

Assessment of Patients' Experience of Cancer Care (APECC) Study

Conducted by:



And



PLEASE READ THESE INSTRUCTIONS CAREFULLY

GENERAL INSTRUCTIONS

- Answer each question as best you can. Please do not leave any question blank.
- Put an x or a ✓ in the box next to your answer and erase or cross out completely if you make any changes.

Example: 1 Yes : 1 Yes

- Please follow any instructions that direct you to the next question.

Example: 2 No → GO TO A11

- If you mark an answer with a line after it, please write the specific information on the line provided.

Example: 1 Other, please specify: cardiologist

- Mark only one response for each question, unless directed to “**MARK ALL THAT APPLY.**” For those questions, please mark every response choice that applies to your situation.
- As far as possible, please try to answer all the questions in one sitting and, where asked, please record the time you started and ended this survey.

A. Your Health History

A1. Please record the time you begin answering this survey. Write the hour on the line and check the box for AM or PM: _____ 1 AM
2 PM

A2. Today's date:

MONTH DAY YEAR

A3. What is your date of birth?

MONTH DAY YEAR

A4. Are you male or female?

- 1 Male
2 Female

Questions A5 to A15 are about your cancer history.

A5. When was the **first time** that a doctor or other health care professional told you that you had cancer?

MONTH YEAR

A6. What type of cancer was it?

- 1 Bladder cancer
2 Colorectal cancer (cancer of the colon or rectum)
3 Leukemia
91 Other, please specify _____
99 Don't know

A7. Did you **ever** have any surgery as part of your cancer treatment? Please DO NOT consider any biopsy you had or insertion of medication ports such as a Hickman catheter to be surgery.

- 1 Yes
- 2 No → **GO TO A8**

A7.a. When was the **last time** you had surgery as part of your cancer treatment?

_____ _____
MONTH YEAR

A8. Did you **ever** receive any chemotherapy as part of your cancer treatment? Please include both IV (that is, intravenous) and oral forms of chemotherapy.

- 1 Yes
- 2 No → **GO TO A9**

A8.a. When was the **last time** you received chemotherapy as part of your cancer treatment?

_____ _____
MONTH YEAR

A9. Did you **ever** receive any radiation therapy as part of your cancer treatment?

- 1 Yes
- 2 No → **GO TO A10**

A9.a. When was the **last time** you received radiation therapy as part of your cancer treatment?

_____ _____
MONTH YEAR

A10. Did you **ever** receive a bone marrow or stem cell transplant as part of your cancer treatment? Please DO NOT consider a bone marrow biopsy to be a bone marrow transplant.

- 1 Yes
- 2 No → **GO TO A11, PAGE 5**

A10.a. When was the **last time** you received a bone marrow or stem cell transplant as part of your cancer treatment?

_____ _____
MONTH YEAR

A11. Did you **ever** receive any other medical treatments for your cancer that were not mentioned above?

- 1 Yes, please specify: _____
- 2 No → **GO TO A12**

A11.a. When was the **last time** you received these other medical treatments for your cancer?

_____ MONTH _____ YEAR

A12. **At any time** since you were diagnosed with cancer, did a doctor or other health care professional tell you that your cancer had come back (that is, you had a recurrence)?

- 1 Yes
- 2 No → **GO TO A13**

A12.a. How many times have you had a recurrence of your cancer?

- 1 Once
- 2 Twice
- 3 More than two times

A12.b. What was the approximate date of your **most recent** recurrence?

_____ MONTH _____ YEAR

A13. In the **last 6 months**, have you received any of the following medical treatments for your cancer?
MARK ALL THAT APPLY

- 0 I did not receive any medical treatment for cancer in the last six months
- 1 Surgery (do not consider biopsy or insertion of medication ports to be surgery)
- 2 Chemotherapy
- 3 Radiation therapy
- 4 Bone marrow or stem cell transplant (do not consider bone marrow biopsy to be a transplant)
- 91 Other, please specify: _____

A14. When was the **last time** you received any medical treatment for your cancer?

- 1 Less than 4 weeks ago
- 2 1 to 3 months ago
- 3 4 to 6 months ago
- 4 7 to 12 months ago
- 5 More than 12 months ago

A15. To the best of your knowledge, are you **now** free of cancer (that is, **at this time**, you don't have cancer in any part of your body)?

- 1 Yes
2 No

A16. Please tell us whether a doctor or other health care professional has **ever** told you that you had any of the following medical conditions in addition to cancer:

	Yes	No	Don't Know
a. Heart attack or myocardial infarction	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Angina or heart-related chest pain	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. Heart failure or congestive heart failure	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Stroke or brain hemorrhage	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e. High blood pressure or hypertension	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f. Chronic lung disease, asthma, emphysema, or chronic bronchitis	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
g. Diabetes or high blood sugar	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
h. Kidney disease or kidney failure	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
i. Liver disease or cirrhosis	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
j. Osteoporosis or brittle bones	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
k. Depression or anxiety	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
l. Arthritis or rheumatism	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
m. Inflammatory bowel disease, Crohn's disease, or colitis	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
n. HIV or AIDS	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
o. Dementia or Alzheimer's disease	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
p. Stomach ulcers or peptic ulcer disease	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
q. Thyroid-related conditions such as hyperthyroidism or hypothyroidism	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
r. Blood clots in the veins of the legs or in the lungs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

B. Cancer Care in the LAST 12 MONTHS

Cancer survivors often see a doctor for follow-up care for many years. Questions in this section are about your experience of getting follow-up cancer care in the LAST 12 MONTHS.

