

Tribal Enrollment and Genetic Testing

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When the NCAI Policy Research Center began developing this resource guide, tribal leaders asked many questions such as, “What is genetic testing? What are good sources of information about genetic testing? What kinds of DNA testing can we use for tribal enrollment? How do we respond to individuals claiming tribal membership based on DNA tests?” This paper was developed to provide tribal leaders with more information on genetic testing related to tribal enrollment. Tribes are sovereign nations and so will decide their own views on genetic testing. This paper provides information to assist in those decisions.

Genetic information (i.e., DNA) collected from individuals, families, and communities can be used in many different ways and it is becoming more of a discussion topic in tribal communities. While research is one possible use of genetic information, this information can also be used to examine how people are related to one another by comparing the similarity of their DNA sequences. Genetic information can also provide clues to ancestral relations. DNA is obtained by collecting biological samples (e. g., blood, hair, cells from a cheek swab, or even from spitting in a cup). Genetic testing has been advertised to



tribes as a tool for determining their enrollment (TallBear 2003). Historically, tribal nations have used a variety of ways to determine their own membership. More background information on tribal determination of enrollment is available in the section entitled [Tribal Sovereignty and Enrollment Determinations](#). This section discusses the use of genetic information in determinations of tribal enrollment. For a quick overview of relevant issues, please see this [summary handout](#).

Types of DNA Testing and Considerations about their Use

What do people mean by DNA testing?

DNA testing has become an umbrella term that refers to many different kinds of genetic testing that provides information about an individual’s genes. Genetic information, or DNA, is found in nearly every cell in the human body. DNA testing technology is constantly changing, and so are the efforts to engage tribes in testing on an individual and group basis. One type of DNA testing called DNA fingerprinting can be used to help document close biological relationships, such as those between parents and children, as well as among other close family members. Other kinds of testing for genetic ancestry use markers to see how similar an individual is to a broader population or group, based on probabilities drawn from databases of research on populations and group genetic characteristics. However, no DNA testing can “prove” an individual is American Indian and/or Alaska Native, or has ancestry from a specific tribe. Genetic testing can provide evidence for the biological relationship between two individuals (e.g., paternity testing), but there are no unique

genes for individual tribes or American Indian/Alaska Native (AI/AN) ancestry in general. While research scientists have found that some genetic markers are found mostly only in AI/ANs, these markers are neither unique to AI/ANs nor predictive of AI/AN identity. This section will discuss various types of DNA testing as well as considerations for tribal leaders and members when engaging with testing companies.

Probability

In almost all genetic testing, information is expressed in terms of probability or a chance of something. For example, genetic testing can estimate the chance of two individuals being related, or sometimes the probability of developing a certain disease^[1]. Commonly this probability or chance is expressed as a percentage of how likely something is (99.5% for example). For parentage of a child, genetic testing can provide a very accurate probability estimate. In trying to determine whether a child is related to others (grandparents, siblings, cousins, aunts and uncles), the probability estimate will be less accurate due to a smaller amount of shared genetic material among distant relatives. However, with genetic testing of distant relatives, probability estimates can become more accurate with a greater number of tested individuals. Generally, genetic testing of possible relationships with previous generations (e.g., parents, grandparents) is more reliable than genetic testing with extended relatives in a person's own generation or later generations (e.g., cousins).

Types of Genetic Testing

Paternity and Maternity Testing – These tests compare a child's genes to those of a probable parent to confirm or deny their relation. The results are expressed as a probability, a mathematical likelihood of the relation between the possible parent and child. Much of this testing is done through [DNA fingerprinting or DNA profiling](#), which compares specific genetic markers between the two reference samples, known as [Variable Number Tandem Repeats \(VNTRs\)](#), because these markers remain extremely similar from parent to child. This kind of comparative analysis is also used in forensics for building a case against a certain suspect, based on genetic evidence (blood, hair, etc.) left at the scene of the crime. DNA fingerprinting could also be a test for determining likelihood of other extended or immediate familial relations, which might prove useful for those tribes utilizing lineal descent rules for membership and wanting to substantiate them through DNA.

