

Survey of California Women's
Awareness of Dense Breast Issues and
California's Breast Density Law
Final Report



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Management Summary

Methodology

Purpose

The primary purpose of this study is to assist Are You Dense Inc. and Are You Dense Advocacy Inc. with its efforts to advocate against the scheduled expiration of the California breast density law in January 2019. The study will also be used by Are You Dense Inc. and Are You Dense Advocacy Inc. to educate the public, provide breast health resources, by documenting:

- Women's level of knowledge regarding the issue of breast tissue type, how important they believe it is that every woman know her breast tissue type, and their personal preference for knowing or not knowing their breast tissue type
- Women's level of understanding of the implications of having dense breast tissue on cancer screening and breast cancer risk
- What percentage of women know their breast tissue type, and how those women who knew their breast tissue type learned their type
- For women with dense breast tissue, what percentage engaged in discussions with health care providers about additional screening
- How women they learned about the topic of breast density
- Women's awareness of legislation in California that addresses the issue of breast density
- Women's preference regarding California's breast density law expiring or not in January 2019, and the reasons for their preference

Sampling

To qualify for the study, the survey respondents had to:

- Be female
- Live in California
- Be between 40 and 74 years old
- Have had a mammogram within the last two years

Methodology (continued)

Survey Instrument Design and Programming

Spectrum Associates prepared a draft survey instrument based on input received from Are You Dense Inc./Are You Dense Advocacy Inc. The draft was submitted to Are You Dense Inc./Are You Dense Advocacy Inc. and revisions were made based on the feedback provided. A copy of the final questionnaire is provided in Appendix A. Once the survey instrument was finalized, Spectrum Associates programmed it for online data collection. A test link was provided to Are You Dense Inc./Are You Dense Advocacy Inc. for review and approval.

Data Collection

Due to changes in our society over the last 10 years with regard to the reduction of landline telephones in homes and increased access to the internet coupled with vast improvements in the quality/representativeness of online panels, online surveys are now the most widely used quantitative methodology in market research. For this study, Spectrum Associates retained the services of Research Now, a leading online panel company to program, host and obtain the 501 completed surveys. The surveys were completed March 22-27, 2018.

71% of the online panel members that clicked into the survey qualified for the study. 23% of the panel members that clicked into the survey were disqualified because they had not had a mammogram in the last 2 years. The remaining 6% were terminated based on gender, age, or where they lived.

While the demographic breakouts of the women included in the study are impacted by who meets the study qualifiers, it should be noted that the racial/ethnic breakouts of the 501 surveys are reflective of the racial/ethnic breakouts of California's population.

Analysis

For this study, the data are analyzed in aggregate. The confidence range for 500 surveys is +/- 4.5 at a 95% confidence level. The +/- 4.5 is the maximum confidence range and can be smaller based on the percentage of the respondents giving a particular response. A chart displaying more specific confidence range information is provided in Appendix B.

Note: Some figures may appear to not total to 100% due to rounding.

Respondent Background Characteristics

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Figures 1 & 2 (page 7) display the demographic background characteristics and self/family member breast cancer diagnosis. These figures provide an overall picture of the study respondents. Note that the demographic characteristics and experience with breast cancer diagnosis will be reflective of the women who qualified for the study (i.e., ages 40 to 74 that had a mammogram in the last two years) and are not reflective of the overall population of women in California.

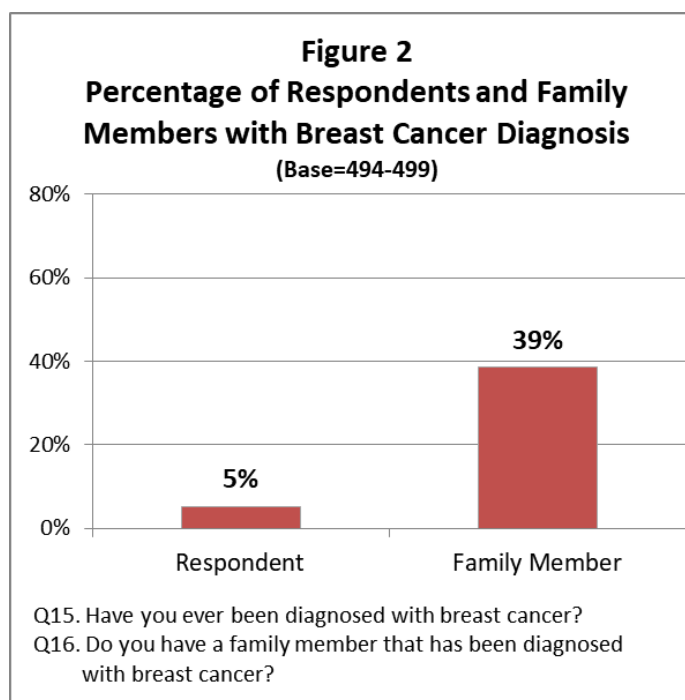
Overall, these figures show:

- There was a good mix of age ranges, education levels and household incomes in the study sample.
- The racial/ethnic representation within the study sample was fairly reflective of the state's population
- 5% of the women had been diagnosed with breast cancer, and 39% had a family member with a breast cancer diagnosis.

