



**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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## Designing Questionnaires and Conducting Surveys for Health Data

Often information is needed about a population, which can only be obtained by conducting a survey—questioning the population itself. Surveys should be considered when there is a specific question to be answered and there is no existing data source to provide the information. Specifically, surveys can be used to obtain many types of information. Some surveys that might prove useful to those providing health services to a population might include a satisfaction survey, behavioral risk factor survey, utilization survey, demographic profile survey, needs assessment survey, health assessment survey, or social and cultural beliefs and practices survey.

To plan and implement a survey, pay attention to these 12 steps: 1) Lay out the objectives of the investigation, 2) Define and locate the target population, 3) Determine what resources are available, 4) Determine sample size, 5) Determine sampling method to be used, 6) Decide on mode of data collection, 7) Decide how data will be processed and analyzed, 8) Develop, field test, and revise the questionnaire, 9) Train the interviewers and conduct field-work, 10) Check for coding errors, 11) Enter, tabulate and analyze the results, and 12) Report the results.

Sampling is used to survey large populations by statisti-

cally selecting a specified number of persons to be representative of the entire population. Sampling offers the advantages of being relatively quick and cheap, and is generally more accurate than a census (full population) survey. However, applying sampling methods and selecting sample sizes can be an intimidating task. Consult a statistician or epidemiologist with experience in sampling when in doubt about this critical step.

Surveys can be categorized by their data collection methods commonly including mail, telephone, personal interview, and observation. However, often more crucial is the questionnaire design process. Keep in mind these useful hints when designing your questionnaire: 1) Keep the questionnaire questions as simple to understand as possible as far as reading level, defining terms, and avoiding technical terms and abbreviations, 2) Make the questionnaire easy to code for the purposes of data entry and analysis, 3) Start out with a few lead questions to give

the participant a chance to warm up and begin to feel comfortable, 4) Collect the needed information *only* and keep it as short as possible, 5) Don't expect the participant to recall information from a previous question, 6) Make the questions as clear and specific as possible to ensure you get the information you need, 7) Have the questions follow a logical flow, going from general to more specific and grouping like questions together, 8) If possible, derive the survey from other surveys that have already been tested, used, and validated saving yourself some work and also allowing later comparisons to other groups, 9) In multiple choice questions, always offer exhaustive responses including options for "no opinion"

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This Newsletter is published by the Great Lakes EpiCenter. For copies, or to be added to the mailing list, contact Dawn McCusker or Stephen Everett at 800-472-7207.

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## Helpful Hints on Survey Development

Many tribal health programs have conducted health surveys in recent years. Both in-person interview and mailed surveys have become popular means of collecting demographic, health and social issue related information in Tribal communities. With the increased surveying of communities has come increasing complaints about being “surveyed to death”. Community members are surveyed on different topics by a variety of people, and often never being included in the reporting of the results. This is unfortunate because it effects the attitude and participation rates of people in tribal communities toward participating in surveys. So, what can be done? Here are some tips for making the most of a community survey:

### Do some planning up front.

- Define goals for the survey project, what questions do you want to have answered.
- Develop the methodology for choosing a sample (understand the ramifications of various sampling techniques and how they might affect the survey results).
- Look at samples of other surveys that ask similar questions.
- Decide on the type of analysis you are interested in
- Get some professional input at the beginning. This does not mean that you have to let someone else determine the survey content, but rather that someone with survey experience helps you maximize what you will get out of each question and to help make sure your goals for the survey are realized.



## Eight Tips for a Better Questionnaire

**1. Write to your audience.** Certain words, phrases, and abbreviations may mean different things to different groups. If you aren't certain every single respondent will know what it means, define it or don't use it. Many people, whether diabetic or not, would not understand the question “what is your HbA1c value?” When developing the question, you should find out what term your target population uses when discussing blood sugar levels.

**2. Keep it short and simple.** Remember that in most cases, the respondent is doing you a favor by filling out your survey. Don't waste their time. Make sure your questions are brief and easy to understand. Avoid “double-barreled questions like “do you eat fruits and vegetables?” The answer to this is not yes or no question but yes/yes, yes/no, no/yes, or no/no, depending on if they eat fruits and if they eat vegetables. It is better to ask two simple questions than as one complex one.

**3. Ask only what you need to know.** You want to keep the number of questions as small as possible. The longer the survey, the lower the response rate. Too often, survey designers try to ask too much. If the question doesn't impact on the reason you're doing the survey in the first place, don't ask it.

### 4. Do not ask leading questions

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**5. Do not ask leading questions.** For example, you send out a vaccination survey that asks, “Have you received a tetanus shot in the past ten years? (Yes or No).” You've pro-

vided both possible answers, but what if the respondent doesn't remember? If there's a possibility that some respondents may not know the answer to a question, be sure that “I don't know” is a choice they can make.

**6. Make sure every possible answer is provided.** Multiple-choice items are the most popular type of survey questions because they generally are the easiest to answer and to analyze. If you don't provide for all possible answers though, you can confuse and frustrate the respondent and affect the quality of your data. A good question leaves no ambiguity. There should be only one correct or appropriate choice for the respondent to make. Say you ask the question “how often do you exercise,” and offer for possible answers *daily*, *weekly*, or *never*. What if the respondent exercises three times a week? What should the answer be? Better choices would be *1-2 times a week*, *3-5 times a week*, *6-7 times a week*, or *never*.

**7. Make sure there's logic to the pattern of questions and answers.** There should be smooth transitions between questions. Jumping back and forth between topics only serve to confuse respondents and make them uncomfortable. Grouping questions that are similar will make the questionnaire easier to complete, and the respondent will feel more comfortable. The only exception to this is when you're asking especially difficult or sensitive questions. Whenever possible leave these questions un- near the end of your survey. People ll be more likely to answer these estions if you have gained their con- e and trust with the survey so far, d if they decide to quit at that point, least they will have answered most your questions.

**Test your questions.** Before releas- g your survey on its target audience, a few test runs first. Have your ends and coworkers take the survey d then question them about the ques- tions, the answers, and the survey as a whole. Then do a pilot test; have a small sample of the target audience

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(about 5-10 people) take the survey and then get their feedback. These people bring a fresh perspective to the survey design process and often make helpful suggestions to make the survey better.

### Designing Questionnaires (cont.)

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or "don't know."

Once you collect the survey information you are ready for data entry, analysis and interpretation of the results. Lastly, don't forget the important step of reporting the results, not only to those who will use the information that you have gathered, but also to those who participated in the survey.

If you would like help designing, implementing, or analyzing a survey, please contact Stephen Everett at 1-800-472-7207.

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### Job Announcement

The EpiCenter has a position open for an Epidemiologist. This position will mainly work with the Tribes in Wisconsin. For more information please contact Nancy Miller-Korth at 800-472-7207 or [nkorth@glitc.org](mailto:nkorth@glitc.org).

### RPMS CORNER

Many people have expressed interest in developing computerized registries for cancer and other conditions. For some people, the Case Management System (an application within RPMS) may be the best option. If you are interested in assistance with developing a registry for tracking clients, give Dina George a call at the EpiCenter. Dina also conducts group and individual training for most RPMS packages. You can reach her at (800)472-7207.

### Reliability and Validity

#### Reliability

Reliability "...is the extent to which an experiment, test, or any measuring procedure yields the same result on repeated trials", (*Colorado State University Writing Guide*). Reliability is concerned with the accuracy of the actual measuring instrument (the survey tool). Reliability of survey questions allows one to have confidence that the question will yield a consistent response.

#### Validity

Validity "...refers to the degree to which a study accurately reflects or assesses the specific concept that the researcher is attempting to measure", (*Colorado State University Writing Guide*). There are two main issues of validity, external and internal validity. External validity refers to the extent to which the results are generalizable to a larger population. Internal validity refers to the rigor with which the survey was conducted. For example, the overall study design, care taken in conducting measurements, and decisions concerning what was measured and not measured on the survey.

### THANKS FOR THE MEMORIES

This is my last article for the EpiCenter newsletter. I am leaving Great Lakes Inter-Tribal Council and the EpiCenter, my last day is May 7th. I have accepted a position as an Epidemiologist with Sonoma County in Northern California.

I wanted to take this opportunity to tell everyone involved with the Great Lakes EpiCenter how thankful I am for having had the good fortune of working with you all. I have learned so very much in the nearly five years I have worked with the EpiCenter project. The people at Great Lakes and those of you that I have worked with and met from all over will hold a special place in my heart.

I have learned first hand that change (even for improving the public's health) can be so incredibly slow and frustrating. And yet, what amazes me is that so many people I have met in public health keep at it, with new and exciting ideas. It's the people who do public health that keep it going and don't allow a slow "system" to stop them. Thank you.



