



NATIONAL CONSUMERS LEAGUE OUTLINES GENETIC PRIVACY RIGHTS

Genetic data is unique to each individual and remains unalterable for life. Unlike a password or a Social Security number, our DNA sequence is distinguished by the fact that it cannot be modified – even if it has been compromised. This places greater importance on prevention measures given the limited solutions available once unwanted parties have access to someone’s DNA information.

NCL believes that informed consent is critical to any effective privacy regime. Unfortunately, many consumers consent to DNA sequencing without understanding the risks. Should the data leave the processing company, it could allow for discrimination based on individual’s’ genetic data. From private entities (like insurance companies and employers denying persons with traits deemed unfavorable) to public bodies (like governments and law enforcement using DNA to track ethnic minorities and political opponents), the potential for misuse is practically limitless.

Given the growing threat of access to genetic databases by state entities (including foreign adversaries like China), the need for stronger consumer protections in this field have become acute. The Chinese government alone could potentially access millions of individuals’ DNA records through BGI, one of the world’s largest genetic data processors. BGI’s connections with the Chinese military, alongside a Chinese national security law that could compel organizations to assist in state intelligence efforts, should concern all consumers.

Domestically, the U.S. government is already accessing these genetic databases for the purposes of law enforcement—something which NCL asked for investigation into three years ago. Unfortunately, it appears that many domestic actors still utilize genomic data without consumers’ knowledge or consent. Such breaches of privacy at home and abroad require immediate action to implement consumer protections for the processing and storage of genetic data.

INDIVIDUALS' GENETIC PRIVACY RIGHTS

● RIGHT TO GENETIC DATA CONFIDENTIALITY

Genetic data is unique to each person and cannot be changed, even once compromised. The potential for discrimination and surveillance using these records demands extreme care when handling this information. Given these facts, confidentiality is critically important. Consumers have the right to complete confidentiality of their genetic data, meaning their data will be treated with the utmost care and respect for consumers' privacy rights. Consumers should be confident that their genetic data will not be used by business entities and domestic or foreign governments for any use beyond the reason it was collected in the first instance or for access, deletion, or portability purposes initiated by the consumer.

● RIGHT TO ACCESS GENETIC DATA RECORDS

Understanding what sensitive information is being held and may be viewed by others is necessary for individuals to take appropriate precautions. Therefore, consumers must have the right to access records concerning their own genetic data in an accessible and easy-to-understand format, including record of all entities that have accessed that genetic data.

● RIGHT TO DELETE GENETIC DATA RECORDS

The permanence of genetic data makes the right to full data deletion necessary. Consumers' ability to delete any genetic data records a company, government, or other entity controls must be easily exercised. For example, if a consumer takes an at-home DNA test, they should also be able to delete their data from home, rather than traveling to a facility.

● RIGHT TO GENETIC DATA RECORD PORTABILITY

Genetic data belongs to the individual who produced it, not the data servicer. Therefore, consumers have the right to genetic data record portability, allowing consumers to easily change data facilities (or cease all processing and storage services completely).

● RIGHT TO ETHICAL USE

The vast potential for the application of genetic data is still being explored. Consumers have the right to know that their genetic information is being used ethically. Unethical uses of genetic data, such as for military, surveillance, or similar purposes, should be explicitly prohibited.

● RIGHT TO GENETIC DATA PROTECTIONS FROM FOREIGN ADVERSARIES

Successive, bipartisan administrations and the Congressionally-chartered National Security Commission on AI have both issued warnings about China's attempts to obtain the genetic data of U.S. citizens through both legal and illegal means. Consumers who share their genetic data should be protected from that data being obtained by countries deemed by the U.S. government to be "foreign adversaries" of the United States.