Native Americans fear potential exploitation of their DNA

Until the advent of genetic genealogy, knowing your ancestry meant combing through old records, decoding the meaning of family heirlooms and listening to your parents and grandparents tell you about the 'good old days.' For anthropologists and archaeologists interested in going back even further in time, the only reliable means of understanding human history were trying to interpret ruins or remnants of skeletons or other information uncovered at the site of remains.

DNA testing has changed all that, allowing us to delve far deeper into our past than before and with a much higher degree of accuracy. Although there are many issues stirred by DNA testing, none is more provocative than interpreting our family and tribal ancestries.

Nowhere is this more apparent than among the Native American tribes in the US. I previously <u>wrote</u> about a large-scale genetic analysis among the American population by personal genetics and genealogy company 23andMe, using its extensive database to begin to decipher the ancestral origins of various ethnic groups in the United States.

Though the study involved more than 160,000 people, less than one percent of those who participated self-identified as Native American. Rose Eveleth, a journalist writing for <u>The Atlantic</u> suggests that this lack of participation may have a lot to do with how native tribes perceive genetic testing,

But when it comes to Native Americans, the question of genetic testing, and particularly genetic testing to determine ancestral origins, is controversial. [...] Researchers and ethicists are still figuring how how to balance scientific goals with the need to respect individual and cultural privacy. And for Native Americans, the question of how to do that, like nearly everything, is bound up in a long history of racism and colonialism.

[...] for Native Americans, who have witnessed their artifacts, remains, and land taken away, shared, and discussed among academics for centuries, concerns about genetic appropriation carry ominous reminders about the past.

Eveleth references the widely publicized case where the Havasupai tribe living near the Grand Canyon sued an Arizona State University scientist for using genetic samples collected from the tribe to conduct research outside of the purpose of the original study. The crux of the issue was the consent form which covered a broad range of uses for the samples—a fact that the tribes claimed were not explained to them appropriately.

Although the tribe won the case, reclaimed the samples, and settled with the university for \$700,000, the issue captured the <u>front page</u> of the *New York Times*. The story put "every tribe in the US on notice regarding genetics research" as Native American tribal research ethics expert Ron Whitener <u>quoted</u> in an article titled "After Havasupai Litigation, Native Americans Wary of Genetic Research" published in the *American Journal of Medical Genetics Part A*.

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The Kennewick Man

Around the same time that the genetics of the Havasupai were being studied, another high-profile issue brought Native American tribes into conflict with researchers. The 'Kennewick Man,' an approximately 9000-year-old skeleton was discovered by accident in 1994 in Kennewick, Washington. The Umatilla tribe, which were indigenous to the region, sought to reclaim the remains under the 1990 Native American Graves Protection and Repatriation Act to bury it under traditions. Anthropology researchers who wanted to study the skeleton, however, argued there wasn't enough evidence to convincingly show that the remains were Native American and therefore should not be returned. This resulted in a widely publicized eight-year-long legal dispute between scientists and the government that ended in 2004 with the court ruling for the archeologists, a decision that the tribes were expectedly unhappy with.

The issue came under the spotlight once again with the *Seattle Times* reporting on January 17, 2015, that preliminary DNA analyses indicated that the Kennewick Man was indeed of Native American ancestry. Apart from settling the academic debate, this finding could reignite the social and political controversy that surrounded the affair as the tribes engage in renewed efforts to retrieve the skeletal remains and prevent further research on it.

While it is understandable that tribes are concerned about how their personal DNA (and that of their ancestors) is used, it is a stretch to think that this information might be used to "develop biological weapons or justify genocide" as Eveleth suggests. Nevertheless, genetic testing for public health or anthropological purposes is a tricky and thorny path to tread, particularly among Native Americans as she points out in her article:

So to many tribal people, having a scientist come in from the outside looking to tell them where they're "really" from is not only uninteresting, but threatening. "We know who we are as a people, as an indigenous people, why would we be so interested in where scientists think our genetic ancestors came from?" asks Kim Tallbear, a researcher at the University of Texas at Austin, the author of <u>Native American DNA: Tribal Belonging and the False Promise of Genetic Science</u>, and a member of the Sisseton-Wahpeton Oyate tribe.

[...]So what should a geneticist do, if she's interested in exploring a question that might involve gathering Native American DNA? It depends. Tallbear says that long before any research questions are formulated and samples are taken, the researcher should actually have a relationship with the tribe. "I think people who want to do genetic research on Native American topics really shouldn't be doing it unless they've got a really considerable history of contact with native communities."

Razib Khan, an evolutionary genetics researcher at the University of California, Davis, takes issue with how Kim Tallbear, an anthropology researcher at the University of Texas at Austin and the author of the book "Native American DNA: Tribal Belonging and the False Promise of Genetic Science," discusses the topic in the Seattle Times article (emphasis Khan's).

Let's not beat around the bush here, Native Americans and the government and culture of the United States have a fraught relationship. That is true. **But today genetics has pretty much zero relevance to the various political debates and arguments.** Issues like tribal membership are determined by the cut & thrust of politics, not genomics.[...] And contrary to the implication that Tallbear makes, most scientists who work on Native American genomics don't do so because of a deep interest in overturning the religious traditions of Native Americans, but because they are interested in the **human story**, of which Native Americans are an essential part. Rather than ethnic particularism the motives of scientists on the whole are those of universalist humanism.

So one can understand why political activists might balk at the inquiries of geneticists, as universalist humanism often causes problems for those engaged in the great game of ethnic particularism. But what about the academics who lend their voice in support of the latter?

In his analysis, Khan is frustrated—not at how the public is debating the issue but specifically at academics, who give in completely to personal biases and refuse to accept unequivocal genetic evidence. He compares Kim Tallbear with sociologist and intelligent design apologist Steve Fuller, ending with this furious volley (emphasis Khan's):

Here is an indisputable fact: science is not religion, and the two are very different enterprises. If you don't accede to this distinction, you have just lost all touch with the empirical world [...] The flight from empiricism is exactly what has occurred to many scholars within science studies, probably because that's where the career incentives are.

Most academics who are skeptical of the "objective" "truth" "claims" of "science" also agree with this fact when they have to put their choices where they mouth is. If they're diagnosed with "cancer" they won't put chemotherapy in quotations or demand the services of a tribal shaman. It's going to be the best science for them and their family. That's not just a theory, that's a fact.

While Khan is right, many tribes are quite reluctant to consent to have their DNA or that of their ancestors used for research and antagonizing the tribes through public personal and legal battles might only serve to alienate them further. In her *Atlantic* essay, Eveleth outlines the cautious approach taken by anthropologist Dennis O'Rourke at the University of Utah and how the native tribes contend with their mixed feelings about research:

... O'Rourke works collaboratively with tribes who are interested in what he's doing. [...] Some tribes, he says, worry about it, while others don't. "It's important to be very clear about what my interest in the research questions are," he said, "so if they're not of interest to the communities they can make that judgment very early and I don't waste their time in trying to pursue things that aren't acceptable."

[Nick Tipon, vice-chairman of the Sacred Sites Committee of the Federated Indians of Graton Rancheria] says that most tribes are struggling to balance what good might come with what harm they might be doing to tradition and their ancestors. "If someone could come to us and say 'yes, if we destroy this ancestor of yours, maybe we'd find a cure to cancer,' would we still have the same feeling? We're still struggling with that. Our traditional cultural feeling is you're buried, that's where you rest in peace, but all societies change. We talk about it. We wonder where the right answers are."

This is one of the forks on the road where science and society could part ways at the cost of both—to travel together will require a commitment to strong science and common sense.

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