

Jefferson Office of Human Research
Verbal Consent with Optional Use of Disclosure of PHI OHR-8H
Version Date – FOR OHR USE: 1/20/20

Department: Medical Oncology

Principal Investigator: Dr. Veda Giri and Dr. Amy Leader

Study Title: “Peer Based Intervention for Genetic Evaluation for Prostate Cancer among African American Men: The Peer Genetic Study”

Lay Title: The PEER Genetics Study

Hello, my name is _____. I’m from Jefferson’s Department of Medical Oncology /Division of Population Science.

I am contacting you because as an established patient of CityLife Neighborhood Clinic, you meet the criteria of eligibility for our study.

We are conducting a research study that consists of asking you questions about your knowledge about prostate cancer, your personal family cancer history, your knowledge of genetic testing and screening, feelings towards genetic testing, beliefs about genetic testing, internal conflict about genetic testing, and intentions to seek genetic counseling in two different surveys. After you consent to the study, you will complete the first study survey with the study coordinator. Then you will be randomly assigned to either receive genetic educational materials by mail or attend a virtual peer-led genetic education group. If you are in the peer education group, you will also complete a feedback questionnaire immediately after the session. One month after you receive the educational material or attend educational group you will complete the second study survey to see if your knowledge and views about genetic testing have changed. You will be compensated \$25 for each study survey that you complete for a total of \$50 for this study.

This will take about between 1 to 3 months to complete. About 176 men will take part in this research at Jefferson and about 192 in the whole study.

The purpose of this research study is to provide genetic education and awareness about prostate cancer through either printed education material or a peer-led education session to evaluate whether which method is more helpful when deciding on genetic counseling and testing. We hope this study will allow us to understand if training African American men as peer genetic educators is a useful strategy to spread awareness and access to genetic testing for prostate cancer.

The alternative to being in this study is to not take part. Your participation is voluntary. It is your choice whether or not you want to take part. If you choose not to take part or choose to stop taking part at any time, there will be no penalty or loss of benefits that you would normally get.

You may not personally benefit from taking part in this research, but other people may be helped by what is learned. You will receive genetic education about prostate cancer, your potential risk for prostate cancer based on your personal or family history and have access to genetic testing, if applicable.

A risk of taking part in this study is that you may not feel comfortable answering some of the questions. If any question makes you feel uncomfortable, you do not have to answer the question.

The other possible risk is a loss of the confidentiality of your information. Information will be collected about you for this study. The information will be seen by the people involved with this research. Steps will be taken to protect your identity. But the information collected about you can never be 100% secure.

Taking part in this study involves certain risks. There may also be risks that are not known at this time. You may become uncomfortable or anxious when talking about your own experiences. The research staff will do everything that they can to minimize this risk. Questions or concerns can be addressed by the person who is facilitating the discussion.

There will be no cost to you for taking part in this study.

You will receive \$25 for completing each of the two surveys for a total of \$50 for this research study.

Jefferson is being paid by the Department of Defense to conduct this study.

New information may come out during this study. You will be given any new information that could change your decision to take part. You may ask to see the information collected about you, but not until the entire study is complete.

HIPAA (Health Insurance Portability and Accountability Act) – This is the law that protects your personal health information.

To do this study, we need to collect, use, and share your personal health information. I will explain why your information is being collected, what information will be collected, and who will have access to it. By agreeing, you are giving us permission to use your information as described in this form.

We are committed to respecting your privacy and to keeping your personal health information confidential. Your personal health information includes the information in your health care

records and information that can identify you. For example, personal information may include your name, address, phone number and medical information. The personal health information that may be collected, used, and shared for this research includes:

- Demographic information such as your name, gender, ethnicity, date of birth and contact information.

Your personal information will be used by and shared with the following:

- Personnel at Thomas Jefferson University and its affiliates for the purpose of this research
- The Institutional Review Board at Thomas Jefferson University (ethics committees that review research)
- The U.S. Department of Defense, which is providing money to the researcher to carry out this research
- Research monitors hired by the sponsor to oversee the study and review health care records to ensure study-related information is correct
- Government Agencies like the Food and Drug Administration (FDA)
- An organization such as a contract research organization (CRO) that has been hired to coordinate the study
- Groups monitoring the safety of the study such as a data and safety monitoring committee
- Others as required by law

When your personal information is provided to some of the people listed, it may no longer be protected under the HIPAA privacy law. You can see your health care records at any time. However, generally you will not be able to see your study records or the study results until the study is completed. A copy of this signed form, information about this study, and the results of any study test or procedure may be included in your health records which may be seen by your insurance company and your health care providers.

This authorization does not have an expiration date. If you want to end your permission to collect your information, please inform the investigator in writing. If you do this, no more information will be collected, but the information already collected will still be used. If you end your permission to use your personal information, you will not be able to continue in this study.

The information from this study may be published in scientific journals or presented at scientific meetings, but you will not be personally identified.

Your private information will not be used or distributed for future research studies, even if the identifiers are removed.

Do you agree to participate in this research study as it has been described to you?

If you have any questions about this research, you can contact:

Name: Nicole Crumpler
Phone Number: (215) 503-5267
Email: Nicole.Crumpler@jefferson.edu

If you need to contact someone other than the study personnel about a concern or your rights as a research subject, please call the Jefferson IRB at: 215-503-0203, 215-503-8966, or 215-955-4239.

Investigator writes name of participant and signs to verify verbal response of subject:

Name of research participant _____

☐ YES, the participant consented

☐ NO, the participant did NOT consent

Name of Investigator

Signature of Investigator

Date

Information Card

Study Coordinator: Nicole Crumpler
Department/ Division: Medical Oncology/ Population Science
Phone Number: (215) 503-5267
Email: Nicole.Crumpler@jefferson.edu

If you need to contact someone other than the study personnel about a concern or your rights as a research subject, please call the Jefferson IRB at: 215-503-0203, 215-503-8966, or 215-955-4239.

Please answer the following questions as best as you are able. There are no right or wrong answers. If you have any questions, please ask me as we go through the survey.

Knowledge about Prostate Cancer

For each of the following statements, choose if it is TRUE or FALSE. You may choose DON'T KNOW for any that you do not know the answer.

1.		TRUE	FALSE	DON'T KNOW
A	The prostate is a walnut-sized organ that only men have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Prostate cancer always has symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	It is important for every man to talk to a doctor about whether prostate cancer screening is right for him.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Screening for prostate cancer can be a blood test called the prostate specific antigen (PSA) or a digital rectal exam (DRE).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E	Prostate cancer is easier to treat if it is detected early.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F	50% (1/2) of inherited genetic information is passed down from a man's mother.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G	Family history of cancer can influence recommendations for cancer screening.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H	A man may be at greater risk for developing prostate cancer if he has several close relatives with prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I	African American men have a higher chance of developing prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J	There is more than one gene that can increase the risk of prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K	A mother can pass down a prostate cancer gene mutation to her sons.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L	If a genetic test indicates that a man has a BRCA2 gene mutation, he is at increased risk for prostate cancer, male breast cancer, and pancreatic cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
M	If a genetic test indicates that a man has a BRCA2 gene mutation, he is at increased risk for lung cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
N	If a man tests positive for a BRCA2 gene mutation, his female relatives' risk for developing breast cancer are lowered.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Now, we are going to ask you questions about screening for prostate cancer.

