# User Guide

This Databrary Access Guide provides information useful for institutions and Authorized Investigators who wish to use Databrary.

## About Databrary

Databrary is a restricted access research data library specialized for storing, streaming, and sharing video and audio recordings and related data. Databrary's mission is to support data sharing among researchers in the behavioral, social, educational, developmental, neural, and computer sciences.

### Protecting participants and accelerating discovery

Widespread data sharing will accelerate discovery and make research more transparent, robust, and reproducible. To realize the full benefits of sharing data about human and non-human animals, research participants and their data must be protected. The responsibility for protecting participants and data is shared among researchers, institutions, and Databrary.

Databrary has a multi-pronged approach to fostering data sharing while upholding ethical research principles. Access is restricted to Authorized Investigators whose access must be approved by their institution. Institutions must provide ethics oversight of Authorized Investigators through a research ethics board or Institutional Review Board (IRB) with standards equivalent to that required to secure Federalwide Assurance (FWA) status from the U.S. Government[[1]](#footnote-1). Authorized Investigators who share human data with others must secure permission to share from research participants and record that permission level for each file stored on Databrary. In turn, Authorized Investigators who access Databrary and use data shared by other Authorized Investigators must follow ethical research principles, including respect for the sharing permissions granted by research participants. Taken together, these features aim to protect the rights of research participants while reducing barriers to data sharing.

### Types of data

Databrary stores and shares images, video, and audio recordings that may include identifiable information, data and metadata that are not typically sensitive, and de-identified data. Exact birth dates may be stored for use in calculating exact ages, but exact birth dates are only exposed to Authorized Investigators or Affiliates given specific access to data. Names, addresses, email addresses, financial information, government ID numbers, detailed geographic location information, and other personally identifiable data elements are not stored or shared on Databrary.

Databrary stores metadata related to full datasets (e.g., title, authors, related publications, description of the dataset, keywords or tags, associated URLs), individual study sessions (e.g. metadata related to participants, study groups and conditions, location, language, and session date and tasks), and video files (e.g., title, duration, tags) related to a dataset.

### Release levels

To make it clear to participants and researchers the level of access granted to specific files, Databrary developed a set of standard release levels that are indicated with consistent icons and language across the site:

* *Unknown*. Consent missing or not obtained. This content is not shared and access is restricted to specific people selected by an Authorized Investigator.
* *Private*. This content is not shared and access is restricted to specific people selected by an Authorized Investigator. *Note*: This is the default for all files and must be specifically changed by an Authorized Investigator (or an Affiliate with suitable privileges).
* *Authorized Users*. This content is restricted to authorized Databrary users (Authorized Investigators and Affiliates granted access to shared Databrary data) and may not be redistributed in any form.
* *Learning Audiences*. This content is restricted to authorized Databrary users (Authorized Investigators and Affiliates granted access to shared Databrary data), who may use clips or images from it in presentations for informational or educational purposes. Note, such presentations may be videotaped or recorded and those videos or recordings may then be made available to the public via the internet (e.g., YouTube).
* *Public*. This content is available openly to anyone.

All Authorized Investigators and Affiliates must follow the restrictions on uses indicated by these release levels. Furthermore, when using files released for access by *Learning Audiences*, Authorized Investigators and Affiliates must exercise professional judgment in deciding which clips or images to show to what audiences and in what contexts.

### Non-research uses

Many uses of Databrary do not constitute research (e.g., browsing shared videos, downloading videos of displays or procedures, or showing excerpts in research or educational presentations). Authorized Investigators (and their Affiliates) must follow Institutional policies concerning whether specific non-research uses of Databrary require prior institutional approval. Moreover, Authorized Investigators and Affiliates must always respect the release level associated with shared files. For example, data marked with an *Authorized Users* release level may only be viewed in research contexts (e.g., in the Authorized Investigator's laboratory) by the Authorized Investigator or people under the supervision of the Authorized Investigator. Similarly, only those data with a release level of *Learning Audiences* or *Public* may be shown in research or educational presentations outside the Authorized Investigator's laboratory.

### Research uses

Authorized Investigators must secure institutional approvals prior to conducting research with data shared on Databrary. In the U.S. context, conducting secondary analysis on shared video data may not qualify as human subjects research because there is no direct contact with research participants. Still, a research project involving video data reuse may require ethics board or IRB review and approval because the data are identifiable.

## For Researchers

### Gaining access

Some materials on Databrary are available to the public, but access to most data requires that a researcher secure formal written authorization from their institution.

