

## Data Sharing Policy for Contributors of Data for ClinGen Gene-Disease Clinical Validity Curation

See also: [ClinGen Academic, Non-Profit, and Commercial Collaboration Policy](#)

### Background

ClinGen's Gene Curation working group has developed a [framework](#) to standardize the approach to determine the clinical validity for a gene-disease pair. ClinGen's [Gene Curation Expert Panels](#) (GCEPs) are using this framework to assess the clinical validity of gene-disease pairs across a range of disease areas.

ClinGen welcomes any external data (from clinical diagnostic laboratories, researchers, non-profit organizations etc.) that can facilitate gene-disease clinical validity classification by our GCEPs. This includes curated evidence supporting or contradicting gene-disease relationships, PMIDs etc.

### How will shared data be used?

Shared data will be provided to ClinGen's GCEPs where it may be incorporated into the evidence used to arrive at a clinical validity classification. Approved clinical validity classifications are published on the ClinGen website along with a summary of the data used to support the gene-disease clinical validity classification. Data contributors may be acknowledged on the gene-disease curation summary page and on the ClinGen collaborators webpage, with their prior permission.

### Each data contributor agrees to the following principles

- By providing data to ClinGen, the contributor agrees that the data can be freely used by ClinGen. This does not preclude the original contributor from publishing their own assertions or utilizing their data in any other manner.
- The data contributor affirms that they have the necessary authorizations to share this data with ClinGen and agrees to the data being used as described herein.
- Sharing of data with ClinGen is not a substitute for public data sharing. Although the data may be made public through our website, it will not be in the form in which it was originally submitted to us, and we cannot guarantee if or when the data would be made public. Therefore, if a data contributor is required to make their data public for any reason, such as publication, this should be done independently.
- In general, we do not view such data sharing as constituting a formal collaboration of the data contributor with ClinGen, however, if the contribution of data is conditioned on establishing a formal affiliation with ClinGen, we are happy to discuss this.
- Data contributors must not use the ClinGen logo on their website, or any social media platforms, without prior authorization from the ClinGen Steering Committee.

For further information, and to share data, please contact [clingen@clinicalgenome.org](mailto:clingen@clinicalgenome.org)