- B1. In the **last 12 months**, did you see any doctor for follow-up cancer care?
This could either be a cancer specialist or some other doctor you saw to get follow-up medical tests, or to treat symptoms and treatment-related side effects, or to get medical treatments for cancer.
- 1 Yes
2 No → GO TO SECTION C, PAGE 22
- B2. In the **last 12 months**, what were the reasons you saw a doctor for follow-up cancer care?
MARK ALL THAT APPLY
- 1 To receive medical treatments for cancer
2 To discuss and/or treat symptoms and side effects
3 To receive follow-up medical tests to check for signs of cancer or other medical problems
4 To receive a physical examination
91 Other, please specify: _____
- B3. In the **last 12 months**, how much of a problem, if any, was it to get the follow-up cancer care that you or a doctor believed was necessary?
- 1 Not a problem
2 A small problem
3 A big problem, please explain: _____
- B4. Specialists are doctors like oncologists, surgeons, cardiologists, urologists, gastroenterologists, and others who specialize in one area of health.
- In the **last 12 months**, did you have to get an approval or a referral to see a specialist for follow-up cancer care?
- 0 I didn't need to see a specialist in the last 12 months → GO TO B6, PAGE 8
1 Yes
2 No
3 Don't know
- B5. In the **last 12 months**, how much of a problem, if any, was it to see a specialist that you needed to see to get follow-up cancer care?
- 1 Not a problem
2 A small problem
3 A big problem

The Doctor You Saw Most Often For Follow-Up Cancer Care in the LAST 12 MONTHS

B6. What is the specialty of the doctor you saw most often for follow-up cancer care in the **last 12 months**?

- 1 Primary care (such as internal medicine, family practice)
- 2 Medical oncologist or hematologist
- 3 Radiation oncologist
- 4 Surgeon
- 5 Gastroenterologist
- 6 Urologist
- 91 Other, please specify: _____
- 99 Don't know

B7. Is this doctor a male or a female?

- 1 Male
- 2 Female

B8. For how many months or years have you been going to this doctor for any kind of medical care?

- 1 Less than 3 months
- 2 More than 3 months but less than 12 months
- 3 1 to 2 years
- 4 More than 2 years but less than 5 years
- 5 5 or more years

B9. In the last **12 months**, how many times did you see this doctor for follow-up cancer care?

- 1 1 time
- 2 2 times
- 3 3 times
- 4 4 times
- 5 5 to 9 times
- 6 10 or more times

B10. When did you **last** see this doctor for follow-up cancer care?

- 1 Less than 4 weeks ago
- 2 1 to 3 months ago
- 3 4 to 6 months ago
- 4 7 to 12 months ago

- B11. In the **last 12 months**, where did you usually go to receive follow-up cancer care from this doctor?
- 1 Your doctor's private practice
 - 2 A clinic in a hospital
 - 3 A clinic run by an HMO
 - 4 A local community health clinic
 - 91 Other, please specify: _____
 - 99 Don't know
- B12. In the **last 12 months**, how often did you get an appointment for follow-up cancer care with this doctor as soon as you wanted?
- 1 Never
 - 2 Sometimes
 - 3 Usually
 - 4 Always
- B13. In the **last 12 months**, when you called this doctor's office or clinic during regular office hours with cancer-related questions, how often did you get the help or advice you needed?
- 0 I didn't call for help or advice during regular office hours in the last 12 months
 - 1 Never
 - 2 Sometimes
 - 3 Usually
 - 4 Always
- B14. In the **last 12 months**, how many minutes late did your appointments with this doctor for follow-up cancer care usually begin?
- 1 None, they usually began on time
 - 2 Less than 15 minutes late
 - 3 16 to 30 minutes late
 - 4 31 to 45 minutes late
 - 5 More than 45 minutes late
- B15. In the **last 12 months**, when you went to see this doctor for follow-up cancer care, how much of a problem was the wait before you got to see the doctor?
- 1 Not a problem
 - 2 A small problem
 - 3 A big problem

In the following questions, “your follow-up care doctor” refers to the doctor you saw most often for follow-up cancer care in the LAST 12 MONTHS.

Overall Communication

B16. In the **last 12 months**, how often did your follow-up care doctor listen carefully to you?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B17. In the **last 12 months**, how often did your follow-up care doctor explain things in a way you could understand?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B18. In the **last 12 months**, how often did your follow-up care doctor show respect for what you had to say?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B19. In the **last 12 months**, how often did your follow-up care doctor encourage you to ask all the cancer-related questions you had?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B20. In the **last 12 months**, how often did your follow-up care doctor answer your cancer-related questions to your satisfaction?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B21. In the **last 12 months**, how often did your follow-up care doctor make sure that you understood all the information he or she gave you?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B22. In the **last 12 months**, how often did your follow-up care doctor spend enough time with you?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B23. In the **last 12 months**, how often did you feel rushed by your follow-up care doctor?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B24. In the **last 12 months**, how often did your follow-up care doctor give you as much cancer-related information as you wanted?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B25. In the **last 12 months**, how often did you leave your follow-up care doctor's office or clinic with unanswered questions related to your cancer?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

Follow-up Medical Tests

B26. In the **last 12 months**, did your follow-up care doctor order any medical tests to check for signs of cancer or other medical problems?

