

**CHILDHOOD CANCER SURVIVOR STUDY**  
**Analysis Concept Proposal Draft**  
**July, 2005**

1. **STUDY TITLE:** Influence of Regional Access on Follow-up Care for Adult Survivors of Pediatric Cancer

2. **WORKING GROUP AND INVESTIGATORS:** Working with the cancer control committee working group, the proposed investigators will include:

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3. **BACKGROUND AND RATIONALE:**

The lifetime risks that survivors of childhood and adolescent cancer face have been well described.<sup>1,2</sup> Depending upon therapeutic exposure used in curing the cancer, survivors are at risk for late mortality from second cancers, cardiovascular disease, and pulmonary disease.<sup>3</sup> Nearly one out of every two adult survivors of childhood cancer has significantly diminished health status.<sup>4</sup> By thirty years following cancer diagnosis, two-thirds are likely to have a chronic health condition, a third likely to have a serious health problem, and a third have multiple conditions.<sup>5</sup> The incidence increases with time and does not appear to plateau. These risks are further exaggerated by unhealthy lifestyles, such as tobacco use and physical inactivity.

Thus, when examining the considerable and growing evidence of these risks, the Institute of Medicine report, *Childhood Cancer Survivorship: Improving Care and Quality of Life*, called for lifetime health care of childhood cancer survivors. Optimum survivor health care includes periodic evaluations to screen for late effects that are amenable to early intervention.<sup>6</sup> Ideally, this monitoring is combined with education targeted at reducing or preventing unhealthy lifestyles that may contribute to risk.

However, most survivors do not receive risk-based health care. In fact, risk-based care with a clinician familiar with the population may not be available for many survivors. Among 9,535 young adult survivors, eighteen years of age or older, enrolled in the Childhood Cancer Survivor Study (CCSS), we reported that while 87% reported some general medical contact, only 42% and 19%, respectively, reported a cancer-related medical visit or a cancer center visit in the previous two years.<sup>7</sup> Cancer screening was well below recommended levels, particularly in those who lacked health insurance, were not concerned about their future health, were younger, and had lower educational attainment.<sup>8</sup> Published studies provide a crude assessment of factors associated with the type of care, or lack thereof. More detailed evaluation is necessary to determine the barriers and facilitators of survivor health care, particularly for those who were treated with therapies known to be associated with developing significant sequelae.

Children with non-cancer related chronic disease (e.g. cystic fibrosis, cerebral palsy, congenital heart disease) are also at increased risk for future health problems and have longitudinal health care needs that are different than the general population. As this population transitions to adulthood, issues of health care needs and access to quality health care are similar to those of pediatric cancer survivors.<sup>1</sup> Primary care physicians play an important role in the longitudinal care of these adults with pediatric-originating problems.<sup>9</sup> In these populations, health care utilization patterns and patient satisfaction appears to be associated with the geographic distance from a tertiary medical center and the area health care characteristics (e.g. numbers of physicians and hospital beds per unit population, socio-economic strata of the area).<sup>10,11</sup> The influence of these two factors on health care utilization patterns are further modified by the complexity of the chronic health condition and the socio-economic status of the patient/family. It is likely that these factors are also important in predicting the likelihood of survivor-related health care.

We have the unique opportunity to assess the relationship of the above factors with different types of survivor health care. The Health Care Needs Survey and the CCSS Follow-Up 2 Questionnaire were conducted in overlapping time periods, with a total of 978 respondents to both questionnaires. From these two sources of data, we have detailed information available to assess survivor health care patterns and patient satisfaction with care. Further, we have data to determine the geographic distance of the survivor to their treating institution and the clinical complexity and the socio-economic risk of the survivor.

By linking this data with the Area Resource File (ARF), we can further assess the modifying influence of the health care characteristics for the area where the survivor lives. The ARF is a county-specific health resources information system for professionals interested in the nation's health care delivery system and factors that may impact health status and health care in the U.S.<sup>12</sup> It is maintained by the Health Resources and Services Administration, Department of Health and Human Services, and the Bureau of Census. ARF comprises data collected from more than 50 sources and is the result of processing millions of micro data records and physician specialty data from the American Medical Association and facilities data from the American Hospital Association. Additional data is regularly incorporated into the ARF database, which is updated and issued annually. The database contains more than 6,000 variables for each of the nation's counties. ARF contains information on health facilities, health professions, measures of resource scarcity, health status, economic activity, health training programs, and socioeconomic and environmental characteristics. In addition, the basic file contains geographic codes and descriptors enabling it to be linked to many other files and to aggregate counties into various geographic groupings.

