Native American Family Health History Project

Funded by the American Cancer Society

Project Report

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Background: Native Americans suffer disproportionate rates of chronic disease including cancer. The Indian Health Services continues to report higher rates of mortality due to malignant neoplasms among the Bemidji Region (Michigan, Wisconsin, and Minnesota) compared to other Indian Health Services Regions in the country.

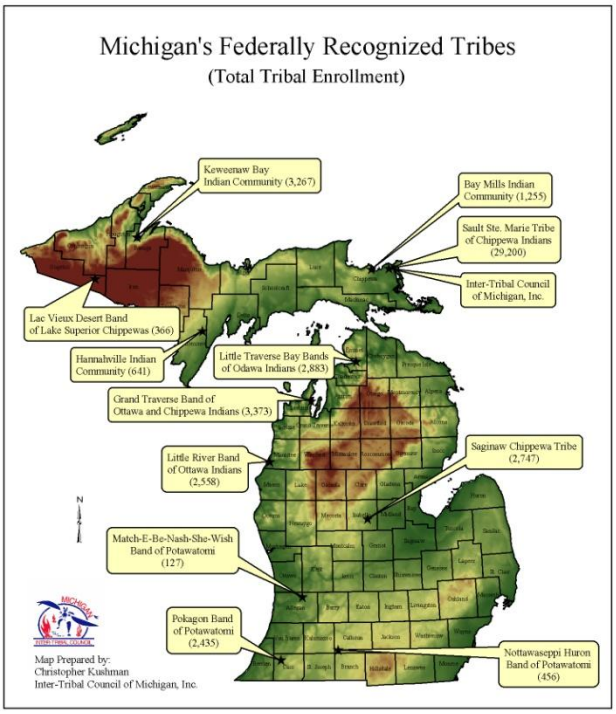
State and local reports support these findings. Many factors are well known to contribute to these increased rates, including obesity, smoking, poor nutrition and lack of physical activity, lack of appropriate screening is also a factor. Behavioral Risk Factor Surveys conducted among the tribal communities, document increased behavioral risk factors and low screening rates for some cancers.

Tribal Clinic Managers and other health care professionals have noted many young cancer cases – specifically for breast and colon. Breast cancer has been diagnosed among Native American women in their 20's. Similarly, some tribes have seen members die of colon cancer between the ages of 20 and 40. These cases are occurring at ages well before the recommended screening guidelines. This suggests the possibility of inherited risk among certain families, which would warrant the need to early screening and treatment.

The importance of tracking and reporting Family Health History is well established. [i,ii,iii] Family history reflects an individual's genes and the behaviors and environmental factors they share with their family members. Family history is a risk factor for many chronic diseases, such as cancer, coronary heart disease, and diabetes, making it an important tool for identifying people at increased risk for these diseases[i]

Native Americans have unique methods of communicating family information, such as storytelling, and a tradition of preparing for future generations that may be incorporated into culturally specific tools and materials for educating, collecting and reporting family health history.[ii] Effective materials that resonate within tribal culture and traditions will help us to identify those at high risk for chronic disease, including some specific types of cancer, which would lead to early interventions, improved quality of life and increased survival rates.

The Project: In response to this, the ACS provided funds to the Inter-Tribal Council of Michigan (ITCM) to develop culturally appropriate and useful Family Health History materials. Through additional collaborations with the Michigan Department of Community Health, the ITCM provided training and resources to tribal clinic providers – aimed to help them identify hereditary risk for cancer among their patients.



<u>The proposed sites of this project are 12 federally recognized tribes located in Michigan</u> , which is part of the I.H.S. Bemidji Region. This region suffers higher rates of cancer and other chronic disease compared to other Indian Health Service Regions in the U.S.[xii] Recent local tribal data reports similar findings. The two leading causes of death for Michigan American Indians are heart disease and cancer.[iii]

The overall goal of the proposed project is to develop and disseminate culturally specific Family Health History education and awareness materials designed to engage tribal community members in recording and reporting their family health history to their health care providers and care givers. A series of focus groups, pilot tests and interviews are included in the action plan.

Community Input: A series of three focus groups were held to review available family health history materials and gather feedback from community members on how a family history might be collected; how the information would be used; and how to share it with their health care providers. <u>Common themes identified through the focus group included:</u>

- The need for this project based on many chronic diseases, including cancer that each member of the group had in their families.
- The need to document the age of onset or death from cancer or other chronic disease – many reported young ages of onset – others did not know
- The ability to discuss or gather family history information at large gatherings: holidays, pow wows, and community events.
- Confirmation that families would be willing to record this information
- Many concerns about privacy and confidentiality were discussed by the group
- It was rare that their health care providers asked them about their family history*
- Use of a story telling format or a focus on future generations as a theme for materials and messages

(The detailed results are attached to this report.)

A series of materials were developed: 1) postcard, 2) brochure with space and instructions for recording family health history, 3) Posters to promote the importance of sharing and documenting family health history. These choices were based on similar past projects specific to successful breast cancer projects. Direct mailings were established as a best practices intervention for improving screening. We've altered this to suit this project. All materials maintained the consistent theme and messages. Initial changes were made to the post cared based on additional feedback from several tribal clinic staff.

- **In response to the results of the focus groups, ITCM and The Michigan Genetics Alliance conducted a webinar with tribal clinic staff on Hereditary Cancer Risk and Management: An interactive approach. CME and CEU's were provided via the Indian Health Services. Follow up evaluation surveys found that the majority of the respondents indicated that they would be making changes in their practices. These changes are aimed at collecting a better health history on their patients, utilizing additional resources, including referrals to a Genetic Consultant as appropriate. We had one provider contact the Presenter as a resource immediately following the*

event to consult on a patient. This indicates use of new knowledge and resources as a result of the training event. The webinar utilized an interactive polling feature to further assess participant's pre/ post knowledge and appropriateness of the content. Overall self reported knowledge about hereditary cancer genetics went from average (pre test) to high (post test). The results were the same for self reported confidence at identifying at risk patients. There was also an increase awareness of the EGAPP and USPSTF guidelines. Participants also indicated that the content of this training was very appropriate and applicable to their work.

Step 1) Tribal members received a post card in November to alert them to the importance of family history and that new materials would be available tin their tribal clinics. The intent was to prepare them to discuss family history during the upcoming holiday events.

Step 2) the brochures were reviewed and sent to the tribal clinics in December. A memo was also sent to the clinic managers to remind them of this initiative and to promote and assess family health history with their patients.

Step 3) Posters were sent to the tribal health centers and posted throughout the community buildings. Posters have been shown to be very effective when the use culturally appropriate images and messages and are reported throughout the tight knit and small community.

Outcomes: We know have available a series of effective and culturally appropriate family health history educational materials. A total of 12,000 post cards were sent to all twelve tribes and to the Urban Indian Health Center in Detroit. Over 2,000 brochure and 200 posters were distributed to the clinics.

Family Health History continues to be a priority for the ITCM and its member tribes. Thank you for your support to this very worthwhile project.

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[i] Centers for Disease Control and Prevention; http://www.cdc.gov/nccdphp/publications/AAG/genomics.htm accessed 8-1-2009.

[ii] Inter-Tribal Council of Michigan, "Opening Doors," funded by the Michigan Department of Community Health, 1996.

[iii] Community Health Profiles, MI, MN, WI, Great Lakes Epidemiology Center, 2000.