

JScreen Survey (Female version)

The first few questions will be used to make sure that you are eligible for participation in the survey.

1. Have you ever had breast or ovarian cancer?
Yes.....1 [Go to Early Close]
No.....2

2. Have you ever been tested for mutations in the *BRCA1* or *BRCA2* cancer susceptibility genes?
Yes.....1 [Go to Early Close]
No.....2
Not Sure.....3

3. Have you ever had surgery to remove your breast(s)?
No1
Yes – one breast.....2
Yes – both breasts.....3 [Go to Early Close]

4. Have you ever had surgery to remove one or both ovaries?
No1
Yes – one ovary2
Yes – both ovaries3 [Go to Early Close]

Early Close: Thank you for your interest in the study. Based on your responses to these questions, you are no longer eligible to continue; however, please keep the gift card as a token of appreciation for your time. If you are unable to locate the gift card information, please e-mail us at jcreensurvey@georgetown.edu or call us at (877) 687-2720.

Now we would like to ask you a few questions about your background.

5. What state do you live in? _____

6. What is your age? _____

7. Did you find out from JScreen that you are a carrier for an inherited disease?
Yes, for one condition.....1
Yes, for more than one condition.....2
Yes, but I can't recall for how many conditions.....3
No.....4
I don't recall.....5

8. When did you receive your results from JScreen? Please provide your best estimate.
Within the last year.....1
1-3 years ago.....2
More than 3 years ago.....3

9. Which of the following describes your current situation?

- Single or never married..... 1
- Married or living as married..... 2
- Divorced or separated..... 3
- Widowed..... 4

10. How many years of school have you completed?

- 8 or less years..... 1
- Some high school..... 2
- High school graduate, or GED..... 3
- Some college..... 4
- College graduate or beyond..... 5

11. Are you currently employed for salary or wages?

- Not employed..... 1
- Full-time employed..... 2
- Part-time employed..... 3
- Retired..... 4

These next questions are about your family and personal history of cancer. Here we are only talking about blood relatives.

12. Have any of your blood relatives been tested for mutations in the *BRCA1* and *BRCA2* cancer susceptibility genes?

- Yes..... 1
- No..... 2 **[Go to Q. 13]**
- Not sure..... 3 **[Go to Q. 13]**

12a. Have any of these relatives received a positive test result (learned that they have an alteration or mutation that causes an increased cancer risk)?

- Yes..... 1
- No..... 2 **[Go to Q. 13]**
- Not sure..... 3 **[Go to Q. 13]**

12b. Which relatives have received a positive test result? [check all that apply]

- Parent, sibling, or child..... 1
- Aunt, uncle, or grandparent..... 2
- Cousin..... 3
- Niece or nephew..... 4
- Unsure/rather not say..... 5

13. Have you ever been diagnosed with cancer of any kind?

Yes..... 1
 No..... 2 **[Go to Q. 14]**

13a. What type(s) of cancer? Check all that apply.

- Colon.. Age at diagnosis _____
 Endometrium/Uterus Age at diagnosis _____
 Cervical Age at diagnosis _____
 Lung Age at diagnosis _____
 Melanoma..... Age at diagnosis _____
 Pancreatic Age at diagnosis _____
 Other... Age at diagnosis _____ Type of cancer _____

14. To the best of your ability, please indicate if any of the female blood relatives below have been diagnosed with any of the following cancers:

	Breast cancer	Ovarian cancer	Pancreatic cancer	None of these
Mother:				
Grandmother:				
Aunt:				
Sister:				

- a. Number of aunts diagnosed with breast cancer:
- b. Number of sisters diagnosed with breast cancer:
- c. Number of grandmothers diagnosed with breast cancer:
- d. Number of aunts diagnosed with ovarian cancer:
- e. Number of sisters diagnosed with ovarian cancer:
- f. Number of grandmothers diagnosed with ovarian cancer:
- g. Number of aunts diagnosed with pancreatic cancer:
- h. Number of sisters diagnosed with pancreatic cancer:
- i. Number of grandmothers diagnosed with pancreatic cancer:

15. Please indicate if any of the male blood relatives below have been diagnosed with any of the following cancers:

	Breast cancer	Pancreatic cancer	Prostate cancer	None of these
Father:				
Grandfather:				
Uncle:				
Brother:				

- a. Number of uncles diagnosed with breast cancer:
- b. Number of brothers diagnosed with breast cancer:
- c. Number of grandfathers diagnosed with breast cancer:
- d. Number of uncles diagnosed with pancreatic cancer:
- e. Number of brothers diagnosed with pancreatic cancer:
- f. Number of grandfathers diagnosed with pancreatic cancer:
- g. Number of uncles diagnosed with prostate cancer:
- h. Number of brothers diagnosed with prostate cancer:
- i. Number of grandfathers diagnosed with prostate cancer:

16. Do you have any biological children?

Yes.....1
No.....2

Some women are concerned about their risk of cancer. We would like to learn what you think about your risks for breast and ovarian cancer.

17. Using a scale from 0 to 100, where 0 means that you believe you definitely won't get breast cancer and 100 means that you believe you definitely will get breast cancer, how likely would you say you are to develop breast cancer? _____
18. Using a scale from 0 to 100, where 0 means that you believe you definitely won't get ovarian cancer and 100 means that you believe you definitely will get ovarian cancer, how likely would you say you are to develop ovarian cancer? _____

The next questions are about your attitudes and opinions on genetic testing.

Scientists have discovered several genes in which alterations (called mutations) lead to a significantly increased risk for developing breast and ovarian cancer in women. Men with these mutations are at increased risk for prostate and breast cancer. Both sexes have an increased risk of pancreatic cancer. The most common and well known of these genes are *BRCA1* and *BRCA2* (*BRCA1/2*). About 1 in 40 (2.5%) Ashkenazi Jewish men and women has a mutation in one of these genes. If a Jewish individual has personal or family history of these cancers, the chance of having a *BRCA1* or *BRCA2* mutation is higher.

Some physicians believe that all Ashkenazi Jewish women should consider *BRCA* testing. Others do not endorse such widespread testing and think that only those with personal or family histories of cancer should be tested. JScreen is considering offering *BRCA1/2* testing for interested Ashkenazi Jewish individuals in conjunction with their reproductive carrier screening. In order to help us make this decision, we have a few questions for you.

19. Before participating in this survey, how much had you heard about the *BRCA1* and *BRCA2* genes associated with hereditary breast and ovarian cancer?
- I had never heard of these genes.....1
- I had heard of these genes, but did not know much about them.....2
- I knew a fair amount about these genes.....3
- I knew a great deal about these genes.....4
20. Mutations in the *BRCA1* and *BRCA2* genes increase a woman's chance of developing breast and ovarian cancers. Based on what you know now, which of the following statements describes you best?
- I probably will get tested for *BRCA1/2* mutations.....1
- I definitely will get tested for *BRCA1/2* mutations.....2
- I probably will not get tested for *BRCA1/2* mutations.....3
- I definitely will not get tested for *BRCA1/2* mutations.....4
- I am unsure whether I want to be tested for *BRCA1/2* mutations.....5
21. Using a scale from 0 to 100, where 0 means that you definitely don't have an altered *BRCA1/2* gene and 100 means that you definitely do have an altered *BRCA1/2* gene, how likely would you say you are to have an altered *BRCA1/2* gene? _____
22. The next few questions are about your opinions, beliefs and attitudes regarding genes for cancer. This is not a test. Please indicate whether you agree or disagree with each statement.

		Agree	Disagree
A	If a woman tests negative for mutations in <i>BRCA1</i> and <i>BRCA2</i> , then she definitely will not get breast or ovarian cancer.		
B	A mother can pass down a <i>BRCA1</i> or <i>BRCA2</i> mutation to her sons.		
C	A father can pass down a <i>BRCA1</i> or <i>BRCA2</i> mutation to his daughters.		
D	If an individual is a carrier of a <i>BRCA1</i> or <i>BRCA2</i> mutation, each of his or her children has a 1 in 4 chance of also having the mutation.		
E	If there is no history of breast or ovarian cancer in my family, I am definitely not at risk for carrying a <i>BRCA1</i> or <i>BRCA2</i> mutation.		

23. There are several possible benefits of *BRCA1/2* testing. On the list of reasons below, please indicate how important each reason is for you at the present time.

Reasons to be tested:	Not at all Important	Somewhat Important	Very Important
A To reduce my chances of developing cancer.			
B To learn about the risk to my children.			
C To provide important risk information to my family members.			
D To reduce my chances of dying from cancer.			
E To provide reassurance and relief if I test negative.			
F To make a decision about surgery to have my breasts or ovaries			

	removed.			
G	To know if I need additional or more frequent cancer screening.			
H	To reduce my uncertainty about my risk.			
I	To make decisions about having (more) children.			
J	To make decisions about whether to use prenatal or other reproductive testing to avoid passing a mutation on to my future children.			
K	To make other important life decisions.			

24. There are also several possible risks or limitations of *BRCA1/2* testing. On the list of reasons below, please indicate how important each reason is for you at the present time.

	Reasons NOT to be tested:	Not at all Important	Somewhat Important	Very Important
A	I am concerned about the effect it would have on my family.			
B	I am concerned about insurance or employment discrimination.			
C	I am concerned about confidentiality.			
D	I am not sure how I would handle it emotionally.			
E	I am concerned about the accuracy of the test.			
F	I am concerned that I might feel labeled or singled out if I tested positive.			
G	I am concerned I might feel guilty if I tested positive.			
H	I am concerned about the impact this could have on my decision about whether or not to have children.			
I	I am concerned that there are no good options for preventing cancer.			
J	I am concerned about the impact this information could have for dating and marriage for me.			
K	I am concerned about the impact this information could have for dating and marriage for my children.			
L	I am concerned that I might feel guilty if I tested negative.			

25. The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way **in the last month**:

	Never	Almost Never	Sometimes	Fairly Often	Very Often
How often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
How often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
How often have you felt that things were going your way?	0	1	2	3	4
How often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

26. When you got your carrier screening through JScreen, what was your relationship/family status (check all that apply):

- Single.....1
- Married or living as married.....2
- Divorced or separated.....3
- Widowed.....4
- I had one or more children.....5
- My partner or I was pregnant at the time.....6
- Rather not say.....7
- Do not remember.....8

27. If you were participating in JScreen today, and were asked to consider *BRCA1* and *BRCA2* testing as part of your JScreen carrier screening, which of the following educational options would you be most likely to choose?

- Review only print educational materials to help make a decision about testing.....1
- Review only interactive web-based information to help make a decision about testing.....2
- Complete individual genetic counseling by telephone before testing.....3
- Complete individual genetic counseling by video chat before testing.....4
- Complete individual in-person genetic counseling outside of JScreen before testing.....5
- Talk with my doctor before testing.....6
- I would not choose to get information or genetic counseling before making a decision....7

28. If you were participating in JScreen today, and had the option to be tested for *BRCA1* and *BRCA2* mutations as part of your JScreen carrier screening, what do you think you would choose?

- I would definitely be tested as part of JScreen.....1
- I would probably be tested as part of JScreen.....2
- I would probably not be tested as part of JScreen.....3
- I would definitely not be tested as part of JScreen.....4

29. How important is it that your partner supports your decision about whether or not to have *BRCA1/2* testing?

- Not at all important.....1
- A little bit important.....2
- Somewhat important.....3
- Very important.....4
- I do not currently have a partner.....5

30. How much would you be willing to pay out of pocket for *BRCA1* and *BRCA2* genetic testing?

- Would not be willing to pay anything.....1
- Less than \$20.....2
- \$20-\$50.....3
- \$51-\$150.....4
- \$151-\$300.....5
- More than \$300.....6

Thank you for your time and for completing the survey. Your participation in the study is now complete. If you have any questions about any aspect of this survey or the study, please contact the Georgetown research study staff at jcreensurvey@georgetown.edu or call us at (877) 687-2720.