



Building Cancer Surveillance Capacity:

Wisconsin Tribal and Urban Indian Clinics

September 2003
University of Wisconsin Comprehensive Cancer Center
Madison, Wisconsin

AUTHORS

Rick Strickland, MA, Project Coordinator
Spirit of EAGLES, UW Comprehensive Cancer Center

Kimmine Pierce, MS, Staff Epidemiologist
Great Lakes Inter-Tribal Council

Laura Stephenson, BA, Program Director
Wisconsin Cancer Reporting System

Nancy Miller-Korth, RN, MSN, Epidemiology Center Director
Great Lakes Inter-Tribal Council

Kristian Knutsen, BS, Program Assistant
Spirit of EAGLES, UW Comprehensive Cancer Center

Jerry Waukau, BA, President
Wisconsin Tribal Health Directors Association

Patrick Remington, MD, MPH, Co-Principal Investigator
Spirit of EAGLES, UW Comprehensive Cancer Center

Judith Kaur, MD, Principal Investigator
Spirit of EAGLES, Mayo Clinic Cancer Center

ACKNOWLEDGEMENTS

This report presents the results of a collaborative effort to improve cancer surveillance practices among Wisconsin Tribal and Urban Indian clinics. Participating partners were the Wisconsin Tribal Health Directors Association, Great Lakes Inter-Tribal Council, the Wisconsin Cancer Reporting System, Mayo Clinic Cancer Center, University of Wisconsin Comprehensive Cancer Center and Spirit of EAGLES: American Indian/Alaska Native Leadership Initiative on Cancer. The project was supported through a grant to Spirit of EAGLES, a National Cancer Institute-funded initiative—grant number U01 CA86098. Thanks are also due to Kathy Wiese, Assistant Director, UW Comprehensive Cancer Center, and Karen Julesberg, Project Director, North Central Cancer Information Service for their consultation on this project.

ADDITIONAL COPIES or QUESTIONS:

Spirit of EAGLES
UW Comprehensive Cancer Center
370 WARF Building
610 N. Walnut St.
Madison, WI 53726
608-262-0072
strickla@uwccc.wisc.edu

Abstract

Objectives: During the period of July-October, 2002, the Cancer Surveillance Capacity Building Project was implemented in clinics operated by eleven tribes and the one urban Indian clinic in Wisconsin. The project was designed to: 1) determine the type of data that was available in clinic records on American Indian cancer patients; 2) identify which cancer screening exams were presently conducted in these settings; 3) implement a trial use of the Wisconsin Cancer Reporting System's Neoplasm Record Form via a retrospective study of 2001 cancer cases available in the records of each clinic; and 4) submit completed Neoplasm Record Forms to the Wisconsin Cancer Reporting System to match with current records.

Methods: The project was developed and implemented collaboratively with the Wisconsin Tribal Health Directors Association, Great Lakes Inter-Tribal Council, Wisconsin Cancer Reporting System, the North Central Spirit of EAGLES initiative at the University of Wisconsin Comprehensive Cancer Center, and the national Spirit of EAGLES at the Mayo Clinic Cancer Center. A structured interview process and training in use of the Neoplasm Record Form were conducted on site at the clinics by Spirit of EAGLES staff.

Results: Six of twelve clinics were aware of the Wisconsin Cancer Reporting System prior to the interview. Three clinics had previously submitted a Neoplasm Record Form to investigate a possible cancer cluster, and none were currently submitting the form to report new cancer cases. All tribal clinics used the Resource Patient Management System (RPMS) software provided by the Indian Health Service, and four clinics also used other medical software systems. RPMS is not available for use by the Urban Indian clinic. Many clinics experienced some difficulty in using the RPMS query function to identify cancer cases, noting that they often consulted the actual medical record to confirm a diagnosis. Clinic staff reported that return of treatment information from referral facilities varied. Eight clinics recorded cancer risk factors in their databases, seven included demographic information in their medical records, and seven noted tribal specific identity in their records. Routine cancer screening exams, including mammograms, pap smears, PSAs, and hemocults were regularly provided to patients by 75-100% or more of the clinics. Seven clinics (58%) organized special screenings days, though the frequency of these days varied significantly. Seventy-five percent of the clinics did not have written cancer screening protocols in place. In addition, reminder card use, biopsy capability, and receipt of pathology results varied among the clinics.

