

Attachment 3d: High Risk Follow-Up Survey

Public reporting burden of this collection of information is estimated to average 25 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-XXXX).

HIGH-RISK FOLLOW UP WEB QUESTIONNAIRE

WINTRO_1 Thank you for agreeing to participate in our study!

Please use the “Next” and “Back” buttons to navigate between the questions within the questionnaire. Do not use your browser buttons.

If at any time during the survey, you would like to exit, please use the “Save & Exit” button above. Using this button will save all of the data you have already entered and ensure you are able to return to the same location to complete the survey.

WEBINEM1/WEBINEM2/WEBINPH1/WEBINPH2

In case you need to exit the survey and complete it at a later time or you get disconnected, please [enter/confirm] your email address so we can send you a link to re-access the survey.

Please enter your email address:

Please reenter your email address:

Prefer not to answer

<Programmer Note: If respondent was recruited by email, please autofill email address here. If accessing from email, use “confirm” else use “enter” >

<Programmer: If respondent logging back into survey>

WINTRO_2 Welcome Back!

Please use the “Next” and “Back” buttons to navigate between the questions within the questionnaire. Do not use your browser buttons.

If at any time during the survey, you would like to exit, please use the “Save & Exit” button above. Using this button will save all of the data you have already entered and ensure you are able to return to the same location to complete the survey.

Continue from where I left off

Section I. General Health

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

<Programmer Note: use autofills if respondent recruited by email>

Q1. In general, how is your health? Would you say it is...?

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

Q2. CANCER (NHIS – CANEV). 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**

<Programmer: If CANCER = Yes, continue to CANCERTYPE. Else, continue to YNMOM.>

Q3. CANCERTYPE (NHIS) What kind of cancer was it?

Q4. DIAGNOSIS (NHIS) How old were you when you were first diagnosed?

_____ years

Section II. Family Communication

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

Q5. ADOPT. Are you adopted?

- Yes
- No
- Prefer not to answer

Q6. Are your **biological** parents still living? By biological, we mean related by blood.

<Programmer Note: Put two items on same screen>.

YNMOM **Mother**
 Living
 Deceased
 Don't Know
 Prefer not to answer

YNDAD **Father**
 Living
 Deceased
 Don't Know
 Prefer not to answer

Q7. RELATLIV2. 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*.

<Programmer Note: Show this list of relatives on a new screen. There should be only one relative at a time on each screen with the three response items>

	Living	Deceased	Not Applicable
YNSISTER Full Sister(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
YNHSISTER Half Sister(s)			
YNBROTHER Full Brother(s)			
YNHBROTHER Half Brother(s)			
YNDAUGHTER Daughter(s)			
YNSON Son(s)			
YNGRANDP Grandparent(s)			
YNGRANDC Grandchild(ren)			

YNUNCLE Uncle(s)
YNAUNT Aunt(s)
YNCOUSIN Cousin(s)

<Programmer Note: If YNSON living=0, then skip SONSAGE>

Q8. SONSAGE. How many biological sons do you have in the following age ranges?

0-5

6-12

13-17

18 or older

- Don't know
- Prefer not to answer

<Programmer Note: If YNDAUGHTER living=0, then skip DAUGHTERSAGE>

Q9. DAUGHTERSAGE. How many biological daughters do you have in the following age ranges?

0-5

6-12

13-17

18 or older

- Don't know
- Prefer not to answer

Section III. Genetic Counseling

Q10. COUNSELING (NHIS 2015 - GCEVER). 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**

<Programmer: If COUNSELING=Yes, go to COUNSELINGSATISFIED. Else Skip to FLEARN>

Q11. COUNSATISFIED (NIEHS) 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**

Section IV. Genetic Testing

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

Q12. FLEARN. How did you hear about genetic testing?

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

Q13. DECISIONCONFLICT (DECISIONAL CONFLICT SCALE). 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:

<Programmer Note: Items placed in matrix. Six items on first screen, five items on second, and four on the third.>.

- I knew which options were available to me.**
- I knew the benefits of genetic testing.**
- I knew the risks of genetic testing.**
- I was clear about which benefits mattered most to me.**
- I was clear about which risks mattered most to me.**
- I was clear about which was more important to me (the benefits or the risks).**
- I had enough support from others to make a choice.**
- I was choosing without pressure from others.**
- I had enough information to make a choice.**
- I was clear about the best choice for me.**
- I felt sure about what to choose.**
- The decision was easy for me to make.**
- I feel I made an informed choice.**
- My decision shows what is important to me.**
- I am satisfied with my decision.**

- Strongly agree**
- Agree**
- Neither agree nor disagree**
- Disagree**

- Strongly disagree
- Prefer not to answer

Q14. DECISION. Who was involved in your decision to get genetic testing? Please check all that apply.

	Yes	No	Don't know	Prefer not to answer
DECMOTHER Mother				
DECFATHER Father				
DECSISTER Full Sister(s)				
DECHSISTER Half Sister(s)				
ECBROTHER Full Brother(s)				
DECHBROTHER Half Brother(s)				
DECDAUGHTER Daughter(s)				
DECSON Son(s)				
DECGRANDP Grandparent(s)				
DECGRANDC Grandchild(ren)				
DECUNCLE Uncle(s)				
DECAUNT Aunt(s)				
DECCOUSIN Cousin(s)				
DECFRIEND Friend(s)				
DECSPOUSE Spouse/Partner				

<Programmer Note: Always show Spouse/Partner and friend(s). For relatives, only show those that respondent entered as living in RELATIV AND RELATIV2.>

Q15. DECISION2. How involved were each of these relatives in your decision to get genetic testing?

<Programmer Note: Show list of people selected in DECISION>

- Very involved
- Somewhat involved
- Not very involved
- Don't Know
- Prefer not to answer

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

Q16. BRCATEST. 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**

<Programmer: If BRCATEST = No, Don't know or Prefer not to answer, go to LYNCHTEST. Else, go to TESTRESULTBR.>

Q17. 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**

Q18. 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**

Q19. LYNCHTEST. Have you ever had genetic testing for Lynch Syndrome or hereditary colorectal cancer?

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

<Programmer: If LYNCHTEST = No, Don't know or Prefer not to answer, go to FINFORM. Else, go to TESTRESULTLYNCH.>

Q20. 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
- No gene mutation was found
- Don't know
- Prefer not to answer

Q21. LYNCHRESULT. Were you surprised by the results of your genetic test(s) for Lynch Syndrome?

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

Have you ever had genetic testing for any other genetic mutations that may increase your cancer risk?

Yes

No

Don't Know

[If answered yes to any item on having genetic testing]

Where did you have genetic testing?

Blood test at doctor's office

Blood test at genetic counselor's office

Spit in mail kit (like those from 23andme, or Color Genomics)

Other, please specify:

[if had testing through spit in mail kit:]

Which laboratory did you use for your mail in genetic testing?

23andMe

Color Genomics

Counsyl

Invitae

Other, please specify:

Q22. FINFORM. The following questions refer to [BRCA/Lynch] testing or any other variants related to [breast/colorectal] cancer. How were you FIRST informed of your genetic test results?

[Programmer: If BRCATEST=Yes, autofill BRCA and breast cancer. Else, if BRCATEST=No and LYNCHTEST=Yes, then autofill with Lynch and colorectal cancer. Else if BRCATEST=No and LYNCHTEST=No, then use "...refer to genetic testing for 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**

Q23. 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**

Q24. LaRocque. How comfortable would you be receiving genetic test results from a healthcare provider via each of the following methods of communication?

RECEIVEFAX	Fax
RECEIVEVM	Personal voicemail
RECEIVEHOM	Home voicemail
RECEIVEEM	Personal email
RECEIVELET	Letter
RECEIVETEXT	Text message
RECEIVEWEB	Password-protected website

- Very comfortable**
- Somewhat comfortable**
- Neither comfortable nor uncomfortable**
- Somewhat uncomfortable**
- Very uncomfortable**
- Don't know**
- Prefer not to answer**

Q25. 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**

Q26. MATERIAL. What materials, if any, were you 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**

<PROGRAMMER NOTE: IF NO MATERIALS PROVIDED, SKIP TO PROVIDERRESOURCESFORFAMRISK.>

Q27. PROVEMAT. 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

Q28. 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

Section V. Tools and Resources

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

Q29. PROVIDERRESOURCESFORFAMRISK (ABOUT - Q14). 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

<Programmer: If No selected, do not allow selection of other response options and skip to ENOUGHINFO>

Q30. RESOURCESFORFAMRISK (ABOUT - Q15). 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

Q31. 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
- Not applicable
- Prefer not to answer

Q32. 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

Q33. OTHERINFO. What other information or materials would be useful for discussions about cancer family history? *Please check all that apply.*

<Programmer Note: Create three matrices. Four items per screen>.

- 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

Q34. 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

Q35. (HINTS). 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.

INFOFROMDOCTOR	A primary care physician
INFOFROMSPEC	A healthcare specialist (e.g., OB/GYN, oncologist)
INFOFROMFAMORFRIENDS	Family or friends
INFOFROMNEWSPAPERORMAG	Newspapers or magazines
INFOFROMRADIO	Radio
INFOFROMINTERNET	Internet
INFOFROMTV	Television
INFOFROMGOV	Government health agencies
INFOFROMCHARITYORG	Charitable organizations
INFOFROMRELIGORG	Religious organizations and leaders

<Programmer: The following response categories will be included in 3 item grids>

- A lot
- Some
- A little
- Not at all
- Don't know
- Prefer not to answer

Section VI: Sharing Genetic Test Results

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.

Q36. ENOUGHINFO. I had 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

Q37. DESIRETODISCUSSGENTESTRESULTS (Family Communication). 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

Q38. (FACTS - Q68). Please indicate if you have shared your most recent genetic test result(s) with any of the following biological or blood relatives.

SHARERESULTSMOTHER	Mother
SHARERESULTSFATHER	Father
SHARERESULTSSISTER	Sister(s)
SHAREDRESULTSHSISTER	Half Sister(s)
SHARERESULTSBROTHER	Brother(s)
SHAREDRESULTSHBROTHER	Half Brother(s)
SHARERESULTSDAUGHTER	Daughter(s)
SHARERESULTSSON	Son(s)
SHARERESULTSAUNTUNCLE	Uncle/Aunt(s)
SHARERESULTSCOUSIN	Cousin(s)
SHAREDRESULTSOOTH	Other, please specify

- 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

<Programmer: Display as a 5/4 grid. Only display relatives that respondent indicated they have in RELATLIV and RELATLIV2. If SHARERESULTS for all = I plan to, but not yet, No (I do not plan to share the result), or I haven't decided, go to NOCONTACT, Else go to SHAREDATE>

Q39. SHAREDATE (NHIS 2015). When did you first share your genetic test result(s) with your <SHARERESULTS>?

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

<Programmer: Ask SHAREDATE for each item where SHARERESULTS = "Yes". Autofill relationship for SHARERESULTS.>

<Programmer: If SHARERESULTSMOTHER=Yes OR SHARERESULTSPARTNER= Yes, OR SHARERESULTSSISTER= Yes, OR SHARERESULTSDAUGHTER= Yes, OR SHARERESULTSAAUNTUNCLE= Yes OR SHARERESULTSCOUNSIN= Yes, then go to FINFORMEDVIATEXT. Else, go to skip logic before MINFORMEDVIATEXT.>

Q40. (McGivern 2004). When you informed FEMALE relatives of your genetic test result, which of the following methods did you use? Please check all that apply.

- | | | |
|---------------------------|--|--------------------------|
| FINFORMEDVIATEXT | Sent a text | <input type="checkbox"/> |
| FINFORMEDVIAEMAIL | Sent an email | <input type="checkbox"/> |
| FINFORMEDVIAPHONE | Told them on the phone | <input type="checkbox"/> |
| FINFORMEDVIAPERSON | Told them in person | <input type="checkbox"/> |
| FINFORMEDGRAPEVINE | I told someone who then told someone else (through the grapevine) | <input type="checkbox"/> |
| FINFORMEDVIAOTHER | Other method | <input type="checkbox"/> |
| <i>FINFORMEDNA</i> | <i>Not applicable</i> | <input type="checkbox"/> |
| <i>FINFORMEDDK</i> | <i>Don't know</i> | <input type="checkbox"/> |
| <i>FINFORMEDPREFER</i> | <i>Prefer not to answer</i> | <input type="checkbox"/> |

<Programmer: If SHARERESULTSFATHER= Yes OR SHARERESULTSPARTNER= Yes, OR SHARERESULTSBROTHER= Yes, OR SHARERESULTSSON= Yes, OR SHARERESULTSAAUNTUNCLE= Yes, OR SHARERESULTSCOUNSIN= Yes, then go to MINFORMEDVIATEXT. Else, go to skip logic before NOCONTACT.>

Q41. (McGivern 2004). When you informed MALE relatives of your genetic test result, which of the following methods did you use? Please check all that apply.

- | | | |
|---------------------------|--|--------------------------|
| MINFORMEDVIATEXT | Sent a text | <input type="checkbox"/> |
| MINFORMEDVIAEMAIL | Sent an email | <input type="checkbox"/> |
| MINFORMEDVIAPHONE | Told them on the phone | <input type="checkbox"/> |
| MINFORMEDVIAPERSON | Told them in person | <input type="checkbox"/> |
| MINFORMEDGRAPEVINE | I told someone who then told someone else (through the grapevine) | <input type="checkbox"/> |
| MINFORMEDVIAOTHER | Other method | <input type="checkbox"/> |
| <i>FINFORMEDNA</i> | <i>Not applicable</i> | <input type="checkbox"/> |
| <i>FINFORMEDDK</i> | <i>Don't know</i> | <input type="checkbox"/> |
| <i>FINFORMEDPREFER</i> | <i>Prefer not to answer</i> | <input type="checkbox"/> |

<Programmer: If SHARERESULTS for any = No (I do not plan to share the result), go to NOCONTACT>

<Programmer: If SHARERESULTS does not = No (I do not plan to share the result) for any but RELATIVESUNDERGONETESTING=Yes, go to WHYSHARE>

Q42. 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**

<Programmer: Autofill those relatives from SHARERESULTS for Q30-32. Ask series of questions for each relative they told.>

Q43. 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?

- TIMEEFFORT** It took a lot of time and effort to share my genetic information with relatives
- FRUSTRATED** I felt frustrated while sharing my genetic information with relatives.
- QUALITY** I was concerned about the quality of the information that I shared.
- DIFFUND** I was concerned that my relatives may have found the information difficult to understand.

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

Q44. (SunTalk – S3). 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.

- NOCONTACT** You are not in contact with him/her.
- NOTIME** You didn't have the time to tell him/her.
- NOCLEAR** You were unsure how to explain it clearly.
- NOTCLOSE** The two of you are not close.
- NOTCARE** He/she wouldn't care.
- NOTUPSET** You didn't want to upset him/her.
- NOTATRISK** He/she is not at risk for developing cancer.
- WHATTO SAY** You didn't know what to say to him/her.
- DIFFCOPING** You were having difficulty coping with your own risk for cancer.
- TOOYOUNG** You feel that he/she is too young to understand.
- NOTALKOTH** Other (please specify)

[Likert scale ranging from 1 (not at all applicable) to 5 (very applicable)]

- Not at all applicable
- 2
- 3
- 4
- Very applicable
- Don't know
- Prefer not to answer

Q45. RELATIVESCOUNSELING1-4 (FACTS - adapted). Please indicate which of your relative(s) have undergone genetic counseling. If no one in your family has received genetic counseling fill in the N/A response option.

- 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**

Q46. Did you get genetic counseling before or after your <RELATIVESCOUNSELING>.

- I got genetic testing BEFORE my < RELATIVESCOUNSELING >.**
- I got genetic testing AFTER my < RELATIVESCOUNSELING >.**
- Don't know**
- Prefer not to answer**

<Programmer Note: Ask question for each relative selected in RELATIVESCOUNSELING>.

Q47. RELATIVESUNDERGONETESTING1-4 (FACTS - adapted). Please indicate which of your relative(s) have undergone genetic testing. If no one in your family has been tested fill in the N/A response option.

- 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

<Programmer Note: If RELATIVESUNDERGONETESTING1-4 in N/A, Don't Know, Prefer not to answer, skip to MARITALSTATUS>

Q48. RELATIVESTESTINGRESULT1-4 (FACTS – adapted). What was the test result for your <RELATIVESUNDERGONETESTING>?

- 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
- Prefer not to answer

Q49. Did you get genetic testing before or after your <RELATIVESUNDERGONETESTING>.

- I got genetic testing BEFORE my <RELATIVESUNDERGONETESTING>.
- I got genetic testing AFTER my <RELATIVESUNDERGONETESTING>.
- Don't Know
- Prefer not to answer

<Programmer Note: Ask question for each relative selected in RELATIVESUNDERGONETESTING>.

