Community-Based and Tribal Participatory Research Approaches

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Why CBPR?

- Include AIAN cultures
- Include social and environmental considerations unique to Indian Country
- Accurately assess potential harms and benefits from research/program
- Improve the research knowledge for AIAN in general – generalizability
Common Community Research Concerns

• History of harm, especially in minority communities
• Indigenous research ethics
• Protection of individual rights
• Protection of community rights
• Research processes
• Dissemination & Application of findings
"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

- 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.

Photo courtesy Stanford Prison Experiment website
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 and other aspects of Havasupai biology, sociology, and history that were not included on the informed consent documents.

Photos courtesy of the New York Times
Principles of CBPR

1. Recognize community as a unit of identity

2. Build on strengths and resources within the community

3. Facilitate collaborative partnerships in all phases of the research

4. Integrate knowledge and action for mutual benefit of all partners

Principles of CBPR

5. Promote a co-learning and empowering process that attends to social inequalities

6. Utilize a cyclical and iterative process

7. Address health from both positive and ecological perspectives

8. Disseminate findings and knowledge gained to all partners

**Application of CBPR Principles**

- Literature Review
  - Scientific Resources
  - “Gray Literature”
  - Community Resources
- Methodology
  - Research Design
  - Sample
  - Recruitment
  - Measures
- Analysis Plan
  - RCT
  - Iterative Process
- Discussion / Dissemination Plan
  - Community review
  - Community contribution
(1) Recognize community as a unit of identity
(2) Build on strengths and resources within the community

Tribal Programs

Schools

Families
(3) Facilitate collaborative partnerships in all phases of the research

Develop the Question

Decide Study Methods

Collect Data

Analyze Data

Report Results

Involve Tribal Program Directors

Involve Community Action Committees

Hire Tribal Members

Ask for review
(4) Integrate knowledge and action for mutual benefit of all partners

**Tribal Program Managers**

<table>
<thead>
<tr>
<th>Results</th>
<th>Interpretation</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>By District</td>
<td>High Risk</td>
<td>New Program</td>
</tr>
<tr>
<td>By School</td>
<td>Low Resources</td>
<td>More $$$$</td>
</tr>
</tbody>
</table>

**Tribal Leaders**

<table>
<thead>
<tr>
<th>Results</th>
<th>Interpretation</th>
<th>Actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall Tribe</td>
<td>Public Health Need</td>
<td>Authorize Funding</td>
</tr>
<tr>
<td>Cost per Child</td>
<td>Available Resources</td>
<td>Explore New Partnerships</td>
</tr>
</tbody>
</table>
(5) Co-learning & empowering to address social inequalities

- Training as needed
  - For researchers on culture?
  - For community members on research?
- Establish equitable research roles across partnership
- Identify ways to use the research findings to reduce disparities
(6) Utilize a cyclical and iterative process

• Hold regular meetings
• Check in on controversial issues
• Make sure stakeholders are involved appropriately / at key decision making points

• Report progress / findings
• Review process regularly
• Track complex decision making timelines
(7) Address health from both positive and ecological perspectives

- Include a strengths-based approach
- Ensure culture is a part of the decision making process
- Discuss ways the findings will be applied at all levels
(8) Disseminate findings and knowledge gained to all partners
American Indian & Alaska Native Groups

- Tribal Sovereignty

- Consultation requirements

- Tribal Governments & tribally-based organizations regulate research

- Data Sharing and Ownership Agreements are one way to address Tribal research concerns
Negotiating Research Relationships with Inuit Communities

A Guide for Researchers

Prepared by:
Inuit Ipiriit Kanatami and
Nunavut Research Institute
2007

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.


It is a companion volume to our previous publication:


https://www.lowitja.org.au/lowitja-publishing/L009

https://www.itk.ca/publication/negotiating-research-relationships-inuit-communities-guide-researchers
Community-Based Participatory Research in American Indian and Alaska Native Communities

Puneet Chawla Sahota, Ph.D.

June 2010

Indigenous peoples & participatory health research: Previous page | 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17

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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.

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A Spanish version of the document is being prepared for circulation and comments.

