Participant ID 0 0 0 0

Six 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. 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 as main/only therapy	○	____ / 2 0 ____	○
f. Active Surveillance/Watchful Waiting	○	____ / 2 0 ____	○
g. No therapy, have not decided yet	○	____ / 2 0 ____	○
h. Other therapy (Please specify):	○	____ / 2 0 ____	○

_____

General Health Questions

3. Have you **ever** had any additional cancers diagnosed (see below)? Do **not** include prostate cancer or non-melanoma skin cancer.

- ○ No *(If No, please go to Question 4)*
- ○ Yes

If yes, please indicate which cancers you had: *(Choose one response on each line)*

	Yes	No
a. Colon or rectal cancer	○	○
b. Lung cancer	○	○
c. Kidney cancer	○	○
d. Bladder cancer	○	○
e. Lymphoma or leukemia	○	○
f. Stomach cancer	○	○
g. Pancreatic cancer	○	○
h. Mouth or oral cancer	○	○
i. Melanoma	○	○
j. Liver cancer	○	○
k. Other cancer, please specify:	○	○

_____

4. Have you **ever** been told by a physician that you have any of the following problems with your breathing? *(Choose one response on each line)*

	No	Yes
a. Emphysema or chronic bronchitis	○	○
b. Asthma	○	○

5. During the **past 6 months**, how many times did you have each of the following? *(Choose one response on each line)*

	Never	Once	Twice	Three or More Times
a. Pneumonia	○	○	○	○
b. Bronchitis for which you took antibiotics	○	○	○	○
c. Flu, with coughing	○	○	○	○

6. During the **past 6 months**, how often did you feel short of breath? *(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. When lying down flat	○	○	○	○	○
b. When sitting or resting	○	○	○	○	○
c. When walking less than one block	○	○	○	○	○
d. When climbing one flight of stairs	○	○	○	○	○
e. When climbing several flights of stairs	○	○	○	○	○

7. Have you **ever** been told by a physician that you have any of the following problems related to your heart or circulation? *(Choose one response on each line)*

	No	Yes
a. Heart attack	○	○
b. Congestive heart failure	○	○
c. Angina	○	○

8. Have you **ever** been told by a physician that you have high blood pressure?

- ○ No *(If No, please go to Question 9)*
- ○ Yes
- ○ Don't know

If yes, please answer the following:

a. How many years have you had high blood pressure?

- ○ Less than 5 years
- ○ 5-9 years
- ○ 10 years or more
- ○ Don't know

b. During the **past 6 months**, did you take medication for your high blood pressure?

- ○ Yes, and the medication controlled my high blood pressure
- ○ Yes, but my blood pressure is still high
- ○ No, I did not take any medication for high blood pressure

9. Have you **ever** had any of the following operations or procedures related to your heart? *(Choose one response on each line)*

	No	Yes
a. Coronary artery bypass surgery (open heart surgery)	○	○
b. Coronary angioplasty (balloon or stent)	○	○
c. Heart catheterization (angiogram)	○	○
d. Exercise test (stress test)	○	○
e. Pacemaker/defibrillator insertion	○	○

10. During the **past 6 months**, how many times have you had any of the following problems related to your heart or circulation? *(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. Chest pain or pressure when you exercise	○	○	○	○	○
b. Chest pain or pressure when resting	○	○	○	○	○
c. Ankles or legs that swell as the day goes on	○	○	○	○	○
d. Fainting or dizziness when you stand up	○	○	○	○	○

11. During the **past 6 months**, how often have you had pain in your back or joints? *(Choose one response on each line)*

	Never	Once or twice only	About once a month	Almost every week	More than once a week
a. That lasted at least half a day	○	○	○	○	○
b. That kept you from sleeping	○	○	○	○	○
c. That kept you from exercising or doing vigorous activities	○	○	○	○	○

12. Have you **ever** been told by a physician that you have any of the following problems with your feet or legs? *(Choose one response on each line)*

	No	Yes
a. Peripheral vascular disease (poor circulation in the legs)	○	○
b. Claudication (cramping in the calf during exercise)	○	○
c. Peripheral neuropathy (numbness, tingling, or burning in the feet)	○	○
d. Foot ulcers	○	○

13. Have you **ever** been told by a physician that you have any of the following problems? *(Choose one response on each line)*

	No	Yes
a. Stroke	○	○
b. Transient ischemic attack (TIA)	○	○
c. Epilepsy or seizure disorder	○	○
d. Parkinson's Disease	○	○
e. Migraines	○	○

14. Have you **ever** had any of the following problems? *(Choose one response on each line)*

	No	Yes
a. Paralysis or weakness on one side of the body	○	○
b. Lost the ability to talk	○	○

15. Have you **ever** been told by a physician that you have any of the following problems with your eyes? *(Choose one response on each line)*

	No	Yes
a. Cataracts (clouding of the lens of the eye)	○	○
b. Glaucoma	○	○
c. Blurred vision (not correctable with eye glasses)	○	○
d. Retinopathy or macular degeneration	○	○

16. Have you **ever** had any of the following operations on your eyes? *(Choose one response on each line)*

	No	Yes, on ONE eye only	Yes, on BOTH eyes
a. Cataract surgery	○	○	○
b. Laser treatment for diabetes	○	○	○

17. Have you **ever** been told by a physician that you have diabetes?

- ○ No *(If No, please go to Question 18)*
- ○ Yes
- ○ Don't know

If yes, please answer the following:

a. How many years have you had diabetes?

- ○ Less than 5 years
- ○ 5-9 years
- ○ 10 years or more
- ○ Don't know

b. Do you take insulin shots?

- ○ No
- ○ Yes
- ○ Don't know

18. Have you **ever** been told by a physician that you have inflammatory bowel disease (Crohn's Disease, ulcerative colitis)?

- ○ No
- ○ Yes
- ○ Don't know

General Health

19. 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	○	○	○

20. 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?	○	○	○	○	○	○

21. 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

22. 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

23. 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

24. 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

25. 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	○	○	○	○	○

26. 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

27. 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	○	○	○	○	○

28. 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

29. 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***

30. 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?	○	○

31. 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)?	○	○	○	○	○

32. 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

33. 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

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

- ○ Very poor
- ○ Poor
- ○ Fair
- ○ Good
- ○ Very good

35. 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

36. 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

37. 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	○	○	○	○	○	○

38. 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	○	○	○	○	○

Satisfaction with Care

39. 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?	○	○	○	○	○	○	○

Problems/Complications

40. 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 41)*

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

_____

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

- ○ Yes
- ○ No

42. 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): _____	○	○

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

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

44. How do you describe yourself? *(Choose one)*

- ○ White/Caucasian (not Latino/Hispanic)
- ○ Black/African-American (not Latino/Hispanic)
- ○ Latino/Hispanic/Mexican-American
- ○ Asian/Oriental/Pacific Islander
- ○ American Indian/Native Alaskan
- ○ Other, please specify: _____

45. What is your approximate annual combined household income? *(Choose one)*

- ○ Less than $10,000
- ○ $10,000 – $30,000
- ○ $30,001 - $50,000
- ○ $50,001 – $100,000
- ○ More than $100,000

46. How much school did you complete? *(Choose one)*

- ○ Grade school or less
- ○ Some high school or technical school
- ○ High school or technical school graduate
- ○ Some college
- ○ College graduate
- ○ Graduate or professional school after college

47. What is your current marital status? *(Choose one)*

- ○ Never married
- ○ Married
- ○ Separated
- ○ Divorced
- ○ Widowed

48. 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: