

NHANES PSA FOLLOUP QUESTIONNAIRE
2003-2004 Version

I am calling from the NHANES program. You participated in our examination survey in *Month/Year*, and on *month/day/year* you were mailed a letter with your PSA test result (also known as the Prostate Specific Antigen test).

Interviewer Instructions: *Explain what letter this is.*

The PSA is a screening test for prostate cancer and other prostate diseases. The PSA results notification letter is different from the complete report of findings that you received. You may have also received letters notifying you of results of tests such as glucose, liver function tests, or cholesterol, for example. The PSA letter that I am talking about had only your PSA test results.

1 (PSQ010). Did you receive a letter in the mail with your PSA test results?

- (1) Yes
- (2) No → <verify address, further describe letter and fact sheet, if absolutely no recall, resend letter, follow-up in two months> **(Give PSA test result to participant over the phone and answer any questions that participant may have about PSA test.) End interview. Remind participant that she/he will be contacted again in 2-3 months for a short telephone interview.**

I would like to ask you some questions about the PSA test (also known as the Prostate Specific Antigen test) and any follow-up you may have taken since getting the letter. The interview will take about 15 minutes. The information will be used by the Centers for Disease Control and Prevention to help researchers understand men's knowledge of the PSA test and prostate problems. All the information you provide is strictly confidential, your participation is voluntary. No penalties or loss of benefits will come from refusing to participate. You may refuse to answer any question you do not want to answer, and you may discontinue the interview at any time without having any effect on you.

(PSQ015) May we proceed with the interview?

If "yes", go to Question 2. If not - set up an appointment for a better time, or note the reason for the refusal.

2 (PSQ020). Before you participated in the NHANES survey, did you hear of the PSA test somewhere else?

- [1]. Yes (go to Question 3)
- [2]. No (go to Question 4)
- [3]. Heard of PSA, but do not know what the test is for (go to Question 3)
- [7]. Refused (go to Question 4)
- [9]. Don't know (go to Question 4)

3 (PSQ030). Where did you hear about the PSA test?, was it from.....(read responses....)

Check: [1] Yes [2] No [7] Refused [9] Don't Know

- [PSQ030A]. A friend or relative
- [PSQ030B]. A doctor
- [PSQ030C]. A health brochure
- [PSQ030D]. Television
- [PSQ030E]. Radio
- [PSQ030F]. Other

4(PSQ040). To your knowledge, did you ever have a PSA test before you were tested in our survey?

- [1]. Yes
- [2]. No (go to 11)
- [7]. Refused (go to 11)
- [9]. Don't know (go to 11)

5 (PSQ050) How long ago did you have your first PSA test? Would you say it was....

- [1]. One year or less
- [2]. 2 to 5 years
- [3]. More than 5 years
- [7]. Refused
- [9]. Don't know

6 (PSQ060) Was the test result in our letter the first time you were told you had a high PSA test result?

- [1]. Yes (go to Question 8)
- [2]. No
- [7]. Refused (go to Question 8)
- [9]. Don't know (go to Question 8)

7 (PSQ070) For about how long have you known that your PSA was high? Would you say...

- [1]. One year or less
- [2]. 2 to 5 years
- [3]. More than 5 years
- [7]. Refused
- [9]. Don't know

8 (PSQ080) Think about your first PSA test. Did you specifically request the test...or was the decision made by your health care provider?

- [1]. I specifically requested the test
- [2]. Health care provider (go to Question 10)
- [7]. Refused (go to Question 11)
- [9]. Don't know (go to Question 11)

9 (PSQ090). Men get the PSA test for different reasons. Please answer “yes” if any of the following reasons were true for you.

[READ EACH RESPONSE OPTION AND WAIT FOR A YES/NO ANSWER]

You requested the test because....

Check: [1] Yes [2] No [7] Refused [9] Don't Know

- [PSQ090A]. You had prostate problems like frequent urination.
- [PSQ090B]. Your wife or partner convinced you to have the test.
- [PSQ090C]. The PSA test was offered at a health fair or community event.
- [PSQ090D]. Men in your family had prostate cancer.
- [PSQ090E]. People of your race or ethnicity are more likely to develop prostate cancer
- [PSQ090F]. You had another reason

Go to Question 11

10 (PSQ100) Health care providers order PSA tests for different reasons. Please answer “yes” if any of the following reasons are true.

[READ EACH RESPONSE OPTION AND WAIT FOR A YES/NO ANSWER]

Check: [1] Yes [2] No [7] Refused [9] Don't Know

Your health care provider ordered a PSA test....

- [PSQ100A]. As part of routine screening for your age
- [PSQ100B]. Because men in your family had prostate cancer
- [PSQ100C]. You had prostate problems like frequent urination.
- [PSQ100D]. An enlarged prostate was detected during your physical exam.
- [PSQ100E]. Because men of your race/ethnicity are more likely to develop prostate cancer.
- [PSQ100F]. Your wife or partner asked the doctor to check your PSA level.

Now I'm going to ask you some questions about what you have done since finding out that your PSA test result was high.

11 (PSQ110) Did you see a doctor or other health professional about your high PSA test result?

- [1]. Yes [skip to Question 13]
- [2]. No
- [7]. Refused
- [9]. Don't know

12 (PSQ120) Do you have an appointment to see a doctor or other health care professional about your high PSA test result?

