

Data Use Agreement of the BBRC ALFA Study Dataset

This Data Use Agreement (“Agreement”) governs access to and use of the BBRC (BarcelonaBeta Brain Research Center) **ALFA Study dataset** from the Alfa Study made available to the broader research community via the AD Data initiative’s data platform, the AD Workbench (for approved use/users).

By submitting a data access request for the *ALFA Study Dataset* through the AD Workbench, you agree to be bound by the following terms and conditions. These terms apply to all researchers and institutions that access the ALFA Study Dataset. Submitting a request constitutes acceptance of these terms in full. If you do not agree to these terms, you may not access the Dataset.

All data access requests will be evaluated by the BBRC’s Data Access Committee (DAC). The Committee reserves the right to approve or reject any request at its sole discretion, based on the scientific merit of the proposal, alignment with BBRC’s research priorities, and ethical and legal considerations. Submission of a data access request does not guarantee approval or access to the dataset.

By accepting these terms, I confirm that:

- I am a qualified researcher affiliated with an academic or research institution.
- I become a data processor (as defined under the General Data Protection Regulation - GDPR) and assume responsibility for compliance with these terms and applicable laws.
- My proposed research has received all necessary ethical approvals and institutional authorisations.
- My proposed research complies with all applicable national and international laws and institutional policies.
- My proposed research complies with these Terms of Data Use and the AD Workbench Terms of Use.

1. Purpose and Scope

1.1. I will use the dataset solely for the research objectives described in my approved access request. Any change in scope, methodology, or personnel must be communicated to BBRC in writing and is subject to DAC approval.

1.2. I acknowledge that access is granted for a defined period as specified in the approval notification. Extensions must be requested in writing and approved by the DAC.

1.3. I will comply with all relevant rules and regulations imposed by my institution and my government. These terms never have prevalence over existing general data protection regulations applicable in my country.

2. Participant Protection and Re-identification

2.1. I will not attempt to establish or retrieve the identity of study participants. I will not link these data to any other database in a way that could provide identifying information.

2.2. I shall not request, access, or accept any pseudonymisation keys that would link these data to an individual's personal information, nor will I accept any additional information about individual participants under these terms.

2.3. If I inadvertently identify individuals, I will notify BBRC within 24 hours at **gdpr@barcelonabeta.org** (cc **bbrctestudy@barcelonabeta.org**) and immediately cease any further analysis, use, or disclosure of the information.

3. Data Access and Security

3.1. I will access the dataset exclusively through the AD Workbench virtual environment. I will not download, copy, extract, screenshot, or otherwise reproduce the raw dataset or any portion thereof outside the virtual environment.

3.2. I may download and use secondary research findings or derived results produced from the dataset (e.g., plots, models, summary statistics), provided they are non-identifiable and cannot lead to individual re-identification.

3.3. I will not redistribute these data or share access with others — including individuals in my own institution — unless they have independently applied and been granted access to the dataset.

3.4. I will implement and maintain appropriate technical and organisational measures to safeguard the confidentiality and security of the dataset.

3.5. I will promptly notify BBRC and ADDI of any security breach, unauthorised access, or suspected compromise of the dataset.

4. Prohibited Uses

I agree that the dataset shall not be used:

4.1. For clinical diagnosis or treatment of human subjects or/and In clinical trials involving human participants.

4.2. For any commercial purpose, sale, lease, licensing, or transfer to third parties, unless explicitly authorised under a separate agreement with BBRC.

4.3. For purposes other than my approved research.

4.4. To publish or disseminate the raw dataset itself, whether in whole or in part, including in supplementary materials, data repositories, or appendices.

5. Derived Data

5.1. I may generate derived data (results, statistical outputs, models, scores, or other materials) as part of my approved research.

5.2. Researchers are encouraged to return derived data to BBRC upon completion of their research. If returned, BBRC may use it for research purposes with appropriate attribution. The return of derived data does not affect my right to use it for my own research and publications.

6. Publication and Dissemination

6.1. I will comply with the BBRC ALFA Study Publication Guidelines (provided separately)

7. Intellectual Property

7.1. I acknowledge that all intellectual property rights in the dataset, including any database rights, remain with BBRC.

