



COLLABORATING FOR CANCER PREVENTION: WORKING WITH INDIAN COUNTRY TO ENSURE CULTURALLY APPROPRIATE RESEARCH, POLICIES, AND PROGRAMS

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**NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS**

Promoting Health. Preventing Disease.

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 a fireside chat / Q&A with two subject matter experts to discuss and provide a general “how-to” engage in American Indian and Alaska Native research and policymaking. Information from this discussion can be adapted specifically to cancer prevention research, program, and policy with cancer disparities in Indian Country. The following is a summary of the fireside chat Q & A, and a recording of the discussion can be viewed at

<https://chronicdisease.org/page/cancerprograms/cancer-prevention-across-the-lifespan/>.

BACKGROUND

Collaborating with Indian Country is essential to improving the health and well-being of American Indians and Alaska Natives (AI/ANs). Engaging Indigenous researchers, community leaders, and policymakers ensures tribal sovereignty and cultural safety while addressing cancer disparities. Through culturally appropriate and respectful relationships, community brokers can support the position of Indigenous communities in self-governance and data sovereignty for research, program, and policy relevance for AI/AN cancer prevention.

PRESENTER BIOS

Ashely Cole, PhD

**(Citizen Potawatomi Nation of Oklahoma)
Assistant Professor of Psychology
Oklahoma State University**

Dr. Ashley B. Cole is an enrolled tribal member of the Citizen Potawatomi Nation of Oklahoma. She completed her Pre-Doctoral Psychology Residency at the University of Mississippi Medical Center (UMMC) in Jackson, MS, in 2018, and she graduated with her PhD in Clinical Psychology, with an emphasis in Quantitative Psychology, from Oklahoma State University.

In 2019, Dr. Cole was appointed as an Assistant Professor in the Department of Psychology at OSU. She is also an affiliate member of the University of Oklahoma Health Sciences Center (OUHSC) and the Stephenson Cancer Center (SCC).

Dr. Cole's research examines health promotion, health inequities, and health behaviors, including substance use and mental health, among Black, Indigenous, and other People of Color (BIPOC) communities, with a particular focus on American Indian (AI) communities. She also investigates social and individual determinants of health among AI communities from both resilience and risk perspectives. The ultimate goal of Dr. Cole's research is to develop culturally-relevant, evidence-based interventions to improve the health of Indigenous peoples by addressing health inequities and bolstering resilience and strengths.

Devin Delrow, JD

**(Navajo)
Acting Principal Advisor for Tribal Affairs
Office of the Secretary
Intergovernmental and External Affairs
U.S. Department of Health and Human Services**

Devin Delrow, an enrolled citizen of the Navajo Nations, serves as the Acting Principal Advisor for Tribal Affairs in the Office of Intergovernmental and External Affairs in the Office of the Secretary. In this role, Devin provides expert analysis, advice, and guidance to HHS senior and political leadership on policy, regulatory and legislative issues that have a significant and direct impact on Tribal governments and Tribal organizations administering HHS programs.

Prior to serving as Acting Principal Advisor for Tribal Affairs, Devin served as the Associate Director for Tribal Affairs in IEA. Before joining HHS, Devin served as the Director of Policy for the National Indian Health Board, where he sought opportunities for advancing the Tribal position in federal policymaking, providing analysis, communications, and advocacy materials to Tribes on key health issues.

Devin earned his B.A. in history from Dartmouth College and a J.D. from the University of New Mexico, School of Law where he also earned the Indian Law Certificate. He is a member of the New Mexico State Bar.

FIRESIDE CHAT

Why is it important to engage American Indian and Alaska Native (AI/AN) communities in your work?

Ashley Cole: It is important to amplify Indigenous voices, to speak truth to harm and wrongdoings of the past, as well as in contemporary times, by an acknowledgment and commitment to do better in research, policy, and the provision of health services. Engagement is necessary to address health equities and promote the resilience and strength of these communities. There is great information we can learn from Indian Country.

Devin Delrow: From a policy perspective, the United States has a special relationship with tribes that dates back to the formation of states. There is a nation-to-nation political relationship. It is critical to work with tribal leaders, citizens, and all aspects of the healthcare system to honor the relationship, respect tribal sovereignty, and enhance the health of AI/ANs.

Who are the most appropriate people to start building relationships with in a community? How do you go about identifying these people and building a relationship with them?

Ashley Cole: Do your homework to better understand how the tribe functions and try to find an “in” that has built the trust to build on an existing relationship. See if the tribe has a research liaison or similar position. Be familiar with the Indian Health Service (IHS) and other resources in the community.

