

UNIVERSITY of WASHINGTON

DATA USE AGREEMENT

I REQUEST ACCESS TO DATA collected by the National Alzheimer's Coordinating Center (NACC). I make this request for the purpose of scientific investigation, teaching, or planning of clinical research studies. In making this request, I agree to the following terms:

- I will receive access to de-identified data and will not attempt to establish the identity of, or attempt to contact, any of the NACC subjects. Further, I will not attempt to identify specific Alzheimer's Disease Research Centers (ADRCs), unless NACC has approved such identification as part of my project's protocol.
- 2. I understand that **distributing these data in any manner to a third party is strictly prohibited**, and therefore I will not distribute these data beyond the uses outlined in this agreement. A third party is defined as anyone who is not a collaborator or co-author on the analysis defined in my proposal that has been submitted to NACC.
- 3. I will require anyone on my team who uses these data (i.e., any collaborator or co-author on the analysis defined in the proposal that I have submitted to NACC) to comply with all the terms of this Data Use Agreement. If I receive an unrestricted data set for non-commercial entities and non-commercial research projects, I understand that I am strictly prohibited from sharing these data with collaborators associated with commercial companies for use by that company.
- 4. I will respond promptly and accurately to NACC requests for updates on the status of my analysis.
- 5. I will comply with any rules and regulations imposed by my institution and its institutional review board in requesting these data, and I will report any use or disclosure of NACC data not permitted by this Agreement. The report, containing full details of the breach, will be made by email to naccmail@uw.edu within 15 days of my becoming aware of such use or disclosure.
- 6. I acknowledge that NACC data **do not constitute a population-based sample** but rather are best thought of as a case series.
- 7. I will review the data documentation provided by NACC and consult with NACC research scientists to ensure the accurate use and description of NACC data in my analysis, as well as to ensure the understanding of subtle data complexities such as missing data, loss to follow-up, and differences due to form version changes.
- 8. I understand that **any data I download may change** as new quality assurance measures are implemented and data records are updated.

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

- 1. I will acknowledge the NACC grant number, and the ADRCs as the source of the data, in the abstract.
- 2. I will submit my abstract to the NACC Publications System for tracking purposes.
- 3. I will acknowledge the NACC grant and Center support by including the statement provided below, in any resulting poster or presentation.

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

1. I will acknowledge the NACC grant and Center support by including the following statement in the acknowledgments section of the manuscript:

The NACC database is funded by NIA/NIH Grant U24 AG072122. NACC data are contributed by the NIA-funded ADRCs: P30 AG062429 (PI James Brewer, MD, PhD), P30 AG066468 (PI Oscar Lopez, MD), P30 AG062421 (PI Bradley Hyman, MD, PhD), P30 AG066509 (PI Thomas Grabowski, MD), P30 AG066514 (PI Mary Sano, PhD), P30 AG066530 (PI Helena Chui, MD), P30 AG066507 (PI Marilyn Albert, PhD), P30 AG066444 (PI John Morris, MD), P30 AG066518 (PI Jeffrey Kaye, MD), P30 AG066512 (PI Thomas Wisniewski, MD), P30 AG066462 (PI Scott Small, MD), P30 AG072979 (PI David Wolk, MD), P30 AG072972 (PI Charles DeCarli, MD), P30 AG072976 (PI Andrew Saykin, PsyD), P30 AG072975 (PI David Bennett, MD), P30 AG072978 (PI Neil Kowall, MD), P30 AG072977 (PI Robert Vassar, PhD), P30 AG066519 (PI Frank LaFerla, PhD), P30 AG062677 (PI Ronald Petersen, MD, PhD), P30 AG079280 (PI Eric Reiman, MD), P30 AG062422 (PI Gil Rabinovici, MD), P30 AG066511 (PI Allan Levey, MD, PhD), P30 AG072946 (PI Linda Van Eldik, PhD), P30 AG062715 (PI Sanjay Asthana, MD, FRCP), P30 AG072973 (PI Russell Swerdlow, MD), P30 AG066506 (PI Todd Golde, MD, PhD), P30 AG066508 (PI Stephen Strittmatter, MD, PhD), P30 AG066515 (PI Victor Henderson, MD, MS), P30 AG072947 (PI Suzanne Craft, PhD), P30 AG072931 (PI Henry Paulson, MD, PhD), P30 AG066546 (PI Sudha Seshadri, MD), P20 AG068024 (PI Erik Roberson, MD, PhD), P20 AG068053 (PI Justin Miller, PhD), P20 AG068077 (PI Gary Rosenberg, MD), P20 AG068082 (PI Angela Jefferson, PhD), P30 AG072958 (PI Heather Whitson, MD), P30 AG072959 (PI James Leverenz, MD).

- 2. I will **submit my manuscript** to the **NACC Publications System** for the required brief administrative review and for tracking purposes prior to submitting my manuscript to a journal.
- 3. I will ensure the **proper submission of all published work to PubMed Central (PMC)** in order to comply with the NIH Public Access Policy.

I understand that **failure to abide by these guidelines will result in termination of my privileges to access NACC data**. By clicking "Submit" below, I agree to the terms of this Data Use Agreement.