



**Overview:** Genealogy has always involved discovering and airing family secrets, but DNA testing poses more immediate risks of disclosing secrets not just from the far distant past but those of living people. How do we use this 21st century tool in the most ethical way for all those impacted?

## INTRODUCTION

Handling family secrets, tales of living people, crediting others' work: the ethical challenges of family history in the twenty-first century can be daunting. And no area of family history poses more ethical questions than genetic genealogy—dealing with the secrets locked away in our very genes. While researching families has always raised the risk of revealing secrets from the past, the immediacy of DNA testing and its implications for disclosing the secrets of those living now—whether they have tested or not—creates unique ethical challenges: how do we use this new tool in a way that lives up to the ethical standards of our field?

Ethical standards are still being developed for this field. The *Genetic Genealogy Standards* (2015) began the move towards standards, and that goal was greatly advanced by the addition of DNA-specific provisions by the Board for Certification of Genealogists to the Genealogist's Code of Ethics (2018, amended 2020) and to its best practices guide, *Genealogy Standards* (2019, amended 2020). But even as formal standards are developed, there is one rule all genealogists can agree to follow: the Golden Rule—treating others the same way we would want to be treated ourselves. Whether it's in understanding and working with the law that governs DNA testing generally or in understanding and working with genealogical ethics as applied to DNA testing, that rule by itself will cover us in many if not most of the situations in which we as genetic genealogists find ourselves.

## DNA AND THE LAW

One concern people have with DNA testing is what the law says about it. Can our DNA results be used against us? Do we have any right to privacy? Are there laws or rules

about what DNA testing is allowed? What do we tell a cousin when we ask that cousin to DNA test? The Golden Rule says we must tell the cousin the truth as we know it and as we'd want that cousin to tell us if our roles were reversed. **Informed consent is the key to ethical DNA testing.**

*DNA and the law generally:* Until very recently it seemed that the DNA tests we use for genealogy had little to do with the DNA research that helps solve crimes. DNA for crime-solving looks for the kinds of markers that make each individual different from everybody else, while DNA for genealogy looks for the kinds of markers that make people alike because of shared heritage. Because DNA tests for genealogy aren't done under controlled conditions (no police officer there watching the test, for example), the results can't be used directly in a court of law. Today, however, it is known that public DNA databases are being actively mined for forensic purposes, to find leads to the family to which a criminal suspect or crime victim belongs. Although more work is needed to link a specific individual, the methodology now is well-known and the risk must be considered.

*The Genetic Information Nondiscrimination Act (GINA):* This 2008 federal statute provides that our DNA results can't be used by employers (with 15 or more employees) or health insurers to discriminate against us. The 2013 amendment to federal privacy rules under the Health Insurance Portability and Accountability Act (HIPAA) also broadened the reach of GINA so that our DNA results can't be used against us by almost any type of health provider. As with any law, GINA can always be amended and protections that now exist may be expanded or repealed.

*State protection for DNA information:* Many states have even broader protections for DNA information than the federal government has. As of 2020, 49 states had laws protecting against discrimination in health insurance, 35 against employment discrimination, and 41 had laws relating directly or indirectly to the privacy of genetic information.

*Regulation of medical genetics:* Use of DNA testing in medical research is regulated by the federal Food and Drug Administration to ensure that results reported by testing companies are accurate and based on valid testing.

## **DNA AND GENEALOGICAL ETHICS**

The bigger concern for us as genealogists is what we can, and should, do ethically with our DNA results and those of cousins whose results match our own. Here, the Golden Rule must be the guide: we must not act in a way that we wouldn't want someone else to act about our results.

*Permission to submit sample:* All DNA companies require that DNA samples be submitted **only** by the person whose DNA is to be tested or by another individual who has the legal authority to act on behalf of that person. A parent has the authority to submit a sample for a minor child; a person who has specific permission has the authority to submit a sample from the person giving permission. But legal authority is relatively narrow: a grandparent does not have legal authority to submit a sample for a grandchild. No-one should submit a sample for someone else without permission, and forging someone else's signature on a permission slip is wrong – and illegal.

*Permission to share results:* At the most, permission slips required by the testing companies give permission for the company to share test results with others who match the person whose sample is tested. These signed permission slips do not give the matches permission to **reshare** that information with others in any public forum, such as on a website or in another type of public database. Specific permission should be secured before publishing to any third person that we share a DNA match with another individual. In particular, even if we paid for a DNA test for a cousin or relative, we must understand that the DNA belongs to another person, and we should be careful not to disclose those results to third persons unless we have permission to do so. This includes even sharing screen shots of our own results when they identify others.

*Attention to disclosures inherent in results:* DNA tests can reveal information that no paper trail discloses: an undocumented adoption, for example, or the fact that someone long believed to be a parent or grandparent has no biological relationship to a child or grandchild at all. This raises two ethical concerns – (1) making sure the person who is testing understands that this kind of information **will** be revealed and (2) making sure we are very circumspect in sharing results of this nature with anyone other than those directly affected (and, even with those people, in a careful, non-public way unless specific permission to disclose is given).

*Refraining from “DNA bullying”:* In her post “No (DNA) Bullying” (#6 on the resource list), *DNAeXplained* blogger Roberta Estes describes a host of actions that go beyond merely asking for participation in DNA testing and cross over into behavior that should be regarded as bullying. Asking a cousin whose DNA we need to solve a genealogical mystery in our heritage to test at our expense is fine; blackmailing that cousin to get a sample after the cousin has refused to test is bullying. Asking a match to share genealogical information to help identify a common ancestor is appropriate; stalking that match to home or office after the match has declined to share information is bullying.

## RESOURCES FOR FURTHER RESEARCH

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18. MyHeritage DNA. "Terms and Conditions." <http://bit.ly/legalgen0046>
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20. National Human Genome Research Institute. "Genetic Discrimination" (including discussion of federal genetic nondiscrimination statute). <https://www.genome.gov/10002077>
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**All URLs verified as of 20 Jan 2022**

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