

This is a complicated process. You will go through three sections.

First - You'll interact with the core ideas of informed consent for the Sage Commons.

Second - You'll read the informed consent agreement, and digitally sign it.

Third - You'll be able to start participating in public genomics research by uploading data.

I understand, and want to proceed

Get Informed

- ☐ Welcome
- ☐ Willingness to Participate
- ☐ Researcher Terms of Use
- ☐ Grant Rights
- ☐ Watch Video
- ☐ Checkpoint
- ☐ Acknowledge Understanding

Consent to Research

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- ☐ Generate ID
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Are you willing to participate in common genetic research?

☐ Yes, I want to participate in common genomic research

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We will impose the following conditions on researchers through [Terms of Use](#), which either must be visible on the website that hosts your data or must be digitally signed by those who access your data.

- o Do not attempt to [re-identify me](#).
- o [Don't harm me](#).
- o [Share your research](#) from my data with the public under open access terms.

However, there are limits to the power of Terms of Use, and there are no guarantees that users will respect all of these conditions. Please make sure to watch the entire video in the following stage of the consent process - it is vital that you understand these considerations if you are going to provide informed consent and participate in public genomics research.

☐ I understand

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These are the rights you are granting to [qualified researchers](#)

- ☐ Right to[do research] with my data
- ☐ Right to [redistribute](#) my data
- ☐ Right to [publish the results of research](#) from my data
- ☐ Right to [commercialize products derived from research](#) on my

All boxes must be checked to move forward in the consent process

Next

Get Informed

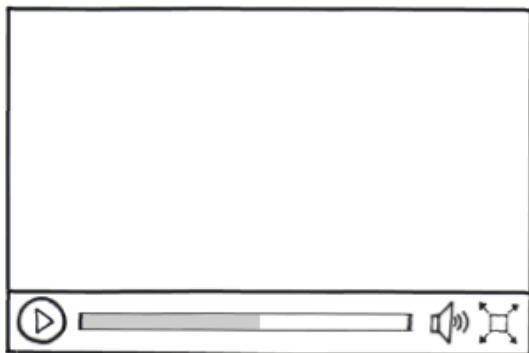
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You must finish watching the video to advance in the consent process.

Next

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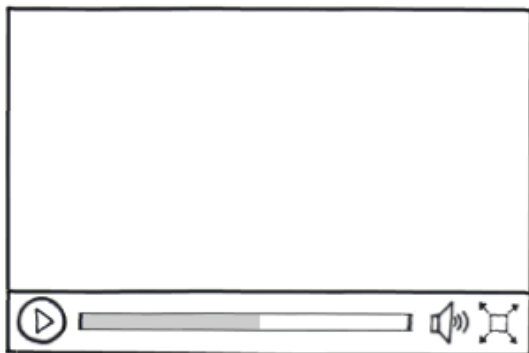
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Click Next to continue the consent process.

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If you don't feel like you know enough about public genetic research to move forward, or are uncomfortable now that you know, this is a good time to stop.

- o [Please take me back to the Sage Bionetworks home page.](#)
- o [Please take me to resources on public genetics.](#)
- o [Please take me to resources on bioethics and informed consent.](#)

I understand, and want to proceed

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Tell us that you understand this informed consent process.

- ☐ I understand [the uncertainty and risk of public genetic research](#).
- ☐ I provide [consent](#) for my data to be used in public genetic research.
- ☐ I understand that although I can [withdraw](#) at any time, I cannot withdraw data that has [already been distributed](#).

All boxes must be checked to move forward in the consent process

☐ I want to give consent

☐ I'm not sure

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Consent Form

Protocol Title: Portable Legal Consent for Public Genomics

Research

Principal Investigator: Stephen Friend

Site-Responsible Investigator's Institution: Sage Bionetworks

Description of Volunteer Population:

We are seeking a diverse range of volunteers from a wide range of genetic, social and environmental backgrounds to participate in common genomics research. Volunteers must be willing to make their genetic and other health and human trait information publicly available as part of this study. In order to provide informed consent to participate, volunteers must be knowledgeable about the science of genetics, the process of human subjects research and the risks of participation in a common genomics research study of this nature. Our goal is to create a network of databases of common genomics information that can be used for studies not yet imagined, so that we might begin as a society to connect the minute differences in our genomes to diseases, drug response, and more.

What is Informed Consent?

