ID

OFFICE USE ONLY

NATIONAL CANCER INSTITUTE

National Survey of Prostate Disease and Quality of Life

Follow-Up Survey

1. Please write today's date _____/_____/_____
Mo. Day Yr.

PLEASE READ ALL INSTRUCTIONS

This survey asks questions about how prostate cancer may affect your daily activities, and asks some questions about your general health. We mailed you a similar survey about 6 months ago, and we would like to know how you are doing now. Your answers to this follow-up survey will help medical researchers better understand changes in your condition over the past 6 months. Even if you did not complete our questionnaire 6 months ago, we would appreciate your helping us with our research by completing this questionnaire.

Answer all questions even if you have not yet had treatment for prostate cancer. Time periods are shown in bold lettering to tell you which time period you are being asked about. After each question, mark the box next to the answer that most closely fits your usual situation. Your answers will be grouped with answers from other men who are medically similar to you. All of your answers are strictly confidential.

Your help is very important to our research study. Please fill out and return this survey as soon as possible in the enclosed postage-paid envelope.

If you have questions, please call our office.

SECTION I: MEDICAL HISTORY

These questions are about your symptoms and medical treatment **in the past 6 months**. Do not include any symptoms or treatments you received before that time.

2. Please write the month and year you were first told you had prostate cancer.

_____/_____
Mo. Yr.

3. Which of the following <u>physical</u> signs or symptoms have you had **in the past 6 months**?

(Please mark "Yes" or "No" for **EACH** sign or symptom.)

Yes	No	
☐	☐	Difficulty or discomfort urinating (passing water)
☐	☐	Weak urinary stream
☐	☐	Pain or aches in back, hips, or legs
☐	☐	More tired or worn out than usual
☐	☐	Lost a lot of weight
☐	☐	Lost appetite (Didn't feel like eating)

4. Some men receive PSA blood tests to check for prostate cancer. **Over the past 6 months**, how often have you had a PSA blood test?

- ☐ Once every month
- ☐ Once every other month
- ☐ Once or twice every 6 months
- ☐ I have not been tested

5. **Over the past 6 months**, has your PSA level:

- ☐ Increased a lot
- ☐ Increased a little
- ☐ Remained about the same
- ☐ Decreased a little
- ☐ Decreased a lot
- ☐ Don't know
- ☐ I have not been tested

6. a) **In the past 6 months**, did a doctor tell you that your prostate cancer had spread to other areas of your body?

☐ Yes ☐ No ☐ Don't know

IF YES → b) Where did prostate cancer spread?

_____

7. Are you free of prostate cancer **now**?

☐ Yes ☐ No ☐ Don't know

8. a) **In the past 6 months**, did a doctor tell you that you had any other cancer besides prostate cancer?

☐ Yes ☐ No ☐ Don't know

IF YES → b) What type of cancer?

_____

9. a) **In the past 6 months**, did you have surgery to remove all or part of your prostate gland?

☐ Yes ☐ No (Skip to 10)

IF YES → b) In what month and year?

____/____

Mo. Yr.

10. a) **In the past 6 months**, did you have surgery to remove cancer from any other body area?

☐ Yes ☐ No (Skip to 11)

IF YES → b) What body area was this?

_____

11. a) **In the past 6 months**, did you have radiation treatment for prostate cancer?

☐ Yes ☐ No (Skip to 12)

IF YES → b) Are you receiving radiation treatment **now**?

☐ Yes ☐ No

12. a) **In the past 6 months**, did you have radiation treatment to any other body areas besides the prostate gland?

☐ Yes ☐ No (Skip to 13)

IF YES → b) What body area was this?

_____

13. a) **In the past 6 months**, did you have hormone shots for prostate cancer?

☐ Yes ☐ No (Skip to 14)

IF YES → b) Are you receiving hormone shots **now**?

☐ Yes ☐ No

14. a) **In the past 6 months**, did you take hormone pills for prostate cancer?

