

# Measurement and Tribal Sovereignty in the Case of Urban AIAN Communities

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# American Indian & Alaska Native Groups

- 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



# Tuskegee Experiment

"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."



Nurses examine one of the Tuskegee syphilis study participants.  
Photo courtesy National Archives



# Stanford Prison Experiment



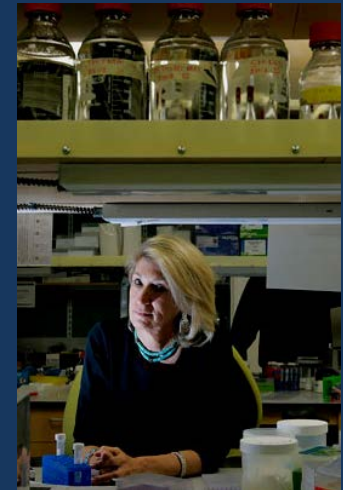
Photo courtesy Stanford Prison Experiment website

- 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

Israel B, Schulz A, Parker E, Becker A. ( 1998 ). Review of community-based research: assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173 ±202.



# 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

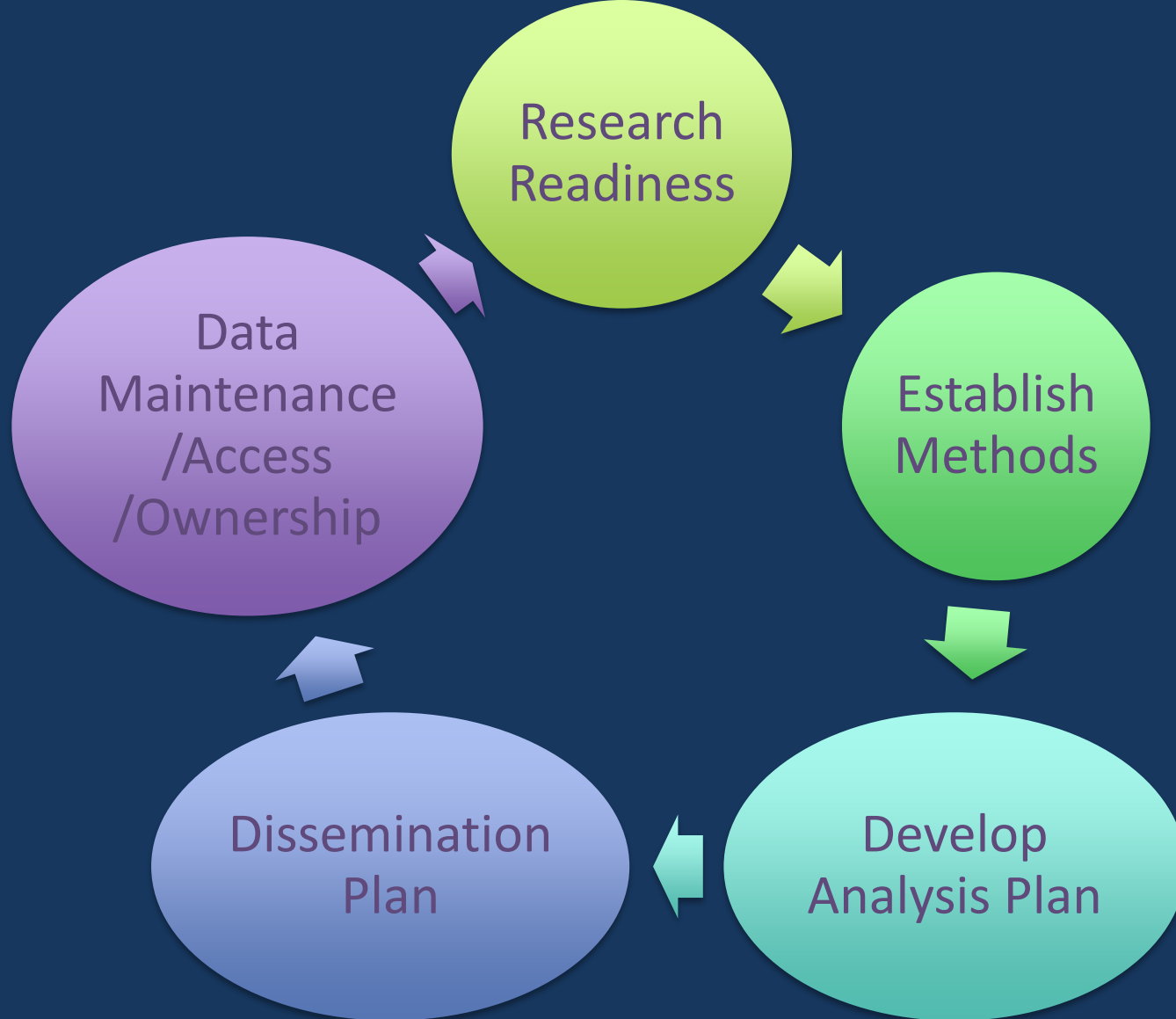
Israel B, Schulz A, Parker E, Becker A. ( 1998 ). Review of community-based research: assessing partnership approaches to improve public health. Annual Review of Public Health, 19, 173 ±202.



