

## Landing page



Form Approved  
OMB No. XXXX-XXXX  
Exp. Date: XXXXXXXX

### Welcome to the *What do you have to say about cancer?* survey

NORC at the University of Chicago is conducting a survey sponsored by the Centers for Disease Control and Prevention. This survey is to learn about your genetic testing for cancer risk and how your family talks about cancer risk. Your participation will help us identify aspects of family communication about cancer and genetic testing to better understand how such information is shared in families.

The survey will take about 20 minutes to complete. The survey will include general demographics and questions related to health and cancer in your family.

Any information you provide will be maintained in a secure manner. No one will know how you answered the questions. Only project staff will have access to the study data. The data we collect from you will be combined with data from other participants.

You taking the survey is your choice. You may skip questions you do not want to answer and you can stop the survey at any time. Eligible participants will receive a \$5 Amazon gift card at the end of the survey.

[Start Survey](#)



If you have any questions about the survey, you can call the NORC IRB Administrator toll-free at: 866-309-0542.

#### BURDEN STATEMENT

Public reporting burden of this collection of information is estimated to average 30 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR, Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-1154).

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## Preliminary Screens



Please confirm you are not a robot.

I'm not a robot



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In case you need to exit the survey and complete it at a later time or you get disconnected, please enter your email address so we can send you a link to reaccess the survey.

Please enter your email address:

Please reenter your email address:

Prefer not to answer

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## Instructions



Thank you for agreeing to participate in our study.

Please use the "Next" and "Back" buttons to navigate between the questions within the questionnaire. You can exit the survey at any time and your progress will be saved for later completion when you use the "Save and Exit" button. Please do not use your browser's navigation buttons. If you step away from your computer for an extended period of time, your session may time out and you may not be able to continue with your current survey session. Please try to complete the survey at one time so that you are able to retrieve your gift code today. There are a limited number that will be given out daily, but you can resume your survey on another day using the following link:

<https://atest-cawi.norc.org/SE/?st=DwKo60S6YzqZ74vuUD%2fe0a2wrf%2f7gSAaR019h43Rjnu%3d&p=G9W2V4>

Please save this link or [print](#) it for your records.

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AGE



How old are you?

years

Prefer not to answer

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SEX



Are you male or female?

Male

Female

Prefer not to answer

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POSSIBLETESTING/RECOMMENDTESTING/RECEIVEDTESTING



The following questions refer to genetic TESTING for cancer risk. That is, testing your blood to see if you carry genes which may predict a greater chance of developing cancer at some point in your life. This does NOT include tests to determine if you have cancer now. Do not include self-testing kits administered at home.

	Yes	No	Don't know	Prefer not to answer
Have you ever discussed the possibility of getting a genetic test for cancer risk with a doctor or other health professional?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Has a medical doctor ever recommended that you get a genetic test for cancer risk?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you ever had a genetic test to determine if you are at greater risk of developing cancer in the future?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Q4



Thank you for your participation in this important study! For this survey, we will start by asking you a few questions about your health.

In general, how is your health? Would you say it is...?

- Excellent
- Very good
- Good
- Fair
- Poor
- Prefer not to answer

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CANCER



**What do you have to  
say about cancer?**

**Have you EVER been told by a doctor or other health professional that you have had cancer or a malignancy of any kind?**

- Yes
- No
- Don't know
- Prefer not to answer

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CANCERTYPE



## What do you have to say about cancer?

We would like to learn about the type(s) of cancer you have experienced.

Could you please tell us what type(s) of cancer you were diagnosed with?

Please click on this box if you would like to enter more than one kind of cancer

Please click on this box if you would like to enter more than two kinds of cancer

Please click on this box if you would like to enter more than three kinds of cancer

Don't know

Prefer not to answer

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### DIAGNOSIS



## What do you have to say about cancer?

How old were you when you were first diagnosed?

years

Don't know

Prefer not to answer

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### ADOPT



The following questions will ask about your communication with family members.

Are you adopted?

- Yes
- No
  
- Prefer not to answer

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YNMOM/YNDAD



Are your biological parents still living? *By biological, we mean related by blood.*

**Mother**

- Living
- Deceased
- Don't know
  
- Prefer not to answer

**Father**

- Living
- Deceased
- Don't know
- Prefer not to answer

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YNSISTER



We would appreciate if you can provide a response. That way, we can direct you to the correct questions in the following questionnaire.

For the following biological or blood relatives, please enter the number that are living and the number who may have died. If you do not have the relative listed, please mark Not Applicable.

