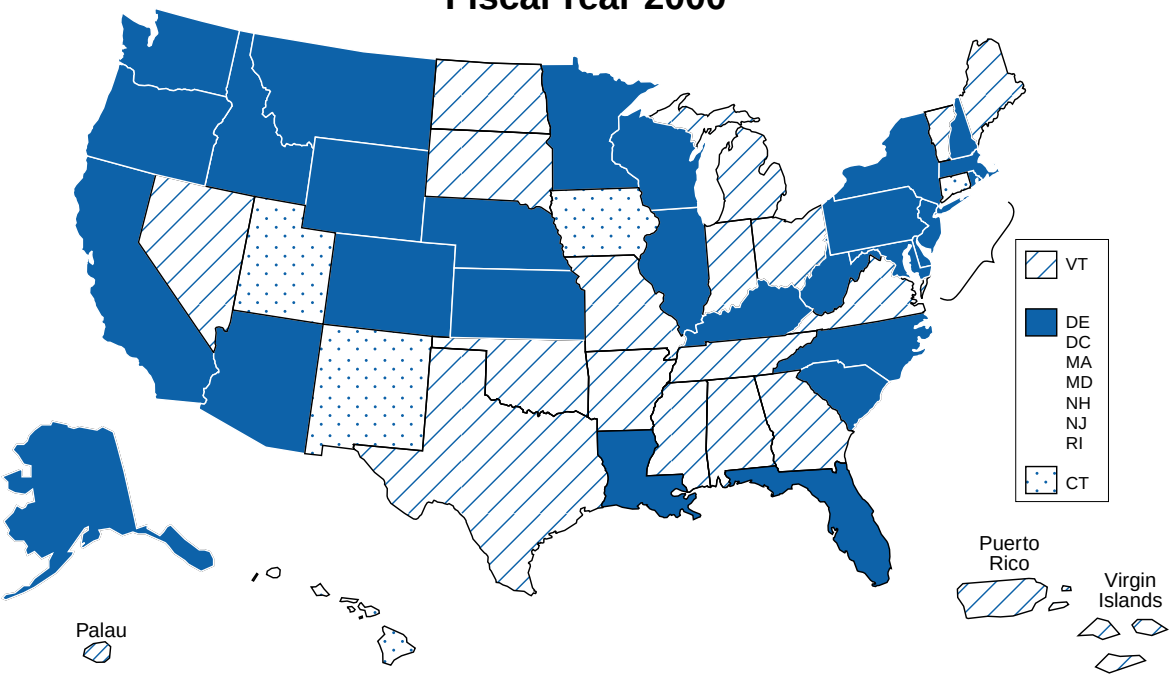
AT A GLANCE

Cancer Registries:

The Foundation for Cancer Prevention and Control 2001

CDC's National Program of Cancer Registries (NPCR), Fiscal Year 2000



NPCR registry, not certified by the North American Association of Central Cancer Registries (NAACCR) for meeting standards of data quality

NPCR registry, certified by NAACCR

Registry funded by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program and certified by NAACCR

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

John Healey, MD
Memorial Sloan-Kettering Cancer Center

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
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Cancer Registries: Collecting Data for Cancer Prevention and Control

The Burden of Cancer

Cancer is the second leading cause of death among Americans. One of every four deaths is from cancer. In 2001, an estimated 553,400 Americans will die of cancer—more than 1,500 people a day.

The American Cancer Society estimates that 8.9 million Americans have a history of cancer. In 2001, about 1.3 million new cases of cancer will be diagnosed. This estimate does not include in situ (preinvasive) cancer or the approximately 1 million cases of nonmelanoma skin cancer expected to be diagnosed this year. According to the National Institutes of Health, each year cancer costs this nation an estimated $180.2 billion, which includes health care expenditures and lost productivity from illness and death.

Effective prevention measures exist to substantially reduce new cases of cancer and prevent many cancer deaths. Reducing the nation's cancer burden requires reducing the prevalence of behavioral and environmental factors that increase cancer risk, as well as ensuring that screening services and high-quality treatment are available and accessible, particularly to medically underserved populations.

Cancer Registries: An Essential National Strategy

Cancer registries collect data about the occurrence of cancer (incidence), the types of cancer that occur, the body site location, the extent of disease at the time of diagnosis (stage), the kinds of treatment received by cancer patients, and the outcome of treatment and clinical management (death or survival). Cancer data are reported to a central statewide registry from a variety of medical facilities including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories.

Data collected by state cancer registries enable public health professionals to better understand and address the cancer burden. Information derived through cancer registries is critical for directing effective cancer prevention and control programs focused on preventing risk behaviors for cancer (e.g., tobacco use and poor diet) and reducing environmental risk factors. Such information is also essential for identifying when and where cancer screening efforts should be enhanced.

State cancer registries are 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 set priorities for allocating health resources.
- Advance clinical, epidemiologic, and health services research.
- Provide information for an aggregated and centralized database of cancer incidence in the United States.

