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## What we learned: Individuals with ILC largely reported challenges with standard breast imaging at diagnosis and in determining accurate tumor sizing

### Background

- Invasive lobular carcinoma (ILC), representing 15% of breast cancer diagnoses in the US annually, is understudied.
- Studies show mammograms are often inferior at detecting ILC.
- Members of the Lobular Breast Cancer Alliance's (LBCA's) community have often shared their frustration about imaging and ILC, later stage at diagnosis, and the need for repeat excisions to obtain clear margins.
- LBCA is an advocacy organization guided by an expert scientific advisory board committed to raising awareness of the distinct aspects of ILC and where more ILC research is needed.

### Objective

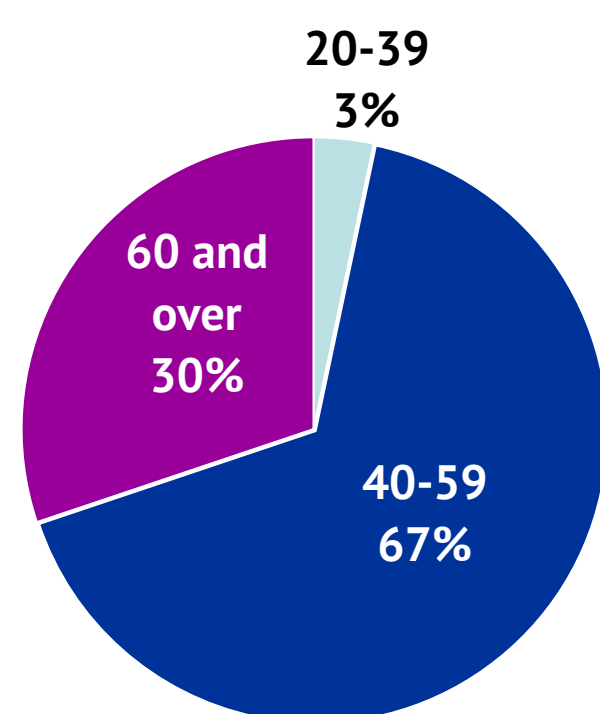
Conduct a survey of LBCA community members with ILC about their experiences with detection of primary and metastatic disease (de novo and recurrent) to shed light on issues of ILC imaging. Survey questions covered:

- Size and stage at initial diagnosis
- Whether tumors were initially detected by mammogram
- Discrepancy in size and number of tumors between screening/initial imaging and pathology/surgical specimens
- Experience with imaging and detection of metastatic ILC

### Methods and Cohort

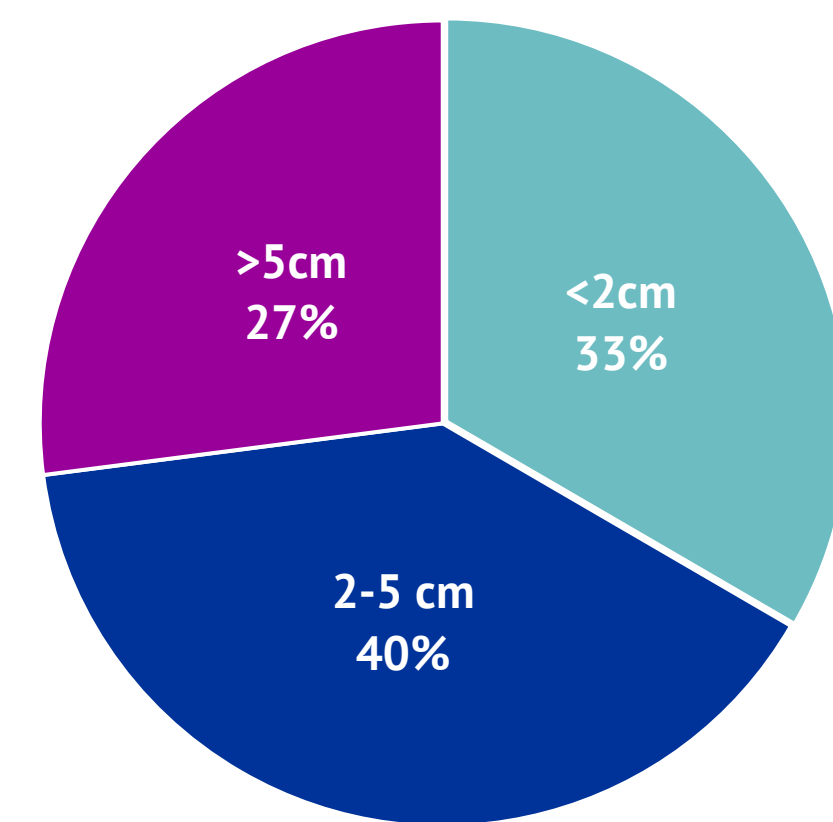
- Online, anonymous survey conducted in June 2021 – recruitment via Newsletter, Website, and Facebook
- 1,476 individual respondents
- 72% of respondents were from US, remaining respondents from 35 additional countries
- Among 167 who reported metastatic ILC sites, most frequent were: bone/bone marrow (77%), GI/stomach/peritoneum (31%), liver (23%), genitourinary (15%), lung/pleura (10%), and skin (7%)