Q50. Who was the first in your family to get genetic testing?

- Myself**
- <RELATIVESUNDERGONETESTING>
- <RELATIVESUNDERGONETESTING>
- <RELATIVESUNDERGONETESTING>
- Don't Know**
- Prefer not to answer**

<Programmer Note: Autofill all relatives who received genetic testing>.

Q51. (McGivern 2004). When you were informed of your <RELATIVESUNDERGONETESTING's> genetic test results, which of the following methods did they use? Please check all that apply.

- | | | |
|-------------------------|---|--------------------------|
| RINFORMVIATEXT | Sent a text | <input type="checkbox"/> |
| RINFORMVIAEMAIL | Sent an email | <input type="checkbox"/> |
| RINFORMVIAPHONE | Told me on the phone | <input type="checkbox"/> |
| RINFORMVIAPERSON | Told me in person | <input type="checkbox"/> |
| RINFORMGRAPEVINE | Told someone else who then told me (through the grapevine) | <input type="checkbox"/> |
| RINFORMVIAOTHER | Other method | <input type="checkbox"/> |

<Programmer Note: Ask question for each relative selected in RELATIVESUNDERGONETESTING>.

Q52. AFFECTHEALTH (Closeness Scale). 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**

Q53. THINKEXP (Closeness Scale). How often do you think about your experience with genetic testing?

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

Q54. TALKEXP (Closeness Scale). 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**

Section VII. Demographics

Finally, we have a few demographic questions.

Q55. MARITALSTATUS (HINTS 4, CYCLE 4 2014 - N5). What is your marital status?

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

Q56. 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**

<Programmer instruction: If No, Don't Know, or Prefer not to answer skip to EDUCATION. Else, continue to INSURTYPE.>

Q57. 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**

Q58. EDUCATION (*HINTS 4, CYCLE 4 2014 - N6*). What is the highest grade or level of schooling you completed?

- Less than 8 years**
- 8 through 11 years**
- 12 years or completed high school**
- Post high school training other than college (vocational or technical)**
- Some college**
- College graduate**
- Postgraduate**
- Prefer not to answer**

<Programmer Note: If respondent recruited by email, skip to OCCUPATIONALSTATUS. Else continue to HISPLATINOSPAN>.

Q59. HISPLATINOSPAN (*HINTS 4, CYCLE 4 2014 - N10*). Are you of Hispanic, Latino/a, or Spanish origin?

- Yes**
- No**
- Prefer not to answer**

<Programmer: If HISPLATINOSPAN = NO, Go to RACE. Else Go to HISPLATINOSPANGROUP >

Q60. HISPLATINOSPANGROUP (GSS 2012). Which group are you from?

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

Q61. RACE (HINTS 4, CYCLE 4 2014 - N11). 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

Q62. OCCUPATIONALSTATUS (HINTS 4, CYCLE 4 2014 - N2). What is your current occupational status?

- Employed
- Unemployed
- Homemaker
- Student
- Retired
- Disabled
- Other-Specify
- Prefer not to answer

*<Programmer: If OCCUPATIONALSTATUS = Other-Specify, Go to OTHEROCCUPATION.
Else Go to HOUSEHOLDINCOME >*

Q63. OTHEROCCUPATION (GSS 2014 - WRKSPEC). Specify other activity:

Q64. HOUSEHOLDINCOME (HINTS 4, CYCLE 4 - N18). 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**

Q65. 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**

INCENTX

Congratulations, in appreciation for your time and effort completing the survey, we want to send you a \$5 Amazon gift card! Please enter your mailing address below so that we can send you the code.

Address

CLOSING SCREEN

This is the end of the survey.

Thank you very much for your time and effort.

If you would like more information about genetic testing for cancer risk, please visit the following resources:

Bring Your Brave (BRCA testing)

https://www.cdc.gov/cancer/breast/young_women/bringyourbrave/

Know: BRCA <https://www.knowbrca.org/>

Talking to family members <http://kintalk.org/>

NCI Cancer Genetics Services Directory <https://www.cancer.gov/about-cancer/causes-prevention/genetics/directory>

If you would like more information about the study, please call 1-312-201-4412 or send an email to 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.