

Databrary Release for [STUDY NAME]

Version date: April 29, 2020

What we are asking

We ask your permission to share data from this session in a secure, web-based library called Databrary (databrary.org) sponsored by New York University. The data may include video/audio recordings, photographs, and images; other information about you, your child, or your family such as age, birth date, sex, ethnicity, education, and self-reported health information; and information supplied by researchers who analyze data from this session. We ask your permission to share these data because sharing will lead to faster progress in research.

Giving permission to share data in Databrary is separate from consenting to participate in this research study. You do not have to give permission to share your information in Databrary. If you agree to share data, we also request permission to allow authorized Databrary researchers to show parts of the video or audio we recorded in scientific presentations and/or for informational and educational purposes. You can agree to share your data, but not agree to allow researchers to show portions of it in scientific presentations for information and educational purposes. Your choices will not affect receipt of payment if offered for participation in this or future studies.

Will the information be confidential (kept private)?

No information will be included in the data library about how to contact you or your family. No data files will be identified by anyone's name. However, other people who see the images or hear the voices of people in the recordings may recognize someone. First and/or last names of people may be spoken aloud and recorded. If the study takes place in your home, aspects of your home may be seen or heard. In addition, we may collect other information about you, your child, or your family and store it with the video or audio recordings. Thus, someone who sees the video or hears the audio might be able to identify you, your child, or other people. However, all researchers who have access to Databrary promise to keep private the identities of all people whose data are stored in Databrary.

Who has access to information in the library?

Only researchers will have access to information in Databrary. Researchers must be formally authorized by their employers before gaining access to Databrary. Researchers granted access agree to use the data for scientific research and education but not commercial purposes. Researchers promise to treat data in Databrary with the same high standards of care that they treat data collected in their own laboratories.

How long will data remain in the library?

Data in the library will be preserved indefinitely in a secure location so that future researchers can use it.

What if I change my mind about sharing?

Databrary does not store information that links your identity to specific files. Therefore, if you want to revoke permission to share data or want a copy of data stored on Databrary, you must contact the researcher conducting this study (NAME OF PI: CONTACT INFORMATION). If you revoke permission to share, Databrary cannot guarantee that data shared prior to the date you revoked permission can be retrieved.

Where is Databrary located?

Databrary is located in the United States and is accessible over the internet. This means that data stored on Databrary may be accessed, downloaded, and reused by authorized researchers located anywhere in the world.

Compensation

There will be no compensation for sharing information in Databrary. [IF ORAL OR WRITTEN ASSENT TO SHARE DATA IS NEEDED, USE THE FOLLOWING SCRIPT]

Assent to Share Script for Child Participants

Spoken to child by Experimenter:

Earlier, we asked you if you wanted to be in the study and if we could record you while you [describe task]. You said yes.

Right now, only the people who work in this room will see the recordings of you or other information about you from this session. Is it okay with you if we put these recordings and other information about you in a library so that other scientists who don't work in this room can also see it? There are many other scientists who want to learn about how children grow and change, but they can't because they don't work in this room.

If you say yes, only other scientists who have approval to use the library will see the recordings or other information. Your friends, your teachers, and your classmates won't be able to see them unless you say it is okay.

You can talk this over with your parents before you decide if you want your recordings and other information to be in the library. I will also ask your parents to give their permission for your recordings to be in the library, but even if your parents say "yes" you can still say "no" and decide not to put your recordings in the library.

If you don't want your recordings and other information to be in the library, we don't have to put them in there. Remember, having your recordings and other information in the library is up to you. No one will be upset if you don't want the recordings and other information to be in there.

You can ask any questions that you have about the library. If you have a question later that you didn't think of now, you can call me or ask [your parents, teacher, whoever the child may choose] to call me at [telephone number].

Would you allow your recordings and other information to be stored in the library?

[Participant answers yes or no; only a definite yes may be taken as permission to share.]

ORAL ASSENT: Researcher must record response in signature table and initial.

WRITTEN ASSENT: *If you can read and write, and want to have your recordings and other information stored in the library, I can show you the box to check in the signature table.*

Would you allow other people besides scientists working in the library to see parts of the recordings?

