

# The National Program of Cancer Registries

*AT-A-GLANCE*

*1997*



---

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

*John Healey, MD,  
Chief of Orthopedic Surgery at Memorial Sloan-Kettering Cancer Center, New York*

---



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



# Why Do We Need a National Program of Cancer Registries?

## The Burden of Cancer

The American Cancer Society (ACS) estimates that more than 7.4 million Americans have a history of cancer. In 1997, about 1.38 million new cancer cases will be diagnosed. This estimate does not include carcinoma in situ or basal and squamous cell skin cancer. More than 900,000 cases of basal or squamous cell skin cancer are expected to be diagnosed this year.

The overall cancer mortality rate for the United States has risen during the last 50 years. However, the death rates for many major cancer sites, except lung, have leveled off or declined. In 1997, about 560,000 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.

*“The success of public health programmes, whether aimed at increased vaccination coverage, reduction of alcohol consumption, or increased utilization of mammography in women over 50, must ultimately be assessed by their impact on morbidity and mortality.”*

Berkelman RL, and Buehler JW.

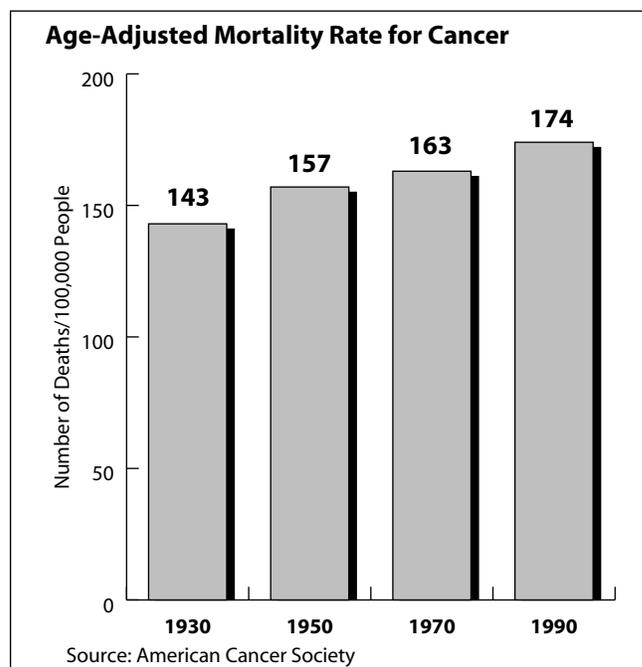
Public health surveillance of non-infectious chronic diseases: the potential to detect rapid changes in disease burden. *International Journal of Epidemiology*, 1990;19:628-35.

## How Are Surveillance Data Used?

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

## Cancer Surveillance: A National Strategy

Cancer surveillance refers to the ongoing, timely, and systematic collection and analyses of cancer incidence and mortality data. Statewide data collected through cancer registries can be used to identify cancer trends, patterns, and variation for directing cancer control efforts, planning and carrying out public health practices, and conducting research. The final step in this surveillance process is the application of data to cancer prevention and control programs by evaluating program effectiveness and planning for the future.



