

ACTCR Meeting

Fall 2021 (October 15, 2021)

Texas Cancer Registry

Texas Department of State Health Services



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Agenda – October 15



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MEETING AGENDA

Advisory Committee to the Texas Cancer Registry (TCR)
Friday, October 15, 2021, 11:30-1:30 PM

Teleconference Only

Presentation, Video and Audio: <https://global.gotomeeting.com/join/575257917>
Phone Only: 1-646-749-3122, Passcode: 575-257-3122

I. Welcome – Philip Lupo, PhD, MPH, ACTCR Chair	
11:30–11:40 pm	<ul style="list-style-type: none">• Call to Order• Approval of Minutes• Welcome New Members and Staff• Caitlin Murphy, PhD, Dept of Health Promotion and Behavioral Sciences, UTHealth• Mary Edgerton, MD, Dept of Pathology, UT MD Anderson, School of Health Information Sciences, UTHealth• Gary Rutenberg, PhD, TCR, DSHS
II. General Updates – Melanie Williams, PhD, TCR Branch Director	
11:40–12:00 pm	<ul style="list-style-type: none">• Staffing, COVID 19, and Office Reconstitution• Calls for Data<ul style="list-style-type: none">◦ Status for 2019, 2020 data◦ Initial SEER Data Submission Results
III. SEER Updates & Discussion – Melanie Williams, PhD, TCR Branch Director, Group Discussion	
12:00–12:40 pm	<ul style="list-style-type: none">• Overview of new SEER activities• National Childhood Cancer registry• Electronic Pathology Reporting for Case Completeness and Rapid Case Ascertainment
IV. Other Updates – Group Discussion	
12:40–12:50	<ul style="list-style-type: none">• ENCLAVE Study and Measures of Texas Asian American or Hispanic/Latino Ethnic Enclaves• The tableau visualization is here: https://cancerregistry.ucsf.edu/enclave• ENCLAVE online publication
V. Member Updates/New Business – Group Discussion	
12:50–1:00 pm	<ul style="list-style-type: none">• Nominations for Vice-Chair/Chair Elect• Member Updates• Next regular meeting in Spring 2022
VI. Adjourn	

General Updates



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NCI Texas SEER Registry Overview



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Background

- The DSHS Texas Cancer Registry (also known as the Cancer Epidemiology and Surveillance Branch) has participated in the CDC - National Program of Cancer Registries (NPCR) since 1994.
- Effective May 1, 2021, the Texas Cancer Registry is also an NCI SEER-designated registry! This has been a TCR goal since the 1980s.
- The NCI's Surveillance, Epidemiology, and End Results (SEER) Program provides information on cancer statistics to reduce the cancer burden among the U.S. population. It is supported by the Surveillance Research Program in NCI's Division of Cancer Control and Population Sciences.

SEER Registry Proposal Overview

- Additional Funding — \$8,887,705 (over 7 years)
 - Funding will support:
 - Migration to SEER*DMS software
 - 10 new TCR staff positions to meet SEER new data collection and project requirements
- Potential Future Funding
 - Participation in ancillary studies and additional projects
 - Patterns of Care Studies, National Childhood Cancer Registry
 - Participation in a Virtual Tissue Repository

SEER History and Research Use

Mission: Monitor cancer trends and support research on the diagnosis, treatment and outcomes of cancer.

SEER Growth Over Time		
SEER Version	Year Initiated	Coverage
SEER-9	1975	9.4%
SEER-13	1992	13.4%
SEER-18	2000	27.8%
SEER-21	2017	36.7%
2021	2021	48%

SEER Utilization Metrics (2020)

Publications to date

17,000+ SEER Data for the Primary Analysis

86,000+ Referencing SEER Data

2,200+ Using SEER-Medicare

Grants 2020 (\$55.3 M)

SEER primary focus (**61/ \$37.3M**)

SEER as reference data Source (**13/ \$4.6M**)

SEER Intramural grant Support (**10/ \$12.9M**)

>4,500 Annual Data Downloads

Enhancing SEER to Meet Real World Data Needs

- How cancer patients are diagnosed and managed is changing so rapidly it is challenging even for clinicians to keep up to date
- There are no data *outside clinical trials* that provide information on:
 - How new diagnostic methods and treatment are used and
 - Their impact on outcomes in the general cancer population
- Guidelines for treatment are based on clinical trials but...
 - These capture <5% of the cancer population
 - Are non-representative - largely white, younger and no comorbidities
- We need ***population level data*** to understand the use and effect of these new treatments in patients outside clinical trials in the real world