2. How concerned are you about getting prostate cancer?

☐ Not concerned at all ☐ A little bit concerned ☐ Neutral ☐ Moderately concerned ☐ Very concerned

3. Have you ever had a conversation with your doctor about prostate cancer screening? ☐ No ☐ Yes

4. Have you ever been screened for prostate cancer? This may include a blood test (PSA) or a digital rectal exam. ☐ No ☐ Yes

b. If yes, when were you last screened? ☐ Less than 1 year ago ☐ More than 1 year ago

Next, please indicate how much you DISAGREE or AGREE with the following statements about your concerns about cancer.

5		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
A	It seems like these days, everything causes cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	There are so many recommendations about how to prevent cancer, it's hard to know which ones to follow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	There's not much you can do to lower your chances of getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	It's important to talk with your family about their history of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E	When I think of cancer, I automatically think of death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F	I'd rather not know my chance of getting prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Family History of Cancer

The next set of questions ask you about your family history of cancer. Please answer as best as you can.

6. Have any men in your family had prostate cancer? (Check all that apply)

- ☐ My father
- ☐ My grandfather: ☐ Mother's side ☐ Father's side
- ☐ My brother: ☐ One brother ☐ More than one brother
- ☐ My uncle: ☐ One uncle on father's side ☐ More than one uncle on father's side
- ☐ ☐ One uncle on mother's side ☐ More than one uncle on mother's side
- ☐ My son: ☐ One son ☐ More than one son
- ☐ Other _____

7. Have any women in your family had breast cancer? (Check all that apply)

- ☐ My mother
- ☐ My grandmother: ☐ Mother's side ☐ Father's side
- ☐ My sister: ☐ One sister ☐ More than one sister
- ☐ My aunt: ☐ One aunt on father's side ☐ More than one aunt on father's side
- ☐ ☐ One aunt on mother's side ☐ More than one aunt on mother's side
- ☐ My daughter: ☐ One daughter ☐ More than one daughter
- ☐ Other _____

8. Has anyone in your family had colon cancer? (Check all that apply)

- ☐ My mother
- ☐ My grandmother: ☐ Mother's side ☐ Father's side
- ☐ My sister: ☐ One sister ☐ More than one sister

- ☐ My aunt:
 - ☐ One aunt on father's side
 - ☐ One aunt on mother's side
 - ☐ More than one aunt on father's side
 - ☐ More than one aunt on mother's side
- ☐ My daughter:
 - ☐ One daughter
 - ☐ More than one daughter
- ☐ My father
- ☐ My grandfather:
 - ☐ Mother's side
 - ☐ Father's side
- ☐ My brother:
 - ☐ One brother
 - ☐ More than one brother
- ☐ My uncle:
 - ☐ One uncle on father's side
 - ☐ One uncle on mother's side
 - ☐ More than one uncle on father's side
 - ☐ More than one uncle on mother's side
- ☐ My son:
 - ☐ One son
 - ☐ More than one son
- ☐ Other _____

9. Have any women in your family had ovarian cancer? (Check all that apply)

- ☐ My mother
- ☐ My grandmother:
 - ☐ Mother's side
 - ☐ Father's side
- ☐ My sister:
 - ☐ One sister
 - ☐ More than one sister
- ☐ My aunt:
 - ☐ One aunt on father's side
 - ☐ One aunt on mother's side
 - ☐ More than one aunt on father's side
 - ☐ More than one aunt on mother's side
- ☐ My daughter:
 - ☐ One daughter
 - ☐ More than one daughter
- ☐ Other _____

10. Has anyone in your family had cancer of the pancreas (pancreatic cancer)? (Check all that apply)

- ☐ My mother
- ☐ My grandmother:
 - ☐ Mother's side
 - ☐ Father's side
- ☐ My sister:
 - ☐ One sister
 - ☐ More than one sister
- ☐ My aunt:
 - ☐ One aunt on father's side
 - ☐ One aunt on mother's side
 - ☐ More than one aunt on father's side
 - ☐ More than one aunt on mother's side
- ☐ My daughter:
 - ☐ One daughter
 - ☐ More than one daughter
- ☐ My father
- ☐ My grandfather:
 - ☐ Mother's side
 - ☐ Father's side
- ☐ My brother:
 - ☐ One brother
 - ☐ More than one brother
- ☐ My uncle:
 - ☐ One uncle on father's side
 - ☐ One uncle on mother's side
 - ☐ More than one uncle on father's side
 - ☐ More than one uncle on mother's side
- ☐ My son:
 - ☐ One son
 - ☐ More than one son
- ☐ Other _____

11. Have any women in your family had cancer of the uterus (uterine cancer)? (Check all that apply)

- ☐ My mother
- ☐ My grandmother:
 - ☐ Mother's side
 - ☐ Father's side
- ☐ My sister:
 - ☐ One sister
 - ☐ More than one sister
- ☐ My aunt:
 - ☐ One aunt on father's side
 - ☐ One aunt on mother's side
 - ☐ More than one aunt on father's side
 - ☐ More than one aunt on mother's side
- ☐ My daughter:
 - ☐ One daughter
 - ☐ More than one daughter
- ☐ Other _____

Thoughts about Genetic Testing

The following statements are about genetic testing. Please choose the number that best describes your personal opinion on a scale from 1 to 7. There is also a "Don't Know" option for each statement. Some questions may appear the same but have different answer choices.

12a. For me, having genetic testing for prostate cancer is:

Very harmful			Neither Harmful nor Beneficial			Very Beneficial	Don't know
1	2	3	4	5	6	7	0

12b. For me, having genetic testing for prostate cancer is:

Not important			Neither Not Important nor Important			Very Important	Don't Know
1	2	3	4	5	6	7	0

12c. For me, having genetic testing for prostate cancer is:

Very Bad Thing			Neither Bad Thing nor Good Thing			Very Good Thing	Don't Know
1	2	3	4	5	6	7	0

12d. For me, having genetic testing for prostate cancer is:

Not Pleasant			Neither Not Pleasant nor Pleasant			Very Pleasant	Don't Know
1	2	3	4	5	6	7	0

12e. Most people who are important to me would approve of me having genetic testing for prostate cancer.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

12f. Most people like me would have genetic testing for prostate cancer.

Unlikely			Neither Unlikely nor Likely			Likely	Don't Know
1	2	3	4	5	6	7	0

12g. I am confident that I could have genetic testing for prostate cancer if I wanted to.

False			Neither False nor True			True	Don't Know
1	2	3	4	5	6	7	0

12h. My having genetic testing for prostate cancer is up to me.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

12i. I intend to make an appointment with a genetic counselor to discuss genetic testing within the next three months.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

12j. I intend to have genetic testing for prostate cancer in the next three months.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

Decisional Conflict:

The next set of statements are about making a decision about having genetic counseling and testing for prostate cancer.

13		Yes	No	Don't Know
A	Do you feel sure about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Do you know the benefits and risks of your option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Do you have enough support and advice to make a decision?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next set of statements are about making a decision about participating in a genetic study about prostate cancer.

14		Yes	No	Don't Know
A	Do you feel sure about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Do you know the benefits and risks of your option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Do you have enough support and advice to make a decision?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Lastly, please answer the following questions about whether you have had prostate cancer.

Please answer the following questions about your prostate cancer history. If you don't know the answer to a question, please check "don't know."

