**BROWN UNIVERSITY**

**GLOBAL UNIQUE IDENTIFIER (GUID)**

**DATA REPOSITORY CONSENT**

[Study Title]

 [Version #, Date]

* **WHAT IS RESEARCH DATA?**

Research data is any information you provide to the research team for the purposes of conducting this research study.

* **WHAT IS A DATA REPOSITORY?**

A data repository holds research data and makes that data available for future use by the broader research community. Many data repositories have rules on who can add and access data.

* **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, fingerprints, and DNA sequence.

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

If you allow us to share your research data with [state the name of the data repository], [state the name of the data repository] would like us 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). A GUID is similar to a social security number for your research data. Your research data will be catalogued using the GUID, so your research data can be linked securely across studies you have participated in without revealing your identity.

We will never share your PII with [name of the data repository] or other researchers. Only the research team at Brown will have your PII. Other researchers can apply to [name of the data repository] to receive a copy of your GUID and research data for their own research.

If you would like us to share your research data with [name of the data repository] but do not want to use your PII to create a GUID, we can create a “pseudo-GUID” instead of a GUID. A pseudo-GUID functions like a GUID, but your research data cannot be linked across research studies in which you have participated. Only a GUID can link your research data across all your research studies. There is no way to connect multiple pseudo-GUIDs to each other. If it is important to you to share and connect your research data across multiple studies, it will be necessary to share your PII with us to create a GUID.

* **WHAT ARE THE RISKS?**

If you allow your research data to be shared with other researchers, there are researchers who may attempt to learn your identity without your consent.

Researchers who receive a copy of your research data may use it for purposes you do not intend, including scientific research that you do not agree with or sharing it with others you do not know.

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

Your GUID/pseudo-GUID and your research data in[name of the data repository] will be destroyed upon your request (see below: Do I Have to Decide Now).

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

* **WHAT ARE THE BENEFITS?**

You will likely not benefit directly by allowing your research data to be shared with [name of the data repository].

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

You do not have to make any decisions right now. Creating a GUID/pseudo-GUID and sharing your research data with [name of the data repository] are **optional** and not required to participate in this study.

You may ask the research team to share or stop sharing your research data with [name of the data repository] at any time by contacting [(name) at (phone # or email XXX@brown.edu)]. The research team will let you know if we are no longer able to share your data with [name of the data repository] (for example, sharing may not be possible if the study has ended).

**DECLINE TO SHARE DATA:**

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

**CONSENT TO CREATE A GUID AND SHARE DATA:**

☐ I give consent 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 [name of the data repository].

**CONSENT TO SHARE DATA USING A PSEUDO-GUID:**

☐ I give consent for the research team to make a pseudo-GUID for me and share my research data with [name of the data repository].

Participant's Signature and Date / PRINTED NAME

**[Participants Ages 15 – 17 and Parent / Guardian Permission]**

**Participants Ages 15 – 17:**

If you are 15 – 17 years old, your parent(s) must also give their permission for you to share your research data with [name of the data repository]. Your parent(s) cannot make this choice for you or override decisions you make about your research data.

**Parent / Guardian Permission:**

You acknowledge that even if you grant permission for the research team to share your child’s research data, if your child declines, or your child agrees and later wants their information destroyed, their decision prevails.

**DECLINE TO SHARE DATA:**

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

**PERMISSION TO CREATE A GUID AND SHARE DATA:**

☐ I give permission for the research team to use my child’s personal information as it appears on my child’s 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 child’s research data with [name of the data repository].

**PERMISSION TO SHARE DATA USING A PSEUDO-GUID:**

☐ I give permission for the research team to make a pseudo-GUID for my child and share my child’s research data with [name of the data repository].

Parent or Guardian Signature and Date / PRINTED NAME

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Parent or Guardian Signature and Date / PRINTED NAME