

TO: Ashley Wilder Smith February 22, 2008

FROM: Martha Stapleton Kudela, Cynthia Robins,
Debra Stark, Debra Dean, Kerry Levin

SUBJECT: Results of AYA cognitive testing

Introduction

For the Adolescent and Young Adult (AYA) Cancer Survivors Study, the National Cancer Institute (NCI) is developing a survey that examines the quality of care and related outcomes among AYA in the first year following their cancer diagnosis. NCI contracted with Westat to conduct two rounds of testing on the survey. The first round used cognitive interview techniques to test survey content. The second round will test the format and layout of the web and paper instruments.

Between January 16 and February 19, 2008, 14 cognitive interviews were conducted by Westat senior survey methodologists with extensive experience in cognitive testing. The interviews were conducted in-person at Westat and lasted an hour to an hour-and-a-half. Respondents were paid \$50 for participating. This memo describes the cognitive testing recruiting effort, documents revisions to the questionnaire made during testing, presents overall observations and key findings, summarizes detailed results and provides recommendations for further questionnaire revisions.

Recruiting

Respondents were recruited via email messages sent by the Lance Armstrong Foundation (LAF) to its group members. The first message was sent on January 10; a second message was sent on February 11. Westat established a toll-free, dedicated telephone line to receive calls from potential respondents. The initial selection criteria included those diagnosed with the cancer types asked about in the survey (see Q6) within the past year. Because of a low response rate (only 27 calls received after the January 10 message went out), selection criteria were expanded on January 17 to include those diagnosed with any cancer other than brain, thyroid, or melanoma within the past 4 years. The three age groups of interest were 15-17, 18-25, and 26-39. Although we accepted calls from those under 18 from the time the first LAF email went out, we did not start screening and scheduling that age group until January 31, when we received approval from the Westat IRB to do so. We scheduled concurrent parent/child interviews for those in the 15-17 age group.

Table 1 shows the dispositions of the 27 calls received. Table 2 shows the demographic characteristics of the 14 respondents.

Table 1. AYA recruiting: Call dispositions

Disposition	Number of cases
Total calls received	27
Screened	19
Eligible	13
Ineligible	6
Out of scope	5
No contact	3
Scheduled for an interview	12+4 parents=16
Completed interviews	11+3 parents=14

Table 2. AYA Respondent characteristics

Respondent ID	Gender	Age	Cancer type	Diagnosis date
R1	F	25	Non-hodgkins lymphoma	1/16/2007
R2	M	28	Hodgkins and non-hodgkins lymphoma	1/11/2008
R3	F	23	Sarcoma (GI)	1/03 & 6/06
R4	F	22	Hodgkin's lymphoma	11/8/2006
R5	F	32	Primolistic leukemia	11/06
R6	F	39	Germ cell(Ovarian)	12/12/2006
R7	M	34	Testicular seminoma	11/14/06
R8	M	32	Germ cell (Testicular)	5/6/2006
R9Youth & R9Parent	M	17	Hodgkins lymphoma	1/26/06
R10Y & R10P	M	16	Acute lymphoblastic leukemia	6/12/06
R11Y & R11P	M	17	Testicular	11/7/07

Protocol development and questionnaire revisions

Westat developed a cognitive interview protocol that consisted of the questionnaire items with cognitive probes inserted after selected questions. The probes were administered using the concurrent think aloud technique. Probe questions asked respondents, for example, to describe how they interpreted survey items, the factors they considered as they selected their answers and whether any questions asked for information they either did not have or could not remember. The following research questions were of specific interest to NCI:

- Are these the right questions for asking about what effect cancer has had on the AYA's lives since diagnosis?
- Do the questions accurately measure the effects of the cancer on the AYA's relationships with parents, on their lives, etc. Are respondents able to use the positive and negative ratings for these questions?
- Are respondents answering the questions for the effects of their cancer itself, the effects of its treatment, or both?
- Are respondents tracking the various switches in referent period (e.g., since you first had symptoms, since you were first told you had cancer, since you first got treatment)?

- In Section B, do youth under 18 need help answering the questions and, if yes, would they ask for help? Do the parents of youth under 18 think their children need help or would ask for help with the questions in Section B?

The questionnaire was revised twice during cognitive testing. On January 30, a new question was added (Q14a) that asks about the one person who has provided the most helpful support. Also, at Q14, slight wording changes were made to some sub-items; the sub-items were reorganized; and the response options were expanded. This version of the questionnaire was administered to 3 adult, 3 youth, and 3 parent respondents. On January 31, text was added to the question stem in Q29b, and one sub-item was added to each of Q32 and Q33. This version was administered to 1 adult, 3 youth, and 3 parent respondents.

Overall observations and key findings

This section presents a brief synopsis of the detailed findings described in the next section. Table 3 shows overall observations and lists the items for which there are key findings.

Table 3. AYA cognitive testing: Key observations and findings

Item(s)	Key observations and findings
_____	<ul style="list-style-type: none"> Several items appear ambiguous with respect to asking respondents to reflect on their life experiences in general versus the impact of the cancer on their lives. If the questions are to more directly assess the impacts of cancer, they need to be reworded to more clearly reflect that.
_____	<ul style="list-style-type: none"> There was a noticeable difference in some of the information provided by parents and by their children (e.g., child's symptoms as a result of the treatment, insurance coverage details, treatment option specifics). Also, parents tended to doubt their child's ability to answer some of the questions, while at the same time the child often seemed to answer those same questions fairly easily. For the cognitive testing, there is no way to know whether the parent underestimated the child's ability or the child overestimated his/her own knowledge. Because of this lack of convergence on what are critical items for NCI (insurance coverage, ability to obtain needed treatments because of coverage, etc.), is there a way to obtain this information from another source such as data abstraction from medical records?
Q5a, Q5b, Q6, Section B	<ul style="list-style-type: none"> Plan for the possibility that respondents "now" (at the time of survey administration) have more than one cancer diagnosis. Consider modifying selected items to accommodate respondents with more than one cancer (e.g., "If you have more than one cancer diagnosis, please think about your most recent one.").
Q7–Q10b	<ul style="list-style-type: none"> Items about respondents' school/work status and living situations may not adequately capture the desired information. Respondents did not interpret them consistently nor were they able to report changes such as extended time off from school or work for treatment.
Q11	<ul style="list-style-type: none"> Depending on the intent of the question, respondents may interpret it too broadly (reporting any experience of the problem, regardless of whether it is related to cancer) or too narrowly (focusing only on problems directly related to the primary cancer treatment). Consider rewording the question to more clearly convey its intent, asking, for example, "Have you experienced any of the following problems before, during, or after your treatment?" If expanding the list of sub-items is an option, use respondent suggestions (listed in the detailed findings) to do so.
Q12-Q14a	<ul style="list-style-type: none"> Youths under 18 may have little say in the decisions their parents make about their medical care. Some in this age group are less likely to pay attention to those discussions than are others. Therefore, their answers to these question may be somewhat artificial. Adult respondents tended to answer not just for influence on medical care decisions but also (or instead) the level of moral support they received from family and friends.
Q14	<ul style="list-style-type: none"> The new version of Q14 appears to do a better job than the old version of allowing respondents to account for changing impacts in their answers. For some respondents, however, answers at different items represented different points in time (e.g., "since the diagnosis" versus "since the surgery"). Some respondents suggested that "relationship with friends" be added (back). Also, the "no impact" response may not adequately capture an impact that balanced out over time from positive or negative to neutral. Note that some of the sub-items may be meaningless to younger respondents.
Q15	<ul style="list-style-type: none"> Some respondents wanted an option between "no more information" and "some more information" because they did not want to rule out the possibility that there is useful information out there that they are not aware of. Neither does the question allow respondents to report the topics for which they already sought information. If consistent with the survey's analytic goals, consider revising the response options to address these needs.

Table 3. AYA cognitive testing: Key observations and findings (continued)

Q16-Q27	<ul style="list-style-type: none">Some parents suggested that a few of these items need to be modified for teen respondents, such as adding “school” to Q18-Q20 and providing teen-related examples of moderate activities in Q17.
Q28a-Q29b	<ul style="list-style-type: none">There was some confusion about whether to include as “yes” answers treatments with purposes other than to eliminate cancer (e.g., surgery to insert a port). Combining the two Q28 items and the two Q29 items by including “chemotherapy” in the list of possible treatments may help respondents stay focused on procedures they underwent to eradicate their cancer (if that is the purpose of these items). A second potential problem with these items is the term “scheduled to have.” Consider rewording the questions to more clearly convey whether they are asking about actual appointments or a general plan for future treatment. Finally, because of some respondent confusion with Q29a-c and Q29b-c, revise to read “bone marrow transplant or stem cell transplant.”
Q30	<ul style="list-style-type: none">Youths may not know if a second opinion was sought.
Q31-Q32	<ul style="list-style-type: none">This item series was somewhat confusing for respondents who were not offered the option of a clinical trial. Consider changing Q31a to “Were clinical trials available for your type of cancer?” and skipping those who say “no” past the remaining clinical trials items.
Q33	<ul style="list-style-type: none">The formatting of this item and the double-barreled response option made it somewhat difficult for some respondents to work with. Consider moving the checkboxes or adding another column for yes/no or agree/disagree responses. Separate need from availability of support services. Revise Q33f to read “Talk with a spiritual or religious counselor” and drop the examples.
Q35a-Q41	<ul style="list-style-type: none">This item series worked relatively well for adult respondents. Youths generally knew whether they had insurance coverage but not the details such as whether it had changed or what their prescription coverage was.
Survey title	<ul style="list-style-type: none">Respondents were split in their preference for the survey title. Five adults and 2 youths preferred the AYA-HOPE acronym. Three adults, one youth, and 3 parents preferred the shorter title.
Internet scenario	<ul style="list-style-type: none">Youths were asked if they would get up from an internet survey to ask their parents for help with items they were unsure of. Two thought they would not and the third said he would fill out the paper survey in front of him rather than take the time to log onto the internet for it.
Medical record scenario	<ul style="list-style-type: none">Parents were asked their opinions about providing permission for survey researchers to examine their children’s medical records. Two were hesitant but thought that ultimately they would, given the involvement of NCI. The third parent had no qualms about releasing his son’s medical records for the research.

Detailed results and recommendations

The remainder of this document describes detailed results for those items that were tested. Tested items appear in blue font and their associated probes appear in purple font. Findings by respondent type (adult [18-39], youth [15-17], and parent) along with item recommendations appear in red boxes.

Section A

The following questions ask about you and your experiences with your medical care. This survey is designed for people of different ages (including adolescents and young adults between age 15 and 40). Please answer as best as you can and feel free to ask a parent or guardian for assistance if you need it.

YOUR PERSONAL CHARACTERISTICS

- 1. What is your date of birth? _____
MONTH DAY YEAR

- 2. Do you consider yourself to be...
 - 1 Hispanic or Latino?
 - 2 NOT Hispanic or Latino?

- 3. Which of the following describes your race? **MARK ALL THAT APPLY**
 - 1 White
 - 2 Black or African American
 - 3 Asian
 - 4 American Indian or Alaska Native
 - 5 Native Hawaiian/ Other Pacific Islander
 - 8 Other (please describe) _____

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

- 1 Grade school – between 1 and 8 years
- 2 Some high school
- 3 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.)

5. Within the past 12 months, were you (or your parent/guardian) told by a doctor or other health care professional that you had cancer?

0 No → **PLEASE STOP and return the questionnaire in the enclosed stamped, pre-addressed envelope.**

1 Yes

- **Please tell me more about that. IF NEEDED, Who told you this information?**

5b. When did the doctor or other health care professional tell you (or your parent/guardian) that you had cancer?

_____ _____
MONTH YEAR

- **Tell me more about that. IF NEEDED, How easy or difficult was it for you to remember this date?**
- **Was this when you first considered you were diagnosed with cancer? IF NO, Tell me more about that.**

Q5a and Q5b

Adults

Respondents did not always hear the “told by a doctor” piece of Q5a and Q5b. Some answered as the date the doctor told them it is likely they have cancer; some as the date the diagnosis was confirmed (e.g., by a biopsy); and some answered in terms of the anomaly that prompted them to seek a doctor’s advice in the first place (“I felt a lump,” “Something didn’t seem right”). For the latter individuals, the cancer experience is not marked by the official declaration by the physician. Rather, pre-diagnosis actions (“felt a lump”) take on meaning because of the salience of the subsequent event. Reference point is therefore likely to vary across responses to this question.

Additionally, given the time lag between drawing the sample and contacting respondents, there may be a window for the emergence of a second cancer diagnosis.

Youths

None of the youth respondents had trouble providing a diagnosis date. One had the initial blood work, which came back abnormal, done on his birthday, but gave the diagnosis date (month and year, and he knew which week of the month it happened) as the date the biopsy showed he had cancer. Another knew the month and year and the third gave an exact date.

Parents

The parent of the youth who had blood work done on his birthday did not think his son would remember a diagnosis date. The others explained that their children are more likely to relate the diagnosis to events in their lives such as “my senior year” or “before Christmas” rather than a month/year date. These parents said their children would understand the question but might have to spend some time “translating” their answers to fit the requested response category.

Recommendation: Plan for the possibility that respondents “now” (at the time of survey administration) have more than one cancer diagnosis. Consider modifying Q5b to accommodate respondents with more than one cancer (e.g., “If you have more than one cancer diagnosis, please think about your most recent one.”)

6. What type of cancer were you diagnosed with?

- 1 Leukemia (Acute Lymphoblastic)
- 2 Lymphoma (e.g. Lymphoblastic, Burkitts, Large Cell, Non-Hodgkins or Hodgkins)
- 3 Germ Cell (e.g. Testicular, Ovarian, Seminoma, Non-seminoma germ cell, Teratoma)
- 4 Sarcoma (e.g. Osteosarcoma, Ewing's Sarcoma, Rhabdomyosarcoma)
- 8 Other (please describe) _____
- 9 Don't know

- **ASK ONLY IF R'S CANCER APPEARS ON Q6 LIST, How easy or difficult was it to identify the cancer you were diagnosed with?**

Q6

Adults

For the most part, Q6 was easy for respondents to answer and at least one commented that the parenthetical lists were helpful. It does, however, have the same potential challenge as Q5 and Q5b in that respondents may have received a second diagnosis between the time they were screened and the time they respond to the survey.

Youths

None of the youths had trouble choosing their cancer type from this list.

Parents

All parents thought it would be easy for their children to choose their cancer types.

Recommendation: Consider adding instructions to prompt respondents to talk about their "most recent" diagnosis.

7. What best describes your current school and/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
- 8 Other (please describe) _____

8a. Has your school or employment status changed since you were diagnosed with cancer?

NO 0 **Go to Question 9.**
YES 1

- **IF YES, Tell me about that.**
- **IF NO, What has been your situation?**

8b. **IF YES:** What was your school/employment status right before you were diagnosed?

- 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
- 8 Other (please describe) _____

- **What does "right before" mean to you?**
- **[If respondent has difficulty selecting a response, ask why they are hesitating]**

Q8a and Q8b

Adults

Respondents appear to understand Q8a and Q8b are attempting to measure the impact of their diagnosis on their working lives, but may have some difficulty keeping their answers within the parameters of what the items define as a change in employment status. Taking significant time off from work, even while staying with the same company, may feel to some respondents like an impact on their work life that is worth reporting. For example, one respondent who was a full-time student both before and after her cancer diagnosis answered “yes” at Q8a because she had to take a medical leave from college. However, her answers at Q7 and Q8b were both “full-time student.” The survey does not capture the fact that this respondent had to delay her education in order to receive her cancer treatments. Another respondent who answered “no” at Q8a switched companies after the cancer diagnosis, but was working full-time in both places. He took pains to point out, however, that the job change was not related to his cancer diagnosis.

Youths

None of the youths had trouble with this item. For at least one of them, however, the survey again misses what may be salient information – that he was taken out of his school to be home schooled while receiving treatment. This youth reported “full-time student” at Q7 and Q8b.

Parents

One parent whose child was home schooled during the semester he was receiving treatment was unsure how to incorporate that information into an answer and said his child would likely need help doing so. The other parents did not mention that their children would have trouble with these items. However, one parent did ask what “status” meant in this context. This parent’s child was never removed from school and did attend when he felt well enough. His official status did not change. But the child ended up not going to school most of the time.

Recommendation: We are somewhat uncertain as to the intent of this item series. If it is simply to capture the degree of transition experienced by this age cohort during the time they have cancer, consider eliminating Q8a so that all respondents are asked their current school/employment status and what their school/employment status was right before diagnosis (and perhaps switch the order of the questions). This allows researchers to make comparisons while at the same time relieving respondents of the impression that they have to infer additional meaning beyond what is explicitly stated in the item series.

If, however, the intent is to gauge the impact of cancer on respondents’ school and employment situations, it may be worth including information to that effect in the question (e.g., “Did your school/employment situation change because of your cancer diagnosis”). Furthermore, asking explicitly about school/employment status during treatment will capture temporary changes such as taking substantial time off.

9. What is your current living situation? **MARK ALL THAT APPLY**

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members)

[Note if there is a new option provided]

Q9

Adults

For those who do not live alone, this question poses some potential challenges. For example, the phrase in response option 5, “other family members,” overlaps with response options 2, 3, and 4. Further, some respondents (at least one adult and one youth, described below) who are members of a “traditional family” (two parents living together with one or more children) seemed somewhat confused by the notion of having to check more than one box to describe that living situation. Missing the “mark all that apply” instruction (as one adult respondent did) may contribute to that confusion. (We will explore in greater depth the utility of skip patterns and survey instructions during the usability testing round.)

Youths

At least one youth said he wanted to lump everyone in his family (two parents, one brother) into one answer. The two other youths both live with their parents and siblings. One checked “other family members” and the other checked “parent” only.

Parents

One parent, possibly thinking more from his own perspective as the home owner/family patriarch, said his son would respond, “living with parents.” Later discussion revealed that there is a second, younger son in the family. It was not clear why this parent did not include the “living with brother/sister” as a response possibility for his son. Another parent thought her son would mark “other family members” and perhaps “parent” as well. She suggested the question ask “Who lives with you at home?” The third parent thought this item would not be a problem for her child. She said the child would select both “parent” and “other family members.” She felt the examples of brothers and sisters was helpful.

Recommendation: The response options are somewhat difficult for respondents to work with. In particular “other family members” is being interpreted as “other than the respondent” instead of “other than the choices listed above.” To alleviate some of the problem, consider rewording as below.

Who do you live with? MARK ALL THAT APPLY

Spouse/partner

My own or my spouse/partner’s children

Parent(s)/guardian

Siblings

Relatives such as grandparents, uncles, aunts, cousins, neices, nephews

Non-family members

I live alone

10a. Has your living situation changed since your cancer diagnosis?

NO 0 **Go to Question 11.**
YES 1

- **IF NO, What has your living situation been?**
- **IF YES, How has your living situation changed?**

10b. **IF YES:** What was your living situation right before you were diagnosed with cancer?
MARK ALL THAT APPLY.

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent(s)/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members or relatives)

[Note if there is a new option provided]

Q10a and Q10b

Adults

Q10a and Q10b raised similar issues to Q8a and Q8b. One respondent who answered “yes” correctly at Q10a was at pains to explain that the addition of a new baby had nothing to do with his cancer. Another who went from living with roommates to living with a significant other also made a point to explain this change was not related to her cancer. Again, it is not clear to respondents if the intent of these items is to find out the impact of the cancer on their life circumstances, or to simply record any change in their life circumstances.

Youths

Two respondents had no change and reported that correctly. The other interpreted the question as asking about lifestyle changes and answered “yes,” explaining that everyone in his family has a heightened awareness of his physical well-being now. When he saw Q10b, however, he understood the intent of the question and changed his answer at Q10a to “no.”

Parents

Parents expressed similar concerns as noted in Q9. One in particular thought that asking “who are you living with” would be easier for her son to answer than about his “living situation.”

Recommendation: Revise in the same manner as for the Q8a and Q8b series. If the items are not revised, delete “or relatives” from response option 6 in Q10b.

CANCER IMPACT AND INFORMATION NEEDS

11. Have you experienced any of the following problems SINCE YOU WERE DIAGNOSED WITH CANCER?

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

- In your own words, what are these items asking about? IF NEEDED: Were you thinking of problems caused by the cancer itself, by the treatment, both, or something else altogether?
- When did you start experiencing this problem?
- What other problems, if any, did you experience that we did not mention?
- IF YES AT Q11g, Please tell me more about that.
- IF NO AT Q11g, What does "tingling, weakness, or clumsiness of the hands or feet" mean to you? IF NEEDED, What might those problems look or feel like?
- Several of the problems include things like frequent or severe stomach pain, frequent headaches, etc. What does "frequent" mean to you?

Q11

Adults

Several respondents across all age groups commented that their answers would be different for before, during, and after treatment. This relates to the issue raised at Q5a and Q5b, that “since your diagnosis” is something of an artificial distinction for respondents, whose cancer narratives may encompass experiences that preceded the diagnosis. Many respondents answered Q11 for during their treatment. A few suggested the question be asked separately for some (e.g., before and during) or all three of these time periods.

Respondents had no trouble understanding the symptoms listed in this item. At least two of them said that they are familiar with these problems because their doctors often ask if they are experiencing them. At least three respondents pointed out that many of these problems are related to common illnesses such as the flu. They further emphasized that they would answer yes only for problems stemming from the cancer. Two respondents noted that “problems with memory, attention, or concentration” is more of a psychological issue than the others, which are largely somatic. Suggestions for additions to the Q11 sub-items included:

- Weight gain (suggested by two respondents)
- Hot flashes, depression, moodiness, anxiety related to premature menopause (2)
- Sleeplessness (2)
- Hair loss
- Cellulitis
- Sties in the eye
- Hearing loss

Interpretation of the word “frequent” varied, including “more than once a week,” “more than typical,” “more often than it should be,” “more than one” (e.g., more than one headache), and “repetitive.” Given that “frequent” is a vague quantifier, this finding is not surprising or unusual.

Youths

One respondent answered these items only for his treatment but suggested the question ask separately for during and after treatment. Another youth did not report the effects of medication that was secondary to his treatment (nausea, joint pain, and stress fractures caused by the steroids he took to counteract the chemo treatments). The third youth commented that although he only had a fever one time, he wanted to report that it was intense and caused him to faint.

Youth respondents also recognized the problems described in Q11. As well, they reported varying interpretations of “frequent.” One respondent suggested adding to the list “tiredness” and high level of stress (because of everything he “was going through”). The others thought the list was complete.

Parents

Two parents interpreted this question as referring only to symptoms arising from treatment and assumed that their children would do so as well. The third believed his son would be able to answer accurately for most symptoms but that Q11j was a possible concern because “he’s a teenager. Of course he has problems with memory and attention, but I’m not sure he’s aware of it and would give a correct answer.”

Recommendation (Q11): Depending on the intent of the question, respondents may interpret it too broadly (reporting any experience of the problem, regardless of whether it is related to cancer) or too narrowly (focusing only on problems directly related to the primary cancer treatment). Consider rewording the question to more clearly convey its intent, asking, for example, “Have you experienced any of the following problems before, during, or after your treatment?” If expanding the list of sub-items is an option, use respondent suggestions above to do so.

12. Have any of the following people helped you with your decisions about your cancer care (for example, deciding choice of treatment or whether to have certain tests)?

MARK ALL THAT APPLY

- 1 Parent/Guardian
- 2 Spouse or Significant Other
- 3 Brother or Sister
- 4 Friend
- 5 Other Relative (please describe) _____
- 8 Other (please describe) _____

- 6 None of the Above, I make all decisions myself **→ Go to Question 14.**

[Note if there is a new option provided besides any of the ones listed]

- Give me an example of “a decision about your cancer care” that came to mind when you answered this question.

Q12

Adults

There were no apparent problems with this item. Some suggestions for additions to this list included:

Boss/co-workers/clients
Internet chat rooms and web support groups
Doctors

Youths

All of the respondents answered “parents,” explaining that it was “up to them” which treatments the children got. Another included “brother or sister” because he got a lot of moral support from his younger brother during his treatment. One respondent could not provide an example of a medical decision that had to be made since the doctor’s recommendations were followed to the letter.

Parents

Parents did not indicate any apparent problems with this item for their children.

Recommendation: If desired, consider adding categories for “work colleagues/classmates,” “internet chat rooms and support groups” and “healthcare practitioners.” Know that some youth are not involved in making healthcare decisions, which are simply presented to them.

Not at All A Little Somewhat A Lot

13. How MUCH are your medical care decisions influenced by family members or friends?

1

2

3

4

- Tell more about your answer.
- What types of medical care decisions were you thinking about?
- IF NEEDED, Describe how family members might influence your medical decisions. Describe how friends might influence your medical decisions.

Q13

Adults

In general, the question seemed unproblematic to respondents. Most were able to answer fairly easily, although quite a few, when asked to explain their answers, described both “influence” and “support” (e.g., “I talk to my parents about what’s going on, but in the end, I follow the advice of my physician.”).

Youths

One youth who answered “a lot” explained that he “can’t choose” his care for himself, it is his parents’ decision to make. Another answered “a lot,” describing his mother’s close, hands-on involvement every step of the way. One youth vacillated between “not at all” and “a little” because his perception is that the doctor makes the decisions. It is worth remembering that youths under 18 likely have little say in the decisions their parents make about their medical care. Some in this age group are less likely to pay attention to those discussions than are others.

Parents

One parent said “a lot” and did not believe his son would have trouble responding. Another pointed out that the friends of a young respondent would have no impact on medical decisions. And a third noted that it is parents who have control over their minor child’s treatment and so this question will differ for those under 18 than for those over 18.

Recommendation: Leave item as is. Keep in mind that respondents may often be answering not just for influence on medical care decisions but the level of moral support they received from family and friends.

Q14a tested on 3 adult, 3 youth, and 3 parent respondents

14a. From the following options, please select the one person who you think has provided you with the most helpful support since your cancer diagnosis.

- 1 Your Mother
- 2 Your Father
- 3 Your Sister
- 4 Your Brother
- 5 Your Friend
- 6 Your Spouse or Significant Other
- 7 Your Boyfriend or Girlfriend
- 8 Other (please describe) _____

- **Tell more about your answer.**

Q14a

Adults

Of the 3 adults who received this question, two were able to answer easily. The third was unable to answer because he said he had such a large social network that it was difficult to choose any one person.

Youths

One respondent asked whether this question is getting at his entire cancer experience or just the treatment. He said he answered for his treatment but was thinking about the general support in “helping me through everything” that his mother provided. All three youths selected their mothers.

Parents

A father said, “I’m not sure how he would answer this question. I would hope that he would indicate ‘other’ and write in ‘my parents.’” A mother who thought she and her son would probably do the survey together said it might be hard for her child to answer with someone other than her while she is sitting there with him. The third parent indicated no problems.

Recommendation: The intent of this question is unclear. At the least, consider adding an option, “your parents.”

Q14 Old Version (tested on 5 adult respondents)

14. Below are some questions about the effect of cancer in your life. Not all of the questions will apply to you. If they don't, please mark "Does not apply".

Overall, what kind of impact has your cancer had on each of the following areas of your life?

	None	Positive	Negative	Does not apply
a. Relationship with your mother	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b. Relationship with your father	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c. Relationship with your sister(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d. Relationship with your brother(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e. Relationship with spouse or significant other	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f. Relationship with friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g. Dating	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h. Plans for getting married	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i. Sexual function/intimate relations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
j. Plans for having children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
k. Spirituality and religious beliefs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <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"/>
m. Feelings about the appearance of your body	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
n. Confidence in yourself	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
o. Ability to make decisions about your healthcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
p. Control over your life	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
q. Plans for education	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
r. Plans for work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
s. Financial situation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

Q14 New Version (tested on 3 adult, 3 youth, and 3 parent respondents)

14. Below are some questions about the effect of cancer in your life. Not all of the questions will apply to you. If they don't, please mark "Does not apply".

Please indicate what kind of overall impact your cancer has had on each of the following areas of your life.

	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"/>	8 <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"/>	8 <input type="checkbox"/>
c. Relationship with your siblings (sisters, brothers)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <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"/>	8 <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"/>	8 <input type="checkbox"/>
f. Dating	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
g. Plans for getting married	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
h. Sexual function/intimate relations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
i. Plans for having children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
j. Spirituality and religious beliefs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
k. 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"/>	8 <input type="checkbox"/>
l. 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"/>	8 <input type="checkbox"/>
m. 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"/>	8 <input type="checkbox"/>
n. Control over your life	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
o. Plans for education	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
p. Plans for work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
q. Financial situation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>

- Tell me more about [SELECT 1-2 ANSWERS FOR R TO ELABORATE]
- FOR Q14k (plans for the future and goal setting), What kinds of things were you thinking of when you answered this question?
- What time period were you thinking about (e.g., since your diagnosis, yesterday, when you were sick...).
- Were the time periods you were thinking about different depending on the item?
- How easy or difficult was it for you to describe the impact of the cancer on these various areas of your life? [IF NEEDED, Were there some items where you wanted to choose both positive and negative? IF YES, How did you choose one or the other?]
- How did you decide on your rating if the impact of the cancer changes?
- In what other areas of your life, if any, has cancer had an impact?

Q14

Adults

Among the 5 respondents who received the original version of Q14, many noted that their cancer experience is not static, but changes constantly. Thus, some impacts could be positive at one time, negative at another. Several of them left items blank or changed their answers as they tried to decide how best to report on their experiences. One respondent wanted to report on the impact of cancer on her life “overall.”

The new version of Q14 appeared to alleviate these problems somewhat, although there was still some evidence that answers at different items represented different points in time (e.g., “since the diagnosis” versus “since the surgery”). Also in the new version, some respondents suggested that “relationship with friends” be added; some noted that the “no impact” response did not adequately capture an impact that balanced out over time from positive or negative to neutral.

Youths

One respondent (just turned 17) appeared to have little difficulty identifying the items that applied to him, answering them and appropriately marking those that did not apply to him. The other two respondents had some trouble. One of them indicated that several items were “too abstract” for him, such as plans for education and plans for work, dating, sexual function, plans for having children. He marked “no impact” rather than “does not apply” for these items. For the new Q14e, “relationship with your children,” one youth left this blank while another marked “does not apply.”

Parents

Of two parents who generally agreed that their children would be able to understand and answer Q14, one said her child may not have thought about all of the sub-items and the other said her child might not answer the “intimate relations” item honestly. A third parent (whose son had no apparent trouble responding to Q14) felt many of the sub-items were problematic. For example, he said Q14o, Q14p, and Q14q would have no meaning for his son. Further, he seemed skeptical that his son would be able to distinguish normal teenage feelings from feelings about his body specifically related to cancer (Q14l).

Recommendation (Q14): Leave item as is but consider adding a question about the impact of cancer on respondents’ “life overall” as well as putting “relationship with friends” back on the list. Be aware that many of these items will not apply or may be meaningless to younger respondents.

15. **At this time**, do you need new information about any of the following?

	<i>I NEED</i>		
	NO more information	SOME more information	MUCH more information
a. Handling possible long-term side effects of cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Handling concern about the cancer returning	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. How to check signs that cancer has returned	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Handling concern about getting another type of cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e. Financial support for medical care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f. Staying physically fit/or getting exercise	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
g. Nutrition and diet	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
h. A family member’s risk of getting cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
j. New treatments for your cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
l. How to talk about your cancer experience with family and friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
n. Any other need for information (please describe): _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

- Tell me more about [SELECT 1-2 ANSWERS FOR R TO ELABORATE]
- Have you ever searched for information? What type?
- When you answered that you needed new information about [something they mention in Q15], when were you thinking about needing it?

- **How easy or difficult was it for you to decide whether you needed more, some, or no information about these various things?**

Q15

Adults

For the most part, respondents appeared able to answer these items fairly easily. At least three of them, however, mentioned that they would have liked an option between “no more information” and “some more information.” For some topics, these respondents felt they were pretty well informed but they did not want to rule out the possibility that there is useful information out there that they are not aware of. Related to this at least one person also pointed out that the question does not allow respondents to report the topics for which they already sought information. A response option set that accounts for both past behavior and future needs may include the following:

“Know enough, don’t need more information”

“Know a lot, but would welcome more information”

“Don’t know much about this and need more information”

“Don’t know much about this and don’t need more information”

Respondents also suggested a few additional topics to include in the list of sub-items such as cooking, exercise, lifestyle/personal care issues, and getting involved in cancer advocacy and fundraising.

Youths

One youth had no trouble with answering, but pointed out that he would only use the “much more” category if he had heard absolutely nothing about the topic. He had heard at least something about all the topics and so never used the “much more” option. A second youth wanted a “haven’t thought about it” option and felt some of the topics (e.g., possible long term side effects) were hard to answer for. The third youth checked “much more information” and indicated this was information he wanted to track far into the future. He knows the current treatment for his condition and wants to assess the advances made in treating his condition in the years to come.

Parents

One parent noted that his son might want a “don’t know” column. In particular, he thought Q15e, Q15h, Q15i, and Q15k would pose problems for his son. The other parents thought their children would have no problem with the question, although one did point out that insufficient attention is given to how to deal with teachers and school when returning from cancer treatment.

Recommendation: Depending on the intent of the question, consider revising the response options as described above and/or adding the additional topics suggested by the respondents.

Q16-Q27

Adults

Adult respondents were not administered these items.

Youths

Youths were not administered these items consistently enough to provide useful information about them.

Parents

Two parents were asked to review the items to see how difficult or easy they felt it might be for their children to answer them. Both said their children would not have a problem understanding and responding to these questions. Both also provided suggestions for making the items somewhat more relevant to teenagers.

Provide examples of teenage activities in Q17, such as sports or school-related.

Add “or school” to “problems with work” in Q18-20.

In Q22, add an explanation to “emotional problems” (e.g., “such as feeling depressed or anxious”).

Recommendation: If it is possible, consider adding in the teen-related examples.

SECTION B. (COMPLETE WITH HELP AS NEEDED)

The following 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.

TREATMENTS RECEIVED

28. The next set of questions will ask about some of the treatments you may have received. Chemotherapy is a medication that is often given through an intravenous (IV) or port in a doctor’s office or hospital, but it may also be given as a pill.

a. Are you now receiving or have you ever had chemotherapy?

NO 0

YES 1

DON'T KNOW 9

- Tell me more about that.

Q28

Adults

This item was not problematic for respondents, although at least one pointed out that the wording is somewhat awkward. He suggested revising to “through an intravenous (IV) or a port.”

Note that respondents with more than one cancer diagnosis will need instruction about how to answer this item.

Youths

None of the respondents had any trouble answering this question (they each received chemotherapy).

Parents

All three parents indicated it would not be a problem for their children to answer this question.

Recommendation: If needed, fix awkward wording and/or add reminder about “most recent diagnosis.” Otherwise, leave item as is.

b. Are you scheduled to have chemotherapy treatments in the future?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

- How easy or difficult was it to provide an answer to this question?
- What does “in the future” mean to you?

Q28b

Adults

Most respondents seemed to understand this question as asking whether there were appointments or treatment plans for chemotherapy in the works and answered accordingly. For example, one respondent who is taking a course of chemo medication for two weeks every 3 months over the next year answered “yes.” Another whose chemotherapy has ended answered “no” and a third who is in the process of deciding whether to pursue this type of treatment answered “don’t know.” However, at least one respondent wondered whether the question was asking if there was actually an appointment or asking if chemotherapy remains in “the realm of possibility.”

Youths

One youth answered “no” with little trouble, explaining that there is nothing “already set up” that he “has to do.” At the same time, he pointed out that he’s not ruling out the possibility of chemotherapy if “something else comes up.” One youth who answered “yes” considered the maintenance medicine he takes on a daily basis to be a “scheduled” treatment. The other respondent answered “no,” apparently correctly.

Parents

All three parents thought their children would have difficulty with this item. One did not think his son would know the answer. Two felt the word “scheduled” was ambiguous and could refer either to an appointment or simply to the chemotherapy being part of a planned treatment.

Recommendation (Q28b): Reword the question to more clearly convey whether it is asking about actual appointments or a general plan for future treatment.

29a. Have you ever had any of the following other treatments for your cancer?

	NO	YES
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>

- Please tell me more about your answer.
- What time frame is this question asking about?

Q29a

Adults

Respondents could answer this item, although a few wondered whether to include in their answers surgery or other procedures they received either to diagnose the cancer or prepare them for treatment (e.g., insertion of a port, bone marrow biopsy).

Youths

One youth marked “yes” for surgery and was thinking of two: a biopsy, which he explained was not part of his treatment but the results of which did help his doctors figure out what kind of treatment to give him; and the insertion of his pick line for the chemotherapy. The other two also counted their surgeries to have a port put in. One of them wanted to distinguish his foot surgery from his cancer treatment, although it may be that his foot’s stress fracture is attributable side effects of his cancer treatment.

Each of the youth respondents asked for clarification of “bone marrow or stem cell transplant” as they tried to figure out whether a bone marrow biopsy should be counted as a “yes.” They decided against it, reasoning that the item is asking whether one has received bone marrow from a donor.

Parents

None of the parents thought this item would pose a problem for their children.

Recommendation: Unless there is a strong analytic reason to keep Q28 and Q29a separate, consider combining them. Including “chemotherapy” in the list of possible treatments at Q29 may help respondents focus on procedures they underwent to eradicate their cancer. Reword Q29a-c to say “bone marrow transplant or stem cell transplant.”

29b. Are you scheduled to have any of the following treatments in the future?

I am scheduled to have:	NO	YES	DON'T KNOW
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>

- How easy or difficult is it to answer this question? (Have respondent elaborate on answer). IF NEEDED: do you usually know the treatments you are scheduled for?

Q29b

NOTE: The phrase “I am scheduled to have” in the top row of the table was added later in cognitive testing. It was received by 1 adult, 3 youth, and 3 parent respondents.

Adults

No apparent problems with Q29b.

Youths

No apparent problems.

Parents

One parent who interpreted this item as asking whether any of these treatments are within the realm of possibility (rather than actually having an appointment for them) thought his son might have trouble deciding on an answer. The other two parents thought their children would be able to answer easily, but might provide inaccurate answers because they do not realize removal of their ports will require surgery.

Recommendations: Revise this item to be consistent with whatever revisions are made to Q28b and Q29a.

30. Did you **ever** seek a second opinion from a health care professional about your cancer treatments?

0 No

1 Yes

9 Don't know



Go to Question 31.

- Tell me about what this question is asking.
- What type of doctor would you seek a second opinion from?
- Would you only seek a second opinion from a doctor?

Q30

Adults

This question appeared to pose no challenges to respondents.

Youths

One youth answered no, saying he felt his doctors knew what was best for him. He acknowledged, however, that his parents may have sought additional information without him. Another respondent similarly felt that the doctors knew the best course of treatment. The third was aware of seeking input from other physicians.

Note that at Q30 one youth wished there were a “don’t know” option. He left all his answers blank because he did not know the reason a second opinion was not sought.

Parents

Two parents felt their children could answer this question easily, the third was skeptical his child would know what was meant by a second opinion.

Recommendation: Leave item as is.

30a. If **NO**, why not? **MARK ALL THAT APPLY**

a. My doctor did not recommend it	1 <input type="checkbox"/>
b. I/we didn't think I needed it	1 <input type="checkbox"/>
c. My health insurance did not cover it	1 <input type="checkbox"/>
d. I/we didn't have time	1 <input type="checkbox"/>
d. I/we didn't know I could do that	1 <input type="checkbox"/>
e. Other (please describe) _____	8 <input type="checkbox"/>

- Are there other reasons not listed about why you might not have asked for a second opinion?

CLINICAL TRIALS AND SUPPORT SERVICES

31. 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. Did any of your doctors or health care professionals mention that enrollment in a clinical trial might be an option for you in treating your cancer?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

- Describe what this question is asking about.
- How easy or hard was it to respond?

b. Did you participate in a clinical trial or experimental study of a treatment for cancer?

NO 0
YES 1
DON'T KNOW 9

Go to Question 33.

- If yes, can you tell me about it?
- Tell me what "participate in a clinical trial or experimental study" means.

32. 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 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 know about clinical trial(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b. None of your doctors recommended a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c. There were no trials available for your type or stage of cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d. You did not think that a clinical trial would help you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e. You were worried about side-effects of the treatment in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
f. You were too sick to have treatment in a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
g. You had a problem with insurance coverage or payment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
h. You were worried that you might get a placebo or sugar pill rather than actual treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
i. You were worried that you might be treated like a guinea pig	1 <input type="checkbox"/>	2 <input type="checkbox"/>
j. You were worried that you might receive treatment that had not been sufficiently tested	1 <input type="checkbox"/>	2 <input type="checkbox"/>
k. You were worried that you would have to switch doctors in order to participate in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
l. You could not find a trial that was near you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
m. Any other reason (Please describe) _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>

- How did you come up with your answers?
- FOR ANY DISAGREE ANSWER, Tell me more about your answer. Would it be easier to answer if the question read, "None of my doctors recommended a clinical trial?"
- What does "placebo or sugar pill" mean to you?
- What do you think it means to be "treated like a guinea pig?"

Q31a-Q32

NOTE: Item Q32c, “There were no trials available for your type or stage of cancer,” was added later in cognitive testing. It was received by 1 adult, 3 youth, and 3 parent respondents.

Adults

This item series was somewhat confusing for respondents who were not offered the option of a clinical trial. The addition of Q32c made that list even more confusing because it emphasized the difference between Q32a-c, which could be considered empirical reasons for not participating in a clinical trial, and Q32d-l, which are more emotional reasons for not participating.

Youths

One youth was offered a clinical trial and, with his parents, decided against it. He had no trouble with these items. The other two youths struggled somewhat. One, who reported “don’t know” at Q31a and “no” at Q31b, explained that he was part of some sort of information sharing arrangement his doctor had with other doctors treating patients with the same condition as his. But he did not think this was a clinical trial. The other wanted a “does not apply” column in Q32.

At least two youths were unfamiliar with the words “placebo.” Both were able to interpret it correctly from the context, however.

Parents

One parent was unsure whether his child would know what a clinical trial is or that it was considered but dismissed. A second parent thought her child would know the meaning of the term but would likely not know that they had decided against one for him. The third parent was confident her child could answer, but her description of the situation differed markedly from her son’s (he said the study was not really a clinical trial; she said it was).

Recommendation: Change Q31a to “Were clinical trials available for your type of cancer?”

If NO or DON’T KNOW, skip to Q33.

If YES, ask Q31b.

Drop Q32a and Q32c.

33. Which of these support services do you feel you need or needed, but did not have during or after your cancer treatment?

Support Services	You feel you need or needed, but did <u>not</u> have?
a. Have a nurse come to your home	1 <input type="checkbox"/>
b. Participate in a support group	1 <input type="checkbox"/>
c. See a psychiatrist, psychologist, social worker or mental health worker	1 <input type="checkbox"/>
d. See a physical or occupational therapist for rehabilitation	1 <input type="checkbox"/>
e. See a pain management expert	1 <input type="checkbox"/>
f. Talk with pastoral counselor, such as a chaplain, minister, priest, rabbi, imam, about your cancer	1 <input type="checkbox"/>
g. Get professional advice to help figure out payment for healthcare	1 <input type="checkbox"/>
h. Other (please describe) _____	1 <input type="checkbox"/>

- When was it that you felt you needed [support service checked in Q33]?
- What are these items asking about?
- What is meant by "support services"?
- IF NOTHING IS CHECKED, tell me why you decided not to check any of the boxes.

Q33

NOTE: Item Q33g, “Get professional advice to help figure out payment for healthcare,” was added later in cognitive testing. It was received by 1 adult, 3 youth, and 3 parent respondents.

Adults

Several respondents hesitated about how to indicate a “needed and had” or “didn’t need” answer. This is likely because the format of this item is different from items such as Q32 and Q15, where there is a place to mark either the presence or absence of the issue in question, or items such as Q8a and Q9, where the location of the checkbox to the left of the response option seems to more clearly convey that only those that apply to the respondent should be marked.

Another problem is that the phrase “need but did not have” is double-barreled. At least one respondent suggested that asking about need separate from what was received would have simplified this item for him.

Finally, two respondents (both in the 18-25 age group) answered “yes” for items that were available to them but which they did not feel they needed at the time (the opposite of what is being asked).

For the most part, respondents appeared to understand what “support services” means and many answered for the time period during which they received their cancer treatments.

Suggestions for additions to the list of support services included “case manager” and “financial advisor.” One respondent pointed out that Q32f is biased toward Western religions and suggested organizing religious leaders alphabetically.

Youths

Two youths received this question. One had no trouble answering it. He did not check anything, but provided sound explanations for why. The other remarked that the one-box format seemed odd and he would prefer a “yes/no” format.

Parents

One parent thought his son would be unable to answer this question without help from his parents (in fact, the son was able to answer it easily). The other two parents were confused by the two parts of the question (“need” and “did not have”).

Recommendation: Change the format of the question to make it easier for respondents to understand how to indicate a negative response. Ask separately about need for and receipt of services. Consider adding “case manager” and “financial advisor.” Revise Q33f to read “Talk with a spiritual or religious counselor” and drop the examples.

34. 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

- **Tell me more about your answer. IF NEEDED, How did you come up with that rating?**

Q34

Adults

Respondents had no trouble with this item, although one wanted to rate the different types of healthcare providers separately.

Youths

The two youths who received this question answered it easily.

Parents

The parents all thought their children would easily be able to answer this item. One parent expressed a desire for the ability to rate the different healthcare providers separately.

Recommendation: Leave item as is.

HEALTH INSURANCE

35a. Are you now covered by any type of health insurance?

- 0 No → **Go to Question 36a.**
- 1 Yes

- **What does "covered by any type of health insurance" mean to you?**

35b. **IF YES:** How is this health insurance provided? **MARK ALL THAT APPLY**

- 1 Through you or your spouse's place of employment or through school
- 2 Through your parent
- 3 Through a policy you have purchased yourself
- 4 Medicaid or other public assistance program
- 5 Other State Program (for example, Medi-Cal, SCHIP)
- 6 Military or Veteran's Benefits
- 8 Other, please specify: _____
- 9 Don't know

- **How easy or hard was it for you to answer this question?**

36a. 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	0 <input type="checkbox"/>	Go to Question 37.
YES	1 <input type="checkbox"/>	
DON'T KNOW	9 <input type="checkbox"/>	Go to Question 37.

- **What time period are you being asked about?**
- **What does "since your diagnosis" mean to you?**
- **What about "after your treatment"?**
- **What does "without insurance" meant to you?**

36b. **IF YES:** How long were you or have you been without insurance?

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

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

- NO 0
- YES 1
- DON'T KNOW 9

- **What time period are you thinking about?**
- **What type of doctor did you first see to get diagnosed?**

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

- NO 0
- YES 1
- DON'T KNOW 9

Go to Question 40.
Go to Question 40.

- **What time period are you thinking about?**

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

a. You changed insurance companies	1 <input type="checkbox"/>
b. You changed to different coverage or product with the same employer	2 <input type="checkbox"/>
c. You lost coverage completely – for example, lost a job and also health insurance that came with it	3 <input type="checkbox"/>
d. You lost partial coverage	4 <input type="checkbox"/>
e. You became eligible for public insurance, such as Medicaid, Medi-Cal, Medicare, or a special State program	5 <input type="checkbox"/>
f. You became eligible for employer-based insurance	6 <input type="checkbox"/>
g. You bought additional insurance	7 <input type="checkbox"/>
h. Other (please describe) _____.	8 <input type="checkbox"/>
i. Don't know	9 <input type="checkbox"/>

Q35a-Q39

Adults

Respondents described a variety of insurance situations, including none at all, through parents, through own or spouse's employment, and switching since having cancer. None of these situations posed any particular challenge and for the most part, respondents were able to answer this item series with little trouble.

Youths

One respondent answered these items with little hesitation except at Q38, where he said his parents would know better whether there had been a change in their insurance situation. The others knew about their health insurance status in general (e.g., that they had it, that it had not changed, that it was provided through a purchased policy) but did not know details such who the policyholder is. At least one of the them also said he would have to ask his parents for help with these items.

Parents

All three parents thought their children would know enough to answer most of these items, but may not know some details such as whether the insurance coverage had changed.

Recommendation: Add "partner" to response option 2 at Q35b (consistent with asking about "spouse/partner" in Q9 and Q10b). Otherwise, leave item series as is.

40. Were there any tests or treatments that your doctor recommended for cancer that you did not get because of problems with insurance coverage or because you were unable to pay for them?

NO	0	<input type="checkbox"/>
YES	1	<input type="checkbox"/>
DON'T KNOW	9	<input type="checkbox"/>

- What is this question asking about?
- What types of tests or treatments were you thinking about?

Q40

Adults

Most respondents had no trouble with this item. Two respondents described situations where treatment options were not covered but their health providers found ways around the restrictions. They answered “no” to this item.

Youths

One youth answered easily and provided an appropriate example of insurance restrictions on treatment. He did say he might consult with his parents to be sure, though. The other youth who received this item also appeared to have no trouble with it.

Parents

One parent thought his son would be unable to answer this question (when the son, in fact, did answer it apparently correctly). The others identified no problems with it.

Recommendation: Is there an interest in capturing information about “work-arounds?” If not, leave item as it is.

41. Does your insurance coverage pay for all or part of your prescription medications?

No, I have no coverage for prescriptions	0 <input type="checkbox"/>
Yes, All of my prescription medication costs are paid for	1 <input type="checkbox"/>
Yes, Part of my prescription medication costs are paid for	2 <input type="checkbox"/>
Don't know	9 <input type="checkbox"/>

- How easy or hard is it for you to answer this question?
- Describe your current insurance coverage for medications.

Q41

Adults

A few respondents were unsure how to answer when some of their medications are fully covered and some are only partially covered. At least two respondents wondered which kinds of medications to think about when answering -- treatment-specific, maintenance, or in general. All but one were able to ultimately provide an answer.

Youths

Two youths answered fairly easily, relating that some of their medications have different co-payments than others. One youth answered "no," although given the additional information he provided to the cognitive interviewer about the insurance plan he has, it seems unlikely that his prescription medications are not covered.

Parents

All three parents said their children would be unable to answer this question.

Recommendation: Leave item as is.

- We are considering two different names for this survey - Adolescent and Young Adult Experiences of Care or AYA-HOPE, which stands for Adolescents and Young Adults Health Outcomes and Patient Experience. [GIVE SURVEY TITLE SHOW CARD TO R] Which of these do you prefer? [HAVE R EXPLAIN ANSWER]

Survey title

Adults

Three respondents did not like AYA-HOPE, saying the word “hope” is “loaded” and “weird.” The rest preferred AYA-HOPE, calling it “cool,” “catchy,” and “positive” in its connotation.

Youths

Two of the youths liked AYA-HOPE, one saying it was “more memorable.” The third preferred the shorter title.

Parents

All three parents preferred the first title (Adolescent and Young Adult Experiences of Care) because they felt it was simpler.

- Imagine you were taking this survey on the internet. How likely or not do you think you'd be to ask for help with any of these questions if you were taking the survey on the internet? (Have R elaborate on answer.)

Hypothetical internet scenario

NOTE: This question was asked only of the youths.

Two youths said they would not get up from filling out the internet survey to ask their parents for help, regardless of whether the survey allowed them to pause or exit and come back later. The third one said if he received a user name and password in the mail, he would just fill out the paper instead of typing that information into the computer.

If needed, we can explore this issue further in the usability testing.

- After this phase of testing the survey items, the survey will be administered nationwide to about 500 adolescents and young adults who have been diagnosed with cancer this year. In conjunction with completing the survey, respondents will be asked permission for researchers to review their medical records. For those under 18, parents will be asked permission to review their child's medical records. What ideas do you have about how we might encourage parental consent for that?

Hypothetical medical record review scenario

NOTE: This question was asked only of the parent respondents.

One parent said that while he had no qualms about releasing his son's medical records, he thought the treating facility might put up a battle because of liability issues. The other two parents were hesitant because of concerns about data security, confidentiality, identity theft and what the record release might mean in general for their child's information. They did think the involvement of NCI was an important plus and one of them said she would be influenced if her child's doctor endorsed the study.

Other issues

One adult respondent noted that the affect of cancer on one's work life (e.g., extended time off, shortened hours) is missing from the survey. Parent respondents made a similar point about the effect of cancer on teenagers' school life (e.g., relationship with teachers) and social life (e.g., peer pressure).

One parent also said she thought that questions about the child's medical experiences were slightly generic. She recommended asking specifically about experiences in the hospital, at a treatment center, with doctors, and separately with nurses.

At least two parents thought it would be a good idea to instruct under 18 respondents to simply give Section B to their parents to fill out.

ADOLESCENT AND YOUNG ADULT EXPERIENCES OF CARE: [EXACT TITLE TBD]

Section A

The following questions ask about you and your experiences with your medical care. This survey is designed for people of different ages (including adolescents and young adults between age 15 and 40). Please answer as best as you can and feel free to ask a parent or guardian for assistance if you need it.

YOUR PERSONAL CHARACTERISTICS

1. What is your date of birth? _____
 MONTH DAY YEAR

2. Do you consider yourself to be...
 - 1 Hispanic or Latino?
 - 2 NOT Hispanic or Latino?

3. Which of the following describes your race? **MARK ALL THAT APPLY**
 - 1 White
 - 2 Black or African American
 - 3 Asian
 - 4 American Indian or Alaska Native
 - 5 Native Hawaiian/ Other Pacific Islander
 - 8 Other (please describe) _____

4. What is the highest level of education you have completed?
 - 1 Grade school – between 1 and 8 years
 - 2 Some high school
 - 3 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.)

5. Within the past 12 months, were you (or your parent/guardian) told by a doctor or other health care professional that you had cancer?

- 0 No
1 Yes

5b. When did the doctor or other health care professional tell you (or your parent/guardian) that you had cancer?

_____ _____
MONTH YEAR

6. What type of cancer were you diagnosed with?

- 1 Leukemia (Acute Lymphoblastic)
2 Lymphoma (e.g. Lymphoblastic, Burkitts, Large Cell, Non-Hodgkins or Hodgkins)
3 Germ Cell (e.g. Testicular, Ovarian, Seminoma, Non-seminoma germ cell, Teratoma)
4 Sarcoma (e.g. Osteosarcoma, Ewing's Sarcoma, Synovial Sarcoma)
8 Other (please describe) _____
9 Don't know

7. What best describes your current school and/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
8 Other (please describe) _____

8a. Has your school or employment status changed since you were diagnosed with cancer?

NO	0 <input type="checkbox"/>	Go to Question 9.
YES	1 <input type="checkbox"/>	

8b. **IF YES:** What was your school/employment status right before you were diagnosed?

- 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
- 8 Other (please describe) _____

9. What is your current living situation? **MARK ALL THAT APPLY**

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members or relatives)

10a. Has your living situation changed since your cancer diagnosis?

NO	0 <input type="checkbox"/>	Go to Question 11.
YES	1 <input type="checkbox"/>	

10b. **IF YES:** What was your living situation right before you were diagnosed with cancer? **MARK ALL THAT APPLY.**

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent(s)/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members or relatives)

CANCER IMPACT AND INFORMATION NEEDS

11. Have you experienced any of the following problems SINCE YOU WERE DIAGNOSED WITH CANCER?

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

12. Have any of the following people helped you with your decisions about your cancer care (for example, deciding choice of treatment or whether to have certain tests)?

MARK ALL THAT APPLY

- 1 Parent/Guardian
- 2 Spouse or Significant Other
- 3 Brother or Sister
- 4 Friend
- 5 Other Relative (please describe) _____
- 8 Other (please describe) _____

6 None of the Above, I make all decisions myself **→ Go to Question 14.**

Not at All A Little Somewhat A Lot

13. How MUCH are your medical care decisions influenced by family members or friends? 1 2 3 4

14. Below are some questions about the effect of cancer in your life. Not all of the questions will apply to you. If they don't, please mark "Does not apply".

Overall, what kind of impact has your cancer had on each of the following areas of your life?

	None	Positive	Negative	Does not apply
a. Relationship with your mother	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b. Relationship with your father	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c. Relationship with your sister(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d. Relationship with your brother(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e. Relationship with spouse or significant other	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f. Relationship with friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g. Dating	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h. Plans for getting married	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i. Sexual function/intimate relations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
j. Plans for having children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
k. Spirituality and religious beliefs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <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"/>
m. Feelings about the appearance of your body	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
n. Confidence in yourself	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
o. Ability to make decisions about your healthcare	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
p. Control over your life	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
q. Plans for education	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
r. Plans for work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
s. Financial situation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

15. **At this time**, do you need new information about any of the following?

<i>I NEED</i>			
	NO more information	SOME more information	MUCH more information
a. Handling possible long-term side effects of cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Handling concern about the cancer returning	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. How to check signs that cancer has returned	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Handling concern about getting another type of cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e. Financial support for medical care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f. Staying physically fit/or getting exercise	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
g. Nutrition and diet	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
h. A family member's risk of getting cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
j. New treatments for your cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
l. How to talk about your cancer experience with family and friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
n. Any other need for information (please describe): _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

GENERAL HEALTH

16. In general, would you say your health is:

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

17. The following questions are about activities you might do during a typical day. Does your overall health **now** limit you in these activities? If so, how much?

	No, Not Limited at All	Yes, Limited a Little	Yes, Limited a Lot
a. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Climbing <u>several</u> flights of stairs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

18. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

IN THE PAST 4 WEEKS, PROBLEMS DUE TO <u>PHYSICAL</u> HEALTH	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. You <u>accomplished less</u> than you would like	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. You were limited in the <u>kind</u> of work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

19. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

IN THE PAST 4 WEEKS, PROBLEMS DUE TO <u>EMOTIONAL HEALTH</u>	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. You <u>accomplished less</u> than you would like	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. You were limited in the <u>kind</u> of work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

20. In the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

- 1 None
 2 A little bit
 3 Moderately
 4 Quite a bit
 5 Extremely

21. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. Have you felt calm and peaceful?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. Did you have a lot of energy?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. Have you felt downhearted and depressed?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

22. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- 1 None of the time
 2 A little of the time
 3 Some of the time
 4 Most of the time
 5 All of the time

HEALTH and SOCIAL ISSUES

Below is a list of things that might be a problem for you. There are no right or wrong answers. Please tell us **how much of a problem** each one has been for you during the **past month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

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

	Never	Almost Never	Some-times	Often	Almost Always
23. General Fatigue (PROBLEMS WITH...)					
a. I feel tired	0	1	2	3	4
b. I feel physically weak (not strong)	0	1	2	3	4
c. I feel too tired to do things that I like to do	0	1	2	3	4
d. I feel too tired to spend time with my friends	0	1	2	3	4
24. About my Health and Activities (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. It is hard for me to walk more than one block	0	1	2	3	4
b. It is hard for me to run	0	1	2	3	4
c. It is hard for me to do sports activity or exercise	0	1	2	3	4
d. It is hard for me to lift something heavy	0	1	2	3	4
e. It is hard for me to take a bath or shower by myself	0	1	2	3	4
f. It is hard for me to do chores around the house	0	1	2	3	4
g. I hurt or feel pain	0	1	2	3	4
h. I have low energy	0	1	2	3	4
25. About My Feelings (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. I feel afraid or scared	0	1	2	3	4
b. I feel sad or blue	0	1	2	3	4
c. I feel angry	0	1	2	3	4
d. I have trouble sleeping	0	1	2	3	4
e. I worry about what will happen to me	0	1	2	3	4
26. How I Get Along with Others (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. I have trouble getting along with my peers	0	1	2	3	4
b. I cannot do things that others my age can do	0	1	2	3	4
c. It is hard to keep up with my peers	0	1	2	3	4
27. About My Work/Studies (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. It is hard to pay attention at work or school	0	1	2	3	4
b. I forget things	0	1	2	3	4
c. I have trouble keeping up with my work or studies	0	1	2	3	4
d. I miss work or school because of not feeling well	0	1	2	3	4
e. I miss work or school to go to the doctor or hospital	0	1	2	3	4

SECTION B. (COMPLETE WITH HELP AS NEEDED)

The following 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.

TREATMENTS RECEIVED

28. The next set of questions will ask about some of the treatments you may have received. Chemotherapy is a medication that is often given through an intravenous (IV) or port in a doctor's office or hospital, but it may also be given as a pill.

a. Are you now receiving or have you ever had chemotherapy?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

b. Are you scheduled to have chemotherapy treatments in the future?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

29a. Have you ever had any of the following other treatments for your cancer?

	NO	YES
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>

29b. Are you scheduled to have any of the following treatments in the future?

	NO	YES
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>

30. Did you **ever** seek a second opinion from a health care professional about your cancer treatments?

- 0 No
 1 Yes **→ Go to Question 31.**
 9 Don't know

30a. If **NO**, why not? **MARK ALL THAT APPLY**

a. My doctor did not recommend it	1 <input type="checkbox"/>
b. I/we didn't think I needed it	1 <input type="checkbox"/>
c. My health insurance did not cover it	1 <input type="checkbox"/>
d. I/we didn't have time	1 <input type="checkbox"/>
d. I/we didn't know I could do that	1 <input type="checkbox"/>
e. Other (please describe) _____	1 <input type="checkbox"/>

CLINICAL TRIALS AND SUPPORT SERVICES

31. 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. Did any of your doctors or health care professionals mention that enrollment in a clinical trial might be an option for you in treating your cancer?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

b. Did you participate in a clinical trial or experimental study of a treatment for cancer?

NO	0 <input type="checkbox"/>	
YES	1 <input type="checkbox"/>	Go to Question 33.
DON'T KNOW	9 <input type="checkbox"/>	

32. 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 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 know about clinical trial(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b. None of your doctors recommended a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c. You did not think that a clinical trial would help you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d. You were worried about side-effects of the treatment in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e. You were too sick to have treatment in a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
f. You had a problem with insurance coverage or payment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
g. You were worried that you might get a placebo or sugar pill rather than actual treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
h. You were worried that you might be treated like a guinea pig	1 <input type="checkbox"/>	2 <input type="checkbox"/>
i. You were worried that you might receive treatment that had not been sufficiently tested	1 <input type="checkbox"/>	2 <input type="checkbox"/>
j. You were worried that you would have to switch doctors in order to participate in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
k. You could not find a trial that was near you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
l. Any other reason (Please describe) _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>

33. Which of these support services do you feel you need or needed, but did not have during or after your cancer treatment?

Support Services	You feel you need or needed, but did <u>not</u> have?
a. Have a nurse come to your home	1 <input type="checkbox"/>
b. Participate in a support group	1 <input type="checkbox"/>
c. See a psychiatrist, psychologist, social worker or mental health worker	1 <input type="checkbox"/>
d. See a physical or occupational therapist for rehabilitation	1 <input type="checkbox"/>
e. See a pain management expert	1 <input type="checkbox"/>
f. Talk with pastoral counselor, such as a chaplain, minister, priest, rabbi, imam, about your cancer	1 <input type="checkbox"/>
g. Other (please describe) _____	1 <input type="checkbox"/>

34. Based on your interactions with your doctors, nurses, and other health care professionals, 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

35a. Are you now covered by any type of health insurance?

- 0 No **—————> Go to Question 36a.**
1 Yes

35b. **IF YES:** How is this health insurance provided? **MARK ALL THAT APPLY**

- 1 Through you or your spouse's place of employment or through school
2 Through your parent
3 Through a policy you have purchased yourself
4 Medicaid or other public assistance program
5 Other State Program (for example, Medi-Cal, SCHIP)
6 Military or Veteran's Benefits
8 Other (please describe) _____
9 Don't know

36a. 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	0 <input type="checkbox"/>	Go to Question 37.
YES	1 <input type="checkbox"/>	
DON'T KNOW	9 <input type="checkbox"/>	Go to Question 37.

36b. **IF YES:** How long have you been without insurance?

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

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

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

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

NO	0 <input type="checkbox"/>	Go to Question 40.
YES	1 <input type="checkbox"/>	
DON'T KNOW	9 <input type="checkbox"/>	Go to Question 40.

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

a. You changed insurance companies	1 <input type="checkbox"/>
b. You changed to different coverage or product with the same employer	2 <input type="checkbox"/>
c. You lost coverage completely – for example, lost a job and also health insurance that came with it	3 <input type="checkbox"/>
d. You lost partial coverage	4 <input type="checkbox"/>
e. You became eligible for public insurance, such as Medicaid, Medi-Cal, Medicare, or a special State program	5 <input type="checkbox"/>
f. You became eligible for employer-based insurance	6 <input type="checkbox"/>
g. You bought additional insurance	7 <input type="checkbox"/>
h. Other (please describe) _____.	8 <input type="checkbox"/>
i. Don't know	9 <input type="checkbox"/>

40. Were there any tests or treatments that your doctor recommended for cancer that you did not get because of problems with insurance coverage or because you were unable to pay for them?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

41. Does your insurance coverage pay for all or part of your prescription medications?

No, I have no coverage for prescriptions	0 <input type="checkbox"/>
Yes, All of my prescription medication costs are paid for	1 <input type="checkbox"/>
Yes, Part of my prescription medication costs are paid for	2 <input type="checkbox"/>
Don't know	9 <input type="checkbox"/>

Thank you for your participation in this important study!

5. Within the past 12 months, were you (or your parent/guardian) told by a doctor or other health care professional that you had cancer?

- 0 No
1 Yes

5b. When did the doctor or other health care professional tell you (or your parent/guardian) that you had cancer?

_____ _____
MONTH YEAR

6. What type of cancer were you diagnosed with?

- 1 Leukemia (Acute Lymphoblastic)
2 Lymphoma (e.g. Lymphoblastic, Burkitts, Large Cell, Non-Hodgkins or Hodgkins)
3 Germ Cell (e.g. Testicular, Ovarian, Seminoma, Non-seminoma germ cell, Teratoma)
4 Sarcoma (e.g. Osteosarcoma, Ewing's Sarcoma, Synovial Sarcoma, Rhabdomyosarcoma)
8 Other (please describe) _____
9 Don't know

7. What best describes your current school and/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
8 Other (please describe) _____

8a. Has your school or employment status changed since you were diagnosed with cancer?

NO	0 <input type="checkbox"/>	Go to Question 9.
YES	1 <input type="checkbox"/>	

8b. **IF YES:** What was your school/employment status right before you were diagnosed?

- 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
- 8 Other (please describe) _____

9. What is your current living situation? **MARK ALL THAT APPLY**

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members)

10a. Has your living situation changed since your cancer diagnosis?

NO	0 <input type="checkbox"/>	Go to Question 11.
YES	1 <input type="checkbox"/>	

10b. **IF YES:** What was your living situation right before you were diagnosed with cancer? **MARK ALL THAT APPLY.**

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent(s)/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members or relatives)

CANCER IMPACT AND INFORMATION NEEDS

11. Have you experienced any of the following problems SINCE YOU WERE DIAGNOSED WITH CANCER?

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

12. Have any of the following people helped you with your decisions about your cancer care (for example, deciding choice of treatment or whether to have certain tests)?

MARK ALL THAT APPLY

- 1 Parent/Guardian
- 2 Spouse or Significant Other
- 3 Brother or Sister
- 4 Friend
- 5 Other Relative (please describe) _____
- 8 Other (please describe) _____

6 None of the Above, I make all decisions myself **→ Go to Question 14.**

Not at All A Little Somewhat A Lot

13. How MUCH are your medical care decisions influenced by family members or friends?

1 2 3 4

13a. From the following options, please select the one person who you think has provided you with the most helpful support since your cancer diagnosis.

- 1 Your Mother
- 2 Your Father
- 3 Your Sister
- 4 Your Brother
- 5 Your Friend
- 6 Your Spouse or Significant Other
- 7 Your Boyfriend or Girlfriend
- 8 Other (please describe) _____

14. Below are some questions about the effect of cancer in your life. Not all of the questions will apply to you. If they don't, please mark "Does not apply".

Please indicate what kind of overall impact your cancer has had on each of the following areas of your life.

	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"/>	8 <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"/>	8 <input type="checkbox"/>
c. Relationship with your siblings (sisters, brothers)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <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"/>	8 <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"/>	8 <input type="checkbox"/>
f. Dating	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
g. Plans for getting married	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
h. Sexual function/intimate relations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
i. Plans for having children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
j. Spirituality and religious beliefs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
k. 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"/>	8 <input type="checkbox"/>
l. 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"/>	8 <input type="checkbox"/>
m. 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"/>	8 <input type="checkbox"/>
n. Control over your life	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
o. Plans for education	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
p. Plans for work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
q. Financial situation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>

15. **At this time**, do you need new information about any of the following?

<i>I NEED</i>			
	NO more information	SOME more information	MUCH more information
a. Handling possible long-term side effects of cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Handling concern about the cancer returning	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. How to check signs that cancer has returned	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Handling concern about getting another type of cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e. Financial support for medical care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f. Staying physically fit/or getting exercise	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
g. Nutrition and diet	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
h. A family member's risk of getting cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
j. New treatments for your cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
l. How to talk about your cancer experience with family and friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
n. Any other need for information (please describe): _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

GENERAL HEALTH

16. In general, would you say your health is:

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

17. The following questions are about activities you might do during a typical day. Does your overall health **now** limit you in these activities? If so, how much?

	No, Not Limited at All	Yes, Limited a Little	Yes, Limited a Lot
a. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Climbing <u>several</u> flights of stairs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

18. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

IN THE PAST 4 WEEKS, PROBLEMS DUE TO <u>PHYSICAL</u> HEALTH	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. You <u>accomplished less</u> than you would like	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. You were limited in the <u>kind</u> of work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

19. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

IN THE PAST 4 WEEKS, PROBLEMS DUE TO <u>EMOTIONAL HEALTH</u>	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. You <u>accomplished less</u> than you would like	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. You were limited in the <u>kind</u> of work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

20. In the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

- 1 None
 2 A little bit
 3 Moderately
 4 Quite a bit
 5 Extremely

21. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. Have you felt calm and peaceful?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. Did you have a lot of energy?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. Have you felt downhearted and depressed?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

22. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- 1 None of the time
 2 A little of the time
 3 Some of the time
 4 Most of the time
 5 All of the time

HEALTH and SOCIAL ISSUES

Below is a list of things that might be a problem for you. There are no right or wrong answers. Please tell us **how much of a problem** each one has been for you during the **past month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

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

	Never	Almost Never	Some-times	Often	Almost Always
23. General Fatigue (PROBLEMS WITH...)					
a. I feel tired	0	1	2	3	4
b. I feel physically weak (not strong)	0	1	2	3	4
c. I feel too tired to do things that I like to do	0	1	2	3	4
d. I feel too tired to spend time with my friends	0	1	2	3	4
24. About my Health and Activities (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. It is hard for me to walk more than one block	0	1	2	3	4
b. It is hard for me to run	0	1	2	3	4
c. It is hard for me to do sports activity or exercise	0	1	2	3	4
d. It is hard for me to lift something heavy	0	1	2	3	4
e. It is hard for me to take a bath or shower by myself	0	1	2	3	4
f. It is hard for me to do chores around the house	0	1	2	3	4
g. I hurt or feel pain	0	1	2	3	4
h. I have low energy	0	1	2	3	4
25. About My Feelings (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. I feel afraid or scared	0	1	2	3	4
b. I feel sad or blue	0	1	2	3	4
c. I feel angry	0	1	2	3	4
d. I have trouble sleeping	0	1	2	3	4
e. I worry about what will happen to me	0	1	2	3	4
26. How I Get Along with Others (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. I have trouble getting along with my peers	0	1	2	3	4
b. I cannot do things that others my age can do	0	1	2	3	4
c. It is hard to keep up with my peers	0	1	2	3	4
27. About My Work/Studies (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
a. It is hard to pay attention at work or school	0	1	2	3	4
b. I forget things	0	1	2	3	4
c. I have trouble keeping up with my work or studies	0	1	2	3	4
d. I miss work or school because of not feeling well	0	1	2	3	4
e. I miss work or school to go to the doctor or hospital	0	1	2	3	4

SECTION B. (COMPLETE WITH HELP AS NEEDED)

The following 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.

TREATMENTS RECEIVED

28. The next set of questions will ask about some of the treatments you may have received. Chemotherapy is a medication that is often given through an intravenous (IV) or port in a doctor's office or hospital, but it may also be given as a pill.

a. Are you now receiving or have you ever had chemotherapy?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

b. Are you scheduled to have chemotherapy treatments in the future?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

29a. Have you ever had any of the following other treatments for your cancer?

	NO	YES
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>

29b. Are you scheduled to have any of the following treatments in the future?

	NO	YES	DON'T KNOW
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>

30. Did you **ever** seek a second opinion from a health care professional about your cancer treatments?

- 0 No
 1 Yes **→ Go to Question 31.**
 9 Don't know

30a. If **NO**, why not? **MARK ALL THAT APPLY**

a. My doctor did not recommend it	1 <input type="checkbox"/>
b. I/we didn't think I needed it	1 <input type="checkbox"/>
c. My health insurance did not cover it	1 <input type="checkbox"/>
d. I/we didn't have time	1 <input type="checkbox"/>
d. I/we didn't know I could do that	1 <input type="checkbox"/>
e. Other (please describe) _____	1 <input type="checkbox"/>

CLINICAL TRIALS AND SUPPORT SERVICES

31. 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. Did any of your doctors or health care professionals mention that enrollment in a clinical trial might be an option for you in treating your cancer?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

- b. Did you participate in a clinical trial or experimental study of a treatment for cancer?

NO	0 <input type="checkbox"/>	
YES	1 <input type="checkbox"/>	Go to Question 33.
DON'T KNOW	9 <input type="checkbox"/>	

32. 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 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 know about clinical trial(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b. None of your doctors recommended a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c. You did not think that a clinical trial would help you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d. You were worried about side-effects of the treatment in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e. You were too sick to have treatment in a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
f. You had a problem with insurance coverage or payment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
g. You were worried that you might get a placebo or sugar pill rather than actual treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
h. You were worried that you might be treated like a guinea pig	1 <input type="checkbox"/>	2 <input type="checkbox"/>
i. You were worried that you might receive treatment that had not been sufficiently tested	1 <input type="checkbox"/>	2 <input type="checkbox"/>
j. You were worried that you would have to switch doctors in order to participate in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
k. You could not find a trial that was near you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
l. Any other reason (Please describe) _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>

33. Which of these support services do you feel you need or needed, but did not have during or after your cancer treatment?

Support Services	You feel you need or needed, but did <u>not</u> have?
a. Have a nurse come to your home	1 <input type="checkbox"/>
b. Participate in a support group	1 <input type="checkbox"/>
c. See a psychiatrist, psychologist, social worker or mental health worker	1 <input type="checkbox"/>
d. See a physical or occupational therapist for rehabilitation	1 <input type="checkbox"/>
e. See a pain management expert	1 <input type="checkbox"/>
f. Talk with pastoral counselor, such as a chaplain, minister, priest, rabbi, imam, about your cancer	1 <input type="checkbox"/>
g. Other (please describe) _____	1 <input type="checkbox"/>

34. 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

35a. Are you now covered by any type of health insurance?

- 0 No **—————> Go to Question 36a.**
1 Yes

35b. **IF YES:** How is this health insurance provided? **MARK ALL THAT APPLY**

- 1 Through you or your spouse's place of employment or through school
2 Through your parent
3 Through a policy you have purchased yourself
4 Medicaid or other public assistance program
5 Other State Program (for example, Medi-Cal, SCHIP)
6 Military or Veteran's Benefits
8 Other (please describe) _____
9 Don't know

36a. 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	0 <input type="checkbox"/>	Go to Question 37.
YES	1 <input type="checkbox"/>	
DON'T KNOW	9 <input type="checkbox"/>	Go to Question 37.

36b. **IF YES:** How long were you or have you been without insurance?

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

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

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

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

NO	0 <input type="checkbox"/>	Go to Question 40.
YES	1 <input type="checkbox"/>	
DON'T KNOW	9 <input type="checkbox"/>	Go to Question 40.

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

a. You changed insurance companies	1 <input type="checkbox"/>
b. You changed to different coverage or product with the same employer	2 <input type="checkbox"/>
c. You lost coverage completely – for example, lost a job and also health insurance that came with it	3 <input type="checkbox"/>
d. You lost partial coverage	4 <input type="checkbox"/>
e. You became eligible for public insurance, such as Medicaid, Medi-Cal, Medicare, or a special State program	5 <input type="checkbox"/>
f. You became eligible for employer-based insurance	6 <input type="checkbox"/>
g. You bought additional insurance	7 <input type="checkbox"/>
h. Other (please describe) _____.	8 <input type="checkbox"/>
i. Don't know	9 <input type="checkbox"/>

40. Were there any tests or treatments that your doctor recommended for cancer that you did not get because of problems with insurance coverage or because you were unable to pay for them?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

41. Does your insurance coverage pay for all or part of your prescription medications?

No, I have no coverage for prescriptions	0 <input type="checkbox"/>
Yes, All of my prescription medication costs are paid for	1 <input type="checkbox"/>
Yes, Part of my prescription medication costs are paid for	2 <input type="checkbox"/>
Don't know	9 <input type="checkbox"/>

Thank you for your participation in this important study!

**ADOLESCENT AND YOUNG ADULT EXPERIENCES OF CARE:
[EXACT TITLE TBD]**

Section A

The following questions ask about you and your experiences with your medical care. This survey is designed for people of different ages (including adolescents and young adults between age 15 and 40). Please answer as best as you can and feel free to ask a parent or guardian for assistance if you need it.

YOUR PERSONAL CHARACTERISTICS

1. What is your date of birth? _____
 MONTH DAY YEAR
2. Do you consider yourself to be...
- 1 Hispanic or Latino?
2 NOT Hispanic or Latino?
3. Which of the following describes your race? **MARK ALL THAT APPLY**
- 1 White
2 Black or African American
3 Asian
4 American Indian or Alaska Native
5 Native Hawaiian/ Other Pacific Islander
8 Other (please describe) _____
4. What is the highest level of education you have completed?
- 1 Grade school – between 1 and 8 years
2 Some high school
3 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.)

5. Within the past 12 months, were you (or your parent/guardian) told by a doctor or other health care professional that you had cancer?

- 0 No
1 Yes

5b. When did the doctor or other health care professional tell you (or your parent/guardian) that you had cancer?

_____ _____
MONTH YEAR

6. What type of cancer were you diagnosed with?

- 1 Leukemia (Acute Lymphoblastic)
2 Lymphoma (e.g. Lymphoblastic, Burkitts, Large Cell, Non-Hodgkins or Hodgkins)
3 Germ Cell (e.g. Testicular, Ovarian, Seminoma, Non-seminoma germ cell, Teratoma)
4 Sarcoma (e.g. Osteosarcoma, Ewing's Sarcoma, Rhabdomyosarcoma)
8 Other (please describe) _____
9 Don't know

7. What best describes your current school and/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
8 Other (please describe) _____

8a. Has your school or employment status changed since you were diagnosed with cancer?

NO	0 <input type="checkbox"/>	Go to Question 9.
YES	1 <input type="checkbox"/>	

8b. **IF YES:** What was your school/employment status right before you were diagnosed?

- 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
- 8 Other (please describe) _____

9. What is your current living situation? **MARK ALL THAT APPLY**

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members)

10a. Has your living situation changed since your cancer diagnosis?

NO	0 <input type="checkbox"/>	Go to Question 11.
YES	1 <input type="checkbox"/>	

10b. **IF YES:** What was your living situation right before you were diagnosed with cancer? **MARK ALL THAT APPLY.**

- 1 Living alone
- 2 Living with spouse/partner
- 3 Living with children at home
- 4 Living with parent(s)/guardian
- 5 Living with other family members - relatives, brothers or sisters
- 6 Living with others (non-family members or relatives)

CANCER IMPACT AND INFORMATION NEEDS

11. Have you experienced any of the following problems SINCE YOU WERE DIAGNOSED WITH CANCER?

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

12. Have any of the following people helped you with your decisions about your cancer care (for example, deciding choice of treatment or whether to have certain tests)?

MARK ALL THAT APPLY

- 1 Parent/Guardian
- 2 Spouse or Significant Other
- 3 Brother or Sister
- 4 Friend
- 5 Other Relative (please describe) _____
- 8 Other (please describe) _____

6 None of the Above, I make all decisions myself **→ Go to Question 14.**

Not at All A Little Somewhat A Lot

13. How MUCH are your medical care decisions influenced by family members or friends?

1 2 3 4

14a. From the following options, please select the one person who you think has provided you with the most helpful support since your cancer diagnosis.

- 1 Your Mother
- 2 Your Father
- 3 Your Sister
- 4 Your Brother
- 5 Your Friend
- 6 Your Spouse or Significant Other
- 7 Your Boyfriend or Girlfriend
- 8 Other (please describe) _____

14. Below are some questions about the effect of cancer in your life. Not all of the questions will apply to you. If they don't, please mark "Does not apply".

Please indicate what kind of overall impact your cancer has had on each of the following areas of your life.

	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"/>	8 <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"/>	8 <input type="checkbox"/>
c. Relationship with your siblings (sisters, brothers)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <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"/>	8 <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"/>	8 <input type="checkbox"/>
f. Dating	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
g. Plans for getting married	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
h. Sexual function/intimate relations	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
i. Plans for having children	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
j. Spirituality and religious beliefs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
k. 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"/>	8 <input type="checkbox"/>
l. 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"/>	8 <input type="checkbox"/>
m. 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"/>	8 <input type="checkbox"/>
n. Control over your life	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
o. Plans for education	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
p. Plans for work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>
q. Financial situation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	8 <input type="checkbox"/>

15. **At this time**, do you need new information about any of the following?

<i>I NEED</i>			
	NO more information	SOME more information	MUCH more information
a. Handling possible long-term side effects of cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Handling concern about the cancer returning	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. How to check signs that cancer has returned	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Handling concern about getting another type of cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e. Financial support for medical care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f. Staying physically fit/or getting exercise	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
g. Nutrition and diet	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
h. A family member's risk of getting cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
j. New treatments for your cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
l. How to talk about your cancer experience with family and friends	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <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"/>
n. Any other need for information (please describe): _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

GENERAL HEALTH

16. In general, would you say your health is:

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

17. The following questions are about activities you might do during a typical day. Does your overall health **now** limit you in these activities? If so, how much?

	No, Not Limited at All	Yes, Limited a Little	Yes, Limited a Lot
a. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Climbing <u>several</u> flights of stairs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

18. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

IN THE PAST 4 WEEKS, PROBLEMS DUE TO <u>PHYSICAL</u> HEALTH	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. You <u>accomplished less</u> than you would like	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. You were limited in the <u>kind</u> of work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

19. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

IN THE PAST 4 WEEKS, PROBLEMS DUE TO <u>EMOTIONAL HEALTH</u>	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. You <u>accomplished less</u> than you would like	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. You were limited in the <u>kind</u> of work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

20. In the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

- 1 None
 2 A little bit
 3 Moderately
 4 Quite a bit
 5 Extremely

21. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	None of the Time	A Little of the Time	Some of the Time	Most of the Time	All of the Time
a. Have you felt calm and peaceful?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. Did you have a lot of energy?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. Have you felt downhearted and depressed?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

22. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

- 1 None of the time
 2 A little of the time
 3 Some of the time
 4 Most of the time
 5 All of the time

HEALTH and SOCIAL ISSUES

Below is a list of things that might be a problem for you. There are no right or wrong answers. Please tell us **how much of a problem** each one has been for you during the **past month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

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

	Never	Almost Never	Sometimes	Often	Almost Always
23. General Fatigue (PROBLEMS WITH...)					
a. I feel tired	0	1	2	3	4
b. I feel physically weak (not strong)	0	1	2	3	4
c. I feel too tired to do things that I like to do	0	1	2	3	4
d. I feel too tired to spend time with my friends	0	1	2	3	4
24. About my Health and Activities (PROBLEMS WITH...)	Never	Almost Never	Sometimes	Often	Almost Always
a. It is hard for me to walk more than one block	0	1	2	3	4
b. It is hard for me to run	0	1	2	3	4
c. It is hard for me to do sports activity or exercise	0	1	2	3	4
d. It is hard for me to lift something heavy	0	1	2	3	4
e. It is hard for me to take a bath or shower by myself	0	1	2	3	4
f. It is hard for me to do chores around the house	0	1	2	3	4
g. I hurt or feel pain	0	1	2	3	4
h. I have low energy	0	1	2	3	4
25. About My Feelings (PROBLEMS WITH...)	Never	Almost Never	Sometimes	Often	Almost Always
a. I feel afraid or scared	0	1	2	3	4
b. I feel sad or blue	0	1	2	3	4
c. I feel angry	0	1	2	3	4
d. I have trouble sleeping	0	1	2	3	4
e. I worry about what will happen to me	0	1	2	3	4
26. How I Get Along with Others (PROBLEMS WITH...)	Never	Almost Never	Sometimes	Often	Almost Always
a. I have trouble getting along with my peers	0	1	2	3	4
b. I cannot do things that others my age can do	0	1	2	3	4
c. It is hard to keep up with my peers	0	1	2	3	4
27. About My Work/Studies (PROBLEMS WITH...)	Never	Almost Never	Sometimes	Often	Almost Always
a. It is hard to pay attention at work or school	0	1	2	3	4
b. I forget things	0	1	2	3	4
c. I have trouble keeping up with my work or studies	0	1	2	3	4
d. I miss work or school because of not feeling well	0	1	2	3	4
e. I miss work or school to go to the doctor or hospital	0	1	2	3	4

SECTION B. (COMPLETE WITH HELP AS NEEDED)

The following 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.

TREATMENTS RECEIVED

28. The next set of questions will ask about some of the treatments you may have received. Chemotherapy is a medication that is often given through an intravenous (IV) or port in a doctor's office or hospital, but it may also be given as a pill.

a. Are you now receiving or have you ever had chemotherapy?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

b. Are you scheduled to have chemotherapy treatments in the future?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

29a. Have you ever had any of the following other treatments for your cancer?

	NO	YES
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>

29b. Are you scheduled to have any of the following treatments in the future?

I am scheduled to have:	NO	YES	DON'T KNOW
a. Surgery	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
b. Radiation	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
c. Bone marrow or stem cell transplant	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>
d. Other (please describe) _____	0 <input type="checkbox"/>	1 <input type="checkbox"/>	8 <input type="checkbox"/>

30. Did you **ever** seek a second opinion from a health care professional about your cancer treatments?

- 0 No
 1 Yes **→ Go to Question 31.**
 9 Don't know

30a. If **NO**, why not? **MARK ALL THAT APPLY**

a. My doctor did not recommend it	1 <input type="checkbox"/>
b. I/we didn't think I needed it	1 <input type="checkbox"/>
c. My health insurance did not cover it	1 <input type="checkbox"/>
d. I/we didn't have time	1 <input type="checkbox"/>
d. I/we didn't know I could do that	1 <input type="checkbox"/>
e. Other (please describe) _____	1 <input type="checkbox"/>

CLINICAL TRIALS AND SUPPORT SERVICES

31. 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. Did any of your doctors or health care professionals mention that enrollment in a clinical trial might be an option for you in treating your cancer?

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

b. Did you participate in a clinical trial or experimental study of a treatment for cancer?

NO	0 <input type="checkbox"/>	
YES	1 <input type="checkbox"/>	Go to Question 33.
DON'T KNOW	9 <input type="checkbox"/>	

32. 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 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 know about clinical trial(s)	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b. None of your doctors recommended a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c. There were no trials available for your type or stage of cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d. You did not think that a clinical trial would help you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e. You were worried about side-effects of the treatment in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
f. You were too sick to have treatment in a clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
g. You had a problem with insurance coverage or payment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
h. You were worried that you might get a placebo or sugar pill rather than actual treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>
i. You were worried that you might be treated like a guinea pig	1 <input type="checkbox"/>	2 <input type="checkbox"/>
j. You were worried that you might receive treatment that had not been sufficiently tested	1 <input type="checkbox"/>	2 <input type="checkbox"/>
k. You were worried that you would have to switch doctors in order to participate in the clinical trial	1 <input type="checkbox"/>	2 <input type="checkbox"/>
l. You could not find a trial that was near you	1 <input type="checkbox"/>	2 <input type="checkbox"/>
m. Any other reason (Please describe) _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>

33. Which of these support services do you feel you need or needed, but did not have during or after your cancer treatment?

Support Services	You feel you need or needed, but did <u>not</u> have?
a. Have a nurse come to your home	1 <input type="checkbox"/>
b. Participate in a support group	1 <input type="checkbox"/>
c. See a psychiatrist, psychologist, social worker or mental health worker	1 <input type="checkbox"/>
d. See a physical or occupational therapist for rehabilitation	1 <input type="checkbox"/>
e. See a pain management expert	1 <input type="checkbox"/>
f. Talk with pastoral counselor, such as a chaplain, minister, priest, rabbi, imam, about your cancer	1 <input type="checkbox"/>
g. Get professional advice to help figure out payment for healthcare	1 <input type="checkbox"/>
h. Other (please describe) _____	1 <input type="checkbox"/>

34. 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

35a. Are you now covered by any type of health insurance?

- 0 No **—————> Go to Question 36a.**
1 Yes

35b. **IF YES:** How is this health insurance provided? **MARK ALL THAT APPLY**

- 1 Through you or your spouse's place of employment or through school
2 Through your parent
3 Through a policy you have purchased yourself
4 Medicaid or other public assistance program
5 Other State Program (for example, Medi-Cal, SCHIP)
6 Military or Veteran's Benefits
8 Other (please describe) _____
9 Don't know

36a. 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	0 <input type="checkbox"/>	Go to Question 37.
YES	1 <input type="checkbox"/>	
DON'T KNOW	9 <input type="checkbox"/>	Go to Question 37.

36b. **IF YES:** How long were you or have you been without insurance?

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

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

NO	0 <input type="checkbox"/>
YES	1 <input type="checkbox"/>
DON'T KNOW	9 <input type="checkbox"/>

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

NO	0 <input type="checkbox"/>	Go to Question 40.
YES	1 <input type="checkbox"/>	
DON'T KNOW	9 <input type="checkbox"/>	Go to Question 40.

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

a. You changed insurance companies	1 <input type="checkbox"/>
b. You changed to different coverage or product with the same employer	2 <input type="checkbox"/>
c. You lost coverage completely – for example, lost a job and also health insurance that came with it	3 <input type="checkbox"/>
d. You lost partial coverage	4 <input type="checkbox"/>
e. You became eligible for public insurance, such as Medicaid, Medi-Cal, Medicare, or a special State program	5 <input type="checkbox"/>
f. You became eligible for employer-based insurance	6 <input type="checkbox"/>
g. You bought additional insurance	7 <input type="checkbox"/>
h. Other (please describe) _____.	8 <input type="checkbox"/>
i. Don't know	9 <input type="checkbox"/>

40. Were there any tests or treatments that your doctor recommended for cancer that you did not get because of problems with insurance coverage or because you were unable to pay for them?

NO	0	<input type="checkbox"/>
YES	1	<input type="checkbox"/>
DON'T KNOW	9	<input type="checkbox"/>

41. Does your insurance coverage pay for all or part of your prescription medications?

No, I have no coverage for prescriptions	0	<input type="checkbox"/>
Yes, All of my prescription medication costs are paid for	1	<input type="checkbox"/>
Yes, Part of my prescription medication costs are paid for	2	<input type="checkbox"/>
Don't know	9	<input type="checkbox"/>

Thank you for your participation in this important study!