

Genetic Testing and Native Peoples: The Call for Community-Based Participatory Research

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GENETIC TESTING AND GENETIC RESEARCH in general are especially powerful in population studies. Genetic research can assess human genetic variation within and between populations, as well as potentially identify specific genetic determinants of disease. In the United States, isolated indigenous communities are genetically unique compared with an ever-growing homogenous population (Santos, 2008). The current dialogue surrounding population studies continues to develop among both researchers and the communities that are highly sought after for such studies, which include Native American Indian (AI) and Alaska Native (AN) tribes. In efforts to further engage in the conversation regarding the intersection of native peoples and genetic research, the National Congress of American Indians, in collaboration with the National Human Genome Research Institute and the National Museum of the American Indian, hosted a symposium in June 2014. The symposium, titled “A Spectrum of Perspectives: Native Peoples and Genetic Research,” was held at the Smithsonian National Museum of the American Indian in Washington, D.C.

Although native people’s perspectives with regard to genetic research are by no means uniform, many tribes approach genetic research with hesitancy and fear attributable to a legacy of western exploitation and ethical misconduct. Many research studies in the past have limited the input of native people and disregarded their traditions, thus causing many tribes to feel like “guinea pigs” participating in studies that didn’t benefit them (Fong *et al.*, 2003). Accordingly, as reflected at the symposium, many new questions have been raised across the United States among the AI and AN people as a way to address the concerns of their tribes and to demand greater collaboration in genetics research.

One of the main concerns among native people is a lack of clarity about the motivations behind genetic research and the question of direct benefits to their tribe. These concerns heightened in the early 1990s when the Havasupai, an AI tribe, teamed with Arizona State University to participate in a research project that was intended to help explain the high rates of type 2 diabetes in their community (Santos, 2008). In accordance with the study, the Havasupai provided blood samples and fingerprints. By the end of the decade, the Havasupai had received little to no information regarding the study and were told their samples were damaged because of a

freezer failure. However, not all the blood samples were destroyed, and instead of receiving permission from the Havasupai, the research team sent the blood samples to other universities. Genetic research continued, and the Havasupai were neither consented for the sample sharing nor informed about the findings of these new studies. As a result, the community filed lawsuits against Arizona State University for the violation of their civil rights (Santos, 2008).

As demonstrated by this example, the Euro-American tradition of research traditionally involves the extraction of data from a population using experts, which is then analyzed and processed elsewhere. This tradition of research is rather undesirable because it lacks an overall feedback component. However, many natives people do support research that is reciprocal and benefits the health of their community. Rather than relying on researchers to shift their framework away from the Euro-American tradition, many tribes have begun to demand greater control in the scientific process. The Kahnawake Mohawk community in Canada reflects an increasing initiative taken by tribes to engage in research through their development of a diabetes intervention program, which includes both a dietary and a physical component (Boweckaty and Davis, 2003).

In addition, many AI and AN tribes are apprehensive about the handling and treatment of individuals’ biospecimens. Although each tribe has different values and spiritual beliefs, biospecimens carry a great deal of value. Dr. Frank Dukepoo (Hopi tribe), a geneticist at Northern Arizona University, demonstrated this value in an interview with the *San Francisco Chronicle*: “To us, any part of ourselves is sacred. Scientists say its just DNA. For an Indian, it is not just DNA, it’s part of a person, it is sacred, with deep religious significance. It is part of the essence of a person” (Petit, 1998).

When researchers approach native people, they follow a framework that is distinct to that community’s cultural, historical, political, and spiritual identities. These various cultural nuances and specific spiritual traditions must be regarded in scientific research because their significance bears a heavy weight for the population under study.

Native people also face anxiety over postulating how genetic research could harm the tribe. Some studies have the potential to question cosmologic views or migration patterns, which could ultimately challenge traditional beliefs, such as

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creation myths (Bowe Katy and Davis, 2003). This discord can cause psychological harm or tensions within and between tribes. Moreover, published studies have the potential to portray AI and AN populations in a negative light, which adds to the social stigmatization of their people. Population studies seek to study small groups in isolated areas, but the AI and AN populations are very distinct. These populations are considered nations, as demonstrated through the commonly used term *Indian Country*, with strong identities. They are unique across many fronts—genetically, spiritually, culturally, politically, and socially—and as a result, the ethical issues surrounding population studies cannot be generalized, for the values and belief systems differ from tribe to tribe.

At the symposium, a common theme that tied many of the speakers together was the call to shift genetic research towards more interactive and collaborative methods. One such existing method currently being used, community-based participatory research (CBPR), requires the following nine factors: (1) recognizes community as a unit of identity, (2) builds on strengths and resources within the community, (3) facilitates collaborative, equitable involvement of all partners in all phases of the research, (4) integrates knowledge and action for mutual benefit of all partners, (5) promotes a co-learning and empowering process that attends to social inequalities, (6) involves a cyclical and iterative process, (7) addresses health from both positive and ecological perspectives, (8) disseminates findings and knowledge gained to all partners, and (9) involves a long-term commitment by all partners (Israel *et al.*, 2001).

The method of CBPR challenges the Euro-American tradition of research by calling for a restructuring of population-based studies, allowing for greater long-term partnerships with the community. It ensures that the genetic research is addressing the community's needs and respects their tradi-

tional beliefs. Through these more collaborative methods, both groups stand to gain. The CBPR method demands clear and transparent guidelines, thus assuaging many of the AI and AN tribes' hesitations and allowing them to approach genetic research with curiosity, instead of fear.

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