## CHILDHOOD CANCER SURVIVOR STUDY Analysis Concept Proposal

**1. TITLE:** Cancer Screening and Prevention Practices of Siblings of Survivors of Childhood Cancer

**2. WORKING GROUP INVESTIGATORS:** This proposed study will be within the Psychosocial Working Group and Cancer Control Working Group.

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## **3. SPECIFIC AIMS:**

There is a rapidly growing population of pediatric cancer survivors because of improved multi-modal treatment regimens. There are now approximately 270,000 survivors of childhood cancer in the United States (US).<sup>1</sup> Five year survival rates of greater than 75 % have led to a rapidly growing population of childhood cancer survivors.<sup>1</sup> The consequences of cure; however, are not without a cost. One such cost is the impact of childhood cancer on siblings. Data from the US census bureau documents that average families have two children.<sup>2</sup> This suggests that there is a rapidly growing population of siblings that are impacted by childhood cancer.

Siblings experience losses with respect to physical and emotional availability of parents, unmet needs with respect to familial communication, involvement in the care of the patient, and support to continue their interests and activities.<sup>3-5</sup> Associated with these losses and unmet needs, previous reports have noted that the health care needs of siblings are often minimized and underreported following the diagnosis of childhood cancer.<sup>6</sup> The long-term impact of this minimization and under-reporting within the context of other cancer-related stressors and familyrelated factors on the cancer screening and prevention practices of siblings has not been studied. Well accepted models that predict future health behaviors such as cancer screening and prevention practices include factors that may be altered by minimization and under-reporting of health care needs as a child.<sup>7-8</sup> As an example, recent reports suggest that siblings endorse the practice of other health risk behaviors (e.g. alcohol and tobacco use) to a greater extent than survivors.<sup>9-11</sup> This is especially concerning based on recent evidence which suggests that members of this rapidly growing population of siblings are at an increased risk of developing cancer.<sup>12-13</sup> Based upon the gap in the medical literature with respect to the impact of cancer upon family members, the National Cancer Institute (NCI), Office of Cancer Survivorship recognizes that it is critical to expand our assessment of the quality of life and care of the family members of cancer survivors.<sup>14</sup> Therefore, as the population of siblings of pediatric cancer survivors grows, the investigation of the long-term impact of childhood cancer on the cancer screening and prevention practices of siblings is an important endeavor.

Progress has been made in the characterization of the cancer screening practices of adult survivors of childhood cancer through the efforts of the Childhood Cancer Survivor Study (CCSS).<sup>15</sup> In fact, an expanded analysis of cancer screening practices is currently underway. This expanded set of analyses focusing on breast, cervical, skin, and colon cancer screening practices uses recent data in order to reflect current guideline, recommendations, and practices. Additionally, comparison will be made between survivors, siblings, and a national sample of peers.

The CCSS has the potential to be a vital resource in understanding the impact of childhood cancer upon siblings. The proposed set of analyses builds upon the analyses which are underway. Our primary aim will be to characterize the impact of childhood cancer upon the cancer screening and prevention practices of siblings and compare them to a national sample. This characterization expands the focus from cancer screening to screening and prevention practices amongst the largest sample of siblings of childhood cancer survivors. Further validation of the analyses which are underway is also provided through the use of a different national sample. Our secondary aim will be to determine those sibling and survivor disease, treatment, and health-related factors that are associated with decreased screening and prevention practices in siblings of childhood cancer survivors. This characterization builds upon the unique strength of the CCSS dataset. Analyzing matched pairs of siblings and survivors will allow us to determine those survivor and sibling factors that are associated with decreased sibling cancer screening and prevention practices.

The proposed study will utilize data from two sources: the CCSS second follow-up questionnaire administered between 2002 and 2004 and the Brief Risk Factor Surveillance System (BRFSS) telephone survey administered in 2000.<sup>16-17</sup> The CCSS data used in this analysis are from a 24-page second follow-up questionnaire completed by self-report or telephone utilizing a trained interviewer. The BRFSS is an annual, standardized, state-based, random-digit-dial telephone survey of the non-institutionalized U.S. population completed with assistance from the Centers for Disease Control and Prevention. Cancer screening and prevention practice variables between the CCSS second follow-up questionnaire and the BRFSS 2000 are closely comparable and allow for assessment of cancer screening specifics across both populations at time points that will ensure the stability of cancer screening and prevention practices (see **Appendix A**). Additionally, these analyses focus upon a contemporary time period which will reflect current guidelines, recommendations, and practices.

