American Indian Cancer Foundation

Cancer Plan 2020-2022

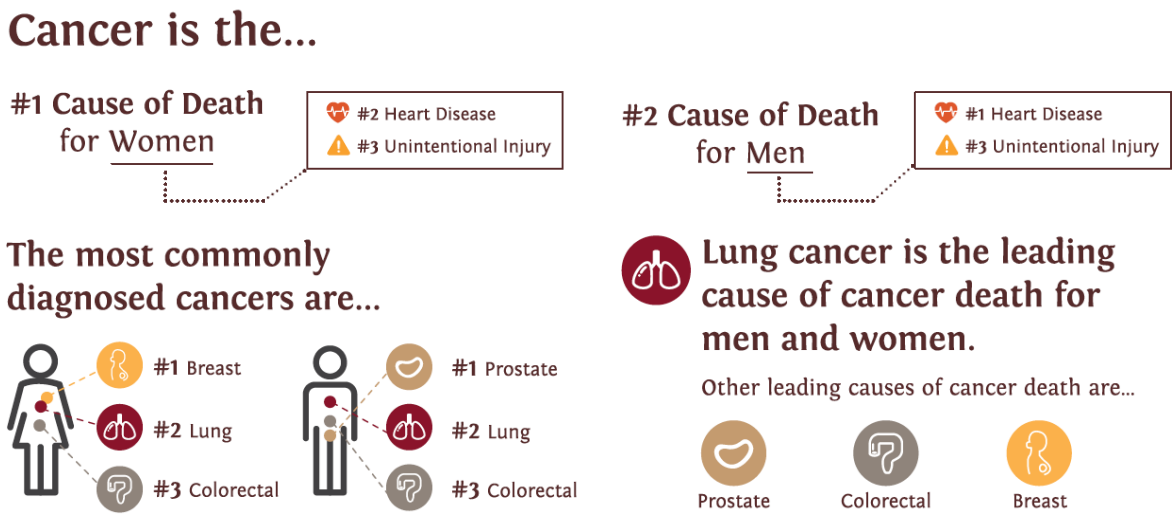
American Indian
Cancer Foundation®

BACKGROUND

American Indian Cancer Foundation

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

American Indian Cancer Burden

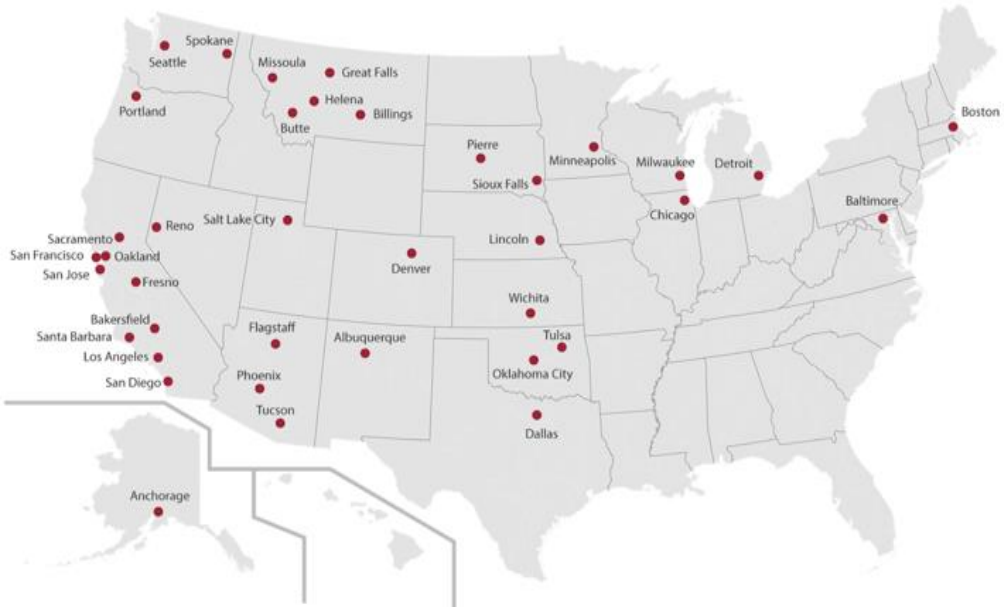


Urban American Indian and Alaska Native Cancer Coalition

The National Urban American Indian and Alaska Native Cancer Coalition seeks to reduce the burden of cancer among urban American Indian and Alaska Native (AI/AN) communities nationwide. To achieve this mission, the coalition works collaboratively with diverse stakeholders with shared interest and goals. Working together, the coalition will advance health systems change processes, identify culturally-tailored evidence-based intervention practices, and set AI/AN cancer goals.

Urban Indian Health Programming

According to the United States Census, 71% of AI/ANs live in urban areas. Reflective of this growing trend, 41 Urban Indian Health Programs (UIHPs) have been established nationwide. UIHPs provide a culturally appropriate place for urban AI/ANs to receive health and social services and engage in cultural activities. Clinics within UIHPs vary by the number of direct primary care offers they offer. Comprehensive clinics provide 40 hours of direct primary care services per week, limited clinics provide less than 40 hours per week, and outreach and referral sites do not provide any on site direct care services. Instead, outreach and referral sites refer patients to external health care providers. (Urban Indian Health Institute, 2016). As cancer is the number one cause of death among AI/AN women and the second leading cause of death among AI/AN men, these 41 UIHPs have a greater potential to more effectively



reach AI/AN cancer survivors and address their cancer-related health outcomes throughout the cancer continuum (Emerson et al., 2017).

ABOUT THIS CANCER PLAN

The cancer continuum outlines the various stages in cancer care and control: primary prevention, screening and early detection, treatment, survivorship, and palliative and end-of-life care. The cancer plan is broken up into six sections that address the cancer continuum and the cross-cutting issue of health equity. Each section provides an overarching goal, objective, and list of potential strategies across the cancer continuum. The baseline and target measures have been provided where applicable. This cancer plan was established in 2020 with goals continuing into 2022 to help address health equity in Indian Country. We plan to revise these goals in 2023.

The purpose of the cancer plan is to:

- Highlight and raise awareness about the important cancer issues, challenges, and barriers faced by urban AI/AN communities
- Set goals and objectives for improvement across the cancer continuum
- Propose potential strategies to achieve goals and objectives
- Draw together a diverse group of stakeholders

Long Term Goals

- Reduce the incidence and mortality rates for all cancers in urban AI/AN communities
- Increase appropriate cancer screening through recommended screenable cancer guidelines in urban AI/AN communities
- Reduce the rate of late-stage diagnosis in urban AI/AN communities
- Increase understanding and practice of cultural humility in UIHP staff

- Increase data surveillance efforts to be complete and accurate to urban AI/AN communities
- Improve the quality of life for urban AI/AN cancer survivors and their caregivers

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 are three areas that have been identified as areas of improvement needed to address data surveillance and reporting. First, much of the baseline data needed for such calculations is either not specific to the AI/AN population due to small sampling sizes, causing a form of erasure in national, regional, and state level data thus not allowing to capture year to year changes in important benchmarks. Secondly, data that is specific to the urban AI/AN population is simply nonexistent. And finally, calculating rates becomes even more complicated when factoring only multiple racial and ethnic statises in conjunction with AI/AN. This is important to note because AI/AN people have the largest proportion of any racial group that identify as multi-racial, and excluding those who identify as multi-racial is another form of erasure.

ACKNOWLEDGEMENT

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This cancer plan was created with support from staff from the American Indian Cancer Foundation, Urban Indian Health Institute, and National Council on Urban Indian Health. Findings from the 2018 SUNRISE Convening with 26 Urban Indian Health Programs was utilized in the development of objectives and strategies. We acknowledge support from the National Urban AI/AN Cancer Coalition and the Advisory Board for their willingness to participate and dedicate their time to address the cancer burdens urban AI/AN community members face.

DEDICATION

Chi Miigwech, Pilamaya, Ketabi, Ahéhee', Niá:wen, Marsee, Yakoke, Kaqinaliyuw, Noshúun lóoviq, S-ap'e, Quyana

Thank you to all our past, present, and future ancestors for your energy. It is through your collective traditions, values, ancestors, and spirits that have brought us to the creation of this Cancer Plan.

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 is what

fuels our passions and inspires all to work diligently to address the burdens of cancer each have faced.

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

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HEALTH EQUITY

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 AI/ANs in health. AI/AN 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 outcomes associated. These conditions are known as social determinants of health.

Our AI/AN ancestors were some of the healthiest people, after colonization those health outcomes changed drastically. The determinants of Indigneous health (DOIH) recognize the experience of colonization and historical and ongoing trauma that AI/AN people face can lead to adverse health outcomes. These disparities are affected by historical and ongoing trauma and systemic practices that deeply affect individual, family, and community health and wellbeing. 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 assimiliation. Adverse health outcomes include high rates of cancer, cardiovascular disease, depression and other mental health problems, early mortality rates, and high rates of infant and maternal mortality.

Another contributing factor to current AI/AN health disparities is the lack of data and tribal data sovereignty. This lack in available data is due to research and surveillance entities that withhold publishing data, due to small population sizes. In order to reduce cancer burdens for AI/ANs, health equity must be prioritized through practices and interventions that are informed and represented by urban AI/AN communities.

Potential Barriers/Challenges

- Misclassification of AI/AN populations in data collection (e.g. birth certificates, death certificates)
- Lack of funding
- Fear of doctors and health systems caused by historical and/or sexual trauma
- Lack of native health care staff
    - Shortage of cancer care expertise
    - Burnout of health care staff
    - Cultural sensitivity & competency

Health Equity Goal: Decrease cancer disparities for urban AI/AN community members through policy, systems, and environmental changes.

Determinants of Indigenous Health	
Objectives	**Strategies**

1. Increase knowledge of Determinants of Indigenous Health (DOIH), trauma-informed care, healing-centered approaches, and Adverse Childhood Experiences (ACEs) by 2022. *Target Audience: Urban AI/AN community and UIHPs*	1A. Develop and disseminate culturally-tailored resources on DOIH, trauma-informed care, healing-centered approaches, and ACEs
	1B. Promote discussions on cultural humility
	1C. Highlight inequities that challenge the wellbeing of the individual, family, and community through messages
	1D. Provide training and technical assistance on DOIH, trauma-informed care, ACEs, and healing-centered care approaches
	1E. Increase the number of UIHPs that use ACEs as it relates to patients health assessment and overall health and wellbeing

Health Equity Advocacy	
Objectives	**Strategies**
2. Increase representation of AI/AN and DOIH in all systems by 2022. *Target Audience: Urban AI/AN community*	2A.Ensure that reducing and eliminating DOIH is a priority at local, state, regional, and national levels
	2B. Recruit UIHP clinic leadership to provide knowledge and insight as they relate to this cancer plan
	2C. Increase AI/AN representation on local, state, and other nationally-based coalitions that address cancer
	2D. Expand and increase AI/AN representation for the National Urban AI/AN Cancer Coalition
	2E. Initiate discussions and form work groups to develop community-informed interventions, systems level changes and support to address DOIH

Culturally Competent Care & Workforce	
Objectives	**Strategies**
3. Increase implementation of culturally tailored patient navigation at all levels of the cancer continuum in UIHPs by 2022 *Target Audience: UIHPs*	3A. Develop and implement technical assistance, training and resources on culturally tailored patient navigation models
	3B. Identify and implement strategies to reduce the barriers to access (e.g. transportation, telehealth, telemedicine)

Data Surveillance	
Objectives	**Strategies**
4. Make available for the first time national cancer incidence data that has been corrected for racial misclassification and is specific to urban AI/AN by 2022. *Target Audience: UIHPs*	4A. Improve the accessibility of cancer surveillance data
	4B. Improve cancer data surveillance to better study cancer burden trends
	4C. Increase reporting to cancer registries to reduce racial misclassification
5. Increase the number of UIHP's that exchange cancer related information cancer treatment centers from 0 to 3 by 2022. *Target Audience: UIHPs and Cancer Centers*	5A. Provide training and education on how to utilize statewide cancer registry data
	5B. Build capacity through education and training on the importance of tribal specific data sets
	5C. Establish relationships and memorandums of understanding with state cancer registries, tribal epidemiology centers, and state departments of health

PRIMARY PREVENTION

The ancestral lifeways of urban 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 which includes traditional medicines, a natural diet, a connection to nature, community, traditions, physical activity, and rest. Systemic efforts to primary cancer prevention reduces or eliminates the risk of cancer. In 2020, more than 1.8 million people will be diagnosed with cancer in the United States. By preventing cancer, the number of new cases of cancer is lowered. Following our ancestral lifeways and improving cultural based disease prevention will reduce the burden of cancer and lower the number of deaths caused by cancer (National Cancer Institute).

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 competent
    - Staff capacity to provide education
    - Public health funding
    - Lack of culturally tailored educational materials and tools
- Accessibility to commercial tobacco products (e.g. cigarettes, e-cigarettes, chewing tobacco)
    - 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 systems are not able to effectively transfer client health records to ensure timely prevention
- Increased exposure to environmental carcinogens (e.g. UV rays, radon)

Primary Prevention Goal: Promote healthy lifeways among urban AI/ANs to reduce risk of cancer.

Commercial Tobacco	
Objectives	**Strategies**

6. Decrease commercial tobacco use among adult smokers ages 18 and older from 24.1% to 22.0% by 2022. *Target Audience: UIHPs*	6A. Promote and revise commercial tobacco screening policies
	6B. Provide training to increase the number of individuals receiving referrals for cessation counseling
	6C. Increase the use of culturally tailored cessation tools to increase quit attempts
	6D. Increase the knowledge and accessibility of culturally tailored smoking quitlines and state quitlines
7. Decrease the number of youth ages 18 and younger who initiate first-time commercial tobacco use from 3.4% to 3.0% by 2022. *Target Audience: Urban AI/AN community*	7A. Reduce exposure to commercial tobacco marketing, especially in areas with large urban AI/AN populations
	7B. Change social norms around commercial tobacco use and exposure for youth and young adults
8. Reduce the proportion of non-smokers exposed to secondhand smoke in the workplace from 37.6% to 33.8%* by 2022. *Target Audience: Urban AI/AN community* **General Population Data*	8A. Increase education efforts on the harmful effects of secondhand smoke
	8B. Create awareness campaigns and resources with messages regarding the dangers of secondhand smoke
9. Increase the proportion of persons covered by indoor commercial tobacco free policies from 83.4% to 90.0% by 2022. *Target Audience: Urban AI/AN community*	9A. Provide guidance for policy development for the implementation of commercial tobacco free spaces
10. Increase the number of UIHPs who provide education, access to, and availability of traditional tobacco from 1 to 3 by 2022. *Target Audience: Urban AI/AN community and UIHPs*	10A. Provide training on the growth and harvesting of traditional tobacco
	10B. Increase the knowledge and accessibility of traditional tobacco resources
	10C. Advocate for the cultivation of traditional tobacco gardens

Physical Activity & Nutrition

Objectives	Strategies
11. Increase the number of health promotion activities in UIHPs from 5 to 10 by 2022. *Target Audience: Urban AI/AN community and UIHPs*	11A. Increase the consumption of fruits, vegetables, and whole grains
	11B. Reduce the consumption of calories from solid fats, added sugars, saturated fats, and sodium through policy development and community advocacy
	11C. Increase the proportion of patients who see a provider for annual wellness checks
12. Increase the number of UIHP policies related to accessibility of healthy foods within the workplace and community events from 0 to 1 by 2022. *Target Audience: Urban AI/AN community and UIHPs*	12A. Increase the number of UIHP policies that support healthy food options at community events
	12B. Increase the percentage of UIHPs that offer nutrition programming and education on healthy indigenous foods
	12C. Improve accessibility of healthy indigenous and traditional foods
13. Increase the promotion of physical activity by 2022. *Target Audience: Urban AI/AN community*	13A. Develop and disseminate resources on physical activity for cancer prevention
	13B. Increase opportunities for school and workplace wellness through policy development and community advocacy