Age at initial diagnosis



### Results

Tumor size at initial diagnosis



**67%**

Of respondents had tumor size greater than 2cm at diagnosis

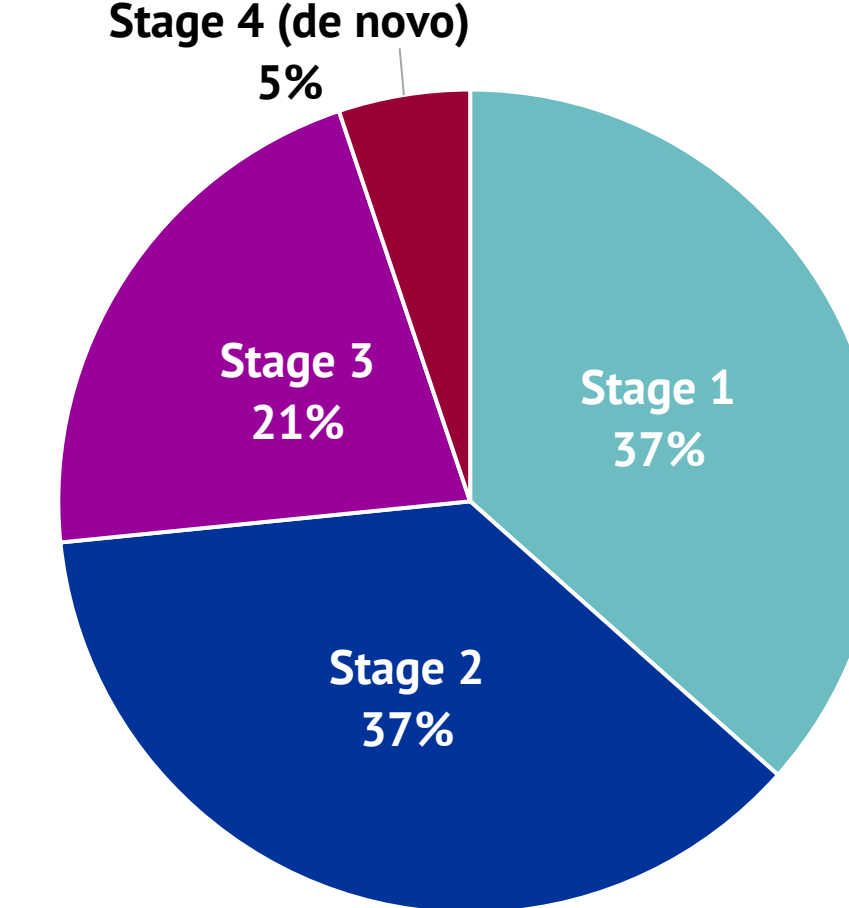