15. Have you ever been diagnosed with prostate cancer?

☐ Yes

1a. What age were you diagnosed?

___ 1. Younger than age 40

___ 2. 41-50

___ 3. 51-60

___ 4. 61-70

___ 5. Older than age 70

☐ No **(Please skip to Q20)**

☐ Don't know **(Please skip to Q20)**

16. How far has your prostate cancer spread (prostate cancer stage)?

___ a. Only within the prostate

___ b. Spread outside of the prostate to local organs (seminal vesicles, lymph nodes)

___ c. Spread to other parts of the body (for example bones, liver)

___ d. Don't know

17. Have you received treatment for your prostate cancer?

☐ Yes

☐ No, my doctor is watching my prostate cancer with PSA and biopsy (also called active surveillance)

☐ No treatment or management **(Please skip question 18)**

☐ Don't know **(Please skip question 18)**

18. Did you participate in a clinical trial for your prostate cancer treatment?

☐ Yes

☐ No

☐ Don't know

19. What is the current status of your prostate cancer?

___ a. No evidence of disease (cure)

___ b. Living with prostate cancer (stable disease)

- ☐ c. Rising PSA but no findings on scans
- ☐ d. Cancer has returned with findings on scans (active disease)
- ☐ e. Don't know

The next set of questions are about your comfort level with medical information.

20. How often do you have someone help you read medical materials?

Never	Occasionally	Sometimes	Often	Always
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21. How confident are you filling out medical forms by yourself?

Not at All	A Little Bit	Somewhat	Quite a Bit	Extremely
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22. How often do you have problems learning about your medical condition because of difficulty understanding written information?

Never	Occasionally	Sometimes	Often	Always
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23. How often do you have a problem understanding what is told to you about your medical condition?

Never	Occasionally	Sometimes	Often	Always
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Please answer the following questions as best as you can.

24. Imagine that we flip a coin 1,000 times. What is your best guess about how many times the coin would come up heads in 1,000 flips?

- ☐ a. 250
- ☐ b. 500
- ☐ c. 750
- ☐ d. 1,000

25. In the BIG BUCKS LOTTERY, the chance of winning a \$10 prize is 1%. What is your best guess about how many people would win a \$10 prize if 1000 people each buy a single ticket to BIG BUCKS?

- ☐ a. 1
- ☐ b. 10
- ☐ c. 100
- ☐ d. 1,000

26. In ACME PUBLISHING SWEEPSTAKES, the chance of winning a car is 1 in 1,000. What percent of tickets to ACME PUBLISHING SWEEPSTAKES win a car?

PEER Genetics Baseline Survey

- ☐ a. 0.1
- ☐ b. 0.01
- ☐ c. 0.001
- ☐ d. 0.0001

These last questions are about yourself.

27. What is your date of birth? _____

28. What is your zip code of residence? _____

29. What is your race?

- ☐ Black or African American
- ☐ White
- ☐ Asian
- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other _____

30. Are you of Hispanic or Latino, or Spanish origin?

- ☐ Yes
- ☐ No
- ☐ Unsure or Prefer Not to Answer

31. What best describes your education?

- ☐ Less than a high school diploma
- ☐ A high school diploma
- ☐ Some college/associate's degree
- ☐ A college degree
- ☐ Some post-college or a graduate degree

32. What is your marital status?

- ☐ Single
- ☐ Married or Living with partner
- ☐ Separated or Divorced
- ☐ Widowed

33. In general, how would you rate your health today?

- ☐ Very bad
- ☐ Bad
- ☐ Moderate
- ☐ Good
- ☐ Very good

34. Do you currently have health insurance?

- ☐ Yes
- ☐ No

35. Have you seen a doctor in the last year when you were not sick?

- ☐ Yes
- ☐ No

36. How tall are you? _____

37. How much do you weigh? _____

Thank you for taking the time to answer these questions. Your answers are very important to us.

We hope you enjoyed the health education session. Please answer the following questions to the best of your ability.

Knowledge about Prostate Cancer

For each of the following statements, choose if it is TRUE or FALSE. You may choose DON'T KNOW for any that you do not know the answer.

1		TRUE	FALSE	DON'T KNOW
A	The prostate is a walnut-sized organ that only men have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Prostate cancer always has symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	It is important for every man to talk to a doctor about whether prostate cancer screening is right for him.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Screening for prostate cancer can be a blood test called the prostate specific antigen (PSA) or a digital rectal exam (DRE).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E	Prostate cancer is easier to treat if it is detected early.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F	50% (1/2) of inherited genetic information is passed down from a man's mother.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G	Family history of cancer can influence recommendations for cancer screening.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H	A man may be at greater risk for developing prostate cancer if he has several close relatives with prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I	African American men have a higher chance of developing prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J	There is more than one gene that can increase the risk of prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K	A mother can pass down a prostate cancer gene mutation to her sons.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L	If a genetic test indicates that a man has a BRCA2 gene mutation, he is at increased risk for prostate cancer, male breast cancer, and pancreatic cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
M	If a genetic test indicates that a man has a BRCA2 gene mutation, he is at increased risk for lung cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
N	If a man tests positive for a BRCA2 gene mutation, his female relatives' risk for developing breast cancer are lowered.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please answer the following questions about your thoughts and feelings about cancer.

2		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
A	It seems like these days, everything causes cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Immediate Feedback Assessment (Intervention Arm Only)

B	There are so many recommendations about how to prevent cancer, it's hard to know which ones to follow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	There's not much you can do to lower your chances of getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	It's important to talk with your family about their history of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E	When I think of cancer, I automatically think of death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F	I'd rather not know my chance of getting prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Thoughts about Genetic Testing

Please choose the number that best describes your personal opinion on a scale from 1 to 7.

There is also a "Don't Know" option for each statement. Some questions may appear the same but have different answer choices.

a. For me, having genetic testing for prostate cancer is:

Very harmful			Neither Harmful nor Beneficial			Very Beneficial	Don't know
1	2	3	4	5	6	7	0

b. For me, having genetic testing for prostate cancer is:

Not important			Neither Not Important nor Important			Very Important	Don't Know
1	2	3	4	5	6	7	0

c. For me, having genetic testing for prostate cancer is:

Very Bad Thing			Neither Bad Thing nor Good Thing			Very Good Thing	Don't Know
1	2	3	4	5	6	7	0

d. For me, having genetic testing for prostate cancer is:

Not Pleasant			Neither Not Pleasant nor Pleasant			Very Pleasant	Don't Know
1	2	3	4	5	6	7	0

Immediate Feedback Assessment (Intervention Arm Only)

e. Most people who are important to me would approve of me having genetic testing for prostate cancer.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

f. Most people like me would have genetic testing for prostate cancer.

Unlikely			Neither Unlikely nor Likely			Likely	Don't Know
1	2	3	4	5	6	7	0

g. I am confident that I could have genetic testing for prostate cancer if I wanted to.

False			Neither False nor True			True	Don't Know
1	2	3	4	5	6	7	0

h. My having genetic testing for prostate cancer is up to me.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

i. I intend to make an appointment with a genetic counselor to discuss genetic testing within the next three months.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

j. I intend to have genetic testing for prostate cancer in the next three months.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

Decisional Conflict:

The next set of statements are about making a decision about having genetic counseling and testing for prostate cancer.

