

# Survey of LBCA-Sponsored Website Users Confirms Value, Identifies Unmet Information Needs



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## Introduction

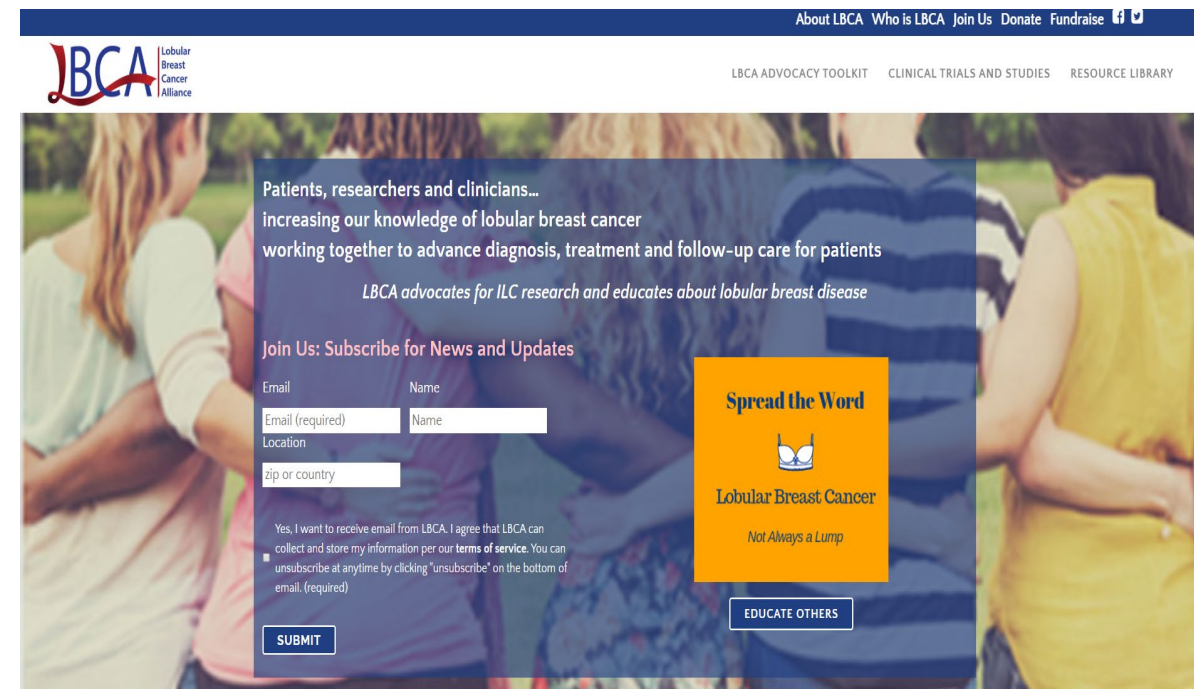
The Lobular Breast Cancer Alliance was founded in 2017 by patient advocates working with a Scientific Advisory Board of breast cancer researchers and clinicians.

**LBCA's goals are to advance research and educate about ILC.**

An early action of the LBCA was to launch a website:

**lobularbreastcancer.org**

to address the need for a central source of quality information about lobular breast cancer.



## Objectives

Conduct a survey of users to determine the value of the website and identify potential ways to improve it.

- ✓ Understand who was visiting the site
- ✓ Identify the information sought
- ✓ Obtain feedback on the usefulness of content
- ✓ Seek input on content and navigation

## Methods and Cohort

**May 1 – June 3 2019**

Online anonymous survey – recruitment via Newsletter, Website, Social Media (Facebook, Twitter)

