NF-OSI Data Sharing Plan (NTAP)

NF-OSI DCC

The goal of this data sharing plan is to support the **FAIR Data Principles (Findable, Accessible, Interoperable, and Reusable)**. It serves as a general guide and allows the data contributor to describe the data that will be shared and how/when they will be released.

Commitment to Data Sharing

Data contributors are required by the Neurofibromatosis Therapeutic Acceleration Program (NTAP) to upload data generated in the performance of research funded by or on behalf of NTAP or one of its affiliates into a customized Synapse NF-OSI project space by the associated progress report deadline, though contributors are encouraged to upload data as soon as possible after being generated. Data will be embargoed from the public and accessible only to the data contributor, the NF-OSI data curation team at Sage Bionetworks, NTAP staff and consultants, during the award period and for 18 months after the end date of the award, unless your contract with NTAP states otherwise. The embargo period will end earlier if the data is published or at the data contributor's discretion. After the embargo period, the data will be made available to the broader research community via the Synapse platform. Any requests by an investigator for an extension of the embargo period (e.g., due to a delay in primary publication), must be made in writing to the NTAP Project Manager.

Data Sharing

Data contributors should upload the **raw data** from their research to enable the data to be analyzed by a third party. This includes any information necessary to interpret the data, such as a description of the cohort or the model system, experimental protocols, descriptions of study instruments and equipment, and code used to generate processed data. *It is not necessary to share aggregated/finalized results (e.g. figures).* Please see our help documentation for some data-specific examples and feel free to email us at nf-osi@sagebionetworks.org with questions or for assistance.

Data will be shared in three stages:

1. Data and all associated metadata will be uploaded to the contributor's Synapse NF-OSI project space hosted by Sage Bionetworks.
2. During the embargo period, file metadata will be made publicly visible through the NF Data Portal to enable discovery of the dataset, pending approval of any institution as may be required under the terms of any applicable funding agreement. The data itself, however, will only be accessible to NTAP, the Co-PIs of the project, and the Sage NF data curation team via the Synapse platform.
3. Following publication of the data by the data contributor, or otherwise when NTAP chooses to make such data public in accordance with the terms of the applicable funding agreement (which in no event will be earlier than 18 months following completion of research), the data will be made available to the broader NF research community.

Data Licensing

Non-human-subjects data will be made publicly available under CC0 1.0 Universal, a Creative Commons license, by default. This is the equivalent to depositing the data in the public domain. **Please be aware that you may be required to obtain permission from your institution to release data under this Creative Commons license. You are responsible for consulting with your institutional contacts and obtaining any required permission.** Contributors may indicate certain Conditions of Use of the data by the broader research community under the Data Sharing Plan section below based on the nature of the data, any applicable informed consent, or prior contractual obligations.

Project Details

Project Title A Test Project

Project Description

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Project Keywords (Disease Focus) Neurofibromatosis type 1

Project Keywords (Disease Manifestations) Schwannoma, Meningioma

Project Grant DOI _____

Name of Principal Investigator Jane Doe

Email Address of Principal Investigator jd@example.org

Name of Point of Contact (Data Coordinator) Dana Coors

Email Address of Point of Contact dc@example.org

Synapse User IDs with Project Admin Access _____

Name of Institution Institute of High Research

Project End Date 2022-05-07

Data Sharing Plan

To help data sharing logistics, please complete the information requested below about the data to be shared. The elements of the data-sharing plan are as follows:

- **What**: the nature of the data being shared and how they relate to your overall project, including 'data type', 'assay' and 'species', which are controlled vocabulary terms described here.
- **How much**: how many samples are you measuring? Samples can be considered aliquots/specimens for which you are running a single experiment. If you have multiple experiments, then each gets a separate row in the table below. In the case of single-cell assays, each cell is considered to be a sample.
- **When**: when the data will be uploaded to the embargoed data platform space.

Data to be Deposited

Label	Assay	Samples	Species	UploadDeadline
Cohort Methylation Dataset	ATACSeq	10	Homo sapiens	2022-05-07
Cohort WES	Whole Exome Sequencing	10	Homo sapiens	2022-05-07
Mouse Experiments	reporter gene assay	5	Mus musculus	2022-05-07

Data Sensitivity Assessment *Please fill in the following to help us understand the nature of the data and help determine if additional governance forms are needed.*

These data:

_____ (1) Are not sensitive (i.e., do not meet any of the criteria below), and can be shared broadly without restriction after the project embargo period ends OR

___X___ (2) Are derived from humans OR

_____ (3) Are not derived from humans but for some other reason cannot be shared openly/need to be shared with restrictions on access or data use after the project period ends OR

_____ (4) I am not sure whether these data are sensitive.

For possibly sensitive data (selection 2, 3, or 4), please read Addendum 1 and fill out Addendum 2 as well.

