**LEADS Data Use Agreement**

I request access to data collected by the Longitudinal Early-Onset Alzheimer’s Disease Study (LEADS) for the purpose of scientific investigation or the planning of clinical research studies and agree to the following terms.

1. I agree to comply with all the elements of the LEADS Data Sharing and Publications Policy.
2. I will receive access to de-identified data and will not attempt to establish the identity of or attempt to contact any of the LEADS subjects.
3. I will not attempt to make direct contact with LEADS PIs or staff at sites concerning the specific results of individual subjects.
4. I will not further disclose these data beyond the uses outlined in this agreement and my data use application and understand that redistribution of data in any manner is prohibited.
5. I will require anyone on my team who utilizes these data, or anyone with whom I collaborate on the analyses of these data, to comply with this data use agreement.
6. I will accurately provide the requested information for persons who will use these data and the analyses that are planned to use these data.
7. I will respond promptly and accurately to annual requests to update this information.
8. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.

If I would like to submit an abstract using data and analysis from LEADS, I agree to the following:

1. I will cite LEADS as the source of data and the LEADS funding sources in the abstract as space allows.
2. I will send the abstract to the LEADS Data Sharing and Publications Committee at least one week prior to submission deadline. I will acknowledge LEADS in the authorship line of the abstract as requested in the LEADS Data Sharing Policy.

If I would like to publish a manuscript using data from LEADS, I agree to the following:

1. On the by-line of the manuscript, after the named authors, I will include the phrase “for the LEAD study\*” with the asterisk referring to the following statement:

\*Data used in preparation of this article were obtained from the Longitudinal Early-onset Alzheimer’s Disease Study (LEADS). As such, the LEADS investigators contributed to the design, implementation, collection, and sharing of data but did not participate in analysis or writing of this report (unless otherwise indicated). A complete listing of LEADS investigators can be found at (Insert Link to LEADS publication acknowledgement list)

1. I will include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the LEADS personnel. Depending upon the length and focus of the article, it may be appropriate to include more or less than the example below, however inclusion of some variation of the language shown below is mandatory.

Data used in the preparation of this article were obtained from the Longitudinal Early-onset Alzheimer’s Disease Study (LEADS) database. The LEADS was launched in 2018, led by Principal Investigators Liana Apostolova, MD, Brad Dickerson, MD, Gil Rabinovici, MD, and Maria Carrillo, PhD. The primary goal of LEADS is to measure baseline and longitudinal cognitive, behavioral and functional characteristics, imaging biomarkers, fluid biomarkers, genetics, and neuropathology between early-onset Alzheimer’s disease (EOAD) and late onset Alzheimer disease (LOAD) patients. For up-to-date information, see <https://leads-study.medicine.iu.edu/>

1. I will acknowledge funding by the LEADS in the support acknowledgement section of the manuscript using language similar to the following:

Data collection and sharing for this project was funded by National Institutes of Health Grant U01 AG057195 and Alzheimer’s Association Grant LEADS GENETICS-19-639372.

1. I will submit all manuscripts to the LEADS Data Sharing and Publications Committee prior to submitting to a journal. This review will not be a scientific review but is intended to ensure that the items above are correctly implemented. The publication committee will maintain confidentiality of the manuscript and will complete its review within 2 weeks.
2. New data generated through analyses of LEADS datasets must be returned to the Executive Committee at the time of submission of the manuscript for review by the Data Sharing and Publications Committee for possible inclusion in the project database or into another NIH‐approved government database such as dbGap or NIAGADS. A six‐month embargo will be placed on returned data to allow publication of results.
3. I will ensure that Investigators who utilize LEADS data use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.
4. I will report any use or disclosure of the data not provided for by this Agreement of which I become aware within 15 days of becoming aware of such use or disclosure.

IMPORTANT NOTE: It is the policy of the Longitudinal Early-Onset Alzheimer disease Study to make analyzed data available to investigators as quickly as possible. However, data analysis for this project is expected to take years as methods for analysis of these datasets evolve. Therefore, I understand that any processed data that I download might be preliminary and that results may change as new methods of analysis are implemented. I will familiarize myself with the analysis methods so that I am aware of the limitations of these data prior to using them for scientific purposes.

Finally, because “preliminary data” will be posted on the database, in the event that I download data from the LEADS database for the purposes of analysis and future publication in the form of abstracts and/or publications, I will note the date and version of the data I download, and I will check the database to determine if updated data has been provided prior to submission of any material for publication.

I understand that failure to abide by these guidelines will result in termination of my privileges to access LEADS data.

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