Respondent Background Characteristics (continued)

Figure 1
Respondent Demographic Characteristics

Age		Base=501
	40 to 54	41%
	55 to 64	35%
	65 to 74	25%
	Total	100%
Race/Ethnicity		Base=496
	Asian	15%
	Black	7%
	Hispanic	39%
	White	36%
	Other	2%
	Total	100%
Highest Level of Education		Base=493
	No high school diploma or GED	2%
	High school graduate or GED	21%
	Technical school/Associates' Degree	22%
	Bachelor's Degree	35%
	Graduate Degree	20%
	Total	100%
Household Income		Base=453
	< \$25,000	5%
	\$25,000-\$49,999	18%
	\$50,000-\$74,999	20%
	\$75,000-\$99,999	21%
	\$100,000-\$124,999	14%
	\$125,000 +	23%
	Total	100%



Key Findings

1. About three-quarters of the women (72%) felt they were at least “fairly” knowledgeable about the topic of breast tissue type. 19% of the respondents felt they were “very” knowledgeable. *(Figure 3)*
2. A large majority of the respondents felt it was important that women be aware of their breast tissue type. Specifically, 85% agreed with the statement “It is important that every woman know her type of breast tissue” and 88% agreed that “I would prefer to know my breast tissue type than not know.” *(Figure 4)*
3. About three-quarters (74%) of the respondents knew that having dense breast tissue makes it more difficult to see cancer on a mammogram. The respondents were evenly divided on dense breast tissue’s impact on breast cancer risk. One-half knew that dense breast tissue puts a woman at increased risk for breast cancer while the other half incorrectly said that it does not increase breast cancer risk. *(Figure 5)*
4. 59% of the respondents knew their breast tissue type; these respondents were asked how they learned their breast tissue type. The respondents were most likely to have learned their breast tissue type from a conversation with their health care provider (68%), followed by from their mammogram results letter (60%). *(Figure 6)*
5. Over three-quarters (78%) of the respondents who learned their breast tissue type from a conversation with their health care provider indicated that their health care provider had initiated the conversation. *(Figure 7)*
6. 82% of the women who knew their breast tissue type reported they have dense breasts. *(Figure 8)*
7. Of the respondents who had dense breasts and had a conversation with their health care provider about their breast tissue, 59% indicated that their health care provider had talked with them about having additional screening due to their having dense breast tissue. *(Figure 9)*
8. Only 9% of the respondents were aware of legislation in California that addresses the issue of breast density. *(Figure 11)*
9. Study respondents were shown a description of California’s Breast Density Law and asked whether they would prefer that the law stay in place or be allowed to sunset (expire) in January 2019. The vast majority (95%) of the respondents preferred to have the law stay in place. *(Figure 12)*

Implications

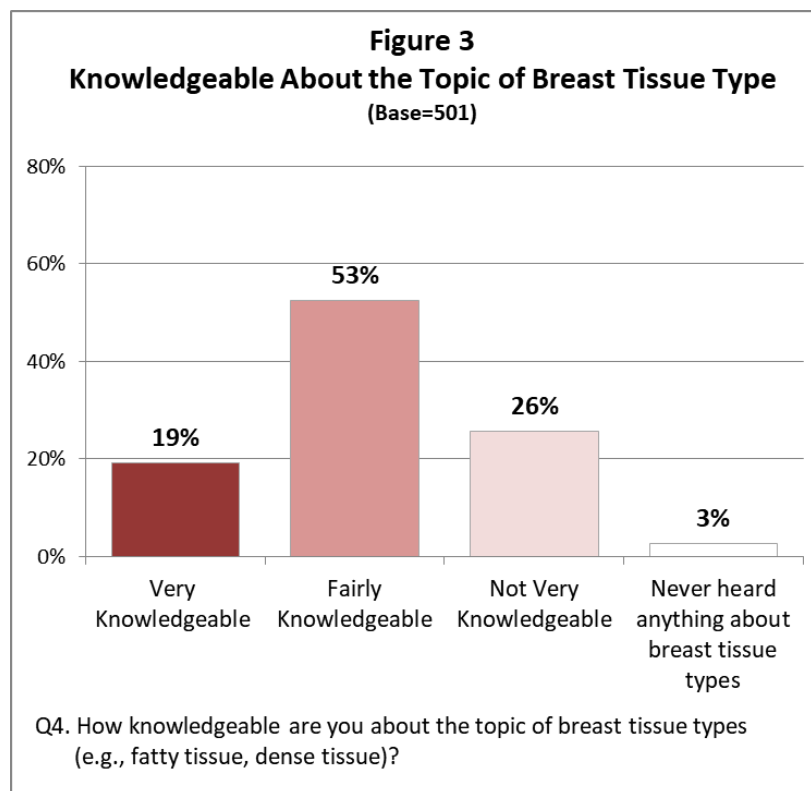
1. The study findings indicate that the advocacy and education work being undertaken by Are You Dense Inc. and Are You Dense Advocacy Inc. is desired by the women of California.
2. The California women included in the study indicated a strong preference for being informed about breast density issues, both for women in general and for themselves.
3. As would be expected based on the desire for information/knowledge, when asked for their preference around keeping the current California breast density law in place or letting it expire, 95% of the respondents want to keep the law in place.

Detailed Findings

Knowledgeable About Breast Tissue Type

When asked how knowledgeable they felt they were about the topic of breast tissue type:

- Just under three-quarters of the women (72%) felt they were at least “fairly” knowledgeable, 19% felt they were “very” knowledgeable
- About one-quarter felt they were “not very” knowledgeable
- 3% indicated they had never heard anything about breast tissue types



Importance of Breast Tissue Type Awareness

To determine how important awareness of breast tissue type is to women, the respondents were asked the degree to which they agreed or disagreed with two statements about the topic. One statement was about women in general and the other asked about the respondent’s personal preference.

Figure 4
Importance of Breast Tissue Type Awareness
 (Base=501)

It is important that every woman know her type of breast tissue	
Completely agree	56%
Mostly agree	29%
Neither agree nor disagree	15%
Mostly disagree	0%
Completely disagree	0%
Total	100%
I would prefer to know my breast tissue type than not know	
Completely agree	65%
Mostly agree	23%
Neither agree nor disagree	9%
Mostly disagree	1%
Completely disagree	2%
Total	100%

- The vast majority of California women felt it was important that women be aware of their breast tissue type. Specifically, 85% agreed that it is important that every woman know her type of breast tissue and 88% agreed that they would prefer to know their breast tissue type than not know.
- Moreover, two-thirds (65%) “completely” agreed with the statement “I would prefer to know my breast tissue type than not know” and over one-half (56%) “completely” agreed with the statement “It is important that every woman know her type of breast tissue.”

Q5. Please record your level of agreement or disagreement with the following statements.

Impact of Dense Breast Tissue on a Mammogram's Cancer Detection Ability and on Breast Cancer Risk

The respondents were asked questions to determine if they knew the impact that having dense breast tissue has on a mammogram's ability to detect cancer and on a woman's risk for breast cancer.

- The respondents were more likely to know the impact that having dense breast tissue has on a mammogram's cancer detection ability than to know its impact on breast cancer risk.
- About three-quarters (74%) of the respondents knew that having dense breast tissue makes it more difficult to see cancer on a mammogram.
- Women were evenly divided on dense breast tissue's impact on breast cancer risk. One-half correctly indicated that dense breast tissue puts a woman at increased risk for breast cancer while the other half incorrectly said that it does not increase breast cancer risk.

Figure 5
Perceived Impact of Having Dense Breast Tissue on a Mammogram's Ability to Correctly Detect Cancer and a Woman's Breast Cancer Risk
 (Base=488)

Dense Breast Tissue Impact on a Mammogram	
Makes it more difficult to see cancer on a mammogram	74%
Does not affect the ability to see cancer on a mammogram	3%
Makes it easier to see cancer on a mammogram	5%
I don't know	18%
Total	100%
Dense Breast Tissue Impact on a Woman's Risk for Breast Cancer	
Puts a woman at increased risk for breast cancer	50%
Does not put a woman at increased risk for breast cancer	50%
Total	100%

Q6. To the best of your knowledge, what is the impact of having dense breast tissue on a mammogram's ability to correctly detect cancer?

Q7. Having dense breasts: does not put a woman at increased risk for breast cancer or puts a woman at increase risk for breast cancer?

Note: For Q6, about half of the respondents had the "dense breasts make it more difficult to see cancer on a mammogram" as the first response option while the other half saw the "dense breasts make it easier to see cancer on a mammogram" as the first response option. For Q7, the order the two response options appeared was randomized so each was first for about half of the respondents.

Respondent Knowledge of Her Breast Tissue Type

The respondents were asked if they knew their breast tissue type, and for those who did, how they learned of their type.

