Participant ID ⌊__⌋__⌋ ⌊__⌋__⌋__⌋__⌋__⌋__⌋__⌋__⌋

Follow-up Survey

CEASAR STUDY

Thank you for your continued participation in the CEASAR (Comparative Effectiveness Analysis of Surgery and Radiation for Localized Prostate Cancer) 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.

For updates on the CEASAR study, please visit www.ceasarprostate.org.

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.

- If you can't remember an exact date, write in your best estimate of the date.

Would you be willing to be contacted about participating in a telephone interview with CEASAR researchers to discuss your "lived experience" with prostate cancer?

In addition to collecting data through surveys, CEASAR researchers wish to conduct telephone interviews with a small number of participants. This will help us learn more about your prostate cancer experience and your chosen treatment(s).

Participation is optional. Even if you do not wish to participate in a telephone interview, we would still like for you to complete and return this survey. If contacted, you will learn more about the interview and then decide if you want to take part. Interview participants will be compensated for their time.

- ○ **No**, I would not like to be contacted at this time
- ○ **Yes**, I would like to be contacted to learn more about participating in a telephone interview and will list my information below:

First/last name: _____

E-mail address: _____

Telephone number(s):

Home: _____

Cellular/Mobile: _____

Work: _____

Best day(s) to contact:

☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday

☐ Friday ☐ Saturday ☐ Sunday

Best time(s) of day to contact:

☐ Morning ☐ Mid-day ☐ Afternoon ☐ Evening

1. Today's date: __ __ / __ __ / __ __ __ __
Month **Day** **Year**

A. Follow-up Care

2. In the last 12 months, have you seen any of the providers below for issues related to your prostate cancer or for routine prostate cancer follow-up (such as ongoing prostate cancer treatment, monitoring of PSA tests, and/or management of side-effects of treatment, like urinary problems, bowel problems, or sexual problems)?

Choose all that apply. **Mark 'Yes' if you have seen any provider in that office (doctor, nurse, nurse practitioner, physician assistant, etc.).**

Yes	Type of provider
○	Urologist
○	Radiation oncologist
○	Medical oncologist
○	Primary care provider (PCP)
○	Other provider not listed above (please specify): _____
○	I don't get any prostate cancer follow-up

3. What was your last PSA value? (approximate value): __ __ __ . __ __ __

4. When was the date of your last PSA? (approximate date): __ __ / __ __ __ __
Month **Year**

B. Prostate Cancer Recurrence

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

- ○ **No**
- ○ **Yes** *[If **YES**, please answer the below question]*
  - **a.** Approximate date of first recurrence or progression: __ __ / __ __ __ __
    Month **Year**

6. To your knowledge, is your prostate cancer currently cured?

- ○ **No** [Answer **'No'** if your PSA is rising, OR you are still taking or receiving treatment for prostate cancer, such as hormone therapy, or if you have had surgery to remove the testicles (orchiectomy)]
- ○ **Yes** [Answer **'Yes'** if your follow-up tests have been normal and you are not taking or receiving any treatment]
- ○ **I don't know** [Answer **'I don't know'** if you have not been getting or receiving follow-up testing for your prostate cancer]

→ **If NO to the above, please answer the following question:**

a. If your prostate cancer is **not cured**, check the areas that have been affected and the approximate date you learned about it:

Yes	Affected areas	Month	Year
○	PSA elevation (biochemical recurrence)	_ _	_ _ _ _
○	Lymph nodes	_ _	_ _ _ _
○	Bones	_ _	_ _ _ _
○	Other areas (please list below):	_ _	_ _ _ _
	_____		

C. Prostate Cancer Treatments

7. What treatments have you gotten, or are you currently getting for prostate cancer? *Choose all that apply.*

Yes	I. Treatment to the prostate	Month received or began	Year received or began
○	**Active surveillance**/watchful waiting (no treatment)	_ _	_ _ _ _
○	**Surgery** to remove the whole prostate	_ _	_ _ _ _
	Radiation		
○	▪ Insertion of radiation seeds/rods to the prostate (brachytherapy)	_ _	_ _ _ _
○	▪ External beam radiation to the prostate (including IMRT [Intensity-Modulate Radiation Therapy] and proton beam)	_ _	_ _ _ _
○	▪ Other types of radiation therapy, or unsure of what type	_ _	_ _ _ _
○	**Ablation** therapy to the prostate, such as cryotherapy (freezing of the prostate) or HIFU (High Intensity Focused Ultrasound)	_ _	_ _ _ _

Yes	II. Other treatments	Month began	Year began	Mark if still taking
○	**Surgery** to remove the testicles (orchiectomy)	_ _	_ _ _ _	
○	**Hormone shots** (Lupron, Zoladex, Firmagon, Eligard, Vantas, etc.)	_ _	_ _ _ _	○
	Hormone pills			
○	▪ Casodex (bicalutamide), Erleda (apalutamide) or Eulexin (flutamide) pills	_ _	_ _ _ _	○
○	▪ Zytiga (abiraterone) or Xtandi (enzalutamide) pills	_ _	_ _ _ _	○
○	▪ I have taken one (or more) of the above pills for my prostate cancer, but am not sure which one(s)	_ _	_ _ _ _	○
○	**Provenge**/immunotherapy (Sipuleucel T)	_ _	_ _ _ _	○
○	**Chemotherapy** (Docetaxel, Cabazitaxel, or other chemotherapy)	_ _	_ _ _ _	○
○	**Radiation to the bones** (either with beams from the outside or Xofigo (Radium-223) therapy)	_ _	_ _ _ _	○
○	**Clinical trial** (please specify below): _____	_ _	_ _ _ _	○
○	**Other therapy** not listed above (please specify below): _____	_ _	_ _ _ _	○

8. Did you get your first prostate cancer treatment within one year of the prostate biopsy that found your prostate cancer?

- ○ **No**, I did not get treatment within the first year of my original prostate cancer diagnosis, but I got treatment later on
- ○ **No**, I did not get treatment within the first year of my original prostate cancer diagnosis, and and I still have not gotten treatment
- ○ **Yes**, I had prostate cancer treatment within one year of my original prostate cancer diagnosis

D. Medications

9. Do you take four (4) or more prescription medications for any reason on a daily basis?

- ○ No
- ○ Yes

10. Since you were diagnosed with prostate cancer, have you taken any of the medications listed below to **strengthen your bones**?

- ○ No
- ○ Yes *[If **YES**, please indicate below which medications you took, when you started taking them, and if you are still taking them. Choose all that apply.]*

Yes	Medications	Month began	Year began	Mark if still taking
○	Injectable medications (Zometa, Prolia, Xgeva)	_ _	_ _ _ _	○
○	Oral prescription medications (Fosamax or Actonel)	_ _	_ _ _ _	○
○	Calcium	_ _	_ _ _ _	○
○	Vitamin D	_ _	_ _ _ _	○

11. In the past 10 years, have you taken any prescription medications for anxiety or depression?

- ○ No
- ○ Yes *[If **YES**, please answer questions a and b below]*

a. When did you first start taking prescription medications for anxiety or depression?

- ○ Before my prostate cancer diagnosis
- ○ Since my prostate cancer diagnosis:
  - ○ Approximate start date: __ __ / __ __ __ __ (**Month** / **Year**)
  - ○ Date unknown
- ○ I don't know whether it was before or after my prostate cancer diagnosis

b. Are you currently taking any prescription medications for anxiety or depression?

- ○ No
- ○ Yes

12. In the past 10 years, have you seen a mental health specialist (psychologist, psychiatrist, therapist, counselor) for mental health issues?

- ○ No
- ○ Yes *[If **YES**, please answer questions a and b below]*

a. When did you first see a mental health specialist?

- ○ Before my prostate cancer diagnosis
- ○ Since my prostate cancer diagnosis:
  - ○ Approximate start date: __ __ / __ __ __ __ (**Month** / **Year**)
  - ○ Date unknown
- ○ I don't know whether it was before or after my prostate cancer diagnosis

b. Are you currently seeing a mental health specialist?

- ○ No
- ○ Yes

13. Since you were diagnosed with prostate cancer, have you taken or received testosterone supplementation?

- ○ No
- ○ Yes *[If **YES**, please answer questions a and b below]*

a. List the approximate date you began testosterone: __ __ / __ __ __ __ (**Month** / **Year**)

b. Are you still taking/receiving testosterone?

- ○ No
- ○ Yes

E. How Prostate Cancer Treatments and Side Effects Compare with Expectations

14. If you had surgery, radiation, or ablation, please choose one response on each line. If you did not have any of these treatments, skip to Question 15.

	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 effectiveness of treatment so far?	○	○	○	○	○
b. Compared to what you expected, how do you rate the side effects of treatment so far?	○	○	○	○	○

F. General Health

15. Have you **ever** had any additional cancers diagnosed? ***Do not include prostate cancer or non-melanoma skin cancer.***

Additional cancers	No	Yes
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 below: *(Do not include prostate cancer or non-melanoma skin cancer)* _____	○	○

16. 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	○	○

17. 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	○	○	○	○

18. 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	○	○	○	○	○

19. 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	○	○

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

- ○ No
- ○ Yes *[If **YES**, please answer questions a and b below]*
- ○ I don't know

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

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

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

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

21. 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	○	○

22. 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	○	○	○	○	○

23. 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	○	○	○	○	○

24. 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	○	○

25. 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	○	○

26. 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	○	○

27. 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	○	○
b. Glaucoma	○	○
c. Blurred vision (not correctable with eye glasses)	○	○
d. Retinopathy or macular degeneration	○	○

28. 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	○	○	○

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

- ○ No
- ○ Yes *[If **YES**, please answer questions a and b below]*
- ○ I don't know

a. How many years have you had diabetes?

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

b. Do you take insulin shots?

- ○ No
- ○ Yes
- ○ I don't know

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

- ○ No
- ○ Yes
- ○ I don't know

G. Activities of Daily Living

31. In general, would you say your health is:

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

32. The following two questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	No, not limited at all	Yes, limited a little	Yes, limited a lot
a. Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
b. Climbing several flights of stairs	○	○	○

33. During the **past 4 weeks** have you had any of the following problems with your work or other regular activities as a result of your physical health?

	No	Yes
a. Accomplished less than you would like	○	○
b. Were limited in the kind of work or other activities	○	○

34. During the **past 4 weeks**, were you limited in the kind of work you do or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

	No	Yes
a. Accomplished less than you would like	○	○
b. Didn't do work or other activities as carefully as usual	○	○

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

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

H. Health Status

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

a. 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

b. 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

c. 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

d. 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

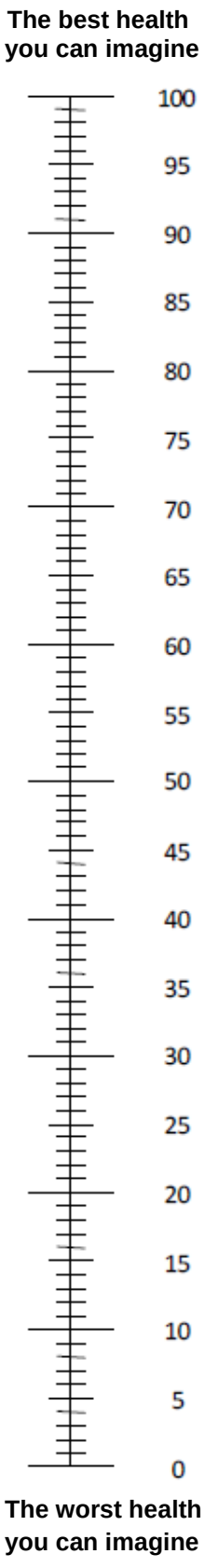
e. Anxiety/Depression

- ○ 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

37. 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 = ☐



I. Mood

38. During the **past 4 weeks**, how often were the following statements true? *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. Have you felt calm and peaceful?	○	○	○	○	○	○
b. Did you have a lot of energy?	○	○	○	○	○	○
c. Have you felt downhearted and blue?	○	○	○	○	○	○
d. How much of your time has your physical heath or emotional problems interfered with your social activities (like visiting with friends, relatives,etc.)?	○	○	○	○	○	○

39. 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 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. I felt hopeful about the future	○	○	○	○
g. I felt fearful	○	○	○	○
h. My sleep was restless	○	○	○	○
i. I was happy	○	○	○	○
j. I felt lonely	○	○	○	○
k. I enjoyed life	○	○	○	○
l. I felt sad	○	○	○	○
m. I could not get "going"	○	○	○	○

40. During the past week, how often were the following statements true? *Choose one response on each line.*

a. I felt tense or 'wound up':
- ○ Most of the time
- ○ A lot of the time
- ○ From time to time, occasionally
- ○ Not at all

b. I get a sort of frightened feeling as if something awful is about to happen:
- ○ Very definitely and quite badly
- ○ Yes, but not too badly
- ○ A little, but it doesn't worry me
- ○ Not at all

c. Worrying thoughts go through my mind:
- ○ A great deal of the time
- ○ A lot of the time
- ○ From time to time, but not too often
- ○ Only occasionally

d. I can sit at ease and feel relaxed:
- ○ Definitely
- ○ Usually
- ○ Not often
- ○ Not at all

e. I get a sort of frightened feeling like 'butterflies' in the stomach:
- ○ Not at all
- ○ Occasionally
- ○ Quite often
- ○ Very often

f. I feel restless as I have to be on the move:
- ○ Very much indeed
- ○ Quite a lot
- ○ Not very much
- ○ Not at all

g. I get sudden feelings of panic:
- ○ Very often indeed
- ○ Quite often
- ○ Not very often
- ○ Not at all

J. Urinary Issues

41. Over the **past 4 weeks**, how often have you leaked urine?

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

42. Which of the following best describes your urinary control during the **last 4 weeks**?

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

43. How many pads or adult diapers **per day** did you usually use to control leakage during the **last 4 weeks**?

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

44. 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	○	○	○	○	○

45. Overall, how big a problem has your urinary function been for you during the **last 4 weeks**?

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

K. Bowel Issues

46. 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	○	○	○	○	○

47. Overall, how big a problem have your bowel habits been for you during the **last 4 weeks**?

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

L. Sexual Issues

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

- ○ No, I do not have a sexual partner
- ○ Yes, I have a sexual partner
- ○ Yes, I have a partner, but we are **not** sexually active

Regardless of your answer to the question above, please try to answer the questions below:

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

	Have NOT tried it	Tried it, but was NOT HELPFUL	It HELPED, but I am NOT using it NOW	It HELPED, and I use it SOMETIMES	It HELPED, and I use it ALWAYS
a. Pills, such as Viagra, Sildenafil, Cialis, Tadalafil, Levitra, Staxyn, Stendra	○	○	○	○	○
b. Urethral pellets or suppositories (Muse)	○	○	○	○	○
c. Vacuum erection device	○	○	○	○	○
d. Penile injections (shots)	○	○	○	○	○
e. Penile prosthesis (surgical implant)	○	○	○	○	○
f. Nutritional supplements or other over-the-counter pills	○	○	○	○	○
g. Other (please specify below): _____	○	○	○	○	○

Regardless of your answers to the questions on the previous page, please report your actual experience in the last 4 weeks for the following questions:

50. 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)	○	○	○	○	○

51. How would you describe the usual QUALITY of your erections during the **last 4 weeks?**

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

52. How would you describe the FREQUENCY of your erections during the **last 4 weeks**?

- ○ 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

53. Overall, how would you rate your ability to function sexually during the **last 4 weeks**?

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

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

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

M. Other Issues

55. 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	○	○	○	○	○

56. During the past 7 days…

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. I feel fatigued	○	○	○	○	○
b. I have trouble starting things because I am tired	○	○	○	○	○

57. In the past 7 days…

	Not at all	A little bit	Somewhat	Quite a bit	Very much
a. How run-down did you feel on average?	○	○	○	○	○
b. How fatigued were you on average?	○	○	○	○	○

58. <u>In the past 7 days…</u>

	Never	**Rarely** (once)	**Sometimes** (two or three times)	**Often** (About once a day)	**Very often** (Several times a day)
a. My thinking has been slow	○	○	○	○	○
b. I have had difficulties finding words	○	○	○	○	○
c. It has seemed like my brain was not working as well as usual	○	○	○	○	○
d. I have had to work harder than usual to keep track of what I was doing	○	○	○	○	○
e. I have had trouble shifting back and forth between different activities that require thinking	○	○	○	○	○

59. <u>In the past 7 days</u>, how often have you felt the following?

	Very poor	**Poor**	**Fair**	**Good**	**Very good**
a. My sleep quality was	○	○	○	○	○

	Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
b. My sleep was refreshing	○	○	○	○	○
c. I had a problem with my sleep	○	○	○	○	○
d. I had difficulty falling asleep	○	○	○	○	○

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

	No	Yes, but no treatment was needed	Yes, and it was treated with medications and/or physical therapy	Yes, and it was treated with a medical procedure or surgery
a. Urethral scarring/stricture/ bladder neck contracture (blockage or narrowing of the tube which you urinate through)	○	○	○	○
b. Urinary incontinence (leakage)	○	○	○	○
c. Fistula (abnormal connection between the urinary tract and bowel)	○	○	○	○
d. Urinary retention (inability to urinate)	○	○	○	○
e. Radiation cystitis (inflammation of the bladder lining from radiation, resulting in urinary symptoms and sometimes bleeding)	○	○	○	○
f. Radiation proctitis (inflammation of the rectum from radiation, resulting in bowel symptoms and sometimes bleeding)	○	○	○	○
g. Deep venous thrombosis / pulmonary embolism / blood clots	○	○	○	○
h. Hernia	○	○	○	○
i. Falls	○	○	○	○
j. Fracture or broken bone	○	○	○	○
k. Shortening of the penis	○	○	○	○

N. Concerns Surrounding Impact of Prostate Cancer

61. 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.*

	Not a burden at all	**Very Small burden**	**Small burden**	**Feel neutral**	**Large burden**	**Very large burden**
a. Our overall health	○	○	○	○	○	○
b. Our social activities	○	○	○	○	○	○
c. Our lifestyle	○	○	○	○	○	○
d. Our finances due to the cost of my health care for prostate cancer, including ongoing visits for cancer or treatment side-effects, tests, treatments, medicines, etc.	○	○	○	○	○	○

62. To what degree has your prostate cancer caused financial problems for you and your family?

- ○ A lot
- ○ Some
- ○ A little
- ○ Not at all
- ○ I don't know

63. The next questions ask about different kinds of financial strategies you or your family may have used to cope with your cancer care expenses including treatments, copays, deductibles, medications, incontinence pads, travel to appointments, etc. **Please continue to think about all the time from when you were first diagnosed with prostate cancer to now.** *Choose one response on each line.*

Altering the care of your prostate cancer

In order to cope with cancer care expenses…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
a. I spread out clinic appointments or treatments	○	○	○	○	○
b. I missed clinic appointments or treatments	○	○	○	○	○
c. I did not have a recommended test (like a bone scan, CT scan, or MRI)	○	○	○	○	○
d. I did not have a recommended procedure (like a biopsy)	○	○	○	○	○
e. I have chosen one doctor over another	○	○	○	○	○
f. I didn't fill a prescription, filled it partially or just made do with samples	○	○	○	○	○
g. I tried to find a way to get medicines cheaper or make them last longer	○	○	○	○	○

Altering your lifestyle due to prostate cancer

In order to cope with cancer care expenses…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
h. I reduced spending on leisure activities (like vacations, eating out, or movies)	○	○	○	○	○
i. I used all or a portion of my savings to pay for my cancer care	○	○	○	○	○
j. I reduced spending on basics like food or clothing to pay for my cancer care	○	○	○	○	○
k. I borrowed money or used credit to pay for my cancer care	○	○	○	○	○
l. I sold possessions or property to pay for my cancer care	○	○	○	○	○
m. I worked more hours to pay for my cancer care	○	○	○	○	○
n. I had family members work more hours to pay for my cancer care	○	○	○	○	○

64. Did you or your family ever file for bankruptcy because of your prostate cancer, its treatment, or the lasting effects of that treatment?

○ No
○ Yes

65. 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	○	○	○	○	○

66. 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	○	○	○	○	○
b. I sometimes worry about dying before my time	○	○	○	○	○
c. I worry about what my doctor will find next	○	○	○	○	○
d. I worry that changes in my medical condition will not be detected early	○	○	○	○	○
e. I am uneasy about the present state of my health	○	○	○	○	○

67. 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	○	○	○	○	○
b. Knowing my PSA level is comforting to me	○	○	○	○	○
c. I live in fear that my PSA will rise	○	○	○	○	○

68. 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	○	○	○	○	○
b. I feel that coping with cancer has made me a stronger person	○	○	○	○	○

O. Social Support

69. 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	○	○	○	○	○

P. Satisfaction with Care

70. 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 am satisfied with the choices I made in treating my prostate cancer	○	○	○	○	○
b. I would recommend the treatment I had to a close friend or relative	○	○	○	○	○
c. I wonder if I would have been better off with a different treatment	○	○	○	○	○
d. I sometimes wonder whether it was really worthwhile being treated at all	○	○	○	○	○
e. I sometimes feel the treatment I had was the wrong one for me	○	○	○	○	○
f. If I had it to do over, I would choose some other treatment	○	○	○	○	○
g. I sometimes wish I could change my mind about the kind of treatment I chose for my prostate cancer	○	○	○	○	○

71. What is your overall feeling about the…
Choose one response on each line

	Completely unsatisfied	Very unsatisfied	Somewhat unsatisfied	Mixed	Somewhat satisfied	Very satisfied	Completely satisfied
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?	○	○	○	○	○	○	○

Q. Demographic Questions

72. What is your current employment status? *Choose all that apply.*

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

73. What is your current marital status? *Choose one.*

- ○ Never married
- ○ Married or in a committed relationship
- ○ Separated
- ○ Divorced
- ○ Widowed

74. 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
- ○ I don't know
- ○ Other, please specify: _____

75. Has your food intake declined over the **past 3 months** due to loss of appetite, digestive problems, chewing, or swallowing difficulties?

- ○ I am eating less than half of normal of my normal amount
- ○ I am eating more than half of my normal amount
- ○ I am eating my normal amount

76. Have you experienced weight loss over the **past 3 months**?

- ○ No weight loss
- ○ Lost 2-7 pounds
- ○ Lost more than 7 pounds
- ○ I don't know

77. What is your current height? __ feet __ __ inches

78. What is your current weight? __ __ __ pounds

79. What is your current waist size (on your pants or belt)? __ __ __ inches (approximate)

80. Do you smoke? *Choose one.*

- ○ 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
- ○ Yes, I do

81. Are there any other things you would like to share about your experience with prostate cancer?

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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: