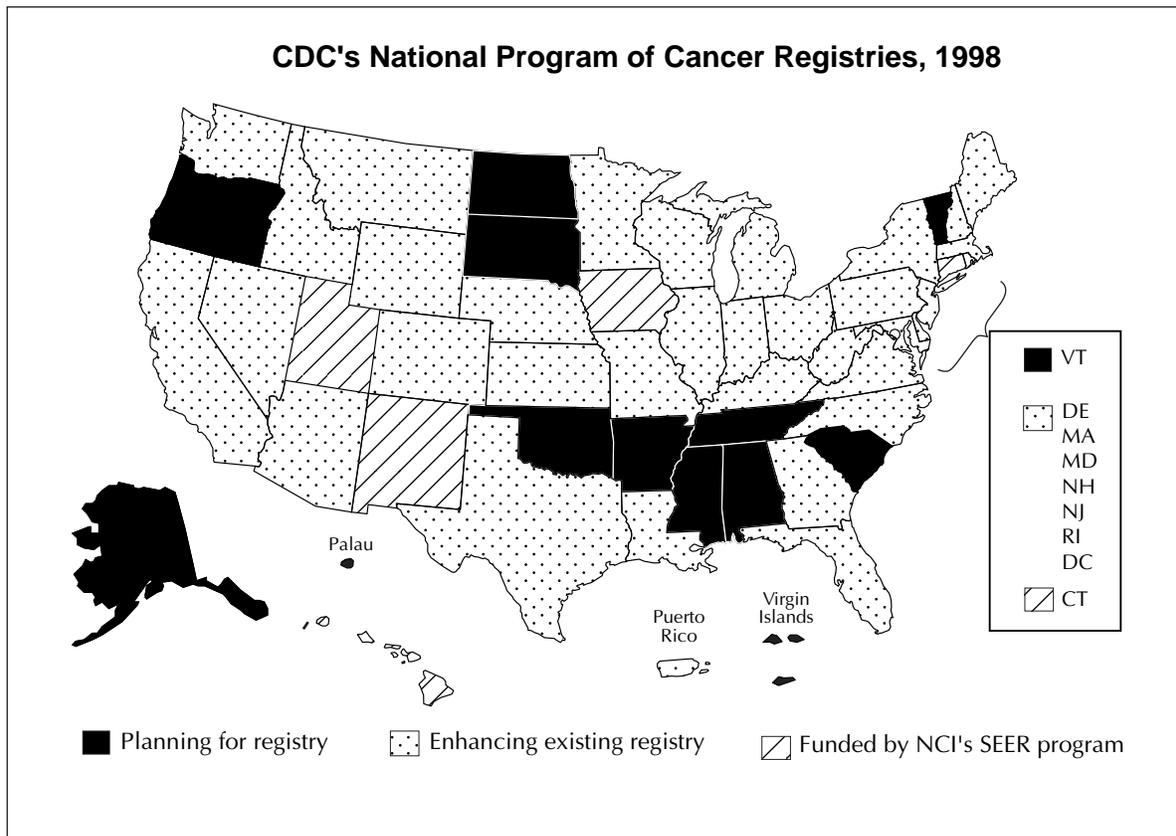


Cancer Registries: The Foundation for Comprehensive Cancer Control

AT-A-GLANCE
1999



*"A network of cancer registries can be our most potent
new weapon against the disease."*

John Healey, MD
Memorial Sloan-Kettering Cancer Center



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Disease Control and Prevention



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The Burden of Cancer

Cancer is the second leading cause of death for Americans. One of every four deaths is from this disease. In 1999, an estimated 563,100 Americans will die of cancer—more than 1,500 people a day.

The American Cancer Society estimates that 8 million Americans have a history of cancer. In 1999, about 1.22 million new cancer cases will be diagnosed. This estimate does not include carcinoma in situ or the approximately 1 million cases of basal and squamous cell skin cancer to be diagnosed this year. Cancer costs this nation an estimated \$107 billion annually, including health care expenditures and lost productivity from illness and death.

