

# Arizona State University Case



# Arizona State University Case Timeline

- **1980s** John Martin, anthropologist
- **1990-1994** Havasupai DNA samples collected for genetic studies on T2D by ASU researchers
- **2003** discovery that samples also used for research on schizophrenia, migration, inbreeding
- **2004** *Havasupai Tribe of the Havasupai Reservation v. Arizona Board of Regents and Therese Ann Markow*
- **2010** settlement (\$770K, funds for clinic and school, return of DNA samples to Tribe)

# What Are the Lessons?

## *Limits of Broad Consent*

- “There may be reasons to include additional limitations for certain donor groups. . . . Certain groups might find specific research topics to be controversial or sensitive, for example studies of human evolution or genetic ancestry.”

- Grady *et al* (2015) *AJOB*

# What Are the Lessons?

## *Insufficient Regulations*

- “Existing federal legal and regulatory protections for human subjects fail to shield the cultural interests of Indian nations”

James, Tsose, Sahota *et al* (2014) *Genet Med*

# What Are the Lessons?

## *Insufficient Regulations*

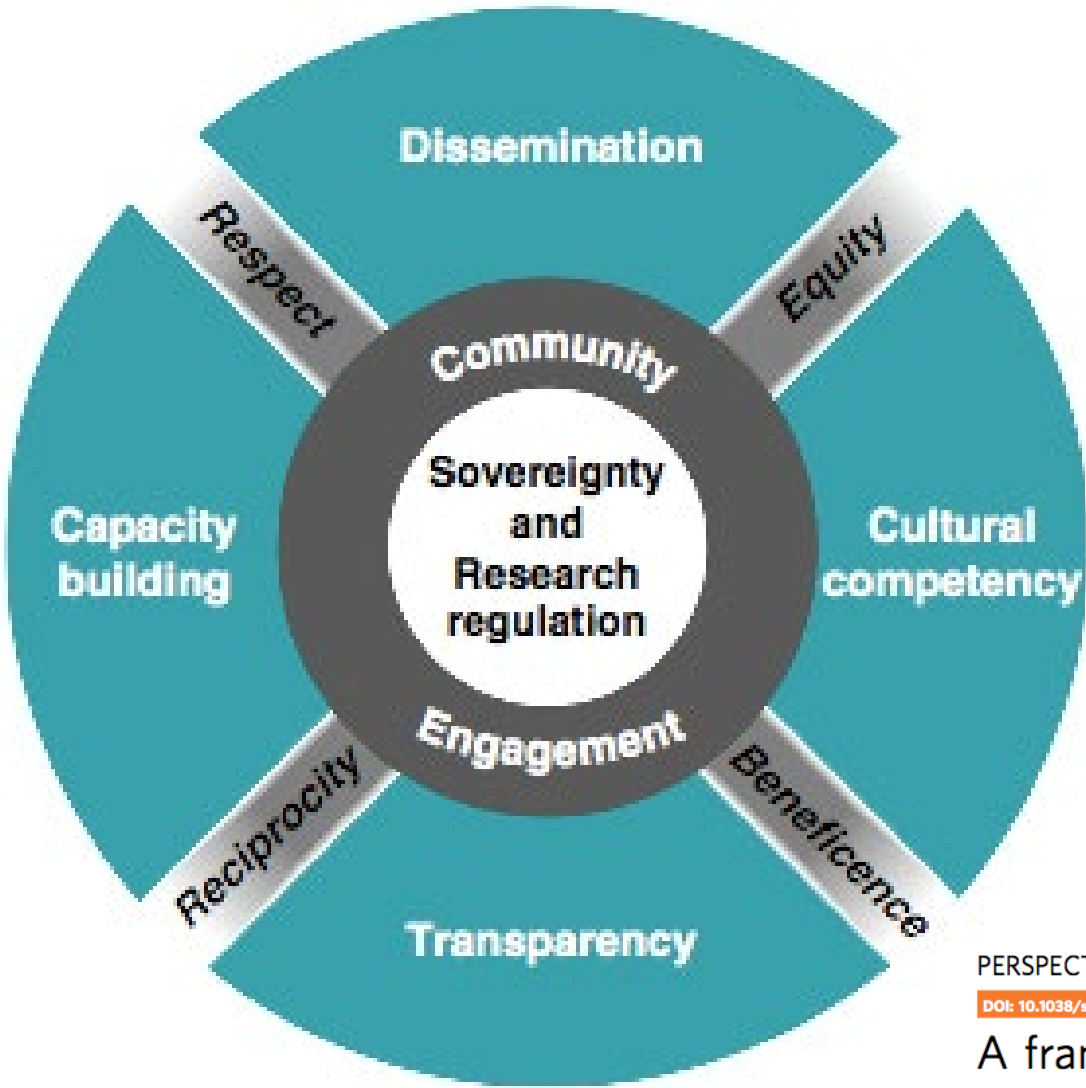
- “[A] profound disconnect exists between common academic research practices and legitimate community expectations, and justice requires that this gap be bridged.”
- “[A]ddressing their [research] needs may require precisely that we address their history of trauma, stigma, and exclusion.”

Goering, Holland, and Fryer-Edwards (2008) *HCR*

# Revised Common Rule: *Acknowledging Tribal Sovereignty*

“Thus, if the official governing body of a tribe passes a tribal law that provides additional protections for human subjects, the Common Rule does not affect or alter the applicability of such tribal law...”

Federal Policy for the Protection of Human  
Subjects/Final Rule 2017, 7158, Executive Summary  
II.E.2








PERSPECTIVE

DOI: [10.1038/s41467-018-05188-3](https://doi.org/10.1038/s41467-018-05188-3)

OPEN

## A framework for enhancing ethical genomic research with Indigenous communities

Katrina G. Claw <sup>1</sup>, Matthew Z. Anderson <sup>2,3</sup>, Rene L. Begay <sup>4</sup>,  
Krystal S. Tsosie <sup>5,6</sup>, Keolu Fox<sup>7</sup>, Summer internship for Indigenous  
peoples in Genomics (SING) Consortium & Nanibaa' A. Garrison <sup>8,9</sup>



BRIEFING ROOM

# Memorandum on Tribal Consultation and Strengthening Nation-to-Nation Relationships

JANUARY 26, 2021 • PRESIDENTIAL ACTIONS

“It is a priority of my Administration to make respect for Tribal sovereignty and self-governance, commitment to fulfilling Federal trust and treaty responsibilities to Tribal Nations, and regular, meaningful, and robust consultation with Tribal Nations cornerstones of Federal Indian policy.”

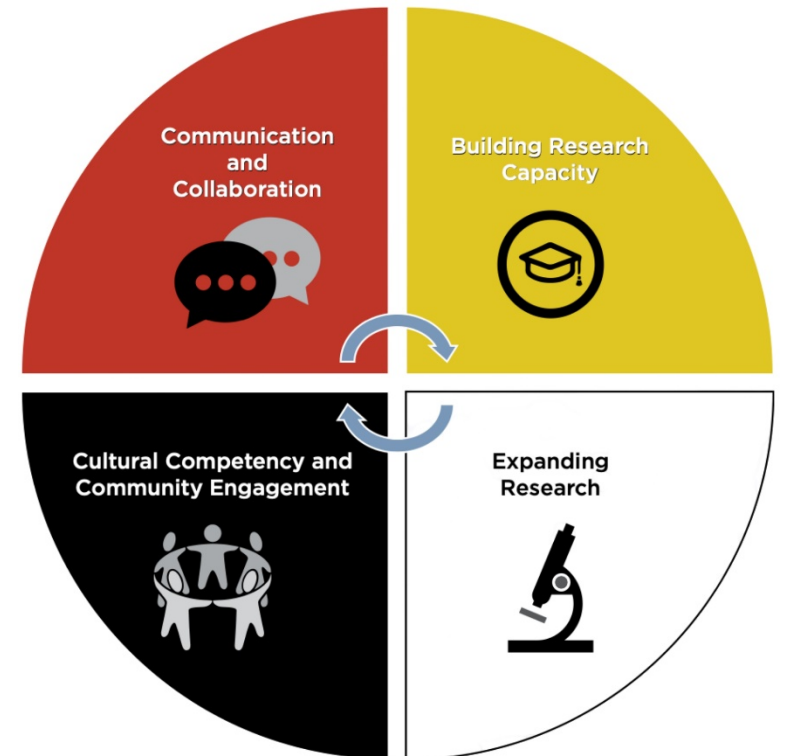
- President Biden, Presidential Memo, January 26, 2021



# Building Research Partnerships for Healthy Tribal Nations

Established in 2015, THRO supports the development of culturally relevant research vital to improving AI/AN health.

- Aims to **build trust** in relationships and further research collaboration between Tribal communities and NIH that is acceptable and useful to AI/AN people
- Coordinates Tribal health research **across NIH**
- Gathers **meaningful input** from Tribes on NIH policies, programs, and activities
- **Creates opportunities** for the next generation of AI/AN researchers at NIH



**NIH** National Institutes of Health  
Tribal Health Research Office  
*Building research partnerships for healthy Tribal Nations*