

Uncover Your Heritage This National Genealogy Month - But Be Aware of the Personal Privacy Risks

This October marks National Genealogy Month, a time to celebrate and explore our family histories. With the help of genetic ancestry services, it's easier than ever to uncover our roots and learn more about our heritage. But before you dive in, it's important to be aware of the potential risks associated with sharing your genetic data.

"Many people are using genetic ancestry services to learn more about their family histories and potentially their health risks," said Neil Richards, the Koch Distinguished Professor in Law and director of the Cordell Institute for Policy in Medicine & Law at Washington University. "However, sharing your genetic data with these services does come with risks."

According to the experts at the Cordell Institute, here are some issues that should be considered before taking a saliva test and enrolling in a genealogy service.¹

Data Privacy and Security: Once your DNA is out there, there's no taking it back. There's always a risk, however small, of a data breach. If the company's database is hacked, your genetic information could be exposed.²

Third-party Sharing: Some companies may share your data with third parties, either in aggregated or individual formats, for research or other purposes. Even if you've consented, you might not be fully aware of how your data is being used.³

Law Enforcement Access: In some cases, law enforcement agencies have sought access to genetic databases to help solve crimes. While this can be seen as beneficial, it might raise concerns for some about privacy and unintended consequences.⁴

¹ Lauren Kirchner, *DNA Dagnet: In Some Cities, Police Go from Stop-and-Frisk to Stop-and-Spit*, PROPUBLICA (Sept. 12, 2016, 8:00 AM), <https://www.propublica.org/article/dna-dagnet-in-some-cities-police-go-from-stop-and-frisk-to-stop-and-spit>; Ayyan Zubair, *DNA Dagnets*, SURVEILLANCE TECH. OVERSIGHT PROJECT (Oct. 15, 2019), <https://www.stopspying.org/latest-news/2019/10/15/dna-dagnets>.

² Sasaha Romanosky et al., *Empirical Analysis of Data Breach Litigation*, 11 J. OF EMPIRICAL LEGAL STUDIES 74, 74-76 (2013).

³ *United States v. Miller*, 425 U.S. 435, 440 (1976) (finding no expectation of privacy in financial records held by a bank); *Smith v. Maryland*, 442 U.S. 735, 745 (1979) (finding no expectation of privacy in records of dialed telephone numbers conveyed to telephone company).

⁴ Andrea Roth, *"Spit and Acquit": Prosecutors as Surveillance Entrepreneurs*, 107 CALIF. L. REV. 405, 417 (2019)

Health and Life Insurance Implications: There's a concern that insurance companies could potentially use genetic information to determine coverage or rates, though in many jurisdictions, there are laws in place to prevent this. Still, the potential for misuse exists.⁵

"It's important to be aware of the potential risks associated with sharing your genetic data," says XXXX "But with the right precautions, you can still enjoy the benefits of exploring your family history this National Genealogy Month."

At the Cordell Institute, we are dedicated to helping people protect their private healthcare data. For more information, visit us at www.cordellinstitute.wustl.edu .

About The Cordell Institute for Policy in Medicine and Law

Founded at Washington University in St. Louis, the Cordell Institute focuses on the interdisciplinary relationship between medicine, healthcare information, and the law. The Institute aspires to become an internationally recognized voice and resource in ethical health and human information policy. Its mission addresses the societal benefits of advancing research and discovery into human wellness and disease while promoting and protecting privacy and autonomy.

⁵ Anya E.R. Prince et al., *Genetic Testing and Insurance Implications: Surveying the US General Population about Discrimination Concerns and Knowledge of the Genetic Information Nondiscrimination Act (GINA)*, 24 RISK MANAGEMENT & INSURANCE REVIEW 341 (2021).