CDC's National Program of Cancer Registries

CDC's National Leadership

Since 1994, CDC has administered the National Program of Cancer Registries (NPCR), which supports efforts by states and territories to

- Plan and establish registries where they do not exist.
- Improve existing cancer registries.
- 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.
- Use cancer data to support cancer prevention and control programs.

Before the NPCR was established, 10 states had no registry, and many of the states with registries lacked

the resources and legislative support to collect needed data. In fiscal year 2000, CDC funded 49 cancer registries at two levels: two states (South Dakota and Tennessee) and two territories (Palau and the Virgin Islands) received funding to plan and establish a registry where a limited or no statewide cancer registry previously existed; and 43 states, one territory, and the District of Columbia received funding to enhance their cancer registries. Of these 49 NPCR programs, 48 have legislation authorizing a statewide cancer registry, and 45 have established all of the regulations specified in the Cancer Registries Amendment Act of 1992 (Public Law 102-515) on the reporting, confidentiality, and use of cancer registry data.

With fiscal year 2001 appropriations of approximately $36 million,* CDC continues to support and enhance state cancer registries and promote use of data. CDC also will develop special research projects such as studies to examine patterns of cancer care in specific populations. CDC's goal is for all states to establish registries that provide high-quality data on cancer and cancer care.

Using Data to Prevent and Control Cancer

The NPCR enables reporting of cancer data by age, sex, race/ethnicity, and area—within a state, between states, and between regions. Special emphasis is placed on obtaining cancer information on residents who travel to other states for diagnosis or treatment. 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.

States have disseminated their registry data through more than 290 published articles and have applied their data in diverse ways, as the following examples illustrate.

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.

Arizona used data from its cancer registry to identify areas with the highest levels of late-stage breast cancer. Data on the stage of cancer at diagnosis were coded and analyzed by ZIP code, and the northeastern part of the state was found to have the highest percentage of breast cancer cases diagnosed at a late stage—42% compared with 27%–33% in other areas of the state. Information from this analysis was provided to county health departments in the northeastern part of Arizona and to the Health Department of the Navajo Nation so that additional outreach efforts to encourage breast cancer screening could be planned.

Cancer registry data in **Minnesota** revealed a persistent excess of mesothelioma in the northeastern portion of the state. This rare type of cancer has only one known cause—asbestos exposure. This observation resulted in legislative funding for investigations to look for cases of occupation-related respiratory disease. One such investigation is assessing whether workers in the mining industry have been exposed to asbestos.

In **Kansas**, hospital administrators and physicians used cancer registry data to examine cancer care in various communities throughout the state. They found that people in some communities lacked access to radiation treatment centers and clinics. As a result, several needed facilities were opened.

New York cancer registry data and state-of-the-art mapping techniques are being used to produce county- and ZIP code-level maps of cancer incidence. Maps showing the distribution of cancer risk factors statewide are also being developed.

Texas public health officials are using cancer registry data to assess the completeness of prostate cancer reporting so that methods to improve case reporting can be identified and tested. Texas is one of several state registries to receive CDC funding for special prostate cancer projects.

*This funding includes salaries and expenses as appropriated in the congressional conference report no. 106-1033.

CDC's Collaboration with States and Partners to Improve the Quality and Usefulness of Cancer Data

Assisting States

CDC provides national leadership and support to

- Help states and national organizations apply cancer data to describe state and national disease burdens, to evaluate cancer control activities, and to identify populations at high risk for certain cancers.
- Provide on-site technical assistance to registry personnel to help ensure data completeness, timeliness, and quality. For example, CDC has developed software to facilitate data transmission and improve the quality of data that hospitals transmit electronically to cancer registries.
- Coordinate and convene meetings of registry personnel for information sharing, problem solving, and training.
- Collaborate with federal, state, and private organizations to design and conduct research using data collected through state registries and to analyze the findings.

Ensuring the Quality of Registry Data

CDC has established national standards to ensure the completeness, timeliness, and quality of cancer registry data. In addition, CDC recommends that central cancer registries incorporate standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR). In 1997, NAACCR established a certification process for registries. During the first 3 years of the certification program, the number of CDC-supported NPCR statewide registries meeting NAACCR's standards has increased from 9 to 29.

Linking with National Partners

CDC's NPCR complements the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) registry program. The SEER program gathers in-depth data on cancer cases diagnosed 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). The metropolitan SEER registries submit their data to the NPCR state registries.

CDC also coordinates data collection 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 National Cancer Institute, the American College of Surgeons, NAACCR, and the National Cancer Registrars Association. The consortium provides a forum for these organizations to collaborate on cancer monitoring and registry operations.

Launching the NPCR-Cancer Surveillance System

CDC's NPCR presents a unique opportunity to strengthen cancer reporting in the United States. The NPCR collects information on cancer cases from registries covering 96% of the nation's population.

In 2001, for the first time, CDC received state data for entry into the NPCR-Cancer Surveillance System. This system will provide valuable feedback to help state registries improve the quality and usefulness of their data and enable important links to other existing databases. Availability of data on regional and national levels 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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