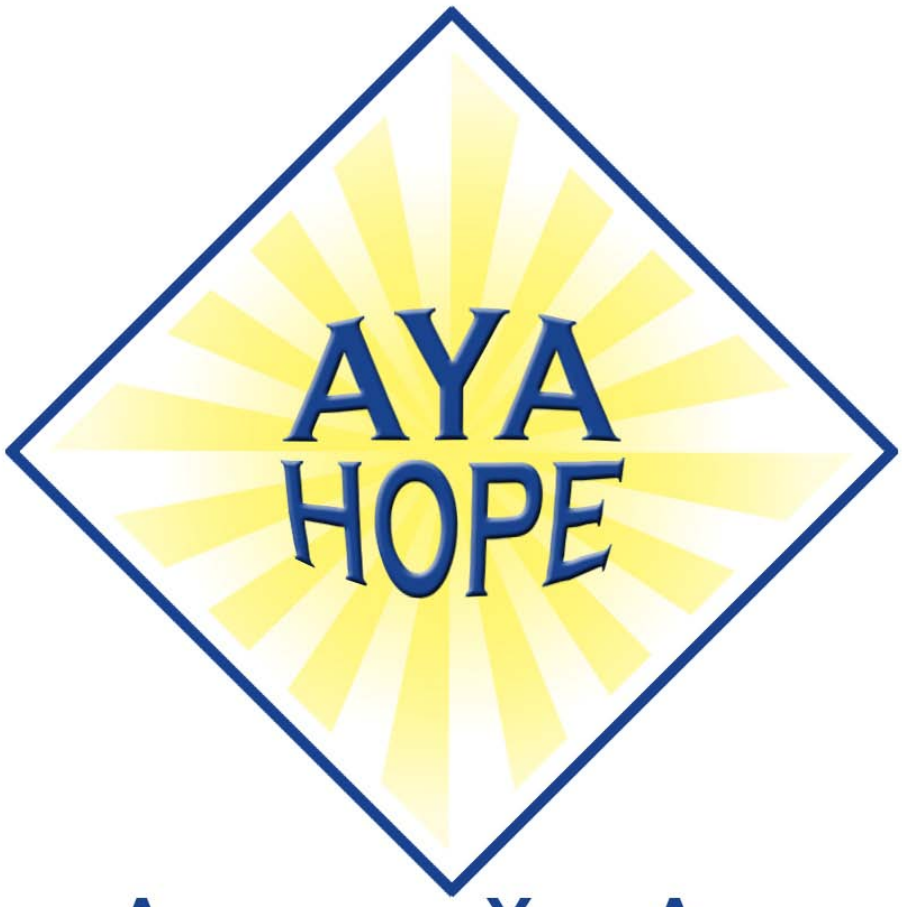

Adolescent and Young Adult Health Outcomes and Patient Experience

Follow-up Survey

Conducted by:

National Cancer Institute
U.S. Department of Health and Human Services
National Institutes of Health

With Support From:

LIVESTRONG
LANCE ARMSTRONG FOUNDATION

AYA HOPE Follow-Up Survey: Information and Instructions

About a year ago, you completed a survey for us -- the *Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Survey*. This is a follow-up survey, to ask about your experiences with cancer, with medical care and how your cancer has influenced different areas of your life. Some of the questions are the same as the first survey, and some are different. 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 16 and 42). 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 Follow-Up 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 before?

0 ☐ No → GO TO QUESTION 2

1 ☑ Yes →

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

1 ☐ 1-5 months ago

2 ☐ 6-12 months ago

3 ☑ More than 12 months ago

2. Have you ever answered a web survey before?

0 ☐ No

1 ☑ Yes

Cancer Status and Care

On the first AYA HOPE survey you completed, we asked some questions about your cancer experience. The following questions ask about your current experience.

