LTFU

Long-Term Follow-Up Study

INSURE

St. Jude Children's Research Hospital Children's Healthcare of Atlanta/Emory University Children's Hospital at Stanford Children's Hospital of Columbus Children's Hospital of Orange County Children's Hospital of Philadelphia Children's Hospital of Los Angeles Children's Hospital of Pittsburgh Children's Hospitals & Clinics of Minnesota, Minneapolis and St. Paul Children's Medical Center of Dallas Children's National Medical Center City of Hope National Medical Center Dana-Farber Cancer Institute/ Children's Hospital Boston Loma Linda University Mattel Children's Hospital at UCLA Mayo Clinic Memorial Sloan-Kettering Cancer Center Miller Children's Hospital Riley Hospital for Children - Indiana University Roswell Park Cancer Institute Seattle Children's Hospital St. Louis Children's Hospital Texas Children's Hospital The Denver Children's Hospital Toronto Hospital for Sick Children UAB/The Children's Hospital of Alabama University of California at San Francisco University of Michigan - Mott Children's Hospital University of Minnesota U.T.M.D. Anderson Cancer Center

Today's date: / 2 0 1

Dear

Thank you for your continued participation in the Long Term Follow-Up Study (LTFU). We would like to inform you of an opportunity to participate in our new research study sponsored by the National Cancer Institute. As a participant in the LTFU you may be eligible to participate.

Little information is available about the health related needs of childhood cancer survivors. The purpose of this research study is to better understand how childhood cancer survivors are doing as adults. About 1430 research participants in the Childhood Cancer Survivor Study will be invited to take part in the research study.

To participate in this study you will complete a questionnaire about your health care needs as a survivor of childhood cancer. The questionnaire takes approximately 45 minutes to complete. You will be compensated \$25 for completing this questionnaire and returning the questionnaire in the pre-paid envelope. Upon receipt of this questionnaire you will be mailed \$25 (your choice of check or gift card). Some participants will be asked to complete the questionnaire a second time (chosen randomly). If you are chosen to complete the questionnaire a second time you will be compensated another \$25.

Because the questionnaire includes questions on emotions and quality of life, the risk of participating in this research study is feelings of sadness and frustration.

The benefit of this study is increased knowledge about childhood cancer survivors' health-related needs and how these needs affect the long-term experience of survivors in adulthood.

Please fill out the questionnaire completely, even if you feel that one or more needs do not pertain to your experience as an adult survivor of childhood cancer.

Your responses to the questionnaire will be kept confidential (private) to the degree allowed by law. Information from your questionnaire(s) will not be given to anyone outside the study unless you agree. You will not be identified in any publication about this study.

Your decision whether or not to enroll in this study will not affect your current or future relationship with St. Jude Children's Research Hospital or your continued participation in the LTFU study. If you decide to enroll, you are free to withdraw at any time.

You can contact a representative of the research team with any questions at 1-866-278-5833 (ext 2379) or insure@stjude.org.

Thank you and we look forward to talking to you in the near future.

Sincerely,

Leslie L. Robison, Ph.D.

Chairman, Department of Epidemiology and Cancer Control

St. Jude Children's Research Hospital

Thank you for completing this survey. You will receive \$25 in the form of a check or a Target gift card. Please indicate your choice by checking the box below. If no choice is indicated, you will be issued a check.

☐ Check ☐ Gift Card

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

- 1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging.
- 2. When marking boxes, make an x inside the box (see examples below).
- 3. Make no stray marks of any kind. Please keep the form as clean as possible.
- 4. Written responses must stay within the boxes provided:

CORRECT

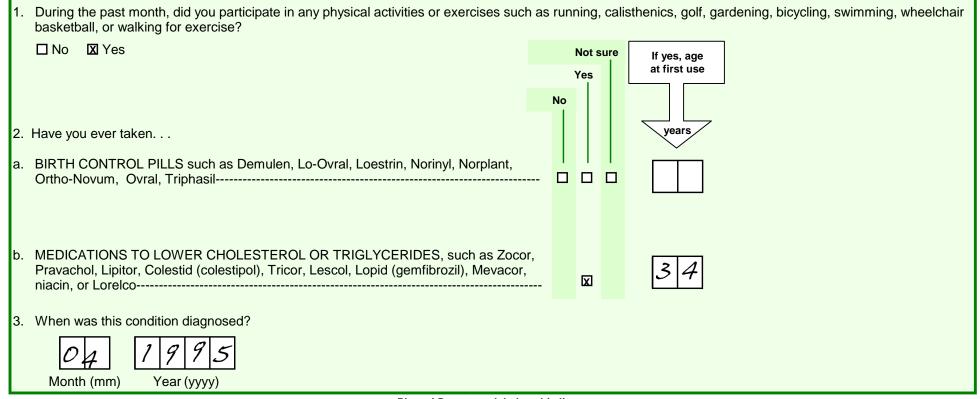
INCORRECT

Grape



MARKING EXAMPLES

Below are some examples of how to fill out this questionnaire. Please look these over before you begin.



