Health Insurance Status Experiences Following Implementation of the Patient Protection and Affordable Care Act among Childhood Cancer Survivors and Siblings: A report from the Childhood Cancer Survivor Study (CCSS)

Working Group(s): Cancer Control and Intervention

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<u>**Background and Rationale:**</u>

The Patient Protection and Affordable Care Act (ACA) was signed into law in 2010 and was intended to increase access to affordable, quality health insurance.[1] The ACA opened up several new avenues for individuals to obtain health insurance, particularly for individuals with pre-existing conditions. The ACA ensured that patients with pre-existing conditions – such as a cancer diagnosis – had access to affordable, comprehensive insurance at the same cost as the general population.[2,3] Provisions intended to increase access to affordable health insurance included: extending employer-sponsored coverage for dependents up to age 26; the formation of the health insurance marketplace with income qualifying subsidized coverage and premium tax credits; and the expansion of Medicaid.[2,3] Prior to the ACA, survivors were more likely to be uninsured and underinsured than their siblings and frequently reported difficulty obtaining health insurance and high out-of-pocket costs, yet had low knowledge about health insurance terminology and utilization.[4-6] While the rates of uninsured individuals in the United States have declined since the implementation of the ACA, little is known about how survivors' health insurance status has changed.[7]

The expansion of insurance coverage and protections provided by the ACA, including mandated out-pocket-maximums, have significantly reduced cancer patient out-of-pocket costs.[8] However, protection against high out-of-pocket costs does not necessarily equate to affordability. Issues of underinsurance – having continuous insurance coverage but still experiencing high out-of-pocket costs relative to income – remain common after ACA implementation. Nearly half of all cancer patients report that their cancer diagnosis was financially catastrophic, resulting in poor treatment adherence during and after therapy.[10] For childhood cancer survivors, the negative financial effects from cancer can last well into adulthood due to school and work disruptions, ongoing health problems, and high medical costs.

Today, comprehensive health insurance remains unaffordable for many middle to low income survivors.[5] Many individuals in the U.S. do not qualify for subsidized insurance or may live in states with partial or no Medicaid expansion. Health insurance challenges based in employment such as job lock, which is the inability to leave a job or seek promotion due to fear of losing health insurance coverage, may remain common.[11] When compared with siblings, survivors of childhood cancer are at a heightened risk of unemployment and are less likely to work in high-income occupations.[12] Employment and earning potential may be further limited by job lock, as survivors stay in jobs to keep their health insurance.[12]

While the ACA was passed 10 years ago with the intent to expand insurance access and affordability, what effects the ACA has had on childhood cancer survivors' insurance are largely unknown. In this proposal, we will focus on examining insurance coverage for childhood cancer survivors ten years into the ACA. We will determine which groups of childhood cancer survivors remain at risk for being uninsured and whether the risk for underinsurance – defined here as spending more than 10% of income on medical out-of-pocket costs – has increased for survivors. We will also examine whether job lock remains common among survivors even after

the ACA implementation and their current insurance stability. Despite large gains in insurance with the ACA, individuals with lower incomes, who are female, and have chronic health conditions, still face limitations with accessing insurance and tend to be underinsured more often than their counterparts. In particular, those with employer-sponsored insurance have become one of the groups most likely to be underinsured in past several years. However, it is unknown whether these trends in the general population are experienced by childhood cancer survivors.

Overview of Aims/Surveys: The current proposal will use insurance and financial data from the Follow Up 6 (FU6) survey of survivors and siblings from the Childhood Cancer Survivor Study, which was launched in 2017, as well as data from FU4 (2007) and a 2010-2011 ancillary insurance survey (PI: Elyse Park). Our use of FU6 is limited to the sample that completed the financial survey version (approximately 1/3 of the CCSS sample). To assist with review of the aims, we provide an overview of available insurance status and insurance coverage questions as these have been asked in different ways across years in the CCSS (**Table 1**).

In Aim 1, we will evaluate how the ACA has affected insurance coverage among survivors and siblings from FU4 (2007) to FU6 (2017). We opted to use FU4 due to the availability of data on insurance status immediately prior to ACA legislation. Because the FU5 (2014) survey was implemented during the roll-out of different ACA provisions (e.g., exchanges, Medicaid expansion), we have opted not to include data from FU5. Only the original cohort participants completed FU4. Aims 2, 3, and 4 will be based on FU6 and focus on describing the current landscape of insurance coverage for survivors and siblings ten years into the ACA including type of insurance, underinsurance, insurance stability, and job lock. Both the original and expansion cohorts will be included. Finally, the exploratory aim will examine changes in insurance type from the 2010-2011 ancillary insurance survey as type of insurance was not ascertained in FU4. However, due to limited sample size, it is unclear whether there will be adequate sample size and so this aim is proposed as an exploratory analysis.

Table 1: Insurance Questions in CCSS

CCSS Survey, Year Survey Started, and Population Surveyed	Insurance Status (Insured vs. Uninsured)	Insurance Type (Employer, Medicaid, etc.)	Concept Proposal Aim
Baseline	X	X	
Expansion Baseline	X	X	
FU1 (2000)	X	X	
FU2 (2003)	X	X	
FU3 (2005)	*Was not asked*	*Was not asked*	
FU4 (2007): *Original cohort surveyed*	X	*Was not asked*	Aim 1
Ancillary insurance survey (Park, PI) (2010): *Subset of 698 survivors*	X	X	Exploratory Aim
FU5 (2014)	X	*Was not asked*	
FU6 (2017): *1/3 CCSS surveyed*	X	X	Aim 1, Aim 2, Aim 3, Aim 4, Exploratory Aim

Blue indicates survey data for current concept proposal

Specific Aims:

Aim 1: To identify the effects of the ACA on health insurance coverage among survivors and siblings.
In this aim, we will investigate insurance coverage among survivors and siblings cross-sectionally using FU4 and FU6 (Aim 1a) and among survivors who responded to both FU4 and FU6 (Aim 1b).
- **Aim 1a:** Compare prevalence of insurance coverage among survivors and siblings at FU4 (2007) vs. FU6 (2017). This will include all participants responding to each survey.
    We hypothesize that survivors and siblings will both have higher levels of insurance coverage in FU6 compared to FU4 due to the ACA.
- **Aim 1b:** Among survivors who participated in both FU4 and FU6, identify sociodemographic factors (e.g., age, sex, race/ethnicity, socioeconomic status (SES)) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with changes in insurance status.
    We hypothesize that the biggest gains in insurance coverage between FU4 and FU6 will occur for survivors who are of lower SES and who have chronic health conditions due to the ACA's expansion of Medicaid and pre-existing conditions protections.

Aim 2: To describe the types of health insurance coverage and underinsurance of survivors and siblings 10 years post-ACA. In this aim, we will utilize FU6 data.

- **Aim 2a**: Compare type of health insurance, and prevalence of underinsurance between survivors and siblings.
  We hypothesize that survivors will be enrolled more often on public insurance (e.g., Medicaid) and be underinsured more often than siblings post-ACA.
- **Aim 2b:** Among survivors, determine sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with type of health insurance and underinsurance.
  We hypothesize that survivors who are of lower SES, female, and with chronic conditions will be more likely to be on public insurance and to be underinsured than their counterparts post-ACA. We also hypothesize that underinsurance, however, will be common across all types of insurance (employer, individual, public) among survivors post-ACA.

Aim 3: To evaluate differences in survivors and siblings' perceived health insurance stability 10 years post-ACA. In this aim, we will utilize FU6 data.

- **Aim 3a:** Compare perceived health insurance stability between survivors and siblings.
  We hypothesize that survivors will perceive their insurance to be more stable than siblings post-ACA.
- **Aim 3b:** Among survivors, identify sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with perceived health insurance stability.
  We hypothesize that survivors who are of lower SES, female, and with chronic conditions will report lower levels of insurance stability than their counterparts post-ACA.

Aim 4: To describe the prevalence of job lock and whether debt or insurance concerns influence the likelihood of job lock among survivors and siblings 10 years post-ACA. In this aim, we will utilize FU6 data.

- **Aim 4a:** Compare job lock among survivors and siblings who were employed within the past two years.
- **Aim 4b:** Determine the influence of debt, amount of debt, ability to pay payments, and bankruptcy on job lock, comparing survivors to siblings.
  We hypothesize that survivors will report higher levels of job lock than siblings and that this will be greater among survivors reporting greater financial burden (e.g., debt, bankruptcy) post-ACA.
- **Aim 4c:** Among survivors, identify sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with job lock.
  We hypothesize that survivors who are of lower SES, female, and with chronic conditions will be more likely to report job lock than their counterparts post-ACA.