7.2. I will not seek intellectual property rights over any part of the dataset.

7.3. If new intellectual property arises from the use of the data, and both BBRC and I have contributed technically, BBRC and I shall be co-owners. Any such arrangement will be formalised in a separate agreement. Any research outputs based on the data must not impair other researchers' ability to access or use the data.

7.4. For-profit users: any exploitation, commercialisation, or patent filing based on the dataset or derived data requires a separate agreement with BBRC addressing exploitation rights, benefit-sharing, and cost-recovery.

8. Data Protection and GDPR Compliance

8.1. I acknowledge that the dataset consists of anonymised data, but I will treat it with the same level of protection as personal data under applicable data protection law.

8.2. I will treat the dataset and all associated documentation as confidential information and will not disclose it to any third party except as expressly permitted by these terms. This obligation survives the expiration or termination of my access.

9. Cooperation and Reporting

9.1. I agree to respond truthfully and within 4 weeks to any reasonable inquiries from BBRC regarding the use of the dataset or research progress.

9.2. I understand that BBRC may request written confirmation that no copies of the dataset have been retained outside the virtual environment.

10. Data Retention and Access Expiration

10.1. I understand that access to the dataset will be revoked upon expiration of the access period or termination of access, whichever occurs first. Revocation of access fulfils the data destruction obligation.

10.2. I may retain derived data for the period required by applicable research data retention policies and regulations (typically 5–10 years after publication). Upon expiration of the applicable retention period, I will delete all derived data and confirm deletion in writing to BBRC.

11. Liability and Disclaimer

11.1. I acknowledge that the dataset is provided "as is." BBRC makes no warranties, express or implied, regarding its accuracy, completeness, fitness for a particular purpose, or non-infringement.

11.2. I acknowledge that BBRC shall not be held liable for any claims, damages, or losses resulting from my use of the dataset.

11.3. I assume full responsibility for the interpretation, analysis, and use of the dataset and for any consequences arising therefrom.

11.4. I agree to indemnify and hold harmless BBRC, its directors, employees, and agents from and against any claims, damages, losses, or expenses arising from my breach of these terms or misuse of the dataset.

12. Conflict of Interest

12.1. I will disclose any actual or potential conflicts of interest at the time of my access request and throughout the access period.

12.2. Any conflict of interest that arises during my research will be promptly disclosed to BBRC in writing.

13. Termination

13.1. This agreement is effective from the date of acceptance and remains in force until the conclusion of my research project, expiration of the access period, or until access is terminated.

13.2. BBRC reserves the right to suspend, limit, or revoke my access at any time at its sole discretion, including in the event of any breach of these terms.

13.3. I may voluntarily relinquish access at any time by notifying BBRC in writing, subject to my obligations under Sections 5 (Derived Data) and 10 (Data Retention).

13.4. Upon termination, Sections 2, 4, 5, 6, 7, 8, 9, 10, 11, and 12 continue to apply.

14. General Provisions

14.1. These terms, together with the approved access request and the BBRC ALFA Study Publication Guidelines, constitute the entire agreement governing my use of the dataset.

14.2. These terms supplement, but do not override, the Terms of Use of the AD Workbench. In the event of any conflict between these terms and the AD Workbench Terms, these terms shall prevail with respect to the ALFA Study Dataset.

14.3. These terms are governed by the laws of Spain. Any dispute shall be submitted to the exclusive jurisdiction of the courts of Barcelona, Spain.

14.4. BBRC reserves the right to update these terms. Continued access to the dataset after notification of changes constitutes acceptance of the updated terms.

14. Participant Overlap with Other AD Workbench Datasets

14.1. I acknowledge that the ALFA+ cohort contributed participants to the AMYPAD Prognostic and Natural History Study (PNHS), whose dataset is also available on the AD Workbench. If I have also requested or intend to request access to the AMYPAD PNHS dataset, I am aware that partial participant overlap exists between the two datasets and that this may affect the independence of my analyses. If I require information on the number of overlapping participants or the extent of variable overlap between the two datasets, I will contact BBRC at datarequest@barcelonabeta.org before proceeding.

Acceptance

By clicking “Accept,” I confirm that:

- I have read and understood these Terms of Data Use.
- I agree to comply with all the terms stated above.
- I agree to comply with the BBRC ALFA Study Publication Guidelines and future updates thereof.

Contact

For questions regarding these terms, data access, or the ALFA Study:

bbrstudy@barcelonabeta.org