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13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information) The purpose of this study was to obtain information on the level of knowledge, beliefs, and screening practices of men with a family history of prostate cancer. Names of prostate cancer cases were obtained from the Los Angeles County Registry, and cases were contacted and asked to provide contact information for their first-degree relatives. Surveys were completed with 1029 first-degree relatives. We obtained an ethnically diverse sample of first-degree relatives (34% of sample was White, 26% African-American, 22% Hispanic, and 17% Asian). The majority of our sample was married, over 60 years old, well educated, earned an income of over \$55,000, and had some health insurance. Most did not endorse many barriers to screening or significant cancer-related distress. Most relatives had some knowledge of risk factors. The vast majority reported having a digital rectal exam sometime in their life (76%) however less had one during the past year. Prostate specific antigen (PSA) testing receipt was lower. Fifty-six percent of relatives reported having had a PSA test sometime in their lifetime whereas 43% reported having a PSA test during the last year. Demographic, knowledge, and attitudinal factors emerged as bivariate and multivariate predictors of PSA receipt in the past year.				
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INTRODUCTION

The purpose of this study was to conduct telephone surveys with first degree relatives of prostate cancer cases to obtain information on knowledge, behavior and psychological distress associated with risk status. The research questions that were addressed included: What do high-risk men know about prostate cancer? What is the level of psychological distress associated with knowledge of risk status? What is the personal cost-benefit ratio for these men when balancing their increased risk for the disease against the morbidity associated with treatment? What are the rates of usage of DRE and PSA in this population? What are the prevalent attitudes and beliefs in this group regarding prostate cancer screening and participation in clinical trials? Are there differences in knowledge, attitudes, behaviors, and psychological distress between different ethnic groups? What demographic, health care system, knowledge, and attitude factors are related to participation in screening and willingness to participate in clinical trials? We used a population-based cancer registry, the Cancer Surveillance Program (CSP) of Los Angeles, to obtain a sample of prostate cancer cases diagnosed in Los Angeles County over a four year period (1997-2000). We contacted cases to request relative information. Then we contacted relatives and asked them to participate in a brief survey, by telephone, on prostate cancer. We planned to conduct surveys with 250 African American and 250 White relatives. The study was continuously approved by the UCLA Human Subject Committee throughout its course.

FINAL REPORT BODY

The funding for this study was received at the end of October 1998, which reduced the first year of the study to 10 months, causing some of the first year's activities to extend into Year 2. In Year 2 we were able to complete all of Task 1 and get well into activities related to Tasks 2, 3 and 5. In the first 6 months of year 3, we completed Tasks 2, 3, and 5. We focused on Tasks 4 and 6 during the no-cost extension. The following section describes some of the major accomplishments associated with each task.

Task 1

Questionnaire (Appendix 1)

In the first year of the study, we conducted a total of 13 focus groups with men from four ethnic groups (52 African-American, 39 Caucasian, 29 Hispanic, 20 Filipino). We also pilot tested the telephone survey with 80 prostate cancer cases and their relatives. Using our focus group and pilot findings, we modified and finalized our survey. It was translated into Spanish and programmed into our Computer Assisted Telephone Interviewing (CATI) database in both languages. The following domains, based on the Adherence Model, were included in the survey:

1. Medical History
2. Family History of Prostate Cancer
3. Psychological Distress
4. Past Adherence
5. Communication with Doctor
6. Demographics
7. Knowledge of Risk Factors
8. Perceived Susceptibility
9. Beliefs in Benefits vs. Costs
10. Subjective Norms
11. Fatalism
12. Social Supports
13. Barriers and Facilitators
14. Knowledge of Screening Guidelines
15. Past Participation, Intentions & Knowledge of Clinical Trials
16. Demographics
17. Health Care Benefits & Coverage

Task 2:

Recruitment

a) Development of ethnically specific recruitment materials (Appendix 2)

We used focus group participant suggestions to develop full-color ethnically specific recruitment materials. We designed separate tri-fold pamphlets for cases and relatives. These pamphlets included information about the purpose of the study and what participation would entail for cases and relatives. Separate pamphlets were designed for each ethnicity (African-American, Asian, White, and Hispanic) and displayed a culturally relevant graphic theme designed to emphasize the specificity of the study to each ethnic community.

b) Cases received from the California Tumor Registry

In total, we received 14,661 prostate cancer cases from the registry (after deleting duplicates) that were still alive. Five thousand three hundred and eighteen cases were diagnosed in 1997, 4577 cases in 1998, 4248 in 1999, and 518 in 2000. As mentioned in our previous annual reports, originally we had proposed to contact cases diagnosed in 1998 and 1999. However, we expanded our recruitment criteria to include 1997. This turned out to be beneficial for the study overall, because reporting of the 1997 cases was much more complete than that of the 1998 cases at the time when we requested these cases. In addition, we obtained available non-white cases diagnosed in 2000 to increase our sample in selected ethnic groups. We received new cases from the Los Angeles Cancer Surveillance Program approximately every two months throughout the course of the project until we discontinued receipt of new cases in January of 2001. We sent 5197 letters (and if needed a second request letter) to physicians to inform them of the study. Physicians of 123 patients recommended we not contact the cases for various reasons, and 110 cases were identified as deceased through physician contact.

c) Cases Contacted

Although we were funded to conduct the study with only African American and White men, we expanded the study to Hispanic and Asian men as well, because of the dearth of existing information on these groups. We contacted a total of 1054 African American cases, 700 Hispanic cases, 973 Asian cases, and 1276 White cases (4003 total cases contacted). Stratified random sampling was used to select White cases in all years. Age was used as the stratifying variable, with 20% of cases being selected from those diagnosed before age 60. Of cases contacted, 1232 did not provide relatives due to the following reasons; case deceased, language ineligible, had no eligible relatives, living outside the US, health problem prevented telephone contact, or no history of prostate cancer. For 636 cases, we did not have valid contact information and were unable to obtain the appropriate information. For an additional 386 cases, we were unable to reach them by mail or by telephone after 10 attempts. We **recruited** a total of 299 African American, 203 Hispanic, 231 Asian, and 412 White cases (1145 total cases) that provided information on at least one male relative between the ages of 40-75. An additional 604 cases refused to provide information about their first-degree relatives resulting in a refusal rate of 35% (604/1749).

d) Relatives Recruited

We received information regarding a total of 653 African American, 457 Hispanic, 498 Asian, and 807 White **relatives** from consenting index cases. Of these, 468 African Americans, 314 Hispanics, 281 Asians, and 531 Whites were eligible for our study based on age, language,

and no previous history of prostate cancer. We contact, by mail or telephone, these 1594 relatives.

Task 3

Interviewers

In year 1 we recruited and trained a total of 6 part-time interviewers for this project. We hired at least one interviewer to match each ethnic group and several interviewers were English-Spanish bilingual. In year 2, due to the large volume of cases and relatives needed to be contacted in a timely manner (and some attrition in our interviewer staff), we hired and trained an additional 6 interviewers. In Year 3 we had 5 interviewers remaining and trained 3 additional interviewers to help complete the remaining surveys and recruitment calls. In year four we had 3 interviewers remaining and hired several additional interviewers to work on the present study and a second study utilizing telephone interviews.

Interviewers were supervised during all day, evening, and weekend shifts. A 5% random sample of respondents were called back to verify that the interview was conducted. Interviewers were debriefed on a monthly basis and retrained as necessary.

Telephone Interviews

We **completed** a total of 1029 surveys (272 African American, 228 Hispanic, 175 Asian, 354 Whites.) One hundred forty-eight of the contacted relatives did not speak English or Spanish, reported having had prostate cancer, were deceased, could not completed interview due to health problem, reported being either younger than 40 or older than 75, were not related by blood to the case, or were no longer living in the country. For sixty-eight relatives we had inaccurate contact information and were not able to locate the correct information. There were also a significant percentage of relatives (19% of contacted relatives) that did not respond to our invitation by mail and whom we were not able to reach by telephone after 10 attempts. One hundred and twelve relatives refused to participate resulting in a refusal rate of 10% (112/1141). We adapted our telephone survey into a brief mail survey in the hope of reaching some of these hard-to-reach relatives (See Appendix 3). The mailed survey contained the following items, also found in the telephone survey:

- age
- health history
- family history
- screening tests and recency of last test (if ever)
- education
- country of birth
- years in the U.S.
- ethnicity
- income

- marital status
- date of birth
- likelihood of getting screened within 12 months
- participation in clinical trials
- health insurance status

Thirty-one relatives completed the mailed survey. These relatives are included in the 1029 completed surveys reported above.

Task 4

Validation of Self-Reported Screening

A validation form was developed to obtain information from subjects' physicians regarding the dates of receipt of Prostate Specific Antigen (PSA) testing in order to validate subject self-report. The validation forms were sent to all subjects with complete contact information (N = 1003). This mailing was started in the spring of 2000 and the last mailing to relatives was completed in January of 2002. The validation form utilized required the signature of each patient, to authorize release of his or her medical information. Initially we sent a letter to every relative that completed the survey requesting written permission to contact his health care provider for validation (see Appendix 4). Later we decided to request verbal permission from relatives during the telephone interview before sending the letter to the relative to request written permission (see Appendix 5). From that point forward, we sent letters requesting written permission for validation only for those relatives who verbally consented during the interview. Reminder letters were mailed to subjects as necessary. Two Hundred Eight-Eight relatives signed the validation form and returned it to us. When the signed validation form was returned to us, we in turn mailed it to their noted physician to obtain the screening information. If necessary, follow-up calls were placed to physicians who did not return the form. See Appendices 4-7 for the validation letters to subjects, physicians and the validation form. All 288 validation forms were sent to physicians requesting validation of self-reported screening behavior through medical record review. Two weeks following the initial mailings to providers requesting validation information, follow-up reminder calls were conducted to remind physicians that did not respond to our mailing to provide validation information. Validation information was obtained for a total of 240 relatives out of the 288 who consented to the validation process through mail and telephone contact with physicians (83% of relatives who consented to validation).

Task 5

Database Management

Project staff conducted regular checks and clean up of our tracking databases for case and relative recruitment for accuracy and consistency of data entry and data coding. Survey data were collected using Computer Assisted Telephone Interviewing (CATI), thereby reducing interviewer error in following questionnaire skip patterns (skips are made automatically by the computer); eliminating out of range responses and missing data (a valid response is required in

order to proceed to the next screen); eliminating the need for coding of most data; and providing immediate access to response frequencies at any time-point in the project. The CATI system generates daily production statistics and detailed reports of interviews completed during the session as well as refusals, scheduled call backs, and non-working phone numbers.

Task 6

Final Analysis and Report Writing

During year 4 (i.e., no cost extension period) the final analysis and final report were completed. The following were completed in regards to this task: conducted item analysis of measures to ensure adequate psychometric properties, examined clustering of responses within family units, intraclass correlations among key variables, and conducted logistic regression analyses, and examined data from the validation study to determine the extent of correspondence between self-reports and chart data.

KEY RESEARCH ACCOMPLISHMENTS

- finalized the questionnaire
- translated questionnaire into Spanish
- finalized the Computer Assisted Telephone Interviewing (CATI) program
- adapted the survey questionnaire into a brief survey to mail to difficult to reach relatives
- translated the brief mail survey into Spanish
- obtained prostate cancer cases diagnosed in 1997, 1998, 1999, and 2000
- contacted physicians of cases diagnosed in 1997, 1998, 1999, and 2000
- developed tracking databases for case and relative recruitment
- trained an additional group of male and female interviewers in study objectives, content of telephone survey, basic probing techniques, cultural sensitivity and communication skills, respondent follow-up protocols and CATI operations
- recruited and completed surveys with a total of 1029 eligible relatives
- obtained permission of 282 relatives to validate self-report of screening through physician verification/medical record review
- validation information was obtained for 210 of 282 consenting relatives (83% of consenting relatives)
- completed analyses and final report

REPORTABLE OUTCOMES

Sample Characteristics

Characteristics of the baseline sample in percentages are represented below in Table 1. Overall, the majority of the sample was married (79%), over the age of 60 (74%), had at least a college education (70%), and had an income of \$55,000 or higher (57%). Chi-square analyses revealed ethnic differences for education, income, and proportion of sample born in the U.S. In general, White and Asian relatives had the highest levels of education and income. As expected, Hispanic and Asian relatives had had a substantial proportion of relatives born outside of the U.S..

Table 1 Demographic Characteristics of Baseline Respondents.¹

Variable	White (N = 354)	Black (N = 272)	Hispanic (N = 228)	Asian (N = 175)	Total (N = 1029)
Age in years	% of sample	% of sample	% of sample	% of sample	% of sample
Age ≤ 60	24	31	22	25	26
Age > 60	76	69	78	75	74
Education					
High school and below	24	37	47	9	30
College and above	76	63	53	91	70
Incomes*					
Below \$55K	31	57	57	33	43
\$55K and above	69	43	43	67	57
Marriage					
Yes	80	75	80	85	79
No	20	25	20	15	21
Born in U.S.					
Yes	94	98	58	47	79
No	6	2	42	53	21

¹ Shaded areas indicate significant Chi-squared test $p < .05$.

Health Insurance

Overall, the majority of our sample had some type of health insurance (86%) and of those, the majority reported that their health insurance would cover the cost of a PSA test (60%). Chi-square analyses revealed numerous ethnic differences in regards to insurance variables. In general, Blacks and Hispanics reported the highest rate of being uninsured. White relatives reported the highest rate of fee-for-service insurance.

Table 2. Health Insurance Questions.²

Question		Response	White (N = 354)	Black (N = 272)	Hispanic (N = 228)	Asian (N = 175)	Total (N = 1029)
			%	%	%	%	%
Health Insurance Type ³	Q81-Q84c	Uninsured	7	11	16	6	10
		Other:	90	82	79	92	86
		HMO	39	61	54	50	50
		PPO	31	25	21	21	26
		FFS	43	32	33	33	37
		Medicare	16	22	14	22	18
		Medicaid	4	10	7	7	6
Does your health insurance cover PSA?	Q85	No	5	2	2	3	3
		Yes	58	58	53	60	60
		Not Insured	7	11	15	6	9
		Don't Know	30	20	31	31	28

² Shaded areas indicate significant Chi-squared test $p < .05$.

³ These column percentages do not sum to 100%, due to the fact that there is overlap between groups.

Barriers to Screening

Table 3 includes the percentage of the sample endorsing barriers to screening by ethnicity and across the sample as a whole. Overall, the majority of the sample did not endorse many barriers to screening such as cost, problems with transportation to clinic, or fear that PSA would show cancer. Chi-square analyses indicated a number of significant ethnic differences in reported barriers to prostate cancer screening. Blacks and Hispanics were most likely to report that they would have difficulty paying for a PSA test. Barriers were added up into a barrier score that was used in the multivariate prediction of PSA screening status (see page 26).

Table 3. Reported Barriers to Prostate Cancer Screening.⁴

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
		%	%	%	%	%	%
Aware should get DRE yearly?	Q62	No	39	46	48	49	45
		Yes	61	64	52	51	55
Know should get PSA yearly?	Q63	No	47	51	56	50.00	50
		Yes	53	49	44	50.00	50
Fearful of getting tested?	Q64	Not Yes	91	92	89	84	90
		Yes	9	8	11	16	11
Is getting PSA important to you?	Q65	Not Yes	15	14	14	16	15
		Yes	85	86	86	84	85
Difficult to pay for PSA?	Q66	Not Yes	91	82	80	90	87
		Yes	9	18	20	10	14
Worried PSA show cancer?	Q67	Not Yes	85	90	77	76	83
		Yes	15	10	23	24	17
Curable if found early?	Q68	Not Yes	9	10	7	5	8
		Yes	91	90	93	95	92
Can DRE cause sex problems?	Q70	Not Yes	99	94	84	96	94
		Yes	1	6	16	4	6
Have problem with doctor transportation?	Q71	Not Yes	98	95	97	97	97
		Yes	2	5	3	3	3
Only need PSA if recommended?	Q72	Not Yes	81	73	64	57	71
		Yes	20	28	36	43	30

⁴ Shaded areas indicate significant Chi-squared test $p < .05$.

PSA Testing

Although there are no official screening guidelines for PSA at this time, the majority of respondents (77%) believed that high risk men such as themselves should begin to have PSA tests beginning no later than age 40 and 75% reported that men should have at least one PSA test every year.

Table 4. PSA Testing. ⁵

Question		Response (N = 354)	White (N = 272)	Black (N = 272)	Hispanic (N = 228)	Asian (N = 175)	Total (N=1029)
At what age should a high-risk man have his first PSA?	Q86	30	15	30	23	20	22
		40	60	55	58	46	56
		50	22	14	16	27	20
		60	3	2	3	7	3
How often should a man such as yourself have a PSA?	Q87	Every 6 m	3	11	6	7	7
		Yearly	76	75	78	71	75
		2-3 Years	18	12	11	20	15
		> 3 Years	3	3	11	4	33

⁵ Shaded areas indicate significant Chi-squared test $p < .05$.

Social Factors and Screening

The majority of our sample reported that at least some members of their social network get prostate cancer screening (86%). Approximately 45% of the sample reported discussing their personal risk for getting prostate cancer with their friends and family and 46% reported discussing their personal risk for getting prostate cancer with their physician. Chi-square analyses revealed significant ethnic differences on social factors. Hispanic relatives were least likely to report that their family members and/or friends received prostate cancer screening.

Table 5. Social Factors and Screening.⁶

Question		Response (N=354)	White (N=272)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
How many friends and family get checked for prostate cancer?	Q77	Most	38	29	16	33	30
		Few	56	60	56	54	57
		None	6	12	28	14	14
Have you discussed personal risk with friends and family?	Q79	No	54	52	59	62	56
		Yes	46	49	41	38	44
Have you discussed personal risk with your doctor?	Q80	No	51	52	59	53	54
		Yes	49	48	41	48	46

⁶ Shaded areas indicate significant Chi-squared test $p < .05$.

Risk Factor Beliefs

Across the total sample, the majority of relatives accurately identified known risk factors for prostate cancer such as older age (75%) and having relatives with cancer (70%). A number of ethnic differences were revealed for risk factor beliefs. Black and Hispanic relatives were least likely to correctly identify older age and having relatives with prostate cancer as risk factors for prostate cancer. Further, Black and Hispanic relatives were also most likely to endorse risk factors with no known link to prostate cancer such as stress and sitting on cold surfaces.

Table 6. Distribution of Risk Factor Beliefs.⁷

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
Older age	Q59a	Not Yes	20	35	27	19	25
		Yes	80	65	73	82	75
Having relatives with cancer	Q59d	Not Yes	19	38	40	30	31
		Yes	81	62	60	70	69
Certain foods	Q59b	Not Yes	65	51	52	57	57
		Yes	35	49	49	43	43
Stress	Q59c	Not Yes	67	59	63	71	65
		Yes	33	41	37	30	35
Alcohol	Q59e	Not Yes	82	78	67	76	77
		Yes	18	22	33	24	23
Lack of exercise	Q59f	Not Yes	59	57	52	61	57
		Yes	41	43	49	39	43
Exposure to chemicals	Q59g	Not Yes	45	43	37	43	42
		Yes	55	57	63	57	58
Too much sex	Q59h	Not Yes	97	96	89	94	94
		Yes	3	4	11	6	6
Sitting on cold surfaces	Q59i	Not Yes	97	88	89	96	93
		Yes	3	12	11	5	8
Lack of sex	Q59j	Not Yes	84	89	82	86	85
		Yes	16	11	18	14	15

⁷ Shaded areas indicate significant Chi-squared test $p < .05$.

Cancer-Related Distress

Overall, the majority of relatives denied experiencing significant cancer-related worry or fear. In the overall sample, 54% of relatives reported they are "not worried", 50% reported they are "not fearful", and 68% reported they are "not nervous" about getting prostate cancer. Alpha coefficients for these items are reported for each ethnicity and across the total sample. Cancer-related distress items were combined to produce a cancer-related distress summary score, that was used in the multivariate prediction of PSA screening status (See page 26).

Table 7. Cancer-Related Distress.⁸

Question		Response	White	Black	Hispanic	Asian	Total
			(N=354)	(N=272)	(N=228)	(N=175)	(N=1029)
			Alpha=.72	Alpha=.78	Alpha=.69	Alpha=.65	Alpha=.71
How often think about cancer?	Q24	Often	10	21	16	11	14
		Once in a While	69	51	54	53	58
		Never	21	28	30	36	27
How worried about cancer?	Q25	Very Worried	4	6	11	7	7
		Somewhat Worried	41	33	43	39	39
		Not Worried	55	61	46	54	54
How fearful of cancer?	Q26	Fearful	7	11	12	14	11
		Somewhat Fearful	44	34	40	38	40
		Not Fearful	49	55	49	48	50
How nervous about cancer?	Q27	Nervous	3	5	5	7	5
		Somewhat Nervous	26	24	30	32	27
		Not Nervous	71	71	66	61	68
Do you think too often about cancer?	Q28	No	78	82	81	88	81
		Yes	22	18	20	12	19

⁸ Shaded areas indicate significant Chi-squared test $p < .05$.

Perceived Susceptibility to Prostate Cancer

Although all participants were first-degree relatives of prostate cancer patient and thus at elevated risk for getting prostate cancer, a substantial proportion of the sample reported that they are “not likely” to get prostate cancer in their lifetime (26%). Black relatives were most likely to accurately identify Black ethnicity as a risk factor for prostate cancer. White relatives were least likely to rate their likelihood of getting prostate cancer as “not likely.”

Table 8. Perceived Susceptibility to Prostate Cancer⁹

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
Who do you think gets prostate cancer most?	Q60	White	6	1	7	9	6
		Black	23	51	12	11	27
		Hispanic	40	0	12	0	3
		Asian	0	0	0	2	37
		No Difference	70	48	69	78	65
What is the likelihood of getting prostate cancer in your lifetime?	Q61	Very Likely	19	16	17	12	17
		Somewhat Likely	63	50	58	55	57
		Not Likely	18	35	25	33	26

⁹ Chi-squared test $p < .05$.