The purpose of the proposed study is to determine the types of survivor care and the satisfaction with care in 978 CCSS participants who responded to the Health Care Needs Survey and the CCSS Follow-Up 2 Questionnaire and to assess the relationship of these two types of outcomes with physician source of care. The modifying influence of the geographic distance, area health care characteristics, clinical complexity of the survivor, and the socio-economic risk of the survivor will be assessed. Because the complex relationships between these factors may not be readily understood through standard multivariate logistic or linear regression models, a hierarchical analysis will also be performed.

#### **4. SPECIFIC AIMS/ OBJECTIVES/ RESEARCH HYPOTHESES**

**Aim 1. Determine if physician source of care (oncologist, primary care physician, shared, neither) is associated with three types of survivor health care: (1) cancer-related visit in the previous two years; (2) basic risk-based care in the previous two years; and (3) planned visit in the next two years to check for health problems related to the previous cancer therapy.**

Hypotheses: Physician source of care is not associated with the likelihood of reporting a cancer-related visit.

Survivors who are seen by an oncologist (oncologist only, shared care) are more likely to report basic risk-based care and plan to have a visit in the next two years to check for health problems related to the previous cancer therapy than survivors followed by primary care physicians only or neither.

**Aim 2. Determine if physician source of care is associated with the survivor's (1) satisfaction with care received at the cancer-related visit and (2) general rating of all health care in the previous two years.**

Hypothesis: The satisfaction with the individual cancer-related visit will be significantly higher in survivors who were seen by an oncologist (oncologist only, shared care) than in those seen by a primary care physician only which will be significantly higher than those seen by neither.

**Aim 3. Determine if geographic distance, area health care characteristics, clinical complexity, and socio-demographic risk modify the relationships of physician source of care with survivor health care (Aim 1) or with patient satisfaction (Aim 2).**

Hypothesis: The combination of greater geographic distance, adverse area health care characteristics, lower clinical complexity, and socio-demographic risk will increase the likelihood of primary care only source of care.

#### **5. ANALYSIS FRAMEWORK**

##### **5a. Sources of data**

*Data from the following CCSS Questionnaires will be used in the analysis:*

- a. CCSS Treatment Abstraction
- b. Health Care Needs Survey ("Barriers Study")
- c. CCSS Follow-Up 2 Questionnaire

*Area Resource File (ARF), February 2003*

## 5b. Outcome variables

Two groups of outcome variables will be used in this analysis: survivor health care and patient satisfaction.

### *Survivor health care:*

#### 1. Cancer-related visit in the previous two years

From the **Health Care Needs Survey**, the categorical variable “CRV2YR” is based on responses to Questions A7 and A8

A7. During this two year period, did you have a health problem that you thought might be related to your cancer?

A8. If yes, did you see a doctor?

#### 2. Basic risk-based care in the previous two years

From the **Follow-Up 2 Questionnaire**, a new dichotomous yes/no variable, “BASIC\_RBCARE” will be created, based on responses to Questions A1, A5, A7, A8a and A8b.

Basic risk-based care = YES is defined as a ‘yes’ response to each of the following questions:

A1. Visit in previous two years

A5. Related to previous cancer

A7. “Your doctor was familiar with health problems that develop after childhood cancer”

A8a. “Your doctor gave you advice about what to do to reduce risks”

A8b. “Your doctor discussed or ordered medical screening tests”

#### 3. Planned visit in the next two years to check for health problems related to the previous cancer therapy

PLAN\_CHKUP is a recoded dichotomous yes/no variable based on responses from Question A15 in the **Health Care Needs Survey**:

A15. “In the next two years, what are the chances that you will go to a doctor to check and see if you have any health problems caused by your previous cancer treatment”

Yes = likely, very likely

No = possibly, unlikely, very unlikely

***Patient satisfaction:***

1. Satisfaction with care received at cancer-related visit

From the **Health Care Needs Survey**, a recoded dichotomous yes/no variable “SATISF\_CRV”, based on responses to Question A10.

- A10. “How satisfied were you with the care that you received at this visit?”  
Yes (satisfied) = somewhat satisfied, very satisfied  
No (unsatisfied) = neutral, somewhat unsatisfied, very unsatisfied

2. General rating of health care in past two years

From the **Health Care Needs Survey**, a continuous variable, SATISF\_GEN, will be obtained from the 10-point scale response to Question D7.

- D7. “We want to know your rating of all of your health care in the past two years from all doctors and other health care professionals.”

5c. **Primary independent variable: Physician source of care**

From the **Health Care Needs Survey**, a four category variable, PHYS\_SOURCE, will be created based on the responses to Questions A9, A11, and A12.

- A9. “What type of doctor did you see first?” (Refers to Question A8). Responses: primary care physician, obstetrician/gynecologist, pediatric oncologist, adult oncologist, emergency room or urgent care physician, or other (specify).  
A11. “Did the doctor refer you to another doctor?” Yes/No  
A12. “If yes, what type of doctor(s) were you referred to?” Responses: obstetrician/gynecologist, pediatric oncologist, adult oncologist, specialist in adult health problems (e.g. cardiologist, gastroenterologist, urologist), psychologist or counselor, other (specify).

