



The EpiCenter currently provides epidemiological services to the Tribes in the Bemidji Area (Michigan, Wisconsin, and Minnesota). Funded in part by the Indian Health Service, the EpiCenter strives to be responsive to the health information and epidemiological needs of the Tribes in the region by providing training and technical assistance in many areas of public health, data management, program planning, and program evaluation.

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Cancer Surveillance Capacity Building Project

The Cancer Surveillance Capacity Building Project was developed to lay a foundation for the cancer surveillance component of the Native American Research Centers for Health (NARCH) grant. The overall goal is that improving cancer surveillance among tribal and urban clinics will lead to improved cancer outcomes for American Indians.

The Capacity Building project was implemented, July-October 2002, through a collaborative effort of the Wisconsin Tribal Health Directors Association, Spirit of EAGLES: American Indian/Alaskan Native Leadership Initiative on Cancer at UW Comprehensive Cancer Center, the Wisconsin Cancer Reporting System (WCRS) and the Great Lakes Inter-Tribal Council.

OBJECTIVES

The project's objectives were: 1.) Determine the type of data available in clinic records on American Indian cancer patients, 2.) Identify which cancer screening exams were conducted in these settings and 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.

METHODS

All eleven of the Wisconsin American Indian Tribes and the Gerald L. Ignace Urban Indian Clinic participated in the Capacity Building Project. Information was collected through a structured interview process conducted

during July and August 2002 by Kimmine Pierce, staff epidemiologist with Great Lakes. The information was obtained from clinic nursing and/or medical records/information systems staff. During this period a train-the-trainer model was employed where Ms. Pierce was trained in completing the Neoplasm Record Form by WCRS staff, and subsequently trained participating clinic staff.

A follow-up session was held on October 30, 2002 at Great Lakes Inter-Tribal Council in Lac du Flambeau, Wisconsin for participating clinic staff and project sponsors. Preliminary results of the structured interview process and the Neoplasm Record Form retrospective study were presented. Valuable feedback was obtained from the clinic staff on their experience in filling out the Neoplasm Record form and their clinic's cancer data and screening practices.

RESULTS

The trial use of the Neoplasm Record Form substantiated the need for local cancer profiling. Initial results showed that 28 of 56 cases identified by the clinics in 2001 were not found in the cancer registry, and that another seven cases were incorrectly identified as non-Indian. Several other important findings from the Capacity Building Project will have direct bearing on how the implementation of the NARCH pilot project, Improving American Indian Cancer

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EpiCenter Work in Minnesota: An Update

Greg Rachu, GLITC's newest epidemiologist, has been busy making visits to Tribal Health sites in Minnesota. As of now, he has been to six of the eleven tribal sites, with plans to travel to the remaining areas in February 2003. During these meetings, Greg and Nancy Miller-Korth, have been providing an overview of the EpiCenter's past and current activities; gaining a better understanding of numbers of health facility personnel, active patient counts, and health services offered at each facility; as well as gathering information on tribal health needs and concerns regarding the collection and use of data. Some other main issues of discussion have been RPMS training and assessments, community based-research training, diabetes surveillance assistance, questionnaire and survey design, health needs assessment assistance, racial misclassification issues, program monitoring & evaluation, and proposal writing. The main health issues raised have been diabetes, cardiovascular disease, youth obesity, increased cancer incidence, and nutrition.

Greg and Nancy have appreciated the informative discussions and have enjoyed touring the various facilities. They also look forward to the upcoming visits in February and establishing working relationships with the Minnesota tribes.

Introducing the Primary Sampling Application in the Tribal Projects

EpicCenter Customer Report, 2002

Public health officials need information on characteristics of populations for planning health and social services, and others. Sometimes, the entire population will be sufficiently small, and then the information of every member of the entire population can be gathered in the study. This type of data collection is called census. However, ordinarily, the population is too large to attempt to survey all of its members. Therefore, a sampling design is needed, which consists of sampling plan and estimation procedure. The sampling plan is the methodology used for selecting the samples from the population and the estimation procedures are used for obtaining estimates of population values from the sample data.

For most tribal survey projects, a probability sampling method is applied. In probability samples, each member of the population has a known non-zero probability of being selected, which means each member has an equal chance of being selected. Probability methods include random sampling, systematic sampling, and stratified sampling. The simple random sampling is used in most tribal survey projects.

To start a sample survey design, first, a special purpose needs to be clarified, so the target population and elementary units can be defined. The target population is the entire set of individuals to which findings of the survey are to be extrapolated, and the elementary units are the individual members of the population whose characteristics are to be measured [1]. Since for tribal specific projects, the target population is all tribal members who may be identified in the tribal member list, a simple random sampling method is usually used.

To take a simple random sample, the first step is to assign a number from 1 to N to each element in the population. For example, if the total population is 450, each member or element of the population would be assigned a number from 1 to 450. The next step is to pick a sample of n of these numbers by use of some random process[1]. Let's say that the sample size needs to be 50. Starting from an arbitrary number, fifty elements will be selected by every 9 numbers without duplication through 450.

Another important procedure in sample design is determining sample size. The sample size needs to be the right size in order for the estimates obtained in the sample

survey to be reliable enough to meet the objectives of the survey. In determining sample size, the first step is to specify the level of reliability needed for the resulting estimates. In general, the larger the sample, the greater will be the reliability and usually use 95 percent confidence level is selected[1]. As for validity, an improvement in validity requires an improvement in the measuring process. Usually, several of the most important variables are chosen from the survey questionnaire and sample sizes are calculated for each of these variables. The final sample size chosen might then be the largest of these calculated sample sizes. For most tribal survey projects, since some parameters of the variables are hard to know, it is best to determine the sample size before the survey is conducted in order to get the best results. Generally, the larger the sample size the better. The EpiCenter staff is available to assist with this determination on a project by project basis.

The criteria for a good sample design include cost, accuracy and feasibility. The criteria of cost and accuracy can be combined into a composite criterion by first deciding on the total cost to be allocated to the survey, and then choosing the sample design that will yield estimates with the lowest sample error at that particular cost. In addition, feasibility has to be considered in executing a particular sample design. However, it is rare to get a 100% return on a survey. Because it is important to receive input from as many people as possible, there are a number of strategies that can be tried. The methods of increasing the response rate include increasing the number of households contacted successfully; increasing the completion rate in mail questionnaires by tracking who has not returned the survey and sending out a second mailing; package surveys in ways that make them attractive and easy to complete; face-to-face interviews and telephone interviews can also increase success. Also sometimes, mail surveys can combine with interviews of non-respondents.

Reference
[1] *Sampling of populations methods and applications.* Paul S. Levy, Stanley Lemeshow. Wiley series in probability and statistics, 1999.

The Great Lake EpiCenter conducted a service quality and training needs survey for Bemidji area in 2002. The survey results have provided staff with an opportunity to assess the customer-determined service quality and satisfaction and to make necessary adjustments to better improve services.

There were total 35 responses collected from three states (Minnesota-4, Wisconsin-17, and Michigan-14). A wide variety of tribal health staff completed the satisfaction survey. The largest numbers of those responding came from the following categories, 30% were tribal health administrators, 17% were DM coordinators, and 11% were public health professionals.

The survey had a number of questions in four different areas: general services assessment, diabetes services assessment, health profile assessment, and RPMS services assessment.

General Services Assessment

This section focused on the assessment of EpiCenter service benefit and quality. We found 71% of those responding to the survey (except MN) have received EpiCenter staff services in the past two years with Wisconsin respondents indicating a higher percent of receiving service (88%) compared to Michigan respondents (50%). Of the service applications, survey results analysis and report, telephone technical assistance, and computer software training had the highest frequency of use. The overall score of the satisfaction for the quality of service score was 4.6 and the score of the promptness of the service was 4.5, which indicated EpiCenter services were well received and prompt. (A Likert scale was used with a range of 1 to 5 with a score of 1 equaling dissatisfaction and 5 equaling excellent satisfaction.)

