

# Databrary Investigator Agreement

## 1. Overview

Databrary contains video and audio files, photographic images, brain images, and other sensitive materials that are not open to the public. With authorization, I can: browse, search, and download from Databrary for non-research purposes; use Databrary for research purposes (with appropriate approval from my institution); and contribute to Databrary.

I understand that in order for me to have access or contribute to Databrary, I must apply for *authorized researcher* or *sponsored researcher* status. If I have principal investigator (PI) status (e.g., professor at a university), I may apply to be an *authorized researcher*. If an authorized researcher agrees to sponsor my application, I may apply to be a *sponsored researcher*. I must renew my status annually.

I agree to complete training in research ethics involving human participants. The training must be offered by an official research ethics training entity. I agree to keep current my human participants training certification with such an entity.

## 2. 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.

Video and audio recordings and photographs contain personally identifying information about research participants and other individuals involved in a study. 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 could be identified from recordings. Any intentional identification of a participants or unauthorized disclosure of confidential information violates the *promise of confidentiality* given to participants and may violate the confidentiality of other persons who are not research participants.

To avoid this, when browsing and downloading data, I agree to:

- protect the identity of individuals depicted in audio and video recordings and photographs, hereafter *depicted individuals*;
- keep data secure on computers with access limited to researchers under my supervision;
- respect the level of sharing permission given by *depicted individuals*.

When contributing data, I agree to:

- remove names and other identifying information from files that are not video or audio recordings or photographs;
- seek, secure, and maintain permission to conduct research from the Institutional Review Board (IRB) or other authority that governs research at my institution and receive IRB approval to ask *depicted individuals* for their permission to share their video or audio recordings or photographs in Databrary;
- ensure that *depicted individuals* sign a copy of the Databrary Sharing Permission Form;
- faithfully represent to Databrary the level of sharing permission given by *depicted individuals*.

### 3. Limitations on Sharing Excerpts of Data with the Public

I will not use Databrary for commercial purposes. I agree not to share raw data with the general public or with researchers who are not authorized by Databrary. However, depending on the permission level granted by *depicted individuals*, I may be able to show or distribute excerpts from video or audio recordings or photographs to public audiences. I promise to exercise professional judgment and uphold ethical principles in determining which excerpts or photographs to show and to what audiences.

I understand that *depicted individuals* may give different levels of permission to share.

*Depicted individuals* may refuse to give permission to share. In this case, Databrary may store recordings or photographs but not share them beyond the set of authorized researchers who are part of the data contributor's IRB approved research team. The full responsibility for identifying who constitutes the set of researchers allowed access is the data contributor's.

Or, *depicted individuals* may give permission for their data to be shared in the library. In this case, recordings and photographs may be shared with other Databrary *authorized researchers* and viewed, downloaded, and analyzed by researchers under the supervision of *authorized researchers*. However, no recordings or photographs may be shown in public settings.

Additionally, depicted individuals may grant permission to show, but not distribute excerpts or photographs to the public. Excerpts from audio or video files selected by an *authorized researcher* may be presented in public settings—in classrooms, at scientific or technical meetings—but may not be published in the media, in textbooks, scientific publications, or on the Internet.

Finally, *depicted individuals* may grant permission to distribute excerpts to the public. Excerpts from audio or video files selected by a Databrary authorized user 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 (with citation) as long as no identifying information about a depicted person is included with the excerpt.

If there is ambiguity about whether a *depicted individual* has granted permission for sharing, viewing or distributing, that data must not be shared, viewed or distributed. Any problems or questions should be addressed to Databrary ([ethics@databrary.org](mailto:ethics@databrary.org)).

#### 4. 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 and researchers under my supervision, a subset of authorized Databrary researchers I choose, 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*. However, Databrary reserves the right to limit the amount or kind of data stored without charge to contributors or the level of service provided to contributors and other researchers.

Authorized researchers may change or revoke access to data at any time. But, I understand that Databrary does not 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.

#### 4. Databrary Rights and Responsibilities

I warrant that I have implicit or explicit copyright to any *data* that I deposit in Databrary.

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 collection;
- describe, catalog, validate and document the 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.

#### 6. Citing Data

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

## **8. Violations**

If Databrary determines that I have violated terms of this agreement, Databrary will act according to its policy on terms of use violations.

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.

If Databrary seeks and secures institution-level agreements. [A range of sanctions are available to institutions including revocation of tenure and termination. If the confidentiality of human subjects has been violated, the case may be reported to the Federal Office for Human Research Protections. This may result in an investigation of the user's institution, which can result in institution-wide sanctions including the suspension of all research grants. A court may award the payment of damages to any individual(s)/organization(s) harmed by the breach of the agreement.]

## **9. 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.

## **10. Definitions**

### *Authorized Researcher*

An individual with principal investigator (PI) status who has received authorization from Databrary to view, download, and contribute data.

### *Depicted Individuals*

People recorded on audio or video or whose images are shown in photographs.

### *Promise of Confidentiality*

A promise to a respondent or research participant that the information the respondent provides will not be disseminated without the permission of the respondent; that the fact that the respondent participated in the study will not be disclosed; and that disseminated information will include no linkages to the identity of the respondent. Such a promise encompasses traditional notions of both confidentiality and anonymity. Names and other identifying information regarding

respondents, proxies, or other persons on whom the respondent or proxy provides information, are presumed to be confidential.

*Research Participant*

A person or organization observed for purposes of research.

*Sponsored Researcher*

An individual without PI status, who has been approved for access to Databrary under the sponsorship and supervision of an Authorized Researcher.

## **11. Signature**

My signature signifies:

- that I have read and understood this document;
- that I have read and understood the Databrary Permission to Share document;
- that I have read and understood the Databrary Standard Operating Procedures;
- and that I agree to abide by the Databrary ethical standards for research.

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Signature

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Printed Name