



ADOLESCENT AND **Y**OUNG **A**DULT
HEALTH **O**UTCOMES AND **P**ATIENT **E**XPERIENCE
SURVEY

CONDUCTED BY:



U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES
National Institutes of Health

WITH SUPPORT FROM:



AYA HOPE: Adolescent and Young Adult Health Outcomes and Patient Experience Survey

Thank you for participating in the Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Survey. The survey is about your experiences with the medical care you receive in the first year following your cancer diagnosis and how your cancer has influenced different areas of your life. Survey results will be used to help improve medical care and support services for cancer patients like you.

The survey should take about 15 minutes to complete. There are no right or wrong answers, so please choose the survey responses that best describe your own situation. There is additional space at the end of the survey should you wish to provide more information about your medical care or experience with cancer.

This survey is designed for people of different ages (including adolescents and young adults between the ages of 15 and 41). Please answer the best you can and feel free to ask a parent or guardian for assistance if you need it. We encourage you to answer all of the questions so that we can best understand your experiences, however you are free to skip any question you do not wish to answer.

Survey Instructions

This information will help you answer the AYA HOPE Survey questions.

- ◆ To answer the questions that apply to you, please mark the box next to your answer choice. The examples show you how.
- ◆ Be sure to read all the answer choices before marking your answer.
- ◆ Arrows show you how to move through the survey. Sometimes you will see an arrow with a note that tells you what question to answer next. And some arrows simply point to the next question. You are sometimes told to skip over some questions in this survey. See the example below.

1a. Have you ever answered a mail survey questionnaire before?

No → GO TO QUESTION 2

Yes →

1b. When was the last time you answered a mail survey questionnaire?

1-5 months ago

6-12 months ago

More than 12 months ago

2. Have you ever answered a telephone survey questionnaire before?

No

Yes



Before taking the *AYA HOPE Survey*, please complete the Health Care Utilization Form that was included in your survey packet.

Your Personal Characteristics

1. What is your date of birth?

MM

DD

YYYY

2. What is the highest level of education you have completed?

- 1 Grade school – between 1 and 8 years
- 2 Some high school
- 3 Completed high school (graduate or GED) - 12 years
- 4 Some college, vocational or training school
- 5 Associate Degree – (e.g., A.A. or A.D. degree)
- 6 College graduate – (e.g., B.A. or B.S. degree)
- 7 Post-graduate education – (e.g., M.A., M.S., J.D., M.D., Ph.D.)

3. Do you consider yourself to be:

- 1 Hispanic or Latino?
- 0 NOT Hispanic or Latino?

4. Which of the following describes your race?

MARK ALL THAT APPLY.

- White
- Black or African American
- Asian
- American Indian or Alaska Native
- Native Hawaiian/Other Pacific Islander
- Other (please describe in the box below)

5. **What was your school/employment status right before you were diagnosed with cancer?**
MARK ALL THAT APPLY.

- Part-time student
- Full-time student
- Working part-time
- Working full-time
- Unemployed
- Full-time homemaker or family caregiver
- Other (please describe in the box below)

6. **How did your school/employment status change because of your cancer or its treatment?**
MARK ALL THAT APPLY.

- It has not changed because of my cancer or its treatment
- I quit working completely
- I quit going to school completely
- I changed my work status from full-time to part-time
- I changed my school status from full-time to part-time
- I took more than 2 weeks total time off from work
- I took more than 2 weeks total time off from school
- Other (please describe in the box below)

7. **Do you currently live alone or with others?**

- 1 Live alone
- 2 Live with others (e.g., parent, roommate, spouse/partner, brother, sister, children)

8. **What is your current marital status?**

- 1 Single (never married)
- 2 Married or living as married
- 3 Divorced
- 4 Separated
- 5 Widowed

9. Are you now responsible for raising any children under the age of 18?

- No
 Yes

10. Have any of the following people provided major support to you since your cancer diagnosis?
MARK ALL THAT APPLY.

- Your Mother
 Your Father
 Your Sister
 Your Brother
 Your Friend
 Your Spouse or Significant Other
 Your Boyfriend or Girlfriend
 No one has provided major support
 Other (please describe in the box below)

Cancer Impact and Information Needs

11. Please indicate what kind of **overall impact** your cancer has had on each of the following areas of your life. If a question doesn't apply to you, mark "Does not apply."

