

# NACP: Partnership for Native American Cancer Prevention

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## ABSTRACT

Cancer trends over a two-decade period show a greater reduction in cancer mortality rates for non-Hispanic Whites than for Native Americans. The Partnership for Native American Cancer Prevention (NACP) was established to address cancer health disparities that impact Native Americans. The partners are Northern Arizona University, the University of Arizona Cancer Center, Arizona's tribal communities and the National Cancer Institute. The activities include outreach, research and cancer education. Overall, NACP seeks to expand capacity for culturally-sensitive and community-relevant research on cancer, and to continue developing respectful collaborations that will empower sovereign Native American communities to define, implement, and achieve their goals for cancer health equity.

**KEYWORDS:** Cancer, health disparities, American Indian, Native American, collaboration, research, education, outreach

**Citation:** Gachupin FC et al (2021) NACP: Partnership for Native American Cancer Prevention. *Cancer Health Disparities* 5:e1-e6. doi:10.9777/chd.2020.1002

Cancer trends over a two-decade period show a greater reduction in cancer mortality rates for non-Hispanic Whites compared with Native Americans (Melkonian et al., 2019; White et al., 2014). High rates of mortality and morbidity are attributed to delays and obstacles in seeking and receiving cancer care. Limited funds allocated to Native American health care; lower socioeconomic status; and cultural, social, and geographic barriers to cancer care impede patients' ability to participate in screening, diagnosis, and treatment (Bastani et al., 2004; Warren-Mears et al., 2013). Low levels of health care literacy, mistrust in the health care delivery system, and dissatisfaction and cultural discordance with providers are further challenges specific to Native Americans (Coughlin et al., 1999; Guadagnolo et al., 2011; Kanekar and Petereit, 2009). Despite improvements in cancer screening techniques and developments in cancer treatment, tribal communities do not benefit equally from these advances. Furthermore, relatively few of the advancements in cancer research address the vulnerabilities and strengths in these communities.

The state of Arizona is well-positioned to address cancer health challenges faced by Native Americans. The state is home to 22 federally recognized sovereign tribal nations, including the largest land-based one in the United States (US) – the Navajo Nation. Arizona Cancer Registry data shows that breast cancer is the most frequently diagnosed type of cancer among Native American women and is responsible for the highest number of deaths compared to other cancers (Timothy Flood, personal communication). This is notable in that non-Hispanic White women's death rates from breast cancer have decreased with effective screening, detection, and treatment options. For Native American men in Arizona, prostate cancer

has the highest incidence and mortality rates. When comparing Native Americans in Arizona to other non-Hispanic Whites, the Native Americans suffer disproportionately from prostate, kidney, stomach, ovarian, and cervical cancers.

The low representation of Native Americans in the biomedical workforce exasperates progress towards addressing cancer disparities in this population. While there has been some progress in the numbers of Native Americans receiving baccalaureate and graduate degrees (Babco, 2015), their representation is much lower than for other minorities. The problem is particularly acute for science and engineering fields. A national survey of doctorate degrees awarded by US universities reports that of the almost 9,000 degrees conferred in the biological and biomedical sciences in 2016, only 11 (0.12%) were awarded to Native Americans (National Science Foundation 2016). The low number of doctorate degrees awarded to Native Americans results in a small number pursuing careers as independent scientists. Data from more than 9,400 National Institutes of Health K-award applications showed that only three Native Americans per year applied for this career development funding (Haak, 2011). This is more than ten times lower than expected based on the size of the Native American population in the US. The representation of Native Americans among Principal Investigators on National Institutes of Health awards drops even further compared to career development awards (Ginther et al., 2011).

Collaborative research with Native American communities to address cancer disparities poses unique challenges as compared to work with other underserved populations. A major challenge is to overcome the history of distrust that developed as

the result of broken treaties, establishment of reservations, forced boarding of schoolchildren, and other patterns of mistreatment (Brave Heart and DeBruyn, 1998). In contemporary times, academic researchers have contributed to this distrust through misguided research approaches that were disrespectful to Native American tribes (Burhansstipanov et al., 2001; Dalton, 2004; Garrison, 2013). Some tribal nations have imposed a moratorium on genetic research.

The Partnership for Native American Cancer Prevention (NACP) began in 2002 as a collaboration between two state universities and tribal communities. It developed from one Navajo leader's concern about the significant cancer burden among his people. This leader's discussions with a University of Arizona biochemistry faculty member blossomed into the initial vision for a partnership to tackle the challenge of cancer health disparities for Native Americans. The partnership brought together Arizona's only National Cancer Institute-designated comprehensive cancer center, the University of Arizona Cancer Center (UACC), with the Native American-serving university in the northern part of the state, North Arizona University (NAU).

NACP is part of the National Cancer Institute's Comprehensive Partnerships to Advance Cancer Health Equity (CPACHE) program. The CPACHE goals are: 1) to increase the participation of underrepresented minority-serving institutions in cancer research and research training, and 2) to increase the involvement and effectiveness of comprehensive cancer centers in developing effective outreach, research, and education programs that encourage diversity among competitive researchers and reduce cancer health

disparities. The CPACHE program's goals shape the vision of NACP's collaborative outreach, research, and education activities. Additionally, the concerns of Native American communities play a critical role in informing the direction of NACP. The rate of change in the cancer burden among Arizona's Native American populations will depend, in part, on NACP's success in engaging these communities and navigating centuries of mistrust, and on these communities determining if research outcomes are beneficial, non-threatening, and useful.

NACP's progress towards building successful, trusting academic/community relationships has resulted in significant outcomes. In the face of historical divides, Partnership leaders have worked to develop relationships with the sovereign nations and gain trust that NACP research would provide greater benefits than harm. Since its launch in 2002, NACP has expanded NAU's research capabilities and capacities, contributing to more than a three-fold increase in its annual National Institutes of Health-funded research. NACP has initiated or fostered the career development of eleven Native American early stage and mid-level investigators. The Partnership has recruited and attracted more than thirty-eight investigators at UACC to address Native American cancer health disparities. The Outreach Core has worked to increase community engagement skills and the competency of NACP students and investigators by providing training on culturally respectful research approaches with tribes and culturally relevant, evidence-based cancer education to tribal communities. Across both institutions, >275 Native American undergraduate and graduate students have participated in NACP's cancer research education activities, with a focused on mentored research experiences. Overall, the

Partnership has engaged fourteen of Arizona's twenty-two sovereign nations through cancer outreach, research, or education.

NACP's current research projects focus on cancers of the stomach, breast and cervix. Data from the Navajo Department of Health (2014) show age-adjusted incidence rates for stomach (gastric) cancer that are three to four times as high as the non-Hispanic White population in Arizona, making this cancer second only to colorectal cancer incidence. One NACP research project is investigating risk factors that contribute to this cancer disparity, including infection of the stomach with *Helicobacter pylori*. Relative to other ethnicities, Native American women have a 30-70% higher risk of dying from breast cancer (Maskarinec et al., 2011; Wampler et al., 2005); they are more likely to be diagnosed with late-stage disease. The incidence of triple-negative breast cancer is higher for Native American than for NHW women at 14.6% of all breast cancers versus 11.6%, respectively (Plasilova et al., 2016). A second NACP research project is investigating signaling pathways that may allow triple-negative breast cancers to avoid detection by the immune system and support aggressive metastatic expansion. The mortality rate from cervical cancer for Native American women is higher than for non-Hispanic White women (2.4 versus 1.8 per 100,000). Infection with specific types of human papilloma virus is the primary cause of cervical cancer (Bosch et al., 2002). An NACP team of researchers is investigating the role of differences in the vaginal microbiome, the microbes that naturally live in the vagina and are important to both health and disease, in persistence of HPV during chronic infection in Native American women.

In addition to the research project teams, NACP has Administrative, Planning and Evaluation, Research Education and Outreach Core teams. A new shared resource core for the current funding cycle is called, *Guiding U54 Investigators to Develop Sustainability* (GUIDeS). The focus for this resource is to provide Native American trainees and early stage investigators with assistance on publications and grant applications that will facilitate their career development and transition to research independence. All of the Partnership activities are guided by NCI Program Directors and three oversight bodies: a Community Advisory Committee, Internal Advisory Committee and Program Steering Committee.

Since the inception of NACP in 2002, a major shift in direction for the Partnership has been from basic bench research to community engaged research. This has been possible through a consistent focus on building relationships with Native American community members that increase their trust in the benefits of NACP's cancer research efforts. NACP's overall goal remains steadfast – to move the state of Arizona closer to cancer health equity for tribal communities. The Partnership's approach is to expand capacity for culturally-sensitive and community-relevant research on cancer and continue to develop respectful collaborations that will empower sovereign Native American communities to define, implement, and achieve their goals for cancer health equity.

## Acknowledgements

Cancer is a critical disease that affects hundreds of Native Americans and families. NACP acknowledges the struggles and challenges of Native American cancer survivors and caregivers and the need for timely outreach, research and education that is culturally appropriate. We also acknowledge the

efforts and contributions of the NACP researchers: Drs. Robin Harris, Priscilla Sanderson, Ken Batai, Julie Armin, Heather Williamson, Julie Baldwin, Hendrick Dirk de Heer, Anna Schwartz, Jennifer Bea, Fernando Monroy, Juanita Merchant, Gregory Caporaso, Naomi Lee, Melissa M. Herbst-Kralovetz, Narendiran Rajasekaran and William Montfort; and, NACP leaders and support: Drs. Andrew Kraft, Jason Wilder, Ron Heimark, and Ms. Maria Jackson and Debora Aguirre.

## Funding

The work reported in this publication was supported by the National Cancer Institute of the National Institutes of Health under the awards for the Partnership of Native American Cancer Prevention U54CA143924 (UACC) and U54CA143925 (NAU).

## Conflict of Interest

The authors declare that no competing or conflict of interests exists. The funders had no role in study design, writing of the manuscript, or decision to publish.

## Authors' Contributions

FCG, JCI, NIT-S and MMB jointly conceived of this article. FCG wrote the first draft. KL and ML-P double-checked the accuracy of the article's content. All authors revised and approved the final version of the article.

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