**63%**

Of respondents were stage 2 or higher, including 5% at stage 4

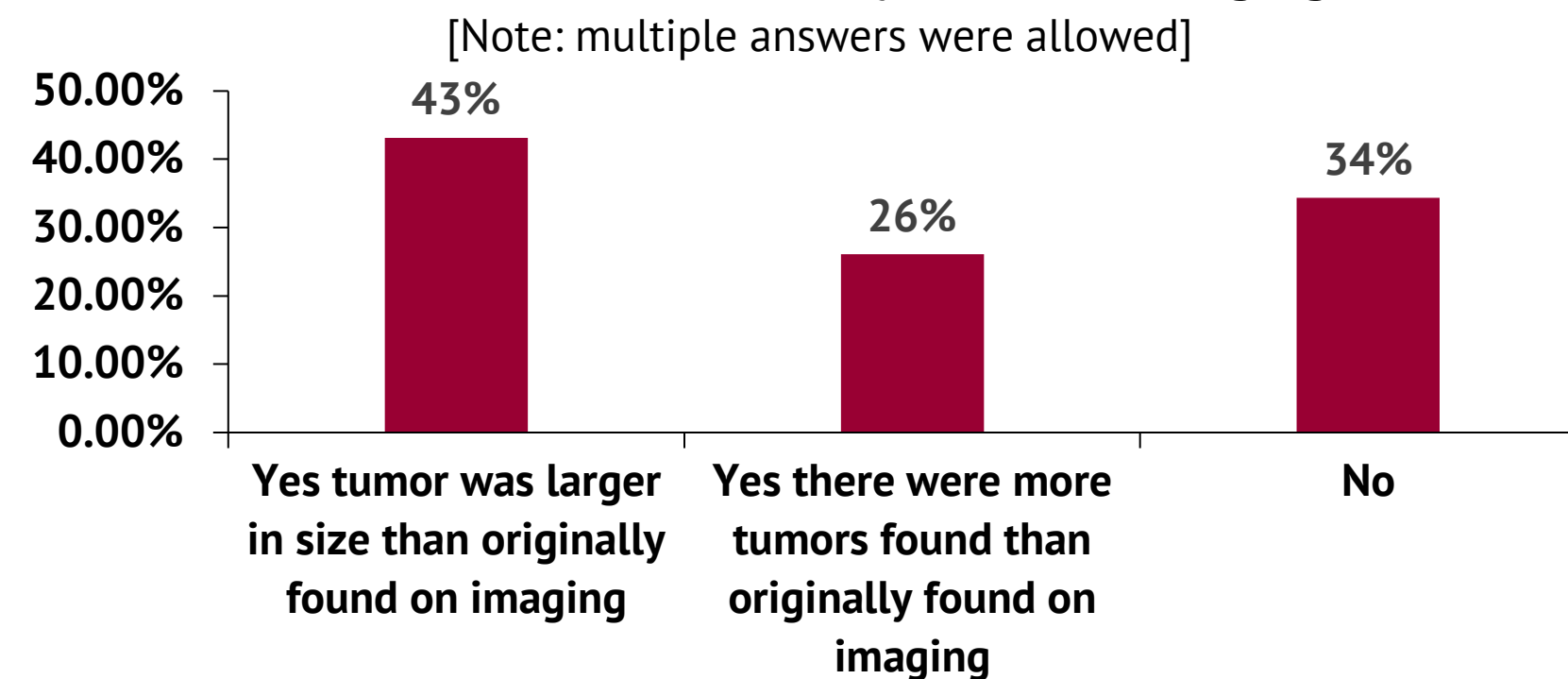
**46%**

Of respondents initially diagnosed with stage 2 or higher reported the tumor was *not* initially detected by mammogram

