

Cases of How Tribes are Relating to Genetics Research

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Introduction



American Indian and Alaska Native communities across the U.S. have diverse views on genetics research. Tribes have been involved in genetic research studies for many years. Some of these studies have raised questions about tribal control and regulation of research, assessing risks and benefits of research participation, and implications of participating in genetic research for tribes. This paper will highlight cases of genetic research in American Indian and Alaska Native communities. Discussion questions at the end of each section are provided for tribal leaders to consider.

The sections below include case studies about genetic research and ways in which genetic technology and testing are being applied (e.g., in tribal enrollment, understanding diseases, and personalizing one's medical treatment). The primary focus of this paper is on genetic research, but the same data that are collected in research studies can be used in many ways. For example, data collected for genetics can also be used for public health monitoring to better understand the prevalence of diseases like type 2 diabetes. Genetic data can also be used for studies examining human origins (i.e., where groups may have first originated in the world). Human origins research may unintentionally have political implications for tribal sovereignty and tribal membership. This is why these other issues are also covered here.

Cases and Examples of Genetic Research in American Indian Communities

Researchers have been conducting research studies on American Indians for centuries. More recently, researchers have been interested in conducting genetic research on American Indians. Today's standard is for research studies to be conducted in partnership with tribes. With the advancements in medicine and technology, tribal leaders and tribal research review boards are receiving more requests for biomedical research participation. This section describes cases and examples in which American Indian tribes have engaged in genetic research or have begun to think about the issues that their involvement in this research raises for their members. Not surprisingly, there is a large range of perspectives on engaging with genetics research across tribes. Some tribes are resistant whereas other tribes support genetic research.

Misuse of Blood Samples

[Havasupai Tribe and the lawsuit settlement aftermath](#)

[Bringing blood back to the Nuu-chah-nulth](#)

Moratorium on Genetic Research Studies

[Discussions on the Navajo Nation](#)

Collaborations with Genetic Researchers

[Cases of Collaborative Genetics Research with Tribes](#)

Genetic Ancestry and Human Migration Studies

[Types of Genetic Ancestry Tests](#)

Controversies in Migration and Ancestry Testing

[The Human Genome Diversity Project](#)

[Genetic Ancestry Tests for Tribal Enrollment](#)

Potential Risks and Benefits of Genetic Research

[Personalized Prescriptions](#)

Collaborative Research

[Data Sharing](#)

Points to Consider (To participate or not to participate?)

The Havasupai lawsuit is yet another reason that tribes have refused to participate in genetic research (Harmon 2010). Other tribes in the United States and Indigenous groups worldwide look to the Havasupai case cautiously as they think about policies, laws, and recommendations for genetic research in their communities. Additionally, very few tribes have benefited or had results returned, creating tension and mistrust.

The National Institutes of Health (NIH) has emphasized the inclusion of ethnic minorities, women, and children in biomedical research studies. However, many Indigenous Americans are hesitant to participate in research. On the other hand, by not participating in research, whether by choice or by being excluded from research, individuals and communities may not benefit from research. In recent years, more efforts have been made to engage research participants in research using community-based participatory research (CBPR) and other engagement practices. Tribal members need to be seen not only as participants in genetic research studies, but also as active contributors. Recent efforts have been made to bridge the divide between tribes and genetic researchers (Jacobs, Roffenbender et al. 2010), particularly in genetic research, such as by providing more educational

opportunities for Native American students to pursue genetic research or research in biological sciences. Other examples include engaging a community in collaborative efforts with researchers or bringing the community together in community-based participatory research in which community members are engaged in the research process and are able to provide input by allowing for respect and cultural exchange of ideas.

First Nations communities in Canada are able to control DNA samples in research studies as described in the paper, "DNA on loan: Issues to consider when carrying out genetic research with Aboriginal families and communities" (Arbour and Cook 2006). "DNA on loan" is a concept that describes how research participants maintain ownership over their samples and dictate its uses. As the authors write:

"the ownership remains with the participant or community, as has been designated. This concept leaves no room for misunderstanding. The researcher is not at liberty to use the sample without consent of the individual, community or designated party, even if the personal identifiers are removed" (p. 156, Arbour and Cook 2006).

Models like "DNA on loan" can provide a starting point for tribes to think about control of biological samples. Other [models for data control and sharing](#) are also available elsewhere in this resource guide, along with [model informed consent form language](#) and [tools to help tribes determine their own positions](#) on genetics research.

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