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# **The Emotional Toll of a Callback: Mammography Patients Speak Out**

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## Introduction

Getting called back after a screening mammogram, while not uncommon, can be scary for patients<sup>1</sup> and cause anxiety about breast cancer screening.<sup>2</sup> Common reasons for recalls include:<sup>3,4,5</sup>

- **Density:** Uneven distribution of breast tissue can look like an abnormality.
- **Cyst:** If the edges are not clearly seen, further tests may be needed.
- **Calcification:** While calcifications are usually normal, irregular groups of calcifications may be the earliest sign of cancer and need further testing.
- **Scarring:** A previous surgery on the breast may have caused a scar. Scar tissue makes images more difficult to read.
- **Mass:** A mass might be cancerous, but it could also be a benign tumor or a cyst.
- **First mammogram:** The radiologist may want to look more closely at an area simply because there is no previous mammogram to compare it with.

- **Hormone changes:** Menopause and hormone replacement therapy (HRT) can cause breasts to look different from year-to-year. Breasts may also become denser after HRT.
- **Enlarged lymph nodes:** If a mammogram shows enlarged lymph nodes and there's not an obvious explanation, the radiologist is likely to consider this an abnormal finding and request additional imaging.
- **Breast implants:** Implants can block the view and make it difficult to position breasts during the mammogram.

## Mammography Patient Survey

To assess the frequency and reasons for a callback and the associated impact on patients, a blind, random, anonymous online survey was conducted in March 2021.<sup>6</sup> Survey respondents were as follows:

- Women between the ages of 40 and 80 across the United States
- Median age 52
- Have had at least one mammogram
- Total of 580 responses included in the analysis

## Key Discoveries

FREQUENCY OF CALLBACKS	PATIENT PERCEPTION
Percentage of respondents who have been called back for additional imaging: 47%	How the callback made the patient feel (multiple free text responses allowed): <ul style="list-style-type: none"> <li>• Scared, frightened, terrified, afraid or fearful: 33%</li> <li>• Nervous: 21%</li> <li>• Worried or concerned: 14%</li> <li>• Anxious, stressed or apprehensive: 10%</li> <li>• Annoyed, irritated, or angry: 3%</li> <li>• Unsettled or uneasy: 3%</li> <li>• Uncomfortable: 2%</li> <li>• Not good: 1%</li> <li>• Upset or sad: 1%</li> <li>• Bewildered, uncertain, skeptical or not sure why: 1%</li> <li>• Helpless or felt it was unnecessary: 1%</li> </ul>
Number of times respondents have been called back: <ul style="list-style-type: none"> <li>• 1-3 times: 93%</li> <li>• 4-6 times: 3%</li> <li>• More than 6 times: 3%</li> <li>• Unsure: &lt;1%</li> </ul>	

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## Patients Share Their Feelings About Getting Called Back

Survey respondents were asked if they remembered why they were asked to come back for additional images and how that made them feel. The following depicts some of the responses.<sup>7</sup>

**“I was called back because I had a lump. It was one of the scariest moments for me.”**

*~ 41-year-old from Oklahoma*

**“They found a shadow which turned out to be scar tissue. I was a little nervous but it’s better to be safe than sorry.”**

*~ 65-year-old from Arizona*

**“There were differences between my recent mammogram and the one I had previously, it was differences in areas of density if I remember correctly. I was so scared!!! I thought I was going to have breast cancer because it runs in my family.”**

*~ 51-year-old from California*

**“I’ve been called back because of unusual scarring and a mass. It made me extremely upset and nervous.”**

*~ 47-year-old from Tennessee*

**“I’ve been called back for additional images because of shadows. I was concerned but was pretty certain it was an old problem.”**

*~ 67-year-old from Michigan*

**“I was called back because there were areas of concern and I needed additional images and an ultrasound. It made me anxious. I am not always 100% confident in my results since I have dense breasts and the lumps are not explained.”**

