

SCCS Cancer Survivor Navigation Questionnaire

The following survey is to be administered to individuals from the Southern Community Cohort Study that mentioned that they had been diagnosed with breast, colorectal, lung, prostate, or another type of cancer in the follow-up survey.

PRE-SCREEN / VERIFICATION (V)

This section will allow us to gather information about your cancer. If you are eligible, you will be asked to continue with the survey.

V1. You recently told us that you were diagnosed with one of the following cancers: breast, colorectal, lung, prostate, a different type, or more than one of the previously mentioned types between the dates of January 1, 2001 and the present. We learned of this information from a follow-up survey that you filled out or from a cancer registry within your home state. Is that correct?

- a. Yes (proceed to question A1 for the corresponding cancer type.)
- b. No (proceed to question V2)

V2. After joining this study in either on or after January 1, 2001 have you been diagnosed with any type of cancer?

- a. Yes (proceed to question V3)
- b. No (please end the questionnaire at this time. Thank you for your participation.)

V3. What type of cancer were you diagnosed with?

- a. Breast (proceed to question V4)
- b. Colorectal (proceed to question V4)
- c. lung (proceed to question V4)
- d. prostate (proceed to question V4)
- e. other (please list _____)
(Please end the questionnaire at this time. Thank you for your participation.)
- f. combination of the above (please list _____)
(Proceed to question V4 if one of the listed cancers is a, b, c, or d.)

V4. When was your cancer diagnosed?

Please specify Month_____ and Year_____. (If the date falls after January 1, 2001 please proceed to question V1a)

(If the date falls before January 1, 2001, please end the survey now. Thank you for your time, but you are not eligible for the current study.)

Please proceed to section I if you were not asked to end the survey. If you were asked to end the study it is because your diagnosis date was prior to the date that you started the study. Thank you for taking time to answer these questions, and keep in mind that we plan to conduct other follow-up studies in the future at which time you may be contacted to participate.

SECTION I. PATIENT RECOGNITION OF PROBLEM (A)

The following questions are about the first time you saw a doctor or nurse before you were diagnosed with breast, colorectal, lung or prostate cancer. The following questions are about your experience between first thinking you might have a problem and your first visits to the doctor for that problem

A1a. If you were diagnosed with breast cancer, what was the *first* thing that made you think you might have a problem?

- a. Was there a problem with your routine mammogram?
- b. Were you having health problems or symptoms?
 - i. Yes
 - ii. No

→ What health problems or symptoms were you having? Please Circle Yes or No for any or all that apply:

- | | | |
|---|-----|----|
| i. A lump on one or both breasts | Yes | No |
| ii. Thickening or swelling of the breast | Yes | No |
| iii. Nipple discharge | Yes | No |
| iv. Change in breast skin color | Yes | No |
| v. Loss of appetite | Yes | No |
| vi. Unexplained weight loss | Yes | No |
| vii. Low energy (or feeling tired all the time) | Yes | No |

- c. Did you have any other symptoms? (Please list) _____
- d. Was there some other reason you thought you might be sick? What was the reason? (Please list) _____

A1b. If you were diagnosed with colorectal cancer, what was the *first* thing that made you think you might have a problem?

- a. Was there a problem with your routine colonoscopy or sigmoidoscopy?
- b. Were you having health problems or symptoms?
 - i. Yes
 - ii. No

→ What health problems or symptoms were you having? Please Circle Yes or No for any or all that apply:

- | | | |
|--|-----|----|
| i. Stomach or abdominal pain | Yes | No |
| ii. Changes in your bowel habits
(such as constipation or diarrhea) | Yes | No |
| iii. Blood in your stool | Yes | No |
| iv. Nausea or vomiting | Yes | No |
| v. Bloating or swelling of your belly | Yes | No |
| vi. Loss of appetite | Yes | No |
| vii. Unexplained weight loss | Yes | No |
| viii. Low energy
(or you were feeling tired all the time) | Yes | No |

- c. Did you have any other symptoms? (Please list) _____
- d. Was there some other reason you thought you might be sick? What was the reason? (Please list) _____

A1c. If you were diagnosed with lung cancer, what was the *first* thing that made you think you might have a problem?

a. Were you having health problems or symptoms?

- i. Yes
- ii. No

→ What health problems or symptoms were you having? Please Circle Yes or No for any or all that apply:

- | | | |
|---|-----|----|
| i. Cough | Yes | No |
| ii. Coughing up blood | Yes | No |
| iii. Difficulty breathing or getting enough air | Yes | No |
| iv. Chest pain | Yes | No |
| v. Loss of appetite | Yes | No |
| vi. Unexplained weight loss | Yes | No |
| vii. Low energy | Yes | No |

(or you were feeling tired all the time)

viii. Did you have any other symptoms? (Please list) _____

b. Was there some other reason you thought you might be sick? What was the reason?
(Please list) _____

A1d. If you were diagnosed with prostate cancer, what was the *first* thing that made you think you might have a problem?

a. Was there a problem with your routine digital rectal exam or

b. Was there a problem with your PSA blood test?

c. Were you having health problems or symptoms?

- i. Yes
- ii. No

→ What health problems or symptoms were you having? Please Circle Yes or No for any or all that apply:

- | | | |
|---|-------|----|
| i. Problems urinating or the need to urinate frequently | Yes | No |
| ii. Blood in your urine | Yes | No |
| iii. Back pain | Yes | No |
| iv. A loss of appetite | Yes | No |
| v. Unexplained weight loss | Yes | No |
| vi. Low energy (or you were feeling tired all the time) | Yes | No |
| vii. Did you have any other symptoms? (Please list) | _____ | |

d. Was there some other reason you thought you might be sick? What was the reason?
(Please list) _____

A1e. If you were diagnosed with a cancer OTHER THAN breast, colorectal, lung or prostate, what was the *first* thing that made you think you might have a problem?

a. Were you having health problems or symptoms?

