Aboriginal Health Research: Creating an Ethical Space

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Goals

- Review the CIHR Guidelines for Health Research Involving Aboriginal People
- To discuss the principles of Community Based Participatory Research
- Illustrate these guidelines and principles in action
Conventional Health Research

- Mass immunizations
- Cancer and cardiovascular disease diagnosis and treatment
- Organ transplantations
- Designer drugs
- Diagnostic technology
Aboriginal Health Disparities

- High infant and maternal morbidity and mortality
- Heavy infectious disease burden
- Malnutrition
- Shortened life expectancy
- Social problems, illnesses and deaths linked to substance use
- Accidents, poisonings, violence, homicide and suicide
- Obesity, diabetes, hypertension, cardiovascular and renal disease
- Diseases caused by environmental contamination

Social Determinants of Health

- Social inclusion
- Employment and social safety net
- Housing and food security
- Access to health care services
- Education
- Empowerment and self-determination
- Early Life

Colonial Oppression

- Loss of traditional territories, traditional lifestyle, and language
- History of subjugation and abuse
- Residential schools - “Stolen Generation”
Captain Richard H. Pratt thought it wiser to …

"Kill the Indian and save the man “

Soul Wound: The Legacy of Native American Schools

Thomas Moore before and after his entrance into the Regina Indian Residential School in Saskatchewan in 1874.

Library and Archives Canada / NL-022474
Some members of the Alexis Nakota Sioux Nation
Aboriginal Health Solutions

- Resilience
- Spirituality
- Medicine Wheel
- Culture/language
- Education
- Self-determination
A researcher should understand and respect Aboriginal world views, including responsibilities to the people and culture that flow from being granted access to sacred knowledge.
Research should be of benefit to the community as well as the researcher.
A researcher should support education & training of Aboriginal people in the community, including training in research methods and ethics.
A researcher should ensure that there is ongoing, accessible and understandable communication with the community.

An Aboriginal community should have the opportunity to participate in the interpretation of data and the review of conclusions drawn from the research to ensure accuracy and cultural sensitivity of interpretation.
Communities should be given the option of a participatory research approach where a genuine research collaboration is developed between researchers and Aboriginal communities.
Community Based Participatory Research …

Collaborative approach to research that produces new knowledge by systematic inquiry in partnership with those affected by the issue being studied for the purpose of education and taking action or affecting social change.

What’s in a Name??

Participatory Action Research

Mutual Inquiry

Community Based Research

Participatory Research

Action Research
Community-Based Participatory Research for Health

Meredith Minkler PhD, Professor of Health and Social Behavior, University of California, Berkeley

Nina Wallerstien MD, Professor of Family Medicine, University of New Mexico
KEY PRINCIPLES

- Recognizes community as a unit of identity
- Facilitates collaborative, equitable involvement of all partners
- Emphasizes the importance of the SDOH
- Disseminates findings and knowledge to all research partners
- Involves a long-term commitment
- Action

### Conventional Academic Research vs. Community Participatory Based Research
(adapted: Strand et al)

<table>
<thead>
<tr>
<th></th>
<th>Conventional Health Research</th>
<th>Community Based Participatory Research</th>
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<tbody>
<tr>
<td>Research question</td>
<td>Investigator-driven evolving from existing work within a discipline</td>
<td>Community-driven evolving from an identified need</td>
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<tr>
<td>Primary goal</td>
<td>Advance knowledge within a discipline</td>
<td>Contribute to betterment of a community</td>
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<tr>
<td>Who designs / conducts research</td>
<td>Academic researcher</td>
<td>Academic researcher / community members</td>
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<tr>
<td>Role of researcher</td>
<td>Outside expert</td>
<td>Collaborative partner</td>
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<tr>
<td>Role of community</td>
<td>Research subjects</td>
<td>Collaborative partner</td>
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<tr>
<td>Relationship of researcher and participants</td>
<td>Short-term, task oriented</td>
<td>Long-term</td>
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<tr>
<td>Value of research</td>
<td>Acceptance by academic peers</td>
<td>Usefulness for community partners and contribution to social change</td>
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<tr>
<td>Ownership of data</td>
<td>Academic researcher</td>
<td>Community</td>
</tr>
<tr>
<td>Mode of dissemination</td>
<td>Peer reviewed academic presentation or publication</td>
<td>Photographic or video presentation, public meetings, legislative body</td>
</tr>
</tbody>
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in-depth interviews

focus groups

randomized trials

Case control study

narrative inquiry

longitudinal cohort study
In Conventional Research...

researchers make all the decisions

“outside research teams swoop down from the skies, swarm all over town, ask nosey questions that are none of their business and then disappear never to be heard of again”

Aboriginal physician

Dr Louis T. Montour 1987

Montour LT, Macaulay AC, 1988. Diabetes Mellitus and Arteriosclerosis: Returning research results to the Mohawk Community, CMAJ.
More….

- Research *with* community, not ‘in’ or ‘about’ community

Is the purpose of the project to facilitate the empowerment of individuals, groups and the community?

Will the project help community participants deal with factors that influence their health and that of their community?
Ethical Space

Western Worldview

Ethical Space

Indigenous Worldview

BENEFITS OF CBPR

- Increases possibility of overcoming distrust on the part of communities
- Enhances the relevance and use of the research data
- Provides heightened awareness of local issues and stronger bonds with the community
MORE BENEFITS…

- Provides resources and employment for communities
- Knowledge contributes to constructive, sustainable change
- Builds community capacity
“As long as the sun shines, grass grows and the rivers flow our treaties are sacred.”
LifeSkills Training
J. Botvin
Institute for Prevention Research

www.lifeskillstraining.com
LIFE SKILLS TRAINING

- Evidence based
- Generic program
- Never evaluated with Canadian Aboriginal children and youth

Alexis Nakota Sioux Nation

Alexis and Stoney Indians in Edmonton, 1890’s. Courtesy of Glenbow Archives
PROJECT GOALS

1. Review and adapt the existing LST© program to ensure it incorporates the language, visual images and cultural teachings of the Alexis Nakota Sioux Nation

2. Evaluate the effectiveness of the modified program

3. Restore and preserve the cultural beliefs, values and language of the ANSN
Alexis Working Committee

- Terms of Reference
- Application for funding
  - Aboriginal Health Strategies Fund
  - Alberta Centre for Child, Family and Community Research
  - Canadian Institutes for Health Research
- Band Council Resolution and Elder Support
Adaptations Committee

- community members and school personnel
- one or more Elders who attend each meeting.
Adaptations

- Alexis Nakota Sioux teachings: ceremonies, prayer, storytelling, and personal life stories
- Language
- Artist’s graphics and pictures
- Student drawings
Nimi Icinohabi
Culturally Adapted Prevention Programs

- those who participate are able to relate more closely to the curricula and are more likely to engage in the program
- can aid in the development of a stronger identity and cultural pride which in turn function as protective factors against substance use
- a community involved in the adaptation and implementation of a prevention program is more likely to feel a sense of ownership and empowerment
Program Evaluation

- Standardized questionnaires before and after program delivery
- Talking circles with school personnel, community members and Elders
- Public Health Agency of Canada Community Capacity Building Tool
Results

- **Questionnaires**
  - positive changes in;
    - Knowledge
    - Attitudes
    - Social Skills

- **Talking Circles**
  - Ownership of and investment in the program
  - Teaching approaches that correspond with the learning context, worldviews and relationships of the community
  - Participation of community members and elders

- **PHAC-CCBT**
  - Longitudinal growth in community capacity
Capacity Building

- Proxy measure of community health
- Includes those attributes that empower a community to take action for the purpose of effecting social change
- Documented longitudinally throughout the development of a CBPR project

Public Health Agency of Canada – Community Capacity Building Tool

- Participation
- Leadership
- Community structures
- External supports
- Asking why
- Obtaining resources
- Skills, knowledge, and learning
- Linking with others
- Sense of community

Communities Build Academic Capacity

- Identify community members who were critical to the success of the project
- Ensure that community protocol was followed
- Direct the creation, ownership and control of specific local cultural knowledge and resources
- Represent the interests and concerns of the community at research meetings
- Identify community resources and experts
- Provide guidance on the best way to take findings back to the community
Humility
Introspection
Solidarity
Social Justice

Pinto & Upshur, 2007. *Global Health Ethics for students, Developing World Bioethics*