- 1 Yes
2 No → **GO TO B31, PAGE 13**

B26.a. Please name some of the medical tests that you received in the **last 12 months**:

B27. In the **last 12 months**, how were the decisions about what medical tests you should get made?

- 1 I made the decisions with little or no input from my doctor
2 I made the decisions after seriously considering my doctor's opinion
3 My doctor and I made the decisions together
4 My doctor made the decisions after seriously considering my opinion
5 My doctor made the decisions with little or no input from me

B28. Which of the following options best describes your level of involvement in making the decisions about what medical tests you should get?

- 1 My level of involvement was less than what I wanted
2 My level of involvement was just right
3 My level of involvement was more than what I wanted

B29. In the **last 12 months**, when you received any medical tests ordered by your follow-up care doctor, how often did you get the test results in a timely manner?

- 1 Never
2 Sometimes
3 Usually
4 Always

B30. In the **last 12 months**, when you received any medical tests ordered by your follow-up care doctor, how often did your doctor or someone from your doctor's office or clinic explain the test results in a way you could understand?

- 1 Never
2 Sometimes
3 Usually
4 Always

Symptoms and Side effects

B31. In the **last 12 months**, were you bothered by any symptoms or treatment-related side effects?

- 1 Yes
2 No → GO TO B37, PAGE 14

B31.a. Please describe some of the symptoms/side effects that bothered you in the **last 12 months**:

B32. In the **last 12 months**, did you discuss any of these symptoms or side effects with your follow-up care doctor?

- 1 Yes
2 No → GO TO B37, PAGE 14

B33. In the **last 12 months**, how often did your follow-up care doctor give you the help you wanted to take care of the symptoms or side effects that were bothering you?

- 1 Never
2 Sometimes
3 Usually
4 Always

B34. In the **last 12 months**, how often did your follow-up care doctor give you clear instructions about what to do if your symptoms or side effects got worse or came back?

- 1 Never
2 Sometimes
3 Usually
4 Always

B35. In the **last 12 months**, how were the decisions about how to treat your symptoms or side effects made?

- 1 I made the decisions with little or no input from my doctor
2 I made the decisions after seriously considering my doctor's opinion
3 My doctor and I made the decisions together
4 My doctor made the decisions after seriously considering my opinion
5 My doctor made the decisions with little or no input from me

- B36. Which of the following options best describes your level of involvement in making the decisions about how your symptoms or side effects should be treated?
- 1 My level of involvement was less than what I wanted
 - 2 My level of involvement was just right
 - 3 My level of involvement was more than what I wanted

Doctor's Decision Making Style

- B37. In the **last 12 months**, were any medical decisions made about your follow-up cancer care?

Some examples of such decisions are:

- Deciding what follow-up medical tests to get to check for signs of cancer or other problems
- Changing how often you get follow-up medical tests
- Getting new medical treatment for your cancer
- Changing the dosage of or stopping any existing medical treatment
- Treating your symptoms or treatment-related side-effects

- 1 Yes
- 2 No → **GO TO B43, PAGE 15**

- B38. When making such medical decisions, did your follow-up care doctor discuss the available options with you in a way you could understand?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

- B39. When making such medical decisions, did your follow-up care doctor encourage you to ask questions or express any concerns you had about the available options?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

- B40. When making such medical decisions, did your follow-up care doctor encourage you to ask questions or express any concerns you had about his or her recommendation?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

B41. When making such medical decisions, did your follow-up care doctor encourage you to give your opinion about the available options?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

B42. When making such medical decisions, did your follow-up care doctor involve you as much as you wanted in the decision making process?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

Health Promotion

B43. In the **last 12 months**, did your follow-up care doctor or someone from your doctor's office or clinic talk with you about specific things you could do to improve your health or prevent illness?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

B44. In the **last 12 months**, did your follow-up care doctor or someone from your doctor's office or clinic give you the help you wanted to make changes in your habits or lifestyle that would improve your health or prevent illness?

- 0 I didn't want help with this
- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

B45. In the **last 12 months**, did your follow-up care doctor or someone from your doctor's office or clinic talk with you about how much or what kind of foods you eat?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

B46. In the **last 12 months**, did your follow-up care doctor or someone from your doctor's office or clinic talk with you about how much or what kind of exercise you get?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

B47. In the **last 12 months**, did you smoke cigarettes on at least some days a month?

- 1 Yes
- 2 No → **GO TO B49**

B48. In the **last 12 months**, did your follow-up care doctor or someone from your doctor's office or clinic talk with you about your smoking?

- 1 Yes, definitely
- 2 Yes, somewhat
- 3 No

Doctor's Interpersonal Behavior

B49. In the **last 12 months**, how often did your follow-up care doctor treat you with respect?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B50. In the **last 12 months**, how often was your follow-up care doctor caring and kind?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B51. In the **last 12 months**, how often did your follow-up care doctor show a genuine interest in you as a person?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

B52. In the **last 12 months**, how often was your follow-up care doctor sensitive to your feelings and emotions?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always

Doctor's Knowledge About You

B53. How would you rate your follow-up care doctor's knowledge of your medical history?

