



HOLDING SPACE:

A TOOLKIT FOR TRIBAL-ACADEMIC PARTNERSHIPS

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June 3, 2018

AGENDA

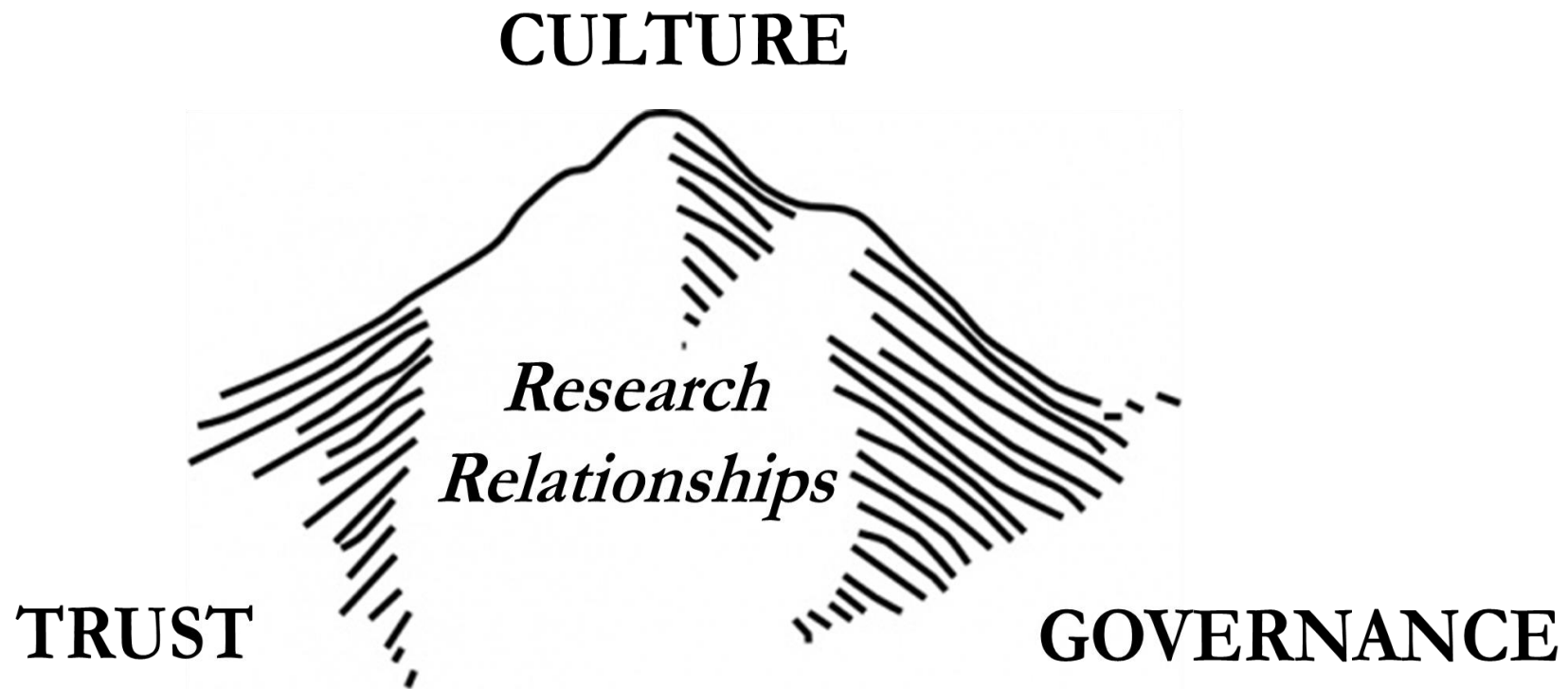
1 Overview of three-pillars

2 Holding Space toolkit

- **Research Futures Game**
 - Experience game
 - Debrief
- **Discussion guide**
 - Governance
 - Trust
 - Culture



FOUNDATIONS OF TRIBAL-ACADEMIC RELATIONSHIPS



Holding Space: A Guide for Partners in Tribal Research. National Congress of American Indians & University of Nevada-Reno, forthcoming.



TRIBAL-ACADEMIC PARTNERSHIP: A VIGNETTE

GOVERNANCE: REGULATION VS. STEWARDSHIP



Holding Space: A Guide for Partners in Tribal Research. National Congress of American Indians & University of Nevada-Reno, forthcoming.

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.

