Follow-Up Care Use and Health Outcomes of Cancer Survivors (FOCUS) Study

Conducted by:

NATIONAL® CANCER INSTITUTE

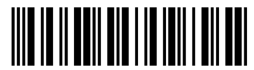
And

NORTHERN CALIFORNIA CANCER CENTER

Los Angeles County Cancer Surveillance Program

CONFIDENTIAL

Study I.D. # | | | | | | | | | | |



INTRODUCTION

Individuals treated for breast, prostate, colorectal, endometrial, and ovarian cancer represent a major portion of the growing population of cancer survivors. Despite this, we know relatively little about the medical follow-up care experiences of this population after completion of cancer treatment. In addition, we are only just beginning to learn about the long-term (chronic) or late (delayed) impact of cancer treatments on individuals' health and well-being. With support from the National Cancer Institute, the Los Angeles County Cancer Surveillance Program and the Northern California Cancer Center are conducting a questionnaire study of survivors of breast, prostate, colorectal, endometrial, and ovarian cancer. You have been selected to participate in this important research study. This information will allow us to identify areas where improvements in quality of care for cancer survivors are needed.

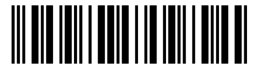
This survey booklet contains questions about your cancer treatment(s), follow-up medical care, health status after cancer, experiences and interactions with your doctors and other health care providers, your satisfaction with the care received, and your current health behaviors and practices. We know of no better way to learn about these issues than to ask cancer survivors themselves.

There are no right or wrong answers, so please respond by giving the answer that best describes your situation. You may find some of the questions to be personal or difficult, and you may not have thought about some issues before. **Even if you feel you must skip a question, please indicate this by writing "SKIP" in the left margin, and proceed to the next question. Your answers to other questions will still be important to us and we will appreciate your responses very much.**

All of the information you provide is **confidential** and will **not** be disclosed to your health care provider or others. The information obtained will be analyzed as grouped data without any personal identification. When you are completing this survey, if any issues concern you about your health, please discuss these with your health care provider. You are also free to contact us by telephone or mail to discuss any issues related to the survey material. If you are from the Los Angeles area and have any questions, please contact: the Los Angeles Site Principal Investigator of the study, Dr. Ann Hamilton, at 323-865-0434, or the Study Coordinator at 323-442-2712. Their address is: FOCUS Study, Los Angeles County Cancer Surveillance Program, 1540 Alcazar St., CHP 204, MC9007, Los Angeles, CA, 90089-9007. If you are from Northern California and have any questions, please contact: the Northern California Site Principal Investigator, Dr. Ingrid Oakley-Girvan at 510-608-5045, or the Study Coordinator Susan Wolff at 510-608-5046. Their address is: Dr. Ingrid Oakley-Girvan (FOCUS Study), Northern California Cancer Center, 2201 Walnut Avenue, Suite 300, Fremont, CA 94538.

We are very grateful to you for the time you will be taking to complete this survey and for helping us to learn how to improve the lives of all cancer survivors. After completing the survey, **please mail it back to us in the enclosed postage-paid envelope.**

Thank you.



PLEASE READ THESE INSTRUCTIONS CAREFULLY

GENERAL INSTRUCTIONS

- Answer each question as best you can. Please do not leave any question blank. If you feel you must skip a question, please indicate this by writing "SKIP" beside the question, or by putting an "X" over the question number.

- Please fill in the oval next to you answer completely using blue or black ink.

  Example: Fill in ovals completely, like this: ⬬ Yes
  Not like this: ⊗ Yes Or this: ◐ Yes

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

  Example: ⬬ No ⟶ **GO TO Question A8**

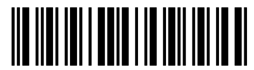
- For a question with a line after it, please write the specific information on the line provided.

  Example: ⬬ Other, please specify: *cardiologist*

- Mark only one response for each question, unless directed to "**PLEASE FILL IN THE OVALS FOR ALL THAT APPLY.**" For those questions, please mark every response choice that applies to your situation.

- When you are asked to provide a date (for example, when you started your cancer treatment), **please** provide an **approximate** date if you cannot remember the exact date.

- As much as possible, please try to answer all the questions in one sitting.



SECTION A. Cancer and Treatment History

A1. Today's date: ___ / ___ / _____
Month Day Year

A2. What is your birthdate?: ___ / ___ / _____
Month Day Year

A3. Are you male or female?

- ○ Male
- ○ Female

A4. Have you ever been told by a doctor or other health care professional that you had cancer?

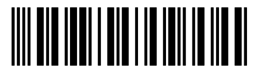
- ○ No ⟶ **<u>Please stop</u> and return the questionnaire in the enclosed stamped, pre-addressed envelope.**
- ○ Yes

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 were you **<u>FIRST</u>** diagnosed with? Some individuals may have been diagnosed with more than 1 cancer, or may have experienced a recurrence. In either of those cases, please mark the box with the name of your **<u>FIRST</u>** cancer diagnosis:

- ○ Breast
- ○ Prostate
- ○ Colon or Rectum
- ○ Ovary
- ○ Endometrial
- ○ Other, please specify: ______________________



A7. **At any time** since you were diagnosed with your **FIRST** cancer, did a doctor or other health care professional tell you that your **FIRST** cancer had come back (that is, you had a **recurrence)**?

- ○ No ⟶ **GO TO Question A8**
- ○ Yes

A7a. **IF YES:** How many times have you had a recurrence of your **FIRST** cancer?

- ○ One time
- ○ Two times
- ○ Three or more times

A7b. What was the approximate date of your **most recent** recurrence of your **FIRST** cancer?

Month: ________ Year: _______________

A7c. Have you completed cancer treatment for your **most recent** recurrence of your **FIRST** cancer?

- ○ No
- ○ Yes

A8. At any time since you were first diagnosed with cancer, did a doctor or other health care professional tell you that you had developed a second cancer (a second cancer is a cancer that is different from your first cancer, for example, ovarian cancer after breast cancer, or a second cancer in the other breast)?

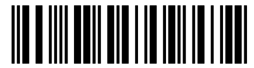
- ○ No ⟶ **GO TO Question A9**
- ○ Yes

A8a. **IF YES:** How many times have you had a "second" cancer?

- ○ One time
- ○ Two times
- ○ Three or more times

A8b. What was the approximate date of your **most recent** "second" cancer?

Month: ________ Year: _______________



A8c. Have you completed treatment for your **most recent** "second" cancer?

- ⬭ No
- ⬭ Yes

A9. Did you **ever** receive 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.

- ⬭ No ⟶ **GO TO Question A10**
- ⬭ Yes

A9a. **IF YES:** On what part(s) of your body did you have surgery?

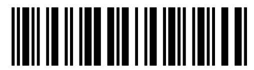
- ⬭ One Breast
- ⬭ Both Breasts
- ⬭ Prostate
- ⬭ Colon or Rectum
- ⬭ One Ovary
- ⬭ Both Ovaries
- ⬭ Uterus
- ⬭ Lymph Nodes
- ⬭ Other, please specify: ______________________

A10. Did you **ever** receive any chemotherapy as part of your cancer treatment? Please include both IV (that is, intravenous) and oral forms of chemotherapy.

