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Permalink

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Journal

Journal of the American College of Radiology, 19(5)

ISSN

1546-1440

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Publication Date

2022-05-01

DOI

10.1016/j.jacr.2022.02.025

Peer reviewed



Published in final edited form as:

J Am Coll Radiol. 2022 May ; 19(5): 615–624. doi:10.1016/j.jacr.2022.02.025.

Breast Density Knowledge in a Screening Mammography Population Exposed to Density Notification

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ClinicalTrials.gov: [NCT02980848](https://clinicaltrials.gov/ct2/show/study/NCT02980848);

Conflicts of Interest: Dr. Kerlikowske reports being a non-paid consultant for GRAIL for STRIVE study. Dr. Miglioretti reports royalties from Elsevier. Dr. Buist reports honorarium for her position on the Data Safety and Monitoring Board for WISDOM Study. The authors declare no other conflicts of interest.

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Abstract

Objective: Women are increasingly informed about their breast density due to state density reporting laws. However, accuracy of personal breast density knowledge remains unclear. We compared self-reported with clinically-assessed breast density, assessed knowledge of density implications and feelings about future screening.

Methods: From December 2017-January 2020 we surveyed women ages 40–74 years without prior breast cancer, with a normal screening mammogram in the prior year, and 1 recorded breast density measures in four Breast Cancer Surveillance Consortium registries with density reporting laws. We measured agreement between self-reported and Breast Imaging-Reporting and Data System breast density categorized as “ever-dense” if heterogeneously or extremely dense within the past 5 years or “never-dense” otherwise; knowledge of dense breast implications; and feelings about future screening.

Results: Survey participation was 28% (1,528/5,408) and 59% (896/1,528) of participants had ever-dense breasts. Concordance between self-report vs. clinical density was 76% (677/896) among women with ever-dense breasts; 14% (89/632) among never-dense. 34% (217/632) with never-dense breasts reported being told they had dense breasts. Desire for supplemental screening was more frequent among those who reported having dense breasts 29% (256/893) or asked to imagine having dense breasts 30% (152/513) vs. those reporting non-dense breasts 15% (15/102) ($p=0.003$, $p=0.002$, respectively). Women with never-dense breasts had 6.3-fold higher odds (95% CI:3.39–11.80) of accurate knowledge in states reporting density to all compared to states reporting only to women with dense breasts.

Discussion: Standardized communications of breast density results to all women may increase density knowledge and are needed to support informed screening decisions.

Summary Sentence:

Our results emphasize a need for both improved density communication and tools to support supplemental screening discussions; this need is heightened by pending implementation of national density reporting regulations.

Keywords

Breast Density; screening mammography; breast density notification; patient reported outcomes

Introduction

The Food and Drug Administration (FDA) proposed updates to the Mammography Quality Standards Act in February 2019, that would require radiology facilities to report breast density information to women and their providers to increase communication about their risk for breast cancer and screening options.^{1,2} Before this proposed update, 39 states and the District of Columbia had enacted breast density notification laws.³ Notification requirements vary substantially by state with some mandating reporting of breast density for all mammography encounters and others only if the woman had dense (heterogeneously or

extremely dense) breasts. Some states also link breast density reports with additional breast cancer screening and risk information.^{3–5} Variable reporting of breast density information may confuse women and limit the impact of state-based legislation.

Increased efforts by health systems to inform individuals about breast density have led to an increase in general awareness and understanding of the implications of breast density.^{6, 7} Implications include dense breast tissue's masking effect on the readability of mammographic imaging and density's classification as an independent risk factor for breast cancer.^{8, 9} Little has been done to understand if those who receive breast density information retain and understand information about their breast density. Individuals without accurate knowledge or understanding of their density may not engage in conversations with providers about their personal breast cancer risk or may harbor unnecessary worry.^{10, 11}

As part of a large study,¹² we surveyed women from several Breast Cancer Surveillance Consortium (BCSC)¹³ registries and compared individuals' self-reported breast density to density as recorded in medical records, individuals' knowledge of the implications of having dense breasts, and density's impact on feelings about future breast cancer screening. We explored potential correlates of density knowledge including whether persons lived in states where all individuals having mammography screening are notified of their density or if only individuals with dense breasts are notified.

Methods

Study setting and data sources:

The BCSC, which captures sociodemographic, breast cancer risk factor, and clinical data for each breast imaging exam, conducted a survey involving women invited through breast imaging registries in multiple states.¹³ For this report eligible participants received screening in a state that had enacted a breast density reporting law. This included participants from 15 mammography facilities from the Carolina Mammography Registry, Sacramento Area Breast Imaging Registry, San Francisco Mammography Registry, and Vermont Breast Cancer Surveillance System.¹³

Participants:

We sampled women who received a screening mammogram within 12-months of survey completion, were screened between 40 and 74 years of age, had 1 recorded breast density measurement, had no abnormal findings or recall for additional imaging on their most recent screening exam, and had no personal history of breast cancer. Individuals were sampled by registry according to imaging modality (digital mammogram or digital breast tomosynthesis), age, race/ethnicity, and breast density (dense, non-dense) to ensure adequate representation across demographic groups.

Recruitment:

Eligible survey participants were identified from BCSC registry databases and mailed invitation letters for a web-based survey (with option to request a paper survey) conducted between December 2017 and January 2020. A \$2 bill incentive was included with mailed

invitations^{14, 15} for all registries except one. Surveys could be completed through an internet link provided in the invitation letter. A unique ID and access code were provided to each invitee. Up to three reminder postcards were sent for non-responders. Participants at three of the four registries were entered for a chance to win a \$100 gift card with one winner per registry. All survey responses were collected on a secure electronic platform. Participating institutions received approval from their institutional review boards.

