

Permissions, Access, and Security



Securely share sensitive and
identifiable data



Overview

- ▶ Challenges in sharing sensitive data, identifiable recordings
- ▶ Walled garden
 - Limit access to trained experts, committed to protecting privacy
 - Informed permission -- letting those affected decide



Self-reported Health Information

- ▶ Sensitive information
- ▶ Will be de-identified, but might be linked to other, identifiable data
 - Risk of inadvertent disclosure



Video Contains Identifiable Information

- ▶ Faces, voices, locations, names
- ▶ Research participants and third parties
- ▶ De-identification possible
 - but expensive
 - devalues video



Creating a “Walled Garden” to Protect Identifiable Info





Full Access to Databrary

- ▶ **Authorized Databrary Investigators**
 - PI-eligible at home institution with IRB
 - Trained in research ethics with human participants (e.g, CITI)
- ▶ **Databrary Affiliate Investigators**
 - Supervised by Investigators



Authorization by Application

- ▶ Name, email, address, phone, institution
- ▶ Institutional representative (IRB) contact
- ▶ Single sign-on?

The screenshot shows a web browser window with the URL <https://databrary.org/register>. The page title is "Databrary" and the main heading is "Databrary User Registration". On the left side of the form is a decorative graphic of a stylized leaf with green and red segments. The form fields on the right are: "E-mail Address" (text input), "Full Name" (text input), "Institution" (dropdown menu with the text "Select or enter Institution..."), "Postal Address" (text input), "Phone Number" (text input), "Password" (text input), and "Confirm Password" (text input). Below these fields is a green button labeled "View User Agreement".



Databrary Investigator Agreement

- ▶ SOPs, Appendix A
- ▶ [http://github.com/databrary/
policies/invest-agmt.md](http://github.com/databrary/policies/invest-agmt.md)
- ▶ Combines browsing/downloading
with contributing



Databrary

Investigator Agreement

1. Overview

Datab
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for access.

...browse, search, and download data from
**Databrary for non-research purposes, use
Databrary for research...**

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](#).

my rights and responsibilities and those of Databrary. Definitions of terms used in this document are listed [here](#).

2. Responsibilities of Databrary *Investigators* and *Affiliate*

Investigator

I understand

Affiliate

university

Investigator

application and supervise my use. Signing this agreement is one part of the application

process

contact

Databrary

keep contact information current...
renew status every year or whenever changing
institutions.

keep research supervision officials informed,
secure approvals when required.

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 Databrary with my *Institution*. If I conduct *Research* with materials shared in Databrary, I agree to complete research ethics training, keep current

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*



Resea

Follow data security best practices, Bill of Rights

cation.

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](#).

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



policies / best-practices.md



dylex a month ago fix newlines

1 contributor



file | 60 lines (46 sloc) | 3.089 kb

Edit

Raw

Blame

History

Databrary

Best Practices for Data Security


Data security evolves. This document represents a set of best practices that Databrary recommends all *Authorized Researchers* and *Sponsored Researchers* adopt:


Personally Identifying Information (PII)

- PII consists of the following:
 - Full name
 - National identification number (e.g., Social Security number)
 - Internet Protocol (IP) address

<https://github.com/databrary/policies/blob/master/best-practices.md>



policies / **bill-of-rights.md** 

 rogilmore a month ago added Bill of Rights, modified README

0 contributors



file | 17 lines (14 sloc) | 1.064 kb

Edit

Raw

Blame

History

Databrary

Bill of Rights

As a person who shares information with Databrary, you have the right to:

- Be free of pressure from anyone else when deciding if you wish to share information
- Make up your mind about sharing information without being rushed
- Have the decision to share information with Databrary be separate from the decision to participate in research
- Be told what information is being shared with Databrary
- Be told if there will be no direct benefit to you
- Ask questions about Databrary at any time before, during or after you participate in a study or agree to share information
- Refuse to share data without penalty

<https://github.com/databrary/policies/blob/master/bill-of-rights.md>



Research Supervision Entity. I agree to keep current my human participants training certification.

