

Informed Consent for DNA: Decisions, Decisions, Decisions and Sharing DNA

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INTRODUCTION

It is a lot more fun to talk about DNA tools and analysis techniques than terms of service and consent forms. However, recent developments in our community make it important that we all understand consent agreements, terms of service, ways others can use our shared DNA data, and potential revelations associated with those results.

Since 2015, our community has supported *Genetic Genealogy Standards* aimed at researchers and related to ethical and privacy issues.¹ The Future of Privacy Forum recently released *Privacy Best Practices for Consumer Genetic Testing Services* aimed at testing companies.² Informed consent is an important concept for ethics, standards, and best practices for sharing DNA data and information found in family history documents. This article summarizes some of those issues, focused on DNA, that are even more important than determining the identity of an ancestor. DNA test results are less understood than traditional data from documents, but both can reveal situations affecting the living.

WHAT IS INFORMED CONSENT

¹All URLs accessed on 1 August 2018.

Genetic Genealogy Standards (<http://www.geneticgenealogystandards.com/>).

²Future of Privacy Forum, *Privacy Best Practices for Consumer Genetic Testing Services* (<https://fpf.org/wp-content/uploads/2018/07/Privacy-Best-Practices-for-Consumer-Genetic-Testing-Services-FINAL.pdf>).

Original publication:

Wayne, Debbie Parker. "Informed Consent for DNA: Decisions, Decisions, Decisions and Sharing DNA" *Stirpes* 57 (September 2018): 18-22; online

(http://debbiewayne.com/pubs/pub_stirpes_201809_consent.pdf).

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Medical ethicists teach that, “Based on the ethical principle of respect for persons, the goal of informed consent is to ensure that subjects are aware of the risks and potential benefits and make a voluntary decision about participating in the research.” The traditions of informed consent are sometimes in conflict with the need for shared information to enable discoveries. The need to “balance the obligation to respect and protect research participants with the larger social interest” may require changes in our traditional methods.³ Now that so many DNA tests are taken by genealogists, those of unknown parentage, and those curious about their ethnicity after seeing television commercials, we must understand the implications of the test results we are sharing so freely.

In the simplest form, informed consent means you understand what you are sharing, how that shared information may be used, how that information may affect others, and you freely agree to share that information. When we ask others to take a DNA test to advance our genealogical research, we *must* provide enough information to allow that person to make an informed decision. After all, it is *their* DNA we are asking for. It is their decision as to how that information should be used, if at all. We should not force, coerce, or mislead anyone when asking for a DNA sample.

Several genealogists have created sample forms that can be used when asking a person to take a DNA test. These have Creative Commons licenses allowing you to modify the forms as needed or your own use.⁴

GENEALOGY AND FAMILY HISTORY INFORMATION FROM GENEALOGICAL DNA TESTS

With DNA evidence, we can

³ Amy L. McGuire and Laura M. Beskow, “Informed Consent in Genomics and Genetic Research,” *Annual Review of Genomics and Human Genetics* (2010 Sep 22) 11: 361–381, doi: 10.1146/annurev-genom-082509-141711.

⁴ Debbie Parker Wayne, “DNA Analysis Consent Forms” *Deb’s Delvings*, 28 September 2017 (<http://debsdelvings.blogspot.com/2017/09/dna-analysis-consent-forms.html>). Also, Blaine Bettinger, “Informed Consent Agreement and Beneficiary Agreement,” *The Genetic Genealogist*, 15 February 2018 (<https://thegeneticgenealogist.com/2018/02/15/informed-consent-agreement-and-beneficiary-agreement/>).

