

Childhood Cancer Survivor Study
Ancillary Study Analysis Concept Proposal
CCSS Insurance Survey

Date: 12/9/13

Title: Impact of Health Insurance on Utilization of Outpatient and Inpatient Health Care Services by Childhood Cancer Survivors: A Report from the Childhood Cancer Survivor Study.

Working Group and Investigators:

This proposal will be set within Cancer Control Working Group.
Secondary oversight: Chronic Disease Working Group.

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Background and Rationale:

Over the last 50 years, major therapeutic advances have transformed the field of pediatric oncology. Today, approximately 4 in 1000 children and adolescents between the age of 0-20 years will be diagnosed with cancer.¹ Improvement in overall cure rates has made it possible for over 3 of every 4 childhood cancer patients to survive into adulthood. As of 2010, there were estimated to be over 379,100 survivors of childhood cancer in the United States.² Research conducted by the Childhood Cancer Survivor Study (CCSS) revealed that two-thirds of all survivors will develop a chronic medical condition, with more than one-third suffering from a severe or life-threatening condition.³ Previous publications have shown that risk-based screening can yield improved recognition of the long term effects of cancer treatment.^{4,5} The combination of growing number of pediatric

cancer survivors and the large proportion suffering from health conditions requiring medical attention pose a complex problem for the health system.

In regards to outpatient care of CCS, there are very few established multi-disciplinary centers able to care for this special population and thus the burden of care often falls on the primary care providers.^{3,11} Previous hierarchical analyses have investigated the types of outpatient medical encounters as they relate to the receipt of survivor-focused care. Survivor-focused care was defined as a medical visit related to their prior cancer in which a screening test was discussed or ordered or the survivor was counseled on how to reduce his/her specific risks. In an analysis of the baseline CCSS questionnaire, Oeffinger discovered that while 87% of survivors reported attending a “general medical visit,” only 41.9% had received a “cancer-related visit” in the last two years. In this same evaluation, patients without health insurance were most at risk for lack of appropriate follow up.³ In another study, Nathan determined that among the survivors that received medical care, those who were black, older age at interview, or uninsured were less likely to have received risk-based, survivor-focused care.¹¹

In a previous analysis of the utilization of inpatient health care among CCSS participants, it was found that CCS are 1.6 times as likely as the general population to be hospitalized. Those with a history of Hodgkin disease and survivors between the ages of 45-54 were even more likely to have increased hospitalization rates. As well, characteristics that were found to be increased risk factors for hospitalization in a multivariable analysis included having medical insurance, having a household income of less than \$20,000 and having a chronic health condition.¹² The authors pointed out that those with low-income households had previously been found to be less likely to seek medical care within the last 2 years, therefore fewer outpatient visits and limited resources to treat chronic medical conditions may have contributed to the increased hospitalization rates. Also those survivors with health insurance that were found to be at increased risk for hospitalization may have been due to the conflict between having insurance but not having the resources to be seen in the outpatient setting for routine visits and preventive health maintenance visits. Therefore, it appears that insurance coverage or quality plays a large role in the receipt of both the outpatient and inpatient care for CCS.

We do know that having adequate health insurance is an important factor in regards to obtaining necessary medical care. This can best be demonstrated by the Oregon example where due to financial constraints Oregon implemented a lottery system in 2008 to allow uninsured, low-income adults of any health status a chance to apply for Medicaid. Those who won the lottery and were enrolled in Medicaid had higher health care utilization, lower out-of-pocket expenses and medical debt than their peers.¹³ Among childhood cancer survivors, Park found that while 84% of survivors had health insurance, 29% had reported having difficulty obtaining coverage as compared with the control sibling cohort rate of only 3%.¹⁴ It is likely that the presence of chronic medical conditions (CMC) were a barrier to the CCS obtaining insurance coverage prior to the implementation of the Affordable Care Act of 2010

(ACA). Yet, CMC may also serve as an impetus for patients to seek care. What is not known is if patients with CMC and no insurance or under-insurance are being seen more frequently in the inpatient setting due to lack of adequate outpatient care.