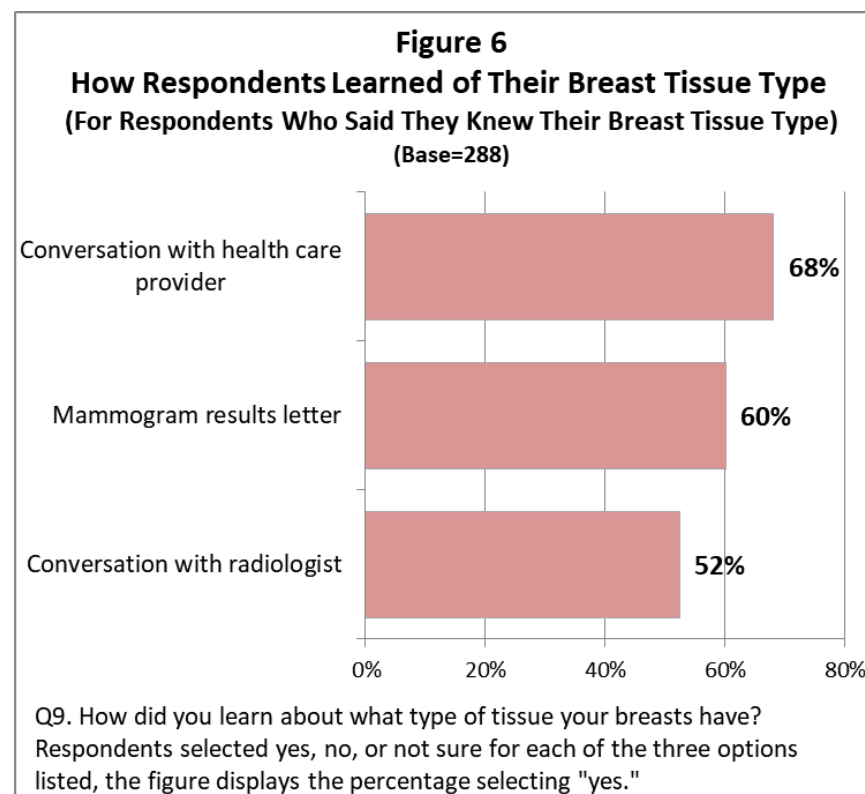
Know Breast Tissue Type

- 59% of the respondents knew their breast tissue type.

How Learned Breast Tissue Type

The 288 respondents who knew their breast tissue type were asked how they learned of their type.

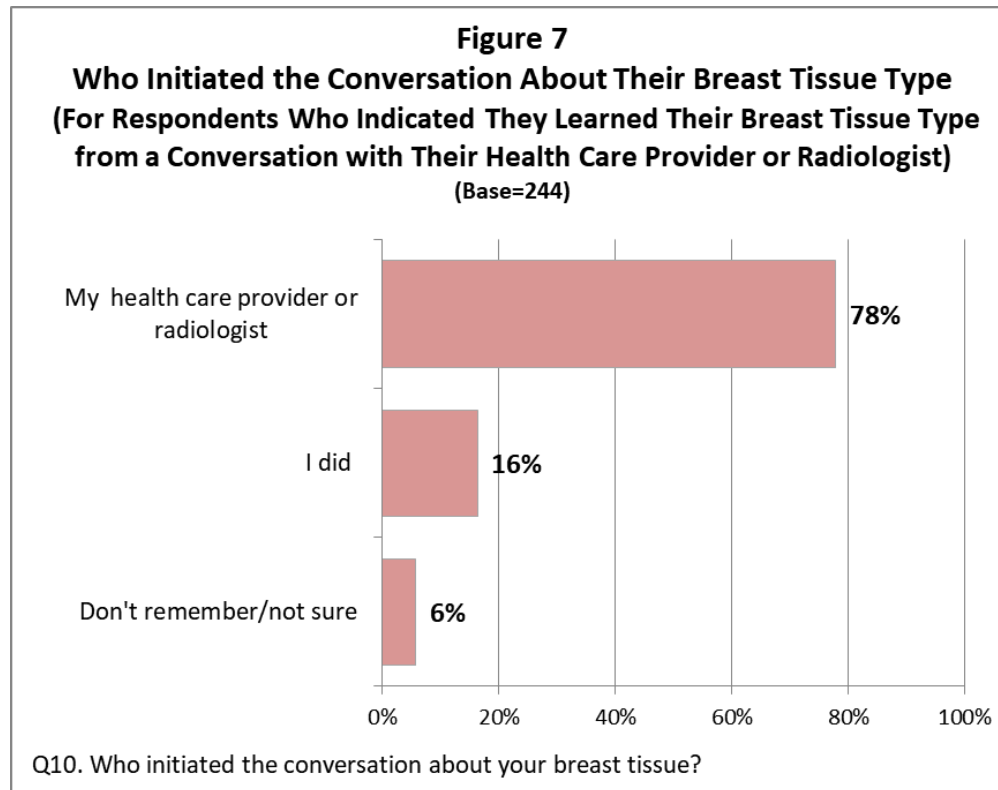
- The respondents were most likely to have learned their breast tissue type from a conversation with their health care provider (68%), followed by from their mammogram results letter (60%).
- Just over one-half (52%) indicated that they heard learned their breast tissue type from a conversation with their radiologist.



Who Initiated Conversation

The 244 respondents who learned of their breast tissue type from a conversation with their health care provider were asked who initiated the conversation: the health care provider or the respondent.

- Over three-quarters (78%) of the respondents indicated that their health care provider had initiated the conversation.