This example from PBS demonstrates how to see similarities in [DNA fingerprinting results between family members](#). Importantly, the PBS example points out that this type of test for paternity can definitively determine who is not the father, and can identify with a slightly less than 100% confidence who is the father. Tribal enrollment officials might find these tests useful to help determine relationships between probable parents and children that are applying for enrollment. If a parent is not available for testing, a grandparent could be tested; however, the certainty of this kind of test is less than that of parental testing because of generational distance. The more distant a familial relationship is, the less certain the DNA fingerprinting results will be.

Genetic Ancestry Testing – This kind of testing looks at many genes from an individual and compares their sample to a larger database of research information. This test is based on probabilities and can provide information about how different or similar an individual's DNA is to that of most people within a larger group of people ("population"). However, these results are limited by the information in current databases, many of which do not contain a lot of information for particular groups (AI/ANs among them). This limitation in the data can produce problems for tribes and individuals seeking information as results may not be accurate or even possible to generate given limited availability of comparative data.

There are many ways to test for genetic ancestry, such as mitochondrial DNA testing (mtDNA), Y-chromosome testing, and analysis of single nucleotide polymorphisms (SNPs). The discussion below explains why these methods are of limited use in tribal enrollment issues.

Mitochondrial DNA (mtDNA): Inside each cell are two structures that contain DNA: the nucleus and hundreds of mitochondria. The mitochondria only come from the mother, as the egg contains the mitochondria that will produce all other mitochondria in the child's cells. The DNA of the mitochondria is identical or extremely similar for the whole of the maternal line. Thus, a genetic test that analyzes mtDNA could provide information about an individual and his/her biological mother as well as other maternal, female relatives in direct lineage, but since this test cannot account for any of the other ancestry of an individual, enrollment officials will only find it of limited use.

Y-Chromosome DNA: Males have a Y-chromosome that comes from their father. The DNA of this chromosome contains sections that remain identical or extremely similar for the whole of the paternal line. A genetic test that analyzes a male's Y-chromosome DNA could thus provide information about that male's biological father and direct paternal, male relatives. However, this test is of limited utility for enrollment officials because it is only applicable for males and it does not account for any of the other ancestry of an individual.

Single Nucleotide Polymorphisms (SNPs): DNA is made up of nucleotides, and these building blocks vary between people and groups. Variations in the building blocks are called single nucleotide polymorphisms (SNPs). Specific variations, or SNPs, can be common in a group, but they are also seen in individual genomes. These small changes help to provide an overall profile of an individual's genotype, which is their whole genetic makeup. This kind of genetic test uses statistical probability to estimate how likely it is that an individual comes from a certain region of the world. However, this kind of test cannot conclusively prove that an individual is from a certain tribe. In fact, there are no genetic tests that are specific to a tribe or even American Indian/Alaska Native heritage. Therefore, while individuals may approach tribal enrollment officials with genetic ancestry test results, other records would be of more value and provide more certainty in determining eligibility for enrollment.

One type of genetic testing called Ancestry Informative Markers (AIMs) uses SNPs to examine a person's genetic ancestry. AIMs convey important information about an individual's likely ancestry and differences between populations from different geographic areas. Research in recent years has attempted to link genes with specific ancestry related to geographical locations. For example, Mark Shriver and his lab group have identified genetic variations that are most common in particular populations, and he suggests these can be used to help determine the geographic ancestry of modern people, small groups, and individual persons. Shriver and colleagues write, "Ancestry informative markers (AIMs) are genetic loci showing alleles with large frequency differences between populations. AIMs can be used to estimate biogeographical ancestry at the level of the population, subgroup (e.g. cases and controls) and individual" (Mark Shriver et al 2003).

