Sequence of Cancer Surveillance Data Flow

Data Collection Sources

Hospitals, clinicians, pathologists, and others

Case Consolidation at Population-Based Central Registries

Active follow-up by registry personnel with hospitals,

physicians, patients, families

Passive follow-up via linkages with state mortality

records, NDI, SSA, CMS

Racial/ethnic identification

**Data Compilation by Population Registries or
National Programs**

Incorporation of CMS records, mortality data from NCHS,

U.S. Census Bureau

Quality improvement

Data Dissemination and Analysis

Publicly accessible publications and reports,

press releases, Web sites

Database development (e.g., public-use analytic file,

SEER-Medicare linked database, SEER-NLMS)

Primary Data Collection

↓

Data Compilation

↓

Data Dissemination and Analysis

NDI – National Death Index
SSA – Social Security Administration
CMS – Centers for Medicare & Medicaid Services
NCHS – National Center for Health Statistics
NLMS – National Longitudinal Mortality Study

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.

SEER Education and Training Programs

The SEER Registries offer various training resources for cancer registrars through the SEER Web site. These resources include self-instructional manuals for tumor registrars, and training for Multiple Primary and Histology Coding Rules. For more information, visit SEER's training Web site at *http://seer.cancer.gov/training*.

Publications

The SEER Program produces publications that include cancer statistics and address health disparities. These publications can be viewed at *http://seer.cancer.gov/publications* (for reports/monographs) and *http://seer.cancer.gov/registrars* (for education/training manuals).

For more information, contact:

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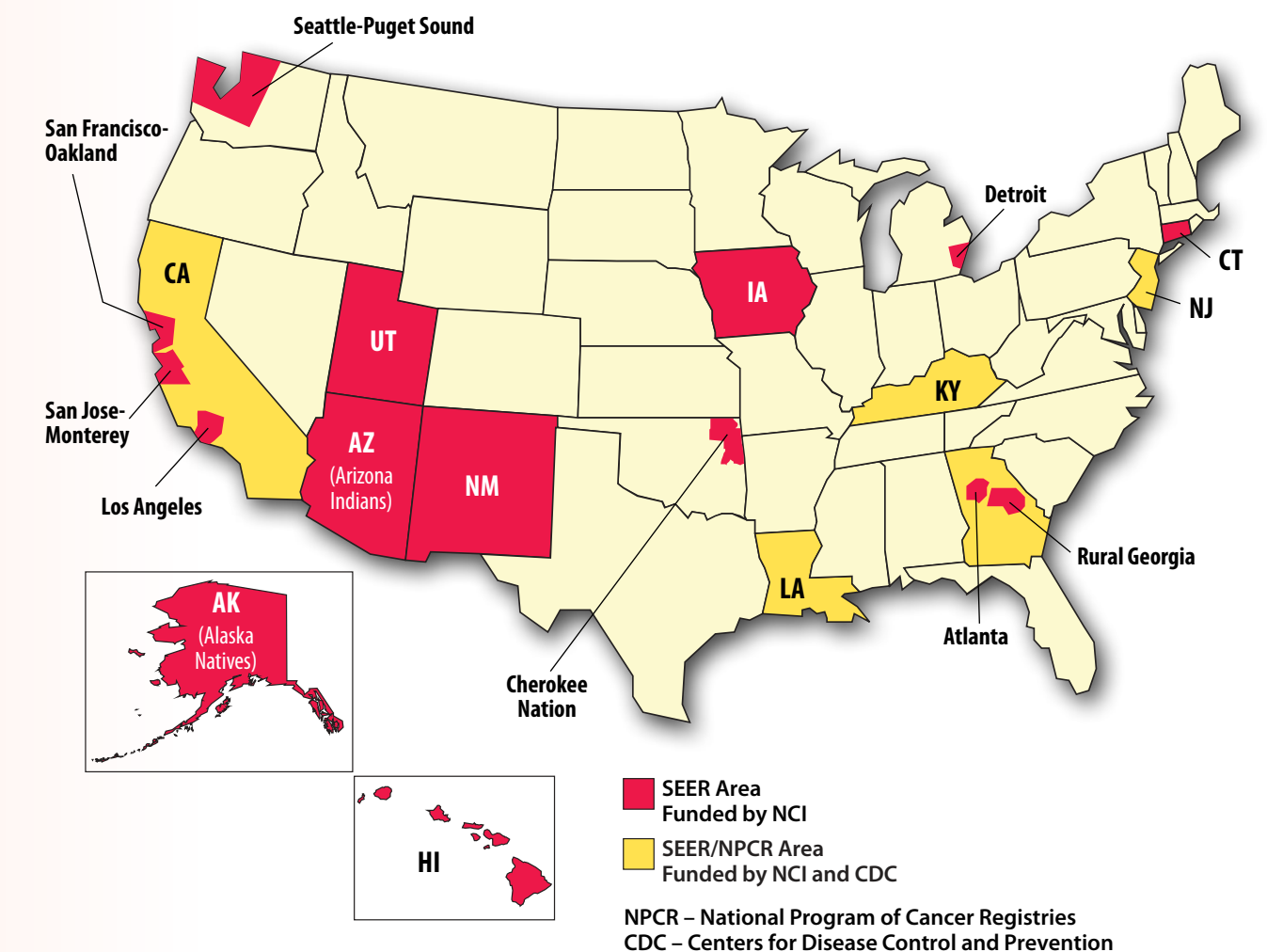
Data Flow in NCI's SEER Registries

