

Are you male or female?	
○ Male	
○ Female	
O Prefer not to answer	
BACK NEXT  For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	SAVE & EXIT
FATHERCANCER	
What do you have to say about cancer?	
We would like to ask you a few questions about your family history of cancer.	
Did your BIOLOGICAL FATHER EVER have cancer of any kind?	
O Yes	
O No	
Adopted or don't know biological father     Don't know	
O Prefer not to answer	
BACK NEXT	SAVE & EXIT
DACK NEXT	
For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	



Colon		
Colon		
Please click on this	box if you would like to enter more than one kind of cancer	
Skin (non-melanoma)	]	
,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		
_		
Please click on this	box if you would like to enter more than two kinds of cancer	
Brain	]	
Brain		
	box if you would like to enter more than three kinds of cancer	
	box if you would like to enter more than three kinds of cancer	
	box if you would like to enter more than three kinds of cancer	
Please click on this	box if you would like to enter more than three kinds of cancer	
Please click on this	box if you would like to enter more than three kinds of cancer	
Please click on this  Liver  O Don't know	box if you would like to enter more than three kinds of cancer	
Please click on this     Liver	box if you would like to enter more than three kinds of cancer	
Please click on this  Liver  O Don't know	box if you would like to enter more than three kinds of cancer	
Please click on this  Liver  O Don't know	box if you would like to enter more than three kinds of cancer	SAVE & E

### **MOTHERCANCER**



O Yes		
O No		
<ul> <li>Adopted or don't k</li> </ul>	now biological mother	
O Don't know		
O Prefer not to answer		
		SAVE



What kind of	cancer did your mother have? Please enter all that apply.	
Breast		
■ Please o	lick on this box if you would like to enter more than one kind of cancer	
Bone		
■ Please o	lick on this box if you would like to enter more than two kinds of cancer	
Kidney		
, workly		
■ Please o	lick on this box if you would like to enter more than three kinds of cancer	
Pancreas		
O Don't kn	οw	
O Prefer no	t to answer	
	DACK NEVT	<b>SAVE &amp; EXIT</b>
	BACK NEXT	
	For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .	

### **NUMBROTHERS**



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.	
O Don't know	
O Prefer not to answer	
	SAVE & EXIT
BACK NEXT	
For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .	



Did any of your full brothers EVER have 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	
O Prefer not to answer	
How many of your full brothers have EVER had cancer of any kind?	
O Don't know Prefer not to answer	
BACK NEXT	SAVE & EX
For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	

**BROTHERCANCERTYPE1-4** 



# What kind of cancer did your full 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 Please click on this box if you would like to enter more than one kind of cancer Skin (Don't know what kind) Please click on this box if you would like to enter more than two kinds of cancer aryno-windpipe Please click on this box if you would like to enter more than three kinds of cancer Bone O Don't know Prefer not to answer BACK NEXT For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **NUMBROTHERCANCER1-4**



What	
How many full brothers have had bladder cancer?  O Don't know  Prefer not to answer	
BACK NEXT  For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	SAVE & EXIT

**NUMSISTERS** 



### 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. O Don't know Prefer not to answer BACK NEXT For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **SISTERCANCER**



## Did any of your full sisters EVER have 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 How many of your full sisters have EVER had cancer of any kind? Don't know Prefer not to answer BACK NEXT For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

SISTERCANCERTYPE1-4



	iving the same biological mother and SISTER as you. The alive and those who may have died.	
Mouth/tongue/lip		
■ Please click on this box	x if you would like to enter more than one kind of cancer	
Ovary		
■ Please click on this box	r if you would like to enter more than two kinds of cancer	
Cervix		
■ Please click on this box	t if you would like to enter more than three kinds of cancer	
Soft tissue (muscle or fat)		
O Don't know		
O Prefer not to answer		
		SAVE 8
	BACK NEXT	
	support, please call 1-312-201-4412 or send an email to CancerSurvey@noi	

ΝI



3252	
How many full sisters have had mouth/tongue/lip cancer?  O Don't know  Prefer not to answer	
BACK NEXT  For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	SAVE & EXIT



APPLAN	
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.  Don't know  Prefer not to answer	
BACK NEXT  For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	SAVE & EXIT
What do you have to say about cancer?	
Did any of your biological sons EVER have 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	

How many of your biological sons have EVER had cancer of any kind?

