



Ancestry DNA Testing and Privacy: A Consumer Guide

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Council for Responsible Genetics

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This consumer guide will help people who are considering purchasing an ancestry genealogy test kit or who have already done so to understand their rights and their risks and to know the limits of the information they obtain. It will walk you through the science, business and privacy issues, so you can make informed decisions about whether to pay for such tests for yourself or others and so that, even if you never take such a test, you can understand how the use of such testing may impinge on, or improve your life.

DNA Ancestry Testing: Some Basics

As of 2017 the International Society for Genetic Genealogy listed thirty nine companies throughout the world that provide DNA ancestry tests directly to consumers in what are called direct to consumer (DTC) genetic testing.¹ By that year it was estimated that one million people had already sent their DNA samples to be tested by these companies. The first company to offer a genetic ancestry test to consumers in 2000 was Family Tree DNA.² Some of the early DNA ancestry companies formed after 2000 have been absorbed in other companies that do a broader range of testing. DTC genetic testing includes medical genetics, paternity tests and ancestry testing. As described in the *American Journal of Human Genetics*: “After the consumer orders the test, the testing company sends a sample collection kit (e.g. buccal (cheek) swab or blood-spot collection). The consumer sends back the sample, and the company performs the test and sends a test report via the Internet or the mail.”³

A 2008 report of the Congressional Research Service pointed out that “since [2000] this [Ancestry] testing has grown in popularity, especially among African Americans attempting to learn more about their history and culture.”⁴ According to Shriver and Kittles (2004), “genealogical research has become the fastest growing hobby in many communities in the

United States.”⁵ Ancestry DNA is reported to have the largest consumer DNA database and by February 2017 had sequenced the DNA of over 3 million people.⁶

There are two different views of ancestry used in the tests: biogeographical ancestry and lineage ancestry.

Biogeographical Ancestry means that one’s ancestry is determined by the geographical location of one’s ancestors, if they could be traced back through a millennium. Since there are no DNA data for people living thousands of years ago, biogeographical ancestry is inferred by comparing one’s proprietary genetic markers with contemporary populations living in those regions. This is called a reference database. All DNA ancestry companies use reference databases to infer a person’s ancestry from their DNA profile. For biogeographical ancestry, each company has its own proprietary database called Ancestry Informative Markers (AIMs) and thus the tests are not standardized. Consumers may get different results for the percentage of their ancestry in different regions of the world. The AIMs panels are derived from databases of Single Nucleotide Polymorphisms (SNPs). Estimates of genome ancestry depend on the number of AIMs used.⁷

The AIMs panels only trace ancestry by accessing a small portion of a person’s genome—maybe 2 percent. The tests may disclose that someone has 50 percent African lineage in that 2 percent of the DNA, but it does not tell you about the other 98 percent of the DNA. Even if the 2 percent of your DNA shows 50 percent African lineage, it does not mean that your ancestry is recently African.

According to one source: “those percentages we see in our autosomal DNA results that suggest how much of our autosomal DNA we’ve inherited from ancestors who lived in different places around the world 500 or 1000 (or even more) years ago...And because of the fact that the

only way to get these percentages is by comparing folks like you and me — alive today — to the test results of other people who are alive today (and not to the actual DNA of our ancient ancestors!!), the science may never really be there.”⁸

The development of Ancestry Informative Markers through high speed genotyping of single nucleotide polymorphisms (SNPs) has contributed to the growth of ancestry testing companies. The reason AIMs are used is that they exhibit large differences in selected DNA sequences (alleles) between populations from different geographical or ethnic groups. According to one study by Pardo-Seco et al. (2014), ancestry analysis using greater than 400 AIMs does a reasonably good job of predicting biogeographical regions, while those analyses using a few dozen AIMs show a large variability in ancestry estimates.⁹

But the AIMs proprietary databases companies use to infer ancestry claims, such as, 30% European and 70% African, are questionable. As Duster (2009) notes: “The public needs to understand that those reference populations comprise relatively small groups of contemporary people. Those groups’ samples may have migrated over several centuries, and thus those researchers must make many untested assumptions in using these contemporary groups to stand as proxies for populations from centuries ago, whether putatively representing a continent, a region, or a linguistic, ethnic or tribal group...Given these intractable barriers to even low-level probabilistic reliability geneticists are on thin ice telling people that they do or don’t have ancestors from a particular people.”¹⁰

The field of Ancestry DNA is growing rapidly with new methods constantly under development to improve accuracy. For example, a project titled Ancestry Composition is described by a scientist at 23andMe as offering “high precision and recall for labeling chromosomal segments across over 25 different populations worldwide.”¹¹ The different

proprietary databases held by companies, however, until they are available to the scientific community and validated raise questions about the confidence in their findings.

Lineage Ancestry is the process of tracing one's paternal or maternal lines of descent by different components of DNA. For maternal lineage testing mitochondrial DNA is used, which is carried across generations through the mother. For paternal lineage testing, the Y chromosome unique to males is used. For example, one company uses a few hundred single point mutations in the Y chromosome that have appeared, we are told, over the past 50,000 years to identify Haplogroup (genetic populations sharing a particular DNA sequence believed derived from a common ancestor on the patrilineal or matrilineal line) trees that reveal the migrations of large groups. These tests only trace ancestry by accessing a small portion of a person's genome—maybe 2 percent. The tests may disclose that someone has 50 percent African lineage in that 2 percent of the DNA, but it does not tell you about the other 98 percent of the DNA. Even if the 2 percent of your DNA shows 50 percent African lineage, it does not mean that your ancestry is recently African.

Much has been written about the quality and validity of the tests. There are no quality assurance guarantees for any of the commercial DTC DNA ancestry tests.¹² A New York Times story by Ron Nixon gave the reporter's personal experience engaging with several DNA ancestry testing companies. "The tests trace only a few of a customer's ancestors and cannot tell exactly where ancestors might have lived, or the specific ethnic group to which they might have belonged."¹³

As noted by Shriver and Kittles (2004), for tracing back African-American heritage, "the best that personalized genetic histories can do is to compare marker-lineages in today's African-

Americans to present day African populations.”¹⁴ Today’s markers do not necessarily match the markers of 400 years ago during the African colonization and enslavement period.

Different companies may reach different conclusions about one’s DNA ancestry because they use different AIMs panels. Each of these commercial databases is proprietary and not open to scholars for analysis, therefore making it difficult to validate results. According to the American Society of Human Genetics (ASHG), even the best databases are a “woefully incomplete” sampling of the human genetic diversity of a biogeographical region.¹⁵ Ancestry testing, according to the ASHG, is an inexact science and inferences are made because the company makes a choice about the type of ancestry to examine.

A caution to consumers who may be given inflated confidence in advertisements that claim to give them scientific evidence of their ancestry by percentages is expressed in this scientific finding.¹⁶

Caution should be exercised when inferring ancestry using AIM panels. The concept of ancestry is a complex one and although it can be operational for particular purposes, it can lead to erroneous perceptions of human variability. As stated by Sankar and Cho [41]: “ the appearance of clustering is a function of how populations are sampled, of how criteria for boundaries between clusters are set, and of the level of resolution used. In the same way that the earth can be described by many different kinds of maps from topological to economic so, too can the naturally occurring genetic variation among populations be divided in numerous ways and be made to highlight any chosen similarity or difference”

This conclusion is particularly important for the general public, who is often not aware of the limitations of ancestry DNA tests; and also in police investigation, where over-interpretation of an ancestry test could have important consequences on the investigation of forensic DNA evidence.

Since direct to consumer genetic tests were first introduced, privacy concerns have been raised. Ancestry clients send their swabbed cells as well as personal data to a company. Their DNA sequences are kept on file along with personal data.¹⁷ Among the privacy issues are: who gets access to the DNA and personal information?; is the DNA sample kept after the DNA is

sequenced?; can the company sell the information?; can the criminal justice system access the information?; what third parties can be affected if the information becomes available to others?; does the company have a research arm that would place the private information into a research database?; can information that has been anonymized be de-identified and what protections do consumers have against this?

Wallace et al. (2015) noted: “Given expertise, resources and will, it is possible to re-identify individuals from anonymized family history data suggesting that procedures such as name removal and encoding are not sufficient to protect against privacy breaches.”¹⁸ For example, in cases where a researcher knows the family tree information associated with an “anonymized” record, the record can be de-anonymized. There is also evidence that consumers do not pay much attention to privacy issues and sign consent forms without carefully reading them or understanding the warrants and liabilities.¹⁹

A study examined the privacy policies of 228 direct-to-consumer genetics testing companies in 2015, including companies offering medical genetics, paternity and ancestry DNA tests. The study concluded: “DTCGT [direct-to-consumer genetic tests] companies either have separate privacy policies or include their privacy policy in their contract. Many DTCGT companies’ privacy policies focus more on data that may be collected on a website via the use of cookies, rather than what is done with genetic data specifically.”²⁰ The study found: 48% of the companies allow for disclosure of personal data or genetic data to third parties in certain circumstances; 25% state that they may disclose data to law enforcement agencies, to comply with the law, courts or health agencies; only 10% will destroy the physical sample either immediately after sequencing or after communicating test results.

The Business of DNA Ancestry Testing

Companies selling DNA ancestry testing make it seem like fun, distracting customers from how such tests pose grave threats to consumer privacy that can disrupt families, cause emotional distress, and even affect financial wellbeing. The genetic industry relies on a new business model largely untested in legislatures and courts of law. Basically, customers pay companies to acquire onto information from which the companies, but not their customers, can profit directly. Historically companies paid for such information, they did not collect payment from those providing it.

Consumers who pay for such tests lose control over their most intimate personal information, the genetic material that makes each person unique. Consumers also relinquish valuable economic rights. The testing companies, and those to which they license, prohibit consumers who paid for genetic tests from sharing in profits from medical products and services based on their genetic information (discussed further below).²¹

Genetic tests that promise to tell people about their ancestors are rapidly gaining in popularity, spurred by ubiquitous advertising that promises to reliably answer who you are. Ancestry DNA companies identify specific information from your genes, the thousands of components in each of your 46 chromosomes that form the basic unit of inheritance determining your unique characteristics as well as parts of your DNA that do not make up your genes (non-coding inter-genic regions). You inherited half of your chromosomes from each parent, as did your parents and so on back through time.

Engaging television ads promise to reveal who your ancestors were, sometimes in ways that undo family lore. In one commercial a cheerful man who grew up being told his ancestors were German discovers that they were Scottish, and so he trades the family lederhosen for kilts.

Other ads promise to reveal your ancestral history with a precision that is scientifically impossible. One radio commercial touts a young man's delight at discovering that he is 18 percent Viking – ignoring the fact that no genetic test can tell if one's ancestors were explorers, traders, and pirates or did any other kind of work. While that commercial can be understood as taking literary license in describing Nordic ancestry, it also illustrates how companies engaged in scientific pursuit will twist facts to further their commercial interests. There is even a broadcast commercial asserting that DNA analysis will reveal a propensity for sleeping on your back rather than your side or stomach.

These and other commercial pitches make genetics, the science of inherited traits, seem like modern magic. And it's easy magic. Just pay \$99 or more for a test kit, swab the inside of your mouth, and mail in the cotton tip to get a supposedly complete report on where your ancestors came from – and perhaps much more.

Consumers should be extremely wary as these come-ons promise more than they can deliver, ignoring problems with accuracy while obscuring a business model in which customers pay for the privilege of giving away valuable information to venture capitalists who expect it will make them very, very rich. “The long game here is not to make money selling kits, although the kits are essential to get the base level,” said Patrick Chung, a 23andMe board member and partner in New Enterprise Associates, a global venture capital firm. “Once you have the data [the company] does actually become the Google of personalized healthcare.”²²

Ancestry tests may not even be consistent across different providers, with different companies reporting different results about where forebears lived or the percentage of their ancestry from a particular region. Ancestry genetic testing companies come to different conclusions because their findings are determined in large part by the size and quality of their

collection of genetic information. People who have sent their genetic material to multiple different laboratories for testing have gotten back reports that come to wildly different conclusions and cannot be reconciled.²³ This lack of reliability is especially significant for African Americans, whose discoverable genealogical history is often short, a legacy of slavery. The Journal *JAMA* reported inconsistent results in consumer genetic tests focusing on medical conditions.²⁴

Pareto-Seco et al (2014) conclude that caution should be exercised when inferring ancestry from AIMs panels. It can often lead to “erroneous perceptions” of human variability. The methods for dividing up populations into groups by different characteristics can depend on a number of assumptions that are somewhat discretionary including the number of AIMs used.²⁵ As was previously noted, Sanker and Cho (2002) summarize the limitations of placing too much significance on individual ancestry tests.²⁶

The business model for the ancestry testing industry is also unique, reflecting the unequal power relationship between the consumer and the testing companies. Consumers pay for the tests, but simultaneously give away rights to their personal genetic information. Ancestry DNA companies are then free to use the genetic material of many people to develop medical tests, products, services and treatments. The DNA testing companies and the manufacturers to which they license data will get all the profits from such products. Consumers will get nothing because they give away their property rights over their own genetic information. Venture capitalists serve on the boards of ancestry companies, expecting huge future profits from using the information that consumers paid the ancestry DNA companies to test.

There are few privacy protections in the contracts consumers must sign to get their genetic material tested, and what little protection these contracts provide can be voided. Your

credit card agreement contains more safeguards than the contracts offered by ancestry DNA companies, which are long on benefits for the companies and nearly devoid of meaningful protections for customers. These consumers effectively relinquish control of their genetic material even if they remove it from the database of the testing firm, or firms, they paid to analyze their genetic material. No government regulatory agency audits to protect against surreptitious use of the data. Many contracts even allow companies to change their terms and conditions at will without notifying each customer in advance.

Imagine that you hit the genetic lottery, that one of your genes turns out to be a key to treating a cancer or preventing an inheritable disease or some other lucrative medical advance. Under the contracts that ancestry DNA customers sign, they give up any financial interest in their own genetic material. While this is, for sure, an unlikely outcome for any individual, this also illustrates how the business model of the ancestry DNA testing industry is designed to exclude you and other consumers from the profits they expect to make from the genetic information customers paid to turn over.

Many other problems lurk in the largely unregulated world of genetic ancestry testing. Some ancestry DNA companies through an optional service post data so that people can look for those who are genetically similar. Thus, a search for paternity or maternity may also be an unintended search for infidelity. Test results may reveal that a sibling is only a half sibling, that a much older sister is in fact one's mother. It could also lead to a knock on the door from a child a man did not know he fathered, or the unintended reopening of a closed adoption, in which the parents' identity was to be concealed from offspring. There are, of course, two sides to the genetic testing coin; a DNA ancestry test may also help locate estranged relatives who desire such a reunion.²⁷

Problems inherent to this business model go unmentioned in the cheery, often funny, advertisements designed to lure people into paying to sign away their rights to their most intimate personal information.

Many of these outcomes pose legal questions that are far from resolved by legislatures and courts about rights and responsibilities. And these tests are being marketed at a time when both legal and political systems are struggling with issues such as whether, following a closed adoption, either parent or child has a right to learn the whereabouts of the other – whether a right to privacy trumps a right to know.

Genetic ancestry testing offers benefits, but consumers also need to understand the many risks they take on when they sign up to have their chromosomes analyzed, especially their expectations of privacy – a right established in Supreme Court decisions, but not found directly in the U.S. Constitution.

Areas of Concern

Companies selling DNA ancestry testing make it seem like fun, distracting customers from how such tests pose grave threats to consumer privacy that can disrupt families, cause emotional distress, and even affect financial wellbeing. Consumers who pay for such tests lose control over their most intimate personal information, the genetic material that makes each person unique. Consumers also relinquish valuable economic rights. The testing companies, and those to which they license, prohibit consumers who paid for genetic tests from sharing in profits from medical products and services based on their genetic information (discussed further below).

Ordering a genetic ancestry test in the hope of learning about your distant relatives can seem like sheer fun, an innocent diversion without significant ramifications for yourself or

society. That's certainly the way the ancestry genetic test industry wants people to think about services. Were it that simple.

The purchase of a direct-to-consumer ancestry genetic test exposes people to a host of risks that are not readily apparent. These range from simply wasting money because the results you get back may not be accurate, for reasons explained below, to so disrupting your family or creating family conflicts. Such tests can reveal infidelities and other secrets and allow people you did not know you were related to, say a child from a long ago fling, to find you. Issues of privacy, employment, and even the risk of arrest because of poorly done or dishonest work by police forensic labs all come into play (discussed further below).

On another level, such testing may well reinforce long-standing myths about race and ethnicity to the detriment of a more nuanced and less reductionist view about structure of societies. It is well known that there is more genetic diversity among people in Africa than between those individuals and people in Northern Europe. When selecting certain genes such as those for skin color, the results will more likely fall into biogeographical regions, but it is only a statistic. A person may show up in an ancestry test for dark skin and still share many similarities with Northern Europeans. Even as scientists claim there is no genetic basis of race, DNA ancestry tests that claim a person is 80 percent of African ancestry may be persuaded otherwise.

Most people who buy such tests will simply get the results with no problems. Many people will, in time, forget about them or incorporate the findings, accurate or not, into their personal understanding of who they are and who came before them.

But once your genetic material has been voluntarily submitted for testing the uses made of it may ultimately be beyond your control.²⁸ Buried in the fine print of the contracts that people who pay for such tests must sign to get their test results is language affecting your rights.

Few people read such dense legalese and even fewer understand it. The genetic ancestry testing companies impose different policies. The privacy policies of some companies can seem, on first reading, to offer strong protections. But these contracts also include clauses that can wipe out those protections, especially if the firm goes bankrupt, is sold or is taken over by another firm.

No genetic ancestry testing company contract establishes an absolute lock on your privacy. Such contracts often contain clauses allowing the companies to change their policies in the future without contacting customers. Instead the burden is placed on the customer to continually check the testing firm's website to determine if any policies have been changed. Thus, if you want to know about a new policy, say one that makes your genetic information available for medical testing or to law enforcement, you have to return to the website and read the terms of service or privacy agreement, a task literally no one is likely to undertake with regularity. Moreover, there can be no guarantees of stolen or hacked information. Companies usually have you sign a warranty against their liability from the theft of your information. Here is the statement from 23andMe.

“Your genetic data, survey responses, and/or personally identifying information may be stolen in the event of a security breach. In the event of such a breach, if your data is associated with your identity, they may be made public or released to insurance companies, which could have a negative effect in your ability to obtain insurance coverage.”²⁹

The Genetic Information Non-Discrimination Act (GINA) of 2008 makes it illegal to discriminate against employees or applicants for health care insurance because of genetic information. GINA does not cover life insurance or long-term care insurance.

When policies do change, customers may have a limited period time, say 30 days, within which they must withdraw their genetic material or take other actions or else they have silently agreed to the new policy. While no such major changes have occurred yet there is good reason to believe they will as genomic science advances, genetic testing companies are reorganized, sold and in some cases closed and as new management assumes control.

Consumer interests get short shrift in the event an ancestry genetic testing company goes bankrupt. That is because federal bankruptcy law is designed to exact the maximum value from a failed business for the benefit of its creditors, not to protect the privileges, protections and rights of consumers, which get virtually no attention in Bankruptcy Court proceedings. Thus were a genetic ancestry testing firm to seek refuge from creditors in Bankruptcy Court and the highest value the creditors could get would be from making your personal data public, even though you were promised confidentiality, a court might allow that.

Your genetic information, in as fine detail as the state of the science can determine, could be passed on without your even knowing about it to corporations and other entities you have never heard of.

While that risk of these seems remote today, under current law there is no way to absolutely ensure that what is by its very nature the most intimate information about you as a living creature will not come under the control of parties unknown, including hostile foreign powers which sometimes use companies as fronts for their own purposes.

For those who do encounter unexpected difficulties the news is not good. The law, in its current state, provides few remedies. Indeed, those who sign up for genetic ancestry tests typically sign away the rights to the use of their own genetic information.

This means that if you should have won the genetic lottery you won't benefit. As previously noted, if genetic ancestry testing results are used for medical research and it turns out that you have a rare, previously unknown or unique mutation that turns out to be immense commercial value you will get nothing. For example, 23andMe states: “Based on the results of this [research study involving your data] 23andMe may develop intellectual property including but not limited to patents, copyrights, trademarks, and/or 23andMe may commercialize products or services, directly, or indirectly. In such cases, you will not receive any compensation.”³⁰

When you sign up for genetic testing you are, in effect, paying a company to tell you something about yourself while giving away legal privileges, protections and rights that would otherwise be yours.

The genetic industry relies on a new business model largely untested in legislatures and courts of law. Basically, customers pay companies to acquire onto information from which the companies, but not their customers, can profit directly. Historically companies paid for such information, they did not collect payment from those providing it.

Should your genetic makeup prove to be a key to preventing a type of cancer or inherited disease like cystic fibrosis, or enabling a medical breakthrough to control or even cure a disease or should it be a path to extending life, or the quality of life, long beyond current expectations, you would get nothing. You would not get paid and you would not even get public recognition.

In all likelihood, based on the contracts of the genetic testing companies and the current state the law, you would never even know of your contribution. From the perspective of the genetic testing industry this makes sense because if people knew their specific genomic information had commercial value they likely would seek share of the profits pie.

The one-sided state of affairs may not be permanent. Legislative enactments and court rulings revise laws in response to human experience and demands placed on lawmakers and courts by individuals, social movements and corporations. Laws can be reformed, meaning improvement, or new laws can restrict your rights while enhancing those of others, including genetic ancestry testing firms. New laws generally are not retroactive, but apply only to future actions.

This is not to suggest individuals should avoid genetic ancestry testing or its cousin, genetic medical testing. What it means, though, is that consumers should order such tests only with a full understanding of the limits on their reliability, the opportunities, however remote, they may be giving up and the risks of disruption to established patterns of family life (see Table 2, Federal Privacy Laws).

The Issue of Consent

When you sign up for a DNA Ancestry test there is usually a consent form that gives the company certain rights over your DNA sample and other information you provide. However your consent over the use of your DNA and of personal information affects more than just yourself. It can affect your family since they share your genetic endowment. As Wallace et al. (2015) note: “The ease with which genealogical and other personal data from the client, and by extrapolation from their relatives, can be shared, linked, and used, raises issues of who gives consent to provide that data and how well all parties are aware of the implications of participation.”³¹ Only a few of the companies warn you that your family may or may not want to know the information derived from your DNA ancestry test and that your relationship with others could be affected once the information is shared and they learn about your DNA analysis.

All of the ancestry DNA companies are bound by federal and state laws including those that address privacy and access to information. One company notes: “We will disclose collected information without your permission when we believe in good faith that such disclosure is required by law, or is necessary or desirable to investigate or protect against harmful activities to customers, employees or others or to property including this site.”³²

Law enforcement may wish to access ancestry DNA data. New York State is considering a proposal to allow familial DNA searches when crime scene DNA evidence does not match anyone listed on the federal or state forensic DNA databases. The idea behind the familial search is that it searches DNA databases to find a close, but not exact match, suggesting that a close family member of the person whose DNA is at the crime scene may have been found. If the DNA databases held by the criminal justice system do not yield close matches, law enforcement may seek other databases including the DNA records held by ancestry DNA companies. Early in 2017 the *New York Times* wrote:

“Leads provided by familial DNA have resulted in errors. A filmmaker in New Orleans was told that he was a suspect in a murder in Idaho based on a DNA sample given by his father years earlier as part of a church-sponsored genealogy project. Ancestry.com, which had purchased the database from a nonprofit that had collected the DNA, was required by a court order to identify the man to the police.”³³

In another example, an Idaho Falls Police Department obtained a warrant to seize information from Ancestry.com to find a familial match in a rape case.³⁴ Unless they have a court warrant, it will be up to each company whether they wish to help law enforcement. It is unlikely you will be asked for your consent.

AncestryDNA states explicitly that it is exempt from invasion of your privacy. “You hereby release AncestryDNA from any and all claims, liens, demands, actions or suits in connection with the DNA sample, the test or results thereof, including, without limitation, errors, omissions, claims for defamation, invasion of privacy, right of publicity, emotional distress or economic loss. This license continues even if you stop using the Website or the Service.”³⁵

What follows is a set of questions highlighting specific areas concern that people considering paying for a genetic ancestry test should consider before turning over their genetic material. The U.S. Federal Trade Commission advises consumers: “Protect your privacy. Before you do business with any company online, read the privacy policy: It should specify how the company secures the information it collects, how it will use your information, and whether it will share your information with third parties.”³⁶

Questions that Consumers of DNA Ancestry Tests Need to Ask before

Submitting DNA Samples

1. Will your DNA sample be retained by the company or destroyed after it is sequenced for your ancestry analysis?
2. Will your identifiable information be shared with third parties?
3. Will your DNA ancestry information or your surname information be placed on a public database?
4. Will your DNA ancestry information and/or other personal information be sold or sent to third parties for research? Does it require your consent? One company states: “Because non-personal information does not personally identify you, we may use non-personal information for any purpose including sharing that information with the Ancestry Group Companies and with other third parties.”

5. Will the company inform you directly of any change in its privacy statement? Will they allow you to opt out if you disapprove of a change in the privacy protection you signed on to?
6. In case the company is sold, will they allow you to remove all your data or at least any personal information before it is transferred to a new company?
7. Will the company require your consent to allow its research partners to access your non-anonymous individual test results?
8. Are you required to give consent when the company allows third parties, i.e. consultants, to get access to your DNA information and to know specifically how they will use it?
9. Are you given access to the privacy policies of third parties that have access to your DNA, information derived from your DNA, or personal information?
10. Does the company accept any liability for your information when there is unauthorized access to it?
11. Are you given an option for excluding your DNA data or information derived from it for aggregate DNA analysis? Do you have an option to exclude the use of that information and your Internet activity for internal research and development of the company?
12. Are you given the right to exclude any information derived from your DNA, personal information or Internet activity for marketing purposes?
13. Are you told what United States (or foreign, if it is a non-US company) laws protect the privacy of your personal information?
14. Are you informed about the dangers of transmitting sensitive or personal information on the Internet and given other options?
15. Are you told exactly how the company will be using your information?
16. Will the company give law enforcement agencies access to your DNA data without a court warrant?
17. Will the company collect via cookies information about your Internet searches? Will that information be shared with other companies?
18. Will any survey information you provide be used for marketing purposes? Can you opt out?
19. If the company claims it will share your information with “trusted” business partners, are you informed who the business partners are? Are you given an opt out?

20. Do you receive any benefits from allowing your information to be used in research? Are the risks of such approval stated for you?

Table 1: Direct-to-Consumer Genetic Ancestry Testing, Privacy Statements

Company	Privacy Policy
African Ancestry Est. 2002 http://www.africanancestry.com	All customer information is kept in confidence; company will not disclose or sell a customer’s name, genetic information or other personally identifiable information to any 3rd party except to employees, consultants or other agents who work for the company ; employees sign non-disclosure agreements; company may make disclosures required by law, rules or regulations, court order or as advised by legal counsel; customers will get 14 days’ notice of such disclosure; company has the right, at its sole discretion, to modify the terms & conditions of the contract.
African DNA Est. 2007 www.africandna.com	There is a double safety net. The first is maintained by African DNA according to State legislation guidelines and the other is maintained by the University of Arizona which is bound by both State and Federal privacy and confidentiality legislation. Your unique number and your surname but no other information is all that the lab will be provided by African DNA. If a genetic match is found between you and another individual who enters the library at some time in the future, both will be given the information that a potential match is in the database provided that BOTH of you have signed the Release Form. Only African DNA will have the ability to cross-reference your unique test kit number with the personal information you provided us in order to determine the names and contact information of family match(es). Privacy and confidentiality will be strictly maintained. African DNA accepts the responsibility to keep your specific data private, at the same time, making enough general information public to allow us to build a Surnames Database library to be used for genealogical purposes.
Ancestry.com Est. 2007 www.ancestry.com	We use industry standard security practices to store your DNA sample, your DNA test results, and other personal data you provide to us. In addition, we store your DNA test results and DNA sample without your name or other common identifying information. You own your DNA data. At any time, you can choose to download raw DNA data, have us delete your DNA test results as described in the AncestryDNA Privacy Statement, or have us destroy your physical DNA saliva sample. We do not share with third parties your name or other common identifying information linked to your genetic data, except as legally required or with your explicit consent. Certified by TRUSTe Privacy Certification. Because Non-Personal Information does not personally identify you, we may use Non-Personal Information for any purpose, including sharing that information with the Ancestry Group Companies and with other third parties. In some instances, we may combine Non-Personal Information with personal information (such as combining your name with your geographical location). If we do combine any Non-Personal Information with personal information, the combined information will be treated by us as personal information, as long as it is combined, and its use by us will be subject to this Privacy Statement. If we decide to change our Privacy Statement, we will issue an updated version of this Statement with an updated date legend and/or notify you via email, via the Website or by other appropriate means prior to the change becoming effective if it is a significant change so that you will be aware of what information we collect, how we use it and under what circumstances we disclose it in accordance with applicable law. You should review this Privacy Statement regularly to ensure you are familiar with any changes to it. If you do not consent to any changes to our Privacy Statement and as a result you would like us not to use or hold personal information about you in accordance with the revised terms, you may notify us here so we can discontinue your account. Additionally, as our business continues to grow and change, we might restructure, buy, or sell

	<p>subsidiaries or business units. In these transactions, customer information is often one of the transferred assets, remaining subject to promises made in then prevailing privacy statements. Also, in the event that AncestryDNA, or substantially all of its assets or stock are acquired, transferred, disposed of (in whole or part and including in connection with any bankruptcy or similar proceedings), personal information will as a matter of course be one of the transferred assets.</p> <p>https://www.ancestry.com/dna/en/legal/us/privacyStatement</p>
<p>Ancestry by DNA Est. 2009 http://ancestrybydna.com</p>	<p>Personal Information is any information that identifies you or would enable someone to contact you, such as your name, email address, phone number and other non-public information that is associated with your order. AncestrybyDNA™ collects personal information when you participate in opportunities we provide. We store personal information for the ongoing operation of our services related to the products and services you purchased from AncestrybyDNA™. We utilize industry-leading standards for data protection to ensure that your personal information stays confidential.</p> <p>Because Non-Personal Information does not personally identify you, we may use and disclose Non-Personal Information for any purpose. In some instances, we may combine Personal and Non-Personal Information such as combining your name with your geographical location. If we combine any Non-Personal Information with Personal Information, the combined information will be treated by AncestrybyDNA™ as Personal Information. Personal information may be disclosed to a third party in the event of any reorganization, merger, sale, joint venture, assignment, transfer or other disposition of all or any portion of AncestrybyDNA™ business, assets or stock (including in connection with any bankruptcy or similar proceedings).</p> <p>http://ancestrybydna.com/privacy.php</p>
<p>Britain's DNA https://www.britainsdna.com/</p>	<p>Your personal information will be kept completely confidential and never shared with outside parties. If you give permission your DNA results will be used for further research to understand more about the history of Great Britain and Europe more generally, this might involve sharing the data with academic groups, but only using an ID number for your sample and never in a way which can be traced back to you. 3/23/2017 Help</p> <p>https://www.mydna.global/faqs/#Whatisyourprivacypolicy 19/36 an ID number for your sample and never in a way which can be traced back to you</p>
<p>Cambridge DNA Services Est. 2007 UK http://www.cambridgedna.com/</p>	<p>Our advertisers and we may have the occasion to collect information in regards to your computer for our services. The information is gained in a statistical manner for our use or advertisers on our site. Data gathered will not identify you personally. It is strictly aggregate statistical data about our visitors and how they used our resources on the site. No identifying personal information will be shared at any time via cookies. You may elect to decline all cookies via your computer. Every computer has the ability to decline file downloads like cookies. Your browser has an option to enable the declining of cookies. Any of our advertisers may also have a use for cookies. We are not responsible, nor do we have control of the cookies downloaded from advertisements. They are downloaded only if you click on the advertisement.</p> <p>Links on our site that belong to third parties may be found. These websites have their Privacy Policy, which you agree to when you link to the site. You should read this third party policy. We do not accept claims of liability or responsibility in any way for these policies or links, as we have no way to control the third party sites.</p> <p>http://www.parkingcrew.net/privacy.html</p>
<p>Determigene Est. 2002 http://www.determigene.com/</p>	<p>The information collected is for statistical purposes. Feldman and Associates, Inc., uses software programs to create summary statistics, which are used for such purposes as assessing the number of visitors to the different sections of the Site, what information is of most and least interest, determining technical design specifications, and identifying system performance or problem areas. For site security purposes and to ensure that our website remains available to all users, Feldman and Associates, Inc., uses software programs to monitor network traffic to identify unauthorized attempts to upload or change information, or otherwise cause damage to the Site.</p> <p>Feldman and Associates, Inc., will not obtain personally-identifying information about you when you visit the Site, unless you choose to provide such information to the Site or Feldman and Associates, Inc., nor will such information be sold or otherwise transferred to unaffiliated third parties without the approval of the user at the time of collection.</p> <p>http://www.determigene.com/privacy.asp</p>
<p>DNA Ancestry and Family Origin Est. 2006 Dubai, UAE http://www.easternbiotech.com/</p>	<p>In Arabic http://dnaancestry.ae/</p>

<p>DNA Exam DNA Identify Testing Center Est. 2006 http://www.800dnaexam.com/</p>	<p>Paternity but not ancestry. Terms of Privacy/Use Statement Bio-Synthesis, Inc. may collect information on clients who visit our website. The information you input into the site is regarded as strictly confidential, and under no circumstance will Bio-Synthesis, Inc. share any of this information with any outside party. We respect your privacy and know that our clients deserve complete confidentiality. Bio-Synthesis, Inc. uses this information for the purposes of completion and support of current activity, Web site and system administration, customization of a Web site to an individual, research and development and contacting visitors for marketing of services or products. This information may be distributed to ourselves and our agents. Moreover, this information could be used in such a way as to personally identify a user. http://www.800dnaexam.com/privacypolicy.aspx</p>
<p>DNA Heritage Est. 2003 UK http://www.dnaheritage.com</p>	<p>Connects to Family Tree DNA</p>
<p>DNA Reference Laboratory Est. 2006 http://dnareferencelab.com/ http://dnareferencelab.com/ancestry/</p>	<p>No privacy policy on line. http://dnareferencelab.com/guarantees/</p>
<p>DNA Solutions Est. 2000 www.dnasolutions.us</p>	<p>Are my test results confidential? DNA Solutions ensure total customer privacy & confidentiality. The results are only issued to the designated persons indicated on your completed paperwork and are password protected. Our state of the art technology ensures that all information is data encrypted and only accessible to authorized personnel working on your case. http://www.dnasolutions.us/dna_testing_question.php; http://www.dnasolutions.us/ancestry.php#top</p>
<p>DNA Testing Systems Parent company: DNA Testing Systems Est. 2003 http://dnaconsultants.com</p>	<p>In general, DNA Consultants does not collect, store, use or disclose personally identifying information except in very specific instances, such as when you create a customer account or place an order, as defined below. Whenever we need to collect such information, we will give you choices regarding whether to provide such information, how it will be used, and to whom it may be disclosed. The instances in which DNA Consultants does collect and use information are specifically described in this Privacy Policy.</p> <p>As part of its Services, DNA Consultants provides links to websites operated by third parties. DNA Consultants also provides search results and similar services to third parties for display on their own websites or applications. DNA Consultants is not responsible for the information collection or privacy practices or the content of any such third party websites or applications. Please be aware that any banner ads on DNA Consultants are provided by third parties that may collect cookies when users click on the ads. These cookies are typically used to track the performance of the banner ads. DNA Consultants does not determine which information will be collected by those third parties; please see the paragraph below for further information.</p> <p>When you order from DNA Consultants, you may choose to provide us with your contact and other personally identifying information, as well as demographic and genealogical information in order to help us fulfill your order. DNA Consultants uses such information to complete your DNA test report order and to notify you if we require additional information.</p> <p>To prevent unauthorized access, maintain data accuracy, and ensure the appropriate use of information, DNA Consultants has physical, electronic, and managerial procedures to safeguard and secure the information it collects online. However, data security is a constantly evolving art and science. You should consider any communication that you transmit to DNA Consultants (such as data, questions or answers, comments, or suggestions) as non-confidential, and you agree that DNA Consultants will not be liable or responsible if information that belongs to you is intercepted and used by an unintended recipient. https://dnaconsultants.com/privacy-policy/</p>
<p>DNA Tribes Est. 2006 http://www.dnatribes.com</p>	<p>DNA Tribes does not rent, sell, or share personal information about you with other people or companies. Your DNA Tribes Native Population Match, Global Population Match, and World Region Match results do not identify you personally. However, your Genetic Profile (Part A of your results) is a unique identifier, and we recommend that you treat that portion of your results as strictly confidential. DNA Tribes will not share, post, or otherwise disclose your personal Genetic Profile to any third parties without your permission.</p> <p>Anonymous, aggregate customer data may be collected and used for research purposes or to improve the quality of our services. This anonymous, aggregate data is never used in any way that can identify any customer individually. If you would like your data excluded from anonymous</p>

	<p>aggregate DNA analysis for internal research and development purposes, please email customer.support@dnatribes.com.</p>
<p>DNA Worldwide Est. 2005 UK http://www.dna-worldwide.com</p>	<p>You may choose to restrict the collection or use of your personal information in the following ways:</p> <ul style="list-style-type: none"> •whenever you are asked to fill in a form on the website, look for the box that you can click to indicate that you do not want the information to be used by anybody for direct marketing purposes •if you have previously agreed to us using your personal information for direct marketing purposes, you may change your mind at any time by writing to or emailing us at info@dna-worldwide.com <p>We will not sell, distribute or lease your personal information to third parties unless we have your permission or are required by law to do so. We may use your personal information to send you promotional information about third parties which we think you may find interesting if you tell us that you wish this to happen. https://www.dna-worldwide.com/privacy-policy</p>
<p>EasyDNA Est. 2006 http://www.easy-dna.com</p>	<p>When users submit sensitive information via the Web site, their information is protected both online and off-line.</p> <p>EasyDNA Limited complies with the requirements of the Data Protection Act 2001 with regard to the collection, storage, processing and disclosure of personal information and is committed to upholding the Act's core Data Protection Principles.</p> <p>In accessing this Web site you accept that electronic mail and other transmissions passing over the Internet may not be free from interference by outside parties and may not remain confidential. In consequence, EasyDNA Limited cannot guarantee the privacy or confidentiality of any information passing over the Internet.</p>
<p>Ethno Ancestry Est. 2004 Scotland & Ireland http://www.ethnoancestry.com</p> <p>See BritainsDNA</p>	<p>BritainsDNA and its associated companies MyDNA Global, ScotlandsDNA, IrelandsDNA, YorkshiresDNA and CymruDNAWales offer direct-to-consumer genetic tests which explore British, Irish, Scottish and Welsh ancestry. The companies are a new incarnation of the former testing company Ethnoancestry. ScotlandsDNA was founded in late 2011.</p> <p>We collect limited non-personally identifying information your browser makes available whenever you visit any website. This log information includes your Internet Protocol address, browser type, browser language, the date and time of your query and one or more cookies that may uniquely identify your browser. We use this information to monitor operation and improve our services.</p> <p>We will disclose collected information without your permission when we believe in good faith that such disclosure is required by law, or is necessary or desirable to investigate or protect against harmful activities to customers, employees, or others, or to property (including this site).</p> <p>The NA MEDIA® service may send a cookie which is sent to your computer that uniquely identifies your browser. A "cookie" is a small file containing a string of characters that is sent to your browsing software when you visit a website. We use cookies to improve the quality of our service and to better understand how people interact with us. You can reset your browser to refuse all cookies or to indicate when a cookie is being sent, and you may clear cookies from your browser. http://www.ethnoancestry.com/privacy_policy.php</p>
<p>Family Builder Est. 2007 https://dna.familybuilder.com</p>	<p>Privacy not in the Internet</p>
<p>Family Tree DNA Est. 2000 https://www.familytreedna.com/</p>	<p>Your consent will be sought for research purposes. Your participation in these initiatives is entirely voluntary and your DNA test results will not be used or disclosed without your consent. Once given, however, consent cannot be revoked. We will ask for your consent in several ways. For example:</p> <ol style="list-style-type: none"> 1.A general consent document will be offered to you as part of your decision to participate in any of the Gene by Gene services offered by any of the websites owned and operated by Gene by Gene. Your consent will allow Gene By Gene to share your test results, anonymized and aggregated with those of others who have consented, with our third-party research partners for the purposes of general scientific research intended to lead to publication in peer-reviewed scientific journals. 2.From time to time, we may ask for explicit consent to participate in specific research, and upon this consent we may allow our research partners to access your individual test results, which will be kept anonymous, for the purposes of general scientific research intended to lead to publication in a peer-reviewed scientific journal. 3.From time to time, we may ask for explicit consent to participate in specific research, and upon

	<p>this consent we may allow our research partners to access your individual test results, which will be kept anonymous, for the purposes of scientific research aimed at advancing genetic knowledge and creating, commercializing, or undertaking activities toward the practical applications that may lead to the improvement of health care.</p> <p>4.From time to time, we may ask for explicit consent to allow our research partners to access your non-anonymized individual test results in connection with a specific research project.</p> <p>Research partners may include commercial or non-profit organizations that conduct or support population genetic studies, scientific/medical research, or the development of drugs or devices to diagnose, predict, or treat health conditions. Gene by Gene may make changes to this Privacy Document from time to time. If we do so, we will issue an updated version of this Privacy Document with an updated date on the Gene by Gene Website (and/or notify you via email or by other appropriate means) so that you will be aware of what information we collect, how we use it and under what circumstances we disclose it in accordance with applicable law. If you do not consent to any changes to our Privacy Document, you may notify us at our Contact Us forms with the subject line PRIVACY DOCUMENT. At Gene by Gene’s option on a case-by-case basis, we will " either continue to apply the previous Privacy Document or delete your information and/or account. https://www.familyreedna.com/privacy-policy.aspx</p>
<p>Genelex Est. 2000 http://www.healthanddna.com</p>	<p>Nothing specific about ancestry, except that its tests for the genes Cytochrome P450 3A4/5 (CYP3A4/3A5) note that about 5% of individuals of European origin have a slow acting, intermediate metabolizer form of CYP3A4. Prevalence of CYP3A5 variants differs widely by ethnic origin. People of African ancestry have an increased prevalence of CYP3A5 Intermediate Expresser or Expressor metabolizer status. CYP3A4 and CYP3A5 are closely related and may process many of the same drugs. Substrates include opioid pain medications, statins, chemotherapeutic drugs and combined oral contraceptives. The company also has genetic tests to determine ethnic sensitivity to Plavix.</p> <p>http://genelex.com/about/privacy-policy/privacy-practices/</p> <p>Your Rights Regarding Your Protected Health Information: The health and billing records we maintain are the physical property of the laboratory. The information in it, however, belongs to you. You have a right to:</p> <ul style="list-style-type: none"> Receive a notice that tells you how your health information may be used and shared. Decide if you want to give permission before your health information can be used or shared for certain purposes. However, we may not grant the request. Ask that incorrect or incomplete information be removed or changed in your health records. Ask that your information not be shared with certain people, groups or companies. Ask to be contacted at different places or in different ways, such as through your office or by mail. Ask to see and get a copy of your health information. File complaints if you believe your health information was used or shared in such a way that is not allowed by law or you were not allowed to exercise your rights.
<p>Genetic Testing Laboratories DNA Diagnostic Center Est. 2002 http://www.gtdna.com No longer available on Internet</p>	<p>We are committed to protecting the security of your information. We use a variety of industry-standard security technologies and procedures to help protect your information from unauthorized access, use, or disclosure. Despite these measures, you should know that we cannot fully eliminate security risks associated with information and mistakes may happen.</p> <p>For customers who engage us for our testing services, we may also collect your genetic information and the genetic information of other individuals necessary for testing purposes (“Testing Information”). We may create anonymous data records from information (including without limitation, Testing Information) by excluding information (such as your name) that makes the data personally identifiable to you. We use this anonymous data to analyze request and usage patterns so that we may enhance the content of our services and improve site navigation. DDC reserves the right to use anonymous data for any purpose in its discretion.</p> <p>We may share some or all of your information with our parent company, any subsidiary, or any other company under a common control (collectively, “Affiliates”), including for marketing purposes. If we do share your information, we will require our Affiliates to honor this Privacy Policy. If another company acquires our company or our assets, that company will possess the information collected by it and us and will assume the rights and obligations regarding your</p>

