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Genetic Research in Native Communities

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“Freedom is the right of an intact community not to be intruded upon by outsiders in pursuit of interests at variance with those of the community.”¹

INTRODUCTION

The Human Genome Project is expected to reap many benefits for science with the potential to prevent, diagnose, and treat genetic diseases, such as diabetes and cancer. While the majority of researchers (mainly Northern Europeans) are studying the “standard genome” others are attempting to study variations within and between populations, searching out genomes of isolated indigenous populations like Native Hawaiians in the Pacific and the Havasupai Indians on the U.S. continent. Indigenous peoples—those special populations who have retained their diverse cultures, customs, and languages because of their relative isolation—are of great interest to genetic researchers because of the genetic uniqueness of their genomes. The challenge in genetic research on indigenous peoples is that it raises complex legal, ethical, social, spiritual, and political issues.²

Research from the Euro-American tradition refers to the usual “extractive” research carried out by universities and governments, who send their “experts” to a community, extract information from “subjects” and take away the data to write their papers, reports and theses with no reciprocity or feedback to the community. In contrast, principles of community-based participatory research (CBPR), which are becoming more widely adopted by Native communities, require that research: 1) address health of the community within its broader cultural, social, economic, and political context; 2) involve community at all levels, from priority setting and planning to interpretation and dissemination of findings; 3) identify community needs and concerns that need to be addressed; 4) build on the strengths and resources within the community; 5) promote co-learning and knowledge transfer; and 6) provide tangible benefits to the community.³

Similar to the rapid growth in computer technology, the field of molecular biology has outpaced the development of new policies and laws that can effectively address the legal, social, and ethical concerns raised by genetic research. As such, for Native communities it is unlikely that their ethical issues will be adequately addressed in the course of research from the Euro-American tradition. This is because although researchers, scientists, and bioethicists meet to discuss ethical issues, benefits, risks and unique questions about genetic research in Native communities, indigenous people are rarely at the table. And, if they are, they are few in number and their voices, even if heard, often are ignored. For the most part, Native viewpoints are not respected or understood because their concerns often require more time, consideration and effort, and do not fall within the structure of the Euro-American research tradition. The current

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genetic research paradigm is one of paternalism and biocolonialism based on previous and on-going practices of Euro-American research.^{2,3}

The purpose of this manuscript is to (1) provide examples of abuse in genetic research and (2) discuss ethical issues that researchers should consider prior to working with Native communities. In doing so, we intend to promote the use of more appropriate research processes like CBPR among researchers from the Euro-American tradition who collaborate with Native communities.

EXAMPLES OF ABUSE IN GENETIC RESEARCH

Until recently, very few indigenous groups were aware of genetic research. For a Native American tribe in Arizona, what would begin with great promise and build upon relationships established between a respected researcher and an impoverished community would result in increased distrust of “research” and destruction of relationships.

In the early 1990s, the Havasupai—an isolated Native American community—agreed to be part of a research project conducted by researchers from Arizona State University, thinking it would help to explain the high incidence of type-2 diabetes among Havasupai. As part of the project, tribal members provided blood samples, handprints, and fingerprints. By the late 1990s, the Havasupai had received no information to indicate a genetic link or predisposition to diabetes. The tribe believed the study was over after a freezer failure at ASU that damaged the blood samples and the move of one of the principal researchers to another university.⁴

However, unbeknownst to the Havasupai, cell lines damaged from the freezer failure were salvaged, and vials of their blood had been sent to other labs and shared with other researchers.⁵ Thus, genetic research on the Havasupai continued beyond their understanding of the scope and duration of the study, robbing them of making an informed decision on whether or not to participate. In addition, none of the other researchers shared their research studies or findings with the Havasupai. These and other actions by the researchers caused great controversy and resulted in lawsuits filed on behalf of the Havasupai, alleging exploitation and violation of civil rights.^{5,6}

Native Hawaiians have a long history as “subjects of research,” dating back to the 1800s, when citizens of the Kingdom of Hawai`i were exiled to Kalaupapa, a Hansen’s disease colony on the remote northern peninsula of the island of Moloka`i. It was here that a government physician Dr. Edward Arning conducted unethical studies on this vulnerable population looking for the mode of transmission of leprosy.^{7,8}