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

B54. How would you rate your follow-up care doctor's knowledge of your responsibilities at home, work, or school?

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

B55. How would you rate your follow-up care doctor's knowledge of how cancer and the medical treatments you received for cancer have affected the quality of your life?

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

Opinion About Your Doctor

B56. Please tell us how much you agree or disagree with the following statements about your follow-up care doctor:

	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
a. I doubt that my doctor really cares about me as a person	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. My doctor is usually considerate of my needs and puts them first	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. I trust my doctor so much that I always try to follow his/her advice	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. If my doctor tells me something is so, then it must be true	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
e. I sometimes distrust my doctor's opinion and would like a second one	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
f. I trust my doctor's judgments about my medical care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
g. I feel my doctor does not do everything he/she should for my medical care	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
h. I trust my doctor to put my medical needs above all other considerations when treating my medical problems	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
i. My doctor is a real expert in taking care of medical problems like mine	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
j. I trust my doctor to tell me if a mistake was made about my treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
k. I sometimes worry that my doctor may not keep the personally sensitive information we discuss totally private	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Staff at Your Doctor's Office

B57. In the **last 12 months**, how often did nurses at your follow-up care doctor's office or clinic treat you with courtesy and respect?

- 0 I didn't see any nurses at my doctor's office/clinic in the last 12 months → **GO TO B59**
1 Never
2 Sometimes
3 Usually
4 Always

B58. In the **last 12 months**, how often were the nurses at your follow-up care doctor's office or clinic as helpful as you thought they should be?

- 1 Never
2 Sometimes
3 Usually
4 Always

B59. In the **last 12 months**, how often did office staff (such as receptionists and other personnel at the front office) at your follow-up care doctor's office or clinic treat you with courtesy and respect?

- 1 Never
2 Sometimes
3 Usually
4 Always

B60. In the **last 12 months**, how often was office staff (such as receptionists and other personnel at the front office) at your follow-up care doctor's office or clinic as helpful as you thought they should be?

- 1 Never
2 Sometimes
3 Usually
4 Always

Coordinating Your Care

B61. In the **last 12 months**, how often did your follow-up care doctor seem informed and up-to-date about the care you received from any other doctors or health professionals you saw for cancer-related issues or problems?


- 0 I didn't see any other doctor/health professional for cancer-related issues in the last 12 months
1 Never
2 Sometimes
3 Usually
4 Always

- B62. In the **last 12 months**, in your opinion, how often did your follow-up care doctor, the nurses, and other staff at your follow-up care doctor's office or clinic seem to work well together as a team?
- 1 Never
 - 2 Sometimes
 - 3 Usually
 - 4 Always

Evaluation of Your Care

- B63. Overall, how would you rate your follow-up care doctor?

Use any one number from 0 to 10 where 0 is the worst doctor possible and 10 is the best doctor possible.

0 1 2 3 4 5 6 7 8 9 10
Worst doctor Possible  Best doctor possible

- B64. Based on your interactions with your doctor, the nurses, and other staff, how would you rate the quality of care you received from your follow-up care doctor's office or clinic in the **last 12 months**?

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

- B65. If you needed follow-up cancer care in the **next 12 months**, would you go back to your follow-up care doctor's office or clinic?

- 1 Definitely Yes
- 2 Probably Yes
- 3 Not Sure
- 4 Probably No
- 5 Definitely No

- B66. Would you recommend your follow-up care doctor's office or clinic to your family members and friends if they needed cancer-related care?

- 1 Definitely yes
- 2 Probably yes
- 3 Not sure
- 4 Probably not
- 5 Definitely not

Questions B67 to B69 are about any other doctors you saw for cancer-related issues or problems in the LAST 12 MONTHS.

B67. In the **last 12 months**, in addition to your follow-up care doctor, did you see any other doctor for cancer-related issues or problems?

1 Yes → How many other doctors did you see? _____

2 No → **GO TO SECTION C, PAGE 22**

B68. What is the specialty of the other doctor or doctors you saw for cancer-related issues or problems in the **last 12 months**?

MARK ALL THAT APPLY

1 Medical oncologist or hematologist

2 Radiation oncologist

3 Surgeon

4 Gastroenterologist

5 Urologist

6 Cardiologist

7 Rheumatologist

8 Endocrinologist

9 Pulmonologist

10 Neurologist

11 Dermatologist

12 Psychiatrist

13 Psychologist, psychotherapist, or any other mental health professional

91 Other, please specify: _____

99 Don't know

B69. How would you rate the quality of care you received from the other doctor or doctors you saw for cancer-related issues or problems in the **last 12 months**?

1 Poor

2 Fair

3 Good

4 Very good

5 Excellent

C. Complementary and Alternative Therapies Used in the LAST 12 MONTHS

C1. In the **last 12 months**, did you use any of the following complementary and alternative therapies?

	Yes	No
a. Special diets such as <u>mostly</u> vegetarian or low fat	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b. Movement or physical therapies such as yoga, tai chi, massage, chiropractic, or electromagnetic therapy	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c. High dose or mega vitamins (DO NOT include 1-a-day multivitamins), nutritional supplements, or herbal remedies	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d. Homeopathy	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e. Mind/body therapies such as guided imagery/visualization, biofeedback, meditation, relaxation techniques, hypnosis/hypnotherapy, energy healing, therapeutic touch, or music therapy	1 <input type="checkbox"/>	2 <input type="checkbox"/>
f. Oriental therapies such as acupuncture, acupressure, Qigong, or Shiatsu	1 <input type="checkbox"/>	2 <input type="checkbox"/>
g. Self-help or support groups (either face-to-face or on the Internet)	1 <input type="checkbox"/>	2 <input type="checkbox"/>
h. Psychological therapy or counseling from a psychologist, psychiatrist, social worker, or any other mental health professional	1 <input type="checkbox"/>	2 <input type="checkbox"/>
i. Faith healing, laying on of hands, or any other spiritual or religious group experience	1 <input type="checkbox"/>	2 <input type="checkbox"/>
j. Personal prayer or personal spiritual healing	1 <input type="checkbox"/>	2 <input type="checkbox"/>
k. Other, please specify: _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>

If you DID NOT USE any of the above therapies in the LAST 12 MONTHS, please go to section D on page 25.

If you USED one or more of the above therapies in the LAST 12 MONTHS, please continue on the next page.

C2. What were the major reasons why you used any of these therapies discussed in question C1 in the **last 12 months**?

MARK ALL THAT APPLY

- 0 I didn't use any of these therapies in the last 12 months → **GO TO SECTION D, PAGE 25**
- 1 To relieve symptoms or any treatment-related side effects (such as pain, nausea, fatigue, anxiety, depression, or other similar symptoms/side-effects)
- 2 To relieve stress
- 3 To treat my cancer
- 4 To prevent my cancer from coming back
- 5 To help deal with a medical condition other than cancer, please specify: _____
- 91 Other, please specify: _____

C3. Overall, how helpful were any of these therapies you used in the **last 12 months** in meeting the above goals?

- 1 Not at all helpful
- 2 Somewhat helpful
- 3 Very helpful

C4. In the **last 12 months**, did you see any complementary and alternative therapy practitioner or doctor to receive any of these therapies?

- 1 Yes
- 2 No → **GO TO C5, PAGE 24**

C4.a. As best as you can, please tell us the specialty of all the complementary and alternative therapy practitioners or doctors you saw in the **last 12 months**:

C4.b. Overall, how would you rate the quality of care you received from the complementary and alternative therapy practitioners or doctors you saw in the **last 12 months**?

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

C5. Did you discuss your use of any of these complementary and alternative therapies with your follow-up care doctor **in the last 12 months**?

- 0 I did not receive follow-up cancer care in the last 12 months → **GO TO SECTION D, PAGE 25**
1 Yes
2 No → **GO TO C6**

C5.a. Which of the following best describes your follow-up care doctor's response?
Your doctor ...

- 1 Encouraged you to use it
2 Didn't care whether you used it or not
3 Told you about the risks in using it
4 Encouraged you to stop using it
5 Made no comment
91 Other, please specify: _____

PLEASE GO TO SECTION D, PAGE 25

C6. What were the main reasons why you didn't discuss your use of complementary and alternative therapies with your follow-up care doctor in the **last 12 months**?

MARK ALL THAT APPLY

- 1 Your doctor never asked
2 You thought that your doctor wouldn't approve
3 It wasn't important for you to tell your doctor
4 You felt your doctor might refuse to continue to be your doctor
91 Other, please specify _____

D. Medical Decisions About Your Follow-up Cancer Care

For the following questions, we would like you to think about how you would prefer to make medical decisions about your follow-up cancer care, IF they were to be made AT THIS TIME.

D1. From the following five options, please mark the one that best describes your preference for how medical decisions about your follow-up cancer care should be made.

Such decisions could include what follow-up medical tests you should get, how your symptoms and side effects should be treated, what medical treatments for cancer you should receive, etc.

- 1 I would prefer to make the decisions with little or no input from my doctor
- 2 I would prefer to make the decisions after seriously considering my doctor's opinion
- 3 I would prefer that my doctor and I make the decisions together
- 4 I would prefer my doctor to make the decisions after seriously considering my opinion
- 5 I would prefer my doctor to make the decisions with little or no input from me

D2. How much do you agree or disagree with the following statement:

In general, I prefer to leave medical decisions about my follow-up cancer care up to my follow-up care doctor.

- 1 Strongly agree
- 2 Somewhat agree
- 3 Neither agree nor disagree
- 4 Somewhat disagree
- 5 Strongly disagree

D3. If **at this time**, you and your follow-up care doctor had to make any medical decisions about your follow-up cancer care, how **confident** are you that you would be able to...

	Not at All Confident	A Little	Somewhat	Very	Completely Confident
a. Take part in a detailed discussion with your doctor about the different available options	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. Let your doctor know if you had any concerns or questions about his or her recommendation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. Tell your doctor about the option you would prefer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. Work out any differences of opinion with your doctor, should they exist	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
e. Take responsibility for making the final decision	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

D4. The following statements represent different opinions cancer survivors may have about participating in medical decisions about their follow-up cancer care. Please tell us how much you agree or disagree with the following statements.

	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
a. I would have less confidence in my doctor if he/she didn't tell me what to do	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. It would offend my doctor if I were to make my own medical decisions	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. Only I can decide which medical options are best for me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. I am not confident about my ability to make good medical decisions	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
e. Doctors aren't perfect so it's important that I'm involved in my medical decisions	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
f. I'd rather be given many choices than to have the doctor make the decisions for me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
g. Participating in my medical decisions is good for my health	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
h. I don't know enough to make my own medical decisions	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
i. If I make the final decision, it'll be my fault if it turns out to be a bad choice	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
j. Making my own medical decisions allows me to be in control of my health	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
k. I'm foolish to trust my doctor completely for medical decisions	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
l. I would end up annoying my doctor if I negotiated medical decisions with him/her	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

Described below are three specific medical decisions that cancer survivors may have to deal with.

While you may have already faced one or more of these decisions, we would like you to think what you would want to do if you and your doctor had to make these decisions **AT THIS TIME**.

D5. **Follow-up Medical Tests**

If **at this time**, you needed to get any follow-up medical tests to check for signs of cancer, how would you want the decision about **what follow-up tests you should get** to be made?

- 1 I would prefer to make the decision with little or no input from my doctor
- 2 I would prefer to make the decision after seriously considering my doctor's opinion
- 3 I would prefer that my doctor and I make the decision together
- 4 I would prefer my doctor to make the decision after seriously considering my opinion
- 5 I would prefer my doctor to make the decision with little or no input from me

D6. **Management of treatment-related side effects**

If **at this time**, you were to be bothered by any side effects of your cancer treatments such as pain, fatigue, or any other treatment-related problem, how would you want the decision about **how to manage these side effects** to be made?

- 1 I would prefer to make the decision with little or no input from my doctor
- 2 I would prefer to make the decision after seriously considering my doctor's opinion
- 3 I would prefer that my doctor and I make the decision together
- 4 I would prefer my doctor to make the decision after seriously considering my opinion
- 5 I would prefer my doctor to make the decision with little or no input from me

D7. **Treatment of Recurrence**

If **at this time**, you were to experience a recurrence of your cancer, that is, your cancer came back, how would you want the decision about **what medical treatments you should receive for your recurrence** to be made?

- 1 I would prefer to make the decision with little or no input from my doctor
- 2 I would prefer to make the decision after seriously considering my doctor's opinion
- 3 I would prefer that my doctor and I make the decision together
- 4 I would prefer my doctor to make the decision after seriously considering my opinion
- 5 I would prefer my doctor to make the decision with little or no input from me

E: Cancer-related Information Seeking

E1. At this time, do you feel you need more information about any of the following cancer-related topics?

Cancer-related Topics	I NEED ...		
	NO more information	SOME more information	MUCH more information
a. Follow-up tests/procedures that you should have	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Symptoms that should prompt you to call your doctor	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. What late and long-term side effects of cancer treatment to expect	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Dealing with late and long-term side effects of cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e. Decreasing the risk of having cancer again	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f. Managing your anxiety about recurrence	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
g. Staying physically fit	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
h. Nutrition and diet	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
i. Cancer risks to your family	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
j. Dealing with sexual problems	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
k. Having children after cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
l. Complementary and alternative treatments	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
m. Medical advances in cancer treatment	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
n. Talking about your cancer experience with family, friends, and co-workers	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
o. Dealing with people who may avoid you	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
p. Getting or retaining health, life, or disability insurance after cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
q. Any other need for information, please specify: _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

E2. Did you search for any cancer-related information in the **last 12 months**?

- 1 Yes
 2 No → **GO TO E5, PAGE 30**

E2.a. Please give us some examples of the type of cancer-related information you searched for in the **last 12 months**:

E3. Listed below are some common sources of information. For each of the following sources, please mark the box that indicates how helpful the source was for you in your search for cancer-related information in the **last 12 months**.

Information Source	Did Not Use	Used, Not at all Helpful	Used, Somewhat Helpful	Used, Very Helpful
a. Spouse or significant other	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b. Other family members	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c. Friends or co-workers	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d. Doctors	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e. Nurses	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f. Counselors or therapists	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g. Medical books	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
h. Scientific journals	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
i. Patient education materials such as brochures or pamphlets	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
j. <u>Face-to-face</u> support groups or self-help groups	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
k. Support groups or self-help groups on the <u>Internet</u>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
l. Other sources on the <u>Internet</u>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
m. Newspapers and magazines	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
n. Radio and television	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
o. Toll free telephone information services (1-800 Number)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
p. Religious community/place of worship	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
q. If you used a source not listed above, please specify: _____	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

E4. Based on your search for cancer-related information in the **last 12 months**, how often did you have the following experiences?

	Never	Sometimes	Usually	Always
a. I wanted more information, but did not know where to find it	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
b. It took a lot of effort to get the information I needed	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
c. I did not have the time to get all the information I needed	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
d. I felt frustrated during my search for the information	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
e. I was concerned about the quality of the information I found	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
f. The information I found was too hard to understand	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>
g. I was satisfied with the information I found	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>

E5. How confident are you that you could get advice or information related to cancer if you needed it **at this time**?

- 1 Not at all confident
- 2 A little confident
- 3 Somewhat confident
- 4 Very confident
- 5 Completely confident

E6. How much do you agree or disagree with the following statements?

	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
a. It is important for people with cancer to learn as much as they can about their illness and its treatments	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. I actively seek out cancer-related information	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. Having information about my cancer and its treatments gives me a sense of control	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. It is my responsibility to learn about my cancer and its treatments	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
e. I prefer to get as much information as possible about my health, good and bad	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

F. General Health

F1*. In general, would you say your health is:

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

F2. Compared to 1 year ago, how would you rate your health in general **now**?

- 1 Much better now than 1 year ago
- 2 Somewhat better now than 1 year ago
- 3 About the same as 1 year ago
- 4 Somewhat worse now than 1 year ago
- 5 Much worse now than 1 year ago

F3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
a. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. <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"/>
c. Lifting or carrying groceries	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
d. Climbing <u>several</u> flights of stairs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
e. Climbing <u>one</u> flight of stairs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
f. Bending, kneeling, or stooping	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
g. Walking <u>more than a mile</u>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
h. Walking <u>several hundred yards</u>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
i. Walking <u>one hundred yards</u>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
j. Bathing or dressing yourself	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

* Questions F1-F11 are from SF-36v2 Standard, US Version 2.0. SF-36v2™ Health Survey © 1996, 2000 by QualityMetric Incorporated and Medical Outcomes Trust – All Rights Reserved. SF-36 is a registered trademark of Medical Outcomes Trust

F4. 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?

	All of the Time	Most of the Time	Some of the Time	A Little of the Time	None of the Time
a. Cut down on the <u>amount of time</u> you spent on work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. <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"/>
c. 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"/>
d. Had <u>difficulty</u> performing the work or other activities (for example, it took extra effort)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

F5. 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)?

	All of the Time	Most of the Time	Some of the Time	A Little of the Time	None of the Time
a. Cut down on the <u>amount of time</u> you spent on work or other activities	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. <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"/>
c. Did work or other activities less <u>carefully than usual</u>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

F6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- 1 Not at all
- 2 Slightly
- 3 Moderately
- 4 Quite a bit
- 5 Extremely

F7. How much bodily pain have you had during the **past 4 weeks**?

- 1 None
- 2 Very mild
- 3 Mild
- 4 Moderate
- 5 Severe
- 6 Very severe

F8. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

- 1 Not at all
- 2 A little bit
- 3 Moderately
- 4 Quite a bit
- 5 Extremely

F9. 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**...

	All of the Time	Most of the Time	Some of the Time	A Little of the Time	None of the Time
a. Did you feel full of life?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. Have you been very nervous?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. Have you felt so down in the dumps that nothing could cheer you up?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. 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"/>
e. 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"/>
f. 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"/>
g. Did you feel worn out?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
h. Have you been happy?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
i. Did you feel tired?	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

F10. 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 All of the time
- 2 Most of the time
- 3 Some of the time
- 4 A little of the time
- 5 None of the time

F11. How TRUE or FALSE is each of the following statements for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. I am as healthy as anybody I know	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. I expect my health to get worse	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. My health is excellent	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

F12. Below is a list of feelings, attitudes, and behaviors that you may have experienced during the **past week**. For each of the following items, please mark the one response that best describes how often you had that experience during the **past week**.

During the **past week** ...

	Hardly Ever or Never	Some of the Time	Much or Most of the Time
a. I did not feel like eating; my appetite was poor	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
b. I felt depressed	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
c. I felt everything I did was an effort	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
d. My sleep was restless	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
e. I was happy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
f. I felt lonely	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
g. People were unfriendly	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
h. I enjoyed life	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
i. I felt sad	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
j. I felt that people disliked me	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>
k. I could not get "going"	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>

G. Health Appraisal

G1. What do you think are the chances that your cancer will come back or get worse within the next 10 years?

- 1 Very low
- 2 Fairly low
- 3 Moderate
- 4 Fairly high
- 5 Very high

G2. How often do you worry that your cancer may come back or get worse?

- 1 Never
- 2 Rarely
- 3 Sometimes
- 4 Often
- 5 All the time

G3. How much do you agree or disagree with the following statements?

	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
a. I would like to feel more certain about my health	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. I worry that my cancer will return or get worse	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. I feel that there is little need to worry about my future health status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. I am bothered by the uncertainty about my health status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
e. When I think about my future health status, I feel some uneasiness	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
f. I am preoccupied with thoughts of the cancer returning or getting worse	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

G4. How much do you agree or disagree with the following statements?

	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
a. No matter how hard I try, my health doesn't turn out the way I would like	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. I am usually unable to find effective solutions for my health problems	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. My efforts to change things about my health are usually ineffective	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. Typically, my plans for my health don't work out well	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

G5. To what extent do you feel you have **control** over...

	No Control at All	A Little Control	Moderate Amount of Control	A Great Deal of Control	Complete Control
a. Your emotional responses to your cancer (such as worrying, feeling anxious, feeling depressed)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. The physical side effects of your cancer and its treatment (such as feeling pain, tiredness)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. The kind of follow-up care you receive for your cancer	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. The course of your cancer (that is, whether your cancer will come back, get worse, or you will develop a different type of cancer)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

H. Background Information

H1. What is the highest level of formal education you have completed?

- 1 Less than high school
- 2 High school graduate or GED
- 3 Some college or technical or vocational school
- 4 College graduate
- 5 Some graduate school
- 6 Graduate degree

H2. Do you consider yourself to be...

- 1 Hispanic or Latino?
- 2 NOT Hispanic or Latino? → **GO TO H3**

H2.a. Which group best describes your Hispanic or Latino origin?

- 1 Mexican, Mexican-American, or Chicano
- 2 Puerto Rican
- 3 Cuban or Cuban-American
- 91 Other, please specify: _____

H3. Which of the following describes your race?

MARK ALL THAT APPLY

- 1 American Indian or Alaska Native
- 2 Black or African American
- 3 Native Hawaiian or Other Pacific Islander
- 4 White
- 5 Asian: Chinese
- 6 Asian: Japanese
- 7 Asian: Filipino
- 8 Asian: Indian
- 91 Other Asian, please specify: _____

H4. What is your **current** marital status?

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

H5. Who lives with you **currently**, at least some of the time?

MARK ALL THAT APPLY

- 1 I live alone
- 2 Spouse or significant other
- 3 Children under age 18, please specify how many: _____
- 4 Children age 18 or older, please specify how many: _____
- 5 One or both parents
- 6 Other relatives, please specify how many: _____
- 7 Friends or roommates
- 8 Pets
- 9 Other, please specify: _____

H6. What is your **current** employment status?

MARK ALL THAT APPLY

- 1 Working full time
- 2 Working part time
- 3 Full-time homemaker or family caregiver
- 4 Retired
- 5 Unemployed
- 6 Student
- 9 Other, please specify: _____

H7. Which of the following categories best describes your total family income, before taxes, from all sources **last year**?

- 1 Less than \$10,000
- 2 \$10,000 to \$19,999
- 3 \$20,000 to \$39,999
- 4 \$40,000 to \$59,999
- 5 \$60,000 to \$74,999
- 6 \$75,000 to \$99,999
- 7 \$100,000 to \$119,999
- 8 \$120,000 or more

H7.a. How many people, adults and children, were supported by this income? _____

H8. During the **last 4 weeks**, did you have adequate financial resources to meet the daily needs of you and your family?

- 1 Yes
- 2 No

H9. How many people do you have living near you that you can count on for help in times of trouble or difficulty, such as, to watch over children or pets, to give rides to the hospital or store, or to help if you are sick?

- 1 0
- 2 1
- 3 2
- 4 3 to 5
- 5 6 to 9
- 6 10 or more

H10. In the **last 12 months**, were you covered by any form of health insurance or health care plan for at least some of the time?

- 1 Yes → **GO TO H11**
- 2 No

H10.a. When you received medical care in the **last 12 months**, how did you usually pay for it?

- 1 Paid by cash (out-of-pocket, self-pay)
- 2 Went to a free or government clinic or health care facility
- 91 Other, please specify: _____

PLEASE GO TO H13, PAGE 40

H11. Was this health coverage provided by a Health Maintenance Organization (HMO)?

- 1 Yes
- 2 No
- 99 Don't know

H12. In the **last 12 months**, was there any time when you had no health insurance coverage at all?

- 1 Yes
- 2 No → **GO TO H13, PAGE 40**

H12.a. For approximately how many months during the **last 12 months** did you have no health insurance coverage at all?

_____ MONTHS

H12.b. During the time in the **last 12 months** when you had no health insurance coverage at all, how did you pay for the medical care you received?

- 0 You did not receive any medical care when you had no health insurance in the last 12 months
- 1 Paid by cash (out-of-pocket, self-pay)
- 2 Went to a free or government clinic or health care facility
- 91 Other, please specify: _____

H13. Are you **now** covered by any form of health insurance or health care plan?

- 1 Yes → **GO TO H14**
- 2 No

H13.a. When you **now** receive medical care, how do you usually pay for it?

- 1 Pay by cash (out-of-pocket, self-pay)
- 2 Go to a free or government clinic or health care facility
- 91 Other, please specify: _____

PLEASE GO TO SECTION I, PAGE 41

H14. What kind of health insurance or health care coverage do you use to pay for your medical care?

MARK ALL THAT APPLY

- 1 Health insurance plan from your employer or workplace
- 2 Health insurance plan from someone else's employer
- 3 Private health insurance plan purchased directly by you or someone else
- 4 Medicaid or MediCal or Medical Assistance
- 5 Medicare
- 6 CHIP (Children's Health Insurance Plan)
- 7 Military health care (including CHAMPUS/TRICARE/CHAMP-VA)
- 8 Indian Health Service
- 9 Other government program or state sponsored plan, please specify: _____
- 10 Single service plan (such as dental, vision, or prescription plan)
- 91 Other, please specify: _____

I. Additional Comments

11. In looking back, what things do you think have helped you the most during the experience of becoming a cancer survivor?

12. Finally, if you have any comments about this survey or would like to share any concerns or problems related to or due to your cancer that we did not cover in this survey, please feel free to do so below:

13. Please note the time at which you finished the survey: _____ 1 AM
2 PM

If you answered the survey in more than one sitting, please fill in the approximate total time you spent answering all the questions in this survey: _____

THANK YOU for taking the time to fill out this survey.

Please return the survey
in the enclosed postage-paid envelope
as soon as possible.