Central Cancer Registries
Design, Management, and Use

Edited by
Herman Menck Charles Smart, MD
Commission on Cancer
American College of Surgeons
Chicago, Illinois

“Every profession has a ‘bible’ which documents basic, key concepts central to the profession. This book could be the bible for Central Cancer Registries. I would recommend it as the basic text for central or regional Cancer Registry staffs.”

Robin D. Otto, RRA, CTR
Pennsylvania Department of Health
Pennsylvania Cancer Registry

Central Cancer Registries are organizations which collect, store, analyze, and interpret data on persons with cancer within a defined population or area, usually covering a hospital or group of hospitals. Central Cancer Registries examines the planning, operations, output, and uses of these organizations. The data collected by the cancer of different types of cancer treatment; evaluate effects of early detection programs; help assess the need for new equipment; identify geographic locations where incidence of cancer is usually high; identify low- and high-risk population groups; contribute to epidemiologic studies to help pinpoint the causes of cancer; and compute long-term survival rates. It is hoped that this data will eventually provide enough information to prevent the further spread of cancer and perhaps even prevent new cases.

The contributors discuss the calculation of incidence rates; preparation and interpretation of survival rates; and descriptive data on age, race, social class, and other demographic variables. Information on case reports, national standards, and recommendations on the selection of computer hardware and software is included. Staffing, personnel training, cost control, confidentiality of records, and other practical topics are addressed.

About the editors
Herman R. Menck, MBA, serves as manager of clinical information for the National Cancer Data Base, a joint project of the Commission on Cancer of the American College of Surgeon, and the American Cancer Society. Charles R. Smart, MD, is retired chief of the Early Detection Branch of the National Cancer Institute’s Division of Cancer Prevention and Control, and past director of the Commission on Cancer. Both editors have directed population-based registries; and have been active in the management, computerization, and analysis of Cancer Registry data, and in numerous local, state, and national Cancer Registry professional associations.

ISBN 3-7186-0587-2(softcover)
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Preface

Cancer registration is an important and fundamental tool in cancer control. A cancer registry has been defined as an organization for the collection, storage, analysis, and interpretation of data on persons with cancer, usually covering a hospital or group of hospitals. A population-based cancer registry collects the data from many hospitals in a defined geographic area and can serve to show incidence trends for cancer of different sites over time or between population subdivisions. It can provide data to assess the effects of different types of treatment over time and to evaluate the effects of early detection programs, such as mammography or colorectal screening.

Cancer registry data can be used for epidemiologic studies to pinpoint causes of cancer. It can be helpful in identifying unusual clusters of cancer cases. Data from cancer registries can be helpful in assessing the need for new hospital construction, new equipment, and to pinpoint locations of facilities for patient care.

Cancer registries depend on the cooperation of physicians and hospital personnel to supply data on cancer patients. The registry reciprocates by providing physicians and hospitals with background information useful for patient follow-up and listing of cases by site or selected patient characteristics.

Cancer registration in the United States goes back more than fifty years. Physicians have realized for some time that carefully controlled records of cancer patients in their hospitals were important in evaluating the type of treatment and care that patients received and for computing long-term survival rates. In 1935 the Connecticut State Health Department started the first statewide cancer registry, combining the data from hospitals throughout the state. Later, the American Cancer Society helped start cancer registries in a number of states, and subsequently the American College of Surgeons became involved in giving assistance to hospital registries throughout the country. A history of the growth of cancer registration in the United States is given in the Appendix.

By providing useful background data on issues involved in operating a central cancer registry, this book is intended as a practical resource for those interested in starting such a registry and to help existing registries with operating problems.
The first three chapters deal with goals and objectives of central cancer registries: the kinds of information that a central registry can produce and how these can be used. It is important to plan and design the operations of a registry carefully to achieve these objectives; this includes the cooperation of doctors, hospitals, and state agencies. There is a need to explain the types of services the central registry can provide to hospitals and physicians. The data to be collected should be carefully planned and defined. Chapter 3 discusses the current national standards for data sets.

The next three chapters deal with practical considerations involved in case-finding. Chapter 4 covers sources of case reports, and how to work with doctors and hospitals in locating cancer cases diagnosed and/or treated in and out of state. Selection of computer hardware and software is an important component. Data and file management and output programs are discussed. Staffing a registry is an important budgetary consideration and helpful tips for selection of professional, administrative, and technical staff as well as compensation guidelines, are given in chapter 6.

An important aspect of any registry is quality control. The chapter on quality control discusses training of personnel and how to assure the highest quality of data information in the registry.