Twelve of thirteen clinics submitted Neoplasm Record Forms, and only one clinic submitted the maximum ten cases. A total of fifty-six cancer cases diagnosed in 2001 were reported by the clinics to the Wisconsin Cancer Reporting System. Twenty-eight of these cases (50%) were not previously registered in the state Cancer Reporting System. Twenty-five percent of the cases identified in the registry (7/28) were misclassified as non-Indian. Consequently, of the 56 cases reported by the clinics, only 21 (38%) had been correctly reported from other sources. The distribution of the 56 American Indian cancer cases for 2001 was similar to the case distribution of the total Wisconsin population for lung, breast, and colorectal cancers, but lower for prostate cancer and higher for kidney cancer and leukemia/lymphoma.

Conclusion: The underreporting of Wisconsin American Indian cancer cases in 2001 suggests that underreporting may be a regular occurrence. This underscores the value of direct reporting by Tribal and Urban Indian health facilities to the Wisconsin Cancer Reporting System. In addition to direct reporting, other opportunities to improve cancer surveillance at these clinics include improving the ease of cancer case identification in clinic databases and implementing systems to routinely obtain cancer patient medical records from non-tribal treatment facilities.

Introduction

Organization

The Cancer Surveillance Capacity Building Project was conducted to assess cancer data and screening practices at Wisconsin Tribal and Urban Indian clinics. It was designed to lay a foundation to implement a follow-up cancer surveillance pilot project, *Improving American Indian Cancer Surveillance and Data Reporting in Wisconsin*, which has been funded through the Great Lakes Native American Research Centers for Health (NARCH) grant. The Capacity Building project was a collaborative effort of Spirit of EAGLES: American Indian/Alaska Native Leadership Initiative on Cancer at UW Comprehensive Cancer Center and Mayo Clinic Cancer Center, the Wisconsin Tribal Health Directors Association, the Wisconsin Cancer Reporting System (WCRS) and Great Lakes Inter-Tribal Council (GLITC).

The proposal for the Capacity Building project resulted from a discussion with GLITC's Epidemiology Center staff. The idea was subsequently presented to the executive committee of the Tribal Health Directors Association, the program direction of WCRS and the PI for Spirit of EAGLES for input and endorsement. All parties enthusiastically endorsed the project and agreed to promote it. The proposal included a provision to distribute an equal amount of funds to each participating tribe and the one urban clinic as partial reimbursement for the professional services of clinic staff that participated in the project.

All eleven of the Wisconsin American Indian Tribes, and the Gerald L. Ignace Urban Indian Clinic, chose to participate in the Capacity Building Project. A total of thirteen clinics were contacted, including the twelve tribal clinics in the state and one urban Indian clinic. The contacted clinics included Bad River Tribal Clinic, Forest County Potawatomi (Potawatomi Health and Wellness Center), Ho-Chunk (Ho-Chunk Health Care Center and The House of Wellness – Wanaiguni Hocira), Lac Courte Oreilles Tribal Clinic, Lac du Flambeau (Peter Christensen, Sr., Health Center), Menominee Tribal Clinic, Oneida Tribal Clinic, Red Cliff Tribal Clinic, Sokaogon Chippewa Tribal Clinic, St. Croix Tribal Clinic, Stockbridge-Munsee Tribal Clinic, and the Gerald L. Ignace Indian Health Center in Milwaukee.

Objectives

The project had two primary objectives:

1. Assess and describe the information available in health clinic records for patients diagnosed with cancer; for example, what specific types of data

-
- were collected, how was the data accessed, and could a composite report be created.
2. Identify cancer screening and diagnostic practices currently used in each clinic.