4		Yes	No	Don't Know
A	Do you feel sure about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Do you know the benefits and risks of your option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Do you have enough support and advice to make a decision?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next set of statements are about making a decision about participating in a genetic study about prostate cancer.

5		Yes	No	Don't Know
A	Do you feel sure about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Do you know the benefits and risks of your option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Do you have enough support and advice to make a decision?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The last set of statements are about the health education session you recently attended.

6		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	I learned a lot from the health education session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	What I learned about men's health surprised me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	The health education session was worth my time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	I understood what was talked about at the health education session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	The health educator was respectful of my thoughts.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	The health educator knew what he was talking about.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	I could ask questions during the health education session and feel comfortable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Overall, I really liked the health education session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Immediate Feedback Assessment (Intervention Arm Only)

The health education session would be helpful for other health decisions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I learned enough about men’s health that I would feel comfortable talking to my doctor about a men’s health issue.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The educational materials were helpful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was helpful to have information to take home.					
The location of the health education session was convenient for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Was the health education session: ☐ Too short ☐ The right amount of time ☐ Too long

8. Is there anything else you’d like to tell us about the health education session?

Please answer the following questions to the best of your ability.

Knowledge about Prostate Cancer

For each of the following statements, choose if it is TRUE or FALSE. You may choose DON'T KNOW for any that you do not know the answer.

1		TRUE	FALSE	DON'T KNOW
A	The prostate is a walnut-sized organ that only men have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Prostate cancer always has symptoms.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	It is important for every man to talk to a doctor about whether prostate cancer screening is right for him.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Screening for prostate cancer can be a blood test called the prostate specific antigen (PSA) or a digital rectal exam (DRE).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E	Prostate cancer is easier to treat if it is detected early.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F	50% (1/2) of inherited genetic information is passed down from a man's mother.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G	Family history of cancer can influence recommendations for cancer screening.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H	A man may be at greater risk for developing prostate cancer if he has several close relatives with prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I	African American men have a higher chance of developing prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J	There is more than one gene that can increase the risk of prostate cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K	A mother can pass down a prostate cancer gene mutation to her sons.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L	If a genetic test indicates that a man has a BRCA2 gene mutation, he is at increased risk for prostate cancer, male breast cancer, and pancreatic cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
M	If a genetic test indicates that a man has a BRCA2 gene mutation, he is at increased risk for lung cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
N	If a man tests positive for a BRCA2 gene mutation, his female relatives' risk for developing breast cancer are lowered.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please answer the following questions about your thoughts and feelings about cancer.

2		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
A	It seems like these days, everything causes cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	There are so many recommendations about how to prevent cancer, it's hard to know which ones to follow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1-Month Follow Up Survey (Both Study Arms)

C	There's not much you can do to lower your chances of getting cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	It's important to talk with your family about their history of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E	When I think of cancer, I automatically think of death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F	I'd rather not know my chance of getting prostate cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Thoughts about Genetic Testing

Please choose the number that best describes your personal opinion on a scale from 1 to 7. There is also a "Don't Know" option for each statement. Some questions may appear the same but have different answer choices.

a. For me, having genetic testing for prostate cancer is:

Very harmful			Neither Harmful nor Beneficial			Very Beneficial	Don't know
1	2	3	4	5	6	7	0

b. For me, having genetic testing for prostate cancer is:

Not important			Neither Not Important nor Important			Very Important	Don't Know
1	2	3	4	5	6	7	0

c. For me, having genetic testing for prostate cancer is:

Very Bad Thing			Neither Bad Thing nor Good Thing			Very Good Thing	Don't Know
1	2	3	4	5	6	7	0

d. For me, having genetic testing for prostate cancer is:

Not Pleasant			Neither Not Pleasant nor Pleasant			Very Pleasant	Don't Know
1	2	3	4	5	6	7	0

e. Most people who are important to me would approve of me having genetic testing for prostate cancer.

1-Month Follow Up Survey (Both Study Arms)

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

f. Most people like me would have genetic testing for prostate cancer.

Unlikely			Neither Unlikely nor Likely			Likely	Don't Know
1	2	3	4	5	6	7	0

g. I am confident that I could have genetic testing for prostate cancer if I wanted to.

False			Neither False nor True			True	Don't Know
1	2	3	4	5	6	7	0

h. My having genetic testing for prostate cancer is up to me.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

i. I intend to make an appointment with a genetic counselor to discuss genetic testing within the next three months.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

j. I intend to have genetic testing for prostate cancer in the next three months.

Disagree			Neither Disagree nor Agree			Agree	Don't Know
1	2	3	4	5	6	7	0

Decisional Conflict:

The next set of statements are about making a decision about having genetic counseling and testing for prostate cancer.

4		Yes	No	Don't Know
A	Do you feel sure about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Do you know the benefits and risks of your option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Do you have enough support and advice to make a decision?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next set of statements are about making a decision about participating in a genetic study about prostate cancer.

5		Yes	No	Don't Know
A	Do you feel sure about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Do you know the benefits and risks of your option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Do you have enough support and advice to make a decision?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

As a participant in this study, you received a booklet about prostate cancer and genetics.

6. Did you share the book with other people?

☐ Yes

☐ No

7. Is there anything you'd like to tell us about participating in this study?

Telephone Script – Calls to Enroll Eligible Participants

If participant does not answer the phone: (message) Hello, I'm calling from Thomas Jefferson University, in regard to a letter you should have received in the mail from City Life Clinic about 2 weeks ago. The letter described an opportunity for men to participate in an educational study about prostate cancer information. Men who complete the study will receive \$50. If you are interested in learning more, please call this number: 215-503-5267. You can also email at peer-genetics@jefferson.edu.

If participant answers the phone: Hello, I'm calling from Thomas Jefferson University, in regard to a letter you should have received in the mail from City Life Clinic about 2 weeks ago. The letter described an opportunity for men to participate in paid educational study about prostate cancer information. Do you remember receiving the letter? Or, do you remember the letter?

If no: I'm sorry that you didn't receive it (Or: I'd be happy to tell you more). [Read text from recruitment letter:

Thomas Jefferson University is partnering with CityLife Clinic to offer an educational study for men to learn about their risk of prostate cancer. You are receiving this letter because you are a patient at CityLife Clinic.

Black men are more likely to get prostate cancer and die from it than white men. Black men are also more likely to have a genetic risk for prostate cancer than white men. It is important for every man to understand his own risk for prostate cancer so that he can make good choices to live a long and healthy life.

In the study, you will learn about prostate cancer and complete two surveys about your experience. You will earn \$50 for being in the study. No one at City Life Clinic or Jefferson Health System will know that you are in the study.]. Are you interested in seeing if you qualify for the study?

If yes: Great. Are you interested in seeing if you qualify for the study?

If no: Thank you for your time. We will not call you again.

If yes: {Review eligibility criteria}.

1) Male

- 2) Between the ages of 35-69
 - 3) Speak English
 - 4) Has not participated in one of the focus groups
-

If not eligible: Unfortunately, you do not qualify to participate in the study. Thank you for your time today.

If eligible: You are eligible to participate in the study. If you have 45 minutes, I can enroll you in the study right now, over the telephone, and get you started.

If not a good time to do enrollment: No problem. What might be a good day/time to call you back?

If OK to complete enrollment:

1. Read consent statement. Participant verbally consents.
 2. Collect baseline survey data.
 3. Determine randomization/ study arm.
 4. Tell participant next steps, depending on study arm.
-

Control Arm: First, we will be mailing you an educational booklet about prostate cancer, family history and genetics. Please read through the booklet at your own pace. In 2 weeks, a member of the study team will call you to ask you questions about the information in the booklet. We will also send a reloadable gift card for your time. We will load on \$25 for your participation today and another \$25 after you complete the second survey. I'd like to schedule the call in two weeks for the second set of questions.

Intervention Arm: Next, we will be mailing you an educational booklet about prostate cancer, family history and genetics. We will schedule you to attend a one-hour online (zoom) session with about 6-8 other men who are also participating in the study.

- Do you have the ability to join us on Zoom?
 - Yes – proceed
 - No – discuss possible in-person sessions

These sessions will be moderated by a male peer educator, who can explain the material in the booklet and give you a chance to ask questions about the material. Two weeks after the session, a member of the study team will call you to ask you questions about information in the booklet. We will also send a reloadable gift card for your time. We will load on \$25 for your participation today and another \$25 after you complete the second survey. I would like to schedule the Zoom appointment now and schedule the call two weeks after the Zoom session.

Do you have any questions for me before we hang up?

Peer Genetic Study

(Control Arm)

Dear Mr. _____:

Thank you for agreeing to participate in our “Peer Genetic Study,” conducted by Thomas Jefferson University in partnership with City Life Clinic. You are receiving an educational booklet included with this letter for the group you are a part of for the study. Please take the time to read through this attached booklet. A month from now, you will receive a follow-up survey to assess your understanding of the information in the enclosed packet.

Upon completion you will receive an additional \$25 for your participation. If you have any questions, feel free to reach out to one of our study staff. The contact information is below.

Nicole Crumpler, Study Coordinator

Thomas Jefferson University

Nicole.Crumpler@jefferson.edu

(215) 503-5267

Peer Genetic Study
(Intervention Arm)

Dear Mr. _____:

Thank you for agreeing to participate in our “Peer Genetic Study,” conducted by Thomas Jefferson University in partnership with City Life Clinic. You are receiving an educational booklet that reviews information about prostate cancer and genetic testing for this study. Please take the time to read through this attached booklet. You will also be assigned to a peer-led genetic education session. Here are the details for your education session:

Peer Education Session Meeting Information

Date: _____

Time: _____

Zoom Meeting ID: _____

Password: _____

A month after your peer-led session, you will receive a follow-up survey to assess your understanding of the information presented during your education session. Upon completion of the survey you will receive an additional \$25 for your participation. If you have any questions, feel free to reach out to one of our study staff. The contact information is below.

Nicole Crumpler, Study Coordinator

Thomas Jefferson University

Nicole.Crumpler@jefferson.edu

(215) 503-5267

Genetic Testing and Prostate Cancer

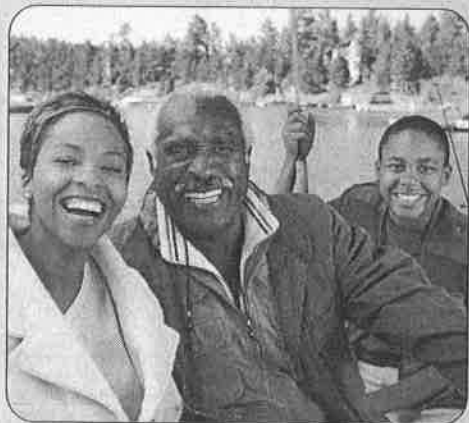
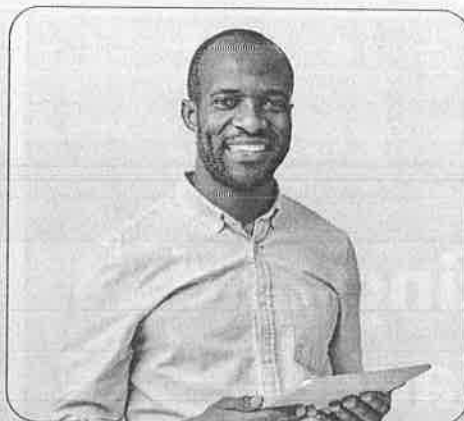
YOUR HEALTH • YOUR LEGACY • YOUR LIFE



Jefferson



CityLife Health



Funding for this study is provided by the U.S. Department of Defense. Veda Giri, MD is the Principal Investigator and Amy Leader, DrPH, MPH is the Co-Principal Investigator, both of Thomas Jefferson University.

Why Genetic Testing Matters in Prostate Health

Welcome!

Many African-American men in Philadelphia aren't aware that they are more at risk for prostate cancer than men from other racial/ethnic groups. About 1 out of every 5 Black men in America will be diagnosed with prostate cancer at some point in their lives, compared to 1 in 7 for all men.

We don't know all of what causes prostate cancer or why Black men are more likely to get prostate cancer. But we want you to have the information you need to understand your own prostate cancer risk and what you can do about it. This allows you to make informed choices.

One reason that men may develop prostate cancer is because of genetic mutations passed down through their family. We're going to give you some information about the prostate, genetics and family health history—and about how all of these things are connected. Then you'll be prepared to take control of your prostate health going forward.

The Basics: What is the prostate? When

What You Need to Know

The prostate is a walnut-sized gland located between the bladder and the penis in males.

Its main function is to secrete prostate fluid, a component of semen.

Symptoms of prostate problems:

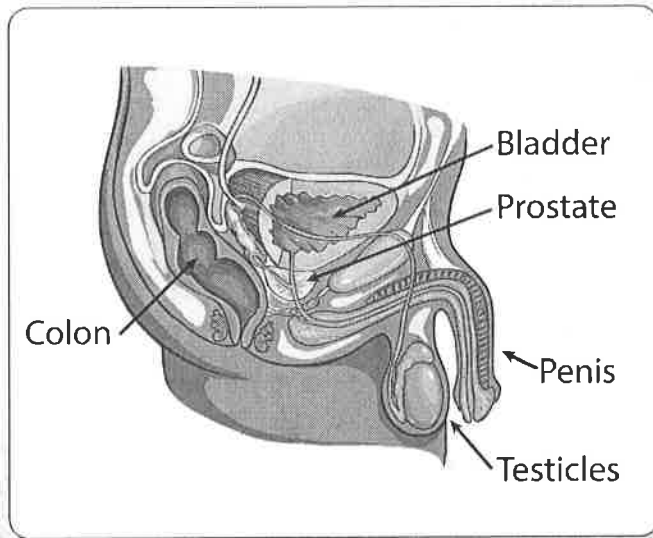
- Having to pee a lot more than usual, especially at night
- Difficulty having or keeping an erection
- Blood in the urine or semen
- Pain during ejaculation

Having symptoms does not mean you have prostate cancer. Many men who *do* have prostate cancer have no symptoms. This is why screening for prostate cancer is important.



is it? What does it do?

The Prostate



Screening for prostate cancer and screening for colon cancer involve different tests looking for different cancers.

Understanding Your Personal Risk for Prostate Cancer

Family History: Prostate cancer runs in some families, although it also occurs in men without a family history of this cancer. Having a father or brother with prostate cancer more than doubles a man's risk. Other cancers may also be linked to prostate cancer in families, such as breast cancer, ovarian cancer, pancreatic cancer, and colon cancer. We'll talk more about why knowing your family health history is important in the next section.