The negative experiences of Native Hawaiians with research have continued into the 21st century. For example, a family in a rural island community suspected of having a rare genetic condition submitted blood samples for research, with no informed consent. There was no follow up with the participants until a Native Hawaiian health organization advocated on their behalf, requiring researchers share the findings, which confirmed a rare genetic disease. The study made no provisions for genetic counseling, genetic testing, or treatment, leaving the family frightened and putting the burden of care on local health providers, who had limited capacity to address this rare disease.⁹

Since 2003, the University of Hawai`i has drawn angry responses from Hawaiian communities for announcing intentions to map the Native Hawaiian genome.¹⁰ These same sentiments have also surfaced with the University’s intent to genetically modify *kalo* (taro),^{11–13} the traditional staple of the Hawaiian diet which is culturally identified as an ancestor by the Hawaiian people.¹⁴

ETHICAL QUESTIONS FOR RESEARCHERS AND COMMUNITIES

Native communities must ask several questions when approached to participate in genetic research.

1. What is the Adequacy of the Informed Consent Process?

More than 400 blood samples were collected from the Havasupai who believed the ASU researchers' concern was the tribe's diabetes epidemic. However, the actual consent form was vague, obtaining participant consent for genetic studies into behavioral and medical disorders.⁵ Thus, the Havasupai were surprised when their blood was used to study schizophrenia, inbreeding, and migration patterns. The vague wording of the consent form appears to be in violation of the guidelines published by the National Commission for the Protection of Human Subjects in the United States. According to the guidelines:

Approved research protocols in which researchers intend to collect and store human specimens or data must include a written description of the intended use of the samples; how they will be stored; how they will be tracked; what will happen to the samples/specimens/data at the completion of the protocol, and what circumstances would prompt the principal investigator to report the loss or destruction of samples.¹⁵

Consent forms should also remind participants that they can withdraw from research at any time without penalty and ask that their samples be destroyed at any time and for any reason. The Havasupai case reminds us that researchers need to be transparent and forthright about the intent of the research and not abuse the written consent process with vague language that allows for potential abuse. For the Havasupai, the informed consent could have stated that participants' specimens would not be used for future research without additional consent.

Another issue about consent is readability. According to the National Institutes of Health, "Consent documents should be written so they are understandable to people who have not graduated from high school." Most of the Havasupai who were asked to give blood had not graduated from high school and had limited English proficiency. Still, more than 100 tribal members signed up in the summer of 1990 before donating their blood.⁵ According to Wallwork, an informed consent process that separates the individual from his or her community may fail to convey the genuine significance of the study to the subject, and thus fall short of truly informed consent.¹

2. Is respect for cultural knowledge demonstrated?

Altruistic motives and good intent should not automatically grant an individual or institution the right to gather, access or use genetic information or material. When working with Native communities, their cosmological world view should take precedence during the design, implementation, analysis and use of findings of any genetic research. For example, the findings on the Havasupai blood suggested they migrated from Asia across the Bering Strait. This announcement challenged the tribe's worldview of their identity and origins, which is based on the belief that the retreating waters from a global flood carved the Grand Canyon and that the Canyon is the birthplace of the human race.⁵

If academic generated research undermines the cultural fabric and beliefs of a group, it is tantamount to stripping them of traditions and practices that have also served as protective factors for generations. To quote Dr. Frank Dukepoo, a geneticist of Hopi and Laguna ancestry, from an interview in 1998 with the San Francisco Chronicle:

“To us, any part of ourselves is sacred. Scientists say it’s 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.”¹⁶

Traditionally, Native Hawaiians were noted researchers in medicine, agriculture and ocean sciences. With their traditional belief that all things possess *mana*, a life force, and the genealogical connections to taro as a recognized ancestor, it is not difficult to understand their reactions to genetic studies that threaten to alter their worldview and traditional ideology. Native Hawaiian who also regard their body parts, hair, nails, teeth, and blood as having a spiritual essence (*mana*) consider research on these specimens to be ethically and culturally wrong.

