HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH

Health Professionals Follow-Up Study

Dear Colleague,

Thank you for your longstanding participation in the Health Professionals Follow-Up Study. As you know, we are studying the determinants of long-term survival from prostate cancer. Through this study, we are gaining valuable insight about how diet, lifestyle, and other factors can improve prognosis and cancer survivorship. **Please note that we have all of your original diagnosis information. The purpose of this mailing, as we do every couple of years, is to obtain new follow-up information regarding your prostate cancer. Even if nothing has changed, that information is still important to our study.**

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We would greatly appreciate it if you could complete the enclosed questionnaire regarding your prostate cancer and return it to us in the envelope provided. We realize this is a lengthy questionnaire; please fill out whatever you can. Your participation is completely voluntary, and if you do not wish to participate in this study on prostate cancer survival, you will still be a valuable member of the Health Professionals Follow-Up Study. By participating, you will be making a key contribution to our understanding of prostate cancer, which may ultimately lead to strategies geared at prevention or cure. Please do not hesitate to call me or Dr. Lorelei Mucci at **617-998-1067** if you have any questions about the study.

Sincerely Yours,

Walter Willett

Lorelei Mucci, ScD.
Principal Investigator

Walter C. Willett, M.D.
Principal Investigator

PLEASE USE AN ORDINARY NO. 2 PENCIL TO ANSWER ALL QUESTIONS.

Fill in the appropriate response circles completely, or write the requested information in the boxes provided. The form is designed to be read by optical-scanning equipment, so it is important that you make NO STRAY MARKS and keep any write-in responses within the spaces provided. Should you need to change a response, erase the incorrect mark completely. If you have comments, please write them on a separate piece of paper.

Please fill in the circles completely; do not mark this way: ✓ ✗ ◒

31a. Mark all of the treatments you have had since January 2024 and provide the dates as best as you can.

Treatment/medication since January 2024 only	Start date or procedure date	End date or...	...Currently doing/taking?
Procedures	**Year**	**Year**	
1. ○ Radical prostatectomy		N/A	
2. ● Radiation to the pelvis (external beam, proton beam, cyberknife, etc.)	2024		●
3. ○ Brachytherapy/seeds		N/A	○
4. ○ Cryosurgery/cryoablation		N/A	○
5. ○ High intensity focused ultrasound (HIFU)		N/A	○

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The research team has great respect for your continued study participation, and therefore would like to remind you of several important points, as is standard practice in research. We do so in recognition of the fact that consent is an ongoing process rather than a one-time agreement. Please do not hesitate to contact us if you have any questions regarding this information.

a. You are participating in a research study that focuses on what happens to men after a cancer diagnosis. Participation involves the completion of this questionnaire.
b. Your participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled.
c. There is a small risk of breach of confidentiality; however we have taken many steps to minimize this risk, and in the 40 years of the study have never had a breach.
d. Samples are sometimes shared with entities outside of Harvard as part of research collaborations; in such cases we use a separate ID number to ensure confidentiality.
e. You will not receive monetary compensation for participating.
f. There are no direct benefits to you from study participation.
g. If you wish to speak with someone not directly involved in this research study about your rights as a research participant, please contact the Harvard TH Chan School of Public Health's Office for Human Research Administration at 617-432-2143 (local calls) or 866-606-0573 (long distance calls), or at: ohra@hsph.harvard.edu.
h. If you have any questions regarding the study itself, please call the study Research Assistant at 617-998-1067.

THANK YOU FOR PREVIOUSLY PROVIDING VALUABLE INFORMATION RELATED TO YOUR PROSTATE CANCER. PLEASE NOTE THAT WE HAVE ALL OF YOUR ORIGINAL DIAGNOSIS INFORMATION. WE NOW SEEK TO UPDATE YOUR INFORMATION.

1. Since January 2024, have you had a recurrence or progression of your prostate cancer indicated by a rise in PSA?

- ○ No – Continue to question 2
- ○ Yes – please complete question 1a:

1a. When did your PSA rise occur? _____ Year

What was your highest PSA value during this rise? _____

2. Have you ever been diagnosed with prostate cancer metastases to lymph nodes, bone, or other organs?

- ○ Yes
- ○ No – continue to question 3

If yes:

- ○ Found *at* initial prostate cancer diagnosis (continue to question 3)
- ○ Found *after* prostate cancer diagnosis (please complete the box below)

2a. At which site(s) were you found to have metastases? Please mark all that apply.

