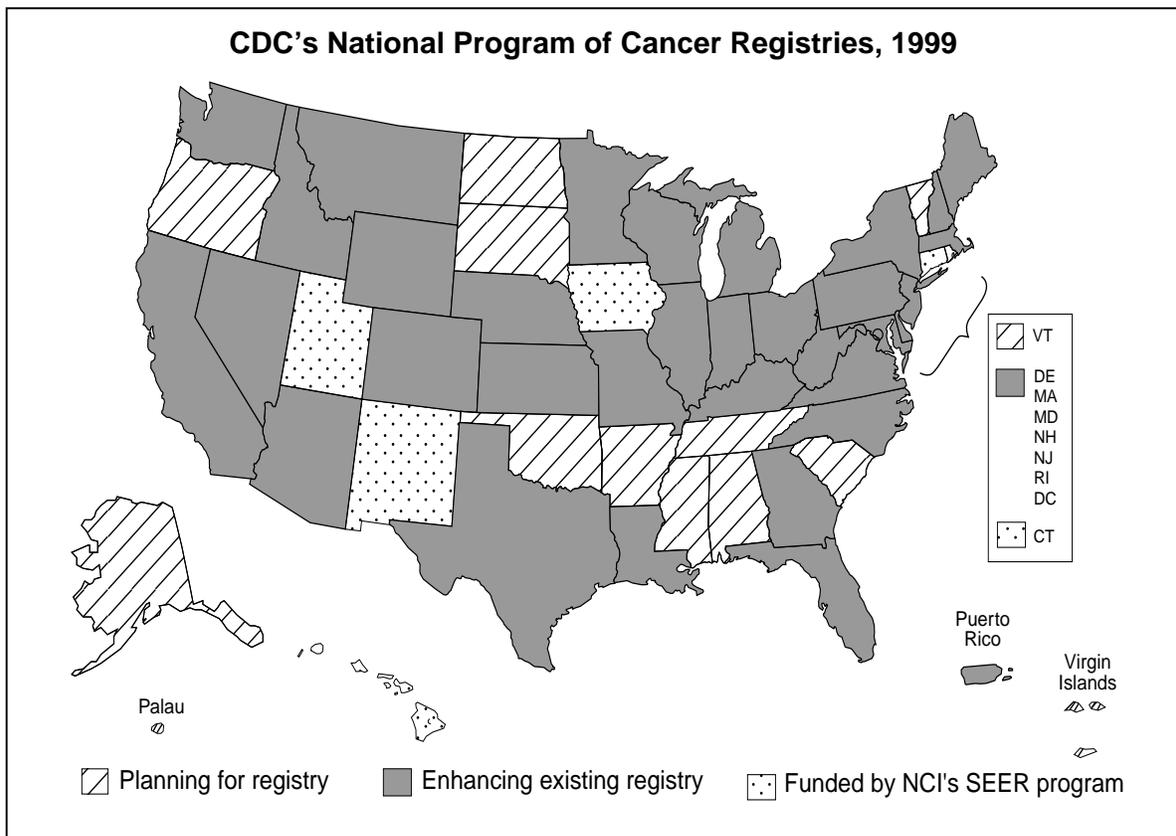


Cancer Registries: The Foundation for Comprehensive Cancer Control

AT-A-GLANCE
2000



*"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 among Americans. One of every four deaths is from this disease. In 2000, an estimated 552,200 Americans will die of cancer—more than 1,500 people a day.

The American Cancer Society estimates that 8.4 million Americans have a history of cancer. In 2000, about 1.2 million new cancer cases will be diagnosed. This estimate does not include in situ (preinvasive) cancer or the approximately 1.3 million cases of nonmelanoma 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, as well as ensuring that screening services are available and accessible—particularly to medically underserved populations—for detecting 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 in the early 1990s. 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 eight states had authorizing legislation and enabling regulations in place to help their registries 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 efforts by 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 1999 funding, CDC supported 45 states, 3 territories, and the District of Columbia for cancer registries. Thirty-four states, 1 territory, and the District of Columbia received funding to enhance established registries, and 11 states and 2 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 2000 appropriations of approximately \$24 million, CDC will continue to support and enhance state cancer registries. The ultimate goal is for all states to establish 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, race/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 information 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 disseminated their registry data through more than 290 published articles and have applied their data in diverse ways. For example,

 **Illinois** has used registry data to identify and target black women aged 40–74 years and white women aged 65–74 years for breast cancer screening interventions. Illinois has also projected cancer incidence for specific geographic regions within the state, thereby providing valuable information for program planning, development, and evaluation activities.

The **California** Cancer Registry routinely reports cancer rates for Asians 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 was able to save thousands of lives and millions of dollars with its cancer registry. In the early 1990s, 35% of Kentucky women diagnosed with breast cancer had advanced (late-stage) disease, for which the survival rate is low. Registry data were used to identify areas of the state that had high rates of late-stage and low rates of early-stage breast cancer. In 1994, Kentucky received CDC funding to enhance registry and breast and cervical cancer activities, enabling the state to expand mammography outreach activities in these communities. In 1996, the percentage of Kentucky women diagnosed with late-stage breast cancer had declined to 30%. In addition to the potential lives saved by detecting these cancers earlier, Kentucky estimates that it has saved more than \$4.7 million in treatment expenditures.

 In **Michigan**, registry data provided important information used to develop recommendations for statewide, comprehensive interventions for controlling cancer. Michigan's Cancer Consortium is now addressing these recommendations.

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, 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 data completeness, timeliness, and quality.
- 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 in their efforts to collect statewide data and to transmit this information

electronically to the central registry. Data are gathered from hospitals, physicians' offices, therapeutic radiation facilities, freestanding 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 data concerns at the source—the medical record—before data are compiled into the central registry.

Ensuring the Quality of Registry Information

CDC has set forth national standards for data completeness, timeliness, and quality for central registries. By these standards, 95% 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, and central registries should incorporate standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR) and recommended by CDC. Beginning in 1997, NAACCR established a certification process for registries. NPCR evaluation data from 1996 showed that the following 15 NPCR programs had already met these certification standards: Arizona, California, Colorado, Idaho, Illinois, Kentucky, Louisiana, Minnesota, Nebraska, New Jersey, Oregon, Rhode Island, Washington, West Virginia, and Wisconsin. Results from the next NAACCR certification review will be available in April 2000.

Linking With National Partners

CDC's NPCR complements existing registries, such as the National Cancer Institute's (NCI'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 and federal organizations in the National Coordinating Council for Cancer Surveillance, a consortium that includes the American Cancer Society, the NCI, the American College of Surgeons, NAACCR, and the National Cancer Registrars Association. The consortium provides a forum for these organizations to collaborate on cancer surveillance and registration issues.

Future Directions

CDC's NPCR represents 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 96% of the nation's population.

To maximize the benefits of state-based cancer registries, CDC is developing the NPCR-Cancer Surveillance System for receiving, assessing, enhancing, aggregating, and disseminating data from NPCR programs. This system will provide valuable feedback to help state registries improve the quality and usefulness of their data, and the system could support important data linkages with other cancer databases. Availability of data on a regional and national level will also facilitate studies in areas such as rare cancers, cancer among children, cancer among racial and ethnic minority populations, and occupation-related cancer.

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