



# INDIGENOUS EVALUATION AND CULTURALLY RELEVANT RESEARCH WEBINAR BRIEF

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*Prepared by*  
**Michelle Rogers**  
International Association for  
Indigenous Aging



# INTRODUCTION

The National Association of Chronic Disease Directors (NACDD) and the International Association for Indigenous Aging (IA2), in partnership with the Centers for Disease Control and Prevention (CDC), hosted two subject matter experts to discuss the Indigenous evaluation and culturally relevant research frameworks. From an Indigenous perspective, health is holistic and connected to the concept of balance with all elements of the universe. Evaluation methods must be comparably broad or open to capture this multi-faceted perspective. The following is a summary of the topics discussed during this webinar. This brief is comprised of the expertise, insight, and discussion provided by our invited experts.



**Nathania Tsosie** is a member of the Navajo Nation and belongs to the Big Water Clan (Tótsohnii) from Burnt Corn, Arizona. Nathania is the Associate Director for the UNM Center for Native American Health (CNAH), an academic program that partners with AIAN students and tribes to promote Indigenous health and well-being. She co-develops and teaches educational curricula on cultural humility and indigenous data justice and is an experienced facilitator and planner. Nathania is also a Lecturer in the UNM School of Medicine's Department of Family and Community Medicine and a Ph.D. candidate in Health Communication (ABD).



**Dr. Nicolette Teufel-Shone** is the co-Principal Investigator in collaboration with Diné College (Navajo Tribal College), on the National Institutes of Health (NIH)-funded Navajo Native American Research Center for Health, which develops and supports a public health education pathway for Indigenous students starting at high school through graduate school and early-stage investigators. She is also Co-director of the Outreach Core of the NIH funded Native American Cancer Prevention Partnership, working with tribal partners to develop innovative approaches to community education to promote cancer screening. Currently, she is part of an NIH-funded team of Indigenous and non-Indigenous scholars and students that is exploring mental wellness and resilience during the COVID-19 pandemic with three Arizona tribes. In addition, she works with the Hualapai Tribe in northwest Arizona on its CDC funded Tribal Practices for Wellness in Indian Country program, and the IHS funded Special Diabetes Program for American Indians and Alaska Natives. She received her doctorate from the University of Colorado.

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# WHAT IS INDIGENOUS EVALUATION?



“Western methods are structured and centered around the researcher. Indigenous evaluation focuses on the person who is sharing their story.”

Dr. Nicolette Teufel-Shone

Indigenous evaluation is a framework guided by cultural perspective and centered on Indigenous core values. Indigenous evaluation varies from traditional Western approaches. It begins with defining what “health” means from an Indigenous perspective. The evaluation methods incorporate qualitative techniques such as open-ended questions, talking circles, and storytelling.

Oral storytelling is central to Indigenous cultures and represents generations of acquired knowledge. The process begins by asking a broad question and allowing the person to lead the direction of the response. Indigenous evaluation can take time and in-person engagement.

# WHAT IS CBPR?

Community Based Participatory Research (CBPR) is an approach to research and inquiry. It integrates a particular group of people’s beliefs, values, and interests in every step of the research process. The approach fosters and engages community relationships while maintaining a constant connection to their values. The goal is to reach a place of understanding and shared power through a process of co-learning.

CBPR shares power between the researcher, the participant, the community, and beyond to include all applicable stakeholders. CBPR approaches recognize that participation may happen on a spectrum, and not every person or community is ready for the same level of engagement.

The key to success in CBPR is to commit to bringing the community’s voice together with ongoing dialogue to create meaningful change.



“I will never know everything. I am not an expert. I’ve learned Western research, but I have much to learn from my native culture.”

Nathania Tsosie

## How are Indigenous evaluation and CBPR related?

CBPR shares fundamental tenets with Indigenous evaluation and is often used simultaneously, as the concepts and approaches are similar. Indigenous frameworks define a broader unit of study. CBPR is about community and defining the community. CBPR is an approach that can be used with any population. The difference is what voice or unit is being explored. Defining the community is the key to defining CBPR approaches for serving the population.

