

## **LLS National Patient Registry FAQ**

### **What is the goal of the LLS National Patient Registry?**

The LLS National Patient Registry collects information from patients with blood cancers (past or present) to learn more about their “real world” experiences and outcomes. This gives health care professionals more information that they can use to tailor how they treat individual patients.

The Registry is currently focused on answering important questions about blood cancer patients and COVID. Everyone with blood cancer is eligible and encouraged to join the Registry regardless of whether or not they have tested positive for COVID-19, and whether or not they plan to be vaccinated against COVID-19.

### **What will the Registry tell us about COVID and blood cancer patients?**

The Registry is designed to answer important questions about the unique risks to blood cancer patients if they get COVID and how they respond to vaccination, which can be less effective in some people with cancer. Not many blood cancer patients were included in the vaccine clinical trials, so this is our best opportunity to learn about how they response to vaccination.

### **Who can join the Registry?**

Everyone with blood cancer, including all forms of leukemia, lymphoma and myeloma is eligible and encouraged to join the Registry at any point in their illness. CAR T patients and bone marrow transplant patients are also eligible.

### **I already received my COVID-19 vaccination or am not sure if I'll get vaccinated- am I still eligible to join the Registry?**

Yes, the Registry is open to all blood cancer patients, regardless of their vaccination status or plans to be vaccinated.

### **What questions will I be asked when enrolling in the Registry?**

The Registry works by gathering and analyzing standardized information from patient medical records, which hold a wealth of valuable data. You “own” your medical records, so will need your consent to obtain them. We will remove the personal identifying information from your records before using them for research, so your privacy is protected.

You need to create an account with Ciitizen, our partner in developing and managing the Registry. Once you do that and provide your consent, you will be asked to complete a brief survey about any COVID-related symptoms or hospitalizations you have experienced, and your plans for COVID vaccination.

That's it! We take over from there and gather your medical records on your behalf. We hope you will agree to share records from all your doctors, including hematologists, cardiologists, dermatologists, primary care and others.

### **Why should I join the LLS National Patient Registry?**

When you join the registry, your medical information—which will be kept anonymous—is helping LLS answer important questions about the risks of COVID and the effectiveness of COVID vaccination for everyone with blood cancer.

But there is also another personal benefit for each person who joins the Registry. Ciitizen will assemble all your medical records into one online, protected file. This file is yours and yours alone. You can access it at any time, share it with new doctors or anyone else who you want to know your medical history. If you decide to leave the Registry, we will delete your files from our encrypted database.

### **Can you tell me more about how the Registry gathers my medical records? Is it safe?**

LLS is collaborating with technology platform [Ciitizen](#) on the COVID Registry. Once you opt-in and consent to participate in the Registry, you will be asked to create a secure online account. You will have the opportunity to tell us which health providers to gather medical records from on your behalf. If you indicate that you will have future visits, we will automatically scan for new, updated records. We recognize that you may be cared for by a team of specialists—we hope you will agree to share records from all of them.

You will need to provide your signature and a clear copy of a government issued ID, such as your driver's license, as proof that you are authorizing the request. We remove your name and other personal identifiers from all records before using them in our research.

### **Do I need to let you know every time I see my doctor?**

No. Once authorized, the LLS National Patient Registry will routinely look for new information from your healthcare team to add to the Registry. As long as you indicate you will have future visits with a provider, we will look for new, updated records on a regular basis.

### **Is it difficult to join the LLS National Patient Registry?**

No, enrolling in the Registry takes just a few minutes. It requires access to a computer or mobile device. To discuss the benefits or any concerns about joining the Registry, please contact an LLS Information Specialist at (800) 955-4572 or via email [here](#). If you want one-on-one technical assistance with joining the Registry, contact 1-855-244-8493 or email [[LLSsupport@ciitizen.com](mailto:LLSsupport@ciitizen.com)].