

## Databrary Access Agreement

The undersigned Institution wishes to allow its Authorized Investigators identified in Annex II ("Authorized Investigators") to access Databrary.

Databrary is a web-based data library housed at New York University designed for sharing developmental and behavioral data, including video files and associated metadata. Authorized Investigators have both contributor and user privileges to all shared data in the library. However, many uses of Databrary do not involve contributing data or conducting research on shared data. IRB approval is not required for access to Databrary; however, IRB approval is required to contribute personally identifiable data to be shared through Databrary or to conduct research on data obtained through Databrary.

By signing this Access Agreement, effective as of the date entered below, both the Institution and Authorized Investigators hereby agree to its terms, including those found in the attached Annex I, and hereby acknowledge receipt of and agree to be bound by the Databrary Access Guide, including the Statement of Rights and Responsibilities for Databrary, for Institutions, and for Investigators, including those provisions regarding the contribution and use of data by Authorized Investigators and the Institution. The Databrary Access Guide may be amended from time to time. In addition, the Institution and Authorized Investigators hereby agree to use Databrary and data obtained through it exclusively for the purpose of scientific research or education under an academic, research, government, health, or commercial entity (but in the last case, solely for non-commercial purposes).

By signing this Access Agreement, the Institution verifies that (a) it maintains an ethics or Institutional review board that reviews and approves research involving human subjects, (b) the Authorized Investigator(s) are eligible to conduct independent research at this Institution and the Institution accepts responsibility for its Authorized Investigators' actions related to the use of Databrary, (c) it grants the Authorized Investigators the authority to choose and manage affiliates who meet Databrary's qualifications and who agree to follow Databrary's ethical principles, and (d) the person executing this Access Agreement on behalf of the Institution has the authority to do so.

The Institution and the 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 Institution's or Authorized Investigator's violations of this Access Agreement. In cases where the Institution is prohibited by law from indemnifying third parties, 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 and each of its Authorized Investigators, as amended from time to time by the Institution and Databrary, to include additional Authorized Investigators as listed in Annex II.

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

Name and title of Authorized Investigator: Sheila Marshall

Signature of Authorized Investigator: Sheila Marshall

Date: October 13, 2016

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

Institution: The University of British Columbia

Name & Title of AOR: Dean Kuusela, Associate Director

Signature of AOR: 

Date: October 27, 2016

## Annex I

### Statement of Rights and Responsibilities

#### Rights Granted to Databrary

Databrary reserves the right to:

- Redistribute the data in Databrary in accordance with investigator's wishes and the permissions chosen by depicted individuals.
- Promote and advertise data.
- 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.
- Revoke sharing of data that poses a risk of violating confidentiality, harm or embarrass individuals, or create other ethical problems.
- Revoke access to Databrary for ethics violations by any person. Databrary reserves the right to limit the amount or kind of data stored without charge or the level of service provided to Investigators. Shared data may be given priority for storage and processing resources.

 Initials of AOR

#### Responsibilities of Institutions

The Institution confirms the eligibility of its investigators by:

- Verifying that Authorized Investigators are eligible to conduct independent research at the Institution.
- Validating that Authorized Investigators have research ethics training that meets the Institution's standards.

The Institution:

- Maintains an ethics or Institutional review board that reviews and approves research involving human subjects.
- Grants Authorized Investigators the responsibility to choose and manage Affiliates who meet Databrary's qualifications and who agree to follow Databrary's ethical principles. The Institution holds Authorized Investigators responsible for the conduct of Affiliates that they select.
- Accepts responsibility for its Authorized Investigator(s) actions related to the use of Databrary.

Regarding data contribution and use, the Institution:

- Asserts that it has the rights to share with Databrary any data the Authorized Investigator contributes; no other entity or individual has ownership rights that prevent the Authorized Investigator from contributing data to Databrary.
- Agrees to allow use of the data exclusively for the purpose of scientific research or education under an academic, research, government, health, or commercial entity (but in the last case, solely for non-commercial purposes unless allowed under the terms of a separate agreement).
- Agrees not to sell or trade data or use it for other commercial purposes.
- Grants each Authorized Investigator authority to decide when and with whom the Authorized Investigator wishes to share data, and the Institution holds the Authorized Investigator responsible for the use of shared data.
- Agrees to follow all relevant national, state, and local laws and regulations that pertain to the use of research data. The Institution agrees to inform Databrary of any suspected violation of confidentiality or ethics. If Databrary determines that an Authorized Investigator at the Institution has violated the terms of the Databrary Access Agreement or other Databrary policies, Databrary may remove the data in question and/or deny the Authorized Investigator or the Institution access to Databrary, temporarily or permanently.

 Initials of AOR

## Responsibilities of Authorized Investigators

Authorized Investigators must adhere to the DataBrary Rights and Responsibilities policy. In addition, Authorized Investigators must acknowledge and agree to comply with DataBrary's three guiding ethical principles, which are to:

- Treat DataBrary data with the same high standard of care that they treat data collected in their own lab.
- Ensure that participants' wishes about sharing their data are respected.
- Take care in authorizing other people (affiliates and collaborators) and take responsibility for their conduct and use of DataBrary data, just as in own lab.

Additionally, Authorized Investigators agree to:

- Comply with their Institution's policies on the conduct of research.
- Have completed research ethics training that meets the Institution's standards.
- Keep your contact information and Institutional affiliation current on DataBrary.
- Not share or disclose their login information with anyone.
- Cite all DataBrary resources used in their scholarly work using DataBrary's suggested format.
- Share data with DataBrary only in accordance with permission granted by subjects. Authorized Investigators must have the right to share with DataBrary any data they contribute; no other entity or individual should have ownership rights that prevent an Investigator from contributing data to DataBrary. Authorized Investigators must obtain the necessary approvals required by their Institution for contributing data.

When contributing data, Authorized Investigators agree to:

- Seek, secure, and maintain permission to conduct research from the entity that governs research at the Authorized Investigator's Institution, and faithfully represent to DataBrary information about any research approval status if requested.
- Receive approval from the entity that governs research at the Institution to ask depicted individuals or their legal parent or guardian for permission to share data in DataBrary.
- Ensure that depicted individuals document their wishes about data sharing by signing copies of the appropriate DataBrary Release documents or through other equivalent means.
- Share identifiable information (including HIPAA or other protected data, as appropriate) according to the terms of the participant release.
- For any identifiable information, provide information to DataBrary about the release level permitted that respects the wishes of depicted individuals.
- Exercise professional judgment in determining what to share.

Authorized Investigators may authorize other users as their Affiliates. Authorized Investigators assume the responsibility for choosing Affiliates who meet DataBrary's qualifications and who agree to follow DataBrary's ethical principles. Authorized Investigators agree to be responsible for the conduct of Affiliates that they select.



Initials of AOR

## Annex II

### Additional Authorized Investigators

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

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

Name and title of Authorized Investigator: \_\_\_\_\_

Signature of Authorized Investigator: \_\_\_\_\_

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

Name & Title of AOR: \_\_\_\_\_

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

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