	<p>information collected by us as described in this Privacy Policy. We may share your information with agents to the extent necessary for them to provide their products and services to us, or to provide you with the products and services that you have requested. For example, if you engage us for testing services through a local laboratory, the laboratory is acting as our agent. Other examples include, database storage, file storage and file destruction.</p> <p>https://dnacenter.com/about-ddc/privacy-policy/</p>
<p>Genetree Est. 2007 http://www.genetree.com</p>	<p>Closed on January 1, 2013 and its assets were transferred to Ancestry.com.</p> <p>In 2012, Ancestry.com announced, "In March, Ancestry.com DNA, LLC acquired access to an extensive collection of DNA assets from SMGF." [7] Genetree.com was discontinued on January 1, 2013 and access to family trees was no longer made available through the GeneTree site. [</p>
<p>HomeDNAdirect Est. 2006 http://www.homednadirect.com</p>	<p>No privacy statement</p> <p>This is a Biogeographical Ancestry test which aims to connect your genes to the 4 main geographical regions; hence, this test will highlight your true origins by analyzing your genetic makeup. The percentages you see in your results show your genetic affiliation to one or more of the 4 ancestral groups. Our DNA Ancestry test analyses a total of 144 Ancestry Informative Markers (AIMs). These Ancestry Informative Markers (AIMs) are important determinants of ancestry, helping us evaluate the geographical origins of our ancestors. From a genetic perspective, Ancestry Informative Markers (AIMs) are sets of polymorphisms that appear in substantially different frequencies between populations from different geographical regions of the world. This means that unique polymorphisms are associated with different populations. The test has undergone numerous validation studies and provides sound results that are 95% accurate.</p>
<p>International Biosciences Est. 2007 UK http://www.ibdna.com</p>	<p>Under the Data Protection Act 1998 we have to explain your rights about information we hold about you on our database. We are committed to ensuring we protect your privacy, this means we will:</p> <ul style="list-style-type: none"> • Collect relevant information about you fairly • Tell you why we are collecting it and how we will be using it • Use it only for our business operations and to comply with the law • Ensure that the information that we collect and hold about you is accurate • Hold it only for as so long is necessary • Keep it secure • We will not pass your data on to any other companies • Ensure you can exercise your rights under the data protection act. <p>We use your information in the following ways: • To deal with administration • To contact you with details of products you have bought • For business analysis and research • To comply with the law or our regulators requirements • To identify you when you contact us • We do not store credit card details nor do we share customer details with any 3rd parties.</p>
<p>Metaphase Paternity Test Est. 2002 http://www.metaphasegenetics.com</p>	<p>Personal Information</p> <p>The types of personally identifiable information that may be collected include the patient's name, address, e-mail address, and telephone number. Agents and contractors of Metaphase Genetics who have access to personally identifiable information are required to protect this information in a manner that is consistent with this Privacy Notice, e.g. not using the information for any purpose other than to carry out the services they are performing for Metaphase Genetics. Some of our sites contain links to other sites whose information practices may be different than ours. Visitors should consult the other sites' privacy notices.</p> <p>Your personal information will only be used for the purpose of carrying out the services performed for you by Metaphase Genetics and will not be used for any other purposes. You can withdraw your consent at any time, but if you do so, you will not be able to continue using the services provided on your account. We do not share, rent or sell any information we collect online to any unaffiliated third party. We may make updates to the Privacy Policy from time to time and recommend that you routinely check this page for changes.</p>
<p>Oxford Ancestors Est. 2000 UK http://www.oxfordancestors.com</p>	<p>We may use the data you provide for our internal business purposes and marketing purposes but we shall not disclose any personally identifiable to any third party other than entities who perform business functions integral to our business administration (and solely for that purpose), when required or permitted by law, or except as specifically detailed in this privacy policy, without your permission. We do not sell or otherwise provide any customer information to mailing list or direct marketing companies. DNA samples are disposed of once the order to which they relate is delivered. Other data is kept only as necessary for our own internal business and marketing purposes.</p> <p>We suggest that each time you visit our website, you re-read our privacy policy so as to keep up</p>

	<p>to date with any changes we make.</p> <p>Please be aware that other web sites that may be accessed through our site may collect personally identifiable information about you. The information practices of those third-party web sites linked to our site are not covered by this privacy statement. Please contact us if you require any further information about the use of your personal data. http://www.oxfordancestors.com/content/view/26/44/</p>
<p>Roots for Real Est. 2002 UK http://www.rootsforreal.com</p>	<p>There are two types of data which may be collected as a result of your visiting our website:</p> <p>Statistics collected as you browse the site. Our web server is always aware of the type of web browser it is conversing with at any time, and the IP address being used. It records a log showing these details and which pages of this site are visited. This log can be analysed statistically to assist us in improving the web experience for all our visitors. It does not contain any personally identifiable information.</p> <p>Personal information you knowingly share with us while submitting enquiries, or as a prerequisite to downloading any files.</p> <p>Your personal information</p> <p>Roots for Real will not sell your personally identifiable information to others. Currently we may share your information with Roots for Real entities and/or authorised distributors for Roots for Real products that are located in other countries (see Worldwide Representation) in order to satisfy your business needs. If at any time you no longer wish to be contacted by us, you may write or email to the above address requesting that your information should no longer be used in this way. If you wish to amend your details in any way then please write or email a request to the above address. Why Roots for Real collects client data.</p> <p>Roots for Real uses this information to better understand your needs and to help you to identify the products and services which will best fulfil your needs. To help us improve your experience, Roots for Real might also track your use of our Website. Roots for Real does not sell, trade, or lease your personal information. We might, however, share your information with our trustworthy and authorised business partners. If you do not want us to share your information with our business partners, simply contact us by mail at the above postal address or e-mail the privacy officer at the address noted above.</p> <p>This Privacy Statement applies only to RootsForReal.com and other websites operated and controlled from the Roots for Real, UK headquarters. It does not cover any other websites which may be linked to or from this site.</p> <p>http://www.rootsforreal.com/privacy.html</p>
<p>The Genographic Project Est. 2005 https://genographic.nationalgeographic.com</p>	<p>We will use and share your personal information as described in this Privacy Policy, including: with the corporate affiliates of the National Geographic Partners and 21st Century Fox (collectively “NatGeo Affiliates”), National Geographic Society and entities that are authorized to use the National Geographic name to brand their products or services (such as National Geographic tour expeditions, the National Geographic MasterCard, and the National Geographic holiday greeting card program). A link to a website that lists NatGeo Affiliates can be found at www.21cf.com; Their use of your personal information will be governed by their own privacy policies; with third parties in in the ordinary course of business in order to process your requests and fulfill your orders for video content offered through the Services; with other selected third parties so that they may send you promotional materials about goods and services that they offer. You have the opportunity to opt out of our sharing information about you as described below in the section entitled “User Access and Control”; in response to legal process and when we believe that doing so is required by law, may be necessary to protect any person’s property, rights, or safety, or to investigate a potential violation of law, will help to enforce any terms of use or other legal agreement, or in the event of a corporate transaction, such as a divestiture, merger, consolidation, bankruptcy or asset sale; in accordance with your consent.</p> <p>When information we collect is aggregated, anonymized or otherwise does not identify you, we may use that information for any purpose or share it with third parties, to the extent permitted by applicable law.</p> <p>We may amend this Privacy Policy at any time by posting the most recent version of the Policy on the Services, along with an indication of the date on which the Policy was amended most recently. If we make any material changes in the way we collect, use, and/or share personally identifiable information that we collect about you through the Services, we will provide appropriate notification to you. http://www.nationalgeographic.com/community/privacy/</p>

<p>Universal Genetics; DNA Testing Laboratory Est. 2009 http://www.dnatestingforpaternity.com</p>	<p>Universal Genetics will not release, transfer, or sell any personal information such as name, case number, or contact information to any third party unless required by law. Universal Genetics, LLC (UG) pledges to take all necessary measures to provide accurate information on our corporate website www.universalgenetics.com (and other domains including www.dnatestingforpaternity.com and www.dnatestforpaternity.com - all UG websites) and protect our clients' personal information provided to us online and off line. http://www.dnatestingforpaternity.com/privacy.html</p>
<p>23andMe Est. 2006 https://www.23andme.com</p>	<p>CONSENT TO THE TRANSFER OF YOUR PERSONAL INFORMATION</p> <p>1. By agreeing to our Privacy Statement and Terms of Service, you consent to the storing and processing of your personal information, including sensitive information, in the USA and countries outside of the country you live in. We use a range of measures to safeguard information but these countries may have laws that are different from those of your country of residence. You also consent to your personal information, including sensitive information, being transferred in the event of a business transition such as a merger, acquisition by another company, or other transaction or proceeding. In such a case, your information would be used as set out in any pre-existing Privacy Statement.</p> <p>2. We will not sell, lease, or rent your individual-level information (i.e., information about a single individual's genotypes, diseases or other traits/characteristics) to any third-party or to a third-party for research purposes without your explicit consent.</p> <p>3. We give you the ability to share information with other individuals through features like DNA Relatives. You will always need to take a positive action to share your information, for example, DNA Relatives is subject to an opt-in requirement before we share your information with potential relative matches.</p> <p>4. You may independently decide to disclose your information to friends and/or family members, doctors, health care professionals, or other individuals outside our Services, including through third-party services such as social networks and third-party apps that connect to our website and mobile apps through our application programming interface ("API"); always review the privacy policies of third-party apps and services before sharing your information.</p> <p>5. We may share anonymized and aggregate information with third-parties; anonymized and aggregate information is any information that has been stripped of your name and contact information and aggregated with information of others or anonymized so that you cannot reasonably be identified as an individual.</p> <p>6. We will use your information and share it with third-parties for scientific research purposes only if you sign a Consent Document. Note that we will disclose your individual-level information only if we obtain additional explicit consent from you.</p> <p>You have the choice to participate in 23andMe Research by providing your consent. "23andMe Research" refers to research aimed at publication in peer-reviewed journals and other research funded by the federal government (such as the National Institutes of Health - NIH) conducted by 23andMe. 23andMe Research may be sponsored by, conducted on behalf of, or in collaboration with third-parties, such as non-profit foundations, academic institutions or pharmaceutical companies. 23andMe Research may study a specific group or population, identify potential areas or targets for therapeutics development, conduct or support the development of drugs, diagnostics or devices to diagnose, predict or treat medical or other health conditions, work with public, private and/or non-profit entities on genetic research initiatives, or otherwise create, commercialize, and apply this new knowledge to improve health care.</p> <p>23andMe Research uses your aggregate or individual-level Genetic Information and Self-Reported Information as specified in the Consent Document.</p> <p>Consent process for research. Your Genetic and Self-Reported Information may be used for 23andMe Research only if you have consented to this use by completing a Consent Document. If you have completed a Consent Document: 1. 23andMe may use individual-level Genetic Information and Self-Reported Information internally at 23andMe for Research purposes. In addition, we may allow select third-party research contractors to access your individual level Genetic and/or Self-Reported Information onsite at 23andMe's offices for the purpose of conducting scientific research, provided that all such research contractors will be supervised by 23andMe and subject to 23andMe's access rules and guidelines.</p> <p>2. When your Genetic Information and/or Self-Reported Information is being used for research purposes, it will not be linked to your Registration Information.</p> <p>If you do not complete a Consent Document or any additional consent agreement with 23andMe, your information will not be used for 23andMe Research. However, your Genetic Information and Self-Reported Information may still be used by us and shared with our third-party service providers to provide and improve our Services (as described in Section 4.a), and shared as Aggregate or Anonymous Information that does not reasonably identify you as an individual (as described in Section 4.d).</p> <p>In the event that 23andMe goes through a business transition such as a merger, acquisition by</p>