## Are CBPR and Indigenous evaluation being incorporated into current research practices?

The idea of CBPR and Indigenous evaluation are trickling into the system. Resources such as Indigenous health journals are more receptive to community-based approaches. However, researchers are hesitant and concerned that community and cultural perspectives may not be acceptable in Western-dominated research venues or grant applications.

There are important differences in cancer incidence rates within the AI/AN regions in the United States. For example, AI/AN populations have higher rates of lung, colorectal, liver, stomach, kidney, and other cancers. Indigenous perspectives and community partners guide research for many diseases including cancer. Indigenous cancer research and treatment offer both community-level screening and a more person-centric focus on health. Considerations include questions like, “How do patients conceptualize the diagnosis, how is a person’s family involved, where or if treatment is going to happen, and how is the provider communicating with the patient?”

Community-specific nuances are integral in a cancer diagnosis and management but are rarely published in the research literature.

## Is cultural competency training important for those trying to gain understanding?

Cultural competency is different from cultural humility. Competency assumes that you can learn enough to be considered competent about any given culture or population. Competency doesn’t recognize that culture is a constantly changing idea. The concept of competency creates a false sense that a few trainings can be enough. In truth, an individual can never be genuinely competent about all that encompasses any given culture.

Cultural humility focuses on a life-long process of seeking a constant evolution in awareness and understanding. Cultural humility emphasizes the learner’s need to seek understanding and interaction. Cultural humility recognizes the inherent power imbalances but acknowledges that individuals can work to narrow the gap (Waters & Asbill, 2013).

## What does CBPR look like in action?

CBPR and Indigenous approaches to evaluation recognize that communication and data collection happens in many ways.

Information can come from video, photographs, artwork, and the art of storytelling. Visualization of a positive result is central to many cultures. Being physically present for data gathering and incorporating native languages, values, and traditions in both collection and dissemination is essential.

The All Nations Wellness and Healing Center is an excellent example of CBPR in action (Parker, 2014). This center is run by the First Nations Community HealthSource (<https://www.fnch.org>), a Federally Qualified Health Center (FQHC) in Albuquerque, NM, providing services to diverse community members including off-reservation American Indian members. The center offers American Indian members access to health information and resources, including approaches that address social determinants of health. The center provides hot meals, a study space, a play space, a kitchen, and health care services. To address both physical and mental health needs, they incorporated a space to enable families to gather. The kinship and family support in this space is critical to physical and emotional health outcomes. The research indicates that this model is working.

# WHY IS DATA AND DATA SOVEREIGNTY IMPORTANT?

“DATA JUSTICE IS BUILT OFF THE TENANTS OF SELF-DETERMINATION, AGENCY, ACCESS, AND THE ABILITY TO USE INFORMATION. THERE IS POLITICAL POWER TO THOSE WHO HAVE DATA.”  
NATHANIA TSOSIE

Data sovereignty is an aspirational idea of moving away from a state of data dependency (Rainie, Lonebear, & Martinez, 2019). Data sovereignty is where Native nations replace non-Native norms and priorities with tribal approaches that define the data, retain control of their data, and determine how data is used for influence.

The “readiness” for data sovereignty is vastly different between communities. Most data systems are currently fragmented, with data housed in many different locations. Some tribes are prepared and taking action, especially those who access and use the tribal epidemiology centers.

There is a need to make space in the process for individual researcher reflection on where each community’s data needs lie. Additionally, Indigenous communities have much to consider regarding what data is needed versus required by external, non-tribal entities.

The idea of data justice goes a step beyond sovereignty. It removes location from the equation and expands the idea of what constitutes data. Data justice recognizes that knowledge and data are everywhere. There is power in knowledge, not just prioritizing knowledge that evolves from scientific methods. Data can emerge from experience, cultural, spiritual, embodied, and environmental factors. Data sovereignty and data justice practices evolved from injustices in using and misusing tribal data.

## Tribal Data Sovereignty



### DECOLONIZING DATA

Occurs as **Native nations replace external, nontribal norms and priorities** with tribal systems that define data, control how it is collected, and influence how it is used.

### INDIGENIZING DATA GOVERNANCE

The act of **harnessing tribal values, principles, and mechanisms and applying them** to the management and control of a Native nation's data ecosystem.

