

Conquering Cancer Through Collaboration

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Figure 1: There are thirty-nine federally recognized tribes in Oklahoma. Shown here are the Oklahoma State Department of Health in Oklahoma City, the Cherokee Nation capital in Tahlequah, and Kaw Nation in Kaw City.

An evolution of collaboration strategies is altering the course of cancer for American Indians in Oklahoma. There, the state department of health and two tribal cancer programs created partnerships and navigated through three different systems of health care, policies and rules. They also signed into implementation the federal Breast and Cervical Cancer Prevention and Treatment Act while dealing with two different poverty levels for eligibility requirements. Their bold efforts produced access to data not otherwise obtainable to each other, an integrated approach to a range of cancer planning activities, and an extended network of support for their respective cancer programs.

The three independent cancer programs are unique and lend themselves to diverse perspectives. For instance,

- ❖ The Kaw Nation Breast and Cervical Cancer Early Detection Program (BCCEDP) based its funding request to the Centers for Disease Control and Prevention (CDC) on the unusual collaboration of screening sites at three tribal clinics and two Indian Health Service (IHS) facilities.
- ❖ Cherokee Nation Cancer Programs (CNCP) merged its resources and know-how with the Cherokee Nation Breast and Cervical Cancer Early Detection Program (CN BCCEDP), the Cherokee Nation Cancer Registry (CNCR), and with the Cherokee Nation Comprehensive Cancer Control (CNCCC) plan and implementation programs.
- ❖ The Oklahoma State Department of Health (OSDH) Central Cancer Registry received a “Gold” level certification for the quality and completeness of its data for 2001 through 2003.

The total number of American Indians and Alaska Natives (AI/AN) living in Oklahoma ranks it second in the nation only to California. As a result, OSDH and all Oklahoma tribes are ever searching for new and creative ways to collaborate effectively to meet their goal of reducing cancer incidence, morbidity and mortality for all their citizens.



Internal Partnership Opportunities

Identifying challenges and rising to meet them

At the core of all successful collaborations is a group of leaders who care deeply about the vision of the work at hand. For the directors of the state and two tribal cancer programs, reducing the burden of cancer for American Indians in Oklahoma is not just a mandate. Breast, cervical, and colorectal cancers are diagnosed at later stages for AI/ANs in Oklahoma, and they are less likely to survive a cancer diagnosis.¹

In tribal settings especially, program managers, medical providers, outreach workers and others often know—through family and community relations—people affected by cancer. As a result, they are deeply invested in the hope that their actions will effectively alter the course of cancer for generations to come.

Beginning in the center of the circle

Kaw Nation BCCEDP relied upon partnerships from the onset of its funding from CDC, because it needed a higher number of eligible women that only a collaboration of tribal and IHS clinics in the area could provide. Though logical, it required constant face-to-face communication from the program director to explain the benefits of the alliance, even after funding was awarded. The challenges and solutions of internal collaboration included,

- ❖ **Quick start-up:** The time between the grant award, start-up and first reporting was just nine months. Yet, because the program director, nurse practitioner and the data manager showed extraordinary willingness to work hard over a short period of time, enrollees were recruited, data entry was completed and screening numbers were met.
- ❖ **Technical assistance** for initiation of the work plan was requested from National Indian Women's Health Resource Center (NIWHRC). Funded through a cooperative agreement with CDC, NIWHRC is considered a partner by many of the tribal BCCEDP programs.
- ❖ **Mentorship:** Through a unique tribe-to-tribe mentoring agreement, Cherokee Nation

The Kaw Nation BCCEDP team includes Lana Nelson, Project Director, and (not shown) Mary Tinsley, Nurse Practitioner; Ginger Gray, Administrative Assistant; and Lisa Wanko, Data Manager



“Constantly communicating the benefits of the program, that’s how people begin to invest in it.”

— Lana Nelson, B.S.
Program Director,
Kaw Nation BCCEDP

BCCEDP helped Kaw Nation BCCEDP with on-site consultation between staff, and with tours to CN tribal clinic screening sites and the Hastings and Claremore IHS hospitals.

- ❖ **Delays occurred in processing** a Memorandum of Agreement with IHS Oklahoma Area, which was required for Kaw Nation BCCEDP to work in Pawnee and Pawhuska IHS clinics. The program director appealed to NIWHRC during start-up for assistance with the problem. Because of their established relationship with IHS, NIWHRC helped expedite the slow-moving process.
- ❖ **Institutional changes:** Screening delays also occurred at the Pawnee and Pawhuska IHS facilities. Staff perceived that the new program would mean more work, and because neither clinic had an extra exam room. Repeated, in-person, conversations helped to build relationships and trust. Eventually, space was made at the clinics. Today the IHS clinics, together with the self-governance tribal clinics at the Iowa Tribe, Ponca Tribe and Kaw Nation, all show enthusiastic participation.

