

Databrary

Data Use and Contribution Agreement

1. Overview

Databrary is a data library intended to foster sharing of information among 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. *Data* in the library might be used to determine the identity of research participants who have been promised confidentiality. *Data* might also be used to harm or embarrass *Research Participants* or other *Depicted Individuals*. Accordingly, Databrary requires prior authorization for full access and requires those granted access to uphold the highest ethical standards. Individuals with authorized access to Databrary are called *Investigators*.

With appropriate approval from a *Research Supervision Entity* (e.g, Institutional Review Board) at an *Institution*, *Investigators* may browse, search, and download *Data* from Databrary for *Non-Research* purposes; use Databrary for *Research* purposes; and contribute *Data*, subject to the *Sharing Permissions* granted by *Research Participants* or other individuals depicted in *Recordings*.

This document sets out my rights and responsibilities, those of my *Institution*, and those of Databrary. Definitions of italicized terms used in this document are listed [here](#).

2. Responsibilities of Databrary *Investigators*

I understand that in order for me to have access, I must apply to Databrary and receive approval before viewing or contributing *Data*. To qualify for *Databrary Principal Investigator* status, I must be a *Principal Investigator (PI)* at my *Institution*. If I am a researcher whose work is overseen by someone who is a *Databrary Principal Investigator*, I may apply to be a *Databrary Affiliate Investigator*. If I do not meet either criterion, Databrary may deem me qualified based on my track record of scientific accomplishment or on the basis of a written reference from someone who is an authorized *Databrary Principal Investigator* and who verifies that my use of *Data* from the library will be strictly for the purpose of legitimate scientific research.

To apply, I must provide Databrary information about my appointment at my *Institution* along with contact and other information that verifies my identity. I must sign and date this agreement. If applicable, I must provide the name of the *Databrary Principal Investigator* who oversees my research or who will write a letter of recommendation on my behalf. If applicable, I must also provide evidence of my record of scientific accomplishment.

I agree to keep current my contact information and other information about me I have provided to Databrary. I agree to renew my status with Databrary every other year or whenever I change *Institutions*.

I agree not to share my login information (user name and password) with anyone and to keep it secure.

I agree to keep officials at my *Institution* who supervise research informed about my use of Databrary. That may include providing Databrary with 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*.

I will comply with all relevant rules and regulations imposed by my *Institution*. I will consult with the appropriate officials at my *Institution's Research Supervision Entity* and secure whatever approvals (or waivers) are required prior to accessing Databrary either for *Non-Research* or *Research* purposes. *Research Supervision Entities* may permit *Non-Research* use of *Data* without requiring formal review or approval.

I agree to follow all relevant national, state, and local laws and regulations that pertain to the use of research *Data*.

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 research ethics training certification.

I agree to follow [best practices in data security](#) for any information I draw from Databrary or collect to contribute to Databrary.

I agree to uphold the [Databrary Bill of Rights](#).

I have read and understand the Databrary [Data Sharing Manifesto](#).

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

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

If I am eligible for and approved as a *Databrary Principal Investigator*, I agree to manage the privileges of *Databrary Affiliate Investigators* whose research I oversee. If I am not eligible to be named or not approved as a *Databrary Principal Investigator*, I understand that my access privileges may be managed or restricted by the *Databrary Principal Investigator* who oversees my research.

3. Privacy of research participants

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

Recordings may contain *Personally Identifying Information* about *Depicted Individuals – Research Participants* as well as other individuals who are incidentally 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 may be identified from *Recordings*. Any disclosure of the identity of *Research Participants* violates the *Promise of Confidentiality* given to them. *Identification* of other individuals depicted in *Recordings* violates their privacy, as well.

De-Identified Data, *Non-Identifiable Data*, and *Metadata* may be combined to identify research participants. *De-Identified Data*, *Non-Identifiable Data*, and *Metadata* may be combined with *Recordings* to identify individuals or cause them harm or embarrassment. These represent significant risks.

Browsing and downloading To reduce them, 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 limited access;
- Ensure that researchers who access *Data* have applied for and been granted independent authorization to access Databrary.
- Respect the *Level of Sharing Permission* given by *Depicted Individuals*.
- Use *Data* exclusively for the purpose of scientific research, technology development or education under the auspices of an academic, research, government, health, or commercial entity.

I also agree not to sell or trade *Data*.

Contributing data When contributing *Data*, I agree to:

- Remove names and other *Personally Identifying Information*, except for birth dates, 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 guardian for 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 grant equivalent permission through other means;
- Faithfully represent to Databrary information about *Research Supervision Entity* approvals and the level of *Sharing Permission* given by *Depicted Individuals*.
- Abide by limitations on *Sharing Excerpts* of *Data* with the *Public*.
- Delete or modify *Data* I have contributed if requested to do so by Databrary.

