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Contact Information

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| **Project Title** | Population-level Burden of Morbidity among Survivors of Childhood Cancer in the United States |

Planned research population (eligibility criteria)

All CCSS Survivors from Original and Expansion Cohorts

Proposed specific aims

Aim 1: Using SEER data, estimate the prevalence of survivors of childhood cancer living in the United States through January 1st, 2021.

> Sub-Aims: We will examine these data by age, gender, type of cancer, and time since diagnosis.

Aim 2: Estimate the prevalence of morbidity among 5-year survivors of childhood cancer in the U.S. by extrapolating data from the CCSS (including survivors treated for cancer through 1999) to SEER data (through 2021), adapting methods described by Phillips et al. (PMID: 25834148).

> Sub-Aims: We will estimate the prevalence of the following:

1. Chronic health conditions, using the modified NCI CTCAE grading system (v4.03), with emphasis on evaluation of CHC severity, multiple CHCs, and CHC burden by organ system
2. Neurocognitive impairment, using the CCSS Neurocognitive Questionnaire (NCQ)
3. Functional impairment, using self-reported functional limitations.

> These will be examined by age, gender, time since diagnosis, cancer type, and treatment era.

Aim 3: Estimate the absolute number of chronic health conditions, neurocognitive impairments, or functional impairments experienced by survivors of childhood cancer in the U.S. (e.g. survivors may have more than one, what is the total number of conditions).

> Sub-Aims: These will be examined by age, gender, type of cancer, time since treatment, and treatment era.

Aim 4: Estimate the absolute number of excess chronic health conditions experienced by survivors of childhood cancer in the U.S. using CCSS estimates (Aims 2/3) for observed rates and general population epidemiological data (e.g., NHANES, BRFSS) for population-based expected rates.

> Sub-Aims: We will also calculate absolute excess risks. All of these analyses will be examined by age, gender, type of cancer, time since treatment, and treatment era. We will also report these data by calendar year to inform on the change over time.

Aim 5: Estimate the projected prevalence of survivors of childhood cancer and the projected prevalence of chronic health conditions, neurocognitive impairments, and functional impairments over the next 20 years in the United States.

> Sub-Aims: These will be examined by age, gender, and type of cancer.

Will the project require non-CCSS funding to complete? No

If yes, what would be the anticipated source(s) and timeline(s) for securing funding?

Does this project require contact of CCSS study subjects for:

Additional self-reported information	No
Biological samples	No
Medical record data	No

If yes to any of the above, please briefly describe.

What CCSS Working Group(s) would likely be involved? (Select all that apply)

	Primary	Secondary
Second Malignancy		
Chronic Disease		✓
Psychology/Neuropsychology		
Genetics		
Cancer Control		
Epidemiology/Biostatistics	✓	

Outcomes or Correlative Factors

	Primary	Secondary	Correlative Factors
Late Mortality			
Second Malignancy			✓

Health Behaviors

	Primary	Secondary	Correlative Factors
Tobacco			
Alcohol			
Physical Activity			
Medical Screening			
Other			

If other, please specify

Psychosocial

	Primary	Secondary	Correlative Factors
Insurance			
Marriage			
Education			
Employment			
Other			

If other, please specify

Medical Conditions

	Primary	Secondary	Correlative Factors
Hearing/Vision/Speech			
Hormonal Systems			
Heart and Vascular			
Respiratory			
Digestive			
Surgical Procedures			
Brain and Nervous System			
Other			

If other, please specify

Medications

Describe medications

Psychologic/Quality of Life

	Primary	Secondary	Correlative Factors
BSI-18			
SF-36	✓		
CCSS-NCQ	✓		
PTS			
PTG			
Other			

If other, please specify

Other

	Primary	Secondary	Correlative Factors
Pregnancy and Offspring			
Family History			
Chronic Conditions (CTCAE v3)	✓		
Health Status			✓

Demographic

	Primary	Secondary	Correlative Factors
Age		✓	
Race		✓	
Sex		✓	
Other			

If other, please specify

Cancer Treatment

	Correlative Factors
Chemotherapy	✓
Radiation Therapy	✓
Surgery	✓

Anticipated Sources of Statistical Support

CCSS Statistical Center	Yes
Local Institutional Statistician	No

If local, please provide the name(s) and contact information of the statistician(s) to be involved.

Will this project utilize CCSS biologic samples?   No

If yes, which of the following?

If other, please explain

Other General Comments

We plan to update and expand upon the analyses done by Phillips et al published in CEBP in 2015. This paper calculated the prevalence of survivors of childhood cancer based on SEER data as of 2011 and also estimated the population prevalence of chronic health conditions and other impairments using only data from the original cohort of the CCSS. Our proposal will update these analyses using SEER data through 2021 and using both the original and expansion cohorts to allow for a more comprehensive estimation. Then we hope to expand on these methods by examining the absolute number of conditions experienced (e.g. 1.5 million) and the absolute number of excess conditions experienced by survivors (e.g. above and beyond what is expected in an age-, sex-, race-matched population to inform on the burden of survivorship. This will be done using population-based estimates for these conditions from cohorts such as NHANES and BRFSS. These cohorts have estimates of the prevalence for diabetes, hypertension, stroke, among others in the US population; depending on the overlap with CCSS conditions, we may limit these analyses to a subset of the most common conditions that affect survivors. We feel this will further inform on the accelerated rate at which survivors experience these conditions relative to their peers.

Agree

I agree to share this information with St. Jude