

HEALTH AND RETIREMENT STUDY (HRS) GENOMIC DATA ACCESS AGREEMENT

This Data Access Agreement (“Agreement”) sets forth the terms and conditions under which the Individual User named below, with the authorization of the Receiving Entity, is granted access to HRS Genomic Data. *A separate agreement must be completed and signed by each individual user.*

HRS Genomic Data

HRS genomic data (e.g. HRS Genotype Data, HRS DNA Methylation Data) are distributed through the NCBI Database of Genotypes and Phenotypes (dbGaP) and the National Institute on Aging Genetics of Alzheimer’s Disease Data Storage Site (NIAGADS). The datasets in these repositories contain minimal phenotype information. This agreement provides User access to the cross-reference files required to link the unique HRS identifier to the identifier assigned to HRS genomic data stored and distributed by the repository, as specified in the User’s Genomic Data Cross-Reference Request Form via the HRS website (see: <https://hrs.isr.umich.edu/data-products/genetic-data/access-summary>).

1. Purpose of Data Use

The User and Receiving Entity jointly agree that all data accessed under this Agreement will be used solely for scientific and public policy statistical research purposes. The data will not be used for any administrative, law enforcement, or commercial purpose.

2. Protection of Subjects’ Privacy

- a. The User shall make no attempt to identify any individual(s) within this or any other HRS dataset.
- b. The User will not transfer HRS Data to any third party.
- c. The User will not allow others to use their username and password to access site.
- d. If the identity of any individual or establishment is inadvertently discovered, the User agrees to:
 - Make no use of the discovered identity.
 - Immediately notify the Director of HRS.
 - Safeguard or destroy all identifying information as instructed by HRS.
 - Not disclose the discovered identity to anyone else.
- e. The Health and Retirement Study (HRS) is protected by a Certificate of Confidentiality issued by the National Institutes of Health (NIH). Under this Certificate, investigators and others who have access to HRS data are prohibited from disclosing identifiable, sensitive information about research participants in any civil, criminal, administrative, legislative, or other proceedings at the federal, state, or local level. This protection applies even under court order or subpoena. Disclosure of information may nevertheless occur as required by law for purposes such as reporting child abuse, intent to harm self or others, or communicable diseases, or when a participant has provided explicit written consent for disclosure. This Certificate is issued in compliance with applicable federal law and regulation to further protect the privacy of research participants and is binding beyond the term of this agreement.

3. Tabulation and Disclosure Control

When generating tabulations for distribution:

- Magnitude Data: No output cells/strata with $n < 5$ individuals may be produced.
- Frequency Data: All tabulations must apply marginal and cell thresholds of $n \geq 5$.
- Complementary Disclosure: Suppress additional cells as necessary to prevent re-identification via subtraction from published marginal totals.

4. Publication Requirements

- a. Only aggregate statistical summaries (such as frequency and magnitude tabulations, means, variances, regression coefficients, correlation coefficients) may be published. These are subject to the disclosure restrictions above.
- b. The User shall acknowledge HRS as the data source in all research reports, papers, or publications based on these data, and shall provide copies of such publications to HRS.
 - **In text:** “The Health and Retirement Study genomic data is sponsored by the National Institute on Aging (grant numbers U01AG009740, RC2AG036495, and RC4AG039029) and was conducted by the University of Michigan.”
 - **In references:** “Health and Retirement Study. Produced and distributed by the University of Michigan with funding from the National Institute on Aging (grant numbers U01AG009740, RC2AG036495, and RC4AG039029), Ann Arbor, MI.”

5. Data Security

The User shall store and use all supplied and derived datasets only within a secure computing environment that complies with the approved dbGaP or NIAGADS data protection plans.

6. Indemnification

- a. To the extent permitted by law, the Accessing Agency assumes all liability for damages which may arise from its use, storage, disclosure, or disposal of the Data.
- b. U-M shall not be liable for any loss or damages, except as otherwise provided by law for gross negligence or willful misconduct.
- c. No indemnification for any loss, claim, damage, or liability is intended or provided by either Party under this Agreement.

7. Cross-Reference File

- a. The cross-reference file may be used solely to link HRS genomic data to HRS public data for statistical analysis and reporting.
- b. The cross-reference file must not be shared or provided to any other party. Note: Each individual member of the research team must sign a separate agreement.
- c. Upon request by HRS, the cross-reference file and all derivatives must be returned or securely destroyed.

8. Prohibition on Commercial Use

- a. HRS genomic data may not be used for commercial purposes. For those affiliated with a commercial entity, use of the data must be strictly limited to research.
- b. HRS will not approve uses subject to consulting or licensing obligations to other institutions, corporations, or business entities.
- c. Approval does not confer or grant patent rights (existing or future) or rights to future use.
- d. If User affiliation is with a commercial entity, use of these data must be restricted to research purposes. Users with a commercial affiliation must attach a description of the intended use of these data as Attachment A “Research Plan”, and this description is incorporated by reference to this agreement.

9. Prohibition of AI and Large Language Model (LLM) Use

The use of AI programs and LLMs—particularly open-source AI—is **prohibited** in conjunction with HRS data. This restriction is in place to protect the confidentiality of HRS data and prevent unauthorized sharing; only individuals with a valid HRS Data Access Agreement may have access. Information regarding the current HRS policy on use of AI and Large Language Models can be found at <https://hrsdata.isr.umich.edu/data-products/ai-llm-use-policy>

10. Agreement Limitations & Termination

- a. This Agreement is contingent upon, and subject to, the requirements of the approved dbGaP or NIAGADS data access application. Expiration or cancellation of the dbGaP or NIAGADS user agreement immediately nullifies this Agreement.
- b. HRS reserves the right to terminate this Agreement immediately and without notice in the event of any breach of its terms by the User or Receiving Entity, including but not limited to unauthorized disclosure, misuse of data, or noncompliance with data security protocols.
- c. Upon expiration or termination of this Agreement, or upon request by HRS, the User and Receiving Entity shall immediately cease using all HRS data, destroy or return any datasets and derivative files as instructed by HRS, and certify in writing to HRS that such destruction or return has been completed.
- d. Expiration, revocation, or non-renewal of relevant institutional approvals or permissions (including IRB approval, if required) will result in immediate termination of this Agreement.

11. Term

This Agreement will become active on the date of the last signature below (“Effective Date”) and will continue for ten (10) years. Extensions to the Agreement may be granted upon the request from the Receiving Entity.

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12. Authority

The Receiving Entity Representative, identified below, warrants that they possess the authority to enter this contractual agreement on behalf of the Receiving Entity.

Project Information

	REQUEST #		APPROVAL DATE
dbGaP		dbGaP Date	
NIAGADS		NIAGADS Date	
Requestor (PI)		PI Affiliation	
Project (Title)			

Signatures

By signing below, each party certifies that they have read, understood, and agreed to abide by the provisions of this Agreement.

USER**Receiving Entity Representative**

Signature/Date
Typed Name
Title
Institution
Building Address
Street Address
City, State, Zip
Phone
Email

Signature/Date
Typed Name
Title
Institution
Building Address
Street Address
City, State, Zip
Phone
Email

Instructions: Attach this completed, signed agreement to your Genomic Data Cross-Reference Request Form.

NOTE: Users affiliated with a commercial entity must attach a description of the intended use of these data, labeled as 'Attachment A: Research Plan'.