Unified policy document

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# Databrary Access Agreement

The undersigned Institution–an academic, research, government, health, or commercial entity–grants permission for its Authorized Investigators identified below and in **Annex II – List of Authorized Investigators** to access Databrary. Databrary is a web-based data library housed at New York University designed for sharing behavioral 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 to conduct research on any data obtained from others through Databrary. Databrary does not, however, require Institutional approval beyond this Databrary Access Agreement for non-research uses. All Institutions and Authorized Investigators agree to use Databrary and data obtained through it exclusively for the purpose of scientific research or education.

By signing this Databrary Access Agreement, the Institution verifies that (a) it maintains or uses a research ethics board or Institutional Review Board with U.S.-equivalent standards that reviews and approves research involving human subjects, (b) it reviews and approves research involving non-human animal subjects (c) its Authorized Investigators have training that addresses research ethics with human subjects and/or non-human animals, (d) its Authorized Investigators are eligible to conduct independent research at the Institution, (e) it accepts responsibility for its Authorized Investigators’ actions related to the use of Databrary, (f) it grants the Authorized Investigators the authority to choose and manage Affiliates, and (g) the person executing this Databrary Access Agreement on behalf of the Institution, an Authorized Organizational Representative, has the authority to do so.

The Institution and its Authorized Investigators agree that Databrary, New York University, The Pennsylvania State University, and the relevant funding agencies bear no responsibility for the use of Databrary or the information contained within it. Except in cases where the Institution is expressly prohibited by law from indemnifying third parties, the Institution indemnifies and renders harmless Databrary, New York University, and The Pennsylvania State University from all claims, losses, liability, and other damages that arise from the Institution’s or its Authorized Investigator’s violations of this Access Agreement. In cases where the Institution is prohibited by law from indemnifying third parties, in accordance with and to the extent permitted and limited by a superseding national, state, or local provision, statute, or law, the Institution agrees that it will be responsible for the payment of claims, including for loss, personal injury, death, property damage, or otherwise, arising out of any act or omission of its employees or agents in connection with the performance of this agreement for which it is held liable under applicable law. It is understood and agreed that this document shall constitute a separate agreement between Databrary and the Institution, as amended from time to time by the Institution and Databrary, to include additional Authorized Investigators as listed in Annex II, to expand the datasets available to Authorized Investigators, or to expand the uses allowed for shared datasets. By signing this Databrary Access Agreement, effective as of the date entered below, both the Institution and its Authorized Investigators hereby agree to its terms, including those found in the attached **Annex I – Statement of Rights and Responsibilities**, and in the attached **Annex III – Databrary Access Guide**. The Databrary Access Guide may be amended from time to time; Databrary will notify the Institution and its Authorized Investigators of any amendments by email.

## Acknowledgment by Authorized Investigator

As an Authorized Investigator, I acknowledge that I have read, understand, and agree to the terms of this agreement.

Name of Authorized Investigator: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

## Approval by Institution

As the Authorized Organizational Representative (AOR), my signature below indicates that I have authority to bind my Institution under this agreement.

Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of AOR: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Title: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Institutional Email: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of AOR: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

# Annex I – Statement of Rights and Responsibilities

## Rights Granted to Databrary

Databrary reserves the right to:

* Redistribute data in Databrary in accordance with the sharing permissions granted by research participants or others whose behaviors are recorded with the permission of Authorized Investigators.
* Describe, catalog, validate, and document data.
* Store, translate, copy or re-format data in any way to ensure its future preservation and accessibility.
* Incorporate metadata or documentation.
* Promote and advertise data (e.g. via the Databrary newsletter or website) unless specifically prohibited from doing so by an Authorized Investigator or Institution.
* Limit the amount or kind of data stored free of charge or the level of service provided to Authorized Investigators.
* Give priority for storage and processing resources to data shared with other Authorized Investigators over data stored on Databrary but not shared.
* Revoke sharing of data that pose a risk of violating confidentiality, harm or embarrass individuals, or create other ethical problems.
* Revoke access to Databrary for ethics violations by any person.
* Remove data and/or deny an Authorized Investigator or Institution access to Databrary, temporarily or permanently, if Databrary determines that the terms of the Databrary Access Agreement are violated.