Effective prevention measures exist to substantially reduce the number of new cancer cases each year and to prevent many cancer deaths. Reducing the nation's cancer burden means reducing the prevalence of behavioral and environmental factors that increase cancer risk and ensuring that screening services are available and accessible for the detection of cancer in its early stages, when treatment is most effective.

Cancer Surveillance: An Essential National Strategy

Cancer surveillance serves as the foundation for a national, comprehensive strategy to reduce illness and death from cancer. Such surveillance is the indispensable tool that enables public health professionals at the national, state, and local levels to better understand and tackle the cancer burden. Information derived through surveillance is critical for directing effective cancer prevention and control

programs focused on preventing risk behaviors for cancer, such as tobacco use and poor diet, as well as reducing environmental risk factors. Such information is also essential in identifying when and where cancer screening efforts should be enhanced.

Cancer surveillance, conducted through state-based registries, is designed to

- Determine cancer patterns among various populations.
- Monitor cancer trends over time.
- Guide planning and evaluation of cancer control programs (e.g., determine whether screening and other prevention measures are making a difference).
- Help prioritize health resource allocations.
- Advance clinical, epidemiologic, and health services research.
- Serve as the basis for an aggregated and centralized database of cancer incidence in the United States.

Despite the critical role registries can play in helping direct cancer prevention efforts, 10 states had no registry at the beginning of this decade. The remaining 40 states had registries operating at some level, but many lacked the financial support and personnel to gather complete, timely, and accurate data on their population and to ensure that the data collected met minimum standards of quality. Only 8 states had authorizing legislation and enabling regulations in place for their registry's operation, further hindering their ability to collect important information.

CDC's National Program of Cancer Registries

CDC's National Leadership

Responding to the needs of the states, Congress established the National Program of Cancer Registries (NPCR) in 1992. Administered by CDC, this program supports states and territories to

- Improve existing cancer registries.
- Plan and implement registries where they do not exist.
- Meet standards for data completeness, timeliness, and quality.
- Develop model legislation and regulations to enhance the viability of registry operations.

- Train registry personnel.
- Establish a computerized reporting and data-processing system.

“The unique role of the central cancer registry is to be the eyes through which cancer control problems can be seen.”

—Thomas C. Tucker, Kentucky Cancer Program

With fiscal year 1998 funding, CDC supported 45 states, 3 territories, and the District of Columbia for cancer registries. Thirty-six states received funding to enhance established registries, and 13 states and territories were supported to develop plans for registries where none had existed previously. Currently, 45 NPCR states and the District of Columbia have authorizing legislation, and 39 states have established all of the regulations specified in the Cancer Registries Amendment Act (Public Law 102-515) on the use of registry information for cancer prevention and control.

With fiscal year 1999 appropriations of approximately \$24 million, CDC will continue to enhance existing state cancer registries and move planning states toward more thorough data collection activities. The ultimate goal is for all states to establish registries and move beyond the enhancement level to comprehensive, quality registries that meet critical cancer information needs.

How States Have Used Information From Registries

The NPCR enables reporting of cancer data by age, sex, ethnicity, and geographic region—within a state, between states, and between regions. Comprehensive, timely, and accurate data about cancer incidence, stage at diagnosis, first course of treatment, and deaths provide useful feedback for evaluating progress toward cancer prevention and control. Special emphasis is placed on obtaining cancer information on residents who travel to other states for diagnosis or treatment.

States have used registry data in a variety of ways and have disseminated information through more than 240 published articles. Examples of how states are applying registry data include the following:

 **Illinois** has used registry data to monitor progress and guide program activities for the early detection of breast and cervical cancer. For example, cancer registry data suggested that black women aged 40–74 years and white women aged 65–74 years should be targeted for breast cancer screening interventions. Illinois has also projected cancer incidence for specific geographic regions within the state. Local health care agencies find this information a valuable resource for program planning, development, and evaluation activities.