As new health care legislation takes effect, health insurance coverage will be changing in the near future. The ACA incorporates new provisions into health care legislation, which will ensure coverage for those with pre-existing medical conditions and hopefully improve ability to obtain and maintain insurance for survivors.¹⁵ Unfortunately, having health insurance does not necessarily equal access to care. Therefore, understanding the relationship between health insurance and health care utilization for CCS could serve as a baseline for future studies on the impact of the ACA on CCS.

The purpose of this concept proposal is to use the information gathered through the ancillary CCSS study entitled "Are Adult Survivors of Childhood Cancer Underinsured?" (Park, PI) to explore and evaluate the current health care utilization of outpatient and inpatient services of the original CCSS cohort, using information not previously documented in the CCSS follow-up surveys. This information will be key as the new era of care coordination is aided by coverage expansion in the ACA, development of Accountable Care Organizations and implementation of patient-centered medical homes occurs in the United States. In the main paper of Park's ancillary study, she will be investigating the differences experienced by CCS and their siblings related to insurance coverage, including source of health insurance, difficulties obtaining insurance, coverage rates, and perceived importance of plan coverage, features, and cost factors.

Of specific interest to this proposal, we will more thoroughly explore the impact of health insurance status, as well as the detailed types of health insurance, on the health care utilization of CCS. The CCS were concurrently asked about their health insurance and health care utilization, including outpatient medical care and hospitalizations over the last year. We will be able to delve deeper into characterizing the provider care arrangements of CCS by quantifying and analyzing the types of providers that delivered medical care and the number of visits, both overall and specific to their previous diagnosis of cancer. Through this detailed data, we will be able to investigate the utilization patterns of high-utilizers, which may provide insight into the subpopulation of CCS with significant medical needs. By evaluating the different provider care arrangements according to health insurance status, type of health insurance and presence of chronic disease we will be able to better understand the current health care utilization patterns of this unique patient population.

In summary, the clinical questions to be answered with this analysis are:

1. Describe the provider care arrangements of CCS.
2. Investigate how the presence of health insurance or CMC impacts the health care utilization, both inpatient and outpatient, of childhood cancer survivors.

Study Aims:

1. Describe provider care types used by the CCS during the past year and evaluate relationship to insurance status, financial stressor/worries, provider care arrangement, and presence of chronic medical conditions. (Table 2 and 3)
 - a. We will characterize the provider care type as both a mutually exclusive category and as a composite variable of a combination of types of providers.
 - i. Primary care physicians (PCP)
 - ii. Specialty care physicians
 - iii. Survivorship clinic provider
 - iv. Nurse practitioner/physician's assistant
 - v. Nurse
 - vi. Composite variable based on above frequencies

Hypothesis: The presence of having health insurance and the presence of Grade 3-4 chronic medical conditions will be associated with increased use of specialty care physicians and receiving care by a survivorship care physician. Survivors with Employee-sponsored insurance will be associated with increased use of primary care physicians.

2. Describe the health care utilization of CCS using the hierarchal definitions of health care utilization described in the two previous CCSS publications on health care utilization.^{3,11} (Table 4 and 5)
 - a. *No health care*
 - b. *General medical care* (one or more visits to a doctor or nurse, none of which were related to their prior cancer)
 - c. *Cancer-related care* (a medical visit related to the prior cancer)

Similarly to Casilla's Longitudinal Health Care Utilization Concept Proposal, we will not include the 4th category, *risk-based survivor focused care*, as described by Nathan et al, due to limitations within our data collected. This hierarchy system was "constructed to classify levels of medical care related specifically to the prior cancer and its risks and is not intended to imply a level of quality of care for health issues unrelated to the previous cancer." In addition, "the assigned level of care is independent of who delivered the care (cancer specialist or primary care clinician) or where the care was received (cancer center or community setting)."¹¹

Hypothesis: The presence of having health insurance and the presence of Grade 3-4 chronic medical conditions will be associated with receiving Cancer-related care.

3. Describe utilization of outpatient health care services (frequency of number of physician visits) and inpatient health care services (frequency of hospitalizations) by CCS and evaluate the relationship to insurance status,

financial stressor/worries, provider care arrangement, and presence of chronic medical conditions. (Table 6 and 7)

Hypothesis: CCS who are uninsured or expressed financial stressors/worries will have decreased use of outpatient care. CCS with Grade 3-4 CMC will have increased use of inpatient care, regardless of insurance status. Older age, Grade 3-4 CMC, and presence of financial stressors will be associated with being a “high utilizer”.

Study Population:

1. Study participants are those individuals in the original CCSS survivor cohort who completed the Health Insurance Ancillary Survey in 2010-2011. U.S. CCSS participants, who had completed the 2007 Follow Up, were randomly sampled by age stratifications (<30, 30-39, or >40 years). Participants completed either the *Insured* or *Uninsured* Questionnaires based on their current insurance status. Questionnaires were completed through either mailed or internet format. The final sample included 699 survivors. There was a 64% response rate among survivors. Siblings will not be included in this analysis.
2. Chronic Medical Conditions will be obtained from the the accumulation of information up to and including the Follow Up 2007 for all CCS who completed the Health Insurance Ancillary Survey.

Analysis Framework:

- Due to the sampling scheme stratified by age at FU 2007, sampling weights will be incorporated into all analyses to produce results consistent with the original age distribution of the population of CCS who participated in the 2007 FU Survey.
- Descriptive statistics will be used to characterize the CCS participants of the Health Insurance Ancillary Survey, including demographics, health insurance status, and presence of chronic medical conditions. (Table 1)

Aim 1:

Outcomes of Interest:

- Provider Care Arrangement:
 - Dichotomous measures, though not mutually exclusive, will be used to describe the types of health care providers that CCS had seen or talked to for medical care in the past year including (Insured Survey Question 17, Uninsured Survey Question 18):
 - Primary care physicians (PCP)
 - Specialty care physicians
 - Survivorship clinic provider

- Nurse practitioner/physician's assistant
 - Nurse
- Composite variables of provider types will be developed based on our analysis of the provider care variables above.
 - Examples could include: PCP Only, Majority Survivorship Clinic, Majority NP/PA, PCP and Subspecialist only, PCP and Survivorship Clinic Only

Independent Variables:

- Sociodemographic Factors
 - Current Age, at time of ancillary survey completion
 - Age at diagnosis
 - Sex
 - Race/Ethnicity
 - Type of cancer
 - Education
 - Household income
- Health Insurance
 - Health Insurance Status
 - Insured vs Uninsured
 - If insured, type of health insurance
 - Employer-sponsored insurance
 - Individual insurance
 - Medicare
 - Medicaid/state public insurance program
 - Other state or local government or community program
 - Military health care
 - Don't know
 - Other
- Chronic Medical Conditions (CMC) – CTCAE Grades completed by Oeffinger and Armstrong using all questionnaires up to and including Follow Up 2007 questionnaire data
 - Severity of conditions is scored using the Common Terminology Criteria for Adverse Events (CTCAE) version 3: grade 1 (mild), 2 (moderate), 3 (severe), 4 (life-threatening or disabling) or 5 (fatal).
 - CMC will be utilized according to the following algorithm:
 - Continuous variable
 - Number of medical conditions
 - Level of severity of medical conditions
 - Dichotomized variables:
 - Quantity and severity of conditions
 - No Chronic Conditions
 - ≥ 1 Condition Grades 1-2
 - ≥ 1 Condition Grades 1-4

- 1 Condition Grades 3-4
- ≥ 2 Condition Grades 3-4

Statistical Approach:

- Provider care arrangements
 - Frequency and percent subjects utilizing each type of provider care arrangements will be summarized overall.
 - Bivariate analyses using chi-square will be conducted to examine the relationship between each binary outcome and each independent variable.
Regression modeling using log-binomial models to directly estimate the relative risk (RR) estimates (or alternate modelling methods if convergence is an issue) will be fit for each of the dichotomous outcomes of provider type to evaluate for associations between provider types and covariates listed above, controlling for socio-demographic factors.