Methods for Increasing SEER Relevance

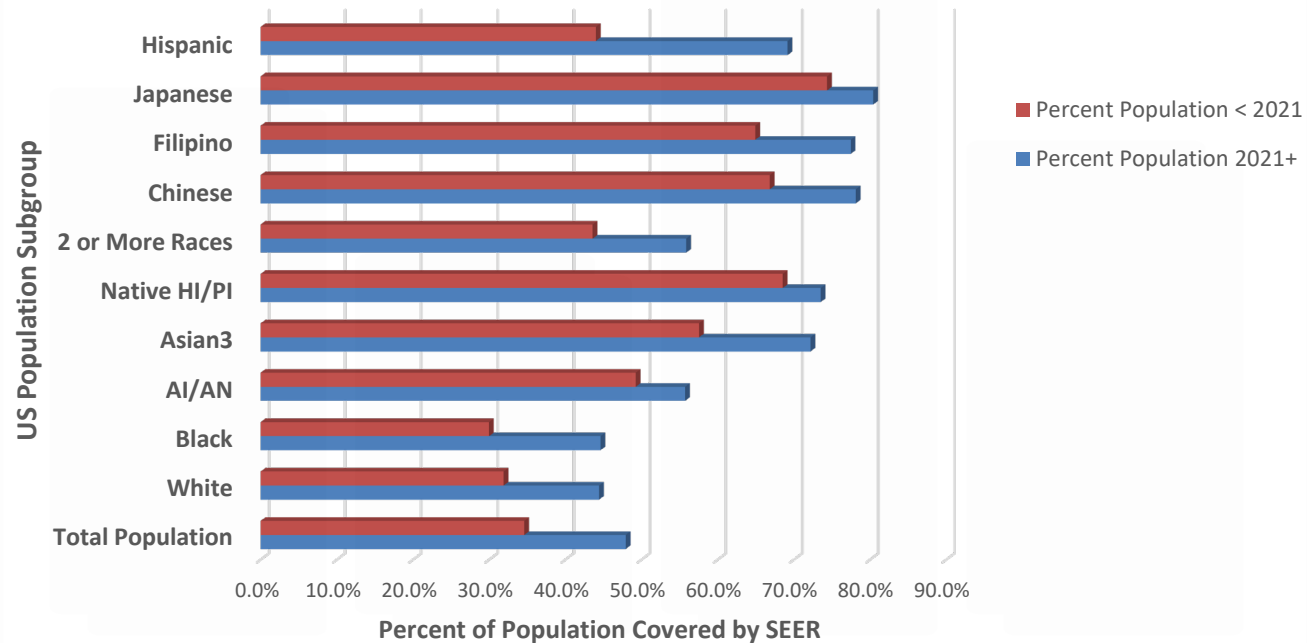
- Expanding the data and methods for data capture through:
 - Linkages with external partners holding key clinical data for understanding cancer care/outcomes
 - Developing automated methods for data capture through deep learning and NLP
- Expanding the breadth of patients covered in SEER

Reasons for SEER Expansion 2021

- Expansion is required so SEER represents real world data at the population level. Expansion increased data coverage to:
 - Enable reporting of trends in more refined, clinical categories such as:
 - histologic subtype
 - biomarkers status
 - treatment categories
 - Represent important population subgroups
- As of June 1, 2021, SEER covers ~50% of the US population.
 - Represents more than 850,000 incident cancers reported annually

Increase in Population Subgroups

Increase in Population Subgroups Covered with SEER Expansion



Percent Increase for US Population Subgroups with SEER Expansion May 2021

Total Populatoin	White	Black	AI/AN	Asian3	Native HI/PI	2 or More Races	Chinese	Filipino	Japanese	Hispanic
13.3%	12.5%	14.6%	6.5%	14.6%	5.0%	12.3%	11.3%	12.5%	6.1%	25.2%

SEER Expansion

Two categories of Registries were added to SEER.

- *Core Registries*- these submit data annually to the SEER program and data accessible to the research community (~50% of US Population)
- *Research Support Registries* –12 additional registries eligible to participate in specific activities such as
 - Virtual Pooled Registry (VPR)
 - Virtual SEER-Linked Biorepository
 - National Childhood Cancer Registry (NCCR)
 - Special Research Projects and Pilots
 - Participation in linkages with external data partners (Pharmacies, genomic laboratories, claims data etc.)

New SEER Registries in 2021

New Core Registries

- Illinois
- New Jersey
- Texas

Research Support Registries

- Colorado
- Missouri
- Oregon
- Tennessee
- Michigan
- Detroit Metro
- Arkansas
- Dartmouth
- Wisconsin

SEER Traditional and Enhanced (New) Data

Data Traditionally Collected

- Demographics
- Geospatial data
- Characterization of the tumor at diagnosis
 - Stage
 - Tumor characteristics (including 32 biomarkers)
- Treatment (first course)
 - Surgery, radiation, Chemo/hormonal (y/n)
- Survival and Cause of death

New Data Being Integrated into SEER

- Treatment
 - *Detailed & longitudinal* Treatment
 - Infusion and oral medication (chemo/hormone/immuno)
 - Radiation
 - Both Initial & subsequent Rx courses
- Expanded tumor characteristics
 - Genomics/Biomarkers (EGFR, ALK, BRAF MSI etc.)
 - Multigene panels for specific cancers (Oncotype, Decipher, Castle LS)
- Capturing Metastatic Recurrence
 - Leveraging multiple data sources (pathology, radiology, claims, hospital reports)
- Longitudinal Residential History

Recent Additions to the SEER Data

- Pharmacy Data—oral antineoplastic agents (2013–2021)
 - CVS, Walgreens/RiteAid
 - United Health Care Pharmacy Data Management (PBM) Data
- Medical Insurance Claims – detailed longitudinal treatment, comorbidities, tests, hospitalizations
 - Unlimited Systems—claims processor for community oncology practice claims (2013–2021)
 - 17% of cases to date
 - United Health Care Claims (2000-2020)
 - 1,615,174 Patients
 - Covers between 6%- 25% of patients by registry (Mean 14.5% coverage)
 - In discussions with other large commercial insurers and Medicare

Recent Additions to the SEER Data

- Genomic data linkages
 - Oncotype DX Breast 2010+
 - 21gene assay 239,178 patients
 - 16 gene assay 5,734 patients
 - Oncotype DX Prostate MultiGene Panel - 13,502 patients
 - Decipher MultiGene Panel - 15,309 patients
 - Castle Life Sciences – Cutaneous & Uveal Melanoma MultiGene Panel - 7,372 cases
- Residential History
 - SEER has captured each patient's residential history back to 2000
 - Purpose
 - Enable linkages longitudinally as cancer patients move – address information is essential
 - Enable linkages with exposure data pre-diagnosis when exposure most relevant
 - Registries capture address at the time of diagnosis only

Automation in SEER: DOE-NCI Collaboration

- API for auto-extraction of key elements (site, histology, behavior, laterality, grade) developed and under refinement
 - Implementing to optimize work-flow in 6 SEER registries
 - Automated process **18,000X** faster than manual extraction
 - Full automated extraction of 20% of all path reports + 50% partial auto-extraction
 - **Initial test in GA registry- automated 24,000 report backlog in <2 minutes!**
- Developing Privacy Preserving version for sharing with CDC, VA and others.
- Ultimate Goal: support near real time incidence reporting
- API for reportability of cancer pathology reports developed
 - modifying for radiology reports (to capture missed cases- CNS tumors and HCC)
- API for recurrent metastatic disease developed for pathology reports
 - modifying for radiology reports

SEER Data Access

- SEER data collected by registries under state public health reporting authority
 - SEER Receives only a limited data set for dissemination
- SEER traditionally broadly available (>4,500 downloads per year)
- Increasingly detailed data increases risk of re-identifiability of individuals
- Therefore, a new Multi-tiered Authentication and Authorization Process is in development with increasing requirements by tier
 - Tier 1- De-identified – no dates or geographic variables- available to all with minimal Data Use Agreement (DUA) (live)
 - Tier 2 – Limited Data set with minimal detailed characterization variables (live)
 - Tier 3 – Limited Data set with special variables (biomarkers, multi-gene panels etc.) (live)
 - Tier 4 – Limited Dataset with longitudinal treatment, dates etc., (May require IRB review) (in dev)

Virtual Pooled Registry (VPR)

- Centralized process for linking cohorts/other studies to all registries in US to
 - Capture information on cancers and outcomes (Survival)
 - Currently 45 US registries are participating (87% US pop)
- Central website for data submission and linkages
- Templated IRB and DUA forms
 - Accepted by ~50% of participating registries to date
- cIRB contract for SRP May 2021
 - Enables central IRB submission and approval through reliance agreements with registries
 - Available to support other data access processes in SRP for SEER data (Tier 4 requests)

The National Childhood Cancer Registry (NCCR)

Centralized data system from 23 registries across the US (77% of all childhood cancers to date)

Base Data

- Complete abstracts from participating state registries (1995+)
- National Death Index (NDI)/State vital records
- Lexis Nexis - Residential History
- Virtual Pooled Registry (VPR) linkage – de-duplication/subsequent cancers

Planned Linkages

- Pharmacy Data (Oral Therapies)
- Longitudinal Radiation oncology data
- Claims data (Comorbidity and treatment)
- Radiology reports + images (case finding/ recurrence)
- Genomic Data
- COG Clinical Trials and Project Every Child DB – evaluate coverage and under representation for COG

Data Access

- Creation of Data platform and data products to enable controlled access by investigators

Feedback and Suggestions



Member Updates/ New Business

Group Discussion



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Member Updates



Next Meeting

- Spring 2022
- 11:30 a.m. – 1:30 p.m.
- Via teleconference



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