

RESEARCH USE STATEMENT AND NON-TECHNICAL SUMMARY

Research Use Statement for Application for Genomic Data from NIAGADS Please limit to 2,200 characters max.

Objectives of the Proposed Research: The proposed research seeks to explore the relationship between genetic variants that have
previously been associated with Alzheimer's Disease (AD) at a level of genome-wide
significance and neuropsychiatric symptom severity and progression as measured at annual
clinic visits through the use of a subset of the Uniform Data Set (UDS) that is stored by the
National Alzheimer's Coordinating Center (NACC).
Study Design: The proposed study is a secondary analysis of previously collected data for the purpose
of a master's thesis. Subjects for whom there is both genetic data in NIAGADS and clinical
data for at least two visits in the NACC will be analyzed. There will be no contact with any
subjects nor any genetic data collected or returned.
Analysis Plan: The following phenotypic information will be evaluated with the NIAGADS

data: Clinical Dementia Rating (CDR) Plus NACC Frontotemporal Lobar Degeneration (FTLD)



RESEARCH USE STATEMENT AND NON-TECHNICAL SUMMARY

item & total scores, Neuropsychiatric Inventory Questionnaire (NPI-Q) item & total scores,
NACC Functional Assessment Scale (FAS) item & total scores, physical/neurological exam
findings, clinician judgment of symptoms, neuropsychological battery summary scores, clinician
diagnosis, clinician-assessed medical conditions, subject demographics (i.e., age, sex, years of
education, race/ethnicity), and subject health history (i.e., stroke, transient ischemic attack,
Parkinson's disease, seizures, traumatic brain injury, other neurological condition). The
phenotypic information comes from the following forms within the NACC's UDS: forms A1, A5,
B4, B5, B7, B8, B9, C1/C2, D1, and D2. The analysis will be quantifying the relationship
between 1) the presence or absence of genetic variants previously identified to be associated
with AD at a level of genome-wide significance and 2) changes in the aforementioned
phenotypic data over time.
Explanation of how the proposed research is consistent with the data use limitations for the requested dataset(s):
NIAGADS data will be used only for the purpose of the master's thesis outlined above, which
is being overseen by the PI and internal collaborator listed in the Data Access Request
and is set to be complete no later than June 12th, 2020. This research has been granted a
category 5 exemption from the University of Washington IRB.
category o exemption from the enversity of vivaenington inte.
category o exemption the emission in the emiss
Brief description of any planned collaboration with researchers at other institutions, including the name of the collaborator(s) and their institution(s).
Brief description of any planned collaboration with researchers at other institutions,



RESEARCH USE STATEMENT AND NON-TECHNICAL SUMMARY

List the NIAGADS datasets you are requesting for analysis (ex. NG00017):
NG00022, NG00023, NG00024, NG00068, NG00069, NG00070, & NG00071
Non-Technical Summary for Application for Genomic Data from NIAGADS Investigators will provide a non-technical summary of their proposed research. If the project is approved, this statement will be publicly available for lay audiences to read the purpose and objectives of the research. Please limit to 1,100 characters. The present study is an effort to determine whether any of the genes that have previously
been associated with Alzheimer's Disease play a role in the progression of specific symptoms
such as memory, attention, language, and ability to manage one's affairs. The thought here is
that the presence of a mutation in one or more of these genes may contribute to a more rapid
decline of cognitive ability. Research of this nature may serve to help inform efforts to develop
treatment for Alzheimer's Disease in the future.