Aim 2:

Outcomes of Interest:

- Hierarchal Model of Care, not indicative of quality
 - *No health care* (No visits to any medical care provider)
 - *General medical care* (One or more visits to a doctor or nurse, none of which were related to their prior cancer)
 - *Cancer-related care* (defined as a medical visit related to the prior cancer, or one in which the survivor is counseled about how to reduce their risks or has surveillance tests ordered or discussed)

Independent Variables:

- Sociodemographic Factors (as in Aim 1)
- Health Insurance (as in Aim 1)
- CMC (as in Aim 1)

Statistical Approach:

- Hierarchal Arrangements of Care
 - Frequency and percent subjects utilizing provider care arrangements will be summarized overall.
 - Bivariate analyses using chi-square will be conducted to examine the relationship between each binary outcome and each independent variable.

- Regression modeling using log-binomial models to directly estimate relative risk (RR) estimates (or alternate modeling methods if convergence is an issue) will be fit for each of the dichotomous outcomes of provider type to evaluate for difference among provider types and covariates listed above, controlling for socio-demographic factors.

Aim 3:

Outcomes of Interest:

- Utilization of health care services:
 - Continuous variables will be used including (Insured Q18-19, Uninsured Q19-20):
 - Number of times that CCS was seen by the following health care providers in the past year, for all reasons:
 - Primary care physicians (PCP)
 - Specialty care physicians
 - Survivorship clinic provider
 - Nurse practitioner/physician's assistant
 - Number of times seen by above providers due to previous illness (cancer diagnosis).
 - Number of hospitalizations in the past year, for all reasons.
 - Number of hospitalizations in the past year, due to previous illness(cancer diagnosis).
 - Explore different ways to conceptualize the “high utilizer variable”
 - A composite variable may be developed to explore the experiences of “high utilizers” based on frequency of outpatient visits and/or hospitalizations. An example of how we may define “high utilizer” is if the CCS were in the top tertile for the frequency of use of both inpatient and outpatient services.
 - We could also look at “high outpatient utilizer” or “high inpatient utilizer”.

Independent Variables:

- Sociodemographic Factors (as in Aim 1)
- Health Insurance (as in Aim 1)
- CMC (as in Aim 1)
- Provider Care Arrangements:
 - Please refer to Aim 1 for description of possible variables to define provider care arrangements.
- Financial Stressors:
 - Dichotomous variables will be made for:

Tables and Figures:

Table 1. Characteristics of Childhood Cancer Survivors Who Completed the Health Insurance Ancillary Study.

	Childhood Cancer Survivors	
	N (Total = 698)	%
Current Age		
22-29	214	11.3
30-29	228	42.3
40-62	256	46.4
Health Insurance Status		
Insured	619	89.8
If Insured, Type of Insurance		
Employer-sponsored/ Military	510	77.5
Medicaid/State	92	11.9
Individual	50	7.0
Medicare	24	3.2
Don't know	6	0.5
Sex		
Female	384	54.5
Race/Ethnicity		
White, non-hispanic	646	93.6
Black, non-hispanic	14	1.7
Hispanic/Latino	24	3.0
Other	12	1.8
Education		
High School or less	98	14.1
Some college or more	179	26.8
Completed college and above	352	59.1
Marital Status		
Single, never married	240	28.5
Married, living as married	393	61.3
Widowed/Divorced/ Separated	59	10.2
Household Income		
<\$20,000	91	12.0
\$20,000 - \$39,999	106	14.9
\$40,000 - \$59,999	104	15.8
\$60,000 - \$79,999	95	14.8
>=\$80,000	240	38.4
Type of Cancer		

Leukemia		35.0
Central Nervous System		14.9
Hodgkin's lymphoma		12.9
Neuroblastoma		6.1
Wilms (Kidney) Tumor		8.1
Soft tissue sarcoma		8.26
Bone		8.1
Non-Hodgkin's lymphoma		6.7
Chronic Medical Conditions		
No Chronic Conditions		
≥ 1 Condition Grades 1-2		
≥ 1 Condition Grades 1-4		
1 Condition Grades 3-4		
≥ 2 Condition Grades 3-4		

Aim 1:

Table 2. Provider Care Arrangements for Childhood Cancer Survivors, over a one-year time span.