#### The Databrary Access Agreement permits data use and data contribution

Databrary restricts access to Authorized Investigators whose institutions sign a formal Databrary Access Agreement. The Databrary Access Agreement is the legally binding document that formalizes the authorization process.

The Databrary Access Agreement combines provisions for data use and data contribution. Unlike data use agreements that allow specific individuals access to a particular dataset for a discrete research purpose, the Databrary Access Agreement allows any Authorized Investigator to access all shared datasets on Databrary and to use the datasets for many different institutionally-approved purposes. In addition, the Databrary Access Agreement permits Authorized Investigators to upload data and to share it with other Authorized Investigators in accord with the sharing permissions granted by participants and any required institutional approvals. Databrary believes that combining data use and data contribution in a single agreement reduces barriers to data sharing, meets emerging funder mandates to share research data, and accelerates progress in research.

#### Applying for Institutional Authorization

Individuals who are eligible to conduct independent research, submit funding proposals as the lead investigator, have Principal Investigator (PI) status, or have tenure-track faculty positions at their Institution, may apply to their institution for approval to be named an Authorized Investigator. To receive authorization, a person must apply for and receive authorization from their institution; Databrary does not grant authorization separate from an institution. In the U.S., a college or university's grants and contracts or sponsored programs office usually takes responsibility for granting authorization by signing the Databrary Access Agreement. Databrary staff will work with a researcher and an institution to secure signatures on the Databrary Access Agreement. The authorization process typically takes a few days to a few weeks.

#### Research ethics review required prior to authorization approval

Some institutions may refer a researcher’s request for authorization to a research ethics board for review or approval prior to signing the DAA. In that case, researchers may use the following language to communicate with a research ethics board.

**Recommended Abstract language**

The purpose of this application is to access Databrary (https://www.databrary.org/about/about-databrary.html), a digital data library specialized for storing, managing, preserving, analyzing, and sharing video. I do not currently have data to contribute to the library; however, I would like to have access to its contents to browse the available data and potentially develop a research project. After I have a research proposal, I will submit a new protocol for IRB review and determination.

**Access to Identifiers**

I will have access to dates directly related to an individual, including birth date, and full face photographic images and comparable images.

**Purpose of accessing Databrary**

The purpose of this application is to access Databrary (https://www.databrary.org/about/about-databrary.html), a digital data library specialized for storing, managing, preserving, analyzing, and sharing video and related data about human and non-human animal behavior. I would like to have access to its contents to browse the data and potentially develop a research idea to submit for IRB approval in a separate future application.

### Using shared data

Using data shared by others (“secondary use”) usually involves low risk to participants because the new study does not involve direct contact with the participants. However, the level of risk depends on the nature of the data, whether the data are identifiable or otherwise sensitive, and the sort of permission that participants initially granted for sharing. Reuse of existing shared data is common practice, so most IRBs have established procedures for determining the level of risk posed by a particular project involving secondary use. For example, many IRBs deem exempt from review projects that involve the secondary use of non-sensitive, de-identified data.

#### Seeking research ethics board approval for use

You will need to request permission from your ethics board or IRB for secondary data use when you move from activities preparatory to research to actually conducting research. For example, when you move from exploring the feasibility of a coding scheme to deciding to apply it systematically to a set of videos, you would need to submit a request to your IRB. You must still protect the data during pre-research or research planning as you normally would for these sorts of data as outlined in the Databrary Access Agreement.

Keep in mind the following definitions from the Code of Federal Regulations (CFR) in the United States:

*Is it Research?*

Research is a “systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge” (45 CFR 46.102(l)).

*Is it a Human Subject?*

A human subject is “a living individual about whom an investigator (whether professional or student) conducting research:

1. obtains information or biospecimens through intervention or interaction with the individual, and uses, studies, or analyzes the information or biospecimens; or
2. (ii) obtains, uses, studies, analyzes, or generates identifiable private information or identifiable biospecimens” (45 CFR 46.102(e)).

If you can answer YES to these two questions, you need to request permission from your IRB. If you are not sure, contact your IRB and they can help you.

### Selecting and managing Affiliates

After being authorized by their institution, Authorized Investigators may then authorize staff, undergraduate or graduate students, and postdoctoral trainees to access Databrary as Affiliates. In granting a person Affiliate status, an Authorized Investigator takes responsibility for that person's use of Databrary.

