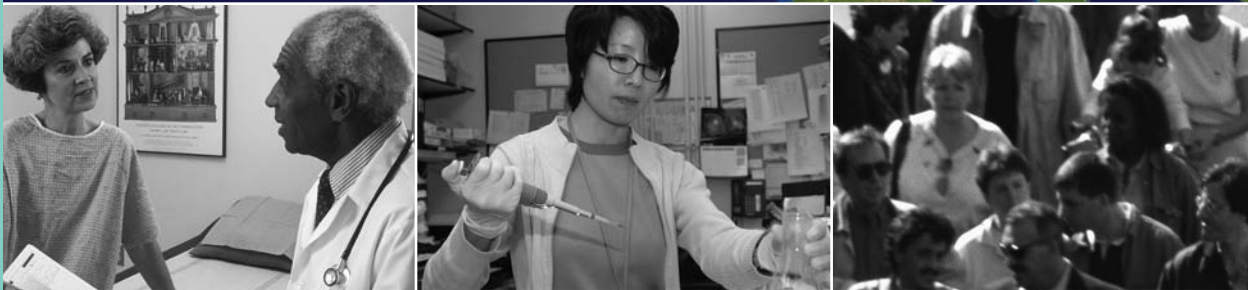


SEER

Surveillance, Epidemiology,
and End Results Program



“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

The SEER Program

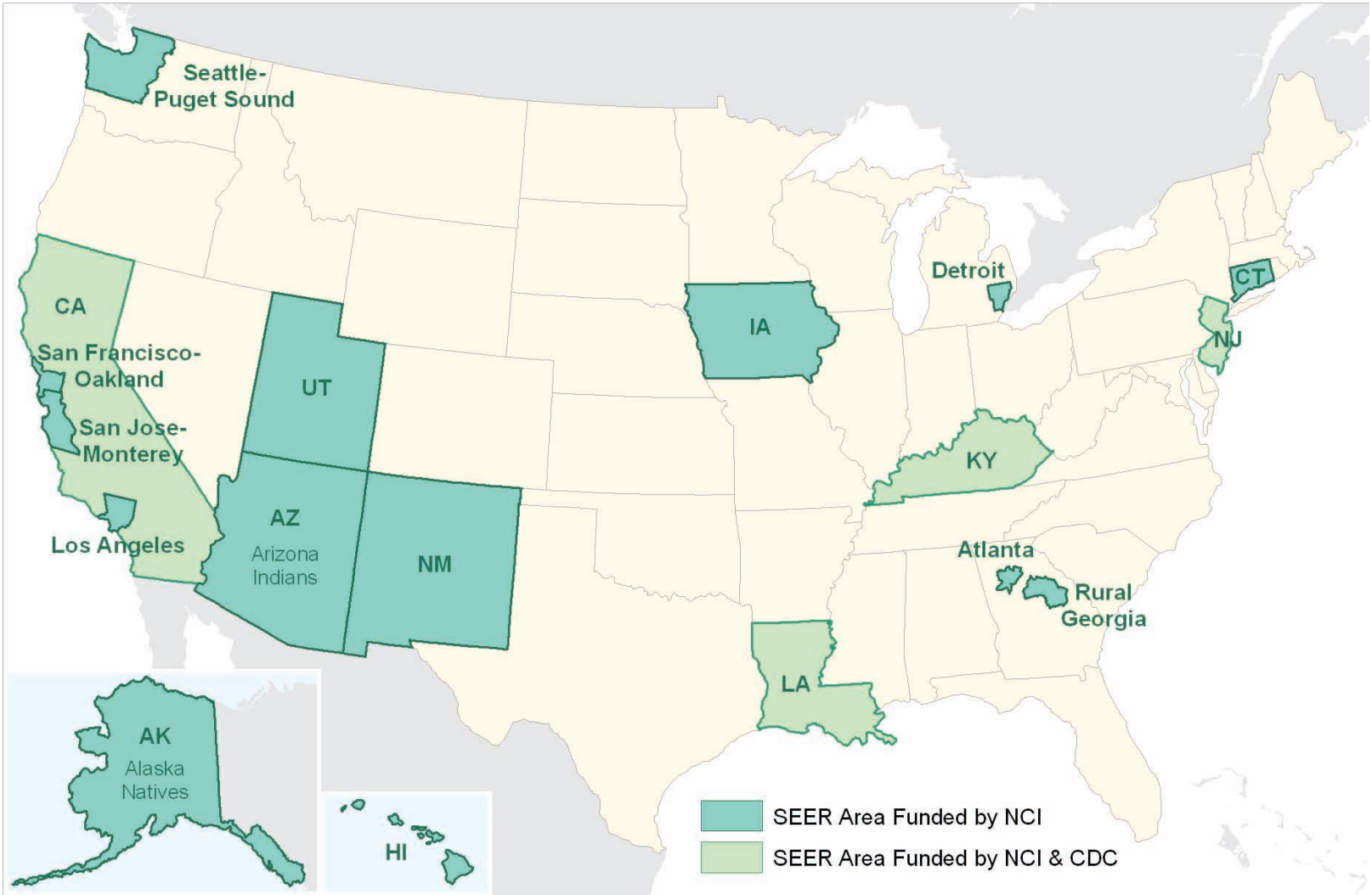
The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is an authoritative source of information on cancer incidence and survival in the United States (<http://seer.cancer.gov>). SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 26 percent of the US population. The SEER Program registries routinely collect data on patient demographics, primary tumor site, tumor morphology and stage at diagnosis, first course of treatment, and follow-up for vital status. The SEER Program is the only comprehensive source of population-based information in the United States that includes stage of cancer at the time of diagnosis and patient survival data.

