NEVADA BREAST CANCER NEEDS ASSESSMENT

A review of best practices and the current state of breast cancer screening barriers

UNR School of Public Health
Nevada Cancer Coalition

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Introduction

Breast cancer is the most common form of cancer in the United States, with nearly 300,000 new cancer cases expected for 2023. Given the high burden of breast cancer among women in the United States, there is a need for education, outreach, and resources that help women navigate breast cancer screening, diagnosis, and treatment to promote positive outcomes. More specifically – given that different groups of women (e.g., Black and African American women, Hispanic and Latina women, and women living in rural areas) experience different rates of breast cancer screening, incidence, and mortality due to a vast network of interconnected biological, genetic, cultural, social, and economic factors, there is desperate need for culturally competent education, outreach, and resources that are specifically targeted to individual groups of women in order to have the greatest impact.

The main aim of this project was to understand factors associated with breast cancer screening knowledge, attitudes, and behaviors among Black and African American women living in Nevada. A series of four listening tours consisting of thirty Black and African American women living in Nevada were conducted in Spring 2023 to meet this aim. A secondary aim was to also understand how certain aspects of screening knowledge, attitudes, and behaviors differ among women of different races and ethnicities, ages, and location of residence within the state. To achieve this aim, a community survey was launched in late 2022 and 586 valid responses were obtained from women living in Nevada.

The findings from the qualitative and quantitative assessments, as well as recommendations for practice, are provided in this report. It is our hope that the findings and recommendations presented in this report can be used by the Nevada Cancer Coalition and other state, local, and community-based groups to improve access to affordable and culturally competent breast cancer screening among this population.

Brief Review of Data and Literature

National Statistics

Breast cancer is the most common type of cancer in the United States, with nearly 300,000 new expected cases and over 40,000 expected deaths in 2023 among females.[1] Nearly 1 in 8 females are expected to develop breast cancer during their lifetime.[2] The age-adjusted annual incidence rate of new breast cancer diagnoses in the United States is 128.1 new cases per 100,000 population. White females have the highest incidence rate (133.7 per 100,000 population), followed by Black females (127.8 per 100,000 population), American Indian/Alaska Native females (111.3 per 100,000 population), Asian females (101.3 per 100,000 population), and

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[1] National Institutes of Health, National Cancer Institute (n.d.). Common Cancer Types. https://www.cancer.gov/types/common-cancers#:~:text=The%20most%20common%20type%20of,are%20combined%20for%20the%20list.

[2] Kaiser Family Foundation (n.d.). *Women's Health Policy*. Coverage of Breast Cancer Screening and Prevention Services. https://www.kff.org/womens-health-policy/fact-sheet/coverage-of-breast-cancer-screening-and-prevention-services/

Hispanic females (99.2 per 100,000 population).[3] The five-year relative survival rate for all women with breast cancer (of all stages) is 91%. For women with localized breast cancer, the five-year survival rate is 99%, highlighting the importance of screening and early detection. According to the Kaiser Family Foundation, differences in breast cancer mortality between white women and women of other races and ethnicities might be due to a combination of several different factors including differences in stage at diagnoses, tumor biology, genetics, and inequities in access to screening, follow up care and treatment caused by a variety of underlying factors. There are also cultural and socioeconomic factors that play an important role in screening behaviors for different groups of women.

Screening Guidelines

Several prominent organizations in the United States, including the American Cancer Society, the American College of Radiology and Society of Breast Imaging, and the American College of Obstetricians and Gynecologists, provide guidance regarding screening recommendations. However, the guidelines set forth by the United States Preventive Services Task Force (USPSTF) govern insurance coverage under the Affordable Care Act (ACA) and thus, are the guidelines typically followed by public and private insurance companies. As of early 2023, under these guidelines, insurance companies are mandated to cover the following screening and prevention services at no cost to the patient: 1) screening mammography at least every 2 years and as frequently as once a year for women ages 40 to 74 with average-risk for breast cancer; 2) genetic counseling and testing for mutation of the BRCA1 and BRCA2 genes in some women with a personal or family history of breast, ovarian, fallopian tube, or peritoneal cancer; 3) preventive medication for some women with elevated risk of breast cancer and at low risk for adverse medication effects.[4]

Screening Behaviors and Barriers

The American Cancer Society states that early detection of breast cancer and receipt of appropriate treatment as soon as possible are the most important predictors of breast cancer survival, highlighting the importance of screening.[5] Despite the widely known importance of screening and early detection, more than one-quarter of all eligible women do not follow the recommended screening guidelines.[6]

Several studies across the United States have examined factors associated with knowledge, attitudes, and barriers to breast cancer screening among women. For example, one large

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[3] American Cancer Society (n.d.). *Analysis Tool*. Incidence Rates 2015 - 2019. https://cancerstatisticscenter.cancer.org/#!/data-analysis/module/cSefQqYf?type=barGraph

[4] Kaiser Family Foundation (n.d.). *Women's Health Policy*. Coverage of Breast Cancer Screening and Prevention Services. https://www.kff.org/womens-health-policy/fact-sheet/coverage-of-breast-cancer-screening-and-prevention-services/

[5] American Cancer Society (n.d.). *Breast Cancer Early Detection and Diagnosis*. American Cancer Society Recommendations for the Early Detection of Breast Cancer. https://www.cancer.org/cancer/types/breast-cancer/screening-tests-and-early-detection/american-cancer-society-recommendations-for-the-early-detection-of-breast-cancer.html

[6] Kaiser Family Foundation (n.d.). *Women's Health Policy*. Coverage of Breast Cancer Screening and Prevention Services. https://www.kff.org/womens-health-policy/fact-sheet/coverage-of-breast-cancer-screening-and-prevention-services/

systematic review summarized the findings of breast cancer screening-related studies involving women from minority populations between 1979 and 2009. The study found that pain and embarrassment associated with screening mammography, low income and lack of health insurance, poor knowledge about breast cancer screening, lack of physician recommendation, lack of trust in hospitals and doctors, language barriers, and lack of transportation were the most frequently identified barriers for receipt of recommended screening.[7] Another systematic review focusing on studies of Hispanic and Latina women found that fear of cancer, fatalistic views on cancer, linguistic barriers, culturally based embarrassment, and low perceived risk of cancer were the most impactful factors associated with screening.[8] Furthermore, studies of Black and African American women report that cultural beliefs and norms (e.g., only going for doctor visits or checkups when very sick), pain and fear of positive test results, low perceived risk of cancer, lack of appropriate health insurance coverage, and cost of testing were all important factors associated with screening in this population.[9-10]

Collectively, these findings highlight the importance of using tailored education and outreach to improve access to appropriate screening among specific groups of women (e.g., Black and African American women or women in rural communities) rather than broad prevention strategies that target all women.

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[7] Jaffee, K., Cohen, M., Faisal, A., Adnan, H., Hiam, H., & Thompson, H. (2021). Cultural Barriers to Breast Cancer Screening and Medical Mistrust Among Arab American Women. Journal of Immigrant and Minority Health, 23(1), 95–102. https://doi.org/10.1007/s10903-020-01019-0

[8] Austin, Ahmad, F., McNally, M.-J., & Stewart, D. E. (2002). Breast and cervical cancer screening in Hispanic women: a literature review using the health belief model. Women's Health Issues, 12(3), 122–128. https://doi.org/10.1016/S1049-3867(02)00132-9

[9] Balenger, A., Seth, G., Bhattarai, S., Collin, L. J., McCullough, L., Gogineni, K., Subhedar, P., Ellison, C., Khan, U., Swahn, M. H., & Aneja, R. (2022). Barriers to breast cancer screening in Atlanta, GA: Results from the Pink Panel survey at faith-based institutions. Cancer Causes & Control, 33(12), 1465–1472. https://doi.org/10.1007/s10552-022-01631-5

[10] Obikunle, A. F., & Ade-Oshifogun, B. (2022). Perspectives of African American women about barriers to breast cancer prevention and screening practices: A qualitative study. African Journal of Reproductive Health, 26(7), 22–28. https://doi.org/10.29063/ajrh2022/v26i7.3

Evaluation of Barriers, Beliefs, and Attitudes About Breast Cancer

Listening Tours

Methods

A total of 35 Black or African American people participated in four listening tours about breast cancer screening across Nevada in early 2023. Three listening tours were conducted in Southern Nevada, and one was conducted in Northern Nevada. The three Southern Nevada listening tours were conducted at separate locations in collaboration with Black and African American community health workers (CHW). The CHWs recruited participants and secured a location for the in-person listening tour. The Northern Nevada listening tour was conducted in partnership with Black Wall Street, who assisted with participant recruitment.

The listening tours were facilitated by a public health outreach specialist from the UNR School of Public Health. The facilitator utilized a semi-structured interview guide to lead each listening tour. The semi-structured guide (see Appendix 1) was developed by the UNR School of Public Health and was revised based on feedback from the Nevada Cancer Coalition, the Nevada Breast Cancer Collaborative, and other members of the UNR School of Public Health team with prior experience conducting listening tours. Listening tour participants were shown breast cancer screening campaign materials from the following CDC website and were asked to provide feedback on the materials and suggestions for improving the materials:
https://www.cdc.gov/cancer/breast/resources/print.htm.

Each listening tour lasted between one and two hours and the audio from each listening tour was recorded and auto transcribed. A condensed thematic analysis was conducted to identify key themes that emerged from the listening tour discussion. A summary of key findings is presented below.

Results

Participant Characteristics

Characteristics of the 35 listening tour participants are presented in Table 1 below. Nearly two-thirds of participants (65.7%) were 40 years of age or older and most (85.7%) participants were either single or married/living with a partner. Focus group participants had diverse financial situations with roughly similar proportions of participants reporting that they live comfortably, meet their needs with a little left over, just meet basic needs, or do not meet basic needs. All but one participant had some form of health insurance coverage and about half of participants (51.7%) see their provider more than once per year. Almost two-thirds of participants (63.6%) reported a family history of cancer. About 60% of women had ever received a mammogram, and among those women, a majority had their last mammogram within the past year.

Table 1. Characteristics of breast cancer screening listening tour participants.

