

Consent to Share Genetic and Health Information

Visit clinicalgenome.org/share to watch a series of short videos explaining the information on this form.

You may also call your laboratory at XXX-XXX-XXXX for more information.

Your health history and your genetic information can help doctors and scientists understand how genes affect human health. Though you may not personally benefit, sharing this information helps:



Doctors

provide better care for their patients.



Laboratories

improve testing.



Researchers

make discoveries.



Right now, [LAB NAME] publicly shares general summary information about the changes in peoples' genes that we find in our laboratory, as well as the reason(s) people were referred for testing.

With your permission, our lab would like to also share more specific information about your individual genetic and health information, including:

- All the information about your genes from your individual test results, and
- Health information provided by your doctor



Your privacy is very important to us, and we will take all appropriate measures to protect your privacy. We do not share any information like address, name, or contact information. All personal identifying information is replaced with a unique code.



With your permission, we would share this more specific individual information with others from around the world who would use it to improve patient care or advance genetic knowledge, for clinical and/or general research purposes. Your information could be shared with others through different types of databases, including:

- Open-access databases:** These are publicly available to anyone with internet access. General information, such as the health information reported by your doctor, age, race, or sex may be shared in these types of databases.
- Controlled-access databases:** These are only available to approved users. More detailed information, such as a complete list of all changes found in your genes during testing, may be found here.

Because of the broad nature of this data sharing, it is unlikely that you will be notified if your information is used, and unlikely that you will receive any results. You will not be paid for your participation.



Risks of sharing genetic and health information include the possibility that you could be identified based on this information, and that it could be used for insurance or employment discrimination. We believe that this is unlikely, though the risk is greater if you have already shared your genetic or health information with public resources, such as genealogy websites. Federal legislation is in place to protect against some types of genetic discrimination.

Your decision is voluntary, and will not change your medical care or affect your laboratory test. If you check "YES" below, your information will be shared indefinitely. You can change your mind at any time by contacting us at [LAB NAME]. If you let us know, we can stop your information from being shared in the future. However, data that has already been sent to other researchers or research databases cannot be removed.

Please check one box below that describes your choice. NO personal identifying information like name, address, and contact information will be shared.

YES, I will let [LAB NAME] share my individual genetic and health information and health using a unique code in open-access and controlled-access databases.

[or]

NO, I DO NOT want to share my individual genetic and health information using a unique code in open-access and controlled-access databases. I understand that [LAB NAME] will continue to publicly share general summary information about gene variants found in my test.

Full name

Date of birth

Signature

Today's date

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