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

I agree

In con
indiv

ownership rights to share
cite Databrary resources using recommended
format

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

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*

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voice

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Res

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when browsing/downloading,
protect identities
keep data secure
respect sharing permission

and

a study

Thus,

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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

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

- When contributing,
- remove identifiers from non-recordings
- get IRB permission (if needed)
- secure written permission to share (if needed)

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



represent sharing permission to Databrary

- no commercial use

- don't share data with public

4. Limitations on Sharing *Excerpts* or *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

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 Databrary.

sharing permission = share with Databrary-approved Investigators

no sharing permission = share only with IRB-approved researchers


excerpt permission separate, may show in public, remove identifying information

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 public

use professional judgment, uphold ethics

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)



**Databrary may limit amount, kind, charges;
shared data have priority**

**Investigators can revoke access, retrieval not
assured**

Widespread sharing encouraged

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

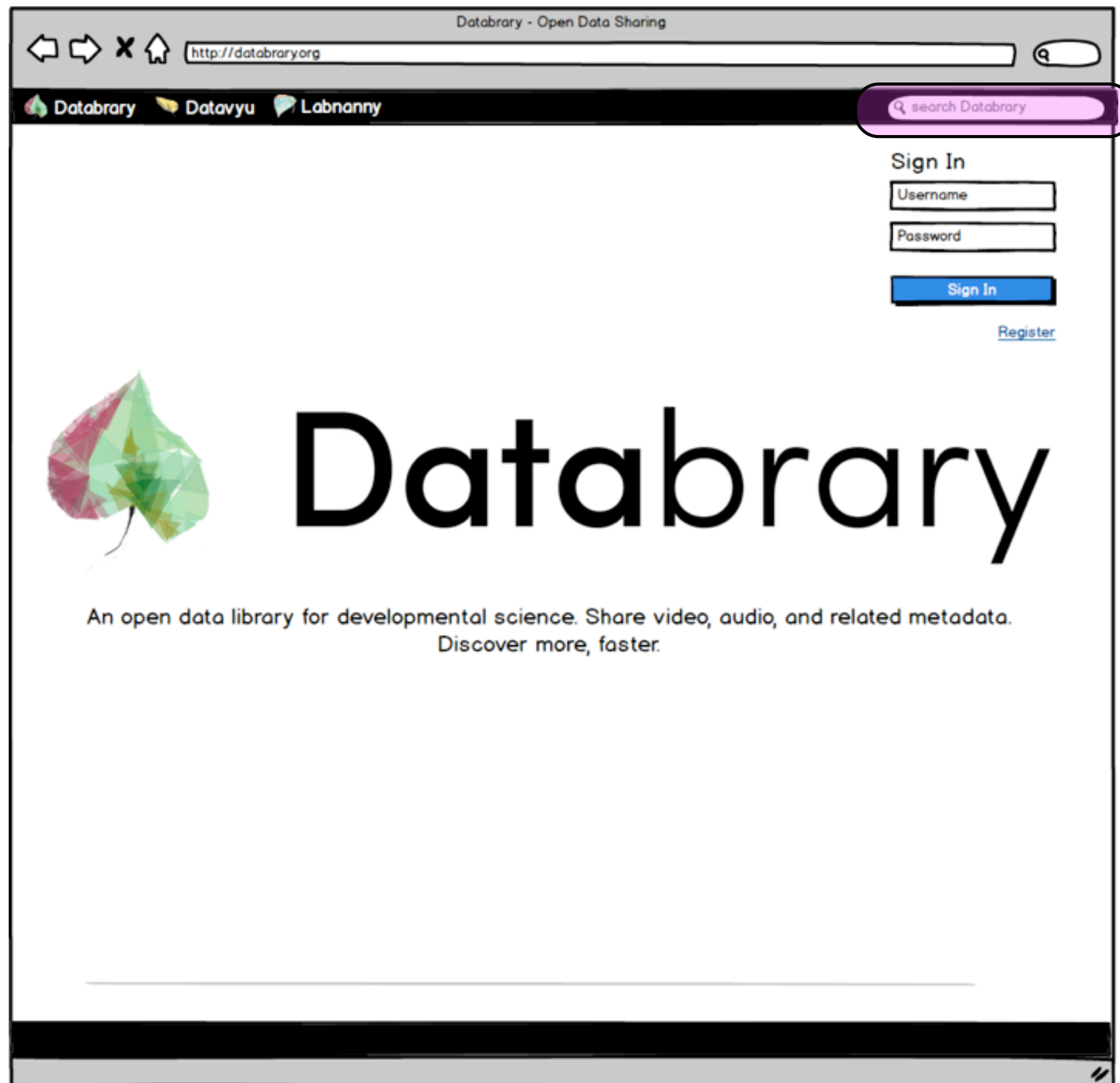
I grant Databrary permission to:

- 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*;



Unrestricted (Public) Access

- ▶ Anyone
- ▶ Only to public/unrestricted assets
 - Materials in public domain
 - Public previews (with excerpt permission)
 - Investigator, study metadata
 - Use metrics
- ▶ Comments disabled



Databrary - Search
https://databrary.org/search?q=Jones+joint+attention

Databrary
Sign In / Register

Jones joint attention
Search
Advanced Search...

Refine Results

Excerpts

☐ Excerpts Available

Excerpt Duration

to

e.g., 1s, 30m, 1h

Species

Human

Participant Data

Age

to

e.g., 1d, 20w, 5m, 2y

Sex

Female

Racial Category

Asian

of Participants


to

Apply


123 Results...



Joint attention in infants; Jones, HX, 2014
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<http://databrary.org/study/143-joint-attention-in-infants>



Word learning and joint attention in infants; Jones, HX, 2015
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<http://databrary.org/study/497-word-learning-and-joint-attention-in-infants>



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<http://databrary.org/study/237-lorem-ipsum-sint-cupidatat-non-proident>



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<http://databrary.org/study/272-etiam-diam-massa-rhoncus-nec-volutpat>




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<http://databrary.org/study/143-morbi-vel-nulla-non-diam-ultrices-auctor>

1 2 3 4 = 24 25 26

Databrary - Toddler Social Referencing with Ambiguous Toy
https://databrary.org/study/143-toddler-social-referencing-with-ambiguous-toy


Databrary
Sign In / Register
search Databrary

Toddler social referencing with ambiguous toy



Lorem ipsum dolor sit amet, consectetur adipiscing elit. Integer facilisis tellus nec dolor ultrices in eleifend sapien porta. Vivamus at ante id sapien ultricies congue. Aliquam sed mauris sit amet est tempor commodo. Ut adipiscing sagittis enim, iaculis viverra purus euismod eget. Morbi posuere magna at augue pretium vitae scelerisque magna adipiscing. Nunc tincidunt ullamcorper lacus, at rhoncus tellus iaculis in. Suspendisse potenti. Mauris ac porta risus. Vivamus metus sapien, tincidunt ut accumsan non, ultrices nec neque. Donec aliquam mi id erat vestibulum a varius mi malesuada. Mauris fringilla, eros ut semper eleifend, nisi tellus lobortis nisl, eu mollis dolor odio eu elit. Aenean iaculis volutpat lectus non viverra. Sed non justo eget justo porttitor varius nec congue velit.

Study Views: 1,294 Study Downloads: 432 Shared on November 2014


JT Investigator
 Leading University

Study Contents

Documents **Data** Excerpts

Participant ID ▲	Age at Test ◆	Sex (M/F) ◆	Contents
Participant 1	292 days	M	1 session video, 1 coding spreadsheet, 1 data file
Participant 2	281 days	F	1 session video, 1 coding spreadsheet, 1 data file
Participant 3	287 days	M	1 session video, 1 coding spreadsheet, 1 data file

Please sign in to access Study

How to cite this dataset

Select citation download format:

Investigator, JT 2014, Toddler social referencing with ambiguous toy, Databrary, <http://databrary.org/study/143-toddler-social-referencing-with-ambiguous-toy>

Article based on these data:

[Investigator, JT. 2014. Toddler Social Referencing](#)



What About the Flowers?





