

How academic-tribal teams cut cancer risks in Native American communities

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Learn how the Native American Center for Cancer Health Excellence addresses cancer health disparities through bidirectional research that honors tribal sovereignty

The American Indian and Alaska Native (AIAN) population faces significant cancer health disparities, with the highest cancer incidence in the US for persons living on or near tribal lands.^(1, 2) Cancer is diagnosed at later stages and receives guideline-concordant care less often than in the general population.^(3, 4) In Oklahoma, which has one of the largest populations of AIAN residents, cancer mortality is 1.4 times higher than the state all-races rate and 1.7 times higher than the U.S. all-races rate.⁽⁵⁾

The Indian Healthcare system ITU system

The Indian Health Service (IHS), a division of the US Department of Health and Human Services, supports health programs for AIAN persons. These include federally administered health programs, tribally administered health programs, and Urban Indian Organizations, collectively comprising the 'ITU' system. An estimated 2.8 million AIAN persons receive direct care from an ITU program.⁽⁶⁾

Most ITU programs lack resources to provide comprehensive oncology services and must refer patients externally. Federal appropriations for ITUs are released annually, with per capita expenditures (\$4,078) in 2023 less than one-third of those for the general US population (\$13,494), as reported by IHS.⁽⁶⁾ Resources often become scarce by the end of the fiscal year, leading to delays in oncological care. The ITU system is often poorly understood, contributing to fragmentation of specialty care, and each ITU program's operations may differ. Given the high cancer mortality facing AIAN populations, research partnerships between cancer centers and Indigenous communities are critically important.

Stephenson Cancer Center – OU Health Campus

The Stephenson Cancer Center (SCC) at the University of Oklahoma Health Campus recognized the need to improve coordination of care for ITU patients upon opening in 2011. With support from two Tribal Nations, SCC created the American Indian Navigation program to facilitate referrals from ITUs. The AI Navigators are valued by patients and providers as they understand ITU systems of care and cultural nuances that may affect care delivery.

The SCC also recognized the lack of research addressing cancer health disparities faced by AIAN communities. Research involving AIAN participants has often been marred by misconduct, abuse, disrespect, and exclusion of community voices in the design, execution, and interpretation of research.^(7, 8) The SCC is committed to research rooted in bidirectionality to ensure the research incorporates Indigenous Knowledge,⁽⁹⁾ reflects community priorities, and honors Tribal Sovereignty.

Bidirectionality and Indigenous Knowledge

To build research partnerships, SCC investigators reached out to tribal programs to offer help in using research to address cancer priorities. Initial efforts led to unfunded but productive partnerships investigating emerging health risks such as indoor tanning and vaping among AI adolescents, finding that rates far exceeded those in the general population. SCC, in partnership with a Tribal Nation, then received funding from the National Institutes of Health (NIH) to study the impact of vaping on commercial tobacco use among AI adults, leading to further funding to study vaping among AI smokeless tobacco users and pregnant AI women. These projects included tribal investigators and were reviewed by tribal health boards and by tribal and IHS Institutional Review Boards. Stewardship of tribal data, respecting Tribal Sovereignty, was incorporated into all projects.

While these efforts provided knowledge about emerging health risks, AI communities need support to directly address critical cancer disparities. In partnership with ITUs, SCC investigators received funding for Implementation Science projects to improve colorectal and lung cancer screening rates. To improve care coordination and supportive services within the cancer center, investigators also obtained funding to implement financial hardship screening, enhanced navigation services, and improved care coordination for AI patients at the SCC.

To further promote cancer research and outreach, the SCC established the Native American Center for Cancer Health Excellence (NACCHE) in 2023. NACCHE's goal is to improve cancer prevention and survival in Native American populations through comprehensive approaches, including research, outreach and education, training, clinical access, and policy development, all centered on principles of bidirectionality and respect for Tribal sovereignty.

As research interest grew, SCC recognized the need for guidance on its research and outreach efforts and, in 2020, created the SCC Tribal Advisory Council (TAC). Two examples of the TAC's impact include critical guidance on genomic research and inclusion of bidirectional approaches to clinical trials education. The TAC noted that not only do AI patients need such education, but also that clinicians need education regarding the concerns AI patients may have about clinical trials.

Two oncology grand rounds presentations were delivered at SCC, leading an oncologist to create a curriculum for medical students, residents, and fellows to improve their awareness and comfort addressing these concerns.

Community priorities guiding research

To guide further research, the TAC and SCC investigators partnered to survey AI communities about their priorities in cancer research and outreach. From 2022 to 2024, the top three topics rated as 'extremely helpful' included early detection (screening), cancer prevention, and communication between cancer care and primary care providers.

Led by NACCHE, the University of Oklahoma-Stephenson Cancer Center received a \$17.2 million grant from NIH for the 'Improving Cancer Outcomes among Native American Communities (ICON)' Center. ICON includes three research projects, each focusing on one of the top three community priorities. 'Lung Cancer Screening in Tribal Communities in Oklahoma' partners with a Tribal Nation to implement a clinical trial of coordinated lung cancer screening within the tribal health system. 'Water for Health: Strengthening Tribal Action for Cancer Prevention' investigates the association between heavy metal exposures in drinking water and cancer and seeks Indigenous Knowledge to develop interventions to limit exposures to these contaminants. This project will include participants from twelve Tribal Nations across four US states. The 'Care Coordination and Communication Program in Oncology for Tribal Health Systems (C3PO)' will design, implement, and test a novel cancer care coordination intervention centered on virtual 'Huddles', including staff from the SCC and six ITU health systems. Guided by the TAC, ICON includes Indigenous Knowledge at all levels of leadership and within each project's team of investigators.

Integrating Indigenous Knowledge and upholding Tribal Sovereignty are critical to developing successful partnerships that address cancer health disparities among AIAN populations.

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