

Surveillance Research Program: Measuring What We Do

RESEARCH SUPPORT

“How is SEER advancing the state of science?”

| Research Grants (2016) | Publications (1973-2016) | Research Study Support Provided | Integration across Multiple Levels of Health Care Delivery |
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| <ul style="list-style-type: none"> Primary grant support N=45/ \$25,075,315 Secondary grant support N=6/ \$1,911,224 Grants using SEER data establishing background N= 45/ \$15,452,525 Grant mechanisms <ul style="list-style-type: none"> R01: 26 U01/U54: 6 R21: 5 PO1: 9 P30: 15 Other: 35 R and D contracts N=73/ \$48,229,581 Intramural N=12/ \$5.72 million Ancillary grant support <ul style="list-style-type: none"> Statistical Modeling (CISNET) Health Disparities Spatial Uncertainties Residential Histories | <ul style="list-style-type: none"> 7,398 Using SEER data for the primary analysis 40,230 Referencing SEER data 1,600 Using SEER-Medicare linked data | <ul style="list-style-type: none"> Clinical Trials/Cohort/Observational/Patient contact Study planning (design/methodology/prescreening for potential sample size) Patient/sample identification for recruitment <ul style="list-style-type: none"> Rapid case ascertainment in real time Retrospective case identification Follow up for patients in studies (outcomes – survival and cause of death) Tissue acquisition linked to registry data <ul style="list-style-type: none"> Residual Tissue Repository (2006-14) Virtual Tissue Repository- Pilot 2015 Representativeness of study participants (compare study subjects to SEER population-based data) | <ul style="list-style-type: none"> Policy and reports (public health) (federal, state, non-profit) Hospital/industry utilization to understand patient population <ul style="list-style-type: none"> Data integration/collaboration with industry (pharmacy chains/genomic labs/commercial insurers) Integration with NCI-Designated Cancer Centers <ul style="list-style-type: none"> Catchment area assessment Integration with research portfolio at cancer centers |

PROGRAMMATIC STRENGTHS

“What makes SEER unique/novel from other registries?”

| Innovative Methodologies and Tools | Quality Activities | Extended Clinical Detail and Relevance | Population Representative for US |
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| <ul style="list-style-type: none"> Novel statistical and analytic approaches Data visualization Research enabling initiatives/systems (SEER*Stat/ Joinpoint, DevCan, etc.) Automation tools for data capture (NLP, deep learning, GIS spatial analysis) Approaches to external partnerships for data exchanges <ul style="list-style-type: none"> Centralized linkages Data exchange New measures of cancer burden (e.g., prevalence estimates) | <ul style="list-style-type: none"> Monitoring data quality with active revision of historical data (PSA example) New and routine quality initiatives Routine Comprehensive QA/QI program Formalized Quality Audit Plan for data Validation of potential new data source quality Patterns of Care Studies Rapid Response Surveillance Studies | <ul style="list-style-type: none"> Supplemental case/tumor characterization based on CAP protocols, AJCC 8th, NCCN guidelines Linkages to improve characterization of cases (genomic data – GHI, Myriad, et al) Guideline-directed data capture (e.g., NCCN and AJCC directed biomarkers) Expanded treatment capture (e.g., detailed initial and subsequent for infusion and orally administered + radiation) | <ul style="list-style-type: none"> Clearly defined catchment area with depth of data unavailable from other surveillance sources Access to real-time data for research Rapid Case Ascertainment based on <ul style="list-style-type: none"> ePath reporting Claims-based treatment Subset of pharmacy data |



INFRASTRUCTURE

“What platforms does SEER provide to support research?”

| Centralized Resources | Data Dissemination | Fostering Community |
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| <ul style="list-style-type: none"> • Development and dissemination of resources available to the surveillance community <ul style="list-style-type: none"> • EOD • Summary stage • APIs for data collection of stage • SEER*DMS • LinkPro (large-scale linkage applications) • Working with not-for-profit partners (AJCC, NAACCR, CAP, NCCN, CDC) to adapt to changing standards for clinical care (AJCC 8th), relevant data items (predictive/prognostic variables) • SEER-led collaborative efforts with external commercial partners (pharmacies, claims processors, insurers, genomic data labs, surgical path labs, EMR vendors) • Validated resources for standardized use of novel data (HCPCS, NDC codes mapping file for public release and integration into data capture process) • Standards and guidelines for appropriate data use | <ul style="list-style-type: none"> • Volume and type of publicly available datasets (>4500 downloads/year) • Custom data set requests (698 users) • Volume and type of data use agreements • Aggregate summaries (Fact sheets, <i>Did You Know</i> videos, Cancer Statistics Review) • Online statistical tools/support <ul style="list-style-type: none"> • Joinpoint (3,205 downloads annually) • SEER*Stat (>191,000 analyses annually) • Others: CI Rank, Prevalence estimations, Cancer Query systems, etc. • Cancer Trends Progress Report: http://progressreport.cancer.gov • CISNET: https://cisnet.cancer.gov • Cancer Prevalence and Cost of Care Projections: http://costprojections.cancer.gov • Geographic Information Systems (GIS): http://gis.cancer.gov • Know Your Chances: http://knowyourchances.cancer.gov • SEER Website: http://seer.cancer.gov • SEER Training Modules: https://training.seer.cancer.gov • Small Area Estimates: http://sae.cancer.gov • SRP Website: http://surveillance.cancer.gov • State Cancer Profiles: http://statecancerprofiles.cancer.gov • StatFund: https://statfund.cancer.gov | <ul style="list-style-type: none"> • Sharing best practices across the surveillance community (federal partners, state and hospital registries) • Partnerships (cancer center, industry, inter- and intra-governmental agencies¹, surveillance programs) • Collaborative standards for data collection • Annual Report to the Nation on the Status of Cancer (partnership with NAACCR, CDC, ACS) • Research investigator training and support <ul style="list-style-type: none"> • Custom training of clinicians at the registry level • National meetings, workshops, and plenaries (NAACCR, ASCO, AACR, CI4CC) • Individual cancer center presentations and training • Public face for cancer statistics • Surveillance training national, state, and local <ul style="list-style-type: none"> • Ask a SEER Registrar (2,062 queries) • SEER*Educate, manuals, online training, fellows, workshops, WebEx seminars |

¹ DCEG, DCP

