

## SURVEY FOR PEOPLE AT HIGH RISK FOR HEREDITARY BREAST AND GYNECOLOGIC CANCER

### Demographics

Gene: (1261 respondents)  
(people could choose all that applied)

Gene	#	%
BRCA2	408	32.3%
BRCA1	327	25.9%
CHEK2	138	10.9%
ATM	115	9.1%
PALB2	104	8.2%
Lynch genes	92	7.3%
BRIP1	23	1.8%
RAD51C	23	1.8%
RAD51D	14	1.1%
TP53	13	1.0%
BARD1	12	1.0%
CDH1	8	0.6%
PTEN	5	0.4%
Multiple genes*	78	6.2%

\*Note: people who indicated multiple genes are also counted included in the individual gene count.

Race/Ethnicity (1049 respondents)  
(people could choose all that applied)

Race / Ethnicity	#	%
Non-Hispanic white	980	91%
Hispanic / Latine	44	4.2%
Black / African American	20	1.9%
Asian / Asian American	16	1.5%
American Indian or Alaskan Native	13	1.2%
Middle Eastern	4	0.4%
Hawaiian / Pacific Islander	0	0%
Bi-racial, multi-racial (Write-in with no additional details)	2	0.2%

Age (1049 respondents)

Age	#	%
18-25	14	1.4%
26-30	26	2.6%
31-35	58	5.7%
36-40	112	11.0%
41-45	123	12.1%
46-50	104	10.2%
51-55	128	12.5%
56-60	120	11.8%
61-65	134	13.1%
66 or older	202	19.8%

Gender (1049 respondents)

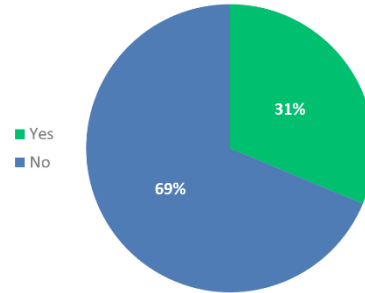
Gender	#	%
Female	1025	97.7%
Male	10	0.95%
Nonbinary, gender-fluid, gender nonconforming	11	1.05%
Prefer not to share	1	0.1%

Transgender – Yes/No (1043 respondents)

Transgender Y/N	#	%
Yes	6	0.58%
No	1034	99.1%
Prefer not to share	3	0.29%

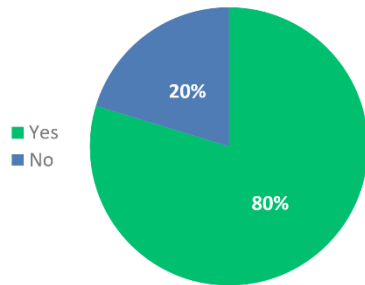
**Q: Have you ever been diagnosed with breast cancer?** (1186 respondents)

	#	%
Yes	371	31%
No	815	69%



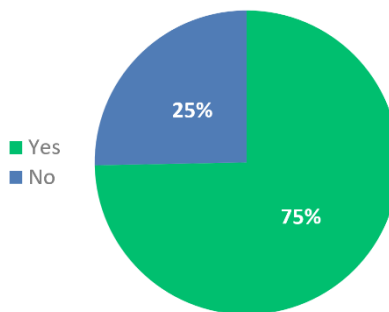
**Q: Has a doctor, nurse or other healthcare provider shown you how to check your breasts for changes and what to look for?** Results are displayed for all the individuals who indicated a mutation associated with increased risk for breast cancer. (690 respondents)

	#	%
Yes	550	80%
No	140	20%



**Q: Do you regularly check your breasts for changes?** Results are displayed for the individuals who indicated a mutation associated with increased risk for breast cancer and who have not undergone a bilateral mastectomy. (336 respondents)

	#	%
Yes	251	75%
No	85	25%



**Q. Related to breast cancer risk management, which of following types of care do you currently receive or have received in the past? (188 respondents)**

Results below are individuals who:

- a) indicated a mutation associated with increased risk for breast cancer
- b) have not had a breast cancer diagnosis
- c) have not had double mastectomies
- d) are older than 25

