Community-Based Participatory Research (CBPR): A Grounding for Action and Social Change

AIHEC Behavioral health Research Network Training
June 18, 2014, Northwest Indian College

Bonnie Duran DrPH, Associate Professor,
University of Washington School of Public Health
Director, Center for Indigenous Health Research
Indigenous Wellness Research Institute [www.iwri.org]
• 58-Single- Mixed race Native, 1\textsuperscript{st} gen college student- Product of the civil rights and women’s movement-

• SFSU (SDSU) & Cal Berkeley

• Grew up \textit{professionally} in urban Indian community clinics and tribal communities

• UNM- 1995- 2006

• IWRI-2007 Theorizing life, work and resistance

• Spiritual traditions
“Our research work must promote *Expert Indians* instead of Indian Experts”

Quote from Navajo Nation IRB Chair, Ms. Beverly Pigman (June 27, 2006)
1. Define and describe community-based participatory research (CBPR) for health

2. Rationale for CBPR

3. Introductions /Share past experience and future plans for CBPR research

4. Examples of CBPR in Indian Country: Research For Change: CBPR process and outcomes research project, TCU studies

5. Identify tools for logic models and theory operationalization in research proposals
What does “authentic community participation in research” mean to you?
Definitions–
Participatory Research is an Umbrella Term:

- Action Research
  - Participatory Action Research
- Emancipatory Research

COMMUNITY-BASED PARTICIPATORY RESEARCH

- popular epidemiology
- cooperative inquiry
- empowerment evaluation

Practice Based Research Networks

Patient Centered Outcomes Research
“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve community health and eliminate health disparities”

~ W.K. Kellogg Foundation Community Health Scholars Program
CBPR Definitions

“Systematic inquiry, with the participation of those affected by an issue for the purpose of education and action or effecting change.” Green et al., 1994, 2003

“A collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.” AHRQ Report, 2004
Principles of CBPR

- Emphasizes local relevance and ecological perspective that recognizes multiple determinants
- Involves system development through cyclical and iterative process
- Disseminates findings and knowledge to all
- Involves long-term process and commitment

Principles of CBPR

- Recognizes community as a unit of identity
- Builds on strengths and resources
- Facilitates partnership in all research phases
- Promotes co-learning and capacity building
- Seeks balance between research and action
Principles for Tribes

- Don’t plan about us without us
- All tribal systems shall be respected and honored, emphasizing policy building and bridging, not a policy wall
- Policies shall not bypass Tribal government review and approval prior to implementation
- Tribally specific data shall not be published without prior consultation
- Data belongs to tribe

CBPR: What it is and isn’t

- CBPR is an orientation to research
  - changes the role of researcher and researched
- CBPR is **not** a method or set of methods
  - Typically thought of as qualitative
  - Fewer epidemiologic examples, but promising
- CBPR is an applied approach
  - Goal is to influence change in community health, systems, programs, or policies
Community-Placed vs. Participatory

- Who chose the problem to be studied?
- How is the budget divided?
- Is there an intervention or service component?
- Where are the results disseminated?
- Who designed the intervention?
- Who made the research policy decisions? (e.g. is there a control group?)
- Who writes papers/makes presentations? Who owns the data?

Source: Adapted in part, from Reyes et al. www.med.umich.edu/.../Fall%202005/Lichtenstein_Community-Based%20Participatory%20Research%20Workshop.ppt
Stages of Research

- Identifying a problem
- Literature review/Theory Development
- Pulling the team together: support letters
- Research proposal
- Getting the funds
- Ethics review
- Making a plan
- Data collection
- Analyzing data
- Interpreting data
- Dissemination of data
- Advocacy: policy and services
Issues at Hand

✓ Has western knowledge production itself contributed to health inequities?

✓ Is there a power/knowledge episteme that replicates colonial relationships?

✓ Can Indigenous communities, other communities of color, health advocates and allies use partnership opportunities and research spaces for indigenous knowledge development?
Colonial Research Practice: Examples of Knowledge/Power Nexus
Indigenist Critique of Western Episteme’s

Research Controlled

History is written by people in power
Coloniality-Modernity
- Starts in Greece and Rome
- Rooted in rhetoric of salvation and progress
- By necessity creates condemnatory logic, savage, primitive, marginalized

Post-Coloniality
- Starts in Greece and Rome
- Privileges “newness” in the archaeology/chronological history of European ideals
- Subjectivities created in language and history

Indigenous Episteme
- Starts with a critique of the limits of Eurocentric knowledge hegemony of “science” as truth: Provincialism as Universalism
- Epistemic disobedience as a set of projects that focus on the common effects of the experience of colonialism
- Shifts the geographies of reason
- Language and concepts as only one vehicle to understand and express “reality”