Exploratory Aim: To identify changes in health insurance status/type and underinsurance among a subset of survivors. In this aim, we will utilize data among survivors who completed both the 2010-2011 insurance survey and FU6 (2017) (N=211). While siblings were also part of the insurance survey, only 210 participated in total, so there are not enough siblings to evaluate changes across the two surveys. Assessment of underinsurance will be limited to survivors who had some type of insurance at both surveys.

- **Aim a:** Identify any changes in health insurance status, type of health insurance, and underinsurance among survivors from 2010-2011 to FU6 (2017).
  We hypothesize that survivors not insured in 2010-2011 will be enrolled more often on public insurance (e.g., Medicaid) at FU6, but not private insurance. We hypothesize that underinsurance will be more common among survivors at FU6 than at 2010-2011 among those insured at both timepoints.
- **Aim b:** Determine the sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with change in insurance status, type of insurance, and underinsurance among survivors from 2010-2011 to FU6 (2017), if sample size allows.
  We hypothesize that survivors who are of lower SES, female, and with chronic conditions will be more likely to gain public insurance coverage from 2010-2011 to FU6, but that these same groups will be more at risk for being underinsured at FU6.

Methods

Participants:

Aim 1a is a cross-sectional analysis and will include all participating survivors and siblings at FU4 (survivors, N=7,505 and siblings, N=2,182) and FU6 (survivors, N=4,151 and siblings, N=1,039). Aim 1b is longitudinal and will include survivors who participated in both FU4 and FU6 (N=1,842). Aims 2, 3, and 4 are cross-sectional and will include survivors and siblings from FU6. The exploratory aim is longitudinal and will focus on survivors who completed both the 2010-2011 insurance survey and FU6 (N=211). Canadian participants will be excluded from all analyses.

Measures of Interest:

Aim 1: Health insurance status in FU4 and FU6

    Dependent Variables
- **Insurance yes/no:** (FU4 B9): Do you currently have health insurance coverage? (FU6 C1): Do you currently have health insurance that covers outpatient care and hospital care? Yes, No; For Aim 1a, we will examine the percentage insured at both FU4 and FU6. For Aim 1b, we will create two outcome variables to examine 1) **losing insurance from FU4 to FU6** and 2) **gaining insurance from FU4 to FU6**.

    Independent Variables: See table below
- Sociodemographic variables
- Treatment
- Chronic conditions

Aim 2: Health insurance type and underinsurance among survivors and siblings in FU6

    Dependent Variables
- **Type of health insurance** (C2): What kind of health insurance coverage do you have? (Check all that apply)…Individual, Employer, Medicare, Medicaid, Indian Health Service, Military/Tricare, other state, other government, don't know, other; will group as private (individual, employer (including military)) and public (Medicare, Medicaid, Indian Health Service, other state, other government). In addition, we will examine Medicaid separately in sub-analyses to explore differences due to Medicaid expansion.
- **Underinsurance** (>10% of income calculated from these variables similar to Nipp et al): C10: During the past year, about how much did you spend out-of-pocket for your medical care? Include out-of-pocket expenses for prescription drugs, co-payments, and deductibles, but do not include health insurance premiums or any costs paid by your health insurance; C21: Over the last year, what was the total income of the household you live in?

    Independent Variables: See table below
- Sociodemographic variables
- Treatment
- Chronic conditions

Aim 3: Perceived insurance stability among survivors and siblings in FU6

    Dependent Variables
- **Perceived insurance stability** (C4): How concerned are you that you may not be able to maintain your current level of insurance coverage over the next 12 months? Not concerned/a little concerned vs. moderately/greatly concerned.

    Independent Variables: See table below
- Sociodemographic variables
- Treatment

- Chronic conditions

Aim 4: Job lock among survivors and siblings in FU6

   Dependent Variables
   - **Job lock**: In the past 2 years, did you ever… Stay at a job in part because you were concerned about losing your health insurance?...Did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family? We will examine these separately and overall.

   Independent Variables: See table below
   - Sociodemographic variables
   - Treatment
   - Chronic conditions
   - Debt items (C27-C31)

Exploratory Aim: Change in health insurance status, type, and underinsurance for survivors between the 2010-2011 insurance survey and FU6.