#### Affiliates outside of the Authorized Investigator’s Institution

An Authorized Investigator may grant Affiliate status to a person outside their institution if permitted by that institution. If a person is eligible to be an Authorized Investigator at their home institution, that person should apply for access to Databrary through their home institution. Except in unusual circumstances, researchers eligible to be Authorized Investigators should not be granted access to Databrary as the Affiliate of another Authorized Investigator.

Authorized Investigators are responsible for ensuring that Affiliates have human subjects and/or animal research training appropriate for the institution and remain in good standing with the institution.

#### Affiliate access to an Authorized Investigator's data

Authorized Investigators determine which of the Authorized Investigator's datasets an Affiliate can access. Authorized Investigators can set each Affiliate's access to one of the following levels:

* *No access*: Affiliate cannot access any of the Authorized Investigator's data. This is the default.
* *Read-only access*: Affiliate has view access to all of the Authorized Investigator's data. (The affiliate may view and download videos and other identifying information, including data that are not released for sharing.)
* *Read/Write Access*: Affiliate can access and edit the Authorized Investigator's datasets. (The affiliate may view, download, add, change, and remove data without restriction.)
* *Manager*: Affiliate can access and change permissions on the Authorized Investigator's data. The Manager can name other people as Affiliates. The Manager may additionally change the access controls and sharing levels of the Authorized Investigator's data. Manager-level permission should be granted with utmost care.

These levels are analogous to granting an Affiliate different levels of access to the Authorized Investigator's laboratory data server. Accordingly, the Investigator must trust Affiliates granted this access and supervise and manage Affiliates granted these privileges. The Authorized Investigator must assign an expiration date to each Affiliate's access.

#### Affiliate access to Databrary

Affiliates can only gain access to data on Databrary that has been shared by *other* Authorized Investigators if specifically granted that access by their supervising Authorized Investigator. The Authorized Investigator must assign an expiration date to each Affiliate's access.

Many Authorized Investigators grant Affiliates access only to datasets the Authorized Investigator controls, not to other datasets shared on Databrary. Some Authorized Investigators grant access to datasets shared on Databrary to senior graduate students, postdoctoral trainees, or trusted research staff.

#### Accessing data shared by other Databrary users

Authorized Investigators automatically have access to data on Databrary that has been shared by other Authorized Investigators. Affiliates have access to shared data on Databrary only if granted that access by the Authorized Investigator who supervises them.

### Contributing data

Only Authorized Investigators and Managers may create new datasets. Only Authorized Investigators may share datasets with others.

#### Types of data

##### Non-sensitive/non-identifiable data or materials

Authorized Investigators may upload to Databrary and share non-identifiable videos of research procedures, computer displays, research protocols, analysis code, and other research materials without any additional approvals, provided that sharing these elements with Databrary does not violate intellectual property rights of any person. De-identified or pseudonymized research data may be uploaded and shared subject to institutional policies and approval. If an Authorized Investigator already has approval to share a de-identified or pseudonymized dataset with other researchers or with the public, then sharing that dataset on Databrary is permitted. All files uploaded to Databrary must be marked with a sharing release level. The default sharing release level is *Private*. Although many non-sensitive, de-identified, or pseudonymized data files could be made available to the public, it may be prudent to share de-identified or pseudonymized datasets only with Authorized Investigators.

##### Identifiable or sensitive data

Authorized Investigators must make preparations to share identifiable or sensitive data with Databrary as described below.

###### Securing Institutional approval

Authorized Investigators must secure approval from their institutions prior to sharing data with Databrary. Institutional approval usually involves research ethics board or IRB review or its equivalent. Approval to share data may be included in a new research protocol application or as an amendment to an existing protocol.

For human subjects data, Databrary recommends adapting the Databrary Release Template although the exact Databrary Release Template language is not required. The Databrary Release Template serves as a guideline. The institutional research ethics board or IRB must determine what specific language should be used for securing data sharing permission and whether requesting permission to share data should be part of the research consent process or separate from it. It is essential that whatever language and permission process the institution requires enables the Authorized Investigator to determine clearly what level of sharing release participants have granted. Authorized Investigators must be able to assign a sharing release level to each file uploaded to Databrary that reflects the sharing permission granted by the research participant.

In some cases, research ethics boards and IRBs have deemed that certain release language in research consent forms from previously collected data permits sharing in Databrary. This has allowed archival data collected prior to the creation of Databrary to be stored and shared in the library. If an Authorized Investigator has archival data, Databrary staff are happy to discuss whether and how these might be stored and shared on the system.

