

Tribal Data Sharing and Genetics Policy Development Workshop: Updates

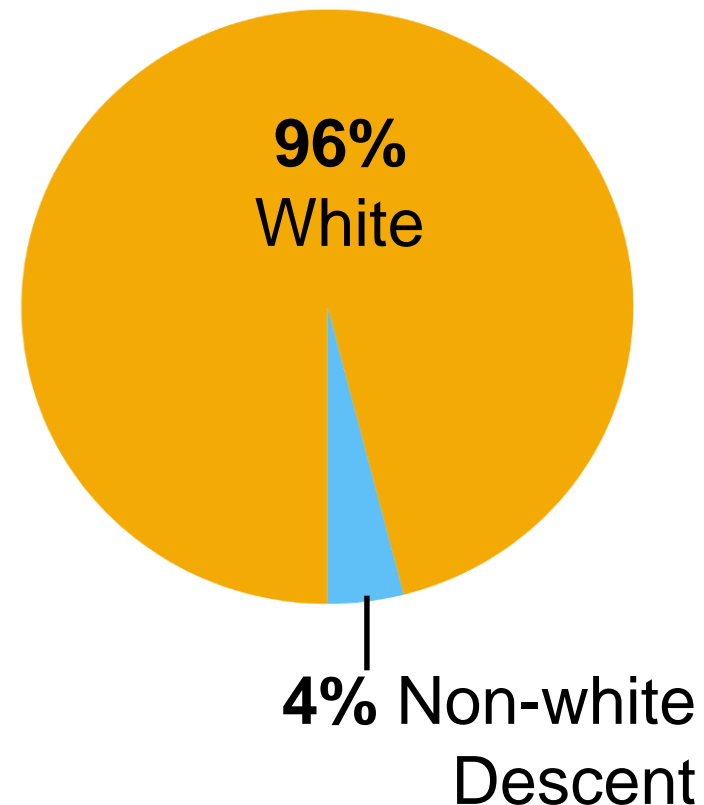
*Honorable Navajo Nation Council Delegate Walter
Phelps*

National Congress of American Indians
Tribal Leader/Scholar Forum
Kansas City, MO
June 5, 2018

Why should genetics matter to the Navajo people?

- Genetics is advancing rapidly, and is leaving out certain groups of people.
- Most genetic studies only include white populations.
- Genetics has the potential to improve our knowledge of disease and health outcomes

Genetic studies



The beginning of discussions on genetic research

Tribal Data Sharing and Genetics Policy Development Workshop

- August 31 & September 1, 2017
- UNM Comprehensive Cancer Center, Albuquerque, NM



Videos available online at: <https://sites.google.com/view/unmcehp17/home>

Meeting highlights

- Key concerns expressed
 - Navajo people and others have survived many unethical experiences including in the area of research.
 - Many health issues impact the Navajo.
 - Many expressed the need for a strong genetics research policy.
 - A policy must be inclusive of Navajo perspectives on and off the Nation.
 - There is the potential that this policy will impact to other tribes in the United States.

Meeting Summary available online at: <https://bit.ly/2xzAmfM>

Outcomes of the meeting

1. Reexamine the Navajo Nation's moratorium on genetic research
 - Provide history and background information of the moratorium
 - Understand and give prominence to Navajo peoples' views and concerns
2. Support the role of the Navajo Nation in addressing these issues
3. With support of various NN stakeholders, began discussions to support and establish the development of a culturally appropriate genetic research policy/methodologies on the Navajo Nation
4. **Creation of the Navajo Nation Genetic Policy Development Working Group**

Conference sponsors and organizers

- **Organized by:**
 - UNM Center for Native Environmental Health Equity Research & Community Environmental Health Program
- **Sponsors:**
 - National Institutes of Health Tribal Health Research Office
 - National Human Genome Research Institute
 - National Congress of American Indians
- **Organizers:**
 - Johnnye Lewis, Ph.D., Director, Center for Native Environmental Health Equity Research & Community Environmental Health Program
 - Nanibaa Garrison, Ph.D., Division of Bioethics, Department of Pediatrics, University of Washington School of Medicine
 - David Wilson, Ph.D., Director Tribal Health research Office, National Institutes of Health
 - David Begay, Ph.D., Community Environmental Health Program & Center for Native EH Equity
 - Carol (CJ) Laselute, Community Environmental Health Program
- **Hosted by:**
 - University of New Mexico Comprehensive Cancer Center

Additional Resources

- Videos available online at:
<https://sites.google.com/view/unmcehp17/home>
- Meeting Summary available online at:
<https://bit.ly/2xzAmfM>

OR

https://dpcpsi.nih.gov/sites/default/files/dpcpsi/document/Meeting_Summary_Tribal_Genetic_Research_and_Data_Sharing_Policy_Workshop_508.pdf