Devin Delrow: As the federal government with a nation-to-nation relationship, it is important to always talk to the tribal leader first. There are a lot of resources, such as an area Indian health board that knows the local tribal leaders and is familiar with local dynamics, including leadership turnover. After engaging with the tribal leader, the tribal health director is another great resource for information or would know the most appropriate person to talk to.

How can funders better understand the challenges of timelines and capacity when it comes to funding announcements/opportunities?

Devin Delrow: Tribal leader involvement in consultation and other discussions with funders is a great opportunity for tribes to share the challenges and why they're challenges. Funders can learn a lot from going to Indian Country and meeting their leaders and community members.

Ashley Cole: Community-engaged and community-based participatory research and building necessary relationships takes a lot of time. There needs to be enough time, not only during the grant period but also for AI/AN communities to be competitive in the grant writing process. It can be helpful to follow guidelines that indigenous researchers and scientists have outlined that can be cited in grant submissions. An example of this is a more appropriate timeline to get a letter of intent from the communities; tribes may need more than a few weeks.

FIRESIDE CHAT

How can people better collaborate and partner with urban AI/AN communities?

Ashley Cole: Do your research to find the AI/AN organizations in your communities. Also, understand that there may be state-recognized tribes or communities that aren't state or federally-recognized in your area and are also unique cultural entities.

Devin Delrow: The government-to-government relationship is with tribes, but urban Indian organizations (UIOs) are a part of the Indian Health Service (IHS) system. IHS is the only federal agency with the legal authority to confer with UIOs, and they're included in the policy-making process. The Administration for Native Americans has a broader reach, working with state-recognized tribes, and is a valuable resource.

Why is it important to disseminate and share findings back with Indian Country?

Ashley Cole: It is important to let tribal and community partners review the findings and have access to the data. The focus should not only be disseminating back to academia, cast a wider net, which can lead to better outcomes in other communities. It is important to disseminate beyond academic conferences, such as podcasts, newsletters, social media, YouTube, etc., to get the information out. A critical piece to consider is honoring the community's sovereignty and only sharing what they are comfortable sharing.

Devin Delrow: After consultations or other engagements, showing that the government is responsive to the community's feedback and input is important. This helps build a trusting relationship and demonstrates the nation-to-nation relationship that is valued.

What do you think funders (local, state, federal) need to know about the importance of planning and implementing successful research, policy, and/or programs within Indian Country?

Ashley Cole: Funders should be familiar with and look to fund entities that are also familiar with the history of the community/communities. Funders should seek to understand the root causes of cancer disparities and inequities, including things like the impact of colonization and racism. It is important to know that these are not only in the past and occur today. It is important to understand the strengths and resilience of a community and not only the deficits. An example of this is traditional knowledge, which is just as valuable as Western medicine. Keep an open mind and listen to how the community views health and how to improve it.

Devin Delrow: The first step is making sure that folks remember to include tribes in the first place. Whenever there is an opportunity for state and local governments, include tribal governments as eligible entities. There are 574 federally recognized tribes, and it is important that they are included in all of the opportunities. For those involved in the budget-making process – bring tribes to the table for consultation. During these times, tribes can provide their input, recommendations, challenges, and innovations. The [25th Annual Tribal Budget and Policy Consultation](#) exemplifies how the U.S. Department of Health and Human Services accomplishes this.



Value community and elder wisdom Don't be tied to a specific research methodology or approach and embrace qualitative data.

-Ashley Cole

FIRESIDE CHAT

How would you go about engaging AI/AN communities in the work that you do and what is the role of advisory committees/boards?

Devin Delrow: A tribal consultation policy guides interaction with tribes and how to work with them in the policy-making process. A critical part of the policy-making process is convening tribal advisory committees with elected tribal leaders. These are in-depth conversations and an opportunity for tribal leaders to work with federal officials to provide guidance on policies to ensure they will work for Indian Country. Finally, listening sessions and roundtables allow community members to sit at the table and have honest discussions before policies are developed.

Advisory committees are the first step in engaging with Indian Country. This comes before tribal consultation, which is how the Department [of Health and Human Services] engages with all of Indian Country. Advisory committees can provide their perspective and refine what the policy will become. They can help ensure that the agency is working in a culturally appropriate and responsive way as they're thinking through the components of the policy. Advisory committees provide time and opportunity to build personal relationships and get to know individuals better.

Tribal consultations occur on a regular basis, such as when a new regulation, budget, or policy regulation that has the potential to impact a singular tribe or tribes at large is introduced. Consultations can be initiated by the government or requested by a tribe. A notice of the consultation is typically distributed 30 days in advance; however, emergencies, such as the COVID-19 pandemic, can result in a shorter notice to seek rapid feedback. Feedback and a summary report are provided after the consultation takes place to ensure everyone has access to the information.