Streamlining existing internal resources

Changes were made within Cherokee Nation Health Services to enhance the infrastructure and maximize the resources and assets of all its cancer programs. This included merging the location of the CNCR, the CNBCCEDP, and the CNCCC program under a single department called the Cherokee Nation Cancer Programs (CNCP).

Besides CNCCC being in the initial planning phase, transition also included a new Cancer Programs Director, a new CNBCCEDP Program Manager, and loss of a key Cancer Registry staff person. Some of the methods Cherokee Nation employed to ensure strong internal collaboration during these major transitions included,

- ❖ **Field staff assistance from CDC staff:** A public health advisor for the CNCCC program was made available on site from CDC on an ongoing basis. However, because all of the CN Cancer Programs operate concurrently, the CDC field-staff consultant assists with questions, and acts as a liaison for information and direction from CDC.
- ❖ **Support from the National Institute of Health (NIH):** CNCR's major grantor began training the new Cancer Registrar right away. This helped Cherokee Nation Cancer Programs and the Oklahoma Cancer Programs regain lost ground on timelines needed to target cancer site priorities, conduct surveillance research, continue planning and begin intervention.
- ❖ **Agreements to partner** with other CN Health Services programs included the Diabetes Program, Steps to a HealthierUS Program, the Geographic Information Systems department (so that the CNCR can map cancer incidences), and many others. Community partners include The Native American Cancer Support Group, and other respected community, council and church leaders.
- ❖ **Technical assistance:** NIWHRC offered a staff-building training, a program walk-through for the new CNBCCEDP manager and evaluation assistance for the new CNCP director. Kaw Nation also returned the mentoring favor they had received at start-up and mentored the new CNBCCEDP manager when she came on board.



The Cherokee Nation Cancer Programs team. (Left to Right) Angela Leach, Dana White, Ruth Hummingbird and Kym Cravatt. Not shown is Ann Wheeler.

“ We don't see this as just coming in and punching a time clock. We genuinely care about people's lives. ”

— Ruth Hummingbird, BBA
Cherokee
Program Coordinator,
CN Comprehensive Cancer Control

Integrating commitment with service

All three cancer program grants at OSDH are housed in the same building under the Chronic Disease Services division. Program directors meet regularly, collaborate on projects, participate in each other's goal setting, planning and evaluation processes. They also serve on each other's advisory committees.

The nature of bureaucracies leads to a tendency of the state health department to operate in silos at the agency level. At the service level, however, the three OSDH cancer programs are closely integrated.

One example of OSDH's commitment to service is the Oklahoma Comprehensive Cancer Plan. Even without a guarantee of funding, (eventually awarded by CDC during the second CCC grant cycle) a group of committed stakeholders began laying the foundation for partnerships and task groups that eventually lead to the final plan, published in 2006.

External Collaboration; Crossing Into New Territory

Creative partnering leads to familiarity, respect and mutual gain

The BCCEDP was among the first group of specific cancer-site programs funded by CDC with awards going to Cherokee Nation in 1994, and OSDH in 1995. Designed on the premise of collaboration via matching funds, and born out of restricted budgets, program managers with grants now into their third funding cycle are long accustomed to partnering for everything from health education events to treatment. As a result, Comprehensive Cancer Control directors from OSDH and Cherokee Nation leaned heavily on the expertise of their precedent programs for collaboration know-how. At the same time, CCC takes collaboration to the next level, requiring involvement with a broad sector of citizenry for the greatest impact over a number of collectively prioritized cancer sites.

Exceptional alliances were forged. The Chair of the Department of Surgery from Hastings IHS Hospital joined the Cherokee Nation CCC Advisory Board. Doctors from both Claremore IHS Hospital and the University of Oklahoma committed to monthly meetings over two years. Important partners also include the Oklahoma Society of Clinical Oncologists, Oklahoma Primary Care Association, the American Cancer Society, IHS Epi-Center and others.

Breaking new ground

Equally remarkable is the partnership between the OSDH and CN Health Services. For the first time, the State of Oklahoma and Cherokee Nation committed to pooling resources to promote prevention, decrease mortality, and increase the quality of life for AI/ANs living in Cherokee Nation's fourteen county-wide Tribal Jurisdictional Service Areas, and throughout the state.