<u>Demographics</u>	
1. What is your gender?	
☐ Male	
☐ Female	
2. To which one of the following groups do you belong?	?
☐ White	
□ Black	
☐ American Indian or Alaskan Native	
☐ Asian	
☐ Pacific Islander	
Other	
Specify	
2a. Are you Hispanic?	
□No	
☐ Yes	
3. What is your marital status? Are you:	
☐ Married	
☐ Never married	
☐ Divorced	
☐ A member of an unmarried couple	

☐ Widowed☐ Separated

4. How many adults are living with you in your household?
5. What is the adult/adult's relationship to you?
6. How many children are living with you in your household?
7. What is the child/children's relationship to you?
8. How many ill adult/adults living in your household require care?
9. How many ill child/children living in your household require care?

10.	What is the highest grade or level of schooling you have now completed?	12. Over the past year, what was the total income of the <u>household</u> you live in?
	☐ 1-8 years (grade school)	☐ Less than \$20,000
	☐ 9-12 years (high school) but did not graduate	□ \$20,000 - \$39,999
	☐ Completed high school/GED	□ \$40,000 - \$59,999
	☐ Training after high school, other than college	□ \$60,000 - \$79,999
	☐ Some college	□ \$80,000 - \$99,999
	☐ College graduate	□ Over \$100,000
	☐ Post graduate level	□ Don't know
	☐ Other	
	If other, please describe.	13. What is your current employment status? Include unpaid work in the family business or farm. (Mark all that apply)
		☐ Working full-time (30 or more hours per week)
		☐ Working part-time (less than 30 hours per week)
11.	Not including you, what is the highest education level among all	☐ Caring for home or family (not seeking paid work)
	people living in your home?	☐ Unemployed and looking for work
	☐ 6th grade or less	☐ Unable to work due to illness or disability
	☐ 8th grade or less	Retired
	☐ Attended some high school	☐ Student
	☐ High school graduate or GED	☐ Other
	☐ Technical School	If other, please describe.
	☐ Some College	
	☐ College graduate	
	☐ Post Graduate Study	
	If other, please describe.	

14.	The following questions are about your present occupation. Please write your job title and brief details of what you do. 14a. Current job title:
	14b. Please briefly describe your primary job tasks:
15.	How many hours do you work each week?
	hours
16.	Do you currently have health insurance coverage?
	□Yes
	□No
17.	Do you have access to health care?
	□Yes
	□No
18.	Which of the following health care providers do you regularly see or talk to for medical care? (This includes routine and sick care.) Mark all that apply.
	□ None □ Physician □ Nurse Practitioner/Physician's Assistant □ Nurse □ Chiropractor □ Physical therapist □ Other
	If other, please describe.

Needs Assessment for Childhood Cancer Survivors

To help us plan better services for people who have survived childhood cancer, we are interested in whether or not your needs, which you may have faced as a result of being diagnosed with and treated for cancer, have been met. You will be presented with a list of possible needs, and there are two sections to the survey.

In the **first** section, "Need should be met", **mark the response** that best describes the extent to which you feel the listed need should be met as a result of having cancer.

There are 5 possible choices:

Strongly Agree

Agree

Disagree

Strongly Disagree

Don't Know

In the **second** section, "No need/Some need," indicate whether you have needed help with this issue as a result of having cancer. **Mark the response** that best describes whether or not you have needed help with this matter.

There are 5 possible choices:

NO NEED No Need Exists – This is not a problem for me as a result of having cancer

Satisfied - I did need help with this, but I found resources to meet the need

SOME NEED Low need for help— This item causes me little concern or discomfort. I have little need for additional help

Moderate need for help – This item caused me some concern or discomfort. I had some need for help.

High need for help – This item causes me a lot of concern or discomfort. I have a strong need for additional help.

