CCSS Statistical Center Report

CCSS Investigator Meeting, June 14, 2021

Wendy Leisenring, Sc.D.

CCSS
Childhood Cancer Survivor Study

St. Jude Children's Research Hospital

An NCI-funded Resource

Outline

CCSS

- Overview and Team Members
- Core Activity Updates
- Priorities for the next 5 years

Statistical Center Core Activities

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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 Grant Development**
  - Design and write in collaboration with investigators
- **Statistical Analyses**
  - Collaborate on analyses via regular virtual meetings with investigators

Staffing

CCSS

Wendy Leisenring, ScD
Lead CCSS Biostatistician
30% Wendy
2 FTE over 3 MS

Yutaka Yasui, PhD
20% Yutaka

Kumar Srivastava, PhD
10% Kumar

Analysts

Pam Goodman
Kayla Stratton
Jillian Whitton

Qi Liu
Yan Chen
Weiyu Qiu
Cindy Im
Nan Li

Wei Liu
Mingjuan Wang
Mengqi Xing
Sedigheh Mirzaei

Frozen CCSS Analytic Database

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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

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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 (http://survivorship.stjude.cloud/)

External Data Linkages

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- **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

CCSS

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

* Current grant funding period

Concept Proposals

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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

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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

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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)