



## 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 and other factors can improve prognosis. **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.**

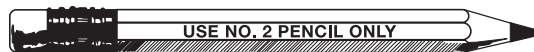
We would greatly appreciate it if you could complete the enclosed questionnaire regarding your prostate cancer and return it to us in the envelope provided. We realize this is a lengthy questionnaire; please fill out whatever you can. Your participation is completely voluntary, and if you do not wish 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*

Walter C. Willett, M.D.  
Principal Investigator

Lorelei Mucci, ScD.  
Co-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:

29c. Mark all of the treatments you have had **SINCE JANUARY 2020** and provide the dates as best as you can (if you cannot remember the month, include just the year).

Treatment/medication since January 2020 only	Start date or procedure date	End date or...	...Currently doing/taking?
<b>Procedures</b>	Year	Year	
1. <input type="radio"/> Radical prostatectomy		N/A	
2. <input checked="" type="radio"/> Radiation to the pelvis (external beam, proton beam, cyberknife, etc.)	2020		<input checked="" type="radio"/>
3. <input type="radio"/> Brachytherapy/seeds		N/A	<input type="radio"/>
4. <input type="radio"/> Cryosurgery/cryoablation		N/A	<input type="radio"/>
5. <input type="radio"/> High intensity focused ultrasound (HIFU)		N/A	<input type="radio"/>

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 36 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](mailto:ohra@hsph.harvard.edu).
- h. If you have any questions regarding the study itself, please call the study Research Assistant at 617-384-8664.

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 2020, 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? [Month/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?

- No - continue to question 3
Yes - found at diagnosis (continue to question 3)
Yes - found after diagnosis (please complete the box below)

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2a. At which site(s) were you diagnosed with metastases? Please mark all that apply.

- Lymph nodes Date diagnosed: [Month/Year]
Bone Date diagnosed: [Month/Year]
Other organs, specify: [ ] Date diagnosed: [Month/Year]

Grid for office use only with columns for dates (Before 2020, 2020-2021, 2022-2023) and rows for sites (1-12).

2b. How were your metastases verified? Please mark all that apply.

- Imaging (bone scan, CT, MRI, PSMA scan, PET)
Metastatic biopsy
Other, specify: [ ]

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

- No
Yes
If yes, what date? [Month/Year]

4. Has your doctor ordered genomic testing of a sample of your tumor (such as Oncotype DX Prostate, Decipher, Prolaris, Promark)?

- No
Yes
Do not know
If yes, would you be willing to share the results with us?
No
Yes (if yes, we may contact you to ask for the test results)

5. Have you had a blood test that gives information about cancer risk inherited within families?

- No
Yes, test(s) ordered through a doctor
Yes, test(s) ordered commercially (23andMe, etc.)
If yes, would you be willing to share the results related to cancer risk with us?
No
Yes (if yes, we may contact you to ask for the test results)
Do not know

PLEASE TURN PAGE OVER

Grid for office use only with columns for dates (2022, 2023, 2024) and rows for sites (1-12).

3/8 PERM

6. The following asks about family history of cancer in your siblings and your children.

Did any of your siblings or children have... (mark if yes)	PROSTATE CANCER	LUNG CANCER	COLON OR RECTAL CANCER	MELANOMA	BREAST CANCER	PANCREATIC CANCER	LYMPHOMA
Sister(s)	N/A	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brother(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daughter(s)	N/A	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Son(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please answer the following questions by darkening the appropriate circle. All questions are about your health and symptoms in the LAST MONTH. Select one answer for each question.