*Aim 1:* To describe the cancer screening and prevention practices (skin cancer prevention, breast / cervical cancer screening practices) of siblings of survivors and compare them to national norms by age, gender (omitted for breast / cervical cancer screening), and race/ethnicity.

# We hypothesize that the cancer screening and prevention practices of siblings of childhood cancer survivors will be decreased when compared with national norms by age, gender, and race/ethnicity.

*Aim 2:* To identify sibling's cancer and health-related factors (bereavement status, poor health status, presence of chronic health conditions, and psychological distress) associated with decreased cancer screening and prevention practices amongst siblings of survivors controlling for sociodemographic factors including sibling age, gender (omitted for breast / cervical cancer screening), race/ethnicity, insurance status, income, education, employment status, and marital status.

We hypothesize that sibling cancer and health-related factors (bereaved status, adverse health status, presence of chronic health conditions, and the presence of psychological distress) will be associated with decreased cancer screening and prevention practices amongst siblings of survivors.

*Aim 3:* To identify survivor disease / treatment (diagnosis, treatment intensity) and health-related factors (presence of a second cancer, poor health status, presence of chronic health conditions, and psychological distress) associated with decreased cancer screening and prevention practices amongst siblings of survivors controlling for sociodemographic factors including sibling age, gender (omitted for breast / cervical cancer screening), race/ethnicity, insurance status, income, education, employment status, and marital status.

We hypothesize that survivor disease / treatment-related factors (specific diagnoses and therapy of greater intensity) and health-related factors (presence of a second cancer, adverse health status, presence of a chronic health conditions, and the presence of psychological distress) will be associated with decreased cancer screening and prevention practices amongst siblings of survivors.

#### 4. BACKGROUND AND RATIONALE:

#### 4.1 Cancer Screening and Prevention Practices of Sibling and Health Behaviors:

Health behavior is defined as any activity undertaken by an individual who believes himself to be healthy for the purpose of preventing or detecting illness in a asymptomatic state.<sup>18</sup> Many well accepted models are used to predict these health behaviors. One such model is the health belief model which describes six domains (general health motivation, perceived vulnerability, perceived severity, perceived benefits of prevention, perceived barriers to actions, and cues to action) predictive of health behaviors.<sup>7-8</sup>

During the acute period of diagnosis and treatment siblings experience a number of losses with respect to parental availability on a physical and emotional level, an array of emotions (e.g. sadness, loneliness, rejection, anxiety, anger, and jealousy), and a host of unmet communication and support needs.<sup>3-5</sup> Associated with these changes, the health care utilization patterns of siblings are altered during the acute period of diagnosis and treatment as demonstrated by parental under-reporting with respect to sibling health and reduced health care utilization amongst siblings.<sup>6</sup>

Long-term morbidity and mortality, so-called "late effects" have been documented in survivors.<sup>19-20</sup> Due to these late effects, losses, emotional distress, and unmet needs continues to impact families long-term.<sup>21</sup> It is likely that health care utilization patterns of siblings remain altered. Additionally, the domains (e.g. general health motivation) that impact future health behaviors of siblings may be altered. In fact, recent reports suggest that siblings demonstrate increased health risk behaviors including the practice of risky alcohol practices and greater tobacco usage when compared with survivors.<sup>9-11</sup> The impact of the childhood cancer experience on other health behaviors such as cancer screening and prevention practices of siblings of childhood cancer survivors have not been studied.

