

FREQUENTLY ASKED QUESTIONS

How is “genetic information” defined?

Any individual consumer’s DNA sequence data and its interpretations derived from genetic, molecular, or computational analyses (e.g., by genotyping, whole or partial genome sequencing).

What measures are in place to ensure a customer’s personal and genetic data is protected?

Members of the Coalition maintain systems that incorporate security by design and support the security principles of confidentiality, integrity, and availability. All of our security methods employ segregation and encryption of personal information and genetic information in separate databases, each with the strictest limitations on access. In addition, if a customer consents to biobanking (the storage of their physical sample), those samples are securely stored without any personal identifiable information affixed to the sample.

Do you sell customer data to third parties?

We do not sell, lease or share individual-level customer information without explicit user consent. We also do not provide genetic information to insurance companies or employers without explicit user consent.

Do your companies send any of its customers’ genetic data to China for processing?

No. And in fact, all our member companies only work with U.S.-based laboratories to process customers’ genetic data.

How do your companies deal with law enforcement?

We never share customer data with law enforcement unless we receive a legally valid request such as a search warrant or written court order. Upon receipt of an inquiry from law enforcement, we use all practical legal measures to challenge such requests in order to protect our collective customers’ privacy. In addition, our companies voluntarily publish transparency reports that are available on our public websites and detail the number of valid law enforcement requests we receive, and whether or not customer data has been disclosed.

Do your companies conduct research using your customers’ genetic data?

When purchasing an at-home genetic test from our companies, customers have the option to share their de-identified (no personal identifiable information associated) genetic data for scientific research. The scientific research is monitored and approved by an Institutional Review Board (IRB) and customers must explicitly consent to the use of their data for research purposes. A customer may also withdraw from research at any time.

Why is federal legislation needed?

Currently, there is a patchwork of policies at the state-level. We would instead welcome comprehensive privacy legislation at the federal level, so that we have a uniform set of rules by which to abide. The Coalition will provide a single voice on these issues, to ensure consumer trust and continued innovation.