Characteristic	N	%
Age		
18 – 39 years old	12	34.3%
40 – 49 years old	10	28.6%
50 – 59 years old	7	20.0%
60 – 69 years old	4	11.4%
70 – 79 years old	2	5.7%
Marital Status		
Single	14	40.0%
Married/Living with partner	16	45.7%
Separated/Divorced	4	11.4%
Widowed	1	2.9%
Educational Attainment		
HS diploma or equivalent	7	20.0%
Some college/trade school	14	40.0%
College degree	14	40.0%
Current Financial Situation		
Live comfortably	9	25.7%
Meet needs with little left over	10	28.6%
Just meet basic expenses	9	25.7%
Don’t meet basic expenses	7	20.0%
Health insurance coverage		
Yes	34	97.1%
No	1	2.9%
Frequency of visits with healthcare provider		
Once every few years	9	25.7%
Once per year	7	20.0%
More than once per year	18	51.4%
Don’t have a healthcare provider	1	2.9%
Ever diagnosed with cancer		
Yes	2	5.9%
No	32	94.1%
Family history of cancer		
Yes	21	63.6%
No	10	30.3%
Don’t know	2	6.1%
Date of last mammogram		
3 or more years ago	3	9.7%
1 – 2 years ago	5	16.1%
Within the last year	10	32.3%
Never received a mammogram	13	41.9%

Note: One participant did not complete the pre-survey at all and several only partially completed the pre-survey.

Knowledge, Behaviors, Attitudes, Perceptions about Breast Cancer Screening

In the beginning portion of the listening tours, the facilitator guided participants through a series of questions regarding their knowledge, behaviors, attitudes, and perceptions about breast cancer screening. A summary of the main findings is presented below.

Knowledge

Importance of self examination

Women were generally knowledgeable about the importance of routine self-checks. Participants discussed the importance of reminders (e.g., shower calendar). Education and reminders from family/friends was frequently brought up as the best way to maximize participation in routine self-examinations. Participants with a family history of cancer, and especially breast cancer, were more knowledgeable about screening for those who have family history.

Screening guidelines

Most participants were generally knowledgeable about screening guidelines and recommendations. Participants also discussed differences in recommendations for those with a family history of those considered high-risk. It is important to note that most participants had health insurance coverage a majority had seen their provider within the past year. This may not be true for the entire underlying population of Black and African American women in Nevada.

Breast density

Knowledge about breast density varied greatly. Some women were very knowledgeable about breast density while other participants had not really heard of breast density before. This may be an important area for targeted education in future outreach.

Screening attitudes, barriers, and facilitators

Trust with provider

In general, those who regularly visited their provider reported more regular mammograms. Participants discussed the importance of having a relationship with a provider they trust. In Northern Nevada, participants highlighted the need for more Black and African American providers.

Fears

Participants discussed several aspects of fear related to receiving mammography results, uncomfortability of getting a mammogram, exposure to radiation during a mammogram, and the cost of mammograms and potential treatment if cancer is detected.

Family history

Participants with a family history were more likely to follow screening guidelines and recommendations and to receive screening on time.

Ease of access

Easy access to screening was discussed as an important facilitator for screening. Participants mentioned that the more difficult it is for people to access screening, the less likely they are to do it.

Access to care

Access to care, including both having health insurance and have a reliable and trusworthy provider, was consistently brought up as a barrier to screening. Participants provided personal anecdotes about members of their community without health insurance coverage who will only seek any form of care when absolutely needed.

Improve screening engagement

Participants discussed possible ideas for improving screening that were generally focused on reducing barriers. Participants recommended continued and increased use of mobile outreach vans to offer services in convenient locations, such as job sites, churches and faith-based institutitons, and community centers. Participants also suggested hosting community events specifically for Black women and providing child care. Participants also described the importance of also providing education and resources for men so that they can talk with their partners about screening.

Factors influencing risk perceptions

Family history

Participants with a family history of cancer generally felt that they had an increased risk of developing cancer. This was also associated with a better understanding of screening guidelines and high levels of knowledge about breast cancer. Some participants with no family history of cancer felt like they weren't really at risk.

Environmental factors

Participants listed their diet, chemicals and additivies in various food and cosmetic products, and exposures to certain chemicals and things in the environment as things that may affect their risk of developing cancer.

Health status

Participants in good health reported very low risk perceptions and less engagement with a provider (i.e., healthy participants didn't feel the need to regularly see their provider or to be screened).

Religion and faith

Participants who were religious discussed the impact of God on their risk and specifically mentioned God's will (i.e. participants felt that whether or not they developed cancer is in God's hands). One participant also described a belief in generational curses (i.e. family history of cancer).

Race

In one listening tour, participants discussed misconceptions in the Black and African community that breast cancer is a disease that primarily affects white women.

Centers for Disease Control and Prevention (CDC) Breast Cancer Screening Awareness Materials

Listening tour participants were shown breast cancer screening campaign materials from the following CDC website and were asked to provide feedback on the materials and suggestions for improving the materials: https://www.cdc.gov/cancer/breast/resources/print.htm. Below is a summary of the main preliminary takeaways about the materials.

Inclusivity

Participants brought up the fact that the materials were obviously very focused on women and suggested either having specific materials for men, or making the materials more inclusive. Participants suggested that this may help to educate men about talking with their partner. Participants also suggested including a variety of different types of Black and African American women, as they noticed that most women in all materials had a very similar skin tone.

Call to Action

On these print materials, the phone number was positively received and was identified as easy to see and a simple call to action. Further, the family pictures were positively received and participants reported that these images reminded them of their kids and grandkids and viewed this as a strong call to action.

Overall Thoughts and Opinions

Participants had several general suggestions to improve upon these materials. Participants felt that minimal text is a good thing and many participants were turned off by one of the graphics that contained a lot of words and information. Even though the quality of the information was great, it was viewed as too much for one graphic. For most of the simpler graphics, the captions positively received and were described by participants and simple and to the point. Participants did mention that future designs should be more considerate of the font style and should avoid cursive when possible, as these fonts on CDC materials reminded participants of fragrance and body works ads.

Breast Cancer Screening Campaign Design and Outreach Events

Participants were asked to describe how they would design a breast cancer screening campaign or an outreach event. A summary of preliminary findings is described below.

Outreach Events

Participants expressed the importance of making events fun and offer incentives to attend and also expressed importance of offering things to keep kids and other family members entertained. One group suggested that events can combine breast cancer screening for women with other services for men and provide childcare or activities for children and can offer food and beverages to incentivize attendance. Participants suggest that door-to-door canvassing and use of trusted figures in the community (e.g., community health workers) can provide a stronger connection with community. In general, participants felt that future events should be marketed better to those who may benefit from the event, as a lot of people who show up to health events are the ones who don't need it the most. One suggestion was to do events in partnership with employers, making it easier for people to attend while at work, and to involve breast cancer survivors to share their stories.

Materials

In regard to the design of future materials, participants strongly recommended that material be kept simple and minimal and that important details can be linked on a website/phone number on flyer. Participants recommended the use of quotes and slogans that are eye-catching and that designers pay attention to font style and text size. Participants strongly recommend utilizing families in images and having short sentences/bullets. Finally, participants recommended including Black doctors and providers in messaging and to involve breast cancer survivors whenever possible.

Limitations

The listening tours had several limitations that are important to note. First, there is potential for reporting and recall bias. However, this potential bias is minimized given the anonymous nature of the listening tours. Participants were asked to use an alias rather than their real name and only the audio was recorded. Further, participants were recruited by Black and African American CHWs and an agency that serves this community. The CHWs and a member of the agency attended the listening tour to assist in building trust and creating a safe space. A second limitation is that due to participants connection to a CHW, it is possible they are more educated on health-related matters than average people in their community. A third limitation is that nearly all participants had some form of health insurance coverage. However, when providing responses to the question prompts and engaging in discussion, participants were also asked to describe knowledge, attitudes, and behaviors from the members of their community and not just their individual experiences.

Survey

Methods

The Nevada Breast Cancer Community Survey was designed to supplement the qualitative data collected from the listening tours and to gain a broader understanding of breast cancer related knowledge, behaviors, and risk perceptions among adults living in Nevada. The survey instrument was developed by the UNR School of Public Health team and thorough feedback was provided by the Nevada Cancer Coalition and the Nevada Breast Cancer Collaborative (see Appendix 2).

Data were collected using Qualtrics, an online survey management software, between November 2022 and May 2023. All adults living in Nevada were eligible to participate and a total of 913 survey responses were submitted during the data collection period. After a thorough data cleaning process, a final dataset of 586 adult women living in Nevada was used for analysis in this report. A complete flow chart of the data cleaning process is shown in Figure 1 below.

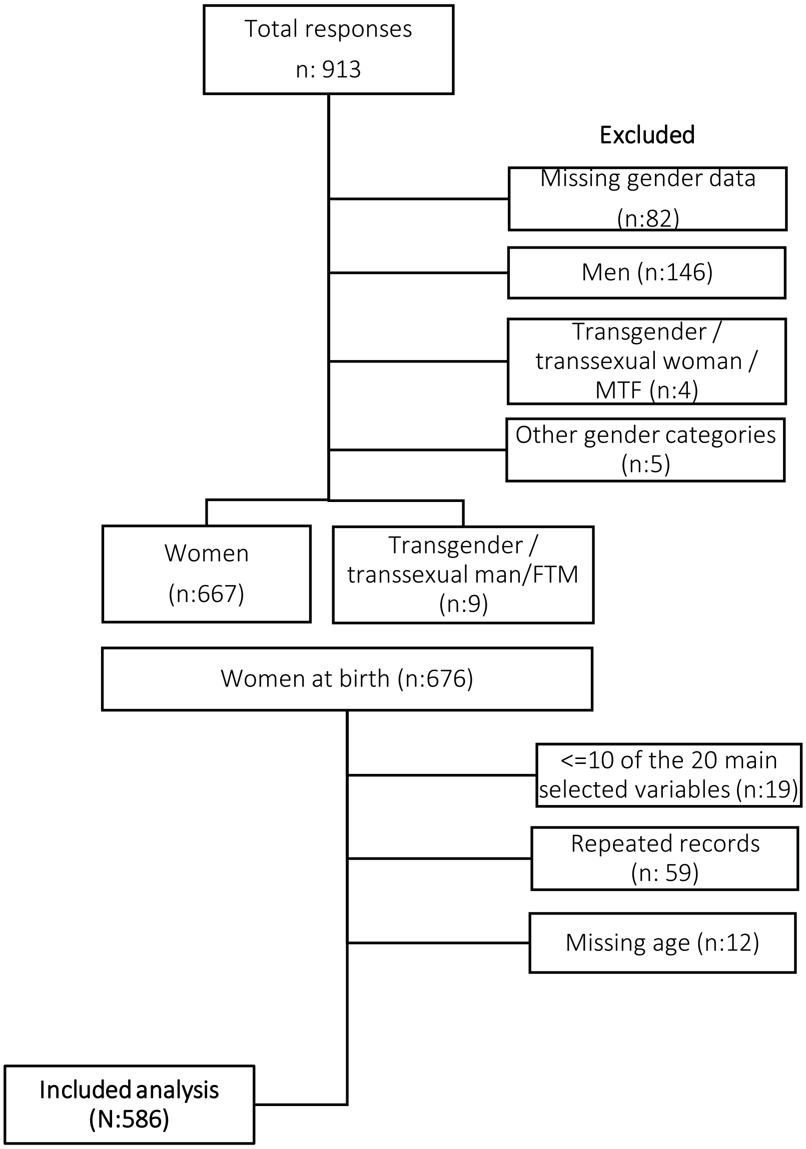


Figure 1. Nevada Breast Cancer Community Survey – Data cleaning flowchart.