[Participant answers yes or no; only a definite yes may be taken as permission to share.]

ORAL ASSENT: Researcher must record response in signature table and initial.

WRITTEN ASSENT: *If you can read and write, and you want to allow other people to see parts of the recordings, I can show you the box to check in the signature table.*

Signatures

All people in the session must decide whether to provide permission for one of the following types of sharing:

Permission to share with authorized researchers

I give permission to share data from this session with authorized researchers in a secure library called Databrary. Authorized researchers may use the material for non-commercial research and educational purposes.

OR

Permission to show excerpts and images

I give permission to share data from this session with authorized researchers in a secure library called Databrary. Authorized researchers may use the data for non-commercial research and educational purposes.

In addition, I give permission for authorized researchers to show selected excerpts or images from shared recordings in public settings for informational or educational purposes. I understand that at times these presentations may be videotaped or recorded by people who sponsor presentations, and that the recordings may be made available to the public via the internet (e.g., YouTube). In giving my permission, I trust that authorized researchers will use their professional judgment and uphold ethical principles in determining which excerpts or images to present and to which

audiences. No one directly associated with this research project or Databrary will make your data directly available to the public.

We will give you a copy of this form and the signature page for your records. If you have any questions about the data-sharing library, please email contact@databrary.org¹. For questions about your rights as a research participant, you may contact [APPROPRIATE CONTACT FOR LOCAL INSTITUTION].

Adults

By signing below, I indicate that I understand this Databrary Release document and have recorded my own choices for sharing the data from this session in Databrary and allowing authorized researchers to show excerpts.

+-----+-----+ | I give permission to share my data with authorized | Yes
No || researchers. ||| | **OR** | +-----+-----+
| I give permission to share my data with authorized | Yes No | | researchers AND permission for authorized
researchers | | to show excerpts and images. | | +-----+-----+

Signature Date Printed Name

+-----+-----+ | I give permission to share my data with authorized | Yes
No || researchers. ||| | **OR** | +-----+-----+
| I give permission to share my data with authorized | Yes No | | researchers AND permission for authorized
researchers | | to show excerpts and images. | | +-----+-----+

Signature Date Printed Name

Children Deciding for Themselves (also requires parental consent)

A researcher must read through the Assent to Share Script with those that can provide oral or written assent. A parent or guardian must also decide whether to allow their child to share, and then sign on their behalf.

+-----+-----+ | I give permission to share my child's data with | Yes No
| | authorized researchers. ||| | **OR** | +-----+-----+
| I give permission to share my child's data with | Yes No | | authorized researchers AND permission for authorized
| | researchers to show excerpts and images. | | +-----+-----+

Printed name of child

Signature of Parent/Guardian Date Printed Name

+-----+-----+ | I give permission to share my child's data with | Yes No
| | authorized researchers. ||| | **OR** | +-----+-----+
| I give permission to share my child's data with | Yes No | | authorized researchers AND permission for authorized
| | researchers to show excerpts and images. | | +-----+-----+

Printed name of child

Signature of Parent/Guardian Date Printed Name

¹<mailto:contact@databrary.org>

Young Children With Parent or Guardian Providing Consent

A parent or guardian must decide whether to allow their child's data to be shared and sign on their behalf.

+-----+-----+ | I give permission to share my child's data with | Yes No
| | authorized researchers. | | | | **OR** | | +=====+
| I give permission to share my child's data with | Yes No | | authorized researchers AND permission for authorized
| | researchers to show excerpts and images. | | +-----+-----+

Printed name of child

Signature of Parent/Guardian Date Printed Name

+-----+-----+ | I give permission to share my child's data with | Yes No
| | authorized researchers. | | | | **OR** | | +=====+
| I give permission to share my child's data with | Yes No | | authorized researchers AND permission for authorized
| | researchers to show excerpts and images. | | +-----+-----+

Printed name of child

Signature of Parent/Guardian Date Printed Name

To Be Completed By Researcher Obtaining Permission

I certify that all participants who were recorded have given their decision about whether or not to share with
Databrary. Yes No -----

Signature of person who explained this Date Printed Name