

# Cancer Registries:

## The Foundation for Cancer Prevention and Control



### The Nation's Cancer Burden

According to the American Cancer Society (ACS), more than a half million Americans will die of cancer in 2004—that is more than 1,500 people a day. One of every four deaths in America is from cancer. About 1.4 million new cases of cancer will be diagnosed in 2004. This estimate does not include diagnoses of in situ (preinvasive) cancer (except for urinary bladder cancer) or the approximately 1 million cases of nonmelanoma skin cancer that will be diagnosed this year.

The National Cancer Institute (NCI) estimates that about 9.6 million Americans with a history of cancer were alive in January 2000. Although some of these individuals were considered to be cured or cancer

free, others continued to live with the disease and may have been receiving treatment.

Effective strategies exist for reducing the number of both new cases of cancer and deaths caused by cancer. These include decreasing the prevalence of behavioral and environmental factors that increase people's cancer risk and ensuring that evidence-based screening tests and treatment services are available and accessible. Resources that can be devoted to such strategies are limited, and must be allocated wisely. Wise resource allocation, in turn, depends partly on the availability of complete, timely, and high-quality cancer data.

Source: American Cancer Society, *Cancer Facts and Figures 2004*.

### Cancer Registries: Essential to Reducing the Burden

Cancer registries collect information about the occurrence (incidence) of cancer, the types of cancers diagnosed and their locations within the body, the extent of cancer at the time of diagnosis (disease stage), and the kinds of treatment that patients receive. These data are reported to a central statewide registry from various medical facilities, including hospitals, physicians' offices, therapeutic radiation facilities, freestanding surgical centers, and pathology laboratories.

A few of these statewide registries also collect additional information on survival after the diagnosis and initial treatments. Data collected by state cancer registries enable public health professionals to better understand and address the cancer burden. Registry data are critical

#### **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.



for targeting programs focused on risk-related behaviors (e.g., tobacco use and exposure to the sun) or on environmental risk factors (e.g., radiation and chemical exposures). Such information is also essential for identifying when and where cancer screening efforts

should be enhanced and for monitoring the treatment provided to cancer patients. In addition, reliable registry data are fundamental to a variety of research efforts, including those aimed at evaluating the effectiveness of cancer prevention, control, or treatment programs.

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## ***CDC's National Program of Cancer Registries***

### **Providing National Leadership**

The Centers for Disease Control and Prevention (CDC) has administered the National Program of Cancer Registries (NPCR) since 1994. Before NPCR was established, 10 states had no registry and most states with registries lacked the resources and legislative support needed to gather complete data. With fiscal year 2004 appropriations of approximately \$50 million, CDC's NPCR supports central registries and promotes the use of registry data in 45 states, the District of Columbia, and the territories of Puerto Rico, the Republic of Palau, and the Virgin Islands. CDC also is conducting special research projects such as studies to examine patterns of cancer care in specific populations. CDC's goal is

for all states to maintain registries that provide high-quality data on cancer and cancer care.

NPCR complements NCI's Surveillance, Epidemiology, and End Results (SEER) registry program. Together, NPCR and the SEER program collect cancer data for the entire U.S. population. The SEER program gathers in-depth data on cancer cases diagnosed in Connecticut, Hawaii, Iowa, New Mexico, and Utah, as well as in six metropolitan areas and several rural/special population areas. The six metropolitan SEER registries and some of the rural/special population registries submit data to NPCR's state registries. In 2001, SEER began providing additional support to four NPCR-supported state registries (California, Kentucky, Louisiana, and New Jersey).

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## ***Expanding Efforts to Improve and Use Cancer Data***

### **Assisting States with Registry Data**

CDC provides leadership and support to improve the quality of cancer registry data and to use these data for cancer control planning. The agency does this by

- Providing technical assistance to registries to help ensure data completeness, timeliness, and quality. (For example, CDC has developed software to facilitate data transmissions and improve the quality of data that hospitals transmit electronically to cancer registries.)
- Coordinating and convening meetings of registry personnel for information sharing, problem solving, and training.
- Helping states and national organizations use cancer data to describe state and national disease burdens, evaluate cancer control activities, and identify populations at risk for certain cancers.
- Collaborating with federal, state, and private organizations to design and conduct research using data collected through state registries.

registries incorporate standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR). In 1997, NAACCR instituted a program that annually reviews member registries' abilities to produce complete, accurate, and timely data. Registries that meet the highest standards receive NAACCR certification. Thirty-five CDC-supported NPCR registries achieved these high standards for their 2001 data, the most recent year for which cancer incidence data are available.

### **Implementing the NPCR–Cancer Surveillance System**

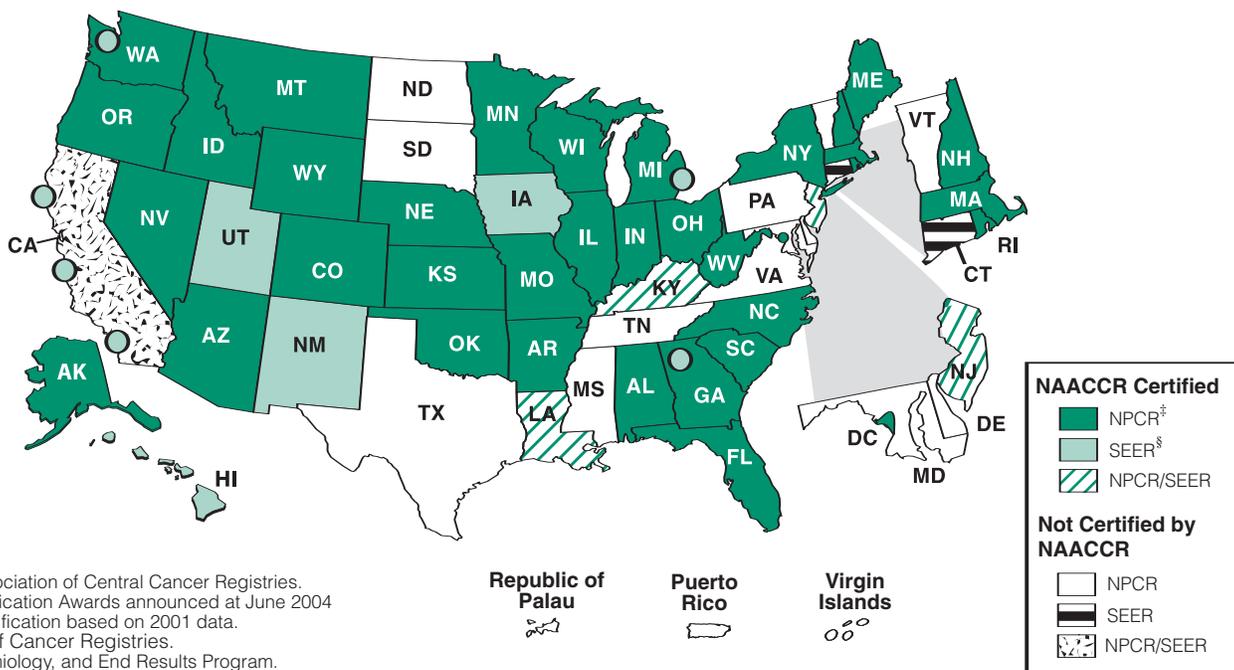
NPCR has a unique opportunity to strengthen cancer reporting in the United States. NPCR registries collect information on cancer cases occurring among 96% of the U.S. population. In 2001, CDC began to receive state cancer data from these registries on an annual basis for entry into the NPCR–Cancer Surveillance System. This repository for cancer data is enabling CDC to provide valuable feedback to help state registries improve the quality and usefulness of their data and link with other databases. In addition, the availability of regional and national data is facilitating studies in areas such as rare cancers, cancer in children, the quality of cancer care, and cancer among specific racial/ethnic minority populations.

### **Ensuring the Quality of Registry Data:**

#### **CDC Standards and NAACCR Certification**

CDC has established national standards to ensure the completeness, timeliness, and quality of cancer registry data. In addition, CDC recommends that central cancer

# NAACCR\*-Certified U.S. Cancer Registries: 2003<sup>†</sup>



\* North American Association of Central Cancer Registries.  
<sup>†</sup> 2003 NAACCR Certification Awards announced at June 2004 Annual Meeting; certification based on 2001 data.  
<sup>‡</sup> National Program of Cancer Registries.  
<sup>§</sup> Surveillance, Epidemiology, and End Results Program.

## Using Data to Prevent and Control Cancer

NPCR enables reporting of cancer data by age, sex, race/ethnicity, and geographic 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. Timely, accurate, population-based data on cancer incidence, stage at diagnosis, first course of treatment, and deaths are being used to evaluate cancer prevention and control efforts and progress toward health objectives. The examples below illustrate some of the many ways in which states are using registry data.

A special study using state cancer registry data from Maine, Vermont, and New Hampshire is addressing concerns of high incidence and death rates of bladder cancer. A rapid case ascertainment procedure was used to allow timely personal interviews of residents diagnosed with bladder cancer. The patients were asked about their dietary behaviors, previous residences and occupations, past medical history, tobacco use, and medications. Drinking water and biological specimens are also being analyzed. Data from this study will be used to estimate the extent to which various lifestyle, occupational, and environmental exposures



explain the increased incidence and mortality of bladder cancer cases in these New England states. The state departments of health, Dartmouth Medical School, the National Institutes of Health, and the U.S. Geological Survey are collaborating in this study. Results can be used to develop and conduct various interventions to educate residents on how best to lower their risks of bladder cancer.