Overall impact of cancer on your...	Very negative impact	Somewhat negative impact	No impact	Somewhat positive impact	Very positive impact	Does not apply
a. Relationship with your mother	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
b. Relationship with your father	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
c. Relationship with your brothers or sisters	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
d. Relationship with your spouse, partner, boyfriend or girlfriend	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
e. Relationship with your child/children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
f. Relationship with friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
g. Dating	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
h. Plans for getting married	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
i. Sexual function/intimate relations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
j. Plans for having children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
k. Spirituality and religious beliefs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
l. Plans for the future and goal setting	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
m. Feelings about the appearance of your body	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
n. Confidence in your ability to take care of your health	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
o. Control over your life	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
p. Plans for education	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
q. Plans for work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>
r. Financial situation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	10 <input type="checkbox"/>

12. **At this time**, do you feel you need **more information** about any of the following?

	I HAVE ENOUGH information	I NEED SOME more information	I NEED MUCH more information	Does not apply
a. Possible long-term side effects of cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
b. Handling concern about the cancer returning	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
c. How to check signs that cancer has returned	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
d. Handling concern about getting another type of cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
e. Financial support for medical care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
f. Staying physically fit or getting exercise	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
g. Nutrition and diet	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
h. A family member's risk of getting cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
i. Having your own children in the future (such as fertility/reproduction issues)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
j. New treatments for your cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
k. Complementary and alternative treatments (such as acupuncture or herbal remedies)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
l. How to talk about your cancer experience with family and friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
m. Meeting other adolescents or young adult cancer patients/survivors	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>
n. Any other need for information (please describe in the box below) <div style="border: 1px solid black; height: 40px; width: 100%; margin-top: 5px;"></div>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	10 <input type="checkbox"/>

General Health

[The SF-12® questions were administered here, under license agreement with QualityMetric.]

Health and Social Issues

20. During the past 4 weeks, have you experienced any of the following problems, whether related to your cancer or not?

	No	Yes
a. Nausea or vomiting	<input type="checkbox"/> 0	<input type="checkbox"/> 1
b. Frequent or severe stomach pain	<input type="checkbox"/> 0	<input type="checkbox"/> 1
c. Diarrhea or constipation	<input type="checkbox"/> 0	<input type="checkbox"/> 1
d. Pain in your joints (for example, knees, ankles, elbows) or bones	<input type="checkbox"/> 0	<input type="checkbox"/> 1
e. Weight loss	<input type="checkbox"/> 0	<input type="checkbox"/> 1
f. Weight gain	<input type="checkbox"/> 0	<input type="checkbox"/> 1
g. Frequent or severe fevers	<input type="checkbox"/> 0	<input type="checkbox"/> 1
h. Hot flashes	<input type="checkbox"/> 0	<input type="checkbox"/> 1
i. Tingling, weakness, or clumsiness of the hands or feet	<input type="checkbox"/> 0	<input type="checkbox"/> 1
j. Frequent or severe headaches	<input type="checkbox"/> 0	<input type="checkbox"/> 1
k. Frequent or severe mouth sores that impact your eating and drinking	<input type="checkbox"/> 0	<input type="checkbox"/> 1
l. Problems with memory, attention, or concentration	<input type="checkbox"/> 0	<input type="checkbox"/> 1

[Questions 21 – 25 are from PedsQL™ (www.pedsq.org). To obtain permission from the Mapi Research Trust to use the PedsQL items and scales, see the [PedsQL™ Conditions of Use](#).]

Below is a list of things that might be a problem for you. There are no right or wrong answers. In the past month, how much of a problem has this been for you...

21. General Fatigue (<i>PROBLEMS WITH...</i>)	Never	Almost Never	Some-times	Often	Almost Always
I feel tired	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I feel physically weak (not strong)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I feel too tired to do things that I like to do	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I feel too tired to spend time with my friends	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

22. About my Health and Activities (<i>PROBLEMS WITH...</i>)	Never	Almost Never	Some-times	Often	Almost Always
It is hard for me to walk more than one block	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
It is hard for me to run	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
It is hard for me to do sports activity or exercise	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
It is hard for me to lift something heavy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
It is hard for me to take a bath or shower by myself	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
It is hard for me to do chores around the house	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I hurt or feel pain	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I have low energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

--	--	--	--	--

In the past month, how much of a problem has this been for you...