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

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

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

- Total control     Occasional dribbling     Frequent dribbling     No urinary control

9. 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

10. 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	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pain or burning with urination	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weak urine stream/incomplete bladder emptying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Need to urinate frequently	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. 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
Rectal pain or urgency of bowel movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Increased frequency of your bowel movements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall problems with your bowel habits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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

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

- Very good     Good     Fair     Poor     Very poor to none

**13. 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

**14. 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

**15. Have you used any of the following erectile dysfunction medications or treatments?**

NAME OF MEDICATION/TREATMENT	STARTED COURSE BEFORE 2020	2020	2021	2022	2023	CURRENTLY TAKING
<input type="radio"/> None						
<input type="radio"/> Viagra, Levitra, Cialis (sildenafil)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/> Intraurethral/penile injectable medications; Vacuum devices; penile prosthesis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/> Testosterone replacement therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**16. How large a problem, if any, has each of the following been for you during the LAST MONTH?**

	No problem	Very small problem	Small problem	Moderate problem	Big problem
Hot flashes or breast tenderness/enlargement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**17. During the past week:**

	Not at All	A Little	Quite a Bit	Very Much
Have you had difficulty remembering things?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Has your physical condition or medical treatment interfered with your <b>family</b> life?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Has your physical condition or medical treatment interfered with your <b>social</b> activities?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
Has your physical condition or medical treatment caused you <b>financial</b> difficulties?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4

**18. In the past month, how often do you feel that you lack companionship?**

- Hardly ever     Some of the time     Often

**19. In the past month, how often do you feel left out?**

- Hardly ever     Some of the time     Often

**20. In the past month, how often do you feel isolated from others?**

- Hardly ever     Some of the time     Often

21. For each question, please mark the <u>one</u> answer that comes closest to the way you have been feeling.	Not at All	A Little	Quite a Bit	Very Much	21
Do you have any trouble doing strenuous activities like carrying heavy shopping bags or a suitcase?	①	②	③	④	
Do you have any trouble taking a <b>long</b> walk?	①	②	③	④	
Do you have any trouble taking a <b>short</b> walk outside the house?	①	②	③	④	
Do you need to stay in bed or a chair during the day?	①	②	③	④	
Do you need help with eating, dressing, washing yourself or using the toilet?	①	②	③	④	

22. During the past week:	Not at All	A Little	Quite a Bit	Very Much	22
Were you limited in doing either your work or other daily activities?	①	②	③	④	
Were you limited in pursuing your hobbies or other leisure activities?	①	②	③	④	
Were you short of breath?	①	②	③	④	
Have you had pain?	①	②	③	④	
Have you had bone pain?	①	②	③	④	
Did you need rest?	①	②	③	④	
Have you had trouble sleeping?	①	②	③	④	
Have you felt weak?	①	②	③	④	
Have you lacked appetite?	①	②	③	④	
Have you felt nauseated?	①	②	③	④	
Have you vomited?	①	②	③	④	
Have you been constipated?	①	②	③	④	
Have you had diarrhea?	①	②	③	④	
Were you tired?	①	②	③	④	
Did pain interfere with your daily activities?	①	②	③	④	
Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	①	②	③	④	
Did you feel tense?	①	②	③	④	
Did you worry?	①	②	③	④	
Did you feel irritable?	①	②	③	④	
Did you feel depressed?	①	②	③	④	





**31. Please read the *entire* list of medications and treatments for prostate cancer and prostate cancer symptoms and mark all of the treatments that you have had SINCE JANUARY 2020.**

**31a. Have you ever had any treatment for your prostate cancer?**

- No  Yes  Active Surveillance / Watchful Waiting Only

**31b. Since January 2020, have you had any treatment or medications for your prostate cancer?**

- No  Yes – please fill out the following table (31c)

