



Participant ID

0 0 0 0



***Five Year Follow-up
Survey***
CEASAR STUDY

Thank you for your continued participation in the CEASAR study. Your participation has been and will continue to be critical to our efforts to learn about your health and experiences in the years after you were diagnosed with prostate cancer, even if you are no longer experiencing problems. Your participation in the CEASAR surveys makes it possible for us to understand the long-term (years after diagnosis) effects of prostate cancer and its treatments. Your responses will help us in our efforts to learn more about how to best treat prostate cancer, and what men experience after treatment.

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.

Information contained within this survey will remain strictly confidential.

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

If we do more surveys in the future, would you be willing to fill them out in electronic form (internet or web-based)?

If so, please provide your email address. Please print as clearly as possible.

Email Address: _____

[Your email address will only be used for this study. It will not be shared with anyone.]



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.



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

A. Follow-up Care

2. Which (if any) of the following medical specialists have you seen for prostate cancer **in the last 12 months?** (*Choose all that apply*)

- Urologist
- Radiation oncologist
- Medical oncologist (doctor who gives medical treatments like chemotherapy or hormone pills or shots; not a surgeon or a radiation oncologist)
- Primary care physician
- Other: _____
- I am not seeing a physician for prostate cancer

3. Did you have a PSA drawn **within the last 12 months?**

- Yes
- No (*If No, please go to Question 6 on the next page*)
- I don't know

4. If you had a PSA drawn **in the last 12 months**, what is your most recent result? .

- I had a PSA drawn in the last 12 months, but I do not know what the result was.
- I don't know the exact value but the doctor told me it was normal.

5. **Over the last 12 months**, roughly how many PSA blood tests did you have?

- 0
- 1
- 2
- 3
- 4 or more
- Don't know



B. Prostate Cancer Recurrence

6. Since you were initially diagnosed, did your doctor ever tell you that your prostate cancer came back (recurred) or progressed (got worse)?

- Yes
- No

7. Since you were diagnosed with prostate cancer, has a doctor ever told you that your prostate cancer had spread to other areas of your body?

- Yes
- No (If No, please go to Question 10)

8. If Yes, when was this first discovered? Approximate month and year:

Month: Year:
 / 20

9. If Yes, what part of your body did it spread to? (Choose all that apply)

- Lymph nodes
- Bones
- Other: _____
- Don't know

10. As far as you know, is your prostate cancer currently cured or in complete remission?

- Yes
- No
- Don't know

Please go to the next page.

**C. Prostate Cancer Treatments**

11. Please think of **ALL** the treatments you have received for your prostate cancer. Answer the questions below using the following instructions:

Column A. Fill in the bubble for "Yes" for all the treatments you have had.

Column B. For each treatment you have had, also fill in the date the treatment started. If you can't remember the exact date that you received or started therapy, please at least enter the year.

Column C. If you are still on or receiving a particular treatment, please also fill in the bubble all the way to the right.

<u>I. Treatment to the prostate</u>	A. Had treatment	B. Date Started:		C. Still taking/receiving?
	Yes	Month	Year	Yes
a. Active surveillance/watchful waiting (no treatment)	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	<input type="radio"/>
b. Robotic/laparoscopic surgical removal of the prostate	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	
c. Open surgical removal of the prostate (using a long incision)	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	
d. Insertion of radiation seeds/rods (brachytherapy)	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	
e. External beam radiation, where beams are aimed in from outside your body (some other names for this treatment include IMRT (Intensity-Modulated Radiation Therapy), IGRT (Image-Guided Radiation Therapy), arc therapy, proton beam, cyberknife, or 3D-conformal beam therapy)	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	<input type="radio"/>
f. Other types of radiation therapy, or unsure of what type	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	<input type="radio"/>
g. Cryotherapy (freezing of the prostate)	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	
h. Other treatments to the prostate (HIFU (High Intensity Focused Ultrasound), RFA (Radio Frequency Ablation), laser, focal therapy)	<input type="radio"/>	<u> </u> / <u>20</u>	<u> </u>	

**II. Other treatments****Column A.** Fill in the bubble for "Yes" for all the treatments you have had.**Column B.** For each treatment you have had, also fill in the date the treatment started. If you can't remember the exact date that you received or started therapy, please at least enter the year.**Column C.** If you are still on or receiving a particular treatment, please also fill in the bubble all the way to the right.

	A. Had treatment	B. Date Started:		C. Still taking/receiving?
	Yes	Month	Year	Yes
i. Surgical removal of the testicles (orchiectomy)	<input type="radio"/>	<u> </u> / <u>2 0</u>		
j. Hormone shots (Lupron, Zoladex, Firmagon, Eligard, Vantas, etc.)	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>
k. Casodex (bicalutamide) or Eulexin (flutamide) pills	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>
l. Zytiga (abiraterone) or Xtandi (enzalutamide) pills	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>
m. Provenge/immunotherapy (Sipuleucel T)	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>
n. Chemotherapy (docetaxel, cabazitaxel, other chemotherapy)	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>
o. Radiation to the bones (either with beams from the outside or Xofigo (Radium-223) therapy)	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>
p. Other therapy (Please specify): _____	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>

12. Since you were diagnosed with prostate cancer, have you taken any of the medications listed below to **strengthen your bones?** Yes (If Yes, please indicate which medications you took, when you started taking them, and if you are still taking them. Choose all that apply) No (If No, please go to Question 13 on the next page)

	Yes	Date Started:		Still taking?	
		Month	Year	Yes	No
a. Injectable medications (Zometa, Prolia, Xgeva)	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>	<input type="radio"/>
b. Oral prescription medications (Fosamax or Actonel)	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>	<input type="radio"/>
c. Calcium	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>	<input type="radio"/>
d. Vitamin D	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>	<input type="radio"/>
e. Parathyroid hormone (PTH)	<input type="radio"/>	<u> </u> / <u>2 0</u>		<input type="radio"/>	<input type="radio"/>

**D. Active Surveillance/Watchful Waiting**

If you initially elected active surveillance/watchful waiting for your prostate cancer, please answer the following questions. If you were never on active surveillance/watchful waiting, please skip these questions and go to Question 16.

13. Since your prostate cancer diagnosis, how many times have you had a **prostate** biopsy?

- 0
- 1
- 2
- 3
- 4
- 5 or more
- Don't know

14. Did you eventually get other treatment (i.e., surgery, radiation, hormones)?

- Yes, and the approximate start date of the treatment was / 2 0
- No (If No, please go to Question 16)

15. If you started on active surveillance/watchful waiting and then got other treatment, why did you get treated? (Choose all that apply)

- My doctor said my prostate cancer had gotten worse
- My prostate cancer was a higher grade (Gleason)
- There was a change on rectal exam
- Higher volume (more cancer on repeat biopsy)
- Higher PSA
- Spouse/partner recommended or encouraged treatment
- I just decided to get treatment
- Other: _____

E. How Treatments and Side Effects Compare with Expectations

16. Please choose one response on each line:

A lot worse A little worse About the same A little better A lot better

- | | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| a. Compared to what you expected, how do you rate the <u>effectiveness of the treatment</u> so far? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b. Compared to what you expected, how do you rate the <u>side effects of treatment</u> so far? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



F. General Health

17. 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 18 on the next page*)
- Yes **If Yes, please indicate which cancers you had.**
(*Choose one response on each line*)

	Yes	No
a. Colon or rectal cancer	<input type="radio"/>	<input type="radio"/>
b. Lung cancer	<input type="radio"/>	<input type="radio"/>
c. Kidney cancer	<input type="radio"/>	<input type="radio"/>
d. Bladder cancer	<input type="radio"/>	<input type="radio"/>
e. Lymphoma or leukemia	<input type="radio"/>	<input type="radio"/>
f. Stomach cancer	<input type="radio"/>	<input type="radio"/>
g. Pancreatic cancer	<input type="radio"/>	<input type="radio"/>
h. Mouth or oral cancer	<input type="radio"/>	<input type="radio"/>
i. Melanoma	<input type="radio"/>	<input type="radio"/>
j. Liver cancer	<input type="radio"/>	<input type="radio"/>
k. Other cancer, please specify:	<input type="radio"/>	<input type="radio"/>
<input type="text"/>		

Please go to the next page.



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

- No (If No, please go to Question 23)
- 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

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

	Yes	No
a. Coronary artery bypass surgery (open heart surgery)	<input type="radio"/>	<input type="radio"/>
b. Coronary angioplasty (balloon or stent)	<input type="radio"/>	<input type="radio"/>
c. Heart catheterization (angiogram)	<input type="radio"/>	<input type="radio"/>
d. Exercise test (stress test)	<input type="radio"/>	<input type="radio"/>
e. Pacemaker/defibrillator insertion	<input type="radio"/>	<input type="radio"/>

24. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Chest pain or pressure when resting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Ankles or legs that swell as the day goes on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Fainting or dizziness when you stand up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



25. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. That kept you from sleeping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. That kept you from exercising or doing vigorous activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. 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)

	Yes	No
a. Peripheral vascular disease (poor circulation in the legs)	<input type="radio"/>	<input type="radio"/>
b. Claudication (cramping in the calf during exercise)	<input type="radio"/>	<input type="radio"/>
c. Peripheral neuropathy (numbness, tingling, or burning in the feet)	<input type="radio"/>	<input type="radio"/>
d. Foot ulcers	<input type="radio"/>	<input type="radio"/>

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

	Yes	No
a. Stroke	<input type="radio"/>	<input type="radio"/>
b. Transient ischemic attack (TIA)	<input type="radio"/>	<input type="radio"/>
c. Epilepsy or seizure disorder	<input type="radio"/>	<input type="radio"/>
d. Parkinson's Disease	<input type="radio"/>	<input type="radio"/>
e. Migraines	<input type="radio"/>	<input type="radio"/>

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

	Yes	No
a. Paralysis or weakness on one side of the body	<input type="radio"/>	<input type="radio"/>
b. Lost the ability to talk	<input type="radio"/>	<input type="radio"/>



29. 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*)

	Yes	No
a. Cataracts	<input type="radio"/>	<input type="radio"/>
b. Glaucoma	<input type="radio"/>	<input type="radio"/>
c. Blurred vision (not correctable with eye glasses)	<input type="radio"/>	<input type="radio"/>
d. Retinopathy or macular degeneration	<input type="radio"/>	<input type="radio"/>

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

	Yes, on ONE eye only	Yes, on BOTH eyes	No
a. Cataract surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Laser treatment for diabetes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

- No (*If No, please go to Question 32*)
- 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

→ 32. Have you **ever** been told by a physician that you have inflammatory bowel disease (Crohn's Disease, ulcerative colitis)?

- No
- Yes
- Don't know

**G. Activities of Daily Living**

33. 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. <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Climbing <u>several</u> flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Climbing <u>one</u> flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Walking <u>more than a mile</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Walking <u>several hundred yards</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Walking <u>one hundred yards</u>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please go to the next page.



H. Mood

34. 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)

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

Please go to the next page.



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

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

I. Urinary Issues

36. 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

37. 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



38. 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

39. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Pain or burning on urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Bleeding with urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Weak urine stream or incomplete emptying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Need to urinate frequently during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

40. 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

Please go to the next page.



J. Bowel Issues

41. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Increased frequency of bowel movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Losing control of your stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Bloody stools	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Abdominal/pelvic/rectal pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

42. 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

Please go to the next page.

**K. Sexual Issues****43.** 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:***44.** 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	<input type="radio"/>	<input type="radio"/>
b. Penile injections (shots)	<input type="radio"/>	<input type="radio"/>
c. Pills, such as Viagra, Cialis, Levitra, Staxyn, Stendra	<input type="radio"/>	<input type="radio"/>
d. Urethral pellets or suppositories (Muse)	<input type="radio"/>	<input type="radio"/>
e. Penile prosthesis (surgical implant)	<input type="radio"/>	<input type="radio"/>
f. Other (please specify):	<input type="radio"/>	<input type="radio"/>

*Regardless of your answer to the question above, please report your actual experience in the **last 4 weeks** for the following questions:***45.** 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Your ability to reach orgasm (climax)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



46. 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
47. 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
48. Overall, how would you rate your ability to function sexually during the **last 4 weeks**? (*Choose one*)
- Very poor
 - Poor
 - Fair
 - Good
 - Very good
49. 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

**L. Other Issues**

50. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Breast tenderness/enlargement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Feeling depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Change in body weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

51. Prostate cancer treatment may result in some other health problems. Have you developed any of the problems listed below after your prostate cancer treatment?

- Yes (*If Yes, choose all that apply below*)
- No (*If No, please go to Question 52 on the next page*)

	Yes	No
a. Urethral scarring/stricture/bladder neck contracture (blockage or narrowing of the tube which you urinate through)	<input type="radio"/>	<input type="radio"/>
b. Urinary incontinence procedure (artificial urinary sphincter, sling)	<input type="radio"/>	<input type="radio"/>
c. Fistula (abnormal connection between the urinary tract and bowel)	<input type="radio"/>	<input type="radio"/>
d. Urinary retention (inability to urinate)	<input type="radio"/>	<input type="radio"/>
e. Deep venous thrombosis/pulmonary embolism/blood clots	<input type="radio"/>	<input type="radio"/>
f. Hernia	<input type="radio"/>	<input type="radio"/>
g. Fracture or broken bone	<input type="radio"/>	<input type="radio"/>
h. Shortening of the penis	<input type="radio"/>	<input type="radio"/>
i. Other, please specify: <input style="width: 400px;" type="text"/>	<input type="radio"/>	<input type="radio"/>

**M. Concerns Surrounding Impact of Prostate Cancer**

52. 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)

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

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

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



54. Health: How true is each of the following for you? (*Choose one response on each line*)

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. My health could take a turn for the worse at any time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I sometimes worry about dying before my time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I worry about what my doctor will find next	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I worry that changes in my medical condition will not be detected early	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I am uneasy about the present state of my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. I live in fear that my PSA will rise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

55. PSA: 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 keep close track of my PSA	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Knowing my PSA level is comforting to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please go to the next page.



56. Treatment choice: How true has each of the following statements been for you? (*Choose one response on each line*)

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I wonder if I would have been better off with a different treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I sometimes wonder whether it was really worthwhile being treated at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I sometimes feel the treatment I had was the wrong one for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. If I had it to do over, I would choose some other treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I sometimes wish I could change my mind about the kind of treatment I chose for my prostate cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

57. Outlook: How true is each of the following statements for you? (*Choose one response on each line*)

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I feel that my cancer has given me a better outlook on life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I feel that coping with cancer has made me a stronger person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please go to the next page.



58. Decision: How true is each of the following statements for you? (Choose one response on each line)

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I had all the information I needed when a treatment was chosen for my prostate cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. My doctors told me the whole story about the effects of treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I knew the right questions to ask my doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I had enough time to make a decision about my treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I am satisfied with the choices I made in treating my prostate cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. I would recommend the treatment I had to a close relative or friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

N. Social Support

59. 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)

	<u>None</u> of the time	<u>A little</u> of the time	<u>Some</u> of the time	<u>Most</u> of the time	<u>All</u> 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Someone to share your most private worries and fears with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Someone to love and make you feel wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Someone to do something enjoyable with or someone to have a good time with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Someone to give you good advice or give you information to help you understand a situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



60. Are you currently participating in any type of prostate cancer support group? (Choose one response on each line)

	Yes	No
a. In-person meetings	<input type="radio"/>	<input type="radio"/>
b. Online community	<input type="radio"/>	<input type="radio"/>
c. Other (please specify):	<input type="radio"/>	<input type="radio"/>
<input type="text"/>		

O. Satisfaction with Care

61. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Effect of cancer treatment in preventing cancer progression or recurrence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Quality of cancer care you have received	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Effect of services in helping relieve symptoms or reduce problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. In an overall general sense, how satisfied are you with the cancer treatment you have received?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



P. Health Status

62. Under each heading, please fill in the ONE oval that best describes your health TODAY

Mobility

- I have no problems walking
- I have slight problems walking
- I have moderate problems walking
- I have severe problems walking
- I am unable to walk

Self-Care

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities (e.g., work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

Pain/Discomfort

- I have no pain or discomfort
- I have slight pain or discomfort
- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed



Participant ID

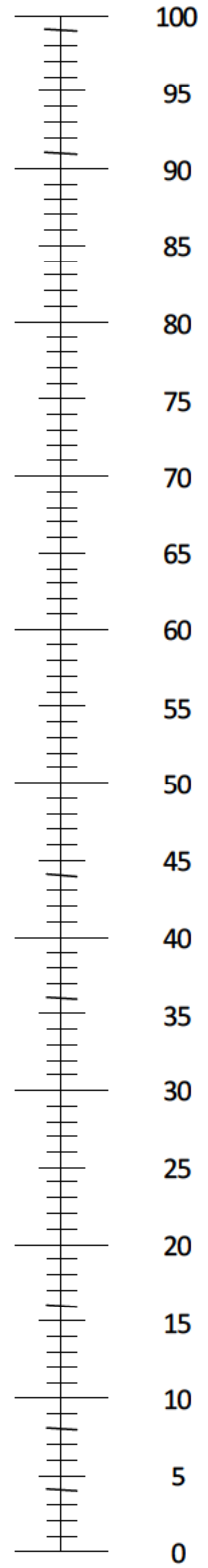
0 0 0 0

63. We would like to know how good or bad your health is TODAY.

- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine. 0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine



Q. Demographic Questions

64. What is your current employment status? (*Choose all that apply*)
- Working full time
 - Working part time
 - Retired
 - Unemployed (or looking for work)
65. What is your current marital status? (*Choose one*)
- Never married
 - Married or in a committed relationship
 - Separated
 - Divorced
 - Widowed
66. 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: _____
67. What is your current height? feet inches
68. What is your current weight? pounds
69. What is your current waist size (on your pants or belt)? inches
70. Do you smoke? (*Choose one*)
- Yes, I do
 - No, but I did and I quit within the last 10 years
 - No, but I did and I quit more than 10 years ago
 - No, I never smoked

