

**Concept Proposal**  
**Childhood Cancer Survivor Study**  
**Ancillary Study Analysis Concept Proposal**

**Title: Financial Burden in Survivors of Childhood Cancer: the Childhood Cancer Survivor Study**

**Investigators:**

Ryan Nipp  
 Anne Kirchhoff  
 Douglas Fair  
 Karen Kuhlthau  
 Paul Nathan (Primary CCSS working group)  
 Kevin Oeffinger (Secondary CCSS working group)  
 Wendy Leisenring  
 Elyse Park\*

[rnipp@mgh.harvard.edu](mailto:rnipp@mgh.harvard.edu)  
[anne.kirchhoff@hci.utah.edu](mailto:anne.kirchhoff@hci.utah.edu)  
[douglas.fair@hsc.utah.edu](mailto:douglas.fair@hsc.utah.edu)  
[kkuhlthau@mgh.harvard.edu](mailto:kkuhlthau@mgh.harvard.edu)  
[paul.nathan@sickkids.ca](mailto:paul.nathan@sickkids.ca)  
[oeffingk@mskcc.org](mailto:oeffingk@mskcc.org)  
[wleisenr@fhcrc.org](mailto:wleisenr@fhcrc.org)  
[epark@mgh.harvard.edu](mailto:epark@mgh.harvard.edu)

\*Senior author

**Background and Rationale:**

As a result of improved cancer therapies, many children with cancer survive into adulthood. In fact, over 80% of children and adolescents diagnosed with cancer survive beyond five years.<sup>1</sup> Recent data suggests that approximately 380,000 survivors of childhood and adolescent cancer remain alive in the United States.<sup>2</sup> Despite these promising survival statistics and the advances in cancer treatment, many of these survivors of childhood cancer experience high rates of chronic illness and adverse health outcomes.<sup>3-5</sup> Thus, childhood cancer survivors need ongoing medical care long after their initial cancer diagnosis, often requiring numerous interactions with a multitude of health care providers and frequent follow-up visits.

Although childhood cancer survivors need ongoing medical surveillance, they frequently experience barriers that prevent them from obtaining adequate care. In prior analyses of the Childhood Cancer Survivor Study (CCSS) cohort, investigators found that while 83.9% of survivors had health insurance, 29% reported having difficulty obtaining coverage as compared with only 3% of the control sibling cohort.<sup>6</sup> Survivors who were younger, unmarried, less educated, and poorer were at greater risk for being uninsured.<sup>6</sup> In addition, there were indicators that many survivors were underinsured (i.e., restrictive and costly plans). In another CCSS study, investigators determined that uninsured survivors received less risk-based, survivor-focused care than those who had health insurance.<sup>7</sup> In a recent qualitative study of CCSS participants, researchers found that uninsured survivors expressed considerable worry about future health care costs.<sup>8</sup> Therefore, childhood cancer survivors encounter obstacles that prevent them from obtaining adequate insurance coverage, and this may result in financial burden. This financial burden, in turn, may affect their care seeking behavior and overall quality of life.

Research on adult cancer patients and survivors of adult cancers has helped inform our knowledge about subsequent financial burden. The rising cost of cancer care and increasing out-of-pocket costs for patients with cancer have led to increased focus on the financial burden experienced by cancer patients.<sup>9-11</sup> In a recent study of adult cancer patients, investigators found that cancer patients have a two-fold higher risk of declaring bankruptcy compared to those without cancer.<sup>12</sup> The financial burden experienced by patients with cancer may have detrimental effects on their treatment outcomes. As a result of the financial burden of their care, cancer patients may not properly adhere with their prescribed therapies,<sup>13-15</sup> and thus jeopardize their care.<sup>16-18</sup> Additionally, financial burden remains a problem for cancer survivors as well. Nearly one-third of survivors in a 2010 health survey reported financial problems.<sup>18</sup> These survivors who reported financial problems were more likely to delay or forgo obtaining necessary medical care and prescription medications.<sup>18,19</sup>

