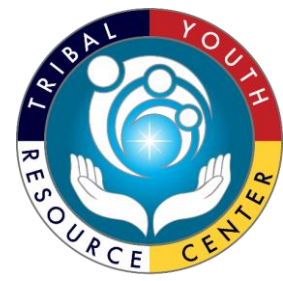




# Cultural Considerations in Qualitative Data Collection



**Tribal Youth Resource Center**  
[www.TribalYouth.org](http://www.TribalYouth.org)



# WELCOME! OPENING IN A GOOD WAY....

*We remember in our appeal to the Creator*

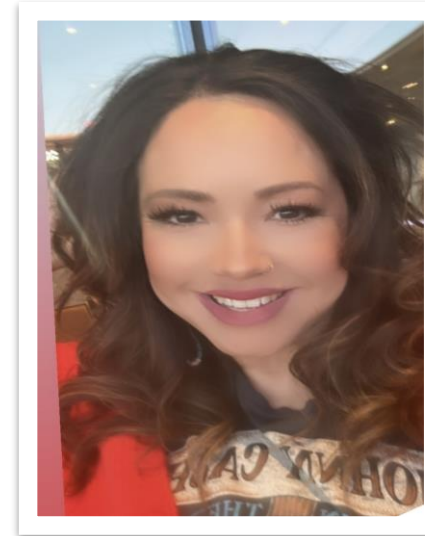
- Those that are in grief, in mourning*
- Those that have health challenges*
- Those who have family health challenges*
- Last but not least, the sacred beings – the children and the future generations*



# ▶ TODAY'S FACILITATORS



**S'ina Ikikcu Win (Takes the Robe Woman)**  
Ethleen Iron Cloud-Two Dogs  
Citizen, Oglala Lakota  
Crow Tribal Ancestry  
Technical Assistance Manager  
Tribal Youth Resource Center  
ethleen@tlpi.org



**Erin Thin Elk (Wanacha Tokahe Hinapah Win)**  
Sicangu Lakota Oyate  
Juvenile Healing to Wellness Court  
Consultant  
Tribal Youth Resource Center  
erin@tlpi.org





## ► Our Time Together Today

- Historical Influences on Research Ethics
- Strategies (Physical, Emotional, Spiritual)
- Cultural Safety in Data Collection
- Questions/Discussion

**What is qualitative data?**

**Why are ethics critical in collecting this data?**



# HISTORICAL INFLUENCES ON RESEARCH ETHICS

## **NUREMBERG CODE (1947)**

10 ethical research principles drafted after the WW2 Nazi concentration camp inhumane and fatal experimentation on prisoners.

## **DECLARATION of HELSINKI (1964)**

Borrowed ethical ideals from the Nuremberg code but expanded by the World Medical Association to ensure safety, health, and wellbeing of human subjects participating in medical research.

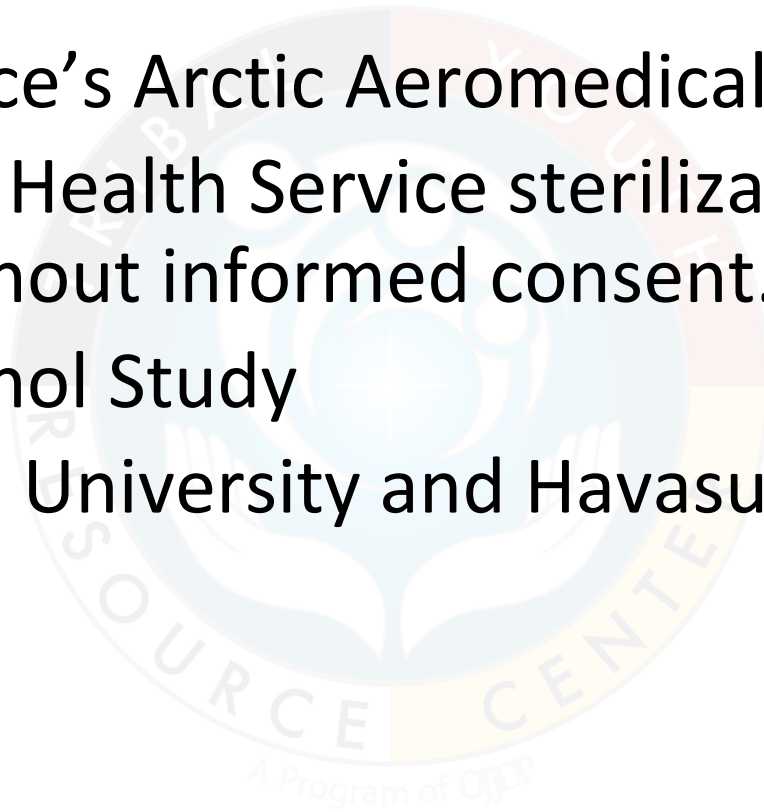
This evolved into the Institutional Review Board (IRB) process.