Immunizations	
Objectives	**Strategies**
14. Increase vaccination rates for human papillomavirus (HPV) vaccine based on age appropriate screening guidelines for females from 51.2% to 55.0% and for males from 47.6% to 55.0% by 2022. *Target Audience: Urban AI/AN community and UIHPs*	14A. Provide training on shared decision making to providers on HPV
	14B. Develop and disseminate culturally tailored HPV educational materials
	14C. Increase the number reminder systems within electronic health record systems as it relates to HPV vaccination

15. Increase hepatitis B virus (HBV) vaccination for high risk adults from 25.8% to 28.0% by 2022. *Target Audience: Urban AI/AN community and UIHPs*	15A. Develop and disseminate culturally tailored HBV infection resources as they relate to liver cancer
	15B. Educate on reducing the risk of HBV
	15C. Increase the number of reminder systems within electronic health record systems as it relates to HBV vaccination
16. Increase the proportion of individuals aware they have a hepatitis C virus (HCV) from 53% to 55% by 2022. *Target Audience: Urban AI/AN community and UIHPs*	16A. Develop and disseminate culturally tailored HCV infection resources as they relate to liver cancer
	16B. Educate on reducing the risk of HCV
	16C. Increase access to HCV screening and treatment
	16D. Increase the number of UIHPs that offer rapid HCV testing
	16E. Increase the number of medication assisted treatment programs based on principles of harm reduction

Oral Health	
Objectives	**Strategies**
17. Increase the proportion of UIHP patients who receive annual oral health services from 28.3% to 30.1% by 2022. *Target Audience: UIHPs* Data Source: Indian Health Services 2019 National Dashboard	17A. Increase the proportion of children, adolescents, and adults who have been seen for oral health preventive services
	17B. Increase the proportion of urban AI/AN health programs that address oral health and prevention of oral cancers
	17C. Develop and disseminate culturally tailored resources as they relate to oral health and cancer

Environmental Exposures	
Objectives	**Strategies**
18. Increase awareness of sun safety measures for skin cancer from 67.0% to 70.0% by 2022. *Target Audience: Urban AI/AN community*	18A. Develop and disseminate culturally tailored resources as it relates to sun safety
	18B. Promote the use of sun protection at community events and cultural activities that have high exposure to sun
19. Increase the proportion of homes with an operating radon mitigation system from 10.2% to 12.0% by 2022. *Target Audience: Urban AI/AN community*	19A. Develop and disseminate culturally tailored resources on radon exposure
	19B. Advocate for radon testing in urban AI/AN homes

Note: This is not a complete list of cancer prevention strategies. These priority areas in primary prevention as they relate to this cancer plan were identified by the Urban American Indian Cancer Coalition Advisory Committee based on current work capacity of coalition members.

SCREENING & EARLY DETECTION

Traditional lifeways encompass every aspect of health and wellbeing. In our traditional ways, the body is sacred and we are meant to honor that by maintaining and being proactive with our health. In addition to traditional practice, western medicine has made it possible to honor our bodies through the creation of medical screenings that are able to detect cancer before it has a chance to grow and spread throughout the body. AI/AN community members are typically diagnosed at later stages of disease compared to other races and ethnicities. Screening for cancer increases the success rate of treatment. Empowering communities to prioritize screening and early detection is an opportunity to address the impact on future generations.

Lower screening rates among AI/AN populations can be attributed to a variety of factors, including, though not limited to, access to care and structural barriers. Many AI/AN people receive primary care through UIHPs alone, making opportunities for a full spectrum of care oftentimes unavailable. Many 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 follow up care. While the IHS' Purchased and Referred Care is aimed at alleviating access to care, the completion of needed screening can be impacted by complications in the delivery service area, priority, and financial barriers.

Potential Barriers/Challenges

- Lack of transportation
- 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)

Screening and Early Detection Goal: Increase screening rates within UIHP to detect cancers at earlier stages

Breast Cancer Screening	
Objectives	**Strategies**
20. Increase age appropriate breast cancer screening among urban AI/AN community members from 42% to 45% by 2022.	20A. Increase access to screening and diagnostic services by utilizing the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) for eligible patients

Target Audience: Urban AI/AN community and UIHPs Data Source: Indian Health Services 2019 National Dashboard	20B. Develop an online tool (Gail Model) to assess five year and lifetime risk of breast cancer
	20C. Increase the proportion of UIHP patients receiving health counseling by their providers regarding mammography
	20D. Reduce structural barriers (e.g. service delivery setting, clinic hours, financial burden, transportation) to breast cancer screening
21. Reduce late stage breast cancer diagnosis by 2022. *Target Audience: Urban AI/AN community and UIHPs* Data does not exist yet	21A. Increase risk-appropriate screening through the implementation and/or improvement of patient and provider reminder systems
	21B. Participate and promote Indigenous Pink campaign during October
	21C. Increase awareness on the importance of breast cancer screening through the development and dissemination of culturally tailored resources

Cervical Cancer Screening	
Objectives	**Strategies**
22. Increase cervical cancer screening rates among urban AI/AN community members of average risk from 36.0% to 39% by 2022. *Target Audience: Urban AI/AN community and UIHPs* Data Source: Data Source: Indian Health Services 2019 National Dashboard	22A. Increase access to screening and diagnostic services by utilizing the NBCCEDP for eligible patients
	22B. Increase the number of patients who report receiving health counseling by their providers regarding pap tests
	22C. Reduce structural barriers (e.g. service delivery setting, clinic hours, financial burden, transportation) to cervical cancer screening

23. Reduce late stage cervical cancer diagnosis by 2022. *Target Audience: Urban AI/AN community and UIHPs* Data does not exist yet	23A. Increase risk-appropriate screening through the implementation and/or improvement of patient and provider reminder systems
	23B. Participate and promote Turquoise Tuesday campaign during January
	23C. Increase awareness about the importance of cervical cancer screening through the development and dissemination of culturally tailored cervical cancer resources

Colorectal Cancer Screening	
Objectives	**Strategies**
24. Increase colorectal cancer screening rates among urban AI/AN community members of average risk from 31.9% to 33% by 2022. *Target Audience: UIHPs* Data Source: Data Source: Indian Health Services 2019 National Dashboard	24A. Increase the number of patients receiving health counseling by providers regarding colorectal cancer screening (e.g. family health history, risk assessment)
	24B. Increase the number of patients receive a stool based test with proper instruction on providing a sample and return instructions
	24C. Increase the number of referrals for colonoscopies for individuals who have completed a stool based test (positive result)
	24D. Reduce structural barriers (e.g. service delivery setting, clinic hours, financial burden, transportation) to colorectal cancer screening
25. Reduce late stage colorectal cancer diagnosis by 2022. *Target Audience: UIHPs* Data does not exist yet	25A. Increase risk-appropriate screening through the implementation of patient and provider reminder systems
	25B. Participate and promote Blue Beads Day campaigns during March

	25C. Conduct targeted outreach for colorectal cancer screening and awareness through a variety of modalities (e.g. social media, community events, provider training)

Lung Cancer Screening	
Objectives	**Strategies**
26.Increase lung cancer screening rates among urban AI/AN community members by 2022. *Target Audience: Urban AI/AN community and UIHPs* Data does not exist yet	26A. Increase the number of patients who report receiving health counseling by providers about lung cancer screening (e.g. family health history, risk assessment)
	26B. Reduce structural barriers (e.g. service delivery setting, clinic hours, financial burden, transportation) to lung cancer screening
	26C. Increase the number of referrals for low-dose CT/MRI screening for individuals
27. Reduce late stage lung cancer diagnosis by 2022. *Target Audience:UIHPs* Data does not exist yet	27A. Increase risk-appropriate screening through the implementation of patient and provider reminder systems
	27B. Increase awareness on lung cancer screening through the development and dissemination of culturally tailored lung cancer screening resources
	27C. Participate in Sacred Breath Day campaign during November
	27D. Conduct focus groups on the barriers, attitudes, and beliefs to lung cancer screening
	27E. Reduce structural barriers (e.g. service delivery setting, clinic hours, financial burden, transportation) to lung cancer screening

Note: Cancers that have limited to no proven screening benefit have been omitted from this plan (e.g., PSA, skin, etc.) For additional information regarding screenable cancers and your own personal risk please speak to a provider for assessment of risk and determination of what screenings are appropriate and/or right for you based on your risk.

TREATMENT

When facing a cancer diagnosis, patients and caregivers will need to understand all of the options available to them for treatment and confidently assess what the right choice is for them. In addition to determining a treatment plan, the patient and their family must consider financial, legal, physical, emotional, mental, and spiritual aspects of how cancer can and will impact their life. Not only does treatment affect the patient, it can also affect a patient's family, friends, and community as a whole. Throughout the treatment process, cancer care teams play a major role in assisting the patients through diagnosis, referral, and treatment.

By empowering our relatives with resources and quality care, we believe that treatment will become more attainable, less stigma associated with screenings and treatment, and setting the bar for standard practice.

Potential Barriers/Challenges

- Community support through medical processes
- Need for education on cancer and cancer treatment with attention to both cultural and health literacy
- Late stage diagnosis
- Time lag in getting patients referred into and starting treatment
- Cost of treatment → IHS Purchased Referred Care funding to UIHP is severely underfunded
- Location and proximity to treatment centers
- Limited financial resources
- Patient navigation and interdepartmental coordination

Treatment Goal: Ensure urban AI/AN cancer patients are receiving the highest quality of care in a timely manner.

Accessible Treatment	
Objectives	**Strategies**
28. Increase access to timely treatment for urban AI/AN individuals diagnosed with cancer by 2022. *Target Audience: UIHPs*	28A. Increase education on the importance of having and maintaining a provider, healthcare coverage, and advocating for your health throughout treatment
	28B. Provide technical assistance and increase the number of referral systems that assist in enrolling patients into eligible

	insurance plans to cover treatment (e.g. Medicaid Treatment Act)
	28C. Implement plans to reduce structural barriers, including the utilization of telemedicine and patient navigation systems
	28D. Provide training and quality improvement efforts that are rooted in shared-decision making models for treatment and non-treatment services
29. Increase access to cancer rehabilitation and wellness services by 2022. *Target Audience: UIHPs*	29. Provide training and technical assistance on motivational interviewing related to pain management and treatment adherence

Culturally Tailored Treatment & Traditional Healing	
Objectives	**Strategies**
30. Increase the number of culturally tailored treatment and traditional healing resources available from 2 to 5 by 2022. *Target Audience: UIHPs and Cancer Centers*	30A. Increase the number of cancer centers providing education that incorporates cultural considerations for the integration of western medicine and traditional practices during treatment
	30B. Champion the inclusion of family during the treatment decision process
31. Increase collaboration and communication between providers and traditional healers throughout treatment *Target Audience: Urban AI/AN community and UIHPs*	31A. Advocate for coordinated care teams throughout the treatment process
	31B. Support the inclusion of cultural leaders and traditional healers in a patient's cancer treatment process

Clinical Trials	
Objectives	**Strategies**

32. Increase participation in cancer treatment clinical trials by 2022. *Target Audience: Urban AI/AN community and UIHPs*	32A. Develop and disseminate culturally-relevant, patient-friendly information on clinical trials
	32B. Identify and address barriers to clinical trials for AI/AN people
	32C. Increase awareness about the importance of diversity in clinical research to ensure that the discoveries, treatments, interventions, and prevention strategies are relevant
	32D. Network and develop relationships with organizations and clinicians that are part of the National Cancer Institute's Clinical Trials Network: Alliance for Clinical Trials in Oncology; ECOG-ACRIN Cancer Research Group; NRG Oncology; SWOG; and Children's Oncology Group

Genetic Testing & Counseling	
Objectives	**Strategies**
33. Increase knowledge and application of genetic testing and counseling by 2022. *Target Audience: UIHPs*	33A. Collaborate with entities to provide genetic counseling, including genetic risk assessment software companies
	33B. Increase provider knowledge on genetic testing and counseling, including Food and Drug Administrative guidelines
	33C. Provide technical assistance and training on the implementation of family health history tools in electronics health records software
	33D. Promote screening and the use of genetic tests to assess inherited cancer risks among relatives of the diagnosed

Complementary & Alternative Medicine	
Objectives	**Strategies**
34. Support complementary and alternative healing practices alongside medical treatment by 2022. *Target Audience: UIHPs and Cancer Centers*	34A. Engage cancer treatment centers on the use of complementary and alternative healing practice during the treatment process

SURVIVORSHIP

Despite advancements in cancer screenings, early diagnosis, and treatment, AI/ANs experience worse five-year cancer survival rates than any other subpopulation in the United States and have a 51% higher risk of dying from cancer compared to Non-Hispanic Whites (Jemal et al., 2017; Siegel, Miller and Jemal, 2020; White et al., 2014). Dedicated efforts to increase cancer surveillance and promote long-term follow up care and quality of life among AI/AN cancer survivors is critical to addressing these disparities. Cancer survivorship begins at diagnosis and endures throughout the lifespan of the individual (Hewitt et al., 2005). Family members, friends, caregivers and those who have been impacted by a cancer diagnosis are also considered survivors (Twombly, 2004).

Potential Barriers/Challenges

- Identifying survivors
    - Racial misclassification in electronic health records and death certificates
    - Lack of AI/AN specific cancer registry
    - Consistency in coding cancer among providers
- Fractured health care system
- Social, mental, and spiritual support

Survivorship Goal: Increase long-term quality of life for every urban AI/AN community member affected by cancer.

Five-Year Survival Rate	
Objectives	**Strategies**
35. Increase the five-year survival rate for cancers among AI/ANs from 60.5* to 61 by 2022. *Target Audience: Urban AI/AN community and UIHPs* Data Source: SEER, NCHS	35A. Increase age-appropriate, guideline-driven support and surveillance of cancer spread, recurrence, secondary cancers, and late effects
	35B. Increase survivor education on a cancer risk reduction lifestyle (e.g. importance of regular screening, commercial tobacco cessation, physical activity, healthy eating)
	35C. Increase access to healthcare coverage regardless of a pre-existing cancer diagnosis for long term follow-up care

Childhood Cancer Survivorship

Objectives	Strategies
36. Increase the five-year survival rate for cancers among children and adolescents by 2022 *Target Audience: Urban AI/AN community and UIHPs*	36A. Increase access to pediatric comprehensive treatment centers
	36B. Increase provision of continuing education and awareness of pediatricians regarding childhood cancer survivorship and referrals to pediatric cancer centers
	36C. Ensure school support for child cancer survivors through an individualized education program and educational consultants

Quality of Life	
Objectives	**Strategies**
37. Measure the physical, psychological, social, and spiritual indicators for quality of life among cancer survivors. *Target Audience: Urban AI/AN community and UIHPs*	37A. Assess and intervene for the medical and psychosocial late effects of cancer (e.g., employment, insurance, and disability concerns)
	37B. Increase the number of culturally appropriate resources that promote coping, respite, and bereavement for family members and caregivers
	37C. Increase access to cancer rehabilitation and wellness services
	37D. Empower and provide opportunities for cancer survivors, families, and caregivers to share their experience around survivorship

Health System Integration	
Objectives	**Strategies**
38. Improve healthcare system integration and coordination between oncology specialists and providers by 2022.	38A. Increase the number of AI/AN survivors reporting receipt of a survivorship care plan and a treatment summary

Target Audience: UIHPs	38B. Increase the number of guideline-driven trainings and technical assistance on AI/AN survivor support
	38C. Increase the number of integrated health systems and multidisciplinary teams developed to support AI/AN survivors

PALLIATIVE & END-OF-LIFE CARE

Palliative care manages and provides relief from the complications of cancer and cancer treatment, such as pain and psychosocial effects, and is represented by the medicine wheel (sacred hoop) in many Indigenous cultures. Though palliative care is a major component of end-of-life care, it is distinct from end-of-life care in that it may be offered concurrently with curative treatment. End-of-life care, also known as hospice, is exclusive to the terminal phase of cancer and is offered when the survivor's health is progressively declining and curative treatment is no longer useful (World Health Organization). It includes bereavement services which, in many Indigenous cultures, include rituals and ceremony.

Palliative care and hospice services improve quality-of-life and enhance the ability to cope effectively (Marr et al., 2012; Temel et al., 2010; World Health Organization). Moreover, early palliative care has been documented to prolong survival for a subset of patients with advanced cancer (Marr et al., 2012; Temel et al., 2010). Since urban AI/AN cancer survivors disproportionately present with late stages of cancer at the time of diagnosis, they may particularly benefit from more targeted and tailored efforts that promote their access to palliative and end-of-life care services (Guadagnolo et al., 2017).

Potential Barriers/Challenges

- Lack of access to assistance with in-home care
- Fear
- Geographic location of treatment facilities
- Cultural practices are not always understood or accepted by providers
- Lack of knowledge on advanced care planning, will planning, etc.

Palliative and End-of-Life Care Goal: Ensure access to patient and family-centered palliative and end-of-life care.

Patient-Centered Palliative & End of Life Care	
Objectives	**Strategies**
39. Increase the number of survivors reporting relief from cancer symptoms and side effects by 2022. *Target Audience: UIHPs*	39A. Develop and disseminate culturally appropriate non-curative treatment resources (e.g. Advance Care Planning)
	39B. Facilitate discussions on the use of pharmaceutical drugs, chemical dependence and its effect on comfort care
	39C. Increase the early development and use of advanced directives

	39D. Reduce structural barriers (e.g., insurance coverage, transportation, language) to comfort and end-of-life care

Family-Centered Palliative & End of Life Care	
Objectives	**Strategies**
40. Increase the number of patients who are offered culturally tailored palliative and end-of-life care from 0 to 2 by 2022. *Target Audience: Urban AI/AN community and UIHPs*	40A. Engage elders and the urban AI/AN community
	40B. Collaborate with spiritual advisors in evaluating and treating spiritual pain for utilizing hospice services
	40C. Raise community awareness about hospice care and relationship-building with providers

Culturally-Centered Palliative & End of Life Care	
Objectives	**Strategies**
41. Broaden clinical teams understanding of cultural considerations as they relate to palliative and end-of-life care by 2022. *Target Audience: Urban AI/AN community and UIHPs*	41A. Integrate ongoing cultural humility training into clinic professional development plans
	41B. Encourage clinics to designate a point of contact for palliative care
	41C. Provide technical assistance for healthcare systems on culturally-tailored hospice and end-of-life care
	41D. Promote clinic policies to support culturally-tailored end-of-life care

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 urban 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 Urban AI/AN Cancer Coalition to reach the long term goal of reducing the morbidity and mortality of cancer among urban AI/ANs and there are many directions that we can take. AICAF recognizes the need for resources on the following:

- Young survivors
- Youth involvement
- 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)

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 urban community members, leaders, health care providers, and others working toward effective and sustainable cancer solutions.

Join us in creating unique and culturally tailored solutions for our relatives to ensure quality care. Contact us at health@aicaf.org.

APPENDIX

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 Plan 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 from cancer etiology, prevention, early detection, diagnosis, treatment, survivorship, and end of life (National Cancer Institute, 2019).

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.

Commercial Tobacco

Commercial Tobacco, shall mean any product containing, made, or derived from tobacco that is intended for human consumption, whether chewed, smoked, absorbed, dissolved, inhaled, snorted, sniffed, or ingested by any other means, or any component, part, or accessory of a tobacco product, including, but not limited to, cigars; cheroots; stogies; periques; granulated, plug cut, crimp cut, ready rubbed, and other smoking tobacco; snuff; snuff flour; cavendish; plug and twist tobacco; fine-cut and other chewing tobacco; shorts; refuse scraps, clippings, cuttings and sweepings of tobacco, and other kinds and forms of tobacco; but does not include cigarettes as defined in this section. Tobacco products excludes any tobacco product that has been approved by the United States Food and Drug Administration for sale as a tobacco cessation product, as a tobacco dependence product, or for other medical purposes, and is being marketed and sold solely for such an approved purpose.

D

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 Indigneous health (DOIH) recognizes 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, conditions, or injury from its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imagining 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 Cigarettes

Electronic Cigarettes, shall mean any electronic oral device, such as one composed of a heating element, battery, and/or electronic circuit, which provides vapor of nicotine or any other substances, and the use or inhalation of which simulates smoking. The term shall include any such device, whether manufactured, distributed, marketed, or sold as an e-cigarette, e-cigar, e-pipe, or under and other product name or descriptor.

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).

G

Gail Model

The Gail Model is a statistical breast cancer risk assessment algorithm that was developed in 1989 by Dr. Mitchell Gail and colleagues with the Biostatistics Branch of the National Cancer Institute's Division of Cancer Epidemiology and Genetics. The Gail Model has provided to be a reasonable tool for estimating breast cancer risk in white women, and other researchers have subsequently supplemented the model to provide accurate risk assessments for African-American, Hispanic, and Asian women.

H

Hepatitis B Virus
A virus that causes hepatitis (inflammation of the liver). It is carried and passed to others through the blood and other body fluids. Different ways the virus is spread include sharing needles with an infected person and being stuck accidentally by a needle contaminated with the virus. Infants born to infected mothers may also become infected with the virus. Although many patients who are infected with the hepatitis B virus may not have symptoms, long-term infection may lead to cirrhosis (scarring of the liver) and liver cancer. Also called HBV (National Cancer Institute, 2020).

Hepatitis C Virus
A virus that causes hepatitis (inflammation of the liver). It is carried and passed to others through the blood and other body fluids. Different ways the virus is spread include sharing needles with an infected person and being stuck accidentally by a needle contaminated with the virus. Infants born to infected mothers may also become infected with the virus. Although many patients who are infected with the hepatitis C virus may not have symptoms, long-term infection may lead to cirrhosis (scarring of the liver) and liver cancer. These patients may also have an increased risk for certain types of non-Hodgkin lymphoma. Also called HCV (National Cancer Institute, 2020).

Human Papillomavirus (HPV)
HPV is a group of more than 150 related viruses. Each HPV virus in the group is given a number which is called its HPV type. HPV is transmitted through intimate skin-to-skin contact commonly spread through vaginal, anal, or oral sex with someone who has the virus. HPV infection can also cause cancer of the cervix, vulva, vagina, penis, anus, or oropharynx.

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.

National Council of Urban Indian Health (NCUIH)
NCUIH is a national 501(c)(3) organization devoted to the support and development of quality, accessible, and culturally-competent health services for American Indians and Alaska Natives living in urban settings.

P

Palliative Care

Care given to improve the quality of life of patients who have a serious or life-threatening disease. 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).

Papanicolaou (Pap) Test

A procedure in which a small brush or spatula is used to gently remove cells from the cervix so they can be checked under a microscope for cervical cancer or cell changes that may lead to cervical cancer. A Pap test may also help find other conditions, such as infections or inflammation. It is sometimes done at the same time as a pelvic exam and may also be done at the same time as a test for certain types of HPV.

Prevention

In medicine, action 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).

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 IHS facility).(IHS, 2020)

R

Radon

A radioactive gas that is released by uranium, a substance found in soil and rock. Breathing in too much radon can damage lung cells and may lead to lung cancer.

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 for developing an inherited disease (National Cancer Institute, 2020).

Secondhand Smoke

The smoke that comes from the burning of a tobacco product and smoke that is exhaled by smokers. Inhaling secondhand smoke is called involuntary or passive smoking. Also called environmental tobacco smoke and ETS (National Cancer Institute, 2020).

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 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 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

Trauma-Informed Care

Trauma-specific interventions are designed to address the consequences of trauma in the individual and to facilitate healing. Treatment programs generally recognize the following: the survivor's need to be respected, informed, connected, and hopeful regarding their own recovery; the interrelation between trauma and symptoms of trauma; the need to work in a collaborative way with survivors, family and friends of the survivor, and other human services agencies in a manner that will empower survivors and consumers (Source, 2020).

Treatment Plan

A detailed plan with information about a patient's disease, the goal of treatment, the treatment options for the disease and possible side effects, and the expected length of treatment. A treatment plan may also include information about how much the treatment is likely to cost and about regular follow-up care after treatment ends (National Cancer Institute, 2020).

Treatment Summary

A detailed summary of a patient's disease, the type of treatment the patient received, and any side effects or other problems caused by treatments. It usually includes results of laboratory tests and imaging tests, and whether a patient took part in a clinical trial. A treatment summary may be used to help plan follow-up care after treatment for a disease, such as cancer (National Cancer Institute, 2020).

U

United States Preventive Services Task Force (USPSTF)

The United States Preventive Services Task Force is an independent, volunteer panel of national experts in disease prevention and evidence-based medicine. USPSTF works to improve the health of all Americans by making evidence-based recommendations about clinical preventive services.

Urban Cancer Solutions (UCS)

Urban Cancer Solutions is an initiative of the American Indian Cancer Foundation funded by the Center for Disease Control and Prevention (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the National Comprehensive Cancer Control Program (NCCCP).

Urban Indian Health Institute (UIHI)

UIHI is leading the way in research and data for urban American Indian and Alaska Native communities. As a public health authority and one of 12 Tribal Epidemiology Centers in the country - and the only one that serves Urban Indian Health Programs nationwide - UIHI conducts research and evaluation, collects and analyzes data, and provides disease surveillance to strengthen the health of American Indian and Alaska Native communities.

Urban Indian Health Programs (UIHPs)

The urban Indian Health Program (UIHP) 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.