Other Risk Factors for Prostate Cancer

Age: Your risk of prostate cancer increases as you get older, especially after age 50.

Race/Ethnicity: Prostate cancer occurs more often in Black, African-American, Afro-Caribbean and other men of color than in men of other race/ethnicity.

Diet: Men who eat a lot of red meat or high-fat dairy products and fewer fruits and vegetables have a slightly higher chance of getting prostate cancer.

Body Weight: Some studies have found that overweight or obese men have a higher risk of having more aggressive or advanced prostate cancer and of dying from it.

Agent Orange exposure: Prostate cancer has been associated with exposure to Agent Orange, a chemical used during the Vietnam War.

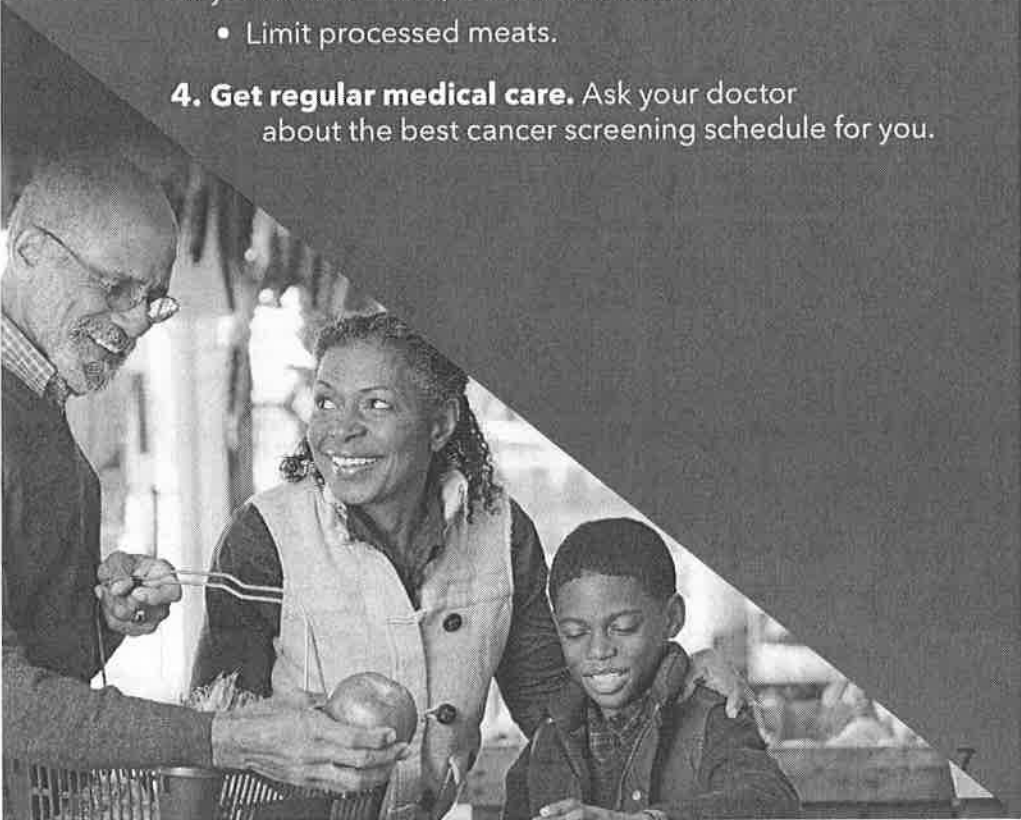
When you meet with your doctor, be sure to mention whether you have any of these risk factors.

Can I Prevent Prostate Cancer?

There are no guarantees, but there are a few things you can do.

Cancer prevention and risk reduction is still evolving. What we do know is that the risk of developing cancer can be affected by lifestyle choices. Consider these tips:

- 1. Get regular cancer screenings.** Early detection saves lives.
- 2. Maintain a healthy weight and be physically active.** This lowers the risk of various types of cancer like prostate, colon and kidney cancers. Physical activity helps you control your weight.
- 3. Eat a healthy diet.** Like #2, it can't prevent cancer, but it reduces your risk
 - Eat plenty of fruits and vegetables
 - If you drink alcohol, do so in moderation
 - Limit processed meats.
- 4. Get regular medical care.** Ask your doctor about the best cancer screening schedule for you.



Family History and Prostate Health

Why is it important to know my family's health history?

We share traits with our family members, like our hair or eye color, our height or the shapes of our noses. But family health history also includes things we *can't* see, like having obesity or an increased risk of diabetes, high blood pressure or certain types of cancer in one's family.

That's why learning about your health history and sharing that information both with other members of your family and with your doctor is important. A family health history can:

- Reveal early warning signs of a condition or disease.
- Provide doctors with information so they can assess your risk of certain diseases or cancers.
- Help you decide which lifestyle choices can help reduce your risks.
- Inform couples about certain genetic tendencies when they are thinking about having a child.
- Determine which types of treatments could work best for you.

An important part of the conversation with your doctor is telling him or her about your family's cancer history:

- Men in your family who have had prostate cancer.
- Other cancers in the family, such as breast, ovarian, pancreatic or colon cancer.
- What type of cancer a family member had and how old he or she was when it was diagnosed.
- If someone died from prostate or other cancer, at what age?
- Men in the family whose prostate cancer (metastatic) had spread from the prostate to other parts of the body.



Collecting Family Health History

If you don't know your family's health history, now is a great time to start finding out about it.

Whose history do I need?

The general rule for family health history is that more is better. In addition to your personal medical history, try to collect information from or about:

- Your parents
- Your brothers and sisters
- Your children

Then move on to other family members... aunts, uncles, cousins and grandparents—and even great-grandparents if you can.

Basic information to collect from/about relatives:

- Name and how you are related (myself, parent, child, etc.)
 - Race, ethnicity and/or origins of family, including any known Ashkenazi Jewish (Eastern European) ancestry
 - Date of birth (or a best guess—for example, "some time in the late 1940's")
 - Country of origin/birth
 - Any cancer(s), how old when diagnosed. If deceased, age and cause of death

How can I capture this information?

Record the conversation or take notes by writing down the health-related information given by your relatives. You can gather the information by doing a survey, face-to-face interview or even a family group discussion—or a combination of all three. Some people use their family reunions as a time to gather this information.

(See page 18 for Tips for Having the Family Health History Conversation)

Testing Related to Prostate Cancer

There are several types of tests for prostate health.

- **Screening tests**, such as the PSA (prostate-specific antigen) blood test or a digital rectal exam, help to see if there is suspicion for prostate cancer being present, but do not diagnose prostate cancer. These tests, usually done by your primary care doctor or a urologist, are used mainly to screen for prostate cancer in men who don't have any symptoms.
- **Diagnostic tests**, such as prostate biopsies, take a piece of your actual prostate tissue to see if there are prostate cancer cells present. This minor invasive procedure is the only way to diagnose prostate cancer.
- **Genetic tests** look at your genes, focusing on ones known to be associated with prostate cancer. It allows doctors to evaluate your DNA for changes that may have been inherited and could be harmful. (More details on p. 14)



Is a Prostate Screening Test Right for Me?

If you're over 45, talk to your doctor about your risk of prostate cancer, even if he or she hasn't brought it up—even if you don't have any symptoms of prostate problems. If you have a father, brother or son who has/had prostate cancer, you should begin screening at age 40.



