

# Databrary Investigator Agreement

## 1. Overview

Databrary is a data library intended to foster sharing of information between researchers. Databrary contains *De-Identified Data*, *Non-Identifiable Data*, and *Metadata*. Databrary also contains *Identifiable Data* – video/audio recordings and photographic images Databrary calls *Recordings* – and other sensitive materials, such as *Self-Reported Health-Related Information*, only some of which are open to the public. Accordingly, Databrary requires prior authorization for full access.

With authorization, I can: browse, search, and download *Data* from Databrary for non-research purposes; use Databrary for *Research* purposes (with appropriate approval from the *Research Supervision Entity* at my *Institution*); and contribute *Data*, subject to the *Sharing Permissions* granted by individuals depicted in *Recordings* or *Research Participants*. This document sets out my rights and responsibilities and those of Databrary. Definitions of terms used in this document are listed here (<https://github.com/databrary/policies/blob/master/definitions.md>).

## 2. Responsibilities of Databrary Investigators and Affiliate Investigators

I understand that in order for me to have access, I must apply to Databrary for *Investigator* or *Affiliate Investigator* status. If I am eligible to be a principal investigator (PI) (e.g., professor at a university) at my *Institution*, I may apply to be an *Investigator*. If I am not eligible to be an *Investigator*, I may apply to be an *Affiliate Investigator* if an *Investigator* agrees to sponsor my application and supervise my use. Signing this agreement is one part of the application procedure. If approved for *Investigator* or *Affiliate Investigator* status I agree to keep current my contact information and other information reported in Databrary. I agree to renew my status with Databrary every year or whenever I change institutions.

I agree to keep officials at my *Institution* who supervise research informed about my use of Databrary by providing accurate contact information about a designated representative from the *Research Supervision Entity* at my *Institution*. I agree that Databrary may share information about my use of the *Data* library with my *Institution*. If I conduct *Research* with materials shared in Databrary, I will consult with the appropriate officials with my *Institution's Research Supervision Entity* (e.g., IRB) and secure whatever approvals are required.

I agree to complete training in research ethics involving human participants. The training must be offered by an official research ethics training entity and acceptable to my *Institution's Research Supervision Entity*. I agree to keep current my human participants training certification.

I agree to follow best practices in data security (<https://github.com/databrary/policies/blob/master/best-practices.md>) for any information I draw from Databrary or collect to contribute to Databrary.

I agree to uphold the Databrary Bill of Rights (<https://github.com/databrary/policies/blob/master/bill-of-rights.md>).

In contributing *Data*, I assert that I have rights to the *Data* I contribute; no other entity or individual has ownership rights that prevent me from contributing *Data* to Databrary.

I agree to cite Databrary resources I use in my scholarly work. Databrary will provide a recommended citation format.

### 3. Privacy of research participants

I promise to treat *Data* taken from or contributed to Databrary with the same high standards of care that I treat *Data* collected in my own laboratory.

*Recordings* contain *Personally Identifying Information* about *Depicted Individuals* -- *Research Participants* and other individuals involved in a study who are recorded or photographed. Images and/or voices may be visible or heard. Names may be spoken out loud. Images and voices of visitors or other people who are not research participants may be recorded. If a study takes place in a home or other setting, aspects of that home or setting may be recorded. Thus, individuals or locations can be identified from *Recordings*. Any intentional identification of *Research Participants* violates the *Promise of Confidentiality* given to them. Identification of other individuals depicted in *Recordings* violates their privacy, as well.

To avoid these breaches, when browsing and downloading *Data*, I agree to:

- protect the identity of all individuals with information in Databrary, especially *Depicted Individuals*;
- keep *Data* secure on computers with access limited to researchers whom I have trained and who are under my supervision or the supervision of the *Investigator* who sponsors me;
- respect the *Level of Sharing Permission* given by *Depicted Individuals*.

When contributing data, I agree to:

- remove names and other *Personally Identifying Information* from all files that are not *Recordings*;
- seek, secure, and maintain permission to conduct research from the *Research Supervision Entity* that governs research at my *Institution* and receive approval to ask *Depicted Individuals* or their legal parent or guardians for their permission to share *Recordings* or *Self-Reported Health-Related Information* in Databrary;

- Ensure that *Depicted Individuals* sign copies of the appropriate Databrary *Permission (or Assent) To Share* documents or have granted equivalent permission through other means;
- Faithfully represent to Databrary the level of *Sharing Permission* given by *Depicted Individuals*.

