



NIH Data Sharing: Selection of a Data Repository (Human Subjects Data)



Proposal Submission



Award and Account Establishment



After Research Commences



Closeout

When working with human participant data, including de-identified human data, here are some additional characteristics to look for in a suitable data repository:



1

Fidelity to Consent

Uses documented procedures to restrict dataset access and use to those that are consistent with participant consent and changes in consent.



2

Restricted Use Compliant

Uses documented procedures to communicate and enforce data use restrictions, such as preventing reidentification or redistribution to unauthorized users.



3

Privacy

Implements and provides documentation of measures (for example, tiered access, credentialing of data users, security safeguards against potential breaches) to protect human subjects' data from inappropriate access.



4

Plan for Breach

Has security measures that include a response plan for detected data breaches.



5

Download Control

Controls and audits access to and download of datasets (if download is permitted).



6

Violations

Has procedures for addressing violations of terms-of-use by users and data mismanagement by the repository.



7

Request Review

Makes use of an established and transparent process for reviewing data access requests.