# 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





# 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



# NEGOTIATING RESEARCH RELATIONSHIPS WITH INUIT COMMUNITIES



## A GUIDE FOR RESEARCHERS

Prepared by:  
Inuit Tapiriit Kanatami and  
Nunavut Research Institute  
2007

<b>Home</b>	<b>Ethics and health</b>
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<b>Publications</b>	
<b>Data and statistics</b>	<b>Acknowledgements</b>
<b>Programmes and projects</b>	This document is based on an initial draft prepared for the World Health Organization (WHO) by Karen Fediuk, MSc, and Harriet V. Kuhnlein, PhD, RD, Centre for Indigenous Peoples' Nutrition and Environment (CINE), McGill University, Quebec, Canada. CINE has continued to work closely with WHO on successive revisions of the document. A statement outlining CINE's approach and response strategy can be found on the back cover of this document.
<b>Ethics and health</b>	A large number of institutions and individuals, both indigenous and non-indigenous, have provided comments and feedback on this document. While these are too numerous to name individually, we sincerely thank all who contributed their time and effort in this way.
<b>Regional activities</b>	Special thanks are due to Bill Erasmus, National Chief of the Dene Nation, Canada, and Chair of the CINE Governing Board, for helpful considerations and comments.
<b>Global summit</b>	A Spanish version of the document is being prepared for circulation and comments.
<b>Bioethics topics</b>	Further comments and suggestions on this document and its use in the field are welcome, and should be addressed to:
<b>Research ethics</b>	<b>Jacqueline Sims</b> Technical Officer Sustainable Development and Healthy Environments (SDE) World Health Organization Avenue Appia 20
<b>Fellowships</b>	
<b>About us</b>	

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## 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 Lowitja 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 Lowitja Institute has released the following Guide. Accompanying resources and case stories can be found in these pages.

Laycock, A. with Walker, D., Harrison, N. & Brands, J. 2011, *Researching Indigenous Health: A Practical Guide for Researchers*, The Lowitja Institute, Melbourne. ([Purchase the Guide](#))

It is a companion volume to our previous publication:

Laycock, A. with Walker, D., Harrison, N. & Brands, J. 2009, *Supporting Indigenous Researchers: A Practical Guide for Supervisors*, Cooperative Research Centre for Aboriginal Health, Darwin. (6.5MB)



# Community-Based Participatory Research in American Indian and Alaska Native Communities

Puneet Chawla Sahota, Ph.D.

June 2010



Tribally-Driven Research



1981-721

## 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.

AND, that we, the Colville Business Council, in Special Session, this 27th day of June, 1981, at the Colville Indian Agency, Nespelem,

THE UNIVERSITY OF ARIZONA



### Tribal Codes/Protocols Pertaining to Research

**Fort McDowell Yavapai Nation**  
Fort McDowell's Law and Order Code, adopted by Resolution No. 90-30, July 9, 1990 and amended in 2000, contains two ordinances that pertain to research: Chapter 15, the Exclusion Ordinance, and Chapter 19, the Antiquities Ordinance. The Exclusion Ordinance provides "for the removal or exclusion of Non-Members from the Nation whose presence may be detrimental to the peace, health, morals or welfare of the Nation [all] and/or who violate tribal laws or ordinances." This ordinance may be interpreted by the Yavapai Nation to govern actions and activities of outside researchers who are perceived to interfere with the administration of the government, or intrude or otherwise interfere with tribal ceremonies without tribal consent.

[Exclusion Ordinance | Antiquities and Archaeological Sites](#)

**Ho-Chunk Nation Code**  
Title 3, Section 3 of the Ho-Chunk Code, Tribal Research Code, was enacted by the Legislature on February 8, 2005 and amended/restated May 5, 2005. The purpose of the Code is "to define the Nation's research policies, and to establish a means by which tribal research policies will be administered by the Ho-Chunk Nation Institutional Review Board (IRB) and to provide for general procedures by which the IRB will grant permission to researchers to conduct research on Nation Territory." The Code encompasses clinical, behavioral, anthropological/archaeological, community-based, environmental, and public health research.

[Tribal Research Code](#)

#### Research Tools

[DATABASE of Research and Outreach in Indian Country](#)

[Multimedia resources](#)

[Tribal Research Ordinances/Codes/Protocols](#)

[Arizona Cooperative Extension Indian Country Research Protocols](#)

[BIBLIOGRAPHY on Academic Research in Indian Country](#)

[Examples of Research Codes: American Indian Law Center Model Research Code](#)

[University of Montana Model Collaborative Agreement](#)

[Additional Research Resources:](#)

[IRB Checklist for Exempt Review](#)

[IRB Checklist](#)

[Tribal Research Assessment Checklist](#)

[NCAI Research Guide](#)

[NCAI Research Regulations](#)



# 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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