

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

Currently Uninsured Persons

The following questions are for currently uninsured persons. If you currently have health insurance, please fill out the green 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 stop and complete the Green survey.**
- No → **If No, please proceed to Question 1 on the next page.**

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

Today's date:

□	□	/	□	□	/	□	□	□	□
M	M		D	D		Y	Y	Y	Y

Please! Do not mark below this line

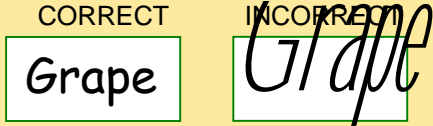
Survey #102

0786406090

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:



CURRENTLY UNINSURED PERSONS

COVERAGE HISTORY

1. How long has it been since you last had health insurance coverage?

- I have never had health insurance coverage. → Skip to Question 6.
- Less than 6 months
- 6 months to 1 year
- More than 1 year to less than 3 years
- 3 or more years
- Don't know

2. 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 was the policy holder for your primary health insurance plan for your most recent coverage?

Please mark one of the following:

- Self
- Spouse/partner
- Parent
- Other (Specify): _____
- Don't know

3. What kind of health insurance coverage did you most recently have? *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:

4. What are the reasons you do not have health insurance? *Please mark all that apply.*

- Lost job or changed employers
- Got divorced or separated
- Became ineligible because of age/left school
- Employer stopped offering coverage
- Cut back to part-time/became temporary employee or contract worker
- Could no longer afford it
- Lost public insurance coverage
- Didn't want or need insurance
- Other

If Other, please specify:

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

- Yes
- No
- Don't know

6. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dental insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Vision insurance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

- Yes
- No
- Don't know

CURRENT EMPLOYMENT

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

- Employed (full-time or part-time)
 - ➔ 8a. How many hours per week do you work at your main job?
 - ➔ 8b. 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 12.

If Other, please specify:

9. Are you self-employed?

- Yes No

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

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

11. 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 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.

12. 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 13.

12a. **IF YES**, do concerns about losing your SSI assistance prevent you from working or working more hours?

- Yes No

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

- Yes
- No
- Don't know

14. 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 15.

14a. **IF YES**, do concerns about losing your SSDI assistance prevent you from working or working more hours?

- Yes No

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

- Yes
- No
- Don't know

16. 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

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

- Yes
- No
- Don't know
- Not applicable - I have never worked or had to change jobs

17a. Did this happen within the past 2 years?
 Yes No

HEALTH CARE UTILIZATION

18. 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
- 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:

19. 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 20.

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

19a. 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.

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

times

20a. How many of these hospitalizations were related to this previous illness?

hospitalizations Not applicable, I am a LTFU sibling participant.

COVERAGE QUALITY

For the following questions, please consider your most recent coverage. If you never had health insurance coverage, please skip to Question 25.

21. Thinking about your most recent coverage, how would you describe it?

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

22. Did you have insurance that covered most, some or none of the following types of services?

	Most	Some	None	Don't know
a. Medical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Dental care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Vision care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Mental health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Prescription medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. Which of the following best describes your last health insurance plan:

- I could see any physician I wanted, and if he/she was out-of-network I had the same co-pay
- I could see any physician I wanted, but if he/she was out-of-network I had a higher co-pay
- I could only see physicians who were within my insurance network
- I don't know

24. Did you need a referral from your primary care provider to see a specialist?

- Yes
- No
- Don't know

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

- Yes
- No
- Don't know

The next question asks about how much was spent on your medical care in the past year. Please answer as best you can.

26. During the past year, about how much did you/your family spend out-of-pocket for your medical care?

\$ _____, _____

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

- Yes No Don't know

28. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Had a medical problem but did not go to a health care provider or a clinic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Did not see a specialist when you or your health care provider thought you needed one	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Put off or postponed preventive care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Put off or postponed dental care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Put off or postponed vision care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Put off or postponed mental health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Had no primary care provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Did not fill a prescription for a medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Took a smaller dose or fewer pills than was prescribed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Been unable to pay for basic necessities like food, heat, or rent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Had to take money out of savings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Spent more than 10% of your income on medical expenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Had to borrow money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Took on credit card debt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Took out a mortgage against your home or took out a loan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Thought about filing for bankruptcy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Filed for bankruptcy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

30. 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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. You wouldn't be able to pay for medical bills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You wouldn't be able to get a medical procedure that you needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. You wouldn't be able to go to the health care providers you wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.

31. 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

Continue on next page.

32. 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

33. 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

34. 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Coverage for acute, cancer-specific care (e.g., cancer recurrence or new cancer) .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Coverage for acute, non-cancer-specific care (e.g., emergency room visits)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Coverage for mental health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Coverage for dental care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Coverage for vision care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Choice of your primary care physician . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Ability to self-refer to a specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Low deductible (i.e., the money you pay before insurance starts to make payments for covered medical services) .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Low co-pay (i.e., the money you pay each time you get a medical service) . . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Affordable premiums (i.e., the money you pay to have coverage, usually paid monthly)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. No coverage limits (lifetime or annual). . .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m. No added expense due to pre-existing conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n. No waiting period before coverage begins	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. 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:

36. 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.

37. 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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Family and Medical Leave Act (FMLA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Health Insurance Portability and Accountability Act (HIPAA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Americans with Disabilities Act (ADA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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 Question 41.*

38. 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

39. What kind of information would you 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:

40. 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.*
- Print materials
- Telephone Individual
- Website Group
- Webinar
- DVD
- Other

If Other, please specify:

BACKGROUND

41. 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

42. Over the last year, what was the total income of the household you live in (family members only)?

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

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

family members including yourself

44. Over the last year, what was your personal income?

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