In the **third** section, if you had **SOME NEED**, mark the response to indicate how recently you have experienced this need.

There are 5 possible choices:

1-3 months

4-6 months

7-9 months

10-12 months

>12 months

	Mark the radescribes you feel the met.	the e	xtent	to v	vhich		Mark the res describes wh have needed matter.	nethei	or n	ot you		If you had SOME NE was this need within					
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I needed:		D	isagr	ee		NEED)			Low		NEED		7-9	mon	ths		
		Agı	ree			NO	Need is sat	tisfied			'	4-6	mor	nths			
Psychological/Emotional	Strongly Ag	aree				NEED	No need exist	s				1-3 mont					
7 Syonologica // Emotional																	
1. Help dealing with fears about the cancer spreading	ng] [· · · · · · · · · · · · · · ·						$\dot{\Box}$	$\dot{\Box}$	<u> </u>	<u> </u>	Ė
2. Help dealing with fears about the cancer returning	g] [· · · · · · · · · · · · · · · · · · ·										
3. Help dealing with fears about pain				– [
4. Help dealing with the worries of those close to me	e			_ [
5. Help dealing with uncertainty about the future				– [
6. Help dealing with anxiety				_ [
7. Help dealing with worry				– [
8. Help dealing with feeling very nervous, afraid, or	tense			- [
9. Help dealing with feeling down or depressed				_ [
10. Help feeling calm and peaceful				- [_
11. Help dealing with feeling angry				_ [
12. Help dealing with fears about losing my independ	dence			_ [
13. Help dealing with the confusion about why I got of	cancer			_ [_
14. Help dealing with feeling bored and/or useless.				_ [🗆										_
15. Help dealing with anxiety about having routine so examinations			0 0				 🗆										
16. Help dealing with fears about physical disability deterioration							🗆		_								_
17. Help feeling in control of my situation				-	o 0		 										_
18. Help making the most of my time] [o 0		 										_
19. Help maintaining a positive outlook				J [0		 										J
20. Help finding meaning in this experience				3 C			 										

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			Disag	ree		NEED)		ı	Low		NEED	7-9 m	onths				
I needed:		Ag	gree			NO [Need is satis	sfied			4-	·6 month	s				
	Strongly A	gree	Ш			NEED	No need exists				1-3 mor	nths					
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21. Help dealing with feelings about death and dying													J 🗆				
22. Help dealing with changes to my usual routine ar																	
lifestyle			_				· · · · · · · · □										
23. Help with reducing stress in life																	
24. Help dealing with loss of control over emotions .																	
25. Help with loneliness] 🗆				
Health System and Information																	
26. Information about the things I can do to keep my	self well																
27. Information (written, diagrams, drawings) about my health after cancer treatment																	
28. Information about the important aspects of my afficare																	
29. Information about support groups in my area																	
30. Help finding out how to access professional cour (e.g., psychologist, social worker, counselor, nurspecialist) if I/family/friends need it	se	П	П		o o		· · · · · · · · · · · · · · · · · · ·			П		пг	1 [пп			
31. To be treated like a person not just another case																	
32. Choices about when to go in for check-ups																	
33. One health care provider with whom I could talk health.	about my											пг					
34. My doctors to talk to each other to coordinate my			_				_	_					. –				
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35. Help to know how to give input to my medical tea order to manage my health																	
36. My complaints about my care heard and address	sed																

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	Strongly Ag	gree					NEED	No	o need exis	sts					1-3 mo	nths				
37. Information about exercise to help me stay health	у																			
38. Infertility information																				
39. Information about who to call for help																		_ !		
Cancer-related Health Information																				
40. Information about genetics and the particular can																				
had		_																		
41. Information about cancer recurrence		_	_		_				•				_							
42. Information about how cancer affected my body.																				
43. Information about what causes cancer																				
44. Information about the late effects of my cancer th	erapy																			
45. Information about what symptoms to report to the	doctor or																			
nurse																				
46. Information about specific diseases that can resu cancer therapy		П	п	П	П	П			1		П	П	П							П
47. Information about what I can do to reduce my cha									•											
developing late effects																				
$\ \textbf{48. Information about my treatments or medications.}$																				
49. Information about my test results as soon as pos	sible																			
50. Information about which organ systems may have affected by my cancer treatment	been								ı				_						_ ,	
51. Information about how cancer will affect my life																				
Physical and Daily Living																				
52. Help with pain																				

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53.	Help with walking									···· 🗀		Ò]		[Ġ	$\dot{\Box}$	$\dot{\Box}$
54.	Help with weight loss] .			· · · · □]		[
55.	Help with cognitive (thinking/memory) problems] .			🗖]		[
56.	Help with my body image									🗖]		[
57.	Help with lack of energy and overcoming fatigue									🗖]		[
58.	Help with lack of pep									🗖]		[
59.	Help with feeling tired									🗖]		[
60.	Help with feeling unwell a lot of the time						J .			🗖]		[
61.	Help with not sleeping well]			🗖]		[
62.	Help with work around the home]			🗆]		[
63.	Help with doing the things that I used to do		П	п		0 0	٦.			П	п	П	пг	1		г				п
	Help with feeding, bathing, or dressing myself			_							_			=						
	Help with preparing meals or doing light housework																			_
	work	•					J .			🗖]		[
66.	Help climbing one flight of stairs] .			🗆]		[
67.	Help with bending, kneeling, or stooping] .			🗖]		[
68.	Help walking more than a mile] .			🗖]		[
69.	Help walking several blocks] .			🗖]		[
70.	Help walking one block						. כ			🗖]		[
71.	Help maintaining overall health						J .			🗖]		[
72.	Help improving overall health]			🗖]		[
73.	Help feeling as healthy as other people] .			🗖]		[

		Mark the r describes you feel th met.	the e	exte	nt to	whic	ch		descr	the resp ibes who needed r.	ether	or no	t you		If you had was this n				
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74	Help with continuing usual hobbies or sports						 -					 _	 						
	Help with managing late effects of cancer therapy.																		
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76.	Help performing work or other daily activities becau physical health									🗖									
77.	Help performing work or other daily activities becau emotional problems									🗆									
78.	Help accomplishing what I would like to because of health									🗖									
79.	Help accomplishing what I would like to because of health					_ [🗆									
Pat	tient Care and Support																		
80.	Reassurance by medical staff that the way I feel is r	normal								🗆									
81.	Health care providers to acknowledge and show semy feelings and emotional needs									🗖									
82.	To be able to see the specialists I need/want to see									🗖									
83.	To secure more timely clinic appointments									🗖									
84.	Someone to respond to my requests for medical he	lp								🗆									
85.	More say in decisions about my medical treatment.									🗖									
	To know that the medical staff is being honest																		
	To know who to call if I have questions									· · · · □									
	To know how to ask my physician to provide me wit options																		
89.	To have my physician understand my points of view	/								🗆									

		Mark the r describes you feel th met.	the o	exte	nt to	whic	ch		Mark the response that best describes whether or not you have needed help with this matter. If you had SON was this need to was this need to was the needed									d within				
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90.	My physician to have more confidence in my ability changes that are good for my health				_						_											
Q1	My physician to be more accepting of me									_								_		•		
	My physician to help me understand how to reduce		Ш	ш						🗖								_				
JZ.	effects risks									🗖										ı		
93.	My physician to encourage me to ask questions																					
94.	To have more trust in my physician									🗖										ı		
95.	My physician to answer my questions fully and care	fully								🗖										ı		
96.	My physician to listen to how I would like to do thing	js								🗖										ı		
97.	My physician to care about me as a person																			ı		
98.	My physician to understand how I see things before																					
00	suggesting a new way to do things												_									
99.	To share my reenings with my physician		Ш	ш	ш					· · · Ц										l		
Sex	cuality																					
	. Help with changes in sexual feelings									🗖												
101	. Help with changes in sexual relationships									🗖										ı		
102	. Information about sexual relationships									🗖												
103	. Counseling related to sexuality or intimacy									🗖										i		
104	. Help with sexual dysfunction																			ı		
105	. Information about how cancer treatment may affect sexual health	•								_							_					
106	. Help dealing with concerns about my ability to part	ticipate in																				
	sexual activity									🗖												