The two secondary objectives were:

3. Use the current Neoplasm Record Form of the Wisconsin Cancer Reporting System to collect information on 10 individual cancer cases, or all cancer cases diagnosed during 2001, whichever was less, and describe the clinic staff's experience in using the form.
 4. Send completed Neoplasm Record Forms to the Wisconsin Cancer Reporting System for matching with current records, and for analysis regarding patterns of care.
-

Methods

Kimmine Pierce, a graduate student in the University of Wisconsin Population Health Sciences program, was hired to implement the Cancer Surveillance Capacity Building Project under the supervision of Patrick Remington, MD, MPH, Co-Principal Investigator for Spirit of EAGLES, and Rick Strickland, the North Central Project Coordinator for Spirit of EAGLES. Pierce and Strickland met on site in Lac du Flambeau, Wisconsin with Nancy Miller-Korth and Chandra Reedy of GLITC's Epidemiology Center to develop an implementation process for the project. Laura Stephenson, Program Director of the Wisconsin Cancer Reporting System, also participated in this meeting via conference call.

Following this meeting, Nancy Miller-Korth prepared and sent a communication to the Wisconsin Tribal and Urban Indian Health Directors that outlined the steps and timeline for the Capacity Building project. This communication included expectations and deliverables for Spirit of EAGLES, the Wisconsin Cancer Reporting System, participating Tribal and Urban Indian clinics and the Great Lakes Inter-Tribal Council. To facilitate timely project implementation, GLITC provided Ms. Pierce with on-site workspace, including telephone and computer access.

A structured interview method was employed to obtain information on each clinic's cancer data and screening practices. Pierce and Strickland prepared the interview questions with input and feedback from Dr. Remington and other project partners. A train-the-trainer model was employed to achieve the objectives regarding a trial use of the Neoplasm Record Form. Ms. Pierce

was trained by Wisconsin Cancer Reporting System staff, and she then trained Tribal and Urban Indian clinic staff. Wisconsin Cancer Reporting System staff was available by telephone for consultation to both Ms. Pierce and clinic staff.

During July and August 2002, Ms. Pierce visited each clinic, conducted the structured interviews and trained clinic staff on use and completion of the Neoplasm Record Form. Participating clinics submitted completed record forms directly to WCRS for analysis. Reports of preliminary project findings were prepared by Spirit of EAGLES (Ms. Pierce) regarding cancer data and screening practices, and by WCRS (Ms. Stephenson) regarding the trial use of the Neoplasm Record Form. These reports were presented to all participating clinic staff and project partners at a follow-up session held October 30, 2002 at GLITC in Lac du Flambeau. The session included time for clinic staff to share their experience with the project, and raise specific questions relative to the preliminary findings and recommendations.

Following the October 2002 meeting, the health director at each clinic was sent preliminary findings concerning available cancer data and screening practices for verification and/or correction. After the verification process was completed, a final draft report was prepared and distributed to each director for comment.

Strickland discussed the final draft with Tribal and Urban Indian Health Directors on February 20, 2003 in Lac du Flambeau. Questions raised by the Health Directors were addressed through a second verification process with each clinic, and appropriate changes were made. In addition, Ms. Stephenson of the Wisconsin Cancer Reporting System plans to forward each health director a report regarding patterns of care evident in the Neoplasm Record Forms submitted by each clinic.

Results: Objective One

The first objective was to compile information about typical data collected by the clinics on cancer patients. A structured interview method was used to collect this information. Seven questions were used to obtain information regarding this objective; the specific questions appear in italics in the ***Questions and Specific Findings*** section below. The question topics were: awareness of the Wisconsin Cancer Reporting System, patient database used, methods for identifying and reporting cancer cases, cancer risk factor identification, medical record-keeping, and racial classification.

Summary and Observations

While six clinics (50%) were aware of the Wisconsin Cancer Reporting System, only three clinics (25%) had submitted Neoplasm Record Forms (NRF) in the past, and usually for the purpose of investigating a possible cancer cluster. At the time this project was implemented, none of the clinics indicated regular use of the NRF to report new cancer cases. The majority of clinics used RPMS software and reported that using this software for both cancer case finding and developing composite reports was difficult and labor intensive. Nine of twelve clinics (75%) did not routinely receive or request detailed reports on patients referred for a suspected cancer. Five of these nine clinics requested this information case-by-case as needed, and if received, this information was included in the patient's medical record. Ten of twelve clinics (83%) did include cancer risk factors in either their databases or medical records.

Development of a clinic cancer profile would benefit by routine receipt of detailed reports on referred patients and routine medical reporting of cancer risk factors and demographic information. Both access to and the extent of cancer information available on-site were adversely impacted by characteristics of the RPMS database commonly used by these clinics.

Questions and Specific Findings

Note: The numbers used to present specific findings are based on twelve reporting entities, not thirteen, because one tribe sponsors two clinics. In addition, we chose to use the general term "clinics" in order to be inclusive of the Gerald L. Ignace Indian Health Center, the urban Indian clinic in Milwaukee.

- *Prior to this project, was your clinic aware of the WI Cancer Reporting System (WCRS)? If so, has your clinic ever submitted reports previously?*

Six of twelve (50%) clinics were aware of WCRS prior to the Capacity Building project. If the clinic was aware of the system, a follow-up question asked whether the clinic had ever submitted a Neoplasm Record Form (NRF). Three of the six clinics (25%) aware of the WCRS had previously submitted a Neoplasm Report. Primary reasons that clinics had submitted reports were related to unusual cancer cases and possible cancer clustering. None of the clinics reported regular use of the NRF to report new cancer cases.

- *What database system does your facility use to record patient information?*

Eleven of twelve clinics (92%) used the Indian Health Service (IHS) database software program, Resource Patient Management System (RPMS), to some extent. RPMS is not available to Urban Indian Health Centers including the Gerald L. Ignace Indian Health Center in Milwaukee. Seven of the eleven clinics (64%) using RPMS, used it solely. Four clinics (36%) used RPMS in conjunction with other medical software, most commonly Medical Manager. In

these four clinics RPMS was used for patient registration or as a diagnostic database.

- *Is your facility capable of identifying cancer cases? If so, what is the mechanism/procedure to identify cancer cases? Is this information readily accessible?*

All clinics were capable of identifying cancer cases. Three of twelve (25%) clinics identified cases by reviewing the actual medical records, while the remainder used the query (Q-Man) capability in RPMS. Several clinics noted that using Q-Man to identify cancer cases was cumbersome and difficult, and that they consulted the actual medical records in addition to the database query for follow-up and verification purposes.

- *Can your facility create a report or profile regarding cancer cases for your own use?*

Ten clinics (83%) indicated that it would be possible to create a profile of cancer cases, but it would be very difficult and time consuming using RPMS' Q-Man. Several clinics indicated that it would be easier to review medical records than query Q-Man because complicated linking and merging were required to use the software program for this purpose.

- *Do your medical records contain current information on the treatment provided to cancer patients by their referring physician/facility?*

Three of twelve clinics (25%) indicated that they routinely receive information on cancer treatment provided to clinic patients by the referring physician/facility. Five clinics (42%) indicated that they received the information if the clinic requested it on an individual patient. Four clinics (33%) reported that they do not routinely have information on cancer treatment provided clinic patients and do not request it from the referring physician/facility.

- *Do you include cancer risk factors in your medical records (i.e. age, smoking, obesity, chemical dependency, environmental exposure, occupation, etc.)?*

Eight of twelve clinics (67%) included cancer risk factors in their databases, two (17%) recorded cancer risk factors in the medical records and two clinics (17%) did not have cancer risk factor information available.

- *Do you include demographic information in your medical records (age sex, race, education level, and income level)?*

Seven clinics (58%) maintained all demographic information on site, either in a database or in individual medical records. Four clinics (33%) had all of the

demographic information except education and income level, and one clinic (8%) did not have demographic information available.

