



National Program of Cancer Registries



State-based cancer registries are data systems that collect, manage, and analyze data about cancer cases and cancer deaths. In each state, medical facilities report these data to a central cancer registry.

Established by Congress through the Cancer Registries Amendment Act in 1992, and administered by the Centers for Disease Control and Prevention (CDC), the National Program of Cancer Registries (NPCR) collects data on the occurrence of cancer; the type, extent, and location of the cancer; and the type of initial treatment.

The Burden of Cancer

The cancer community has made extraordinary progress in the development and use of cancer prevention strategies, early detection interventions, and treatments during the past two decades. Nonetheless, every year cancer claims the lives of more than half a million Americans (1). Cancer is the second leading cause of death in the United States, exceeded only by heart disease (2).

More than 557,000 people—more than 1,500 people a day—died of cancer in the United States in 2002 (3). That same year, more than 1,240,000 Americans were diagnosed

with cancer (3).^{*} This number excludes diagnoses of preinvasive cancer (except for urinary bladder cancer) and the approximately one million cases of nonmelanoma skin cancer that were diagnosed in the United States in 2002 (4).

In addition to its devastating personal impact, cancer cost this country an estimated \$210 billion overall in 2005, including nearly \$136 billion for lost productivity and more than \$70 billion for direct medical costs (5).

^{*} Incidence counts cover approximately 93% of the U.S. population. Death counts cover 100% of the U.S. population. Use caution in comparing incidence and death counts.

Functions of State Cancer Registries

State cancer registries are designed to

- Monitor cancer trends over time.
- Determine cancer patterns in various populations.
- Guide planning and evaluation of cancer control programs (e.g., determine whether prevention, screening, and treatment efforts are making a difference).
- Help set priorities for allocating health resources.
- Advance clinical, epidemiologic, and health services research.
- Provide information for a national database of cancer incidence.

Accomplishments

Before NPCR was established, 10 states had no registry, and most states with registries lacked the resources and legislative support they needed to gather complete data. Today, NPCR supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, the Republic of Palau, and the Virgin Islands. These data represent 96% of the U.S. population. Together, NPCR and the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program collect data for the entire U.S. population.

Data collected by state cancer registries help public health professionals understand and address the nation's cancer burden. Vital information about cancer cases and cancer deaths improves health agencies' ability to report on cancer trends, assess the impact of cancer prevention and control efforts, participate in research, and respond to reports of suspected increases in cancer occurrence. Following are some of NPCR's accomplishments to date:

Accomplishments (continued)

United States Cancer Statistics

Since 2002, CDC and NCI have combined their data sources to publish annual federal cancer statistics in the *United States Cancer Statistics (USCS): Incidence and Mortality* report. Produced in collaboration with the North American Association of Central Cancer Registries, this publication is available at www.cdc.gov/cancer/npcr/uscs/. Also available in a Web-application format, this year's report includes cancer incidence data from registries covering 93% of the U.S. population, and mortality data from all states and the District of Columbia.

WONDER: Online Data-Reporting System

CDC has collaborated with NPCR-funded programs to define, test, and release NPCR data in WONDER, an online reporting system hosted by CDC. This new system, launched in early 2006, allows more access to NPCR data than previously was available. Finding critical data that can help guide and evaluate interventions focused on cancer prevention and control now is easier than ever.

Software for Submitting Data

NPCR has developed software programs to make the process of submitting data easier for hospitals. By standardizing the way data are checked for validity, EDITS software improves the quality of the data. Hospitals also can use any of the Registry Plus suite of programs for routine or special data collection. CDC provides and distributes these software programs, which are compliant with national standards, free of charge to the public health community.

Cancer Surveillance Research

To improve the quality of data in cancer registries and enhance the data's usefulness, CDC has initiated many cancer surveillance research projects. Examples include

- A data-linkage project, involving NPCR registry data and administrative records from the Indian Health Service, designed to improve case reporting and decrease the misclassification of the American Indian/Alaska Native race.
- The Breast, Colon, and Prostate Cancer Data Quality and Patterns of Care study, which used population-based cancer registry data to describe the patterns of care that cancer patients receive. The study also compared the quality of treatment-related data and stage-related data in 10 central registries with re-abstracted data from medical records.
- A colorectal cancer monograph—developed in coordination with NCI, states' central cancer registries, and the American Cancer Society (and covering 88% of the U.S. population)—designed to highlight the magnitude of the national burden of colorectal cancer, and to guide cancer control and cancer prevention activities.

More information about NPCR's accomplishments and current activities is available at www.cdc.gov/cancer/npcr. Information about NCI's SEER program is available at www.seer.cancer.gov.

New Jersey Cancer Registry Identifies Need for Increased Cancer Screening

When New Jersey's State Cancer Registry used geographic information systems to study cancer incidence and mortality trends in the state, researchers identified two areas in the northeastern part of the state that have unusually high proportions of late-stage breast cancer. In these areas, more than 90% of women who had been diagnosed with breast cancer lived within 2 miles of a mammography screening center.

Demographic information showed that the populations of these communities tended to be black, Hispanic, or foreign-born, and tended to speak a language other than English at home. To increase screenings in these areas, New Jersey produced, in a variety of languages (including Arabic, Polish, and Spanish), culturally-sensitive information about the availability of mammography. The state also trained personnel at the screening centers in cultural sensitivity and diversity.