## Status of State Registries

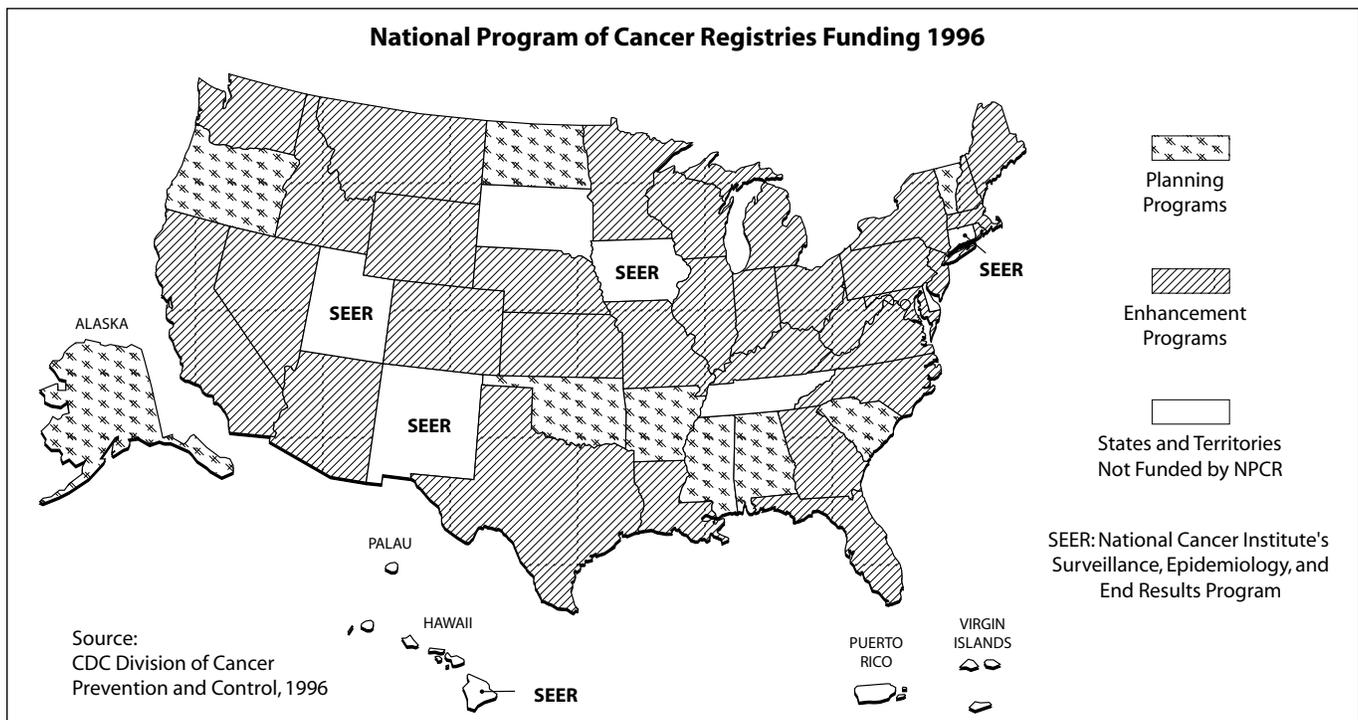
In 1990, 10 states had no registry, and 40 states had registries operating at some level — but many lacked the financial support and the personnel to gather complete, timely, and accurate data on their population or to ensure minimum standards of quality. A number of states also lacked legal support for their operations, which further hindered their ability to collect necessary information. Data have not been uniformly available at the state and local levels, although numerous cancer control programs have been initiated for breast, cervical, skin, and other cancers. Therefore, many states lacked an important tool for guiding efforts to prevent and control cancer.

## Congress Takes Action

### The Cancer Registries Amendment Act

In response to the needs of states and consumers, in October 1992 Congress established the National Program of Cancer Registries (NPCR) 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 viability of registry operations; to set standards for completeness, timeliness, and quality; and to provide training.

As of September 1996, 42 states and the District of Columbia were receiving CDC support for cancer registries: 34 for enhancement of established registries and 9 for developing registries where none had been organized previously. With fiscal year 1997 appropriations of \$22.3 million, CDC hopes to increase the number of states receiving support and will provide extra resources for enhancing activities to those states whose current awards are insufficient. These resources will also allow CDC to work with state partners and national organizations to start aggregating individual state data into a national data set. This data set, in turn, will provide an opportunity for analysis of the cancer burden in the United States on a regional and national basis.



## NPCR Activities

### Timely and Complete Reporting

The NPCR enables reporting of cancer data by age, ethnicity, and geographic region — within a state, between states, and between regions. The information collected will cover at least 95 percent of the states' populations. Comprehensive, timely, and accurate data about cancer incidence and stage at diagnosis provide useful feedback for evaluating progress toward cancer control in all 50 states and the territories.

### Computerized Data Collection

The NPCR supports the states to develop and collect statewide computerized data and to electronically transmit codes and text to the central registry. Facilities such as hospitals, therapeutic radiation facilities, free-standing surgical centers, and pathology laboratories 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 a central registry.

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

### Quality Assurance

All central cancer registries are expected to have a section or unit responsible for ensuring quality by editing and reviewing data, merging and matching cases, training state personnel and hospital cancer registrars, abstracting and auditing cases, or developing or maintaining written policies and procedures.