Screening Rates

The majority of our sample had received a DRE at some point during their lifetime (76%) although a minority reported that their most recent DRE was within the last 12 months (41%). A slightly lower percentage of the sample reported having a PSA at some point during their lifetime (56%) and a smaller percentage of those respondents (43%) indicated having their most recent PSA during the last 12 months. A number of ethnic differences emerged for screening variables. White and Black relatives were most likely to report having had a DRE and a PSA. White and Black relatives were most likely to report having had the screening tests during the last year.

Table 9. Screening Behavior by Race.¹⁰

Question		Response	White	Black	Hispanic	Asian	Total
DRE			(N=354)	(N=272)	(N=228)	(N=175)	(N=1029)
			%	%	%	%	%
Have you ever heard of a DRE?	Q31	No	7	11	10	27	12
		Yes	93	89	90	73	88
Have you ever had a DRE?	Q32	No	16	22	28	36	24
		Yes	84	78	72	64	76
When was your most recent DRE?	Q33	< 1 Year	44	48	31	36	41
		> 1 Years	40	30	41	28	35
		Never	16	23	28	36	24
PSA							
Have you ever heard of a PSA?	Q34	No	9	16	35	27	20
		Yes	91	84	65	73	80
Have you ever had a PSA?	Q37*	No	40	38	54	46	44
		Yes	60	62	45	54	56
When was your last PSA?	Q39*	< 1 Year	43	50	37	42	43
		1-2 Years	14	7	7	10	10
		> 2 Years	3	5	1	2	3
		Never	40	38	56	45	44

¹⁰ Shaded areas indicate significant Chi-squared test $p < .05$.

Table 9. Screening Behavior by Race.¹¹ (continued)

Sig/Col							
Have you ever heard of Sig/Col?	Q42	No	9	16	21	28	17
		Yes	91	84	79	72	83
Have you ever had a Sig/Col?	Q43	No	63	63	72	69	66
		Yes	37	37	38	31	34
When was your most recent Sig/Col?	Q44	≤ 5 Years	38	32	22	27	27
		> 5 Years	9	6	6	4	7
		Never	63	62	72	69	66
FOBT							
Have you ever heard of an FOBT?	Q45	No	29	25	28	27	31
		Yes	71	75	62	63	69
Have you ever taken an FOBT?	Q46	No	61	57	72	64	63
		Yes	40	43	28	36	37
When was your most recent FOBT?	Q47	< 1 Year	15	17	11	14	15
		1-2 Years	7	7	7	9	8
		> 2 Years	16	18	11	13	15
		Never	61	58	72	64	63

¹¹ Shaded areas indicate significant Chi-squared test $p < .05$.

Predicting PSA Receipt (Bivariate predictors)

Demographic Variables as Bivariate Predictors of Lifetime Receipt of PSA

Overall, among demographic variables, age was the only factor predictive of lifetime receipt of a PSA test across the total sample as well as within each ethnic group. Analyses indicated that relatives over the age of 60 were significantly more likely to have had a PSA than relatives under the age of 60. Across the total sample, having a college education or higher predicted an increased likelihood of PSA receipt as compared to relatives with lower levels of education however this relationship was not significant within ethnic groups. Income level similarly was predictive of an increased likelihood of PSA receipt among the total sample in that higher income levels were associated with increased likelihood of PSA receipt however the effect was only observed for the total sample and for Black relatives. Marital status was also predictive of increased likelihood of PSA receipt among all relatives with married relatives being more likely to have received a PSA than unmarried relatives. Being born in the USA was also a significant predictor of increased likelihood of PSA receipt as compared to relatives that were immigrants to the U.S. across the total sample.

Table 11. Percentage of Men Who Have Had a PSA, Given Demographic Characteristics of Baseline Respondents.¹²

Variable	White (N=354)	Black (N=272)	Hispanics (N=228)	Asian (N=175)	Total (N=1029)
Age*	%	%	%	%	%
Age < 60	51	48	31	45	45
Age ≥ 60	78	79	73	65	75
Education					
High school and above	54	54	39	38	48
College and above	58	60	42	52	54
Incomes*					
Below \$55K	55	49	38	42	46
\$55K and above	58	66	41	54	56
Marriage					
Yes	61	62	43	51	55
No	42	43	30	46	40
Born in U.S.					
Yes	57	57	43	49	54
No	48	80	38	52	46

¹² Shaded areas indicate significant two sample Z test for proportions, total and by race, $p < .05$.

Demographic Variables as Bivariate Predictors of Receipt of PSA within last 12 Months

Fewer significant predictors were found for the outcome of receipt of PSA in the last 12 months. Only age and marital status emerged as significant predictors of receipt of a PSA test during the last 12 months with older and married relatives having an increased likelihood of being screened during the last 12 months as compared to their younger and un-married counterparts.

Table 12. Percentage of Men Who Have Had a PSA within the Last 12 Months, Given Demographic Characteristics of Baseline Respondents.¹³

Variable	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
Age*	%	%	%	%	%
Age < 60	32	40	23	33	32
Age ≥ 60	65	58	64	48	61
Education					
High school and below	42	40	31	31	37
College and above	40	49	34	40	41
Incomes*					
Below \$55K	44	38	31	35	37
\$55K and above	40	54	32	40	42
Marriage					
Yes	44	49	36	41	43
No	28	33	22	31	28
Born in USA					
Yes	41	45	35	38	41
No	38	60	29	40	36

¹³ Shaded areas indicate significant two sample Z test for proportions, total and by race, $p < .05$.

Knowledge of Screening Guidelines as Bivariate Predictor

Level of knowledge in regards to screening guidelines was a significant predictor of receipt of a PSA ever and receipt of a PSA within the last 12 months. Belief that PSA screening should begin at an early age and should occur frequently (i.e., every 6 month) was predictive of higher rates of lifetime PSA screening and receipt of PSA during the last 12 months as compared to beliefs that screening should start at later ages and should occur less frequently.

Table 13. Percentage of Men Who Have Had a PSA, Given Screening Guidelines Knowledge.

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
At what age should he have his first PSA?	Q86	30	63	56	38	76	56
		40	56	60	45	49	53
		50	59	58	26	40	48
		60	20	25	17	45	29
How often should a man such as yourself have a PSA?	Q87	Every 6 m	64	82	50	75	71
		Yearly	60	58	44	57	55
		2-3 Years	49	41	21	26	38
		> 3 Years	27	43	18	25	27

Table 13a. Percentage of Men Who Have Had a PSA within 12 Months, Given Guideline Screening Knowledge.

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
At what age should he have his first PSA?	Q86	30	43	43	31	52	42
		40	39	47	36	36	40
		50	45	45	24	38	40
		60	10	25	17	45	26
How often should a man such as yourself have a PSA?	Q87	Every 6 m	55	68	42	75	62
		Yearly	44	47	35	43	43
		2-3 Years	32	21	21	19	25
		> 3 Years	9	29	9	0	12

Risk Factors Beliefs as Bivariate Predictor

Overall, risk factors beliefs were poor predictors of PSA screening status with only two factors emerging as significant predictors of only one PSA outcome, receipt of PSA ever. Specifically, relatives who cited certain foods and exposure to chemicals as risk factors for prostate cancer were less likely to ever have had a PSA test than were relatives who did not identify diet and chemical exposure as risk factors. No risk factors predicted receipt of a PSA during the last 12 months.

Table 14. Percentage of Men Who Have Had a PSA, Given Risk Factor Beliefs.¹⁴

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
Older age	Q59a	Not Yes	51	54	33	53	48
		Yes	58	59	44	50	54
Certain foods	Q59b	Not Yes	60	60	41	55	55
		Yes	51	55	40	45	49
Stress	Q59c	Not Yes	60	57	39	53	54
		Yes	50	58	43	45	50
Having relatives with cancer	Q59d	Not Yes	62	54	49	46	53
		Yes	56	60	35	63	52
Alcohol	Q59e	Not Yes	57	58	40	54	53
		Yes	56	56	42	42	49
Lack of exercise	Q59f	Not Yes	61	55	41	52	54
		Yes	50	62	40	49	51
Exposure to chemicals	Q59g	Not Yes	61	60	44	54	56
		Yes	53	56	39	48	50
Too much sex	Q59h	Not Yes	57	58	40	40	52
		Yes	60	58	42	60	52
Sitting on cold surfaces	Q59i	Not Yes	57	58	43	50	53
		Yes	58	58	20	75	47
Lack of sex	Q59j	Not Yes	58	58	42	50	53
		Yes	50	58	35	58	50

¹⁴ Shaded areas indicate significant two sample Z test for proportions, total only $p < .05$.

Table 14a Percentage of Men Who Have Had a PSA within 12 Months, Given Risk Factor Beliefs.¹⁵

Question		Response	White (N=354)	Black (N=272)	Hispanic (N=228)	Asian (N=175)	Total (N=1029)
			%	%	%	%	%
Older age	Q59a	Not Yes	32	47	25	44	37
		Yes	42	45	36	38	41
Certain foods	Q59b	Not Yes	43	48	32	43	42
		Yes	35	42	33	35	37
Stress	Q59c	Not Yes	44	47	30	43	41
		Yes	32	44	37	32	37
Having relatives with cancer	Q59d	Not Yes	44	44	39	37	41
		Yes	40	46	28	41	39
Alcohol	Q59e	Not Yes	41	45	32	42	41
		Yes	37	47	24	30	38
Lack of exercise	Q59f	Not Yes	44	44	34	42	42
		Yes	35	47	31	36	38
Exposure to chemicals	Q59g	Not Yes	43	49	35	43	43
		Yes	39	43	31	36	37
Too much sex	Q59h	Not Yes	40	46	33	38	40
		Yes	60	33	31	60	41
Sitting on cold surfaces	Q59i	Not Yes	40	46	35	39	40
		Yes	50	42	16	50	36
Lack of sex	Q59j	Not Yes	41	46	34	38	40
		Yes	38	39	25	46	36

¹⁵ Shaded areas indicate significant two sample Z test for proportions, total only $p < .05$.

Cancer-related Distress as Bivariate Predictor

Psychometric analysis of items assessing cancer-related distress indicated that these items could be combined to compute a cancer-related stress summary score. The composite cancer-related distress score did not predict PSA receipt ever or during the past 12 months and was very similar for men of all ethnic groups.

Table 15 Average Cancer-Related Distress Score and Relationship to PSA Receipt in the Past 12 Months.¹⁶

Variable	White	Black	Hispanics	Asian	Total
No PSA < 12 Mo.	1.72	1.77	1.83	1.78	1.74
PSA < 12 Mo.	1.78	1.76	1.79	1.81	1.75

Multivariate Prediction of PSA Screening Status

Logistic regression analysis was performed for the total sample and for the four ethnic subgroups with receipt of PSA during the last 12 months as the outcome. In all models predictor variables included age, marital status (married vs. not married), education, health insurance, sum of barriers score. Country of birth (born in U.S. vs. born out of U.S.) was added for Hispanic and Asian subgroup analyses. Bivariate analyses detected consistent significant relationships between income and other demographic predictor variables, therefore all logistic regression analyses were performed controlling for income by entering income prior to all other predictor variables. As indicated in Table 17 below, for the total sample, age, marital status, insurance, and barriers emerged as significant predictor variables. That is, older married participants with health insurance who endorsed fewer barriers to screening were more likely to have received a PSA test during the last 12 months. For White relatives, only age and barriers emerged as significant predictors such that older participants reporting fewer barriers to screening were more likely to have received a PSA test during the last year. Among Black and Hispanic participants, age, barriers, and insurance were significant predictors. Regression analyses performed within the Asian sample found age and insurance to be the only significant predictors of PSA receipt during the last 12 months. Furthermore, among Asian relatives no relatives who received screening were uninsured therefore multivariate prediction of screening by insurance was not possible.

Table 17. Logistic Regression Analyses: Predicting PSA Receipt in past 12 months

Predictor	Total Sample (N=1029)		White (N=354)		Black (N=272)		Hispanic (N=228)		Asian (N=175)	
	OR	CI	OR	CI	OR	CI	OR	CI	OR	CI
Age	3.45*	2.47-4.82	4.00*	2.26-7.10	2.14*	1.16-3.98	6.72*	2.88-15.69	4.20*	1.76-10.01
Married	1.48*	1.03-2.13	1.81	.95-3.43	1.37	.71-2.66	1.80	.76-4.23	1.13	.43-2.95
Education	1.01	.97-1.06	1.01	.93-1.10	1.08	.98-1.18	.95	.86-1.05	1.10	.96-1.27
Insured	3.33*	1.75-6.31	2.33	.70-7.74	3.14*	1.07-9.22	4.56*	1.29-16.16	N/A	N/A
Barriers	.65*	.56-.76	.52*	.39-.70	.71*	.53-.95	.59*	.41-.86	.77	.56-1.07
US Born	-	-	-	-	-	-	1.15	.56-2.33	.69	.34-1.39

¹⁶ Shaded areas indicate significant two sample t-test, total and by race, $p < .05$.

Attitudes about Participation in Clinical Trials

Overall, a very low percentage of all relatives (5%) reported any history of participation in a clinical trial and no significant differences were observed across ethnicity. Approximately 37% of the overall sample reported they would participate in the Prostate Cancer Prevention (PCPT) Trial, 55% in the Prostate, Lung, Colorectal, and Ovarian Cancer Screening (PLCO) trial, and 55% in the Selenium and Vitamin E Cancer Prevention (SELECT) Trial. Black and Hispanic relatives were most likely to report that they would participate in PCPT and PLCO trials. All ethnic groups appeared equally willing to participate in the SELECT trial. Concern with experiencing side effects was the most commonly cited reason for not participating in a clinical trial with 68% of the sample endorsing this reason. Other major concerns were "having to take a pill daily" (41%), the length of the trial (38%), and having to get a biopsy (33%). Men were less concerned about blood tests, a rectal exam, and completion of questionnaires.

Table 16. Willingness to Participate in Particular Clinical Trials¹⁷

Question		Response	White	Black	Hispanic	Asian	Total
Have you participated in a clinical trial?	Q92	No	94	95	96	97	95
		Yes	6	5	4	3	5
PCPT Study							
Would you participate?	Q95	Not Yes	67	59	56	69	63
		Yes	33	41	44	31	37
Which are reasons not to participate?							
Take a pill daily	Q96a	Not Yes	63	58	60	50	59
		Yes	37	42	40	50	41
Possible side effects	Q96b	Not Yes	31	33	31	30	32
		Yes	68	67	69	70	68
Having to get biopsy	Q96c	Not Yes	65	69	71	62	67
		Yes	35	31	29	38	33

¹⁷ Chi-squared test $p < .05$.

Table 16 (continued) Willingness to Participate in Particular Clinical Trials

PLCO Study							
Would you participate?	Q97	Not Yes	60	40	39	47	45
		Yes	50	60	60	53	55
Which are reasons not to participate?							
Having to get blood test	Q98a	Not Yes	96	97	93	95	95
		Yes	4	3	7	5	5
Having to get rectal exam	Q98b	Not Yes	86	85	96	89	86
		Yes	14	15	14	11	14
Having to fill out questionnaires	Q98c	Not Yes	90	91	88	90	90
		Yes	10	9	12	10	10
Vitamin E							
Would you participate?	Q99	Not Yes	42	45	43	53	45
		Yes	58	55	56	57	55
Which are reasons not to participate?							
Having to take vitamins	Q100a	Not Yes	88	89	85	81	86
		Yes	12	11	15	19	14
The length of the trial	Q100b	Not Yes	63	68	63	50	62
		Yes	37	32	37	50	38

Represented below in Table 17 are reported barriers to participation in clinical trials, that were assessed in a series of closed-ended questions. In the total sample, the most frequently endorsed barriers were “never thought about participating”, “doctor never recommended participating”, and fear of being a guinea pig.

Table 17. General Reasons Not to Participate in Clinical Trials.¹⁸

Question		Response	White	Black	Hispanic	Asian	Total
Afraid of being a guinea pig	Q101a	Not Yes	73	65	63	60	66
		Yes	27	35	37	40	34
Afraid will get cancer as a result	Q101b	Not Yes	89	82	77	74	82
		Yes	11	18	23	26	18
Fear of becoming impotent	Q101c	Not Yes	93	81	77	76	84
		Yes	7	19	23	23	16
Never thought about participating	Q101d	Not Yes	52	56	52	51	53
		Yes	48	44	48	49	47
Doctor never recommended participating	Q101e	Not Yes	54	70	52	60	59
		Yes	46	31	48	40	41
It is associated with homosexuality	Q101f	Not Yes	99	96	95	95	97
		Yes	1	4	5	5	3
Too uncomfortable or painful	Q101g	Not Yes	84	77	71	73	78
		Yes	16	23	29	27	22

¹⁸ Shaded areas indicate significant Chi-squared test $p < .05$.

A substantial number of respondents also endorsed positive attitudes towards clinical trials. Most relatives (89%) believed that they may learn something by participating in a clinical trial that will benefit their health. Less than half (45%) believed that participation would prolong their lives. There was more uncertainty about benefits regarding prolonged life than about the educational benefits, as reflected in the "no opinion/don't know" category.

Table 18. Beliefs and Attitudes about Clinical Trials.¹⁹

Question		Response	White	Black	Hispanic	Asian	Total
Participating in clinical trials will prolong my life.	Q103	Disagree	37	30	23	32	31
		No Opinion / DK	27	26	21	20	24
		Agree	36	44	56	48	45
I may learn something that will benefit my health.	Q104	Disagree	5	4	2	5	4
		No Opinion / DK	6	8	7	5	6

Validation Analyses

We assessed the validity of self-reported PSA receipt by calculating the percent agreement between self-report and physician report of PSA receipt for both PSA during the last 12 months and lifetime receipt of PSA. The percent agreement between self-report and physician report of lifetime receipt of PSA was high. Physician report of lifetime PSA receipt was verified for 151 of the 178 relatives who reported receiving a PSA at sometime during their life resulting in 85% agreement. However, the percent agreement for receipt of PSA during the last 12 months was lower. Self-report of PSA receipt during the last 12 months was verified by physician report for 83 of the 144 relatives who self-reported PSA receipt in the last 12 months resulting in a 58% agreement. The lowered agreement between self-report and physician report for PSA receipt during the last 12 months may be due to inaccurate subject recall of the timing of the test. Previous research has found that medical patients tend to underestimate the time interval since their last cancer screening procedure.

¹⁹ Shaded areas indicate significant Chi-squared test $p < .05$.

CONCLUSION

Our recruitment method was successful in obtaining an ethnically diverse population-based sample of first-degree relatives of prostate cancer cases. We obtained contact information for first-degree relatives by requesting the information from consenting prostate cancer cases listed through the California Cancer Registry. Among cases and relatives that could be contacted, refusal rates were reasonable. The higher refusal rate among cases (35%) as compared to relatives (10%) probably occurred because many cases felt uncomfortable giving out personal information about their relatives. Relatives, however, aware that the case was participating in our study, were less likely to refuse participation. Through our recruitment efforts, we were able to recruit relatively large samples of White, Asian, African-American, and Hispanic first-degree relatives. However, there were a large percentage of cases and relatives who could not be reached due to incorrect addresses, discontinued telephone numbers, etc., thus compromising the representativeness of the sample and generalizability of findings.

Through our survey, we obtained a substantial amount of information about our sample including demographic information, knowledge of prostate cancer screening, reported barriers to PSA testing, prevalence of cancer-related distress and prostate cancer screening rates. Overall, the majority of the sample was married, over the age of 60, with at least some college education and an income of \$55,000 or higher. Further, the vast majority of our sample reported having some type of health insurance. Most did not endorse many barriers to screening such as cost, problems with transportation to the clinic, or fear that a screening test would find cancer. Most relatives believed that due to their higher risk status, as first-degree relatives, that they should begin to have a yearly PSA test beginning at the age of 40. Most relatives were aware of the known risk factors for prostate cancer including older age and having relatives with prostate cancer; however, the majority of relatives also inaccurately believed that exposure to chemicals may increase their risk for prostate cancer. The majority of our sample reported no significant cancer-related distress. The vast majority of relatives reported having a DRE sometime in their life (76%) however less than half had a DRE during the last 12 months. Rates were lower for PSA receipt with only 56% of the sample reporting having a PSA sometime during their lifetime and only 43% having a PSA test during the last 12 months.

We also examined bivariate predictors of both lifetime receipt of a PSA and receipt of a PSA test during the last 12 months. Age (60 years or older), income (\$55,000 or over), being born in the US, and being married were bivariately predictive of higher rates of lifetime PSA receipt. Higher rates of lifetime receipt of PSA were also found among men who believed that PSA testing should start at earlier ages (i.e., 30 years) and should occur more frequently (i.e., every 6 months) as compared to men who believed that PSA testing should start at later ages and less frequently. Men who were less informed about risk factors for prostate cancer had lower lifetime rates of screening than men who were more knowledgeable about risk factors. Similar bivariate relationships detected for prediction of PSA testing during the last 12 months although fewer significant relationships were found.

Finally, we conducted logistic regression analyses to predict receipt of PSA testing during the last 12 months. Due to bivariate relationships detected between income and other demographic predictors, all logistic analyses were performed controlling for income. Analyses revealed that older married participant with health insurance who endorsed fewer barriers to screening were more likely to have received a PSA test during the last 12 months as compared to

other participants. This suggests that barriers counseling might be a successful strategy to increase PSA screening.

We also assessed attitudes about and participation in clinical prevention trials. A low proportion of the sample (5%) reported ever participating in a prevention or screening trial. The majority of participants indicated that they would be willing to participate in two out of three prostate cancer prevention trials that were described in detail. The most common reasons reported for not participating in a prevention trial was not receiving a doctor recommendation to participate and not having thought about participation in the past. Other reasons reported less frequently included fear of being a guinea pig, fear that participation might be painful or uncomfortable, and fear of getting cancer because of participation. This underscores the important role that physicians play in clinical trials recruitment.

