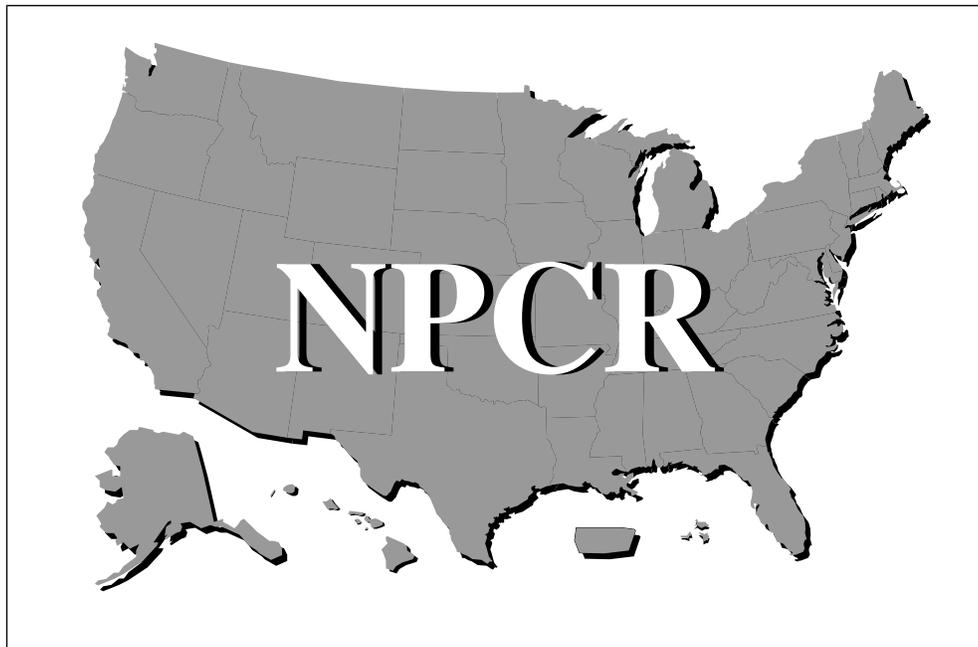


The National Program of Cancer Registries

AT-A-GLANCE

1998



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

John Healey, MD
Memorial Sloan-Kettering Cancer Center, New York



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



Why Do We Need a National Program of Cancer Registries?

The Burden of Cancer

The American Cancer Society estimates that 8 million Americans have a history of cancer. In 1998, about 1.23 million new cancer cases will be diagnosed. This estimate does not include carcinoma in situ or basal and squamous cell skin cancer. About one million cases of basal or squamous cell skin cancer are expected to be diagnosed this year.

In 1998, an estimated 564,800 Americans will die of cancer—more than 1,500 people a day. One out of every four deaths in the United States is from cancer.

Cancer Surveillance: A National Strategy

Cancer surveillance is the key to a unified scientific and public health approach to fighting cancer. Such surveillance is the ongoing, timely, and systematic collection and analysis of information on cancer deaths, new cancer cases, extent of disease, screening tests, treatment, and survival. Data collected through statewide cancer registries can be used to identify trends over time, to discover cancer patterns among various populations, and to show whether screening and other prevention measures are making a difference. This information is essential to states in directing effective cancer prevention and control efforts.

Despite the critical role registries can play in helping direct cancer prevention efforts, 10 states had no registry in 1990. Although the remaining 40 states

How Are Surveillance Data Used?

- To monitor trends in cancer incidence and mortality.
- To guide cancer control program planning and evaluation.
- To assist in prioritizing health resource allocations.
- To advance clinical, epidemiologic, and health services research.
- To serve as the foundation of a national comprehensive cancer control strategy.

had registries operating at some level, many lacked the financial support and the personnel to gather complete, timely, and accurate data on their population or to ensure that the data collected had minimum standards of quality. A number of states also lacked legal support for their registry's operation, which further hindered their ability to collect important information. Data had not been uniformly available at the state and local levels, although numerous cancer control programs had been initiated for breast, cervical, skin, and other cancers. Many states thus lacked an important tool for guiding efforts to prevent and control cancer.

“The goal of this program is to reduce cancer mortality as part of a national disease prevention strategy. We know that the burden of cancer for Americans varies widely by geographic location and by ethnicity. A national system of cancer registries can help us understand the disease better and use our resources to the best effect in prevention and treatment.”

