

Conducting responsible and ethical research with AIAN communities: Changes to the CITI human subject training curriculum

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Acknowledgements

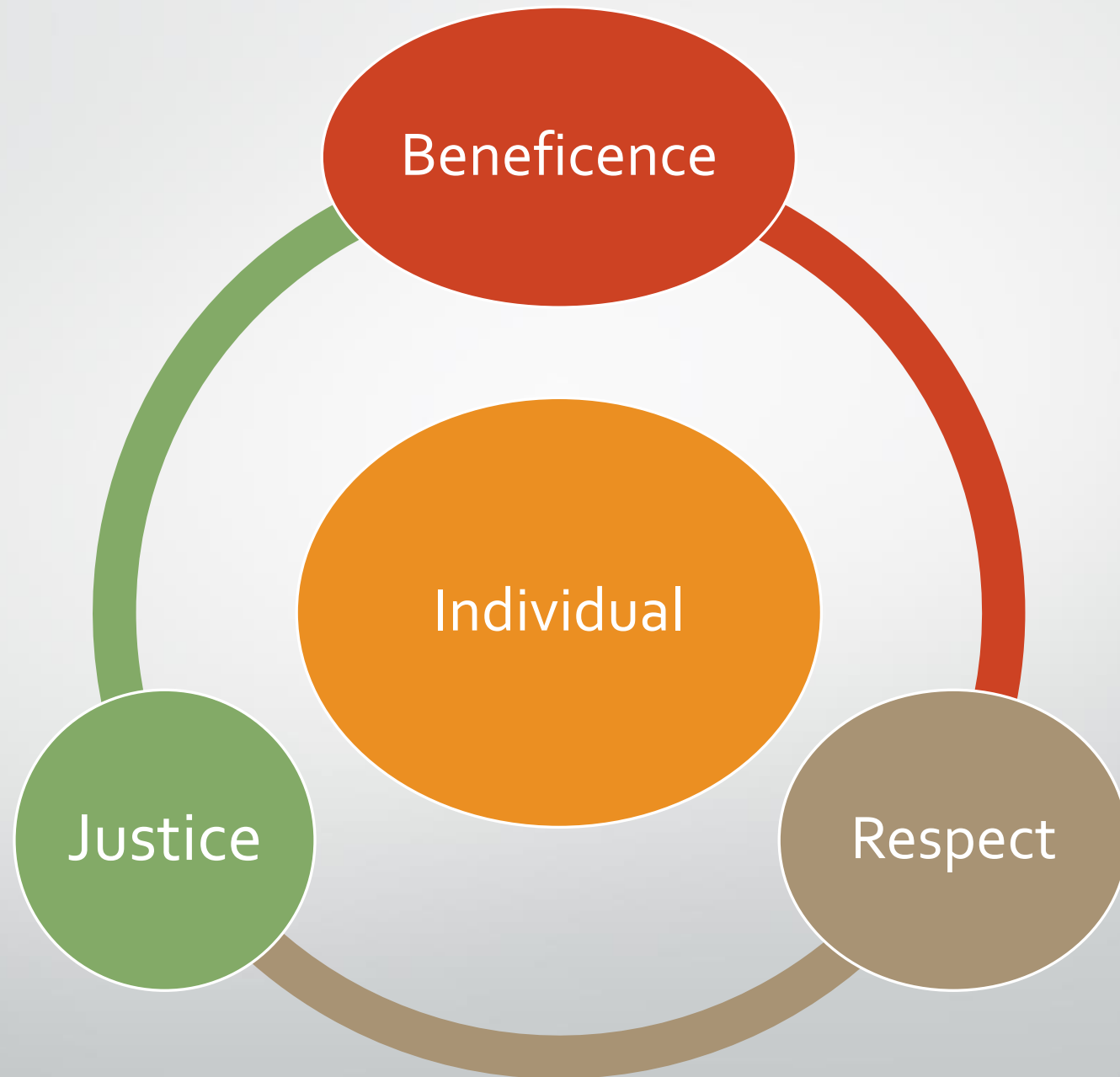


Roadmap

- Identify bodies of research that have served to pathologize AIAN communities
- Understand the ethical principles that guide concern for how research shapes or reinforces stereotypes
- Apply Belmont principles at a community level and identify ways to minimize harm and maximize benefits from research
- Explore how researchers, community review boards, and IRBs can be mindful of how each phase of a study represents an opportunity to ensure ethical and responsible research



Belmont Report Principles



individual AND community in research

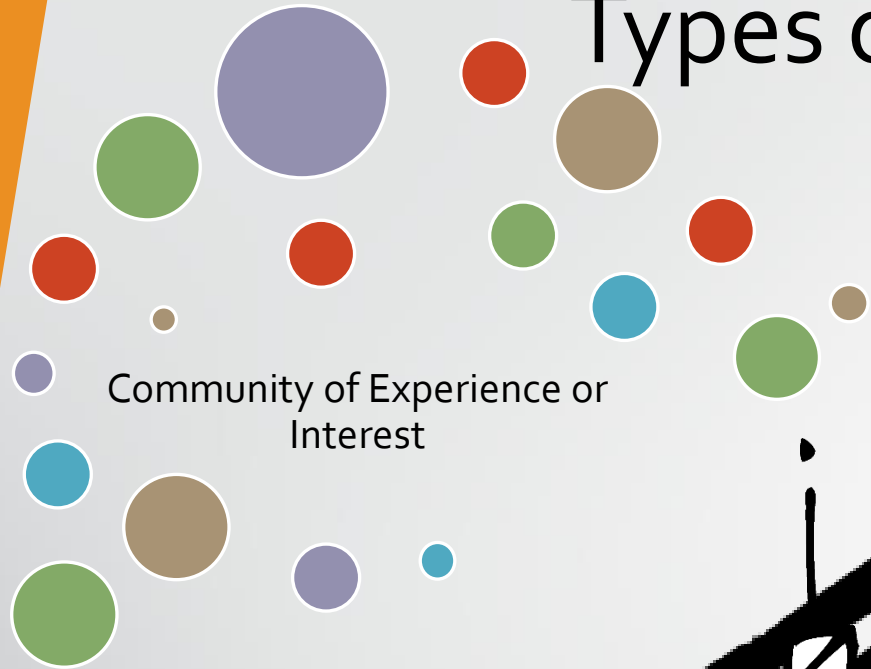


Types of Community

Community of Experience or Interest

Community of Place

Community of Commonality



Barriers to Engagement

- The US/AIAN History
 - Research/events that has pathologized AIAN
 - Research shapes/reinforce stigmatizing stereotypes

Research that has Served to Pathologize AIANs

Understanding
US/AIAN History



Columbus: AIAN population > 12 million
 4 Centuries later: Reduced by 95% to 237,000



Manifest Destiny: 19th century U.S. “moral mission”

Using quasi-Darwinist reasoning to argue that because its ‘Anglo-Saxon heritage’ made America supremely fit, it had become the nation’s ‘manifest destiny’ to extend its influence beyond its continental boundaries



Medical experimentation & the Boarding schools

"Transfer the savage-born infant to the surroundings of civilization, and he will grow to possess a civilized language and habit," said Pratt



Over 100 Boarding Schools (<http://www.amnestyusa.org/node/87342>)

- Removal of organs and radiation exposure

- Expose to TB to test (The Bacillus Calmette-guerin TB Vaccine Experiment)

From 1879 until 1918, > 10,000 AIAN children from 140 tribes attended Carlisle.

Only 158 graduated. Hunt, Darek. "[BIA's Impact on Indian Education Is an Education in Bad Education.](#)" 30

Jan 2011. Retrieved 2 Nov 2012

Pathologized as dysfunctional, not directly informed

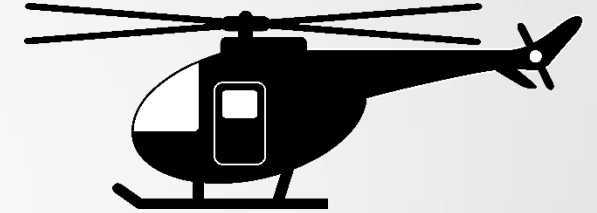
- Force sterilization of Native girls and women
 - 1928 Alberta passed legislation allowing school officials to conduct sterilization
 - 1933 British Columbia followed suit
 - 1973 through 1976, Indian Health Service sterilized 3,500 Native women

Research shapes or reinforces stereotypes



Where there is no benefit there should be no research

- Helicopter researcher: careers flourish
 - Academic publications vs community reports
- Misuse of data and stigmatizing reporting
 - Havasupai & Arizona State University
- Obtaining wrong or insufficient community approval
 - Identifying a tribe

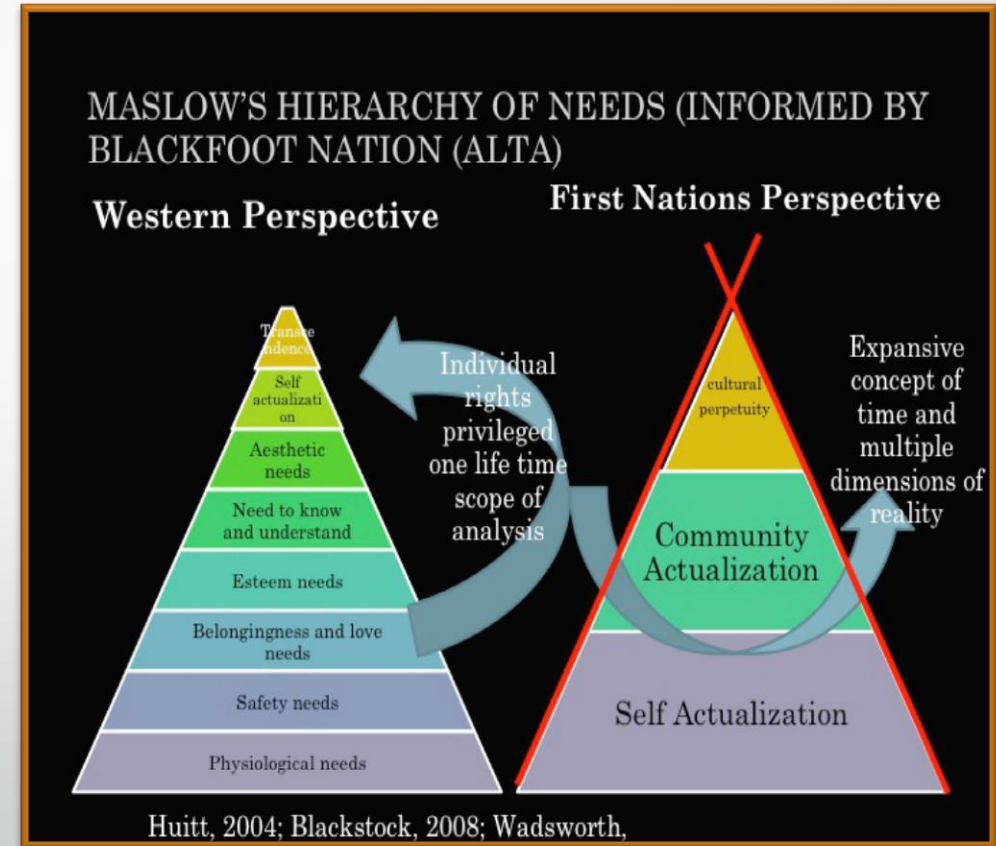


Misappropriation of Cultural knowledge and AIAN Contribution to Science



Medicine:
Willow bark
now aspirin

Agriculture:
Planting of corn,
beans, and
squash



Funders: Focus on negative outcomes

- HIV research focuses on substance use,
 - i.e. drinking BUT AIAN have higher rates of abstinence than the general population
- How are these factor distinctly AIAN or what are the preconditions
 - Individual level behaviors a result from historical oppression, cultural loss, racism (Waldram 2004)



ETHICS

<http://ethics.iwri.org/>

Ethical principles that guide research to enhance engagement

Eunice Kennedy Shriver National Institute of Child Health and Human Development. (1R01HDo82181, Pearson; 9/2014-8/2018)



Beneficence

- A value common across AIAN communities is to “*do good,*”
- Research **MUST** benefit AIAN people
 - Involving community helps ensure the research will likely benefit AIAN
- Good research requires a purposeful approach to improve AIAN health and wellbeing.
 - To ensure research is a good fit for the community, ask if the research will benefit AIAN people and their communities or if it is simply for the sake of research

To learn more about conducting good research in AIAN communities, see [Walking Softly and listen carefully: Building relationships with Tribal communities](#)
National Congress of American Indians (NCAI)



Respect for Persons/Community


- Respecting AIAN tribal sovereignty and community autonomy is critical to building trust
- Gaining trust takes active listening, a humble approach, and acknowledging the expertise that each community member brings to the research

Justice

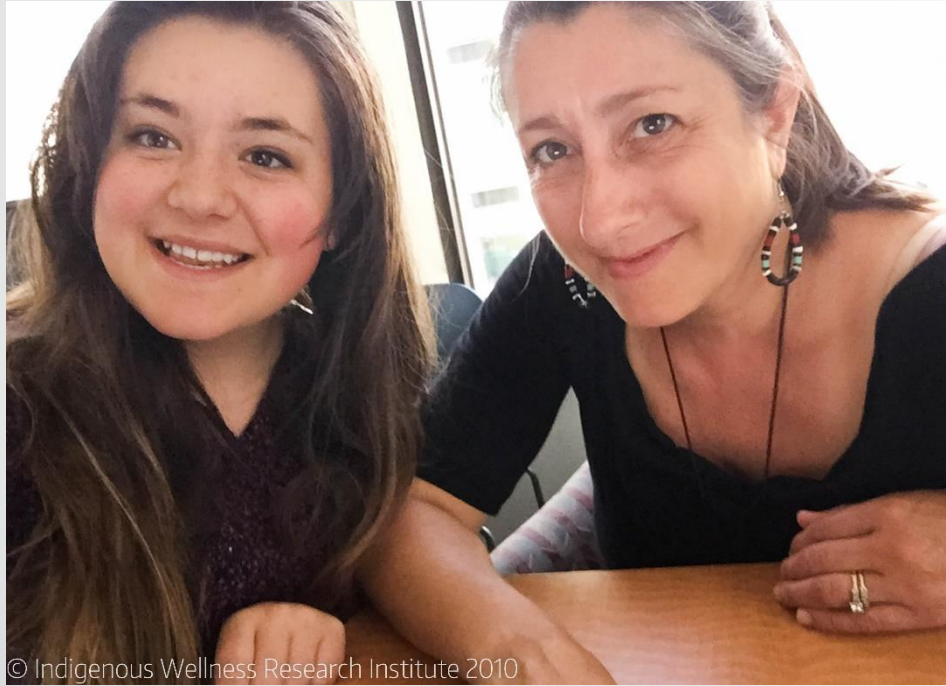
- Distributive justice
 - Those who experience the risks should also experience the benefits
- Procedural justice
 - Procedures are fair and non-exploitative
 - Seek to understand the science and **ways to conduct science** through the eyes of the people who are impacted by the study
 - *How should science change*
 - Science from a western perspective brings with it inherit worldviews from the dominate society

Defining Human Subjects: Living Individuals?

- Many tribal members view deceased individuals, their stories, and their belongings (otherwise known as their data) as sacred, which means they retain rights to privacy and confidentiality
- Tribes may require that genetic and other body specimens are returned to the community at the end of the study to respect cultural beliefs
- At a minimum, researchers who are interested in including data from AIAN people or communities must thoroughly investigate how to meet community standards of research



Enhancing AIAN community involvement:
Minimize harm and maximize benefits of
research



© Indigenous Wellness Research Institute 2010

Minimize Harms

Strategies to enhance participation in research

Invasion of Privacy



- Individual's tribal identifiers
 - i.e. affiliation, geographic location, population size
- Use of publically available information
- Whenever a tribe is named in a research report the researcher should request prior permission from the tribe
- Consulting with community stakeholders to review study materials and to review release of tribal identifiers on study findings is important when trying to minimize invasion of privacy to the tribal community

Wrong or Insufficient Tribal Permission

- Tribal approval processes vary across tribes, rural or urban settings, and type of study
 - tribal coalition; health committee; tribal institutional review board (IRB); tribal council; urban Indian center health board; the Indian Health Service IRB (national and/or regional); or any combination above.
- Researchers should ensure they have approval from the appropriate regulatory committees.
- AIAN tribes have a unique sovereign status in the United States. Tribes may have laws requiring how researchers should protect privacy and conduct research in their community. These laws must be considered while conducting research in tribal communities

Breach of Confidentiality

- Disclosure of tribal level data regarding physical or emotional distress could harm a tribe's reputation
- Misuse, taking, or claiming of AIAN cultural or spiritual property is unethical and in many cases illegal
- Unauthorized release of data could have a negative impact on the participant and tribal community's psychological, social, or economic status

Study Procedures & Methods

- The Chance and Extent of Harm
 - Sound research design
 - Situation, place, culture, and time
 - Site of research activity could create harm i.e., old boarding school
- Researchers or IRBs alone may not be able to fully assess risk within a community or their study protocol

Assessing Risk Objectively

- Confirmed with each new research project, even for secondary data analysis of an already approved project
 - Important to have meaningful community involvement in the research planning process to help assess risk at every phase of the research process

Interpretation of Data and Reporting of Results

- How data will be handled: data sharing agreements – who “owns the data”
- Data own by the tribe and least back to the research institute for the purspoe of the aims of the grant

Ways to Mitigate Harm - Summary

- AIAN communities have the **time, space, & privacy**
 - to make decisions about the research that is conducted within their communities
- AIAN communities are offered the **choice**
 - to benefit from research; given enough information to make that choice
- In tribal settings, **tribal approval is obtained**
 - This looks very different across tribal communities
- In urban settings, meaningful discussions
 - with urban AIAN leadership take place and **AIAN groups provide permission** for the research



Maximize Benefits

Strategies to enhance participation in research

Research Resources

- Facilitate community involvement in the research process
 - Opportunities for community members to conduct research
 - i.e., Design, deliver interventions, collect data, interpret data
 - Co-Author papers
- Distribution of resources
 - Fair compensation for effort, Sub contracts
- Support community grant acquisition
 - Community reports
 - Balance of giving and taking
 - Program evaluations vs. research

Research Review*

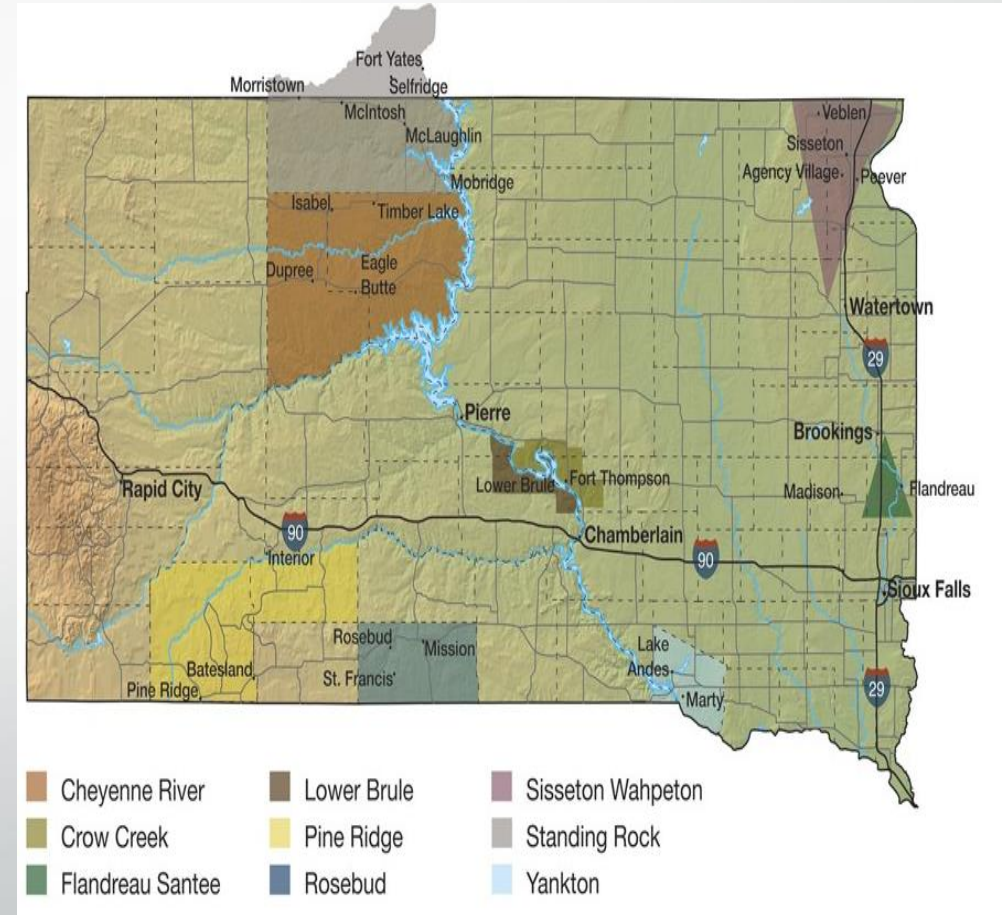
- Community permission may need to be obtained from:
 - Tribal coalition; Tribal council; Community health committee; Elder groups
- IRB review
 - Tribal institutional or research review board
 - Urban or regional Indian health board
 - Indian Health Service IRB (national or regional)
 - University, research or medical center IRB
 - Tribal epidemiology centers (epi centers)
 - Any combination of the above

* Community review of protocol is required for all AIAN and Allies researchers



An Important Clarification

If research activities take place within tribal lands, the research falls under tribal jurisdiction, or if the analysis includes tribal identity, the research must be approved by the tribe.



Tools for Strong Partnerships

- CBPR training
 - Meeting communities where they're at
- Research protocols & Data use agreements
 - Legally Binding?
 - Implications for protection from harm (i.e. stigma)
 - Data integrity, transferring data back to the community
- Publication agreements (authorship)
- Letters of support, MOU, Resolutions



what reviewers can look for

- Researcher or research group new to a community
- Tribal approval – very tricky
 - Is there only one letter of support for an RCT?
- If there community review?
 - What type, by whom?
- Research or publication protocols?
- Are agreements binding?
- If there benefit to the community?
- How and who is assessing risk?



Discussion



Help Develop a Research Ethics Training Curriculum

- Do you self-identify as AIAN?
- Are you 18 years of age or older?
- Never taken an ethical research training course (or has it been over 5 years)?
- Currently collaborate with academic researchers or are you interested in research?
- Do you have your own email address and access to a computer with internet?

Participation Includes:

- Participate in a 10 minute phone screening interview
- Take an online training for approximately 4 hours on conducting ethical research with AIAN communities.


You will receive \$150 for your participation in the study.

Would you like more information to participate?

Contact **(877) 880-6758** or **(goethics@uw.edu)**

**** Please note that we cannot ensure the confidentiality of email. ****





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