Measures, Definitions, and Outcomes:

Our survey development was informed by focus groups that explored women's knowledge, perceptions, and experiences with breast cancer screening.¹⁶

Demographics—Age, education, insurance type, screening frequency, and previous recall for additional imaging were self-reported through our survey. Race/ethnicity and first-degree family history of breast cancer were provided through self-reported BCSC health history questionnaires at the time of breast imaging. BCSC 5-year invasive cancer risk was calculated using a combination of survey and registry data and the BCSC version 2 risk calculator.¹⁷

Breast Density Classification and Knowledge—Our primary outcome was percentage agreement between self-reported and Breast Imaging-Reporting and Data System (BI-RADS) breast density. Breast density measurements from five years before the survey date were obtained from BCSC registry databases. Breast density was recorded as part of routine clinical practice by the interpreting radiologist as a=almost entirely fat, b=scattered fibroglandular densities, c=heterogeneously dense, or d=extremely dense. BI-RADS a and b were considered “non-dense” breasts and BI-RADS c and d were considered “dense” breasts.¹⁸ Based on survey participant's mammography screening histories over the prior five years, they were classified in mutually exclusive categories as “ever-dense” or “never-dense” according to whether BI-RADS c or d were ever observed in those five years or not.

We collected self-reported density by asking participants “have you ever been told by a health care provider that you have dense breasts” and calculated the percentage of individuals with self-reported density concordant with their clinical BI-RADS density classification (ever vs. never-dense over the prior five years). If an individual reported ever being told they had dense breasts and had a mammogram resulting in a clinical BI-RADS density c or d, they were categorized as having accurate knowledge of their density. Likewise, if an individual reported never being told they had dense breasts and did not have a mammogram resulting in BI-RADS density c or d, they were categorized as having accurate knowledge.

Among participants who reported ever being told their breast density and who completed the web survey, we compared their BI-RADS four-category density as reported on their most recent screening mammogram with their self-reported density and report percentage correct per BI-RADS density category.

Breast Density Implications and Feelings About Future Screening—To assess knowledge of the implications of breast density, we asked what does, or what would, having

dense breasts mean with a list of responses for which participants could check all that applied (see Appendix). To assess density's impact on feelings about future breast cancer screening, we asked how does knowing your breast density affect your feelings about future breast cancer screening. For participants not knowing their density, we asked how do you think having dense breasts would affect your feelings about future breast cancer screening.

State Density Reporting Laws—Based on state density reporting laws in effect during our survey, and no earlier than five years prior to study initiation,^{4, 5, 19} mandatory density reporting was classified as going to: 1) only individuals with dense breasts (8 facilities from two registries) or 2) all individuals regardless of breast density (7 facilities from two registries).

Statistical Analysis:

Descriptive statistics were calculated for participant characteristics with comparisons made between those who were ever vs. never-dense using Chi-square tests. We calculated the odds of correct breast density knowledge (ever vs. never-dense over the prior five years), and stratified by ever or never-dense according to clinical records. We modeled the association between patient characteristics and each outcome using logistic regression. We used the backward stepwise method with the likelihood ratio test for model selection, which sequentially entered the most significant variable with $p < 0.10$ and then after each entered variable removed variables that did not maintain significance at $p < 0.05$. We purposely included breast density reporting legislation in our models and tested age categories, race/ethnicity, education, insurance type, screening frequency, previous recall, first degree family history of breast cancer, and BCSC 5-year breast cancer risk categories. Analyses were performed using STATA 16.1.

Results

Overall we had 28% participation (1,528/5,408). More than half (59%, 896/1,528) of participants had clinically-documented mammographically dense breasts in the prior five years. Overall, our sample was highly educated with 91% (1,371/1,514) having some college or graduate education, 99% (1,505/1,518) insured, and 95% (1,444/1,526) receiving regular breast cancer screening every 1–2 years (Table 1).

Breast Density Knowledge

Among individuals who were ever-dense, 76% (677/896) correctly reported being told they have dense breasts, 2% (16/896) reported being told they did not have dense breasts, and 23% (203/896) reported not being told or not knowing if they have been told their breast density (Table 2). This differed among individuals who were never-dense; 14% (89/632) correctly reported they did not have dense breasts, 34% (217/632) reported being told they have dense breasts, and 52% (326/632) reported not being told or not knowing if they have been told their density. Knowledge examined across the four BI-RADS density classifications is shown in Table 3.

Breast Density Implications and Feelings About Future Screening

The percentage who did not know what having dense breasts means was higher among individuals who did not know if they were told or were not told their density 41% (212/512) vs. those told they have non-dense breasts 7% (7/103) $p<0.001$; and higher among those told they have dense breasts 16% (142/894) vs. non-dense breasts 7% (7/103) $p=0.01$ (Figure 1). Overall, 62% (931/1,509) knew dense breasts make it harder to detect cancer, but only 13% (191/1,509) knew that having dense breasts means increased breast cancer risk.

Confidence that a mammogram will find any cancer in their breasts was higher for those who reported being told they have non-dense 25% (25/102) vs. dense breasts 8% (71/893) $p<0.001$. Confidence was also higher for women told they have non-dense breasts compared to women who did not know their density and were asked how they would feel if they had dense breasts 3% (14/513) $p<0.001$. Individuals who reported being told they have dense breasts more frequently reported that they take breast cancer screening more seriously 30% (271/893) compared to those told they have non-dense breasts 10% (10/102) $p<0.001$. Desire for another type of breast cancer screening test in addition to a mammogram was higher for those who reported being told they have dense breasts 29% (256/893) or asked to imagine being told they have dense breasts 30% (152/513) than in those told they have non-dense breasts 15% (15/102) $p=0.003$ and $p=0.002$ respectively.

Correlates of Correct Breast Density Knowledge

Individuals whose breasts were never-dense in the prior five years had increased odds (odds ratio [OR]:6.32; 95% confidence interval [CI]: 3.39–11.80) of correctly knowing their density when they received their mammography in a state that reports density to all women, compared to states that report to only individuals with dense breasts (Table 4).

Among participants with never-dense breasts in the prior five years, having a high school degree or less was associated with a lower odds of correctly knowing their density compared to those with a 4-year college or post graduate degree (OR:0.32; 95% CI: 0.13–0.80; Table 4). Individuals with ever-dense breasts were also less likely to correctly know their density if they held a high school degree or less (OR:0.29; 95% CI: 0.16–0.54).