* From at least a “post” perspective
Assumptions of Western Episteme

- Western values and culture are universal and the pinnacle of social evolution;
- Science is neutral;
- Subjectivity is universal and transparent;
- Resistance is ignorance;
- Learning is uni-linear

When Science Became Western
Historiographical Reflections

By Marwa Elshakry*

ABSTRACT

While thinking about the notion of the “global” in the history of the history of science, this essay examines a related but equally basic concept: the idea of “Western science.” Tracing its rise in the nineteenth century, it shows how it developed as much outside the Western world as within it. Ironically, while the idea itself was crucial for the disciplinary formation of the history of science, the global history behind this story has not been much attended to. Drawing on examples from nineteenth-century Egypt and China, the essay begins by looking at how international vectors of knowledge production (viz., missionaries and technocrats) created new global histories of science through the construction of novel genealogies and through a process of conceptual syncretism. Turning next to the work of early professional historians of science, it shows how Arabic and Chinese knowledge traditions were similarly reinterpreted in light of the modern sciences, now viewed as part of a diachronic and universalist teleology ending in “Western science.” It concludes by arguing that examining the global emergence of the idea of Western science in this way highlights key questions pertaining to the relation of the history of science to knowledge traditions across the world and the continuing search for global histories of science.

THE CONTINGENCY OF THE TERM “SCIENCE”—shaped by different eras, geographies, and epistemological traditions—means that it is not always clear what historians of science are or even should be studying. This is a point that medievalists and early modernists have long debated, and it has lent the discipline methodological depth by historicizing the very subject of its inquiry and by suggesting, in particular, what is modern about modern science. Yet some contingencies have mattered more than others. Imagine a map of the world as represented by the profession: it would be a largely Anglo-American and Eurasian one, with a severely truncated southern hemisphere and the Atlantic world predominating in the northern one.

Ironically, this wasn’t the picture of the world that the discipline began with: indeed,
Apparatus of Colonization

- Colonization -
  - Geographical incursion
  - Ideological “stories” about race & skin color
  - Socio-cultural dislocation
  - External political control
  - Provision of low-level social services

- Governance of “frontier” by ‘central’ authority

- Main governance institutions:
  - Church
  - Medicine/Public Health
  - Education/Research
  - Business/Industry

- Both similar and different from larger global imperial projects

“Promiscuous sexual intercourse among the unmarried of the Apache Indians is common. They are polygamist. The women are unclean and debased. The Navajos’, a branch of the Apache tribe, live in the rudest huts and lead a drunken worthless life. The women are debased and prostituted to the vilest purposes. Syphilitic diseases abound...."
“it seems ..a reproach upon Him...that she should be the most poorly prepared ..for the reproduction of her kind…”

Some Sacred Objects of the Navajo Rites.

By Washington Matthews, Surgeon, U. S. Army.

Someone has said that a first-class museum would consist of a series of satisfactory labels with specimens attached. This saying might be rendered: “The label is more important than the specimen.” When I have finished reading this paper, you may admit that this is true in the case of the little museum which I have here to show: a basket, a fascicle of plant fibres, a few rudely painted sticks, some beads and feathers put together as if by children in their meaningless play, form the total of the collection. You would scarcely pick these trifles up if you saw them lying in the gutter, yet when I have told all I have to tell about them, I trust they may seem of greater importance, and that some among you would be as glad to possess them as I am. I might have

NOT so long ago that the period and conditions are reminiscent or unfamiliar to those individuals who have aided and are still aiding in the moral, spiritual and physical advancement and perpetuation of the Red Man, the fight against disease was waged under the most trying disadvantages.

Then the Indian had just begun reluctantly and doubtfully to yield to the influences of civilization and, though accepting some of its customs, still clung with tenacious hold to the ideas and habits formed in the early history of the race and regarded with mingled skepticism, unfoundled and from.

eral exceptions, in the vast region extending from the Mississippi River to the Pacific Ocean and from the Gulf of Mexico to the Canadian border. The exception referred to are the hospitals located at Carlisle, Pa., Cherokee, N. C., Mount Pleasant, Mich., Hayward, Keshena and Oneida, Wis.†

The school hospitals are designed solely for the treatment of children and the typical plan usually provides two separate wards for the sexes with screened and glazed porches adjunct thereto, convalescent ward, operating, waiting, nurses', dining, bath and toilet rooms and kitchen. At some
Surveillance and normalizing judgment work together to form “discipline” BIOPOWER

- ...the greatest, most precise, productive, and comprehensive system of control of human beings will be built on the smallest and most precise of bases.

- “…determine question of whether true Indian is dying out’.


Health research served as a “roadmap” for colonizers who utilized IHS to overcome difficulties of transportation and communication in more remote, previously inaccessible locations.
Knowledge, race and social position

- Interpreter, health educator, health systems navigator, medicine person...
- ...driver

Nursing outlook,
June 1961
Science and the Sacred

“The intuitive mind is a sacred gift and the rational mind is a faithful servant. We have created a society that honors the servant and has forgotten the gift.”

-Albert Einstein
Evidence Based Interventions vs..

- Evidence based Interventions may be a form of forced acculturation.
- Indigenous health promotion and treatment is often effective “cultural revitalization.”
“Furthermore, community-based prevention involves decisions among groups of people about how to live in society, how the physical environment is built, what food is served in schools, and so on. Thus, the process by which interventions are decided upon and undertaken needs to be treated as a valued outcome. If a community decides to tell people what they can or cannot do, or what they should or should not do, the decisions need to have the legitimacy—the added value—that comes from an open and inclusive group decision-making process.”

IOM report 2012
Decolonizing Research

- DR is a purposeful approach to “transforming the institution of research, the deep underlying structures and taken-for-granted ways of organizing, conducting, and disseminating research knowledge”

- DR enables indigenous communities to theorize their own lives connecting with past and future generations

Indigenous knowledge (IK) as ancient, communal, holistic, spiritual and systematic knowledge about every aspect of human existence

Local communities through accumulated IK gained from generation to generation, knew:

- Social order through culture-based sanctions and rewards for appropriate behavior
- Longevity through Indigenous Public Health
- Healthy physical environments through stewardship,
- Etc, etc, etc...
Indigenous Episteme

- “Logic of the gift” as one foundational epistemic convention grounded in valuing

- *Gifting* functions as a system of social relations, forming alliances, solidarity

- *Gifting* extends to giving and receiving in the natural and spiritual realms

- Reconstructing indigenous Epistemes offers alternative paradigm for *everyone*, not just Natives.

Cumulative vulnerability that colonization has on the physical manifestation of health among indigenous peoples.; i.e.,

- epidemic diseases,
- forced removal,
- warfare,
- starvation
- western cultural hegemony
- Indigenous cultural genocide
Indigenous and Hybrid Approaches
Base Interventions on Wellness & Cultural Revitalization

- Story telling
- Sweat Lodge
- Talking circle
- Vision quest
- Wiping of tears
- Drumming
- Smudging
- Traditional Healers
- Herbal remedies
- Traditional activities
Research for Change: Cross-Site Multicultural Community-Based Participatory Research

Funding NIDA, OBSSR, NCRR, IHS, NARCH 5
The NCAI Policy Research Center is a tribally-driven think tank that supports Native communities in shaping their own future by gathering credible data, building tribal research capacity, providing research support, and convening forums addressing critical policy questions.

As sovereign nations, tribes have a role in the research that is conducted in their communities and in regulating research which occurs on their land and with their citizens.

- Joe Garcia,
  Former President, NCAI
Mission to support collaborative environment aligned with core values of community partnership, equity, and participatory engagement to co-create new knowledge and translate existing knowledge to improve quality of life among New Mexico’s diverse populations.

- **Training Activities**: CBPR Institute for Health, Indigenous & Critical Methodologies, Empowerment Education, etc..

http://hsc.unm.edu/som/fcm/cpr/
Research Teams
1. Describe the variability of CBPR across dimensions in the model to identify differences and commonalities across partnerships

2. Describe and assess the impact of governance on CBPR processes and outcomes across AI/AN and other communities of color.
3. Examine the associations among group dynamic processes and three major CBPR outcomes:

- culturally-responsive and centered interventions;
- strengthened research infrastructure and other community capacities; and
- new health-enhancing policies and practices, under varying conditions and contexts.

4. Identify and disseminate best and promising practices, assessment tools, and future research needs.
MODELS ARE “AN IDEALIZED REPRESENTATION OF REALITY THAT HIGHLIGHTS SOME ASPECTS AND IGNORES OTHERS.”*

“MODELS OF COURSE ARE NEVER TRUE, BUT FORTUNATELY IT IS ONLY NECESSARY THAT THEY BE USEFUL”**


Figure 21.1: Conceptual Logic Model of Community-Based Participatory Research: Processes to Outcomes

**Contexts**
- National & Local: Policies/Trends/Governance
- Historic Context of Collaboration
- Community: Capacity & Readiness
- University: Capacity & Readiness
- Health Issues

