Data Flow in NCI's SEER Registries

The National Cancer Institute’s (NCI) Surveillance, Epidemiology, and End Results (SEER) Program registries are among the most accurate and complete population-based cancer registries in the world. The SEER Program is comprised of 18 cancer registries, including state, central, metropolitan, and the Alaska Native registries. Together, they gather data from approximately 28 percent of the U.S. population.

SEER Program registries collect data from 18 geographic areas across the United States. There are 10 state registries (Connecticut, Georgia, Greater California, Hawaii, Iowa, Kentucky, Louisiana, New Jersey, New Mexico, and Utah), five metropolitan area registries (metropolitan Atlanta and rural Georgia; San Francisco-Oakland; Los Angeles; Seattle-Puget Sound; and Detroit), and three Native American registries (Alaska Native Tumor Registry, Arizona Indians and the pilot Cherokee Nation Cancer Registry). The primary objective of the SEER Program registries is to maintain high-quality population-based cancer reporting systems and use these systems to collect cancer-related data.

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.

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This diagram illustrates the temporal sequence of cancer surveillance, which begins with primary data collection and proceeds through a complex process to data dissemination and analysis. This process is a result of the SEER Program’s collaboration with many organizations.
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This diagram depicts the flow of information through the SEER Program registries. Initially, the SEER Program’s central cancer registry receives cancer-related data from local sources, including hospital registries, pathology laboratories, and physicians’ offices. SEER performs active follow-up of patients for vital status through these sources. Additional information and follow-up data are received passively by linking with other organizations, such as the Social Security Administration, state vital records departments, the National Death Index, and the Centers for Medicare & Medicaid Services.

The SEER Program’s 18 cancer registries are responsible for consolidating and validating data and for removing all personal identifiers (e.g., name, social security number, address, date of birth). Once this information has been removed, data are sent to SEER on a regular basis (at least annually), where they are combined with other data and stored in a central database. NCI then disseminates these datasets to researchers and the general public via fact sheets, reports, limited-use databases, analytical software (i.e., SEER*STAT or SEER*PREP), and Web sites (e.g., http://www.seer.cancer.gov).