While mounting evidence expounds the adverse effects of the financial burden experienced by patients with cancer, little research has addressed the financial burden experienced by childhood cancer survivors. Thus, in our current proposal we aim to use data from an ancillary study of CCSS survivors to evaluate the financial burden experienced. First, we will describe childhood cancer survivors' out-of-pocket medical expenditures and determine what percentage of their annual income is spent on out-of-pocket (OOP) costs. Next, we will determine the financially-motivated behaviors experienced by survivors with higher OOP costs compared to those with lower OOP costs. Then, we will report the differences in health care utilization among the survivors with higher OOP costs compared to those with lower OOP costs. Finally, we plan to explore survivors' willingness to pay for and their opinions of their ideal health insurance plan. The results generated from these analyses will provide valuable information about the financial burden experienced by survivors of childhood cancer.

Given that financial burden can result in significant distress and poor treatment outcomes among patients with cancer, a better understanding of the financial burden experienced by childhood cancer survivors should aid in the development of future interventions aimed at alleviating the financial burden they experience.

### Study Aims:

**1) To describe childhood cancer survivors' financial characteristics: out-of-pocket medical expenditures [#28], household income [#44], personal income [#46], and frequency of OOP costs  $\geq 10\%$  of income (a marker of underinsurance).**

**2) To explore characteristics associated with OOP costs  $\geq 10\%$  of their income.**

*Hypothesis:* Characteristics of survivors reporting OOP costs exceeding 10% of their income will include: younger age, male sex, uninsured, racial/ethnic minority, less education, unmarried, more children, unemployment, and more chronic medical conditions.

**3) To compare the health care utilization [#17, 18, 19] among survivors with OOP costs  $\geq 10\%$  of their income compared to survivors with OOP costs  $< 10\%$  of their income.**

*Hypothesis:* Survivors who report greater OOP health expenditures will report having utilized more health care services in the past year (i.e. #17: primary care, specialty care, mental health care; #18: primary care, specialty care; #19: hospitalizations).

**4) To determine concerns and behaviors associated with patient-reported financial burden (lifestyle changes [#31], medical care changes [#30], worry [#32], and trouble paying medical bills [#29]) experienced by survivors, comparing those with OOP costs  $\geq 10\%$  of their income to those with OOP costs  $< 10\%$  of their income.**

*Hypothesis:* Survivors who report OOP costs  $\geq 10\%$  of their income will report experiencing more financially-motivated behaviors (i.e. #31: Been unable to pay for basic necessities like food, heat, or rent, Had to borrow money, Had to take money out of savings; #30: Took a smaller dose or fewer pills than was prescribed, Did not fill a prescription for a medicine, Had a medical problem but did not go to a health care provider or a clinic; #32: You wouldn't be able to pay for medical bills, You wouldn't be able to go to the health care providers you wanted; #29: problems paying medical bills in the past year) than those with lower OOP expenditures.

**5) To evaluate the percent of their income survivors want to pay for their ideal health insurance plan [#35] compared to the percent of their income they are actually paying [#27].**

*Hypothesis:* Survivors who currently spend  $\geq 10\%$  of their income on health insurance will report wanting to pay a lower percent of their income on their ideal plan than those who currently spend a lower percent of their income on health insurance.

### Study Population:

Study participants will include individuals in the original CCSS survivor cohort who completed the Health Insurance Ancillary Survey. We sent the survey to a random sample of CCSS participants and asked them to return the completed survey via mail or internet. Depending on their insurance status, we asked participants to fill out either the insured version or the uninsured version of the survey. We sent the surveys to 1100 CSS survivors, and 698 (63.5%) completed the form. We will use the insured version of the survey when referring to specific survey items below.

### Measures:

#### Aim 1:

##### Out-of-pocket medical expenditures [#28]

During the past year, about how much did you/your family 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.

##### Personal income [#46]

Over the last year, what was your personal income?