		Mark the r describes you feel th met.	the e	xtent	to w	hich		Mark the res describes wh have needed matter.	nether	or not y	/ou		If you had SOME NEED , was this need within				
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	reillance																
107.	Information about what screening tests I need base treatment history	•			J C	1 0			1 🗆		П						
108.	Information about how I will feel during screening to				1 -			<u>L</u>	. ப		_						
	bone scans, echo)] [] 🗆								
109.	Information on how to prepare for screening tests.] [] [] 🗆								
110.	Information about how I will feel after screening tes	ts] [] [
111.	Information about how screening tests are performed	ed] [] [
112.	Information about why screening tests need to be p	erformed.] [] [
113.	Information about which tests will help detect late e treatment				J C] [
114.	Help with responsibilities so that I can participate in recommended health screenings				. .												
115.	Realistic information about how much time screenii will take	0			. .	ı 🗆] [
Сор	ing																
116.	Help with body image issues				. .												
117.	Help adjusting to changes in my body				J C] [
118.	Help dealing with changes in how I feel as a man o	r woman.			. .] [
119.	The opportunity to talk to someone who understand has been through a similar experience				J C] [
120.	To talk to other people about cancer				3 C	o 0] [
121.	Emotional support																
122.	Help coping with the unpredictability of the future				. .] 🗆] [

	с У	Mark the response that be describes the extent to wh you feel the need should be met.				whi	ch		Mark the response that best describes whether or not you have needed help with this matter.					If you had SOME NEED , was this need within						
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l ne	eded:		Αç	gree		П		NO [Need is satisfied				,	4-6 months					
		Strongly Ag	ree			П		NEED \	No	need exists					1-3 me					
123.	Help accepting my disease		 	 -		 -						 				-		 -		
Fina	ncial/Economic																			
124.	Help with concerns about my financial situation																			
125.	Help paying for prescription medications															. 🗖				
126.	Help paying for medical treatments															. 🗖				
127.	Help paying for physician or hospital costs															. 🗆				
128.	Help meeting my basic living expenses															. 🗖				
129.	Help dealing with extra expenses because of cancer	er														. 🗖				
130.	Help dealing with reduced income because of canc	er														. 🗖				
131.	Help paying for medical screenings															. 🗆				
Rela	tionships																			
132.	Help engaging in social activities because of physic or emotional problems															. 🗆				
133.	Someone that I could really talk to																			
134.	Help with feeling alone																			
135.	Help with difficulties with my family or spouse															. 🗖				
136.	Help dealing with changes in other people's attitude behavior toward me.															. 🗖				
137.	Help dealing with increased tension or arguments a	t home														. 🗖				
138.	Help dealing with increased emotional problems at	home																		

))	Mark the response that best describes the extent to which you feel the need should be met.				Mark the response that best describes whether or not you have needed help with this matter.														
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I ne	eded:		Ą	gree				NO [N	Need is satisfied		d			4	-6 mo	nths			
		Strongly Ag	ree					NEED	No ı	need exists	,				1-3 mo	nths				
139.	Help taking part in community activities									<u> </u>]						
140.	Help communicating with friends/relatives]						
141.	Help dealing with difficulty in interacting with friends/relatives		п	П	п	П	П				ιп	П	пг	1		П	П	П		
142.	Help interacting with children																			
143.	Help communicating with partner/spouse]						
144.	Help interacting with partner/spouse]						
145.	Help dealing with overprotection by partner/spouse]						
146.	Others to acknowledge the impact of cancer on my	life]						
147.	To be more reassured by my relatives									· · · · · □]						
148.	To feel more useful within my family]						
149.	Help talking about my health with my family and frie	ends								□]						
Life	Perspective																			
150.	Help dealing with feeling a loss of control over my I	ife]						
	Making decisions about my life																			
152.	Help trying to make my life count]						
153.	Help moving on with my life]						
154.	Help making sense or meaning of my illness									□]						
Serv	vices																			
155.	Infertility treatment/services]						

		describes	Mark the response that best describes the extent to which you feel the need should be met.					describe	e respons es whethe eded hel	er or r	not you	If	If you had SOME NEED , was this need within				
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			Stron	ngly Di	sagre	е	SOME			Mode	rate	SOME NEED		10-1	2 mor	nths	
				Disagr	ee		NEED			Low		MEED		7-9 mc	onths		
I ne	eded:		Ag	ree			NO [Need is satisfied		ı ı		,	4-6	months			
		Strongly Ag	gree				NEED	No need	exists				1-3 month	ns			
156	Adoption services		_								<u> </u>			<u> </u>	Ţ	<u> </u>	
	Complementary/alternative health care services .																
	•					_											
	Information about camps, retreats		_														
	Child care																
	Legal services.					_											
	Alcohol or drug abuse counseling					_				_							
162.	Internet websites for cancer survivors																
Tran	sportation																
163.	Transportation to and from medical appointments,																
404	screenings																
	Transportation for work or household activities														_		
	More accessible parking at health care center																
	Transportation to do errands and go shopping								🗆 🗆								
167.	Transportation to school or work																
Етр	loyment																
168.	Help keeping my job								🗆 🗆								
169.	Help making the same salary																
170.	Help with difficulty working																
171.	Help with at-work concerns																
172.	Help with being unable to work because of pain				. .												

