

# National Program of Cancer Registries

# Facts

FROM THE DIVISION OF CANCER PREVENTION AND CONTROL

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State-based cancer registries are data systems that collect, manage, and analyze data about cancer cases and cancer deaths. In each state, medical facilities (including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories) 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 during the past two decades in developing and using cancer prevention strategies, early detection interventions, and cancer treatments. Nonetheless, every year cancer claims the lives of more than half a million Americans.<sup>1</sup> Cancer is the second leading cause of death in the United States, exceeded only by heart disease.<sup>1</sup> One of

every four deaths in the United States is due to cancer.<sup>1</sup>

According to the *U.S. Cancer Statistics: 2004 Incidence and Mortality* report, 553,880 people—about 1,500 people a day—died of cancer in the United States in 2004.<sup>\*2</sup> That same year, 1,342,126 Americans were diagnosed with cancer.<sup>2</sup> This number excludes diagnoses of preinvasive cancer (except for urinary bladder cancer) and the approximately 1 million cases of nonmelanoma skin cancer that were diagnosed in the United States in 2004.<sup>2,3</sup>

In addition to its devastating personal impact, cancer cost the country an estimated \$219 billion overall in 2007, including nearly \$130 billion for lost productivity and more than \$89 billion in direct medical costs.<sup>4</sup>

*\* Incidence counts cover approximately 98% 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 (i.e., 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, and the U.S. Pacific Island Jurisdictions. 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 is necessary for health agencies 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. Some of NPCR's accomplishments to date include:

### **United States Cancer Statistics (USCS)**

Since 2002, CDC and the National Cancer Institute (NCI) have combined their data sources to publish annual federal cancer statistics in the *United States Cancer Statistics: Incidence and Mortality* report. Produced in collaboration with the North American Association of Central Cancer Registries, this report is available at <http://apps.nccd.cdc.gov/uscs/>. This year's report includes cancer incidence data from registries covering 98% of the U.S. population, and mortality data from all states and the District of Columbia.

### **Cancer Incidence in Five Continents**

Published by the International Agency for Research on Cancer, *Cancer Incidence in Five Continents* is a recognized reference source on the incidence of cancer in populations around the world and is available at [www-dep.iarc.fr](http://www-dep.iarc.fr). The ninth volume includes cancer incidence data from 32 NPCR-funded registries.

### **Software for Collecting and Processing Data**

Since 1996, CDC has developed Microsoft® Windows®-based software programs to make the process of collecting and processing data easier for medical facilities and registries. The Registry Plus™ suite (available at [www.cdc.gov/cancer/npcr/tools/registryplus/](http://www.cdc.gov/cancer/npcr/tools/registryplus/)) consists of nine programs that may be customized for routine or special study data collection. CDC 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 activities. 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 linked data have been published in the *Annual Report to the Nation on the Status of Cancer, 1975–2004, Featuring Cancer in American Indians and Alaska Natives*.
- The Breast, Colon, and Prostate Cancer Data Quality and Treatment Patterns of Care Study that used registry data on approximately 7,600 patients diagnosed in 1997 to describe the patterns of care that cancer patients received and their quality of treatment. The study's results and conclusions have been shared in various posters, oral presentations, and publications.

### **California Cancer Registry Identifies Need for Increased Cancer Screening**

The California Cancer Registry (CCR) has demonstrated a successful use of registry data to inform cancer control planning efforts. The CCR data identified local areas with a high proportion of colorectal cancer cases diagnosed at a late stage using Medical Service Study Areas (MSSA)—an aggregate of census tracts defined by California's Office of Statewide Health Planning and Development (OSHPD). Using registry data, CCR identified MSSAs that had a 20% or higher proportion of colorectal cancer cases diagnosed at a late stage. The results were presented at a statewide cancer control planning stakeholders meeting, with plans to monitor the progress toward reducing the proportion of colorectal cancers diagnosed at late stage. In addition, CCR is exploring opportunities to use alternative geographic areas, such as legislative district, which may provide a powerful tool for presenting cancer-related information to policy and decision-makers.

### **Oregon State Cancer Registry Collaborates to Reduce State's Cancer Burden**

In partnership with the Oregon Comprehensive Cancer Control Program (OCCCCP), the Oregon State Cancer Registry (OSCaR) provides data for defining cancer burden, identifying priorities for action, and evaluating progress. In turn, OCCCCP has identified opportunities to share cancer registry data with individuals such as cancer survivors, and organizations such as health care providers, who are unaware of OSCaR and its wealth of information. One of OCCCCP's goals is to present OSCaR data in a consistent, understandable, and adequately cited format. The three key outcomes of the OSCaR and OCCCCP collaboration are enhanced awareness and use of state, local, and national cancer registry data among diverse partners; consistent use and format for reporting cancer data; and a forum for addressing cancer burden, treatment, survivorship, and quality of care issues.

- The current Breast and Prostate Cancer Data Quality and Patterns of Care Study is building on previous work to examine further the patterns of care that cancer patients receive and the quality of treatment-related data. The study is being conducted in collaboration with seven registries across the country for approximately 24,000 patients diagnosed with breast or prostate cancer in 2004.