Donna E. Shalala, PhD
Secretary, U.S. Department of Health and Human Services

Congress Takes Action

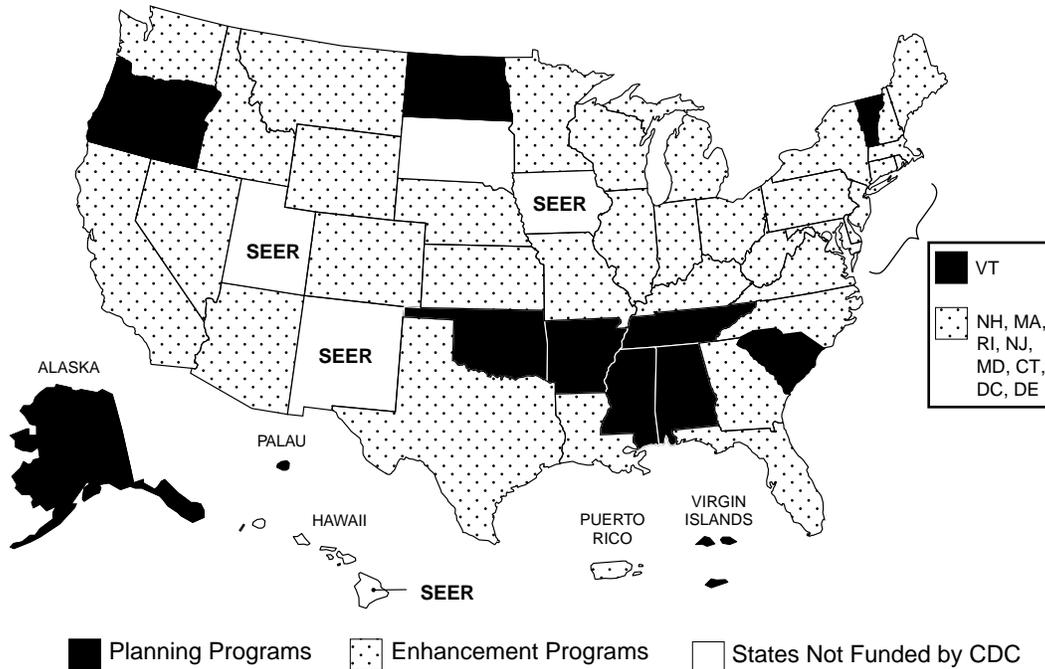
Establishment of the National Program of Cancer Registries

Responding to the needs of states and their citizens, Congress established the National Program of Cancer Registries (NPCR) in 1992 by enacting the Cancer Registries Amendment Act (Public Law 102-515). This legislation authorizes the Centers for Disease Control and Prevention (CDC) to provide funds to states and territories to improve existing cancer registries; to plan and implement registries where they do not exist; to develop model legislation and regulations for states to enhance the viability of registry operations; to set standards for data completeness, timeliness, and quality; to provide training for registry personnel; and to help establish a computerized reporting and data-processing system.

In fiscal year 1997, CDC supported 45 states, 3 territories, and the District of Columbia for cancer registries: 37 for enhancing established registries and 12 for developing registries where none had been

organized previously. With fiscal year 1998 appropriations of \$24.2 million, CDC will continue supporting these programs and will provide extra resources for enhancing activities to those states whose current awards are insufficient. These resources will better equip states to meet CDC's standards of timeliness, completeness, and quality of cancer registry data. Improvements in these areas, in turn, will advance state cancer registries as critical components of a national cancer prevention and control strategy. These new appropriations will also enable CDC to work with state partners and national organizations toward developing an aggregated and centralized database of cancer incidence in the United States. This type of database can provide an opportunity for analyzing the cancer burden in the United States on a regional and national basis. CDC will also begin to explore ways to enhance states' resources and abilities for responding to communities' cancer inquiries through development of model cancer inquiry response systems.

National Program of Cancer Registries Funding, 1997



*The National Cancer Institute's SEER program also funds cancer registries in Connecticut.
Source: Centers for Disease Control and Prevention, 1997.

National Program Activities

Timely and Complete Reporting

The NPCR enables reporting of cancer data by age, sex, ethnicity, and geographic region—within a state, between states, and between regions. States are expected to collect information on at least 95% of cancer cases diagnosed or treated in their state each year. 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 control in all 50 states and the territories. Priority is also placed on obtaining cancer information on residents who travel to other states for diagnosis or treatment.

Computerized Data Collection

The NPCR supports funded states to develop and collect computerized statewide data and to electronically transmit data to the central registry. Information is gathered from facilities such as hospitals, physicians' offices, therapeutic radiation facilities, free-standing surgical centers, and pathology laboratories, which are required by state law or regulation to report cases of cancer. Hospitals are the reporting source for a large proportion of cases reported to the central registry.

Computerized reporting from hospitals will improve data quality and timeliness by incorporating standard data checks that can be applied before cancer reports are submitted to the registry. This approach helps to resolve errors or inconsistencies at the source—the medical record—before the data are compiled into the central registry.

Quality Assurance

CDC requires all central cancer registries to ensure the quality of the data. 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 developing or maintaining written policies and procedures.

Technical Assistance

In providing support for the NPCR, the CDC

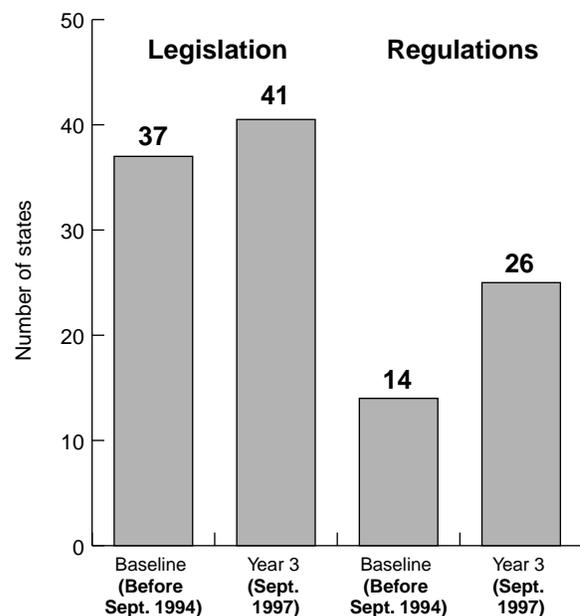
- Convenes meetings of funded registry states for information sharing, problem solving, and training.
- Visits registries to assess program progress and mutually resolve problems.

- Assists states and national organizations in using cancer surveillance data to describe state or national disease burden, to evaluate cancer control activities, and to identify populations at high risk for certain cancers.
- Collaborates with federal, state, and private organizations in designing, conducting, and analyzing surveillance research related to cancer.

Progress to Date

- Before the NPCR was established, only eight states had authorizing legislation and enabling regulations in place for proper legal support of registry operations. Currently, 40 NPCR states and the District of Columbia have authorizing legislation, and 26 states have established all 8 regulations specified in Public Law 102-515.
- CDC has set national standards for central cancer registry completeness, timeliness, and quality.
 - Ninety-five percent of unduplicated, expected malignant cases of reportable cancer occurring in state residents should be reported each diagnosis year.
 - Cancer cases should be reported to the central registry within 6 months of diagnosis.

Number of States in Compliance With Legislation or Regulations*



*Includes District of Columbia.

Source: Centers for Disease Control and Prevention, 1997.

- The NPCR requires each funded state to incorporate the standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR) and endorsed by CDC.
- Quality assurance activities for the NPCR are provided through CDC collaboration with NAACCR. These activities include providing audits of funded statewide cancer registries and training for states to improve deficiencies in cancer registry management, operations, and quality control; conducting site visits to provide technical assistance to funded states; and establishing an Internet site to provide information about the national organization and cancer registries.
- CDC supports special projects in selected NPCR states to design, implement, and evaluate interventions to improve data quality.
- NPCR staff maintain ongoing liaisons with the Department of Veterans Affairs, the Department of Defense, and American Indian/Alaska Native organizations to encourage and facilitate voluntary reporting of cancer cases from federally supported facilities to state registries.
- NPCR computer specialists assist state registries by developing new software, such as CDC EDITS, a program that standardizes the methods for checking errors and inconsistencies in cancer registry data. CDC staff also contribute to the development of central registry systems and provide technical assistance for enhancing data-processing capabilities of statewide cancer registries.

How Does the NPCR Complement Existing Cancer Registries?

NPCR-funded central registries complement existing registries, such as the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program, which monitors trends in incidence, treatment, survival time, and extent of disease. 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 works closely to coordinate its efforts with other federal agencies and with national organizations such as the American Cancer Society, the American College of Surgeons, NAACCR, and the National Cancer Registrars Association. These groups have formed a working consortium, the National Coordinating Council for Cancer Surveillance, to provide an opportunity for collaborating on cancer surveillance and registration issues.

The NPCR represents an important step in the evolution of cancer surveillance and an opportunity to strengthen cancer reporting and registration in the United States. When fully operational, the NPCR will collect incidence data on 97% of the U.S. population.

National standardization of data formats and edits will significantly increase the ability to compare the cancer experience from location to location (for example, cancer cluster investigations). In addition, such standardization will facilitate analysis of cancer incidence by region—an important benefit, since potential risk factors or environmental exposures may not be limited by geopolitical boundaries. Emphasizing completeness of cancer case reporting and ensuring that central cancer registry data are statewide and population-based will improve the representativeness of data, provide more stable estimates of cancer incidence for racial and ethnic minority groups, and point to additional research needed on less common cancers. Rigorous attention to quality control of data collection and processing will ensure the accuracy of cancer data for research and disease surveillance. Reporting data more quickly and more efficiently without compromising completeness or quality will make cancer information more readily available to those who need to know: the public, researchers, clinicians, public health officials, and policymakers. In all of its components, this national strategy has a single driving goal: accelerating efforts to prevent and control the burden of cancer.

**For more information or additional copies of this document, please contact the
Centers for Disease Control and Prevention,
National Center for Chronic Disease Prevention and Health Promotion, Mail Stop K-64,
4770 Buford Highway NE, Atlanta, GA 30341-3717, (770) 488-4751.
cancerinfo@cdc.gov
<http://www.cdc.gov/nccdphp/dcpc>**