	Living	Deceased	Don't know	Not Applicable
Full Sister(s)	<input type="text" value="0"/>	<input type="text" value="0"/>	<input type="radio"/>	<input type="radio"/>

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## YNHSISTER



For the following biological or blood relatives, please enter the number that are living and the number who may have died. If you do not have the relative listed, please mark Not Applicable.

	Living	Deceased	Don't know	Not Applicable
Half Sister(s)	<input type="text"/>	<input type="text"/>	<input type="radio"/>	<input type="radio"/>

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## YNBROTHER



For the following biological or blood relatives, please enter the number that are living and the number who may have died. If you do not have the relative listed, please mark Not Applicable.

	Living	Deceased	Don't know	Not Applicable
Full Brother(s)	<input type="text"/>	<input type="text"/>	<input type="radio"/>	<input type="radio"/>

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## YNHBROTHER





For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Half Brother(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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## YNDAUGHTER



For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Daughter(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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## YNSON



For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Son(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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## YNGRANDP



For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Grandparent(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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YNGRANDC



For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Grandchild(ren)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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YNUNCLE



For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Uncle(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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YNAUNT



For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Aunt(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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## YNCOUSIN



For the following **biological or blood** relatives, please **enter the number** that are living and the number who may have died. *If you do not have the relative listed, please mark Not Applicable.*

	Living	Deceased	Don't know	Not Applicable
Cousin(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="radio"/>	<input type="radio"/>

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## SONSAGE



How many biological sons do you have in the following age ranges?

0-5	<input type="checkbox"/>
6-12	<input type="checkbox"/>
13-17	<input type="checkbox"/>
18 or older	<input type="checkbox"/>

- Don't know  
 Prefer not to answer

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## DAUGHTERSAGE



How many biological daughters do you have in the following age ranges?

0-5	<input type="checkbox"/>
6-12	<input type="checkbox"/>
13-17	<input type="checkbox"/>
18 or older	<input type="checkbox"/>

- Don't know
- Prefer not to answer

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## COUNSELING



These next few questions refer to genetic counseling for cancer risk. Genetic counseling involves a discussion with a specially trained health care provider about your family history of cancer and how likely you are to develop cancer. It may also include a discussion about whether genetic testing is right for you.

Have you ever received genetic counseling for cancer risk?

- Yes
- No
- Don't know
- Prefer not to answer

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## COUNSATISFIED



How satisfied are you with the communication you have had with your genetic counselor about your cancer risk?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
  
- Prefer not to answer

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FLEARN



Now we are going to ask you about your experiences with genetic testing.

How did you hear about genetic testing?

	Yes	No	Don't know	Prefer not to answer
A friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A family member	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A nurse, doctor, or other healthcare provider	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Twitter, Facebook, or Snapchat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other social media, online advertisements, Google, or other internet sources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Posters, signs, or billboards	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Ads or campaigns in the community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any other place, specify	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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DECISONCONFLICT



We would now like for you to think back about your decision to get genetic testing. Please rate your level of agreement with each of the following:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Prefer not to answer
I knew which options were available to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew the benefits of genetic testing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew the risks of genetic testing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was clear about which benefits mattered most to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was clear about which risks mattered most to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was clear about which was more important to me (the benefits or the risks).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please rate your level of agreement with each of the following:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Prefer not to answer
I had enough support from others to make a choice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was choosing without pressure from others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had enough information to make a choice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was clear about the best choice for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt sure about what to choose.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please rate your level of agreement with each of the following:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Prefer not to answer
The decision was easy for me to make.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I made an informed choice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My decision shows what is important to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am satisfied with my decision.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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DECISION



Who was involved in your decision to get genetic testing?

	Yes	No	Don't know	Prefer not to answer
Mother	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Father	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Full Sister(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Half Sister(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Full Brother(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Half Brother(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daughter(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Who was involved in your decision to get genetic testing?

	Yes	No	Don't know	Prefer not to answer
Son(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grandparent(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grandchild(ren)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uncle(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aunt(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cousin(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friend(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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DECISION2





How involved were each of these relatives in your decision to get genetic testing?

	Very involved	Somewhat involved	Not very involved	Don't know	Prefer not to answer
Mother	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Father	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Full Sister(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Half Sister(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Full Brother(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Half Brother(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Daughter(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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How involved were each of these relatives in your decision to get genetic testing?

	Very involved	Somewhat involved	Not very involved	Don't know	Prefer not to answer
Son(s)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grandparent(s)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Grandchild(ren)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uncle(s)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aunt(s)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cousin(s)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friend(s)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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We previously asked if you ever had genetic testing. Now, we would like to ask you about the type of genetic testing you had.

