Information Systems, Technology, and Dissemination in the SEER Program





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http://.seer.cancer.gov



The Surveillance, Epidemiology and End Results (SEER) Program is a premier source for cancer statistics in the United States. SEER collects and reports data on incidence, prevalence, and survival from specific geographic areas representing

26 percent of the U.S. population. In addition, SEER reports on cancer mortality for the entire country. SEER is a valuable source of evidence for evaluating cancer prevention and early detection (screening) programs and the quality of cancer care, identifying various risk factors (e.g., environmental, behavioral) related to cancer, documenting disparities, demonstrating the effectiveness of public health interventions, and guiding the translation of research into health policy and practice. To successfully provide these services and resources to the public and the research community, the SEER Program makes

extensive use of information systems and technology for both data collection and dissemination.

Information systems include various types of people, procedures, data, software, and hardware that are used to gather and analyze information. In a broad sense, the term "information systems" refers to the interaction between algorithmic processes and technology. This interaction can occur within or across organizational boundaries. An information system is not only the technology an organization uses, but also the way in which the organization interacts with the technology and the way in which the technology works with the organization's business processes. There are various types of information systems. This document provides a brief summary of the information systems and technology used by the SEER Program.

SEER Data Management System (SEER*DMS)

http://seer.cancer.gov/seerdms



The SEER Data Management System (SEER*DMS) is a unified, distributed application used by most SEER Registries.

SEER*DMS provides support for all core cancer registry functions: case finding (electronic pathology screening and coding), importing data, editing, abstracting, visual editing, quality control, matching/linkage to existing patient sets, record consolidation (health, supplemental, and other types of records), follow-up/follow-back, rapid case ascertainment, file extraction, tracking, reporting, abstracting, and data security. SEER*DMS is supplied as an appliance solution and includes a hardware/software package. Most enhancements, updates, and upgrades are developed centrally and distributed simultaneously to all locations. The program can be customized at individual locations. For example, SEER*DMS supports site-specific data fields and edits, and choice of matching algorithms. Customization also is facilitated by the modular design of the SEER*DMS workflow. SEER*DMS improves cost efficiency and reduces duplication of effort in system maintenance and administration. In addition, the program ensures data quality and consistency among the various registries by facilitating the collection and reporting of high-quality cancer incidence, treatment, and survival data, and by enabling data sharing among users.

Beyond its use by most SEER Registries, SEER*DMS is beneficial to other stakeholders, including SEER affiliates and other organizations (e.g., universities, researchers, public health departments, hospitals). The program is managed and operated by a governing body known as the Change Control Board (CCB), a committee that includes SEER*DMS project staff from NCI and Information Management Services, Inc. (IMS) and registry representatives. In addition, an active SEER*DMS Users Group focuses on best practices, user issues, and enhancements.

SEER*DMS was developed by IMS under a Division of Cancer Control and Population Sciences Biomedical Computing Contract (N02-PC-85018-55).

SEER

Electronic Pathology (E-Path) Software

http://www.aim.on.ca/products/ePath.jsp



Electronic Pathology (E-Path) supports and facilitates the process of efficiently collecting complete and accurate pathology information from

numerous hospital-based and freestanding pathology laboratories that report to SEER's centrally based cancer registries. In its basic form, E-Path reports cancers that are diagnosed through histology, which comprise about 95 percent of all cancers. The scope of casefinding can be extended by integrating E-Path with other types of electronic records, such as other laboratory results (e.g., diagnostic imaging, hematology) or admission, discharge, and transfer (ADT) information. Cancer registries rely heavily on pathology reports to identify new cases and determine key characteristics of a cancer required for its classification standards. Using information technology to standardize and automate this process is cost effective, labor saving, and reduces errors when compared to handson methods. E-Path uses an automated ICD-03

coding assistant in conjunction with natural language processing technology and pathology-specific terminology to automatically identify, index, abstract, and codify potentially reportable cancers from text-based reports. Cases then can be transmitted electronically from the pathology laboratory to the registry, increasing both the timeliness of case reporting and the quality of information transmitted.

Electronic Pathology software is supplied to the SEER Program under a contract with Artificial Intelligence in Medicine, Inc. (AIM). E-Path is provided to all SEER Registries and their major reporting laboratories and has been implemented in more than 200 reporting hospitals and laboratories in Atlanta, Connecticut, Detroit, Greater California, Hawaii, Iowa, Kentucky, Los Angeles, Louisiana, New Jersey, New Mexico, Northern California, and Utah.

SEER Web Dissemination

http://seer.cancer.gov

Through its Web site, http://seer.cancer.gov, the SEER Program provides interested users access to a variety of resources, including statistical tables, graphs, maps, data sets, tools, software, and publications. SEER data are accessed and used by thousands of researchers, clinicians, cancer registrars, public health officials, legislators,

policymakers, community groups, and members of the public. The SEER Web site serves as an authoritative source of information for anyone interested in U.S. cancer statistics, cancer research activities, and cancer surveillance methods. The materials available through the Web site are produced by the SEER Program or through collaborative efforts between SEER and affiliated organizations.



Annually Updated Statistical Reports

SEER Cancer Statistics Review (CSR), 1975-2006. Also known as CSR, this searchable online report, available at http://seer.cancer.gov/csr, includes tables showing cancer statistics by race, sex, age, and year of diagnosis for the major cancer sites and for all cancers combined.

Annual Report to the Nation on the Status of Cancer. Staff from the National Cancer Institute (NCI), the American Cancer Society (ACS), the Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries (NAACCR), and

other experts collaborate to provide an annual update on cancer occurrence and trends in the United States. Available at http://seer.cancer.gov/report_to_nation.

United States Cancer Statistics, 1999-20xx, Cancer *Incidence and Mortality Data.* A Web-based report, available at http://apps.nccd.cdc.gov/uscs, makes highquality cancer incidence and mortality data available to the general public. Staff from the CDC, SEER Registries, and NAACCR collaborate to ensure that the most up-todate data are provided on this Web site.

Special Reports

An Update on Cancer in American Indians and Alaska Natives, 1999–2004. This supplemental monograph, available at http://seer.cancer.gov/publications/aian, provides a comprehensive description of the cancer burden in the American Indian/Alaska Native population in the United States. The report gives medical providers and the public information about challenges faced by this ethnic group and promotes further research designed to improve survival and quality of life for members of this community.

Cancer Incidence and Mortality Patterns among Specific Asian and Pacific Islander Populations in the U.S. This statistical report, http://seer.cancer.gov/publications/apicancer, focuses on cancer incidence, mortality, and stage distributions among Asians and Pacific Islanders (API) residing in the United States. Health disparities are reported using the cancer experience of the non-Hispanic white population as the referent group.

Selected Comparisons of Measures of Health Disparities: A Review Using Databases Relevant to Healthy People 2010 Cancer-Related Objectives. This monograph, available at http://seer.cancer.gov/publications/disparities2, presents results from 22 separate analyses in 10 case studies and includes assessments of socioeconomic, racial, ethnic, and geographic disparities in a range of cancer-related outcomes such as mortality, incidence, risk factors, and screening. The report demonstrates that choosing particular methods to measure health disparities can make a substantive difference in the results and interpretation of data. The Web version of this monograph is 508 compliant.

Special Reports (continued)

SEER Survival Monograph: Cancer Survival Among Adults: U.S. SEER Program, 1988–2001, Patient and Tumor Characteristics. This monograph examines cancer survival with regard to patient and tumor characteristics. The data represent cancer in approximately 25 percent of the U.S. population. Patient characteristics include age, race, and sex. Tumor characteristics vary by cancer site and may include subsite, size of tumor, extension of the tumor, lymph nodes positive, distant metastases, and histologic type.

Cancer Mortality Maps & Graphs. This Web site shows geographic patterns and cancer death rate trends for more than 40 cancers for the time period 1950–1994. Go to http://seer.cancer.gov/statistics and click on the Cancer Mortality & Graphs link. Click on the Cancer Mortality Maps & Graphs Web site link and then Interactive Mortality Charts and Graphs and Customizable Mortality Maps to create maps such as this one by choosing from the variables shown.





For information on additional published reports and statistical monographs, visit http://seer.cancer.gov/publications or the searchable SEER Bibliography at http://seer.cancer.gov/pubsearch.

The SEER Bibliography

The SEER Bibliography, available at http://seer.cancer.gov/pubsearch, is a comprehensive bibliography of SEER publications produced by registry and program staff. As

of the fall of 2009, approximately 6,000 SEER publications were available via the SEER Bibliography.



Up-to-Date Web-Based Cancer Statistics

Cancer Stat Fact Sheets. The Cancer Stat Fact Sheets are a collection of statistical summaries for various common cancer types. Go to http://seer.cancer.gov/statfacts to access Cancer Stat Fact Sheets such as this one for myeloma.



http://seer.cancer.gov/statfacts/html/mulmy.html

Cancer Query Systems. The Cancer Query Systems data-

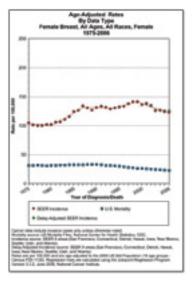
retrieval applications, available at http://seer.cancer.gov/

set of cancer statistics than Fast Stats, but also require

more user input.

canques/index.html, provide more flexibility and a larger

Fast Stats. The Fast Stats interactive tool links to tables, charts, and graphs containing cancer statistics for all major cancer sites by age, sex, race, and time period. Go to http://seer.cancer.gov/statistics and click on the Fast Stats link to create a chart such as this by choosing from the variables listed.



State Cancer Profiles. State Cancer Profiles are a comprehensive system of dynamic maps and graphs that enable the investigation of cancer trends at the national, state, and county levels.

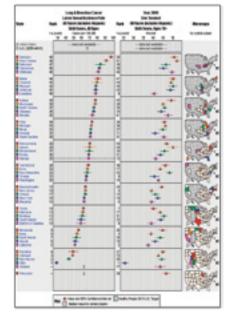
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http://seer.cancer.gov/canques/incidence.html



http://statecancerprofiles.cancer.gov/micromaps

Access to Datasets and Tools

SEER releases limited-use data files, SEER*Stat analytical software, the HD*Calculator, and the SEER Bibliography, all of which are made available to the public via the SEER Web site. These data and software tools can be used to address issues in cancer research.



SEER*Stat. SEER*Stat statistical software provides a convenient, intuitive mechanism for analyzing SEER and other

cancer-related databases. It is a powerful personal computer tool for producing statistics for use in studying the impact of cancer on a population. Available at: http://seer.cancer.gov/seerstat

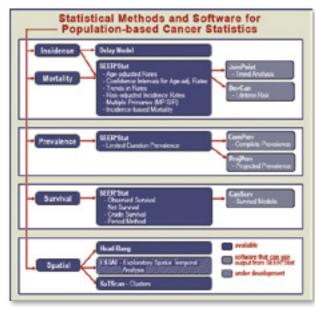


*HD*Calc.* This statistical software generates multiple summary measures for evaluating and monitoring health dispar-

ities. HD*Calc can be used either as an extension of SEER*Stat or on its own with other population-based health data. Data such as cancer rates, survival, and stage at diagnosis can be used with HD*Calc to generate absolute and relative summary measures of disparity. Available at: http://seer.cancer.gov/hdcalc

SEER*Prep. SEER*Prep is used to convert user-supplied ASCII text data files to the SEER*Stat database format, allowing analysis of population-based registry data using SEER*Stat. Available at: http://seer.cancer.gov/seerprep

SEER also provides various analytic software tools that have been developed for the analysis and reporting of cancer statistics. More information about these tools can be found at http://seer.cancer.gov/resources.



http://srab.cancer.gov/software

SEER and the Biomedical Informatics Grid

http://cabig.cancer.gov



The Cancer Biomedical Informatics Grid®, known as caBIG®, was launched by NCI's Center for Bioinformatics (NCICB) in February 2004. The goal of caBIG® is to accelerate the development of new approaches for the prevention, detection, diagnosis, and treatment of cancer in the United States by developing a collaborative network of informatics infrastructures, tools, and ideas that

enables the collection, analysis, and sharing of data and knowledge along the entire research pathway, from the laboratory bench to the patient's bedside.

caBIG® encourages networking through the development of open access and open-source software, applications, tools, and database technologies. Since its debut, caBIG® has expanded to include cancer centers and numerous other NCI-supported research endeavors. Researchers are developing software and networks that will make other cancer-related databases and networks (i.e., SEER) more accessible on the caBIG® Grid.

CaSEER: SEER Data on the Grid

Through caBIG®, the SEER Program is able to link its data to other cancer-related databases and networks and provide researchers with access to information and interactive tools that are essential for cancer surveillance. By combin

ing its resources with other databases on the grid, SEER contributes to the development of common standards such as shared vocabulary, data elements, data models, analytical services, and interoperable applications.

Future Directions for SEER

The SEER Program aims to become more efficient and effective at data collection by facilitating the expansion, standardization, and interoperability of its data sources and electronic reporting capabilities. Currently, the SEER Program has four priority data areas for electronic reporting:

- 1. Diagnosis
- 2. Comorbidities
- 3. Detailed treatment
- 4. Electronic radiology data

Future sources for collecting and coding electronic data may include Health Maintenance Organizations (HMOs), including the Cancer Research Network (CRN), their affiliated research programs and staff, enrolled patient populations, and data systems. Access to these entities will facilitate timely access to the electronic health records of numerous doctors, pathologists, radiologists, primary care providers, and other medical entities. Collaboration with other networks, such as caBIG®, the Centers for Medicare and Medicaid Services (CMS), hospitals, and other similar resources, also will expedite the SEER Program's ongoing efforts to capture, compile, and process medical data in an efficient manner. This data will enable the SEER program to more effectively conduct studies on access to care, cancer prevention, early detection, treatment, long-term care, outcomes, and other important cancer-related issues.

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