## Responsibilities of Institutions

The Institution confirms the eligibility of its investigators by:

* Verifying that its Authorized Investigators are eligible to conduct independent research at the Institution.
* Verifying that Authorized Investigators who collect or use data from human subjects have completed research ethics training that meets the Institution’s standards concerning policies and protections for human research subjects.
* Verifying that Authorized Investigators who collect or use data from non-human animal subjects have completed research ethics training that meets the Institution’s standards concerning policies and protections for non-human animals.

Further, the Institution agrees that it:

* Maintains or uses a research ethics board or Institutional Review Board with U.S.-equivalent standards that reviews and approves research involving human subjects.
* Maintains or uses a research ethics board or Institutional Animal Care and Use Committee with U.S.-equivalent standards to review and approve research involving non-human animal subjects.
* Grants Authorized Investigators the responsibility to choose and manage Affiliates.
* Holds Authorized Investigators responsible for the conduct of Affiliates that they select.
* Accepts responsibility for its Authorized Investigators’ actions related to the use of Databrary.

Regarding data contribution and use, the Institution:

* Asserts that the Authorized Investigator has the right to share with Databrary any data the Authorized Investigator contributes and that no other entity or individual has ownership rights that prevent the Authorized Investigator from contributing data to Databrary.
* Represents that its Authorized Investigators have the right and authority to store data on Databrary in accordance with any applicable protections set forth by the EU General Data Protection Regulation (GDPR).
* Represents that it shall follow all applicable laws, including but not limited to the GDPR, in the collection, storage, security, and use of data stored on Databrary.
* Agrees to allow use of the data exclusively for the purpose of scientific research or education by an academic, research, government, health, or commercial entity.
* Agrees to prohibit commercial uses of data stored on Databrary unless specifically allowed for under the terms of a separate agreement.
* Agrees not to sell or trade data retrieved from Databrary or use it for other commercial purposes.
* Grants its Authorized Investigators the authority to decide when and with whom to share data via Databrary.
* Agrees to inform Databrary of any suspected violation of confidentiality or ethics.

## Responsibilities of Authorized Investigators

Authorized Investigators agree to adhere to the terms of the **Databrary Access Agreement**, **Annex I – Statement of Rights and Responsibilities**, and **Annex III – Databrary Access Guide**.

Authorized Investigators acknowledge and agree to comply with Databrary’s three guiding ethical principles, which are to:

* Treat data stored and shared via Databrary with the same high standards of care that Authorized Investigators treat data collected in their own labs.
* Respect the permissions research participants have given regarding data sharing.
* Take care in granting Affiliates access to Databrary and take responsibility for Affiliates’ conduct and use of Databrary.

Additionally, Authorized Investigators agree to:

* Comply with the Institution’s policies on the conduct of research.
* Complete training that meets the Institution’s standards addressing the ethics of research with human subjects and, as applicable, research with non-human animal subjects.
* Keep contact information and Institutional affiliation information current on Databrary.
* Keep login information confidential and not share it with any other person.
* Cite all Databrary resources used in scholarly work using Databrary’s suggested format or an equivalent.
* Ensure that Affiliates complete training in the ethical use of research data, including the protection of confidentiality, and see to it that Affiliates follow Databrary’s ethical principles.
* Secure data downloaded from Databrary with the highest safeguards specified by the Institution’s policies concerning sensitive research data.
* Follow all relevant national, state, and local laws and regulations that pertain to the access, storage, security, and use of human subjects or animal research data.

When contributing data, Authorized Investigators agree to:

* Seek, secure, and maintain permission to conduct research from the entity that governs research at their Institution, and faithfully represent to Databrary information about any research approval status if requested.
* Secure approval from the entity that governs research at the Institution to ask research participants for permission to share their data in Databrary.
* Ensure that research participants document their permission regarding data sharing by signing documents with Institutionally-approved language comparable to the Databrary Release Template (Annex III) or through other equivalent means.
* Share personally identifiable information with other Authorized Investigators on Databrary no more widely than the data sharing permission given by research participants.
* Provide information to Databrary about the data sharing permission permitted for each data file uploaded to Databrary in accord with the permission granted by research participants.
* Provide licensing information when uploading materials subject to copyright where access should be restricted via a license.
* Exercise professional judgment in determining what to data to store and share on Databrary.
* Store or share with Databrary only those data that the Authorized Investigator has rights to share.
* Assert that no other entity or individual has ownership rights that prevent the Authorized Investigator from contributing data to Databrary.