## **BELMONT REPORT (1979)**

The United State Public Health Service and the Tuskegee Institute began a study of syphilis with African American men in 1932 with no informed consent. An advisory panel in 1972 concluded the study was ethically unjustified. The Tuskegee experiment led to the creation of the National Commission for the Protection of Human Subject who created the Belmont Report.

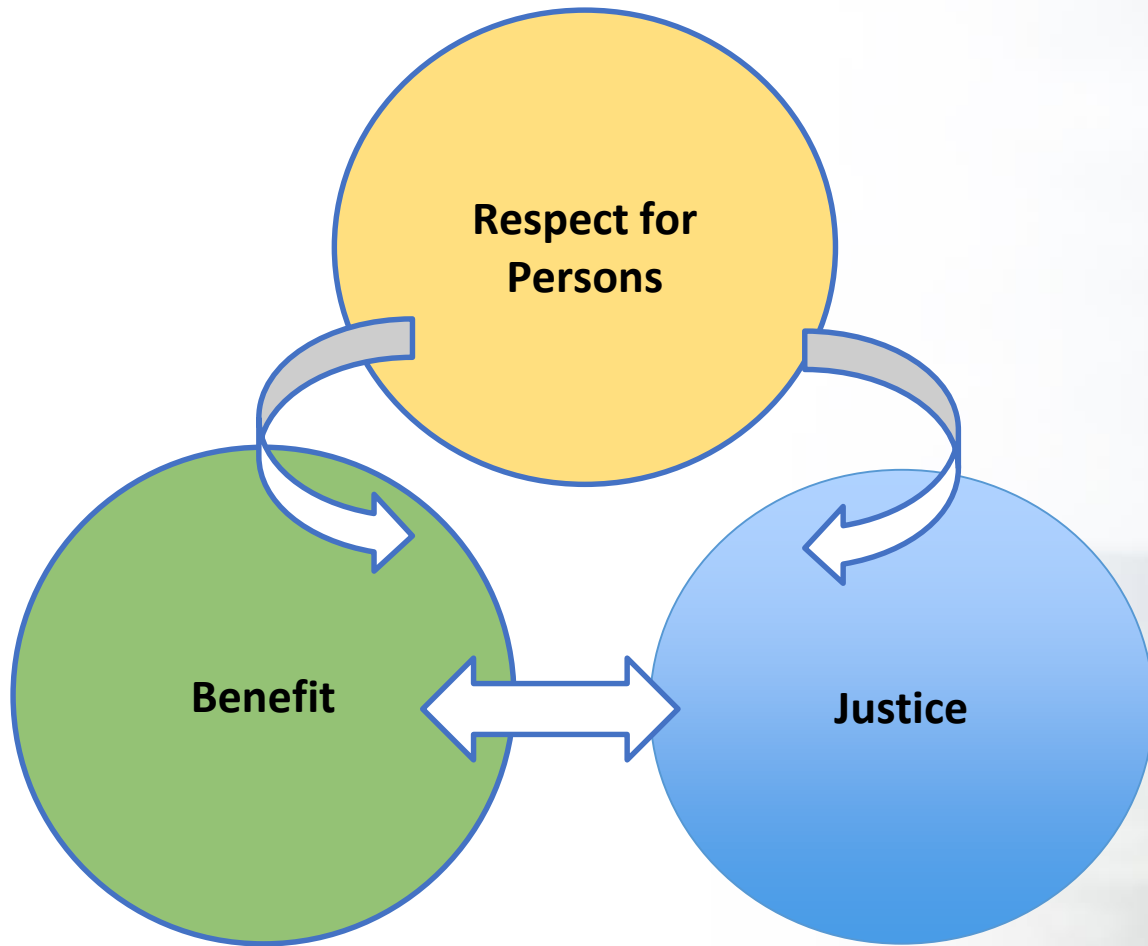
# ▶ HISTORICAL INFLUENCES (CONT.)

- 1950's U.S. Air Force's Arctic Aeromedical Laboratory
- Mid 1970's Indian Health Service sterilization of Native women without informed consent.
- 1979 Barrow Alcohol Study
- 1990 Arizona State University and Havasupai





# ▶ BELMONT REPORT





# ▶ INFORMED CONSENT

**PURPOSE** (describes participant eligibility, sponsor, the why/goal, duration)

**RIGHTS** (describes participant rights such as CONFIDENTIALITY, the right to opt out or to consent to data collection, to skip questions if they don't feel comfortable, etc.)

**RISKS** (describes any potential risks associated with the data collection, such as feelings of uncomfortableness due to possible sensitive questions.)

**BENEFITS** (describes perceived benefits of data collection, such as increased knowledge of youth aged 12-18 after school behavior. This also includes any possible incentives.

**HOW THE DATA WILL BE USED, STORED AND SHARED WITH THE COMMUNITY.**

[www.citiprogram.org](http://www.citiprogram.org)





## TRAUMA-SENSITIVE DATA COLLECTION AND EVALUATION

- 
- Building relationships through trust and engagement while gathering accurate information and avoiding re-traumatization.

# CULTURAL DATA COLLECTION STRATEGIES

## Spiritual aspects:

- Avoid questions that relate to ceremonial participation
- Avoid scheduling data collection during respective Tribes' ceremonial season, e.g. Pueblo feast days, Lakota Sundance

## Mental aspects:

- Informed consent should be written and spoken verbally in all identified languages.
- Use age -appropriate language and context.

## Emotional aspects:

- Be thoughtful and considerate with language and how questions are phrased.
- Only ask what is needed and nothing more.
- Responses to sensitive questions require appropriate resources. Give breaks as needed.
- Remember informed consent (RIGHTS). Remind of confidentiality.
- Be respectful of periods of silence as deliberation and not as refusal to respond

## Physical aspects:

- Give the option of choosing a setting for data collection, e.g. home, outside, another location
- Give space
- In some indigenous cultures, direct eye contact is inappropriate; also sitting/standing in close proximity to the individual may be uncomfortable.

**Tribal Best Practice:** Run consent forms, instruments and protocols through a Community Advisory Committee before dissemination to ensure the language and structure mirrors the local language and culture.





# SPECIAL CONSIDERATIONS

**Sovereignty of the respective Tribe needs to be honored, follow their rules, protocols, codes.**

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**Assess risk to cultural safety of the data collection and analysis process, e.g., reinforcing or promoting stereotypes, increasing vulnerability.**

**Is the tool culturally appropriate for the population?**

- Is it linguistically competent?

**How will the data be analyzed and used?**

- Who will review the data? Who will have access to data? Who owns the data?
- Where will it be stored and for how long?

# ▶ TABLE TALK: QUESTIONS FOR DISCUSSION

- What are some data collection strategies that are culturally respectful and culturally appropriate that you are currently using in your program?
- Given the information shared in this session, what are some action items that come to mind related to data collection for your program?
- If there's time, feel free to share highlights of discussion







# QUESTIONS/DISCUSSION







# THANK YOU!

