# ClinGen Academic, Non-Profit, and Commercial Collaboration Policy

August 2018

The Clinical Genome Resource (ClinGen) aims to collect phenotypic and clinical information on variants across the genome, to develop a consensus approach to identify clinically relevant genetic variants, and to disseminate information about the variants to researchers and clinicians. NIH-funded grantees are working closely with the National Center for Biotechnology Information (NCBI)'s team (together comprising the ClinGen Consortium) to create a publically-available database to improve the understanding of the phenotypic and functional effects of genetic variants and their clinical value. Please see this announcement about the ClinGen program: http://www.genome.gov/27555151.

We welcome the participation of additional academic, non-profit, and industry collaborators who are interested in developing this *precompetitive* resource provided that each collaborator agrees to these principles:

- **Data Availability.** Gene- and variant-level data including population allele frequencies, pathogenicity determinations, and determinations of clinical actionability will be available through both the ClinGen portal and ClinVar. These data shared with and generated by ClinGen will be made publically available at no cost.

- **Analyses and Curation Contributions**. Contributions to literature curation, disease/gene association efforts, variant level pathogenicity determinations, or other activities undertaken by collaborators are encouraged, and all results will be made freely and publicly available.

- **Individual-level Data Access.** Provided that collaborators apply through the standard controlled-access data request mechanisms and agree to abide by NIH's data sharing policies, all collaborators (academic, non-profit, and commercial) will have access to the individual-level data and resources generated by ClinGen.[1]

- **Non-endorsement.** Collaboration with ClinGen does not imply endorsement of the product or the collaborator by the NIH. While collaborators can cite that they followed ClinGen guidelines, they cannot claim ClinGen endorsement.

- **Non-exclusivity**: Collaborators will not have exclusive agreements with the ClinGen project for any activity they undertake as part of their involvement in the project.

- **Publication**: All collaborators are expected to abide by the ClinGen publication policy. In summary, all project data are made freely available (either publicly or with access controls, depending on the data types) to encourage the community to use ClinVar, ClinGen Curation Interfaces, and the ClinGen website in their research and analyses. Researchers who submit data have the right to publish their own data and work products without approval from the ClinGen Steering Committee. Publications that rely on data or work products from multiple sites, or that make extensive use of ClinGen-generated procedures/guidelines are considered multi-site

[1] NIH Genomic Data Sharing Policy: http://grants.nih.gov/grants/guide/notice-files/NOT-OD-14-124.html.

Please direct all questions to Erin Ramos (ramoser@mail.nih.gov).

projects, and manuscripts should be sent to the ClinGen Steering Committee for approval prior to submission.