

Privacy Best Practices for Consumer Genetic Testing Services

This document provides highlights from FPF's Privacy Best Practices for Consumer Genetic Testing Services, published in July 2018. The Best Practices were produced in coordination with 23andMe, Ancestry, Helix, and other leading consumer genetic and personal genomic testing companies.

Promotes Transparency

- Provides a publicly available high-level overview of key privacy protections
- Provides educational resources about the basics, risks, benefits, and limitations of genetic and personal genomic testing
- Requires transparency reporting detailing law enforcement requests for genetic data on at least an annual basis

Provides Consumer Choices

- Requires detailed express consent for collection and use of Genetic Data
- Requires separate express consent for transfer of Genetic Data to third parties and incompatible secondary uses
- Requires informed consent for internal research and for transfer of Genetic Data to third parties for research purposes
- Requires notice and consent for material changes to the policy and transfer of ownership
- Provides the right to access, correction, and deletion

Enhances Protections

- Bans the sharing of Genetic Data with third parties (such as employers, insurance companies, educational institutions, and law enforcement) without consent or as required by law
- Restricts marketing based on Genetic Data
- Requires valid legal process for disclosing Genetic Data to law enforcement
- Provides a process for the handling of Genetic Data in the case of a consumer's death or incapacitation
- Requires that the individual submitting the Biological Sample or the Genetic Data is the owner or include reasonable steps to ensure that consent has been obtained from the owner of the Biological Sample or Genetic Data
- Requires strong data security and privacy by design