



# American Indians and Research: Building Partnerships of Trust

Sharon Austin, PhD





# Center for HOPE

(Health Outcomes & Population Equity)



**David Wetter, PhD**

Director, Center for Health Outcomes and Population Equity (HOPE)

**Sharon Austin, PhD**

Community Liaison for the Center for HOPE

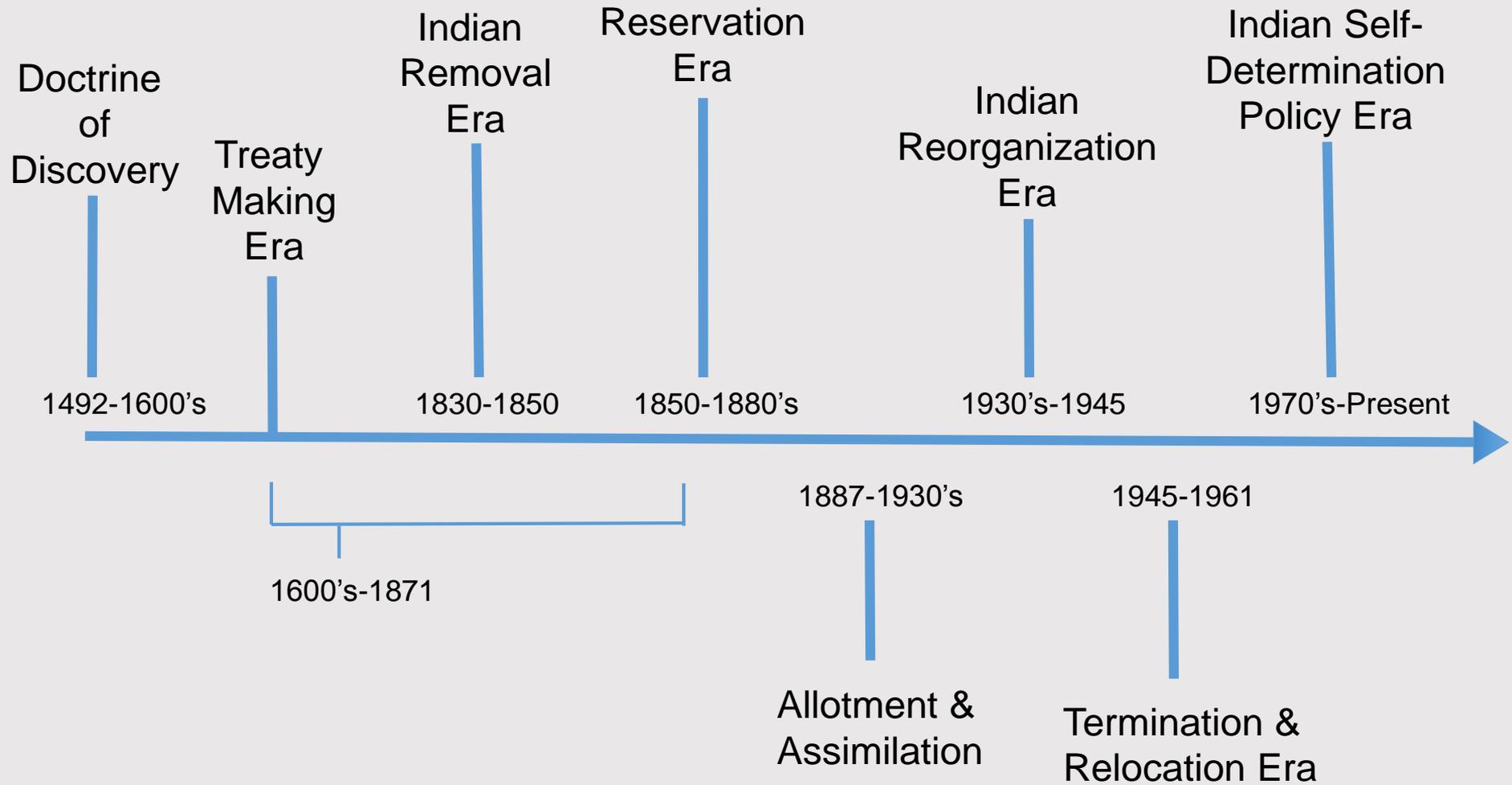


# Overview

- Timeline of Federal Indian Policy
- History of Human Subjects Protections
- Research & American Indians
- Havasupai “Diabetes” research
- Building Trust
- QuitSMART Utah



