



TEXAS CANCER RESEARCH BIOBANK

Open Access Data Release

Participant Education

You just signed a research consent form. What does that mean?

You agreed to participate in a research project. The purpose of that project is to collect, store, and use tissue samples and health information for research. The tissue samples and health information will become part of a biobank.

What are tissue samples?

Tissue samples are materials that are taken from the body, like blood or pieces of tumor.

What is health information?

Health information does NOT include any personal information, like your name, address, or social security number.

Health information does include information about your health history, such as your diagnosis and medical procedures you have undergone.

What is a biobank?

A biobank is a collection of tissue samples and health information that are stored and used for research.

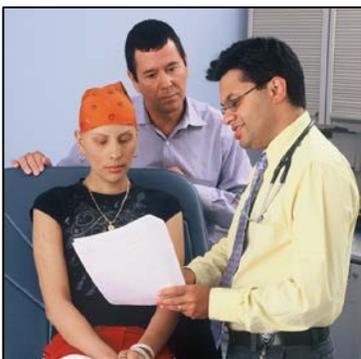


Photo Credit: National Cancer Institute

Research



Photo Credit: US Navy

Tissue Sample Collection



Photo Credit: childrenofthe90s.ac.uk

Biobank

What types of studies will be done with your tissue samples and health information?

There are many types of studies that may be done with your tissue samples and health information. Some of these studies may involve genetic analysis.

What is genetic analysis?

Genetic analysis is the process by which researchers look at your genetic information.

What is genetic information?

Your genetic information is unique to you. It is the information that is contained in your genes. Genes are pieces of DNA that give the instructions for building the proteins that make your body work. DNA stores this information in the form of a code.

This is the code that you inherit from your parents and pass on to your children. This means you share some of your genetic information with your biological (blood-related) family members.

Your genetic information contains information about you and your family. For example, it is possible to learn about some of your health risks or health risks that may be in your family by looking at your genetic information. It is also possible to learn about where your ancestors may have come from.

Researchers can learn a lot about health and disease by studying genetic information from many people.

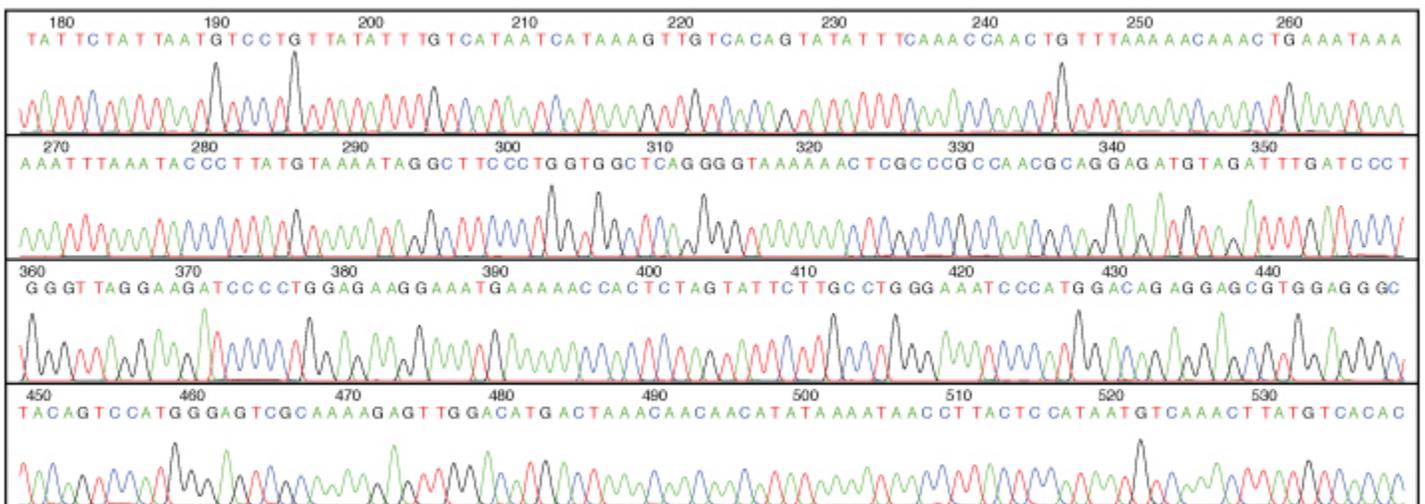


Image Credit: National Human Genome Research Institute

Genetic Information

Some of your genetic and health information may be put into scientific databases.

What are scientific databases?

Researchers can do more powerful studies when they share genetic and health information with each other. They do this by putting the information into electronic databases that can be accessed through the internet. There are two kinds of electronic scientific databases: controlled access databases and open access databases.

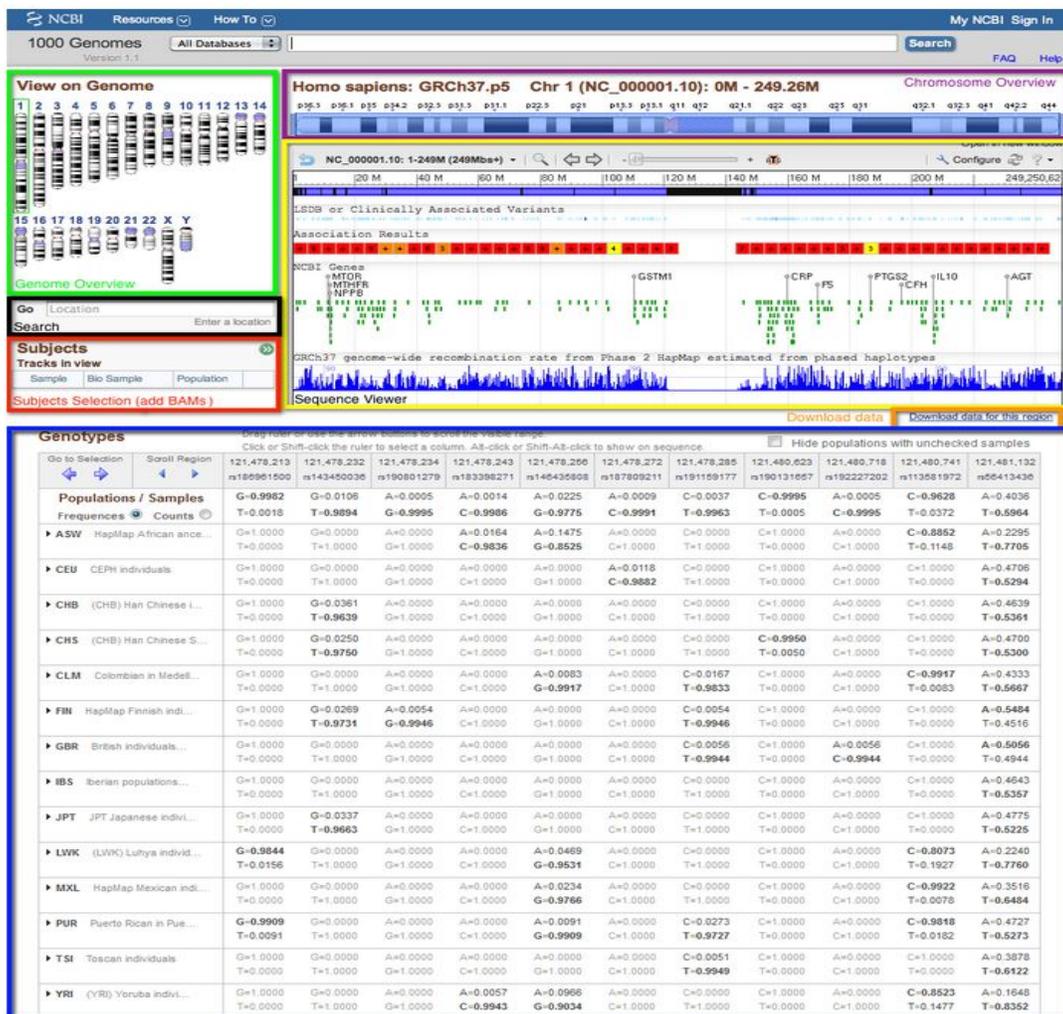


Image Credit: 1000 Genomes Project

A scientific database

When you signed the research consent form, you agreed to allow your genetic and health information to be put into a controlled access database.

What is a controlled access database?

A controlled access database is a database that only approved researchers can access.

To get approval, the researcher must fill out an application and agree to only use the information for approved research purposes. They must also agree to keep the information confidential.

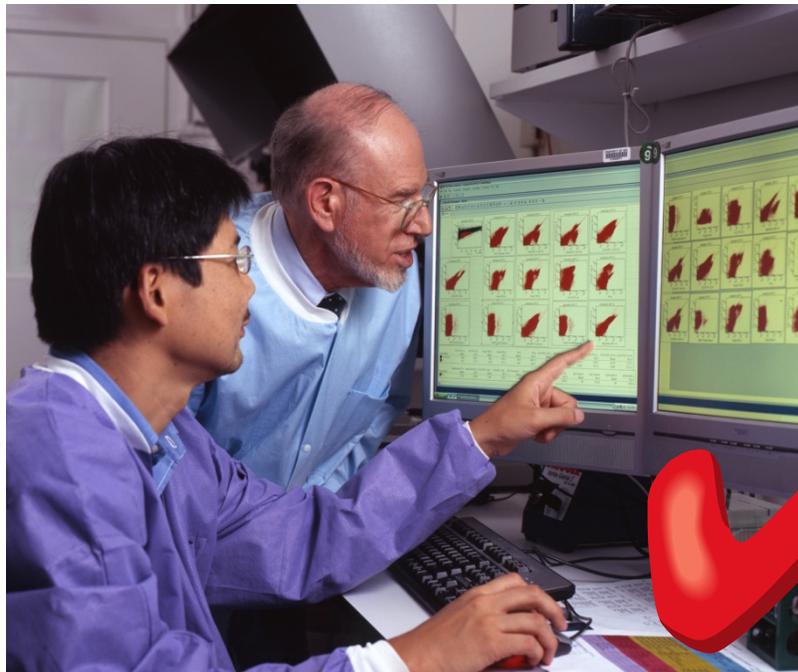


Photo Credit: National Cancer Institute

Only approved researchers can access the data in a controlled access database

In the research consent form, we gave you an option to also allow your genetic and health information to be put into an open access database.

You chose to allow your genetic and health information to be put into an open access database.

What is an open access database?

An open access database is a database that anyone on the internet can access and use for any purpose without approval. This is also sometimes called a “public database.”



Anyone can access the data in an open access database

What kind of information will go into the scientific databases?

We may put some of your genetic and health information, along with information from other people, into controlled and open access databases.

Your personal information, like your name, address, or social security number, will NOT go into either kind of database.

What are the benefits of allowing my genetic and health information to be put into an open access database?

Researchers can learn a lot about health and disease by studying genetic and health information from many people.

Though this may not benefit you directly, these studies will help researchers better understand what causes certain diseases, like cancer. It may also help researchers figure out how different patients respond to treatments. This may lead to better treatments for everyone.

Making this kind of information available in open access databases makes it easier for more researchers to access it and use it for their studies. This could help advance research more quickly.

Is it possible for someone using a scientific database to trace your genetic information back to you?

Yes, it is possible for someone to trace your genetic information from a scientific database back to you.

Researchers who are approved to access the information in controlled access databases have agreed to keep the information confidential.

Because anyone on the internet can access the information in an open access database without approval, there is a greater risk of someone tracing your information back to you.