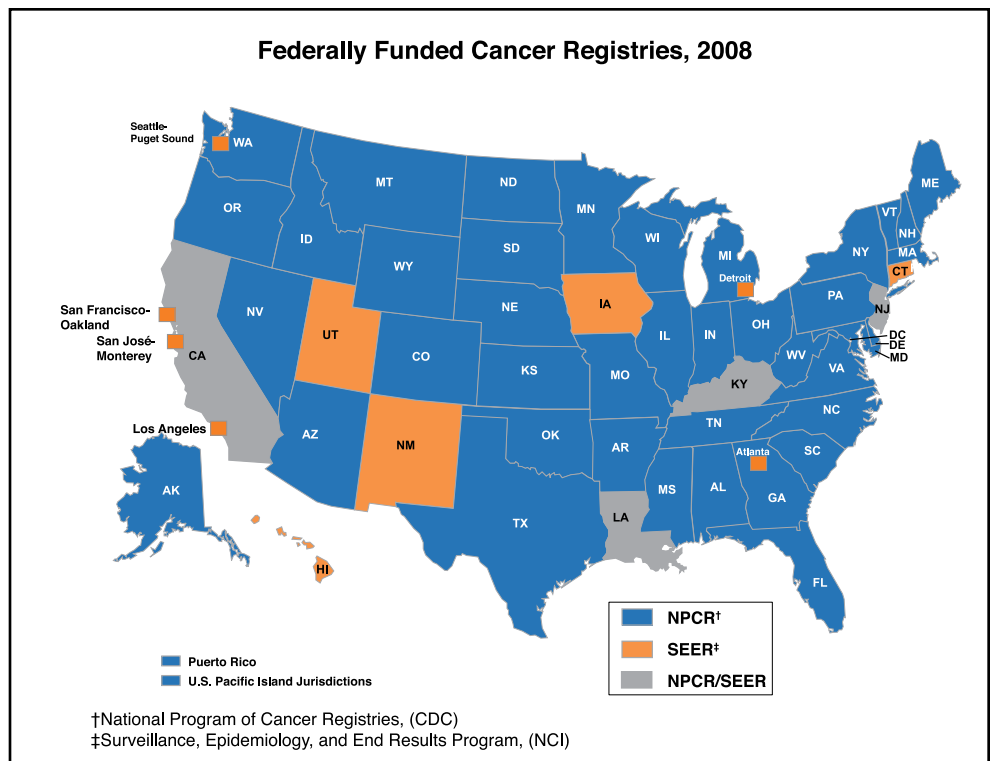
- Publications that have featured the combined NPCR and SEER data sources, including a report on the decline of breast cancer incidence published in CDC's *Morbidity and Mortality Weekly Report*.

These and other public health efforts that address cancer registries support CDC's overarching goal of healthy people in every stage of life. They also address the U.S. Department of Health and Human Services' Healthy People 2010 goal of increasing the number of states that have a statewide population-based cancer registry and that capture case information on at least 95% of the expected number of reportable cancers.

### Ongoing Work

NPCR's cancer monitoring activities for fiscal year 2008 include:

- Collecting and analyzing registry data and preparing the *United States Cancer Statistics: 2005 Incidence and Mortality* web application. The application will provide state-specific and regional data for diagnosed cancer cases and cancer deaths that occurred in 2005, the most recent year for which data are available.
- Continuing collaborations with national partner organizations and state registries on publications using registry data, such as the *Annual Report to the Nation on the Status of Cancer* and two supplements to the journal *Cancer*. One supplement focuses on cancers associated with the human papillomavirus. The other supplement focuses on the cancer burden among American Indians and Alaska Natives.
- Assessing the completeness and accuracy of data required to be collected by NPCR registries, including data about race and ethnicity, stage at diagnosis, and treatment.
- Continuing studies that focus on the patterns of care for cancer patients.
- Supporting ongoing efforts to link registry data with the National Death Index that would allow for cancer surveillance studies on survival and survivorship.
- Leading a collaborative effort to develop a model for sending data from clinical electronic health records to hospitals and registries.



- Supporting ongoing efforts to test the collection of data in an electronic format using national data transmission standards. One pilot project is testing the reporting of data from a national pathology laboratory to the registries, and another is testing the collection of discrete data items directly from anatomical pathology reports using standardized checklists.
- Conducting a multiyear 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.

### Future Directions

CDC's NPCR will expand the use of information technology designed to support, improve, and enhance 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 data are used to monitor and target cancer control activities related to access to care. In partnership with

representatives from NPCR-funded state registries, CDC is in the planning stages of allowing access to de-identified, individual record-level data to approved applications, including researchers at national cancer organizations and universities.

In addition, linkage of cancer registry data with state vital records, the Social Security Death Index, and the National

Death Index will provide follow-up information needed for survival and survivorship studies. NPCR will work on data collection and methodologic issues related to improving the measurement of survival time, including projections of short-term and long-term survival for recent cohorts of patients, to measure and estimate prevalence.

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## References

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