LTFU | Long-Term Follow-Up Study

Help us improve treatment and care of patients and long-term survivors

The LTFU Study has helped improve the lives of patients and long-term survivors around the world. Your help makes this possible. For more than 25 years, survivors have shared their experiences through the LTFU survey.

Survey responses have helped doctors and scientists:

- Know more health problems caused by treatments
- Make changes in treatments to prevent health problems later in life
- Increase awareness about screening and prevention

Your responses will help change lives. Please complete this LTFU survey.

Choose the method that works best for you.

Online

Login to myLTFU: Go to stjude.org/ltfuapp
Activate myLTFU: Go to ltfu.stjude.org/myLTFU
Set up your account using key code

Scan here to access the survey

Phone

Call 1-800-775-2167.

Mail

Mail to us in the prepaid envelope.

Email

Email LTFU@stjude.org

Complete this survey and we will send you a $10 gift card. If you complete an online or phone survey, you will also be entered into a drawing for a smart watch.

Thank you! Your responses make a difference.

St. Jude Children's Research Hospital®

Please! Do not mark below this line

Edit | Survey #330 | Code

4217071653

03/10/2023 08:37:41 AM

Your survey is important.

The more LTFU participants who complete this survey the more accurate our results will be. LTFU's detailed, continuously updated data is what makes it such a powerful research resource. Thanks to you, we know more than ever before about how to:

- Help survivors live healthier lives
- Improve care for children now, and for generations to come

Visit **ltfu.stjude.org** to read about the study's **research results** or to browse a complete list of more than 400 publications since the study began.

Start here!

Today's date:

☐☐ / ☐☐ / ☐☐☐☐
m m d d y y y y

The questions in this survey relate to:

Person completing this survey is:

Your relationship:

☐ Self ☐ Parent ☐ Other: _____

If you are completing the survey on the participant's behalf, be aware that all survey questions are about

Please! Do not mark below this line

6693071653

In the past we have asked you questions similar to those below. We would like to update this information.

A1. What is your current height without shoes?

☐ ☐☐
Feet Inches

A2. What is your current weight without shoes?

☐☐☐
Pounds

A3. Since this time last year, have you lost more than 10 pounds unintentionally (not due to dieting or exercise)?

- ☐ Yes
- ☐ No
- ☐ Not sure

A4. What is your current living arrangement? (Check all that apply)

- ☐ Live with spouse/partner
- ☐ Live with parent(s)
- ☐ Live with roommate(s)
- ☐ Live with brother(s) and/or sister(s)
- ☐ Live with other relative(s) (not including minor children)
- ☐ Live with minor children (<18 years old)
- ☐ Live alone
- ☐ Other

Specify

A5. Which of the following best describes your current marital status?

- ☐ Single, never married or never lived with partner as married
- ☐ Married
- ☐ Living with partner as married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated or no longer living as married

HEALTH AND WELL-BEING

B1. These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please mark the one answer that comes closest to the way you have been feeling. How much of the time during the PAST 4 WEEKS. . .

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	☐	☐	☐	☐	☐
b. Did you have a lot of energy?	☐	☐	☐	☐	☐
c. Did you feel worn out?	☐	☐	☐	☐	☐
d. Did you feel tired?	☐	☐	☐	☐	☐

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

	No	Yes, and the condition is still present	Yes, but the condition is no longer present	Not sure	If yes, age at first occurrence
B2. Weakness or inability to move arm(s)?	☐	☐	☐	☐	☐☐
B3. Weakness or inability to move leg(s)?	☐	☐	☐	☐	☐☐

Please! Do not mark below this line

7916071652

Physical Activity

The following questions are about exercise, recreation, or physical activities other than your regular job duties.

B4. During the past month, did you participate in any physical activities or exercises such as running, aerobics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

☐ No

☐ Yes

We are interested in three types of physical activity: vigorous, moderate, and light.

- **Vigorous activities cause large increases in breathing or heart rate.**
- **Moderate activities cause small increases in breathing or heart rate.**
- **Light activities cause no increase in breathing or heart rate.**

B5. Now thinking about the vigorous physical activities you do in a usual week, do you do vigorous activities for at least 10 minutes at a time, such as running, aerobics, wheelchair basketball, heavy yard work, or anything else that causes large increases in breathing or heart rate?

☐ No → **Go to Question B8.**

☐ Yes

B6. How many days per week do you do these vigorous activities for at least 10 minutes at a time?

☐☐ Days per week

B7. On days when you do vigorous activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

☐☐☐ Minutes per day

B8. Now, thinking about the moderate physical activities you do in a usual week, do you do moderate activities for at least 10 minutes at a time, such as brisk walking, bicycling, gardening, manual operation of a wheelchair, or anything else that causes small increases in breathing or heart rate?

☐ No → **Go to Question B11.**

☐ Yes

B9. How many days per week do you do these moderate activities for at least 10 minutes at a time?

