

# 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, Tsosie, 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*

# “American Indian and Alaska Native Cultural Wisdom Declaration”

## *Recommendations*

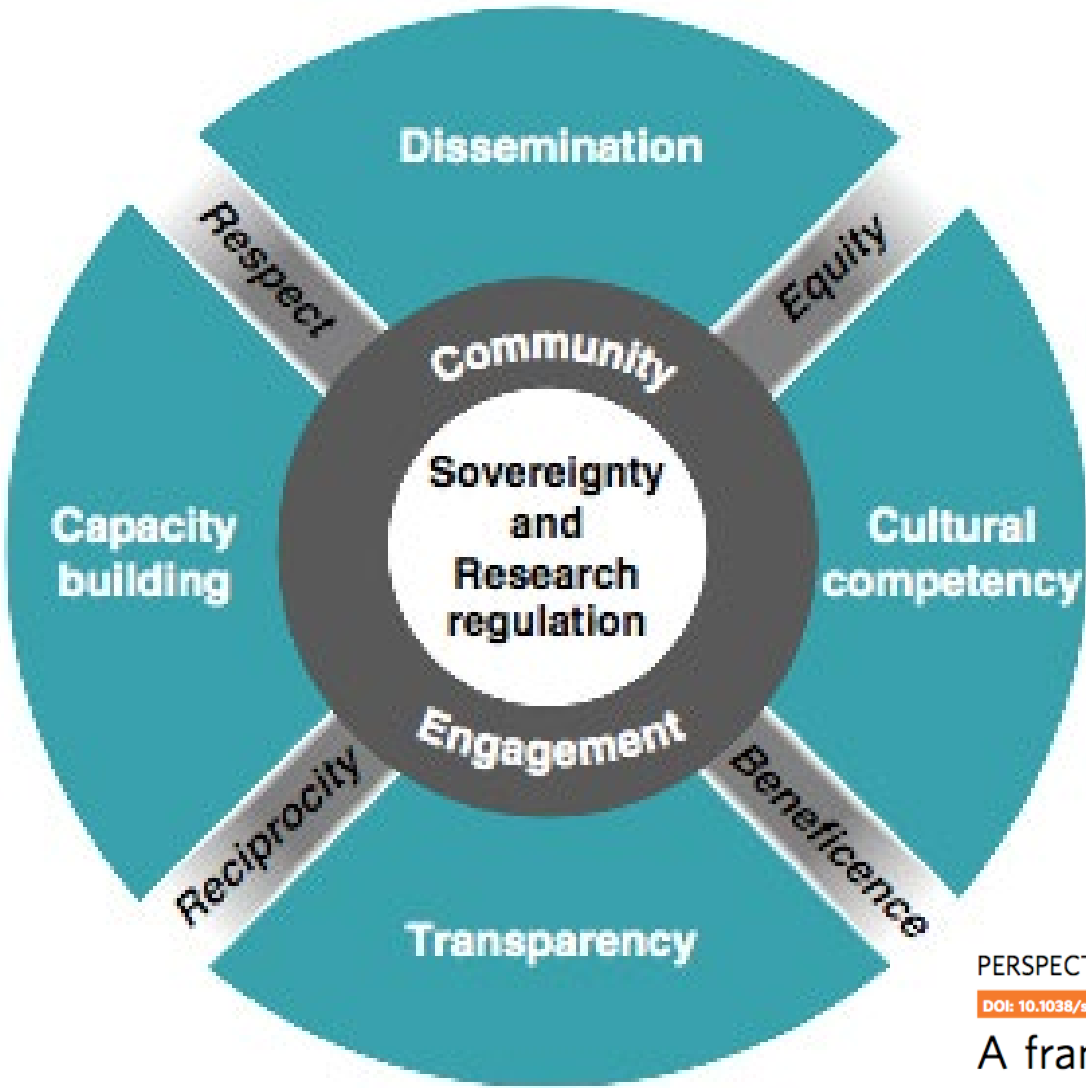
- “Modify your requirements to fit the relevant traditional tribal paradigm or allow room for flexibility when evaluating proposals submitted by American Indian and Alaska Native tribal nations.”

<https://www.nihb.org/docs/12052016/FINAL%20TBHA%2012-4-16.pdf>

# 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

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

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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>



# Presidential Memorandum on Tribal Consultation (11/5/09)

- “[E]xecutive departments and agencies are charged with engaging in regular and meaningful consultation and collaboration with tribal officials in the development of Federal policies that have tribal implications, and are responsible for strengthening the government-to-government relationship between the United States and Indian tribes.”