An essential part of a registry operation is follow-up. This chapter discusses the limits of active versus passive follow-up, costs, standards of follow-up completeness, and other practical tips on follow-up methods.

The chapters on output and uses of a central cancer registry include sources of population data; calculation of incidence rates; and preparation and interpretation of survival rates. They also describe how to develop hypotheses from descriptive data on age, race, social class, and other demographic variables, plus other factors such as occupations, histology, and time trends. The differences between case-control studies and cohort studies based on registry data are described. One of the uses of a central registry is to identify and analyze purported cancer clusters.

The final chapter is devoted to prevention and control applications. A central cancer registry can be very useful in studying the patterns of care related to stage and treatment for individual sites and the costs of cancer care. Data prepared and summarized by the central registry on these topics can help physicians and hospital administrators in reviewing and evaluating their case loads. Also covered in this book are matters related to confidentiality of records and legal issues involved in the maintenance of the confidential nature of data in the files of a central cancer registry.

Lawrence Garfinkel
William Haenszel
Types of Registries: Goals and Objectives

DONALD F. AUSTIN

Cancer registries have over half a century of well established history in the U.S.\textsuperscript{1} There are several types which have different modes of operation and are oriented toward meeting different goals. Some registries have been designed \textit{a priori} to accomplish specific goals. Other registries have started out in a particular setting with defined characteristics and have evolved over time toward different operations and goals influenced by changing events.

This chapter describes and categorizes types of registries with regard to their source of cases, organizational setting, data set components, mode of operation and goals, as well as their geographic area of data collection.

HOSPITAL-BASED REGISTRIES

Hospital-based registries, those who report their cases on the basis of care at a particular hospital, have as their primary goal the improvement of patient care. In addition they may also be used for research, typically clinically oriented, or case series studies with the registry caseload serving as the source of clinical material. Other uses include various administrative functions, such as patient demographics or facility utilization.

Normally, all patients receiving part or all of their definitive care in the institution are accessioned. Accordingly, recorded cases are newly diagnosed and not previously treated.

Each element of a registry should be planned and implemented based on a clear understanding of the intended goals and objectives.

Three organizational structures can be differentiated: single-institution, multiple/joint institution, and national. There are approximately 2000 hospi-
tchal registries in the U.S., a few of which are joint, and one national hospital-based registry.

The data set is typically rather inclusive. The patient care oriented goal dictates the type of data gathered and the patients on whom the data are collected. Data items are typically of the following types: patient identification and characterization, basis of diagnosis, tumor identification including factors effecting prognosis, treatment rendered, and outcome.

The design of these data sets, which is discussed in Chapter 3, has been influenced by publications of the Commission on Cancer of the American College of Surgeons and the Surveillance, Epidemiology, and End Results (SEER) Program and its predecessors. These data elements can be referred to in short form as patient identification (ID), and cancer ID, treatment, and outcome.

Hospitals tend to use their registries like a medical audit data system. For an effect on patient care to result from the registry, several associated activities must occur in the institution. First, standards or desired outcomes must be identified by medical staff. Second, data must be collected and summarized to address the desired outcomes. Third, an administrative review must be conducted, and undesirable or unacceptable outcomes identified. Lastly, there must be an intervention effort in the institution. Usually this is in the form of professional education or some hospital administrative procedure.

Usually, if a hospital-based registry is related to a population-based registry, the latter supports and facilitates the hospital’s efforts, which are the source of its data, with standardized analyses and reports. The population-based registry serves as a pooled data source against which institutions can compare their individual experience.

Patient care-oriented hospital-based registries are the historical model for cancer registries in the U.S., setting precedent for the program rationale, the activities of the registry, and the data items included. The strength and general familiarity of this type of registry has sometimes created difficulties when non-hospital agencies attempt to establish a registry program for non-hospital purposes.

Many clinical consultants are most familiar with hospital-based registries so that agencies and institutions needing expert advice either for technical or constituency reasons are likely to be guided to establish the new registry in this traditional mold. However, a few agencies have managed to create registry designs to meet other goals and, when funded, they have been quite successful in meeting their goals.