Ongoing Work

NPCR's cancer monitoring activities for fiscal year 2006 included

- Collecting and analyzing registry data, and preparing the *United States Cancer Statistics: 2003 Incidence and Mortality* report and Web application. The *USCS: 2003* report will provide state-specific and regional

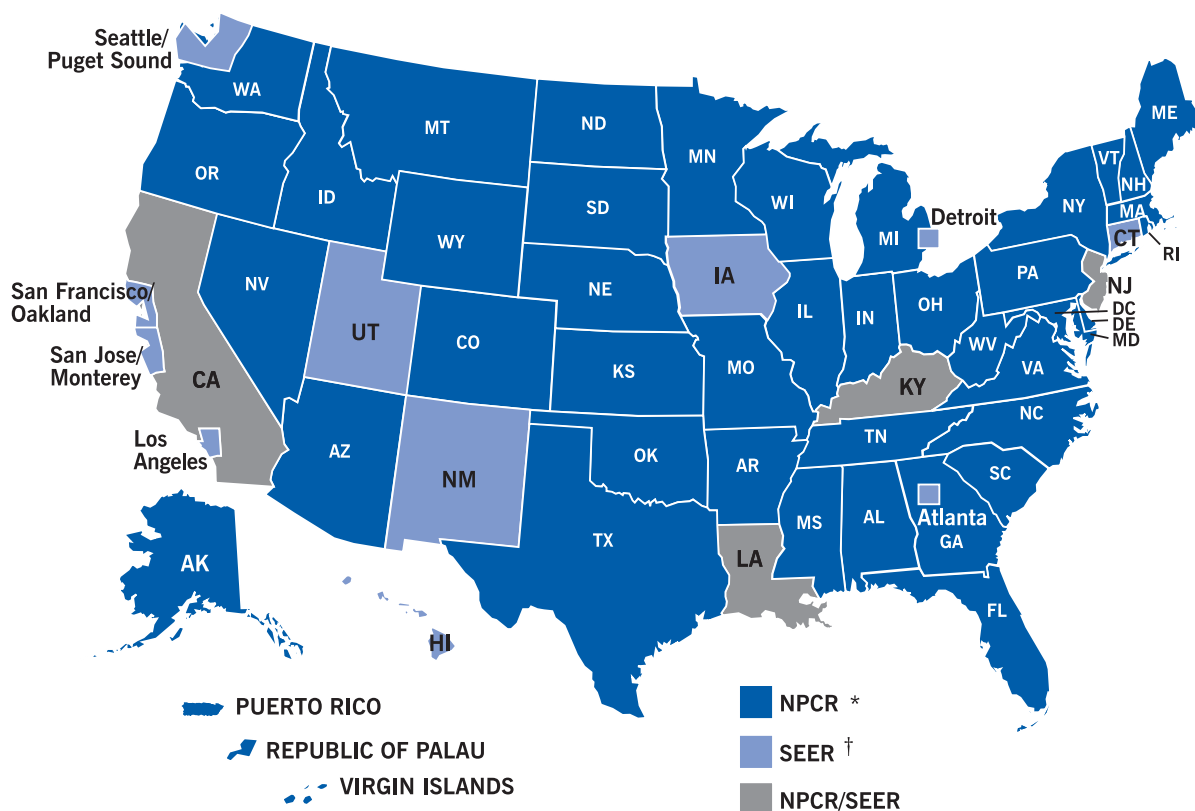
data for cancer cases diagnosed and cancer deaths that occurred in 2003, the most recent year for which data are available.

- Evaluating the quality of data in NPCR registries, including data about race and ethnicity, stage at diagnosis, and treatment.

- Continuing studies that focus on the patterns of care that cancer patients receive.
- Supporting ongoing efforts to link registry data with the Indian Health Service's database of patients, to correct the underreporting of data concerning American Indians/Alaska Natives.
- Supporting a demonstration project to develop a model for transferring cancer incidence data from hospitals' cancer registries to each state's central cancer registry. This project is developing a standards-based electronic format and other technology to enhance registries' operations.
- Conducting a multi-year economic analysis of NPCR, to compare operating costs for registries that have achieved standards for high-quality data with costs for registries that have not. The study will examine the costs of performing core surveillance activities, enhancing the infrastructure and operation of NPCR registries, and performing advanced surveillance activities. Researchers will determine factors and variables that influence costs, and will develop a resource-allocation model based on cost-effectiveness.

The preceding activities support CDC's overarching goals of improving health and creating healthy places for Americans to live and work.

Federally Funded Cancer Registries, 2005



* National Program of Cancer Registries (CDC)
 † Surveillance, Epidemiology, and End Results Program (NCI)

Future Directions

CDC's NPCR will expand the use of information technology (IT) designed to support, improve, and enhance the management and exchange of electronic data in cancer surveillance activities, particularly in cancer registries. This effort supports the U.S. Department of Health and Human Services' mandate to develop a national health information infrastructure, and, as part of that infrastructure, to develop the electronic health record.

NPCR will continue to develop innovative IT approaches to cancer surveillance. For example, NPCR plans to update and improve registry-related software programs, which include EDITS and Registry Plus. One example is Web Plus, designed for abstracting and editing cancer cases securely over the Internet. Several states' cancer registries are pilot-testing this program. Plans also include additional usability reviews of the Registry Plus and EDITS Web sites.

Contact Information

Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion

Division of Cancer Prevention and Control

Mail Stop K-64
4770 Buford Highway, NE
Atlanta, GA 30341-3717

1 (800) CDC-INFO – Fax (770) 488-4760
CDC-INFO@cdc.gov – www.cdc.gov/cancer

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