From these responses, PHYS\_SOURCE will be a four category variable:

- a. Oncology only (including pediatric or adult oncology)
- b. Primary care only
- c. Shared care: oncology and primary care included in visit(s)
- d. Neither: no care or care by a provider other than an oncologist or a primary care physician

## 5d. Modifier variables

Four groups of modifier variables will be assessed:

### 1. Geographic distance

From the **Health Care Needs Survey**, a recoded dichotomous yes/no variable, GEODIS, is based on responses to Question D5.

D5. "How far do you currently live from the hospital where you received most of your cancer treatment?" 0-50 miles; 51-100 miles, 101-200 miles; more than 200 miles.

GEODIS = YES if D5 = more than 200 miles or more

### 2. Area Health Care Characteristics

From the Area Resource File, February 2003, two dichotomous yes/no variables, AREA\_HEALTH\_ZIP and AREA\_HEALTH\_COUNTY, will be created. Yes = overall area health system characteristics at or above median; No = overall area health system characteristics below the median. The two variables will be based on the zip code or county the survivor lives in at the time of responding to the Health Care Needs Survey.

By dichotomizing the Area Resource File into two summative variables, much of the richness and depth of the dataset may be lost. For this reason, other components of the dataset, such as density of physicians in area, will be explored in the analysis.

### 3. Clinical complexity

Some survivors have more complex follow-up care needs than others. This complexity is based upon future risk for health problems secondary to the cancer therapy and current late effects. A new variable, CLIN\_COMPLEX, will be created from data from the **CCSS Treatment Abstraction** and the **Health Care Needs Survey**.

From the CCSS Treatment Abstraction data, the dichotomous yes/no variable, HIGH\_RISK, will be created for survivors at higher risk for severe to life-threatening health conditions. This variable is based on the Chronic Health Condition analysis, and includes survivors who were exposed to any of the following combinations of cancer therapy:

- a. Chest radiation and pelvic or abdominal radiation
- b. Chest radiation and anthracycline or Bleomycin
- c. Abdominal or pelvic radiation and alkylating agent

From the Health Care Needs Survey, the dichotomous yes/no variable, CHRONIC\_COND, will be created from responses to Questions A17 and A18.

A17. "Do you have any chronic health problems (that have lasted longer than six months) related to your cancer or cancer treatment?"

A18. "If yes, how would you rate your main chronic health condition?" Mild, moderate, severe, life-threatening. Anchors describing each of these was included.

CHRONIC\_COND = Yes if A17 = Yes and A18 = severe or life-threatening

CLIN\_COMPLEX = Yes if HIGH\_RISK = Yes or CHRONIC\_COND = Yes

#### 4. Socio-Demographic Risk

Based on responses to the CCSS Follow-Up 2 Questionnaire and the Health Care Needs Survey, a new variable, SOCIO\_RISK will be created.

Health insurance status (HINSUR) - CCSS Follow-Up 2 Questionnaire, Question M1. HINSUR = yes/Canadian versus no

Highest level of educational attainment (EDUC\_2) - Data from the CCSS Baseline Questionnaire, and the CCSS Follow-Up 2 Questionnaire will be used to create this variable. EDUC\_2 = Did not graduate from high school, versus high school graduate

Household income (HINCOME) - from the CCSS Follow-Up 2 Questionnaire. Dichotomous: < \$20,000 versus  $\geq$  \$20,000

Race/ethnicity (RACE) - Race and ethnic background, when adjusted for household income and educational attainment, was not significantly associated with health care utilization patterns. A dichotomous (white, non-Hispanic versus minority) will be assessed in the models and included in the models only if it remains significant after adjusting for other SES factors.

SOCIO\_RISK = Yes if no health insurance, did not graduate from high school, or household income < \$20,000.

#### 5e. **Other independent variables**

The following additional variables will be evaluated in the bivariate and multivariate models:

- a. Gender
- b. Age at cancer diagnosis (0-4, 5-9, 10-14, 15-20)
- c. Age at response to Health Care Needs Survey (18-24, 25-29, 30-34, 35-39,  $\geq$  40)
- d. Cancer diagnosis - this variable is strongly correlated with HIGH\_RISK.

## **5f. Analytic approach**

After merging and linking the databases and creating the above new variables, frequencies, percents, and distributions for the outcome, primary independent, modifying, and other independent variables will be calculated. The bivariate relationships between the outcome variables and the primary independent, modifying, or other independent variables will be determined. Collinearity of variables will be assessed.