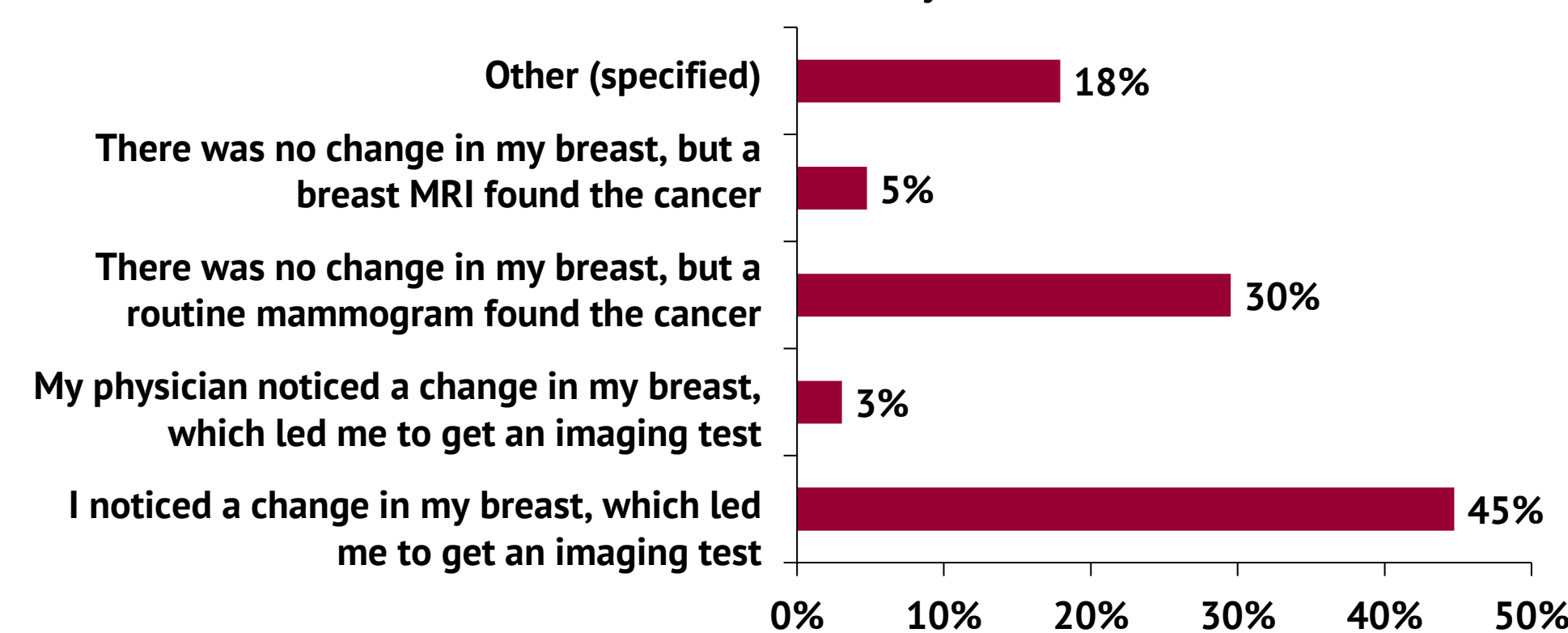
Stage at initial diagnosis



After surgery, was tumor(s) size larger, or were there more tumors than initially found on imaging?



Which scenario best describes how your ILC was detected?

