

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 surveys 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.
Matchmaker Exchange Via GeneMatcher	Controlled	Unlinked	Unlinked	<ul style="list-style-type: none"> • Matchmaker Exchange is a federated network of rare disease databases established to facilitates the matching of cases with similar genetic and health profiles to enable rare disease discovery. One connected dataset is GeneMatcher. • GeneMatcher is a resource that enables queries between patients, clinicians, and researchers. GeneMatcher is maintained by the Baylor-Hopkins Center for Mendelian Genomics. • ClinGen shares genes shared by registry participants that are not associated with disease (candidate genes or genes of uncertain significance) with GeneMatcher. • Only gene names are submitted to GeneMatcher and are only accessible if someone inputs a matching query. If someone matches with GenomeConnect, the GenomeConnect team reviews the match request and will only share de-identified genetic and health information.
ClinVar	Public	Linked	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 the information in the database is available to the 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.