Among participants with ever-dense breasts, those who had a prior recall for additional imaging had increased odds of correctly reporting their density compared to those without a recall (OR:2.15; 95% CI: 1.46–3.16; Table 4). Among ever-dense breasts, odds of having correct density knowledge were increased among those with high BCSC breast cancer risk (OR:2.78; 95% CI: 1.49–5.21) vs. average risk.

Discussion

Breast density notification will soon be implemented in all states pending enactment of national density reporting regulations.² While density notification has the potential to increase woman and provider awareness of density, and support conversations about breast cancer risk and additional screening options,¹ this will only be successful to the extent that women and providers understand their notifications and information shared during clinical encounters. We found that a relatively high proportion of respondents with

mammographically dense breasts accurately knew their density. However, almost a quarter of these women with clinically dense breasts reported not knowing if they were told their density or never being told even though all participants received their mammograms in facilities with density notification for those with dense breasts. Furthermore, knowledge of the implications of breast density was mixed with a higher proportion of individuals with non-dense compared to dense breasts indicating an understanding of density's masking effect on ability to see cancers on mammograms. This suggests that density reporting may be increasing knowledge and suggests there is opportunity for improvement to identify and reach populations that may be missed under current practices.

We found that about one third of individuals with no history of dense breasts in the prior five years reported they had been told they have dense breasts. While participants may have been given density information more than five years ago or at a non-BCSC facility, this raises the possibility that they may have misunderstood information shared with them about their breast density especially considering that these participants consistently had non-dense BI-RADS measurements in the prior five years. Previous work found density notifications to be above the average person's literacy level.^{20, 21} We found that lower education was highly associated with decreased odds of correctly knowing one's own breast density. Similar results have been found in other studies.^{22, 23} This adds further evidence to previous conclusions that efforts should be made to improve density notification language to be at a level accessible to a wide range of literacy levels.²⁰

A primary goal of breast density reporting is to equip women with knowledge that supports conversations with their providers about their breast cancer risks and screening options.² Yet, women do not necessarily initiate these discussions,²⁵ and the ever growing complexities of providers' clinical and administrative responsibilities require that clinicians have appropriate supports to facilitate these conversations. When asked to consider breast density's impact on their feelings about future breast cancer screening, participants who reported being told they have dense breasts were less confident in mammography and more frequently wanted additional screening than women told they have non-dense breasts. Some individuals with dense breasts are not at increased breast cancer risk,²⁶ and evidence suggests that other risk factors should be considered to better inform the trade-offs between benefits and harms of supplemental screening.^{27, 28} Supplemental screening comes with potential for false-positives,⁸ and uses limited resources in constrained health systems, a particularly relevant problem during the COVID-19 pandemic.²⁹ This further highlights the importance of support systems for provider communications with women to discuss potential benefits and harms of supplemental screening.

While there is growing evidence to support supplemental imaging for certain breast cancer risk groups,^{26, 30} more must be done to reach consensus on evidence-based guidelines for supplemental screening. Guidelines should address when these conversations should be prompted. A Mayo clinic staff physician survey found variability in communications with women related to breast density,³¹ and focus groups we conducted in preparation for this survey¹⁶ found that women reported having little or no discussion about breast density at the time of screening.

Physician awareness of supplemental imaging for breast cancer screening is likely to have increased given state density laws and the pending FDA rule, but new clinical workflow implementations have long been documented as a challenging process due to resource and time constraints, and resistance to changing institutional practice norms.^{32–34} Decision support tools for supplemental screening should be considered to minimize the additional challenge brought by ambiguity about which additional tests are best for which women.^{8, 35}

Density reporting legislation requiring all breast density categories be included in mammography reports shared with women was associated with an increased odds of density knowledge for individuals with never-dense breasts. While having non-dense breasts does not necessarily equate to low or average breast cancer risk, our results indicate that individuals who think they have non-dense breasts have lower levels of impact on their feelings about future screening and more confidence in mammography. Potential benefits of density notifications for those with non-dense breasts is worth further exploration.

Limitations

Our interpretations are limited by the cross-sectional design of our study. Response bias is a common concern with survey work.^{36, 37} While we made efforts to invite a socio-demographically diverse sample, participants who took our survey predominantly identified as holding a bachelor's or graduate degree. Our categorization of density knowledge as correct or incorrect may have errors if participants were told their density from a mammography examination completed prior to the five year period included in our clinical data or from a non-BCSC facility. Radiologists' interpretations of mammographic imaging varies with the highest variation between BI-RADS b and c^{12, 38} (a change from never to ever-dense or vice versa). Although breast density may change over a woman's lifetime, with aging the change is to lower density tissue.³⁹ By including all measurements from the prior five years of BI-RADS c or d in our ever-dense classification, we accounted for the chance that a woman was told she had dense breasts even in women who may have also had BI-RADS a or b (non-dense). The BCSC collects data from geographically diverse registries, yet only three states were used to form our binary density law reporting variable. There may be state specific biases impacting the association between density notification law and correct knowledge of density that we were unable to measure, including the health system incorporating density information in mammography reports for all patients when it is not mandated by state legislation.

While most women with ever-dense breasts correctly knew their density most with never-dense breasts did not. Standardized communications of density results to all women may increase density knowledge. Desire for additional breast cancer screening was highest among women who thought they had dense breasts and those who did not know their density. Our results emphasize a need for both improved density communication and tools to support supplemental screening discussions; this need is heightened by pending implementation of national density reporting regulations.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments:

Research reported in this work was funded through a Patient-Centered Outcomes Research Institute (PCORI) Program Award (PCS-1504-30370). Data collection for this research was additionally supported by the Breast Cancer Surveillance Consortium with funding from the National Cancer Institute (P01CA154292, U54CA163303). The collection of UC Davis data was supported in part by the UC Davis Comprehensive Cancer Center, the Placer County Breast Cancer Foundation, and the UC Davis Clinical and Translational Science Center. The collection of cancer data used in this study was supported in part by several U.S. state public health departments and cancer registries (<https://www.bscs-research.org/about/work-acknowledgement>). All statements in this report, including its findings and conclusions, are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee, nor those of the National Cancer Institute or the National Institutes of Health. We thank the participating women, mammography facilities, and radiologists for the data they have provided for this study. You can learn more about the BCSC at: <http://www.bscs-research.org/>.