# Annex II – List of Authorized Investigators

To be completed by the Institution.

# Annex III – Databrary Access Guide

## For Institutions

### What is Databrary?

Databrary is a data library whose mission is to accelerate the sharing of data, especially video and audio recordings, that required restricted access because the data may contain personally identifiable information. Databrary has a two-pronged approach to fostering the sharing of these data. Access is restricted to Authorized Investigators whose access must be approved by their Institution. Authorized Investigators who share data with others must secure permission to share from research participants and record that permission level on Databrary. These features aim to to reduce barriers to sharing data while protecting the rights of research participants.

The responsibility for protecting research data is shared among Authorized Investigators and their Affiliates, Institutions, and Databrary.

### 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 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 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.

### Video 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 videos for these purposes.

### 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 uses. However, in signing the Databrary Access Agreement, all Authorized Investigators promise to secure research ethics board or IRB approval whenever their use of Databrary requires it under the Institution’s policies.

Pre-research and educational use cases may not require research ethics board or IRB review. Institutions decide which use cases require research ethics board or IRB 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 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 typically **not** stored and shared on Databrary without a separate agreement to do so.

### Securing permission to share

In order to contribute and share identifiable data with Databrary, Authorized Investigators must secure permission from research participants and other people (e.g., research staff) whose behaviors are recorded.

Databrary has developed a Sharing Release Template (see below) that informs people depicted in recordings of the potential risks associated with sharing data on Databrary. The Sharing Release Template is one of the resources that Databrary has made available. 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 in order to provide equivalent protections.

Whether de-identified data may be shared with Databrary without seeking explicit permission from research participants depends on the Authorized Investigator’s Institutional research ethics board or IRB. Some ethics board or IRBs may allow de-identified 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 their 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 and 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 and any Affiliates the Authorized Investigator selects. An Authorized Investigator may elect to create a minimal description of a dataset when it is created and make the minimal description publicly available. This overview can serve as the public face of the dataset while the dataset is being collected and analyzed. 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 then choose to share the dataset with other Authorized Investigators on Databrary. This makes the data contained in the dataset available to other Authorized Investigators, but only to the extent that participants agreed to share. Access to datasets labeled *Private* remains solely under the control of the Authorized Investigator indefinitely.

### Databrary and GDPR

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

Note that Databrary’s servers are currently located in the United States and that data stored on Databrary may be accessed, downloaded, and re-used by Authorized Investigators and their Affiliates located outside of the EEA. 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, Authorized Investigators should communicate this information to research participants.

Institutions and Authorized Investigators assume responsibility for ensuring that research participants give sharing data permission that satisfies the 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, 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. Databrary does not guarantee that data previously shared on 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 previously shared on Databrary.

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 meets relevant GDPR provisions.

## For Researchers

This section explains how to apply for authorization, select and manage affiliates, collect data that can be shared, upload and manage datasets and studies, and explore, re-use, and extend the resources shared with Databrary.

### Getting Authorized

Some materials on Databrary are available to the public, but access to most data and materials requires that a person secure authorization from an Institution. The Databrary Access Agreement is the legally binding document that formalizes the authorization process.

Individuals who are eligible to conduct independent research, submit funding proposals as a 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 help secure signatures on the Databrary Access Agreement. The authorization process typically takes a few days to a few weeks.