- ○ Lymph nodes ..... Date diagnosed: ____ Month / ____ Year
- ○ Bone ..... Date diagnosed: ____ Month / ____ Year
- ○ Other organs, specify: _____ Date diagnosed: ____ Month / ____ Year

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1 2 3 4	Before 2024	a
5 6 7 8	2024 2025	M
9 10 11 12	2026 2027	Y
1 2 3 4	Before 2024	M
5 6 7 8	2024 2025	Y
9 10 11 12	2026 2027	
1 2 3 4	Before 2024	M
5 6 7 8	2024 2025	Y
9 10 11 12	2026 2027	O

Please answer the following questions by darkening the appropriate circle. Questions 3 to 9 are about your health and symptoms in the last month. Select one answer for each question.

3. How large a problem, if any, has each of the following been for you?

	No problem	Very small problem	Small problem	Moderate problem	Big problem
Urinary dripping or leakage	○	○	○	○	○
Pain or burning with urination	○	○	○	○	○
Weak urine stream/incomplete bladder emptying	○	○	○	○	○
Need to urinate frequently	○	○	○	○	○
Rectal pain or urgency of bowel movements	○	○	○	○	○
Increased frequency of your bowel movements	○	○	○	○	○
Overall problems with your bowel habits	○	○	○	○	○
Hot flashes or breast tenderness/enlargement	○	○	○	○	○
Lack of energy	○	○	○	○	○
Feeling depressed	○	○	○	○	○

1 2 3 4	2026
5 6 7 8	2027
9 10 11 12	2028

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4. How much of a problem has your urinary function been for you?

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

5. Which of the following best describes your urinary control?

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

6. How many pads or adult diapers per day have you been using for urinary leakage?

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

**We realize that sexuality and sexual function are important for many men independent of age.
Please answer questions 7 to 9 as far as applicable to you.
As always, your responses will remain confidential.**

7. How would you rate your ability to reach orgasm (climax)?

○ Very good ○ Good ○ Fair ○ Poor ○ Very poor to none

8. How would you describe the usual quality of your erections?

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

9. Overall, how large a problem has your sexual function or lack of sexual function been for you?

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

Question 10 asks about your animals in your life.

10. Do you own or live with any animals?

○ No. Skip to question 11. ○ Yes – mark all that apply in 10a. and indicate which of the feelings or behaviors apply to you in 10b.

10a. ○ Dog ○ Cat ○ Rabbit ○ Parrot/other bird ○ Horse ○ Farm animals ○ Other animal

10b. Please indicate the extent to which you agree or disagree with each statement based on your experience with the pet you indicated above.

	Strongly Disagree	Disagree	Agree	Strongly Agree
I consider my pet to be a friend.	○	○	○	○
I often talk to other people about my pet.	○	○	○	○
Quite often I confide in my pet.	○	○	○	○
Owning a pet adds to my happiness.	○	○	○	○
I play with my pet quite often.	○	○	○	○
I feel that my pet is a part of my family.	○	○	○	○

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11. This question asks how well you have slept in the past 4 weeks.	No, not in the past 4 weeks	Yes, less than once a week	Yes, 1 or 2 times a week	Yes, 3 or 4 times a week	Yes, 5 or more times a week
Did you have trouble falling asleep?	○	○	○	○	○
Did you wake up several times at night?	○	○	○	○	○
Did you wake up earlier than you planned to?	○	○	○	○	○
Did you have trouble getting back to sleep after you woke up too early?	○	○	○	○	○

12. Overall, how would you describe your typical night's sleep during the past 4 weeks?

○ Very sound or restful ○ Sound or restful ○ Average quality ○ Restful ○ Very restless

13. During the past year, what was your average time per week spent at each of the following recreational activities?

	TIME PER WEEK									
	Zero	1-4 Min.	5-19 Min.	20-59 Min.	One Hour	1-1.5 Hrs.	2-3 Hrs.	4-6 Hrs.	7-10 Hrs.	11+ Hrs.
Walking for exercise or walking for transportation or errands	○	○	○	○	○	○	○	○	○	○
Jogging (slower than 10 minutes/mile)	○	○	○	○	○	○	○	○	○	○
Running (10 minutes/mile or faster)	○	○	○	○	○	○	○	○	○	○
Bicycling: **stationary exercise bike** Intensity: ○ Low ○ Medium ○ High	○	○	○	○	○	○	○	○	○	○
Bicycling: **outside, separated from traffic (e.g., bike path)** Intensity: ○ Low ○ Medium ○ High	○	○	○	○	○	○	○	○	○	○
Bicycling: **outside on road** Intensity: ○ Low ○ Medium ○ High	○	○	○	○	○	○	○	○	○	○
Pickleball, tennis, squash, or racquetball Racquet sport intensity: ○ Low ○ Medium ○ High	○	○	○	○	○	○	○	○	○	○
Lap swimming Swimming intensity: ○ Low ○ Medium ○ High	○	○	○	○	○	○	○	○	○	○
Other aerobic exercise (e.g., aerobic dance, ski or stair machine, etc.)	○	○	○	○	○	○	○	○	○	○
Lower intensity exercise (e.g., yoga, stretching, toning)	○	○	○	○	○	○	○	○	○	○
Other vigorous activities (e.g., lawn mowing)	○	○	○	○	○	○	○	○	○	○
Weight training or resistance exercises (include free weights or resistance machines) — Arm weights	○	○	○	○	○	○	○	○	○	○
Weight training or resistance exercises (include free weights or resistance machines) — Leg weights	○	○	○	○	○	○	○	○	○	○

14. During the past year, on average, how many hours per week did you spend:

	TIME PER WEEK								
	Zero Hrs.	One Hour	2-5 Hrs.	6-10 Hrs.	11-20 Hrs.	21-40 Hrs.	41-60 Hrs.	61-90 Hrs.	Over 90 Hrs.
Standing or walking around at work or away from home?	○	○	○	○	○	○	○	○	○
Standing or walking around at home?	○	○	○	○	○	○	○	○	○
Sitting at work or away from home or while driving?	○	○	○	○	○	○	○	○	○
Sitting at home while watching TV/DVD/movies?	○	○	○	○	○	○	○	○	○
Other sitting at home (e.g., reading, meal times, at desk)?	○	○	○	○	○	○	○	○	○

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15. What is your usual walking pace outdoors?

○ Unable to walk ○ Easy, casual (less than 2 mph)
○ Normal, average (2-2.9 mph) ○ Brisk pace (3-3.9 mph) ○ Very brisk/striding (4 mph or faster)

16. For each question, please mark the one answer that comes closest to the way you have been feeling.	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
Do you have any trouble doing strenuous activities like carrying heavy shopping bags or a suitcase?	○	○	○	○
Do you have any trouble taking a **long** walk?	○	○	○	○
Do you have any trouble taking a **short** walk outside the house?	○	○	○	○
Do you need to stay in bed or a chair during the day?	○	○	○	○
Do you need help with eating, dressing, washing yourself or using the toilet?	○	○	○	○

For the following two questions, please select the number between 1 and 7 that best applies to you.

17. How would you rate your overall health during the past week?

① ② ③ ④ ⑤ ⑥ ⑦
Very Poor Excellent

18. How would you rate your overall quality of life during the past week?

① ② ③ ④ ⑤ ⑥ ⑦
Very Poor Excellent

19. Listed are a number of statements concerning a person's beliefs about their own health. In thinking about the past week, please indicate how much you agree or disagree with each statement.

	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
Because cancer is unpredictable, I feel I cannot plan for the future.	○	○	○	○
My fear of having cancer getting worse gets in the way of my enjoying life.	○	○	○	○
I am afraid of my cancer getting worse.	○	○	○	○
I am more nervous since I was diagnosed with prostate cancer.	○	○	○	○

20. Have you ever been told by your physician that you have castration-resistant prostate cancer?

○ No ○ Yes If yes, what date? ____ / ____
Month Year

21. In the past month, please report how often you felt the following ways.

	Hardly Ever	**Some of the time**	**Often**
How often did you feel that you lacked companionship?	○	○	○
How often did you feel left out?	○	○	○
How often did you feel isolated from others?	○	○	○

