Databrary

Investigator/Affiliate Investigator 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. 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* (e.g, Institutional Review Board) at my *Institution*; 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 (definitions.pdf).

${\bf 2.} \ \ {\bf Responsibilities} \ \ {\bf of} \ \ {\bf Databrary} \ \ {\bf Investigators} \ \ {\bf and} \ \ {\bf Affiliate} \ \ {\bf Investigators}$

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 of Databrary, pursuant to Databrary policies and procedures. Signing this agreement is one part of the application procedure. I must also provide Databrary information about my appointment at my Institution, contact and other information that verifies my identity. 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 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*. If I conduct *Research* with materials shared in Databrary, I will consult with the appropriate officials at my *Institution's Research Supervision Entity* 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 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 Databrary resources I use in my scholarly work. Databrary will provide a recommended citation format.

If I am eligible to endorse *Affiliate Investigators* for authorization to use Databrary, I take responsibility for their training and agree to supervise their *Non-Research* and *Research* activities involving Databrary resources.

If I am authorized as an *Investigator*, I may give other research *Collaborators* access to my *Data* on *Databrary*. My *Collaborators* may or may not be Databrary *Investigators* or *Affiliate Investigators*.

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 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 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 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 have granted 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*:

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 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.

Depicted Individuals may refuse to give permission to share Recordings or Self-Reported Health-Related Information. In this case, Databrary may store Data, Recordings, or Self-Reported Health-Related Information but will not permit access by other Investigators or Affiliate Investigators unless I give permission. As Data Contributor, I may choose to permit access to my Data to Collaborators under an existing research protocol approved by a Research Supervision Entity. I assume full responsibility for identifying who constitutes the set of researchers allowed access to my Data, controlling that access using Databrary's tools, and for any actions they take with my Data.

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 Authorized Investigators or Affiliate Investigators, or my Collaborators. Data that are retrieved from Databrary for viewing, downloading, and analyses must be handled according to best practices in data security. No recordings of any parts of the video may be shown in public.

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 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).

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 within the parameters defined by Databrary, which may be amended from time to time. I may share only among members of my approved research protocol, with selected *Collaborators*, or with all authorized Databrary *Investigators* and *Affiliate Investigators*.

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 polices 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 broadly with all Databrary *Investigators* and *Affiliate 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 the *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 I contribute. If I share Data with Research Staff or Collaborators who are not authorized Databrary Investigators or Affiliate Investigators, my Institution holds me responsible for their use of the Data.

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 Data;
- revoke access to Data that pose a risk of violating confidentiality 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. 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 Investigator/Affiliate

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:
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:			