

Division of Cancer Control and Population Sciences Surveillance Research Program



Overview of American Indian/Alaska Native Initiatives

The National Cancer Institute (NCI) supports several projects in American Indian/Alaska Native (AI/AN) populations, largely in collaboration with its Network for Cancer Control Research Among American Indian/Alaska Native Populations. This group of Native and non-Native researchers and educators provides a forum to exchange information on cancer control research and improve community links to NCI researchers, other federal agencies, to NCI researchers, other federal agencies, and the American Cancer Society.

The Network strives to:

- increase the number of AI/AN researchers, scientists, and medical students involved in cancer control activities in AI/AN communities;
- develop curricula and mentor students in the Native Researchers' Cancer Control Training Program; and
- convene national conferences on "Cancer in Indian Country."

Network members collaborated with other experts to produce the monograph "An Update on Cancer in American Indians and Alaska Natives, 1999–2004," which describes the cancer burden in the AI/AN population in the United States. This publication combines cancer incidence data from the Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries and NCI's Surveillance, Epidemiology, and End Results (SEER) Program, along with record linkages and geographic factors. More information and copies of the monograph are available at <http://seer.cancer.gov/publications/aian>.

Alaska Native Tumor Registry

The Alaska Native Tumor Registry (ANTR) began in 1974 in collaboration with NCI and

CDC. From its initiation, the ANTR followed the policies and procedures of NCI's SEER Program. The ANTR received technical assistance from SEER over the years and now is a full member of the SEER Program. In 1999, the ANTR completed its first survival analysis, which was distributed statewide to medical providers, tribal health board members, and key tribal personnel. The ANTR published "Cancer in Alaska Natives 1969–2003: 35-Year Report" in 2006. The report is available at http://www.anthc.org/chs/epicenter/upload/Cancer_Incidence_35-Year_Report.pdf.

Cherokee Nation Cancer Registry

The population of the state of Oklahoma includes more American Indians than any other state, but there is a shortage of quality data on American Indian cancer incidence, treatment, and survival trends; and under-reporting of their cancer mortality resulting from racial misclassification is likely. NCI is partnering with the Cherokee Nation of Oklahoma to fund a pilot cancer registry with the goal of building an infrastructure that conforms to SEER standards in case finding, patient followup, data processing, data reporting, and quality assurance. The target population includes all American Indians residing in the Cherokee Nation's 14-county tribal jurisdictional service area who are eligible for health care through tribal or Indian Health Service (IHS) facilities. A Memorandum of Agreement between the Cherokee Nation Cancer Registry and the Oklahoma Central Cancer Registry has enabled the registries to collaborate and share needed data. Data from the Cherokee Nation Cancer Registry were used to obtain funding from CDC to establish the Cherokee Nation Comprehensive Cancer Control Program.



Northwest Portland Tribal Registry Project

During the past 10 years, health care delivery for Northwest AI/AN has evolved from a centralized system maintained by the IHS to a diverse and complex environment. The Registry Project was developed in 1999 by the Northwest Tribal Epidemiology Center, under the Northwest Portland Area Indian Health Board in Portland, OR. The Registry Project works with state health organizations to correct racial misclassification and increase the quality of disease surveillance data for AI/AN in the states of Idaho, Oregon, and Washington. The project has four goals:

- Determine the amount of racial misclassification in disease registries.
- Obtain accurate estimates of the cancer burden for Northwest AI/AN.
- Use linked case information to generate health status information for tribes and health programs.
- Correct misclassification in state cancer registries.

The Northwest Portland Tribal Registry Project uses probabilistic linkage software to match IHS Resource and Patient Management System records with state health records and verify correct racial classification in state data. The Registry Project also provides technical assistance including guidance on cancer and other health statistics to tribal health professionals and community health advocates; works with the Northwest Tribal Cancer Control Project to disseminate cancer data and identify tribal cancer data needs; and serves the 43 federally recognized tribes in Idaho, Oregon, and Washington. Details of the results of the record linkage are included in the article “Improving Cancer Incidence Estimates for American Indians and Alaska Natives in the Pacific Northwest” (see Selected Publications).

Patterns of Care Among AI/AN

Limited information, especially in published form, is available on current cancer care in AI/AN populations. Dramatic changes have occurred in the health care delivery systems for AI/AN tribes, and significant changes also have occurred in cultural perceptions of cancer among Native populations.

NCI funds pilot studies on patterns of care similar to projects supported under the special studies mechanism of the SEER Program. In the pilot studies, data

from several sources, including SEER and IHS, are combined and augmented by abstracted data from medical records in a sample of cancer cases.

Native C.I.R.C.L.E.

The Native American Cancer Information Resource Center and Learning Exchange (C.I.R.C.L.E.) has operated as a national clearinghouse for cancer education materials specific to Native communities since 1998. During the past decade, Native C.I.R.C.L.E. has evolved into the educational arm of the AI/AN Community Networks Program “Spirit of Eagles,” which was funded by an NCI grant from the Center to Reduce Cancer Health Disparities. Supplemental funding from the Surveillance Research Program enabled Native C.I.R.C.L.E. to hire a full-time coordinator to meet the demands for materials and Web site service. With a national reputation, Native C.I.R.C.L.E. distributed more than 23,000 videos and pieces of literature in 2009, including materials for more than 75 conferences. Native C.I.R.C.L.E. also maintains a current bibliography on cancer in AI/AN populations.

Selected Publications

1. An Update on Cancer in American Indians and Alaska Natives, 1999–2004. *Cancer* 2008;113(S5):1113-1273.
2. Becker TM, Bettles J, Lapidus J, Campo J, Johnson CJ, Shipley D, Robertson LD. Improving cancer incidence estimates for American Indians and Alaska Natives in the Pacific Northwest. *Am J Public Health* 2002;92(9):1469-71.
3. Espey DK, Wu XC, Swan J, Wiggins C, Jim MA, Ward E, Wingo PA, Howe HL, Ries LA, Miller BA, Jemal A, Ahmed F, Cobb N, Kaur JS, Edwards BK. Annual report to the nation on the status of cancer, 1975–2004, featuring cancer in American Indians and Alaska Natives. *Cancer* 2007 Nov 15;110(10):2119–52.
4. Swan J, Breen N, Burhansstipanov L, Satter DE, Davis WW, McNeel T, Snipp CM. Cancer screening and risk factor rates among American Indians. *Am J Public Health* 2006 Feb;96(2):340-50.
5. Swan J, Edwards BK. Cancer rates among American Indians and Alaska Natives: is there a national perspective? *Cancer* 2003 Sep 15;98(6):1262-72.

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