- a) None
- b) \$1-\$9,999
- c) \$10,000-\$19,999

- d) \$20,000-\$39,999
- e) \$40,000-\$59,999
- f) \$60,000-\$79,999
- g) \$80,000-\$99,999
- h) \$100,000 and over
- i) Don't know

Household income [#44]

Over the last year, what was the total income of the household you live in (family members only)?

- a) Less than \$20,000
- b) \$20,000-\$39,999
- c) \$40,000-\$59,999
- d) \$60,000-\$79,999
- e) \$80,000-\$99,999
- f) \$100,000 and over
- g) Don't know

Household size [#44]

During the past year, how many family members in this household were supported on this income?

- a) Response: \_\_\_ \_\_\_ family members including yourself

Frequency that OOP costs exceed 10% of income

- a)  $\text{Out-of-pocket medical expenditures [#28]} \div \text{Personal income [#46]} = \% \text{ of personal income spent on OOP costs}$
- b)  $\text{Out-of-pocket medical expenditures [#28]} \div \text{Household income [#44]} = \% \text{ of household income spent on OOP costs}$
- c)  $\text{Out-of-pocket medical expenditures [#28]} \div \text{Household income [#44]} \div \text{Number of family members in this household supported on this income [#45]} = \% \text{ of household income per person spent on OOP costs}$
- d)  $\text{Total number with } \geq 10\% \text{ of personal income spent on OOP costs [see 'a' above]} \div \text{Total Cohort} = \% \text{ of survivors with } \geq 10\% \text{ of personal income spent on OOP costs}$
- e)  $\text{Total number with } \geq 10\% \text{ of household income spent on OOP costs [see 'b' above]} \div \text{Total Cohort} = \% \text{ of survivors with } \geq 10\% \text{ of household income spent on OOP costs}$
- f)  $\text{Total number with } \geq 10\% \text{ of household income per person spent on OOP costs [see 'c' above]} \div \text{Total Cohort} = \% \text{ of survivors with } \geq 10\% \text{ of personal income spent on OOP costs}$

**Aim 2:  
Demographics and Clinical Characteristics**

Current Employment [#7]

What is your current employment status?

- a) Employed
- b) Unemployed and looking for work
- c) Unable to work due to illness/disability
- d) Other

Marital Status [#43]

Which of the following best describes your current marital status?

- a) Married
- b) Unmarried

Current Age

- a) 25-34
- b) 35-44
- c)  $\geq 45$

Health Insurance Status [#2]

- a) Insured
- b) If Insured, Type of Insurance
- c) Employer-sponsored

- d) Individual private
- e) Medicare
- f) Medicaid
- g) Military Health Care
- h) Don't know

Sex

- a) Male
- b) Female

Race/Ethnicity

- a) White, non-hispanic
- b) Black, non-hispanic
- c) Hispanic/Latino
- d) Other

Education

- a) High School or less
- b) Some college or more

No. of children in family

- a) 0
- b) 1
- c) >=2

Type of Cancer

- a) Leukemia
- b) Central Nervous System
- c) Hodgkin's lymphoma
- d) Neuroblastoma
- e) Wilms (Kidney) Tumor
- f) Soft tissue sarcoma
- g) Bone
- h) Non-Hodgkin's lymphoma

Chronic Medical Conditions

- a) None
- b) Any One condition Grade 1-4
- c) >=2 Grade 3-4
- d) >=3 Grade 3-4

**Aim 3:**Health care utilization [#17, 18, 19]

[#17] During the past year, which of the following health care providers did you see or talk to for medical care? This includes routine care and sick care.

Respondents were asked to "Please mark all that apply."

- a) None
- b) Primary care physician
- c) Specialty care physician (e.g., cardiologist)
- d) Provider who sees cancer survivors for routine follow-up care (e.g., survivorship clinic)
- e) Nurse Practitioner/Physician's Assistant
- f) Nurse
- g) Chiropractor
- h) Physical therapist/Occupational therapist/Speech-language pathologist/Audiologist
- i) Dentist
- j) Eye doctor
- k) Mental health care professional
- l) Other [free response box]

[#18] During the past year, how many times did you see the following health care providers?

