

Childhood Cancer Survivor Study Analysis Concept Form

I. Title:

Access to Health Information Technology and Health Information Seeking in Adult Survivors of Childhood Cancer

II. Working Group:

The study will be within the Epi/Biostats Working Groups. Proposed investigators will be:

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III. Background and Rationale:

Childhood cancers and subsequent treatment place survivors of childhood cancer at a greater risk for certain life-threatening illnesses and long-term complications than most individuals. It is known that survivors of childhood cancer are at an increased risk for subsequent cancers and other serious late effects due to their previous diagnosis and treatment for cancer. Hence, it is important for childhood cancer survivors to be knowledgeable about their illness, their treatment, and the importance of maintaining their health to improve their future health and quality of life. Many adult childhood survivors are not aware of their on-going health risks, possible late effects, and the significance of consistent regular check-ups. Therefore, to better understand information-seeking strategies of cancer survivors would be valuable for designing future interventions and health education materials for this at risk population. It is also important to determine the most appropriate method of communication to provide health information to long-term cancer survivors about their risk for these various late effects.

The Childhood Cancer Survivor Study (CCSS) is a large retrospectively ascertained cohort study of childhood cancer survivors diagnosed between 1970 and 1986. The CCSS represents the largest epidemiological research cohort of childhood cancer survivors ever assembled in North America. CCSS provides a unique opportunity to study adults who have already been identified in a larger group of childhood cancer survivors. The Health Information Survey from CCSS will enable us to determine whether childhood cancer survivors seek health information, and if so, how they obtained it. CCSS will also assist in identifying the types of health information obtained as well. Available demographic and treatment information as well as follow-up surveys on the CCSS cohort will enable us to identify groups of survivors based on type of cancer, age of diagnosis, income, and other exploratory variables that will be beneficial in analysis.

In the general population, eight in ten internet users have searched online for health information (Pew Internet and American Life Project, 2012). In a 2002 survey by Pew Internet and American Life project, 80% of U.S adults use the internet and 88% of U.S adults own a cell phone (Pew Internet and American Life Project, 2002). Of this, 80% of the internet users, or 59% of U.S adults, looked online for health information and 17% of cell phone owners, or 15% of adults, have used their phone to look up health or medical information (Pew Internet and American Life Project, 2002). In addition, survivors of other diseases, especially chronic illnesses, use the internet as a source of information for a broad range of medical topics. In a previous survey, Diaz et al. determined patients' use of the internet for medical information (Diaz et al., 2002). Of the 512 patients who were surveyed in this study, 53.5% (274) stated that they used the internet for medical information and 60% felt that the information on the internet was the "same as" or better than information from their doctors (Diaz et al., 2002).

In other studies, patients living with HIV/AIDS used the internet for information, support, and health related activities (Kalichman et al., 2002; Kalichman et al., 2006; Kalichman et al., 2005). One particular study in 2002 by Kalichman et al. identified that searching for HIV/AIDS specific health and advocacy information was very common amongst the HIV/AIDS population (Kalichman et al., 2002). 64% of the people with home access searched for HIV treatment information online compared to the 47% who used the internet elsewhere. On average, participants with home access searched for health information nearly eight times in the previous three months compared to two times for those without home access. Also, in another survey using infectious disease clinics in inner-city areas of Atlanta, GA, HIV positive internet users reported using the internet for a wide range of purposes, with health related searches for information accounting for one out of three internet activities (Kalichman et al., 2005). However, within this population, people with greater income and more education were more likely to use the internet for these health functions.

One good resource for a comparison population is The Health Information National Trends Survey (HINTS). This survey collects nationally representative data routinely about the American public's use of cancer-related information (National Cancer Institute [NCI], 2012). The HINTS data collection program was created to monitor changes in the rapidly evolving field of health communication). The survey provides updates on changing patterns, needs, and information opportunities in health, identifies changing communications trends and practices, assesses cancer information access and usage, and provides information about how cancer risks are perceived. The data is used to understand how adults 18 years and older use different communication channels, including the internet, to obtain vital health information for themselves and their loved ones. In a previous survey, using data from three iterations of the National Cancer Institute's HINTS administered in 2003, 2005, 2008, overall half the sampled cancer survivors reported using the internet and over half of the internet-using survivors who searched for cancer information reported using the internet as the first source (Chou, Liu, Post, &Hesse, 2011).

Also, The Pew Internet & American Life Project is another good source for the comparison population. This project which makes up one for the seven projects of the Pew Research Center provides information on the issues, attitudes, and trends shaping America and the world (The Pew Internet & American Life Project, 2012). The project produces reports exploring the impact of the internet on families, communities, work and home, daily life, education, health care, and civic and political life. The project analyzes the evolution of the

internet through surveys that examine how Americans use the internet and how their activities affect their lives.