Available funding and revenue-generating potential should not dictate the aims of genetic research in Native communities. Researchers are remiss and naïve to assume that beneficence” as described in the Belmont Report is limited to western-perceived benefits for the individual like money or even the altruistic contribution of adding to the body of knowledge to finding cures for diseases. An editorial in Nature suggests that the Havasupai’s concerns served to obstruct scientific progress:

Some ethicists suggest that an obsession with the details of consent have caused research subjects to forget they have an opportunity to help not only their own tribe, but all mankind. For Native Americans, this is a hard concept to accept. Having seen their people and cultures abused for centuries, they are understandably hypersensitive. But it could be a new form of empowerment for them to realize that their culture helped cure a disease.¹⁷

According to Singeo, the University of Hawaii proposed patenting the Native Hawaiian genome with the purpose of generating both economic and health-related benefits for the Native Hawaiian people. However, this was strongly opposed by the Native Hawaiian community, which viewed it as an unwelcome imposition of Western property concepts upon their traditional ideology.¹⁰

3. Will the Research Harm the Group?

Based on the Nuremberg Code and Belmont Report, researchers have a moral obligation of beneficence. As such, Institutional Review Boards that review research are charged with assuring that research maximize possible benefits and minimize possible harms. However, basic standards in research involving human subjects only require that the benefits of the research at least equal the risk. Interestingly, most population-based genetic research does not meet this requirement because most researchers seek different outcomes of research, such as more research, published papers, professional advancement and recognition – all the benefits received by the lead ASU researcher from the Havasupai study. Researchers are not skilled in understanding “risk” as perceived by indigenous groups. One example is the emphasis of the informed consent process on the individual or “subject” versus the group or community. This is opposite to the value held by many indigenous groups including Hawaiians, who put family and community before self. Beneficence as it applies to research is meant to require researchers to avoid harm not just to individuals, but to community needs, interests, and values.¹

In regards to “provable harm,” a term used in the case of the Havasupai, the question researchers should be required to ask is not whether harm is provable, but whether harm, including group harm, is likely. This includes issues of group harm, such as social stigmatization (associated to mental illness) and insurance discrimination based on genetic predisposition for a disease.

One of the researchers in the Havasupai study hypothesized that the high prevalence of diabetes was caused by deficient nutrition during fetal development.⁵ If the “best interests” of the tribe

was the intent of the study, an intervention involving prenatal nutrition education could subsequently have been developed and implemented to address the high incidence of diabetes. The application of CBPR principles might have avoided this situation by including the community's involvement in prioritizing community needs and in translating and applying data findings to tangible interventions. Instead, the study left the Havasupai's health situation unchanged and their questions unanswered.

4. Who Profits from the Research?

Indigenous communities view commercially-driven genetic research that secures ownership for profit or academic advancement as biocolonialism. Biocolonialism in the form of genetic bioprospecting often arrives in Native communities without invitation. Such was the case of the Havasupai, who believed their blood samples were to be used solely for their collective benefit and well-being, not the academic benefit of researchers, particularly unknown researchers who did not have an established relationship with the tribe or its members. By early 2002, 23 academic papers, articles, and dissertations had been published on research that examined Havasupai blood. Of these, 15 focused on schizophrenia, inbreeding, and migration...not diabetes. One of the principal researchers on the study moved up the academic ladder to the highest level in the state's university system -- and won acclaim as one of the nation's top scientists.⁵

One-fifth of human genes in the U.S. have been patented.¹⁸ Indigenous groups are opposed to the idea of patenting genetic sequences because genetic sequences are part of a life form which cannot be claimed as invented. Biotechnological inventions resulting from genetic materials may be financially lucrative to researchers and patent holders, but rarely benefit the individual or community from whom the DNA is taken. No one knows this better than John Moore, who in 1976 was diagnosed with hairy-cell leukemia and referred to a researcher affiliated with a well-known biomedical institution, which required Mr. Moore to travel from his home in Seattle to Los Angeles for visits he was told were necessary and required for his health and well-being. He later learned that a patent was granted for his cell line, without his knowledge or consent, naming the researcher and research assistant as the inventors.¹⁹ Once again, the researchers garnered royalties and the subject received no compensation.

The Euro-American-centric bioresearch model assumes that an individual has the right to sell or give away genetic material or traditional knowledge.² This model fails to acknowledge indigenous belief of stewardship and ancestral endowment. There is also the responsibility that goes hand-in-hand with the holding of traditional knowledge, which is of no consequence to a researcher concerned only with having the data to test his/her hypothesis. The traditional knowledge indigenous people have about their environment, as cohabitants of their ecosystems, is seen as a new gold mine for commercial benefit by profiteers from outside that place, culture, or community. Because indigenous populations represent a significant percentage of the world's human diversity, at a time of diminishing resources, their knowledge systems and biological resources are therefore extremely threatened by exploitation and appropriation.²

The Paoakalani Declaration written by Native Hawaiians is an expression of their collective right to self-determination in the perpetuation of their culture, under threat of theft and commercialization of traditional knowledge.²⁰ It states:

“In Hawai`i, bioprospecting and biotechnology institutions and industries are imposing western intellectual property rights over traditional, cultural land-based resources. This converts our Kanaka Maoli (Native Hawaiian) collective cultural property into individual property for purchase, sale and development. The biogenetic materials of our peoples, taken for medical research for breast cancer and other diseases attributable to western impact have been obtained through misrepresentation,

and without the free, prior, or informed consent of our people. We view these activities as biopiracy and condemn these acts as biocolonialism.”

CONCLUSION

Genetic research is a given and will continue. The potential problems are also a given and must be addressed. Research should be about ethically rigorous processes and effectively tailored interventions that address community needs, interests, and values. Even if the research for a genetic cause of the Havasupai’s diabetes was initiated with honest intentions and good will the process was flawed and compounded by arrogance due to paternalistic and biocolonialistic attitudes.

Over the past decade, indigenous peoples and minority groups are more actively applying and using CBPR principles when approached to participate in research. Applying these principles can help insure that genetic and other research address community priorities and are respectful of traditional beliefs and practices. Through sincere partnerships there are opportunities to build community capacity to engage as equal partners and beneficiaries in research. Success has been achieved among indigenous groups using CBPR with behavioral and intervention research^{21–23} Its application to genetic research, coupled with policy to protect the rights of indigenous peoples, like the work of the Indigenous People’s Council on Biocolonialism will provide a better foundation that reflects and supports the interests of the Native community.

Having a proactive community IRB may be one of the most effective means toward achieving equal and ethical treatment in population/group-based research.²⁴ In Hawai`i, the Native Hawaiian Health Care Systems (NHHCS) IRB assures that research is targeted to community priorities, is culturally sensitive, has tangible benefits for the community, and is attentive to group harm. The NHHCS IRB recognizes that, despite past wrongs, research focused on developing and improving health programs is valuable for Native Hawaiian communities. Thus this body serves as a mechanism for increasing knowledge about and involvement in research among Native Hawaiians, including genetic research. The IRB also supports the community’s right to receive data findings first and to negotiate with researchers the distribution, use and ownership of data, as well as authorship on resulting publications.

The NHHCS IRB supports the engagement of Native Hawaiians as equals in research. As a result, more Native Hawaiians are serving as principal investigators, co-investigators, and research associates. Since 2005, NHHCS IRB founders have mentored other community-based organizations in establishing their own community IRBs.²⁵

In summary, indigenous voices are stronger today because of the lessons learned from egregious past abuses. The challenge for indigenous peoples and their communities will be in regulating activities that have the potential to result in “mining” of genetic specimens. Indigenous leadership has the responsibility to advocate for policies regulating the framework in which funding decisions and research projects are carried out, as well as demand that institutions through their funding mechanisms require research result in tangible benefits for the community. The Indigenous People’s Council on Biocolonialism has already begun to enact local ordinances and codes to ensure tribal interests are protected.² Researchers have the responsibility of employing research processes like CBPR to equitably engage the community in the entire research process, including research aims, decision making and the interpretation and dissemination of data. This will also allow parties to acknowledge cultural nuances that need to be addressed in genetic research. Hopefully, the issues highlighted here will caution researchers not to build on the misfortunes and misunderstandings of Native communities and strive for research that is enhanced by community participation; leaving indigenous people with a legacy of empowerment, hope, and tangible benefits.

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