Have you ever had genetic testing for a BRCA1 or BRCA2 mutation for increased breast and ovarian cancer risk?

- Yes
- No
- Don't know
  
- Prefer not to answer

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TESTRESULTBR



What was the result of your BRCA test?

- I carry a gene mutation that is associated with greater cancer risk for me or my family
- I was found to have a gene mutation, but it is not clear whether it is associated with cancer risk for me or my family (also known as a variant of unknown significance or VUS)
- No gene mutation was found
- Don't know
  
- Prefer not to answer

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BRCARESULT



Were you surprised by the results of your genetic test(s) for the BRCA mutation?

- Yes
- No
- Don't know
- Prefer not to answer

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LYNCHTEST



Have you ever had genetic testing for Lynch Syndrome or hereditary colorectal cancer?

- Yes
- No
- Don't know
- Prefer not to answer

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TESTRESULTLYNCH



What was the result of your genetic test for hereditary colorectal cancer?

- I carry a gene mutation that is associated with greater cancer risk for me or my family
- I was found to have a gene mutation, but it is not clear whether it is associated with cancer risk for me or my family (also known as a variant of unknown significance or VUS)
- No gene mutation was found
- Don't know
  
- Prefer not to answer

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## LYNCHRESULT



Were you surprised by the results of your genetic test(s) for Lynch Syndrome?

- Yes
- No
- Don't know
  
- Prefer not to answer

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## FINFORM



The following questions refer to BRCA testing or any other variants related to breast cancer. How were you FIRST informed of your genetic test results?

- Received an email
- Told on the phone
- Told in person
- Received a letter
- Other method, please specify
- Don't know
- Prefer not to answer

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SATISFAC



How satisfied were you with this form of communication?

- Very satisfied
- Somewhat satisfied
- Neither satisfied nor dissatisfied
- Somewhat dissatisfied
- Very dissatisfied
- Don't know
- Prefer not to answer

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RECEIVEFAX/RECEIVEVM/RECEIVEHOM/RECEIVEEM/RECEIVELET/RECEIVETEXT/  
RECEIVEWEB



How comfortable would you be receiving genetic test results from a healthcare provider via each of the following methods of communication?

	Very comfortable	Somewhat comfortable	Neither comfortable nor uncomfortable	Somewhat uncomfortable	Very uncomfortable	Don't know	Prefer not to answer
Fax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal voicemail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home voicemail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal email	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Letter	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Text message	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Password-protected website	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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IMPROVERESULT



How could the process for receiving your genetic test results have been improved? Please check all that apply.

- Receive the results sooner
- More compassion from provider sharing the results
- More resources provided with the results
- Better explanation of the results
- Better explanation of what results mean for family members
- Other, please specify
- I do not believe the process could be improved
- Prefer not to answer

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## MATERIAL



What materials, if any, were given to you along with your genetic test results? Please check all that apply.

- Genetic report
- Personalized medical report
- Brochure/pamphlet
- Fact sheet/Frequently asked questions (FAQs)
- Other, please specify
- No materials were provided
- Don't know
- Prefer not to answer

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## PROVMAT



Who provided you with these materials? Please check all that apply.

- Genetic counselor
- Gastroenterologist
- Surgeon
- Primary care provider
- OB/GYN
- Oncologist
- Nurse
- Laboratory who performed the test
- Other, please specify

- Prefer not to answer

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## SHAREMAT



With whom did you share these materials? Please check all that apply.

- Family members who have been tested
- Family members who have not been tested
- Friends
- Colleagues
- Medical provider
- Other, please specify

- Not applicable, I did not share these materials

- Prefer not to answer

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## PROVIDERRESOURCESFORFAMRISK





The following questions ask about resources and information you may have received regarding genetic testing.

Did your health care provider (genetic counselor, physician, nurse, etc.) provide you resources to help you inform family members about what the results of your genetic test mean for your family? Please check all that apply.

- Yes, they provided me a template for a letter to family members
- Yes, they discussed ways of speaking with family members about genetic testing
- Yes, they provided a brochure or other printed material from the health care provider
- Yes, they provided material from the laboratory that did the testing
- Yes, they told me about organization(s) that serve people with hereditary cancer
- Yes, they provided me a video about genetic testing
- Yes, they provided me with another type of information, please specify

- No, I was not provided with any resources
- Prefer not to answer

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## RESOURCESFORFAMRISK



Who provided you with resources to help you inform family members about what the results of your genetic test mean for your family? Please check all that apply.

- Genetic counselor
- OB/GYN
- Oncologist
- Nurse
- Laboratory who performed the test
- I was not provided with any resources
- Prefer not to answer

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## RESOURCEHELPFUL



Please select how much you agree with the following statement.

The resources provided were helpful in my discussions with family members about family cancer history.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
  
- Prefer not to answer

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OTHERINFO\_O



Thinking back to when you first received your genetic test results. What information or materials do you feel would have been most helpful for discussions about cancer family history?

- Don't know
- Prefer not to answer

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OTHERINFO



What other information or materials would be useful for discussions about cancer family history? Please check all that apply.

- More discussion with genetic counselor
- Discussions with physician
- Information pamphlets or FAQs
- Referral to support group
- General information about genetic mutations
- What genetic test results mean for you and your risk
- How genetic test results might impact future cancer screenings
- Where and who to go see if you have additional questions
- Where and who to go see for emotional or psychological support
- Insurance coverage for genetic testing
- Understanding choices or options for cancer prevention
- How to reduce cancer risk
- What genetic testing results mean for your children, siblings, and other family members
- None of the above
  
- Prefer not to answer

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Q37



What is your preferred method for receiving genetic testing information? Please check all that apply.

- Printed materials (e.g., brochures or pamphlets)
- Online
- Computer kiosk in a clinic
- Speaking directly with medical provider
- Genetic counselor
- Other, please specify

- Prefer not to answer

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Q38



Regardless of whether you received information from the following sources, please indicate how much you would trust additional information about genetic risk for cancer from each of the following.

	A lot	Some	A little	Not at all	Don't know	Prefer not to answer
A primary care physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A healthcare specialist (e.g., OB/GYN, oncologist)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family or friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Newspapers or magazines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Regardless of whether you received information from the following sources, please indicate how much you would trust additional information about genetic risk for cancer from each of the following.

	A lot	Some	A little	Not at all	Don't know	Prefer not to answer
Radio	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Regardless of whether you received information from the following sources, please indicate how much you would trust additional information about genetic risk for cancer from each of the following.

	A lot	Some	A little	Not at all	Don't know	Prefer not to answer
Government health agencies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Charitable organizations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious organizations and leaders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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ENOUGHINFO



The next series of questions will ask about your experiences sharing your genetic test results with family members.

Please select how much you agree with the following statement.

I have enough information about genetics and cancer to speak with family members.

- Strongly agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Strongly disagree
  
- Prefer not to answer

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DESIRETODISCUSSGENTESTRESULTS



For me, talking to my family members about my genetic test result is:

- Very easy
- Somewhat easy
- Neither easy nor difficult
- Somewhat difficult
- Very difficult
- Don't know
  
- Prefer not to answer

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SHARERESULTSMOTHER/SHARERESULTSFATHER/SHARERESULTSSISTER/SHARE  
DRESULTSHSISTER/SHARERESULTSBROTHER/SHAREDRESULTSHBROTHER



Please indicate if you have shared your most recent genetic test result(s) with any of the following biological or blood relatives.

	Yes	I plan to, but not yet	No (I do not plan to share the result)	I haven't decided	Not applicable	Prefer not to answer
Mother	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Father	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sister(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Half Sister(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brother(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Half Brother(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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SHARERESULTSDAUGHTER/SHARERESULTSSON/SHARERESULTSAUNTUNCLE/SH  
ARERESULTSCOUSIN/SHAREDRESULTSOOTH



Please indicate if you have shared your most recent genetic test result(s) with any of the following biological or blood relatives.

	Yes	I plan to, but not yet	No (I do not plan to share the result)	I haven't decided	Not applicable	Prefer not to answer
Daughter(s)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Son(s)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Uncle/Aunt(s)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cousin(s)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, please specify <input type="text"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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SHARED DATE



When did you first share your genetic test result(s) with your mother?

- Within a week
- Within a month
- Within a year
- Don't know
- Prefer not to answer

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FINFORMEDVIA TEXT/FINFORMEDVIA EMAIL/FINFORMEDVIA PHONE/FINFORMED VIA PERSON/FINFORMED GRAPEVINE/FINFORMEDVIA OTHER



When you informed FEMALE relatives of your genetic test result, which of the following methods did you use? Please check all that apply.