 The **California** Cancer Registry routinely reports cancer rates for Asian and Pacific Islanders and for Hispanics. These rates can then be compared with the more readily available rates for whites and blacks. The registry's most recent report suggested that the state's tobacco control program may have helped decrease incidence rates for lung cancer among women in racial and ethnic minority populations.

 **Kentucky** has used cancer registry data to identify districts with high rates of invasive cervical cancer. In poorer Appalachian areas, death rates for cervical cancer were double the national rate. Through community outreach programs, Kentucky officials have targeted more Pap test screening services to these areas.

 The **Louisiana** Tumor Registry is comparing occupation as reported from the medical record with that from the death certificate. Collecting this information helps registry personnel identify occupational exposures that may increase cancer risk.

 In **New Jersey**, an investigation in Dover Township (Toms River) is studying a higher-than-expected incidence of cancer among children. Surveillance information is an essential tool in this investigation.

CDC's Assistance to States

In providing national leadership and support for the NPCR, the CDC

- Assists states and national organizations in applying cancer surveillance data to describe state and national disease burden, to evaluate cancer control activities, and to identify populations at high risk for certain cancers.
- Provides on-site technical assistance to registry personnel to help ensure completeness, timeliness, and quality of data.
- Coordinates and convenes meetings of registry personnel for information sharing, problem solving, and training.
- Collaborates with federal, state, and private organizations to design, conduct, and analyze surveillance research.

Taking Advantage of New Technology

CDC supports funded states to collect statewide data and to electronically transmit data to the central registry. Information is gathered from hospitals, physicians' offices, therapeutic radiation facilities, free-standing surgical centers, and pathology laboratories.

To facilitate data transmission and improve data quality, CDC has developed software, including EDITS, a program that standardizes methods for identifying errors and inconsistencies in cancer registry data. Computerized reporting from hospitals will improve data quality and timeliness by applying standard data checks before cancer reports are submitted to the registry. This approach helps resolve errors or inconsistencies at the source—the medical record—before the data are compiled into the central registry.

Ensuring the Quality of Registry Information

CDC has set national standards for central cancer registry completeness, timeliness, and quality. For example,

- Ninety-five percent of expected cancer cases occurring among state residents should be reported each year.
- Cancer cases should be reported to the central registry within 6 months of diagnosis.
- The NPCR requires each funded state to incorporate standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR) and recommended by CDC.

Quality assurance activities for the NPCR are provided through CDC collaboration with NAACCR. Data quality is maintained through conducting regular edits and reviews, merging and matching cases, training state personnel and hospital cancer registrars, abstracting and auditing cases, and ensuring adherence to written policies and procedures.

Linking With National Partners

CDC's NPCR complements existing registries, such as the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. The SEER program gathers in-depth data on a selected sample of the population in five states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and six metropolitan areas (Atlanta, Detroit, Los Angeles, San Francisco/Oakland, San Jose/Monterey, and Seattle), covering about 14% of the U.S. population.

CDC also coordinates efforts with other federal agencies, such as the Department of Veterans Affairs, the Department of Defense, and American Indian/Alaska Native organizations. In addition, CDC participates with national organizations, such as the American Cancer Society, the American College of Surgeons, NAACCR, and the National Cancer Registrars Association, in a working consortium called the National Coordinating Council for Cancer Surveillance. The consortium provides a forum and opportunities for these organizations to collaborate on cancer surveillance and registration issues.

Future Directions

CDC's NPCR represents a pivotal step in the evolution of cancer surveillance and a unique opportunity to strengthen cancer reporting and registration in the United States. When fully operational, the NPCR will collect information on cancer cases for 97% of the U.S. population.

To maximize the usefulness and benefit of state-based cancer registries, there is a critical need to develop a national, centralized database on cancer. Without such a database, this country has limited ability to analyze cancer burden on a regional and national level. Availability of data on these broader levels would greatly facilitate studies in specific areas, such as rare cancers, cancer among children, cancer among racial and ethnic minority populations, and occupation-related cancer. In addition, CDC is exploring ways to enhance the capability of states to respond to cancer-related inquiries from individual communities.

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