Not all doctors agree that all men should be screened for prostate cancer. Consider what your doctor says and talk to other important people in your life who you trust, then decide if screening is the right decision for you.

Genetics 101

(See the glossary for terms you may be unfamiliar with)

What is a genetic mutation—and what causes it?

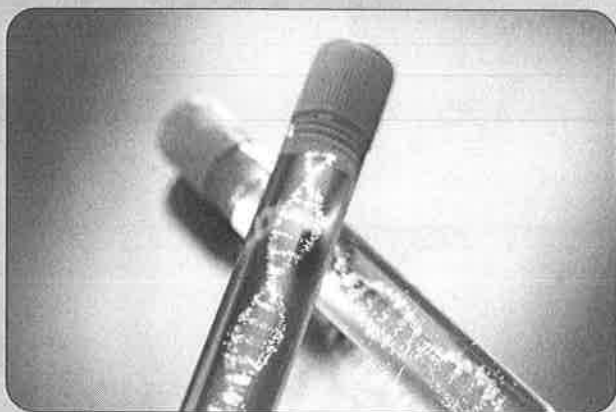
- A mutation is a change in a gene, causing the gene to not function properly.
- Mutations that are inherited may occur spontaneously during egg and sperm development. When these egg and sperm unite, the offspring then inherit the mutation. This can lead to increased risk for cancer in a person's lifetime.
- Some genes function to stop cancers from happening and if there is a mutation in one of these genes, that gene may not be able to stop cancers from happening.

Can you inherit cancer?

- Certain genes that we are born with, passed down by our parents, can contribute to cancer risk.
- Approximately 5 to 10% of cancers are hereditary, meaning they are caused by a genetic change, or mutation, that is passed down through the family.

What still needs to be discovered?

- We do not yet know all of the mutations that cause cancer.
- We don't know all of the causes of cancer.
- Only some cancers have tests that would find disease before it happens
- Not every cancer has treatment that will work.



Which genetic mutations are important in prostate cancer risk?

Several genes are associated with increased risk for prostate cancer. Some of the genes with the most information about prostate cancer risk include the BRCA1 and BRCA2 genes, Lynch syndrome genes, and HOXB13.

BRCA1 and BRCA2: Mutations in these two genes can increase the risk for prostate cancer, male breast cancer and breast and ovarian cancer in women, as well as pancreatic cancer and melanoma (skin cancer) in both men and women.

Lynch Syndrome: This is caused by mutations in a group of genes (MLH1, MSH2, PMS2, MSH6, EPCAM) that can increase risk for prostate cancer and other cancers, such as colon, uterine, ovarian, stomach and pancreatic cancer.

HOXB13: Mutations in this gene can increase risk for prostate cancer, especially at a younger age, such as in a man in his 40's.

This table below helps to see the cancers linked with these gene mutations. This is not a complete list, as many other genes can now be tested when evaluating risk for prostate cancer. New genes are also always being discovered.

Gene Mutation	Other Cancer Risks						
	Breast	Ovarian	Pancreatic	Skin	Colon	Uterine	Stomach
BRCA1 & BRCA2			
Lynch Syndrome	
HOXB13							

Genetic Testing for Prostate Cancer

If what you find out in your family health history shows that prostate cancer runs in your family, or even that other cancers do, you may want to take the next step and consider undergoing genetic testing. This next section explains what it is and what you will likely learn—then what you can do with that information.

What is genetic testing?

Genetic testing looks for mutations in genes known to cause increased cancer risk. The test is usually done with a blood or saliva sample.

Why is genetic testing important for prostate cancer?

Genetic testing can help you understand cancer risks for you and for your family. Your results may be important for your whole family, including your children, siblings, parents, grandparents, aunts and uncles, cousins and any other blood relatives. What you find out will help them understand their own risks for cancer—and how they could reduce those risks.

For you, the genetic test results can help your doctor decide on the type of prostate cancer screening you need, at what age you should start screening and whether there is a need to screen for other cancers.

Genetic testing can be considered by men with or without prostate cancer.

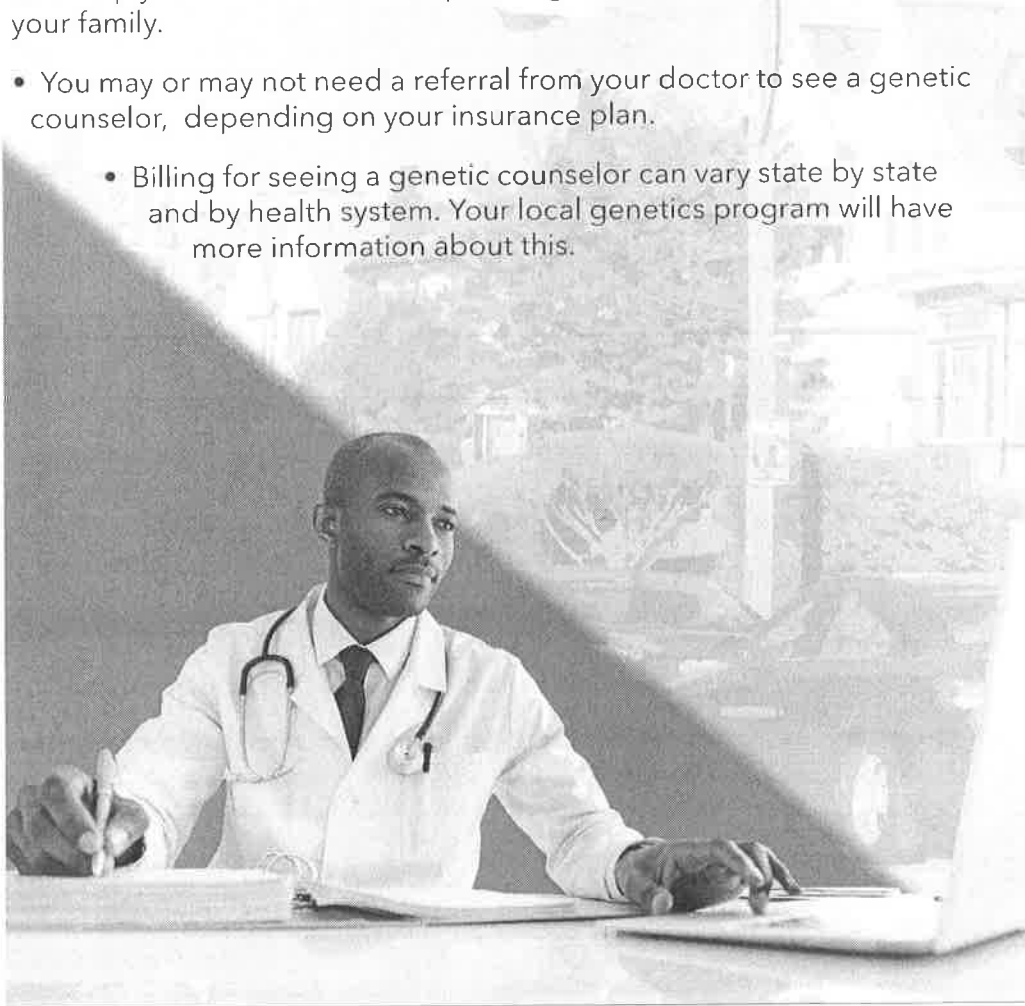
Genetic Testing: What's Best for You?