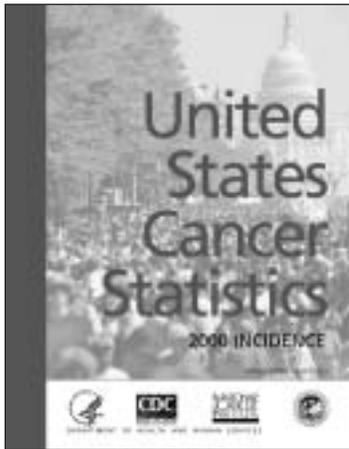


The Oregon State Cancer Registry (OSCaR) annually receives more than 200 requests for information from citizens who are concerned about cancer clusters in their community.

Historically, several different state agencies and programs handled such requests, creating not only duplication of work but variability in the methods, responsiveness, and public health messages used to respond to citizens' concerns. OSCaR developed a protocol to respond to these concerns; the protocol focused on reducing overlap among state agencies, eliminating inconsistencies in response, establishing clear guidelines for telephone and written responses, and addressing citizens' concerns by using local data. The development and use of a protocol to address people's concerns about cancer clusters have reduced duplication of effort among state agencies, as well as the number of cancer cluster requests that result in unnecessary investigation or follow-up.

## CDC Collaborations for Cancer Monitoring

In addition to providing financial and technical assistance to state cancer registries, CDC works with private-sector organizations, NCI, the Department of Veterans Affairs, the Indian Health Service, the Department of Defense, and other federal agencies to support cancer surveillance efforts. Following are several examples of these collaborative activities.



### Annual Publication of Federal Cancer Statistics

CDC's NPCR and NCI's SEER program, in collaboration with NAACCR, jointly produce official federal cancer incidence statistics from each state having high-quality registry data. This year's report, *U.S. Cancer Statistics (USCS): 2000 Incidence*, underscores the progress achieved in creating a national system

for cancer monitoring. This report provides state-specific and regional data for cancer cases diagnosed in 2000, the most recent year for which data are available. Cancer statistics from 41 states, 6 metropolitan areas, and the District of Columbia—geographic areas comprising about 84% of the U.S. population—are included in the publication. For the first time, *USCS: 2000 Incidence* includes data for childhood cancers and for Asians/Pacific Islanders. Plans are to produce the report annually, expand the scope of racial/ethnic data included, and add state-specific mortality data.

### National Coordinating Council for Cancer Surveillance

CDC participates in the National Coordinating Council for Cancer Surveillance, a consortium that also includes ACS, NCI, NAACCR, the American College of Surgeons, and the National Cancer Registrars Association. The council provides a forum through which these organizations can collaborate on cancer monitoring and registry operations.

### Report to the Nation on the Status of Cancer

Another collaborative project is the Annual Report to the Nation on the Status of Cancer. This document has been published annually since 1998. The 2004 edition, which includes a special section on survival, was produced jointly by ACS, CDC, NAACCR, and NCI. The report highlights the progress made in reducing the burden of cancer, and trends in cancer incidence and mortality by race/ethnicity.

### Special Projects

#### Patterns of Care Study

The NPCR Breast, Colon, and Prostate Cancer Data Quality and Patterns of Care study is designed to 1) use population-based cancer registry data to describe the patterns of care for cancer patients and 2) compare the quality of treatment and stage data in 10 central registries with reabstracted data from medical records.

#### Recent Trends in Cancer Mortality—MMWR/SS

CDC has prepared a special *Morbidity and Mortality Weekly Report Surveillance Summary* of mortality trends over the last decade in the United States. Mortality data collected by CDC's National Center for Health Statistics for all cancer sites combined and for the top four cancers causing death are included in this report, as well as mortality trends from 1990–2000. In addition, death rates for the 10 primary cancer sites with the highest age-adjusted rates will be presented for each state and the District of Columbia.

#### Data Linkage with Indian Health Service Records

The Indian Health Service (IHS) and the NPCR are linking data in 46 central cancer registries and the IHS clinical encounter database. This ongoing study is designed to improve the completeness of case reporting and to decrease the misclassification of the American Indian/Alaska Native race.

For additional information on selected studies, visit the following Web site:  
<http://www.cdc.gov/cancer/ataglan.htm#science>.

### For more information or additional copies of this document, please contact:

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  
 (770) 488-4751 • Voice Information System 1 (888) 842-6355 • Fax (770) 488-4760  
[cancerinfo@cdc.gov](mailto:cancerinfo@cdc.gov) • <http://www.cdc.gov/cancer>