As participants on each other's respective CCC committees, OCCC and CNCCC members and other state-wide partners, including physicians, administrators, volunteers and others accomplished the following:

- ❖ Registry data was collected and mapped

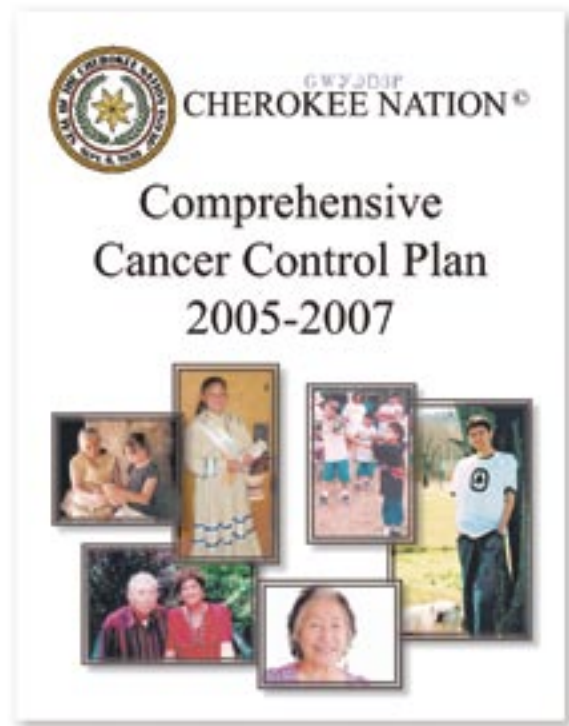


Figure 2: The Cherokee Nation CCC Plan.

- ❖ A needs assessment to identify gaps was developed
- ❖ Research papers were written and chapters in the CCC plan were presented to peers on collected data on cancer sites
- ❖ Outreach strategies were developed
- ❖ Workgroup performance evaluations were developed, and measures of effectiveness were identified to help keep members on track
- ❖ Survivorship issues were identified and meetings were attended to gain input and insight

Core members—or “partners over the long haul” as they are considered—continue to support cancer programming efforts as the CNCCC and OCCC execute the implementation phase of their respective CCC programs.

Record Linkage

The key to high quality data

The Oklahoma Central Cancer Registry's (OCCR) misclassification of American Indian Race once stood as high as forty-eight percent.² The partnership between OCCR and the Cherokee Nation Cancer Registry (CNCR)—the only tribally operated cancer registry in the nation—helped change that. Some of the gains from collaboration for the state and Cherokee Nation's cancer registry programs and, indeed, for all of the cancer related programs in the state, are as follows:

- ❖ OCCR is mandated to collect and analyze all diagnosed and treated cancers in the state. CNCR helps the state provide this core public health function by providing data on AI/ANs otherwise unavailable to the state.
- ❖ Accurate reporting for AI/ANs in Oklahoma increased. For example, using record linkages between CNCR and IHS, OCCR showed that the true incidence of cancer in Oklahoma among AI/ANs between 2001 and 2003, is 521 per 100,000 rather than the 271 per 100,000 previously reported with pre-linkage data.³

How data linkage exchange works:

- ❖ CNCR collects data from tribal health clinics and IHS, but IHS is not required to give data access to OCCR.
- ❖ CNCR shares that data with OCCR.
- ❖ OCCR collects data from public and private hospitals in the state who are not obligated to report to Cherokee Nation.
- ❖ OCCR contacts IHS to link the cases they have collected to update and correct the race fields only. This applies only to persons seen at private hospitals and also at IHS.
- ❖ Then OCCR shares their data with CNCR.

- ❖ High quality data available from OCCR helps Cherokee Nation and the other tribes in Oklahoma to be competitive for national funding sources. This brings resources and programs to the tribes that help support their needs.