Type of screening	Annually or more frequently		Every 2 years or less		Received in the past but not currently		I have never received this	
	#	%	#	%	#	%	#	%
Mammogram	163	87%	4	2%	5	3%	16	9%
MRI	142	76%	7	4%	6	3%	32	17%
Clinical breast exam	159	85%	13	7%	12	6%	3	2%

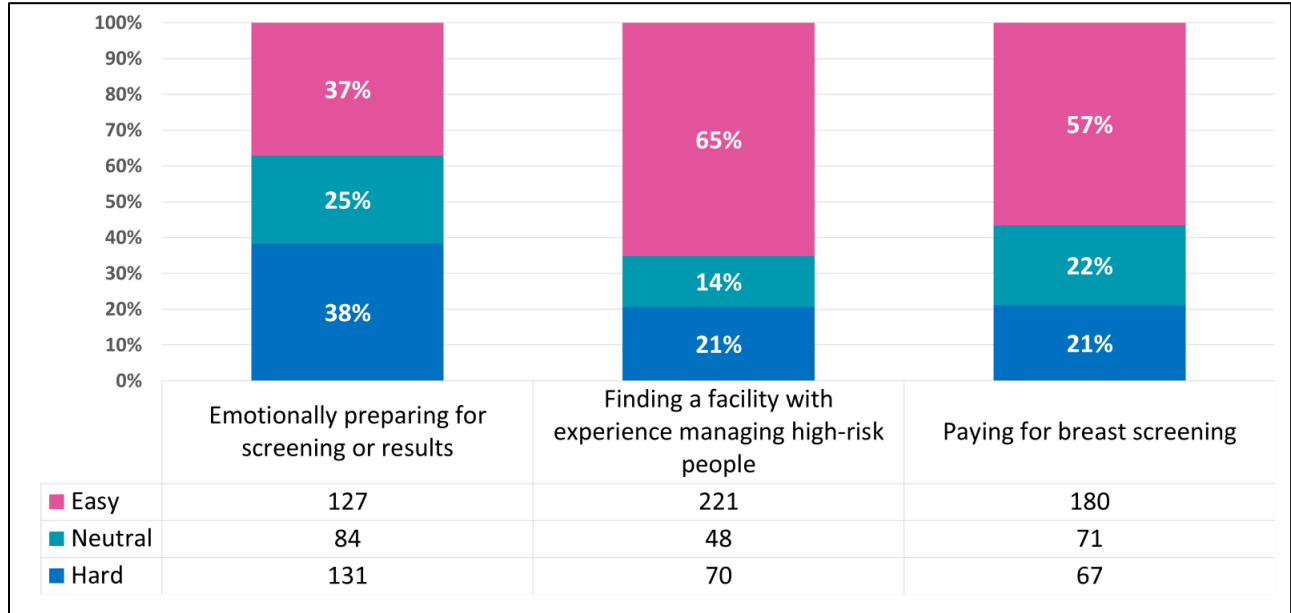
**Q. Related to breast cancer risk management, which of following types of care do you currently receive or have received in the past? (116 respondents)**

Results below are for cisgender women who:

- a) indicated a BRCA1 or BRCA2 mutation
- b) have not had a breast cancer diagnosis
- c) have not had double mastectomies
- d) are age 25 or older

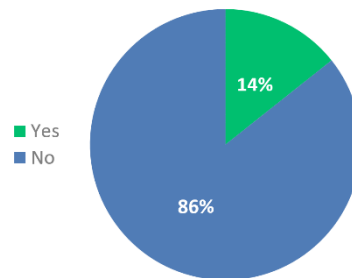
Type of screening	Annually or more frequently		Every 2 years or less		Received in the past but not currently		I have never received this	
	#	%	#	%	#	%	#	%
Mammogram	104	90%	2	2%	2	2%	8	7%
MRI	93	81%	5	4%	4	3%	13	11%
Clinical breast exam	98	85%	11	10%	6	5%	0	0%

**Q. Related to your breast cancer screening, please indicate how easy or difficult each of the following was for you.** Results below are for people who indicated they were told they were at high risk for breast cancer and had not had bilateral mastectomies. (355 respondents)



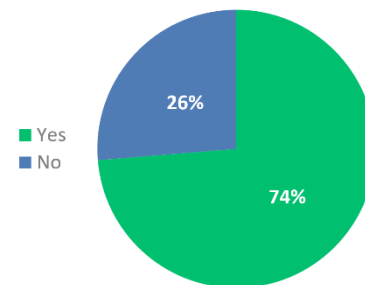
**Q. Has a doctor, nurse or other healthcare provider spoken to you about participating in research or clinical trials related to breast cancer risk management?** Results below are for people who indicated they were told they were at high risk for breast cancer and had not had bilateral mastectomies. (356 respondents)

	#	%
Yes	51	14%
No	305	86%



**Q. Are you interested in participating in research or clinical trials related to breast cancer risk management?** Results below are for people who indicated they were told they were at high risk for breast cancer and had not had bilateral mastectomies. (327 respondents)

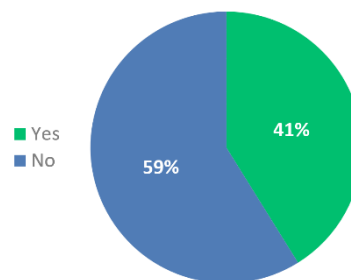
	#	%
Yes	241	74%
No	86	26%



**Q. Do you know how to find research or clinical trials related to breast cancer risk management?**

Results below are for people who indicated they were told they were at high risk for breast cancer and had not had bilateral mastectomies. (333 respondents)

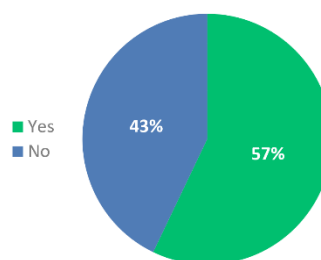
	#	%
Yes	137	41%
No	196	59%



**Q. Have you had, or are you in the process of scheduling a double mastectomy with or without reconstruction?**

Results below are individuals who indicated they tested positive for a mutation associated with increased risk for breast cancer, including people who have received a breast cancer diagnosis. (919 respondents).

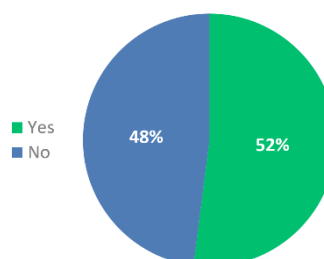
	#	%
Yes	525	57%
No	394	43%



**Q. Have you had, or are you in the process of scheduling a double mastectomy with or without reconstruction?**

Results below are individuals who indicated they tested positive for a mutation associated with increased risk for breast cancer who have never received a breast cancer diagnosis. (644 respondents).