Results

Participant Characteristics

As shown in Table 2, more than two-thirds of participants (68.4%) were between ages 18 and 40, while the remaining participants were 40 or older (30.9%). A majority of participants were white (67.7%), followed by Native American or Alaska Native (11.4%), Hispanic or Latina (10.6%) and Black or African American (6.0%). A majority of participants were married (73.2%) and over one-third had a bachelor's degree or higher (38.4%).

Table 2. Age groups, race/ethnicity, relationship status and education of survey participants.

Variable	Categories	Frequency (N)	Percentage (%)
Age groups	18 to 29	166	28.3%
	30 to 39	235	40.1%
	40 to 49	75	12.8%
	50 to 74	106	18.1%
	>=75	4	0.7%
Race and Ethnicity	White	397	67.7%
	Native American or Alaska Native	67	11.4%
	Hispanic or Latina	62	10.6%
	Black or African American	35	6.0%
	Asian	9	1.5%
	Native Hawaiian or Pacific Islander	8	1.4%
	Other	3	0.5%
Relationship status	Married	429	73.2%
	Single	76	13%
	Non-marital partner	27	4.6%
	Separated/Divorced	28	4.8%
	Widowed	6	1.0%
	Missing	20	3.4%
Education	Never attended school or only attended kindergarten	2	0.3%
	Elementary/Middle School (Grades 1 through 8)	8	1.4%
	Some high school (Grades 9 through 11)	36	6.1%
	High school graduate (Grade 12 or GED)	71	12.1%
	Some college (College 1 to 3 years)	167	28.5%
	Associate's degree or technical/trade school	57	9.7%
	College graduate (Bachelor's degree)	133	22.7%
	Graduate or professional degree	92	15.7%
	Missing	20	3.4%

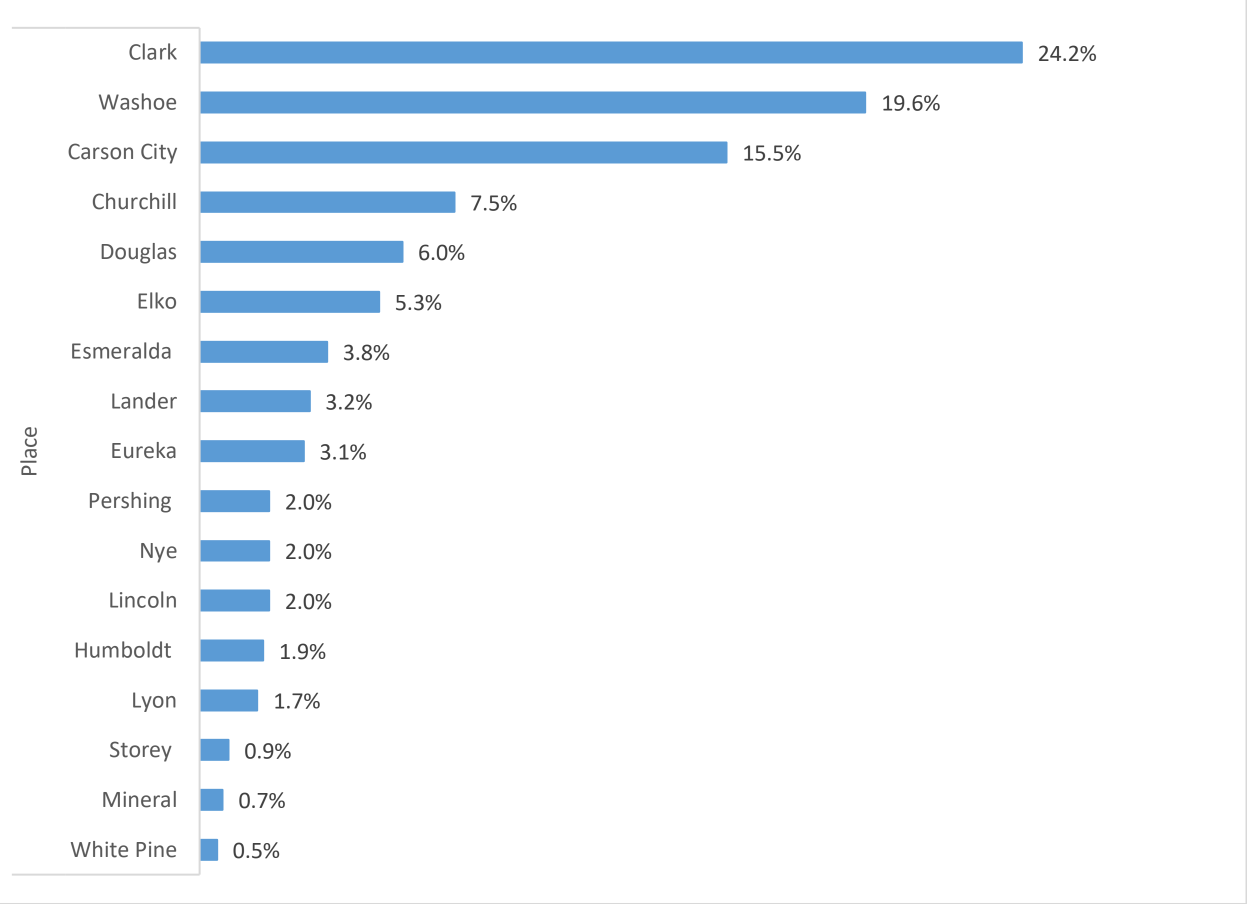


Figure 2. County of residence of survey participants.

As shown in Figure 2, 59.3% of participants were from Carson City, Clark, and Washoe counties. The remaining 40.7% of participants were from rural areas of the state, led by Churchill (7.5%), Douglas (6.0%), and Elko (5.3%) counties. Overall, representation from rural areas of the state was high, which was a desired aim for the community survey.

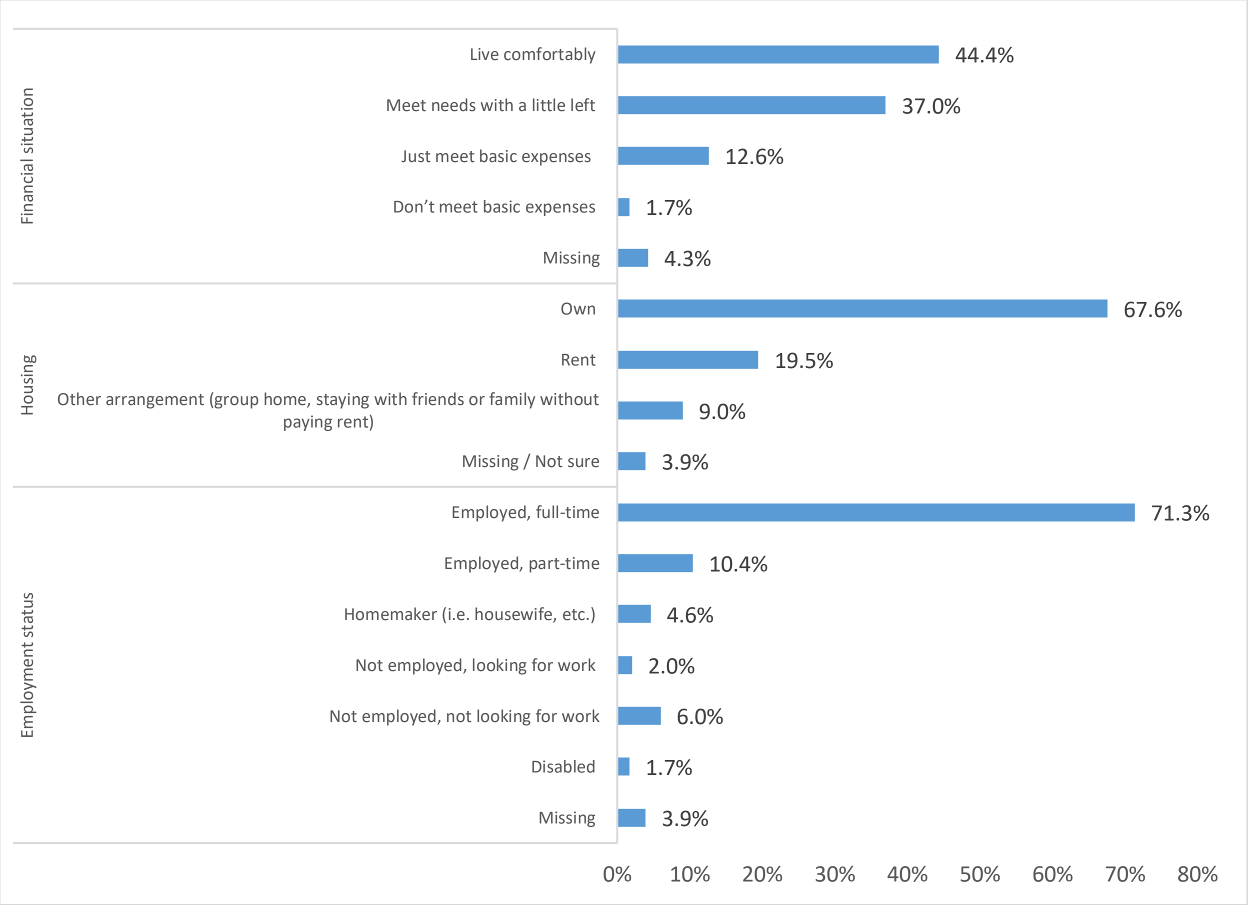


Figure 3. Financial situation, housing, and employment status of survey participants.

In regard to the financial situation of participants, most participants (81.4%) either live comfortably or meet their needs with a little money left over. Around 15% of participants either just meet their basic needs or do not meet their basic needs. A majority of participants were employed full-time (71.3%), while 10.4% worked part-time, and 6.0% were not employed and not looking for work. Just over two-thirds of participants (67.6%) owned a home, while 19.5% rented and 9.0% had another living arrangement (e.g., staying with family or friends without paying rent).