1. **What was the date of your last cancer treatment – that is, surgery, radiation, chemotherapy, bone marrow, or stem cell transplant? Please DO NOT consider a bone marrow biopsy to be a bone marrow transplant. If you are <u>currently</u> undergoing treatment, please indicate the current month and year.**

MM YYYY

2. **Are you currently scheduled to receive future cancer treatment?**

0 ☐ No
1 ☐ Yes
8 ☐ Don't Know

3. **To the best of your knowledge, are you now free of cancer?**

0 ☐ No
1 ☐ Yes
8 ☐ Don't Know

4. **In the last 12 months, have you gone to a doctor for any kind of health or medical care?**

0 ☐ No → Skip to Question 7
1 ☐ Yes

5. **In the last 12 months, <u>what types</u> of the doctors have you gone to for any kind of health or medical care?**

MARK ALL THAT APPLY

01 ☐ Primary care (such as general practictioner, internal medicine, family practice)
02 ☐ Pediatric oncologist
03 ☐ Medical oncologist or hematologist
04 ☐ Radiation oncologist
05 ☐ Surgeon
06 ☐ Urologist
07 ☐ Obstetrician/Gynecologist
08 ☐ Orthopedic physician
09 ☐ Psychiatrist
98 ☐ Don't know
99 ☐ Other (please describe all others in the box below)

6. **In the past 12 months, what were the reasons you saw a doctor?**

MARK ALL THAT APPLY.

- 1 ☐ Ongoing cancer treatment
- 2 ☐ To discuss and/or treat cancer symptoms and side effects
- 3 ☐ To receive follow-up medical tests to check for signs of cancer or other medical problems
- 4 ☐ To receive a general physical examination (e.g., routine physical, annual gynecology visit)
- 5 ☐ Cold/Flu, or illness other than cancer
- 6 ☐ Injury
- 9 ☐ Other (please describe in the box below)

SKIP to Question 8

7. **What are the main reasons you did NOT see a doctor?**

MARK ALL THAT APPLY

- 01 ☐ I felt I didn't need follow-up care
- 02 ☐ My doctor(s) told me I didn't need follow-up care
- 03 ☐ It cost too much OR insurance didn't cover it
- 04 ☐ I didn't know a good doctor
- 05 ☐ It made me anxious or worried
- 06 ☐ I didn't have the time for it
- 07 ☐ It was too difficult to schedule an appointment
- 08 ☐ I didn't like my doctor
- 09 ☐ Child care was a problem
- 10 ☐ School/work made it too difficult
- 11 ☐ Social life made it too difficult
- 12 ☐ Transportation was a problem
- 13 ☐ Other (please describe in the box below)

8. **Please indicate whether you have seen any of the following providers or have received any of the following services for cancer in the past 12 months.**

	Yes	No
a. Have a nurse come to your home	1 ☐	0 ☐
b. Participate in a support group	1 ☐	0 ☐
c. See a psychiatrist, psychologist, social worker or mental health worker	1 ☐	0 ☐
d. See a physical or occupational therapist for rehabilitation	1 ☐	0 ☐
e. See a pain management expert	1 ☐	0 ☐
f. Talk with a spiritual or religious counselor about your cancer	1 ☐	0 ☐
g. Get professional advice to help figure out payment for healthcare	1 ☐	0 ☐
h. Other (please describe in the box below)	1 ☐	0 ☐

9. **Based on your interactions with your doctors, nurses, and other health care professionals, overall, how would you rate the quality of care for cancer that you received?**

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

Cancer Impact

10. Please indicate what kind of <u>overall impact</u> 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☐	2☐	3☐	4☐	5☐	10☐
b. Relationship with your father	1☐	2☐	3☐	4☐	5☐	10☐
c. Relationship with your brothers or sisters	1☐	2☐	3☐	4☐	5☐	10☐
d. Relationship with your spouse, partner, boyfriend or girlfriend	1☐	2☐	3☐	4☐	5☐	10☐
e. Relationship with your child/children	1☐	2☐	3☐	4☐	5☐	10☐
f. Relationship with friends	1☐	2☐	3☐	4☐	5☐	10☐
g. Dating	1☐	2☐	3☐	4☐	5☐	10☐
h. Plans for getting married	1☐	2☐	3☐	4☐	5☐	10☐
i. Sexual function/intimate relations	1☐	2☐	3☐	4☐	5☐	10☐
j. Plans for having children	1☐	2☐	3☐	4☐	5☐	10☐
k. Spirituality and religious beliefs	1☐	2☐	3☐	4☐	5☐	10☐
l. Plans for the future and goal setting	1☐	2☐	3☐	4☐	5☐	10☐
m. Feelings about the appearance of your body	1☐	2☐	3☐	4☐	5☐	10☐
n. Confidence in your ability to take care of your health	1☐	2☐	3☐	4☐	5☐	10☐
o. Control over your life	1☐	2☐	3☐	4☐	5☐	10☐
p. Plans for education	1☐	2☐	3☐	4☐	5☐	10☐
q. Plans for work	1☐	2☐	3☐	4☐	5☐	10☐
r. Financial situation	1☐	2☐	3☐	4☐	5☐	10☐

11. How concerned are you about each of the following?

	Not at all concerned	A little Concerned	Somewhat concerned	Very Concerned
a. Possible long-term side effects of cancer treatment	1☐	2☐	3☐	4☐
b. The possibility of the same type of cancer returning	1☐	2☐	3☐	4☐
c. How to check signs that cancer has returned	1☐	2☐	3☐	4☐
d. The possibility of getting another type of cancer	1☐	2☐	3☐	4☐
e. Having financial support for medical care	1☐	2☐	3☐	4☐
f. Physical fitness or getting enough exercise	1☐	2☐	3☐	4☐
g. Nutrition or having a healthy diet	1☐	2☐	3☐	4☐
h. A family member's risk of getting cancer	1☐	2☐	3☐	4☐
i. Having your own children in the future (such as fertility/reproduction issues)	1☐	2☐	3☐	4☐
j. Having enough information about your treatment	1☐	2☐	3☐	4☐
k. The potential long term effects of cancer on your health	1☐	2☐	3☐	4☐
l. How to talk about your cancer experience with family and friends	1☐	2☐	3☐	4☐
m. Meeting other adolescents or young adult cancer patients/survivors	1☐	2☐	3☐	4☐
n. Any other concerns: (please describe in the box below) ☐	1☐	2☐	3☐	4☐

Health and Social Issues

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

[Questions 19 – 23 are from PedsQL™ (www.pedsql.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…

19. General Fatigue (*PROBLEMS WITH…*)	Never	Almost Never	Some-times	Often	Almost Always
I feel tired	0☐	1☐	2☐	3☐	4☐
I feel physically weak (not strong)	0☐	1☐	2☐	3☐	4☐
I feel too tired to do things that I like to do	0☐	1☐	2☐	3☐	4☐
I feel too tired to spend time with my friends	0☐	1☐	2☐	3☐	4☐

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

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

21. About My Feelings (*PROBLEMS WITH…*)	Never	Almost Never	Some-times	Often	Almost Always
I feel afraid or scared	0☐	1☐	2☐	3☐	4☐
I feel sad or blue	0☐	1☐	2☐	3☐	4☐
I feel angry	0☐	1☐	2☐	3☐	4☐
I have trouble sleeping	0☐	1☐	2☐	3☐	4☐
I worry about what will happen to me	0☐	1☐	2☐	3☐	4☐

22. How I Get Along with Others (*PROBLEMS WITH…*)	Never	Almost Never	Some-times	Often	Almost Always
I have trouble getting along with my peers	0☐	1☐	2☐	3☐	4☐
I cannot do things that others my age can do	0☐	1☐	2☐	3☐	4☐
It is hard to keep up with my peers	0☐	1☐	2☐	3☐	4☐

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

Fertility

24. Have you ever been told that your cancer treatments may affect your fertility (i.e., your ability to have your own biological children)?

0 ☐ No → Skip to Question 26
1 ☐ Yes

25. IF YES, who talked with you about your cancer treatment and possible fertility risks? MARK ALL THAT APPLY.

1 ☐ Medical Oncologist
2 ☐ Pediatric Oncologist
3 ☐ Radiation Oncologist
4 ☐ Surgeon / Surgical Oncologist
5 ☐ Obstetrician/gynecologist
6 ☐ Urologist
7 ☐ Reproductive endocrinologist
8 ☐ Nurse
9 ☐ Physician assistant
10 ☐ Psychiatrist
11 ☐ Psychologist
12 ☐ Social worker
13 ☐ Another patient/cancer survivor
14 ☐ A family member
99 ☐ Other (please describe all others in the box below)

26. Did a healthcare professional involved in your cancer care talk with you about options to preserve your fertility (e.g., sperm banking or freezing of eggs, embryos, or ovarian tissue) before you started cancer treatment?