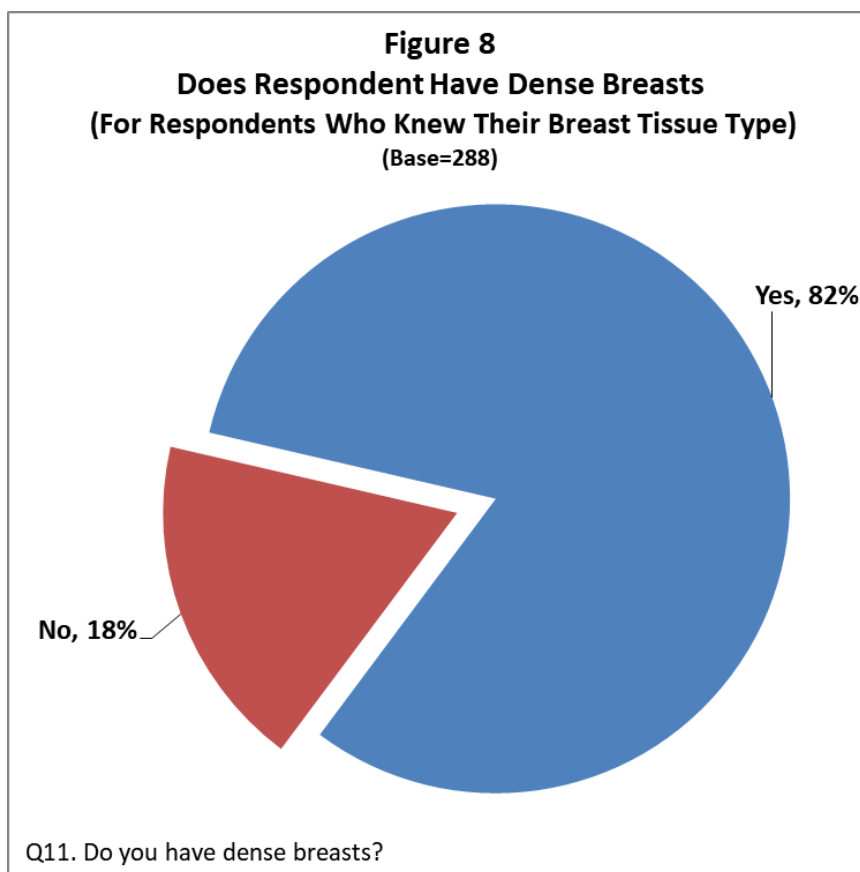


Respondents with Dense Breast Tissue

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Respondents who indicated they knew their breast tissue type were asked if they have dense breast tissue.

- 82% of the women who knew their breast tissue type reported they have dense breasts.

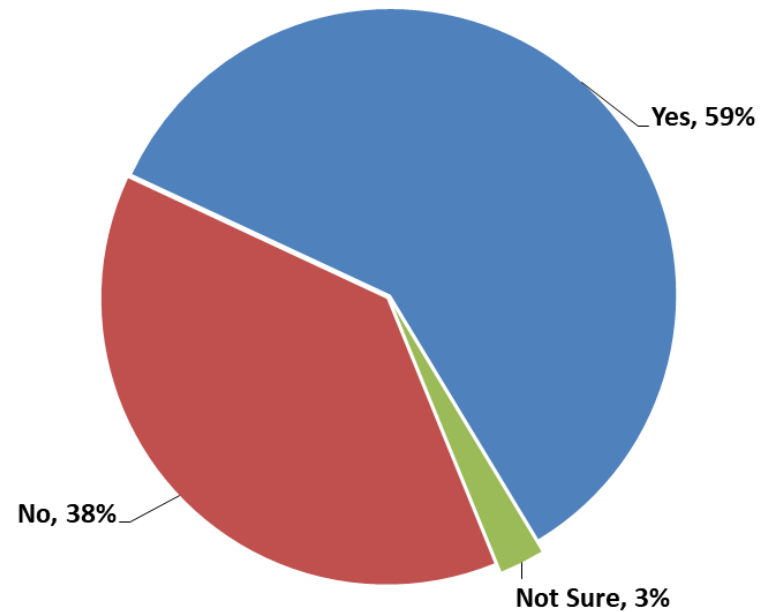


Additional Screening

Respondents who indicated they have dense breasts and had talked with their health care provider about their breast tissue type were asked if their health care provider had spoken to them about having added screening for their breasts.

- 59% of the respondents indicated that their health care provider had talked with them about having additional screening due to their having dense breast tissue.

Figure 9
Percent of Respondents Whose Health Care Provider Talked to Them About Having Additional Screening Due to Dense Breast Tissue
(For Respondents Who Had a Conversation with their Health Care Provider/Radiologist about Their Dense Breast Tissue)
(Base=197)



Q12. Did your health care provider talk to you about having added screening (e.g., ultrasound, MRI) for your breasts because you have dense tissue?

Information Sources

Respondents were asked where they had learned about the topic of breast density.