SEER began collecting data on cancer cases on January 1, 1973, in the states of Connecticut, Iowa, New Mexico, Utah, and Hawaii and the metropolitan areas of Detroit and San Francisco-Oakland. In 1974-1975, the metropolitan area of Atlanta and the 13-county Seattle-Puget Sound area were added. In 1978, 10 predominantly black rural counties in Georgia were added, followed in 1980 by the addition of American Indians residing in Arizona. Three additional geographic areas participated in the SEER program prior to 1990: New Orleans, Louisiana (1974-1977, rejoined 2001); New Jersey (1979-1989, rejoined 2001); and Puerto Rico (1973-1989). The National Cancer Institute also funds a cancer registry that, with technical assistance from SEER, collects information on cancer cases among Alaska Native populations residing in Alaska. In 1992, the SEER Program was expanded to increase coverage of minority populations, especially Hispanics, by adding Los Angeles County and four counties in the San Jose-Monterey area south of San Francisco. In 2001, the SEER Program expanded coverage to include Kentucky and the remaining counties in California (Greater California); in addition, New Jersey and Louisiana once again became participants. For the expansion registries (Kentucky, Greater California, New Jersey, and Louisiana), NCI funds are combined with funding from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries and with funding from the states.

NCI staff work with the North American Association of Central Cancer Registries (NAACCR) to guide all state registries to achieve data content and compatibility acceptable for pooling data and improving national estimates. The SEER team is developing computer applications to unify cancer registration systems and to analyze and disseminate population-based data. Use of surveillance data for research is being improved through Web-based access to the data and analytic tools, and linking with other national data sources. For example, a new Web-based tool for public health officials and policy makers, State Cancer Profiles (<http://statecancerprofiles.cancer.gov>), provides a user-friendly interface for finding cancer statistics for specific states and counties. This Web site is a joint project between NCI and CDC and is part of the Cancer Control PLANET Web site (<http://cancercontrolplanet.cancer.gov>) which provides links to comprehensive cancer control resources for public health professionals.