- ⬭ No ⟶ **GO TO Question A11**
- ⬭ Yes

A10a. **IF YES:** To the best of your knowledge, what chemotherapy drugs were you given? **(PLEASE FILL IN THE OVALS FOR ALL THAT APPLY)**

- ⬭ Cytoxan (also known as cyclophosphamide)
- ⬭ Adriamycin (also known as doxorubicin)
- ⬭ Taxol
- ⬭ Fluorouracil
- ⬭ Cisplatin (also known as carboplatin)
- ⬭ Methotrexate
- ⬭ Other, please specify: ______________________
- ⬭ Do not know the specific ones



A10b. When was the **FIRST time** you received chemotherapy? (You do not have to remember exact dates, an approximate date is fine.)

Month: ________ Year: _______________

A10c. When was the **LAST time** you received chemotherapy? (You do not have to remember exact dates, an approximate date is fine.)

Month: ________ Year: _______________

A11. Did you **ever** receive any radiation therapy as part of your cancer treatment?

- ⬭ No ⟶ **GO TO Question A12.**
- ⬭ Yes

A11a. IF YES: When was the **FIRST time** you received radiation therapy?

Month: ________ Year: _______________

A11b. When was the **LAST time** you received radiation therapy?

Month: ________ Year: _______________

A12. Did you **ever receive or are you currently receiving** any medicines to prevent cancer from recurring or to prevent a second cancer (for example, tamoxifen for breast cancer or hormones for prostate cancer). (These are sometimes referred to as 'maintenance' medicines.)

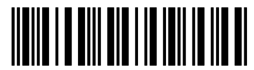
- ⬭ No
- ⬭ Yes, please specify name of this maintenance medicine:

  ____

- ⬭ Do not know

A13. To the best of your knowledge, are you **now** free of cancer (that is, **at this time**, your cancer is in remission)?

- ⬭ No
- ⬭ Yes
- ⬭ Do not know



SECTION B. Follow-Up Care After Cancer

Cancer survivors often see a doctor for follow-up care after their cancer diagnosis. The reasons for this care could include getting follow-up medical tests, treating symptoms and treatment related side effects, as well as getting additional therapy. These next questions are about your experience with getting follow-up care after your cancer treatment.

B1. At any time **since you were first diagnosed with cancer**, were you ever told by any of the doctors that treated you for cancer that you needed regular follow-up care and monitoring even after cancer treatments were over?

- ○ No ⟶ **GO TO Question B2**
- ○ Yes

B1a. IF YES: Were the reasons for receiving this follow-up care discussed with you?

- ○ No, did not discuss ⟶ **GO TO Question B2**
- ○ Yes, discussed somewhat
- ○ Yes, discussed in detail

B1b. IF YES: Please mark all the reasons for follow-up care after cancer that your doctor discussed with you. **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

- ○ To check for a recurrence of your original cancer.
- ○ To receive additional treatment for your cancer if needed.
- ○ To determine if you have developed any health problems as a result of your cancer or its treatment.
- ○ To receive treatment for any symptoms or side effects of treatment.
- ○ To receive a routine physical exam.
- ○ To receive any **screening test for other cancers** (including such tests as a mammogram or Pap smear for women, colonoscopy, sigmoidoscopy, stool check for blood, or PSA test or digital rectal exam (for men))
- ○ To receive test or exams for non-cancer diseases such as diabetes, heart disease, hypertension, or
- ○ To obtain a referral to other specialist(s).
- ○ Other, please specify: ______________________________

B1c. Which of the following reasons do you consider to be the **most important one** for receiving follow-up care after cancer? **(SELECT ONLY ONE)**

- ⬭ To check for a recurrence of your original cancer.
- ⬭ To receive additional treatment for your cancer if needed.
- ⬭ To determine if you have developed any health problems as a result of your cancer or its treatment.
- ⬭ To receive treatment for any symptoms or side effects of treatment.
- ⬭ To receive a routine physical exam.
- ⬭ To receive any **screening test for other cancers** (including such tests as a mammogram or Pap smear for women, colonoscopy, sigmoidoscopy, stool check for blood, or PSA test or digital rectal exam (for men).
- ⬭ To receive test or exams for non-cancer diseases such as diabetes, heart disease, hypertension, or arthritis.
- ⬭ To obtain a referral to other specialist(s).
- ⬭ Other, please specify: ______________________________

B2. Has a doctor or health care professional **ever** discussed with you what late or long-term side effects of cancer treatment (chemotherapy drugs, radiation or other treatments) you may experience over time?

- ⬭ No, did not discuss
- ⬭ Yes, discussed somewhat
- ⬭ Yes, discussed in detail

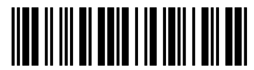
B3. At the completion of your cancer treatment, did you receive a written summary from your doctor(s) that mentioned details of the treatment you had received and provided other important details regarding your cancer care?

- ⬭ No ⟶ **GO TO Question B4**
- ⬭ Yes ⟶
- ⬭ Not sure

> **B3.a. IF YES:** Can you easily find the summary if needed?
>
> - ⬭ No
> - ⬭ Yes
> - ⬭ Not Sure
>
> **GO TO Question B5**

B4. Would you have liked to receive a written summary from the doctor(s) treating you for cancer regarding the cancer treatment(s) you had received and other details of your cancer care?

- ⬭ No
- ⬭ Yes
- ⬭ Not sure



B5. About how many months or years has it been since you spoke by telephone or in person with the doctor(s) at the clinic or hospital where you received all or most of your cancer treatment for your cancer, or received a checkup at the clinic or hospital where you were first treated for cancer?

- ○ Within the past year (12 months)
- ○ Between 1 year and less than 2 years ago
- ○ Between 2 years and less than 3 years ago
- ○ Between 3 years and less than 4 years ago
- ○ 4 years ago or more

Next we are asking about any follow-up care you received to specifically monitor your cancer and any subsequent effects from it or from your treatment. We refer to this as your <u>cancer-related follow-up care</u>. Some survivors see the same doctor for their <u>regular medical care</u> and <u>cancer-related follow-up care</u>, while others see different doctors.

B6. Since you were diagnosed with cancer, have you **<u>ever</u>** seen a doctor for cancer-related follow-up care?

- ○ No ⟶
- ○ Yes

GO TO <u>Question B7</u>

B6a. **IF NO,** What are the main reasons you did NOT see a doctor for <u>cancer-related follow-up care</u>?
(PLEASE FILL IN OVALS FOR ALL THAT APPLY)

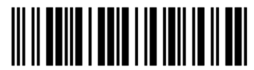
- ○ I felt I didn't need follow-up care
- ○ My doctor(s) told me I didn't need follow-up care
- ○ Cost too much OR insurance didn't cover it
- ○ Didn't know a good cancer doctor
- ○ It made me anxious or worried
- ○ Getting to the doctor was hard
- ○ I didn't have the time for it
- ○ It was too difficult to schedule an appointment
- ○ Child care was a problem
- ○ I didn't know about it
- ○ Other, please specify:

____

GO TO <u>Question C1</u>

B7. Below are some opinions and feelings that cancer survivors have expressed about cancer-related follow-up care. Please mark whether you agree or disagree with the following statements about cancer-related follow-up care visits?

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
a. Regular cancer follow-up visits give me a feeling of security	○	○	○	○	○
b. I always get nervous before my cancer follow-up visit	○	○	○	○	○
c. I always feel reassured after my cancer follow-up visit	○	○	○	○	○
d. I don't sleep as well in the week before my cancer follow-up visit	○	○	○	○	○
e. I usually postpone new plans till after the cancer follow-up visit	○	○	○	○	○
f. Cancer follow-up visits have more advantages than disadvantages	○	○	○	○	○
g. I would worry more about my cancer if there were no follow-up visits	○	○	○	○	○
h. I normally dread my cancer follow-up visits	○	○	○	○	○
i. I would rather have cancer follow-up visits less frequently	○	○	○	○	○
j. I believe regular follow-up care will help me live longer after cancer	○	○	○	○	○
k. I believe regular follow-up care will me me live better (with higher quality of life) after cancer	○	○	○	○	○



Your Follow-Up Care over the PAST 2 YEARS

These questions are about your cancer related follow-up care **in the past two years only**.