Informed Permission to Share

- ▶ Analogous to informed consent
- ▶ Viewers limited to Investigators/
Affiliates (except for excerpts)
- ▶ Researchers promise to uphold ethical
standards— keep confidentiality.
- ▶ Extends “zone of trust”
- ▶ Permission to Share templates



Databrary

Permission to Share Recordings of Children Under 12

Permission to share \neq consent to participate
Don't have to give permission
Choice won't affect payment

Giving permission to share is entirely separate from giving consent to participate in a research study. I do not have to give permission to share my child's video/audio recordings or still images in the library. My choice will not affect payment if offered for participation in this or future studies.

Information kept private, code numbers, no
contact info

Will the information be private?

My child's information will be kept private. Researchers will identify all of my child's information by a code number, not by name. No information will be included in the data library about how to contact me, my child, or my family.

My child's image and/or voice may be seen or heard on the video/audio recordings or still images. My child's name may be spoken aloud. The images and/or voices of me, visitors or other members of my family may also be seen or heard. If the study takes place in my home, aspects of my home



the library. My choice will not affect payment if offered for participation in this or future studies.

What will be shared?

With my permission, video/audio recordings or still images of my child will be included in the library.

How recordings affect privacy
Investigators promise to keep identities private

My child's image and/or voice may be seen or heard on the video/audio recordings or still images. My child's name may be spoken aloud. The images and/or voices of me, visitors or other members of my family may also be seen or heard. If the study takes place in my home, aspects of my home

Access only to authorized researchers
Researchers sign contract

Who can access information in the library?

Only authorized researchers have access to information in the library. Researchers who are granted access to the library must sign a contract that requires them to maintain confidentiality and not to use the information for commercial purposes. Researchers promise to treat information in the library with the same high standards of care that they treat information collected in their own laboratories.



Information preserved forever Unless removal requested

of 2

How long will the information remain in the library?

Information in the library will be preserved forever in a secure location. Databrary does not intend to erase the information. Databrary intends to store the information so that future researchers may be able to use it.

If in the future I no longer wish to have my child's video/audio recordings or still images stored in the library, I will contact Databrary at ethics@databrary.org.

Permissions

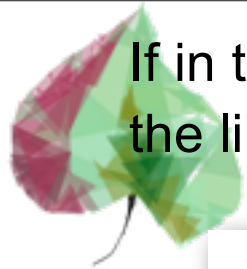
Permission to share with authorized researchers

- ☐ I give permission to share my child's video/audio recordings or still images with authorized researchers in a secure data library.

Permission to share excerpts with the public

- ☐ I give permission for authorized researchers to select excerpts from my child's video/audio recordings or still images and to share excerpts with the public for scientific and/or educational purposes.

I trust that authorized researchers will use professional judgment and uphold ethical principles in determining which excerpts to share.



If in the future I no longer wish to have my child's video/audio recordings or still images stored in the library, I will contact Databrary at ethics@databrary.org.

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Permission to share?

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Share excerpts with the public?
Trust researchers will use judgment, uphold ethics

Permission to share excerpts with the public

☐ I give permission for authorized researchers to select excerpts from my child's video/audio recordings or still images and to share excerpts with the public for scientific and/or educational purposes.

I trust that authorized researchers will use professional judgment and uphold ethical principles in determining which excerpts to share.

Payment

My child will not be paid for the use of information in the library.

Signatures

My signature indicates that I understand this document and agree to what it says.