☐☐ Days per week

B10. On days when you do moderate activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

☐☐☐ Minutes per day

B11. Now, thinking about the light physical activities you do in a usual week, do you do light activities for at least 10 minutes at a time, such as a slow casual walk, or anything else that does not cause an increase in your breathing or heart rate?

☐ No → **Go to Question B14.**

☐ Yes

B12. How many days per week do you do these light activities for at least 10 minutes at a time?

☐☐ Days per week

B13. On days when you do light activities for at least 10 minutes at a time, how much total time per day do you spend doing these activities?

☐☐☐ Minutes per day

B14. Over the last 2 years, how long (if at all) has your health limited you in each of the following activities?

(Mark one box for each item.)

	Not limited at all	Limited for 3 months or less	Limited for more than 3 months
a. Walking uphill or climbing a few flights of stairs	☐	☐	☐
b. Eating, dressing, bathing, or using the toilet	☐	☐	☐

Continue on next page.

Please! Do not mark below this line

PROBLEM SOLVING

B15. Please respond to each item by marking one box per row.

	Never	Rarely	Sometimes	Usually	Always
a. I have trouble doing all of my regular leisure activities with others.	☐	☐	☐	☐	☐
b. I have trouble doing all of the family activities that I want to do.	☐	☐	☐	☐	☐
c. I have trouble doing all of my usual work (include work at home).	☐	☐	☐	☐	☐
d. I have trouble doing all of the activities with friends that I want to do.	☐	☐	☐	☐	☐
e. I have to limit the things I do for fun with others.	☐	☐	☐	☐	☐
f. I have to limit my regular activities with friends.	☐	☐	☐	☐	☐
g. I have to limit my regular family activities.	☐	☐	☐	☐	☐
h. I have trouble doing all of the work that is really important to me (include work at home).	☐	☐	☐	☐	☐

B16. Please respond to each question or statement by marking one box per row.

In the <u>past 7 days</u>. . .

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. My mind has been as sharp as usual.	☐	☐	☐	☐	☐
b. My memory has been as good as usual.	☐	☐	☐	☐	☐
c. My thinking has been as fast as usual.	☐	☐	☐	☐	☐
d. I have been able to keep track of what I am doing, even if I am interrupted.	☐	☐	☐	☐	☐

C. Below is a list of statements that describe problems people can have. We would like to know if you have had any of these problems over the <u>PAST 6 MONTHS</u>. Please complete all items. Please think about yourself as you read these statements and mark one response on each line.

	Never a problem	Sometimes a problem	Often a problem
1. I get upset easily	☐	☐	☐
2. It takes me longer to complete my work	☐	☐	☐
3. I am disorganized	☐	☐	☐
4. I forget instructions easily	☐	☐	☐
5. I have problems completing my work	☐	☐	☐
6. I have difficulty recalling things I had previously learned (e.g., names, places, events, activities)	☐	☐	☐
7. I get frustrated easily	☐	☐	☐
8. My mood changes frequently.	☐	☐	☐
9. I have trouble finding things in my bedroom, closet or desk	☐	☐	☐
10. I forget what I am doing in the middle of things	☐	☐	☐
11. I have problems getting started on my own	☐	☐	☐
12. I am easily overwhelmed	☐	☐	☐
13. I have trouble doing more than one thing at a time	☐	☐	☐
14. My desk/workspace is a mess	☐	☐	☐
15. I have trouble remembering things, even for a few minutes (such as directions, phone numbers, etc.)	☐	☐	☐
16. I have trouble prioritizing my activities.	☐	☐	☐
17. I read slowly	☐	☐	☐
18. I am slower than others when completing my work	☐	☐	☐
19. I have trouble solving math problems in my head	☐	☐	☐
20. I don't work well under pressure.	☐	☐	☐
21. I have trouble staying on the same topic when talking	☐	☐	☐
22. I have a messy closet	☐	☐	☐
23. People say I am easily distracted	☐	☐	☐
24. I have angry outbursts	☐	☐	☐
25. I have a short attention span	☐	☐	☐
26. I overreact emotionally	☐	☐	☐
27. I have trouble organizing work	☐	☐	☐
28. I overreact to small problems	☐	☐	☐
29. I have problems organizing activities.	☐	☐	☐
30. I have emotional outbursts for little reason	☐	☐	☐
31. I leave the bathroom a mess	☐	☐	☐
32. I react more emotionally to situations than my friends	☐	☐	☐
33. I leave my room or home a mess	☐	☐	☐

Please! Do not mark below this line

HEALTH CONDITIONS

D. Please indicate whether or not you have any of the following health conditions and the severity of the condition. If you have more than one condition in a category, pick the one that is **most severe**. Name the specific condition you are rating.

