

Community Engagement Case Study

Improving American Indian Cancer Surveillance and Data Reporting in Wisconsin

Case Study Retrieved from: Principles of Community Engagement Second Addition*

“Background: Spirit of EAGLES, a Special Populations Network program funded by the National Cancer Institute to address comprehensive cancer control through partnerships with American Indian communities, and its partners submitted a letter of intent in response to an invitation by the Great Lakes Inter-Tribal Council. After the Wisconsin Tribal Health Directors’ Association had reviewed the letter, Spirit of EAGLES and its partners were invited to prepare a full proposal for submission as part of the larger Great Lakes Native American Research Center for Health grant proposal to NIH and the Indian Health Service. Following scientific review, this cancer surveillance research study was funded and conducted through a subcontract to Spirit of EAGLES.

Initially, the project staff spent significant time traveling and meeting with the director and staff of each American Indian tribal and urban health clinic in the state. Eight of the 11 Wisconsin tribes and one urban health center agreed to partner in the project. These nine partners decided that Spirit of EAGLES and the academic staff of the University of Wisconsin Paul B Carbone Comprehensive Cancer Center in Madison should be responsible for the coordination of this large, multisite project. The clinics agreed to participate in each step of the research study and to audit the cancer cases in their records. Funds were provided to each participating clinic to help offset the demands on their staff time. All partners agreed to a core set of questions to be answered by abstracting data from clinic records, but the clinics could include additional questions specific to their community.

Methods: The project had two phases: (1) a community-specific phase to provide each participating American Indian health clinic with a retrospective profile of its cancer burden, and (2) a statewide phase in which all the cases identified by the individual health clinics were matched with the state cancer registry and an aggregate report was prepared. Project staff taught staff members at the American Indian clinics how to abstract data; after abstraction, the data were analyzed at the Great Lakes Tribal Epidemiology Center. Spirit of EAGLES and staff at the center drafted an individual report for each community that described its cancer burden. American Indian health directors, clinic staff, and project staff met to discuss and interpret findings. Final, clinic-specific reports were presented to each clinic. Presentations were made to health boards or tribal government committees as requested.

During the second phase, staff from the Wisconsin Cancer Reporting System matched cancer cases to the state registry and provided a de-identified database to tribal epidemiology center staff, who analyzed the aggregate data. At the time of publication, a draft report of the aggregate data and matches had been developed and presented for review and input at a meeting of the Wisconsin Tribal Health Directors’ Association. The final aggregate report was to be disseminated to each participating community; each community would receive a report of the match between the cancer cases identified by its clinic and those identified by the Wisconsin Cancer Reporting System.

Results: Assessing the local cancer burden of American Indian communities in Wisconsin and improving the accuracy of the state American Indian cancer data necessitated multisite partnerships. Project leads embraced and used the diversity of backgrounds, skills, and experience of the partnering institutions.”

*https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf page 75-77

Matloub J, Creswell PD, Strickland R, Pierce K, Stephenson L, Waukau J, et al. Lessons learned from a community-based participatory research project to improve American Indian cancer surveillance. *Progress in Community Health Partnerships: Research, Education, and Action* 2009;3(1):47-52.