

SUPPLEMENTAL MATERIALS

Impact of Panel Gene Testing for Hereditary Breast and Ovarian Cancer on Patients

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Table 1S. Simple median regression models of the association between patient characteristics and outcome variables

(a) Age

	Constant	Coefficient for age (SE)	p value
IES, total	5.6	-0.07 (0.05)	0.17
IES, intrusion	0.20	-0.002 (0.002)	0.17
IES, avoidance	0.33	-0.004 (0.003)	0.19
IES, hyperarousal	0	0 (0.0007)	1.00
MICRA, distress	0	0 (0.01)	1.00
MICRA, uncertainty	3	0 (0.03)	1.00
MICRA, positive experience	10.1	-0.11 (0.05)	0.04
MICRA Total	24.2	-0.23 (0.06)	<0.001
SWD	20.3	0.06 (0.03)	0.04

(b) Race

	Constant	Coefficient for White Hispanic† (SE)	p value	Coefficient for African American† (SE)	p value	Coefficient for Asian† (SE)	p value	Coefficient for Other† (SE)	p value
IES, total	2	-1 (2.3)	0.66	7 (2.9)	0.016	0 (3.3)	1.0	0 (3.3)	1.0
IES, intrusion	0	0 (0.09)	1.0	0.4 (0.1)	0.001	0 (0.1)	1.0	0.1 (0.1)	0.31
IES, avoidance	0.1	-0.1 (0.1)	0.39	0.38 (0.2)	0.044	0.1 (0.2)	0.55	-0.1 (0.2)	0.55
IES, hyperarousal	0	0 (0.02)	1.0	0.2 (0.03)	<0.001	0 (0.03)	1.0	0 (0.03)	1.0
MICRA, distress	0	0 (0.4)	1.0	0 (0.5)	1.0	0 (0.6)	1.0	1 (0.6)	0.079
MICRA, uncertainty	3	-1 (1.4)	0.46	0 (1.7)	1.0	-2 (1.9)	0.30	2 (1.9)	0.30
MICRA, positive experience	5	0 (2.1)	1.0	0 (2.6)	1.0	0 (3.0)	0.74	3 (3.0)	0.32
MICRA Total	12	1 (2.7)	0.71	0 (3.4)	1.0	3 (3.9)	0.44	5 (3.9)	0.20
SWD	25	-3 (1.2)	0.016	-3 (1.6)	0.060	-5 (1.8)	0.006	-4 (1.8)	0.027

†Compared to race = Caucasian, non-Hispanic

(c) Education level

	Constant	Coefficient for college graduate or higher (SE)	p value
IES, total	3	-1 (1.7)	0.57
IES, intrusion	0	0 (0.06)	1.0
IES, avoidance	0.25	-0.25 (0.1)	0.052
IES, hyperarousal	0	0 (0.01)	1.0
MICRA, distress	0	0 (0.2)	1.0
MICRA, uncertainty	3	0 (1.2)	1.0
MICRA, positive experience	4	1 (1.7)	0.56
MICRA Total	12	1 (2.5)	0.69
SWD	21	4 (0.9)	<0.0001

(d) Time from genetic testing to questionnaire administration in months

	Constant	Coefficient for time to questionnaire in months (SE)	p value
IES, total	2	0 (0.11)	1.00
IES, intrusion	0	0 (0.004)	1.00
IES, avoidance	0.17	-0.007 (0.01)	0.42
IES, hyperarousal	0	0 (0.001)	1.00
MICRA, distress	0	0 (0.02)	1.00
MICRA, uncertainty	2.2	0.1 (0.07)	0.14
MICRA, positive experience	3.7	0.06 (0.11)	0.60
MICRA Total	7.4	0.39 (0.15)	0.01
SWD	25.2	-0.17 (0.07)	0.02

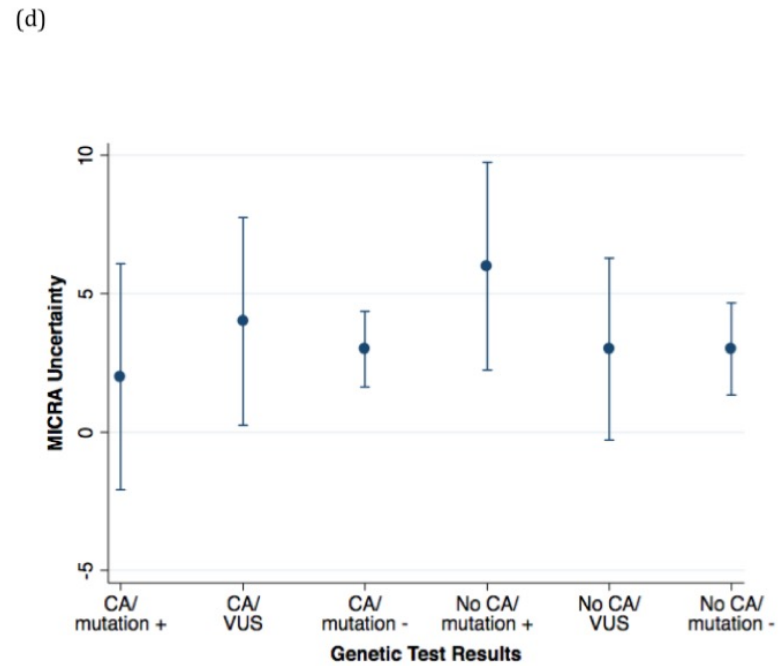
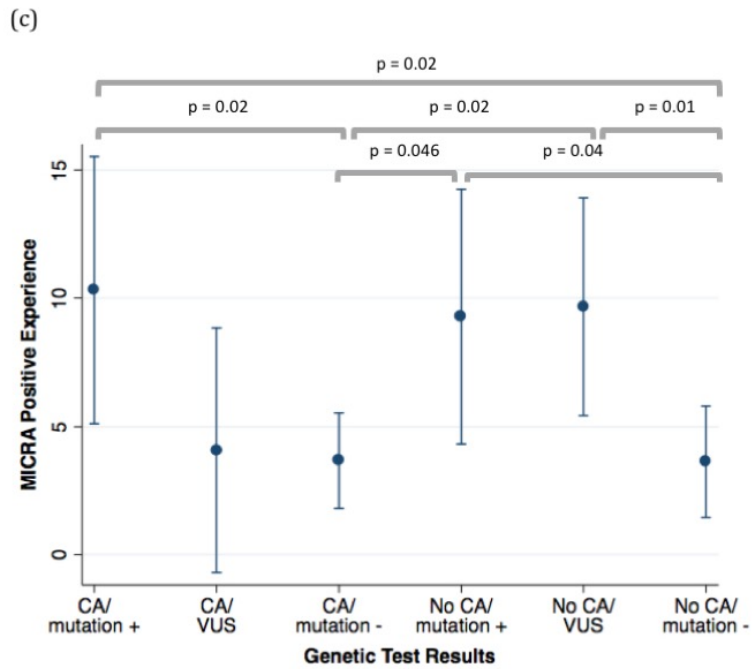
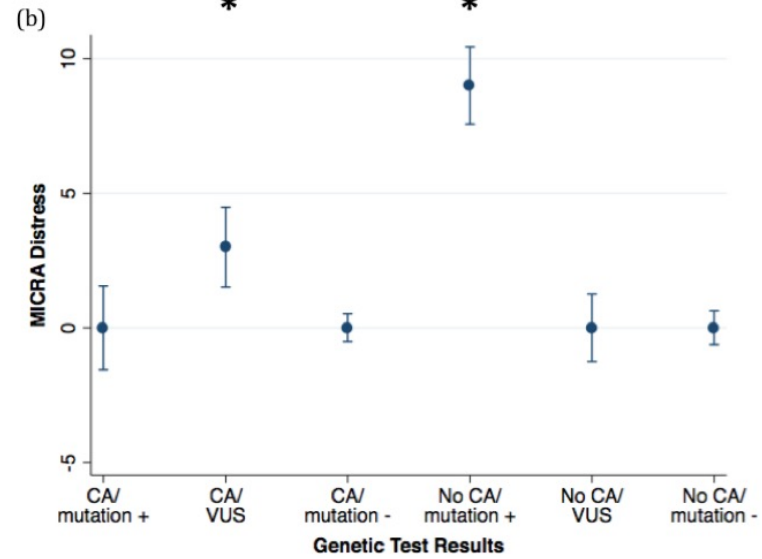
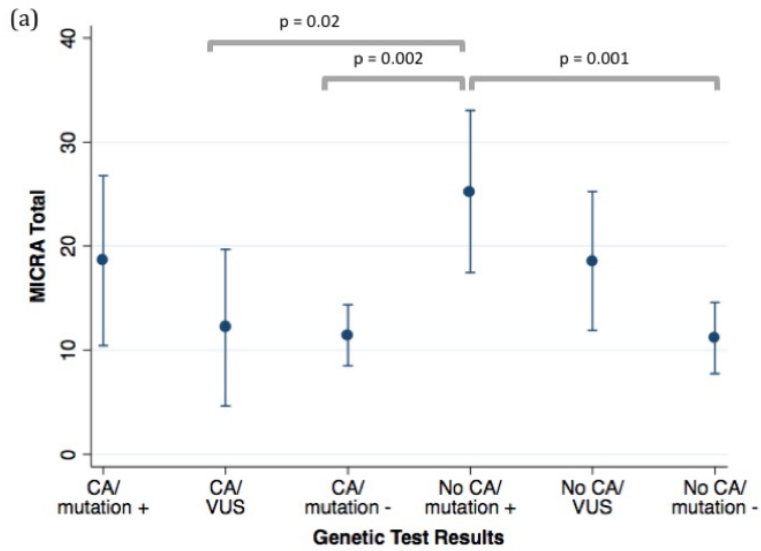
(e) Ambiguity tolerance

	Constant	Coefficient for AT-20 (SE)	p value
IES, total	4.9	-0.29 (0.21)	0.18
IES, intrusion	0.18	-0.01 (0.01)	0.25
IES, avoidance	0.36	-0.02 (0.01)	0.10
IES, hyperarousal	0	0 (0.004)	1.00
MICRA, distress	0	0 (0.04)	1.00
MICRA, uncertainty	3	0 (0.13)	1.00
MICRA, positive experience	2.75	0.25 (0.21)	0.24
MICRA Total	11.3	0.14 (0.30)	0.64
SWD	21.3	0.22 (0.15)	0.14

(f) Genetics knowledge

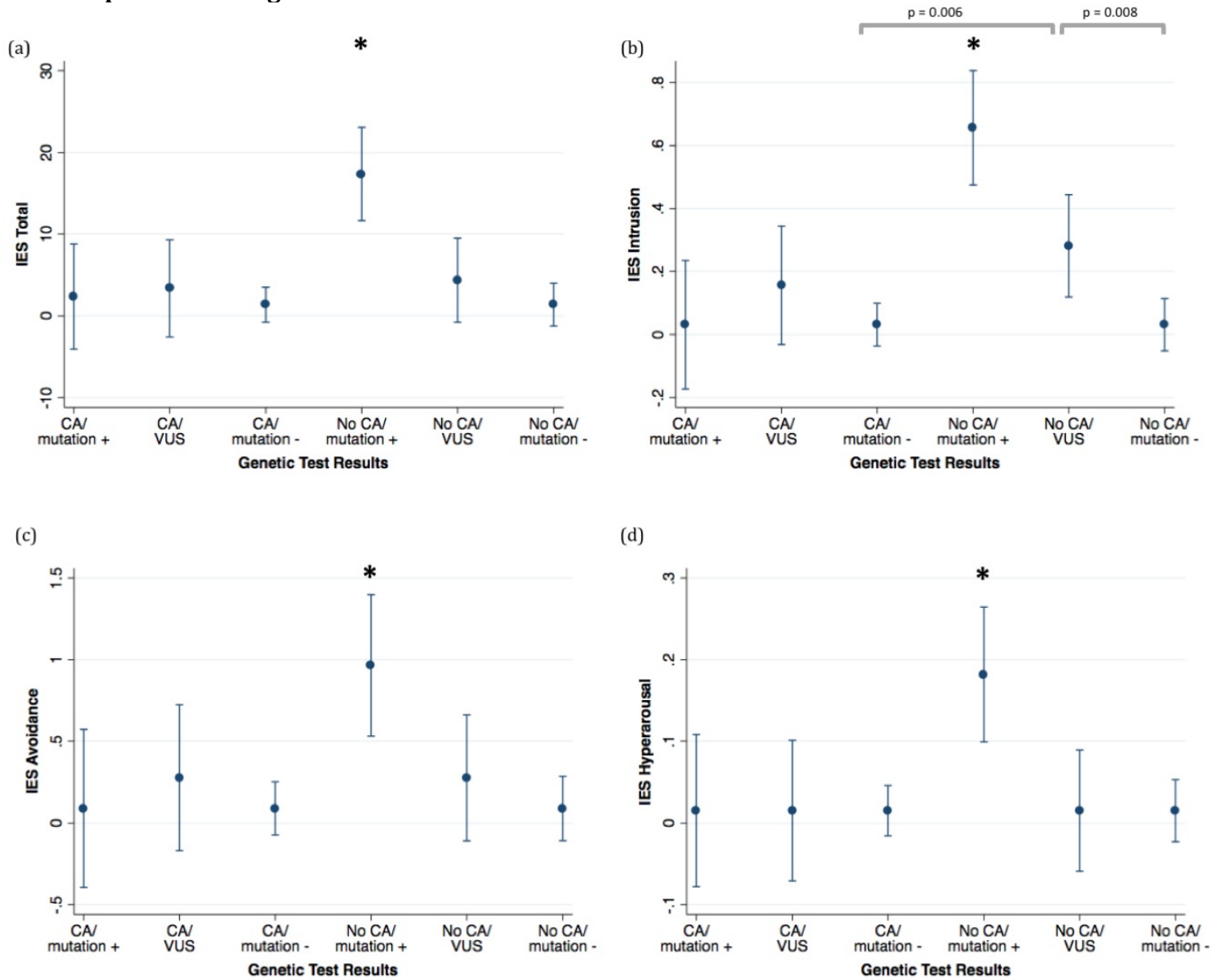
	Constant	Coefficient for genetics knowledge (SE)	p value
IES, total	7.7	-0.07 (0.05)	0.20
IES, intrusion	0	0 (0.002)	1.00
IES, avoidance	0.83	-0.008 (0.004)	0.03
IES, hyperarousal	0	0 (0.0005)	1.00
MICRA, distress	0	0 (0.01)	1.00
MICRA, uncertainty	0.5	0.025 (0.03)	0.44
MICRA, positive experience	3.6	0.014 (0.07)	0.80
MICRA Total	15.8	-0.0375 (0.08)	0.62
SWD	16.2	0.086 (0.03)	0.01

Figure 1S. Estimates for median MICRA total, distress, positive experience, and uncertainty scores by genetic test results based on multiple median regression models



* Significantly greater than all other groups

Figure 2S. Estimates for median Impact of Event Scale total, intrusion, avoidance, and hyperarousal scores by genetic test results based on multiple median regression models



* Significantly greater than all other groups

Study ID: _____

IMPACT OF GENE PANEL TESTING FOR BREAST CANCER

Thank you for agreeing to participate in our study on the impact of genetic testing for breast cancer. Completing this questionnaire should take between 20-30 minutes. **All your answers will be completely confidential. Your responses will not affect your clinical care.** Before you begin, please review the instructions below.

INSTRUCTIONS

Please only fill out this survey if you have a diagnosis of breast cancer or if you have a family history of breast cancer.

- **Do not** write your name anywhere on the questionnaire.
- Cross out completely any answer you wish to change.
- You may choose not to provide a response for any question that you do not wish to answer.
- If you have any questions, please call 212-305-5077 to speak to our project staff.

For most questions, you'll answer by marking the checkbox that corresponds to your answer choice.

What is your gender?

- Male
 Female

For some questions, you'll circle the number that corresponds to your answer choice.

I am satisfied with my decision

1 2 **3** 4

For other questions, there may be follow-up questions depending on your answer. Please make sure to answer these.

What effect do you think this had?

- It brought us closer
 It drove us apart

If so, what effect do you think this had?

- I am not sure _____

1. What is your date of birth? ___/___/___ (Month/Day/Year)

2. What is your gender?

- Male
- Female

3. Are you of Hispanic, Latino or Spanish origin?

- Yes
- No

4. Which of the following best describes your race? Select one or more responses.

- White
- Black or African American
- Asian or Pacific Islander
- American Indian or Alaska Native
- Other race (specify): _____

5. What is your marital status?

- Never married
- Married or living as married with partner
- Married, not living together
- Separated
- Divorced
- Widowed

6. In what country were you born?

- U.S.A.
- Another country: _____

7. In what country was your mother born?

- U.S.A.
- Another country: _____

8. In what country was your father born?

- U.S.A.
- Another country: _____

9. From what countries did your ancestors come? _____

10. What is the highest level of education you completed?

- None
- Some grade school (grades 1 to 7)
- Grade school graduate (grade 8)
- Some high school (grade 9-12)
- High school graduate or GED
- Post high school training other than college (vocational, technical, etc.)
- Some college or associate's degree
- College graduate
- Master's degree /some graduate degree
- Doctoral degree

11. Which one of the following best describes your current main daily activities and/or responsibilities?

- Employed full-time (including full-time self-employment)
- Working for wages or salary part-time (including part-time self-employment)
- Unemployed or laid off
- Keeping house or raising children full-time
- Retired
- Temporarily disabled
- Permanently disabled
- Other (specify: _____)

12. Have you ever had breast cancer (now or in the past)?

- I have had breast cancer
- I have never had breast cancer

13. Have you ever been diagnosed with another type of cancer besides breast cancer?

- Yes (Please specify. If you are not sure, please write "unsure.")

- No

14. If you have a diagnosis of breast cancer, at what age were you diagnosed with breast cancer? If you are not sure, please write "unsure."

15. Do you have a family history of breast cancer in blood relatives?

- Yes, I have family members with breast cancer
- No, I do not have family members with breast cancer
- I am not sure if I have family members with breast cancer

16. Has anyone in your family died due to breast cancer?

- Yes, I have family members who have died from breast cancer
- No, I do not have family members who have died from breast cancer
- I am not sure if I have family members who have died from breast cancer

17. Have you had genetic testing for breast cancer?

- Yes, I had genetic testing for breast cancer
- No, I did not have genetic testing breast cancer
- I am not sure whether I had genetic testing for breast cancer

Please answer questions 18-20 **only** if you have had breast cancer **and** had genetic testing

18. Did you have genetic testing performed before or after you were diagnosed with breast cancer?

- Genetic testing was performed before I was diagnosed with breast cancer
- Genetic testing was performed after I was diagnosed with breast cancer

19. What do you understand the results of your genetic testing to be?

- Positive genetic test results. The genetic mutation that caused my breast cancer was identified.
- Negative genetic test results. No genetic mutation was identified, but there still could be a genetic mutation that caused my breast cancer.
- Negative genetic test results. No genetic mutation was identified, which means my breast cancer was not caused by a genetic mutation.
- A variant of uncertain significant (VUS) was identified
- A genetic mutation that causes a different type of cancer was identified
- My test results are not clear to me.

20. Did your genetic test results play a role in your decision to do any of the following?

Type of surgery to treat breast cancer (mastectomy versus lumpectomy)	No	Yes
Receive radiation for breast cancer	No	Yes
Receive chemotherapy for breast cancer	No	Yes
Receive another type of treatment for breast cancer	No	Yes
Change treatment for breast cancer	No	Yes
Stop treatment for breast cancer	No	Yes
Have prophylactic surgery	No	Yes
Receive a drug to prevent breast cancer	No	Yes
Have more frequent or additional cancer screening	No	Yes

If you answered yes to any of these statements, please explain why and how.

Please fill out questions 21 and 22 **only** if you have **not** had breast cancer **and** had genetic testing

21. What do you understand the results of your genetic testing to be?

- Positive genetic test results. A genetic mutation was identified and therefore, I will develop breast cancer.
- Positive genetic test results. A genetic mutation was identified and therefore, I have an increased chance of developing breast cancer.
- Negative genetic test results. No genetic mutation was identified and therefore, I will not develop breast cancer.
- Negative genetic test results. No genetic mutation was identified and therefore, I am less likely to develop breast cancer.
- Negative genetic test results. No genetic mutation was identified, and these results give me no information about my risk for developing breast cancer.
- A variant of uncertain significant (VUS) was identified.
- A genetic mutation that causes a different type of cancer was identified.
- My test results are not clear to me.

22. Did your genetic test results play a role in your decision to do any of the following?

Have prophylactic surgery	No	Yes
Receive a drug to prevent breast cancer	No	Yes
Have more frequent or additional cancer screening	No	Yes

If you answered yes to any of these statements, please explain why and how.

23. When deciding whether to undergo genetic testing, were you given various options to have different numbers of genes tested for hereditary breast cancer?

- Yes
- No
- I do not remember/I do not know

24. If you were given various options to have different numbers of genes tested for hereditary breast cancer, were you sufficiently informed about the pros and cons of the options?

- No, the pros and cons of these options were not discussed.
- No, the pros and cons of these options were discussed, but I did not understand this information.
- Yes, the pros and cons of these options were discussed and I was given sufficient information to understand the issues.
- Yes, the pros and cons of these options were discussed and I understood what they meant, but more information would have been helpful.
- I am not sure if I felt sufficiently informed.

25. When deciding whether to undergo genetic testing, were you informed about the possibility of identifying variants of uncertain significance (VUS)?

- Yes, I was informed about the possibility of identifying VUS and understood what that meant
- Yes, I was informed about the possibility of identifying VUS and but it was not clear what that meant
- No, I was not informed about the possibility of identifying VUS before I underwent genetic testing but was after I received my results
- No, I was never informed about the possibility of identifying VUS
- I am not sure if I was informed about the possibility of identifying VUS

26. How did you weigh the possibility of identifying genetic variants of uncertain significance (VUS)?

- I would like to know more information about my genes, even if it is unclear what to do with that information.
- I do not like the uncertainty of knowing information when it is unclear what to do with that information.
- I am not sure how I weighed the possibility of identifying variants of uncertain significance (VUS).
- I was unaware about the possibility of identifying variants of uncertain significance (VUS).

27. Would you have preferred having more time to make the decision about how many genes to test for hereditary breast cancer and possibly discuss your options with others?

- Yes
- No
- I do not remember/I do not know

28. Who helped you to make your decision about how many genes to be tested for hereditary breast cancer? (Select one or more responses)

- My oncologist
- My surgeon
- My primary care doctor
- Other doctors
- My genetic counselor
- My children
- My significant other
- Other family members
- Friends
- Nobody
- I was not given various options to have different numbers of genes tested for hereditary breast cancer
- Other (please specify): _____

Please answer questions 29-39 **only** if you had genetic testing.

29. Approximately how many genes were you tested for?

- Two genes (BRCA1 and BRCA2)
- Small panel of 5 genes
- Medium panel of ~11 genes
- Large panel of ~25 genes
- One specific mutation that runs in my family
- I am not sure how many genes I was tested for

30. Did you feel sufficiently informed when you underwent genetic testing for breast cancer?

- No, I did not realize I was having genetic testing performed
- No, I was told I was having genetic testing, but I didn't understand what that specifically meant.
- Yes, I was told I was having genetic testing and was given sufficient information to understand what that meant.
- Yes, I was told I was having genetic testing and understood what that meant, but more information would have been helpful.
- I am not sure if I felt sufficiently informed.

31. If you had genetic testing and know the results, do you feel you understand what these results mean?

- Yes
- No
- I had genetic testing, but I do not know the results

32. Have you contacted a genetic counselor again since receiving your genetic test results?

- Yes, and I found this helpful
- Yes, but I did not find this helpful
- No, I did not feel that I needed to
- No, but I would like to
- I do not remember if I contacted a genetic counselor again since receiving my genetic test results

33. The questions below are about some specific responses you may have had after receiving your genetic test results. Please indicate if, within the last week, you have experienced each emotion never, rarely, sometimes or often, by circling the number corresponding to your answer in the columns next to each symptom.

Symptoms in the last week	Never	Rarely	Sometimes	Often
Feeling upset about my test result	1	2	3	4
Feeling sad about my test result	1	2	3	4
Feeling anxious or nervous about my test result	1	2	3	4
Feeling guilty about my test result	1	2	3	4
Feeling relieved about my test result	1	2	3	4
Feeling happy about my test result	1	2	3	4
Feeling a loss of control	1	2	3	4
Having problems enjoying life because of my test result	1	2	3	4
Worrying about my risk of getting breast cancer	1	2	3	4
Having difficulty making decisions about breast cancer screening or prevention (e.g., having preventive surgery or getting medical tests done)	1	2	3	4
Understanding clearly my choices for breast cancer prevention or early detection	1	2	3	4
Feeling frustrated that there are no definite breast cancer prevention guidelines for me	1	2	3	4
Thinking about my test results has affected my work or family life.	1	2	3	4

Symptoms in the last week	Never	Rarely	Sometimes	Often
Feeling concerned about how my test results will affect my insurance status	1	2	3	4
Having difficulty talking about my test results with family members	1	2	3	4
Feeling that my family has been supportive during the genetic counseling and testing process	1	2	3	4
Feeling satisfied with family communication about my genetic test result	1	2	3	4
Worrying that the genetic counseling and testing process has brought about conflict within my family	1	2	3	4
Feeling regret about getting my test results	1	2	3	4
Worrying about the possibility of my child(ren) getting breast cancer (Please answer, regardless of your test result, if you have children)	1	2	3	4
Feeling guilty about possibly passing on the disease risk to my child(ren) (Please answer, regardless of your test result, if you have children)	1	2	3	4
Feeling that the genetic test result has made it harder to cope with my breast cancer (Please answer, if you have breast cancer or have had it in the past)	1	2	3	4
Feeling that the genetic test result has made it easier to cope with my breast cancer (Please answer, if you have breast cancer or have had it in the past)	1	2	3	4

34. Have you experienced discrimination in any of the following ways following genetic testing? (Select one or more responses)

- People changing the way they feel about me and interact with me
- Problems with life insurance
- Problems with long-term care insurance
- Problems with disability insurance
- Problems with disability claim
- Someone accessing my genetic information without my permission
- Problems with work
- Being fired from a job
- Being denied a job
- Being denied a promotion
- Denial of a house or apartment for rental
- Denial of a mortgage

35. With whom did you share your results? (Select one or more responses)

- My oncologist
- My primary care doctor
- Other doctors
- My parents
- My brothers/sisters
- My aunts/uncles
- My nieces/nephews
- My cousins
- My grandparents
- My children
- My significant other
- Friends
- Nobody
- Other (please specify): _____

36. If you shared your genetic test results with your family, what was their initial response to your results? (Select one or more responses)

- Sad
- Happy
- Relieved
- Anxious
- Concerned
- Confused
- Ambivalent (didn't care either way)
- Angry
- Other (please specify): _____

37. If you shared your genetic test results with your family, over time, have their feelings changed?

- Yes, they feel better about the information I shared with them
- Yes, they feel worse about the information I shared with them
- No, they feel the same about the information I shared with them
- I am not sure

38. If genetic testing was performed, what effect do you think this had on the family?

- I am not sure
 - Having genetic testing did not change our family dynamic
 - It brought the family members closer together
 - It was disruptive to the family
- If having genetic testing performed was disruptive, please explain what specific issues arose within the family following genetic testing:
-

39. Did you hide your genetic test results from anyone due to fear of discrimination?

- No
 - Yes
- If so, from whom? _____

40. As far as you know, are there any laws that protect you from discrimination based on genetic test results?

- Yes
- No
- Not sure

41. Have you worried about experiencing discrimination in any of the following ways following genetic testing? (Select one or more responses)

- People changing the way they feel about me and interact with me
- Problems with life insurance
- Problems with long-term care insurance
- Problems with disability insurance
- Problems with disability claim
- Someone accessing my genetic information without my permission
- Problems with work
- Being fired from a job
- Being denied a job
- Being denied a promotion
- Denial of a house or apartment for rental
- Denial of a mortgage

42. Did/would your genetic test results play a role in your decision to change your job?

- No
- Yes

If yes, why and how? _____

43. Did/would your genetic test results play a role in your decision to move to another state or country?

- No
- Yes

If yes, why and how? _____

44. Did/would your genetic test results play a role in your decision to get married?

- No
- Yes

If yes, why and how? _____

45. Did/would your genetic test results play a role in your decision to get divorced?

- No
- Yes

If yes, why and how? _____

46. Did/would your genetic test results play a role in your decision to have a biological child?

- No
- Yes

If yes, why and how? _____

47. Did/would your genetic test results play a role in your decision to adopt a child?

- No
- Yes

If yes, why and how? _____

48. Did/would your genetic test results play a role in your decision to consider retiring?

- No
- Yes

If yes, why and how? _____

49. Did/would your genetic test results play a role in your decision to buy new or more life insurance?

- No
- Yes

If yes, why and how? _____

50. Did/would your genetic test results play a role in your decision to buy new or more disability insurance?

- No
- Yes

If yes, why and how? _____

51. Below is a list of difficulties people sometimes have after certain life events. Please read each item and then indicate how distressing each difficulty has been for you since you've had genetic testing by circling the corresponding number.

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Any reminder brought back feelings about it	1	2	3	4	5
I had trouble staying asleep	1	2	3	4	5
Other things kept making me think about it	1	2	3	4	5
I felt irritable and angry	1	2	3	4	5
I avoided letting myself get upset when I thought about it or was reminded of it	1	2	3	4	5
I thought about it when I didn't mean to	1	2	3	4	5
I felt as if it hadn't happened or wasn't real	1	2	3	4	5
I stayed away from reminders of it	1	2	3	4	5
Pictures about it popped into my mind	1	2	3	4	5
I was jumpy and easily startled	1	2	3	4	5
I tried not to think of it	1	2	3	4	5
I was aware that I still had a lot of feelings about it, but I didn't deal with them	1	2	3	4	5
My feelings about it were kind of numb	1	2	3	4	5
I found myself acting or feeling like I was back at that time	1	2	3	4	5
I had trouble falling asleep	1	2	3	4	5
I had waves of strong feelings about it	1	2	3	4	5
I tried to remove it from my memory	1	2	3	4	5
I had trouble concentrating	1	2	3	4	5

Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart	1	2	3	4	5
I had dreams about it	1	2	3	4	5
I felt watchful and on-guard	1	2	3	4	5
I tried not to talk about it	1	2	3	4	5

52. Use the following scale to answer questions referring to your decision to pursue OR NOT pursue genetic testing.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I am satisfied that I am adequately informed about the issues important to my decision	1	2	3	4	5
The decision I made was the best decision possible for me personally	1	2	3	4	5
I am satisfied that my decision was consistent with my personal values	1	2	3	4	5
I am satisfied that this was my decision to make	1	2	3	4	5
I am satisfied with my decision	1	2	3	4	5

53. Please indicate whether the following statements are true or false.

A gene is a piece of DNA	True	False
There are genes that affect intelligence	True	False
Genes are the only determinants of intelligence	True	False
If close relatives have diabetes, you are more likely to have diabetes	True	False
An individual with a mutation in a cardiac disease gene, he/she may never develop cardiac disease	True	False
Healthy parents can have a child with a hereditary condition.	True	False
A deaf couple could have a hearing child.	True	False
Children of a woman with a mutation in a gene will always inherit the mutation.	True	False
A father can pass down a mutation in a breast cancer gene to his daughters.	True	False
A mutation in a gene may not cause disease until later in adult life.	True	False

54. Please do not spend too much time on the following items. There are no right or wrong answers and therefore your first response is important. Circle True or False for each statement below. Be sure to answer every question.

A problem has little attraction for me if I don't think it has a solution.	True	False
I am just a little uncomfortable with people unless I feel that I can understand their behavior.	True	False
There's a right way and a wrong way to do almost everything.	True	False
I would rather bet 1 to 6 on a long shot than 3 to 1 on a probable winner.	True	False
The way to understand complex problems is to be concerned with their larger aspects instead of breaking them into smaller pieces.	True	False
I get pretty anxious when I'm in a social situation over which I have no control.	True	False
Practically every problem has a solution.	True	False
It bothers me when I am unable to follow another person's train of thought.	True	False
I have always felt that there is a clear difference between right and wrong.	True	False
It bothers me when I don't know how other people react to me.	True	False
Nothing gets accomplished in this world unless you stick to some basic rules.	True	False
Vague and impressionistic pictures really have little appeal for me.	True	False
Were I a scientist, it would bother me that my work would never be completed (because science will always make new discoveries).	True	False
If I were a doctor, I would prefer the uncertainties of a psychiatrist to the clear and definite work of someone like a surgeon or x-ray specialist.	True	False
Before an examination, I feel much less anxious if I know how many questions there will be.	True	False
The best part of working a jigsaw puzzle is putting in that last piece.	True	False
Sometimes I rather enjoy going against the rules and doing things I'm not supposed to do.	True	False
I don't like to work on a problem unless there is a possibility of coming out with a clear-cut and unambiguous answer.	True	False
I like to fool around with new ideas, even if they turn out later to be a total waste of time.	True	False
Perfect balance is the essence of all good composition.	True	False

55. Please add any additional comments or concerns you have about your health or genetic testing in the space below.

56. Would you be willing to speak with us about your experience with genetic testing?

- Yes
- No

If yes, please provide your contact information.

Telephone: _____

Email: _____

Thank you for taking the time to complete this questionnaire. Your participation is very much appreciated.