- Sent a text
- Sent an email
- Told them on the phone
- Told them in person
- I told someone who then told someone else (through the grapevine)
- Other method
- Not applicable
- Don't know
  
- Prefer not to answer

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MINFORMEDVIATEXT/MINFORMEDVIAEMAIL/MINFORMEDVIAPHONE/MINFORMEDVIAPERSON/MINFORMEDGRAPEVINE/MINFORMEDVIAOTHER



When you informed MALE relatives of your genetic test result, which of the following methods did you use? Please check all that apply.

- Sent a text
- Sent an email
- Told them on the phone
- Told them in person
- I told someone who then told someone else (through the grapevine)
- Other method
- Not applicable
- Don't know
  
- Prefer not to answer

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WHYSHARE





Why did you share your genetic test result(s) with these family members? Please check all that apply.

- I felt it was my responsibility
- It gave my family information that was useful for them
- My family asked me about my test results
- My genetic counselor and/or doctor(s) advised me to share the results with my family
- Other, please specify

- Don't know
- Prefer not to answer

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**TIMEEFFORT/FRUSTRATED/QUALITY/DIFFUND**



Based on your experiences with sharing the results of your genetic test(s) with your relatives, how much do you agree or disagree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Prefer not to answer
It took a lot of time and effort to share my genetic information with relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt frustrated while sharing my genetic information with relatives.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned about the quality of the information that I shared.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was concerned that my relatives may have found the information difficult to understand.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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NOCONTACT/NOTIME/NOCLEAR/NOTCLOSE/NOTCARE/NOTUPSET/NOTATRISK/W  
HATTOSAY/DIFFCOPING/TOOYOUNG/NOTALKOTH



Now I'd like you to think about those family members you said you didn't speak with about increased cancer risk. People have many different reasons for speaking with their family members and for not speaking with their family members. Below is a list of some of the reasons people have for not speaking to their family members about cancer risk. Please slide the bar to indicate how much each reason applies to you on a scale of 1 to 5, where 1 is not at all applicable to you, and 5 is very applicable to you.

			Don't Know	Prefer not to answer	
You are not in contact with him/her.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
You didn't have the time to tell him/her.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
You were unsure how to explain it clearly.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
The two of you are not close.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
He/she wouldn't care.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
You didn't want to upset him/her.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
He/she is not at risk for developing cancer.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
You didn't know what to say to him/her.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
You were having difficulty coping with your own risk for cancer.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
You feel that he/she is too young to understand.	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>
Other (please specify)	not at all applicable	1 	very applicable	<input type="radio"/>	<input type="radio"/>

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## RELATIVESCOUNSELING1-4



Please indicate which of your relative(s) have undergone genetic counseling. If no one in your family has received genetic counseling fill in the Not Applicable (N/A) box below.

- Mother
- Father
- Sister
- Brother
- Daughter
- Son
- Paternal grandmother
- Paternal grandfather
- Father's sister
- Father's brother
- Maternal grandmother
- Maternal grandfather
- Mother's sister
- Mother's brother
- N/A I know of no one in my family who has received genetic counseling
- Don't know
  
- Prefer not to answer

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Q49



Did you get genetic counseling before or after your daughter?

- I got genetic counseling BEFORE my daughter.
- I got genetic counseling AFTER my daughter.
- Don't know
  
- Prefer not to answer

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RELATIVESUNDERGONETESTING1-4



Please indicate which of your relative(s) have undergone genetic testing. If no one in your family has been tested fill in the Not Applicable (N/A) box below.

- Mother
- Father
- Sister
- Brother
- Daughter
- Son
- Paternal grandmother
- Paternal grandfather
- Father's sister
- Father's brother
- Maternal grandmother
- Maternal grandfather
- Mother's sister
- Mother's brother
- N/A I know of no one in my family who has been tested
- Don't know
  
- Prefer not to answer

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RELATIVESTESTINGRESULT1-4



What was the test result for your paternal grandmother?

- Test was positive for the mutated gene
- Test was negative for the mutated gene
- Test was not informative/indeterminate/of unclear significance
- I don't know the test result
- Don't know
  
- Prefer not to answer

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Q52



Did you get genetic testing before or after your paternal grandmother?

- I got genetic testing BEFORE my paternal grandmother.
- I got genetic testing AFTER my paternal grandmother.
- Don't know
  
- Prefer not to answer

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Q53



Who was the first in your family to get genetic testing?

- Myself
- Paternal grandmother
- Don't know
  
- Prefer not to answer

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Q54



When you were informed of your paternal grandmother's genetic test results, which of the following methods did they use? Please check all that apply.