- [1]. Yes [skip to Question 21]
- [2]. No [skip to Question 21]
- [7]. Refused [skip to Question 21]
- [9]. Don't know [skip to Question 21]

13 (PSQ130) Think back to when your doctor explained what a high PSA result means. Answer "yes" if you remember hearing your doctor tell you any of the following statements.

[READ EACH STATEMENT AND WAIT FOR A YES/NO RESPONSE.]

Check: [1] Yes [2] No [7] Refused [9] Don't Know

A high PSA could mean....

- [PSQ130A].** You may have an inflamed prostate gland.
- [PSQ130B].** You may have an enlarged prostate gland.
- [PSQ130C].** You may have prostate cancer.
- [PSQ130D].** Your result was a possible laboratory error
- [PSQ130E].** Other

14 (PSQ140) When you saw a doctor or other health professional about your high PSA test result, did you have other tests or procedures to check your prostate for possible problems?

- [1]. Yes
- [2]. No (skip to Question 18)
- [7]. Refused (skip to Question 18)
- [9]. Don't know

15 (PSQ150) Did you have a prostate biopsy?

- [1]. Yes
- [2]. No (skip to Question 18)
- [7]. Refused (skip to Question 18)
- [9]. Don't know (skip to Question 18)

16 (PSQ160) Do you know the results of you prostate biopsy?

- [1]. Yes
- [2]. No (skip to Question 18)
- [7]. Refused (skip to Question 18)
- [9]. Don't know (skip to Question 18)

17 (PSQ170) What did your prostate biopsy show?

[INTERVIEWER: READ EACH STATEMENT WITH ITS NUMBER AND CHECK ANY THAT APPLY]

- Check: [1] Yes [2] No [7] Refused [9] Don't Know
- Your biopsy showed...
- [PSQ170A].** An inflammation of your prostate gland
 - [PSQ170B].** Normal prostate tissue
 - [PSQ170C].** Prostate cancer.
 - [PSQ170D].** Other

18 (PSQ180) Did your doctor or health care professional tell you that you need treatment for your prostate condition?

- [1]. Yes
- [2]. No (skip to Question 21)
- [7]. Refused (skip to Question 21)
- [9]. Don't know (skip to Question 21)

19 (PSQ190) Did you receive (or are you currently receiving) the treatment that your doctor recommended?

- [1]. Yes (skip to Question 21)
- [2]. No
- [7]. Refused (skip to Question 21)

[9]. Don't know (skip to Question 21)

20 (PSQ200) Why did you decide not to get treated? (Chose all that apply)

[READ EACH RESPONSE OPTION AND WAIT FOR A YES/NO RESPONSE]

Check: [1] Yes [2] No [7] Refused [9] Don't Know

Was it because ...

- [PSQ200A]. The side effects to the treatment are unpleasant.
[PSQ200B]. The results following treatment is uncertain
[PSQ200C]. The treatment is too expensive.
[PSQ200D]. There is hope of better treatment in the future.
[PSQ200E]. You decided to wait and see how the condition progresses (Watchful waiting).
[PSQ200F]. You were afraid.
[PSQ200G]. Or is there some other reason?

We would like to know what you have learned about the PSA test and prostate problems that may be associated with high PSA test results. Please tell me if you believe the following statements are true, false, or if you don't know.

21 (PSQ210) Although it is possible that men who have a high PSA may have prostate cancer, they probably just have a large prostate.

- [1]. True
[2]. False
[7]. Refused
[9]. Don't know

22 (PSQ220) Additional tests are usually required for your doctor to determine if a high PSA is caused by cancer or some other condition.

- [1]. True
[2]. False
[7]. Refused
[9]. Don't know

23 (PSQ230) Some men who develop prostate cancer live to be 70 years of age or more.

- [1]. True
[2]. False
[7]. Refused

[9]. Don't know

24 (PSQ240) Some men who develop prostate cancer may have rapid disease and die within five years.

- [1]. True
- [2]. False
- [7]. Refused
- [9]. Don't know

25 (PSQ250) Men are at a higher risk for developing prostate cancer if they have more than one relative, their father, or a brother that have been diagnosed with prostate cancer.

- [1]. True
- [2]. False
- [7]. Refused
- [9]. Don't know

26 (PSQ260) African American men have a higher risk of developing prostate cancer compared to other racial/ethnic groups.

- [1]. True
- [2]. False
- [7]. Refused
- [9]. Don't know

27 (PSQ270) There are several different types of treatment available to men diagnosed with prostate cancer.

- [1]. True
- [2]. False
- [7]. Refused
- [9]. Don't know

28 (PSQ280) Almost all options for treating and managing prostate cancer have some risk of side effects, including, loss of bladder control and problems with sexual performance.

- [1]. True
- [2]. False
- [7]. Refused
- [9]. Don't know

29 (PSQ290) There are support groups for men with prostate cancer.

- [1]. True

- [2]. False
- [7]. Refused
- [9]. Don't know

End Interview

Thank you for your time. We want to emphasize that everything you have told us will be held strictly confidential. We appreciate your participation in the National Health and Nutrition Examination Survey.

If you have any questions about this study, you may call Dr. Kathryn Porter of the U.S. Public Health Service at 1-800-452-6115. If you have questions about your rights as a research participant, call the Institutional Review Board Chair at 1-800-223-8188.

30 (PSQ300) What language was used for the interview?

- [1]. English
- [2]. Spanish
- [3]. English and Spanish
- [4]. Other