**BROWN UNIVERSITY**

**CONSENT ADDENDUM FOR** **OPTIONAL DATA SHARING WITH A**

**NATIONAL INSTITUTE OF HEALTH (NIH) DATA REPOSITORY**

[Title of study]

[*For multi-consent studies*: List the sub-title that identifies the specific population or activity covered by this consent.]

Addendum

[Version #, date]

* **WHAT IS A DATA REPOSITORY?**

A data repository holds research data and makes that data available for future use by the broader research community. Data repositories may have specific requirements about the research topic, data re-use and access, file format, and data structure that can be used. Many data repositories have restrictions on who can add and access data.

* **WHAT IS RESEARCH DATA?**

Research data is any information or biospecimens (identifiable or anonymous) you provide to the research team for the purposes of conducting this research study.

* **WHAT IS PERSONALLY IDENTIFIABLE INFORMATION (PII)?**

Personally Identifiable Information (PII) is the information that can be used to recognize or trace your identity, such as your name, social security number, finger prints, and DNA sequence.

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

If you allow us to share your research data with an NIH data repository, we will need to collect your personal information as it appears on your birth certificate (first name, middle name [if applicable], last name, date of birth, sex, and town/city/municipality of birth). This PII will be used to create a Global Unique Identifier (GUID), so your research data can be properly catalogued in the data repository. Your PII will never be shared with the data repository.

Other researchers can apply to the data repository to receive a copy of your GUID and research data for their own research. Your PII will never be shared with these researchers.

* **WHAT ARE THE RISKS?**

Your research data could be accidentally shared with someone who may attempt to learn your identity.

* **WHAT ARE THE BENEFITS?**

You will likely not benefit directly from allowing your research data to be shared with the data repository.

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

You may decide to share or stop sharing your research data with the data repository at any time by contacting the research team (email and phone number) and asking them to start or stop sharing your research data with the data repository.

Creating a GUID and sharing your data with the data repository are optional and not required to participate in this study.

* **CAN INFORMATION ABOUT ME BE DESTROYED?**

Your GUID and your research data *in the repository* will be destroyed upon your request.

However, *once shared with other researchers*, the shared copy of your GUID and your research data cannot be destroyed.

**DECLINE TO SHARE DATA:**

☐ I do not want the research team to share my research data with an NIH data repository.

**PERMISSION TO SHARE DATA:**

☐ I give permission for the research team to use my personal information as it appears on my birth certificate (first name, middle name [if applicable], last name, date of birth, sex, and town/city/municipality of birth) to create a GUID and share my research data with an NIH data repository.

Participant's Signature and Date / PRINTED NAME