###### Removing data destruction clauses from research consent documents

Researchers and IRBs often have misconceptions about regulations pertaining to data destruction, especially where video or audio recordings are concerned. In the U.S., NIH and NSF do not require data destruction. Data destruction clauses inherently conflict with the ability to store and share data indefinitely via repositories like Databrary. Rather than promising to destroy data after some time period in a research protocol, Databrary recommends the following language: "Data will be stored for an indefinite period in a restricted data library on the internet (databrary.org)."

###### Obtaining participant release for sharing

After research protocol approval has been granted, Authorized Investigators may start securing permission from participants and recording those permissions.

Authorized Investigators must ensure that the process used for obtaining participant release for sharing meets relevant regulatory requirements, such as the GDPR.

Why ask

Video and audio recordings of participants are inherently identifiable. Thus, to share identifiable data on Databrary, Authorized Investigators must secure permission from the people depicted in recordings or images. Authorized Investigators can share identifiable research recordings (or other identifiable data elements like birth dates) only when the Authorized Investigators (a) get approval from their Institutions to do so, (b) inform participants about what sharing these data elements means, and (c) secure participants' permission to share. Databrary calls this data sharing permission a "release" because it involves releasing data for use by other researchers.

When to ask

Databrary recommends that Authorized Investigators ask participants for permission to share at the end of data collection after participants acquire first-hand knowledge about the study procedures. This ensures that consent to participate is completely separate from permission to share and it mitigates the risk that asking participants about sharing their data will affect their decision about whether to participate in the research. However, some institutions may prefer to have Authorized Investigators incorporate data sharing permission into the research consent process or even to have data sharing permission be part of an entirely separate protocol. The important and essential point is to secure sharing permission and record it faithfully.

How to ask

To standardize the process of obtaining data sharing releases from participants—and make it as simple as possible for researchers—Databrary developed the Databrary Release Template. The template can be added to or incorporated within human subjects research ethics protocols. The Databrary Release Template was developed and refined in close consultation with the IRB office at NYU. It gives researchers a standardized way to obtain the necessary permissions to share data in Databrary. The template makes it clear and unambiguous to participants about what agreeing to share data in Databrary will mean.

#### Uploading to Databrary

##### What to upload

In addition to video, Databrary can store many types of data and supplemental files associated with a research project such as images, displays, stimuli, graphs, protocols, blank questionnaires, coding manuals, coding spreadsheets, physiological data, imaging data, analysis code, analysis spreadsheets, and blank consent or release documents. Databrary permits Authorized Investigators to store any information permitted by the institution. However, some information poses greater risks to participants than others, and these should be stored on Databrary only after special consideration. For example, first or last names, home location information more specific than state, and contact information are generally considered high risk for the disclosure of participants' identities. These data items should not be uploaded to Databrary.

Video and audio recordings may be uploaded to Databrary if the Authorized Investigator has secured participant (or parent/guardian) permission and the institution approves. Under some circumstances, an institution may determine that participant (or parent) permission is not necessary to store video and audio recordings on Databrary. For example, for recordings collected a long time in the past, participant (or parent) permission may be unavailable, and the institution may determine that the risk to participants is sufficiently low to allow sharing. Or, an Authorized Investigator may choose to store video and audio recordings on Databrary for sharing only among collaborators and Affiliates specifically chosen by the Authorized Investigator, but have no plans to share the videos with the broader Databrary community. This use of Databrary is permitted, but discouraged, because the purpose of Databrary is to foster data sharing beyond an individual research project or group.

Exact birth dates or test dates may also be considered identifiable data elements. However, these dates can be highly valuable for future research uses, and may pose a lower level of risk to participants than other data elements. Accordingly, Databrary permits storage of exact dates, but treats exact dates with special care. The system only exposes exact dates to Authorized Investigators or their Affiliates who upload the data, and only exposes exact dates in shared datasets if the participant has agreed to share data (i.e., participant grants sharing release at the *Authorized User*, *Learning Audiences*,or *Public* levels).

Other low risk data items such as race, ethnicity, gender, and related personal characteristics may be stored on Databrary without specific permission.

##### Assignment of sharing release level

The only essential item of information required for uploading files to Databrary is the sharing release level. Authorized Investigators are responsible for recording participant sharing release permissions and assigning them to files uploaded to Databrary. Databrary assigns all files a default release level of *Private*, so an Authorized Investigator must change the default *Private* release setting to share a file with people other than their Affiliates or research collaborators on a specific dataset.

##### Who may upload

Authorized Investigators may upload data, and Authorized Investigators determine who among their Affiliates may also upload data to Databrary.

##### When to upload

Authorized Investigators need not wait until a research project ends to upload data to Databrary. Authorized Investigators may upload files to Databrary as soon as possible after a data collection. This is called active curation. It distributes the time required to curate a dataset for sharing and thereby reduces the overall burden of data sharing.

#### Sharing data

##### With project collaborators

Authorized Investigators can grant their Affiliates or other Authorized Investigators on Databrary access to research data and materials stored on Databrary at any time. The data remain accessible only to the specific individuals chosen by the Authorized Investigator. That is, all data, even that marked for wider sharing, remain *Private*. Sharing a dataset with the larger community of Databrary Authorized Investigators or the public requires a separate step.

##### With the Databrary community

At a time when the Authorized Investigator chooses—e.g., when a paper goes to press or a grant period ends—the Authorized Investigator may choose to share the dataset with the community of Authorized Investigators on Databrary. This makes each data file contained in the dataset available to other Authorized Investigators and possibly the public, but only in accordance with the sharing levels selected by Authorized Investigators and always subject to the permission granted by participants. That is, individual data files marked *Private* remain accessible only to people the Authorized Investigator specifically selects. Similarly, access to entire datasets labeled *Private* remains solely under the control of the Authorized Investigator.

To share a dataset, the Authorized Investigator simply changes the access level on that dataset. Datasets receive a persistent identifier (DOI) when shared. Authorized Investigators may "unshare" a dataset, but except under unusual circumstances, this is not considered best practice.

#### Non-human animal data

We are developing guidance for the use of Databrary to store non-human animal data. Please contact us if you are interested in doing so.

### Removing or altering participant data

Research participants in the European Economic Area (EEA) have certain rights under the General Data Protection Regulation (GDPR) pertaining to the use, sharing, and removal of their personal data.

Since Databrary does not typically store information that maps personal identities to the data stored on Databrary without a separate agreement, Authorized Investigators and Institutions are responsible for responding to any requests to provide copies of, change, restrict access to, or delete a participant’s personal data stored on Databrary. Databrary cannot guarantee that personal data previously shared on Databrary can be retrieved from all Authorized Investigators who have accessed the data. Thus, in seeking permission from research participants to share personal data via Databrary, Authorized Investigators should communicate that there are limits to a participant's right to modify or delete personal data previously shared on Databrary.

### Changing institutions

Authorized Investigators who change institutions must notify Databrary of the change and its effective date. As soon as possible, the Authorized Investigator must secure authorization from their new institution. Authorized Investigators who are awaiting authorization from their new institution will have access to their own data but not to non-public data shared by other Authorized Investigators on Databrary. After an Authorized Investigator has secured approval from their new institution, full access privileges will be restored.

Your access to Databrary is granted by executing a Databrary Access Agreement (DAA), a legally binding agreement between your institution and Databrary. If you plan to change institutions, you therefore MUST NOTIFY DATABRARY IMMEDIATELY so that we can execute a DAA with your new institution.

You must:

● Notify Databrary within ten (10) days of your intention to leave your current institution.

● Act promptly to sign and submit any necessary paperwork to your new institution.

If you do not have a signed DAA with your new institution within thirty (30) days of your start date, your access to Databrary will be terminated until such time as we have an executed agreement.

As a reminder, your new institution must verify that:

a. it maintains an ethics or Institutional Review Board with U.S.-equivalent standards that reviews and approves research involving human subjects,

b. you have ethics training that addresses human subjects policy and issues,

c. you are eligible to conduct independent research at this institution and the institution accepts responsibility for its Authorized Investigators’ actions related to the use of Databrary,

d. it grants you the authority to choose and manage affiliates who meet Databrary's qualifications and who agree to follow Databrary's ethical principles, and

e. the person executing this Access Agreement on behalf of the institution has the authority to do so.

See the Databrary Access Agreement and Databrary's full policy on ethics oversight for more information. If your new institution does not meet these requirements, you will not be able to continue to access Databrary.

What happens if I leave my institution and no longer have Authorized Investigator Status?

Your access to Databrary is granted by executing a Databrary Access Agreement (DAA), a legally binding agreement between your institution and Databrary. If you plan to leave an institution and would no longer qualify to have Authorized Investigator Status, you MUST NOTIFY DATABRARY IMMEDIATELY.

You must:

● Notify Databrary within ten (10) days of your intention to leave your current institution.

See the Databrary Access Agreement and Databrary's full policy on ethics oversight for more information. If your new institution does not meet these requirements, you will not be able to continue to access Databrary.

