

# UCSF MEMORY AND AGING CENTER DATA USE AGREEMENT FOR LIMITED DATA SET(S)

This Data Use Agreement (“Agreement”) is between the Memory and Aging Center at the University of California, San Francisco (MAC) and the Data Recipient (noted in Section B) and is effective as of the “Effective Date” (noted in Section H).

Both parties are committed to complying with local, state, and federal laws and regulations (including the Privacy Rule under the Health Insurance Portability and Accountability Act [HIPAA] of 1996 (P.L. 104-191), 42 U.S.C. Section 1320d, et. seq., and regulations promulgated there under, as may be amended from time to time) relating to privacy, security and confidentiality of the Limited Data Set.

## A. Name of Entity Releasing the Limited Data Set

Memory and Aging Center  
Department of Neurology  
University of California, San Francisco  
San Francisco, California  
United States of America

## B. Name of Recipient of the Data Set: \_\_\_\_\_

## C. Preparation of the Limited Data Set

The Limited Data Set provided under this Agreement excludes identifiers as required by the HIPAA Privacy Regulations for the creation of a Limited Data Set and does not contain any of the following elements:

- Names
- Street or postal address, other than town or city, state or zip code
- Telephone numbers
- Fax numbers
- Electronic mail addresses
- Social Security numbers
- Medical record numbers
- Health plan beneficiary numbers
- Account numbers
- Certificate/license numbers
- Vehicle identifiers and serial numbers, including license plate numbers
- Device identifiers and serial numbers
- Web universal resource locators (URLs)
- Internet protocol (IP) address numbers
- Biometric identifiers, including finger and voice prints
- Full face photographic images and any other comparable images

## D. Purpose of Limited Data Set Disclosure

The Recipient of the Limited Data Set (named in Section B above) and the Agents to whom the Recipient provides the Limited Data Set are permitted to use and disclose the Limited Data Set for the following purpose(s)

specifically in the laboratory of its Principal Investigator and members of the laboratory who are under direct supervision of the Principal Investigator:

- Human subjects research *OR* to conduct research for the project titled: \_\_\_\_\_
- Educational activities (i.e., teaching activities, development of clinical guidelines)

## E. Responsibilities of the Recipient

The Recipient of the Limited Data Set (named in Section B above) and the Agents to whom the Recipient provides the Limited Data Set to agree to:

1. Use or disclose the Limited Data Set only as permitted by this Agreement or as required by law.
2. Use appropriate safeguards to prevent the use or disclosure of the Limited Data Set other than as permitted by this Agreement.
3. Ensure that any Agents to whom the Recipient provides the Limited Data Set(s) agree to the same conditions and restrictions on the use and disclosure of the Limited Data Set(s) that apply to the Recipient through this Agreement. Individuals not working directly with the Recipient should obtain the Limited Data Set(s) directly from the MAC at the University of California, San Francisco and complete a Data Use Agreement for Limited Data Set(s).
4. Not attempt to use the information in the Limited Data Set to identify or contact the persons from whom the data originated or their relatives, employers or household members.
5. Accept all responsibility for data analysis, results from analyses and any consequences resulting from breaching study participant privacy in connection with the analysis.
6. Obtain approval from the Recipient's local IRB, if required, before the initiation of any analyses.
7. Cite and acknowledge the MAC Project for the source data set and its funding sources in all abstracts, presentations and publications, using language detailed in the MAC Publication Guidelines (see Appendix A) and make a good faith effort to follow the other provisions of these guidelines.
8. Report any use or disclosure of the Limited Data Set not permitted by this Agreement in writing to the MAC (email [Rosalie.Gearhart@ucsf.edu](mailto:Rosalie.Gearhart@ucsf.edu)) within five (5) days after the Recipient becomes aware of the unauthorized use or disclosure.

## F. Term and Termination

1. **Term.** The term of this Agreement shall commence on the Effective Date (noted in Section H below) and shall continue for a maximum of 18 months or until the number of approved samples have been provided, whichever comes first, *OR* as long as the Recipient and their Agents retain the Limited Data Set, unless terminated sooner as set forth in this Agreement.
2. **Termination by Recipient.** The Recipient may terminate this Agreement at any time by notifying the University of California, San Francisco and returning and/or destroying the Limited Data Set and any copies of the Limited Data Set.
3. **Termination by University of California, San Francisco.** The University of California, San Francisco may terminate this Agreement at any time by blocking the Recipient's access to the MAC online resource management system as well as access to any additional data sets, images and other study materials.
4. **Termination for Cause.** Upon the University of California, San Francisco's knowledge of a material breach of this Agreement by the Recipient (and/or the Recipient's Agents), the University of California, San Francisco shall either provide an opportunity for the Recipient to cure the breach or end the violation *OR* terminate this Agreement if the Recipient does not satisfactorily cure the breach or end the violation within the timeframe set forth and to the satisfaction of the University of California, San Francisco. The University of California, San Francisco may immediately terminate this Agreement if cure is not possible by blocking the Recipient's access to the MAC online resource management system as well as access to any additional data sets, images and other study materials.

## G. Miscellaneous

1. **Regulatory References.** A reference in this Agreement to a section in the HIPAA Privacy Regulations means the section as in effect or as amended.

2. **Amendment.** The Parties agree to take action as is necessary to amend this Agreement from time to time as is necessary for the University of California, San Francisco to comply with changes in local, state and federal laws and regulations relating to privacy, security and confidentiality of the Limited Data Set.
3. **Interpretation.** Any ambiguity in this Agreement shall be resolved to permit the University of California, San Francisco *OR* parties to comply with local, state and federal laws and regulations relating to privacy, security and confidentiality of the Limited Data Set.

## H. Agreement Execution

By signing "I Agree" below, the Recipient is certifying that he/she as well as any Agents to whom the Recipient provides the Limited Data Set, agrees to use or disclose the information contained in the Limited Data Set only as permitted in Sections D and E in this Agreement.

I agree to use or disclose the data only as permitted in this Agreement.

Effective Date of Data Use Agreement: \_\_\_\_\_

Data Recipient (First Name, Middle Initial, Last Name): \_\_\_\_\_

Signature: \_\_\_\_\_

# APPENDIX: CITATION AND ACKNOWLEDGMENT OF THE UCSF MAC

## **A. Required Citation and Acknowledgment of the UCSF Memory and Aging Center Project that was the Source of the Data Set**

As part of the Data Use Agreement, Recipients and their Agents agree that in publications using data from MAC Projects they will acknowledge the MAC Project as the source of the data, including the version number of the data sets used.

1. Meeting abstracts.

*Methods section:* “Data for these analyses are from the UCSF Memory and Aging Center [insert project title].”

2. Papers and journal articles

*Methods section:* “Data used in the preparation of this article were obtained from the UCSF Memory and Aging Center [insert project title] database. Specific data sets used are [version numbers].”

*Acknowledgment:* “This manuscript was prepared using a UCSF Memory and Aging Center [insert project title] data set and does not necessarily reflect the opinions or views of the UCSF Memory and Aging Center investigators, the NIH or the private funding partners.”

3. Presentations

*Methods section:* “Data for these analyses are from a UCSF Memory and Aging Center [insert project title] data set.”

*Acknowledgment:* “This presentation was prepared using a UCSF Memory and Aging Center [insert project title] data set and does not necessarily reflect the opinions or views of the UCSF Memory and Aging Center investigators, the NIH or the private funding partners.”

## **B. Informing the MAC about Publications Based on MAC Project Related Data**

Recipients are requested to inform the MAC of articles published using MAC data so that publications can be tracked. Email Rosalie Gearhart at [Rosalie.Gearhart@ucsf.edu](mailto:Rosalie.Gearhart@ucsf.edu).