Overall, we were able to recruit a large and diverse sample of first-degree relatives of prostate cancer cases and gain a better understanding of their knowledge, attitudes, and behaviors in regards to prostate cancer screening. We also assessed their level of distress in regards to their risk status and assessed their attitudes towards and participation in prevention and screening clinical trials.

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N/A

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LIST OF PERSONNEL

BASTANI,ROSHAN
BEDDO,VANESSA C
DURAN,MICHELLE
EVERETT,JAMAAR PRINCE
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LITWIN, MARK
MAXWELL,ANNETTE E
MOJICA,CYNTHIA M
PLATERO,JUAN C.
QUEVEDO JR,RAYMOND H
RAWAF,MUSTAFA MOAIUD
RIOS,FATIMA LOURDES
RUNAS,FRANCIS MATTHEW
SCHROEDER,JUSTINE ELISABETH
SWANSON,KAREN A
WALDEN,THOMAS EUGENE
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YAN,KANGXIONG
ZAMORA,ERIC
ZHUANG,JEFF ZU LIANG

APPENDICES (SEE ATTACHED)

1. Final version of questionnaire (English & Spanish versions)
2. Case and relative recruitment materials (Two case & two relative samples included)
3. Mailed questionnaire
4. Letter to relative requesting permission to verify receipt of tests (English, Spanish)
5. Letter to subjects who verbally agreed to validation during survey(English,Spanish)
6. Verification form (English, Spanish)
7. Letter to providers requesting validation of self-report

Appendix 1: Final Version of Questionnaire (English & Spanish translation)

INTRODUCTION/VERBAL CONSENT

NOTE FOR 1st PARAGRAPH:

*IF RID = "2" CHOOSE SON, IF RID = "4" CHOOSE BROTHER, IF RID = "6" CHOOSE FATHER.

*INSERT PTFNAME AND PTLNAME IN SECOND BLANK

Hello, my name is _____, and I am calling from the UCLA Cancer Center. Your [BROTHER, FATHER, SON] _____ gave us your name. Did he talk to you about this study?

- 1 YES → Good. Let me remind you...
0 NO → Let me explain that...

We are doing telephone interviews with close relatives of men who have had prostate cancer. The interview will take about 20 minutes and asks your opinion and belief about cancer, your health practices and some background information about you. Your answers will help us develop programs to educate people about early detection of prostate cancer.

We recently sent you some materials explaining the study. Did you receive it?

Let me assure you that all your answers will be confidential. All information will be used only for the purposes of this study. No information which identifies you will be released without your consent. Your participation is completely voluntary and you can stop the interview at any time.

If you would like, I can give you the telephone number for Dr. Bastani, who is conducting this project, so that you can contact her if you have any questions now or in the future.
[DR. BASTANI'S NUMBER IS: 310.206.9266; RESPONDENTS MAY CALL COLLECT]

I can also give you the Vice Chancellor's [310.825.8714] and the Human Subjects Protection Committee number [310.825.7122] at UCLA.

NOTE: FOR Q0A, IF ANSWER IS "NO" SURVEY WILL BE TERMINATED. ENTER CODE "7" FOR SRVSTAT1 AND CODE "3" TO SRVTERM1 IN RELATIVE TRACKING DATABASE

Q0A Would you be willing to answer some questions?

- 1 YES → CONTINUE
0 NO → I understand your decision. If you do have questions about prostate cancer, early detection and treatment, you can call the Cancer Information Service. Would you like their toll free number? (1-800-4-CANCER). If you change your mind about participating, please feel free to call us toll-free at 1-877-278-8506. Thank you for your time. Good bye. **GO TO SUMMARY SCREEN.**

Q0B Is this a good time for you?

1 YES → CONTINUE

0 NO → When may I call you again? _____ **GO TO LOGSHEET**

Let me assure you that there is **no** right or wrong answer. We are interested only in finding out what **you** feel and what **you** believe about cancer and other issues.

Q001. Let me begin by verifying that you are between the ages of 40 and 75. Is that correct?

- | | |
|----------------------|-------|
| 1 YES (GO TO → Q004) | W. DK |
| 0 NO | X. RF |

Q003w. "I appreciate your willingness to participate at this time. Unfortunately, the telephone survey is conducted only with those who are between 40 and 75 years of age. Do you have any questions for me before we end this call? Thank you for your time. Good-bye."

NOTE: AFTER READING Q003W, ENTER '0' VARIABLE "RELIG2" ALSO ENTER "7" IN SRVSTAT1 AND "7" IN SRVTERM1]

GO TO SUMMARY SCREEN BEFORE RETURNING TO LOG SHEET

Q004. I'd like to ask you some questions about your health.

Has a doctor ever told you that you have or had any type of cancer?

- | | |
|---------------------|----------------------|
| 1 YES | W. DK (GO TO → Q007) |
| 0 NO (GO TO → Q007) | X. RF (GO TO → Q007) |

NOTE: IF Q005a, or Q005b, or Q005c = '2', SUBJECT IS INELIGIBLE FOR STUDY. GO TO Q0006 AND END CALL. [MAKE NOTE IN RELATIVE TRACKING DATABASE VARIABLE RELIG2 = "2", SRVSTAT1 = "7", SRVTERM1 = "8"]

GO TO SUMMARY SHEET BEFORE RETURNING TO LOG SHEET

Q005. What type of cancer? Q005a _____, Q005b _____, Q005c _____

1. Colon (GO TO → Q007)
2. Prostate
5. Lung (GO TO → Q007)

V. Other _____ (Q005S) (GO TO → Q007)
W. DK (GO TO → Q007)
X. RF (GO TO → Q007)

Q006 "I'm sorry to hear that. I appreciate your willingness to participate in this study. Unfortunately, the telephone survey is conducted only with those who have not had prostate cancer. Do you have any questions for me before we end this call? Thank you for your time. Good-bye."

Q007. In general, would you say your health is ...

- | | |
|--------------|-------|
| 1. Excellent | |
| 2. Very good | W. DK |
| 3. Good | X. RF |
| 4. Fair | |
| 5. Poor | |

Q008. Has a doctor ever told you that you have an enlarged or swollen prostate? This is also known as benign prostatic hyperplasia (BPH)?

1. YES W. DK
0. NO X RF

Q009 DELETED

NOTE: FOR Q010:

* IF RID = "2", CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER

*INSERT PTFNAME IN FIRST BLANK. IF RID = "6", AFTER ASKING Q010, SKIP TO Q012.

Q010. Now I'd like to ask you some questions about your family and their health.

Let's start with your [FATHER, BROTHER, SON] _____ who gave us your name. Aside from being diagnosed with prostate cancer, has he been diagnosed with any other type of cancer?

1. YES W. DK (GO TO → Q011)
0 NO (GO TO → Q011) X RF (GO TO → Q011)

What type of cancer? At what age was he diagnosed?

(Q010a1) _____ (Q010b1) _____
(Q010a2) _____ (Q010b2) _____

1. Colon
2. Prostate
3. Breast
5. Lung

V. Other
W. DK
X. RF

Q011. Now I'll read you a list of your other relatives. Please tell me if any of them have had any type of cancer?

Your father? _____

- 1 YES W. DK (GO TO → Q012)
0. NO (GO TO → Q012) X RF (GO TO → Q012)

What type of cancer? At what age was he diagnosed?

Is your father...(1) related to you by "blood"
OR (2) your stepfather?

(Q011a1) _____ (Q011b1) _____ (Q011c) _____
(Q011a2) _____ (Q011b2) _____

1. Colon
2. Prostate
3. Breast
5. Lung

V. Other

W. DK
X. RF

W. DK
X. RF

Q012. Your mother? _____

1 YES
0 NO (GO TO → Q013)

W. DK (GO TO → Q013)
X RF (GO TO → Q013)

What type of cancer? At what age was she diagnosed?

Is your mother... (1) related to you by "blood"
OR (2) your stepmother?

(Q012a1) _____ (Q012b1) _____
(Q012a2) _____ (Q012b2) _____

(Q012c) _____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

W. DK
X. RF

V. Other

W. DK
X. RF

NOTE FOR Q013:

ONLY DISPLAY THE CORRESPONDING NUMBER OF BROTHER SECTIONS INDICATED IN Q013a

IF A BROTHER WAS THE "CASE" PHRASE Q013 AS:

**"ASIDE FROM THE BROTHER WHO GAVE US YOUR NAME, HAVE ANY OF YOUR OTHER BROTHERS BEEN
DIAGNOSED WITH CANCER?"**

Q013. Have any of your brothers? _____

1. YES → How many? _____ (Q013a)
0. NO (GO TO → Q014)

W. DK (GO TO → Q014)
X. RF (GO TO → Q014)

BROTHER 1:

What type of cancer? At what age was he diagnosed?

(Q013_1aTyp) _____ (Q013_1aAge) _____
(Q013_1bTyp) _____ (Q013_1bAge) _____

1. Colon
2. Prostate
3. Breast
5. Lung

V. Other
W. DK
X. RF

Q013_1c. Is your brother...

- 1 related to you by "blood" (GO TO →BRO 2, (IF ANY), SISTER Q014)
- 2 your half brother
- 3 your step brother (GO TO →BRO 2, (IF ANY), SISTER Q014)

W. DK (GO TO →BRO 2, (IF ANY), SISTER Q014)
X. RF (GO TO →BRO 2, (IF ANY), SISTER Q014)

Q013_1d Is your half brother from your mother's or father's side?

- 1 MOTHER
- 2 FATHER

W DK
X RF

BROTHER 2:

What type of cancer? At what age was he diagnosed?

(Q013_2aTyp) _____ (Q013_2aAge) _____
(Q013_2bTyp) _____ (Q013_2bAge) _____

1. Colon
2. Prostate
3. Breast
5. Lung

V. Other
W. DK
X. RF

Q013_2c Is your brother...

- 1 related to you by "blood" (GO TO →BRO 2, (IF ANY), or SISTER Q014)
- 2 your half brother
- 3 your step brother (GO TO →BRO 2, (IF ANY), SISTER Q014)

W DK (GO TO →BRO 2, (IF ANY), SISTER Q014)
X RF (GO TO →BRO 2, (IF ANY), SISTER Q014)

Q013_2d Is your half brother from your mother's or father's side?

- 1 MOTHER
- 2 FATHER

W DK
X RF

BROTHER 3:

What type of cancer? At what age was he diagnosed?

(Q013_3aTyp) _____ (Q013_3aAge) _____
(Q013_3bTyp) _____ (Q013_3bAge) _____

- 1. Colon
- 2. Prostate
- 3. Breast
- 5. Lung

- V. Other
- W. DK
- X. RF

Q013_3c Is your brother...

- 1 related to you by "blood" (GO TO →BRO 3, (IF ANY), SISTER Q014)
- 2 your half brother
- 3 your step brother (GO TO →BRO 3, (IF ANY), SISTER Q014)

- W. DK (GO TO →BRO 3, (IF ANY), SISTER Q014)
- X. RK (GO TO →BRO 3, (IF ANY), SISTER Q014)

Q013_3d Is your half brother from your mother's or father's side?

- 1 MOTHER
- 2 FATHER

- W DK
- X RF

NOTE FOR Q014:

ONLY DISPLAY THE CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q014a

Q014. Any of your sisters? _____

- 1. YES → How many? _____(Q014a)
- 0. NO (GO TO → Q015)

- W. DK (GO TO → Q015)
- X. RF (GO TO → Q015)

SISTER 1:

What type of cancer? At what age was she diagnosed?

(Q014_1aTyp) _____ (Q014_1aAge) _____
(Q014_1bTyp) _____ (Q014_1bAge) _____

- 1. Colon
- 3. Breast

4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q014_1c Is your sister...

- 1 related to you by "blood" (GO TO →SISTER 2, (IF ANY), SON Q015)
- 2 your half sister
- 3 your step sister (GO TO →SISTER 2, (IF ANY), SON Q015)

W. DK (GO TO →SISTER 2, (IF ANY), SON Q015)
X. RF (GO TO →SISTER 2, (IF ANY), SON Q015)

Q014_1d Is your half sister from your mother's or father's side?

- 1 MOTHER
- 2 FATHER

W DK
X RF

SISTER 2:

What type of cancer? At what age was she diagnosed?

(Q014_2aTyp) _____ (Q014_2aAge) _____
(Q014_2bTyp) _____ (Q014_2bAge) _____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q014_2c Is your sister...

- 1 related to you by "blood" (GO TO →SISTER 3 (IF ANY)OR SON Q015)
- 2 your half sister
- 3 your step sister (GO TO →SISTER 3 (IF ANY)OR SON Q015)

W DK
X RF

Q014_2d Is your half sister from your mother's or father's side?

1 MOTHER
2 FATHER

W DK
X RF

SISTER 3:

What type of cancer? At what age was she diagnosed?

(Q014_3aTyp) _____ (Q014_3aAge) _____
(Q014_3bTyp) _____ (Q014_3bAge) _____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q014_3c Is your sister...

- 1 related to you by "blood" (GO TO ->Q015)
- 2 your half sister
- 3 your step sister (GO TO ->Q015)

W. DK
X. RF

Q014_3d Is your half sister from your mother's or father's side?

1 MOTHER
2 FATHER

W DK
X RF

NOTE FOR Q015:

ONLY DISPLAY THE CORRESPONDING NUMBER OF SON SECTIONS INDICATED IN Q015a

IF A SON WAS THE "CASE" PHRASE Q015 AS:

"ASIDE FROM THE SON WHO GAVE US YOUR NAME, HAVE ANY OF YOUR OTHER SONS BEEN DIAGNOSED WITH CANCER?"

Q015. Have any of your **sons** been diagnosed with cancer? _____

1. YES -> How many? _____(Q015a)

0. NO (GO TO → Q016)

W. DK (GO TO → Q016)

X. RF (GO TO → Q016)

SON 1:

What type of cancer? At what age was he diagnosed?

(Q015_1aTyp) _____ (Q015_1aAge) _____

(Q015_1bTyp) _____ (Q015_1bAge) _____

1. Colon
2. Prostate
3. Breast
5. Lung

V. Other

W. DK

X. RF

Q015_1c Is your son...

1 related to you by "blood" (GO TO → SON 2 (IF ANY) OR DAUGHTER Q016)

2 your adopted son (GO TO → SON 2 (IF ANY) OR DAUGHTER Q016)

3 your step son (GO TO → SON 2 (IF ANY) OR DAUGHTER Q016)

W. DK (GO TO → SON 3 (IF ANY) OR DAUGHTER Q016)

X. RF (GO TO → SON 3 (IF ANY) OR DAUGHTER Q016)

SON 2:

What type of cancer? At what age was he diagnosed?

(Q015_2aTyp) _____ (Q015_2aAge) _____

(Q015_2bTyp) _____ (Q015_2bAge) _____

1. Colon
2. Prostate
3. Breast
5. Lung

V. Other

W. DK

X. RF

Q015_2c Is your son...

1 related to you by "blood" (GO TO → SON 3 (IF ANY) OR DAUGHTER Q016)

2 your adopted son (GO TO → SON 3 (IF ANY) OR DAUGHTER Q016)

3 your step son (GO TO → SON 3 (IF ANY) OR DAUGHTER Q016)

W. DK (GO TO → SON 3 (IF ANY) OR DAUGHTER Q016)

X. RF (GO TO → SON 3 (IF ANY) OR DAUGHTER Q016)

SON 3:

What type of cancer? At what age was he diagnosed?

(Q015_3aTyp) _____ (Q015_3aAge) _____
(Q015_3bTyp) _____ (Q015_3bAge) _____

1. Colon
2. Prostate
3. Breast
5. Lung

V. Other
W. DK
X. RF

Q015_3c Is your son...

- 1 related to you by "blood"
- 2 your adopted son
- 3 your step son

W. DK
X. RF

NOTE FOR Q016:

ONLY DISPLAY THE CORRESPONDING NUMBER OF DAUGHTER SECTIONS INDICATED IN Q016a

Q016. Any of your daughters? _____

1. YES → How many? _____ (Q016a)
0. NO (GO TO → Q017)

W. DK (GO TO → Q017)
X. RF (GO TO → Q017)

DAUGHTER 1:

What type of cancer? At what age was she diagnosed?

(Q016_1aTyp) _____ (Q016_1aAge) _____
(Q016_1bTyp) _____ (Q016_1bAge) _____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q016_1c Is your daughter...

- 1 related to you by "blood" (GO TO → DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

2 your adopted daughter (GO TO →DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

3 your step daughter (GO TO →DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

W. DK (GO TO →DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

X. RF (GO TO →DAUGHTER 2 (IF ANY) OR GRANDFATHER Q017)

DAUGHTER 2:

What type of cancer? At what age was she diagnosed?

(Q016_2aTyp) _____ (Q016_2aAge) _____
(Q016_2bTyp) _____ (Q016_2bAge) _____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q016_2c Is your daughter...

1 related to you by "blood" (GO TO →DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

2 your adopted daughter (GO TO →DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

3 your step daughter (GO TO →DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

W. DK (GO TO →DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

X. RF (GO TO →DAUGHTER 3 (IF ANY) OR GRANDFATHER Q017)

DAUGHTER 3:

What type of cancer? At what age was she diagnosed?

(Q016_3aTyp) _____ (Q016_3aAge) _____
(Q016_3bTyp) _____ (Q016_3bAge) _____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q016_3c Is your daughter...

1 related to you by "blood"

2 your adopted daughter

3 your step daughter

W. DK
X. RF

NOTE FOR Q017:

ONLY DISPLAY THE CORRESPONDING NUMBER OF GRANDFATHER SECTIONS INDICATED IN Q017a

Q017. Any of your grandfathers? _____

- 1. YES → How many? ____ (Q017a)
- 0. NO (GO TO → Q018)

W. DK (GO TO → Q018)

X. RF (GO TO → Q018)

GRANDFATHER 1:

What type of cancer? At what age was he diagnosed?

(Q017_1aTyp) _____ (Q017_1aAge) _____
(Q017_1bTyp) _____ (Q017_1bAge) _____

- 1. Colon
- 2. Prostate
- 3. Breast
- 5. Lung

V. Other
W. DK
X. RF

Q017_1c. Is this your maternal or paternal grandfather?

- 1 MATERNAL (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER)
- 2 PATERNAL (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER)

W. DK (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER)
X. RF (GO TO GRANDFATHER 2 (IF ANY) OR GRANDMOTHER)

GRANDFATHER 2:

What type of cancer? At what age was he diagnosed?

(Q017_2aTyp) _____ (Q017_2aAge) _____
(Q017_2bTyp) _____ (Q017_2bAge) _____

- 1. Colon
- 2. Prostate
- 3. Breast
- 5. Lung

V. Other
W. DK
X. RF

Q017_2c Is this your maternal or paternal grandfather?

1 MATERNAL
2 PATERNAL

W. DK
X. RF

NOTE FOR Q018:

ONLY DISPLAY THE CORRESPONDING NUMBER OF GRANDMOTHER SECTIONS INDICATED IN Q018a

Q018. Your grandmothers? _____

1. YES -> How many? ____ (Q018a)
0. NO (GO TO -> Q019)

W. DK (GO TO -> Q019)
X. RF (GO TO -> Q019)

GRANDMOTHER 1:

What type of cancer? At what age was she diagnosed?

(Q018_1aTyp) _____ (Q018_1aAge) _____
(Q018_1b Typ) _____ (Q018_1bAge) _____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q018_1c. Is this your maternal or paternal grandmother?

- 1 MATERNAL (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019)
2 PATERNAL (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019)

W. DK (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019)
X. RF (GO TO GRANDMOTHER 2 (IF ANY) OR OTHER FAMILY Q019)

GRANDMOTHER 2:

What type of cancer? At what age was she diagnosed?

(Q018_2aTyp) _____ (Q018_2aAge) _____

(Q018_2bTyp)_____

(Q018_2bAge)_____

1. Colon
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

Q018d. Is this your maternal or paternal grandmother?

- 1 MATERNAL
2 PATERNAL

W. DK
X. RF

Q019. Is there anybody else in your family who has been diagnosed with cancer?

1. YES
0. NO (GO TO → Q021)
- W. DK (GO TO → Q021)
X RF (GO TO → Q021)

Q020. WHO?

(Q020a1)_____ (Q020b1) Type of cancer? _____ (Q020c1) Age at diagnosis? ____
(Specify relationship)

(Q020a2)_____ (Q020b2) Type of cancer? _____ (Q020c2) Age at diagnosis? ____
(Specify relationship)

(Q020a3)_____ (Q020b3) Type of cancer? _____ (Q020c3) Age at diagnosis? ____
(Specify relationship)

1. Niece
2. Nephew
3. Aunt
4. Uncle
5. Cousin
6. Granddaughter
7. Grandson

V. Other
W. DK
X. RF

1. Colon
2. Prostate
3. Breast
4. Cervical
5. Lung
6. Ovarian
7. Endometrial

V. Other
W. DK
X. RF

W. DK
X. RF

NOTE FOR Q021:

* IF RID = "2" CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER
* INSERT PTFNAME IN BLANK

IF CASE HAS DIED, SKIP Q021

Q021. Now thinking back to your [father/brother/son]_____ who had prostate cancer...

Would you say his prostate cancer has...

1. Come back
2. Not come back
3. Spread to other parts of the body

W. DK
X. RF

IF CASE HAS DIED, READ Q023 AS FOLLOWS:

"BEFORE HE DIED, HOW DID YOU SEE HIS TREATMENT FOR PROSTATE CANCER. WOULD YOU SAY IT WAS..."

Q023. Would you say his treatment and recovery from prostate cancer was...

1. Very hard
2. Somewhat hard
3. Not hard

W. DK
X. RF

Q024. Next, I'd like to ask about your feelings regarding prostate cancer.