Over the past decade, the internet and various other forms of technology have changed the way adolescent cancer survivors can assess types of health-related information regarding their illness. In conjunction with searching for health-related information online, survivors can also participate in online health-related activities to seek information regarding their diagnoses and treatment as well. Access to effective health information assist patients in making beneficial decisions regarding their health and also improves health status for patients with chronic illnesses. People with cancer, HIV/AIDS, and other chronic diseases demonstrate health benefits from increased access to health information about their condition and treatment options on the World Wide Web.

We propose to study the adult childhood cancer survivors in the Childhood Cancer Survivor Study (CCSS) cohort to assess the types of information technology that are available to CCSS survivors, and their interest in seeking health related information. In the same cohort, we also propose to study the types of information survivors seek, and how they are interested in receiving this information. For this proposal, we will use data from the Health Information Survey, which was distributed to a random sample of 2000 CCSS participants, stratified on diagnosis and age (18-25, > 25), with 125 participants selected within each category. Data from this survey included questions from the HINTS 2 survey and from PEW surveys, for comparison purposes.

IV. Objective/Specific aims/Research Hypotheses:

Objective:

The objectives of this study are to assess the types of information technology that is available to childhood cancer survivors and their interest in seeking health-related information. Also, we will determine the type of information survivors seek and how they are interested in receiving this information.

1. To determine internet usage and health information seeking among childhood cancer survivors

We hypothesize that:

- Childhood Cancer Survivors are more likely to seek health related information than a similar age group in the general population.
 - Childhood Cancer Survivors with higher level education are more likely to seek health information than those with lower education levels.
 - Childhood Cancer Survivors between the ages of 18-25 will be more likely to seek health information than survivors ages 26 and older.
2. To determine the types of information childhood cancer survivors seek
 - We propose to quantify the various health information sources accessed by childhood cancer survivors
 3. To evaluate childhood cancer survivor health information sources

- We propose to quantify preferences and the means by which childhood cancer survivors obtain their health information.

V. Analysis Framework:

Population:

We propose to conduct our analysis on 2000 randomly selected survivors invited to participate in the Health Information Survey, stratified on diagnosis and on age (18-25, >25). Respondents within each diagnosis were: Leukemia (213), CNS tumor (175), HD (140), Kidney (188), Neuroblastoma (159), STS (205), and Bone (150). The questionnaire was distributed between 11/05 - 08/06, subsequent to the Follow-up 2003 Survey. The questionnaire design consisted of 20 questions in which seven questions were obtained from the HINTS 2 Survey examining cancer and health information, three questions were obtained from the PEW survey examining health info, and ten other questions from literature with five examining access to internet and usage and five examining questions regarding seeking cancer information.

Number of survivors within each diagnosis:

Diagnose	Frequency	Percent
Leukemia	213	15.03%
CNS	175	12.35%
HD	140	9.88%
NHL	187	13.20%
Kidney (Wilms)	188	13.27%
Neuroblastoma	159	11.22%
Soft Tissue Sarcoma	205	14.47%
Bone Cancer	150	10.59%
Total	1,230 (respondents)	

Outcome of Interest:

The total sample consists of the 2000 survivors who received the HIS survey. We will use the 1,230 who responded to the HIS survey as our outcomes sample, stratified on age because different age groups can have different experiences with accessing information using technology thus causing different outcomes.

The outcomes of interest are the types of information technology used, how often does one look for health related information, what types of information does survivors seek, and which health information sources are majorly used. The outcomes of interest will be measured by questions from the LTFU HIS survey. The scores will be analyzed as comparison variables with population controls (HINTS and Pew data) and odds ratios will be calculated for each outcome. Based on the participants responses in the questionnaire on health information we will examine and analyze all of the listed the outcome variables.

The outcomes of interest the LTFU HIS survey are:

Internet usage (Types of information technology used):

Question 2F: Got information from the internet about a health issue that affects you or someone you know

Question 5B: How much would you like to receive health-related information or advice from an internet site

Question 9: Ever used internet for health advice

Health information seeking (How often does one look for health related information):

Question 3: Pay attention to health information

Question 4D: Trusted information from the internet

Question 7: How often do you look for health-information?

