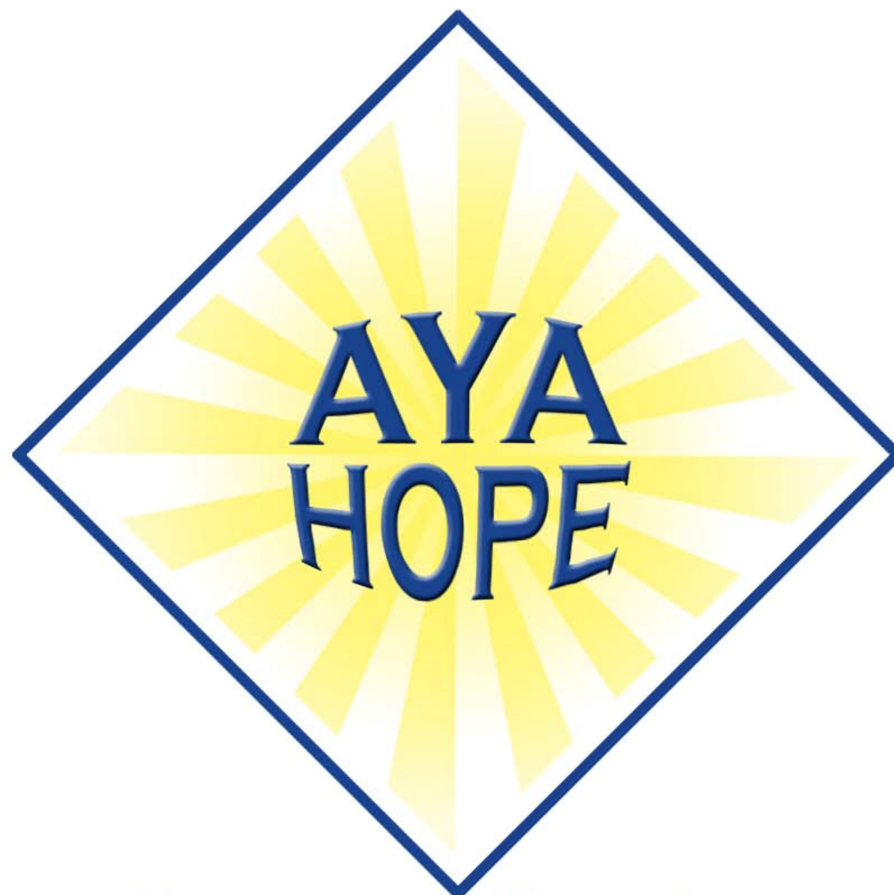
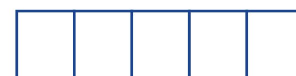


Adolescent and Young Adult Health Outcomes and Patient Experience Survey

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?

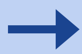
- [ ] 0 No → GO TO QUESTION 2
- [x] 1 Yes →

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

- [x] 1 1-5 months ago
- [ ] 2 6-12 months ago
- [ ] 3 More than 12 months ago

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

- [ ] 0 No
- [x] 1 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?

- [ ] 0 No
- [ ] 1 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 ☐	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 ☐

12. <u>At this time,</u> do you feel you need <u>more information</u> 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 ☐	2 ☐	3 ☐	10 ☐
b. Handling concern about the cancer returning	1 ☐	2 ☐	3 ☐	10 ☐
c. How to check signs that cancer has returned	1 ☐	2 ☐	3 ☐	10 ☐
d. Handling concern about getting another type of cancer	1 ☐	2 ☐	3 ☐	10 ☐
e. Financial support for medical care	1 ☐	2 ☐	3 ☐	10 ☐
f. Staying physically fit or getting exercise	1 ☐	2 ☐	3 ☐	10 ☐
g. Nutrition and diet	1 ☐	2 ☐	3 ☐	10 ☐
h. A family member's risk of getting cancer	1 ☐	2 ☐	3 ☐	10 ☐
i. Having your own children in the future (such as fertility/reproduction issues)	1 ☐	2 ☐	3 ☐	10 ☐
j. New treatments for your cancer	1 ☐	2 ☐	3 ☐	10 ☐
k. Complementary and alternative treatments (such as acupuncture or herbal remedies)	1 ☐	2 ☐	3 ☐	10 ☐
l. How to talk about your cancer experience with family and friends	1 ☐	2 ☐	3 ☐	10 ☐
m. Meeting other adolescents or young adult cancer patients/survivors	1 ☐	2 ☐	3 ☐	10 ☐
n. Any other need for information (please describe in the box below) ☐	1 ☐	2 ☐	3 ☐	10 ☐

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	₀☐	₁☐
b. Frequent or severe stomach pain	₀☐	₁☐
c. Diarrhea or constipation	₀☐	₁☐
d. Pain in your joints (for example, knees, ankles, elbows) or bones	₀☐	₁☐
e. Weight loss	₀☐	₁☐
f. Weight gain	₀☐	₁☐
g. Frequent or severe fevers	₀☐	₁☐
h. Hot flashes	₀☐	₁☐
i. Tingling, weakness, or clumsiness of the hands or feet	₀☐	₁☐
j. Frequent or severe headaches	₀☐	₁☐
k. Frequent or severe mouth sores that impact your eating and drinking	₀☐	₁☐
l. Problems with memory, attention, or concentration	₀☐	₁☐

[Questions 21 – 25 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…

21. 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 ☐

22. 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…

23. 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 ☐

24. 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 ☐

25. 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 ☐

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?

- 0 ☐ No → 26b
- 1 ☐ 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?

- 0 ☐ No → b
- 1 ☐ Yes → GO TO QUESTION 28
- 9 ☐ I don't know → b

b. Have you ever received chemotherapy?

- 0 ☐ No
- 1 ☐ Yes
- 9 ☐ I don't know

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

	No	Yes
a. Surgery	0 ☐	1 ☐
b. Radiation	0 ☐	1 ☐
c. Bone marrow transplant or stem cell transplant	0 ☐	1 ☐
d. Other (please describe in the box below)	0 ☐	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?

- ☐ 0 No → GO TO QUESTION 31 ON PAGE 14
- ☐ 1 Yes → (go to b)
- ☐ 9 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?

- ☐ 0 No
- ☐ 1 Yes
- ☐ 9 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?

- ☐ 0 No → GO TO QUESTION 30 ON THE NEXT PAGE
- ☐ 1 Yes → GO TO QUESTION 31 ON PAGE 14
- ☐ 9 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	1 ☐	2 ☐
b. You were worried about side-effects of the treatment in the clinical trial	1 ☐	2 ☐
c. You were too sick to have treatment in a clinical trial	1 ☐	2 ☐
d. Your insurance would not cover part or all of the payment for the clinical trial	1 ☐	2 ☐
e. You were worried that you might get a placebo or sugar pill rather than actual treatment	1 ☐	2 ☐
f. You were worried that you might be treated like a guinea pig	1 ☐	2 ☐
g. You were worried that you might receive treatment that had not been sufficiently tested	1 ☐	2 ☐
h. You were worried that you would have to switch doctors in order to participate in the clinical trial	1 ☐	2 ☐
i. You could not find a trial that was near you	1 ☐	2 ☐
j. Any other reason (please describe in the box below)	1 ☐	2 ☐

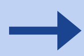
31. Please indicate whether you have received any of the following services before, during or after your cancer treatment. Also indicate whether you feel you now need or have needed any of these services.

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

32. Based on your interactions with your doctors, nurses, and other health care professionals, overall, how would you <u>rate the quality of care</u> 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 <u>first went to see a doctor</u> to get diagnosed and treated for your cancer, did you have health insurance coverage?

- ☐ No (0)
- ☐ Yes (1)
- ☐ I don't know (9)

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

- ☐ No → GO TO QUESTION 37a ON THE NEXT PAGE (0)
- ☐ Yes → (1)
- ☐ I don't know → GO TO QUESTION 37a ON THE NEXT PAGE (9)

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?**

- 0 ☐ No → GO TO QUESTION 38
- 1 ☐ Yes → 37b
- 9 ☐ I don't know → GO TO QUESTION 38

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

- 0 ☐ No
- 1 ☐ Yes
- 9 ☐ 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.**

- 1 ☐ I answered all of the questions with **no help**
- 2 ☐ I answered the questions with **some help** from my parent, guardian, spouse, or significant other
- 3 ☐ 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