O Don't know

O Don't know

O Prefer not to answer

O Prefer not to answer

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

**SONCANCERTYPE1-4** 



What kind of cancer did your sons	nave: 1 leade enter an trial	чр.у.	
Please click on this box if you we	ould like to enter more than o	ne kind of cancer	
Esophagus			
■ Please click on this box if you we	ould like to enter more than to	vo kinds of cancer	
E i louse click on this box ii you we	oute the to thick more than to	o kinds of carloss	
Gallbladder			
Please click on this box if you we	ould like to enter more than th	ree kinds of cancer	
Search cancer type			
O Don't know			
O Prefer not to answer			
	DACK NEVE		SAVE
	BACK NEXT		

### **NUMSONCANCER1-4**



How many sons have had <u>bladder cancer</u> ?  O Don't know	
O Prefer not to answer	
BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	

**NUMBERDAUGHTERS** 



### 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. O Don't know O Prefer not to answer **SAVE & EXIT** BACK NEXT For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

### **DAUGHTERCANCER**



	genetically related; related by bloo		
Please include any w	o are alive and those who may hav	e alea.	
Yes			
O No			
O Don't know			
O Prefer not to answe			
How many of your bid O Don't know Prefer not to answe	logical daughters have EVER had c	ancer of any kind?	
O Don't know		ancer of any kind?	

**DAUGHTERCANCERTYPE1-4** 



What kind of cancer did your daughters have? Please enter all that apply.	
Lymphoma	
Please click on this box if you would like to enter more than one kind of cancer	
Bone	
Please click on this box if you would like to enter more than two kinds of cancer	
Rectum	
Please click on this box if you would like to enter more than three kinds of cancer	
Search canoer type	
O Don't know	
O Prefer not to answer	
	<b>SAVE &amp; EXIT</b>
BACK NEXT	
For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	

### NUMDAUGHTERCANCER1-4



University described a basic had himself area cannot?	
How many daughters have had <u>lymphoma cancer</u> ?	
O Don't know	
O Prefer not to answer	
	SAVE & I
BACK NEXT	O/WE at
For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	

NUMSECONDCANCER



The next few questions are about the number of blood relatives who have been diagnosed with breast or ovarian cancer. 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 O Prefer not to answer **SAVE & EXIT** BACK NEXT For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org. **SECBREASTCAN** How many of them were diagnosed with breast cancer before the age of 50? O Don't know O Prefer not to answer SAVE & EXIT BACK NEXT For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**SECOVARIANCAN** 



How many of your grandmothers, aunts, nieces, or granddaughters have ever been diagnosed with cancer?	ovarian
O Don't know	
O Prefer not to answer	
BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.	
CANCERWORRY  What do you have to say about cancer?	
How worried are you about getting cancer?	
O Extremely	
O Moderately	
O Somewhat	
O Slightly Not at all	
O Not at all	
O Prefer not to answer	
BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .	
WORRYCANCSPECIFIC/ WORRYBACKOFMIND/ WORRYCHANCECANCER	



### In general, how much do you agree with the following?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Prefer not to answer
I think about breast/ovarian/colorectal cancer more than most diseases	0	0	0	0	0	0
Getting breast/ovarian/colorectal cancer is often in the back of my mind	0	0	0	0	0	0
I am often bothered by thoughts or worry about my chances of getting breast/ovarian/colorectal cancer.	0	0	0	0	0	0

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

### PERCEIVEDCOLONCANCERRISK



Compared to the average woman your age	, would you say tha	at you are more likely to g	et colon or rectal
cancer, less likely, or about as likely?			

- More likely
- Less likely
- About as likely
- O Don't know
- O Prefer not to answer

SAVE & EXIT

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.



<u></u>	SAV
	NEXT

PERCEIVEDOVARCANCERRISK



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

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

PRIMARYPLACEFORHEALTHADVICE



Is there a place that you most frequently 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

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**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.

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.