Goals of the SEER Program

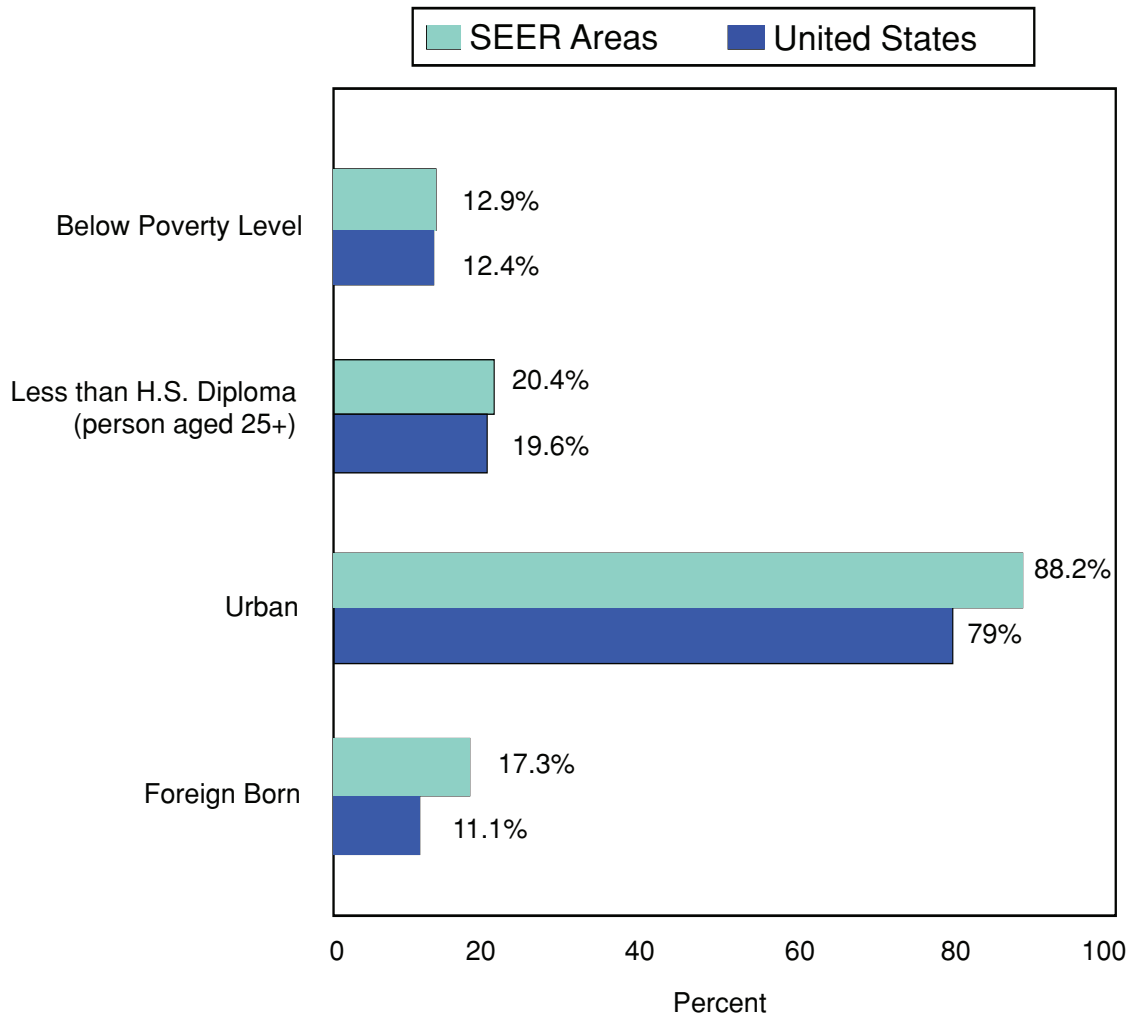
- Collect complete and accurate data on all cancers diagnosed among residents of geographic areas covered by SEER cancer registries.
- Conduct a continual quality control and quality improvement program to ensure the collection of high quality data.
- Periodically report on the cancer burden as it relates to cancer incidence and mortality, and patient survival overall and in selected segments of the population.
- Identify unusual changes and differences in the patterns of occurrence of specific forms of cancer in population subgroups defined by geographic, demographic, and social characteristics.
- Describe temporal changes in cancer incidence, mortality, extent of disease at diagnosis (stage), therapy, and patient survival as they may relate to the impact of cancer prevention and control interventions.
- Monitor the occurrence of possible iatrogenic cancers, i.e., cancers that are caused by cancer therapy.
- Collaborate with other organizations on cancer surveillance activities, including the CDC's National Program of Cancer Registries and NAACCR.
- Serve as a research resource to the National Cancer Institute providing for the conduct of studies that address issues dealing with cancer prevention and control as well as Program and registry operations.
- Provide research resources to the general research community including a public use file each year, and software to facilitate the analysis of the database.
- Provide training materials and web-based training resources to the cancer registry community.



SEER Reporting Areas and Registries

Reporting Area	Counties	Entered SEER Program	First Full Year of Data	Registry	Web Site
Alaska Natives	All	1999	1999	Alaska Native Tumor Registry	http://anthc.org/cs/chs/oanhr/
Arizona Indians	All	1973	1973	New Mexico Tumor Registry	http://hsc.unm.edu/epiccpro/
California:					
Los Angeles	Los Angeles	1992	1992	Los Angeles County Cancer Surveillance Program	http://www.usc.edu/lacsp/
San Francisco-Oakland	Alameda, Contra Costa, Marin, San Francisco, San Mateo	1973	1973	Greater Bay Area Cancer Registry	http://www.nccc.org/ResearchandTraining/research_gbareg.html
San Jose-Monterey	Monterey, San Benito, Santa Clara, Santa Cruz	1992	1992		
Greater California	All other CA counties	2001	2000	California Cancer Registry	http://www.ccrca.org/
Connecticut	All	1973	1973	Connecticut Tumor Registry	http://www.dph.state.ct.us/OPPE/hptumor.htm
Georgia:					
Atlanta metro area	Clayton, Cobb, DeKalb, Fulton, Gwinnet	1974	1975	Georgia Center for Cancer Statistics	http://www.sph.emory.edu/GCCS/
Rural Georgia	Glascocock, Greene, Hancock, Jasper, Jefferson, Morgan, Putnam, Taliaferro, Warren, Washington	1974	1978		
Hawaii	All	1973	1973	Hawaii Tumor Registry	http://www.crch.org/SerHTR.htm
Iowa	All	1973	1973	Iowa Cancer Registry	http://www.public-health.uiowa.edu/shri/
Kentucky	All	2001	2000	Kentucky Cancer Registry	http://web.kcr.uky.edu/
Louisiana	All	2001	2000	Louisiana Tumor Registry	http://www.lcltfb.org/registry.html
Michigan:					
Detroit metro area	Macomb, Oakland, Wayne	1973	1973	Metropolitan Detroit Cancer Surveillance System	http://www.karmanos.org/epid/
New Jersey	All	2001	2000	New Jersey State Cancer Registry	http://www.state.nj.us/health/cancer/njsr1b.htm
New Mexico	All	1973	1973	New Mexico Tumor Registry	http://hsc.unm.edu/epiccpro/
Utah	All	1973	1973	Utah Cancer Registry	http://uuhsc.utah.edu/ucr/
Washington:					
Seattle-Puget Sound area	Clallam, Grays Harbor, Island, Jefferson, King, Kitsap, Mason, Pierce, San Juan, Skagit, Snohomish, Thurston, Whatcom	1974	1974	The Cancer Surveillance System at the Fred Hutchinson Cancer Research Center	http://css.fhcc.org/

Characteristics of the SEER Population Compared With the Total United States Population (Source: 2000 Census)



SEER areas included in this figure are the States of Connecticut, Hawaii, Iowa, Louisiana, New Jersey, New Mexico, Utah; multi-country areas of Atlanta & rural Georgia, Detroit, San Francisco-Oakland, Seattle-Puget Sound, San Jose-Monterey, Los Angeles county, remaining counties of California; and American Indians/Alaska Natives in Arizona and Alaska.

SEER Population Coverage by Racial/Ethnic Group¹

	White ²	Black ²	American Indian / Alaska Native ²	Asian ^{2,3}	Native Hawaiian / Pacific Islander ^{2,4}	Hispanic ⁵
Total U.S.	211,460,626	34,658,190	2,475,956	10,242,998	398,835	35,305,818
Total SEER	49,492,549	7,872,174	1,044,137	5,455,680	278,584	14,271,987
SEER % of US	23.4%	22.7%	42.2%	53.3%	69.8%	40.4%
NORTHEAST						
Connecticut	2,780,355	309,843	9,639	82,313	1,366	320,323
New Jersey	6,104,705	1,141,821	19,492	480,276	3,329	1,117,191
SOUTH						
Atlanta	1,588,734	1,039,151	7,030	123,117	1,350	229,427
Kentucky	3,640,889	295,994	8,616	29,744	1,460	59,939
Louisiana	2,856,161	1,451,944	25,477	54,758	1,240	107,738
Rural Georgia	63,917	53,603	209	334	24	1,840
NORTH CENTRAL						
Detroit	2,784,071	1,011,038	13,375	101,386	979	118,641
Iowa	2,748,640	61,853	8,989	36,635	1,009	82,473
WEST						
Hawaii	294,102	22,003	3,535	503,868	113,539	87,699
New Mexico	1,214,253	34,343	173,483	19,255	1,503	765,386
Seattle-Puget Sound	3,253,688	169,042	57,340	289,373	20,679	213,215
Utah	1,992,975	17,657	29,684	37,108	15,145	201,559
San Francisco-Oakland	2,340,035	396,908	22,635	791,663	26,243	733,249
San Jose-Monterey	1,356,968	65,282	18,629	464,406	8,043	685,372
Los Angeles	4,637,062	930,957	76,988	1,137,500	27,053	4,242,213
Remainder of California⁶	11,835,994	870,735	215,094	1,303,944	55,622	5,305,722
Arizona⁷	--	--	255,879	--	--	--
Alaska⁷	--	--	98,043	--	--	--

¹ Source: U.S. Bureau of Census, Census 2000, Summary File 1, Table DP-1.