	No problem	Mild problem but I do not need medication	Moderate problem, I need daily medication	Severe problem, uncontrolled with medication, or requiring multiple medications	Very severe problem requiring immediate treatment or medical care or significantly limits my daily function
a. **Heart problem** - Examples: chest pain or angina, heart attack or myocardial infarction, abnormal heartbeat or arrhythmia, valve problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
b. **Vascular problem** - Examples: circulatory problems like peripheral artery disease, hypertension (high blood pressure), high cholesterol, vascular surgery/repair for arteries in neck or legs, abdominal aortic aneurysm. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
c. **Blood problem** - Examples: anemia, hypercoagulability (easy clotting), or any other blood problem that affects the spleen or lymphatic system. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
d. **Respiratory problem** - Examples: asthma, emphysema, bronchitis, pulmonary embolism (clot in lungs), lung surgery. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
e. **Eye, ears, nose, throat, larynx** - Examples: glaucoma, cataract, loss of vision, hearing loss, vertigo, dizziness, loss of smell, throat problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
f. **Stomach/digestion** - Examples: heartburn/reflux, swallowing problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
g. **Intestinal problems** - Examples: intestinal hernia, constipation, anal problems, incontinence, colon problems/surgery. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
h. **Liver and pancreas** - Examples: includes gall bladder problems/removal, impaired liver function or infection. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
i. **Kidney** - Examples: kidney infection, poor kidney function, kidney surgery. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
j. **Urinary** - Examples: stones, infection, incontinence, surgery for kidney stones. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
k. **Musculoskeletal** - Examples: arthritis, other joint problems, osteoporosis, carpal tunnel, fibromyalgia, skin problems. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
l. **Neurologic** - Examples: stroke, peripheral neuropathy, headache, cognitive decline. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
m. **Endocrine/metabolic** - Ex.: thyroid problem, obesity, diabetes, hormonal problem. . . . . Name of Most Severe Condition: _____	☐	☐	☐	☐	☐
n. **Psychiatric/behavioral** - Ex.: depression, anxiety, alcohol or drug abuse, eating disorder. Name of Most Severe Condition: _____	☐	☐	☐	☐	☐

Please! Do not mark below this line

MEDICAL CARE

E1. During the PAST 2 YEARS, how many times did you see or talk to the following healthcare providers for medical care?

	None	1-2 times	3-4 times	5-10 times	11-20 times	More than 20 times
a. Primary care doctor in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)	☐	☐	☐	☐	☐	☐
b. Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)	☐	☐	☐	☐	☐	☐
c. Other medical specialist (e.g., endocrinologist, cardiologist, surgeon)	☐	☐	☐	☐	☐	☐
d. Psychiatrist	☐	☐	☐	☐	☐	☐
e. Psychologist or counselor	☐	☐	☐	☐	☐	☐
f. Physical or occupational therapist	☐	☐	☐	☐	☐	☐
g. Alternative health practitioner (e.g., acupuncturist, herbalist, chiropractor)	☐	☐	☐	☐	☐	☐
h. Other specify: _____	☐	☐	☐	☐	☐	☐
i. Other specify: _____	☐	☐	☐	☐	☐	☐

If you had any visits, how many of these visits were related to health problems from your cancer or cancer treatments?

	0 visits	1 - 2 visits	3 - 4 visits	5 - 6 visits	7 - 10 visits	11 - 20 visits	More than 20 visits
a. Primary care doctor in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant)	☐	☐	☐	☐	☐	☐	☐
b. Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist)	☐	☐	☐	☐	☐	☐	☐
c. Other medical specialist (e.g., endocrinologist, cardiologist, surgeon)	☐	☐	☐	☐	☐	☐	☐
d. Psychiatrist	☐	☐	☐	☐	☐	☐	☐
e. Psychologist or counselor	☐	☐	☐	☐	☐	☐	☐
f. Physical or occupational therapist	☐	☐	☐	☐	☐	☐	☐
g. Alternative health practitioner (e.g., acupuncturist, herbalist, chiropractor)	☐	☐	☐	☐	☐	☐	☐
h. Other specify: _____	☐	☐	☐	☐	☐	☐	☐
i. Other specify: _____	☐	☐	☐	☐	☐	☐	☐

E2. When was the LAST TIME you saw a healthcare provider (e.g., doctor, nurse practitioner, physician's assistant) in each of the following locations where the provider asked you questions or examined you to see whether you had any health problems from your cancer or your cancer treatment?

	Less than 1 year ago	1-2 years ago	More than 2 but less than 5 years ago	5 or more years ago	Never
a. At a cancer survivor clinic	☐	☐	☐	☐	☐
b. At a cancer center, but not in a cancer survivor clinic	☐	☐	☐	☐	☐
c. At my primary care doctor's office	☐	☐	☐	☐	☐
d. Other specify: _____	☐	☐	☐	☐	☐
e. Other specify: _____	☐	☐	☐	☐	☐

E3. At your LAST check-up at each of the places in the previous question, did your healthcare provider give you advice about what to do to reduce your risks arising from your cancer or cancer therapy?

	Yes	No	Not sure	Never had a check-up there
a. At a cancer survivor clinic	☐	☐	☐	☐
b. At a cancer center, but not in a cancer survivor clinic	☐	☐	☐	☐
c. At my primary care doctor's office	☐	☐	☐	☐
d. Other specify: _____	☐	☐	☐	☐
e. Other specify: _____	☐	☐	☐	☐

Please! Do not mark below this line

E4. Do you currently have a cancer survivorship care plan and/or a summary of treatment for your cancer (records from your cancer doctor that have details about your cancer treatment and medical tests you should have to check for future health problems)?

- ☐ No
- ☐ Yes
- ☐ Not sure

E5. Does your primary care doctor have a copy of your cancer survivorship care plan and/or a summary of your treatment for your cancer?

- ☐ I do not have a primary care doctor
- ☐ I have a primary care doctor but he/she does not have a copy of my cancer survivorship care plan and/or a summary of my treatment for my cancer
- ☐ Yes
- ☐ Not sure

E6. Are you aware of the Children's Oncology Group screening recommendations for long-term survivors of childhood and adolescent cancers?

- ☐ No
- ☐ Yes
- ☐ Not sure

E7. Have you ever had an infection with the COVID (SARS-CoV-2) virus?

- ☐ No
- ☐ Yes
- ☐ Not sure

a. ***IF YES,*** how old were you when you were *first* infected?

☐☐ Age in Years

b. ***IF YES,*** did you have a positive test for this infection?

☐ No ☐ Yes ☐ Not sure

E8. Have you been vaccinated for COVID?

☐ No ☐ Yes ☐ Not sure

MEDICAL TESTS

F. The following questions are about medical screening tests you may have received.

When was the last time you had . . .

	Never	Less than 1 year ago	1-2 years ago	More than 2 years but less than 5 years ago	5 or more years ago	I had one, but I don't recall when	I don't know if I ever had one
a. An echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or a cardiac MRI?	☐	☐	☐	☐	☐	☐	☐
b. Sigmoidoscopy or colonoscopy to view the colon for signs of cancer or other problems?	☐	☐	☐	☐	☐	☐	☐
c. DNA stool testing for colon cancer (such as Cologuard)?	☐	☐	☐	☐	☐	☐	☐
d. A skin exam for skin cancer performed by a healthcare provider?	☐	☐	☐	☐	☐	☐	☐
For females							
e. A mammogram?	☐	☐	☐	☐	☐	☐	☐
f. A breast ultrasound?	☐	☐	☐	☐	☐	☐	☐
g. A breast MRI?	☐	☐	☐	☐	☐	☐	☐
h. A pap smear and/or cervical HPV test?	☐	☐	☐	☐	☐	☐	☐
For males							
i. A PSA or blood test to detect prostate cancer?	☐	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

EMERGENCY ROOM (ER) VISITS

We are interested in any emergency room (ER) visits that you may have had in the last 2 years.

G1. Have you been to the ER in the last 2 years?

☐ No → **Go to Section H, next page.**

☐ Yes

G2. How many times have you been to the ER in the last 2 years? ☐☐

G3. What was the main reason for the first ER visit?

a. If there were other reasons please list them here.

b. Date of first ER visit:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. Did this ER visit result in being admitted to the hospital?

☐ No

☐ Yes

If you have been to the ER more than once in the last 2 years. . .

G4. What was the main reason for the second ER visit?

a. If there were other reasons please list them here.

b. Date of second ER visit:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. Did this ER visit result in being admitted to the hospital?

☐ No

☐ Yes

Please use a separate sheet of paper for additional ER visits

Please! Do not mark below this line

HOSPITALIZATIONS

We are interested in any admissions to the hospital for illness, surgical, or diagnostic procedures, including psychiatric/mental health hospitalization, day surgery, or short stays of 24 hours or less that you may have had in the last 2 years. DO NOT INCLUDE PREGNANCY RELATED ADMISSIONS or EMERGENCY ROOM VISITS.

H1. Have you been admitted to a hospital in the last 2 years?

☐ No → **Go to Section I, next page.**

☐ Yes

H2. How many times have you been admitted to a hospital in the last 2 years? ☐☐

H3. What was the main reason for the first hospitalization?

a. If there were other reasons please list them here.

b. Date of first hospitalization:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. How long did you stay in the hospital?

☐☐ Days

If you were admitted to the hospital more than once in the last 2 years. . .

H4. What was the main reason for the second hospitalization?

a. If there were other reasons please list them here.

b. Date of second hospitalization:

☐☐ Month (mm) ☐☐☐☐ Year (yyyy)

c. How long did you stay in the hospital?

☐☐ Days

Please use a separate sheet of paper for additional hospitalizations

Please! Do not mark below this line

CANCER, LEUKEMIA, OR TUMOR

I1. Have you been diagnosed with another cancer, leukemia, tumor, skin cancer, or a recurrence (relapse) since you last provided us information in %LastMo%, %LastYr%?

☐ No → **Go to Section J, next page.**

☐ Yes

I2. What was the name of this disease?