## 4.2 Cancer Screening and Prevention Practices and the General Population:

#### Skin Cancer Prevention Practices

Skin cancer is the most common cancer diagnosed in the US.<sup>22-23</sup> Melanoma, the most serious of skin cancer subtypes, is estimated to impact nearly 60,000 individuals in the US annually, a number which continues to rise.<sup>22-23</sup> Melanoma also accounts for approximately 80% of skin cancer related deaths in the US.<sup>22-23</sup> Important risk factors for the development of skin cancer have been identified. One modifiable risk factor includes unprotected exposure to ultraviolet (UV) radiation.<sup>24-25</sup> This risk factor is especially important when considering UV radiation exposure at younger ages.<sup>26</sup> Despite the threat of skin cancer and the presence of modifiable risk factors, prevention behaviors are the exception rather than the rule.<sup>27-28</sup> In order to address these issues, nation-wide health initiatives such as Healthy People 2010 have focused on increasing skin protection practices and decreasing mortality rates associated with skin cancer.<sup>29</sup> Recommendations have been provided by various groups including the US Preventative Services Task Force and the International Agency for Research on Cancer.<sup>30-31</sup> These recommendations include the use of protective clothing and hats to avoid skin exposure to UV radiation, the application of sunscreen that meets a threshold sun protection factor, and the avoidance of midday sun exposure. Using these recommendations approaches aimed at realizing the goals set forth in nation-wide health initiatives have been implemented with some success.<sup>32-33</sup> Various risk factors have also been associated with suboptimal rates of skin cancer prevention behaviors. Demographic factors associated with decreased skin cancer prevention behaviors include younger age, male gender, lower socioeconomic status, and minority status.<sup>27-28</sup>

#### **Breast and Cervical Cancer Screening**

For women, breast cancer and cervical cancer are significant contributors to morbidity and mortality.<sup>22-23</sup> Breast cancer is the most common cancer which impacts women in the US excluding skin cancer. Nearly 180,000 women are diagnosed annually in the US and nearly 40,000 die each year from this cancer falling just behind lung cancer. Cervical cancer impacts roughly 10,000 women in the US annually. It accounts for approximately 4,000 cancer-related deaths annually in the US. Preventative screening efforts have played a role in the mortality reduction associated with breast and cervical cancer as increasing numbers of women are receiving appropriate cancer screening (e.g. mammograms and Pap tests).<sup>34</sup> Current recommendations regarding cancer screening practices focus on: 1) yearly mammography starting at the age of 40 years 2) cervical cancer screening starting 3 years after beginning sexual intercourse and no later than 21 years of age. Cervical cancer screening may be completed yearly with traditional Pap Testing and every two years with liquid Pap Testing. For those women with three consecutive normal exams the testing may be completed every 2 -3 years.<sup>35</sup> Various risk factors have been associated with decreased rates of cancer screening including lower socioeconomic status, less access to care (e.g. uninsured), and minority status.<sup>36-40</sup>

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

## 5.1 Sample:

The CCSS identified 20,602 eligible five year survivors. Of those contacted, 14,054 participated by completing a baseline questionnaire. A random sample of survivors was asked to identify their nearest age living sibling. The analyses of skin cancer prevention practices will utilize siblings who are  $\geq$ 18 years of age at the time of completing the second follow-up

questionnaire (n=2980). The analyses of breast and cervical cancer screening practices will utilize female siblings who are  $\geq$ 18 years of age at the time of completing the second follow-up questionnaire (n=1601) and their matched survivors. The BRFSS 2000 will utilize data from participants in the 7 states which included the Women's Health and Skin Cancer Modules including Colorado, Maryland, South Dakota, Utah, Virginia, and Washington. Participants matching the age range of the CCSS Siblings, age  $\geq$  18 years will be used. Weights which reflect the distribution of the sample of siblings by age, race/ethnicity, and gender (where appropriate) will be applied.

#### 5.2 Outcomes of Interest and Predictor Variables:

## Aim 1: Outcomes of interest

- A. Skin Cancer Prevention
  - a. Sunscreen Use
  - b. Protective Clothing Use
  - c. Wearing a Hat
  - d. Staying in Shade
- B. Breast and Cervical Cancer Screening
  - a. Mammogram
  - b. Pap Test

#### **Predictor Variable:**

Not applicable (descriptive data)

#### Aim 2 and 3: Outcomes of interest

- A. Skin Cancer Prevention
  - a. Sunscreen Use
  - b. Protective Clothing Use
  - c. Wearing a Hat
  - d. Staying in Shade
- B. Breast and Cervical Cancer Screening
  - a. Mammogram
  - b. Pap Test

## **Predictor Variable**

- A. Sibling Factors
  - a. Bereavement
  - b. Health Status
  - c. Chronic Health Conditions
  - d. Psychological Distress
- B. Survivor Factors
  - a. Diagnosis
  - b. Treatment Intensity
  - c. Second Malignant Neoplasm
  - d. Health Status
  - e. Chronic Health Conditions
  - f. Psychological Distress

E. Controlling for the effects of previously identified risk factors including age, gender (omitted for breast / cervical cancer screening), race/ethnicity, insurance status, income, education, employment status, and marital status.