31c. Treatment/medication since January 2020 only	Dates of Treatment (Year)		...Currently doing/taking?	FOR OFFICE USE ONLY		
	Start	End		Treatment Code:	Start year:	End year:
<b>Procedures</b>	<b>Year</b>	<b>Year</b>		1 2 3 4 5 6 7 8 9 T	Before 2020	
1. <input type="radio"/> Radical prostatectomy		N/A		10 11 12 13 14 15 16 17 18	<input type="radio"/> 2020 <input type="radio"/> 2021	
2. <input type="radio"/> Radiation to the pelvis (external beam, proton beam, cyberknife, etc.)			<input type="radio"/>	19 20 21 22 23 24 25 26 27	<input type="radio"/> 2022 <input type="radio"/> 2023	
3. <input type="radio"/> Brachytherapy/seeds		N/A	<input type="radio"/>	28 29 30 31 32	<input type="radio"/> 2020 <input type="radio"/> 2021	
4. <input type="radio"/> Cryosurgery/cryoablation		N/A	<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
5. <input type="radio"/> High intensity focused ultrasound (HIFU)		N/A	<input type="radio"/>			
<b>Oral medications</b>	<b>Year</b>	<b>Year</b>				
6. <input type="radio"/> Casodex (bicalutamide), Eulexin (flutamide)			<input type="radio"/>	1 2 3 4 5 6 7 8 9 T	Before 2020	
7. <input type="radio"/> Estrogens and DES			<input type="radio"/>	10 11 12 13 14 15 16 17 18	<input type="radio"/> 2020 <input type="radio"/> 2021	
8. <input type="radio"/> Nilandron (nilutamide)			<input type="radio"/>	19 20 21 22 23 24 25 26 27	<input type="radio"/> 2022 <input type="radio"/> 2023	
9. <input type="radio"/> Zytiga (abiraterone)			<input type="radio"/>	28 29 30 31 32	<input type="radio"/> 2020 <input type="radio"/> 2021	
10. <input type="radio"/> Xtandi (enzalutamide)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
11. <input type="radio"/> Lynparza (olaparib)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
12. <input type="radio"/> Erleada (apalutamide)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
13. <input type="radio"/> Nubeqa (darolutamide)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
14. <input type="radio"/> Rubraca (rucaparib)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
15. <input type="radio"/> Zejula (niraparib)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
16. <input type="radio"/> Talzenna (talazoparib)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
17. <input type="radio"/> Orgovyx (relugolix)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
<b>Injections/implants/infusions</b>	<b>Year</b>	<b>Year</b>				
18. <input type="radio"/> Lupron/Eligard/Viadur (leuprolide)			<input type="radio"/>	1 2 3 4 5 6 7 8 9 T	Before 2020	
19. <input type="radio"/> Zoladex (goserelin)			<input type="radio"/>	10 11 12 13 14 15 16 17 18	<input type="radio"/> 2020 <input type="radio"/> 2021	
20. <input type="radio"/> Trelstar (triptorelin)			<input type="radio"/>	19 20 21 22 23 24 25 26 27	<input type="radio"/> 2022 <input type="radio"/> 2023	
21. <input type="radio"/> Plenaxis (abarelix)			<input type="radio"/>	28 29 30 31 32	<input type="radio"/> 2020 <input type="radio"/> 2021	
22. <input type="radio"/> Firmagon (degarelix)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
23. <input type="radio"/> Vantas (histrelin)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
24. <input type="radio"/> Zometa (zoledronic acid)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
25. <input type="radio"/> Xgeva (denosumab)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
26. <input type="radio"/> Jevtana (cabazitaxel)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
27. <input type="radio"/> Taxotere (docetaxel)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
28. <input type="radio"/> Provenge (sipuleucel-T)			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
29. <input type="radio"/> Xofigo (Radium-223)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
30. <input type="radio"/> <sup>177</sup> Lu-PSMA-617			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	
31. <input type="radio"/> Keytruda (pembrolizumab)			<input type="radio"/>		<input type="radio"/> 2020 <input type="radio"/> 2021	
32. <input type="radio"/> OTHER, specify:			<input type="radio"/>		<input type="radio"/> 2022 <input type="radio"/> 2023	

**Thank you for your participation!**

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

1	1	1	1	1	1	1	1	1	1
2	2	2	2	2	2	2	2	2	2
4	4	4	4	4	4	4	4	4	4
8	8	8	8	8	8	8	8	8	8
P	P	P	P	P	P	P	P	P	P

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