LTFU

Long-Term Follow-Up Study

Health Insurance Survey

St. Jude Children's Research Hospital
Children's Healthcare of Atlanta/Emory University
Children's Hospital at Stanford
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 Memorial Hospital
Children's National Medical Center
City of Hope National Medical Center
Cook Children's Hematology-Oncology Center
Dana-Farber Cancer Institute/ Children's Hospital Boston
Mattel Children's Hospital at UCLA
Mayo Clinic
Memorial Sloan-Kettering Cancer Center
Miller Children's Hospital
Nationwide 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 Chicago Comer Children's Hospital
University of Michigan - Mott Children's Hospital
University of Minnesota
U.T.M.D. Anderson Cancer Center

Our mailing address is:
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

Toll-free phone number:
1-800-775-2167

e-mail: LTFU@stjude.org
ltfu.stjude.org

Currently Insured Persons

The following questions are for currently insured persons. If you currently do not have health insurance, please fill out the yellow survey.

You can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

Do you currently have health insurance that covers doctor and hospital care?

☐ Yes → *If Yes, please proceed to Question 1 on the next page.*

☐ No → *If No, please stop and complete the Yellow survey.*

Today's date: ☐☐ / ☐☐ / ☐☐☐☐
M M D D Y Y Y Y

Please! Do not mark below this line

Survey #101

7460470301

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. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box. (Example: ☒ Yes ☐ No ☐ Not sure)
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

Grape

INCORRECT

CURRENTLY INSURED PERSONS

CURRENT COVERAGE AND COVERAGE HISTORY

1. Health insurance plans are usually obtained in one person's name, even if other family members are covered. This person is called the policy holder. Who is the policy holder for your primary health insurance plan? *Please mark one of the following:*

☐ Self ☐ Other (Specify): _____

☐ Spouse/partner ☐ Don't know

☐ Parent

2. What kind of health insurance coverage do you have now? *Please mark all that apply.*

☐ Employer-sponsored insurance (through a policy offered by a place of employment)

☐ Individual insurance (through a policy purchased by you/your policy holder)

☐ Medicare

☐ Medicaid/state public insurance program

☐ Other state or local government or community program

☐ Military health care (Tricare/VA/Champ-VA)

☐ Don't know

☐ Other

If Other, please specify:

3. As an adult, have you ever been covered by your state's Medicaid/public insurance?

☐ Yes

☐ No

☐ Don't know

4. Have you ever been denied any of the following types of coverage because of your health history?

	Yes	No	Don't know
a. Health insurance	☐	☐	☐
b. Dental insurance	☐	☐	☐
c. Vision insurance	☐	☐	☐

5. In the past 2 years, have you had difficulty in obtaining health insurance because of your health history?

☐ Yes

☐ No

☐ Don't know

6. Was there any time in the past 2 years when you were completely without any health insurance coverage?

☐ Yes

☐ No

☐ Don't know

Please! Do not mark below this line

CURRENT EMPLOYMENT

7. What is your current employment status?
Please mark all that apply.

- ☐ Employed (full-time or part-time)
  - → 7a. How many hours per week do you work at your main job? ☐☐☐
  - → 7b. How many hours per week do you work at additional job(s)? ☐☐☐
- ☐ Caring for home or family (not currently employed and not looking for paid work)
- ☐ Unemployed and looking for work
- ☐ Unable to work due to illness or disability
- ☐ Retired
- ☐ Student
- ☐ Other

Please skip to Question 11.

If Other, please specify:

8. Are you self-employed?

- ☐ Yes
- ☐ No

9. Including yourself, about how many people work for your employer?

- ☐ 1
- ☐ 2-14
- ☐ 15-50
- ☐ 51-100
- ☐ Over 100
- ☐ Don't know

10. Do you currently have health insurance coverage through your employer?

- ☐ Yes → ***Please skip to Question 11.***
- ☐ No

10a. Why don't you have coverage through your employer? ***Please mark all that apply.***

- ☐ I'm not eligible because I don't work enough hours.
- ☐ I'm not eligible because I haven't worked there long enough.
- ☐ I'm not eligible because I am a temporary employee or contract worker.
- ☐ My employer does not provide health insurance to its employees.
- ☐ The cost is too high.
- ☐ I have insurance through a family member.
- ☐ I used up available benefits.
- ☐ Other

If Other, please specify:

Some U.S. programs provide assistance to people with long-term disabilities. Supplemental Security Income provides income assistance, and Social Security Disability Insurance provides disability benefits and Medicare coverage for persons under age 65.

