

Alzheimer's Disease Neuroimaging Initiative (ADNI) DATA USE AGREEMENT

I request access to data collected by the Alzheimer's Disease Neuroimaging Initiative (ADNI) for the purpose of scientific investigation, teaching or the planning of clinical research studies and agree to the following terms.

- 1. I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact any of the ADNI subjects.
- 2. I will not attempt to make direct contact with ADNI PIs or staff at sites concerning the specific results of individual subjects.
- 3. 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.
- 4. I will require anyone on my team who utilizes these data, or anyone with whom I share these data to comply with this data use agreement.
- 5. I will accurately provide the requested information for persons who will use these data and the analyses that are planned using these data.
- 6. I will respond promptly and accurately to annual requests to update this information.
- 7. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data.

If I publish abstracts using data from ADNI, I agree to the following:

- 8. I will cite ADNI as the source of data and the ADNI funding sources in the abstract as space allows.
- 9. Acknowledgement of ADNI will not be cited in the authorship line of the abstract.

If I publish manuscripts using data from ADNI, I agree to the following:

10. On the by-line of the manuscript, after the named authors, I will include the phrase "for the Alzheimer's Disease Neuroimaging Initiative*" with the asterisk referring to the following statement and list of names:

*Data used in preparation of this article were obtained from the Alzheimer's Disease Neuroimaging Initiative (ADNI) database (adni.loni.usc.edu). As such, the investigators within the ADNI contributed to the design and implementation of ADNI and/or provided data but did not participate in analysis or writing of this report. A complete listing of ADNI investigators can be found at:

http://adni.loni.usc.edu/wp-content/uploads/how_to_apply/ADNI_Acknowledgement_List.pdf

[For manuscripts that use metabolomics data generated by the Alzheimer's Disease Metabolomics Consortium (ADMC) in the by-line of the manuscript, after the named authors, I will include the phrase "for the Azheimer's Disease Metabolomics Consortium**" with the double asterisk referring to the following statement and list of names;

ADNI Alzheimer's Disease Neuroimaging Initiative

**Data used in preparation of this article were generated by the Alzheimer's Disease Metabolomics Consortium (ADMC). As such, the investigators within the ADMC provided data but did not participate in analysis or writing of this report. A complete listing of ADMC investigators can be found at: <u>https://sites.duke.edu/adnimetab/team/</u>.

11. I will include language similar to the following in the methods section of my manuscripts in order to accurately acknowledge data gathering by the ADNI 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 Alzheimer's Disease Neuroimaging Initiative (ADNI) database (<u>adni.loni.usc.edu</u>). The ADNI was launched in 2003 as a public-private partnership, led by Principal Investigator Michael W. Weiner, MD. The primary goal of ADNI has been to test whether serial magnetic resonance imaging (MRI), positron emission tomography (PET), other biological markers, and clinical and neuropsychological assessment can be combined to measure the progression of mild cognitive impairment (MCI) and early Alzheimer's disease (AD). For up-to-date information, see <u>www.adni-info.org</u>.

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

Data collection and sharing for the Alzheimer's Disease Neuroimaging Initiative (ADNI) is funded by the National Institute on Aging (National Institutes of Health Grant U19 AG024904). The grantee organization is the Northern California Institute for Research and Education.

In the past, ADNI has also received funding from the National Institute of Biomedical Imaging and Bioengineering, the Canadian Institutes of Health Research, and private sector contributions through the Foundation for the National Institutes of Health (FNIH) including generous contributions from the following: AbbVie, Alzheimer's Association; Alzheimer's Drug Discovery Foundation; Araclon Biotech; BioClinica, Inc.; Biogen; Bristol-Myers Squibb Company; CereSpir, Inc.; Cogstate; Eisai Inc.; Elan Pharmaceuticals, Inc.; Eli Lilly and Company; EuroImmun; F. Hoffmann-La Roche Ltd and its affiliated company Genentech, Inc.; Fujirebio; GE Healthcare; IXICO Ltd.; Janssen Alzheimer Immunotherapy Research & Development, LLC.; Johnson & Johnson Pharmaceutical Research &Development LLC.; Lumosity; Lundbeck; Merck & Co., Inc.; Meso Scale Diagnostics, LLC.; NeuroRx Research; Neurotrack Technologies; Novartis Pharmaceuticals Corporation; Pfizer Inc.; Piramal Imaging; Servier; Takeda Pharmaceutical Company; and Transition Therapeutics.

Metabolomics Consortium (ADMC) will include the following language: Data collection and sharing for this project was funded by the Alzheimer's Disease Metabolomics Consortium (National Institute on Aging R01AG046171, RF1AG051550 and 3U01AG024904-09S4).



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- 13. I will submit all manuscripts to the ADNI Data and Publications Committee (DPC) prior to submitting to a journal. This review will not be a scientific review, but is intended to ensure that items 7-12 above are correctly implemented. The DPC will maintain confidentiality of the manuscript and will complete its review within 2 weeks.
- 14. I will ensure that Investigators who utilize ADNI data use appropriate administrative, physical and technical safeguards to prevent use or disclosure of the data other than as provided for by this Agreement.
- 15. 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 Alzheimer's Disease Neuroimaging Initiative 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 ADNI database for the purposes of analysis and future publication in the form of abstracts and/or publications, I will note the 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 ADNI data.

Electronic Signature of User