Further comments and suggestions on this document and its use in the field are welcome, and should be addressed to:

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CHAPTER 6-6 RESEARCH REGULATION

6-6-1 Authority
This regulatory Chapter is established by the Colville Business Council under authority contained in the Constitution and By Laws of the Colville Tribe of the Colville Reservation including the Amendments thereto.

6-6-2 Purpose
The purpose of this Chapter is 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.

6-6-3 Permit Required
Any individual, corporation, agency or institution, whether public or private wishing to undertake a study, survey or research project for any purpose on the Colville Indian Reservation, not specifically requested or contracted for by the Colville Confederated Tribes, must first obtain a permit approved by the Business Council, or its designate, authorizing the conduct of such study, survey or research project on the Colville Indian Reservation pursuant to provisions of this Chapter.

6-6-4 Written Agreement Required for Issuance of Permit
No permit will be issued for any study, survey or research project, not specifically requested or contracted for by the Colville Confederated Tribes, unless and until the individual, corporation, agency or institution wishing to conduct the project has executed a written agreement with the Colville Confederated Tribes regarding the manner in which the study, survey, or research project is to be conducted, creating a fiduciary relationship, and limiting the right of the individual, corporation, agency or institution conducting the study to publish the results or conclusions resulting therefrom without affording the Colville Confederated Tribes an opportunity to review and comment upon the intended publication, and including whatever comments are officially made by or on behalf of the Colville Tribes as part of the final published product.

6-6-5 Information Required for Issuance of Permit
No permit shall be issued for the conduct of any study, survey or research project until the following information has been provided to, and approved by the chairman of the Tribal Business Council or his designate:

(a) Name and signature of individual applicant or authorized agent of any corporation, agency or institution desiring to conduct or participate in the conduct of the study, survey or research project;

http://www.nptao.arizona.edu/

http://www.colvilletribes.com/chapter_6_6_research_regulation.php
Applying CBPR

Daughter attends tribal school

- Study proposes to use student data to investigate parent-child relationship and obesity
- Teacher married to tribal chair opposing health research

Mother works at IHS clinic

- Tribe unhappy with direct service
- Upcoming election

Aunt works as Admin Asst for Tribe

- Political appointment
- Unemployment rate is 60%

Clan Uncle sits on tribal council

- Up for re-election
- Does not have good relationship with health committee chair
## Activity: Applying CBPR in Your Project

1. Community?
2. Strengths and resources?
3. Collaborative partnerships?
4. Integrate knowledge and action?
5. Co-learning and empowering addressing social inequalities?
6. Cyclical and iterative process?
7. Positive and ecological perspectives?
8. Disseminate findings and knowledge?
Why the Concern?

Identifiable data resulting from measurement:

• at the Individual level
• at the Community level
Why the Concern?

Proximity and migration of tribal members to and from major urban areas where measurement may occur.
Declaration of the Rights of Indigenous Peoples

Article 31 – “Indigenous people have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources...”
Declaration of the Rights of Indigenous Peoples

Article 31 – “...They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.

2. In conjunction with indigenous peoples, States shall take effective measures to recognize and protect the exercise of these rights.”
Intercultural Justice Framework

Native nations can:

- Enter contracts with researchers, securing adherence to tribal standards as a condition of the research agreement (Tsosie, 2007).
- Be a part of the research process, to develop working relationships with researchers and research institutions (James, et al., 2014; Oetzel, et al., 2015).
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?
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
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
Ethics Training for Health in Indigenous Communities Study (ETHICS)

• RCT exploring effectiveness of a culturally-adapted human subjects training curriculum in AIAN communities.

• Includes AIAN ethical principles and applications.

• Provides AIAN research context for understanding ethics issues.

Summary of Approaches

- Review measures – how are AIAN included or excluded?
- Investigate tribal authority and review – is a tribal community identifiable?
- Consider ethical principle of Justice – how does it apply in this research setting with regard to potential AIAN participants?
Summary of Approaches

• Consider adopting community-based participatory research principles
• Discuss method of protecting individual AIAN, tribal communities, and urban Indian communities from potential harm with these communities – meaningful consultation
• Tools: Indigenous research models / data sharing and ownership agts / ETHICS training
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References