**Group Dynamics**
- Structural Dynamics:
  - Diversity
  - Complexity
  - Formal Agreements
  - Real Power/Resource Sharing
  - Alignment with CBPR Principles
  - Length of Time in Partnership
- Individual Dynamics:
  - Cultural Identities & Values
  - Cultural Humility
  - Individual Beliefs
  - Community Reputation of PI
- Relational Dynamics:
  - Dialogue/Mutual Learning
  - Leadership/Stewardship
  - Influence/Power Dynamics
  - Flexibility
  - Self & Collective Reflection
  - Participatory Decision Making & Negotiation
  - Integration of Local Beliefs to Group Process
- Intervention:
  - Intervention adapted within local culture
  - Intervention informed by local institutions
  - Research design reflects partnership input
  - More likely to be sustained

**Outcomes**
- System & Capacity Changes:
  - Policies/Practices
  - Sustained Interventions
  - Cultural Renewal
- Improved Health & Disparities:
  - Social Justice

**CBPR System & Capacity Changes:**
- Cultural Revitalization & Renewal
- Empowerment: Community & University Reflection
- Change in Power Relations
- Change in Practices & Policies
- Culturally-Based & Sustainable Interventions

**Health Outcomes:**
- Overcoming Disparities
New Scale: Culture-Centeredness

- Voice
  - Problem definition
  - Dissemination - Solutions
  - Data Collection
- Power Relations
  - Reflexivity
  - Participatory decision making
- Transformation
  - Structural changes
  - Communicative resources
<table>
<thead>
<tr>
<th>Culture-Centeredness</th>
<th>“The culture-centered approach to health ...is built on the notion of centralizing cultural voices in the articulation of health problems and solutions...through the engagement with subaltern...”</th>
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<td></td>
<td>“Culturally supported interventions ...emerge out of grass roots, educational and social service programs for Hispanic, Native and other communities of color... and are often based on revitalizing cultural principles/ traditions or on validating new emerging social identities and networks.”</td>
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</tbody>
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Indigenous Wellness Research Institute- Center for Indigenous Health Research
Tribal College and Universities Partnerships
TCU Studies

1. Drug and Alcohol Problem and Solutions Study

2. Tribal College Behavioral Wellness Studies – Psychiatric Epidemiology Study

3. Adaption of Brief Alcohol Screening, Intervention for Colleges (BASICS)
Adaptation Process in TCU Basics Project

- Conduct TCU Staff/Student Survey
- Conduct TCU Key Stakeholder Interviews and Focus Groups
- Meet with TCU Advocates and Advisory Group Members

Alcohol/Substance Abuse
Behavioral Health
Retention
Identified as Priority Concerns

Identify/Review Available Evidence-based Substance Abuse Interventions, with a Focus on Those Developed and Validated with College and AIAN Populations

Present to the UW Research Teams
Present to TCU Advocates and Advisory Group
Conduct Focus Groups with TCU Staff and Students
Initiate Curriculum Development/Adaptation Work

TCU & Research Workgroups Adapt BASICS Intervention, Making it Culturally Appropriate for TCUs
BASICS Adaptation Process

- **What to Measure**: Decisions about what domains, both risk and protective, to include in assessment
- **How to Measure**: What specific questionnaires, taking into account length, focus, redundancy, and relevance, to use to measure these domains
- **What about Feedback**: Whether language, pictures, descriptions are culturally appropriate and fit with TCU student population
<table>
<thead>
<tr>
<th>Trust phase</th>
<th>Characteristics</th>
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</thead>
<tbody>
<tr>
<td>Ideal or Authentic</td>
<td>✤ Recognizes difference, privilege, &amp; power</td>
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<tr>
<td></td>
<td>✤ Can make mistakes &amp; changes</td>
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<td></td>
<td>✤ Commitment to keep working together</td>
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<td></td>
<td>✤ Interpersonal relationships are primary</td>
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<tr>
<td>Critical Reflective</td>
<td>✤ Use of agreements for reflection/ownership</td>
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<tr>
<td></td>
<td>✤ Walk the talk, over time</td>
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<tr>
<td></td>
<td>✤ &quot;Mistrust has purpose&quot;</td>
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<tr>
<td></td>
<td>✤ Transparency of expectations</td>
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<tr>
<td></td>
<td>✤ Reciprocal trust</td>
</tr>
<tr>
<td>Proxy</td>
<td>✤ Trust because someone I trust, trusts you</td>
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<td></td>
<td>✤ Gatekeepers</td>
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<tr>
<td></td>
<td>✤ Probationary trust</td>
</tr>
<tr>
<td>Functional</td>
<td>✤ Accepting, but time limited &amp; for specific purpose</td>
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<tr>
<td></td>
<td>✤ Risk or perceived threat at play</td>
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<tr>
<td>Neutral</td>
<td>✤ Neither trust/mistrust dominates</td>
</tr>
<tr>
<td></td>
<td>✤ Naïveté</td>
</tr>
<tr>
<td></td>
<td>✤ Development of trust possible</td>
</tr>
<tr>
<td>Unearned</td>
<td>✤ Trust based on title or role such as a researcher or physician</td>
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<tr>
<td></td>
<td>✤ Trust based on agency/coalition which does not represent community</td>
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<tr>
<td>Proxy mistrust</td>
<td>✤ Mistrust based on personal experience or experience of others</td>
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<tr>
<td></td>
<td>✤ Someone you don’t trust endorses someone</td>
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<tr>
<td>Trust deficit</td>
<td>✤ Nothing you can do or say will earn trust</td>
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<tr>
<td></td>
<td>✤ Complete and total mistrust</td>
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<td></td>
<td>✤ Fear of hidden agenda</td>
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**TRUST INDICATORS FOR INTERORGANIZATIONAL RELATIONSHIPS**

- **FUNCTIONAL TRUST**
  - Assumptions:
    - Trust is not linear or binary
    - Time is a salient feature that is often overlooked
    - Contextual & Historical factors need to be considered

- **NEUTRAL TRUST**

- **UNEARNED TRUST**

- **PROXY TRUST**

- **CRITICAL REFLECTIVE TRUST**

- **IDEAL OR AUTHENTIC TRUST**

3/16/2010  Developed by UNM CBPR Research Team
Adapted Indigenist model of trauma, coping, and health outcomes

**Stress**
- Historical Trauma
- Discrimination
- Life Trauma
- Family Violence
- Multiple Losses

**Coping**
- Cultural Buffers
  - Traditional Health & Healing Practices
  - Identity Attitudes
  - Enculturation
  - Spiritual Coping

**Health Outcomes**
- Health
  - HIV risk
  - Mortality
- Alcohol/Drug
  - Use/abuse
  - Dependence
- Mental Health
  - Depression
  - PTSD/Anxiety
- Health Parity & Equity
  - Mental, Physical & Spiritual Health
  - Health Equity

Adapted from Indigenist model of trauma, coping and health outcomes for American Indian Women, Walters and Simon, American Journal of Public Health April 2003, Vol 93, No. 4
Human Subjects Protections

- Northwest Indian College Institutional Review Board (IRB) Approval – Full Review 6/22/11
- University of Washington IRB Approval - Expedited Review 7/6/11

June 22, 2011
Bonnie Duran, PI,
School of Social Work
University of Washington
Box 354900
Seattle, WA 98105
bonduran@u.washington.edu

Project: CBPR TCU Alcohol Problems and Solutions
NWIC IRB Project Number: # 2008-08

Approval Date: 8/17/2011
Approval Expiration Date: 6/30/2012
Approval Category: Major Modification Review
Risk Category: NOT greater than minimal risk IF all conditions (if any) are met

Dear Dr. Duran:

The Northwest Indian College IRB has APPROVED the Major Modification of your research protocol CBPR. TCU Alcohol Problems and Solutions. You may begin your recruitment and consent process and the research.

Please submit the post NWIC IRB Annual/Closure Form at least six (6) weeks before the
PI attended NNHRRB & OSTIRB in-person to seek approval to conduct study – 01/2012 & 2/12

Approvals
Participation in CBPR

- Builds capacity and reduces dependency on “professional outsiders”
- Ensures cultural and local competence
- Facilitates sustainability
- Enhances fit and productivity of programs
- Addressed concerns of manipulation

Power issues in CBPR

Role Play
Identifying TCU Research Values
Stewardship: being responsible for the needs of a community
- To protect from harm
- To enhance well-being

Culture Matters:
What do we need to know to do real CBPR?

- understanding the mission and the values of CBPR
- knowing theoretical frameworks, models, and methods of planning, implementation, and evaluation of CBPR
- being able to translate the process and findings of CBPR into policy
- institution has the requisite resources and infrastructure
- ability to be self-reflective and admit mistakes
- capacity to work within different power structures
- Humility
- interpersonal and facilitation skills
- sensitivity to community needs
- Good communication skills
- Grant writing skills

Kellogg Foundation
Israel et al
Values of CBPR

- Community Knowledge is valued and valid
- Research is not culturally neutral
- Responsible stewardship / management includes understanding data and research
- Community leaders must exercise authority in directing research and managing data
- Research must benefit community members
What skills or qualities do you want to see in partners?

- ?
What does AIHEC’s behavioral health logic model look like?