

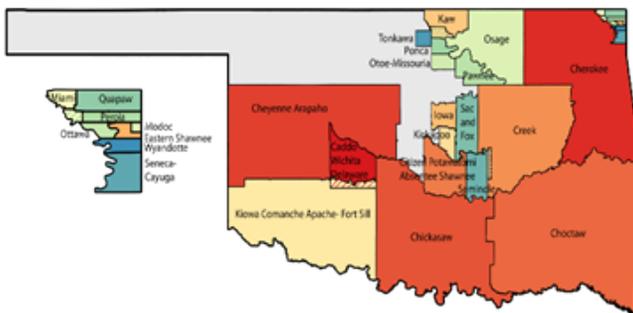
Community Outreach and Engagement Stephenson Cancer Center

Catchment Area

The Stephenson Cancer Center at The University of Oklahoma's (SCC) catchment area includes the entire state of Oklahoma, with tribal outreach and engagement activities encompassing all tribal nations in the state.

American Indian Population in Oklahoma

SCC has a strong focus on addressing cancer health disparities among Oklahoma's large American Indian population. More than 360,000 American Indians reside in Oklahoma (9.2 percent of the total population). Nationally, Oklahoma has the second highest number of American Indian residents (after California) and the second highest percentage of American Indian residents (after Alaska). Oklahoma's 38 federally recognized tribal nations cover the entire state, with particularly large populations in the northeast (Cherokee Nation), east central (Muscogee Nation), southeast (Choctaw Nation), south central (Chickasaw Nation), and southwest (Southern Plains Nations).



Cancer Health Disparities among American Indians in Oklahoma

High cancer incidence and mortality rates affect the state's large American Indian population:

- American Indians in Oklahoma have an overall incidence rate that is 1.4 times higher than the U.S. (all races) rate. Oklahoma has the highest age-adjusted American Indian cancer incidence rate for all cancers of any state.
- American Indians in Oklahoma have an overall cancer mortality rate that is 1.5x higher than the U.S. (all races) rate.
- In Oklahoma, mortality rates among American Indians are 50 percent to 99 percent higher for lung, prostate, and colorectal cancer; over 100 percent higher for cervical cancer; and over 200 percent higher for kidney cancer.

SCC investigators are actively collaborating with tribal health systems and communities throughout the state to address these health disparities.

Community Engagement Focus

The mission of SCC is to improve patient outcomes and reduce the burden of cancer in Oklahoma (SCC catchment area) and the nation. As Oklahoma's only NCI-Designated Cancer Center, SCC is uniquely positioned to provide statewide leadership in research, treatment, education, and outreach to advance this mission. A central resource in this effort is SCC's Community Outreach and Engagement (COE) Core, the aims of which are to:

1. Promote research on cancer-relevant issues specific to SCC catchment area, with an emphasis on unique or unusual cancer incidence, underserved populations, and cancer health disparities.
2. Engage populations, especially those underrepresented in research, in clinical studies.
3. Decrease cancer incidence and mortality rates in SCC catchment area through the development, implementation, and evaluation of health policy.
4. Partner with community-based entities with aligned missions to extend the impact of SCC activities.

The COE Core also fosters relationships with mission-aligned organizations and community partners across the state, including tribes, to extend the reach and impact of SCC activities.

Collaborations with Tribal Nations

SCC has partnered with numerous tribal entities in a broad range of initiatives focused on decreasing the burden of cancer among American Indians. Important partners include the Cherokee, Choctaw, Chickasaw, Creek, Cheyenne & Arapaho, Osage, and other tribal nations; Oklahoma City Indian Clinic; the Indian Health Care Resource Center of Tulsa; the Indian Health Service; and the Southern Plains Tribal Health Board.

At a Glance

Promoting Engagement for Cancer Biology Research in American Indian Communities

The goal of this supplement is to foster dialogue about American Indian and Alaska Native participation in basic science research at the cancer center. The project engages tribal stakeholders across the state to identify a range of perspectives regarding the balance between data sharing and data control in developing resources for basic biological research on cancer, and work with leadership of tribal nations in Oklahoma to move toward a model for the stewardship of American Indian and Alaska Native samples and data for basic biological research in cancer. Stakeholder engagement activities focus on efforts to

jointly articulate questions, explore concerns and needs regarding how the cancer center handles tissue and data from American Indian and Alaska Native participants, and develop protocols to answer these questions.

Collaborators

This project was based on a collaboration between the Cancer Prevention and Control Program and Cancer Therapeutics Program, with participation from COE.

The Stephenson Cancer Center prioritizes partnerships with Tribal Nations and entities across the state and established a Tribal Advisory Council (TAC) in 2020 to guide the cancer center's engagement and work involving Oklahoma tribes. The TAC provides direction, recommendations, and connections to tribal stakeholders on which the work of the supplement depends; likewise, progress updates and findings from the supplement work will be reported back to the TAC. Regular consultations with the TAC have been key to navigating the challenges of conducting community engagement during a pandemic.

Engage stakeholders to ensure that research promotes clear pathways to benefits for those being asked to take part.

The Approach

The original approach involved the convening of partners from each participating tribal community to jointly articulate a question regarding how the cancer center handles tissue and data from American Indian and Alaska Native participants and develop protocols to implement this guidance in addressing colorectal cancer disparities. Our NHRGI-funded Center for the Ethics of Indigenous Genomic Research has developed a model of

co-facilitated deliberations in which university-based researchers partner with community leaders to jointly develop protocols for deliberation. In the original design, each participating tribal community would host a separate deliberation event, to include 15–20 people for 1.5 days and be jointly facilitated by a member of the research team and a community member. We quickly anticipated that this original design would be modified into virtual deliberations over a longer time period to protect participant safety during the pandemic.

But additional significant changes to the supplement design were necessitated by the pandemic's strain on tribal health care systems. A number of the tribal partners and organizations with whom we partner are situated in health care systems, or include individuals working in health care delivery, and those delivering or receiving primary care. Consultation with tribal partners and guidance from the TAC reinforced our concern that the process of organizing and conducting virtual or in-person deliberations would impart additional strain on already burdened health care systems and personnel.

We remain committed to the original goal of the deliberative discussions, which was to identify salient issues to inform policy about the stewardship of American Indian and Alaska Native samples and data for basic biological research in cancer. So, in our final design, we modified our original approach to instead engage stakeholders individually, as consultants informing the development of our policy, through brief phone calls and Zoom meetings. These phone and Zoom conversations are underway and have thus far included discussions with primary care providers, tribal health leadership, tribal governance officials, elected tribal leaders, and others identified as relevant stakeholders.

The conversations have proven productive, pointing to several common themes that we expect to explore in further detail as conditions permit:

- Transparency in research; including but not limited to clear communication of research goals, outcomes, risks and benefits, patient rights, tribal oversight, and commercial use of specimens
- Acknowledgment and accountability for historical abuses and harms resulting from unethical research and institutional practices in medicine
- Importance of outreach and engagement activities, acknowledgment of the formal tribal consultation process
- Importance of partnerships
- Engagement of tribal stakeholders in determining risks and interpretation and dissemination of research findings, ensuring benefit from research
- Respectful stewardship of Indigenous samples
- Demonstration of benefit to tribes; ensuring that research goals promote pathways to benefits for tribes

Implementation Guidance

Based on our experience, we offer the following advice:

- Ongoing outreach and engagement should occur at all stages of the process; beyond data collection and dissemination of findings, it is critical to engage community stakeholders throughout the process of research design and implementation so that modifications to the protocol are responsive to changing community needs and stakeholder priorities. This is already a cornerstone of community-based research practices, but the pandemic has necessitated the willingness of researchers to remain flexible, engaged, and responsive so that research serves the needs of community partners.
- Utilizing a range of communication tools is key to maintaining outreach and engagement activities throughout the pandemic. Phone calls and virtual conferencing, in particular, have facilitated quick and productive conversations with individual stakeholders who otherwise would be unable to meet in person.

While group discussions and deliberations remain central to our overall approach, we have been able to utilize and benefit from individual conversations given the constraints imposed by the pandemic.

The concurrent development of our Tribal Advisory Council has permitted us to develop this work in dialogue with SCC investigators and tribal health leadership in ways that we did not anticipate in the original proposal.

The emergence of technology to support virtual interactions during the pandemic has also facilitated national collaborations for this work. One such partnership is with researchers at the Center for Indigenous Cancer Research at the Roswell Park Cancer Center, with whom we are exploring opportunities to co-develop models for responsible stewardship of American Indian and Alaska Native samples and data for basic biological research in cancer research centers.



Find Out More

If you are interested in finding out more information, please contact the Community Outreach and Engagement Core staff at scc-outreach@ouhsc.edu. You can also find more information on the Stephenson Cancer Center [here](#).

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Community outreach and engagement (COE) activities across the translational research continuum

National Cancer Institute (NCI)-designated cancer centers' COE efforts should span all cancer center programs, including basic, clinical, translational, and population research. In FY20, NCI issued a call for Cancer Center Administrative Supplements to support COE activities that focus on either basic science or the translation of evidence-based interventions into community practice. The long-term goal of the supplement initiative is to build capacity for cancer centers' COE programs to adapt and implement evidence-based programs and successfully collaborate with cancer center investigators across research programs and in partnership with community members. To learn more, visit us at: <https://cancercontrol.cancer.gov/research-emphasis/coe>