	PCP	Specialty Care Physician	Survivorship Clinic Provider	NP/PA	Nurse	Composite Variable (TBD)
	N (%)					
All CCS (n=693)	555 (80)	352 (51)	96(14)	208 (30)	83 (12)	
Insurance Status						
Insured						
Uninsured						
If Insured, Type of Insurance						
Employer-sponsored						
Individual private						
Medicare						
Medicaid						
Military Health Care						
Don't know						
Current Age						
25-34						
35-44						
>=45						
Sex						
Female						

Comment [WL1]: For Aims 1 and 2 there should be some similar tables showing the results of the risk factor modelling you describe in the analysis sections i.e. Relative risks, 95% CI's etc.

Male						
Race/Ethnicity						
White, non-hispanic						
Black, non-hispanic						
Hispanic/Latino						
Other						
Education						
High School or less						
Some college or more						
Marital Status						
Married						
Unmarried						
Household Income						
<\$20,000						
\$20,000 - \$39,999						
\$40,000 - \$59,999						
\$60,000 - \$79,999						
>=\$80,000						
Type of Cancer						
Leukemia						
Lymphoma						
Solid tumor						
CNS tumor						
Chronic Medical Conditions						
No Chronic Conditions						
≥ 1 Condition Grades 1-2						
≥ 1 Condition Grades 1-4						
1 Condition Grades 3-4						
≥ 2 Condition Grades 3-4						

Table 3. Predictors of Childhood Cancer Patients Receiving Care by Primary Care Physician.

(Similar tables will be constructed for each Outcome for Analysis 1)

Predictor Variables	Unadjusted			Adjusted		
	RR	95% CI	p-value	RR	95% CI	p-value
Insurance Status						
Insured	1			1		
Uninsured						
If Insured, Type of Insurance						
Employer-sponsored	1			1		
Individual private						
Medicare						
Medicaid						
Military Health Care						
Don't know						
Current Age						
25-34	1			1		
35-44						
>=45						
Sex						
Female	1			1		
Male						
Race/Ethnicity						
White, non-hispanic	1			1		
Black, non-hispanic						
Hispanic/Latino						
Other						
Education						
High School or less	1			1		
Some college or more						
Marital Status						
Married	1			1		
Unmarried						
Household Income						
<\$20,000	1			1		
\$20,000 –						

\$39,999						
\$40,000 - \$59,999						
\$60,000 - \$79,999						
≥\$80,000						
Type of Cancer						
Leukemia	1			1		
Lymphoma						
Solid tumor						
CNS tumor						
Chronic Medical Conditions						
No Chronic Conditions	1			1		
≥ 1 Condition Grades 1-2						
≥ 1 Condition Grades 1-4						
1 Condition Grades 3-4						
≥ 2 Condition Grades 3-4						

Aim 2:

Table 4. Hierarchical Medical Care for Childhood Cancer Survivors, over a one-year time span.

	No Care	General Medical Care	Cancer-related Care
	N (%)		
All CCS (n=698)			
Insurance Status			
Insured			
Uninsured			
If Insured, Type of Insurance			
Employer-sponsored			
Individual private			
Medicare			
Medicaid			
Military Health Care			
Don't know			

Current Age			
25-34			
35-44			
>=45			
Sex			
Female			
Male			
Race/Ethnicity			
White, non-hispanic			
Black, non-hispanic			
Hispanic/Latino			
Other			
Education			
High School or less			
Some college or more			
Marital Status			
Married			
Unmarried			
Household Income			
<\$20,000			
\$20,000 - \$39,999			
\$40,000 - \$59,999			
\$60,000 - \$79,999			
>=\$80,000			
Type of Cancer			
Leukemia			
Lymphoma			
Solid tumor			
CNS tumor			
Chronic Medical Conditions			
No Chronic Conditions			
≥ 1 Condition Grades 1-2			

≥ 1 Condition Grades 1-4			
1 Condition Grades 3-4			
≥ 2 Condition Grades 3-4			

Table 5. Predictors of Childhood Cancer Patients Receiving Cancer-Related Care.