B8. In the **past 2 years,** did you see any doctor specifically for **cancer-related follow-up care**? This could either be a cancer specialist or some other doctor.

- ⬭ No →
- ⬭ Yes ↓

B8a. IF NO, What are the main reasons you did NOT see a doctor for cancer-related follow-up care in the **past 2 years**? **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

- ⬭ I felt I didn't need follow-up care
- ⬭ My doctor(s) told me I didn't need follow-up care
- ⬭ Cost too much OR insurance didn't cover it
- ⬭ Didn't know a good cancer doctor
- ⬭ It made me anxious or worried
- ⬭ Getting to the doctor was hard
- ⬭ I didn't have the time for it
- ⬭ It was too difficult to schedule an appointment
- ⬭ Child care was a problem
- ⬭ I didn't know about it
- ⬭ Other, please specify: ____________________

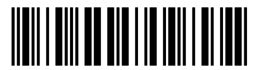
B8b. When was the **last time** you saw a doctor for a cancer-related follow-up care?

Month: ________ Year: _______________

GO TO Question B20

B9. In the **past 2 years**, what were the reasons you saw **any** doctor for cancer-related follow-up care? **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

- ⬭ To check for a recurrence of your original cancer
- ⬭ To receive additional treatment for your cancer if needed
- ⬭ To determine if you have developed any health problems as a result of your cancer or its treatment
- ⬭ To receive treatment for any symptoms or side effects of treatment
- ⬭ To receive a routine physical exam
- ⬭ To receive any **screening test for other cancers** (including such tests as a mammogram or Pap smear for women, colonoscopy, sigmoidoscopy, stool check for blood, or PSA test or digital rectal exam (for men))
- ⬭ To receive test or exams for non-cancer diseases such as diabetes, heart disease, hypertension, or arthritis.
- ⬭ To obtain a referral to other specialist(s)
- ⬭ Other, please specify: ____________________



B10. In the **<u>past 2 years,</u>** how many **times** did you see **<u>any</u>** doctor for <u>cancer-related follow-up care</u>?

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

B11. In the **<u>past 2 years,</u>** how many **different doctors** did you see for <u>cancer-related follow-up care</u>?

- ⬭ One
- ⬭ Two
- ⬭ Three
- ⬭ Four
- ⬭ Five or more
- ⬭ Not sure

B12. What were the **specialties of the doctors** you saw for <u>cancer-related follow-up care</u> in the **<u>past 2 years</u>**? **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

- ⬭ Primary care (such as internal medicine, family practice)
- ⬭ Cancer specialist (such as medical, radiation, surgical or gynecologic oncologist)
- ⬭ Obstetrician / Gynecologist (Ob-Gyn)
- ⬭ Urologist
- ⬭ Gastro-Enterologist
- ⬭ Other, please specify: ____
- ⬭ Not sure

B13. When did you **<u>last</u>** see **any doctor** for <u>cancer-related follow-up care</u>?

- ⬭ Less than 4 weeks ago
- ⬭ 1 to 3 months ago
- ⬭ 4 to 6 months ago
- ⬭ 7 to 12 months ago
- ⬭ More than 1 year ago

B14. Where did you usually see a doctor for cancer-related follow-up care?

- ⬭ At the doctor's stand-alone office
- ⬭ At a general medicine clinic, not located at a hospital
- ⬭ At a specialty clinic or center, not located at a hospital
- ⬭ At a hospital-based clinic
- ⬭ At the emergency room
- ⬭ Other
- ⬭ Not sure / Do not know

B15. In the **past 2 years,** did your cancer-related follow-up care doctor(s) order any medical tests for any reason?

- ⬭ No → **GO TO Question B17**
- ⬭ Yes

B16. In the **past 2 years,** when your cancer-related follow-up care doctor(s) order any medical tests:

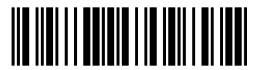
	Never	Sometimes	Usually	Always
a. how often was the need for or purpose of these tests explained to you in a way you would understand?	⬭	⬭	⬭	⬭
b. how often did you get the test results in a timely manner?	⬭	⬭	⬭	⬭
c. how often were the test results explained to you in a way you could understand?	⬭	⬭	⬭	⬭

B17. In the **past 2 years,** did you experience any symptoms that you thought might have been related to your cancer or its treatment?

- ⬭ No → **GO TO Question B19**
- ⬭ Yes

B18. In the **past 2 years,** how often did your cancer-related follow-up care doctor(s) give you the help you wanted to take care of the symptoms or side effects that you were experiencing?

- ⬭ Never
- ⬭ Sometimes
- ⬭ Usually
- ⬭ Always

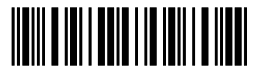


B19. In the **past 2 years, how often** did your cancer-related follow-up care doctor(s) ...

	Never	Some-times	Usually	Always
a. listen carefully to you?	⬭	⬭	⬭	⬭
b. explain things in a way you could understand?	⬭	⬭	⬭	⬭
c. show respect for you had to say?	⬭	⬭	⬭	⬭
d. encourage you to ask all the cancer-related questions you had?	⬭	⬭	⬭	⬭
e. make sure that you understood all the information he or she gave you?	⬭	⬭	⬭	⬭
f. spend enough time with you?	⬭	⬭	⬭	⬭
g. give you as much cancer-related information as you wanted?	⬭	⬭	⬭	⬭
h. involve you in decisions about your medical care as much as you wanted?	⬭	⬭	⬭	⬭

B20. Overall, how yould you rate the quality of the cancer-related follow-up care that you received in the **past 2 years**?

⬭ Poor
⬭ Fair
⬭ Good
⬭ Very Good
⬭ Excellent



Your Main Cancer-Related Follow-Up Care Doctor

These next questions focus on ONE specific cancer-related follow-up care doctor:

B21. Of all the doctors you have seen for cancer-related follow-up care **since you were diagnosed**, is there any one doctor you consider to be your main doctor for cancer-related follow-up care?

- ○ No → **GO TO Question C1**
- ○ Yes

B21a. IF YES: Which doctor is this? **(SELECT ONE ONLY)**

- ○ Primary care (such as internal medicine, family practice
- ○ Cancer specialist (such as medical, radiation, surgical or gynecologic oncologist)
- ○ Obstetrician / Gynecologist (Ob-Gyn)
- ○ Urologist
- ○ Gastro-Enterologist
- ○ Other, please specify: ______________________
- ○ Not sure

B21b. Is this doctor a male or a female?

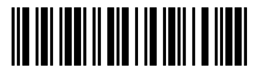
- ○ Male
- ○ Female

B21c. Which of the following best describes your doctor? Your doctor is ... **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

- ○ Hispanic or Latino
- ○ White
- ○ African-American
- ○ Asian
- ○ Other
- ○ Not sure / Do not know

B21d. Where do you usually see this doctor?

- ○ At the doctor's stand-alone office
- ○ At a general medicine clinic, not located at a hospital
- ○ At a specialty clinic or center, not located at a hospital
- ○ At a hospital-based clinic
- ○ At the emergency room
- ○ Other
- ○ Not Sure / Don't know



B21e. For how many months or years have you been going to this doctor for any kind of medical care?