Ashley Cole: Community-engaged and community-based participatory research and working with community members from the initial project development stage focused on helping the community and their priorities is imperative. The community should be involved from project conceptualization to development and all the way through dissemination. Researchers should view community members as the experts; their feedback throughout the process is important. Feedback can be garnered through incorporating community advisory boards/community research councils where researchers can host regular meetings and provide updates. If a tribe has an internal review board (IRB), they should be the IRB on record and can help guide the process.

Researchers should consider "non-traditional" partners in the process. An example of this could be community members with lived experiences relevant to the outcome being studied. They can speak to what barriers and facilitators they encounter in their lives. While they may not have the "credentials" researchers look for, their lived experiences can be invaluable.



It is critical to work in collaboration with tribes to ensure the policy is responsive to the needs of tribes, respects tribal sovereignty, and honors the commitment that that United States government has to them.

-Devin Delrow

IMPORTANT CONSIDERATIONS WHEN ENGAGING WITH INDIAN COUNTRY

Research

- Do your research on the community to understand its history and culture to help determine what is appropriate not do. For example, tobacco may be sacred to the community; therefore, it is important to clarify commercial tobacco use versus ceremonial tobacco use.
- Do your research to understand who from the community should be involved in the work: tribal leaders, elders, community members, and even people on the ground doing the work.
- Be aware of AI/AN communities' capacity, which are often very under-resourced. Many tribes do not have an in-house grant writer that can complete an application in a month.
- Be mindful of tribal elections and other community-wide events that may impede timelines, for example, elections. Most tribes have elections in November, making it a very difficult time to attend outside meetings, submit grant applications and/or reports, or even letters of intent.

Trust Building

- Pick up the phone, don't rely on an email to get buy-in.
- Build person-to-person relationships with members of the community. This can be critical when unforeseen issues arise and/or there is leadership turnover. It will also give you additional insights into the history and culture of the community.
- Going to Indian Country is vital in building relationships and understanding these communities. Additionally, this helps to build best practices that can be shared with other communities.
- Ongoing and regular communication is key to being a true partner. Be transparent and recognize that it is nearly impossible to make everyone happy. Consider all options, including those from an indigenous lens, before making a final decision and communicate the reasons why that decision was made.
- Please get informed consent from participants to ensure they understand what will be shared. Using the tribe's Internal Review Board (IRB) is a great way to ensure the tribe is leading the work.

Cultural Appropriateness

- Provide food when meeting with AI/AN communities and consider other ways to make it easier, such as providing child care.
- Understand the importance of physical, mental, emotional, and spiritual well-being.
- Recognize there is no one-size-fits-all. There are 574 federally recognized tribes, state-recognized tribes, and urban communities comprising hundreds of tribes.
- It is important to recognize your boundaries and competencies. If you're not sure about something, ask! That is another reason having personal relationships is key to this work.

Sustainability

- Work to create systems-level change within the community. Train the community members and hire within the community to complete the work. Build the capacity of the community to sustain the change. An example of this is the train-the-trainer model, a sustainable model to train community members to have lasting tools and skills, even after the funding is over. Have this built into the project to ensure it happens.
- Consider disseminating information at AI/AN conferences and through indigenous journals to ensure it goes back into Indian Country. These are also great resources to see what others are doing in the field to help develop future projects.

References

Beyond Land Acknowledgements - Ways to Support Local Indigenous Communities in Your Area:
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International Association for Indigenous Aging: <https://iasquared.org/>

National Council of Urban Indian Health: <https://www.ncuih.org>

National Indian Health Board: <https://www.nihb.org/>

National Tribal Behavioral Health Agenda:
https://www.nihb.org/behavioral_health/behavioral_health_agenda.php

Oklahoma State University Center for Indigenous Health Research and Policy:
<https://scholars.okstate.edu/en/organisations/center-for-indigenous-health-research-and-policy>

U.S. Department of Health and Human Services Office of Intergovernmental and External Affairs Tribal Affairs:
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U.S. Department of Health and Human Services Tribal Consultation:
<https://www.hhs.gov/about/agencies/iea/tribal-affairs/consultation/index.html>

U.S. Department of Health and Human Services 25th Annual Tribal Budget and Policy Consultation recording is available at <https://www.youtube.com/watch?v=e5v5r4QnNQI>. This is a great resource that demonstrates the commitment of HHS to ensuring tribes are considered when developing the upcoming budget and policy recommendations.

U.S. Department of Health and Human Services Office of Intergovernmental and External Affairs Tribal Affairs biweekly newsletter with upcoming tribal consultations and funding opportunities: Email tribalaffairs@hhs.gov to subscribe.

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