Multi-institution registries sometimes do not participate in patient care evaluations but, because of their pooled data, often try to meet a secondary goal of establishing the natural history of the disease or, rather, the prognosis
### GOALS AND OBJECTIVES

**TABLE 1–1**

Types of Cancer Registries

<table>
<thead>
<tr>
<th>Hospital-based</th>
<th>Population-based</th>
<th>Other/Multi-Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Organizational Setting:</td>
<td>B. Data Set:</td>
<td>A. Organizational Setting:</td>
</tr>
<tr>
<td>Single-institution</td>
<td>Patient ID</td>
<td>Government Adm. Agency</td>
</tr>
<tr>
<td>Multi-institution</td>
<td>Cancer ID</td>
<td>Research Institution</td>
</tr>
<tr>
<td>Data Services Supplier</td>
<td>Treatment</td>
<td>Health Care Organization</td>
</tr>
<tr>
<td>Military/Other Government</td>
<td>Outcome</td>
<td>Cancer Control Agency</td>
</tr>
<tr>
<td>Health Care Organization</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

C. Goals:

- Improvement of patient care
- Professional education
- Administrative information
- Clinical research

<table>
<thead>
<tr>
<th>A. Organizational Setting:</th>
<th>B. Data Set:</th>
<th>C. Goals:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government/Adm. Agency</td>
<td>Patient ID</td>
<td>Prevention</td>
</tr>
<tr>
<td>Research Institution</td>
<td>Cancer ID</td>
<td>Early detection</td>
</tr>
<tr>
<td>Health Care Organization</td>
<td>Stage</td>
<td>Cancer rates and trends</td>
</tr>
<tr>
<td>Cancer Control Agency</td>
<td>Treatment</td>
<td>Patterns of care, outcome</td>
</tr>
</tbody>
</table>

C. Goals:

- Cancer rates and trends
- Incidence-related research

- Prevention
- Early detection
- Cancer rates and trends
- Patterns of care, outcome
- Research
- Evaluation of control efforts

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given the community standard of care of the collective institutions for as many disease and population subcategories as possible. This is useful, so that hospitals may compare their institutional experience and clinicians may provide individual prognoses. These registries are well served by the hospital
registry model, since they aggregate hospital registry data and are oriented towards meeting the same goal.

Several data system and services suppliers pool the data of their client institutions into a single file which can then be used for comparative purposes. These databases are defined by the regional dispersion of the particular clients. Some of these include in excess of 500,000 historical case reports.

Some registries operate as a central repository for hospitals from one or more of the military services, or the Veterans Administration. An example of one of these military central registries is ACTUR. Hospital-based data are collected on a national level by the National Cancer Data Base (NCDB) Program. A recent year of data, 1991, included a convenience sample of approximately 46 percent of U.S. incident cancer cases.

**POPULATION-BASED REGISTRIES**

Population-based registries report all cases diagnosed in a specifically defined population-at-risk (e.g., the state of Illinois). Conceptually, there are two types of population-based registries which have in common the need to attempt to register all cases of cancer occurring in a defined population, usually a geopolitical entity such as a county or state. The two types may be further categorized by their primary goals which in turn dictate the data gathered and the procedures used. In practice, many also try to meet secondary goals.

**Incidence Only**

This type is usually operated by a government health agency and has, as its primary goal, determination of cancer rates and their trends in the population. Optimal requirements include: an accurate and complete case count; reasonable reporting timeliness, generally twelve to twenty-four months after the close of the calendar year; quality control, i.e., standardized casefinding, casefinding quality control, and case data accuracy quality control; and data necessary to categorize patients and tumors by those categories for which rates are computed.

There is generally no need for treatment data or outcome data, unless some routine analytic evaluation is conducted for trends in incidence, clinical data characterizing diagnostic procedures, or the stage of cancer at diagnosis.
GOALS AND OBJECTIVES

Generally the desire for an incidence-only registry stems from a perceived need by a health agency to have incidence and trend data directly applicable to its health jurisdiction, for placing cancer morbidity in perspective with regard to all health problems, and to use the information in setting resource allocations.

Death certificate data are sometimes considered satisfactory for meeting these objectives, even though morbidity is poorly represented by cancer mortality data. It is not unusual for a health agency to elect incidence-only reporting, when faced with the cost of obtaining follow-up data, with political resistance to collecting detailed treatment and diagnostic procedure data, and with the operational barriers to collecting complete and timely data.

Recognizing the advantage of collecting only those data required to meet the administrative goals of a state health department, Bender, et al., designed a pathologist-based cancer reporting system for implementation in Minnesota. The operating cost of this proposed registry was projected to be about a third of the cost of a traditional registry following hospital oriented methodology, and upon publication of a successful feasibility stage the registry secured funding for the operational stage. This registry collects only fifteen items on a routine basis, with all other data collected on an ad hoc basis for special projects or studies.

