

# TEXAS CANCER GUIDE

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American Indian  
Cancer Foundation®

2023 - 2032



# BACKGROUND

American Indian Cancer Foundation



## "Healing with Culture. Reclaiming Indigenous Health."

At the heart of American Indian Cancer Foundation (AICAF) are various values that frame our approach: 'Healing with culture. Reclaiming Indigenous health' through kinship and relationships. These values include: interrelatedness, non-linearity, sustainability, lifeways rooted in culture, balance, respect, and respect for all living things. In addition to these, AICAF deeply values self-determination, Tribal sovereignty, and relatedly, personal sovereignty. Interwoven throughout our programming is the power of storytelling and family/kinship relations.

## AICAF Approach

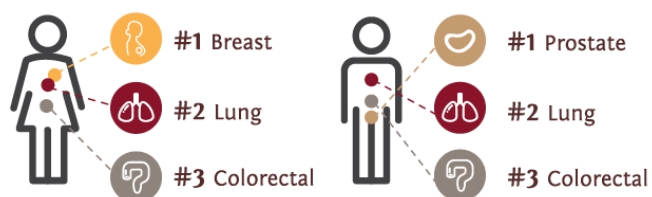
We believe Native communities have the wisdom to find the solutions to cancer inequities but are often seeking the organizational capacity, expert input, and resources to do so.

We support innovative, community-based interventions that engage Native populations in the discovery of their own cancer best practices.

We strive to be a partner trusted by Tribal and Urban community members, leaders, health care providers, and others working toward effective and sustainable cancer solutions.

## Cancer Burdens in Indian Country

### The most commonly diagnosed cancers are...



### Lung cancer is the leading cause of cancer death for men and women.

Other leading causes of cancer death are...



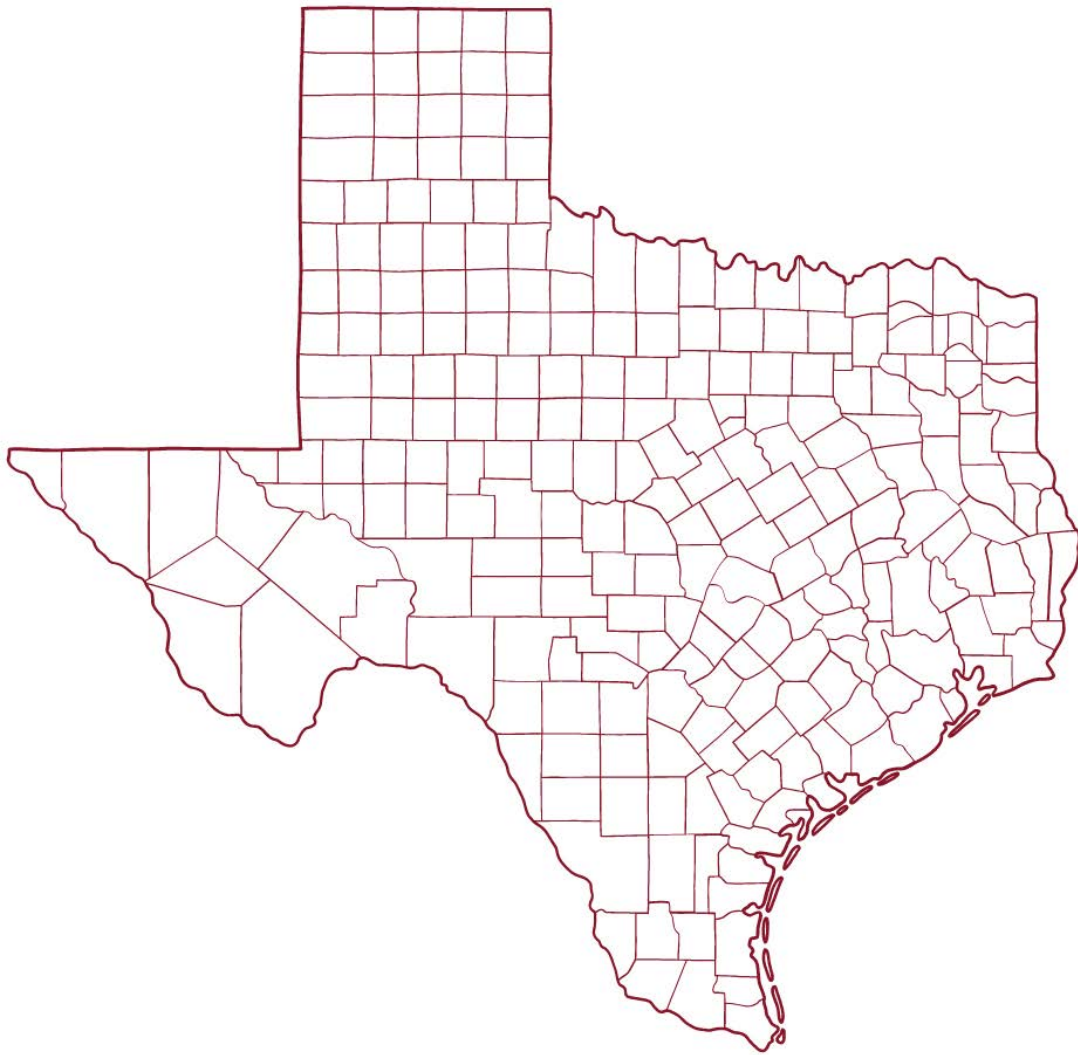
Data source: Disparities in Cancer Mortality and Incidence Among American Indians and Alaska Natives in the United States | AJPH | Vol. 104 Issue S3 (aphapublications.org).

## Indigenous Cancer Solutions Coalition

Indigenous Cancer Solutions (ICS) Texas Coalition seeks to reduce the burden of cancer among tribal and urban Native people in the Texas region. The coalition works collaboratively with diverse stakeholders with shared interests and goals to achieve this mission. Working together, the coalition will advance health systems, change processes, identify culturally tailored evidence-based intervention practices, and set Indigenous cancer goals.

## Texas

Texas state comprises 268,597 square miles and is the second largest state by both area and population in the U.S.<sup>1</sup> Texas is home to 794,062 American Indian and Alaska Natives either alone or in combination.<sup>2</sup> The three cancers with the highest death rates in Texas for Natives include lung and bronchus, female breast, and colon and rectum. The cancers with the highest incidence rates are female breast, prostate, lung and bronchus.<sup>3</sup> Currently, in Texas, there are 3 federally recognized Tribes, including Alabama-Coushatta, Ysleta Del Sur Pueblo, and Kickapoo.<sup>4</sup> However, there are numerous federally unrecognized tribes located in Texas. With tribes not recognized, it's important to consider inaccurate or suppressed data. Lastly, Natives are often overlooked or lumped into categories described as "Other," leaving them essentially invisible, and the needs of Native people often go unrecognized in tribal, federal, state, and local policy-making decisions due to a lack of representation.



The image above represents the counties in Texas.

About 2.6 million AI/AN people receive health services through Indian Health Services (IHS).<sup>5</sup> IHS's role in providing health care to Natives is complicated and often misunderstood, yet it is a critical institution in securing the health and wellness of Natives. It is essential to recognize that IHS is not an insurance provider but rather a funding source for health systems to provide health care to eligible American Indian/Alaska Natives (AI/AN) within a defined area. Of the \$48 billion per year required to fully fund the IHS, only \$6.23 billion was budgeted for FY 2021.<sup>6</sup> In FY 2017, the IHS per capita expenditures for patient health services were just \$3,332, compared to \$9,207 per person for health care spending nationally.<sup>7</sup>

# ABOUT THIS CANCER GUIDE

The cancer guide outlines the various priorities that our Texas coalition is focused on in cancer care and control. These include primary prevention, screening and early detection, and survivorship. The cancer guide is divided three sections that address the cross-cutting issue of health equity. Each section provides an overarching goal, objective, and list of potential strategies. The baseline and target measures have been provided where applicable. This cancer guide was established in 2023 with goals continuing into 2032.

The purpose of the comprehensive cancer guide is to:

- Highlight and raise awareness about the critical cancer issues, challenges, and barriers faced by Native people located in Texas.
- Set goals and objectives for improvement across the cancer continuum.
- Propose potential strategies to achieve goals and objectives.
- Empower partners to implement achievable strategies in their communities to reduce the incidence of late-stage cancer diagnosis.
- Draw together a diverse group of stakeholders.

## Long Term Goals

- Reduce the incidence and mortality rates for all cancers in Tribal and Urban communities located in Texas.
- Increase appropriate cancer screening through recommended screenable cancer guidelines in Tribal and Urban communities located in Texas.
- Reduce the rate of late-stage diagnoses for all cancers in Tribal and Urban communities located in Texas.
- Increase understanding and practice of cultural humility in clinical or organizational practice.
- Increase data surveillance efforts to be complete and accurate to Tribal and Urban communities located in Texas.
- Improve the quality of life for Tribal and Urban AI/AN cancer survivors and their caregivers.
- Incorporate and implement Indigenous values and worldview.

## Cancer Guide Layout

Within each section of the Cancer Guide, there is a brief description on the cancer continuum section. Following this, there are a number of common barriers listed. This list is not a comprehensive list of the challenges that our relatives, clinics, community, and organizations encounter, rather it is a list of often-discussed challenges. Next, we list each topic by:

- Potential Barriers and Challenges
- Objectives
- Strategies
- AICAF Health Systems Activities - provides context on previous activities performed to support cancer control work within Indigenous communities
- Indigenous-specific recommended Health Systems Changes - PSE (Policy, System, and Environmental Change)
- AICAF Recommended Resources