0 ☐ No
1 ☐ Yes
2 ☐ I don't remember

27. Did you make arrangements for any type of fertility preservation?

0 ☐ No → Skip to Question 29
1 ☐ Yes

28. Did you make fertility preservation arrangements before or after starting chemotherapy?

1 ☐ Before starting chemotherapy
2 ☐ After starting chemotherapy
3 ☐ I did not have chemotherapy

SKIP to Question 30a

29. Why did you NOT make arrangements for fertility preservation? MARK ALL THAT APPLY.

1 ☐ I was too young / old to consider this
2 ☐ I was not aware of my options
3 ☐ It was too expensive or insurance didn't cover it
4 ☐ I did not want to delay starting my cancer treatments
5 ☐ My doctor advised me not to delay starting my cancer treatments
6 ☐ I was worried about effects of my cancer or its treatment on a future child
7 ☐ I do not want to have biological children in the future
8 ☐ Other (please describe in the box below)

30a. **Are you now covered by any type of health insurance, including Medicaid or another government insurance program?**

0 ☐ No → SKIP to Question 31a

1 ☐ Yes →

30b. **How is this health insurance provided?**

MARK ALL THAT APPLY.

1 ☐ Through your employer/school

2 ☐ Through your spouse's employer/school

3 ☐ Through your parent

4 ☐ Through your own, purchased individual policy

5 ☐ Medicaid or other public assistance program

6 ☐ Other State Program (for example, Medi-Cal, SCHIP)

7 ☐ Military or Veteran's Benefits

8 ☐ COBRA

9 ☐ Other (please describe in the box below)

☐

10 ☐ I don't know

31a. **In the past 12 months, has there been any time that you have had <u>no health insurance coverage</u> at all, including Medicaid or another governmental insurance program?**

0 ☐ No → GO TO QUESTION 33 ON THE NEXT PAGE

1 ☐ Yes →

9 ☐ I don't know → GO TO QUESTION 33 ON THE NEXT PAGE

31b. **How long were you or have you been without health insurance?**

1 ☐ Less than 2 months

2 ☐ Between 2 and 6 months

3 ☐ More than 6 months

32a. In the past 12 months, were there any tests or treatments (including prescription medication for treatment or side effects) that your doctor recommended for cancer that your health insurance did <u>not</u> cover?

0 ☐ No → GO TO QUESTION 33

1 ☐ Yes →

9 ☐ I don't know → GO TO QUESTION 33

32b. Did you receive the test or treatment anyway?

0 ☐ No

1 ☐ Yes

9 ☐ I don't know

33. Have you ever had difficulty obtaining <u>life insurance</u> because of your health history?

0 ☐ No

1 ☐ Yes

2 ☐ Never tried to obtain life insurance

34. Do you currently have <u>life insurance</u> coverage?

0 ☐ No

1 ☐ Yes

Your Education, Work, and Family

35. 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.)

36. What is your current school or employment status?

MARK ALL THAT APPLY.

1. ☐ Part-time student
2. ☐ Full-time student
3. ☐ Working part-time
4. ☐ Working full-time
5. ☐ Unemployed
6. ☐ Full-time homemaker or family caregiver
7. ☐ Other (please describe in the box below)

37. In the past 12 months, has your school or employment status changed because of your cancer or its treatment?

MARK ALL THAT APPLY.

1. ☐ It has not changed because of my cancer or its treatment
2. ☐ I quit working completely
3. ☐ I quit going to school completely
4. ☐ I changed my work status from full-time to part-time or I reduced my hours
5. ☐ I changed my school status from full-time to part-time
6. ☐ I increased my work hours (from not working or part-time work to part- or full-time work)
7. ☐ I increased my school attendance from none or part-time to part- or full-time
8. ☐ I took more than 2 weeks total time off from work
9. ☐ I took more than 2 weeks total time off from school
10. ☐ Other (please describe in the box below)

38. Do you currently live alone or with others?

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

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

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

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

- 0 ☐ No
- 1 ☐ Yes

41. **Please mark the statement that best describes the level of help you needed in answering this survey.**

- 1 ☐ I answered all of the questions with **no help**
- 2 ☐ I answered the questions with **some help** from my parent/guardian
- 3 ☐ My parent/guardian answered all of the questions

42. **Please use the space below to tell us anything else about your medical care or experience with cancer. Feel free to include additional pages.**

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Please write the date you completed this survey: ☐☐ MM ☐☐ DD ☐☐☐☐ YYYY

Thank you for participating in this important study!
Please return this booklet in the postage-paid envelope