Diabetes Services Assessment

We found 65% of the survey respondents used EpiCenter services for diabetes audit and other diabetes programming.

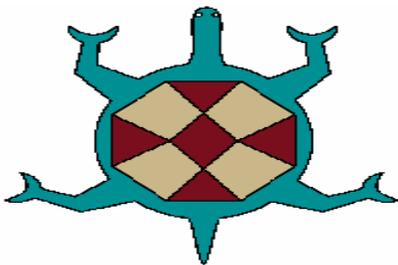
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Cancer Surveillance Capacity Building Project

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Surveillance and Data Reporting in Wisconsin, will proceed. Among these findings were:

- None of the clinics were currently submitting Neoplasm Record Forms;
- The majority of clinics used RPMS software and found it difficult to use for cancer case finding and report development;
- There was great variation among the clinics in the detail of information available on cancer patients;
- The majority of clinics did not routinely receive detailed reports on patients referred for a suspected cancer and often requested this information case by case on an as needed basis;
- Almost all clinics provided mammogram, pap smear, hemocult and PSA screening exams; however screening frequencies varied significantly depending on individual provider, patient circumstances and clinic resources; A large majority of clinics did not have formal screening protocols.



SMALLPOX

Smallpox, because of its high case-fatality rates and transmissibility, now represents one of the most serious bioterrorist threats to the civilian population. Over the centuries, naturally occurring smallpox, with its case-fatality rate of 30 percent or more and its ability to spread in any climate and season, has been universally feared as the most devastating of all the infectious diseases.

Smallpox was once worldwide in scope; before vaccination was practiced almost everyone eventually contracted the disease. In 1980, the World Health Assembly announced that smallpox had been eradicated and recommended that all countries cease vaccination.

An aerosol release of smallpox virus would disseminate readily given its considerable stability in aerosol form and epidemiological evidence suggesting the infectious dose is very small. Even as few as 50-100 cases would likely generate widespread concern or panic and a need to invoke large-scale, perhaps national emergency control measures.

Several factors fuel the concern: the disease has historically been feared as one of the most serious of all pestilential diseases; it is physically disfiguring; it bears a 30 percent case-fatality rate; there is no treatment; it is communicable from person to person; and no one in the U.S. has been vaccinated during the past 25 years. Vaccination ceased in this country in 1972, and vaccination immunity acquired before that time has undoubtedly waned.

Smallpox spreads directly from person to person, primarily by droplet nuclei expelled from the oropharynx of the infected person or by aerosol. Natural infection occurs following implantation of the virus on the oropharyngeal or respiratory mucosa.

Contaminated clothing or bed linen could also spread the virus. A smallpox outbreak poses difficult problems because of the ability of the virus to continue to spread throughout the population unless checked by vaccination and/or isolation of patients and their close contacts.

Between the time of an aerosol release of smallpox and diagnosis of the first cases, an interval of as much as two weeks is apt to occur. This is because there is an average incubation period of 12 to 14 days.

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EpiCenter Customer Report, 2002

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Wisconsin respondents indicated a higher percent of using those services (88%) than Michigan (36%). The most frequently used diabetes service applications included diabetes chart audit data entry and chart audit analysis or report with the percent using these services being over 50%.

Health Profile Assessment

One of the services provided by the EpiCenter is the preparation of tribally specific health profiles. We were interested in finding out if these were useful to the tribes and if so how were they being used. We found that over 40% of the survey respondents used the tribal and three-state health profiles for program planning and program related-presentations. The overall score for the profiles' usefulness was 4.3, which indicated the profiles were well used. (A Likert scale was used with a range of 1 to 5 with a score of 1 equaling dissatisfaction and 5 equaling excellent satisfaction.)

RPMS Services Assessment

RPMS (IHS clinical software) training and support is one of the services offered through the EpiCenter. We found that 36% survey respondents answered that their staff had been trained for RPMS by EpiCenter staff in Bemidji area (except MN). The most frequently used training application was RPMS data entry (29%). The training was well done as the score of satisfaction was 4.2. In addition, the greatest training needs were found to be the diabetes package (51.4%), women's health (45.7%), Q-man (40%), and immunization (40%). (A Likert scale was used with a range of 1 to 5 with a score of 1 equaling dissatisfaction and 5 equaling excellent satisfaction.)

Please note that due to the small sample size, the results could be over or underestimated.

For a copy of the complete survey results, please contact Nancy Miller-Korth at nkorth@glitc.org

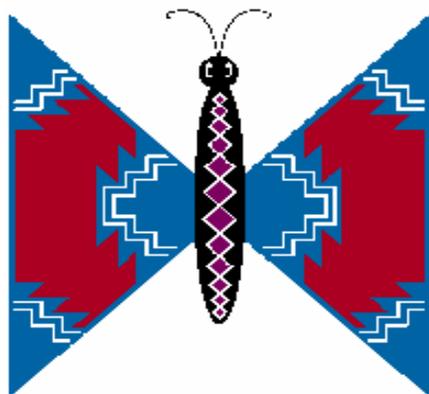
Smallpox

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After the incubation period, the patient experiences high fever, malaise, and prostration with headache and backache. Severe abdominal pain and delirium are sometimes present. A maculopapular rash then appears, first on the mucosa of the mouth and pharynx, face and forearms, spreading to the trunk and legs. Within one or two days, the rash becomes vesicular and later pustular. The pustules are characteristically round, tense and deeply embedded in the dermis; crusts begin to form about the eighth or ninth day. When the scabs separate, pigment-free skin remains, and eventually pitted scars form. Treatment of smallpox is limited to supportive therapy and antibiotics as required for treating secondary bacterial infections. There are no proven antiviral agents effective in treating smallpox.

For further update information go to CDC website at

www.cdc.gov/smallpox



EpiCenter Welcomes Four New Team Members

This new year the EpiCenter as been expanded. This Fall we have hired four new employees; epidemiologists Kimmime Pierce and Greg Rachu, student development coordinator Karen Goulet and Secretary Amy Poupart.

Greg Rachu

Greg is the Epidemiologist that will be serving the Minnesota Tribes. He grew up in Wisconsin and has his BS in Pharmaceutical Sciences from the University of Wisconsin's School of Pharmacy. He spent two years teaching science in a small village of Eritrea, East Africa, as a Peace Corps volunteer. Upon his return to the United States, Greg completed his MPH from Tulane University in New Orleans, Louisiana. He then returned to East Africa for another year and a half working on refugee relief projects, war zone health assessments, and data collection for an HIV project. Greg currently resides in Arbor Vitae, Wisconsin.

Kimmime Pierce

Kimmime is the Epidemiologist that will be serving the Michigan Tribes. She comes to us as a fresh graduate of the University of Wisconsin-Madison Masters of Science program Population Health Science with an emphasis in Epidemiology. Her previous research has been on chronic diseases such as diabetes, cardiovascular disease, peripheral vascular disease and cancer. Kimmime is Native Hawaiian, however, grew up in the Madison area. She frequents the pow wow trail and is a women's traditional dancer. She has started to get settled in and has recently bought a house in St. Germain, Wisconsin.

Karen Goulet

Karen is the new student development coordinator. She received her BA from The Evergreen State College in Olympia, Washington and MFA from the University of Wisconsin-Madison. She has been working in education and advocacy since graduating. She had various roles working with students in

higher education as an instructor, advisor, and in administrative capacities. She as also worked in community outreach activities, and has mentored students on an individual basis. Karen is an enrolled member of the White Earth Ojibwa Tribe in Minnesota and she brings to us experience with events planning, consensus building, and working with various agencies and diverse populations. Being from family of educators, her interest is in education and she is committed to being an educator and enjoys opportunities to support intellectual growth. Karen is also an artist, poet and a member of the National Indian Education Association, Wisconsin Women of Color Network, and Women's Caucus for Art.

Amy Poupart

Amy is an enrolled member of the Lac du Flambeau Tribe and has lived the majority of her life in Lac du Flambeau. After completing high school and some college. She worked for a multi-faceted insurance brokerage in Lac du Flambeau. She joined GLITC in mid-December, and excited to be working with the Epicenter. She has one son, Cole, who is currently seven years old, two naughty cats, and a dog.



NATIVE RESEARCHER'S CANCER CONTROL TRAINING

The program:

Under the sponsorship of the National Cancer Institute, this grant-funded program is designed to enhance the research skills of and increase the number of Native people involved in cancer control activities.

The curriculum will include, but not be limited to the following:

- Epidemiologic methods
- Design and implementation of cancer intervention studies
- Data management and data analysis
- Grant and manuscript preparation
- Software relevant to cancer control activities
- Questionnaire design
- Use of Medline and other software for library searches
- Use of national databases
- Human subjects protection
- Grant funding agencies and potential funding sources
- Grant budget management

Who should apply?

Anyone in the health care, academic, or research field; those interested in cancer research; and people in a position to implement cancer research or intervention programs in a Native community.

Dates (Attendance at both sessions is necessary):

June 15-27th, 2003

Oregon Health & Science University
Portland, OR

October 19-24, 2003

University of Arizona
Tucson, AZ

Cost: Full Scholarships are available. The training program will be offered as an all expenses paid scholarship to qualified candidates. This includes airfare, ground transportation to and from the airport, hotel, books, and meals

during the three weeks of training.

For more information and applications Contact: Esther Dunn
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Do You Have Any RPMS Training Needs?

Dina George, MIS Analyst at the Great Lakes EpiCenter may be able to help. She is able to do one-on-one on-site and group training on various RPMS packages. Please feel free to contact Dina at 1-800-472-7207.



The Resource Patient Management Systems (RPMS) Diabetes Management System Training in Bemidji Area

In conjunction with the Bemidji Area Office and the Epicenter sponsored the RPMS Diabetes Management System training for all the Native American Indian tribes in the states of Wisconsin, Minnesota and Michigan. This training was made possible through the grant support from the IHS National Diabetes Program.

The Diabetes Management System training was offered to all the Diabetes Coordinators. The first day and a half of the training focused on the Q-man search function of the RPMS system. The remaining time was spent on reviewing Diabetes Register maintenance, Data retrieval, and for procedures recording and entering diabetes related data respectively.

Wisconsin tribes received their training in December 17-19, 2002, in Rhinelander, WI. Seven tribes participated and the attendance was poor partly because of the bad weather.

Minnesota Diabetes Management System training was held at the Mille Laes Grand Casino in Onamia, MN,

from January 21-23, 2003. Sixteen members of the Minnesota tribes participated. The Michigan training was held at the Grand Travers Health Facility in Suttons Bay, from January 28-30, 2003. All the available 18 slots were taken and was very well attended.

The students were asked to rate on the content, organization, teaching methods, knowledge and skills gained, hands on-training, relevancy to work, quality of facility, time for questions and discussion, and instructors knowledge, the overall training score was 4.4 and score 1 being poor and 5 being excellent.

We would like to thank the Bemidji Area Office, for the use of their computer equipment and for their cooperation. In addition, we also want to thank Gary Lawless, from Cimarron Medical Informatics, for conducting the RPMS Diabetes Management System training sessions for all the Tribes in the Bemidji Area Office.

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