How often do you think about your possibility of developing prostate cancer? Would you say ...

1. Very often
2. Once in a while
3. Never

W. DK
X. RF

Q025. How worried are you that you may get prostate cancer? Would you say ...

1. Very worried
2. Somewhat worried
3. Not worried

W. DK
X. RF

Q026. When you think about getting prostate cancer, how fearful are you? Would you say ...

1. Very fearful
2. Somewhat fearful
3. Not fearful

W. DK
X RF

Q027. Would you say you are very nervous, somewhat nervous, or not nervous that you may get prostate cancer?

- 1. VERY NERVOUS
- 2. SOMEWHAT NERVOUS
- 3. NOT NERVOUS
- W. DK
- X. RF

Q028. Do you think about getting prostate cancer more often than you would like *to think about it*?

- 1. YES
- 0. NO
- W. DK
- X RF

Q029 DELETED

Q030. Now, I'd like to ask you a few questions about your health and some screening tests for prostate cancer.

During the past 12 months, have you had a complete physical exam?

- 1. YES
- 0. NO
- W. DK
- X RF

Q031. One test that is done to find prostate cancer is the DRE or the "digital rectal exam". For this test a finger is inserted in the rectum to check for problems with the prostate and large bowel. Have you ever heard of a digital rectal exam?

- 1. YES
- 0. NO
- W. DK
- X RF

Q032. Have you ever had a digital rectal exam?

- 1. YES
- 0. NO (GO TO → Q034)
- W. DK (GO TO → Q034)
- X RF (GO TO → Q034)

Q033. When was your most recent digital rectal exam? Was it ...?

- 1. Within the last 12 months
- 2. 1- 2 years ago
- 5. 2-3 years ago
- 3. 3-5 years ago
- 4. More than 5 years ago
- W. DK
- X RF

Q034. In addition to the digital rectal exam, there is a special blood test used to check for prostate cancer. This blood test is called a PSA or "prostate specific antigen" test. Have your ever heard of a PSA?

- 1. YES
- 0. NO
- W. DK
- X RF

Q035. Has your doctor (or nurse) ever recommended that you get a PSA blood test?

- 1. YES
- 0. NO
- W. DK
- X RF

Q036 DELETED

Q037. Have you ever had a PSA blood test?

- | | |
|----------------------|----------------------|
| 1. YES | W. DK (GO TO → Q041) |
| 0. NO (GO TO → Q041) | X RF (GO TO → Q041) |

Q038. How many PSAs have you had? Would you say ...?

- | | |
|------------------|-------|
| 1. One | W. DK |
| 2. More than one | X RF |

Q039. When was your most recent PSA? Was it ...?

- | | |
|------------------------------|-------|
| 1. Within the last 12 months | W. DK |
| 2. 1- 2 years ago | X RF |
| 5. 2-3 years ago | |
| 3. 3-5 years ago | |
| 4. More than 5 years ago | |

Q040. Why did you have this PSA? Was it for a health problem or was it part of a routine screening check-up, when you did not have any problems?

1. BECAUSE OF A HEALTH PROBLEM
 2. PART OF A ROUTINE SCREENING CHECK UP
- V. OTHER (Specify) _____ (Q040s)
- W. DK
- X RF

Q041. Have you ever been to a urologist? A urologist is a doctor who treats diseases of the kidneys, bladder, testicles, and prostate.

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

The next few questions have to do with tests that are used to detect other types of cancer.

Q042. A sigmoidoscopy or colonoscopy or "procto" is when a long *thin* bendable tube with a light on the end is inserted in the rectum and into the colon to check for problems. Have you ever heard of such an exam?

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

Q043. Have you ever had a sigmoidoscopy or colonoscopy?

- | | |
|----------------------|-----------------------|
| 1. YES | W. DK (GO TO → Q045) |
| 0. NO (GO TO → Q045) | X RF (GO TO → Q045) |

Q044. When was your most recent sigmoidoscopy or colonoscopy? Was it ...?

- | | |
|------------------------------|-------|
| 1. Within the last 12 months | W. DK |
| 2. 1-2 years ago | X RF |
| 5. 2-3 years ago | |

3. 3-5 years ago
4. 5-10 years ago
6. More than 10 years ago

Q045. Another test that is done to **check for** colon cancer is the take home stool blood test, **where** the stool is tested for blood. For this test, you place a small amount of your stool on a card every day for 3 days **and it is analyzed by a clinic**. You are usually asked not to eat red meat or certain fruits and vegetables during **this time**. Have you ever heard of a stool blood test?

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

Q046. Have you ever done a take home stool blood test?

- | | |
|----------------------|----------------------|
| 1. YES | W. DK (GO TO → Q048) |
| 0. NO (GO TO → Q048) | X RF (GO TO → Q048) |

Q047. When was your most recent test for blood in your stool? Was it ...?

- | | |
|------------------------------|-------|
| 1. Within the last 12 months | W. DK |
| 2. 1-2 years ago | X RF |
| 5. 2-3 years ago | |
| 3. 3-5 years ago | |
| 4. More than 5 years ago | |

Q048. Now, I'd like to ask you a few questions for statistical purposes only. Remember that your answers are confidential.

What is the highest level in school that you have completed?

NO SCHOOL	00							
GRADE SCHOOL	01	02	03	04	05	06	07	08
HIGH SCHOOL	09	10	11	12				
COLLEGE	13	14	15	16				
POST COLLEGE	17	18	19	20				
W DK								
X RF								

Q049. Were you born in the United States?

- | | |
|-------------------------|-------|
| 1. YES (GO TO Q → Q052) | W. DK |
| 0. NO | X. RF |

Q050. In what country were you born? _____

- W. DK
X. RF

Q051. How long have you lived in the U.S.? Years:(Q051yy) _____ Months:(Q051mm) _____

W. DK
X. RF

Q052. What is your ethnicity?

1. Black/African American (GO TO → Q054)
2. Hispanic/Latino (GO TO → Q055)
3. Asian/Asian-American (GO TO → Q056)
- B. Asian Indian (GO TO → Q057)
8. Middle Eastern (GO TO → Q057)
9. Eastern European (GO TO → Q057)
- A. Western European (GO TO → Q057)
5. American Indian/Native American (GO TO → Q057)
6. Pacific Islander (Hawaii, Guam, Samoa, other South Pacific Island) (GO TO → Q057)
4. White/Caucasian (GO TO → Q057)
7. Mixed (Bi- or Multi-Racial) specify _____(Q052s1) GO TO → Q053)
- V. Other: (specify) _____(Q052s2) (GO TO → Q057)

W. DK X. RF

Q053. Which race do you identify with most? _____ (GO TO → Q057)

W. DK X. RF

Q054. Are you ...? (GO TO → Q057)

- | | |
|------------------------------|-----------------------|
| 1. African American | 4. South American |
| 2. West Indian | 5. Puerto Rican |
| (includes Caribbean Islands) | V. Other _____(Q054s) |
| 3. Cuban | W. DK |

X RF

Q055. Are you ...? (GO TO → Q057)

- | | |
|---------------------|-----------------------|
| 1. Mexican | 6. Puerto Rican |
| 2. Mexican American | 7. Cuban |
| 3. Chicana | V. Other _____(Q055s) |
| 4. Central American | W. DK |
| 5. South American | X RF |

Q056. Are you ...?

- | | |
|---------------|----------------------|
| 1. Chinese | 6. Asian Indian |
| 2. Japanese | 7. Indonesian |
| 3. Filipino | 8. Korean |
| 4. Vietnamese | V. Other _____(Q56s) |
| 5. Cambodian | W. DK |
| | X RF |

Q057. Which of the following best describes your total household income, that is, the yearly income of all family members living with you? I don't need the exact amount...just a range. And remember, your answer is confidential. Would you say approximately ...?

- | | |
|-----------------------|---------------------------|
| 1. Less than \$10,000 | (0 - \$ 833/month) |
| 2. \$10,000 - 24,000 | (\$ 833 - \$2,000/month) |
| 3. \$25,000 - 39,000 | (\$2,083 - \$3,250/month) |
| 4. \$40,000 - 54,000 | (\$3,333 - \$4,500/month) |
| 5. More than \$55,000 | (More than \$4,583/month) |
| W. DK | X RF |

Q058. Are you currently married or living with someone as married?

1. YES
0. NO
X. RF

Q058A. What is your date of birth, please? ____/____/____
MM DD YY

Q059. Now I'm going to read a list of things that some people think make a man more likely to get prostate cancer. For each one, please tell me whether or not you believe it can make a man more likely to get prostate cancer.

"Do you believe _____ can make a man more likely to get prostate cancer?"

Yes No Possibly DK RF

Q059a. older age 1 .. 0 ... 2 ... W .. X

Q059b. certain things you eat 1 .. 0 ... 2 ... W .. X

Q059c. too much stress 1 .. 0 ... 2 ... W .. X

Q059d. having relatives with prostate cancer 1 .. 0 ... 2 ... W .. X

Q059e. drinking alcohol 1 .. 0 ... 2 ... W .. X

Q059f. not getting enough exercise/physical activity 1 .. 0 ... 2 ... W .. X

Q059g. exposure to harmful chemicals or radiation at work or
in the community 1 .. 0 ... 2 ... W .. X

Q059h. too much sex 1 .. 0 ... 2 ... W .. X

Q059i. sitting on cold surfaces 1 .. 0 ... 2 ... W .. X

Q059j. lack of sex 1 .. 0 ... 2 ... W .. X

Q060. Who do you think gets prostate cancer most often?

1. Whites/Caucasians
2. Hispanics/Latinos
3. Black/African Americans
4. Asian/Asian Americans
5. *Or do you think it makes no difference*

W. DK
X RF

Q061. How likely are you to get prostate cancer during your lifetime? Would you say ...?

1. Very likely
2. Somewhat likely
3. Not very likely

W. DK
X RF

The next set of questions have to do with your beliefs about screening for prostate cancer.

	YES	NO	NO OPINION	DK	RF
Q065. Is getting a PSA blood test important to you?	1	0	2	W	X
Q066. Would it be difficult for you to pay for a PSA?	1	0	2	W	X
Q071. Would you have a problem getting transportation to the doctor?	1	0	2	W	X
Q064. Are you fearful of getting tested?	1	0	2	W	X
Q067. Are you worried that screening will show you have prostate cancer?	1	0	2	W	X
Q068. <i>Do you think</i> prostate cancer can be cured if found early?	1	0	2	W	X
Q070. Do you think getting a DRE can cause sexual problems?	1	0	2	W	X
Q072. Do you think you only need to get a PSA test if your doctor recommends it?	1	0	2	W	X
Q062. <i>Were you aware</i> that you should get a digital rectal exam every year?	1	0	2	W	X
Q063. Did you know that you should have a PSA (prostate specific antigen) blood test every year?	1	0	2	W	X

Q069 DELETED

Q073. Would you say you agree or disagree with the following statements.

The benefits of getting a PSA blood test are greater than any inconvenience.

Q074. You only need a prostate cancer screening test when you have symptoms.

Q075. Going through prostate screening is too much trouble for what you get out of it.

Q076. You do not have time to get tested.

- | | |
|-------------|-------|
| 1. Agree | W. DK |
| 2. Disagree | X RF |

Q077. How many of your friends and family do you think get checked for prostate cancer? Would you say ...?

- | | |
|---------|-------|
| 1. Most | |
| 2. Few | W. DK |
| 3. None | X RF |

Q078. Do you think there is anything you can do to prevent getting prostate cancer?

- | | |
|----------|-------|
| 1. YES | |
| 0. NO | W. DK |
| 2. MAYBE | X RF |

Q079. Have you ever discussed your personal risk for getting prostate cancer with any friends or relatives?

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

Q080. Have you ever discussed your personal risk for getting prostate cancer with your doctor?

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

Q081. I'd like to ask you some questions about your insurance.

Do you have Medicare?

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

Q082. Do you have Medicaid/Medical?

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

Q083. Do you have any other health insurance?

- | | |
|-----------------------|----------------------|
| 1. YES | W. DK (GO TO → Q085) |
| 0. NO (GO TO → (Q085) | X RF (GO TO → Q085) |

Q084 Is it ...?

- | | 1 | 0 | W | X |
|--|-----|----|----|----|
| Q084a. An HMO with its own staff physicians and clinics
(like Kaiser, FHP, or Maxicare) | YES | NO | DK | RF |
| Q084b. A plan that lists physicians in private practice that you can
use (like Prudential, Health Net, California Care, Care America) | YES | NO | DK | RF |
| Q084c. Private insurance that will pay for any doctor you choose
(like Blue Cross, Aetna, Travellers, or Mutual of Omaha) | YES | NO | DK | RF |
| Q084s Other (Specify) _____ | YES | NO | DK | RF |

NOTE: FOR Q085:

IF Q081, Q082, OR Q083 = '1', ASK Q085, OTHERWISE GO TO Q086

Q085. Does your health insurance cover the cost of a PSA blood test?

- | | |
|--------|-------|
| 1. YES | W. DK |
| 0. NO | X RF |

Q086. A routine prostate cancer screening is for check-up purposes only, when no symptoms are present. For the next question please think about somebody like yourself who has a close relative with prostate cancer.

At what age should he have his first PSA? Would you say at age ...?

- | | |
|-------|-------|
| 1. 30 | |
| 2. 40 | |
| 3. 50 | W. DK |
| 4. 60 | X RF |

Q087. How often should a man such as yourself have a PSA test? Would you say ...?

- | | |
|---------------------|-------|
| 1. Every 6 months | |
| 2. Every year | |
| 3. Every 2-3 years | W. DK |
| 4. Every 3-5 years | X RF |
| 5. Every 5-10 years | |

NOTE FOR Q088 & Q089:

* IF RID = "2", CHOOSE SON; IF RID = "4" CHOOSE BROTHER; IF RID = "6" CHOOSE FATHER

33% OF SUBJECTS WILL RANDOMLY BE ASSIGNED TO RECEIVE SNR1; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR2; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR3. SNR3 WILL ONLY RECEIVE QUESTIONS: Q088 AND Q089. THEY WILL NOT RECEIVE A SCENARIO.

In this next section, I will read you a brief scenario followed by two questions. Please be patient and listen closely.

Q088. (SNR1) SCENARIO ONE: A scenario for a random 33% of the sample will read as follows:

Prostate cancer is the second leading cause of death from cancer in men. Having a **BROTHER, FATHER, SON** with prostate cancer increases your risk of getting it yourself. Doctors agree that early detection of prostate cancer is important. But doctors disagree about the widespread use of the PSA test to screen for prostate cancer.

Some doctors feel that the PSA blood test is not very accurate. For example, if a man has a **high PSA test**, this may mean that he has cancer, but it may also mean that his prostate is just swollen. To know for sure whether he has cancer or not, he would have to get a biopsy, which is a test where a small tissue sample is taken from the prostate for further checking.

Now, if a man has a **normal PSA blood level**, most of the time this means that he does not have cancer. But some men can have a normal PSA blood level and have cancer.

Currently, the PSA blood test is the only test available. Doctors feel that the PSA test can detect prostate cancer early, and 9 out of 10 cancers that are detected early can be cured. That's why many doctors, and the American Cancer Society, recommend that men over 40 have an annual PSA blood test, especially if they have a family member with prostate cancer.

Given what you have heard....

Q088 (SNR2) SCENARIO TWO: A scenario for a random 33% of the sample will read as follows:

Prostate cancer is the second leading cause of death from cancer in men. Having a **BROTHER, FATHER, SON** with prostate cancer increases your risk of getting it yourself. Doctors agree that early detection of prostate cancer is important. But doctors disagree about the widespread use of the PSA test to screen for prostate cancer.

Currently, the PSA blood test is the only test available. Doctors feel that the PSA test can detect prostate cancer early, and 9 out of 10 cancers that are detected early can be cured. That's why many doctors, and the American Cancer Society, recommend that men over 40 have an annual PSA blood test, especially if they have a family member with prostate cancer.

Some doctors feel that the PSA blood test is not very accurate. For example, if a man has a **high PSA test**, this may mean that he has cancer, but it may also mean that his prostate is just swollen. To know for sure whether he has cancer or not, he would have to get a biopsy, which is a test where a small tissue sample is taken from the prostate for further checking.

Now, if a man has a **normal PSA blood level**, most of the time this means that he does not have cancer. But some men can have a normal PSA blood level and have cancer.

Given what you have heard...

Q088 (SNR3) SCENARIO THREE: ASK QUESTIONS ONLY. THERE IS NO TEXT

How likely are you to ask your doctor (or nurse) about getting screened for prostate cancer?

- | | |
|--------------------|-------|
| 1. Very likely | W. DK |
| 2. Somewhat likely | X RF |
| 3. Not likely | |

Q089. How likely are you to get a PSA blood test within the next 12 months?

- | | |
|----------------|-------|
| 1. Very likely | W. DK |
|----------------|-------|

- X RF

NOTE: Q090 AND 091 WERE DELETED DUE TO REDUNDANCY. SAME QUESTIONS AS Q088 AND Q089

Q092. In this last section I will be asking you questions about clinical trials. A clinical trial is a research study done by doctors to find out how best to prevent a disease or treat a disease. Some trials are done with cancer patients to test different treatments. Other trials study if things like diet, exercise, or early detection can prevent diseases in healthy people.

1. YES W. DK (GO TO → Q094)
0. NO (GO TO → Q094) X RF (GO TO → Q094)

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X RF

1. YES W. DK
0. NO X RF

Q095. The Prostate Cancer Prevention Trial is a study to test whether the drug *finasteride* can prevent prostate cancer. In this trial, half of the men will be given the drug and half will be given a sugar pill. Men will not know if they are taking the drug or a sugar pill. At the end of 7 years, all men will have a biopsy of their prostate gland, in which a small sample of tissue is taken.

1. YES W. DK
0. NO X. RF

	YES	NO	DK	RF
Q096a. having to take a pill daily for 7 years	1	0	W	X
Q096b. the possible side effects	1	0	W	X
Q096c. having to get a biopsy	1	0	W	X

Q097. Another clinical trial is the PLCO. This is a study to see if a PSA blood test and a rectal exam can detect prostate cancer early. Half of the men will receive the PSA blood test and a rectal exam once a year for 4 years and half will not receive the tests at all. All the men, whether they receive the tests or not, will have to fill out a questionnaire each year.

If you were asked to participate in a trial like this, would you participate?

1. YES
0. NO

W. DK
X RF

Q098. Which of the following would be a reason for you not to participate in the trial?

	YES	NO	DK	RF
Q098a. having to get a blood test	1	0	W	X
Q098b. having to get a rectal exam	1	0	W	X
Q098c. having to fill out questionnaires	1	0	W	X

Q099. There is a new clinical trial that may be starting soon which will test whether Vitamin E and the mineral selenium can prevent prostate cancer. Men would have to take Vitamin E and selenium for a minimum of 7 years and a maximum of 12 years. This trial would not require men to take any other medications or get a biopsy.

If you were asked to participate in a trial like this, would you participate?

1. YES
0. NO

W. DK
X RF

Q100. Which of the following would be a reason for you not to participate in the trial?

	YES	NO	DK	RF
Q100a. having to take vitamins	1	0	W	X
Q100b. the length of the trial (7-12 yrs)	1	0	W	X

Q101. There are many reasons people give for not participating in clinical trials. Please tell me if any of the following reasons apply to you.

	Yes	No	DK	RF
Q101a. Afraid of being used as a guinea pig	1	0	W	X
Q101b. Afraid you'll get cancer as a result of participating	1	0	W	X
Q101c. Fear you will become impotent	1	0	W	X
Q101d. Never thought about participating.	1	0	W	X
Q101e. Doctor never recommended participating...	1	0	W	X
Q101f. It is associated with homosexuality.	1	0	W	X

Q101g. It is too uncomfortable or painful 1 0 W X

Q101h. Can you think of any other reasons why you would not participate? _____

Q102. Please tell me whether you agree or disagree with the following statements.

	Agree	Disagree	No Opinion	DK	RF
Participating in clinical trials will help others.	1	0	2	W	X
Q103. Participating in clinical trials will prolong my life.	1	0	2	W	X
Q104. I may learn something that will benefit my health.	1	0	2	W	X

Q105. This concludes the survey. Before I hang up, I'd like to **briefly give you a few facts** about prostate cancer. Earlier in the interview, I asked you about what you think makes a man more likely to get prostate cancer. We think it's important to tell everyone we talk to what is **scientifically known** about prostate cancer. The following things are believed by scientists to make a man more likely to get prostate cancer. A combination of them increases the risk even more.

- older age (over 55 years old)
- having relatives with prostate cancer (especially a father, brother, or son)
- having a relative diagnosed before the age of 60
- being African American

You should also know that exercise and eating a low-fat diet may decrease your risk.

Q106. Many men believe other things make a man more likely to get prostate cancer which are not true. The following things are not related to prostate cancer.

- too much stress
- too much sex
- lack of sex
- sitting on cold surfaces

Also, drinking alcohol has not been scientifically proven to cause prostate cancer.

Q107. If you would like more information about prostate cancer, early detection and treatment, you can call the Cancer Information Service. Would you like the number?

1 YES [1-800-422-6237]
0 NO

NOTE FOR Q108M:

PLEASE DISPLAY RADDRES1, RADDRES2, RCITY, RSTATE, RZIP, RPHONE1, RPHONE2, AND RPHONE3
FROM RELATIVE TRACKING DATABASE

!!!

Q108M I would like to verify your address so that I can send you some information *on prostate cancer*. I would also like to get a telephone number, *of a relative or friend*, where we can reach you or leave you a message.

(REPEAT ADDRESS AND PHONE NUMBER ON FILE- SPECIFY NEW ADDRESS AND PHONE NUMBERS
_____ (Q108M MEMO FIELD). (BLANK O.K.)