What does it mean if someone traces your genetic information back to you?

This would mean that someone was able to figure out that the information in the database came from you.

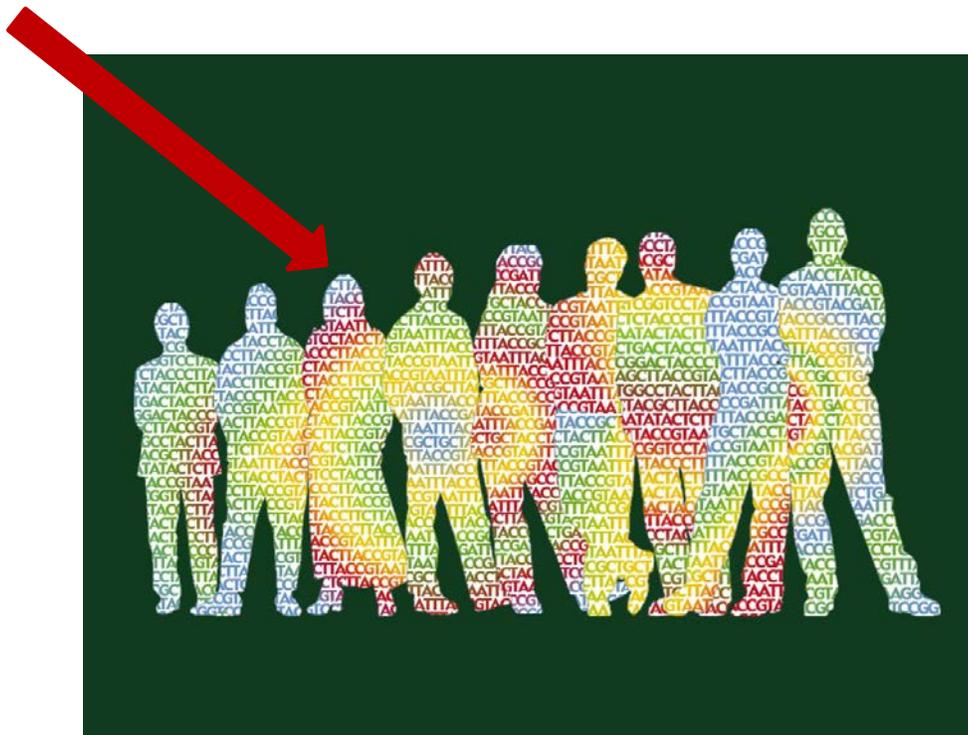


Image Credit: National Human Genome Research Institute

What could happen if someone traced your genetic information back to you?

Although we believe the risks to you are small, these are some things that could possibly happen:

1. Someone could discriminate against you based on your genetic information. There are laws that help protect you, but they don't protect you in all situations.
2. Because you share some genetic information with your biological (blood-related) family members, someone could trace your genetic information to your biological family members, like your parents, siblings, and children.
3. There may also be other risks that we cannot predict at this time.

Can you change your mind about allowing your information to go into an open access database?

Yes, you can change your mind at any time. [Participants are given the option to change their consent choice at the end of this education session and survey.]

However, if you decide to change your mind *after* your information has been put into an open access database, we may not be able to remove it. Even in cases where we can remove it from the database, your information may have already been accessed and used. If others had already made copies of the data before we removed it, we would not be able to stop them from sharing it.

To Review:

1. You agreed to participate in a research project.
2. Researchers may analyze your genetic information.
3. You agreed to allow us to put some of your genetic and health information into an open access database.
4. Your personal information, like your name, address, or social security number, will NOT be put into any scientific database.
5. It is possible for someone to trace your genetic information from an open access database back to you.
6. Risks of allowing your information to be put into an open access database may include:
 - a. Discrimination against you based on your genetic information
 - b. Implications for your biological (blood-related) family members
 - c. Other risks we cannot predict