Note: See additional racial/ethnic populations covered by SEER registries at <http://seer.cancer.gov/registries/data.html>

² Since each person could report multiple races in the 2000 Census, race-specific counts and percentages in this table are based on persons self-reporting only one race.

³ SEER currently codes the following Asian groups: Chinese, Japanese, Korean, Asian Indian/Pakistani, Vietnamese, Hmong, Kampuchean, Thai, other Asian.

⁴ SEER currently codes the following Pacific Islander groups: Hawaiian, Chamorroan, Guamanian, Tahitian, Samoan, Tongan, Fiji Islander, New Guinean, other Melanesian, other Micronesian, other Polynesian, other Pacific Islander.

⁵ Hispanic ethnicity is tabulated independently of race, so Hispanic persons may be of any race.

⁶ Remainder of California calculated by subtracting the number for San Francisco-Oakland, San Jose-Monterey, and Los Angeles from the California state totals.

⁷ Only the American Indian/Alaska Native populations within these states are covered by SEER.

SEER Database

The SEER Program currently collects and publishes cancer incidence and survival data from 15 population-based cancer registries that cover one quarter of the US population. Data on more than six million in situ and invasive cancer cases are included in the database with more than 350,000 cases being added each year from the SEER coverage areas. The SEER Program is the only source of population-based historical as well as current information on patient survival and stage of disease. The mortality data reported by SEER are provided by the National Center for Health Statistics. The population data used in calculating cancer rates is obtained periodically from the Census Bureau.

Quality Control Activities

The SEER Program is considered the standard for data quality around the world. Quality control has been an integral part of SEER Program activities since its inception in 1973. Currently, quality control studies of various types, including casefinding, recoding, and reliability, are conducted in even number calendar years. The first two study types are carried out by a group of auditors which includes a qualified staff member from each SEER registry. The auditors travel to registries other than their own in order to collect data. These studies are designed using appropriate statistical procedures that provide for obtaining measures that can be used to assess the performance of registry. Registries that do well are recognized, and individuals that do well in the reliability studies are recognized as well. In odd numbered calendar years, training programs are conducted at selected SEER registries and in conjunction with the annual meeting of the National Cancer Registrars Association that focus on problem areas identified from the quality control studies as well as any changes being introduced in data collection procedures. Another quality control tool is the Data Quality Profile which is created for each registry. This profile provides an assessment of the extent to which each registry provides data that meet certain standards that pertain to the percent of cases for which a data item is unknown, reporting delay, and the quality of data on vital status. The SEER Program has also developed an extensive set of inter- and intra- field edits that are used to identify and correct errors in the data.

Research Activities

The SEER Program is also utilized by the NCI to conduct a program of special studies, referred to as Rapid Response Surveillance Studies, which address topical issues in cancer prevention and control. These studies may include the collection of additional information from cancer cases through surveys, personal interviews, medical record reviews, and/or the collection of biological materials. Research areas addressed in these studies include reasons for geographic and population differences in cancer patterns; the influence of occupational, environmental, sociocultural, and personal lifestyle factors on cancer incidence and patient survival, quality of life subsequent to diagnosis and treatment, and the diffusion into the medical community of the

use of state-of-the-art treatments. Further information about these studies can be obtained at <http://seer.cancer.gov/rapidresponse/>.

The SEER data have also been linked to data from the Centers for Medicare and Medicaid Services (CMS), and this linked database is available to researchers. The linkage of the SEER-Medicare data is a collaborative effort of the NCI, the SEER registries, and the CMS. To link SEER with Medicare data, the registries participating in the SEER program send individual identifiers for all persons in their files. These identifiers are matched with identifiers contained in Medicare's master enrollment file. The linkage was first completed in 1991 and has been updated in 1995, 1999, and 2003. For each of the linkages, 93 percent of persons age 65 and older in the SEER files were matched to the Medicare enrollment file. NCI and CMS plan to update the SEER-Medicare linkage every three years, with Medicare claims for linked cases extracted in the intervening years. The SEER-Medicare data are available to outside investigators for research purposes. Information on how to get access to the linked data is available at <http://healthservices.cancer.gov/seermedicare/>.