In recent years it has become common for government health agencies to evaluate cancer clusters and suspected cancer problems related to possible environmental contamination. To meet this extra requirement, case reporting must be more timely, i.e., three to nine months after diagnosis instead of the twelve to twenty-four months which is common among central registries.

Other/Multi-Purpose

These other population-based registries serve a broader function, often combining incidence, patient care, and end results reporting with various other research and cancer control activities. Their data set is often the same as that of their reporting hospitals, including treatment and outcome as well as incidence-only information.

Two subtypes of the multi-purpose population-based registry are familiar, sometimes referred to by their primary function: research or control.

The research-oriented registry is usually operated by a university. Such a registry typically serves the research needs of the institution, usually epidemiologic research focused on etiology. Research requirements often include rapid case ascertainment, so that patients can be contacted as soon as possible after diagnosis.
The primary objective of a registry to support epidemiologic research is to get the notification of eligible study subjects to the study manager as quickly as possible. Therefore, the case ascertainment must be as soon as possible after diagnosis and usually dictates a pathology-report based system, rather than a medical record-based system. Thus, cases not histologically diagnosed are typically excluded. This is not usually a serious handicap for research projects since cases not histologically diagnosed are frequently considered undesirable for the study.

For many research questions, there should be no selection bias in casefinding or demographic and tumor classification. Incomplete casefinding is undesirable because it compromises the generalizability of results. However, research registries can often tolerate five to ten percent under-reporting. Finally, there must be such tumor and demographic data as are necessary to effectively identify cases eligible for specific research projects.

Other research data, in addition to pathology data, are usually collected on a project-specific basis by an ad hoc mechanism of chart review, interview, or some other special procedure.

In its first fifteen years of operation, the Cancer Surveillance Program of Los Angeles County was a prime example of a rapid case ascertainment registry. It supported etiologic research in a population growing from 7 million in 1974 to 8.5 million in 1988. Late in the 1980's the Cancer Surveillance of Los Angeles County became incorporated into the California Regional Registry system, which required the registry to expand its data set and data collection procedures, while still maintaining a rapid reporting capability.

Conversely, a cancer control type of registry is operated primarily to support the targeting and evaluation of control programs. The registry may be limited to specific types of cancer for which specific intervention strategies are available.

Generally there is no need for tumor or demographic classifications any more detailed than would be the basis for an intervention strategy, or would be the basis of an evaluation of an intervention effect.

Outcome measures, and in particular intermediate outcome measures, are very desirable. Therefore, stage at diagnosis is desirable. Measures of those risk factors known to influence the risk of disease and which may be intervention targets may also be collected, provided measures of the risk factors are also available in the population.

Many registries are, in effect, combinations, attempting to be several types, but one usually predominates because of the mission of the funding source. The California Regional Reporting System is a combined type, designed to meet administrative, cancer control, and research requirements while facilitating patient care uses.
<table>
<thead>
<tr>
<th>Data Item Requirements</th>
<th>Patient Care</th>
<th>Incidence Only</th>
<th>Cancer Control</th>
<th>Epidemiologic Research</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Information</strong></td>
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<tr>
<td>Identifying</td>
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<td>+</td>
<td>+</td>
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<tr>
<td>Demographic</td>
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<td>+</td>
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<tr>
<td>Social</td>
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<td>+</td>
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<tr>
<td><strong>Tumor Characteristics</strong></td>
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<td>Grade</td>
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<td>Stage</td>
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<tr>
<td><strong>Diagnostic Procedures</strong></td>
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<td>Treatement Type</td>
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<td><strong>Outcome</strong></td>
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<td>Tumor Status</td>
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<tr>
<td>Functional Status</td>
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<th>Epidemiologic Research</th>
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<td>Timeliness*</td>
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<tr>
<td>Rapid Ascertainment*</td>
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<tr>
<td>Screening Procedures</td>
<td>1</td>
<td>2</td>
<td>+</td>
<td>1</td>
</tr>
</tbody>
</table>

+ Usual requirement
1 Varies
2 May be an ad hoc requirement
* Timeliness refers to the promptness with which case reporting for an incidence year is considered complete; Rapid Ascertainment refers to how soon after diagnosis individual cases are reported.

Table 1-2 provides a summary of the types of data and the operating requirements for different types of registries. Patient information can be categorized into three types:
Identifying: e.g., name, date of birth, Social Security number, address

Demographic; e.g., age, race, sex

Social; e.g., marital status, religion, occupation

It should be emphasized that since most registry types require identifying data on each patient, they may serve as a basis for linking to another file, such as an industrial cohort or an insured group, to study disease incidence or distribution in the cohort.