- Sent a text
- Sent an email
- Told me on the phone
- Told me in person
- Told someone else who then told me (through the grapevine)
- Other method
- Not applicable
- Don't know
  
- Prefer not to answer

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AFFECTHEALTH



How much has your (or your family's) experience with genetic testing affected how you think about your health?

- Not at all
- A little
- A lot
  
- Prefer not to answer

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THINKEXP



How often do you think about your experience with genetic testing?

- Never
- Some time
- A lot of the time
  
- Prefer not to answer

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TALKEXP



How much time have you spent talking with friends or family members about any concerns you had about your experience with genetic testing?

- No time
- Some time
- A lot of time
  
- Prefer not to answer

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MARITALSTATUS





Finally, we have a few demographic questions.

What is your marital status?

- Married/partnered
- Living as married
- Divorced
- Widowed
- Separated
- Single, never been married
  
- Prefer not to answer

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## ORIENTATION



Which of the following best represents how you think about yourself?

- Lesbian or Gay
- Straight, that is, not lesbian or gay
- Bisexual
- Something else
- I don't know how to answer
  
- Prefer not to answer

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## IDENTITY



How do you describe yourself? (Select One)

- Female
- Male
- Transgender
- Do not identify as female, male, or transgender
  
- Prefer not to answer

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HEALTHINSUR



Are you covered by any kind of health insurance or some other kind of health care plan?

- Yes
- No
- Don't know
  
- Prefer not to answer

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INSURTYPE



What kind of health insurance or health care coverage do you have? Please check all that apply. Exclude private plans that only provide extra cash while hospitalized.

- Private health insurance, including those obtained through a state or federal exchange or healthcare.gov, or through the Affordable Care Act, also known as Obamacare
- Medicare
- Medi-Gap
- Medicaid
- SCHIP
- Military health care (TRICARE/VA/CHAMP-VA)
- Indian Health Service
- State-sponsored health plan
- Other government program
- Single service plan (e.g. dental, vision, prescription)
- No coverage of any type
- Prefer not to answer

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## EDUCATION



Finally, we have a few questions solely for statistical purposes.

What is the highest grade or level of schooling you completed?

- Grade 11 or less
- Completed high school
- Post high school training other than college (vocational or technical)
- Some college
- College graduate
- Postgraduate or graduate degree
- Prefer not to answer

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## HISPLATINOSPAN



Are you of Hispanic, Latino, or Spanish origin?

- Yes
- No
  
- Prefer not to answer

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HISPLATINOSPANGROUP



Which group are you from?

- Mexican, Mexican American, Chicano
- Puerto Rican
- Cuban
- Dominican
- Central or South American
- Other Hispanic, Latino, or Spanish origin
  
- Prefer not to answer

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RACE



What is your race? You may select multiple categories.

- White
- Black or African American
- Asian
- Native Hawaiian or Pacific Islander
- American Indian or Alaska Native
  
- Prefer not to answer

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## OCCUPATIONALSTATUS/OTHEROCCUPATION



What is your current occupational status?

- Employed
- Unemployed
- Homemaker
- Student
- Retired
- Disabled
- Other-Specify

- Prefer not to answer

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## HOUSEHOLDINCOME



Thinking about all the members of your family living in your household, what is your combined annual income, meaning the total pre-tax income from all sources earned in the past year?

- Less than \$20,000
- \$20,000 to \$49,999
- \$50,000 to \$99,999
- \$100,000 to \$199,999
- \$200,000 or more
- Don't know
  
- Prefer not to answer

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Q70



What region of the United States do you live in?

- Northeast
- Southeast
- Midwest
- West
- Not in the United States
- Don't know
  
- Prefer not to answer

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INCENTX



Congratulations, you are eligible for a \$5 Amazon gift card. Would you like to collect your gift card?

- Yes
- No

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Would you like us to email the gift code number to you?

- Yes
- No

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CLOSING SCREEN



This is the end of the survey.

Thank you very much for your time and effort.

If you would like information regarding genetic testing or treatment resources, please visit the following CDC webpage: <https://www.cdc.gov/cancer/dcpc/resources/index.htm>.

If you would like more information about the study, please call 312-201-4412 or send an email to [CancerSurvey@norc.org](mailto:CancerSurvey@norc.org). If you have questions about your rights as a survey participant, you may call the NORC Institutional Review Board Administrator (toll-free) at 1-866-309-0542.

**SUBMIT**

For technical support, please call 1-312-201-4412 or send an email to [CancerSurvey@norc.org](mailto:CancerSurvey@norc.org).