**950**

Responders

**71.5%**

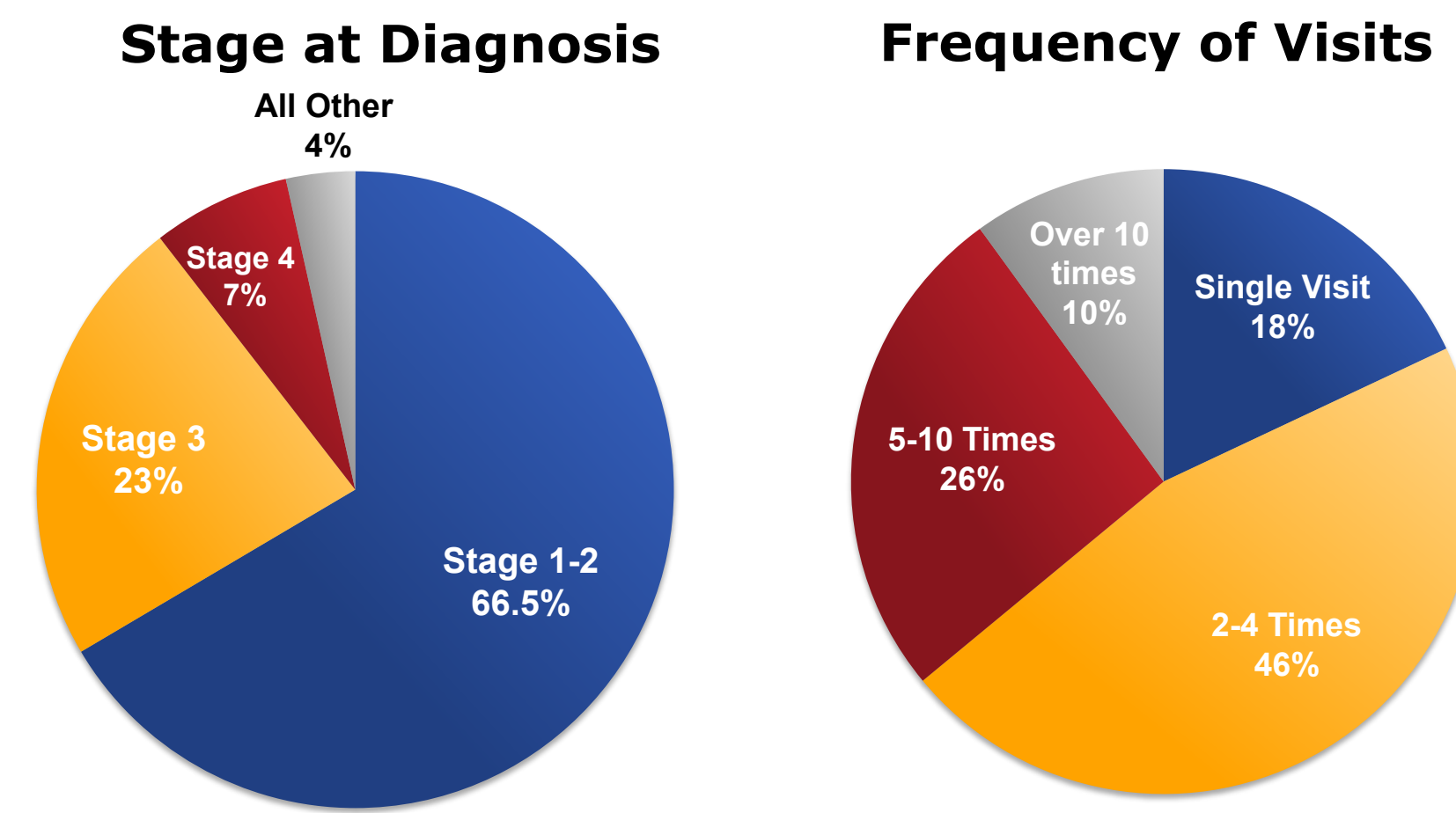
Age 46 - 65

**25%**

Responders resided outside of the United States

## Results

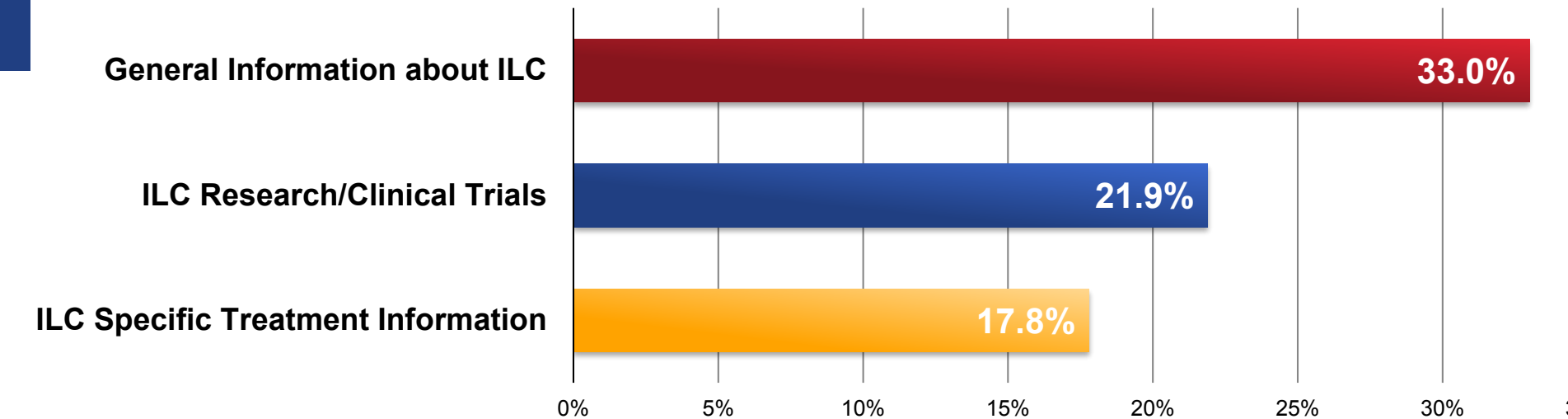
### Who Visits the LBCA Website?



