## **CCSS Statistical Center Report**

CCSS Investigator Meeting, June 14, 2021

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## Outline

Overview and Team Members

Core Activity Updates

Priorities for the next 5 years

## Statistical Center Core Activities

#### Data Management

- Close collaboration with Coordinating Center (weekly meetings)
- Cleaning data
- Generating analytic data sets
- Linkage with external data sources

#### Concept Proposal and Grant Development

Design and write in collaboration with investigators

#### Statistical Analyses

Collaborate on analyses via regular virtual meetings with investigators

#### CCSS

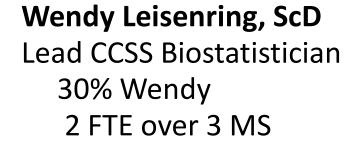
## Staffing

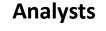


St. Jude Children's Research Hospital

Finding cures. Saving children.







Pam Goodman Kayla Stratton Jillian Whitton



Yutaka Yasui, PhD 20% Yutaka

Qi Liu Yan Chen Weiyu Qiu Cindy Im

Nan Li



Kumar Srivastava, PhD 10% Kumar

Wei Liu Mingjuan Wang Mengqi Xing Sedigheh Mirzaei

## Frozen CCSS Analytic Database

#### **Survey Data**

- Survey Response data through FU6 data
- Subsequent Neoplasms reported and confirmed through FU6
- Chronic Health Conditions coded through FU5

#### Mortality

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

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

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

## Cloud Data Repositories

#### CCSS dbGaP Data Repository Update:

- Phenotype data set available now on dbGaP
  - All 25,665 survivors and 5,501 siblings
  - Demographic, Cancer characteristics, Treatment exposures (chemotherapy, RT body regions)
  - Outcomes: Mortality, SMNs, Chronic Condition Grades /ages
  - Within dbGaP, phenotype data will be linkable with subset of survivors with genetic data available (N = 5.912) with appropriate approvals.

#### St Jude Cloud

- CCSS Expansion cohort subjects with Whole Genome Sequencing data (N=2,641)
- CCSS Phenotype data similar to that described above for dbGaP has been uploaded
- Online tools at St Jude Cloud available (<a href="http://survivorship.stjude.cloud/">http://survivorship.stjude.cloud/</a>)

CCSS

## External Data Linkages

- Completed: Society for Assisted Reproductive Technology (SART)
  - Linkage accomplished between CCSS and SART data
  - Obtained data for CCSS survivors who received ART
  - Analyses completed and manuscript draft written
- Ongoing: Virtual Pooled Registry (VPR)
  - State by state linkage of cancer registries to CCSS survivors
  - 30 participating registries we have data from 22 so far
  - Analyses initiated to evaluate the utility of this process for identifying subsequent neoplasms

• Initiating: Medicaid Data

- Approved concept, grant submitted
- CCSS participants alive and aged 18-64 years as of Jan 1, 2010
- 2009-2016 Medicaid claims data

# Manuscript and Analyses Volume Supported by the CCSS Statistical Center

January 1, 2017-Present*:	
Published Manuscripts:	96
Currently Submitted Manuscripts:	7
Manuscripts in Preparation:	25
Analyses Ongoing/Data sent:	45

<sup>\*</sup> Current grant funding period

# Concept Proposals

Concepts Approved, waiting for specific data:	
Approved Concepts in Queue Waiting for Analyst:	4
Approved Concepts in Queue Waiting for Linkage/Data:	3
Concept Proposals Under Development:	10+

## Challenges

#### 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.

### Priorities: Next 5 Years

Analyses: Maintain productivity and quality on analytic projects

**Data:** The Coordinating Center's "Next 5 years" list items will nearly all provide data to us to clean, incorporate and analyze.

**Study Designs**: Support ancillary studies, including in-home frailty assessment, 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 novel therapies (immunotherapy, targeted/biologic, proton beam radiation)