- O Yes, we've talked about this in depth
- O Yes, we've talked about this a little
- O No
- O Prefer not to answer

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

DOCTORRISK2



Has a doctor, or other health professional, ever told you that you have a higher chance of getting ca other women your age?	ncer than
○ Yes	
O No	
O Don't know	
O Prefer not to answer  BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .	
2014CATICFIED	

### COMSATISFIED



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 O Very dissatisfied O Prefer not to answer **SAVE & EXIT** BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**DOCEASYTOUNDERSTAND** 



	nary care provider explain things about your family's history of cancer and your own cancer risk was easy to understand?
O Yes	
O Prefer no	t to answer
	BACK NEXT
	For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .
DOCLISTEN	What do you have to say about cancer?
Did your prim cancer risk?	nary care provider listen carefully to you about your family's history of cancer and your own
O Yes	
O Prefer no	it to answer
	BACK NEXT
	For technical support, please call 1-212-201-4412 or send an amail to CancerSuprev@nors org

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

SAVE & EXIT

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **COUNSELINGREASON**



What was the MAIN reason you had genetic counseling?

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

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

**COUNSATISFIED** 



) Satisfied	
N N - M	
) Neither	
) Dissatisfied	
Very dissatisfied	
) Prefer not to answer	

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **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>

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

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

SAVE & EXIT



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**TESTRESULTBR** 



What was the result of your BRCA test?  O 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
O No gene mutation was found
○ Don't know
O Prefer not to answer
SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### LYNCHTEST



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

Yes
No
Don't know
Prefer not to answer

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**TESTRESULTLYNCH** 



What was the result of your genetic test for	r hereditary colorectal cancer:
--	---------------------------------

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

BACK NEXT

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

SHARERESULTSMOTHER/SHARERESULTSFATHER/SHARERESULTSPARTNER/SHARERESULTSSISTER/SHARE RESULTSBROTHER



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

	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	•	0	0	0	0	0
Father	0	•	0	0	0	0
Spouse/Partner	0	•	0	0	0	0
Sister(s)	0	•	0	0	0	0
Brother(s)	•	0	0	0	0	0

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

SHARERESULTSDAUGHTER/SHARERESULTSSON/SHARERESULTSAUNTUNCLE/SHARERESULTSCOUSIN



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

	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)	0	0	0	0	0	0
Son(s)	0	0	0	0	0	0
Uncle/Aunt(s)	0	0	0	0	0	0
Cousin(s)	0	0	0	0	0	0

BACK NEXT

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **SHAREDATE**



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

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

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

FINFORMEDVIATEXT/ FINFORMEDVIAEMAIL/FINFORMEDVIAPHONE/ FINFORMEDVIAPERSON/ FINFORMEDGRAPEVINE/ FINFORMEDVIAOTHER



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
Sent a text	•	0	0	0
Sent an email	•	0	0	0
Told them on the phone	•	0	0	0
Told them in person	•	0	0	0
I told someone who then told someone else (through the grapevine)	•	0	0	0
Other method	0	0	0	0

SAVE & EXIT

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

MINFORMEDVIATEXT/ MINFORMEDVIAEMAIL/ MINFORMEDVIAPHONE/ MINFORMEDVIAPERSON/ MINFORMEDGRAPEVINE/ MINFORMEDVIAOTHER



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
Sent a text	0	0	0	0
Sent an email	0	0	0	0
Told them on the phone	0	0	0	0
Told them in person	0	0	0	0
I told someone who then told someone else (through the grapevine)	0	0	0	0
Other method	0	0	0	0

BACK NEXT

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### NOCONTACT/NOTCLOSE/NOTCARE/NOTUPSET /NOTATRISK/WHATTOSAY/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 very applicable	0	0
The two of you are not close.	not at all applicable very applicable	0	0
He/she wouldn't care.	not at all applicable very applicable	0	0
You didn't want to upset him/her	not at all applicable very applicable	0	0
He/she is not at risk for developing cancer.	not at all applicable very applicable	0	0
You didn't know what to say to him/her.	not at all applicable very applicable	0	0
You were having difficulty coping with your own risk for cancer.	not at all applicable very applicable	0	0
You feel that he/she is too young to understand.	not at all applicable very applicable	0	0
Other (please specify)	not at all applicable very applicable	0	0

SAVE & EXIT



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**RELATIVESTESTINGRESULT1-4** 



### What was the test result for your mother?

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

SAVE & EXIT

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **RELMINFORMED**



### How were you FIRST informed of your mother's test results?

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

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**BREASTTESTS** 



### Have you had any of the following tests?

	Yes	No	Don't know	Prefer not to answer
Ultrasound	0	0	0	0
Breast MRI	0	0	0	0
Additional mammogram(s)	0	0	0	0
Biopsy	0	0	0	0
Other	0	0	0	0

SAVE & EXIT

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **PREVENTION**



### Which of the following, if any, have you done in order to reduce your risk of cancer?

	Yes	No	Don't know	Prefer not to answer
Removal of breasts that didn't have cancer (mastectomy)	0	0	0	0
Removal of ovaries that didn't have cancer (oophorectomy)	0	0	0	0
Taking Tamoxifen or Raloxofine (or other chemopreventive drug)	0	0	0	0
Quit smoking	0	0	0	0
Cut back on or quit drinking	0	0	0	0
Increased exercise	0	0	0	0
Healthier diet	0	0	0	0

BACK NEXT

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**SEEKCANCERINFO** 



Have you ever looked for information about genetic risk of cancer from any source? O Yes O No O Prefer not to answer **SAVE & EXIT** BACK NEXT For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**INFOSEEK** 



The last time you looked for information about cancer or cancer screening, where did you go? Internet O Books O Brochures or pamphlets O Cancer organization O Family, friend, or co-worker O Doctor or health care provider Library Magazine or newspaper O Telephone information number O Complementary or alternative practitioner O Prefer not to answer **SAVE & EXIT** BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

CANCERLEVELOFEFFORT/CANCERFRUSTRATED/CANCERCONCERNEDQUALITY/CANCERHARDTOUNDERST AND



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?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Prefer not to answer
It took a lot of effort to get the information you needed	0	0	0	0	0	0
You felt frustrated during your search for the information	0	0	0	0	0	0
You were concerned about the quality of the information	0	0	0	0	0	0
The information you found was hard to understand	0	0	0	0	0	0

**SAVE & EXIT** 



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**SHARECANCERWORRIES** 



The next section is about communication among your family members.

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.

I have someone I trust that I can talk to about my concerns about developing cancer

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

**SAVE & EXIT** 



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **SPEAKOPENLY**



My family speaks openly about their worries about other family members developing cancer.

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

SAVE & EXIT



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

LISTENCONCERNS



My family listens to each other's cond	cerns about cancer			
Strongly agree	oonio about danden			
Somewhat agree     Neither agree nor disagree				
<ul> <li>Somewhat disagree</li> </ul>				
O Strongly disagree				
O Don't know				
Prefer not to answer				
				SAVE & EXIT
	BACK NEXT			
	<ul> <li>Strongly agree</li> <li>Somewhat agree</li> <li>Neither agree nor disagree</li> <li>Somewhat disagree</li> <li>Strongly disagree</li> <li>Don't know</li> </ul>	O Somewhat agree Neither agree nor disagree Somewhat disagree Strongly disagree Don't know Prefer not to answer	<ul> <li>Strongly agree</li> <li>Somewhat agree</li> <li>Neither agree nor disagree</li> <li>Somewhat disagree</li> <li>Strongly disagree</li> <li>Don't know</li> <li>Prefer not to answer</li> </ul>	<ul> <li>Strongly agree</li> <li>Somewhat agree</li> <li>Neither agree nor disagree</li> <li>Somewhat disagree</li> <li>Strongly disagree</li> <li>Don't know</li> <li>Prefer not to answer</li> </ul>

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

### **ENCOURAGESHARE**



My family encourages family members to share their concerns about cancer.

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

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

**COMFORTNO** 



O Strongly agree		
O Somewhat agree		
<ul> <li>Neither agree nor disagree</li> </ul>		
<ul> <li>Somewhat disagree</li> </ul>		
<ul> <li>Strongly disagree</li> </ul>		
O Don't know		
O Prefer not to answer		
	BACK NEXT	SAVE 8

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

### **OFFLIMITS**



	rs the topic of cancer is 'off-limits.'	
<ul> <li>Strongly agree</li> </ul>		
<ul> <li>Somewhat agree</li> </ul>		
<ul> <li>Neither agree nor disag</li> </ul>	jree	
<ul> <li>Somewhat disagree</li> </ul>		
<ul> <li>Strongly disagree</li> </ul>		
O Don't know		
O Prefer not to answer		
	BACK NEXT	SAVE & E

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

CHANGETOPIC



O Strongly agree		
O Somewhat agree		
<ul> <li>Neither agree nor disagree</li> </ul>		
<ul> <li>Somewhat disagree</li> </ul>		
<ul> <li>Strongly disagree</li> </ul>		
O Don't know		
O Prefer not to answer		
		SAVE

**BECOMEANGRY** 



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

Members of my family will become angry when the topic of cancer is discussed.

