

Surveillance Research Program (SRP)

Surveillance, Epidemiology and End Results (SEER) Program Metrics



In 2020 the SEER Program consisted of 16 central cancer registries (19 geographic areas, representing 35% of the US population) and collected approximately 550,000 cancer cases per year. As of 2021, coverage has grown to 48% and 800,000 cases per year.

SEER Research Support

Research Studies

- Clinical trials, cohort studies, observational studies, patient contact
- Study planning, including design methodology, pre-screening for potential sample size
- Patient or sample identification for recruitment for rapid case ascertainment in real time and retrospective case identification
- Follow-up for patients in studies, including outcomes such as survival and cause of death
- Tissue acquisition linked to registry data
- Residual Tissue Repository (RTV): 2006–2014
- Virtual Tissue Repository (VTR) Pilot: 2015–present
- Representativeness of study participants in comparison to SEER population-based data
- SEER-Medicare linkages

Multiple Levels of Health Care Delivery

- SEER data are utilized for federal, state, and nonprofit reports and policy changes
- Hospital and industry utilization to better understand patient populations
- Data collaboration with industry partners, including pharmacy, claims, genomics, labs, and commercial insurers
- Integration with NCI-Designated Cancer Centers, including assessment of catchment areas and integration with research portfolios

SEER Data in Publications (1973-2020)

- 17,000+ using SEER Data for the Primary Analysis
- 86,000+ referencing SEER Data
- 2,200+ Using SEER-Medicare, SEER-Consumer Assessment of Health Providers and Systems (CAHPS), and SEER-Medicare Healthcare Outcomes Survey (MHOS) Linked Data

Research Grants and Contracts (2020)

- Primary grant support: N=61/\$37.3M
- Secondary grant support: N=13/\$4.6M
- Grants using SEER data establishing background: N=56/\$21.5M
- Intramural: N=10/\$12.9M
- Grant Mechanisms
 - R01: 32
 - P01/P20: 8
 - U01/U54: 9
 - P30: 23
 - R21: 5
 - Other: 53
- Research and Development Contracts: N=32/\$46.3M

Data Dissemination (2020)

- Volume and type of data use agreements (DUAs)
 - Research DUA's: 12,800
 - Treatment DUA's: 3,000
- Aggregate summaries, including fact sheets, 'Did You Know?' videos, Cancer Statistics Review
- Online statistical tools: Joinpoint (5,318 downloads), SEER*Stat (304,856 analyses), CI Rank, SEER Cancer Query Systems (Casques)
- Websites: SEER, SRP, Cancer Trends Progress Report, CISNET, Cancer Prevalence and Cost of Care Projections, Geographic Information Systems (GIS), Know Your Chances, Small Area Estimates, State Cancer Profiles, StatFund

SEER Infrastructure and Collaborations

Centralized Resources

- Development and dissemination of resources available to the surveillance community
 - Solid Tumor Rules
 - SEER Program Coding Manual
 - SEER*Educate
 - SEER Training Website
 - Ask a SEER Registrar
 - SEER Inquiry System (SINQ)
 - SEER*Rx
 - SEER Abstracting Tool (SEER*Abs)
 - Extent of Disease (EOD)
 - Summary Stage
 - Hematopoietic Rules and Database
 - Application Programming Interface (API) for data collection of stage
 - SEER*Data Management System (DMS)
 - SEER*Registry Staging Assistant (SEER*RSA)
 - Glossary for registrars
 - Casefinding Lists
- Data use and data quality standards and guidelines
- Working with nonprofit partners (ACS, AJCC, ASCO, CAP, CDC, NAACCR, NCCN, NCRA) to adapt to changing standards for clinical care (AJCC TNM) and relevant data items, including predictive and prognostic variables
- SEER-led collaborative efforts with external commercial partners, including pharmacies, processors, insurers, genomic data labs, surgical path labs, electronic medical record (EMR) vendors
- Leveraging Match*Pro, a large scale linkage application
- Validated resources for standardized use of novel data, including Healthcare Common Procedure Coding System (HCPCS) and National Drug Codes (NDCs)
- CanMED

Fostering Community

- Sharing best practices across the surveillance community with federal and state partners, and hospital registries
- Partnerships with cancer centers, industry, inter- and intra-governmental agencies, surveillance programs
- Collaborative standards for data collection
- Annual Report to the Nation on the Status of Cancer (partnership with NAACCR, CDC, ACS)
- Custom presentations and trainings for cancer registrars at registry, state, and national levels.
- National meetings and plenaries including NAACCR, NCRA, ASCO, AACR, CI4CC
- Fellowships and training workshops at national, state, and local levels

SRP Programmatic Strengths

Innovative Methodologies and Tools

- Novel statistical and analytic approaches
- Data visualization
- Research-enabling systems, including SEER*Stat, Joinpoint, and DevCan
- Automation tools for data capture, including natural language processing, deep learning, and spatial analysis
- New measures of cancer burden (e.g., modeling)

Data Quality Activities

- New and routine quality initiatives with active revision of historical data
 - Comprehensive quality improvement program with Quality Audit Plans (QAPs)
- Validation of quality of new data sources
- Patterns of Care Studies provide information on variations in treatment across different population groups
- Rapid Response Surveillance Studies (RRSS) to pilot innovative methods that can be scaled across SEER

Extended Clinical Detail and Relevance

- Additional tumor characterization based on CAP protocols, AJCC 8th ed., NCCN guidelines
- Expanded treatment capture through linkages with key data sources (e.g., pharmacies)
- Guideline-directed data capture (e.g., NCCN and AJCC directed biomarkers)

Population Representativeness for the US

- Clearly defined catchment area with large segments of diverse populations
- Access to real-time data for research
 - Rapid Case Ascertainment based on electronic pathology (e-path) reporting, claims-based treatment, and subset of pharmacy data
- Percentage of 2018 cases with e-path reporting by registry: 24%-96%*
*Lower end of range is a conservative estimate

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