23. About My Feelings (<i>PROBLEMS WITH...</i>)	Never	Almost Never	Some-times	Often	Almost Always
I feel afraid or scared	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I feel sad or blue	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I feel angry	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I have trouble sleeping	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I worry about what will happen to me	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

24. How I Get Along with Others (<i>PROBLEMS WITH...</i>)	Never	Almost Never	Some-times	Often	Almost Always
I have trouble getting along with my peers	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I cannot do things that others my age can do	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
It is hard to keep up with my peers	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

25. About My Work/Studies (<i>PROBLEMS WITH...</i>)	Never	Almost Never	Some-times	Often	Almost Always
It is hard to pay attention at work or school	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I forget things	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I have trouble keeping up with my work or studies	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I miss work or school because of not feeling well	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
I miss work or school to go to the doctor or hospital	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Please complete this last section of the survey with help if you need it.

The remaining questions ask about your medical care and health insurance. You may want to ask your parent(s) or guardian to complete this section with you.

Cancer Treatments

26a. Are you currently receiving treatment for your cancer?

- No →
 Yes → GO TO QUESTION 27

26b. When was the last time you received treatment for your cancer?

MM			YYYY			

27. Chemotherapy is a medication that is often given in a doctor's office or hospital, through an IV (intravenous) or through a port, but it may also be given orally as a pill.

a. Are you now receiving or are you currently scheduled to receive chemotherapy?

- No →
 Yes → GO TO QUESTION 28
 I don't know →

b. Have you ever received chemotherapy?

- No
 Yes
 I don't know

28. Have you ever received any of the following other treatments for your cancer?

	No	Yes
a. Surgery	<input type="checkbox"/> 0	<input type="checkbox"/> 1
b. Radiation	<input type="checkbox"/> 0	<input type="checkbox"/> 1
c. Bone marrow transplant or stem cell transplant	<input type="checkbox"/> 0	<input type="checkbox"/> 1
d. Other (please describe in the box below)	<input type="checkbox"/> 0	<input type="checkbox"/> 1

Clinical Trials and Support Services

29. Clinical trials are research studies that may include surgery, radiation, chemotherapy, drugs or other treatments. Clinical trials are sometimes also called experimental studies or protocols.

a. Are there clinical trials or experimental studies available for your type or stage of cancer?

No → GO TO QUESTION 31 ON PAGE 14

Yes →

I don't know if there are any clinical trials available → GO TO QUESTION 31 ON PAGE 14

b. Did your doctor ever recommend a clinical trial to you?

No

Yes

I don't know

c. Have you ever participated or are you currently in a clinical trial or experimental study of a treatment for cancer?

No → GO TO QUESTION 30 ON THE NEXT PAGE

Yes → GO TO QUESTION 31 ON PAGE 14

I don't know → GO TO QUESTION 31 ON PAGE 14

30. Below is a list of possible reasons that people do not participate in clinical trials. For each of the following, please indicate whether you agree or disagree that it was a reason you did not participate in a clinical trial.

You did not participate in a clinical trial because...	Agree	Disagree
a. You did not think that a clinical trial would help you	<input type="checkbox"/>	<input type="checkbox"/>
b. You were worried about side-effects of the treatment in the clinical trial	<input type="checkbox"/>	<input type="checkbox"/>
c. You were too sick to have treatment in a clinical trial	<input type="checkbox"/>	<input type="checkbox"/>
d. Your insurance would not cover part or all of the payment for the clinical trial	<input type="checkbox"/>	<input type="checkbox"/>
e. You were worried that you might get a placebo or sugar pill rather than actual treatment	<input type="checkbox"/>	<input type="checkbox"/>
f. You were worried that you might be treated like a guinea pig	<input type="checkbox"/>	<input type="checkbox"/>
g. You were worried that you might receive treatment that had not been sufficiently tested	<input type="checkbox"/>	<input type="checkbox"/>
h. You were worried that you would have to switch doctors in order to participate in the clinical trial	<input type="checkbox"/>	<input type="checkbox"/>
i. You could not find a trial that was near you	<input type="checkbox"/>	<input type="checkbox"/>
j. Any other reason (please describe in the box below) <div style="border: 1px solid black; height: 40px; width: 450px; margin-top: 5px;"></div>	<input type="checkbox"/>	<input type="checkbox"/>

31. Please indicate whether you have received any of the following services before, during or after your cancer treatment. Also indicate whether you feel you now need or have needed any of these services.

	SERVICE RECEIVED?		SERVICE NEEDED?	
	Yes	No	Yes	No
<i>Check <u>two</u> for each row</i>				
a. Have a nurse come to your home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Participate in a support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. See a psychiatrist, psychologist, social worker or mental health worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. See a physical or occupational therapist for rehabilitation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. See a pain management expert	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Talk with a spiritual or religious counselor about your cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Get professional advice to help figure out payment for healthcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Other (please describe in the box below)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<div style="border: 1px solid black; height: 40px; width: 450px; margin-left: 20px;"></div>				

32. Based on your interactions with your doctors, nurses, and other health care professionals, overall, how would you rate the quality of care you received since your cancer diagnosis?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Excellent

Health Insurance



Please ask your parent/guardian for help with these questions if you don't know the answers.

33a. Are you now covered by any type of health insurance?

No → GO TO QUESTION 34a

Yes →

33b. How is this health insurance provided?
MARK ALL THAT APPLY.

- Through your employer/school
- Through your spouse's employer/school
- Through your parent
- Medicaid or other public assistance program
- Other State Program (for example, Medi-Cal, SCHIP)
- Military or Veteran's Benefits
- Other (please describe in the box below)
- I don't know

34a. Was there any time since your diagnosis or after your treatment that you had no health insurance coverage at all, including Medicaid or other governmental insurance programs?

No → GO TO QUESTION 35 ON THE NEXT PAGE

Yes →

I don't know → GO TO QUESTION 35 ON THE NEXT PAGE

34b. How long were you or have you been without insurance?

- Less than 2 months
- Between 2 and 6 months
- More than 6 months

35. When you first went to see a doctor to get diagnosed and treated for your cancer, did you have health insurance coverage?

- No
- Yes
- I don't know

36a. Has your insurance coverage changed between the time you first went to see a doctor about your cancer and now?

- No → GO TO QUESTION 37a ON THE NEXT PAGE
- Yes →
- I don't know → GO TO QUESTION 37a ON THE NEXT PAGE

36b. How has your health insurance coverage changed? **MARK ALL THAT APPLY.**

- Changed insurance companies
 - Changed to a different type of coverage or product with the same employer
 - Lost coverage completely – for example, lost a job and also health insurance that came with it
 - Became eligible for public insurance, such as Medicaid, Medi-Cal, Medicare, or a special State program
 - Became eligible for employer-based insurance
 - Bought additional insurance
 - Other
(please describe in the box below)
-
- I don't know

37a. Were there any tests or treatments (including prescription medication for treatment or side effects) that your doctor recommended for cancer that your insurance did not cover?

- No → GO TO QUESTION 38
- Yes →
- I don't know → GO TO QUESTION 38

37b. Did you receive the tests and treatments anyway?

- No
- Yes
- I don't know

38. Please mark the statement that best describes the level of help you needed in answering Questions 26a through 37b, about your cancer treatment and health insurance.

- I answered all of the questions with **no help**
- I answered the questions with **some help** from my parent, guardian, spouse, or significant other
- My parent, guardian, spouse, or significant other answered all of the questions

39. Please use the space below to tell us anything else about your medical care or experience with cancer.

Thank you for participating in this important study!

**Please return this booklet in the
postage-paid envelope**



ADOLESCENT AND YOUNG ADULT
HEALTH OUTCOMES AND PATIENT EXPERIENCE
SURVEY

**NATIONAL
CANCER
INSTITUTE**

U.S. DEPARTMENT OF
HEALTH AND HUMAN SERVICES
National Institutes of Health

LIVESTRONG™
LANCE ARMSTRONG FOUNDATION