- Primary care physician
- Specialty care
- Provider who sees cancer survivors for routine follow-up care (e.g. survivorship clinic)
- Nurse Practitioner/Physician's Assistant

[#18a] As you know, you were asked to participate in this study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of these times were related to this previous illness?

- Response: \_\_\_ \_\_\_ times

[#19] During the past year, how many times were you hospitalized (stayed in the hospital overnight for one or more days)?

- Response: \_\_\_ \_\_\_ times

[#19a] How many of these hospitalizations were related to this previous illness?

- Response: \_\_\_ \_\_\_ times

#### **Aim 4:**

##### Trouble paying medical bills [#29]

In the past year, have you/your family had any problems paying your medical bills?

- Yes
- No
- Don't know

##### Worry questions [#32]

In the past year, how much did you worry that:

Respondents were asked to respond: "a great deal," "a fair amount," "a little," or "not at all" for the following:

- You or your spouse would lose your job
- A change in job or school would result in loss of or lower quality health insurance coverage
- You wouldn't be able to pay for medical bills
- You wouldn't be able to get a medical procedure that you needed
- You wouldn't be able to go to the health care providers you wanted
- Health insurance would become so expensive you wouldn't be able to afford it
- Your health insurance plan would change terms (e.g., costs that were once covered will no longer be covered)
- You would need some health care services that were not covered

##### Lifestyle changes [#31]

In the past year, have any of the following happened because of medical expenses?

Respondents were asked to respond: "Yes," "No," "Don't know" for the following:

- Put off major purchases, such as a new home or car
- Been unable to pay for basic necessities like food, heat, or rent
- Had to take money out of savings
- Spent more than 10% of your income on medical expenses
- Had to borrow money
- Took on credit card debt
- Took out a mortgage against your home or took out a loan
- Thought about filing for bankruptcy
- Filed for bankruptcy

##### Medical care changes [#30]

In the past year, was there a time when you did any of the following because you were worried about the cost?

Respondents were asked to respond: "Yes," "No," "Don't know" for the following:

- Skipped a medical test, treatment, or follow-up that was recommended by a health care provider
- Had a medical problem but did not go to a health care provider or a clinic
- Did not see a specialist when you or your health care provider thought you needed one
- Put off or postponed preventive care
- Put off or postponed dental care
- Put off or postponed vision care
- Put off or postponed mental health care
- Had no primary care provider

- i) Did not fill a prescription for a medicine
- j) Took a smaller dose or fewer pills than was prescribed

**Aim 5:**Willingness to pay for health insurance [#35]

What is the most you would be willing to pay each month for health insurance coverage?

- a) \$ \_\_\_ \_\_\_ per month for an individual policy
- b) \$ \_\_\_ \_\_\_ per month for a family policy

(Amount willing to pay per month [#35] X 12 months) ÷ Household income [#44] = % of household income willing to pay  
 (Amount willing to pay per month [#35] X 12 months) ÷ Personal income [#44] = % of personal income willing to pay

Amount currently paying for health insurance [#27]

During the past year, about how much did you/your family spend on health insurance premiums?

- a) \$ \_\_\_ \_\_\_ during the past year

Amount currently paying [#27] ÷ Household income [#44] = % of household income spent on OOP costs

Amount currently paying [#27] ÷ Personal income [#46] = % of personal income spent on OOP costs

**Statistical Approach:**

Dr. Nipp is currently training in biostatistics via the Master of Public Health program at the Harvard School of Public Health. While he will lead the analyses, he will receive weekly supervision from Drs. Kirchhoff and Park as well as input from Dr. Leisenring and the ancillary survey study team throughout all aspects of the analyses. For all analyses, we will use sample weights to reweight the survey data to reflect the age distribution of the overall CCSS sample.

We will use descriptive statistics to describe the demographics and clinical characteristics of the entire cohort of childhood cancer survivors. We will report the mean and standard deviation for out-of-pocket expenditures, household income, and personal income for each of the demographics and clinical characteristics (Table 1). Additionally, we will report the percentages of household income and personal income spent on out-of-pocket costs (Table 1). Also in Table 1, we will report the rates of survivors who spent ≥10% of their household and personal income on out-of-pocket costs.

We will use generalized linear models, either with a logistic link or log link, depending on the prevalence of the outcome, to explore patient sociodemographics and clinical characteristics associated with having OOP costs equal to or exceeding 10% of income. Initially, we will evaluate each characteristic in univariable models and then build a multivariable model based on those that are identified as significant at the  $p < 0.10$  level in univariate models, or which have been identified for clinical purposes (Table 1a).

We will use a chi-squared test to compare the rates of utilization for each type of health care provider among survivors with higher OOP costs versus those with lower OOP costs (Table 2). We will then use T-test and Wilcoxon rank sum, as appropriate to compare the mean, or median, number of times survivors reported seeing the health care providers, and for the number of hospitalizations in the past year between survivors with higher OOP costs versus those with lower OOP costs (Table 2).

We will use a chi-squared test to compare the frequencies of each of the financially-motivated behaviors (lifestyle changes [#31], medical care changes [#30], worry [#32], and trouble paying medical bills [#29]) between survivors with higher OOP costs versus those with lower OOP costs (Table 3).

Additionally, we will use T-test and Wilcoxon rank sum, as appropriate to compare the mean, or median, percent of their income survivors reported they would be willing to pay for an individual or family policy between survivors currently paying more for insurance versus those currently paying less (Table 4).

Finally, for the outcomes demonstrated in Tables 2, 3, and 4 we will use regression modeling (linear models for continuous outcomes and logistic models for binary outcomes). Specifically, these models will allow us to adjust for any sociodemographic and clinical differences between the survivors with OOP costs equal to or exceeding 10% of income and those with OOP costs <10% of income.

Tables and Figures:

**Table 1. Childhood cancer survivors' out-of-pocket medical expenditures, household income, personal income, and frequency that OOP costs exceed 10% of income [Aims 1 &2]**

Characteristic	Childhood Cancer Survivors		Out-of-Pocket Costs ≥ 10% of Personal Income	Out-of-Pocket Costs ≥ 10% of Household Income	Out-of-Pocket Costs ≥ 10% of Household Income per person
	N	%	%	%	%
<b>Current Age</b>					
25-34					
35-44					
>=45					
<b>Health Insurance Status</b>					
Insured					
If Insured, Type of Insurance					
Employer-sponsored					
Individual private					
Medicare					
Medicaid					
Military Health Care					
Don't know					
<b>Sex</b>					
Male					
Female					
<b>Race/Ethnicity</b>					
White, non-hispanic					
Black, non-hispanic					
Hispanic/Latino					
Other					
<b>Education</b>					
High School or less					
Some college or more					
<b>Marital Status</b>					
Married					
Unmarried					
<b>No. of children in family</b>					
0					
1					
>=2					
<b>Employment Status</b>					
Employed					
Unemployed and looking for work					
Unable to work due to illness/disability					
Other					
<b>Type of Cancer</b>					
Leukemia					
Central Nervous System					
Hodgkin's lymphoma					
Neuroblastoma					
Wilms (Kidney) Tumor					
Soft tissue sarcoma					
Bone					
Non-Hodgkin's lymphoma					
<b>Chronic Medical Conditions</b>					
None					
Any One condition Grade 1-4					
>=2 Grade 3-4					
>=3 Grade 3-4					

**Table 1a. Multivariable model based on those identified as significant at the p<0.10 level in univariate models**

Covariates	Out-of-Pocket Costs ≥ 10% of Personal Income			Out-of-Pocket Costs ≥ 10% of Household Income			Out-of-Pocket Costs ≥ 10% of Household Income per person		
	OR	P	95% CI	OR	P	95% CI	OR	P	95% CI
covariate 1									
covariate 2									
covariate 3									
covariate 4									
covariate 5									
covariate 6									
covariate 7									
covariate 8									



