Measurement and Tribal Sovereignty in the Case of Urban AIAN Communities

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- Tribal Sovereignty – an inherent right of native nations
- Consultation requirements – Executive Order 13175
- Tribal Governments & tribally-based organizations regulate research
- Data Sharing and Ownership Agreements can address Tribal and AIAN Community concerns regarding research
Common Community Research Concerns

- History of harm, especially in minority communities
- Protection of individual rights
- Protection of community rights
- Research processes
"For 40 years, the U.S. Public Health Service has conducted a study in which human guinea pigs, not given proper treatment, have died of syphilis and its side effects," Associated Press reporter Jean Heller wrote on July 25, 1972. "The study was conducted to determine from autopsies what the disease does to the human body."
Stanford Prison Experiment

- Summer 1971
- Stanford students in psychology department.
- 2 week experiment ended in 6 days as prisoners exhibited signs of severe stress and guards became sadistic.
Havasupai DNA Case

Tribal members had given DNA samples to ASU researchers hoping for genetic clues to the tribe’s high rate of diabetes. Members later learned that their blood samples had been used to study mental illness.

Photos courtesy of the New York Times
Havasupai Tribal Headquarters

Photo courtesy of the New York Times
Issues in Research & Measurement

**Research**
- Who owns the data?
- Who has access to the data?
- Who has the right to determine how the data is used?
- Who is involved in the data analysis?

**Measurement**
- Who decides on the measures to be used?
- Who evaluates measures for cultural fit?
- Who is involved in revising measures?
- Who has intellectual property rights over measures created / adapted?
Principles of CBPR

• Recognize community as a unit of identity

• Build on strengths and resources within the community

• Facilitate collaborative partnerships in all phases of the research

• Integrate knowledge and action for mutual benefit of all partners

Principles of CBPR

- Promote a co-learning and empowering process that attends to social inequalities
- Utilize a cyclical and iterative process
- Address health from both positive and ecological perspectives
- Disseminate findings and knowledge gained to all partners

Application of CBPR Principles

- Assessing Community Research Readiness
  - Scientific Resources
  - Community Resources
- Establishing Methodology
  - Research Design
  - Sample
  - Recruitment
  - Measures
- Developing Analysis Plan
- Discussion / Dissemination Plan
Research Readiness

Data Maintenance / Access / Ownership

Establish Methods

Dissemination Plan

Develop Analysis Plan
CBPR Principles in Data Sharing and Ownership Agreements

• Informed consent process
• Document development
• Institutional Review Board requirements
• Community requirements
  – Readability
  – Community Harms
  – Community Benefits
  – Data retention plan
Researching Indigenous Health: 
A Practical Guide for Researchers

Indigenous health research needs to be driven by priorities set by Indigenous people, to be of practical use to the Indigenous health sector and to develop research capacity within the Indigenous community. The Lowlja Institute and its predecessor the CRC for Aboriginal Health, have developed resources in response to a growing need for resources in this area.

Recently the Lowlja Institute has released the following Guide. Accompanying resources and case studies can be found in these pages.


It is a companion volume to our previous publication:

RESOLUTION

WHEREAS, a proposed Ordinance to regulate studies, surveys, research and service delivery projects on the Colville Reservation in order to preserve and protect the rights of the Colville Indian Tribes and their tribal members, their privacy and integrity, and their interests in the results and products of the such studies, surveys, research and service delivery projects, has been submitted to HEW Committee for review, and

WHEREAS, it is the recommendation, of the HEW Committee of the Business Council, to approve the attached Ordinance to regulate research on the Colville Indian Reservation.

BE IT RESOLVED that we, the Colville Business Council, this 27th day of January, 1981, by order of the Business Council, do hereby pass the attached Ordinance.
Agreement Provisions

• Privacy and Confidentiality – Removal of personal and tribal identifiers

• Publication and Dissemination – Prior tribal/TCU review required

• Secondary Data Use – Approval by the tribe/TCU required
Agreement Provisions

- Data Storage – Tribal data repository and when it will be destroyed
- Data Use – Application to the Tribe for continued access to data
- Responsibilities of the Research Institution
Thank You

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Photo courtesy of Dr. Duran