ENTER Y IF ADDRESS ETC. CHANGED , = = UPPER CASE ONLY

Q109. If we do a follow-up study in the future, may we contact you again?

1. YES W. DK
0. NO X. RF

On behalf of our project, I'd like to thank you for the time you dedicated to this survey. Good - bye.

!!!

RID:

THE INTERVIEW OF THIS RELATIVE IS OVER!

STATUS CODE OF THIS CASE'S INTERVIEW RECORD:

LANGUAGE OF INTERVIEW (E/S):

PREVIOUSLY RECORDED INTERVIEWER:

INTERVIEWER TO BE RECORDED:

2 OR 3 LETTER INITIALS, NO SPACE OR SYMBOL,
WILL BE CONVERTED TO UPPER CASE AUTOMATICALLY

NOTE FOR 1st PARAGRAPH:

* IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' AND PSEX = '2' CHOOSE PAPA.

* INSERT PTFNAME AND PTLNAME IN SECOND BLANK

Hola, mi nombre es _____, le estoy llamando del Centro de Cancer en UCLA. Recibimos su nombre de su [HERMANO, PAPA, HIJO] [FIJAR NOMBRE]. ¿Le habló él sobre este estudio?

- ☐ SI → Me da gusto. Dejeme recordarle que...
☐ NO → Dejeme explicarle que...

Estamos entrevistando a familiares cercanos de pacientes con cáncer de la próstata. La entrevista tomara aproximadamente 20 minutos y le preguntaremos sus opiniones, creencias sobre el cáncer, sus costumbres, y algunos antecedentes sobre su salud. Sus repuestas ayudaran a desarrollar programas para educar a las personas sobre la detección temprana del cáncer de la próstata.

¿Recientemente le enviamos algunos materiales explicandole el estudio, los recibió? Dejeme asegurarle que todas sus respuestas serán confidenciales. Toda información se utilizara solamente para este estudio. Ninguna información que lo identifique sera revelada sin su consentimiento. Usted puede parar la entrevista a cual quier momento.

Si usted desea y tiene alguna pregunta, le puedo dar el numero de la Doctora Bastani, quien conduce este estudio. (DR. BASTANI'S NUMBER IS: 310-206-9266; RESPONDENTS MAY CALL COLLECT).

También le puedo dar el numero del Vice Canciller (310-825-8714) y de la Oficina de Protección a Sujetos de Investigación en UCLA, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095-1694, (310) 825-8714.

NOTE: FOR Q0A, IF ANSWER IS "NO" SURVEY WILL BE TERMINATED. ENTER CODE "7" FOR SRVSTAT1 AND CODE "3" TO SRVTERM1 IN RELATIVE TRACKING DATABASE

Q0A ¿Estaría dispuesto a contestar algunas preguntas?

- (1) SI -> Continue
(0) NO Entiendo su decisión. Si tiene alguna pregunta sobre el cáncer de la próstata, la detección temprana, y sus tratamientos, puede llamar al Servicio de Información Sobre el Cáncer. ¿Le gustaría el numero? (1-800-422-6237 o 1-800-4-CÁNCER). Si cambia de opinión y quiere participar, por favor llamenos gratis al numero 1-877-278-8505. Gracias y adiós.

Q0B ¿Tiene tiempo ahora?

- (1) SI -> Continue
(0) NO -> ¿Cuándo le puedo llamar? _____
(GO TO LOGSHEET)

Dejeme asegurarle que ninguna respuesta es correcta o incorrecta. Estamos interesados en saber que es lo que usted siente y cree sobre el cáncer de la próstata.

NOTE FOR Q001:

- * ASK IF PLET1STA ='1' AND RAGE <>'—' OTHERWISE GO TO Q03
- * IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' CHOOSE PAPA
- * INSERT PTFNAME AND PTLNAME IN FIRST BLANK
- * INSERT RAGE IN SECOND BLANK

Q001 Dejemé empezar por verificar su edad. Usted tiene entre las edades de 40 a 75 años, no?

1 SI (GO TO ->Q04)
0 NO

W DK

X RF

NOTE: FOR Q003 IF PARTICIPANT IS UNDER 40 YEARS OF AGE OR OVER 75 YEARS OF AGE, THEY ARE NOT ABLE TO PARTICIPATE. PLEASE SAY,...

(Q003w) Gracias. Agradezco su deseo de participar en este momento. Desafortunadamente, la encuesta telefónica es solamente para personas entre la edad de 40 a 75 años. ¿Tiene alguna pregunta para mí antes de terminar la llamada? Gracias por su tiempo. Adiós.

NOTE: AFTER READING Q003W, ENTER '0' VARIABLE "RELIG2" ALSO ENTER "7" IN SRVSTAT1 AND "7" IN SRVTERM1

Q004 Ahora me gustaría hacerle algunas preguntas sobre su salud.

¿Alguna vez su doctor le dijo que tiene o que ha tenido algún tipo de cáncer?

1 SI

0 NO

(GO TO -> Q007)

W DK

(GO TO -> Q007)

X RF

(GO TO -> Q007)

NOTE: IF Q005A OR Q005B OR Q005C = '2', SUBJECT IS INELIGIBLE FOR STUDY. GO TO Q006 AND END CALL. [MAKE NOTE IN RELATIVE TRACKING DATABASE VARIABLE RELIG2 = "2", SRVSTAT1 = "7", SRVTERM1 = "8"]

GO TO SUMMARY SCREEN BEFORE RETURNING TO LOG SHEET

Q005 ¿Que tipo de cáncer?

(Q05a)____ (Q05b)____ (Q05c)____

1 COLON

2 PRÓSTATA

5 PULMONES

(GO TO -> Q007)

V Other -> specify____ (Q005v) (GO TO -> Q007)

W DK

(GO TO -> Q007)

X RF

(GO TO -> Q007)

Q006 Siento mucho oír esto. Le agradezco su deseo de participar en este estudio. Desafortunadamente, la encuesta telefónica se esta haciendo solamente con personas que no han tenido cáncer de la próstata. ¿Tiene algunas preguntas para mi antes de terminar la llamada? Gracias por su tiempo. Adiós.

Q007 En general, diría usted que su salud es...

1 excelente

2 muy buena

3 buena

4 regular

5 mala

W DK

X RF

Q008 ¿Alguna vez le ha dicho un doctor que tiene la próstata agrandada o hinchada? Esto también es conocido como hiperplasia prostático benigno (BPH).

1 SI

0 NO

W DK

X RF

NOTE FOR Q010:

* IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' CHOOSE PAPÁ

* INSERT PTFNAME IN FIRST BLANK

* IF RID = "6", AFTER ASKING Q010, SKIP TO Q012.

Q010 Ahora me gustaría hacerle algunas preguntas sobre su familia y la salud de ellos. Comenzaremos con su [PAPÁ, HERMANO, HIJO] _____ quien lo recomendó para este estudio. ¿Ademas de ser diagnosticado con cáncer de la próstata, ha sido el diagnosticado con algún otro tipo de cáncer?

1 SI

0 NO

(GO TO → Q011)

W DK

(GO TO → Q011)

X RF

(GO TO → Q011)

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q010a1) _____

(Q010b1) _____

(Q010a2) _____

(Q010b2) _____

TIPO DE CÁNCER:

1 COLON

2 PRÓSTATA

3 SENO

5 PULMONES

V OTRO

W DK

X RF

Ahora, le voy a leer una lista de sus otros familiares . Digame si algunos de ellos han tenido algun cancer.

Q011 Su papa? ____

1 SI

0 NO

(GO TO → Q012)

W DK

(GO TO → Q012)

X RF

(GO TO → Q012)

(Q011a1)____
(Q011a2)____

(Q011b1)____
(Q011b2)____

(2) su padrastro?

(Q011c)____

TIPO DE CÁNCER:

- 1 COLON
- 2 PRÓSTATA
- 3 SENO
- 4 PULMONES

V OTRO
W DK
X RF

Q012 ¿Su MAMÁ?

1 SI
0 NO

(GO TO ->Q013)

W DK
X RF

(GO TO ->Q013)

(GO TO ->Q013)

Que tipo de cáncer?

A que edad fue diagnosticada?

Su MAMÁ es...(1) su mamá biológica
o (2) su madrastra

(Q012a1)____
(Q012a2)____

(Q012b1)____ (W=DK X=RF)
(Q012b2)____ (W=DK X=RF)

(Q012c)____

TIPO DE CÁNCER:

- 1 COLON
- 3 SENO
- 4 CERVIZ
- 5 PULMONES
- 6 OVARIOS
- 7 ENDOMETRIO

V OTRO
W DK
X RF

NOTE FOR Q013:

ONLY DISPLAY THE CORRESPONDING NUMBER OF BROTHER SECTIONS INDICATED IN Q013a

IF BROTHER WAS THE "CASE" PHRASE Q013 AS:

HAN SIDO ALGUNOS DE SUS DEMAS HERMANOS DIAGNOSTICADOS CON CANCER?

1 SI -> Cuantos? _____ (Q013a)
0 NO (GO TO -> Q014)

W DK (GO TO -> Q014)
X RF (GO TO -> Q014)

HERMANO 1:

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q013_1aTyp) _____
(Q013_1bTyp) _____

(Q013_1aAge) _____
(Q013_1bAge) _____

TIPO DE CÁNCER:

1 COLON
2 PRÓSTATA
3 SENO
4 PULMONES

V OTHER
W DK
X RF

Q013_1c Su hermano es...

1 su hermano biológico
2 su medio hermano
3 su hermanastro

(GO TO -> BRO2, (IF ANY), SISTER Q014)

(GO TO -> BRO2, (IF ANY), SISTER Q014)

W DK
X RF

(GO TO -> BRO2, (IF ANY), SISTER Q014)

(GO TO -> BRO2, (IF ANY), SISTER Q014)

Q013_1d ¿Es su medio hermano por parte de su MAMÁ o de su PAPÁ?

1 MAMÁ
2 PAPÁ

W DK
X RF

HERMANO 2:

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q013_2aTyp) _____
(Q013_2bTyp) _____

(Q013_2aAge) _____
(Q013_2bAge) _____

TIPO DE CÁNCER:

1 COLON
2 PRÓSTATA
3 SENO

V OTRO
W DK
X RF

Q013_2c Su hermano es ...

1 su hermano biológico (GO TO -> BRO2, (IF ANY), SISTER Q014)
2 su medio hermano
3 su hermanastro (GO TO -> BRO2, (IF ANY), SISTER Q014)

W DK (GO TO -> BRO2, (IF ANY), SISTER Q014)
X RF (GO TO -> BRO2, (IF ANY), SISTER Q014)

Q013_2d Es su medio hermano por parte de su MAMÁ o de su PAPÁ?

1 MAMÁ
2 PAPÁ

W DK
X RF

HERMANO 3:

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q013_3aTyp)_____
(Q013_3bTyp)_____

(Q13_3aAge)_____
(Q13_3bAge)_____

(W=DK X=RF)
(W=DK X=RF)

TIPO DE CÁNCER:

1 COLON
2 PRÓSTATA
3 SENO
5 PULMONES

V OTRO
W DK
X RF

Q013_3c Su hermano es...

1 su hermano biológico
2 su medio hermano
3 su hermanastro

W DK
X RF

Q013_3d ¿Es su medio hermano por parte de su MAMÁ o de su PAPÁ?

1 MAMÁ
2 PAPÁ

W DK
X RF

NOTE FOR Q014:

ONLY DISPLAY THE CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q014.

Q014 ¿Algunas de sus hermanas? _____

1 SI -> Cuantas? _____ (Q014a)
0 NO (GO TO -> Q015)

W DK (GO TO -> Q015)
X RF (GO TO -> Q015)

HERMANA 1:

¿Que tipo de cáncer?

¿A que edad fue diagnosticada?

(Q014_1aTyp) _____
(Q014_1bTyp) _____

(Q014_1aAge) _____
(Q014_1bAge) _____

TIPO DE CÁNCER:

1 COLON
3 SENO
4 CERVIZ
5 PULMONES
6 OVARIOS
7 ENDOMETRIO

V OTRO
W DK
X RF

Q014_1c Su hermana es...

1 su hermana biológica (GO TO -> SISTER2, (IF ANY) OR SON Q015)
2 su media hermana (GO TO -> SISTER2, (IF ANY) OR SON Q015)
3 su hermanastra (GO TO -> SISTER2, (IF ANY) OR SON Q015)

W DK (GO TO -> SISTER2, (IF ANY) OR SON Q015)
X RF (GO TO -> SISTER2, (IF ANY) OR SON Q015)

Q014_1d ¿Es su media hermana por parte de su MAMÁ o de su PAPÁ?

1 MAMÁ
2 PAPÁ

W DK
X RF

HERMANA 2:

(Q014_2bTyp) _____

¿Que tipo de cáncer?

(Q014_2aTyp) _____

¿A que edad fue diagnosticada?

(Q014_2aAge)_____

(Q014_2bAge)_____

TIPO DE CÁNCER:

1 COLON

3 SENO

4 CERVIZ

5 PULMONES

6 OVARIOS

7 ENDOMETRIO

V OTRO

W DK

X RF

Q014_2c Su hermana es

1 su hermana biológica

(GO TO → SISTER3, (IF ANY), SON Q015)

2 su media hermana

3 su hermanastra

(GO TO → SISTER3, (IF ANY), SON Q015)

W DK

(GO TO → SISTER3, (IF ANY), SON Q015)

X RF

(GO TO → SISTER3, (IF ANY), SON Q015)

Q014_2d ¿Es su media hermana por parte de su MAMÁ o PAPA?

1 MAMÁ

2 PAPA

W DK

X RF

HERMANA 3:

¿Que tipo de cáncer?

¿A que edad fue diagnosticada?

(Q014_3aTyp)_____

(Q014_3aAge)_____

(Q014_3bTyp)_____

(Q014_3bAge)_____

TIPO DE CÁNCER:

1 COLON

3 SENO

4 CERVIZ

5 PULMONES

6 OVARIOS

7 ENDOMETRIO

V OTRO
W DK
X RF

Q014_3c Su hermana es..

1 su hermana biológica	(GO TO -> Q015)
2 su media hermana	
3 su hermanastra	(GO TO -> Q015)
W DK	(GO TO -> Q015)
X RF	(GO TO -> Q015)

Q014_3d ¿Es su media hermana por parte de su MAMÁ o de su PAPÁ?

1 MAMÁ
2 PAPÁ

W DK
X RF

NOTE FOR Q015:

ONLY DISPLAY THE CORRESPONDING NUMBER OF SON SECTIONS INDICATED IN Q015a

IF A SON WAS THE CASE, PHRASE Q015 AS:

HAN SIDO ALGUNOS DE SUS DEMAS HIJOS DIAGNOSTICADOS CON CANCER?

Q015 ¿Han sido algunos de sus hijos diagnosticados con cáncer?_____

1 SI -> Cuantos? _____ (Q015a)	
0 NO	(GO TO ->Q016)
W DK	(GO TO ->Q016)
X RF	(GO TO ->Q016)

HIJO 1:

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q015_1aTyp)_____
(Q015_1bTyp)_____

(Q015_1aAge)_____
(Q015_1bAge)_____

TIPO DE CÁNCER:

1 COLON
2 PRÓSTATA
3 SENO
5 PULMONES

V OTRO
W DK
X RF

Q015_1c Es su hijo...

- 1 su hijo biológico
- 2 su hijo adoptivo
- 3 su hijastro

(GO TO → SON2, (IF ANY), OR DAUGHTER Q016)
(GO TO → SON2, (IF ANY), OR DAUGHTER Q016)
(GO TO → SON2, (IF ANY), OR DAUGHTER Q016)

W DK

(GO TO → SON2, (IF ANY), OR
DAUGHTER Q016)

X RF

(GO TO → SON2, (IF ANY), OR DAUGHTER Q016)

HIJO 2:

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q015_2aTyp)_____
(Q015_2bTyp)_____

(Q015_3aAge)_____
(Q015_3bAge)_____

TIPO DE CÁNCER:

- 1 COLON
- 2 PRÓSTATA
- 3 SENO
- 5 PULMONES

V OTRO

W DK

X RF

Q015_2c Es su hijo...

- 1 su hijo biológico
- 2 su hijo adoptivo
- 3 su hijastro

(GO TO → SON3, (IF ANY), OR DAUGHTER Q016)
(GO TO → SON3, (IF ANY), OR DAUGHTER Q016)
(GO TO → SON3, (IF ANY), OR DAUGHTER Q016)

W DK
X RF

(GO TO → SON3, (IF ANY), OR DAUGHTER Q016)
(GO TO → SON3, (IF ANY), OR DAUGHTER Q016)

HIJO 3:

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q015_3aTyp)_____
(Q015_3bTyp)_____

(Q015_3aAge)_____
(Q015_3bAge)_____

TIPO DE CÁNCER:

- 1 COLON
- 2 PRÓSTATA
- 3 SENO
- 5 PULMONES

V OTRO

W DK

X RF

Q015_3c Es su hijo...

- 1 su hijo biológico
- 2 su hijo adoptivo
- 3 su hijastro

W DK
X RF

NOTE FOR Q016:

ONLY DISPLAY THE CORRESPONDING NUMBER OF DAUGHTER SECTIONS INDICATED IN Q016a

Q016 ¿Algunas de sus hijas?_____

1 SI -> Cuantas?_____ (Q016a)

0 NO

(GO TO -> Q017)

W DK

(GO TO -> Q017)

X RF

(GO TO -> Q017)

HIJA 1:

¿Que tipo de cáncer?

¿A que edad fue diagnosticada?

(Q016_1aTyp)_____

(Q016_1aAge)_____

(Q016_1bTyp)_____

(Q016_1bAge)_____

TIPO DE CÁNCER:

1 COLON

3 SENO

4 CERVIZ

5 PULMONES

6 OVARIOS

7 ENDOMETRIO

V OTRO

W DK

X RF

Q016_1c Es su hija...

1 su hija biológica

(GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017)

2 su hija adoptiva

(GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017)

3 su hijastra

(GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017)

W DK

(GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017)

X RF

(GO TO ->DAUGHTER2, (IF ANY), OR GRANNDFATHER Q017)

HIJA 2:

¿Que tipo de cáncer?

¿A que edad fue diagnosticada?

(Q016_2aTyp)_____

(Q016_2aAge)_____

(Q016_2bTyp)_____

(Q016_2bAge)_____

TIPO DE CÁNCER:

1 COLON

3 SENO

4 CERVIZ

5 PULMONES

6 OVARIOS

V OTRO
W DK
X RF

Q016_2c Es su hija...

1 su hija biológica (GO TO ->DAUGHTER3, (IF ANY), OR GRANNDFATHER Q017)
2 su hija adoptiva (GO TO ->DAUGHTER3, (IF ANY), OR GRANNDFATHER Q017)
3 su hijastra (GO TO ->DAUGHTER3, (IF ANY), OR GRANNDFATHER Q017)

W DK (GO TO ->DAUGHTER3, (IF ANY), OR GRANNDFATHER Q017)
X RF (GO TO ->DAUGHTER3, (IF ANY), OR GRANNDFATHER Q017)

HIJA 3:

¿Que tipo de cáncer?

¿A que edad fue diagnosticada?

(Q016_3aTyp)_____
(Q016_3bTyp)_____

(Q016_3aAge)_____
(Q016_3bAge)_____

(W=DK X=RF)
(W=DK X=RF)

TIPO DE CÁNCER:

1 COLON
3 SENO
4 CERVIZ
5 PULMONES
6 OVARIOS
7 ENDOMETRIO

V OTRO
W DK
X RF

Q016_3c Es su hija...

1 su hija biológica
2 su hija adoptiva
3 su hijastra

W DK
X RF

NOTE FOR Q017:

ONLY DISPLAY THE CORRESPONDING NUMBER OF GRANDFATHER SECTIONS INDICATED IN Q017a

Q017 ¿Algunos de sus abuelos? _____

1 SI ----> Cuantos? _____ (Q017a)
0 NO

(GO TO -> Q018)

W DK
X RF

(GO TO -> Q018)
(GO TO -> Q018)

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q017_1aTyp)_____

(Q017_2aAge)_____

(Q017_1bTyp)_____

(Q017_2bAge)_____

TIPO DE CÁNCER:

1 COLON

2 PRÓSTATA

3 SENO

5 PULMONES

V OTRO

W DK

X RF

Q017_1c ¿Es su abuelo materno o paterno?

1 MATERNO

(GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018)

2 PATERNO

(GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018)

W DK

(GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018)

X RF

(GO TO GRANDFATHER2 (IF ANY) OR GRANDMOTHER Q018)

ABUELO 2:

¿Que tipo de cáncer?

¿A que edad fue diagnosticado?

(Q017_2aTyp)_____

(Q017_2aAge)_____

(Q017_2bTyp)_____

(Q017_2bAge)_____

TIPO DE CÁNCER:

1 COLON

2 PRÓSTATA

3 SENO

5 PULMONES

V OTRO

W DK

X RF

Q017_2c ¿Es su abuelo materno o paterno?

1 MATERNO

2 PATERNO

W DK

X RF

NOTE FOR Q018:

ONLY DISPLAY THE CORRESPONDING NUMBER OF SISTER SECTIONS INDICATED IN Q018a

1 SI -> Cuantas? _____(Q018a)
0 NO (GO TO -> Q019)

W DK (GO TO -> Q019)
X RF (GO TO -> Q019)

ABUELA 1:

¿Que tipo de cáncer? ¿A que edad fue diagnosticada?
(Q018_1aTyp)_____ (Q018_2aAge)_____
(Q018_1bTyp)_____ (Q018_2aAge)_____

TIPO DE CÁNCER:

1 COLON
3 SENO
4 CERVIZ
5 PULMONES
6 OVARIOS
7 ENDOMETRIO

V OTRO
W DK
X RF

Q018_1 ¿Es su abuela materna o paterna?