- The information source identified most often by the respondents, by far, was their health care provider (59%).
- The next most often used sources of information were talking with family, friends or colleagues and doing online searches/research, each identified by 17% of the respondents.

Figure 10
How Respondents Learned About the Topic of Breast Density
(Base=488)

From my health care provider	59%
Talking with family, friends, colleagues	17%
Doing online searches/research	17%
Magazine or newspaper	6%
Patient advocacy websites (e.g., AreYouDense.org, Komen.org, ACS.org)	6%
Radio or TV	4%
Social media	4%

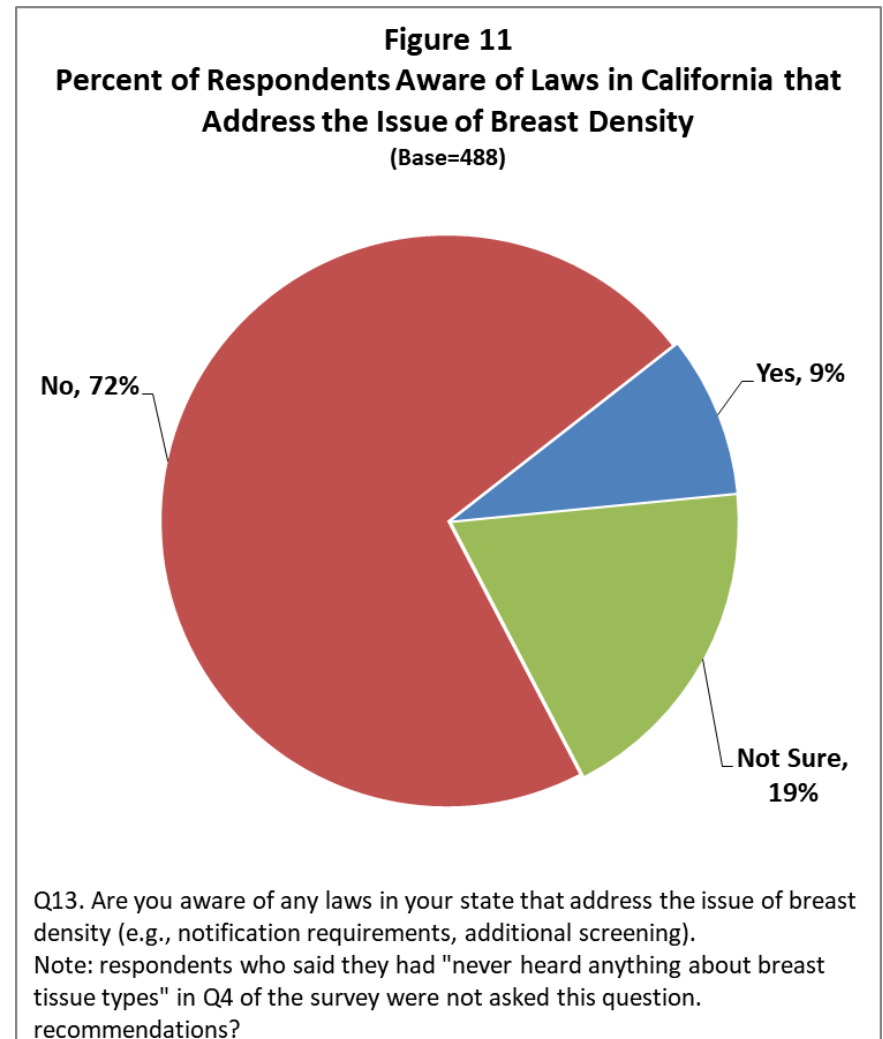
Q14. Where have you learned about breast density? Respondents were provided the list of options and were able to select as many as applied. There was also space to record "other" sources.

Note: Respondents who said they had "never heard anything about breast tissue types" in Q4 of the survey were not asked this question.

Awareness California State Breast Density Law

The respondents were asked if they were aware of any laws in California that address the issue of breast density.

- The vast majority of the respondents were not aware of a state law that addressed the issue of breast density (72% selected the “no” response and 19% selected “not sure”).
- Only 9% of the respondents were aware of the legislation.



Preference for California's Breast Density Law

Study respondents were shown a description of California's Breast Density Law (see below) and asked whether they would prefer that the law stay in place or be allowed to sunset (expire) in January 2019.

- 95% of the respondents preferred to have the law stay in place.

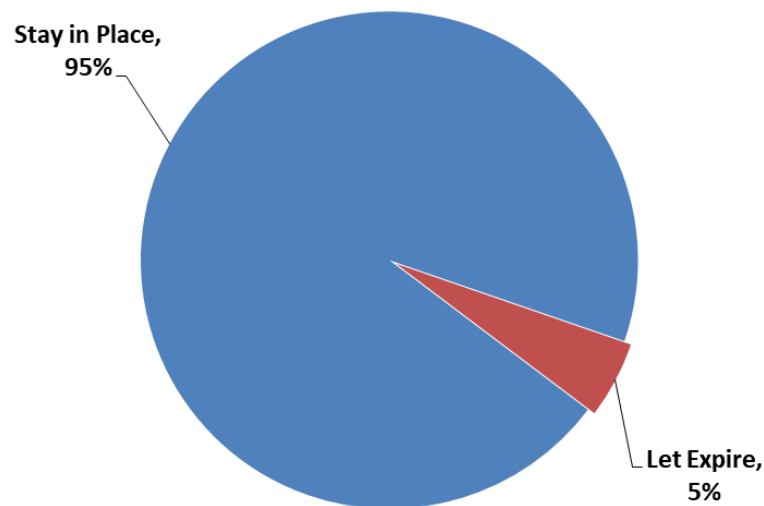
Description of California's Breast Density Law

California enacted a law that addressed the issue of breast density that became effective on April 1, 2013. The law requires imaging facilities to include in the patients' mammogram results letter a finding of dense breast tissue to those women whose mammogram shows dense breast tissue. The language of the letter is as follows:

"Your mammogram shows that your breast tissue is dense. Dense breast tissue is common and is not abnormal. However, dense breast tissue can make it harder to evaluate the results of your mammogram and may also be associated with an increased risk of breast cancer. This information about the results of your mammogram is given to you to raise your awareness and to inform your conversations with your doctor. Together, you can decide which screening options are right for you. A report of your results was sent to your physician."

This law is due to sunset (expire) in January 2019. If this happens, the imaging facilities will no longer be required to report dense tissue findings to patients in the mammogram results letter.

Figure 12
Respondent Preference for California's Breast Density Law
(Base=488)



Appendix A: Survey Instrument

Are You Dense Survey – California Only
(3/19/2018)

Screening Questions

0. Please record your gender:

- Female1
- Male.....2 (TERMINATE)

1. Into which age range do you fall:

- Under 25.....1 (TERMINATE)
- 25 to 39.....2 (TERMINATE)
- 40 to 54.....3
- 55 to 64.....4
- 65 to 74.....5
- 75 or older6 (TERMINATE)

2. What state do currently you live in: (DROP DOWN MENU OF STATES, TERMINATE IF DO NOT LIVE IN U.S. OR LIVE IN WASHINGTON DC)

3. When is the last time you had a mammogram:

- Have never had a mammogram1 (TERMINATE)
- Within the last 2 years.....2
- More than 2 years ago3 (TERMINATE)

Main Survey Questions

4. How knowledgeable are you about the topic of breast tissue types (e.g., fatty tissue, dense tissue)?

- Very knowledgeable..... 1
- Fairly knowledgeable..... 2
- Not very knowledgeable 3
- I've never heard anything about breast tissue types 4

5. Please record your level of agreement or disagreement with the following statements:

Completely Mostly Neither Agree Mostly Completely
Agree Agree nor Disagree Disagree Disagree

- a. It's important that every woman know her type of breast tissue (e.g., fatty tissue, dense tissue) 1..... 2.....3 45
- b. I would prefer to know my breast tissue type than not know 1..... 2.....3 45

IF Q4=4, SKIP TO Q15

6. To the best of your knowledge, what is the impact of having dense breast tissue on a mammogram’s ability to correctly detect cancer?

(PROGRAMMING NOTE: For about ½ of the respondents codes 1 and 3 will be flipped)

- Dense breasts make it easier to see cancer on a mammogram 1
- Dense breasts do not affect the ability to see cancer on a mammogram 2
- Dense breasts make it more difficult to see cancer on a mammogram 3
- I don’t know..... 4

7. Having dense breasts:

(PROGRAMMING NOTE: For about ½ of the respondents the order of the response codes will be flipped)

- Does not put a woman at increased risk for breast cancer 1
- Puts a woman at increased risk for breast cancer 2

8. Do you know what type of tissue your breasts have (e.g., fatty breasts, dense breasts)?

- Yes1
- No2 SKIP TO Q13
- Not sure3 SKIP TO Q13

9. How did you learn about what type of tissue your breasts have?

Don’t
Yes No Remember

- a. It was in my mammogram results letter 1 2 3
- b. A conversation with my healthcare provider 1 2 3
- c. A conversation with the radiologist..... 1 2 3

10. (ASK IF Q9b=1 or Q9c=1) Who initiated the conversation about your breast tissue?

- I did1
- My doctor or radiologist did..... 2
- Don’t remember/not sure..... 3

11. Do you have dense breasts?

- Yes1
- No 2

12. (ASK IF (Q9b=1 OR Q9c=1) AND Q11=1) Did your healthcare provider talk to you about having added screening (e.g., ultrasound, MRI) for your breasts because you have dense tissue?

- Yes1
- No2
- Not sure3

13. Are you aware of any laws in your state that address the issue of breast density (e.g., notification requirements, additional screening recommendations)?

