

Long-Term Follow-Up Study

UNIVERSITY OF MINNESOTA

*University of Minnesota
The Denver Children's Hospital
Children's Hospital of Pittsburgh
Children's Hospital at Stanford University
Dana-Farber Cancer Institute
Children's National Medical Center
U.T.M.D. Anderson Cancer Center
Memorial Sloan Kettering Cancer Center
Texas Children's Hospital
University of California at San Francisco
Seattle Children's Hospital & Medical Center
Toronto Hospital for Sick Children
St. Jude Children's Research Hospital
Children's Hospital of Columbus
Roswell Park Cancer Institute
Mayo Clinic
Children's Health Care - Minneapolis
Children's Hospital of Philadelphia
St. Louis Children's Hospital
Children's Hospital of Los Angeles
UCLA Medical Center
Miller Children's Hospital
Children's Hospital of Orange County
Riley Hospital for Children-Indiana University
UAB/The Children's Hospital of Alabama
University of Michigan-Mott Children's Hospital
Children's Medical Center of Dallas*

Our new mailing address is:

Long-Term Follow-Up Study
Department of Pediatrics
University of Minnesota
420 Delaware St SE, MMC 715
Minneapolis, MN 55455

Toll-free phone number:

1-800-775-2167

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ccss@epi.umn.edu

HEALTH CARE NEEDS SURVEY

The University of Minnesota appreciates your continuing involvement in the Long-Term Follow-Up Study. Your participation provides us with valuable information in the fight against cancer and similar illnesses.

We are very interested in understanding how you feel about your health care needs and any type of problems that you may have experienced when going to a doctor.

Please fill out the following brief questionnaire to tell us about your experience with the health care system. In order for us to educate physicians and health care administrators, it is important that you answer these questions as honestly as possible. Many of the questions have no "correct" answer - we want to know how you think or feel about things.

You can be assured that we will respect your privacy at all times. Your answers will not be seen by your doctor or health care provider.

Your generosity in participating is greatly appreciated.

Person completing this questionnaire is:

(Please print your full name)

Today's date: _____
(Month/day/year)



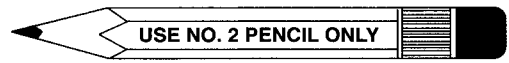
DO NOT WRITE IN THIS AREA

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Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use the *No. 2 pencil enclosed* (Please do *not* use pen).
2. Completely darken your answers, that is, fill in the full circle.



CORRECT A B C ● ○ INCORRECT X ✓ ● ○

Written responses must stay within the boxes provided.

3. Make no stray marks of any kind. Other than your responses, please keep the form as clean as possible. Erase cleanly any answer you wish to change. Do not use "white-out".

CORRECT

grape

INCORRECT

grape

As you know, you were asked to participate in this study because you were treated for cancer, leukemia, tumor, or a similar illness. Hereafter, when a question says "cancer", it is referring to your previous illness.

A.1 Between July 1, 1998 and June 30, 2000 (2 year period), did you see a health care professional for any type of health problem?

- No (Go to question A.5)
- Yes

A.2 Where did you receive your health care?
(Mark all that apply)

- Primary care physician's office (family physician, general practitioner, internist, pediatrician)
- Obstetrician/Gynecologist
- Cancer specialist's office
- Cancer Center
- Hospital
- Emergency Room or Urgent Care Center
- Other (specify in the box below)

A.3 During this two year period (July 1, 1998 - June 30, 2000), how many times did you see a doctor? (If 0 times, go to Question A.7.)

0	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9

In this survey, when we refer to "doctor", we mean a physician, such as a primary care physician or a cancer specialist.

A.4 As you know, you were asked to participate in this study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of the above visits were related to this previous illness?

0	0
1	1
2	2
3	3
4	4
5	5
6	6
7	7
8	8
9	9

A.5 For your non-emergency care, do you have a primary care physician or a place you go for medical care?

- No
- Yes

A.6 During this two year period, did you go to a doctor for a "routine medical check-up"?

- No
- Yes

A.7 During this two year period (July 1, 1998 - June 30, 2000), did you have a health problem that you thought might be related to your cancer?

- No (Go to question A.13)
- Yes

A.8 If yes in question A.7, did you see a doctor?

- No - Why not? (specify in the box below)

- Yes

A.9 If yes in question 8, what type of doctor did you see (first)? (Mark only one)

- Primary care physician (family physician, general practitioner, internist, pediatrician)
- Obstetrician/Gynecologist
- Pediatric oncologist (cancer specialist for children)
- Adult oncologist (cancer specialist for adults)
- Emergency Room or Urgent Care physician
- Other (specify in the box below)

A.10 How satisfied were you with the care that you received at this visit?

- Very Unsatisfied
- Somewhat Unsatisfied
- Neutral
- Somewhat Satisfied
- Very Satisfied

A.11 Did the doctor that you saw in question A.9 refer you to another doctor?

- No (Go to question A.13)
- Yes

A.12 If yes in question A.11, what type of doctor(s) were you referred to: (Mark all that apply)

- Obstetrician/Gynecologist
- Pediatric oncologist (cancer specialist)
- Adult oncologist (cancer specialist)
- Specialist for adult health problems (e.g., cardiologist, gastroenterologist, urologist)
- Psychologist or counselor
- Other (specify in the box below)

A.13 During this two year period (July 1, 1998 - June 30, 2000), did you see an alternative health practitioner (for example, an acupuncturist, chiropractor, or herbalist) for any problems related to your previous cancer?

- No
- Yes (specify in the box below)

A.14 During the next two years, what are the chances that you will go to a doctor for a routine check-up?

- Very Unlikely
- Unlikely
- Possibly
- Likely
- Very Likely

A.15 In the next two years, what are the chances that you will go to a doctor to check and see if you have any health problems caused by your previous cancer treatment?

- Very Unlikely
- Unlikely
- Possibly
- Likely
- Very Likely

A.16 Would you say your health is (mark only one):

- Poor
- Fair
- Good
- Very Good
- Excellent

A.17 Do you have any chronic health problems (that have lasted longer than six months) related to your cancer or cancer treatment?

- No (Go to question A.19)
- Yes (Please describe your main chronic health problem in the box below)

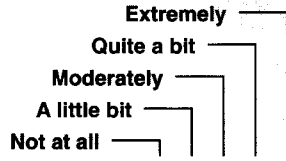
A.18 If yes in question A.17, how would you rate your main chronic health problem?

- Mild Do not take any medications and it does not affect my daily life.
- Moderate Take medications regularly or have to go to the doctor more often for testing or monitoring.
- Severe Has significantly changed my daily activities and/or requires close monitoring by a doctor.
- Life-threatening

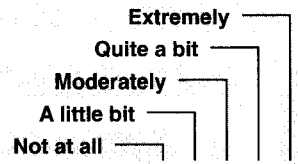
A.19 Since you finished your treatment for cancer, have you ever seen a primary care physician (family physician, general practitioner, internist, pediatrician) for a problem that you thought might be related to your previous cancer?

- No
- Yes - When? (approximate month, year in the box below)

The following questions ask about how you feel. There are no right or wrong answers - please answer how you feel.

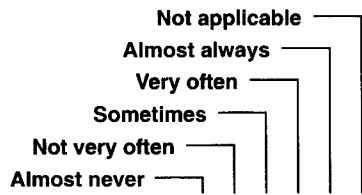


- B.1 Some people are very concerned about their health, while others are not as concerned. How concerned are you about your own health? ○○○○○
- B.2 Some people are very interested in going to the doctor for a general physical exam to check on their health, while others are not as interested. How interested are you about going to a doctor for "routine medical check-ups"? ○○○○○
- B.3 How important do you feel it is for you to have a routine check-up to see if you have any problems caused by the treatment of your previous cancer? ○○○○○
- B.4 Some survivors of childhood cancer think that they can develop a health problem from their treatment several years later, while others do not think that they can ever have any more problems related to their previous cancer. How likely do you think it is that you might develop a health problem related to your previous treatment for cancer? ○○○○○
- B.5 Some people are quite concerned about the chance of getting sick, while others are not as concerned. How concerned are you about the chance of getting sick? .. ○○○○○
- B.6 If you had a problem that you thought was related to your previous cancer, do you feel that it would be easy to find a doctor to see you? ○○○○○
- B.7 If you wanted to go see a doctor for a problem that you thought was related to your previous cancer, would transportation be much of a problem? ... ○○○○○
- B.8 If you wanted to go see a doctor for a problem that you thought was related to your previous cancer, would health insurance coverage be much of a problem? ○○○○○



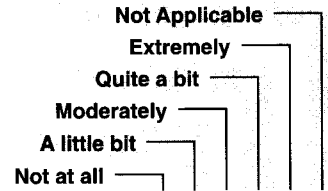
- B.9 In general, do you feel that doctors take enough time to answer your questions? ... ○○○○○
 - B.10 Today, when you think about your cancer treatment, how painful do you remember it being? ○○○○○
-
-
- B.11 Do you ever feel uncertain about your future health? ○○○○○
 - B.12 Do you ever worry that your cancer will come back? ○○○○○
 - B.13 Do you ever feel like you are different from others because you had cancer? ... ○○○○○
 - B.14 Do you ever feel like you want to forget that you had cancer, and just be like everyone else? ○○○○○
 - B.15 Do you ever worry about being called a complainer or a hypochondriac? ○○○○○
 - B.16 Do you ever worry that a problem with your health will be discovered if you go to a doctor for a routine check-up? ○○○○○
 - B.17 In general, do you feel that you can ask a doctor questions about your previous cancer? ○○○○○
 - B.18 Do you feel that your fears or concerns regarding your previous cancer have been addressed by doctors or nurses? ... ○○○○○
 - B.19 In general, how often do you feel that a primary care physician (family physician, general practitioner, internist, pediatrician) can handle problems that may have been caused by your cancer treatment? ○○○○○

The following questions ask about your health and experiences with your family and friends. There are no right or wrong answers - please answer how you feel.



- C.1 How often do you think your parent(s) worry about your health? ○○○○○○
- C.2 If you are married, how often do you think that your spouse worries about your health? ○○○○○○
- C.3 Do members of your family ever tell you that because you are cured from your cancer, you do not need to see a doctor for follow-up? ○○○○○○
- C.4 Do your friends or family ever tell you that you should "be grateful" that your cancer was cured? ○○○○○○
- C.5 Do members of your family ever tell you "to put it all behind you and get on with life?" ○○○○○○
- C.6 When you were growing up, did your mother go to a doctor for routine physical examinations?
- Never
 - Rarely
 - Some of the time
 - Most of the time
 - Every year
 - Do not know
- C.7 When you were growing up, did your father go to a doctor for routine physical examinations?
- Never
 - Rarely
 - Some of the time
 - Most of the time
 - Every year
 - Do not know

Some people trust doctors, while others do not. For the following three questions, indicate how much you and your family trust doctors.



- C.8 In general, how much do you trust doctors? ○○○○○○
- C.9 In general, how much do your parent(s) trust doctors? ○○○○○○
- C.10 In general, how much does your spouse trust doctors? ○○○○○○

The following questions are about your health care.

- D.1 About how many years has it been since you last talked by telephone or in person with a doctor or a nurse from the hospital where you received most of your cancer treatment?
- Within the last year (12 months)
 - Between 1 - 2 years ago
 - Between 2 - 3 years ago
 - Between 3 - 4 years ago
 - More than 4 years ago
- D.2 When was the last time you had a check-up at the hospital where you received most of your cancer treatment?
- Within the last year (12 months)
 - Between 1 - 2 years ago
 - Between 2 - 3 years ago
 - Between 3 - 4 years ago
 - More than 4 years ago
- D.3 Have you ever been given a written summary of the treatment you received for your previous cancer?
- No (Go to question D.5)
 - Yes
 - Not sure (Go to question D.5)
- D.4 If yes in question D.3, could you easily find the summary?
- No
 - Yes

Please continue on the next page.

D.5 How far do you currently live from the hospital where you received most of your cancer treatment?

- 0 - 50 miles
- 51 - 100 miles
- 101 - 200 miles
- More than 200 miles

D.6 Which of the following describes the area where you live?

- Rural
- Urban
- Suburban

D.7 We want to know your rating of all of your health care in the past two years from all doctors and other health care professionals (mark only one number):

- 1 - Worst health care possible
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10 - Best health care possible
- Not Applicable

D.8 During these past two years, how difficult was it getting a referral to a specialist if you needed one?

- Very difficult
- Fairly difficult
- Little difficult
- Fairly easy
- Very easy
- Not applicable

D.9 During these past two years, how difficult was it dealing with your health maintenance organization (HMO)?

- Very difficult
- Fairly difficult
- Little difficult
- Fairly easy
- Very easy
- Not applicable

D.10 During these past two years, did you read a newspaper or magazine article about long-term health problems related to childhood cancer?

- No (Go to question D.12)
- Yes

D.11 If yes in question D.10, did the article make you feel like you wanted to go to a doctor for a check-up?

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

D.12 In these past two years, did you read a newsletter from the Long-Term Follow-Up Study?

- No (Go to question D.14)
- Yes

D.13 If yes in question D.12, did the newsletter make you feel like you wanted to go to a doctor for a check-up?

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

D.14 In these past two years, did you see a television or news program about long-term health problems related to childhood cancers?

- No (Go to question D.16)
- Yes

D.15 If yes in question D.14, did the television or news program make you feel like you wanted to go to a doctor for a check-up?

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely

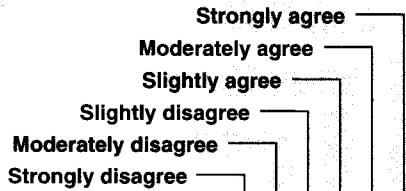
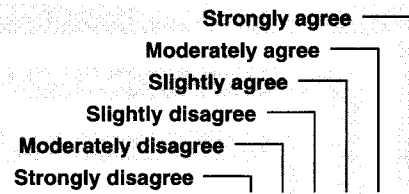
D.16 During these past two years, did a family member suggest that you should go to a doctor for a check-up?

- No
- Yes

D.17 During these past two years, did a friend suggest that you should go to a doctor for a check-up?

- No
- Yes

Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to mark the circle of the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you mark. The more you disagree with a statement, the lower the number you mark. Please make sure that you answer EVERY ITEM and that you mark ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

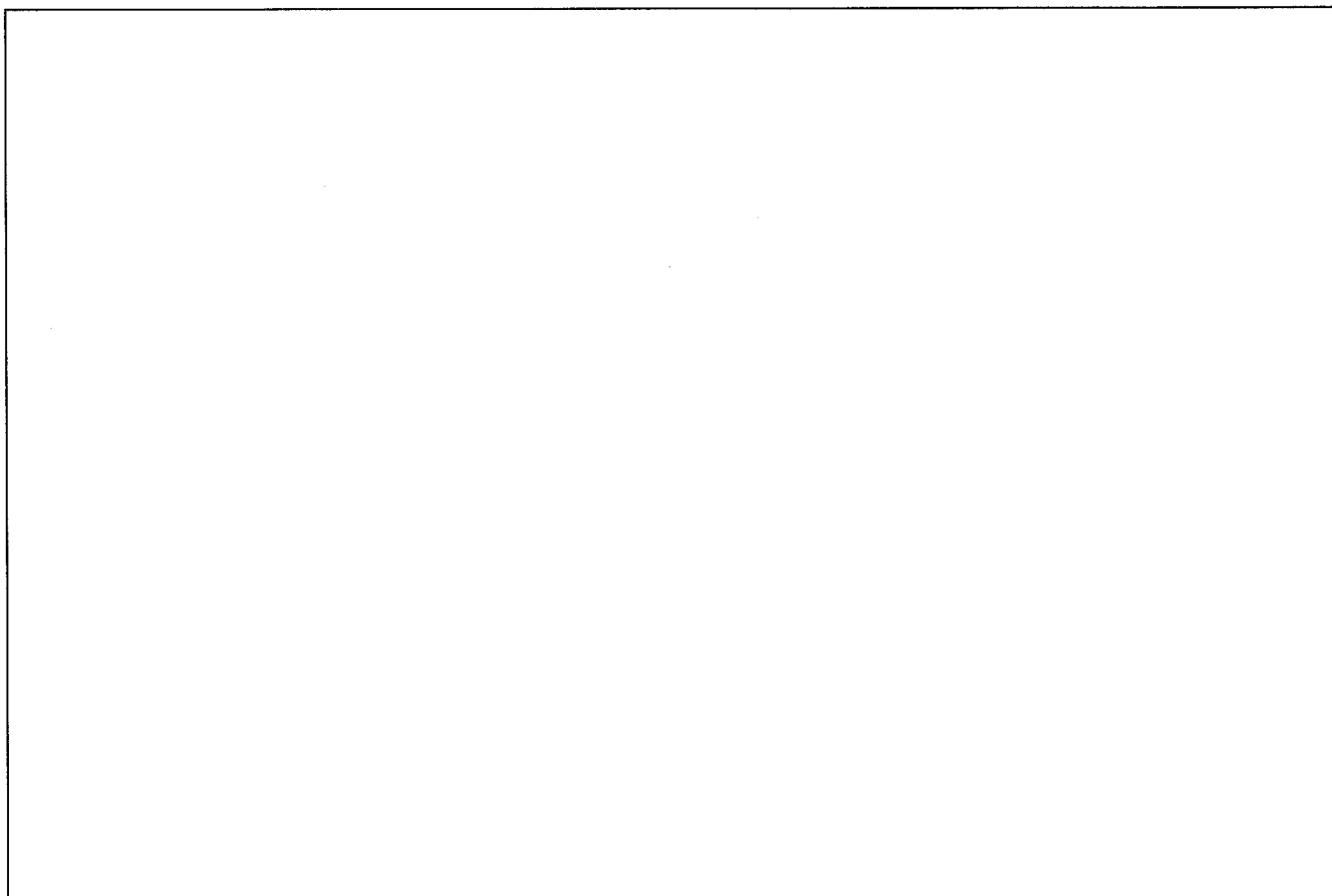


- E.1 If I get sick, it is my own behavior which determines how soon I get well again
- E.2 No matter what I do, if I am going to get sick, I will get sick
- E.3 Having regular contact with my physician is the best way for me to avoid illness
- E.4 Most things that affect my health happen to me by accident
- E.5 Whenever I don't feel well, I should consult a medically trained professional ..
- E.6 I am in control of my health
- E.7 When I get sick, I am to blame
- E.8 Luck plays a big part in determining how soon I will recover from an illness ..
- E.9 Health professionals control my health
- E.10 My good health is largely a matter of good fortune
- E.11 The main thing which affects my health is what I myself do
- E.12 If I take care of myself, I can avoid illness

- E.13 Whenever I recover from an illness, it's actually because other people (for example, doctors, nurses, family, friends) have been taking good care of me
- E.14 No matter what I do, I'm likely to get sick
- E.15 If it's meant to be, I will stay healthy
- E.16 If I take the right actions, I can stay healthy
- E.17 Regarding my health, I can only do what my doctor tells me to do

Please continue on the next page.

This questionnaire is designed to find out from Long-Term Follow-up Study participants' problems, fears, or frustrations related to their cancer treatment, medical follow-up, or medical care in general. If there is something that is not included in one of the above questions and you would like to tell us about it, please write your comments in the space below.



After completing this questionnaire, please return by using the enclosed envelope, and mail to:

Long-Term Follow-Up Study
Department of Pediatrics
University of Minnesota
420 Delaware St SE, MMC 715
Minneapolis, MN 55455

Again, thank you for your help and your participation in this study!