		describes	Mark the response that best describes the extent to which you feel the need should be met.						Mark the response to describes whether on have needed help water.						If you had SOME NEED , was this need within						
					Don	't Kn	ow	ſ	High				High	>			12 mo	onths			
			Stro	ngly l	Disag	ree		SOME			M	loderat	e	SOME			I 0- 12 m	onths	s		
			ı	Disag	gree			NEED)			L	.ow		NEED		7-9	month	s			
l ne	eded:		Ą	gree		Ш		NO [Need is satisfied		sfied			,	4-	6 mor	1				
		Strongly Ag	aree			Ш		NEED	No ne	ed exists	П				1-3 mon						
Spir	itual Needs					Ш			110 110												
173.	Religious or spiritual counseling		$\dot{\Box}$	Ġ	$\dot{\Box}$	Ċ	Ċ				Ġ	ė ė				Ġ	<u> </u>	ı			
174.	Help exploring spiritual beliefs																				
175.	Help with changes to beliefs																				
176.	Help with difficulties in keeping confidence in Go religion	d or 				_												J 🗆			
Nutr	ition																				
177.	Information about a healthy diet																				
178.	Information about how many servings of fruits ar vegetables to eat per day																	J 🗆			
179.	Information about which fats to cut down or out .									🗆											
180.	Information about which foods are high or low in sugar																	J \square			
181.	Information about the different types of fiber and benefits	their																ı 🗆			
	Information about which foods can reduce or inc chances of getting cancer									□	_							ı 🗆			
183.	Information about supplements such as vitamins herbal products, soy, and plant extracts																	ı 🗆			
Insu	rance																				
184.	Insurance coverage for my medications									🗀											
185.	Insurance coverage for my other medical expens	ses								🗀] [
186.	Help understanding my health insurance coverage	ge																			
187.	Help completing insurance forms																				

Mark the r describes you feel th met.			ktent t	o wh	ich		Mark the response that best describes whether or not you have needed help with this matter.					If you had SOME NEED was this need within					
			Don't Know				High				>			12 mo	nths		
	Strongly Disagree				SOME NEED	Moderate			SOME NEED	10-17 ma			onths	,			
	Disagree							L	.ow				7-9	month	s		
I needed:		Agree		NO S	Need is satisfied				,	4-6	mon	ths					
	Strongly Ag	gree				NEED	No need exists	5				1-3 mont	hs I				
188. Help with payments for care denied by my insurar	nce	ı	' '	'	ı		ı	- 1	1 1	ı			ı	1 1	ı	1	
carrier																	
189. Assistance with disability or social security																	
190. Help obtaining life/travel insurance] 🗆		

To help us better understand the needs of childhood cancer survivors, please answer a few additional questions:

- 1. How well do you think the items in the survey covered the needs of childhood cancer survivors?
 - ☐ Very Well
 - □ Somewhat
 - ☐ Neutral/Don't Know
 - ☐ Fair
 - Not at All

Continue on next page.

If you have experienced a need that was not listed above, please write it in the space below.								
2. To what extent do you feel comfortable answering items about personal problems?								
☐ Very Comfortable								
☐ Somewhat Comfortable								
☐ Neutral								
☐ Somewhat Uncomfortable								
☐ Very Uncomfortable								
Please! Do not mark below this line								
Please: Do not mark below this fine	3253536490							

3.	To what extent do you have a need that you expect will not be met and therefore you do not express it?
	□ Always
	☐ Occasionally
	□ Sometimes
	□ Never
	☐ Don't Know
4.	Please list the five biggest needs you feel you have as a result of having had cancer.

We are always interested in your input in the follow-up study. Use this space for any additional comments you may have:											
Please enter an updated address, phone number, and email in the box below:											
Address											
City		State									
Zip Code	Phone Number		Email								
	•										

When you have completed this questionnaire please return it to us in the enclosed envelope.

Mail to:

LONG-TERM FOLLOW-UP STUDY

St. Jude Children's Research Hospital Department of Epidemiology Mail Stop 735 262 Danny Thomas Place Memphis, TN 38105-3678

Thank you!

