

## **TERMS OF ACCESS AGREEMENT FOR DATA**

This Terms of Access Agreement ("Agreement") is by and between The Trustees of the University of Pennsylvania ("Covered Entity") and (Institution/Organization) on behalf of (School/Department/Unit&PI). This Agreement is effective as of the date of the last signature below ("Effective Date").

WHEREAS, Covered Entity maintains certain protected health information that Data Recipient wishes to use and/or disclose for research purposes;

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

NOW, THEREFORE, the Data Recipient and steward of Covered Entity's confidential patient information, before receiving access to confidential patient information for the purposes of research, acknowledges and agrees to the following:

1. Data Recipient agrees to abide by the terms of this Agreement as well as applicable federal and state laws, and contractual obligations.
2. Data Recipient agrees that all terms used in this document will have the same definition as those set forth in the HIPAA Privacy Regulations.
3. The Data Set referred to in this agreement is defined in Appendix 1.
4. Data Recipient may be granted access to proprietary or confidential patient information. Data Recipient agrees that privacy and security of this information is their personal duty and responsibility.
5. Data Recipient hereby certifies that anyone given access to the Data Set under the terms of the agreement herein has completed all applicable privacy, human subjects, and security training.
6. Data Recipient understands that, for the purposes of this study, they will be receiving a de-identified Data Set. Data Recipient understands that they must utilize the same level of protection for this de-identified Data Set as they would any other confidential, non-public information.
7. Data Recipient agrees not to use any data contained in the Data Set except as minimally necessary to perform research.
8. The Data Recipient agrees to abide by the conditions of the Data Use Certification Agreement, submitted as part of the application to NIAGADS Data Sharing Service (DSS) to obtain permission to access the Data.
9. Data Recipient understands that only the Principal Investigator and the persons listed on the approved DAR (collectively "Authorized Parties"), are authorized to use the Data Set or any part of it on behalf of Data Recipient. All Authorized Parties agree to abide by the terms of this Agreement. Secondary data sharing is not permitted and the Data Set cannot be provided to non- Authorized Parties, except as described in Secondary Data Sharing described in Schedule 1.

10. Data Recipient agrees not to use these Data for any purpose other than the study identified in Appendix 1 attached to this Agreement.
11. Data Recipient agrees to use all reasonable means to protect the privacy and security of data in their control and prevent it from being inappropriately accessed or disclosed including but not limited to encrypting the data when in storage and in transit.
12. Data Recipient agrees not to attempt to re-identify the subjects that provided DNA for the study or to contact the individuals whose information is contained within the Data Set.
13. Data Recipient understands that, for the purposes of this agreement Covered Entity means the entity who provides the data they are receiving.
14. Data Recipient understands that the data provided may be aggregated with the data of other Covered Entities for this project.
15. Data Recipient will not use or disclose the data in the Data Set for marketing or fundraising purposes.
16. Data Recipient agrees that when their employment, affiliation, privileges, or assignment and this study ends, they will not take any data with them.
17. Data Recipient agrees to report to Covered Entity any use or disclosure of the data or any part of the data if not provided for by this Agreement of which Data Recipient or any Authorized Party becomes aware.
18. Any notice permitted or required by this Agreement shall be provided in writing and sent to the contact address as noted below.
19. Data Recipient understands that if they do not maintain the privacy and security of the Data Set they are in breach of this agreement and the agreement may be immediately terminated.
20. If this agreement is terminated, the Data Set must be immediately returned and/or destroyed as appropriate with confirmation from a University signing official or the equivalent.
21. Data Recipient understands that unauthorized use or disclosure of Personal Health Information (PHI) (including re-identification of a de-identified Data Set) may violate federal or state law and could result in criminal or civil penalties.
22. Further, Data Recipient agrees to indemnify, defend, and hold Covered Entity harmless from all costs and expenses (including attorney fees) that relate to a breach of Data Recipient's obligations hereunder.
23. Data Recipient understands that, in any publication about the study, Covered Entity will be acknowledged for its participation. Other than acknowledgment, Covered Entity will not be specifically mentioned in the publication without the written permission of Covered Entity.
24. This Agreement and exhibits embody the entire understanding between the Parties relating to the subject matter hereof and cancel and supersede all prior agreements between the Parties, whether written or oral. No waiver, modification, or amendment of any provision of this Agreement shall be valid or effective unless made in writing referencing this Agreement and signed by a duly authorized representative of each Party.

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**[Signatures on Next Page]**

Data 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:

**COVERED ENTITY**

**THE TRUSTEES OF THE UNIVERSITY  
OF PENNSYLVANIA**

**AUTHORIZED SIGNATURE**

X \_\_\_\_\_  
Printed Name: \_\_\_\_\_  
Title: \_\_\_\_\_  
Date: \_\_\_\_\_

**READ AND ACKNOWLEDGED  
PRINCIPAL INVESTIGATOR**

X \_\_\_\_\_  
Printed Name: \_\_\_\_\_  
Title: \_\_\_\_\_  
Date: \_\_\_\_\_

**RECIPIENT  
INSTITUTION**

**AUTHORIZED SIGNATURE**

X \_\_\_\_\_  
Printed Name: \_\_\_\_\_  
Title: \_\_\_\_\_  
Date: \_\_\_\_\_

**READ AND ACKNOWLEDGED  
PRINCIPAL INVESTIGATOR**

X \_\_\_\_\_  
Printed Name: \_\_\_\_\_  
Title: \_\_\_\_\_  
Date: \_\_\_\_\_

### **Schedule 1.**

**Secondary data sharing – item 9 above:** Signatories of this document are allowed to exchange the Data Set and data derived (secondary analysis data) from the Data Set with the PIs listed as collaborators and with approved Data Access Requests from the NIAGADS DSS. Sharing with other parties outside those specified as above are prohibited except with explicit approval by the NIAGADS ADRD Data Access Committee (NADAC).

## **APPENDIX 1**

1. Description of the Data Set the Recipient is requesting.

All controlled access datasets provided by the NIAGADS DSS as approved by the the NIAGADS ADRD Data Access Committee (NADAC) regarding your active Data Access Request(s).

2. Description of the project the data will be used for.

Insert DAR ID and Research Use Statement from NIAGADS DSS application for access to requested data here.