

Goal: Develop community-informed AI/AN/NH research initiatives, programs, and clinical trials to be prioritized into a national and regional strategic plan for partnerships between Indian Health Service, Tribal, and Urban (ITU) Indigenous People and NCI-designated cancer centers and their affiliates.

Year 01 Activities and accomplishments (Huntsman Comprehensive Cancer Center)

Goals Year 01 in-person Working Meeting:

- Determine the key cancer health issues within AI/AN/NH communities that CCs can help address using community-centered and multilevel approaches.
- Understand how to combine traditional ways of knowing with Western science to develop innovative solutions.
- Develop innovative and sustainable interventions that will increase the cancer survival for AI/AN/NH populations.

Process

- Four breakout groups during the 2 days; Themes
 - ✓ Issues and Recommendations
 - ✓ Action Items and Rationale
 - ✓ Clinical Trials Engagement
- Groups 1 & 2: Outreach, Education, Risk Reduction, Early Detection/Screening
- Group 3: Diagnosis, Treatment
- Group 4: Symptom Management, Palliation, Survivorship, Quality of Life, End of Life

Breakout Sessions Summary of Key Issues

• **Outreach, Risk Reduction and Education/ Early Detection and Screening**

- ✓ **Barriers:** Limited education about cancer and available screenings; fear among elders; misinformation; siloed data; lack of outreach.
- ✓ **Needs:** Better communication from tribal leadership; culturally tailored education; stronger community engagement; mobile units; community-based events.
- ✓ **Opportunities:** Leverage traditional knowledge and spiritual practices in outreach and screening.

• **Diagnosis & Treatment**

- ✓ **Barriers:** Delays in diagnosis (“time to tissue”); inconsistent referral pathways; insufficient informed consent; lack of cultural sensitivity among providers.
- ✓ **Needs:** Streamlined referral processes; more Indigenous patient navigators; education about insurance options beyond IHS; culturally competent providers.
- ✓ **Opportunities:** Use of AI for referrals; visual maps for services; Indigenous ethics committees to advocate for patients.

• **Symptom Management, Palliation, Survivorship, Quality of Life, End of Life**

- ✓ **Barriers:** Lack of continuity in care; weak follow-up systems; inadequate integration of traditional healing practices; social barriers (housing, travel).
- ✓ **Needs:** Consistent communication; spiritual spaces in hospitals; culturally inclusive survivorship messaging.
- ✓ **Opportunities:** Integrate storytelling and traditional foods/nutrition; involve cancer survivors in programming; increase support staff with cultural knowledge.

• **Data & Research**

- ✓ **Barriers:** Cancer-related data is fragmented and not community-accessible; lack of tribal sovereignty over data; limited community involvement in research design, trial designs may not align with Indigenous values or realities.
- ✓ **Needs:** Clear data sharing/use agreements; community-friendly reporting; tribal member presence on ethics/research boards.
- ✓ **Opportunities:** Empower tribal data analysts; organize community “data town halls”; build local capacity in research.

• **Clinical Trials recruitment and retention**

- ✓ **Barriers:** Historical and ongoing mistrust in medical research; clinical trials are not effectively communicated to Indigenous communities; logistical challenges.
- ✓ **Needs:** Trust-building measures, culturally informed/aligned research practices, transparently explain the risks and benefits, financial and logistical support to reduce participation, utilize systems like RAICRS (Regional American Indian Community Review System) and ROCRS (Research in Oregon Communities’ Review System) to ensure community oversight.
- ✓ **Opportunities:** Increase awareness and understanding of CTs with AI/AN/NH communities through targeted education. Involve AI/AN/NH community members in the design and review of clinical trials.

Misconceptions of AI/AN/NH communities

- ✦ **Barriers:** Stereotyping and homogenization; assuming that all native communities identical in culture, spirituality, and political status, or all natives live on reservations or Hawaiian Islands. Research participation misconceptions; false belief that native communities don't want to participate in research. Provider Bias; assumption about health issues (e.g., diabetes, obesity, substance use) and focus solely on health deficits rather than community strengths. Structural/systems issues; limited technology and broadband access, also confusion about federal vs. state tribal recognition, and misunderstanding of Alaska Native corporate structure vs. Tribal systems.
- ✦ **Needs:** Education and awareness; Healthcare providers need education about AI/AN/NH diversity and tribal sovereignty. Research approaches; fair non-exploitative research partnerships, centering community driven research priorities. Healthcare delivery; culturally appropriate care models that focus on strength-based rather than deficit-based approaches.
- ✦ **Opportunities:** Develop cultural competency programs addressing these specific misconceptions. Address structural barriers and racism in healthcare systems. Build on community desire to participate in meaningful research and center community strengths and cultural assets. Develop culturally responsive care models that honor traditional practices, that utilize traditional knowledge alongside Western medicine
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Recommendations

Culturally Tailored Patient Navigation & Communication

- ✦ Hire and train Indigenous patient navigators to assist in consent, insurance education, and referrals.
- ✦ Educate care teams including providers on Tribal sovereignty, cultural communication, and traditional knowledge.
- ✦ Co-develop educational cancer screening/risk reduction materials with community to insure they are culturally appropriate.

Strengthen Referral and Diagnostic Systems

- ✦ Create standardized, visual referral maps for providers.
- ✦ Ensure physicians—not just staff—obtain informed consent.
- ✦ Use telehealth and AI to bridge diagnostic and geographic gaps.
- ✦ Integrate mobile screening units for rural and frontier patients.

Empower Sovereignty in Data and Policy

- ✦ Develop and enforce Tribal-specific data use agreements.
- ✦ Include Indigenous representatives in ethics committees and research boards.
- ✦ Promote CBPR (Community-Based Participatory Research) rooted in cultural strengths.
- ✦ Adapt clinical trial eligibility criteria and trial protocols to reflect Indigenous perspectives.
- ✦ Co-develop with AIANNH communities research education programing “What is research?”

Integrate Traditional Practices and Spiritual Care

- ✦ Incorporate spiritual spaces (e.g., smudge rooms) in hospitals.
- ✦ Make available prayer supplies (e.g., tobacco, sage, sweetgrass)
- ✦ Use storytelling and Elders/traditional healers in survivorship and prevention programs.
- ✦ Co-design wellness and outreach events with AIANNH community for increased community engagement.
- ✦ Incorporate protection of the environment and other than human relatives in cancer center priorities.

Expand Insurance & Financial Navigation

- ✦ Educate patient care team about Medicaid/Medicare as complements to IHS.
- ✦ Cancer centers should proactively help patients assess coverage and financial assistance.
- ✦ Improve access to low-cost housing, gas cards, and food pantries.
- ✦ Co-develop trainings for local communities on research and grant applications.

Workforce Development & Retention

- ✦ Invest in Indigenous healthcare workforce training programs.
- ✦ Create/support more pathways for indigenous people to become healthcare professionals.

- ✧ Offer incentives and build infrastructure to retain culturally competent providers.
- ✧ Increase cancer center leadership/staff/faculty understanding of Indigenous communities, AI/AN tribal sovereignty, ITU (HIS, Tribal, Urban) health systems, and which AI/AN nations and Native Hawaiian communities are in their catchment area.

Year 02 Activities and accomplishments Lineberger Comprehensive Cancer Center

Collaborative monthly webinars were conducted from August 2025 through February 2026 to support ongoing engagement among NCI-designated Cancer Centers and their Indigenous community partners. The purpose of these webinars was to ensure that all participants were informed about one another's progress and activities in advance of the March 2026 in-person working meeting.

On the evening of Sunday, March 15, prior to the working meeting, staff from the University of North Carolina's American Indian Center hosted participants for a traditional, healthy dinner featuring foods representative of North Carolina Tribes (federally recognized, state-recognized, and urban communities). Approximately 34 working group participants attended; several others were unable to join due to travel delays and flight cancellations.

The working group was honored to have Dr. Doug Lowy, Deputy Director of the National Cancer Institute (NCI), attend in person for the morning session. Dr. Lowy actively engaged participants by initiating discussions and posing critical questions focused on the challenges of delivering high-quality cancer care and the persistent gap between the potential of cancer care and the realities experienced by many Indigenous patients and their families.