   Dependent Variables
   - **Insurance yes/no**: (2011 Insurance Survey: Do you currently have health insurance that covers doctor and hospital care?); (FU6: C1); Do you currently have health insurance that covers outpatient care and hospital care? Yes, No; We will create two outcome variables to examine 1) **losing insurance from 2010-2011 to FU6** and 2) **gaining insurance from 2010-2011 to FU6**.
   - **Type of health insurance** (FU6: C2) (2011 Insurance Survey, insured: 2), We will create two outcome variables to examine; 1) **change from public to private from 2010-2011 to FU6** and 2) **change from private to public from 2010-2011 to FU6**.
   - **Underinsurance** (>10% of income) (FU6: C10, C21) (2011 Insurance Survey: 28, 44); we will calculate a variable to examine 1) **change from underinsured in 2010-2011 to not underinsured in FU6** and 2) **change from not underinsured in 2010-2011 to underinsured in FU6**, among those who had some type of insurance at both timepoints.

   Independent Variables
   - Sociodemographics
   - Chronic health conditions
   - Treatment factors

Table 2: Variables

Variable	Dataset	Definition
Date of birth	CCSS data	Will examine different age groups
Sex	CCSS data	Male; female
Race	CCSS data	White; Black; American Indian or Alaska Native; Asian or Pacific Islander; Other, specify
Hispanic	CCSS data	Yes; No
Socioeconomic Status/Federal Poverty Level	FU6 C21/C20	Household income: Less than $20,000; $20,000-39,999; $40,000-59,999; $60,000-79,999; $80,000-99,999; $100,000 or more; Don't know; Prefer not to answer; How many people live in your household (including you)? (including dependent children); We will also estimate federal poverty level thresholds using the 2017 Federal Poverty guidelines: https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-thresholds.html; due to the income categories, we will use the midpoint of each income level.
Health Insurance Type	FU4 B9 FU6 C2	Individual insurance (through a policy purchased by you/your policy holder); Employer-sponsored insurance (through a policy purchased by your employer or your spouse or significant other's employer); Medicare; Medicaid; Indian Health Service; Military health care (VA or TRICARE); Other state-sponsored health plan; Other government program; Don't know; Other

Chronic health conditions	CCSS data	Chronic health condition (severity score: no condition, grade 1, grade 2, grade 3, grade 4, grade 5); Number of chronic health conditions (0, 1, 2, or 3); we will create groupings of the chronic conditions grade (i.e., any grade 1-4, any grade 3-5, >1 grade 3-5 condition, etc).
Specific diagnosis	CCSS data	Leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, Central nervous system tumor, Wilms tumor, Neuroblastoma, Soft tissue sarcoma, osteosarcoma, Ewing sarcoma
Age at diagnosis	CCSS data	Will examine different age groups
Any cancer recurrence	CCSS data/FU6 A5	Yes, include date of recurrence; no
Second cancers	CCSS data/FU6 A5	Yes, including type (not including basal cell carcinoma) and date of onset; No; this will be investigated separate from the chronic health conditions as SMN are included in the chronic health conditions.
Chemotherapy	CCSS data	Any; cyclophosphamide equivalent dose (CED); anthracycline cumulative dose category (doxorubicin equivalent dose: none, 1-299 mg/m2, >= 300 mg/m2);
Radiation	CCSS data	Yes/no; brain (yes/no); chest (yes/no); abdominal or pelvic (yes/no); limb (arm, leg, foot, or hand); total body; missing or unknown; Maximum dose (cranial)
Surgery	CCSS data	Yes, No
Debt	FU6 C27	Yes, No, Don't know
Amount of debt	FU6 C28	$0-25,000; $25,001-50,000; $50,001-100,000; $100,001-250,000; $250,001-500,000; $500,001 or more; Don't know; Prefer not to answer
Inability to pay debt (collections)	FU6 C29	Yes, No
Bankruptcy	FU6 C30	Yes, No
Most recent bankruptcy	FU6 C31	Year

Data Analysis

For all analysis that include SES/poverty level, we will examine different cut-points for this variable due to the differences in Medicaid expansion (only 39 states have expanded) and income levels required for subsidized coverage under the ACA (https://www.healthcare.gov/glossary/subsidized-coverage/). In addition, we will create a variable for indicating those residing in a Medicaid expansion state or not and evaluate whether that has an influence on our findings. Finally, as the ACA greatly increased insurance coverage for those under age 26 due to the dependent coverage expansion, we will explore whether to include participants under age 26 or potentially stratify our analyses on age.

There are other considerations for our analyses. First, we may consider inverse probability weighting to adjust for nonparticipation. To do this, we will look to see what characteristics are associated with participation at FU and FU6. If these participants differ than the overall CCSS sample, participation probability weights will be applied to the analyses. Second, among major groups, such as gender, we may consider interactions to identify whether survivor/sibling differences exist for Aims 1b, 2b, 3b, and 4c. These will likely be conducted as sub-analyses at the end of the primary analyses. Third, while we are examining chronic conditions overall, we will potentially consider specific organ systems in our analyses to identify whether certain survivor groups are more likely to experience changes in coverage due to the ACA protections. Finally, we will examine diagnosis and treatment type in separate models due to potential collinearity of disease and treatment.

Aim 1a: Compare prevalence of insurance coverage among survivors and siblings at FU4 (2007) vs. FU6 (2017).
Generalized linear models with generalized estimating equations (GEE) regressions will be used to generate models to examine the prevalence insured at FU4 and FU6 among survivors and siblings. We will use a binomial distribution with a log-link to generate proportions reporting the outcome of interest and adjust for relevant factors (age, gender, race). We will use a binomial distribution with a log-link to generate both relative risks and prevalence. Family ID will be included as a cluster variable in the models to account for any within-family correlation. Robust standard errors will be used to correct for any incorrect assumptions about the response correlation. We evaluate interactions between survivor/sibling status and associated with insurance coverage in the general population (e.g., age and gender). We will also examine differences in age- and gender-stratified models.

Aim 1b: Among survivors who participated in both FU4 and FU6, identify sociodemographic factors (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with changes in insurance status.
Two sets of GEE models will be fit to examine factors associated with change in insurance status: 1) FU4 to FU6 – losing insurance; 2) FU4 to FU6 – gaining insurance, adjusting for relevant factors (age, gender, race, etc.). We will test for interactions between the predictors of interest (e.g., age, sex, SES, treatment, chronic conditions) and timepoint (FU4 vs. FU6), to evaluate whether certain factors increase the risk of insurance changes over time among survivors.

Aim 2a: Compare type of health insurance, and prevalence of underinsurance between survivors and siblings.
Aim 3a: Compare perceived health insurance stability between survivors and siblings.
Aim 4a: Compare job lock among survivors and siblings who were employed within the past two years.
Aim 4b: Determine the influence of debt, amount of debt, ability to pay payments, and bankruptcy on job lock, comparing survivors to siblings.
These analyses will focus on survivors and siblings who completed FU6. Generalized linear models with GEE will be used to estimate the difference between survivors and siblings in prevalence of the outcomes of interest for each aim, adjusting for factors such as current age, sex, and race. We will use a binomial distribution with a log-link to generate both relative risks and prevalence. Family ID will be included as a cluster variable in the models to account for any within-family correlation. Robust standard errors will be used to correct for any incorrect assumptions about the response correlation. Where relevant, we will run stratified models to investigate differences in the associations between survivor/sibling status and age/gender. Finally for Aim 4b, we will evaluate interactions between survivor/sibling status and debt/bankruptcy to understand differences in job lock across these groups.

Aim 2b: Among survivors, determine sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with type of health insurance and underinsurance.
Aim 3b: Among survivors, identify sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with health insurance knowledge and perceived health insurance stability.
Aim 4c: Among survivors, identify sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with job lock.
These analyses will be limited to survivors from FU6. We will perform survivor-specific analyses using similar modeling approaches to look at differences in our outcomes by sociodemographic and treatment factors using generalized linear models, adjusting for relevant factors such as age, sex, and race. We will assess whether differences in prevalence exist for survivors between treatment groups (e.g., higher dose cranial radiation) and by our sociodemographic factors of interest.

Exploratory
Aim a: Identify any changes in health insurance status, type of health insurance, and underinsurance among survivors from 2010-2011 to FU6 (2017).
Aim b: Determine the sociodemographic and chronic health conditions that are associated with change in insurance status, type of insurance, and underinsurance among survivors from 2010-2011 to FU6 (2017).
These analyses will focus on survivors who completed both the 2010-2011 and FU6 surveys. We will run several sets of GEE models to examine factors associated with change in insurance status, change in insurance type, and change in underinsurance, adjusting for relevant factors (age, gender, race, etc.). We will test for interactions between the predictors of interest (e.g., age, sex, SES, treatment, chronic conditions) and timepoint (FU4 vs. FU6), to evaluate whether certain factors increase the risk of insurance changes over time among survivors.

Table Shells: Table Shells are presented in the order that the aims are listed in the analytic plan above.

Aim 1a: Compare prevalence of insurance coverage among survivors and siblings at FU4 vs. FU6.

Aim 1a: Survivor and Sibling Differences in Prevalence of Insurance Coverage from FU4 to FU6										Relative Risks/ 95% CI*
	Survivors					Siblings				
	FU4 (N=)		FU6 (N=)			FU4 (N=)		FU6 (N=)			
	N	% insured	N	% insured	p	N	% insured	N	% insured	p	
Overall											
Age, years											
18-24 (ref)											
26-34											
35-39											
40-44											
45 and older											
We will explore different age cut-points											
Sex											
Female (ref)											
Male											
Race											
White (ref)											
Black											
Asian											
AIAN											
Native Hawaiian or PI											
Hispanic or Latino											
Yes											
No (ref)											

* Relative risks or prevalence will be reported

Aim 1b: Among survivors who participated in both FU4 and FU6, identify sociodemographic factors (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with changes in insurance status.

Aim 1b: Multivariate regressions for risk of survivors losing and gaining insurance between FU4 and FU6				
	Losing insurance		**Gaining insurance**	
	Relative risk*	**95% CI**	**Relative risk***	**95% CI**
Age, years				
18-25 (ref)				
26-34				
35-39				
40-44				
45 and older				
We will explore different age cut-points				
Sex				
Female (ref)				
Male				
Race				
White (ref)				
Black				
Asian				
AIAN				
Native Hawaiian or PI				
Hispanic or Latino				
Yes				
No (ref)				
Income				
Less than $20,000 (ref)				
$20,000-$39,999				
$40,000-$59,999				
$60,000-$79,999				
$80,000-$99,999				
$100,000 or more				
Age at diagnosis				
0-4 (ref)				
5-9				
10-14				
15-20				
Diagnosis				
Leukemia (ref)				
Central nervous system tumor				
Hodgkin disease				
Non-Hodgkin lymphoma				
Wilms (Kidney) tumors				
Neuroblastoma				
Soft tissue sarcoma				
Bone tumors				

Retinoblastoma

Any chemotherapy
 Yes
 No (ref)
 Cyclophosphamide dose (CED)
 Anthracycline cumulative dose
 None (ref)
 1-299 mg/m2
 >= 300 mg/m2

Any Radiation
 Yes
 No (ref)
 Chest
 Yes
 No (ref)
 Abdominal/pelvic
 Yes
 No (ref)
 Limb (arm, foot, hand)
 Yes
 No (ref)
 Total Body Irradiation
 Yes
 No (ref)
 Cranial radiation max dose

Any Surgery
 Yes
 No (ref)

Chronic health conditions
 Yes
 No (ref)
 Severity of chronic health conditions
 Grade 3-4
 Grade 1-2
 None (ref)

Note: Diagnosis type and treatments will be explored in separate models.
* Relative risks or prevalence will be reported

Aim 2a: Compare type of health insurance, and prevalence of underinsurance between survivors and siblings.

Aim 2a: Survivor and Sibling Differences in Type of Insurance at FU6											Public Insurance: Relative Risks/ 95% CI*	Private Insurance: Relative Risks/ 95% CI*
	Survivors					Siblings						
	Public		Private			Public		Private				
	N	%	N	%	p	N	%	N	%	p		
Overall												
Age, years												
18-24 (ref)												
26-34												
35-39												
40-44												
45 and older												
We will explore different age cut-points												
Sex												
Female (ref)												
Male												
Race												
White (ref)												
Black												
Asian												
AIAN												
Native Hawaiian or PI												
Hispanic or Latino												
Yes												
No (ref)												

* Relative risks or prevalence will be reported

Aim 2a: Survivor and Sibling Differences in Prevalence of Underinsurance at FU6						Relative Risks/ 95% CI*
	Survivors		Siblings			
	N	%	N	%	p	
Overall						
Age, years						
18-24 (ref)						
26-34						
35-39						
40-44						
45 and older						
We will explore different age cut-points						
Sex						
Female (ref)						
Male						
Race						
White (ref)						
Black						
Asian						
AIAN						
Native Hawaiian or PI						
Hispanic or Latino						
Yes						
No (ref)						

* Relative risks or prevalence will be reported

Aim 3a: Compare perceived health insurance stability between survivors and siblings.

Aim 3a: Survivor and Sibling Differences in Insurance Stability at FU6	Survivors		Siblings			Relative Risks/ 95% CI*
	N	%	N	%	p	
Overall						
Age, years						
18-24 (ref)						
26-34						
35-39						
40-44						
45 and older						
We will explore different age cut-points						
Sex						
Female (ref)						
Male						
Race						
White (ref)						
Black						
Asian						
AIAN						
Native Hawaiian or PI						
Hispanic or Latino						
Yes						
No (ref)						

* Relative risks or prevalence will be reported

Aim 4a: Compare job lock among survivors and siblings who were employed within the past two years.
Aim 4b: Determine the influence of debt, amount of debt, ability to pay payments, and bankruptcy on job lock, comparing survivors to siblings.

Aim 4a and 4b: Survivor and Sibling Differences in Job Lock at FU6						Relative Risks/ 95% CI*
	Survivors		Siblings			
	N	%	N	%	p	
Overall						
Age, years						
18-24 (ref)						
26-34						
35-39						
40-44						
45 and older						
We will explore different age cut-points						
Sex						
Female (ref)						
Male						
Race						
White (ref)						
Black						
Asian						
AIAN						
Native Hawaiian or PI						
Hispanic or Latino						
Yes						
No (ref)						
Debt						
Yes						
No (ref)						
We will explore different groupings of the amount of debt						
Inability to pay debt						
Yes						
No (ref)						
Bankruptcy						
Yes						
No (ref)						

* Relative risks or prevalence will be reported

<u>Aim 2b</u>: Among survivors, determine sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with type of health insurance and underinsurance.

Aim 2b: Multivariate regressions for factors associated with type of insurance and underinsurance among survivors at FU6						
	Insurance Type				**Underinsurance**	
	Public		**Private**			
	Relative risk	**95% CI**	**Relative risk**	**95% CI**	**Relative risk**	**95% CI**
Age, years						
18-25 (ref)						
26-34						
35-39						
40-44						
45 and older						
We will explore different age cut-points						
Sex						
Female (ref)						
Male						
Race						
White (ref)						
Black						
Asian						
AIAN						
Native Hawaiian or PI						
Hispanic or Latino						
Yes						
No (ref)						
Income						
Less than $20,000 (ref)						
$20,000-$39,999						
$40,000-$59,999						
$60,000-$79,999						
$80,000-$99,999						
$100,000 or more						
Age at diagnosis						
0-4 (ref)						
5-9						
10-14						
15-20						
Diagnosis						
Leukemia (ref)						
Central nervous system tumor						
Hodgkin disease						
Non-Hodgkin lymphoma						
Wilms (Kidney) tumors						
Neuroblastoma						
Soft tissue sarcoma						

Bone tumors
Retinoblastoma
Any chemotherapy
    Yes
    No (ref)
  Cycophosphomide dose (CED)
  Anthracycline cumulative dose
    None (ref)
    1-299 mg/m2
    >= 300 mg/m2
Any Radiation
    Yes
    No (ref)
  Chest
    Yes
    No (ref)
  Abdominal/pelvic
    Yes
    No (ref)
  Limb (arm, foot, hand)
    Yes
    No (ref)
  Total Body Irradiation
    Yes
    No (ref)
  Cranial radiation max dose
Any Surgery
    Yes
    No (ref)
Chronic health conditions
    Yes
    No (ref)
  Severity of chronic health conditions
    Grade 3-4
    Grade 1-2
    None (ref)

* Relative risks or prevalence will be reported
Note: Diagnosis type and treatments will be explored in separate models.

Aim 3b: Among survivors, identify sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with perceived health insurance stability.

Aim 4c: Among survivors, identify sociodemographic (e.g., age, sex, race/ethnicity, SES) and treatment/health factors (e.g., diagnosis, type of treatment received, chronic health conditions) that are associated with job lock.

Aim 3b and 4c: Multivariate regressions for factors associated with perceived insurance stability and job lock among survivors at FU6				
	Perceived Insurance Stability		Job Lock	
	Relative risk	95% CI	Relative risk	95% CI
Age, years				
18-25 (ref)				
26-34				
35-39				
40-44				
45 and older				
We will explore different age cut-points				
Sex				
Female (ref)				
Male				
Race				
White (ref)				
Black				
Asian				
AIAN				
Native Hawaiian or PI				
Hispanic or Latino				
Yes				
No (ref)				
Income				
Less than $20,000 (ref)				
$20,000-$39,999				
$40,000-$59,999				
$60,000-$79,999				
$80,000-$99,999				
$100,000 or more				
Age at diagnosis				
0-4 (ref)				
5-9				
10-14				
15-20				
Diagnosis				
Leukemia (ref)				
Central nervous system tumor				
Hodgkin disease				
Non-Hodgkin lymphoma				
Wilms (Kidney) tumors				

Neuroblastoma
Soft tissue sarcoma
Bone tumors
Retinoblastoma
Any chemotherapy
Yes
No (ref)
Cycophosphomide dose (CED)
Anthracycline cumulative dose
None (ref)
1-299 mg/m2
>= 300 mg/m2
Any Radiation
Yes
No (ref)
Chest
Yes
No (ref)
Abdominal/pelvic
Yes
No (ref)
Limb (arm, foot, hand)
Yes
No (ref)
Total Body Irradiation
Yes
No (ref)
Cranial radiation max dose
Any Surgery
Yes
No (ref)
Chronic health conditions
Yes
No (ref)
Severity of chronic health conditions
Grade 3-4
Grade 1-2
None (ref)

* Relative risks or prevalence will be reported
Note: Diagnosis type and treatments will be explored in separate models.

Exploratory Aim:

Aim a: Identify any changes in health insurance status, type of health insurance, and underinsurance among survivors from 2010-2011 to FU6 (2017).

Aim b: Determine the sociodemographic and chronic health conditions that are associated with change in insurance status, type of insurance, and underinsurance among survivors from 2010-2011 to FU6 (2017).

Exploratory Aim a and Aim b: Multivariate regressions for factors associated with being insured, type of insurance, and underinsurance among survivors from 2010-2011 to FU6											
	Insurance Status				Type of Insurance				Underinsurance			
	Losing insurance		Gaining insurance		Change from public to private		Change from private to public		Change from underinsured to not underinsured		Change from not underinsured to underinsured	
	Relative risk*	95% CI	Relative risk*	95% CI	Relative risk*	95% CI	Relative risk*	95% CI	Relative risk*	95% CI	Relative risk*	
Age, years												
18-25 (ref)												
26-34												
35-39												
40-44												
45 and older												
We will explore different age cut-points												
Sex												
Female (ref)												
Male												
Race												
White (ref)												
Black												
Asian												
AIAN												
Native Hawaiian or PI												
Hispanic or Latino												
Yes												
No (ref)												
Income												
Less than $20,000 (ref)												
$20,000-$39,999												
$40,000-$59,999												
$60,000-$79,999												
$80,000-$99,999												
$100,000 or more												
Age at diagnosis												
0-4 (ref)												
5-9												
10-14												

15-20

Diagnosis
  Leukemia (ref)
  Central nervous syste

  Hodgkin disease
  Non-Hodgkin lymphor
  Wilms (Kidney) tumor
  Neuroblastoma
  Soft tissue sarcoma
  Bone tumors
  Retinoblastoma

Any chemotherapy
  Yes
  No (ref)
  Cyclophosphamide
dose (CED)
  Anthracycline
cumulative dose
    None (ref)
    1-299 mg/m2
    >= 300 mg/m2

Any Radiation
  Yes
  No (ref)
  Chest
    Yes
    No (ref)
  Abdominal/pelvic
    Yes
    No (ref)
  Limb (arm, foot,
hand)
    Yes
    No (ref)
  Total Body
Irradiation
    Yes
    No (ref)
  Cranial radiation
max dose

Any Surgery
  Yes
  No (ref)

**Chronic health
conditions**
  Yes
  No (ref)
  Severity of chronic
health conditions
    Grade 3-4
    Grade 1-2

None (ref)	

* Relative risks or prevalence will be reported

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