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- find cousins we can collaborate with as we research to extend our family trees further back
- find cousins whose DNA corroborates whether our documentary research has linked families correctly
- find cousins whose DNA refutes that documentary research (in which case we may discover misattributed parentage due to false or incorrectly interpreted documentary evidence; that evidence may be for recent generations or several generations back in time)
- find out that we or a family member have a close biological relative we did not know of or have not claimed before (this can include children switched at the hospital, men that were never informed they had fathered a child, formal and informal adoptions, donor-conceived children, and so many other situations)

The possible unexpected findings from a DNA test should be considered before testing. In some cases, the DNA evidence may refute long-held family legends about ancestors. This can alienate some relatives who want that legend to be true—most of us enjoy being related to famous persons or favorite persons in our tree. When that favorite ancestor is many generations back in our tree and we find we are not really related, the emotional impact on living persons may be strong, but most people will cope with the emotions. When misattributed parentage in recent generations is uncovered, the emotional impact can be devastating to living persons. Finding out that the parent or sibling one has lived with since birth is not a biological relative is difficult for most people to handle. Most people may think “this won’t happen in my family,” but studies have found there is a one to two percent rate of misattributed parentage per generation.⁵ That makes it probable many of us will find misattributed parentage somewhere in our families.

Before asking someone to take a DNA test, discuss the potential for such discoveries and whether the test taker wants to know the results no matter what may be discovered. The test taker should also understand that his or her DNA test results may have an impact on other family members—the test taker may be the child of the parents-of-record, but a sibling may share only one of those parents. The test taker is the person who should make an

⁵ Larmuseau, et al., “Low historical rates of cuckoldry in a Western European human population traced by Y-chromosome and genealogical data,” *Proceedings of the Royal Society B*, 280 (December 2013), (doi: 10.1098/rspb.2013.2400).

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informed decision as to how he or she wishes to proceed, taking into consideration the effects on the family and others. The researcher requesting someone else take a test should not be the one making these decisions.

SCIENTIFIC AND MEDICAL RESEARCH FROM GENEALOGICAL DNA TESTS

Many DNA testing companies wish to use our DNA data for scientific and medical research. Most test takers probably gloss over the Terms of Service and Consent Forms without carefully reading them. This is a mistake if the test taker is concerned about privacy and how the test results may be used by others. With all of the companies, useful genealogical information is only available if the test taker allows the test results to be compared to others test takers in the company database. This will result in a match list of “cousins” who share some amount of DNA with each other. This is the most basic information we use to further genealogical research with DNA findings. Most companies give more information on the location of the shared segments allowing more in-depth analysis of the DNA. Some small number of test takers opt-out of DNA matching with relatives after seeing the test results.

Some opt-out of sharing for medical and other non-genealogical research purposes. The companies have different policies on sharing the DNA data with research partners and others. These policies are defined in the Terms of Service and Consent Forms. *The terms and partners can also be changed so test takers should periodically review the terms to determine whether or not they still wish to participate.*

Generally, identifying information is stripped and DNA results of many test takers are aggregated before sharing with medical and scientific research partners. However, it may be possible for others to identify a test taker if enough facts are provided. This happened a few years ago with the *Personal Genome Project*.⁶

⁶ Adam Tanner, “Harvard Professor Re-Identifies Anonymous Volunteers in DNA Study,” *Forbes* (<https://www.forbes.com/sites/adamtanner/2013/04/25/harvard-professor-re-identifies-anonymous-volunteers-in-dna-study/#3de864c92c9b>).

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Most research groups do not provide any information to the test takers who allow their DNA data to be used for medical and scientific research projects. As more in-depth tests, such as whole genome sequences, are used for research, scientists may discover some actionable medically-significant DNA markers; most will not inform test takers when such a significant discovery is made that may impact a test taker's life. To many, this does not seem to be the right way to proceed, but some test takers may not understand these implications. Laws and regulations covering these situations should be developed along with procedures to help lay-persons understand the implications and how to discuss this with medical care providers. Our world is changing and we must educate ourselves to keep up.

FamilyTreeDNA, so far, is the only company with a stated policy that the DNA results of test takers will not be used in any other way unless the test taker is contacted and asked for additional consent for a specific use.⁷ *FamilyTreeDNA* provides easy ways for a test taker to share the DNA data, if preferred, by joining projects. They no longer support mtDNAcommunity, Ysearch, and mitoSearch, which used to allow DNA test results to be uploaded no matter which testing company had been used.

23andMe has always focused on medical research, allowing test takers to opt-in, if desired, to sharing data with partners performing the research and to participate in surveys to provide information to the researchers. Recently, *23andMe* decided to work with only one "big pharma" company, *GlaxoSmithKline*.⁸ Most test takers may prefer to continue working with *23andMe* even if their DNA data is not being widely shared with more research partners. Others may prefer to find more participative places where the DNA data can be shared instead of restricting the value to one company. That is an individual choice and neither choice is right or wrong.

