# **Databrary**

### **Definitions**

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# People

Principal Investigator (PI), Principal Investigator (PI) Status An employee of an *Institution* who has the background and training in scientific and administrative oversight necessary to conduct and manage a sponsored project. *Institutions* determine who may have PI status, but the definition typically includes tenure-track faculty (Instructor through Professor, sometimes Emeritus), research or clinical faculty faculty, and may include archivists, curators, and librarians. Research Associates, Research Assistants, and other staff are not considered to be independent investigators, and therefore are not typically granted PI status.

**Databrary Principal Investigator(s) or Authorized Principal Investigator(s)** An individual with *Principal Investigator (PI)* status at an *Institution* who has received authorization from Databrary to view, download, and contribute *Data*.

**Databrary Affiliate Investigator(s) or Affiliate Investigator(s)** An individual, affiliated with an *Authorized Investigator*, who has been authorized for access to Databrary under that *Investigator's* sponsorship and supervision. The access privileges of *Affiliate Investigators* are under the control of one or more *Databrary Principal Investigators*.

Data Contributor(s) An *Investigator* who contributes *Data* to Databrary.

**Depicted Individual(s)** A person depicted in *Recordings*.

**Research Participant(s)** A person observed for purposes of *Research*.

**Third-Party User(s)** An individual who wishes to obtain access to Databrary, but has not yet been granted an *Investigator* or *Affiliate Investigator* account.

**Private Person(s)** Any individual (including an individual acting in his official capacity) and any private entity (i.e., non-government partnership, corporation, association, organization) or any combination thereof including family, household, school, neighborhood, health service, or institution.

**Representative of the Institution** A person authorized to enter into contractual agreements on behalf of an *Investigator's Institution*.

Minor(s)	A person under the age of 18.

#### **Entities**

**Research Supervision Entity(ies)** An Institutional Review Board (IRB) or equivalent authority charged with supervising research at an *Institution*.

**Institution(s)** A university or research organization (including commercial entities), or a government agency at which an *Investigator* will conduct scientific activities, including *Research* using *Data*.

#### **Documents**

**Databrary Investigator/Affiliate Investigator Agreement** Written or electronic agreement that sets out the rights and responsibilities of *Investigators* and *Affiliate Investigators* in their use of Databrary resources.

**Permission/Assent to Share Recordings** Written or electronic documentation that an adult or *Minor Depicted Individual* has given permission/assent to allow *Recordings* to be shared.

**Permission/Asssent to Share Data** Written or electronic documentation that an adult *Depicted Individual* has given permission to allow *Identifiable Data* to be shared.

**Permission/Assent to Excerpt** Written or electronic permission or assent given by Depicted Individuals to allow *Investigators* to show or distribute *Excerpts* from *Recordings*.

**Permission to Share Self-Reported Health-Related Information** Written or electronic permission or assent to allow *De-identified Self-Reported Health-Related Information* to be shared with Databrary.

### **Data-types**

**Identifiable Data** Collections of *PII* that might be used singly or in combination to determine the identity of *Research Participants* or other individuals depicted in *Recordings*.

Non-Identifiable Data Collections of information that do not contain *Identifiable Data*.

**De-identified Data** Collections of information from which *PII* has been removed or altered in such a way as to prevent the identification of individual persons.

**Recordings** Video or audio recordings or still (photographic) images.

### Personally Identifying Information (PII) See also: HIPAA indentifiers

- Full name
- National identification number (e.g., Social Security number)
- Internet Protocol (IP) address
- Vehicle registration plate number
- Driver's license number
- Health certificate or insurance number
- Fingerprints, or handwriting
- Credit card or financial account or access numbers
- Digital identity (e.g., Facebook, Twitter, LinkedIn, email account names)
- Date of birth
- Birthplace
- Address
- Telephone number
- Faces and voices.

**Shareable Identifiable Data** Identifiable Data for which a Depicted Individual has granted Assent to Share Data or Permission to Share Data.

**Metadata** Information that describes how, where, why, and by whom *Identifiable Data*, *De-Identified Data* or *Non-Identifiable Data* were collected.

**Self-Reported Health-Related Information** Information about an individual or *Minor* child's health status that is reported by the individual or an individual's parent or legal guardian, not by a health-care provider.

Data Any Identifiable Data, De-Identified Data, Non-Identifiable Data or Metadata.

## Contributed Data

Any Data that a Data Contributor has contributed to Databrary and permitted Databrary to share with others.

**Excerpts** An excerpt is a still frame or a selection from a larger *Recording* that illustrates a particular point or demonstrates a finding. It is typically no more than a few seconds or minutes in length, substantially less than the full length of a *Recording*. *Investigators* or *Affiliate Investigators* may select segments of a recording as an *Excerpt* for display in public settings if the *Depicted Individuals* have granted appropriate sharing permission.

**Digital Files** Video or audio recordings or photographs stored in an electronic form that may be readily shared (copied or sent) to other people who are not *Research Staff* over electronic networks like the Internet.

Best Practices in Data Security Measures taken to shield digital information from unauthorized access and to preserve it for future authorized use. See Databrary best practices for examples.

#### Actions

**Permission/Consent, Sharing Permission/Consent (Level)** Specific rights for sharing and public release granted by *Depicted Individuals* in a *Permission to Share Data* document.

Databrary currently supports four (4) levels of Sharing Permission:

## 1. No-sharing (Private)

• 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 approved by a Research Supervision Entity. The full responsibility for identifying who constitutes the set of researchers allowed access in this case is the Data Contributor's.

### 2. Sharing with Databrary Investigators and Affiliate Investigators (Shared)

• Data may be shared with other Databrary Investigators or Affiliate Investigators, but no Recordings or Excerpts may be shown in public.

### 3. Sharing and Public Excerpts Permitted (Excerptable)

• Data may be shared with other Databrary Investigators or Affiliate Investigators. Excerpts may be selected by an Investigator and 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 is included with the Excerpt.

#### 4. Public

• Data, including recordings, may be shared openly with the Public.

**Access Permissions (Level)** Specific permissions placed on a study or other digital object by a Researcher controlling its access by other Databrary users. These are distinct from and may have more flexibility than Sharing Permission.

Authorization, User/Investigator Authorization (Level) Privileges granted to individuals to access Databrary.

**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.

**Deductive Disclosure** The discerning of an individual's identity or confidential information through the use of known characteristics of that individual. Disclosure risk is present if an unacceptably narrow estimation of an individual's confidential information is possible or if determining the exact attributes of the individual is possible with a high level of confidence.

**Public Showing** Playing an audio or video segment or showing a photograph to an audience that is not limited to *Research Staff*.

**Research** A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge. 45 CFR 46.102(d)

Non-Research, Non-Research Activities, Non-Research Scientific Activities Work by *Investigators* or *Affiliate Investigators* involving *Data* that falls outside the scope of *Research*, but respects research ethics principles.