#### 5.3 Statistical analysis plan:

Descriptive statistics will include sibling and national sample demographic characteristics, such as, age of the sample, gender, race/ethnicity, insurance status, income, education, employment status, and marital status.

The primary outcomes of interest including skin cancer prevention practices (sunscreen, protective clothing, hat, and shade use) will be recoded for siblings and their peers. A dichotomous recoding scheme will be used in which the responses of always, often / near always will be recoded as demonstrating the prevention practice. The responses of sometimes, rarely / seldom, and never will be recoded as not demonstrating the prevention practice.

The primary of outcome of interest of breast and cervical cancer screening will be demonstrated by the presence or absence of mammography or Pap Testing, respectively. A dichotomous recoding scheme will be used in which responses will be recoded for siblings and their peers. The responses of less than 1 year age / within past year; 1-2 years ago / within the past 2 years; more than 2 years ago, but less than 5 years ago / within the past 3 years / within the past 5 years will be recoded as demonstrating the screening practice. The responses of 5 or more years ago, don't know, never, and refused will be recoded as not demonstrating the screening practice.

Sibling disease and treatment-related risk factors will include the presence or absence of bereavement. Survivor disease and treatment-related risk factors will include diagnosis and treatment. Cancer diagnosis will be recoded to include CCSS eligible diagnoses including leukemia, CNS tumor, Hodgkin disease, Non-Hodgkin lymphoma, neuroblastoma, kidney tumor, sarcoma, and bone tumor. Treatment will be operationalized as treatment intensity and will be recoded as very intense (combined surgery, radiation, chemotherapy), moderately intense (combination of two modalities of therapy), and not intense (one modality of therapy).

Sibling health-related risk factors will include self-reported health status, the presence or absence of chronic health conditions as defined in previous CCSS publications using the NCI CTCAE.<sup>20</sup> Psychological distress will be measured by the Brief Symptom Inventory-18 (BSI-18).<sup>41</sup> The BSI-18 is an 18 item instrument which includes a summary measure or so-called "global severity index" (GSI). There are three symptom specific subscales including a depression, somatization, and anxiety subscale. This is a standardized, self-report inventory using five-point Likert scale items exploring the degree to which particular problems had distressed the respondent during the last 7 days (0 "not at all" to 4 "extremely"). Responses to items will be summed to provide the GSI (range 0-72) and subscales (range 0-24). They will then be transformed to T-scores using gender specific community norms. In order to facilitate comparisons, norms have a mean of 50 and a standard deviation of 10. A T-score of > 63represents the upper 10<sup>th</sup> percentile of scores reported in the normative sample and is considered significantly elevated. With respect to sibling health status and psychological distress it is important to note that only a subset of siblings completed these measures at the second follow-up questionnaire which may limit the inclusion of these variables in selected analyses. Survivor health-related risk factors are identical aside from the inclusion of the presence or absence of a second malignant neoplasm.

Sibling sociodemographic control variables will include current age, gender, race / ethnicity, insurance status, household income, educational status, employment status, and marital status. Age will recoded into 10 year increments (e.g. <20 years, 20-30 years, 30-40 years, 40-50

years, 50+ years). Gender will not be recoded. Race / ethnicity will be recoded as a dichotomous variable (e.g. White / non-Hispanic and other). Insurance status will not be recoded. Household income will be recoded as a dichotomous variable (e.g. <\$20,000, >\$20,000). Educational status will be recoded and re-categorized (e.g. less than high school education, high school graduate, greater than high school education). Employment status will be recoded as a dichotomous variable (e.g. employed, unemployed). Employment will consist of those respondents that are working full-time, working part-time, employed for wages, or self-employed. All other categories will make up the categorization of unemployment. Marital status will be recoded as a dichotomous variable (e.g. married, unmarried). Married will consist of those respondents that are married or living as married. All other categories will make up the categorized will make up the categorized will make up the categorized of unmarried.