	<p>another company, or sale of all or a portion of its assets, your information will likely be among the assets transferred. In such a case, your information would remain subject to the promises made in any pre-existing Privacy Statement. https://www.23andme.com/about/privacy.</p>
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Table 2: Federal Privacy Laws:

- [GENETIC INFORMATION NONDISCRIMINATION ACT OF 2008- 29 U.S. Code 1635 and following](#)

The Genetic Information Nondiscrimination Act of 2008, in general, makes it illegal to use a person’s genetic information to discriminate in the following areas;

(a) It is unlawful for an employer to discriminate against an individual on the basis of the genetic information of the individual in regard to hiring, discharge, compensation, terms, conditions, or privileges of employment.

(b) It is unlawful for an employment agency to fail or refuse to refer any individual for employment or otherwise discriminate against any individual because of genetic information of the individual.

(c) It is unlawful for a labor organization to exclude or to expel from the membership of the organization, or otherwise to discriminate against, any member because of genetic information with respect to the member.

(d) It is an unlawful employment practice for any employer, labor organization, or joint labor-management committee controlling apprenticeship or other training or retraining programs, including on-the-job training programs to discriminate against any individual because of the individual's genetic information in admission to, or employment in, any program established to provide apprenticeship or other training or retraining.

§ 1635.9 of the law provides for Confidentiality in the treatment of genetic information, but genetic information that a covered entity acquires through sources that are commercially and publically available, is not considered confidential genetic information, but still may not be used to discriminate against an individual in the areas covered by this law.

- [Driver's Privacy Protection Act of 1994 - 18 U.S. Code 2721 and following](#). This federal law puts limits on disclosures of personal information in records maintained by State departments of motor vehicles.
- Electronic Communications Privacy Act of 1986 - 18 U.S. Code sections [2510-2522](#), [2701-2711](#), [3121,1367](#). This law amends the federal wiretap law to cover specific types of electronic communications, such as e-mail, radio-paging devices, cell phones, private communications carriers, and computer transmissions. It also extends the ban on interception to the communications of wire or electronic communication services and sets restrictions on access to stored wire and electronic communications and transaction records.

- [Family Educational Rights and Privacy Act of 1974 \(FERPA\) - 20 U.S. Code section 1232g](#). This law restricts the disclosure of educational records maintained by educational agencies and institutions that receive federal funding.
- [Fair Credit Reporting Act \(FCRA\) - 15 U.S. Code sections 1681-1681u](#). This law is designed to promote accuracy, fairness, and privacy of information in the files of the credit bureaus that gather and sell information about consumers to creditors, employers, landlords and other businesses.
- [Fair Debt Collection Practices Act - 15 U.S. Code sections 1692-1692p](#). The purpose of this is “to eliminate abusive debt collection practices by debt collectors, to insure that those debt collectors who refrain from using abusive debt collection practices are not competitively disadvantaged, and to promote consistent State action to protect consumers against debt collection abuses.” For more information, see the [FTC Fair Debt Collection guide](#).
- [Federal Privacy Act of 1974 - 5 U.S. Code section 552a](#). This law applies to the access to, and disclosure of, records of individuals held by federal executive and regulatory agencies. It requires such agencies, with some exemptions, to limit disclosure, provide access to the individual, and to apply basic Fair Information Practice Principles to such records containing the personal information of individual U.S. citizens and legal alien residents.
- [Financial Services Modernization Act of 1999, Gramm-Leach-Bliley \(GLB\), Privacy Rule - 15 U.S. Code sections 6801-6809](#). The federal GLB law permits the consolidation of financial services companies and requires financial institutions to issue privacy notices to their customers that explain their information sharing practices and give customers the opportunity to opt-out of some sharing of personally identifiable financial information with outside companies. For more information, see <http://business.ftc.gov/privacy-and-security/gramm-leach-bliley-act>.
- [Video Privacy Protection Act of 1988 - 18 U.S. Code section 2710](#). This law was originally intended to limit the conditions under which a video rental or sales outlet may disclose personally identifiable information about consumers, including viewing history. Even though video tapes have been practically replaced by other technology, such as DVDs and streaming video, this law still applies to such “similar audio visual materials.” Consumers have the right to opt-out from disclosure of their name and address (e.g., in a mailing list), and can sue for actual and punitive damages, and attorneys’ fees and costs, if they are harmed by a violation of this law. This law was recently amended to enable sharing of viewing history, still with consumers’ written consent, on Internet sites such as Facebook and Netflix.

Table 3: State Genetic Privacy Laws (as of 2008)

- Laws in 17 states require informed consent for a third party either to perform or require a genetic test or to obtain genetic information. Twenty-seven states require consent to disclose genetic information. Alaska, Colorado, Florida, Georgia, and Louisiana explicitly define genetic information as personal property. Alaska also extends personal property rights to DNA samples. In 2001 Oregon repealed its property right to DNA samples and genetic information. Four states mandate individual access to personal genetic information, and 19 states have established specific penalties - civil, criminal or both - for violating genetic privacy laws.

State and Statute	Personal Access to Genetic Information Required	Consent Required to				Define as Personal Property		Specific Penalties for Genetic Privacy Violations
		Perform/Require Genetic Test	Obtain/Access Genetic Information	Retain Genetic Information	Disclose Genetic Information	Genetic Information	DNA Samples	
Total	4	12	7	8	27	5	1	19

WHO- Genomics resource center- [Websites: genetics legislation and policy](#)

ASLME - [State Statutes Declaring Genetic Information to be Personal Property](#)

- Four states—Alaska, Colorado, Florida, and Georgia—declare genetic information to be the personal property of the individual to which it pertains. Note that only Alaska expressly includes DNA samples as private property, although a broad interpretation of the phrase “genetic information” may include DNA or biological samples. The relevant statutory language is presented below:
 1. **Alaska:** “[A] DNA sample and the results of a DNA analysis performed on the sample are the exclusive property of the person sampled or analyzed.” Alaska Stat. § 18.13.010(a)(2).
 2. **Colorado:** “Genetic information is the unique property of the individual to whom the information pertains.” Colo. Rev. Stat. Ann. § 10-3-1104.7(1)(a).
 3. **Florida:** “[T]he results of such DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested, are confidential, and may not be disclosed without the consent of the person tested.” Fla. Stat. Ann. § 760.40(2)(a).
 4. **Georgia:** “Genetic information is the unique property of the individual tested.” Ga. Code Ann. § 33-54-1(1)

Appendix: Glossary

This glossary contains terms found in the text of this report but also includes terms not in the report that are useful for the consumer in reading company documents that consumers might receive as a result of DNA testing.

ACGT: An acronym for adenine (A), cytosine (C), guanine (G), and thymine (T), which form the base pairs of DNA molecules, which consist of two strands wound around each other in a double helix shape and held together by bonds between the bases. Adenine pairs with thymine, and cytosine pairs with guanine. The sequence of bases in a portion of a DNA molecule, called a gene, carries the instructions needed to assemble a protein.

Adhesion Contract (or Contract of Adhesion): A standard form contract not subject to negotiation of the terms, but offered on a take-it or leave-it basis. Typically, a business sets the terms and customers must adhere to the terms of the contract. All direct-to-consumer ancestry DNA testing firms offer adhesion contracts.

Admixture: The result of interbreeding between two or more previously isolated populations within a species. In humans, one use of admixture refers to ancestry from more than one recent population group.

Allele: One of two or more versions of a gene or non-coding sequences of DNA. An individual inherits two alleles for each gene, one from each parent. When two are the same, an individual is homozygous for that gene; when different, the individual is heterozygous. Though the term allele was originally used to describe variation among genes, it now also refers to variation among non-coding DNA sequences.

Allele Frequency: A measure of the relative frequency that specific alleles, of variant forms of a gene that are located at the same position on a chromosome, are found a population. This can be used in attempting to determine ancestry.

Ancestral Haplotype: In genetic genealogy, the ancestral haplotype is the set of selected DNA markers correlated to your ancestors.

Ancestry: An individual's forebears, beginning with parents. For each prior generation, the number of forebears doubles. Humans have two parents, four grandparents, eight great grandparents and so on. Assuming 25 years per generation, going back 200 years, or eight generations, means 256 ancestors contributed genetic information, while going back 500 years, or 20 generations, means each individual has more than one million ancestors.

Ancestry DNA Testing: There are two basic types of ancestry genetic tests, lineage and biogeographical. The most fully developed lineage tests are Y-Line, or Y-DNA

(Y chromosome) for men, and Mitochondrial DNA or mtDNA for women. These trace direct ancestors of the same sex. A newer technique and less developed involves autosomal DNA (the autosomes are chromosomes other than X, Y and mitochondrial DNA), sometimes referred to as at-DNA. This technique is primarily useful for identifying living or recent relatives, but not those born two centuries or more earlier. Autosomal tests provide information about a person's biogeographical ancestry by identifying sections of the DNA (single nucleotide polymorphisms) that best match reference databases of modern populations with geographical or ethnic identifications.

Ancestry-informative Marker: Variations for a particular DNA sequence that appear in substantially different frequencies among populations from different regions in the world. The markers (AIMs) are used to estimate the geographical origins of an individual's ancestors, typically by continent of origin (Africa, Asia, or Europe).

Autosome: Any of the chromosomes, except for sex chromosomes. Humans have 22 pairs of autosomes and one pair of sex chromosomes (see X and Y chromosomes). Autosomes are numbered in relation to size. Chromosome 1 has about 2,800 genes, while chromosome 22 has about 750 genes. A large group of shared autosomal DNA indicate a likely blood relationship.

Base Pair: Any of the pairs of nucleotides connecting the complementary strands of a molecule of DNA or RNA and consisting of a purine linked to a pyrimidine by hydrogen bonds. The base pairs are adenine-thymine and guanine-cytosine in DNA, and adenine-uracil and guanine-cytosine in RNA or in hybrid DNA-RNA pairing forming the rungs of the twisted ladder-like structure known as the double helix.

