



# Surveillance, Epidemiology, and End Results (SEER) Surveillance Research Program (SRP) Metrics, 2018

The SEER Program consists of 16 central cancer registries (19 geographic areas, representing 35% of the US population) and collects approximately 550,000 cancer cases per year.

## SEER Research Support

### Research Studies

- Clinical trials, cohort studies, observational studies, patient contact
- Study planning, including design methodology, prescreening 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: 2006–2014
- Virtual Tissue Repository 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 is utilized for federal, state, and nonprofit reports and policy changes
- Hospital and industry utilization to better understand patient population
- Data collaboration with industry partners, including pharmacy, claims, genomic, labs, and commercial insurers
- Integration with NCI-Designated Cancer Centers, including assessment of catchment areas and integration with research portfolios

## SEER Data in Publications (1973–2018)

- 9,600+ Using SEER data for the primary analysis
- 50,000+ Referencing SEER data
- 2,000+ Using SEER-Medicare, SEER-Consumer Assessment of Healthcare Providers and Systems (CAHPS), and SEER-Medicare Healthcare Outcomes linked data

## Research Grants & Contracts (2018)

- Primary grant support: N=45/\$31.0M
- Secondary grant support: N=7/\$7.4M
- Grants using SEER data establishing background: N=88/\$17.8M
- Intramural: N=12/\$13.1M
- Ancillary grant support
  - Statistical Modeling (CISNET)
  - Health Disparities
  - Spatial Uncertainties
  - Residential Histories
  - New Informatics Tools & Methods
- Grant mechanisms
  - R01: 32
  - U01/U54: 11
  - R21: 4
  - P01/P20: 6
  - P30: 53
  - Other: 38
- Research and Development contracts: N=39/\$45.9M

## Data Dissemination (2018)

- Volume and type of publicly available datasets (8,000 downloads)
- Custom dataset requests (1,350 users)
- Volume and type of data use agreements (DUAs)
  - Research DUAs: 8,500
  - Treatment DUAs: 2,350
- Aggregate summaries, including fact sheets, Did You Know videos, Cancer Statistics Review
- Online statistical tools: Joinpoint (3,915 downloads), SEER\*Stat (232,480 analyses), CI Rank, Cancer Query systems
- 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
  - Extent of Disease (EOD)
  - Summary stage
  - Application Programming Interface (API) for data collection of stage
  - SEER\*Data Management System (DMS)
- Data use standards and guidelines
- Working with nonprofit partners (ACS, AJCC, ASCO, CAP, CDC, NAACCR, NCCN) to adapt to changing standards for clinical care (AJCC 8th) and relevant data items, including predictive and prognostic variables
- SEER-led collaborative efforts with external commercial partners, including pharmacies, claims 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 partners, state 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 clinicians at the registry level, individual cancer centers, and research investigators
- National meetings and plenaries including NAACCR, ASCO, AACR, CI4CC
- Ask a SEER Registrar (3,081 queries)
- SEER\*Educate, manuals, online training, fellowships, and training workshops at national, state, and local level

## Contact

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## 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 therapy across different population groups
- Rapid Response Surveillance Studies to pilot innovative methods that can be scaled across SEER

### Extended Clinical Detail & Relevance

- Additional tumor characterization based on CAP protocols, AJCC 8th, 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 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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