Primary Funding Source:

PCORI/PCS-1504-30370;

Data Statement:

The authors declare that they had full access to all of the data in this study and the authors take complete responsibility for the integrity of the data and the accuracy of the data analysis.

Appendix A

Self-reported Breast Density:

1. Have you ever been told by a health care provider (doctor, nurse, nurse practitioner, or technician) that you have “dense breasts”?
 - a. I was told I have dense breasts
 - b. I was told I don’t have dense breasts
 - c. I have not been told if I have dense breasts or not
 - d. I don’t know
2. Only displayed for the on-line version of the survey. If chose “a” (told dense) of “b” (told non-dense) for Question 1 answer: What is your breast density?
 - a. Almost entirely fatty
 - b. Scattered areas of fibroglandular density
 - c. Heterogeneously dense tissue
 - d. Extremely dense tissue
 - e. I don’t know

Knowledge of Breast Density Implications:

5. If chose “*a*” (told dense) for Question 1 answer: What does having dense breasts mean to you?

If chose “*b*” (told non-dense), “*c*” (not told) or “*d*” (don’t know) for Question 1 answer: What would having dense breasts mean to you?

(Please check all that apply.)

- a. It is/would be hard to see cancers on my mammogram
- b. It is/would be easier to see cancers on my mammogram
- c. It is/would be more difficult for a doctor to read my mammogram
- d. My mammogram often has/ would often have to be repeated to get a better picture;
- e. Other imaging tests are/ would be needed to see breast cancer
- f. I might be more likely to get breast cancer
- g. I might be less likely to get breast cancer
- h. I don’t know what it means/ would mean

Breast Density Future Screening Feelings:

6. If chose “*a*” (told dense) for Question 1 answer: How does having dense breasts affect your feelings about future breast cancer screening?

If chose “*b*” (told non-dense) for Question 1 answer: How does knowing your breast density affect your feelings about future breast cancer screening?

If chose “*c*” (not told) or “*d*” (don’t know) for Question 1 answer: Do you think having dense breasts would affect your feelings about future breast cancer screening?

(Please check all that apply.)

- a. It doesn’t/would not change how I feel
- b. I am worried/would worry about breast cancer screening
- c. I want/would want another type of breast cancer screening test in addition to my mammogram
- d. I want/would want another type of breast cancer screening test other than a mammogram
- e. I want/would want to have breast cancer screening more often
- f. I’m/ would be less likely to get a mammogram on a regular basis
- g. I take/would take breast cancer screening more seriously
- h. I am/would be confident that mammograms will find any cancer in my breasts

- i. I am not/would not be confident that mammograms will find cancer early enough
- j. I don't know (only shown if chose "c"(not told) or "d" (don't know) for Question 1)

References:

1. US Food and Drug Administration. FDA advances landmark policy changes to modernize mammography services and improve their quality. Accessed January 14, 2021, <https://www.fda.gov/news-events/press-announcements/fda-advances-landmark-policychanges-modernize-mammography-services-and-improve-their-quality>
2. FDA. Mammography Quality Standards Act Proposed Rule. Federal Register. March 28, 2019;84(60)
3. DenseBreast-info Accessed December 11, 2020, <https://densebreast-info.org/legislative-information/national-reporting-standard/>
4. DHHS-NC. Article 7 Chronic Disease: Part 1 Cancer https://schs.dph.ncdhhs.gov/units/ccr/documents/Article7_pages1_3.pdf
5. Vermont General Assembly. 18 VSA § 158. Accessed November 23, 2020, <https://legislature.vermont.gov/statutes/section/18/004/00158>
6. Cappello NM, Richetelli D, Lee CI. The Impact of Breast Density Reporting Laws on Women's Awareness of Density-Associated Risks and Conversations Regarding Supplemental Screening With Providers. *J Am Coll Radiol*. Feb 2019;16(2):139–146. doi:10.1016/j.jacr.2018.08.009 [PubMed: 30287178]
7. Santiago-Rivas M, Benjamin S, Andrews JZ, Jandorf L. Breast Density Awareness and Knowledge, and Intentions for Breast Cancer Screening in a Diverse Sample of Women Age Eligible for Mammography. *J Cancer Educ*. Feb 2019;34(1):90–97. doi:10.1007/s13187-017-1271-y [PubMed: 28808894]
8. Melnikow J, Fenton JJ, Whitlock EP, et al. U.S. Preventive Services Task Force Evidence Syntheses, formerly Systematic Evidence Reviews. Supplemental Screening for Breast Cancer in Women With Dense Breasts: A Systematic Review for the US Preventive Service Task Force. Agency for Healthcare Research and Quality (US); 2016.
9. Institute of M, National Research Council Committee on New Approaches to Early D, Diagnosis of Breast C. The National Academies Collection: Reports funded by National Institutes of Health. In: Joy JE, Penhoet EE, Petitti DB, eds. *Saving Women's Lives: Strategies for Improving Breast Cancer Detection and Diagnosis*. National Academies Press (US) Copyright © 2005, National Academy of Sciences.; 2005.
10. Yeh VM, Schnur JB, Margolies L, Montgomery GH. Dense breast tissue notification: impact on women's perceived risk, anxiety, and intentions for future breast cancer screening. *J Am Coll Radiol*. Mar 2015;12(3):261–6. doi:10.1016/j.jacr.2014.11.001 [PubMed: 25556313]
11. Pacsi-Sepulveda AL, Shelton RC, Rodriguez CB, Coq AT, Tehranifar P. "You probably can't feel as safe as normal women": Hispanic women's reactions to breast density notification. *Cancer*. Jun 15 2019;125(12):2049–2056. doi:10.1002/cncr.32002 [PubMed: 30768781]
12. Assessing Breast Density's Value in Imaging - A Comparative Effectiveness Study (BCSC-ADVANCE). NIH. Accessed August 11, 2021. <https://clinicaltrials.gov/ct2/show/NCT02980848>
13. Breast Cancer Surveillance Consortium Accessed December 22, 2020, <https://www.bcscresearch.org/>
13. Smith MG, Witte M, Rocha S, Basner M. Effectiveness of incentives and follow-up on increasing survey response rates and participation in field studies. *BMC Med Res Methodol*. Dec 5 2019;19(1):230. doi:10.1186/s12874-019-0868-8 [PubMed: 31805869]
14. Perneger TV, Etter JF, Rougemont A. Randomized trial of use of a monetary incentive and a reminder card to increase the response rate to a mailed health survey. *Am J Epidemiol*. Nov 1 1993;138(9):714–22. doi:10.1093/oxfordjournals.aje.a116909 [PubMed: 8237986]