Biogeographical Analysis: The study of how an organism varies genetically with respect to its geographic location. In genetic genealogy, we are all part of the human race. For us, biogeographical analysis refers to analyzing the differences that have developed between separated population groups. These are small changes that have happened since our common ancestors migrated from Africa.

Bioinformatics: A specialty within biology and computer science concerned with the acquisition, storage, analysis, and dissemination of biological data, usually DNA and RNA sequences, but more recently epigenetic markers, to establish evolutionary relationships and other genetic knowledge.

Buccal Cell: A type of cell found in cheek tissue inside the mouth.

Cell: A basic building block of living things in two varieties: eukaryotes and prokaryotes. A eukaryote has a nucleus and specialized parts bound by membranes called organelles, while a prokaryote is a single cell with no specialized parts. Plants and animals are composed of eukaryotic cells. Bacteria and -algae are prokaryote cells. An adult human is composed of many trillions of eukaryote cells, perhaps 100 trillion such cells.

Centimorgan: A unit for measuring genetic linkage, defined as the distance between chromosome positions (also termed loci or markers). Often rendered as cM for genetic centimorgan or map unit (m.u.).

Chromosome: A threadlike structure found in the nucleus of cells. Different organisms have different numbers of chromosomes. Humans have 23 pairs of chromosomes -- 22 pairs of numbered chromosomes, called autosomes, and one pair of sex chromosomes, called X and Y. Each person gets half of their chromosomes from their mother and half from their father. A chromatid is one of the two strands of chromosome.

Coding Region: A coding region is DNA that contains genes, which are the templates from which cells synthesize proteins and other molecules. In genetic genealogy, this most often refers to the part of the mitochondrial genome that contains genes.

Codominance and Incomplete Dominance. With incomplete dominance we get a blending of the dominant & recessive traits so that the third phenotype is something in the middle (red x white = pink). In Codominance, the "recessive" and "dominant" traits appear together in the phenotype of hybrid organisms.

Consent: When a person voluntarily agrees to undertake an action, such as submitting a DNA sample for genetic ancestry testing. Signing a contract with conditions establishes consent and binds the signer to the conditions, even if the person signing did not read the contract or understand the legal terms and the benefits, consequences and risks.

Contract: An agreement creating obligations enforceable by law. Contracts are promises that can be enforced and provide remedies for violating, or breaching, the contract. Genetic testing contracts typically include a clause in which the consumer gives up any right to sue to enforce the contract and must instead take any dispute to binding arbitration, agreeing to pay some or all of the costs of arbitration in advance.

Crossing Over: A shuffling of genetic material in sex chromosomes that occurs during formation of egg and sperm cells and results in genetic variation seen among offspring of the same parents.

Cytosine: One of four chemical bases in DNA, which bonds with guanine (G). Adenine (A) bonds with thymine (T). The sequence of four DNA bases encodes the cell's genetic instructions.

Diploid: A full set of genetic material, consisting of paired chromosomes, half from each parent. The diploid human genome has 46 chromosomes, including two sex chromosomes.

DNA Amplification: The production of many DNA copies from one or a few copies or fragments, usually achieved by the method of Polymerase Chain Reaction or PCR.

DNA (Deoxyribonucleic Acid): The molecule that carries genetic instructions in all living things. Each DNA molecule consists of two strands that wind around one another to form a shape, like a twisted ladder, known as a double helix. Each strand has a backbone made of

alternating sugar (deoxyribose) and phosphate groups. The sequence of the bases determines the unique characteristics and functions of the organism.

DNA Identification sometimes called DNA Fingerprinting: A laboratory technique for establishing a link between biological evidence and a suspect in a criminal investigation. DNA collected at a crime scene is compared to DNA samples from suspects, who may be in custody or may have put their DNA in a database, such as one for people interested in their ancestry, to determine if the DNA samples match. This technique can point investigators to a relative, such as a parent, child, sibling or identical twin and can also clear someone as a suspect. DNA fingerprinting is also used to establish paternity.

DNA Marker: A gene or other fragment of DNA whose location in the genome is known.

DNA Sequencing: A laboratory technique used to determine the exact sequence of bases (A, C, G, and T) in a DNA molecule. The DNA base sequence carries the information a cell needs to assemble protein and RNA molecules. DNA sequence information is important to scientists investigating the functions of genes.

Dominant: The relationship between two versions of a gene. Individuals receive two versions of each gene, known as alleles, from each parent. If the alleles of a gene are different, one allele will be expressed; it is the dominant gene. The effect of the other allele, called recessive, is masked.

Double Helix: The structure of a DNA molecule, which consists of two strands that wind around each other like a twisted ladder. Each strand has a backbone made of alternating groups of sugar (deoxyribose) and phosphate groups. Attached to each sugar is one of four bases: adenine (A), cytosine (C), guanine (G), or thymine (T). The two strands are held together by bonds between the bases, adenine forming a base pair with thymine, and cytosine forming a base pair with guanine.

Evolution: Natural process by which organisms change over time. Mutations produce genetic variation in populations, which may persist or die out.

Family Tree DNA Time Predictor (FTDNATiP™): Family Tree DNA Time Predictor is a program used to calculate estimates of Time to the Most Recent Common Ancestor (TMRCA) for paternal lineages. It is the world's first calculator that incorporates mutation rates specific to each marker. This increases the power and precision of estimates.

First Degree Relative: A family member who shares about 50 percent of their genes with a particular individual in a family. First degree relatives include parents, offspring, and siblings.

Gene: The basic physical unit of inheritance. Parents each pass half of their genes to their offspring, conferring inherited traits. Genes are arranged, one after another, on structures called chromosomes. Humans have about 20-30,000 genes arranged on their 46 chromosomes.

Gene Expression: The process by which a gene's coded information is converted into proteins and other products that contribute to the structure and function of cells.

Genetic Code: The instructions in a gene that govern how cells make specific proteins. The four chemicals in each DNA strand - A, C, G, and T – combine to specify which amino acids are produced to make proteins.

Genetic Drift: A mechanism of evolution. Random fluctuations in the frequencies of alleles can, over multiple generations, change which inherited traits are dominant or disappear from a population.

Genetic Map: A type of visual representation of chromosomes that shows the relative locations of genes and DNA markers. Two or more genes which are physically closer to each other on the chromosome are more likely to be inherited together.

Genetic Markers: Genes, or DNA sequences, with a known location on a chromosome that can be used to identify an individual, a tissue, a cell, a nucleus, a chromosome, or a gene and to study the transmission of genetic disease.

Gene Pool: The total genetic diversity found within a species or a population. The larger the gene pool the greater the genetic diversity.

Genetics: The study of the patterns of inheritance of specific traits.

Genetic profile: The known information about an individual's genes, which might include a complete sequence, a set of genetic markers, or a set of selected single nucleotide polymorphisms (SNPs).

Genetic Variation: The diversity in gene frequencies. Genetic variation can refer to differences between individuals or to differences between populations. Mutations in genes, sexual reproduction especially among parents from differing genetic backgrounds and genetic drift all contribute to genetic variation.

Genomics: The science of studying the entire genome of an organism; the related term *genetics* refers to the study of a particular gene.

Genotype: An individual's collection of genes. The term also can refer to the two alleles inherited for a particular gene. The genotype is expressed when the information encoded in the genes' DNA is used to make proteins and RNA molecules. The expression of a genotype contributes to the individual's observable traits, called the phenotype.

Guanine: One of the four bases in DNA that make up the letters ATGC, guanine is the "G". The others are "A" for adenine, "C" for cytosine, and "T" for thymine. Guanine always pairs with cytosine, while adenine always pairs with thymine.

Haplogroup: A genetic population group of people who share a common ancestor on the patrilineal or matrilineal line. Haplogroups provide a way of examining ancient ancestry and ancient global migration patterns.

Haplotype: A closely associated set of alleles inherited together as a genotype. A Haplotype can refer to a combination of alleles or to a set of single nucleotide polymorphisms (SNPs) found on the same chromosome.

Haplotype, Ancestral: The haplotype of the most recent common ancestor of two people, determined by comparing descendants' haplotypes and eliminating mutations. "Haplo" is derived from the Greek word for "single."

Heredity: The handing down of certain traits from parents to their offspring. The process of heredity occurs through the DNA. Epigenetic markers can also be inherited.

Homologous Recombination: A type of genetic recombination in which nucleotide sequences are exchanged between two similar or identical molecules of DNA. It is most widely used by cells to accurately repair harmful breaks that occur on both strands of DNA, known as double-strand breaks.

Homology: The similarity of a structure or function of parts of different origins based on their descent from a common evolutionary ancestor.

Hypervariable Region (HVR): A location within nuclear DNA or the D-loop of mitochondrial DNA in which base pairs of nucleotides repeat (in the case of nuclear DNA) or have substitutions (in the case of mitochondrial DNA). Changes or repeats in the hypervariable region are highly polymorphic (several alleles of the same sequence).

Hypervariability: High degree of variation among individuals within local populations at a given genetic marker.

Identical by State (IBS): IBS stands for identical by state, meaning the DNA matches by coincidence. When two individuals share numerous individual results without being related, those results are IBS.

Inherited Trait: Genetically determined characteristic or quality such as hair color resulting from the combination of genes from parents. Many traits are influenced by both genes and environment.

Karyotype: The number and visual appearance of the chromosomes in the cell nuclei of an organism or species. Also, a laboratory technique that produces an image of an individual's chromosomes. The karyotype can be useful in looking for abnormal numbers. A *phenotype* (from Greek *phainein*, meaning 'to show', and *typos*, meaning 'type') is the composite of an organism's observable characteristics or traits, such as its morphology, development, biochemical or physiological properties, behavior, and products of behavior (such as a bird's nest). or structures of chromosomes.

Linkage: Linkage is the close association of genes or other DNA sequences on the same chromosome. The closer two genes are to each other on the chromosome, the greater the probability that they will be inherited together.

Loci (plural); Locus (single): The position on a chromosome or may also refer to the DNA at that position on a chromosome. Also, a section or stretch of DNA at a particular place on a particular chromosome — often used for a 'gene' in the broad sense, meaning a stretch of DNA being analyzed for variability (e.g., a microsatellite locus).

Mapping: Creating a visual representation showing the relative locations of genes and other features of a chromosome. Genetic maps estimate the relative locations of genes to estimate common ancestry.

Marker: A DNA sequence with a known location on a chromosome. DNA segments close to each other on a chromosome tend to be inherited together. Markers are used to track the inheritance of a nearby gene that has not yet been identified but whose proximate location is known. The marker may be a part of a gene or may have no known function. Markers can help link an inherited disease with the responsible genes.

Microsatellite: Also called short tandem repeats (STR), are polymorphic DNA loci containing repeated nucleotide sequences, typically from 2 to 7 nucleotides per unit. The length of the repeated unit is the same for the majority of the repeats within an individual microsatellite locus; the number of repeats for a specific locus may differ, resulting in Microsatellite sequences consist of non-coding DNA and are not parts of genes.