*Specific Aim 1*: Data will be analyzed for the CCSS sibling sample and the BRFSS sample. The sample description, the prevalence of cancer screening and prevention practices will be examined for the siblings and the national sample. Adjusted odds ratios and 95% confidence intervals will be calculated controlling for the potential contribution of demographic variables. Since the outcome variables are dichotomous logistic regression models will be estimated.

*Specific Aim 2 and 3*: Analyses will also be performed using only the sibling and matched survivor data in order to examine sibling and survivor disease, treatment, and health-related factors that are associated with the absence of cancer screening and prevention practices amongst siblings. Adjusted odds ratios and 95% confidence intervals will be calculated controlling for the potential contribution of demographic variables. Since the outcome variables are dichotomous logistic regression models will be estimated.

Analysis will be completed using the STATA PC software package version 10 (College Station, TX).

# APPENDIX A

Equivalency of Cancer Screening and Prevention Practice Questions between the Childhood Cancer Survivor Study and the Behavioral Risk Factor Surveillance System Survey

Skin Cancer Prevention Practices

Childhood Cancer Survivor Study Follow-	Behavioral Risk Factor Surveillance System
Up 2 Questionnaire	2000
C.11 When you were outside last summer for	Module 17, Question 1 When you go outside
more than 15 minutes how often did you	on a sunny summer day for more than one
protect yourself from the sun by applying	hour, how often do you use
sunscreen with a SPF of 15 or more on all sun	sunscreen or sunblock?
exposed skin areas?	
Never	Always
Rarely	Near always
Sometimes	Sometimes
Often	Seldom
Always	Never
C.11 When you were outside last summer for	Module 17, Question 5 When you go outside
more than 15 minutes how often did you	on a sunny summer day for more than an hour,
protect yourself from the sun by wearing	how often do you wear long-sleeved shirts?
protective clothing such as long-sleeved shirts	
and long pants?	Always
	Near always
Never	Sometimes
Rarely	Seldom
Sometimes	Never
Often	
Always	
C.11 When you were outside last summer for	Module 17, Question 4 When you go outside
more than 15 minutes how often did you	on a sunny summer day for more than an hour,
protect yourself from the sun by wearing a hat?	how often do you wear a
	wide-brimmed hat or any other hat that shades
	your face, ears, and neck from the sun?
	Always
	Near always
Never	Sometimes
Rarely	Seldom
Sometimes	Never
Often	
Always	

C.11 When you were outside last summer for	Module 17, Question 3 When you go outside
more than 15 minutes how often did you	on a sunny summer day for more than an hour,
protect yourself from the sun by staying in the	how often do you stay in the
shade?	shade?
Never	Always
Rarely	Near always
Sometimes	Sometimes
Often	Seldom
Always	Never

Breast / Cervical Cancer Screening

Childhood Cancer Survivor Study Follow-	Behavioral Risk Factor Surveillance System
Up 2 Questionnaire	2000
B.4 When was the last time you had a	Core Section 11, Question 2 How long has it
mammogram?	been since your last mammogram?
Less than 1 year ago	Within the past year (1 to 12 months ago)
1-2 years ago	Within the past 2 years (1 to 2 years ago)
More than 2 years ago, but less than 5 years	Within the past 3 years (2 to 3 years ago)
ago	Within the past 5 years (3 to 5 years ago)
5 or more years ago	5 or more years ago
Don't know	Don't know/Not sure
Never	Refused
B.5 When was the last time you had a Pap	Core Section 11, Question 8 How long has it
smear (test for cancer of the cervix)?	been since you had your last pap smear?
Less than 1 year ago	Within the past year (1 to 12 months ago)
1-2 years ago	Within the past 2 years (1 to 2 years ago)
More than 2 years ago, but less than 5 years	Within the past 3 years (2 to 3 years ago)
ago	Within the past 5 years (3 to 5 years ago)
5 or more years ago	5 or more years ago
Never	Don't know/Not sure
	Refused

