

Cancer Surveillance in the United States

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There is no single national cancer surveillance system in the United States that collects data on all cases diagnosed each year. Distinct segments of the U.S. population are covered by separate programs sponsored by government or private organizations, and these programs provide reliable data to their varying audiences. All the programs are built on a foundation of cancer registries that exist or are being established throughout the country to record and report on cases in their service areas. Significant steps are being taken to move toward the use of a uniform data set, and reconcile differences in data collection, analysis, and reporting in order to facilitate compilation for collaborative use. The National Coordinating Council for Cancer Surveillance (NCCCS) was organized in 1995 to encourage such an allied public/private endeavor.

THE ROLE OF CANCER SURVEILLANCE IN CANCER CONTROL

High quality surveillance can delineate variations in disease incidence, mortality, and survival rates among populations or geographic regions and alert us to areas in need of increased attention and research. This, in turn, influences the efforts of clinicians, public health officials, community groups and others to implement successful interventions, to improve treatment protocols, or to adopt changes in public policy. Careful observation and analysis of data such as cancer incidence rates, staging, and five-year survival help to evaluate the impact of advances made in treatment and diagnosis, increased application of cancer control efforts, improved access to screening and treatment, or changes in risk exposure for population groups in areas covered by cancer registries. The monitoring of cancer outcomes can provide an indication of quality of care for hospitals and other health care delivery systems. Indeed, information collected by cancer registries on survival and other outcome measures has become a necessary part of accreditation for these institutions.

SCOPE OF THE CANCER REGISTRATION EFFORT

Collection of cancer data in the United States has developed under several systems of registries, and the data collected vary according to the purposes served. Generally, they include *hospital registries*, which may be part of a facility's cancer program, and *population-based registries*, which are usually associated with state health departments or the institutions to which they delegate authority. Hospital registries provide complex data for the evaluation of care within the hospital, and they are the primary source of data for state registries. Population-based registries record and consolidate information regarding all cases diagnosed within a specific geographic area, providing data that can determine rates across regions of the country.

Cancer registration is primarily performed by cancer registrars, who serve as medical "detectives" in tracking down and locating the wide variety of cancer data that is required to be collected. Whatever the venue, registries function best when staffed by cancer registrars who have met stringent standards of training, testing, and continuing education--the highest level being Certified Tumor Registrar (CTR).^{1 2}

National Cancer Data Base

Established in 1989, the National Cancer Data Base (NCDB) is a program of hospital and selected ambulatory care registries of the Commission on Cancer (COC), administered by the American College of Surgeons (AcoS), and co-sponsored by the American Cancer Society (ACS), for the purpose of ensuring

quality cancer care by providing data for evaluation of patient management within hospitals and other treatment centers and for comparisons between institutions or regions of the country. Approximately 1,500 cancer treatment centers in the United States contribute to the NCDB. The *NCDB Annual Review of Patient Care* provides nationwide data on trends and patterns of care for specific cancer sites. In addition, NCDB analysts prepare many special reports to aid ACS area divisions and educators in pinpointing locations where increased cancer control efforts may be needed. University researchers are also able to use the analytic file for specific studies of interest. In addition, subcommittees of specialists design and monitor patient care evaluation (PCE) studies to provide timely information on patterns of care related to geographic, socioeconomic and clinical factors.

Surveillance, Epidemiology, and End Results Program

The Surveillance, Epidemiology, and End Results (SEER) Program is a population-based system of registries of the NCI and an outgrowth of the National Cancer Act of 1971, which included a mandate to collect, analyze, and disseminate data that would aid in the prevention, treatment, and diagnosis of cancer. SEER was established to provide continuous coverage in certain regions of the United States with authorizing legislation in place for central data collection. These data, along with data on cancer-related deaths from the National Center for Health Statistics (NCHS), are analyzed to provide incidence, mortality, and survival rates and are published annually in the *SEER Cancer Statistics Review*, which is available on the Internet. Currently covering 14 percent of the U.S. population, SEER is being expanded. Uses of SEER data include research on cancer trends and their relationship to cancer control efforts such as screening programs or passage of tobacco-related legislation, identification of populations at risk for higher rates of cancer, comparisons of cancer incidence, mortality, and risk factors in specific geographic areas, and studies of patterns of cancer care.

National Program of Cancer Registries

The National Program of Cancer Registries (NPCR) of the Centers for Disease Control and Prevention (CDC) supports population-based registries in state health departments. It was authorized by the Cancer Registries Amendment Act in 1992, in response to the observation that, although many states had established registries, only the SEER states and California covered 95 percent or more of their respective populations. Ten states had no central registry at all in 1990.³ Uses of state registry data will include health planning and resource allocation, evaluation of cancer control programs, identification of populations at risk, and comparisons of cancer incidence across specific geographic areas. The state registries also will serve as population-based sampling frames for epidemiologic and clinical research.

Role of the American Cancer Society

As a nation-wide community-based, voluntary health organization, the ACS has a highly visible role in disseminating and interpreting cancer data. The ACS uses data collected by other NCCCS members to measure progress in cancer control for the public, the scientific and public health community, the media, and ACS volunteers. For more than 30 years, the ACS has forecast estimates of the number of new cancer cases and deaths expected to occur in the United States during the upcoming year, based on SEER incidence data, NCHS mortality data, and population statistics. The ACS annually summarizes risk factor information, including but not limited to smoking, the use of cancer screening tests, dietary intake, alcohol consumption, obesity, and physical activity.

REGISTRARS AND REGISTRY OVERSIGHT

The registrar must seek out the sources of patient information, abstract and integrate the data into a comprehensive and useful format, resolve discrepancies and conflicting information, and protect patient confidentiality while reporting data to the regular users--whether a hospital tumor board, the state registry,

the national registry programs, the Joint Commission on Accreditation of Healthcare Organizations, or the ACS. Several organizations assist registrars and the institutions supporting registries as they work to meet standards for completeness, timeliness, and quality of data. The SEER Program's focus on quality is widely recognized and the ACoS has a long history of registry oversight. Organized in 1974, the National Cancer Registrars Association (NCRA) is the primary organization representing cancer registrars and providing educational standards for the profession. The North American Association of Central Cancer Registries (NAACCR) was established in 1987 to assist registries in achieving high standards of completeness, timeliness, and quality of the data assembled and reported. NAACCR now plays a leadership role as the umbrella organization that provides a process for setting standards and working toward compatibility of methods, working with government agencies, professional associations, private organizations, and cancer registrars in a collaborative arrangement that currently includes most of the central registries in the United States and Canada.

REFERENCES

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