

A decorative graphic of a DNA double helix runs across the top and down the left side of the slide. The top portion is red and white, while the left portion is blue and white. The background features a light blue gradient with wavy patterns at the bottom.

Genomic Research and Community Engagement with Indigenous Communities

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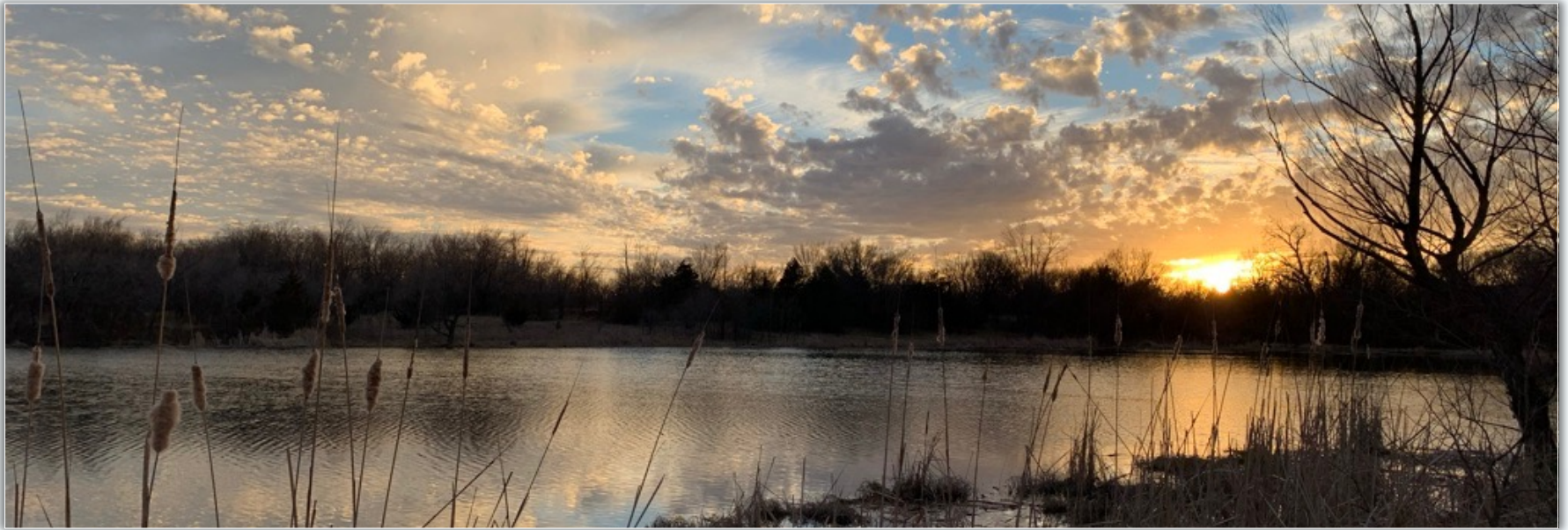
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Acknowledgements

I join you today from Oklahoma, the ancestral lands of the “Hasinai” Caddo Nation and “Kirikirꞑi:s” Wichita & Affiliated Tribes and now home to 39 Tribal Nations. Thank you to the Alaska Native Tribal Health Consortium and Alaska Pacific University, and conference organizers.
Thank you to those in attendance.

burden

affect change

Complicit

anthropologist

Reflective

persistent and imposing

White privilege

Benefit to community

Practice

Positionality

Non-Indigenous

community-engaged research

trust

Humble

in service to the community

Be in "good community"

Principles

Truth

Work in communities

Extractive practices

honest

take

underrepresented

Independent research

Poll

Tensions around Genetics Research in Indigenous Communities



- Legacy of biocolonialism and scientific exploitation
- Unethical research practices
- Group harm, stigmatization
- Benefits of genomics research remain elusive
- Failure to observe sovereignty

Assumptions

- *“There is no place for genetics within Indigenous knowledge systems.”*
- *“Genetics is taboo.”*
- *“Genetics reinforces narratives about migration that contradict tribal origin stories.”*
- *“Native communities do not trust genetics research(ers).”*
- *“Engaging Indigenous communities about genetics research is hard.”*
- *“Genomics research can be done without tribal permission”*

Concerns

- failure to address the interests and priorities of Indigenous communities (Garrison et al 2019)
- pose challenges to privacy rights, property rights, informed consent, and group rights (R. Tsosie, 2007); weaken land and other legal claims (Harry and Dukepoo in TallBear 2000)
- researchers’ failure to engage Indigenous communities in ethical and inclusive ways (Claw et al 2018)
- lack of robust engagement and consultation (K. Tsosie et al, 2020)
- alienate Indigenous communities from the research process and limit the effectiveness of access and benefit-sharing protocols (Hudson et al, 2020)
- deficits in individual consent and research protections models (K. Tsosie et al, 2019, Saunkeah et al, 2021).

Center for the Ethics of Indigenous Genomic Research (CEIGR)

a consortium of tribal
partners, university
researchers and community-
based institutions focused on
systematic inquiry into tribal
*concerns about genomic
research*



CEIGR Values

- Sovereignty: The legal and political designation of sovereignty should inform all research endeavors with tribal communities.
- Integrity: Conducting research that is ethical and responsive to community interests
- Collaborative: Building research capacity and co-development of resources
- Innovative: Developing new approaches to data collection and community engagement
- Intersections: Exploring the intersections of genomics and culture, politics, health, law, and identity
- Dissemination of knowledge: Sharing our learning first with partner communities, and then with the scientific community



Authentic community engagement in tribal contexts insists on the exercise of tribal sovereignty over research.

Example: Cross-site deliberations about genomic research

Thank you!



<https://www.ou.edu/cas/anthropology/ceigr/>

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