Types of information survivors seek:

Question 6A, B: Reading material and Question 6C, D, E: Website material

Question 8A: Experiencing new symptoms or a change in your health Question 8D: Wanting to learn more about the effects of treatment for the cancer or similar illnesses you had when younger

Question 16I: Finding internet sites that talk about health issues related to life after cancer

Health information sources:

Question 9: Ever used internet for health advice

Question 5B: How much would you like to receive health-related information or advice from an internet site

Questions 10A: Looked for health or medical information for yourself and Question 10B: Looked for health or medical information for someone else

Question 14A: Being reminded about my health problems and Question 14D: Learning things that would make me scared or worried about my health

Question 16I: Finding internet sites that talk about health issues related to life after cancer

Question 17: Use of resources about issues related to cancer survivorship

Question 18: Ever called the National Cancer Institute's cancer information hotline

Question 19: Have you ever called the American Cancer Society's cancer hotline

Question 20: Have you found a website for cancer survivors that was helpful to you

Question 11: Have you ever talked to a doctor, nurse, or other health care provider about any kind of health information you have gotten from the internet?

Question 12: When you talked with a health care provider, how interested were they in hearing about the information you found online?

Question 13: How much do you agree or disagree regarding health information searches

Exploratory Variables:

Other variables that may prove to be important or should be taken into consideration in analyzing the data are:

Demographic/cancer information

Age at HIS survey completion

Gender
Race/Ethnicity
Diagnosis
Age at diagnosis
Time since diagnosis to HIS survey completion
Types of treatment
 Chemotherapy (Y/N)
 Radiation (Y/N)

From the Follow-up 2003 Survey:

Question 1: Education
Question 2: Marital Status
Question 4: Employment status
A.1: See/Talk with health care providers in previous 2 years
A.3: # of Physician visits
A.5: Frequency of visits related to previous cancer
A.6: Discuss specific issues with provider (list)
A.7: Familiarity with health problems
A.8: At check-up provider gave/discussed (list)
A.9 Have treatment summary
A.10: Provider has summary
E.1: Ranking of health
E.21: Body Pain
E.22: Body pain interferes with activities
F.19: Pain as result of cancer
F.20: Anxiety/Fears as result of cancer
M.1, 1a, 1b: Insurance status
S.3: Personal Income
T1: Long-Term Follow-up newsletter
T.2: Newsletter makes you feel anxious
T.3: Seeking more info (LTFU Newsletter)
T.4: Resources for more information
T.5: Specific health problems of interest
T.6 Share newsletter with provider

(See tables under proposed tables)

Comparison Population:

For the comparison population for this study, we will use the Health Information National Trends Survey (HINTS). HINTS was created to monitor changes in the rapidly evolving field of health communication. These data are used to understand how adults 18 years and older use different communication channels, including the internet, to obtain vital health information for themselves and their loved ones. This data is used to overcome barriers to health information usage across populations, and obtaining the data needed to create more effective communication strategies. There are 6,369 participants over the age of 18 years old in the HINTS study. For our study, we will choose an age range identical to the CCSS for comparison.

Also for the comparison population for this study, we will use Pew Internet and American Life data. This data set reports on the impact of the internet on families, communities, work and home, daily life, education, health care, and civic and political life. There are 2,253 participants over the age of 18 years old in the PEW study. For our study, we will choose an age range identical to the CCSS for comparison.

Statistical Analyses:

Frequency distributions will be used to summarize the categories of relevant outcome variables, descriptive variables, and covariates for subsequent analysis by question within each specific aim.

Chi-Square will be calculated to describe survivor characteristics, including age at completion of the HIS survey, gender, education, race/ethnicity, ranking of health, and personal income of those who responded to the HIS and those who did not respond to the HIS survey. We will also compose summary information of similar factors for the HINTS and PEW studies.

To address the first objective, ‘to determine internet usage and health information seeking among childhood cancer survivors’, associations between the use of internet for advice or info related to health and the amount of attention given to information about health, or medical topics on radio and television, in newspaper and magazines will be evaluated and compared with HINTS data and general population (Pew) controls. This will allow us to analyze the technology usage of childhood cancer case survivors when compared to other populations. Odds ratios and the 95% confidence intervals will be calculated for this analysis comparing the CCSS subjects to the other populations for the relevant questions asked of each group. A univariate analysis will be performed for comparing old age versus young age and higher versus lower levels of education groups within the CCSS population. If the univariate analysis shows statistical significance, then a multivariate analysis will be performed.

To address the second objective, ‘to determine the types of information childhood cancer survivors seek’, associations between the types of information survivors seek and the exploratory variables listed will be evaluated to determine which may lead childhood cancer survivors to look for health information and medical information. We will summarize the various health information sources accessed by childhood cancer survivors.

To address the third objective, ‘to evaluate childhood cancer survivor health information sources’, childhood cancer survivor’s interest in using the internet for health related information and how survivors would like to receive health-related information will be evaluated. We will quantify preferences and the means by which childhood cancer survivors would like to obtain their health information.