Data Availability

SEER data are updated annually, provided as a public service in print and electronic formats, and are routinely used by thousands of people including researchers, clinicians, public health officials, legislators, policymakers, and the lay public. Reports on cancer statistics can be obtained from the SEER web site (<http://seer.cancer.gov>). The SEER web site also provides instructions on how to access the SEER public use file free of charge which currently can be obtained on a CD-ROM or access may be provided through a server at NCI. Software is also provided free of charge by NCI that aids in the analysis of the SEER database (SEER*Stat) and can be used to analyze data from other cancer registries (SEER*Prep and SEER*Stat).

SEER Information Resources

See <http://seer.cancer.gov/> for a complete list of resources and tools on topics such as:

Finding Cancer Statistics

- Cancer statistics listed by common cancer type using *FastStats*
- *Cancer Stat Facts* – printable summaries of frequently requested statistics for common cancer types
- Annually updated statistical reports
- Statistics by geographic location

- Help finding and understanding cancer statistics and terminology
- Statistical resources beyond SEER
- Links to cancer treatment and clinical trial information

Information for Cancer Registrars

- Coding and staging manuals and data collection tools
- Resources for SEER registries including data submission requirements
- Links to resources for cancer registrar training
- Links to cancer registrar information available beyond SEER

Statistical Resources

- Help in determining which statistical tools to use
- Interactive internet tools to quickly access cancer statistics in tabular or graphical form
- Links to available software for generating cancer statistics
- SEER public-use data and other databases used in the calculation of cancer statistics
- Data reporting tools, including definitions of variables used in the reporting of cancer statistics
- Documentation for the SEER public-use data
- Funding opportunities in biostatistical research

SEER Publications

- Links to annually-updated statistical reports
- Statistical monographs
- Online order form for SEER publications available in hardcopy or on CD-ROM
- An extensive, searchable bibliography of articles authored by SEER registry and program staff
- Links to published resources beyond SEER

About SEER

- An overview of the SEER program
- Contact information
- Web site policies
- Detailed information about SEER registries and data
- Links to information about SEER studies (incl. *Rapid Response Surveillance Studies* & *Landmark Studies*) and related surveillance activities

Selected SEER Publications

See <http://seer.cancer.gov/publications> for a continually updated list of publications available online or in hardcopy.

SEER Cancer Statistics Review

Annual Report to the Nation on the Status of Cancer

Joint NCI/CDC Report: US Cancer Statistics, Incidence and Mortality

US Predicted Cancer Incidence, 1999: Complete Maps by County and State From Spatial Projection Models

Area Socioeconomic Variations in US Cancer Incidence, Mortality, Stage, Treatment, and Survival, 1975-1999

Cancer Incidence and Survival among Children and Adolescents, 1975-1995

Prostate Cancer Trends, 1973-1995

Racial/Ethnic Patterns of Cancer in the United States, 1988-1992

Collaborative Surveillance Activities

NCI staff responsible for managing the SEER Program act as liaisons to, and coordinate activities and collaborate with, a number of other organizations that are also involved in cancer surveillance and related disciplines.

The organizations include:

- American Cancer Society: <http://www.cancer.org>
- American College of Surgeons Commission on Cancer: <http://www.facs.org/cancer>
- Centers for Disease Control and Prevention: <http://www.cdc.gov>
- International Association for Research on Cancer: <http://www.iarc.fr/>
- International Association of Cancer Registries: <http://www.iacr.com.fr/>
- National Cancer Registrars Association: <http://www.ncra-usa.org/>
- North American Association of Central Cancer Registries: <http://www.naacrr.org/>
- World Health Organization: <http://www.who.int/en/>

Activities include setting standards for data collection by cancer registries, providing for the interchange of ideas and tools for cancer surveillance, training and providing educational materials for the credentialing of cancer registrars, leading workshops to provide advanced training in data collection and coding, collaborating in the analysis and reporting of cancer rates, and supporting efforts to expand existing cancer surveillance and to establish new cancer reporting systems. The NCI-SEER staff also provides technical assistance to registries in the CDC's National Program of Cancer Registries and to other registries around the world upon request, subject to available resources. This may include conducting workshops on data collection procedures and registry operations or training classes in the use of personal computer software used to format registry databases and to perform statistical analysis of the registry data. The SEER*Stat software is used by many of these registries including use by the CDC for analysis of data from the National Program of Cancer Registries.

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