

# CCSS Statistical Center Report

CCSS Investigator Meeting, May 27, 2022

---

Wendy Leisenring, Sc.D.

**CCSS**

Childhood Cancer  
Survivor Study



St. Jude Children's  
Research Hospital

---

An NCI-funded Resource

- Overview and Team Members
- Core Activity Updates
- Challenges and Priorities

# Staffing

CCSS



**Wendy Leisenring, ScD**  
Lead CCSS Biostatistician  
30% Wendy

## Analysts

~2 FTE funded  
Pam Goodman  
Kayla Stratton  
Jillian Whitton



**Yutaka Yasui, PhD**  
Epidemiology/Biostat WG Chair  
20% Yutaka

~3 FTE (non-CCSS) funded  
Qi Liu  
Yan Chen  
Weiyu Qiu  
Huiqi Wang



**Kumar Srivastava, PhD**

10% Kumar



**Sedigheh Mirzaei, PhD**

10% Sedigheh

## Analysts

~1 FTE (**non-CCSS**) funded  
Mingjuan Wang  
Himani Darji

~1 FTE (**non-CCSS**) funded  
Mengqi Xing  
Shalini Bhatia  
Himani Darji

- **Data Management**
  - Close collaboration with Coordinating Center (weekly meetings)
  - Cleaning data
  - Generating analytic data sets
  - Linkage with external data sources
- **Concept Proposal and Ancillary Study Grant Development**
  - Design and write in collaboration with investigators
- **Statistical Analyses**
  - Collaborate on analyses via regular virtual meetings with investigators

## Survey Data

- **Survey Response data** through FU6
  - Currently cleaning / freezing FU7 data
- **Subsequent Neoplasms** reported and confirmed through FU6
- **Chronic Health Conditions** coded through FU5
  - FU7 reported conditions will be coded later this year

## Mortality

- **Vital status** and cause of death through 2017 (National Death Index linkage)

## Treatment for Primary Cancer (to 5 years post dx)

- **Chemotherapy** abstracted from medical records, cumulative dose
- **Radiation Dosimetry** to body regions and select organs (MD Anderson)
- **Surgery** Operative notes coded to ICD9

# Cloud Data Repositories

CCSS

## dbGaP Data Repository:

- GWAS data for n=5,912 original cohort survivors
- Whole Exome Sequencing for n=5,451 original cohort survivors
- CCSS phenotype data for n=25,665 survivors; N=5,051 siblings

## St Jude Cloud

- CCSS Expansion cohort subjects with Whole Genome Sequencing data (N=2,641)
- Online tools at St Jude Cloud available (<http://survivorship.stjude.cloud/>)
- CCSS Phenotype data for these 2,641 survivors

## Phenotype Data includes:

Characteristics	Treatment Exposures	Outcome Measures
Demographics	Chemotherapy (Y/N and Doses), HCT	Mortality
Primary Cancer related	Radiation (body region Y/N and Doses)	Subsequent Neoplasms /recurrences
	Surgeries (summary, icd9code/label)	Chronic conditions overall and by organ system (max grade, age)

# External Data Linkages with CCSS cohort

CCSS

## Completed

- **Society for Assisted Reproductive Technology (SART)**
  - Identified 137 survivors / 33 siblings who used ART
- **Medicaid Data**
  - CCSS participants alive and aged 18-64 years as of Jan 1, 2010
  - Matched to 2009-2016 Medicaid claims data

## Ongoing

- **Virtual Pooled Registry (VPR)**
  - 26 states' linkage of cancer registries to CCSS in hand
  - Adding ~15 more
- **Center for International Blood and Marrow Transplant Research (CIBMTR)**
  - Preliminarily identified ~1000 matched stem cell transplant recipients
  - Will provide detailed transplant characteristics (donor, conditioning, etc.) and graft vs host disease



# Manuscript and Analyses Volume

CCSS

January 1, 2017-Present*:	
Published Manuscripts:	115
Currently Submitted Manuscripts:	12
Manuscripts in Preparation:	26
Analyses Ongoing/Data sent:	47

\* Manuscripts with a statistician from CCSS involved.

## Concepts Approved, waiting for specific data:

Approved Concepts in Queue Waiting for Analyst:	9
---	---

Approved Concepts in Queue Waiting for Linkage/Data:	3
--	---

## Methodological:

- **Drop-out concerns:** Bias due to non-participation / Loss to follow-up
- **(One) solution:** We have advocated using inverse probability weighting (IPW) to adjust all analyses.
- **Participation Weights:** We have generated weights to ameliorate bias due to non-participation / drop-out across all surveys.
- **Challenge:** Have applied weights to recent analyses
  - Overly complicates some analyses and can be time consuming to implement
  - Still advocating, but thus far, bias is minimal. Be flexible and vigilant.

- **Analyses:** Maintain productivity and quality on analytic projects. Continue to evaluate and account for drop out.
- **Data:** Many incoming data sources for us to clean, incorporate and analyze.
- **Study Designs:** Support core and ancillary studies including in home assessments of frailty, neurocognitive assessments, health services research initiatives, and intervention trials with innovative and rigorous study designs and analyses.
- **Planning for Cohort Expansion:** With others, we will develop a plan for cohort expansion in the future, aimed at studying late effects of modern therapies (used from 2000-2020)