What is Databrary? And who has access?

Databrary is federally funded by the NSF and the NIH to create a library for sharing video and metadata for developmental and behavioral research. Access is limited to Databrary Authorized Investigators. To become authorized, a PI must sign the Databrary Investigator Agreement and must be verified by their university. The university approves by co-signing the agreement. The only data that is visible to anyone is data that has been released by the participants for sharing in Databrary and that has been released for sharing by the contributing Investigator.

How can identifiable data be shared outside of my lab?

Data can only be shared with Databrary if the subject(s) in the video have agreed to have their data shared. To standardize the process and make it as simple as possible for researchers, we have developed a Databrary Release Template that can be added to individual's IRB protocols and used with subjects.

The Databrary Release Template was developed and refined in close consultation with the IRB office at NYU to give Databrary Investigators a standardized way to obtain with the necessary permissions to be shared in Databrary. The template form is designed to make it as clear and unambiguous as possible to participants about what agreeing to share their data in Databrary will mean.

Instructions for using the Databrary Release Template

To use the template, each investigator needs to enter their lab or study information and add the form to their IRB protocol. The template language in the Databrary Release can be adapted to suit the unique needs of each investigator and/or project, as well as the local IRB policies that govern an investigator's research. If you need any help using the Databrary Release form for sharing data, or if you have helpful feedback about using the forms, please contact Lisa Steiger at lisa@databrary.org.

Preparing to share data

Investigators who wish to contribute to Databrary must do some planning in advance. They must:

- 1. Determine the source(s) of the data to be deposited;
- 2. For recordings and related information, determine whether depicted individuals or research participants must give permission to share—in most cases, the answer is yes;
- 3. Seek and be granted, as appropriate, permission to collect and share data from the research supervision entity that governs research at the Investigator or clinician's home institution;
- 4. Secure permission to share from research participants and all individuals whose image or voice is recorded using the Databrary Release Template or equivalent language that has been approved by the Investigator's research supervision entity;
- 5. Apply for and be granted Databrary Investigator or Affiliate Investigator status with Databrary;
- 6. Prepare recordings for sharing with Databrary, including tagging files with the level of permission granted by all depicted individuals. Remove personally identifying information from other data and metadata.

Seeking permission to share data

Researchers who wish to share data with Databrary should seek permission to do so from their governing research supervision entity, such as an IRB. Individuals whose scientific activities are not governed by a research supervision entity may choose to have their protocol reviewed by another entity with similar authority.

In preparing applications to the research supervision entity, researchers are strongly encouraged to refer to and use the Databrary Release Template provided by Databrary.

Links to all of the relevant Databrary documents concerning permissions and access may be found on the Databrary website (http://databrary.org/about/#policies).

Sources

There are two main sources of recordings: (1) recordings collected by researchers or clinicians in laboratory, or clinical contexts, and (2) recordings collected from incidental sources not intended for research or clinical purposes. The latter may include home movies or videos, recordings from security cameras or microphones, cameras or other recordings made in public places, and recordings shared with the public via web portals such as YouTube (http://www.youtube.com) or Vimeo (http://vimeo.com). Laws governing whether recordings made in public places may be used for research purposes vary. Researchers who wish to deposit recordings from these or other non-laboratory/non-clinical setting sources should consult with their local research supervision entities for specific permission to share such recordings with Databrary.

Sample Script for Introducing the Databrary Release Form

Now that you have finished this session, there's one more thing we want to ask you. The data that researchers collect from babies and families are incredibly valuable for helping scientists to understand how children develop.

So we wanted to ask if you are comfortable with allowing us to share the data we collected from this session with other researchers just like the professor who runs this lab/project. The data would be shared in a secure, online library, it's not available to the public,—only researchers that are authorized by their University would be able to access the information in the library.

This permission form also asks whether you would allow other professors/ researchers like Dr. [PI's Name] to show short bits of the videos to students or researchers for educational and scientific purposes. These data will not be used or shown for commercial purposes.