**94.7%**  
Current or former ILC patients

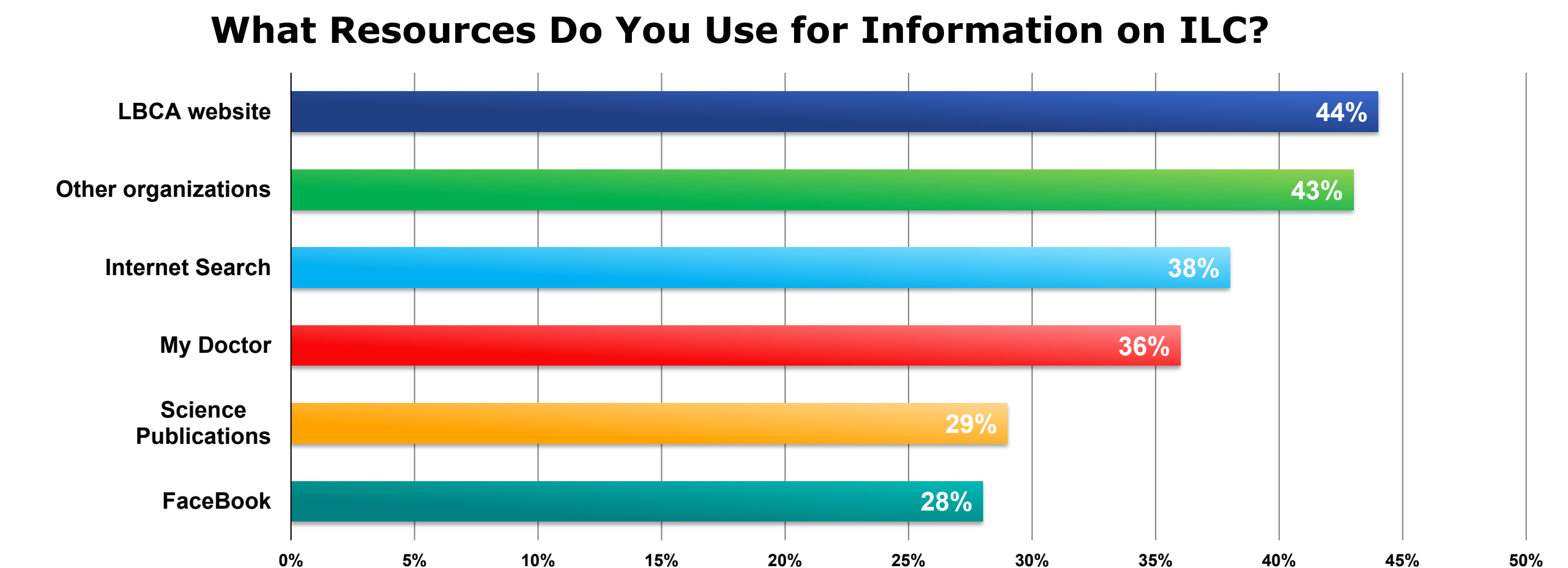
**83.7%**  
Found the information they were seeking

### What are LBCA Visitors Looking For?



**45.4%**  
Agreed that the LBCA website provided information they could not find elsewhere

### Where Do Users Go For Information About ILC?



### Additional Information Requested

**17%**  
More frequent updates on research and treatment guidelines

**6.5%**  
List of providers with expertise treating ILC

**6%**  
Request for LBCA to provide education on ILC to Doctors

## Conclusions

- Patients most frequently reported frustration seeking quality in-depth information about ILC and best courses of treatment from their providers and the current state of knowledge among practitioners about ILC.
- The survey shows high levels of interest in more ILC research.
- LBCA is driving awareness of lobular breast cancer by sponsoring a website providing research-based information about ILC.



## Future Direction

- The LBCA will continue to provide a central online resource for information about lobular breast cancer to educate the community and enable patients to advocate for their self-care.
- The LBCA will integrate more research findings into the website.
- The survey highlights that lobular breast cancer is under-researched. LBCA will continue to advocate for additional studies and clinical trials to refine treatments, imaging and follow up care for patients.
- The LBCA is a sponsor of the 2nd International Invasive Lobular Breast Cancer Symposium in May 2020. [ILCSymposium2020.com](http://ILCSymposium2020.com) #lobular2020