

Diabetes Research Project Development Report

June 25, 2007

Prepared for:

NAHNDAHWEH TCHIGEHGAMIG
The Wikwemikong Health Centre Health
Services Committee

Did Somebody Say Diabetes?

The information contained in this report was made possible by the efforts of the Wikwemikong Health Centre Diabetes Research Team, The Principle Investigators, Research Assistants, Staff and Consultants, and by the support and commitment of the Wikwemikong Health Services Committee. This project is an on-going collaborative research strategy between the Wikwemikong Health Centre and Kristen Jacklin at the Northern Ontario School of Medicine

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This research was generously supported by the Indigenous Health Research Development Program (www.IHRDP.ca) and the Northern Ontario School of Medicine Research Department Intern Program.

This report was prepared for the Wikwemikong Health Centre Health Committee for Approval and Acceptance. Upon ratification this report will be available to Wikwemikong community members and any one who participated in the research upon request.

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Executive Summary

This research report represents the work undertaken by the Wikwemikong Diabetes Research Team from May 2006 to May 2007. This developmental research project was initiated to address research needs related to diabetes in Wikwemikong. Diabetes research was deemed the priority area for research by Wikwemikong Health Centre (WHC) senior management and the Health Services Committee following consultations in 2005 and 2006.

The goals of the developmental diabetes research study was to engage in a community consultation with community member's to hear their opinions on a larger scale diabetes research project and whether or not they would support such a project. This developmental stage of the research also sought to collect preliminary data concerning diabetes in Wikwemikong to support and inform future research proposals.

This research was conducted in partnership with the Wikwemikong Health Centre Diabetes Research Team and Kristen Jacklin, Medical Anthropologist and Assistant Professor at the Northern Ontario School of Medicine. The research activities and approach used were developed by the Wikwemikong Diabetes Research Team and received approval from the Wikwemikong Health Centre Health Services Committee. This research received ethics approval from the Laurentian University Research Ethics Review Board.

The research methodology included a community survey (n=245) administered at local powwows during the summer of 2006, community focus groups (n=4, with 38 participants), WHC staff focus groups (n=5, with 29 participants), key informant interviews (n=7) a literature review and production of an annotated bibliography concerning diabetes in Aboriginal peoples, and a review of internal data and documents concerning diabetes.

Analysis of the data collected during this research supports the notion that diabetes is an important health concern for people in Wikwemikong. Survey results indicate the 16% of the population report being diagnosed with diabetes and 50% of the population who is over 50 years of age report being diagnosed with diabetes. Exceedingly high blood sugar levels were found to be affecting the client population. Reports of sustained levels of between 20-30, and as high as 43, came from WHC staff and community members. Participants believe that diabetes rates are increasing in the younger population and that secondary complications appear earlier and are more severe in Wikwemikong. It was determined that currently the health centre has no way of knowing how many clients have diabetes, have complications associated with diabetes, if there has been an increase or decrease in diabetes over time, or how many people require dialysis.

A key theme that threaded discussions on mental and physical health concerns surrounding diabetes was the interconnectedness of illness in Wikwemikong. Any larger research study will greatly benefit from an approach that examines the co-incidence of chronic and infectious diseases and mental illnesses with a diabetes diagnosis. This is increasingly referred to as a "syndemic approach."

Connections between mental health problems and diabetes were discussed by most participants and it was felt that mental health and diabetes have a cause-and-effect and effect-and-cause relationship; that is to say, mental health problems contribute to the development and onset of diabetes and secondary complications and mental health problems are produced by diabetes. A key theme that appeared from the focus groups and interviews was the idea that diabetes and complications such as amputations have become normalized in Wikwemikong resulting in an attitude of acceptance and passiveness concerning the disease.

Participants openly discussed issues concerning the care of diabetes clients. It was suggested that the WHC may improve care by adopting an inter-disciplinary and collaborative 'team-approach' in the clinic area. Most participants also expressed keen interest in the use of traditional medicine to treat diabetes and suggested that this may be an important research topic.

The results indicate strong support from the community for a large scale, multi-year, diabetes research strategy in Wikwemikong. All participants in the focus groups were in favour of such a research study and 74% of those surveyed said they would support and participate in a door-to-door interview and blood glucose test (only 4% said they would not participate). The analysis of all of the data resulted in the elucidation of the following diabetes research priorities for the community:

- a. Local epidemiology of diabetes and complications arising from diabetes
- b. Pathogenesis of diabetes in Wikwemikong and Anishnabe people (that is, the development and effect of the disease)
- c. The role and efficacy of Traditional Medicine in the treatment and prevention of diabetes
- d. Interconnections of mental and physical health in diabetes onset, disease progression and outcomes
- e. Health services evaluation for effectiveness of diabetes care

Testing the capacity of the research team and the WHC to carry out a large scale project was one of the outcomes of the developmental research stage. We have learned lessons that we can take with us as we proceed to the next phase of research. We have learned for example that it will be essential to engage and partner with the Manitoulin Health Centre and the Little Current Medical Associates in order to access data, access laboratory facilities, and effect change over the long term. Finally, central to the success of such an ambitious research study will be research capacity building at the WHC. The development of research capacity in Wikwemikong is critical in order for the community to ensure they are equal partners and collaborators with external researchers.

Key Findings

Results Section One: Survey

- ✚ Most survey participants reported that they have had their blood sugar checked (73%). More women (83%) reported having had their blood sugar checked than men (58%).
- ✚ 16% of survey respondents reported that they have been told by a health professional that they have diabetes. The percentage of people with diabetes increases with age and 50% of those over 50 years of age reported having diabetes. This is consistent with the results reported in the Wikwemikong Community Health Plan 2001.
- ✚ 70% of survey respondents reported that someone in their immediate family has diabetes. The analysis revealed that on average each respondent has two immediate family members with diabetes.
- ✚ 89% of respondents believe diabetes is a significant health concern in Wikwemikong and 74% of respondents support and would participate in future research concerning diabetes including a door-to-door survey of the community consisting of an interview and blood sugar test. Only 4% of respondents stated they would not participate.

Results Section Two: Focus Groups and Interviews

- ✚ Wikwemikong has no accurate figures concerning incidence and prevalence of diabetes in Wikwemikong. Community members and staff hold several theories about the incidence and prevalence of diabetes; such as: the belief that the percentage of people with diabetes is high, age of onset is becoming younger and youth are at risk, men have poorer outcomes, and secondary complications from diabetes are a major contributor to the disease burden. However, there is no data collection process in place that allows for confirmation of these theories.
- ✚ Participants expressed concern that diabetes and complications arising from diabetes are 'normalized' in the community, and that people have come to accept these illness outcomes as inevitable. This is viewed as an impediment to effective prevention and management of type 2 diabetes in Wikwemikong.
- ✚ Participants suggested many residents lacked access to nutritious food choices. Low income levels, monthly subsidized income programs, and a lack of resources were all reported to be major barriers to the prevention and management of diabetes in Wikwemikong.
- ✚ Sustained blood glucose levels of 20 and 30 are felt to be commonplace in Wikwemikong and levels in the 40s are not unheard of. Levels over 10 in people with diabetes indicates poorly managed diabetes and places the person at increased risk for secondary complications. Results suggest that these high blood glucose levels are a result of either poor patient care and/or poor self care resulting from denial, fear, and/or acceptance. This finding requires further research and immediate action.

- # The incidence of secondary complications from diabetes is believed to be high. Participants think that secondary complications manifest at younger ages compared to the non-Aboriginal population and that deterioration occurs more rapidly. Neither staff nor physicians have accessible data on the incidence or prevalence of secondary complications of diabetes in Wikwemikong or how many band members are receiving dialysis.
- # Focus group and key informant interviews revealed that there is interest and support for research concerning the use of traditional medicine in the treatment and prevention of diabetes. Three key research areas emerged: 1) effectiveness of current treatments, 2) how to combine western and traditional medicines safely - models of care and drug interactions, and 3) the role of traditional culture in promoting healthy living.
- # Staff agreed that there was a lack of coordination of services at the WHC when it came to servicing the needs of patients with diabetes. Community members reported that services and programming were available but access to physicians made the management of their diabetes difficult. Staff at the WHC suggested piloting a diabetes team approach to care that would include physicians, Noojmowin Teg staff and WHC staff from Mental Health, Wellness, Traditional Medicine and Clinic (potentially others) and evaluating its success.

Results Section Three: Data from WHC Internal Documents

- # No information on the results of blood glucose screening clinics has been maintained by the WHC.
- # Data extracted from the WHC Health Transfer Evaluation Report (2004) indicates that diabetes inpatient admissions to the Manitoulin Health Centre for Wikwemikong increased between 1999 and 2004. Physicians estimated that 50% of their clients in Wikwemikong have diabetes.
- # Both the 2006 diabetes research and research reported in the Wikwemikong Community Health Plan (2001) report the percentage of people in Wikwemikong with diabetes as 16% of the population (all age groups).
- # Researchers found no data is being collected by the WHC on diabetes. We were unable to ascertain how many patients are diagnosed with diabetes and/or how many patients are receiving specialized treatment for diabetes.

Recommendations

The recommendations are related to future research opportunities and priorities as well as to the implementation of data collection, production and analysis at the Wikwemikong Health Centre. It should be noted that not all of the activities described in the recommendations require research funding to implement. It may be possible to implement some of these recommendations with current resources at the WHC and NOSM. Other recommendations will require applications for funding and ethics approval.

1. Given the recent turnover in Diabetes Research Team membership it is recommended that the team meet to discuss our composition, role, and future directions. Consideration must be given to including other agencies in the community as well as community members as either members of the research team or as an advisory group.
2. It is recommended that the WHC Health Services Committee discuss their expectations for the “role-out” of the larger diabetes research strategy and provide clear guidelines on the authority of the Health Director and the authority of the Diabetes Research Team related to the implementation of the multi-year diabetes research strategy.
3. It is recommended that the Diabetes Research Team, supported by the management and health committee at the Wikwemikong Health Centre, meet with the diabetes research team working in the other First Nations on Manitoulin Island to discuss research findings, share knowledge, and explore any potential research collaborations for the future.
4. It is recommended that the Diabetes Research Team, in collaboration with managers at the WHC create a research capacity development plan that will seek to mentor staff in research theory and methods and help to ensure the sustainability of diabetes research in the community.
5. It is recommended that diabetes screening activities resume at the WHC and that data on the client (age, sex, weight, height), the results of the screening, and any follow-up referral and diagnosis be tracked. This could be implemented by the physician assistant as a regular part of every client visit and may require a protocol similar to that used for communicable disease tracking.
6. It is recommended that the WHC put a process in place to collect data related to diabetes from all clients. The research team, in collaboration with the appropriate program managers, should be charged with the responsibility of determining what information can be collected, how it will be compiled and managed. This must be implemented using patient chart numbers or another unique identifier in order to protect patient confidentiality. Areas for data collection on clients should include:
 - a. Blood screening results and follow up lab results for all WHC clients
 - b. Diabetes diagnosis
 - c. Diabetes as a cause of death
 - d. Secondary complications associated with diabetes diagnosis
 - e. Dialysis treatments resulting from diabetes diagnosis

7. A chart review or chart audit should be undertaken in order to investigate the prevalence of exceedingly high blood sugar levels and potential causes, for example as related to care-plans or self-care.
8. Based on the findings from the community consultations during this developmental diabetes research project, it is recommended that the WHC conduct a multi-year diabetes research strategy in partnership with the Manitoulin Health Centre, the Little Current Medical Associates and potentially other First Nations addressing the following research priorities:
 - a. Local epidemiology of diabetes and complications arising from diabetes: prevalence, incidence, frequency of undiagnosed cases.
 - b. Pathogenesis of diabetes in Wikwemikong and Anishnabe people; for example, rapid deterioration after diagnosis, functioning with exceedingly high blood sugar levels (how, why, consequences), stress as a cause and effect of diabetes, and the role of access to prevention resources (i.e., healthy food, money, exercise, healthy home life, safe environment) as a cause and effect of diabetes.
 - c. The role of Traditional Medicine in the treatment and prevention of diabetes: effectiveness of current treatments, how to combine western and traditional medicines safely - models of care and drug interactions, and the role of traditional culture in promoting healthy living.
 - d. Co-incidence of infectious, chronic, mental illness with diabetes (syndemics); that is, the interconnections of mental and physical health in diabetes onset, disease progression and outcomes: the relationship between people's ability to cope with diabetes and disease progression, and the role of trauma, depression, fatalism, acceptance and fear in disease outcomes.
 - e. Health services evaluation for effectiveness of diabetes care: can better coordination improve diabetes outcomes? Can better training of staff and physicians improve outcomes?
9. It is recommended that the Diabetes Research Team review the research questions that have emerged and create a collaborative workplan to address the various research areas through the initiation of internal client tracking and the development of research proposal and ethics applications.
10. It is recommended that the Diabetes Research Team meet to discuss a dissemination plan to share results with the community, the funders and to scholarly journals and conferences.

Diabetes Research Project Development

Overview of the Research

This research was conducted in partnership with the Wikwemikong Health Centre Diabetes Research Team and Kristen Jacklin, Medical Anthropologist and Assistant Professor at the Northern Ontario School of Medicine. The research was funded by the Indigenous Health Research Development Program (IHRDP) – A Canadian Institute of Health Research (CIHR) ACADRE centre – through a joint proposal submitted by principal investigators: Phyllis Kinoshameg and Kristen Jacklin. The research activities and approach used were developed by the Wikwemikong Diabetes Research Team and received approval from the Wikwemikong Health Centre Health Services Committee. This research received ethics approval from the Laurentian University Research Ethics Review Board.

Purpose and Rationale

The Diabetes Research Project Development for the Wikwemikong Unceded Indian Reserve is a developmental research project. This developmental research project sought to compile and analyze existing materials on diabetes maintained by the Wikwemikong Health Centre and to solicit community member's opinions on diabetes research needs for Wikwemikong. The information collected during this project is intended to be used to develop a larger multi-year collaborative diabetes research strategy for the Wikwemikong Unceded Indian Reserve.

The Diabetes Research Team created a preliminary list of research questions they hoped to address over the long term as more funding is secured (Appendix A). The seed funding received from the IHRDP was intended to begin to develop research capacity in the community, to gather relevant resources and information on diabetes, and to organize and analyze this material to create a foundation for future research and a strong well substantiated research proposal or proposals.

Authority and Consent

Conducting research in First Nations requires the consent of the community as well as the individual participants. Community consent usually comes in the form of a Band Council Resolution or approval from a representative and recognized organizational or community committee. In accordance with Band Council Motion #385-2004, WUIR Council Meetings #2004-30, each Band Council committee has full delegated authority to act on their decision. Consent to conduct the research outlined here has been granted by the Wikwemikong Health Centre Health Services Committee. This committee reports to the WUIR Chief and Council through their liaison, the Health Services Portfolio Holder and by way of committee minutes.

Individual informed consent was obtained by everyone who participated in an interview, focus group, or who completed a survey. As per our ethics application, informed consent was given verbally and recorded by research assistants for focus groups and interviews. Consent for survey participation was indicated by the participant checking off the appropriate box on the survey after having their rights described by a research assistant and being given a paper copy of those rights.

Methodology

The following represents research methodology. Originally the intent was to immediately involve other First Nations on Manitoulin Island and to conduct surveys and focus groups in all of the other communities. However, due to the existence of a second and simultaneous diabetes research project in the other First Nations and time constraints, the Wikwemikong Diabetes Research Team decided to focus only on Wikwemikong for the initial research phase, and to plan, consult, and collaborate, with the other First Nations once Wikwemikong's results were compiled.

Literature Review: Research assistants and investigators engaged in environmental scans of diabetes resources in the community and in the academic and government literature. The scan covered academic and grey literature studies in Canada for the previous 20 years. References were categorized according to type of study, for example, genetics, co-morbidity, research methods etc., and were then entered into a bibliography reference program. Key references were identified and annotated.

Review of WHC data on Diabetes: A scan of program and research data held at the Wikwemikong Health Centre was undertaken and any data was compiled and reported.

Survey: A community survey was administered to Aboriginal people at local powwows in June and August 2006. The survey contained a series of questions concerning diabetes in order to determine awareness of diabetes issues in the communities and to gauge local support for a multi-year diabetes research strategy in the community. Participants were given a wristband as a gift for participation.

Focus Groups and Interviews: Focus groups were conducted with staff and community members. Focus Group interviews were used to gather data concerning community member's and frontline workers opinions of the research needs of diabetes and willingness for a long term research project in their community. Key informant interviews were conducted with individuals with specialized knowledge. Interviews and focus groups were transcribed. Transcriptions were coded and analyzed in the qualitative software package Atlas.ti. The information obtained through these focus groups will play a key role in laying the foundation for future research activities and funding proposals.

Data Management: Data is co-managed by the principal investigator at the Northern Ontario School of Medicine and the Wikwemikong Health Centre. Databases containing community information is password protected and accessible only to those directly involved in the entry and/or analysis of the data. All project members have signed the WHC oath of confidentiality prior to accessing research information.

Data Analysis: Qualitative data was recorded, transcribed, coded and analyzed using the qualitative software package Atlas.ti. Quantitative data was entered and analyzed in Microsoft Access.

Dissemination Plan: During the developmental portion of this research dissemination will be to the Wikwemikong Health Centre Health Committee, workers, community members and key informants. Dissemination to the Health Centre representatives will be in the form of presentations and reports. Dissemination will also include sending research grant proposals to funding agencies such as CIHR, SSHRC, and the Canadian Diabetes Association.

Outcomes

The diabetes research team was successful in most of what we hoped to accomplish. The literature review was conducted and the team produced an annotated bibliography in hard copy and electronic form containing approximately 150 article summaries. Community consultations in the form of focus groups, key informant interviews and surveys were completed by October 2006. Community participation in these activities varied. Community focus groups had less attendance than we hoped. As a result, our target of seven community focus groups was reduced to four. However, the number of participants at these focus groups was optimal. Total **community consultations** in each of the activities is noted below:

- 319 surveys were completed at Buzwah and Wikwemikong Powwows; 245 of those were residents of Wikwemikong
- 4 community focus groups were held and 38 community members participated
- 29 WHC workers participated in focus groups
- 7 Key Informants were interviewed
- Total Number of Consultations with community members: 319¹

At the time of writing and submitting the report, no **collaboration** or consultation has occurred with the other First Nations. Researchers did involve the Manitoulin Health Centre and the Little Current Medical Associates in this preliminary research, but were given direction to delay consultations with other First Nations until the report had been compiled.

¹ It should be noted that a single community member may have been consulted more than one time, for example if they participated in the survey at the powwow and in a focus group.

Finally, **research capacity building** was challenging during this project due to already heavy workloads managed by the members of the Diabetes Research Team. Efforts were further hindered by the loss of two of the research team members just prior to the completion of this report. The developmental research was successful in hiring and training local research assistants, using local expertise for translation, transcription and facilitation. In total, eleven WHC staff and/or community members worked on this developmental research project in various roles: research team member, principal investigator, translator, research assistant, consultants. A total of three NOSM and Laurentian students and research staff participated in this initiative and one principal investigator from the Northern Ontario School of Medicine.

Results

The results from the survey and focus groups are presented in the next section of this report. *Results Section One* reports on the methodology and findings from the community survey administered at the local powwows during the summer of 2006. *Results Section Two* reports on the methodology and findings from the staff and community focus groups and the key informant interviews. *Results Section Three* reports on the internal environmental scan undertaken in the summer of 2006.

The annotated bibliography has been prepared as an independent document and has been distributed separately.

Dissemination and Sharing the Results

One responsibility of research is dissemination of results. Primary dissemination of these results will be to the Wikwemikong Health Services committee and subsequently to research participants and community members as per our ethics application. Securing future research dollars will be highly dependent on sharing these findings more widely in conference presentations and scholarly journals. Presently, the research team has presented the research model we developed at one scholarly conference:

2006 June 1-2, Northern Health Research Conference, Sault Ste. Marie,

Collaborative Community Based Research: Developing a Diabetes Research Strategy with the Wikwemikong Health Centre, Manitoulin Island Kristen Jacklin, Assistant Professor, Northern Ontario School of Medicine
Phyllis Kinoshameg, Wikwemikong Health Centre

The research team will discuss other findings it deems important to share with a wider audience and bring forward proposals for dissemination of these results to the health committee for consideration.

It is advisable that the results of this study be shared with other First Nations in the Manitoulin District so that meaningful discussions of collaboration can occur.

Results Section One: Wikwemikong Community Diabetes Survey

Introduction

The Wikwemikong Diabetes Survey, initiated in summer 2006, was created with the purpose of consulting with community members on the development of a large scale diabetes research project in the community. It was also used as an opportunity to begin preliminary investigations into long-term research questions in order to inform future research proposals for funding.

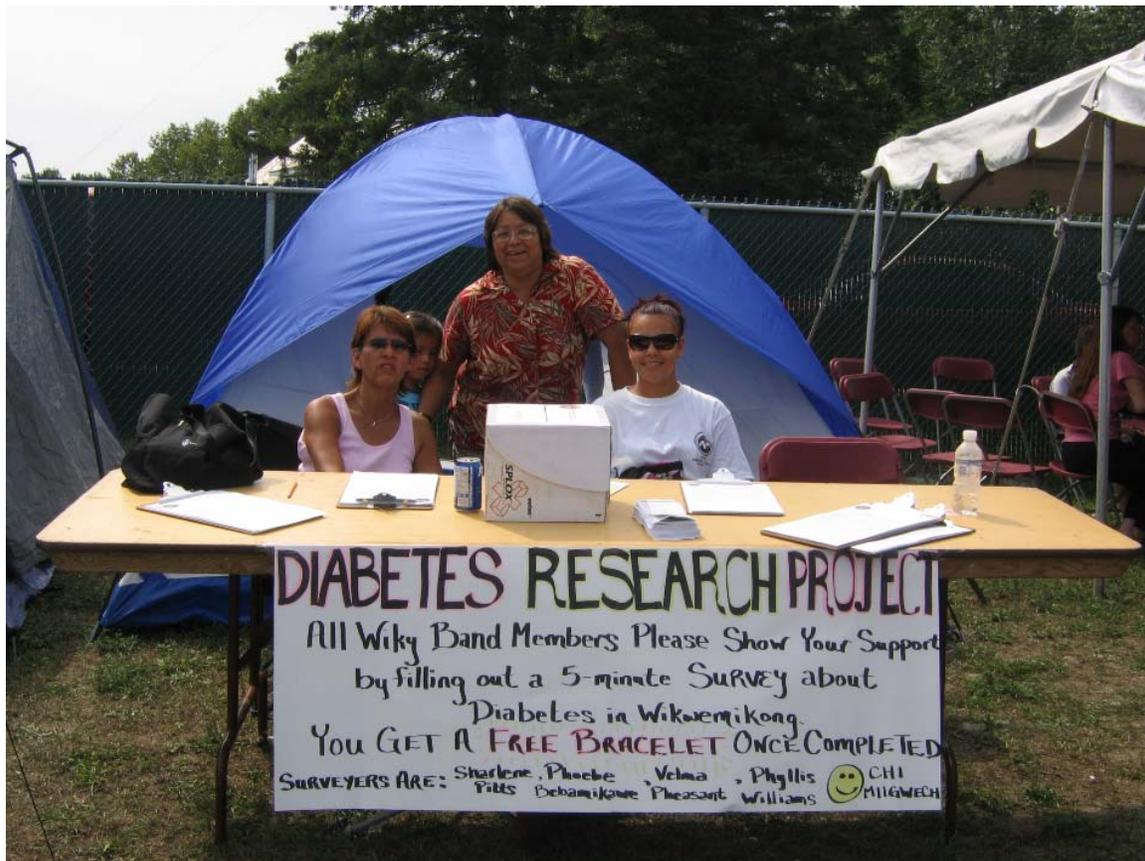
Methods

The survey questions were developed by the diabetes research team and research assistants (Appendix B). The questions were unique to the needs of this research project and although secondary sources and literature were reviewed, the questions were not derived from them. The survey was pre-tested by research assistants and fine-tuned prior to administering the survey.

Survey Administration

Survey data was collected during local powwows. We received permission from the powwow organizing committees to conduct our survey during the powwows in Buzwah and Wikwemikong in the summer of 2006. Participants were asked to answer a one-page survey. They were informed of the purpose of the project, their rights as a participant and their right to refuse to participate. They were given a document outlining the project, their rights and contact information for the Principal Investigators. The survey asked resident band members a series of questions concerning diabetes in order to determine awareness of diabetes issues in the villages. The survey was anonymous with no identifying fields. Respondents completed the survey and placed it into a sealed box. Respondents were given a small non-monetary gift for their participation (a wrist band with the project logo). Local research assistants, who are fluent in Ojibwa, were available for verbal translation if requested by participants. Survey respondents were representative of the youth (ages 16-24), adults (24-50) and the elderly, and were representative of both sexes.

Survey Research at the Wikwemikong Powwow August 2006



Research Assistants: Velma Pheasant, Phyllis Williams and Sharlene Pitts

Data Entry and Analysis

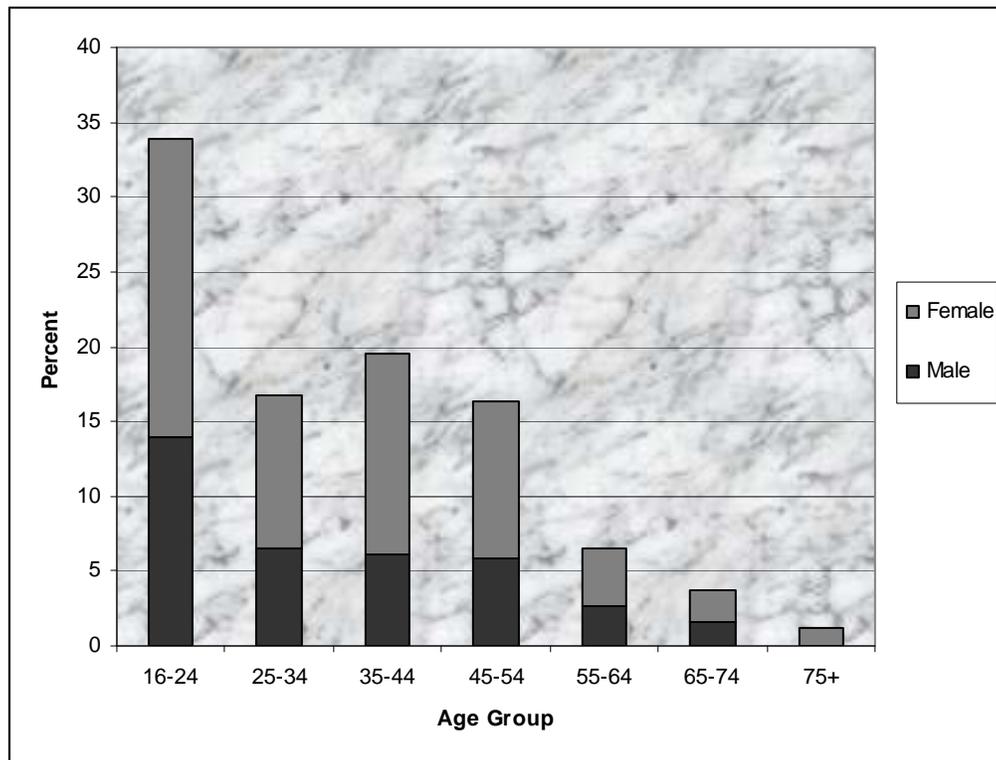
Data from the surveys was entered into a Microsoft Access database by a research assistant. Results were then tabulated and frequencies calculated. Surveys completed by non-residents were entered into the database but were not included in the tabulations or analysis. The diabetes research team and health services committee reviewed the preliminary tabulations and had the opportunity to request new tabulations or cross-tabulations.

Results and Findings

Demographics Profile of Respondents

Two-hundred and forty five (245) Wikwemikong band members were surveyed. More women than men were surveyed: 63% of respondents who answered the survey were women, 37% were men. The higher percent of women surveyed is not reflective of the Wikwemikong on-reserve population which is comprised of approximately 52% men, 48% women.

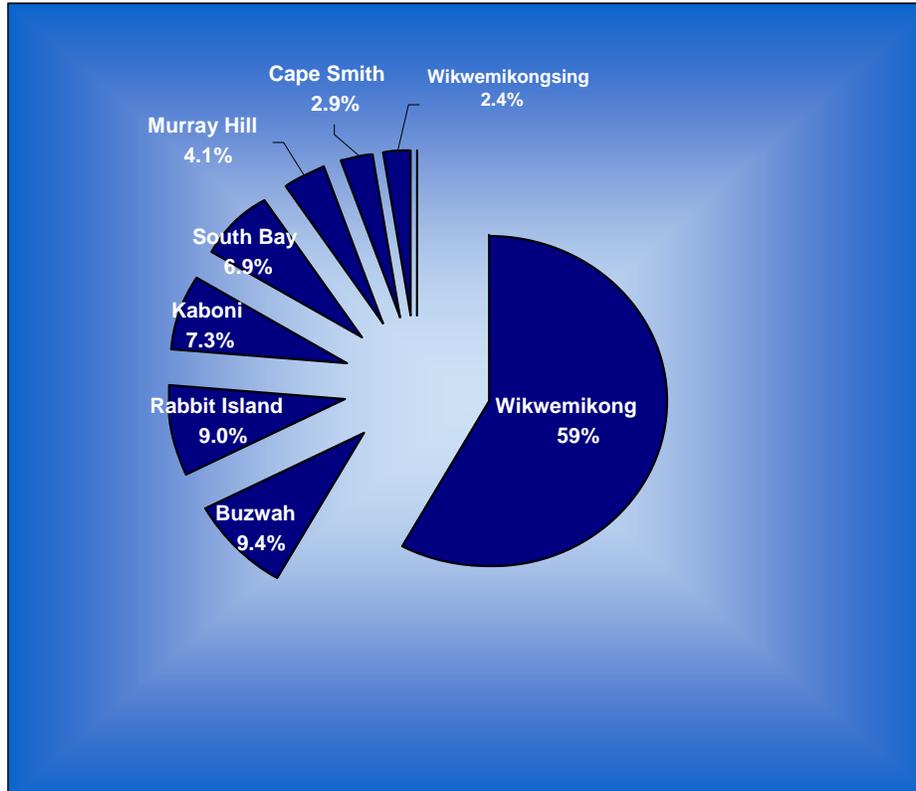
Figure 1: AGE AND SEX DISTRIBUTION OF SURVEY RESPONDENTS



Satellite Representation

There was representation from all satellite villages in Wikwemikong. Figure 2 shows the percent of respondents who were from each satellite.

Figure 2: PERCENT OF RESPONDENTS FROM EACH SATELLITE VILLAGE



Community Services and Prevention

The Diabetes Survey asked a number of questions designed to assess the use of community services in the prevention of diabetes. Special attention was given to blood sugar checked by health care professionals.

Blood Sugar Check

This set of questions was aimed at discovering if respondents have had their blood sugar level checked by a health care professional. It was found that the majority of respondents have had their blood sugar checked by a health care professional (73%) (Figure 3). Further cross tabulation revealed that women are more likely to have had their blood sugar checked than men in all age categories; 83% of women had their blood sugar

checked and 58% of men. A further breakdown showing age and gender of respondents who have had their blood sugar checked can be found in Figure 4. It should, however, be noted that 10 of the 179 respondents who have had their blood sugar checked did not provide responses to age and gender. As such, Figure 4 represents 169 participants.

- ✚ Most survey participants reported that they have had their blood sugar checked (73%). More women (83%) reported having had their blood sugar checked than men (58%).

Furthermore, of the 179 respondents who have had their blood sugar checked, reports of high, low, normal, and borderline blood sugar levels were found. A significant number of respondents reported not remembering what level they had been told (8.9%) (Figure 5).

Figure 3: PERCENT OF RESPONDENTS WHO HAVE HAD THEIR BLOOD SUGAR CHECKED

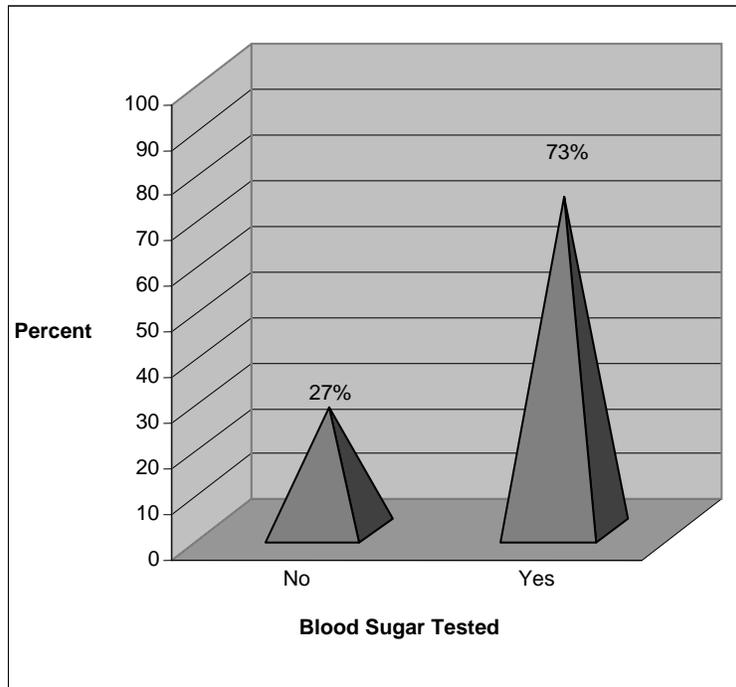


Figure 4: AGE AND SEX DISTRIBUTION OF RESPONDENTS WHO HAVE HAD THEIR BLOOD SUGAR CHECKED

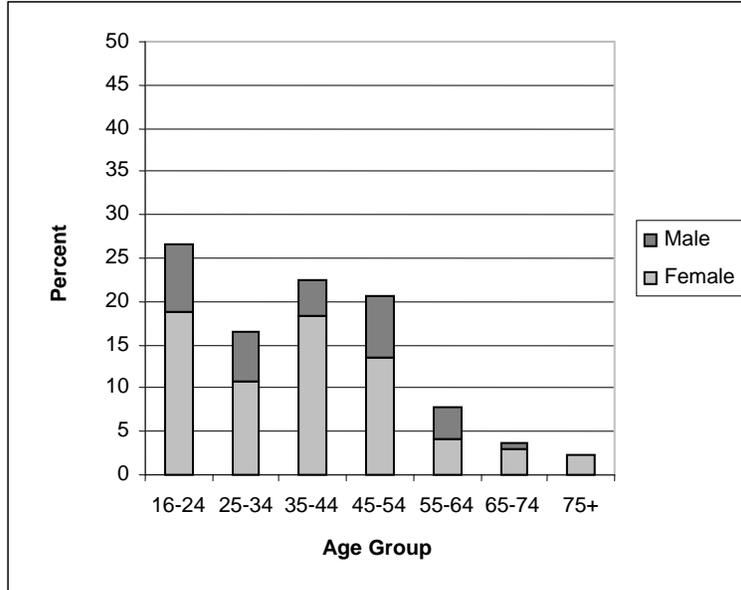
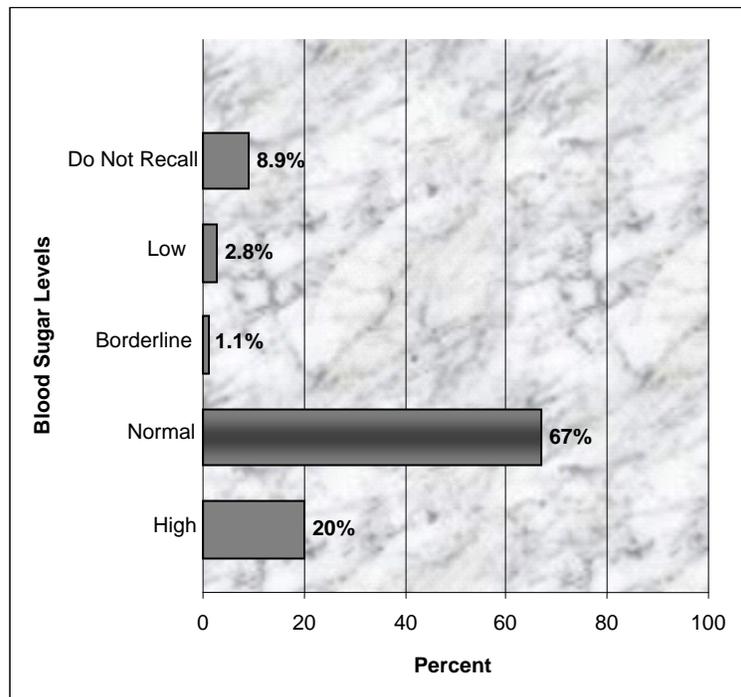


Figure 5: BLOOD SUGAR LEVELS OF RESPONDENTS WHO HAVE HAD THEIR BLOOD SUGAR CHECKED

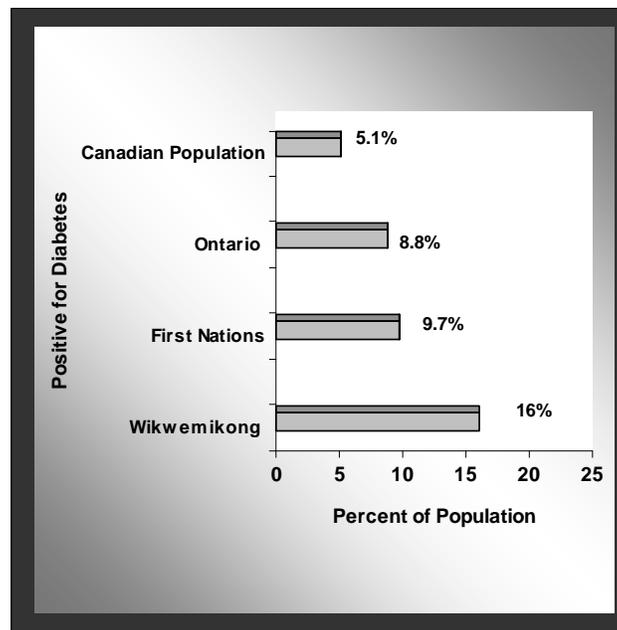


Health Status of Wikwemikong Residents

Diabetes

38 survey respondents (16%) report they have been told by a health care professional that they have diabetes. This would be considered “self-reported” incidence of diabetes. Wikwemikong has a higher than average percent of diabetes when compared to First Nations (on reserve) (9.7%)², the Ontario adult population (8.8%)³, and the Canadian population as a whole (5.1%)⁴ (Figure 6).

Figure 6: PERCENT OF DIABETES IN WIKWEMIKONG COMPARED TO CANADA, ONTARIO, AND FIRST NATIONS



- ✚ 16% of survey respondents reported that they have been told by a health professional that they have diabetes. The percentage of people with diabetes increases with age and 50% of those over 50 years of age reported having diabetes. This is consistent with the results reported in the Wikwemikong Community Health Plan 2001.

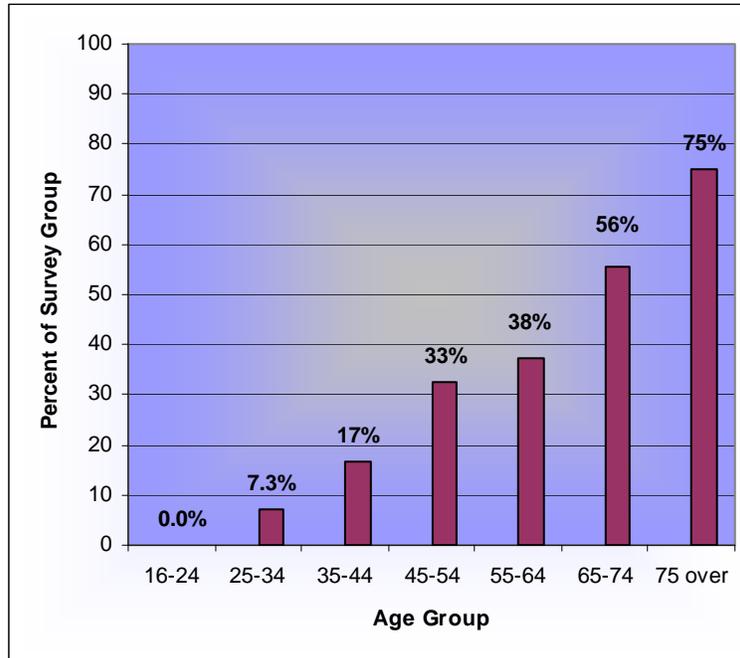
² Self-reported prevalence of diabetes, First Nations (on reserve). Health Canada, First Nations and Inuit Health Branch, secondary analysis of Ipsos-Reid, *Awareness and Knowledge Levels of Type 2 Diabetes Among Aboriginal Peoples in Canada*, 2002. The First Nations and Inuit Regional Health Survey reported 10.5% of First Nations people having diabetes (FNIHRS 1999).

³ In 1995, 5.2% of the adult population of Ontario, had diabetes. By 2005, that prevalence had increased to 8.8%, <http://www.bmj.com/cgi/contrny/extract/334/7592/501-c>

⁴ Prevalence of diabetes (all types) excluding New Brunswick and Newfoundland and Labrador. Health Canada, *Healthy Canadians: A Federal Report on Comparable Health Indicators*, 2004.

Figure 7 shows the number of people diagnosed with diabetes among total survey group according to age. This data suggests a correlation between an increase in the prevalence of diabetes and an increase in age. We found 50% of those over the age of 50 reporting they have been diagnosed with diabetes.

Figure 7: PERCENT OF RESPONDENTS DIAGNOSED WITH DIABETES AMONG TOTAL SURVEY POPULATION



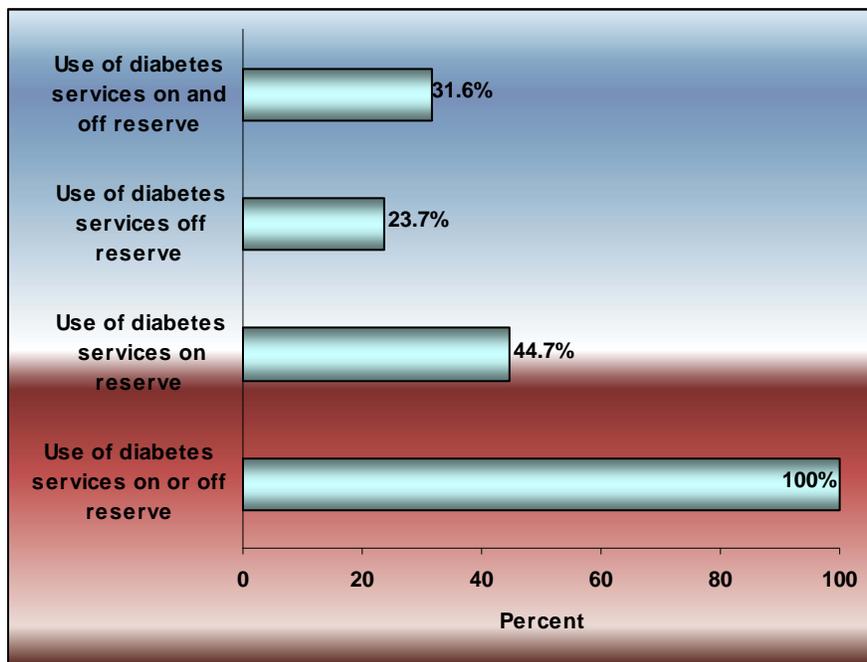
Type of Diabetes

Of the 38 of respondents who reported being told by a health care professional that they have diabetes, 23 reported on a type of diabetes. The majority of individuals reported having Type 2 diabetes (78%). The data shows that 17% of respondents reported being affected by Type 1 diabetes. The high percentage of respondents affected by Type 1 diabetes conflicts with local knowledge, however, there is no mechanism currently in place to verify this statistic. Moreover, during the first survey distribution in Buzwah, participants were not asked to report on a type of diabetes. Therefore, these statistics may not be reflective of the entire population.

Use of Community Services

The second set of questions on the topic of community services was designed to assess the use of diabetes services both on and off reserve. A total of 38 individuals reported being diagnosed with diabetes, and all 38 individuals reported having used diabetes services either on or off reserve. In total, 17 respondents (44.7%) reported having used diabetes services within Wikwemikong, 9 respondents (23.7%) reported having used diabetes services outside Wikwemikong, and 12 respondents (31.6%) reported having used diabetes services both on and off reserve (Figure 8).

Figure 8: PERCENT OF RESPONDENTS WHO HAVE USED DIABETES SERVICES

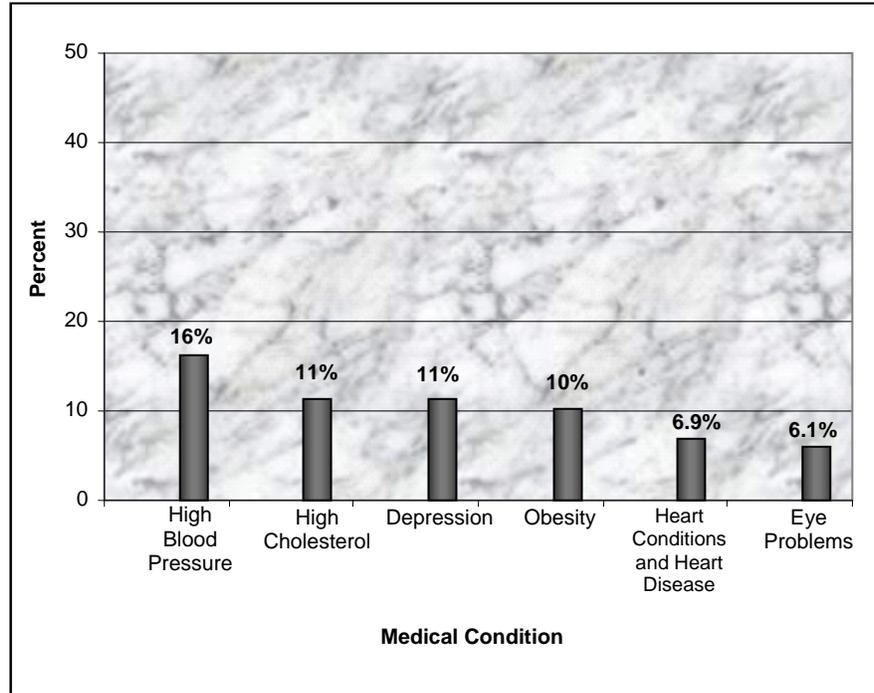


Other Medical Conditions

Although 16% of respondents reported having been told by a health care professional that they have diabetes, it should not be overlooked that 45% of all respondents reported health factors that may be associated with risk of diabetes. These risk factors include high blood pressure, high cholesterol, obesity, heart conditions and heart disease, and eye problems not helped by glasses, including cataracts, glaucoma, retinitis, pigmentosa, and diabetic retinopathy. In addition, a significant percent of respondents reported having been told by a health care professional that they had depression (11%).

Figure 9 shows the self-reported proportion of other medical conditions that may be associated with risk of diabetes.

Figure 9: OTHER MEDICAL CONDITIONS REPORTED BY SURVEY POPULATION



Family Health

Survey respondents were asked if their immediate family members have diabetes. Two-hundred and forty participants responded to this question, and 70% reported having a member of their immediate family with diabetes. It should be noted that a total of 439 immediate family members with diabetes were reported by 240 participants. This result indicates an approximate average of 2 immediate family members with diabetes per respondent. The survey also found that 16% of respondents report having at least one parent and one grandparent with diabetes. In addition, female family members represent the greatest percentage of family members with diabetes. This statistic may suggest that women are more likely to be diagnosed with the disease than men, however, further investigation would be required. Figure 10 shows the percent of respondents who reported having an immediate family member with diabetes. Figure 11 shows the breakdown of immediate family members with diabetes by relation to respondent.

- ✚ 70% of survey respondents reported that someone in their immediate family has diabetes. The analysis revealed that on average each respondent has two immediate family members with diabetes.

Figure 10: PERCENT OF IMMEDIATE FAMILY MEMBERS WITH DIABETES

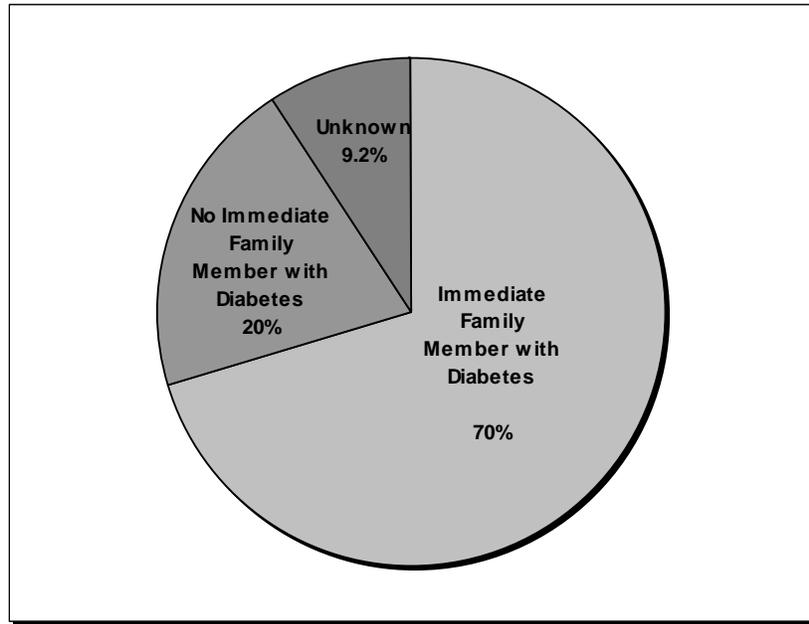
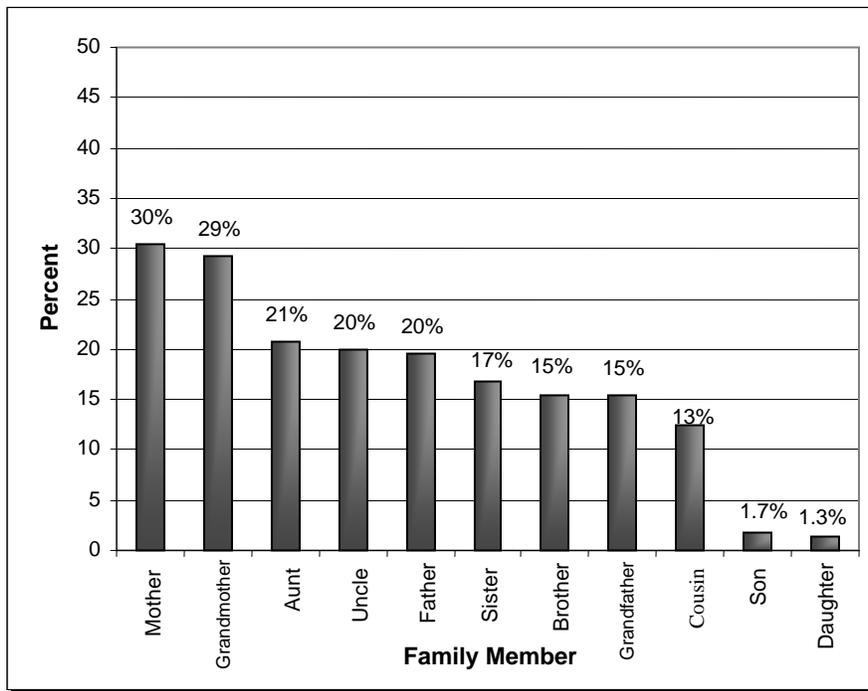


Figure 11: IMMEDIATE FAMILY MEMBERS WITH DIABETES



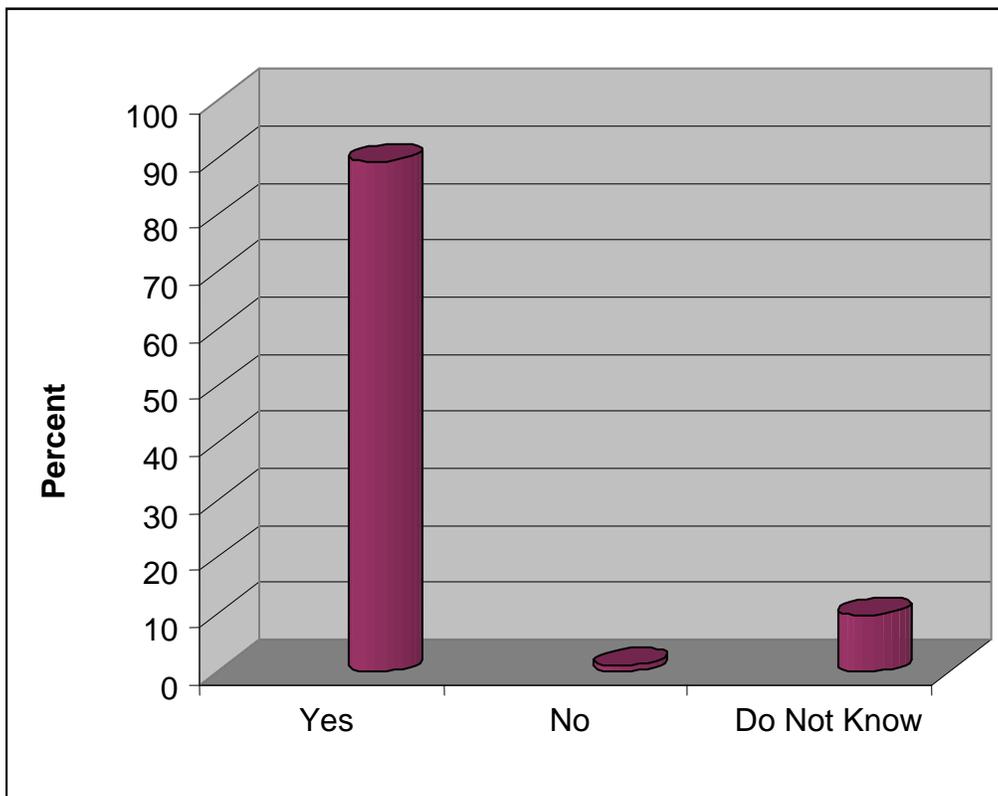
Community Health Concerns

In this section of the survey, participants were asked their opinion on: whether or not diabetes was an important health concern in Wikwemikong, the type of diabetes information and services they would like to see provided, the type of research study they would like to see done in support of enhanced diabetes information and services, and whether or not they would be willing to participate in a door-to-door study of diabetes consisting of a blood sugar test and interview about diabetes.

Diabetes as an Important Health Concern

Participants were asked if, in their opinion, diabetes was an important health concern in Wikwemikong. Of the 231 respondents, 89% believe diabetes to be an important health concern in Wikwemikong, 9.9% are uncertain, and only 0.9% believes diabetes to be of no concern in Wikwemikong (Figure 12).

Figure 12: PERCENT OF RESPONDENTS WHO FEEL DIABETES IS AN IMPORTANT HEALTH CONCERN IN WIKWEMIKONG



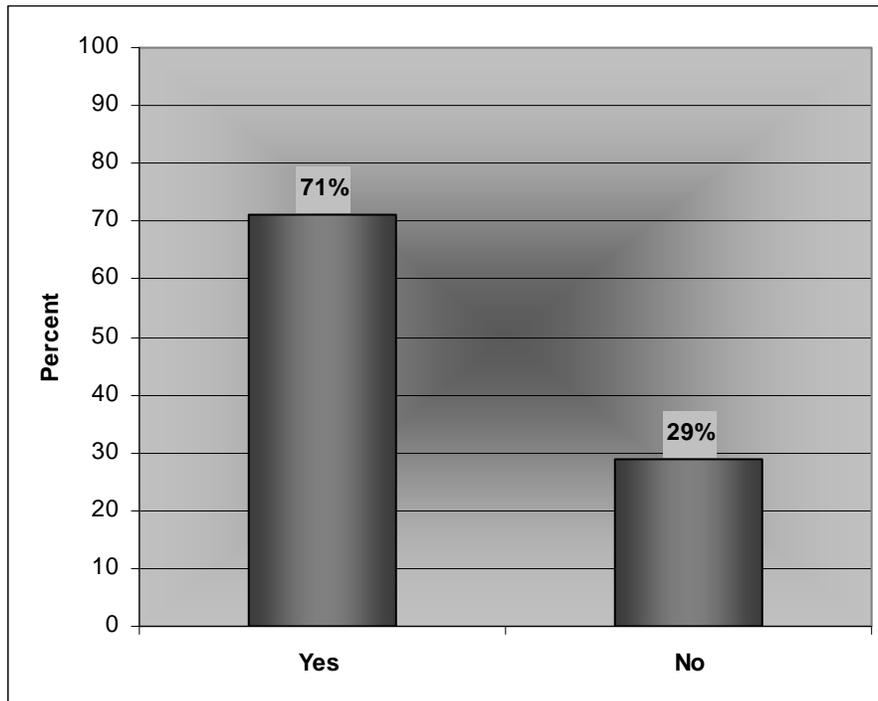
Visions for the Future

This section asked a series of questions aimed at understanding community needs and wants for new diabetes information and service provision, as well as community opinions on future diabetes studies.

Diabetes Information and Services

The first question in this series of questions asked participants if they would like to know more about diabetes. Out of 245 respondents, 71% agreed that they would like to know more about diabetes (Figure 13).

Figure 13: PERCENT OF RESPONDENTS WHO WOULD LIKE TO KNOW MORE ABOUT DIABETES



Next, participants were asked to list the type of diabetes information and services they would like to see provided in Wikwemikong. Just over half of total participants (52%) answered this question. Figure 14 shows a breakdown of the types of diabetes services and information participants would like to see in the future.

Figure 14: TYPES OF DIABETES SERVICES AND INFORMATION THE COMMUNITY WOULD LIKE TO SEE IN THE FUTURE

Types of Diabetes Services	Percentage
<ul style="list-style-type: none"> • Workshops, seminars • Support groups • Prevention/awareness • Maintenance/history • Prevalence in Aboriginal communities 	71%
<ul style="list-style-type: none"> • Diet, exercise and lifestyle changes 	21%
<ul style="list-style-type: none"> • Services aimed at youth 	9.4%
<ul style="list-style-type: none"> • Medical clinics • Blood screening 	6.3%
<ul style="list-style-type: none"> • Other medical conditions that may be related to diabetes 	2.3%
<ul style="list-style-type: none"> • Traditional medicines 	1.6%
<ul style="list-style-type: none"> • Services aimed at elders 	1.6%

Diabetes Studies

Participants were asked to list topics they believe should be studied if future studies on diabetes were done. Half of the total survey participants responded to this question (50%). Figure 15 shows a breakdown of the types of diabetes studies respondents would like to see in the future.

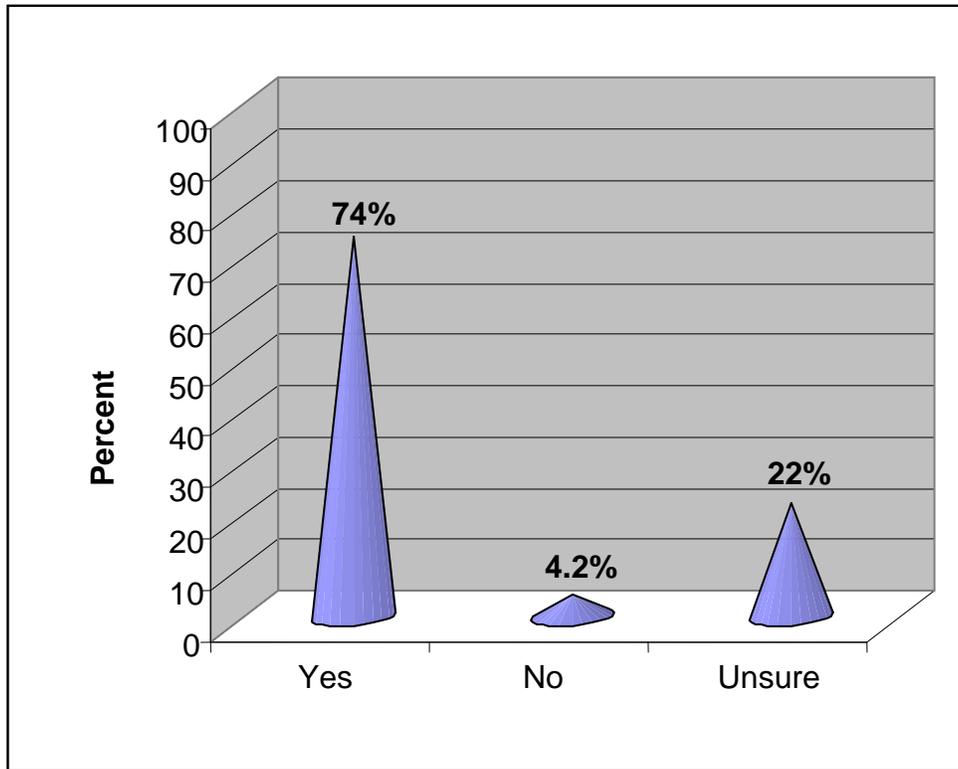
Figure 15: TYPES OF DIABETES STUDIES AND RESEARCH THE COMMUNITY BELIEVES SHOULD BE DONE

Types of Diabetes Studies	Percentage
• Any general diabetes study in Wikwemikong	47%
• Diet, exercise and lifestyle	29%
• Reasons for high prevalence of diabetes within Wikwemikong	11%
• Other medical conditions that may be related to diabetes	7.3%
• Youth and diabetes	6.5%
• Community support	5.7%
• Role of Traditional medicines	4.9%

The final survey question asked respondents if they would be willing to participate in a door-to-door study of diabetes that included a blood sugar test and an interview about how diabetes affects their family. 240 participants responded to this question with overwhelming support for this study type. 74% of respondents stated that they would participate in such a study, 22% were undecided, and only 4% responded no (Figure 16).

- ✚ 89% of respondents believe diabetes is a significant health concern in Wikwemikong and 74% of respondents support, and would participate in future research concerning diabetes consisting of a door-to-door survey of the community including an interview and blood sugar test.

Figure 16: PERCENT OF RESPONDENTS WHO WOULD PARTICIPATE IN A DOOR-TO-DOOR STUDY



Conclusion

It should be noted that diabetes continues to be a major health concern to the Wikwemikong community. Data revealed that the prevalence of diabetes among Wikwemikong community members is substantially higher than the prevalence as measured within First Nation, Ontario, and the Canadian adult populations. It is also important to note that the majority of survey participants report having had their blood sugar checked. Moreover, all participants diagnosed with diabetes report using community diabetes services. However, a substantial proportion of the survey population report being affected by other medical conditions that may be related to diabetes. As such, areas of concern include: continued and enhanced access to diabetes services and information in the form of workshops, support groups, diet, exercise and lifestyle changes, among others; and community commitment to future diabetes related studies with overwhelming support for a door-to-door study including blood sugar testing and interviews.

The data from the Diabetes Research Development Survey is not limited to what is presented in this report. Planners should keep in mind that the database can be queried in the future to obtain different or more specific information that was not presented here

Results Section Two: Focus Groups and Interviews

Introduction

Focus groups with Wikwemikong community members and WHC staff were another tool used to explore diabetes perceptions and care in the community. Focus group sessions lasted between 1-2 hours and a meal was provided for participants. The sessions were led by two researchers associated with the project and were digitally recorded and transcribed. The content of the transcripts were coded according to the topic under discussion. The inventory of codes can be found in Figure 17. Coding each line in all transcripts allowed for the responses to be analyzed in a qualitative software program, Atlas Ti. This software allows the qualitative data to be compiled and/or counted based on the topics being discussed by participants. Further, using this program, researchers are able to explore the inter-relationships between concepts and themes and ‘map’ out complex connections between qualitative variables.

Focus groups and interviews with staff and community members were used to: 1) explore peoples’ perceptions of diabetes in their community; 2) ask about how diabetes effects them or their family; 3) learn the current level of knowledge in the community concerning diabetes; 4) understand better what services are required and desired; 5) hear what residents thought needed to be researched concerning diabetes in Wikwemikong; and 6) determine if there was support in the community for a multi-year diabetes research strategy. Focus group questions are found in Appendix C.

Staff focus groups were well attended in all program areas within the health centre. Twenty-nine staff participated in the focus groups during the months of July and August 2007. Staff from the following program areas were asked to participate in the focus groups: Mental Health, Clinic/Nurses, Wellness, Long-Term Care and Youth Centre. We found that staff members were enthusiastic about participation and had very important messages to convey.

Community focus groups were advertised as widely as possible in the community. This included the distribution of flyers to each household, posting of flyers in public places, notices on Wiky TV5, and notices in the WHC Wellness Newsletter (Appendix D). We had anticipated conducting seven community focus groups but found it difficult to recruit participants to these sessions. Research assistants believe that the difficulty was related to 1) a reluctance of people to discuss diabetes publicly, 2) conducting the research in the summer, and 3) the scheduling of some focus groups on evenings when other community events were scheduled, especially bingos. As a result, we conducted four community focus groups with a total of 38 band members participating. Two focus groups were open to all concerned band members, one focus group was conducted only with youth and, one focus group with seniors. Three of the four focus groups were held in the main village (youth centre, long-term care common room, and WHC multipurpose room) and one in Rabbit Island at the community centre.

Figure 16: List of Codes Used in Atlas.ti.

Statistics

Rate Estimates
Lack of Statistics
Age of onset
Youth

Physical Health

Blood Sugar Levels
Secondary complications
Amputations

Mental Health

General Mental Health
Stress
 Economic
 Poverty
 Unemployment
 Historical
 Colonialism
 Residential schools
 Family Life

Substance Abuse
Grief and Loss
Depression

Service Needs

Team Approach – Clinical
Community Approach
Dietician
Fitness/Recreation
Mental Health
Foot Care
Education
Prevention

Service Needs (continued)

Traditional Medicine
Technology and Equipment
Physician Services
Food – Availability
Gaps in Information
Suggestions to Address Diabetes

Attitudes and Beliefs

Fatalism
Acceptance
Fear

Explanatory Models

Genetics
Spiritual
Lifestyle

Traditional Medicine

Traditional Lifestyle
Traditional Medicine Use
Use of Western and Traditional
medicines

Research

Needs
Poor Understanding of Concept
Support
Traditional Medicine
Incidence/Prevalence
Causes

Co-Incidence of Illness

Mental Health
Physical Health
Syndemics

Seven key informant interviews were conducted with individuals who were either potential collaborators, stakeholders, or who had local knowledge concerning diabetes. Questions for the interviews were similar to those used in focus groups but researchers took liberty to adjust the questions based on the position held by the interviewee. The interviews were face-to-face, semi-structured and open-ended. Key informant interviews included interviews with a physician from the Little Current Medical Associates, the CEO of the Manitoulin Health Centre, two traditional healers, a nurse, a wellness worker, and a director of a health service centre in Wikwemikong.

Results

The results from the interviews and focus groups are organized by the predominate themes that emerged from the sessions as they relate to potential areas of research. The data is generally presented as aggregated; however, in some cases where suitable, the data collected from the community and the staff is discussed separately. The identity of the interviewee is not revealed but when confidentiality will not be compromised we have indicated with which focus group or program area specific quotes are associated.

There is a wealth of information contained in this qualitative database which will allow for a more thorough investigation of many of these issues and others in the future. The discussion presented here is limited to the original intent and scope of this preliminary research study aimed at community consultations regarding research.

General Comments

As in the community survey, we found overwhelming support for a large scale multi-year diabetes research study from the key informants, staff and community members participating in the focus groups and interviews. There was also a degree of surprise that diabetes research has not already occurred in the community:

*Group: I thought that they have been doing this research for a long time already.
What have they been doing?*

Group: That is what I was going to say; how come it has been so late in coming? [Community Member Focus Group]

A considerable amount of time in the sessions was devoted to a discussion of research. On occasion it was clear that the idea of research was not always well understood by both staff and community members, and some explanation was necessary. For example, both staff and community members would confuse education, programming and research. Generally, some people understood research to mean interventions such as providing workshops or programs in schools. Others, however, clearly understood research and articulated very concrete research questions to the research team.

Interestingly, although in previous research studies in Wikwemikong community members had expressed that they feel they have ‘been researched to death,’ no such comments were received during these community consultations. In fact, the discussion has shifted to one in which

community members are seeing the value in research and seeing a role for themselves and the leadership:

I plead with people to address the recommendations [of the research], never say you can't. We can't just give up if we don't get money for programs that the research indicates we need. Wiki is determined and things can get done even when there is no money. [Key Informant Interview]

But I mean I am very interested in seeing what the results are. And even in the interpretation, when you start interpreting the data. That is the crucial point. We can get any kind of data but it is how it is interpreted is important for us from an Aboriginal perspective. Make sure that you capture that. Because we have somebody looking at it from a medical view, then you are not going to get it. So make sure that you have people from Aboriginal taught to look at the data. And they can help you interpret it. [Key Informant Interview]

Some community members also emphasized the importance of collaboration with other First Nations. In general, it was felt that diabetes is an Anishnabe problem and that communities should work together to tackle it. Others felt it would provide a comparison, and finally, there was the thought that Wikwemikong families are represented in other First Nations as well.

Group: Besides this community being like a research project, are there neighboring first nation communities that are also doing some work.

Group: that would be interesting to get an idea how many are out there. Other communities are going to be different. But it would be interesting to see those statistics too.

Group: Yeah I think there should be some collaboration of some sort. [Rabbit Island Focus Group]

You could look at that as from the island view that there is some Wiki people, we have had people in Zhiibaahaasing, we have people in Sheshegwaning that are from Wiki. So we are all over the place. So if you are just going to look at Wiki itself, next thing you know you have someone moving from you know west end or Birch Island or from here. Even Sucker Creek [has] members [from] Wiki. [Key Informant Interview]

Statistics and Epidemiological Studies

Focus groups and interviews all revealed the lack of reliable and accessible statistics on diabetes in Wikwemikong to be a concern. It is not unreasonable to think that community members would not know how many people have diabetes in the community, but even staff and physicians reported that they have no mechanism in place that would allow them to answer this question or to track the rate over time. In general, everyone believes the percentage of community members with diabetes to be excessively high. Responses to this question from the staff in focus groups ranged from 30% to 100% of the population. Staff based their responses on the number of clients

they see with diabetes, the number of staff they know to have diabetes, and the prevalence of other health indicators such as obesity. The following staff focus group discussion provides an example of the difficulty staff have answering this question:

Group: I am betting over 30 (percent)
Group: At least.
Group: Yeah..
Group: A little bit more.
Group: Because like a lot of places where people work 50 percent of the workers have diabetes or even are borderline.
Group: I would say every [program] client that I had last year, which is probably 60 [clients]; there is a question on the [program] form about family health history.
Group: I would say I can't think of one who has not told me that someone in their immediate family is diabetic. So that is 100 percent.

For the staff, this gap in knowledge is a significant issue. One staff member remarked:

Everyone wants to know how many people have diabetes. We don't even know. No one knows. The health centre doesn't know. Nobody knows.

Yet, staff also clearly stated that their knowledge of community health (local knowledge) allows them to see trends and guess at the rates because of the intimate nature of contact they have with WHC clients and their own family experiences which they feel are reflective of the community experience.

Group: We see, because of our connection to different, to the health centre, different programs. Whatever. We see people who participate in programming. Right. And our families, they all have diabetes. Now it's younger.
Group: I was only 25, how old were you?
Group: I don't remember. Probably thereabouts, maybe 27. [Staff Focus Group]

When pressed in this regard staff were able to better rationalize their estimates. For example, nurses in the Nurse/Clinic Focus Groups stated: “*but if you think about how many have been diagnosed with type 2, like it happens on a weekly basis.*” The notion that diabetes is being diagnosed weekly was independently discussed by staff in Wellness who stated: “*I would put it at one new diagnosis per week.*”

During community focus groups band members estimated between 50% to 90% of the community to have diabetes. These estimates were based on their knowledge as well as deliberations during the focus groups where one participant offered an estimate which would then be debated by the group.

The gathering of reliable and accurate statistics emerged as a significant research topic. When participants were asked what research questions they felt needed to be answered concerning diabetes in Wikwemikong, knowing the ‘numbers’ was a central theme. Staff clearly articulated their desire to have these numbers in order to be able to track, over time, any impact their programming may be having on the prevalence of diabetes in the community.

Support for the collection of local statistics on the incidence and prevalence also extended to a concern in extrapolating statistics from national surveys or other community reports which may not be suitable for Wikwemikong.

It would be interesting to get a number of how many [people with diabetes] are out there. Other communities are going to be different. But it would be interesting to see those statistics too. [Community Focus Group]

I know there is stuff out there on incidence in Aboriginal populations and I think many of those populations are geographically isolated and not the same as what is here for many reasons and so you might see a difference. [Physician]

Finally, concerning statistics, the collection of this information was also viewed as necessary to test local theories concerning diabetes. Generally, staff and community members believe that an increasing number of youth are being diagnosed with diabetes; however no one was able to offer any evidence that this is true.

Well it is scary the way it is going up fast. And the kids are carrying around big bottles of pop [Seniors Focus Group]

I think the problem is going to get much worse, especially by the size of the kids around here. They are overweight. [Nurses/Clinic Focus Group]

We're seeing it in young people, but not the tremendously great incidence, there are not that many type two's that we deal with that are kids you know. But there's some in the twenty to thirty year olds, there seems to be an increase in the incidence. [Key Informant, Physician]

Likewise, there was a general feeling that men were at higher risk than women for diabetes and that resources should be allocated to the management and prevention of diabetes in men. Again, no one was able to offer any evidence of higher rates of diabetes in men. Lastly, there is the belief that secondary complications of diabetes are excessive, but there is no method currently in place to track this.

I would say men because I wish they hope they do a study on men but one of the things that we are seeing is men are quite susceptible to diabetes because they don't know how to deal with stress. So they contain it. [Key Informant Interview]

We don't know much about the men I guess...but it does interest me. [Nurses/Clinic Focus Group]

Clearly, research in the area of incidence and prevalence of diabetes is supported and warranted. Incidence refers to the rate of development of a disease over a certain period of time; prevalence refers to the number of cases in the population at a point in time and provides an indication of the scope of a health problem in the community at that time (Friss and Sellers 2004). Therefore, prevalence must be determined and a baseline established with which frequencies over time can be compared with (i.e. incidence). Staff and community members all expressed the need for accurate and reliable statistics on diabetes for the purposes of resource allocation, intervention monitoring (that is, tracking the effectiveness of local prevention and intervention programs), and to support funding requests. Some also felt that if community members understood the magnitude of the problem they would do more to prevent it in their families or in their own lives.⁵

I think if numbers were published, then people would become more vigilant about preventing diabetes in their family, no, not in their family but changing their lifestyle to prevent it, prevent themselves from getting it. [Community Focus Group]

Participants also felt that research focusing on establishing the number of people with diabetes through screening programs would also generate information on the number of people who are undiagnosed (which is also believed to be high). An interesting research question proposed by physicians concerned the diagnosing of so-called “pre-diabetics” and enrolling them into a research study that would seek to understand what factors may lead to them developing diabetes:

I think the most useful contribution of the research could be identifying that pre-diabetic group and identify the history of progression; you know, when do they switch over? What were the variables? Weight? Stress? Time? Age? Sex? You know, those kinds of things. [Key Informant Physician Interview]

Related to these epidemiological questions was the desire, on the part of participants, to better understand how many people are experiencing secondary complications from diabetes including both physical and mental health problems. Furthermore, the issue of dialysis needs was raised, although it was not a question in our interview,. We found that the WHC does not have information on the number of community members requiring dialysis presently, and without information on incidence and prevalence there is no way to predict future needs.

⁵ It is important to consider that a study revealing high numbers of people with diabetes may also have the alternate effect of creating a sense of hopelessness in the community. [see discussion on fatalism]

- ✚ Wikwemikong has no accurate figures concerning incidence and prevalence of diabetes in Wikwemikong. Community members and staff hold several theories about the incidence and prevalence of diabetes; such as: the belief that the percentage of people with diabetes is high, age of onset is becoming younger and youth are at risk, and secondary complications from diabetes are a major contributor to the disease burden. However, there is not any data collection process in place that allows for confirmation of these theories.

Mental Health

Most focus groups and interviews addressed issues of mental health as related to diabetes. Within the realm of mental health participants identified: stress, coping, acceptance and denial as areas with research potential. Participants noted that diabetes is looked at as a “death sentence”; and that, poor health, diabetes, and amputations are “normal” in Wikwemikong.

Stress was identified by participants as possibly contributing to the onset of diabetes and/or promoting the development of secondary complications. It was noted that men may be more susceptible to diabetes because they seem to have greater difficulty coping with stress. Participants also linked stress to other chronic conditions such as hypertension and cancer and emphasized that stress is felt to be a factor in many illnesses in the community. Stress was related to economics, work, family violence, and past and present traumas such as residential schools.

*So and then looking at the historical factors in Wicky there is also a lot of that stemming from stress and... I hope I am not going ahead of myself. There is a lot of stress factors in the community... Because of the historical factors that still haven't been addressed like the residential school, I mean that is still ongoing.
[Key Informant]*

Many participants discussed stress as it is directly related to youth. In general, people felt that youth were experiencing extreme episodes of stress, both in the schools from teasing and bullying, as well as in their home life. Home life stress for youth was believed to stem from unresolved trauma and grief that they have experienced or their parents have experienced. In addition, it was felt that youth suffer from stress due to economic hardship.

Participants also identified denial as an area for research. There was interest in determining why some people adopt healthy lifestyles following a diabetes diagnosis while others do not. It was generally acknowledged that economics was one factor in preventing healthy lifestyles, but it was also felt that there are some people with diabetes who are either in denial about their diagnosis or who give up after a diagnosis and so do not make an effort to prevent the progression of the disease. In the examination of theme relationships it was clear that: denial, fear, acceptance and stress were linked. Some participants labeled this to be research on ‘coping’.

Group: So how do those people deal with it? And why do these other people throw their arms and say 'okay I give up'? And they don't take care of themselves, they don't check their blood sugar, they don't do anything like that. So that would be interesting to find out.

Group: Why one has such good coping mechanisms and good strategies. And why the other person just throws their hands up and gives up.

Group: That may be due to lack of knowledge, or denial. [Mental Health Focus Group]

A particularly profound discussion on this topic occurred in the Mental Health Focus Group session as members of that program area reflected on their experience with clients newly diagnosed with diabetes. The excerpt below exemplifies the intimate links between mental health and disease management:

G (Group): It is part of like when you are stressed out especially for someone who does not know about diabetes. They cry because they know there is no cure for it. But to help them find ways to cope with the diagnosis.

G: They need to be told that if you have diabetes you are always going to have it but it can be controlled. It is always going to be there but it can be controlled if you implement the food, watching what you are eating and exercising, implement exercise control. Because you can live a healthy lifestyle if you follow those steps.

G: And ..., you know, all of us are going to be aware of what they are going to go through. Because I have heard them talk about it and I have known one person that says "Well give me a gun." Because, you know, she knew she was never going to get well. And it is very serious. The first time you hear it.

Inter-connections of Illnesses

The discussion surrounding mental health and diabetes is complex. Research participants also mentioned the relationship between other mental illnesses and diabetes. Specifically, many discussed depression and were curious about the relationship between depression and diabetes. Participants believe that depression may be a cause of diabetes as well as a secondary complication.

That they can get that you go from real highs and lows and you get agitated and have anxiety. And go into depression, depending on what your blood sugar is. So a lot of people do not know that they have it. And even having symptoms, they do not know that those are the symptoms of diabetes and that they should go to the doctor and get checked. [Youth Centre Staff Focus Group]

As previously discussed, stress is seen as a cause of diabetes as well as a factor in the progression of the disease and poorly controlled blood sugars: “Well, stress makes the blood sugars rise. Stress. Internal stress. It is like massive stress issues because the body is under attack from itself.” [Wellness Focus Group]

Another form of stress discussed by participants was grief and loss. A community member diagnosed with diabetes explained the correlation between grief, loss, and his diabetes:

I never knew that, myself, about the stress being a part of my diabetes but when I went through. I have been diabetic for a long time. And then but, during those three years when I had those losses, the first time, the first year, that is when I noticed it was a year later when my sugars became uncontrollable. Then I tried to seek that help. I got that help, then I suffered another loss. After that time passed, I recognized too, I put myself in all these programs. Well I am going to go in grief recovery and I am going to do this and this and this because I already know that I need that to save myself from my sugars getting worse. But I recognized that myself, but other people might not know that. And there is a lot of people who are really unhappy and they are just suffering. And their diabetes are just... there is one person I know she is the same age as me and she is already having dialysis. But she is so isolated and so probably unhappy with life and I think that is probably a part of that. Yeah. [Community Focus Group]

The discussion of grief extended to one on unresolved grief in some focus groups and interviews. Unresolved grief discussed by participants included that which was caused by residential schools, the suicide epidemic and subsequent suicides in the community, family losses, and cultural losses. One Key Informant reflected on a feeling of normalized trauma that may exist in the community:

...you know, we became so normalized to that, you know, that's major trauma, like, there was just one person after another, I don't even know how many we lost that year, about thirty or forty people, you know, it was major year for that, so it was almost, like the trauma, the effects of the trauma, it was almost normal, just like the suicide, you know, every time, we almost started you know, there was somebody killing themselves, and even now, you know, still, we still have suicides, so it's almost like, it's almost a part of our lives now, you know, these, these things happen, other people at other places have earthquakes and catastrophes, over here we have diabetes and suicide, you know, it's almost like those are, almost like trauma, we're traumatized, so I forget what they would call that technically, but I know that it is an effect of trauma, it's normal as it has become so, you know, almost come to expected [Key Informant]

Related to this is the idea that poor health has also been normalized in Wikwemikong, and specifically with a diagnosis of diabetes:

G (Group): I think for one of the main concerns is that people accept it as a way of life and it's not something that they can change. Like we're... people are accepting our amputations and they are just very matter of fact.

G: Procedures. And they are invasive - very invasive. But, people just, it's just very matter of fact. We don't see it as being an extreme. We don't see it being on the extreme end of -things...

G: So, I do agree that we do kind of see it as a way of life and we just go "Oh Okay. Diabetes. I got to live with it now." Rather than trying to prevent it from coming on. And maybe it's because we always heard it's higher in Aboriginal communities. So, maybe, we almost expected it? Rather than trying to prevent it. [Mental Health Focus Group]

Later in the interview the group returned to the topic:

G: The other part is what I think, we talk about the prevalence and how people are not horrified at the thought of amputations anymore. It is just "oh yeah. Someone got three toes amputated today." "Oh, diabetes." "Yeah. Oh." You know, then it is the knee and it is just we are not horrified by that kind of... we should be. We should because this guy lost three toes. If he had lost them in an accident we would be going "Oh my God." Right? But because it is related to diabetes, we just "oh well." And it shouldn't be that way.

This topic also emerged in another staff focus group:

Group: They do not see the consequences. We have people lose limbs and they still don't see it, They just figure, oh, that is what happens when you have diabetes.

Group: I think people think that it is normal to lose a toe or a foot when you have diabetes. [Long Term Care Focus Group]

This normalization of diabetes and its complications is part of the larger issue of acceptance. Participants took the opportunity during many different lines of questioning in the focus groups to send the message that people in Wikwemikong accept diabetes as part of their life. A participant noted: "That is where we get the attitude it was meant to be. I am Aboriginal. I am from Wiky and we have like mega...even our cats get diabetes!" (Mental Health Focus Group). Nurses also discussed this as a significant problem when trying to advise clients on prevention:

I find that there's kind of an unfortunate acceptance by some people that they are just going to be diabetic, so what ever. That kind of thing rather than having the mindset that there are things that they could do to prevent it, its just kind of like, 'well my family is diabetic so I will be. So I'll deal with it.' I hear that a lot. [Nurse/Clinic Focus Group]

- ✚ Participants expressed concern that diabetes and complications arising from diabetes are ‘normalized’ in the community, and that people have come to accept these illness outcomes as inevitable. This is viewed as an impediment to effective prevention and management of type 2 diabetes in Wikwemikong.

The role of alcoholism was another point of interest to participants. Again, people believe that alcoholism likely leads to the development of diabetes but they also think that alcohol is used to cope with a diabetes diagnosis and thus contributes to the early onset of secondary complications. Likewise, although family violence was regarded as part of the cause of diabetes in its role in fatalism and denial; it was also regarded as a secondary complication when blood sugar levels increased:

And a lot of family violence comes into play too because diabetes, when somebody has diabetes the sugars are running high. And people are mad and people are mad and they don't know why they are mad. You know things happen. [Wellness Focus Group]

Family

Participants discussed the role of the family in the care and management of diabetes as well as in relation to the mental health effects on the family when a member is diagnosed with diabetes. A key informant discussed the emotional impact on family members when someone that they love and care about does not try to prevent the progression of the disease due to fear, denial or acceptance. The informant indicated that this leads the family member to question their own place and value in the life of the other individual.⁶

A healthy cohesive family unit was also believed to be central to diabetes care and management.

“And if the family is sick they are not going to listen to their kids because they are sick too. So this is where you need to do healing on the whole family.” [Key Informant Interview]

Socio-Economic Circumstances

We have placed the discussion of socioeconomic (Income, Employment and Education) within Mental Health because this is where community members most often placed it. Similar to what was reported in the Wikwemikong Community Health Plan (2001), community members clearly link their level of income to stress. In relation to diabetes. One Key Informant stated: “*So the wholistic health is affected in terms of diabetes. Like the financial. You can't pay your bills, you can't eat. You know, that is a stress.*” Also linked to this is how changes to health policy and reductions in benefits contributes to this stress and ultimately peoples' health:

⁶ This may be likened to the effects on the family when one member suffers from alcoholism.

They are telling people well look for your own ride if you are going to see a specialist. And we don't even have anybody to ask for a ride. And the mileage compensation has been decreased which is another blow to the individual. You know, you can only get this much and the escalating gas prices. It is like we are already up the poverty level in First Nations communities and then we have this on top of that stress; that, as if we don't really need the money. [Key Informant Interview]

Access to healthy foods was discussed by every focus group. The general feeling was that poverty is a major contributing factor to poor diabetes management. Respondents from the staff and community feel that people can not afford to buy fruits, vegetables and milk, and that items such as pop, chips and processed foods were less expensive in the community. This research did not audit local stores to determine actual costs. Many participants added that it is even more difficult for families without cars who cannot travel to Little Current or Espanola where groceries are thought to be less expensive and where there are thought to be healthier food choices.

I find sometimes they know what they are supposed to be doing but they don't have access to the right foods. I think this is something where most people say they don't have a car. They shop [here]. They're limited in what they can get. [Long-Term Care Focus Group]

However, others who participated in the research believed that local stores have been responding to the community needs and have been making greater efforts to lower prices. As one staff participant noted “*It's changed. We are almost there. It is getting better.*” A participant in a community focus group also felt that the local stores had been responding and the issue was more about teaching community members about making healthy food choices and meal planning. Other's noted that meal planning and budgeting is difficult for people who receive a monthly income from programs such as Ontario Works: “*If they do buy really healthy foods, it won't last.*” Regardless of community availability, access to income to purchase healthy foods was a concern shared by participants in all staff and community focus groups.

They don't care about their blood sugar if they don't have money for food. If you've got five bucks for the rest of the week you eat hot dogs and white bread and you don't eat fruits and vegetables because they are too expensive. That is just the way it is. You've got to eat something. We have babies eating carnation milk. [Nurse/Clinic Focus Group]

- ✚ Participants suggested many residents lacked access to nutritious food choices. Low income levels, monthly subsidized income programs, and a lack of resources were all reported to be major barriers to the prevention and management of diabetes in Wikwemikong.

Pathogenesis

Pathogenesis refers to the development and effects of disease. Participants in focus groups and key informant interviews were better able to articulate research questions related to pathogenesis than mental health for example. We have taken a liberal interpretation of the medical definition of pathogenesis and included social factors as well. Key areas of concern and research identified were secondary complications, high blood sugar levels, stress as a cause of diabetes, and the effects of limited resources as a cause and effect of diabetes.

Community members and staff both expressed grave concern at the excessively high blood sugar levels being reported in the community. Researchers associated with this project are gravely concerned about this finding. Target blood sugar levels for people diagnosed with diabetes are 4 to 7 for fasting levels and 5 to 10 for two hours after eating (Canadian Diabetes Association). Long-Term Care nurses reported seeing clients with blood sugars in the 30-32 range, Mental Health Staff reported seeing blood sugar levels of 17, Nurses discussed how patients who are in the 20's believe they are well managed because they are not in the 30's, and Wellness staff also reported patients with blood sugars in the 20's and 30's and wondered why these patients were not in a coma. The highest blood sugar level reported was 43 by the Traditional Medicine Coordinator.

Equally disturbing and perplexing was the effect of lowering blood sugars in patients who are 'normally' in the 20's and 30's. Nurses and the Traditional Medicine Coordinator both discussed having patients become sick when their blood sugars are reduced to a normal range.

Community members participating in focus groups also reported high blood sugar levels. A participant at a community focus group reported that she can go to 20 before she starts to feel it; she also believes that physicians accept this as normal for the Anishnabe people and are not overly concerned about it.

Due to the seriousness of these reports this issue required further inquiry. In speaking with the WHC Health Records Clerk we verified that indeed these high values are being reported in patient charts and in "emerge notes" received from the Manitoulin Health Centre when Wikwemikong Health Centre clients use their services. Further the clerk reported filing many lab reports for WHC clients where blood glucose levels are in excess of 20 and some that have come back with special notations "indicates panic levels."

Evidence based medical research suggests that reducing blood sugar levels in people with diabetes is associated with decreased rates of microvascular and neurologic complications such as retinopathy (damage to the retina in the eye), nephropathy (damage to the kidneys) and neuropathy (damage to nerves), as well as macrovascular complications (cardiovascular outcomes) such as stroke, cardiovascular death non-fatal MI, and angina.⁷

⁷ UpToDate (www.uptodate.com) – "UpToDate is a comprehensive evidence-based clinical information resource available to clinicians on the Internet, personal computer and PDA. UpToDate is designed to get clinicians the concise, practical answers they need when they need them the most - at the point of care."

- ✚ Sustained blood glucose levels of 20 and 30 are felt to be commonplace in Wikwemikong and levels in the 40s are not unheard of. Levels over 10 in people with diabetes indicates poorly managed diabetes and places the person at increased risk for secondary complications. Results suggest that these high blood glucose levels are a result of either poor patient care and/or poor self care resulting from denial, fear, and/or acceptance. This finding requires further research and immediate action.

One community member asked:

I have a question. Why does it, we as Anishnabek, when our sugar goes too 32 or 38 we are still standing? When a Caucasian, they would be surprised they are standing?[Rabbit Island Community Focus Group]

Participants were concerned about the rates of secondary complications for people in Wikwemikong diagnosed with diabetes. It was generally felt that there is a high prevalence of secondary complications. The development of secondary physical complications is most certainly linked to these excessively high blood glucose levels but also to mental health issues that may contribute to the poor management of their diabetes.

Participants in two separate focus groups, one staff and one community group, felt that blood sugar monitoring and the effects of high blood sugar on Anishnabe are probably not well understood by either doctors or patients as the effects may be confused with other mental health issues, especially depression.

Participants felt that people with diabetes do not take care of themselves until secondary complications arise and they can see the effects. *“I think with diabetes they don’t see the effects right away; it’s not until down the road when they have heart problems or an ulcer or lose a limb. It is not like immediate, like if their sugar is 30 a lot of our clients don’t even feel it, they feel fine”* (Nurses/Clinic Focus Group).

Observations made by community members and staff indicate that not only do they believe that band members are being diagnosed younger, but also that secondary complications are coming earlier and deterioration faster. Wellness staff reported: *“I have seen young people who have had type two that got diagnosed when they were 15-16. By the time they were 21 they had full blown complications.”* And a community member commented: *“There is this one person I know she is the same age as me and she is already having dialysis.”*

Physicians reported that over time they believe there has been an improvement in the number of cases of severe secondary complications they are seeing. They reported seeing much more cardiac, renal and end-organ complications 10 years ago; although they also admit this is an observation and they also do not have the data to support this. Physicians had a specific research question in relation to secondary complications: what is the effect of home care on the development of complications and the management of diabetes?

- ✦ The incidence of secondary complications from diabetes is believed to be high. Participants think that secondary complications manifest at younger ages compared to the non-Aboriginal population and that deterioration occurs more rapidly. Neither staff nor physicians have accessible data on the incidence or prevalence of secondary complications of diabetes in Wikwemikong or an idea of how many band members are receiving dialysis.

Traditional Medicine

Staff, community members and key informants alike were interested in traditional medicine as a treatment option and as a research topic.

The Traditional Medicine Coordinator, Ron Wakegijig, shared his vision for traditional medicine research. He is interested in documenting and researching the use of the traditional medicine he uses for people with diabetes. His approach is one that is complementary to western approaches and does not seek to replace biomedical approaches or to use traditional medicine in isolation of others. The approach he described was one that could be defined as “harmonization.” Several aspects of the traditional care model currently used at the WHC would be suitable for such studies. There is great interest on his part to work on this collaboratively with interested physicians, nurse practitioners and others.

Physicians from the Little Current Medical Associates also reported being interested in a research question on traditional medicine. They submitted the following question for consideration: What are traditional methods for managing type 2 diabetes and what impact do they have in the control of diabetes.

Community members and staff were also very interested in this topic.

Group (G): And what about the traditional medication?

G: Yeah. That is another thing that we need to have education on that. What is it exactly? Is it better than taking the four pills that I take today? Do I take it in conjunction with the medication that you are taking right now?

G: I think that something should be done with it too because sort of a data thing. Is it better than taking the pills?

G: Somebody could do research on that.

G: Yeah somebody could do research on that.

G: Diabetics on traditional medicine. [Staff Focus Group]

In one of the community focus groups a band member commented: “they are doing a lot of studies on Native medicines regarding diabetes and the different herbs they use to control it. They should be promoted because they are, pills are affecting people” (Seniors Focus Group). However this group also cautioned that “Native Medicine” should not replace western medicine and is not an excuse to not take care of oneself. Staff reported knowing that many clients do take both western and traditional medicines and believed that patients disclose this to local staff but not physicians.

It was expressed by some that people did not have a good understanding of traditional medicine and for this reason they do not use it. Community focus group respondents clearly wanted to know more.

Staff, key informants and community members all discussed the importance of traditional values and culture in the prevention and treatment of diabetes. They offered simple suggestions on how to incorporate this way of life into care and prevention such as walking, eating wild foods, fishing, picking medicines, and picking berries; and people emphasized that it is about how you live your life and not just the elements a person ingests. One key informant said “*Fully utilize or culture and our ways of dealing with these issues and then having the doctors there to prescribe necessary meds.*” Another said: “*Like it is medicine, it is not just the tangible medicine, it is also the way you walk.*” Another informant suggested that Traditional teachings promote self-care and healthy living and so it is a sustainable tool for people. Currently there is their belief that many people turn to traditional medicine as a last resort when the disease has progressed and secondary complications have arisen.

- ✚ Focus group and key informant interviews revealed that there is interest and support for research concerning the use of traditional medicine in the treatment and prevention of diabetes. Three key research areas emerged: 1) effectiveness of current treatments, 2) how to combine western and traditional medicine safely - models of care and drug interactions, and 3) the role of traditional culture in promoting healthy living.

Service Delivery and Evaluation

Staff and key informants universally agreed that they are willing to adjust programming in their areas to meet the increasing needs of people with diabetes in Wikwemikong. Along with this, participants also agreed that they would be willing to collect evaluation and research data which would contribute to a multi-year diabetes strategy. In fact, some program areas began discussions on what data they have or what questions could be added to already existing tools that may aid the research team.

Training

Workers in many program areas reported that they had received little or no training on diabetes. All were willing and interested in developing skills related to diabetes. Since many staff in different program areas are involved in diabetes care would be beneficial for the clients is they received relevant training on care, education and prevention. The reality is that most clients who come through the doors of the WHC can benefit from such knowledge.

I don't think there is any on-going training; the training we received is from school. And what we've learned on our own. But no, we never do any up-grading.

Mostly the doctors are our main teachers for diabetes.

Staff discussed opportunities to incorporate diabetes education into existing programming; for example, the CPNP and HBHC programs, health teaching at the schools, sessions at Rainbow Lodge, and Mental Health health promotion sessions. They also discussed the need for specific

training or specialties: RN diabetes educator, insulin training, and culturally and community appropriate dietary counseling. Staff and community participants in the focus groups, who themselves have diabetes, described the diabetes education they received as basic and technical and they would like to have been given more in-depth information on the biological pathways and mechanisms in their bodies; for example, the role of insulin, the role of the pancreas. However, it should be noted that this was not expressed in the senior's focus group. Seniors were satisfied with the teachings they had received.

Staff and community members put forward suggestions and ideas for diabetes education for the community. Since this report focuses on future research directions, these ideas are not reported here but will be compiled and shared with the management team and health committee in the future.

Physician Services

Physicians were supportive of a multi-year diabetes research strategy for Wikwemikong and are willing to collaborate. Physicians from the Little Current Medical Associates participated in the research as key informants and also supplied researchers with a list of their top five research questions (appendix E).

The research suggests that there is room for improved interactions between physicians and the WHC and its clients. Physicians and community members alike identified areas of concern. There was a general concern expressed that access to physicians is a problem affecting diabetes care in Wikwemikong. Participants spoke about long waiting lists to see physicians, not having access to physicians through the Little Current Clinic, and having only very brief consults with physicians.

Community members suggested that people with diabetes should always be placed on the waiting list for their next appointment. We heard people talk about being missed on the waiting list and as a result not seeing a physician for their diabetes for eight months. Another community member had been on a waiting list for her family doctor for seven months and at the time of the interview had still not been scheduled. Wait times seemed to be dependent on which doctor the person was trying to make the appointment with.

From the physician perspective there may be much to be gained by better organized referral systems, requisition forms and charting at the WHC. Specifically it was reported that physicians do not have a good sense of the diabetes programming in the community and therefore are not sure where to refer patients. They make referrals to other programs such as LTC and the dietician, but complained that forms are usually difficult to find and follow-up is poor. Physicians, like community members are looking for ways to improve the quality of care being delivered in Wikwemikong.

Research in this area could easily focus on implementing and evaluating new models of diabetes care and/or retrospective quality of care studies looking for system deficiencies (performed by chart audit).

Service Coordination

During an early focus group, staff participants put forward the idea of developing a well-trained diabetes team within the WHC consisting of workers across all relevant program areas. The group discussed this team as a case management approach to the care of individual clients when they are newly diagnosed with diabetes. The team was described to include: a mental health worker, a nurse (clinic or LTC), a wellness worker, the dietician, and the traditional healer. It would also be reasonable to include someone from the medical transportation unit. The diabetes team approach was supported in all subsequent staff focus groups.

Coordination of services also emerged as an issue in relation to role definition. Diabetes screening clinics were discussed by participants as a method to improve diagnosis in the community. It was clear, however, that during the research period and for sometime before, screening clinics were not being conducted because neither nurses nor CHRs believed it was their role. The periodic lack of a school nurse was also viewed as a detriment to diabetes education. It was felt that a school nurse should carry that mandate but that the nurse should collaborate with other program areas such as wellness and traditional medicine.

These discussions concerning coordination of services lead the group to ponder the research question: Can better coordination of care improve diabetes outcomes for our clients?

- ✚ Staff agreed that there was a lack of coordination of services at the WHC when it came to servicing the needs of patients with diabetes. Community members reported that services and programming were available but access to physicians made the management of their diabetes difficult. Staff at the WHC suggested piloting a diabetes team approach to care that would include physicians, Noojmowin Teg staff and WHC staff from Mental Health, Wellness, Traditional Medicine and Clinic (potentially others) and evaluating its success.

Conclusions

The focus groups and key informant interviews resulted in the collection of a wealth of qualitative data concerning diabetes in Wikwemikong. Although the primary goal of these sessions was community consultation on research priorities, the rich discussion of diabetes which ensued has given the research team valuable insight into many of our long-term research questions.

The session revealed that the key research priorities for the staff and community members are similar to one and other and to those originally proposed by the diabetes research team. There was agreement that the key topics for study should include (1) a study of the prevalence and incidence of diabetes and complications arising from diabetes in Wikwemikong, coupled with the collection of data on contributing factors and circumstances such as income and access to care, (2) a study of the efficacy and application of traditional medicine to the treatment and prevention of diabetes, (3) a study on the connections between Anishnabe mental health issues and diabetes and elicitation of culturally appropriate coping strategies, and (4) the implementation and evaluation of pilot programs aimed at improving coordination of services and patient care.

Results Section Three: Data from WHC internal documents

Principal Investigator, Kristen Jacklin, was given access to WHC annual reports, evaluation reports, and the Community Health Plan during the summer of 2006. Any information relating to diabetes was extracted and is presented in this section. In general it was found that there is a serious lack of program data concerning diabetes. This is also true of most other chronic diseases and those which are not required to be tracked as communicable diseases. Finally, although we believed we would have access to blood glucose screening results, we found that program staff only tracked that they held a screening clinic and did not maintain any of the information on the results of the clinic. This information was reportedly shredded. In general, we found that the only useful information for the project team would be contained in patient charts which were not accessed for the purposes of this developmental stage of the research.

✚ No information on the results of blood glucose screening clinics has been maintained by the WHC.

WHC Health Transfer Evaluation Report 2004, Warry and Jacklin

p. 82-83 Inpatient data from the MHC shows declining trends in hospital admissions for some diseases and stable trends for a few. Among those showing no improvement between 1999-2004 is “endocrine, nutritional, metabolic diseases and immunity disorders.” When only those diagnosis containing “diabetes” are extracted the analysis shows that diabetes admissions have increased over this five year period and in one year accounted for all admissions in that ICD category.

p. 85 When researchers interviewed the health centre staff, doctors and community members about the most important community health needs, all identified diabetes, mental health, disease prevention/health promotion and youth sexual health as the most important community priorities.

p. 40 “Diabetes quickly surfaced as the major health concern of the Staff, Doctors, and Health Services Committee Members we interviewed. Doctors estimated that 50% of their clients [in Wikwemikong] are diabetic.”

p. 40 The traditional coordinator cites ‘non-compliance’ as a major barrier when working with diabetics. He also suggested that many diabetics do not understand the dietary counseling they receive, it is too complicated, and many cannot afford the prescribed diets.

p. 40 “Health Centre Workers feel there is a need for a diabetes program that integrates both the Western biomedical model and the traditional model of health and healing. This along with comments from the traditional coordinator support the need for a comprehensive diabetes program that draws on both traditional and western specialists in the field and is highly integrated in the organizational structure of the Health Centre.”

- ✚ Data extracted from the WHC Health Transfer Evaluation Report (2004) indicates that diabetes inpatient admissions to the Manitoulin Health Centre for Wikwemikong increased between 1999 and 2004. Physicians estimated that 50% of their clients in Wikwemikong have diabetes.

Wikwemikong Youth Needs Assessment Report 2002, Kristen Jacklin

Key Findings iii – The results suggest that Wikwemikong youth spend a great amount of time during the school week involved in sedentary activities, especially watching television. This leaves Wikwemikong youth at a high risk for obesity and diseases associated with obesity.

Community Needs Assessment Report 2001, Kristen Jacklin

Diabetes

- 16% of respondents report that they have been told by a health professional that they have diabetes. This would be considered “self-reported” incidence of diabetes
- 10% of women who have given birth report being diagnosed with gestational diabetes.
- The age breakdown of those suffering from diabetes is available in Figure 12.⁸ As expected, older age groups are more affected than younger age groups; but, it should not be overlooked that 7% of those 24-30 report that they have diabetes.
- It was also found that women (at 17%) have higher rates than men (at 13%).

- ✚ The 2006 diabetes research and that reported in the Wikwemikong Community Health Plan (2001) both report the percentage of people in Wikwemikong with diabetes as 16% of the population (all age groups).

Respondents who reported they had been told by a health professional that they have diabetes were then asked how they treat or monitor their condition, and what they think caused their condition. Most diabetics (46%) reported that they treat and monitor their condition by prevention activities: lifestyle changes, diet changes, monitoring blood sugar level. Some reported a combination of prevention and drug therapy (16%). Just over a quarter (27%) of diabetics relied solely on medication to control their disease. When we asked if they knew the cause of their diabetes most answered “genetics,” “heredity,” “runs in the family” (35%). Other explanations included lifestyle (e.g., dietary habits) (3.5%), and a combination of lifestyle and genetics (9%). Fifty two percent of diabetics did not answer this portion of the question.

⁸ All of the age and sex breakdowns in this section take into account the number of people in each age category that participated.

It is encouraging that 62% of diabetics are engaged in some prevention activity to help treat their condition.

There seems to be a lack of understanding of the relationship between lifestyle/behaviour (e.g., diet, exercise) factors and genetic factors that bring on the disease. That is, people are more likely to cite heredity as the cause than a combination of their diet and exercise behaviour and heredity.

When residents were asked if they had ever been tested for diabetes 57% answered yes.

68 residents who have a BMI of 27 or greater (indicating they are overweight) have not been tested for diabetes; that is, 37% of those at a definite risk for diabetes have not been tested.

Diabetes impacts every aspect of life for sufferers. One band member commented on his diabetes when completing the medicine wheel exercise:

My vision is to control my diabetes and avoid complications. I would like to extend the period before complications will arise. I want to put that reality off until later in my life. My whole well-being surrounds the fact that I have diabetes.

Wikwemikong Health Centre Annual Reports 1998/99 to 2004/05

There is very little information in the annual reports that is useful to the diabetes research team.

- ✚ Researchers found no data is being collected by the WHC on diabetes. We were unable to ascertain how many patients are diagnosed with diabetes and/or how many patients are receiving specialized treatment for diabetes.

1998/99

Dietician reports 58/121 visits were diabetes care and 28/121 were for weight control. Diabetes was by far the highest number of visits.

The Anishnabe Mishkiki Diabetes Project (only year it reports) – reports 912 footcare clients and 6 new diabetic referrals.

1999/00

HIS report shows type 1 diabetes = 32; type 2 diabetes = 197

The Anishnabe Mishkiki Diabetes Project (last year it reports) – reports 481 footcare clients and 14 self-referrals

2000/01

165 footcare (clinic based – chiropodist or nurse)

HIS, type 1 = 32, type 2 = 197

Traditional Medicine reports 8-12 visits per week (all illnesses); reports having 30 diabetics using the diabetes remedy in conjunction with western medicines; and spends 2 hours per week replenishing diabetes medications.

2001/02

Footcare – no numbers or totals (just a chart)

No diabetes report

2002/03

Footcare = 531

2003/04

Footcare = 551

2004/05

Footcare = 474

Concluding Remarks

Pilot studies such as this one ultimately result in testing the capacity of the researchers and community to undertake the research. As we move forward in this research we take with us important lessons we have learned from this pilot (listed below). The research team went through a transition just prior to the submission of this report as two of our members left the WHC. We anticipate that we will need to re-group and re-evaluate our objectives, and our team as we prepare to move forward with the next phase.

Lesson's Learned

- Collaboration and the roles and responsibilities of the research team, principal investigators and research assistants should be clearly established early in the research process.
- In order to secure qualified research assistants we must adequately compensate them.
- Research assistants must be qualified above all else. If we proceed with a large project we will need a qualified senior research coordinator in the community who can work with local research assistants, provide training and direction. More specifically, we need a coordinator who is knowledgeable in research protocols and methods including library research, data management and analysis, data organization, ethics, experience using Excel, Access and Atlas ti or NVivo for health research projects. Consideration should soon be given to either the hiring or mentoring of someone for this position.
- The research team should be evaluated and membership should be open to interested individuals, local experts on research, as well as staff in key program areas.
- We need a supportive environment at the local research site (WHC). At the very least a workstation with a phone (research grant and/or NOSM can provide computer and printer). Ideally a private office – this has to do with the nature of the work, the confidential nature of the files, the need to have quiet space to read, transcribe, and analyze data.
- On-site library access would facilitate capacity building for research. It would provide local research coordinators, partners and the co-investigator with access to current journals and databases.
- We should have milestone reporting specified for Health Services Committee updates

Appendix A: Research Questions Defined by the Wikwemikong Diabetes Research Team, January 2006

These questions are the preliminary set of questions we will incorporate into the CIHR and other proposals. During the consultation period and in the spirit of true research partnerships we anticipate that this list may be modified or negotiated as other research partners are consulted. Research questions identified thus far by the Wikwemikong health centre include:

- 1. What is the epidemiological profile of people living with diabetes for the Aboriginal population on Manitoulin Island and specific First Nations like Wikwemikong?**
 - What is the current situation of diabetes in Wikwemikong and in the other Manitoulin First Nations? What is the prevalence? How many people are at risk but have not been screened or diagnosed?
 - How many diabetics are at risk of other diseases (co-morbidity), disability and amputation? Mental illness?
 - What is the age distribution of diabetics in Wikwemikong? What age are people when they are diagnosed?

- 2. How can current resources be used more effectively to treat and manage diabetes?**
 - What resources on diabetes programs and services and its prevention are currently available to Wikwemikong residents? How are they utilized? What are the gaps?
 - Are First Nation people on Manitoulin Island receiving the same standards of care as non-Aboriginal diabetics?
 - What is the best utilization of Health Centre/community resources on diabetes?
 - What role does traditional medicine play in the treatment and prevention of diabetes?

- 3. How have the colonial legacy and trauma experienced by Aboriginal people contributed to a feeling of helplessness and fatalistic perceptions towards individual health and healing?**
 - Why has health knowledge not translated into action in the form of healthy lifestyles for some people diagnosed with diabetes?

- 4. How can the harmonization of Traditional and Western medicines improve diabetes care?**
 - How does the Traditional Medicine program at the Wikwemikong Health Centre work with physicians to harmonize approaches to diabetes care?
 - How successful has the Traditional Medicine program at the Wikwemikong Health Centre been in helping clients effectively manage their diabetes symptoms?

As the research progresses into the CIHR funded stage we expect to add to these questions with “big picture” research questions such as:

- How can surveillance of diabetes incidence and prevalence lead to improved programming?
- How can research be used to inform policy?
- How do we create diabetes programming that is accessible and appropriate for all band members and communities?
- How effective are Indigenous approaches for the treatment and prevention of diabetes?ⁱ
- What accounts for fatalism? Culture and spiritual beliefs of acceptance or feelings of defeat brought on by trauma?

Appendix B: Wikwemikong Diabetes Survey 2006



Diabetes Research Project Development

For the Wikwemikong Unceded Indian Reserve

Summer 2006

Our Purpose: Diabetes research has been identified as a priority by the Wikwemikong Health Services Committee, Health Services Director, and Program Managers at the WHC. We are currently consulting with community members as well as regional organizations to develop a multi-year diabetes research strategy for the Wikwemikong Unceded Indian Reserve. It is our hope that this research will tell us the number of people living with diabetes in Wikwemikong and how the disease is affecting the community. We hope that this information will help us to design and deliver more effective programs and reduce the number of people with diabetes in Wikwemikong. This developmental research is a partnership between The Wikwemikong Health Centre and Kristen Jacklin at the Northern Ontario School of Medicine. The findings from these consultations and surveys will be incorporated into summary reports that will be used to formulate research funding proposals for this initiative. Results from this developmental work will be available by March 2007 and may be requested from the Principal Investigators. The participant information pamphlet given to you by our research assistant contains all contact information for this study. Please retain this pamphlet for your future reference.

Your Participation: By participating in this survey, you will be contributing to the development of a multi-year diabetes research strategy for the Wikwemikong Unceded Indian Reserve. We are requesting that you participate in a survey that will take approximately five minutes to complete. **PLEASE ONLY COMPLETE THIS SURVEY ONCE.** You do not need to write your name anywhere on the survey so you will not be identified with your responses. Also, you will be given a small gift as our thanks. The survey asks questions about community perceptions of diabetes and diabetes services and whether more reliable diabetes related information would be useful to you. If you prefer the survey can be verbally translated to Ojibway and an interviewer can record your responses on the form; please let me know and we will accommodate your preference. The questions we ask concerning diabetes and diabetes services in Wikwemikong may be sensitive to you and you may feel some anxiety. We have included a list of community based organizations in the pamphlet that can be contacted if you experience this anxiety and need to talk to someone about it.

Your participation in this development research is strictly voluntary and you have the right to refuse to participate, withdraw or skip a question at anytime without consequence. Your responses will still be included in our analysis even if you choose to skip some questions. You have the right to stop the survey at any time and request that the information you have given be excluded. You may request a copy of our findings after March 1st 2007.

Confidentiality: *We have taken precautions to make sure that the information you provide will be kept confidential and your participation will be anonymous. All of the people working on this project have signed an oath of confidentiality at the Health Centre. Your name will not appear on the survey document and the survey cannot be linked to you in any way. The data we collect will be stored in a locked cabinet and the Northern Ontario School of Medicine for seven years and then will be destroyed by shredding.*

Please indicate your agreement to participate by checking the appropriate box

Yes I agree to participate
participate

No I do not agree to

Chi Miigwetch!

PLEASE ENTER RESPONSES IN CHECK BOXES AND/OR IN WRITING

1. What is your age? _____
2. Are you male or female? Male Female
3. What satellite/village do you live in?
- Wikwemikong South Bay Murray Hill
- Buzwah Rabbit Island Kaboni Wikwemikonsing Cape
- Smith Other (SPECIFY) _____
4. Have you ever had your blood sugar level checked by a health professional? Yes No
- 4a If you remember, were you told it was: High Low Normal Don't remember
5. Have you ever been told by a health care professional that you have diabetes? Yes No

If you answered Yes to the above question #5, please answer the following:

- 5a. What year were you told this? _____
- 5b. At any time have you used any diabetes services in Wikwemikong?
- Yes → Which Ones? _____
- No → Why Not? _____
- 5e. At any time have you used any diabetes services outside of Wikwemikong?
- Yes → Which Ones? _____
- No → Why Not? _____

6. Have you ever been told by a health care professional that you have any of the following medical conditions? **Please check all that apply**
- Heart Conditions or Heart Disease High Cholesterol High Blood Pressure
- Obesity Depression Gestational Diabetes
- Eye problems not helped by glasses (cataracts, glaucoma, retinitis, pigmentosa, diabetic retinopathy)
- None of the Above

7. Does anyone in your immediate family have diabetes?

Yes No Don't Know *(If No or Don't Know SKIP TO QUESTION 8)*

7a. If Yes, Who? (Please check all that apply)

Mother Father Brother Sister Son
Daughter
 Grandmother Grandfather Grandchild Aunt Uncle
Cousin

8. In your opinion is diabetes an important health concern in Wikwemikong? Yes No Don't know

9. What type of diabetes information or services would you like to see provided in Wikwemikong?

10. Would you like to know more about diabetes? Yes No

10a. If Yes, what would you like to know?

11. If we had to do a study in Wikwemikong what do you think we should study about diabetes?

12. If we did a door-to-door study of diabetes that included a blood sugar test and an interview about how diabetes affects your family and life would you be willing to participate?

Yes No Not Sure

Chi Miigwetch!

Appendix C: Focus Group Questions

1. What comes to your mind when you hear the word “diabetes”?

2. How many people in Wiky do you think would have diabetes? Do you think diabetes is something youth in Wiky need to worry about?

3. Can you tell me how diabetes affects you? - or affects your life? (personal experiences with diabetes)

4. Have you ever attended information sessions on diabetes? What did you learn?
 - ✿ Where did you learn this information? (Probe here around on-off reserve service use – reasons people went where they did for information?)

 - ✿ What do you still think you need to learn about diabetes or want to learn about it?

 - ✿ How could services be delivered differently in the community to improve access to information and knowledge about diabetes for people like yourselves?

5. Has your household ever changed your daily diet and exercise routine as a result of learning about diabetes?
 - ✿ Let them explore this... why or why not? What are the barrier to change?

6. What kinds of programs would help you and your family live a healthy life?

7. As we move forward in our research can you think of anything we should be looking at? What research questions do you think we should be asking. What do you want to know about diabetes in your community?

8. Would you support a multi-year research strategy on diabetes in Wikwemikong?

Appendix D: Community Advertising

Did Somebody Say Diabetes?



Diabetes Research Project: In The Developmental Phase

Diabetes has been identified as a priority research area by the Wikwemikong Health Centre and Health Services Committee. Previous research has shown that diabetes is a major health concern in Wikwemikong. The Wikwemikong 2001 community needs assessment survey reports that 16% of the survey population has been diagnosed with diabetes. Tracking the prevalence of diabetes is very difficult as some people may not even know if they have diabetes or not.

As diabetes research has been identified as a priority, a local Diabetes Research Team (in partnership with a researcher at the Northern Ontario School of Medicine) has been developed. This team consists of Kristen Jacklin (Assistant Professor at the Northern Ontario School of Medicine), Phyllis Kinoshameg (Researcher), Elaine Johnston (Health Services Director), Ronnie Wakegijig (Traditional Medicine), Mary Pheasant (Wellness Program), Sharlene Pitts and Phoebe Bebamikawe (Research Assistants).

The Diabetes Research Team is consulting with community and regional organizations as well as community members to develop a multi-year diabetes research strategy for Wikwemikong.

During the summer you may be contacted by our research assistants who will be conducting surveys on your perceptions of diabetes and diabetes services, or you may be asked to participate in one of the focus groups for the input on the diabetes research strategy. Feel free to contact the following members of the team if you have any questions about this project or if you wish to be included among those for a focus group.

Kristen Jacklin- (705) 662-7277
Phyllis Kinoshameg and Ronnie Wakegijig—859-3164
Sharlene Pitts. Phoebe Bebamikawe and Marv Pheasant—

Appendix E: Research Questions Supplied by Little Current Medical Associates Physicians

(The following is taken verbatim from a fax received from this group on Oct 12, 2006)

1. What are the traditional methods for managing Type II diabetes and what impact do they have on the control of Type II diabetes.
2. Prevalence of incidence in the community of Type II diabetes, diabetic nephropathy, diabetic neuropathy.
3. Does screening for pre-diabetes as per current guidelines delay the onset or decrease the incidence of the development of Type II diabetes.
4. Is there an effect of home care in the management of diabetes as managed by Hg A1C, end organ problems and ultimately mortality?
5. Does treatment of Type II diabetes or the treatment of pre-diabetes reduce cardiovascular risk? Does childhood obesity, First Nations population convey an increased risk of development of Type II diabetes in adulthood.

Mention was also made of other safe food programs, healthy eating programs in schools would contribute to an increased risk of diabetes and other questions regarding defining a life style program suitable to First Nation's communities or other sets of programs have an impact on prevalence of Type II diabetes.

ⁱ Ronnie Wakegijig, the Traditional Medicine Coordinator at the Wikwemikong Health Centre, has expressed interest in developing a second research funding proposal to look specifically at the issue of efficacy.