## **Intended Audience**

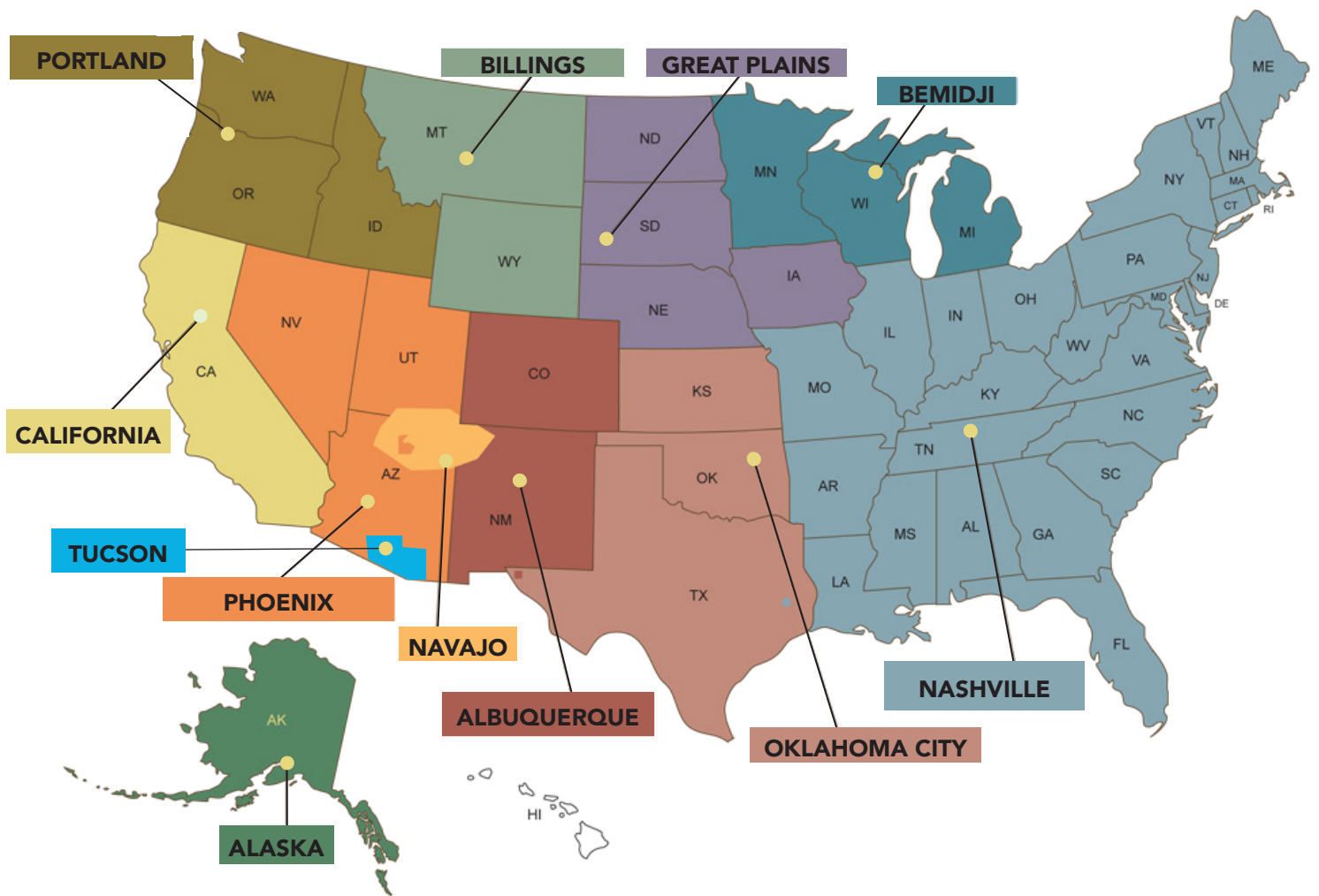
AICAF received new funding from the Centers for Disease Control and Prevention (CDC) National Breast and Cervical Early Detection Program and the National Comprehensive Cancer Control Program for our Screen Our Circle Program and Indigenous Cancer Solutions Coalition. This key funding will support Tribal and Urban Indian clinics and organizations in Texas, ensuring that we can close the gap on disparities in cancer screenings and improve health and wellness for cancer survivors.

According to the CDC's website, all 50 states, the District of Columbia, 6 U.S. Pacific Island jurisdictions and Puerto Rico, and 8 Tribes and Tribal organizations have produced 63 plans. In addition to these plans, the Cancer Council of the Pacific Islands developed a Pacific Regional Plan.<sup>8</sup>

## **Indigenous Cancer Solutions Coalition History**

The American Indian Cancer Foundation was funded in 2017 by the Centers for Disease Control and Prevention National Comprehensive Cancer Control Program or NCCCCP. Through this funding, in October 2019, the National Urban American Indian and Alaska Native Cancer Coalition were founded. The mission of this coalition was to work collaboratively with diverse stakeholders through shared interests and goals to support the 41 Urban Indian Health Programs (UIHP) nationally. We worked to advance health systems change processes, identify culturally tailored evidence-based intervention practices, and set AI/AN cancer goals. One key deliverable in this funding was to create a National Cancer Guide for UIHPs to utilize and create positive change for community members through prevention, early detection, screening, treatment, and survivor support. We have 55 members from various backgrounds, from cancer survivors to research centers, Tribal/Urban clinic systems, and cancer centers. Funding was concluded for this project in June of 2022.

AICAF reapplied for the NCCCCP programming. Unfortunately, we could not apply as a National program as in 2017. Our new funding aims to support the Indian Health Service (IHS) Nashville region.



## Indigenous Cancer Solutions Coalition Overview

**Mission:** To reduce the burden of cancer among Indigenous people throughout Indian Country, with a particular emphasis on the state of Texas.



**American Indian Cancer Foundation's**

## **INDIGENOUS CANCER SOLUTIONS**

### **Goals:**

1. Implement Indigenous Cancer Solutions' comprehensive Cancer Guide.
2. Incorporate and implement Indigenous values and worldviews.
3. Reduce the incidence and mortality rates for all cancers in Indigenous communities.
4. Increase appropriate cancer screening through recommended screenable cancer guidelines in Indigenous communities.
5. Reduce the rate of late-stage diagnoses in Indigenous communities.
6. Increase understanding and practice of cultural humility in clinical/organizational staff.
7. Increase data surveillance efforts to be complete and accurate for Indigenous communities.
8. Improve the quality of life for Indigenous cancer survivors and their caregivers.
9. Create a space for diverse stakeholders to collaboratively seek practical and sustainable cancer solutions.
10. Seek opportunities for policy change to afford Indigenous people more comprehensive cancer services.
11. Identify barriers that may be systematically in place for Indigenous people and strive to create sustainable changes.

### **Coalition Structure**

#### **Leadership**

Responsibilities: The Coalition Leader assists in operating the coalition, engaging the community, recruiting new members, planning strategic coalition development, implementing the AICAF Cancer Guide, and evaluating coalition efforts. In addition to attending the ICS Coalition meetings, Leaders are expected to attend operations and planning meetings for the coalition.



## **Coalition Member**

Responsibilities: A Coalition Member is responsible for attending the coalition meetings, engaging with other coalition members through peer-to-peer learning, and applying the opportunities provided in the meetings to implement strategies to reduce cancer burdens among Indigenous communities.

## **Workgroup Member**

Responsibilities: Workgroups are a part of the larger ICS Coalition. Workgroups focus on reducing cancer burdens in Texas. As a Workgroup member, you are responsible for attending the coalition and workgroup meetings, engaging with other coalition members through peer-to-peer learning, and applying the opportunities to implement evidence-based interventions (EBIs) provided in the meetings.

- Utilize specific strategies and EBIs to prevent, reduce, and or treat cancer in targeted geographical areas as defined by AICAF, which could include participation in local cancer awareness events and social media campaigns.
- Provide updates based on workgroup progress to the ICS Coalition.
- Participate in evaluating the impact of the EBIs or other interventions and their outcomes.
- Collaborate across groups and sectors to work towards a common goal.
- Engage in conversations and provide insights into pertinent workgroup topics.
- Be willing to receive coalition emails and share them within your networks.
- Implement tools and resources developed through the coalition within the community and support the evaluation of the impact these tools and resources had on a community.

## **Get Involved**

Any organization, clinic, or individual interested in reducing the burden of cancer among Indigenous people in Texas may join the coalition at no cost. For more information regarding the Indigenous Cancer Solutions (ICS) Coalition, please contact [health@americanindiancancer.org](mailto:health@americanindiancancer.org).

## **About the Evaluation**

The Cancer Guide sets forth goals and suggested activities to reach the long-term goals of reducing cancer incidence and mortality in Texas Native communities. To better understand how we are progressing toward our goals and learning more about our communities, an evaluation plan was developed to accompany the Cancer Guide. AICAF acknowledges the persistently problematic history of evaluation and research in Native Communities and aims to align its evaluation design with several Indigenous Evaluation frameworks, including those developed by the American Indian Higher Education Consortium and the Urban Indian Health Institute.

Indigenous Cancer Solutions Evaluation Plan includes a series of activities, including tracking key indicators of the Cancer Guide, hearing from Coalition members and leadership on the implementation process, and sharing our findings to continue improving the implementation. The evaluation activities will occur along the entire lifecycle of the Cancer Guide. In 2024, an intentional and semi-structured discussion with the Coalition Leadership will be held to assess progress and identify how values are being carried out through the Cancer Guide implementation.

In 2025, the Coalition members will be surveyed to learn how to best engage members and set priorities for the next several years of the Coalition and Cancer Guide. In 2032, AICAF will plan to obtain updated population level health indicators to compare and assess progress towards targets. Additional evaluation activities will be designed and implemented in response to needs and interest of Coalition leaders and members. All evaluative activities will be approached with a desire to understand and learn, improving and aligning activities as the Cancer Guide moves forward.

## **About the Data**

Accurate reporting and data collection is paramount to the improvement of cancer care and control as a means to measure such things as incidence, mortality, and survival rates. These three areas have been identified as areas of improvement needed to address data surveillance and reporting. First, much of the baseline data needed for such calculations are not specific to the Native population due to small sampling sizes, causing a form of erasure in national, regional, and state-level data, thus not allowing the capture of year-to-year changes in important benchmarks. Finally, calculating rates becomes even more complicated when factoring differences in how race and ethnicity data is reported, especially for multiple racial and ethnic statuses. This is important to note because Native people have the largest proportion of any racial group identifying as multi-racial, and excluding those identifying as multi-racial is another form of erasure.<sup>9</sup> Given these data availability and quality limitations, individual baseline measures included in this Cancer Guide may not all correspond to the same year.

## **ACKNOWLEDGEMENT**

"We acknowledge the Centers for Disease Control and Prevention, for its support of the American Indian Cancer Foundation staff, and the printing and distribution of the monograph under cooperative agreement #NU58DP007169 awarded to the American Indian Cancer Foundation. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC." Findings, content, and conclusions are contributions from a diverse group of stakeholders and do not represent the official position of the CDC.

This cancer guide was created with support from staff from the American Indian Cancer Foundation, Urban Indian Health Institute, AICAF Cancer Survivors Leadership Advisory Council, clinic partners, and AICAF's Indigenous Cancer Solutions Coalition. The support, collaboration, and knowledge garnered from these individuals and organizations have been instrumental in the conception and overall development of the Cancer Guide. With a concerted and targeted goal to reframe and address the cancer burdens for Native people.

## DEDICATION

Chi Miigwech, Pilamaya, Ketabi, Ahéhee', Niá:wen, Marsee, Yakoke, Kaqinaliyuw, Noshúun lóoviq, S-ap'e, Qu yana. Thank you.

Thank you to the earth and all of our past, present, and future ancestors for your energy. Your collective traditions, values, ancestors, and spirits have brought us to the creation of this Cancer Guide.

We honor our cancer survivors, their families, and our communities that have been impacted by the burdens of cancer. The strength and resiliency of each and every community are what fuel our passions and inspire all to work diligently to address the burdens of cancer each has faced.

AICAF values the understanding that “we are all related,” and when cancer affects one of us, it affects all of us. This Cancer Guide was created as a living document dedicated to all of our relatives.



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## **Data Surveillance/Data Sovereignty/Partnerships**

Health is a fundamental human right. Equity is the absence of avoidable, unfair, or remediable differences among people, and this ideal is not a reality for Native people in terms of health. Native people have the right to access quality, timely, and affordable health care. Where people live, learn, work, and play can affect their health risks and the associated outcomes. These conditions are known as social determinants of health.

Our Indigenous ancestors were some of the healthiest people, but after colonization, those health outcomes changed drastically. Determinants of Indigenous health include our ancestral Indigenous lifeways, including kinship relationships, storytelling, connection to land, language, ceremonies, and connection to culture through traditions, ceremonies, movement practices (like ricing, fishing, hunting, etc.), best practices, and others. The distinction of their presence indicates that our health has been impacted by colonization and historical and ongoing trauma, leading to exacerbated and new adverse health outcomes. These disparities are affected by historical and ongoing trauma and systemic practices that deeply affect individual, family, and community health and well-being. At the root of these disparities are laws and policies that criminalize AI/AN cultural and traditional practices while also effectively dehumanizing AI/AN people through genocide, forced removal from ancestral and ceremonial homelands, termination, and assimilation. Adverse health outcomes became apparent as a direct impact of these laws and policies. Some of these adverse health outcomes include high rates of cancer, cardiovascular disease, diabetes, depression, and other mental health problems, early mortality rates, and high rates of infant and maternal mortality.

Other important factors to consider related to data for AI/AN populations is Tribal data sovereignty and the lack of accurate and up to date data. This lack of available data is due, in part, to research and surveillance entities that withhold publishing data due to small population sizes. In order to reduce cancer burdens for AI/ANs, it is critical that health equity must be prioritized through practices and interventions that are informed and represented by AI/AN communities.

### **Potential Barriers/Challenges**

- Misclassification of AI/AN populations in data collection (e.g., birth certificates, death certificates, survey data, clinical data)
- Blood quantum
- Lack of funding
- Transportation
- Not residing in the IHS Purchased Referred Care service area
- Removal of family support due to location of health services
- Lack of religious freedom- traditional medicine access
- Fear of doctors and health systems caused by historical and/or sexual trauma
- Lack of Native representation in health care staff (including nurse practitioners, physicians, etc.)

- Shortage of cancer care expertise
- Burnout of health care staff
- Cultural sensitivity & competency
- Lack of insurance - employed in low-wage jobs that typically do not offer health coverage
- Limited access to mental health resources -rural Native communities

**Data Surveillance/Partnership Goal:** Decrease cancer disparities for Tribal and Urban communities located in the state of Texas, through policy, systems, and environmental changes.

Data Surveillance/Data Sovereignty/Partnerships	
Objectives	Strategies
<p><b>1.</b> By June 2032, the ICS TX coalition will have made a connection to the TX state cancer registry, disseminated 3 burden data communication pieces, and increased the number of Tribal and Urban data communication sources.</p>	<p><b>1A.</b> Improve the accessibility of cancer surveillance data through communication sources.</p>
	<p><b>1B.</b> Improve cancer data surveillance and communication sources to better study cancer burden trends.</p>
	<p><b>1C.</b> Meet with state programs to discuss data communication.</p>
<p><b>2.</b> By June 2032, the ICS TX coalition will have created five surveillance data reports that will outline baselines and targets informed by our Cancer Guide in partnership with our coalition. At least 10 policy/environmental scans will be presented and reviewed through the coalition.</p>	<p><b>2A.</b> Provide training and education on how to utilize statewide cancer registry data to identify and collaborate with populations and geographic locations with the greatest burdens.</p>
	<p><b>2B.</b> Build capacity through education and training on the importance of policy scans and review.</p>
<p><b>3.</b> By June 2032, the ICS TX coalition will have facilitated at least 90 meetings while establishing a multi-sectoral group that consists of at least 40 members with roles that may include coalition leadership, work groups, and advisory committees.</p>	<p><b>3A.</b> Establish relationships with various entities which may include state cancer registries, Tribal epidemiology centers, and state and local departments of health, and health organizations.</p>
	<p><b>3B.</b> Establish routine coalition meetings to maintain productive discussions which will lead to implementation of objectives.</p>



### **AICAF Health Systems Activities**

- AICAF staff helped to write a paper “Cancer Disparities Among Non-Hispanic Urban American Indian and Alaska Native Populations in the United States, 1999-2017”

### **Recommendations on Health Systems Changes Policy**

- Ensure standardized collection of race and ethnicity data in local/state health jurisdictions, federal agencies, and health systems according to the 1997 Office of Management and Budget (OMB) standards, which allows for reporting race in one of five categories, allowing individuals to specify more than one race rather than one “multiracial” category, and permitting self-identification of race and ethnicity
- Create a policy and procedure for employees to follow when working with a patient collecting data surveillance information

### **Systems**

- Develop or update processes and interventions to support data standardization
- Consider developing a data sovereignty training for clinic staff

### **Environment**

- Install signs at registration alcoves as it relates to data practices
- Increase the number of resources available to patients and staff regarding data sovereignty practices

# PRIMARY PREVENTION

The ancestral lifeways of AI/AN communities are cancer prevention and risk reduction lifestyles. AI/AN traditions nurture sustainability, interrelatedness, a non-linear perspective of time, respect for all living things, balance, and lifeways rooted in culture. These values form the basis of cultural-based disease prevention, including traditional medicines, a natural diet, a connection to nature, community, traditions, physical activity, and rest. In 2023, about 2.0 million people in the United States will be diagnosed with cancer.<sup>10</sup> Primary prevention is a key part of reducing the number of new cancer cases. Following our ancestral lifeways and improving culturally based disease prevention will reduce the burden of cancer and lower the number of deaths caused by cancer.<sup>11</sup>

Behavioral change is not the only factor to consider on this healing journey. The places we live can be determinants of how we learn, work, exercise, and eat; influences within our environments are what determine if a person, family, or community is healthy.

## Potential Barriers/Challenges

- Limited prevention and education-related services available, especially those that are culturally relevant
  - Staff capacity to provide education
  - Public health funding
  - Lack of culturally tailored educational materials and tools
- Accessibility of commercial tobacco products (e.g. cigarettes, e-cigarettes, chewing tobacco, etc.) and inaccessibility of traditional tobacco and knowledge of keeping tobacco sacred
  - AI/AN targeted marketing by commercial tobacco companies
  - Inadequate knowledge and acceptable use of traditional tobacco practices
- Increase of sedentary lifestyle and poor diet (e.g. lack of fresh fruits and vegetables)
  - Limited access to outdoor or recreational spaces
  - Food deserts
  - Unaffordability of healthy food options
- Different electronic health records (EHR) systems are not able to effectively transfer client health records to ensure timely prevention
- Increased exposure to environmental carcinogens (e.g. UV rays, radon, arsenic, asbestos, other manmade contaminants from industrialization, such as buildings, pipelines, etc.)
- Stigma related to cancer screenings

**Primary Prevention Goal:** Promote healthy lifeways among AI/ANs to reduce the use of commercial tobacco.

Commercial Tobacco	
Objectives	Strategies
<p><b>4.</b> By June 2032, decrease the percentage of AI/AN adults ages 18+ in TX that currently smoke from 23.8% (2021) to 15.9% through a multicomponent intervention.</p> <p>Data Source: USCS Data Visualizations Tool</p>	<p><b>4A.</b> Promote and revise commercial tobacco screening policies</p>
	<p><b>4B.</b> Provide training to increase the number of individuals receiving referrals for cessation counseling</p>
	<p><b>4C.</b> Increase the use of culturally tailored cessation tools to increase quit attempts</p>
	<p><b>4D.</b> Increase the knowledge and accessibility of culturally-tailored smoking quit lines and state quit lines</p>

### AICAF Health Systems Activities

- Developed a Commercial Tobacco Cessation Policy to be implemented among staff at an organization in Spring 2022
- Started conversations with the American Indian Commercial Tobacco Project to discuss the accessibility of the quit line for a specific clinic

### Recommendations on Health Systems Changes:

#### Policy

- Create and implement a clinic/organization policy on traditional tobacco and commercial tobacco smoking

#### Systems

- Screen each patient that receives care in your clinic for commercial tobacco use and offer cessation options during the appointment using the 5 A's
- Utilize the EHR to gain knowledge of commercial tobacco use in your community.
- Provide opportunities for community members to be notified of cessation options
- Provide opportunities for monthly or quarterly training for staff on commercial and traditional tobacco



## **Environment**

- Provide a garden space with traditional tobacco and other ancestral medicines with the words for these plants in Tribal languages
- Ban commercial tobacco smoking within a certain distance of your clinic or organization

*Note: This is not a complete list of cancer prevention strategies. These priority areas in primary prevention as they relate to this Cancer Guide are specific to Texas priorities.*

# SCREENING & EARLY DETECTION

Lower screening rates among Native populations can be attributed to various factors, including, but not limited to, access to care and structural barriers. Many Native people receive primary care through Tribal and Urban Indian Organizations (UIO)s, making opportunities for a full spectrum of care oftentimes unavailable. Many health care facilities do not have the capacity to perform screening and/or needed diagnostic follow-up, resulting in barriers for patients as they navigate screening and diagnostic follow-up care. While the IHS' Purchased and Referred Care (PRC) aims to alleviate access to care, the completion of needed screening can be impacted by complications in the service delivery area, priority of service, and financial barriers.

## Potential Barriers/Challenges

- Lack of transportation
- Fatalistic fears of screening
- Complex approvals process for referrals to screening
- Underfunded health care system
- Lack of health insurance coverage
- Gaps in continuity of care (e.g. screening, follow up, referral)
- Lack of data collection pertaining to patient family history
- Behavioral health factors negatively impact care (e.g. trauma, addiction)
- Lack of integrated care to address and document trauma (historical and current)
- Access to clinical trials- equitable clinical trials ecosystems
- Legislative support and policies to support and represent the need for earlier screenings and insurance coverage to support this effort
- Inequity of funding for Indigenous organizations and communities
- Digital technology access
- Lack of child care to initiate screening and diagnostic follow up services
- Provider vacancies at health centers
- Limited amount of time allocated with health care provider
- Health care service hours

**Screening and Early Detection Goal:** Increase colorectal cancer screening rates to detect cancers at earlier stages

Colorectal Cancer Screening	
Objectives	Strategies
<p><b>5.</b> By June 2032, the ICS TX coalition will work to improve colorectal cancer screening rates among AI/AN community members in Texas through multicomponent interventions.</p>	<p><b>5A.</b> Increase the number of patients receiving health counseling by providers regarding colorectal cancer screening (e.g. family health history, risk assessment)</p>
	<p><b>5B.</b> Increase the number of patients who receive an in-home stool-based test with proper instruction on providing a sample and return instructions</p>
	<p><b>5C.</b> Increase the number of referrals for colonoscopies for individuals who have completed a stool-based test (positive result)</p>
	<p><b>5D.</b> Reduce structural barriers (e.g. service delivery setting, clinic hours, financial burden, transportation) to colorectal cancer screening</p>
	<p><b>5E.</b> Participate and promote Blue Beads Day campaigns in March</p>
	<p><b>5F.</b> Increase risk-appropriate screening through the implementation of patient and provider reminder systems</p>

#### AICAF Health Systems Activities

- Created a colorectal flipbook to support varied CRC screening options
- Created a men's health resource that had a partial focus on CRC screening options
- Held a webinar with a medical provider that discussed various CRC screening options
- Developed and disseminated CRC postcards that included reminders to discuss screening options with health care providers
- Created implementation plans that focused on CRC efforts
- Identify existing data sources and new data collection methods to establish Texas baseline measures for CRC screening



## **Recommendations on Health Systems Changes Policy**

- Create a colorectal cancer screening policy which outlines the purpose, responsibility, procedure, goals, any exclusion criteria and client reminders along with EHR support
- Implement clinic onboarding guide which will help gauge the potential partnership with a new clinic
- Implement pilot project on reducing structural barriers

## **System**

- Initiate outreach with the state health department prior to approaching/onboarding a new clinic.
- As a part of the cancer leadership team, collaborate across the NBCCEDP grantees to enhance cancer screening and clinical services for women.

## **Environmental**

- Work with a national organization to provide support to those living with cancer, improve the quality of cancer care, or address legislative and regulatory issues that affect cancer care and research.

# **SURVIVORSHIP**

Despite advancements in cancer screenings, early diagnosis, and treatment, Indigenous people experience some of the worst five-year cancer survival rates compared to any other subpopulation in the United States and have an 18% higher risk of dying from cancer compared to Non-Hispanic Whites.<sup>12,13</sup> Dedicated efforts to increase cancer surveillance and promote long-term follow up care and quality of life among Indigenous cancer survivors is critical to addressing these disparities. Cancer survivorship begins at diagnosis and endures throughout the lifespan of the individual. Family members, friends, caregivers and those who have been impacted by a cancer diagnosis are also considered survivors.<sup>14</sup>

## **Potential Barriers/Challenges**

- Identifying survivors
  - Racial misclassification in electronic health records and death certificates
  - Lack of nationwide AI/AN specific cancer registry
  - Consistency in coding cancer among providers
- Fractured health care system
  - Continuity of care
  - EHR capabilities to track patients from primary care to referral sites
  - Reporting back on labs, radiology, screening reports, etc.
- Social, mental, and spiritual support
  - Health literacy
- Strong orientation to family and community vs. personal health

**Survivorship Goal:** Increase the long-term quality of life for every Native community member affected by cancer.

Five-Year Survival Rate	
Objectives	Strategies
<p><b>6.</b> By June 2032, increase the 5-year survival rate for all cancers among AI/AN community members in Texas from 71.7% to 75%</p> <p>Data Source: USCS Data Visualizations Tool</p>	<p><b>6A.</b> Increase age-appropriate, guideline-driven support and surveillance of cancer spread, recurrence, secondary cancers, and late effects</p>
	<p><b>6B.</b> Increase survivor education on a cancer risk reduction lifestyle (e.g., the importance of regular screening, commercial tobacco cessation, physical activity, healthy eating)</p>
	<p><b>6C.</b> Develop train-the-trainer modules to implement cancer support circles</p>
	<p><b>6D.</b> Create digital survivorship support platform</p>
	<p><b>6E.</b> Develop Native survivorship resources</p>
<p><b>AICAF Health Systems Activities</b></p> <ul style="list-style-type: none"> <li>• Provided infographics, webinars, and held discussions on cancer risk reduction</li> <li>• During awareness months, AICAF held opportunities for clinics to participate in small evidence-based interventions such as small media, provider assessment and feedback, and 1:1 education.</li> <li>• In the process of developing a resource on how healthcare teams can enhance their time with patients</li> </ul>	

### **Recommendations on Health Systems Changes:**

- Explore opportunities to provide insurance options to your community. Look into a medical benefits specialist to support and enhance this conversation.

### **Policy:**

- Establish policies on risk reduction activities. For example:
  - Create policies that increase the consumption of fresh fruits and vegetables at community gatherings.
  - Include a policy on using time off for cancer screenings.

### **Systems:**

- Utilize data in your electronic health systems based on cancer issues to better understand the community you serve to build and support health promotion interventions.

### **Environment:**

- Install signs that promote the use of walking trails locally.
- Explore partnerships with local food suppliers and farmers to provide fresh healthy traditional foods during community events.
- Have a resource hub located in your building. This is a place where community members may go to learn more about cancer risk reduction. Perhaps offer a computer so they may look up resources as well.

## PROMISING DIRECTIONS

Our vision is a world where cancer is no longer the leading cause of death for Indigenous people. Through hard work, culturally appropriate community-based programs, and policy change that affords Native people access to the best prevention and treatment strategies, we hope to see a day where Native communities are free of the burdens of cancer.

Reducing the burden of cancer in our AI/AN communities requires a multicomponent approach to address various cancer topics. This approach requires input from stakeholders who have different skill sets that add to the AI/AN Cancer Coalition to reach the long-term goal of reducing the morbidity and mortality of cancer among AI/ANs and there are many directions that we can take. AICAF recognizes the need for resources on the following:

- Young survivors
- EHR Support
- Provider Education
- Cultural Competency Training
- Youth involvement
- Healthcare provider education
- Electronic Health Records
- Health Literacy
- Survivor Cancer Plan
- Palliative and End-of-life care
- Cultural Practice
- Environmental effects of carcinogens
- Promotion of STEM education among AI/AN individuals
- Incorporating Adverse Childhood Experiences (ACEs) into health history
- Social determinants of health (SDOH)
- Determinants of Indigenous health (DOIH)

**Join us in creating unique and culturally tailored solutions for our relatives to ensure quality care. Contact us at [health@aicaf.org](mailto:health@aicaf.org).**



# GLOSSARY OF TERMS & ABBREVIATIONS

## A

### **American Indian and Alaska Native (AI/AN)**

American Indian and Alaska Native refers to anyone who belongs to the Tribal nations of the continental United States (American Indian) and the Tribal nations and villages of Alaska (Alaska Native)(National Congress of American Indians, 2020). For the purpose of this Cancer Guide, we will be using AI/AN.

### **American Indian Cancer Foundation (AICAF)**

The American Indian Cancer Foundation (AICAF) is a 501(c)3 non-profit organization that was established to address the tremendous cancer inequities faced by American Indian and Alaska Native communities. The mission is to eliminate the cancer burdens of Indigenous people through improved access to prevention, early detection, treatment, and survivor support.

### **Adverse Childhood Experiences (ACEs)**

Adverse childhood experiences, or ACEs, are potentially traumatic events that occur in childhood (0-17 years). For example: experiencing violence, abuse, or neglect; witnessing violence in the home or community; and having a family member attempt or die by suicide. Also included are aspects of the child's environment that can undermine their sense of safety, stability, and bonding, such as growing up in a household with substance misuse, mental health problems, or instability due to parental separation or household members being in jail or prison. (CDC, 2020).

## C

### **Cancer Continuum**

The Cancer continuum has been used since at least the mid-1970s to describe the various stages of cancer etiology, prevention, early detection, diagnosis, treatment, survivorship, and end of life (National Cancer Institute, 2019).

### **Caregiver**

The person who often helps the person diagnosed with cancer throughout treatment and, often, beyond that. A caregiver can be a spouse, partner, parent, child, or relative and sometimes is unpaid.

### **Center for Disease Control and Prevention (CDC)**

The CDC is a federal agency that conducts and supports health promotion, prevention, and preparedness activities in the United States with the goal of improving overall public health. Established in 1946 and based in Atlanta, Georgia, the CDC is managed by the Department of Health and Human Services.

### **Colonization**

Any kind of external control, and it is used as an expression for the subordination of a people (including Native people) and their rights.

## **D**

### **Data Sovereignty**

Data Sovereignty refers to a group or individual's right to control and maintain their own data. (National Library of Medicine).

### **Determinants of Indigenous Health (DOIH)**

The social determinants of health are the conditions in which people are born, grow, live, work, and age. These circumstances are shaped by the distribution of money, power, and resources at global, national, and local levels (WHO, 2020). The determinants of Indigenous health (DOIH) recognize the social determinants of health but further identifies the experience of colonization and historical and ongoing trauma that AI/AN people face, which influences adverse health outcomes.

### **Diagnosis**

The process of identifying a disease, condition, or injury from its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imaging tests, and biopsies, may be used to help make a diagnosis (National Cancer Institute, 2020).

## **E**

### **Early Detection**

Recognizing possible warning signs of cancer and taking prompt action leads to early diagnosis. Increased awareness of possible warning signs of cancer, among physicians, nurses, and other healthcare providers as well as among the general public, can have a great impact on the disease (WHO, 2020).

### **Electronic Health Record**

An electronic (digital) collection of medical information about a person that is stored on a computer. An electronic health record includes information about a patient's health history, such as diagnoses, medicines, tests, allergies, immunizations, and treatment plans. Electronic health records can be seen by all healthcare providers who are taking care of a patient and can be used by them to help make recommendations about the patient's care. Also called EHR and electronic medical records (National Cancer Institute, 2020).

# H

## **Health Literacy**

Health literacy is where individuals can find and understand information and use it to inform their health decisions or actions for themselves and or others.

# I

## **Indian Health Services**

Indian Health Services (IHS) delivers health care to Native Americans and Alaska Natives. Funding is also provided to Tribal and Urban health organizations and programs.

# M

## **Racial Misclassification**

Inaccurate perception of another individual's racial or ethnic background in the context of how "race" is discussed in American society.

# N

## **National Breast and Cervical Cancer Early Detection Program (NBCCEDP)**

The CDC established the NBCCEDP in 1991 to provide low-income, uninsured and underserved women access to timely breast and cervical cancer screening and diagnostic services. As of 2018, the NBCCEDP funds all 50 states, the District of Columbia, six U.S. territories, and 13 tribes and Tribal organizations.

## **National Comprehensive Cancer Control Program (NCCCP)**

The CDC established the NCCCP in 1998 to support comprehensive cancer control by providing funding and technical advice to create, carry out and evaluate comprehensive cancer control plans, which focus on issues like prevention, detection, treatment, survivorship, and health disparities. As of 2018, the NCCCP funds all 50 states, the District of Columbia, six U.S. associated Pacific Islands and Puerto Rico, and eight tribes and Tribal organizations.

# P

## **Palliative Care**

Care is given to improve the quality of life of patients who have a serious or life-threatening disease without treating the cause of the condition. The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, supportive care, and symptom management (National Cancer Institute, 2020).

## **Prevention**

In medicine, action is taken to decrease the chance of getting a disease or condition. For example, cancer prevention includes avoiding risk factors (such as smoking, obesity, lack of exercise, and radiation exposure) and increasing protective factors (such as getting regular physical activity, staying at a healthy weight, and having a healthy diet) (National Cancer Institute, 2020).

## **Provider**

A health care provider is licensed to provide health care to patients, which could include medications, medical devices, diagnosis, treatment, and surgeries.

## **Purchased Referred Care (PRC)**

Medical/dental care provided at an Indian Health Service (IHS) or Tribal health care facility is called Direct Care. The Purchased/Referred Care (PRC) Program at IHS is for medical/dental care provided away from an IHS or Tribal health care facility. PRC is not an entitlement program and an IHS medical referral does not imply the care will be paid. If IHS is requested to pay, then a patient must meet the American Indian/Alaska Native Tribal affiliation, residency requirements, notification requirements, medical priority, and use of alternate resources (including the IHS facility). (IHS, 2020)

## **R**

### **Relatives**

Kinship is made up of blood-related and non-blood-related extended family, Tribal community.

## **S**

### **Screening**

Checking for disease when there are no symptoms. Since screening may find diseases at an early stage, there may be a better chance of curing the disease. Examples of cancer screening tests are the mammogram (for breast cancer), colonoscopy (for colorectal cancer), and the Pap test and HPV tests (for cervical cancer). Screening can also include doing a genetic test to check for a person's risk of developing an inherited disease (National Cancer Institute, 2020).

### **Sovereignty**

Sovereignty refers to the right of American Indians and Alaska Natives to govern themselves. U.S. Constitution recognizes Indian tribes as distinct governments and they have with a few exceptions the same powers as federal and state governments to regulate their internal affairs.

### **Survivorship**

In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care, late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience (National Cancer Institute, 2020).

### **Survivorship Care Plan**

A detailed plan is given to a patient after treatment ends, which contains a summary of the patient's treatment, along with recommendations for follow-up care. In cancer, the plan is based on the type of cancer and the treatment the patient received. A survivorship care plan may include schedules for physical exams and medical tests to see if cancer has come back or spread to other parts of the body (National Cancer Institute, 2020).

## T

### **Termination**

A series of laws directed to dismantling Tribal sovereignty.

### **Tobacco**

#### **Commercial Tobacco**

Tobacco is manufactured by companies for recreational and habitual use in cigarettes, e-cigarettes, smokeless tobacco, pipe tobacco, cigars, hookahs, and other products.

#### **Traditional Tobacco**

Tobacco and/or other plant mixtures grown or harvested and used by American Indians and Alaska Natives for ceremonial or medicinal purposes.

## U

### **Urban Indian Health Programs (Urban Indian Organization (UIO)s)**

The urban Indian Health Program (Urban Indian Organization (UIO)) consists of 41 non-profit 501 (c)(3) programs nationwide. The programs are funded through grants and contracts from the IHS, under Title V of the Indian Health Care Improvement Act. UIOs provide all people, especially American Indian and Alaska Native people, in their service area with a range of health and social services, from outreach and referral to full ambulatory care.

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