1 MATERNA (GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019)
2 PATERNA (GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019)

W DK (GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019)
X RF (GO TO GRANDMOTHER2 (IF ANY) OR OTHER FAMILY Q019)

ABUELA 2:

¿Que tipo de cáncer? ¿A que edad fue diagnosticada?
(Q018_2aTyp)_____ (Q018_2aAge)_____
(Q018_2bTyp)_____ (Q018_2bAge)_____

TIPO DE CÁNCER:

1 COLON
3 SENO
4 CERVIZ
5 PULMONES
6 OVARIOS
7 ENDOMETRIO

V OTRO
W DK
X RF

Q018_2c ¿Es su abuela materna o paterna?

- 1 MATERNA
- 2 PATERNA

W DK
X RF

Q019 ¿Hay alguien más en su familia que haya tenido cáncer? _____

- 1 SI
- 0 NO

(GO TO → Q021)

W DK
X RF

(GO TO → Q021)
(GO TO → Q021)

Q020 ¿Quien?

¿Relación?

¿Tipo de cáncer?

¿A que edad fue diagnosticado/a?

(Q021a1) _____
(Q021a2) _____
(Q021a3) _____

(Q021b1) _____
(Q021b2) _____
(Q021b3) _____

(Q021c1) _____
(Q021c2) _____
(Q021c3) _____

RELACIÓN

- 1 SOBRINA
- 2 SOBRINO
- 3 TÍA
- 4 TÍO
- 5 PRIMO/A
- 6 NIETA
- 7 NIETO

V OTRO
W DK
X RF

TIPO DE CÁNCER:

- 1 COLON
- 2 PRÓSTATA
- 3 SENO
- 4 CERVIZ
- 5 PULMONES
- 6 OVARIOS
- 7 ENDOMETRIAL

V OTRO
W DK
X RF

NOTE FOR Q021:

* IF RID = '2' CHOOSE HIJO; IF RID = '4' CHOOSE HERMANO; IF RID = '6' CHOOSE PAPÁ

* INSERT PTFNAME IN BLANK

IF CASE HAS DIED, SKIP Q021

Q021 Con respeto a su [PAPA, HERMANO, HIJO] _____ quien tuvo cáncer de la próstata diría usted el cancer se le ha ...

- 1 regresado
- 2 no ha regresado
- 3 desarrollado a otras partes del cuerpo

W DK

X RF

NOTE FOR Q023 IF CASE HAS DIED READ: ANTES DE EL MORIR, COMO VIO USTED SU TRATAMIENTO DE CANCER. DIRIA QUE FUE...

Q023 Diría usted que su tratamiento y su recuperación del cáncer de la próstata fue...

- 1 muy difícil
- 2 un poco difícil
- 3 nada difícil

W DK

X RF

Q024 Ahora me gustaría hacerle unas preguntas acerca de sus sentimientos sobre el cáncer de la próstata.

¿Con que frecuencia piensa usted en la posibilidad de desarrollar cáncer de la próstata? Diría que....

- 1 muy seguido
- 2 de vez en cuando
- 3 nunca

W DK

X RF

Q025 ¿Que tan preocupado esta de que pueda desarrollar cáncer de la próstata? Diría que...

- 1 muy preocupado
- 2 algo preocupado
- 3 nada preocupado

W DK

X RF

Q026 ¿Cuando piensa en la posibilidad de desarrollar cáncer de la próstata, que tan temeroso se pone? Diría que...

- | | |
|-----------------|------|
| 1 muy temeroso | W DK |
| 2 algo temeroso | X RF |
| 3 nada temeroso | |

Q027 ¿Diría que usted esta muy nervioso, algo nervioso, o nada nervioso de que pueda desarrollar cáncer de la próstata?

- 1 MUY NERVIOSO
- 2 ALGO NERVIOSO
- 3 NADA NERVIOSO

W DK
X RF

Q028 ¿Piensa, mas de lo que usted desea , en que pueda desarrollar cáncer de la próstata?

- 1 SI
- 0 NO

W DK
X RF

Q030 Ahora le quiero hacer unas preguntas sobre su salud y algunos de los exámenes para el cancer de la prostata.

Durante los últimos 12 meses, ha tenido un examen físico completo?

- 1 SI
- 0 NO

W DK
X RF

Q031 Un examen que se hace para detectar el cáncer de la próstata es el DRE o sea examen digital del recto. Para este examen un dedo es introducido en el recto para examinar el área por algún problema con la próstata y el intestino mayor. ¿Alguna vez usted ha oído hablar de este análisis?

- 1 SI
- 0 NO

W DK
X RF

Q032 ¿Ha tenido alguna vez un examen digital del recto- DRE?

- 1 SI
- 0 NO (GO TO - Q034)

W DK (GO TO - Q034)
X RF (GO TO - Q034)

Q033 ¿Cuando fue su examen mas reciente digital del recto?

- 1 en los últimos 12 meses
- 2 de 1 a 2 años
- 5 de 2 a 3 años
- 3 de 3 a 5 años
- 4 mas de 5 años

W DK
X RF

- Q034 En adición al examen digital del recto, existe un análisis de sangre que se usa para detectar cáncer de la próstata. Este análisis de sangre se llama PSA o sea "antígenos específicos de la próstata". ¿Ha tenido usted alguna vez un análisis de sangre PSA?
- 1 SI
0 NO
- W DK
X RF
- Q035 ¿Le ha recomendado su doctor (o enfermera) que se haga un análisis de sangre PSA?
- 1 SI
0 NO
- W DK
X RF
- Q037 ¿Ha tenido usted alguna vez un análisis de sangre PSA?
- 1 SI
0 NO (GO TO Q041)
- W DK (GO TO Q041)
X RF (GO TO Q041)
- Q038 ¿Cuántos análisis PSA ha tenido? ¿Diría que?
- 1 uno
2 mas de uno
- W DK
X RF
- Q039 ¿Cuando fue su análisis de sangre PSA mas reciente? Diría que fue...
- 1 en los últimos 12 meses W DK
2 de 1 o 2 años X RF
5 De 2 a 3 años
3 de 3 a 5 años
4 mas de 5 años
- Q040 ¿Por que le hicieron el análisis PSA? Fue por algún problema de salud o como parte de un examen de rutina?
- 1 POR UN PROBLEMA DE SALUD
2 PARTE DE UN EXAMEN RUTINARIO
- V OTHER (Specify) _____ (Q040s)
W DK
X RF

Q041 ¿Alguna vez a ido con un urólogo? Un urólogo es un doctor que se especializa en los problemas de los riñones, vesícula, testículo y próstata.

1 SI
0 NO

W DK
X RF

Las siguientes preguntas son acerca de exámenes utilizados para detectar otros tipos de cancer.

Q042 Una sigmoidoscopia o colonoscopia es cuando un instrumento largo y flexible con una luz terminal se introduce al recto y al colon para examinar posibles problemas. ¿Había usted oído hablar de este examen?

1 SI
0 NO

W DK
X RF

Q043 ¿Ha tenido usted alguna vez una sigmoidoscopia o una colonoscopia?

1 SI
0 NO (GO TO Q045)

W DK (GO TO Q045)
X RF (GO TO Q045)

Q044 ¿Cuándo fue su mas reciente sigmoidoscopia o colonoscopia? Diría usted que fue...

1 en los últimos 12 meses
2 de 1 o 2 años
3 de 2 a 3 años
4 de 3 a 5 años
5 de 5 a 10 años
6 mas de 10 años

W DK
X RF

Q045 Otro análisis que se hace para detectar el cáncer del colon es el examen de excremento que detecta si hay sangre en el excremento. Para este examen usted pone una poco de su excremento en una tarjeta, todos los días por 3 días y es analizado por una clínica. Usualmente se le pedirá que se abstenga de comer carne roja o ciertas frutas y vegetales durante este tiempo. ¿Alguna vez ha oído hablar del examen de excremento que detecta sangre?

1 SI
0 NO

W DK
X RF

Q046 ¿Alguna vez se ha hecho en casa el examen de excremento que detecta sangre?

1 SI
0 NO (GO TO Q048)

Q047 ¿Cuando se hizo el examen mas reciente de excremento para detectar sangre? Diria que fue...

- 1 en los últimos 12 meses
- 2 de 1 o 2 años
- 5 de 2 a 3 años
- 3 de 3 a 5 años
- 4 mas de 5 años

W DK
X RF

Q048 Ahora le voy hacer algunas preguntas solamente para propósitos de estadísticas generales.
Recuerde que sus preguntas son confidenciales.

¿Cual es el nivel de educación mas alto que usted ha completado?

NINGUNA ESCUELA	00								
ESCUELA ELEMENTARÍA	01	02	03	04	05	06	07	08	
SECUNDARIA	09	10	11	12					
UNIVERSIDAD	13	14	15	16					
MAS DE UNIVERSIDAD (4 YRS)	17	18	19	20					

W DK
X RF

Q049 ¿Nació usted en los Estados Unidos?

1 SI (GO TO -> Q052)
0 NO

W DK
X RF

Q050 ¿En que país nació? _____

W DK
X RF

Q051 ¿Cuanto tiempo tiene viviendo en los Estados Unidos?
(Q051yy)Años: _____ (Q051mm)Meses: _____

W DK
X RF

Q052 ¿Se considera Usted...?

1 Afro-Americano	(GO TO -> Q054)
2 Hispano / Latino	(GO TO -> Q055)
3 Asiático / Asiático-Americano	(GO TO -> Q056)
B Indio Asiatico	(GO TO -> Q057)
8 Europeo	(GO TO -> Q057)
9 Europeo del este	(GO TO -> Q057)

- A Europeo del oeste (GO TO -> Q053)
5 Americano Indigena/ Americano Nativo (GO TO -> Q057)
6 Isleno del Pacifico (Hawaii, Guam Samoa, other South Pacific Island) (GO TO -> Q057)
4. Blanco (GO TO -> Q057)
7 de dos razas o de diversas razas (specify)_____ (Q052s1) (GO TO -> Q053)

V. Other: (specify)_____ (Q052s2) (GO TO -> Q057)

W DK

X RF

Q053 ¿Con cual nacionalidad se identifica mas? _____

Q054 Es usted...

- 1 Afro-Americano
2 Indio del Oeste (incluye Islas del Caribe)
3 Cubano
4 Sur Americano
5 Puertorriqueño

V OTHER _____ (Q054s)

W DK

X RF

Q055 Es Usted...

- 1 Mexicano
2 Mexicano Americano
3 Chicano
4 Centro Americano
5 Sur Americano
6 Puertorriqueño
7 Cubano

V Other (Specify) _____ (Q055s)

W DF

X RF

Q056 Es Usted...

- 1 Chino
2 Japones
3 Filipino
4 Vietnamita
5 Camboyano
6 Indígena Asiático
7 Indonesio
8 Coreano

V OTHER _____ (Q056s)

W DK

X RF

Q057 / Cual de las siguientes cantidades mejor describe el ingreso total en su hogar, o sea el ingreso total de todas las personas viviendo con usted. No necesito una cantidad exacta, solamente un estimado. Recuerde, sus respuestas son confidenciales. Diría que aproximadamente...

- 1 Menos de \$10,000 (0-833.33/mes)
- 2 \$10,000 - 24,000(833.33 - 2000/mes)
- 3 \$25,000 - 39,000 (2083.33 - 3250/mes)
- 4 \$40,000 - 54,000(3333.33 - 4583.33/mes)
- 5 mas de \$55,000 (mas de 4,583.33/mes)

W DK
X RF

Q058 ¿Es usted casado o esta viviendo como casado?

1 SI
0 NO

W DK
X RF

Q058A ¿Cual es su fecha de nacimiento, por favor? ______?
MM DD YY

Q059 Ahora le voy a leer una lista de cosas que algunas personas piensan que hacen a un hombre mas probable de desarrollar cáncer de la próstata. Para cada una de estas preguntas dígame si usted cree o no cree que hace a un hombre mas probable de desarrollar cáncer de la próstata.

“¿Cree usted que _____ hace a un hombre mas probable de desarrollar cáncer de la próstata”?

- Q059a edad avanzada? _____
- Q059b ciertos alimentos? _____
- Q059c demasiado “estrés” ? _____
- Q059d tener familiares con cáncer de la próstata? _____
- Q059e beber alcohol? _____
- Q059f falta de ejercicio o actividad física del cuerpo? _____
- Q059g estar expuesto a químicos o radiación en el empleo o en la comunidad? _____
- Q059h tener demasiadas relaciones sexuales? _____
- Q059i sentarse sobre una superficie fría? _____
- Q059j ausencia de relaciones sexuales? _____

1 SI
0 NO
2 POSIBLEMENTE

W DK
X RF

Q060 ¿Quien cree usted que desarrolla cáncer de la próstata con mas frecuencia? Diría que...

- 1 Blancos
- 2 Hispanos/Latinos
- 3 Afro-Americanos
- 4 Asiáticos/Asia-Americanos
- 5 No hay diferencia

W DK
X RF

Q061 ¿Que tan probable es que usted desarrolle cáncer de la próstata durante su vida? Diría usted...

- 1 muy probable
- 2 poco probable
- 3 nada probable

W DK
X RF

Las siguientes preguntas son relacionadas con sus creencias acerca del análisis de sangre PSA- Antígenos específicos de la próstata.

- Q065 ¿Es importante para usted tener un análisis de sangre PSA? _____
- Q066 ¿Le seria a usted difícil pagar los costos de un análisis de sangre PSA? _____
- Q071 ¿Usted piensa que tendrá problemas en obtener transportación para ir a su cita con el doctor? _____
- Q064 ¿Esta temeroso de que le hagan estos análisis? _____
- Q067 ¿Tiene temor que durante estos análisis demuestren que usted tiene cáncer de la próstata? _____
- Q068 ¿Cree Ud que se puede curar el cáncer de la próstata si es encontrado temprano? _____
- Q070 ¿Usted piensa que los análisis de la próstata pueden causar problemas sexuales? _____
- Q072 ¿Cree usted que solamente necesita examinarse la sangre con un análisis de PSA nomas cuando un doctor lo recomienda? _____
- Q062 ¿Antes de que habláramos hoy, sabia usted que debe de tener un examen digital del recto cada año? _____
- Q063 ¿Sabia usted que debe de hacerse un análisis de sangre PSA cada año? _____

- 1 SI
- 0 NO
- 2 NINGUNA OPINION

W DK
X RF

Q073 Diría usted que esta de acuerdo o no esta de acuerdo con las siguientes declaraciones:

Los beneficios de un examen de sangre PSA son mayores que cualquier inconveniencia.

- 1 esta de acuerdo
- 2 no esta de acuerdo

W DK
X RF

Q074 Uno solamente necesita un análisis preventivo de la próstata cuando tiene los síntomas.

- 1 esta de acuerdo
- 2 no esta de acuerdo

W DK
X RF

Q075 Es mucha molestia tener que examinarse para el cáncer de la próstata y poco el beneficio que se obtiene.

- 1 esta de acuerdo
- 2 no esta de acuerdo

Q076 Usted no tiene tiempo para hacerse estos análisis.

- 1 esta de acuerdo
- 2 no esta de acuerdo

W DK
X RF

Q077 ¿Cuántos de sus amigos o familiares se hacen los análisis de cáncer de la próstata? Diría usted que...

- 1 la mayoría
- 2 algunos
- 3 ninguno

W DK
X RF

Q078 ¿Piensa usted que puede hacer algo para prevenir el cáncer de la próstata?

- 1 SI
- 0 NO
- 2 tal vez

W DK
X RF

Q079 ¿Alguna vez ha discutido su riesgo personal de desarrollar cáncer de la próstata con algún amigo o familiar?

- 1 SI
- 0 NO

W DK
X RF

Q080 ¿Alguna vez ha discutido su riesgo personal de desarrollar cáncer de la próstata con su doctor?

- 1 SI
- 0 NO

W DK
X RF

Q081 Ahora me gustaria hacerle preguntas sobre su seguro medico.

¿Esta usted cubierto por Medicare?

- 1 SI
- 0 NO

W DK
X RF

Q082 ¿Tiene usted Medicaid/MediCal?

1 SI
0 NO

W DK
X RF

Q083 ¿Tiene algún otro seguro medico?

1 SI
0 NO

(GO TO ->Q084)

W DK
X RF

(GO TO ->Q084)

(GO TO ->Q084)

Q084 ¿Es?

Q084a Un HMO con sus propios médicos y clínicas (como Kaiser,FHP, o Maxicare)_____

Q084b Es un plan con una lista de médicos que usted pueda escoger (como Prudential, Health Net, California Care, or Care America)?_____

Q084c Seguro medico privado que paga por cualquier doctor que usted escoja (como Blue Cross, Aetna, Travellers, or Mutual of Omaha)_____

Q084s Es otro tipo de seguro medico? Specify_____

1 SI
0 NO

W DK
X RF

IF Q081, Q082 OR Q083 = "1", ASK Q085, OTHERWISE SKIP TO Q086.

Q085 ¿Cubre su seguro medico el costo de un análisis de sangre PSA?

1 YES
0 NO

W DK
X RF

Q086 Un examen de rutina de la prostata PSA se hace para chequeo solamente, cuando no hay ningún síntoma presente. Para la proxima pregunta, piense en alguien como usted que tiene un familiar cercano con cáncer de la próstata.

¿A que edad debe alguien como usted empezar a hacerse este examen? Diría que a la edad de...

1 30
2 40
3 50
4 60

W DK
X RF

Q087 ¿Con que frecuencia debe un hombre como usted hacerse un análisis de sangre PSA (antígenos específicos de la próstata) diría usted?

- 1 Cada 6 meses
- 2 Cada año
- 3 Cada 2-3 años
- 4 Cada 3-5 años
- 5 Cada 5-10 años

W DK

X RF

NOTE FOR Q088 & Q089:

*IF RID = "2" CHOOSE HIJO; IF RID = "4" CHOOSE HERMANO; IF RID = "6" CHOOSE PADRE. 33% OF SUBJECTS WILL BE RANDOMLY BE ASSIGNED TO RECEIVE SNR1; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR2; 33% OF SUBJECTS WILL BE RANDOMLY ASSIGNED TO RECEIVE SNR3. SNR3 WILL ONLY RECEIVE QUESTIONS Q088 AND Q089. THEY WILL NOT RECEIVE A SENARIO.

En esta proxima seccion, le voy a leer un breve escenario y dos preguntas. Por favor tenga paciencia.

Q088. (SNR1) Escenario uno: Un escenario al azar para un 33% de la muestra de los participantes; esto se leerá de la siguiente manera:

El cáncer de la próstata es la segunda causa de muerte de cancer en los hombres. Si usted tiene un hermano, padre, hijo con cáncer de la próstata esto aumenta su riesgo para desarrollar cáncer de la próstata. Los doctores están de acuerdo que la detección temprana de cáncer de la próstata es muy importante. Pero los doctores están en desacuerdo con el uso extendido de PSA como un análisis preventivo.

Algunos doctores sienten que el análisis PSA no es muy preciso. Supongamos que un hombre tiene niveles altos de PSA en su sangre. Esto puede significar que el tiene cáncer, pero también puede significar que su próstata esta inflamada. Porque uno no sabe lo que realmente es, el paciente puede necesitar una biopsia para saber con seguridad. Durante una biopsia una muestra pequeña de tejido de la próstata es extraída y analizada.

Ahora, supongamos que un hombre tiene un nivel normal de PSA en su sangre. La mayor parte del tiempo un nivel normal de PSA significa que la persona no tiene cáncer. Sin embargo, un hombre puede tener un nivel normal de PSA en su sangre y si tener cáncer.

Actualmente, el análisis de sangre PSA es el único análisis disponible Los doctores piensan que un análisis de sangre PSA puede detectar el cáncer tempranamente. De cada 10 canceres que son detectados temprano 9 pueden ser curados. Entonces, los doctores, como también la Asociación Americana de Cáncer, recomiendan altamente que hombres mayores de 40 años tengan un examen anual de sangre PSA, especialmente si tiene un miembro de la familia que haya tenido cáncer de la próstata.

Dado a lo que ha escuchado.....

Q088. (SNR2) Escenario dos: Un escenario al azar para un 33% de la muestra de los participantes; esto se leerá de la siguiente manera:

El cáncer de la próstata es la segunda causa de muerte del cancer en los hombres. Si usted tiene un [hermano, padre, hijo] con cáncer de la próstata esto aumenta su riesgo para desarrollar cáncer de la próstata. Los doctores están de acuerdo que la detección temprana de cáncer de la próstata es muy importante. Pero los doctores están en desacuerdo con el uso extendido de PSA como un análisis preventivo.

Actualmente, el análisis de sangre PSA es el único análisis disponible. Los doctores piensan que un análisis de sangre PSA puede detectar el cáncer tempranamente. De cada 10 canceres que son

detectados temprano 9 pueden ser curados. Es por eso que muchos doctores, como también la Asociación Americana de Cáncer, recomiendan altamente que hombres mayores de 40 años tengan un examen anual de sangre PSA, especialmente si tiene un miembro de la familia que haya tenido cáncer de la próstata.

Algunos doctores sienten que el análisis PSA no es muy preciso. Supongamos que un hombre tiene niveles altos de PSA en su sangre. Esto puede significar que el tiene cáncer, pero también puede significar que su próstata está inflamada. Porque uno no sabe lo que realmente es, el paciente puede necesitar una biopsia para saber con seguridad. Durante una biopsia una muestra pequeña de tejido de la próstata es extraída y analizada.

Ahora, supongamos que un hombre tiene un nivel normal de PSA en su sangre. La mayor parte del tiempo un nivel normal de PSA significa que la persona no tiene cáncer. Sin embargo, un hombre puede tener un nivel normal de PSA en su sangre y si tener cáncer.

Dado lo que ha escuchado.....

Q088. (SNR3) SCENARIO THREE: NO TEXT ONLY QUESTIONS ASKED 33% OF PARTICIPANTS.

Que tan probable es que usted le pida a su doctor/a (o enfermera/o) que le hagan un análisis para el cáncer de la próstata?

