

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. However, the entire dataset amounting to over 150TB cannot be reasonably distributed over the Internet, so provisions for those seeking to obtain WGS Assembly data are the focus of this document.

Roles and Responsibilities

The investigator seeking to obtain WGS Assembly data [data recipient] 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. Requests for data will be filled in the order received. LONI [data distributor] will contact the data recipient when ready for the hardware to be shipped. Once the hardware is received, LONI will copy the WGS Assembly data (BAM files) onto the data recipient's hardware, assuming that the data recipient is an authorized ADNI investigator in good standing, and has signed the agreement. LONI will make every effort to ensure data is complete and free from error and to return hardware in the same condition as received.

The data recipient will be responsible for making arrangements for return shipping including all associated costs. The data provider will communicate to the data recipient's designated contact when the hardware is ready to be picked up.

Hardware Requirements

The data recipient is responsible for providing hardware that is in good working condition and that meets one of the configurations listed below.

- A. Three 48TB disk arrays with 1Gbps interfaces
- B. Six 16TB drives (USB 3.0)



LONI must receive the following signed agreement in order to copy the WGS data to the data recipient's hardware.

Scan and send the agreement to adni@loni.usc.edu with the subject 'WGS Agreement'.

Or send by mail to the address as follows:

Attn: Jessica Yaros, WGS
Laboratory of Neuro Imaging (LONI)
Institute for Neuroimaging and Informatics (INI)
Keck School of Medicine at University of Southern California
2001 North Soto Street, SSB1-102,
Los Angeles, CA 90032

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.
- You must provide media on which to copy the data that is in good working condition and that meets the hardware requirements detailed in the Hardware Requirements section.

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: _____