11. Please indicate whether you currently receive Supplemental Security Income (SSI).

- ☐ Yes, I currently receive Supplemental Security Income
- ☐ No, but I used to receive it
- ☐ No, and I have never received it
- ☐ Don't know

Please skip to Question 12.

11a. *IF YES,* do concerns about losing your SSI assistance prevent you from working or working more hours?

- ☐ Yes
- ☐ No

Please! Do not mark below this line

12. Have you ever applied for SSI in the past and been denied?

- ☐ Yes
- ☐ No
- ☐ Don't know

13. Please indicate whether you currently receive Social Security Disability Insurance (SSDI).

- ☐ Yes, I currently receive Social Security Disability Insurance
- ☐ No, but I used to receive it
- ☐ No, and I have never received it
- ☐ Don't know

Please skip to Question 14.

13a. *IF YES,* do concerns about losing your SSDI assistance prevent you from working or working more hours?

- ☐ Yes
- ☐ No

14. Have you ever applied for SSDI in the past and been denied?

- ☐ Yes
- ☐ No
- ☐ Don't know

15. When you were first thinking about the type of work you wanted to do (e.g., career choice, field of work), did the ability to get health insurance coverage affect your decision?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Not applicable - I have never worked

16. Have you ever decided to stay in a job rather than take a new job in order to keep health insurance coverage?

- ☐ Yes → **16a. Did this happen within the past 2 years?** ☐ Yes ☐ No
- ☐ No
- ☐ Don't know
- ☐ Not applicable - I have never worked or have never changed jobs

HEALTH CARE UTILIZATION

17. During the past year, which of the following health care providers did you see or talk to for medical care? This includes routine care and sick care.
Please mark all that apply.

- ☐ None → *Please skip to Question 19.*
- ☐ Primary care physician
- ☐ Specialty care physician (e.g., cardiologist)
- ☐ Provider who sees cancer survivors for routine follow-up care (e.g., survivorship clinic)
- ☐ Nurse Practitioner/Physician's Assistant
- ☐ Nurse
- ☐ Chiropractor
- ☐ Physical therapist/Occupational therapist/Speech-language pathologist/Audiologist
- ☐ Dentist
- ☐ Eye doctor
- ☐ Mental health care professional
- ☐ Other

If Other, please specify:

18. During the past year, how many times did you see the following health care providers?
If you have not seen any of the following health care providers, go to Question 19.

Primary care physician . . . . . ☐☐ times

Specialty care physician . . . . . ☐☐ times

Provider who sees cancer survivors for routine follow-up care (e.g. survivorship clinic) . . . . . ☐☐ times

Nurse Practitioner/Physician's Assistant . . ☐☐ times

18a. As you know, you were asked to participate in this study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of these times were related to this previous illness?

☐☐ times

☐ Not applicable, I am a LTFU sibling participant.

Please! Do not mark below this line

19. During the past year, how many times were you hospitalized (stayed in the hospital overnight for one or more days)?
If zero times, go to question 20.

☐☐ times

19a. How many of these hospitalizations were related to this previous illness?

☐☐ hospitalizations

☐ Not applicable, I am a LTFU sibling participant.

COVERAGE QUALITY

20. Overall, how would you rate your current health insurance coverage?

☐ Excellent ☐ Fair
☐ Very good ☐ Poor
☐ Good ☐ Don't know

21. Do you currently have insurance that covers most, some or none of the following types of services?

	Most	Some	None	Don't know
a. Medical care	☐	☐	☐	☐
b. Dental care	☐	☐	☐	☐
c. Vision care	☐	☐	☐	☐
d. Mental health care	☐	☐	☐	☐
e. Prescription medication	☐	☐	☐	☐

22. Which of the following best describes your current health insurance plan:

☐ I can see any physician I want, and if he/she is out-of-network I have the same co-pay
☐ I can see any physician I want, but if he/she is out-of-network I have a higher co-pay
☐ I can only see physicians who are within my insurance network
☐ I don't know

23. Do you need a referral from your primary care provider to see a specialist?

☐ Yes ☐ No ☐ Don't know

24. In the past year, were you able to get most of the medical care that you needed?

☐ Yes ☐ No ☐ Don't know

25. In the past year, did a health care provider or hospital not accept your insurance that covers your:

	Yes	No	Don't know	Not applicable, did not have coverage in the past year
a. Medical care	☐	☐	☐	☐
b. Dental care	☐	☐	☐	☐
c. Vision care	☐	☐	☐	☐
d. Mental health care	☐	☐	☐	☐

26. How many people (including you) are covered on your current health insurance plan?

☐☐

The next two questions ask about how much was spent on your medical care in the past year to cover people on this plan. Please answer as best you can.

27. During the past year, about how much did you/your family spend on health insurance premiums?

$ ____,____

28. During the past year, about how much did you/your family spend out-of-pocket for your medical care? Include out-of-pocket expenses for prescription drugs, co-payments, and deductibles, but do not include health insurance premiums or any costs paid by your health insurance.

$ ____,____

29. In the past year, have you/your family had any problems paying your medical bills?

☐ Yes
☐ No
☐ Don't know

Please! Do not mark below this line

30. In the past year, was there a time when you did any of the following because you were worried about the cost?

	Yes	No	Don't know
a. Skipped a medical test, treatment, or follow-up that was recommended by a health care provider	☐	☐	☐
b. Had a medical problem but did not go to a health care provider or a clinic	☐	☐	☐
c. Did not see a specialist when you or your health care provider thought you needed one	☐	☐	☐
d. Put off or postponed preventive care	☐	☐	☐
e. Put off or postponed dental care	☐	☐	☐
f. Put off or postponed vision care	☐	☐	☐
g. Put off or postponed mental health care	☐	☐	☐
h. Had no primary care provider	☐	☐	☐
i. Did not fill a prescription for a medicine	☐	☐	☐
j. Took a smaller dose or fewer pills than was prescribed	☐	☐	☐

31. In the past year, have any of the following happened because of medical expenses?

	Yes	No	Don't know
a. Put off major purchases, such as a new home or car	☐	☐	☐
b. Been unable to pay for basic necessities like food, heat, or rent	☐	☐	☐
c. Had to take money out of savings	☐	☐	☐
d. Spent more than 10% of your income on medical expenses	☐	☐	☐
e. Had to borrow money	☐	☐	☐
f. Took on credit card debt	☐	☐	☐
g. Took out a mortgage against your home or took out a loan	☐	☐	☐
h. Thought about filing for bankruptcy.	☐	☐	☐
i. Filed for bankruptcy	☐	☐	☐

32. In the past year, how much did you worry that:

	A great deal	A fair amount	A little	Not at all
a. You or your spouse would lose your job.	☐	☐	☐	☐
b. A change in job or school would result in loss of or lower quality health insurance coverage	☐	☐	☐	☐
c. You wouldn't be able to pay for medical bills	☐	☐	☐	☐
d. You wouldn't be able to get a medical procedure that you needed	☐	☐	☐	☐
e. You wouldn't be able to go to the health care providers you wanted	☐	☐	☐	☐
f. Health insurance would become so expensive you wouldn't be able to afford it	☐	☐	☐	☐
g. Your health insurance plan would change terms (e.g., costs that were once covered will no longer be covered)	☐	☐	☐	☐
h. You would need some health care services that were not covered	☐	☐	☐	☐

HEALTH CARE REFORM ACT AND INSURANCE-RELATED BENEFITS AND PROTECTIONS

In March 2010, the Affordable Care Act was signed into law. The following questions will ask you about your familiarity with and opinions on this law as well as priorities and willingness to pay for future coverage.

33. Please rate how familiar you are with the health insurance-related benefits and protections that will be available under the new health care reform law:

- ☐ Very familiar
- ☐ Somewhat familiar
- ☐ Not too familiar
- ☐ Not at all familiar

Please! Do not mark below this line

34. Do you think that the new health care reform law will make it more likely or less likely that someone with your health history will be able to get quality health insurance coverage?

