

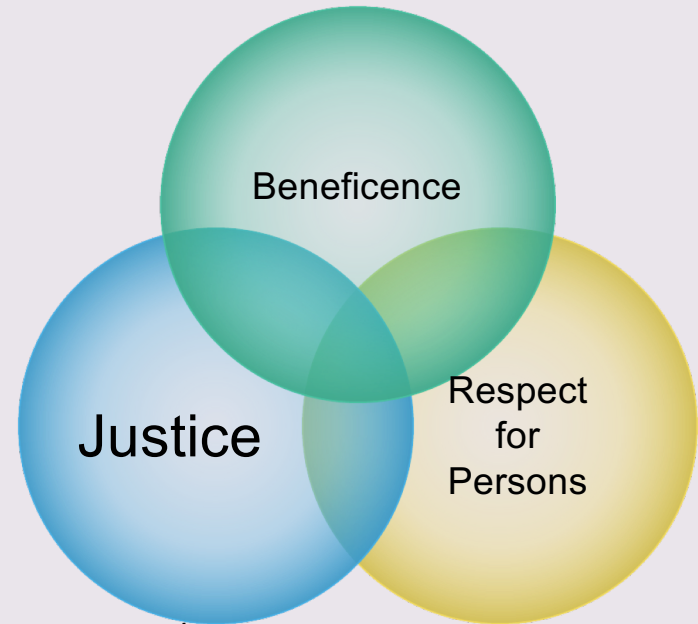


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Commission on Native Children  
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**rETHICS**



Distributive Justice - those who experience the risks should also experience the benefits

# Ensuring Access to Research for Native youth



## *emancipated minors*

are self-supporting or not living at home, married, pregnant, parenting, in the military, **or** declared to be emancipated legally by a court.



## **Decision Making Authority**

Many tribal governments and states give decision-making authority to youth who are not emancipated.

These youth have decision-making capacity (mature minors), live independently, or are seeking care for individual health problems that might not otherwise receive appropriate attention (sexually transmitted diseases, pregnancy, or substance abuse).

Researcher should consult local tribal laws and work with their IRBs to respect local guidance

Definition of Emancipation: Committee on Bioethics "Informed Consent, Parental Permission, and Assent in Pediatric Practice" PEDIATRICS, Volume 95 Number 2, Pages 314-317, February 1995. <http://www.cirp.org/library/ethics/AAP/>

# MyPEEPS



- A national RCT of the efficacy MyPEEPS Mobile Ap vs. a delayed intervention among males aged 13 to 18 years to prevent or reduce sexual risk for HIV acquisition
- Recruitment
  - Study staff at 4 regional sites met with participants in person or via video conferencing
  - Local CBO, posted materials via free and paid online national advertisements on Reddit, Facebook, SnapChat, & Instagram
- Target sample = 70/subgroup; Analytic sample =56/subgroup

We recruited 43 American Indian or Alaskan Native

# Friends: Peers influence response to threat



- Mixed-method intervention design study
  - Question: How do teens act and feel about themselves and others when supporting a friend experiencing social threat or receiving support when threatened themselves?
- Recruitment
  - Community members where well respected among the youth
  - Design approach & questions with community adults and youth
    - We used games, and pictures and images to express feeling or thoughts
  - Reviewed/tested content with potential consumers
  - Hire staff from the local area and of the same racial ethnic back ground of the youth being interview
- Sample
  - 268 middle school and high school adolescents 13-18 years old. Ethnic identity as African American (25.0%), European American (22.0%), Mexican American (23.9%), and Native American (29.1%)

# Stories of Transition



- Students to participate in a culturally derived leadership curriculum to increase knowledge and self-efficacy in sexual health and substance use decision making
- Partner: a local native nonprofit who provided extra curriculum activities at the school over past ~ 5 years
- Sample: 120 freshman students
- Recruitment: Community Partner: Posted flyer, information sessions

# Healthy Transition – Tribal Ownership



- Youth (16-24 years) with a mental health Dx transition to adulthood
- Adaptation of a western model
  - Began with asking community elders, youth service providers, and potential consumers –youth
    - “If there were to be a program to help youth transition to adulthood - what would that look like in this community?”
    - Adapting – ongoing validity checks and feedback.
- Community completely embraces the model as their own

## Recommendations <sup>(1)</sup>: rETHICS

- Grounded in the Belmont principles of Justice, AI/AN youth have the right to participate in research that potentially may benefit them.
- Researchers and those who support youth must respect youth autonomy and their situation.
  - They must consult local tribal laws to determine if youth have decision making authority for consent to participate in research without parental permission and work with their IRB to support that decision
  - They must know the definition of emancipated minor – it is more than a court order document
  - They must do the “hard work” to ensure AI/AN youth access to research



## Recommendations (2):

- Youth Engagement - Youth should be engage in the research design
  - Specifically in assessment questions, recruitment materials, recruitment approach.
  - Materials must resonate with the NA youth – word of month is the \*best\* recruiter
- Adults Serving Youth Engagement
  - The research team should have an adult serving the specific youth population as a member of the research team AND an active advisory board to help champion the project within the youth's setting
  - Partner must be well respected but should not replace the role of the researcher
- Research and funders must be flexible to respond to the community situations
- Research must resonate with the consumer and the product must transfer from developer to consumer ownership
- Funding should be available to manualized successful interventions

# Data & Intellectual Property Agreements

- Data use:
  - *The Tribe shall maintain sole ownership and control of the Project's Data. The UW and the National Institute of Health ("NIH") are hereby granted a royalty free, nonexclusive right to use the Data to develop and publish reports or other academic publications for educational and research purposes in furtherance of the aims of the Project, ...*
- Intellectual property/ Work agreement:
  - Defines "Work" for each party
  - Ownership of what is produced by the tribe and what is consultant copyrighted materials
  - Pre-existing exception & Use: What is licensed to whom and for what use
  - Confidentiality of work
  - Injunction Relief: What would happen if there is a breach in the agreement