I3. Where was it located? (Example: right upper arm, left ear)

I4. Where was this diagnosed?

Doctor's name
Hospital or clinic
Address
City, State, Zip code

I5. Was this a:

☐ Recurrence of original diagnosis

☐ New cancer, leukemia, tumor, or similar illness

☐ Don't know

Date of Recurrence or New Diagnosis:

Month (mm) Year (yyyy)

I6. Have you had more than one additional cancer, leukemia, tumor, or skin cancer since %LastMo%, %LastYr%?

☐ No → **Go to Section J, next page.**

☐ Yes

I7. What was the name of this disease?

I8. Where was it located? (Example: right upper arm, left ear)

I9. Where was this diagnosed?

Doctor's name
Hospital or clinic
Address
City, State, Zip code

I10. Was this a:

☐ Recurrence of original diagnosis

☐ New cancer, leukemia, tumor, or similar illness

☐ Don't know

Date of Recurrence or New Diagnosis:

Month (mm) Year (yyyy)

Please use a separate sheet of paper for additional cancers

Please! Do not mark below this line

ACTIVITIES OF DAILY LIVING

J1. For each of the following, select the description that best describes you. (The word "assistance" means supervision, direction, or personal assistance.)

a. Bathing - either sponge bath; tub bath, or shower

- ☐ I receive no assistance (get in and out of tub by myself if tub is usual means of bathing)
- ☐ I receive assistance in bathing only one part of the body (such as back or a leg)
- ☐ I receive assistance in bathing more than one part of the body (or do not bathe)

b. Dressing - get clothes from closets and drawers - including underclothes, outer garments and using fasteners (including braces if worn)

- ☐ I get clothes and get completely dressed without assistance
- ☐ I get clothes and get dressed without assistance except for assistance in tying shoes
- ☐ I receive assistance in getting clothes or in getting dressed, or stay partly or completely undressed all day

c. Toileting - going to the "toilet room" for bowel and urine elimination; cleaning self after elimination, and arranging clothes

- ☐ I go to "toilet room", clean myself, and arrange my clothes without assistance (may use object for support such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in morning)
- ☐ I receive assistance in going to "toilet room" or in cleaning or in arranging clothes after I am done urinating or having a bowel movement on the toilet or in use of night bedpan or commode
- ☐ I am not able to go to the "toilet room" to urinate or have a bowel movement

d. Transfer

- ☐ I move in and out of my bed as well as in and out of chairs without assistance (may use object for support such as cane or walker)
- ☐ I move in and out of bed or chair with assistance
- ☐ I do not get out of bed

e. Urination and Bowel Movements

- ☐ I control urination and bowel movements completely by myself
- ☐ I have occasional "accidents"
- ☐ I require supervision to keep urine or bowel control; I use a catheter, or I am incontinent

f. Feeding

- ☐ I feed myself without assistance
- ☐ I feed myself except for getting assistance in cutting meat or buttering bread
- ☐ I receive assistance in feeding or am fed partly or completely by using tubes or intravenous fluids

J2. For each category, check the item description that most closely resembles your highest functional level.

a. Ability to Use Telephone

- ☐ I operate the telephone on my own - look up and dial numbers, etc.
- ☐ I dial a few well-known numbers
- ☐ I answer the telephone but do not dial
- ☐ I do not use the telephone at all

b. Shopping

- ☐ I take care of all my shopping needs
- ☐ I shop independently for small purchases
- ☐ I need to be accompanied on any shopping trip
- ☐ I am unable to shop

c. Food Preparation

- ☐ I plan, prepare and serve meals independently
- ☐ I prepare meals if supplied with ingredients
- ☐ I heat and serve prepared meals
- ☐ I need to have meals prepared and served

d. Housekeeping

- ☐ I maintain my house alone or with occasional assistance (e.g., "heavy work domestic help")
- ☐ I perform light daily tasks such as dish washing, bed making
- ☐ I perform light daily tasks but cannot maintain an acceptable level of cleanliness
- ☐ I need help with all home maintenance tasks
- ☐ I do not participate in any housekeeping tasks

e. Laundry

- ☐ I can do personal laundry completely
- ☐ I launder small items - rinse socks, stockings, etc.
- ☐ All my laundry must be done by others

f. Mode of Transportation

- ☐ I travel independently on public transportation or drive my own car
- ☐ I arrange my own travel via taxi, but I do not otherwise use public transportation
- ☐ I travel on public transportation when assisted or accompanied by another
- ☐ My travel is limited to taxi or automobile with assistance of another
- ☐ I do not travel at all

g. Responsibility for Own Medications

- ☐ I am responsible for taking medication in correct dosages at correct time
- ☐ I take responsibility if my medication is prepared in advance in separate dosages (pill box)
- ☐ I am not capable of dispensing own medication

h. Ability to Handle Finances

- ☐ I manage financial matters independently (budgets, write checks, pays rent, bills, goes to bank), collect and keep track of income
- ☐ I manage day-to-day purchases, but I need help with banking, major purchases, etc.
- ☐ I am incapable of handling money

Needs Assessment for Childhood Cancer Survivors

To help better plan 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 columns in this Needs Assessment. Please read the below instructions before starting.

In **Column 1**, indicate whether you have ever 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 UNMET NEED

No Need Existed - This was not a problem for me as a result of having cancer.
Need was Satisfied - I did need help with this, but I found resources to meet the need.
(Note: If "No need existed" or "Need was satisfied" is selected, leave Column 2 blank.)

SOME UNMET NEED

Low need for help - This item caused me little concern or discomfort. I had 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 caused me a lot of concern or discomfort. I had a strong need for additional help.
(Note: If "Low need for help", "Moderate need for help", or "High need for help" is selected, check one of the boxes in Column 2.

In **Column 2**, if you had **SOME UNMET NEED**, mark the response to indicate when you MOST RECENTLY experienced this need.

There are 4 possible choices:
Current need
Within last year
1-2 years ago
More than 2 years ago

K. Mark the response that best describes whether or not you needed help with this matter.

I needed:

Health Care Concerns

	Column 1					Column 2			
	NO UNMET NEED		SOME UNMET NEED			If you had **SOME UNMET NEED**, when did the need **MOST RECENTLY** occur?			
	Need was satisfied	No need existed	Low	Moderate	High	Current need	Within last year	1-2 years ago	More than 2 years ago
1. Information about the important aspects of my after-cancer care.	☐	☐	☐	☐	☐	☐	☐	☐	☐
2. Information about support groups in my area.	☐	☐	☐	☐	☐	☐	☐	☐	☐
3. Help finding out how to access professional counseling (e.g., psychologist, social worker, counselor, nurse specialist) if I/family/friends need it.	☐	☐	☐	☐	☐	☐	☐	☐	☐
4. To be treated like a person not just another case.	☐	☐	☐	☐	☐	☐	☐	☐	☐
5. Choices about when to go in for check-ups.	☐	☐	☐	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

2138071653

Mark the response that best describes whether or not you needed help with this matter.

Column 1

Column 2

If you had **SOME UNMET NEED**, when did the need **MOST RECENTLY** occur?

I needed:

	SOME UNMET NEED				NO UNMET NEED		SOME UNMET NEED				
	High	Moderate	Low		Need was satisfied	No need existed		More than 2 years ago	1-2 years ago	Within last year	Current need
6. One health care provider with whom I could talk about my health.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
7. My doctors to talk to each other to coordinate my care.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
8. Help to know how to give input to my medical team in order to manage my health.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
9. My complaints about my care heard and addressed.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
10. Information about who to call for help.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
Cancer-related Health Information											
11. Information about cancer recurrence.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
12. Information about how cancer affected my body.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
13. Information about what causes cancer.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
14. Information about the late effects of my cancer therapy.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
15. Information about what symptoms to report to the doctor or nurse.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
16. Information about specific diseases that can result from cancer therapy.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
17. Information about what I can do to reduce my chances of developing late effects.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
18. Information about my treatments or medications.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
19. Information about my test results as soon as possible.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
20. Information about which organ systems may have been affected by my cancer treatment.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
21. Information about how cancer will affect my life.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
Survivor Care and Support											
22. Reassurance by medical staff that the way I feel is normal.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
23. Health care providers to acknowledge and show sensitivity to my feelings and emotional needs.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
24. To be able to see the specialists I need/want to see.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
25. To secure more timely clinic appointments.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
26. Someone to respond to my requests for medical help.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐
27. More say in decisions about my medical treatment.	☐	☐	☐	☐	☐	☐		☐	☐	☐	☐

Please! Do not mark below this line

Mark the response that best describes whether or not you needed help with this matter.

Column 1

Column 2

If you had **SOME UNMET NEED**, when did the need **MOST RECENTLY** occur?

SOME UNMET NEED

NO UNMET NEED

I needed:

	Column 1					Column 2			
	Need was satisfied	No need existed	Low	Moderate	High	Within last year	1-2 years ago	More than 2 years ago	Current need
28. To know that the medical staff is being honest.	☐	☐	☐	☐	☐	☐	☐	☐	☐
29. To know who to call if I have questions.	☐	☐	☐	☐	☐	☐	☐	☐	☐
30. To know how to ask my physician to provide me with choices/options.	☐	☐	☐	☐	☐	☐	☐	☐	☐
31. To have my physician understand my points of view.	☐	☐	☐	☐	☐	☐	☐	☐	☐
32. My physician to have more confidence in my ability to make changes that are good for my health.	☐	☐	☐	☐	☐	☐	☐	☐	☐
33. My physician to be more accepting of me.	☐	☐	☐	☐	☐	☐	☐	☐	☐
34. My physician to help me understand how to reduce my late effects risks.	☐	☐	☐	☐	☐	☐	☐	☐	☐
35. My physician to encourage me to ask questions.	☐	☐	☐	☐	☐	☐	☐	☐	☐
36. To have more trust in my physician.	☐	☐	☐	☐	☐	☐	☐	☐	☐
37. My physician to answer my questions fully and carefully.	☐	☐	☐	☐	☐	☐	☐	☐	☐
38. My physician to listen to how I would like to do things.	☐	☐	☐	☐	☐	☐	☐	☐	☐
39. My physician to care about me as a person.	☐	☐	☐	☐	☐	☐	☐	☐	☐
40. My physician to understand how I see things before suggesting a new way to do things.	☐	☐	☐	☐	☐	☐	☐	☐	☐
41. To share my feelings with my physician.	☐	☐	☐	☐	☐	☐	☐	☐	☐
Surveillance									
42. Information about what screening tests I need based on my treatment history.	☐	☐	☐	☐	☐	☐	☐	☐	☐
43. Information about how I will feel during screening tests (e.g., bone scans, echo).	☐	☐	☐	☐	☐	☐	☐	☐	☐
44. Information on how to prepare for screening tests.	☐	☐	☐	☐	☐	☐	☐	☐	☐
45. Information about how I will feel after screening tests.	☐	☐	☐	☐	☐	☐	☐	☐	☐
46. Information about how screening tests are performed.	☐	☐	☐	☐	☐	☐	☐	☐	☐
47. Information about why screening tests need to be performed.	☐	☐	☐	☐	☐	☐	☐	☐	☐
48. Information about which tests will help detect late effects of treatment.	☐	☐	☐	☐	☐	☐	☐	☐	☐
49. Help with responsibilities so that I can participate in the recommended health screenings.	☐	☐	☐	☐	☐	☐	☐	☐	☐
50. Realistic information about how much time screening tests will take.	☐	☐	☐	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

Mark the response that best describes whether or not you needed help with this matter.

I needed:

	Column 1					Column 2			
	SOME UNMET NEED					If you had **SOME UNMET NEED**, when did the need **MOST RECENTLY** occur?			
	NO UNMET NEED								
Financial Concerns	Need was satisfied	No need existed	Low	Moderate	High	SOME UNMET NEED	Within last year	1-2 years ago	More than 2 years ago
51. Help paying for prescription medications.	☐	☐	☐	☐	☐		☐	☐	☐
52. Help paying for medical treatments.	☐	☐	☐	☐	☐		☐	☐	☐
53. Help paying for physician or hospital costs.	☐	☐	☐	☐	☐		☐	☐	☐
54. Help paying for medical screenings.	☐	☐	☐	☐	☐		☐	☐	☐
55. Transportation to and from medical appointments/screenings. . .	☐	☐	☐	☐	☐		☐	☐	☐
56. Insurance coverage for my medications.	☐	☐	☐	☐	☐		☐	☐	☐
57. Insurance coverage for my other medical expenses.	☐	☐	☐	☐	☐		☐	☐	☐
58. Help with payments for care denied by my insurance carrier. . . .	☐	☐	☐	☐	☐		☐	☐	☐

In the future, we would like to send a questionnaire to one of your close family members or friends who could answer some basic questions about any problems you may be having. Sometimes, our family sees some of our struggles before we do. The questions would be very brief, asking about sleep, social activities, physical function, and emotional stress in your life. This person could be a family member, roommate, or anyone else who is familiar with your daily life.

1. Is there someone who could answer these questions about you?

☐ Yes

☐ No → **Continue on next page.**

2. What is this person's relationship to you?

☐ Spouse or Partner ☐ Sibling (brother/sister)

☐ Parent ☐ Friend

☐ In-Law ☐ Other

☐ Child

Specify

3. Please list their name, address, phone number, and preferred email address:

Name: _____

Address: _____

_____

_____

Phone number: _____

Email address: _____

Please! Do not mark below this line

4523071653

4. Do you use a cell phone?

☐ Yes ☐ No → **Skip to Question 5, then continue below to verify or update your contact information.**

4a. Would you be willing to send/receive study-related texts?

☐ Yes ☐ No ☐ My phone is not text capable

Your phone number: (☐☐☐) ☐☐☐ - ☐☐☐☐

5. Which of the following devices do you have access to? ***(Mark all that apply)***

☐ Computer or laptop ☐ Other, specify:

☐ Tablet (iPad or similar)

☐ Smartphone

6. Do you have access to Wi-Fi?

☐ Yes ☐ No

We want to make sure we can stay in touch with you. Please verify or update your contact information.

We have your current address as:

☐ Correct

☐ Not correct (please update below)

☐ Moving. Anticipated move date:
(provide new address below if known)

☐☐ / ☐☐ / ☐☐☐☐
m m d d y y y y

Address:		
City:	State:	Zip code:

How long have you lived at your current address? _____

Please let us know if these phone numbers are still current. Please also provide us with any updated phone numbers below.

Phone number	Current	Not current
	☐	☐
	☐	☐
	☐	☐

Updated phone numbers:

Home phone:	Other phone number:
Cell phone:	

Please let us know if these email addresses are still current. Please also provide us with any updated email addresses below.

Email address	Current	Not current
	☐	☐
	☐	☐
	☐	☐

Updated email addresses:

Email address 1:
Email address 2:

Please provide the name and address of someone who could give us your new address should you move. We will contact this person only if we are unable to reach you.

Name:		
Address:	Relationship to	
City:	State:	Zip code:
Cell phone:	Home phone:	Work phone:

Please! Do not mark below this line

1808071656

HIPAA Authorization Form

If you sign this form, you are giving St. Jude Children's Research Hospital permission to use or disclose (give out) medical information. It will allow St. Jude to get copies of certain parts of your (your child's) medical record that we may need to review, such as treatment history for your (your child's) childhood illness or records for later illnesses.

LONG-TERM FOLLOW-UP STUDY
HIPAA[1] AUTHORIZATION TO USE AND DISCLOSE HEALTH INFORMATION FOR RESEARCH

1. Purpose. As a research participant and at my request, I give Greg Armstrong, M.D., M.S.C.E., and the researcher's staff permission to use and disclose my (my child's) health information for a research project called Long-Term Follow-Up (LTFU) Study.

2. Individual Health Information to be Used or Disclosed. My (My child's) health information that may be used or disclosed for this research may include my (my child's) medical records.

3. Who May Disclose My (My Child's) Health Information? During this study, the researcher and the researcher's staff may get my (my child's) health information from hospitals, clinics, and health care providers who have treated me.

4. Who May Receive My (My Child's) Health Information? The health information disclosed by researchers and information given by me during the research study may be received and used by Greg Armstrong, M.D., M.S.C.E., the researcher's staff, LTFU collaborators, the LTFU Biopathology Center (Columbus, OH), the LTFU Biorepository (Cincinnati, OH), the LTFU Radiation Physics Center (Houston, TX), and the LTFU Statistical Center (Seattle, WA).

5. Right to Refuse to Sign this Authorization. I do not have to sign this form. If I decide not to sign the form, I may not be allowed to take part in this study. However, my decision not to sign this form will not affect any other treatment, payment, or enrollment in health plans or eligibility for benefits.

6. Right to Revoke. I can change my mind and revoke (take back) this authorization (permission) at any time by sending a written notice of my decision to Dr. Greg Armstrong, St. Jude Children's Research Hospital, Department of Epidemiology and Cancer Control, 262 Danny Thomas Place, Memphis, TN 38105. If I take back my permission, the researcher may use and disclose only the protected health information already collected for the research study. No further health information about me will be collected by the researcher or disclosed to the researcher for this study.

7. Possible Re-disclosure. After my (my child's) health information is given out under this authorization form, there is a chance that it might be re-disclosed outside this study and no longer covered by this form. However, I understand that the research team and the St. Jude Institutional Review Board (IRB) are very careful to protect my (my child's) privacy and limit the use of information that can identify me (my child). (The IRB is the committee that reviews studies to be sure that the rights and safety of those taking part in the study are protected). In addition, the LTFU study maintains a Certificate of Confidentiality from the National Institute of Health to protect the identity of research subjects.

For those taking part in the research study who are not legal adults, this authorization form will expire when they become legal adults (unless the person taking part in the study has appointed a legal guardian to provide authorization). A new form will be required when the child becomes a legal adult. For a legal adult taking part in this study, this authorization (permission) expires at the end of the study.

I am the research participant, or I am legally authorized to act on behalf of the person taking part in the study.

I have read this information and have received a copy of the form.

Printed name of research participant _____ Date of birth _____

Signature of research participant or legal guardian _____ Date _____

Printed name of legal guardian _____

Describe how the person signing has authority to act on behalf of the research participant _____

[1] HIPAA is the Health Insurance Portability and Accountability Act of 1996, a federal law related to privacy of health information.

Please! Do not mark below this line

5159071659

Thank you for completing your survey!

As a small token of our appreciation, we will send you a $10 Amazon gift code after we receive your completed survey. Some participants have mentioned that they do not want the gift code because they want to donate it to the study. Please check the box below if you *do not* want a gift code. Otherwise, it is our pleasure to send you this as a "thank you."

☐ Please donate my $10 gift code to the LTFU Study *(optional)*

Important new study opportunity:

To advance this critically important research, we will contact you in the next month to ask you to complete new online cognitive tests. This will be our first direct measurement of key areas of attention and memory.

The online tests will involve game-like activities that take about 20 minutes and we will send you a $10 gift code when you are done. If you do not have a computer, don't worry, we will loan you one to use.

If you are interested in learning more, please feel free to send us an email at **LTFU@stjude.org** or call us toll free at 800-775-2167. Otherwise, we will send you more information in the near future.

Questions or comments?

We want to know what you think! You can write to us, or contact us by:

- Phone **1-800-775-2167**
- Email **LTFU@stjude.org**
- Online **ltfu.stjude.org**

Please! Do not mark below this line

4860071657