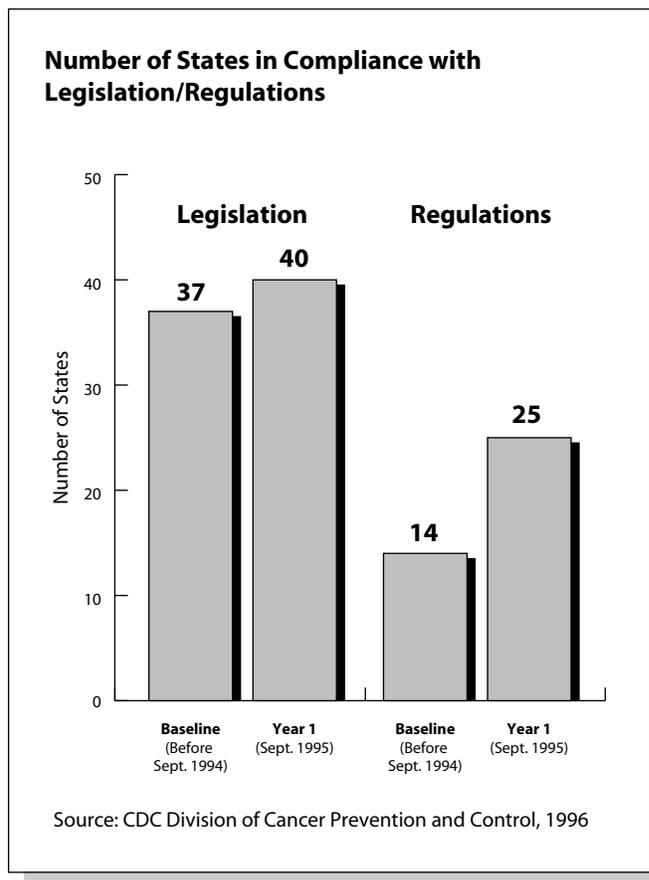
### Technical Assistance

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 burdens, to evaluate cancer control activities, and to identify populations at high risk of certain cancers;
- collaborates with federal, state, and private organizations in designing, conducting, and analyzing surveillance research related to cancer.

### Progress to Date

- Before NPCR, only 33 of the funded states had a statewide, population-based cancer registry. By the end of fiscal year 1996, 41 funded states were collecting statewide cancer data. Forty states have authorizing legislation that is in compliance with Public Law 102-515, and 25 states have established the required regulations.
  - \* 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.
  - \* The NPCR requires each funded state to incorporate the standards for data quality and format as described by North American Association of Central Cancer Registries (NAACCR) and endorsed by the CDC.
- NPCR staff have worked to improve reporting of the usual occupation and industry of persons diagnosed with cancer. Through special projects, staff have also examined data availability and reliability.
- CDC has set national standards for central cancer registry completeness, timeliness, and quality:



- Quality assurance activities for the NPCR are provided through special 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; establishing a world wide web Internet site to provide information about the national organization and cancer registries; and participating in cancer registration and control workshops sponsored by CDC.
- NPCR staff initiated and maintain ongoing liaison with the Department of Veterans Affairs and the Department of Defense to encourage voluntary reporting of cancer cases from federally supported hospitals to state registries.
- CDC has developed EDITS — a standardized data-editing software system. When fully implemented, this system will standardize the methods and algorithms for editing and for checking errors or inconsistencies in U.S. cancer registry data.

*“The reason for collecting, analyzing, and disseminating information on a disease is to control that disease. Collection and analysis should not be allowed to consume resources if action does not follow.”*

Foege WH, Hogan RC, Newton LH.  
Surveillance projects for selected diseases.  
*International Journal of Epidemiology*. 1976;5:29-37.

## 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. The SEER program gathers in-depth data on a 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 percent of the U.S. population. It monitors trends in incidence, treatment, survival time, and extent of disease. To ensure coordination of efforts, CDC works closely with other federal agencies and with national organizations such as the ACS, American College of Surgeons, NAACCR, National Cancer Registrars Association, and other professional organizations.

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, NPCR will collect incidence data on 93 percent 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 permit regional analysis of cancer incidence, which is especially important because possible 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 minorities, and lead to additional research 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 policy makers.

*“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. Health and Human Services

**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 30341-3724, (770) 488-4751.  
cancerinfo@cdc.gov  
<http://www.cdc.gov/nccdphp/dpcp>**