☐ Yes ☐ No (Skip to 15)

IF YES → b) Are you taking hormone pills **now**?

☐ Yes ☐ No

15. **In the past 6 months**, did you have surgery to remove the testicles?

☐ Yes ☐ No

16. a) **In the past 6 months**, did you have chemotherapy for any type of cancer?

☐ Yes ☐ No (Skip to 17)

IF YES → b) What type of cancer was this?

☐ Prostate cancer

☐ Other cancer _____
(specify)

The next questions are about medical conditions you may have besides prostate cancer.

17. Look at each medical condition below and check "Yes" or "No" to show whether a doctor has **EVER told you** that you had the condition.

If you have been told you have the condition, then answer both questions B and C about the condition:

B. Check "Yes" or "No" to show whether the condition limits any of your current daily activities; and

C. Check "Yes" or "No" to show whether you are currently taking any prescription medicines for the condition.

If "Yes" to A, answer B and C.

	A. Has a doctor EVER told you that you had this condition?			**B. Are any of your current activities limited by this condition?**		**C. Do you currently take prescription medicine for this condition?**	
	No	Yes		No	Yes	No	Yes
Arthritis or rheumatism	☐	☐	IF YES ➡	☐	☐	☐	☐
Diabetes or high blood sugar or sugar in urine	☐	☐	IF YES ➡	☐	☐	☐	☐
Inflammatory bowel disease or colitis or Crohn's Disease	☐	☐	IF YES ➡	☐	☐	☐	☐
Bleeding from stomach ulcers	☐	☐	IF YES ➡	☐	☐	☐	☐
Chronic lung disease or bronchitis or emphysema	☐	☐	IF YES ➡	☐	☐	☐	☐
Heart failure or congestive heart failure	☐	☐	IF YES ➡	☐	☐	☐	☐

If "Yes" to A, answer B and C.

	A. Has a doctor EVER told you that you had this condition?			B. Are any of your current activities limited by this condition?		C. Do you currently take prescription medicine for this condition?	
	No	Yes		No	Yes	No	Yes
Stroke or brain hemorrhage	☐	☐	IF YES →	☐	☐	☐	☐
High blood pressure (hypertension)	☐	☐	IF YES →	☐	☐	☐	☐
Heart attack or myocardial infarction	☐	☐	IF YES →	☐	☐	☐	☐
Chest pain or angina	☐	☐	IF YES →	☐	☐	☐	☐
Liver disease or cirrhosis	☐	☐	IF YES →	☐	☐	☐	☐
Depression or anxiety	☐	☐	IF YES →	☐	☐	☐	☐

18. Do you have any other medical conditions or problems that limit your **current** daily activities?

☐ Yes ☐ No (Go to next page)

↓ IF YES

Please write conditions here:

_____

_____

_____

_____

SECTION II: URINARY HABITS

This section is about your urinary habits **OVER THE PAST MONTH**. Mark the answer that best describes your usual situation for the past month.

19. **Over the past month,**
which of the following best describes your urinary control?

- ☐ Total control
- ☐ Occasional leaking
- ☐ Frequent leaking
- ☐ No control

20. **Over the past month,**
how often did you leak or drip urine (been incontinent)?

- ☐ Not at all
- ☐ Less than once a week
- ☐ About once a week
- ☐ Once or twice a day
- ☐ More than twice a day

21. **Over the past month,**
how many pads or adult diapers, if any, did you usually use to help with leaking or dripping?

- ☐ No pads
- ☐ 1 pad per day
- ☐ 2 pads per day
- ☐ 3 or more pads per day

22. **Over the past month,**
overall, how big a problem did you have with leaking or dripping urine?

- ☐ No Problem
- ☐ Very Small Problem
- ☐ Small Problem
- ☐ Moderate Problem
- ☐ Big Problem

23. **Over the past month,**
how often did you have to urinate again less than 2 hours after finishing urinating?

- ☐ Rarely or not at all
- ☐ Less than half the time
- ☐ About half the time
- ☐ More than half the time
- ☐ Almost always

24. **Over the past month,**
how often did you have to push or strain to begin urination?

- ☐ Rarely or not at all
- ☐ Less than half the time
- ☐ About half the time
- ☐ More than half the time
- ☐ Almost always

25. One problem some prostate cancer patients have is called strictures. Strictures or scar tissue can form in the urinary tract and can make it hard to urinate.

In the past 6 months, has a doctor had to stretch your urinary tract or perform any surgery **to treat strictures**?

☐ Yes ☐ No ☐ Don't know

26. a) **In the past 6 months**, did you wear a clamp or a bag and catheter to help with urine leakage?

☐ Yes ☐ No (Skip to 27)

IF YES → b) Do you wear a clamp or a bag and catheter **now**?

☐ Yes ☐ No

27. Are you **now** taking any pills to help control urine flow (prevent incontinence)?

No ☐ Yes ☐ IF YES → How much does this help?

☐ A lot
☐ Somewhat
☐ Not at all

28. You may write down any other information about urinary problems you may have had **over the past 6 months.**

_____

_____

_____

_____

_____

_____

SECTION III: BOWEL HABITS

This section is about your bowel habits **OVER THE PAST MONTH**. Mark the answer that best describes your usual situation for the past month.

29. **Over the past month,**
how often did you have more than 3 bowel movements on a single day?

- ☐ Almost every day
- ☐ Some days
- ☐ Rarely or not at all

30. **Over the past month,**
how often did you have any pain or discomfort before, or during, bowel movements?

- ☐ Almost every day
- ☐ Some days
- ☐ Rarely or not at all

31. **Over the past month,**
how often did you have urgent bowel movements (you could not wait to go to the bathroom)?

- ☐ Almost every day
- ☐ Some days
- ☐ Rarely or not at all

32. **Over the past month,**
how often did you have wetness in the rectal area?

- ☐ Almost every day
- ☐ Some days
- ☐ Rarely or not at all

33. **Over the past month,**
how often did you have problems with painful or bleeding hemorrhoids?

- ☐ Almost every day
- ☐ Some days
- ☐ Rarely or not at all

34. **Over the past month,**
overall, how big a problem did you have with urgent, frequent, or painful bowel movements?

- ☐ No Problem
- ☐ Very Small Problem
- ☐ Small Problem
- ☐ Moderate Problem
- ☐ Big Problem

35. **In the past 6 months,** did you try any of the following to help deal with bowel problems?

a) Did you change your diet?

No ☐ Yes ☐ IF YES ➡ How much did this help?

- ☐ A lot
- ☐ Somewhat
- ☐ Not at all

b) Did you take medicine? (including those <u>not</u> prescribed)

No ☐ Yes ☐ IF YES ➡ How much did this help?

- ☐ A lot
- ☐ Somewhat
- ☐ Not at all

c) Did you take enemas or suppositories?

No ☐ Yes ☐ IF YES ➡ How much did this help?

- ☐ A lot
- ☐ Somewhat
- ☐ Not at all

d) Did you get a blood transfusion or take iron pills?

No ☐ Yes ☐ IF YES ➡ How much did this help?

- ☐ A lot
- ☐ Somewhat
- ☐ Not at all

36. You may write down any other information about bowel problems you may have had **over the past 6 months.**

_____

_____

_____

_____

SECTION IV: SEXUAL FUNCTION

This section is about sexual function and sexual satisfaction **OVER THE PAST MONTH**. Mark the answer that best describes your usual situation during the past month. REMEMBER, YOUR NAME DOES NOT APPEAR ANYWHERE ON THIS SURVEY, AND ALL RESPONSES ARE STRICTLY CONFIDENTIAL.

37. **Over the past month,**
how interested were you in sexual activity (including kissing, hugging, fondling, having intercourse, or masturbating)?

- ☐ A lot
- ☐ Somewhat
- ☐ Only a little
- ☐ Not at all

38. **Over the past month,**
how often did you engage in <u>any</u> sexual activity?

- ☐ Several times a week
- ☐ Once a week
- ☐ 2-3 times
- ☐ Once
- ☐ Not at all

39. **Over the past month,**
did you have any erections firm (hard) enough for sexual intercourse?

- ☐ Yes
- ☐ No

40. **Over the past month,**
did you have any partial erections that were not firm enough for sexual intercourse?

- ☐ Yes
- ☐ No

41. **Over the past month,**
how much difficulty did you have **keeping** an erect penis during sexual activity?

- ☐ No difficulty at all
- ☐ A little difficulty
- ☐ Some difficulty
- ☐ A lot of difficulty
- ☐ Do not get erections at all

42. **Over the past month,**
overall, how big a problem did you consider your sexual function to be?

- ☐ No Problem
- ☐ Very Small Problem
- ☐ Small Problem
- ☐ Moderate Problem
- ☐ Big Problem

43. **Over the past month,**
did you have a sexual partner?

- ☐ Yes
- ☐ No

44. **Over the past month,**
how often did you have hot flashes?

(Check ONE answer.)

- ☐ Never
- ☐ Less than once a week
- ☐ Once a week
- ☐ More than once a week

45. **Over the past month,**
to what extent did you have breast swelling?

(Check ONE answer.)

- ☐ Not at all
- ☐ Only a little
- ☐ Somewhat
- ☐ A lot

46. **In the past 6 months,** did you try any of the following to help with problems with sexual function?

a) Have you used a vacuum suction device?
☐ No ☐ Yes IF YES ➡ How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

b) Did you have penile injections (shots)?
☐ No ☐ Yes IF YES ➡ How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

c) Did you take any medicine?
☐ No ☐ Yes IF YES ➡ How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

d) Did you talk with a sex therapist or psychologist?
☐ No ☐ Yes IF YES ➡ How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

e) Did you get a penile implant or prosthesis?
☐ No ☐ Yes IF YES ➡ How much did this help?
☐ A lot
☐ Somewhat
☐ Not at all

47. You may write down any other information about problems with sexual function you may have had **over the past 6 months.**

SECTION V: GENERAL HEALTH STATUS

(Please read instructions.)

The following questions (Questions 48 through 53) are about your health in general. For these questions, consider the effects of **any** medical conditions or problems you have, including prostate cancer.

48. In general, would you say your health is:
(Check ONE answer.)

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

49. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of your **PHYSICAL HEALTH**?

a. Cut down the **amount of time** you spent on work or other activities
☐ Yes ☐ No

b. **Accomplished less** than you would like
☐ Yes ☐ No

c. Were limited in the **kind** of work or other activities you did
☐ Yes ☐ No

d. Had **difficulty** performing work or other activities (for example, it took extra effort)
☐ Yes ☐ No

50. **During the past 4 weeks**, have you had any of the following problems with your work or other regular daily activities as a result of any **EMOTIONAL PROBLEMS** (such as feeling depressed or anxious)?

a. Cut down the **amount of time** you spent on work or other activities

☐ Yes ☐ No

b. **Accomplished less** than you would like

☐ Yes ☐ No

c. Didn't do work or other activities as **carefully** as usual

☐ Yes ☐ No

51. How much **bodily** pain have you had **during the past 4 weeks**? (Check ONE answer.)

☐ None
☐ Very mild
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe

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

☐ Not at all
☐ Slightly
☐ Moderately
☐ Quite a bit
☐ Extremely

53. These questions are about how you feel and how things have been 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. (Check ONE answer on each line.)

How much of the time **during the past 4 weeks**...

	ALL OF THE TIME	MOST OF THE TIME	A GOOD BIT OF THE TIME	SOME OF THE TIME	A LITTLE OF THE TIME	NONE OF THE TIME
a. Did you feel full of pep?	☐	☐	☐	☐	☐	☐
b. Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
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 downhearted and blue?	☐	☐	☐	☐	☐	☐
g. Did you feel worn out?	☐	☐	☐	☐	☐	☐
h. Have you been a happy person?	☐	☐	☐	☐	☐	☐
i. Did you feel tired?	☐	☐	☐	☐	☐	☐

SECTION VI: OVERALL EFFECTS OF PROSTATE CANCER

(Please read instructions.)

This section contains some questions about your prostate cancer. For each question, please give the **ONE** answer that comes closest to how you have usually felt over the past **MONTH**.

54. Please answer all the questions below, **whether or not you have had any treatments for your prostate cancer.**

(Check ONE answer on each line.)

	A LOT	SOME	ONLY A LITTLE	NONE AT ALL
a. How much physical discomfort have you had because of anything related to your prostate cancer or your treatment?	☐	☐	☐	☐
b. How much do you worry about your health because of anything related to your prostate cancer or your treatment?	☐	☐	☐	☐
c. How much have your daily activities been limited by anything related to your prostate cancer or your treatment?	☐	☐	☐	☐
d. Overall, how much have you been bothered by anything related to your prostate cancer or your treatment?	☐	☐	☐	☐

55. Overall, how do you feel about how your treatment (or not getting treatment) for prostate cancer has worked out?

(Check ONE answer.)

- ☐ Delighted
- ☐ Pleased
- ☐ Mostly Satisfied
- ☐ Mixed, about equally satisfied and dissatisfied
- ☐ Mostly Dissatisfied
- ☐ Unhappy
- ☐ Terrible

56. Would you make the same treatment decisions again if you had the chance?

- ☐ Definitely Yes
- ☐ Probably Yes
- ☐ Probably Not
- ☐ Definitely Not

57. **Over the past 6 months,** have you had any problems related to prostate cancer not covered in this survey?

- ☐ Yes
- ☐ No

If yes, please briefly describe the problem(s):

_____

_____

_____

_____

_____

_____

Thank you for your cooperation with this survey.
Please return the questionnaire in the enclosed postage-paid envelope as soon as possible.

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NATIONAL CANCER INSTITUTE

National Survey of Prostate Disease and Quality of Life

Supplement to Follow-Up Survey

SECTION VII: GENERAL QUESTIONS

Please answer all these questions which are about general information.

1. What is your race or ethnic group?

- ☐ White
- ☐ Black or African-American
- ☐ American Indian
- ☐ Alaskan Native
- ☐ Asian or Pacific Islander
- ☐ Mixed or other, please specify: _____

2. Are you of Spanish, Latino, or Hispanic descent?

- ☐ Yes
- ☐ No
- ☐ Don't know

3. What is the highest level of education you have completed?

- ☐ 8 Grades or less
- ☐ Some high school
- ☐ High school graduate
- ☐ Some college
- ☐ College graduate
- ☐ Advanced or graduate training

4. Are you **now** married?

- ☐ Yes
- ☐ No

5. How many persons are living in your household, including yourself?

Number: _____

6. What is your employment status **now**?
(Check ONE answer.)

- ☐ Working full-time
- ☐ Working part-time
- ☐ Retired
- ☐ Other

7. To what extent did your prostate cancer cause financial problems?
(Check ONE answer.)

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A lot

8. To what extent has your insurance coverage (or lack of coverage) influenced your decisions about treatment for prostate cancer?
(Check ONE answer.)

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A lot

9. Which best describes your 1994 total household income before taxes? Include all sources of income (wages, pensions, social security, investments).
(Check ONE answer.)

- ☐ Under $10,000
- ☐ $10,001 up to $20,000
- ☐ $20,001 up to $30,000
- ☐ $30,001 up to $40,000
- ☐ $40,001 up to $50,000
- ☐ $50,001 up to $75,000
- ☐ $75,001 or more
- ☐ Not sure

Thank you for your cooperation with this survey.
Please return this supplement with the questionnaire in the enclosed postage-paid envelope as soon as possible.