



We would like to acknowledge the Dena'ina, as the ancestral stewards of the lands where we gather today. Thank you to the Alaska Native Tribal Health Consortium (ANTHC) and the Alaska Pacific University (APU) conference organizers and hosts for the invitation to speak today.  
Thank you to those in attendance, in person and virtually.



# Center for the Ethics of Indigenous Genomic Research

Advancing Research on the Ethical, Social and Legal  
Implications of Genomics in Tribal Communities

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Panel:

Jessica Blanchard and Julie Beans: *Advancing Dialogue About Genomics in Tribal Contexts*

Joseph Yracheta: *Indigenous Perspectives on Unrestricted Access to Genomic Data*

Dalaki Livingston: *Genomics and Ethics Program for Native Students*

Funding for this work provided by NHGRI- RMHG009042, R25HG010132





# Center for the Ethics of Indigenous Genomic Research

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



- a consortium of tribal partners, university researchers and community-based institutions focused on systematic inquiry into tribal *concerns about genomic research*
- research that is *partner-centered*, emphasizing equity and community control by distributing power and decision-making across all partner sites
- *ELSI- Ethical, Legal and Social Implications*



# Tensions around Genetics Research in Indigenous Communities

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

## Assumptions

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*“There is no place for genetics within Indigenous knowledge systems.”*

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*“Genetics is taboo.”*

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*“Genetics reinforces narratives about migration that contradict tribal origin stories.”*

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*“Native communities do not trust genetics research(ers).”*

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*“Engaging Indigenous communities about genetics research is hard.”*

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*“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).

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

**Engage stakeholders to ensure that research promotes clear pathways to benefits for those being asked to take part.**

# Deliberations in Tribal Communities

- **What is public deliberation?**
  - A form of engagement that brings diverse citizens together for in-depth discussion of public policy challenges and value-laden issues.
  - Deliberations include structured discussion to enable reflection, reasoned exchange, and careful weighing of issues.
  - Deliberation has been studied extensively in the areas of public consultation, policy making, and community engagement
  - Deliberative forums designed exclusively for and with AI/AN populations are rare; some have included Indigenous people, but few have been designed exclusively for and with Indigenous peoples.



# Deliberative goals

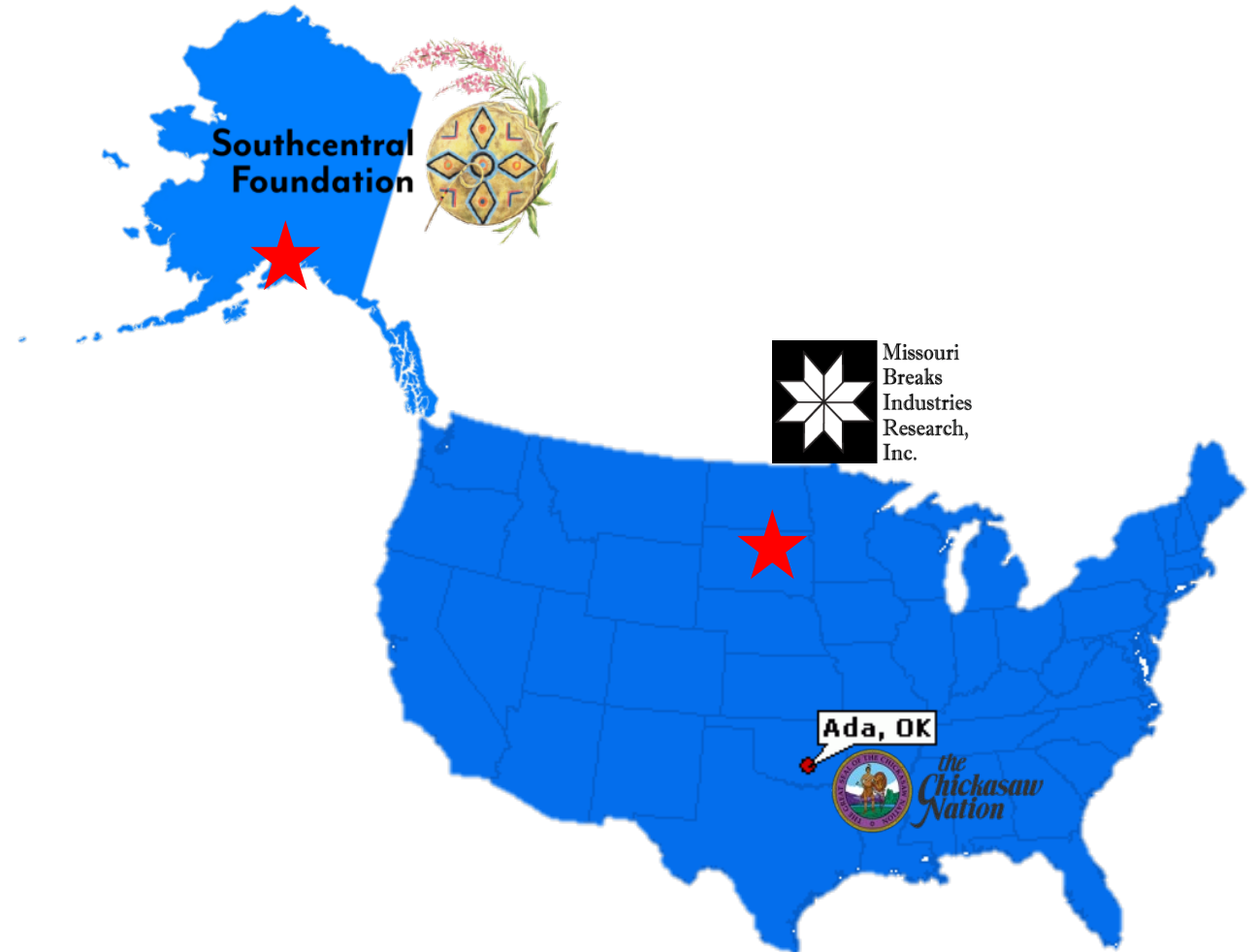
- Understand the utility of deliberations designed by our tribal partners, where the deliberative process focuses *exclusively* on their own questions with the goal of making public policy recommendations for their own communities.

To that end...

- to design, implement, and assess deliberations about ethical questions raised genomic research and related issue with three tribal communities
- to understand the value of deliberative engagement as an approach to convening and gathering input of tribal communities into ethics of genomic research and related issues

# CEIGR Deliberation Projects 2018-2019

- Chickasaw Nation
  - Perceptions of Genetic Research & Biobanking
  - September 15-16, 2018 - completed
- South Central Foundation
  - Return of Results
  - January 25-26, 2019 - completed
- Missouri Breaks Industries Research, Inc.
  - Data sovereignty
  - September 13-14, 2019 - completed



# Cross-site Deliberation: Adapting a Model

## COMMON FEATURES

- Planning & Objectives
- Core Deliberation Team & Co-facilitation
- Participant Sampling
- Tribal IRBs
- General Structure\* (i.e. Scenarios)
- Types of Data\*
- Executive Reports/Deliberant Feedback

## DISTINCTIVE FEATURES

- Tribal Partners and Tribal-serving organizations
- Topics
- Recruitment Strategies
- Next Steps

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## Deliberative Engagement: Reflections and Considerations

“I think just learning a lot of different perspectives is what I’ve taken away. Cause there are things that [man’s name] has shared from the multiple groups that I never would have thought about in a million years....and I also have an appreciation for the process of how you guys gathered information cause this is not easy to kind of keep honing us back in when we’re all off on tangents out on right field. Just an appreciation for all of you as well.” (SCF deliberant)

“I couldn't quit thinking. Couldn't go to sleep and then got up at 3:00 thinking...” (CN deliberant)

"I've facilitated a lot of different things...this doesn't feel a lot different than a lot of the other things I've facilitated, but throughout the day, it's kind of proven to me that it is quite a bit different. Everybody had some meaningful input and we've got proof of that all over the walls, all over the notes, and all over those recordings” (MBIRI Co-Facilitator)

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# CEIGR Workshops

- Multiday virtual workshop to bring together stakeholders to discuss cultural, ethical, and legal issues that have and may arise from genetic research with tribal citizens occurring outside of tribal jurisdictions
- Stakeholder representation
- Overarching question: *What principles should govern genetic research with tribal citizens outside of tribal jurisdictions?*

## Workshop Planning

Oct 2020-  
March 2021

## Meeting 1

3/5/21

Legal  
Constructs  
& Founda-  
tional  
concepts

## Meeting 2

3/19/21

Genomic  
Research:  
Urban  
Indian  
Contexts

## Meeting 3

4/2/21

Indigenous  
Data  
Sovereignty

## Meeting 4

4/16/21

Wrap Up,  
Emergent  
Topics,  
Writing  
Priorities

## Debrief and Content Review

March  
2021-  
ongoing

# Urban Indian Data: Why Now?

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- 'Big Data' Concerns
- Lack of Adherence to Tribal Oversight
- 7 out of 10 AI/AN live in urban areas





# Engagement

- Tribal and Urban considerations
  - Relationships and Time
    - Consortium building
    - Preliminary activities to inform initiatives
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- Evolving roles
  - Responsive to changing needs





- Solidarity
  - “Solidarity means caring for members of the group. This perspective on a Tribal community’s obligations to its own members should be communicated to researchers.” (workshop attendee)
- Indigenous Views of Data
  - Genetic data derived from Indigenous people cannot be separated from the responsibilities that Indigenous peoples have to their families and communities- past, present and future.
- Protecting Tribal Communities
  - Inadequate Protections, Misaligned values
  - “...We seem perfectly comfortable recognizing corporate rights as a form of collective right, but real discomfort with tribal rights.”
- Opportunities to instill Tribal Community protections in research
  - Tribal, Institutional, National and International
- Awareness
  - Extending the Conversation: Advising the NIH TAC

# Discussion Questions

- What are some of considerations when thinking about the benefits (and harms) of more widespread applications of group consent?
- Is solidarity, even when sovereignty is not present, sufficient to grant communities governing authority over research that pertains to them?
- What does it mean to understand the governance of genomic data through a human rights lens?
- Does undergoing the tribal review process and interacting with tribal leaders constitute community engagement?
- What kinds of institutional changes can still be made? What does institutional change mean if historical and structural harms are not acknowledged?

# Thank you.

Funding provided by NHGRI RM1 HG 009042

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