- i. Yes
- ii. No

→ What health problems or symptoms were you having? Please Circle Yes or No for any or all that apply:

- | | | |
|------------------------------|-----|----|
| i. Pain | YES | NO |
| ii. Loss of appetite | YES | NO |
| iii. Unexplained weight loss | YES | NO |
| iv. Low energy | YES | NO |
- (or you were feeling tired all the time)

v. Did you have any other symptoms? (please list) _____

- b. Was there some other reason you thought you might be sick? What was the reason?
(Please list) _____

A2. If you indicated that you had symptoms for any of the above questions, please indicate how long were you having symptoms before your first doctor's visit about your problem?

Number of _____ (circle one) days weeks months years

The following questions are about the doctors you saw between the time when you first thought you had a problem and when you were told you definitely had cancer.

A3. Please fill in the following information for the doctor(s) you saw during the time before your diagnosis:

First Doctor: _____

Name of clinic or hospital: _____

City and state where the doctor is located: _____

What kind of care does the doctor provide?

- a. A family doctor (also called a general practitioner)
- b. A local community health center doctor
- c. A specialist or hospital doctor (please proceed to question A4)
- d. An emergency room doctor
- e. Some other type of doctor? (Please specify) _____

Did this doctor perform or order any tests to see if you had cancer?

- a. Yes (please proceed to question B1)
- b. No (please proceed to question B6)

Were you referred to this doctor by a different doctor?

- a. Yes (please list the doctor who gave you the referral _____)
- b. No

Second Doctor: _____

Name of clinic or hospital: _____

City and state where the doctor is located: _____

What kind of care does the doctor provide?

- a. A family doctor (also called a general practitioner)
- b. A local community health center doctor
- c. A specialist or hospital doctor
- d. An emergency room doctor
- e. Some other type of doctor? (Please specify and proceed to question B1)

Did this doctor perform or order any tests to see if you had cancer?

- a. Yes (please proceed to question B1)
- b. No (please proceed to question B6)

Were you referred to this doctor by a different doctor?

- a. Yes (please list the doctor who gave you the referral _____)
- b. No

Third Doctor: _____

Name of clinic or hospital: _____

City and state where the doctor is located: _____

What kind of care does the doctor provide?

- a. A family doctor (also called a general practitioner)
 - b. A local community health center doctor
 - c. A specialist or hospital doctor
 - d. An emergency room doctor
 - e. Some other type of doctor? (please specify and proceed to question B1)
-

Did this doctor perform or order any tests to see if you had cancer?

- a. Yes (please proceed to question B1)
- b. No (please proceed to question B6)

Were you referred to this doctor by a different doctor?

- a. Yes (please list the doctor who gave you the referral _____)
- b. No

Fourth Doctor: _____

Name of clinic or hospital: _____

City and state where the doctor is located: _____

What kind of care does the doctor provide?

- a. A family doctor (also called a general practitioner)
 - b. A local community health center doctor
 - c. A specialist or hospital doctor
 - d. An emergency room doctor
 - e. Some other type of doctor? (please specify and proceed to question B1)
-

Did this doctor perform or order any tests to see if you had cancer?

- a. Yes (please proceed to question B1)
- b. No (please proceed to question B6)

Were you referred to this doctor by a different doctor?

- a. Yes (please list the doctor who gave you the referral _____)
- b. No

Fifth Doctor: _____

Name of clinic or hospital: _____

City and state where the doctor is located: _____

What kind of care does the doctor provide?

- a. A family doctor (also called a general practitioner)
 - b. A local community health center doctor
 - c. A specialist or hospital doctor
 - d. An emergency room doctor
 - e. Some other type of doctor? (please specify and proceed to question B1)
-

Did this doctor perform or order any tests to see if you had cancer?

- a. Yes (please proceed to question B1)
- b. No (please proceed to question B6)

Were you referred to this doctor by a different doctor?

- a. Yes (please list the doctor who gave you the referral _____)
- b. No

SECTION II: TESTING (B)

The following questions are about your experiences being tested for cancer.

B1. Were you given a choice of where you could go to have your tests?

- a. Yes
- b. No

B2. Were you given a choice of the date and time when you could have your tests?

- a. Yes
- b. No

B3a. If you were diagnosed with breast cancer, please circle any and all of the following tests you had:

- a. A breast exam
- b. A mammogram
- c. An imaging scan
- d. A blood test
- e. A biopsy
- f. You had some other test (please specify _____)
- g. You did not have any tests (please proceed to question B6)

B3b. If you were diagnosed with colorectal cancer, please circle any and all of the following tests you had:

- a. A fecal occult blood test
- b. A sigmoidoscopy
- c. A colonoscopy
 - Did the doctor find any polyps? YES NO
 - Did the doctor remove (or cut out) those polyps? YES NO
- d. A barium enema
- e. An imaging scan
- f. A biopsy
- g. You had some other test (please specify _____)
- h. You did not have any tests (please proceed to question B6)

B3c. If you were diagnosed with lung cancer, please circle any and all of the following tests you had:

- a. A pulmonary (or lung) function test
- b. A sputum test
- c. A bronchoscopy
- d. A blood test
- e. An imaging scan
- f. A biopsy

- g. You had some other test (Please specify _____)
- h. You did not have any tests (Proceed to question B6)

B3d. If you were diagnosed with prostate cancer, please circle any and all of the following tests you had:

- a. A PSA blood test
- b. A digital rectal exam
- c. A bone scan
- d. An imaging scan
- e. A biopsy
- f. You had some other test (Please specify _____)
- g. You did not have any tests (Proceed to question B6)

B3e. If you were diagnosed with a type of cancer other than breast, colorectal, lung, or prostate, please circle any and all of the following tests you had:

- a. An imaging scan
- b. A blood test
- c. A biopsy
- d. You had some other test (Please specify _____)
- e. You did not have any tests (Proceed to question B6)

B4. Did your doctor (or nurse) explain to you how long you would have to wait for your test results?

- a. Yes
- b. No

B5. Did your doctor (or nurse) explain to you what your test results meant?

