



2021 Public-Private Analytic Exchange Program  
Evolving Cyber Legal Landscape

Direct-to-Consumer Genetic Testing (DTC-GT)

# IS YOUR FAMILY TREE AT RISK?

How to protect yourself, your family, and future generation's genetic privacy.

Educate Yourself | Mitigate The Risk | Elevate Safeguards

## Educate Yourself



Genetic Testing reveals the highly specific “DNA coding” of who you are. DNA (deoxyribonucleic acid) carries the information about how a living thing looks and functions and determines such things as eye color and body type.



Direct-to-Consumer Genetic Testing (DTC-GT) companies can take saliva or a cheek swab, extract the DNA, process it, and “decode” a lot of information about you. They can determine your family heritage, confirm family relations, and identify genetic markers for disease, addictions, and more.



What happens to your information after they send out your results? It can be copied and sold to researchers like universities and pharmaceutical companies, or accessed by third-party entities including law enforcement. As with any digital information, it could be exposed in a data breach.



### The Most Valuable Thing You Own

- Your DNA contains highly personal details of your past, present and potential future.
- Your genetic code can detect if you are prone to addiction and some diseases, which can dictate treatment options and enable tailored healthcare delivery.



### Safeguard Your Information

- Fingerprints are just one marker of a person's identity, but your DNA contains numerous markers.
- Genetic testing is not only sharing your DNA, but your family, relatives, and future generations, and cannot be undone.



### Be an Informed Consumer

- Choose a company with strong privacy protections that emphasizes informed consent and lets you control what happens after testing.
- Ask about the testing company's partnerships and data sharing agreements and read the fine print.

## Mitigate The Risk



The best mitigation is education. Do your research and ask questions before you use a genetic testing company to make sure concerns are addressed. Knowledge of different genetic testing companies will allow you to take control of your information.



Comprehensive legislation does not exist to protect DNA data, require informed consent for its use, and remedy potential risks. Contact your elected officials to enlist their participation in protecting consumer DNA information.



If you've already provided your DNA for genetic testing and are concerned about the risks, protecting your data may be difficult. Some steps may help mitigate the risks to yourself, your family, and future generations. Consider the following measures.



### Who Else Has Your DNA?

- At present, there are few restrictions on sharing consumer DNA data.
- Find out if (and with whom) your genetic testing company will share “their” DNA data.
- You cannot replace or change your DNA, unlike a credit card.



### Just Delete It

- Ask your genetic testing company to delete or return your physical and digitized DNA information.
- The deletion process will vary by company; but be persistent. Your efforts can prevent your data from being misused, stolen, or sold.



### Talk to Friends and Family

- Family and friends considering genetic testing services may not be aware of the risks. Mitigate the risks to yourself and others by educating them.
- Help them become informed consumers. They may be moved to take precautions after hearing your concerns.

## Elevate Safeguards



There is a legislative imbalance providing limited restrictions on what DTC-GT companies can do with consumer data. Currently, comprehensive legislation governing the industry within the United States does not exist.



There are no federal requirements for companies to obtain consumers' consent to share or sell collected genetic information. International transparency guidelines – related to confidentiality, privacy, and secondary use of data – are also lacking.



Law enforcement is currently able to use warrants to obtain genetic data from DTC-GT companies, and can even use this data to identify family members of the DTC-GT consumers, who are not a part of the database.



### Maintain Data Authenticity

- Some companies allow users to upload previously acquired DNA data to their databases.
- Malicious actors could “catfish” for information whereby “matches” could allow them to deduce personal information on unsuspecting members.



### Shed Light on Business Practices

- Companies should provide consumers adequate and explicit information about privacy and the implications of genetic testing, disclosing health information and their policy on releasing data to third parties.



### National Security

- Acquisition of DTC-GT companies (through mergers or sales) by foreign entities poses a risk to the genetic data of the DTC-GT consumers.
- We must guard against large amounts of U.S. population genetic data being collected by foreign adversaries.



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## 2021 Public-Private Analytic Exchange Program (AEP)

This program enables U.S government analysts and private sector partners to gain a greater understanding of how their disparate, yet complementary, roles can work in tandem to ensure mission success. Participants work to create joint analytic products of interest to both the private sector and the U.S. Government.

Sources for additional information

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YuLin B.

This product was produced by AEP participants, including

YuLin Bingle, Champion  
Tamara E.  
Donna H.  
Nicholas R.

Joshua Medeiros  
Jazmin Perez  
Jeff H.  
K. Lostoski

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