

Data Sharing Plan Checklist

- Supplement R01 Other grant mechanism

- PI will send whole blood samples from each subject and send to the NIDA Center for Genetic Studies to create cell lines, DNA, and possibly plasma or RNA. All of these biological components are stated explicitly in the data sharing plan

- All data (clinical and phenotypic) are covered under the sharing plan, including:
 - Subject ID #
 - Family ID #
 - Site ID #
 - Parental ID #s
 - Sex
 - Death status
 - Ethnicity or geographic origin of ancestry
 - Age and/or year of birth
 - Twin status
 - DSM-III-R diagnoses
 - DSM-IV diagnoses
 - Instrument used to establish diagnoses
 - Answers to all of the questions in the structured interview or, minimally, the answers to those questions from which the addiction diagnoses were established.
 - Other descriptive information collected about the drug abuse/addiction phenotypes, such as age of onset, quantity and frequency of peak lifetime use of addictive substances, etc.
 - Proband

- Data will be verified as needed and regular updates will be provided to the NIDA Center for Genetic Studies throughout the project

- Genotyping data, including the DNA marker names, description of SNPs (single nucleotide polymorphisms) or allele sizes in base pairs and corresponding frequencies, and relative map distances

- PI will participate in NGC meetings twice a year

- The sharing plan has an appropriate informed consent by which all databases and biological materials can be widely searched or distributed by qualified investigators

- The plan has a timetable (including 18 month proprietary period) specifying when various elements of the database and biological material will be:*
 - Submitted to the repository, and
 - Available for distribution

Informed Consent Form Checklist

- ❑ Ability to re-consent
- ❑ Explanations of the project are clearly stated
 - Risks
 - Reason for participation
 - Opportunity to ask questions
 - Opportunity to withdraw from the study
 - How participant's data will be stored
 - Researchers will not benefit financially from use of data/material from participant
 - Participant will not be identified
- ❑ Contact number and name listed for future questions
- ❑ Blood will be obtained for plasma, DNA, and possible cell line generation
- ❑ Consents forms are appropriate for age group
- ❑ Consent form includes a form for revocation of consent with detailed instructions as to how to deal with biological and clinical data
- ❑ Consent form includes options for subjects in terms of what types of studies the samples can be used for in the future