Ethics of Biospecimen Use: Considerations for Tribes and Genetics Researchers

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Overview of Presentation
• Experiences of communities
  • Havasupai Tribe
  • Nuu-Chah-Nulth Tribe
  • Additional tribal perspectives
• Indigenous approaches to Bioethics

Under-Representation in Genetic Research

Havasupai Tribe’s experience
• A genetic study of diabetes
• Approval from the ASU Institutional Review Board (IRB)
• An informed consent process was conducted for studies on “behavioral / medical problems”
• Blood samples were collected from ~400 tribal members
Objections to misuse of DNA samples

- Inconclusive results for Diabetes study
- Samples were shared with other researchers; used in studies on schizophrenia, inbreeding, and migration
- Tribe sued ASU researchers over misuse of DNA samples

The aftermath of the settlement

- Media attention, important ethical issues raised, and an impact on tribes
- No legal precedent after the out-of-court settlement
- Technicalities (timing of lawsuit, informed consent form, etc.)
- DNA samples were returned

Nuu-chah-nulth donated blood

- In the 1980’s, Nuu-chah-nulth donated 800 samples to the study (U British Columbia)
- Tribe has high rates of rheumatoid arthritis

Samples aided other research

- Investigator took samples with him to U Utah, then to U Oxford (UK)
- Studies conducted on ancestry, HIV/AIDS, and drug abuse
- Published >200 papers throughout his career, never reported results to tribe
Return of blood samples

“Our family has been hit pretty hard by arthritis. It’s really, really hard to watch someone you love suffer like that when you can’t do anything to help. It’s hell.” - Cosmos Frank (Ahousaht Elder)

“DNA on Loan” concept developed
See Arbour and Cook (2006) “DNA on Loan: Issues to Consider when Carrying Out Genetic Research with Aboriginal Families and Communities” in Community Genetics

Body Fragmentation

• Examination of community members’ views on specimen use and disposition (after a study ends)
• Reflections on the study findings/themes (discussion)
  • Views on blood and biospecimens
  • Connection to spirituality (ceremony and blessings), a holistic view of self
  • Sense of ownership ('DNA on Loan,' trust in the researchers)
  • Dangers of body fragmentation


What should be done with samples when a research study is over?

Table 2. Views on biological specimen disposition by traditional person status

<table>
<thead>
<tr>
<th>Aspect of Biological Specimen Disposition</th>
<th>Self-identification as traditional person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specimen fate at the end of a research study:</td>
<td>Self-identification as traditional person</td>
</tr>
<tr>
<td>Disposed of</td>
<td></td>
</tr>
<tr>
<td>Option for specimen being returned to research participant</td>
<td>20 (74%)</td>
</tr>
<tr>
<td>Skipped for future use</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Returned to the community</td>
<td>3 (12%)</td>
</tr>
<tr>
<td>Skipped for research participant</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Shared with other researchers</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Option for specimen being returned to research participant</td>
<td>8 (30%)</td>
</tr>
<tr>
<td>Skipped for future use</td>
<td>2 (9%)</td>
</tr>
<tr>
<td>Returned to the community</td>
<td>5 (19%)</td>
</tr>
<tr>
<td>Skipped for research participant</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>Shared with other researchers</td>
<td>1 (4%)</td>
</tr>
</tbody>
</table>
Dangers of Body Fragmentation

There are a lot of old traditions that people still follow. Our traditions say that if you have your leg taken off, it means you’re going to walk in the next world with one leg. Usually, when people do that, they try to keep the bones with them. That’s one of the reasons that a lot of the people don’t want to do kidney donations. And that—that’s an issue that really needs to be talked about to help your fellow Native Americans.

• Feeling of not being “whole”
• Fear of having to journey into the next world (death) while being incomplete

An indigenous perspective on DNA

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.

- Frank Dukepoo, Ph.D. (Hopi geneticist, 1943-1999)

Navajo Nation Moratorium

Approved, April 2002

RESOLUTION OF THE HEALTH AND SOCIAL SERVICES COMMITTEE OF THE NAVAJO NATION COUNCIL

Approving a Moratorium on Genetic Research Studies Conducted Within the Jurisdiction of the Navajo Nation Until Such Time that a Navajo Nation Human Research Code has Been Approved by the Navajo Nation Council

• Discussions took place over whether or not to allow genetic research
• Concerns were raised about possible stigmatization, biased interpretations, and lack of direct benefit
• No policies or guidance were in place to evaluate genetic research protocols

Indigenous Approaches
Indigenous ways of incorporating Ethics

• “DNA on Loan”
  • First Nations (Canada)
  • DNA is on loan to the researchers
  • DNA remains property of the donor/community
• Alaska Area Specimen Bank
  • Most (85%) are from Alaska Native people
  • Tribally controlled


Collaborative research with Yup’ik Alaska Native

• Community-based participatory research (CBPR) framework
• Investigating activity and a traditional Yup’ik diet with genetics
• Core values: respect, responsibility, and reciprocity
• Building research capacity, train fellows to conduct research
• Return clinically-actionable

www.uaf.edu/canhr (3 minute video)
Center for Alaska Native Health Research
- PI: Bert Boyer (U of Alaska, Fairbanks)

Community-based discussions

• Northwest-Alaska Pharmacogenomics Research Network (PGRN)
  • Discussions on risks/benefits, overcoming mistrust, and control
• Data Sharing
  • Who makes decisions about data access?
  • If my data are in dbGaP, do I have a say in how the data are used?
  • These concerns are not unique to tribal communities.


Genetics Resource Guide

- Resource for Tribal Leaders and Researchers
- Webinar discussions with Tribal Leaders
- Initiated by the National Congress of American Indians

http://genetics.ncai.org/
Indigenizing health discussions
• Collaborative efforts
  • Diné College and Mayo Clinic, funded by National Cancer Institute
  • Terms in Navajo to English to Navajo
  • Creation of new terms:

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Iólóó doo náátsílii
“Sore” “not” “heal, the one”
Ats’íis bítóló dáb diníshéh
áádóó hā’íté’ hóló yílích.
Cells in the body that grow uncontrollably
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http://www.dinecollege.edu/institutes/CP/CancerGlossary.pdf

Questions?
Ahéhee’ (Thank you)
Contact: naniba@uw.edu

Resources

Web Resources
• Genetic Education for Native Americans:
  http://www.natamcancerinitiatives.org/GENA/GENA.html
• NCAI Genetics Resource Guide: http://genetics.ncai.org/
• Glossary for Basic Cancer Terminology in the Navajo Language,
  http://www.dinecollege.edu/institutes/CP/CancerGlossary.pdf

Academic Publications