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

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**AVOIDTOPIC** 



<ul> <li>Strongly agree</li> </ul>	
<ul> <li>Somewhat agree</li> </ul>	
<ul> <li>Neither agree nor disagree</li> </ul>	
<ul> <li>Somewhat disagree</li> </ul>	
<ul> <li>Strongly disagree</li> </ul>	
O Don't know	
O Prefer not to answer	
	SAVE 8

### **ENCOURAGEFAMGENTESTING**



When a genetic test showed that I or my family had an increased risk for cancer, I...

Encouraged my family members to get genetic testing

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

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

**ENCOURAGECHILDBROSISSCREEN** 



When a genetic test showed that I or my family had an increased risk for cancer, I...

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

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

### **FAMWORRYFROMRESULTS**



O Strongly agree		
O Somewhat agree		
Neither agree nor disagree		
<ul> <li>Somewhat disagree</li> </ul>		
<ul> <li>Strongly disagree</li> </ul>		
O Don't know		
O Prefer not to answer		
	BACK NEXT	SAVE & E

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

**DESIRETODISCUSSGENTESTRESULTS** 



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.	
Very easy Very difficult	
O Don't Know	
O Prefer not to answer	
BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .	
CENTECTDES II TRESPONSIBILITY	

### **GENTESTRESULTRESPONSIBILITY**



<ul> <li>Strongly agree</li> </ul>	
<ul> <li>Somewhat agree</li> </ul>	
<ul> <li>Neither agree nor disagree</li> </ul>	
<ul> <li>Somewhat disagree</li> </ul>	
<ul> <li>Strongly disagree</li> </ul>	
O Don't know	
O Prefer not to answer	
	SAVE 8

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

COMMINFLUENCESFAMDECMAKING



Talking to my family members about my genetic test result gave them information that wa	s useful	for them
when making their own decisions about their health:		

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

**SAVE & EXIT** 



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

# FAMDISCUSSHISTORY/ FAMDISCUSSTESTINGREASON/ FAMDISCUSSSCREENING/ FAMDISCUSSPREVSURGERY



#### Did you discuss any of the following topics with any of your family members?

	Yes	No	Don't know	Prefer not to answer
Your family history of cancer	0	0	0	0
The reasons why you decided to be tested	0	0	0	0
Cancer screening	0	0	0	0
Preventive surgery	0	0	0	0

**SAVE & EXIT** 



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

FAMDISCUSSTESTFEELINGS/ FAMDISCUSSBRCA1/2GENE/ FAMDISCUSSBRCA1/2COST/ FAMDISCUSSINSURANCEDISCRIM



# Did you discuss any of the following topics with any of your family members?

	Yes	No	Don't know	Prefer not to answer
Your feelings about your test result	0	0	0	0
His/her risk of having an altered BRCA1/2 gene	0	0	0	0
The cost of BRCA1/2 genetic testing	0	0	0	0
The possibility of insurance discrimination	0	0	0	0

SAVE & EXIT

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

# GENINFORESPONSIBLITY



# Who do you think should be responsible for disclosing genetic information to at-risk relatives?

	Yes	No	Don't know	Prefer not to answer
Geneticist	0	0	0	0
Nurse	0	0	0	0
Physicians	0	0	0	0
Myself or the person who has attended genetic counseling	0	0	0	0

SAVE & EXIT

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

PROVIDERRESOURCESFORFAMRISK



Did your health care provider (genetic counselor, physician, nurse, etc.) provide you resources to help you inform family members about cancer risk?

	Yes	No	Prefer not to answer
They provided me a template for a letter to family members	0	0	0
They provided a brochure or other printed material from the health care provider	0	0	0
They provided material from the laboratory that did the testing	0	0	0
They told me about organization(s) that serve people with hereditary cancer	0	0	0
They provided me with another type of information	0	0	0
I was not provided with any resources	0	0	0

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

# RESOURCESFORFAMRISK



Who provided you with resources to help you inform family members about cancer risk?

