

Appendix: eConsent Video Script

Video Script 10 May 17
<p>0.</p> <p>If you would like to take part in the <i>All of Us</i> Research Program, we will need your consent.</p> <p>The consent process is very important. It helps you understand what taking part means.</p> <p>If you complete the consent, the next step will be sharing your health data. We hope this will help researchers find new things, including maybe the next big health breakthrough.</p> <p>We're now going to go over exactly what you can expect if you choose to take part in this exciting new research program.</p>
<p>1.</p> <p><i>All of Us</i> is a long-term research program. If you decide to join, we will need to know how to keep in touch with you.</p> <p>We will ask for the phone number or email address of a friend or family member. This will only be used in case we can't reach you.</p> <p>We might use social media or public databases to help us keep your contact information up to date.</p>
<p>2.</p> <p>If you decide to join, you'll be asked to answer some basic questions about yourself.</p> <p>Your answers will help researchers better understand health and disease.</p> <p>We will ask about your health history, family, home, and work. These surveys will take about 30 to 60 minutes to fill out. You can choose not to answer any questions that you're not sure about, or would rather not answer.</p> <p>The <i>All of Us</i> Research Program will last more than 10 years. We may also ask you follow-up questions from time to time.</p>
<p>3.</p> <p>You may be asked to have your physical measurements taken by a trained <i>All of Us</i> staff member.</p>

These may include measuring your height and weight, hips and waist, blood pressure, and heart rate. The data we collect will help researchers understand how our differences impact our health. However, you may refuse any measurement at any time.

The measurements will take about 15 minutes, not including any travel time to the clinic or enrollment center.

4.

You may also be asked to contribute a blood and urine sample. Again, this is not required, but these samples are very helpful to researchers.

We will send all of the samples to the Mayo Clinic in Minnesota. Samples are stored securely in their research biobank.

Researchers will study your samples. They may measure things that naturally occur within our bodies—for example, cholesterol. They may also look at outside factors that affect health (for example, environmental toxins, medications, or drugs).

Researchers may also want to study your DNA. DNA is your unique genetic information. We can study it from your blood sample. There will be a separate form for you to sign if you decide to let researchers study your DNA. Whether or not you share your DNA with us is entirely up to you. You can say no and still take part in *All of Us*.

5.

If you have a fitness tracker, we may ask you to share data from it. If you don't have a fitness tracker, we may provide you with one to use.

6.

To get more details about you, we will add other sources of data.

Some of this data will be more general. We will use where you live and work to add data about things that might affect your health (for example, the weather or pollution in your area, or how close you are to a grocery store or park).

We will also gather data that is specific to you. For example, we will get your pharmacy records and health insurance data. To do this, we will use data that identifies you, like your name and date of birth.

Health problems are very complex. That is why we need to add data from such records. It will give researchers a wide variety of data they can use to help make medical discoveries.

7.

If you have an electronic health record, we may ask for access. You can decide yes or no.

If you decide to share your health records with us, we will be able to see data about your health conditions, test results, medical procedures, images (like X-rays), and medicines you take.

Your health records may contain sensitive data. For example, they may tell us about your mental health, or use of alcohol or drugs. They may also show sexual or other infections, including HIV status.

There will be a separate form for you to sign if you decide to give us access to your health records. Whether or not you share these records with us is entirely up to you. You can say no and still take part in the *All of Us* Research Program.

8.

We will remove your name and other identifiers—like your date of birth—from your data, and replace them with a unique code.

Before researchers can access the coded *All of Us* data, there are steps they must follow. First, they have to be screened and approved by a special committee. They must follow strict data security rules. Also, they have to sign an agreement saying they will not try to find out who you are.

These researchers are from all over the world, and are investigating all kinds of topics. We will also tell you about other research studies that might interest you. You can learn more at www.joinallofus.org.

9.

We are working with top privacy experts and using highly advanced security tools to keep your data safe.

We have several steps in place to protect your data.

First, the data we collect from you will be stored on computers with extra security protection. A special team will have clearance to process and track your data.

Only a few people will have access to the list that links names to data. This list will be kept separate from the data. The data will be stored without any names on it.

In the unlikely event of a data breach, we will notify you. You are our partner, and your privacy will always be our top priority.