Several other comments regarding registry classification and terminology are worthy of note. As described above, registries, whether hospital- or population-based, can be thought of as local, regional (city/county/state), central, or national. In most common usage, local (hospital) registries report to regional registries, and regional registries, if they report to anyone, report to central registries which may or may not be national. Some ambiguity exists in usage of the descriptors regional vs. central, and central vs. national. Sometimes they are used as synonyms, sometimes not.

Several examples follow regarding the suggested use of regional vs. central descriptors. In California, the state is split into regions which collect data from local hospitals, and in turn, report to the state registry. Thus each local hospital reports to their respective regional registry which in turn reports to a central registry, the state. The SEER Program has eleven regional registries, defined variously by state, county and other boundaries, which report to SEER which could then be described as a central registry, operating at the national level.8

The term regional, connoting geography, is only appropriate for population-based registries. In the case of the NCDB, some hospitals (local) report directly to the NCDB, which is a central registry, and some report to the NCDB through their vendor, which in this case can also be classified as a central registry.

IDENTIFYING THE GOALS OF A REGISTRY

Hospital-based

Most hospital registries plan their initial operations based on the patient care model of the Commission on Cancer, and on the assumption that the cancer program will be included in the hospital budget. The suggested goals, resources, and other characteristics of such programs are well described.9

Often a prominent clinician at the hospital seeks to interest other clinicians and, ultimately, administrators in a hospital cancer program including estab-
lishment of a cancer committee, cancer conferences, patient care evaluations, and a cancer registry. The Commission has 2200 hospital liaison physicians, many of whom initiated or succeeded the initiator of the cancer program and registry at their hospital.

Some medical centers have defined their own cancer registry data set and mode of operation. One notable example, the Centralized Cancer Patient Data System (CCPDS) including central registry aspects, was a data system planned for the U.S. Comprehensive Cancer Centers.¹⁰

Population-Based

Often the impetus for initiating a population-based cancer registry starts from a well publicized local problem, such as a report of a cancer cluster or of possible environmental exposure. Other beginnings trace to research or clinical groups seeking to establish specific programs.

Usually there is some potential funding source that the early leaders envision. In general, the early thoughts about possible funding sources coincide with the primary mission. Many state registries are funded by the state legislature based on the legislators’ perception that the public is concerned about what impact cancer is having on their families, i.e., the nature of cancer etiology, its frequency, and prognosis.

Because a population-based registry is necessarily exclusive for that community or state, a certain level of cooperation among the potential major players, often including public health officials, prominent medical centers, and interested universities, is required. Usually organizational meetings are held in which the proposed host/lead institution and registry director are identified, and the cooperation of the others is solicited. The lead organization may provide some monies, professional services and/or leadership as a part of its commitment, in return for its selection as the host. At some point the necessary critical mass for program definition and funding solicitation is achieved.

At these planning meetings, in addition to the interests of the lead organization, the desires and needs of the other interested parties usually surface and must be carefully considered. Since the registry is, in effect, a local monopoly, a consensus must be reached. The number of functions and interests a central registry serves directly affects the mode of operation and costs. A registry that meets a wide range of administrative, research, and control objectives is more difficult to organize and costs more. A careful balance must be reached between what is desired by all parties, and what can be funded in a continuing fashion.
Considerations include whether this central registry will be incidence only, a less expensive goal often associated with non-hospital interests, whether it will meet hospital clinical needs, including follow-up, or whether it will attempt to be funded for both. If the central registry does not satisfy hospital interests, how will hospital participation with its attendant costs be achieved?

In these early stages of the discussion of the registry goals, the cheapest approaches to meeting various needs can be considered, and the loss in utility weighed against the cost savings. For example, can a regulation be passed requiring hospital participation? How can the cheapest computerization be achieved? What geographic area can be reasonably covered? Can minimized case ascertainment be rationalized? Will a minimum data set suffice? Can passive follow-up be used?

Often, fact finding trips to other central registries or registry meetings are helpful. However, once the goals are established they should be carefully defined in writing and agreed upon, because they are the linchpin of the early proposal effort as well as the focus of the continuing registry operations.

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GOALS AND OBJECTIVES

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STUDY QUESTIONS

1–1. What are the two main types of cancer registries? How do they differ?
1–2. What is the relationship between the objectives of a cancer registry and its data set?
1–3. What are the main purposes of cancer registries?