- 1 Muy probable
- 2 Algo probable
- 3 Nada probable

W DK
X RF

Q089 ¿Que tan probable es que usted se haga un análisis de sangre PSA en los próximos 12 meses?

- 1 muy probable
- 2 algo probable
- 3 nada probable

W DK
X RF

PRUEBAS CLÍNICAS

Q092 En esta ultima seccion le hare preguntas sobre las pruebas clinicas. Una prueba clínica es un estudio de experimentación hecho por doctores para encontrar la mejor manera de prevenir una enfermedad o tratar una enfermedad. Algunas pruebas son hechas con pacientes de cáncer para probar diferentes tratamientos. Otros estudios examinan cosas como si la dieta, ejercicio, o detección temprana puede prevenir una enfermedad en personas saludables.

¿Alguna vez a participado en una prueba clínica?

- 1 SI
- 0 NO

W DK (GO TO Q092)
X RF (GO TO Q092)

Q093 ¿Que clase de prueba fue?
Por favor especifique: _____

W DK

Q094 ¿Alguna vez ha oído hablar de las pruebas preventivas para el cáncer de la próstata, pulmones, colon, o cáncer de los ovarios?

1 SI
0 NO

W DK
X RF

Q095 Las siguientes pruebas son estudios grandes las cuales incluyen miles de hombres saludables. Estas pruebas son gratis.

La prueba de Prevención de Cáncer de la Próstata (PCPT) es un estudio hecho para ver si el medicamento *finasteride* puede prevenir cáncer de la próstata. En este estudio se le dará la droga a mitad de las hombres y a la otra mitad se les dará una pastilla de azúcar. Al terminar los 7 años, todos los hombres tendrán una biopsia de la glándula de la próstata, en la cual una pequeña prueba de tejido es tomada.

¿Si le pidieran que participe en un estudio como este, participaría?

1 SI
2 NO

W DK
X RF

Q096 ¿Cual de las siguientes seria una razón por la cual no participaría en este estudio?

	SI	NO	DK	RF
Q096a tener que tomar una pastilla diariamente por siete años	1	0	W	X
Q096b los posibles efectos secundarios	1	0	W	X
Q096c tener una biopsia	1	0	W	X

Q097 Otra prueba clínica es el PLCO. Es un estudio de para ver si un análisis de sangre PSA y un análisis del recto puede detectar cáncer de la próstata temprano. La mitad de los hombres recibirán el análisis de sangre PSA y un examen del recto una vez al año por 4 años, y la otra mitad no recibirá ningún análisis. Todos los hombres, que hayan recibido o que no hayan recibido los análisis tendrán que llenar un cuestionario cada ano.

¿Si le pidieran que participe en un estudio como este, participaría?

1 SI
2 NO

W DK
X RF

Q098 Cual de las siguientes seria una razón por la cual no participaría en este estudio?

	SI	NO	DK	RF
Q098a tener que recibir un análisis de sangre	1	0	W	X
Q098b tener que recibir un análisis del recto	1	0	W	X

Q099 Hay una nueva prueba clínica que comenzara pronto. Hombres tendran que tomar la vitamina E y el mineral selenio y mirara si la vitamina E y el selenio puede prevenir cancer de la prostata por un mínimo tiempo de 7 años y un máximo tiempo de 12 años. Este estudio no requiere tomar medicamentos o tener una biopsia.

¿Si le pidieran que participe en un estudio como este, participaría?

1 SI

2 NO

W DK

X RF

Q100 ¿Cual de las siguientes seria una razón por la cual no participaría en este estudio?

	SI	NO	DK	RF
Q100a el tener que tomar vitaminas	1	0	W	X
Q100b la duración del estudio (7-12años)	1	0	W	X

Q101 Hay muchas razones por las cuales algunas personas no participan en pruebas clínicas. Por favor digame si algunas de las siguientes razones le aplican a usted:

- Q101a Tener miedo de ser utilizado como un animalito de prueba _____
- Q101b Tener miedo de desarrollar cáncer como un resultado de su participación _____
- Q101c Temor de quedar impotente _____
- Q101d Nunca ha pensado poder participar _____
- Q101e Doctor nunca le recomendó participar _____
- Q101f Es asociado con la homosexualidad _____
- Q101g Es muy incómodo o doloroso _____
- Q101h Puede pensar en otras razones por la cual no participa? _____

1 SI

0 NO

W DK

X RF

Q102 Por favor digame si usted esta de acuerdo o no esta de acuerdo con las siguientes frases:

El participar en pruebas medicas puede ayudar a otros.

1 De acuerdo

0 No esta de acuerdo

2 No tengo ninguna opinión

W DK

Q103 El participar en pruebas medicas me va a prolongar la vida.

- 1 De acuerdo
- 0 No esta de acuerdo
- 2 No tengo ninguna opinión

W DK

X RF

Q104 Yo puedo aprender algo que beneficie mi salud.

- 1 De acuerdo
- 0 No esta de acuerdo
- 2 No tengo ninguna opinión

W DK

X RF

Q105 Esto concluye la entrevista. Antes de colgar le quisiera dar brevemente unos datos acerca del cáncer de la próstata. Al comenzar la entrevista le pregunte su opinión acerca de lo que usted piensa que hace a un hombre mas probable a desarrollar cáncer de la próstata. Creemos que es muy importante decirles a todas las personas lo que esta científicamente comprobado de causar cáncer de la próstata. Una combinación de los siguientes aspectos incrementa la probabilidad de desarrollar cáncer de la próstata.

- ❖ Edad avanzada [mayor de 55 anos de edad]
- ❖ Tener familiares con cáncer de la próstata como su padre, hermano o hijo.
- ❖ Tener un familiar diagnosticado antes de la edad de 60 anos.
- ❖ Ser Afro-Americano

Usted debe de saber que hacer ejercicio y una dieta baja en grasa puede reducir su riesgo.

Q106 Muchos hombres piensan que otras cosas hacen a un hombre probable de desarrollar cáncer de la próstata, las siguientes ideas no son relacionadas con cáncer de la próstata.

- ❖ Tener muchas relaciones sexuales
- ❖ Tener demasiada tención [stress]
- ❖ Ausencia de relaciones sexuales
- ❖ Sentarse sobre superficies frías

Ademas, tomar alcohol no has sido comprobado científicamente de causar cáncer de la próstata.

Q107 Si quisiera mas información acerca del cáncer de la próstata, detección temprana y tratamiento, puede llamar al centro de información de cáncer. ¿Quisiera que le diera este numero?

NOTE FOR Q108M:

PLEASE DISPLAY RADDRES, RCITY, RZIPCOD, RPHON_W, AND RPHON_M FROM
RELATIVE TRACKING DATABASE

Q108 Quisiera verificar su domicilio para poder mandarle información sobre el cancer de la
prostata. También me gustaría tomar numero de teléfono de un pariente o una amistad
donde lo podamos encontrar o dejar un mensaje.

(REPEAT ADDRESS AND PHONE NUMBER ON FILE- SPECIFY NEW ADDRESS AND
PHONE NUMBERS _____(Q108M MEMO FIELD). (BLANK O.K.)

ENTER Y IF ADDRESS ETC. CHANGED, = = UPPER CASE ONLY

Q109 Si continuamos con el estudio en el fututo, ¿podríamos comunicarnos con usted de nuevo?

1 SI

0 NO

W DK

X RF

De parte de nuestro proyecto le agradezco su tiempo. Adiós.

Appendix 2: Sample recruitment materials

- **Case recruitment: White cases**
- **Case recruitment: Asian cases**
- **Relative recruitment: African-American relatives**
- **Relative recruitment: Hispanic relatives (in English)**
- **Relative recruitment: Hispanic relatives (in Spanish)**

Appendix 3: Mailed questionnaire

UCLA Prostate Cancer Survey

Please be assured that there are no or wrong answers. We are interested in finding out what you feel and what you believe about cancer and other issues.

1. Please tell us your age: _____ years. (Q001)

2. Has a doctor ever told you that you have or had prostate cancer?

_____ YES (1) _____ NO (0) (Q004)

PLEASE NOTE: If you are not between the ages of 40 and 75 years of age or if you have had prostate cancer, you do not need to fill out this survey. This study is only for people who are between 40 and 75 years of age, AND who have never had **prostate** cancer. Please return the survey for our records. Your help is appreciated. Thank you.

3. Has a doctor ever told you that you have an enlarged or swollen prostate? This is also known as Benign Prostatic Hyperplasia (BHP)?

_____ YES (1) _____ NO (0) (Q008)

4. Have any of your relatives been diagnosed with cancer?

_____ YES (1) _____ NO (0) (Q011)

If YES, in the table below, please list (1) the name of your relative who has been diagnosed with cancer, (2) his/her relationship to you (for example, mother, father, sister, brother, daughter, son, aunt, uncle, cousin, grandfather, grandmother), (3) his/her age when diagnosed with cancer, and (4) the type of cancer. If you need more space, please use the back of this page.

Name of Relative (1)	Relationship (2)	Age at Diagnosis (3)	Type of Cancer (4)
i.e. James Hill	Brother	47	Colon

The next few questions are about screening tests for prostate cancer.

5. One test that is done to find prostate cancer is the Digital Rectal Exam (DRE). For this test, a finger is inserted into the rectum to check for problems with the prostate and large bowel. Have you ever heard of a Digital Rectal Exam?

_____ YES (1) _____ NO (0) (Q031)

6. Have you ever had a Digital Rectal Exam?

_____ YES (1) _____ NO (0) (Q032)

Note: Please skip question 7, if you answered NO to question 6.

7. When was your most recent Digital Rectal Exam? Was it... (Q033)

____ Within the last 12 months (1)
____ 1 to 2 years ago (2)
____ 2 to 3 years ago (5)
____ 3 to 5 years ago (3)
____ More than 5 years ago (4)

8. The Prostate Specific Antigen (PSA) test is a special blood test that is used to check for prostate cancer. Have you ever heard of a PSA?

_____ YES (1) _____ NO (0) (Q034)

9. Have you ever had a Prostate Specific Antigen test?

_____ YES (1) _____ NO (0) (Q037)

Note: Please skip question 10, if you answered NO to question 9.

10. When was your most recent Prostate Specific Antigen test? Was it...

(Q039)

- ☐ Within the last 12 months (1)
- ☐ 1 to 2 years ago (2)
- ☐ 2 to 3 years ago (5)
- ☐ 3 to 5 years ago (3)
- ☐ More than 5 years ago (4)

11. Have you ever been to a urologist? A urologist is a doctor that treats disease of the kidneys, bladder, testicles, and prostate.

☐ YES (1)

☐ NO (0)

(Q041)

The next section is for our general information only. Remember that your answers are confidential.

12. What is the highest level in school that you have completed?

(The numbers represent the years of schooling you have completed. Please circle one answer.)

(Q048)

NO SCHOOL	00							
GRADE SCHOOL	01	02	03	04	05	06	07	08
HIGH SCHOOL	09	10	11	12				
COLLEGE	13	14	15	16				
POST COLLEGE	17	18	19	20				

13. In which country were you born? _____

(Q050)

14. If you were not born in the U.S., how long have you lived in the U.S.?

(Q051)

☐ Years (Q051yy) ☐ Months (Q051mm)

15. Which of the following do you consider yourself to be? (Q052)

- ☐ Black/African-American, *specify* _____ (1)
☐ Hispanic/Latino, *specify* _____ (2)
☐ Asian/Asian-American, *specify* _____ (3)
☐ Middle Eastern (8)
☐ Eastern European (9)
☐ Western European (A)
☐ White/Caucasian - American (4)
☐ American Indian/ Native American (5)
☐ Pacific Islander (Hawaii, Guam, Samoa, other South Pacific Island) (6)
☐ Mixed (Bi- or Multi-racial), *specify* _____ (7) (Q053)
☐ Other, *specify* _____ (V) (Q052s2)

16. Which of the following best describes your total household income, that is the yearly income of all family members living with you? We do not need the exact amount, just a range. And remember, your answer is confidential. Would you say approximately... (Q057)

- ☐ Less than \$10,000 (\$0 - \$833.33/month) (1)
☐ \$10,000 - \$24,000 (\$833.33 - \$2000/month) (2)
☐ \$25,000 - \$39,000 (\$2083.33 - \$3250/month) (3)
☐ \$40,000 - \$54,000 (\$3333.33 - \$4500/month) (4)
☐ More than \$55,000 (More than \$4583.33/month) (5)

17. Are you currently married or living with someone as married?

- ☐ YES (1) ☐ NO (0) (Q058)

18. What is your date of birth? (Q058A)

____/____/____
MM DD YYYY

19. How likely are you to ask your doctor (or nurse) about getting screened for prostate cancer? (Q088)

- ☐ Very Likely (1)
☐ Somewhat Likely (2)
☐ Not Likely (3)

20. How likely are you to get a PSA blood test within the next 12 months? (Q089)

- ☐ Very Likely (1)
☐ Somewhat Likely (2)
☐ Not Likely (3)

21. Have you ever participated in a clinical trial?

- ☐ YES (1), *specify* _____
☐ NO (0) (Q093)

22. Do you have health insurance?

- ☐ YES (1), *What type of insurance?* _____
☐ NO (0) (Q083)

This is the end of the survey. If you would like to be contacted for future studies, please give us a telephone number where we can reach you. Telephone # (____)_____. On behalf of our project, thank you for the time that you dedicated to the survey. Please send the completed to us in the enclosed envelope.

**Nilsa Gallardo, Psy.D, Project Director
University of California, Los Angeles
Division of Cancer Prevention and Control Research
School of Public Health and
Jonsson Comprehensive Cancer Center
Room A2-125 CHS
Box 956900
Los Angeles, California 90095-6900**

RID ETHNICITY

Appendix 4: Letter to subjects requesting permission to verify screening tests

English and Spanish translation

Letter to subjects requesting permission to verify receipt of screening tests

Date

FIELD(rfname) FIELD(rlname) FIELD(rlname)
FIELD(raddress1) FIELD(rADDRESS2)
FIELD(rcity), FIELD(rstate) FIELD(rzip)

Dear Mr. FIELD(rlname):

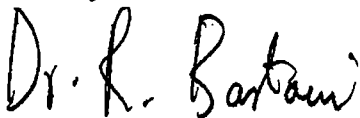
Thank you for participating in our study on men with a family history of prostate cancer and for completing our telephone survey. Because sometimes it is difficult for people to remember all the cancer screening tests they have had, we would like your permission to contact your health care provider. We will ask for no other information other than what is listed on the form and all the information will be kept confidential. We will send you \$5 once we receive the form from you.

In order to help us complete this important prostate cancer study, we need you to do the following three things:

- 1) Sign your name and date on the enclosed form.
- 2) Write in the name, address, and phone number of your health care provider.
- 3) Return this form in the postage-paid envelope and mail it to us at UCLA. We will forward it to your health care provider.

Thank you again for your continued participation in this study.

Sincerely,



Roshan Bastani, Ph.D.
Principal Investigator

Enclosure

Spanish letter to subjects requesting permission to verify receipt of screening tests

Date in Spanish

FIELD(rfname) FIELD(rlname) FIELD(rlname)
FIELD(raddress1) FIELD(rADDRESS2)
FIELD(rcity), FIELD(rstate) FIELD(rzip)

Estimado Sr. FIELD(rlname):

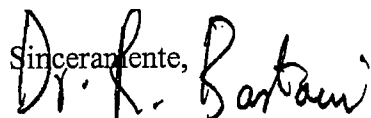
Le damos las gracias por haber participado en la entrevista telefonica para el estudio de familiares y pacientes de cancer de la próstata. Por el hecho de que puede ser dificil recordar todas las fechas de sus análisis para el cancer de la próstata, queremos pedirle permiso para ponernos en contacto con su medico. La unica información que le pediremos a su doctor esta delineada en la siguiente forma. Toda informacion sera confidencial. Al regresar la forma que hemos incluido, le enviaremos \$5 como agradecimiento.

Necesitamos que haga lo siguiente para completar este estudio de cancer:

- 1)Firme su nombre y fecha en el siguiente documento.
- 2)Escriba el nombre, la direccion y el numero telefonico de su medico.
- 3)Regrese los documentos a UCLA en el sobre incluido. Nosotros enviaremos la documentacion necesaria a su doctor.

Queremos recordarle que solamente pediremos la informacion delineada en la forma incluida que usted firmo. Toda información sera confidencial. Al regresar la forma que hemos incluido, le enviaremos \$5 como agradecimiento.

Gracias.

Sinceramente,


Roshan Bastani, Ph.D.
Investigadora Principal

Appendix 5: Letter to subjects who agreed to validation during the survey

English and Spanish translation

Letter to subjects who verbally agreed to validation during survey

Date

FIELD(rfname) FIELD(rlname) FIELD(rlname)
FIELD(raddress1) FIELD(rADDRESS2)
FIELD(rcity) FIELD(rstate) FIELD(rzip)

Dear Mr. FIELD(rlname):

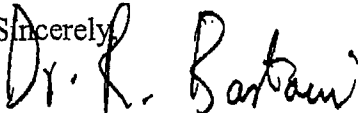
Thank you for agreeing to let us contact your health care provider in our last telephone conversation with you. Because sometimes it is difficult for people to remember all the cancer screening tests they have had, this is the best way for us to check the specific dates.

In order to help us complete this important prostate cancer study, we need you to do the following three things:

- 1) Sign your name and date on the enclosed form.
- 2) Write in the name, address, and phone number of your health care provider.
- 3) Return this form in the postage-paid envelope and mail it to us at UCLA. We will forward it to your health care provider.

We will ask for no other information other than what is listed on the form and all the information will be kept confidential. We will send you \$5 once we receive the form from you.

Thank you again.

Sincerely,


Roshan Bastani, Ph.D.
Principal Investigator

Enclosure

Spanish letter to subjects who verbally agreed to validation during survey

Date in Spanish

FIELD(rfname) FIELD(rlname) FIELD(rlname)
FIELD(raddress1) FIELD(rADDRESS2)
FIELD(rcity), FIELD(rstate) FIELD(rzip)

Estimado Sr. FIELD(rlname):

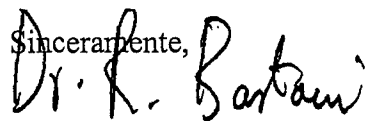
Le damos las gracias por habernos dado permiso para comunicarnos con su medico. Por el hecho de que puede ser difícil recordar todas las fechas de sus análisis para el cancer de la próstata, el permiso que nos da nos ayudara a obtener las fechas exactas de sus analisis.

Necesitamos que haga lo siguiente para completar este estudio de cancer:

- 1)Firme su nombre y fecha en el siguiente documento.
- 2)Escriba el nombre, la direccion y el numero telefonico de su medico.
- 3)Regrese los documentos a UCLA en el sobre incluido. Nosotros enviaremos la documentacion necesaria a su doctor.

Queremos recordarle que solamente pediremos la informacion delineada en la forma incluida que usted firmo. Toda información sera confidencial. Al regresar la forma que hemos incluido, le enviaremos \$5 como agradecimiento.

Gracias.

Sinceramente,


Roshan Bastani, Ph.D.
Investigadora Principal

Appendix 6: Verification form (English, Spanish translation)



A Study of Men with a Family History of Prostate Cancer, UCLA

PATIENT MEDICAL RELEASE

PATIENT:

FIELD(rfname) FIELD(rmname) FIELD(rlname)
FIELD(raddres1) FIELD(raddres2)
FIELD(rcity) FIELD(rstate) FIELD(rzip)

Please do the three following things:

1. *I authorized my licensed physician, medical practitioner, hospital, clinic or other medical related facility, or care provider permission to send Dr. Roshan Bastani at the UCLA Jonsson Comprehensive Cancer Center the dates and results of all my most recent cancer screening test listed in the box below. This authorization will be valid 24 months from the date signed unless I revoke it in writing. A photocopy of this authorization is as valid as the original.*

Signature _____ Date: _____
FIELD(rfname) FIELD(rmname) FIELD(rlname) FIELD(ptid)-FIELD(rid)

2. Name, address and phone number of my health care provider:
(provider with most of my medical records)

Name: _____

Address: _____

Telephone: () _____

3. Mail this form to: Dr. Roshan Bastani
UCLA Cancer Prevention & Control/JCCC
650 Charles Young Drive South
Room A2-125 CHS/ Box 956900
Los Angeles, CA 90095-6900

PROVIDER (Cash reimbursement enclosed)

Cancer Screening Test (To be completed by health care provider and signed below)

Test	<u>Most Recent</u> (Insert Date)	<u>Reason*</u>	<u>Result</u> P= positive N= negative	<u>Next Most Recent</u>	<u>Reason*</u>	<u>Result</u> P= positive N= negative
Prostate specific antigen (PSA)						

* Reason: S=screening of asymptomatic patient or D= diagnosis of symptomatic patient

Signature: _____ Date: _____
(Health Care Provider)

AUTORIZACIÓN MEDICAL PACIENTE

Paciente:

FIELD(rfname) FIELD(rmname) FIELD(rlname)
FIELD(raddres1) FIELD(raddres2)
FIELD(rcity), FIELD(rstate) FIELD(rzip)

Favor de completar lo siguiente:

1) Yo autorizo a mi doctor/a, hospital, clínica o facilidad médica que mande información sobre las fechas y resultados de los más recientes exámenes del cáncer de la próstata a la Dra. Roshan Bastani en el centro de cáncer de UCLA. Esta autorización será válida hasta 24 meses despues de la fecha indicada con mi firma al menos que yo revoque la validez por escrito. Una fotocopia de esta autorización es igualmente válida que la original.

