

## AABC Consortium Data Use Terms

I request access to de-identified demographic, clinical, behavioral, imaging and other non-genomic data collected by the Aging Adult Brain Connectome (AABC) Consortium, and I agree to be bound by the following:

1. The provided AABC data (the “Data”) will be used solely for academic research and other not-for-profit scholarly purposes that are undertaken at a non-profit or government institution. The Data may not be sold, licensed, or commercialized in any way. Any commercial use, sale, or other monetization is prohibited.
2. Other than the rights granted herein, Washington University in St. Louis (the “University”), which hosts the data, retains all rights, title, and interest to the Data.
3. I will have access to de-identified data. I will not attempt to re-identify the Data in any way or establish the identity of any of the individuals who are or may be the sources of the Data. In the event that I inadvertently receive identifiable information or otherwise re-identify a subject, I will promptly notify the University in writing, and follow its reasonable written instructions, which may include return or destruction of the identifiable information.
4. I understand that under no circumstances will the code that would link these data to individuals be given to me, nor will any additional information about individual human participants be released to me under these Data Use Terms.
  - a) I acknowledge that the Data are covered by a Certificate of Confidentiality (CoC) from the National Institutes of Health to protect the privacy of enrolled participants. All users of the Data and their institutions are subject to the requirements of the CoC that prohibit the disclosure of protected information for non-research purposes to anyone not connected with the research. The protection of the CoC covers the original Data and all copies shared for other research in perpetuity.
5. I will use the Data only in compliance with all applicable federal, state, and local laws and regulations. I will comply with all relevant rules and regulations imposed by my institution and/or local regulatory bodies. This may mean that I need my research to be approved or declared exempt by a committee that oversees research on human subjects, e.g., my local Institutional Review Board (IRB) or Ethics Committee. It is my responsibility to ensure compliance with institutional policies and applicable law prior to accessing the Data. If needed and upon request, the AABC will provide a certificate evidencing acceptance of the Data Use Terms.
6. I may download a copy of the Data to my local institution for non-commercial research use. However, re-distribution, transfer, or sharing of the Data OUTSIDE of

my institution is NOT PERMITTED without specific prior approval and a separate written agreement.

- a) I may share the Data WITHIN MY INSTITUTION (e.g., on a shared server), as long as that sharing is conducted under these same Data Use Terms. In particular, it is required that EACH INDIVIDUAL that is given access to a local copy of the Data must first become an approved, registered user of the Data with the BALSAs repository and agree to these same Data Use Terms on BALSAs. If I am sharing the Data with others at my institution, I agree that it is my responsibility to ensure that each local user has become an approved, registered user of the Data through the BALSAs repository *prior to granting them local access to the Data*. I agree, if requested for auditing purposes, to provide a list of individuals at my institution that have access to the copy of the Data for which I am responsible.
- b) I agree to store any local copy of the Data with appropriate physical and technical security controls to protect against unauthorized use or disclosure, to ensure that only authorized persons have access to the Data, and to maintain appropriate control over the Data at all times. I also agree to promptly report in writing any unauthorized access, use, or disclosure of the Data not provided for by these Data Use Terms. I also acknowledge and agree that all obligations with respect to downloaded data as set forth in these Data Use Terms survive the termination of the agreement.
- c) Users may create research results and derivative works. The University will have no right, title, or interest in any such research results. Derivative works that represent new, unique results may be distributed under these same Data Use Terms. Users are allowed to re-process the Data if they wish but are encouraged to consult with the AABC since the data released has already been processed carefully using the latest version of the HCP Pipelines being developed as part of the project. However, distribution outside of your institution of alternatively processed versions of the already existing processed Data (i.e., distribution of different forms or variants of data “pre-processing”) is not permitted without written approval from AABC.
- d) The association of specific participant IDs with individual data elements in abstracts, publications, figures, tables, supplemental material, or any other publicly accessible output in which the recipients are not all bound by these same Data Use Terms is not permitted without written approval from AABC. In seeking permission users should describe how such association (1) serves a compelling, necessary scientific purpose (e.g., identifying an outlier that others should consider excluding) AND (2) how the participant ID is associated with only a small number of data elements for that individual so

as to pose no risk that a successful attempt could be made to re-identify the individual from those data elements.

7. I have provided accurate information, including current contact information, as part of my registration for the Data through the BALSAs repository. By registering for an account, I consent to be contacted by the University. The University may use, and I hereby grant the University a non-exclusive, worldwide, perpetual, irrevocable license to use any data I provide to the University, including any personally identifiable information. I will respond promptly and accurately to any requests to update my information. In the event that I move between institutions, I will promptly update my affiliation and contact information with BALSAs prior to moving data between institutions.
8. I will acknowledge the use of the Data in all written, visual, or oral public disclosures using the Data.
  - a. Papers, book chapters, books, posters, oral presentations, and all other printed and digital presentations of results derived from the Data should contain the following wording in the acknowledgments section:
  - b. "Data, methods used, and/or research reported in this [publication/press release/presentation] were provided in whole or in part by the Aging Adult Vulnerability and Resiliency in the Aging Adult Brain Connectome (AABC) project (U19AG073585) and the Human Connectome Project in Aging (HCP-A, U01AG052564) funded by the National Institute of Aging of the National Institutes of Health. HCP-A was further supported by funds provided by the McDonnell Center for Neuroscience at Washington University in St. Louis."
  - c. Authors of publications or presentations using the Data should cite relevant publications describing the methods used by the AABC to acquire and process the data. The specific publications that are appropriate to cite in any given study will depend on what Data were used and for what purposes. An annotated and appropriately up-to-date list of publications that may warrant consideration is available at <https://agingadultbrainconnectome.wustl.edu/research/authorship-program-acknowledgement/>
  - d. The AABC Consortium should not be recognized as a "group/corporate" author in any publications or presentations external to the Consortium.
9. These Data Use Terms do not expire. However, AABC and Washington University in St. Louis reserve the right to terminate and/or amend this agreement if required by changing regulations, a changed interpretation of the regulations, or other changes to the data privacy landscape. In the event that a revision to these Data Use Terms

is deemed necessary, I will have 3 months to agree to the revised Terms; or in the event I do not agree with the revised Terms, I agree to cease any further use of the Data, and to return or destroy all previously downloaded copies of the Data, and any derived derivatives, except that I may retain a secure copy of the minimum data necessary to comply with institutional scientific data retention policies.

10. Failure to abide by these Data Use Terms will result in termination of my privileges to access and use the Data. In the event of a material breach of these Data Use Terms, I agree to abide by a request from the AABC PIs or the University that all previously downloaded copies of the Data, and any derived derivatives, be returned or destroyed, and will certify that in writing. I acknowledge that my institution may also be contacted and informed that I have violated these Data Use Terms if I do not comply with them.
  
11. I ACKNOWLEDGE AND AGREE THAT THE AABC DATA ARE PROVIDED “AS IS” WITH NO WARRANTIES OF ANY KIND, EXPRESS OR IMPLIED, INCLUDING BUT NOT LIMITED TO WARRANTIES OF MERCHANTABILITY, FITNESS FOR A PARTICULAR PURPOSE, OR THAT THE USE OF THE DATA WILL NOT INFRINGE ANY PATENT, COPYRIGHT, TRADEMARK, OR OTHER PROPRIETARY RIGHTS. THE UNIVERSITY AND AABC CONSORTIUM WILL HAVE NO LIABILITY WHATSOEVER ARISING FROM MY ACCESS OR USE OF THE DATA.
  
12. I acknowledge that the BALSAs repository will keep a record of my download activity linked to my account for audit purposes. I waive any right for my download history to be anonymous, forgotten, or deleted.
  
13. I certify that I am a qualified researcher at an academic, non-profit, or government institution, have provided a valid institutional email address when registering for AABC data access on BALSAs, and will use the AABC Data only for non-commercial research that I will conduct at this institution.

Click box at bottom of the Data Use Terms:

"I Agree"