



BIOCARD – Biomarkers of Cognitive Decline among Normal Individuals: the BIOCARD Study

BIOCARD Data Use Agreement

To protect the confidentiality of study participants, the BIOCARD Informatics Core has taken several steps in order to de-identify the data distributed to outside investigators. A new set of study IDs have been generated specifically for these data, images and biospecimen. Data records are free of the personal identifiers specified in section 164.514(b)(2)(i) of the Federal Privacy rule. Indirect identifiers that could potentially compromise the anonymity of participants are suppressed in all datasets released for public use (e.g., date of birth). These de-identified data resources, and associated documentation, are available to users under the conditions specified in this data use agreement.

I am requesting access to de-identified data, brain images, and/or biospecimen collected by BIOCARD investigators for the purposes of scientific investigation, and agree to the following terms:

1. I will receive de-identified data, brain images and/or biospecimen and will not attempt to establish the identity of, or attempt to contact, BIOCARD study participants.
2. I will not contact BIOCARD investigators or staff to discuss individual study participants.
3. I will not disclose BIOCARD data, brain images, and/or biospecimen beyond the uses described in this agreement and my data use application, and understand that the redistribution of data, brain images or biospecimen in any manner is prohibited.
4. I will ensure that my co-investigators and other collaborators will comply with this agreement.
5. I will seek local institutional review board approval (or acknowledgment of exemption) for the analysis of BIOCARD data, brain images, and/or biospecimen.
6. If I publish abstracts using BIOCARD data, I will cite the BIOCARD study as a source of the data and in the abstract, as space allows. An acknowledgement in the authorship byline of the abstract is not necessary.
7. If I publish manuscripts using BIOCARD data, I agree to the following:
 - a. On the byline of the manuscript, after the authors names, I will include the phrase 'for the BIOCARD Study team*', with the asterisk referring to the following statement:

*Data used in preparation of this article were derived from BIOCARD study, supported by grant U19 – AG033655 from the National Institute on Aging. The BIOCARD study team did not participate in the analysis or writing of this report, however, they contributed to the design and implementation of the study. A listing of BIOCARD investigators can be found on the BIOCARD website (on the 'BIOCARD Data Access Procedures' page, 'Acknowledgement Agreement' document).

8. On an annual basis, I will provide updates on the progress of my analyses and any resulting publications, so that the BIOCARD study team can report this productivity to the National Institute on Aging. This includes the following:
 - a. I agree to submit any manuscripts derived from the BIOCARD study to the National Institute of Health Manuscript Submission (NIHMS) system. This will assure that publications are in compliance with the NIH public access policies.
 - b. I agree to provide a copy of the accepted manuscript to the BIOCARD study team.
 - c. I agree that if funding results from the use of BIOCARD data, I will provide information about the funded project (s) (i.e., grant title, grant number, sponsor, funding amount, study start and end dates).
9. If any unauthorized use or disclosure of the data, brain images, or biospecimen not provided for by this agreement occurs, I agree to report such disclosure within 15 days of learning of the event.
10. I understand that BIOCARD Study data collection is ongoing and findings may change as additional data, brain images, and biospecimen are collected or analysis methods evolve. I will therefore report the version date assigned to the data, brain images and/or biospecimen I receive in any publications.
11. I understand that a failure to abide by the BIOCARD Data Use Agreement will result in the termination of my privileges to access BIOCARD data.

E-Signature and Date