

# **Ambassadors Resource Guide**

## Lung Cancer Registry “How-To”, Benefits, and FAQ

**THE LUNG CANCER REGISTRY** is a community for people with all forms of lung cancer. Patient powered by **YOUR DATA**, this platform gives patients a voice. It provides researchers and clinicians information on participants as data repository as well as a research tool. Your participation may help us discover findings that improve patient’s lives through better care, better outcomes and new treatments.

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As a member, you have access to many valuable registry features:

- Use the Registry data tab to see all de-identified information from the registry participants
- Receive information that is relevant to you and your health condition
- Take health-related at any time

Visit your account at any time to add more information, including:

- Medical reports or test results
- Healthcare provider information
- Change your password
- Change your contact and sharing preferences

## **How to sign up**

Log into and sign up at: [www.lungcancerregistry.org](http://www.lungcancerregistry.org). There, you will be asked to enter some basic information about yourself and can create your account.

## **What is the registry and why is it important?**

A registry is a place where people living with lung cancer can participate to store detailed medical information. Additionally, children who are younger than 18 years of age, or adults who cannot make their own medical decisions, must have their legal guardian, parent, or custodian register on their behalf. When a child who is registered turns 18 years old (and if they are able), they will be asked if they want to continue participating. A parent, spouse, or child of a patient who has died of lung cancer may also create an account.

It takes whole communities to help people living with medical conditions lead healthier and happier lives. The more information we collect about lung cancer the closer we can get to helping communities find treatments that work.

By collecting health information from as many people as possible, together we can make a difference. We can:

- Study why individuals have different symptoms
- Learn about how certain treatments work and don't work
- Help medical professionals improve how they treat affected individuals with the condition
- Speed up research by collecting information that scientists can use
- Let those living with lung cancer (or their family) know when they may be eligible for research studies or clinical trials

## **How you can benefit from registering**

There has never been a more important time to participate and be on the vanguard of research and information about relevant opportunities in lung cancer!

- Completing the survey with your information is your chance to help push lung cancer developments forward faster.
- Learn about the experiences of other lung cancer patients. By participating in the registry, you gain access to aggregated data gathered from the community.
- Be on the cutting edge of patient powered research in lung cancer with access to new data and research opportunities that are relevant to you!
- Be a part of registry research surveys and publications that help improve patient care and patient outcomes and advance science and new treatments.

## **Your Information and Privacy Concerns**

The Lung Cancer Registry (TLCR) takes your privacy very seriously. Only trained registry managers will have access to your identifying information. Your identity, such as your name or email address, is shared only if you request it otherwise, all personal identifiers, are removed before they are shared. Only The Lung Cancer registry coordinators will send you messages, in accordance with your contact preferences.

We believe that open sharing of lung cancer health information is how medical discoveries will happen, and we invite you to share. To advance the understanding of lung cancer, we ask you to contribute your de-identified survey answers (no personal identity is shared) into the pool of other participant answers. If possible, the information will be made available to the greater medical community, including other non-profit organizations, doctors, research scientists, medical investigators, regulatory agencies, pharmaceutical, biotech, and biomedical companies. Even non-profit groups that promote the registry need your permission to see the pool of survey answers from you and the other participants. As a participant you also have immediate access to the pool of survey answers.

Patients own their data. Period. Patients opt in and choose to share their information, and they can just as easily opt out. If you ever change your mind about sharing information, you can withdraw your information from the registry at any time. Simply contact the registry coordinator and all of your information will be removed from the registry. De-identified information shared before you leave the registry cannot be recalled.

## **Cost/Money Concerns**

Joining the registry will always be free.

## **Time Concerns**

Participating in the registry is simple and can be completed as you have time. In fact, you may learn a lot just from participating. After setting up the account, you can take an initial baseline survey and after completion, view data on how others in the registry have answered the same questions. You can stop and return to a survey at any time. We will ask you to update some information in your account throughout the year.

## **Does joining the registry guarantee a spot in a clinical trial?**

One goal of the registry is to make it easier for people to participate in research; however, there is no guarantee that that you or your family member will be eligible for a clinical trial or study.

Remember, scientists cannot contact you directly. The registry coordinator will send you information about a study or trial by email. If you are interested, we will tell you how to get involved. Please also be aware that if we inform you about the existence of a study or trial, this does not imply that we endorse it or guarantee your acceptance. To participate in any trial, you will need to fill out a separate informed consent form.

### **Should you join if you don't want to be involved in a clinical trial?**

Absolutely! We hope that you will still register, even if you don't want to take part in a study or trial. Your information can help the entire medical community, including yourself as well as people you've never met. Even if you are involved with another registry through your doctor or other researchers, you can still join this registry.

### **What if I'm not sure if I may have already registered**

1. If you believe you have an account with TLCR, first try to log into the website
2. Select the Login tab, located at the top of the page
3. Select "Forgot username/ password?", located under the blue login button
4. Follow the on-screen directions and select the appropriate choice and enter information
5. If you are continuing to have issues or questions, click the Contact Us tab, located on the top of the page where you will find two options
  - a. If you have questions or would like more information please contact the foundation at: [Registry@lungcancerfoundation.org](mailto:Registry@lungcancerfoundation.org)
  - b. For technical issues and questions, please contact us at: [lungcancercoordinator@invitae.com](mailto:lungcancercoordinator@invitae.com)

### **What if I forget my username or password?**

1. Click "Login" on top of the page
2. Click "Forgot username/password?", located under the blue "Login" button
3. Check the box for "Lost Username" or for "Lost Password".
4. Enter your information.
5. Click "Send Username" or "Send Password".
6. Your username or temporary password will be sent to your email address.

### **How do I change my password? How do I change my email address?**

1. Login to your account.
2. Click the tab for Profile, if you are not automatically directed there.
3. Click the link for Update, located in the Account Information box.
4. The password and email fields are at the bottom of the page.
5. Click the Update button once you have changed your password or email.

### **How can I update/change/view my survey responses?**

You will be asked to update your information periodically and when new surveys become available. We will send you a reminder if you'd like but you can easily opt out of communication from the registry. Also, we may ask you to fax or upload relevant test results or other related reports. The registry can be updated anytime there is a health change.

### **How do I update my survey or complete an annual update?**

1. Login to your account.
2. Below the participant's name, locate the tab for "Medical Surveys."
3. Tip: If you have not completed the initial survey, you will be directed to take the survey automatically.
4. To update a survey, click the name of the survey you want to update.
5. Click the name of the survey, and then click the link to "Re-take the Survey".
6. Tip: Surveys that are incomplete will have a caution  icon. Simply click the survey name to complete it.

### **How do I change an answer to a single question?**

1. Login to your account.
2. Below the participant's name, locate the tab for "Medical Surveys."
3. Tip: If you have not completed the initial survey, you will be directed to take the survey automatically.
4. Click the name of the survey that has the question you want to update.
5. The sections in the survey are listed. Click the section name to see the questions in the section.
6. Use the edit icon next to each question to update a single answer.
7. Tip: For yearly updates, please choose the link to "Re-take the survey."

### **How do I see answers in the registry?**

1. Login to your account.
2. Click button for "View Data" and choose the section of interest to see the charts for each question.
3. Tip: Don't see the charts? In order to see the survey results, you must complete the initial survey.
4. Take more surveys and see more charts!

## **The Lung Cancer Registry**

Participate in the Lung Cancer Registry. A community powered by patients and the patient voice. Together moving lung cancer developments forward.