



REQUEST FOR MOST RESEARCH DATASET

Attach Data Use Agreement and email to MOSTOnline@psg.ucsf.edu

DATE OF REQUEST: _____

NAME: _____

INSTITUTION: _____

PHONE: _____ EMAIL: _____

DATASET(S) REQUESTED:

MOST Clinical Datasets

- Baseline Telephone Screen and Enrollment Visit (V0ENROLL)
- 15-month Telephone Interview and Clinic Visit (V1ENROLL)
- 30-month Telephone Interview and Clinic Visit (V2ENROLL)
- 60-month Telephone Interview and Clinic Visit (V3ENROLL)
- 72-month Telephone Interview (V4ENROLL)
- 84-month Telephone Interview and Clinic Visit (V5ENROLL)

MOST Endpoints Datasets

- Outcomes: Baseline to 30-month Joint Replacement and Baseline to 60-month X-ray and Death Outcomes (OUTCOMES) – *No longer available*
- Outcomes: Baseline to 60-month Joint Replacement and Baseline to 84-month X-ray and Death Outcomes (OUTCOMES)
- Outcomes: 84-month Joint Replacement (OUTCOMES) – *Not currently available*

MOST Knee Radiograph Assessments Datasets

- Longitudinal Baseline to 30-month PA and Lateral Knee Radiograph Assessments (V012XRAY) – *No longer available*
- Longitudinal Baseline to 60-month PA and Lateral Knee Radiograph Assessments (V0123XRAY) – includes Baseline Full-limb (Hip-Knee-Ankle) Mechanical Alignment Assessments – *No longer available*
- Longitudinal Baseline to 84-month PA, Lateral, and Full-limb (Hip-Knee-Ankle) Mechanical Alignment Knee Radiograph Assessments (V01235XRAY)

MOST Knee MRI Assessments Datasets

- Baseline to 15-month Incident Knee Symptoms Cases and Controls (V01WORMS)
- Baseline to 30-month Subset of Knees with Baseline OA (V02WORMS_BLROA)
- Baseline to 30-month Incident Radiographic OA Cases and Controls (V02WORMS_INCIDENTROA)
- Baseline to 60-month MRI Assessments – *Not currently available*
- Baseline to 84-month MRI Assessments – *Not currently available*

FORMAT REQUESTED:

- SAS® v9.4 (64 bit)
- SAS® transport file
- ASCII text (*Note that descriptive variable and value labels are not available in ASCII text format.*)

SPECIAL REQUEST, COMMENTS, OR QUESTIONS:

HOW DID YOU HEAR ABOUT MOST?:



MULTICENTER OSTEOARTHRITIS STUDY (MOST)

DATA USE AGREEMENT FOR LIMITED DATASET

Email signed and dated form to MOSTOnline@psg.ucsf.edu

This Data Use Agreement is between the Multicenter Osteoarthritis Study (MOST) coordinators at the SF Coordinating Center, UCSF Department of Epidemiology and Biostatistics, and the Recipient (identified in section #6) of a limited research dataset. The agreement is effective on the Effective Date (indicated in section #6).

Both parties are committed to complying with local, state, and federal laws and regulations, including the Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 relating to the protection and privacy of health information and regulation 45 CFR 164.514(e) relating to limited datasets.

1. Name of Entity Releasing the Limited Dataset:

Multicenter Osteoarthritis Study (MOST)

SF Coordinating Center

University of California, San Francisco Department of Epidemiology and Biostatistics
San Francisco, California, U.S.A.

MOST Online (<http://most.ucsf.edu>)

Principal Investigator: Michael Nevitt, Ph.D.

