

WISCONSIN

Wisconsin Cancer Reporting System (WCRS); Mary Foote, WCRS Epidemiologist

How Wisconsin Has Addressed the High Burden of Cancer Among its American Indian* Population, 2004 - 2018

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: There are eleven federally recognized tribal governments in Wisconsin. The Wisconsin Cancer Reporting System (WCRS) has been addressing the problem of high incidence and mortality rates among American Indians for 15 years, to meet the National Program of Cancer Registries (NPCR) and Wisconsin 2020 Healthy People objectives of reducing disparities in prevention, diagnosis and treatment. Starting in 2004, WCRS made a long-term commitment to monitor trends and develop a relationship with tribal health directors. In 2018, WCRS published its most comprehensive American Indian (AI) specific data ever published, and found a reduction in incidence of three major cancers.

Successful collaboration between tribal and state level health programs is necessary to identify key tribal health issues. WCRS has been an integral partner in collaborating on cancer prevention and control efforts and research by providing timely and culturally relevant cancer data for monitoring the burden of cancer among American Indians. Projects involving WCRS have had two major foci: (1) a tribal-focused approach to provide each tribal health clinic with a profile of their cancer incidence and mortality burden, and (2) publishing AI-specific data to increase awareness of Wisconsin's high AI cancer rates for cancer control organizations, health practitioners, and researchers.

CHALLENGE: American Indians face persistent disparities in health status and health care, including barriers to obtaining cancer screening, diagnosis and treatment. Race misclassification and under reporting also hamper collecting accurate data on cancer incidence among American Indians. To rectify this, WCRS routinely links cancer case data to the Indian Health Service patient record registry. Another method WCRS employs is selecting American Indian cases residing in Contract Health Service Delivery Area (CHSDA) counties. American Indians in Wisconsin CHSDA counties experience the highest cancer incidence rate of any racial group for females and both genders combined. This population also has the highest cancer mortality rate among all racial groups for both males and females. To meet the Wisconsin Comprehensive Cancer Control Plan 2015-2020 and Healthy People 2020 goals of addressing racial disparities, the disproportionate cancer burden among American Indians needs to be addressed.

SOLUTION: WCRS' collaborative efforts involved working not only with the tribal health directors, but also with a diverse group of partners including the National Cancer Institute funded Spirit of EAGLES (Education, Advocacy, Grants, Leadership, Elders, Survivors, Scholarships), the Great Lakes Inter-Tribal Epidemiology Center, the Wisconsin Comprehensive Cancer Control Program, the Wisconsin Well Women Program, the Wisconsin Native American Tobacco Network, the Medical College of Wisconsin's Healthier Wisconsin Partnership Program and the Department of Health Services (DHS) Tribal Affairs Office. Working with these organizations allowed collaborators to form trusting partnerships, highlighting the importance of understanding tribal member perceptions and identifying available local resources for initiating cancer control activities.

*The 2017 population estimate for American Indian/Alaska Natives in Wisconsin was 54,526. American Indians comprise almost 100% of this population group in Wisconsin; 217 people in Wisconsin are identified as Alaska Native. Therefore, this report refers to American Indians exclusively, although data reported include both races.

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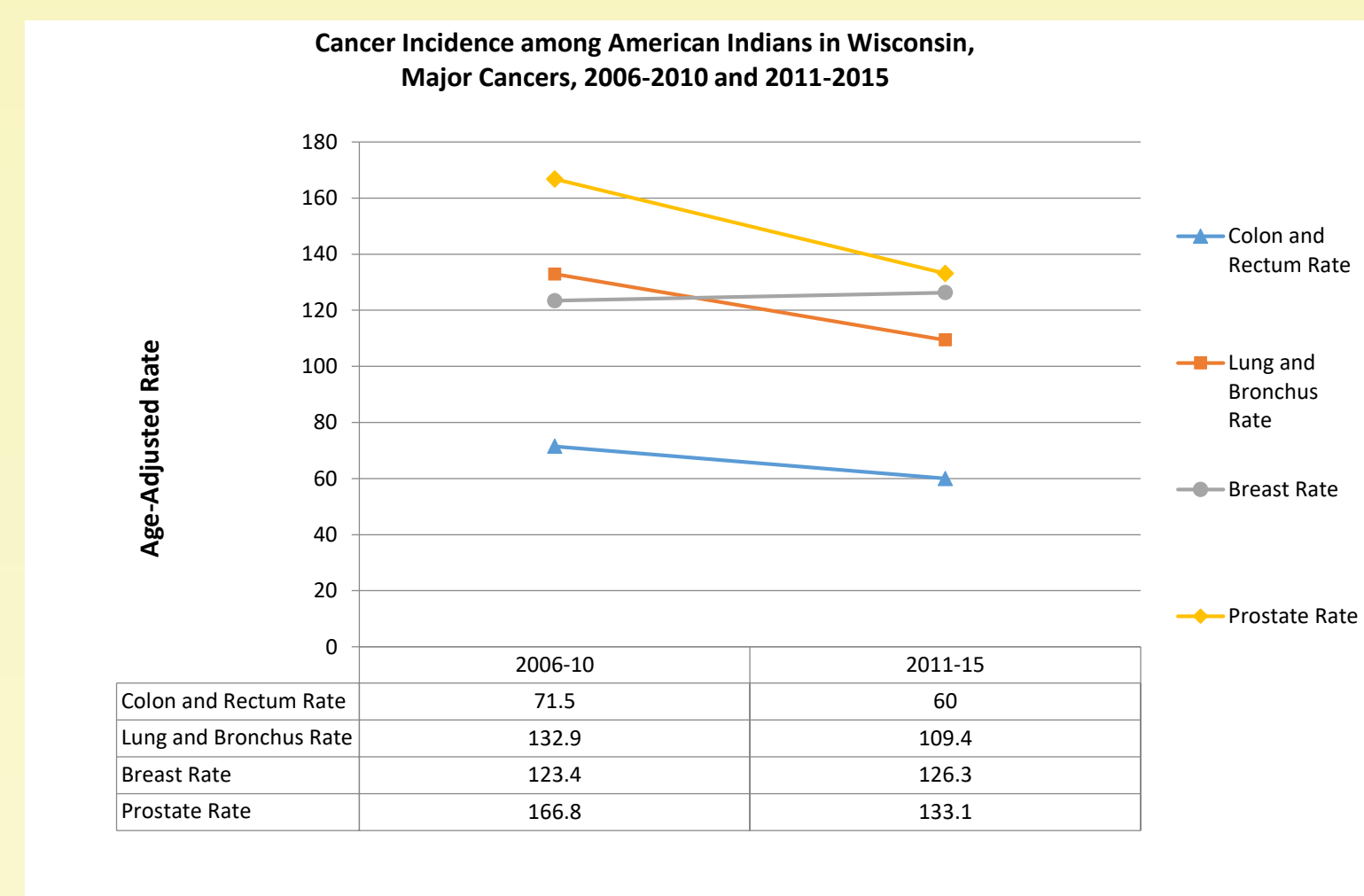
In January 2018, WCRS enhanced this trust by providing data to tribal health directors and clinic staff in all 11 tribes, for local analysis and interpretation prior to public release and submission for journal publication. This allowed tribal clinic personnel to provide unique perspectives on the data, resulting in community-specific cancer interventions developed using their insights. In addition, by sharing the data with all the clinics, the diversity between the tribes was acknowledged.

The American Indian CHSDA incidence and mortality rates provided to the tribes included a summary findings page and a series of tables providing rates by one, five, and ten year intervals, and also five and ten year rolling averages. The tribal health directors requested these tables so they could have detailed data for grant applications, mediation programs, and cancer surveillance to share with tribal members. The directors received an email from WCRS (approved by the DHS Tribal Affairs office) in advance of posting the data on the WCRS web site. The tables were also shared with the project's cancer control partners and the Tribal Affairs Office. The tables and summary are available at: <https://www.dhs.wisconsin.gov/publications/p02110-keynotes-1995-2014.pdf>

Contributing data and publications include:

- Factsheet: Leading Causes of Death by Race and Ethnicity, Wisconsin, 2011-2015 (September 2018) <https://www.dhs.wisconsin.gov/publications/p02252.pdf>
- Data for all tribes in cancer profiles – data analyzed by WCRS and distributed by University of Wisconsin Cancer Health Disparities Initiative and Carbone Cancer Center. Incidence and mortality data included age-adjusted rates, standard errors, confidence intervals, rate ratios (AI/Whites), and P values for colorectal, lung, breast and prostate cancers. (2015-2016)
- Journal publications targeting physicians in the Wisconsin Medical Journal: 1. Foote M, Strickland R, Lucas-Pipkorn S, Williamson A, Lamers L. [The High Burden of Cancer Among American Indians/Alaska Natives in Wisconsin. Wisconsin Medical Journal, February, 2016;115 \(1\): 11-16.](#) 2. Improving cancer incidence estimates for American Indians in Wisconsin. Mary Foote, Jackie Matloub, Rick Strickland, Laura Stephenson, Heather Vaughan-Batten WMI: 08/2007; 106(4):196-204.
- Wisconsin's Burden of Cancer report: Wisconsin Cancer Facts & Figures 2016 provide rates for American Indian populations. <https://www.dhs.wisconsin.gov/publications/p01573b.pdf>
- Wisconsin Interactive Statistics on Health public use query site: provides detailed incidence and mortality data for American Indians in the state. <https://wish.wisconsin.gov/cancer/incidence.htm>

RESULTS: This ongoing effort demonstrates the application of complex, multi-faceted data through collaboration with multiple partners. Success is measured not only in terms of improving the accuracy of cancer data for American Indians in Wisconsin, and expanding dissemination of cancer surveillance statistics, but also by developing ongoing, trustworthy relationships. Incidence rates for three major cancers have declined over the last 10 years (see graph) and, while the effectiveness of any one approach to reduce the burden is difficult to determine, it is an indication of progress from the collaborative impact.



Notes: Rates are per 100,000 and age-adjusted to the 2000 U.S. standard population. Rates represent those cases residing in a CHSDA county at the time of diagnosis. Data accessed September 2018.

SUSTAINING SUCCESS: WCRS data dissemination efforts have helped American Indian tribes in Wisconsin prioritize cancer control. Cancer control programs continue efforts to increase awareness within American Indian communities to promote healthy lifestyles and increase access to cancer screening and treatment. WCRS will continue to support tribal initiatives through annual AI data updates to tribal health directors, attendance at the annual Share the Care conference (an AI-specific cancer conference focusing on prevention, screening and survivorship that is sponsored by Wisconsin's tribes and the Wisconsin Well Woman Program), and assistance with data dissemination to a variety of audiences with the objective to reduce the burden of cancer among American Indians.

WCRS' 15 years of collaboration with the tribes and cancer control programs demonstrate that a long-term commitment is essential for tribal community engagement to succeed.

NPCR
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Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion