Best Practices: Sharing Human Subjects Data

Dryad Requirements

Researchers are responsible for ensuring that all contents of their data package do not contain information that can be used alone, or in aggregate, to identify any individual.

Dryad's policies on human subjects data are in accordance with accepted international standards for de-identifying data from such trusted sources as General Data Protection Regulation (GDPR), HIPPA privacy rules, the Act on the Protection of Personal Information (APPI), and the Personal Information Protection Law (PIPL). Dryad will uphold the policies and publication requirements set in keeping with our responsibility to protect human participants and maintain the integrity of the research data we publish – regardless of whether the data submitted is or will be openly available elsewhere.

Due to the potential risk for indirect re-identification of research participants, Dryad does <u>not</u> accept transcripts from interviews, focus groups, observation studies, or images, audio, or video recordings derived from or displaying human subjects. Properly de-identified micro-level or aggregated quantitative data and summarized qualitative data derived from human participant research submissions are acceptable pending curator analysis if the requirements mentioned above are met.

These guidelines apply to human subjects data for both living and deceased participants.

Preparing Your Data

Dryad does not publish any direct identifiers. A direct identifier is information that is sufficient, on its own, to disclose the identity of a research participant. Examples include name, address, postal code, telephone number, voice, video, or photograph. Dryad also does not accept transcripts.

Datasets may contain **no more than three indirect identifiers**, such as demographic, biological, and geographic data, that could lead to re-identification if combined with other available data (either collected as part of your research or available elsewhere). Examples include institutional affiliations, occupation, geographic region, unique values, or characteristics (outliers).

To properly de-identify your data, consider direct and indirect identifiers and evaluate whether the combination of identifiers could lead to re-identification. For example, the age of participants, uncommon characteristics of the individual (e.g., rare health condition, number of children), geographic/regional location, named facility and/or service provider, and highly visible characteristics of the individual (e.g., ethnicity, race).

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A partial listing of common **direct and indirect identifiers** is provided in the table on **pages 2-3.** Because this is not a definitive list of potentially concerning identifiers, we recommend referencing the table to guide your understanding of the type of variables that *can be* identifying and help you recognize and categorize other direct or indirect identifiers in your data.

A detailed description of your process for de-identifying data should be included in your README file. Additionally, if your research funder requires a [Data Management Plan](#) (DMP), statements of protections for privacy, rights, and confidentiality of human research participants will be required. Click [here](#) to view an example of a publicly available DMP.

De-Identifying Your Data

Reducing, eliminating, or modifying your data can be challenging in scenarios when identifiers included in a dataset are essential for full analysis and to facilitate reuse. Therefore, Dryad provides mechanisms for authors to assess potentially re-identifying data and **techniques for de-identifying the data** (**see page 4**).

To minimize the risk of disclosure, work with your institutional review boards and/or directly with study participants. Whenever possible, obtain informed consent to release participant-level data at the time of data collection and preparation. If you are unable to preserve critical data points to meet Dryad guidelines for publication, consider an alternate repository that offers controlled access to human subject data.

Direct Identifiers (none allowed)	Indirect Identifiers (3 maximum)
➢ Name or initials	➢ Year of birth or exact age
➢ Names of relatives	➢ Ethnicity, race, Indigenous status
➢ Participant IDs that were assigned using a combination of characters or numbers linked to an individual (e.g., initials, birth year, etc.)	➢ Gender or sex
	➢ Criminal record
➢ Exact dates related to an individual (e.g., birth, hospitalization dates)	➢ Place of birth, treatment, residence, or geographic location
➢ Unique identifying numbers (e.g., social security number, individual digital identifier, medical record number)	➢ The inclusion of minors (under 18 years old) in the study
	➢ Socioeconomic data (e.g., occupation, job title, place of work, income, education)
➢ Address, including full or partial postal code	

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Direct Identifiers (none allowed)	Indirect Identifiers (3 maximum)
➢ Telephone or fax numbers, email address ➢ Vehicle identifiers (e.g., license plate, VIN) ➢ Medical device identifiers (e.g., serial numbers, manufacturer info) ➢ Web or Internet protocol (IP) address ➢ Fingerprints, retina scans, dental scans, ECG data ➢ Facial or cranial scans (e.g., fMRI scans showing facial or cranial structures, and including any resulting mapping data from those scans, etc.) ➢ Audiotapes or videos with participants' voices ➢ Photographs or videos with participants' faces or other identifiable features (e.g., tattoos, unique features, etc.)	➢ Household or family composition ➢ One or more pregnancies, fertilization methods, pregnancy/birth outcomes ➢ Sexual attitudes, practices, or orientation ➢ Organizational membership or affiliation (e.g., religious, political, trade group) ➢ Anthropometric measures (e.g., height, weight) ➢ Biometric data (e.g., BMI, heart rate variability, etc.) ➢ Information regarding an individual's psychological well-being or mental health; including family history (e.g., alcoholism, genetic conditions) ➢ Rare disease or treatment (defined as <200,000 in the United States, <4.85M globally, or the equivalent proportion of the population in the country of study) ➢ Name of health professional or facility responsible for care ➢ Sensitive data and/or stigmatized condition (e.g., illicit drug use, HIV/AIDS, vaccination status) ➢ Small population size — (not to be conflated with small *sample* size) ➢ Consumer habits, privileged ownership of or access to uncommon or scarce tangible items ➢ Verbatim responses

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De-Identification Techniques

There are many de-identification techniques that can be used to modify the variables in your data package. The table below lists some of the more common techniques used to de-identify data. Additional methods and guidance for preparing human subject data for publication are available on **page 5**.

Technique	Description	Examples
Aggregate	Place data in ranges	Use age ranges instead of the date of birth or exact age (e.g., 10-20, 90 or older); report group average vs individual values
Collapse and/or combine variables	Merge the concepts embodied in two or more variables by creating a new summary variable	Change exact dates to time intervals between events (e.g., duration of time spent on a survey)
Eliminate outliers	Restrict the upper or lower ranges of a continuous variable to avoid outliers	Group income or age into broader categories. A 72-year-old → grouped in "people in their 70s" or "senior citizens"
Generalize	Adjust the precision of the data	Specific professional position → occupation or area of expertise Date of birth → Year or decade Town → region
Limit the number of indirect identifiers to three (3) maximum	Be cautious when using small subgroups or small areas; avoid submitting tables with small cell sizes (i.e., cells with fewer than 5 respondents)	🚫 Age + sex + job title + # kids ✅ Age (aggregated) + sex + occupation
Remove/Suppress	Determine the data necessary for reproducibility and remove the rest	Eliminate unique identifying numbers, characteristics, or codes including telephone/fax, email addresses, postal codes, medical record numbers, IP addresses, URLs, certificate/license numbers, device identifiers, and serial numbers, health plan beneficiary numbers, account numbers, vehicle identifiers, and serial numbers

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Tools

Amnesia: Used to remove and transform identifiers in a dataset: https://amnesia.openaire.eu/

pydeface and mri_defaceddress: Used to remove/obscure facial structures in fMRI data (please note that even after this is done, Dryad may not accept the data): https://pypi.org/project/pydeface/

ARX De-Identifier: https://arx.deidentifier.org/

Tool for creating unique identifiers for study participants: https://fitbir.nih.gov/content/global-unique-identifier

10 Data Anonymization Tools & Techniques:
https://blog.gramener.com/10-best-data-anonymization-tools-and-techniques-to-protect-sensitive-information/

5 Free Data Anonymization tools: https://aircloak.com/top-5-free-data-anonymization-tools/

Applications to De-Identify Human Subject Research (Johns Hopkins University):
https://dataservices.library.jhu.edu/resources/applications-to-assist-in-de-identification-of-human-subjects-research-data/#image

Resources

HIPAA privacy rule: https://www.hhs.gov/hipaa/for-professionals/privacy/index.html

HIPAA Safe Harbor Identifier List:
https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html#safeharborguidance

Methods for De-identification of Protected Health Information in Accordance with the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule:
https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html#standard

Direct and Indirect Identifiers:
https://uwaterloo.ca/research/sites/default/files/uploads/documents/direct_and_indirect_identifiers_access_check_done_0.pdf

Qualitative Data Repository (Syracuse University):
https://qdr.syr.edu/guidance/human-participants/deidentification

Personally Identifiable Information Guide: a list of PII examples:
https://matomo.org/personally-identifiable-information-guide-list-of-pii-examples/

Human Research Protection Program (HRPP): https://irb.ucsf.edu/definitions#indirectly_identifiable

IRB Table of De-Identification Techniques:
https://www.sjsu.edu/research/docs/irb-deidentification-techniques-table.pdf

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