
DATA MANAGEMENT AND SHARING PLAN

If any of the proposed research in the application involves the generation of scientific data, this application is subject to the NIH Policy for Data Management and Sharing and requires submission of a Data Management and Sharing Plan. If the proposed research in the application involves the generation of large-scale genomic data, the Genomic Data Sharing Policy also applies and must be addressed in this Plan. Refer to guidance on [Writing a Data Management and Sharing Plan](#). When preparing your plan, you should delete the text in italics. There is no “form page” for the Data Management and Sharing Plan. The DMS Plan must be provided in the *format* shown below.

1. Will there be [maximum appropriate sharing of scientific data](#) underlying peer-reviewed publications and other findings resulting from the work supported by this award (including preprints, refereed papers reported at conferences, and other findings)?

Yes ☒ No ☐

2. Will the scientific data underlying peer-reviewed publications be shared by the time of publication, or for other findings, by the end of the period of performance, which includes no-cost extensions?

Yes ☒ No ☐

3. Will shared scientific data be made available for at least as long as required by applicable data repository policies and/or journal policies?

Yes ☒ No ☐

4. If you answered “no” to elements 1, 2, or 3, or if you anticipate that sharing will be limited in some other way, please describe these limitations and the ethical, legal, or technical factors for them. Your response should specify a particular reason(s) for limiting sharing. [300 words maximum]

The proposed research will involve a small sample (less than 20 participants) recruited from clinical facilities in the New York City area with Williams syndrome. This rare craniofacial disorder is associated with distinguishing facial features. Even with the removal of all identifiers, we believe that it would be difficult if not impossible to protect the identities of subjects given the physical characteristics of subjects, the type of clinical data (including imaging) that we will be collecting, and the relatively restricted area from which we are recruiting subjects. Therefore, we are not planning to share the data.

5. If scientific data derived from human research participants will be shared, will privacy, rights, and confidentiality of participants be protected as outlined in [NOT-OD-22-213](#)?

Yes ☐ No ☐ Not Applicable ☒

6. In the table below, please list [100 words maximum]:

- a. Key types of scientific data anticipated to be generated during the project, including the species and modality, if known (e.g., “human genomic data,” “rat functional magnetic resonance imaging data”). NIH recognizes that not all data types expected to be generated in the study will meet the definition of scientific data or can be anticipated in advance. If a data type does not appear on the list, it does not imply that that data type will not be shared if it is generated in the study.
- b. The repository or an example of a repository where the scientific data may be managed and shared, if the scientific data is known at time of application. NIH expects the use of established repositories for preserving and sharing scientific data when they are available.

Expected Data Type	Established Repository or Example
Mouse scRNA-seq	Gene Expression Omnibus (GEO)
Mouse functional magnetic resonance imaging data	OpenNeuro
Mouse tissue histology staining images	Zenodo
Human genomic data	Database for Genotypes and Phenotypes (dbGaP)
Human survey and interview data	Inter-university Consortium for Political and Social Research ICPSR

7. For studies subject to the NIH Genomic Data Sharing Policy (GDS) (e.g., using NIH funds to generate large-scale human genomic data):

- a. Will you share all large-scale human genomic and associated data in a NIH-designated repository according to the accelerated timelines expected in the GDS Policy?

Yes ☒ No ☐ Not Applicable ☐

If "no," address in element 4.

- b. Do you anticipate that when sharing you will be able to meet the [expectations of the Institutional Certification](#) in the GDS Policy?

Yes ☒ No ☐ Not Applicable ☐

If "no," address in element 4.