*~ 61-year-old from Texas*

**“I was called back because of a mole.”**

*~ 52-year-old from Wisconsin*

**“I was called back for additional images because I have dense tissue that made it hard to read. It makes you nervous when something is unclear or in question.”**

*~ 54-year-old from Indiana*

**“I was called back because I have dense breast tissue. They needed increased depth and magnification. It made me worried and stressed. I think more information over the phone when asking a patient to return would be nice.”**

*~ 40-year-old from Michigan*

**“I’ve been called back twice. One time they wanted additional films because I had bleeding from a nipple and the other time was because my breast was too dense. I was very scared but I was glad they did additional films to rule out any issues.”**

*~ 52-year-old from Ohio*

**“I have dense breasts and there were shadows so I was called back for additional images. My anxiety was in high gear!”**

*~ 48-year-old from South Carolina*

**“I was called back because of large nodes. It made me feel uncomfortable. They need to explain more.”**

*~ 59-year-old from Nevada*

**“I’ve been called back a few times. Once I had to have a biopsy, other times, they didn’t get good pictures. I was terrified. I have never been called back since I started getting the 3D mammograms.”**

*~ 45-year-old from Ohio*

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**“I have cysts and they wanted to get better pictures. I would have been nervous but I’ve known for a long time that I had cysts.”**

*~ 47-year-old from New Jersey*

**“I’ve not been called back but I just wish they made it more informative. I would love for someone to show you what they look for, to teach you a little as to why it’s important.”**

*~ 54-year-old from Florida*

**“They said my breast had dense areas so I was called back. I was concerned but glad the techs were making sure everything was fine.”**

*~ 70-year-old from Virginia*

**“I had to have additional images taken to make sure I didn’t have cancer. It was scary, but I felt very comfortable because the technician made me feel comfortable.”**

*~ 47-year-old from Pennsylvania*

**“It was my first mammogram and my doctor forewarned me that when you have your first mammogram, you’re usually called back. I wasn’t terribly nervous but I was a little anxious.”**

*~ 43-year-old from Ohio*

**“I’ve been called back at least four times because I’ve had breast cancer. I was a little scared but confident the imaging center was doing their job.”**

*~ 63-year-old from New Jersey*

## **Suggestions for Breast Imaging Centers**

The results of the patient survey presented here underscore the emotional toll recalls have on patients. While many women understand and appreciate that the goal is to ensure nothing important is missed, it can be a worrisome and scary experience. Moreover, anxiety and fear have been reported to have a major impact on breast cancer screening behaviors.<sup>8</sup>

