

# **Databrary Permission to Share Self-Reported Health-Related Information About Children Under 12**

## **Overview**

This form requests permission to include self-reported health-related information about my child in a secure data library on the Internet (Databrary.org). The library allows authorized researchers to share data. Data sharing will help researchers to learn more and will lead to faster progress in our understanding of human development.

Giving permission to share is entirely separate from giving consent to participate in a research study. I do not have to give permission to share self-reported health-related information about my child in the library. My choice will not affect payment if offered for participation in this or future studies.

## **What will be shared?**

With my permission, self-reported health-related information about my child will be included in the library.

## **Will the information be private?**

My child's information will be kept private. Researchers will identify all of my child's information by a code number, not by name. No information will be included in the data library about how to contact me, my child, or my family.

If I also agree to share video/audio recordings or still images, my child's image and/or voice may be seen or heard on the video/audio recordings or still images. My name may be spoken aloud. The images and/or voices of visitors or other members of my family may also be seen or heard. If the study takes place in my home, aspects of my home may be seen or heard. Someone might be able to identify me, my child, or other people unintentionally. But, the authorized researchers with access to the data library promise to keep private the identities of all people in the video/audio recordings or still images.

## **Who can access information in the library?**

Only authorized researchers have access to information in the library. Researchers who are granted access to the library must sign a contract that requires them to maintain confidentiality and not to use the information for commercial purposes. Researchers promise to treat information in the library with the same high standards of care that they treat information collected in their own laboratories.

## How long will the information remain in the library?

Information in the library will be preserved forever in a secure location. Databrary does not intend to erase the information. Databrary intends to store the information so that future researchers may be able to use it.

If in the future I no longer wish to have self-reported health-related information about my child stored in the library, I will contact Databrary at [ethics@databrary.org](mailto:ethics@databrary.org).

## Permissions

### Permission to share with authorized researchers

- ☐ I give permission to share self-reported health-related information about my child with authorized researchers in a secure data library.

## Payment

My child will not be paid for the use of information in the library.

## Signatures

My signature indicates that I understand this document and agree to what it says.

My child's name:

Parent/Guardian's Name:

Parent/Guardian's Signature:

Researcher obtaining permission:

Date:

Date:

I will receive a copy of this form for my records. If I have any questions about the data-sharing library, I will send email to [ethics@databrary.org](mailto:ethics@databrary.org). For questions about my rights as a research participant, I may contact [APPROPRIATE CONTACT FOR LOCAL INSTITUTION].