As research generates more information, some genetic markers, such as SNPs, appear more commonly in some populations than others. However, these genetic markers do not reflect all of the genetic information in a person's ancestry. With genetic ancestry testing, there are limits to the information available for AI/AN individuals because there are few samples from the AI/AN population in the current databases being used for these tests. Further, these tests do not provide information about all of a person's ancestors. Kim TallBear describes this limitation well in her articles, including an explanation of how a person with AI/AN ancestry may not show up on a genetic test as AI/AN, or may be told they are of East Asian or other descent (TallBear 2003, TallBear and Bolnick 2004). Brett Shelton and Jonathan Marks have also described the limits of DNA testing with respect to Native identity. There is also some concern, highlighted by Marks and

Shelton, that [both false positives and false negatives occur in these tests](#). In other words, genetic ancestry testing using AIMs is not totally accurate or precise. With this testing, an individual can be misidentified as AI/AN even if they do not have the genetic markers that are more common among AI/AN peoples. On the other hand, an individual could be misidentified as non-AI/AN even if they do have the genetic markers found more often in AI/AN groups. For this reason, genetic ancestry testing can be viewed as just one piece of a larger puzzle about an individual's ancestry. Other tools should be used to fill in the information throughout the puzzle, or the enrollment application. Kenneth Weiss and Jeffrey Long highlight that “not many documented single nucleotide polymorphisms (SNPs) are useful [ancestry informative markers]...For example, an AIM intended to reveal Native American ancestry may also be common in East Asians, and not private after all.” These authors conclude that “Although DNA data have the aura of providing definitive answers to population and individual ancestry questions, they require careful interpretation in terms of both the laws of inheritance and the evolutionary process. Untrained individuals, and even some professionals, will have a difficult time reconciling the nuances of interpretation with the bottom-line aura that DNA carries” ([Weiss and Long 2009](#)). Thus, scholars have argued that genetic ancestry tests should be interpreted with caution, especially because there is currently not enough data from AI/AN populations to make specific claims to ancestry based on genetic testing.

Considerations Regarding DNA Testing Companies

Tribes that have decided to use DNA testing will face decisions about how to get this testing completed in an ethical and respectful way. Tribes might choose to use genetic testing to provide information about tribal members' family relationships or ancestry. This type of genetic testing is usually done by private, commercial genetic testing laboratories. The section below discusses considerations for tribes in working with these private labs. Other sections of this resource guide discuss the [collection of genetic information for research](#), which is different from fee-for-service genetic testing done by private companies. However, because the information encoded in genetic samples and the information attached to those samples (such as family and tribal identities) has potential commercial value, tribes should make certain that samples and identifying information of individuals, their families, and tribes is handled according to tribal preferences. To ensure that tribal preferences in these areas are honored, there should be protective language contained in contracts with DNA testing companies allowed to work with tribal members, as well as clearly defined consequences for failure to observe those contract requirements. Some terms tribes may wish to include in contracts are protections of confidentiality with the samples and predetermined services or monies owed to the tribe if the contract is breached.

Working with Private Labs for Testing – In using genetic tests, most tribes will work with private labs for their testing. As with all data collected from tribal citizens, it is important to ensure the [protection of the citizens, applicants, and samples](#) submitted to the labs. Written contracts and proper informed consent should be in place to document how specimens and test results will be used. Tribes may wish to work directly with genetic testing labs so that they can ensure the quality of test results provided to individuals who are applying for tribal enrollment, and the security of the information. More information about lab quality assurance is available on the Genetics Home Resource, particularly under the section “How can consumers be sure a genetic test is valid and useful?” This resource includes information about [certification of labs according to Clinical Laboratory Improvement Amendments](#). Testing centers may also provide information on their own websites about choosing a lab. For additional considerations in choosing a lab, please see this [summary handout](#).

Direct to Consumer (DTC) Testing – Many companies will perform testing of a person's DNA profile or genetic ancestry for a fee. The information that these companies provide has a limit to

accuracy (in how much of one's ancestry it can reflect). It also needs to be interpreted by professionals, such as doctors for health information, or scientists who can understand the implications and limitations of information about genetic ancestry. Claims by genetic testing companies should be evaluated by the consumer for accuracy. Tribal officials, tribal members, and potential members would benefit from carefully examining any company's claims before getting testing or using that testing for enrollment. For example, the [American Society for Human Genetics](#) issued a statement about ancestry testing companies in 2008. Knowing which company provides what information, and what that information can and cannot do for a consumer (whether tribe or individual), is important.

Issues and Considerations in Using DNA Testing for Tribal Enrollment

Recent advances in DNA testing have brought with them possibilities for using DNA testing as criteria for tribal enrollment. Many people have found the prospect that these DNA tests can provide a concrete yes or no answer about biological relationships (parentage and descent) to be an attractive and positive aspect of using these tests. However, using DNA testing may limit the understanding of tribal identity to only a biological understanding if it is not supplemented with other tools or methods of determining tribal identity (or enrollment eligibility). Further, there are concerns that DNA testing within families and communities could reveal information about parents and lineage that contradicts other claims or family stories. More specifically each kind of testing offers particular positive aspects and some challenges above and beyond these basics.

Parental Testing – This kind of testing determines the parentage of a given child.

Positive Aspects: Can prove biological parentage. Confirms or denies the biological connection between two sampled individuals.

Challenges: Restricts definition of “family” to biological relationships, versus a more expansive understanding of kinship.

DNA Fingerprinting – This kind of testing looks at larger relationships in a family or community, not only direct parental lineage.

Positive Aspects: Can prove larger family connections, including parentage and some other types of relatedness. Confirms or denies the biological connection between two sampled individuals.

Challenges: Could reveal information about familial connections previously unknown or contradict family histories.

Ignores and potentially contradicts some tribal concepts of family that are not biologically based.

Genetic Ancestry Testing – This kind of testing looks at more historical connections; however, it cannot reflect the whole of a person's ancestry but instead traces ancestry through specific variations in genes.

Positive Aspects: Mitochondrial DNA testing proves maternal connections, and can prove clan as traced through the mother. Y-chromosome testing proves paternal connection, and can prove clan as traced through the father for a son.

AIMs can be very specific to a geographical area, and their use may enable tribes to organize in new ways.

Confirms or denies biological connection to a population or historical sample.

Challenges: Mitochondrial DNA testing restricts information to maternity of a particular child, and to the female line of descent. Y-chromosome testing restricts information to the father-son relationship, and to the male line of descent. Biologically determined but not definitely culturally specific. Only as accurate as the comparison samples and research in a database (for AIM testing). Could produce evidence that undermines homeland or historical descent claims. Ignores and potentially contradicts other tribal conceptualization of relationships. Can be used to undermine tribal ancestral stories.

The use of DNA testing for tribal enrollment raises many issues. Tribal enrollment criteria each represent a different value or set of values that the community holds. Over time, as the community changes so too might the membership criteria or the value that they represent. For example, lineal descendancy demonstrates a value of proven biological relation to a particular historical census record of tribal members. DNA testing may provide another tool to uphold such a value, but it has limits and is not the only tool that may be useful. When considering tribal membership requirements and whether DNA testing should become one, tribal leaders and community members might consider the values of the current criteria, the added (or not) value of DNA testing, the potential challenges associated with using a particular kind of DNA test, and particularly how it compares to other DNA testing. While genetic tests cannot determine whether an individual is AI/AN or not, they can determine whether people are likely related to one another. This limitation means that genetic testing will not be helpful in many enrollment cases, but it can be helpful for some areas with less documentation of family relationships or the need to confirm direct biological relationships.

Case Studies: How Tribes Are Currently Using DNA Testing

Case Study A: Using DNA testing to inform new tribal enrollment decisions

The [Mashpee Wampanoag](#) and the [Eastern Band of Cherokee Indians](#) have used DNA testing to prove or disprove both maternity and paternity claims by potential tribal enrollees. While the Mashpee have been using the testing for a decade as one piece of information obtained in their application for enrollment, the EBCI turned to this method of corroborating birth records and supporting applications for tribal enrollment after [an audit of the rolls](#) by the Falmouth Institute indicated that many documents, such as birth certificates, were missing from files of enrolled citizens.

The audit report from the Falmouth Institute is provided for information about the status of the EBCI's enrollment records immediately prior to the change in criteria. Also, links to newspaper articles about how community members reacted to the use of DNA are included below for additional information.

