

DATA ACCESS AGREEMENT

This Data Access Agreement ("Agreement") is by and between The Trustees of the University of Pennsylvania ("Provider"), on behalf of the National Institute on Aging Genetics of Alzheimer's Disease Data Storage Site (NIAGADS), and _____ ("Recipient"), on behalf of _____ ("School/Department/Unit & PI"). This Agreement is effective as of the date of the last signature below ("Effective Date").

WHEREAS, Provider maintains certain protected health information that Recipient wishes to use for research purposes;

WHEREAS, Provider and Recipient are committed to protecting the privacy and security of confidential patient information in accordance with HIPAA Privacy Regulations, other federal and state laws, and contractual obligations;

WHEREAS, Recipient plays a crucial role in ensuring the privacy and security of this confidential information;

WHEREAS, Recipient wishes to receive genetic data from individuals recruited from its own center in the form of CRAMs, gVCFs and pVCFs ("Genetic Data") from Provider;

WHEREAS, Recipient also will receive from the National Alzheimer's Coordinating Center the key to map Alzheimer's Disease Sequence Project (ADSP) identifiers to Recipient's original Alzheimer's Disease Center identifiers;

WHEREAS, individuals recruited by Recipient have the understanding and expectation that Recipient will have access to and use Genetic Data pertaining to them in connection with specific genetic research projects ("Research Projects").

WHEREAS, Recipient desires to use Genetic Data at its sole risk and at no expense to Provider;

NOW THEREFORE, it is mutually agreed as follows:

1. Recipient will submit to Provider this signed and dated Agreement to request Genetic Data.
2. Provider agrees to transfer to Recipient Genetic Data and accompanying documentation for use by the Principal Investigator and other faculty, employees, fellows, students and agents employed by Recipient who are under supervision of the Principal investigator and whose obligations of access to and use of the Genetic Data are consistent with this Agreement (collectively known as "Recipient Personnel"). This Agreement is not transferrable to another institution.
3. Genetic Data received from Provider will be used by Principal Investigator in Research

Projects for which Principal Investigator has sole responsibility, and which are explicitly consistent with protocols and informed consent language approved by Recipient's Institutional Review Board ("IRB").

4. Recipient agrees to retain control over Genetic Data received from NIAGADS and further agrees not to provide them, with or without charge, or otherwise grant access to the Genetic Data to any other entity or any individual other than Principal Investigator(s) and Recipient Personnel. Recipient will comply with the Security Rule of the Health Insurance Portability and Accountability Act of 1996 and take the appropriate security measures, including the implementation of the administrative, physical and technical safeguards specified in 45 CFR §§ 164.306, 164.308, 164.310, 164.312 and 164.316 to protect the confidentiality, integrity and availability of Genetic Data and to prevent any use or disclosure of Genetic Data other than as provided by this.

5. Recipient agrees to use Genetic Data in compliance with all applicable laws, rules and regulations, as well as professional standards applicable to such research.

6. No rights of Recipient(s) under this Agreement may be assigned or otherwise conveyed to any party, including a purchaser of Recipient(s), without the specific written agreement of NIAGADS.

7. Recipient will acknowledge the contribution of Provider as the source of Genetic Data in any and all oral and written presentations, disclosures, publications, and patents concerning Recipient's research using Genetic Data, as appropriate in accordance with scholarly standards. Principal Investigator(s) will use the following acknowledgement:

Acknowledgment statement for any data distributed by NIAGADS: Data for this study were prepared, archived, and distributed by the National Institute on Aging Alzheimer's Disease Data Storage Site (NIAGADS) at the University of Pennsylvania (U24-AG041689 and related awards), funded by the National Institute on Aging.

Acknowledgement for the Alzheimer's Disease Sequencing Project: Principal Investigator(s) will use the following acknowledgement for users of the ADSP data:

<https://www.niagads.org/adsp/content/acknowledgement-statement>.

Acknowledgement for studies using data that is not a component of the ADSP: It is expected that investigators will contact NIAGADS for a list of investigators and award numbers to be used in the acknowledgment section of the manuscript.

9. NO WARRANTIES, EXPRESS OR IMPLIED, ARE OFFERED AS TO THE MERCHANTABILITY OR FITNESS FOR ANY PURPOSE OF THE GENETIC DATA PROVIDED TO RECIPIENT UNDER THIS AGREEMENT, OR THAT THE GENETIC DATA MAY BE EXPLOITED WITHOUT INFRINGING THE INTELLECTUAL PROPERTY OR PROPRIETARY RIGHTS OF ANY THIRDPARTIES.

10. Recipient(s) agree(s) not to claim, infer, or imply endorsement by the US Government of the Research Project, Recipient or Recipient Personnel or any resulting commercial product(s). To the extent permitted by law, non-US Government Recipients agree to hold the US Government and Provider harmless and to indemnify all such parties for all liabilities, demands, damages, expenses, and losses (including attorney fees) arising out of Recipient's use for any purpose of Genetic Data received from Provider, or out of Recipient's breach of obligations under this Agreement, except to the extent permitted by law when caused by the gross negligence or willful misconduct of Provider.

11. Failure to comply with any of the terms specified herein may result in disqualification of Recipient from receiving additional genetic analysis data and associated phenotypic data from NIAGADS.

12. Neither party shall use the other party's name, trademarks, or other logos in any publicity, advertising, or news release without the prior written approval of an authorized representative of that party. The parties agree that each party may disclose factual information regarding the existence and purpose of the relationship that is the subject of this Agreement for other purposes without written permission from the other party provided that any such statement shall accurately and appropriately describe the relationship of the parties and shall not in any manner imply endorsement by the other party whose name is being used.

13. Provider may terminate this Agreement if Recipient is in default of any of the terms specified herein and if the deficit has not been remedied within 30 days after the date of written notice by Provider of such deficit. Upon termination, Recipient shall promptly return or destroy Genetic Data received from Provider in connection with this Agreement. If return or destruction of Genetic Data is not feasible, Recipient shall continue the protections required under this Agreement for Genetic Data consistent with the requirements of this Agreement and applicable HIPAA privacy standards.

14. Recipient agrees to report to Provider, in writing, any misuse, unauthorized use or disclosure that is not authorized under this Agreement within 5 days.

15. Any modification of this Agreement must be made in writing and executed by duly-authorized representatives of both parties.

16. Recipient expressly certifies that the contents of any statements made or

reflected in this Agreement are truthful and accurate. Unless otherwise specified, this Agreement embodies the entire understanding between Provider and Recipient regarding the transfer of Genetic Data for the Research Projects.

17. This Agreement shall be construed in accordance with Federal law as applied by the Federal courts in the Commonwealth of Pennsylvania. Venue for any claim, action or suit, whether state or federal, between Recipient and Provider shall be Philadelphia County, Pennsylvania.

Recipient has had the opportunity to read and understand this Terms of Access Agreement and agree to its terms and obligations as indicated by signing below:

RECIPIENT

Principal Investigator

Institutional Official

Signature

Signature

Printed Name

Printed Name

Title

Title

Date

Date

THE TRUSTEES OF THE UNIVERSITY OF PENNSYLVANIA

Principal Investigator

Institutional Official

Signature

Signature

Printed Name

Printed Name

Title

Title

Date

Date