- ☐ More likely
- ☐ No change
- ☐ Less likely
- ☐ Don't know

35. What is the most you would be willing to pay each month for health insurance coverage?

$ ___,___,___ per month for an individual policy

$ ___,___,___ per month for a family policy

36. Think about your ideal health insurance plan. Please rate how important each of the following health insurance features are for you:

	Very important	Somewhat important	Not too important	Not at all important
a. Coverage for primary care	☐	☐	☐	☐
b. Coverage for acute, cancer-specific care (e.g., cancer recurrence or new cancer)	☐	☐	☐	☐
c. Coverage for acute, non-cancer-specific care (e.g., emergency room visits)	☐	☐	☐	☐
d. Coverage for mental health care	☐	☐	☐	☐
e. Coverage for dental care	☐	☐	☐	☐
f. Coverage for vision care	☐	☐	☐	☐
g. Choice of your primary care physician	☐	☐	☐	☐
h. Ability to self-refer to a specialist	☐	☐	☐	☐
i. Low deductible (i.e., the money you pay before insurance starts to make payments for covered medical services)	☐	☐	☐	☐
j. Low co-pay (i.e., the money you pay each time you get a medical service)	☐	☐	☐	☐
k. Affordable premiums (i.e., the money you pay to have coverage, usually paid monthly)	☐	☐	☐	☐
l. No coverage limits (lifetime or annual)	☐	☐	☐	☐
m. No added expense due to pre-existing conditions	☐	☐	☐	☐
n. No waiting period before coverage begins	☐	☐	☐	☐

37. Do you have any concerns about the health insurance-related benefits and protections that will be available under the new health care reform law?

- ☐ Yes
- ☐ No
- ☐ Don't know

If Yes, please specify:

38. Do you feel hopeful about the health insurance-related benefits and protections that will be available under the new health care reform law?

- ☐ Yes
- ☐ No
- ☐ Don't know

If Yes, please describe reasons for feeling hopeful:

Now we would like to ask you about health insurance-related benefits and protections.

39. Please rate how familiar you are with the health insurance-related benefits and protections available under:

	Very familiar	Somewhat familiar	Not too familiar	Not at all familiar
a. Consolidated Omnibus Budget Reconciliation Act (COBRA)	☐	☐	☐	☐
b. Family and Medical Leave Act (FMLA)	☐	☐	☐	☐
c. Health Insurance Portability and Accountability Act (HIPAA)	☐	☐	☐	☐
d. Americans with Disabilities Act (ADA)	☐	☐	☐	☐

Please! Do not mark below this line

EDUCATIONAL PROGRAM

We are thinking about designing an educational program to help childhood cancer survivors learn more about health insurance coverage.
If you are a LTFU sibling participant, please skip to Ouestion 43.

40. How interested would you be in a program to help childhood cancer survivors learn more about health insurance coverage? Please mark on a 0 to 10 scale, with 0 being "not at all interested" and 10 being "very interested."

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Not at all interested — Very interested

41. What kind of information would <u>you</u> want to learn about? *Please mark all that apply.*

- ☐ General education about health insurance coverage (e.g., premiums, exclusions).
- ☐ Resources about available health insurance plans and their characteristics.
- ☐ Resources about health insurance benefits, protections, and legal rights/services.
- ☐ Childhood cancer-specific preventive care
- ☐ Other childhood survivors' health insurance experiences.
- ☐ How to find health care providers with experience treating survivors.
- ☐ How to negotiate with your insurer (e.g., getting services covered, making an appeal).

Please write in any other ideas or comments that you have about this program:

42. How would you want this program to be delivered? *Please mark up to 3.*

- ☐ In-person → Would you prefer an individual or group format? ***Please mark only 1.***
  - ☐ Individual
  - ☐ Group
- ☐ Print materials
- ☐ Telephone
- ☐ Website
- ☐ Webinar
- ☐ DVD
- ☐ Other

If Other, please specify:

BACKGROUND

43. Which of the following best describes your <u>current</u> 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

44. Over the last year, what was the total income of the <u>household</u> you live in (family members only)?

- ☐ Less than $20,000
- ☐ $20,000-$39,999
- ☐ $40,000-$59,999
- ☐ $60,000-$79,999
- ☐ $80,000-$99,999
- ☐ $100,000 and over
- ☐ Don't know

45. During the past year, how many family members in this household were supported on this income?

☐☐ family members including yourself

46. Over the last year, what was <u>your</u> personal income?

- ☐ None
- ☐ $1-$9,999
- ☐ $10,000-$19,999
- ☐ $20,000-$39,999
- ☐ $40,000-$59,999
- ☐ $60,000-$79,999
- ☐ $80,000-$99,999
- ☐ $100,000 and over
- ☐ Don't know

Please! Do not mark below this line