CULTURE

“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

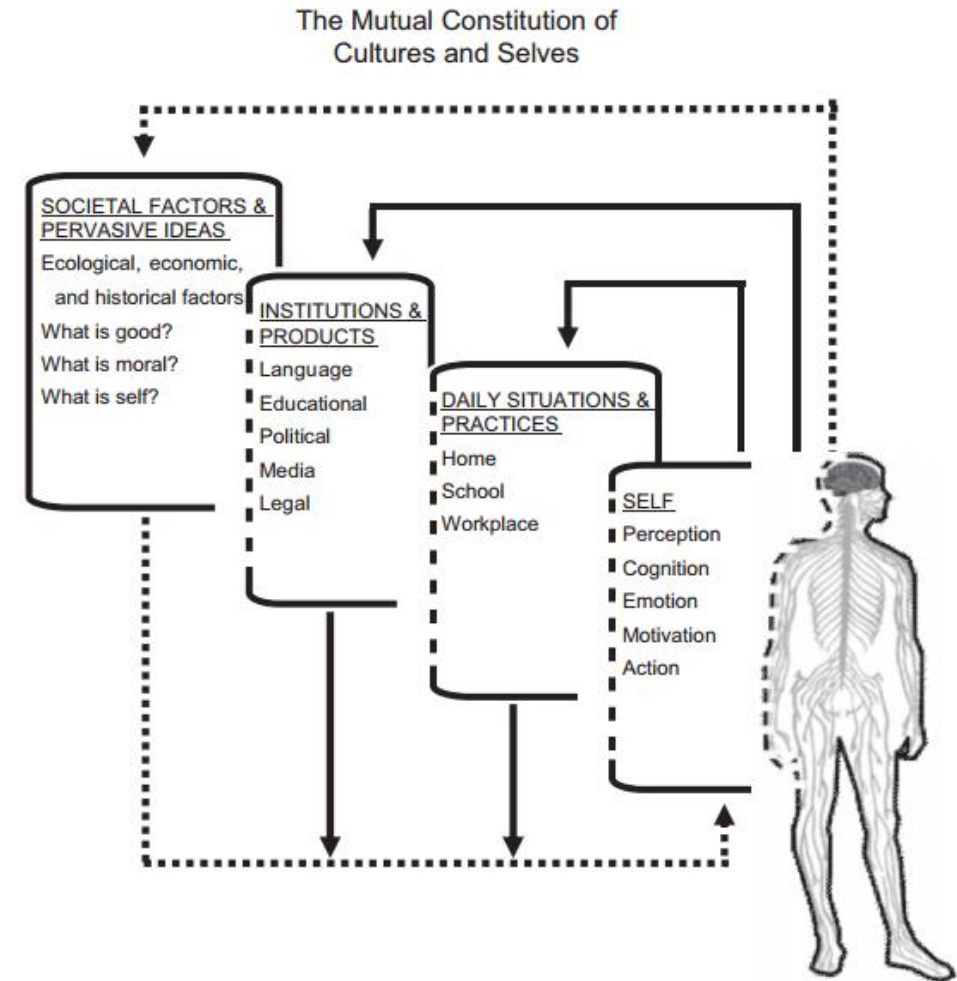


Fig. 1. The mutual constitution of cultures and selves. Figure adapted from Markus and Kitayama (1994) and Fiske et al. (1998).

The background of the entire image is a teal color with a subtle, repeating pattern of feather-like textures. A dark blue horizontal band is centered across the image, containing the title text in white.

HOLDING SPACE:

RESEARCH FUTURES GAME FOR TRIBAL-ACADEMIC PARTNERSHIPS



Future Game Workshop

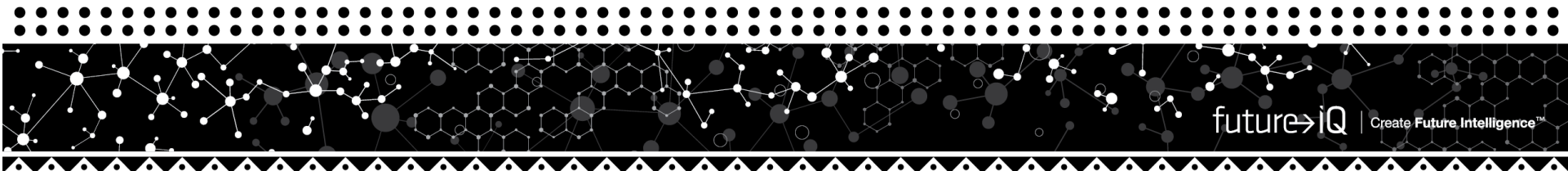
Data Inspired; Culturally Driven



University of Nevada, Reno

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





TheFutureGame

NCAI TRIBAL RESEARCH

FutureGame

SIMULATION
LEARNING



University of Nevada, Reno



National
Congress of
American
Indians

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 suppressing investment in institutional science and health research, driving innovation into the private sector.

As part of whole health industry funding shake-up, major funding cuts are announced. National Institutes of Health (NIH) faces 40% cut over next three years. Funding is increasingly being devolved to State level.

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.

Hello – Welcome to the Game!

Biomedical Engineering is becoming a big deal.

Biomedical engineering is the application of engineering principles and design concepts to medicine and biology for healthcare purposes (e.g. diagnostic or therapeutic). This field seeks to close the gap between engineering and medicine, combining the design and problem-solving skills of engineering with medical biological sciences to advance health care treatment, including diagnosis, monitoring, and therapy.

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.



RECENT NEWS

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Special Diabetes ...
be reauthorized by
local diabetes cli...

Biomedical engineer
or thera...

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YEAR 1

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HEALTH ALERT

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Group Number

Year 1

DECISION SHEET

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Decision to be made:

A cutting-edge biomedical engineering company in Silicon Valley, called Futures BioMed, has set a target to end new diabetes diagnoses nationwide in the next 20 years—and they are making great advances using 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/ethnic diversity of their trials, your community-based research partnership has been invited to apply to become one of their Regional Research Consortiums (join three other research partnerships), with a potential budget of upwards of \$15 million in private industry funds. These Consortiums will have the ability to conduct research in advanced research facilities and have access to leading experts in diabetes prevention and care to potentially reduce diabetes in their local communities.

Your choices are:

A Wait and see how these next trials go, then determine future participation.

B Apply to become a Regional Research Consortium.

Record group's choice of A or B

Group's Choice

Record the number of votes for and against the group's choice

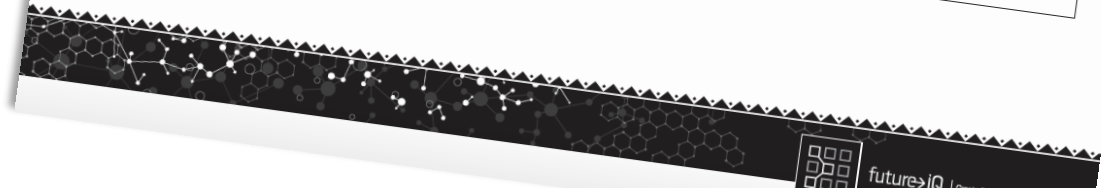
For	Against

Other information:

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

	Essential	Very important	Important	Minor	Not relevant
Culture					
Governance					
Trust					

Comments (if any):



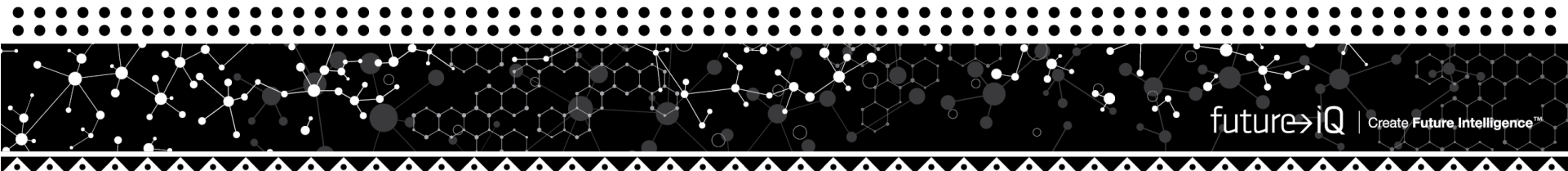


Your Future Begins....

Data Inspired; Culturally Driven



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Plausible Scenario Matrix

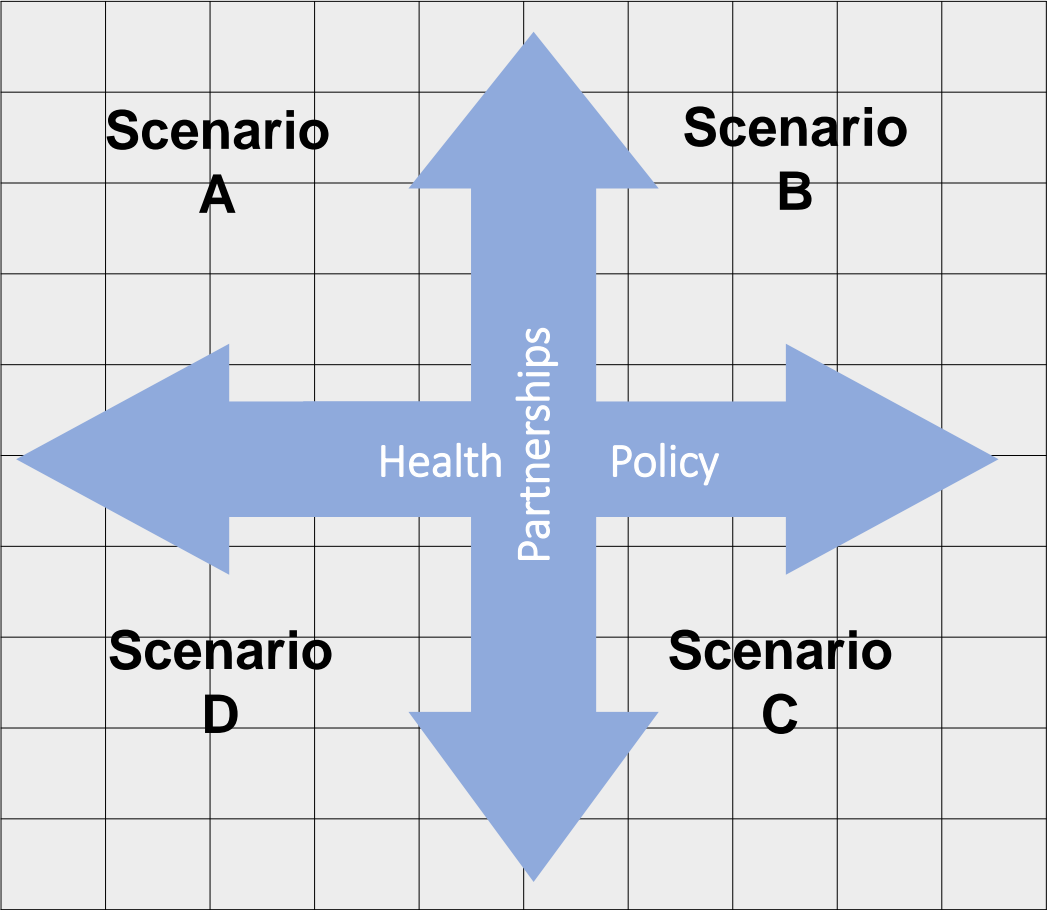


The capacity has been created to build and sustain high quality collaborative partnerships. These span dimensions of geography, sector and expertise.

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

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.

**Tribal
Research
Environment
2030**



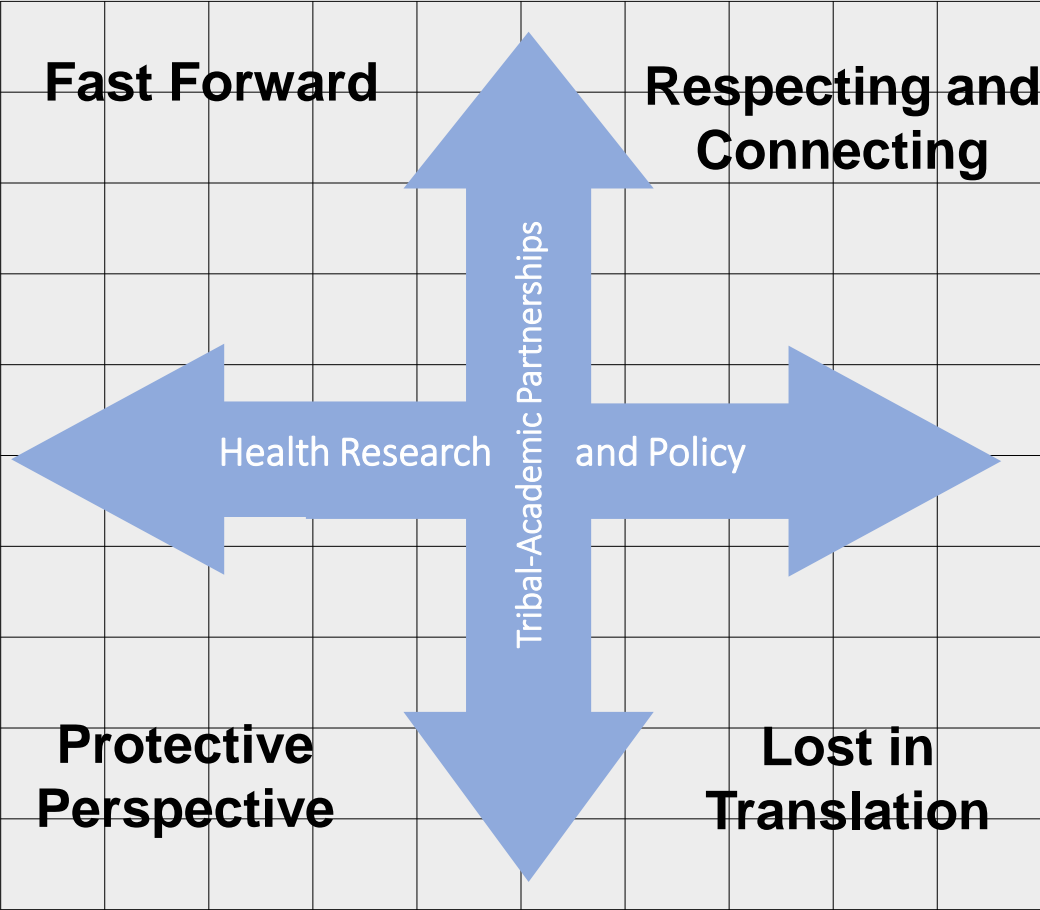
Partnerships are difficult to create and sustain. Trust is eroded, and most groups / tribes and institutions operate on a self interest and risk adverse basis.

Plausible Scenario Matrix



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

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.



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.

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.

Tribal Research Environment 2030
Combined from focus group sessions

TheFutureGame®

NCAI TRIBAL RESEARCH



future*IQ* | Create Future Intelligence®
www.future-iq.com

Year 1
A cutting-edge biomedical engineering company in Silicon Valley, called *Futures BioMed*, has set a target to end new diabetes diagnoses nationwide in the next 20 years—and they are making great advances using 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/ethnic diversity of their trials; your community-based research partnership has been invited to apply to become one of their Regional Research Consortia (join three other research partnerships), with a potential budget of upwards of \$15 million in private industry funds. These Consortia will have the ability to conduct research in advanced research facilities and have access to leading experts in diabetes prevention and care to potentially reduce diabetes in their local communities. Your choices are:

A Wait and see how these next trials go, then determine future participation.

B Apply to become a Regional Research Consortium.

Year 2v1
Medical trials have proceeded and the preliminary results are outstanding; diabetes rates among enrolled participants are on a dramatic decline. Both tribal and academic communities are frustrated that they missed out on this opportunity. The biomedical engineering company is now accepting applications for yet another wave of Research Consortia, but participation now comes with a steep cost of \$5,000 per patient enrolled. Alternatively, the research partnership has found a smaller grant opportunity to advance its ongoing cardiovascular disease treatment and prevention activities. Your choices are:

A Stay out of the national study, apply for the smaller grant.