Prevalence of Breast Cancer Screenings

Participants reported a high prevalence of having ever a completed a breast self-examination (88.7%) and receiving a mammogram (80.5%) in their lifetime. On the other hand, about one of ten participants (9.9%) have never performed a breast self-examination and about one of six (17.4%) have never had a mammogram (Figure 4).

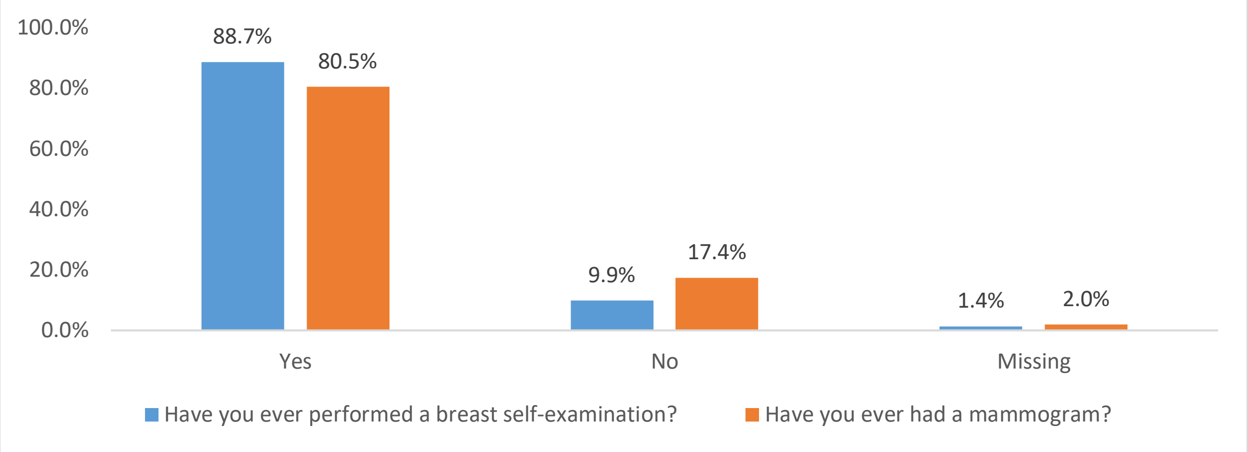


Figure 4. The prevalence of having ever a breast self-examination and a mammogram among survey participants.

Breast self-examination

Table 3 below shows the prevalence of breast self-examination by various sociodemographic indicators. There were no significant differences in the prevalence of breast self-examination by age, race and ethnicity, relationship status, education, financial situation, and resident's location. However, participants who were employed full-time reported higher self-examination compared to women with other types of jobs. Further, participants who rented accommodations reported a lower prevalence of breast self-examination compared to those who own a home and those living in a group home or staying with friends or family without paying rent and non-response.

Table 3. Associations between sociodemographic characteristics and breast self-examination among survey participants.

		Have you ever performed a breast self-examination?					
		Yes		No		Total	
		N	**%**	**N**	**%**	**N**	**%**
Age groups	<40 years old	361	90.0%	40	10.0%	401	100.0%
	40 years and older	159	85.9%	26	14.1%	185	100.0%
Race and ethnicity	White	355	89.4%	42	10.6%	397	100.0%
	Non-white	165	87.3%	24	12.7%	189	100.0%
Relationship status	Single, separated, divorced, widowed	94	85.5%	16	14.5%	110	100.0%
	Married, non-marital partner	407	89.3%	49	10.7%	4516	100.0%
Education	Less than college	124	90.5%	13	9.5%	137	100.0%
	Some college and higher	396	88.2%	53	11.8%	449	100.0%
Financial situation	Live comfortably	233	89.6%	27	10.4%	260	100.0%
	Meet needs with a little left	189	87.1%	28	12.9%	217	100.0%
	Just meet basic expenses or don't meet	75	89.3%	9	10.7%	84	100.0%
Housing	Own	359	90.7%	37	9.3%	396	100.0%
	Rent	90	78.9%	24	21.1%	114	100.0%
	All other and missing	52	94.5%	3	5.5%	55	100.0%
Employment status	Full time employed	384	91.9%	34	8.1%	418	100.0%
	All others	136	81.0%	32	19.0%	168	100.0%
Location	Urban (Clark and Washoe)	230	89.5%	27	10.5%	257	100.0%
	Rural (Other counties)	290	88.1%	39	11.9%	329	100.0%

Mammogram

There were more differences in the prevalence of ever having a mammogram between sociodemographic groups, as shown in Table 4 below. While the prevalence of having a mammogram increased with age, this was not a significant difference in this dataset. The percentage of women who ever had a mammogram was lower for non-white race and ethnicity (compared to white group), single, separated, divorced, and widowed women (compared to married or non-marital relationship), and in women living in urban counties (compared to rural counties). Further, the prevalence of having received a mammogram was higher rates among women with higher socioeconomic status measured by living comfortably and home ownership.

Table 4. Associations between sociodemographic characteristics and receipt of a mammogram among survey participants.

		Have you ever had a mammogram?					
		Yes		No		Total	
		N	**%**	**N**	**%**	**N**	**%**
Age groups	<40 years old	316	78.8%	85	21.2%	401	100.0%
	40 years and older	156	84.3%	29	15.7%	185	100.0%
Race and ethnicity	White	342	86.1%	55	13.9%	397	100.0%
	Non-white	130	68.8%	59	31.2%	189	100.0%
Relationship status	Single, separated, divorced, widowed	72	65.5%	38	34.5%	110	100.0%
	Married, non-marital partner	382	83.8%	74	16.2%	456	100.0%
Education	Less than college	110	80.3%	27	19.7%	137	100.0%
	Some college and higher	362	80.6%	87	19.4%	449	100.0%
Financial situation	Live comfortably	219	84.2%	41	15.8%	260	100.0%
	Meet needs with a little left	168	77.4%	49	22.6%	217	100.0%
	Just meet basic expenses or don't meet	63	75.0%	21	25.0%	84	100.0%
Housing	Own	334	84.3%	62	15.7%	396	100.0%
	Rent	77	67.5%	37	32.5%	114	100.0%
	All other and missing	43	78.2%	12	21.8%	55	
Employment status	Full time employed	341	81.6%	77	18.4%	418	100.0%
	All others	131	78.0%	37	22.0%	168	100.0%
Location	Urban (Clark and Washoe)	191	74.3%	66	25.7%	257	100.0%
	Rural (Other counties)	281	85.4%	48	14.6%	329	100.0%

Table 5 shows the prevalence of various reasons for not having received a mammogram. Among participants who had never had a mammogram, the most common reasons for never having received a mammogram was "feeling too young for a mammogram." However, all but one of these participants were below recommended screening age. Other common reasons for not having received a mammogram included not feeling at risk for breast cancer (23.7%), fear of getting a mammogram (22.8%), and fear of knowing if they have breast cancer (21.9%). Barriers related to never having received a mammogram included not having time to go to the doctor (28.1%) and not being able to afford the cost of a mammogram (17.5%). The respondents who reported that they couldn't get mammogram due to not affording the cost are mostly non-white (14 participants of 20), and difficulty in terms of financial situation. Of the 114 respondents who never had a mammogram, 45 (39.5%) reported at least one barrier of those mentioned above. Of those 45 respondents, 37 reported only one barrier, 6 reported two barriers, and 2 reported three barriers.

Table 5. Reasons for never having received a mammogram (among survey participants who never had a mammogram.

Reasons for not having received a mammogram.	N	%	
I feel that I am too young for a mammogram [1]	45	39.5%	Reasons related to awareness
I don't think that I am at risk for breast cancer [3]	27	23.7%	
I am afraid of getting a mammogram	26	22.8%	
I am afraid to know if I have breast cancer	25	21.9%	
No time to go to the doctor [2]	32	28.1%	Barriers
I can't afford the cost of a mammogram [4]	20	17.5%	
The distance to doctor's office is too far	3	2.6%	
Don't know / Not sure	9	7.9%	
Total (women who have never had mammogram)	114	100.0	

[1] Of those 45 respondents, 1 (2.2%) was in the 40-49 age group.

[2] Of those 32 respondents, 23 (71.9%) were married or in a non-marital partnership; 15 (46.9%) were worked full-time and 8 (25.0%) worked part-time.

[3] Of those 27 respondents, 1 (3.7%) was in the 40-49 age group.

[4] Of those 20 respondents, 6 (30.0%) were White, 14 (70.0%) non-White; 8 (40.0%) just met or didn't meet basic needs regarding their financial situation.

Influences On Having a Mammogram

Among the 472 participants who had ever had a mammogram, the most common influence or motivation to get a mammogram was encouragement by family or friends, while the second most common influence or motivations was having the mammogram scheduled by their doctor (Table 6).

Table 6. Influences and motivations for receiving a mammogram (among survey participants who had received a mammogram).

Influences and motivations for receiving a mammogram	N	%
All participants (n:472)		
Family member, friend encourage you to get screened	189	40.0%
Scheduled by your doctor	110	23.3%
Messages on social media, internet, etc.	56	11.9%
Messages through TV or radio	21	4.4%
Receiving a reminder card in the mail	18	3.8%
Someone you know has cancer	31	6.6%
I don’t need any reminder	45	9.5%
Missing	2	0.4%
All participants who have ever had mammogram	472	100.0%

Interestingly, the main sources of influence and motivation differed by age (Figure 7). While more than half of younger participants reported a motivation or influence being encouragement from family or friends, participants who were 40 and older mostly reported scheduling by doctor (32.7%) and not needing any reminder (28.2%). It is also noteworthy that the younger respondents reported higher rates of influence and motivation from social media. This is important for building the programs for young women awareness of breast cancer screening.

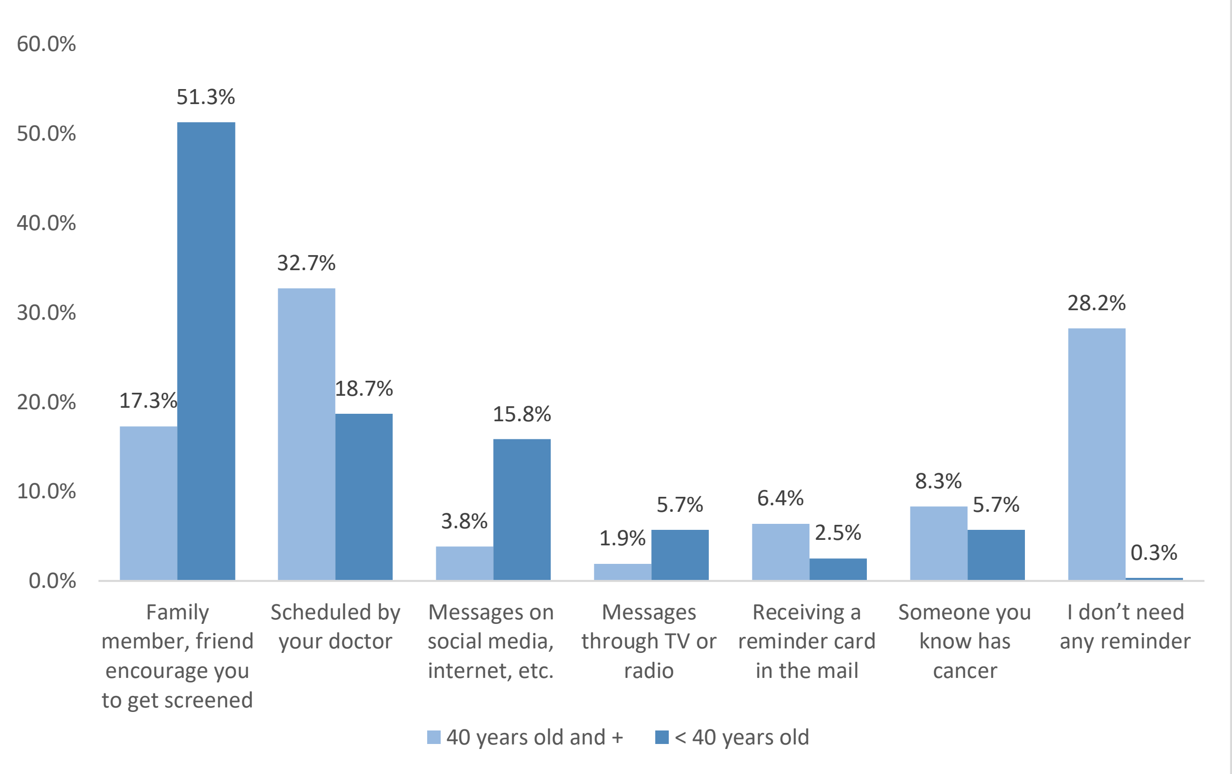


Figure 5. The influences and motivational sources for getting a mammogram among survey participants, by age.

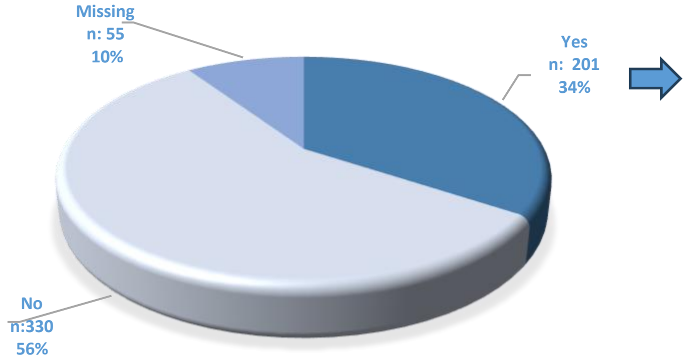
Table 7 shows the sources of reminders and encouragement for receiving a mammogram among survey participants aged 40 and older. The most common source of reminders and encouragement was health care providers (48.6%), followed by friends (25.9%), parents (25.9%), spouse (20.0%), sibling (14.6%), and child (5.4%). Among women aged 40 and older who had received a mammogram, encouragement from a health care provider was the most common source (93.3%), followed by friends (87.5%).

Table 7. Sources of reminders and encouragement for mammograms among survey participants aged 40 and older.

Has anyone around you ever reminded or encouraged you to get a mammogram?	All women aged 40+		Received Mammogram (+)		Never Received Mammogram (-)	
	N	%	N	%	N	%
Yes, health care provider	90	48.6%	84	93.3%	6	6.7%
Yes, friend	48	25.9%	42	87.5%	6	12.5%
Yes, parent	48	25.9%	36	75.0%	12	25.0%
Yes, spouse	37	20.0%	26	70.3%	11	29.7%
Yes, sibling	27	14.6%	22	81.5%	5	18.5%
Yes, child	10	5.4%	8	80.0%	2	20.0%
No / Don’t know / Not sure	26	15.2%	20	83.3%	4	16.7%

Mammograms and Cancer Risk in the Family

Family history of cancer is one of the important risk factors for of various cancer types – especially breast, uterine, and colon cancers.[11] Among survey participants, 34% reported a history of some type of cancer in their family. The most reported cancer history was breast cancer (23.5%). Among these women, 40.6% reported a history of breast cancer from their grandmother, 37.0% from their mother, 30.4% from their aunt, 18.8% from their sister, 2.9% from their cousin/niece, and 0.7% from their daughter.



Types of cancer	N	%
Breast	138	23.5%
Colon /colorectal	36	6.1%
Respiratory system	34	5.8%
Cervical	30	5.1%
Prostate	24	4.1%
Ovarian	17	2.9%
Bladder	13	2.2%
Leukemia	11	1.9%
Liver and stomach	11	1.9%
Pancreatic	10	1.7%
Endometrial	8	1.4%
Kidney	3	0.5%
Thyroid	3	0.5%
Other types	10	1.7%

Figure 6. History of cancer in the family and types of cancer among survey participants.

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[11] Centers for Disease Control and Prevention (n.d.). *Risk Factors and Cancer*. Family Health History and Cancer. https://www.cdc.gov/cancer/family-health-history/index.htm

Among participants, having any type of cancer family history, and specifically breast cancer, was not significant in terms of predicting whether a participants had a mammogram, although the rate of mammogram is slightly higher in case of positive breast cancer history in the family (Table 8). When analyzing data from women who had never received a mammogram despite having breast cancer family history, these participants were younger, mostly non-white, single (divorced, widowed), employed other than full-time (unemployed, part-time worker, housemaker), and living in urban area.

Table 8. Prevalence of having received a mammogram by family cancer history among survey participants.

		Received Mammogram					
	History of cancer in the family	Yes		No		Total	
		N	%	N	%	N	%
Any type of cancer	Cancer history	198	77.3%	58	22.7%	256	100.0%
	No cancer history	274	83.4%	56	16.6%	385	100.0%
Breast cancer	Cancer history	102	73.9%	36	26.1%	138	100.0%
	No cancer history	370	82.6%	78	17.4%	448	100.0%

Having Mammogram and Access to Health Care

In the community survey, the prevalence of having received a mammogram did not significantly differ by the type of health insurance, although the participants who don't have any form of health insurance reported lower rates of having received a mammogram (Table 9).

Table 9. The prevalence of having received a mammogram by type of health insurance among survey participants.

		Received a Mammogram					
		Yes		No		Total	
		N	%	N	%	N	%
Type of health insurance	No health insurance coverage	18	78.3%	5	21.7%	23	100.0%
	Insurance through current employer	171	77.7%	49	22.3%	220	100.0%
	Medicaid and Medicare	207	83.1%	42	16.9%	249	100.0%
	Other	70	80.5%	17	19.5%	87	100.0%

Despite of having health insurance, having a personal doctor, OB/GYN or health care provider was associated with the prevalence of participants who had received a mammogram. This finding, in conjunction with results presented in previous sections, highlights the importance of health care providers in improving rates of breast cancer screenings.

Table 10. The prevalence of having received a mammogram by having a personal doctor or health care provider among survey participants.

		Mammogram					
		Yes		No		Total	
		N	%	N	%	N	%
Personal doctor or health care provider	Yes	263	85.1%	46	14.9%	309	100.0%
	No	209	75.5%	68	24.5%	277	100.0%
Gynecologist and/or an OBGYN	Yes	240	84.5%	43	15.2%	283	100.0%
	No	232	76.6%	71	23.4%	303	100.0%

Participants were asked to identify any unmet health care needs, as this is an important element related to accessing adequate health care. Figure 7 shows the unmet health needs of the respondents in the past 12 months for any type of reason. Among all reasons of unmet need, not having time to go to a doctor was rated the most common reason (24.9%), followed by fear of results (22.2%), cost of seeing a doctor (16.0%), fear of seeing a doctor (13.8%), distance to doctor's office (7.0%), not trusting doctors (3.1%), and cultural or language barriers (2.4%).

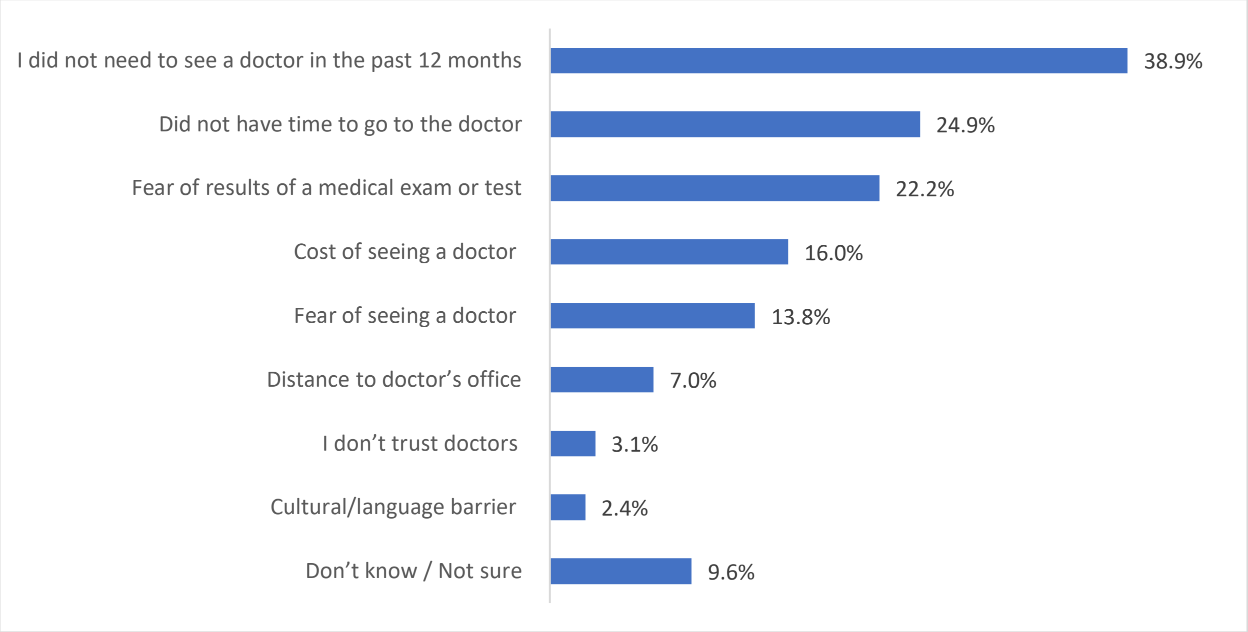

Figure 7. The frequency of the reasons for not seeing a doctor or provider when needed among survey participants.

The relationship between reasons for not seeing a doctor or provider when needed and having received a mammogram are presented in Table 11. The prevalence of having received a mammogram was lower than the average (80.5% in overall) among the participants who reported unmet need due to not trusting doctors, cost of seeing a doctor, not having time to go to the doctor, and fear of seeing a doctor. Among all reasons for unmet need, only the cost of seeing a doctor shows a statistically significant difference. When we focus on the women aged 40 and older, the cost barrier was no longer significant, however, not having time to go to the doctor was a significant barrier.

Table 11. The prevalence of unmet health needs of survey participants for any health issue in the past 12 months.

Unmet heath care need	Mammogram					
	Yes		No		Total	
	N	%	N	%	N	%
I did not need to see a doctor in the past 12 months	188	82.5%	40	17.5%	228	100.0%
I don't trust doctors	12	66.7%	6	33.3%	18	100.0%
Cost of seeing a doctor [1]	65	69.1%	29	30.9%	94	100.0%
Did not have time to go to the doctor	111	76.0%	35	24.0%	146	100.0%
Fear of seeing a doctor	65	80.2%	16	19.8%	81	100.0%
Fear of results of a medical exam or test	109	83.8%	21	16.2%	130	100.0%
Cultural/language barrier	12	85.7%	2	14.3%	14	100.0%
Distance to doctor's office	37	90.2%	4	9.8%	41	100.0%
Don't know / Not sure	47	83.9%	9	16.1%	56	100.0%

Perceptions of Risk Factors

The community survey assessed perceptions of risk factors for breast cancer (shown in Table 12 below). The most common perceived risk factor for breast cancer was family history (55.6%), followed by breast density (47.4%), obesity (35.3%), and smoking (33.3%). The lowest perceived risk factors for breast cancer were lack of exercise (12.5%), poor diet (18.8%), and external hormone use/hormone replacement therapy (HRT). Participants less than 40 years old and participants with less than a college education were less likely to perceive family history as a risk factor for breast cancer.

Table 12. The percentage of survey participants who perceived various factors as things that can increase their breast cancer risk.

	N	%	Groups with lower levels of perceived risk
Lack of exercise	73	12.5%	All ages except 30 to 39 years; low- and middle-income
Poor Diet	110	18.8%	40 yrs and older
External hormone use/Hormone Replacement Therapy (HRT)	120	20.5%	40 yrs and older; College educated; lower income
Alcohol use	139	23.7%	40 yrs and older; Single
Older Age	151	25.8%	NA
Smoking	195	33.3%	NA
Obesity	207	35.3%	40 yrs and older; Single
Breast Density	277	47.3%	18 to 29 yrs; Less than college education
Family History	326	55.6%	Younger than 40 yrs; Married; Less than college education

Risk perception on breast cancer

Community survey participants were also asked about their perceived risk of getting breast cancer, as individual risk perception has a profound impact on screening behaviors. Table 13 shows the prevalence of risk perceptions among participants. Nearly half of participants thought it was unlikely or very unlikely they would develop breast cancer in the future (48.5%), while 34.1% of participants thought it was likely or very likely and 17.4% of participants didn't know or were not sure. Nearly one-third of participants felt they were about as likely to develop breast cancer compared to the average person, while 14.3% felt more likely and 42.8% felt less likely. Only 6.8% of participants mostly or always worried about developing breast cancer, while nearly half of participants (48.4%) never or rarely worried about it.

Table 13. Risk perceptions about breast cancer among survey participants.

Variable	Categories	Frequency (N)	Percentage (%)
Likelihood of developing breast cancer in the future	Very unlikely	62	10.6%
	Unlikely	222	37.9%
	Likely	145	24.7%
	Very likely	55	9.4%
	Don't know/Not sure	102	17.4%
Risk of developing breast cancer compared to the average person	More likely	84	14.3%
	Less likely	251	42.8%
	About as likely	174	29.7%
	Don't know/Not sure	77	13.1%
Frequency of worrying about developing breast cancer	Never	47	8.0%
	Rarely	237	40.4%
	Sometimes	239	40.8%
	Most of the time or always	40	6.8%
	Don't know/Not sure	23	3.9%

Table 14. Risk perception of developing breast cancer in the future by family history of breast cancer.

		How likely do you think it is that you will develop breast cancer in the future?					
		Unlikely /very unlikely		Likely/very likely		Don't know/ Not sure	
		N	%	N	%	N	%
Breast cancer family history	Yes	30	21.7%	88	63.8%	20	14.5%
	No	254	56.7%	112	25.0%	82	18.3%
Total		284	48.5%	200	34.1%	102	17.4%

Participants with a family history of breast cancer reported feeling it was likely/very likely they would develop breast cancer in the future (63.8%) at a higher percentage than those without family history (25.0%) (Table 14).

Table 15. Risk perception of developing breast cancer in the future by family history of breast cancer.

		Compared to the average person your age, would you say that you are...							
		More likely to get breast cancer		Less likely to get breast cancer		About as likely to get breast cancer		Don't know/ Not sure	
		N	%	N	%	N	%	N	%
Breast cancer family history	Yes	61	44.2%	22	15.9%	44	31.9%	11	8.0%
	No	23	5.1%	229	51.1%	130	29.0%	66	14.7%
Total									

Participants with a family history of breast cancer reported feeling more likely to get breast cancer (44.2%) at a higher percentage than those without a family history (5.1%).

Table 16. Risk perception of developing breast cancer in the future by family history of breast cancer.

		How often do you worry about getting breast cancer?							
		Never/Don't know/Not sure		Rarely		Sometimes		Most or all of the time	
		N	%	N	%	N	%		
Breast cancer family history	Yes	12	8.7%	22	15.9%	75	54.3%	29	21.0%
	No	58	12.9%	215	48.0%	164	36.6%	11	2.5%
Total		54							

Participants with a family history of breast cancer reported more worry about getting breast cancer compared to those without a family history (Table 16).

Limitations

There are a few important limitations to note with respect to the community survey. First, convenience sampling (non-random) was used to solicit survey participation and thus, survey participants are not representative of all women in Nevada. Further, the community survey was primarily administered online, and therefore, older populations and those without access to adequate technology are likely to be underrepresented in the sample of participants. Secondly, because participants were entered into a raffle to receive an incentive for participation, there is the potential for fraudulent survey responses (e.g., persons completing the survey without honestly answering questions to be entered into the raffle). The UNR School of Public Health team spent a significant amount of time combing through individual survey submissions in order to find and exclude possible fraudulent responses using several key factors, such as multiple submissions from the same IP address, the amount of time it took to the complete the survey, and cross-validation of certain survey questions (e.g., logic checks for consistency of responses).

Recommendations

Based on the findings from the listening tours with Black and African American women living in Nevada and the survey with adult women living in Nevada, three primary domains emerged: Education, Access, and Communication/Outreach. A brief overview of recommendations within each of these domains is provided below.

Education

Primary recommendations regarding breast cancer-related education include:

1. Improve knowledge of risk factors
2. Dispel breast cancer myths
3. Leverage friends, family, community health workers to discuss breast cancer risk and screening with their friends and loved ones

Education was one of the most prevalent topics discussed in the listening tours. There was a general base knowledge of breast cancer, screening guidelines, and risk factors, however, the depth of the knowledge was not pervasive. There were many myths discussed about breast cancer. For example, when discussing perceived risk factors for developing breast cancer, one participant said: “My mom always told me don't get hit in the chest.” Another participant stated: “My mom would tell me not to sleep while wearing a bra because that would make me susceptible to breast cancer.” The most well-known perceived risk factor was family history. This led participants to draw conclusions on their own risk perceptions and showed the lack of education on other potential risk factors. While participants understood breast cancer screening guidelines and the necessity of screening, there was a lack of sense of urgency because they did not perceive themselves to be at risk of breast cancer. The women knew that screening was something that they should do, and communicated that people in their community knew that, but they were not concerned with getting them done as they had other more pressing concerns. This sentiment was echoed among survey participants as well, with about one-quarter of women who never received a mammogram stating they hadn't done so because they felt they were not at risk for developing breast cancer.

In both the listening tours and the community survey, participants expressed a desire to receive information and education from their family and friends. In the community survey, 40.0% of women who received a mammogram stated that their greatest influence or motivation for getting a mammogram was a friend or family member. Similar discussions were had in listening tours, where participants expressed comfort discussing breast cancer and screening with their friends and loved ones. In the listening tours, participants also discussed the benefits of talking with a community health worker (CHW) who is from their community about breast cancer. Extensive research has shown the benefit that CHWs and the Community Preventive Services Taskforce has even issued a formal recommendation for leveraging CHWs to assist with improving breast cancer screening.[12]

Access

Primary recommendations regarding access to breast cancer screening include:

1. Build trust with healthcare professionals through representation, especially for the Black and African American community
2. Help individuals to navigate insurance coverage
3. Market available resources by working with local community organizations and community health workers

Many participants in both the listening tours and community survey knew the importance of screening, but described issues with access to care. This was for a variety of reasons including insurance barriers, lack of knowledge of available resources, transportation, childcare, and time. Insurance is a common barrier to access to care, but it is not as simple as a lack of insurance. Those who have insurance also described difficulties with access: "When you're over 65 they don't like to cover a lot." Other participants discussed the lack of knowledge of available resources like mobile mammography services (e.g., Mammovan) and other free resources. Participants suggested more communication campaigns on available resources to inform the community. This included partnering with local community organizations who work with the Black and African American community to disseminate that information. In the community survey, participants with a personal doctor or healthcare provider and participants with an OBGYN were more likely to have received a mammogram, further highlighting the importance of access to care on breast cancer screening.

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[12] Cancer screening: Interventions engaging community health workers - breast cancer. The Community Guide. (2023, April 29). https://www.thecommunityguide.org/findings/cancer-screening-interventions-engaging-community-health-workers-breast-cancer.html

Listening tour participants also described widespread mistrust of providers among the Black and African American community for many reasons (e.g., the Tuskegee Study and lack of Black and African American providers). Many community members discussed that this inhibited them from seeking care of any kind. The solutions discussed included having more Black and African American doctors and providers or having Black and African American doctors and providers to disseminate information as a trusted source. They discussed demystifying health care through trusted and representative sources. When it is not possible to connect community members to a Black or African American provider, having a Black or African American provider as a part of education efforts can help to build trust.

Communication/Outreach

Primary recommendations regarding communications and outreach initiatives include:

1. Develop materials and resources with minimal text and a simple a clear call to action
2. Engage the entire family, including men
3. Offer outreach events for the family

Recommendations for communication campaigns were solicited from listening tour participants. Among Black and African American listening tour participants, recommendations for print media (e.g., flyers, social media graphics, posters) were as follows: minimal text, one simple call to action, make sure words are clear and easy to read, link to more information, and include Black and African American representation. Based on these participant suggestions, we developed the following a set of specific recommendations that leverage best practices for public health communication campaigns from the Centers for Disease Control and Prevention (CDC). These recommendations are presented in Appendix 3.

A common suggestion for communication campaigns was outreach events to engage the local community. The event should have incentives and activities (such as food, drinks, games, etc.), resources, and be educational for those attending. An event that is inclusive to children, husbands, and all family members can allow women to take the time to get their mammogram. It also helps to improve familial knowledge and support. Others suggested door-to-door canvassing and use of trusted figures in the community to inform community members of resources and the importance of screening. Another important point was that the people who need these events the most do not know about them, so it is necessary to go out into the community and market these events.

Appendices

Appendix 1: Listening Tour Interview Guide and Participant Pre-Survey

Introduction (10 minutes)

Facilitator [READ]:

Thank you for taking the time to meet with us today. My name is _______. I will be asking the questions today and running the group. This is ___________ who will be taking notes on what we discuss here today so we can make sure not to miss any of your thoughts. We are talking to you today because we'd like to understand how your thoughts and feelings about breast cancer screening. We are going to ask you all questions and then have a discussion where we hope to hear from everyone here. There are no right or wrong answers.

This discussion is voluntary, meaning that you are answering these questions because you want to, not because you have to. If you prefer to not answer a question, that is okay. You can also leave the discussion at any time. This will not impact services that you receive. We may share the aggregate data, or the general information that we learn, publicly so that others may learn from this discussion. If you agree to participate in this discussion, we will be using your demographic information in our analysis and reports, including your age, and race/ethnicity. This will help us to identify trends and differences in responses. No names or personally identifiable information will be collected.

We are also asking everyone here to please keep what others share private so that everyone can talk openly and honestly. Also, we want you to ask questions or let us know if you don't understand something, or if something that we said is bothering you in any way. We are recording the audio from this discussion so we can take notes and not miss anything that was said. The recording will also be transcribed after the session. The recording will not be shared with anyone outside our team. Your personally identifiable information will not be included anywhere in the transcript or notes.

Thank you so much for being here and being willing to do this! Your thoughts and ideas are really helpful in understanding the barriers to breast cancer screening. Before we begin, do you feel comfortable participating in this discussion and answering my questions? Do you have any questions before we start?

I want to highlight three key points again.

- *Your name and personally identifiable information will not be shared in any reports.*
- *Your participation in this interview is voluntary.*
- *You can stop answering questions or leave at any time. This will not impact the services you receive.*

Do you understand, and do you agree to continue?

Informed consent was obtained from participants: □ Yes □ No

Questions / Discussion topics

1. Intro/Risk Perception:

What do you know about breast cancer?

Probes:

- Has anyone in your life been affected by breast cancer?
- Do you think that you are at risk for breast cancer? Family history?

2. Screening behaviors:

What do you know about breast cancer screening?

Probes:

- Do you think that it is beneficial to women's health?
- Do mammograms help to prevent women's health issues?
- Are you aware of guidelines regarding screening? Age? Frequency?
- Do you know how to identify or examine yourself for breast cancer?
- If people know about screening, we can ask how they know or who they heard it from.

What are some reasons why people don't regularly get breast cancer screenings? What are the barriers and difficulties for people in your community? What things make it easier for people in your community to get screened?

Probes:

- How does insurance status affect you or people in your community?
- How do household duties and responsibilities (for example childcare) affect you or people in your community?
- What cultural factors influence you or people in your community?
- Do you and your peers have a provider that you trust?
- What cultural or religious factors affect perceptions of breast cancer screening in your community?
- Do you think that cancer can be cured? Why or why not?
- Do you believe that if you have breast cancer it is your destiny or God's will?
- Do you believe that the consequences of breast cancer are something we cannot change?

3. Communication:

Creative Activity: Imagine you are given the opportunity to design a breast cancer screening health campaign for black women. Walk me through the process.

- Visuals
    - Which colors do you think would catch your attention and make you feel represented?
    - What kind of model will attract your attention and symbolize representation?
        - Probe: demographic representation in terms of age, representation

    - Who would you like to see as a model of the ad representing health issues? Who would be the best spokesperson to motivate you?
- Language
    - Which words would you use to attract the attention of the black community? Can you give us 5 or more words as an example?
- Content:
    - Which topics/key messages should be covered in the campaign?
    - Can you give us three topics?
- Obstacles:
    - Which obstacles or hesitation of the community should be acknowledged in a campaign to gain community trust?
- Appeals
    - Which type of emotions do you think appeal to the black people?
        - Prob: For example, fear has been used in campaigns to encourage people to quit smoking. Which emotions should be used for the messages designed for the topics and barriers that you just mentioned earlier?
- Deployment
    - How would you get this campaign and information out to black women over 40?
    - Can you give us examples of 2 or more such spaces?
    - Who should deliver the health message to gain your trust and attention?
        - Probe: Do you have any particular person or professional you think would be trusted?
    - If you wanted to create a health campaign to get more black people screened for breast cancer, how might you go about this? Where would you begin?

Health communication campaigns are all around us, from commercials trying to sell specific pharmaceuticals, to advertisements aimed at reducing negative health behaviors like smoking, to specifically targeted messages for specific conditions like diabetes. I'm going to show you a health communication campaign for breast cancer. I'd like you to look at them and take a brief survey and then talk me through your reactions.

Facilitator: Distribute print materials and have participants fill in survey (included with print materials) for each. Collect when finished.

Listening Tour Pre-Survey

1. What is the zip code where you live? _______

2. What is your age? ___________ years old

3. What is your marital status today? (Check **ONLY ONE**)
☐ Single
☐ Married
☐ Living with a partner
☐ Separated/Divorced
☐ Widowed
☐ Other, please specify: _________________

4. What is the highest degree or level of school you have completed? (Check **ONLY ONE**)
☐ Never attended school or only attended kindergarten
☐ Grades 1 through 8 (elementary)
☐ Grades 9 through 11 (Some high school)
☐ Grade 12 or GED (High school graduate)
☐ College 1 to 3 years (some college or technical school)
☐ College 4 years or more (college graduate)
☐ Don't know

5. Considering your own income and income from any other people who help you, how do you describe your overall personal financial situation? (Check **ONLY ONE**)
☐ Live comfortably
☐ Meet needs with a little left
☐ Just meet basic expenses
☐ Don't meet basic expenses

6. What is your employment status? (Check **ONLY ONE**)
☐ Employed, full-time
☐ Employed, part-time
☐ Not employed, looking for work
☐ Not employed, not looking for work
☐ Presently not employed outside the home, not looking for work (housewife)
☐ Student
☐ Other, please specify: _________________

7. What type of health insurance do you have? (If you have more than one type of coverage, check the **ONE** that you usually use to cover doctor and hospital bills)
☐ I have NO health insurance coverage
☐ Insurance through a current employer (such as employer's health plan)
☐ Insurance through a former employer (COBRA, retiree health benefits)

☐ Insurance through someone else’s employer (such as spouse, partner, parents, etc.)
☐ Private insurance that you or someone in your family purchased
☐ Medicare
☐ Medicaid
☐ Military health care/TRICARE-Champus/ Veterans Administration
☐ Student health insurance through a college or university
☐ Don’t know
☐ Other, please specify: _________________

8. How often do you visit your family doctor or health care provider (not including emergency care)? (Check **ONLY ONE**)
☐ I don’t have a family doctor or health care provider
☐ Once every few years
☐ Once per year
☐ More than once per year

9. Have you ever been diagnosed with cancer? (Check **ONLY ONE**)
☐ Yes
☐ No
☐ Don’t know

10. If yes, what types of cancer? (Check **ALL THAT APPLY**)
☐ Bladder cancer
☐ Breast cancer
☐ Colon / colorectal cancer
☐ Lung cancer
☐ Endometrial cancer
☐ Leukemia
☐ Liver and intrahepatic bile cancer
☐ Pancreatic cancer
☐ Prostate cancer
☐ Other
☐ Don’t know

11. Is there a history of cancer in your family? (Check **ONLY ONE**)
☐ Yes
☐ No
☐ Don’t know

12. If yes, what types of cancer? (Check **ALL THAT APPLY**)
☐ Bladder cancer
☐ Breast cancer
☐ Colon / colorectal cancer
☐ Lung cancer

☐ Endometrial cancer
☐ Leukemia
☐ Liver and intrahepatic bile cancer
☐ Pancreatic cancer
☐ Prostate cancer
☐ Other
☐ Don’t know

13. When was the last mammogram you received? (Check **ONLY ONE**)
☐ I have never received a mammogram
☐ 3 or more years ago
☐ 1 or 2 years ago
☐ Within the last year

Appendix 2: Community Survey

Nevada Breast Cancer Prevention Need Assessment
Community Survey

Thank you for agreeing to participate in this anonymous survey. Your answers to this survey will be used to improve breast cancer screening and prevention services, education, and outreach in Nevada.

This survey is anonymous, so please DO NOT include your name or other personal identifying information on this form. Please answer all questions accurately and honestly.

Thank you for taking the time to help us make better programs to improve breast cancer screening in Nevada.

Part 1: Eligibility

1. How old are you?

☐ ___

>>> If you are under 18, STOP! You are not eligible to participate.

2. In what part of Nevada do you live? (Check **ONLY ONE**)

☐ Carson City
☐ Churchill County
☐ Clark County
☐ Douglas County
☐ Elko County
☐ Esmeralda County
☐ Eureka County
☐ Humboldt County
☐ Lander County
☐ Lincoln County
☐ Lyon County
☐ Mineral County
☐ Pershing County
☐ Nye County
☐ Storey County
☐ Washoe County
☐ White Pine County
☐ I don’t live in Nevada **>>> STOP! You are not eligible to participate.**

3. What is your **<u>primary</u>** race/ethnicity? (Check **ONLY ONE**)

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Hispanic or Latinx
☐ Native Hawaiian or Pacific Islander
☐ White
☐ Other, please specify: __________________

4. What is your **<u>primary</u>** gender identity today? (Check **ONLY ONE**)

☐ Male
☐ Female
☐ Transgender man/transsexual man/FTM (female to male)
☐ Transgender woman/transsexual woman/MTF (male to female)
☐ Genderqueer/Non-binary/gender fluid/two-spirit
☐ Agender
☐ Other, please specify: __________________

Part 2: Breast cancer screening

5. Have you ever performed a breast self-examination? (Check **ONLY ONE**)
☐ Yes
☐ No
☐ Don't know / Not sure

6. Have you ever had a mammogram? (Check **ONLY ONE**)
☐ Yes
☐ No **>>> Skip to question 9.**
☐ Don't know / Not sure

7. How long has it been since you had your last mammogram? (Check **ONLY ONE**)
☐ Within the past year (anytime less than 12 months ago)
☐ Between 1 and 2 years ago (more than 1 year ago but less than 2 years ago)
☐ 2 or more years ago
☐ Don't know / Not sure

8. What influenced (or motivated) you to get a mammogram in the past 2 years? (Check **ALL THAT APPLY**)
☐ Family member, friend encourage you to get screened
☐ Scheduled by your doctor
☐ Messages on social media, internet, etc.
☐ Messages through TV or radio
☐ Receiving a reminder card in the mail
☐ Someone you know has cancer
☐ I don't need any reminder

9. If you have not had a mammogram, what are the reasons why? (Check **ALL THAT APPLY**)
☐ I don't think that I am at risk for breast cancer
☐ I feel that I am too young for a mammogram
☐ No time to go to the doctor
☐ Too far distance to doctor's office
☐ I can't afford the cost of a mammogram
☐ I am afraid of getting a mammogram
☐ I am afraid to know if I have breast cancer
☐ Don't know / Not sure

10. Has anyone around you ever reminded or encouraged mammography testing? (Check **ALL THAT APPLY**)
☐ Yes, parent
☐ Yes, sibling
☐ Yes, child
☐ Yes, friend

☐ Yes, spouse
☐ Yes, health care provider
☐ Yes, other, please specify: _______
☐ No
☐ Don’t know / Not sure

11. Have you ever heard of something called breast density? (Check **ONLY ONE**)
☐ Yes
☐ No
☐ Don’t know / Not sure

12. Have ever you spoken to your healthcare provider and talked about your individual breast density? (Check **ONLY ONE**)
☐ Yes
☐ No
☐ Don’t know / Not sure

13. Have you had or have you been given a screening related to dense breast tissue? (Check **ONLY ONE**)
☐ Yes
☐ No
☐ Don’t know / Not sure

Section 3: Family history

14. Is there a history of cancer in your family? (Check **ONLY ONE**)
☐ Yes
☐ No **>>> Skip to question 13.**
☐ Don’t know **>>> Skip to question 13.**

15. If yes, what types of cancer? (Check **ALL THAT APPLY**)
☐ Bladder cancer
☐ Breast cancer
☐ Cervical cancer
☐ Colon / colorectal cancer
☐ Lung cancer
☐ Endometrial cancer
☐ Leukemia
☐ Liver and intrahepatic bile cancer
☐ Pancreatic cancer
☐ Prostate cancer
☐ Ovarian cancer
☐ Other
☐ Don’t know

16. Has your mother, grandmother, sister, aunt, daughter, or another immediate family member ever been diagnosed breast cancer? (Check **ALL THAT APPLY**)
☐ Yes, my mother
☐ Yes, my grandmother
☐ Yes, my sister(s)
☐ Yes, my aunt(s)
☐ Yes, my daughter(s)
☐ Yes, another immediate family member, please specify: _______
☐ No

Part 4: Behaviors

17. Have you ever used birth control (i.e. contraceptive pills, injections, etc.)? (Check **ONLY ONE**)
☐ Yes
☐ No

18. Have you ever had an abortion? (Check **ONLY ONE**)
☐ No
☐ 1 abortion
☐ 2 and more abortions

19. Have you ever had invitro fertilization (IVF)? (Check **ONLY ONE**)
☐ Yes
☐ No

20. How old were you when you first had menstruation? (Please type)
☐ _______ years
☐ Don't know / not sure

21. How old were you when you went into menopause? (Please type)
☐ _______ years
☐ I am not in menopause
☐ Don't know / not sure

22. Have you ever had hormone replacement therapy (HRT)? (Check **ONLY ONE**)
☐ Yes
☐ No

Part 5: Health care access

23. What type of health insurance do you have? (If you have more than one type of coverage, check the **ONE** that you usually use to cover doctor and hospital bills)

☐ I have NO health insurance coverage
☐ Insurance through a current employer (such as employer's health plan)
☐ Insurance through a former employer (COBRA, retiree health benefits)
☐ Insurance through someone else's employer (such as spouse, partner, parents, etc.)
☐ Private insurance that you or someone in your family purchased
☐ Medicare
☐ Medicaid
☐ Military health care/TRICARE-Champus/ Veterans Administration
☐ Student health insurance through a college or university
☐ Don't know
☐ Other, please specify: _________________

24. In the past 12 months, where did you usually go for medical care or assistance when you were sick? (Check the **ONE** place you usually went)
☐ Emergency Room
☐ Urgent care
☐ Private doctor's office
☐ Health clinic or health center (paid)
☐ Health clinic or health center (free)
☐ V.A. (Veterans Administration) clinic or hospital
☐ I did not go to any providers
☐ Don't know
☐ Other, please specify: _________________

25. Do you have a person you think of as your personal doctor or health care provider?
☐ Yes
☐ No
☐ Don't know / Not sure

26. Do you have a gynecologist and/or an OBGYN?
☐ Yes
☐ No
☐ Don't know / Not sure

27. Was there a time in the past 12 months when you needed to see a doctor but could not **due to one of the reasons below**? (Check **ALL THAT APPLY**)
☐ I did not need to see a doctor in the past 12 months
☐ Did not have time to go to the doctor
☐ Distance to doctor's office
☐ Cost of seeing a doctor
☐ Fear of seeing a doctor
☐ Fear of COVID-19
☐ I don't trust doctors
☐ Cultural/language barrier

☐ Fear of results of a medical exam or test
☐ Don't know / Not sure

Part 6: Risk perception and awareness

28. How likely do you think it is that you will develop breast cancer in the future? (Check **ONLY ONE**)

☐ No risk
☐ Low risk
☐ Moderate risk
☐ High risk
☐ Don't know / Not sure

29. Compared to the average woman your age, would you say that you are… (Check **ONLY ONE**)

☐ More likely to get breast cancer
☐ Less likely to get breast cancer
☐ About as likely to get breast cancer
☐ Don't know / Not sure

30. How often do you worry about getting breast cancer? (Check **ONLY ONE**)

☐ Never
☐ Rarely
☐ Sometimes
☐ Most or all the time
☐ Don't know / Not sure

31. In your opinion, which are the **<u>TOP THREE</u>** factors that may increase a person's risk of getting breast cancer? (Check ONLY **THREE**)

☐ Alcohol use
☐ Smoking
☐ Obesity
☐ Older Age
☐ Family History
☐ Breast Density
☐ Poor Diet
☐ Lack of exercise
☐ External hormone use/Hormone Replacement Therapy (HRT)
☐ Other, please specify: __________________

Part 7: Sociodemographic Characteristics

32. What is the ZIP code where you currently live?

____

33. What is your marital status today? (Check **ONLY ONE**)
☐ Single
☐ Married
☐ Non-marital partner
☐ Separated/Divorced
☐ Widowed
☐ Other, please specify: __________________

34. What is the highest degree or level of school you have completed? (Check **ONLY ONE**)
☐ Never attended school or only attended kindergarten
☐ Grades 1 through 8 (elementary)
☐ Grades 9 through 11 (Some high school)
☐ Grade 12 or GED (High school graduate)
☐ College 1 to 3 years (some college)
☐ Associate's degree or technical/trade school
☐ Bachelor's degree (college graduate)
☐ Graduate or professional degree
☐ Don't know

35. What is your employment status? (Check **ONLY ONE**)
☐ Employed, full-time
☐ Employed, part-time
☐ Not employed, looking for work
☐ Not employed, not looking for work
☐ Homemaker (i.e. housewife, etc.)
☐ Other, please specify: __________________

36. Do you own or rent your home? (Check **ONLY ONE**)
☐ Own
☐ Rent
☐ Other arrangement (group home, staying with friends or family without paying rent)
☐ Don't know/ not sure

37. Considering your own income and income from any other people who help you, how do you describe your overall personal financial situation? (Check **ONLY ONE**)
☐ Live comfortably
☐ Meet needs with a little left
☐ Just meet basic expenses
☐ Don't meet basic expenses

38. How many people live in your household, including yourself? (Do not include adults living away from home, such as students away at college) (please type)

____

39. Do you take care of someone among your household members? (Check **ALL THAT APPLY**)
☐ Yes, preschool child(ren)
☐ Yes, disabled child(ren)
☐ Yes, disabled adult
☐ Yes, parents
☐ No

40. Would you say that in your health is:
(Check **ALL THAT APPLY**)
☐ Excellent
☐ Very good
☐ Good
☐ Fair
☐ Poor

Appendix 3: Best Practice Recommendations for Breast Cancer Communication Campaigns and Materials

Identify target demographic and establish a clear goal

- When developing messaging, answer the following questions: Who is the message intended for?; What is the message?; Where are they?; How do we reach them?; What is the main goal of this message?

Use data to inform communications

- Surveillance can be leveraged to identify priority populations.
- Surveys, focus groups, and key informant interviews within priority populations can be used to understand knowledge, attitudes, and behaviors about breast cancer, which can ultimately be leveraged to design communications.

Engage target populations and key stakeholders in the process

- When developing communications, solicit feedback from the intended target population.
- Trusted community stakeholders (e.g. faith-based institutions, non-profit organizations, and community leaders) can offer a direct connection point to target audiences.

Foster cultural competency

- Consider transcreation and avoid simply translating English communications to another language.
- Future initiatives should aim to develop tailored communications to specific populations.

Tell real stories

- Real stories and lived experiences are an impactful way to share health communications.

Target your reach

- Understand your target demographic and the best way to reach them.
- Leverage a variety of outlets to reach your intended audience, including social media, television and radio, and community events to supplement existing efforts.

Evaluate and adapt

- After developing and disseminating communications, it is important to evaluate and adapt.
- Those designing communications should consider ways to evaluate the communications during the development process.
- Examples include conducting focus groups or key informant interviews, tracking website/social media impressions and sentiment, monitoring placement on TV and radio, etc).