HOLDING SPACE: A TOOLKIT FOR TRIBAL-ACADEMIC PARTNERSHIPS

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AGENDA

1. Overview of three-pillars

2. Holding Space toolkit
   - Research Futures Game
     - Experience game
     - Debrief
   - Discussion guide
     - Governance
     - Trust
     - Culture
Foundations of Tribal-Academic Relationships

TRIBAL-ACADEMIC PARTNERSHIP: A VIGNETTE
GOVERNANCE: REGULATION VS. STEWARDSHIP

IRB (HARM TO HUMANS)

TRIBAL OVERSIGHT (RESEARCHER BURDEN)

BALANCE NEEDED

Trust Conceptualization

• **Respect and safety** is providing particular attention to an individuals thoughts and opinions while ensuring a culturally and emotionally safe environment to voice thoughts and opinions. Cultural safety means ‘no assault on a person’s identity.’

• **Sense of responsibility** is demonstrated as being able to complete tasks, dependable, reliable, and accountable. All of which move the partnership forward.

• **Shared values and goals** creates camaraderie and solidarity; confidently knowing that each partnership member will strive to achieve the same goals.

Lucero, J.E.. (2013). Trust as an ethical construct in community based participatory research partnerships. (Published doctoral dissertation), University of New Mexico, Albuquerque, NM
“As humans, we are culture-bearing, culture-making, and culture-sharing beings.”

Source: Cultures and Selves: A Cycle of Mutual Constitution. Perspectives on Psychological Science 5, Markus & Kitayama, 2010
HOLDING SPACE:
RESEARCH FUTURES GAME FOR TRIBAL-ACADEMIC PARTNERSHIPS
Future Game Workshop

Data Inspired; Culturally Driven
Steps in playing the game

• Forward from Year 1 to Year 20
• Identify roles
• Five game steps (Year 1, 2, 5, 10, 20) – at each step:
  • Table Sheet and Decision Sheet
  • 10 minutes to discuss and debate
  • Make decision at 1-minute warning
  • Choose 1 of the 2 options
  • Record on decision sheet
  • Hand in decision sheet – receive next one
ROLES

- Postdoctoral Researcher
- Young Tribal Leader
- Senior Researcher
- Elder Tribal Leader
- Tribal Grant Administrator
**RECENT NEWS**

- **New study shows that diabetes in USA is on the rise, particularly in low-income and marginalized communities.** Native Americans populations have the highest rate of diabetes worldwide.

- **Study released that shows government funding cuts are squeezing innovation in institutional science and health research.** Funding is being directed into the private sector.

- **Special Diabetes Program for Indians fails to be reauthorized by congress, meaning many local diabetes clinics may soon be shuttered.**

- **Progress in artificial intelligence presents promising opportunities for health treatments.** Diagnostic and treatment recommendations are being offered by AI systems, that include genetic screening.

**YEAR 1**

**KEY BACKGROUND INFORMATION**

Three years ago, a tribal nursing student was concerned with trends in cardiovascular health in the community. After receiving approval from tribal leadership, she approached the University to support research on heart attack rates and risk factors. A research team of university and tribal representatives was formed—with a few members shifting over time and election cycles. A one-year pilot study was designed and went through the University’s Institutional (Research) Review Board (IRB). Tribal members and graduate students were trained to run surveys, health tests, and conduct interviews in the community. Tribal leaders and program administrators have begun to change their policies and services in response to the research findings.

**HEALTH ALERT**

Genomic breakthroughs bring first new treatments to the market. Single-shot injections offer the cure for rare diseases, but come with a very high price tag, often close to $1 million.
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**DECISION SHEET**

**Year 1**

**Scenario:**
A cutting-edge biotech company in Silicon Valley, called FutureBioMeds, has set a target to bring a new diabetes diagnostic device to market in the next 20 years. They are making great strides in developing genetic tests and gene therapies. They have already begun human trials, and are now FDA-approved to move to the next phase of research. In the interest of expanding the geographic and racial diversity of their trials, your community-based research partnership has been invited to apply to become one of three regional research consortia.

Join three other community partners, with a potential budget of up to $10 million in research funds. Those involved will have the ability to conduct research in advance of potentially reducing diabetes in their local communities.

**Your choices are:**

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<tr>
<td><strong>A</strong></td>
<td><strong>B</strong></td>
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<tr>
<td>Well and see how these next trials go, then determine future participation.</td>
<td>Apply to become a Regional Research Consortium.</td>
</tr>
</tbody>
</table>

**Group’s Choice:**

**Other Information:**

In making your choice, tell us how much the elements of the triple-bottom line were factored into your decision. Check one box in each row.

<table>
<thead>
<tr>
<th>Culture</th>
<th>Essential</th>
<th>Very Important</th>
<th>Important</th>
<th>Minor</th>
<th>Negligible</th>
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</thead>
<tbody>
<tr>
<td>Governance</td>
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<tr>
<td>Trust</td>
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<tr>
<td>Comments (if any):</td>
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Your Future Begins....

Data Inspired; Culturally Driven
Health policy is defensive in posture, with concern about loss of individual and tribal rights and identity. Policy is locally determined, and referenced against immediate local concerns such as individual safety and health.

Partnerships are difficult to create and sustain. Trust is eroded, and most groups / tribes and institutions operate on a self-interest and risk adverse basis.

The capacity has been created to build and sustain high quality collaborative partnerships. These span dimensions of geography, sector and expertise.