#### **4. Limitations on Sharing Excerpts of Data with the Public**

I will not use Databrary for commercial purposes. I agree not to share *Data* with the general public or with researchers who are not authorized by Databrary.

I understand that *Depicted Individuals* may give different levels of permission (or assent) to share *Recordings* or *Self-Reported Health Information* with Databrary.

*Depicted Individuals* may refuse to give permission to share *Recordings* or *Self-Reported Health-Related Information*. In this case, Databrary may store *Recordings* or *Self-Reported Health-Related Information* but not share them beyond the set of Investigators who are part of the *Data Contributor's* approved research team under an existing research protocol. The full responsibility for identifying who constitutes the set of researchers allowed access is the *Data Contributor's*.

Alternatively, *Depicted Individuals* may give permission for their *Recordings* or *Self-Reported Health-Related Information* to be shared. In this case, *Recordings* or *Self-Reported Health-Related Information* may be shared with other Databrary *Authorized or Affiliate Investigators* and viewed, downloaded, and analyzed by *Research Staff* under the supervision of *Investigators*. Viewed, downloaded, and analyzed *Data* retrieved from Databrary must be handled according to best practices in data security. No *Recordings* may be shown in public.

Additionally, *Depicted Individuals* may grant permission to show and distribute *Excerpts* to the public. *Excerpts* selected by an *Investigator* may be presented in public settings—in classrooms, at scientific or technical meetings—and may be published in the media, in textbooks, scientific publications, or on the Internet as long as no *Personally Identifying Information* about a *Depicted Person* is included with the *Excerpt*.

I promise to exercise professional judgment and uphold ethical principles in determining which *Excerpts* to show and to what audiences.

If there is ambiguity about whether a *Depicted Individual* has granted *Permission To Share* or *Permission to Excerpt*, those *Recordings* or *Self-Reported Health-Related Information* must not be shared, viewed or distributed. Any problems or questions should be addressed to Databrary ([ethics@databrary.org](mailto:ethics@databrary.org)).

I promise to cite all *Excerpts* following Databrary citation practices.

## 5. Rights of Contributors

If I contribute *Data* to Databrary, I can decide whether to share, when to share, and with whom I want to share. I may share only among members of my IRB protocol or all authorized Databrary researchers.

I understand that Databrary will store my data regardless of what I decide, and will make the data available according to my wishes and the sharing permission level granted by *Depicted Individuals* or *Research Participants*. However, Databrary reserves the right to limit the amount or kind of *Data* stored without charge to *Data Contributors* or the level of service provided to *Data Contributors* and other researchers. *Data* that can be and are shared with Databrary *Investigators* and *Affiliate Investigators* will have priority for storage and processing resources.

*Investigators* may change or revoke access to *Data* at any time. But, I understand that Databrary cannot guarantee that *Data* previously shared can be retrieved.

Databrary encourages researchers to share the products of their scientific work, including *Metadata*, lab notebooks, analysis code, figures, manuscripts, and other materials as broadly as possible.

## 6. Databrary Rights and Responsibilities

I grant Databrary permission to:

- redistribute the *Data* in Databrary in accordance with my wishes and the permissions chosen by *Depicted Individuals*;
- promote and advertise the *Data*;
- describe, catalog, validate and document *Data*;
- store, translate, copy or re-format the *Data* in any way to ensure its future preservation and accessibility;
- incorporate *Metadata* or documentation;
- revoke access to *Data* that pose a risk of violating confidentiality;
- revoke access to Databrary for ethics violations.

## 7. Violations

If Databrary determines that I have violated terms of this agreement, Databrary may remove the data in question or deny access to Databrary, temporarily or permanently. The violation may be reported to the Research Integrity Officer, Institutional Review Board, or Human Subjects Review Committee of my *Institution*.

If denied access, I may request a formal inquiry and review by the Databrary Ethics Committee.

## 8. Disclaimer

I understand 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. I indemnify and render harmless Databrary, New York University, and the Pennsylvania State University against any actions at law or in equity or in similar courts of any jurisdictions arising from violations of any of the points in this agreement.

## 9. Signature

My signature signifies:

- that I have read, understood, and agree to the provisions in this document;
- that I have read and understood the Databrary *Permission to Share* documents (see <http://github.com/databrary/policies>);

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

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

Printed Name: \_\_\_\_\_