Non-human data only: Instead of CC0 (default) I would like the data to be licensed as _____.

Addendum 1

Guidelines for human sample data

Prior to submitting data each contributor will ensure that:

- The data submission and subsequent data sharing for general research purposes are consistent with applicable national, tribal and state laws and regulations as well as institutional policies.
- An Institutional Review Board/Privacy Board or equivalent body, as applicable, has assured that submission and subsequent sharing of human data for general research purposes (including data such as that being submitted by the contributor) are consistent with the informed consent of study participants from whom the data was obtained.
- The identity of research participants will not be disclosed to NF-OSI members and/or Sage Bionetworks:
  - All submitted human data has been de-identified according to HHS 45 CFR 46.102(f) regulation and the de-identification standards of the HIPAA privacy rules, 45 CFR § 164.514(b), so that individual subjects' identities cannot be ascertained by NF-OSI members or through secondary data use.
  - The de-identified data has been assigned random, unique identifier codes that legally may be made visible to anyone on the web (i.e., the identifier codes do not include any information that can be used to re-identify the study participant).
  - The study PI will inform Sage Bionetworks if any metadata contains potentially identifiable information.
  - The data contributor will review data after submission, before they are released, to verify that no identifying information has been submitted accidentally.
  - Filenames will not contain identifiable information and legally may be made visible to anyone on the web.

- The study PI will notify Sage Bionetworks if there are quality concerns about any data that has been submitted (not limited to potentially identifiable information).
- Data quality corrections will be submitted as soon as possible.

_____

Addendum 2

Project Description and Data Use Conditions

This addendum should be completed for any data that require restrictions for access after the data embargo period ends.

Please complete the form below to characterize the data that will be contributed to Synapse and to verify the terms and conditions of data access through the repository.

Part A: Data Characterization

A.0 Please identify where the specimen/data were obtained:

___X___ Living humans (if so, check here ___X___ to confirm that you agree to Addendum 1)
___X___ Deceased humans (if so, check here ___X___ to confirm that you agree to Addendum 1)
_____ Animal model (mice, rats, etc.)
_____ In-vitro cell culture
_____ Other (please specify): _____

Please complete the following questions if you checked "Living humans" or "Deceased humans".

A.1 Is the data being provided to Sage Bionetworks anonymized?
Anonymization eliminates all personal data and any links between the data and a data subject held by any person anywhere, so that no one could identify the data subjects from the data, either alone or in combination with other information.

___X___ YES, data is anonymized _____ NO

A.2 Is the data being provided to Sage Bionetworks de-identified according to HIPAA?
De-identification in accordance with HIPAA requires removing all of 18 specific types of identifiers listed at 45 C.F.R. § 164.514(b)(2) or obtaining an expert opinion that the data are de-identified, following the standards set forth at 45 C.F.R. § 164.514(b)(1).

___X___ YES, data is de-identified _____ NO

A.3 Does the human data constitute a Limited Data Set?
A Limited Data Set is Protected Health Information (PHI) that excludes all identifiers of an individual except for age, dates and geographic information at the zip code, town, city, or state level.

___X___ YES _____ NO

If you checked "YES," please indicate which HIPAA identifiers are included:
___X___ Specific ages
___X___ Dates
_____ Geographic information at the zip code, town, city, or state level

A.4 Is the data from a vulnerable population (i.e., children, prisoners, pregnant women)?

_____ YES ___X___ NO

A.5 Does the data include information about individuals that was collected either from the individuals or others located outside of the United States of America?

_____ YES ___X___ NO

If YES, please list (1) all countries where the individuals were located at the time of collection (2) all countries where the collector of the data was located at the time of collection, and (3) any applicable laws protecting the privacy of the data (e.g., GDPR):

_____

Part B

B.1 Does the data include omics or sequencing data?

___X___ YES _____ NO

B.2 Does the data include raw data (has not undergone data processing)?

___X___ YES _____ NO

Data Use Conditions

Disposition Requirements upon the termination of (if applicable) a data Transfer Agreement between Sage Bionetworks and the Data Contributor (or equivalent), or expiration of Data Recipient access:

Interesting Disposition Requirements....

Please list any additional data use limitations as required by contract, institutional policy or any applicable informed consent form (e.g., IRB approval requirement, other project-specific terms of use, etc.):

_____

Please indicate any acknowledgement and/or citation statement(s) required for publications resulting from use of the data.

_____

Form Date 2022-04-13

We will review and send you a copy of what we have on file, but feel free to use `Ctrl+P` to save a copy now. If any adjustments to this plan need to be made, please email nf-osi@sagebionetworks.org and your NTAP contact.

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