Boilerplate for IRB Amendment to donate data to Platform for Accelerating Genetic Discovery for Cerebrovascular Disease

Based on the consent of the subject, we plan to donate data collected under this protocol to The Platform for Accelerating Genetic Discovery for Cerebrovascular Disease, located at The Broad Institute and Massachusetts General Hospital, created under NIH-NINDS grant 1R24NS092983 – 01 and approved under Partners Healthcare IRB protocol #2015P001017. The goal of the Platform is to establish a central resource for storing, analyzing and sharing genetic, imaging and clinical data collected from patients with stroke in order to maximize the yield of investments made in collecting and genotyping these samples, and ultimately to accelerate the search for novel treatments to prevent and treat stroke.

The data will be stored at The Broad Institute and will never be downloaded by the Platforms’ end users. All data will be de-identified prior to upload and the key to linkage will remain with our institution. All users who are granted access to the Platform will be required to supply their Platform-assigned user name and a password. All analysis performed must be approved by the Platforms’ Steering Committee, which includes Principal Investigators from the International Stroke Genetics Consortium (ISGC). A final results file will be provided for each analysis performed on the Platform. Associated data will not be downloaded by the end user.

The Broad takes active measures, both administrative and technical, to protect the privacy and security of all data stored on the Platform. Protection is imposed and user access will be strictly limited. The Broad use industry best practices to secure their network and all computers within it. This includes, but is not limited to, firewalls, anti-virus software and monitoring. The Broad retains information on all access to data, to insure there has been no unauthorized access.