Carroll, S. R., Rodriguez-Lombao, D., & Martinez, A. (2019). Indigenous Data Governance: Strategies from United States Native Nations. *Data Science Journal*, 18(2), 10. DOI: 10.1186/s13052-019-0010-0

## Tenets of Data Justice



Each group must decide for themselves what data justice looks like.

**Self-Determination**  
Knowledge can be used as political leverage to advance community-determined agendas for change.

**Agency**  
Capacity to make our own free choices.

**Access to data**  
Equitable access to data external to our communities.

**Ability to use data**  
Cultivating capacity, resources, power, time, and space to use data.

What recommendations would you make to government agencies to help them acknowledge and embrace the value of Indigenous evaluation and CBPR methods?

Tribal nations often face piecemeal funding mechanisms for health and public health. Tribes are forced to chase funding opportunities and have few venues to apply community-defined necessities to create new projects that support their needs. Funding opportunities from non-Indigenous funding sources often do not define health in ways that align with Indigenous population priorities. Alternative funding opportunities and mechanisms that allow the community to define needs, cancer priorities, and the tribe's unique contributions to personal and community health are needed.

The use of well-conducted community health assessments is key. Allowing the community the time and opportunity to assess its own needs naturally produces recognition of the need for more public health-based interventions. These assessments are then used to determine how to approach research or program implementation.

Recognize that not every community is ready for large-scale research. Current funding mechanisms prioritize a reviewer's subjective opinion of the project's ability to succeed relative to traditional scientific measures. More pilot funding would allow tribal communities to develop ideas and create evidence demonstrating the potential for new community-based models of success.

Understand that concepts and measures will look different for Indigenous populations. Non-Indigenous scholars often measure and report on things that can be counted, for example, people who "follow through" with treatment or appointments. Many factors contribute to a person's ability to access a center or care, for example, transportation and compatibility with providers.

**CBPR offers the potential to help to identify and understand social determinants of health unique to populations and communities.**

# References

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Chavez, V. (2012). Cultural Humility: People, Principles & Practices [YouTube Video]. Retrieved from <https://youtu.be/SaSHLbS1V4w>.

DataCenter (n.d.). What is research justice? Retrieved October 7, 2021, from Datacenter.org website: <https://www.datacenter.org/services-offered/research-justice/>

The Dine' Educational Philosophy provides a framework to guide research and evaluation specifically in the Navajo Nation. To review the framework as developed by Dine' College, see this link

[https://www.dinecollege.edu/about\\_dc/educational-philosophy/](https://www.dinecollege.edu/about_dc/educational-philosophy/)

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Walter, M., & Andersen, C. (2016). *Indigenous statistics: A quantitative research methodology*. Routledge.

Waters, A., & Asbill, L. (2013). Reflections on cultural humility. Retrieved February 11, 2020, from American Psychological Association website: <https://www.apa.org/pi/families/resources/newsletter/2013/08/cultural-humility>

## **For resources demonstrating the application of the framework, see the following citations:**

Bauer, M. (2016). Connection and community: Dine college emphasizes real-world experience in public health. *Tribal College*, 27(4), 40.

Dreifuss, H. M., Belin, K. L., Wilson, J., George, S., Waters, A. R., Kahn, C. B., ... & Teufel-Shone, N. I. (2022). Engaging Native American High School Students in Public Health Career Preparation Through the Indigenous Summer Enhancement Program. *Frontiers in Public Health*, 10.

Garrison, E. R. (2007). The Dine educational philosophy (DEP) and its incorporation into the associate of science degree program in public health at Dine College. *Journal of Interprofessional Care*, 21(sup2), 64-78.

Kahn, C. B., Dreifuss, H., Teufel-Shone, N. I., Tutt, M., McCue, K., Wilson, J., ... & Bauer, M. C. (2021). Adapting summer education programs for Navajo students: Resilient teamwork. *Frontiers in Sociology*, 6, 617994.

## **For Interest in Indigenous Evaluation using quantitative approaches:**

Navajo Nation Epidemiology Center <https://www.nec.navajo-nsn.gov/>

Great Plains Epidemiology Center <https://gptec.gptchb.org/>