Access to non-public data shared with other Authorized Investigators will be suspended when you leave your institution. This suspension extends to your Affiliates. In other words, you and your Affiliates will be able to access only data that you uploaded to your profile page. Only after a new institution grants authorization will you be able to regain access to non-public data shared by other Authorized Investigators.

## For research staff, students, and trainees

Databrary encourages research staff, undergraduate and graduate students, and other research trainees to use Databrary. Databrary calls these users Affiliates to indicate that they are affiliated with an Authorized Investigator. An Affiliate is a person who (1) conducts research under an Authorized Investigator’s sponsorship and supervision and (2) has been granted access to Databrary by the Authorized Investigator. In most cases, Affiliates are students or research staff and are not themselves eligible for Authorized Investigator status. Thus, the access privileges of Affiliates are under the control of one or more Authorized Investigators.

### Requesting access to Databrary

Add Step by Step Instructions

8.1 How do I request access from my Supervising Professor?

### Accessing a specific data set

8.2 I want to access a specific dataset on Databrary. How do I do this?

You must be sponsored by an Authorized Investigator and they need to grant you access to ALL Shared Databrary Data. (Add link to Section 6?)

### Affiliates’ rights and responsibilities

As an Affiliate, you have the same responsibilities to protect data and research participants as do Authorized Investigators.

Every individual working with Databrary needs to have their own account. Lab Databrary accounts are not permitted. Sharing of Databrary account login credentials is not permitted.

Affiliates are not able to share their own data, nor may Affiliates authorize other Affiliates on their own behalf to access Databrary.

### Moving to a faculty or independent research position

When Databrary Affiliates move on to an independent research or faculty position they become eligible for Authorized Investigator status. Contact Databrary staff to discuss the process of applying for authorization at a new institution.

## For Institutions

### What is Databrary?

Databrary is a restricted access, web-based data library housed at New York University. Databrary is designed for sharing identifiable or sensitive research data, including video files and associated metadata. Authorized Investigators approved by their institutions for access to Databrary may access data shared by others and/or contribute data for others to access. Databrary requires that an Authorized Investigator secure institutional approval, usually from a research ethics board, before contributing personally identifiable human or non-human animal data to Databrary or conducting research on any data obtained from others through Databrary. Databrary, however, does not require institutional approval for permitted non-research uses (e.g., pre-research, preliminary analysis, self-study, teaching) beyond this Databrary Access Agreement.

All institutions and Authorized Investigators agree to use Databrary and data obtained through it exclusively for the purpose of non-commercial scientific research or education.

Databrary is supported by the U.S. National Institutes of Health, the U.S. National Science Foundation, DARPA, and private foundations.

### How Databrary differs from other data repositories

Databrary has several features that distinguish it from other data repositories:

* A single binding agreement between NYU/Databrary and a researcher’s institution (Databrary Access Agreement) permits both data use and contribution.
* Researchers granted institutional authorization to access Databrary may use data shared by other Authorized Investigators without having to secure (i) additional permission from the data contributor or (ii) approval from Databrary.
* Databrary requires that Authorized Investigators (i) secure all necessary institutional approvals to upload data to the site and (ii) secure explicit data sharing permission from human participants.
* Institutions take responsibility for authorizing researchers and reviewing and monitoring their research and non-research activities involving Databrary.
* Researchers take responsibility for securing required approvals from the institution and sharing permission from research participants, for protecting data, and for selecting, training, and managing access to restricted data by their staff, students, trainees, and others.

### Data security, integrity, and preservation

Data and metadata stored on Databrary are subject to the security policies and best practices implemented by NYU. For more information about these policies and services, visit NYU ITS Computer & Network Security at <http://www.nyu.edu/its/security/>.

Files uploaded to Databrary are assigned a unique identifier and have metadata associating them to files that are uploaded to replace them. Though only the latest version of a file is typically exposed to Databrary site users. Files, once uploaded, are never deleted.

### For officials with signature authority

Some materials on Databrary are available to the public. but access to most data requires that a researcher secure formal written authorization from an institution. The Databrary Access Agreement (DAA) is the legally binding document that formalizes the authorization process.

#### The Databrary Access Agreement permits data use and data contribution

The Databrary Access Agreement combines provisions for data use and data contribution. Unlike data use agreements that allow specific individuals access to a particular dataset for a discrete research purpose, the Databrary Access Agreement allows Authorized Investigators to access all shared datasets on Databrary and to use the datasets for many different institutionally-approved purposes. In addition, the Databrary Access Agreement permits Authorized Investigators to upload data and to share it with other Authorized Investigators in accord with the sharing permissions granted by participants and any required institutional approvals. Databrary believes that combining data use and data contribution in a single agreement reduces barriers to data sharing, meets emerging funder mandates to share research data, and accelerates progress in research.

#### Applying for Institutional Authorization

Individuals who are eligible to conduct independent research, submit funding proposals as the lead investigator, have Principal Investigator (PI) status, or have tenure-track faculty positions at their institution, may apply to their institution for approval to be named an Authorized Investigator. To receive authorization a person must apply for and receive authorization from their institution; Databrary does not grant authorization separate from an institution. In the U.S., a college or university's grants and contracts or sponsored programs office usually takes responsibility for granting authorization by signing the Databrary Access Agreement. Databrary staff will work with a researcher and an institution to secure signatures on the Databrary Access Agreement. The authorization process typically takes a few days to a few weeks.

#### When Authorized Investigators leave an Institution

Authorized Investigators are expected to inform Databrary when they leave an institution. Institutions may also inform Databrary.

Access to non-public data shared with other Authorized Investigators will be suspended when an Authorized Investigator leaves their institution. The suspension extends to an Authorized Investigators’ Affiliates. Authorized Investigators will continue to have password-protected access to data they uploaded to Databrary after they leave an institution. When a new institution grants authorization, Authorized Investigators will regain access to non-public data shared by other Authorized Investigators.

If an Authorized Investigator retires, is incapacitated due to illness, or dies, the institution should inform Databrary so that the Authorized Investigator’s account may be suspended. An institution may choose to designate a data steward for the Authorized Investigator’s data and authorize that person to manage access to the data. If the institution does not identify and authorize a data steward, Databrary staff will serve that role. However, the Databrary staff serving as data steward will not change the data sharing status of any specific dataset without explicit written guidance from the institution.

#### Selecting Affiliates

If permitted by their institution, an Authorized Investigator may grant a person outside their institution Affiliate status. Institutions may establish policies governing the selection and management of Affiliates by their Authorized Investigators.

If a person is eligible to be an Authorized Investigator at their home institution, that person must apply for access to Databrary through their home institution. Except in unusual circumstances, researchers eligible to be Authorized Investigators at their home institution should not be granted access to Databrary as the Affiliate of another Authorized Investigator either from the same institution or a different one. Databrary welcomes questions about these policies at [contact@databrary.org](mailto:contact@databrary.org).

### For research ethics boards

#### Video's use cases extend beyond research

In addition to its many uses in research, video may be used for a variety of pre-research and non-research uses, such as the documentation of methodological details, the demonstration of computer-based tasks, or the showing of video clips for teaching or scientific presentations. Databrary encourages the storage and sharing of video for all of these purposes, in a manner consistent with participant permissions and institutional approvals.

#### Institutions determine when research ethics board or IRB approval is necessary

Databrary does not require prior research ethics board or IRB approval for an Authorized Investigator to be granted access to the system or to use Databrary's shared resources for non-research, educational, or pre-research uses. However, in signing the Databrary Access Agreement, all Authorized Investigators promise to secure research ethics approval whenever their use of Databrary requires it under the institution's policies.

Non-research, educational, or pre-research use cases may not require research ethics board or IRB review and approval at every institution. Institutions decide which use cases require research ethics board or IRB review and approval.

#### What data are shared

Databrary contains images, video, and audio recordings that may be identifiable, data and metadata that are not typically sensitive, and de-identified data. Exact birth dates may be stored for use in calculating exact ages, but exact birth dates are only exposed to Authorized Investigators or Affiliates. Names, addresses, email addresses, financial information, government ID numbers, detailed geographic location information, and other personally identifiable data elements are not stored and shared on Databrary.

#### Securing permission to share

To contribute and share identifiable data with Databrary, Authorized Investigators must secure permission to store the recordings on Databrary from research participants and any other people (e.g., research staff) who are recorded.

Databrary developed a Sharing Release Template that informs people depicted in recordings of the potential risks associated with sharing video and other data on Databrary. The Sharing Release Template is one of the resources Databrary makes available to researchers. The Sharing Release Template may be adapted for use at any institution and added to any research ethics or IRB protocol. However, an institution may require other release language to provide equivalent protections.

Whether de-identified or pseudonymized data may be shared with Databrary without seeking explicit permission from research participants depends on the Authorized Investigator's institution. Some ethics boards or IRBs may allow de-identified or pseudonymized data to be shared without the explicit permission of the research participant.

#### Uploading data and assigning sharing permission levels

Authorized Investigators who upload data to Databrary must assign to each file the level of data sharing granted by research participants—from none to public access. The sharing level assigned to each file by default is *Private*, meaning that no person other than the Authorized Investigator who uploaded the file and any Affiliates granted access by the Authorized Investigator, may view the file.

Not only are data files assigned a *Private* sharing level by default, but all newly created datasets are initially made *Private*, accessible only to an Authorized Investigator, any Affiliates the Authorized Investigator selects, and any other individual Authorized Investigators granted specific access to the dataset. An Authorized Investigator may elect to create an overview of a dataset when it is created and make the overview publicly available. The overview can serve as the public face of the dataset while the dataset is being collected and analyzed. This can be useful in documenting progress on a research grant to sponsors. The dataset overview does not expose data unless the Authorized Investigator chooses to do so.

#### Sharing data

At a time when the Authorized Investigator chooses—e.g., when a paper goes to press or a grant period ends—the Authorized Investigator may choose to share the dataset with other Authorized Investigators on Databrary. This makes the data contained in the dataset available to other Authorized Investigators and possibly the public, but only in accordance with the sharing levels selected by Authorized Investigators and always subject to the permission granted by participants. That is, individual data files marked *Private* remain accessible only to people the Authorized Investigator specifically selects. Similarly, access to datasets labeled *Private* remains solely under the control of the Authorized Investigator.

#### Databrary and GDPR

Authorized Investigators may collect personal data from research participants who have rights under the General Data Protection Regulation (GDPR). GDPR governs the collection of personal data in the European Economic Area (EEA).

Databrary's servers are currently located in the United States, and data stored on Databrary may be accessed, downloaded, and reused by Authorized Investigators and their Affiliates located outside of the EEA. Hundreds of institutions across the globe have signed the Databrary Access Agreement. Databrary maintains a list of Authorized Investigators who have access to shared research data at <https://nyu.databrary.org/search?volume=false&f.party_authorization=4&f.party_is_institution=false>.

In seeking permission to collect data from research participants governed by GDPR or similar provisions, Authorized Investigators should communicate to research participants information about who may have access to shared data on Databrary and where the data are stored. Institutions and Authorized Investigators assume responsibility for ensuring that research participants give sharing data permission that satisfies the provisions of GDPR and for abiding by other provisions of GDPR.

Databrary does not typically store information that links a person's identity to specific files unless there is a separate agreement between the Authorized Investigator, the institution, and Databrary to store this type of data. Therefore, if a research participant requests a copy of data stored on Databrary or the modification or deletion of personal data that is stored on Databrary, the Authorized Investigator or institution is responsible for responding to the request, not Databrary. Also, Databrary cannot guarantee that data previously shared with other Authorized Investigators via Databrary can be retrieved from all Authorized Investigators who accessed a participant's personal data prior to its modification or removal. Thus, Authorized Investigators should communicate to research participants that there are limits to a participant's right to modify or delete personal data that have already been shared on Databrary. The Databrary Release Template contains language for this purpose.

When accessing data shared by other Authorized Investigators, institutions and their Authorized Investigators assume responsibility for ensuring that the sharing permission research participants have given in other contexts outside of the EEA meet relevant GDPR provisions.

## How to…

Coming soon!

### Find data

### Download data

### Get ethics board approval

### Upload data

### Share data

### Manage Affiliates

# Definitions

**Access Agreement**: The Databrary Access Agreement between an Authorized Investigator and his or her Institution and New York University (NYU) on behalf of Databrary.

**Affiliate**: A person who conducts research under an Authorized Investigator's sponsorship and supervision and who has been granted access to Databrary by the Authorized Investigator. In most cases, Affiliates are students or research staff and are not eligible for Authorized Investigator status.

**Authorized Investigator**: A person who has permission from an Institution to conduct independent research and who has received authorization from an Institution and from Databrary to access Databrary.

**Authorized Organizational Representative (AOR)**: A person granted authority by an Institution to sign the Databrary Access Agreement on behalf of the Institution and thereby bind the Institution to the terms of the Databary Access Agreement.

**Institution**: An academic, not-for-profit, research, government, or health entity whose employees or students conduct scientific research or educational activities.

1. https://www.hhs.gov/ohrp/register-irbs-and-obtain-fwas/ [↑](#footnote-ref-1)