

Database	Access?	Multiple Genetic Changes?	Personal Information	Description
GenomeConnect Or Other Registry/Patient Insight Network	Controlled	LINKED	LINKED	<ul style="list-style-type: none"> Private database that only approved registry and ClinGen staff can access. Will include: responses to any questionnaires you complete, information listed on genetic test reports you submit, and your personal contact information. Though your personal information is linked to your profile in the registry, any information that is shared with other databases will NOT include this information.
ClinGen	Controlled	LINKED	UNLINKED	<ul style="list-style-type: none"> Clinical Genome Resource (ClinGen) staff authorized by ClinGen may have access to this data for ClinGen related activities.
ClinVar	Public	UNLINKED	UNLINKED	<ul style="list-style-type: none"> PUBLICLY AVAILABLE database of genetic changes and their reported relationships to human health. Maintained by the National Center for Biotechnology Information (NCBI), a group within the NIH. Available to anyone with internet access, though the most common users are doctors, researchers, and other genetics professionals.

Access? – This column describes whether or not the information in the database is available to the public (PUBLIC) or only to certain individuals (CONTROLLED). In general, people must apply to have access to controlled databases and have a clear defined purpose for having access to this data.

Multiple Genetic Changes? – This column describes what happens if you share more than one genetic change with the registry. There is a small risk that information on multiple genetic changes could be used to identify you. If you have reported more than one genetic change, we will only keep them together, or “LINK” them, when we transfer data to secure, controlled access databases. Data we send to public databases will not indicate that these genetic changes were found in the same person (UNLINKED).

Personal Information? – This column described what happens to your personal information (name, date of birth, etc). Your personal information is only linked to your genetic and health information within the registry – this is so we can contact you if needed. Whenever we share your genetic and health information with others, we UNLINK it from your personal information.