



SUGGESTED INFORMED CONSENT DATA SHARING LANGUAGE

This document contains suggested informed consent document language for both controlled access and open access genetic data sharing. This language is intended to be used as part of a biobank informed consent document. Please refer to the TCRB Consent Form Template for additional information.

Who else will have access to my genetic information?

Researchers can do more powerful studies when they share with each other the information they get from studying human samples. They share this information by putting it into scientific databases. These databases store information from many studies conducted in many different places. Researchers can then study the combined information to learn even more about health and many different diseases.

There are many scientific databases; some are maintained by [Institution], some by the federal government, and some by private companies. There are also different kinds of databases; some are controlled access and some are open access. With controlled access databases, only researchers who apply and are approved can access the information in them. With open access databases, anyone on the Internet can access the information stored in them. No matter which kind, your name and other information that could easily identify you (such as your address or social security number) will not be placed into any scientific database.

If you take part in this project, we may place some of your genetic and health information into controlled access databases. If you agree, we may also place some of your genetic and health information into open access databases. Because your genetic information is unique to you, it is possible that someone using these databases could trace the information back to you. Researchers who are approved to access the information in controlled access databases have a professional duty to protect your privacy and to keep your information confidential. Because anybody can access the information in an open access database, the risk of being identified may be greater. Please see the section below called "Potential Risks and Discomforts" for more information on the possible risks to your privacy and the steps we take to protect your privacy.

The decision of whether to allow your genetic and health information to be put into open access databases is completely up to you. There will be no penalty to you if you decide not to allow release of your information to open access databases, and your decision will not affect your participation in this research.

I consent to release of my genetic and health information to open access databases.

Yes _____ No _____ Initials _____