# Timeline of Federal Indian Policy





# History of Human Subjects Protections

- All Biomedical & Anthropology Research began ~1890's
- 1947 -- Nuremberg War Crime Trials set the standards for the draft of the Nuremberg Code to protect human subjects.
- 1974 -- National Research Act established the existence of IRBs to review biomedical/behavioral research & Universities started adopting review boards
- 1979 -- Belmont Report on ethical principles & guidelines for Human Subjects protections
- 1983 -- U.S. Dept. of Health & Human Services created a federal policy on human subjects
- 1991 – Common Rule





# Research & American Indians

- Unethical research
- Research focus is often for the researcher & not the community
- Many AI communities feel they have been over-researched
- Many feel that most research does not benefit their communities
- Mistakes
  - Lack of Tribal and Federal approvals
  - No updates
  - No Final reports



# Havasupai “Diabetes” research (1989)

- High prevalence of diabetes: 45% women, 50% men
- Tribal members approached ASU researchers
- Tribal Council stressed sole interest in Diabetes research
- Blood for DNA was collected with the statement it was for diabetes research
- Consent obtained was to study behavioral/medical disorders
- Researcher studied the genetics of diabetes
- Conclusion was Havasupai diabetes did not have a genetic basis





# Havasupai “Diabetes” research (1989)

- IHS clinic records were reviewed for indications of schizophrenia
  - No approvals: ASU, ASU IRB, IHS IRB, Tribal, nor participant
- Population migration dissertation study was conducted.
  - No Tribal approvals
- Investigation concluded that scientists used the blood/DNA to study schizophrenia, inbreeding, population migration at ASU and other Universities.
  - No Tribal approvals
- The majority of publications were not related to diabetes.
  - No Tribal approvals

# Havasupai “Diabetes” research (1989)

- Two separate lawsuits filed by the Havasupai
- Cases were tied up for 6 years
- Agreement was made in 2010
- Returned: Blood samples, DNA, lab books
- \$700,000 payment
- No ongoing research will be approved
- Provide the tribe with a list of individuals & institutions that have blood samples

## Indian Tribe Wins Fight to Limit Research of Its DNA



Jim Wilson/The New York Times

Edmond Tilousi, 56, who can climb the eight miles to the rim of the Grand Canyon in three hours. [More Photos »](#)

By AMY HARMON

Published: April 21, 2010

# Building Trust

- American Indians have poor health outcomes
- Little research on American Indian health and disease
- Research is needed to create effective clinical and public health approaches
- So how do we build trust?



# Building Trust: Community

Understand & acknowledge each community's history

What can you offer in terms of services?

Understand past research & how it impacted the community

Be upfront about expectations & intentions

Be present & listen to community members



Acknowledge the expertise of community members



# Building Trust: Risk

- Identification of individuals
  - Communities are often small & identification is possible
- Stigmatization of individuals & communities
  - Study topics can imply the entire community is affected
  - Stigma is often on the community and not just individuals



# Building Trust: Respect

- Acknowledge Tribal Sovereignty
  - Tribes/Nations are Federal entities & have their own laws
  - Tribes may want ownership of the data that is collected
  - Only use the data gathered for the research that you obtained permission to conduct.



**RESPECT**

- Community members have expertise. Get their input.

# Building Trust: Developing Research

- Developing mutually beneficial partnerships
  - Data ownership. Start discussions early.
  - Engaging tribes
    - Ask about research needs
    - Obtain feedback/input in the development



- Develop mutually beneficial research
  - Learn about community issues → research topic





# Building Trust: Obstacles

- **Costly**
- **Time Consuming**
- **Long Distances**
- **Weather**
- **Government Turnover**





# QuitSMART Utah

- Pragmatic Clinical Trial on Tobacco Cessation
- Based in FQHC clinics
- Connect patients electronically to the Utah Quitline
- Goal is to: enroll tobacco users into the quitline and determine efficacy of quitting



# QuitSMART Utah

- Risk
- Community
- Respect
- Development of Research
- Engaging in Research
- Obstacles



Ahéhee' Thank You

Questions?