



Data and Tissue Available for Sharing

Access to DIAN data is dependent on review and approval by the DIAN Steering Committee and agreement to compliance with DIAN data sharing policies.

DIAN Clinical Core

General Information about the clinical assessment:

Participants are evaluated in a uniform manner at entry and longitudinally thereafter with instruments to include: the clinical and cognitive batteries that comprise the Uniform Data Set (UDS) (Morris et al., 2006) and additional DIAN-specific testing listed below. Each site has designated a study coordinator who manages the day-to-day conduct of the study, ensures accurate administration of all instruments at the site, and supervises accurate data collection. Sites are responsible for identifying trained clinicians and raters to complete assessments such as the Clinical Dementia Rating (CDR), and the Neuropsychiatric Inventory (NPI), etc. It is the site's responsibility to train interviewers and all other personnel who assess the participant and caregiver. Typically the CDR rater is a trained MD Clinician, but a RN or a PhD can also train and become certified for CDR rating. All clinicians must be blinded to the genetic status of DIAN participants. Clinicians must successfully complete the training modules in order to administer the DIAN assessments.

The clinical assessment, psychometric testing, MRI, PET PIB, FDG PET, and blood and CSF collection may be completed over a few days or in several visits spread over no more than 12 weeks. The exact order of measures is not dictated by the protocol, but it is highly recommended that the clinical assessment be performed first. The rationale is that the clinical assessment could reveal that the participant is unable to complete all of the measures within the protocol prescribed 12-week window. The frequency of the in-person follow-up interval is determined by the current age of the participant (P) in relation to the parent's age at onset (AAO). If cognitive decline is detected at an in-person visit, the in-person visit frequency becomes annual, regardless of the interval between the participant's age and the parental age at onset. If the participant is cognitively normal, the affected parent's AAO is used as the index for the frequency of assessments as stated on the worksheet.

Available Clinical Data:

- Estimated Parental Age at Onset
- Participant Demographics
- Informant Demographics
- Exercise Questionnaire
- Hollingshead Index of Social Position (including participant level of education)
- Clinical Dementia Rating (CDR)
- Geriatric Depression Scale (GDS)
- Functional Assessment Questionnaire (FAQ)
- Neuropsychiatric Inventory-Q (NPI-Q)
- United Parkinson's Disease Rating Scale (UPDRS)-Motor
- Hachinski Ischemic Score/Cerebrovascular Risk Factors
- Clinician Judgment of Symptoms (UDS Form B9)
- Form D1: Clinician Diagnosis – Cognitive Status and Dementia
- Vital Signs
- Neurologic Exam Findings
- Physical Exam Findings

Psychometrics include:

- Category fluency for animals and vegetables (Goodglass 1983 a,b)
- Trailmaking A and B (Armitage, 1946)
- Word list recall (immediate and delayed) designed specifically for DIAN
- Letter Fluency for F, A, S
- International Personality Item Pool (IPIP)

DIAN Genetics Core

Tissue:

Upon approval from DIAN Steering Committee, DNA/cell lines may be obtained from the National Cell Repository for Alzheimer's Disease (NCRAD). Researchers requesting DNA samples will have two request options: A) pre-made plates that will have a reduced cost structure and are sent out rapidly; or B) customized set of samples that have a higher cost structure and will have a delay in shipment time due to preparation. The DNA for both options is cell line derived DNA and available in 25ug aliquots. There is a fee to obtain tissue is from NCRAD.

Data:

APOE Genotype

Mutation Status (request must permit adequate de-identification, e.g. more than a few participants)

DIAN Biomarker Core

Tissue:

Fasted cerebrospinal fluid (CSF)

Fasted plasma

Fasted serum

Data:

CSF Ab1-42 (INNOTEST ELISA)

CSF Ab1-42, total tau, ptau181 (INNO-BIA xMAP)

Plasma Ab1-40, Ab1-42, Abx-40, Abx-42 (INNO-BIA xMAP for plasma)

DIAN Imaging Core

Available Data Formats

For PIB

Full or Partial Scan Download from CNDA

Regional Distribution Volume Ratios based on Manual Regions of Interest

Normal Cortex: 1.1-1.2

Amyloid Deposition: 2-2.5

For FDG

Full or Partial Scan Download from CNDA

Regional Averages of activity to assess relative metabolism based on Manual Regions of Interest

For MRI

Full or Partial Scan Download from CNDA

Regional volumetric/subcortical volumetric and cortical thickness using Freesurfer Version 4.5

Pipelines are in the process of being created, after which, PIB and FDG will be available in the CNDA.

Additional Image Analyses: Investigators can submit proposals for additional data analysis to the DIAN Executive Imaging Committee and DIAN Steering Committee. Once the proposal is approved, investigators may be given access to the DIAN Global Project in the Central Neuroimaging Data Archive (CNDA, primary data repository for DIAN). Requested modalities will be available in the CNDA for specified approved analysis.

DIAN Neuropathology Core

DIAN-NPC Block Sampling

Formalin-fixed, paraffin wax embedded tissue blocks from the following 16 areas from the left cerebrum will be available:

1. Middle frontal gyrus
2. Superior and middle temporal gyri
3. Inferior parietal lobe (angular gyrus)
4. Occipital lobe to include the calcarine sulcus and peristriate cortex
5. Anterior cingulate gyrus at the level of the genu of the corpus callosum
6. Posterior cingulate gyrus and precuneus at the level of the splenium
7. Amygdala and entorhinal cortex
8. Hippocampus and parahippocampal gyrus at the level of the lateral geniculate nucleus
9. Striatum (caudate nucleus and putamen) at the level of the anterior commissure
10. Lentiform nuclei (globus pallidus and putamen)
11. Thalamus and subthalamic nucleus
12. Midbrain
13. Pons
14. Medulla oblongata
15. Cerebellum with dentate nucleus
16. Spinal cord

Frozen Tissue

1. Frontal lobe to include striatum;
2. Frontal and temporal lobe at the level of the mamillary body;
3. Temporal and parietal lobes at the level of the lateral geniculate nucleus;
4. Occipital lobe to include the calcarine sulcus;
5. Cerebellar hemisphere to include dentate nucleus.

For more detailed information about the Biomarker, Neuropathology and Imaging core data, please consult the available PDFs at <http://www.dian-info.org/ResourceDB/default.htm>.

If you have other questions about DIAN data and sample collection procedures, please contact Natalie Selsor at selsorn@abraxas.wustl.edu.