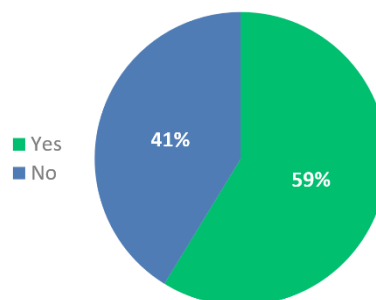
	#	%
Yes	335	52%
No	309	48%



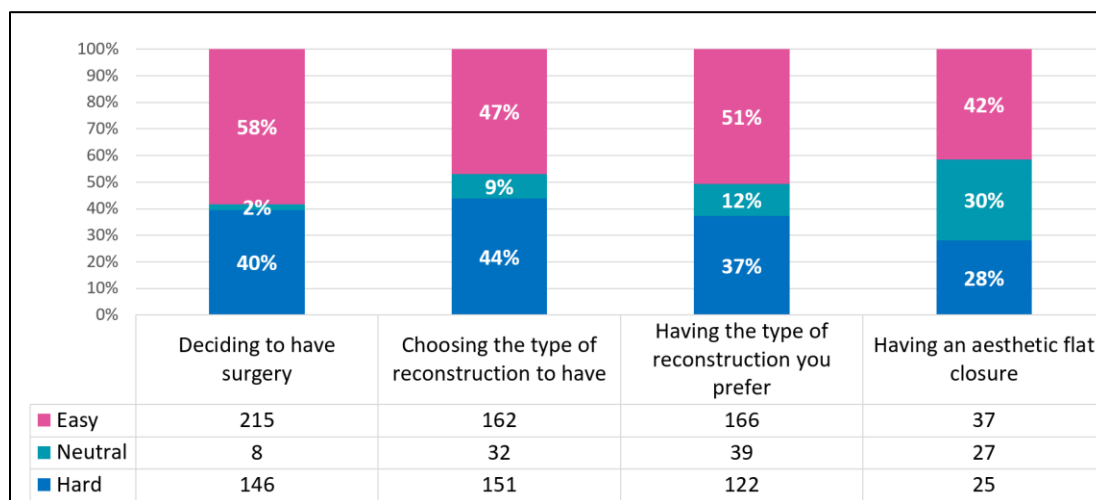
**Q. Have you had, or are you in the process of scheduling a double mastectomy with or without reconstruction?** Results below are individuals who indicated they tested positive for a mutation in BRCA1, BRCA2, CDH1, PALB2, PTEN, STK11 or TP53 who have never received a breast cancer diagnosis. (514 respondents)

Note: NCCN guidelines for the genes above recommend that doctors discuss the benefits, risks and limitations of risk-reducing mastectomy and engage in shared decision-making.

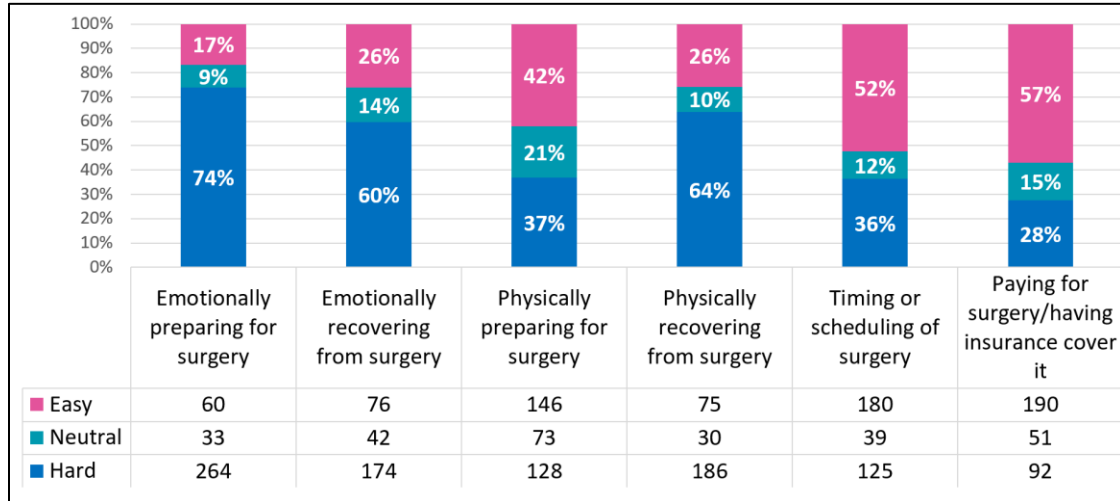
	#	%
Yes	302	59%
No	212	41%



**Q. Related to your double mastectomy with or without reconstruction, please indicate how easy or difficult each of the following was for you.** Results below are for people who had never been diagnosed with breast cancer who indicated they had or were in the process of planning a double mastectomy. (373 respondents)



**Q. Related to your double mastectomy with or without reconstruction, please indicate how easy or difficult each of the following was for you.** Results below are for people who had never been diagnosed with breast cancer who indicated they had or were in the process of planning a double mastectomy. (373 respondents)



**Q. Have you ever provided support or care for a relative with cancer??** (Results below are individuals who indicated they tested positive for a mutation associated with increased risk for cancer). (1264 respondents).

	#	%
Yes	850	67%
No	414	33%

