

SEER

... as a Research Resource



“The SEER Program is one of NCI’s most important data collection and dissemination activities. In addition to providing essential information for tracking the Nation’s progress against cancer, SEER data and data analysis tools provide researchers with unique opportunities to explore and explain cancer trends. The impact of SEER on science, policy, and practice reflects both the quality of the data collected and the creative expertise of the many scientists who use it.”

Robert T. Croyle, Ph.D.

Director, Division of Cancer Control and Population Sciences, NCI

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www.seer.cancer.gov



The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is a coordinated system of population-based cancer registries strategically

located across the United States. These registries monitor cancer trends and provide timely, accurate, and continuous data on cancer incidence, the extent of disease at diagnosis, therapy, and patient survival.

As a research resource, SEER serves as a platform for studies that address emerging issues in the field of cancer and cancer-related care. SEER also plays a critical role in increasing the breadth of scientific research to include various factors such as health disparities, access to and quality of health care, geographic determinants, and other attributes. The results of these studies can then be translated into public health policy, planning, and practice.

Reporting

The SEER Program currently collects cancer incidence and survival data from 18 geographic areas in the United States. There are nine states (New Mexico, Hawaii, Utah, Iowa, Connecticut, Greater California, Kentucky, Louisiana, New Jersey), five metropolitan areas (Metro Atlanta plus a sample of rural Georgia, the Greater Bay Area [San Francisco-Oakland and San-Jose Monterey], Los Angeles, Seattle, Detroit), and the Alaska Native Tumor Registry, which together represent approximately 26 percent of the U.S. population. This broad coverage allows SEER to account for various diverse populations throughout the

United States. SEER registries routinely collect data on patient demographics, primary tumor site, morphology, stage at diagnosis, first course of treatment, and follow-up for vital status. These data then are made available to researchers and the general public through the dissemination of factsheets, reports, databases, analytical software, Web sites, and linkages to other national data sources.

For more information, visit SEER's online resources:

The SEER Web site: www.seer.cancer.gov

Fast*Stats: <http://seer.cancer.gov/faststats>

Cancer Query System: <http://seer.cancer.gov/canques>

SEER*Stat: <http://seer.cancer.gov/seerstat>

Cancer Statistics Review: http://seer.cancer.gov/csr/1975_2005

Annual Report to the Nation: http://seer.cancer.gov/report_to_nation

Several of the most frequently used resources include the following:

SEER Cancer Statistics Review, 1975–: The SEER Cancer Statistics Review (CSR) is the annual report of the most recent cancer incidence, mortality, survival, prevalence, and lifetime risk statistics. The current edition includes statistics from 1975 through the most recent year for which data are available. More information about SEER's Cancer Statistics Review is available at http://seer.cancer.gov/csr/1975_2005/index.html.

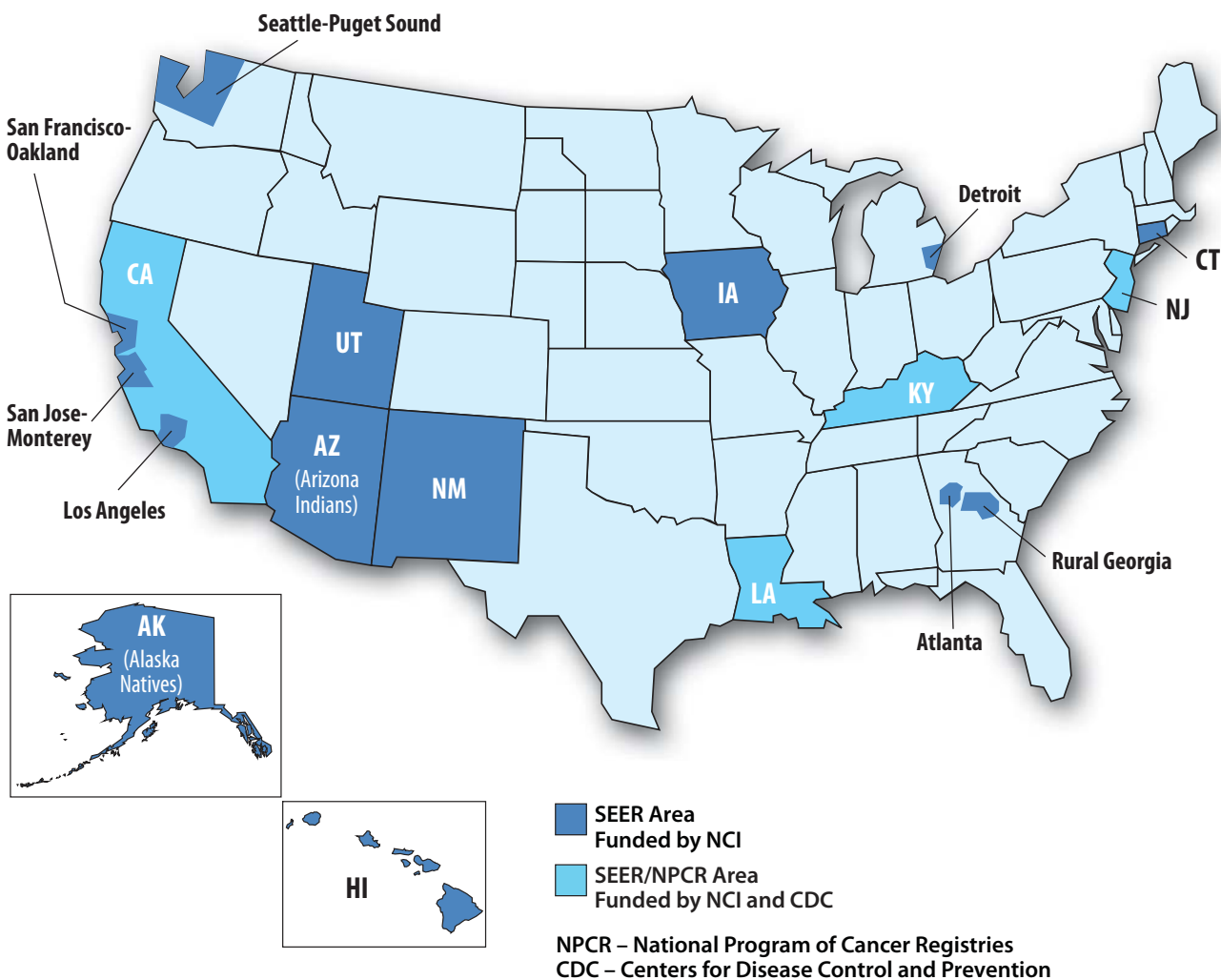
SEER Bibliography: The SEER Program produces various publications related to cancer statistics. SEER's Web-based, searchable bibliography has more than 5,000 entries, with more to come in the near future. These publications address areas such as basic research, clinical oncology, general medical research, public health, and internal/general medicine. Find more information at <http://seer.cancer.gov/publications>, and view the SEER Bibliography at <http://www.seer.cancer.gov/pubsearch>.

Surveillance Partnerships and Collaborations

The SEER program engages in a number of ongoing public and private partnerships. These partnerships ensure the sharing of high-quality data, along with the use of common standards for data collection and reporting. SEER collaborates with the American Cancer Society (ACS), Centers for Disease Control and Prevention (CDC), North American Association of Central Cancer Registries (NAACCR), and various other external organizations. These cooperative efforts result in joint reports such as the *Annual Report to the Nation* and monographs, which provide detailed information on cancer statistics and trends among specific population groups in the United States.

National Longitudinal Mortality Study (NLMS) Database:

The National Longitudinal Mortality Study (NLMS) is a database that was developed and is sponsored by NCI; the National Heart, Lung, and Blood Institute (NHLBI); National Institute on Aging; National Center for Health Statistics (NCHS); and the U.S. Census Bureau. The purpose of the database is to examine the relationships between mortality and self-reported demographic and socioeconomic characteristics among a representative sample of the U.S. noninstitutionalized population. Sociodemographic data, collected by the U.S. Census Bureau via in-person and telephone interviews as part of the annual Current Population Surveys (CPS), are combined with cause-of-death information from official state



death certificates for study cohorts ranging from 1979–2002. The NLMS database includes records on approximately 3 million persons and cause-of-death information on more than 250,000 individuals. Additional data have been linked to the NLMS and are available for analysis, including Medicare claims data for the period 1991–2001 and tobacco use supplements for the NLMS cohort years of 1985, 1992, 1993, 1995, 1996, 1999, and 2001. A bibliography of NLMS-related publications and studies can be found at <http://www.census.gov/nlms/bibliography.html>.

The Linked SEER-NLMS Database: SEER patient records for 1973–2003 have been linked with 1979–2002 NLMS cohorts to provide additional individual-level socioeconomic and demographic information on SEER cancer cases, expanding opportunities for analyzing differentials in cancer incidence, survival, and tumor characteristics. In addition, the tobacco use and Medicare claims data that have been linked to the NLMS also are linked to the SEER-NLMS database and are available for analysis. Studies conducted using these data have shown that the SEER-NLMS database serves as a significant resource for evaluating disparities in cancer outcomes according to a variety of individual-level socioeconomic, demographic, racial, and health care characteristics. Find more information about the NLMS and the linked SEER-NLMS database at <http://surveillance.cancer.gov/disparities/nlms>.

The SEER-Medicare Database: The SEER-Medicare database is a unique resource that can be used for research related to the health care provided to persons age 65 and older with cancer. The database results from the linkage of two large population-based data sources: SEER cancer registries data and Medicare enrollment and claims files. Medicare’s master enrollment file is used to identify persons in the SEER data who are Medicare beneficiaries. For people who are Medicare eligible, the SEER-Medicare data

include claims for covered health care services, including hospital, physician, outpatient, home health, and hospice bills. Currently, the SEER-Medicare database includes more than 2.4 million persons with cancer. The linked SEER-Medicare data can be used for various studies that span the continuum of cancer control activities, such as:

- Treatment and outcomes
- Quality of care
- Health care systems and services
- Screening and surveillance
- Economics of cancer
- Survivorship and end-of-life issues

The SEER-Medicare Database is a collaborative effort of NCI, the SEER registries, and the Centers for Medicare and Medicaid Services (CMS). More information is available at <http://healthservices.cancer.gov/seermedicare>.

Residual Tissue Repository (RTR) Program: The SEER Program provides a unique potential for performing biospecimen studies on representative samples of cancer cases from specific geographic areas. NCI created the SEER Residual Tissue Repository (RTR) program to prevent, to the extent possible, loss of biological specimens from SEER patients. The RTR was initiated to preserve pathology specimens associated with SEER cancer cases that otherwise would be discarded, and to use these specimens to test hypotheses relevant to population-based samples.

The RTR:

- Enables studies on rare cancers for which no single registry has enough cases to allow statistically valid conclusions to be drawn.
- Allows validation studies on specimens from population-based registries.
- Allows comparison of cases with biospecimens to all cases in the registry for the purpose of assessing population-based representativeness.

- Allows analysis of trends in incidence and the potential for correlation with treatment trends based on the long history and diversity of the SEER registries.
- Makes possible updating of information after the tissue microarray (TMA) is formed without violating confidentiality and privacy protections.

Find more information about the RTR Program at <http://www.seer.cancer.gov/biospecimen>.

State Cancer Profiles: The State Cancer Profiles Web site is a comprehensive system of interactive maps and graphs that enable the investigation of cancer trends at the national, state, and county levels. It is part of Cancer Control P.L.A.N.E.T., a portal that provides access to data and research-tested resources for the design, implementation, and evaluation of cancer control programs.

The objectives of the State Cancer Profiles Web site are to characterize the cancer burden in a standardized manner, integrate surveillance into cancer control planning, differentiate areas and demographic groups, and expose health disparities. The Profiles focus on cancer sites for which there are evidence-based interventions. Interactive graphics and maps provide visual support for deciding where to focus cancer control efforts. Data for State Cancer Profiles are collected from public health surveillance systems through their published reports or public use files.

The target audiences for the State Cancer Profiles Web site primarily are health planners, policy makers, and cancer information providers. The site provides quick and easy access to descriptive cancer statistics that can assist in prioritizing investments in cancer control. In addition, epidemiologists may find the site useful for identifying research opportunities. State Cancer Profiles are a

collaborative effort of NCI and CDC. For more information on State Cancer Profiles, see <http://statecancerprofiles.cancer.gov>.

The Rapid Response Surveillance Studies: The Rapid Response Surveillance Studies began in 1987, when the SEER registries conducted the first population-based Patterns of Care Study. In 1992, the Rapid Response Surveillance Studies were expanded to include a broader range of topics, including emerging issues related to cancer prevention and control. This mechanism allows studies to move from the initial concept through completion in a relatively short interval, usually within 2 years. Research areas addressed have included evaluation of cancer surveillance methodologies, comparing cancer treatment outcomes, and monitoring screening practices linked to cancer outcomes. In addition, Rapid Response Surveillance Studies have supported research on procedures for enhanced monitoring of health behaviors and risk factors, pilot linkage of SEER with other databases, and improvement of the technical aspects of cancer registry operations. Studies conducted under this mechanism have served as background for larger research initiatives funded by other federal and private mechanisms.

Research areas addressed by Rapid Response Surveillance Studies include:

- Evaluation of cancer surveillance methodologies
- Evaluation of cancer treatment and outcomes
- Monitoring screening practices
- Health behaviors and risk factors
- Linking databases
- Improving technical aspects of registry operations

More information about Rapid Response Surveillance Studies is available at <http://seer.cancer.gov/rapidresponse>.

“SEER has been a vital source of information for tracking the use of recommended cancer care in the community. It is the foundation for many studies evaluating a number of diverse issues among cancer patients and survivors, including quality of life, health behaviors, and treatment outcomes.”

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