

Your electronic health record questions

answered



Top facts

- An electronic health record (EHR) contains information about your health care. If you have many providers, you may have many EHRs. Only certain people can look at your EHRs.
- Your EHRs have valuable health information that you can choose to share with researchers.
- The more people who share their EHRs, the more researchers can learn about health and medicine.

What is an electronic health record?

An electronic health record, or EHR, is a digital version of your medical chart. This record has information about your health and care you have received. If you see a lot of health care providers, you may have many EHRs. Your health care providers, pharmacists, medical labs, and hospitals usually can see your EHRs.

What information is in my EHR?

Your EHR lists your name and contact information. Your EHR could include symptoms and diseases you may have experienced. It may show medicines you have taken and results from medical tests, such as EKGs. It might have X-rays. If you have had surgery, your EHR may mention it. Your EHR may contain other things you have talked about with your health care provider. Your EHR also likely has notes written by your health care provider.

Is there sensitive information in my EHR?

Yes. Your EHR has information about you, your health, and care you have received. So if you talked to your health care provider about using illegal drugs or alcohol, your EHR might mention that. If you have seen counselors or other providers for mental health issues, your EHR could include your diagnosis and treatment. Your EHR also could have results from genetic (DNA) tests.

Why does the *All of Us* Research Program want to look at my EHRs?

EHRs are the most complete record of a person's health. When researchers can study EHR information from many people, they can find patterns. Those patterns can help them understand what keeps people healthy, what happens when people get sick, and even why some drugs cause side effects. It also could lead to new ways to prevent or treat disease. Without EHRs, these discoveries will be harder to make and take longer. Your EHR information will help speed up health research and medical breakthroughs, which is the purpose of the *All of Us* Research Program.

How will the program keep my EHR information secure?

The *All of Us* Research Program is doing everything it can to protect your privacy and identity. This includes using state-of-the-art technologies and processes to protect the data you give us from being destroyed, tampered with, or stolen.



(844) 842-2855



help@joinallofus.org



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RESEARCH PROGRAM

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How will you get my EHRs?

It depends. If you get care at one of our affiliated health care provider organizations, your providers will send them to us. If you get care elsewhere, we will provide easy ways to gather your EHRs. At that time, you can decide whether to share your EHRs.

What if I don't have an EHR?

It's okay if you don't have an EHR right now. The *All of Us* Research Program will last at least 10 years. You might get an EHR during that time. You can decide then to share it.

Do I get to choose whether to share my EHRs with the program?

Yes, and we respect your choice. If you are willing to share your EHRs, you can participate in other parts of the *All of Us* Research Program. For instance, we may ask to take physical measurements and blood and urine samples so we can learn even more about health and medicine. We may use the blood sample to analyze your genes (DNA), which play a role in health and disease.

Who will use the information in my EHR?

Researchers who get permission from the *All of Us* Research Program will be able to see some of your EHR information. These researchers must follow strict rules to use any of the data about you, including the information from your EHRs. We will use the best available technology to remove your name, address, and other identifying information from your EHRs. Despite our best efforts, it is possible that some identifying information may remain in the data available to researchers. Researchers who can access the data must promise they won't try to learn who you are or use identifying information that may still be included. The researchers may be from anywhere in the world and study many different topics. They may work for businesses like drug companies. They may work at universities. Some researchers may be members of the public who do science in their spare time.

When will you collect my EHR information?

With your permission, we will collect your EHR information at least once a year. We will start collecting it sooner from people who use a health care provider within the *All of Us* Research Program. If you get care elsewhere, we will let you know when we have a way of getting your EHRs. We may ask you again to share access to your EHRs. We will make this process easy and clear for you.

If I'm not willing to share my EHRs, can I still participate in the program?

Yes. You can fill out surveys and participate in some other ways. But you may not be asked to provide physical measurements or samples, and you will not receive \$25 for your participation. This is because samples and genetic information are most useful when they are linked with health information from EHRs. Your decision to share or not to share your EHRs will not impact how your health care providers will treat you or your health care.

What if I say yes and then change my mind about sharing my EHR information?

That's okay. You can change your mind at any time. Just let us know by either using the app or website (JoinAllofUs.org), or by calling us toll free at (844) 842-2855. However, if researchers already have your data or samples for their studies, we at *All of Us* cannot get them back. Also, we will let researchers check the results of past studies. If they need your old data to do this work, we will give it to them.

Where can I learn more about the *All of Us* Research Program?

You can learn more about the program at JoinAllofUs.org. Also, the *All of Us* Research Program's Support Center is open every day (except public holidays) to answer your questions. You can call toll free at (844) 842-2855 or email help@joinallofus.org.



**For more information,
visit JoinAllofUs.org**

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