- *What degree of racial classification do your medical records contain (i.e. American Indian, Tribal specific, etc.)?*

All twelve clinics identified patients as American Indian/Alaska Native in the medical records. In addition, seven clinics (58%) had tribal specific information, and one (8%) clinic had blood quantum information. All clinics require Enrollment/Membership information.

Follow-up Discussion with Clinic Staff

The issues that emerged through discussion with clinic staff concerned cancer case identification, referring physicians, standard protocols, and a cancer-specific database.

RPMS was considered difficult to use for cancer case finding. For example the RPMS query function (Q-Man) automatically includes cases where a patient has a family history of cancer, though was never personally diagnosed, and includes each clinic visit by this same patient. Consequently, staff noted that 'ruling out' codes was difficult when running a report, because it was necessary to look beyond the codes to see if there was an actual cancer diagnosis. Some clinic staff indicated they routinely returned to the actual medical record to confirm a diagnosis. Staff suggested that developing a template in RPMS to help locate actual cancer cases would be more useful than to develop a new database because of double entry demands.

Clinic staff noted that the best method of obtaining information from a referring physician was to secure a patient release of information and to request the information from the appropriate source. Some clinics have a tracking system in place with a specific staff person identified to track referrals. One clinic with a tracking system and appointed staff person reported that they have no trouble with obtaining information; they routinely call one month later if they have not received the information. Another clinic stated that they experience a problem tracking referrals and that they do not have a specific staff person assigned to follow-up on requests. This clinic calls for the follow-up reports on a case-by-case basis when requested by a clinic provider.

Results: Objective Two

The second objective examined current screening practices. The topics included cancer screenings performed by individual clinics (mammograms, pap

smears, PSAs, hemocults, colonoscopies), clinic use of reminder cards, the location of tissue analyses and subsequent use of reports, and formal cancer screening protocols.

Summary and Observations

All clinics provided screenings for at least one type of cancer. Screenings were provided routinely according to standard guidelines, on special screening days and to diagnose suspected medical problems. Twelve clinics provided mammograms, ten provided pap smears and PSAs, and nine provided hemocults. Only two clinics routinely provided colonoscopy screening. Two clinics had mammography available on site and conducted these screenings as regularly recommended by a provider. Seven clinics offered mammograms on special screening days organized for this purpose. The frequency of these screening days varied significantly among the seven clinics. Eight clinics also sent out reminder cards for mammograms and seven sent reminders for pap smears. No information was obtained on current cancer screening rates at the participating clinics.

Tissue analysis was performed by outside pathology laboratories. Clinics that performed their own biopsies automatically received pathology reports from those laboratories. All clinics that received pathology reports recorded this information in the patient's medical record, and one of the clinics also included it in a separate database. Nine clinics did not have formal written cancer screening protocols in place. Screening practices were dependent upon clinic standards, the individual provider, patient circumstances and available resources.

Questions and Specific Findings

All clinics provided mammograms, but the screening rates among clinics varied significantly. Two of twelve (17%) clinics had mammograms available in their facility and provided screening routinely or as providers recommended. One clinic noted that it accepted self-referrals. Three clinics referred the patient to local outside facilities. The other seven (58%) clinics offered mammograms via a mobile unit that made site visits to the clinics. The frequency of mobile unit visits varied among the seven clinics; the frequency rates were once per year, twice per year, once per month, or twice per month.

Pap smears, PSAs, hemocults, and colonoscopies were provided by the clinics as routine health maintenance based on age and gender specific guidelines; and for diagnostic purposes when recommended by a provider. Ten clinics (83%) provided pap smears, while another designated two days per year for this type of screening. Likewise, ten (83%) clinics provided PSAs, nine (75%) clinics provided hemocults, and two (17%) clinics provided colonoscopies.

Types of Cancer Screenings Provided	Clinics	Percentage
Mammogram		
- Screenings in facility	2	17%
- Patients are referred out	3	25%
- Screenings provided by mobile unit	7	58%
Pap Smear	10	83%
PSA	10	83%
Hemoccult	9	75%
Colonoscopy	2	17%
Biopsies		
- Skin	10	83%
- Cervical	3	25%
Colposcopy	4	33%

- *Does the clinic send reminder cards about screenings for mammography and/or pap smears?*

Eight clinics (66%) sent reminder cards for mammography, while five clinics (42%) sent reminder cards for pap smears.