15. Schifferdecker KE, Tosteson ANA, Kaplan C, et al. Knowledge and Perception of Breast Density, Screening Mammography, and Supplemental Screening: in Search of “Informed”. *J Gen Intern Med.* Jun 2020;35(6):1654–1660. doi:10.1007/s11606-019-05560-z [PubMed: 31792869]
16. BCSC. NCI-funded Breast Cancer Surveillance Consortium (P01 CA154292 and HHSN261201100031C). Accessed August 27, 2019, <https://tools.bcscc.org/BC5yearRisk>.
17. American College of Radiology. Breast Imaging Reporting and Data System (BI-RADS). Reston, VA: American College of Radiology; 2013.
18. Simitian A, Runner Nielsen. California Senate Bill No. 1538. Accessed November 23, 2020, https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=201120120SB1538
20. Kressin NR, Gunn CM, Battaglia TA. Content, Readability, and Understandability of Dense Breast Notifications by State. *Jama.* Apr 26 2016;315(16):1786–8. doi:10.1001/jama.2016.1712 [PubMed: 27115382]
19. Nguyen DL, Ambinder EB, Jones MK, Mullen LA, Harvey SC. Improving State-Mandated Breast Density Notifications. *J Am Coll Radiol.* Mar 2020;17(3):384–390. doi:10.1016/j.jacr.2019.08.023 [PubMed: 31541654]
20. Nickel B, Copp T, Brennan M, Farber R, McCaffery K, Houssami N. The Impact of Breast Density Information or Notification on Women’s Cognitive, Psychological, and Behavioral Outcomes: A Systematic Review. *J Natl Cancer Inst.* Feb 5 2021;doi:10.1093/jnci/djab016
21. Kyanko KA, Hoag J, Busch SH, et al. Dense Breast Notification Laws, Education, and Women’s Awareness and Knowledge of Breast Density: a Nationally Representative Survey. *J Gen Intern Med.* Jul 2020;35(7):1940–1945. doi:10.1007/s11606-019-05590-7 [PubMed: 31916210]
22. Warner ET, Kennedy M, Maschke A, Hopkins MF, Wernli K, Gunn CM. Evaluation of existing patient educational materials and development of a brochure for women with dense breasts. *Breast.* Apr 2020;50:81–84. doi:10.1016/j.breast.2020.02.001 [PubMed: 32086135]
23. Rhodes DJ, Radecki Breitkopf C, Ziegenfuss JY, Jenkins SM, Vachon CM. Awareness of breast density and its impact on breast cancer detection and risk. *J Clin Oncol.* Apr 1 2015;33(10):1143–50. doi:10.1200/jco.2014.57.0325 [PubMed: 25732156]
24. Kerlikowske K, Sprague BL, Tosteson ANA, et al. Strategies to Identify Women at High Risk of Advanced Breast Cancer During Routine Screening for Discussion of Supplemental Imaging. *JAMA Intern Med.* Jul 1 2019;179(9):1230–9. doi: 10.1001/jamainternmed.2019.1758 [PubMed: 31260054]
25. Schousboe JT, Kerlikowske K, Loh A, Cummings SR. Personalizing mammography by breast density and other risk factors for breast cancer: analysis of health benefits and cost-effectiveness. *Ann Intern Med.* Jul 5 2011;155(1):10–20. doi:10.7326/0003-4819-155-1-201107050-00003 [PubMed: 21727289]
26. Mandelblatt JS, Stout NK, Schechter CB, et al. Collaborative Modeling of the Benefits and Harms Associated With Different U.S. Breast Cancer Screening Strategies. *Ann Intern Med.* Feb 16 2016;164(4):215–25. doi:10.7326/m15-1536 [PubMed: 26756606]
29. Lowry KP, Bissell M, Miglioretti DL, et al. Breast Biopsy Recommendations and Breast Cancers Diagnosed during the COVID-19 Pandemic. *Radiology.* Oct 19 2021:211808. doi:10.1148/radiol.2021211808
27. Berg WA, Zhang Z, Lehrer D, et al. Detection of Breast Cancer With Addition of Annual Screening Ultrasound or a Single Screening MRI to Mammography in Women With Elevated Breast Cancer Risk. *JAMA.* 2012;307(13):1394–1404. doi:10.1001/jama.2012.388 [PubMed: 22474203]
28. Maimone S, McDonough MD, Hines SL. Breast Density Reporting Laws and Supplemental Screening-A Survey of Referring Providers’ Experiences and Understanding. *Curr Probl Diagn Radiol.* Mar-Apr 2017;46(2):105–109. doi:10.1067/j.cpradiol.2016.05.001 [PubMed: 27289137]
29. Lee CI, Lehman CD. Digital Breast Tomosynthesis and the Challenges of Implementing an Emerging Breast Cancer Screening Technology Into Clinical Practice. *J Am Coll Radiol.* Nov 2016;13(11s):R61–r66. doi:10.1016/j.jacr.2016.09.029 [PubMed: 27814817]
30. Casey CM, Parker EM, Winkler G, Liu X, Lambert GH, Eckstrom E. Lessons Learned From Implementing CDC’s STEADI Falls Prevention Algorithm in Primary Care. *Gerontologist.* Aug 2017;57(4):787–796. doi:10.1093/geront/gnw074 [PubMed: 27130270]