	Yes	No	Prefer not to answer
Genetic counselor	0	0	0
OB/GYN	0	0	0
Oncologist	0	0	0
Nurse	0	0	0
Laboratory who performed the test	0	0	0
I was not provided with any resources	0	0	0

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

RESOURCEHELPFUL



Please select how much you agree with the following statements. The resources provided were helpful in my discussions with family members about family cancer history. O Strongly agree Somewhat agree O Neither agree nor disagree O Somewhat disagree O Strongly disagree O Prefer not to answer **SAVE & EXIT** BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

#### **ENOUGHINFO**



I have enough information about genetics and cancer to speak with family members. Strongly agree Somewhat agree O Neither agree nor disagree O Somewhat disagree O Strongly disagree O Prefer not to answer SAVE & EXIT BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**OTHERINFO** 



# What other information would be useful for discussions about cancer family history?

	Yes	No	Prefer not to answer
More discussion with genetic counselor	0	0	0
Discussions with physician	0	0	0
Printed materials	0	0	0
Referral to support group	0	0	0
Something else	0	0	0

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

# **MARITALSTATUS**



What is your mari			
Living as marr	ried		
O Divorced	ilou		
○ Widowed			
<ul> <li>Separated</li> </ul>			
O Single, never I	been married		
O Prefer not to an	nswer		

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

**CURRINS** 



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

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

# **INSURTYPE**



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

	Yes	No	Prefer not to answer
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	0	0	0
Medicare	0	0	0
Medi-Gap	0	0	0
Medicaid	0	0	0
SCHIP	0	0	0

**SAVE & EXIT** 

BACK NEXT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.



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

	Yes	No	Prefer not to answer
Military health care (TRICARE/VA/CHAMP-VA)	0	0	0
Indian Health Service	0	0	0
State-sponsored health plan	0	0	0
Other government program	0	0	0
Single service plan (e.g. dental, vision, prescription)	0	0	0

**SAVE & EXIT** 



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.

#### **EDUCATIONGP**



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

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

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

**SAVE & EXIT** 



For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

**ORIENTATION** 



Which of the following best represents how you think about yourself?	
<ul> <li>Lesbian or Gay</li> <li>Straight, that is, not lesbian or gay</li> <li>Bisexual</li> <li>Something else</li> <li>I don't know how to answer</li> </ul>	
O Prefer not to answer	
BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .	

**IDENTITY** 



How do you describe yourself? (Select One)	
O Female	
O Male	
○ Transgender	
O Do not identify as female, male, or transgender	
O Prefer not to answer	
	SAVE & EX
BACK NEXT	

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

HISPLATINOSPAN



Are you of Hispanic, Latina, or Spanish origin?	
○ Yes ○ No	
O Prefer not to answer	
BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a> .	

# HISPLATINOSPANGROUP



1

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

RACE



SAVE &

OCCUPATIONALSTATUS/ OTHEROCCUPATION



<ul> <li>Employed</li> </ul>			
<ul> <li>Unemployed</li> </ul>			
<ul> <li>Homemaker</li> </ul>			
Student			
<ul> <li>Retired</li> </ul>			
<ul> <li>Disabled</li> </ul>			
Other-Specify			
O Prefer not to answ	er		
			SAVE & I

HOUSEHOLDINCOME



Thinking about all the members of your family living in your hincome, meaning the total pre-tax income from all sources e	
<ul> <li>Less than \$20,000</li> <li>\$20,000 to \$49,999</li> <li>\$50,000 to \$99,999</li> <li>\$100,000 to \$199,999</li> <li>\$200,000 or more</li> <li>Don't know</li> <li>Prefer not to answer</li> </ul>	
BACK NEXT	SAVE & EXIT
For technical support, please call 1-312-201-4412 or	end an email to <u>CancerSurvey@norc.org</u> .
Gift Card	

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

O Yes

BACK NEXT

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

hat do you have to say about cancer?



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

O Yes

O No

BACK NEXT

SAVE & EXIT

For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.



Below is your gift code number:

2DDP-VRDD3S-BN8S

Please write this down or print it for your records.

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: <a href="https://www.cdc.gov/cancer/dcpc/resources/index.htm">https://www.cdc.gov/cancer/dcpc/resources/index.htm</a>.

If you would like more information about the study, please call 312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>. 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 <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>.

End 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: <a href="https://www.cdc.gov/cancer/dcpc/resources/index.htm">https://www.cdc.gov/cancer/dcpc/resources/index.htm</a>.

If you would like more information about the study, please call 312-201-4412 or send an email to <a href="mailto:CancerSurvey@norc.org">CancerSurvey@norc.org</a>. 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.



For technical support, please call 1-312-201-4412 or send an email to CancerSurvey@norc.org.