**BROWN UNIVERSITY**

**GLOBAL UNIQUE IDENTIFIER (GUID)**

**DATA REPOSITORY ASSENT**

[Study Title]

 [Version #, Date]

* **WHAT IS A DATA REPOSITORY?**

A data repository is a place where data can be kept forever. Researchers can ask to use that data and learn from it. You can think of a data repository as a kind of online library that keeps the information data collected from you and others during research studies.

* **WHAT WILL HAPPEN TO MY DATA?**

By joining this study, you are letting the research team collect data about you to help answer a question. If it is okay with you and your parent/guardian gives permission, we would like to share that data with [state the name of the data repository] so that other researchers can use and learn from your data, too. If you agree, we will use the information from your birth certificate to make a special code of letters and numbers. This code will be used to hide your identity when we put your research data into [name of the data repository].

We will never share your birth certificate information with [name of the data repository] or other researchers. Only the research team at Brown will have this information. Other researchers can ask [name of the data repository] to get a copy of your code and data for their own research.

If you would like us to share your data with [name of the data repository] but do not want to use your birth certificate information to create this code, we can create a fake code instead. This fake code acts like the real code, but your data cannot be connected if you have been in any other research studies. Only the real code can connect your data across all your research studies. There is no way to connect fake codes to each other. If you think it is important to share and connect your data from other studies, you will need to share the information on your birth certificate with us to create a real code.

* **COULD ANYTHING BAD HAPPEN IF I SHARE MY DATA?**

If you say it’s okay to share your information, other researchers might use your data to try to find out who you are. You may not know how or why other researchers are using your data.

* **CAN DATA THAT IS SHARED ABOUT ME BE ERASED?**

You can ask to have your real code/fake code and your data erased from [name of the data repository] anytime you want. But if another researcher already has a copy of your real code/fake code and data from [name of the data repository] before you asked to erase it, the researcher will be able to keep it and use it for their own study. No one will be mad at you, and you won’t get in trouble if you tell the research team that you want to stop sharing your data.

* **COULD SHARING MY DATA HELP ME?**

Sharing your information with [name of the data repository] may not help you.

* **DO I HAVE TO DECIDE NOW?**

You do not have to make any decisions right now. It is your choice to make a real code/fake code and share or not share your data. If you do not want to share your data, you can still be in this study. No one will be upset if you say no.

You can ask the research team to share or stop sharing your data with [name of the data repository] at any time. You can let the research team know now or later by contacting [(name) at (phone #), *for 13-14 year-old participants only*, email XXX@brown.edu)] and asking them to start or stop sharing your data.

* **WHAT DO I DO IF I HAVE A QUESTION ABOUT SHARING MY DATA?**

You can ask questions at any time. The researchers want you to understand what it means to share your data and they want to answer all of your questions. If you think of a question later, you or your parent(s)/guardian(s) can call the research team and to answer your questions.

[*The person obtaining assent should ask the child the following questions to assess understanding. If the child is unable to answer correctly, the appropriate section of the assent form should be reviewed again with the child.*]

1. How would you describe a data repository?
2. Will other researchers know that the data came from you?
3. Will putting data in the repository help you?
4. Can you take your data out of the repository?
5. Do you have to share your data with the repository?

When you are ready to decide, please check one of the boxes below to let the research team know if they can share your data with [name of the data repository].

**I DO NOT WANT TO SHARE MY DATA:**

☐ I do not want the research team to share my data with [name of the data repository].

**I GIVE MY PERMISSION TO CREATE A REAL CODE AND SHARE MY DATA:**

☐ It is okay for the research team to use my birth certificate information (like my name, birthday, and where I was born) to create a real code and share my data with [name of the data repository].

**I GIVE MY PERMISSION TO SHARE MY DATA USING A FAKE CODE:**

☐ It is okay for the research team to make a fake code for me and share my data with [name of the data repository].

Child’s Signature and Date / PRINTED NAME