31. Drainoni ML, Koppelman EA, Feldman JA, et al. Why is it so hard to implement change? A qualitative examination of barriers and facilitators to distribution of naloxone for overdose prevention in a safety net environment. *BMC Res Notes*. Oct 18 2016;9(1):465. doi:10.1186/s13104-016-2268-z [PubMed: 27756427]
32. Chima S, Reece JC, Milley K, Milton S, McIntosh JG, Emery JD. Decision support tools to improve cancer diagnostic decision making in primary care: a systematic review. *Br J Gen Pract*. Dec 2019;69(689):e809–e818. doi:10.3399/bjgp19X706745 [PubMed: 31740460]
33. Sheikh K, Mattingly S. Investigating non-response bias in mail surveys. *J Epidemiol Community Health*. Dec 1981;35(4):293–6. doi:10.1136/jech.35.4.293 [PubMed: 6461711]
34. Ebert JF, Huibers L, Christensen B, Christensen MB. Paper- or Web-Based Questionnaire Invitations as a Method for Data Collection: Cross-Sectional Comparative Study of Differences in Response Rate, Completeness of Data, and Financial Cost. *J Med Internet Res*. Jan 23 2018;20(1):e24. doi:10.2196/jmir.8353 [PubMed: 29362206]
35. Sprague BL, Conant EF, Onega T, et al. Variation in Mammographic Breast Density Assessments Among Radiologists in Clinical Practice: A Multicenter Observational Study. *Ann Intern Med*. Oct 4 2016;165(7):457–464. doi:10.7326/m15-2934 [PubMed: 27428568]
39. Checka CM, Chun JE, Schnabel FR, Lee J, Toth H. The relationship of mammographic density and age: implications for breast cancer screening. *AJR Am J Roentgenol*. Mar 2012;198(3):W292–5. doi:10.2214/ajr.10.6049 [PubMed: 22358028]

Take home Points:

- A low proportion of women with never-dense and 76% with ever-dense breasts correctly reported their breast density.
- Density reporting to all breast density categories was associated with an increased odds of density knowledge for individuals with never-dense breasts.
- Providers engaging in decision making with women will need tools to keep informed of evolving evidence on supplemental screening, who may benefit most from it, how to balance any potential benefits with potential harms, and how best to share that information with women.

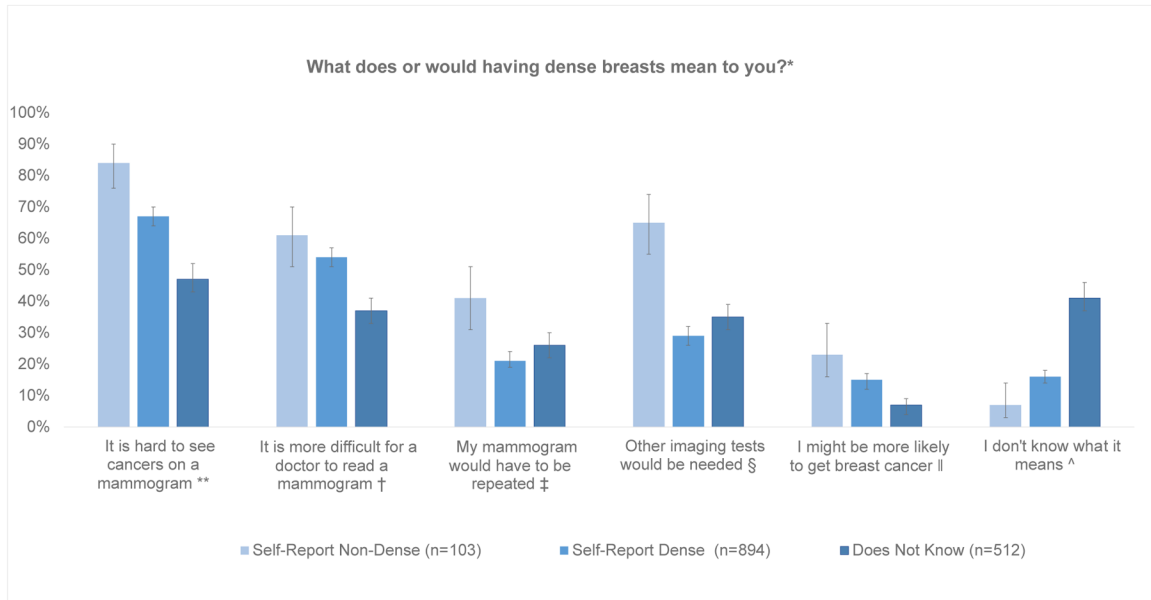


Figure 1.

Knowledge of Breast Density Implications by Self-Reported Breast Density~

* Check all that apply, Error bars = 95% confidence intervals on frequency of response

** For all comparisons $p < 0.001$

† Self-report non-dense vs. Does not know $p < 0.001$; Self-report dense vs. Does not know $p < 0.001$

‡ Self-report non-dense vs. Does not know $p = 0.002$; Self-report dense vs. Does not know $p < 0.001$

§ Self-report non-dense vs. Does not know $p < 0.001$; Self-report dense vs. Does not know $p = 0.02$; Self-report non-dense vs. Self-report dense $p < 0.001$

|| Self-report non-dense vs. Does not know $p < 0.001$; Self-report dense vs. Does not know $p < 0.001$; Self-report non-dense vs. Self-report dense $p = 0.03$

^ Self-report non-dense vs. Does not know $p < 0.001$; Self-report dense vs. Does not know $p < 0.001$; Self-report non-dense vs. Self-report dense $p = 0.01$

~ All comparisons not listed did not reach statistical significance ($p > 0.05$)

