What is Genomic Research Data?
Genomic studies examine genetic differences across the human genome (set of human genes). Researchers study the association between these genes and health conditions or personal characteristics like vision, obesity, or behavioral traits like addiction.

As part of this study, we will be collecting information about your health and your individual genes. We will use this information for our study objectives. In addition, this information, along with information about other people in this study, will be shared with the U.S. National Institutes of Health (NIH) genomic database called dbGAP (Database of Genotypes and Phenotypes). This database is a “repository” of all kinds of genomic data from studies funded by the NIH and conducted in the U.S. and around the world.

The aim of collecting this information in a repository is to allow qualified researchers to look for genetic connections for a range of topics in the future. The information may be used to learn if certain genes:

- may increase the likelihood of getting a certain disease (such as asthma, cancer, diabetes, heart disease or mental illness) or a condition (such as high blood pressure or obesity,
- may affect the progress of a certain disease or condition, or
- may affect treatments (medicines, etc.) that work for certain diseases in some people, but not in others.

We will remove direct identifiers such as your name and instead code your information before sending it to the NIH genomic data repository. NIH will never get this code or the identifiers we have removed.

Your individual data that we send to NIH will be shared through a controlled-access repository. Controlled-access data will be shared with other researchers from around the world who apply to the NIH. The NIH will review the proposals to make sure they are scientifically sound and that the data will be protected and used only for the proposed purpose. They will share the data with the researchers whose applications meet those standards and are approved.

We will not know what types of health-related research will be done with the data that are sent to the database.
**What are the risks of data being stored in a Genomic Data Repository?**

There may be risks to your privacy and the privacy of your blood relatives from storing your information in a genomic data repository.

Although we believe that the NIH privacy measures make this unlikely, there is a risk that your identity could become re-connected with your genetic and health information.

If this happened –

- Information could be revealed that could lead to denial of employment or insurance for you or a relative, or
- Law enforcement agencies might be able to demand information about you in connection with an investigation

**Are there benefits to being in a Genomic Data Repository study?**

There is no direct personal benefit to you from genomic data research. The information from your data may lead to a better understanding of how genes affect health and health-related characteristics. The findings of this research may help other people in the future.