**BROWN UNIVERSITY**

**PARENT PERMISSION TO SHARE INFORMATION WITH A DATA REPOSITORY**

[Title of study]

 [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 (identifiable or anonymous) the research team gathers about your child 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 child’s identity, such as their name, social security number, finger prints, 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 a data repository, we will need 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), so your child’s research data can be properly catalogued in the data repository. Your child’s PII will never be shared with the data repository.

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

* **WHAT ARE THE RISKS?**

Your child’s research data could be accidentally shared with someone who may attempt to learn their identity.

* **WHAT ARE THE BENEFITS?**

Your child will likely not benefit directly from allowing their research data to be shared with the data repository.

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

You and your child may decide to share or stop sharing their research data with the data repository at any time by contacting the research team [(name) at (phone # or email XXX@brown.edu)] and asking them to start or stop sharing your child’s research data with the data repository.

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

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

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

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

You acknowledge that even if you grant permission for the research team to share your child’s research information, 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 a data repository.

**PERMISSION TO 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 a data repository.

Parent or Guardian Signature and Date / PRINTED NAME

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Parent or Guardian Signature and Date / PRINTED NAME