B Opt in and share the cost for enrolling patients.

Year 2v2
After many months of waiting, your research team learns that your application was accepted! Planning is now underway to work out both the legal and design aspects of the trials. On the legal side, *Futures BioMed* has stipulated that data management and use agreements undergo formal research ethics review (through an Institutional Review Board). Currently, the only IRB with federal-wide assurance is housed at the University, although there is an opportunity to establish a new IRB that is controlled by the tribes in the Regional Research Consortium. On the research design side, a huge number of tribal participants are interested in enrolling for the trials; the waitlist grows every day. In the multi-million dollar budget allocated, \$150,000 has been designated for startup costs—to be used as the Consortium sees fit. Your choices are:

A Employ the University's IRB and use funds to enroll 100 more participants.

B Invest in the development of a Regional Intertribal IRB.

Year 5v1
Your partnership received the grant and with the added support, the local tribal clinic is now able to address cardiovascular health more effectively—and even expand treatment for diabetes, in a limited fashion. However, clinicians note that depression is a common diagnosis alongside these physical health concerns, and there is a sense of urgency to support mental health and wellness in the wake of several recent suicides in the community. Your choices are:

A Use university programs to train more tribal behavioral health providers.

B Develop a wellness & suicide prevention program rooted in tribal culture.

Year 5v2
The new trials begin and your tribal participants are enrolled. However, in the transfer of electronic health records to *Futures BioMed*, data breaches to sensitive information are discovered. The extent and severity of the breach remains uncertain, but the blame has fallen on the University researchers in the Regional Research Consortium. Your choices are:

A Withdraw participation from the trials and refocus on local solutions.

B Stay in the trial and work to strengthen data management protocols, cybersecurity.

Year 5v3
Futures BioMed has noticed a distinct pattern in the trial results emerging from your region. It appears that American Indian and Alaska Native participants have unique genetic mutations from all other racial/ethnic groups in the study. To explore this pattern more fully, the firm has offered a new infusion of funds, amounting to \$5 million, to manage and continue to research the tribal genetic samples collected—with recognition that tribes own the data. Once more, the Consortium has flexibility in deciding how to designate these funds. Your choices are:

A Build a Regional Intertribal Biobank to protect the tribal genetic samples, vet proposals for secondary research through Intertribal IRB.

B Establish an Intertribal Biomedical Research Firm to conduct research and development for health innovations.

Year 10v1
The tribal behavioral health provider program has grown over the years, despite funding challenges. These new health providers are working in the clinic and prescribing medicines to treat depression. The tribe also notices now that the use of prescription opioids is dramatically increased—and there is a growing concern for public safety and a diminished sense of cultural connectedness to the community. Your choices are:

A Boost public safety campaigns and create Rapid Response Teams for opioid overdoses.

B Engage the community in developing a cultural revitalization & wellness program.

Year 10v2
Programmatic efforts to improve community health at the local level struggle to gain ground. Increasingly, tribal members in the research partnership feel that the challenges to community health may be connected to changes in the environment. Your choices are:

A Monitor water and soil quality over time, connect to tribe's traditional harvest activities.

B Invest in the development of a 10-year strategic plan for tribal climate resilience.

Year 10v3
The data are now protected, but over the past several years, the tribal community has struggled to see the sustained benefit of research. While the tribes in the Regional Research Consortium own the data, the majority of research was driven by the University for publication in academic journals. A tribal member with a newly minted doctoral degree returns home and is eager to ramp up tribally-driven research efforts. Your choices are:

A Ask the tribal researcher to conduct a review of current data and tribal health priorities.

B Align with tribal researcher to pursue the establishment of a Tribal Research Office.

Year 10v4
The Intertribal Biomedical Research Firm has been wildly successful and has garnered numerous private and public grants over the past 3 years. Citing business sustainability and growth, the research partnership sees an opportunity to reinvest earnings and build a legacy. Your choices are:

A Build local capacity by sponsoring individual tribal graduate research fellowships.

B Establish Research Centers of Excellence at universities across the region that showcase tribal science and contributions to Western medicine.

Year 20v1
Protective Perspective
The tribal-academic research partnership focuses on the most pressing and urgent health needs of the tribal community, matching funding to small-scale research projects. Health policy is more reactive and there is some question of the value and impact of research, given present needs.

Year 20v2
Lost in Translation
There is interest in harnessing innovative practices in health research and policy, however, the tribal-academic partnership seems to be speaking past each other. Progress is difficult to facilitate and expectations for the pace and impact of research rarely meet reality.

Year 20v3
Slow and Steady
Progress in health research and policy is careful and methodical. The tribal-academic research partnership is vetted and will likely be long-term. Improvements in community health outcomes are steady and facilitated by joint research endeavors.

Year 20v4
Fast Forward
Ambitious tribal-academic partnership seeks similarly ambitious research projects and health innovations. Health policy tends to grow out of the research pursuits, making it difficult to fully capitalize on investments and tribal capacity growth. While community health improves, new ideas and partnerships are sought out.

Year 20v5
Respecting and Connecting
Strong and reliable tribal-academic research partnership, built on high levels of trust. Progressive health policies propel innovation and improve community health. Western and Indigenous approaches to science are respected as equal. The value of research is felt broadly and is seen as supportive of tribal sovereignty.



National Congress of American Indians



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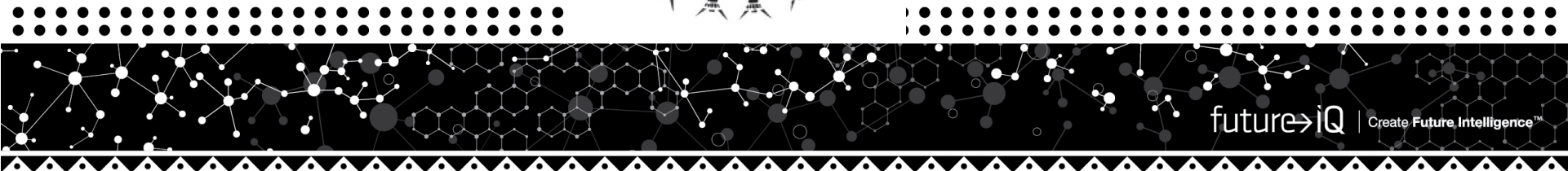


Future Game Workshop

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The background of the entire slide is a teal color with a subtle, high-resolution texture that resembles the fine, parallel lines of a feather. Two larger, more distinct feather-like shapes are visible, one in the upper left and one in the lower left, both pointing towards the right. These shapes have a more pronounced, layered structure, with some fraying at the edges, giving them a natural, organic appearance. The overall effect is a sophisticated and culturally resonant design.

HOLDING SPACE:

DISCUSSION GUIDE FOR TRIBAL-ACADEMIC PARTNERSHIPS

PROJECT HISTORY

PARTNERS:



National
Congress of
American
Indians



YEARS:

2009 – 2013

QUANTITATIVE STRATEGY:

- Recruited 318 partnerships for national online survey
- 60% response rate
- 450 individuals

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, U26IHS300293

A THEMATIC ANALYSIS

Partnership Outcomes	Synergy	Personal Outcomes	Agency Outcomes	Power relations	Sustainability	Community change	Community health	Overall outcome
Governance	X	X	X	X	-	X	-	X
Trust	X	-	X	X	X	-	-	X
Culture	X	-	-	X	X	-	-	-

- 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

Duran, B., Oetzel, J., Pearson, C., Magarati, M., Zhou, C., Villegas, M., Muhammad, M., Belone, L., & Wallerstein, N., (submitted) Promising Practices and Outcomes: Learnings from a CBPR cross-site national study. Progress in Community Health Partnerships

NARCH VII: DISSEMINATION & IMPLEMENTATION



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Indians



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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

DISCUSSION GUIDE: MODULE CONTENT

GOVERNANCE

- Resource sharing
- Capacity building & enhancing
- Ethical stewardship

TRUST

- Transparency
- Open communication
- Power balances
- Conflict negotiation
- Alignment of values

CULTURE

- Relevance of research topic
- Roles of Engagement
- Cultural safety, humility

GOVERNANCE

The WHEN of Governance

Does governance take place only during the moment when the tribal council (or other vested entity) decides to approve or not approve research proposal?

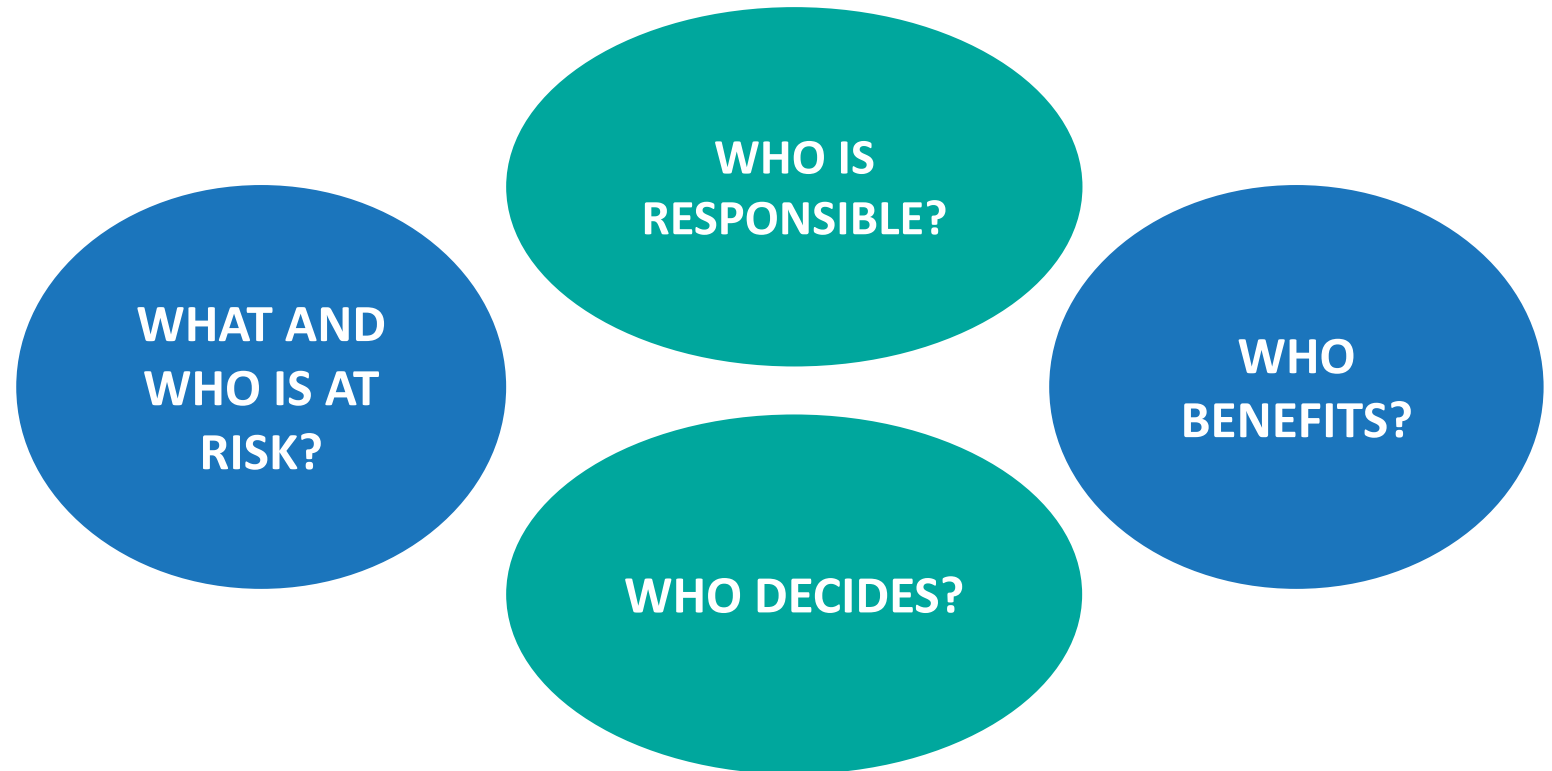
Does governance take place when the parameters of research design and outreach to research participants are being negotiated?

Does governance take place only during times of conflict?

Does governance take place over the course of the research project?

GOVERNANCE AS STEWARDSHIP

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.



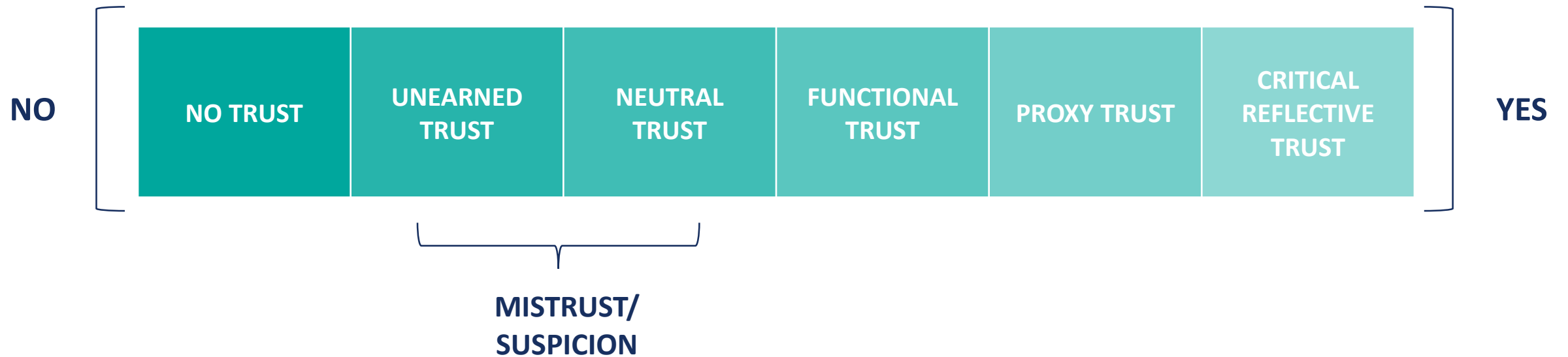
Holding Space: A Guide for Partners in Tribal Research. National Congress of American Indians & University of Nevada-Reno, forthcoming.

TRUST IN TRIBAL RESEARCH

“[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.”

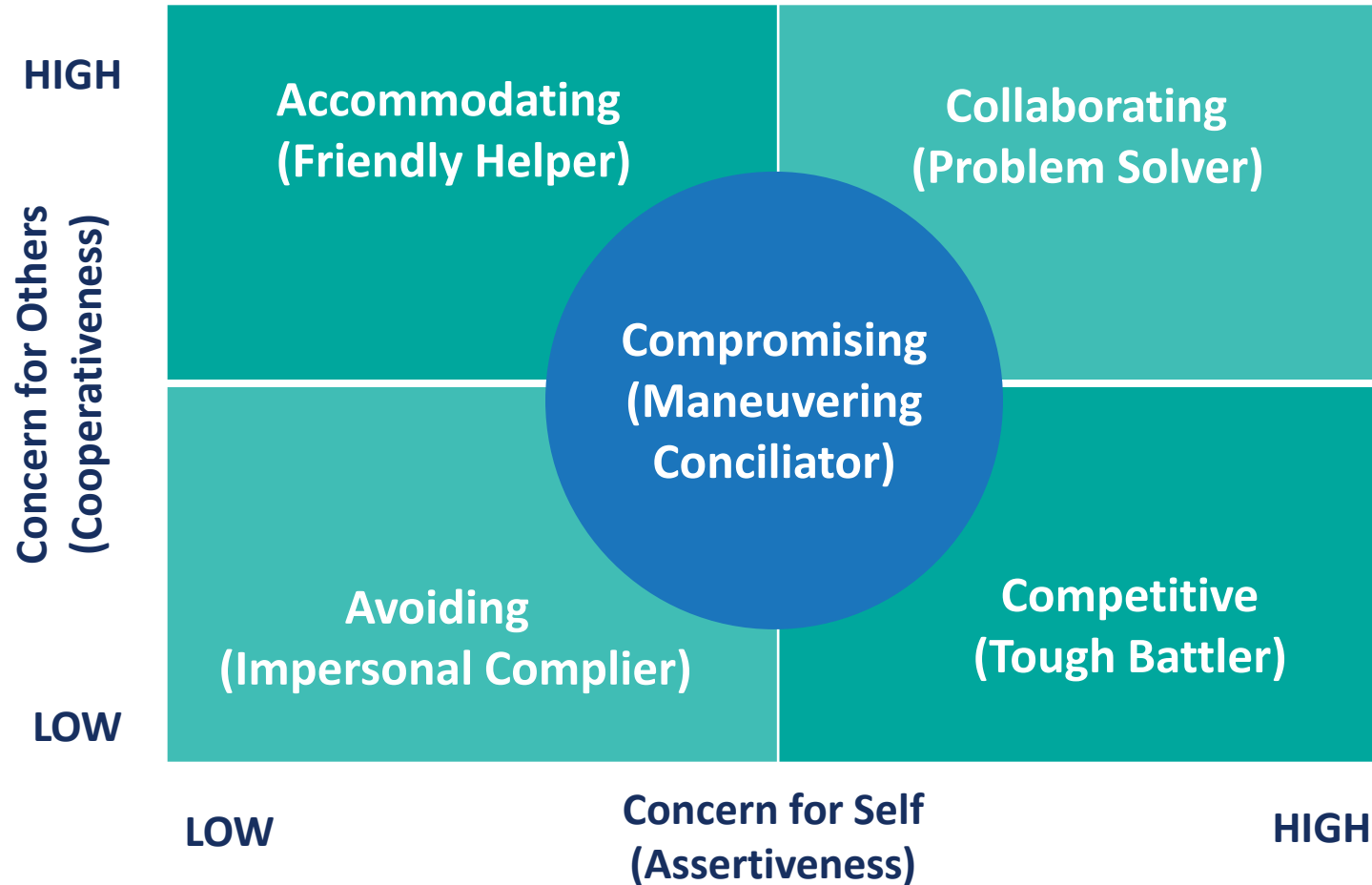
Walk Softly, Listen Carefully, p.14, emphasis added

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

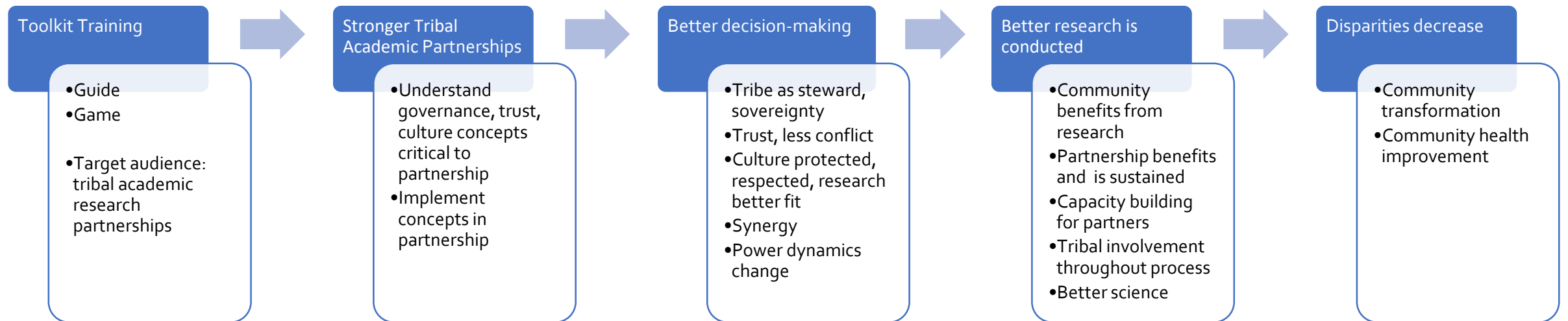
Principles of Cultural Humility

- 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?

IDEAL PATH OF RESEARCH PARTNERSHIPS



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