- ⬭ Less than 1 year
- ⬭ 1 to 2 years
- ⬭ More than 2 years but less than 5 years
- ⬭ 5 or more years

B21f. Is this the same doctor who you saw for your initial cancer treatment?

- ⬭ No
- ⬭ Yes

Section C: Preferences For Cancer-Related Follow-Up Care

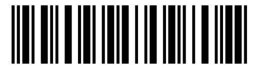
For the following questions, we would like you to think about how you would prefer to make medical decisions about your cancer-related follow-up care, IF they were to be made AT THIS TIME.

C1. From the following five options, please mark the one that best describes your preference for how medical decisions about your cancer-related follow-up cancer care **should be made.** Such decisions could include what follow-up medical tests you should get to check for cancer or other illnesses, how your symptoms and side effects should be treated, whether existing medications need dosage changes or need to be stopped, etc.

- ⬭ I would prefer to make the decisions with little or no input from my doctor(s)
- ⬭ I would prefer to make the decisions after seriously considering my doctor's opinion
- ⬭ I would prefer that my doctor(s) and I make the decisions together
- ⬭ I would prefer my doctor(s) to make the decisions after serisouly considering my opinion
- ⬭ I would prefer my doctor(s) to make the decisions with little or no input from me

C2. If **at this time**, you and your cancer-related follow-up care doctor(s) 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	⬭	⬭	⬭	⬭	⬭
b. Let your doctor know if you had any concerns or questions about his or her recommendation	⬭	⬭	⬭	⬭	⬭
c. Tell your doctor about the option you would prefer	⬭	⬭	⬭	⬭	⬭
d. Work out any differences of opinion with your doctor, should they exist	⬭	⬭	⬭	⬭	⬭
e. Take responsibility for making the final decision	⬭	⬭	⬭	⬭	⬭



Your Views Regarding Your Ideal Follow-Up Care

Next are some questions regarding your perceptions and thoughts about your ideal cancer-related follow-up care doctor, the setting in which you wish to receive such care, and the services, tests, procedures you may want to receive at these visits.

C3. **Who** do you personally feel would be your **ideal** cancer-related follow-up care doctor? **(SELECT ONE ONLY)**

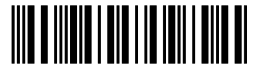
- ○ Cancer Specialist / Oncologist
- ○ Primary Care Doctor
- ○ Other, please specify: ______________________________
- ○ Not sure

C3a. What are the most important reasons **why** this person would be your **ideal** follow-up care doctor? **(SELECT UP TO THREE REASONS)**

- ○ Knowledge or expertise
- ○ Caring Attitude
- ○ Convenient location
- ○ Ease in making appointments
- ○ Communication skills
- ○ Other, please specify: ______________________________
- ○ Not sure

C4. Would you **ideally** want this doctor to be the same doctor who you saw for your initial cancer treatment?

- ○ No
- ○ Yes

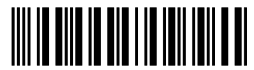


C5. **What** examinations, test, procedures, would you **ideally** want to receive in each follow-up care visit? **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

- ○ Consultation/conversation with your doctor regarding your health since you last saw him/her
- ○ General physical examination
- ○ Laboratory tests
- ○ Tumor Markers (e.g., PSA, CA 15-3, CEA, CA-125)
- ○ X-Rays
- ○ Bone Scans
- ○ CT scan or MRI
- ○ Ultrasound
- ○ Any **screening test for other cancers** (including such tests as a mammogram or Pap smear for women, colonoscopy, sigmoidoscopy, stool check for blood, or digital rectal exam (for men))?
- ○ Tests or exams for non-cancer diseases such as diabetes, heart disease, hypertension, or arthritis?
- ○ Referral to other specialists
- ○ Other, please specify: ______________________
- ○ Not sure

C6. Where would you **ideally** like to go for your cancer-related follow-up care visits?

- ○ To the doctor's stand-alone office
- ○ To a general medicine clinic, not located at a hospital
- ○ To a specialty clinic or center, not located at a hospital
- ○ To a hospital-based clinic
- ○ To the emergency room
- ○ Other
- ○ Not sure / Don't know



SECTION D. Other Medical Care

The following questions are about other medical care that you may have received <u>in addition to</u> OR <u>instead of</u> cancer-related follow-up care:

D1. For your non-emergency care, do you have a primary care physician or a place you go for routine medical care?

- ○ No
- ○ Yes

D2. During the **<u>past 2 years</u>**, did you <u>go</u> to a doctor **other than** your cancer-related follow-up care doctor(s) for a "routine medical check-up" or other medical problems?

- ○ No ⟶ **GO TO <u>Question D3</u>**
- ○ Yes

D2a. **IF YES:** Were any of your "routine medical check-up" visits or visits for other medical problems during the **<u>past 2 years</u>** related to health problems that you think might have resulted from your cancer or its treatment?

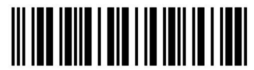
- ○ No
- ○ Yes
- ○ Not sure

D2b. Approximately how many "routine medical check-up visits" or visits for other medical problems did you have during the **<u>past 2 years</u>**?

- ○ One
- ○ Two
- ○ Three
- ○ Four
- ○ Five or more
- ○ Not sure

D2c. What is the specialty of the doctor you saw most often for your "routine medical check-up" or other medical problems? **(SELECT ONE ONLY)**

- ○ Primary care (such as internal medicine, family practice
- ○ Cancer specialist (such as oncologist, for care not previously mentioned)
- ○ Obstetrician / Gynecologist (Ob-Gyn)
- ○ Urologist
- ○ Other, please specify:
- ○ Not sure



D2d. Did the doctor you saw most often for your "routine medical check-up" or other medical problems refer you to another doctor(s)?

- ⬭ No ⟶ **GO TO Question D3**
- ⬭ Yes

D2e. **IF YES,** What type of doctor(s) were you referred to?
(PLEASE FILL IN OVALS FOR ALL THAT APPLY)

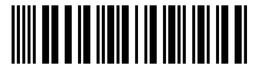
- ⬭ Oncologist
- ⬭ Obstetrician / Gynecologist (Ob-Gyn)
- ⬭ Cardiologist
- ⬭ Rheumatologist
- ⬭ Endocrinologist
- ⬭ Urologist
- ⬭ Psychologist / Psychiatrist
- ⬭ Other, please specify: ______________________

D3. During the **past 2 years**, how difficult has it been to get a referral to a specialist if you needed one?

- ⬭ Not at all difficult
- ⬭ A little difficult
- ⬭ Somewhat difficult
- ⬭ Very difficult
- ⬭ I did not need to see a specialist (e.g., cardiologist, urologist, etc.)
- ⬭ I did not need a referral

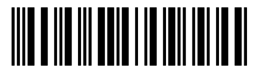
D4. In the **past 2 years,** did any of your doctors (including your cancer-related doctor(s) as well as regular care doctor(s)) or someone from your doctor's office or clinic …

	No	**Yes**	**Don't Know**	**Not Needed/Not Applicable**
a. talk with you about specific things you could do to improve your health or prevent illness?	⬭	⬭	⬭	⬭
b. give you the help you wanted to make changes in your habits or lifestyle that would improve your health or prevent illness?	⬭	⬭	⬭	⬭
c. talk with you about how much or what kind of foods you eat?	⬭	⬭	⬭	⬭
d. talk with you about how much or what kind of exercise you get?	⬭	⬭	⬭	⬭
e. talk with you about your smoking?	⬭	⬭	⬭	⬭



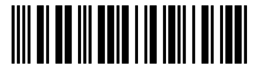
D5. When was the **last time** you had the following **screening tests**?

	Within the past 2 years	2-5 years ago	More than 5 years ago	Never had this test	Not sure
a. **Colonoscopy** (this is an examination of the rectum and entire colon using a lighted instrument called a colonscope)	○	○	○	○	○
b. **Sigmoidoscopy** (this is an examination of the rectum and lower colon using a lighted instrument called a sigmoidoscope)	○	○	○	○	○
c. **Stool check for blood or Fecal Occult Blood Test (FOBT)**	○	○	○	○	○
For men only: d. **PSA test**	○	○	○	○	○
For women only: e. **Mammogram** ○ Not required	○	○	○	○	○
f. **Pap Smear**	○	○	○	○	○



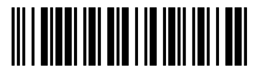
D6. **At any time** since you were first diagnosed with cancer, have you used any of the following complementary and alternative therapies?

	No	Yes	If yes: →	Have you used them in the past year?
a. Special diets such as mostly vegetarian or low fat	○	○	→	○ No ○ Yes
b. Movement or physical therapies such as yoga, tai chi, massage, chiropractic, or electromagnetic therapy	○	○	→	○ No ○ Yes
c. High dose or mega vitamins (DO NOT include 1-a-day multivitamins), nutritional supplements, or herbal remedies	○	○	→	○ No ○ Yes
d. Homeopathy (small doses of drugs that in a healthy person would produce symtpoms like those of the disease)	○	○	→	○ No ○ Yes
e. Mind/body therapies such as guided imagery/visualization, biofeedback, meditation, relaxation techniques, hypnosis/hypnotherapy, energy healing, therapeutic touch, or music therapy	○	○	→	○ No ○ Yes
f. Oriental therapies such as acupuncture, acupressure, Qigong, or Shiatsu	○	○	→	○ No ○ Yes
g. Self-help or support groups (either face-to-face or on the Internet)	○	○	→	○ No ○ Yes
h. Psychological therapy or counseling from a psychologist, psychiatrist, social worker, or any other mental health professional	○	○	→	○ No ○ Yes
i. Faith healing, laying on of hands, or any other spiritual or religious group experience	○	○	→	○ No ○ Yes
j. Personal prayer or personal spiritual healing	○	○	→	○ No ○ Yes
k. Other, please specify: ______	○	○	→	○ No ○ Yes



D7. What were the major reasons why you used any of these therapies discussed above in question **D6**? **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

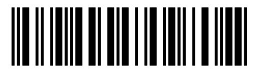
- ⬭ I didn't use any of the above therapies ⟶ **GO TO <u>Question E1</u>**
- ⬭ To relieve symptoms or any treatment-related side effects (such as pain, nausea, fatigue, anxiety, depression, or other similar symptoms/side-effects)
- ⬭ To relieve stress
- ⬭ To treat my cancer
- ⬭ To prevent my cancer from coming back
- ⬭ To help deal with a medical condition other than cancer, please specify: ____________________
- ⬭ To get support and cancer-related information
- ⬭ Other, please specify: ____________________



Section E. Health Problems Experienced in the PAST 12 MONTHS

Have you experienced any of the following problems in the PAST 12 MONTHS?

		No	Yes
E1.	Shortness of breath or difficulty breathing	○	○
E2.	Ankle swelling	○	○
E3.	Problems with memory, attention, or concentration	○	○
E4.	Frequent headaches or migraines	○	○
E5.	Numbness or tingling	○	○
E6.	Dizziness, vertigo or problems with balance or equilibrium	○	○
E7.	Tremors (shaking of fingers or hands), or weakness in arms or legs	○	○
E8.	Frequent cough	○	○
E9.	Frequent or severe heartburn, indigestion, or stomach pain	○	○
E10.	Blood in the urine	○	○
E11.	Ringing in the ears	○	○
E12.	Blurred or double vision, or dry eyes	○	○
E13.	Dry mouth	○	○
E14.	Sensitivity (of teeth) to hot or cold, or other dental problems (e.g., cavities, bleeding gums)	○	○
E15.	Joint pains	○	○
E16.	Leg or muscle cramps	○	○
E17.	Frequent back or neck pain	○	○
E18.	Unexplained weight loss	○	○
E19.	Unexplained weight gain	○	○
E20.	Frequent fevers	○	○
E21.	Lack of restful sleep	○	○
E22.	Frequent tiredness or fatigue	○	○
E23.	Dry skin or frequent itching	○	○
E24.	Night or cold sweats	○	○
E25.	Hot flashes	○	○
E26.	Abdominal Bloating	○	○



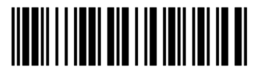
Section F. Other Medical Conditions

Has a <u>doctor or other health care professional EVER told you</u> that you had any of the following conditions?

		No	Yes	If yes: →	Did you have this condition **before** your cancer diagnosis?
F1.	Irregular heartbeat or palpitations or frequent skipped beats	○	○	→	○ No ○ Yes
F2.	Heart failure or congestive heart failure	○	○	→	○ No ○ Yes
F3.	Weak heart muscle (cardiomyopathy)	○	○	→	○ No ○ Yes
F4.	Heart attack or myocardial infarction	○	○	→	○ No ○ Yes
F5.	Chest pain or angina	○	○	→	○ No ○ Yes
F6.	High blood pressure (hypertension)	○	○	→	○ No ○ Yes
F7.	Fluid around your heart (pericarditis)	○	○	→	○ No ○ Yes
F8.	Stiff or leaking heart valves	○	○	→	○ No ○ Yes
F9.	Blood clots in the veins of the legs or in the lungs	○	○	→	○ No ○ Yes
F10.	Stroke or brain hemorrhage	○	○	→	○ No ○ Yes
F11.	Epilepsy	○	○	→	○ No ○ Yes
F12.	Seizures or convulsions	○	○	→	○ No ○ Yes
F13.	Nerve pain (neuropathy)	○	○	→	○ No ○ Yes
F14.	Chronic lung disease or bronchitis or emphysema	○	○	→	○ No ○ Yes
F15.	Asthma	○	○	→	○ No ○ Yes
F16.	Inflammation of lining of the lungs (pleurisy)	○	○	→	○ No ○ Yes
F17.	Scarring of the lung (lung fibrosis)	○	○	→	○ No ○ Yes
F18.	Pneumonia	○	○	→	○ No ○ Yes
F19.	Medical tests indicating abnormal liver function	○	○	→	○ No ○ Yes
F20.	Liver disease or cirrhosis	○	○	→	○ No ○ Yes
F21.	Inflammatory bowel disease or colitis or Crohn's disease	○	○	→	○ No ○ Yes

Has a doctor or other health care professional EVER told you that you had any of these conditions?

		No	Yes	If yes: →	Did you have this condition **before** your cancer diagnosis?
F22.	Gallbladder problems, such as gallstones	○	○	→	○ No ○ Yes
F23.	Kidney stones	○	○	→	○ No ○ Yes
F24.	Kidney or bladder infections	○	○	→	○ No ○ Yes
F25.	Overactive thyroid gland (HYPERthyroid)	○	○	→	○ No ○ Yes
F26.	Underactive thyroid gland (HYPOthyroid)	○	○	→	○ No ○ Yes
F27.	Diabetes or high blood sugar	○	○	→	○ No ○ Yes
F28.	Osteoporosis or brittle bones	○	○	→	○ No ○ Yes
F29.	Weakening or degeneration of bones of hip or shoulder joint (avascular necrosis)	○	○	→	○ No ○ Yes
F30.	Partial or complete deafness in one or both ears	○	○	→	○ No ○ Yes
F31.	Cataracts	○	○	→	○ No ○ Yes
F32.	Problems with the retina	○	○	→	○ No ○ Yes
F33.	Arthritis or rheumatism	○	○	→	○ No ○ Yes
F34.	Swelling of arm or leg due to collection of lymph fluid (lymphedema)	○	○	→	○ No ○ Yes
F35.	Anemia	○	○	→	○ No ○ Yes
F36.	Shingles	○	○	→	○ No ○ Yes
F37.	Sciatica	○	○	→	○ No ○ Yes
F38.	Depression or anxiety	○	○	→	○ No ○ Yes
F39.	Reduced or limited fertility (potential difficulty in having children of your own)	○	○	→	○ No ○ Yes



F40. Do you have any <u>other</u> medical condition(s) not mentioned so far? Please specify the condition(s) below and whether you had the condition(s) **before** your cancer diagnosis: **(Please limit your responses to the 2 most important other conditions, if you have more than two)**

Specify other conditions:		Did you have this condition **before** your cancer diagnosis?
1) ______________________	→	○ No ○ Yes
2) ______________________	→	○ No ○ Yes

F41. Are any of your **<u>current daily activities</u>** limited by **any** health condition(s) <u>selected in questions **F1 to F40**</u>?

- ○ I don't have any medical condition(s) listed in **F1 to F40** → **GO TO <u>Question F43</u>**
- ○ No, not limited at all
- ○ Yes, limited somewhat
- ○ Yes, limited a lot

F42. From the conditions you listed in **F1 to F40**, please list below the **top 1 to 3** you feel are causing you the most problems **<u>currently</u>**.

○ None are causing me problems at this time

Conditions causing the most problems for me right now are:

1) ______________________

2) ______________________

3) ______________________

F43. During the **<u>past year</u>**, did you take any of the following **<u>NON-prescription</u>** pain medicines for at least 30 days during the year?

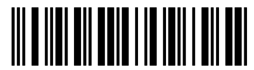
	No	**Yes**	**Not sure**
a. Aspirin	○	○	○
b. IBUPROFEN (also known as Motrin or Advil)	○	○	○
c. NAPROSYN (also known as Aleve)	○	○	○
d. ACETAMINOPHEN (also known as Tylenol)	○	○	○

F44. <u>In the past year</u> did you take any **<u>prescription</u>** medicine?

- ○ No → **GO TO <u>Question G1</u>**
- ○ Yes

F45. During the **past year**, did you take any of the following **prescription** medicines for at least 30 days during the year?

	No	Yes	Not sure
a. **ANTIBIOTICS** such as amoxicillin, bactrim, erythromycin, penicillin or others	○	○	○
b. **FEMALE HORMONES (ESTROGENS OR PROGESTERONES)** such as Estrace, Estraderm patch, Premarin, Provera, Prempro, estrogen cream, Medroxyprogesterone or others	○	○	○
c. **OTHER HORMONES** (such as Delatesteral, Testosterone cypionate, enanthate or others)	○	○	○
d. **THYROID MEDICATIONS** such as L-thyroxin, Levothyroid, Levothyroxin, Synthroid or others	○	○	○
e. **DIABETES MEDICATION** such as Insulin, Diabinase, Glucotrol, Micronase, Orinase, Tolinase or others	○	○	○
f. **MUSCLE RELAXANTS** such as Baclofen, Flexeril, Valium, Chlorzoxazone (Paraflex) or others	○	○	○
g. **PRESCRIBED PAIN MEDICINES** such as Tylenol with codeine (Tylenol #3), Ansaid, Disaicid, Feldene, Florecet or others	○	○	○
h. **ANTI-EPILEPTIC (ANTI-SEIZURE) DRUGS** such as Dilantin, Phenobarbital, Depakane, Tegretol (Carbamazepine), Klonipen, Promidone (Mysoline), Zarontin or others	○	○	○
i. **HIGH BLOOD PRESSURE MEDICINE OR HEART MEDICINE** such as Atenolol (Tenoretic), Captopril, Digoxin (Lanoxin), Lasix (Furosemide), Inderal, Lethyl-Dopa, Dyazide (Triamterene), Procardia, Vasolec or others	○	○	○
j. **PRESCRIBED ANTACIDS** (for excess stomach acid or ulcers) such as Tagomet (Cimetidine), Zantac (Ranitidine), Pepcid (Famotidine) or others	○	○	○
k. **ANTIDEPRESSANTS OR OTHER PRESCRIBED DRUGS FOR DEPRESSION OR OTHER MOOD DISORDERS** such as Elavil, Prozac, Paxil, Zoloft, Navane, Ritalin or others	○	○	○



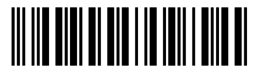
Section G. Information About Health Related Topics

G1. Little is known about the information needs of long-term cancer survivors. **At this time**, would you like more information about any of the following **health-related topics**?

Health Related Topics	No	Yes	Not Sure
a. Cancer-related follow-up tests/procedures that you should have	○	○	○
b. Symptoms that should prompt you to call your doctor	○	○	○
c. What late and long-term side effects of cancer treatment to expect	○	○	○
d. Managing your anxiety about recurrence	○	○	○
e. Staying physically fit	○	○	○
f. Nutrition and diet	○	○	○
g. Cancer risks to your family	○	○	○
h. Dealing with sexual problems	○	○	○
i. Having children after cancer treatment	○	○	○
j. Complementary and alternative treatments	○	○	○
k. Medical advances in cancer treatment	○	○	○
l. Getting or retaining health, life, or disability insurance after cancer	○	○	○
m. Any other need, please specify: ______________________	○	○	○

G2. How confident are you that you could get advice or information related to cancer if you needed it **at this time**?

- ○ Not at all confident
- ○ A little confident
- ○ Somewhat confident
- ○ Very confident
- ○ Completely confident



Section H. General Health

H1.* In general, would you say your health is:

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair
- ○ Poor

H2. 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. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
b. Climbing several flights of stairs	○	○	○

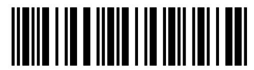
H3. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Accomplished less than you would like	○	○	○	○	○
b. Were limited in the kind of work or other activities	○	○	○	○	○

H4. 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. Accomplished less than you would like	○	○	○	○	○
b. Did work or other activities less carefully than usual	○	○	○	○	○

* Questions H1-H7 are from SF-12v2 Standard, US Version 2.0. SF-12v2™ Health Survey ©1994, 2002 by QualityMetric Incorporated and Medical Outcomes Trust - All Rights Reserved. SF-12 is a registered trademark of Medical Outcomes Trust



H5. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

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

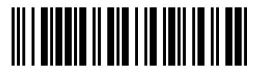
H6. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

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. Have you felt calm and peaceful?	○	○	○	○	○
b. Did you have a lot of energy?	○	○	○	○	○
c. Have you felt downhearted and depressed?	○	○	○	○	○

H7. 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.)?

- ○ All of the time
- ○ Most of the time
- ○ Some of the time
- ○ A little of the time
- ○ None of the time



Intimate Relationships

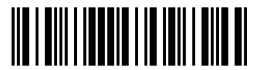
Although the questions in this section are sensitive and personal, they are important in determining how cancer and its treatments may have affected your sexual functioning. Please be assured that your responses to these questions will remain confidential.

H8. In the **past 4 weeks**, how big a problem did you consider your sexual functioning to be?

- ○ No problem
- ○ Very small problem
- ○ Small problem
- ○ Moderate problem
- ○ Big problem

H9. In the **past 4 weeks**, how satisfied were you with your sex life?

- ○ Not at all satisfied
- ○ A little satisfied
- ○ Somewhat satisfied
- ○ Very much satisfied
- ○ Completely satisfied



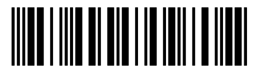
Section I. Health Appraisal And Expectations

I1. How often do you worry that your cancer may come back or get worse?

- ○ Never
- ○ Rarely
- ○ Sometimes
- ○ Often
- ○ All of the time

I2. 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**.
(FILL IN ONLY ONE OVAL FOR EACH LINE)

During the past week:	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)
a. I was bothered by things that usually don't bother me	○	○	○	○
b. I had trouble keeping my mind on what I was doing	○	○	○	○
c. I felt depressed	○	○	○	○
d. I felt that everything I did was an effort	○	○	○	○
e. I felt hopeful about the future	○	○	○	○
f. I felt fearful	○	○	○	○
g. My sleep was restless	○	○	○	○
h. I was happy	○	○	○	○
i. I felt lonely	○	○	○	○
j. I could not "get going"	○	○	○	○

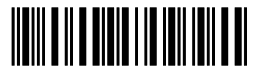


I3. Please tell us how much you agree or disagree with the following statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
a. In uncertain times, I usually expect the best	○	○	○	○	○
b. If something can go wrong for me, it will	○	○	○	○	○
c. I'm always optimistic about my future	○	○	○	○	○
d. I hardly ever expect things to go my way	○	○	○	○	○
e. I rarely count on good things happening to me	○	○	○	○	○
f. Overall, I expect more good things to happen to me than bad	○	○	○	○	○

I4. 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)	○	○	○	○	○
b. The physical side effects of your cancer and its treatment (such as feeling pain, tiredness)	○	○	○	○	○
c. The kind of follow-up care you receive for your cancer	○	○	○	○	○
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)	○	○	○	○	○



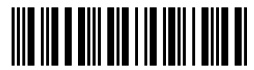
Section J. Social Support Available to You

J1. From the following options, please mark the **one person** who is most likely to **provide you help with day to day activities** if you needed this?
(PLEASE SELECT ONLY ONE)

- ○ Your child (son or daughter)
- ○ Your partner (spouse or significant other)
- ○ Your sibling (brother or sister)
- ○ Your parent (mother or father)
- ○ Your friend
- ○ Other, please specify: ______________________

J2. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?

- ○ None
- ○ One
- ○ Two
- ○ Three
- ○ Four
- ○ Five or more



J3. People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Someone to help you if you were confined to bed	⬭	⬭	⬭	⬭	⬭
b. Someone to take you to the doctor of you needed it	⬭	⬭	⬭	⬭	⬭
c. Someone to have a good time with	⬭	⬭	⬭	⬭	⬭
d. Someone to give you information to help you understand a situation	⬭	⬭	⬭	⬭	⬭
e. Someone to confide in or talk to about yourself or your problems	⬭	⬭	⬭	⬭	⬭
f. Someone who hugs you	⬭	⬭	⬭	⬭	⬭
g. Someone to get together with for relaxation	⬭	⬭	⬭	⬭	⬭
h. Someone to prepare your meals if you were unable to do it yourself	⬭	⬭	⬭	⬭	⬭
i. Someone to help with daily chores if you were sick	⬭	⬭	⬭	⬭	⬭
j. Someone to turn to for suggestions about how to deal with a personal problem	⬭	⬭	⬭	⬭	⬭
k. Someone who understands your problems	⬭	⬭	⬭	⬭	⬭
l. Someone to love you and make you feel wanted	⬭	⬭	⬭	⬭	⬭

Section K. Women's Health

If you are MALE, GO TO Question L1.

K1. At the time you were **first diagnosed** with cancer, what was your menstrual status?

- ⬭ I hadn't had a menstrual period for at least 12 months ⟶ **GO TO Question K4**
- ⬭ I was having a menstrual period every month
- ⬭ I was having a menstrual period once every few months

K2. **At this time**, what is your menstrual status?

- ⬭ I hadn't had a menstrual period for at least 12 months ⟶ **GO TO Question K4**
- ⬭ I was having a menstrual period every month
- ⬭ I was having a menstrual period once every few months

K3. **Since you were first diagnosed** with cancer, how has your menstrual **cycle length**, or menstrual **flow** changed? **(PLEASE FILL IN OVALS FOR ALL THAT APPLY)**

- ⬭ My menstrual flow got lighter
- ⬭ My menstrual flow got heavier
- ⬭ My menstrual flow got more variable and/or unpredictable
- ⬭ The length of my menstrual cycle got shorter
- ⬭ The length of my menstrual cycle got longer
- ⬭ The length of my menstrual cycle got more variable and/or unpredictable
- ⬭ Other, please specify: ______________________

K4. Have you **ever** had any gynecologic (female) surgery?

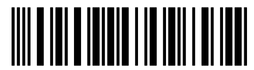
- ⬭ No ⟶ **GO TO Question L1**
- ⬭ Yes

K4a. **IF YES**, what type of surgery did you have?

- ⬭ Removal of the **uterus or womb only** (hysterectomy)
- ⬭ Removal of **ovaries only** (oophorectomy)
- ⬭ Removal of the **both** the uterus **and** ovaries
- ⬭ Removal of the uterus or womb, but unsure about removal of ovaries
- ⬭ Other, please specify: ______________________

K4b. When did you have this surgery?

- ⬭ Before my cancer diagnosis
- ⬭ After my cancer diagnosis



Section L. Health Behaviors

L1. How tall are you without shoes? ______ feet ______ inches

L2. What is your **current** weight? ______ lbs

L2a. Approximately what was your weight **a year before** you were **first diagnosed** with cancer?

_______ lbs

L2b. Approximately, what was your weight when you were **age 20**?

_______ lbs

L3. Do you participate in any regular activity or program (formal or your own design) to improve or maintain your physical fitness? (By regular we mean you do the activity at least once a week.)

- ○ No
- ○ Yes

L4. In the **past 4 weeks**, did you get regular vigorous exercise *(that is, at least once a week)* through activities such as running, aerobics, heavy yard work, tennis, or any other activity that causes large increases in breathing or heart rate?

- ○ No ⟶ **GO TO Question L5**
- ○ Yes

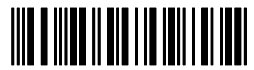
↓

L4a. **IF YES:** In the **past 4 weeks**, how many times each week did you do such activities?

- ○ Once
- ○ 2 to 4 times
- ○ 5 to 7 times
- ○ 8 to 10 times
- ○ 11 or more times

L4b. On an average, how many minutes did you do such activities each time?

- ○ Under 10 minutes
- ○ 10 to 19 minutes
- ○ 20 to 29 minutes
- ○ 30 to 59 minutes
- ○ 60 minutes or more



L5. In the **past 4 weeks**, did you get regular moderate exercise *(that is, at least once a week)* through activities such as walking, playing golf, gardening, or any other activity that causes small increases in breathing or heart rate?

- ⬭ No ⟶ **GO TO Question L6**
- ⬭ Yes

L5a. **IF YES:** In the **past 4 weeks**, how many times each week did you do such activities?

- ⬭ Once
- ⬭ 2 to 4 times
- ⬭ 5 to 7 times
- ⬭ 8 to 10 times
- ⬭ 11 or more times

L5b. On an average, how many minutes did you do such activities each time?

- ⬭ Under 10 minutes
- ⬭ 10 to 19 minutes
- ⬭ 20 to 29 minutes
- ⬭ 30 to 59 minutes
- ⬭ 60 minutes or more

L6. Have you smoked at least 100 cigarettes in your **entire lifetime**?

- ⬭ No ⟶ **GO TO Question L7**
- ⬭ Yes

L6a. **IF YES:** Did you smoke cigarettes **at the time** you were **first diagnosed** with cancer?

- ⬭ Yes, I smoked daily
- ⬭ Yes, I smoked some days a month
- ⬭ No, I did not smoke at the time of my cancer diagnosis

L6b. Do you **currently** smoke?

○ No →

L6c. **IF NO:** When did you quit smoking?
- ○ 1 to 6 months ago
- ○ 7 to 12 months ago
- ○ 1 to 4 years ago
- ○ 5 to 9 years ago
- ○ 10 or more years ago

○ Yes →

L6d. **IF YES:** How often do you smoke?
- ○ Every day
- ○ Some days

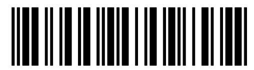
L6e. How many packs of cigarettes do you usually smoke/day?
- ○ <1 pack/day
- ○ 1-2 packs/day
- ○ >2 packs/day

L7. Have you had more than 10 drinks of alcohol in your life? (A drink means a can of beer, a glass of wine, a wine cooler, a shot of hard liquor, or a mixed drink that has a shot of hard liquor in it.)

○ No → **GO TO Question M1**
○ Yes

L7a. **IF YES:** On how many of the **past 14 days** did you have a beer, glass of wine, whisky, or any other alcoholic drink?
- ○ None
- ○ 1 to 3 days
- ○ 4 to 6 days
- ○ 7 to 9 days
- ○ 10 to 12 days
- ○ 13 to 14 days

L7b. On the days that you did drink during the **past 14 days**, how many drinks per day, on average did you have?
- ○ 1 to 2 drinks
- ○ 3 to 4 drinks
- ○ 5 to 9 drinks
- ○ 10 or more drinks



Section M. Impact of Cancer

M1. Looking back, **since the time** you were first diagnosed with cancer, how much of an **impact** has cancer and its treatments had on the following areas of your life?

	Does not apply	Very negative impact	Somewhat negative impact	No impact	Somewhat positive impact	Very positive impact
a. Your education plans	○	○	○	○	○	○
b. Your work life or career	○	○	○	○	○	○
c. Your ability to date people	○	○	○	○	○	○
d. Your desire to have children	○	○	○	○	○	○
e. Your ability to have children	○	○	○	○	○	○
f. Your relationship with your spouse/partner	○	○	○	○	○	○
g. Your sex life	○	○	○	○	○	○
h. Your relationship with your children	○	○	○	○	○	○
i. Your relationship with other family members and friends	○	○	○	○	○	○
j. Your participation in social activities	○	○	○	○	○	○
k. Your financial situation	○	○	○	○	○	○
l. Your diet	○	○	○	○	○	○
m. Your exercise activities	○	○	○	○	○	○
n. Your smoking of tobacco	○	○	○	○	○	○
o. Your alcohol consumption	○	○	○	○	○	○
p. Your retirement plans	○	○	○	○	○	○
q. Your ability to get or retain health, life, or disability insurance	○	○	○	○	○	○
r. Your religious or spiritual beliefs	○	○	○	○	○	○
s. Your ability to enjoy life	○	○	○	○	○	○

Section N. Background Information

N1. What is the highest level of formal education you have completed?

- ○ Less than high school
- ○ High school graduate or GED
- ○ Some college or technical / vocational school
- ○ College graduate
- ○ Some graduate school
- ○ Graduate degree

N2. Do you consider yourself to be …

- ○ Hispanic or Latino?
- ○ NOT Hispanic or Latino?

N3. Which of the following best describes your race?
(PLEASE FILL IN OVALS FOR ALL THAT APPLY)

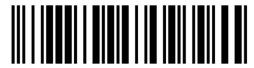
- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African-American
- ○ Native Hawaiian/ Other Pacific Islander
- ○ White

N4. What is your **current** marital status?

- ○ Married or living as married
- ○ Divorced
- ○ Separated
- ○ Widowed
- ○ Single (never married)

N5. Who lives with you currently, at least some of the time?
(PLEASE FILL IN OVALS FOR ALL THAT APPLY)

- ○ I live alone
- ○ Spouse or significant other
- ○ Children under 18, please specify:
  ○ One ○ Two ○ Three ○ Four ○ Five or more
- ○ Children 18 or older, please specify:
  ○ One ○ Two ○ Three ○ Four ○ Five or more
- ○ One or both parents
- ○ Other relatives, please specify:
  ○ One ○ Two ○ Three ○ Four ○ Five or more
- ○ Friends or roommates
- ○ Other, please specify: ______________________________



N6. 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?

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

N7. What best describes your current employment status?

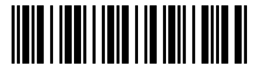
- ○ Working full-time
- ○ Working part-time
- ○ Full-time homemaker or family caregiver
- ○ Retired
- ○ Student
- ○ Unemployed
- ○ Other, please specify: ____________________

N8. Which of the following categories best describes your total household income, before taxes, from all sources **past year**?

- ○ Less than $20,000
- ○ $20,000 to $29,999
- ○ $30,000 to $39,999
- ○ $40,000 to $59,999
- ○ $60,000 to $74,999
- ○ $75,000 to $99,999
- ○ $100,000 to $119,999
- ○ $120,000 or more

N9. During the past 4 weeks, did you have adequate financial resources to meet the daily needs of you and your family?

- ○ No
- ○ Yes



N10. Do you **currently** have any form of health insurance coverage?

- ⬭ No ⟶ **GO TO <u>Question O1</u>**
- ⬭ Yes

N10a. IF YES: What type of insurance do you have?
(PLEASE FILL IN OVALS FOR ALL THAT APPLY)

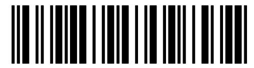
- ⬭ PPO
- ⬭ HMO or managed care
- ⬭ Medicare or Medical
- ⬭ Medicaid
- ⬭ Military (VA or CHAMPUS)
- ⬭ Other, please specify: ____________________
- ⬭ Do not know

N10b. How is this health insurance provided?
(PLEASE FILL IN OVALS FOR ALL THAT APPLY)

- ⬭ Through my employer
- ⬭ Through my spouse's or parent's policy
- ⬭ Through a private policy I purchased
- ⬭ Through the government
- ⬭ Other, please specify: ____________________

N10c. During the **past 2 years** how difficult has it been to deal with your Health Insurance company or HMO?

- ⬭ Not at all difficult
- ⬭ Little difficult
- ⬭ Somewhat difficult
- ⬭ Very difficult
- ⬭ Did not need to interact with medical insurance company



Section O. Additional Comments

O1. In looking back, what things do you think have helped you the most during the experience of becoming a cancer survivor?

O2. 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.

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

Please return the survey in the enclosed postage-paid envelope.

May we contact you in the next few months to participate in a focus group to discuss these issues further?

○ Yes, you may contact me at: ______________________
(telephone number)

○ No, I prefer not to be contacted