## ***Note to Investigators:*** *Orange italicized text is provided for guidance. Remove all orange, italicized help text and any instructional text prior to submitting this document. This form should be used when a minor’s data will be deposited into a repository or data bank.*

**DATA REPOSITORY ASSENT**

**(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS AN IRB APPROVAL STAMP WITH CURRENT DATES HAS BEEN APPLIED TO THIS DOCUMENT.)**

**Title of research study:** Insert title of research study here with protocol number, if applicable

**Investigator:** Insert name of principal investigator

***Sponsor:*** Include the name of the sponsor or any funding sources

**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 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. Other researchers can ask for permission to use your data for their own studies.

**Could anything bad happen if I share my data?**

If you say it’s okay to share your data, other researchers might know who you are or 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 data erased from *[name of the data repository]* anytime you want. But if another researcher already has a copy of your data from *[name of the data repository]* before you asked to erase it, that 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.

**Can sharing my data help me?**

Sharing your data 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 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 # and email]* 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 data repository help you?*
4. *Can you take your data out of the data repository?*
5. *Do you have to share your data with the data 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]*.

**DATA REPOSITORY DECISION**

☐ It is okay for the research team to share my data with *[name of the data repository]*.

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

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Child’s Signature Date

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Child’s Printed Name

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Signature of Person Obtaining Assent Date

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Printed Name of Person Obtaining Assent