Health policy is open and progressive, with an eye for futuristic cutting edge best practice solutions. The focus is on optimal and ambitious population and community health outcomes.
The tribal community is suspicious of health research and assumes a defensive posture against its use and practice. If health research is conducted, it is initiated by external agendas. Local policies, if present, are referenced against immediate community concerns and tend to be reactive.

Research partnerships are difficult to create or maintain. Tribal nations and academic institutions operate on a risk adverse basis and display gatekeeping behaviors owing to a lack of trust. Tribal culture is not integrated into any aspect of the research process.

Research partnerships are built on mutual trust, respect, and are oriented towards community benefit. Tribal culture is valued as an integral part of research and there is a reciprocal exchange of knowledge/expertise among partners. Governance of the research is collaborative, but deferential to the sovereign authority of the tribe. Resources are shared and there is commitment to build community capacity over time.

Health research is driven by the desire to deliver optimal and ambitious population and community health outcomes. Local policies are anticipatory and progressive, defining and applying culturally-rooted best practices to ensure community benefit.

Tribal Research Environment 2030
Combined from focus group sessions
Future Game Workshop

Data Inspired; Culturally Driven
HOLDING SPACE:
DISCUSSION GUIDE FOR TRIBAL-ACADEMIC PARTNERSHIPS
PROJECT HISTORY

PARTNERS:

QUALITATIVE STRATEGY:
5 case studies

1. A substance abuse prevention partnership with Northwestern tribes
2. A colorectal cancer screening project in Chinatown, San Francisco
3. A rural African-American economic development and cardiovascular disease project
4. A NARCH Lakota cancer control project
5. A Latino environmental justice policy partnership

Funded by NARCH V, U261HS300293
### Partnership Outcomes

<table>
<thead>
<tr>
<th>Partnership Outcomes</th>
<th>Synergy</th>
<th>Personal Outcomes</th>
<th>Agency Outcomes</th>
<th>Power relations</th>
<th>Sustainability</th>
<th>Community change</th>
<th>Community health</th>
<th>Overall outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>Trust</td>
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<tr>
<td>Culture</td>
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- Governance: Resource sharing and written agreements.
- Trust: Partnership principles, participation, and trust at partnership start.
- Culture: Community principles and partner values

Funded by NARCH V, U26IHS300293

To disseminate within and support American Indian/Alaska Native communities in CBPR partnerships to:

Implement best practices learned from previous research
  • Governance, Culture and Trust are crosscutting themes that matter to research partnerships

Inform and improve the quality of AI/AN health disparities research
  • Promote genuine community-academic partnerships
<table>
<thead>
<tr>
<th>GOVERNANCE</th>
<th>TRUST</th>
<th>CULTURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource sharing</td>
<td>Transparency</td>
<td>Relevance of research topic</td>
</tr>
<tr>
<td>Capacity building &amp; enhancing</td>
<td>Open communication</td>
<td>Roles of Engagement</td>
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<tr>
<td>Ethical stewardship</td>
<td>Power balances</td>
<td>Cultural safety, humility</td>
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<td></td>
<td>Conflict negotiation</td>
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<td></td>
<td>Alignment of values</td>
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### The WHEN of Governance

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
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<tr>
<td>Does governance take place only during the moment when the tribal council (or other vested entity) decides to approve or not approve research proposal?</td>
<td></td>
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<tr>
<td>Does governance take place when the parameters of research design and outreach to research participants are being negotiated?</td>
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<tr>
<td>Does governance take place only during times of conflict?</td>
<td></td>
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<tr>
<td>Does governance take place over the course of the research project?</td>
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</table>
Ethical governance in research is more than regulation, it is **responsible stewardship** that manages risks and ensures benefits for individuals and the community as a whole. Tribal nations, as sovereigns, duly exercise oversight for the welfare of their citizens.
“[M]any Native people are wary of research and do not trust researchers, the academic institutions they represent, and/or the funding agencies. This is largely due to the fact that the term ‘research’ can remind Native people of the legacy left by researchers who did not prioritize the benefits of Native peoples and who, in some cases, caused harm by exploring inappropriate questions, misusing data and biological specimens, and using data gathered from community members to address issues that have little or no relevance to the community.”

Walk Softly, Listen Carefully, p.14, emphasis added
TRUST CONSTRUCTION

Lucero, J.E.. (2013). Trust as an ethical construct in community based participatory research partnerships. (Published doctoral dissertation), University of New Mexico, Albuquerque, NM
KNOWING YOUR CONFLICT STYLE

Source: Based on Managing Conflict on the Farm by Guy Hutt and Robert Milligan.
CULTURAL HUMILITY IN RESEARCH

**Principles of Cultural Humility**

1. Lifelong learning & critical self-reflection
2. Recognizing & challenging power imbalances
3. Institutional accountability & respect

**Partner Relations**

- What do you know about your research partner?
- What are the benefits of partnering?
- What are the costs (or risks) of partnering?
- What does it mean to be culturally safe in the context of a research project?

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IDEAL PATH OF RESEARCH PARTNERSHIPS

- Toolkit Training
  - Guide
  - Game
  - Target audience: tribal academic research partnerships

- Stronger Tribal Academic Partnerships
  - Understand governance, trust, culture concepts critical to partnership
  - Implement concepts in partnership

- Better decision-making
  - Tribe as steward, sovereignty
  - Trust, less conflict
  - Culture protected, respected, research better fit
  - Synergy
  - Power dynamics change

- Better research is conducted
  - Community benefits from research
  - Partnership benefits and is sustained
  - Capacity building for partners
  - Tribal involvement throughout process
  - Better science

- Disparities decrease
  - Community transformation
  - Community health improvement