Multivariate logistic regression models will be developed for both groups of the outcome variables and primary independent, modifying, or other independent variables determined to be significant ( $p < 0.1$ ) in the bivariate analysis. Multivariate linear regression will be used when the outcome is the continuous variable for general satisfaction with care.

It is hypothesized that the source of care is associated with the type of care and/or patient satisfaction and that the modifying variables (geographic distance, area health care systems, clinical complexity, socio-demographic risk) predict the source of care. Analysis with multivariate logistic or linear regression may not be adequate to understand these complex relationships. A hierarchical analysis will be performed to assess the relationship of the four modifying variables, the source of care, and the two groups of outcome variables. Estimation of all models will incorporate features of the study design related to the cluster and multistage stratification of sample.

## **6. REFERENCES**



## 7. TABLES

**Table 1. Demographics of 978 adult survivors of pediatric cancer**

<b>Category</b>	<b>N</b>	<b>Percent</b>
<b>Sex</b>		
Female		
Male		
<b>Race/ethnicity</b>		
Non-Hispanic white		
Minorities		
<b>Education</b>		
Did not complete high school		
HS grad, no further education		
HS grad + some college/training		
<b>Income, household</b>		
< \$20,000		
≥ \$20,000		
<b>Health insurance</b>		
No		
Yes or Canadian		
<b>Cancer diagnosis</b>		
Leukemia		
Central nervous system tumor		
Hodgkin disease		
Non-Hodgkin lymphoma		
Wilms' tumor		
Neuroblastoma		
Sarcoma		
Bone		
<b>Cancer Treatment</b>		
<i>Chemotherapy</i>		
No chemotherapy		
Alkylating agent		
Anthracycline		
Other chemotherapy		
No chemotherapy records		
<i>Radiation therapy</i>		
No radiation therapy		
Brain radiation		
Chest radiation		
Abdominal or pelvic radiation		
No radiation records		
<b>Age at interview, y</b>		
Mean (SD)		
Range		
<b>Interval from cancer diagnosis, y</b>		
Mean (SD)		
Range		

**Table 2. Frequencies and percent of adult survivors with three types of health care, by category**

<b>Category</b>	<b>Cancer-Related Visit in Past 2 YRS</b>	<b>Risk-Based Care in Past 2 YRS</b>	<b>Plan for Check-Up in Next 2 YRS</b>
<b>Sex</b>			
Female			
Male			
<b>Race/ethnicity</b>			
Non-Hispanic white			
Minorities			
<b>Education</b>			
Did not complete high school			
HS grad			
<b>Income, household</b>			
< \$20,000			
≥ \$20,000			
<b>Health insurance</b>			
No			
Yes or Canadian			
<b>Geographic setting</b>			
> 200 miles from treating institution			
Rural setting			
Either			
<b>Clinical complexity</b>			
High risk therapy*			
Severe or life-threatening condition			
Either			
<b>Area health care resources</b>			
Above median			
At or below median			

**Table 3. Patient satisfaction in adult survivors of pediatric cancer; by category**

	<b>Satisfaction with Clinical Visit</b>	<b>Satisfaction with General Care</b>
<b>Sex</b>		
Female		
Male		
<b>Race/ethnicity</b>		
Non-Hispanic white		
Minorities		
<b>Education</b>		
Did not complete high school		
HS grad		
<b>Income, household</b>		
< \$20,000		
≥ \$20,000		
<b>Health insurance</b>		
No		
Yes or Canadian		
<b>Geographic setting</b>		
> 200 miles from treating institution		
Rural setting		
Either		
<b>Clinical complexity</b>		
High risk therapy*		
Severe or life-threatening condition		
Either		
<b>Area health care resources</b>		
Above median		
At or below median		

**Table 4. Multivariate odds ratios (OR) and 95% confidence intervals (95% CI) in three types of health care by category, adjusted for age at study.**

<b>Category</b>	<b>Cancer-Related Visit in Past 2 YRS</b>	<b>Risk-Based Care in Past 2 YRS</b>	<b>Plan for Check-Up in Next 2 YRS</b>
<b>Sex</b>			
Female			
Male			
<b>Race/ethnicity</b>			
Non-Hispanic white			
Minorities			
<b>Education</b>			
Did not complete high school			
HS grad			
<b>Income, household</b>			
< \$20,000			
≥ \$20,000			
<b>Health insurance</b>			
No			
Yes or Canadian			
<b>Geographic setting</b>			
Within 200 miles of treating institution			
Over 200 miles			
<b>Clinical complexity</b>			
Increased clinical complexity			
Standard or low clinical complexity			
<b>Area health care resources</b>			
Above median			
At or below median			

**Table 5. Multivariate odds ratios (OR) and 95% confidence intervals (95% CI) predicting patient satisfaction, adjusted for age at study.**

Same variables as in Table 4.

**Figure 1. Hierarchical analysis of factors associated with types of health care and patient satisfaction.**