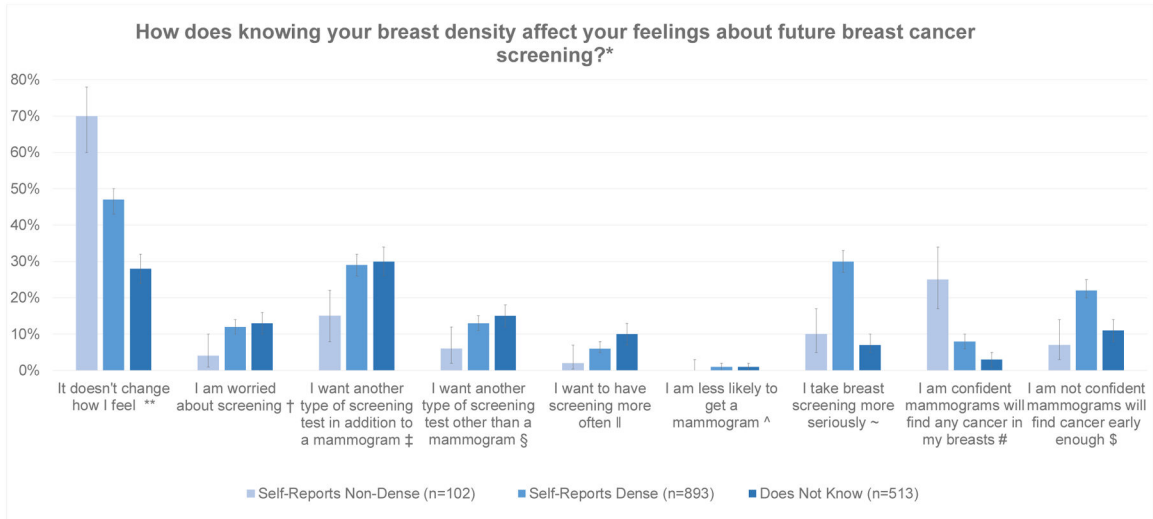


Figure 2.
Breast Density Impact on Feelings About Future Screening by Self-Reported Breast Density⁺

* Check all that apply, Error bars = 95% confidence intervals on frequency of response, Question stem if woman does not know her breast density: Do you think having dense breasts would affect your feelings about future breast cancer screening?

** For all comparisons p <0.001

† Self-report non-dense vs. Does not know p=0.01; Self-report non-dense vs. Self-report dense p=0.01

‡ Self-report non-dense vs. Does not know p=0.002; Self-report non-dense vs. Self-report dense p=0.003

§ Self-report non-dense vs. Does not know p=0.02

|| Self-report non-dense vs. Self-report dense p=0.01; Self-report non-dense vs. Does not know p=0.01

^ No statistically significant differences (p 0.05)

~ Self-report non-dense vs. Self-report dense p<0.001; Self-report dense vs. Does not know p<0.001

For all comparisons p <0.001

\$ Self-report non-dense vs. Self-report dense p<0.001; Self-report dense vs. Does not know p<0.001

+ All comparisons not listed did not reach statistical significance (p 0.05)

Table 1.

Survey Participant Demographic Characteristics by Binary BI-RADS* Breast Density Measured on Mammography or DBT† Screening Exams in 5 Years Prior to Survey

Characteristics	Participants Overall n=1,528 (%)	Binary BI-RADS* Breast Density Measured on Exams in Prior 5 Years		p-value
		Never-Dense** n=632 (%)	Ever-Dense** n=896 (%)	
Age, years ‡§				0.15
40–49	446 (29)	177 (28)	269 (30)	
50–64	569 (37)	225 (36)	344 (38)	
65–75	513 (34)	230 (36)	283 (32)	
Race-Ethnicity				<0.001
Non-Hispanic White	996 (65)	417 (66)	579 (66)	
Non-Hispanic Black	110 (7)	64 (10)	46 (5)	
Asian/Native Hawaiian/Pacific Islander	126 (8)	30 (05)	96 (11)	
Hispanic	181 (12)	77 (12)	104 (12)	
Native American/Alaskan Native	14 (1)	4 (1)	10 (1)	
Other/Unknown/Mixed	101 (7)	40 (6)	61 (7)	
Education ‡				0.001
High School or Less	143 (9)	73 (12)	70 (8)	
Some College or 2-year Degree	415 (27)	192 (31)	223 (25)	
4-year College or Post Graduate	956 (63)	361 (58)	595 (67)	
Insurance Status ‡				0.06
Medicare	529 (35)	238 (38)	291 (33)	
Private/Other	953 (63)	371 (59)	582 (65)	
Medicaid	23 (2)	10 (2)	13 (1)	
Uninsured	13 (1)	8 (1)	5 (1)	
Screening Frequency ‡				0.38
Annual	1,195 (78)	482 (76)	713 (80)	
Biennial	249 (16)	111 (18)	138 (15)	
Triennial	34 (2)	14 (2)	20 (2)	
No Regular Screening	48 (3)	24 (4)	24 (3)	
First Degree Family History of Breast Cancer				0.39
Yes (vs. No)	341 (26)	134 (25)	207 (27)	
Previous Recall for Additional Imaging ‡				<0.001
Yes (vs. No)	814 (53)	294 (47)	520 (58)	
BCSC 5-year Risk ¶				<0.001
Low 0% - <1.00%	366 (24)	224 (36)	142 (16)	
Average 1.00% - 1.66%	581 (39)	290 (47)	291 (33)	
Intermediate 1.67% - 2.49%	360 (24)	80 (13)	280 (32)	
High >2.49%	192 (13)	22 (4)	170 (19)	

Characteristics	Participants Overall n=1,528 (%)	Binary BI-RADS* Breast Density Measured on Exams in Prior 5 Years		p-value
		Never-Dense** n=632 (%)	Ever-Dense** n=896 (%)	
State Breast Density Reporting Law Notifies for Dense and Non-Dense (vs. Dense only)	826 (54)	338 (53)	488 (54)	0.70

* BI-RADS = Breast Imaging-Reporting and Data System

† Digital Breast Tomosynthesis (DBT)

** Never-dense = Did not receive a BI-RADS c or d in prior 5 years; Ever-dense = Received a BI-RADS c or d in the prior 5 years

‡ Self-Reported through survey

§ Women 40–74 years at time of mammography screening were eligible for survey invitation. 16 women were 75 years old by the time they answered our survey

// Breast Cancer Surveillance Consortium (BCSC) risk calculation includes age, race, first-degree family history of breast cancer, history of benign breast disease, and BI-RADS breast density from BCSC databases

Table 2.

