of the information in their possession. Hospital registries usually develop additional policies to ensure data confidentiality and patient privacy.

Registry information is generally de-identified to avoid individual patients being traced; however, individual information must be included in the registry to avoid duplication across registries, ensure accurate tracking and linking of a patient's data over time, and maximize the usefulness of hospital registry data.[4] Registries should have established processes for requesting as well as evaluating requests for registry information.

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Depending on the purpose, the use of individual or aggregate data may be more appropriate. Aggregate data is typically used for patient care, quality control, administration, planning and education purposes. Individual data is typically used for research and may be used for quality control.

Registries need standard processes to avoid unauthorized access to data and to safeguard data. Such processes may include the use of encryption, passwords and access rules. See the *Cancerpedia: Equipment and Technology* chapter for more information.

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