**BROWN UNIVERSITY**

**GLOBAL UNIQUE IDENTIFIER (GUID)**

**DATA REPOSITORY PARENT PERMISSION**

[Study Title]

 [Version #, Date]

* **WHAT IS RESEARCH DATA?**

Research data is any information the research team gathers about your child 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 restrictions 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 child’s identity, such as their name, social security number, fingerprints, and DNA sequence.

* **WHAT WILL HAPPEN TO MY CHILD’S RESEARCH DATA?**

If you and your child allow us to share your child’s research data with [state the name of the data repository], the [state the name of the data repository] would like us to collect your child’s personal information as it appears on their 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 child’s research data. Your child’s research data will be catalogued using the GUID, so your child’s research data can be linked securely across studies your child has participated in without revealing their identity.

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

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

* **WHAT ARE THE RISKS?**

If you and your child allow your child’s research data to be shared with other researchers, there are researchers who may attempt to learn your child’s identity without your child’s assent or your permission.

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

* **CAN INFORMATION ABOUT MY CHILD BE DESTROYED?**

Your child’s GUID/pseudo-GUID and their research data in[name of the data repository] will be destroyed upon you and your child’s requests (see below: Do My Child And I Have To Decide Now).

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

* **WHAT ARE THE BENEFITS?**

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

* **DO MY CHILD AND I HAVE TO DECIDE NOW?**

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

You and your child may ask the research team to share or stop sharing your child’s 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 child’s data with [name of the data repository] (for example, sharing may not be possible if the study has ended).

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 assents 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 GUIDE 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