### Selecting and managing Affiliates

Authorized Investigators may authorize staff, undergraduate or graduate students, or 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. An Authorized Investigator may grant a person outside their Institution Affiliate status if permitted by their Institution. If a person is eligible to be an Authorized Investigator at their home Institution, they should apply for access to Databrary through that 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 ethics 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 has access to. Authorized Investigators can set an Affiliate’s access to one of the following levels:

* *No access*: Affiliate cannot access any of the Authorized Investigator’s data.
* *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 from all sessions, including data that is not released for sharing.)
* *Read/Write Access*: Affiliate can access and edit all of the Authorized Investigator’s. (The affiliate may view, download, add, change, and remove data as the Authorized Investigator without restriction)
* *Manager*: Affiliate can access and change permissions on all of the Authorized Investigator’s data. (The Affiliate 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 access to the Authorized Investigator’s lab data server. As such, the Investigator must trust Affiliates granted this access and supervise and manage Affiliates granted these privileges.

#### 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 others

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

#### Release levels

In order to make it clear to participants and researchers what level of access should be granted to specific files, Databrary has developed a set of standard release levels. These levels are indicated with consistent icons and language across the site. The levels are as follows:

* *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.
* *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 that 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 use professional judgment in deciding what clips or images to show to what audiences and in what contexts.

#### Non-research uses

Many uses of Databrary do not constitute research, for example, 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., 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. But a research project involving video data reuse may still require ethics board or IRB review and approval because the data are identifiable.

### Contributing new data

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

#### 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, or 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 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 dataset with other researchers or with the public, then sharing that dataset on Databrary is permitted. All files uploaded and shared must be marked with a sharing release level. The default sharing release level is *Private*. While many if not most non-sensitive/non-identifiable files can be made available to the public, it may be prudent to share de-identified datasets only with Authorized Investigators.

#### Identifiable or sensitive data

Authorized Investigators must make preparations to share identifiable or sensitive data with Databrary. The next section describes some of these.

##### 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. Approval to share data may be included in a new 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 made archival data collected prior to the creation of Databrary to be stored and shared in the library. If you have archival data, Databrary staff are happy to discuss whether and how these might be stored and shared on the system.

#### Non-human animal data

*Work in progress*

#### Removing data destruction clauses

There are often 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

Once 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, e.g. GDPR.

#### Why ask

Video and audio recordings of participants are inherently identifiable. In order 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” since 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 have acquired first hand knowledge about the study. This ensures that consent to participate is completely separate from permission to share and the risk that asking participants about sharing their data will affect their decision about whether or not to participate in 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 has 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. These can be images, graphs, stimuli, protocols, blank questionnaires, analysis code, and 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. These should **not** be uploaded to Databrary without a specific separate agreement between Databrary, the Institution, and the Authorized Investigator.

Video and audio recordings may be uploaded to Databrary if the Authorized Investigator has secured participant (or parent) 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, regarding 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 low. Or, an Authorized Investigator may choose to store video and audio recordings on Databrary for sharing only among collaborators and Affiliates chosen by the Authorized Investigator, but have no plans to share the videos with the broader Databrary community. This use is permitted, but discouraged, as 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 items. However, these dates can highly valuable for future research uses, and pose a lower level of risk to participants than some other data elements. Accordingly, Databrary permits the storage of exact dates. Databrary treats exact dates with special care. The system only exposes exact dates to Authorized Investigators or their Affiliates.

Other low risk data items like 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 release setting in order to share a file with people other than an Authorized Investigator’s Affiliates or collaborating Authorized Investigators.

#### Who may upload

Authorized Investigators determine who among their Affiliates may 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 session. This reduces the overall burden of data sharing.

### Sharing data

Authorized Investigators determine when data stored on Databrary are ready to be shared with the broader community of Databrary Authorized Investigators. Typical ‘triggers’ for sharing a data collection are when a paper goes out for review or goes to press, when a grant report is prepared, or a grant period ends. To share a dataset, the Authorized Investigator simply changes the access level on that dataset. This then makes metadata about all data and materials visible so that other Authorized Investigators can access them–subject to the sharing release levels indicated for each shared file. 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.

#### 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 participants’ 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.

## Definitions

**Access Agreement**: The Databrary Access Agreement between an Authorized Investigator and his or her Institution and 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.

**Authorized Investigator**: An 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, health, or commercial entity whose employees or students conduct scientific research or educational activities.

