AgingResearchBiobank

Data Submission Worksheet

# General Instructions

Use the worksheet below as a guide for compiling and preparing documentation and data for submission to the AgingResearchBiobank. Guidelines for preparing data for submission to the Data Repository are available [here](https://www.agingresearchbiobank.nia.nih.gov/submit-datasets/). Investigators are encouraged to review the worksheet checklist prior to initiating data collection and throughout the Study lifecycle to facilitate data curation at Study close out.

Using the worksheet checklists below, assemble the required materials and submit these to the Data Repository as directed by the Study’s NIA Program Official. Questions or comments regarding the worksheets and questionnaire may be sent to the Data Repository using the AgingResearchBiobank “[Contact Us](https://www.agingresearchbiobank.nia.nih.gov/contact/)” page on the [AgingResearchBiobank website](https://www.agingresearchbiobank.nia.nih.gov/).

# Submission Elements

Data Submission Worksheet

Study Details Worksheet

Informed Consent Questionnaires for Data and Specimens

Original Study participant ID to new randomized ID link/crosswalk file

De-identified data sets, all data elements with descriptive labels

Study documentation elements

Additional materials for clinical trials and/or biospecimens

# Study Documentation Elements (All Studies)

Study protocol

Manual of Operations/Manual of Procedures (e.g. Venipuncture, Blood Pressure, Event Ascertainment, Quality Control, etc.)

Annotated data collection forms

Code book or data dictionary containing variables and the values to which they map e.g. for marital status 1=Married, 2=Divorced/Separated, 3=Widowed, 4=Never Married (if applicable)

For SAS based data sets with embedded formats, the SAS formats library, data set, or SAS program file that provides definitions of numeric category indicators, see examples above

Calculated variables documentation, e.g. algorithms, guidance for use, publication references, etc. of data which have undergone expert adjudication (diagnosis or outcome data), summary scores from procedures (Echocardiography, spirometry, CT scans, ECGs, etc.), and scored questionnaires.

Summary of de-identification changes made to the data

Summary of the study and submitted materials including the dataset names and descriptions

Any other guidance that would be helpful for someone unfamiliar with the study or data

# Additional materials for Clinical Trials

A summary of changes made to the protocol over time (PDF, Excel or Word)

Primary publication (if published)

Frozen datasets used for the primary publication, or variables indicating the study population used in the primary publication

# Additional materials for Studies depositing biospecimens

Private full clinical datasets (will not be shared)