

NO LUMP REQUIRED

The Inflammatory Breast Cancer Research Foundation Registry

Part 3: Taking the Survey

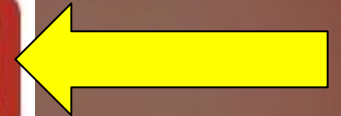
The Inflammatory Breast Cancer Research Foundation Registry

The new IBC community's 'privacy assured' registry is the best chance we have to collect information that will facilitate the diagnosis of inflammatory breast cancer and help to improve treatment. We need you to participate by sharing your information! Simply click on [Start Now!](#) to begin, or [Sign In](#) if you are a returning user.



It's Easy as 1, 2, 3

- 1 Register (or sign in) [Start Now!](#)
- 2 Enter Health Information
- 3 Let Researchers Find YOU!



Not currently signed in? Sign in please!

Sign Up

This service uses Private Access to allow you to specify exactly who can see your information and for what purpose. If you do not already have a free account, enter valid email address to sign up now.

Returning user?

 remember me[forgot username](#)

First time user?

 I am at least 18 years or older (In Colorado, 21 years or older)

Sign in using this box and your previously created username.

Sign in

This service uses Private Access to allow you to specify exactly who can see your information and for what purpose.

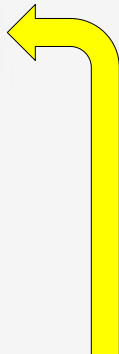
Image : red poppies [What's this?](#)



Password

Sign in

[Forgot Password? Click Here](#)



You will see your previously selected image. Enter your password.

List of Activities

Select from any of the following activities...

[View Answers](#)

No Lump Required: About You & Your IBC

Not Started

Start

Click to start the survey.

Remember you can sign out to take a break, then sign back in to finish.

Survey: No Lump Required: About You & Your IBC

[< Previous Subject](#)

Current Subject: Let's Get Started

[< Upcoming Subject](#)

▼ Welcome to No Lump Required!

▼ Let's Get Started

This survey will take approximately 45 minutes to complete, depending on how much detail you provide. We'll ask some questions about you, followed by some questions about your inflammatory breast cancer and your health in general.

If you get tired you can take a break, and when you return, continue from where you left off. However, **it is very important that you complete the entire survey** so that everyone in the community has answered the same questions.

Thank you for your willingness to take part in this important work!

Select "Continue" to begin...

Continue



This survey asks the patient (or parent, or child of someone with IBC) to enter information about her (or his) IBC experience.

The survey includes sections of 'common data elements' such as gender, height, weight, etc. There are also questions about exercise, smoking, alcohol use, and other general health topics. These are included for epidemiological purposes.

This survey consists of questions in several formats. Examples will be illustrated here.

▼ My IBC hormone receptor status was...

Please select all that apply.

- Estrogen+/ER+
- Progesterone+/PR+
- HER2+
- Triple negative
- Other
- Don't know

Some questions have a **Don't know** option.

Reset

Skip

Save and Continue

If you select the wrong button, click **Reset** to remove your check mark.

After making your selection(s) click **Save and Continue** to go to the next question.

▼ My primary source of information for living with my cancer is...

- Doctor
- Nurse practitioner
- Physician's assistant
- Nurse
- Local Health Department
- Internet medical sites
- Support group
- Other patients
- Internet information sites (not a support group)
- Other

Reset

Skip

Save and Continue

Sometimes **Other** is the best answer for your circumstances. After you hit **Save and Continue**, you will see a fill in the blank box where you can explain what you mean by "other."

▼ My "other" source for information about my cancer is...

For most questions, you will be able to see how others have responded.

▼ I have been involved in a face-to-face support group...

61% Yes

39% No

* compared with all respondents who have used this site to date

[Click here](#) to update your answer

A screenshot of a survey question. The question is "I have been involved in a face-to-face support group...". Below the question is a progress bar showing 61% for "Yes" and 39% for "No". The "Yes" option is selected with a radio button. Below the progress bar is a note: "* compared with all respondents who have used this site to date". At the bottom of the question box is a link: "Click here to update your answer".

If you selected the wrong button, click to change it.

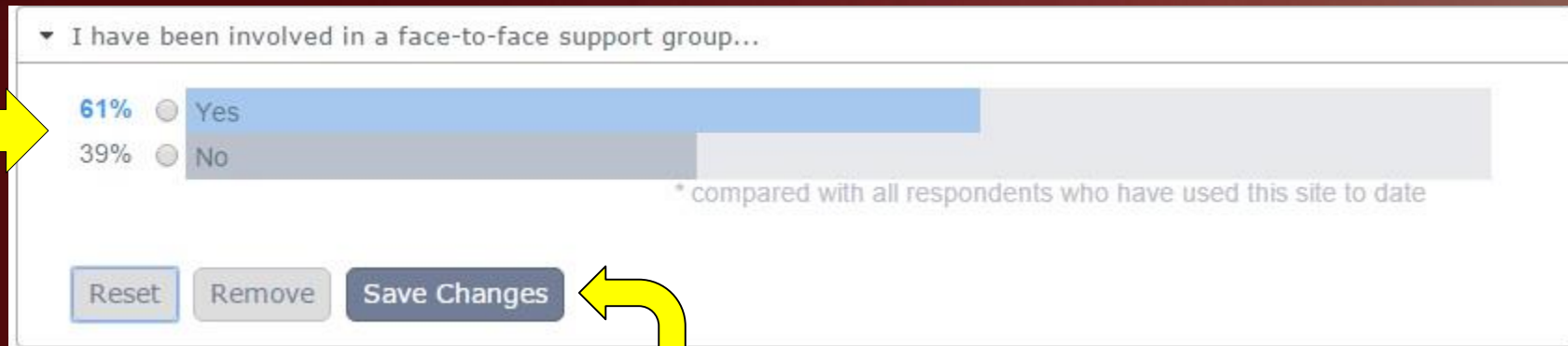
▼ I have been involved in a face-to-face support group...

61% Yes

39% No

* compared with all respondents who have used this site to date

Reset Remove Save Changes

A screenshot of the same survey question as above. The "Yes" radio button is now unselected, and the "No" radio button is selected. Below the question box are three buttons: "Reset", "Remove", and "Save Changes". The "Save Changes" button is highlighted with a yellow arrow.

Select the answer you wish, and click Save Changes.

▼ Care

▼ I received care for my IBC at...

Please list the centers at which you received care for your IBC. Please separate multiple entries with commas.

Some questions ask for your input in a text box.



A few questions have a pop up box with a scroll bar on the right side.

Scroll down to see all possible choices.

▼ I am able to...

	Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
Do chores such as vacuuming or yard work	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Go up and down stairs at a normal pace	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Go for a walk of at least 15 minutes	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Run errands and shop	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Reset

Skip

Save and Continue

A few questions are in a chart format. Select an answer for each line item.

▼ Researchers Should Know

▼ The most important thing I want scientists and physicians engaged in research for this disease, as well as drug approval agencies such as the FDA, to know is...

Reset Skip Save and Continue

A couple of questions are open-ended, and you type into the box.

Congratulations!

You have now finished your survey.

Most published IBC patient data has focused on one institution and typically comes from the physician point of view. With NO LUMP REQUIRED we hope to capture the actual patient experience not what someone else thinks you experienced.

Thank you for taking time to assist the Inflammatory Breast Cancer Research Foundation with this critically important, patient focused, research project.