7 "FamilyTreeDNA Privacy Statement," *FamilyTreeDNA* (<https://www.familytreedna.com/legal/privacy-statement>).

8 "A Note On 23andMe's New Collaboration with GSK," *23andMe* (<https://blog.23andme.com/news/a-note-on-23andmes-new-collaboration-with-gsk/>). Also, "GSK and 23andMe sign agreement to leverage genetic insights for the development of novel medicines," *GSK* (<https://www.gsk.com/en-gb/media/press-releases/gsk-and-23andme-sign-agreement-to-leverage-genetic-insights-for-the-development-of-novel-medicines/>).

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AncestryDNA has several research partners defined on their website.⁹ Test takers may opt-in to share DNA data with the research partners.

AncestryDNA used to preset the choice to opt-in, and may still do so. Test takers should carefully read all consent forms before choosing to opt-in.

FindMyPast recently formed a partnership with *LivingDNA*.¹⁰ *LivingDNA* does not seem to list their research partners; their terms also state the test takers agree to indemnify the company.¹¹

MyHeritage does not currently list any research partners, but in the past they have made offers to customers based on DNA findings, matches, and previously purchased products.¹²

Some sites that are not testing companies also allow DNA data sharing for genealogical, scientific, medical, and now, law enforcement research.

DNA.Land is a database created to allow test takers to share their DNA data for research. It is a “not-for-profit and run by the Erlich and Pickrell labs affiliated with Columbia University and the New York Genome Center.”¹³ Contributors have access to some genealogical tools in exchange for allowing scientists access to the data for other research.

GEDmatch is a database created to allow genealogists access to family trees (via uploaded GEDCOM files) and DNA analysis tools. Law enforcement agencies have recently begun using GEDmatch databases and this notice was added to inform users of this development:

“[GED
match]® Tools for DNA & Genealogy Research
April 28, 2018 While the database was created for genealogical
research, it is important that GEDmatch participants understand the

9 “AncestryDNA Research and Collaboration,” *AncestryDNA*
(<https://www.ancestry.com/cs/collaborations>).

10 “Living DNA and FindMyPast Announce Partnership,” *LivingDNA*
(<https://www.livingdna.com/press-releases/334/findmypast-and-living-dna-announce-partnership>).

11 “Research Consent,” *LivingDNA* (<https://www.livingdna.com/research-consent>). Also,
“Terms & Conditions,” *LivingDNA* (<https://www.livingdna.com/terms-conditions>). Also,
“Privacy Policy,” *LivingDNA* (<https://www.livingdna.com/privacy-policy>).

12 “MyHeritage Privacy Policy,” *MyHeritage*
(https://www.myheritage.com/FP/Company/popup.php?p=privacy_policy).

13 “Terms of Consent,” *DNA.Land* (<https://dna.land/consent>).

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possible uses of their DNA, including identification of relatives that have committed crimes or were victims of crimes. If you are concerned about non-genealogical uses of your DNA, you should not upload your DNA to the database and/or you should remove DNA that has already been uploaded. Users may delete their registration/profile and associated DNA and GEDCOM resources. Instructions are available. Click here to find more information.”

GenBank ® is the U.S. National Institutes of Health (NIH) genetic sequence database, an annotated collection of all publicly available DNA sequences.¹⁴ Genealogists have primarily donated full mitochondrial DNA sequences for scientific studies. (See Ian Logan’s tools to format mtDNA data for submission.¹⁵) Now that whole genome sequences are becoming more affordable, it may be possible to donate these in the future. No identifying information is included with the DNA data submissions. Contributors do not receive any direct benefits, but may identify their sequence number listed in scientific papers.

As DNA testing becomes more popular and profitable, new companies seem to pop up every week. Before sending your DNA sample or DNA data to any company, it is smart to investigate that company and also to be sure it is located in a country where you feel comfortable sending your DNA.¹⁶

LAW ENFORCEMENT INVESTIGATION FROM GENEALOGICAL DNA TESTS

*Forensic Files*¹⁷ has long been a popular television show, along with all of the other crime scene investigation shows that have proliferated these last twenty or so years. These shows illustrate how DNA has become a staple of law enforcement. Years ago the FBI developed the CODIS database which stores the DNA marker profiles taken from offenders in the U.S.¹⁸

14 “GenBank Overview,” *GenBank, NCBI, NIH* (<https://www.ncbi.nlm.nih.gov/genbank/>)

15 “Submitting a Complete Sequence (FGS) to GenBank,” *Ian Logan* (<http://www.ianlogan.co.uk/submission.htm>).

16 “List of DNA testing companies,” *ISOGG Wiki* (https://isogg.org/wiki/List_of_DNA_testing_companies).

17 *Forensic Files*, *CNN* (<https://www.cnn.com/shows/forensic-files>).

18 “Frequently Asked Questions on CODIS and NDIS,” Criminal Justice Information Service, FBI (<https://www.fbi.gov/services/laboratory/biometric-analysis/codis/codis-and-ndis-fact-sheet>).

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Genealogists have long wondered why law enforcement does not use the type of autosomal DNA tests used for genealogy even if it would require an extension of the CODIS database. Genealogy tests cover many more markers than those in the CODIS database and the price for tests is lower.

Recent publications include a plethora of articles about how law enforcement is now solving cold cases uses genealogy databases.¹⁹ Investigation into recent cases also now use genealogy databases.²⁰ Instead of developing their own databases to cover the extensive markers tested by genealogy tests, investigators took a short cut. They are using public genealogy databases that already contain millions of DNA profiles and the same techniques used by genealogists and adoptees to find ancestors and biological relatives.²¹

The informed genealogists using *GEDmatch* and any other sites to which DNA test results are uploaded for DNA analysis must explain to DNA test takers that the DNA results may be used by law enforcement. Many are happy if their DNA can help catch a criminal. Others are worried about the possible misinterpretation of the DNA resulting in accusations of innocent people.

CONCLUSION

Our world is rapidly changing with others making more uses of the DNA data we use for genealogy and family history. As researchers, we must

19 Roberta Estes, "The Golden State Killer and DNA," *DNA-eXplained*, 20 April 2018 (<https://dna-explained.com/2018/04/30/the-golden-state-killer-and-dna/>). Also, Seth Augenstein, "'Buck Skin Girl' Case Break Is Success of New DNA Doe Project," *Forensic Magazine*, 16 April 2018 (<https://www.forensicmag.com/news/2018/04/buck-skin-girl-case-break-success-new-dna-doe-project>). Also, Antonio Regalado and Brian Alexander, "The citizen scientist who finds killers from her couch," *MIT Technology Review*, 22 June 2018 (<https://www.technologyreview.com/s/611529/the-citizen-scientist-who-finds-killers-from-her-couch/>).

20 Antonio Regalado, "Genetic genealogy is now solving recent crimes, not just cold cases," *MIT Technology Review*, 30 July 2018 (<https://www.technologyreview.com/the-download/611748/genetic-genealogy-is-now-solving-recent-crimes-not-just-cold-cases/>).

21 Sarah Zhang, "How a Tiny Website Became the Police's Go-To Genealogy Database," *The Atlantic*, 1 June 2018 (<https://www.theatlantic.com/science/archive/2018/06/gedmatch-police-genealogy-database/561695/>).

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understand how our data is being used, whether we wish to consent to those uses or decline to use some sites or tools, and how to explain this to others when we ask them to take a DNA test for us. We should be obtaining written permission forms from test takers for our own use and protection, not just asking test takers to sign the forms a company requires for the test.

Debbie Parker Wayne, CG, CGL, is experienced using DNA analysis as well as more traditional techniques for genealogical research in Texas, the South and the West. She coordinated the first genetic genealogy courses at the three major U.S. genealogy institutes and is the Texas State Genealogical Society's DNA Project director. She wrote the NGS *Continuing Genealogical Studies: Autosomal DNA* course and co-authored the first genetic genealogy workbook, *Genetic Genealogy in Practice*, published by NGS. See <http://debbiewayne.com/> for more information.

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