

Memorandum of Understanding

Topic: Participation in the Epi25K WES/WGS Consortium

Version: Jan, 2016

The Epi25k Consortium represents the unification of various consortia dedicated to the study of epilepsy, including Epi4K, EPIGEN, EuroEPINOMICS, the Epilepsy Phenome/Genome Project, EpiPGX, SANAD, and EpiCURE. Each of these large, multinational projects maintains a DNA repository. The objective of this collaboration is to combine genotype, phenotype, and genomic sequencing data from Epi25K GWAS and genome sequencing (WES and WGS) studies, and to perform joint analyses of these datasets. Participants in this memorandum of understanding (MOU) agree to the following principles:

1. The organizational structure will consist of an Executive Committee and a data access and advisory committee. We will create a centralized database at the Broad Institute for the studies, to which each site will have access.
2. Participants and sites who have access to the centralized database agree that they cannot use the entire dataset on their own, for purposes other than to perform joint analyses pre-approved by the committee.
3. Each site will be able to access and download their own data for further analysis without permission from the broader group.
4. The meta-analysis will be guided by a data advisory committee and the analyses will be implemented by an analytic team determined by the committee. All groups will have access to the data produced by the meta-analysis. No publications or presentations will use these data without consent of all consortium partners.
5. All study decisions will be made by an Executive Committee comprised of the PIs from each study. Decisions will be made by majority vote with each PI's vote being weighted by the number of samples contributed.
6. In principle, we will likely publish under a consortium authorship such as The Epi25K Consortium, with members and their contributions listed in a footnote. However, the Executive Committee will seek to find authorship solutions that acknowledge the effort of junior investigators who have contributed to the project, for example, by having a short author list of juniors followed by the consortium byline.
7. The initial analysis will focus on detection and testing of genetic variants for disease association with epilepsy, focused on rare variant and burden testing.
8. Participants in this MOU are not in any way limited in the use and publication of their own data.
9. All genotype and phenotype data will be kept strictly confidential and will not be made available to individuals outside the consortium without prior agreement of the consortium. The data will not be transferred to any publicly accessible data repository (e.g. dbGAP) without prior permission of the group providing the data, and data sharing and release will follow NIH guidelines.
10. There is a shared commitment to protect the confidentiality of data and to protect the joint analysis activity by insuring that no use of the data can be published in advance of an agreed-upon group publication and/or data release. At the same time we also recognize that each participating group (either individually or as consortia) are actively pursuing follow-up genetic and functional work. Thus, individual parties performing additional experiments on genes identified or replicated in exchanges of data are not in violation of this agreement. However, we reaffirm that results of downstream experiments of genes identified in the meta-analysis cannot be published in advance of meta-analysis release or publication and we affirm a desire that purely genetic confirmation experiments (i.e., typing in additional replication samples) be done as a component of a continued collaboration between our groups.

11. If an invention is generated by a group that directly utilized genotype and phenotype data or results from any other or all consortium participants, under a pre-approved joint analysis plan, that group needs to inform the others in writing. Consortium participants agree that the invention can be assigned to this group's institution for filing and further exclusive commercialization of the discovery, provided that (i) inventorship is properly determined and (ii) an agreement is executed between the commercialization institution and the consortium participants that will provide the right to all participants to perform educational, research and development activities, and will provide to consortium participants a reasonable compensation for their relative contribution, which may be paid as a share of the benefits from the commercialization of the invention in a manner that is proportional with the individual and respective contributions of the number of genotyped samples, after the commercialization institution has recovered all reasonable costs from the filing, development and commercialization process.

You are to indicate your agreement with this MOU via email to _____.