Issues in Genetic Testing in Navajo Populations

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American Indian populations have unique genetic issues:

• Specific disorders are more common, others more rare
• Special status and protection in genetic studies
• Group/tribal identity; issues of group autonomy
• Historical issues with federal authorities
• Importance of origin beliefs
• Consequences of the NAGPRA
• Strong, negative and widespread views on genetics and genetic studies
• Genetic diseases are found in every population
• Some populations have a higher incidence of specific genetic diseases:
  - CF in Northern Europeans
  - Sickle Cell Anemia in Africans, etc.
• These populations can facilitate the identification of the disease-associated genes
More Frequent Genetic Disorders among the Navajo and Athabaskan Peoples

- Albinism
- Athabaskan Severe Combined Immunodeficiency
- Athabaskan Brain Stem Dysgenesis
- Navajo Neuropathy
- Poikiloderma with Neutopenia
- Microvillar Inclusion Disease
Genetic Bottleneck (founder effect)
In 2002, the Navajo Nation Council established a moratorium on genetic research within its jurisdiction. The Council said the ban would be maintained until the nation’s human research code could be amended to speak to issues of gene therapy and potential discrimination.
Not just the Navajo

Declaration of Indigenous Peoples of the Western Hemisphere Regarding the Human Genome Diversity Project

“In the long history of destruction which has accompanied western colonization we have come to realize that the agenda of the non-indigenous forces has been to appropriate and manipulate the natural order for the purposes of profit, power and control.

Genetic technologies which manipulate and change the fundamental core and identity of any life form is an absolute violation of these principles, and creates the potential for unpredictable and therefore dangerous consequences.

We denounce and identify the instruments of intellectual property rights, patent law, and apparatus of informed consent as tools of legalized western deception and theft.

We demand an immediate moratorium on collections and/or patenting of genetic materials from indigenous persons and communities by any scientific project, health organization, governments, independent agencies, or individual researchers.”
Why a Moratorium?

- Human Genome Diversity Project
- Lack of Immediate Medical Benefits
- Examples of misuse of samples
- Origin/Identity beliefs may be in conflict
- Patent/Money/Therapy Issues
- Tribal Privacy/Sovereignty/Autonomy
Human Genome Diversity Project

“To sample and archive the world's human genetic diversity.”

“To study human origins and patterns of population genetics.”

"The populations that can tell us the most about our evolutionary past are those that have been isolated for some time, are likely to be linguistically and culturally distinct, and are often surrounded by geographic barriers." - Luca Cavalli-Sforza

These "vanishing populations" might disappear before science could gain knowledge about the evolutionary process from them, enrich our understanding of race formation, and enable us to better understand and treat a variety of diseases.
The high rate of Diabetes in Pima Indians has been studied for more than 40 years.
After 35 years, what have you got to tell us about the genetics of diabetes?

"Well, we think about clusters here and there and chromosome so-and-so."

Have you really elucidated a genetic mechanism?

"Not so far, it's still kind of fuzzy. There may be genetic underlying mechanisms, but precise mechanisms, no we don't know that."

Well, after 35 years of studying I don't know how many millions, if not billions, in that study, a lot of professional training, a lot of papers, a lot of professional preparedness, and climbing that ladder, post-docs, everybody else in there, what have you got to say after 35 years of study?

"Frank, two things: watch your diet and get plenty of exercise."

- Frank Dukepoo
“Arizona’s Broken Arrow”
by Jana Bommersbach
Phoenix Magazine, November, 2008

Blood/DNA collected for diabetes research, but used for schizophrenia and population origin studies

http://www.phoenixmag.com/lifestyle/200811/arizona-s-broken-arrow/

See also:

Civil case settled in April 2010

After spending $1.7 million fighting lawsuits by tribe members and acknowledging a desire to “remedy the wrong that was done,” the university’s Board of Regents agreed to pay $700,000 to 41 of the tribe’s members, return the blood samples and provide other forms of assistance to the impoverished Havasupai — a settlement that legal experts said was significant because it implied that the rights of research subjects can be violated when they are not fully informed about how their DNA might be used.
Distrust!

Human Diversity Project – many tribes
Lack of direct benefit to community - Pima
Research abuse - Havasupai

Results not accessible
Rewards to researchers, not to subjects
Not a partnership
Progress towards engaging the Navajo in Genetics Education

- First met with Navajo IRB July 2007
- Open communication/planning with tribal members/officials
- Local partnership with Dine’ College, March 2008
- “Genetics Forum/Exchange” (two-way communication)
- Dine’ College venue
- One day event with lunch provided
- Opening and closing ceremony
- Local catering
- Local advertising (print and radio)
- Local & outside speakers & local consumers
- April 2009 held “Community Conversation on Genetics” in Shiprock, NM
“Community Conversation on Genetics”

- What is Genetics?
- New-born screening
- Genetics and health of the Navajo People
- Genetic research – promise and problems
- The future of Genetics and the Navajo People

Refreshments provided, Public invited!

Diné College
Shiprock Campus
Friday, April 3, 2009
College Gymnasium
9:30 am to 5:00 pm
Participants

There were over 100 attendees at the Shiprock community conversation, including:

- Navajo community members
- Representatives of academic institutions in the region
- Community-based organizations and programs
- Students of Diné College
- The Navajo Institutional Review Board
- The Indian Health Service
PROGRAM

Video on Genetics: “A Gift of Life” (in Navajo)
Opening Ceremony - Johnson Dennison (in Navajo)
Welcome and Introductions - Local Emcee

- What is Genetics?
- Newborn Screening
  - Lunch -
- Genetics and health of the Navajo People
- Genetic Research: Promise and Problems
- The Future of Genetics and the Navajo People
This was a real conversation…

Between speakers and the audience

and

Among the Navajo themselves

Consumers (parents of children with genetic disorders) discussed their needs and hopes with IRB and other policy setters.
Evaluation

- Over 70% of respondents said they learned something new.
- Four out of five respondents indicated that their understanding of genetics improved, that they saw the value of genetics in newborn screening and that they understood the value of genetics and health.
- More than 85% of respondents said they understood the issues related to genetic research.
What worked

• Patience
• Partnering with a local institution
• Including as many local speakers as possible
• Acknowledging the autonomy of the population
• Listening - it’s a conversation
• Collaborative planning
The Community Conversation on Genetics was developed and supported in collaboration with:

• Diné College of Shiprock, NM
• The University of New Mexico School of Medicine, Department of Pediatrics
• The University of Arizona, Genetics Program
• The National Newborn Screening and Genetics Resource Center
• The National Coordinating Center for the Genetics and Newborn Screening Regional Collaborative Groups
• The Health Resources and Services Administration, Maternal and Child Health Bureau, Genetic Services Branch
What I’ve learned

There is a need for BOTH Native Americans AND medical researchers to learn about issue surrounding genetic research.

Genetic studies will be helpful to Native Americans.

There are valid reasons for Native American hesitancy when it comes to genetic studies.

Currently NBS is not primarily DNA-based and is considered part of medical care. But what happens when it is DNA based?

Only through dialogue (true two-way) can we come to a mutual understanding.
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Speakers: Johnson Dennison, Edward Garrison, Murray Brilliant, Nanibaa’ Garrison, Randall Heidenreich, Susie John, Jennifer Puck, Yolanda Sandoval, Robert Erickson, Mark Bauer, Martha Austin-Garrison, Anslem Roanhorse, Jack Jackson, Beverly Becenti-Pigman, Gilbert John.