(Similar tables will be constructed for each Outcome for Analysis 2)

Predictor Variables	Unadjusted			Adjusted		
	RR	95% CI	p-value	RR	95% CI	p-value
Insurance Status						
Insured	1			1		
Uninsured						
If Insured, Type of Insurance						
Employer-sponsored	1			1		
Individual private						
Medicare						
Medicaid						
Military Health Care						
Don't know						
Current Age						
25-34	1			1		
35-44						
>=45						
Sex						
Female	1			1		
Male						
Race/Ethnicity						
White, non-hispanic	1			1		
Black, non-hispanic						
Hispanic/Latino						
Other						
Education						
High School or less	1			1		
Some college or more						
Marital Status						

Married	1			1		
Unmarried						
Household Income						
<\$20,000	1			1		
\$20,000 - \$39,999						
\$40,000 - \$59,999						
\$60,000 - \$79,999						
>=\$80,000						
Type of Cancer						
Leukemia	1			1		
Lymphoma						
Solid tumor						
CNS tumor						
Chronic Medical Conditions						
No Chronic Conditions	1			1		
≥ 1 Condition Grades 1-2						
≥ 1 Condition Grades 1-4						
1 Condition Grades 3-4						
≥ 2 Condition Grades 3-4						

Aim 3:

Table 6. Utilization of Outpatient Services and Hospitalizations for Childhood Cancer Survivors, over a one-year time span.

	All Reasons		Due to Previous Cancer Diagnosis	
	Outpatient	Hospitalization	Outpatient	Hospitalization
	Average Number of Visits (Range)			
All CCS				
Insurance Status				
Insured				
Uninsured				
If Insured, Type of Insurance				
Employer-				

sponsored				
Individual private				
Medicare				
Medicaid				
Military Health Care				
Don't know				
Current Age				
25-34				
35-44				
>=45				
Sex				
Female				
Male				
Race/Ethnicity				
White, non-hispanic				
Black, non-hispanic				
Hispanic/Latino				
Other				
Education				
High School or less				
Some college or more				
Marital Status				
Married				
Unmarried				
Household Income				
<\$20,000				
\$20,000 - \$39,999				
\$40,000 - \$59,999				
\$60,000 - \$79,999				
>=\$80,000				
Type of Cancer				
Leukemia				
Lymphoma				
Solid tumor				

CNS tumor				
Chronic Medical Conditions				
No Chronic Conditions				
≥ 1 Condition Grades 1-2				
≥ 1 Condition Grades 1-4				
1 Condition Grades 3-4				
≥ 2 Condition Grades 3-4				
Provider Care Arrangement (examples)				
Majority PCP				
Majority Survivorship Clinic				
Majority NP/PA				
Compositive Var -TBD				
Financial Stressors				
>10% Income Borrowed money				
Credit debt				
Financial Worries				
Unable to pay				
Unable to see providers				
Afford health insurance				

Table 7. Predictors of Childhood Cancer Patients being High Utilizers of Health Care Services

Predictor Variables	Unadjusted			Adjusted		
	RR	95% CI	p-value	RR	95% CI	p-value
Insurance Status						
Insured	1			1		
Uninsured						
Current Age						
25-34	1			1		

35-44						
>=45						
Sex						
Female	1			1		
Male						
Race/Ethnicity						
White, non-hispanic	1			1		
Black, non-hispanic						
Hispanic/Latino						
Other						
Education						
High School or less	1			1		
Some college or more						
Marital Status						
Married	1			1		
Unmarried						
Household Income						
<\$20,000	1			1		
\$20,000 - \$39,999						
\$40,000 - \$59,999						
\$60,000 - \$79,999						
>=\$80,000						
Type of Cancer						
Leukemia	1			1		
Lymphoma						
Solid tumor						
CNS tumor						
Chronic Medical Conditions						
No Chronic Conditions	1			1		
≥ 1 Condition Grades 1-2						
≥ 1 Condition Grades 1-4						
1 Condition Grades 3-4						
≥ 2 Condition						

Grades 3-4						
Provider Care Arrangement (Examples)						
Majority PCP	1			1		
Majority Survivorship Clinic						
Majority NP/PA						
Compositive Var -TBD						
Financial Stressors						
No stressors	1			1		
>10% Income						
Borrowed money						
Credit debt						
Financial Worries						
No worries	1			1		
Unable to pay						
Unable to see providers						
Afford health insurance						

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