Dr. Shobha Srinivasan, Senior Advisor in the Office of the Director at NCI, was also an active participant throughout the meeting and provided important clarification regarding federal initiatives, priorities, and funding opportunities.

The Southeastern American Indian Cancer Health Equity Partnership (SAICEP) was strongly represented by both University of North Carolina faculty and community members, reflecting the importance of sustained regional collaboration.

Two NCI-Designated Cancer Centers are recipients of the National Institute on Minority Health and Health Disparities (NIMHD) initiative, *Improving American Indian and Alaska Native Cancer Outcomes (U19)*. Dorothy A. Rhoades, MD, MPH (Kiowa Nation), Professor in the Department of Medicine and Director of the Native American Center for Cancer Health Excellence (NACCHE) at the Stephenson Cancer Center (Oklahoma), and Myra Parker, PhD, JD, MPH (Mandan and Hidatsa), Associate Professor and Director of Seven Directions: A Center for Indigenous Public Health at the University of Washington School of Medicine, each presented local AIAN cancer data and highlighted key elements of their respective programs.

Three community panels provided critical perspectives on local Indigenous priorities and experiences. Community Panel 1 included patients, caregivers, survivors, and thrivers; Community Panel 2 included health professionals and researchers; and Community Panel 3 included community cultural representatives. Each panel shared both strengths and challenges related to systemic issues, as well as solutions and effective programs from their respective perspectives.

Breakout groups were organized according to phases of the cancer continuum, ranging from outreach and education through end-of-life care. Each group was tasked with two objectives: (1) to respond to questions specific to their assigned phase of the cancer continuum, and (2) to begin identifying priorities for local strategic plans using a template adapted from the 1993 *National Strategic Plan for Cancer Prevention and Control to Benefit the Overall Health of American Indians and Alaska Natives*. Each breakout group reported key highlights from their discussions. Collectively, participants identified cross-cutting issues of national importance, which will inform the development of a comprehensive national AIANNH partnership strategic plan.

Key Outcomes and Impact

The March 2026 AIANNH Partnerships Working Meeting resulted in several important outcomes that advance both local and national efforts to improve cancer care for Indigenous populations:

1. Strengthened Cross-Site Collaboration and Shared Learning

Participants from 14 states and multiple NCI-designated Cancer Centers and Indigenous organizations deepened relationships, exchanged promising practices, and identified opportunities for sustained collaboration. The integration of pre-meeting webinars with the in-person convening enhanced continuity and alignment across sites.

2. Identification of Priority System-Level Gaps

Participants consistently identified critical barriers impacting Indigenous cancer care, including challenges related to timely access, care coordination, workforce capacity, data limitations specific to Indigenous populations, and the need for culturally grounded models of care. These findings provide clear direction for institutional and national-level action.

3. Integration of Community and Cultural Perspectives into Planning and Implementation

The inclusion of patients, caregivers, cultural representatives, and community leaders ensured that lived experiences

and Indigenous knowledge systems were central to discussions. This approach reinforced the importance of culturally respectful, community-informed strategies in improving patient experience and outcomes.

4. **Development of a Framework for Local Strategic Planning**

Breakout group activities resulted in the identification of priority areas across the cancer continuum and established a structured approach for participating sites to develop or refine local strategic plans tailored to their communities.

5. **Foundation for a National AIANNH Partnership Strategic Plan**

Through synthesis of breakout group findings and panel discussions, participants identified cross-cutting priorities of national significance. These priorities will inform the development of a coordinated national AIANNH partnership strategic plan aimed at reducing disparities and improving cancer outcomes.

6. **Enhanced Federal and Institutional Alignment**

Active engagement from NCI leadership strengthened alignment between community priorities and federal initiatives, supporting future opportunities for policy development, funding, and programmatic collaboration.

7. **Reinforcement of Indigenous Leadership and Representation**

With more than half of participants identifying as Indigenous, the meeting elevated Indigenous leadership and expertise in shaping cancer care strategies. This representation is essential to ensuring the relevance, trustworthiness, and sustainability of future efforts.