Firma: _____ Fecha: _____
FIELD(rfname) FIELD(rmname) FIELD(rlname) FIELD(ptid)-FIELD(rid)

2) Nombre, Dirección y numero telefónico de mi doctor/a:
(El doctor que tenga lo más de sus datos médicos)

Nombre: _____

Dirección: _____

Numero Telefónico: (____) _____

3) Envie la información a:

Jonsson Comprehensive
Cancer Center

Box 956900

Los Angeles, CA 90095-6900

ATTN: Dra. Roshan Bastani

Exámenes Preliminares (Esta porcion debe ser llenada por su doctor/a):

Examen	Fecha (más reciente)	Razón	Resultado P=positivo N=negativo	Fecha (segunda más reciente)	Razón	Resultado P=positivo N=negativo
ASP						

Razón: S= Examen de un paciente sin sintomas
D= Diagnosis de un paciente con sintomas

Firma: _____
(Firma del doctor/a)

Fecha: _____

Appendix 7: Letter to providers requesting validation of self-report

Letter to Providers

Date

Name

Address

Dear Dr. Name:

Your patient << Patient Name >> has signed a release form for us to obtain the dates of their most recent prostate specific antigen (PSA) cancer screening test. (See enclosed form). This is an important part of our study of men with a family history of prostate cancer, in which your patient is enrolled. (See enclosed abstract.) We need this information to validate the screening information your patient gave us over the telephone.

We have enclosed \$10 to help offset the cost of obtaining this information. The enclosed signed release form is also the record abstraction form for your office staff to fill out and return to us in the postage-paid envelope. Alternatively, you or one of your staff may call and give us the information over the phone or leave it on our voice mail at the following number: (877) 278-8506. If you have any questions about this study, please do not hesitate to call me.

Thank you for your assistance.

Sincerely,

Roshan Bastani, Ph.D.
Principal Investigator

Enclosure

*"You are key to the health
of your family"*

A note to you:

You can help in the fight against prostate cancer by joining in the **Healthy Families** research study. This study aims to catch prostate cancer early and save lives.

Why am I key?

You are key because you have had prostate cancer.

The men in your family are more likely to get prostate cancer than men who have no prostate cancer in their family. The **Healthy Families Project** wants to develop new programs to help fight prostate cancer in close family members. We need your help in contacting your father, brothers and adult sons, even if they do not have prostate cancer.

What will happen to the information my family members provide?

We will use it to develop new programs to fight prostate cancer in close family members.

Do I need to participate?

No, but we hope you will for your family's health. Your participation is voluntary and all information will be confidential. There is no cost to you to participate. Your choice to take part will not affect the services you receive from your doctor or the Los Angeles County Cancer Surveillance Program. If you do not want us to call you or your family members, just mark the box on the form that says "I do not want to participate" and return it in the enclosed envelope.

Who can I call if I have questions?

You may call us toll-free at (877) 278-8506. We will be happy to answer your questions.

*"You are key to the health
of your family"*



What will I need to do?

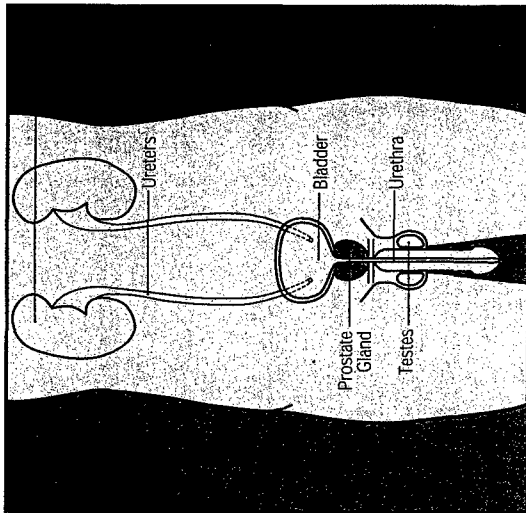
All you need to do is:

1. Fill out the attached Family Information Form.
2. Return the form in the enclosed stamped envelope.

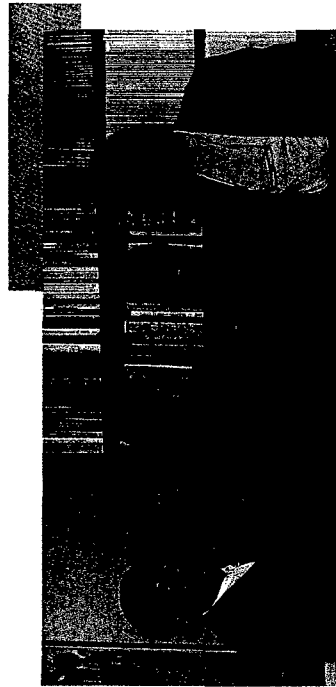
What will my family members need to do?

We will call your family members to ask them to participate in telephone interviews. If they agree, we will ask them about what they know and how they feel about prostate cancer and its early detection.

Early Detection



The prostate is a gland found only in men. It produces a thick fluid that forms part of the semen. The prostate is about the size of a walnut. It is located below the bladder. The prostate surrounds the upper part of the urethra, the tube that empties urine from the bladder.



Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.

*You are key
to the health
of your family!*



UCLA

HEALTHY FAMILIES

PROJECT

- Los Angeles County Cancer Surveillance Program, a member of the California Cancer Registry
- Every cancer diagnosed in California is required by law to be reported to the California Department of Health Services, which is responsible for the registry.
- Information on individuals with cancer can only be released for research purposes to qualified researchers who have obtained approval for the study from a federally approved Committee for the Protection of Research Subjects.

Jonsson Comprehensive Cancer Center

Division of Cancer Prevention and Control

650 Charles Young Drive South

Room A2-125 CHS

Box 956900

Los Angeles, CA 90095-6900



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Why am I key?

You are key because you have had prostate cancer.

The men in your family are more likely to get prostate cancer than men who have no prostate cancer in their family. The Healthy Families Project wants to develop new programs to help fight prostate cancer in close family members. We need your help in contacting your father, brothers and adult sons, even if they do not have prostate cancer.

What will happen to the information my family members provide?

We will use it to develop new programs to fight prostate cancer in close family members.

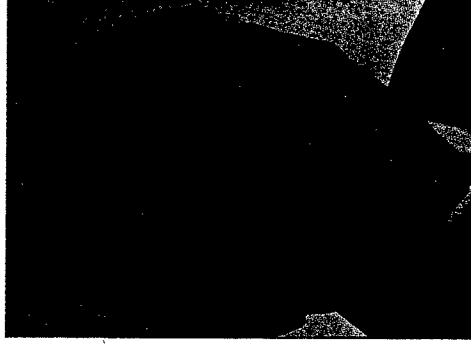
Do I need to participate?

No, but we hope you will for your family's health. Your participation is voluntary and all information will be confidential. There is no cost to you to participate. Your choice to take part will not affect the services you receive from your doctor or the Los Angeles County Cancer Surveillance Program. If you do not want us to call you or your family members, just mark the box on the form that says "I do not want to participate" and return it in the enclosed envelope.

Who can I call if I have questions?

You may call us toll-free at (877) 278-8506. We will be happy to answer your questions.

*"You are key to the health
of your family"*



What will I need to do?

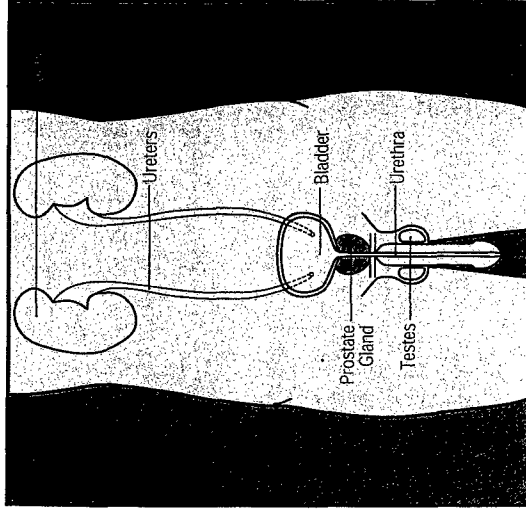
All you need to do is:

1. Fill out the attached Family Information Form.
2. Return the form in the enclosed stamped envelope.

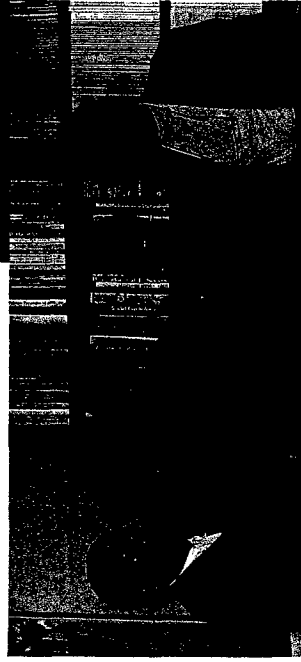
What will my family members need to do?

We will call your family members to ask them to participate in telephone interviews. If they agree, we will ask them about what they know and how they feel about prostate cancer and its early detection.

Early Detection



The prostate is a gland found only in men. It produces a thick fluid that forms part of the semen. The prostate is about the size of a walnut. It is located below the bladder. The prostate surrounds the upper part of the urethra, the tube that empties urine from the bladder.



Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.

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UCLA

PROJECT

- Los Angeles County Cancer Surveillance Program, a member of the California Cancer Registry.
- Every cancer diagnosed in California is required by law to be reported to the California Department of Health Services, which is responsible for the registry.
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Jonsson Comprehensive Cancer Center

Division of Cancer Prevention and Control
650 Charles Young Drive South
Room A2-125 CHS

Box 956900

Los Angeles, CA 90095-6900



"You are key to your health"

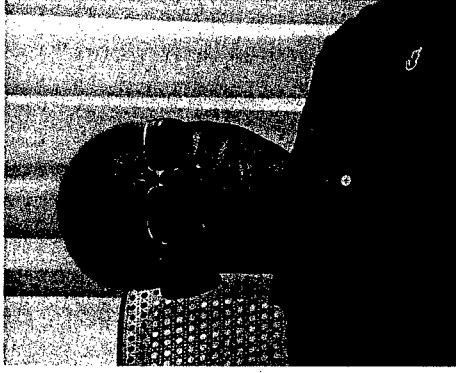
A note to you:

You can help in the fight against prostate cancer by joining in the **Healthy Families** research study. This study aims to catch prostate cancer early and save lives.

Why am I key?

You are key because someone in your family has had prostate cancer.

You are key because you are at higher risk of getting prostate cancer than men who have no prostate cancer in their family. We at the **Healthy Families** Project are committed to recruiting African American men such as yourself. This is so that we can get information on your special needs and concerns. The information you



provide will be used to develop new programs to fight prostate cancer in close family members.

What will I need to do?

All you need to do is:

Take part in a 20 minute telephone interview. We will ask you questions about what you know and how you feel about prostate cancer and its early detection.

Do I need to participate?

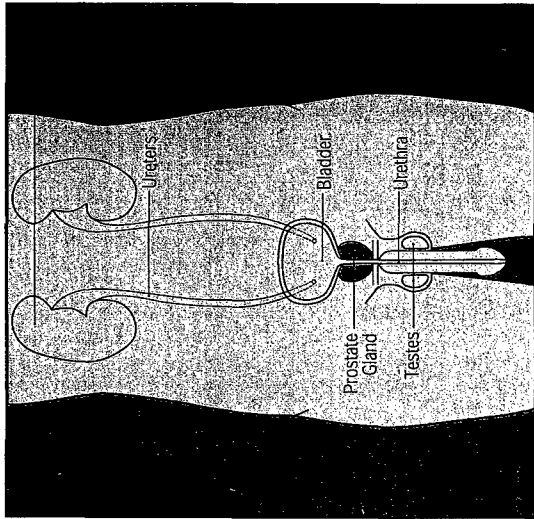
No, but we hope you will for your health and the health of the adult men in your family. Your participation is voluntary and all information will be confidential. There is no cost to you to participate. If you do not want to participate please mark the box on the form that says "I do not want to participate" and return it in the envelope provided. You can leave the study at any time.

Who can I call if I have questions?

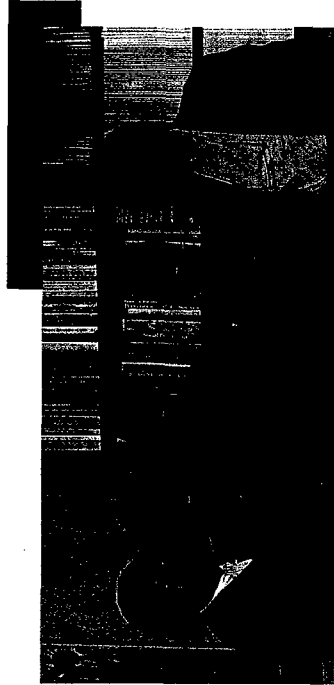
You may call us toll-free at (877) 278-8506. We will be happy to answer your questions. If you have more questions, thoughts, or concerns, you can write the Office for Protection of Research Subjects, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095, (310) 825-8714.

"You are key to your health"

Early Detection

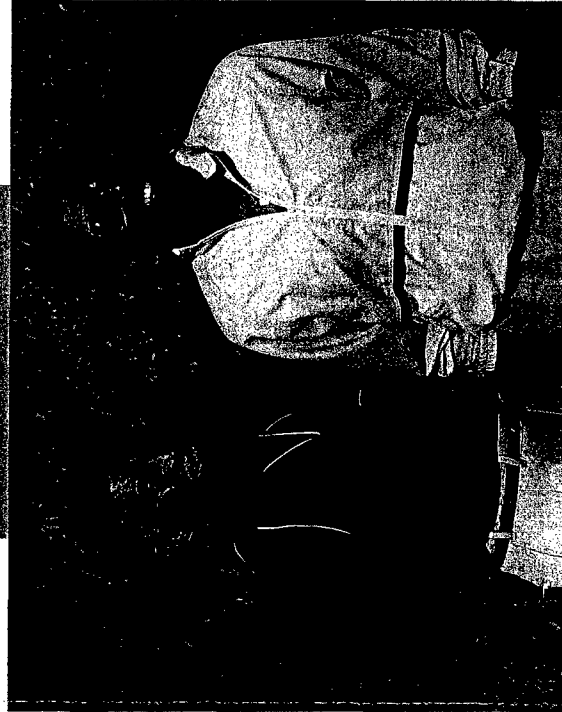


The prostate is a gland found only in men. It produces a thick fluid that forms part of the semen. The prostate is about the size of a walnut. It is located below the bladder. The prostate surrounds the upper part of the urethra, the tube that empties urine from the bladder.



Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.

*You are
key to
your health!*



UCLA

HEALTHY FAMILIES

PROJECT

Please be aware that, since they are providing funding for this study, representatives from the U.S. Army Medical Research and Material Command (and, where applicable, the Food and Drug Administration) may inspect the records of the research in their duty to protect human subjects in research.

Jonsson Comprehensive Cancer Center

Division of Cancer Prevention and Control

650 Charles Young Drive South

Room A2-125 CHS

Box 956900

Los Angeles, CA 90095-6900



"Usted es clave para su salud"

Una nota para usted:

Usted puede ayudar en la lucha contra el cáncer de la prostata uniendose al estudio de investigación Familias Saludables. Este estudio aspira detectar cáncer de la prostata temprano y así salvar vidas.

¿Por que soy yo clave?

Usted es clave porque alguien en su familia ha tenido cáncer de la prostata.

Usted es la clave porque esta en mas alto riesgo de desarrollar cáncer de la prostata que personas que no tienen cáncer de la prostata en su familia. Nosotros en el Programa de Familias Saludables estamos comprometidos a reclutar hombres hispanos como usted para obtener información en especial sobre sus necesidades y preocupaciones. La información que



usted proporcione sera usada para desarrollar nuevos programas para combatir el cáncer de la prostata en familiares cercanos.

¿Que tendré que hacer?

Lo unico que usted tiene que hacer es:

Participar en una entrevista telefónica de 20 minutos. Le haremos preguntas acerca de lo que sabe y siente sobre el cáncer de la prostata y su detección temprana.

¿Tengo que participar?

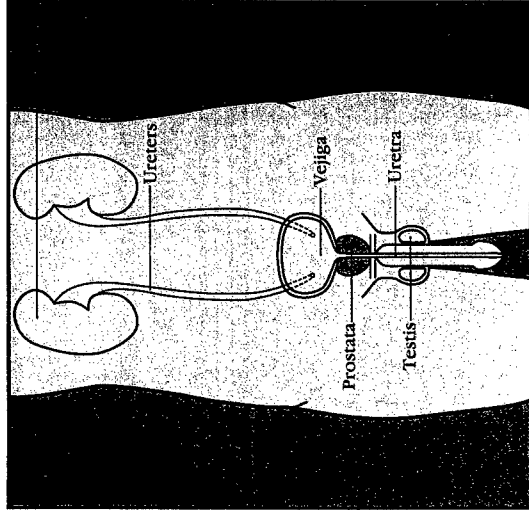
No, pero esperamos que lo haga por su salud y la de su familia. Su participación es voluntaria y toda la información sera confidencial. No hay ningun costo para participar. Si usted no quiere participar por favor marque la caja que dice "Yo no quiero participar" en el formulario y regresele en el sobre adjunto. Usted puede dejar de participar en el estudio en cualquier momento.

¿A quien puedo llamar si tengo preguntas?

Usted puede llamarnos gratis al numero (877) 278-8506. Estaremos encantado/as de contestar sus preguntas. Si tiene mas preguntas, opiniones, o inquietudes, usted puede escribir a la Oficina de Protección a Sujetos de Investigación, 2107 Peter V. Ueberroth Building, Box 951694, Los Angeles, CA 90095, (310) 825-8714.

"Usted es clave para su salud"

Detección Temprana



La próstata es una glándula que se encuentra solamente en los hombres. Ella produce un líquido espeso que forma parte del semen. La próstata es mas o menos del tamaño de una nuez. Esta localizada bajo la vejiga. La próstata rodea la parte superior de la uretra, el tubo que vacía la orina de la vejiga.

Equipo conduciendo el Programa para la Prevención del Cáncer de la Prostata. De izquierda a derecha: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.

Favor este consciente que, por que han dado fondos para este estudio, representantes del comando de investigación medico y de materiales de las fuerzas armadas de los Estados Unidos (y donde es pertinente, la Administración de Alimentos y Drogas) pueden inspeccionar los expedientes de la investigación en su obligación a proteger sujetos humanos en investigaciones.

Jonsson Comprehensive Cancer Center
Division of Cancer Prevention and Control

650 Charles Young Drive South

Room A2-125 CHS

Box 956900

Los Angeles, CA 90095-6900



"You are key to your health"

A note to you:

You can help in the fight against prostate cancer by joining in the Healthy Families research study. This study aims to catch prostate cancer early and save lives.

Why am I key?

You are key because someone in your family has had prostate cancer.

You are key because you are at higher risk of getting prostate cancer than men who have no prostate cancer in their family. We at the Healthy Families Project are committed to recruiting Hispanic men such as yourself. This is so that we can get information on your special needs and concerns. The information you provide will be



used to develop new programs to fight prostate cancer in close family members.

What will I need to do?

All you need to do is:

Take part in a 20 minute telephone interview. We will ask you questions about what you know and how you feel about prostate cancer and its early detection.

Do I need to participate?

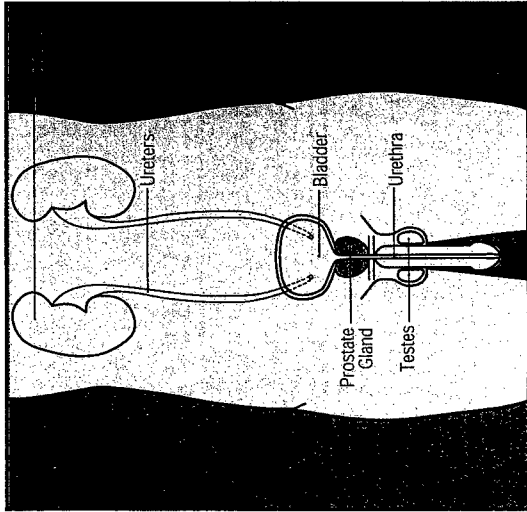
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Early Detection



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Team conducting the Prostate Cancer Prevention Project. From left to right: Drs. David Huang, Roshan Bastani, Mark Litwin, Nilsa Gallardo, Clarence Bradford.

Please be aware that, since they are providing funding for this study, representatives from the U.S. Army Medical Research and Materiel Command (and, where applicable, the Food and Drug Administration) may inspect the records of the research in their duty to protect human subjects in research.

Jonsson Comprehensive Cancer Center
Division of Cancer Prevention and Control
650 Charles Young Drive South
Room A2-125 CHS

Box 956900
Los Angeles, CA 90095-6900





DEPARTMENT OF THE ARMY
US ARMY MEDICAL RESEARCH AND MATERIEL COMMAND
504 SCOTT STREET
FORT DETRICK, MD 21702-5012

REPLY TO
ATTENTION OF

MCMR-RMI-S (70-1y)

15 May 03

MEMORANDUM FOR Administrator, Defense Technical Information
Center (DTIC-OCA), 8725 John J. Kingman Road, Fort Belvoir,
VA 22060-6218

SUBJECT: Request Change in Distribution Statement

1. The U.S. Army Medical Research and Materiel Command has reexamined the need for the limitation assigned to technical reports written for this Command. Request the limited distribution statement for the enclosed accession numbers be changed to "Approved for public release; distribution unlimited." These reports should be released to the National Technical Information Service.

2. Point of contact for this request is Ms. Kristin Morrow at DSN 343-7327 or by e-mail at Kristin.Morrow@det.amedd.army.mil.

FOR THE COMMANDER:

Encl


PHYLLIS M. RINEHART
Deputy Chief of Staff for
Information Management

ADB266022	ADB265793
ADB260153	ADB281613
ADB272842	ADB284934
ADB283918	ADB263442
ADB282576	ADB284977
ADB282300	ADB263437
ADB285053	ADB265310
ADB262444	ADB281573
ADB282296	ADB250216
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ADB269117	ADB274387
ADB283887	ADB285530
ADB263560	
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