

CCSS Data and Statistics Center Report

CCSS Investigator Meeting, June 14, 2023

Kumar Srivastava, Ph.D. -> India

Wendy Leisenring, Sc.D. -> Could not come

Yutaka Yasui, Ph.D.

CCSS

Childhood Cancer
Survivor Study



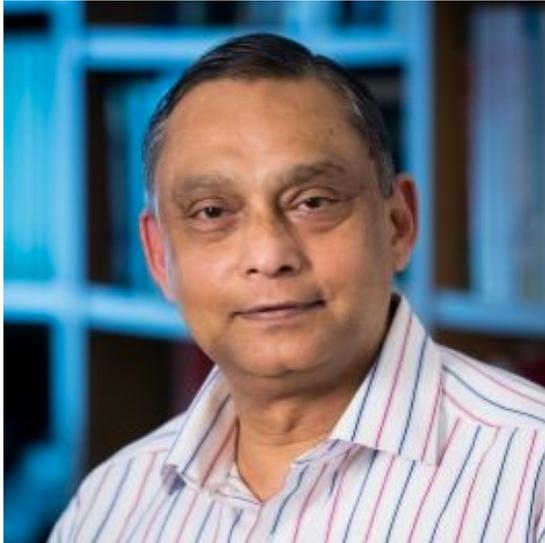
St. Jude Children's
Research Hospital

An NCI-funded Resource

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

New Lead Biostatistician as of May 1, 2023

CCSS



Kumar Srivastava, PhD
Lead CCSS Biostatistician

Analysts

Mingjuan Wang
Nivya George
Lu Xie
Grace Zhou

Thank you, Wendy! Her new role in CCSS

CCSS



Wendy Leisenring, ScD
Co-Chair Epidemiology/Biostat WG

2004-2023

20-years

Lead Biostatistician of Data & Statistics Center

ccss



2023-
30-years?



2004-2023
20-years



1995-2004
10-years

Staffing

CCSS



Sedigheh Mirzaei, PhD

Analysts

Mengqi Xing
Shalini Bhatia



Wendy Leisenring, ScD
Co-Chair Epidemiology/Biostat WG

Pam Goodman
Kayla Stratton



Yutaka Yasui, PhD
Co-Chair Epidemiology/Biostat WG

Qi Liu Weiyu Qiu
Yan Chen Huiqi Wang
(Jessica Baedke)
Farideh Bagherzaden-Khiabani

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- **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 ([involve us early!](#))
- **Statistical Analyses**
 - Collaborate on analyses via regular virtual meetings with investigators

Manuscript and Analyses Volume

CCSS

January 1, 2018-Present*:	
Published Manuscripts:	129
Currently Submitted Manuscripts:	10
Manuscripts in Preparation:	28
Analyses Ongoing/Data sent:	63

* Manuscripts with a statistician from CCSS involved.

Status	N
Approved Concepts in Queue Waiting for Analyst:	3
Approved Concepts in Queue Waiting for Linkage/Data/DUA:	3

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 as ICD9

Survey Data

- Survey Response data through FU7
- Subsequent
- Chronic Health
- FU7 rep

Updated Frozen Data expected by Fall 2023

- SN, Chronic Conditions through FU7
- Mortality through 2021

Mortality

- **Vital status** and cause of death through 2017 (National Death Index linkage)
 - Deaths through 2021 update to NDI linkage underway. To be finished by Fall 2023

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 on clouds 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

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Completed

- **Society for Assisted Reproductive Technology (SART)**
 - Identified 137 survivors / 33 siblings who used ART
 - Manuscript under review
- **Medicaid Data**
 - CCSS participants alive and aged 18-64 years as of Jan 1, 2010
 - Matched to 2009-2016 Medicaid claims data
 - [Hear Xu Ji in plenary session today!](#)
- **Center for International Blood and Marrow Transplant Research (CIBMTR)**
 - Identified 1018 matched stem cell transplant recipients
 - Provides transplant characteristics (donor, conditioning, etc.) and graft vs host disease

Ongoing

- **Virtual Pooled Registry (VPR) for subsequent cancer identification**
 - Piloted with 26 states' linkage of cancer registries to CCSS
 - 43 states total available and in process

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 for likelihood of dropout.
 - **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.
- **Self-reported Outcomes:** Potential recall/reporting bias
 - **Validation data in subset:** Could improve analyses?
 - **Presentation at plenary session by Sadie Mirzaei later today!**

- **Analyses:** Maintain productivity, quality and consistency on analytic projects. Continue to evaluate and account for drop out.
- **Data:** Many incoming data sources for us to clean, incorporate and analyze. Transitioning this process to St Jude.
- **Study Designs:** Support core and ancillary studies with innovative and rigorous study designs and analyses.
- **Planning for Cohort Expansion:** Working 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)
 - Innovations in data collection, validation