Attachment 3c:
High Risk Survey

HIGH-RISK INDIVIDUALS 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 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

<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**

We would like to ask you a few questions about your family history of cancer.

Q1. FATHERCANCER *(NHIS_2015 - FHFCAN).* **Did your BIOLOGICAL FATHER EVER have cancer of any kind?**

○ **Yes**
○ **No**
○ **Adopted or don't know biological father**
○ **Don't know**
○ Prefer not to answer

<Programmer: If FATHERCANCER=YES, Go to FATHERCANCERTYPE. Else Go to MOTHERCANCER>

Q2. FATHERCANCERTYPE1-4 *(NHIS_2015 - FHFTYP_1-4).* **What kind of cancer did your father have? Please enter all that apply.**

○ **Bladder**
○ **Bone**
○ **Brain**
○ **Breast**
○ **Colon**
○ **Esophagus**
○ **Gallbladder**
○ **Kidney**
○ **Larynx-windpipe**
○ **Leukemia**
○ **Liver**
○ **Lung**
○ **Lymphoma**
○ **Melanoma**
○ **Mouth/tongue/lip**
○ **Pancreas**
○ **Prostate**
○ **Rectum**
○ **Skin (non-melanoma)**
○ **Skin (Don't know what kind)**
○ **Soft tissue (muscle or fat)**
○ **Stomach**
○ **Testis**

○ **Throat-pharynx**
○ **Thyroid**
○ **Other**
○ **Don't know**
○ Prefer not to answer

<Programmer: Include an open-ended box and use "Search" Function which include all the cancer types on this list>

Q3. **MOTHERCANCER** *(NHIS_2015 - FHMCAN).* **Did your BIOLOGICAL MOTHER EVER have cancer of any kind?**

○ **Yes**
○ **No**
○ **Adopted or don't know biological mother**
○ **Don't know**
○ Prefer not to answer

<Programmer: If MOTHERCANCER=YES, Go to MOTHERCANCERTYPE. Else Go to NUMBROTHERS>

Q4. **MOTHERCANCERTYPE1-4** *(NHIS_2015 - FHMTYP_1-4).* **What kind of cancer did your mother have? Please enter all that apply.**

○ **Bladder**
○ **Bone**
○ **Brain**
○ **Breast**
○ **Cervix**
○ **Colon**
○ **Esophagus**
○ **Gallbladder**
○ **Kidney**
○ **Larynx-windpipe**
○ **Leukemia**
○ **Liver**
○ **Lung**
○ **Lymphoma**
○ **Melanoma**
○ **Mouth/tongue/lip**
○ **Ovary**
○ **Pancreas**
○ **Rectum**
○ **Skin (non-melanoma)**
○ **Skin (Don't know what kind)**
○ **Soft tissue (muscle or fat)**

○ **Stomach**
○ **Throat-pharynx**
○ **Thyroid**
○ **Uterus**
○ **Other**
○ **Don't know**
○ **Prefer not to answer**

<Programmer: Include an open-ended box and use "Search" Function which include all the cancer types on this list>

Q5. NUMBROTHERS *(NHIS_2015 - FHBNUM).* **How many full brothers do you have?**

By full brothers we mean having the same biological mother and father as you.
Please include any who are alive and those who may have died.

☐☐

○   **Don't know**
○ **Prefer not to answer**

<Programmer: If NUMBROTHERS>0, Go to BROTHERCANCER. Else go to NUMSISTERS>

Q6. BROTHERCANCER *(NHIS_2015 - FHBCAN).* [Fill 1: **Did your full brother EVER have cancer of any kind?**]
[Fill 2: **Did any of your full brothers EVER have cancer of any kind?**
(If yes) **How many of your full brothers have EVER had cancer of any kind?**]

By full brothers we mean having the same biological mother and father as you.
Please include any who are alive and those who may have died.

○ **Yes**
○ **No**

☐☐

○   **Don't know**
○ **Prefer not to answer**

<Programmer: If NUMBROTHERS>1, then Fill 1, Else Fill 2>
<Programmer: If BROTHERCANCER = Yes, go to BROTHERCANCERTYPE. Else go to NUMSISTERS>

Q7. BROTHERCANCERTYPE1-4 *(NHIS_2015 - FHBTYP_1-4).* **What kind of cancer did your full** [Fill 1: **brother**/Fill 2: **brothers**] **have? Please enter all that apply.**

By full brothers we mean having the same biological mother and father as you.
Please include any who are alive and those who may have died.

- ○ **Bladder**
- ○ **Bone**
- ○ **Brain**
- ○ **Breast**
- ○ **Colon**
- ○ **Esophagus**
- ○ **Gallbladder**
- ○ **Kidney**
- ○ **Larynx-windpipe**
- ○ **Leukemia**
- ○ **Liver**
- ○ **Lung**
- ○ **Lymphoma**
- ○ **Melanoma**
- ○ **Mouth/tongue/lip**
- ○ **Pancreas**
- ○ **Prostate**
- ○ **Rectum**
- ○ **Skin (non-melanoma)**
- ○ **Skin (Don't know what kind)**
- ○ **Soft tissue (muscle or fat)**
- ○ **Stomach**
- ○ **Testis**
- ○ **Throat-pharynx**
- ○ **Thyroid**
- ○ **Other**
- ○ **Don't know**
- ○ **Prefer not to answer**

<Programmer: If BROTHERCANCER>1, then Fill 1, Else Fill 2>
<Programmer: Include an open-ended box and use "Search" Function which include all the cancer types on this list>

<Programmer: If BROTHERCANCER>1 Go to NUMBROTHERCANCER, Else Go to NUMSISTERS>

Q8. NUMBROTHERCANCER1-4(*NHIS_2015 - FHBMAN1*). **How many full brothers have had [Fill: BROTHERCANCERTYPE1-4]?**

⎕⎕

○ **Don't know**
○ Prefer not to answer

<Programmer: Ask NUMBROTHERCANCER for each item selected in BROTHERCANCERTYPE. Autofill cancer type for BROTHERCANCERTYPE.>

Q9. NUMSISTERS *(NHIS_2015 - FHSNUM).* **How many full sisters do you have?**

By full sisters we mean having the same biological mother and father as you.
Please include any who are alive and those who may have died.

⎕⎕

○ **Don't know**
○ Prefer not to answer

<Programmer: If NUMSISTERS>0, Go to SISTERCANCER. Else Go to NUMBERSONS>

Q10. SISTERCANCER *(NHIS_2015 - FHSCAN).* Fill 1: **Did your full sister EVER have cancer of any kind?**]
[Fill 2: **Did any of your full sisters EVER have cancer of any kind?**
(If yes) **How many of your full sisters have EVER had cancer of any kind?**]

By full sisters we mean having the same biological mother and father as you.
Please include any who are alive and those who may have died.

○ **Yes**
○ **No**

⎕⎕

○ **Don't know**
○ Prefer not to answer

<Programmer: If NUMSISTERS=1, then Fill 1, Else Fill 2. Yes/No for Fill 1. Boxes for Fill 2>
<Programmer: If SISTERCANCER=Yes, Go to SISTERCANCERTYPE, Else go to NUMSONS>

Q11. SISTERCANCERTYPE1-4 *(NHIS_2015 - FHSTYP_1-4).* **What kind of cancer did your full** [Fill 1: **sister**/Fill 2: **sisters**] **have? Please enter all that apply.**

By full sisters we mean having the same biological mother and father as you.
Please include any who are alive and those who may have died.

○ **Bladder**
○ **Bone**
○ **Brain**
○ **Breast**
○ **Cervix**
○ **Colon**
○ **Esophagus**
○ **Gallbladder**
○ **Kidney**
○ **Larynx-windpipe**
○ **Leukemia**
○ **Liver**
○ **Lung**
○ **Lymphoma**
○ **Melanoma**
○ **Mouth/tongue/lip**
○ **Ovary**
○ **Pancreas**
○ **Rectum**
○ **Skin (non-melanoma)**
○ **Skin (Don't know what kind)**
○ **Soft tissue (muscle or fat)**
○ **Stomach**
○ **Throat-pharynx**
○ **Thyroid**
○ **Uterus**
○ **Other**
○ **Don't know**
○ **Prefer not to answer**

<Programmer: If SISTERCANCER=1, then Fill 1, Else Fill 2>
<Programmer: Include an open-ended box and use "Search" function which include all the cancer types on this list>

<Programmer: If SISTERCANCER>1 Go to NUMSISTERCANCER. Else skip to NUMBERSONS>

Q12. NUMSISTERCANCER1-4 *(NHIS_2015 - FHSMAN1).* **How many sisters have had [Fill: SISTERCANCERTYPE1-4]?**

<div style="border:1px solid black; display:inline-block;">⬚⬚</div>

○ **Don't know**
○ **Prefer not to answer**

<Programmer: Ask NUMSISTERCANCER for each item selected in SISTERCANCERTYPE. Autofill cancer type for SISTERCANCERTYPE. >

Q13. NUMBERSONS *(NHIS_2015 - FHNNUM).* **How many biological sons do you have?**

By biological we mean genetically related; related by blood.
Please include any who are alive and those who may have died.

<div style="border:1px solid black; display:inline-block;">⬚⬚</div>

○ **Don't know**
○ **Prefer not to answer**

<Programmer: If NUMBERSONS>0, Go to SONCANCER. Else Go to NUMBERDAUGHTERS>

Q14. SONCANCER *(NHIS_2015 - FHNCAN).* Fill 1: **Did your biological son EVER have cancer of any kind?**]
[Fill 2: **Did any of your biological sons EVER have cancer of any kind?**
(If yes) **How many of your sons have EVER had cancer of any kind?**]

By biological we mean genetically related; related by blood.
Please include any who are alive and those who may have died.

○ **Yes**
○ **No**

<div style="border:1px solid black; display:inline-block;">⬚⬚</div>

○ **Don't know**
○ **Prefer not to answer**

<Programmer: If NUMBERSONS=1, then Fill 1, Else Fill 2. Yes/No for Fill 1. Boxes for Fill 2>
<Programmer: If SONSCANCER=Yes or >0, Go to SONCANCERTYPE, Else go to NUMBERDAUGHTERS>

Q15. SONCANCERTYPE1-4 *(NHIS_2015 - FHNTYP_1-4)*. **What kind of cancer did your** [Fill 1: **son**/Fill 2: **sons**] **have? Please enter all that apply.**

○ **Bladder**
○ **Bone**
○ **Brain**
○ **Breast**
○ **Colon**
○ **Esophagus**
○ **Gallbladder**
○ **Kidney**
○ **Larynx-windpipe**
○ **Leukemia**
○ **Liver**
○ **Lung**
○ **Lymphoma**
○ **Melanoma**
○ **Mouth/tongue/lip**
○ **Pancreas**
○ **Prostate**
○ **Rectum**
○ **Skin (non-melanoma)**
○ **Skin (Don't know what kind)**
○ **Soft tissue (muscle or fat)**
○ **Stomach**
○ **Testis**
○ **Throat-pharynx**
○ **Thyroid**
○ **Other**
○ **Don't know**
○ **Prefer not to answer**

<Programmer: Include an open-ended box and use "Search" Function which include all the cancer types on this list>

<Programmer: If SONCANCER=1, then Fill 1, Else Fill 2>

<Programmer: If SONCANCER>1 Go to NUMSONCANCER1-4. Else Skip to NUMBERDAUGHTERS>

Q16. NUMSONCANCER1-4 *(NHIS_2015 - FHNMAN1).* **How many sons have had [Fill: FHNTYP_1]?**

○ **Don't know**
○ **Prefer not to answer**

<Programmer: Ask NUMSONCANCER for each item selected in SONCANCERTYPE. Autofill cancer type for SONCANCERTYPE.>

Q17. NUMBERDAUGHTERS *(NHIS_2015 - FHDNUM).* **How many biological daughters do you have?**

By biological we mean genetically related; related by blood.
Please include any who are alive and those who may have died.

○ **Don't know**
○ **Prefer not to answer**

<Programmer: If NUMBERDAUGHTERS>0, Go to DAUGHTERCANCER. Else go to NUMSECONDCANCER>

Q18. DAUGHTERCANCER *(NHIS_2015 - FHDCAN).* Fill 1: **Did your biological daughter EVER have cancer of any kind?**] [Fill 2: **Did any of your biological daughters EVER have cancer of any kind?**
(If yes) **How many of your daughter have EVER had cancer of any kind?**]

○ **Yes**
○ **No**

○ **Don't know**
○ **Prefer not to answer**

<Programmer: If NUMBERDAUGHTERS=1, then Fill 1, Else Fill 2. Yes/No for Fill 1. Boxes for Fill 2>
<Programmer: If DAUGHTERCANCER=Yes or >0, Go to DAUGHTERCANCERTYPE, Else go to NUMSECONDCANCER >

Q19. DAUGHTERCANCERTYPE1-4 *(NHIS_2015 - FHDTYP_1-4).* **What kind of cancer did your** [Fill 1: **daughter**/Fill 2: **daughters**] **have? Please enter all that apply.**

○ **Bladder**
○ **Bone**
○ **Brain**
○ **Breast**
○ **Cervix**
○ **Colon**
○ **Esophagus**
○ **Gallbladder**
○ **Kidney**
○ **Larynx-windpipe**
○ **Leukemia**
○ **Liver**
○ **Lung**
○ **Lymphoma**
○ **Melanoma**
○ **Mouth/tongue/lip**
○ **Ovary**
○ **Pancreas**
○ **Rectum**
○ **Skin (non-melanoma)**
○ **Skin (Don't know what kind)**
○ **Soft tissue (muscle or fat)**
○ **Stomach**
○ **Throat-pharynx**
○ **Thyroid**
○ **Uterus**
○ **Other**
○ **Don't know**
○ **Prefer not to answer**

<Programmer: Include an open-ended box and use "Search" Function which include all the cancer types on this list>

<Programmer: If DAUGHTERCANCER>1, then Fill 1, Else Fill 2>

<Programmer: If DAUGHTERCANCER>1 Go to NUMDAUGHTERCANCER. Else Skip to NUMSECONDCANCER>

Q20. NUMDAUGHTERCANCER1-4 *(NHIS_2015 - FHDMAN1).* **How many daughters have had [Fill: DAUGHTERCANCERTYPE1-4]?**

⬚⬚

○ **Don't know**
○ **Prefer not to answer**

<Programmer: Ask NUMDAUGHTERCANCER for each item selected in DAUGHTERCANCERTYPE. Autofill cancer type for DAUGHTERCANCERTYPE1-4. >

The next few questions are about the number of blood relatives who have been diagnosed with breast or ovarian cancer.

Q21. NUMSECONDCANCER. *(NHIS 2015 – FHSDBR)* **How many of your grandparents, aunts, uncles, nieces, nephews, or grandchildren have ever been diagnosed with breast cancer?**
Please answer only for the blood relatives listed.

⬚⬚

○ **Don't know**
○ **Prefer not to answer**

<Programmer: If NUMSECONDCANCER>0 Go to SECBREASTCAN. Else skip to SECOVARIANCAN>

Q22. SECBREASTCAN. *(NHIS – FHSDBN)* **How many of them were diagnosed with breast cancer before the age of 50?**

⬚⬚

○ **Don't know**
○ **Prefer not to answer**

Q23. SECOVARIANCAN. *(NHIS – FHSDOV)* **How many of your grandmothers, aunts, nieces, or granddaughters have ever been diagnosed with ovarian cancer?**

⬚⬚

○ **Don't know**
○ **Prefer not to answer**

Q24. CANCERWORRY *(HINTS - M4).* **How worried are you about {getting cancer/cancer recurrence}?**

○ **Extremely**
○ **Moderately**
○ **Somewhat**
○ **Slightly**
○ **Not at all**
○ **Prefer not to answer**

<Programmer: Display 'cancer recurrence' if CANCERTYPE ne "". Else, display 'getting cancer'.>

Q25. In general, how much do you agree with the following?
[Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree)]

WORRYCANCSPECIFIC	**I think about cancer more than most diseases**
WORRYBACKOFMIND	**Getting cancer is often in the back of my mind**
WORRYCHANCECANCER	**I am often bothered by thoughts or worry about my chances of getting cancer.**

○ **Strongly agree**
○ **Somewhat agree**
○ **Neither agree nor disagree**
○ **Somewhat disagree**
○ **Strongly disagree**
○ **Prefer not to answer**

<Programmer: If CANCERTYPE in ('Colon', 'Colorectal', 'Rectal', 'Rectum'), skip to Q27. PERCEIVEDBREASTCANCERRISK.>

Q26. *<Programmer: Do not show 'ovarian' in the questions above if SEX = Male.>***PERCEIVEDCOLONCANCERRISK** *(NHIS - GTCCLOM).* **Compared to the average [fill1: man/woman} your age, would you say that you are more likely to get colon or rectal cancer, less likely, or about as likely?**

○ **More likely**
○ **Less likely**
○ **About as likely**
○ **Don't know**
○ **Prefer not to answer**

<Programmer: If SEX=Female, fill woman, If SEX=Male, fill man>
<Programmer: If SEX ne Male, and CANCERTYPE ne 'Breast', go to PERCEIVEDBREASTCANCERRISK. Else, if SEX ne Male and CANCERTYPE = 'Breast', go to PERCEIVEDOVARCANCERRISK.
If SEX = Male, go to PRIMARYPLACEFORHEALTHADVICE.>

Q27. PERCEIVEDBREASTCANCERRISK *(NHIS - GTCBOM).* **Compared to the average woman your age, would you say that you are more likely to get breast cancer, less likely, or about as likely?**

○ **More likely**
○ **Less likely**
○ **About as likely**
○ **Don't know**
○ Prefer not to answer

<Programmer: If CANCERTYPE = 'Ovarian', skip to EVERYTHINGCAUSESCANCER. Else, continue to PRIMARYPLACEFORHEALTHADVICE.>

Q28. PERCEIVEDOVARCANCERRISK *(New).* **Compared to the average woman your age, would you say that you are more likely to get ovarian cancer, less likely, or about as likely?**

○ **More likely**
○ **Less likely**
○ **About as likely**
○ **Don't know**
○ Prefer not to answer
Now we'd like to ask you some questions about your personal health.

Q29. PRIMARYPLACEFORHEALTHADVICE *(NHIS 2015 - AUSUALPL).* **Is there a place that you <u>most frequently</u> go to when you are sick or need advice about your health?**

○ **Yes, clinic or health center**
○ **Yes, doctor's office**
○ **Yes, hospital emergency room**
○ **Yes, hospital outpatient department**
○ **Yes, urgent care clinic**
○ **Yes, some other place**
○ **There is NO place**
○ **Don't know**
○ **Prefer not to answer**

<Programmer: If PRIMARYPLACEFORHEALTHADVICE = There is NO place, hospital emergency room, or urgent care clinic, then skip to COUNSELING. Else, continue to DOCTORRISK.>

The next questions are about your primary care provider. A primary care provider is the person you would see if you need a check-up, want advice about a health problem, or get sick or hurt.

Q30.   DOCTORRISK *(NIEHS)* **Have you talked with your primary care provider about what your family history of cancer might mean for your own health and cancer risk?**
Please do not include conversations with specialists, such as oncologists.
○ **Yes, we've talked about this in depth**
○ **Yes, we've talked about this a little**
○ **No**

○ **Prefer not to answer**

<Programmer: If Yes (to either "yes" option), ask the following. Else, skip to COMSATISFIED>

> **Has a doctor, or other health professional, ever told you that you have a higher chance of getting cancer than other <men/women> your age?**
> ○ **Yes**
> ○ **No**
> ○ **Prefer not to answer**

<Programmer: If SEX = Male, prefill men. If SEX = Female, prefill women.>

Q31.   COMSATISFIED *(NIEHS)* **How satisfied are you with the level of communication you have had with your primary care provider about your family's history of cancer and your own cancer risk?**

○ **Very satisfied**
○ **Satisfied**
○ **Neither**
○ **Dissatisfied**
○ **Very dissatisfied**
○ **Prefer not to answer**

Q32. DOCEASYTOUNDERSTAND *(CAHPS - 4.0).* **Did your primary care provider explain things about your family's history of cancer and your own cancer risk in a way that was easy to understand?**

○ **Yes**
○ **No**
○ **Prefer not to answer**

Q33. DOCLISTEN *(CAHPS 4.0).* **Did your primary care provider listen carefully to you about your family's history of cancer and your own cancer risk?**

○ **Yes**
○ **No**
○ **Prefer not to answer**

Q34. 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 COUNSELINGREASON. Else Skip to BRCATEST>

Q35. COUNSELINGREASON *(NHIS 2015 - GCMREAS).* **What was the MAIN reason you had genetic counseling?**

○ **Your doctor recommended it**
○ **You requested it**
○ **Family member suggested it**
○ **You heard or read about it in the news**
○ **Other**
○ **Don't know**
○ Prefer not to answer

Q36. COUNSATISFIED *(NIEHS)* **How satisfied are you with the level of communication you have had with your genetic counselor about your family's history of cancer and your own cancer risk?**

○ **Very satisfied**
○ **Satisfied**
○ **Neither**
○ **Dissatisfied**
○ **Very dissatisfied**
○ Prefer not to answer

<Programmer: If RECEIVEDTESTING=NO, and RELATIVESUNDERGONETESTING ne N/A, DK, or R, go to RELATIVESTESTINGRESULT. If RECEIVEDTESTING=NO and RELATIVESUNDERGONETESTING = N/A, DK/, or R, go to COLONCANCERTESTS. Else, go to BRCATEST.>

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. <u>Do not include self-testing kits administered at home.</u>

Q37. 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.>

Q38. 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**
○ **No gene mutation was found**
○ **Don't know**
○ Prefer not to answer

Q39. 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 SHARERESULT. Else, go to TESTRESULTLYNCH.>

Q40. 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

Programmer: If BRCATEST = No, Don't know or Prefer not to answer, AND LYNCHTEST = No, Don't know, or prefer not to answer AND RELATIVESUNDERGONETESTING ne N/A, DK, or R, go to RELATIVESTESTINGRESULT. If BRCATEST = No, Don't know or Prefer not to answer, AND LYNCHTEST = No, Don't know, or prefer not to answer AND RELATIVESUNDERGONETESTING = N/A, DK/, or R, go to COLONCANCERTESTS. Else, continue.

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:

[if had testing through spit in mail kit:]
How satisfied were you with the information you received about your genetic testing results?
Very Satisfied
Somewhat Satisfied
Neither satisfied, nor dissatisfied
Somewhat Dissatisfied
Very Dissatisfied

Q41. *(FACTS - Q68).* **Please indicate if you have shared your most recent genetic test result(s) with any of the following people.**

SHARERESULTSMOTHER	**Mother**
SHARERESULTSFATHER	**Father**
SHARERESULTSPARTNER	**Spouse/Partner**
SHARERESULTSSISTER	**Sister(s)**
SHARERESULTSBROTHER	**Brother(s)**
SHARERESULTSDAUGHTER	**Daughter(s)**
SHARERESULTSSON	**Son(s)**
SHARERESULTSAUNTUNCLE	**Uncle/Aunt(s)**
SHARERESULTSCOUSIN	**Cousin(s)**

Following response categories will be included in 5/4 grid items.
○ **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: 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>

Q42. SHAREDATE *(NHIS 2015).* **When did you first share your genetic test result(s) with your <SHARERESULTS>?**
○ **Within a week**
○ **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 SHARESULTSPARTNER= Yes, OR SHARERESULTSSISTER= Yes, OR SHARERESULTSDAUGHTER= Yes, OR SHARERESULTSAUNTUNCLE= Yes OR SHARERESULTSCOUNSIN= Yes, then go to FINFORMEDVIATEXT. Else, go to skip logic before MINFORMEDVIATEXT.>

Q43. *(McGivern 2004).* **When you FIRST informed FEMALE relatives of your genetic test result, which of the following methods did you use?**

	Yes	No	Don't know	Prefer not to answer
FINFORMEDVIATEXT Sent a text	○	○	○	○
FINFORMEDVIAEMAIL Sent an email	○	○	○	○
FINFORMEDVIAPHONE Told them on the phone	○	○	○	○
FINFORMEDVIAPERSON Told them in person	○	○	○	○
FINFORMEDGRAPEVINE I told someone who then told someone else (through the grapevine)	○	○	○	○
FINFORMEDVIAOTHER Other method	○	○	○	○

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

Q44. *(McGivern 2004).* **When you FIRST informed MALE relatives of your genetic test result, which of the following methods did you use?**

	Yes	No	Don't know	Prefer not to answer
MINFORMEDVIATEXT Sent a text	○	○	○	○
MINFORMEDVIAEMAIL Sent an email	○	○	○	○
MINFORMEDVIAPHONE Told them on the phone	○	○	○	○
MINFORMEDVIAPERSON Told them in person	○	○	○	○
MINFORMEDGRAPEVINE I told someone who then told someone else (through the grapevine)	○	○	○	○
MINFORMEDVIAOTHER Other method	○	○	○	○

<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* RELATTESTINGDATE. >
<Programmer: If SHARERESULTS does not = No (I do not plan to share the result) for any and *RELATIVESUNDERGONETESTING = N/A, DK, or Prefer not to answer, skip to COLONCANCERTEST. >*

Q45. *(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.**
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.**
WHATTOSAY	**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

<Programmer: If RELATIVESUNDERGONETESTING = N/A, DK, or Prefer not to answer, skip to COLONCANCERTESTS. Else, continue to RELATIVESTESTINGRESULT.>

Q46. 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

<Programmer: If RELATIVESTESTINGRESULT = "I don't know the test result" then skip RELMINFORMED and either ask the subsequent RELATIVESTESTINGRESULT for the next family member or skip to COLONCANCERTESTS. Else, continue to RELMINFORMED. >

Q47. RELMINFORMED *(New)* **How were you FIRST informed of your <RELATIVESUNDERGONETESTING> test results?**

○ **Received a text**
○ **Received an email**
○ **Told on the phone**
○ **Told in person**
○ **Heard through the grapevine**
○ **Other method**
○ **Don't know**
○ Prefer not to answer

<Programmer: Cycle through RELATTESTINGDATE and RELATIVESTESTINGRESULT for each item selected in RELATIVESUNDERGONETESTING. Autofill relative for RELATIVESUNDERGONETESTING1-4. >

<Programmer: If SEX=Male, go to PREVENTION. Else, go to BREASTTESTS.>

Q48. BREASTTESTS *(NHIS 2015 – MFOLLOW1).* **Have you had any of the following tests? Select all that apply.**

○ **Ultrasound**
○ **Breast MRI**
○ **Additional mammogram(s)**
○ **Biopsy**
○ **None**
○ **Other**
○ **Don't know**
○ Prefer not to answer

Q49. PREVENTION *(New).* **Which of the following, if any, have you done in order to reduce your risk of cancer?**

○ **Removal of breasts that didn't have cancer (mastectomy)**
○ **Removal of ovaries that didn't have cancer (oophorectomy)**
○ **Taking Tamoxifen or Raloxofine (or other chemopreventive drug)**
○ **Quit smoking**
○ **Cut back on or quit drinking**
○ **Increased exercise**
○ **Healthier diet**
○ **None of these**
○ **Don't know**
○ Prefer not to answer

<Programmer: If SEX = Male, do not display first three options. Allow selection of multiple responses. If select None of these, Don't know, or Prefer not to answer, do not allow selection of other responses.>

Q50. SEEKCANCERINFO *(HINTS - SEEKCANCERINFO).* **Have you ever looked for information about genetic risk of cancer from any source?**

○ **Yes**
○ **No**
○ Prefer not to answer

<Programmer: If SEEKCANCERINFO=No or Prefer not to answer, Go to INFOFROMDOCTOR. Else, go to INFOSEEK.>

Q51. INFOSEEK *(HINTS)* **The last time you looked for information about cancer or cancer screening, where did you go?**

○ **Internet**
○ **Books**
○ **Brochures or pamphlets**
○ **Cancer organization**
○ **Family, friend, or co-worker**
○ **Doctor or health care provider**
○ **Library**
○ **Magazine or newspaper**
○ **Telephone information number**
○ **Complementary or alternative practitioner**

Q52. *HINTS.* **Based on the results of your most recent search for genetic information about cancer, how much do you agree or disagree with each of the following statements?**

CANCERLEVELOFEFFORT *(CANCERLEVELOFEFFORT).* **It took a lot of effort to get the information you needed**
CANCERFRUSTRATED *(CANCERFRUSTRATED).* **You felt frustrated during your search for the information**
CANCERCONCERNEDQUALITY *(CANCERCONCERNEDQUALITY).* **You were concerned about the quality of the information**
CANCERHARDTOUNDERSTAND *(CANCERTOOHARDUNDERSTAND).* **The information you found was hard to understand**

[Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree)]
○ **Strongly agree**
○ **Somewhat agree**
○ **Neither agree nor disagree**
○ **Somewhat disagree**
○ **Strongly disagree**
○ **Prefer not to answer**

The next section is about communication among your family members.

Q53. *(SunTalk – U1-U8).* **Now we would like to ask you some questions about how information about cancer is discussed within your family overall. All families have different styles of communicating information and there is no one right or wrong way to discuss information within families. Please read the following statements about different communication styles and select how strongly you agree or disagree with each statement.**

SHARECANCERWORRIES	**I have someone I trust that I can talk to about my concerns about developing cancer**
SPEAKOPENLY	**My family speaks openly about their worries about other family members developing cancer.**
LISTENCONCERNS	**My family listens to each other's concerns about cancer.**
ENCOURAGESHARE	**My family encourages family members to share their concerns about cancer.**
COMFORTNO	**My family feels comfortable discussing cancer topics.**
OFFLIMITS	**For certain family members the topic of cancer is 'off-limits.'**
CHANGETOPIC	**When family members do not want to discuss cancer, they change the topic or leave the room.**
BECOMEANGRY	**Members of my family will become angry when the topic of cancer is discussed.**
AVOIDTOPIC	**When certain family members are around, we avoid bringing up the topic of cancer.**

[Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree)]
○ **Strongly agree**
○ **Somewhat agree**
○ **Neither agree nor disagree**
○ **Somewhat disagree**
○ **Strongly disagree**
○ **Don't know**
○ Prefer not to answer

<Programmer: If RECEIVEDTESTING = Yes and any TESTRESULT not in (No gene mutation was found, Don't know, Prefer not to answer, Missing), continue to ENCOURAGEFAMGENTESTING. Else, if (BRCATEST = Yes and/or LYNCHTEST = Yes), skip to FAMWORRYFROMRESULTS. Else, skip to MARITALSTATUS.>

Q54. (*Ceballos 2008).* **When a genetic test showed that I or my family had an increased risk for cancer, I…**

ENCOURAGEFAMGENTESTING Encouraged my family members to get genetic testing ENCOURAGECHILDBROSISSCREEN Encouraged my children/brothers/sisters to begin or increase their cancer screening

- ○ **Strongly agree**
- ○ **Somewhat agree**
- ○ **Neither agree nor disagree**
- ○ **Somewhat disagree**
- ○ **Strongly disagree**
- ○ **Don't know**
- ○ Prefer not to answer

Q55. FAMWORRYFROMRESULTS *(Family Communication).* **If I told my family members about my genetic test result I believe it would cause them a lot of worry and concern.**

- ○ **Strongly agree**
- ○ **Somewhat agree**
- ○ **Neither agree nor disagree**
- ○ **Somewhat disagree**
- ○ **Strongly disagree**
- ○ **Don't know**
- ○ Prefer not to answer

Q56. DESIRETODISCUSSGENTESTRESULTS *(Family Communication).* **For me, talking to my family members about my genetic test result is:**
Please slide the bar from 1 to 5 to select your answer.

- ○ **1 Very easy**
- ○ **2**
- ○ **3**
- ○ **4**
- ○ **5 Very difficult**
- ○ **Don't know**
- ○ Prefer not to answer

Q57. GENTESTRESULTRESPONSIBILITY *(Family Communication).* **Talking to my family members about my genetic test result is my responsibility:**

○ **Strongly agree**
○ **Somewhat agree**
○ **Neither agree nor disagree**
○ **Somewhat disagree**
○ **Strongly disagree**
○ **Don't know**
○ Prefer not to answer

Q58. COMMINFLUENCESFAMDECMAKING *(Family Communication).* **Talking to my family members about my genetic test result gave them information that was useful for them when making their own decisions about their health:**

○ **Strongly agree**
○ **Somewhat agree**
○ **Neither agree nor disagree**
○ **Somewhat disagree**
○ **Strongly disagree**
○ **Don't know**
○ Prefer not to answer

<Programmer: IF BRCATEST ne Yes AND LYNCHTEST ne Yes, go to MARITALSTATUS. Else continue to FAMDISCUSSHISTORY>

Q59. *McGivern 2004.* **Did you discuss any of the following topics with any of your family members?**

FAMDISCUSSHISTORY	**Your family history of cancer**
FAMDISCUSSTESTINGREASON	**The reasons why you decided to be tested**
FAMDISCUSSSCREENING	**Cancer screening**
FAMDISCUSSPREVSURGERY	**Preventive surgery**
FAMDISCUSSTESTFEELINGS	**Your feelings about your test result**
FAMDISCUSSBRCA1/2GENE	**His/her risk of having an altered BRCA1/2 gene**
FAMDISCUSSBRCA1/2COST	**The cost of BRCA1/2 genetic testing**
FAMDISCUSSINSURANCEDISCRIM	**The possibility of insurance discrimination**

<Programmer: This item will be included in two small grids with Yes, No, DK, and Prefer not to answer categories>

Q60. GENINFORESPONSIBLITY *(Roshanai 2010).* **Who do you think should be responsible for disclosing genetic information to at-risk relatives?**

○ **Geneticist**
○ **Nurse**
○ **Physicians**
○ **Myself or the person who has attended genetic counseling**
○ **Don't know**
○ **Prefer not to answer**

<Programmer: GENINFORESPONSIBILITY is a select all that apply question.>

<Programmer: If RECEIVEDTESTING = Yes AND (BRCATEST = Yes and/or LYNCHTEST = Yes), continue to PROVIDERRESOURCESFORFAMRISK. Else, skip to MARITALSTATUS.>

Q61. PROVIDERRESOURCESFORFAMRISK *(ABOUT - Q14).* **Did your health care provider (genetic counselor, physician, nurse, etc.) provide you resources to help you inform family members about cancer risk? (Please select all that apply).**

○ **Yes, they provided me a template for a letter to family members**
○ **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 with another type of information**
○ **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 MARITALSTATUS>

Q62. RESOURCESFORFAMRISK *(ABOUT - Q15).* **Who provided you with resources to help you inform family members about cancer risk? (Please select 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**

Please select how much you agree with the following statements.

Q63. RESOURCEHELPFUL. 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**
○ **Prefer not to answer**

Q64. ENOUGHINFO. 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**

Q65. OTHERINFO. What other information would be useful for discussions about cancer family history? (Please select all that apply).

○ **More discussion with genetic counselor**
○ **Discussions with physician**
○ **Printed materials**
○ **Referral to support group**
○ **Something else: _____**
○ **None of the above**
○ **Prefer not to answer**

Finally, we have a few demographic questions.

Q66. 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

Q67. INSURTYPE. What kind of health insurance or health care coverage do you have? (Select 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

Q68. 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

Q69. 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 >

Q70. 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

Q71. 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

Q72. 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 >

Q73. OTHEROCCUPATION *(GSS 2014 - WRKSPEC).* **Specify other activity:**

Q74. 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

INCENTX

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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.