**Table 2. Health care utilization among survivors with higher OOP costs to those with lower OOP costs**

**[Aim 3]**

Health care utilization	Cancer Survivors with Out-of-Pocket Costs ≥ 10% of Income		Cancer Survivors with Out-of-Pocket Costs < 10% of Income		OR	95% CI	P
	N	%	N	%			
<b>During the past year, did you see any of the following health care providers?</b>							
Primary care physician							
Specialty care physician							
Survivorship clinic							
Nurse Practitioner / Physician's Assistant							
Nurse							
Chiropractor							
PT/OT/Speech-language pathologist/Audiologist							
Dentist							
Eye doctor							
Mental health care professional							
<b>During the past year, how many times did you see the following health care providers?</b>	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>	<b>Beta</b>	<b>95% CI</b>	<b>P</b>
Primary care physician							
Specialty care physician							
Survivorship clinic							
Nurse Practitioner / Physician's Assistant							
<b>How many of these times were related to prior cancer?</b>							
<b>No. of hospitalizations in the past year</b>							
<b>No. of hospitalizations related to prior cancer</b>							

Odds ratio and Beta adjusted for sociodemographic and clinical differences between the survivors with OOP costs equal to or exceeding 10% of income and those with OOP costs <10% of income.

**Table 3. Concerns and behaviors of survivors with higher OOP costs compared to those with lower OOP costs****[Aim 4]**

Concerns and behaviors	Cancer Survivors with Out-of-Pocket Costs $\geq$ 10% of Income		Cancer Survivors with Out-of-Pocket Costs < 10% of Income		OR	95% CI	P
	N	%	N	%			
<b>In the past year, have you/your family had any problems paying your medical bills?</b>							
Yes							
<b>In the past year, how much did you worry that:</b>							
You or your spouse would lose your job							
A change in job or school would result in loss of or lower quality health insurance coverage							
You wouldn't be able to pay for medical bills							
You wouldn't be able to get a medical procedure that you needed							
You wouldn't be able to go to the health care providers you wanted							
Health insurance would become so expensive you wouldn't be able to afford it							
Your health insurance plan would change terms (e.g., costs that were once covered will no longer be covered)							
You would need some health care services that were not covered							
<b>In the past year, have any of the following happened because of medical expenses?</b>							
Put off major purchases, such as a new home or car							
Been unable to pay for basic necessities like food, heat, or rent							
Had to take money out of savings							
Spent more than 10% of your income on medical expenses							
Had to borrow money							
Took on credit card debt							
Took out a mortgage against your home or took out a loan							
Thought about filing for bankruptcy							
Filed for bankruptcy							
<b>In the past year, was there a time when you did any of the following because you were worried about the cost?</b>							
Skipped medical test, treatment, or follow-up							
Had a medical problem but did not go to a health care provider or a clinic							
Did not see a specialist							
Put off/postponed preventive care							
Put off/postponed dental care							
Put off/postponed vision care							
Put off/postponed mental health							
Had no primary care provider							
Did not fill a prescription							
Took a smaller dose/fewer pills than prescribed							

Odds ratio adjusted for sociodemographic and clinical differences between the survivors with OOP costs equal to or exceeding 10% of income and those with OOP costs <10% of income.

**Table 4. Percent of their income survivors are willing to pay for their ideal health insurance plan [#35] compared to the percent of their income they are actually paying**

[Aim 5] – could present as a figure (box plots)

Ideal health insurance plan	Cancer Survivors currently paying $\geq$ 10% of Income		Cancer Survivors currently paying < 10% of Income		Beta	95% CI	P
	Mean	SD	Mean	SD			
<b>For an individual policy</b>							
% of household income willing to pay							
% of personal income willing to pay							
<b>For a family policy</b>							
% of household income willing to pay							
% of personal income willing to pay							

Beta adjusted for sociodemographic and clinical differences between the survivors with OOP costs equal to or exceeding 10% of income and those with OOP costs <10% of income.

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