Self-Report of Breast Density by Binary BI-RADS* Breast Density in 5 Years Prior to Survey

Have you ever been told by a health care provider that you have “dense breasts”?	Participants Overall n=1,528 (%)	Binary BI-RADS* Breast Density Measured on Exams in Prior 5 Years	
		Never-Dense** n=632 (%)	Ever-Dense** † n=896 (%)
I was told dense breasts	894 (59)	217 (34)	677 (76)
I was told do not have dense breasts	105 (7)	89 (14)	16 (2)
I have not been told dense breasts or not	307 (20)	199 (31)	108 (12)
I don't know/no response	222 (15)	127 (20)	95 (11)

* BI-RADS = Breast Imaging-Reporting and Data System

** Never-dense = Did not receive a BI-RADS c or d in prior 5 years; Ever-dense = Received a BI-RADS c or d in the prior 5 years

† Chi-square $p < 0.001$ comparing self-report and clinically measured density

Table 3.

Self-Report of BI-RADS* Breast Density by Clinical BI-RADS Breast Density Measured at Most Recent Screening Exam

What is your breast density?	Overall n=999 (%)	Binary BI-RADS* Breast Density Measured on Screening Exams in Prior 5 Years			
		Non-Dense		Dense	
		Fatty n=63 (%)	Scattered n=293 (%)	Heterogeneously n=537 (%)	Extremely [†] n=106 (%)
Almost entirely fatty	50 (5)	27 (43)	17 (6)	3 (1)	3 (3)
Scattered areas of fibroglandular density	95 (10)	5 (8)	55 (19)	31 (6)	4 (4)
Heterogeneously dense tissue	92 (9)	0 (0)	12 (4)	74 (14)	6 (6)
Extremely dense tissue	90 (9)	1 (2)	8 (3)	50 (9)	31 (29)
I don't know/ no response	672 (67)	30 (48)	201 (69)	379 (71)	62 (58)

* BI-RADS = Breast Imaging-Reporting and Data System

[†] Chi-square $p < 0.001$ comparing self-report and clinically measured density

Table 4.

Association between participant characteristics and odds of Correct Knowledge of Personal Breast Density by Binary BI-RADS* Breast density in past 5 years

Characteristics	BI-RADS* Breast Density Measured on Screening Exams in 5 Years Prior to Survey			
	Never-Dense ^{**} , † (n=632)		Ever-Dense ^{**} , † (n=896)	
	Unadjusted OR [‡] (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age, years [§]				
40–49	1.85 (1.03–3.30)	--	1.81 (1.24–2.65)	4.03 (2.31–7.05)
50–64	1 [Reference]	--	1 [Reference]	1 [Reference]
65–75	1.59 (0.90–2.78)	--	1.67 (1.15–2.42)	1.21 (0.76–1.92)
Education				
High School or Less	0.40 (0.17–0.97)	0.32 (0.13–0.80)	0.24 (0.15–0.41)	0.29 (0.16–0.54)
Some College or 2-year Degree	0.43 (0.25–0.76)	0.33 (0.18–0.62)	0.52 (0.37–0.75)	0.57 (0.38–0.86)
4-year College or Post Graduate	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]
Insurance Status				
Medicare	1 [Reference]	--	1 [Reference]	--
Medicaid/Uninsured	0.85 (0.19–3.90)	--	0.31 (0.12–0.85)	--
Private/Other	1.24 (0.77–2.00)	--	0.87 (0.62–1.22)	--
Screening Frequency				
Annual	1 [Reference]	--	1 [Reference]	1 [Reference]
Biannual	0.73 (0.39–1.37)	--	0.89 (0.58–1.36)	1.39 (0.80–2.39)
Triannual or No Regular Screening	0.30 (0.07–1.29)	--	0.41 (0.22–0.76)	0.48 (0.22–1.01)
Previous Recall for Additional Imaging				
Yes (vs. No)	1.12 (0.71–1.76)	--	2.07 (1.51–2.83)	2.15 (1.46–3.16)
BCSC 5-year Risk				
Low 0% - <1.00%	1.35 (0.82–2.21)	--	1.00 (0.64–1.56)	0.43 (0.24–0.78)
Average 1.00% - 1.66%	1 [Reference]	--	1 [Reference]	1 [Reference]
Intermediate 1.67% - 2.49%	1.10 (0.54–2.27)	--	1.30 (0.89–1.90)	1.43 (0.88–2.32)
High >2.49%	1.51 (0.49–4.72)	--	2.54 (1.96–3.28)	2.78 (1.49–5.21)
State Breast Density Reporting Law				
Notifies for Dense and Non-Dense	5.24 (2.93–9.35)	6.32 (3.39–11.80)	0.70 (0.51–0.95)	0.63 (0.43–0.92)
Notifies for Dense Only	1 [Reference]	1 [Reference]	1 [Reference]	1 [Reference]

* BI-RADS = Breast Imaging-Reporting and Data System

** Never-dense = Did not receive a BI-RADS c or d in prior 5 years; Ever-dense = Received a BI-RADS c or d in the prior 5 years

† Never-dense group: Adjusted for Education and State Breast Density Reporting Law; Ever-dense group: Adjusted for Age, Education, Screening Frequency, BCSC 5-year Risk, and State Breast Density Reporting Law

‡ OR=odds ratio

§ Women 40–74 years at time of mammography screening were eligible for survey invitation. 16 women were 75 years old by the time they answered our survey

// Breast Cancer Surveillance Consortium (BCSC) risk calculation includes age, race, first-degree family history of breast cancer, history of benign breast disease, and BI-RADS breast density from BCSC databases

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