Sharing Permission Levels I understand that *Depicted Individuals* may grant different levels of *Permission (or Assent) to Share Recordings or Self-Reported Health Information* with Databrary, and I agree to abide by the levels of permission granted. Those levels are as follows:

Sharing only within a research group *Depicted Individuals* may refuse to give permission to share *Recordings or Self-Reported Health-Related Information* outside a specific research group. In this case, Databrary may store *Data, Recordings, or Self-Reported Health-Related Information* but will not permit access by *Investigators* unless the *Data Contributor* gives permission. As *Data Contributor*, I may choose to permit access to my *Data* to other *Investigators* under an existing research protocol approved by a *Research Supervision Entity*. I assume full responsibility for identifying who is allowed access to my *Data*, for controlling that access using Databrary’s tools, and for any actions others with whom I have shared take with my *Data*.

Sharing with all Databrary *Investigators*, Public Excerpts Prohibited Alternatively, *Depicted Individuals* may give permission for their *Recordings or Self-Reported Health-Related Information* to be shared with other researchers, but not for excerpts to be shown for educational and scientific purposes. In this case, *Recordings or Self-Reported Health-Related Information* may be shared with other Databrary *Investigators*. *Data* that are retrieved from Databrary for viewing, downloading, and analyses must be handled according to [best practices](#) in data security. No images or parts of *Recordings* may be shown in public.

Sharing with all Databrary *Investigators*, Public Excerpts Allowed Finally, in addition to giving permission for their *Recordings or Self-Reported Health-Related Information* to be shared with other researchers, *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*, with the exception of faces, voices, and location information typically contained in *Recordings*, is included with the *Excerpt*.

I warrant that I will exercise professional judgment and uphold ethical principles in determining which *Excerpts* to show and to what audiences. I warrant that I will select *Excerpts* and edit them to minimize the possibility that a *Depicted Individual* can be identified, embarrassed, or harmed by the public showing of an *Excerpt*.

If there is uncertainty 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.

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

5. Rights of *Data Contributors*

If I contribute *Data* to Databrary, I may decide whether to share, when to share, and with whom I want to share within the parameters defined by Databrary. I may share only among members of my approved

research protocol, with selected Databrary *Investigators*, with all authorized Databrary *Investigators*, or with the public.

I understand that Databrary will store my *Data* regardless of what I decide, and will make the *Data* available according to the designations I have elected pursuant to Databrary's policies and procedures 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 **all** Databrary *Investigators* will have priority for storage and processing resources.

I may change or revoke the rights for other Databrary users to access my *Data* at any time. But, I understand that Databrary cannot guarantee *Data* previously shared can be retrieved.

Databrary encourages researchers to share the products of their scientific work, including *Metadata*, links to publications resulting from *Data*, coding manuals, coding spreadsheets, lab notebooks, analysis code, figures, manuscripts that are not copyrighted, and other materials as broadly as possible. Databrary's philosophy about sharing is embodied in the [Data Sharing Manifesto](#).

6. Rights and Responsibilities of *Institutions*

My *Institution* verifies that I am eligible to apply for Databrary authorization. My *Institution* maintains a *Research Supervision Entity* that oversees my scientific activities and validates my research ethics training. My *Institution* asserts that I have rights to share with Databrary any *Data* I contribute; no other entity or individual has ownership rights that prevent me from contributing *Data* to Databrary. My *Institution* grants me authority to decide with whom I wish to share *Data* that I contribute, and my *Institution* holds me responsible for its use.

7. 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;
- assist others with questions about the *Data*;
- revoke access to *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.

8. Violations

My *Institution* and I agree to inform Databrary of any suspected violation of confidentiality or ethics. If Databrary determines that I have violated terms of this agreement, Databrary may remove the *Data* in question or deny my 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*. My *Institution* agrees to treat the violation as it would violations of any of the explicit terms of its policies on scientific integrity and misconduct.

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

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. 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.

10. Signature of Applicant

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://databrary.org/about/#policies>).

Printed Name: _____

Signature: _____

Date: _____

I am not a *PI*, but my research activities are overseen by the following individual(s) who are *PI's* and who will be contacted to approve my application:

Printed Name: _____

Email: _____

Printed Name: _____

Email: _____

Signature of Authorizing Official/Authorized Representative from Institution:

As the *Authorizing Official* of this *Institution*, my signature below indicates either that I have authority to bind my *Institution* under this agreement or that a person with such authority agrees to the statements in this document.

Printed Name: _____

Title: _____

Signature: _____

Date: _____