www.seer.cancer.gov

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 and San Jose-Monterey; 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.

Seattle-Puget Sound
San Francisco-Oakland
Detroit
CT
CA
IA
NJ
UT
KY
San Jose-Monterey
AZ (Arizona Indians)
NM
Los Angeles
LA
Rural Georgia
AK (Alaska Natives)
Atlanta
Cherokee Nation
HI

SEER Area Funded by NCI
SEER/NPCR Area Funded by NCI and CDC

NPCR – National Program of Cancer Registries
CDC – Centers for Disease Control and Prevention

Data Flow in NCI's SEER Program Registries

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*).

Data Sources
Case Identification

Patient   Doctor   Pathology Lab   Hospital Registries

Active Follow-up

Population-Based Central Registry (18 SEER Registries)
Case Consolidation

Confidential Case Record
- Demographic data
- Clinical/diagnostic information (e.g., histology/stage)
- Treatment plan

Racial/Ethnic Identification
NAACCR Asian/Pacific Islander Identification Algorithm (NAPIIA)
NAACCR Hispanic Identification Algorithm (NHIA)
American Indian/Alaska Native (Indian Health Service)

Record De-Identification

Linkages for Vital Status
- State Mortality Data
- National Death Index

NDI

- Social Security Administration

- Centers for Medicare & Medicaid Services

CMS

Passive Follow-up

Population Data Sets
- Death Rates: National Center for Health Statistics, Centers for Disease Control and Prevention (CDC)

CDC

- Population Counts: U.S. Census Bureau

National Cancer Institute's SEER Program

NATIONAL CANCER INSTITUTE

SEER — SURVEILLANCE EPIDEMIOLOGY AND END RESULTS

- Quality Improvement
- Training
- SEER Manuals

SEER Research Resources
- Public Use Data File
- Publications and Reports (e.g., *SEER Cancer Statistics Review*)
- Interactive Web Sites (e.g., Fast Stats, State Cancer Profiles, SEER Bibliography)
- Researcher Access (e.g., SEER*Stat, Cancer Query Systems)
- SEER-Medicare Research Database
- SEER and the National Longitudinal Mortality Study (SEER-NLMS)
- Residual Tissue Repository (RTR, biospecimens and data)

National Reports

Annual Report to the Nation on the Status of Cancer
(SEER, State Registries funded by CDC/National Program of Cancer Registries (NPCR), The North American Association of Central Cancer Registries (NAACCR), American Cancer Society (ACS)), and others.

United States Cancer Statistics
(CDC, NAACR, NCI)

Cancer Facts & Figures
(SEER , ACS, CDC)

International Reports

Cancer in North America
(SEER, Canadian Provinces and Territories , CDC , NAACCR)

Cancer Incidence in Five Continents
(World Health Organization, International Agency for Research on Cancer)