#### **Before We Get Started**

### We value your response EVEN IF you did NOT receive BRCA testing

#### **Directions:**

counseling

requirement

Ordered

Taken

Thank you for your help with this survey. Please select **one answer choice** for each question unless the question indicates **Mark all that apply**.

As a token of appreciation, you will be entered into a drawing for an iPad mini once you return this survey **BY MARCH 1, 2016**. In addition, if you are one of the first 1,000 survey participants to return this survey, you will be mailed or emailed a \$15 gift card from below. You will be unable to change your selection after you return this survey. These gifts are only available with the return of this mailed survey.

Please pick ONE:  □ \$15 Amazon Gift Card □ \$15 Target Gift Card □ \$15 Barnes and Noble Gift Card
Address or email address you wish your gift card sent to:
Email:
Address:
Definitions:
<b>BRCA Test Definition</b> : Genetic test to see if you have any mutations in your BRCA1 or BRCA2 genes
<b>Genetic Counselor Definition</b> : A licensed professional other than your doctor that discusses your genetic history and risks of possessing mutations.
Process Timeline:
Pre-genetic counseling requirement  Counseling requirement  BRCA Test Sample → BRCA Test Run → Results Delivered
Post-genetic DDCA Toot Comple Constite DDCA Toot DDCA Toot

Counselor

Run

**Results Delivered** 

#### **About You**

- 1. Gender
  - o Male
  - o Female
- 2. Ethnicity
  - Caucasian
  - o Hispanic/Latino
  - o Black or African American
  - o Native American
  - o Asian/Pacific Islander
  - o Other
- 3. Age Range
  - o 18-25 years old
  - o 26-35 years old
  - o 36-45 years old
  - o 46-55 years old
  - o 56-65 years old
  - o 66+ years old
- 4. What category best describes your annual household income?
  - o Less than \$24,999
  - o \$25,000 to \$49,999
  - o \$50,000 to \$99,999
  - o \$100,00 or more
- 5. How would you rate your current health?
  - Excellent
  - Very Good
  - o Good
  - o Poor
- 6. At the time you or your physician were considering BRCA testing, were you diagnosed with breast, ovarian, both, or other cancer?
  - o Breast
  - o Ovarian
  - o Both breast and ovarian
  - Other cancer
  - Cancer free (no cancer)
- 7. At the time of testing, were any of your family members diagnosed with breast, ovarian, both, or other cancer?
  - o Breast
  - o Ovarian
  - Both breast and ovarian
  - Other cancer
  - Cancer free (no cancer)

#### **BRCA Testing Process and Prior Genetic Counseling Questions** 8. Did you or your doctor request BRCA genetic testing? Myself Doctor Neither Other 9. If recommended by your doctor or healthcare provider, what was the reason you were told that this test was being recommended? (Mark all that apply) ☐ To help plan cancer treatment ☐ To help plan cancer screening ☐ To determine risks for family members ☐ Because mutations are a common cause of breast cancer ☐ Curiosity ☐ Because all women should be tested ☐ No reason was given ☐ I don't recall 10. Did you give a sample (blood or mucosal wash) to be tested for a BRCA mutation? No 0 o Unknown 11. At the time you or your doctor requested testing did your health plan require genetic counseling before BRCA testing? o Yes **If Yes**, how did you find out about the genetic counseling requirement? Doctor Health Insurance Plan Genetic Testing Laboratory o Unknown Other\_\_ $\circ$ No Unknown 12. Did you receive genetic counseling from a licensed provider (not your doctor) prior to BRCA testing? (more answer choices on next page) o Yes **If Yes**, why did you receive genetic counseling? (Mark all that apply) ☐ Insurance requirement ☐ Benefit to family's future

☐ Recommended by doctor or health care provider

☐ Chance to better understand the test results or appropriateness of testing

☐ Recommended by family member

□ Other\_\_\_\_\_

If Yes, I understand the circumstances that brought me to genetic counseling.								
o Do not agree								
<ul> <li>Somewhat agree</li> </ul>								
<ul> <li>Completely agree</li> </ul>								
<ul> <li>Do not know</li> </ul>								
o No								
If No, why did you NOT receive genetic counseling? (Mark all that apply)								
☐ Time restraints								
☐ Logistic Concerns (Transportation, Daycare)								
☐ Anxiety/emotions regarding meeting								
☐ Insurance issues/requirements								
☐ Cost of appointment								
☐ Discouraged by family member								
☐ Was not aware genetic counseling was available or an option								
☐ Inconvenience of an additional step								
☐ Not interested in pursing								
☐ Not important enough								
□ Other								
o Unknown								

## **BRCA testing results**

- 13. Did you complete BRCA genetic testing?
  - o Yes Go to Page 5
  - o No Go to Page 6

## If you completed BRCA genetic testing (Please complete if you answered YES to Question 13, go to page 6 if you answered NO to Question 13)

14. Do you recall receiving your BRCA genetic testing results?							
o Yes							
o No							
15. What were your BRCA test results?							
<ul> <li>A mutation was found</li> </ul>							
<ul> <li>No mutation was found</li> </ul>							
<ul> <li>The result was uncertain</li> </ul>							
<ul> <li>I do not understand my results</li> </ul>							
o Unknown							
16. Did you receive genetic counseling after testing to discuss your BRCA test results?							
o Yes							
o No							
17. Who all discussed the BRCA test results with you? (Mark all that apply)							
□ Doctor							
□ Nurse							
☐ Genetic counselor							
☐ Other Health Care Provider (Nurse practitioner, Physician's Asst., etc., Medical Assistant)							
□ Other							
□ Don't recall							
18. Have you used the information from your genetic testing in any of the following ways? (Mark							
all that apply)							
☐ The test result helped me plan my cancer treatment							
☐ Based on my test result, I had surgery to remove my breasts or ovaries to prevent cancer							
from developing							
☐ Based on my test result, it is appropriate for me to have routine breast cancer screening							
(annual mammogram and clinical breast exam for women age 40 and over)							
☐ Based on my test result, my risk for breast cancer is increased and additional breast							
cancer screening with breast MRI is appropriate							
☐ I have talked to my family members about my test result							
☐ Other ways you have used the information:							
19. Do you feel like you made an informed choice about BRCA testing? ( <b>Choose one</b> )							
Do Not Know							
Refuse to Answer							
Strongly Disagree Disagree Neither Disagree Agree Strongly Agree							
Strongly Disagree Disagree Neither Disagree Agree Strongly Agree  nor Agree							

# If you did not complete BRCA genetic testing (Please complete if you answered NO to Question 13, skip if you answered YES to Question 13)

20. Why d	id you <b>NOT</b> 1	undergo BRCA	testing (Mark all	that apply)					
	Costs								
	Testing not recommended by Genetic Counselor								
	1 Testing recommended for another family member								
	Did that	family membe	er get tested? Cir	cle your answer:	Yes	No			
	A different g	genetic test wa	s recommended						
	Did you	receive those t	esting results? <b>C</b>	ircle your answer	: Yes	No			
	☐ Concerns about the emotional consequences of the BRCA results								
☐ I learned that the likelihood of having a BRCA mutation in my family was low, and I									
		to have testing	_	J	,	,			
	·								
☐ Confused as to why I needed the test and/or didn't understand implications of the test									
	Other	, to why i need	ca the test and, of	ardir t direct staria	ппрпса	cions of the test			
		 ng was not a re	auirement would	you still like to kn	ow vour	test results?			
0	Yes	ig was not a re	quirement, would	you sem me to kin	ow your	test results.			
0	No								
0	Undecided								
•		u made an info	rmed choice abou	t BRCA testing? ( <b>Cl</b>	10060 01	na)			
22. D0 y0t	i ieei iike yot								
Ļ	J	Ļ	Ļ	닏	ļ.	Do Not Know OR			
-						Refuse to Answer			
Strongly D	)isagree	Disagree	Neither Disagree	Agree	Strongly A	Agree			
		2.346.44	nor Agree	J					
23. Do you	need more	advice and info	ormation about yo	our cho <u>ice</u> s for BRC	A testing	g? (Choose one)			
	]					Do Not Know			
Ī	_	T	T	T	T	<b>OR</b> Refuse to Answer			
Γ									
Strongly D	Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly A	\gree			
24 Would	vou liko to r	rocojvo accieta	<u> </u>	etic counseling reso	nurcoe ec	o vou could try			
	ng genetic te		nce in midnig gen	etic counseling rest	Jui ces sc	you could try			
pursur	Yes	estilig agaili							
· ·	No								
O 25 If was		no roccona tha	t way and interpret	ad in this informati	on? (Ma	nlr all that annlr)			
25. If yes, what are some reasons that you are interested in this information? (Mark all that apply)									
☐ To help plan cancer treatment									
☐ To help plan cancer screening									
☐ To determine risks for family members									
☐ Because mutations are a common cause of breast cancer									
	Curiosity								
	Other				_				

### Complete if you ever saw a genetic counselor at any time

- 26. Did you receive a benefit from genetic counseling?
  - o Yes
  - o No
- 27. Would you recommend genetic counseling to family or friends?
  - o Yes
  - o No
- 28. Would you utilize genetic counseling in the future?
  - $\circ$  Yes
  - o No