Tri-BCCEDP— A Triangular Approach

Oklahoma is just one of eight states where tribal (or tribal affiliated) and state level BCCED Programs operate simultaneously. While Cherokee and Kaw Nations' own BCCED Programs focus on screening eligible AI/AN women in their service areas, OSDH is mandated to reach its eligible citizens statewide. As a result, Tri-BCCEDP was formed to coordinate screening services in all of Oklahoma more effectively. The group's efforts include the following:

- ❖ **Quarterly meetings:** In addition to membership on each other's advisory committees, program directors meet regularly to share outreach strategies, resources, and training opportunities. For instance, recently when it was OSDH's turn to host a meeting, speakers from other state health programs were invited to share their expertise and to network with the entire staff from the tribal cancer programs.
- ❖ **Serving all women:** When services were expanded to the Iowa Tribal clinic, eligible native women were seen on screening days by the Kaw Nation BCCEDP Nurse Practitioner in the mornings, and non-native eligible women were seen by the OSDH BCCEDP Provider in the afternoons.
- ❖ **Mammography openings filled:** Evolving cooperation has lead OSDH BCCEDP to offer Cherokee Nation unfilled spaces on their mobile mammography schedules. That way, AI/AN women are seen weeks sooner than if they waited for an opening in the backlogged tribal schedules.

^{2/3}Source: Janis Campbell, Ph.D.; OSDH Surveillance Coordinator.

The Far Reaching Hoops

Collaboration reflects many native communities' cultural values of strength through contribution

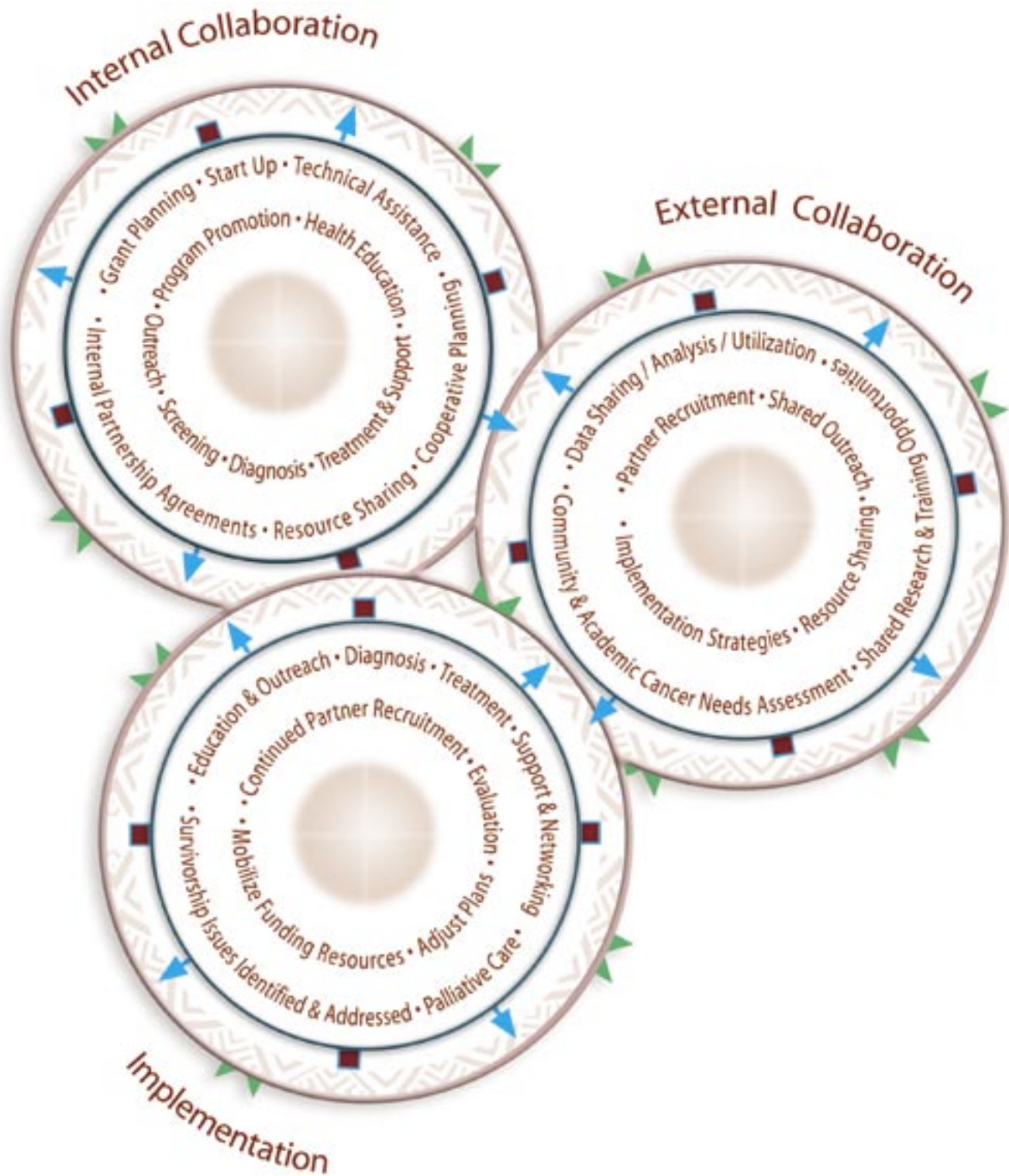


Figure 3: Concurrent circles of collaboration.

Collaborative Synergy

Using high-quality leadership skills to implement a Federal Act

History was made the day the tribal leaders from Cherokee Nation and from Kaw Nation joined the directors of the Oklahoma State Department of Health, the Oklahoma Health Care Authority, and the Oklahoma Department of Human Services to sign Oklahoma State's Breast and Cervical Cancer Prevention and Treatment Act (BCCPTA). Never before had two tribes and three state agencies come together in Oklahoma to debate, discuss, and develop language for such a significant document. The process required moving beyond historical issues of trust and the interaction with sovereign nations.

About the Act

Effective January 1, 2005, the State of Oklahoma began providing Medicaid benefits to uninsured women under 65, who are identified through the State and Tribal National Breast and Cervical Cancer Early Detection Programs (NBCCEDP), and are in need of treatment for breast or cervical cancer (including pre-cancerous conditions and early stage cancer). These benefits are the result of the federal Breast and Cervical Cancer Prevention and Treatment Act of 2000 and the Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001.

Two standards of eligibility

The five-agency team, called "Oklahoma Cares," met over six intensive months to develop language that would accommodate the state and tribal stakeholders. It was a remarkably fast process given the unknown challenges and differences that developed.

For example, the poverty level guideline for BCCEDP for the state of Oklahoma is 185 percent, while the guideline for Kaw and Cherokee Nation is 250 percent, making Oklahoma the only state in the United States with two different guidelines for BCCEDP. Addressing this unique issue meant venturing into territory not ever traveled by state and tribal officials, anywhere else.



The Oklahoma State Department of Health Cancer Programs team. (Clockwise from left) Susan Lamb, OSDH Program Manager OSDH CCC; Janis Campbell, Ph.D., Surveillance Coordinator; and Cheryl, "Charlie" Jones, R.N., Program Director, OSDH BCCEDP.

“ At the heart of our collaborations is respect for each other, and for the people we serve. ”

Cheryl "Charlie" Jones, RN
Choctaw
Program Director,
OSDH BCCEDP

The leadership qualities used to arrive at an agreed-upon document to implement the new law included,

- ❖ **Commitment:** Devoting staff time, resources and attention to accomplishing the work
- ❖ **Integrity:** Upholding promises, doing what you say you will do
- ❖ **Willingness** to learn, willingness to teach
- ❖ **Perseverance:** Keeping at it, finding ways to address challenges, taking whatever time needed
- ❖ **Recognition and respect** for other cultures, for others' expertise and knowledge, for the contribution that diversity brings to the table

Support for the Future

The Comprehensive Cancer Control Leadership Institute

One of the largest cancer networking and resource sharing opportunities for tribal health programs held in the United States was the 2005 Comprehensive Cancer Control Leadership Institute for AI/AN Tribes. More than two-hundred participants representing over seventy tribal cancer programs, urban Indian health clinics, state health departments, medical universities and others, came together from as far away as the Arctic Slope Native Association in Barrow, Alaska, to the Poarch Creek Indian Tribe in Alabama. Numerous national organizations partnered with CDC to sponsor the specially focused institute, which featured presentations by program directors, doctors, health administrators and researchers on everything from tobacco control in Indian Country, to urban American Indian health issues. For five in-depth days, participants shared their knowledge and expertise and networked with others to further their efforts in planning and implementing cancer control for AI/AN across the continent.

Assessment, revision, and expansion

Accurate data, integrated planning, mobilizing funding resources, enhancing infrastructure, effective implementation; these are indeed the outcomes to cancer collaboration. However, it is familiarity, trust, and a

“Cherokee Nation’s planning phase was a year ahead of ours. As a coalition member on their board, I was able to look at their model for direction and guidance for our own process.”

—Susan Lamb, BA
Program Manager,
OSDH Comprehensive Cancer Control Program

sincere desire to support the well-being of neighbors and fellow citizens that is the root of investing time, material, and especially heart, into the future.

Effective collaboration is fluid. Constant assessment of data, plans and outcomes requires constant revision and further inclusion of partners and resources. *Where can we go next, and how can we affect greater health?* These are just two of the many questions that need to be asked—and answered—again and again, especially as the future of cancer for American Indians and Alaska Natives unfolds.

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