It is important to discuss genetic testing and your family history of cancers with a genetics specialist before having genetic testing to make sure you are making the best decision for yourself.

How do I find a genetic counselor?

Ask your doctor about finding a genetic counselor. This specialist, with training in genetics, helps patients understand genetic testing. They also help you understand the impact of genetic test results for you and your family.

- You may or may not need a referral from your doctor to see a genetic counselor, depending on your insurance plan.
- Billing for seeing a genetic counselor can vary state by state and by health system. Your local genetics program will have more information about this.



Genetic Testing: What's Best for You?

What happens at genetic counseling?

Your first appointment with the genetic counselor will involve discussing your medical history and your family history. They will discuss all of the ways genetic testing can be done, the benefits, and the limits of testing.

If you decide to have genetic testing, the genetic counselor will collect your saliva sample or a blood sample to send to the laboratory for testing. The results take about 4-6 weeks to return.

Once the results are back, you will have a second appointment with the genetic counselor to review the results, understand the findings, and get information on what the results mean:

- For your prostate cancer screening (if you do not have prostate cancer),
- For prostate cancer treatment (if you have had prostate cancer), and
- How to handle any other cancer risks.

They will also review what the results mean for members of your family and whether they should also consider genetic testing.



Glossary of Terms

Note: The following entries refer to the terms used in this booklet. Please go to the Reference section to do any additional research.

DNA, short for deoxyribonucleic acid, is the molecule that contains the genetic instructions for the development and function of the cells of all living things. In other words, whenever organisms reproduce, a portion of their DNA is passed along to their offspring.

Genes are pieces of DNA that operate the cells in our bodies found in the DNA. They are passed down from parents to their children. Genes determine what characteristics we inherit, such as what we look like (eye or hair color) and how we react to things we come in contact with, like foods, germs and pollutants in the environment. They can also impact your risk for cancer and how it grows in your body.

Genetics is the study of how different characteristics are passed down from grandparents to parents to children. Each of our parents gives us some of their genes. The way they combine makes us unique. Genetics explains why family members look alike and why some diseases run in families.

Genetic Testing looks for DNA mutations that can cause disease or cancer. It can find a related mutation long before someone has symptoms of the disease.

Genetic Variations are the small differences in our genes that determine why people look different. There are genetic variations that we can see—for example, differences in people's height or skin color. There are other genetic variations that we can't see, for example, how our bodies respond to medicines or foods.

Mutations happen when one or more genes in the DNA inside a cell are changed or become damaged. When it is mutated, a gene no longer works the way it should. DNA mutation is a type of genetic variation that can lead to disease or make us more susceptible to a particular disease or cancer.

Personalized medicine, including genetic testing, is a new way to look at disease prevention and treatment. Personalized medicine takes into account the differences in each person's genes, the things that we are exposed to, and the way we live. If you are diagnosed with cancer, personalized medicine uses information about the genes in your cancer tumor to find the most effective ways to treat it.

Tips for Having the Family Health History Conversation

Prepare ahead of time

- Write down what you know—such as family members' names, where they were born, or how many children they have.
- Prioritize the questions you will ask ahead of time; that way you will be sure to get the most important information

Having the talk

- Do not expect people to know the answers to all of your questions. Sometimes you will have to piece together information over time, bit by bit. Be patient!
- Try to keep your questions short. Avoid questions that can be answered with a simple "yes" or "no"—you want details and context.
- Ask your family member to show you pictures, recipes, letters and other family keepsakes. These can help people remember details and lead to more family stories.
- Use follow-up questions, such as "Why...?" "How...?" and "Can you give me an example?"
- Try not to interrupt—let your family members tell their stories in their own language and style.
- Respect a person's wishes not to talk about certain people or topics.

Now that you know...share what you've learned

- Talking with your family about your shared cancer history may be an uncomfortable conversation. Health, particularly related to cancer, can often be an emotionally charged topic.
- Share what you have learned and why you think it's important for others to know. Then, listen carefully and try to be as respectful and patient as possible.
- Just because your parents or other family members have a condition doesn't mean you have it now or will in the future.
- Be as open and honest as possible about your own health journey, particularly if you have made the decision to undergo genetic testing. It will make sharing those results easier.

References

We encourage you to do your own additional research about prostate health and genetic testing. Please use the following links as a starting point. Be sure to speak to your doctor, a genetic counselor or other healthcare professional about resources and specific questions.

Where to Find More Information About...

Cells

- National Institutes of Health, MedlinePlus on Genetics - (ghr.nlm.nih.gov/primer/basics.pdf)
- Genome: Unlocking Life's Code (Smithsonian National Museum of Natural History - (unlockinglifescode.org/media/animations/515))

Genetics

- The National Institutes of Health - (<https://nigms.nih.gov/education/genes>)
- Genome: Unlocking Life's Code - (unlockinglifescode.org)

DNA Mutation

- National Human Genome Research Institute - (Genome.gov/25520880/)
- U.S. National Library of Medicine - (ghr.nlm.nih.gov/primer/mutationsanddisorders/genemutation)

Genetic Testing & Personalized Medicine

- Genetic Testing FAQ Sheet - (Genome.gov/19516567/faq-about-genetic-testing/)
- National Cancer Institute - (Cancer.gov/about-cancer/causes-prevention/genetics/genetic-testing-fact-sheet)

Family History

- U.S. Centers for Disease Control, a web-based tool, Family Health Portrait - (Phgkb.cdc.gov/FHH/html/index.html)
- Family History Collection Form - (Healthline.com/hlcmsresource/images/Family_Health_History_Healthline.pdf)



Jefferson™

&



CityLife Health

Be Healthy

Respect your body and take care of it. It's the only one you've got. Eat healthy and keep your body moving. Recognize that stress affects your health too, so find positive ways to cope with it. There are risk factors you can change or control and those you can't. We can't give you a guaranteed recipe for how to prevent prostate cancer, but a healthy diet and regular exercise and physical activity will help.

Know Your Family History

Knowing your family health is important because it gives you the information you need to take steps to reduce your risk of prostate cancer.

Talk to Your Doctor

Know your rights! You have a right to be part of every decision affecting your health. Now you can be informed and empowered to lead the discussion to figure out what works best for you.

**If you have any
questions, we can help.**

**Call Us!
(215) 503-5267**



Dear Mr. _____:

Thomas Jefferson University is partnering with CityLife Clinic to offer a research study for men to learn about their risk of prostate cancer. You are receiving this letter because you are a patient at CityLife Health.

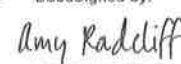
Black men are more likely to get prostate cancer and die from it than white men. Black men are also more likely to have a genetic risk for prostate cancer than white men. It is important for every man to understand his own risk for prostate cancer so that he can make good choices to live a long and healthy life.

In the research study, you will learn about prostate cancer and complete two surveys about your experience. You will earn \$50 for being in the study. No one at CityLife Health or Jefferson Health System will know that you are in the study.

In two weeks, we will contact you to tell you more about the study. If you do not want to hear about the study, you can call us at 215-503-5267 and we will not call you.

We wish you good health in the new year and look forward to talking to you about this important study.

Sincerely,

DocuSigned by:

Amy Radcliff

Chief Operating Officer



Veda N. Giri, MD
Study Principal Investigator

OHR-8F

7/2006

CityLife Health

Thomas Jefferson University