

DRAFT (March 1, 2012)
Data Sharing Permission for Child [Adult]

This form requests your permission to include [your data and] your child's data in a data library on the Internet (Databrary.org). The library allows researchers interested in development and behavior to share findings. Data sharing will help researchers to learn more from the data they collect and will lead to faster progress in our understanding of human development.

Giving permission to share data is entirely separate from giving consent to participate in the research study. You do not have to give permission to share [your or] your child's images or other data in the library. If you choose not to share [your or] your child's data with the library it will not affect your receipt of payment if offered or [your or] your child's participation in this or future studies.

What data will be shared?

With your permission, we will include video recordings of [you or] your child's behavior in the data library. We will also include basic information about [you or] your child such as age, sex, race, ethnicity, and geographic region. We may also include information from interviews and questionnaires and/or information collected with other recording methods such as motion tracking, eye tracking, and brain imaging. If researchers code and analyze the video files and/or other sources of information, this information will also be shared.

If [you or] your child [have] has a medical diagnosis, we may wish to include that information in the library. If you provide health-related information about [you or] your child's condition, prior treatments, medications, or family history of illness during this study, it may be shared in the library. But, because this information may be more private, we will request your permission to include these data in the library on a separate data release form.

Will the data be confidential or anonymous?

All of [your or] your child's data will be filed by an identification code, not by name. No information will be included in the data library about how to contact you or your child (child's last name, parents/guardians' last names, address, phone number, email, etc.). Authorized users of the library must agree not to try to contact you or your child.

Your child's image and/or voice will be visible on the video. Your child's name and/or your name may be spoken out loud on the video. Your image and/or voice and those of visitors or other members of your family may also be seen on the video; if the study takes place in your home, aspects of your home may be seen on the video. Thus, it is possible that you, your child, or other people could be identified from the video by accident. However, authorized users of the library must agree not to mention the name of any person on the video in published reports of data from the library.

Who can Access the Data in the Library?

Videos and other data describing the behavior of individuals can only be viewed and downloaded from the library by authorized users. Researchers who wish to have access to the data must formally apply for access. Only researchers whose research is supervised by Institutional (Human Subjects) Review Boards or similar organizations that supervise research will be authorized for access. Researchers must renew their authorization for access to the library every year.

Authorized users must sign a data use agreement. It requires them to maintain the confidentiality of the data, treat human subjects ethically, and **not** use the data for commercial

purposes. Authorized users must treat data in the library with the same high standards of care that they would treat data collected in their own laboratories.

How long will the data be in the library?

Data in the data-sharing library will be preserved indefinitely in a secure facility.

Permissions:

Please check the appropriate boxes below:

☐ I do not give permission for any of [my data or] my child's data to be included in the data library.

or

☐ I give permission for [my data or] my child's data to be shared in the library.

I wish to limit who can view data, images, and video of [me or] my child, as follows:

☐ [My data or] my child's data can be viewed *only by authorized users and researchers under their supervision* in the conduct of scientific research.

☐ [My data or] my child's data, including photographic images and video excerpts can be viewed by *public audiences* for scientific purposes (e.g., professional conferences, talks) and/or educational purposes (e.g., classroom lectures, workshops).

I wish to limit how digital files of images or video excerpts of [me or] my child can be shared outside the library, as follows:

☐ I do not give permission to release any digital files outside the library.

☐ I give permission to release digital files to individuals who are not authorized users of the data library. I trust that authorized users of the data library will exercise professional judgment and uphold ethical principles in determining which files to release, to whom, and how.

Compensation

There will be no compensation to you or to your child for the use of data in the library.

Print child's name

Print parent/guardian's name

Parent/guardian's signature

Date

Researcher obtaining consent

Date

We will give you a copy of this form for your records. If you have any questions about the data-sharing library, please email to **[Databrary EMAIL CONTACT]**. For questions about your rights as a research participant, you may contact **[APPROPRIATE CONTACT FOR LOCAL INSTITUTION]**.