Informed consent means you understand the procedures, risks, possible benefits, and alternatives before you voluntarily agree to participate in a research study. Before you elect to participate, you need to understand if or how this study may affect you and your family. This form, along with the educational software and content around it and available at <http://weconsent.us>, is intended to help you make an informed decision about your participation in this study. The website will be updated as needed, possibly on a frequent basis, and participants and prospective participants should check the website regularly to obtain the most current information about this study.

Who is Eligible to Participate in this Study?

The Portable Legal Consent for Common Genomics Research (PLC-CGR) study is open to anyone

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[SIGNATURE](#)

1100 Fairview Ave. N, Mailstop M1-C108, Seattle WA USA 98109. Telephone +1 (206) 667-2062.

12.2 Additional Contact Information

If you wish to discuss your rights as a participant in a research study, or if you feel under any pressure to enroll in this study you may contact: [IRB / OHRP contact information]

[To Complete This Informed Consent Form, Your Signature Is Required on the Following Page]

SIGNATURE

- ☐ I have read this entire informed consent form and I understand it completely. I confirm that I understand the purpose of this study, the study procedures, the possible risks and discomforts of participating in this study, the potential benefits that I may experience, and the alternatives to my participation in this study. All of my questions have been answered to my complete satisfaction.
- ☐ I understand that by signing this informed consent form, I am acknowledging and agreeing to all of the terms and conditions of my participation set forth above, and I am providing my informed consent to participate in Portable Legal Consent for Common Genomic Research.

Name

Please enter your full name.

Date

I want to give consent

I'm not sure

Generate Sage Commons User ID

The data we collect here will be used to generate a unique ID that you can use to access your profile. You will provide this ID when you return to update your data files, change profile settings, or withdraw from the study.

First Name:

Last Name at Birth:

Birth City:

Birth Country:

 ▼

Birth Date:



Generate ID

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User Profile

Set up your user profile and login credentials:

Full Name:

User Name:

Password:

Re-enter Password:

E-mail:

Re-enter E-mail:

Please enter a challenge question and answer that only you would know, for password recovery:

Question:

Answer:

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Your Profile Has Been Created

You will receive an email confirming your registration. The last step is to log in to your account and upload your data. If you should choose to do this at a later time, you may use the link in the confirmation email to return here and log in. Use the user ID and password you entered on the previous screen.

[Log in and Upload Data Now](#)

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1. Take Our Survey TO DO

Thanks for helping us make our informed consent process better by alpha testing. But you're not off the hook yet. Please take the survey below - it'll only take a few minutes - so that we can learn where we need to improve. This data will form part of our submission to the required privacy and ethics authorities, so it's vital that you fill it out.

Take the survey

2. Upload Your Data TO DO

Select a file from your computer to upload. You may upload genotype data from personal genomics providers (e.g., [23andMe](#), [Navigenics](#), [deCODEMe](#), etc.) or medical data, such as Blue Button, [My Family Health Portrait](#), or other electronic health records. For more assistance on file types and uploading, [click here](#).

Select the file to upload:

Choose File...

Upload

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Select a file from your computer or upload from providers (e.g., [23andMe](#), [Navi](#), [Family Health Portrait](#), or other), or upload, [click here](#).

Select the file to upload:

Choose File...

Upload

You are uploading your personal medical or genomic data. Once you click Confirm, it will be uploaded to a database where researchers can use it to build models of disease and drug response.

Confirm

Cancel

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Take the survey

2. Upload Your Data TO DO

Here's what we think you uploaded - correct anything we got wrong:

genome_Andrew_Evans_Full_20101210115106.txt

Data contained in file: Source: Version (optional):

SNP Genotype

23andMe

v2

Tags (optional):

AMD, atrial fibrillation

Enter any keywords you can think of, separated by commas, or click tags in the cloud to add

Write anything else you'd like to say about this file:

Looks Good - Save Settings

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Take the survey

2. Upload Your Data DONE

File	Source	Version	Date
genome_Andrew_Evans_Full_20101210115106.txt	23andMe	v2	2012-03-07 13:29:30

If you would like to upload another file:

Select a file from your computer to upload. You may upload genotype data from personal genomics providers (e.g., [23andMe](#), [Navigenics](#), [deCODEme](#), etc.) or medical data, such as Blue Button, [My Family Health Portrait](#), or other electronic health records. For more assistance on file types and uploading, [click here](#).

Select the file to upload:

Choose File...

Upload

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