## Predictor Variables

Domain	Item #	Item Wording
Sibling Disease / Treatment, Health-Related Factors		
Bereavement	Second Follow-Up	
Health Status	E.1	In general, would you say your health is excellent, very good, good, fair, poor?
Chronic Health Conditions	Baseline	Chronic Health Severity Index using NCI CTCAE <sup>19</sup>
Psychological Distress	G.1-G.18	Brief Symptom Inventory-18 Includes a global measure (global severity index) and subscales for depression, anxiety, and somatization <sup>40</sup>
<u>Survivor Disease /</u> <u>Treatment, Health-Related</u> <u>Factors</u>		
Diagnosis	Baseline	
Treatment Intensity	Baseline	
Second Malignant Neoplasm	R.1	Since you last provided us information, have you been diagnosed with another cancer, leukemia, tumor, or a recurrence?
Health Status	E.1	In general, would you say your health is excellent, very good, good, fair, poor?
Chronic Health Conditions	Baseline	Chronic Health Severity Index using NCI CTCAE <sup>19</sup>
Psychological Distress <sup>41</sup>	G.1-G.18	Brief Symptom Inventory-18 Includes a global measure (global severity index) and subscales for depression, anxiety, and somatization <sup>40</sup>

Additional Control Variables

Question	Childhood Cancer Survivor Study	Behavioral Risk Factor		
		Surveillance System 2000		
Current Age	Baseline Survey A.1 What is your date of	Core Section 10, Question 1		
	birth?	What is your age?		
	Code date	Code age in years		
		Don't know/Not sure		
		Refused		
Gender	Baseline Survey A.2 What is your sex?	Core Section		
		What is the sex of the		
	Male	respondent?		
	Female	-		
		Male		
		Female		
Race/ethnicity	Baseline Survey A.4 To which one of the	Core Section 10. Ouestion 2		
	following groups do you belong?	What is your race?		
	White	Would you say:		
	Black	would you say.		
	American Indian or Alaskan Native	h Black		
	Asian or Pacific Islander	c Asian Pacific Islander		
	Other (specify)	d. American Indian. Alaska		
	Suler (speenig)	Native		
	A. 4a	e. Other (specify)		
		Don't know/Not sure		
	Are you Hispanic?	Refused		
	No	34 Are you of Spanish or		
	Yes	Hispanic origin?		
		a Ves		
		h No		
		Don't know/Not sure		
		Refused		
Insurance Status	Follow-Up 2, Question M.1 Do you	Do you have any kind of		
	currently have insurance?	health care coverage including		
		health insurance, prepaid plans		
	Canadian Resident	such as an HMO, or		
	No	government plans such as		
	Yes	Medicare?		
		Yes		
		No		
		Don't Know / Not Sure		
		Refused		

Household	Follow-Up 2, Question S.1 Over the last	Core Section 10, Question 8.
Income	year, what is the total income of the	Is your annual household
	household you live in?	income from all sources:
	Less than \$19,999	a Less than \$25,000
	\$20,000 \$30,000	b. Less than \$20,000
	\$40,000 - \$59,999	c. Less than $$20,000$
	\$60,000 - \$79,999	d Less than $$10,000$
	\$80,000 - \$99,999	e. Less than $$35,000$
	Over \$100.000	f Less than $$50,000$
	Don't know	g Less than $$75,000$
		h $$75,000 \text{ or more}$
		Don't know/Not sure
		Refused
Education	Follow-Up 2 Question 1 What is the highest	Core Section 10 Question 6
20000000	grade of level of schooling that you have	What is the highest grade or
	completed?	vear of school vou completed?
	I I I I I I I I I I I I I I I I I I I	jin i ni jin i r
		a. Never attended school or
	1-8 years (grade school)	kindergarten only
	9-12 years (high school), but did not	b. Grades 1 through 8
	graduate	(Elementary)
	Completed high school	c. Grades 9 through 11 (Some
	Training after high school, other than	high school)
	college	d. Grade 12 or GED (High
	Some College	school graduate)
	College graduate	e. College 1 year to 3 years
	Post Graduate Level	(Some college or technical
		school)
		f. College 4 years or more
		(College graduate)
		Refused
Employment	Follow-Up 2, Question 4 What is your	Core Section 10, Question 7
	current employment status?	Are you currently:
	Working full-time	a. Employed for wages
	Working part-time	b. Self-employed
	Caring for home or family	c. Out of work for more than 1
	Unemployed and looking for work	year
	Unable to work due to illness or disability	d. Out of work for less than 1
	Retired	year
	Student	e. Homemaker
	Other	t. Student
		g. Ketired
		h. Unable to work
		Refused

Question	Childhood Cancer Survivor Study	Behavioral Risk Factor
		Surveillance System 2000
Marital Status	Follow-Up 2, Question 2 Which of these	Core Section 10, Question 4
	possibilities best describes your current	Are you:
	marital status?	
		a. Married
	Married	b. Divorced
	Living as married	c. Widowed
	Widowed	d. Separated
	Divorced	e. Never been married
	Separated or no longer living as married	f. A member of an unmarried
		couple
		Refused

# **APPENDIX B**

Variable	Sibling	N =	(%)	BRFSS	N =	(%)
Age			</td <td></td> <td></td> <td><u></u></td>			<u></u>
18-20						
20-29						
30-39						
40-50						
50+						
Gender						
Male						
Female						
Race/ethnicity						
White						
Non-white						
Insurance						
Insured						
Uninsured						
Household Income						
<u>&lt;</u> \$20,000						
>\$20,000						
Education						
Less High School (HS)						
HS graduate						
More than HS						
Employment						
Unemployed						
Employed						
Marital Status						
Married						
Unmarried						
Survivor Diagnosis						
Leukemia						
CNS						
Hodgkin						
NHL						
NBL						
Sarcoma						
Bone						
Survivor Treatment						
Very Intense						
Moderately Intense						
Mildly Intense						

# **TABLE 1:** Demographics by dataset

**TABLE 2:** Skin cancer prevention practices by dataset. Percent with each screening practice among sibling and BRFSS participants. Crude and adjusted odds ratios for each screening practice for siblings compared to their peers.

Variable	Sibling	BRFSS	Crude OR	Adjusted OR
	N = (%)	N = (%)	Sibling vs.	Sibling vs.
			BRFSS	BRFSS
Sunscreen Use				
Yes				
No				
<b>Protective Clothing</b>				
Use				
Yes				
No				
Wearing a Hat				
Yes				
No				
Staying in Shade				
Yes				
No				

**TABLE 3:** Characterization of skin cancer prevention practices described in the CCSS and BRFSS. Table will include prevalence described by sibling and general population subdivided by racial ethnic groups, gender, and age at interview.

	Sunscree n Use	Protectiv e Clothing Use	Wearin g a Hat	Stayin g in the Shade	BRFSS Sunscree n Use	BRFSS Protectiv e Clothing Use	BRFSS Wearin g a Hat	BRFS S Stayin g in the Shade
Race Ethnicit y White Non- white								
<b>Gender</b> Male Female								
Age at intervie w 18-20 20-29 30-39 40+								

**TABLE 4:** The crude odds ratio (COR) for sibling skin cancer prevention practices given risk factor. The adjusted odds ratios (AOR) for screening practices predicts screening practices controlling for well known risk factors for suboptimal screening practices.

Variable	Sunscreen	Sunscreen	Protective	Protective	Wearing a	Wearing	Staving	Staying in the
	Use	Use	Clothing	Clothing	Hat	a Hat	in the	Shade
	COR	AOR	Use	Use	COR	AOR	Shade	AOR
	95 % CI	95 % CI	COR	AOR	95 % CI	95 % CI	COR	95% CI
	<i>70 %</i> CI	<i>ye</i> // er	95 % CI	95 % CI	<i>)0</i> /0 CI	<i>70 /0</i> CI	95% CI	<i>50</i> 70 CI
Survivor			20 10 01	70 10 01			2010 01	
Diagnosis								
Leukemia								
CNS								
Hodøkin								
NHL								
NBL								
Sarcoma								
Bone								
Survivor								
Treatment								
Intensity								
Very Intense								
Moderate								
Intense								
Not Intense								
Survivor SMN								
Yes								
No								
Survivor								
Health Status								
Excellent/Verv								
Good/Good								
Fair/Poor								
Survivor								
<b>Chronic Health</b>								
Condition								
None/Mild								
Moderate/Severe								
Survivor								
<b>Global Distress</b>								
Yes								
No								
Depression								
Yes								
No								
Somatization								
Yes								
No								
Anxiety								
Yes								
No								

**TABLE 5:** The crude odds ratio (COR) for sibling skin cancer prevention practices given risk factor. The adjusted odds ratios (AOR) for screening practices predicts screening practices controlling for well known risk factors for suboptimal screening practices.

Variable	Sunscreen	Sunscreen	Protective	Protective	Wearing a	Wearing	Staying	Staying in the
	Use	Use	Clothing	Clothing	Hat	a Hat	in the	Shade
	COR	AOR	Use	Use	COR	AOR	Shade	AOR
	95 % CI	95 % CI	COR	AOR	95 % CI	95 % CI	COR	95% CI
			95 % CI	95 % CI			95% CI	
Sibling								
Bereavement								
Yes								
No								
Sibling Health								
Status								
Excellent/Very								
Good/Good								
Fair/Poor								
Sibling Chronic								
Health								
Condition								
None/Mild								
Moderate/Severe								
Sibling Global								
Distress								
Yes								
No								
Depression								
Yes								
No								
Somatization								
Yes								
No								
Anxiety								
Yes								
No								

**TABLE 6:** Cancer screening practices by dataset. Percent with each screening practice among
 sibling and BRFSS participants. Crude and adjusted odds ratios for each screening practice for siblings compared to their peers.

Variable	Sibling	BRFSS	Crude OR	Adjusted OR
	N = (%)	N = (%)	Sibling vs.	Sibling vs.
			BRFSS	BRFSS
Pap Testing <sup>A</sup>				
Yes				
No				
Mammography <sup>B</sup>				
Yes				
No				

<sup>A</sup> Papinicolaou testing within the last five years <sup>B</sup> For females > 40 years of age, report of having undergone a mammogram in the last five years

TABLE 7:	Characterization	of cancer s	screening	practices	descrit	oed in the	e CCSS a	and BR	FSS.
Table will in	nclude prevalence	described	by sibling	g and ger	ieral po	pulation	subdivic	ied by r	acial
ethnic group	os and age at inter	view.							

	Sibling	Sibling	BRFSS	BRFSS
	Pap Smear <sup>A</sup>	Mammogram <sup>B</sup>	Pap	Mammogram <sup>B</sup>
			Smear <sup>A</sup>	
Race				
Ethnicity				
White				
Non-white				
Age at				
interview				
18-20				
20-29				
30-39				
40 +				

**TABLE 8:** The crude odds ratio (COR) for screening practices given risk factor. The adjusted odds ratios (AOR) for screening practices predicts screening practices controlling for risk factors for decreased screening practices.

Variable	Sibling	Sibling	Sibling	Sibling
	Pap Smear <sup>A</sup>	Pap Smear <sup>A</sup>	Mammogram <sup>B</sup>	Mammogram <sup>B</sup>
	COR	AOR	COR	AOR
	95 % CI	95 % CI	95 % CI	95 % CI
Diagnosis				
Leukemia				
CNS				
Hodgkin				
NHL				
NBL				
Sarcoma				
Bone				
Treatment				
Intensity				
Very Intense				
Moderate Intense				
Mild Intense				
Survivor SMN				
Yes				
No				
Survivor Health				
Status				
Excellent/Very				
Good/Good				
Fair/Poor				
Survivor				
Chronic Health				
Condition				
None/Mild				
Moderate/Severe				
Survivor Global				
Distress				
Yes				
No				
Depression				
Yes				
No				
Somatization				
Yes				
No				
Anxiety				
Yes				
No				

**TABLE 9:** The crude odds ratio (COR) for screening practices given risk factor. The adjusted odds ratios (AOR) for screening practices predicts screening practices controlling for risk factors for decreased screening practices.

Variable	Sibling Pap Smear <sup>A</sup> COR 95 % CI	Sibling Pap Smear <sup>A</sup> AOR 95 % CI	Sibling Mammogram <sup>B</sup> COR 95 % CI	Sibling Mammogram <sup>B</sup> AOR 95 % CI
Sibling				
Bereavement				
Yes				
No				
Sibling Health				
Status				
Excellent/Very				
Good/Good				
Fair/Poor				
Sibling Chronic				
Health				
Condition				
None/Mild				
Moderate/Severe				
Sibling Global				
Vos				
No				
110				
Depression				
Yes				
No				
110				
Somatization				
Yes				
No				
Anxiety				
Yes				
No				

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