

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 Principal 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 visible to anyone are data that have been released by the participants for sharing in Databrary and that has been released for sharing by the contributing investigator.

Where can shared recordings or still images come from?

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](#) or [Vimeo](#). 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.

How can identifiable data that I collect be shared outside of my lab?

Data can only be shared with other Databrary authorized users if (i) the data are [de-identified](#), or (ii) the data are video or audio recordings or photographs in which the people depicted have given permission to share.

Many flat-file data sets can be easily de-identified, but de-identifying recordings is complicated, expensive, and diminishes their value to other researchers. So, to share recordings without removing personal identifiers, Databrary asks researchers to get permission to share from those people who are depicted in recordings. To standardize the process and make it as simple as possible for researchers, we have developed a [Databrary Template Release](#) that can be added to IRB protocols and used with participants.

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.

When do I have to share data?

You never have to share data if you do not wish to do so. See our [Data Sharing Manifesto](#) for our philosophy about data sharing. However, even if you aren't sure you want to share any time soon, you may want to be ready to share data in the future. Or, maybe you have archival data you would like to share now, but you aren't sure whether you are able to do so. Here are the steps to take.

How do I share data I've already collected?

Some investigators already ask research participants for permission to share [recordings](#) with other researchers or to show them for educational or scientific purposes. This permission is often acquired by means of a video/audio/photo release form separate from the consent to participate in research. If you have permission to

share or show recordings, you may be able to share these with Databrary if your IRB or research supervision entity rules that your video/audio/photo release is equivalent to Databrary's or that you require no such release to share.

Here's what you should do:

- Ask your IRB for permission to share recordings with Databrary under the provisions of your current (IRB-approved) video/audio/photo release form. You will want to provide your IRB copies of your current release form and the [Databrary Template Release](#).
- Make sure that your informed consent documents **do not** contain data destruction clauses. If they do, you cannot share your recordings with Databrary. Databrary intends to store recordings and other data indefinitely. So, check your consent form and release form language to see whether you have promised to destroy data after a certain date.
- If your informed consent documents contain data destruction clauses, you may still be able to share [de-identified data](#) or [metadata](#) about your study with Databrary.
- Once you have permission from your IRB to share data, you may contact Databrary for help in uploading and sharing your data or you may choose to upload and share the data yourself.

How should I get ready to share with Databrary at some future date?

Here's what you should do:

- Modify your existing IRB protocol(s) to enable sharing with Databrary.
 - As part of the modification, you will want to adapt the [Databrary Template Release](#) and submit it for review.
 - You will also want to review your informed consent documents and remove any data destruction clauses. Rather than promise to destroy data after some period of time, say "Data will be stored indefinitely in a secure library on the internet."
- Once you have permission from your IRB to ask participants about data sharing, you may start securing and recording those permissions from participants.
- At some date in the future when you are ready to share data, contact Databrary for help.
- You may also decide to upload data to Databrary *prior* to sharing it with anyone. In this way, Databrary can act like a lab file server. You can decide later whether you want to share data with researchers who are not part of your approved IRB protocol.

Guidelines 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 are recorded. Investigators may use the Databrary Release Template or equivalent language that has been approved by the Investigator's research supervision entity;
5. Apply for and be granted Principal 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.

Data Destruction Clauses

Some informed consent documents have “data destruction” clauses that say the researchers will destroy data after a certain period of time. Data destruction clauses are incompatible with sharing through Databrary, and are **not** required by NIH. In seeking approval to share with Databrary, investigators should make certain that existing informed consent documents do not have data destruction clauses. Databrary recommends that informed consent documents used in a protocol state that “all information will be stored indefinitely in a secure data library on the internet.” Links to all of the relevant Databrary documents concerning permissions and access may be found on the [Databrary website](#).

Sample script for introducing the Databrary Release Form to participants

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.