- *Does the clinic perform skin or cervical biopsies or colposcopies?*

Ten of twelve clinics (83%) were capable of doing skin biopsies, and three clinics (25%) were capable of doing a cervical biopsy. Four clinics (33%) were capable of performing colposcopies.

- *On what basis does the clinic receive tissue analysis from outside pathology laboratories? How are the reports filed?*

External pathology laboratories conducted all tissue analysis. Seven (58%) clinics automatically received the pathology report, while two (17%) received the pathology report if they requested it. Of the nine clinics that received the pathology reports, all filed them in patient medical records and one also entered them into a database specifically used for laboratory results. All clinics that performed their own biopsies automatically received the pathology report.

- *Are cancer screening practices formulated into a written protocol?*

Formulation of cancer screening practices into written protocols varied among the twelve clinics. One clinic (8%) used the American Medical Association (AMA) and American Cancer Society (ACS) recommended protocols. Two clinics (17%) had formal written protocols for mammography, and another three clinics indicated they were in the process of developing written

protocols. The remaining six (50%) clinics had no formal written cancer screening protocols.

Follow-up Discussion with Clinic Staff

Clinic staff indicated that when they used the term “as suspected,” it meant both screenings included in a routine annual physical, and screenings done for diagnostic reasons at a provider’s request. Staff strongly recommended the development of written cancer screening protocols at each clinic and thought these would be very helpful in both increasing cancer awareness and education, and in standardizing practice at a particular clinic.

Results: Objectives Three & Four

Findings from the clinics’ trial use of the Neoplasm Record Form will be presented in this section. The purpose of this trial use was to train tribal and urban clinic staff in using the Neoplasm Record Form and to learn what would be found when clinic cases were matched with current Wisconsin Cancer Reporting System data. The project involved a retrospective study of cancer cases diagnosed in 2001 and found in the medical records of Tribal and Urban Indian clinics in Wisconsin. For the purposes of the trial, clinics were asked to report all 2001 cancer cases in their records up to a maximum of ten cases.

Summary and Observations

Twelve of thirteen clinics provided data for this report. Only one clinic provided the maximum ten cases. Fifty-six cases were reported to the Wisconsin Cancer Reporting System. When matched with current Wisconsin Cancer Reporting System records, it was found that 28 (50%) of the cases were not in the state registry. In addition, seven (25%) of the 28 cases found in the registry were misclassified as non-Indian. Consequently, of the 56 cases reported in the pilot program, only 21 (38%) were correctly reported from other sources.

The cancer site profile of the 56 submitted American Indian cases was similar to the overall Wisconsin cancer site profile. Both show a similar distribution for lung, breast and colorectal cancers; however, these American Indian cases show a lower distribution of prostate cancer and higher distributions of kidney cancer and leukemia/lymphoma than the Wisconsin population as a whole. Cancer treatment information was not included in a significant majority of the submitted records, confirming earlier project findings regarding the detail of information available in clinic records, and/or difficulty in interpreting this information.

Cases Reported to the Wisconsin Cancer Reporting System

There were fifty-six reported cases from the clinics. Seventeen of the reported cases were male, and thirty-nine were female.

<i>Clinics</i>	A	B	C	D	E	F	G	H	I	J	K	L	Total
<i>Cases Reported</i>	10	9	7	5	5	4	4	3	3	3	2	1	56

Case Distribution by Racial Classification

Twenty-eight of the fifty-six cases reported in the study were listed in the state registry. Thus, one-half of the cases compiled from the clinics had never been reported to the state registry.

<i>Coding</i>	Listed in State Registry	American Indian	White	Misclassified as White or Unknown	Needed Follow-up with Clinic
<i>Number</i>	28	19	1	7	1

Case Distribution by Cancer Site in the Body

Generally, this case distribution follows that of the general Wisconsin population for lung, breast, and colorectal cancers. However, these figures indicate a higher distribution of leukemia/lymphoma and kidney cancer among Wisconsin American Indians in 2001, and a lower distribution of prostate cancer.

<i>Cancer</i>	Lung	Breast	Colorectal	L/L	Kidney	Prostate	Other	Unknown
<i>Number</i>	12	11	6	5	5	3	10	4

Location of Treatment

Of the fifty-six reported cases, only twelve reports included treatment information. Among those cases reporting treatment, two reported hormone therapy treatment performed at a tribal clinic. Ten reports indicated that treatment was performed by another facility. Nine of these treatments included surgery, while one was chemotherapy. Of the nine reported surgery treatments, one case each also included chemotherapy and radiation treatment.

Follow-up Session Discussion with Clinic Staff

Most clinics noted that it took about twenty minutes to fill out the NRF, commenting that it was not hard once the chart was in front of them. However, at least one clinic found that it took up to sixty minutes to complete a record form. Staff uniformly indicated that the most difficult and time-consuming task was to locate the case and go through the diagnostic codes. Staff also indicated that they expected the time needed to fill out each form would decrease once they were familiar with the format. The pathology questions in the form were often difficult to complete because this information was often absent from the chart, or in some cases, difficult to interpret. Staff also noted in cases where palliative

care was the preferred treatment, there was no additional treatment information. In general, staff found that they would use the RPMS database to identify cases and then revert to patient charts to confirm diagnoses and abstract information requested by the Neoplasm Record Form.

Discussion

The Cancer Surveillance Capacity Building Project underscored the value of examining cancer patient records at Tribal and Urban Indian clinics and matching them with the state cancer registry, as well as the value of engaging local clinic staff in cancer data improvement projects. The project revealed that there was similarity in the types of cancers being screened by Wisconsin Tribal and Urban Indian clinics, and yet great variability in the frequency of those screenings. There was also variability in the degree of information available in clinic records on cancer patients. The interest and responsiveness of Tribal and Urban clinic administrators and staff was notable and contributed significantly to the successful outcome of the project.

The design of the project included certain limitations. The structured interview process used to achieve objectives one and two relies upon the self-report of key informants who are employees of the clinics. Neoplasm Record Forms are sometimes submitted as much as twelve months following the close of the calendar year (particularly from out-of state facilities), and the analysis of this trial use of the Neoplasm Record Form was completed October 30, 2002. It should be noted that the NRFs submitted by the Wisconsin Tribal and Urban Indian clinics were for American Indians who sought care in these clinics, not necessarily all American Indians living in the clinic service area or in Wisconsin, nor all tribal members. One participating tribal clinic submitted the maximum number of cases requested (10) and it is not known whether the clinic had additional cancer cases diagnosed in 2001. It is also not known whether the 28 submitted records which were not previously identified in the cancer registry would have been identified through a data matching process between the Indian Health Service and the Wisconsin Cancer Reporting System.

The findings of the project have several distinct implications regarding work activities and processes that would aid implementation of the pilot project, *Improving American Indian Cancer Surveillance and Data Reporting in Wisconsin*. These implications will be addressed in collaboration with the WI Tribal and Urban Health Directors Association, Great Lakes Inter-Tribal Council and the Wisconsin Cancer Reporting System. Beneficial future activities include:

-
1. Develop a method of regular reporting by Tribal and Urban Indian clinics to the Wisconsin Cancer Reporting System.
 2. Develop an RPMS database template for use in cancer case finding and reporting.
 3. Phase in clinic involvement over the three years of the pilot project in relationship to the detail of data available on cancer patients in clinic records.
 4. Provide clinics information on screening protocols for major cancers.
 5. Provide training on epidemiology principles and practices for clinic staff as needed or requested.
 6. Work with clinics and referring facilities to develop best practices in securing reports from referring physicians and incorporating any risk factors and demographic information in records where they are absent.