## Databrary Sharing Release Template

Release for [STUDY NAME]

**What we are asking**

This form requests your permission to share material from this session in a secure, web-based data library called Databrary (databrary.org). Material from this session may include video/audio recordings, photographs, and images; other information such as age, birth date, sex, ethnicity, education, and self-reported health information; and information supplied by researchers who analyze data from this session. The library allows only authorized researchers to have access to shared information. Data sharing will lead to faster progress in research on human development and behavior. In this form, we first request permission to share the data from this session as part of the Databrary library. If you agree to share your data, this form also requests permission to allow authorized Databrary researchers to show selected video excerpts and images from recordings of this session for scientific presentations and/or informational and educational purposes, but never for commercial purposes. Giving permission to share your information in Databrary is separate from consenting to participate in a research study. You do not have to give permission to share your information in the library. You can also agree to share your data, but not agree to allow researchers to show excerpts and images. 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 Databrary library about how to contact you or your family. No data files will be identified by anyone’s name. However, viewers watching or listening to the images and/or voices of people in the recordings may recognize participants if they already know them. First and/or last names of people may be spoken aloud. If the study takes place in your home, aspects of your home may be seen or heard. In addition, other information may have been collected about you, your child, or your family in conjunction with this session. Thus, someone who sees the video of this session might be able to identify you, your child, or other people. However, all authorized Databrary researchers have agreed to maintain confidentiality and not to reveal the identities of people in the library.

**Who has access to information in the library?**

Only authorized researchers will have access to data in the library. Researchers who are granted access must agree to maintain confidentiality and not use 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 information remain in the library?**

Information in the library will be preserved indefinitely in a secure location so that future researchers can use it. Permission to share can be revoked, but information previously shared cannot be retrieved. To revoke sharing permission, contact NAME OF PI: CONTACT INFORMATION. For questions, contact [contact@databrary.org](mailto:contact@databrary.org).

**Compensation**

There will be no compensation for sharing information in the library or allowing excerpts to be presented.

[IF ORAL OR WRITTEN ASSENT TO SHARE DATA IS NEEDED, USE THE FOLLOWING SCRIPT]

Assent to Share Script

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. We also have the opportunity to put these recordings and other information about you in a secure 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. Is that okay with you? If you say yes, we will only allow approved scientists to use the library and 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 the material from this session with authorized researchers in a secure data library called Databrary. Authorized researchers may use the material for non-commercial research and educational purposes.

OR

**Permission to share with authorized researchers and show excerpts and images in presentations**

I give permission to share the material from this session with authorized researchers in a secure data library called Databrary. Authorized researchers may use the material for non-commercial research and educational purposes. In addition, I give permission for authorized researchers to show selected excerpts and images as part of presentations that are given in public settings for informational or educational purposes. I also understand that at times these presentations may be videotaped or recorded by people who sponsor presentations, and 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 and images to present and to which audiences. No one directly associated with this project or the Databrary library will make the contents of this session 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.org](mailto:contact@databrary.org). For questions about your rights as a research participant, you may contact [APPROPRIATE CONTACT FOR LOCAL INSTITUTION].

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

ADULTS

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Name | I give permission to share with authorized researchers | I give permission to share with authorized researchers and permission to show excerpts and images | Adult’s Signature | Date |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |

CHILDREN DECIDING FOR THEMSELVES (ALSO REQUIRES PARENTAL CONSENT)

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

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Name | I give permission to share with authorized researchers | I give permission to show excerpts and images | Participant’s Signature | Parent/Guardian Signature | Date |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |  |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |  |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |  |

YOUNG CHILDREN WITH PARENT OR GUARDIAN PROVIDING CONSENT

Parent or guardian must decide whether to allow their child to share and sign on their behalf.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Name | I give permission to share with authorized researchers | I give permission to show excerpts and images | Parent/Guardian Signature | Date |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |
|  | ☐ Yes ☐ No | ☐ Yes ☐ No |  |  |

TO BE COMPLETED BY RESEARCHER OBTAINING PERMISSION

|  |  |  |  |
| --- | --- | --- | --- |
| Researcher’s Name | I certify that all participants that were recorded have given their decision about whether or not to share with Databrary | Researcher’s Signature | Date |
|  | ☐ Yes ☐ No |  |  |