

## **DATA SHARING POLICY**

The data sharing policy reflects both internal and external data sharing concerns.

Internal data sharing relates to the sharing of data between the three sites in the study (UM, CUMC, and Mount Sinai). The study database will reside at Columbia University, where it has been located for the past 21 years. It is necessary to locate the database there as the data collection activities will primarily occur at CU, and there is real-time need for access to the data for monitoring and quality assurance purposes. The UM study statistical programmer will receive updated datasets on a quarterly basis from the CU data manager. The live database will be monitored and maintained by Columbia University Neurology Department IT staff and the study data manager. Use of the dataset for study-related analyses by the three sites will be assigned by the Steering Committee, which includes members of the Data Management Team.

External data sharing relates to requests from external investigators to utilize data collected by NOMAS. NOMAS has a long history of collaborating with external investigators, including provision of data for individual analyses of NOMAS data, meta-analyses in which NOMAS data has been combined with data from other studies, and provision of data for inclusion in competitive grant proposals. We expect that external investigators will continue to request data from NOMAS. The Steering Committee will review and prioritize these requests, and ad-hoc committees may be required to address these requests in further detail. See Data/Resource Sharing Plan for more details on data sharing.