



Alzheimer's Disease Neuroimaging Initiative (ADNI) Whole Genome Sequencing (WGS) Agreement

Introduction

Researchers appreciate the benefits and responsibilities surrounding the use of genetic data collected from human subjects. The purpose of this document is to stipulate the conditions under which provision of ADNI Whole Genome Sequencing data may occur.

Background

In July 2012 the Brin-Wojcicki Foundation and the Alzheimer's Association donated funds to support whole genome sequencing (WGS) of 818 ADNI participants. Samples were sent to Illumina where non-CLIA WGS, as well as Illumina Omni 2.5M genome-wide association study (GWAS) single nucleotide polymorphism (SNP) arrays, were performed on each sample. Basic quality control checks were then performed. Additional details are contained in an [introduction and procedures document](#) which is available on the ADNI website.

SNPs data is currently available to authorized ADNI investigators from within the [ADNI repository](#) hosted by the Laboratory of Neuro Imaging (LONI). However, the entire dataset is available via Aspera software transfer, so provisions for those seeking to obtain WGS data are the focus of this document.

Roles and Responsibilities

The investigator seeking access to the WGS data is required to obtain and maintain an active ADNI data use account and to follow all provisions of the ADNI [Data Use Agreement](#) including protecting data from unauthorized access and following all aspects of the ADNI [Data Sharing and Publications Policy](#). In addition, the data recipient must agree to the terms of the Whole Genome Sequencing Agreement (page 2).

Data recipients must contact adni@loni.usc.edu to be added to the requestor list and attach a scanned copy of the Whole Genome Sequence Agreement, with the subject line 'ADNI WGS Agreement'. Requests for data will be filled in the order received. LONI will contact the data recipient with Aspera login credentials and instructions for the data transfer. The password will expire 30 days after the data recipient is notified that their access is established.



Whole Genome Sequence Agreement

- You must maintain the genetic data in confidence with the same degree of care you hold your own confidential information.
- You must not attempt to use the data to identify ADNI subjects.
- You must use the genetic data only for the purpose of performing the analyses approved by the ADNI Data Sharing and Publications Committee (DPC).
- You must not transfer or redistribute data in any way.
- You must follow all provisions of the ADNI [Data Use Agreement](#), the ADNI [Publications Policy](#) and your institution's rules and regulations.

Additionally:

- You will not acquire any rights, including, but not limited to, patent rights and trade secrets in the genetic data, and nothing in this document shall be construed as granting you a license to any patent rights or other intellectual property rights.
- Any significant violation of the points in this document will lead to suspension of analytic privileges

Signature: _____

Printed name: _____ Date: _____

Email address of authorized ADNI account holder: _____

