## Sharing Data with the National Institutes of Health (NIH)

### Why will my data be shared with the National Institutes of Health (NIH)?

(Include this sentence only if the NIH is providing funding.) The NIH is funding this study. The NIH’s goal is to maximize the benefits that come from the research.

The NIH repository stores genetic information and phenotypic data from many studies. The NIH then shares that information with researchers. We will send the information about you and the other participants to a repository at the NIH. The information will be de-identified (no names or other direct information about you will be included). The NIH will not be able to re-identify you or any other individual.

The NIH intends to share the collected information with other researchers. The researchers who receive data must promise to keep the data confidential and to use it only for the purpose approved by NIH. They must also promise to not try to re-identify anyone.

The goal of genetic studies is to look for genetic connections that may explain how to identify, prevent, and treat health problems. For example, genetic data may be used to find out:

* Who is more likely to develop a certain illness, such as asthma, cancer, or diabetes, or a condition like high blood pressure or obesity;
* What genes affect the progress of a certain disease or condition; and
* What genes may affect treatments which now may or may not work in certain people.

### Risks Associated with Sharing Data with the NIH

There are risks associated with sharing your data with the NIH but they are very unlikely to occur. There is only a very small chance that someone could find out that the data came from you. If that happened, it’s possible that someone could deny you a job or health insurance. Or you could experience stress, anxiety or embarrassment.

### Benefits Associated with Sharing Data with the NIH

Sharing your information for future research will not directly benefit you. It is hoped that it will lead to a greater understanding of the interaction between genes and health. This knowledge could help others in the future.

**Controlled or Unrestricted Access**

The data about you can either be made available by the NIH through controlled access or unrestricted access. Controlled access means the data are made available for other research only after investigators have obtained approval from NIH to use the requested data for a particular project. Unrestricted access means that the data are publicly available to anyone (e.g., The 1000 Genomes Project). (Include the following sentence if only offering unrestricted access.) For this study, we are requesting unrestricted access.

## Consent to Share Data with the NIH

Please indicate whether you will allow us to share your information with the NIH by putting your initials next to one of the following choices:

\_\_\_\_\_ (initials) No, I do not consent to sharing my de-identified information with the NIH

\_\_\_\_\_ (initials) Yes, I do consent to sharing my de-identified information with the NIH for controlled access (Delete this option, if only offering unrestricted access)

\_\_\_\_\_ (initials) Yes, I do consent to sharing my de-identified information with the NIH for unrestricted access