Mitochondria; mitochondrion (singular, rarely used): Specialized subunits (organelle) within cells. In humans, mitochondria are responsible for cell respiration and for producing energy. Because they were once independent, they have their own mitochondrial DNA (mtDNA) genome. This genome is passed from mother to child. DNA in the mitochondrial organelle is used in ancestry lineage searches.

MRCA: Acronym for Most Recent Common Ancestor of all persons in a group.

Mitochondrial DNA (mtDNA):

Non-Coding DNA: Sequences of DNA that do not code for amino acids. Most non-coding DNA is found between genes on chromosomes, many of their function as yet unknown. Introns, another form of non-coding DNA, is found within genes. Some non-coding DNA plays a role in the regulation of gene expression.

Nucleic Acid: The class of macromolecules (a complex organic biopolymer) present in living cells, especially DNA or RNA, whose molecules consist of many nucleotides linked in a long chain. Nucleic acid is found in all cells and viruses involved in storage and expression of genetic information.

Nucleus: An organelle found in eukaryotic cells. Inside its fully enclosed nuclear membrane, it

contains the majority of the cell's genetic material. This material is organized as DNA molecules, along with a variety of proteins, to form chromosomes.

Pedigree: A chart of an individual's ancestors used in human genetics to analyze Mendelian inheritance of certain traits, especially of familial diseases.

Phenotype: A phenotype is the composite of an organism's observable characteristics or traits, such as its morphology, development, biochemical or physiological properties, behavior, and products of behavior.

Phylogeny: The evolutionary history of a species.

Polymorphism: A naturally occurring or induced variation in the sequence of genetic information (greater than 1% frequency) on a segment of DNA, important in detecting inherited diseases.

Recessive: A relationship between two alleles, or versions of a gene, in which one dominates and the other is masked. Individuals who a recessive gene from both parents may develop an inherited disease.

RNA (Ribonucleic Acid): Any of three types of molecules similar to DNA, but that are single stranded, unlike DNA's double strand structure. Messaging RNA (mRNA) carries instructions on the creation or synthesis of proteins in a cell in conjunction with ribosomal RNA (rRNA), and transfer RNA (tRNA). RNAs are also involved in regulating gene expression.

Sequencing: Determination of the order of base sequences, or nucleotides in a DNA (AGCT) or RNA (AGCU) molecule. Also, the order of amino acids in a protein.

Sequence Tagged Site (STS): A short DNA sequence (200 to 500 base pairs) that has a single occurrence in the human genome and whose location and base sequence are known. STSs are useful for genetic mapping and sequencing.

Sex Chromosome: The X or Y chromosome in human beings that determines the sex of an individual. Females have two X; males have an X and a Y chromosome. The sex chromosomes comprise the 23rd chromosome pair in a karyotype.

Sex Linked: Any trait in which a gene is located on a sex chromosome. In humans, the term generally refers to traits that are influenced by genes on the X chromosome, which contains many more genes than the smaller Y chromosome found only in males.

Single Nucleotide Polymorphism (SNP): A variation in a single nucleotide that occurs at a specific position in the genome, where each variation is present to some appreciable degree within a population (e.g. > 1%). About 30 million SNPs are thought to exist. They can be used as genetic markers and also prove useful in studying inherited diseases.

Species: a group of living organisms consisting of similar individuals capable of exchanging genes or interbreeding. The species is the principal natural taxonomic unit, ranking below a genus and denoted by a Latin binomial, e.g., *Homo sapiens*.

Tandem Repeat Sequences: Multiple copies of the same base sequence on a chromosome; used as a marker in physical mapping.

Taxon; Taxa (plural); Taxonomy: The classification and grouping of organisms. From the Greek word *tax* meaning “is.”

Thymine: One of four chemical bases in DNA, usually represented as a capital T, which joins with adenine (A). The other two chemical bases are cytosine (C), and guanine (G), which also form pairs. The sequence of these DNA bases encodes genetic instructions for each cell.

Trait: A trait is a specific characteristic of an organism. Traits can be determined by genes or the environment, or more commonly by interactions between them. The genetic contribution to a trait is called the genotype. The outward expression of the genotype is called the phenotype.

X and Y Chromosomes: One of two sex chromosomes. Humans and most mammals have two sex chromosomes, X and Y. Females have two X chromosomes, while males have X and Y chromosomes. Egg cells contain only X chromosomes, while sperm cells contain an X or a Y chromosome, which determines the sex of offspring.

Y-DNA: Male specific genetic information that can be used for males to trace back direct male ancestors.

X-Linked: A trait inherited from a gene is located on the X chromosome.

Notes

¹ International Society for Genetic Genealogy, https://isogg.org/wiki/List_of_DNA_testing_companies; see also, C.D. Royal, J. Novembre, S. M. Fullerton, D.B. Goldstein, J.C. Long, M.J. Bamshad, A.G. Clark. Inferring genetic ancestry: Opportunities. Challenges and implications. *American Journal of Human Genetics* 86:661-673 (May 14, 2010).

² Amanda K. Sarata. Genetic Ancestry Testing. Congressional Research Service Report to Congress. March 12, 2008. RS22830.

³ American Society of Human Genetics Statement, *American Journal of Human Genetics* 81:635 (September 2007).

⁴ Sarata, 2008.

⁵ Mark D. Shriver and Rick A. Kittles. Genetic ancestry and the search for personalized genetic histories. *Genetic Reviews: Genetics* 5:611-618 (August 2004).

⁶ <https://blogs.ancestry.com/ancestry/2017/01/10/ancestrydna-surpasses-3-million-customers-in-dna-database/> Accessed March 2, 2017; Joyce C. Harper, Debbie Kennett, and Dan Reisel. The end of donor anonymity: how

genetic testing is likely to drive anonymous gamete donation out of business. *Human Reproduction* 31(6):1135-1140 (2016).

⁷ Jacobo Pardo-Seco, Federico Martín-Torres and Antonio Salsa. Evaluating the accuracy of AIM panels at quantifying genome ancestry. *BMC Genomics* 15:543-554(2014), p. 543.

⁸ <https://www.legalgenealogist.com/2013/10/27/those-pesky-percentages/> Accessed March 22, 2017.

⁹ Pardo-Seco et al. 2014

¹⁰ Troy Duster Ancestry testing and DNA: Uses, limitations and caveat emptor. *GeneWatch* Bulletin of the Council for Responsible Genetics, 2009.

¹¹ E.U. Durand, C.B. Do, J.L. Mountain, J.M. Macpherson. Ancestry composition: A novel, efficient pipeline for ancestry deconvolution. BioRxiv doi: <https://doi.org/10.1101/010512>
<http://biorxiv.org/content/early/2014/10/18/010512>

¹² Royal et al. 2010, p. 670.

¹³ Ron Nixon. DNA ancestry testing leaves some in doubt. *New York Times* December 2, 2007.

¹⁴ Shriver & Kittles, 2004.

¹⁵ American Society of Human Genetics. Ancestry Testing Statement, November 13, 2008.

¹⁶ Jacobo Pardo-Seco, Federico Martín-Torres, Antonio Salas. Evaluating the accuracy of AIM panels at quantifying genome ancestry. *BMC Genomics* 15 :543- (2014).

¹⁷ Ancestry.com maintains: “Our service providers act on 23andMe's behalf. While we implement procedures and contractual terms to protect the confidentiality and security of your information, we cannot guarantee the confidentiality and security of your information due to the inherent risks associated with storing and transmitting data electronically....We may share aggregate information with third-parties, which is any information that has been stripped of your [Registration Information](#) (e.g., your name and contact information) and aggregated with information of others so that you cannot reasonably be identified as an individual ("Aggregate Information").” The operative term here is “you cannot reasonably be identified.” <https://www.23andMe.com/en-gb/about/privacy> Accessed March 3, 2017.

¹⁸ Susan E. Wallace, Eli G. Gourn, Viktoriya Niolova and Nicola A. Sheehan. Family tree and ancestry inference: is there a need for ‘generational’ consent. *BMC Medical Ethics* 16:87-96 (2015), p. 94.

¹⁹ Wallace et al. 2015, p. 94.

²⁰ Anelka M. Phillips. Genetic privacy and direct-to-consumer genetics. *IEEE CS Security and Privacy Workshops*. 2015, pp. 60-64 at p. 62.

²¹ The company Portable Genomics, which deals with health information, advertises that consumers may realize financial benefits from contributing their DNA and health information.

²² Elizabeth Murphy, Inside 23andMe Founder Ann Wojcicki's \$99 DNA Revolution. Fast Company October 13, 2014. <https://www.fastcompany.com/3018598/for-99-this-ceo-can-tell-you-what-might-kill-you-inside-23andme-founder-anne-wojcickis-dna-r> Accessed January 25, 2017.

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- ²³ Ron Nixon. DNA tests find branches but few roots. *New York Times* November 24, 2007. <http://pages.jh.edu/~pfleming/bioinform/files/DNATestsFindBranchesFewRootsNYT.pdf> Accessed March 8, 2017. Direct to consumer DNA medical tests have also produced varied results. Kir Peikoffdec, I had my DNA picture taken, with varying results. *New York Times* December 30, 2013. http://www.nytimes.com/2013/12/31/science/i-had-my-dna-picture-taken-with-varying-results.html?_r=0 Accessed March 8, 2017.
- ²⁴ Bridget M. Kuehn. Inconsistent results, inaccurate claims plague direct-to-consumer gene tests. *JAMA* 304 (12):313-315 (September 22/29, 2010).
- ²⁵ Pardo-Seco et al., 2014.
- ²⁶ P. Sanikar and M.K. Cho. Genetics: Toward a new vocabulary of human genetic variation. *Science* 298 (5597):1337-1338 (2002).
- ²⁷ Rachel L. Swarns. With DNA testing, suddenly they are family. *New York Times* January 23, 2012. <http://www.nytimes.com/2012/01/24/us/with-dna-testing-adoptees-find-a-way-to-connect-with-family.html> Accessed March 8, 2017.
- ²⁸ 23andMe states: “At your request we will delete your account and personal information linked to your account from our systems.”
- ²⁹ 23andMe website. <https://www.23andMe.com/about/consent>. Accessed January 25, 2017.
- ³⁰ 23andMe website. <https://www.23andMe.com/about/consent>. Accessed January 25, 2017.
- ³¹ Wallace et al., 2015, p. 88.
- ³² Ethno Ancestry Est. 2004 Scotland & Ireland. <http://www.ethnoancestry.com> See Table 1.
- ³³ Eli Rosenberg, Family DNA searches seen as a crime-solving tool, and intrusion on rights. *New York Times* January 27, 2017.
- ³⁴ Jessica Chia, Man became suspect in murder and rape case after DNA his father donated to Mormon genetic research was sold to Ancestry.com and then tested by police. *Daily Mail* Online. March 26, 2016. <http://www.dailymail.co.uk/news/article-3510568/Law-enforcement-investigators-seek-private-DNA-databases.html> Accessed January 29, 2017.
- ³⁵ <http://dna.ancestry.com>
- ³⁶ Federal Trade Commission website. <https://www.consumer.ftc.gov/articles/0166-direct-consumer-genetic-tests> Accessed January 29, 2017.

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