[Morris and Giles "Cherokee Enrollment Quandary leads to talk of DNA testing"](#)

[Morris and Giles, "Tribe moves to implement DNA for new applicants to Cherokee rolls"](#)

These two tribal enrollment ordinances and the newspaper reporting on one of them may help in considering the following questions:

1. What benefits might tribes gain from using maternity and paternity testing?
2. How do tribes deal with the potential challenges of such testing, including "entitlement" claims from outsiders?
3. What benefits might individuals seeking tribal enrollment gain from using maternity and paternity testing?
4. What challenges might such testing pose for individuals?
5. What methods exist for appealing a decision of the enrollment committee?
6. What do these methods of appeal offer for the tribe, the enrollment process, and for applicants?
7. Does such an appeals process exist in your tribe? Would it be useful or not?

Case Study B: DNA Testing for Disenrollment: DNA testing has been used not only as a criterion for tribal enrollment, but also for disenrollment. When DNA testing is used on the current citizenry, the testing may contradict family relationships described in original enrollment applications. However, this discrepancy may not even be known by the citizen in question because they may have

been raised to believe certain information about their parentage and family. For example, in an article published in [Indian Country Today](#), Kevin Taylor presents the stories of individuals disenrolled from tribal citizenship as a result of DNA testing. He also discusses how other individuals are using DNA testing to make a case for their enrollment applications to tribal nations. The article demonstrates that there are still many complications within a choice to use DNA testing for any aspect of tribal enrollment, and not all groups will agree on how or if they want to use this technology. Taylor's article may help in considering the following questions:

1. What values are represented by using DNA testing as a tool for determining tribal enrollment?
2. What are the benefits of applying DNA testing to the current tribal rolls? What are the challenges?
3. How does DNA compare with other criteria for creating unity and identity for a tribal group?
4. Does using DNA testing potentially contradict any of your tribe's traditions concerning family and relationships?

Case Study C: Federal Recognition of Tribes: In 2000, legislation was introduced in the Vermont legislature in an attempt to secure federal recognition for the Western Mohegan tribe after they paid for DNA testing [\[2\]](#) to prove their genetic similarity to a federally recognized tribe in Wisconsin. The Western Mohegan tribe used these genetic test results to argue for the historical existence of their tribe as part of their application for federal recognition. These efforts indicate a hope for DNA to do what has previously been unsuccessful by certain tribal groups: to prove their community identity. However, the wording of the legislation would have caused other Vermont tribes to require DNA testing, and the legislator who introduced the bill spoke of American Indians as a biologically and racially determined group instead of sovereign nations. Kim TallBear's article (2003, pg. 85-86) describes these events in more detail. TallBear's article helps in considering the following questions:

1. What problems of recognition does this use of DNA testing solve? Which might it create?
2. What should be the role, if any, of state or federal legislation related to tribal use of DNA testing?
3. How might the use of DNA testing at the outset to prove the connection of this tribal group to another influence enrollment requirements of either tribe?
4. What impacts could genetic testing have for a person, their family, their tribe, or their community?

In sum, identity is a sensitive issue for many American Indian peoples and nations. The ability to determine the political and legal identity of citizens/members remains within the realm of tribal sovereignty. How enrollment is determined through certain criteria is specific to each and every tribal nation. These differences mean that while DNA testing may be useful for some tribes, it may not be useful to others. Further, what works now may not be the same as what is needed or wanted in future generations, just as past generations adapted enrollment practices over time with different technologies, methods, and documents. The sections above have reviewed the use of DNA testing as a potential tribal enrollment criterion. The questions offered are intended to help tribal leaders and community members consider how DNA testing might be used in their own community contexts, should they decide to do so.

[\[1\]](#)In some cases, a genetic test can conclusively say that if an individual has a specific gene(s), they will develop a disease (e.g., Huntington's Disease). Other genetic tests can indicate if an individual is more likely to develop a chronic disease (e.g., diabetes or heart disease).

[2] Specifically, this tribe used a form of DNA testing not previously discussed that looks at genes of the immune system and compares these between individuals. This type of testing is most commonly used for organ transplantation. The tests discussed in this paper, and more often available and marketed to tribes, are more comprehensive types of DNA testing.

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