- Yes1
- No2
- Not sure3

13a. (ASKED ONLY OF CALIFORNIA RESIDENTS) California enacted a law that addressed the issue of breast density that became effective on April 1, 2013. The law requires imaging facilities to include in the patients' mammogram results letter a finding of dense breast tissue to those women whose mammogram shows dense breast tissue. The language of the letter is as follows:

"Your mammogram shows that your breast tissue is dense. Dense breast tissue is common and is not abnormal. However, dense breast tissue can make it harder to evaluate the results of your mammogram and may also be associated with an increased risk of breast cancer. This information about the results of your mammogram is given to you to raise your awareness and to inform your conversations with your doctor. Together, you can decide which screening options are right for you. A report of your results was sent to your physician."

This law is due to sunset (expire) in January 2019. If this happens, the imaging facilities will no longer be required to report dense tissue findings to patients in the mammogram results letter.

Please record below your preference for what happens to the California breast density law:

- I prefer that the law stay in place past January 2019 1
- I prefer that the law be allowed to sunset or expire in January 2019 2 **SKIP TO Q13c**

13b. (ASK IF Q13a=1) Why do you prefer that the law stay in place?

GO TO Q14

13c. (ASK IF Q13a=2) Why do you prefer that the law be allowed to sunset or expire?

14. Where have you learned about the topic of breast density? *Please select all that they apply.*

- From my healthcare provider..... 1
- On patient advocacy websites (e.g., AreYouDense.org, Komen.org, ACS.org)..... 2
- Talking with family, friends, colleagues 3
- From the radio or tv 4
- From a magazine or newspaper 5
- From social media 6
- Doing online searches/research..... 7
- Other (please specify: _____)..... 8
- None 9
- Don't remember..... 10

15. The last few questions will be used to compare responses by the different background characteristics of the women who participate in this survey.

Have you ever been diagnosed with breast cancer?

- Yes1
- No2
- Prefer not to answer3

16. Do you have a family member that has been diagnosed with breast cancer?

- Yes1
- No2
- Prefer not to answer3

17. Which of the following best describes your highest level of education:

- No high school diploma or GED..... 1
- High school graduate/GED 2
- Technical school/Associates degree.... 3
- Bachelor's degree 4
- Graduate degree 5
- Prefer not to answer 6

18. Please select the appropriate range for your 2017 total household income before taxes:

- Less \$25,000..... 1
- \$25,000-\$49,999 2
- \$50,000-\$74,999 3
- \$75,000-\$99,999 4
- 100,000-\$124,999 5
- \$125,000 or more..... 6
- Prefer not to answer 7

19. Which of the following race/ethnicity category do you most associate with:

- Asian 1
- Black 2
- Hispanic 3
- White 4
- Other 5
- Prefer not to answer 6

Thank you very much for taking the time to participate in our survey.

Appendix B: Confidence Range Chart

Chart of 95% Confidence Range

Sample Size	Percentage Result Obtained						
	50%	40% or 60%	30% or 70%	20% or 80%	10% or 90%	5% or 95%	1% or 99%
25	+/- 19.6	+/- 19.2	+/- 18.0	+/- 15.7	+/- 11.8	+/- 8.5	+/- 3.9
50	+/- 13.9	+/- 13.6	+/- 12.7	+/- 11.1	+/- 8.3	+/- 6.0	+/- 2.8
75	+/- 11.3	+/- 11.1	+/- 10.4	+/- 9.1	+/- 6.8	+/- 4.9	+/- 2.3
100	+/- 9.8	+/- 9.6	+/- 9.0	+/- 7.8	+/- 5.9	+/- 4.3	+/- 2.0
150	+/- 8.2	+/- 8.0	+/- 7.5	+/- 6.6	+/- 4.9	+/- 3.6	+/- 1.6
200	+/- 7.1	+/- 7.0	+/- 6.5	+/- 5.7	+/- 4.3	+/- 3.1	+/- 1.4
250	+/- 6.3	+/- 6.2	+/- 5.8	+/- 5.0	+/- 3.9	+/- 2.7	+/- 1.2
300	+/- 5.8	+/- 5.7	+/- 5.3	+/- 4.6	+/- 3.5	+/- 2.5	+/- 1.1
400	+/- 5.0	+/- 4.9	+/- 4.6	+/- 4.0	+/- 3.0	+/- 2.2	+/- 1.0
500	+/- 4.5	+/- 4.4	+/- 4.1	+/- 3.6	+/- 2.7	+/- 2.0	+/- 0.9
600	+/- 4.1	+/- 4.0	+/- 3.8	+/- 3.3	+/- 2.5	+/- 1.8	+/- 0.8
800	+/- 3.5	+/- 3.4	+/- 3.2	+/- 2.8	+/- 2.1	+/- 1.5	+/- 0.7
1,000	+/- 3.2	+/- 3.1	+/- 2.9	+/- 2.6	+/- 1.9	+/- 1.4	+/- 0.6