### UPCOMING MEETINGS/TRAINING

#### Bemidji Area Nurses Conference (BANC), June 25-26, 2002

Grand Casino, Mille Lacs, MN. For more information and registration contact the Coordinator in your state, MN- Cathy Bird (218) 759-3421, MI- Rick Haverkate (906) 635-4208, WI- Bert Doud (800) 472-7207

#### Maternal and Child Health Epidemiology Conference, December 11-13, 2002, in Clearwater Beach, Florida

Go to [www.cdc.gov/nccdphp/drh](http://www.cdc.gov/nccdphp/drh) for more information and registration.

#### 4th Annual Families Helping Families Gathering, June 26-28, 2002

Chula Vista Resort, Wisconsin Dells Call Jeanette Pearson or Sharon Belknap at 800-472-7207 for information

#### The Changing Face of Diabetes in Minnesota, June 3, 2002

Contact Janice Schumacher 651-281-9849 for more information.

## YOUTH SPEAK OUT, A PARTICIPATORY RESEARCH MODEL: ASSESSMENT, ASSET DEVELOPMENT, AND KNOWLEDGE BUILDING TO GOOD HEALTH.

By Denise Marth, R.N., M.S.N

This participatory research model was constructed to involve the Baraga County Michigan youth in an asset development framework; to create a database of information as it relates to health behaviors and attitudes. Communities can replicate this model to empower youth with current health information in order to reduce risks and prevent the development of chronic disease.

Participatory research with youth in any given community weaves health promotion and disease prevention into the asset model that strengthens capacity building from within. It gives youth a sense of hope, of possibility, and reassurance that they have choices for their own well being. This approach also has the potential to influence youth in becoming more involved with science and health curricula. Consequently they may seek careers in science and health care fields. When youth become more self-reliant and health conscious, they have an innate influence not only on their peers, but also upon their families and siblings. Youth may develop the sense that they have the power to create their own future. A spiritual healer once said, "people have the power to make their own blessings".

While participatory research promotes capacity building and knowledge building it plays a strong role in policy advocacy. This can be seen on a local and state level. Through out the process of participatory research and up until the end of data dissemination. The process involves building networks, coalitions, and alliances of like-minded individuals, willing to address the health status of the community. It also requires structuring of dialogues across differing perspectives and players. The health data collected provides the vehicle to lobby, campaign and create public education moments through a variety of methods.

Researchers are able to make the connection and enlist the community throughout the process as they contribute towards empowering the people. The

communities are your collaborators.

This participatory research project produced survey results from 382 youth. The health behavior and attitude data collected was gathered in 2001 from Baraga County youth, grades 6<sup>th</sup> -12<sup>th</sup>. The aggregated data includes a separate result compilation of 85 Native American youth from the Keweenaw Bay Indian Community. These Native American youth represent 22.3% of the total population surveyed.

National and statewide research indicates that nutrition and exercise is a primary contributing factor in preventable mortality. However, nominal research and funding resources are directed towards prevention in adolescent populations. A lack of assessment involving adolescent health perceptions and behaviors is prevalent in the research field. Native American youth are at particularly high risk for developing chronic disease. Due to the lack of assessment of adolescent health perceptions and behaviors a participatory model was developed to gain youth involvement in an asset development framework and to begin creating a database of youth, health information. Without this type of research, in all likely hood, funding would never be allocated. This research provides the necessary impetus.

**Methods:** Carolee Dodge Francis, MA, consultant to the project, developed the questionnaire tool. This survey tool was designed to collect demographic data, perception of family health history, lifestyle

habits/practices, health care practices, and health educational needs. The tool was disseminated to 6th-12 graders in the two local high schools through on-site Health Fairs. Follow-ups with educational presentations were conducted in both schools, plus individual notification based upon abnormal clinical findings. In addition, a weeklong summer session was offered to youth focusing on exercise and nutrition information among other asset development activities. Collaborating agencies included; Baraga and L'Anse schools, tribal and non-tribal Health Departments, Extension Agencies, Keweenaw Bay Ojibwa Community College, Keweenaw Bay Indian Community and especially the youth of Baraga County.

**Results:** The survey results indicated that Native American youth were not significantly different statistically than the non-Indian population in regard to Health Behaviors and Attitudes. However, there were a few racial differences to question responses. For instance, when asked about their general health, a racial difference was noticeable between Native American students and the other students surveyed. Native American students were more likely than non-Native American students to state their health as "Okay" rather than "Great". While there were other differences, there were far more similarities between respondents.

**Conclusions:** The project results indicated that youth have a limited knowledge base regarding chronic diseases and prevention practices. But, more importantly, the project reinforces the theory that unhealthy behaviors are established at a young age and are a contributing factor to lifelong practices that may put an individual at risk for chronic disease later in life. These findings demonstrate the need to develop early education and prevention strategies directed towards the



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adolescent population. This early health education initiative could empower youth in preventing the development of chronic disease and the costly medical care associated with it. Participatory research and community feedback creates a climate for positive ownership, intervention and sustainability. Collaboration among Tribes and various agencies assures success, implementation and replication possibilities. Repetition may be redundant, but it needs to be said, **"WANT GOOD HEALTH? IT'S UP TO YOUTH!"**

The combination of data outcomes and the research process has resulted in the following:

- Expanded hours of local school gyms, increased youth access at KBOCC Fitness Center.
- Assemblies in schools discussing health care issues.
- Nutritionist visits to local schools throughout the school year.
- Planned asset development "Family Fun" exercise activities and socialization.
- Increased awareness of impact of culture on health care attitudes and behaviors.
- Dissemination of participatory research project locally and nationally.
- Plans for future testing of youth and health fairs.
- Increased collaboration within tribal and non-tribal communities.
- Planning for a UP Regional Asset Development Conference with MSU staff.
- Development of articles for publication regarding the participatory research project.

This participatory research project was made possible by the collaboration of the Baraga County Peer Educator/Adult Mentor Group-Office of Minority Health, Michigan; Baraga and L'Anse Community Schools; Baraga County Community Foundation; MI AIDS Fund; Baraga County Parent Network; Keweenaw Bay Ojibwa Community College; Community Health Staff of

DHHS/KBIC; staff of Great Lakes EpiCenter, Great Lakes Inter-Tribal Council Inc.; Leslie Bek, Les is More consulting; and most of all through the participation of our most valuable assets...the youth of Baraga County

*For more information about this project, please contact the researchers Carolee Dodge Francis, M.A. cfrancis@uplogon.com and Denise Marth R.N., M.S.N. 906-334-2763.*

### **Great Lakes EpiCenter Survey Policy**

More and more Tribal programs are beginning to use surveying as a methodology to determine health needs and practices in their communities. While this is a great way to find out information, there are some pitfalls.

The EpiCenter staff is very willing to help Tribal programs with survey development, data entry and survey analysis. We have developed a policy with the purpose of helping you to avoid pitfalls and insure the highest quality of results for survey activities.

Simply stated any survey project for which the Great Lakes EpiCenter is asked to do data entry or analysis, we request that you contact EpiCenter staff to assist with the development of the survey tool and sampling methodology. So, if you are thinking about doing a health survey in your commu-



### **EpiCenter and IHS Prepare Bioterrorism CD-ROM for Area Tribes**

Being located in largely rural areas far away from large urban centers, conventional wisdom considers the risk for most tribes becoming a target of a terrorist attack as small. Yet, between October 2001 and February 2002, the Indian Health Service responded to 23 different tribal incidents regarding a potential bioterrorism threat. Although all turned out to be either hoaxes or false alarms, action still had to be taken and resources expended.

A bioterrorism preparedness plan would prepare a tribe for events such as these, limiting resources wasted and anxiety caused. The Great Lakes EpiCenter and the Bemidji Area Office of the Indian Health Service have created a reference manual to inform and assist tribes in developing their own preparedness plans. The guide is by no means all there is to know regarding bioterrorism preparedness nor will it present specific instructions on how to prepare. Due to the diversity of the area tribes in location, size, and resources, a "cookie-cutter approach" is not feasible; the needs and resources of Red Lake Nation aren't the same as that of the Ho-Chunk Nation, and neither resemble those of the Huron Potawatomi. Instead, the information will serve to guide planning, showing where to focus time and energy.

Due to the size and number of documents that will be part of the reference manual, the EpiCenter and BAO have decided to send the information out on compact disk. The CD will allow users to access the documents they need quickly and easily and not add yet another large manual to already limited shelf space. The only requirements to run the CD will be a computer with a CD-ROM drive and an Internet Web browser such as Netscape Navigator or Microsoft Internet Explorer. Adobe's Acrobat Reader will also be required, but will be contained on the CD-ROM for those that don't have the program.

The Bioterrorism Preparedness Reference Manual CD-ROM will be sent out to Tribal Health Centers this June. If you have any questions, please call Stephen Everett or Nancy Miller-Korth at (800) 472-7207.

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