Participant ID 0 0 0 0

Twelve Month Follow-up Survey

CEASAR STUDY

Thank you for your continued participation in the CEASAR study. This follow-up questionnaire is about your quality of life and other experiences related to your prostate cancer and its treatment. To help us get the most accurate information, it is important that you answer all questions honestly and completely about your own experience. You may skip any questions that you are uncomfortable answering. Your responses will help us in our efforts to learn more about how to best treat prostate cancer.

Information contained within this survey will remain strictly confidential.

Thank you very much for your assistance in answering these questions.

Participant ID _ _ 0 0 0 0 _ _ _ _

General Instructions

PLEASE READ THESE INSTRUCTIONS CAREFULLY

- Answer each question as best you can. If you choose to skip a question, please write 'skip' next to it.

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

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

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

  Example: ⬬ No ***(If no, go to the 'If no' section on the next page)***

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

  Example:

  ⬬ Other, please specify: *my friend who is a doctor*

- Mark only one response for each question, unless other instructions are given.

- If you mark the wrong oval by mistake, put an X through it and fill in the correct answer, like this: ⊗⬬

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

Participant ID ____ 0 0 0 0 ____

1. Today's date: ____ / ____ / 2 0 ____
Month **Day** **Year**

Prostate Cancer Treatment

2. What is your most recent PSA result? ____.____

○ Don't know

3. Have you received any of these treatments for your prostate cancer? *(Choose all that apply)*.

	Yes	If Yes, Date Started: Month / Year	Did **Not** Receive
a. Surgery (Robotic/Laparoscopic removal of prostate)	○	____ / 2 0 ____	○
b. Surgery (Open removal of prostate/traditional approach with incision)	○	____ / 2 0 ____	○
c. Seeds/Rods (Brachytherapy)	○	____ / 2 0 ____	○
d. External Beam Radiation (IMRT/3-D CLRT)	○	____ / 2 0 ____	○
e. Hormone Therapy	○	____ / 2 0 ____	○
f. Cryotherapy (freezing of the prostate)	○	____ / 2 0 ____	○
g. Active Surveillance/Watchful Waiting	○	____ / 2 0 ____	○
h. No therapy, have not decided yet	○	____ / 2 0 ____	○
i. Other therapy (Please specify): _____	○	____ / 2 0 ____	○

General Health

4. The following items are activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? *(Choose one response on each line)*

	Yes, I am LIMITED a lot	Yes, I am LIMITED a little	No, I am NOT LIMITED at all
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
c. Lifting or carrying groceries	○	○	○
d. Climbing several flights of stairs	○	○	○
e. Climbing one flight of stairs	○	○	○
f. Bending, kneeling, or stooping	○	○	○
g. Walking more than a mile	○	○	○
h. Walking several hundred yards	○	○	○
i. Walking one hundred yards	○	○	○
j. Bathing or dressing yourself	○	○	○

5. These questions are about how you feel and how things have been going 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** …
(Choose one response on each line)

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
a. Did you feel full of life?	○	○	○	○	○	○
b. Have you been very nervous?	○	○	○	○	○	○
c. Have you felt so down in the dumps that nothing could cheer you up?	○	○	○	○	○	○
d. Have you felt calm and peaceful?	○	○	○	○	○	○
e. Did you have a lot of energy?	○	○	○	○	○	○
f. Have you felt down-hearted and depressed?	○	○	○	○	○	○
g. Did you feel worn out?	○	○	○	○	○	○
h. Have you been happy?	○	○	○	○	○	○
i. Did you feel tired?	○	○	○	○	○	○

6. During the **past 4 weeks** how often were the following statements true? *(Choose one response on each line)*

	None of the time	Some or a little of the time	Occasionally	Most or all of the time
a. I was bothered by things that usually don't bother me	○	○	○	○
b. I felt that I could not shake off the blues even with help from my family or friends	○	○	○	○
c. I had trouble keeping my mind on what I was doing	○	○	○	○
d. I felt depressed	○	○	○	○
e. I felt that everything I did was an effort	○	○	○	○
f. My sleep was restless	○	○	○	○
g. I was happy	○	○	○	○
h. I enjoyed life	○	○	○	○
i. I felt sad	○	○	○	○

Specific Health Issues

Urinary Issues

7. Over the **past 4 weeks**, how often have you leaked urine? *(Choose one)*

- ○ More than once a day
- ○ About once a day
- ○ More than once a week
- ○ About once a week
- ○ Rarely or never

8. Which of the following best describes your urinary control during the **last 4 weeks**? *(Choose one)*

- ○ No urinary control whatsoever
- ○ Frequent dribbling
- ○ Occasional dribbling
- ○ Total control

9. How many pads or adult diapers per day did you usually use to control leakage during the **last 4 weeks**? *(Choose one)*

- ○ None
- ○ 1 pad per day
- ○ 2 pads per day
- ○ 3 or more pads per day

10. How big a problem, if any, has each of the following been for you during the **last 4 weeks**? *(Choose one response on each line)*

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Dripping or leaking urine	○	○	○	○	○
b. Pain or burning on urination	○	○	○	○	○
c. Bleeding with urination	○	○	○	○	○
d. Weak urine stream or incomplete emptying	○	○	○	○	○
e. Need to urinate frequently during the day	○	○	○	○	○

11. Overall, how big a problem has your urinary function been for you during the **last 4 weeks**? *(Choose one)*

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

Bowel Issues

12. How big a problem, if any, has each of the following been for you during the **last 4 weeks**? *(Choose one response on each line)*

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Urgency to have a bowel movement	○	○	○	○	○
b. Increased frequency of bowel movements	○	○	○	○	○
c. Losing control of your stools	○	○	○	○	○
d. Bloody stools	○	○	○	○	○
e. Abdominal/Pelvic/Rectal pain	○	○	○	○	○

13. Overall, how big a problem have your bowel habits been for you during the **last 4 weeks**? *(Choose one)*

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

Sexual Issues

14. Do you have a sexual partner at this time?

○ Yes
○ No

} ***Regardless of your answer to this question, please try to answer the questions below***

15. Do you currently use any of the following to help with problems with sexual function? *(Choose one response on each line)*

	Yes	No
a. Vacuum suction device?	○	○
b. Penile injections (shots)?	○	○
c. Pills, such as Viagra, Cialis, Levitra?	○	○
d. Urethral pellets or suppositories (Muse)?	○	○
e. Penile prosthesis?	○	○
f. Other (Please specify):	○	○

_____

16. How would you rate each of the following during the **last 4 weeks**? (*Choose one response on each line)*

	Very poor to none	Poor	Fair	Good	Very good
a. Your ability to have an erection?	○	○	○	○	○
b. Your ability to reach orgasm (climax)?	○	○	○	○	○

17. How would you describe the usual QUALITY of your erections during the **last 4 weeks**? *(Choose one)*

○ None at all
○ Not firm enough for any sexual activity
○ Firm enough for masturbation and foreplay only
○ Firm enough for intercourse

18. How would you describe the FREQUENCY of your erections during the **last 4 weeks**? *(Choose one)*

- ⬭ I NEVER had an erection when I wanted one
- ⬭ I had an erection LESS THAN HALF the time I wanted one
- ⬭ I had an erection ABOUT HALF the time I wanted one
- ⬭ I had an erection MORE THAN HALF the time I wanted one
- ⬭ I had an erection WHENEVER I wanted one

19. Overall, how would you rate your ability to function sexually during the **last 4 weeks**? *(Choose one)*

- ⬭ Very poor
- ⬭ Poor
- ⬭ Fair
- ⬭ Good
- ⬭ Very good

20. Overall, how big a problem has your sexual function or lack of sexual function been for you during the **last 4 weeks**? *(Choose one)*

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

Hormonal Issues

21. How big a problem during the **last 4 weeks**, if any, has each of the following been for you? *(Choose one response on each line)*

	No problem	Very small problem	Small problem	Moderate problem	Big problem
a. Hot flashes	○	○	○	○	○
b. Breast tenderness/enlargement	○	○	○	○	○
c. Feeling depressed	○	○	○	○	○
d. Lack of energy	○	○	○	○	○
e. Change in body weight	○	○	○	○	○

Concerns Surrounding Impact of Prostate Cancer

22. Overall, how much of a burden is your having prostate cancer on you and your family in each of the following areas? *(Choose one response on each line)*

	Very large burden	Large burden	Feel neutral	Small burden	Very small burden	Not a burden at all
a. Our overall health	○	○	○	○	○	○
b. Our social activities	○	○	○	○	○	○
c. Our lifestyle	○	○	○	○	○	○
d. Our finances in general	○	○	○	○	○	○
e. Our finances due to the cost of my treatment	○	○	○	○	○	○
f. Our finances due to the other costs of health care for prostate cancer (such as visits to the doctor, etc.)	○	○	○	○	○	○
g. Our finances due to the cost of my health insurance because I have prostate cancer	○	○	○	○	○	○

23. How true has each of the following statements been for you during the **past 4 weeks**? *(Choose one response on each line)*

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I am confident that my cancer is under control	○	○	○	○	○
b. I worry that my cancer might come back	○	○	○	○	○
c. I worry about my cancer spreading	○	○	○	○	○
d. I wonder whether the treatment I got for prostate cancer really worked	○	○	○	○	○
e. It worries me that I can't tell what is going on with my prostate cancer	○	○	○	○	○

24. 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? *(Choose one response on each line)*

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Someone who can help you out if you need it - for example, by helping you get to the doctor or prepare your meals if you are unable to do it yourself	○	○	○	○	○
b. Someone to share your most private worries and fears with	○	○	○	○	○
c. Someone to love and make you feel wanted	○	○	○	○	○
d. Someone to do something enjoyable with or someone to have a good time with	○	○	○	○	○
e. Someone to give you good advice or give you information to help you understand a situation	○	○	○	○	○

Your Relationship with your Doctor and the Healthcare System

Your responses to these questions, like all the questions on this survey, are confidential. They will not be shared with anyone associated with your healthcare, including your doctor.

25. Please think about the care you have received since you were diagnosed with prostate cancer. *(Choose one response on each line)*

	Never	Rarely	Sometimes	Often	Very often
a. How often did the doctors who take care of your prostate cancer ask you to take some of the responsibility for your treatment?	○	○	○	○	○
b. If there were a choice between treatments, how often would the doctors who take care of your prostate cancer ask you to help make the decision?	○	○	○	○	○
c. How often did the doctors who cared for your prostate cancer make an effort to give you some control over treatment decisions?	○	○	○	○	○

26. How often do the doctors who take care of your prostate cancer: *(Choose one response on each line)*

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
a. Offer choices in your medical care?	○	○	○	○	○
b. Discuss the pros and cons of each option with you?	○	○	○	○	○
c. Ask you to state which choice or option you would prefer?	○	○	○	○	○
d. Take your preferences into account when making treatment decisions?	○	○	○	○	○

27. The following questions ask about your beliefs about health and health care. For each statement, please fill the oval on the scale that comes closest to how much you agree or disagree with the statement.
(Choose one response on each line)

	Strongly Agree	Moderately Agree	Feel Neutral	Moderately Disagree	Strongly Disagree
a. I often feel that no matter how hard I try I am helpless (when it comes to influencing my medical care) to change the kind of medical care I get	○	○	○	○	○
b. More and more, I feel helpless to control my disease	○	○	○	○	○
c. I often feel like giving up on my medical care	○	○	○	○	○
d. Almost all treatment decisions are better left up to the doctor	○	○	○	○	○
e. Even when patients have had diseases for a long time, it is better for the doctor to make all the treatment decisions	○	○	○	○	○
f. People who are pushy with doctors are not good patients	○	○	○	○	○

Satisfaction with Care

28. What is your overall feeling about the ... *(Choose one response on each line)*

	Completely Satisfied	Very Satisfied	Somewhat Satisfied	Mixed	Somewhat Unsatisfied	Very Unsatisfied	Completely Unsatisfied
a. Effect of health care services in helping you deal with your cancer and maintain your well-being?	○	○	○	○	○	○	○
b. Effect of cancer treatment in preventing cancer progression or recurrence?	○	○	○	○	○	○	○
c. Quality of cancer care you have received?	○	○	○	○	○	○	○
d. Effect of services in helping relieve symptoms or reduce problems?	○	○	○	○	○	○	○
e. In an overall general sense, how satisfied are you with the cancer treatment you have received?	○	○	○	○	○	○	○

Family History

29. Do you have a father or brother who has had prostate cancer?

- ○ Yes, a father
- ○ Yes, a brother
- ○ Yes, both father and a brother
- ○ No, neither a father nor a brother
- ○ I don't know

Problems/Complications

30. Did you have any problems from your prostate cancer treatment?

- ○ Yes *(If Yes, choose all that apply below)*
- ○ No *(If No, please go to Question 30)*

	Yes	No
a. Urethral scarring/stricture	○	○
b. Infections	○	○
c. Pneumonia	○	○
d. Deep venous thrombosis/pulmonary embolism/blood clots	○	○
e. Hernia	○	○
f. Other, please specify:	○	○

_____

31. Since receiving treatment for your prostate cancer, have you been admitted to the hospital for any prostate cancer-related issues?

- ○ Yes
- ○ No

32. Which of the following health professionals have you seen in the **last 6 months**? Please do not include any visits while you were in the hospital or for receiving a medication injection only. *(Choose one response on each line)*

	Yes	No
a. Primary Physician, Internist or General Practitioner	○	○
b. Urologist	○	○
c. Medical Oncologist (cancer specialist)	○	○
d. Radiation Oncologist/Radiologist, Radiation Technician/Therapist for treatment	○	○
e. Mental Health Professional (psychiatrist, psychologist, etc.)	○	○
f. Nurse Practitioner or Physician's Assistant	○	○
g. Gastroenterologist, Proctologist (digestive tract specialist)	○	○
h. Cardiologist (heart disease specialist)	○	○
i. Optometrist, Opthalmologist (eye specialist)	○	○
j. Dermatologist (skin specialist)	○	○
k. Allergist	○	○
l. Ear, Nose and Throat physician	○	○
m. Orthopedist (bone specialist)	○	○
n. Podiatrist (foot specialist)	○	○
o. Neurologist (nervous system specialist)	○	○
p. Other Physicians (please specify, for example: pain clinic, pulmonologist): _____	○	○
q. Chiropractor	○	○
r. Other Health Workers (please specify, e.g: dietician, physical therapist, social worker): _____	○	○

33. What is your current employment status? *(Choose all that apply)*

- ○ Working full time
- ○ Working part time
- ○ Retired
- ○ Unemployed (or looking for work)

34. What type of health insurance or health care coverage do you currently have? *(Choose all that apply)*

- ○ No insurance
- ○ Private health insurance or HMO
- ○ Medicare
- ○ Veteran's Administration (VA) Health Care
- ○ Military health care (including CHAMPUS/TriCARE, CHAMP-VA)
- ○ Medicaid
- ○ Indian Health Service, Tribal Health Program, or Urban Indian Clinic
- ○ Don't know
- ○ Other, please specify: _____

Thank you very much for your participation. Please mail the survey back in the enclosed postage paid envelope. If you have any questions, please contact: