Strategies in Conducting Ethical Research with AIAN Communities

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Pathway

• CBPR: Engaging AIAN communities in Research
  • A brief overview

• Foundations in conducting ethical research
  • Understanding the principles of the Belmont report
  • Knowing history and how research has created harm & mistrust

• Ethical considerations when conducting research with AIAN communities: Findings from ETHICS
Approach: Community Based Participatory Research
What it is and is not
- does it make a difference?
CBPR: What it is and is not

• CBPR is an **approach** to research that changes the roles of the researcher and the community to be researched

• CBPR is **not a method** or set of methods

• The goal of CBPR is almost always to influence change in community health, norms, systems, programs, policies
select problem
review existing literature
state hypothesis/research question
design study
collect data
analyze and interpret
present results
replicate
Community-Based Participatory Research Approach

- Select problem
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- Replicate
Balance of Power and Control
Benefits and Challenges of CBPR

Benefits
- Facilitates identification of research risk and benefits; Boosts Recruitment
- Builds community research & service infrastructure
- Enriches external validity
- Enhances translation research
  - Development EBP at the real world level
- Attends to issues of mistrust
- Tackle complex social problems expanding beyond western epistemologies

Challenges
- Increase time commitment – not a 40 hour a week commitment
- Requires lots of training and bi-directional learning
- Increase cost
- Community politics and agendas
- Cultural protocols
- Keeping community members engaged
The Belmont Report: Foundations in conducting ethical research

- Describes the Ethical Principles of the Belmont Report
- Rules & regulation for IRB
- Defines “Research” with “Human Subjects”
  - Exempt from review, expedited review, full review
- Details
  - Inform consent and autonomy
  - Privacy and confidentiality
  - Assessing risk and benefits
- Subpart B: Pregnant women, human fetuses, and neonates
- Subpart C: Prisoners
- Subpart D: Children
Belmont Report Principles

- Beneficence
- Individual
- Justice
- Respect
Individual AND community in research
Types of Community

- Community of Experience or Interest
- Community of Place
- Community of Commonality
Research Harms

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.
Not directly informed

• Boarding school era
  • Medical experimentation

• 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
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
Misappropriation of Cultural knowledge and AIAN Contribution to Science

Medicine: Willow bark now aspirin

Agriculture: Planting of corn, beans, and squash
Stigmatization
Funding applications & reporting 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)
What are some benefits that you’ve experience or heard of from research in your communities?
Ethical principles that guide research with AIAN communities

Eunice Kennedy Shriver National Institute of Child Health and Human Development. (1R01HD082181, Pearson; 9/2014-8/2018)
Community Expert Panel (n=12)
Community member who conduct research with their community

Antony Stately, PhD (Ojibwe/Oneida)

Travis L. Lane (Navajo/Southern Ute)

Emily White Hat, JD (Sicangu Lakota/Rosebud Sioux Tribe)

Vanessa Hiratsuka (Navajo/Winnemem Wintu)

Dr. Brenda Dial Deese (Lumbee Tribe)

Lucy SmartlowitBriggs (Yakama Nation)

Beverly Patchell, PhD, APRN, CNS, PMH-BC (Cherokee/Creek)

Billie Jo Kipp, Ph.D. President of Blackfeet Community College

CeCe Big Crow (Oglala Lakota)

Lynnette Jordan (Ojibwe & Colville)

Sandra Stroud Choctaw Nation

Amanda Gaston, MAT (Zuni Pueblo)
Scientific Expert Panel (n=14)
Indigenous scholars & allies with >15 years working with AIAN

Dr. Ronny Bell (Lumbee)
Center for Health Equity at the Wake Forest School of Medicine

Rodney C. Haring, (Beaver Clan, Seneca Nation) PhD, MSW
Roswell Park Cancer Institute
University of Arizona

Melissa L. Walls (Ph.D., Bois Forte and Couchiching First Nations Anishinabe)
University of Minnesota

Dr. Lee Anne Nichols (Cherokee) is on faculty at The University of Tulsa

Ms. Angal (MPH, CIP)
Director of the Regulatory Knowledge Core CRCAIH - SD

Dr. Julie Baldwin, (Cherokee) Professor
Northern Arizona University

Dr. Irene Vernon (Mescalero -Apache)
Colorado State University

Dr. Belcourt (Otter Woman)
University of Montana
(descendant of Mandan, Hidatsa, Blackfeet, and Chippewa Nations).

Tassy Parker, PhD, RN
Seneca Nation Beaver clan

Scarlett Hopkins, RN,
MA Center for Alaska Native Health research

Jada L. Brooks, PhD,
MSPH, RN (Lumbee)
University of NC

Dr. Julie Dickerson, D.O., M.P.H. (Inupiaq) UCLA

Dr. Irenie Belcourt (Otter Woman)
University of Montana
(descendant of Mandan, Hidatsa, Blackfeet, and Chippewa Nations).

Nicolette Teufel-Shone Ph.D.
U Arizona

Julie E. Lucero Ph.D., MPH, U Nevada
Policy/IRB member Expert Panel (n=5)
Tribal IRB administrators & regional/nation policy expert

Francine C. Gachupin, PhD, MPH, Pueblo of Jemez in New Mexico, University of Arizona (Tucson).

Dr. Malia Villegas
Director NCAI Policy Research Center (Native Village of Afognak in Alaska)

Donald Warne, MD, MPH
Professor and Chair of the Department of Public Health
North Dakota State University

Stephanie Craig Rushing, PhD, MPH, is a Project Director at the Northwest Portland Area Indian Health Board

Dr. Gary Ferguson
Senior Director of Community Health Services at Alaska Native Tribal Health Consortium

William L. (“Bill”) Freeman, MD, MPH
Overall Reviews

• Cultural relevance including reference to research relevant to unique aspects of AIAN culture and laws
• Clarified concepts including removing jargon, simplifying language, or expanding explanations as needed
• Highlighted similarities and differences
• Added examples relevant to AIAN populations that have occurred often or are more reflective of events in AIAN communities, i.e. misuse of data, focus on events likely in community settings versus a technologically advanced setting
• Added community level risk and benefit issues to address a critical gap in ethical training pertinent to AIAN
Findings
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
  • 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
Strategies to Minimize Harms
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

• Respect: AIAN communities have the **time, space, & privacy** to make decisions about the research that is conducted within their communities
  • In tribal settings, **tribal approval is obtained**
  • In urban settings, meaningful discussions with urban AIAN leadership take place

• Justice: AIAN communities are offered the **choice**
  • to benefit from research; given enough information to make that choice

• Beneficence: more than do no harm must benefit AIAN
Strategy to Maximize Benefits
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
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
Discussion