Study Title: Multicenter Osteoarthritis Study (MOST)

Study Sponsor: National Institutes of Health/National Institute on Aging
Grant #: AG19069

Human Subjects Institutional Review Board Federalwide Assurance (FWA):
FWA00000068 University of California, San Francisco

2. Preparation of the Limited Dataset. The dataset provided under this agreement excludes direct subject identifiers, as required by the HIPAA Privacy Rule, and does not contain any of the following elements:

1. Names
2. Geographic subdivisions smaller than a state (including addresses and zip codes)
3. Dates directly related to an individual
4. Telephone numbers
5. Facsimile numbers
6. Electronic mail addresses

7. Social Security numbers
 8. Medical record numbers
 9. Health plan beneficiary numbers
 10. Account numbers
 11. Certificate/license numbers
 12. Vehicle identifiers and serial numbers
 13. Device identifiers and serial numbers
 14. Universal resource locators (URLs)
 15. Internet Protocol (IP) address numbers
 16. Biometric identifiers, including fingerprints and voiceprints
 17. Full face photographic images and any other comparable images
 18. Other identifying numbers directly related to an individual
3. Purpose of Limited Dataset. The Recipient of the dataset, and the agents to whom the Recipient provides the dataset, are permitted to use and disclose the dataset for the following purpose(s):
- o Human subjects research
 - o Educational activities (i.e., teaching activities, development of clinical guidelines)
4. Responsibilities of the Recipient. The Recipient of the dataset, and agents to whom the Recipient provides the dataset, agrees to:
- A. Use or disclose the dataset only as permitted by this agreement or as otherwise required by law.
 - B. Use appropriate safeguards to prevent the use or disclosure of the dataset other than as permitted by this agreement. The Recipient is committed to securing the data using appropriate computer technology and other standard measures, such as password protection, encryption of the data, and access restrictions to computer and data storage areas.
 - C. Ensure that any agents to whom the Recipient provides the dataset (including subcontractors, students, fellows, analysts, etc.) agrees and adheres to the same conditions and restrictions on the use and disclosure of the dataset that apply to the Recipient through this agreement. Individuals not working directly with the Recipient must sign a Data Use Agreement and obtain a dataset by following steps described on MOST Online (<http://most.ucsf.edu>).
 - D. Not use the information in the dataset to identify or contact the research participants from whom the data originated, their relatives, employers, household members, or other related parties.
 - E. Accept all responsibility for data analysis, results from analyses, and any consequences resulting from a breach of research participant privacy in connection with the dataset.

- F. Obtain approval from the Recipient's local Institutional Review Board (IRB), if required for any use or disclosure of the dataset, before the initiation of analyses. Recipient agrees to provide documentation of his/her local IRB approval or exemption to MOSTOnline@psg.ucsf.edu if requested by MOST coordinators.
- G. Cite and acknowledge the Multicenter Osteoarthritis Study (MOST) and its funding source in all abstracts, presentations, and publications, using language detailed in the MOST Guidelines for Publications Using Public Use Datasets available on MOST Online (<http://most.ucsf.edu>), and make a good faith effort to follow the other provisions of these guidelines.
- H. Report any use or disclosure of the dataset not permitted by this agreement in writing to MOSTOnline@psg.ucsf.edu within five days after the Recipient becomes aware of the unauthorized use or disclosure.

5. Term and Termination.

- A. Term. The term of this agreement shall commence on the Effective Date (indicated in section #6) and shall continue for as long as the Recipient and their agents retains the dataset, unless terminated sooner as set forth in this agreement.
- B. Termination by Recipient. The Recipient may terminate this agreement at any time by notifying MOSTOnline@psg.ucsf.edu and destroying the dataset and any copies of the dataset.
- C. Termination by University of California, San Francisco. University of California, San Francisco may terminate this agreement at any time by blocking the Recipients access to additional datasets and other study materials.
- D. 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 a cure is not possible.
- E. Miscellaneous
 - i. Regulatory references. Reference in this agreement to the HIPAA Privacy Rule and regulation 45 CFR 164.514(e) means the regulation as in effect or as amended.
 - ii. 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 the use and disclosure of the dataset.

- iii. Interpretation. Any ambiguity in this agreement shall be resolved to permit the University of California, San Francisco to comply with local, state and federal laws and regulations relating to the use and disclosure of the dataset.
- iv. Agreement Execution. ***By signing below, the Recipient is certifying that he/she, and any agents to whom the Recipient provides the dataset, agrees to use or disclose the information contained in the dataset only as permitted in this agreement.***

6. Recipient Information, Signature, and Effective Date.

Full Name *(Please print)*: _____

Institution: _____

Address: _____

Phone: _____

Fax: _____

Email: _____

Signature: _____

Effective Date: _____