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22. During the past week:	Not at All	A Little	Quite a Bit	Very Much
Have you had difficulty remembering things?	○	○	○	○
Has your physical condition or medical treatment interfered with your **family** life?	○	○	○	○
Has your physical condition or medical treatment interfered with your **social** activities?	○	○	○	○
Has your physical condition or medical treatment caused you **financial** difficulties?	○	○	○	○
Were you limited in doing either your work or other daily activities?	○	○	○	○
Were you limited in pursuing your hobbies or other leisure activities?	○	○	○	○
Were you short of breath?	○	○	○	○
Have you had pain?	○	○	○	○
Have you had bone pain?	○	○	○	○
Did you need rest?	○	○	○	○
Have you had trouble sleeping?	○	○	○	○
Have you felt weak?	○	○	○	○
Have you lacked appetite?	○	○	○	○
Have you felt nauseated?	○	○	○	○
Have you vomited?	○	○	○	○
Have you been constipated?	○	○	○	○
Have you had diarrhea?	○	○	○	○
Were you tired?	○	○	○	○
Did pain interfere with your daily activities?	○	○	○	○
Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	○	○	○	○
Did you feel tense?	○	○	○	○
Did you worry?	○	○	○	○
Did you feel irritable?	○	○	○	○
Did you feel depressed?	○	○	○	○

23. In the past 12 months, have you used any cannabis product for medicinal or recreational purposes? (smoke, vape, edibles, creams/lotions, etc.)

○ No ○ Yes, containing CBD only ○ Yes, containing THC ○ Prefer not to answer

24. How often have you practiced mindfulness and/or meditation in the last month?

○ Never ○ Less than twice a week ○ 2-6 times/week ○ Once a day ○ More than once a day

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25. **Have you ever had any treatment for your prostate cancer?**

◯ No ◯ Yes ◯ Active Surveillance / Watchful Waiting Only

26. **Since January 2024, have you had any treatment or medications for your prostate cancer?**

◯ No ◯ Yes – please fill out the following table (26a)

26a. **Please mark all of the treatments that you have had since January 2024.**

	Dates of Treatment (Year) Start	Dates of Treatment (Year) End	...currently doing/taking?
Procedures	**Year**	**Year**	
1. ◯ Radical prostatectomy		N/A	
2. ◯ Radiation to the pelvis (external beam, proton beam, cyberknife, etc.)			◯
3. ◯ Brachytherapy/seeds		N/A	◯
4. ◯ Cryosurgery/cryoablation		N/A	◯
5. ◯ High intensity focused ultrasound (HIFU)		N/A	◯
Oral medications	**Year**	**Year**	
6. ◯ Casodex (bicalutamide), Eulexin (flutamide)			◯
7. ◯ Nilandron (nilutamide)			◯
8. ◯ Zytiga (abiraterone)			◯
9. ◯ Xtandi (enzalutamide)			◯
10. ◯ Lynparza (olaparib)			◯
11. ◯ Erleada (apalutamide)			◯
12. ◯ Nubeqa (darolutamide)			◯
13. ◯ Rubraca (rucaparib)			◯
14. ◯ Zejula (niraparib)			◯
15. ◯ Talzenna (talazoparib)			◯
16. ◯ Orgovyx (relugolix)			◯
Injections/implants/infusions	**Year**	**Year**	
17. ◯ Lupron/Eligard/Viadur (leuprolide)			◯
18. ◯ Zoladex (goserelin)			◯
19. ◯ Trelstar (triptorelin)			◯
20. ◯ Plenaxis (abarelix)			◯
21. ◯ Firmagon (degarelix)			◯
22. ◯ Vantas (histrelin)			◯
23. ◯ Zometa (zoledronic acid)			◯
24. ◯ Xgeva (denosumab)			◯
25. ◯ Jevtana (cabazitaxel)			◯
26. ◯ Taxotere (docetaxel)			◯
27. ◯ Pluvicto (^{177}Lu-PSMA-617)			◯
28. ◯ Keytruda (pembrolizumab)			◯
29. ◯ OTHER, specify: ________________			◯

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Treatment Code: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32
Start year: ◯ Before 2024 ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027
End year: ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027

Treatment Code: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32
Start year: ◯ Before 2024 ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027
End year: ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027

Treatment Code: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32
Start year: ◯ Before 2024 ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027
End year: ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027

Treatment Code: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32
Start year: ◯ Before 2024 ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027
End year: ◯ 2024 ◯ 2025 ◯ 2026 ◯ 2027

27. **Did you (the participant) have help with filling out this questionnaire?**

◯ No (I filled it out alone) ◯ Yes (Someone helped me)

Thank you for your participation!

Please return form to:
HSPH, 665 Huntington Ave.,
Boston, MA 02215

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