VI. Special Considerations:

The proposed research will be used as a graduate thesis for Mechelle Claridy for completion of her MPH from Morehouse School of Medicine. Upon approval, she will request the data described above to complete the analysis herself, under direct supervision of her research mentor,

Ann Mertens, PhD. We acknowledge that some results may not be of sufficient impact to warrant publication, given the changes in technology and social networking over the past 7 years. Upon completion of the thesis analysis, we will review the results and determine which aspects of the analyses could be published. We will request a review of the analysis by CCSS biostatisticians prior to publication.

Proposed Tables:

Survivor Characteristics

	Completed HIS Survey N(%)	Did not complete HIS survey N(%)	Chi-Square
Age at HIS survey completion:			
18-25			
25 - up			
Gender:			
Male			
Female			
Education:			
Grade school			
High school			
Completed High school/GED			
Some College			
College Graduate			
Post graduate level			
Race/Ethnicity:			
Caucasian			
African American			
Hispanic			
Asian or Pacific Islander			
American Indian or Alaskan Native			
Ranking of health:			
Excellent			
Very good			
Good			
Fair			
Poor			
Personal Income:			
None			
Less than \$19,999			
\$20,000 –\$39,999			
\$40,000- \$59,999			
\$60,000-\$79,999			
\$80,000-\$99,999			
Over \$100,000			

Objective 1: Internet Usage

Question 9. Have you ever used the internet to look for advice or information related to your health?

	Yes N(%)	No N(%)	Odds ratio	95% Confidence interval
Age at HIS survey completion:				
18-25				
25 - up				
Gender:				
Male				
Female				
Education:				
Grade school				
High school				
Completed High school/GED				
Some College				
College Graduate				
Post graduate level				
Race/Ethnicity:				
Caucasian				
African American				
Hispanic				
Asian or Pacific Islander				
American Indian or Alaskan Native				
Ranking of health:				
Excellent				
Very good				
Good				
Fair				
Poor				
Personal Income:				
None				
Less than \$19,999				
\$20,000 –\$39,999				
\$40,000- \$59,999				
\$60,000-\$79,999				
\$80,000-\$99,999				
Over \$100,000				

Question 2: Have you ever done any of the following?

	Yes N(%)	No N(%)
Downloaded music from the internet		
Used email or instant messaging		
Forwarded or downloaded email attachments		
Downloaded photos from email or a website		
Downloaded video from email or a website		
Got information from the internet about a health issue that affects you or someone you know		
Got information from the internet about things that are hard to talk about with other people		
Listened to the radio streamed through the internet		
Accessed your personal health record online		
Visited a chat room		
Subscribed to a listserv		
Other		

Question 5: Thinking about your own health, how much would you like to receive health-related information or advice in the following ways?

	A lot N(%)	Some N(%)	A little N(%)	Not at all N(%)
By email				
From an internet web site				
By watching a video tape or DVD				
By listening to an audio tape or compact disc				
By reading a pamphlet newsletter, magazine, or some other publication				
By talking with health professional, in person or over the phone				

Objective1b: Health Information Seeking

Question 3. In general, how much attention do you pay to information about health or medical topics on radio and television, in newspaper and magazines?

	A lot/Some N(%)	A little/Not at all N(%)	Odds ratio	95% Confidence interval
Age at HIS survey completion:				
18-25				
25 - up				
Gender:				
Male				
Female				
Education:				
Grade school				
High school				
Completed High school/GED				
Some College				
College Graduate				
Post graduate level				
Race/Ethnicity:				
Caucasian				
African American				
Hispanic				
Asian or Pacific Islander				
American Indian or Alaskan Native				
Ranking of health:				
Excellent				
Very good				
Good				
Fair				
Poor				
Personal Income:				
None				
Less than \$19,999				
\$20,000 –\$39,999				
\$40,000- \$59,999				
\$60,000-\$79,999				
\$80,000-\$99,999				
Over \$100,000				

Question 4: How do you trust information about health or medical topics from sources listed below?

	CCSS N(%)				HINTS N(%)			
	A lot	Some	A little	Not at all	A lot	Some	A little	Not at all
Radio								
Television								
Family or Friends								
Internet								
Doctor or other health care professional								
Newspaper								
Magazines								

Question 7: Still thinking specifically about your own health, about how often do you look for health-related information from any source?

	CCSS N(%)	PEW N(%)
Once a week		
Once a month		
Every few months		
Once or twice a year or less		
Never		

Objective 2: Types of Information Survivors Seek

Question 6: Still thinking about your own health, please indicate how much you like the options listed below.

