

Derek Nguyen MD<sup>1</sup>, Emily Ambinder MD<sup>1</sup>, Mary Kate Jones MD<sup>1</sup>, Lisa Mullen MD<sup>1</sup>, Susan Harvey MD<sup>2</sup>

Russell H. Morgan Department of Radiology and Radiological Sciences<sup>1</sup>, Johns Hopkins Hospital, Baltimore, MD

Division of Breast and Skeletal Health<sup>2</sup>, Hologic Inc., Danbury, CT

## Introduction

- Increased awareness of the relationship between dense breast tissue and breast cancer risk has led to state legislatures requiring notification statements alerting women that breast tissue density may impact their health.
- Currently, breast density notifications (BDNs) have become mandatory in 38 states<sup>1</sup>.
- BDNs are mailed directly to women as a component of their screening mammogram lay letter.
- Since 2016, the complex language of state-mandated BDNs has been challenged, as it is perceived to be beyond the comprehension of most patients<sup>2</sup>.

## Objective

- To assess whether a revised BDN written at an appropriate reading level can improve perceived associated breast cancer risk and likelihood of patient-initiated discussion with their providers regarding their breast density compared to the current state-mandated BDN.

## Materials and Methods

- Readability of our state’s BDN was assessed and calculated by using the multiple readability techniques: Automated Readability Index (ARI), Coleman-Liau Index (CLI), Gunning Fog Index (GFI), Flesch-Kincaid Grade Level (FKGL), Flesch-Kincaid Reading Ease (FRES), and Simple Measure of Gobbledygook (SMOG). A revised notification with equivalent medical information was formulated at a lower FKGL.
- A single three-page paper survey was created which presented both our state-mandated and revised notifications for review.
- The survey asked questions evaluating patients’ perceived associated breast cancer risk and likelihood of initiating conversation regarding their breast tissue density with their provider.
- Surveys were distributed by simple randomization in waiting rooms at our institution’s four outpatient breast imaging centers between January 2019 and February 2019.

## Results

- 500 surveys were analyzed: 283 patients obtained less than a college degree and 217 patients obtained at least a college degree.
- More women perceive** that dense breast tissue results **indicate a “high” associated breast cancer risk with the state’s BDN** (56.6% [283/500]) compared to the revised notification (2.2% [11/500]), (p < 0.001).
  - With the state’s notification, the **majority of patients** who **perceived a “high” associated breast cancer risk achieved less than a college degree** (74.9% [212/283]).
  - On multivariate analysis, achieving at least a college degree was an independent predictor of increasing the likelihood of selecting the appropriate associated breast cancer risk (adjusted OR 7.3, 95% CI 4.7-11.7).
- The **majority of women** were more likely to **initiate a discussion with their provider** regarding breast tissue density **after reading the revised notification** (96.0% [480/500]) as opposed to the state’s BDN (32.8% [164/500]), (p < 0.001).
  - With the state’s notification, the **majority of patients** who were **unlikely to initiate** this discussion **achieved less than a college degree** (72.0% [242/336]).
  - On multivariate analysis, achieving at least a college degree was an independent predictor of increasing the likelihood of patient-initiated discussion with a provider (adjusted OR 5.2, 95% CI 3.4-8.0).

### Figure 1. Lay Paragraph Implemented in Maryland Notifying Patients of Dense Breast Tissue as Mandated by House Bill 312

If your mammogram shows that your breast tissue is dense, you should know that dense breast tissue is a common finding and is not abnormal, with about half of women having dense or highly dense breasts. However, dense breast tissue can make it harder to find cancer on a mammogram and may also be associated with an increased risk of cancer. This information about the results of your mammogram is given to you to raise your awareness and to inform your conversations with your physician. Together, you can decide whether additional screening options are right for you based on your mammogram results, individual risk factors, or physical examination. A report of your results was sent to your physician.

### Figure 2. Revised Lay Paragraph Notifying Patients of Dense Breast Tissue

If your breasts look dense on your mammogram, this is normal. About half of all women have dense breasts. But dense breast tissue can sometimes make it harder to find cancer on a mammogram. It can also mean an increased risk of breast cancer in some women. This message is to help you learn more about breast density. You should talk to your doctor if you any questions. Together, you and your doctor can find out if you need any other tests based on your health history. A report of your results was sent to your doctor.

Table 1<sup>2</sup>

Breast density notifications’ readability metrics

Metric	Current	Revised
Automated readability index	13.8	5.3
Coleman-Liau index	12.2	7.5
Gunning fog index	15.2	7.3
Flesch-Kincaid grade level	12.2	4.9
Flesch-Kincaid reading ease	49.5	81.1
Simple measure of gobbledygook	13.6	8.1
Mean (95% confidence interval)	13.4 (12.3-14.5)	6.6 (5.4-7.9)

Note: Mean was calculated by summing the scores of all metrics except the Flesch-Kincaid reading ease and dividing by 5.

Table 2<sup>2</sup>

Perceived breast cancer risk associated with dense breast tissue between the current and revised notifications

	Appropriate Risk	High Risk	No Risk	Unsure
<b>Overall (n = 500)</b>				
Revised	481 (96.2)	11 (2.2)	0 (0.0)	8 (1.6)
Current	132 (26.4)	283 (56.6)	26 (5.2)	59 (11.8)
<b>Less than college degree (n = 283)</b>				
Revised	270 (95.4)	10 (3.5)	0 (0.0)	3 (1.1)
Current	24 (8.5)	212 (74.9)	21 (7.4)	26 (9.2)
<b>At least college degree (n = 217)</b>				
Revised	211 (97.2)	1 (0.5)	0 (0.0)	5 (2.3)
Current	108 (49.8)	71 (32.7)	5 (2.3)	33 (15.2)
<b>Health care providers (n = 65)</b>				
Revised	65 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)
Current	30 (46.2)	24 (36.9)	2 (3.1)	9 (13.9)

Note: Data are expressed as number (percentage).

Table 3<sup>2</sup>

Likelihood of patient-initiated discussion regarding breast density (n = 500)

Response	Revised Notification	Current Notification
Likely and very likely	480 (96.0)	164 (32.8)
In between	18 (3.6)	86 (17.2)
Unlikely and very unlikely	2 (0.4)	250 (50.0)

Note: Data are expressed as number (percentage).

## Conclusion

- A breast density notification written at a lower reading grade level improves perception of associated breast cancer risk and increases the likelihood of patient-initiated discussions regarding breast tissue density with their providers.

1. Are You Dense. About Are You Dense, Inc. Available at: <https://www.areyoudense.org/about/>Date accessed: October 1, 2019

2. Nguyen DL, Ambinder EB, Jones MK, Mullen LA, Harvey SC. Improving State-Mandated Breast Density Notifications. J Am Coll Radiol 2019. In Press.