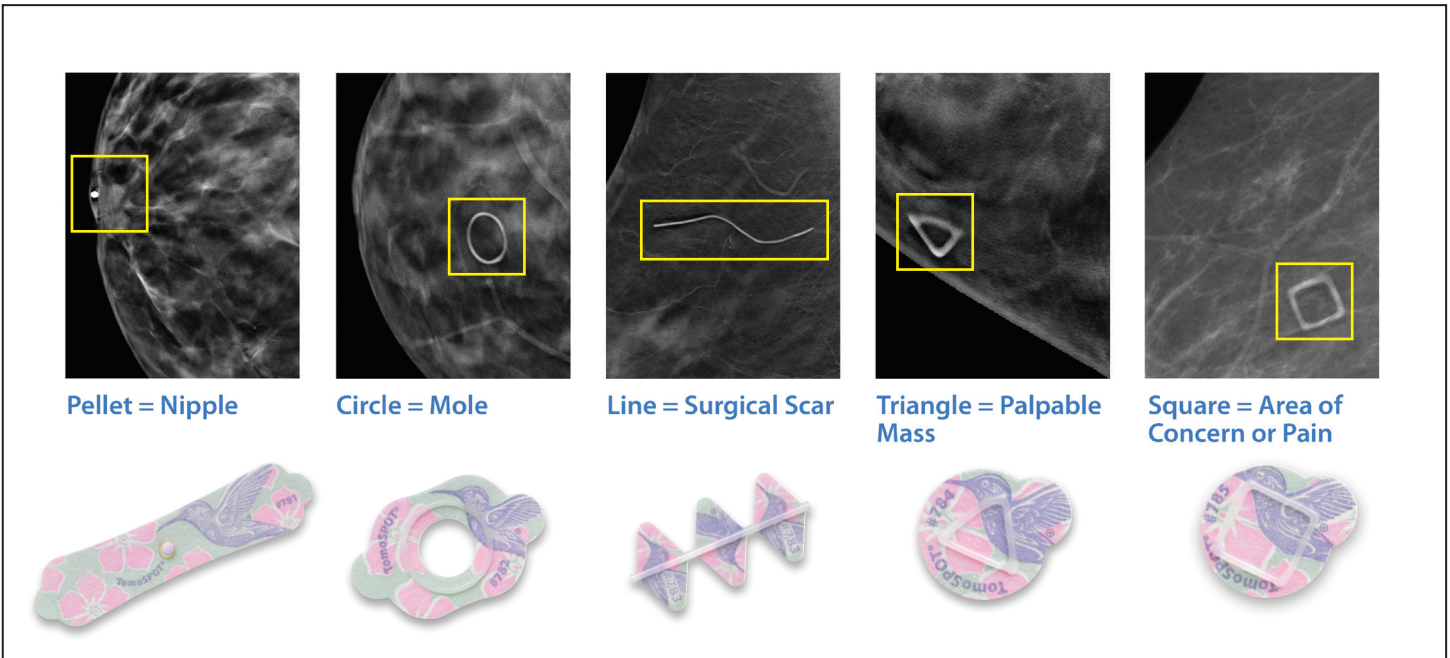
Any steps that can be taken before, during and after the mammogram to reassure patients and ultimately minimize unnecessary callbacks should be taken.

### **Suggestions include:**

- Explain the various steps of the mammogram and encourage a dialog with the patient.
- Conduct a clinical history interview and collect data to be conveyed to the radiologist. This should include a history of breast surgeries including all biopsies, lumpectomies, augmentations or reductions.<sup>9</sup>
- Perform a visual check of the breast. It is important that the technologist identify moles, keratosis, skin tags or surgical scars on the skin surface and note the location of palpable lumps. The nipple should be marked especially when it is not imaged in profile.<sup>10</sup>
- Ensure everyone who communicates with the patient is thorough and compassionate, including front desk staff or other personnel who may contact the patient for a callback. Provide additional training if necessary.
- Utilize a skin marker when appropriate and explain to the patient why it is being used, how it helps the radiologist and can prevent an unnecessary callback associated with a mole or surgical scar or “out of profile” nipple.
- Encourage and support radiologists who look to establish protocols calling for standard use of skin markers.

It is recommended that all mammography facilities develop a standard marking system protocol using skin markers.<sup>11</sup> Moreover, a skin marking system that consists of unique and distinctive shapes can provide added certainty for the radiologist. The Beekley Skin Marking System<sup>®</sup> has five

different shapes that uniquely identify the area of interest on the breast: a circle for a raised area on the skin such as a mole, a line for a previous surgery, a triangle for a palpable mass, a solid pellet for the nipple, and a square for non-palpable areas of concern or pain.



Skin Marking System for Mammography<sup>12</sup>

Featured skin markers: TomoSPOT<sup>®</sup> Skin Markers for Digital Breast Tomosynthesis, Beekley Medical<sup>®</sup>

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6. Blind, random, anonymous online survey conducted March 29, 2021 via Survey Monkey<sup>®</sup>. Incomplete and invalid responses excluded from results.
7. Based on responses to multiple choice and open-ended questions in blind, random, anonymous online survey conducted March 29, 2021 via Survey Monkey<sup>®</sup>.
8. Harvey S, Gallagher AM, Nolan M, Hughes CM. Listening to Women: Expectations and Experiences in Breast Imaging. *J Womens Health (Larchmt)*. 2015;24(9):777-783, doi:10.1089/jwh.2015.29001.swh, retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4589306/>.
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