- a. Yes
- b. No

B6. Were there any tests or procedures that your doctor (or nurse) recommended that you did **NOT have?**

- a. Yes
- b. No (please proceed to question C1)

B7. Why didn't you have the tests recommended by your doctor (or nurse)? Please reply yes or no to any and all of the follow options that apply:

- | | | |
|--|-----|----|
| a. You did not think that the tests would help you | YES | NO |
| b. You had a problem with insurance coverage or your ability to pay | YES | NO |
| c. You were too sick to have the tests | YES | NO |
| d. You were afraid or anxious about the tests | YES | NO |
| e. You did not have someone to help you make the visit appointments or go with you | YES | NO |
| f. Your visit appointment times were hard to fit into your schedule | YES | NO |
| g. You did not have a way to get there (you did not have transportation) | YES | NO |
| h. Are there any other reasons why you did not have the tests?
(Please specify _____) | | |

SECTION III: DIAGNOSIS (C)

This next set of questions is about the time period when you were **first** told that you **definitely** had cancer.

Please only respond to this question if you only saw one doctor before you were diagnosed with cancer (Please refer to question A3 on page 6 to determine how many doctors you listed.) If you saw more than one doctor before you were diagnosed, please proceed to question C1a.

- C0.** Was the doctor we have been talking about the **first** doctor to tell you that you definitely had cancer?
- a. Yes (Please proceed to question C2)
 - b. No (Please proceed to question C1a)

C1a. Please list the name of the doctor (or nurse) who **first** told you that you **definitely** had cancer?

C1b. Please list the name of the clinic or hospital where this doctor (or nurse) is located?

C1c. Please list the city and state where this doctor (or nurse) is located?

City: _____ State: _____

C2. How long was it between **your first visit with this doctor about your problem** and **when you were told you definitely had cancer**? Was it: (please select only one of the following options)?

- a. The same day,
- b. 1 day,
- c. 2 to 6 days,
- d. 1 to 2 weeks,
- e. 3 to 4 weeks,
- f. 1 to 2 months,
- g. More than 2 months

C3. How did you feel about the amount of time between **your first visit with this doctor about your problem** and **when you were told you definitely had cancer**? Was it: (please select only one of the following options)?

- a. Too short,
- b. About right, or
- c. Too long

C4. Did any of these problems add delays to the time between **your first visit with this doctor about your problem** and **when you were told you definitely had cancer**? (please select only one of the following options)?

- a. Your visits were cancelled or postponed
- b. You were kept waiting for more than 30 minutes
- c. Your first doctor had not sent your medical records to your new doctor
- d. You had problems with your insurance or your ability to pay
- e. You did not have someone to help you make the visit appointments or go with you
- f. Your visit appointment times were hard to fit into your schedule
- g. You did not have a way to get to your doctor's office or you did not have transportation
- h. You did not trust your doctor or did not think your doctor could help you
- i. You had another problem (please list) _____
- j. You did not have any problems

C5. Please specify which options from question C4 was the ***biggest problem you experienced?***

C6. Overall, when you were being tested to see if you had cancer, how often did your doctors explain things in a way you could understand? (Please select only one of the following options.)

- a. Always,
- b. Usually,
- c. Sometimes, or
- d. Never

C7. Overall, when you were being tested to see if you had cancer, how often did your doctors give you as much information as you wanted? (Please select only one of the following options.)

- a. Always,
- b. Usually,
- c. Sometimes, or
- d. Never

SECTION IV. TREATMENT DECISION-MAKING (D)

The following questions are regarding the time when you were ***deciding*** about your cancer treatment. Please answer these questions even if you ended up not having any cancer treatment.

D1. Other than the doctors you have already told me about, did you ***talk*** to any ***NEW*** doctors ***BEFORE*** getting any treatments for your breast, colorectal, lung, prostate, or other type of cancer?

a. Yes, please provide the following information for the doctor:

Doctor's Name: _____

Name of clinic or hospital: _____

City and state where the doctor is located: _____

What kind of care does the doctor provide?

- a. A family doctor (also called a general practitioner)
- b. A local community health center doctor
- c. A specialist or hospital doctor
- d. An emergency room doctor
- e. Some other type of doctor? (please specify and proceed to question B1)

b. No

D2. Did your doctors (or nurses) ***talk*** with you about the different kinds of treatment you could have?

a. Yes

b. No (please proceed to question D4)

D3a. If you were diagnosed with breast cancer, what types of breast cancer treatments did they ***talk*** with you about? Did you ***talk*** about having any of the following (please circle all that apply)?

a. Surgery

→ What kinds of surgery? Did you ***talk*** about (please circle all that apply)?

i. A lumpectomy

ii. A mastectomy

iii. Did you talk about any other kinds of surgery?

(please list) _____

iv. Don't know

v. Refuse

b. Radiation

- What kinds of radiation? Did you **talk** about (please circle all that apply)?
 - i. External radiation
 - ii. Radiation implants
 - iii. Did you **talk** about any other kinds of radiation?
(please list) _____
 - iv. Don't know
 - v. Refuse
- c. Chemotherapy (either by itself or together with another therapy)
- d. Hormone Therapy (including shots and pills)
- e. Did you **talk** about any other kinds of treatment for your breast cancer? If yes, please list _____

D3b. If you were diagnosed with colorectal cancer, what types of colorectal cancer treatments did they **talk with you about? Did you **talk** about having any of the following (please circle all that apply)??**

- a. Surgery
 - What kinds of surgery? Did you **talk about** (please circle all that apply)?
 - i. Colostomy or ileostomy
 - ii. Did you **talk** about any other kinds of surgery?
(please list) _____
- b. Radiation
 - What kinds of radiation? Did you **talk** about (please circle all that apply)?
 - i. External radiation or
 - ii. Radiation implants or
 - iii. Did you **talk** about any other kinds of radiation?
(please list) _____
- c. Chemotherapy (either by itself or together with another therapy)
- d. Did you **talk** about any other kinds of treatment for your colorectal cancer? If yes, please list _____

D3c. If you were diagnosed with lung cancer, what types of lung cancer treatments did they **talk with you about? Did you **talk** about having any of the following (please circle all that apply)?**

- a. Surgery
 - What kinds of surgery? Did you **talk** about (please circle all that apply)?
 - i. Wedge resection
 - ii. Lobectomy
 - iii. Pneumonectomy
 - iv. Did you **talk** about any other kinds of surgery?
(please list) _____
- b. Radiation
 - What kinds of radiation? Did you **talk** about (please circle all that apply)?
 - i. External radiation
 - ii. Radiation implants
 - iii. Did you **talk** about any other kinds of radiation?
(please list) _____
- c. Chemotherapy (either by itself or together with another therapy)
- d. Did you **talk** about any other kinds of treatment for your lung cancer?
If yes, please list _____

D3d. If you were diagnosed with prostate cancer, what types of prostate cancer treatments did they **talk with you about? Did you **talk** about having any of the following (please circle all that apply)?**

- a. Surgery
 - What kinds of surgery? Did you **talk** about surgery to (please circle all that apply)?
 - i. Remove your prostate,
 - ii. Remove your testicles, or
 - ii. Did you **talk** about any other kinds of surgery?
(please list)_____
- b. Radiation
 - What kinds of radiation? Did you **talk** about (please circle all that apply)?
 - i. External radiation or
 - ii. Radiation implants or
 - iii. Did you **talk** about any other kinds of radiation?
(please list)_____
- c. Chemotherapy
- d. Cryotherapy
- e. Hormone Therapy (including shots and pills)
- f. No treatment at this time or “wait and see”
- g. Did you **talk** about any other kinds of treatment for your prostate cancer?
If yes, please list_____
- h. Don’t know
- i. Refuse

D3e. If you were diagnosed with a type of cancer other than breast, colorectal, lung, or prostate cancer, what types of cancer treatments did they **talk with you about? Did you **talk** about having any of the following (please circle all that apply)?**

- a. Surgery
- b. Radiation
 - What kinds of radiation? Did you **talk** about (please circle all that apply)?
 - i. External radiation
 - ii. Radiation implants
 - iii. Did you **talk** about any other kinds of radiation?
(please list)_____
- c. Chemotherapy (either by itself or together with another therapy)
- d. Hormone Therapy (including shots and pills)
- e. Did you **talk** about any other kinds of treatment for your cancer?
If yes, please list_____

D4. Were there any treatments that your doctors (or nurses) said you could **not have (please circle one option)?**

- a. Yes if so, did they explain **why** you could **not** have other treatments?
Please explain and proceed to question D5)

- b. No (Please proceed to question D6)

D5. Why **couldn't you have those treatments? Was it because (please circle all that apply)?**

- a. Your doctors did not think that treatment would help you (or the treatment was not appropriate for you)
- b. You had a problem with insurance coverage or ability to pay for your visit
- c. You were too sick to have these treatments
- d. Were there any other reasons why they were not available to you?
Please list_____

The following questions are about any information your doctors (or nurses) gave you about possible side effects during and after treatment.

- D6.** Did your doctors (or nurses) give you information about any of the following? (please circle all that apply)
- a. Pain
 - b. Fatigue
 - c. Anxiety
 - d. Fear
 - e. Depression
 - f. Nutrition
 - g. Your doctors (or nurses) did not give you information about any of these (proceed to question D7b)

D7a. Did you get enough information?

- a. Yes
- b. No

If no, would you have preferred more information (circle one)? YES NO DON'T KNOW

D7b. Would you have wanted them to give you this information?

- a. Yes
- b. No

D8. If you were diagnosed with breast cancer, did your doctors (or nurses) **talk** with you about the following physical side effects and late effects that you might have during and/or after your treatment? Did you **talk** about problems with (please circle all that apply)?

- a. Hot flashes
- b. Swelling or lymphedema
- c. Loss of sexual libido
- d. Nausea and vomiting
- e. Hair loss
- f. Weight loss
- g. You **talked** about other side effects or late effects

Please list _____

- h. You did not **talk** about any side effects or late effects (please proceed to question D10a)

If you selected any answer from a through f above, then please proceed to question D9a.

D8. If you were diagnosed with colorectal cancer, did your doctors (or nurses) **talk** with you about the following physical side effects and late effects that you might have during and/or after your treatment? Did you **talk** about problems with (please circle all that apply)?

- a. Bowel movements
- b. Urination
- c. Sexual intercourse
- d. Nausea and vomiting
- e. Hair loss
- f. Weight loss
- g. You **talked** about other side effects or late effects

Please list _____

- h. You did not **talk** about any side effects or late effects (please proceed to question D10a)

If you selected any answer from a through f above, then please proceed to question D9a.

D8. If you were diagnosed with lung cancer, did your doctors (or nurses) **talk** with you about the following physical side effects and late effects that you might have during and/or after your treatment? Did you **talk** about problems with (please circle all that apply)?

- a. Increased sputum (or mucus) in the lungs
- b. Blood clots (or thrombosis)
- c. Nausea and vomiting
- d. Hair loss
- e. Weight loss
- f. You **talked** about other side effects or late effects

Please list _____

- g. You did not **talk** about any side effects or late effects (please proceed to question D10a)

If you selected any answer from a through e above, then please proceed to question D9a.

D8. If you were diagnosed with prostate cancer, did your doctors (or nurses) **talk** with you about the following physical side effects and late effects that you might have during and/or after your treatment? Did you **talk** about problems with (please circle all that apply)?

- a. Erections
- b. Urination
- c. Bowel movements
- d. Nausea and vomiting
- e. Hair loss
- f. Weight loss
- g. You **talked** about other side effects or late effects

Please list _____

- h. You did not **talk** about any side effects or late effects (please proceed to question D10a)

If you selected any answer from a through e above, then please proceed to question D9a.

D8. If you were diagnosed with a cancer other than breast, colorectal, lung, or prostate cancer, did your doctors (or nurses) **talk** with you about the following physical side effects and late effects that you might have during and/or after your treatment? Did you **talk** about problems with (please circle all that apply)?

- a. Nausea and vomiting
- b. Hair loss
- c. Weight loss
- d. Bowel movements
- e. You **talked** about other side effects or late effects

Please list _____

- f. You did not **talk** about any side effects or late effects (please proceed to question D10a)

If you selected any answer from a through e above, then please proceed to question D9a.

D9a. Was it enough information?

- a. Yes
- b. No

If no, would you have liked more information (please circle one)? YES NO DON'T KNOW REFUSE

D9b. How important was the information about physical side effects and late effects when you were deciding about your treatment? Was it (please circle all that apply)?

- a. Very important
- b. Somewhat important,
- c. A little important, or
- d. Not important at all

Please proceed to question D12.

D10a. Would you have wanted them to give you this information?

- a. Yes
- b. No

D10b. Looking back, if you had received this information, would your **treatment decision** have been different?

- a. Yes
- b. No

D11. How much time were you given to think about your **treatment choices before the treatment decision** was made? Was it (please circle only one)?

- a. The same day,
- b. 1 to 2 days,
- c. 3 to 7 days,
- c. 1 to 2 weeks,
- d. 3 to 6 weeks,
- e. More than 6 weeks

D12. How did you feel about the amount of time you were given to think about your **treatment choices before the treatment decision** was made? Was it (please circle only one)?

- a. Too short,
- b. About right, or
- c. Too long

D13. Did your doctors (or nurses) tell you that you could change your mind about which treatment to have?

- a. Yes
- b. No

D14. Which of these statements best describes how you feel about your role in making **decisions** for your cancer treatment (please circle only one option)?

- a. My role was as big as I wanted,
- b. My role was bigger than I wanted, or
- c. I wish I had a bigger role

D15. In addition to you and your doctors (and nurses), did any of the following people help to choose which treatment plan you were going to have (circle all that apply)?

- a. Your family 4
- b. Your friends
- c. A religious or spiritual advisor
- d. Some other person. Please specify _____
- e. None of these people helped choose your treatment plan

D16. How confident were you that the **treatment decision** made was the best one for you? Were you (please circle only one option)?

- a. Fully confident,
- b. Confident, but with some doubts, or
- c. Not confident

SECTION V. TREATMENT DELIVERY (E)

This next set of questions is about your cancer *treatment*.

E1. Have you had any treatments for your cancer?

- a. Yes
- b. No (please proceed to question E19)

E2. How long was it from the time when ***your treatment decision was made*** until your ***first doctor's visit related to your treatment***? Was it (please select only one)?

- a. The same day,
- b. 1 to 2 days,
- c. 3 to 7 days,
- c. 1 to 2 weeks,
- d. 3 to 6 weeks,
- e. More than 6 weeks

E3. How did you feel about the amount of time between when ***your treatment decision was made*** and ***your first doctor's visit related to your treatment***? Was it (please select only one)?

- a. Too short,
- b. About right, or
- c. Too long

The following questions are about the *specific treatments* you have had for your cancer.

E4a. If you were diagnosed with breast cancer, what types of treatment have you had? Have you had (please circle all that apply)?

- a. Surgery
 - Did you have (please circle only one)?
 - i. A Lumpectomy,
 - ii. A Mastectomy or
 - iii. Some other kind of surgery?
- b. Radiation
 - What type of radiation did you have (circle all that you apply)?
 - i. External radiation or
 - ii. Radiation implants or
 - iii. Some other type of radiation?Please specify _____
- c. Chemotherapy (either by itself or together with another therapy)
- d. Hormone Therapy (including shots and pills)
- e. Have you had any other treatment for your breast cancer?
Please specify _____

E4b. If you were diagnosed with colorectal cancer, what types of treatments have you had? Have you had (please select all that apply)?

a. Surgery

→ Did you have (please select only one)?

- i. A Colostomy or ileostomy
- ii. A Colectomy or Ileectomy, or
- iii. Some other kind of surgery?

b. Radiation

→ What type of radiation did you have (please select all that apply)?

- i. External radiation or
- ii. Radiation implants or
- iii. Some other type of radiation?

Please specify _____

c. Chemotherapy (either by itself or together with another therapy)

d. Have you had any other treatment for your colorectal cancer?

Please specify _____

E4c. If you were diagnosed with lung cancer, what types of treatments have you had? Have you had (please select all that apply)?

a. Surgery

→ Did you have (please select only one)?

- i. A Wedge resection,
- ii. A Lobectomy,
- iii. A Pneumonectomy, or
- iv. Some other kind of surgery?

Please specify _____

b. Radiation

→ What type of radiation did you have (please select all that apply)?

- i. External radiation or
- ii. Radiation implants or
- iii. Some other type of radiation?

Please specify _____

c. Chemotherapy (either by itself or together with another therapy)

d. Have you had any other treatment for your lung cancer?

Please specify _____

E4d. If you were diagnosed with prostate cancer, what types of treatments have you had? Have you had (please select all that apply)?

a. Surgery

→ Did you have surgery to (please select only one)?

- i. Remove your prostate,
- ii. Remove your testicles, or
- ii. Did you have some other kind of surgery?

Please specify _____

b. Radiation

→ What type of radiation did you have (circle all that apply)?

- i. External radiation,
- ii. Radiation implants, or
- iii. Some other type of radiation?

Please specify _____

- c. Chemotherapy
- d. Cryotherapy
- e. Hormone Therapy (including shots and pills)
- f. No treatment (or "wait and see")
- g. Some other kind or treatment for your prostate cancer?

Please specify _____

E4e. If you were diagnosed with a cancer other than breast, colorectal, lung, or prostate cancer, what types of treatments have you had? Have you had (circle all that apply)?

- a. Surgery
- b. Radiation
 - What type of radiation did you have (circle all that apply)?
 - i. External radiation or
 - ii. Radiation implants or
 - iii. Some other type of radiation?

Please specify _____

- c. Chemotherapy (either by itself or together with another therapy)
- d. Hormone Therapy (including shots and pills)
- e. Have you had any other treatment for your cancer?

Please specify _____

The next questions refer to all of the places where you were treated for your cancer.

E5. The following set of questions is to gather information for each type of treatment that you selected in question E4.

If you underwent surgery:

- a. What is the name of the clinic or hospital where you had your **first/next course of** treatment that you specified in question E4?

Please list _____

- b. What is the city and state where you had your **first/next course of** treatment that you specified in question E4?

Please list _____

- c. To the best of your memory, when did you have your **first visit at this** location?

Month: _____ Year: _____

- d. Did you have any [E4] treatments at a different clinic or hospital?

Please list _____

If you underwent radiation:

- a. What is the name of the clinic or hospital where you had your **first/next course of** treatment that you specified in question E4?

Please list _____

- b. What is the city and state where you had your **first/next course of** treatment that you specified in question E4?

Please list _____

- c. To the best of your memory, when did you have your **first visit at this** location?

Month: _____ Year: _____

- d. Did you have any [E4] treatments at a different clinic or hospital?

Please list _____

If you underwent chemotherapy:

- a. What is the name of the clinic or hospital where you had your **first/next course of** treatment that you specified in question E4?
Please list _____
- b. What is the city and state where you had your **first/next course of** treatment that you specified in question E4?
Please list _____
- c. To the best of your memory, when did you have your **first visit at this** location?
Month: _____ Year: _____
- d. Did you have any [E4] treatments at a different clinic or hospital?
Please list _____

If you underwent hormone therapy (including shots and pills):

- a. What is the name of the clinic or hospital where you had your **first/next course of** treatment that you specified in question E4?
Please list _____
- b. What is the city and state where you had your **first/next course of** treatment that you specified in question E4?
Please list _____
- c. To the best of your memory, when did you have your **first visit at this** location?
Month: _____ Year: _____
- d. Did you have any [E4] treatments at a different clinic or hospital?
Please list _____

If you underwent any other cancer treatment: (Please list _____)

- a. What is the name of the clinic or hospital where you had your **first/next course of** treatment that you specified in question E4?
Please list _____
- b. What is the city and state where you had your **first/next course of** treatment that you specified in question E4?
Please list _____
- c. To the best of your memory, when did you have your **first visit at this** location?
Month: _____ Year: _____
- d. Did you have any [E4] treatments at a different clinic or hospital?
Please list _____

IF YOU HAD A SURGERY PLEASE ANSWER THE FOLLOWING QUESTIONS:

E6. After your surgery, did you have any of the following problems? I'll read you a list, and you can tell me yes or no to each. Did you have (circle all that apply)?

- a. Pain
- b. Fatigue
- c. Nausea and vomiting
- d. Swelling (or lymphedema)
- e. Infections related to your surgery
- f. Did you have any other problems?
Please list _____
- g. You did not have any problems?

E7. Did your surgeon (or nurses) help you manage any symptoms or side effects you were having **while you were in the hospital?** (please circle one of the following options):

- a. Yes → i. Was it enough help? YES NO DON'T KNOW REFUSE
→ ii. Did you need more help? YES NO DON'T KNOW REFUSE
- b. No → Would you have wanted them to help you? YES NO DON'T KNOW REFUSE

E8. Did your surgeon (or nurses) talk with you about how you could manage any symptoms or side effects **at home after leaving the hospital?** (please circle one of the following options):

- a. Yes → i. Was it enough information? YES NO DON'T KNOW REFUSE
→ ii. Would you have liked more information? YES NO DON'T KNOW REFUSE
- b. No → Would you have wanted them to give you this information?
YES NO DON'T KNOW REFUSE

IF YOU HAD ANY TREATMENTS IN ADDITION TO SURGERY, PLEASE ANSWER THE FOLLOWING QUESTIONS.

E9. When you were getting your treatment, did you have any of the following problems? I'll read you a list, and you can tell me yes or no to each. Did you have (circle all that apply)?

- a. Pain
- b. Fatigue
- c. Nausea and vomiting
- d. Weight loss
- e. Hair loss
- f. Problems with urination
- g. Problems with your bowel movements
- h. Problems with sexual intercourse
- i. Did you have any other problems? Please list _____
- j. You did not have any problems?

E10. Did your doctors (or nurses) help you manage any symptoms or side effects you were having **while you were being treated?**

- a. Yes → i. Was it enough help? YES NO DON'T KNOW REFUSE
→ ii. Did you need more help? YES NO DON'T KNOW REFUSE
- b. No → Would you have wanted them to help you? YES NO DON'T KNOW REFUSE

E11. Did your doctors (or nurses) talk with you about how you could manage any symptoms or side effects **after your treatment is finished?**

- a. Yes → i. Was it enough information? YES NO DON'T KNOW REFUSE
→ ii. Would you have liked more information? YES NO DON'T KNOW REFUSE
- b. No → Would you have wanted them to give you this information?
YES NO DON'T KNOW REFUSE

E12. Have you finished getting **all** of your treatments for your cancer?

- a. Yes
- b. No (Please proceed to question F1)

E13. Looking back on all of your treatment, how often did you feel like you could talk to your doctors (or nurses) about any concerns related to your treatment (please circle only one)?

- a. Always,
- b. Most of the time,
- c. Some of the time,
- d. A little, or
- e. Not at all

E14. Looking back on all of your treatment, did any of these problems cause delays during the time when you were getting treatment for your cancer? (please circle all that apply)

- a. Your visits were cancelled or postponed
- b. You were kept waiting for more than 30 minutes
- c. Your first doctor had not sent your medical records to your new doctor
- d. You had problems with your insurance or your ability to pay
- e. You did not have someone to help you make the visit appointments or go with you
- f. Your visit appointment times were hard to fit into your schedule
- g. You did not have a way to get to your doctor's office or you did not have transportation
- h. You did not trust your doctor or did not think your doctor could help you
- i. You had another problem (please list _____)
- j. You did not have any problems

E15. If you selected more than one answer in E14, of those problems, which **one** was the **biggest**? If you only selected one answer please proceed to question E15.

Please list only one _____

E16. Did any of your doctors (or nurses) recommend follow-up visits and regular tests in case your cancer comes back after finishing all of your treatment?

- a. Yes
- b. No

E17. Do you have regular tests to check for cancer?

- a. Yes →
 - i. What is the name of the clinic or hospital where you go?
please list _____
 - ii. What is the city and state where it is located?
please list _____
- b. No (please proceed to question F1)

E18. How often are you **currently** being tested for cancer (please select only one)?

- a. 1 time per month,
- b. 4 times per year,
- c. 3 times per year,
- d. 2 times per year,
- e. 1 time per year, or
- f. Less than 1 time per year

Please proceed to question F1 after answering question E18.

- E19.** Why haven't you had any treatments for your cancer? Was it because (please select all that apply)?
- Your doctors did not think that treatment would help you
 - You did not think that treatment would help you
 - You had a problem with insurance coverage or ability to pay for the visit
 - You were too sick to have treatment
 - You were afraid or anxious about the treatment
 - You did not have someone to help you make the visit appointments or go with you
 - Your visit appointment times were hard to fit into your schedule
 - You did not have a way to get there (you did not have transportation)
 - Were there any other reasons why you haven't had any treatments? [SPECIFY]

SECTION VI. SUPPORT CARE (F)

The next couple of questions are about **support services**. These services are used to help cancer patients with long-term management of their symptoms, pain, and medications as well as to provide nutritional, physical, and emotional education and support. Patients can start these services at any time in their cancer journey, and they can use them even after they have finished their treatment.

- F1.** Have you received any support services as part of your cancer care? (please circle all that apply)
- Have you had someone come to your home to help you with medical or self-care (for example, someone who comes in to help with taking medicine)
 - Have you seen a psychiatrist, psychologist, or mental health worker
 - Have you seen a social worker
 - Have you seen a physical (or occupational) therapist
 - Have you seen a doctor or nurse to help with your pain
 - Have you talked with a religious counselor, such as a chaplain, minister, priest or rabbi about your cancer
 - Have you had some other support service?
Please specify _____
 - You have not had any support services (please proceed to question F4)

IF YOU CIRCLED ANY ANSWER FROM A TO G PROCEED TO QUESTION F2

- F2.** Did any of your doctors (or nurses) arrange these support services during the time when your cancer was being **tested**?
- Yes
 - No
- F3.** Did any of your doctors (or nurses) arrange these support services during the time when your cancer was being **treated**?
- Yes
 - No

- F4.** Were there any support services that you feel you needed but did not receive?
- Yes (please proceed to question F5)
 - No (please proceed to question F7)

- F5.** What support services do you feel you needed but did not receive?
- Have you had someone come to your home to help you with medical or self-care (for example, someone who comes in to help with taking medicine)
 - Have you seen a psychiatrist, psychologist, or mental health worker
 - Have you seen a social worker
 - Have you seen a physical (or occupational) therapist
 - Have you seen a doctor or nurse to help with your pain
 - Have you talked with a religious counselor, such as a chaplain, minister, priest or rabbi about your cancer
 - Have you had some other support service?
Please specify _____
 - You have not had any support services

- F6.** Why did you **not** receive the support services you felt you needed? Was it because (please circle all that apply)?
- You had a problem with insurance coverage or ability to pay for the support services
 - You did not have someone to help you make the visit appointments or go with you
 - Your visit appointment times were hard to fit into your schedule
 - You did not have a way to get there (did not have transportation)
 - You were too sick to get the support services
 - You were afraid or anxious about the support services
 - Can you think of any other reasons?
Please specify _____

- F7.** Have you seen another kind of healer other than your regular doctors, such as an acupuncturist, chiropractor, or herbalist to help you treat or relieve the symptoms of your cancer?
- Yes
 - No (please proceed to question G1)

- F8.** Are your doctors (or nurses) aware that you are seeing other healers?
- Yes
 - No

SECTION VII. QUALITY OF CARE (G)

The following questions refer to all of the cancer care you have received.

- G1.** Since you were told that you definitely had cancer, how many different doctors have you seen because of your cancer?
Please write out the number _____ -

- G2.** Overall, how would you rate the quality of health care you received for the **testing (or diagnosis)** of your cancer? Would you say it has been (please circle only one):
- Excellent,
 - Very good,
 - Good,
 - Fair, or
 - Poor

G3. Overall, how would you rate the quality of health care you received for the **treatment** of your cancer? Would you say it has been (please circle only one):

- a. Excellent,
- b. Very good,
- c. Good,
- d. Fair, or
- e. Poor

G4. Would you say that you received medical care that was better than, about the same as, or worse than other patients with cancer (please circle only one)?

- a. Better (please proceed to question G6)
- b. About the same (please proceed to question G6)
- c. Worse

G5. Why do you think that the medical care you received was worse than other patients with cancer? Do you think it was because of your (circle all that apply)?

- a. Age
- b. Gender
- c. Race or ethnic group
- d. Education level
- e. Health or disability
- f. Type of insurance
- g. Lack of insurance
- h. Level of income
- i. Religion
- j. Can you think of any other reasons?
Please list _____

G6. Now I would like you to think about all of the different doctors (or nurses) you saw for your cancer. (please circle one answer for each of a-f)

a. How often did you trust your doctors (or nurses) were doing everything possible to help you?

ALWAYS USUALLY SOMETIMES NEVER N/A DON'T KNOW REFUSE

b. How often did you know who to ask when you had questions related to your cancer?

ALWAYS USUALLY SOMETIMES NEVER N/A DON'T KNOW REFUSE

c. How often did your doctors (or nurses) encourage you to ask all the cancer-related questions you had?

ALWAYS USUALLY SOMETIMES NEVER N/A DON'T KNOW REFUSE

d. How often did you think that your cancer-related health problems were handled quickly enough?

ALWAYS USUALLY SOMETIMES NEVER N/A DON'T KNOW REFUSE

e. How often were you able to see the doctors or specialists you wanted to see for your cancer?

ALWAYS USUALLY SOMETIMES NEVER N/A DON'T KNOW REFUSE

- f. How often did your doctors (or nurses) seem to be aware of the tests and/or treatments for your cancer that other doctors recommended or performed?

ALWAYS USUALLY SOMETIMES NEVER N/A DON'T KNOW REFUSE

SECTION VIII. QUALITY OF LIFE AND EMPLOYMENT (H)

This next set of questions is about the effect of your cancer on your quality of life. On a scale of 1 to 100, where 1 is NOT AT ALL and 100 is A LOT; please tell how much your cancer has affected the following:

H1. How much have the side effects and late effects of your cancer treatment been a problem for you?
(please indicate a number 1-100 as described above)_____

H2. How much are you afraid of the following...

- a. Future tests for cancer (please indicate a number 1-100 as described above)_____
- b. Your cancer coming back (please indicate a number 1-100 as described above)_____
- c. Your cancer spreading in your body (please indicate a number 1-100 as described above)_____
- d. Getting a new cancer (please indicate a number 1-100 as described above)_____

H3. How much has your cancer interfered with your family life?
(please indicate a number 1-100 as described above)_____

H4. How much has your cancer interfered with your social activities?
(please indicate a number 1-100 as described above)_____

H5. How much has your cancer and treatment caused financial problems?
(please indicate a number 1-100 as described above)_____

The next few questions are about the effect of your cancer on your employment.

H6. When you were diagnosed with your cancer, were you working for pay?
a. Yes
b. No

H7. Are you working for pay now?
a. Yes
b. No

If you answered no, don't know or refuse for H6 or H7, please proceed to question I1

H8. As a result of your cancer, have any of the following happened to you? I'll read you a list and you can tell me yes or no to each. Have you (please circle all that apply)?

- a. Changed jobs or employers
- b. Taken a leave of absence
- c. Quit your job
- d. Been let go or fired
- e. Missed work
- f. Worked fewer hours
- g. Turned down a job or promotion
- h. Felt that your work suffered
- i. Felt your co-workers treated you badly
- j. Felt your supervisor treated you badly

SECTION IX. HEALTH INSURANCE (I)

These next questions are about how having cancer affected your health insurance.

I1a. Do you currently have health insurance?

- a. Yes (Please proceed to question I1b)
- b. No (Please proceed to question I2)

I1b. What kind of health insurance do you have? I'll read you a list and you can tell me yes or no to each. Do you have (circle all that apply)?

- a. Medicaid (Please proceed to question I4)
 - b. Medicare (Please proceed to question I4)
 - c. Private insurance (Please proceed to question I4)
 - d. Military insurance (Please proceed to question I4)
 - e. Did you have some other type of insurance? (Please proceed to question I4)
- Please list _____

I2. What is the **one main reason** why you do not have any health insurance? Is it because (please circle only one)?

- a. You changed employers or lost your job
- b. Your family situation changed
- c. You lost your public program coverage
- d. Your employer does not offer insurance
- e. You can't afford it [or it is too expensive]
- f. You don't believe in insurance
- g. You are not eligible for health insurance

Please list why you are not eligible _____

h. You don't need insurance

Please specify why you don't need insurance _____

i. Is there some other reason you do not have health insurance?

Please specify _____

I3. How do you get health care **most of the time**? Do you go to (please circle only one)?

- a. A walk-in clinic (or community health center), or
- b. The emergency room, or
- c. An alternative healer
- d. Do you go somewhere else?

Please list _____

Please proceed directly to question 17.

14. Between when you were *first* tested for cancer and today, was there ever a time that you did not have health insurance?

- a. Yes → For how many months (please indicate the total number of months even if they were not back-to-back)? Number of months _____ (please proceed to question 15)
- b. No (Please proceed to question 17.)

15. What was the *one main reason* why you did not have any health insurance? Was it because (please select only one)

- a. You changed employers or lost your job
- b. Your family situation changed
- c. You lost your public program coverage
- d. Your employer does not offer insurance
- e. You can't afford it [or it is too expensive]
- f. You don't believe in insurance
- g. You are not eligible for health insurance

Please specify why you are not eligible _____

h. You don't need insurance

Please specify why you don't need insurance _____

i. Is there some other reason you do not have health insurance?

Please list _____

16. During the time when you had no health insurance, how did you get health care *most of the time*? Did you go to (please select only one)?

- a. A walk-in clinic (or community health center), or
- b. The emergency room, or
- c. An alternative healer
- d. Did you go somewhere else?

Please list only one _____

17. What type of health insurance did you have when you were being *tested* for cancer? Was it (please select only one)?

- a. Medicaid
- b. Medicare
- c. Private insurance
- d. Military
- e. Did you have some other type of insurance?

Please list _____

18a. Did your health insurance change between when you were being *tested* and when you were being *treated* for your cancer?

- a. Yes (please proceed to question 18b)
- b. No (please proceed to question 110)

18b. What kind of health insurance did you have when you were being *treated*? I'll read you a list and you can tell me yes or no to each. Did you have (please select all that apply)?

- a. Medicaid
- b. Medicare

- c. Private insurance
- d. Military insurance
- e. Did you have some other type of insurance?

Please list _____

19. Why did your insurance change? Was it because of your cancer or was it because of some other reason? (please select only one)

- a. Because of cancer, or
- b. Some other reason
please specify _____

110. When you were being **tested** to see if you had cancer, were there any tests your doctor (or nurse) wanted you to get that you did not get because of problems with insurance or because you could not afford them?

- a. Yes, please specify what the tests were _____
- b. No

111. When you were being **treated** for your cancer, were there any treatments your doctor (or nurse) wanted you to get that you did not get because of problems with insurance or because you could not afford them?

- a. Yes, please specify what the treatments were _____
- b. No

112. Did any of your doctors (or nurses) give you financial information on free or low-cost health benefits or welfare?

- a. Yes
 - i. Did you receive this information when you were being tested or treated? (circle one)

TESTED TREATED BOTH DON'T KNOW REFUSE

- ii. Did this information help you? (circle one)

YES NO DON'T KNOW REFUSE

- iii. Did you apply for the benefits? (circle one)

YES NO DON'T KNOW REFUSE

- b. No
 - Would you have wanted them to give you this information? (circle one)

YES NO DON'T KNOW REFUSE