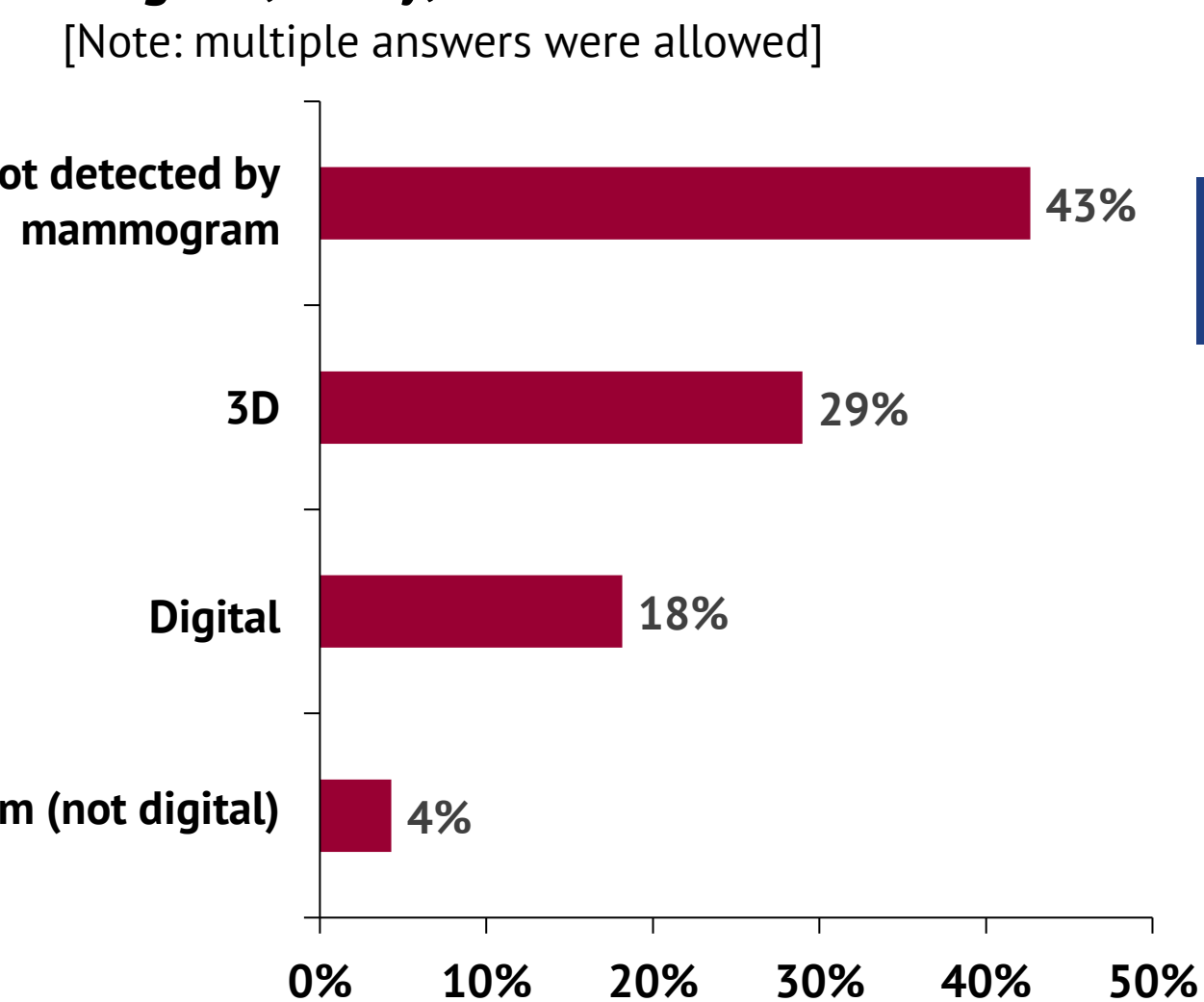


\*264 respondents to this question provided a response "other" than the choices listed above, demonstrating the unique and circuitous ways ILC is detected or not detected

Of women who reported more or larger tumors post surgery:

- 43% of women with more tumors than imaging originally showed said ILC was not detected by mammogram
- 38% of women with larger tumors than imaging originally showed said ILC was not detected by mammogram

Among respondents with dense breasts, type of mammogram, if any, which visualized ILC



### Discussion

*"Cancer never found [by imaging] in breast. MRI found bone and bone marrow metastasis."*

*"I noticed a change, but nothing showed the cancer. Not mammogram, ultrasound, or MRI. The only way they found it was a biopsy. I have it in both breasts."*

- To the best of our knowledge this represents the largest survey of ILC patients' experiences with imaging and diagnosis.
- Results from this survey confirmed patients' perspective that ILC is difficult to detect, diagnose, and stage using mammography.
- Of note, most respondents had tumors diagnosed at stage 2 or higher and/or had tumors >2cm. Furthermore, mammography failed to visualize 46% of ILC cases at stage 2 or higher.
- Nearly half of respondents reported their ultimate tumor size from pathology was larger than seen on initial imaging.

### Limitations

- Self-selected/not random sample
- Open-ended questions on race/ethnicity were difficult to quantify as a large majority of respondents indicated country of origin rather than race or ethnicity
- Too few survey questions to adequately assess challenges with imaging for individuals with metastatic ILC

### Next Steps / Acknowledgements

- The impressively large cohort and great percentage for whom ILC tumors were missed or mischaracterized on imaging validates the urgent need from patients' perspectives for better screening and surveillance tools specifically for ILC.
- Further research is also needed specifically on imaging and metastatic ILC.
- LBCA thanks all survey respondents, the volunteers, and LBCA Scientific Advisory Board members who contributed to the design and synthesis of survey results.