	CCSS N(%)				HINTS N(%)			
	A lot	Some	A little	Not at all	A lot	Some	A little	Not at all
Reading material that provides health information of interest to anyone								
Reading material that uses information from your medical record to provide health related information specific to you								
A website where you could type in personal information such as age, health history, smoking habits, etc., to receive health information specific to you								
A website that provides health information of interest to everyone								
A secure website that uses information from your medical record to provide health-related information specific to you								

Question 8: Which of the following reasons would lead you to look for health or medical information?

	CCSS N(%)		PEW N(%)	
	No	Yes	No	Yes
Experiencing new symptoms or a change in your health				
Being diagnosed with a new health problem				
Hearing or seeing something in the news that you wanted to learn more about				
Wanting to learn more about the effects of treatment for the cancer or similar illness you had when younger				
Dealing with an ongoing medical condition, like diabetes or high blood pressure				
Deciding to change your diet or exercise habits				
Your doctor prescribed a new medication, test, or course of treatment				
Having unanswered questions after a visit to the doctor or clinic				
Not having time to visit your doctor				
Being unable to get a referral or an appointment for a health-related problem				
Other				

Question 16: How interested are you in the following?

	Extremely Interested N(%)	Fairly Interested N(%)	Somewhat Interested N(%)	Not very interested N(%)	Not at all interested N(%)
Learning more about the kind of cancer or related illness I had when I was younger					
Learning more about my treatment for cancer when I was younger					
Learning more about screening tests my doctor might recommend					
Learning more about things I can do to avoid future health problems					
Hearing stories about people with health histories like mine					
Joining an internet discussion group where I could communicate with people like me					
Being able to ask an expert questions about symptoms that concern me					
Getting reassurance about my health					
Finding internet sites that talk about health issues related to life after cancer					
Locating books and articles about health issues related to life after cancer					

Objective3: Health Information Sources

Question 9: Have you ever used the internet to look for advice or information related to your health?

	CCSS N(%)		Pew N(%)	
	Yes	No	Yes	No
Have you ever used the internet to look for advice or information related to you health?				

Question 5: Thinking about your own health, how much would you like to receive health-related information or advice in the following ways?

	CCSS N(%)				HINTS N(%)			
	A lot	Some	A little	Not at all	A lot	Some	A little	Not at all
By email								
From an internet web site								
By watching a video tape or DVD								
By listening to an audio tape or compact disc								
By reading a pamphlet newsletter, magazine, or some other publication								
By talking with health professional, in person or over the phone								

Question 10: In the past 12 months, which of the following things have you done while using the internet?

	CCSS N(%)		HINTS N(%)	
	No	Yes	No	Yes
Looked for health or medical information for yourself				
Looked for health or medical information for someone else				
Bought medicine or vitamins online				
Participated in an online support group for people with a similar health or medical issue				
Used email or internet to communicate with a doctor or a doctor's office				
Looked for information about physical activity or exercise				
Looked for information about protecting yourself from the sun				
Looked for information about quitting smoking				
Done anything else health-related on the internet				

Question 14: If you used the internet to look for health-related information, how concerned would you be about the following?

	Very Concerned N(%)	Somewhat concerned N(%)	A little concerned N(%)	Not at all concerned N(%)	Don't know/no opinion N(%)
Being reminded about my health problems					
Having to answer too many personal questions					
My health information won't be kept private					
Learning things that would make me scared or worried about my health					
If you have other concerns besides those listed above, please specify:					

Question 16: How interested are you in the following?

	Extremely Interested N(%)	Fairly Interested N(%)	Somewhat Interested N(%)	Not very interested N(%)	Not at all interested N(%)
Learning more about the kind of cancer or related illness I had when I was younger					
Learning more about my treatment for cancer when I was younger					
Learning more about screening tests my doctor might recommend					
Learning more about things I can do to avoid future health problems					
Hearing stories about people with health histories like mine					
Joining an internet discussion group where I could communicate with people like me					
Being able to ask an expert questions about symptoms that concern me					
Getting reassurance about my health					
Finding internet sites that talk about health issues related to life after cancer					
Locating books and articles about health issues related to life after cancer					

Question 17: If a resource were available that provided information about issues related to cancer survivorship – things like health risks, healthy living habits, insurance, employment, and so on, which of the following best describes how you would use that resource?

	No N(%)	Yes N(%)
I would use it		
I would use it if I developed a health problem		
I would use it to see what problems I might develop in the future		
I would use it to change my lifestyle and health habits		
I would discuss it with my doctor or health care provider		
I would discuss it with my family and friends		
Other		

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