My child's name:

Parent/Guardian's Name:



Excerpts for Public Viewing

- ▶ Permission to share excerpts with the public \neq permission to share complete raw video data
- ▶ Can't effectively control audiences once files shown in public
- ▶ Researchers vow to uphold ethical principles in selecting, showing, sharing, creating anew



Procedures

- ▶ Request after data collection
- ▶ Requesting permission (from everyone)
- ▶ Written documentation of permission/
assent given
 - Standard templates
- ▶ IRB must approve protocol modification
to permit sharing
 - Eliminate data destruction clauses in
consent documents

The screenshot shows the Penn State Research website. The header includes the Penn State logo, the text "office of the vice president for RESEARCH AT PENN STATE", and search links for people, penn state, and department. A search bar is also present. Below the header is a navigation menu with links: About Us, Research Capabilities, For Industry, Patents & Licensing, Proposals & Awards, Research Protections, Education & Training, and Contact Research Support Offices. A "log in" link is also visible. The main content area is titled "YOU ARE HERE >> Home > Research Policies > Research Protections > Human Participant Research > IRB Guideline XI - Research Involving Audio, Video or Digital Recordings of Research Participants". A sidebar on the left lists categories: Research Policies, Intellectual Property, Research Protections (with a sub-menu for Use of Vertebrate Animals, Regulated and Biohazardous Materials, and Human Participant Research), and a "PDF Version" link. The main content area is titled "IRB Guideline XI - Research Involving Audio, Video or Digital Recordings of Research Participants" and includes a "General Overview" section. A pink callout box highlights a paragraph: "Because audio, video or digital recordings include images or voices of research participants, they pose a greater concern to the IRB than do data that do not have readily available identifying information. Therefore, to best protect research participants, the IRB requires that any such recordings be destroyed within a definitive timeframe (e.g., five years following the making of the recordings, five years after data are collected)."

...Therefore, to best protect research participants, the IRB requires that any such recordings be destroyed within a definitive timeframe (e.g., five years following the making of the recordings, five years after data are collected).

1. Included in the application must be sound justification for archiving recordings indefinitely.
2. The informed consent form must include the following:
 - a) A statement indicating where and how recordings will be stored, secured
 - b) A statement indicating who will have access to recordings
 - c) Space for participants to indicate whether they
 - i) want recordings to be destroyed by the timeframe specified, or
 - ii) permit the recordings to be archived for future research within a given research area (e.g., language development, spatial perception, conversational attributes).

PLEASE NOTE: The application may need to be reviewed at the Full Review level, allowing the IRB to decide collectively whether or not archiving the recordings increases risk to participants. The time required for full reviews is tied to IRB meeting dates. Please see [IRB Full Meeting Dates](#) for meeting dates and submission deadlines.



Using Other Researchers' Data in Databrary

- ▶ Many use cases are NOT research



<http://www.assetstorage.co.uk/AssetStorageService.svc/GetImageFriendly/721493384/428/570/0/0/1/80/ResizeBestFit/0/FRU/D5B07E7C7D4EF45E0CD78756A1D82EB2/poking-a-dead-raccoon-is-not-research.jpg>



<http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.102>

§46.102 Definitions.

(a) *Department or agency head* means the head of any federal department or agency and any other officer or employee of any department or agency to whom authority has been delegated.

(b) *Institution* means any public or private entity or agency (including federal, state, and other agencies).

(c) *Legally authorized representative* means an individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research.

(d) *Research* means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. Activities which meet this definition constitute research for purposes of this policy, whether or not they are conducted or supported under a program which is considered research for other purposes. For example, some demonstration and service programs may include research activities.

Research means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.



Using Other Researchers' Data in Databrary

- ▶ Many use cases are NOT research
 - Browsing to see what researcher did
 - Whether findings have face validity
 - Evaluating feasibility of procedures
 - Preliminary/pilot data analyses
 - etc.



Using Databrary for Research

- ▶ Investigators apply to their IRB
- ▶ Return IRB approval, coding, analyses to Databrary
- ▶ Cite dataset source using Databrary format
- ▶ Maintain data security, participant confidentiality



Summary

- ▶ Permission to share
 - Data/recordings and excerpts
- ▶ Access restricted
- ▶ Obligations documented
 - Databrary Investigator Agreement
 - Permission to Share templates
- ▶ Goal: Simplicity and transparency



Issues and Potential Solutions

- ▶ How to enable clinicians and educators who aren't PIs to participate?
- ▶ Databrary Ethics Committee
- ▶ Sharing archival data
- ▶ Institutional agreements

Permissions, Access, and Security: Discussion

